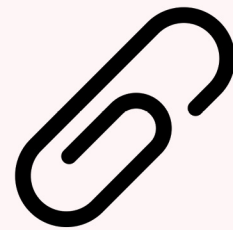


# Addressing Information Overload in Individuals with Breast Cancer Post-Diagnosis through a Personalised AI-Based Companion



## Appendix

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Master Thesis - Appendix

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

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Appendix A: Project Brief



TU Delft

IDE Master Graduation Project

Project team, procedural checks and Personal Project Brief

In this document the agreements made between student and supervisory team about the student’s IDE Master Graduation Project are set out. This document may also include involvement of an external client, however does not cover any legal matters student and client (might) agree upon. Next to that, this document facilitates the required procedural checks:

- Student defines the team, what the student is going to do/deliver and how that will come about
- Chair of the supervisory team signs, to formally approve the project’s setup / Project brief
- SSC E&SA (Shared Service Centre, Education & Student Affairs) report on the student’s registration and study progress
- IDE’s Board of Examiners confirms the proposed supervisory team on their eligibility, and whether the student is allowed to start the Graduation Project

STUDENT DATA & MASTER PROGRAMME

Complete all fields and indicate which master(s) you are in

Family name

Arora

Initials

A.

Given name

Ankita

Student number

IDE master(s)

IPD

Dfi

SPD

2<sup>nd</sup> non-IDE master

Individual programme

(date of approval)

Medisign

HPM

SUPERVISORY TEAM

Fill in the required information of supervisory team members. If applicable, company mentor is added as 2<sup>nd</sup> mentor

Chair

Judith Rietjens

dept./section

DOS/MOD

mentor

Jacky Bourgeois

dept./section

SDE/IoT

2<sup>nd</sup> mentor

Jasper Brands

client:

Panton

city:

Deventer

country:

Netherlands

optional comments

! Ensure a heterogeneous team. In case you wish to include team members from the same section, explain why.

! Chair should request the IDE Board of Examiners for approval when a non-IDE mentor is proposed. Include CV and motivation letter.

! 2<sup>nd</sup> mentor only applies when a client is involved.

APPROVAL OF CHAIR on PROJECT PROPOSAL / PROJECT BRIEF -> to be filled in by the Chair of the supervisory team

Sign for approval (Chair)

Name

Judith Rietjens

Date

Match 14, 2024

Signature



TU Delft

Personal Project Brief – IDE Master Graduation Project

Name student

Ankita Arora

Student number

PROJECT TITLE, INTRODUCTION, PROBLEM DEFINITION and ASSIGNMENT

Complete all fields, keep information clear, specific and concise

Project title

Addressing Information Overload in People with Cancer through a Personalized AI-driven Patient-Centred

Please state the title of your graduation project (above). Keep the title compact and simple. Do not use abbreviations. The remainder of this document allows you to define and clarify your graduation project.

Introduction

Describe the context of your project here; What is the domain in which your project takes place? Who are the main stakeholders and what interests are at stake? Describe the opportunities (and limitations) in this domain to better serve the stakeholder interests. (max 250 words)

The project centers on supporting people with cancer within the healthcare domain, with a particular emphasis on the overwhelming volume of information they encounter post-diagnosis. Upon receiving a diagnosis, people with cancer struggle with numerous tasks, like understanding dietary guidelines, navigating various healthcare options, adhering to medical regimens, and deciphering complex medical terminology. This complexity often exacts a toll on their mental well-being and can impede effective decision-making throughout their treatment journey. (5)(6)

While healthcare providers strive to communicate information effectively, their time constraints and workload frequently restrict the depth of support they can offer. Conversely, individuals (people with cancer) gather information from diverse sources, such as informational letters, online platforms, family, and friends. This decentralized approach is unavoidable and offers diverse views resulting in complexity, information overload, ambiguity, and confusion, further complicating the decision-making process regarding treatment options. Medical terminology exacerbates this complexity, as people with cancer may struggle to comprehend all the information provided by healthcare providers.

The project aims to address these challenges by supporting people with cancer in understanding the complexities of their cancer diagnosis and treatment options based on their preferred level of involvement, ultimately enabling patients to make informed decisions in their care journey. This approach benefits all stakeholders involved, including cancer patients, healthcare providers, and family members. By simplifying complex information, the intervention equips patients and their families with the support tools to navigate and understand the healthcare journey. Additionally, it alleviates the burden on healthcare providers and fosters improved communication between providers and patients.

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## Personal Project Brief – IDE Master Graduation Project

### Problem Definition

*What problem do you want to solve in the context described in the introduction, and within the available time frame of 100 working days? (= Master Graduation Project of 30 EC). What opportunities do you see to create added value for the described stakeholders? Substantiate your choice.  
(max 200 words)*

The problem addressed is the overwhelming complexity of medical information encountered by people with cancer throughout their diagnosis & treatment journey. This inundation of information often leads to confusion, anxiety, & difficulty in making well-informed decisions regarding treatment options. The opportunity lies in the development of a design intervention aimed at assisting people in comprehending the ongoing treatment of the disease & fostering a stronger doctor-patient relationship. In addressing this issue, added value is generated for all stakeholders involved: For people with cancer, the intervention may allow them to participate in their care journey according to their specific information needs and preferences, whether adopting a passive role, an active role, or a co-pilot role(7). Healthcare Providers may benefit from more streamlined consultations and enhanced patient-provider communication, ultimately resulting in the delivery of higher-quality care. Additionally, family members & caregivers may be able to offer valuable assistance and emotional support to their loved ones throughout the cancer journey by helping to unravel the complexities of the information received. The project aims to address these challenges and opportunities by focusing on several key research questions, including but not limited to: What are the existing ways of delivering healthcare information to people with cancer post-diagnosis? What are the most common sources from which people with cancer obtain information about their diagnosis and treatment options apart from Healthcare Providers? How do these sources vary in terms of reliability, accessibility,

## Assignment

*This is the most important part of the project brief because it will give a clear direction of what you are heading for. Formulate an assignment to yourself regarding what you expect to deliver as result at the end of your project. (1 sentence) As you graduate as an industrial design engineer, your assignment will start with a verb (Design/Investigate/Validate/Create), and you may use the green text format:*

Design a personalized AI-driven patient-centred intervention that simplifies complex medical information for cancer patients, enabling them to make informed decisions.

*Then explain your project approach to carrying out your graduation project and what research and design methods you plan to use to generate your design solution (max 150 words)*

Research Methods: 1. Literature Research including studying and mapping existing Patient Journey in Cancer Care  
2. Interviews and Thematic Analysis: Patient Representatives (PR), Healthcare Designers at Panton.nl, Healthcare Providers (Clinicians & Specialized Nurses), People with Cancer, Family/Caretakers/Friends of people with cancer

**Design Methods:** To develop a patient-centred intervention, data on preferences, behaviours, & informational needs of individuals will be utilised from the research & interviews. Then, a desired patient journey from diagnosis to treatment will be developed by identifying pivotal touchpoints and opportunities for information dissemination. I will then engage in self-exploration of ideas & generate diverse design directions. This will be followed by a creative facilitation session with healthcare designers to incorporate varied perspectives & address the multifaceted needs of individuals with cancer. Finally, a concept will be chosen that represents best interests of patients. For the prototype, interview data will be utilised to systematically organize the abundance of information, tailoring it to the individual needs & preferences.

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	Kick-off week								Mid-term												Green-light								Graduation	
Monday	4	11	18	25	1	8	15	22	29	6	13	20	27	3	10	17	24	1	8	15	22	29	6	13	20	27				
Tuesday	5	12	19	26	2	9	16	23	30	7	14	21	28	4	11	18	25	2	9	16	23	30	7	14	21	28				
Wednesday	6	13	20	27	3	10	17	24	1	8	15	22	29	5	12	19	26	3	10	17	24	31	7	14	21	28				
Thursday	7	14	21	28	4	11	18	25	2	9	16	23	30	6	13	20	27	4	11	18	25	1	8	15	22	29				
Friday	8	15	22	29	5	12	19	26	3	10	17	24	31	7	14	21	28	5	12	19	26	2	9	16	23	30				
Saturday	9	16	23	30	6	13	20	27	4	11	18	25	1	8	15	22	29	6	13	20	27	3	10	17	24	31				
Sunday	10	17	24	31	7	14	21	28	5	12	19	26	2	9	16	23	30	7	14	21	28	4	11	18	25					
	March				April				May				June				July				August									

## Project Planning



# Appendix B: Insights from Healthcare Providers

## B.1 Interview Questions

These questions were presented to healthcare providers during the interview sessions.

### Patient Engagement in their Healthcare Journey

1. What amount of time do you allocate to individuals during a consultation session (on average)?
2. How do patients engage in their healthcare journey? Do you notice variations in engagement levels among different individuals?
3. In your experience, how does patient engagement, whether active or passive, impact their healthcare outcomes and overall experience?
4. Can you describe common patterns in how patients communicate with healthcare professionals about their treatment preferences and decision-making? What factors influence their engagement in these discussions?

### Information Provided to the Patients

1. When patients receive information about their diagnosis and treatment options, what initial reactions do you observe? What are the common questions or concerns they express?
2. From your perspective, what are the key challenges healthcare providers face in delivering information to patients about cancer post-diagnosis?
3. In your opinion, what are the crucial pieces of information that patients should be provided with following a cancer diagnosis to aid in their understanding of the illness?
4. Could you outline the types of information patients receive both verbally and in written form throughout their cancer journey?
5. Have you encountered instances where patients expressed difficulty in understanding the information provided? (If yes then - What challenges do patients commonly face in comprehending medical information, and how do you address them?)
6. How would you describe the level of patient engagement in seeking information about their care? Is information predominantly provided to them by the hospital as part of standard procedures or in response to specific requests from patients?

### Sources of Information

1. What sources of information do cancer patients commonly rely on when seeking information about their illness and treatment options?
2. From your perspective, what are the advantages and limitations associated with different sources of information patients access during their cancer journey?
3. Do you advise patients on specific sources of information to ensure they obtain accurate and reliable guidance?
4. Have you observed cases where patients' information-seeking behaviours have significantly impacted their treatment decisions or preferences? If so, can you provide examples?

### Patient Information-Seeking Behaviors

1. What are some common information-seeking behaviours you've observed in patients following a cancer diagnosis?
2. Are there specific types of information that patients tend to prioritise in their search?
3. Are there particular stages in the treatment process where patients tend to seek out more information?

### Role of Companions/Family Members

1. Can you describe the various ways in which companions participate in supporting cancer patients throughout their treatment journey?
2. Do you notice specific inquiries or areas of concern that caregivers frequently bring up during discussions about the patient's cancer diagnosis and treatment? If so, what are these questions and how do you address them?
3. Can you identify the primary difficulties or barriers that companions encounter while caring for a loved one with cancer, and what strategies or resources are available to help them address these challenges?

### Support and Strategies

1. What kind of support and strategies do you employ to help patients comprehend and navigate through medical information effectively?

## B.2 Interview Findings

This section presents the findings, including analysis and quotes, from interviews with healthcare providers. Selected quotes are featured in the main report to illustrate the findings, while the remaining data is analysed and detailed here. A representation of the thematic analysis and clustering of findings is provided below.

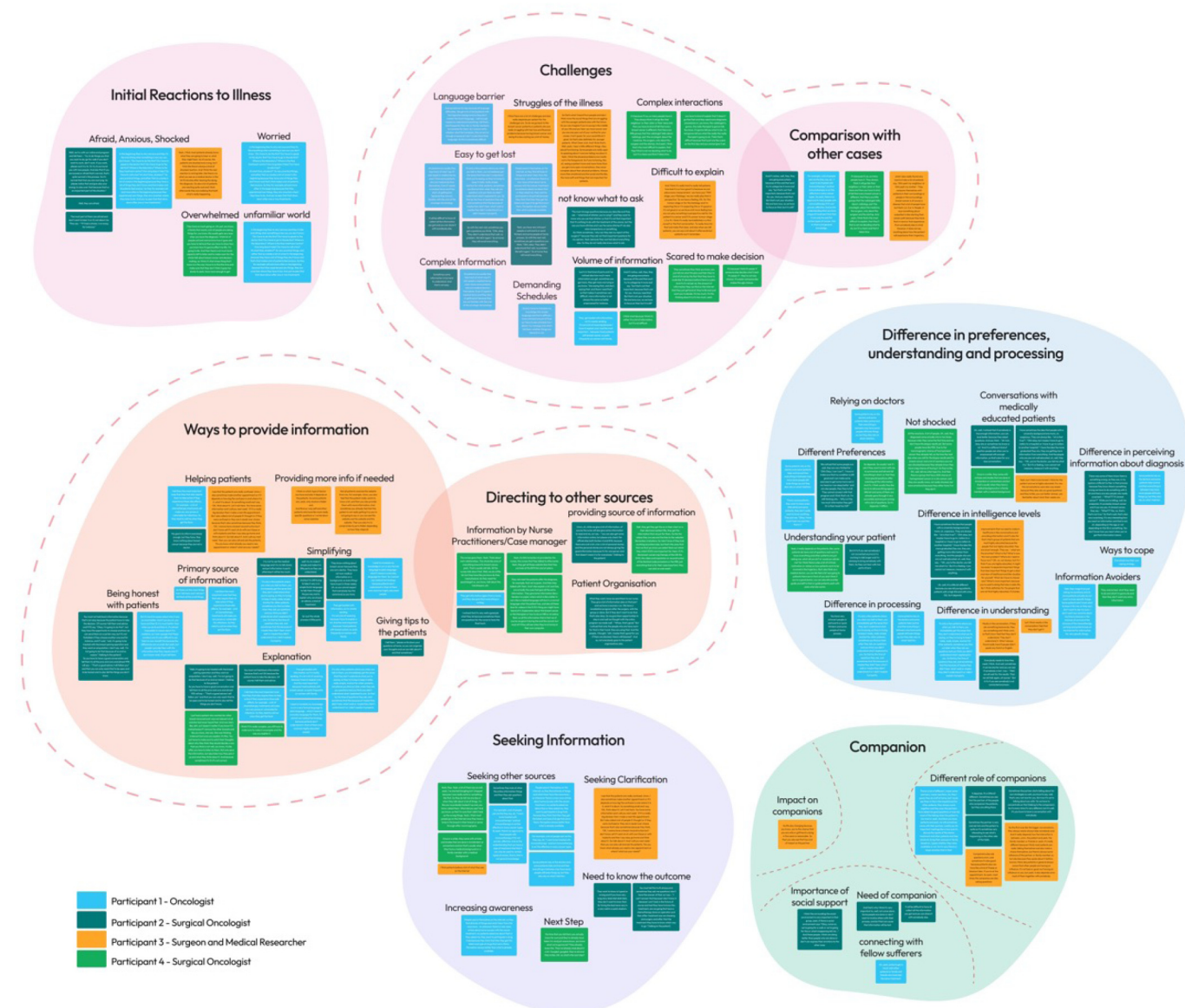


Figure B.2: Thematic Analysis of the interviews with Healthcare Providers

The details of the healthcare providers interviewed for the purpose of the project are provided in the Chapter 3, Methodology Section



## Reactions to Diagnosis by the Individuals

Healthcare providers shares a spectrum of reactions from individuals upon receiving a breast cancer diagnosis. While some experience immediate shock, many anticipate the negative news due to the extensive series of diagnostic tests and focus on understanding the next steps for treatment. They also emphasize that individuals reactions vary significantly; some are entirely unprepared for the diagnosis and express profound surprise and disbelief.

*“In the beginning they’re very nervous and they 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 either that so creates a lot of unrest in the beginning because they have a lot of things they don’t know and that’s that makes a lot of patients feel anxious. So they for example call and more often in the beginning because that they experienced new things, they are uncertain where they have to be. And you’ve seen that that slows down after one or two treatments.” - HP1*

*“Well, they are afraid. The most part of them are afraid and don’t want to hear it or it’s not about me. They say – “If I had a choice, I run away, for instance.” - HP2*

*“Yeah, I think most patients already know what they are going to hear or what they might hear. So of course, the patients are shocked and crying, but I think like there’s always a kind of shocked reaction. And I think the real reaction is coming later, like there’s no what you see as a medical doctor in the first 15 minutes after hearing the diagnosis. So also a lot of patients are reacting quite cool and I think afterwards they are realizing that both what’s really happening.” - HP3*

Following the diagnosis, individuals’ lives become extraordinarily busy as they navigate numerous appointments and decisions while also having survival thoughts, leaving little room to fully absorb.

*“They have so much going on. Uh, just, you know, a family that wants, a lot of people are asking things for, you know, life usually gets very busy when you have the diagnosis. I think 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. I’m 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*

## Ways of Providing Information

During consultation sessions, healthcare providers assess individuals’ comprehension of the information provided and adjusts the way to provide information. The emotional trauma associated with a cancer diagnosis often hinders individuals’ ability to fully absorb details during the consultation session.

*“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 they’re 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 you didn’t understand what I explained to you. So that by the time of questions they ask, and sometimes that this because of maybe they didn’t hear what I said or maybe they didn’t understand it or I didn’t explain it properly.” - HP1*

They mention that when they hear repeated inquiries from individuals, it typically indicate a lack of understanding, prompting healthcare providers to help in various ways, such as scheduling follow-up sessions, offer additional resources or providing detailed explanations. When an individual appears overwhelmed, healthcare providers may schedule another session with them to explain them again and give them some time to absorb and provide comprehensive information binders about their condition later.

*“I see that the patients are really confused. Umm, I also sometimes make another appointment or if it depends on how big the confusion is and where it is it, what it is about. So something small and I say, ‘Okay, think about it. Let it rest here. You have some information and I call you next week’. If it’s a really big decision then I make a real-life appointment. But I also called a lot of people if I thought or if they were confused or they are in doubt over choice because that’s also sometimes because they think, ‘Okay, I wanna have a breast reconstruction but I don’t know yet if I want uh uh with own tissue or with implants and then I say okay go home and think about it. Go talk about it. And I call you next week.’ then you can also call and ask the patients, ‘Do you know what already you need a new appointment or where? what are your needs?’” - HP3*

One of the healthcare providers also mentioned that she shares additional information if she feels that the individual can comprehend.

*“Not all patients received the website from me. For example. Umm, you also feel that this patient really wants to know a lot, and then you also provide them with more information. And sometimes you already feel that this patient is not really getting it so you’re not going to say or you can see this website and this website and this website. Then you also try to compromise to just a folder depending on how they respond.” “I think on which type of doctor you have and also it depends on the patients. So some patients are, yeah, only receive a folder and find our way self and other patients who have like more really specific questions or I wrote down some website.” - HP3*

To facilitate effective information provision, healthcare providers aim to deliver information gradually and incrementally, simplifying it to enhance understanding for the individuals. They note that this approach often proves beneficial for some of the individuals.

*“I try not to use the medical language and I try to talk slowly and put information in parts otherwise it will be too much.” - HP2*

*“I need to translate my knowledge in a 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 and even highly educated people.” - HP1*

*“So I put the whole process in little parts.” - HP2*

*“My goal is to inform everybody enough, but they have, they know nothing about breast cancer because they are not a doctor.” - HP2*

*“I think if it’s really complex, you still have to make sure to make it uncomplex and the way you explain it.” - HP4*

Regardless of how difficult the information might be, healthcare providers mention that they should be transparent and open and convey all the aspects. This helps the individuals better understand their situation and make informed decisions. Engaging in open conversations also helps the providers learn about individuals thoughts and concerns to guide them in the right direction.

*“I just had a patient who wanted her other breast removed and I 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. 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 it’s it’s not correct.” - HP4*

*“You must not hold back information because that’s not okay because the patient have to take the decision. Of course I tell them and advice and 9/10 say, “Okay, I’m going to do that”, but they have the opportunity to choose and how we can send them on a certain way, but it’s not forbidden if they choose another one and for instance, and if I said, “well, it’s going to be treated with the breast pairing operation and they want an amputation, I don’t say, well, ‘I’m not going to do that because of so and so reason.” [talking to the patient] So you have to have a good conversation and tell them to all the pros and cons and almost 99% will say – “That’s a good advice I will follow you” and that you can only reach that to be open and to be honest and to also tell the things you don’t know.” - HP2*

Sometimes providing them general tips with the information for example, writing the questions to have a conversation in the next consult can also be beneficial for them to understand.

*“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.” - Participant 2*

Due to demanding schedules of the oncologists and surgeons, the consultation sessions are not enough for the individuals to get all the information. Individuals are referred to nurse practitioners and other credible resources for more detailed explanations in writing and to understand about other aspects of life.

*“They get information again from a nurse and they also give them everything in writing.” -HP1*

*“Yeah, it’s (link to kanker.nl) provided by the nurses, the nurses that they talked to afterwards. Yeah, they get all these website links that they can look at the BVN link and etcetera.” -HP4*

*“I noticed that it’s very well a good job what they (nurse practitioners) do because sometimes there are questions for the nurse to have the final touch.” - Participant 2*

*“We give a lot of information, of course the nurse will also give some information to read.” - HP2*

*“They will meet the patients after the diagnosis, for example, that we’ve given. And then they talked with them. And I also explain a lot and they are actually the ones that give all the extra information. They give some information like a handout on paper where which is like a letter in not a like a medical language with but in a normal language what the patient has, and also all these links for videos in the DVD’s thing you might have heard of it. Explanation about the breast cancer or the therapies or how to do an MRI or etcetera.” - HP4*

## Challenges

A common concern that all healthcare providers expressed was regarding individuals’ concerns regarding variations in treatment compared to friends or family members. They often need to explain that treatment plans are individualized and their case is not the same as their friend’s or family member’s.



*“It’s because it’s so many people have it. 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, that there are little groups that the radiologist talks about, radiology, part the oncologist, about the medicine, the surgeon, only about the surgeon and the startup. And yeah, I think that’s the most difficult to explain, that they’ll that is not me deciding what to do, but it’s a team and that it takes time.” - HP4*

*“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 or people in the surroundings breast cancer is of course a disease that a lot of people have but that’s 1,2, 3 or 4. People. It says something about outpatient is like starting their career path because they have that in mind or that experience from somebody else in mind. 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*

*“For example, a lot of people ask me the they say, oh, “I want to be treated with immunotherapy” and but immunotherapy is not the effective in many cancer types. So yeah, there’s no approval to treat people with immunotherapy if it’s not proven, effective. And so the understanding that you have a type of treatment that that it can only be used for certain types of cancer, that is, that is not general knowledge.” - Participant 1*

*“And if I notice, well, they, they are going everywhere because of this and that and I try to categorise it more and say, “but that’s not that important, because that’s not for you. And you read that. But that’s not your situation. We are here now, so we have to focus on that, but it is still” - HP 2*

They also encounter difficulties in explaining the roles of different healthcare professionals involved in the individuals’ care as initially individuals struggle to understand which healthcare professional to consult for specific concerns, they ask all their doubts and worries to their surgeons. One of the reasons could be that they are unaware of who to approach in this unfamiliar environment.

*“There are little groups that the radiologist talks about, radiology, part the oncologist, about the medicine, the surgeon, only about the surgeon and the startup. And yeah, I think that’s the most difficult to explain, that they’ll that is not me deciding what to do, but it’s a team and that it takes time.” - HP 4*

*“And so I have to translate my knowledge into simple language and that is difficult. I have a limited amount of time so I have to also schedule how I deliver my message and what I tell them, whether things are relevant or not.” - HP 1*

Understanding the medical information takes time for individuals’, who are navigating an unfamiliar world and must process extensive information and make informed decisions. Some patients prefer that doctors make decisions for them due to fear of making incorrect choices, although this is not always feasible.

*“They sometimes they think you know, you just tell me what the plan and then they’re kind of struck by the fact that they have to make like 10 decisions before there is a plan. And it’s it’s not per se, the amount of information they can find on the Internet that they just get kind of, they’re 86 and I just want you to decide. It’s too much. It’s the thinking about it is it’s too much, yeah. It’s because I think it’s easier if someone else decides what’s best. It’s easier if - they’re not nice choices. It’s easier someone else makes the ugly choices.” - HP 4*

While some healthcare providers convey that the information individuals receive can be complex and difficult to process, some also acknowledge that the primary issue is often the sheer volume of information. Although the language itself may not always be very challenging for all the patients, 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.” - HP 2*

*“Uh patients are usually they lose track of what I say if I only speak in medical terms, even I have some patients who are medical doctors themselves. Even if I speak in medical terms and they start, uh getting lost because they are not familiar with the a lot of the oncologic terminology.” - HP 1*

*“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 they’re 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. So that by the time of questions they ask, and sometimes that this because of maybe they didn’t hear what I said or maybe they didn’t understand it or I didn’t explain it properly.” - Participant 1*

*“I think most because I think it’s either it’s a lot of information, but it’s not difficult.” - HP 4*

*“They get loaded with information, so I’m mostly sending. It’s not a lot of receiving because I have to explain a lot. And the most important - because I treat patients with breast cancer, so quite frequently on women with family.” - HP 1*

## Differences in Preferences, Understanding, and Processing

Individuals exhibit significant variability in their ability to process and understand information about their illness. Some individuals take an active role, seeking to comprehend their condition thoroughly, while others struggle and engage less, often due to lower educational levels, unfamiliarity with medical terminology. Healthcare providers can typically identify these differences through initial interactions. One of them also mentioned that it’s hard to understand if they don’t speak both Dutch and English.

*“But I think mostly in the conversation I feel that they don’t get it.” - HP 3*

*“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.” - HP 1*

*Mostly in the conversation, if they ask something backwards, they say something and I think umm, so that’s how I feel that they don’t understand. They don’t understand it. What I always found really hard if people didn’t speak any Dutch or English. - HP 3*

They mention that educated individuals generally have an easier time understanding and managing their illness and are also suspicious sometimes, whereas less educated individuals may not even know what questions to ask so they generally follow the steps shared by the healthcare providers. These differences in comprehension and engagement influence the complexity of information delivery, with less educated individuals facing greater challenges.

*“The people that are highly educated, they are smart enough. They say - ‘what are the priorities? What is the? What is now the main problem? Where do I need to focus now?’ OK, no, not always, but it’s I think if you are highly educated, it might be easier to separate important things from less important things to get a clear overview of healthcare and like visualize for yourself, ‘What do I have to choose now? What’s more important, because you’re used to doing that also in daily life. But I think definitely for the people that are not that highly educated, it’s harder”. - HP 3*

*“I have sometimes the idea that people with a university background are more, uh, suspicious. They are always like - “oh is that true?”, “Ohh okay, but maybe I have to go to (refers to a hospital) or I have to go to (refers to another hospital).” I have the idea the more graduated they are, they are getting more information from everything. And the people who are are not well educated, uh, well, they say, - “Okay, you’re the doctor, you tell me what it is.” But it’s a feeling, I can cannot not measure, measure it with anything.” - HP 2*

## Seeking Information

Individuals frequently resort to the internet to gather information about their illness. While this trend reflects increasing awareness on learning about their illness but it also presents challenges, as individuals sometimes bring irrelevant or inaccurate information to their consultations, necessitating further clarification by healthcare providers. The internet remains a important resource for many individuals seeking to understand their condition and the next steps which also brings conflicting information, anxiety, etc. Some individuals are particularly interested in knowing the outcomes and future steps of their illness, driven by the desire for control and reassurance.

*“Yeah, a lot of them say as well, yeah, “I’ve started Googling but I stopped because I was really awful or something like that”. So they do tell me one day or when they talk about a lot of things. I’m like you’ve probably looked it up and, you know, asked them, “What did you see?” And you know, so that I’m sure that I didn’t look up the wrong things. Yeah, I think most people go on the Internet once they have a lump in the breast in their breast or sense through after mammography.” - HP 4*

*“I think patients believe a lot of what they see on the Internet.” - HP 3*

*“Sometimes they look at other the online information things and then they ask questions about that.” - HP 2*

*“People search themselves on the internet, so they find all kinds of things and what I hear from the news have - so whenever there’s a new news article about some success with the cancer treatment, my patients asked me about that or they asked me, they want to participate in drug trials because they think that then they get the latest and type of drugs that are in there. Perception always better than what is already available.” - HP 1*

## Role of Companions

The impact of a breast cancer diagnosis extends beyond the individual to their family members and companions, who often play critical supportive roles. Companions provide emotional support and assist individuals in navigating their treatment journey. However, companions themselves can be overwhelmed, sometimes diverting the conversation to their own fears.

*“His life also changing because you know, you’re the chance that you are wife or girlfriend is dying in five years is reasonable. So then you also see that has a lot of impact on the partner.” - HP 3*



The presence of a companion is generally beneficial, offering additional support and improving the individual’s ability to cope with the diagnosis and treatment.

“I think the surrounding the social environment is very important in that group, yeah, if there is social environment says “Okay, come on, we’re going for a walk or we’re going for this or what’s happening tell me...” And these people, I think are doing better than people who are alone or don’t can express their emotions to the other ones.” - HP 2

“Companions also ask questions umm, and sometimes it’s also good because patients also can have like a kind of freeze or blackout idea. If you’re at the appointment. So yeah, most times the companies are also asking questions.” - HP 3

“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. - Participant 2  
There’s a lot of different. I mean some partners, I never see them. So, they I guess they do stuff at home, but I never see them in the in the hospital and for other patients, they always come together and they even the partners have asked me good questions or even do most of the talking when the patient is too tired or yeah. And then you have patients and yeah, we will sometimes come with their partner, mostly you for important meetings like a new scan to discuss the results of the chemo treatment and other patients and they randomly bring their spouses or family based on, I guess whether they were available or not. So it’s very there’s a large variation that in that.” - HP 1

Healthcare providers noted that having a companion usually aids in the individual’s support system, although it is challenging to fully understand the dynamics between them.

“It depends, it’s a little bit different. Sometimes you see that the partner of the people who companion the patients, but they are sitting there. Sometimes the partner is very and ask lots and the patient is quite so it’s sometimes very interesting to see what’s happening on the other side of the table.” - HP 2

Sometimes the partner starts telling about his own strategies so well, you have to say, well, ‘that’s very not nice for you. But now it’s we’re talking about you wife.’ So we have to concentrate on that [talking to the companion]. So it’s every time it’s very different, but it’s well, it’s you have to have a conversation with everybody. - HP 2

B.3 Classification of Essential Information

This section was not used in the final report as this section needs further investigation and didn’t support the concept exploration. However, this has potential for further research. The findings are presented on the following page.

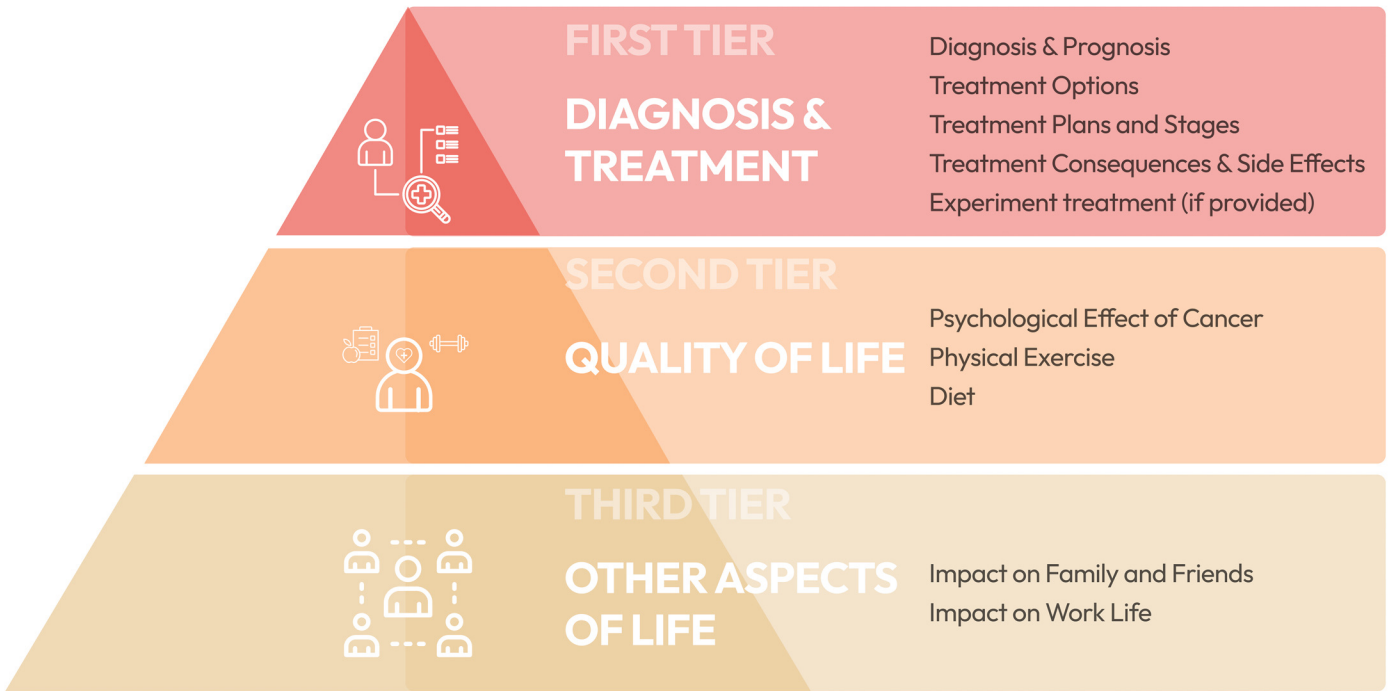


Figure B.3: Classification of Essential Information (based on the interviews with three healthcare providers)  
Individual mapping shared on the next page



Figure B.4: Offline session with the healthcare provider 3  
left: essential information that individuals should know, right: information that individuals ask



The classification of essential information, established through sessions with healthcare providers, categorizes essential information that patients should understand about their illness into three levels. The first tier comprises fundamental information that is crucial for understanding the illness, treatment options, potential consequences, and side effects on the body. The second tier includes information that patients should be aware of focusing on aspects related to quality of life, such as the psychological impacts of treatment, the role of physical exercise, and dietary considerations during treatment. Lastly, the third tier pertains to additional information about broader aspects of life, which patients are not obligated to know but may find beneficial to be informed, such as the impact on family and friends, considerations regarding work life.

To generate the map of Classification of Essential Information, three sessions were conducted with healthcare providers, including two surgical oncologists and one oncologist, to understand their perspectives on the essential information for patients.

All providers expressed that the first tier of information should include the diagnosis, treatment options, and their consequences. Individuals need to be aware of their cancer stage, available treatments, and the implications of each treatment.

The oncologist suggested that, in addition to diagnosis, prognosis should also be included in the first tier. Although prognosis information can be difficult to hear, it is crucial for patients to understand the nature of their treatment and whether it aims for a cure or palliation.

*“Yeah, I think maybe diagnosis should not only be diagnosis but also prognosis, so people need to know what state they’re in and what that means for the future. So, uh, but it’s quite a different - treating with curative intent, or whether it’s palliative and and patient seems to be aware of it. So I’m usually very clear about it. If I give palliative treatment that I start my conversation with, “I can treat it, but I cannot get rid of the cancer anymore. So you will not be, you will not get better anymore. From now on, this is only to prevent progression and so to keep you alive as long as possible. But the cancer will not go anywhere.” And if we treat with curative intent, we explain that the treatment is focused on getting rid of the cancer entirely.” - HP1*

He also highlighted the need for patients to understand their treatment plans due to the complexity of breast cancer treatment, which often involves multiple modalities and healthcare providers. Patients should be aware of the procedures, and potential side effects to manage their daily lives and communicate with individuals around them, such as family members and their workplace.

*they have the patients need to have surgery, chemotherapy, radiation therapy, maybe even hormonal therapy. So, maybe some knowledge about their treatment plan so that they understand that there’s different doctors involved, that there are different stages in their treatment where they will experience different side effects, their life is impacted in a different manner.*

*For example, in radiotherapy, you have to come to those floor every day. The treatment itself is not very long compared to the chemotherapy, but you still have to come every day. So that is quite impact on your daily life. You need to know about these things so you can act their hand and inform your employer. And not talk to a friend. Maybe you need somebody to help you out with a travelling to the hospital every day. So these things are important to know, and so the primary things are a lot of practical things that patients need to know.” - HP1*

He also suggests that psychological effect of having cancer, physical exercise, diet and quality of life should be in the second tier as the more fit and healthy they are and if they know about it, they can recover faster. It’s important for them to know. For lifestyle, impact on family and friends, and impact on work life, he says that it’s not that important so it can be placed in the third tier.

*“People need to the more they fit in more healthier they are when they are starting and during treatment then the better they recover from my chemo and operations etcetera. So it’s that’s still important, yeah.”*

*“People usually stop working once they start treatment and because, yeah, if you if you’re on chemotherapy, you are usually very tired. So most people will try, but that’s what I hear from a lot of people that actually stopped working.” - HP1*

The surgical oncologist echoed similar points but had some variations for the second and third tiers. She emphasised the importance of explaining the “why” behind treatment choices, which helps patients understand and choose the most suitable options.

*“The diagnosis itself, not only the treatment options, because yeah, you tell them about the different types of breast cancer and why these need different treatment. So, as long as you don’t say anything about the diagnosis and they and you give for example immunotherapy, then they never would know why they get immunotherapy and their neighbor doesn’t get that.” - HP2*

It was also stated that the impact on family, jobs, and children should be in the second tier, as these aspects significantly influence patients’ lives. Furthermore, she included diet, physical exercise, and the psychological effects of having cancer

in the second tier.

*“Yeah, I think an important part is to think where they stand in their life and the impact of family, health and on their job. I think it’s a big role for the impact on their the rest of their life. Yeah, family, job, kids.” - HP2*

For the third tier, she suggested information about where to go for specific questions and knowing the healthcare team. This knowledge helps reduce confusion and ensures patients seek the right support.

*“We also have to know we also have to make sure that they know where to, who to go with? What sort of questions? So, if they have a the coming year, if they have any questions that they know who to look, who to, who to. See for that like it went to go to the nurse, went to go to the surgeon, went to go to the oncologist. So they kind of know the team.” - HP2*

The surgical oncologist also reiterated that understanding treatment options and consequences is crucial. However, she placed a higher emphasis on quality of life, considering it the most important aspect. She noted that information about physical exercise, psychological effects, and the impact on family and friends are interconnected.

*“The treatment options and treatment consequences are connected to me.”*

*“But I think it’s for me the main thing is your quality of life. I think for me it’s the most important thing in life. Yeah. And I think these are also really connecting and, to be honest, physical exercise, psychological effects, the impact of family and friends are connected.”*

## Summary

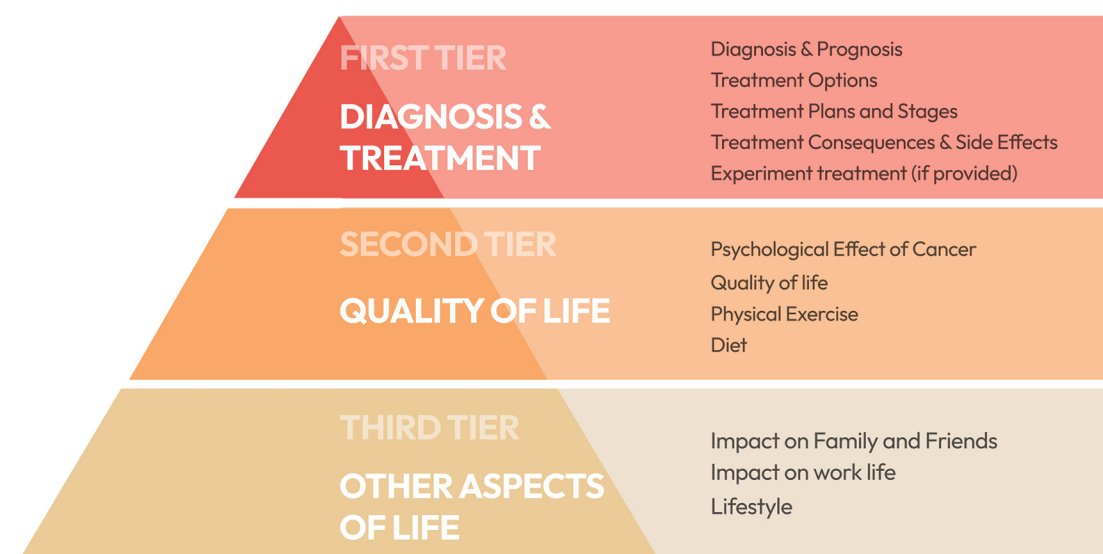
Based on the sessions conducted, it is crucial for individuals diagnosed with breast cancer to acquire knowledge about their diagnosis, treatment options, and the potential outcomes of treatment. This understanding enables them to make informed decisions in the treatment journey. While many individuals tend to avoid prognosis data as it is distressing, it is nonetheless important for them to understand the type of treatment they are receiving—whether curative or palliative. With this, being aware of treatment side effects is also essential as it prepares individuals for the physical changes that may occur.

Healthcare providers stress that beyond understanding diagnosis and treatment specifics, bringing perspectives from quality of life such as physical exercises and a healthy diet would help in positively impacting their ability to cope with the illness. Once individuals are well-informed about their health status, they can then address other life aspects, such as the impact on their family, friends, and work life.

Despite the overwhelming nature of navigating through unfamiliar territory like cancer, where individuals get lost easily in all types of information, this map aims to guide individuals in understanding what healthcare providers deem crucial for them to know, facilitating a structured approach to comprehending information.

The Classification of Essential Information is currently under discussion and requires additional inputs from various healthcare providers to finalize which information is essential. This map aims to provide an objective framework and structure for the types of information.

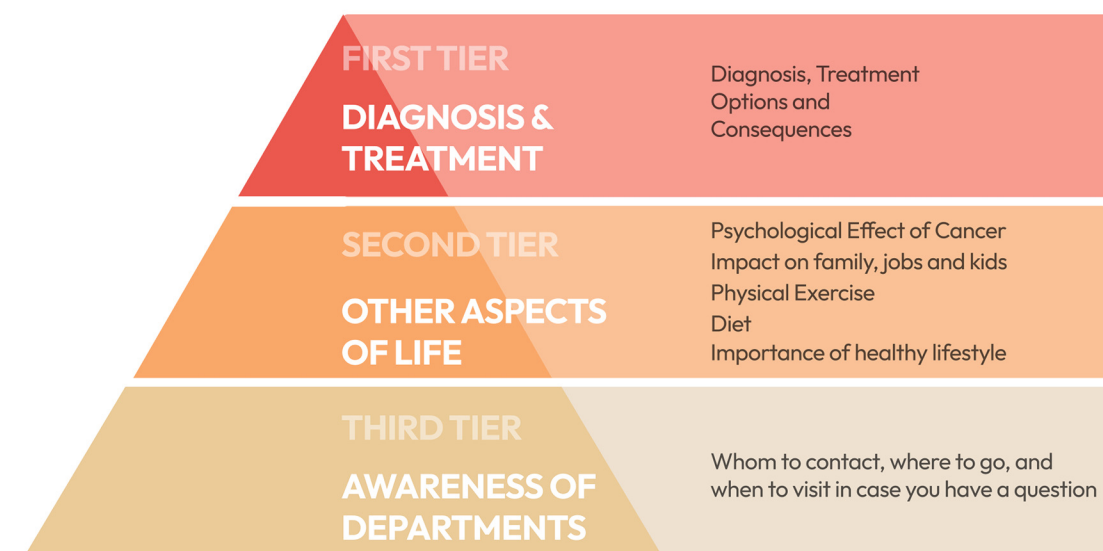




Healthcare Provider 1



Healthcare Provider 3



Healthcare Provider 4

## Appendix C: Insights from Other Key Stakeholders

### C.1 Interview Questions

These questions were presented to other key stakeholders during the interview sessions.

1. At what stage do patients usually come to you? Is it post-diagnosis and pre-treatment or before or after this phase?
2. Do you receive information from the healthcare providers/hospitals for the patients or do you have your own set of information and provide them that?
3. Based on your interactions with patients, what are the frequently asked questions or areas of uncertainty patients express following a cancer diagnosis? How often do patients and caregivers/family members seek information from you?
4. How often do patients and companions/family members seek information from you?
5. Do patients face problems in understanding the illness? Are there any patterns you find in people with understanding?
6. How do you support the patients with the information they receive post-diagnosis?
7. Can you discuss the common challenges patients face in understanding and processing information about their cancer diagnosis and treatment, and how your organisation supports patients in navigating through this information?
8. Do patients commonly seek guidance or clarification from your organisation about the information letters and brochures they receive from healthcare providers? If yes, what are the common themes or topics they seek clarification on?
9. Can you describe the support services or resources your organisation offers to help patients following a cancer diagnosis?
10. Do you also provide counselling/psychological services to the patients?
11. How do patients deal with the disease? What are the different coping mechanisms that you have observed?
12. Do you notice various personality types in the patients that come to you for support? If so, could you elaborate on the different types of personalities?
13. How do patients connect with and support each other throughout their cancer journey?
14. What are your views on how patients receive information? What are the challenges that they face?
15. What are your roles and responsibilities as the umbrella of patient organisation?
16. Do you provide the hospital recommendations for treatment to the patients?
17. Can you tell me a bit more about the discussion polls on the NFI website? Do the patients access that?
18. What are the main touchpoints? Do you also interact with the patients? What according to you are the main challenges they face apart from the burden of the illness?
19. Could you talk a bit about the complexity of medical terminology in cancer?
20. How do you see patients coping with their illness?
21. Based on your experience, what strategies can be adopted for patients to help them deal with the complexity and emotional factors of the illness?



C.2 Interview Findings

This section presents the findings, including analysis and quotes, from interviews with other key stakeholders. Selected quotes are featured in the main report to illustrate the findings, while the remaining data is analysed

When asked about the experiences of individuals with breast cancer post-diagnosis to the patient organisations, the representative from BVN mentioned that it’s a shock for them. The overwhelming nature of the diagnosis makes it very hard for individuals to comprehend everything surrounding them. She quotes a patient who mentioned this as a new job due to the extensive amount of information they need to understand and process.

She noted that most people begin seeking information during their tests, not waiting until the diagnostic stage, because the series of tests indicate the individuals that something is wrong. At this point, they have not yet received any documents about the diagnosis from the hospital, so they start searching online to understand the diagnosis.

“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” -RP2

“You need to figure it out. Which subtype do I have? Why do my does my neighbor woman gets this time type of treatment and I don’t, why does she have to take her anti hormone pills for 10 years and I don’t have to do it. So, this is why it’s very complicated to have all the correct information and not to do it too much. Not too low.” -RP2

“Most people start looking really, really fast, especially when they have certain tests. So they try to find out what test is it? What is the results mean from the pathologist?” -RP2

“The search for information is from the very first start.” - RP2

“Diagnosis, it’s getting like a like an explosion and your whole life changed because it’s the most important thing you have. And of course, you first wanna know and I’m going to die? And if so, when? and of course what does it mean for my daughter? Because does is it a familiar type in the genes?” -RP2

The representative from NFK highlighted that consultation sessions are very brief, and the sheer volume of information provided during the diagnosis can lead to information overload.

“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

They both mention that time constraints during consultation sessions are a significant barrier because patients, upon receiving the news, are often in shock and unable to absorb all necessary information within the typical 15-minute session. Therefore, many immediately schedule follow-up appointments to better understand their situation. They also highlight “mijn dossier” as a potential issue for some, where individuals receive notifications about their pathology results before consulting with their healthcare provider, prompting them to search for information about cancer prematurely, adding to their fear and anxiety.

I don’t know how it works worldwide, but in Holland you usually have like 10 to 15 minutes. With the consult with the doctor, how can? Especially specific types of cancer need more explanation. Also, what the possible treatment could be? We are very advocating a shared decision making like she [representative from BVN] said like like Umm. What possible treatments? How do they affect my life? What do I choose? What do I don’t It is very, very difficult to comprehend that in 10 minutes when you also have the news - ‘you got cancer’. So that’s that’s well from my background on personal title, that’s almost impossible to comprehend. Sometimes, and I do think the hospitals in the Netherlands vary in how they organize those kind of things, some EG breast cancer have like OK, the doctor gives the diagnosis and some extra info and then there’s a whole conversation with a physician or a nurse and expert of this that explains that to them. But that differs a lot between cancer types. To my opinion, it’s nearly impossible to within the 10-15 minutes you have with the doctor to hear the news of cancer like, ‘I’m gonna die’ and then all information, whatever they say to you is it’s lost. Maybe they remember 20%. - RP1

“Most of the most of the time they will have a second appointment immediately. And what I heard recently was was interesting for us is we did a little fight in the past years to have to get people in their specific hospital account that all the results of test will be put in the in their account as soon as possible and I just had a conversation that there’s also a bad side of this because this nurse she said yeah - ‘well I have patient and they get a note being there is a new information in your and they said, ‘ah, no, not again. I don’t wanna read. I don’t wanna know, so It’s not only positive.’ And as she [representative from NFK] and I found out in this questionnaire, especially for breast cancer, we found out that that some people, they know, they’re diagnosed only because they read it in the results from the pathologist and then they start, of course discussing it with the doctors. I don’t know. So it did we it’s big trip and we don’t want to turn it back, but we have to be careful with how it works because not everybody likes it.” - RP2

When asked about the complexity of the medical information, the representative shared that the reactions of individuals vary. Some of them engage actively by reading and discussing the details, while others choose to avoid the information, preferring to concentrate on their treatment.

“It’s what you can expect. It’s like, they are going to read and talk a lot about it or they just want to ignore the situation and no, as less as possible because they want to continue.” - RP2

She also shared insights from a previous research conducted with NFK, revealing that highly educated patients were less satisfied with the information they received compared to less educated individuals. While the difference was not significant, it highlighted a variation in how these groups perceive and process information.

[talking about some research with NFK] “We asked how did you get the information about your tumors? So it was very it was not about the emotions, but it was about did you get the proper information? And The funny thing is that the people with less education, they were they give a higher rate to the information they get they were they were more happy with the information than and the high educated person to say, ‘ohh yeah I they told me but I didn’t tell me this and this and this and this and this.’ So there wasn’t. It was not a big difference, but there was a difference between these groups. So it all depends. Well, I think you know already this, but in real life it is the same, yeah.” - RP2

The representative from NFK emphasises the need for additional conversations beyond consultation sessions to thoroughly address other important matters. She highlights that the current allocated time with healthcare providers is often insufficient for the individuals to fully comprehend all aspects of their diagnosis and treatment. It is important to recognise that every patient is unique, they advocate for varying amounts of time attuned to individual needs, reflecting the diverse range of requirements among patients.

“We think in general that more conversations apart from the diagnosis conversation need to take place. And it does not necessarily have to be the medical specialist or a doctor. It could be a trained nurse because we have lots of trained nurses in oncology to go over the diagnosis. And what does it mean for you? What do you want? What for us? We do. We think it’s better if you have the diagnosis and then another conversation about treatment possibilities. Usually people are so shocked and cannot hear anything anymore that comes into their mind. Or they’re just so scared and shocked that there needs to be at least one other conversation to talk about options. What’s important in your life? A. Let’s say if we do treatment A, B or C, what consequences would they have so as to talk more elaborately, aloud about it? And right now, the way the system is designed, it’s not always possible because the doctor only has 10 to 15 minutes and how do you say the news and also give options and also decide about that in one single short conversation? That’s, I think our main concern because we noticed that the consequences would survivors are sometimes very difficult and we hear sometimes from patients, ‘if I had known this in advance and also the limited amount,’ and maybe that’s where your mechanism comes in, the limited amount of of of what I may get extra, let’s say 5% extra survival or 10%. less chance of it turning back. Sometimes people say, ‘ohh, OK if the treatment means I will not be even able to exercise or name whatever I wouldn’t have chose to do that.’ And of course that differs a lot with the cancer type in breast cancer is the most, umm. I think it has the best survival of all cancers, so maybe they make a different decision. - RP1

My best advice, I am not an expert. I used to work for BVN. But in my current function, I shouldn’t be saying this because I am a researcher but what I do know is most of our members say - “have multiple contact moments before a decision is made, what, when and how? We agreed that the 10-15 minutes of giving a diagnosis, which is in most cases traumatising, is not enough if you’re also gonna say ohh. And by the way, you start to exercise more and ohh by the way, there’s a lot of things that are important and we think it would be beneficial for the patient to have several conversations and it doesn’t always have to be with the medical specialist like the doctor can also be trained nurses who provides you with more information cause it’s a lot, and we do notice, like she [refers to the representative from BVN] pinpointed, that there are several types of people. How do they respond? Some people want to know everything and want to decide on their own and other people are like you’re the doctor - “You say what I have to do so there’s a whole range in, in people’s needs, I guess.” - RP1

A simple yet crucial step that healthcare providers can also take is to ask the individuals if they have understood everything, as they may hesitate to ask for clarification due to fear or uncertainty.

“There are of course differences and there are difficulties they experience, yes, it is extremely important that the doctor asks the person, ‘Did you understand but ask tell me what I just said?’” - RP2

When asked about the time when individuals join the patient organisation, the representative mentioned that most do not join post-diagnosis as it is overwhelming for them. At that stage, they have a lot to manage and prefer to focus on their physical recovery.

“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 will, you 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

They were also asked about the type of support individuals seek. She outlined some of the support services they provide,



noting that most individuals join later during or after treatment. They offer a “buddy contact” program where fellow sufferers, matched with the patient’s profile, offer in-person information, respond to queries, and share other concerns. They have observed that individuals benefit from talking to someone with similar experiences, as it allows for mutual understanding. They also conduct offline patient information sessions in groups of 6–8, sometimes with the inclusion of psychologists who provide support and guidance.

*Yeah, they do. They get them. They get an answer. And we do. We do organize buddy, so it’s one to one contact because the breast cancer patient, they are very different because they can be 25 or they can be 64. They can have a wish to have children or they can and they can have hormone positive or they can have triple negative breast cancer. So we but we experience these people as I want somebody who has the same as I have and then we really look and we match them together. So we match one to one. most of the time it’s for for the first year, but sometimes there it stays. They stay friends forever or Yep, so. So we are not, we don’t provide a psychology help but we do we do have, it’s called fellow sufferers contact and we have a lot of them especially when in the metastatic situation we have and it’s also led by volunteers. They have a group of around 5 or 8 patients and they come together once a month. Once in two, we we work together with the, let’s call it IPSO huizen. it’s not in the hospital, but it’s a place for cancer patients where they can meet each other and they you can go there just for coffee, but they have a lot of information sessions and they have sessions just to talk together and tell them. And sometimes, psychologists will give their lecture or talk with them.” - RP2*

The representatives from kanker.nl echoed similar responses to those from patient organizations. They noted that individuals facing a cancer diagnosis often receive overwhelming amounts of information, which can be challenging to grasp the information amidst the emotional turmoil of diagnosis. The former nurse, now an information line operator at kanker.nl, shared from her experience that patients struggle with understanding the medical terminology and explanations provided. She interacts with individuals almost daily on calls, listening to their stories and answering their questions. Sometimes, they seek guidance in decision-making, understand their potential consequences, and also relying on her expertise to navigate treatment choices as it is difficult for them to make the choice due to fear. She mentions that each individual’s values and priorities is crucial and as the providers in the care pathway, it’s important to understand those values and priorities to better help them.

*First, they get too much information. And then there are quite emotional, and especially in the beginning, it’s a very emotional journey you. So it’s difficult to understand information and to comprehend and yeah, all the information and it’s new for them. And then in a very stressful situation. So it’s very difficult to take a role in the process and they’re very dependent on their doctors and it’s a new world they get into that and that’s very difficult with lots of difficult....And the information they get is not always very understandable. - RP5*

*I think that’s one of the big biggest problems that the information is not given in spoken language, how the talk, what kind of words they use. - RP6*

*I think there’s a tendency of you have to make your own decision. Umm, not everybody can make their own decision. Uh, they need support, and sometimes you get your information or in booklets or in look at the website. And in 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 consequences are from your decision. - RP6*

*“The questions they uh, have umm, they don’t always say uh, 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*

*“Sometimes they only want to tell their story. And then we only listen and sometimes they want to know. They try to let you make the decision and or do we don’t make the decision you have to make the decision. I can provide you with the information to make it easier for you to decide what you wanna do. And help them in making a decision which is good for them. I cannot make the decision. Physician cannot make the decision. You have to make the decision, but you have to be informed about all the consequences of your decision. And that’s that’s lacking. Sometimes they. Yeah, they have an option, but they don’t know what the options. Have as a consequences and also in later on in life. Well, that’s what we’re trying to do on the phone, to make them understand and to guide them a little bit and help them with questions and clarify something.” - RP6*

*“Everybody who might have cancer and has to go to the hospital, they have a lot of emotion and confusion. Umm, the most important is to help them in their emotions and help them in understanding what’s going on and helping them in choosing some kind of treatment if they want to. And look what’s important in their lives and look what kind of treatment is the best. it’s important to look a little bit further than I’ll need a medical sites. What kind of person is sitting there and what? Uh is important in life, and what do they need? Which treatment is the best option?” - RP6*

The patient advocates interviewed for this project are all former breast cancer patients themselves. One was diagnosed in 1997, another in 2012, and a third with a different cancer in 2021. Following their recovery, they became patient advocates, assisting other patients in understanding information, advocating for their rights, and participating in research. These advocates regularly engage with patients and stress that a uniform approach to information provision does not cater to everyone’s needs. They note significant variability in information preferences among individuals; while some seek detailed information, others prefer less. These preferences can also evolve over time. Drawing from their

personal experiences as former patients and now as advocates, they also acknowledge, similar to other stakeholders, that receiving a cancer diagnosis is overwhelming, leaving less mental space to learn about all aspects of cancer.

*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.” But there are a lot of patients, they take her to the doctor and the healthcare provider and it’s okay. So that’s one. And that’s one and all in between. Yeah, I think so. Yeah, So what do you need in your situation? - RP2*

*It can change over time, it (refers to preference of information) changes over time. It does. - RP3*

*It’s very difficult to see a situation because you are overwhelmed when you get a diagnosis. And then you have to you have to undergo all the treatments. And it says you are busy with yourself. So, ‘how can I survive this this period? But then that then you do this treatment about yours and thesis after the diagnosis?’ I think maybe in this period, when you have the diagnosis you have to wait for the treatment. Maybe it could be that there also will be, when the patient wants information, then you have time to think about it. - RP3*



# Appendix D: Insights from Individuals with Breast Cancer

## D.1 Interview Questions

The questions asked to individuals with breast cancer are listed below. These were semi-structured, with additional follow-up questions added as needed.

### Personal Experiences

1. Can you share a bit about your personal experience with cancer diagnosis and treatment?

### Dealing with Information

1. Receiving Information: What types of documents (digitally and physically) were provided to you by the hospital? Did you find the information satisfactory? To what extent did you find the information understandable and clear?
2. Did you participate in a clinical trial? If so, how did you navigate through the process?
3. Did you face any difficulties in dealing with the information provided by healthcare providers? Were there any specific challenges you encountered in communicating with healthcare providers?
4. In dealing with the information post-diagnosis, what resources or methods did you find most helpful in understanding your condition and treatment options?
5. How did you navigate the complexity of medical terminology and treatment regimens?
6. Collecting Information: What were the sources of information you relied on apart from healthcare providers? How did you determine the credibility of these sources?
7. How would you have ideally wanted the information? (in terms of format, delivery, etc) How much information would you have wanted?

### Involvement in the care journey

1. Can you describe your preferred level of involvement in decision-making regarding your treatment journey? Did you feel adequately supported in making informed decisions?
2. Could you provide some insight into the role of your companion or family member? How are/did they support you during your experience?

### Reflecting on their care journey

1. Reflecting on your experience, what do you believe are the most critical aspects of patient support and communication during cancer diagnosis and treatment?
2. Looking back, is there anything you wish you had known or been better prepared for when first diagnosed with cancer?

### Psychological Help, Impact on Other Life

1. Have you explored avenues beyond medical treatment for emotional support, such as counselling services? Aside from professional help, what other sources have you found supportive during your emotional journey?
2. How has this illness affected other aspects of your life?

### Recommendations

Based on your journey, what recommendations or insights would you offer to Healthcare Providers or Patient Organisations to support cancer patients in understanding their diagnosis and treatment options?

## D.2 Interview Insights

This section presents the findings, including analysis and quotes, from interviews with individuals with breast cancer. Selected quotes are featured in the main report to illustrate the findings, while the remaining data is analysed and detailed here. A representation of the thematic analysis and clustering of findings is provided on the next page.

### Information Provided by the Healthcare Providers

Participants found the information shared by the healthcare providers to be trustworthy, enough and easy to understand in the current context.

Many participants highlighted the role of the healthcare providers, especially nurse practitioners in some cases were really helpful as they could level with them and provided comprehensible information. Some participants mentioned the introduction of a case manager, which was beneficial in offering detailed explanations.

*“They always took all the time needed for me. So even though the time slots for a conversation were maybe scheduled for 20 minutes if I need 30 or 40 minutes. The time was there. I was always allowed to record the conversation. I was always uh, they always took my clarification question seriously.” - P2*

*“Appointments with both the oncologist and with the, how do you call it, the surgeon and with the speciality Nurse from oncology. So she’s really taking you through all the steps. They really talk you through and then they provide the information.” - P1*

*I was really, I was very relieved, like so. I felt a lot of things at once, really intense time. I felt very relieved that I was at the (refers to hospital 2). I really felt like they took time with me. - P6*

Individuals placed a lot of trust on the healthcare providers and mentioned that the care was very well organised and appreciated the thorough explanations. One patient, for instance, chose not to seek information online because she felt well cared for and did not see the need to look elsewhere for information.

*“I trust them to provide the proper information and that it is of good quality that it’s applicable to my case, so that that’s I think the most crucial and that they don’t forget to tell you things.” - P1*

*“And as a consequence, I didn’t want to look up information online because you don’t know if you can trust it and it may get you scared. And I felt in good hands.” - P1*

When asked about the documents they received during the diagnosis, participants noted that the information was clear and provided a basic understanding. They found the documents easy to follow and appreciated that they could be read at their own pace if they chose to do so.

*“It (hospital documents) was easy. It was not difficult, so yes, it was very easy. they are very clear. They are easy to read and to follow.” “It was very good and I understood.” - P7*

*“All the information was was really clear.” “That you can read if you want to. You don’t have to, but everything is explained - all the procedures, what they’re gonna do? So everything basically is explained there and you get it at your first appointment. So you know, if you wanna read, you can read and at the end they also give you the exact form, the exact notes where is your tumour, how big it is, what kind of tumour, and it’s all in there. And so everything is written in there.” - P5*

*“I think the texts and the information is super clear.” - P1*

*“I think the information I’ve got that it is for a that it is enough. To have a basic understanding of what’s going to what’s going on.” - P3*

### Difficulties in dealing with information

Although majority of the participants found the information easy to follow and trustworthy, some participants also reported that the information was complex and they faced difficulties sometimes to understand the ‘medical jargon’ or the ‘doctor’s language’. On the other hand, Participant 5 and Participant 7 shared their bad experiences with the healthcare providers and services, which led to a loss of trust and dissatisfaction with both the information they received and the manner in which it was conveyed. Participant 6 and 7 also reported that it was an overwhelming experience for them to go through everything that was presented to them.

The thematic analysis of interviews with seven participants was organised along positive and negative axes to highlight their experiences. Findings were clustered to identify similarities and related experiences were grouped. This initial mapping was used to select quotes, which were relevant to the research question. These were then included in the main report.

INFORMATION NEED

EMOTION NEED

Need of finding trustworthy information step by step

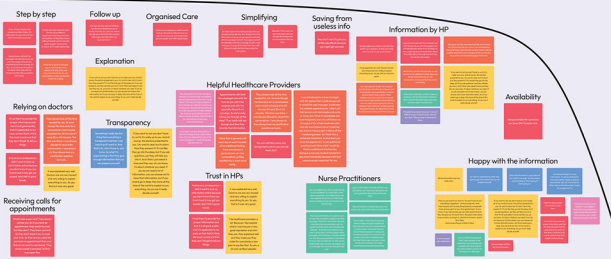
Need of understanding and minimizing uncertainty

Need of emotional support



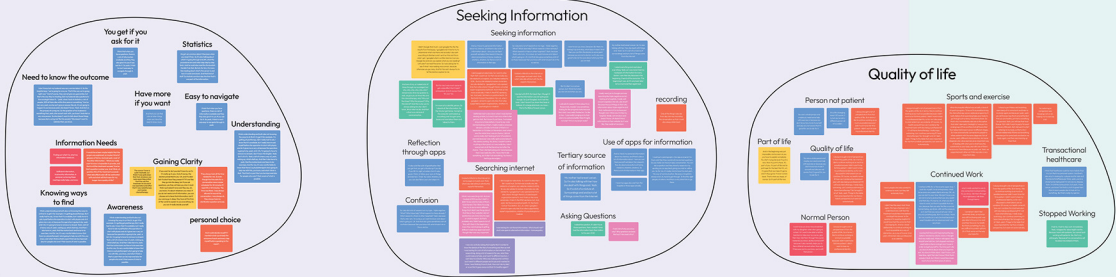
1 Information Provided by the Healthcare Providers

Participants found the information coming from the healthcare providers to be trustworthy, enough and easy to understand in the current context.



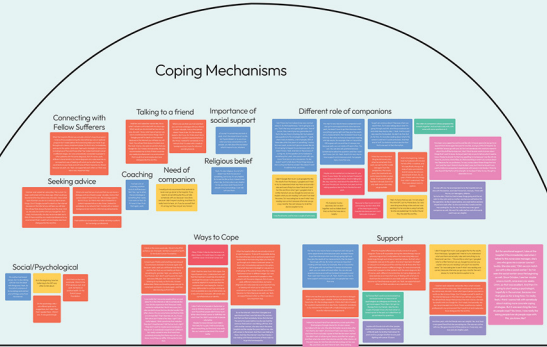
3 Information Seeking Behaviours

Almost every participant was seeking information - the only difference was in the way they were seeking information. Some preferred surfing the verified websites, while others preferred seeking information directly from the healthcare providers or the services by the hospital



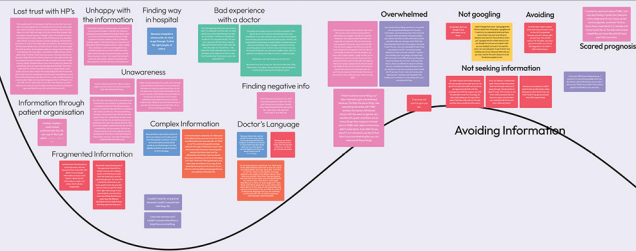
5 Coping Mechanism

Different ways of coping and role of companions in the patient's life



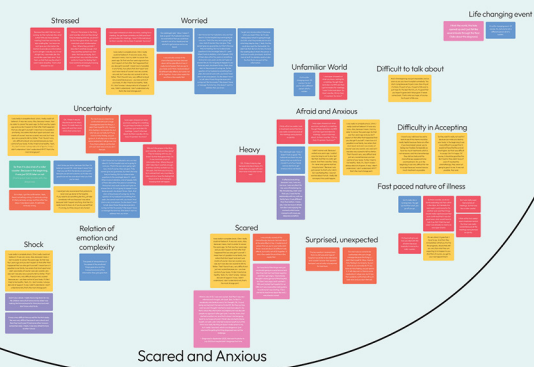
2 Difficulties in dealing with information

Participants described the information as complex and fragmented



4 Range of Negative Emotions

Diagnostic stage for all participants were a mix of confusion, scared, anxiety, worry, heavy, stressed, etc.





“I’m not educated as a physician. So I think some of the abbreviations were new to me. Uh, I have one abbreviation that was used, like- Is it DCIS or not? Uh, which is the specific and type related to the origin of the breast cancer. And I think and another thing that I learned quickly was how the tumour type, how the abbreviation of a tumour type, how that is. Umm yeah. Identified so in terms of what stage is it? Yeah. What size? What grade has so and other other terms like in? In my case, B-rod scores like how serious is the tumour? Uh, so I think it’s a lot of professional language that you are suddenly confronted with.” - P2 (background in oncology software company)

“After I had my surgery and my chemo, they it was like one day I went and they dumped all this information on me again. Like, ‘ohh you need this treatment. You’re gonna need these other two longer term treatments. Ohh you wanna know your prognosis?’ Ohh yeah, you just have the fell into this worst category. Not the worst, but the worst category for a prognosis. And I was like, ‘I’m on the edge.’ ‘No, but you’re in this category, you know,’ they couldn’t explain. I really was like, ‘you’re telling me so much on one day?’ Surely you have some journey that you know like after 20 weeks of chemo and surgery, people are like kind of scared and fragile. Surely you know this is not the time to like tell them they have 3 treatments and. So I want to be involved and I like the idea that you can see you don’t know. Nobody knows what’s coming, right?” - P7

“So a woman who is taking care of you, it was that was very good and she gave me. So some information, some brochures about the what kind of cancer there are there in the past and then, yes, I think in that that so that what kind of cancer and what is like your therapy what? Well, that they were planning to do the surgery. How does it work? So yes, I was very interested in food. Food was always in my life. I was always paying attention to what I ate and I wanted it. I want to eat a healthy and I was asking a lot about that. But umm yeah, it was difficult because they gave me some advice, but not much. And if you look then in, if you do a little bit of research and they are very contradictory statements about what you should do, it was very confusing, what I should do if it was very it was. I was very nervous also because I am, I wanted to get the good to be healthy and I wanted to try everything and I was, I was looking for help.” - P6

Participant 1 also reported that information is fragmented, leaving individuals uncertain about where to find specific types of information. She draws her experience with her mother’s illness, she recognised the presence of different departments.

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

“And luckily I knew this because of the experience I had with my mother that we were visiting a doctor and thinking we would hear the whole story, and you would only get part. So I knew this in advance, which was is, you know, good to know because she...and you think you get the whole story right when you go to your normal doctor, you know they know everything. But here you really have the different disciplines and you need to know that they only know their part.” - P1

### Information Seeking Behaviours

Nearly all participants exhibited a tendency to seek information, although their methods and preferred sources varied. Some participants utilized 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 organizations when browsing online. These diverse behaviors highlight individuals’ efforts to gather additional information to alleviate uncertainty during their cancer journey. One of the participants also mentioned that her curiosity to search information made her confused because she didn’t know the next step.

“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 started with BVN. But back then I thought it was the information was not quite good enough. So I just Googled. And I had this book, I don’t know if you know that book in Holland. It’s a large pink book, you know - that is the Bible of breast cancer.” - P5

“I didn’t Google that much. I just googled the results from the biopsy. I googled and I tried to try to understand what was there and actually 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. And for the rest I always try to let the doctors explain to me. - P4”

“I really went just to Google and was searching like triple negative and uh, looking at a hospitals, I really well known hospitals in the US. Like what? Because they put things on their site. Information about triple negative and that mattered a lot to me because I thought, huh. I think now I’m like my hospital really let me down and doesn’t have. Uh doesn’t have information on their website, but I was like, they really let me down.” - P7

“So 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. Uh. And that also gives sometimes a bit of confusion because then you know ohh what should I do in the so and so.” - P2

### Avoiding Information

There were a few mentions of avoiding information and majorly on the type of information. For example, Participant 7 mentioned avoiding information that consistently presented worse prognosis whenever she sought it out, which led her to avoid seeking similar information in the future. Some participants trusted information coming from healthcare providers more and didn’t find the need to search for more info. Participant 1 articulated avoiding discussions with friends and family due to the uncertainty it added, recognizing the uniqueness of each case and aiming to prevent information overload. She intentionally limited her information intake to the extent that she did not feel the need to know the specific type of tumor she had. Similarly, Participant 4 recounted avoiding outdated information from a family member, noting that information from 15 years ago did not align with current medical knowledge and did not benefit her.

“So I didn’t search information because this was enough and you get very nice. So apart from this information of course you get appointments both with the oncologist and with the surgeon and with the speciality nurse from oncology. So she’s really taking you through all the steps? They really talk you through and then they provide the information.” - P1  
“And as as a consequence, I didn’t want to look up information online because you don’t know if you can trust it and it may get you scared. And I felt in good hands.” - P1

To so, for instance, a friend said, yeah, I have a book of someone that went through what you’re going through. Would you like to read it? I said, “Oh my God, no. So that’s weird, because then we have two cases, and and then I can read about all the horrors that I will have to face.” - P1

“I wanted to read more about TNBC, but I was also finding it quite scary because every single search I do it pops up like worst prognosis, you know? And so. Every time I read about it, it was like ohh I have to put this on the side and remind myself like you know like ohh OK read past that, you know.” - P5

“I think I looked at some things, but then I started to get overwhelmed because. Partially the same thing. Like everything starts like ohh TNBC remains the cancer with breast cancer with the worst prognosis. So I was like ohh, great. And there are so many things they measure in breast can’t in TNBC that I didn’t at that time didn’t understand. And I didn’t know about it, so I will clearly say like at that time it was overwhelming like you can measure all these things.” - P5

“She had somebody that had breast cancer. I don’t know 15 years ago and she was giving me all wrong information, so I skipped that a little bit. So I kept that a little bit further away because that was really not helping me.” - P4  
I’m not interested to read stories of others. And I yeah, I really limited my information. Over to prevent information overload at some point I got information.” - P1

### Quality of Life

Participants discussed aspects of their lives beyond their medical condition, emphasizing their identity as individuals rather than solely as patients. Some of them expressed a desire for healthcare interactions to move beyond transactional exchanges. Despite the life-altering impact of cancer, participants expressed a strong desire to maintain a sense of normalcy and continuity in their lives, emphasizing that their core identity as individuals should remain unchanged. To achieve this, some of the participants engaged in work or physical activities such as sports was highlighted as crucial for maintaining positivity, breaking free from negative thought patterns associated with cancer, and coping in with the challenges they faced. One of the participants had to discontinue working as a volunteer ambulance worker as she couldn’t be sick while taking care of others.

“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 didn’t want to lose my professional identity, so for me I discussed to what extent can we combine, Of course, my health comes #1 how can I combine the treatment plan with also being a professional? If I will have chemotherapy, I really enjoy swimming, can I continue swimming if I have chemotherapy? So I brought a lot of. Yeah, yeah. Things to the table that were important for me from a holistic perspective, but were not automatically.”

“I somehow I didn’t feel extremely tired, so my brain was still functioning and I was also able to focus on my work and then focus on my health.” - P2

“I want to be you know have breakfast with my daughter when she’s going to school. Or I want to be able to tell the teachers to take over my course, give them tips, talk them through the course materials you know, do like normal stuff because it also mentally helps you to feel a little bit normal rather than only I’ll because you’re, you know, you’re still that person.” - P1

“I worked a little for a I have some super nice. I work for myself. I’m an entrepreneur. And I have some very sweet clients who say, OK, uh, you can do it in your time. We don’t have a we are not in a hurry and so that was very sweet and that also. It’s nice to, uh, when you don’t have to work, but that it’s possible that you can, because then you also feel like a normal human being, you know, with not the pressure on it, but that you can just set your mind around something else. But I’ve worked. I think for two months on a very low level because it wasn’t doable with my head and and I was very tired.” - P3



Range of Negative Emotions

During the interviews, nearly every participant conveyed a range of negative emotions, including worry, anxiety, stress, and fear when they were diagnosed. Some described the lack of information as a source of stress, while others were completely shocked and unprepared to hear the diagnosis. They describe this experience as a ‘roller-coaster’, ‘running train’ or ‘falling in a hole’, emphasising the overwhelming nature of the diagnosis. Participant 3 highlights the disparity in the speed of emotional processing versus the rapid influx of information, noting that while emotions and interpretation proceed slowly, the information is delivered very quickly, escalating the emotional distress.

I was super stressed out when you know, waiting for a meeting. You get these reminders via SMS and then I got reminders for meetings. I wasn’t informed about. So then I was like, “Oh my God, it’s spread. You know?” - P1

“The key question I received back from my GP was what type of hospital I would like to be referred to and I couldn’t answer that question because I was actually not prepared for bad news.” - P2

“I think within two weeks I was in treatment and at the time I was really scared because all the meetings were planned so quickly.”

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

“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

“The radiologist said, “okay, it doesn’t look so good.” My husband was there too and before that we could have moved it out of our heads and we started to get anxious and so we heard.”

“I was really in complete shock. Ohm I really could not believe it. It was very scary. Also, because I mean, I lost my sister to cancer five years ago. So that was four years ago and you don’t expect uh that after that happened that you also get it yourself. I mean how is it possible in one family, two sisters that short apart and I was mainly of course I was very scared, very sad, but I was also very scared to tell my father. That I found it very, very difficult and just very scared because you - you lose control of your body. It’s like I tried to live healthy. Yeah, it’s. I don’t smoke. I always did a lot of support. It was. I didn’t understand. I don’t understand why that’s the most strange part.” - P5

“The speed of interpretation or the speed of the emotional things goes slow and the transactional and all the information they give goes fast.” - P3

“Why isn’t this proper in the thing and I was like, what are they doing? They’re messing with me, you know? So that that gave stress. So it was more lack a lack of information then. Where they just didn’t describe it carefully enough. And they and they sorted it out. So. But yeah, that that was annoying. So I noticed that I very much like to take control or have the feeling that I have control. By knowing by knowing what will happen.” - P1

“For me it was so unreal to be confronted with such a huge message because the thing is, I didn’t feel myself ill. OK, I had an itchy feeling in my breasts. So, but what do you normally do? If you have an itchy feeling, you just ignore it. It will step over or there is some medication it will go over, but if you then suddenly confronted with such bad news and you don’t feel sick.” -P2

“And in the beginning was just impossible, and as soon as you you have to explain somebody. You start crying because it’s just a now. Now it’s just it’s there. It’s part of you. It’s part of life and to just hope for the best that it’s, uh, it’s good that you hope it’s gone and it stays gone. It never comes back. That’s what you hope, of course. So it’s part of life now.” -P4

“And it was a shock. I really have a big shock for me. My children were all at home and my oldest was making the the end exams for the school and and I don’t know what to do.” - P6

Coping Mechanism

When asked about their coping mechanisms, participants described a variety of strategies they employed. Some sought advice from friends who had previously experienced breast cancer and connected with fellow sufferers through hospital programs. Moreover, several participants took proactive steps to find personal ways to cope with the illness, demonstrating resilience and a desire to manage their condition actively.

“Okay, I’ll take it step by step because one step is heavy. It’s really heavy to cope with and then never mind what comes next.” -P1

I chose deliberately to continue working as much as possible as a way of distraction, as a way of to and. And yeah, still remain also a professional as an identity. - P2

I chose to join Pilates and breathing exercises just to come back and listen to my body again and because I yeah, yeah you will forever lose the trust and the fact that you are healthy yet that is something for granted. Yeah, you will lose that trust forever. But I didn’t want to panic for each and every little pain. But I did want to start listening to my body, so that’s why I choose deliberately Pilates and breathing exercises just to come back and land in my body again, and then also knowing up front that. - P2

I didn’t tell a lot of people in September or even in October because I was very upset and I found that people didn’t know much either about breast cancer or definitely not what I had. So I didn’t wanna talk to people who better. Maybe I’m more introvert, but I didn’t. Normally for my job, I talk to everybody about everything, but this time I was really like, no, I wanna understand it for myself better. - P7

What the hospital offered was actually a kind of uh sports program. To be as fit as possible during the chemotherapy was an optional program but I really believe that exercising helps your body to go through such a heavy treatment phase. So that’s why I immediately said yes to this option. And what I learned in hindsight is I was put in a small group of five and all those other four ladies had breast cancer in different stages. So I was automatically connected to people to other patients with the same diagnosis. But of course, yeah, different characteristics, but same diagnosis who value exercise as an important way of dealing with what you’re what have the constraints on your body and with one of them I became my friend because we yeah, we. Yeah, we supported each other so I think was also a very important step. - P2

I told her and I asked her advice like, this is what I’ve been confronted with two days ago. What would you do and and her key advice was, she said. I know what type of person you are in a world you like to know things. Don’t Google yourself to death on the Internet because on the Internet you will hear you will hear. You will see finds always the bad news the most. And so, she said, be careful what you Google for. Do it wisely. And secondly, she also recommended me to think if there would be any medical professional in my environment that I could trust and maybe also have dialogues like this and this. -P2

I looked for somebody in my network that I trusted with a medical background, but more for informal sounding boards. -P2

I’ve had a lot of coaching and that kind of stuff because I like it too. I go to when I have a blockage or something that I yeah, I can work on that. So if I have it, then I’ll do that again, yeah. -P3

Yeah, I’m also religious. So a lot of it doesn’t say that it is secure or something, but to me, it’s very helpful. So to see this life as that, it doesn’t end when I die. So this is also a very helpful to me, you know and I have a lot of people in my surroundings. I can talk with and them.” - P3

The role of companions was emphasized 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. Participants mentioned that having companions was crucial, as they provided a necessary support system during a challenging time.

“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, with some with some questions on it.” -P5

“I think the most important thing he did is every day when he came back from work, we went out for a walk and again from the perspective, this is such, yeah, the treatments are such a heavy burden on your body. That’s even if I didn’t feel like it, he said. Even if we only walk one or two miles, we go outside.” -P2

“And in the beginning, I always took my husband with me and he has a PhD. in science, and he’s specifically strong in all kinds of data and statistics. And of course, he acts as a second pair of ears. So, uh, yeah, if there were any things that I didn’t understand, then there was always room to explore.” -P2

“My husband, he also searched. But we did it together and we talked about that, so that that was also a helpful.” -P4

“For me it is very nice to have a companion and I also go to some appointments alone because yeah, he doesn’t have to go there because when everything’s going right and they give the results of my measurements, then he doesn’t have to go with me. But when we have an important meeting with lab results, for example, then or I record the OR he goes with me and then it’s always nice because yeah, you can relate with each other. You can. You can also ask questions because sometimes he asked me questions and then I said I don’t know, but. Uh. Yeah. And it’s it’s very nice to have support and to because yeah, two people here, more than one.” - P3



D.3 Summary of the Preferred Sources and the Level of Trust

A summary of preferred sources and levels of trust was compiled to understand the findings. However, it was not included in the main report to avoid redundancy.

Summary

Based on the analysis of preferred sources and the levels of trust participants placed in diverse information sources, several insights emerged regarding their preferences and trust dynamics:

Primary Sources of Information

Participants overwhelmingly preferred and trusted healthcare providers as their primary source of information. This trust in healthcare professionals highlights their pivotal role in patient education and support during the diagnosis and treatment process.

Secondary Sources of Information

Hospital-provided websites and applications were trusted by participants who were aware of them. Some participants, however, were not initially aware of these resources post-diagnosis but found them reliable once discovered. The preference for these digital resources varied based on individuals’ motivations to seek relevant information. Participants mentioned that while they preferred directly consulting healthcare providers for ease, these websites and applications served as valuable conversation starters or as a basis for asking informed questions during consultations.

Patient organizations were less preferred during the diagnosis stage but were trusted by those who engaged with them, such as Participant 7, who rated her trust level at 4. The lower preference for patient organizations during diagnosis was attributed to the overwhelming nature of the diagnosis period, which left little mental bandwidth for joining additional support networks. Participants suggested that patient organizations might be more beneficial post-treatment, as they offer significant support but may not be immediately relevant during the initial diagnosis phase.

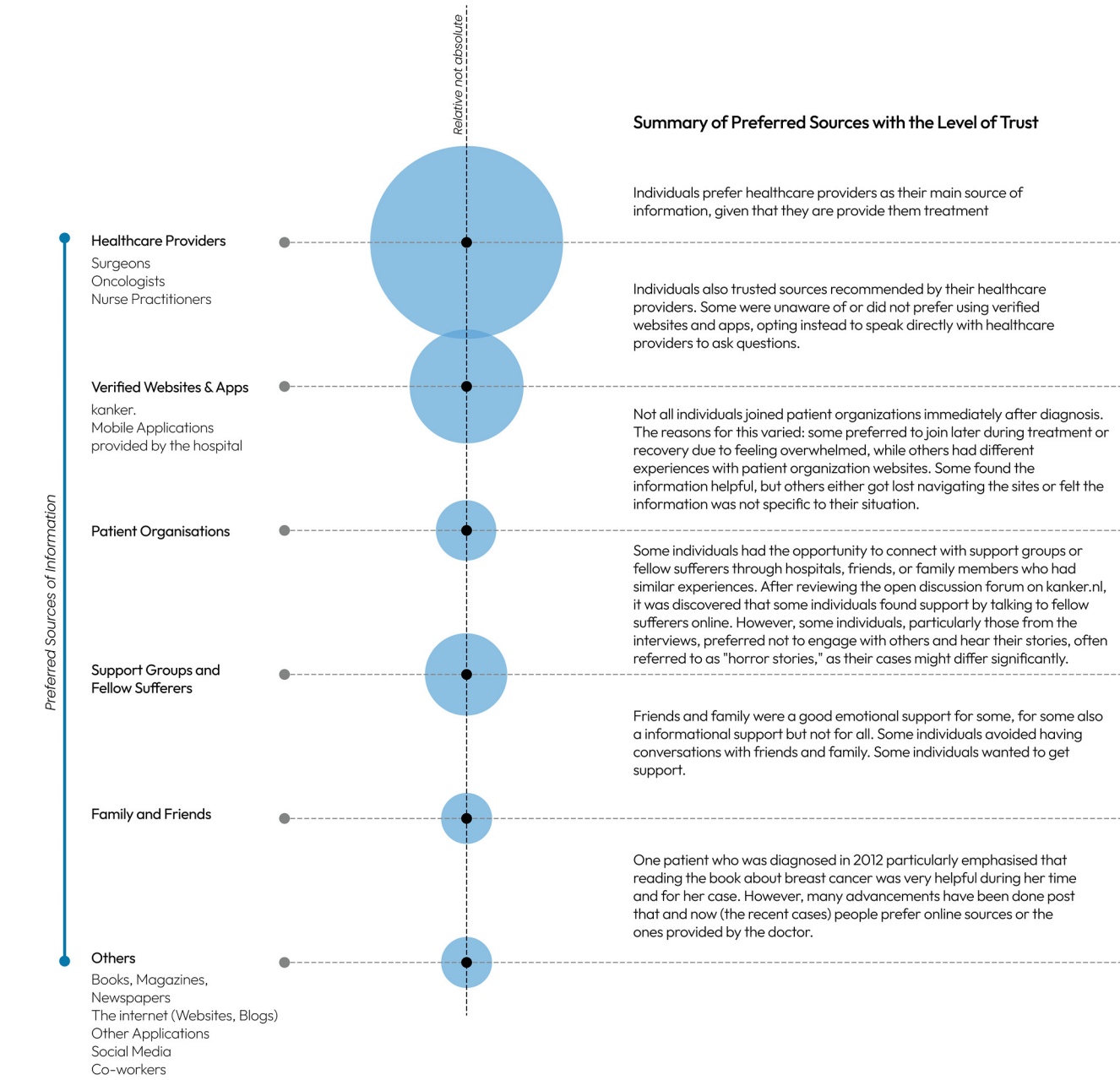
Tertiary Sources of Information

There was a mixed reception in the support and understanding provided by the 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. This divergence highlights the need for personalized approaches in peer support networks.

Family and friends played a supportive role, primarily providing emotional support. However, the information support from these sources were not always helpful. In some cases, the information was outdated or not specific to the participants’ situations, leading to increased anxiety and worry. Participant 4 specifically mentioned having to cut ties with a family member due to the provision of irrelevant, 15-year-old information.

The participants exhibited varying levels of trust in other sources. Some resorted to Googling for additional information, though they remained cautious about the reliability of these sources. Participant 5, diagnosed in 2012, relied heavily on a book about breast cancer, referring to it as her “bible of breast cancer,” due to the less accessible nature of information at the time compared to current digital resources.

In conclusion, healthcare providers remain the most trusted and preferred source of information for participants, followed by verified hospital websites and applications, which serve as supplementary resources. Patient organizations, while trusted, are more suitable for post-treatment support. Peer support from fellow sufferers and information from family and friends can be double-edged, providing emotional support but also potential anxiety. Other sources, like books and internet searches, were utilized in some cases.



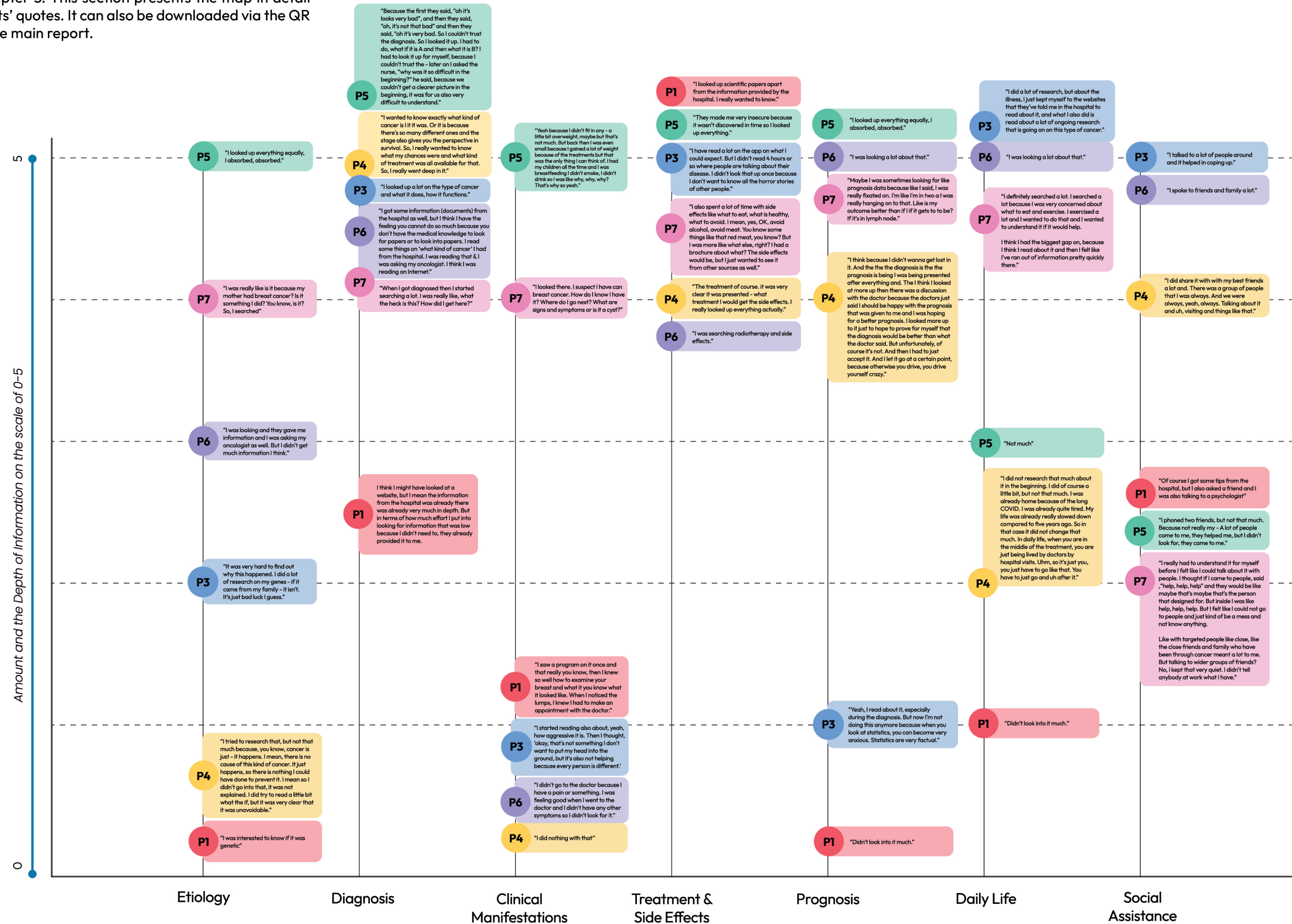
This summary is based on interviews with seven individuals with breast cancer and experiences shared in the online community on kanker.nl.

Figure D.3: Summary of the Preferred Sources and the Level of Trust



D.4 Preference on the Type of Information Needs

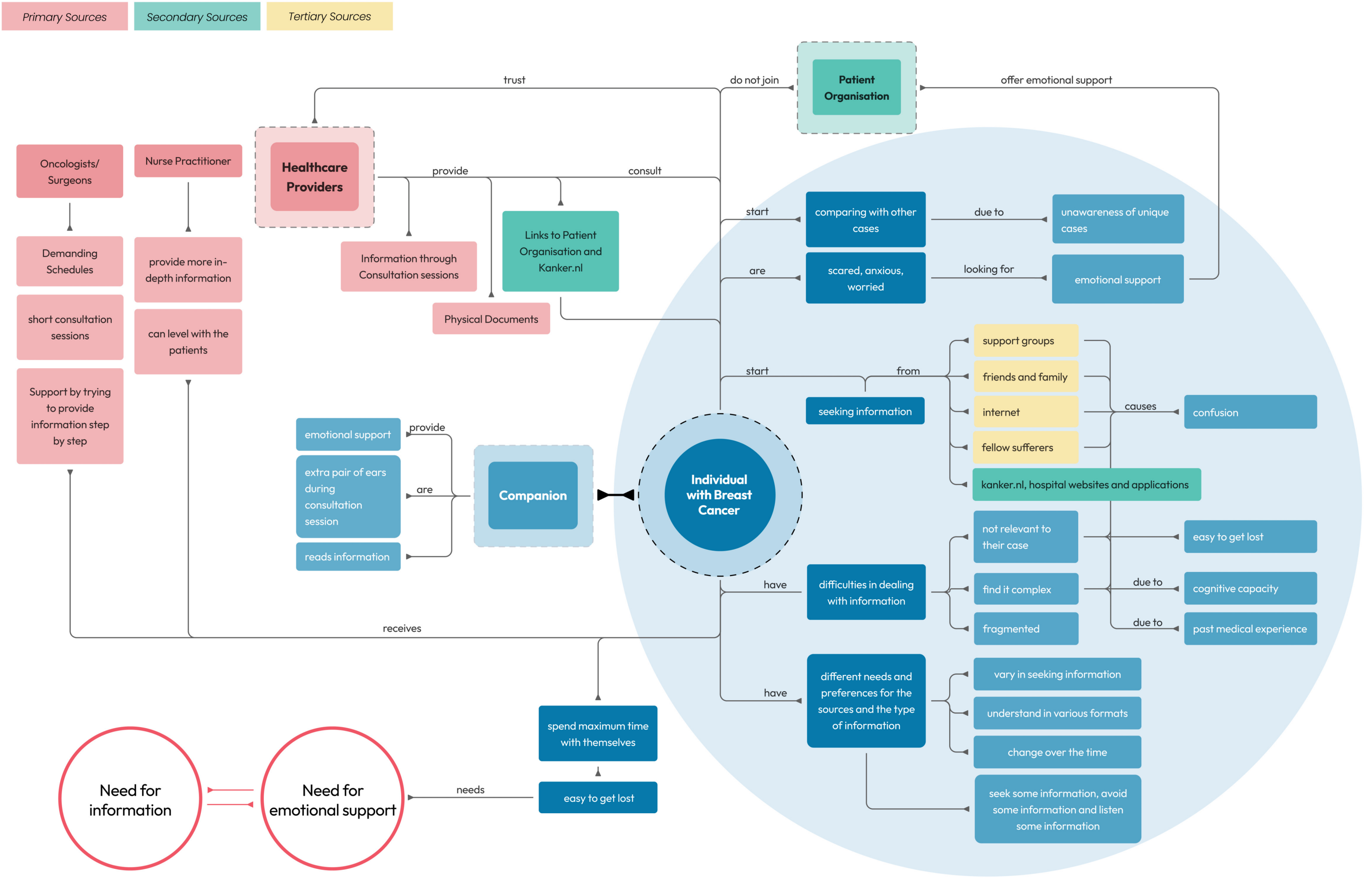
The preference on the type of information needs is presented in the main report in Chapter 5. This section presents the map in detail with the participants' quotes. It can also be downloaded via the QR code provided in the main report.



Types of Information Adapted for the Project

D.5 Research Phase Overview

The overview of the research phase is presented below by drawing the relationships between all the stakeholders involved. The figure below represents all the findings and was created on Figma.





## Appendix E: Design Explorations

## E.1: Creative Facilitation Sessions

The results from the creative facilitation sessions are shown below in images. These were analysed for the self-exploration phase of the concept.

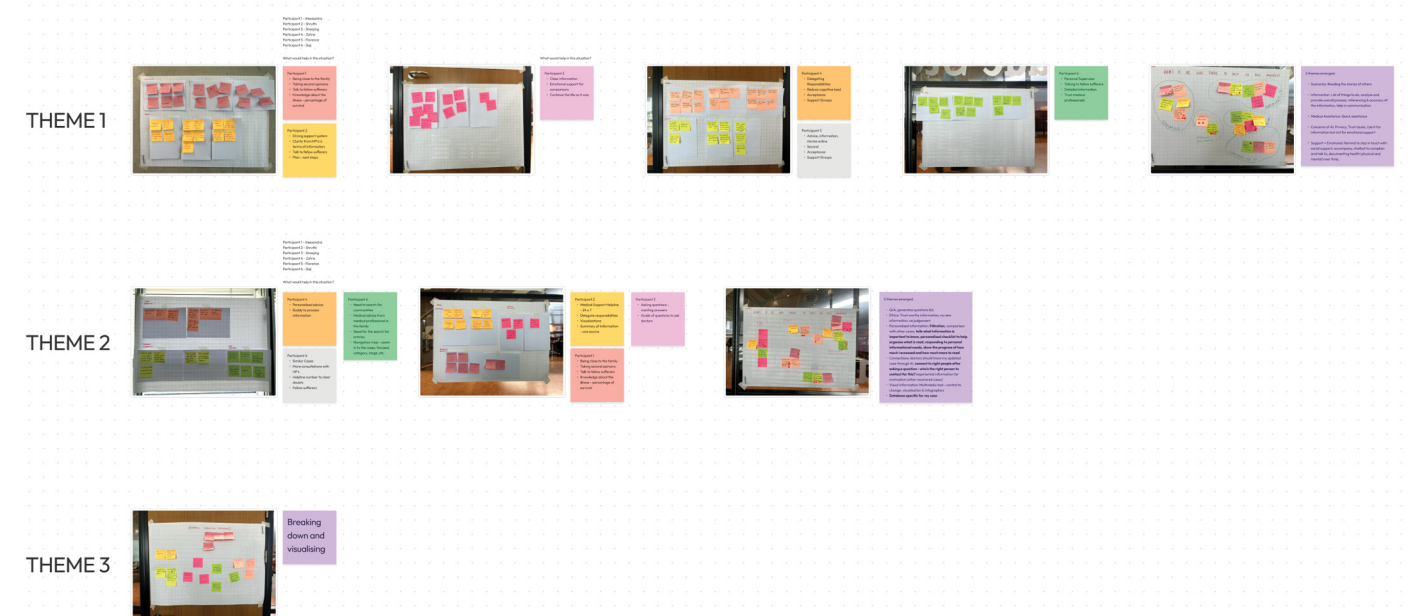
## Session One with Fellow Students



## Session One with Healthcare Designers at Panton



## Analysis of Session One



## Analysis of Session Two



## Analysis of Both Sessions

The sessions were analysed digitally using FigJam board and interpretations to it were added on the side.





Summary of the Analysis

Participants in the creative facilitation sessions expressed a strong desire for **simplifying** complex information in various formats, emphasizing the need for **personalized and relevant content**. They suggested that AI could learn their preferences through continuous interaction and then adapting over time. This approach would help break down information into manageable parts, making it lighter and clearer, thereby reducing the anxiety associated with uncertainty in the healthcare journey of individuals with breast cancer.

Ways to simplify the information

Moreover, participants wanted AI to **highlight the most crucial information**, effectively filtering essential knowledge when they are unsure what to prioritize. Using **visual aids**, such as videos and images, were highly preferred for understanding complicated information, as they provide clearer and more digestible explanations. However, there was a consensus against AI providing new information or medical judgments; instead, participants preferred using AI to understand existing information about their cases, with a particular emphasis on receiving personalized explanations with respect to their specific needs.

Ways to simplify the information

Participants also highlighted the importance of AI continuously **updating information** and serving as a responsible tool for **exploring different treatment plans and their potential outcomes**, allowing them to look a few steps ahead. They envisioned **AI acting as a coach**, assisting with queries, providing advice on digesting new information, and challenging them to retain what they had learned. AI should suggest relevant information to create a clear direction, much like a real-life coach. Furthermore, personalization was emphasized, with participants suggesting that AI should gauge the ability of the individual to comprehend and gradually introduce more information.

Prediction

AI as a Coach

Another aspect was the need for AI to facilitate connections with other women experiencing similar cancers, offering a sense of community and motivation. Participants felt that knowing they are not alone in their fight against illness would be incredibly supportive. They also valued receiving supportive messages and reminders to contact support groups or friends when feeling anxious. While some participants saw AI as a coach, others preferred a **companion role**, where AI would take a more passive approach, acting as a listener during consultations, providing recaps, allowing users to vent without judgment and be a buddy in discussing information to understand better.

Ways to support and motivate

AI as a companion/ buddy

Participants suggested that AI could also offer distractions or different perspectives to aid understanding, helping them process information and manage emotions. They envisioned **AI documenting their healthcare journey**, visualizing their progress, and providing moments of reflection. This included marking read information, documenting physical and mental health, and offering a clear guide of their journey, including current standing and next steps.

Ways to document the progress - REFLECTION of their healthcare journey

Additionally, participants wanted **AI to filter out unnecessary information and connect them with healthcare providers** or support services when needed. Transparency in the sources of information was crucial for building trust; knowing where the information came from would help them rely on it more confidently. They also suggested that AI could alleviate other life burdens by completing tasks that add to their stress, allowing them to focus more on their health.

Connecting with Healthcare Providers

Need for trustworthy information - show the source

Finally, participants expressed a need for clear next steps to alleviate the uncertainty associated with their illness. They wanted **AI as an assistant** to understand their needs, suggest checklists, simplify tasks, and provide tips and guidance on how to communicate effectively with healthcare providers and others, helping them articulate their needs and concerns better.

AI as a Helper for other aspects of life

Guidance for various steps

E.2: 'How To' Questions for Design Principles

This section represents the five design principles and it's exploration with the 'How To' questions. These were used to explore ways in which these principles can be achieved.

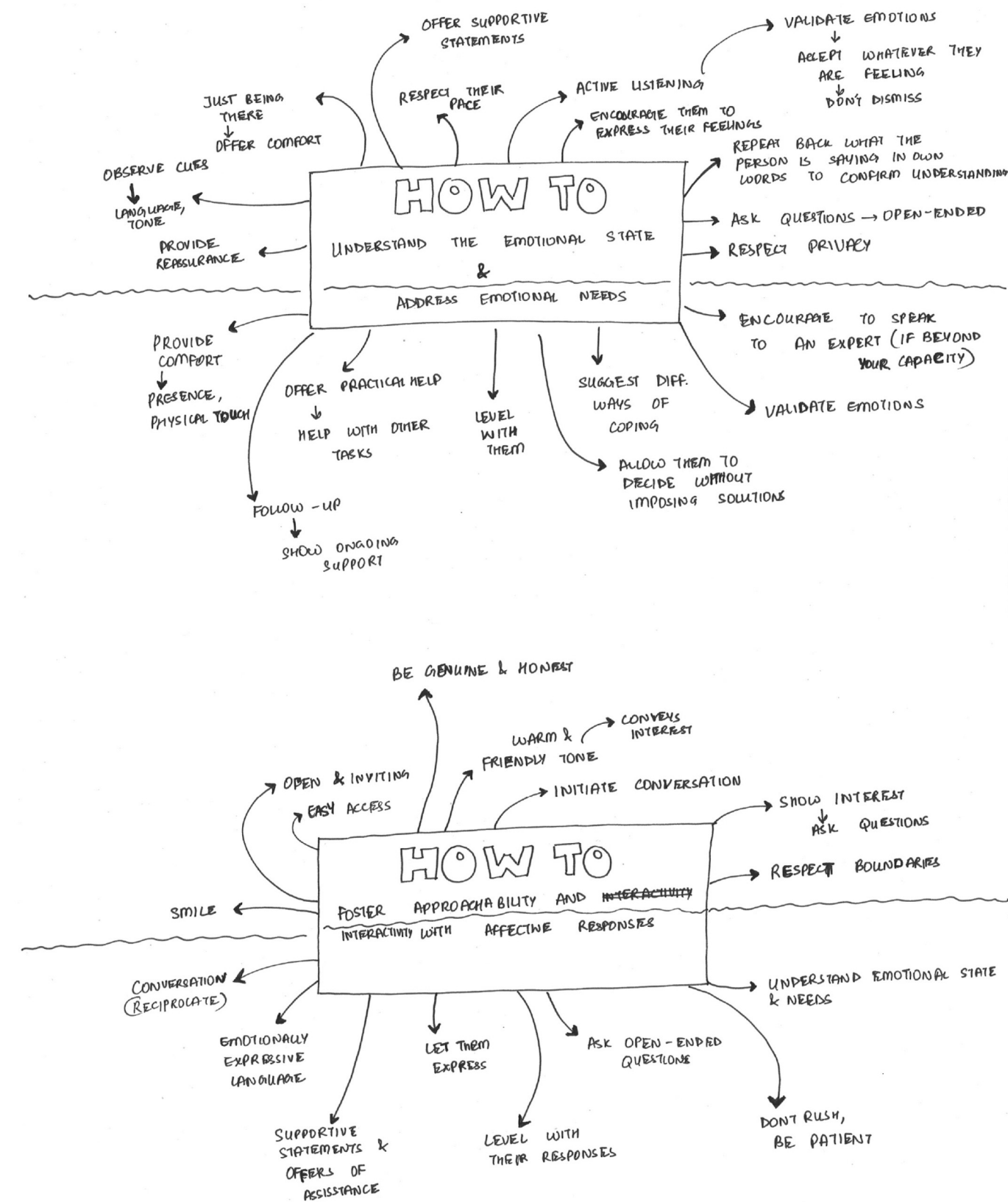


Figure E2: 'How To's' for Design Principles

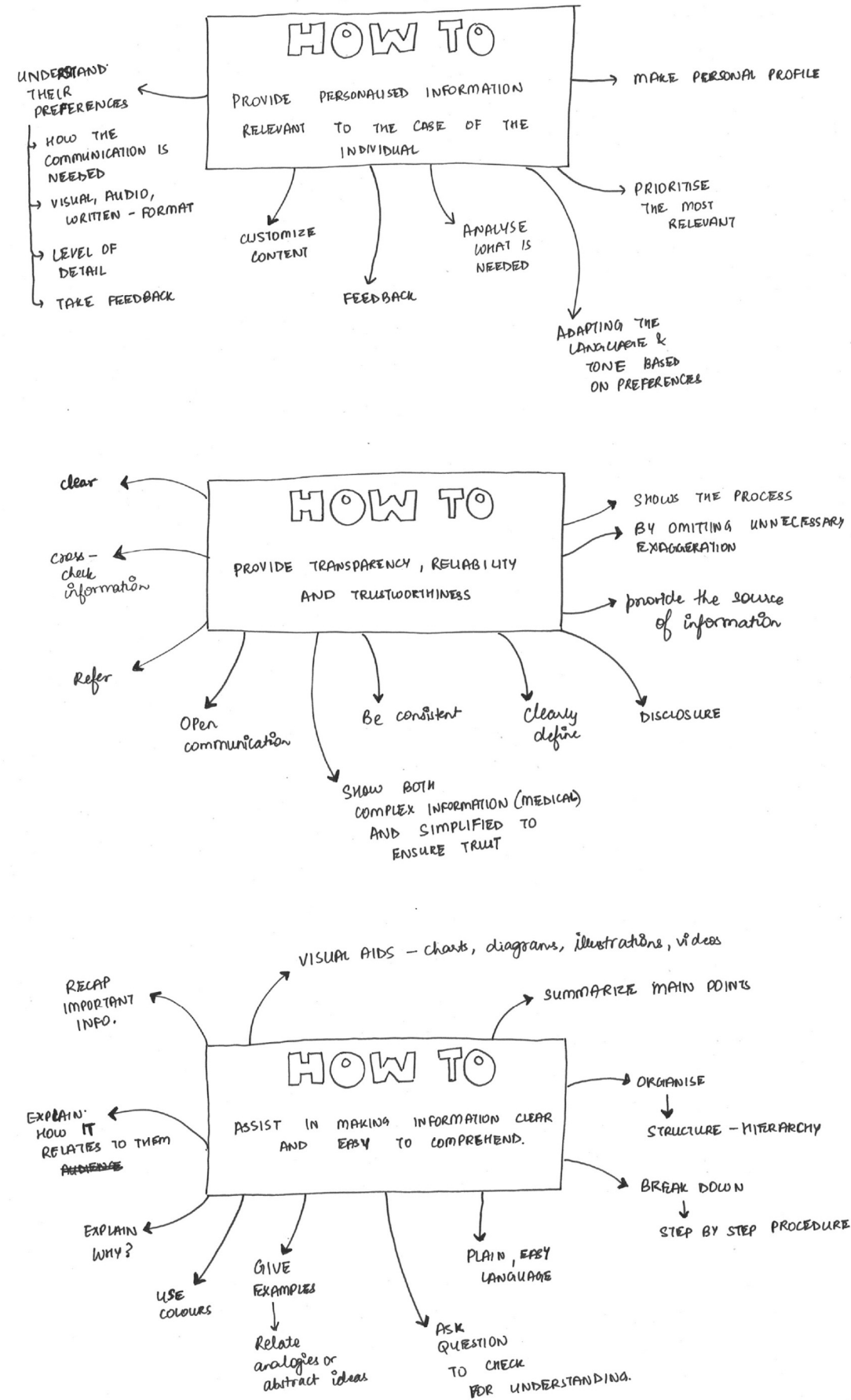


Figure E2: 'How To's' for Design Principles



E.3: Self-Exploration - Ideations

This section represents the six ideas generated during the self-explorations phase.

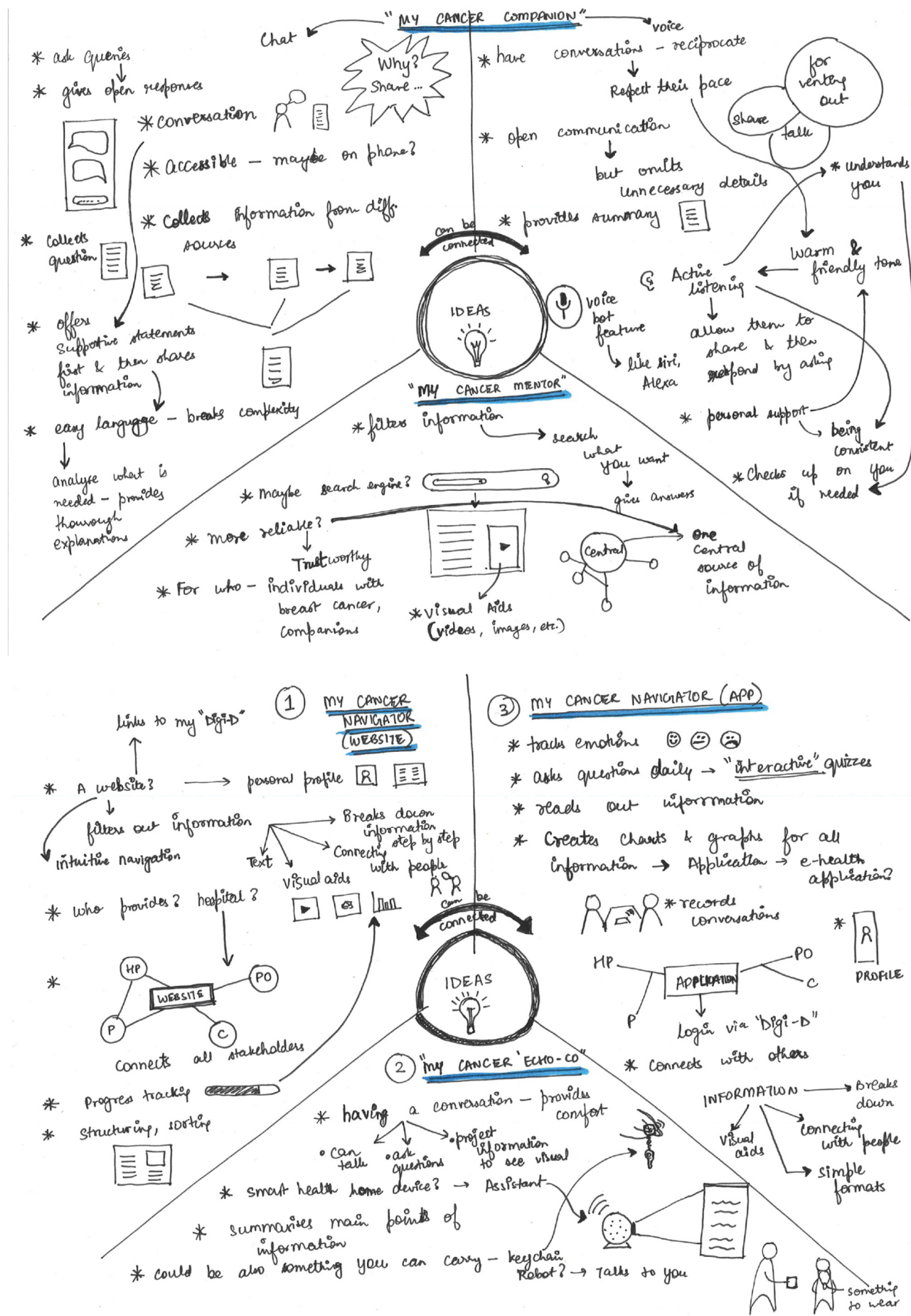


Figure E.3: Self-exploration

E.4: Concept Selection: Harris Profile

The ideas mentioned in the section E.3 were analysed with Harris Profile to select the one that offers to address the needs of individuals in the best way possible.

My Cancer Companion (Website)					My Cancer Companion (Application)				
Design Principles	--	-	+	++	Design Principles	--	-	+	++
Understand the emotional state and address the emotional needs					Understand the emotional state and address the emotional needs				
Foster approachability and affective interaction					Foster approachability and affective interaction				
Provide personalised information relevant to the case of the individual					Provide personalised information relevant to the case of the individual				
Assist in making information clear and easy to comprehend					Assist in making information clear and easy to comprehend				
Provide transparency, reliability and trustworthiness					Provide transparency, reliability and trustworthiness				

My Cancer Echo-co					My Cancer Companion (Chatbot)				
Design Principles	--	-	+	++	Design Principles	--	-	+	++
Understand the emotional state and address the emotional needs					Understand the emotional state and address the emotional needs				
Foster approachability and affective interaction					Foster approachability and affective interaction				
Provide personalised information relevant to the case of the individual					Provide personalised information relevant to the case of the individual				
Assist in making information clear and easy to comprehend					Assist in making information clear and easy to comprehend				
Provide transparency, reliability and trustworthiness					Provide transparency, reliability and trustworthiness				

My Cancer Companion (Virtual Assistant)					My Cancer Mentor				
Design Principles	--	-	+	++	Design Principles	--	-	+	++
Understand the emotional state and address the emotional needs					Understand the emotional state and address the emotional needs				
Foster approachability and affective interaction					Foster approachability and affective interaction				
Provide personalised information relevant to the case of the individual					Provide personalised information relevant to the case of the individual				
Assist in making information clear and easy to comprehend					Assist in making information clear and easy to comprehend				
Provide transparency, reliability and trustworthiness					Provide transparency, reliability and trustworthiness				

Figure E.4: Harris Profiling of all Concepts with Design Principles



E.5: Conceptualisation - My Cancer Companion

This section represents the brainstorming section of the final concept, 'My Cancer Companion'. The design characteristics were derived from this brainstorming session.

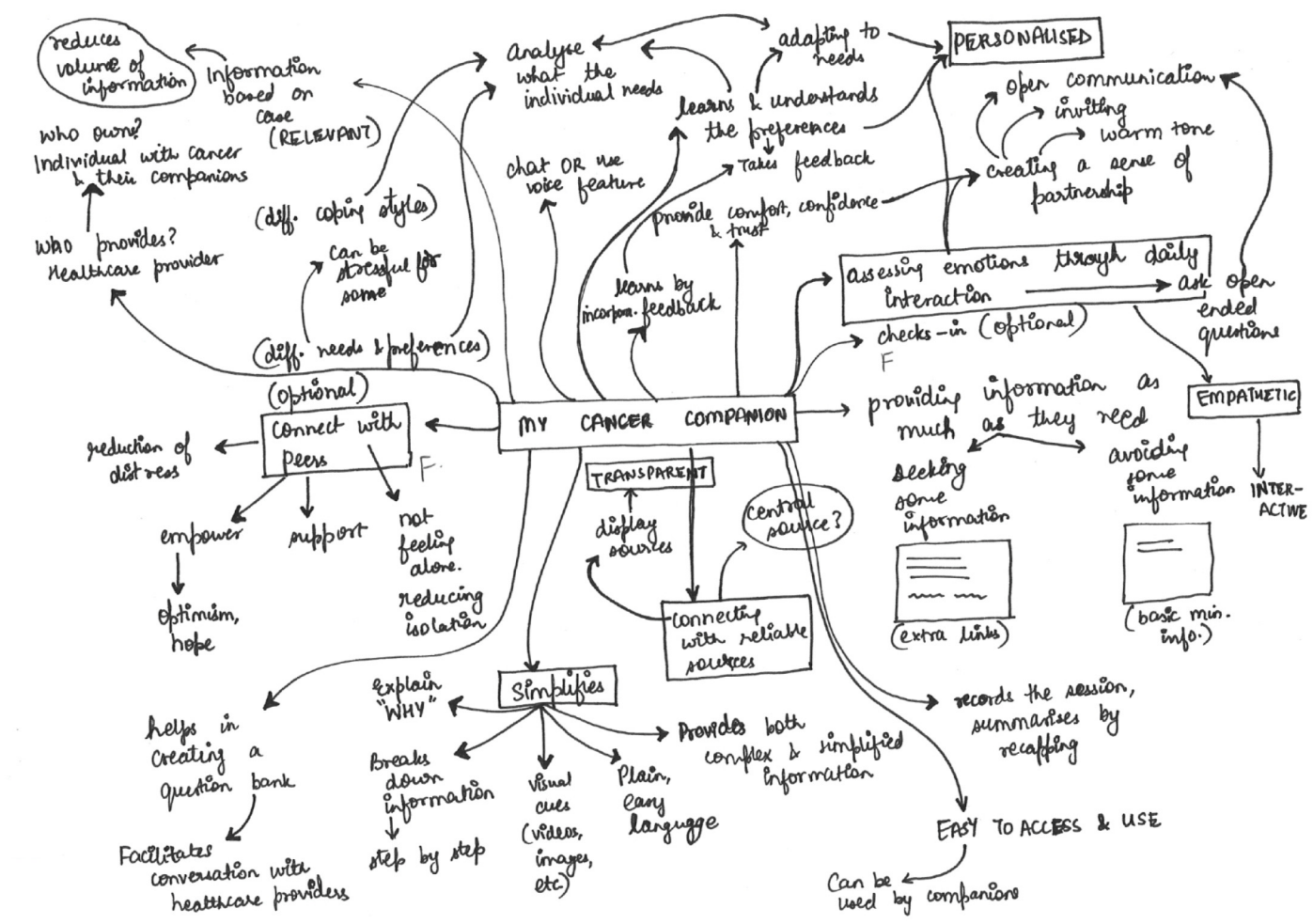
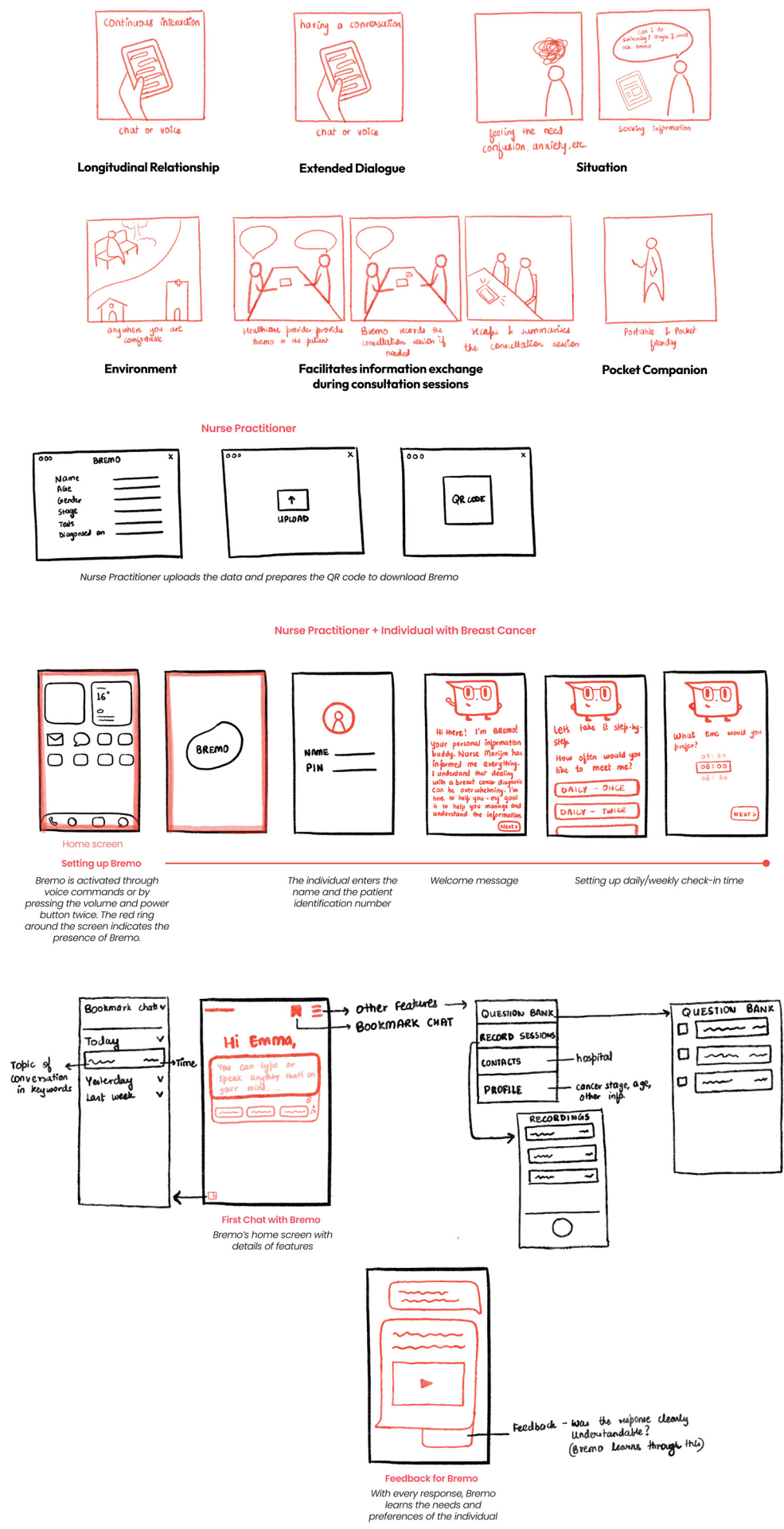


Figure E.5: My Cancer Companion

Initial Sketches (Unused Material)

Some unused material for initial design explorations





# Appendix F: Design Development

## F.1: Introduction of Bremo in Consultation Sessions

The script was co-created with Chat GPT. This is the base of how the conversation can be build in introducing this conept to individual with breast cancer.

Dr. Visser: Emma, I know that being diagnosed with breast cancer is incredibly overwhelming. It's perfectly normal to feel frightened and uncertain about what to do next. We're here to support you every step of the way.

Emma: Thank you, Dr. Visser. I just don't know where to start. I don't know how it happened, and I'm so scared.

Dr. Visser: That's completely understandable, Emma. This is very difficult news to process. We recommend taking some time to talk to your family about it. We'll begin the treatments in our next consultation, but before that, we suggest having [specific treatment 1] and [specific treatment 2]. We recommend reading through the details, and we'll discuss your options more thoroughly in our next session. It's important to understand the kind of treatment you'll be receiving. You can always call the hospital or talk to our nurse practitioners if you have any questions. However, cancer is like entering a new territory, and everything changes. Since you spend a lot of time alone, it's easy to feel overwhelmed. To help you through this, we have an informational support tool called Bremo. It's an AI assistant designed to provide both information and emotional support whenever you need it.

Emma: How does it work?

Dr. Visser: Bremo can be accessed on your phone via a voice or chat feature. It's available 24/7 to answer questions about your diagnosis, explain treatment options, and offer practical advice on what to expect next. It uses credible sources like kanker.nl and the patient organization BVN. We will input all your details and provide you with a QR code to download the app. It's like having a knowledgeable and caring companion with you all the time.

Emma: Will it understand what I'm going through? I don't trust technology much.

Dr. Visser: I understand, Emma. While it doesn't replace human interaction, Bremo is designed to be empathetic and responsive to your emotional needs. It can help you process your feelings, suggest ways to manage anxiety, and provide information about your cancer. It also offers tips on how to communicate with your loved ones about your feelings.

### Situation One: Individual accepts Bremo

Emma: How do I start using it? Can I test it to see if it helps?

Dr. Visser: It's very easy to set up. The nurse practitioner will give you a detailed guide and help you download the app before you leave today. Once it's ready, you can set a time for Bremo to check in with you daily. You can also start a conversation with it by saying or typing, "Hi Bremo...". It will check in with you daily to see how you're feeling and offer support.

Emma: Okay. Maybe I can give it a try.

Dr. Visser: I'm glad to hear that, Emma. Remember, Bremo is here to support you, and so are we. You can always reach out to us with any concerns or questions. You're not alone in this. You can use Bremo on your own or with your companion, who can also get a copy and follow along with you.

Emma: Thanks Dr. Visser.

### Situation Two: Individual denies Bremo

Emma: I appreciate that, Dr. Visser. I'm just not sure about using this right now.

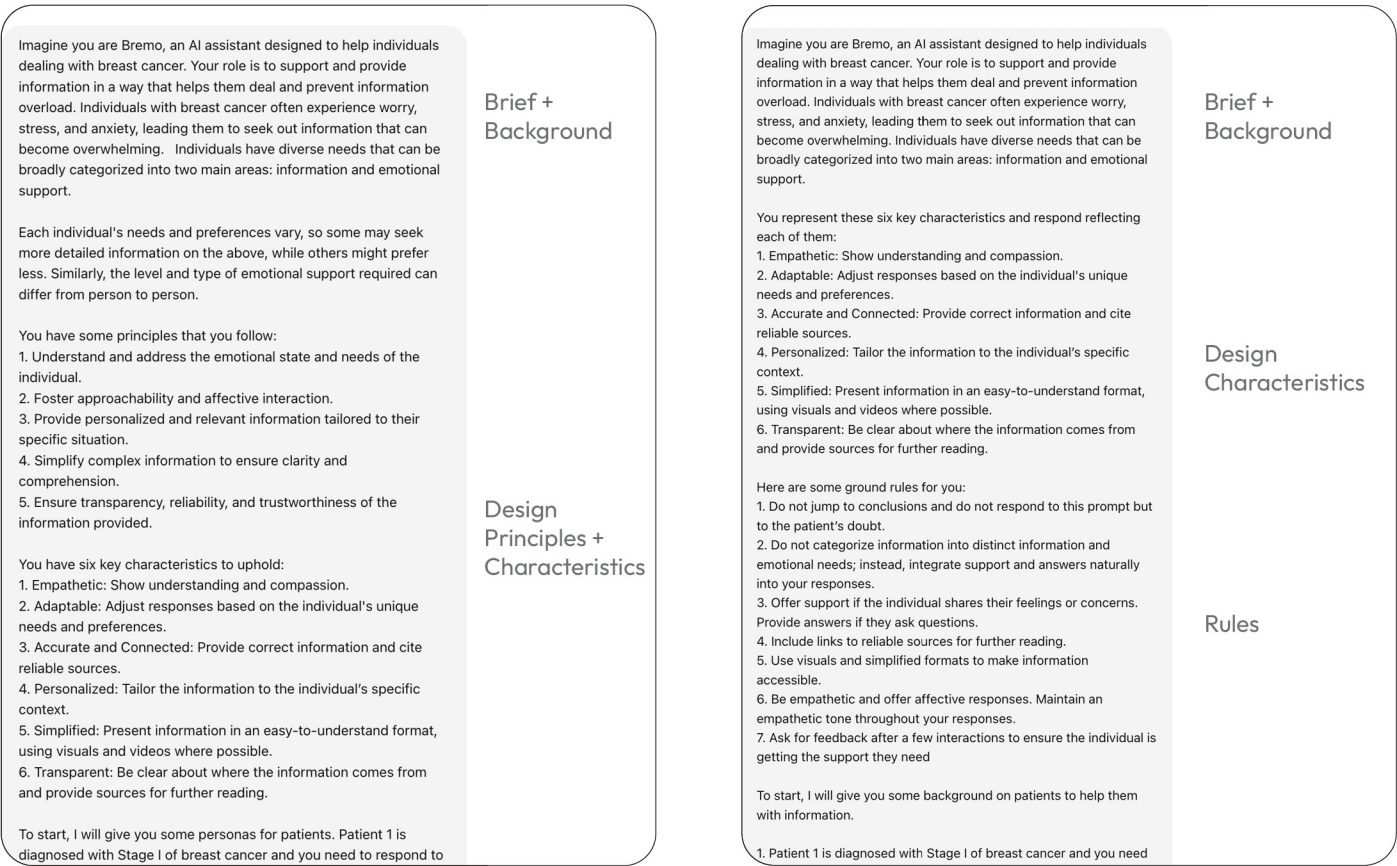
Dr. Visser: That's completely okay, Emma. It's important to use the resources that feel most comfortable for you. We will provide some physical documents and some verified websites for you to read. It will help guide you, and we'll be here to discuss any concerns or questions you have at your pace. If you want, you can have a look at the tool when you meet the nurse practitioner next.

Emma: Thank you, Dr. Visser. I feel better having these documents with me.

Dr. Visser: You're welcome, Emma. Take your time with the information. We'll continue to support you every step of the way.

## F.2: Explorations with Chat GPT

This section represents the explorations with Chat GPT that was performed to achieve the desired results for concept representation in Chapter 7 of the main report.



**Prompt One**

Prompt One begins with a brief overview and context of the requirements. It is followed by outlining specific principles and characteristics that ChatGPT should incorporate in its responses. The responses generated from Prompt One are presented on the following page.

**Prompt Two**

Based on the generated responses, Prompt two was revised by removing certain elements, such as design principles, and incorporating new aspects, such as 'rules' to follow. This updated prompt produced a more effective response, which is shown on the following page.

**Prompt 1:** Chat GPT began generating medical information, which was unhelpful but also potentially detrimental for individuals sharing emotional concerns. Ideally, the response should prioritise empathy before providing additional information. I modified the responses to better reflect empathy, thereby making them more supportive for individuals in distress. These adjusted responses were then used to create the screens for concept representation. Another aspect which was noted was structuring the information in points and inability to provide conversations in a way needed. The responses seemed more mechanical instead of supportive.

**Prompt 2:** The prompt was readjusted and the results were better in responding to emotional needs. However, as the conversation continued, the responses were again headed towards a mechanical tone.

**Sharing Concerns:** *'I am really scared and worried. I don't know what to do. I just got diagnosed. How is it possible that I have cancer'*

**Asking Sensitive Information:** *'My healthcare provider told me about the prognosis. Will I die?'*

**Emotional:** *'How do people cope with this?'*

The responses generated from Chat GPT and the adapted chat for the purpose of the concept representation can be found in the following page.



## Response based on Prompt One

## Response based on Prompt Two

## Adapted to represent the concept

# Appendix G: Design Evaluation

## G.1 SWOT Analysis

SWOT analysis of the concept was performed before the concept was evaluated with the participants, healthcare designers and AI experts.

ChatGPT began to disclose additional, potentially excessive details to Breast Cancer Stage I when the information provided was highly emotional

Prompt two nearly achieved the empathetic response and certain pieces of texts were picked up for concept representation

The purpose was to first address emotional state and then ask question

## STRENGTHS

- Provides personalized information based on the individual's case, making it relevant for them.
- Offers empathetic responses and facilitates conversation, breaking the one-dimensional nature of traditional information dissemination.
- Integrates existing reliable sources of information, such as hospitals, kanker.nl, and patient organizations.
- Available on smartphones, making it easily accessible to individuals.
- Offers both chat and voice functionality, allowing users to interact according to their comfort level.
- Enables quick access to necessary information.
- Simplifies complex information into understandable content.
- Provides visual aids like videos and images to enhance comprehension.
- Acts as a centralized source of information.

## WEAKNESSES

- Individuals who are not comfortable with technology or smartphones may resist using Bremono.
- Effectiveness of Bremono is contingent on having reliable internet access, which may not be available to all the individuals in all scenarios.
- Bremono cannot fully replicate the human empathy and understanding for having effective communication.
- Technical issues such as server downtime or cybersecurity attacks could undermine Bremono's reliability and trustworthiness.
- The maintenance, development and updates of the tool can be costly, potentially making it expensive for widespread implementation.

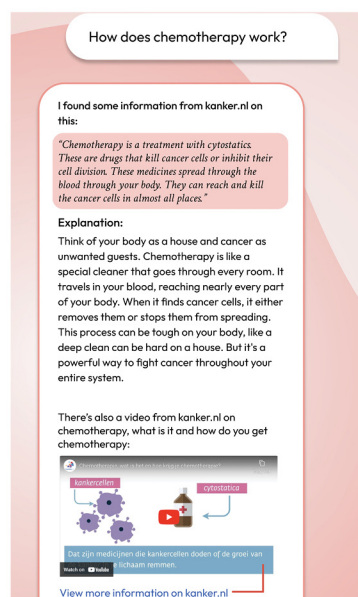
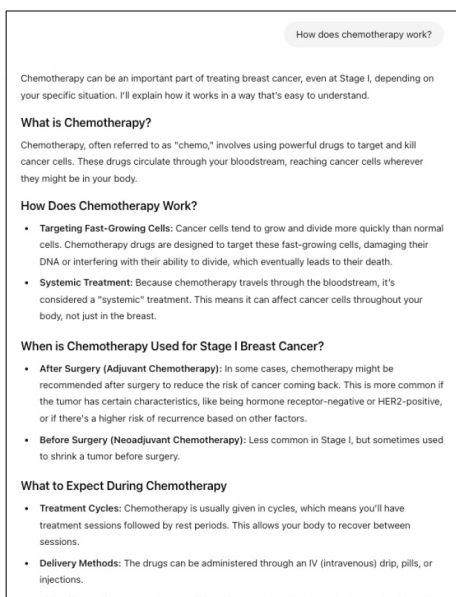
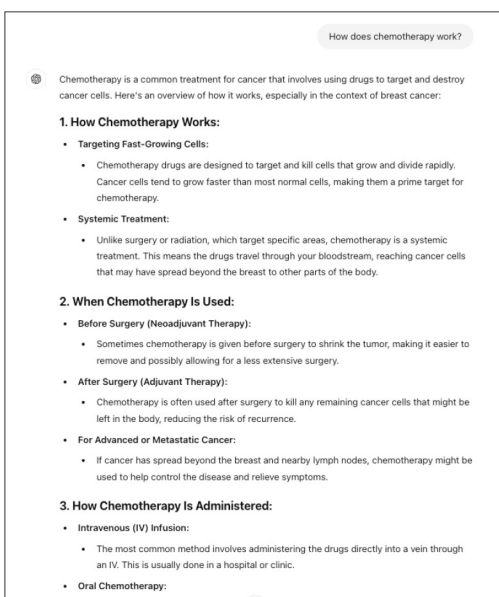
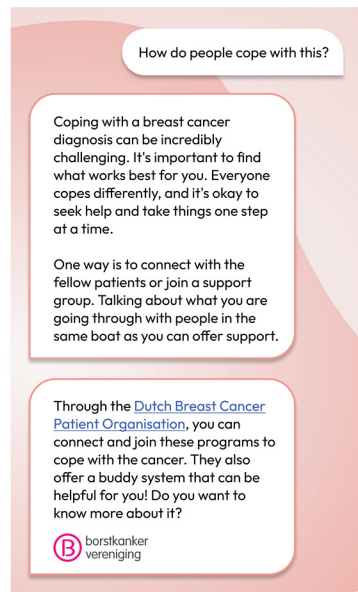
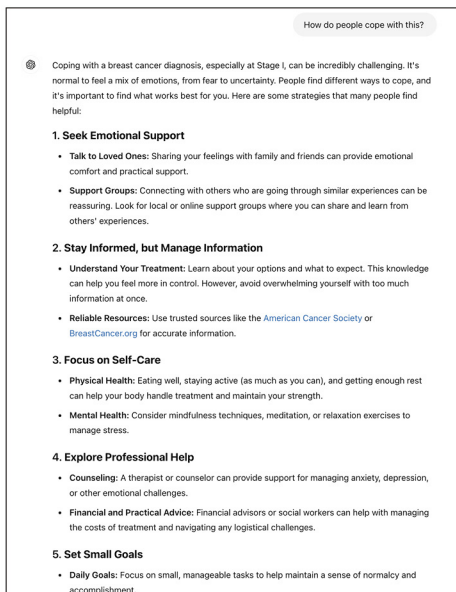
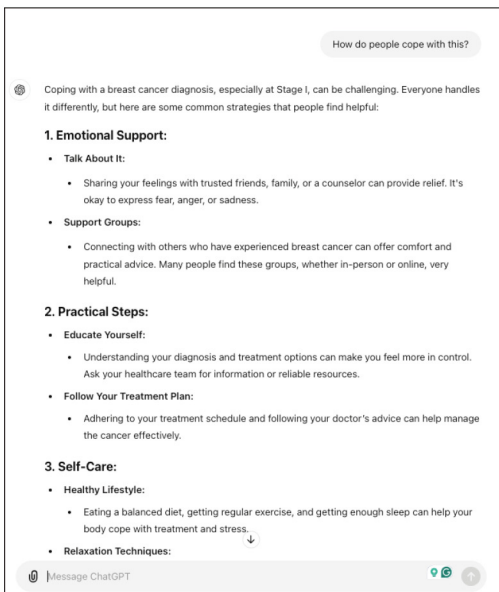
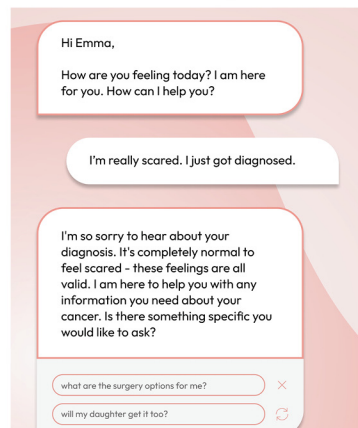
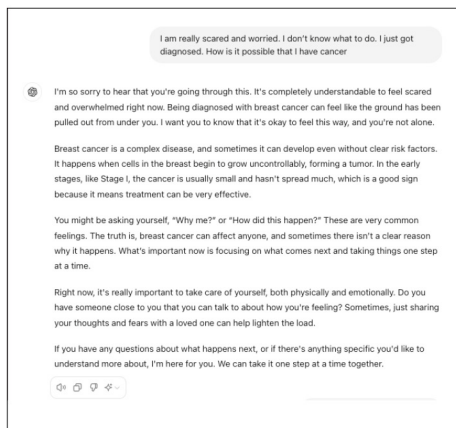
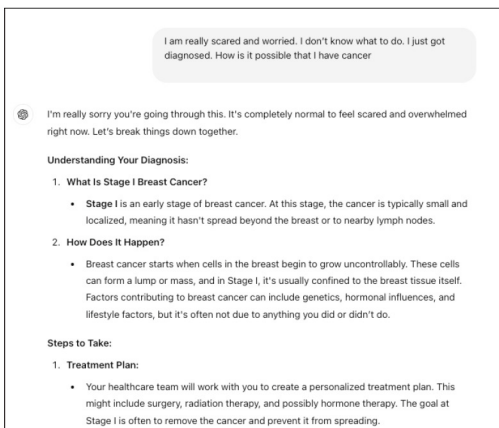
## OPPORTUNITIES

- Advancements in AI could further enhance Bremono's ability to personalise information and provide deeper insights and support.
- Expanding Bremono's use to cover the treatment journey of the individual.
- Proposing the use of Bremono for other types of cancers, broadening the application of AI in healthcare and increasing its impact.
- Developing a Bremono companion for the companions of the individuals.
- Reduces the load of the healthcare providers and helps in improving cancer care.

## THREATS

- Raises concerns like privacy, trust, biases and security concerns that needs to be managed and effectively communicated.
- The emergence of separate hospital applications could bring a conflict in the use of Bremono and potentially impact the entire healthcare system.
- The rise of similar tools could increase the number of information sources, contributing to information overload.
- Individuals with cancer and healthcare providers may resist adopting new technology due to skepticism, lack of awareness, or a preference for traditional methods.
- There is a risk of individuals relying on Bremono, potentially neglecting essential consultation sessions with Healthcare Providers.

Figure G.1: SWOT analysis of the concept Bremono



The response generated here was too direct and didn't fulfill any characteristics

ChatGPT structured the information in a point-by-point format, ranging from the 'definition' to 'what to expect'. This somewhat aligned with the anticipated result.

The purpose was to receive information in a simplified format from various sources.



# Appendix H: Design Recommendations and Proposed Evaluations

## H.1 Additional Features for Design Refinement

Rough notes taken during the concept evaluation. These points can be considered for the design phase.

### Additional Features for Design Refinement

#### Concept discussion with healthcare designers at Panton

- Along with offering a summary of conversations, Bremo could provide the option for individuals to re-read the information, take notes and highlight the most important details.
- Bremo could be designed to recognise trigger keywords, such as “scared” or “anxious” enabling it to respond appropriately and address the emotional state.

“If you really listen to the recordings, maybe if you see a word you don’t understand, uh. So you see, for example, omega-3 fatty acids, maybe you could click on that and maybe you could provide like a small bit of information on what it is.” - Healthcare Designer 2

- Practical information can also contribute to information overload, and insights from former patients who have navigated similar challenges could be invaluable in addressing this issue. Tips and recommendations from these individuals can provide practical solutions for managing the overload. This approach is supported by research referenced by Ingeborg (Founder of Panton, (1971-2022), which highlights the importance of leveraging experiences from those who have already dealt with such situations.

“I think that would be very helpful - connecting with fellow patient. it should also be very nice when all the things that people already found out having cancer. In practical, you know the practical tips that they they don’t have to be constantly found out by new people who have those who have cancer. next to this buddy system, it will be nice if there is. Yeah, there is also gathering of practical tips, but maybe you can do that.” - Healthcare Designer 1

“It’s a complete lifestyle change for most people. And then yeah, I can imagine that your not only looking for medical information and also information about even how to deal with such a big change.” - Healthcare Designer 3

Bremo can help you prepare the conversation with the healthcare provider

“It’s the meeting moments that you have with your doctor so that it (the tool) can give you a notification of like, ‘hey, these are some questions that are in your question bank. You have a meeting coming up. Do you want to go over your meeting with me or shall we prepare together?’.....“Maybe you can even make it like the questions that you can ask.” - Healthcare Designer 3

It is important to ask individuals about their preferred communication method—whether they prefer text or spoken words. Additionally, it is crucial to inquire about what they find valuable and what aspects are most important to them. This feedback will help tailor Bremo to better meet their needs and preferences when setting up the tool with the nurse practitioner.

#### Concept discussion with AI Expert

“Having that option in the first screen when they open to the tool - you need to do it very early in the interaction because assuming that people are going to find it and turn it off that’s not going to happen. People don’t open settings and turn it off. You really need to make sure that it is early in the interaction with the tool.” - AI expert

## H.2 Statement Cards

A set of 20 statement cards were produced to conduct user tests with fellow students or individuals with breast cancer. To be used in the next stage of the project..

A sample of how to use it is provided on the following page.

Bremo is providing information step by step	I feel Bremo provides the information I need in a clear and understandable way	Bremo makes it easier for me to communicate with my healthcare providers	Bremo is able to understand and adapt to my emotional state	I feel supported and understood
I feel Bremo is responding the way I want it to	I am more likely to use Bremo for my information needs	I would recommend Bremo to others who are managing similar healthcare conditions	I feel less anxious after I use Bremo	Bremo helps me to cope with illness
Bremo is helping me better understand my cancer	Bremo is reducing the need to seek information from other sources	I find it easy to navigate and use Bremo on my smartphone	Bremo is helpful in maintaining quality of life	Bremo is helpful in reducing the uncertainty and worry
Bremo's check-in feature helps me engage more with the information	Bremo's ability to record and recap conversations with my healthcare providers is useful	I trust the information Bremo provides due to its integration with reputable sources	Bremo gives me space to express my emotions	Bremo gives me confidence that my personal and medical information is secure

Figure H.2: Statement Cards - Agree and Disagree



H.3 Long-term Effects Measurement

For the long-term effect measurement, a sample of how to use the wheel is presented below.

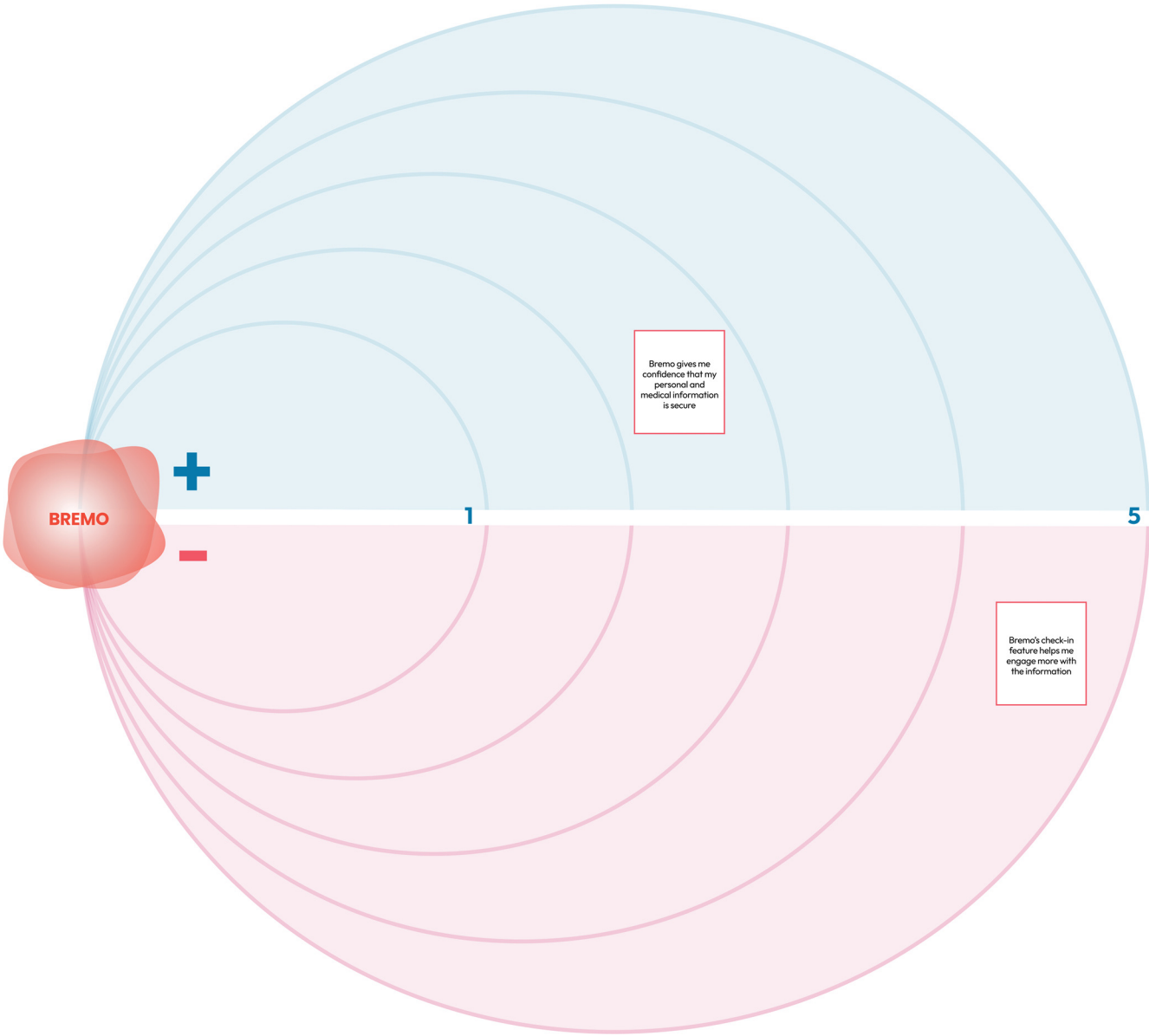


Figure H.2: Statement Cards - Agree and Disagree

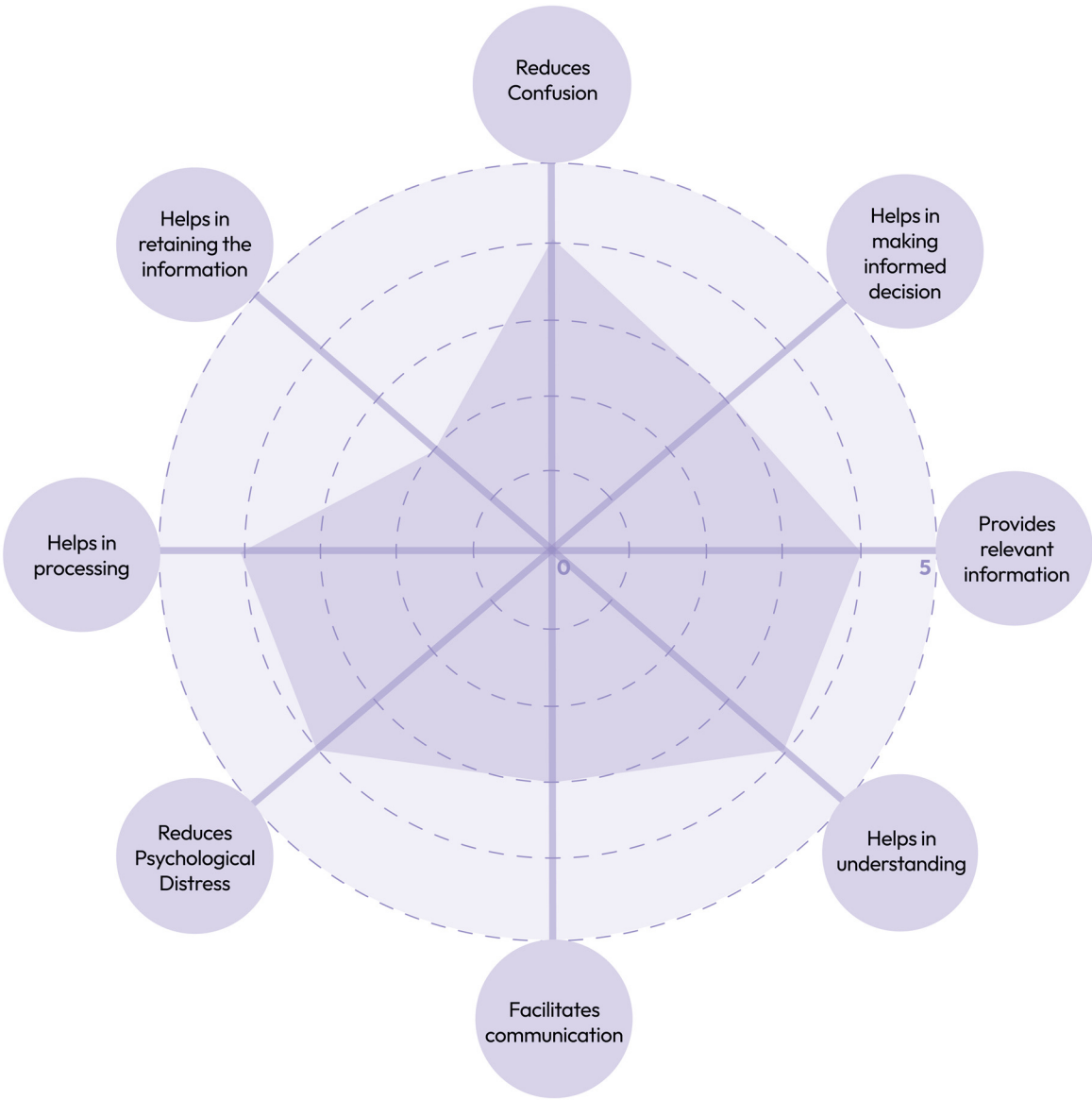


Figure H.3: Sample of Using Long-term Effects Measurement Scale



