

Addressing Information Overload in Individuals with Breast Cancer Post-Diagnosis through a Personalised AI-Based Companion

Master Graduation Project
August 2024



Ankita Arora

MSc. Design for Interaction
Faculty of Industrial Design Engineering,
Delft University of Technology

Master Thesis

Addressing Information Overload in Individuals with Breast Cancer Post-Diagnosis through a Personalised AI-Based Companion

Author

Ankita Arora

5817676

MSc. Design for Interaction

August 2024, Delft, the Netherlands

**Faculty of Industrial Design Engineering,
Delft University of Technology**

Landbergstraat 15

2628 CE Delft

Supervisory Team, TU Delft

Prof. d.r Rietjens, J.A.C.

Delft University of Technology

Department of Design, Organization and Strategy (DOS, TU Delft)

Dr. ir. Bourgeois, J.

Delft University of Technology

Department of Sustainable Design Engineering (SDE, TU Delft)

External Mentor

Ir. Brands, J. MDM

Panton, Deventer



Executive Summary

Cancer is a complex disease marked by uncontrolled cell growth and has a widespread impact on individuals and society. Its incidence has been increasing globally, with a notable rise in cases in the Netherlands from 56,000 in 1989 to 118,000 in 2019. There will be approximately 232,000 new cancer diagnoses by 2032 (Source: iknl.nl).

Breast cancer, the most frequently diagnosed cancer among females worldwide, is a significant concern amid rising cancer rates (WHO, 2024). In the Netherlands, it is among the most prevalent cancers, with 15,634 cases reported in 2023 (NKR Viewer, n.d.). Despite significant advancements in diagnosis and treatment, cancer remains a severe and multifaceted challenge and impacts individuals, their families, and society as a whole. For individuals, the illness inflicts significant physical harm, manifesting as chronic pain, fatigue, loss of appetite, and other symptoms that drastically reduce quality of life. The psychological and emotional toll is equally profound, with individuals and their loved ones experiencing intense fear, anxiety, and stress (Costa et al., 2016). Following a diagnosis, individuals encounter a flood of information related to their condition, treatment options, supportive care resources, medical regimens, etc. making it overwhelming and complex. This complexity is amplified in breast cancer due to the multitude of subtypes and variants, accompanied by a wealth of information accessible online.

While healthcare providers strive to communicate information effectively through verbal and written formats for the individuals to navigate in this unfamiliar world, their time constraints and workload frequently restrict the depth of support they can offer. This results in individuals turning to gather information from diverse sources, such as online platforms, family, friends, etc. This decentralised approach is unavoidable and offers diverse views resulting in complexity, ambiguity, and confusion and leading to “information overload”. Information overload is a multi-dimensional construct and a complex phenomenon and usually occurs when the available information surpasses one’s capacity to absorb it effectively. There are several factors that cause information overload and these factors result into intertwined effects like inability to effectively process, understand and utilise the information, etc.

Given the prevalence, the focus of the study is on breast cancer in females and aims to address these challenges by supporting them in understanding the complexities of the cancer diagnosis and treatment options based on their preferred level of involvement, ultimately enabling them to make informed decisions in their care journey. The findings from this project can benefit the healthcare system as a whole, the stakeholders involved, including individuals with breast cancer, their companions, and healthcare providers, by equipping them with the support tools to navigate and understand the healthcare journey. Furthermore, it can provide the necessary information support to individuals post-diagnosis, alleviate the burden on healthcare providers and strengthen communication between providers and patients.

Critical Reflection on the Writing

In this report, I have used “individuals”, “people”, and “females” interchangeably when referring to breast cancer patients. This choice is intentional and reinforces the intention behind inclusive and gender-neutral language.

The term “females” is used to refer biological sex, while “Individuals” and “people” are used to emphasise the human aspect of the patients. This approach recognises the importance of inclusivity in language, especially in a field where both biological and social factors play significant roles.

The terms “illness,” “condition,” and “cancer” are also used interchangeably and reflects the variability in how breast cancer may be discussed or understood from section ‘1.2 Project Scope’.

“Patients” is used in certain contexts to align with conventional established terminologies such as “patient population” and “patient-centred care.”



Panton, a healthcare design consultancy based in Deventer, Netherlands, specialises in creating innovative solutions for the healthcare sector. The company is dedicated to enhancing the quality and efficiency of healthcare services through the application of user-centred design methodologies. Panton collaborates extensively with healthcare professionals, patients, and other stakeholders to develop innovative solutions that address the complex challenges within the healthcare industry. One of their notable innovations is the Metro Mapping Tool, a service design method to design and optimise care pathways.

Founded in 2005 by Ingeborg Griffioen (1971-2022), who brought her expertise as a designer to the healthcare field, Panton is now led by Jasper Brands and Mario de Zeeuw.

This project would not have been possible without the invaluable support of the designers at Panton and Jasper, who trusted, guided, and mentored me throughout.

Acknowledgments

I would like to express my deepest gratitude to my personal support community...

_To all my mentors for untangling the complexity everytime I overloaded you with information. Thank you for always showing me the brighter side of the work, and for pushing me to think beyond.

Judith and Jacky, thank you for your guidance throughout this project for believing in me for this graduation opportunity. I have learned a lot about research from both of you and your proactiveness and critical questions constantly pushed me to think deeper.

Jasper, it has been a pleasure knowing you and working under your guidance. I am thankful to Judith for introducing me to Panton. Thank you for always encouraging me, providing me opportunities to explore and helping me break the silos in design thinking.

and everyone in the Panton team who helped me in the creative facilitation sessions and discussion of the concept.

_To all the healthcare providers, representatives from the research institutes and patient organisations and patient advocates who shared their boundless knowledge and experiences with me. The conversations with you were the driving force of this project.

_To all the strong beautiful individuals who participated in my research while fighting the illness. I am immensely grateful to have the opportunity to interact with you and documenting your experiences helped me achieve the results.

_To all the researchers and experts from TU Delft who had conversations with me and gave me different perspective. You brought all the sun to the course of this graduation project.

_To the fellow students from TU Delft who participated in the creative facilitation sessions. Thank you for your contribution.

_To my family, Mom, Dad, Ritika, Kanishk & Hrishik for being an amazing source of support in every aspect of my life. I wouldn’t have been here without your support.

_To all my lovely friends here in Delft and in other parts of the world, thank you for being a sounding board throughout the project and encouraging me. Special thanks to Swetha - thank you for being my working buddy after green light. I enjoyed working with you!

Table of Contents

01. Introduction1

1.1 Cancer Journey in the Netherlands3

1.2 Project Scope5

1.3 Overview of Cancer Care in the Dutch Context6

1.4 Gaps in the Current Approach7

1.5 Aim of the Study8

1.6 Research Question8

02. Scoping of Literature9

2.1 Breast Cancer10

2.2 Information-Seeking Behaviour10

2.3 Understanding Information Overload12

2.4 Strategies to Deal with Information Overload13

2.5 Artificial Intelligence in Healthcare14

2.6 Summary15

03. Methodology17

Overview of Methodology24

04. Defining the Framework: Information Overload25

4.1 The Framework of Information Overload26

4.2 Factors of Information Overload26

4.3 Effects of Information Overload27

4.5 Factors Considered for the Study31

4.5 Conclusion32

05. Mapping Needs and Preferences33

5.1 Information Map in Breast Cancer Care35

5.2 Categorising Sources of Information37

5.3 Insights from Stakeholders40

5.4 Needs and Preferences of Individuals with Breast Cancer43

5.5 Research Outcome50

06. Design Exploration53

6.1 Design Goal54

6.2 Design Explorations55

6.3 Design Characteristics57

6.4 Desired Interaction59

6.5 Design Outcome: Bremo59

07. Design Development61

7.1 Positioning of Bremo in the Healthcare System62

7.2 Current and Desired Interactions63

7.3 Introduction of Bremo in Consultation Sessions65

7.4 Scenarios67

7.5 Summary71

08. Design Evaluation73

8.1 With Participants74

8.2 With Healthcare Designers at Panton and AI Experts74

09. Design Recommendations and Proposed Evaluations77

9.1 Design Recommendations78

9.2 Proposed Evaluation Methods80

9.2.1 Outcome Evaluation

9.2.2 Impact Evaluation

10. Discussion85

10.1 Summary86

10.2 Limitations90

10.3 Future Research Directions91

10.4 Personal Reflection92

References

01

Introduction

This chapter establishes the foundation for the master thesis by defining the context, scope, and emphasis. It further studies cancer care in the Dutch context, identifies key stakeholders and concludes with highlighting the existing gaps, defining the aim and the overarching research question.

Cancer is a complex illness characterised by the uncontrolled growth and spread of abnormal cells in the body. It is one of the most severe human illnesses, resulting in millions of deaths annually worldwide. This growing challenge of cancer is underlined in the World Health Organisation's (WHO) report of 10 million deaths globally in 2020 with the incidence expected to rise significantly in the coming decades due to ageing populations and lifestyle changes (World Health Organization, 2020).

In 1989, the Netherlands recorded nearly 56,000 cancer diagnoses, which grew to over 118,000 by 2019 (Figure 1.1). A report from the Netherlands Comprehensive Cancer Organisation (IKNL) projects that by 2032, there will be approximately 232,000 new cancer diagnoses. This equates to an average of 18 people being diagnosed with cancer every hour over the next ten years.

Despite many years of efforts to fight the disease, cancer continues to be a severe illness that has not been entirely eradicated, and its impact remains significant (Wang & Feng, 2022). The impact of cancer and its treatment is intense and exerts a varied impact, affecting not just individuals dealing with it but also their families, and society as a whole. Individuals with the illness are inflicted with serious physical harm, such as chronic pain, fatigue, loss of appetite, and other symptoms that drastically reduce quality of life (Okamoto et al., 2011), (Hubbard et al., 2008). The psychological and emotional toll is equally intense

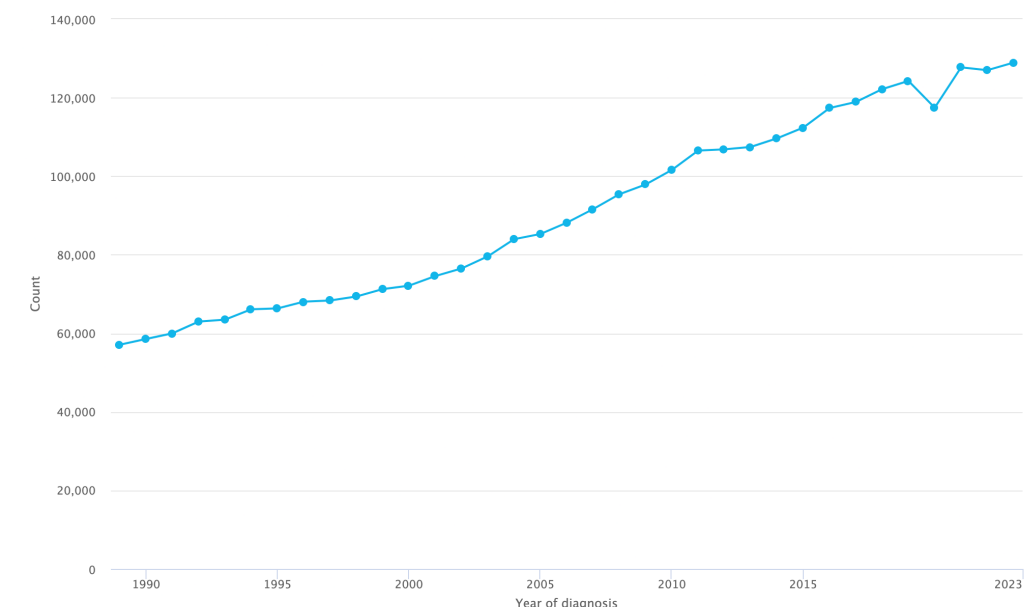
as the illness comes with a lot of uncertainty, loss of control over life and the fear of death. Individuals diagnosed with cancer and their loved ones experience intense fear, anxiety, and stress (Costa et al., 2016). Beyond the physical and psychological consequences, cancer also imposes substantial economic burdens due to the high costs of treatment, increasing the financial strain and contributing to the overall hardship. The illness alters life intensely, reshaping social dynamics and work life, creating a new reality with physical, mental, and financial challenges (Okamoto et al., 2011).

The experiences of individuals with cancer can be broadly categorised into four stages: pre-diagnosis, post-diagnosis before treatment, short-term after treatment, and long-term after treatment (Wang & Feng, 2022). Following a diagnosis, they face severe ongoing challenges after their illness is diagnosed and go through intense emotional distress such as anxiety, fear, denial, etc. (Velasco-Durantez et al., 2024), (Rodriguez-Gonzalez et al., 2022), (Lewandowska et al., 2020), (Park et al., 2020) They are then provided with information to understand their illness and make a decision about the treatment. While healthcare providers strive to communicate information effectively through written and verbal explanations (Herbert et al., 2020), their time constraints and workload frequently restrict the depth of support they can offer.

Incidence by year, Count

All cancer types

Sex: Male and female | Age group: All ages | Region: The Netherlands | Stage: Total



2023, 2022: Provisional figure.

NKR
Source: nkr-cijfers.iknl.nl

Figure 1.1: Growth of Cancer in the Netherlands (Source: nkr-cijfers.iknl.nl)

The process of making treatment decisions can be overwhelming for the individuals and their families and navigating the information relevant to their condition becomes an additional challenge (Ormel et al., 2021). Individuals in turn gather information from diverse sources, such as informational letters, online platforms, family, friends, and social media, etc. as a way of coping (Reifegerste et al., 2021). This decentralised approach is unavoidable and offers diverse views, possibly resulting in complexity, ambiguity, and potential misinformation or biased information (Conley et al., 2021), (De Rosa, 2022). This may lead to “information overload”, further complicating the decision-making process regarding treatment options (Coronado et al., 2017). It not only complicates the lives of individuals but also increases the workload of healthcare providers as they have to spend more time in clarifying the information. This issue is also prevalent in other illnesses and is a topic of concern in recent news, as highlighted by a survey conducted by NOS and the medical federation KNMG (Neijland, 2024).

As advancements in healthcare continue, the system is increasingly adopting technological innovations, such as applications and websites to meet illness-related information needs (Richards et al., 2019). Individuals are increasingly using various digital tools to navigate this challenge, such as searching the internet for information (Swar et al., 2017) to understand their condition. While these resources are beneficial, they can encounter significant challenges with these tools, such as conflicting information (De Rosa, 2022), increasing volume due to the fragmented nature of information, making it difficult for individuals to determine what is relevant (Swar et al., 2017) and accurate. This way of engaging with information can cause anxiety and confusion, further contributing to information overload (Khaleel et al., 2020). While the healthcare system is actively implementing various strategies to address these issues, the inherent complexity and demands of the system necessitate additional support.

In light of these issues, digital technologies like AI emerges as a promising solution. Digital platforms can offer the needed support. AI is transforming healthcare delivery by enhancing efficiency, accuracy and patient outcomes (Favour et al., 2024). It is playing a crucial role in improving patient engagement by personalising information and support, thereby addressing the issues associated with information overload (Bekbolatova et al., 2024). AI technologies can ensure that individuals receive relevant, accurate, and comprehensible information by tailoring

it to their specific needs and preferences. This personalised approach may not only improve the overall experience of individuals but also has the potential to help them better understand their condition (Alowais et al., 2023) and aid in informed decision-making. Thus, while digital technologies present both opportunities and challenges, AI stands out for its potential to significantly enhance patient engagement and communication.

1.1 Cancer Journey in the Netherlands

The journey from experiencing initial symptoms to receiving a diagnosis is complex, filled with uncertainty, anxiety, and confusion (Dinapoli et al., 2021) and may vary between individuals (Ormel et al., 2021) (Figure 1.2). Typically, when individuals first notice symptoms, they consult a General Practitioner (GP). If the GP has concerns, they may refer individual to a specialist for further testing. Following a series of evaluations and consultations, if a serious condition is identified, a cancer diagnosis may be confirmed. At this juncture, the cancer’s stage is assessed, and individuals are faced with making critical decisions regarding their treatment. An often overlooked yet essential aspect of this process is the need for a thorough understanding of the illness itself. For individuals, receiving news about cancer can be emotionally distressing (Ormel et al., 2021), as it introduces an unfamiliar reality for many, requiring immediate treatment and health-related decisions and significant lifestyle changes.

Interactions in Cancer Care

The cancer care landscape involves a range of individuals, including patients, their families, healthcare providers and other medical professionals. Individuals are the central focus of the cancer care delivery system, as they navigate the complex medical and emotional journey of cancer. They engage with various stakeholders that can appear like a complex web of interactions, as depicted in Figure 1.3. These interactions can be overwhelming as they navigate through medical consultations, diagnostic tests, and healthcare procedures with the involvement of multiple stakeholders such as healthcare providers, family members, and support networks, shaping the experience of the individual and emotional well-being during this critical period of uncertainty and decision-making.

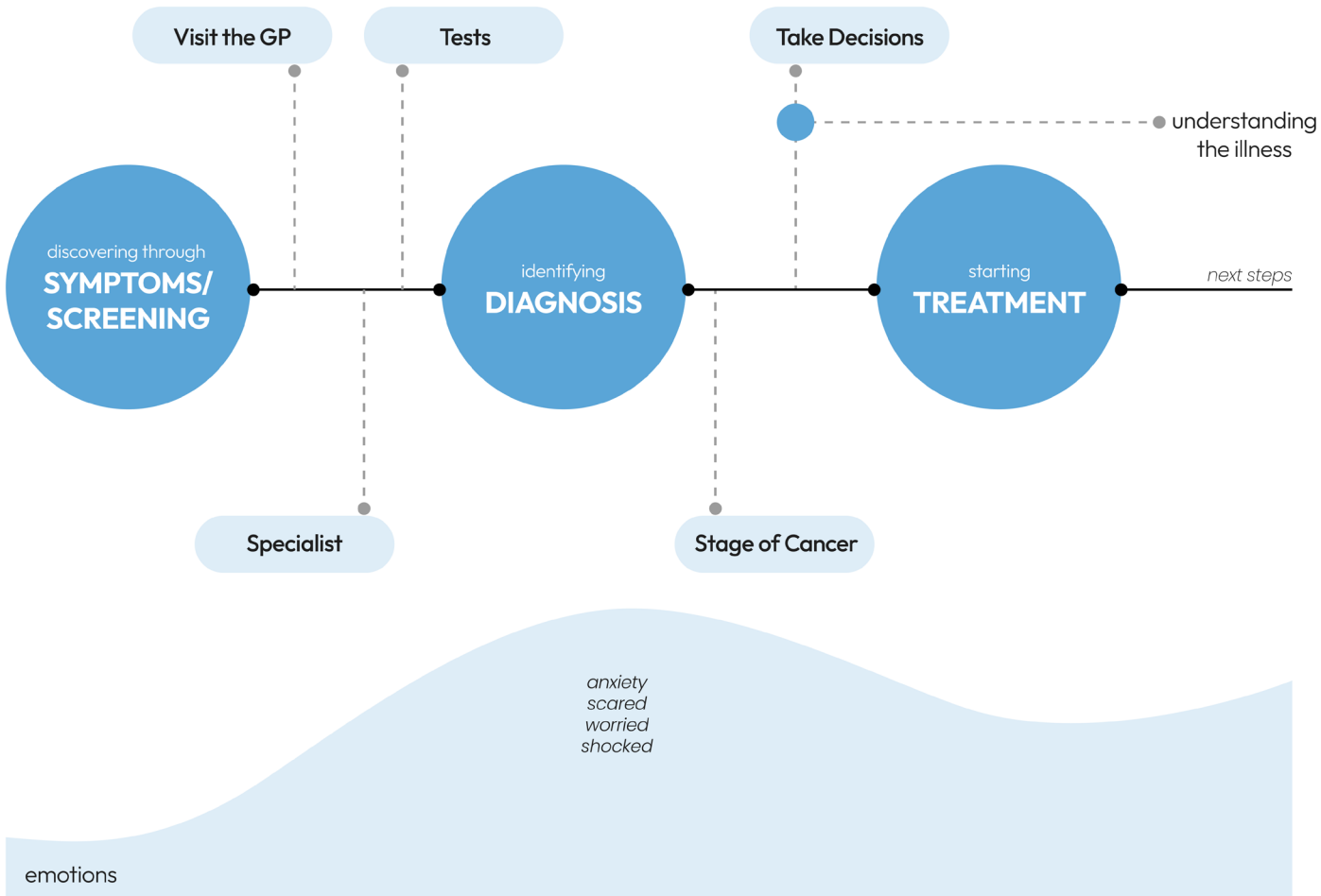


Figure 1.2: Representation of a Typical Journey from First Signals (Pre-Diagnosis) to Post-Diagnosis

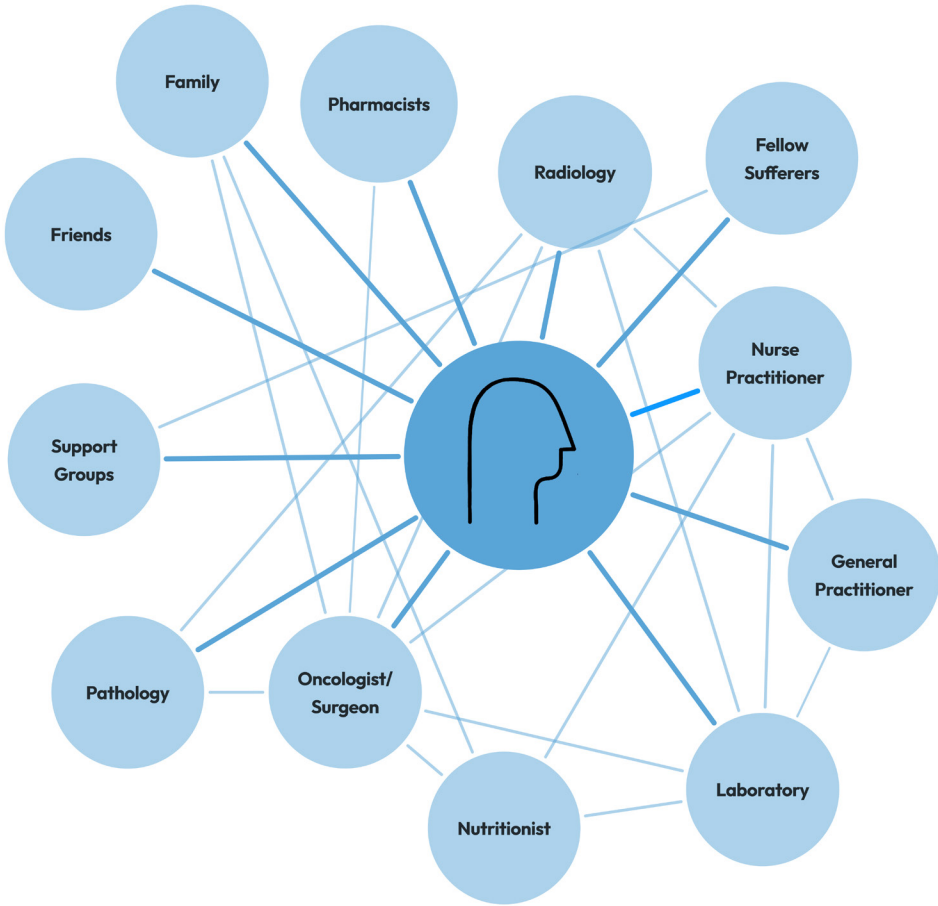


Figure 1.3: Representation of a Complex Web of Interactions in Cancer Care

1.2 Project Scope

Breast cancer is the most frequently diagnosed cancer among females globally (Herbert et al., 2020), representing roughly 25% of all cancer cases in females (Bray et al., 2018). In 2020, there were an estimated 2.3 million new cases and 685,000 deaths worldwide from breast cancer (Sung et al., 2021). Although the illness primarily affects females, it can also occur in males, though less commonly. In the Netherlands, breast cancer is one of the most widespread cancers, with 15,634 new cases recorded in 2023 (NKR Viewer, n.d.) (Figure 1.4).

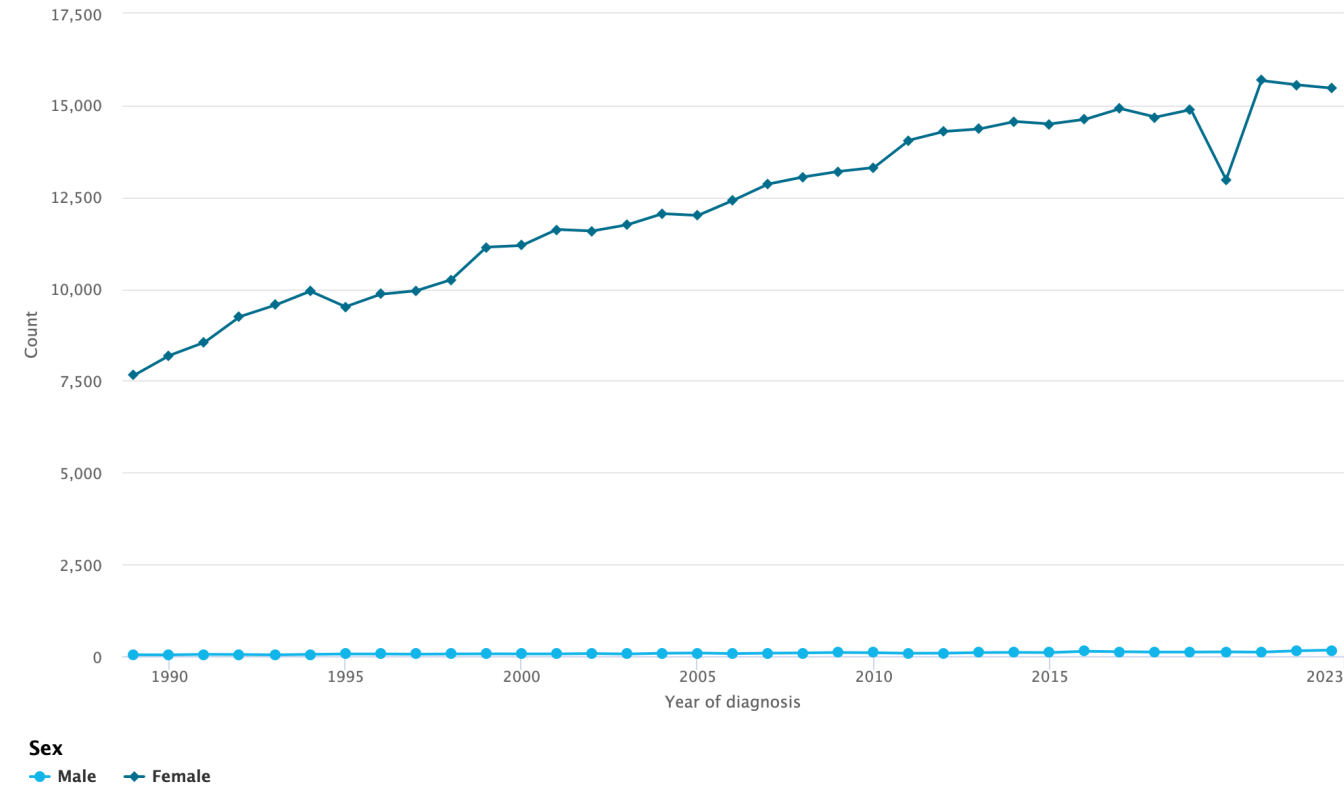
Breast cancer remains a major health challenge due to its prevalence and the complexity of the treatment decisions (De Rosa, 2022). The complexity lies in its heterogeneous nature, with various subtypes that can behave and respond uniquely to treatments. This variability necessitates personalised treatment plans, which can include a combination of surgery, chemotherapy, radiation, hormone therapy, and targeted biological treatments (Yersal & Barutca, 2014).

The rapid evolution of breast cancer treatment presents unique challenges with the ever-expanding body of knowledge surrounding breast cancer diagnosis and treatment, contributing to the abundance of information available (Ormel et al., 2021) through multiple sources which could be conflicting, unreliable (De Rosa, 2022) or outdated. The diagnosis of breast cancer is also emotionally overwhelming as it fundamentally affects an individual’s identity with self (Herbert et al., 2020), with implications such as fertility concerns, and risks of recurrence.

The focus of the master thesis is to propose an AI-driven intervention for individuals with breast cancer due to its pervasive impact on individuals and multifaceted challenges. The research specifically centres around the post-diagnosis and pre-treatment phases of breast cancer, aiming to identify and understand the challenges they encounter in dealing with information. The study will primarily concentrate on females, as breast cancer is significantly more prevalent in this group.

Incidence by year, Count

Breast
Age group: All ages | Region: The Netherlands | Stage: Total



2023, 2022: Provisional figure.

Source: NCR
Changed on: 15 February 2024

Figure 1.4: Breast Cancer Cases in 2023, The Netherlands (Source: NCR)

1.3 Overview of Cancer Care in the Dutch Context

Cancer care in the Netherlands reflects a comprehensive, patient-centred approach, with various stakeholders working collaboratively to optimise the quality of care and outcomes for individuals. There are research institutes and societies such as the Dutch Federation of Cancer Patient Organisations (Nederlandse Federatie van Kankerpatiëntenorganisaties), The Netherlands Cancer Institute (NKI), Netherlands Comprehensive Cancer Organisation (IKNL), Dutch Cancer Society (KWF), and kanker.nl. They are involved in advancing cancer research, provide funding and facilitating knowledge translation to improve patient care. Below is an outline of the contributions of each stakeholder:

NFK - Dutch Federation of Cancer Patient Organizations (Nederlandse Federatie van Kankerpatiëntenorganisaties)

The NFK represents the interests of various cancer patient organisations in the Netherlands, advocating for the rights and well-being of individuals with cancer and their families. They aim to ensure that the needs and viewpoints of individuals are considered into the development of cancer-related policies and initiatives. Officially accredited as a Comprehensive Cancer Center, the NKI is considered one of the top 10 such centres in Europe.



Dutch Breast Cancer Association (Borstkankervereniging Nederland, BVN)

The Dutch Breast Cancer Association is a patient organisation dedicated to providing support to individuals affected by breast cancer. Apart from information, they offer a wide range of services including patient support, such as a buddy system, support groups, support sessions and events with healthcare providers and psychologists, etc., They are also involved in breast cancer research, policy-making, etc.



Cancer.nl (Kanker.nl)

Kanker.nl is a comprehensive online resource closely associated with NFK, IKNL and the KWF and provides reliable information and support for individuals affected by cancer in the Netherlands. The website offers details on cancer diagnosis, treatments, and consequences of the disease. They also facilitate access to peer support, allowing users to connect with others in similar situations. Kanker.nl hosts an activity calendar of events and initiatives organised for those impacted by cancer across the country and operates an information hotline that offers support via phone, email or chat. The website further provides a collection of trustworthy apps and decision-making tools that users can access for free.



The Netherlands Cancer Institute (NKI)

The NKI is the primary institute for cancer research and care in the Netherlands. The institute comprises both an acclaimed research centre and a dedicated cancer clinic, enabling rapid translation of research into clinical applications.



Netherlands Comprehensive Cancer Organisation (IKNL)

IKNL is the central quality institute for oncological and palliative care in the Netherlands. It works closely with healthcare professionals, researchers, policymakers, and patients to continuously improve cancer and palliative care. IKNL maintains the Netherlands Cancer Registry (NCR), which collects and compiles clinical data on all new cancer diagnosis in the Netherlands, providing valuable insights to drive quality improvements.



Dutch Cancer Society (KWF Kankerbestrijding)

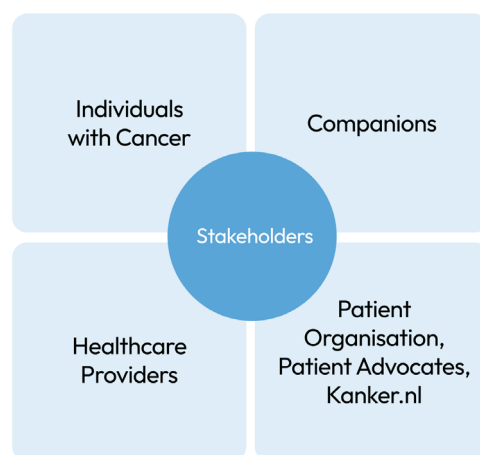
The Dutch Cancer Society, founded in 1949 is committed to supporting individuals with cancer and their loved ones throughout their cancer journey, from prevention to palliative care. They are engaged in cancer research, policy development, and knowledge sharing to improve the lives of individuals (Kankerbestrijding, 2024).



These entities work together through collaborative research, funding support and knowledge translation to maintain the quality of life in cancer care in the Netherlands. They also collaborate with healthcare providers, and other professionals making significant contributions to patient care.

Key Stakeholders

In addition to understanding various dimensions in cancer care through the institutes, it is crucial to define the key stakeholders for this research study. Central to this project are the individuals with experience of breast cancer. Alongside them, several other key stakeholders play a crucial role in the cancer care. Their repeated and layered interactions play a vital role in shaping the patient experience.



Individuals with Breast Cancer

They are the primary focus of the research study and are engaged in managing their illness, navigating the complex nature of the cancer diagnosis with both physical and emotional challenges post-diagnosis. Their experiences and needs are critical to understanding how to provide them with appropriate support.

Companions

Companions include individuals' loved ones, such as partners, family members, and friends. They provide essential support throughout the cancer journey by accompanying patients to medical appointments, offering emotional encouragement, and assisting with day-to-day needs. Their presence and involvement are crucial in helping patients cope with the stresses of treatment and maintaining their overall well-being.

Healthcare Providers

Oncologists and Surgeons: Oncologists are the primary caregivers responsible for diagnosing and treating cancer patients. They provide guidance and support to individuals and their families through developing treatment plans and performing necessary medical procedures.

Nurse Practitioners: Nurses work closely with oncologists to administer treatments, monitor individuals' progress and manage side effects. They also provide valuable support and education to individuals and their families to understand the treatment process and make informed decisions about their care.

Patient Organisation, Patient Advocates and kanker.nl

The Dutch Breast Cancer Association (BVN), Patient Advocates and kanker.nl play a vital role in supporting individuals emotionally by advocating for their interests, organising peer support meetings, and providing essential and credible information to individuals via various ways such as information hotline, websites, etc.

1.4 Gaps in the Current Approaches

In the context of breast cancer care, several significant gaps in current approaches have been identified. Despite the rapid pace of discoveries and advancements in technology, individuals continue to experience unmet information needs (Ector et al., 2020). Although a wealth of information is available, much of it is either irrelevant to the specific situations of individuals (Lu et al., 2020) or presented in complex, jargon-heavy language that is difficult to understand (McRoy et al., 2018).

Moreover, there is a deficiency in emotional support, which is essential given the distressing and life-changing nature of breast cancer (Ke et al., 2023, Lu et al., 2020). Current information tools and resources often fail to address the diverse needs (Halbach et al., 2016) and preferences (Ke et

al., 2023) of individuals, highlighting a significant gap in personalised care. This gap is widened by healthcare providers, who are often limited by demanding schedules (Halbach et al., 2016). As a result, they may lack the time and resources to offer the emotional support and tailored information that patients need. The current one-size-fits-all approach to information does not accommodate the varied needs, preferences, and information-seeking behaviors of individuals, leaving many without the support and understanding required to navigate their diagnosis and treatment effectively.

1.5 Aim of the Study

The aim of this master thesis is to investigate the difficulties and challenges faced by individuals with breast cancer and to assist them in dealing with information overload in the post-diagnosis and pre-treatment phases. Through identifying the specific needs and preferences of individuals, and examining the roles of companions, healthcare providers, patient organisations, and patient advocates, the study aims to develop an intervention to support individuals in navigating the complexities of breast cancer.

1.6 Research Question

How can an AI-based intervention support individuals with breast cancer in dealing or preventing information overload post-diagnosis?

The overarching research question for this master thesis is to determine how can an AI-based intervention effectively address information overload in individuals diagnosed with breast cancer. This research question is supported by two other research questions which are introduced at the end of 'Chapter 2: Scoping of the Literature'.

Through the design outcome by the end of this report, the research questions will be thoroughly discussed in the current context and future research and design recommendations.

02

Scoping of Literature

The chapter navigates through various literature around information in breast cancer care. It begins by understanding the information landscape in breast cancer, then dives into understanding information-seeking behaviour, their needs and preferences and identifies the causes information overload. Further understanding the existing strategies to address information overload, it covers the role of AI in healthcare and oncology. It concludes with laying groundwork for the research questions, setting the stage for further investigations.

2.1 Breast Cancer

Breast cancer, the most common cancer diagnosed in females aged 45-74 in the Netherlands (NKR Viewer, n.d.-b) is mostly found in the ductal epithelium (i.e., ductal carcinoma) but can also be developed in breast lobules (i.e., lobular carcinoma) (Menon et al., 2024). According to the National Institute of Public Health and the Environment of the Netherlands, approximately one in eight females will develop breast cancer in the Netherlands at some point in their lives. In the Netherlands, breast cancer in individuals is diagnosed either through initial symptoms (like lumps or irregular mass or discharge around the breasts), Bevolkingsonderzoek i.e. population screening for females age 50-75 or through accidental findings. The National Institute for Public Health and the Environment (Rijksinstituut voor Volksgezondheid en Milieu), the independent agency of the Ministry of Health, Welfare and Sport, Netherlands provides information about breast cancer screening program to educate the public about symptoms of breast cancer and the importance of getting screened. However, not all females attend the screening program (Dassen et al., 2023).

The factors associated with the risk of breast cancer are either family history, early puberty, late motherhood, dense breast tissue, or physical inactivity (National Institute of Public Health and the Environment of the Netherlands). Breast Cancer is diagnosed through physical examination, breast imaging and tissue biopsy. The treatment is highly individualised and depends on the stage and nature of the tumour, as well as personal circumstances (Carlson et al., 2005), (Ormel et al., 2021). The treatment options include a combination of different modalities like surgery, chemotherapy, radiation, hormonal therapy and immunotherapy (Menon et al., 2024) (Yersal & Barutca, 2014) delivered in diverse sequences (Łukasiewicz et al., 2021).

The growth in the number of breast cancer cases has raised a need for information to learn about the illness, its treatment options and to manage symptoms and make decisions (McRoy et al., 2018).

The Information Landscape in Breast Cancer

The information landscape in breast cancer is vast

and complex with the growing advancements and discoveries of subtypes and various treatment options (Van Vliet et al., 2021). Upon receiving a breast cancer diagnosis, individuals are introduced to complex information (De Rosa, 2022), (Van Vliet et al., 2021), with medical jargon (Herbert et al., 2020) to learn about the treatment options, prognostic data, nutritional advice, etc. This wealth of information can help the individuals get a deeper understanding of their condition, available treatment options, become active participants in their care and make informed decisions (Shea-Budgell et al., 2014) (Davison & Breckon, 2012). Navigating this vast landscape may become overwhelming and confusing (Ormel et al., 2021) as many individuals suffer from severe emotional distress, which can impair their ability to cope with illness (Park et al., 2020) and may struggle to understand and process (Hyatt et al., 2022) the information. While healthcare providers strive to communicate information effectively through verbal and written formats (Herbert et al., 2020), their time constraints and heavy workloads often limit the depth of support they can provide. As a result, individuals turn to various sources to seek information and demonstrate different behaviours.

2.2 Information Seeking Behaviours

The information-seeking behaviour refers to how an individual acquires information about their health and illness, the types of information they seek, and the sources they prefer. In cancer care, the information is primarily provided by healthcare providers (Rexhepi et al., 2021), (Reifegerste et al., 2021), such as oncologists, surgeons and nurse practitioners. They deliver essential information on diagnosis, treatment options, prognosis etc. However, individuals also seek additional information through diverse sources, such as the Internet, support groups, medical literature, social media (Reifegerste et al., 2021), (Lu et al., 2020) friends and family, other patients (Ormel et al., 2021) (Valero-Aguilera et al., 2013), etc. This behaviour is driven by several factors, including the demanding schedules of healthcare providers, lack of emotional support during communication, and the complexity of information, (Van Vliet et al., 2021) which can leave the individuals feeling dissatisfied and urge them to seek support and information (Reifegerste et al., 2021). Every source from which an individual seeks information serves as a coping mechanism for

them, (Valero-Aguilera et al., 2013), a way to reduce the uncertainty of cancer (Reifegerste et al., 2021) and provide a sense of cognitive control (Davison & Breckon, 2012).

The information-seeking behaviours of individuals depend on their individualistic information needs (Tariman et al., 2014), (Rees & Bath, 2001) and can change during the illness (Leydon, 2000) (Lu et al., 2020). According to the research conducted by S. M. Miller, 1987, later adapted by Bol et al., 2020, some individuals actively seek information and have high levels of information needs are referred to as ‘*information seekers*’, others, referred to as ‘*information avoiders*’, tend to avoid information and have low levels of information needs. These variations in the seeking behaviour reflect the different coping mechanisms for dealing with cancer (Kyngäs et al., 2001); some of them seek to reduce uncertainty, while others avoid to escape the negative feelings associated with information. The variations in information-seeking behaviour are influenced by both the context of information need and barriers in accessing the information with various factors that influence these needs, such as personal, social or environmental factors (Davison & Breckon, 2012), (Boadi et al., 2021), (Ferraris et al., 2023) as highlighted in the ‘Wilson’s model of information seeking behaviour’ (Wilson, 1999).

Information Needs

The information needs of the individuals are highest at the beginning of the treatment (Germini et al., 2015) and derive from the coping strategy or attitude they have to manage their cancer (Leydon, 2000). It varies with gender, age, type and the stage of cancer (Davison & Breckon, 2012), (Bernstein et al., 2011), (Rolnick et al., 2007), (Tariman et al., 2014) and are unique to the individual and their circumstances (Hyatt et al., 2022) and context. For instance, many newly diagnosed individuals prefer to be informed about cancer statistics and prognosis (Vromans et al., 2021) (Fletcher et al., 2017). While findings from another research indicates that the most critical information needs were related to self-care, emotional and psychological support, treatment duration, and the likelihood of recurrence (Ghazavi-Khorasgani et al., 2018). Another study reveals needs ranging from side effects and dietary advice to treatment options, symptoms, coping mechanisms, second opinions, and financial concerns (Hyatt et al., 2022).

The evolving needs, motivations, and experiences of the individuals lead to the emergence of different patterns of information seeking, as well as preferences for various information sources. Moreover, the stronger the need for cancer information, the stronger the preference for reliable and trustworthy sources (Barnes et al., 2017).

Source Preferences

The preferences for sources of information seeking vary among individuals as well. Research shows that individuals with cancer actively seek information from various sources depending on emotions, education, age and stage of cancer (Vromans et al., 2019), (Fletcher et al., 2017). While the internet is the most popular, followed by consultations with healthcare providers and reading through written documents and pamphlets provided (Ramsey et al., 2017), the research indicates that healthcare providers are the primary source of cancer information for a majority of individuals (Gedefaw et al., 2020). Other sources such as peer groups, podcasts, videos, and advice from family or friends are also utilised but to a lesser extent (Hyatt et al., 2022). Individuals were also inquired about their preferred formats and most of them responded with their preference for written information online followed up with written information in a booklet, some videos online, podcasts, etc. (Hyatt et al., 2022)

Individuals seek information from diverse sources (Reifegerste et al., 2021) to find relevant data (Ormel et al., 2021), based on their needs and preferences. This requires additional time and effort (A Review Towards Developing a Moment of Information Overload Model, 2016) of sorting, identifying, and relying on diverse sources, thereby increasing the volume of information. As a result, this can lead to feelings of being overwhelmed and experiencing “information overload” post-diagnosis.

Although researchers provide various definitions, information overload generally occurs when the volume of available information exceeds an individual’s capacity to absorb it effectively. In such a state, individuals may struggle to process and utilise the information due to multiple factors. The next section draws a relationship between information-seeking behaviour and information overload and then compiles various definitions of information overload both in a general context and within the broader scope of healthcare to provide a foundation for understanding the topic.

Relationship Between Information Seeking Behaviour and Information Overload

For individuals with cancer, information is considered a key coping mechanism, allowing them to gain a sense of control and alleviate anxiety (Hardwick & Lawson, 1995), (Molem, 1999), (Leydon, 2000), (Kyngäs et al., 2001), (Rutten et al., 2005) (Chen, 2017), (Hyatt et al., 2022). Individuals may seek information from various sources, including healthcare professionals, support groups, and the internet to reduce uncertainty. Research indicates that when individuals with cancer have access to the information they need, they are more likely to actively participate in their care, feel satisfied with the treatment choices they make, and experience improved coping skills and reduced anxiety (Chen, 2017) (Eheman et al., 2009). However, seeking information from multiple sources (Bawden & Robinson, 2008) increases the abundance of information, creates confusion and can also contribute to information overload (Jensen et al., 2014), leading to stress, and difficulty in making informed decisions. This information-seeking is unavoidable and there is a need to understand and address the challenge of information overload associated with it and fulfill the needs of individuals.

2.3 Understanding Information Overload

Information overload has been addressed across various disciplines, spanning from business administration to healthcare. Its conceptualisation is not novel, dating back to the twelfth century and coinciding with the inception of the Gutenberg printing press, which fed individuals with an abundance of information necessary for societal contribution (Kashada et al., 2020). Since then, the concept of information overload has been approached from various perspectives by different scholars (Figure 2.1).

The early understanding of the term ‘information overload’, as expressed by Jacoby (1977) and Malhotra et al. (1982), focused on the idea that humans have a finite ability to process information. In a similar layer, Rudd and Rudd (1986, p.305) described information load as the “amount of information actually acquired by a processing system,” implying that information overload represents the surplus information that cannot be processed. While there’s no single, universally accepted definition of information

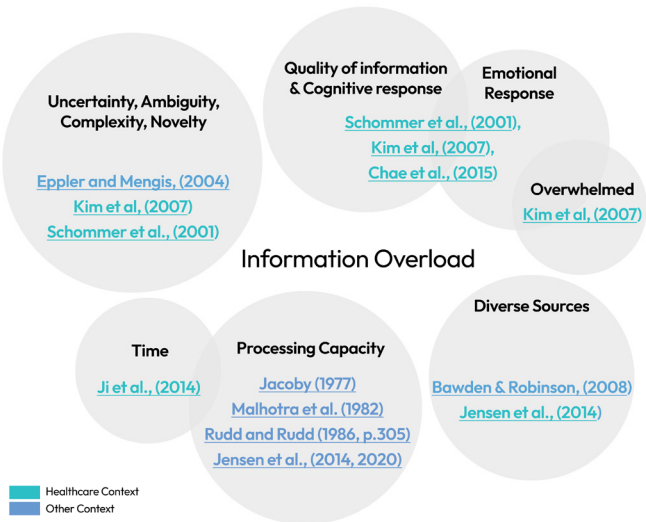


Figure 2.1: Definitions of Information Overload by Various Researchers

overload, it is generally understood as the point where information becomes a hindrance rather than a benefit (Bawden et al., 1999). This aligns with the findings of Jackson and Farzaneh, 2012, extensive literature review of information overload and refers it to the state of feeling overwhelmed by the volume of information presented, exceeding our ability to process it effectively (Jensen et al., 2014), (Jensen et al., 2020). This feeling of overload can be so intense that individuals may not even recognise they are experiencing it (A Review Towards Developing a Moment of Information Overload Model, 2016).

Moving beyond the core concept of information overload as simply exceeding processing capacity, scholars have explored its interplay with other factors. Eppler and Mengis, (2004) highlight the significance of information characteristics, often characterised quality, frequency, intensity and the quality of information. These characteristics can further intensify the feeling of overload. Furthermore, scholars explored information overload in relation to information quality, cognitive or emotional responses, and resultant outcomes (Schommer et al., 2001), (Chae et al., 2015), (Kim et al., 2007). Ji et al., (2014) emphasise the limitation of processing excessive information within constrained time frames, while Kim et al. highlight the detrimental effects of information overload on decision-making, defining it as a perception of feeling overwhelmed and confused by incoming information, ultimately hindering learning and impairing decision-making abilities (Kim et al., 2007).

While some researchers explored it from a cognitive perspective, other researchers explored its emotional impact. Schommer et al., 2001 examined the emotional responses triggered by information overload, highlighting feelings like

confusion, frustration, and anxiety experienced when confronted with excessive information. Similarly, Chae et al. (2015) investigated information overload in the context of cancer information, defining it as a state of being overwhelmed and unable to categorize new information effectively due to insufficient learning resources. By examining certain definitions through a review, Kim et al., 2007 synthesised the key components of information overload such as (a) an overflow of information, (b) ineffective management due to limited capacity, (c) stress or anxiety, and (d) ambiguity.

Several researchers have also investigated information overload within the context of diverse communication channels and personal sources. Bawden & Robinson, 2008 suggested that information when received from multiple formats and channels contributes to overload and Jensen et al., 2014 posit that exposure to information from various mediated channels and personal interactions further contributes to overload. The prolonged exposure to information overload has adverse effects on both physical and mental well-being (Kashada et al., 2020). In the context of cancer, these causes and effects may be more prominent considering the nature of the life-threatening illness.

According to (Eppler and Mengis, 2004), information overload can be caused by five key aspects: Information, Person, Tasks and Processes, Organisational Processes, and Information and Communication Technology (ICT). Information overload related to information characteristics involves the quantity, frequency, intensity, and quality of the information. At the personal level, factors such as the individual's attitude, qualifications, experience, competencies, skills, and motivation can influence information overload. At the level of tasks and processes, work tasks and collaboration with others can contribute to overload. Organisational processes, including formal and informal work structures, can increase information flow, especially during changes. The emergence and use of new technologies at the ICT level also play a significant role in causing information overload. Each of these aspects necessitates a distinct approach to effectively manage information overload.

In the healthcare context, information overload is a well-documented phenomenon. The widespread availability of internet has significantly increased individuals' access to information. Jansen et al., 2014 describes Cancer Information Overload (CIO) as the feeling of being overwhelmed by

the extensive amount of cancer-related content present in the information environment. This surge in accessible data is closely related to information-seeking behavior, particularly in the context of cancer. While the availability of high-quality and relevant information can be beneficial, it also contributes to the overall volume of information, further complicating the already complex nature of medical information. The extent of information overload is also influenced by an individual's ability to understand and process this information (Lee et al., 2017) (Hong & Kim, 2020).

In alignment with this comprehensive understanding, the next section details out the strategies of information overload in the current context proposed by some researchers and then builds a nuanced framework of information overload, which will be outlined in Chapter 4.

2.4 Strategies to Deal with Information Overload

The current strategies to deal with information overload incorporates both traditional and technological approaches at various levels and contexts.

In the context of business administration, Arnold et al., 2023 have summarized the work of multiple researchers, focusing on the five aspects identified by Eppler and Mengis, 2004: information, person, tasks and processes, organisational processes, and ICT. At the information level, Graf and Anotoni, 2020 emphasise distinguishing between the quality and quantity of information, both of which contribute to information overload. Quantity refers to the volume of information, while quality pertains to its complexity or relevance (Arnold et al., 2023). A key strategy to manage information involves breaking it down into smaller, more digestible parts. This process includes identifying primary sources, understanding objectives, and focusing on the most relevant and trustworthy information (Savolainen, 2007).

Additionally, providing information in visual formats can facilitate easier comprehension. At the personal level, several recommendations focus on managing time and improving individual competencies to better handle information overload. At the task and process level, strategies such as filtering and prioritising information are crucial (Bergström et al., 2010). At the organizational and technological levels, the introduction of new systems and the use of algorithms to

filter and extract essential information are recommended. Researchers suggest employing universal structuring dimensions to categorise and manage information effectively (Königer & Janowitz, 1995). The effective use of information technology, including techniques for filtering and personalisation while minimizing the use of excessive notifications, is also recommended as a solution (Bawden, 2009) to deal with information overload.

In the context of healthcare, information overload can be managed by carefully selecting and processing the most relevant and valuable health information, which can help individuals make informed decisions about their medical conditions and treatment options (Khaleel et al., 2020). Cancer care providers can employ various strategies to address the information needs of their individuals, such as improving communication and information-sharing practices and leveraging technology-enabled solutions to deliver tailored and interactive content (Doak et al., 1998) (Ishikawa & Yano, 2008). Using plain language, simplifying content, and providing visual aids are practical approaches that can significantly enhance comprehension, making information easier to digest (Greene et al., 2017). Another important strategy is to prioritise and filter the vast amount of health information available. This may involve directing individuals to reputable, curated sources, and helping them identify the most salient and trustworthy information to address their specific needs (Matsuyama et al., 2011). Furthermore, the utilisation of personalised information delivery platforms can support individuals in navigating the complexities of cancer care by providing them with relevant (Chua et al., 2018), customised and manageable information (Arnold et al., 2023). One effective method is the digital representation of information, which leverages technology to filter and tailor content (Ector et al., 2020). Advanced technologies, particularly Artificial Intelligence (AI), provide substantial opportunities to mitigate information overload through various innovative strategies (Siegel et al., 2024). The role of Artificial Intelligence will be covered in depth in the following section.

2.5 Artificial Intelligence in Healthcare

With the rapid advancement of information technology, there is a wide range of available information sources which are easy to use and access and are immediately available (Ma et al., 2023). Since the 2019 COVID pandemic, healthcare has undergone a digital transformation which has revolutionised healthcare. The pandemic coerced the healthcare industry to adopt digital technologies (Poalelungi et al., 2023). There are various digital health technologies that have been increasingly applied in the context of healthcare, such as Electronic Health Records (EHR), Health Information Exchange (HIE), telemedicine, m-health, robots, virtual reality to have interactions, wearable sensors, artificial intelligence applications, precision medicine, clinical decision support, surgical visualisation, surgical robotics, and hospital scheduling systems (Shreve et al., 2022), (Alowais et al., 2023), (Stein et al., 2020) (Soferman, 2019). Artificial Intelligence, one of the emerging technologies, provides a backdrop to transformations in healthcare. Its integration into the healthcare systems has the ability to enhance efficiency, accuracy and patient outcomes (Favour et al., 2024). AI facilitates the adoption of the 4P model of medicine - predictive, preventive, personalised, and participatory - thereby empowering patient autonomy (Kuwaiti et al., 2023). It is becoming a useful and necessary tool in oncology (Torrente et al., 2022), (Luchini et al., 2021) and its applications span diverse domains including medical imaging, diagnostics, virtual patient care, research and drug discovery, patient engagement, rehabilitation and administrative functions (Taylor et al., 2023), (You et al., 2022).

The adoption of digital technologies is thought to have the potential to reduce the overload, enhance the performance of healthcare providers, the quality of patient care, patient engagement, as well as organisational practice (Stein et al., 2020). However, technology's impact on information overload can be both positive and negative, depending on its application. On one hand, the increase in information available through the internet, social media, and other digital channels leads to information overload, where individuals struggle to process and make sense of the vast amount of health information available (Swar et al., 2017). And on the other hand, digital tools such as chatbots, smartphone apps, and wearable devices have the potential to support patients by connecting them to medical staff and providing personalised information

and care (Sun & Zhou, 2023), (Chaix et al., 2019). AI-powered tools can provide valuable support by streamlining repetitive and time-consuming tasks of healthcare providers and managing the intricate nature of patient care. Given the broad capabilities and the advantages it offers, these systems can ensure timely and personalised information delivery, and enhance overall patient engagement (Taylor et al., 2023), thereby supporting individuals. This way, it also reduces their reliance on healthcare providers (Goodman et al., 2023) for information which in turn helps to alleviate the workload of the providers (Cardoso et al., 2022), (Alowais et al., 2023). AI algorithms are capable of performing a wide range of tasks like cognitive functions, such as learning, reasoning, and decision-making. It can complete a wide range of specific tasks such as translating between languages, listening and responding to human instructions, etc. (Carter et al., 2020).

Machine learning, a subset of AI, involves algorithms that improve with exposure to more data, enhancing their accuracy and adaptability. AI and machine learning offer a broad range of techniques applicable to healthcare, including natural language processing, which focuses on understanding and generating human language. This capability is crucial for tasks such as emotion detection, text classification, and information extraction (Sarfaraz et al., 2023) particularly in providing support to individuals (Papachristou et al., 2023). All of this could facilitate in timely access to information, improve overall quality of care (Goodman et al., 2023), and enhance patient support (Xu et al., 2021). With AI, it is possible to tailor educational content to the specific needs of each individual (Soferman, 2019), ensuring that the information is relevant to their particular stage of cancer and treatment plan. Moreover, AI-driven tools can offer personalised guidance on treatment options, potential side effects, and strategies for managing symptoms, thereby helping individuals make informed decisions about their care. Moreover, AI can facilitate continuous patient engagement through interactive platforms like chatbots, which can provide responses to questions and concerns of individuals, easing the cancer-associated anxiety (Sun & Zhou, 2023), (Xu et al., 2021), (Bajwa et al., 2021), (Chaix et al., 2019). Some existing ways that have been helpful so far are the use of websites, and chatbots have been used to provide patient education (Briggs et al., 2022) (Alowais et al., 2023), (A. Wang et al., 2023), (Xu et al., 2021).

While AI can provide us with lots of opportunities in tailoring information provision, it comes with its challenges (Ector et al., 2020). The enhancement of care personalisation through AI, which relies on sensitive patient data like medical records and lifestyle information, raises significant concerns about data privacy and security (Alowais et al., 2023), (Lee & Yoon, 2021), (Bajwa et al., 2021). Protecting patient information requires implementing strong measures, including strong data encryption, secure storage solutions, and stringent access controls (e.g., Digi-D in the Netherlands), (Khan, 2023). To mitigate biases, it is essential to thoroughly evaluate the training data and ensure the development process is fair, transparent, and accountable, with ongoing monitoring of AI systems. Individuals using these AI tools should be fully informed about their intended purpose, as well as any potential risks and benefits associated with AI-driven interventions. Overall, it is crucial to ensure that AI-driven solutions are accessible to all, while addressing issues of data biases, inclusivity, and accessibility. This approach will help in leveraging AI in a manner that upholds ethical standards, equity, and patient-centred care (Goodman et al., 2023), (Karimian et al., 2022), (Khan et al., 2023).

This master's thesis focuses on exploring how AI can help manage information overload. This overarching research introduced in section 1.4 will be further elaborated in 'Chapter 3: Methodology.'

2.6 Summary

As research in breast cancer advances, news subtypes and treatment options are continually emerging, leading to an increasing volume of information available. The availability in information has made it more accessible but also more overwhelming for individuals who have recently been diagnosed. They are faced with complex medical information during an emotionally challenging time and may struggle to process and understand it effectively.

Healthcare providers offer support through consultations, documents, and hospital applications. However, due to time constraints and the high number of cases they manage, their ability to provide in-depth assistance is limited. This can lead individuals to seek information from multiple sources. While healthcare providers are the primary source of information, individuals also seek information from the internet, support

groups, social media, fellow patients, etc. which is abundant in nature.

Individuals on the other hand have varying needs and preferences for information. Some actively seek information, referred to as 'information seeker,' while others prefer to avoid information, known as 'information avoiders.' The seeking or avoiding information is to often to reduce feelings of uncertainty, but the complexity and volume of available information can lead to confusion and information overload.

Information overload occurs when the available information exceeds an individual's capacity to process it effectively. It can be caused by the quantity and complexity of information or from an individual's cognitive and emotional capacity and can have negative effects, making it a concern in cancer care. To deal with information overload, several strategies are used such as streamlining information using visual aids, filtering and prioritising information to make it more understandable. Technological interventions presents a promising solution by offering personalised information that simplifies and organises information according to personal needs and preferences.

The COVID-19 pandemic expedited the integration of digital health technologies, including AI, which has now become essential in healthcare for improving efficiency, precision, and patient outcomes. AI is increasingly used in oncology for diagnostics, patient engagement, and managing the complex nature of patient care. The integration of AI has contributed to a reduction in the workload of healthcare providers while also improving patient engagement and other organisational practices.

The cognitive capabilities of AI, such as learning and reasoning, enable it to process and analyze vast amounts of data to uncover meaningful patterns. This capability is particularly beneficial in healthcare, where AI enhances patient engagement by facilitating dynamic interactions between patients and healthcare providers. Through the use of chatbots, virtual assistants, and mobile applications, AI can provide timely responses to patient inquiries, delivering support precisely when needed. AI has made it possible to deliver information in a way that matches the needs and preferences of individuals.

Despite the promising applications of AI in healthcare, its integration presents challenges, particularly concerning issues of privacy, trust,

and confidentiality - areas of critical importance in healthcare domain due to its sensitive nature. Therefore, it is imperative to approach the incorporation of AI in patient care with careful consideration and thorough ethical scrutiny.

Given these ethical considerations, it becomes essential to carefully examine how AI can be applied in specific contexts like patient care in cancer. However, before addressing the overarching research question, the literature study highlights the importance of defining and understanding two key aspects in the context of cancer care in the Netherlands. First, given the wide understanding of information overload in the literature, it is crucial to define its causes, and effects for the purpose of this project. Second, it is important to explore individuals' information-seeking behaviour, including their needs and preferences, and how these factors may contribute to information overload. Gaining a comprehensive understanding of the needs, preferences, and behaviours contributing to information overload will enable me to address the gap between the current cancer care context and the unmet needs of individuals.

The overarching research question then examines how an AI intervention can address the challenge of dealing or preventing information overload by considering the current information-seeking behaviour of individuals and how it contributes to information overload. To fully understand the relationship it is essential to identify the information provision and sources in the current context. These considerations form the foundation for the sub-research questions, which will be discussed in detail in the following chapter.

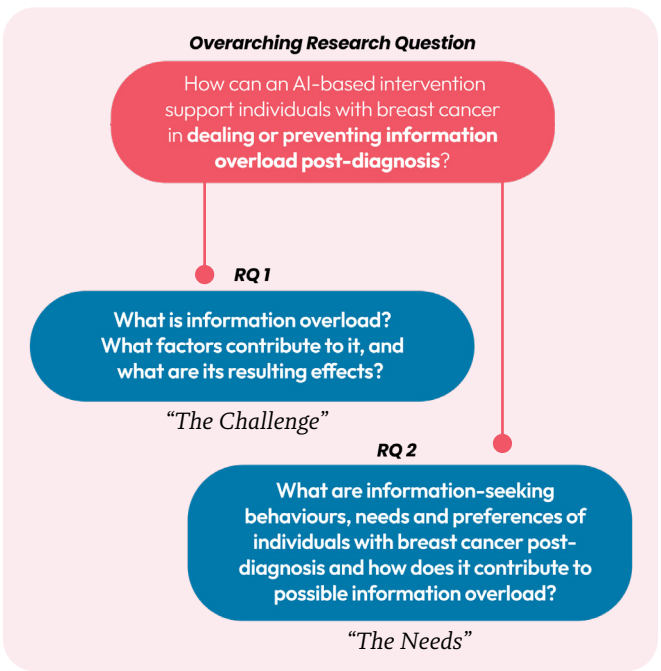
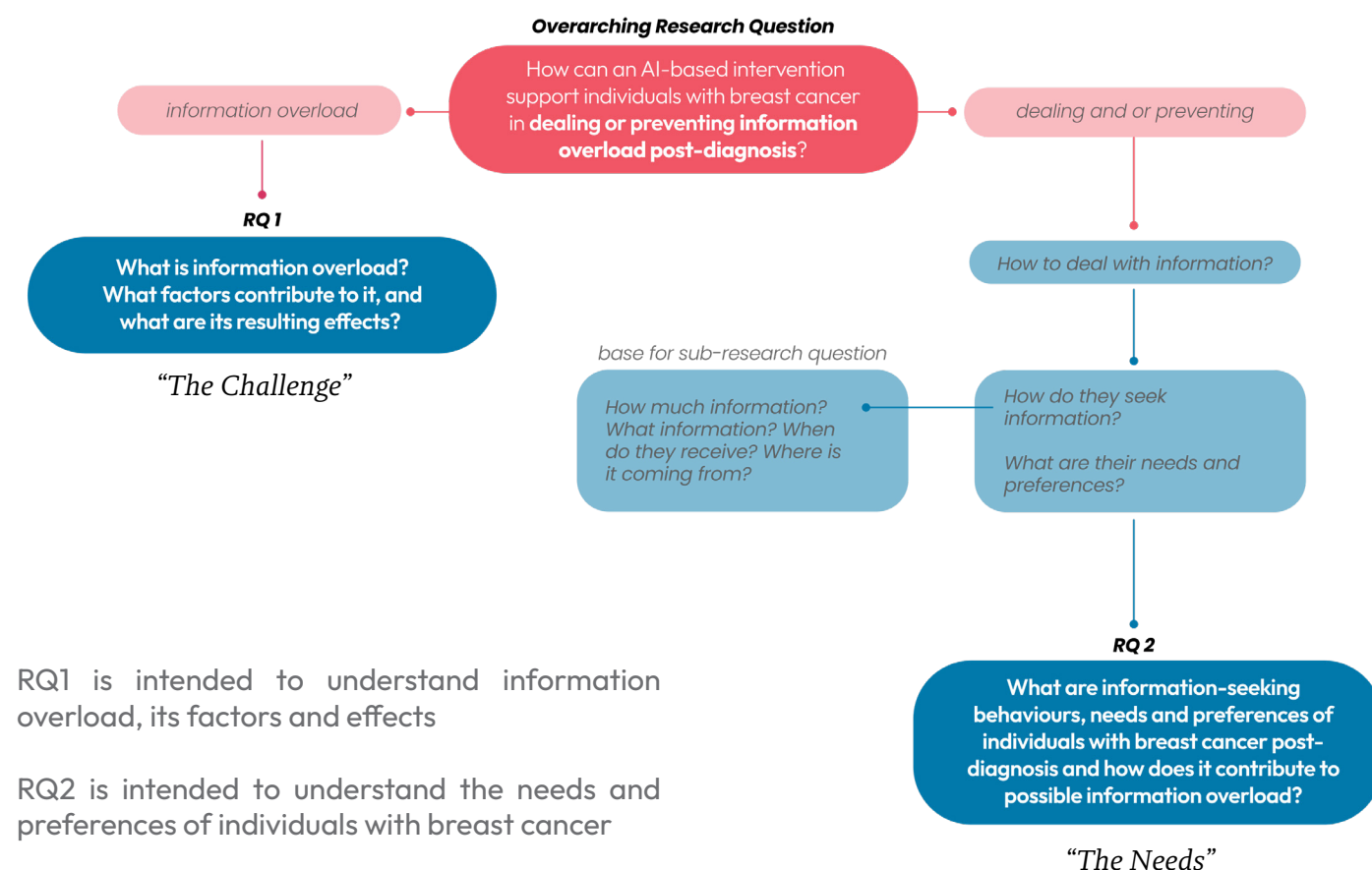


Figure 2.3: Research Questions for the Study

03

Methodology

The knowledge gained from scoping the literature serves as a foundation for further activities in the project. This chapter details the methodology behind the study from research to design.



This thesis project follows a Research for Design (RfD) methodology and began with a broad investigation into information overload in cancer care and scoped to breast cancer due to its various subtypes and variants. After defining the overarching research question and gaining an understanding through the literature, two additional research questions were defined. This process informed the study of the **'Challenge':** "Understanding Information Overload," which addresses RQ1 through defining a framework of information overload and the **'Needs':** "Mapping Needs and Preferences of Individuals with Breast Cancer," addressing RQ2 through mapping activities and interviews with various stakeholders. Both of the research questions helps to understand the current context of cancer care in the Netherlands and to address the overarching research question.

Challenge

Understanding Information Overload

**RQ 1: What is information overload?
What factors contribute to it, and
what are its resulting effects?**

Purpose

The purpose was to broaden my understanding of information overload and its present context in cancer care in order to define it for this master thesis.

Method

In addition to understanding the literature, I conducted exploratory interviews with former patients and a nurse practitioner. Based on these discussions, I identified the key factors of information overload considered for the study. An application was submitted to the Human Research Ethics Committee (HREC) at TU Delft, to ensure ethical compliance given the sensitivity of the healthcare domain. There were potential risks, including emotional distress while sharing personal experiences, confidentiality issues, language barriers, and limited interview time. These were managed by offering support, ensuring privacy by clearly stating the intent, anonymising the data and allowing enough time for interviews to help them express clearly.

Recruitment and Demographics

Participants included former patients (now patient advocates), and a nurse practitioner specialising in pancreatic cancer. They were recruited through my supervisor's network and the nurse

practitioner was approached via email. Nurse practitioners, due to their direct interactions with individuals, possess detailed knowledge of their experiences. The patient advocates, having previously been patients themselves, now engage regularly with other patients, providing insights into their experiences. Both groups offer significant perspectives based on their extensive interactions with a diverse patient population. The participant's profile are highlighted in Table 3.1.

Informed Consent

Prior to the interviews, participants were presented with written informed consent documents outlining the study's objectives, permission to record and transcribe the interviews, the voluntary nature of the participation, and assurance regarding confidentiality.

| Code | Occupation | Cancer Type |
|---------|--------------------------------------|----------------------------|
| P1 - EI | Former Patient, Now Patient Advocate | Lymphoma |
| P2 - E2 | Former Patient, Now Patient Advocate | Sarcoma (Rare Cancer Type) |
| P3 - E3 | Nurse Practitioner | Pancreatic Cancer Care |

Table 3.1: Participant's Profile - Exploratory Interviews

Procedure

Data Collection

A semi-structured interview questionnaire was developed to guide the interviews. This approach allowed for consistent data collection while providing the flexibility to explore individual experiences in greater depth. The questionnaire included both open-ended and specific questions to capture a comprehensive understanding of participants' perspectives on information overload in cancer care. The former patients, now patient advocates, were asked to discuss their personal experiences following their diagnosis, including the challenges they faced in managing information at that time. The nurse practitioner was questioned about her experiences with individuals during diagnosis and the information they received. Both groups were also asked about their experiences with the term information overload and its effects observed in the individuals. All the interviews were conducted via Microsoft Teams, lasted between 30 and 45 minutes and were recorded for analysis.

Data Analysis

The data was anonymised before analysis to ensure participant confidentiality and prevent selective reporting. Thematic analysis was conducted

following Braun & Clarke’s (2006) approach, using an inductive method to generate initial codes. These codes were created on a Figjam board and then cards were sorted into semantic themes, focusing on the explicit meanings within the data. Themes that directly supported the research findings were selected for inclusion in the main report. Card sorting was used to organise the findings, identify common themes, and iteratively refine them for a more nuanced understanding.

The literature study and interviews facilitated the development of a comprehensive framework for understanding information overload, including its contributing factors and effects. After analysing the interviews, I identified which effects were most prominent and selected two key factors of information overload for further study. This framework and the rationale behind the selection of these factors are detailed in ‘Chapter 4, Defining the Framework: Information Overload’ of this report.

Needs

Mapping Needs and Preferences of Individuals with Breast Cancer

RQ 2: What are information-seeking behaviours, needs and preferences of individuals with breast cancer post-diagnosis and how does it contribute to possible information overload?

After defining the framework of information overload, the next step was to investigate and map various aspects, including the types of information (what?) individuals receive, the timing (when?) and methods (how?) of information provision, and the sources (where and who?) of that information.

Purpose

The purpose to gain a deeper understanding of the information provision in breast cancer journey, perspectives of healthcare providers and other stakeholders, information-seeking behaviours of individuals with breast cancer and their needs and preferences.

Method

To find the answers to research question two, I raised sub-research questions and conducted interviews and mapping sessions with various stakeholders, including healthcare providers (oncologists, surgeons, and nurse practitioners) in breast cancer care (n=4), individuals with breast cancer experience (n=7), patient organizations (n=1), patient advocates (n=3), companions (n=2),

and representatives of the research institutes in cancer care (n=3). The profile of the participants is outlined in Table 3.2, Table 3.3 and Table 3.4.

Sub-Research Questions:

What are the key actors involved in breast cancer care from the initial signs to diagnosis? At which stages do individuals receive information? What types of information are provided, and through what channels is it delivered?

What are the current sources of breast cancer information, and how reliable and accessible are these sources perceived to be?

From the perspective of healthcare providers and other stakeholders, what challenges do individuals with breast cancer face following the diagnosis?

What are the preferred sources for obtaining information about breast cancer, and to what extent do individuals trust these sources? What types of information do they seek?

What are the unmet informational needs of individuals diagnosed with breast cancer?

Recruitment and Demographics

Participants were recruited through multiple channels, including my supervisor’s LinkedIn network, Pantons professional connections, emails sent to healthcare providers via hospital websites, and outreach through a representative from kanker.nl. Additionally, a snowball sampling technique was used with each interview to identify and connect with further participants. As an international student with limited access to the Dutch healthcare system, these methods were crucial for broadening the participant pool.

These participants represent the key stakeholders (‘1.3 Overview of Cancer Care in the Dutch Context’) such as individuals with breast cancer, healthcare providers, patient organisation, patient advocates, and representatives from kanker.nl. These key stakeholders interact and engage continually with individuals post-diagnosis. Their diverse perspectives were essential to capture the various dimensions of cancer care and identifying key challenges within the current context. Gathering perspectives from various stakeholders was crucial because it provided a more comprehensive understanding from a system level down to individual level.

Individuals with Breast Cancer

Through the outreach efforts, I recruited seven participants (Table 3.2), including individuals currently undergoing treatment and others in the recovery phase. Two of the individuals (one former patient and now patient advocate and one individual undergoing treatment) were approached on BVN meeting day held at Driebergen-Rijnsburg on May 25th, 2024.

Healthcare Providers

Four healthcare providers (Table 3.3), including oncologists and surgeons, were interviewed. Two of these providers were based in the South of Netherlands, while the remaining two were located in the North of Netherlands.

Other Stakeholders

Seven stakeholders (Table 3.4), from patient organisations and kanker.nl were recruited. One

researcher from NFK and one patient advocate from the Dutch Breast Cancer Association (BVN) were interviewed together online. Two additional patient advocates were interviewed in person during the BVN meeting in Driebergen-Rijnsburg. The remaining three representatives from kanker.nl were interviewed online.

Informed Consent

Prior to the interviews, participants were presented with written informed consent documents outlining the study’s objectives, permission to record and transcribe the interviews, the voluntary nature of the participation, and assurance regarding confidentiality. For individuals with breast cancer, the option to conduct the interviews in multiple sessions was also offered considering their health condition. Their well-being and comfort were prioritised throughout the interview process.

| Code | Occupation | Age | Stage of Cancer | Year Since Diagnosis |
|------|--|---------------------|-----------------------------------|----------------------|
| P1 | Professor | 50+ | Not Known | (1 Year) 2023 |
| P2 | Patient Advocate | 53 | Stage IV, Metastatic I | (4 Years) 2020 |
| P3 | Entrepreneur | 50+ | Triple Negative | (1 Year) 2023 |
| P4 | Homemaker (Post-COVID) | 50+ | Stage II | (1 Year) 2023 |
| P5 | Patient Advocate (now), Volunteer - Ambulance (during Diagnosis) | 42 during diagnosis | Stage II (DCIS - Tumour Invasive) | (12 Years) 2012 |
| P6 | Homemaker | 45+ | Stage I | (3 Years) 2021 |
| P7 | Managing Role at a Pharmaceutical Company | 55 | Stage II A, Triple Negative | (1 Year) 2023 |

Table 3.2: Participant’s Profile - Individuals with Breast Cancer

| Code | Occupation | Region |
|------|--|--------------------------|
| HP1 | Oncologist | South of the Netherlands |
| HP2 | Surgical Oncologist | North of the Netherlands |
| HP3 | MD and PhD Researcher in Medical Decision Making | South of the Netherlands |
| HP4 | Surgical Oncologist | North of the Netherlands |

Table 3.3: Participant’s Profile - Healthcare Providers

| Code | Role | Organisation |
|------|--|--|
| RP1 | Researcher | Dutch Federation of Cancer Patient Organisations (NFK) |
| RP2 | Patient Advocate | Dutch Breast Cancer Association (BVN) |
| RP3 | Patient Advocate | |
| RP4 | Patient Advocate | |
| RP5 | Business Developer | kanker.nl |
| RP6 | Former Nurse and Information Line Operator | kanker.nl |
| RP7 | Patient Advocate | kanker.nl |

Table 3.4: Participant’s Profile - Other Stakeholders

Procedure

Data Collection

A semi-structured interview was developed to guide the interviews. The procedure included open-ended questions to allow the participants to share their experiences from their perspective during a cancer diagnosis. The interviews with the individuals with breast cancer lasted up to 60 minutes with the option to break them into multiple sessions if needed. The interviews with the healthcare providers and other stakeholders ranged between 20 to 60 minutes based on their availability.

The individuals with breast cancer were asked (Appendix D.1) about information-seeking behaviours, the sources they consulted, their involvement in the care journey, the challenges they encountered, their navigation strategies, and their utilisation of counselling services or support from patient organisations. During the interviews, I also conducted several mapping exercises and participants were presented with the sources of information and their needs and preferences were recorded.

The healthcare providers were asked (Appendix B.1) to share their experiences on the same topics with a diverse patient population. In a session with healthcare providers, the breast cancer care journey was mapped out from the initial signs to the treatment phase.

Other stakeholders were asked (Appendix C.1) questions from their perspective on the concerns that individuals have, their coping mechanisms, support services offered to them, etc. They were also presented with the effects of information overload and asked to identify, based on their experience, which effect was most prominent. Their input was also used to categorise the sources of information. All the interviews were conducted online through Microsoft Teams and were recorded transcribed and anonymised for data analysis.

Data Analysis

The interview recordings were revisited, and the automated transcripts were refined by correcting errors and ensuring accuracy. The transcripts were analysed using thematic analysis, specifically through inductive open coding. This approach was selected to allow for the discovery of unanticipated themes, invite diverse experiences, and minimise personal biases. The flexibility of inductive coding enabled the identification of novel themes across

all interviews. Thematic analysis was conducted following Braun & Clarke's (2006) approach, using an inductive method to generate initial codes on atlas.ti, which enabled an in-depth exploration of the interviews and a better understanding of the context from the perspectives of various participants.

The emergent codes from atlas.ti were then organised and sorted on a FigJam board using card sorting, where they were clustered according to semantic themes. Themes that directly supported the research findings were selected for inclusion in the main report. Card sorting was used to organise the data, identify common themes, and iteratively refine them for a more nuanced understanding.

For individuals with breast cancer, quotes were mapped along an axis ranging from positive to negative experiences, and those directly addressing or related to the research question were selected for the purpose of this report and the rest are outlined in Appendix D.2. Themes from interviews with healthcare providers are outlined in Appendix B.2 and for other stakeholders in Appendix C.2. The analysis across all three groups was conducted to identify gaps in the current context, leading to the identification of unmet needs for individuals with breast cancer.

Design Development

Design Explorations

Purpose

Drawing from the needs of individuals with breast cancer identified during data analysis, I translated those needs to formulate the design principles for the concept. These principles were intended to address unmet needs and to inform the next stages of the design process. The principles were then expanded into actionable 'How to' (Appendix E.2) guidelines, outlining various methods through which the needs can be addressed.

Method

The design exploration process was structured into three phases: creative facilitation sessions (Appendix E.1), self-exploration, and conceptualisation. Insights from the creative facilitation sessions were analysed before beginning the self-exploration (Appendix E.3) phase, with ideas that aligned with the overarching research question being carried forward. Following these two phases, I applied the Harris Profile (Appendix E.4) method to select

concept that met all design principles. The final step involved conceptualising the selected concept in preparation for the design development phase.

Procedure

Creative Facilitation Session

I organised creative facilitation sessions with two distinct groups: one with fellow students to generate a range of ideas from a design student's perspective, and the other with healthcare designers at Panton to understand the perspective of experienced healthcare design professionals. Both of the sessions were analysed and re-clustered (Appendix E.1) and the ones that were addressing the research question were carried further.

Self-Exploration Session

As part of the design exploration process, I brainstormed various ideas through sketching guided by the design principles, focusing on those that aligned with the identified needs. These ideas (Appendix E.2) were then systematically organised using a mind map. Utilising the Harris Profile, all the concepts were analysed and the ones that satisfied all the design principles were chosen for the final conceptualisation.

Conceptualisation

Drawing from insights gained during both the creative facilitation sessions and the self-exploration phase, I conducted a final conceptualisation session aimed at addressing the identified needs and adhering to the design principles through Harris Profile (Appendix E.4).

Design Development

Purpose

The purpose of design development was to represent the design characteristics through a digital representation.

Method

Through the concept selection, I defined the design characteristics and envisioned the interaction of the final concept. This phase also included determining the concept's placement within the healthcare system, introduction during the consultation sessions, brainstorming features informed by interview insights, and outlining relevant scenarios. I produced initial sketches (Appendix E) to illustrate these elements and the responses in the concept screens were co-created with Chat GPT (Appendix F.2) prior to the digital representation through Figma.

Design Evaluation

Desirability, Feasibility and Viability

The design concept was presented to three healthcare designers at Panton and one AI expert from TU Delft. Given their expertise in healthcare design and AI, the desirability, feasibility, and viability was discussed with them. The concept was also discussed with two participants from the research phase. Their feedback and recommendations are documented and discussed in 'Chapter 8, Design Evaluation'.

Design Recommendations and Proposed Evaluation Frameworks

Design recommendations, guidelines for design characteristics and two evaluation frameworks were proposed to guide the project's further development.

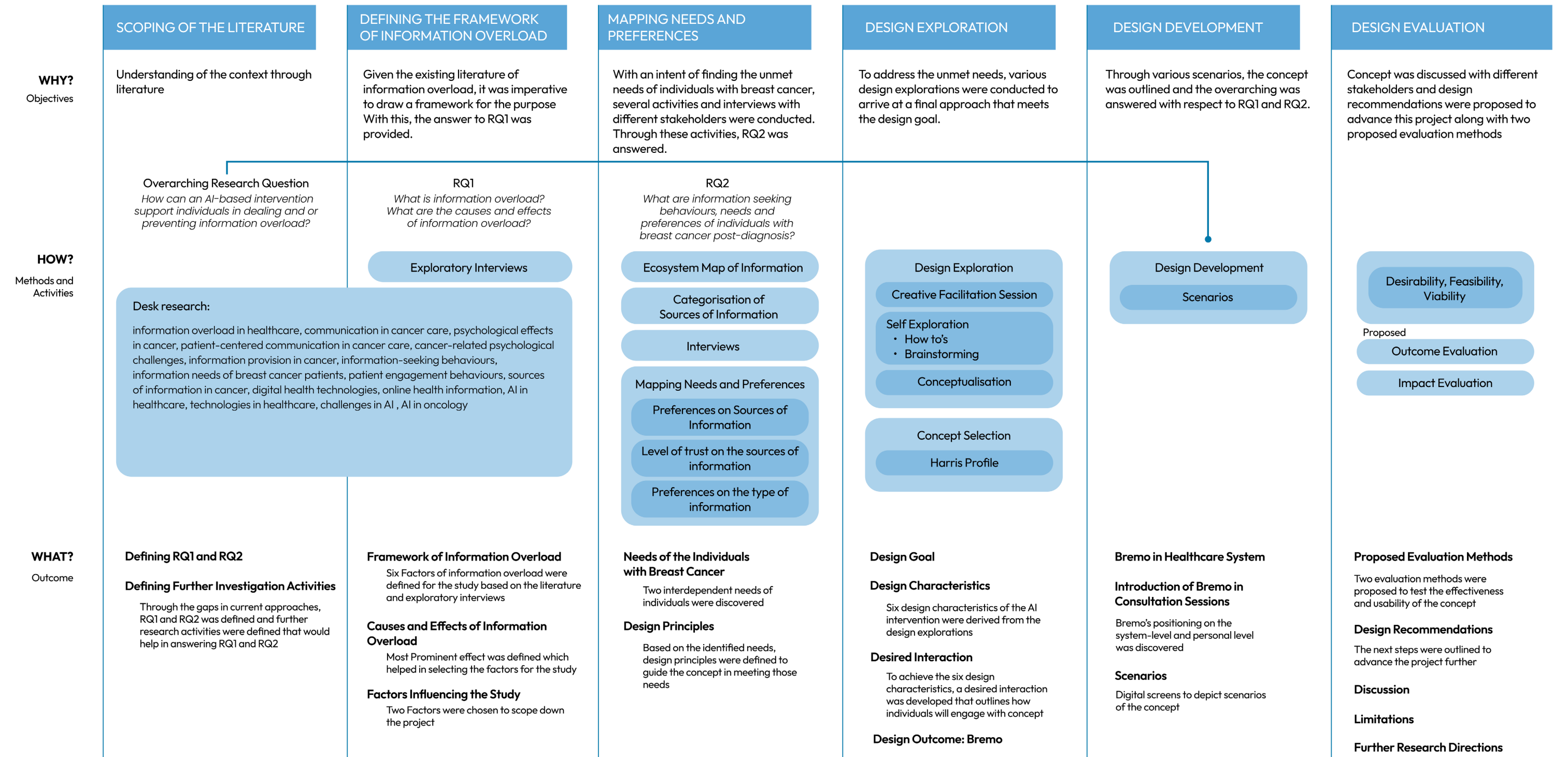
Outcome Evaluation

The evaluation plan involves assessing the design's effectiveness through the procedure outlined in 'Chapter 9, Design Recommendations and Proposed Evaluation'. The participants will review the functional design by using the adapted questionnaires from validated evaluation scales. These will help determine if the concept addresses the unmet needs and supports individuals in managing information post-diagnosis.

Impact Evaluation

For long-term evaluation, a framework has been proposed to transform the effects of information overload (as discussed in Chapter 4) into beneficial outcomes for the concept. This framework is designed for future testing of the concept's long-term viability. The guidelines are outlined in 'Chapter 9, Design Recommendations and Proposed Evaluation'.

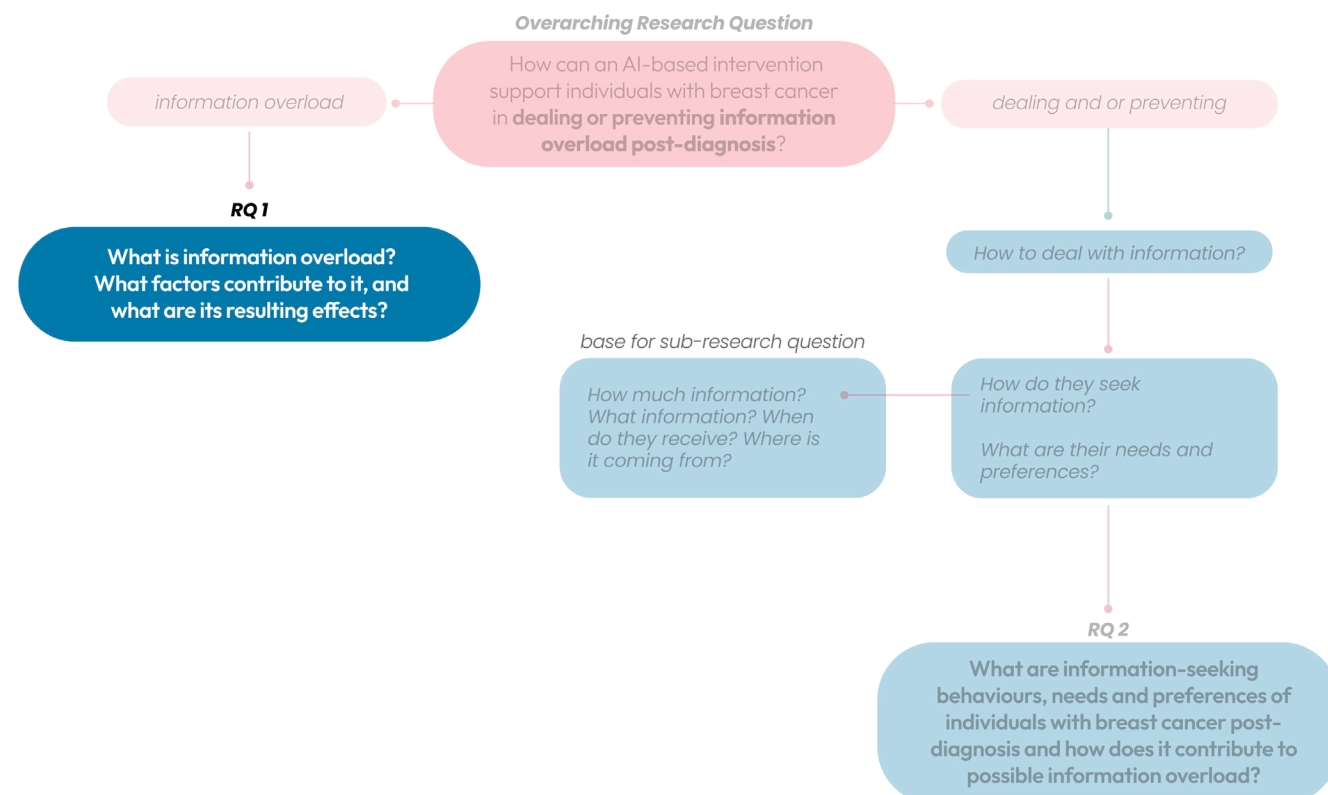
An overview of the methodology is presented in the following section.



04

Defining the Framework: Information Overload

Following a thorough scoping of the literature, it became essential to establish a framework for understanding information overload within the scope of this study. This chapter addresses that RQ1 by defining the framework, exploring the key factors and effects associated with information overload, and concluding with the selection of two specific factors that will be the focus of the study.



Drawing from the literature described in section '2.4 Understanding Information Overload' of this report, the factors contributing to information overload were synthesised in the context of breast cancer and I developed a framework for information overload (Figure 4.1) for the purpose of this master thesis.

4.1 Defining Information Overload

Information overload is a multi-dimensional construct and a complex phenomenon which is triggered by volume and complexity and the fragmented nature of information, emotional state, the cognitive capacity of individuals and the available time between the diagnosis and the treatment phase. It denotes the feeling of being overwhelmed by these factors, making it challenging to understand the available information.

4.2 Factors of Information Overload

The factors contributing to information are articulated as follows: Volume of Information, Cognitive Capacity, Emotional Response, Complexity of Information, Fragmented Information and Available Time (Figure 4.1).

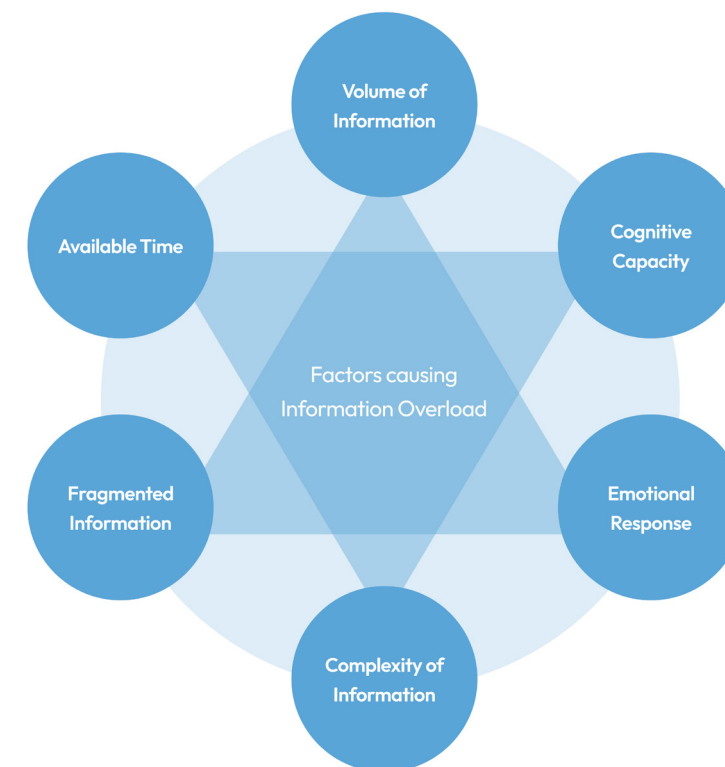
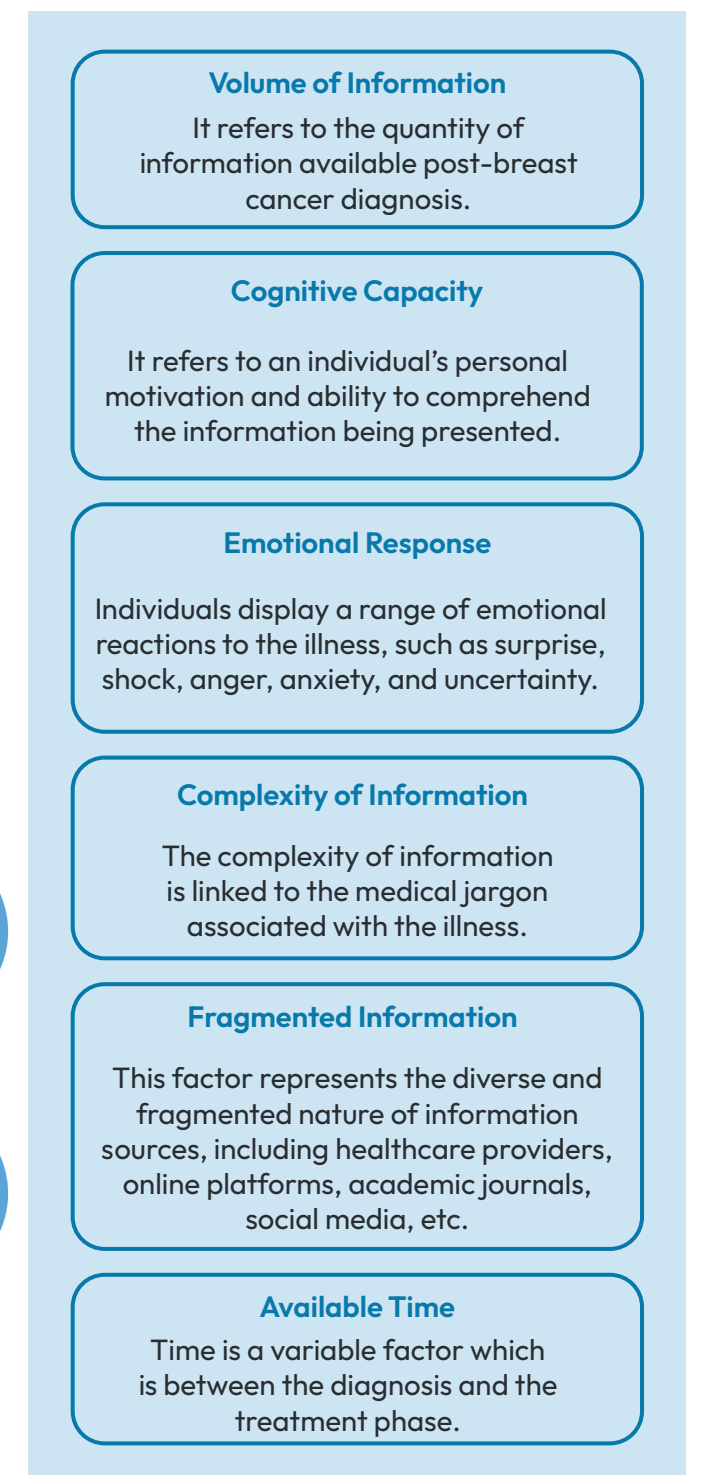


Figure 4.1: Framework of Information Overload

Each of these factors contributes to information overload in various ways, either individually or in combination, and at varying times. Information overload can be triggered by emotions, the complexity of information, the volume of information, or any combination of two or more of these factors.

Among these factors, certain factors are extrinsic (external factors); Volume of information, available time, complexity of information and fragmented (diverse sources) while others are intrinsic (internal factors): emotional response and cognitive capacity.



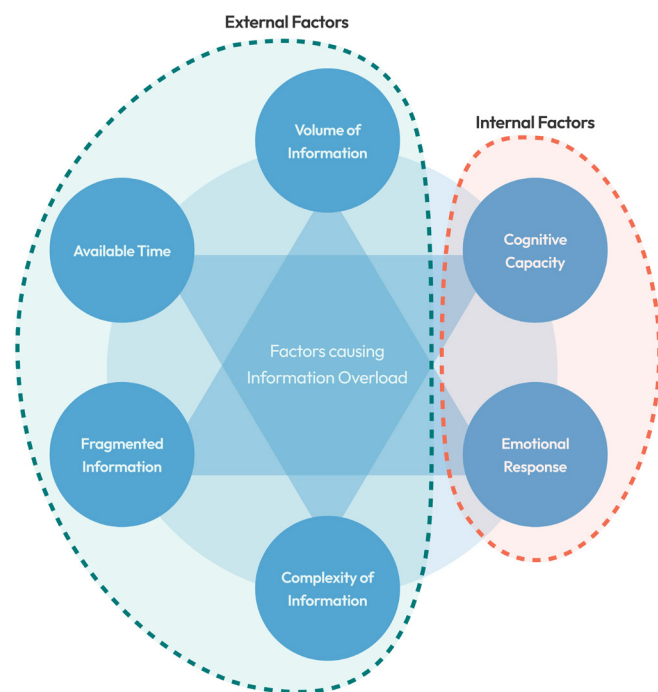


Figure 4.2: External and Internal Factors of Information Overload

4.3 Effects of Information Overload

To understand and define the effects of information overload on individuals with breast cancer, I first drew a relationship between the factors and information overload.

Relationship Between Factors and Information Overload

The factors influence and interconnect with each other. The amount of information through the sources that are fragmented can increase the volume and can lead to confusion and difficulty in identifying the relevant information. The volume of information can surpass the capacity to process the information effectively and contribute to information overload. Time constraints can hinder the capacity to navigate through various information sources, as well as manage the volume and complexity of the information.

Emotional responses serve as cognitive filters, significantly influencing how individuals perceive and interpret information. In the context of illness, emotional responses are particularly critical, as they are closely linked to survival instincts, which can either facilitate or obstruct understanding and make it challenging to comprehend large volumes of fragmented medical information within a limited time. The complexity of cancer-related information can challenge an individual's cognitive capacity, and when cognitive capacity is limited, the information may seem even more difficult to process, leading to emotional distress. The complexity of the information can also be intensified by the amount of information and the fragmented nature of its sources.

Since these factors are influenced by each other and are interconnected, they also lead to intertwined effects (Figure 4.3). The effects of information overload can include confusion, decision paralysis, challenges in difficulty in finding relevant information, difficulties in understanding and communicating, psychological distress, and trouble in processing and retaining information.

Prominence of the Effects

After defining the factors and effects, insights were gathered from medical professionals, including a former nurse now working as an information helpline operator (with 18 years of experience), one medical researcher, one surgical oncologist, and a

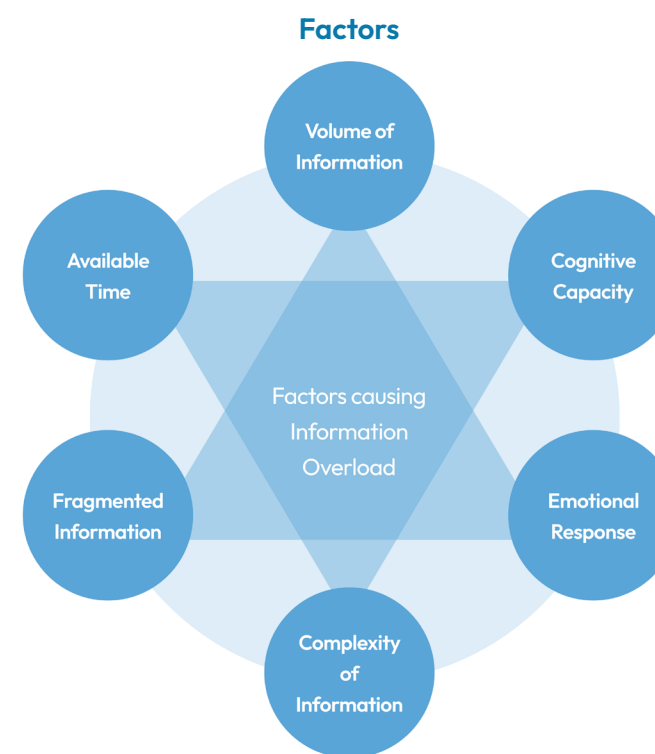


Figure 4.3: Effects of Information Overload

- Effects**
- Difficulty in Processing
 - Causes Confusion
 - Difficulty in Finding Relevant Information
 - Difficulty in Understanding
 - Decision Paralysis
 - Difficulty in Retaining
 - Psychological Distress
 - Difficulty in Communicating

patient advocate (who is also a former patient) (Figure 4.4). The aim was to explore which factors have the most significant impact. These insights were sought to gain understanding from the perspective of medical professionals and their daily interactions with a broad range of individuals diagnosed with breast cancer. The information collected from these experts were presented in a map through Figure 4.5 and informed the selection of factors for the study's findings.

The former nurse and information helpline operator assists individuals with cancer over the phone, often receiving calls from those simply needing someone to talk to or asking medical questions about the illness. During the session, the most prominent effects that were identified were difficulties in processing and understanding information. Individuals diagnosed with breast cancer experience often psychological distress along with receiving an overwhelming amount of information. The complexity of treatment options further complicates the understanding of breast cancer. For example, after undergoing surgery, individuals may question the need for additional treatments like radiation therapy. They struggle to grasp the purpose of the information and frequently ask, "Why is this part of the treatment necessary?" This highlights the lack of clear explanations from healthcare providers.

On the other hand, healthcare providers, including oncologists and surgeons, also find it challenging

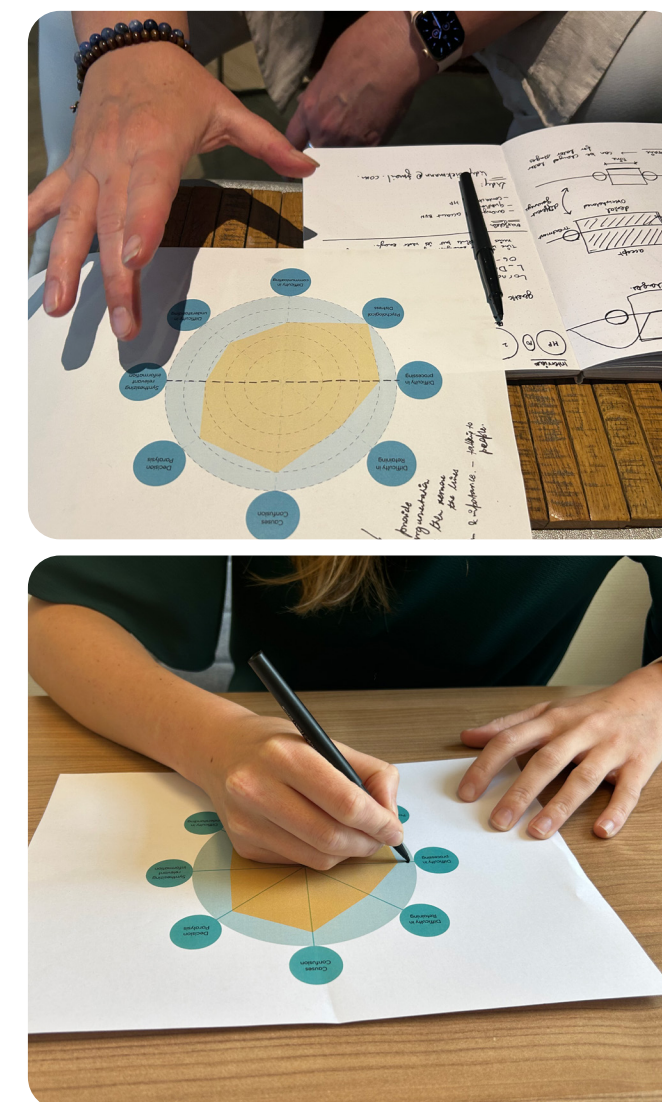


Figure 4.4: Offline Sessions with - up: Patient Advocate, down: Medical Researcher on Determining the Prominence of the Effects of Information Overload

to justify treatments and predict outcomes due to the many variables involved, such as the severity of the illness and the body's response to chemotherapy.

Individuals, seek reassurance and clear explanations but often face uncertainty, which makes it difficult for them to process information both intellectually and emotionally. Moreover, the complex medical terminology used can further hinder their understanding. The surgical oncologist highlights that this information overload can lead to decision-making difficulties and increased psychological distress and highlights the need for effective communication; healthcare providers need to connect with individuals, understand their concerns, and offer clear, relevant information tailored to their needs. This approach helps individuals manage confusion and make informed

However, not everyone is able to do so independently and may need additional support. Although family and friends often step in to assist, their involvement can sometimes add to

the confusion. It was also noted that this period is exceptionally busy and the resulting psychological distress significantly contributes to the feeling of being overloaded.

"All of them are very important, but I think it's the difficulty of understanding what's going on and the difficulty in processing all the information you get on which kinds of treatment you can get is difficult. The psychological distress is always a factor throughout the illness."

"I think that the information they getting is, sometimes very difficult. It's not in the language [refers to the medical jargon] people talk."

- RP6, Former Nurse and Information Line Operator

During an in-person session with the patient advocate, she reiterated similar concerns, emphasising the importance of pinpointing relevant information and the challenges involved in understanding it. She stresses that individuals often struggle to understand their case and stage of illness, as they are primarily focused on seeking treatment and recovery. They often lack insight

into the complexities and various factors of their illness and are unsure which treatments are most suitable and effective for their situation.

"And I think there's a tendency for you [you refers to patient here] to make your own decision - not everybody can make their own decision. They need support, and sometimes you get your information in booklets or by looking at the website. And a week later, you have to make a decision without talking to a physician or somebody who can help you understand what kind of decision you have to make and what the consequences are of your decision."

- RP6, Former Nurse and Information Line Operator

"I think there's a big difference between highly educated people and less educated people. They have lesser problem while there is way more problem for the less educated people in processing, communicating and understanding."

- HP3, MD & PhD Researcher, Medical Decision Making

In conclusion, although all effects of information overload are interrelated and equally significant, much like the factors contributing to it, these factors are neither absolute nor easily quantifiable. Although the effects are similar in the majority of the individuals, their impact varies, influenced by personal circumstances, emotional states, and the complexity of the information encountered. Addressing information overload requires a nuanced approach that considers these variables and aims to provide tailored support to help individuals deal with information. The findings here in this chapter are specific to information overload and further investigation needs to be done and connect the other aspects like information-seeking behaviour, understanding needs and preferences, and various perspectives within breast cancer care.

Based on this, the next section on the following page considers the factors for the purpose of the study.

Finally, the medical researcher highlights and segregates different aspects of highly educated individuals generally facing fewer difficulties in processing, communicating, and understanding information compared to those with less education. However, regardless of education level, all individuals experience challenges in retaining information, dealing with psychological distress and confusion, and identifying relevant details to make informed decisions.

"I just had a patient who wanted her other breast removed and it was not relevant at all and she had never heard that. And now she's like, 'ohh, so it doesn't matter if you know if it metastasizes if I remove the other breasts', and like you know, she was thinking irrelevant but once you explain, it's fine. You just have to make sure to catch their thoughts about why they think they should decide a way that you think is not well, you know, it's like after you have to listen to them. Not only send the information, but also listen how they pick it up and what they think about it. And because sometimes it's not correct."

- HP4, Surgical Oncologist

"They have so much going on. A lot of people are asking things for, you know, life usually gets very busy when you have the diagnosis. I think a lot of people call and wanna know 'how it goes and you have to tell and then you have to show how you know, 'How it's gonna affect my life, Am I going to die?' And then there's not much brain capacity left to listen and to make room for the whole talk about breast cancer and decision-making. So I think it's that stress thing that I know is in the way I have to find the time and make sure that they don't think it goes too slowly to yeah, have room enough to get."

- HP4, Surgical Oncologist

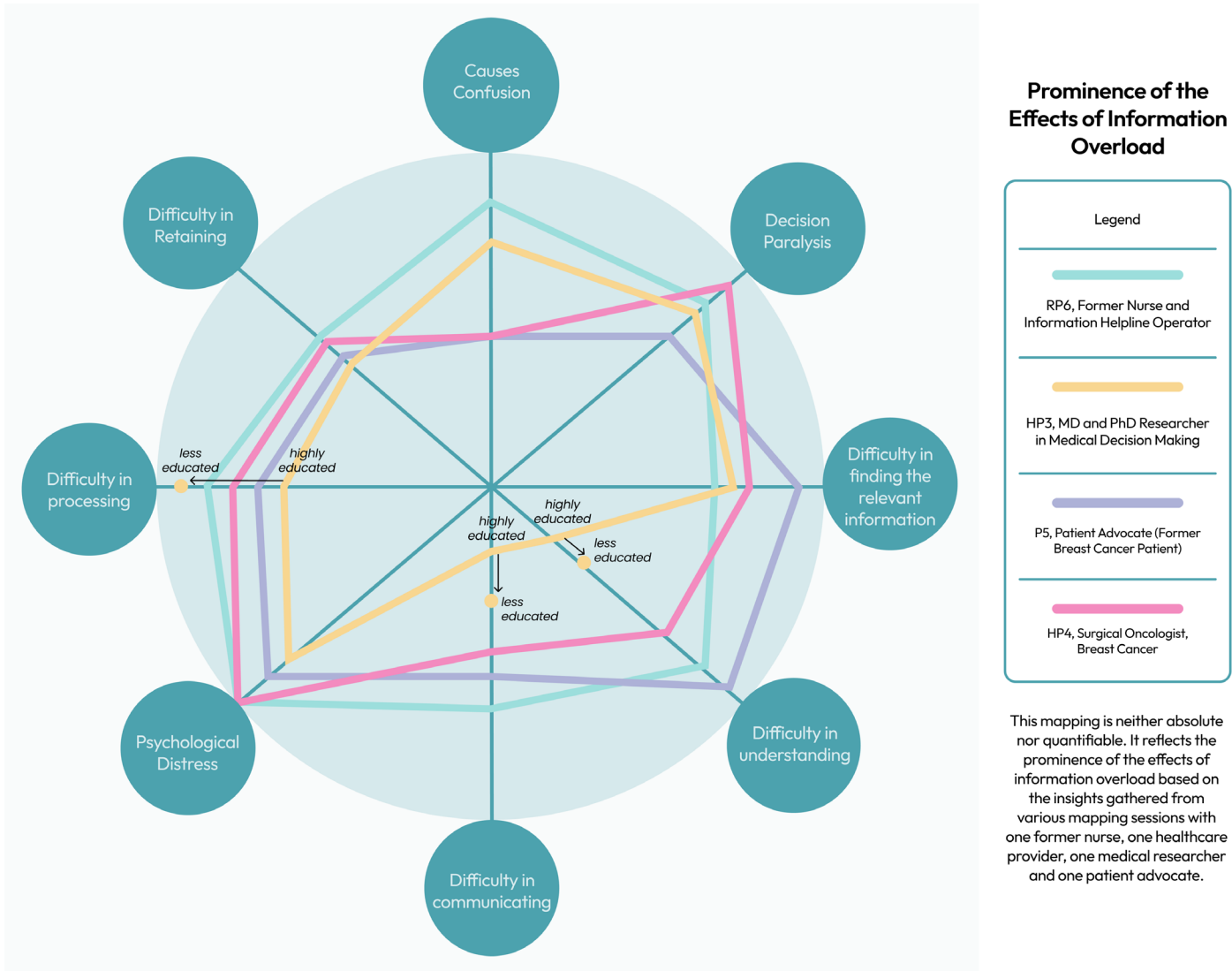


Figure 4.5: Mapping the Prominence of the Effects with Healthcare Stakeholders

4.4 Factors Considered for the Study

This research project prioritises two key factors of information overload that impact individuals diagnosed with breast cancer: complexity of information and emotional response (Figure 4.6). These factors were chosen because they offer unique opportunities for design interventions, unlike other aspects such as fragmented information sources, cognitive capacity, available time, and volume of information. The selection of these factors followed exploratory interviews with former patients (now patient advocates), a nurse practitioner specialising in pancreatic cancer, and a representative from kanker.nl, which provided valuable insights into how individuals experience and are influenced by these factors.

The complexity of breast cancer, often conveyed through intricate medical terminology, poses a considerable challenge for individuals dealing with the illness. As a life-threatening condition, cancer introduces patients to a realm of terminology that is frequently unfamiliar and difficult to understand, especially for those without a medical background. In a conversation with a patient advocate, who is also a former lymphoma patient, she shared her personal experience with cancer-related language.

She described the difficulty of adapting to the medical terminology used by healthcare providers and highlighted the disparity between

the technical language employed by doctors and the more accessible language familiar to patients. This communication gap, she noted, is not a reflection of any inadequacy on the part of healthcare providers, who are trained to use precise terminology, but it does contribute to the challenge patients face in comprehending the complexities of their illness.

In the context of breast cancer, the complexity of information is amplified by the inclusion of various subtypes and treatment options, adding layers to the complexity. On the other hand, the emotional response to a breast cancer diagnosis is highly individualised; it varies greatly among individuals, ranging from anticipation to shock and disbelief. This internal factor significantly influences a patient's ability to cope with the diagnosis and navigate their treatment journey. While some individuals may feel mentally prepared, others may be caught off guard, struggling to come to terms with their new reality. Given the diverse range of emotional reactions, it's challenging to predict how each individual will respond to such a situation.

Interaction Between Factors

The emotional response and the complexity of information are positively correlated and mutually influence each other. Increased emotional distress can impair one's ability to absorb, process, and comprehend information. On the other hand, complex information can overwhelm individuals, complicating decision-making processes and increasing the burden of considering potential outcomes.

“First, they get too much information and then they are quite emotional, and especially in the beginning, it's a very emotional journey. So it's difficult to understand information and to comprehend all the information and it's new for them. And then in a very stressful situation to take a role in the process & they're very dependent on their doctors and it's a new world they get into and that's very difficult with lots of difficult language.”

- RP6, Former Nurse and Information Line Operator

“So you have a medical file and the doctors, they write doctor's language. So not patient language, doctor's language.” “That's just the way that they are being trained.”

- P1 - EI, Patient Advocate & Former Patient (Lymphoma)

As also highlighted by the representative from kanker.nl, individuals often experience emotional distress during their cancer journey, particularly in the initial stages and this in turn makes it difficult for them to comprehend the information presented to them. The nurse practitioner's point further emphasises this point, noting that the individuals often struggle to absorb the information provided to them and it becomes hard for them to fully comprehend and internalise.

“I think patients do not mention it by saying it directly, but I can see it in the kind of questions I get and the way they look at me. Sometimes they're looking at me and looking through me and I can see that all the information did not land somewhere. And I think that's the most important way I can see it or if they call me with the kind of questions I know they haven't heard everything during the talk and maybe sometimes they call me a day later.”

- P3 - EI, Nurse Practitioner, Pancreatic Cancer Care

These factors, while distinct, intersect in shaping the experience of breast cancer patients. The complexity of information represents an external factor (system focussed), with a focus on the healthcare system's structure, information representation and communication practices. While, the emotional response is an internal factor (person-focussed), centred around the individual's emotional state and coping mechanisms. Both of these factors are important to address in order to support individuals on their journey post-diagnosis. Despite their differences, there's an opportunity to mitigate both through design interventions.

4.5 Conclusion

This chapter concludes by addressing the first research question:

RQ 1: What is information overload? What factors contribute to it, and what are its resulting effects?

Information Overload is a complex, multi-dimensional construct which is caused due to various external factors, such as volume of information, complexity of information, fragmented sources, available time and internal factors like cognitive capacity and emotional response. These factors lead to numerous effects such as difficulty in processing, causes confusion, difficulty in understanding, difficulty in retaining, psychological distress, difficulty in communicating and difficulty in finding relevant information. For the purpose of this study, one external and one internal factor were selected where I, as a designer, can intervene in and help the individual with breast cancer in dealing with the information post-diagnosis.

The findings will inform the next steps in the research, which include interviewing various stakeholders to gain their perspectives, mapping the breast cancer care journey and information dissemination in the current context. Finally, the needs and preferences of individuals with breast cancer will be identified through a series of mapping activities.

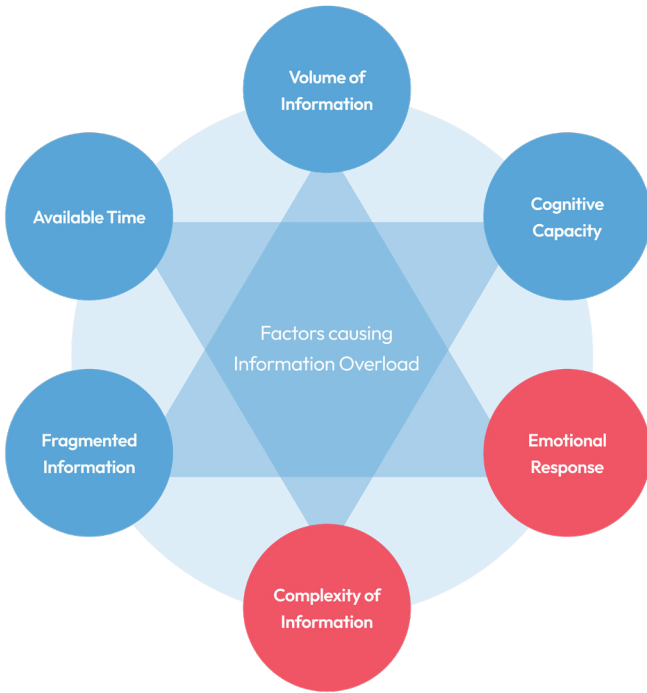
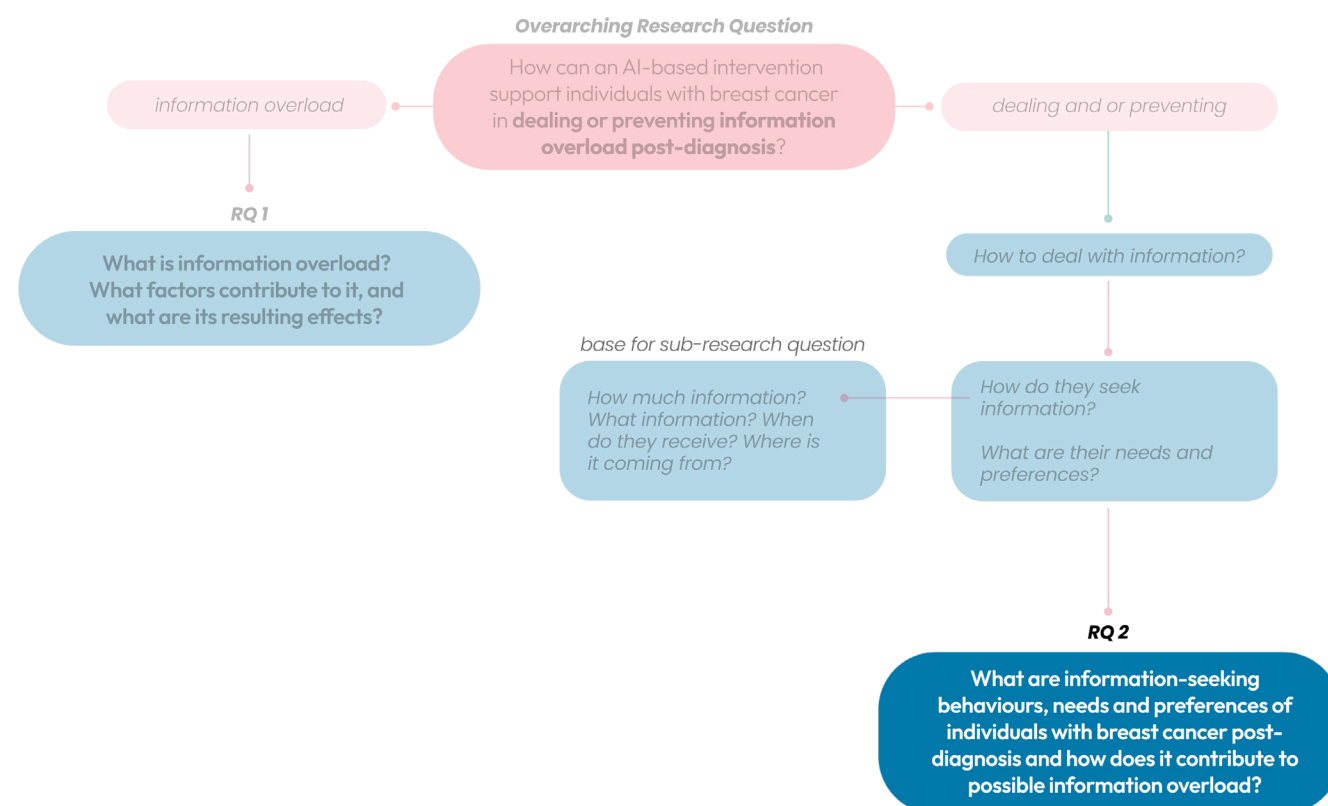


Figure 4.6: Factors Considered for the Study

05

Mapping Needs and Preferences

This chapter derives the unmet information and emotional support needs of individuals with breast cancer by addressing RQ2 and its sub-questions. This is done by mapping the journey of breast cancer along with the layer of information, categorising the existing sources, understanding the perspectives of all the stakeholders, as well as the needs and preferences of individuals. The chapter concludes by outlining the research outcome and defines the design principles, guiding the design exploration phase.



Based on the research activities like interviews and mapping exercises, I identified that the primary needs of individuals with breast cancer fall into two main categories: informational needs and emotional needs. The findings align with existing literature, which also highlights the interconnectedness and continuous interaction of these needs. Individuals require support that addresses both their informational and emotional needs to help reduce stress and improve their ability to cope with their illness (Duimel et al., 2022), (Bol et al., 2022), (Slevin et al., 1996). The type and level of support each individual needs and seeks can vary, influencing their behaviour in seeking information and emotional support. This chapter will elaborate on how these needs were identified through RQ2.

RQ 2: What are information-seeking behaviours, needs and preferences of individuals with breast cancer post-diagnosis and how does it contribute to possible information overload?

To address this research question, it was essential to investigate the existing methods of information dissemination, identify the various sources through which individuals seek information, assess the level of trust attributed to these sources, and understand the specific needs and preferences of individuals. Several sub-research questions were formulated to guide this investigation:

- What are the key actors involved in breast cancer care from the initial signs to diagnosis? At which stages do individuals receive information? What types of information are provided, and through what channels is it delivered?
- What are the current sources of breast cancer information, and how reliable and accessible are these sources perceived to be?
- From the perspective of healthcare providers and other stakeholders, what challenges do individuals with breast cancer face following the diagnosis?
- What are the preferred sources for obtaining information about breast cancer, and to what extent do individuals trust these sources? What types of information do they seek?
- What are the unmet informational needs of individuals diagnosed with breast cancer?

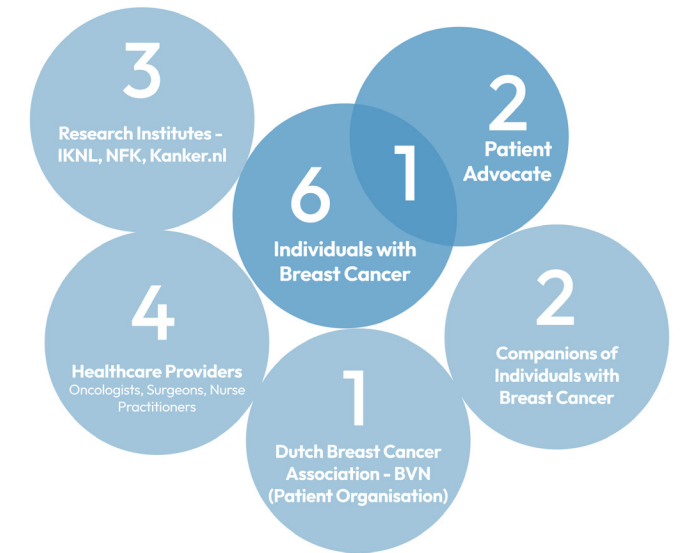


Figure 5.1: Interviews with Different Stakeholders

The sub-research questions will be outlined in sections of this chapter, with findings addressed through various activities and interviews (Figure 5.1) conducted with individuals and key stakeholders.

Healthcare providers (n=4) were inquired about their experiences with the individuals during the diagnosis stage, their engagement behaviours, their queries regarding understanding the information, the role of companions they observe during consultation sessions, challenges they face in providing information, and the strategies they are currently adopting to help the individuals understand the information. With the healthcare providers, I also mapped the cancer journey with the Metro Mapping Tool (Metro Mapping, n.d.), to understand the information dissemination and actors in the journey from first signals to diagnosis stage. With the patient organisation, patient advocates and representatives from kanker.nl (n=7), I inquired about their experiences with the individuals on the difficulties that they experience post-diagnosis, both on the complexity of information and emotional response (4.4 Factors Considered for the Study). Then I categorised all the sources of information into primary, secondary and tertiary sources. After understanding the perspectives of all, I conducted interviews with individuals with breast cancer (n=7) to understand their experiences post-diagnosis with the information they received and mapped their needs and preferences in terms of the source they preferred, the level of trust they placed in these sources and the type of information they sought during the diagnosis.

The interview questions for healthcare providers are outlined in Appendix B.1, for patient organisation and patient advocates in C.1 and for individuals with breast cancer in D.1.

5.1 Information Map in Breast Cancer Care



Information Map in Breast Cancer Care

Colours

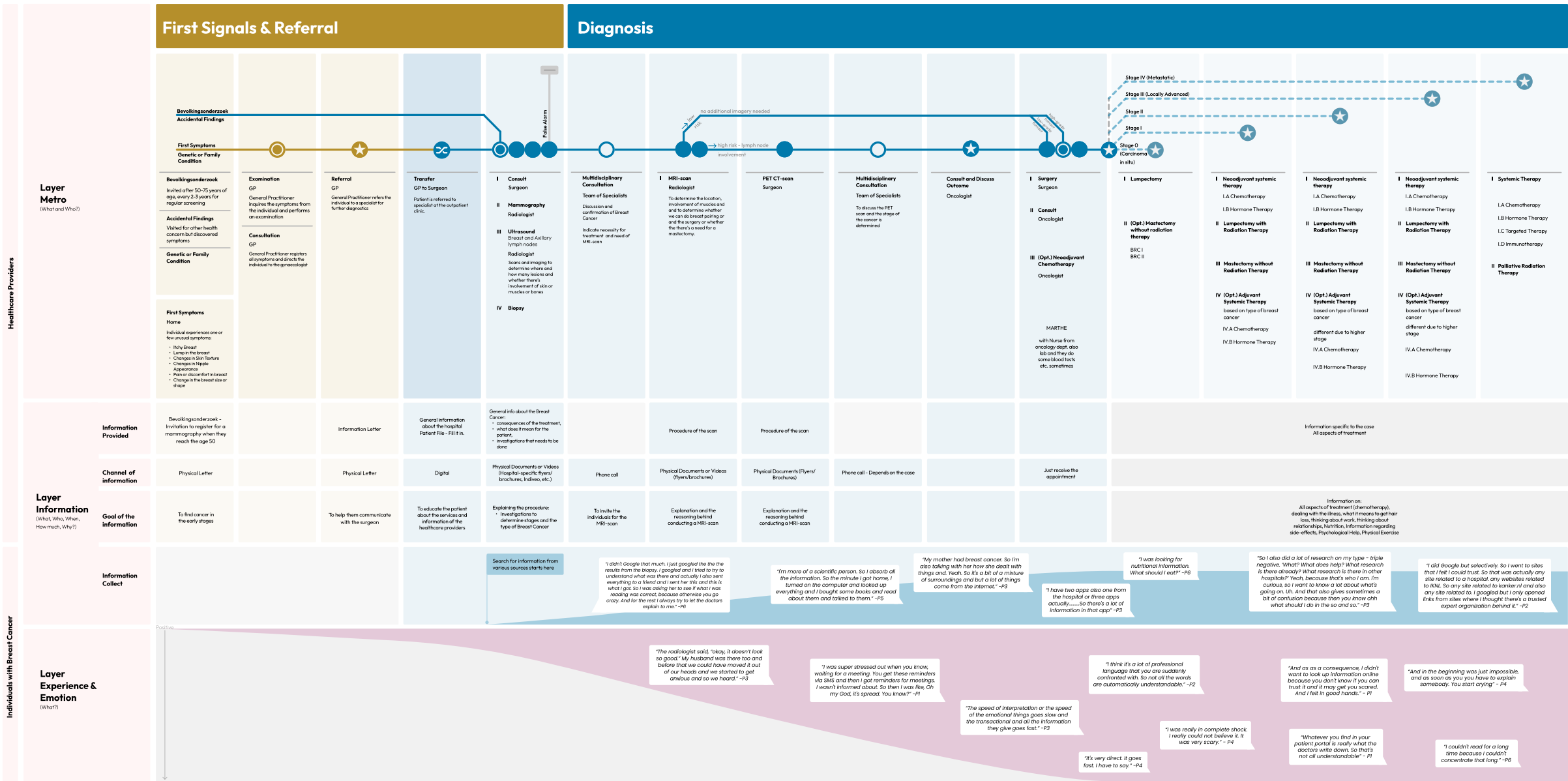
- First Signals and Referral
- Diagnosis
- Stages of Breast Cancer

Legend

- Transfer path of the patient
- Stages of Breast Cancer
- Consultation - discussion with patient (possibility to change path)
- Treatment Step
- Step without participation or presence of the patient (e.g. Multidisciplinary Consult)
- ★ Discussion with patient and planned SDM moment
- ⌂ Transfer of Phase: Continuation of path in another Metro Line
- Patient Stops the Treatment

This map has been co-created with two healthcare providers in an online session and a healthcare designer from Pantón.

The experiences during the cancer diagnosis and information-seeking behaviours are generalised and based on the interviews with seven individuals with breast cancer. They may not represent the entire patient population.



QR code to download Information Map in Breast Cancer Care

Figure 5.2: Information Map in Breast Cancer Care using Metro Mapping Tool (Metro Mapping, n.d.).

To thoroughly understand the current state of information in breast cancer care, it was necessary to investigate the journey from the initial symptoms to the diagnosis stage in the Netherlands and identify the key actors and channels of information dissemination. This mapping of information allowed me to address the first sub-research question.

What are the key actors involved in breast cancer care from the initial signs to diagnosis? At which stages do individuals receive information? What types of information are provided, and through what channels is it delivered?

To map the breast cancer care journey, I engaged with two healthcare providers—an oncologist and a surgical oncologist—to gain insights into the information flow within the breast cancer care pathway and a healthcare designer from Pantón. The treatment pathway, from the initial signs of breast cancer to diagnosis, was mapped using the Metro Mapping tool (Metro Mapping, n.d.).

Layer Metro
The “Layer Metro” maps the breast cancer care trajectory, outlining the critical steps that individuals undergo from the first symptoms to the diagnosis stage. These steps are represented by distinct symbols, which are explained in the legend of the Metro Map. The journey encompasses various stages, such as diagnostic tests and consultation sessions, leading up to the determination of the cancer stage.

Layer Information
The “Layer Information” is divided into four components: information provided, channels of information, goals of information, and information collected. The first three components—information provided, channels, and goals—are addressed by healthcare providers at different stages of the care trajectory, detailing what information is given, through which medium, and for what purpose. The “information collected” component specifies the information individuals seek out independently. The curve on the map visually illustrates the timing and intensity of information-seeking, though it is not a quantifiable measure. This search usually begins during diagnostic testing, when individuals start to suspect an issue and reaches its highest point following diagnosis.

Layer Experience and Emotion
This layer captures the emotional experiences of the individuals during the diagnosis process, represented through quotes from interviews. The curve on this layer illustrates the negative emotions experienced by the individuals, providing a visual representation of their emotional journey.

This information map offers a detailed view of the breast cancer care trajectory, illustrating the stages at which information is provided, the types of information disseminated, and the channels used for delivery. The quotes of the individuals with breast cancer were added after conducting interviews with them. The map can be accessed via the QR code provided in Figure 5.2. and serves as a foundation for understanding the subsequent findings.

5.2 Categorising Sources of Information

What are the current sources of breast cancer information, and how reliable and accessible are these sources perceived to be?

Through the information map presented in the previous section and the literature review, I found that individuals gather information from various sources available to them. To bring structure and clarity to these sources, I classified them into three distinct categories. This classification helps streamline the sources as per their existence and comes to use in the later sections of the findings when individuals were questioned about their preferred source. The categorisation into primary, secondary, and tertiary sources was reviewed and validated by three healthcare professionals in online sessions, where we also evaluated the accessibility and trustworthiness of these sources through quadrant mapping.



Figure 5.3: Categorising Sources of Information

Primary Source

Primary sources of information in breast cancer care are the healthcare providers, (oncologists, surgeons, nurse practitioners, radiologists, and genetic experts). These professionals serve as the primary point of contact for patients, offering essential medical information about diagnosis, treatment options, and care plans to individuals. They play a key role in guiding individuals through the complexities of their cancer journey, providing clear explanations, addressing concerns, and offering support in the way they can to help individuals understand their condition.

Oncologists offer detailed information about treatment options, while surgeons provide insights related to surgical procedures. Nurse practitioners extend the information given by oncologists and surgeons during consultation sessions, offering further details on patient organisations, addressing queries about side effects, and providing general information about the hospital. Radiologists perform diagnostic tests and explain the imaging results, and genetic experts provide

crucial information about the genetic aspects of the illness. The primary sources provide information either in the form of verbal, written or through flyers, brochures, etc.

Secondary Source

The secondary sources are patient organisations, verified websites such as kanker.nl and hospital-specific applications, websites and blogs by medical professionals. The patient organisation provides factual information through their websites, flyers, brochures, and helplines, as well as emotional support via blogs, offline support groups, buddy systems, and call helplines. Verified websites like kanker.nl and hospital apps similarly provide factual and emotional support information and facilitate connections among patients, allowing them to share experiences and support each other online (Figure 5.4). The blogs from the medical professionals can also be helpful and provide a guide to the individuals.

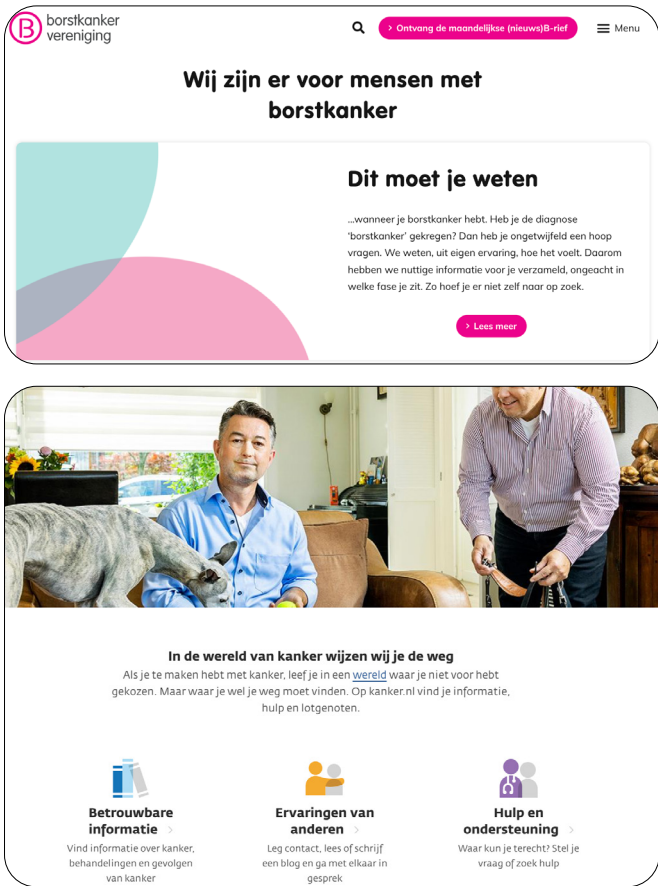


Figure 5.4: Secondary Sources of Information
up: borstkankervereniging, down:kanker.nl

Tertiary Source

The tertiary source of information, encompasses a broad range of additional resources that can provide information to individuals. These sources include experiential knowledge obtained through support groups (Figure 5.5), interactions with

fellow patients, co-workers, family, and friends, as well as content from social media platforms (e.g., Facebook, Reddit, etc.), blogs, and YouTube videos. These resources often offer not only information but also emotional support. The internet, on the other hand, serves as a vast repository of information, including research papers, search engines like Google, and other traditional media such as books, magazines, and newspapers also fall under this category, offering a diverse array of information on cancer-related topics.

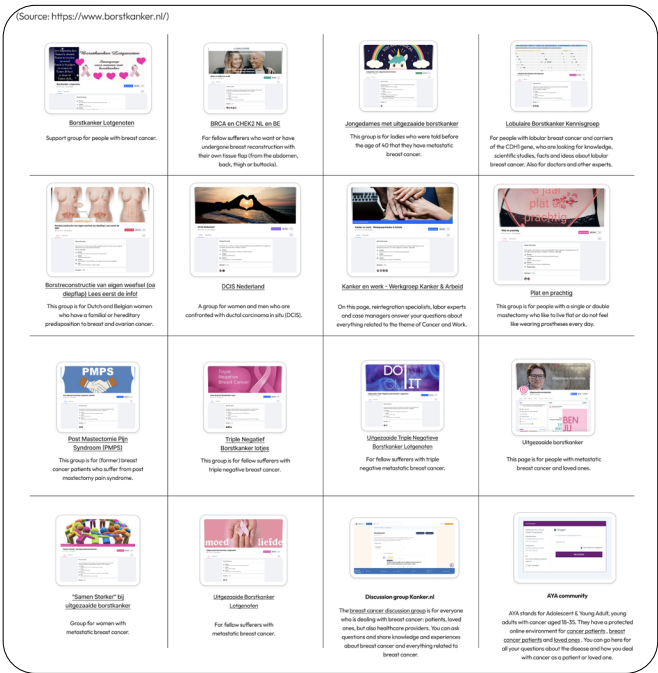


Figure 5.5: Support Groups on Online Platforms

Following the initial mapping process of the sources into primary, secondary and tertiary information sources, assessing the accessibility and trustworthiness of these sources was crucial. I categorized them into four quadrants and sought input from medical professionals and patient advocates to determine which sources they considered most reliable and accessible to individuals with breast cancer.

Within the spectrum of the primary sources of information, healthcare providers (oncologists, surgeons, nurse practitioners) trustworthiness was universally attributed. However, accessibility varied among different professionals. Due to the demanding schedules and availability, oncologists and surgeons were less accessible as compared to other sources. The radiologists on the other hand were trustworthy and accessible, yet their primary focus remained on conducting imaging and scans, without offering additional information beyond this domain. Nurse Practitioners were highly trusted and accessible, their ability to connect and level with the individuals to provide detailed explanations was highlighted by individuals with breast cancer and patient advocates in the

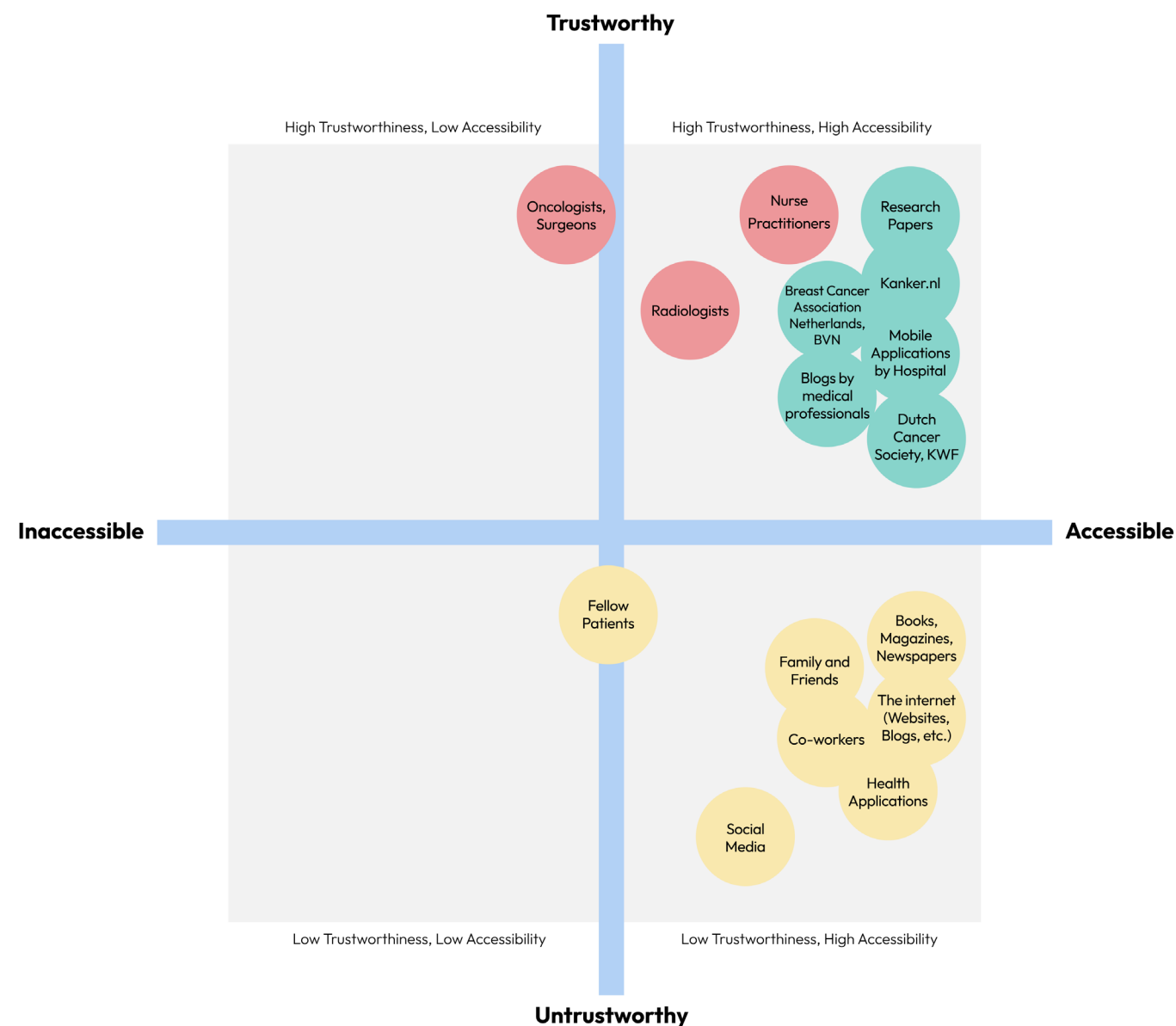


Figure 5.6: Mapping the Sources of Information based on Trustworthiness and Accessibility

was highlighted by individuals with breast cancer and patient advocates in the exploratory interviews and upcoming findings as well.

“The most reliable source is still your physician, your oncologist, or your nurse practitioner..... The primary source is the most important. But the secondary and tertiary are even important but one has to see them in the right context.”
-RP6 - Former Nurse and Information Line Operator

Breast Cancer Association Netherlands (BVN) and kanker.nl (secondary sources of information) were found to be both in high-trustworthiness and high-accessibility resources. Healthcare providers provide these resources to individuals during consultation sessions to read more about their cancer. They offer support and allow individuals to access information or engage with professionals

via the information helpline at their own pace and convenience. Medical research papers, Dutch Cancer Society (KWF), mobile applications etc. were similarly identified as trustworthy and readily accessible sources of information. Individuals can access these resources at their own pace and convenience.

“They (individuals) rely a lot on family and friends and social media. There’s a lot of this information on social media which influences them in making a correct decision for themselves.”

“And uh, outside factors. All the stories you hear from relatives and family and people who try to help and give this information confuse you.”

- RP6 - Former Nurse and Information Line Operator

Among the array of tertiary sources of information, all were classified as untrustworthy but highly accessible. They were referred to as “community” by the former nurse and information line operator as they provided more emotional support.

5.3 Insights from Stakeholders

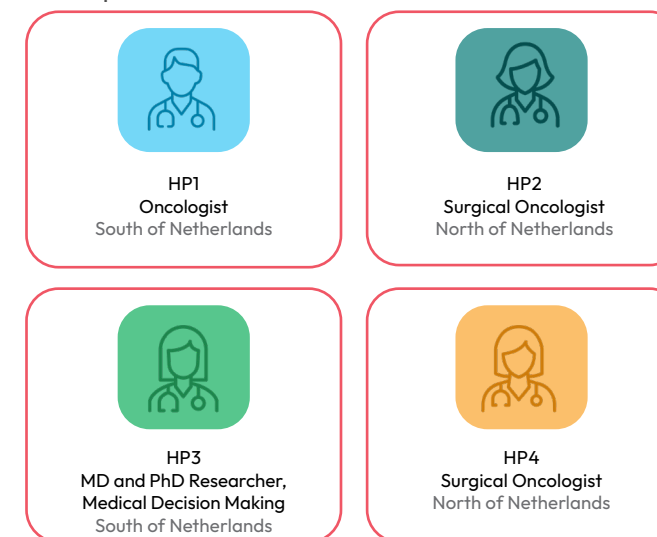
Establishing a foundational understanding of the breast cancer care journey, along with the accessibility and trustworthiness of various information sources was essential before gathering insights from healthcare providers and other key stakeholders for a large patient population. This groundwork was important for formulating specific interview questions and addressing the third sub-research question:

From the perspective of healthcare providers and other stakeholders, what challenges do individuals with breast cancer face following the diagnosis?

Healthcare Providers

I interviewed four healthcare providers in breast cancer care: one oncologist, two surgical oncologists, and one MD and PhD researcher in medical in decision making. Out of the four interviews, three interviews were conducted online, while one was conducted in person and lasted between 30–45 minutes each depending on the availability.

Participants’ Profile



I translated the interviews using a thematic analysis and summarised the relevant findings below. The rest of the findings can be found in Appendix B.2.

Emotional Reactions Following a Breast Cancer Diagnosis

They shared a spectrum of reactions from individuals upon receiving a breast cancer diagnosis. Many of them are scared, nervous and confused as there are too many things to do and it’s an uncertain world for them, others sometimes anticipate due to the series of tests they go through. It’s an overwhelming experience for all.

“

In the beginning, they’re very nervous and it’s like everything when something is new you you don’t know. ‘Do I have to do this first? Do I have to speak to the doctor first? Do I have to go to the lab first? Where is the laboratory? Where is the treatment centre? How long does it take? Do I have to call a taxi? At what time, etcetera?’ So very practical things, and that creates a lot of unrest in the beginning because they have a lot of things they don’t know and that makes a lot of patients feel anxious. They call more often in the beginning because they experience new things, they are uncertain where they have to be. And you’ve seen that slows down after one or two treatments.

-HP1, Oncologist

”

Nature of Information: Complex and Abundant

They also convey that the information individuals receive can be complex and difficult to process, some also acknowledge that the primary issue is often the volume of information that makes it hard to understand. Although the language itself may not always be very challenging for all individuals, the overwhelming amount of information significantly adds to the burden of the illness and it’s easy to get lost in it.

“Sometimes some information is too hard to understand. And that’s not easy.”

- HP2, Surgical Oncologist

“They get loaded with information, so I’m mostly sending. It’s not a lot of receiving because I have to explain a lot.”

- HP1, Oncologist

To address their queries and receive further clarifications, they are referred to nurse practitioners and other credible resources for more detailed explanations to learn about the changes in other aspects of life.

Variability in Seeking and Understanding Information

Individuals start seeking information through various sources to understand information about their illness. Healthcare Providers state that some individuals take an active role, seeking to comprehend their condition thoroughly, while others struggle and engage less, often due to lower educational levels, and unfamiliarity with

medical terminology. They can typically identify these differences through initial interactions.

“There’s some patients, they want to know every little detail and some patients, they don’t really want to know anything. They just say, “*Okay, I have it just treat me and then that’s it.*”

“It’s only a few patients where you when you talk to them, you immediately get the sense that they don’t understand what you’re saying, so I am trying to keep it really, really simple. And but for other patients, sometimes you find out later when they ask you questions and you think they didn’t understand what I explained to them.”

- HP1, Oncologist

Influence of Seeking Information from Various Other Sources

Healthcare providers note that as individuals seek information, they often turn to the internet and discuss their situation with friends and family. This can lead them to believe in what they hear, bringing up irrelevant or inaccurate information and making comparisons to the experiences of others. Providers frequently have to explain that treatment plans are personalised and that each case is unique, differing from those of their friends or family members.

“What I also really found very hard is it also a lot of patients say, ‘*Ohh yeah my neighbour*’ or ‘*Ohh yeah my mother*’. They compare themselves with patients in their surroundings....However, it does not say anything about how the patient will experience their trajectory.....They always think it will go like their neighbour or their sister or their niece and then you have to kind of tell that every breast cancer is different.”

- HP3, MD and PhD Researcher, Medical Decision Making

Existing Strategies to help them Understand Information

They are able to assess comprehension of the information provided to people and adjust the way of delivering the information. They note that providing information gradually, incrementally and simplifying it enhances the understanding for individuals. Sometimes also give some general tips, for example, writing the questions to have a conversation in the next consult can facilitate their understanding.

“I need to translate my knowledge in a very formal language to plain language - what it means in everyday language for them. So I cannot use medical terminology because patients don’t understand it. Most of them even are highly educated people.”

- HP1, Oncologist

“I tell them, “please write down your questions at home, so you can organize your thoughts and we can talk about it and that sometimes.”

- HP2, Surgical Oncologist

Another way that has proven to be helpful is through bringing the companions during the consultation sessions. The presence of a companion is usually beneficial, offering additional support and improving the people’s ability to cope with the diagnosis and treatment. Some companions provide emotional support and assist individuals in navigating their treatment journey. Although, not everyone has the same kind of support from the companions or have companions.

“And that’s why I think it’s very important to, well, not come alone. Some people are alone or don’t want to involve others with their process, and but that can cause that information will be lost.

- HP2, Surgical Oncologist

There’s a lot of difference. I mean, I never see some partners.....for other patients, they always come together and the partners have asked me good questions or even do most of the talking when the patient is too tired....there’s a large variation in that.”

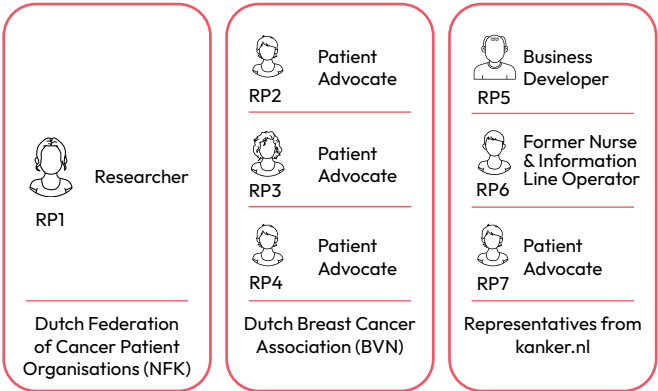
- HP1, Oncologist

Other Key Stakeholders

Patient Organisation, Representatives from kanker.nl and Patient Advocates

Insights were also gathered from the other stakeholders. The interviews included representatives from patient organisations such as the Dutch Federation of Cancer Patient Organisations (NFK) and the Dutch Breast Cancer Association (BVN), interviewed together, two representatives from kanker.nl (one from business development and another from the information line operator), and three patients advocates. These stakeholders provide emotional support through the buddy programs, and support groups, and interact with the individuals to provide information in person or through an information

Participants’ Profile:



line about their breast cancer. The interviews lasted between 30 and 60 minutes, depending on the participants’ availability.

The representatives from patient organisations, kanker.nl and patient advocates echoed similar responses to those with healthcare providers when asked about the experiences of individuals with breast cancer post-diagnosis. They are scared, nervous and shocked and the overwhelming nature of the diagnosis makes it very hard for individuals to comprehend everything surrounding them.

“she said, “*now I have a new job because it’s the job is now breast cancer*”

They mention that the duration of the consultation session acts as a barrier because individuals are in shock and are unable to absorb all necessary information within the 15-minute session. The representative from NFK suggests the need for additional conversations beyond consultation sessions that can help the individuals in making a decision.

“It’s of course a shock. So it’s very hard to get the information correctly in your head and it’s too much because one of our patients, she said, you know, “*now I have a new job because it’s the job is now breast cancer*”....They don’t always say, ‘*I don’t understand the information*’, but by the way, they have the questions, you know, they don’t understand what’s has been told.”

-RP6 - Former Nurse and Information Line Operator

“Usually the medical profession only has like 10 to 15 minutes to inform you about diagnosis so that’s very difficult. And like I said, it’s so much information - it’s an overload.

-RP1 - Researcher, NFK

Many individuals find joining a patient organisation overwhelming and choose not to participate. While some may reach out to information lines for support, becoming an active member of a patient organisation was described as ‘too much to handle’.

They don’t become a member of BVN because it’s too much. It’s too much and they if you get it diagnose, you [refers to individual with cancer] will turn into survival mode and the whole first year you will be in survival mode and you just focus on getting better and making it okay for my kids, making it okay for my husband and just trying to figure it out with work and getting better.”

-RP2 - Patient Advocate, BVN

In relation to information-seeking behaviours, other key stakeholders align with the perspectives of healthcare providers, observing that individuals differ in the amount of information they seek, with some requiring more detailed and comprehensive information than others.

I think it differs from patient to patient. Some patients want a lot of information, some patients don’t want information said, - “*Oh, no. The doctor says this. It’s okay for me.*” And other patients want to know everything. “*I want to know everything.*”

-RP2 - Patient Advocate, BVN

Key Takeaways from Stakeholder Interviews

- ◆ Despite their demanding schedules, healthcare providers strive to deliver information through step-by-step explanations. However, other key stakeholders note that consultation sessions are often brief, limiting the time available for providers to convey all necessary details.
- ◆ There are differing views among healthcare providers on the causes of information overload. Some attribute it to the complexity of the information, while others point to the volume of information combined with lifestyle change.
- ◆ Healthcare Providers report that a lot of individuals compare their cases with those of acquaintances, making it challenging and time-consuming for them to explain that each case is unique and requires treatment attuned to their stage.
- ◆ Both healthcare providers and other key stakeholders mention that individuals seek information from the internet and have varied levels of understanding and processing, which may be influenced by educational levels or other situational factors.
- ◆ The presence of a companion during consultations and treatments is considered highly beneficial for absorbing information.
- ◆ Most individuals do not join patient organisations immediately post-diagnosis but rather later in their treatment journey or after completing treatments as it is quite overwhelming for them.

5.4 Needs and Preferences of Individuals with Breast Cancer

I conducted interviews with seven individuals who have experienced breast cancer to explore the two sub-research questions. This section will outline their personal experiences, document their preferences, and identify any unmet needs.

What are the preferred sources for obtaining information about breast cancer, and to what extent do individuals trust these sources? What types of information do they seek?

What are the unmet informational needs of individuals diagnosed with breast cancer?

Participants' Profile

| | | | |
|----|--|----------------------|---------------|
| P1 | | Cancer Stage | Not Known |
| | | Age | 50+ |
| | | Year Since Diagnosis | 1 year (2023) |
| | | Profession | Professor |

| | | | |
|----|--|----------------------|------------------------|
| P2 | | Cancer Stage | Stage IV, Metastatic I |
| | | Age | 53 |
| | | Year Since Diagnosis | 4 years (2020) |
| | | Profession | Patient Advocate |

| | | | |
|----|--|----------------------|-----------------|
| P3 | | Cancer Stage | Triple Negative |
| | | Age | 50+ |
| | | Year Since Diagnosis | 1 year (2023) |
| | | Profession | Entrepreneur |

| | | | |
|----|--|----------------------|--------------------|
| P4 | | Cancer Stage | Stage II |
| | | Age | 50+ |
| | | Year Since Diagnosis | 1 year (2023) |
| | | Profession | None at the moment |

| | | | |
|----|--|----------------------|---------------------|
| P5 | | Cancer Stage | STAGE II |
| | | Age | 42 during diagnosis |
| | | Year Since Diagnosis | 12 years (2012) |
| | | Profession | Patient Advocate |

| | | | |
|----|--|----------------------|--------------------|
| P6 | | Cancer Stage | Stage I |
| | | Age | 45+ |
| | | Year Since Diagnosis | 3 years (2021) |
| | | Profession | None at the moment |

| | | | |
|----|--|----------------------|-----------------------------|
| P7 | | Cancer Stage | Stage II A, Triple Negative |
| | | Age | 55 |
| | | Year Since Diagnosis | 1 year (2023) |
| | | Profession | Professor |

Insights from Interviews

In the interviews, individuals were asked to share their experiences during the time of diagnosis. These semi-structured interviews lasted 60 minutes, for those currently undergoing treatment, the interviews were split into two sessions to prioritise their well-being and comfort. They were presented questions about the documents they received from the hospital, their experiences with the information provided, and how they managed the associated challenges. Additionally, they were questioned about the sources they used to seek information, their preferred level of involvement in their care, and other aspects of their lives such as work, the role of companions, and whether they sought support from support groups or joined patient organisations. I translated the findings of the interviews and through thematic analysis (Appendix D.2), identified distinct clusters. The relevant findings are presented in the following section.

Based on the interviews, I also mapped the experience of the participants with medical language (Figure 5.7). It is important to note that this mapping is relative and helps in understanding their varied experiences with the information received during diagnosis.

Participants 6, 4, 7, 3, and 1 demonstrated a lower level of familiarity with the medical language as compared to Participants 5 and 2. This variation is due to the professional backgrounds of Participants 5 and 2, which provided them with a better understanding of the complex medical information.

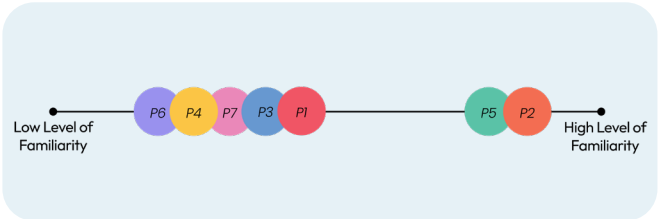


Figure 5.7: Participants Experience with Medical Language (Relative Mapping)

Overwhelming Experiences during Diagnosis

During the interviews, nearly every participant conveyed a range of emotions, including worry, anxiety, stress, and fear when they were diagnosed. They describe this experience as a ‘roller-coaster’, ‘running train’ or ‘falling in a hole’, emphasising the overwhelming nature of the diagnosis.

“I think the world, this hole opened up and I just fell like several levels through the floor.”
- P7

“So it’s really like a running train. You get up and then woof, you go off you go.”
- P3

“It was really super fast and lots of meetings. So that was like a roller coaster.”
- P1

Difficulties in Dealing with Information

Some participants found the information was complex and they faced difficulties in understanding the ‘medical jargon’ or found conflicting information. They also mentioned that the information is fragmented, which was difficult for them to navigate.

“Whatever you find in your patient portal is really what the doctors write down. So that’s not all understandable.”
- P1

“I’m not educated as a physician. So I think some of the abbreviations were new to me.....so I think it’s a lot of professional language that you are suddenly confronted with.”
- P2

“I already knew this because my mom had cancer, but and because of that I knew, ‘Okay, with doctor X, you only get information on topic X and Doctor Y gives you the information on topic Y, etc’. So it’s all very fragmented.”
- P1

Variations in Information-Seeking Behaviours

Nearly all participants exhibited a tendency to seek information, although their methods and preferred sources varied. Some participants utilised search engines like Google, while others relied on advice from friends and family who had previous experience with cancer. Certain individuals sought information from books, research papers and hospital applications, and a few combined online searches with discussions with friends and companions while others selectively used trusted websites such as kanker.nl, IKNL, or patient organisations when browsing online. These diverse behaviours highlight individuals’ efforts to gather additional information to alleviate

uncertainty during their cancer journey. There were a few mentions of avoiding information, some from stories of others and some on the type of information.

“I also did a lot of research on my type - triple negative. ‘What? What does help? What research is there already? What research is there in other hospitals?’ Yeah, because that’s who I am. I’m curious, so I want to know a lot about what’s going on and that also gives sometimes a bit of confusion because then, you know, ‘ohh what should I do in the so and so.’”
- P3

I’m not interested in reading stories of others. And I yeah, I really limited my information. Over to prevent information overload at some point I got information.”
- P1

“I’m more of a scientific person. So I absorb all the information. So the minute I got home, I turned on the computer and looked up everything and I bought some books and read about them and talked to them.”
- P5

“I didn’t Google that much. I just googled the results from the biopsy.”
- P4

Emotional Support and Coping Strategies

The role of companions was emphasised significantly. The majority of participants found solace in their companions, who provided various forms of support, for example accompanying them to appointments, reading information together, serving as extra ears during consultation sessions, and discussing the details post-consultation.

“I was the director, and he was a couple of extra ears. We [refers to companion] always prepared the consults together. And we had a note with some questions on it.”
- P5

“I also sent everything to my friend and I sent her, ‘this and this is what I got. I googled what is written here but can you Google too and can you explain what you are reading? Let’s see if we read the same.’ So I was asking her to see if what I was reading was correct, because otherwise you go crazy.”
- P4

Some sought advice from friends who had previously experienced breast cancer and connected with fellow patients through hospital programs as a way of coping. Moreover, several participants took proactive steps to find personal ways to cope with the illness for example continuing working, connecting with fellow patients, finding someone to talk to choosing not

to talk about it, etc.

“I always brought a lot of perspectives in from the quality of life. So in terms, I like to continue working as as much as possible because I didn’t want to be full time patient.....I looked for somebody in my network that I trusted with a medical background, but more for informal sounding boards.....I chose deliberately to continue working as much as possible as a way of distraction, as a way to still remain also a professional as an identity”.

- P2

“I worked a little.....that you can just set your mind around something else.....I’ve worked for two months on a very low level because it wasn’t doable with my head and I was very tired.”

- P3

“I didn’t tell a lot of people in the starting because I was very upset.....so I didn’t wanna talk to people.”

- P7

Mapping Needs and Preferences

Through the insights from interviews, I gained an understanding of experiences and challenges of people with cancer. As also noted in the literature, people have high information needs and varied preferences for the sources they use to obtain this information apart from healthcare providers. Depending on whether they actively seek out information or tend to avoid it, the sources they use and the information they gather contribute differently to their experience of information overload. To further explore the diversity in information-seeking behaviors, I conducted mapping exercises with participants during the interviews, focusing on the following aspects:

Preferred Source of Information

Level of Trust in the Preferred Source of Information

Preferences on the Type of Information Needs

Preferred Sources of Information

During the interviews, I drew the relationship with the section ‘5.2 Categorising Sources of Information’ and inquired participants on their preferred sources of information. The mapping of these preferences is illustrated in Figure 5.8, which includes the sources mentioned by the interviewees. It should be noted that this map is based solely on the preferences of the seven individuals I interviewed and is not necessarily

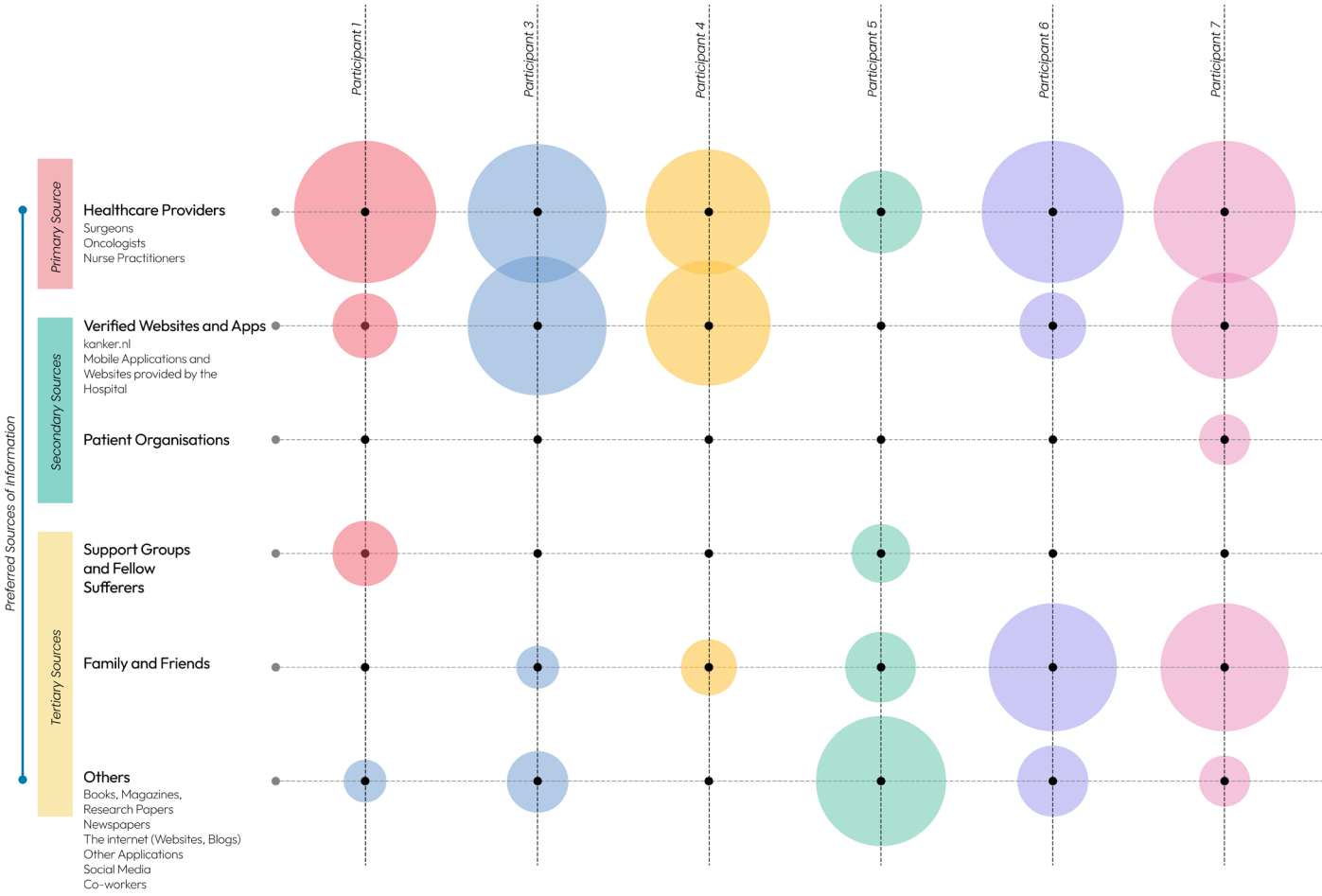
Nearly all participants relied on healthcare providers as their primary source of information, followed up by verified websites and applications. At most, one participant expressed a preference for obtaining information from a patient organisation, while others reported that they found it overwhelming during the diagnosis phase. Additionally, two participants highlighted a preference for engaging with fellow patients for both informational and emotional support, whereas many others sought support from friends and family. Some participants also mentioned relying on other resources, such as books and internet browsing. followed up by verified websites and applications. At most, one participant expressed a preference for obtaining information from a patient organisation, while others reported that they found it overwhelming during the diagnosis phase. Additionally, two participants highlighted a preference for engaging with fellow patients for both informational and emotional support, whereas many others sought support from friends and family. Some participants also mentioned relying on other resources, such as books and internet browsing.

Level of Trust in the Preferred Source of Information

After identifying their preferred sources of information, participants were then asked to rate the level of trust they placed in these sources. Figure 5.9 illustrates the preferred sources of information along the vertical axis, with trust levels rated on a scale of 0-5, where 5 indicates the highest level of trust.

Nearly all participants rated their trust in healthcare providers between 4 and 5. However, one participant rated it lower due to a less satisfactory experience with a surgeon. For verified apps and websites, trust levels varied; some participants rated them highly, while others were neutral, having been unaware of these sources immediately post-diagnosis. One of the participants preferred patient organisation and trusted them for information but others on the other hand didn’t engage with the organisation during the diagnosis. This was also mentioned by the representative from patient organisation during the other key stakeholder interviews.

There was a mixed reception in placing trust in support groups and fellow sufferers. While some found it beneficial, others viewed such interactions as potentially anxiety-inducing, referring to them as “horror stories” due to the variability and severity of individual cases. The



This map is relative in nature and is generated based on interviews with seven women with experience of breast cancer. Insights could not be collected from Participant 2 due to limited time for the interview

Figure 5.8: Mapping of the Preferred Sources of Information

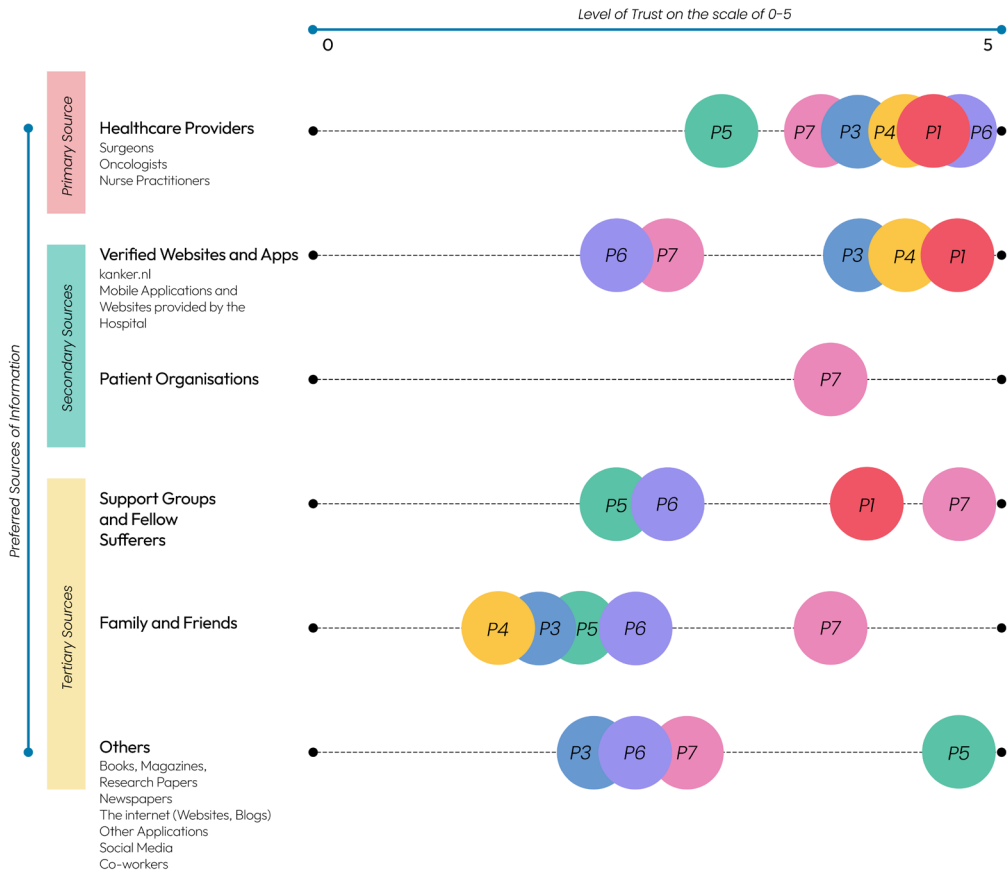


Figure 5.9: Mapping of the Level of Trust on the Preferred Source of Information

trust levels ranged from high to low among those who engaged with these groups, and some participants did not provide a rating, having not participated in such interactions.

Many participants place a high level of trust in family and friends, although this was not universal. Family and friends played a supportive role, primarily providing emotional support. However, the informational support from these sources was less reliable, as it was sometimes outdated or not directly applicable to their specific situations, which in turn led to increased anxiety and concern. Trust in other sources, such as books, magazines, and social media, was generally moderate to low, with only one participant expressing a high level of trust in these mediums.

Preferences on the Type of Information Needs

Once the preferred sources and the level of trust

participants placed on the sources, the next step was to understand their types of information needs during the diagnosis stage. To capture the variations in information-seeking behaviors, participants were asked to rate the type of information they searched for on a scale of 0 to 5, with 0 indicating no interest in seeking information and 5 representing a thorough search for detailed information.

The map illustrated in Figure 5.10 features the amount and the depth of information sought on the vertical axis, while the horizontal axis listed various types of information. These categories were adapted from two key studies: Lu et al. (2020) and Bol et al. (2020). The latter study applied the QUOTE constructs (cancer-specific and generic issues) developed by Van Weert et al. (2009), originally intended to measure the information needs of individuals undergoing chemotherapy. For this research, the type of information was tailored and adapted (Table 5.1) to reflect the

| Lu et al., 2020 | Bol et al., 2020 (based on QUOTE constructs - Van Weert et al., 2009) | Types of Information Adapted for the Project |
|--------------------------------------|---|--|
| Prevention and food | Disease and Diagnostic Test-related Information | Etiology |
| Etiology | Treatment-related Information | Diagnosis |
| Diagnosis | Prognosis Information | Clinical Manifestations |
| Clinical Manifestations | Daily Life Information | Treatment and Side Effects |
| Treatment | Coping Information | Prognosis |
| Prognosis | Interpersonal Communication | Daily Life |
| Impact and Resumption of Normal Life | | Social Assistance |
| Scientific Research | | |
| Social Assistance | | |

Table 5.1: Types of Information Adapted for the Study

| Categories of the Types of Information Adapted for the Project | Description <i>Referred Lu et al., 2020, Bol et al., 2020 and adapted for the project considering the context and scope</i> |
|--|--|
| Etiology | Cause or the origin of cancer |
| Diagnosis | Diagnosis; purpose and results of diagnostic tests; tests and procedures; stage of cancer |
| Clinical Manifestations | Signs and symptoms of tumour |
| Treatment and Side Effects | Purpose of treatment; side effects; information about how treatment works; treatment preparation |
| Prognosis | Survival rates; risk of complications; survival statistics of treatment regimens; risk of recurrence |
| Daily Life | Influence of cancer on daily life; influence of treatment on sexuality; strategies to improve quality of life |
| Social Assistance | Counselling; support from fellow patients, support groups, family and friends |

Table 5.2: Description of the Type of Information Needs

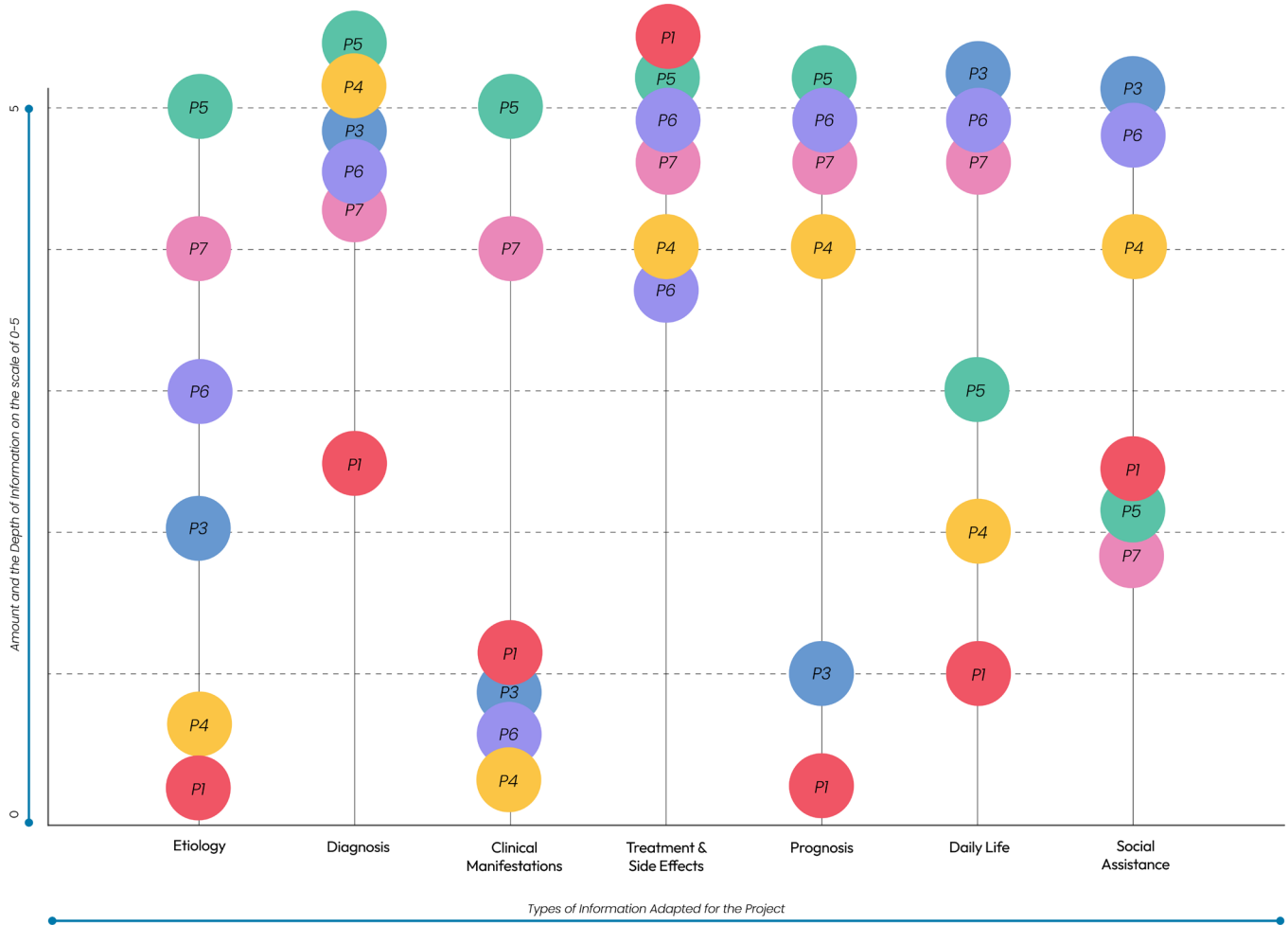


Figure 5.10: Mapping of the Preferences on the Type of Information Needs

needs of individuals undergoing chemotherapy. For this research, the type of information was tailored and adapted (Table 5.1) to reflect the specific needs of individuals post-diagnosis. Topics like prevention, nutrition, and scientific research from Lu et al. (2020) were excluded, as they were more relevant to pre-diagnosis stages. Additionally, interpersonal communication and coping information from Bol et al. (2020) were reclassified under social assistance for this research.

By using these established frameworks through literature, the mapping exercise aimed to record a general understanding of the types of information needs participants had during their cancer diagnosis. The details of this categorization are described further and presented in Table 5.2.

Etiology
Etiology refers to the causes or origins of the cancer, including factors such as genetics, hormones, environment, lifestyle, family history, and age. The etiology of the breast cancer showed significant variability in the information preferences among participants. Some participants exhibited a minimal interest in information, primarily seeking

confirmation regarding the genetic nature of the condition while some displayed more interest, driven by the history in the family or a desire to consume all types of information.

Diagnosis
Diagnosis involves identifying a disease based on its signs, symptoms, and diagnostic tests. All participants expressed a high level of interest, uniformly rating their preference as 5. They utilised various resources, including online platforms and hospital-provided documents, to gather information about the specific type of cancer and the path leading to diagnosis.

Clinical Manifestations
Clinical manifestations refer to the signs and symptoms that characterise the cancer. Participants had divergent preferences regarding information about clinical manifestations. Some expressed less interest mentioning the lack of importance or absence of visible symptoms before they visited the hospital.

Treatment and Side Effects
This category addresses the purpose of the treatment, the necessary preparation, and understanding how the treatment works to make

informed decisions. Participants demonstrated significant interest in this area, with ratings ranging between 4 and 5. They sought information on the proposed treatment methods and anticipated side effects, with some delving into scientific literature or exploring the correlation between nutrition and side effects. Understanding the consequences of treatment was a shared concern among all participants.

Prognosis

Prognosis refers to survival rates, risk of complications and the likelihood of recurrence. There was variability in participants’ attitudes towards prognosis. Some demonstrated limited interest due to anxiety from survival changes and some had to search because of some conversations with the healthcare providers and or their general interest in seeking information.

Daily Life

The impact of the illness on daily life includes effects on work, physical exercise, nutrition, and other day-to-day activities. There was also variability in participants’ preferences regarding information on daily life; some explored from the perspective of daily life implications, some sought dietary and exercise considerations. One of the participant noted a scarcity of available information on this topic, expressing a desire for more accessible information.

Social Assistance

Social assistance involves support services, such as help from friends and family, counselling, for example, consulting a therapist or joining support groups, or speaking with fellow patients. Interest in social assistance varied between 2 and 3 among participants. Some sought minimal assistance initially, preferring to understand the situation themselves before seeking support from friends. Others actively sought social assistance as a coping mechanism, finding it beneficial and supportive in navigating their illness.

The preferences for the type of information needed, along with the participants’ quotes, are accessible through the QR code provided in Figure 5.11.



Figure 5.11: QR Code to View the Preferences on the Type of Information Needs with Participants Quotes

As stated previously, there’s a variation in the amount and the type of information needs of people. The study conducted by S. M. Miller, 1987, also discussed in the literature findings, section ‘2.2, Information-Seeking Behaviour’, revealed two profiles: ‘Information Seekers’ and ‘Information Avoiders’ to highlight the variations in seeking. However, research findings through this thesis project, it was discovered that there is no clear division of patient profiles and they cannot be strictly categorised as information seekers or avoiders. While one profile may be dominant, people often display mixed behaviours, such as actively seeking information about treatment options while avoiding information about prognosis or clinical manifestations. This finding was also discussed with two healthcare providers, who acknowledged that it is challenging to label individuals strictly as seekers, or avoiders. From their experience, they have witnessed that while one may have certain profile dominant in nature as a way of coping and reducing anxiety, they cannot be exclusively classified under one category of a ‘seeker’ or an ‘avoider’.

“It is difficult to put certain types of labels to that. I don’t think it’s necessarily they don’t want to know. It’s just that any discussion about their disease or their treatment gives them so much anxiety that that is why they avoid these conversations or try to minimize them. I don’t think they are necessarily less curious. It just gives them too much anxiety and then the dominant emotion that they experience, so the resulting avoidance of trying to find out to get more information is a coping mechanism to reduce their anxiety.”

- HP1

This section concludes by answering the RQ2:

RQ 2: What are information-seeking behaviours, needs and preferences of individuals with breast cancer post-diagnosis and how does it contribute to possible information overload?

Based on the interviews with seven participants, information-seeking behaviours vary significantly among people and is influenced by individual coping mechanisms, such as the need for information and the preferences for sources. Although healthcare providers were the most preferred and trusted source of information, people also preferred obtaining information from secondary sources like verified websites and applications or tertiary sources like family, friends, fellow patients, etc. People tend to seek out specific types of information that is personally important and relevant to them and tend to avoid

other types, both as a way of coping and to reduce anxiety. Information-seeking behaviour increases the volume of information and sometimes introduces conflicting information from various fragmented sources. This also increases the complexity of information and makes it challenging to navigate, hence contributes to possible information overload.

In conclusion, the interviews and mapping exercises with seven participants, revealed some key takeaways:

Key Takeaways from Interviews and Mapping Activities

- ◆ Cancer diagnosis is an overwhelming experience for most people, often triggering a wide range of emotional responses such as worry, anxiety, stress, fear, and uncertainty.
- ◆ Some participants noted that the information provided is often complex, while others mentioned that the fragmented nature of information makes it difficult to navigate.
- ◆ Although participants sought information from various sources, healthcare providers consistently emerged as the most trusted and preferred source. This is followed by secondary sources, such as verified applications and websites. Tertiary sources, like friends, family, and fellow patients, are primarily approached for emotional support.
- ◆ People have different coping mechanisms and operates on two levels:
 - Information-seeking: Some individuals actively seek out specific information, while others may tend to avoid it altogether. Both seeking and avoiding information serve as coping mechanisms, reflecting different needs and preferences regarding the sources, amount, and depth of information they pursue.
 - Emotional Support: Some people choose to share their experiences and connect with fellow patients, while others prefer to process their emotions privately. Additionally, some find comfort in their work or engage in physical exercise as a means of coping.

5.5 Research Outcome

This section provides a summary of the research phase by deriving at the needs of individuals with cancer. The research phase overview is also provided in Appendix D.5.

Based on insights (Figure 5.12) gathered from interviews with healthcare providers, key stakeholders, and individuals, it was found that a breast cancer diagnosis is an overwhelming and an emotionally distressing time. They are presented with information which is complex in nature. Healthcare providers extend support through consultation sessions and information documents. However, due to the demanding schedules, heavy workloads, and the short duration of consultation sessions, their ability to provide comprehensive support that individuals require during this distressing time is limited. Nurse practitioners, on the other hand, can provide more detailed information and emotional support, but their availability is also limited. Patient organisations offer support in various ways, but as stated by the representative from the organisation, many individuals do not participate as it becomes overwhelming for them.

As a result, individuals often feel the need to seek additional information from various other sources to reduce the uncertainty and anxiety. This information-seeking from various fragmented sources results in increasing the volume of information and individuals can encounter conflicting information which can be complex to understand. These various sources are a combination of secondary and tertiary sources.



Figure 5.12: Recap of Findings from all Interviews

individuals attempt to gain clarity and control over their situation.

Among the sources they turn to, some are credible, accessible and trustworthy, such as kanker.nl, Dutch Breast Cancer Association (BVN) and other hospital applications and websites and offer both information and emotional support by various ways. Other tertiary sources that they turn to are accessible but can be confusing by unknowingly offering misleading or contradictory information.

The secondary sources are valuable resources of information in the Netherlands and are recommended by the healthcare providers during consultation sessions. Individuals trust and prefer these sources to obtain information in addition to consulting healthcare providers. However, these sources fall short in providing information that is relevant for the individual's unique situation, making them easy to get lost in identifying what's applicable to them.

While these challenges are shaped by various reasons, individuals also have varied information-seeking behaviours. This variability affects how much information they seek, interpret and the influence it has on them. Some individuals have a dominant seeking profile, while others may avoid some information. As a result, while external factors such as volume, complexity and fragmented sources contribute to information overload, the experience is highly individualised due to these different seeking behaviours.

Despite the support available from various sources, including companions, families, healthcare providers, and online resources, the overwhelming nature of a cancer diagnosis makes individuals feel isolated and highlights the need for more emotional and personalised support.

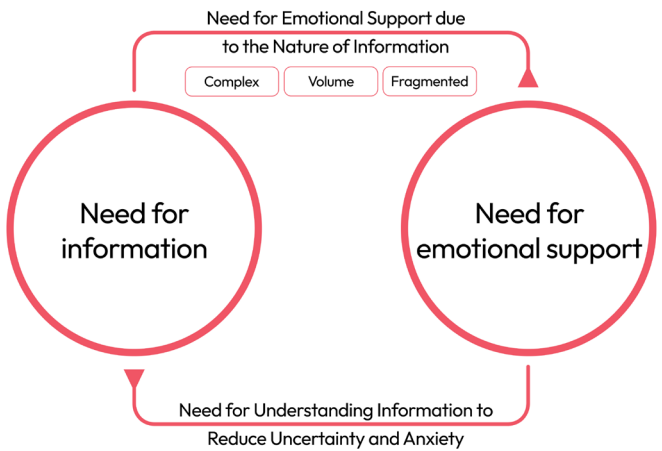


Figure 5.12: Interdependent Informational and Emotional Need of Individuals

To deal or prevent information overload, it is crucial to fill the gaps in the current care system and address both need for information and need for emotional support. These needs interconnected, continuously interact with each other (Figure 5.12) and are complemented by literature studies. One cannot be effectively addressed without considering the other, as there is considerable overlap between these needs (Duimel et al., 2022), (Bol et al., 2022), (Slevin et al., 1996). Although these needs overlap, they vary from person to person.

The need for understanding information is closely tied to emotional support. When individuals receive clear, understandable and reliable information about their illness, it helps reduce uncertainty, stress and improve their ability to cope with their condition.

The nature of information is complex, abundant and fragmented. Individuals require emotional support, as their emotional needs also influence how individuals seek, process, and respond to information. When individuals feel emotionally supported, they are better equipped to handle the complexities of medical information.

To conclude, these needs are closely intertwined, and to meet these needs through an AI-based intervention, I created a set of design principles to guide the further phase of the project. These principles are intended to meet these overlapping needs and will guide the development of AI intervention. The design principles will also serve as a foundation and shape the design characteristics discussed in the following chapter.

Design Principles

The concept should...

Understand the Emotional State and Address the Emotional Needs

The concept should acknowledge and understand the emotional state of individuals, anticipate their needs and provide support that aligns with their preferences and situations.

Foster Approachability and Affective Interaction

The concept should be easily accessible, engaging, and welcoming. It should offer comforting and supportive interactions.

Provide Personalised and Relevant Information

The concept should deliver relevant information that is specifically tailored to the individual's situation and needs.

Assist in Making Information Clear and Easy to Comprehend

The concept should aim to enhance the clarity and accessibility of complex medical information, ensuring that it is presented in a manner that aligns with the individual's level of understanding.

Ensure Transparency, Reliability and Trustworthiness

The intervention should offer reliable and trustworthy information, and it should ensure transparency by disclosing the source of information.

5.6 Modifications in the Factors Considered for the Study

Although the chosen factors for the study (section '4.4, Factors Considered for the Study') from the framework of information overload were complexity of information and emotional response, from the findings of interviews, I discovered that the nature of information; i.e. complexity, volume and fragmented sources needs to be addressed as well to support the needs to deal and prevent information overload post-diagnosis. Addressing only the two chosen factors was insufficient to fully meet the needs of individuals, highlighting the importance of considering these additional aspects.

The design intervention will focus on addressing all these four factors (Figure 5.13) to address information overload through the discovered needs.

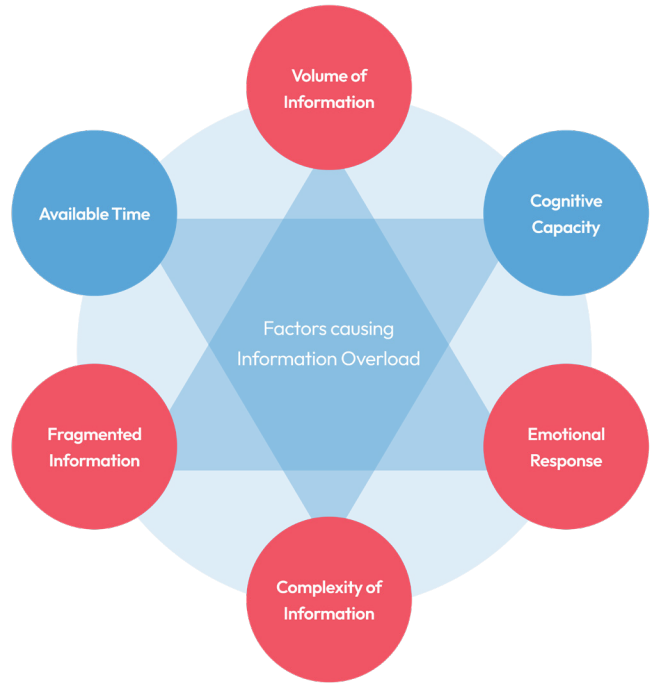
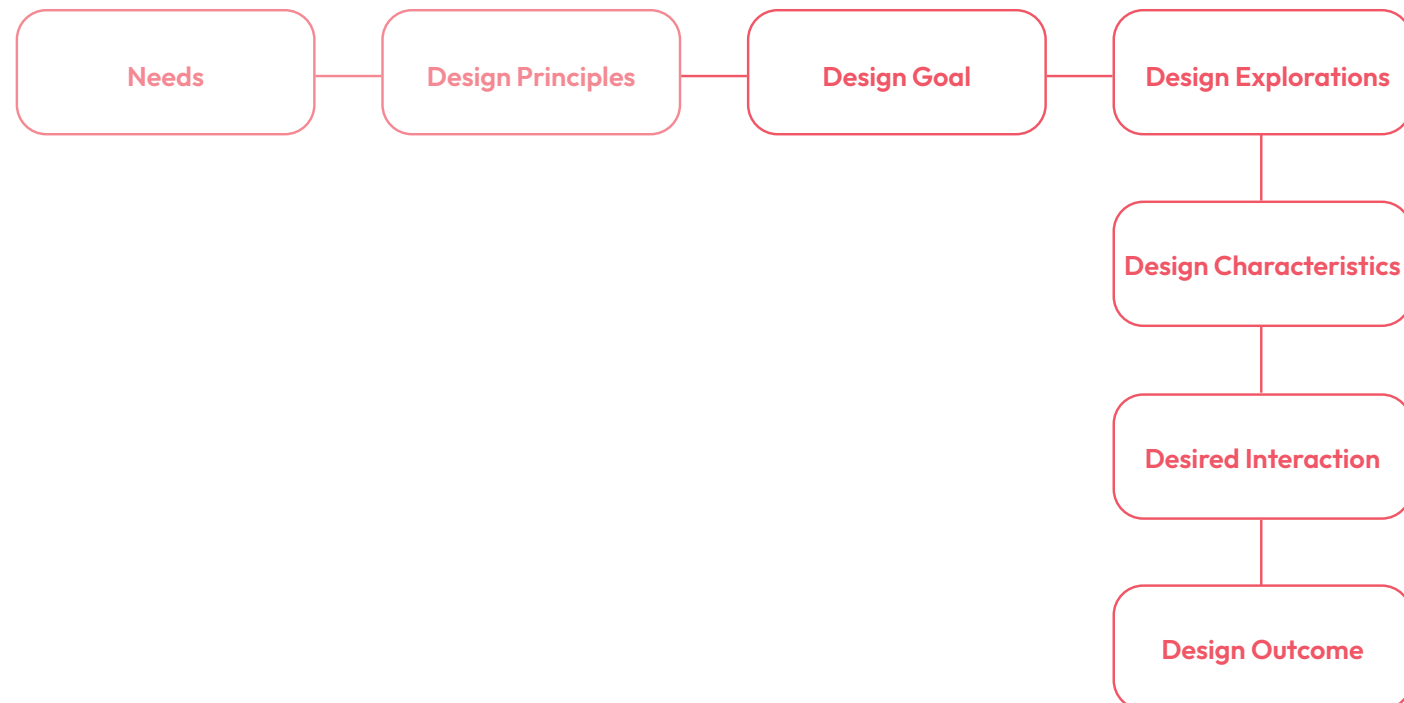


Figure 5.13: Modifications in the Factors Considered for the Study

06

Design Exploration

This chapter begins by setting a design goal as the foundation for exploring design intervention. Through various design methods such as creative facilitation sessions and brainstorming, the chapter outlines several concepts. These concepts are then assessed through Harris Profile to identify the most suitable option and helps in defining the design characteristics. The design characteristics extends a vision of how the design will interact, leading to the define the final design outcome.



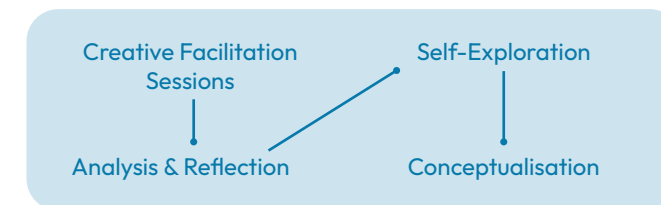
6.1 Design Goal

With the findings of the conducted research, the outcomes of the needs of people and the formulation of the design principles, the next step was to create a base for the design. A design goal was formulated based on the overarching research question to carry out the design explorations.

“To create an AI-driven intervention that supports people with breast cancer in dealing or preventing information overload post-diagnosis”

6.2 Design Explorations

The design explorations began with two creative facilitation sessions with fellow students and healthcare designers at Panton followed by self-exploration session and concluding with the conceptualisation.



Creative Facilitation Sessions

I conducted two creative facilitation sessions (Figure 6.2), each with a distinct group, to gather diverse insights on the support needs of individuals post-diagnosis. The goal of the creative facilitation sessions was to explore how AI could fulfill the information and emotion need and support in dealing or preventing information overload. The first session involved fellow students from the Industrial Design Engineering Department, TU Delft, aimed at gaining a broader understanding of the potential support required. The purpose of this session was to introduce fresh perspectives and generate a wide range of ideas from design students. The second session was conducted with healthcare designers at Panton, to benefit from the expertise of design professionals who work within the healthcare domain and to gain a system-level perspective.

I analysed the outcomes of both sessions (Figure 6.2) to identify and cluster commonalities, which helped to reveal key themes that supported the design goal. These clusters were then used in self-exploration session to generate the ideas.

More details about the sessions can be found in Appendix E.1.



Figure 6.1: Creative Facilitation Sessions
up: with fellow students at IDE, TU Delft, down: healthcare designers at Panton



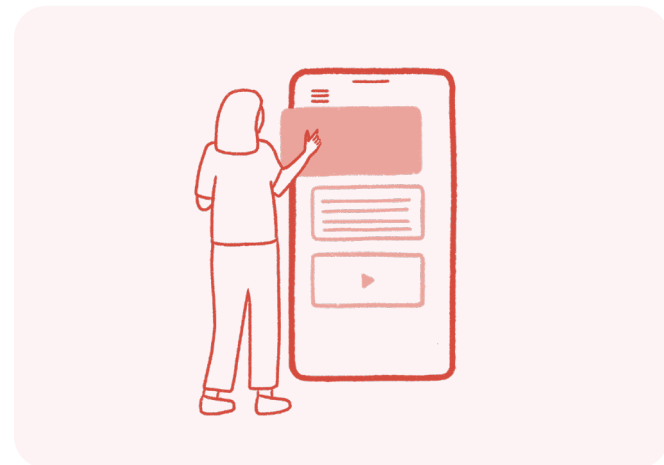
Figure 6.2: Analysis and Reflection of Creative Facilitation Sessions

Self-Exploration

In this phase of ideation, I initiated the exploration by formulating ‘How To’ questions for each design principle. These questions were created to explore how various solutions could be helpful in achieving the principles and guide the generation of potential solutions. With these ideas in hand, I proceeded with a brainstorming session (Appendix E.3) to generate ideas that aligned with the design goal. The objective was to explore a range of concepts that could support the informational and emotional needs of people. The brainstorming resulted in six distinct ideas, although two of these ideas shared similar functionalities, they differed in their delivery mediums. Below is a brief overview of each concept:

My Cancer Navigator

My Cancer Navigator is an AI-driven informational tool that can be implemented through two primary mediums: a website and an application. These platforms are widely recognised in healthcare for their accessibility and effectiveness in information dissemination, as detailed in section ‘2.6, *AI in Healthcare*.’ The concept’s primary objective is to support users by providing personalised information tailored to their specific medical conditions. This information is supplemented with visual aids to enhance clarity and understanding.

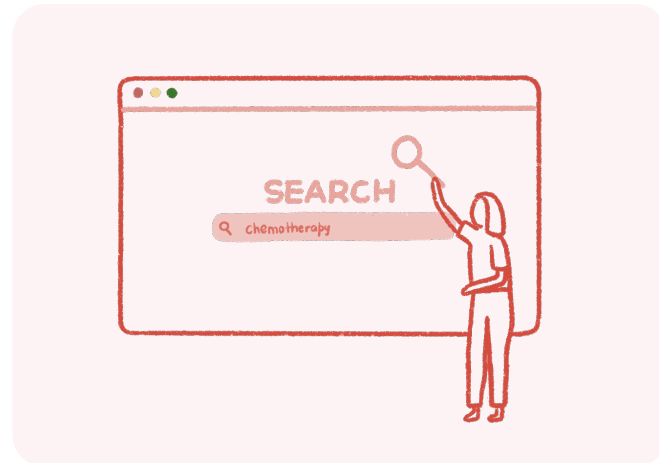


My Cancer Mentor

The Cancer Mentor concept is designed as a centralised information hub that efficiently filters and delivers relevant information to users. This tool connects various information sources to provide comprehensive, relevant content, supported by visual aids to facilitate easier comprehension of complex data.

This concept is envisioned as a specialised search engine for breast cancer, minimising the reliance on

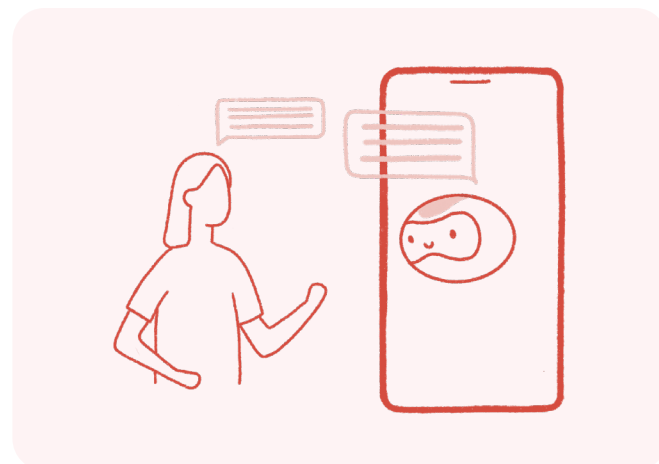
potentially unreliable sources by offering credible and relevant information. Taking insights from the research findings, individuals encountered challenges in the fragmented information sources, which resulted in confusion and added to the volume of information. My Cancer Mentor addresses it by providing relevant information.



My Cancer Companion

My Cancer Companion was ideated as an interactive chatbot designed to engage individuals in personalised, conversational support. This bot is intended to offer accessible and tailored assistance by interacting with individuals through text (chatbot) or voice (virtual assistant), responding to their questions or worries with clear, understandable explanations.

The AI bot would serve as both a source of information and emotional support, simplifying complex information in a step-by-step manner through supportive responses. It adapts its interactions based on the needs and preferences of people, offering personalised support.



My Cancer Echo-Co

My Cancer Echo-Co was envisioned as an AI intervention that can offer interactive support for people with breast cancer. This concept would

engage individuals through conversations, providing information and assistance tailored to their specific needs. My Cancer Echo-Co could be developed as a portable device for on-the-go support or as a home-based system. It aims to address the ongoing interplay between informational and emotional needs through continuous dialogue, providing support and information in a manner that aligns with the preferences of people.



These concepts represent different approaches to providing informational and emotional support to people. Following the ideation phase, the next step was to select a single concept for further development and conceptualisation. Utilising the Harris Profile, the concept that best met the design principles criteria was chosen. A detailed account of the ideas and the concept selection process can be found in Appendix E.4.

Conceptualisation

After two exploratory sessions, the next step was to bring the ideas together in a conceptualisation session. This session aimed to identify key elements from the different concepts and combine those that best addressed the design principles.

The “My Cancer Companion” Chatbot and Voicebot emerged as the concept that most effectively met the needs and design criteria. Other ideas, such as websites, apps, and search engines, were not pursued further for several reasons, such as these platforms already exist and introducing another source of information risked overloading with another platform and offered limited support and did not fully address the varied needs of people.

The “My Cancer Companion” was therefore developed further, with specific design features being clearly defined. More details on this development process are available in Appendix E. Based on the section ‘5.6 *Modifications in the*

Factors Considered for the Study’, My Cancer Companion aims to address both the external factors (complexity of information) and internal factors (emotional responses) of information overload and meet the unmet informational and emotional needs of individuals with breast cancer. This AI-driven tool is proposed to be easy to access and use, adapting to the preferences of each person.

In recognition of the diverse needs and preferences of people with breast cancer, ‘My Cancer Companion’ is conceptualised as a tool that comprehends the emotional state of users and responds to both informational and emotional needs through personalised interactions and empathetic communication. It provides clear explanations and context for the information by drawing from relevant, credible sources, ensuring people have access to additional details when needed. My cancer companion deconstructs the complex information into easily understandable, step-by-step explanations through open, warm, and supporting dialogue.

Recognising the varied needs of people, the concept also offers optional features that facilitate connections with fellow patients and regular check-ins, fostering a sense of community and support if needed. It also offers personalised recommendations on coping strategies and quality of life, such as engaging in work or joining a support group, physical exercises, etc.

The design principles provided the foundational goals and values that shaped the vision and guided the development of tangible attributes called Design Characteristics. Figure 6.3 illustrates how these characteristics align with the core principles, demonstrating that the design effectively meets its intended objectives.

From the factors and effects of information overload to the needs and preferences and now to the principles and characteristics, the relations are intertwined. To understand and address emotional states and needs, the concept must be *empathetic* and *adaptable*. The concept fosters approachability and meaningful interactions by being *empathetic*, *adaptable*, *accurate*, *connected*, and *personalised*. For My Cancer Companion to deliver information that is relevant and tailored to the individual, it should be both *personalised* and *simplified*. To ensure that information is clear and easily comprehensible, the concept must be *accurate*, *connected*, *personalised*, and *simplified*. Additionally, to achieve transparency, reliability, and trustworthiness, the concept should maintain

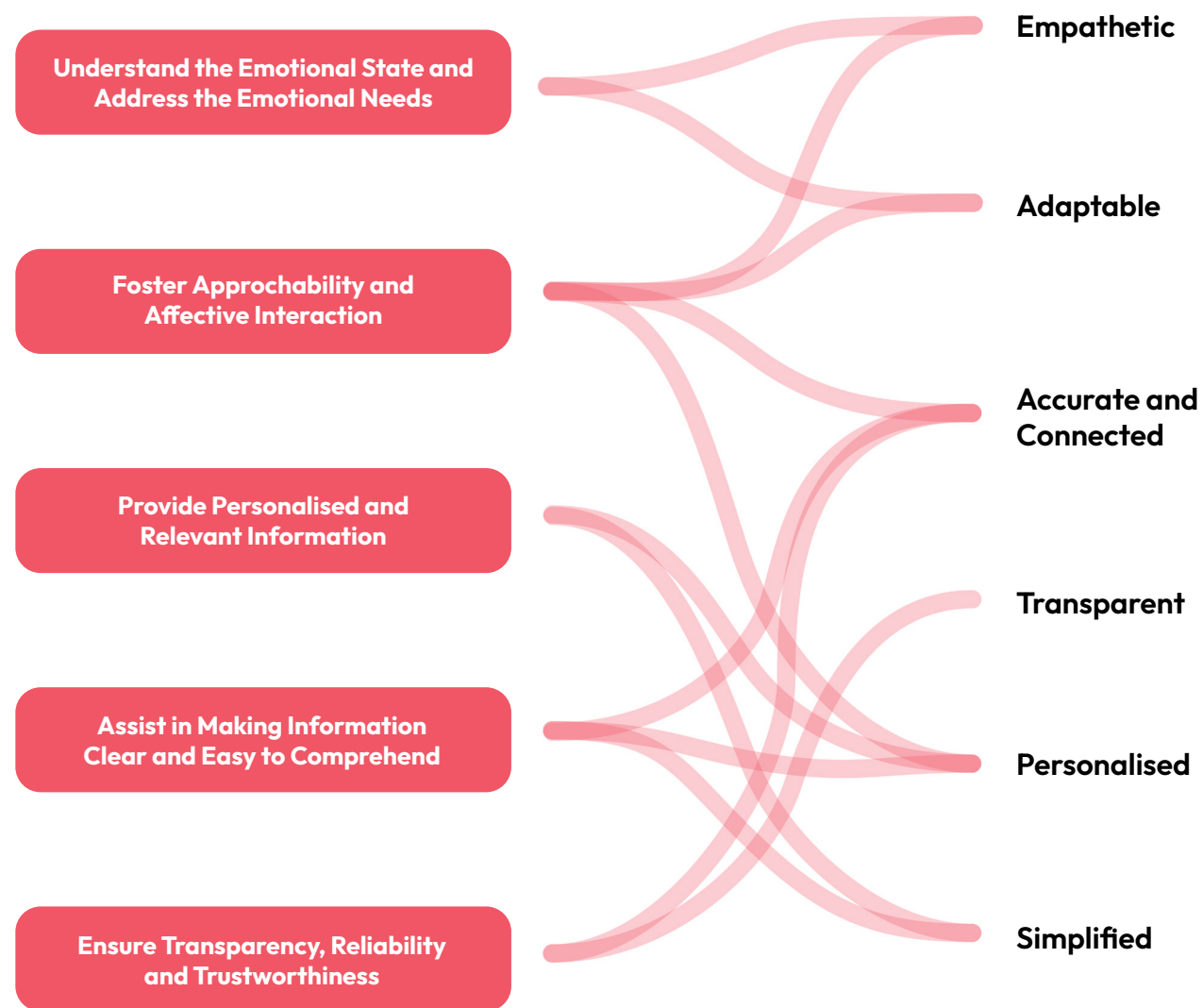


Figure 6.3: Relationship between Design Principles and Design Characteristics

accuracy, transparency and connect with various sources.

The following section will provide a detailed explanation of these design characteristics and explore how they align with the design principles.

6.3 Design Characteristics

The core of the design principles is captured in the following six design characteristics: Empathetic, Adaptable, Personalised, Accurate and Connected, Transparent, and Simplified (Figure 6.4). These qualities represent the desired interactions for the AI intervention. To specify how the concept will function and provide support, these characteristics are elaborated using the WHY, WHAT, and HOW framework, as outlined in Table 6.1.

Each characteristic has a distinct underlying purpose and the approach to achieve the desired outcome. However, the characteristics are

interdependent and cannot function effectively alone or in partial combinations.

They are interconnected and collectively address both informational and emotional needs. For instance, when an individual is experiencing distress, it is essential to first address their emotional state by adapting to their level. This involves acknowledging their feelings and providing support that resonates with their emotional states. Once their emotional state is addressed, the information requested can be delivered in a simplified manner that conforms to their preferences. This entails presenting personalised information derived from credible sources and displaying sources to maintain transparency and build trust.

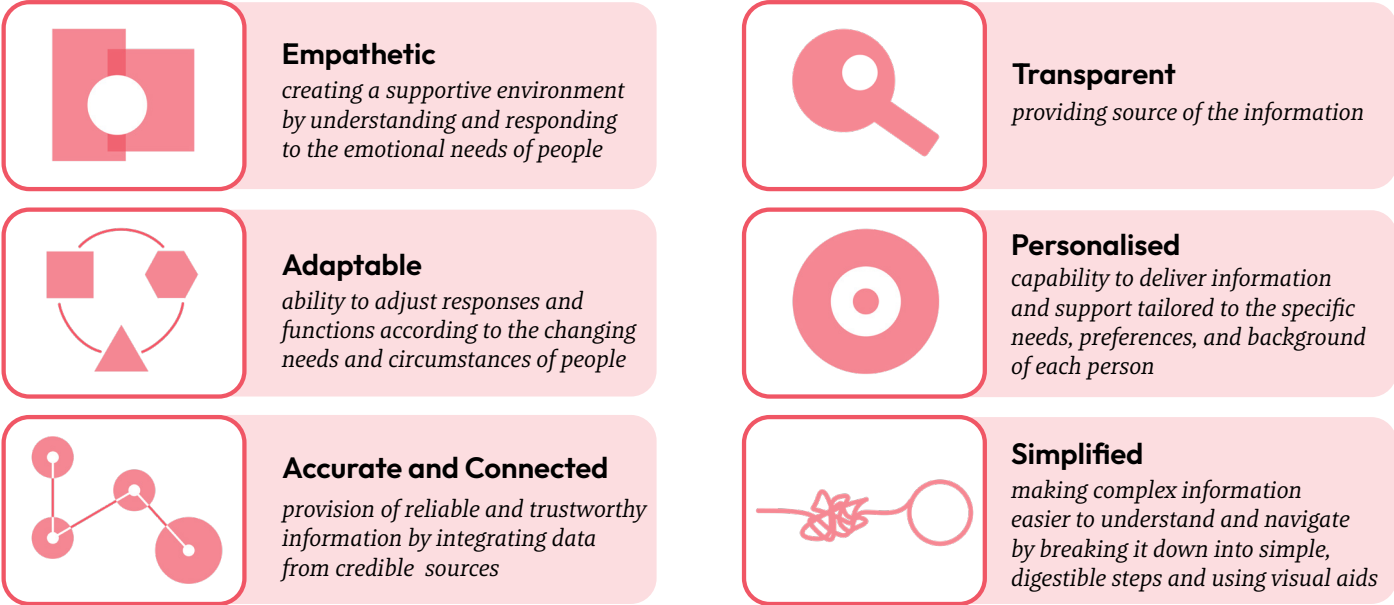


Figure 6.4: Descriptions of Design Characteristics

| Design Characteristics | Why? <i>underlying purpose</i> | What? <i>desired outcome</i> | How? <i>the approach</i> |
|------------------------|---|--|---|
| Empathetic | To reduce the emotional distress that is experienced post-diagnosis | Responds in an empathetic way and addresses their emotional needs | By aligning responses with the individual's emotional state |
| Adaptable | To address the changing needs of individuals | Addresses the changing needs of individuals | By tailoring responses based on individual feedback and requirements |
| Accurate and Connected | To minimise the need of seeking information from various fragmented sources and provide trustworthy information | Prevents reliance on untrustworthy sources, enables informed conversations with healthcare providers | By integrating information from trusted sources like hospitals, kanker.nl and patient organisations |
| Transparent | To inform about the sources of the information | Provides awareness on the source of information | By providing and highlighting the sources of information |
| Personalised | To fulfill the varied needs and preferences of individuals and reduce the volume of information | Delivers relevant and specific information tailored to each individual's situation | By meeting requirements of individuals |
| Simplified | To make information easily understandable and reduce the difficulties in dealing with information | Helps individuals comprehend complex information about their cancer | By breaking down information into steps and using visual aids like texts and videos |

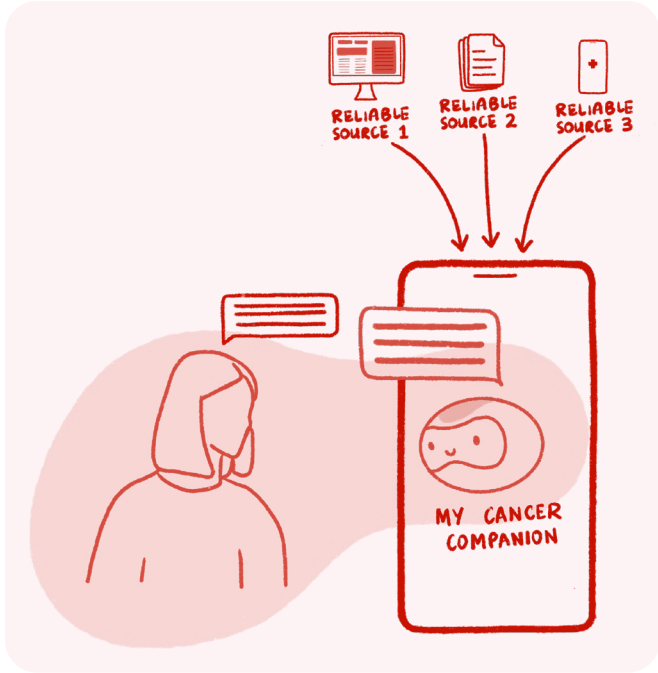
Table 6.1: Design Characteristics of Brema

6.4 Desired Interaction



Current Interaction

In the current interaction, individual consults the healthcare provider and receive documents to better understand their illness. They then seek additional information from various sources, driven by the need to reduce uncertainty and make sense of complex information. However, this often leads to an overwhelming amount of fragmented and one-dimensional information, resulting in information overload.



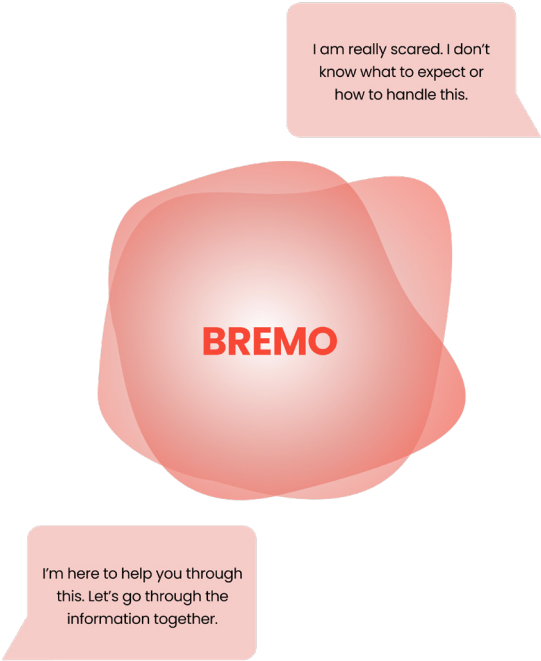
Desired Interaction

Through the desired interaction, My Cancer Companion helps in minimising the need to seek information from unreliable sources as it retrieves information from various trusted sources and provides information in simple, clear and interactive conversations. This reduced the

volume and also provides an accurate centralised source of information that offers empathetic conversations.

6.5 Design Outcome: BREMO

Building on the established design characteristics, My Cancer Companion has been further developed as Bremo. Bremo is an AI-driven personal assistant designed to be accessible via chat or voice interaction. Its primary function is to support people with breast cancer in dealing or preventing information overload post-diagnosis. Bremo aims to achieve two main objectives: firstly, to facilitate access to information from credible sources such as kanker.nl, hospitals, and patient organisations; and secondly, to comprehend and address the emotional needs of people. By addressing the four chosen factors of information overload for this study—complexity of information, volume of information, fragmented sources and emotional response—Bremo is proposed to meet the informational and emotional needs through the application of six design characteristics.

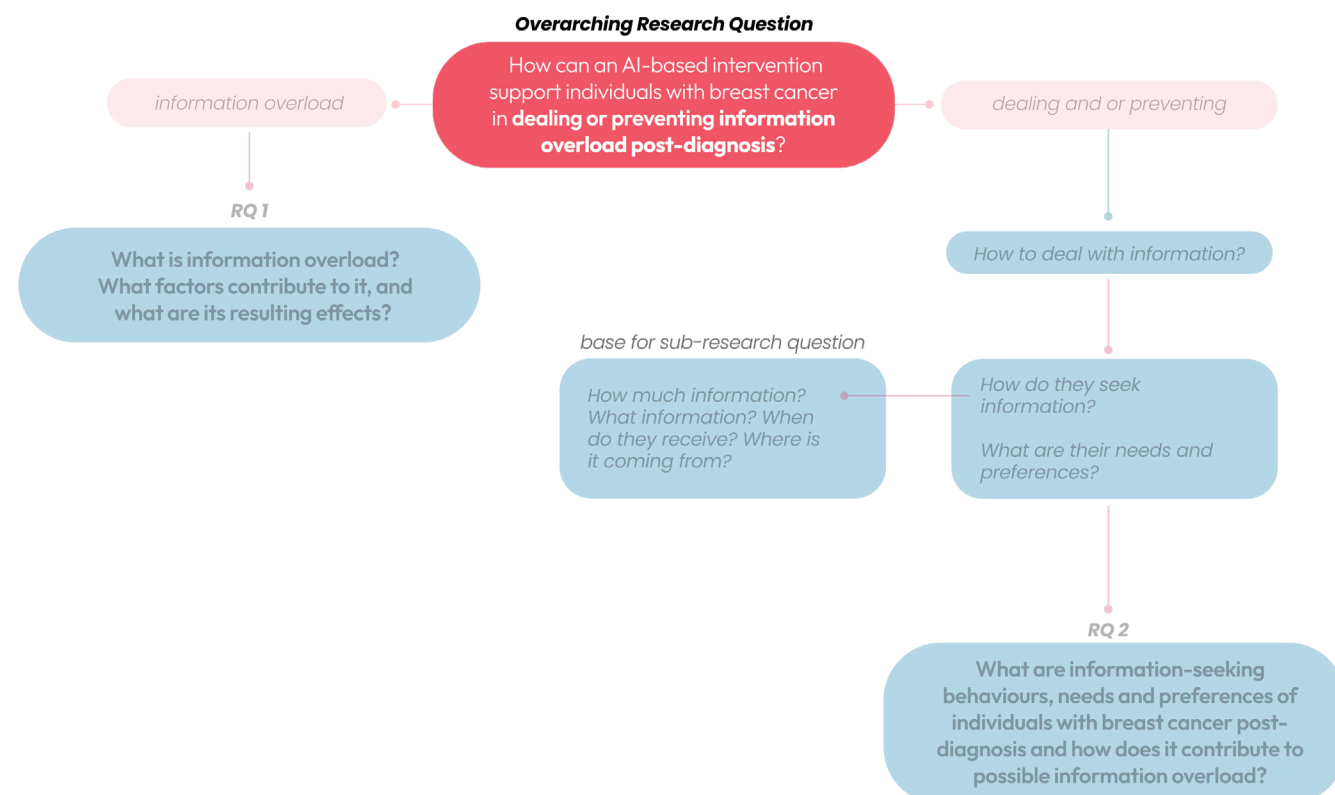


The next chapter outlines the design development and features of Bremo, illustrating how it sits in the healthcare system and supports individuals in dealing or preventing information overload through various scenarios.

07

Design Development

This chapter elaborates on the concept of Bremo, outlining its intended functionalities and interactions across various scenarios. Exploring how Bremo will be integrated into the healthcare system and utilised during patient consultations, this chapter also highlights the features and operational scenarios through illustrative digital screens. It concludes by addressing the main research questions, linking the findings to RQ1 and RQ2, and assessing how Bremo aligns with the study's objectives.



To effectively introduce a new concept into healthcare, it was crucial to assess its impact on both the system and individual. This involved a dual exploration of system-level integration and individual-level interaction to understand how the concept fits within the healthcare system and reaches individual. Prior to this analysis, it was necessary to map the existing cancer care system and the relationships between various institutions. Through the multiple conversations I had during interviews and desk research outlined in section '1.5, Overview of Cancer Care in the Dutch Context', I mapped the interconnections to provide a comprehensive understanding of the current system.

The cancer care in the Netherlands is well-established and emphasises patient-centred approaches to provide information to people. Netherlands Comprehensive Cancer Care Organisation (IKNL), Dutch Cancer Society (KWF), and NFK currently fund the operation of the kanker.nl platform. The Dutch Breast Cancer Association (BVN) is affiliated with umbrella organisation NFK and is integrated with kanker.nl. The hospitals provide their set of information (physical documents, hospital applications, websites, etc.) and links to kanker.nl and BVN to people during consultation sessions. However, despite some integration across these sources, the information remains fragmented for those accessing it and hence increasing the volume of information.

7.1 Positioning of Bremo in the Healthcare System

Bremo is introduced into the healthcare system as a centralised gateway connecting various existing credible sources of information available to people with breast cancer (Figure 7.1). The integration of this AI tool within the current cancer care system makes it a centralised access point of information for people. It is intended to reduce the need to search across multiple platforms and sources by retrieving accurate and relevant information from existing reliable sources such as hospitals, kanker.nl and patient organisation and delivering it through conversational interactions. Bremo is envisioned as a secondary source of information that provides various types of information along with the corresponding links of the original sources to maintain transparency and for those seeking further details. The tool is proposed to be accessible via smartphones, recommended and provided by healthcare providers during consultation sessions.

In addition to retrieving and delivering information from various sources, Bremo will enhance patient engagement and address diverse needs through the defined design characteristics. The ways in which Bremo will meet these needs are outlined through the desired interactions, elaborated in the next section of this chapter.

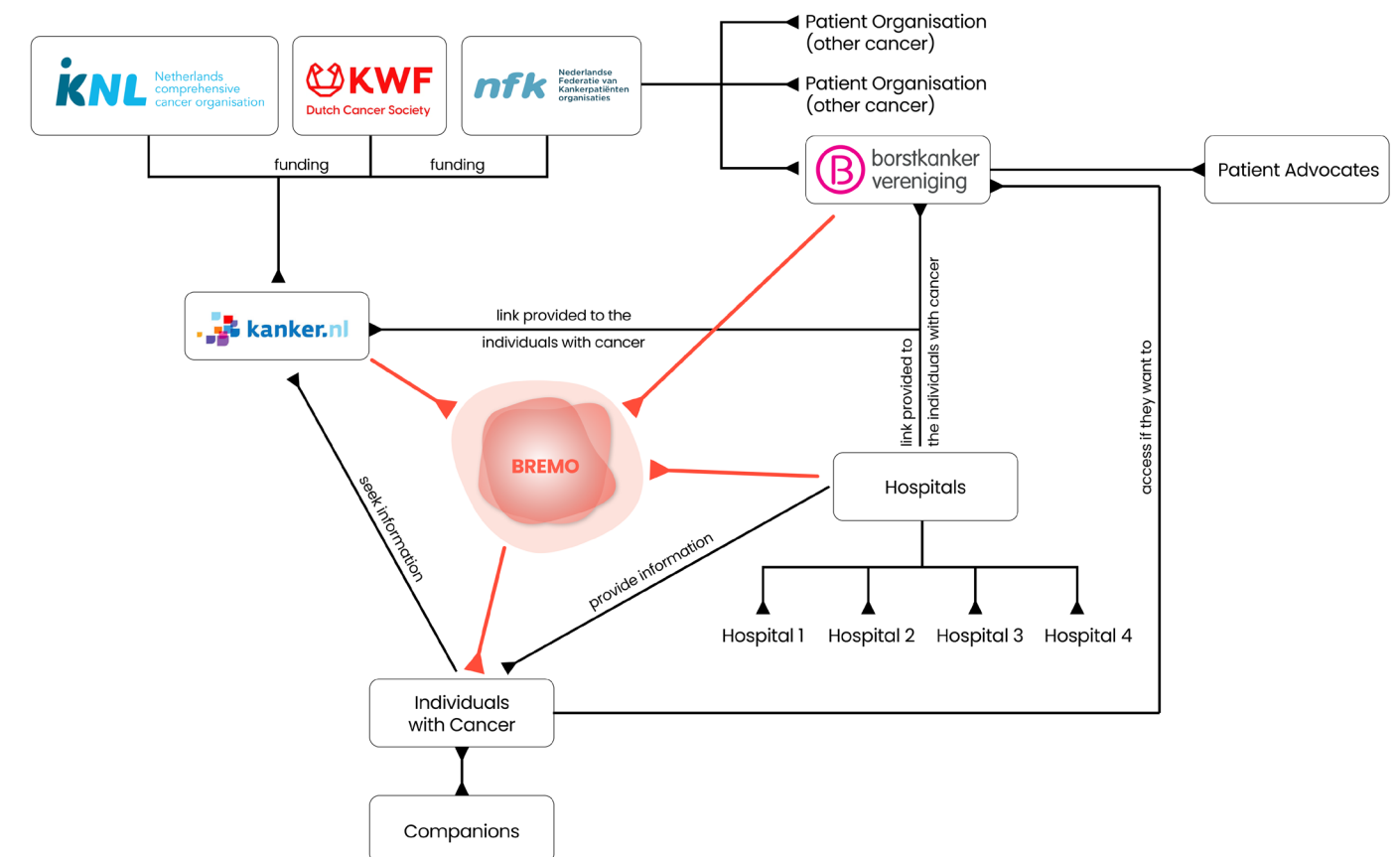


Figure 7.1: Positioning of Bremo in the Healthcare System


7.2 Current & Desired Interactions

At Home

During Consultation Session


Current Interaction

Complex Information




The information is complex in nature which can be overwhelming and difficult to understand

One-dimensional



Currently, individuals receive physical documents and website links, which are often one-dimensional and they have difficulties in understanding


Fragmented Information



Finding relevant information from various sources like websites and hospital documents can be time-consuming, overwhelming and increase the volume of information


Desired Interaction

Simplified Information




Bremo is designed to simplify complex information by presenting it in a step-by-step format, making it easier for individuals to understand, while personalising the information based on their specific needs and preferences.

Interactive Conversations



Bremo is proposed to address the limitations of one-dimensional documents by providing interactive conversations and emotional support, adapting to each individual's emotional state


Centralised Source of Information



Bremo is a centralised source of information that can retrieve information from various credible sources and provide the relevant information

Current Interaction

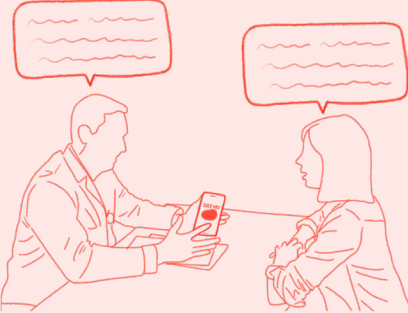
Communication Barriers and Lack of Clarity



After hearing about the diagnosis, most individuals are in a state of shock which makes it difficult to retain the information conveyed to them during the short duration of consultation sessions. They may leave the consultation with unanswered questions or confusion about the treatment plan or next steps due to emotional distress


Desired Interaction

Facilitating Conversation




Bremo aids in facilitating discussions with healthcare providers, enabling individuals to access and review the information shared during the consultation at a later time. Additionally it offers two more features to facilitate conversations:

Record and Recap Conversations



Bremo can assist in recording conversations with healthcare providers, allowing people to review and revisit and comprehend the information at their own pace

Creates a List of Questions in Question Bank

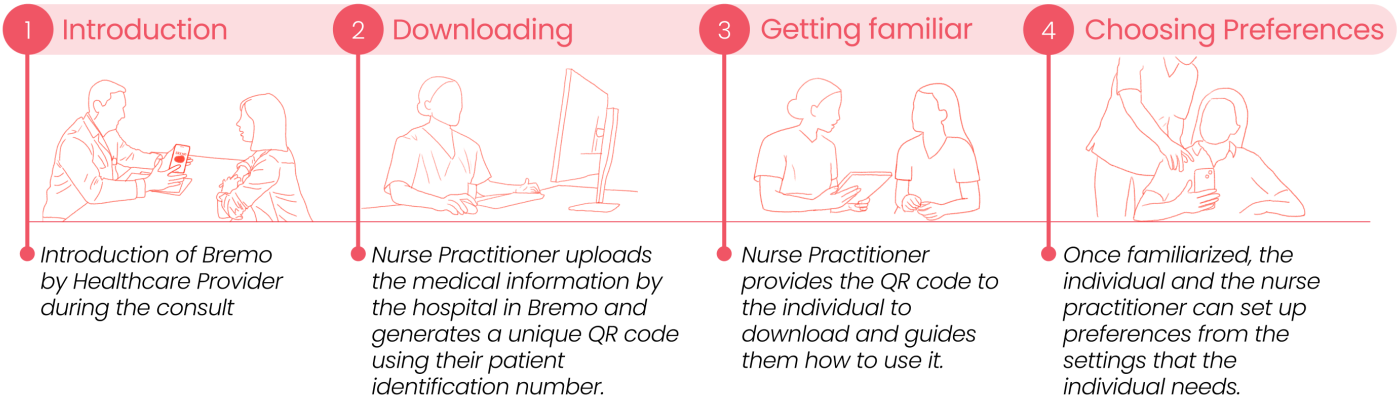


Bremo can assist in compiling a comprehensive list of questions to be addressed during the consultation session

7.3 Introduction of Bremo during Consultation Session

Following the proposed integration of Bremo into the healthcare system, it will be introduced to people with breast cancer during consultation sessions through the following steps:

patient organisation and generates a QR code linked to their patient identification number. The code is provided to the people to download the Bremo assistant on their phone. After downloading the assistant, the individual can login via DigiD to set it up. Figure 7.2 represents the process of logging in to Bremo.



1. Introduction
Bremo is introduced by the healthcare provider during a consultation session. A conversation between the healthcare provider and individual who just got diagnosed with breast cancer is described in Appendix H.

2. Downloading
The nurse practitioner inputs all the information specific to individual from hospital, kanker.nl and

3. Getting Familiar
After the login, the nurse practitioner assists individual in getting acquainted with using Bremo by explaining its intent and demonstrating how to navigate and use the assistant on their phones to. This interaction with the nurse practitioner guides people in accessing and interpreting information through Bremo.

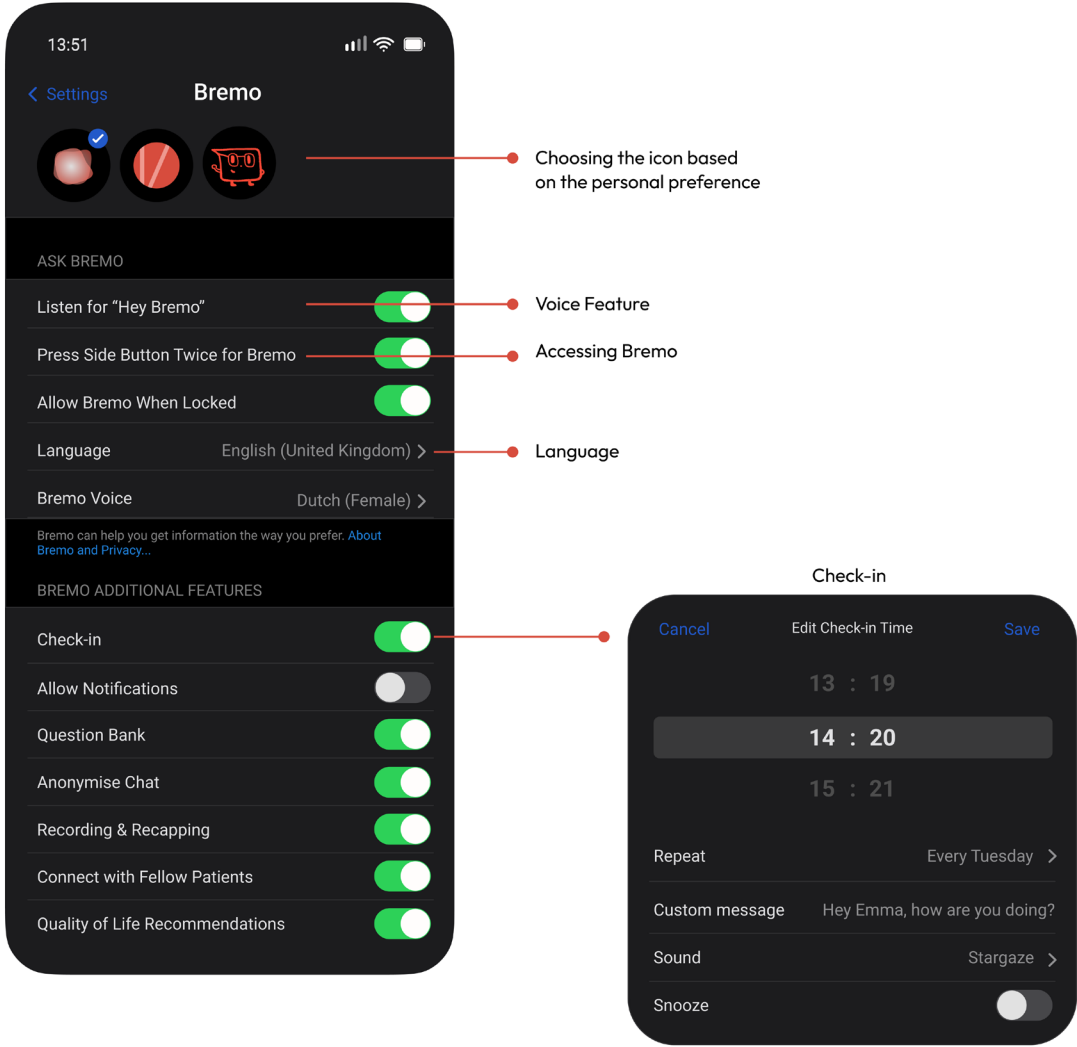


Figure 7.3: Settings Screen on Mobile Phone to Set Preferences for Bremo

4. Choosing Preferences
Once familiarised, individual and the nurse practitioner can set up preferences from the settings of the phone that individual needs. The settings screen on mobile phone to set preferences for Bremo is illustrated in Figure 7.3.

- > **Chat or Voice Feature**
Bremo is accessible through both text-based chat and voice commands, activated by saying, “Hey Bremo!”
- > **Anonymous Chats**
For those who prefer to keep certain information confidential, Bremo allows for anonymous chats. This ensures that personal details are kept private and not shared with the hospital.
- > **Question Bank**
Bremo provides an option to collect and organise questions or concerns they may have in advance.
- > **Check-in Option**
An optional check-in feature allows individuals to

schedule regular interactions with Bremo, either daily or weekly, based on their preference.

> **Connecting with Fellow Patients and Support Groups**
Drawing reference from the preferred sources and the level of trust individuals placed on fellow patients, connecting with fellow patients was desired by a few of them. Bremo provides an optional feature for the same.

> **Providing Purposeful Activities**
It also provides coping mechanisms and quality of life recommendations like to the purposeful activities such as physical exercise, etc.

> **Recording and Recapping the Consultation Sessions**
Bremo also provides a recording feature for consultations sessions, enabling individuals to replay and review conversations at their own pace.

A digital representation of these optional features is highlighted in the following section.

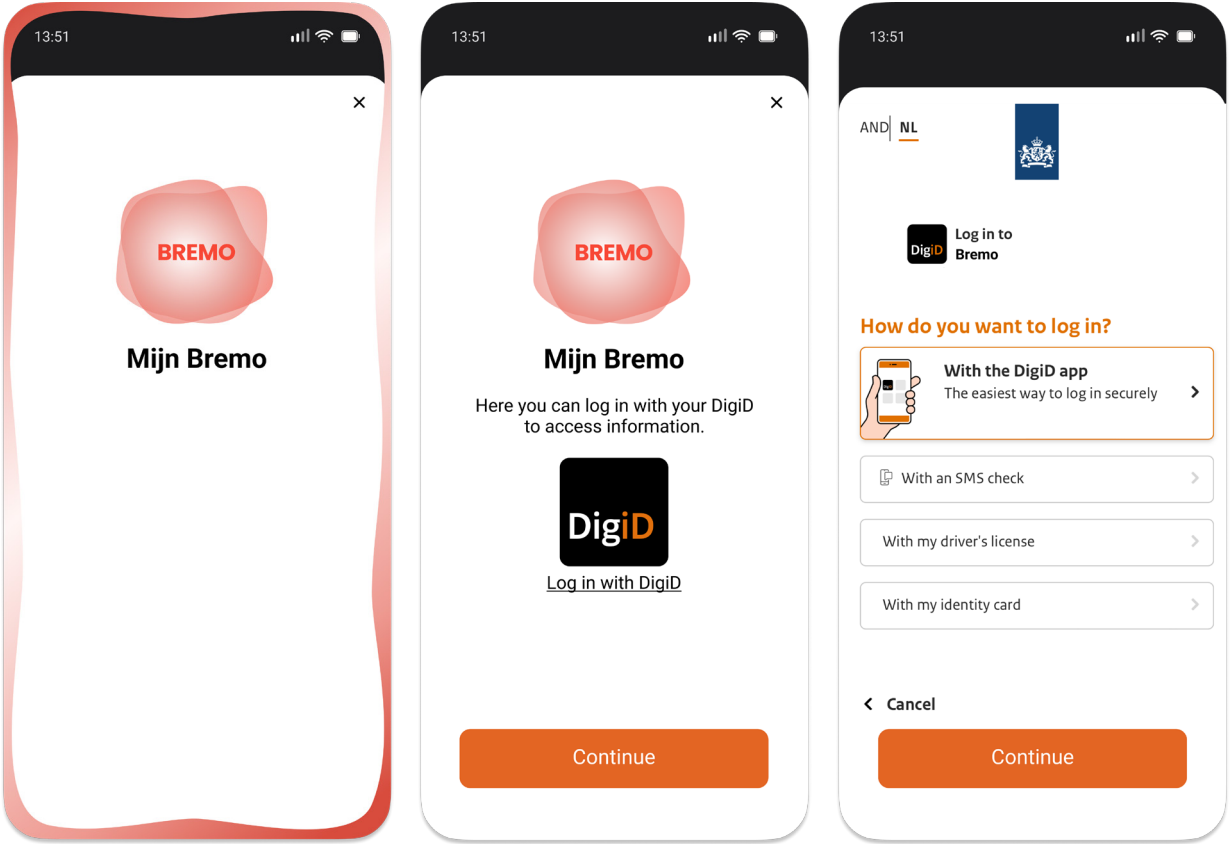


Figure 7.2: Logging in Bremo via Digi-D

7.4 Scenarios

This section presents the various scenarios in which Bremo engages with individuals across different contexts, offering support that meets both their informational and emotional needs. These scenarios represent potential situations that may occur and how Bremo responds to and addresses these needs through it's characteristics. Figure 7.4 illustrates the first screen that individuals see upon logging in through Digi-D. The intent of Bremo is outlined for individuals to understand the purpose and the ways in which it is designed to support them.



Figure 7.4: Initial Screen of Bremo Outlining the Intent

The responses shown in these digital screens are co-created with Chat GPT 4.0 to illustrate the concept and functionality of the assistant. The process of how these responses were generated is provided in Appendix F.2. While this section concentrates on various scenarios related to information provision, the following page highlights additional features and functionalities of Bremo. These features are drawn from interviews with participants, who are currently using these and find it effective in dealing with the illness. Given the current fragmented state of these features, Bremo brings them together to support people.

Retreiving Information and Connecting with Different Sources

Bremo curates information from a variety of credible sources and presents it in an easily digestible format tailored to the individual's specific situation. It also provides links and visual aids like videos, images, etc. and suggests related topics for additional reading. If individual is seeking more information, the 'view more information on....' can be accessed and it directs to the original source of information. This process is highlighted through Figure 7.5 from 'Simplified information from Different Sources to Original Source'.

Anticipating Emotional State and Addressing Emotional Need

In situations where an individual expresses emotional distress, Bremo prioritises offering an empathetic response, connecting with the individual on an emotional level before sharing any information. It adapts to their emotional needs and provides appropriate support. During interactions, Bremo asks questions and suggest possible topics that the individual might consider asking. Only after addressing emotional concerns does it provide the requested information. An example of how Bremo addresses emotional states is shown in Figure 7.6.

Dealing with Sensitive Information

When dealing with sensitive information, Bremo acknowledges its limitations and refers users to healthcare providers via its 'Notifying the Hospital' feature, avoiding the risk of providing inaccurate or misleading information (Figure 7.7). In such cases, the hospital can follow up with the individual to offer appropriate support.

Unavailable Information

If the requested information is not available, Bremo offers two options: it can either add the query to the Question Bank to be addressed in the consultation session or notify the hospital directly. The hospital can follow up with the individual to offer appropriate support based on the severity of the query. This is represented through Figure 7.8.

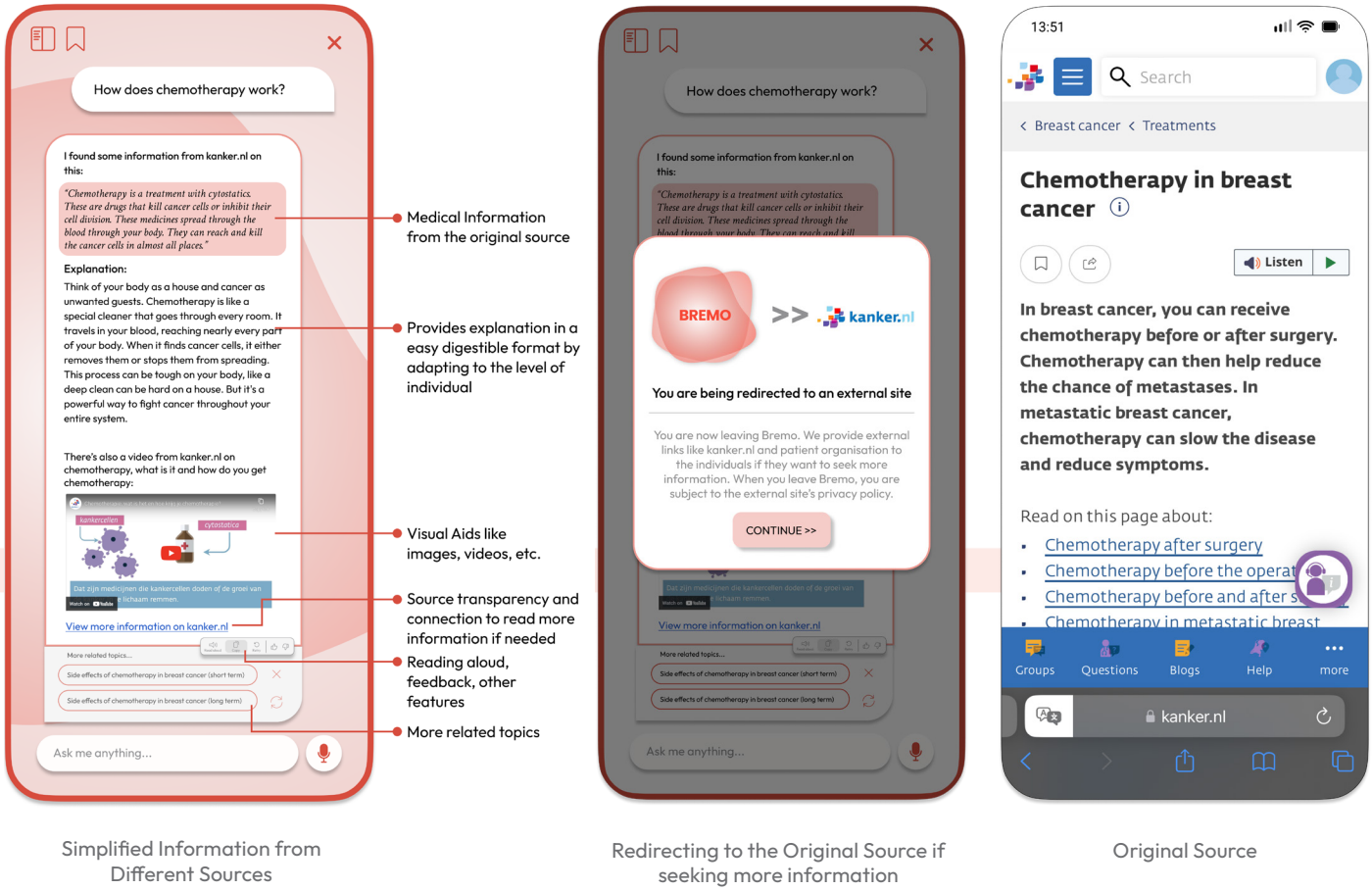


Figure 7.5: Retreiving Information and Connecting with Different Sources

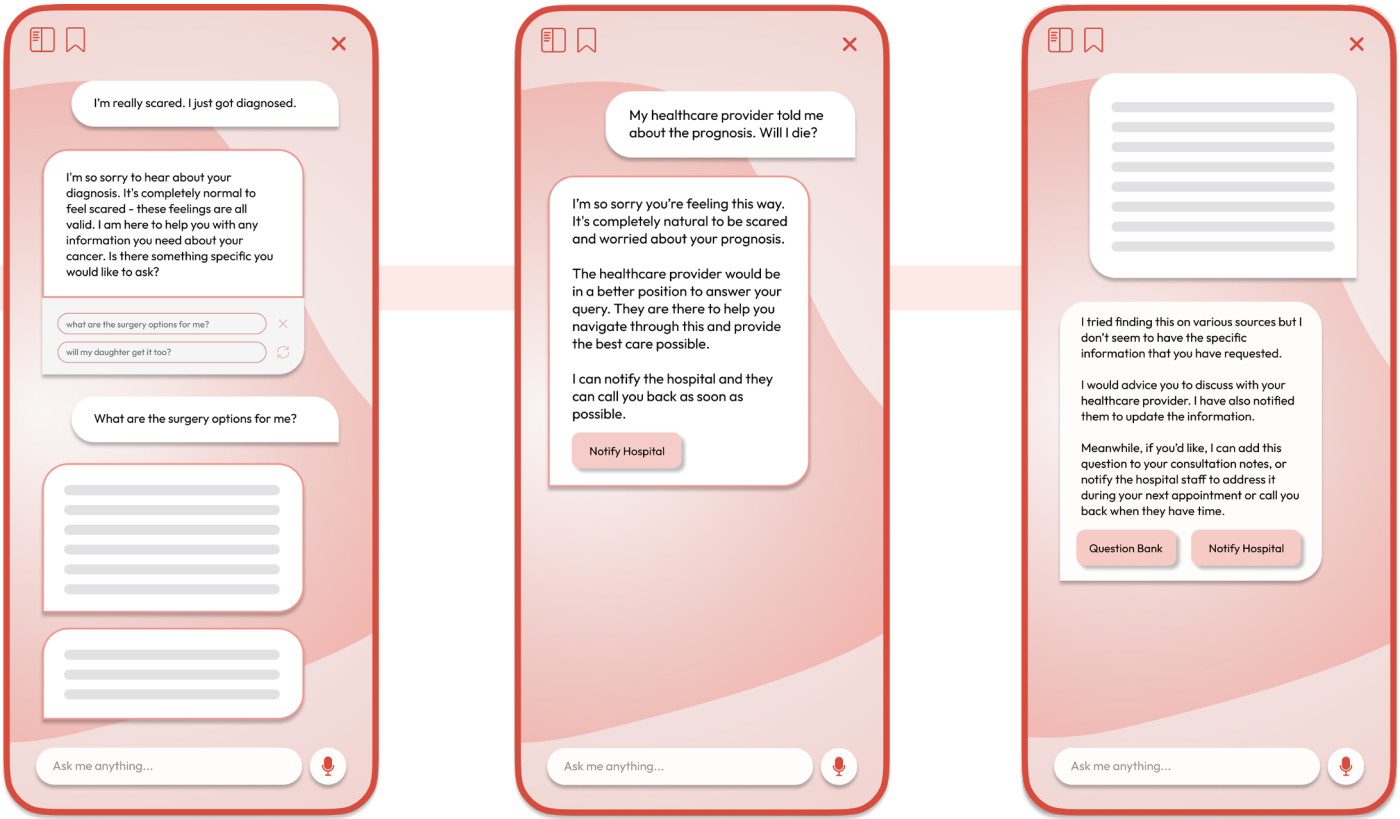


Figure 7.6: Anticipating Emotional State and Addressing Emotional Need

Figure 7.7: Dealing with Sensitive Information

Figure 7.8: Unavailable Information

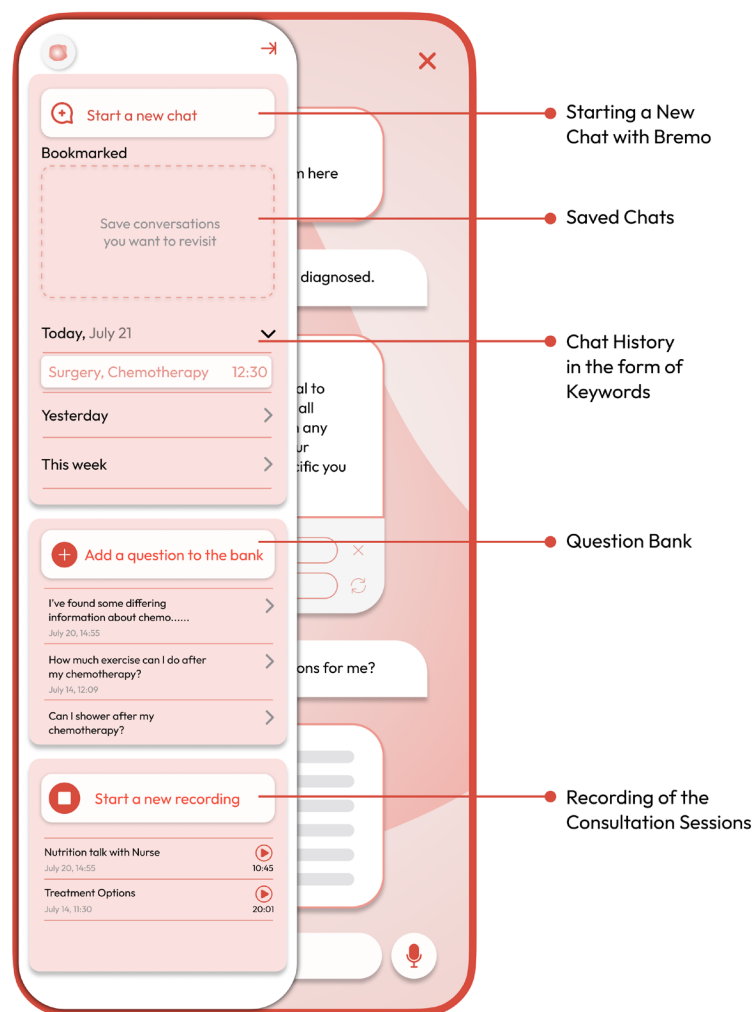


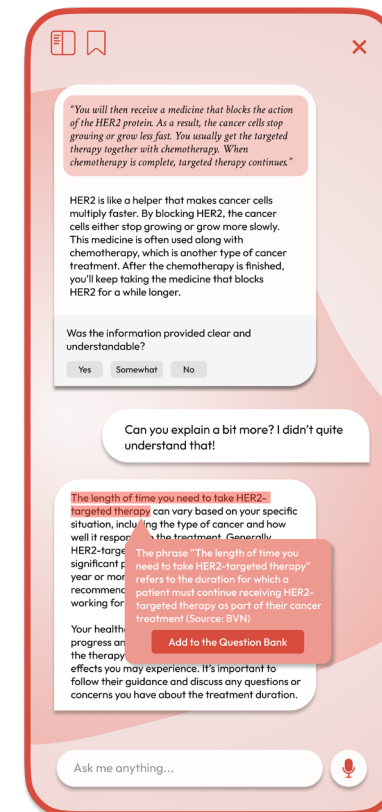
Figure 7.9: Additional Features

> In addition to providing empathetic responses and integrating various information sources, Brema enhances communication with healthcare providers through additional features (Figure 7.9) like the 'Recording and Recapping' of consultation sessions and 'Question Bank'. Brema also allows individuals to record sessions and provides recaps, summarising key points with a transcript to highlight important aspects of the conversation. It generates keywords from the chat and stores them in a history log, complete with date and time, so individuals can easily revisit past conversations. (Figure 7.10)

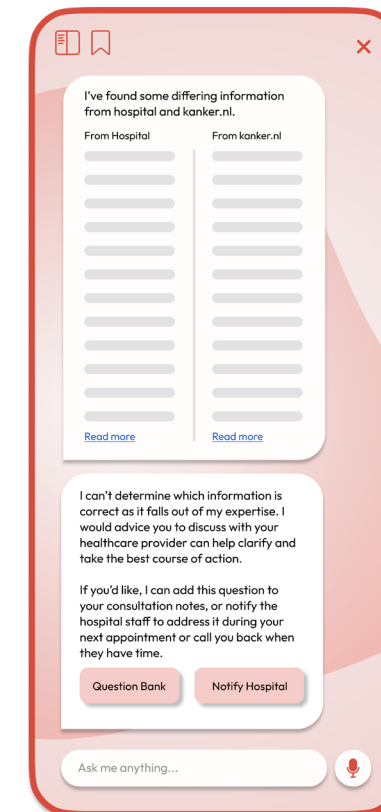
> Figure 7.11 illustrates the ways a query can be added to the question bank.

> If an individual hasn't reviewed relevant information before their next consultation, Brema will curate and compile a list of essential topics to read and can even read along with individual to prepare for the session (Figure 7.12).

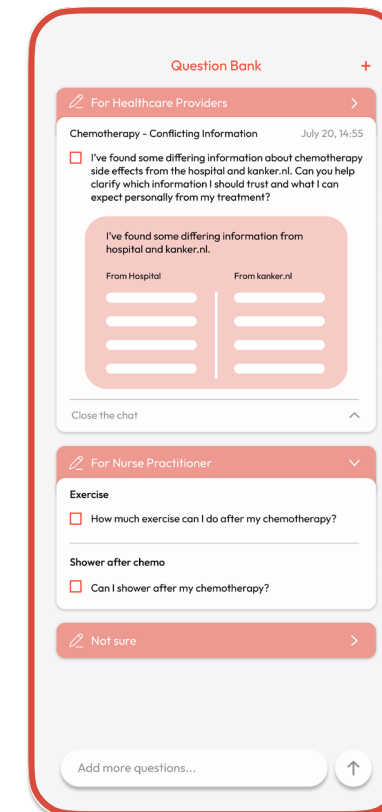
> Individuals can activate a optional check-in feature (Figure 7.13), for daily or weekly follow-ups, if desired and can also connect with a fellow patient through the Dutch Breast Cancer Patient Organisation (Figure 7.14).



Clarifying Medical Jargon
A pop-up box addresses the complex medical jargon by highlighting and can be added to the question bank

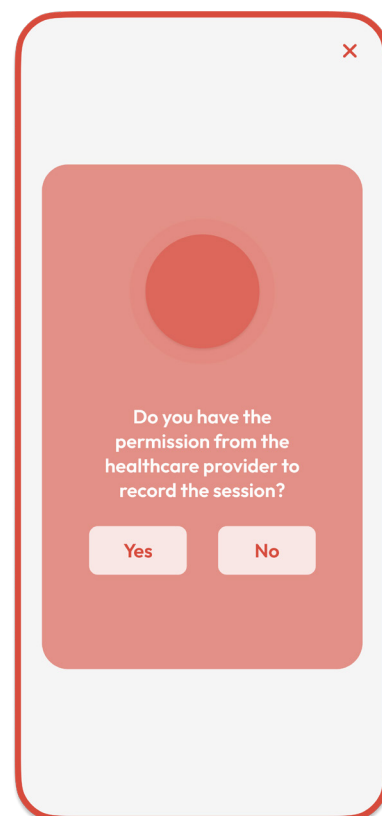


Conflicting Information
In case of encountering with a conflicting information, Brema redirects to the question bank feature or notifying the hospital



Question Bank List
Includes a list of all questions, both those highlighted from the chat or added voluntarily.

Figure 7.11: Multiple Ways of Accessing Question Bank



Recording the Consultation Session

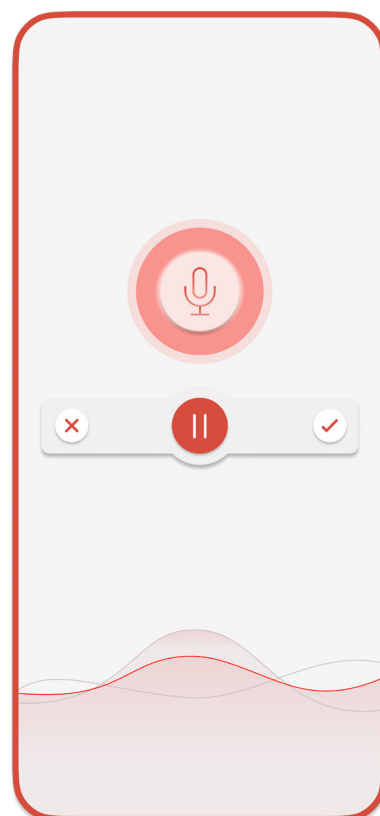
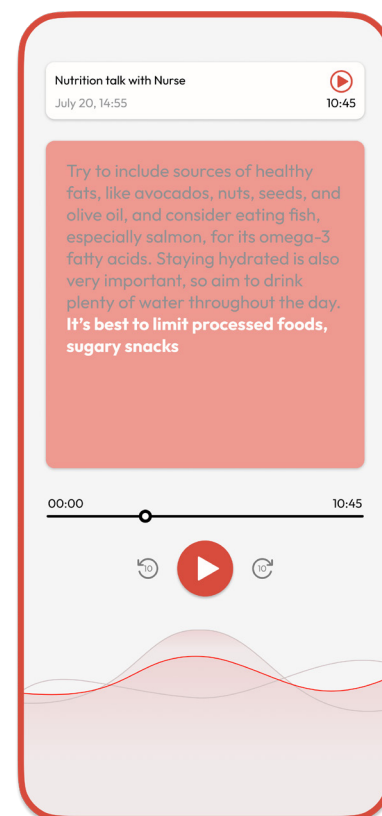


Figure 7.10: Recording the Consultation Session



Recapping of the Consultation Session

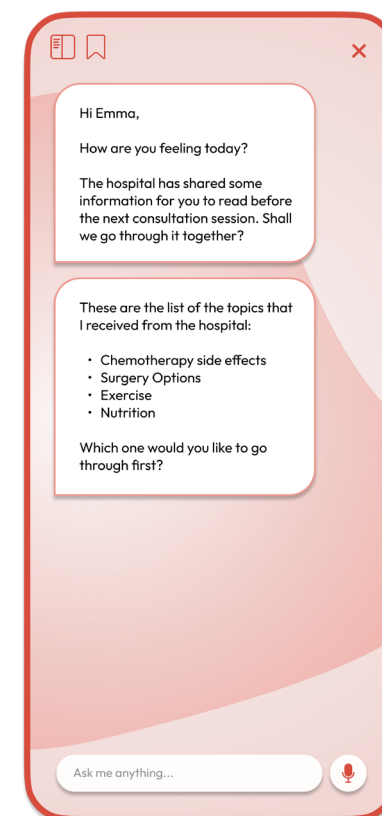


Figure 7.12: Curating Information Package

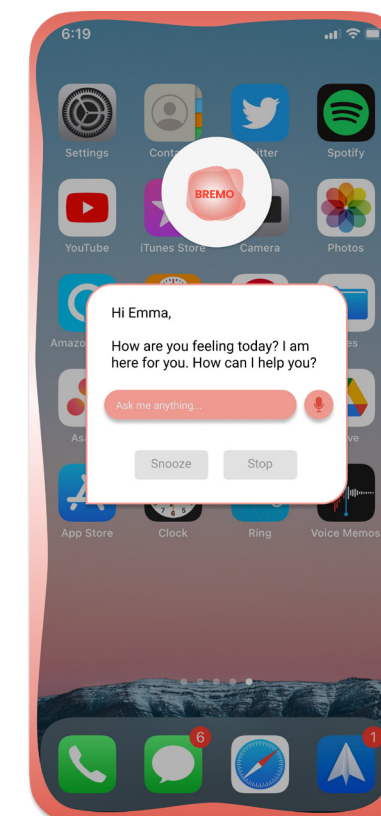


Figure 7.13: Check-in Feature

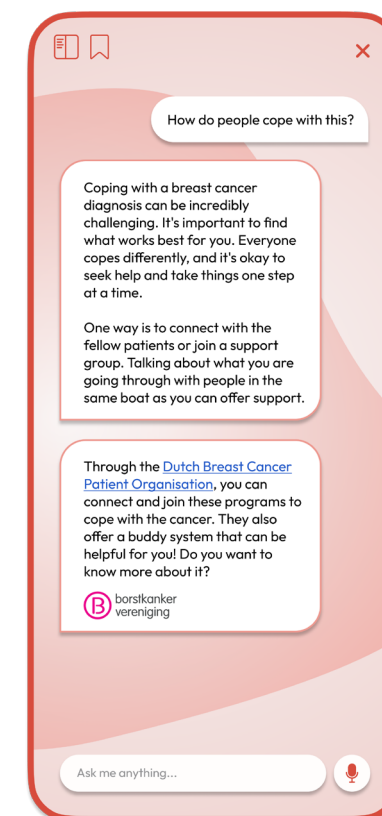
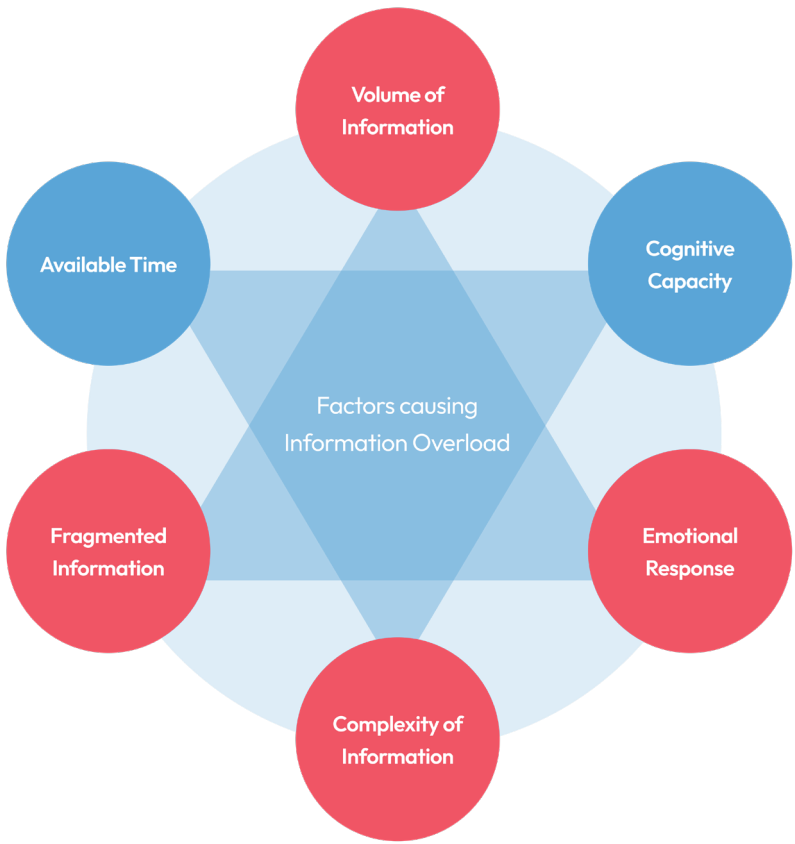


Figure 7.14: Connecting with Fellow Patients

7.5 Summary

To encapsulate the design development for this master thesis, this section outlines the answers to all three research questions:

Overarching Research Question: The Role of Bremo through the design characteristics, supporting individuals in dealing and preventing information overload post-diagnosis



RQ1: Factors Influencing Information Overload

How does chemotherapy work?

I found some information from kanker.nl on this:

"Chemotherapy is a treatment with cytostatics. These are drugs that kill cancer cells or inhibit their cell division. These medicines spread through the blood through your body. They can reach and kill the cancer cells in almost all places."

Explanation:

Think of your body as a house and cancer as unwanted guests. Chemotherapy is like a special cleaner that goes through every room. It travels in your blood, reaching nearly every part of your body. When it finds cancer cells, it either removes them or stops them from spreading. This process can be tough on your body, like a deep clean can be hard on a house. But it's a powerful way to fight cancer throughout your entire system.

There's also a video from kanker.nl on chemotherapy, what it is and how you get chemotherapy:

View more information on kanker.nl

More related topics...

Side effects of chemotherapy in breast cancer (short term)

Side effects of chemotherapy in breast cancer (long term)

Ask me anything...

Design Characteristic

- Accurate and Connected
- Simplified
- Transparent

Bremo consolidates information from various fragmented sources, thereby reducing the amount of information. It also simplifies complex information needed to process. This approach addresses three factors of information overload: complexity, information volume, and fragmentation.

I'm really scared. I just got diagnosed.

I'm so sorry to hear about your diagnosis. It's completely normal to feel scared - these feelings are all valid. I am here to help you with any information you need about your cancer. Is there something specific you would like to ask?

What are the surgery options for me?

Will my daughter get it too?

What are the surgery options for me?

Ask me anything...

Design Characteristic

- Empathetic
- Adaptable
- Personalised

Bremo anticipates individuals' emotional states from their responses and addresses their emotional needs by attuning to their level and adapting accordingly. It provides empathetic responses and personalises its approach to align with individuals' preferences.

RQ2: Needs and Preferences of Individuals

INFORMATION NEED

"You will then receive a medicine that blocks the action of the HER2 protein. As a result, the cancer cells stop growing or grow less fast. You usually get the targeted therapy together with chemotherapy. When chemotherapy is complete, targeted therapy continues."

HER2 is like a helper that makes cancer cells multiply faster. By blocking HER2, the cancer cells either stop growing or grow more slowly. This medicine is often used along with chemotherapy, which is another type of cancer treatment. After the chemotherapy is finished, you'll keep taking the medicine that blocks HER2 for a while longer.

Was the information provided clear and understandable?

Yes Somewhat No

Can you explain a bit more? I didn't quite understand that!

The length of time you need to take HER2-targeted therapy can vary based on your specific situation, including the type of cancer and how well it responds to the treatment. Generally, HER2-targeted therapy is taken for 1 year or more, depending on how the treatment is working for you. Your health progress on the therapy affects you may experience. It's important to follow their guidance and discuss any questions or concerns you have about the treatment duration.

Add to the Question Bank

Ask me anything...

Design Characteristic

- Personalised
- Simplified
- Transparent

Through feedback, Bremo learns individual preferences and offers personalised information. It also simplifies complex medical terminology using a pop-up feature that provides additional explanations and enables users to add these terms to the question bank for further clarification with the healthcare provider.

RQ2: Needs and Preferences of Individuals

EMOTION NEED

How do people cope with this?

Coping with a breast cancer diagnosis can be incredibly challenging. It's important to find what works best for you. Everyone copes differently, and it's okay to seek help and take things one step at a time.

One way is to connect with the fellow patients or join a support group. Talking about what you are going through with people in the same boat as you can offer support.

Through the [Dutch Breast Cancer Patient Organisation](#), you can connect and join these programs to cope with the cancer. They also offer a buddy system that can be helpful for you! Do you want to know more about it?

borsstkanker vereniging

Ask me anything...

Design Characteristic

- Accurate and Connected
- Empathetic
- Adaptable

Some individuals seek to address their emotional needs through interactions with other patients for emotional support. Bremo supports this by connecting users to BVN, which has a pre-existing buddy system. This allows individuals to receive both informational and emotional support from those who have experienced similar situations.

08

Design Evaluation

The chapter includes the evaluation of the concept 'Brema' with participants, healthcare designers at Panton and AI experts on Desirability, Viability and Feasibility.

The concept, Brema, was first self-analysed through SWOT analysis (Appendix G.1) and later discussed with two participants from the research phase, three healthcare designers from Panton and one HCI PhD candidate from Industrial Design Department at TU Delft. The concept was mapped on the quadrant of desirability and feasibility with the healthcare designers and the feedback from other sessions were considered for future design recommendations.

8.1 With Participants

While the participants found the concept intriguing, they had differing opinions. One participant preferred receiving a physical handout rather than using the concept on a phone. Another participant appreciated the integration of various existing sources.

"I would I would not prefer to read it on my phone because it's a lot of information. So that's tricky. Of course, you could have it as a PDF, but I prefer to get a handout. But it's maybe not everyone, so I would always have it double."

- P1

"I like your idea of not reinventing the content, but using the really good content that's out there and maybe these sites all do talk a lot about what is it. I think you found something that there's a gap and then it's valuable. And umm, I like that it's very integrative with various established data sources."

- P7

Both participants provided feedback on the "Question Bank" and "Notify the Hospital" features. One participant raised a concern that the "Notify the Hospital" feature could potentially overwhelm healthcare facilities, as individuals might submit multiple inquiries with an expectation of immediate responses. To address this issue, several potential solutions could be considered. One approach might involve having a nurse practitioner assess the urgency of each query, allowing for necessary follow-up while non-urgent questions could be added to the question bank for discussion during subsequent consultation sessions. However, this solution could increase the workload for nurse practitioners. Introducing a new role within the system to review queries and collaborate with nurse practitioners could be helpful. Alternatively, the frequency of such inquiries could be analysed to determine whether it is more efficient to update information on Brema (though this may be time-intensive) or to provide links to existing, reliable resources. Given the variability of individual cases, any approach would need to be tailored to the specific nature of the query, requiring further investigation.

"But the thing notifying the hospital may actually overload the hospital. Because it's an invitation to notify them, and then you expect them to do something with it."

- P1

"I think that's a good idea too because I do find that I had always had like a little running list of questions."

- P7

8.2 With Healthcare Designers and AI Expert

During a discussion with healthcare designers from Panton and a PhD candidate in Human-Computer Interaction, I discussed the desirability, feasibility and viability of the concept. The designers found the concept desirable, useful, and practical for supporting individuals with breast cancer by consolidating existing information into a single platform accessible for individuals.

The concept screens were reviewed with healthcare designers. It was determined that conflicting information would be neither desirable for patients nor feasible, as it could potentially cause confusion. The current function, which involves handling sensitive information and adapting to the emotional state of patients, was also found to be neither feasible nor desirable, as the effectiveness of the check-in feature depends largely on the patient's engagement. However, several features were identified as both desirable and feasible. These include connecting with fellow patients, question banks, recording and recapping sessions, situations where information is not known, and logging in with Digi-D. According to the designers, the directions that adds value to the lives of individuals through this tool is the collation of information from different sources into a single, unified screen and the recording and recapping feature. The desirability and feasibility mapping is presented in Figure 8.1 on the following page.

"As also from the hospital and the organisation's perspective, I think it could be useful to give transparent information to them."

- Healthcare Designer 1

"Yeah, I think maybe the only thing here would be that there needs to be enough information, because if there is not enough information on the platforms and you still have to go Google all your information together, cause your disease or form of breast cancer is different then it's no use to you."

- Healthcare Designer 3

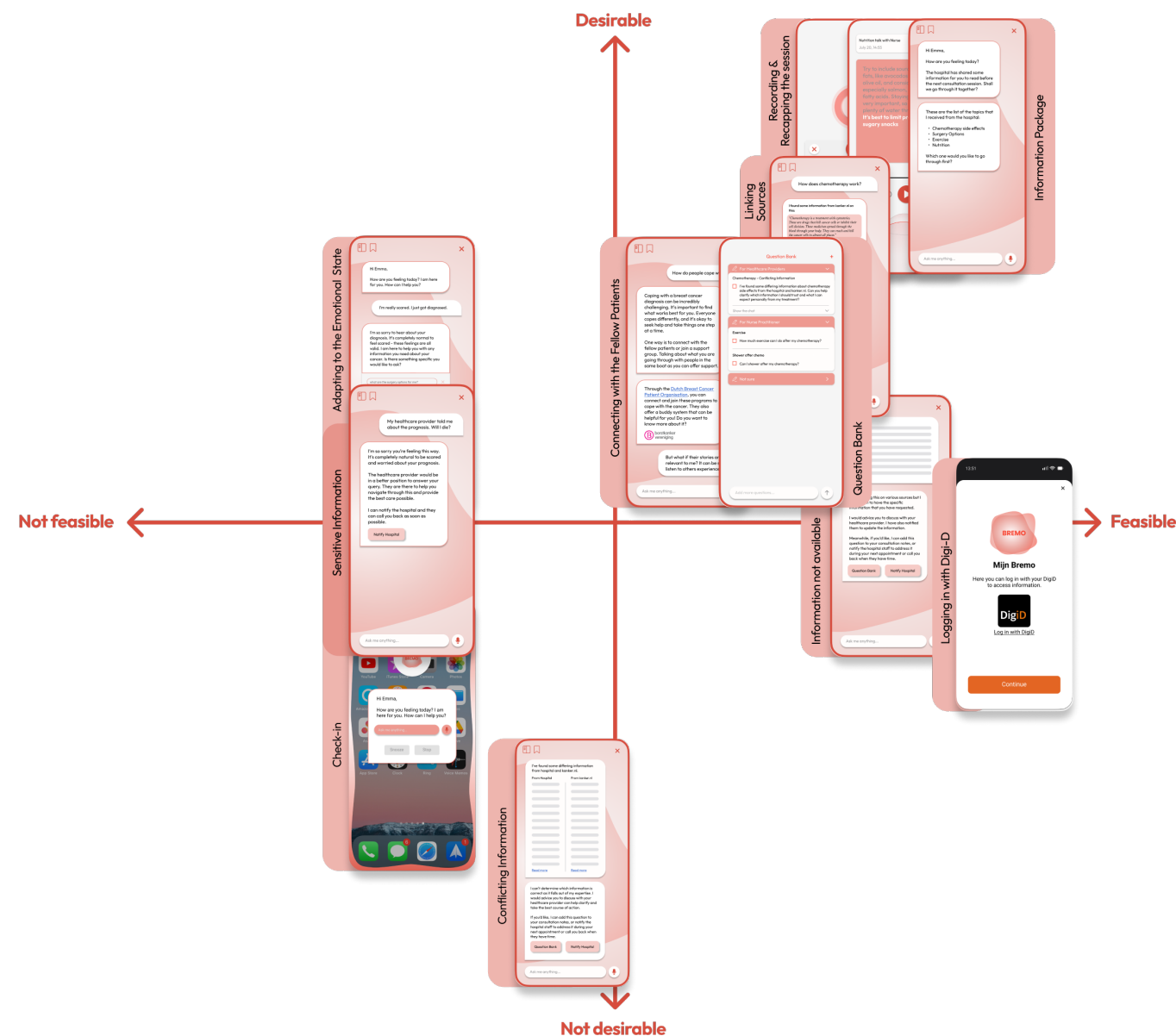


Figure 8.1: Desirability and Feasibility Mapping of Bremo with Healthcare Designers at Panton

The viability of the project was discussed with the AI expert, who emphasised that the financial investment required would largely depend on the model used for the generator. If an external API located outside the EU is employed, significant investment would be necessary. This approach also poses a risk, as sensitive healthcare data would be processed and stored by a company outside the EU, raising concerns about data security and compliance. Alternatively, local systems could be used, but this might result in slower response times, depending on the number of users interacting with the tool. Healthcare designers mentioned that there's a huge investment required and specified that the financial model should be aligned with the project's goals. Typically, a pilot phase funded by insurance is conducted, during which the tool's scalability is assessed on the basis of key considerations like impact on improving patients' quality of life (QoL), ability to reduce healthcare professionals' time, and the challenges

associated with nationwide implementation. While it represents a big investment for the healthcare sector, potential funding could come from sources such as kanker.nl and hospitals.

During the discussion, concerns were raised about using Bremo to address individuals' emotional needs. The designers emphasised that this is a highly sensitive area, and the use of AI in this context could lead to unintended negative consequences. Given the complexities involved in emotional support within healthcare, they recommended that the tool be focused on more tasks, such as connecting users with a peer support network, providing clear and reliable information, or facilitating communication with a case manager. It's essential that both users and healthcare providers understand the tool's limitations. The AI should not be used for providing treatment advice, and clear guidelines must be established to ensure the tool is used appropriately and effectively.

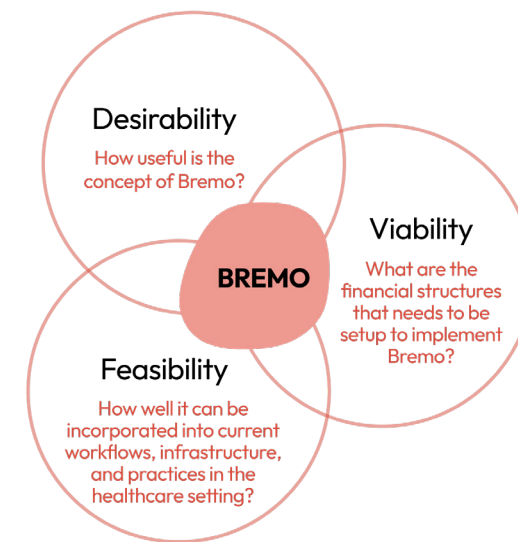


Figure 8.2: Thoughts on Desirability, Feasibility and Viability of the Concept Bremo

"Maybe in the future, but right now, I don't know! I think that is very, very slippery slope....I think trust is the least of the issues and I think getting a complex emotional response is very hard."
- Healthcare Designer 2

Meanwhile, the AI expert noted that ongoing research is exploring how AI tools can exhibit empathy as AI continues to advance. However, she highlighted that significantly more testing is required, as the task of detecting emotions such as anxiety or sadness is far more complex for Large Language Models (LLMs) than for traditional machine learning models focused on sentiment analysis. She recommended experimenting with the current capabilities of LLMs over an extended period, allowing for multiple interactions and continuous adjustments to better understand what approaches are most effective in achieving empathetic responses.

Building on these discussions, I have outlined the next steps for advancing this project. The upcoming chapter presents design recommendations, including guidelines for shaping the design

| | |
|--------------|---|
| Desirability | <p>"I would maybe say a very useful because if you can use, use it as a recording app for your conversations and have it summarize it, and also have the the only your information that you need in one app then is yeah, it would make your complete patient journey a little easier and even and we reduce some of the stress." - Healthcare Designer 3</p> <p>"I think very effective. I think that is the the one of the best way of using AI is like simplifying complex information and getting large text to be small and comprehensible." - Healthcare Designer 2</p> |
| Viability | <p>"It depends on the number of users and the model used to generate the response. External API is fast but the data is going to be processed and held by another company. Local system will be slower but safe with healthcare data." - AI Expert</p> <p>"It should be possible and I think a big advantage is that you connect the the information that all the difference in organisations provide. You also the end of the organisations help them to give uniform information. This could really help" - Healthcare Designer 1</p> |
| Feasibility | <p>"I think it could be quite effective. It depends on like how you implement the system and what kind of explanation it generates like how the simple the language is, how long or short the explanation is. It has the potential to be very effective. It could be very good at summarisation and it depends also on how you design it." - AI Expert</p> <p>"It could be an information tool that can be integrated into different existing tools." - Healthcare Designer 1</p> |

"There have been some research papers recently where people say like health information and similar services, patients prefer chatbots as they are more empathetic because they give longer answers and they don't feel as judge-y as talking to another person."...."It's a possibility but I wouldn't imagine it would be incredibly right out of the box. You will have to do some tweaking with the current capacity of LLMs and play around with it to get what you want for a long period of time - not with just one response, in multiple interactions over several days."
- HCI PhD Candidate

characteristics while building the prototype, and introduces two proposed evaluation methods to evaluate. Further reflection on desirability, feasibility and viability is provided in 'Chapter 10, Discussion.'

Design Recommendations and Proposed Evaluation

Due to the complexity of the topic, extensive research phase and the limited time period of the master thesis, the design stage was rather brief, which led to propose a concept rather than a implementable design solution. This chapter however suggests the next step that can guide the further development of the design and proposes two evaluation frameworks to test if the AI intervention can help the individuals in dealing and/or preventing information overload post-diagnosis phase.

9.1 Design Recommendations

The next phase in progressing this project entails developing BreMO according to the outlined steps.

Methodology

Using a Research through Design (RtD) approach. This method will place design activities at the core of knowledge generation and insight development, allowing for the framing and reframing of objectives and the creation of prototypes through self-exploration and small-scale tests with fellow students. These prototypes will then be tested with people with breast cancer and other stakeholders to evaluate BreMO's effectiveness. Building on the suggestions from the previous chapter, the process should start with desk research focusing on the following:

Desk Research

Literature Study: Although the next step for this project is design-oriented, it would be beneficial to consider recent literature on the role of AI, particularly the 'Empathetic' design characteristic. As research on the ability of large language models to provide emotional support in healthcare is expanding, integrating these findings could enrich the design process. This is also further discussed in the next chapter 'Discussion'.

Studying Existing Tools: During my research, I found some implemented chatbots (askellyn.ai (Robinson, n.d.) and ViK chatbot (Chaix et al., 2019) for people with breast cancer to access information. I believe exploring and analysing these existing tools could provide valuable insights and relevant references for the development of BreMO. This exploration would help in understanding the functionality and interact with the concept within the given context. While there may be other chatbots for breast cancer, it is crucial to focus on those that closely align with one or more of BreMO's design characteristics.

Building BREMO

During the concept development phase, particularly in section '7.4 Scenarios', I co-created responses with Chat GPT 4.0 to design the digital screens. This prompt testing aimed to explore whether Chat GPT could aid in evaluating the concept. However, as previously noted, the tool's effectiveness is heavily reliant on the quality of the responses generated by BreMO. Due to accuracy and reliability concerns, limitations in understanding the complex contexts, other ethical and legal implications and lack of understanding

the data of this project, Chat GPT was unable to produce the required results. There's also a possibility that the exploration was rather brief than it should have been to achieve the desired results. Another reason is that it doesn't contain the required dataset from hospital, kanker.nl and patient organisation, so the desired results could not be achieved.

However, this exploration led to define the guidelines and establish a foundation to build BreMO. The exploration with Chat GPT can be found in Appendix F.2.

Guidelines for Design Characteristics

Empathetic

This aspect is very important and complex to achieve. It remains an area of ongoing exploration in the field of artificial intelligence, as achieving true empathy in AI interactions is delicate and challenging. In healthcare, providing appropriate empathetic responses is especially crucial because inappropriate or poorly judged responses can have serious consequences for individuals. Therefore, it is essential to carefully define the extent of empathy that the AI should exhibit and continuous monitoring should be adopted to regulate it. This involves being attuned to emotional states, delivering context-aware responses, and understanding individual preferences.

Adaptable

BreMO should be adaptable to the evolving needs of the people and the dynamic landscape of healthcare information.

Accuracy and Connected

BreMO should not provide fabricated or generate its own information and provide non-sensical data. Researchers term this as 'hallucination' (Maynez et al., 2020). Hallucination refers to instances where AI systems produce plausible but incorrect or nonsensical data. It should offer links to the sources of information when available, allowing individuals to access additional details if they wish to read further. In situations where information is unavailable or insufficient, BreMO should refrain from providing speculative or potentially inaccurate details. Instead, it should clearly communicate the limitations of its knowledge and, where applicable, direct users to consult with healthcare professionals for further assistance.

Transparency

Transparency is crucial in maintaining user trust.

Individuals and healthcare providers need to know where the information was shared from to ensure accountability and trust. Bremono should always disclose the sources of the information it presents.

Personalised

Personalisation is partially achieved when the hospital uploads health information linked to the patient’s identification number, ensuring that individuals receive details tailored to their specific circumstances. Further personalisation can be attained when AI not only meets individual needs and preferences but also continuously learns and tailors information and support aligned with those needs and preferences.

Simplified

To find the right balance of simplification that makes the information clear and accessible, it is crucial to conduct extensive user testing. Simplification requires thorough investigation from the lens of healthcare providers to maintain the integrity of the information while aligning with individual preferences. Bremono should avoid both oversimplification, which can omit important details, and undersimplification, which may cause confusion.

In discussions with healthcare providers at Panton during the design evaluation, several additional design features were suggested for consideration during the design phase. These potential features could contribute to the design characteristics and are outlined in Appendix H.1.

Meeting these guidelines can be challenging without a baseline of responses. To understand that further, the next step is to build the library.

Building a Question and Response Library

In discussions about the concept with participants in the last chapter, I had also inquired about the types of questions they would ask Bremono. Some of their responses are shown in Figure 9.1. This exploration could be expanded by developing a “Library” that collects common questions individuals might ask and the responses they anticipate from Bremono.

To build the library, a survey could be distributed through platforms such as kanker.nl or the Dutch Breast Cancer Association (BVN), after obtaining the necessary permissions and completing the HREC approval process. These organisations have the experience and access to a network of individuals who could provide valuable insights on the questions that individuals ask and the

responses they provide to make individuals feel supported.

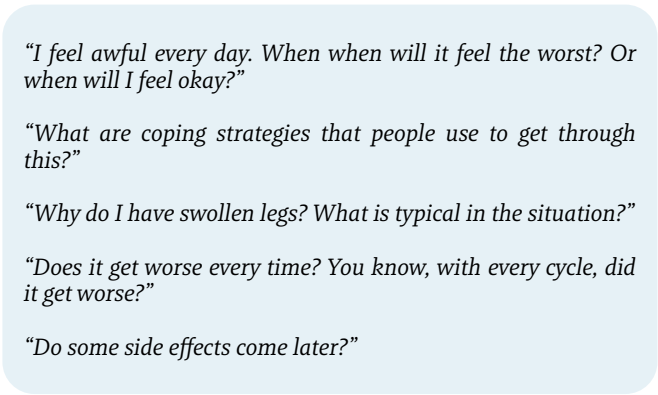


Figure 9.1: Base to Create Library of Type of Questions Participants Might Ask Bremono

Based on the question library and by following the foundations of design characteristics, the companion could be created using voiceflow (tool to build voice and chatbots) or any other online AI chatbot builder to conduct user tests.

User Tests

Session One

Goal

To evaluate the effectiveness of characteristics of Bremono independently.

Method and Participants

The initial round of testing can involve fellow students from IDE, TU Delft. This phase aims to assess the functionality of each design characteristic by conducting small-scale tests. Participants will interact with the tool by entering prompts and providing feedback on their experiences and expectations regarding Bremono’s responses. Approximately four to five participants can be involved to get initial insights.

Procedure and Time

This testing can be conducted using a paper prototype or via a simulated ‘Wizard of Oz’ setup on WhatsApp for rapid results. A short session of about 30 minutes, followed by an interview should be sufficient to gather opinions.

Interview

The interview can contain open-ended questions to understand their thoughts of the participants. For example, ‘Does this response exhibit the [design characteristic of Bremono]?’, ‘What additional features would you expect to meet the [design characteristic]?’

Analysis

The responses from interview can be analysed through thematic analysis using card sorting on FigJam or Miro. Card sorting will allow to revisit, iterate and cluster the themes accordingly.

Session Two

The insights obtained from session one will be used to refine the design characteristics. Through Session two, these refined characteristics will then be further examined to evaluate how the interconnected characteristics interact together.

Goal

To evaluate the Bremono’s effectiveness and the interrelationships between design characteristics.

Procedure

Method

The testing phase will involve examining the design characteristics of Bremono using prompt engineering with OpenAI’s API or a Voiceflow model. The testing can be carried out with around nine to ten participants. For the purpose of this phase, I created a set of 20 statement cards (Figure 9.2) (Appendix H.2) along with a scale from agree (positive sign) to disagree (negative sign), ranging from 0 to 5. This can be used to create an interactive session. Through this, participants can be asked to articulate their thoughts and provide deeper insights into their experiences.

Participants

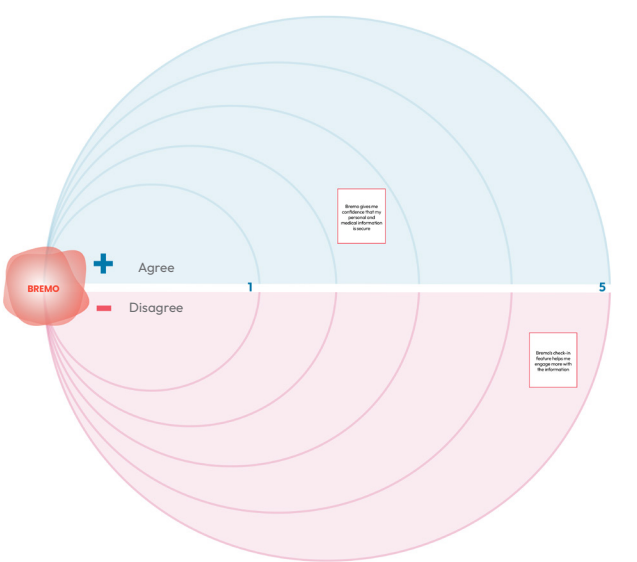
The participants for this testing phase will primarily include fellow students from the Industrial Design Engineering department or students from other departments at TU Delft. Additionally, consultations with AI experts (~n=3) will be conducted to evaluate the integration and functionality of the AI components. The feedback from these experts will be crucial for refining the AI aspects of the project.

Time

Each testing session is anticipated to last between one hour and one and a half hours. This duration allows sufficient time for participants to interact with the design features, provide feedback, and engage in thoughtful discussion guided by the open-ended questions posed during the sessions.

Assessment

The feedback obtained from this session will be used to make necessary refinements and adjustments to the tool. If further changes are needed, the testing cycle can be repeated to



Sample of Using Agree and Disagree Scale

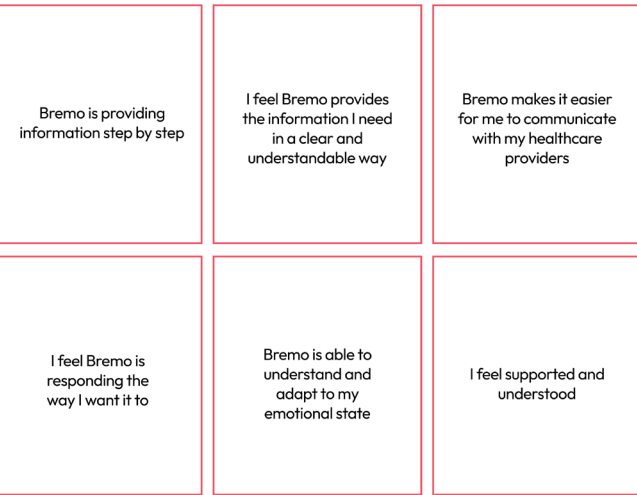


Figure 9.2: Statement Cards for Testing Bremono (Full Set of 20 Statement Cards can be found in Appendix H.2)

incorporate these updates before progressing to the next phase. Additionally, increasing the number of interviews may help gather a wider range of perspectives.

After the tool is developed, the evaluation methods outlined below can be used to assess how effectively Bremono meets the needs of individuals with breast cancer by conducting an evaluation session with them and other stakeholders.

9.2 Proposed Evaluation Methods

Outcome Evaluation

Outcome evaluation was suggested to determine whether Bremono meets user needs by adapting questionnaires from validated evaluation scales.

Impact Evaluation

The impact evaluation focuses on assessing the long-term effects of using Bremono, developed

and adapted based on the ‘effects of information overload’ from the Chapter 4 of this report.

9.2.1 Outcome Evaluation

The AI intervention Bremo can support people with breast cancer in dealing or preventing information overload by addressing the informational and emotional needs through the design characteristics. These design characteristics shape how effectively Bremo meet those needs, and evaluating them requires testing the desired outcomes. The sub-goals were formulated from the ‘What: Desired Outcome’ (Table 6.1).

Hajesmaeel-Gohari et al., 2022 conducted a literature review on the most used questionnaires for evaluating outcomes of mobile health. For the evaluation of the proposed concept, relevant validated questionnaires were selected, examined, and adapted to define the outcome evaluation. The selected questionnaires included a combination of Health IT Usability Evaluation Scale (Health-ITUES) (Yen et al., 2010), mHealth App Usability Questionnaire (MAUQ) (Zhou et al., 2019), System Usability Scale (SUS) (Lewis, 2018) and Technology Acceptance Models in Health Informatics (TAM) (Davis, 1989). These were adapted and a few more questions were

formulated that aligned with the design goal.

Bremo, an AI companion proposed in a sensitive context like healthcare, must undergo evaluation by various stakeholders and AI experts (Figure 9.3) to assess its effectiveness. People with breast cancer will evaluate the tool in its entirety as they are the primary users, healthcare providers will assess the accuracy of information provided through Bremo and the AI experts will evaluate the responses in relation to AI’s capabilities. Furthermore, to test emotional support of the tool, patient organisations and advocates can assess the responses based on empathy, given their experience in working closely with a diverse patient population. An overview of the sub-goals, evaluation participants, methods, and the specific questionnaires to be used is provided in Table 9.1.



Figure 9.3: Evaluation Participants

For Healthcare Providers

1. I think Bremo is a positive addition to cancer care in the Netherlands

strongly disagree disagree neutral agree strongly agree

2. Using Bremo makes it easier to share information with individuals with breast cancer

strongly disagree disagree neutral agree strongly agree

3. Bremo provides an acceptable way to deliver healthcare information to individuals

strongly disagree disagree neutral agree strongly agree

4. Bremo made it convenient for me to communicate with individuals during consultation sessions

strongly disagree disagree neutral agree strongly agree

5. The information provided by Bremo is accurate

strongly disagree disagree neutral agree strongly agree

6. Bremo simplifies the information for individuals correctly

strongly disagree disagree neutral agree strongly agree

Figure 9.4: Proposed Questionnaire to Evaluate Design Characteristics of Bremo with Healthcare Providers

The questionnaires to be used during evaluation for healthcare providers and people with breast cancer are outlined in Figure 9.4 and Figure 9.5 respectively.

For People with Breast Cancer

1. My interaction with Bremo is clear and understandable

strongly disagree disagree neutral agree strongly agree

2. I find Bremo to be flexible to interact with

strongly disagree disagree neutral agree strongly agree

3. Bremo is easy to use

strongly disagree disagree neutral agree strongly agree

4. I found the various functions in this system were well integrated

strongly disagree disagree neutral agree strongly agree

5. I think that I would like to use Bremo frequently

strongly disagree disagree neutral agree strongly agree

6. The information in Bremo is simplified so I could easily understand the information

strongly disagree disagree neutral agree strongly agree

7. I feel supported and understood when I use Bremo

strongly disagree disagree neutral agree strongly agree

8. Bremo is able to understand and adapt to my emotional state

strongly disagree disagree neutral agree strongly agree

9. Bremo reduces uncertainty and provides the information in the way I prefer

strongly disagree disagree neutral agree strongly agree

10. Bremo is a reliable and trustworthy tool

strongly disagree disagree neutral agree strongly agree

Figure 9.5: Proposed Questionnaire to Evaluate Design Characteristics of Bremo with Individuals with Breast Cancer

| Needs <i>Why?</i> | Design Characteristics <i>How?</i> | Sub-Goals <i>What?</i> | Evaluation Participants <i>Who?</i> | Method |
|---|---------------------------------------|--|---|--|
| <div>Information Need</div> <div>Emotion Need</div> | Empathetic | Individuals can feel supported and understood | Individuals with Breast Cancer, Patient Organisation, Patient Advocates | Individuals with Breast Cancer: Interviews + Questionnaire The questionnaire, adapted from the TAM and SUS frameworks, and specific questions to evaluate whether Bremo meets the intended needs |
| | Adaptable | The changing needs of individuals can be fulfilled | AI experts and Individuals with Breast Cancer | |
| | Accurate and Connected | Individuals rely less on unreliable sources, and helps them in having informed conversations with healthcare providers | Healthcare Providers and AI Experts | |
| | Transparent | Individuals are aware of the source of information | AI Experts | AI experts: Interviews The aim is to gain a nuanced understanding and suggest improvements for the tool |
| | Personalised | Individuals receive relevant information specific to their situation | Individuals with Breast Cancer | |
| | Simplified | Individuals are able to comprehend complex information and be informed of their illness | Healthcare Providers and Individuals with Breast Cancer | Interviews with Patient Organisations and Patient Advocates: Interviews The goal is to understand a nuanced view from the perspective of large pool of patients |
| | | | | For Healthcare Providers: Interviews + Questionnaire The questionnaire, adapted from the Health-ITUES and MAUQ, and specific questions to evaluate design characteristics like reviewing accuracy and level of simplification of information |

Table 9.1: Overview of Sub-Goals, Evaluation Participants and Methods

9.2.2 Impact Evaluation

In the ‘Chapter 4, Defining the Framework: Information Overload’, the effects of information overload were identified, and the prominence of the effects were mapped through interviews with healthcare providers and other key stakeholders. These effects are not typically observed in the short term but rather over an extended period. Therefore, to assess the long-term impact of the concept, I used these effects of information overload and reframed them as positive outcomes to evaluate whether Bremono can help achieve these benefits.

The evaluation framework will be presented to participants using a wheel that illustrates the effects of using Bremono in Figure 9.6 similar to the one provided to the healthcare providers and other key stakeholders during the research phase (Figure 4.5). Participants will assess how effectively Bremono helps them achieve these positive outcomes in their lives, creating a visual representation of their experiences using a Likert scale ranging from 0 to 5. While the effects of information overload were not quantified, it was found that expressing opinions and attitudes about these experiences can be difficult. Therefore, a Likert scale of 0 to 5 has been proposed for evaluating long-term effects to help them assess and express their opinions. An example of how the wheel will be used by participants is illustrated in Appendix H.3.

Participants: For preliminary insights, the impact evaluation can be tested with around 10 participants. To increase the validity of the findings and enable more detailed analysis and comparisons, a larger sample of approximately 30-40 participants is recommended. The participants should have used Bremono following their diagnosis to understand information about their cancer.

Both of these evaluation methods can be implemented through the extension of this design thesis by further developing Bremono. Therefore, the following section offers design recommendations to advance this project by refining Bremono’s design characteristics based on user feedback and developing a high-fidelity prototype through multiple rounds of testing.

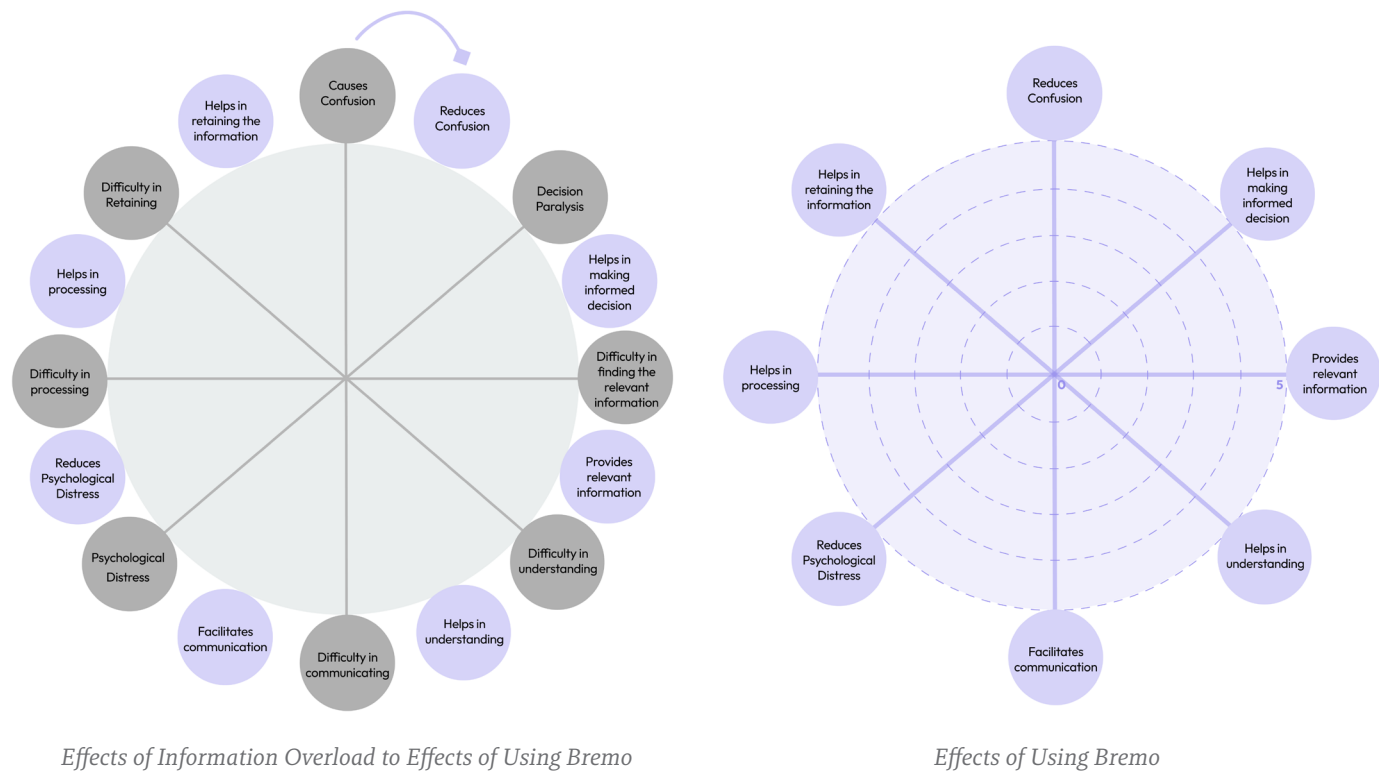
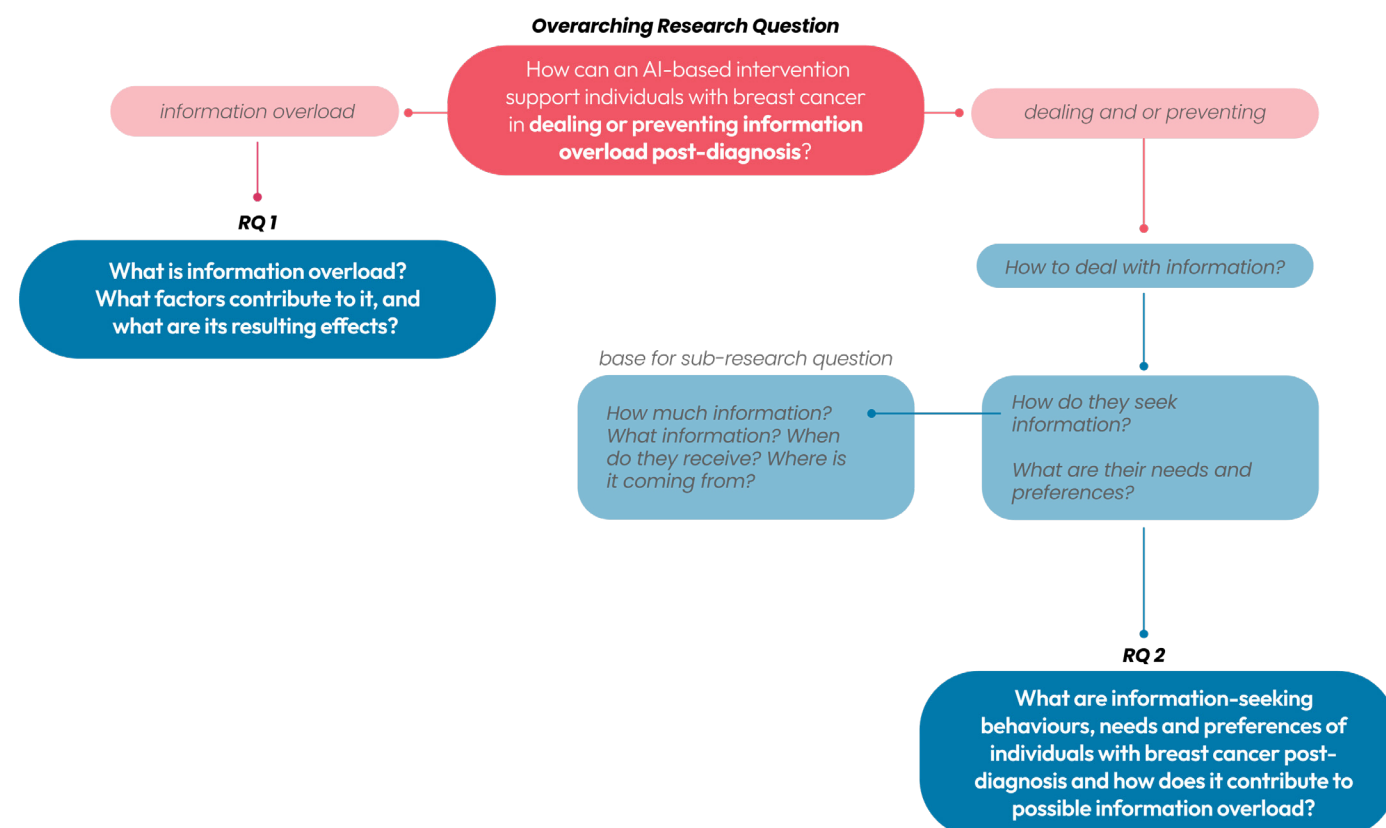


Figure 9.6: Long-Term Effects Evaluation of Bremono

10

Discussion

This chapter provides a comprehensive discussion of the research findings, addressing the project's research questions while highlighting the contributions made o bridge the gaps in the current approach.



10.1 Summary

Receiving a cancer diagnosis is often emotionally intense and challenging experience, filled with uncertainty. Many individuals find themselves isolated and this challenge is intensified by their efforts to seek information to reduce the uncertainty. The shift towards patient-centred care and the emergence of digital health technologies has enabled individuals to become more involved in their care journeys and play an active role in decision-making (Kuwaiti et al., 2023). While these advancements has increased involvement of individuals and access to information, they can also contribute to information overload. The goal of the master thesis was to explore how AI can assist individuals with breast cancer in dealing or preventing information overload. To achieve the objective, it was first essential to first understand the concept of information overload and what causes it (addressing RQ1) and to investigate individuals' information-seeking behaviors, including their needs and preferences regarding sources, amount, and type of information and understand how these factors may contribute to information overload (addressing RQ2).

A personal AI assistant called 'Bremo' was proposed to address the challenge of information overload by meeting their needs. The concept was discussed with two participants from the research phase and desirability, feasibility, and viability was discussed with the healthcare designers at Panton and AI experts. Finally, design recommendations and evaluation frameworks were proposed for outcome and impact measurement as a part of the next step in advancing this project.

Through the literature studies, it was identified that the despite the support provided by healthcare providers post-diagnosis, individuals seek information from various other sources like internet, support groups, friends and family, etc. This information-seeking behaviour varies and is driven by several factors such as the demanding schedules of healthcare providers, lack of ability in providing emotional support during communication, the complexity of information, a way to reduce uncertainty, etc. As a result, information-seeking behaviours and preferences for source of information differ depending on individuals' specific needs and situation.

However, the process of acquiring of information from multiple sources can lead to information overload - a term widely studied and defined by various researchers. While the rapid advancement and growing use of digital technologies in healthcare have made a wide range of information sources easily accessible, these sources, though convenient, can also contribute to information overload. There remains a gap in the current approach, as individuals continue to have unmet information needs. Despite the wealth of available resources, the information provided is often irrelevant or too complex for individuals to understand.

Artificial Intelligence, one of the emerging technologies, has become a useful and necessary tool in oncology and its applications span diverse domains, including patient engagement. Given its wide capabilities, the adoption of AI has the potential to address information overload. However, concerns like data privacy, ethics, security, etc. remain and must be carefully addressed in a sensitive domain like healthcare.

To bridge the gaps in the current approaches, it was imperative to first understand the existing context. Given the breadth of existing literature, it was essential to clearly define information overload, identify its contributing factors, and understand its effects for the purpose of this project (RQ1). Furthermore, it was crucial to understand the information-seeking behaviours, needs and preferences of individuals and how it possibly contributes to information overload in the current context of cancer care in the Netherlands (RQ2). Addressing RQ1 and RQ2 was necessary to answer the overarching research question:

How can an AI-based intervention support individuals with breast cancer in dealing or preventing information overload post-diagnosis?

**RQ 1: What is information overload?
What factors contribute to it, and what
are its resulting effects?**

In response to RQ1, I created a framework for understanding information overload, identifying six contributing factors based on the literature study. Information overload is a complex phenomenon which typically refers to a state when an individual is exposed to more information that they can effectively process. Information overload is caused by external factors such as the volume of information, complexity, fragmented sources, and available time, and internal factors such as emotional responses and cognitive capacity. These factors produce intertwined effects such as difficulties in understanding, retaining, and processing information, as well as psychological distress. Building upon one external and one internal factor of information overload; complexity of information and the emotional response, I investigated further and conducted interviews with all the stakeholders (individuals with breast cancer: n=7, healthcare providers: n=4, patient organisation: n=1, patient advocates: n=3, companions of individuals with breast cancer: n=2, representatives of the research institutes in cancer care n=3) to understand their perspectives.

**RQ 2: What are information-seeking
behaviours, needs and preferences of
individuals with breast cancer post-
diagnosis and how does it contribute to
possible information overload?**

Through the research activities like interviews and mapping needs and preferences, it was discovered that individuals with breast cancer have unmet information and emotional needs, a finding also supported by literature. In an effort to reduce uncertainty and anxiety during the overwhelming experience of illness, individuals often turn to various sources for information to understand information. However, this increases the volume of information as the sources are fragmented and there is a risk of encountering conflicting information, which adds to the complexity. This information-seeking behaviour stems from a lack of sufficient support that individuals require. During the interviews, a point also supported by the literature, it was noted that the consultation sessions are often brief, which is not enough to introduce all the information. Moreover, the nature of information is abundant

and lacks the relevance to the specific situations and varied needs and preferences of individuals.

The current information sources, such as information from healthcare providers, kanker.nl, hospital applications, and support group initiatives by patient organisations, are valuable resources but fall short in providing support to the varied needs of individuals due to the broad scope they cover for a large patient population and the limited number of organisations involved. While these sources provide comprehensive information and are currently recommended by healthcare providers, individuals find it challenging to search for information that is relevant to their specific situation and characteristics. Moreover, the information provided is often fragmented and one-dimensional, typically presented in static documents that lack interactivity and visual aids like videos, images, etc. This can be inadequate for individuals with cancer with varying levels of understanding and processing.

Information-seeking behaviours also differ among individuals. Some, with a dominant seeking profile, actively pursue more information and may seek more information in depth from various sources, while others may avoid to do so and may have a dominant avoiding profile. Both healthcare provider and other key stakeholders suggested that these behaviours could be influenced by education levels, background factors or characteristics such as age, family situation, or other characteristics and requires further research.

In the current context, all these factors contribute to a highly individualised experience of information overload, highlighting the need for a personalised approach that supports individuals according to their preferences. My findings suggested that, to effectively address information overload within the current cancer care system in the Netherlands, it is essential to consider two additional factors from the conceptual framework: the volume of information and fragmented sources. Given the abundant and fragmented nature of available information, these external factors, along with the complexity of information and emotional responses, significantly contribute to information overload and it was imperative to include these factors in concept development to collectively address both the informational and emotional needs of individuals.

Artificial intelligence, the driving factor of the proposed intervention, offers a direction in addressing these diverse needs and preferences by personalising and adapting to the level of individuals to address their informational and emotional needs. AI has the potential to respond empathetically while delivering trustworthy information tailored to the individual's situation. However, considering one of the identified causes of information overload, the introduction of a source of information could potentially contribute to information overload. This brought a crucial question during the design phase: *'How is this tool introduced in the healthcare system?'*

The mapping activity of the current healthcare system, as depicted in Figure 7.1, provided valuable insights from a system-level perspective. It aimed to address the external factors of information overload by not contributing to volume of information and reducing fragmentation by establishing a centralised information source. While this addresses information overload from system level, the intervention needed to also address individual-level concerns like variability in understanding information, information-seeking behaviours, providing relevant information specific to individual's situation and addressing their emotional needs.

A personal AI companion - 'Bremo' was proposed with six design characteristics that support both the needs of individuals. It meets these needs by anticipating and addressing the emotional states by simplifying complex information into a step-by-step format, making it easier for individuals to understand and utilise the information relevant to their case. In addition to that, it retrieves information from the existing reliable sources like kanker.nl, patient organisations and hospitals, making it a centralised source of information. This consolidation reduces the need to search untrustworthy sources on the internet. Bremo is intended to facilitate and not replace or augment contact with healthcare practitioners. It is proposed to enhance the conversations between individuals and the healthcare providers and supports individuals in navigating their healthcare journey and make informed decisions.

Breaking the traditional, one-dimensional approach of static documents by offering interactive, conversational access to information from multiple reliable sources, Bremo serves as a sounding board where individuals can share their feelings and concerns. This interactivity and empathetic responses reduce the urge to seek information from less reliable sources on

the internet. Companions can also stay informed through Bremo and can offer more practical and needed assistance, improving the quality of life for both individuals and their families.

According to IZA Zorgakkoord (Ministerie van Volkshuisvesting, Ruimtelijke Ordening en Milieubeheer, 2024), the Dutch healthcare system faces increasing pressure due to a shortage of healthcare providers, a tight labour market, and an ageing population, all while individuals requiring more support. In this context, accessible, high-quality, and affordable care becomes crucial.

Bremo aims to alleviate the burden on healthcare providers by addressing individuals' information concerns, potentially enhancing the quality of consultation sessions and saving time. This aspect will require thorough testing and evaluation with stakeholders and participants once the concept is fully developed, as outlined in the previous chapter, *'Design Recommendations and Proposed Evaluations'*. Healthcare providers can gain insights into the needs and preferences of the individuals and adapt their communication strategies to better meet their needs. Similarly, research institutes, patient organisations, and other cancer care entities benefit from a clearer understanding of needs of individuals, facilitating better support and connections with fellow patients when required.

During the discussion with healthcare designers and AI expert on desirability, feasibility and viability, it was found Bremo was desirable for the current healthcare system as it can simplify the complex information and connect the existing information. In terms of implementation, it suggested to integrate Bremo with the existing systems and tools like Lusci (Lusci, n.d.), an OMRON healthcare service while keeping the proposed intent of connecting the existing sources. Lusci, which integrates with other applications such as BeterDichtbij for digital communication with caregivers, ChipSoft HiX for electronic patient records, Epic, etc. is already widely used by healthcare providers and individuals. Integrating Bremo with such applications could facilitate wider adoption and scalability. As Bremo reaches a broader population and demonstrates its impact on the healthcare system, securing financial investment for nationwide implementation may become more feasible.

Empathy, AI, and Emerging Careers in Healthcare

During the concept discussion, concerns emerged about AI's capability to deliver empathetic responses. This brought to mind a conversation with a participant from research phase who had expressed feeling dehumanised by the transactional nature of healthcare, perceiving herself more as a patient than as an individual. She conveyed a desire for a more holistic approach to care. To address these concerns, I reviewed the relevant literature to explore this further.

Healthcare is transitioning from "patient-centred" to "person-centred" care, which emphasises treating individuals as equal and active participants in the healing process. Person-centred is personalised, enabling and recognising that a person may need more comprehensive support that goes beyond traditional medical care. As people increasingly seek to take charge of their health, the healthcare system must evolve to provide them with the necessary knowledge, skills, and confidence (Coulter & Oldham, 2016). This shift is supported by recent literature, including studies like *'Unmet supportive care needs among cancer patients: exploring cancer entity-specific needs and associated factors' (Springer et al., 2024)*, *'Perspectives on Emotional Care: A Qualitative Study with Cancer Patients, Carers, and Health Professionals' (Krishnasamy et al., 2023)*, *'Psychosocial Care after Cancer Diagnosis: Recent Advances and Challenges' (Tack et al., 2022)*, which underscore the importance of addressing both informational and emotional needs in a holistic manner. Person-centred approach is also supported in this report by the use of "individuals" and not "patients" wherever possible.

From a design and Human-Computer Interaction perspective, Bremono introduces an opportunity of integrating AI in healthcare to support person-centred care. AI, as explored in the literature, is moving towards meeting the varied needs and preferences of individuals, thereby helping healthcare providers reduce their workload. Addressing these interdependent information and emotional needs of individuals, AI tools like Bremono can lead to more holistic care strategies, potentially improving patient outcomes and quality of life.

Although using AI to address emotional states in healthcare is considered a *"slippery slope"*, as healthcare designers at Panton quote it, it presents a challenge, but also inspires further

research into the emotional dimensions of cancer care. Based on feedback from the design evaluation sessions, I delved into the literature on the potential of AI (particularly chatbots) for providing emotional support. The growing body of literature, including studies such as *"The Potential of Chatbots for Emotional Support and Promoting Mental Well-Being in Different Cultures: Mixed Methods Study" (Chin et al., 2023)*, *'Emotional Support from AI Chatbots: Should a Supportive Partner Self-Disclose or Not?' (Meng & Dai, 2021)*, *'Artificial empathy in healthcare chatbots: Does it feel authentic?' (Seitz, 2024)* highlights the expanding role of AI in mental health chatbot applications. These include therapy-focused chatbots (Park et al., 2022), emotional health apps, and smart mental health tools (Olawade et al., 2024) that monitor mood, stress levels, energy, and sleep patterns, often suggesting therapeutic techniques based on responses of individuals (Thakkar et al., 2024). In cancer care, chatbots like, "askellyn.ai" (Robinson, n.d.), "Vivibot" (Greer et al., 2019), "Vik" (Chaix et al., 2019) are being used for different purposes - some assist following diagnosis, some focus on post-treatment emotional support. However, it is essential to acknowledge the distinct difference between AI applications designed for mental health and those intended for life-threatening illnesses such as cancer diagnosis. While integrating AI into cancer care is challenging, the expanding research on AI in mental healthcare offers valuable insights that could be adapted to address the emotional needs in cancer care for people.

This master thesis is emphasising the importance of addressing holistic needs alongside the clinical care and the potential of AI to support this approach. The findings from this research provide valuable insights that could inform future research and personalised information provision to address the diverse needs of individuals. With the growing work in AI in healthcare, tools like Bremono can serve as an illustrative direction for future Human Computer Interaction design projects, particularly those aiming to address complex and varied needs during vulnerable moments of individuals in healthcare.

Nevertheless, the implementation of AI tools like Bremono in the healthcare system will present opportunities for new roles including AI researchers and developers to design and develop algorithms, data scientists to analyse datasets for training and validating models to provide accurate information, and AI support technicians to offer technical support and troubleshoot issues. Nurse practitioners from the medical team may have

an additional task to monitor the call requests and oversee updates to the information. Kanker.nl, patient organisations and hospitals will have to update their information based on the queries received by the individuals. There will also be a need for psychologists in the development team to offer insights into the empathetic responses that Bremono can elicit. Additionally, a design team will also be needed to understand the latent needs of individuals and propose interventions.

With opportunities also comes challenges related to trust, privacy, and confidentiality of patient data with AI. It is imperative for individuals to be informed about the use of AI through Bremono and to clearly understand what to expect. AI systems are inherently complex and unpredictable, raising concerns about patient harm, bias, and privacy breaches (Steerling et al., 2023). These challenges can be effectively addressed by rigorously testing various aspects of the tool and adhering to best practices in AI implementation. For the scope of this project, one of the challenges is addressed by retrieving information from established and reliable sources and integrating the Dutch government's Digi-D initiative, which ensures trust, privacy, and confidentiality of information sources. However, logging through Digi-D every time to access information can be annoying for some but reassuring for others and a necessity to maintain privacy.

The healthcare designers at Panton proposed a few potential solutions. One suggestion was to incorporate face unlock or a PIN code, which could be generated after an initial login through Digi-D, a method also used by the Luscii application. Another recommendation involved distinguishing general information, such as details on diagnosis and treatment, from personal information, like questions about fertility, or sexuality. General information could be made accessible without logging into Digi-D, while personal information would require a Digi-D login.

Despite these measures, the risk of patient harm, lack of human empathy and bias persists, as Bremono is intended to anticipate individual needs based on interactions with individuals which can be complex. This necessitates meticulous consideration during the design phase in the future work. Tools like Bremono might influence the further development and enhancement of ethical guidelines for AI in healthcare. It should be ensured that they are accessible and effective across diverse patient population prior to implementation.

To conclude, AI in healthcare should not be viewed as a replacement for healthcare providers but as a facilitator within the system, aiming to reduce workload of providers and improve patient access to information. AI solutions in healthcare reflects the importance of interdisciplinary collaborations in creating tools that address complex healthcare challenges through advancements in cancer research, design and human computer interaction.

10.2 Limitations

During the course of this master's thesis, I encountered several limitations in both research and design processes. Design research in the healthcare sector involves unique challenges, such as navigating the sensitivity of the context and managing delicate situations, (Groeneveld et al., 2018). and recruiting participants. Due to the demanding schedules, time constraints, limited reachability as an international student and language barrier, access to the participants in the healthcare sector was challenging. All interviews were conducted online, which may have contributed to a less personal approach, potentially affecting the findings. Online interviews can influence the openness of responses and limit the observation of non-verbal cues, such as body language and facial expressions. These non-verbal elements provide important context and insights into the participants' emotions, which are important to understand in the sensitive context of healthcare.

Findings

The limited sample included four healthcare providers (two oncologists and two surgical oncologists). Despite the efforts, I was unable to connect with and recruit any nurse practitioner which may resulted in missing some crucial insights from their perspective and interactions with individuals. Nurse practitioners have the ability to provide more comfort, confidence and trust in individuals and can recognise the level of emotional distress in them (Lyu et al., 2024). There is a possibility of missing valuable insights into the post-diagnostic period from their viewpoint and experience with a large patient population. These reasons may have resulted in a narrow view of the issues, affecting the comprehensiveness of the findings.

Interviews with individuals with breast cancer were constrained by the small size of seven individuals, which in the given circumstances is adequate, but may not have fully captured the diversity of conditions, experiences and

responses that a larger sample might reveal. The sample size didn't account for the variability in the stages of cancer, other rare conditions or complications such as breast cancer during pregnancy and Dutch-speaking participants. These limitations affect the relevance of the findings and lead to an incomplete understanding of other potential factors contributing to information overload.

The recruitment of the participants did not specifically target individuals from low-education or high-education groups, nor those from varied socio-economic backgrounds, which may have led to the underrepresentation or absence of these perspectives. Several factors contributed to this: as an international student with limited proficiency in Dutch and restricted access to the healthcare system, I had limited opportunities to engage with individuals from various socio-economic groups. Additionally, given the complexity of the topic due to the extensive literature on information-seeking behavior and information overload, it was crucial to first understand these concepts broadly within the Dutch context before focusing on specific groups and their needs.

There one of the participant who was diagnosed in 2012, had significantly different experiences from the more recent individuals, although this does highlight changes and advancements in patient care over time. Another participant had a negative experience during diagnosis with one hospital, resulting in post-diagnosis experiences that differ from others in the sample.

The emotional and psychological states of the individuals during the interviews and their illness may have significantly impacted their responses and interactions. Factors such as the stage of their illness (including both the cancer stage and their current phase of treatment), their personal circumstances (such as employment status, presence or absence of a companion), and even the time of day, may have impacted their responses. The demographics (such as age, ethnicity and socioeconomic status), cultural beliefs and other social determinants (such as economic and environmental factors) play a significant role in individuals behaviours and engagement patterns.

Lastly, as only a limited number of interviews were conducted, quotes from companions could not be included in the report. Nevertheless, the insights gained from their interviews were incorporated into the research outcomes and design phase.

Design

Due to the complexity of the topic, the extensive research phase and the limited time period of the master thesis, the design stage was rather brief, which led to the proposal of a concept rather than the developed design. The concept was discussed with two individuals' ongoing treatment to understand if it is moving towards needs. However, this small sample size limits the broader applicability of the concept for a wider audience. Hence, the design of the personal AI companion Bremono could further be explored and tested with the stakeholders following the next steps for advancing this project through the 'Design Recommendations' outlined in the previous chapter.

10.3 Future Research Directions

There is a significant scope for further research to support the individuals and enhance the depth and breadth of understanding of information overload post-diagnosis. The research on information overload in cancer can be expanded in several ways:

> First, conducting additional qualitative interviews with all relevant stakeholders is essential to gain a more nuanced comprehension of their needs and to identify specific gaps in the current approach. Complementing these qualitative insights with quantitative research would provide a more comprehensive view, helping to validate and expand upon the initial findings of this master thesis.

> Information overload can also be caused by the numerous activities and lifestyle changes that individuals must navigate, as well as the practical information they need to process. Ingeborg, the founder of Panton (1971-2022), referred to this as "Resilience" and compiled a list of 180 common questions that patients typically worry about after a diagnosis and during the treatment phase. To mitigate this overload, further studies could be conducted and implemented within Bremono to address the practical information that often overwhelms patients post-diagnosis.

> The research could be expanded to include different stages of breast cancer and various other types of cancers or illnesses. There's also a possibility to investigate information overload from the initial symptoms to post-diagnosis and from post-diagnosis to treatment stages could offer insights into the evolving information and emotional needs.

> Contextual variability is also a critical factor to consider; the study included interviews with healthcare providers from both the south and north of the Netherlands. Their experiences and perceptions, shaped by their specific regional contexts, may not be generalisable to other locations, contexts, cultures or personal beliefs. This could also be similar for individuals with breast cancer. Therefore, further research should account for regional variations, including differences in hospital operations, demographics, and lifestyle factors, to better understand how these factors influence insights and outcomes for the individuals. Initially, this research should focus on different regions within the Netherlands, with subsequent expansion to other countries. Healthcare systems, information provision, and consumption practices differ significantly across countries, leading to differing experiences of information overload. While some findings may be consistent across regions, variations are often influenced by local behaviours, cultural norms, and personal beliefs.

> It is also crucial to understand the differences between the highly educated and the less educated individuals by conducting interviews to differentiate their needs and preferences. Their experiences could reveal varied insights also considering the language preferences, which would be helpful in personalising the AI intervention for them. Finally, another research direction could be to segregate individuals with companions and individuals without companions to understand their distinct needs and experiences while dealing with the illness.

10.4 Personal Reflection

This project starts my journey in healthcare design and it has been a transformative experience. It has provided me with invaluable insights of working as a designer in a sensitive domain like healthcare. Being an international student, navigating in the foreign healthcare system was challenging but I had the privilege of connecting with exceptionally kind and supportive individuals, some of whom went above and beyond to assist me with my project.

As a Design for Interaction student, I learned a great deal, from understanding how individuals interact with information to going broader and understanding the interactions between various stakeholders and healthcare system. With the wealth of valuable findings I gathered, integrating them into a design solution that aligned with the project's specific goals and converging the relevant findings for this report was very challenging. However, this experience was immensely educational, and I am deeply grateful to my supervisors for their guidance throughout the process.

While I write this personal reflection, I recall a conversation with one of the participants in which she expressed feeling dehumanised, perceiving herself not as an individual but merely as a patient. She described her experience with healthcare as overly transactional and expressed a desire for a more holistic approach. Her quote stood by me during the design phase - *"The speed of interpretation or the speed of the emotional things goes slow and the transactional and all the information they give goes fast."* This insight guided me to focus on integrating time and empathy into Bremono. Moving forward, I am committed to ensuring that my work does not perpetuate a transactional experience but instead encourages a more empathetic and person-centred approach in healthcare design.

To conclude, both healthcare design and AI are complex fields and integrating AI in healthcare is very promising but full of challenges. I was able to apply the knowledge that I gained from my studies here at TU Delft in various aspects of this project, including writing, conducting interviews, facilitating creative sessions, and engaging with diverse stakeholders to understand their perspectives. Designing within the context of the Netherlands provided me with extensive learning opportunities. While I wish I had more time to explore AI applications, this project marks the beginning of further exploration!

References

A review towards developing a moment of information overload model. (2016, August 1). IEEE Conference Publication | IEEE Xplore. <https://ieeexplore.ieee.org/document/7857964>

Alowais, S. A., Alghamdi, S. S., Alsuhebany, N., Alqahtani, T., Alshaya, A. I., Almohareb, S. N., Aldairem, A., Alrashed, M., Saleh, K. B., Badreldin, H. A., Yami, M. S. A., Harbi, S. A., & Albekairy, A. M. (2023). Revolutionizing healthcare: the role of artificial intelligence in clinical practice. BMC Medical Education, 23(1). <https://doi.org/10.1186/s12909-023-04698-z>

Arnold, M., Goldschmitt, M., & Rigotti, T. (2023). Dealing with information overload: a comprehensive review. Frontiers in Psychology, 14. <https://doi.org/10.3389/fpsyg.2023.1122200>

Bajwa, J., Munir, U., Nori, A., & Williams, B. (2021). Artificial intelligence in healthcare: transforming the practice of medicine. Future Healthcare Journal, 8(2), e188–e194. <https://doi.org/10.7861/fhj.2021-0095>

Barnes, L. L., Khojasteh, J. J., & Wheeler, D. (2017). Cancer information seeking and scanning: Sources and patterns. Health Education Journal, 76(7), 853–868. <https://doi.org/10.1177/0017896917717542>

Bawden, D., & Robinson, L. (2008). The dark side of information: overload, anxiety and other paradoxes and pathologies. Journal of Information Science, 35(2), 180–191. <https://doi.org/10.1177/0165551508095781>

Bekbolatova, M., Mayer, J., Ong, C. W., & Toma, M. (2024). Transformative Potential of AI in Healthcare: Definitions, applications, and navigating the ethical landscape and public perspectives. Healthcare, 12(2), 125. <https://doi.org/10.3390/healthcare12020125>

Bergström, J., Dahlström, N., Henriqson, E., & Dekker, S. W. A. (2010). Team coordination in escalating Situations: An empirical study using Mid-Fidelity Simulation. Journal of Contingencies and Crisis Management, 18(4), 220–230. <https://doi.org/10.1111/j.1468-5973.2010.00618.x>

Bernstein, K. I., Promislow, S., Carr, R., Rawsthorne, P., Walker, J. R., & Bernstein, C. N. (2011). Information needs and preferences of recently diagnosed patients with inflammatory bowel disease. Inflammatory Bowel Diseases, 17(2), 590–598. <https://doi.org/10.1002/ibd.21363>

Boadi, B., Banji, G. T., Adzobu, P., & Okyere, S. (2021). Information needs of breast cancer patients and how educational status influence their information needs in Ghana. Journal of Librarianship and Information Science, 53(4), 686–698. <https://doi.org/10.1177/0961000620981611>

Bol, N., Linn, A. J., Smets, E. M., Verdam, M. G., & Van Weert, J. C. (2020). Tailored communication for older patients with cancer: Using cluster analysis to identify patient profiles based on information needs. Journal of Geriatric Oncology, 11(6), 944–950. <https://doi.org/10.1016/j.jgo.2020.01.004>

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. Qualitative Research in Psychology, 3(2), 77–101. <https://doi.org/10.1191/1478088706qp063oa>

Breast cancer in the Netherlands. (n.d.). RIVM. <https://www.rivm.nl/en/breast-cancer-screening-programme/breast-cancer-in-netherlands>

Briggs, L. G., Labban, M., Alkhatib, K., Nguyen, D., Cole, A. P., & Trinh, Q. (2022). Digital technologies in cancer care: a review from the clinician’s perspective. Journal of Comparative Effectiveness Research, 11(7), 533–544. <https://doi.org/10.2217/cer-2021-0263>

Cancer diagnoses in the Netherlands rising to 156,000 a year in the next decade. (n.d.). <https://iknl.nl/en/news/cancer-diagnoses-in-netherlands-rising#:~:text=In%201989%20there%20were%20almost,with%20cancer%20in%20the%20Netherlands>
Cardoso, M. J., Houssami, N., Pozzi, G., & Séroussi, B. (2022). Artificial intelligence (AI) in breast cancer care – leveraging multidisciplinary skills to improve care. Artificial Intelligence in Medicine, 123, 102215. <https://doi.org/10.1016/j.artmed.2021.102215>

Carlson, R. W., Anderson, B. O., Burstein, H. J., Cox, C. E., Edge, S. B., Farrar, W. B., Goldstein, L. J., Gradishar, W. J., Hayes, D. F., Hudis, C., Jahanzeb, M., Ljung, B., Marks, L. B., McCormick, B., Nabell, L. M., Pierce, L. J., Reed, E. C., Silver, S. M., Smith, M. L., . . . Wolff, A. C. (2005). Breast Cancer clinical practice guidelines in Oncology. Journal of the National Comprehensive Cancer Network, 3(3), 238. <https://doi.org/10.6004/jnccn.2005.0015>

Carter, S. M., Rogers, W., Win, K. T., Frazer, H., Richards, B., & Houssami, N. (2020). The ethical, legal and social implications of using artificial intelligence systems in breast cancer care. The Breast, 49, 25–32. <https://doi.org/10.1016/j.breast.2019.10.001>

Chae, J., Lee, C., & Jensen, J. D. (2015). Correlates of cancer information overload: focusing on individual ability and motivation. Health Communication, 31(5), 626–634. <https://doi.org/10.1080/10410236.2014.986026>

Chaix B, Bibault JE, Pienkowski A, Delamon G, Guillemassé A, Nectoux P, Brouard B. When Chatbots Meet Patients: One-Year Prospective Study of Conversations Between Patients With Breast Cancer and a Chatbot. JMIR Cancer. 2019 May 2;5(1):e12856. doi: 10.2196/12856

Chen, S. (2017). Information behaviour and decision-making in patients during their cancer journey. The Electronic Library, 35(3), 494–506. <https://doi.org/10.1108/el-03-2016-0062>

Chua, G. P., Tan, H. K., & Gandhi, M. (2018). Information sources and online information seeking behaviours of cancer patients in Singapore. Ecancermedicalsecience, 12. <https://doi.org/10.3332/ecancer.2018.880>

Conley, C. C., Otto, A. K., McDonnell, G. A., & Tercyak, K. P. (2021). Multiple approaches to enhancing cancer communication in the next decade: translating research into practice and policy. Translational Behavioral Medicine, 11(11), 2018–2032. <https://doi.org/10.1093/tbm/ibab089>

Coronado,A.C.,Tran,K.,Chadder,J.,Niu,J.,Fung,S.,Louzado,C., & Rahal, R. (2017). The Experience of Patients with Cancer during Diagnosis and Treatment Planning: A Descriptive Study of Canadian Survey Results. Current Oncology, 24(5), 332–337. <https://doi.org/10.3747/co.24.3782>

Costa, D. S., Mercieca-Bebber, R., Rutherford, C., Gabb, L., & King, M. T. (2016). The impact of cancer on psychological and social outcomes. Australian Psychologist, 51(2), 89–99. <https://doi.org/10.1111/ap.12165>

Coulter, A., & Oldham, J. (2016). Person-centred care: what is it and how do we get there? Future Hospital Journal, 3(2), 114–116. <https://doi.org/10.7861/futurehosp.3-2-114>

Dassen, R., Pelders, S., De Munck, L., Jager, A., Hooning, M., Van Dam, J., & Heemskerk-Gerritsen, B. (2023). The effect of attendance in the Dutch breast cancer screening program on breast tumor characteristics among migrant women. The Breast, 69, 290–298. <https://doi.org/10.1016/j.breast.2023.03.008>

Davison, B. J., & Breckon, E. N. (2012). Impact of Health Information-Seeking Behavior and Personal Factors on preferred role in treatment decision making in men with newly diagnosed prostate cancer. Cancer Nursing, 35(6), 411–418. <https://doi.org/10.1097/ncc.0b013e318236565a>

De Rosa, A. (2022, October 14). Cancer information overload may be a crucial determinant of adjuvant aromatase inhibitor adherence. European Review. <https://www.europeanreview.org/article/29889>
Dinapoli, L., Colloca, G., Di Capua, B., & Valentini, V. (2021). Psychological aspects to consider in breast cancer diagnosis and treatment. Current Oncology Reports, 23(3). <https://doi.org/10.1007/s11912-021-01049-3>

Doak, C. C., Doak, L. G., Friedell, G. H., & Meade, C. D. (1998). Improving comprehension for cancer patients with low literacy skills: strategies for clinicians. CA a Cancer Journal for Clinicians, 48(3), 151–162. <https://doi.org/10.3322/canjclin.48.3.151>

Duimel, S. L. L., Linn, A. J., Smets, E. M. A., Smit, E. S., & Van Weert, J. C. M. (2022). Profiling cancer patients based on their motives for seeking informational and emotional support online. Health Communication, 38(14), 3223–3237. <https://doi.org/10.1080/10410236.2022.2144287>

Ector, G. I., Hermens, R. P., & Blijlevens, N. M. (2020). Filling the gaps of patient information and comprehension. Current Opinion in Oncology, 32(4), 262–268. <https://doi.org/10.1097/cco.0000000000000633>

Eheman, C. R., Berkowitz, Z., Lee, J., Mohile, S., Purnell, J., Rodriguez, E. M., Roscoe, J., Johnson, D., Kirshner, J., & Morrow, G. (2009). Information-Seeking styles among cancer patients before and after treatment by demographics and use of information sources. Journal of Health Communication, 14(5), 487–502. <https://doi.org/10.1080/10810730903032945>

Eppler, M. J., & Mengis, J. (2004). The Concept of Information Overload: A Review of Literature from Organization Science, Accounting, Marketing, MIS, and Related Disciplines. The Information Society, 20(5), 325–344. <https://doi.org/10.1080/01972240490507974>

Favour, Olaoye & Doris, Lucas & Potter, Kaledio. (2024). Influence of AI on Healthcare Delivery. Machine Learning.

Ferraris, G., Monzani, D., Coppini, V., Conti, L., Pizzoli, S. F. M., Grasso, R., & Pravettoni, G. (2023). Barriers to and facilitators of online health information-seeking behaviours among cancer patients: A systematic review. Digital Health, 9. <https://doi.org/10.1177/20552076231210663>

Fletcher, C., Flight, I., Chapman, J., Fennell, K., & Wilson, C. (2017). The information needs of adult cancer survivors across the cancer continuum: A scoping review. Patient Education and Counseling, 100(3), 383–410. <https://doi.org/10.1016/j.pec.2016.10.008>

Gedefaw, A., Yilma, T. M., & Endehabtu, B. F. (2020). <p>Information Seeking Behavior About Cancer and Associated Factors Among University Students, Ethiopia: A Cross-Sectional Study</p> Cancer Management and Research, Volume 12, 4829–4839. <https://doi.org/10.2147/cmar.s259849>

Germeni, E., Bianchi, M., Valcarenghi, D., & Schulz, P. J. (2015). Longitudinal qualitative exploration of cancer information-seeking experiences across the disease trajectory: the INFO-SEEK protocol. BMJ Open, 5(10), e008933. <https://doi.org/10.1136/bmjopen-2015-008933>

Ghazavi-Khorasgani, Z., Ashrafi-Rizi, H., Mokarian, F., & Afshar, M. (2018). Health information seeking behavior of female breast cancer patients. Journal of Education and Health Promotion, 7(1), 138. https://doi.org/10.4103/jehp.jehp_17_18

Goodman, R. S., Patrinely, J. R., Stone, C. A., Zimmerman, E., Donald, R. R., Chang, S. S., Berkowitz, S. T., Finn, A. P., Jahangir, E., Scoville, E. A., Reese, T. S., Friedman, D. L., Bastarache, J. A., Van Der Heijden, Y. F., Wright, J. J., Ye, F., Carter, N., Alexander, M. R., Choe, J. H., . . . Johnson, D. B. (2023). Accuracy and reliability of Chatbot responses to physician questions. JAMA Network Open, 6(10), e2336483. <https://doi.org/10.1001/jamanetworkopen.2023.36483>

Graf, B., & Antoni, C. H. (2020). The relationship between information characteristics and information overload at the workplace – a meta-analysis. European Journal of Work and Organizational Psychology, 30(1), 143–158. <https://doi.org/10.1080/1359432x.2020.1813111>

Greer, S., Ramo, D., Chang, Y. J., Fu, M., Moskowitz, J., & Haritatos, J. (2019). Use of the chatbot “Vivibot” to deliver positive Psychology skills and promote Well-Being among Young People after Cancer Treatment: Randomized Controlled Feasibility trial. JMIR Mhealth and Uhealth, 7(10), e15018. <https://doi.org/10.2196/15018>

Groeneveld, B., Dekkers, T., Boon, B., & D’Olivo, P. (2018). Challenges for design researchers in healthcare. Design for Health, 2(2), 305–326. <https://doi.org/10.1080/24735132.2018.1541699>

Hajesmaeel-Gohari, S., Khordastan, F., Fatehi, F., Samzadeh, H., & Bahaadinbeigy, K. (2022). The most used questionnaires for evaluating satisfaction, usability, acceptance, and quality outcomes of mobile health. BMC Medical Informatics and Decision Making, 22(1). <https://doi.org/10.1186/s12911-022-01764-2>

Halbach, S. M., Ernstmann, N., Kowalski, C., Pfaff, H., Pfortner, T., Wesselmann, S., & Enders, A. (2016). Unmet information needs and limited health literacy in newly diagnosed breast cancer patients over the course of cancer treatment. Patient Education and Counseling, 99(9), 1511–1518. <https://doi.org/10.1016/j.pec.2016.06.028>

Hardwick, C., & Lawson, N. (1995). The information and learning needs of the caregiving family of the adult patient with cancer. European Journal of Cancer Care, 4(3), 118–121. <https://doi.org/10.1111/j.1365-2354.1995.tb00068.x>

Herbert, S. L., Wöckel, A., Kreienberg, R., Kühn, T., Flock, F., Felberbaum, R., Janni, W., Curtaz, C., Kiesel, M., Stüber, T., Diessner, J., Salmen, J., Schwentner, L., Fink, V., Bekes, I., Leinert, E., Lato, K., Polasik, A., Schochter, F., & Singer, S. (2020). To which extent do breast cancer survivors feel well informed about disease and treatment 5 years after diagnosis? *Breast Cancer Research and Treatment*, 185(3), 677–684. <https://doi.org/10.1007/s10549-020-05974-y>

Hong, H., & Kim, H. J. (2020). Antecedents and consequences of information overload in the COVID-19 pandemic. *International Journal of Environmental Research and Public Health*, 17(24), 9305. <https://doi.org/10.3390/ijerph17249305>

Hubbard, G., Kidd, L., & Donaghy, E. (2008). Involving people affected by cancer in research: a review of literature. *European Journal of Cancer Care*, 17(3), 233–244. <https://doi.org/10.1111/j.1365-2354.2007.00842.x>

Hyatt, A., Shelly, A., Cox, R., Humphries, E., Lock, G., & Varlow, M. (2022). How can we improve information for people affected by cancer? A national survey exploring gaps in current information provision, and challenges with accessing cancer information online. *Patient Education and Counseling*, 105(8), 2763–2770. <https://doi.org/10.1016/j.pec.2022.04.009>

Ishikawa, H., & Yano, E. (2008). Patient health literacy and participation in the health care process. *Health Expectations*, 11(2), 113–122. <https://doi.org/10.1111/j.1369-7625.2008.00497.x>

Jackson, T. W., & Farzaneh, P. (2012). Theory-based model of factors affecting information overload. *International Journal of Information Management*, 32(6), 523–532. <https://doi.org/10.1016/j.ijinfomgt.2012.04.006>

Jensen, J. D., Carcioppolo, N., King, A. J., Scherr, C. L., Jones, C. L., & Niederdeppe, J. (2014). The cancer information overload (CIO) scale: Establishing predictive and discriminant validity. *Patient Education and Counseling*, 94(1), 90–96. <https://doi.org/10.1016/j.pec.2013.09.016>
Jensen, J. D., Pokharel, M., Carcioppolo, N., Upshaw, S., John, K. K., & Katz, R. A. (2020). Cancer information overload: Discriminant validity and relationship to sun safe behaviors. *Patient Education and Counseling*, 103(2), 309–314. <https://doi.org/10.1016/j.pec.2019.08.039>

Ji, Qihao & Ha, Louisa & Sypher, Ulla. (2014). The Role of News Media Use and Demographic Characteristics in the Prediction of Information Overload. *International Journal of Communication*. 8. 699-714.

Karimian, G., Petelos, E., & Evers, S. M. a. A. (2022). The ethical issues of the application of artificial intelligence in healthcare: a systematic scoping review. *AI And Ethics*, 2(4), 539–551. <https://doi.org/10.1007/s43681-021-00131-7>

Kashada, A., Isnoun, A., & Aldali, N. (2020). Effect of information overload on decision’s quality, efficiency and time. *ResearchGate*.

Ke, Q., Timmins, F., Furlong, E., & Stokes, D. (2023). Unmet care needs of women who have undergone breast cancer surgery: A scoping review. *Journal of Advanced Nursing*, 80(5), 1732–1749. <https://doi.org/10.1111/jan.15953>

Khaleel, I., Wimmer, B. C., Peterson, G. M., Zaidi, S. T. R., Roehrer, E., Cummings, E., & Lee, K. (2020). Health information overload among health consumers: A scoping review. *Patient Education and Counseling*, 103(1), 15–32. <https://doi.org/10.1016/j.pec.2019.08.008>

Khan, A. (2023). Transforming Healthcare through AI: Unleashing the Power of Personalized Medicine. *International Journal of Multidisciplinary Sciences and Arts*, 2(1), 67–77. <https://doi.org/10.47709/ijmdsa.v2i1.2424>

Khan, B., Fatima, H., Qureshi, A., Kumar, S., Hanan, A., Hussain, J., & Abdullah, S. (2023). Drawbacks of artificial intelligence and their potential solutions in the healthcare sector. *Deleted Journal*, 1(2), 731–738. <https://doi.org/10.1007/s44174-023-00063-2>

Kim, K., Lustria, M. L., Burke, D., & Kwon, N. (2007). Predictors of cancer information overload: findings from a national survey. *Inf. Res.*, 12.

Königer, P., & Janowitz, K. (1995). Drowning in information, but thirsty for knowledge. *International Journal of Information Management*, 15(1), 5–16. [https://doi.org/10.1016/0268-4012\(94\)00002-b](https://doi.org/10.1016/0268-4012(94)00002-b)

Krishnasamy, M., Hassan, H., Jewell, C., Moravski, I., & Lewin, T. (2023). Perspectives on Emotional Care: A Qualitative Study with Cancer Patients, Carers, and Health Professionals. *Healthcare*, 11(4), 452. <https://doi.org/10.3390/healthcare11040452>

Kuwaiti, A. A., Nazer, K., Al-Reedy, A., Al-Shehri, S., Al-Muhanna, A., Subbarayalu, A. V., Muhanna, D. A., & Al-Muhanna, F. A. (2023). A review of the role of artificial intelligence in healthcare. *Journal of Personalized Medicine*, 13(6), 951. <https://doi.org/10.3390/jpm13060951>

Kyngäs, H., Mikkonen, R., Nousiainen, E. M., Ryttilähti, M., Seppänen, P., Vaattovaara, R., & Jämsä, T. (2001). Coping with the onset of cancer: coping strategies and resources of young people with cancer. *European Journal of Cancer Care*, 10(1), 6–11. <https://doi.org/10.1046/j.1365-2354.2001.00243.x>
Lee, D., & Yoon, S. N. (2021). Application of Artificial Intelligence-Based Technologies in the Healthcare Industry: Opportunities and challenges. *International Journal of Environmental Research and Public Health*, 18(1), 271. <https://doi.org/10.3390/ijerph18010271>

Lee, K., Roehrer, E., & Cummings, E. (2017). Information overload in consumers of health-related information: a scoping review protocol. *The JBI Database of Systematic Reviews and Implementation Reports*, 15(10), 2457–2463. <https://doi.org/10.11124/jbisrir-2016-003287>

Lewandowska, A., Rudzki, G., Lewandowski, T., & Rudzki, S. (2020). The Problems and Needs of Patients Diagnosed with Cancer and Their Caregivers. *International Journal of Environmental Research and Public Health*, 18(1), 87. <https://doi.org/10.3390/ijerph18010087>

Lewis, J. R. (2018). The system usability scale: past, present, and future. *International Journal of Human-Computer Interaction*, 34(7), 577–590. <https://doi.org/10.1080/10447318.2018.1455307>

Leydon, G. M. (2000). Cancer patients' information needs and information seeking behaviour: in depth interview study. *BMJ*, 320(7239), 909–913. <https://doi.org/10.1136/bmj.320.7239.909>

Lu, H., Xie, J., Gerido, L. H., Cheng, Y., Chen, Y., & Sun, L. (2020). Information Needs of Breast Cancer Patients: Theory-Generating Meta-Synthesis. *Journal of Medical Internet Research*, 22(7), e17907. <https://doi.org/10.2196/17907>

Luchini, C., Pea, A., & Scarpa, A. (2021). Artificial intelligence in oncology: current applications and future perspectives. *British Journal of Cancer*, 126(1), 4–9. <https://doi.org/10.1038/s41416-021-01633-1>

Łukasiewicz, S., Czezelewski, M., Forma, A., Baj, J., Sitarz, R., & Stanisławek, A. (2021). Breast Cancer—Epidemiology, Risk factors, Classification, Prognostic Markers, and Current Treatment Strategies—An Updated Review. *Cancers*, 13(17), 4287. <https://doi.org/10.3390/cancers13174287>

Lyu, X., Jiang, H., Lee, L., Yang, C., & Sun, X. (2024). Oncology nurses' experiences of providing emotional support for cancer patients: a qualitative study. *BMC Nursing*, 23(1). <https://doi.org/10.1186/s12912-024-01718-1>

M. Grene, Y. Cleary and A. Marcus-Quinn, “Use of Plain-Language Guidelines to Promote Health Literacy,” in *IEEE Transactions on Professional Communication*, vol. 60, no. 4, pp. 384–400, Dec. 2017, doi: 10.1109/TPC.2017.2761578

Ma, X., Liu, Y., Zhang, P., Qi, R., & Meng, F. (2023). Understanding online health information seeking behavior of older adults: A social cognitive perspective. *Frontiers in Public Health*, 11. <https://doi.org/10.3389/fpubh.2023.1147789>

Malhotra, N. K., Jain, A. K., & Lagakos, S. W. (1982). The Information Overload Controversy: An Alternative Viewpoint. *Journal of Marketing*, 46(2), 27–37. <https://doi.org/10.1177/002224298204600204>

Matsuyama, R. K., Wilson-Genderson, M., Kuhn, L., Moghanaki, D., Vachhani, H., & Paasche-Orlow, M. (2011). Education level, not health literacy, associated with information needs for patients with cancer. *Patient Education and Counseling*, 85(3), e229–e236. <https://doi.org/10.1016/j.pec.2011.03.022>

Maynez, J., Narayan, S., Bohnet, B., & McDonald, R. (2020b, May 2). On faithfulness and factuality in abstractive summarization. *arXiv.org*. <https://arxiv.org/abs/2005.00661>
McRoy, S., Rastegar-Mojarad, M., Wang, Y., Ruddy, K. J., Haddad, T. C., & Liu, H. (2018). Assessing unmet information needs of breast cancer survivors: Exploratory study of online health forums using text classification and retrieval. *JMIR Cancer*, 4(1), e10. <https://doi.org/10.2196/cancer.9050>

Menon, G., Alkabban, F. M., & Ferguson, T. (2024, February 25). Breast cancer

Metro Mapping. (n.d.-b). Metro Mapping - De zorg verbeteren met Metro Mapping. <https://metromapping.org/>
Miller, S. M. (1987). Monitoring and blunting: Validation of a questionnaire to assess styles of information seeking under threat. *Journal of Personality and Social Psychology*, 52(2), 345–353. <https://doi.org/10.1037/0022-3514.52.2.345>

Ministerie van Volkshuisvesting, Ruimtelijke Ordening en Milieubeheer. (2024, June 21). Het Integraal Zorgakkoord - samenwerken aan gezonde zorg. *Kwaliteit Van De Zorg | Rijksoverheid.nl*. <https://www.rijksoverheid.nl/onderwerpen/kwaliteit-van-de-zorg/integraal-zorgakkoord>

Neijland, T. (2024, May 20). Werkdruk artsen neemt toe door desinformatie: “Soms heel vervelende gesprekken.” *NOS*. <https://nos.nl/artikel/2521146-werkdruk-artsen-neemt-toe-door-desinformatie-soms-heel-vervelende-gesprekken>

NKR Viewer. (n.d.). https://nkr-cijfers.iknl.nl/viewer/incidentie-per-jaar?language=en_GB&viewerId=1734f60f-d5fa-4649-98fe-ac34dd50a0b0

Okamoto, I., Wright, D., & Foster, C. (2011). Impact of cancer on everyday life: a systematic appraisal of the research evidence. *Health Expectations*, 15(1), 97–111. <https://doi.org/10.1111/j.1369-7625.2011.00662.x>

Ormel, I., Magalhaes, M., Josephson, D., Tracey, L., & Law, S. (2021). How to know what to know: Information challenges for women in the diagnostic phase of breast cancer. *Patient Education and Counseling*, 104(1), 179–185. <https://doi.org/10.1016/j.pec.2020.06.030>

Papachristou, N., Kotronoulas, G., Dikaio, N., Allison, S. J., Eleftherochorinou, H., Rai, T., Kunz, H., Barnaghi, P., Miaskowski, C., & Bamidis, P. D. (2023). Digital transformation of cancer care in the era of Big Data, Artificial Intelligence and Data-Driven Interventions: Navigating the field. *Seminars in Oncology Nursing*, 39(3), 151433. <https://doi.org/10.1016/j.soncn.2023.151433>

Park, S. K., Park, H., & Lee, J. (2020). Understanding the Public's Emotions about Cancer: Analysis of Social Media Data. *International Journal of Environmental Research and Public Health*, 17(19), 7160. <https://doi.org/10.3390/ijerph17197160>

Perceived usefulness, perceived ease of use, and user acceptance of information technology on JSTOR. (n.d.). www.jstor.org. <https://www.jstor.org/stable/249008?seq=5>

Poalelungi, D. G., Musat, C. L., Fulga, A., Neagu, M., Neagu, A. I., Piraianu, A. I., & Fulga, I. (2023). Advancing Patient Care: How Artificial intelligence is transforming healthcare. *Journal of Personalized Medicine*, 13(8), 1214. <https://doi.org/10.3390/jpm13081214>

Ramsey, I., Corsini, N., Peters, M. D., & Eckert, M. (2017). A rapid review of consumer health information needs and preferences. *Patient Education and Counseling*, 100(9), 1634–1642. <https://doi.org/10.1016/j.pec.2017.04.005>

Rees, C. E., & Bath, P. A. (2001, June 1). Information-Seeking Behaviors of Women with Breast Cancer
Reifegerste, D., Rosset, M., Czerwinski, F., Baumann, E., Gaiser, A., Kludt, E., & Weg-Remers, S. (2021). Understanding the Pathway of Cancer Information Seeking: Cancer Information Services as a Supplement to Information from Other Sources. *Journal of Cancer Education*, 38(1), 175–184. <https://doi.org/10.1007/s13187-021-02095-y>

Rexhepi, H., Huvila, I., Åhlfeldt, R., & Cajander, Å. (2021). Cancer patients' information seeking behavior related to online electronic healthcare records. *Health Informatics Journal*, 27(3), 146045822110247. <https://doi.org/10.1177/14604582211024708>

Richards, R., Kinnersley, P., Brain, K., Staffurth, J., & Wood, F. (2019). The preferences of patients with cancer regarding apps to help meet their Illness-Related Information needs: Qualitative Interview study. *JMIR Mhealth and Uhealth*, 7(7), e14187. <https://doi.org/10.2196/14187>

Robinson, E. W. (n.d.-b). AskEllyn.ai – A breast cancer journey is bewildering, lonely and terrifying. You and your family don't have to do it alone. Let me hold your hand. *AskEllyn.ai*. <https://askellyn.ai/>

Rodriguez-Gonzalez, A., Velasco-Durantez, V., Martin-Abreu, C., Cruz-Castellanos, P., Hernandez, R., Gil-Raga, M., Garcia-Torralba, E., Garcia-Garcia, T., Jimenez-Fonseca, P., & Calderon, C. (2022). Fatigue, Emotional Distress, and Illness Uncertainty in Patients with Metastatic Cancer: Results from the Prospective NEOETIC_SEOM Study. *Current Oncology*, 29(12), 9722–9732. <https://doi.org/10.3390/curroncol29120763>

Rolnick, S. J., Altschuler, A., Nekhlyudov, L., Elmore, J. G., Greene, S. M., Harris, E. L., Herrinton, L. J., Barton, M. B., Geiger, A. M., & Fletcher, S. W. (2007). What women wish they knew before prophylactic mastectomy. *Cancer Nursing*, 30(4), 285–291. <https://doi.org/10.1097/01.ncc.0000281733.40856.c4>

Rudd, M. J., & Rudd, J. (n.d.). The impact of the information explosion on library users: overload or opportunity?. <https://eric.ed.gov/?id=EJ342904>

Rutten, L. J. F., Arora, N. K., Bakos, A. D., Aziz, N., & Rowland, J. (2005). Information needs and sources of information among cancer patients: a systematic review of research (1980–2003). *Patient Education and Counseling*, 57(3), 250–261. <https://doi.org/10.1016/j.pec.2004.06.006>

Sarfaraz, S., Khurshid, Z., & Zafar, M. S. (2023). Use of artificial intelligence in medical education: A strength or an infirmity. *Journal of Taibah University Medical Sciences*, 18(6), 1553–1554. <https://doi.org/10.1016/j.jtumed.2023.06.008>

Savolainen, R. (2007). Filtering and withdrawing: strategies for coping with information overload in everyday contexts. *Journal of Information Science*, 33(5), 611–621. <https://doi.org/10.1177/0165551506077418>

Schommer, J. C., Doucette, W. R., & Worley, M. M. (2001). Processing prescription drug information under different conditions of presentation. *Patient Education and Counseling*, 43(1), 49–59. [https://doi.org/10.1016/s0738-3991\(00\)00145-2](https://doi.org/10.1016/s0738-3991(00)00145-2)

Shea-Budgell, M. A., Kostaras, X., Myhill, K. P., & Hagen, N. A. (2014). Information Needs and Sources of Information for Patients during Cancer Follow-Up. *Current Oncology*, 21(4), 165–173. <https://doi.org/10.3747/co.21.1932>

Shreve, J. T., Khanani, S. A., & Haddad, T. C. (2022). Artificial intelligence in Oncology: current capabilities, future opportunities, and ethical considerations. *American Society of Clinical Oncology Educational Book*, 42, 842–851. https://doi.org/10.1200/edbk_350652

Siegel, M. G., Rossi, M. J., & Lubowitz, J. H. (2024). Artificial intelligence and machine learning may resolve health care information overload. *Arthroscopy the Journal of Arthroscopic and Related Surgery*, 40(6), 1721–1723. <https://doi.org/10.1016/j.arthro.2024.01.007>

Slevin, M. L., Nichols, S. E., Downer, S. M., Wilson, P., Lister, T. A., Arnot, S., Maher, J., Souhami, R. L., Tobias, J. S., Goldstone, A. H., & Cody, M. (1996). Emotional support for cancer patients: what do patients really want? *British Journal of Cancer*, 74(8), 1275–1279. <https://doi.org/10.1038/bjc.1996.529>

Soferman, R. (2019). The transformative impact of artificial intelligence on healthcare outcomes. *Journal of Clinical Engineering*, 44(3), E1–E3. <https://doi.org/10.1097/jce.0000000000000345>

Springer, F., Mehnert-Theuerkauf, A., Gebhardt, C. et al. Unmet supportive care needs among cancer patients: exploring cancer entity-specific needs and associated factors. *J Cancer Res Clin Oncol* 150, 190 (2024). <https://doi.org/10.1007/s00432-024-05715-4>

Steerling, E., Siira, E., Nilsen, P., Svedberg, P., & Nygren, J. (2023). Implementing AI in healthcare—the relevance of trust: a scoping review. *Frontiers in Health Services*, 3. <https://doi.org/10.3389/frhs.2023.1211150>

Stein, A. T., Ben, Â. J., Pachito, D. V., Cazella, S. C., Van Dongen, J. M., & Bosmans, J. E. (2020). Digital Health Technology Implementation: Is it effective in a healthy healthcare perspective? In Springer eBooks (pp. 197–220). https://doi.org/10.1007/978-3-030-59467-1_9

Sun, G., & Zhou, Y. (2023). AI in healthcare: navigating opportunities and challenges in digital communication. *Frontiers in Digital Health*, 5. <https://doi.org/10.3389/fdgth.2023.1291132>

Swar, B., Hameed, T., & Reychav, I. (2017). Information overload, psychological ill-being, and behavioral intention to continue online healthcare information search. *Computers in Human Behavior*, 70, 416–425. <https://doi.org/10.1016/j.chb.2016.12.068>

Tack, L., Schofield, P., Boterberg, T., Chandler, R., Parris, C. N., & Debruyne, P. R. (2022). Psychosocial Care after Cancer Diagnosis: Recent Advances and Challenges. *Cancers*, 14(23), 5882. <https://doi.org/10.3390/cancers14235882>

Tariman, J. D., Doorenbos, A., Schepp, K. G., Singhal, S., & Berry, D. L. (2014, April 1). Information Needs Priorities in Patients Diagnosed with Cancer: A Systematic review. *PubMed Central (PMC)*. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4042668/>

Taylor, C. R., Monga, N., Johnson, C., Hawley, J. R., & Patel, M. (2023). Artificial intelligence applications in breast imaging: current status and future directions. *Diagnostics*, 13(12), 2041. <https://doi.org/10.3390/diagnostics13122041>

Torrente, M., Sousa, P. A., Hernández, R., Blanco, M., Calvo, V., Collazo, A., Guerreiro, G. R., Núñez, B., Pimentao, J., Sánchez, J. C., Campos, M., Costabello, L., Novacek, V., Menasalvas, E., Vidal, M. E., & Provencio, M. (2022). An Artificial Intelligence-Based Tool for Data Analysis and Prognosis in Cancer Patients: Results from the Clarify Study. *Cancers*, 14(16), 4041. <https://doi.org/10.3390/cancers14164041>

Valero-Aguilera, B., Bermúdez-Tamayo, C., García-Gutiérrez, J. F., Jiménez-Pernett, J., Cózar-Olmo, J. M., Guerrero-Tejada, R., & Alba-Ruiz, R. (2013). Information needs and Internet use in urological and breast cancer patients. *Supportive Care in Cancer*, 22(2), 545–552. <https://doi.org/10.1007/s00520-013-2009-y>

Van Der Molen, B. (1999). Relating information needs to the cancer experience: 1. Information as a key coping strategy. *European Journal of Cancer Care*, 8(4), 238–244. <https://doi.org/10.1046/j.1365-2354.1999.00176.x>

Van Vliet, L. M., Meijers, M. C., Van Dulmen, S., Van Der Wall, E., Plum, N., Stouthard, J., & Francke, A. L. (2021). Addressing challenges in information-provision: a qualitative study among oncologists and women with advanced breast cancer. *BMC Palliative Care*, 20(1). <https://doi.org/10.1186/s12904-021-00836-w>

Van Weert, J. C., Jansen, J., De Bruijn, G., Noordman, J., Van Dulmen, S., & Bensing, J. M. (2009). QUOTEchemo: A patient-centred instrument to measure quality of communication preceding chemotherapy treatment through the patient’s eyes. *European Journal of Cancer*, 45(17), 2967–2976. <https://doi.org/10.1016/j.ejca.2009.06.001>

Velasco-Durantez, V., Cruz-Castellanos, P., Hernandez, R., Rodriguez-Gonzalez, A., Montes, A. F., Gallego, A., Manzano-Fernandez, A., Sorribes, E., Zafra, M., Carmona-Bayonas, A., Calderon, C., & Jiménez-Fonseca, P. (2024). Prospective study of predictors for anxiety, depression, and somatization in a sample of 1807 cancer patients. *Scientific Reports*, 14(1). <https://doi.org/10.1038/s41598-024-53212-y>

Vromans, R. D., Van Eenbergen, M. C., Geleijnse, G., Pauws, S., Van De Poll-Franse, L. V., & Krahmer, E. J. (2021). Exploring cancer survivor needs and preferences for communicating personalized cancer statistics from registry data: Qualitative multimethod study. *JMIR Cancer*, 7(4), e25659. <https://doi.org/10.2196/25659>

Wang, A., Qian, Z., Briggs, L., Cole, A. P., Reis, L. O., & Trinh, Q. (2023). The use of chatbots in oncological Care: A Narrative review. *International Journal of General Medicine*, Volume 16, 1591–1602. <https://doi.org/10.2147/ijgm.s408208>

Wang, Y., & Feng, W. (2022). Cancer-related psychosocial challenges. *General Psychiatry*, 35(5), e100871. <https://doi.org/10.1136/gpsych-2022-100871>

Wilson, T. (1999). Models in information behaviour research. *Journal of Documentation*, 55(3), 249–270. <https://doi.org/10.1108/eum0000000007145>

World Health Organization: WHO. (2022, February 3). Cancer. <https://www.who.int/news-room/fact-sheets/detail/cancer>

Xu, L., Sanders, L., Li, K., & Chow, J. C. L. (2021). Chatbot for health care and oncology applications using Artificial Intelligence and Machine Learning: Systematic review. *JMIR Cancer*, 7(4), e27850. <https://doi.org/10.2196/27850>

Yen, P., Wantland, D., & Bakken, S. (2010). Development of a customizable health IT usability Evaluation scale. *PubMed Central (PMC)*. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3041285/>

Yersal, O., & Barutca, S. (2014). Biological subtypes of breast cancer: Prognostic and therapeutic implications. *World Journal of Clinical Oncology*, 5(3), 412. <https://doi.org/10.5306/wjco.v5.i3.412>

You, Y., Lai, X., Pan, Y., Zheng, H., Vera, J., Liu, S., Deng, S., & Zhang, L. (2022). Artificial intelligence in cancer target identification and drug discovery. *Signal Transduction and Targeted Therapy*, 7(1). <https://doi.org/10.1038/s41392-022-00994-0>

Zhou, L., Bao, J., Setiawan, I. M. A., Saptono, A., & Parmanto, B. (2019). The MHealth App Usability Questionnaire (MAUQ): Development and Validation study. *JMIR Mhealth and Uhealth*, 7(4), e11500. <https://doi.org/10.2196/11500>

