SDAE

A toolkit for developing remote patient monitoring in social, daily activity and related emotion

A study in colorectal cancer patients during the follow-up phase in the Netherlands

Master Thesis Yingtao Sun August, 2023

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A study in colorectal cancer patients during the follow-up phase in the Netherlands

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0.1

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To all above and other people who have helped me, wish you all the best.

0.2

Abstract

Colorectal cancer is the third most common cancer disease worldwide with highly fatal. It has accounted for 10% of the global cancer incidence (Bray et al., 2018). In the Netherlands, patients who have undergone treatment and surgery for colorectal cancer typically enter a five-year follow-up phase. During this period, patients often experience long-term health issues. Colorectal cancer not only has physical implications for patients but also significantly affects various aspects of their daily lives, including their social networks and mental health (Arndt et al., 2006). On the other hand, remote patient monitoring (RPM) can enhance efficiency and improve patient care delivery. However, there has been a noticeable lack of research and design focusing on the inclusion of social and mental health monitoring within these systems. According to the World Health Organization, health should include “Physical, Social and Mental” aspects. Therefore it’s important to focus on how to develop remote patient monitoring in these aspects.

The project first used a patient community journey map (Jung, 2023) to summarize the experiences of colorectal cancer patients from a large number of posts on an online communication platform and invited medical experts from the Netherlands to a co-creation session to validate the map and explore research directions.

The final research question was defined as: How to develop a remote patient monitoring system for patients’ social and daily activity and related emotion when they are away from the hospital?

The research question was followed by user research. Patients received diary studies, including finishing a probe based on their activities. Upon completion of the diary studies by the patients, there is a follow-up interview to obtain patients' feedback and sentiments regarding the probe. Subsequently, the insights from the user research act as input during a collaborative designers’ brainstorm session. Finally, these research findings were exported into the initial guidelines for developing the RPM in social, daily activity and related emotions for colorectal cancer patients. After evaluations, the final guidelines for colorectal cancer patients’ RPM and a toolkit summarizing the "develop" and "deliver" phases were presented. This toolkit allows future researchers to develop RPM in social and daily activity and related emotion for patients in other contexts besides colorectal cancer patients, supporting the remote patient monitoring system’s evolution of physical, social and mental health.

0.3

Abbreviations

AI	Artificial Intelligence
CRC	Colorectal Cancer
ESM	Experience Sampling Method
HRQoL	Health-Related Quality of Life
LDA	Latent Dirichlet Allocation
IoT	Internet of Things
NMF	Non-negative Matrix Factorization
PJM	Patient Journey Map
QoL	Quality of Life
RPM	Remote Patient Monitoring
WHO	World Health Organization
BERTopic	Bidirectional Encoder Representationsfrom Transformers(BERT)

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Chapter 1

Introduction

Introduction of the project

1.1 Background

1.2 Problem Statement

1.3 Research Approaches

This chapter serves as the beginning of the dissertation and focuses on the background of the project and research, the research questions, and the research methodology. The background of the project includes a contextualization of colorectal cancer, remote patient monitoring, and graduation program reliance. The research question for this project is also listed in the problem statement. The research approaches introduce the double diamond design process applied in the project and the specific methods used for each step of the process.

1.1

Background

This section focuses on colorectal cancer, remote patient monitoring, and the context of the project.

Colorectal Cancer and Remote Patient Monitoring

Colorectal cancer is the third most common cancer disease worldwide with highly fatal. It has accounted for 10% of the global cancer incidence (Bray et al., 2018) and is expected to exceed 3 million in twenty years (Xi & Xu, 2021). However, recent advances in medical technology and diversification have led to an increase in treatment options for colorectal cancer (Dekker et al., 2019). They are effective in halting the progression of cancer and allowing colorectal cancer patients to live longer (Siegel et al., 2019).

In the Netherlands, patients who have undergone treatment and surgery for colorectal cancer typically enter a five-year follow-up phase. This phase involves regular meetings between patients and healthcare professionals to monitor their recovery progress and provide necessary information and support. During this period, patients often experience long-term health issues. In terms of physical health, the side effects resulting from treatments like chemotherapy and radiotherapy do not vanish as the cancer is controlled. Instead, these side effects can persist for an extended period, and in some cases, even for a lifetime (Denlinger & Barsevick, 2009). Some patients also need to hold a stoma for life. Moreover, it is common for patients to face multiple symptoms simultaneously (Albusoul et al., 2017; Miaskowski et al., 2017), which can significantly impact their quality of life (QoL) (Sprangers et al., 1995). Colorectal cancer not only has physical implications for patients but also significantly affects various aspects of their daily lives, including their social networks and mental health (Arndt et al., 2006). Therefore, it is important to pay attention to all aspects of a colorectal cancer patient's health in the follow-up phase to enhance the patient's quality of life.

However, on the other hand, the combination of an aging population and an increased prevalence of cancer places a strain on healthcare systems worldwide. Hospitals are facing staff shortages creating challenges in providing quality care to patients ("The State of Cancer Care in America, 2014," 2014). Hospitals need to rely on less manpower to care for more patients. As the number of elderly individuals requiring medical care rises, hospitals face the task of managing complex and chronic conditions associated with aging, including cancer. These conditions often require specialized care, which further strains available resources.

To address these challenges, healthcare systems are exploring various strategies. One of them is remote patient monitoring (RPM), which can enhance efficiency and improve patient care delivery. It breaks down the limits of distance and allows hospitals to keep track of patients while they are away from the hospital (Kofoed et al., 2012). This allows for timely intervention in the

event of an abnormal situation not only from the hospital, but patients also can proactively identify any deviations or fluctuations in their health metrics and promptly take appropriate actions. Therefore, patient empowerment can be effectively promoted through remote monitoring, enabling patients to develop a heightened awareness of their health status and take more active roles in self-management (Suter et al., 2011).

Context of the Project

In collaboration with Erasmus Medical Centre, we are committed to improving the quality of life of colorectal cancer patients after surgery through remote patient monitoring and patient empowerment. This graduation project is an offshoot of a project called "PROMISE". PROMISE aims to enhance the healthy quality of life in colorectal cancer patients during the postoperative follow-up phase. In the context of this wider project, I explored and did a series of research to understand the needs of colorectal cancer patients, which proved the need and value of this monitoring system. As a designer and researcher, I brought the creativity and design methods of the designer into the project. For example, use a patient community journey map to explore patient needs, a visual presentation of big data, and finally design a toolkit to help researchers gain deeper insights.

In addition to the collaboration with the Erasmus Medical Centre, I also completed part of the research with a master's student in computer science from Delft University of Technology. This interdisciplinary collaboration between the design and computer fields allows me to study from a new perspective, which is not achievable only for me.

As a result, the fields of design, medicine and computing have merged to provide strong support for the project.

After evaluating the guidelines, the final version of the guidelines came out. Also, after iterating with several researchers and designers, a final toolkit summarizing the develop and deliver phases was presented. The final toolkit also went through validations and had some results.

1.2

Problem Statement

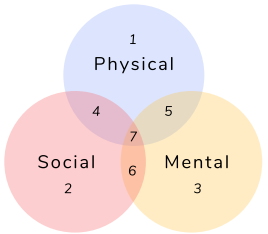
The World Health Organization (WHO) defines health in three aspects: physical, social and mental health, which are all essential to health-related quality of life (HRQoL). Some researchers believe that these three aspects are related to each other and have developed a framework called the "Three-dimensional Theoretical Framework of Health" (Figure 1) (van Leeuwen et al., 2018). This framework leads us to believe that the intersection of the three has an equally high impact on the quality of life of patients' health but is often overlooked.

In numerous studies conducted thus far, the emphasis of remote monitoring system design for patients has primarily revolved around aspects regarding physical health, specifically the monitoring of vital signs (Jamil et al., 2020). However, there has been a noticeable lack of research and design focusing on the inclusion of social and mental health monitoring within these systems. This discrepancy highlights the need to broaden the scope of remote monitoring to encompass the holistic well-being of patients.

After a series of studies, the research question was summarized as:

How to develop a remote patient monitoring system for patients' social and daily activity and related emotion when they are away from the hospital?

During the process of problem definition, the scope of the study is narrowed to a certain extent. The specific process of problem definition can be seen in Chapter 3.



1 *Physical condition*
Physical functioning
Satisfaction with physical functioning
Mobility
Prior health

2 *Family functioning*
Marital functioning

3 *Mental illness*
Anxiety
Depression
Psychological distress
Psychological well-being
Positive affect
Cognitive functioning

4 *Role limitations due to physical problems*

5 *Energy/ fatigue*
Sleep problems
Health perceptions
Physical Symptoms
Health distress
Health outlook
Pain

6 *Role limitations due to emotional problems*
Feelings of belonging

7 *Role limitations due to health*
Sexual functioning
Social activity limitations due to health

Figure 1 Three-dimensional theoretical framework of health (van Leeuwen et al., 2018).

1.3

Research Approaches

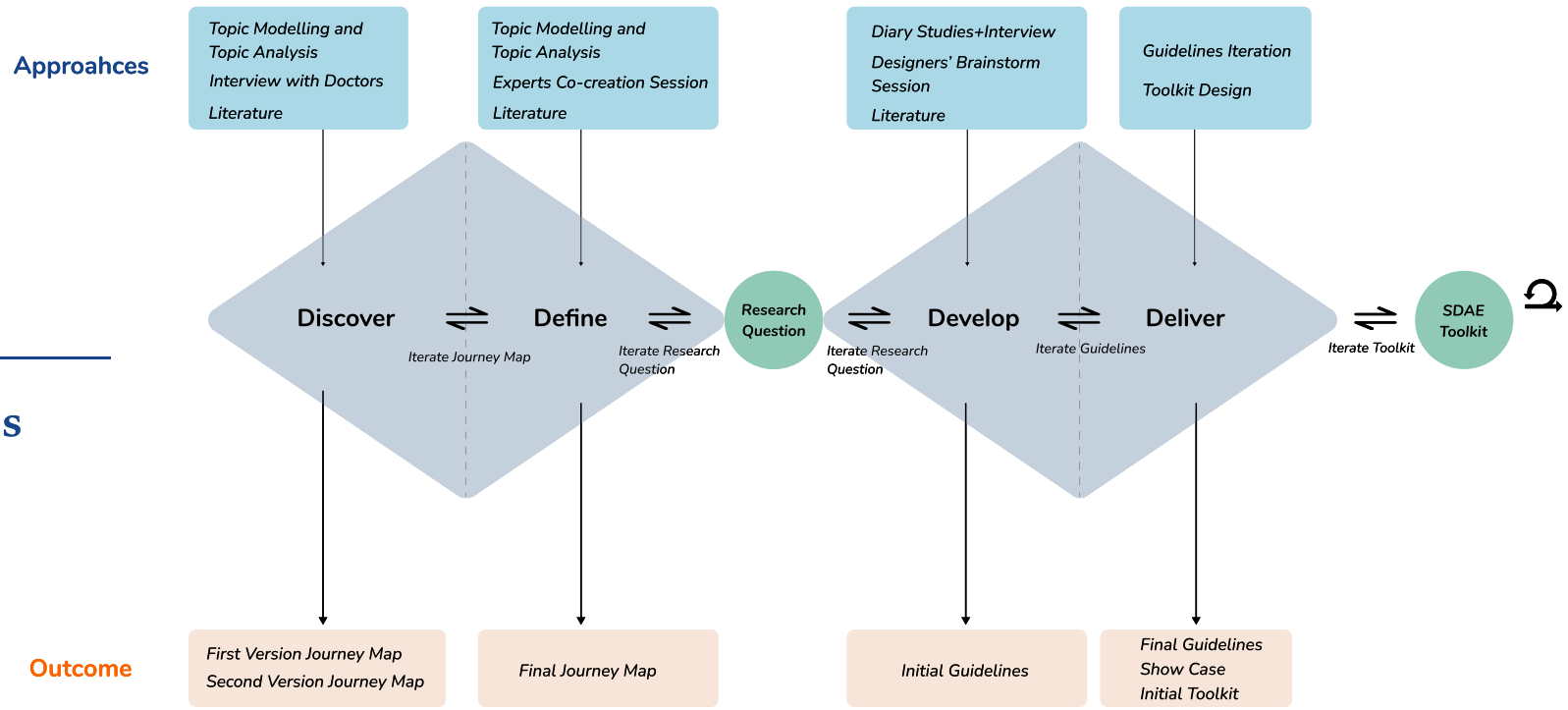


Figure 2 Overall of the Research Approaches.

This section describes the research approaches applied in the project, including an overall method of Double Diamond and other methods adopted in each stage.

Overall Approach: Double Diamond

Throughout the process, I followed the double diamond design process model (UK Design Council, 2019) approach which is very popular in the design field to complete the research and design. It consists of four stages: discover, define, develop and deliver (Figure 2). The reason for using this model is that it has two divergences and convergences, consistent with the fact that this project has gone through two processes of exploration and conclusion. The first exploration was to gain a broad understanding of the experiences of colorectal cancer patients, and through this process, the research question was defined and summarized. The second exploration was to explore this research question and ultimately summarize the answer to the question. The second exploration was also the process of designing and iterating on this toolkit.

Research Methods for Each Stage

Different research methods were applied in each stage (Figure 2).

Discover. In the first phase, I aimed to explore the overall situation of colorectal cancer patients and to understand their needs and struggles. Here I used the patient community journey map approach, developed by Jiwon Jung (Jung, 2023). It is a quantitative method for developing a patient journey map by crawling data from patient online forums and deriving the different topics discussed by patients using the topic modelling skill. These topics are positioned within the colorectal cancer patient care path, resulting in a big data-based patient journey map. As there is no well-developed care pathway for colorectal cancer patients in the Netherlands for the time being, I conducted interviews with doctors and together we mapped out this care path. In conjunction with the literature, I completed the first part of our exploration. The outcome includes two versions of the journey map, because when we changed the model in the topic modelling.

Define. In the second part, I engaged in a co-creation session with medical experts, utilizing the patient community journey map from the first phase as the foundation. During this session, we not only verified the accuracy of the journey map but also delved into potential directions for further research. By combining insights from the literature and the co-creation session, I completed the final version of the patient community journey map and defined the final research question.

Develop. The research question was followed by user research. A designed probe was used in the diary studies. Upon completion of the diary studies by the patients, there are follow-up interviews to obtain patients' feedback and sentiments regarding the probe. Subsequently, the insights from the user research were utilized as input during a collaborative brainstorming session involving designers from various fields. Finally, these research findings were exported into the initial guidelines.

Deliver. After evaluating the guidelines, the final version of the guidelines came out. I designed some show cases to demonstrate the possible outputs of these guidelines when applied. Also, after iterating with several researchers and designers, a final toolkit summarizing the "develop" and "deliver" phases was presented. The final toolkit also went through validations and had some results.

Chapter 2

Context Exploration

Understand Colorectal Cancer Patients Experience

2.1 Introduction of Patients Community Journey Map

2.2 Initial Maps

2.3 Experts Co-creation Session

2.4 Final Patient Community Journey Map

2.5 Summary of Key Insights

This chapter focuses on exploring the experiences of patients with colorectal cancer, starting with a series of design approaches to gain insights into patients' needs, pain points, coping strategies and so on.

As the project's context is in the follow-up stage, I will focus on the insights that emerge from this stage. However, as a designer with limited knowledge of colorectal cancer, it is not prudent to focus on only one stage during the exploration period. To gain a comprehensive understanding of colorectal cancer patients from the ground up, it is essential to conduct a thorough analysis of the experience (Weston et al., 1989) so that I can deep dive into the context and empathize with the patient's perspective. Therefore, the method "Patient Community Journey Map" developed by Jiwon Jung (Jung, 2023) was a starting point. A large number of descriptions of the patient's experience were summarized from the online platforms by the computer, thus providing a holistic understanding of patients' experience. This process was carried out by a computer science student and me.

In this chapter, I will introduce the patient community journey map method and describe in detail how the map was created. As the database used for the map is from the USA but the context of the project is the Netherlands, I conducted an experts co-creation session with Dutch medical experts to validate the content of the map and co-create inspiring directions for the remote monitoring system together. Throughout the process, three versions of the map were created. We adopt different models in the first and second versions of maps, which resulted in relatively significant alterations. The second version of the map was used as material for the session, while the last version was an iteration based on the co-creation session.

2.1

Introduction of Patient Community Journey Map

This section introduces the patient community journey map approach and what the goals are for using this approach.

Patient Community Journey Map

In the design field, a customer journey map is a household method for discovering the user experience over time (Richardson, 2010). A patient journey map (PJM) is an important application of a customer journey map in the healthcare field. In the PJM, the target group is more specifically defined as patients rather than a wide range of users. Due to the complexity of the healthcare sector, this visualised tool reflects clearly on patients' behaviour, needs, pain points, and other elements through time, thus helping healthcare professionals to understand their patients more efficiently and create patient-centred services (Trebble et al., 2010).

Of all diseases, cancer patients have the most complicated care paths (Kushniruk et al., 2020). Even after the surgery, patients still need to go through a follow-up stage that lasts for years, which leads to going back and forth to the hospital (Warrington et al., 2015). Nevertheless, the whole journey is known only by patients themselves because they are going through all the processes, while medical workers have their own roles in the journey. This means that the medical workers only know that part of their job and not the overview of the journey (Ben-Tovim et al., 2008). By illustrating the entire journey, the employees in the medical system can fill in the blanks and understand the whole process from a patient's perspective. This understanding can lead to better communication and empathy between medical staff and patients, resulting in a more positive healthcare experience.

However, the traditional development of the patient journey map mainly relies on qualitative methods (Madathil et al., 2020). Although qualitative methods produce deeper insights, the problem of small sample sizes can also lead to a lack of generalizability in PJM. If a problem is more difficult to define, it could be wise to start by collecting data from a larger sample size (Apuke, 2017), which means the results are more representative.

To address the limitations of qualitative patient journey mapping, researchers have begun to incorporate quantitative methods into their approach. In this colorectal cancer project, I use the "Patient Community Journey Map" method, developed by Jiwon Jung. It takes online patients' stories as a data source and then uses natural language processing skills, such as topic modelling, to analyze the texts that patients create (Jung, 2023). In this way, it provides a good starting point for designers who didn't know the context behind a specific disease before.

In this project, the journey map is composed of two parts: the colorectal cancer patient journey in the Netherlands, and the topic modelling for the online forum. The whole patient care path for the

	LDA	NMF	Bertopic
Description	*Considering that each document is a combination of topics, and each topic is characterized by a distribution of words.*	*Aims to factorize the term-document matrix (or any other matrix representation of the text data) into two non-negative matrices, typically referred to as W and H.*	*Using transformer-based models like BERT (Bidirectional Encoder Representations from Transformers). It combines the power of pre-trained language models with clustering techniques to perform topic modelling on large text datasets.*
Prone to topic overlap	Yes	No	No
Applied in first version of map	✓		
Applied in second version of map		✓	
Applied in final map		✓	
Applied in diary studies			✓

Figure 3 Overview of the Three Models.

journey part was developed by interviewing two CRC doctors two times. For the topic modelling part, together with a computer scientist, we crawled posts from the open-source online patients' forum and then used the topic modelling for the posts to develop the map. These scattered posts were classified into certain topics based on the computer's understanding of the words in the posts.

Context of the Project

Topic modelling is a text mining skill of extracting topic patterns from sentences or paragraphs (Egger&Yu, 2021). To give an easy-to-understand example, words like "tiger" "lion" and "sheep" appear in a paragraph, it can conclude that this paragraph is talking about animals because these terms are semantically related. This is the principle of how the posts can be gathered into different topics.

When doing the topic modelling, three common models are well-known: (1) Latent Dirichlet Allocation (LDA); (2) Non-negative Matrix Factorization (NMF); (3) Bertopic.

We conducted LDA and NMF for the journey map and the results from Bertopic were used in a later study as a supplement material (Figure 3). The shift from LDA to NMF is mainly because LDA presents too many overlapping topics, while NMF has relatively more differentiated topics, which will be easier for me to summarize. A detailed

description of the reasons for this can be found in the “Second Version Map” section. As for Bertopic, we didn’t use it for the journey map. This is because Bertopic generated more detailed topics, which is more suitable for diary studies as a supplement. Since these models were utilized on the same platform and database, we opted not to proceed with the application of Bertopic to the journey map considering the satisfactory performance of NMF and the time limitations.

Goals of the Map

By using the patient community journey map methods, I want to have an overall understanding of CRC patients’ experiences, including their focuses, needs, and pain points during their cancer journey. The analysis and results from the journey map will also define the design focus for a later stage.

As the database is unfiltered, the patients’ discussions from all stages of the care path are included, which means that this map can provide an overview of colorectal cancer patients' experiences. In this case, the map is not only a research method, but it also provides visualized information for those who want to know more about colorectal cancer patients.

2.2

Initial Maps

In this stage, there are two versions of the journey map in total. This is because we use two different topic modelling models: LDA (First Version) and NMF (Second Version). We first implement LDA to model the online platform, but what LDA presents is not satisfying enough for us, prompting us to transition to NMF. While both models were applied to process the same database, it is important to note that the results are not identical. As a result, I proceed to draw individual conclusions for each journey map.

This section mainly introduces how the maps were developed, the reasons why we switched from LDA to NMF, and the results for the two journey maps.

Data Collection and Analysis

Journey Part. As mentioned before, the patient community journey map has two parts. In the first part of the journey, as there is no ready-made care path for colorectal cancer in the Netherlands, I conducted two interviews with colorectal cancer experts (Figure 4) to develop a care path for it. The first interview aims to illustrate the care path (Figure 4) together with the experts and make an initial of the care path afterwards. Then I invited them for a second interview to validate the draft and defined the final version of the journey (Shown in all the patient community journey maps later).

As this journey has been developed in conjunction with medical experts, it is primarily undertaken

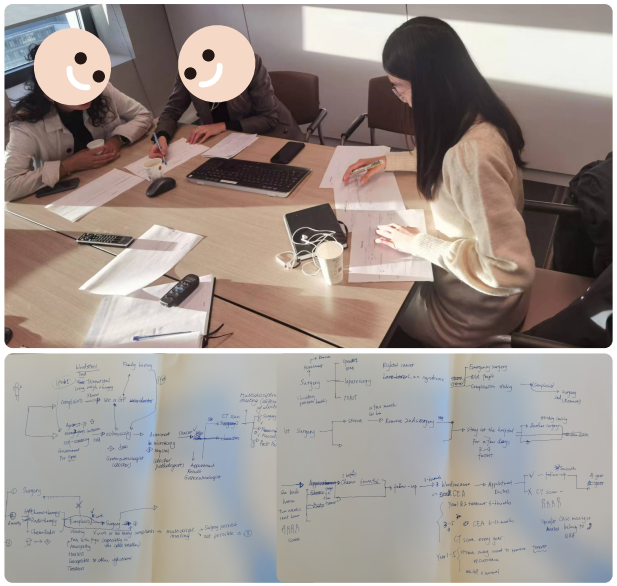


Figure 4 Interview with the medical experts.

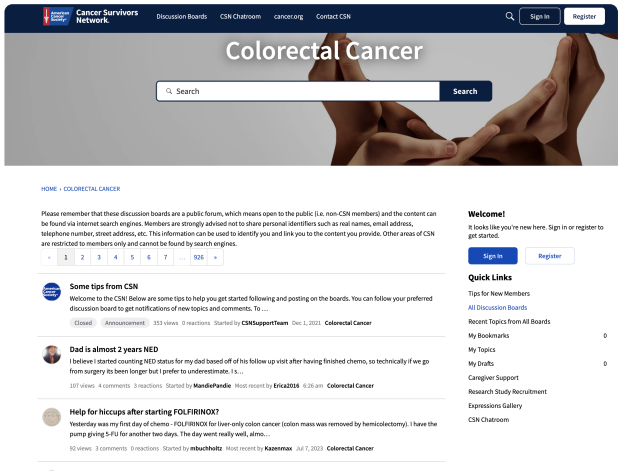


Figure 5 Cancer Survivors Network (https://csn.cancer.org/categories/colorectal).

from a hospital perspective. Missing here is the journey once the patients are away from the hospital. Therefore, the topic modelling is necessary to provide more views from patients' perspective when they leave the hospital.

Topic Modelling Part. When it comes to the topic modelling section, we used natural language processing to identify and categorise over 200,000 posts and then allow me to read, understand and verify the main content of each topic.

The first step to building the dataset is looking for online platforms. As the context of the project is mainly in the Netherlands, the goal is to find information about forums in regions with the same or similar medical context, mainly in Europe, Australia and the USA. Finally, an online forum called Cancer Survivors Network (Figure 5) from the USA was selected because it has a very large data set with a total of over 294,166 posts. On top of that, the platform has a great diversity of topics, covering basically everything from diseases to everyday life. Variety in topics is very suitable as a dataset in the exploratory phase for generating different insights.

It is worth noting that although the US and the Netherlands have similar healthcare scenarios, there are still many very different contexts, such as culture. Therefore, the final results will require some validation. This will then be achieved through co-creation with medical experts in the Netherlands (more on this later).

Regardless of which model of topic modelling is used, the computer scientist generates the following information about each topic for me (Figure 6):

(1) Top related keywords to the topic: The most relevant keywords for the generated topics.

(2) Weight of keywords: Specific values for the weighting of these keywords.

(3) Top 50 relevant posts for each topic: 50 posts most relevant to the topic

However, LDA, NMF and Bertopic can only generate keywords instead of descriptive sentences after programming. This can somewhat make it difficult to summarise a topic sometimes. To provide more context for me, the computer scientist also adopts the GPT-3.5 (model: text-davinci-003) to generate the description of each topic based on the top keywords. So, in addition to the three mentioned above, there is a fourth piece of information:

(4) GPT-3.5 generated description: A description of each topic based on the top keywords.

Earlier I mentioned that designers receive data in four aspects from the computer scientist. This is where the data analysis started.

I started with understanding the keywords for each topic and their weights, and reading the GPT-3.5 generated its understanding of each topic. Then I read the top 50 posts of each topic and summarized my own understanding of the topic (Figure 7). Reading the top 50 posts from the forum allows me to deep dive into each topic and have a context behind the topics. In addition to that, GPT's description is not always that accurate since it is generated only based on keywords. The top 50 posts are also evidence for humans to validate the GPT's description for each topic.

Due to the relatively large number of topics (usually 50-100 topics), I created upper clusters after defining the description of each topic. These clusters are named and classified based on the content (Figure 7). Those topics with similar themes will be classified into one cluster. This process also uses the computer-generated dendrogram and intertropical distance map as references. These two graphics show how the computer recognizes the relevance between topics so that I can create the upper clusters better.

topic	keywords	weights	GPT topic_description	GPT keywords
0	['chemo', 'work', 'great', 'well', 'insurance', 'pray', 'keep', 'result', 'pay', 'hear']	[0.01897945, 0.015820298, 0.011817918, 0.010751712, 0.0102995215, 0.009541342, 0.009182008, 0.008420595, 0.008191266, 0.00797155]	The LDA discovered topic is about dealing with the financial implications of chemotherapy. The keywords indicate that the topic may be about managing insurance, paying for treatments, and praying for good results. The weights suggest that these are all important aspects of the topic, with paying for treatments and praying for good results having a slightly higher importance than the other aspects.	Chemotherapy, work, insurance, prayer, results.
1	['chemo', 'well', 'cancer', 'year', 'day', 'time', 'thing', 'feel', 'treatment', 'really']	[0.012987182, 0.012292476, 0.011061726, 0.010850508, 0.010664458, 0.010017009, 0.009089918, 0.0086251395, 0.0067075994, 0.0064463494]	This LDA discovered topic is about chemotherapy treatments for cancer. The keywords chemo, cancer, treatment, and really indicate that the topic is related to chemotherapy, and the associated weights suggest that this is the primary focus. The other keywords such as well, year, day, time, thing, and feel indicate that the topic may also cover the experience of undergoing chemotherapy, including what to expect and how to cope with it.	Cancer chemotherapy treatment experience.
2	['well', 'work', 'feel', 'day', 'much', 'treatment', 'help', 'great', 'really', 'time']	[0.013111653, 0.010016038, 0.009783108, 0.009540772, 0.008815336, 0.008180419, 0.007635459, 0.0072563887, 0.007223023, 0.006878718]	Based on these keywords and weights, the LDA discovered topic appears to be about mental health and well-being. The words "well," "feel," "treatment," and "help" indicate that the topic is related to mental health, while the words "work," "day," "much," "great," "really," and "time" suggest that the topic is discussing how to maintain mental health and well-being in day-to-day life.	Well-being through work and treatment.
3	['pain', 'chemo', 'day', 'well', 'start', 'liver', 'first', 'back', 'time', 'bad']	[0.020989977, 0.0151404645, 0.011143439, 0.011014273, 0.010913455, 0.0091864895, 0.008923006, 0.008755577, 0.008728825, 0.008614737]	This LDA discovered topic appears to be about the effects of chemotherapy on the liver. The keywords of "pain", "chemo", "liver", "first", "back", and "bad" all point to this topic. The weights of the keywords also suggest that this topic is about the physical and emotional pain that can come with chemotherapy, the difficulty of returning to normal life after the first treatment, and the overall negative impacts of the experience.	Painful chemo on liver first day.
	['well', 'time', 'year', 'last',	[0.014523212, 0.014168057, 0.011457237,	This LDA discovered topic is about reflecting on the past. The keywords indicate that it	Reflecting on past

Document_No	Dominant_Topic	Topic_Perc_Contrib	post
9359	0	0.9834	to ,Wow- that's amazing and maddening that told you after 6 months that you had reached your "lifetime benefit amount"! I guess some other people have also had problems with them. My HMO has actually been very good to me. My problem wasn't being caused by - it was the fault of my former employer. They switched from using to Health Net and "forgot" to include me, a paying customer on COBRA status. Apparently, all the regular employees already have their new cards & I was just overlooked. I don't work there and don't talk to my former coworkers as often as I used to. Even so, I spoke to a couple recently, but it never occured to them to bring up the insurance. It probably was not intentional, because by law I have to be covered under the new insurance carrier they're picking up (sure they know that. Since November 1st, I've been paying the insurance company directly and no longer my former employer, so I guess "out of sight, out of mind" or something like that. It will get taken care of in another week, to Jan 1st.
12122	0	0.9825	Hi is generally given when other chemo drugs have stopped working as efficiently as they were in the past. This is the reason he is probably getting this...it does have a good effect in managing tumors. From what you are saying, I'm wondering if he is having trouble with his bile ducts in the liver? Perhaps, they are not draining correctly due to a blockage or something. Can they do a or perhaps an ultrasound to get a better idea?Your brother is definitely a fighter - a trait that I admire very much. I'm not sure what else could be wrong, these are just thoughts that came to mind. If things don't move better, you might want to consider getting another opinion from another oncologist - it's amazing how many folks here (including myself) have benefited from a "change of scenery." Still wishing you all the best and please post back with you find.
14378	0	0.9815	is there any one on here that takes/took CBD oils/products/ medical mj as a complimentary treatment? while i don't believe (at the moment any way) medical mj/CBD products can cure cancer I do believe that is is a important complimentary treatment that is just starting to be studied . It seems that it is the CBD products that have the most medical benefit but having said that if you have cancer and the high helps you get through why not as long as it doesn't affect your tradional treatments? Some CBD products have just been made legal here in for pallitive care. Doctors can now prescibe/import CBD products without a ministry of health clearance. I am so happy about this. I would love hear from people who have legal access to medical mj/CBD products from other parts of the world and what, if any, benefits they got from it as I find it very interesting. Thank you
9180	0	0.9782	FEELING DOWN?Good morning....Nice to meet you. Are you still up? We know about the sleepless nights and maybe you should ask your doctor for some meds. for that. I want to say "Welcome Aboard", but I wish it were under better circumstances. We just now are recovering from ...."The Monster". Our journey was one of the lucky ones, but tough none the less. My husband, , was DX'd Dec. 19, 2008...surgery Jan. 21 2009.Can you tell us more about yourself and your situation? When were you DX'd?...What type...What does your doctor say? You'll find the people in this group to be very, very supportive, caring and full of knowledge. I'm so sorry it seemed no one wAs awake or on line when you needed to talk....Now's your chance....let us hear from you...and what is your first name?Hugs and ,Hop and
11269	0	0.9777	Found out recently that my colon is clean, is way low- my status continues.After worrying all fall and convinced my neck was in a job-loss-noose, my union came to the rescue, they convinced HR to reclassify my job today and now I am sitting pretty dang good for job security.I coach my high school Mock Trial team- we are now 4-0 and play in the regional final tomorrow afternoon. If we win that, we play in state competition March 9 and 10. Here is hoping for a win to continue my lucky streak!
			just post away your worries and share your great ideaswhats the point of having great ideas or worries if you don't share them.at least we will understand. I start my chemo tomorrow which is Tuesday here what a small world, we get our chemo on the same day, what delicious cocktail does

Figure 6 Top Related Keywords, Weight, GPT-3.5 Generated Description and Top 50 posts.

Cluster	Topic Number	Designer's Summary
Cluster 1: Experience around medical professonals' opinion	39	Doubts about treatment opinions from medical professionals
	45	Suggestion to look for a second medical opinion; suggestion on dealing port in the best way.
Cluster 2: Understanding treatment including alternatives and adjunctive therapy	30	Patients share their research about alternative therapy options from websites and articles, making a judgement on options.
	10	Making treatment decisions for the future with regard to the best outcome and
	33	Listing type, side effect, regimen, and effectivenss of drugs (folfox, oxaliplatin, avastin, and irinotecan) and the
	14	Sharing experience on using Traditional Chinese Medicine to manage health
	21	Share experiences and recommendations for supplements and medication.
	48	Sharing information about and holding a

Figure 7 My Summary and Clusters.

First Version of Map

The first version of the patient community journey map (Figure 8) shows the colorectal patients' discussed topics on the online forum. It shows what patients mainly discuss on the online platform as the journey progresses. The map comprises two essential sections: the "journey" and the "topic", as previously discussed.

The "journey" section provides a detailed description of the various stages a colorectal cancer patient in the Netherlands may experience, commencing from the moment of diagnosis, progressing through treatment procedures like chemotherapy and surgery, and concluding with a thorough five-year follow-up stage. It is the result of the interview with medical experts.

The "topic" section provides the outcomes derived from topic modelling, specifically adopting the LDA model. Through several rounds of iterations and extensive processing, the computer generated a set of 48 topics based on the collection of 294,166 posts from the online forum. Subsequently, I classified these 48 topics into 19 upper clusters after defining the meaning of each topic. In combination with the journey, it is clear to know patients' focused topics at each stage.

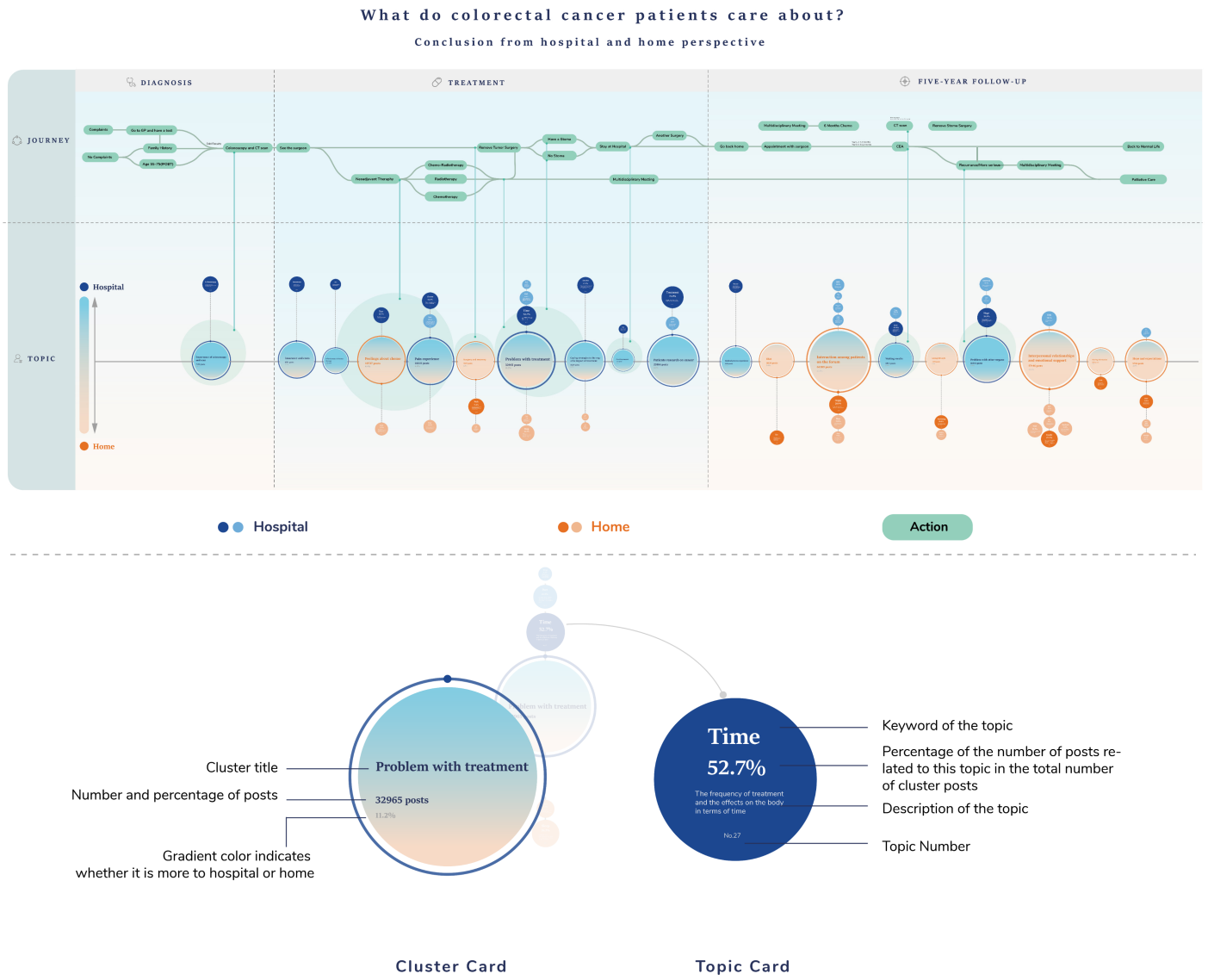


Figure 8 First Version Colorectal Cancer Patient Journey Map.
(Download original file here: https://sunny990115.wixsite.com/sdae)

Dimension 1: Hospital and Home Perspective. Throughout the journey, particularly during the follow-up phases, cancer patients often spend less time at the hospital and primarily visit when necessary, while healthcare professionals predominantly operate within a hospital setting. Consequently, this physical distance leads to a limited exchange of information between patients and healthcare institutions. This gap is where the development of remote monitoring systems becomes crucial.

To delve deeper into these two contexts, I introduce a vertical dimension in the topic section, distinguishing between “Hospital” and “Home”. It is important to note that “Home” is not narrowly defined here, it mainly refers to when the patient is away from the hospital context, which can include activities such as going out to work, socializing etc. “Hospital” also not only refers to the location but also to some intangible scenarios such as the medical system. The 48 topics under 19 upper clusters are classified based on their relevance to these contexts. Visually, I assigned colours to differentiate the two contexts. If a topic primarily concerns issues that require attention from the hospital side or is closely associated with the hospital setting, it is assigned more topside and marked in blue. Conversely, if a topic is more relevant to the home context, it is positioned more downside and marked in orange. The colours of the clusters also show the distribution of their topics’ context. The clusters with a mixed context of topics are in blue and orange gradient colours.

Results. Horizontally speaking, each topic has a different attribute within the topic section. Some are particularly biased towards a particular context, while others are in the middle. To get an overview on the x-axis, I extracted only the keywords for each topic and placed them in the diagram shown in Figure 9. These keywords only show whether it is closer to the hospital or home context, or more in the middle.

First, when looking only at the keywords on the hospital side, the keywords "Colonoscopy", "Insurance", "Liver" "Chemo", "Drug", etc. can reflect the concerns of patients in the hospital context. Combined with the descriptions, the topics to which these keywords belong tend to be more oriented towards practical issues and the physical aspects of cancer. Patients are often seeking an answer or solution to a problem with cancer. Words like “Wait” and “Help” also imply that they are not satisfied and feel frustrated with the experience happening in the hospital context. However, despite the complaints, the overall context of the hospital remains in the tone of rational and advice-based discussions.

Compared to the hospital, the home context has a more emotional atmosphere. Here comes more discussion on patients’ daily life and feelings, as shown in the words like “Feel” “Work” “Sleep” and “Family”. Terms describing emotions, such as “Bad” and “Positive”, also appear in the home context. Concerning the content of the topics, it is easy to conclude that patients become more sensual when they are in a home situation. The tone is not only about seeking advice and complaining, but it is also more mixed and complicated sentiments including positive and negative aspects.

When it comes to the middle of the hospital and home context, the keywords become more about time and full of uncertainty, which means that the time elements are very important in both the hospital and home context. Time has multiple meanings in the topics: Patients may be calculating the date of their survival, or they may be discussing the date of the scan. In reading the post, I also discovered that patients could become sensitive to time after developing colorectal cancer. They tend to list the activities happening in the future or the past accurately and have lots of feelings about time.

This part also shows the uncertainty, referring to keywords “Ask” “Help” and “Find”, and is overall in the mid to late stages. Consequently, in both hospital and home contexts, patients are shrouded in unpredictability. They keep asking questions, finding solutions, and seeking help in either a rational or emotional way.

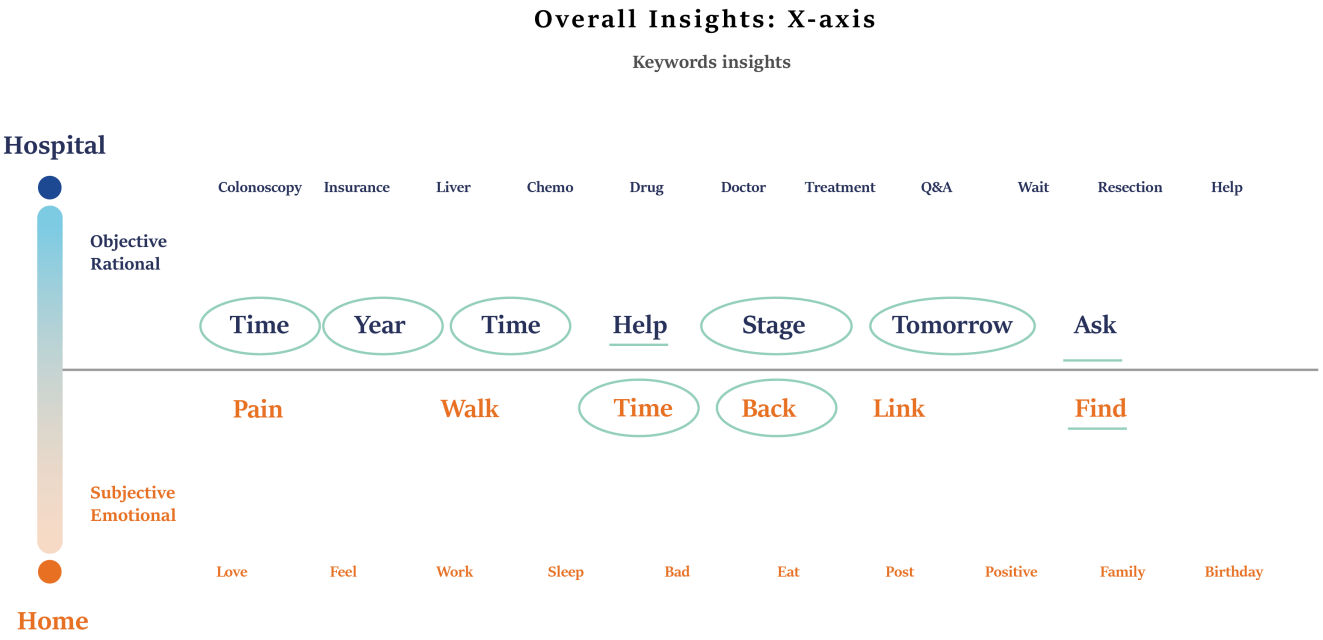


Figure 9 X-axis: Keywords Insights.

TAKEAWAYS

First Version of Journey Map

- The more to the hospital, the more rational patients will be.
- The more to home, the more emotional and life-related patients will be.
- Time elements are important to patients, and they can be uncertain when something is related to both the hospital and home.
- In the follow-up phase, except for physical health, patients are also focused on how the cancer affects their daily life and their surroundings.

Second Version of Map

Although the first version of the journey map provided many interesting insights, it still had many overlapping topics that fitted with the previously mentioned characteristics of LDA. As this is in the exploratory phase, the diversity of topics is quite important because it provides more varied insights. Therefore, the computer scientist and I decided to take another model of NMF and develop a new map (Figure 10).

Comparison with the First Map. In the second version of the patient community journey map (Figure 10), the hospital and home dimensions were still applied to classify the topics. Still, the computer-generated 50 topics based on the collection of 294,166 posts. The biggest change is that we conducted the NMF model for topic modelling instead of using LDA, which means that the results are different. Because of that, the direction of the topics also shifted from vertically distributed to horizontally distributed within each cluster after evaluation by me. In addition to that, 12 topics were excluded with a clear platform identity. This means that posts like patients congratulating each other or expressing regret were not considered, as they have very little relevance to the patient experience. Consequently,there were 38 topics and 10 clusters based on the topics. The computer scientist also generated the top 20 relevant keywords for each topic instead of 10 for offering more information about the topics.

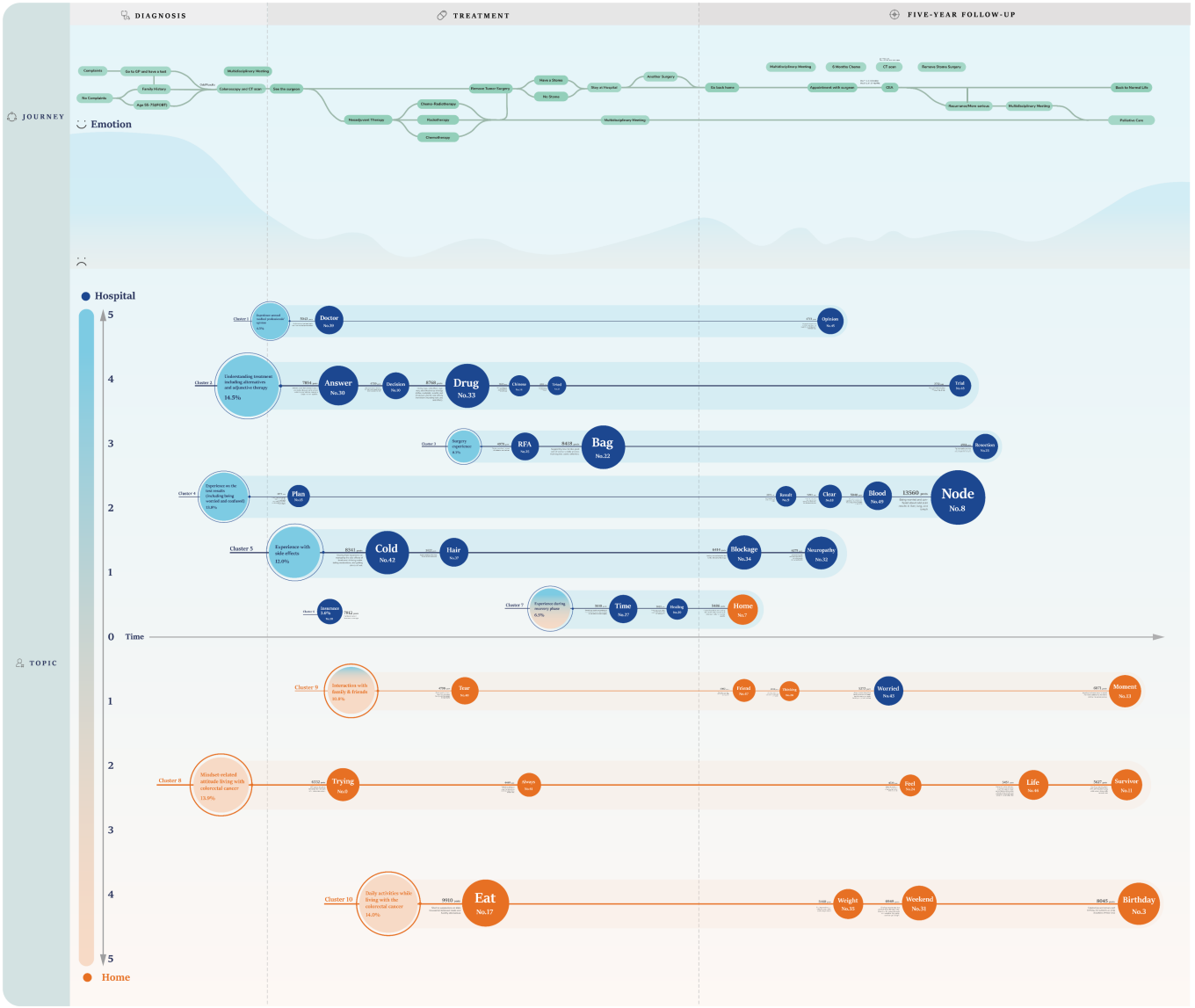


Figure 10 Second Version Colorectal Cancer Patient Journey Map.
(Download original file here: https://sunny990115.wixsite.com/sdae)

	First Journey Map	Second Journey Map
Model	LDA	NMF
Number of topics	48	38
Exclude topics or not	No	Exclude 12 platform-related topics
Number of clusters	19	10
Emotion curve	No	Yes
Distributed direction of topics	Vertically	Horizontally
Deep analysis	Yes	No
Used as materials later	No	Used for experts co-creation session

Figure 11 Comparison of the Two Maps.

While the actions in the journey part remain the same, there is a new emotion curve in the journey part. This curve is based on designer's subjective judgment after browsing the full range of topics and clusters.

This second journey map was not analyzed in depth for the reason that it would be validated in the experts co-creation session (Section 2.3). Some topics and clusters may be changed after validation, so at this stage, it has only approximate results.

Compared to the hospital, the home context has a more emotional atmosphere. Here comes more discussion on patients' daily life and feelings, as shown in the words like "Feel" "Work" "Sleep" and "Family". Terms describing emotions, such as "Bad" and "Positive", also appear in the home context.

Reasons from LDA to NMF. Although the first version of the journey map was well-developed, the process of analysis and the results presented by LDA were not satisfactory. From my perspective, the biggest problem with the results presented by LDA is that there is so much similarity between topics. The topics show limited differentiation, leading to overlapping in the content. As there is a lot of duplication or similarity between topics, this also leads to a less efficient analysis of posts, which means that many posts that could have formed some new topics were merged into the existing ones.

In addition to my decision that the NMF was better, the computer scientist also evaluated the results of the LDA and NMF using three metrics from the computing domain. These three are: (1) Mean jaccard similarity score; (2) NMF is a deterministic model; (3) Topic coherence. In every aspect of the three, NMF outperforms LDA. For more information see the paper by the computer scientist (Patandin, in progress)

As a result of this change, the topic becomes clearer and more differentiated. Based on this, the topic becomes easier to distinguish which stage it belongs to in the journey. The clusters thus are presented with a long or short timeline. This is also why the distribution of topics has changed from vertical to horizontal.

Results and Role of the Second Map In the second version of the map, it is not hard to see from the emotion curve that the most difficult time for the patient is during the treatment stage, and they suffer from falling off a cliff in mood in the diagnosis stage. However, the most ups and downs time is during the follow-up phase. Although the clusters start at different times, most of them tend to last for a relatively long time. This also means that these clusters have a long-lasting effect on the patient.

I did not go into depth in the analysis of the second journey map because it was used as material in an experts co-creation session. In this session, medical experts were asked to validate the map and develop design directions together with me. Due to the potential for changes in the map following the session, the map was not fully analyzed at this time.

TAKEAWAYS

Second Version of Journey Map

- Patients are most negative during the treatment phase, fall off a cliff in mood during the diagnosis phase, and most up and down during the follow-up phase.
- The clusters tend to last for a long time.
- Less in-depth analysis of the second journey map. It would be used as a material for the experts co-creation session.

2.3

Experts Co-creation Session

This section introduces an experts co-creation session that took place after finishing the second version of the journey map. The goal of this session is to validate the second version of the journey map and engage in collaborative discussions with medical experts on the focus of the design. As this database is from the USA while our study was carried out in a Dutch context, it became important to have access to the views of Dutch medical experts, which is also the main reason for this session. At the same time, designers can co-create with medical experts to think about what meaningful and interesting design directions might be based on this journey map.

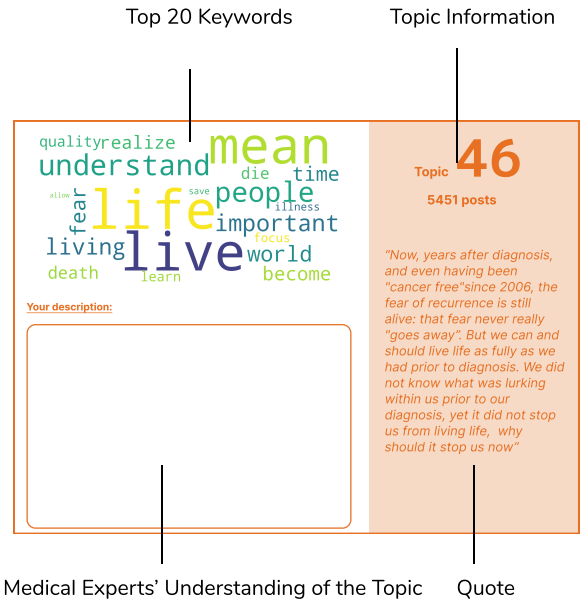
In this chapter, a theoretical framework was referred for the analysis of the data. It is called the "Three-dimensional Theoretical Framework of Health" (van Leeuwen et al., 2018), which is a development based on the theory of "Physical, Social and Mental Health" (Stewart et al., 1992, p. 17-18). As this framework extends our knowledge of assessing health-related quality of life (HRQoL) and is also consistent with the results of the journey map and co-creation session because they also empathize on focusing whole health of patients, I relied on this framework throughout this project.

Session Set-up

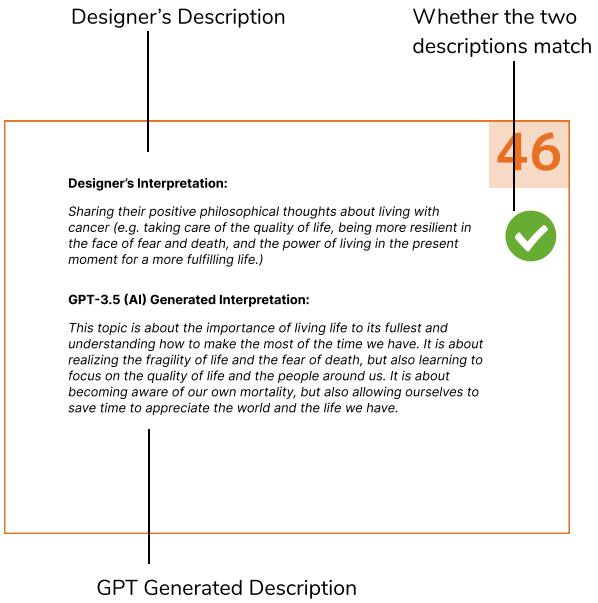
Participants. Five medical experts from healthcare area were invited (Figure 12). As it is shown, I included a wide variety of specialists with different levels of professional experience and in different fields. Three of them are specialists in colorectal cancer, one is concerned with the quality of life of patients, and one is from the department of surgery and oncology. Such a diverse group of experts can provide insight and inspiration from a variety of perspectives on the project. Three of them are specialists in colorectal cancer, one is concerned with the quality of life of patients, and one is from the department of surgery and oncology. Such a diverse group of experts can provide insight and inspiration from a variety of perspectives on the project.

	Expertise	Year of Expertise
Expert 1	Epidemiologist and Quality of Life	15
Expert 2	Researcher in CRC Patients	3
Expert 3	Researcher in CRC Patients	3.5
Expert 4	Surgery and Oncology	20
Expert 5	Treating CRC Patients	12

Figure 12 Overview of the Participants.



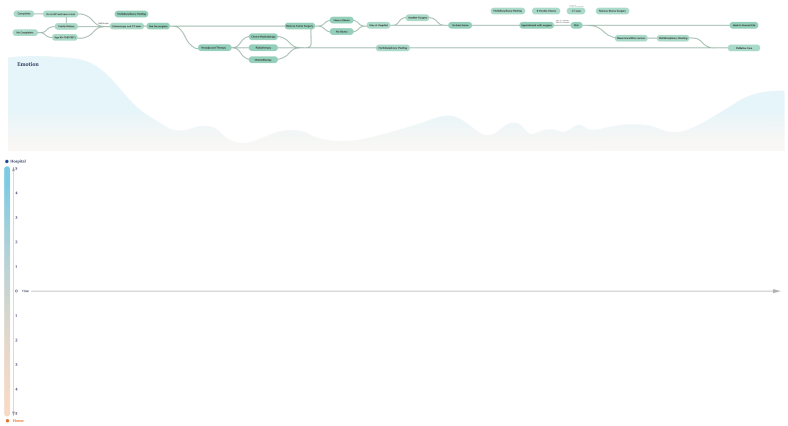
Front Side of the Topic Card



Back Side of the Topic Card



Printed Topic Card

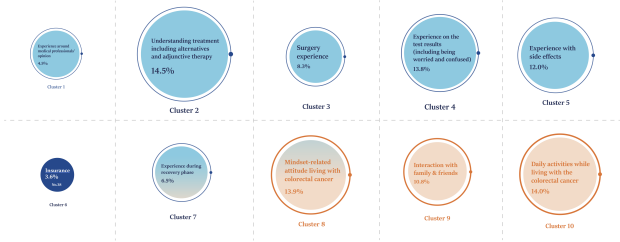


Blank Journey Map

Figure 12 Overview of the Participants.

Materials. In this session, I mainly used topic cards, cluster cards and a blank journey map as materials (Figure 13). The front side of the topic card includes the topic number, the number of posts belonging to this topic, the top 20 keywords, a representative quote from the topic 50 posts, and a space for experts to write their own descriptions of the topic. The back side of the topic card includes both descriptions from me and GPT. The printed topic cards are classified into cluster cards according to the second journey map. The purpose of the topic cards and cluster cards is to enable the experts to quickly understand the topic and to set the stage for the subsequent selection of topics to be placed in the blank journey map. In the blank journey map, the journey part stays the same but all the topics and clusters in the topic part were removed, so that experts can have a chance to input their own thoughts and understanding.

Through these materials, medical experts had the opportunity to input their own views. These materials become a trigger to stimulate their knowledge and creativity.



Cluster Cards

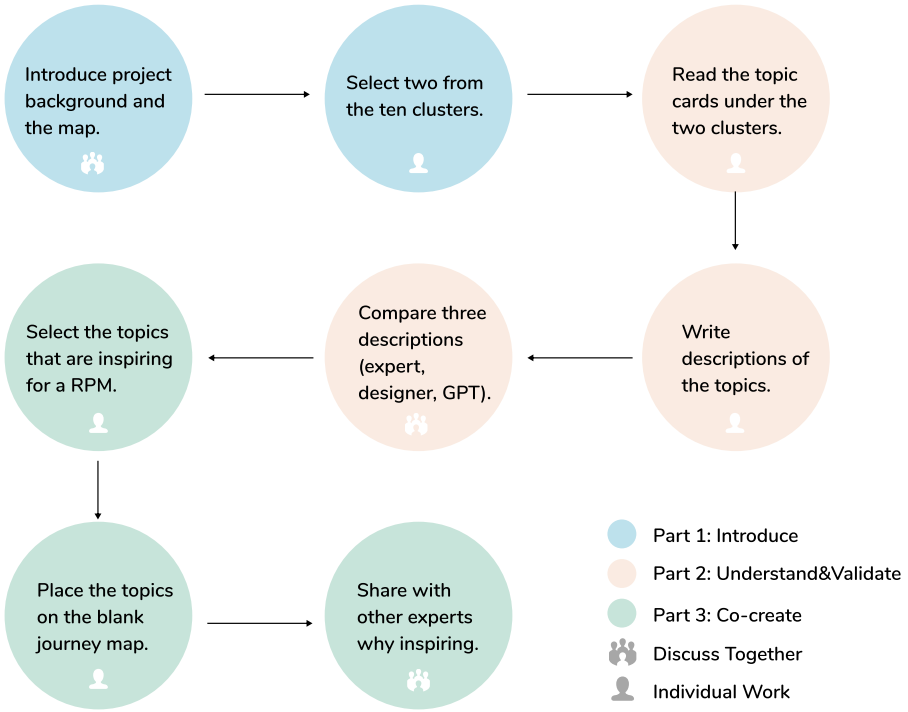
Session Content

This 90-minute session consists of three parts in total: background introduction, understanding and validation of the topics and co-creation of the inspirations for a remote monitoring system.

In the background introduction, I presented the background of the project and the journey map, including the process of making the journey map and its results. Then the experts needed to choose two clusters they found the most interesting and only read the front side of the topic cards under the two clusters. They were required to write down their personal interpretation of each topic after reading the quote and top 20 keywords on the topic card. Then they could turn around the cards to see the descriptions from me and GPT and give comments on the three descriptions.

By this point, they had read all the topics under the two clusters and had some idea of the context of what the patients were discussing. Therefore, I asked them to select topics from the two clusters that they thought would be inspiring for a remote monitoring system and placed them in the blank journey map. By doing this, I was able to know where these topics should be on the journey map from their point of view and the reasons behind them.

In the final stage, I invited them to share the journey maps they had filled in. From the journey maps, we had an inspiring discussion on the similarities and differences between the Dutch and American contexts and the insights on building a remote monitoring system for CRC patients.





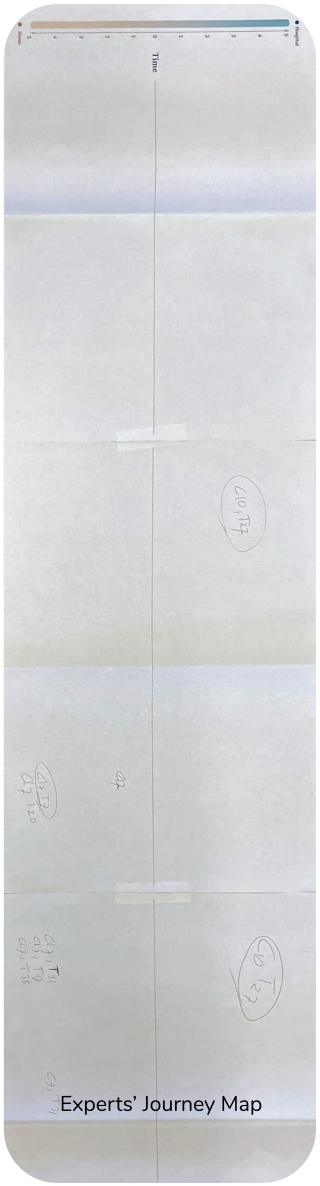


Figure 14 Experts Co-creation Session Process.

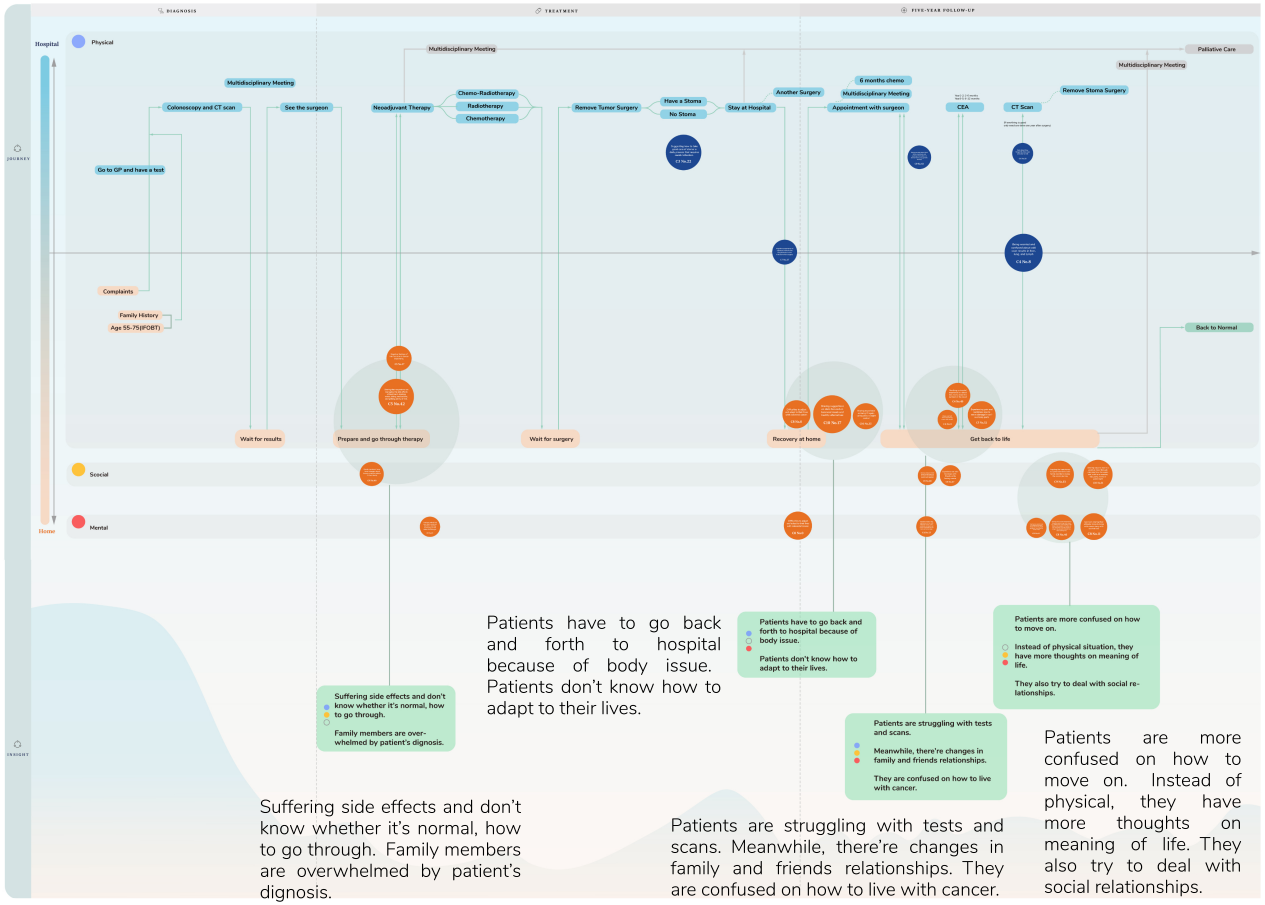


Figure 15 The Map for Analysis.

Analysis: Physical, Social and Mental Health

A series of analyses were carried out after the co-creation session.

The Map for Analysis. In collating the topics chosen by the experts, the journey maps, and the discussion, I have found that medical experts are not only concerned with the physical health of patients but also with their social and mental status, which are also very vital in measuring their health-related quality of life (Stewart et al., 1992, p. 17-18). The concept of health, as defined by the World Health Organization (WHO), includes complete well-being in terms of physical, mental, and social aspects. Therefore, I brought this definition in analysing the session.

I first identified the topics selected by experts and me based on the three aspects. In Figure 15, I continued to use the journey map to analyse these topics, so I named it "The Map for Analysis". In this map, I have also divided the actions in the journey part according to the dimension of the hospital and home, so the original green box has become blue and orange. Of the physical, social and mental aspects, it is relatively easy to deduce that the physical is more in the hospital context, as it is the main aspect of the patient's connection to the hospital. The social and mental aspects are relatively closer to the home context, as social interaction, daily activities, and emotional changes often take place at home.

Three-dimensional Theoretical Framework. By combining the maps created by the experts (Figure 14), all the selected topics were placed together in Figure 15. In the process, however, some topics did not quite fit into only one category. They had the potential to involve more than one aspect, for example, whether socializing is healthy can also affect a person's mental health.

To accurately express the categories to which these topics belong, I carried out research further and found that the original definition from WHO was iterated upon by a number of researchers and a new framework was summarized, which is called the "Three-dimensional Theoretical Framework of Health" (Figure 25) (van Leeuwen et al., 2018). This theoretical framework not only includes the original three aspects but also explains the overlaps among them. As this framework was consistent with the findings of the research, it was adopted to continue the analysis.

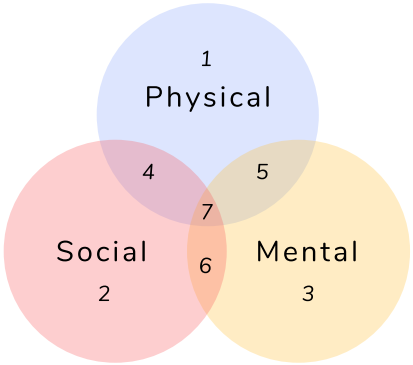


Figure 16 Three-dimensional Theoretical Framework of Health (van Leeuwen et al., 2018).

1 *Physical condition*
Physical functioning
Satisfaction with physical functioning
Mobility
Prior health

2 *Family functioning*
Marital functioning

3 *Mental illness*
Anxiety
Depression
Psychological distress
Psychological well-being
Positive affect
Cognitive functioning

4 *Role limitations due to physical problems*

5 *Energy/ fatigue*
Sleep problems
Health perceptions
Physical Symptoms
Health distress
Health outlook
Pain

6 *Role limitations due to emotional problems*
Feelings of belonging

7 *Role limitations due to health*
Sexual functioning
Social activity limitations due to health

Results

After the analysis three aspects of the results were summarized: the results of the meetings, the results of the map analysis and the results of the combined framework analysis.

Results of the Session. During the co-creation, the experts and I engaged in some insightful conversations. It became evident that the remote monitoring system holds significant value for healthcare professionals. Nevertheless, they broke away from the conventional doctor's image and reached a consensus that the remote monitoring system should not only focus on the physical health of the patients but also other not-so-medical aspects, such as their daily activities. In fact, an expert even suggested that the remote monitoring system should not overly emphasize its medical attribute. Yet, it was also apparent that medical experts have limited understanding of patients' experiences outside the hospital context, revealing a knowledge gap. This underscores the importance of defining the "Home" context.

Expert 4

> ***I want to know more about daily activity... and I don't want to make the remote monitoring too medical."***

Expert 1

> ***Patients want to stay at hospital. By remote control we can convince patients to leave hospital: Even leave hospital you are still protected. "***

Expert 5

> ***It is important for patients to be able to understand all aspects of their health, to be able to have the right to participate in health decision-making, and to be given the opportunity to intervene when appropriate "***

Results of the Map for Analysis. Figure 15 shows that the topics mainly gather at the follow-up stage, with lots of home, social and mental related topics, which were summarized into four insights for the remote monitoring system:

(1) At the beginning of the treatment stage, patients can suffer from many side effects. They don't know whether it's normal or not and how to go through it. At the time, family members are usually overwhelmed and frustrated because they don't know how to get along with patients.

(2) After the surgery, when patients have just returned home from the hospital, they typically require frequent visits for postoperative care. At the same time, they have just been discharged from the hospital environment and therefore often feel confused as to how to adjust to the changes in their lives afterwards.

(3) As this process proceeds, the patient begins to face many regular tests and scans. At the same time, they begin to feel some changes in their environment, for example from the interpersonal side. These changes make them feel overwhelmed.

(4) After this, in addition to focusing on their physical health, they also have more thoughts about cancer and life. Patients can create many philosophical statements. They also try to deal with the relationships around them, so that they can find gradually find a pace of life and ways of living that suit them.

Overall in Figure 15, it is apparent that in the follow-up stage, the patients have more conversations on social and mental aspects that are usually in the home context compared to the diagnosis and treatment stage, which medical experts and I think is inspiring for a remote monitoring system.

Results of Combining the Framework. After adopting the theoretical framework, I categorized the selected topics according to the framework but added one more layer of hospital and home context (Figure 17). The diagram shows that the topics of interest to experts and designers are mainly in sections 5 and 6, which is exactly where they cross. Common to both sections is mental health, suggesting that whether physical or social health is mentioned, attention needs to be paid to the impact they have on mental health. It is worth noting that I did not find topics in all three areas during this analysis, which may indicate that medical experts and designers still want a certain focus on the remote monitoring system.

In addition to this, I counted and classified the number of times experts and designers chose the topic. Out of a total of 40 selections, 13 were related to physical and mental health, 10 were mental and 9 were social and mental aspects, which gives a clear conclusion that the physical, social and related mental could be very insightful for a remote monitoring system.

Conclusion. From the above results, the medical experts and designers consider physical and mental, social and mental to be very important and relevant in the follow-up phase of a remote monitoring system, regardless of the analysis. Monitoring of the physical or social aspect in combination with the mental is therefore quite essential.

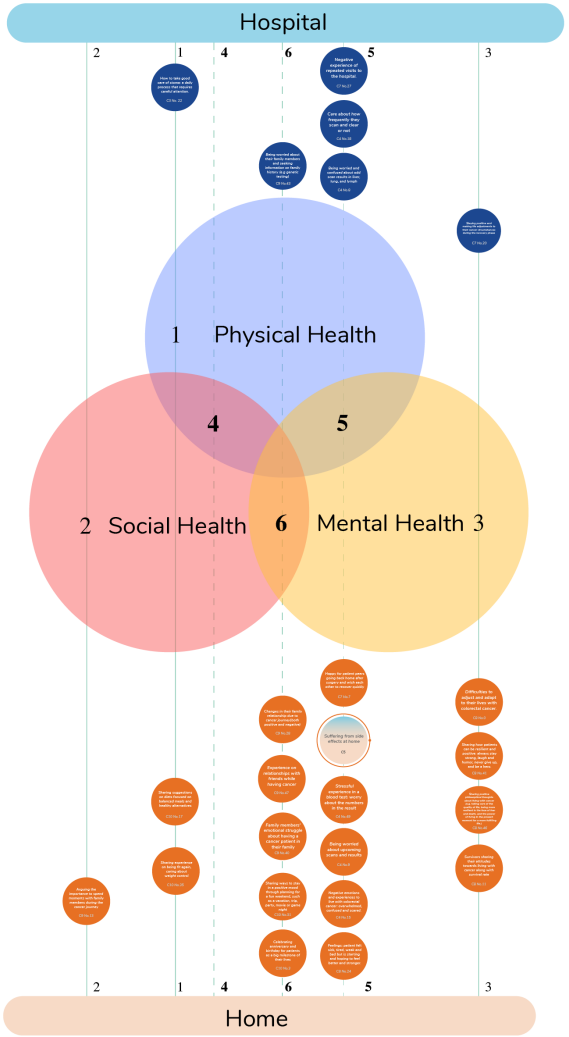
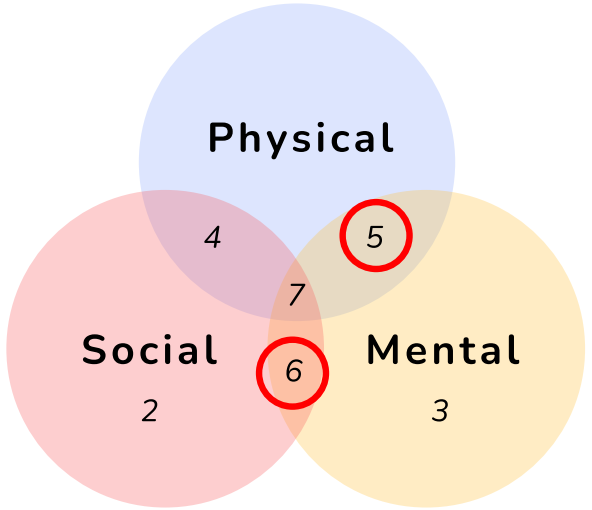


Figure 17 Selected Topics in the Framework.

TAKEAWAYS

Experts Co-creation Session

- The Map of Analysis (Figure 15): In the follow-up stage, the patients have more conversations on social and mental aspects that are usually in the home context, which can be insightful for the RMS.
- Selected Topics in the Framework (Figure 17): Medical experts and the designer selected topics gather in two parts: physical and mental overlap, and social and mental overlap.
- Statistics on the number of selections: The overlap of physical and mental, mental and the overlap of social and mental health are the focus.
- There is a gap between the knowledge possessed by medical experts and patients in the home context. The experts lack understanding and express a desire to comprehend the context during the patient's absence from the hospital environment.
- Overall: Monitoring of the physical or social aspect in combination with the mental is quite essential.



2.4

Final Patient Community Journey Map

Combining the second version of the journey map, insights from the experts co-creation session and the three-dimensional framework, I improved and developed a final patient community journey map. In this final version of the map (Figure 18), I retained the primary dimension of the hospital and home context while incorporating the previously mentioned theoretical framework. Thus, it adds one more layer to the map, giving each topic two attributes.

The first dimension, the hospital and home context, has already been introduced in the first version of the journey map section, which points out the reasons for introducing this dimension and the value it brings. Similarly, the second dimension of the three-dimensional framework provides richer insights into the whole journey. With these two dimensions of measurement, I can not only see what topics will correspond to the actions in the journey but also determine at what point the patient has a discussion related to the hospital or home context. Furthermore, it's straightforward to ascertain the main aspect of health that patients are primarily concerned about at different stages of their journey.

Storyboard

After designing the final version of the journey map, I used a storyboard (Figure 19) design method to depict the journey. It serves as a means of vividly presenting concepts to the audience and ensuring their accessibility to individuals from different fields (van der Lelie, 2006).

However, given that the project primarily emphasizes the follow-up stage, I intentionally detailed this stage. It is also important to acknowledge that this storyboard does not present a comprehensive narrative of the entire journey because of the large volume of data. Instead, it merges elements from the journey map and online forum posts, drawing upon my intuition and summaries. Consequently, it offers key insights rather than exhaustive details. Through this storyboard, the reader can gain a general idea of the struggling faced by a colorectal cancer patient, particularly during the follow-up phase, in an engaging and captivating way.

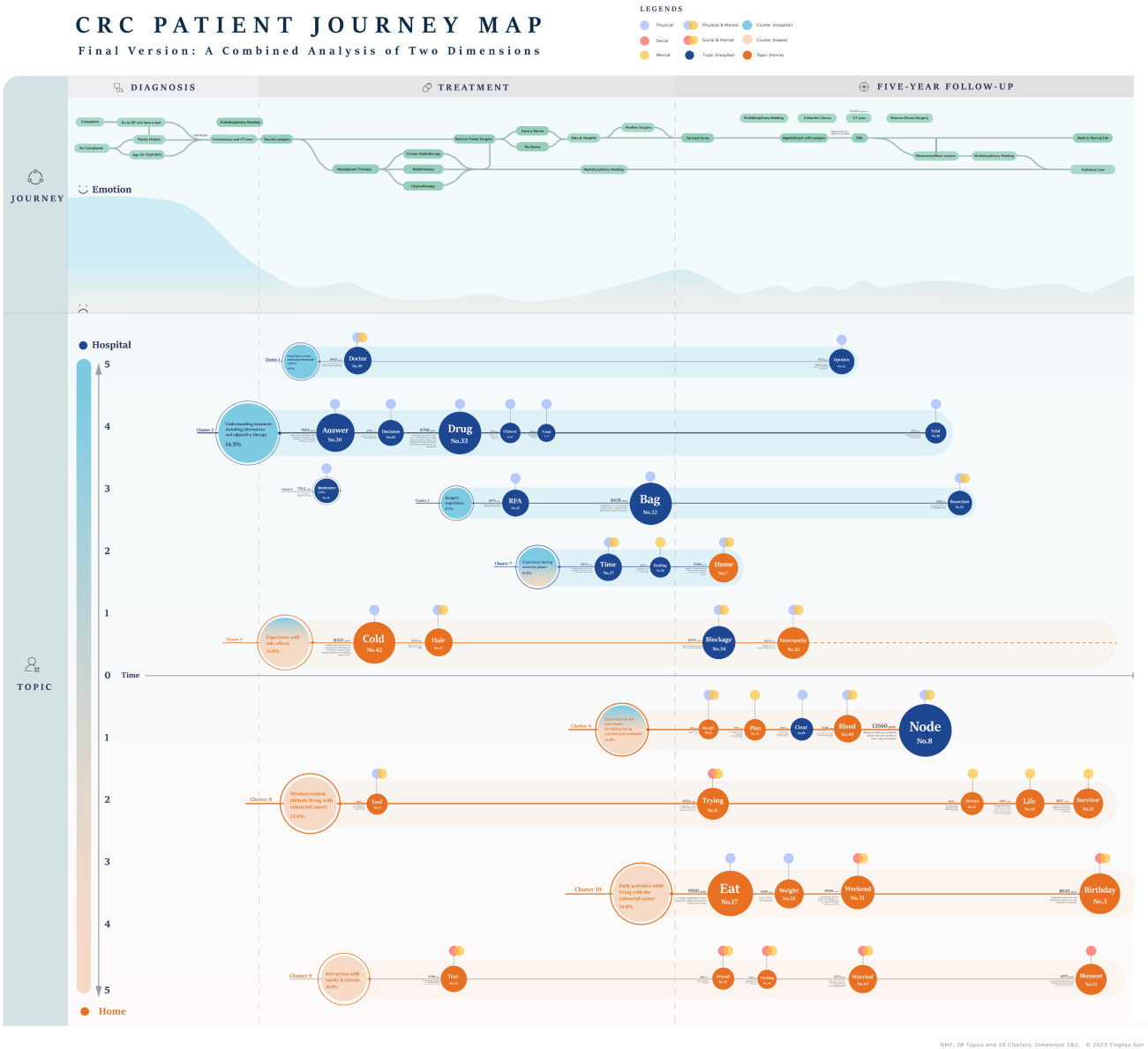


Figure 18 Final Colorectal Cancer Patient Journey Map. (Download original file here: https://sunny990115.wixsite.com/sdae)

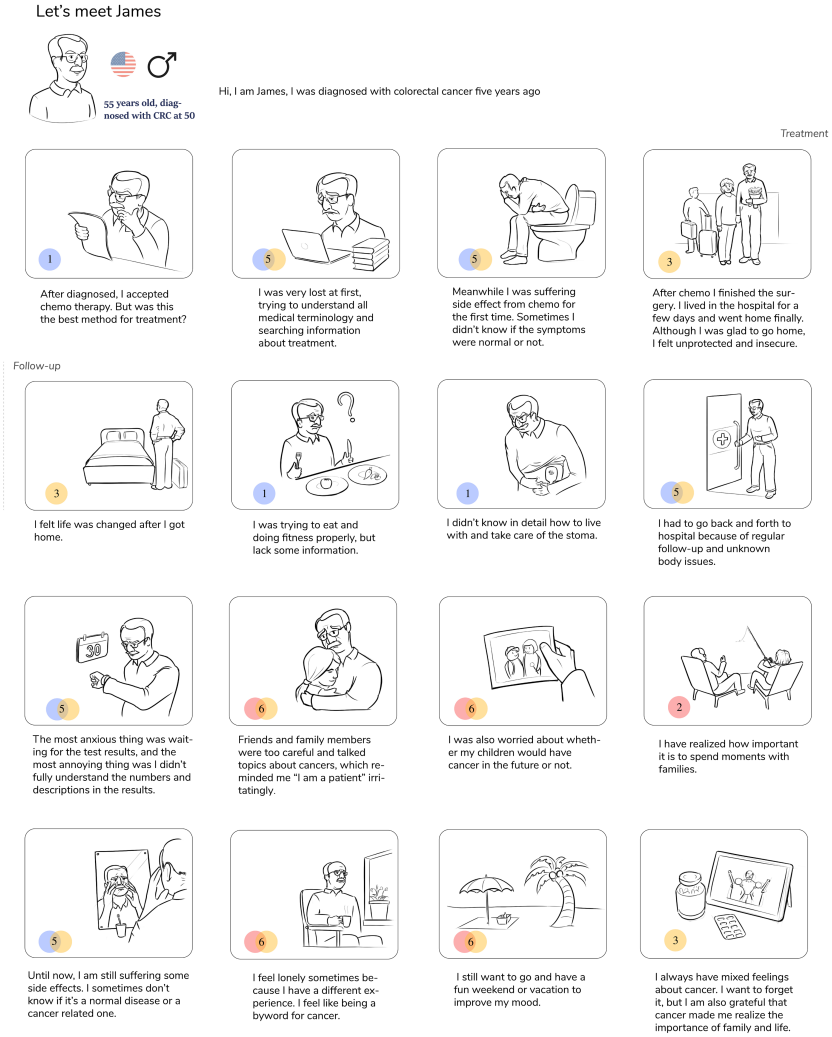


Figure 19 Storyboard. (Download original file here: https://sunny990115.wixsite.com/sdae)

Results

In terms of the hospital and home dimensions, my categorization distinguishes the topics in these two contexts. Topics under the hospital context are mostly related to physical health, pathological knowledge, medical procedures, and medical systems. Conversely, topics within the home context primarily revolve around daily life, social interactions, and personal reflections. Upon reviewing the topics and posts, I arrived at a key observation: patients tend to approach discussions within the hospital context in an objective, rational, and focused manner, while discussions within the home context tend to be more emotionally charged and subjective when patients are describing. This is exactly in line with the findings of the first version of the journey map.

When combined with the three-dimensional theoretical framework of health, the topics in the hospital context are mainly related to physical health. A significant number of topics are at the intersection of physical and mental health. By analyzing the topics and posts, I discovered a notable trend between these two aspects: mental health is frequently influenced by physical health. For example, side effects often cause a lot of physical pain and living inconvenience, which can be quite stressful for the patient and further affect mental health. I also see the same trend between social and mental health, which occurs usually in the home context. A patient may become emotional about a changed social relationship, as an illustration, often depending on whether the change is positive for the patient.

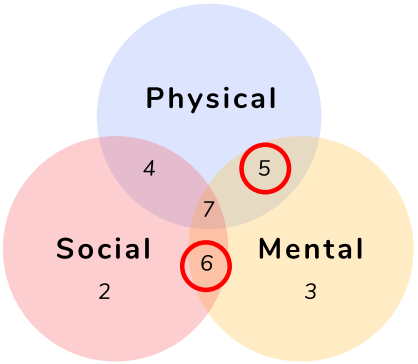
When the focus is shifted to the follow-up stage (on the right side of Figure 18), there is a significant increase in the number of topics in the home context, while the number of topics associated with the hospital context is relatively limited. In addition to this, social and mental related topics are also emerging at this stage. Accordingly, during the diagnosis and treatment phase, patients are often busy looking after their physical health. While this can lead to a certain amount of mental stress, much of this stress comes from cancer. However, during the follow-up phase, patients are becoming more aware of the disease itself and are therefore relatively relaxed. At this time they begin to have the energy to focus on things other than their bodies, such as socializing and daily activities. They gradually notice that their surroundings are changing as well. These changes are frequently attributed to the impact of cancer and can also lead to emotional fluctuations in the patient.

In general, the patients' experience during the follow-up stage becomes more complex due to the involvement of social and mental health. Therefore, when undertaking a project focused on the follow-up phase, it is essential to direct attention not only to the physical well-being of the patients but also their social and mental well-being.

Cluster 1			
Experience around medical professionals' opinion	39	Doubts about treatment opinions from medical professionals
	45	Suggestion to look for a second medical opinion; suggestion on dealing port in the best way.
Cluster 2			
Understanding treatment including alternatives and adjunctive therapy	30	Patients share their research about alternative therapy options from websites and articles, making a judgement on options.
	10	Making treatment decisions for the future with regard to the best outcome and path.
	33	Listing type, side effect, regimen, and effectivenss of drugs (folfox, oxaliplatin, avastin, and irinotecan) and the side effects from them (including rash, cell, and affect).
	14	Sharing experience on using Traditional Chinese Medicine to manage health.
	21	Sharing experiences and recommendations for supplements and medication.
	48	Sharing information about and holding a positive attitude towards clinical trials.
Cluster 3			
Surgery experience	25	Sharing experience around RFA ablation for the liver.
	22	Suggesting how to take good care of stoma -a daily process that requires careful attention.
	23	Sharing negative experience about resection in liver and lung: complications happens.
Cluster 4			
Experience on the test results (including being worried and confused)	9	Being worried about upcoming scans and results.
	18	Sharing their outcomes (clear or not) from scanning and caring about how frequently they scan.
	49	Decribing a stressful experience in a blood test; worry about the numbers in the result.
	8	Being worried and confused about odd scan results in liver, lung, and lymph.
	15	Sharing negative emotions and experiences to live with colorectal cancer: overwhelmed, confused and scared, especially for the tests and screenings.
Cluster 5			
Experience with side effects	42	Sharing their experience on managing the side effects of treatment: drinking water, taking medications, and getting plenty of rest.
	37	Negative feelings of hair loss due to cancer treatments.
	34	Feeling uncomfortable due to the intestinal blockage.
	32	Experiencing pain and numbness due to nerve damage in various body parts of the body.
Cluster 6			
Confusion with Insurance	38	Confusion about insurance coverage.

Figure 20 Topic Descriptions and Clusters in the Final Map.

Cluster 7	27	Describing negative experience of repeated visits to the hospital due to the infection after surgery.
Experience during recovery phase	20	Staying positive and making life adjustments to their cancer circumstances during the recovery phase.
	7	Happy for patient peers going back home after surgery and wish each other to recover quickly.
Cluster 8	24	Sharing their feelings: sick, tired, weak and bad but is starting and hoping to feel better and be stronger.
	0	Difficulties to adjust and adapt to their lives with colorectal cancer.
Mindset-related attitude living with colorectal cancer	41	Sharing how patients can be resilient and positive: always stay strong, laugh and humor, never give up, and be a hero.
	46	Sharing their positive philosophical thoughts about living with cancer (e.g. taking care of the quality of life, being more resilient in the face of fear and death, and the power of living in the present moment for a more fulfilling life).
	11	Survivors sharing their attitudes towards living with cancer along with survival rate.
Cluster 9	40	Family members' emotional struggle about having a cancer patient in their family.
	47	Experience on relationships with friends while having cancer.
Interaction with family & friends	28	Sharing changes in their family relationship due to cancer journey (both positive and negative).
	43	Being worried about their family members and seeking information on family history (e.g genetic testing).
	13	Arguing the importance to spend moments with family members during the cancer journey.
Cluster 10	17	Sharing suggestions on diets focused on balanced meals and healthy alternatives.
Daily activities while living with the colorectal cancer	35	Sharing experience on being fit again, caring about weight control.
	31	Sharing ways to stay in a positive mood through planning for a fun weekend, such as a vacation, trip, party, movie or game night.
	3	Celebrating anniversary and birthday for patients as a big milestone of their lives.



TAKEAWAYS

Final Journey Map

- In the follow-up stage, the number of topics grew a lot in social and mental health-related topics while physical-related topics are reducing, so it's important to notice these aspects.
- Although there are fewer physical health related topics during the follow-up phase, they affect the patient in the long term, leading to the patient's mental health being affected as well.
- As these social and mental health-related topics often occur in the home context, a remote monitoring system for these areas is necessary.

2.5

Summary of Key Insights

	First Journey Map	Second Journey Map	Final Journey Map
Model	LDA	NMF	NMF
Dimension 1: Hospital and Home	Yes	Yes	Yes
Dimension 2: Three-dimensional Framework of Health	No	No	Yes
Number of topics	48	38	38
Exclude topics or not	No	Exclude 12 platform-related topics	Exclude 12 platform-related topics
Number of clusters	19	10	10
Emotion curve	No	Yes	Yes
Distributed direction of topics	Vertically	Horizontally	Horizontally
Deep analysis	Yes	No	Yes
Used as materials later	No	Used for experts co-creation session	Used for storyboard and follow-up research

Figure 21 Summary of the Three Maps.

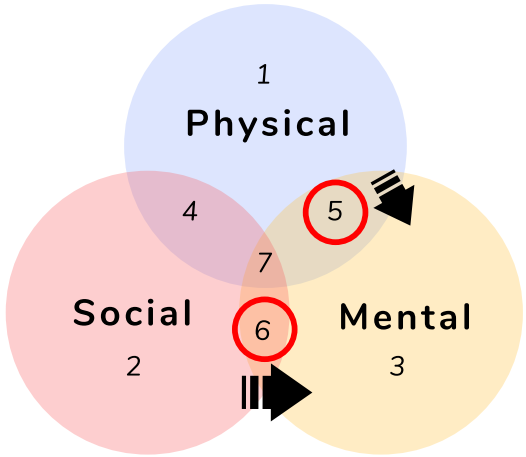


Figure 22 Summary of the Focus of RPM from the Framework.

1. Three versions of the journey map were developed, presenting an iterative relationship between them. Therefore, to effectively show the similarities and differences among the three versions, I summarized them in Figure 21.

2. Patients are more rational when the discussion is related to the hospital context, while in the home context, they are more emotional.

3. Social and mental health usually belongs to the home context.

4. Mental health is often affected by social and physical health (Figure 22).

5. In the follow-stage, patients are more concerned with social and mental health. Mental health also overlaps with physical health, expanding beyond purely physical concerns (Figure 22).

5. There is a gap between the knowledge possessed by medical experts and patients in the home context. The experts lack understanding and express a desire to comprehend the context during the patient's absence from the hospital environment.

Chapter 3

Problem Definition

Define Research Question Based on Chapter 2

3.1 Problem Definition

3.2 Summary of Key Insights

This chapter focuses on how the research problem is defined in the combination of Chapter 2 and literature and how it points to a design vision.

It takes three steps to finish defining the problem. Firstly, I establish the research scope that focuses on studying the patient's (social and daily) activity and related emotions. Next, I illustrate the significance of this scope by combining relevant literature with insights from the patient community journey map. Lastly, I reinforce the necessity for the proposed connection by highlighting an existing "gap" between medical experts and the defined scope.

3.1

Problem Definition

There are a total of three steps in defining the research question. First the scope of the study was defined, as the scope defined by the theoretical framework in the previous chapter is still relatively broad. Then the problem was defined by combining the current situation of remote patient monitoring (RPM) and the views of hospitals respectively.

Step 1: Defining Research Scope

From the journey map and the experts co-creation session in Chapter 2, I have concluded that the development of a remote monitoring system for “social and mental health” and “physical and mental health” during the follow-up phase is very necessary. This means not only monitoring social and physical activities but also taking into account the mental health they affect. However, since all three dimensions of health are relatively broad, it is necessary to provide a specific research scope that fits this project.

The first aspect pertains to the specific definition of physical and mental health. In the three-dimensional theoretical framework of health, the researchers use some issues such as sleep and fatigue, as indicators of QoL (van Leeuwen et al., 2018). The previous research shows a more obvious direction of flow, which is that mental health is often influenced by physical and social health. The sources of stress and distress for colorectal cancer patients extend beyond physical pain, encompassing the frustration of being unable to engage in activities as they did before the illness (Changyai et al., 2020; Jakobsson et al., 2017). These types of activities typically take place within the home context, often accompanied by a range of emotions. Such aspects are often overlooked or difficult to know by doctors, who possess extensive familiarity and expertise in physical health in the hospital context (Best et al., 2014). In this project, therefore, our definition of physical and mental health focuses on the patient's daily activity and related emotion, which is mainly about physical activity with low interactions with other people.

The second aspect is the definition of social and mental. In the framework, it refers to "role limitations due to emotional problems and a sense of belonging" (van Leeuwen et al., 2018). The patient journey map shows that many topics related to social and mental health emerged during the follow-up phase. Along with some positive or negative emotions, this aspect often involves the "people" with whom the patient interacts. A very common example is peer support, which involves patients engaging in conversations with one another, and has been demonstrated to be beneficial and capable of fostering positive emotions (Dunn et al., 2003; Hoey et al., 2008). The patient's emotions can also be significantly influenced by the interactions between colorectal cancer patients and their family and friends (Ó Céilleachair et al., 2012; Ohlsson-Nevo et al., 2012). In addition to this, I have also found from the journey map that social health often involves other people and is often

accompanied by emotional changes that may further affect mental health. Therefore the scope of social and mental health was defined as the social activity and related emotion.

In general, the original position 5 refers to daily life and related emotions when colorectal cancer patients are alone, while position 6 mainly refers to social activity and related emotions (Figure 22). Since social activity and daily activity intersect to some extent, the level of human interaction acts as the primary differentiating factor. To enhance the convenience of descriptions, I will collectively refer to these two aspects as "patients' activity and related emotions, which will be the research scope of the project.

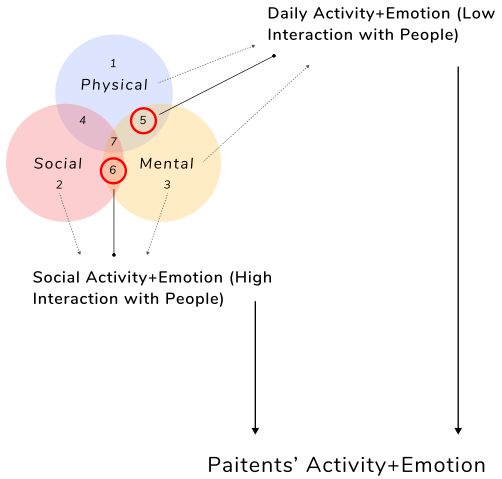


Figure 23 The Final Scope in This Project.

Step 2: Combining the Remote Patient Monitoring

In today's world, there are numerous designs for the remote patient monitoring (RPM) system in the healthcare area. From a medical standpoint, they hold significant value in gaining insights into a patient's physical health and even reduce the time for clinical decision-making (Crossley et al., 2011). RPM empowers patients to stay well-informed about their health and therefore enhances their self-awareness and confidence to self-management (De San Miguel et al., 2013; Gorst et al., 2016; Walker et al., 2019). It also provides a degree of security as it keeps an eye on the patient's health and makes them feel at ease even when they are alone (Lu et al., 2014; Rahimpour et al., 2008).

In many of the existing studies, the design of remote monitoring systems for patients has mostly been about physical health aspects, such as monitoring vital signs (Jamil et al., 2020). The development of these systems is often driven by technology focusing on physical health, including the Internet of Things (IoT), artificial intelligence (AI) and sensor technology (Islam et al., 2020; Jamil et al., 2020; Kishor & Chakraborty, 2022; Majumder & Deen, 2019; Malasinghe et al., 2019). When I adopt a patient-centred perspective, it becomes evident that the social and mental well-being of patients in the telemonitoring system is relatively neglected in comparison to their physical health. Many activity monitoring systems are still focused on physical health based on technology (Sapci & Sapci, 2019; Vitabile et al., 2019) and fail to integrate the other two aspects of health.

The patient's journey map also reveals numerous topics concerning social and daily activities and related emotions that are often overlooked by the medical system, because they fall outside the scope of the hospital context. Therefore, there exists a need to bridge this oversight and develop a remote patient monitoring system tailored to address these aspects.

Step 3: Combining Hospital's Perspective

In Chapter 2 of the study, I mentioned that the experts co-creation session revealed that the doctors were not aware of the patient's situation at home, but they want to know what happens when the patient is away from the hospital context. The hospital, as the primary player in the medical system, should take on the responsibility of fully understanding patients regarding quality of life, including social and mental health. Although there are currently QoL questionnaires that cover the areas (Gujral et al., 2007), there is still a lack of in-depth understanding of patients.

At the same time, patients' emotions can easily be overlooked during the communication between the doctor and patient, which may suggest that they have mental health problems (Lelorain et al., 2018). It is often difficult for people to recall the activity that occurred (Bernard et al., 1984),

while the emotions are involuntarily expressed. Therefore, the need for doctors to capture the patient's emotions and understand the reasons behind them is a quick way to grasp all three aspects of the patient's health. The ability of doctors to perceive patients' emotions and show empathy for their experiences in the clinical process can build a strong doctor-patient relationship (Anderson et al., 2008; Finset et al., 2013). Therefore, it is important for doctors to also care for the mental health of their patients when interacting with them.

In general, to improve the quality of life of patients, it is important to focus on not only the physical but also the social and mental health of patients from the hospital's perspective. However, there is still a gap between medical experts' knowledge and the CRC patients' activities in the social and mental aspects (Figure 24) which will require some effort.

Conclusion

In summary, the problem is defined in three steps. I first defined the scope of the study in terms of the journey map, the experts co-creation session and the literature. The scope was defined as the "patients' activity and related emotion", where activity refers to social and daily activity. Then through the literature and journey map, I illustrated the significance of this scope for QoL but few existing telemonitoring systems reflect this aspect of the design. In the end, I use the combination of the experts co-creation session and literature to show that although medical experts express interest in this scope, they are not aware of the context. This is where a "Gap" emerged.

Therefore, the defined research question is:

How to develop a remote patient monitoring system for patients' social and daily activity and related emotion when they are away the from the hospital?

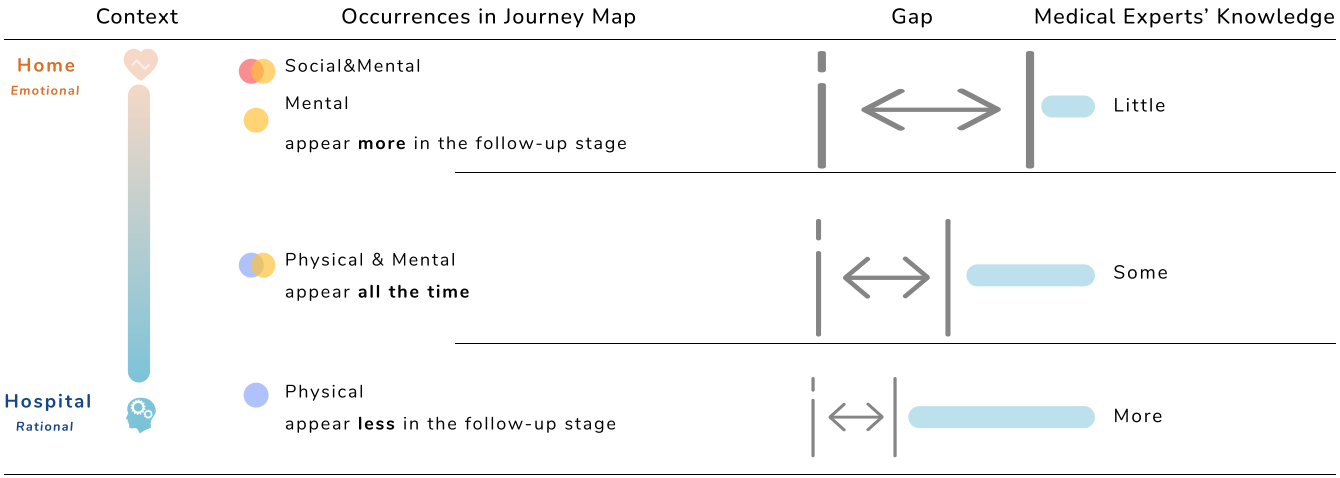


Figure 24 Defining the "Gap".

3.2

Summary of Key Insights

The whole process and the research question are shown in Figure 25.

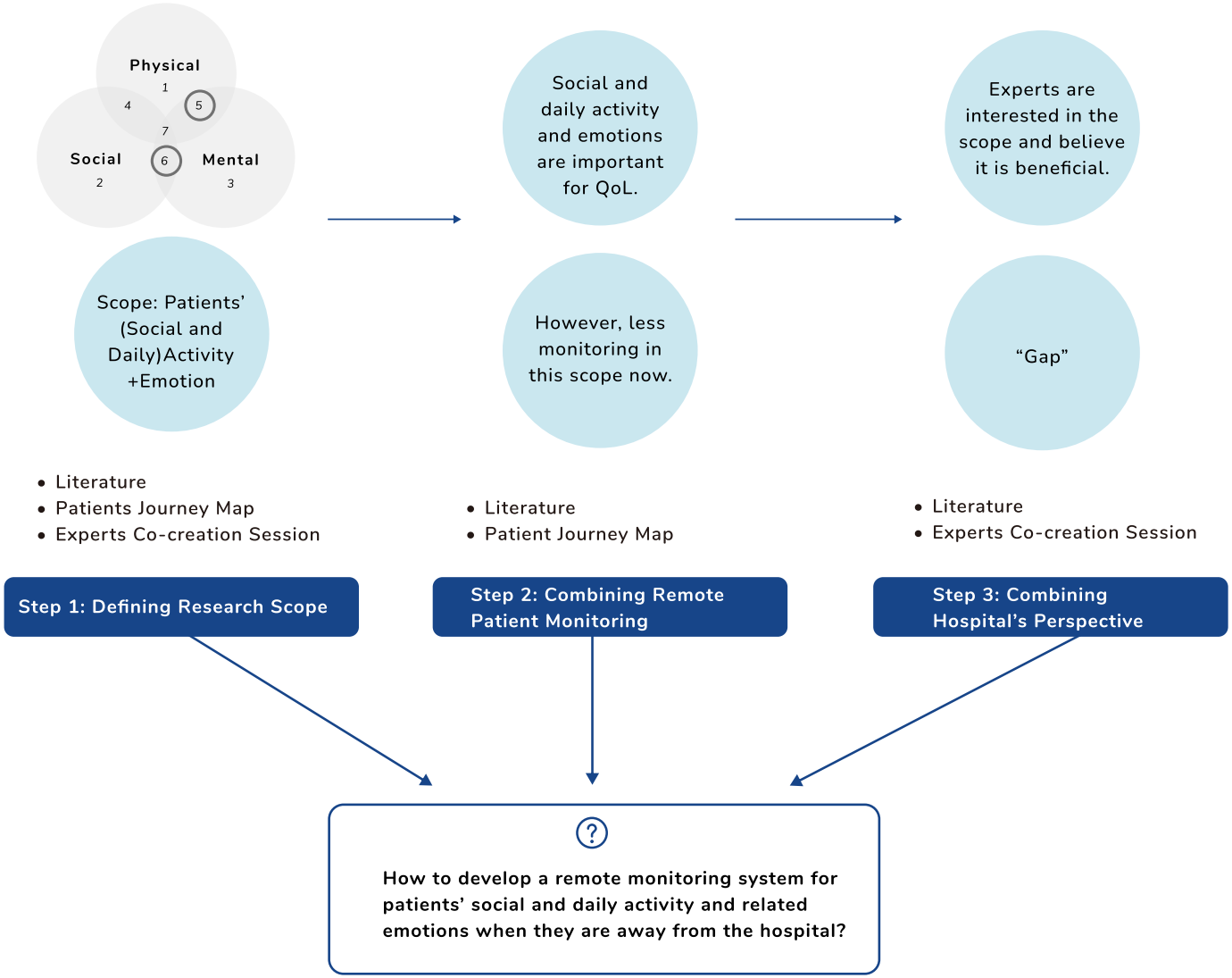


Figure 25 Process of Problem Definition.

Chapter 4

User Research and Conceptualization

Explore Research Question and Conceptualize Outcome

4.1 User Research Methods Selection

4.2 Probe Introduction

4.3 Diary Studies and Follow-up Interview

4.4 Designers' Brainstorm Session

4.5 Summary of Key Insights

This chapter focuses on how I have used some research methods and a probe to understand patients' attitudes towards monitoring activities and emotions. This series of methods consisted mainly of diary studies and follow-up interviews with patients. After gaining insights, I applied the results of our diary research and interviews to a brainstorming session with designers. I invited designers from different disciplines to think together about what direction should take. This was a way to gain inspiration for the design and prevent bias.

The special feature of this study is that the content of the material used in the diary studies was a probe for exploring the research question. The probe can be also understood as a prototype for monitoring the activity and emotion, but it's more like a trigger for patients to know about the context and provide more valuable insights. The probe is purely paper-based and contains only the important elements for the patient to fill in, which was developed from the Five Ws method.

The patients' diary studies and interviews, and the designers' brainstorm session suggest a variety of answers to the 'How' of the research question. These answers were summarized in guidelines and can be followed in the next chapter (Chapter 5).

4.1

User Research Methods Selection

This section is about the reasons for choosing diary studies and interviews as research methods by comparing several common user research methods.

Comparison of Five Common Methods

In selecting research methods, I focused on five commonly used user research methods for comparison (Figure 26).

Among the five methods, both semi-structured interviews and focus groups are well-suited for obtaining in-depth insights. However, they have limitations when it comes to continuous and real-time monitoring, preventing patients from actively trying out the probe. These methods rely on retrospective reporting of activities and emotions, potentially resulting in the loss of valuable insights. On the other hand, the observation method allows for continuous monitoring of a patient's behaviour over time. However, implementing this method can be challenging due to site constraints. Furthermore, the lack of interaction with the patient between observation sessions may limit the depth of insights obtained.

Another common method used in data collection is the experience sampling method (ESM), which is often accompanied by questionnaires (Csikszentmihalyi & Larson, 2014). It is a method of collecting data at a fixed point over a period of time and relies heavily on self-reporting by the user (Csikszentmihalyi & Larson, 2014).

This method is also often applied to measure daily quality of life (Hektner et al., 2007). In this method, however, the users usually fill in a questionnaire when they receive a signal, rather than entering the data completely voluntarily. The questionnaire is usually already set up with questions, which also leads to limitations in insight and creation. Users may lose interest after a few fillings.

Combine Diary Studies and Interview

A combination of diary studies and interviews becomes the final choice for the study method.

Diary studies, as a qualitative research method, can provide qualitative information such as people's experiences over a period (Horstmann, 2021). Originally a method in the field of psychology, it has been also used in the field of design to understand the behavior of users (Blaynee et al., 2016). I finally chose this method because it is an approach that is easier for patients to understand and get started with while capturing a lot of contexts. It also simulates remote monitoring in a very basic way as patients were sharing their data. Hence, the diary studies serve a dual purpose, serving not only as a research method but also as the fundamental prototype of the RPM. The content designed for the diary acting as a tool captures the essence and foundational elements of the envisioned remote patient monitoring system. Although it is not always possible for events to occur and be

	Diary Studies	Questionnaire in ESM	Semi-Structured Interview	Focus Group	Observation
Qualitative or quantitative method	Qualitative	Quantitative	Qualitative	Qualitative	Qualitative
In-depth insights	More	Less	More	More	Less
Single / Multiple participants	Single	Single	Single	Multiple	Single or Multiple
Real-time/ Retrospective style	Both real-time or retrospective	Retrospective	Retrospective	Retrospective	Real-time
Tracking over time	Yes	Yes	No	No	No
Interact with the patient	No	No	Yes	Yes	No
Creative Material Interventions	Yes	No	Yes	Yes	No
Restrictions on insights output	Low	High	Low	Low	Low
Site restrictions	No	No	No	No	Yes

Figure 26 Comparison of Five Common Research Methods.

recorded at the same time, it is usually possible to complete recall and recording within a day. As participants were able to record their own behavior over a period of time using a number of materials, this was in line with the desire to monitor patient activity and emotions.

Meanwhile, conducting a follow-up interview after the diary study is a valuable approach to gain a deeper understanding of patients' experiences and their attitudes towards the probe. Since the diary study does not involve direct researcher intervention, it can be challenging to gather specific insights about patients' feelings and recommendations regarding the probe.

By conducting a follow-up interview, I can engage in a more interactive conversation with patients, allowing them to express their thoughts, emotions, and recommendations in a more nuanced and detailed manner. This follow-up interview can provide valuable insights into patients' overall satisfaction, challenges they encountered, benefits they experienced, and suggestions they have for improving the probe.

4.2

Probe Introduction

This section introduces the probe used in diary studies to monitor activities. The probe can be understood as a simple prototype for monitoring patients' activity and emotions. One of the essential approaches applied is the Five Ws method, which helps answer the question of "how to monitor the activity" by providing a framework for capturing activity details. By systematically considering these five elements, the probe can effectively monitor activities and build a comprehensive activity context. The collected information enables researchers to gain a deeper understanding of the patient's daily routines, behavioural patterns, and emotional fluctuations.

Five Ws Method: Building the Activity Context

When building a remote patient monitoring system, the first thing to consider is what to monitor. The target is monitoring social and daily activity and related emotions. Emotion itself can be monitored as an element, but activity requires some effort to define as it is relatively abstract and difficult to describe.

In this project, the "Five Ws" method was applied to build the content of the activity. Five Ws refers to "What, When, Who, Where and Why". It serves as the basic questions for collecting information and can build a very rich context for an event. Five Ws originates in the field of journalism and has been spread in several areas. For example, some researchers have created a visualized information system using this method in the healthcare field, which reduces the effort for doctors to obtain rich patient information (Zhang et al., 2013).

The utilization of the Five Ws allows for a comprehensive portrayal of the colorectal cancer patient's activity context, facilitating a more thorough examination of the factors contributing to the patient's lack of healthy social or daily activity. This not only provides valuable insights for medical experts but also empowers patients to engage in introspection and take charge of their own well-being by detailing activity descriptions (Ewart, 2009).

In conclusion, describing the activity using the Five Ws can help patients think about and record the activities with a rich context.

Inside the Probe

The probe includes:

(1) Instruction of the probe (Figure 27).

(2) A background card (Figure 28).

(3) Diary for a day: a cover (Figure 29), diary cards (Figure 30) and an emotion curve card (Figure 31).

(4) Social and daily activity context generator (Figure 32).

Instruction of the Probe. Figure 27 shows the Instruction document. In this section, I introduce the contents of the probe, their functions and a description of how to complete the research. In addition to the four elements described above, I also provide the patient with a website called "Emotion Typology" (Fokkinga & Desmet, 2022). It includes 60 positive and negative emotions which help patients describe their emotions in a detailed way.

Background Card. The primary aim of the background card is to gather essential information about the patient, including age, gender, career, and year of diagnosis. Additionally, it provides a space for the patient to describe their personality using a set of keywords. Alongside the basic information, I included a brief self-assessment and survey in the background card. Utilizing a 5-point Likert scale, patients need to evaluate three aspects of their recent health. Towards the conclusion, I posed two additional questions that they only need to answer with yes/no:

-Do you feel a change in social and daily activity after being diagnosed with cancer?

-Do you feel these changes affect your emotion? (both positively and negatively)

The purpose of the background card is to promote self-awareness and reflection in the patient by giving them a sense of “creating a personal profile”. The process of describing their personality, for instance, offers insights into how they perceive themselves from their own perspective. This additional layer of patient perspective information will share with the hospital to enrich medical experts’ understanding of the patients.

Moreover, the background card facilitates my understanding of the patient's background and current health status. Combined with the later-filled diary card and emotion curve, it provides comprehensive insights for me and contributes to a more in-depth and empathetic interview later.

The inclusion of the last two questions served two purposes: to quickly validate the necessity of the research question and to prompt patients to think about the activity and emotions. It also established a context for the subsequent diary entries, enabling patients to delve deeper into their experiences and provide valuable insights aligned with the research objectives.

Social and Daily Activities Context Generator. The social and daily activities context generator is an inspirational information card for patients. It does not require any filling in by the patient but rather provides inspiration for patients when they do not know what to fill in. As the patient is learning how to use this probe, giving possibilities or examples of Ws can inspire the patient to fill in the content without being overwhelmed (Sowell, 2017).

Only four Ws excluding “Why” were mentioned in this generator, because “Why” is more of a descriptive process and it is the result of patients’ own thinking and thoughts. It is difficult to make it

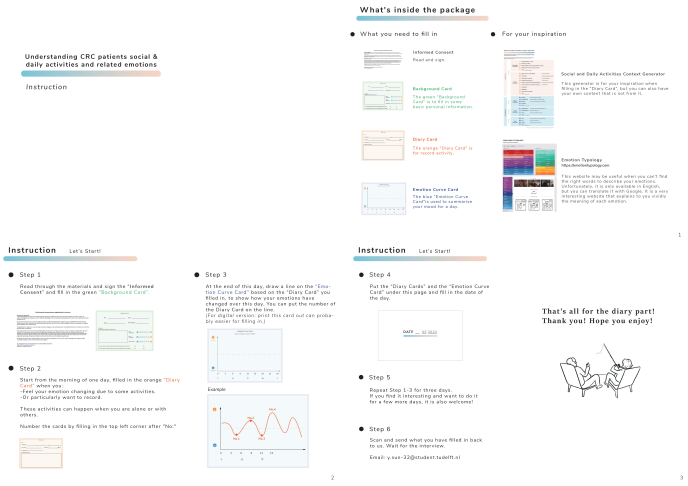


Figure 27 Instruction.

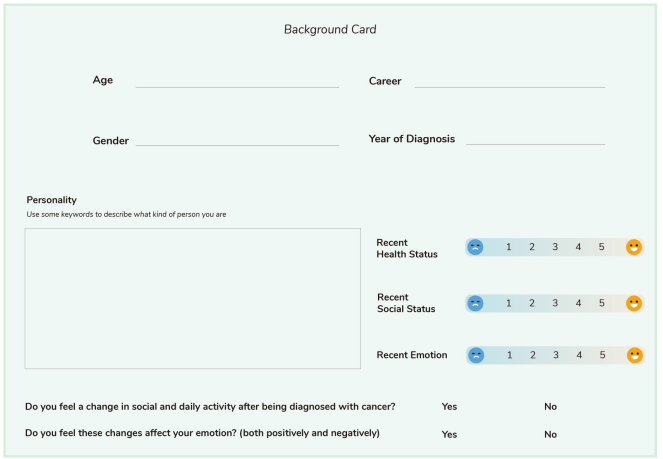


Figure 28 Background Card.

generic. The "What" information is the key element. It will lose the basic content if “What” is missing. I used three sources to give examples of “What”: the three-dimensional framework (van Leeuwen et al., 2018), the 38 topics generated by NMF and the 100 topics generated by Bertopic. All the “What” examples are from these three sources.

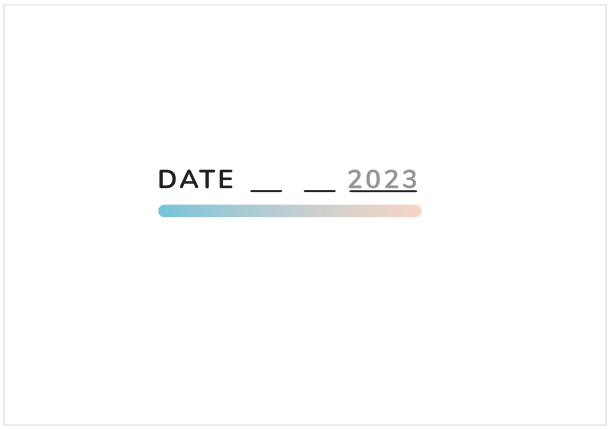


Figure 29 Diary for a day: Cover.

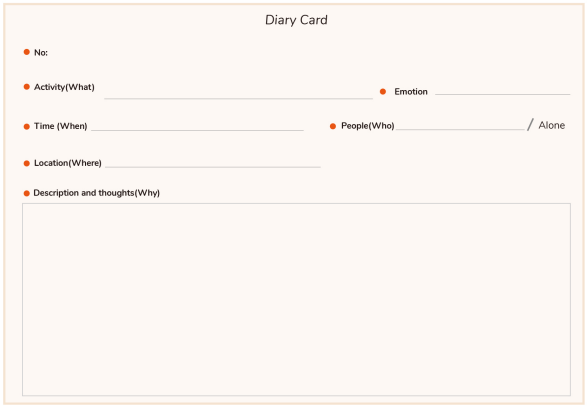


Figure 30 Diary for a day: Diary Card.

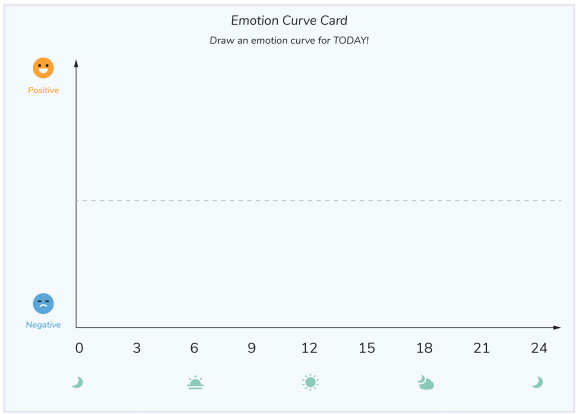


Figure 31 Diary for a day: Emotion Curve Card.

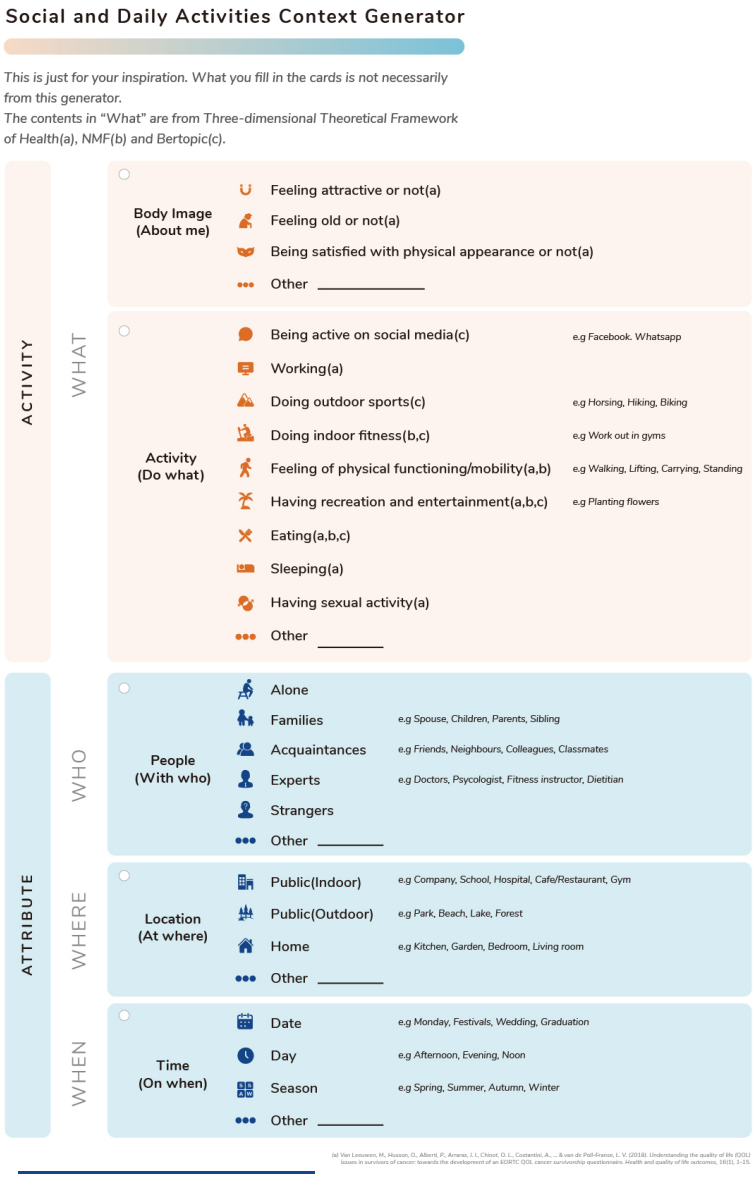


Figure 32 Social and Daily Activities Context Generator.

4.3

Diary Studies and Follow-up Interview

This section is about how the diary studies and follow-up interviews were conducted. During this process, the patients used the probe as the research material. The diary studies, which lasted 3 days, and the 30-minute follow-up interview provided a lot of insight for the next step.

Diary Studies Process

Recruitment and Participants. When it comes to recruiting patients, I sent invitations including a recruitment poster (Figure 33) and a link to online registration to various colorectal cancer-related websites and social media platforms in the Netherlands.

The minimum requirement for participating in this study is for post-operative patients over 18 years of age with colorectal cancer. The probe is particularly beneficial during the 1–3-year follow-up stage. However, there are no mandatory restrictions for the last requirement, allowing for broader usage and application.

Although I am an international student, to be inclusive and avoid excluding any groups based on language skills, I still didn't choose to impose restrictions on language. As a result, all our materials and posters were created in a bilingual format, catering to both English and Dutch speakers. Additionally, to ensure effective communication during the follow-up interviews, I invited a Dutch-speaking medical student who is also studying CRC patients' needs to assist me.

This approach allows me to engage with a wider range of participants and ensure equal access to the study.

After about two weeks of recruitment, I finally recruited a total of four patients (Figure 34) to participate in this study. All of them took part in diary studies and 30-minute interviews. The main distribution of these four patients is around 40-60 years of age. With the exception of one patient who was diagnosed with colorectal cancer in 2014, all patients were diagnosed within 5 years.



Figure 33 Recruitment Poster.

During the Study. Once collecting the participants' contact information, the probe was sent through email as they chose. In this study, I adopted a relatively casual approach and did not impose strict requirements on the patients regarding the completion of their activities. They were encouraged to record their activities when they felt it was necessary or relevant to do so. Although the study spanned over a period of 3 days, participants had the flexibility to extend the number of recorded days based on their own discretion. I provided a total of 10 days for participants to complete the diary studies and it was not mandatory for three days to be consecutive.

Upon receiving the probe, participants are required to begin by signing an informed consent form and carefully reading the instructions provided. They should then proceed to complete the background card, followed by the daily entries in the "diary for a day" section. Typically, participants record their activities on the diary card throughout the day. At the end of each day, they are encouraged to create an emotion curve on the emotion curve card, using the numbered diary card as a reference for the day's entries.

Throughout the entire process, there was no involvement from the designers or other researchers, ensuring that the patients remained independent and uninfluenced. Since the materials were sent via email, participants had the flexibility to choose their preferred method of filling them in. As a result, I observed various forms of completion during data collection, including paper-based entries as well as the use of iPads or other electronic devices.

As evident from the description above, I intentionally created a more voluntary and non-intrusive atmosphere. The probe also includes only the essential elements, without focusing on aesthetic appeal. The primary objective of this was to sense the patients' attitudes towards monitoring their activities and emotions. Following the submission of the completed materials, I conducted follow-up interviews to gain deeper insights into their experiences and perspectives regarding the process and the sharing of data. These follow-up interviews play a crucial role in gathering feedback and perspectives from the participants.

After receiving the completed materials from the patients, I summarized the completion of the participants (Figure 34), read the materials, and invited the patients to participate in the following interviews.

From Figure 34, I found that the four patients had different characteristics. Participant A failed to complete the three-day study. When I received her materials, she described it as difficult for her. I speculated that this might be due to the year of the diagnosis which has been a long time, and this hypothesis was confirmed in a follow-up interview with her. Participant B, on the other hand, did an additional day of the diary study, and the number of diary cards increased over the four days. Participants C and D did three days of the

	Age	Year of Diagnosis	Finished Days	Number of Diary Cards Per Day	Language	Online/Offline Interview
Participant A	61	2014	2	Day 1: 1 Day 2: 2	Dutch	Online
Participant B	53	2021	4	Day 1: 1; Day 2: 2 Day 3: 3; Day 4: 7	Dutch	Online
Participant C	45	2019	3	Day 1: 6 Day 2: 7 Day 3: 9	English	Online
Participant D	50	2021	3	Day 1: 3 Day 2: 3 Day 3: 3	English	Offline

Figure 34 Four Participants and the Completion of the Study.

study as originally planned, but Participant C recorded a very rich variety of activities each day, while Participant D was relatively even with three cards each day.

Interview Preparation and Analysis

Interview Format. The interviews were conducted individually, following a one-to-one and semi-structured format, with each conversation lasting approximately 30 minutes. To ensure that the participants' recollection of their diary study experience was still fresh, I scheduled the interviews approximately a week after receiving their completed materials. In order to accommodate the language preferences of the participants, two interviews were conducted in Dutch, while the other two were conducted in English. Additionally, three participants opted for online interviews, while one participant chose to have an offline interview.

Interview Guide. Before the interviews started, an interview guide (Figure 35) was written in order to clarify the framework of the semi-structured interviews. This interview guide is made up of five parts.

The first part acts as an ice-breaking function, which aims to get acquainted with the patient and to open the conversation. The questions in this section therefore explore a general feeling and the patient does not have to give detailed answers to any particular parts. The second part of the

Ice-breaking How did you feel about filling in the the diary overall? -How did you feel about the filling in the diary cards? -How did you feel about drawing the emotion curve? -Which part is the most interesting and the most difficult, why?	*2 minute*	**Goal:** **Ice-breaking and get overview of patients' feeling.**
About the diary Show the emotion curve for a particular day **(Patients can also talk about other days)** -Which of these activities were easier to fill in and which were difficult, WHY? -Are there any of these activities that stuck out to you the most? -Are there any activities on this day that are not written on here and why are they not on here? -When do you think is the best moment for intervention? -What types of activities do you think are necessary to be recorded (that may be relevant to your health) and what types are not necessary? In your past experience, are there any activities/times when you felt you should do something like this diary study, in order to let your doctor know or you think will be important to your health? Compare to those days when you didn't need to fill in the diary(before/after), do you feel any difference? -If you do, what's that? Will that be important for you? -If don't, why?	*15 minute*	**Goal:** **Recall patients on the diary they have filled in and find out their feelings and opinions on the process.** **Know what they think can be important to their health regarding the content in the diary.**
Evaluation on the diary Any ideas on how to improve? This can be: -Timing of data collection -Elements in the diary -Method of data collection -Involving other people -Any other things	*3 minute*	**Goal:** **Encourage patients to have opinions on how to improve.**
Sharing Data How do you feel about seeing other patients' activities? Are you willing to share this kind of data with other CRC patients? How do you think about letting other people to know your social and daily activities and emotion situation? How do you think about letting the hospitals (doctors, nurses or other medical experts) to know your social and daily activities and emotion situation. -Is there anything that is NOT in the diary study, but you feel important for doctors to know?	*5 minute*	**Goal:** **Discover the attitude about sharing data with other stakeholders.**
Last questions Any other thing you want to say?	*5 minute*	**Goal:** **Give an opportunity for the patient to add.**

Figure 35 Interview Guide.

interview focused on exploring the patients' subjective experiences and feelings related to the “diary for one day “part. To facilitate the conversation, I presented relevant materials that would be explained in detail later. This part aims to gain insights into how the patients felt while filling out various sections of the diary. I used the recorded activities as clues to discuss reflective questions, such as the most memorable activities, any missing activities, and activities that had a significant impact on their health. This process helped patients recall specific activities and motivate their thinking of attitude in relation to them. I also asked the patients to compare their experiences with the days when they didn't have to fill in the diary. This comparison prompted them to reflect on the overall impact of the probe on their well-being.

When the patient's memory and thinking were mobilized, I introduced the patient's evaluation of the probe in the third part. This evaluation can be about any aspect, such as when, how, and elements to fill in. In this section the patient has already recalled most of the diaries and feelings, so this is a good time to be critical and creative.

The fourth part aims to build a system. This mainly refers to the introduction of other people's participation in the process of using the probe. The purpose of this section is primarily to explore patients' perceptions and willingness to share the probe data with different stakeholders, with a focus on medical experts and other patients.

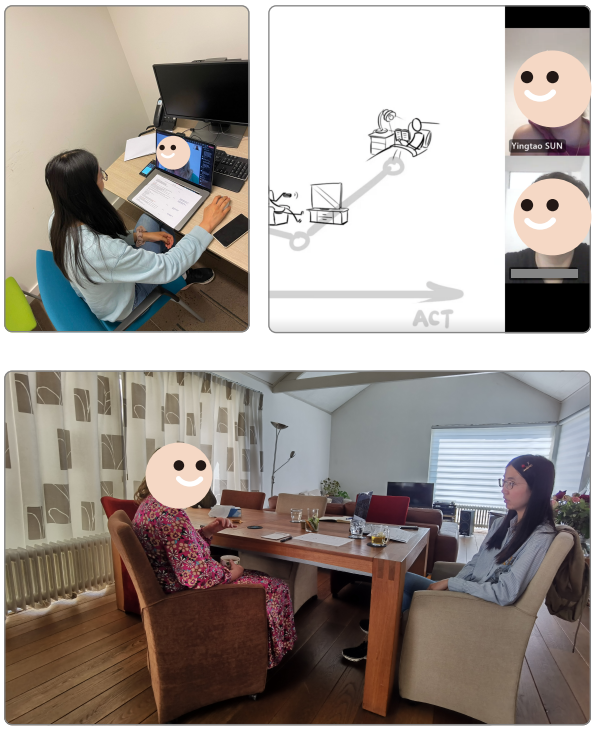
The conversation ended by asking the patient if they have anything to add to check if anything they would like to share but has not been mentioned.

As I do not speak Dutch, I invited a medical student who speaks Dutch and is also studying the experience of colorectal cancer patients to help. She interviewed two of the patients on behalf of me. The guide, therefore, contains a number of questions that were shared with the student. After she had understood my purpose for the interview and read the interview guide, she would still conduct the interview in a semi-structured rather than structured format. I stuck to a semi-structured interview format because I recognized the significance of deep dive into the reasons behind the insights shared by the patients. This approach allowed us to gain a deeper understanding of how to enhance the probe based on their valuable input. Semi-structured interviews were particularly suitable for this purpose, as they provided the necessary flexibility to explore why from diverse perspectives and uncover valuable feedback to inform future improvements (Fylan, 2005).

Interview Materials. To prompt the participants' recollection of their diary cards, I incorporated a visual component during the interviews (Figure 36 and Figure 37). In the second part of the interview guide that Figure 36 was used, I randomly selected completed diary cards were displayed to the participants, allowing them to visually revisit their recorded activities and emotions.

Furthermore, I chose one of the emotion curve cards from a specific day and plotted the corresponding activities on it. This visual representation served as a catalyst to stimulate the participants' memory recall and encouraged them to share additional insights and perspectives.

Figure 37 was also introduced in the fourth part of the interview guide. I showed patients the emotions and activities of a fictitious "someone" and asked them what they thought of seeing the states of another patient. Through this picture, they can form a more intuitive feeling and share meaningful views.



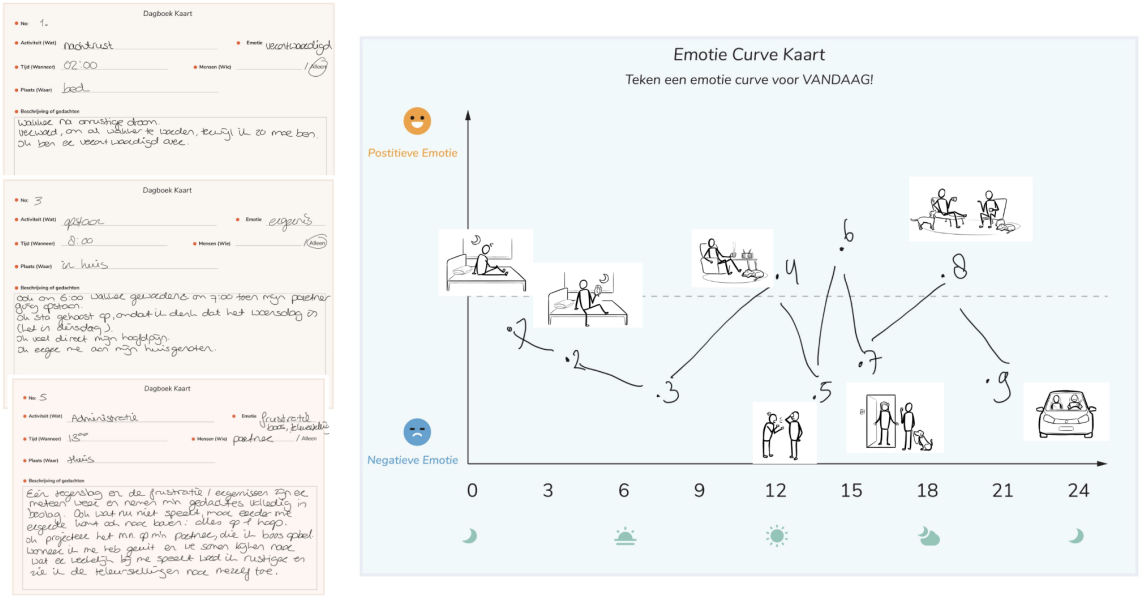


Figure 36 Materials for Recollection in the Second Part.

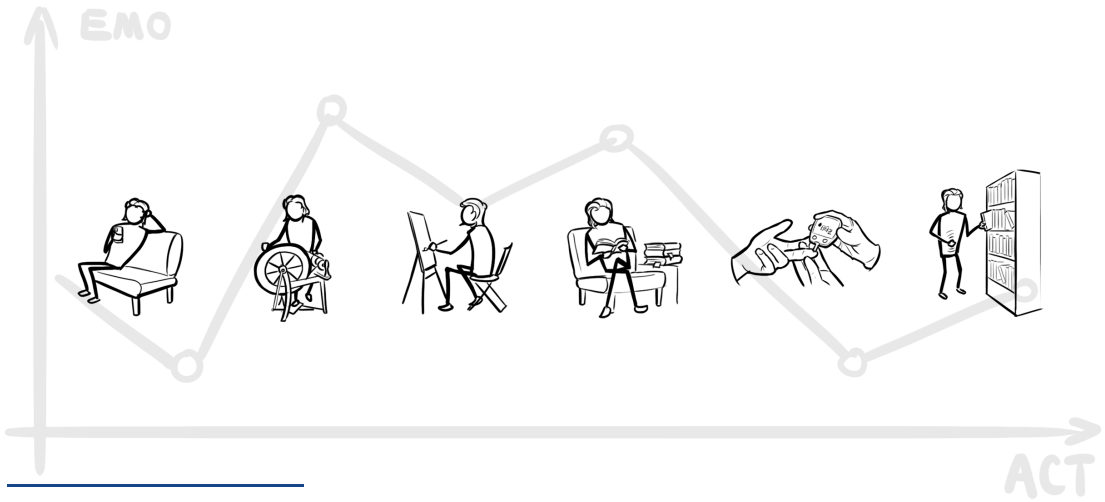


Figure 37 Materials for Sharing Data in the Fourth Part.

Follow-up Interview Analysis. The transcribed and translated interviews were printed out for analysis. The first round of analysis didn't translate the content during the coding process. Instead, I just summarized the original dialogue. Once all the codes were completed, I took on the role of categorizing them. This involved referring to the original text to ensure accurate categorization and assigning names to each category. Throughout this process, I used memos to record various ideas and reflections.

Once the categories were identified, I transitioned the role from the researcher to the designer and began asking questions and summarizing each code or a combination of codes. The purpose of this step was to provide inspiration to me and establish a connection between the research findings and the design ideation (Figure 38).



Code and Inspiration

Difficulties	
When everyday is the same, it's difficult to draw a curve.	**How to deal with low activity levels days/moments/groups?**
Hard to find a word to describe emotions. Hard to evaluation/quantify emotion level in a curve. Hard to fill and admit the angry feelings and what had happened.	**How to monitor and translate "Emotion"?**
Hard to fill in a dialogue with other people.	**How to record the interaction with other people?**
Not all things were recorded because it was hard to juggle recording and doing things.	**How to record easier?**
When is a good time to record the diary?	
Hard to fill in the morning. Don't want to be negative. Don't want to be too specific on the diary. Best to fill in the afternoon because evening is too low energy. Fill in the evening after dinner.	**More in the afternoon and evening.**
How to record better?	
It's nice to look back sometimes. Write at the moment is better. "I realised I didn't have my mindful moment yesterday. So I will pick up again." Like to have an overview of the activities in a day. "I make some conclusions of myself." "When I think I had a bad day, I look back the diary and I think, oh, it wasn't so bad. There were just two bad moments."	**Record real-time, but show a overview to make patients reflect regularly. This will influence the following days.**
How long should the diary take?	
Good to start from the beginning of cancer, make it a journey so that you can look back and see your improvements. In the beginning of the cancer period is also a good time for emotions. After the surgery will be different. Lots of ups and downs. Time could be longer. For example, a month.	**Tend to record(especially emotions) the whole journey of cancer.**
About the form	
Diary is more personalized than a questionnaire. Diary brings out more of conscious.	**Prefer diary study than a questionnaire.**
App is better because it can track things easier, more real-time. Writing in hand is better because you are more intensely involved. You can also think better.	**Paper+digital. Digital as primary, paper as secondary.**
About the content	
Emotions at work and the activity at the end of day are easy to fill in.	**Divide activities into categories and design accordingly?**
Activities in house are easier than outdoor.	**Divide indoor/outdoor context?**
Too small things were not recorded but can also effect health. Daily routine/Small daily things were not recorded, only if there's special feelings or a real change.	**How to deal with the "small things" in the product?**
Social change: more patients than before. Lack of energy because there are lots of social contacts. Social change: what and who gives me energy and make choice of friends. Something takes too much energy will frustrate me. Side effect: brain and mind will not be so active.	**ENERGY LEVEL: an important indicator for patients.**
Drawing the curve is a good way to show people how do I really feel.	**Visuals can shows something that can't express in words.**
The" Emotion Typology" is very useful for describing my feelings.	**Consider merge "Emotion Typology"**
About sharing data with others	
Want to see other patients' activities but no communications with others. Just out of curiosity. Sharing and seeing others' activities will help a lot. Don't want to see and share with patients because I will start compare. It is a wrong stimulation and will put me a bit down.	**Share with other patients, but with limited permissions**
Willing to share with doctors, to show how I am doing personally. Willing to share with doctors because more attention to how patients feel and doing is important. Willing to share with doctors and also hear back that other patients who also have same things.	**Sharing with (medical) experts is very positive**
Willing to share with coaches because they will provide advise.	
Want to share with others because I feel alone when I can only process emotions myself. Share with physiotherapist and husbands help me a lot. Want to share because it makes you feel less lonely.	
Patients' Behaviour	
Reduces social interaction when in a bad mood. More emotions come up when at home.	**How to engage the patient's emotions?** **Home is a good place to monitor.**
The Impact of Cancer	
Tired of explaining feelings to others.	**Show the feelings through visual?** **Share the probe?**
Social groups become smaller due to limited energy.	**Maintaining social connections through probe?**
More patients are present in social circles.	**Peer support.**

Figure 38 Code and Inspiration.

Results

Overall, four patients had a very positive attitude towards this probe. Even one patient did not complete the 3-day study as required, she said she enjoyed the process very much. The difficulty she found was simply due to the timing, as many years had passed since her colorectal cancer diagnosis. "If I had been invited to do this study five years ago, I am sure there would have been very much to record", she said. This further validates the significance of monitoring patients' activity and emotions during the follow-up phase after surgery, affirming its high value.

Attitude towards the probe. Most participants expressed that the process of recording their activities and emotions had heightened their self-awareness and facilitated a deeper understanding of themselves, as the following quotation illustrates:

> ***It (probe) can make you think more about the activities and how you feel about it. For me I am shocked to see how I feel." ——Participant B***

This self-awareness enables patients to be aware of what activities can have an impact on their mental health:

> ***It was for me a bad week. I wasn't feeling well and then because of it (probe) I was very aware that my homies were my biggest triggers. So I understand more on what happened between them and me." —— Participant C***

Some patients have reported that this probe can influence their way of seeing a day and even subsequent behaviours in a positive way:

> ***When I think I had a bad day, I look back the diary and I think, oh, it wasn't so bad. There were just two bad moments... And what this awareness bring as extra is some influence on me...On the third day of the diary study, I realized I didn't have my mindful moment like before which made me realized that it is so important to me, so I'll pick up again." ——Participant C***

Patients also expressed that they like the probe more than questionnaire because it's more personalized and attractive:

> ***I prefer that one(probe) because it's about me." —— Participant A***

> ***The process is like a story that I can look back on from time to time." ——Participant D***

Difficulties in Diary Studies. The main difficulties for patients were in how to record. For them, most of the recall and recording was done sometime during the day, rather than in real-time. Patients found it difficult to find the time to complete such detailed records while activity was taking place, and late recording made it easy to forget information such as the emotional state of the moment:

> ***Sometimes there was a moment and I thought oh I should write about this later and then I filled in the afternoon all my moments. But it's more specific if you can write at that moment when you realize: there's a change in my emotion, something happening. This is important to write immediately." ——Participant C***

Therefore, it is essential for patients to be recorded quickly and in real-time. This also leads us to the topic of recording formats. The four patients chose different forms of documentation, including paper, computer, or iPad. Apart from one patient who enjoyed the handwriting process a lot, all three said that a digital probe, such as an app, would be acceptable and more convenient.

> ***I recorded the activity afterwards because it was hard for me to track it. If I had app and then and I track it, or like I have a Fitbit. That will be nice. Cause you can really see, for instance, for your sleep, what it has happened. That also could be entering straight away by putting a happy smile and would be much easier than filling it in." ——Participant D***

On this issue, which has generated disagreement, I believe that a decision needs to be made as to whether it is specifically digital or paper based on the content. As the reason given by the patient who preferred paper was because it was easier to summarize and reflect by hand, it may be necessary to consider a combination of paper and digital, with the paper part being used to record reflections and the electronic to capture data in real-time. However, this will need to be discussed further in the subsequent design phase.

In addition, some patients found it difficult to find the exact words to express their emotions, but the website "Emotion Typology" provided to the was very helpful in realizing exactly what they were feeling. However, it was still hard to assess and compare the level of positivity between different activities when drawing the emotion curve.

> *But sometimes there wasn't a word for what I was feeling...and the score is...What is high? What is low? How high? How low? That's hard." ——Participant C*

Therefore, being too specific in asking patients to describe emotions may be an additional burden and is also unnecessary. This section needs to be streamlined in the subsequent design.

Time of recording. In terms of the timing of the recordings, I found that patients were concentrating on afternoon and evening recordings. They also gave the corresponding reasons:

> *Yesterday I did in the afternoon. I just think back. But it's not happened even at the end of the day, because then my energy is low, and I cannot think very well." ——Participant D*

> *In the evening after dinner, I wrote everything down, and that's saying a day is over." ——Participant A*

This observation highlights the fact that patients are more open and responsive to interventions from the probe during the afternoon and evening hours. Additionally, the finding suggests that the probe places a significant burden on patients and requires them to invest a considerable amount of time and thought to complete it. This aspect should be taken into consideration in the design process to ensure that the probe can be completed quickly. However, it is also important to incorporate regular reflection within the probe design.

What's missing from the diary. The first one is to check if there were any activities in the patients' daily lives that were not being recorded to assess the effectiveness of the probe. When discussing missing sections of the diary, patients mentioned that major events were generally recorded. However, the missing sections often consisted of mundane daily routines such as brushing teeth or washing up. These routine activities tend to go unrecorded unless there is a notable change or deviation from the usual routine:

> *Perhaps the small things that are so regular, unless there was a real change." ——Participant C*

In addition to this, during conversations with patients, I found that they were very concerned about their energy levels which is not an element in the probe. This energy level is the basis for some of the patient's activities and can even affect their emotions:

> *It's taking so much energy...so many things to start up and then I'm not able to do anything and that frustrates me of course." ——Participant D*

In general, in addition to the elements already contained in the probe itself, energy levels may also need to be considered. Small things like daily routines should not be mandatory for recording.

Sharing Data. In this section I explored patients' willingness and attitudes to sharing data. In general, patients showed a more positive attitude towards sharing data to hospitals (doctors), even other experts such as lifestyle coaches. However, when it comes to the rest of the population, such as other patients or family and friends, attitudes are not entirely consistent.

Patients feel that sharing their activities and emotions with their doctors enables them to understand themselves better. They feel that the doctor or hospital does not pay particular attention to the patient's state of life and emotional state. These activities or emotions often need to be addressed on their own, but they often affect their health very much. This also shows the importance of being able to give some feedback to patients after they have recorded and reported:

> *I want to share with doctors to show how I am doing personally because I feel alone when only processing the negative emotion myself." ——Participant A*

> *I am willing to share with my doctor, especially when I think I need help. Because I also understand that doctors are very busy." ——Participant D*

> *I really think it's helpful and I think every coach should advise his client to keep a daily data for himself." —— Participant C*

When asked if they would be willing to share their data with other patients, the majority of patients said they would be willing to do the same, but not for the same reasons. Some were motivated by curiosity, others felt that sharing would help them take away negativity and strengthen their connection:

> *"But it's really nice to share your story with other patients that I woke up and then I got a leakage again. And there are a lot of more information I would share with them." ——Participant D*

However, a patient mentioned that she preferred not to share with other patients, as she believed it could foster a comparison behavior.

> *I think I will start to compare. I will look at where I'm doing worse than the other." ——Participant C*

This can be concluded that sharing data with hospitals is generally viewed as positive and optimistic. However, it is important to approach sharing with caution and establish connections with other patients thoughtfully. Whether sharing data with hospitals or other individuals, it is crucial to be clear about the purpose and not share the source data indiscriminately. From our observations, I can infer that the information shared with others except for experts will likely be filtered and summarized to ensure privacy and confidentiality.

Conclusion. This can be concluded that sharing data with hospitals is generally viewed as positive and optimistic. In general, the attitude of the patients towards the probe is very positive, but as the probe is also a research method, there are still many imperfections that need to be designed and improved. However, the main purpose of the diary studies was to test the patients' attitudes towards monitoring activities and emotions in the simplest possible way, and to explore where the boundaries of monitoring lie. The views expressed by the patients through the interviews therefore also provide much inspiration for my next steps.

TAKEAWAYS

Diary Studies and Interviews

- Patients are positive towards the probe. They prefer the probe to a questionnaire.
- The main difficult parts for patients are: not having a real-time and fast recording and hard to express and evaluating specific emotions.
- The afternoon and evening are better times for the probe intervention.
- The normal daily routine is not necessary for recording.
- The energy level is important for patients.
- Patients want to share data with the hospital. But sharing with other people should be careful.
- Visual is sometimes more intuitive than texts.

4.4

Designers' Brainstorm Session

Up to this point, I have dedicated lots of effort to studying the context and patients' attitudes towards remote patient monitoring systems in relation to the activity and associated emotions. I developed an initial version of the probe, which has been applied in user research and has generated valuable insights. To ensure an unbiased approach and gather diverse perspectives, a brainstorming session was organized involving designers from various fields. Before the session, I prepared stimulating materials to fuel creativity, drawing upon the insights gathered from user research as valuable input. These materials were strategically designed to inspire innovative thinking and encourage designers to explore new possibilities.

In the end, I summarized a list of key properties for design as a result of this session. It is a conclusion and reflection of the designers' viewpoints during a quick design and thinking process.

Session Set-up and Process

Participants. In this session, I invited three designers from different areas of expertise: industrial design, user experience design and visual design (Figure 39). The designers from different backgrounds were able to bring different perspectives to the design of this project.

Materials and Process. The whole process consists of five parts and lasts two hours. I began by presenting the background of the project to the other designers, which mainly includes the contextual exploration that have been completed and the research question. The designers were asked to write down (using Figure 60) and discuss initial ideas for the research question only. It is important to note that the results of the user research were not presented at this point. The purpose is to enable the designers to tap into their own expertise and background knowledge to generate diverse inspirations while avoiding being limited by specific research findings.

After a series of discussions, I moved on to the second part, which is about building connections between patients and hospitals. Figure 41 shows the materials needed for this section. It has two parts of patients and hospital sides, with the elements that build the activity context and the indicators including emotions and energy level.

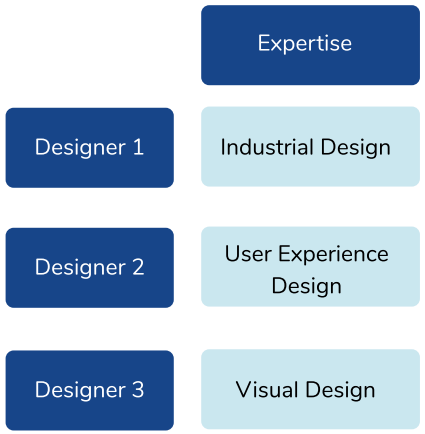


Figure 39 Participants of the Brainstorm Session.

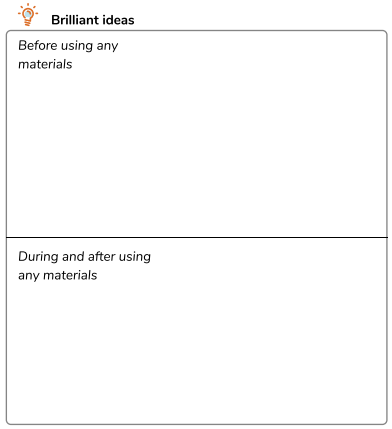


Figure 40 For Ideas.

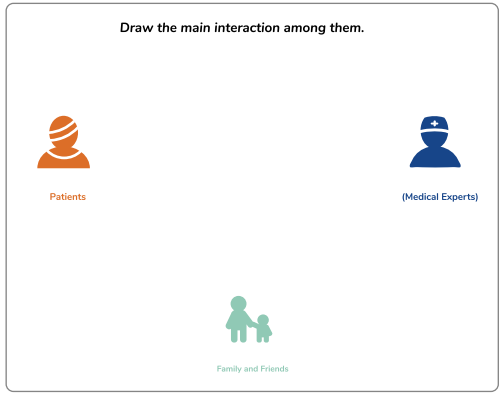


Figure 42 For Main Interaction Among Three Parties.

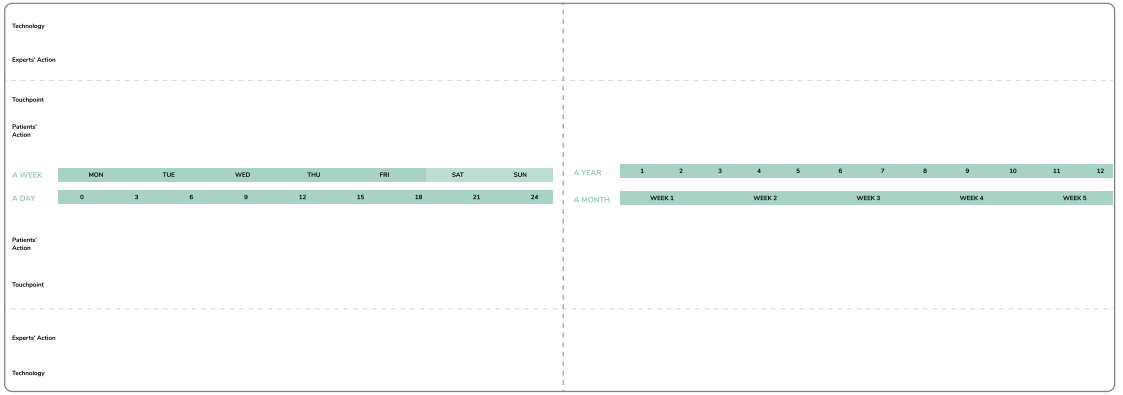


Figure 43 For Main Interaction Among Three Parties.

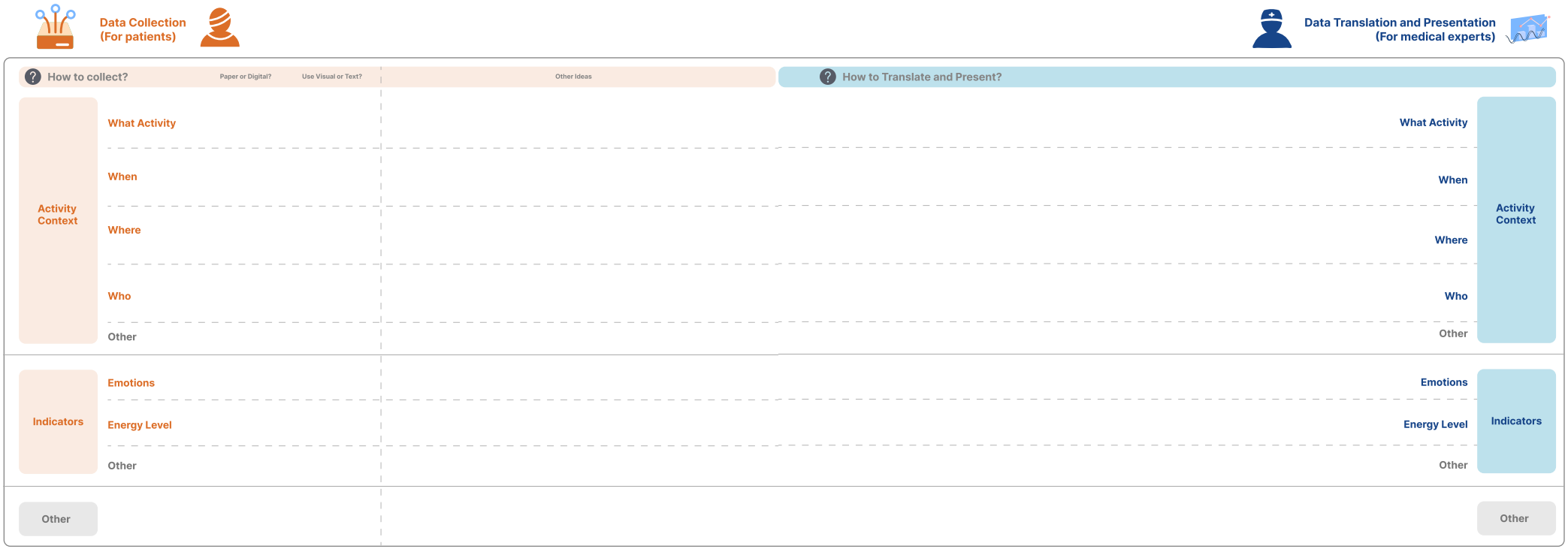


Figure 41 For Elements In the Probe.



The orange section on the left indicates patients, while the blue section on the right indicates hospitals and medical professionals. The patient side focuses on what data can be collected and how to collect it; the hospital side focuses on how to translate and present the data and the guidelines for this process.

After taking into account the relationship between patients and hospitals, I utilized Figure 42 to prompt designers to illustrate the interactions not only between patients and medical experts but also involving family and friends. It aimed to gain insights into how different designers envisioned the roles of these three parties within the system. By incorporating diverse perspectives, I sought to explore and understand the multifaceted dynamics among these stakeholders from the designers' views.

The designers then used the material from Figure 43 to explore the possible points of intervention of the probe according to the timeline, acting also as a summary for all the previous processes.

In the end, the designers also wrote a sentence or some keywords on stickers to express their vision of this probe and the system behind it.

The process followed a logic from vague to specific, from between to systemic relationships, and from the point in time to timeline. The reason for going from the vague to the concrete is that the designers themselves have a certain amount of creativity and intuition that allows them to make quick designs even when they only know the context (Tovey, 1997). Creativity is not easily limited in a fuzzy context (Agogué et al., 2015; Bonnardel, 2012). Limitations were reintroduced as they went deeper step by step. This process allows the designer to be as creative as possible. The change from a patient-medical experts' relationship to a multi-party relationship and time point to timeline is a direction from simple to complex, which allows the designer to gradually deep dive. Participants would be overwhelmed by complex issues if they were right off the bat (Bammer, 2019).



Figure 44 During the Session.

Results

In this session, we had a series of creative processes and discussions mainly on this remote monitoring system and came to some conclusions.

In general, the designers mainly used a user-centred way of thinking, believing that the whole design for patients and hospitals should be user-friendly.

From the patient's point of view, completely passive monitoring is likely to still pose certain privacy issues for the patient and is often less detailed. Active self-reporting, in turn, can be somewhat burdensome. Finding a balance and a good design, therefore, seems important. The designers feel that a combination of the two approaches was the better option, with some elements of passive data collection, such as time and place, being an option, but with the specific content and mood of the activity involved favouring patient self-reporting would be more beneficial.

Therefore, patients need to be encouraged to adhere to a tracking activity over time. This requires consideration of how adequate data can be ensured without adding too much to the patient's burden. The designers believe that this can rely primarily on quick and easy real-time recording, timely feedback, interesting and visualized processes, blurring detailed information of activity and periodic and decreasing records.

For medical experts and hospitals, the need is to see all patient information quickly and visually, but only in detail when necessary. This means that they can have the status of a large number of patients in a short period of time and, if necessary, learn more about each individual patient.

It is also important to build patient and hospital interactions. As well as giving patients quick feedback, such as visual feedback on the patient side after they have performed a certain action, long-term feedback, such as from the hospital, should also be considered: how the patient is reporting data that affect the hospital and how it affects the patient in turn. How patients can use this data once it is available to them to promote patient empowerment is also something that needs to be considered in the design.

When discussing the role of family and friends in this, the designers believe that they should assume a supporting role, but not as an obligatory intervention. This is because too much involvement tends to make the patient more of a burden.

From these above, I summarized a list of key properties for design (Figure 45). This is the consensus among designers from different backgrounds, which will be very valuable for the RPM development in activity and emotion.

Key Properties for Design

What properties should be kept in mind when designing?

	Properties	Evidence Example
Patients	Timely Feedback	*"Providing timely feedback encourages patients to continue to track and use the RPM."——Designer 2 (Reflected from Diary Studies)*
	Real-time Record	*"Real-time recording is the scene of the moment. It's inevitably a bit different if it's retrospective." ——Designer 3 (Reflected from Diary Studies)*
	Quick Record	*"Record quickly can reduce the burden on patients. Little burden for each time, and more often record is better." ——Designer 1 (Reflected from Diary Studies)*
	Convenient Record	*"Patients should be able to record in a more convenient way, otherwise it can be too much work for them over time." ——Designer 3*
	Multiple Record Formats	*"The form of recording should also be diversified. For example, in addition to typing it can also be recorded in a way similar to Instagram 'Story'. Different forms of recording can be used for different situations or purposes." ——Designer 2*
	Visualized Product	*"Visuals can attract the patient to be in the RPM. It is possible to visualize the interface, the data, and some symbolism can also be considered." ——Designer 3*
	Interesting Interaction	*"Interesting interactions are also an important aspect that will keep patients using the system. For example, immersing the patient in a game-like context." ——Designer 1*
	Clear Statistic	*"I think there should be some kind of general overview for patients to be able to see how they are doing for a period of time." ——Designer 3*
	Personalized Product	*"Differentiation enables patients to feel that it is personal to them and not the same for everyone. For example, this can also be visualized using data to represent their personal data." ——Designer 3 (Reflected from Diary Studies)*
	Periodic but Decreasing Cycles	*"If there's a cycle, like 21 days, where the patient can do something or some feedback is given, they're better able to develop some habits or be more self-aware." ——Designer 1*
	Afternoon and Evening Interventions	*"The afternoons and evenings are better for some reflection or some intervention. These are the two times when the patient is more active." ——Designer 2 (Reflected from Diary Studies)*
	Regular Reflection	*"Regular reflections can help patients understand themselves better and these reflections summarize their own. These reflections can also help them talk to their doctors." ——Designer 3 (Reflected from Diary Studies)*
	Paper and Digital	*"Some patients still prefer paper, then I think when deep thinking is required, such as reflection, it may be better suited to paper-based forms." ——Designer 3 (Reflected from Diary Studies)*
Medical Experts	Direct Information	*"For them, the most direct information, rather than details and explanations, can help medical professionals to be more effective."——Designer 2*
	Quick Browsing with Highlights	*"They need to see the problem at a glance when quickly browsing."——Designer 3*
	Convenient Browsing	*"The ability to easily navigate through many patients' data is important for efficiency-conscious healthcare workers."——Designer 1*
	Visualized Interface	*"Visualization, especially the presentation of data visualizations can improve their efficiency."——Designer 3*
	General overview with details when necessary	*"While there is a need to see the data efficiently, there is also a need to understand the details when a patient has a problem"——Designer 2*

Figure 45 Results: Key Properties for Design.

4.5

Summary of Key Insights

1. Colorectal cancer patients have a positive attitude towards the probe.

2. Patients believe that probe can increase their self-awareness.

3. It is necessary to share data with caution, and anonymity is necessary when treating people other than hospitals and family and friends.

4. Patients enjoy the diary studies than a questionnaire.

5. Key properties for design (Figure 45).

Chapter 5

Guidelines of Developing RPM for CRC

Outcome: Guidelines and Show Case on Applying the Guidelines

5.1 Initial Guidelines

5.2 Final Guidelines

5.3 Show Case for the Guidelines

5.4 Summary of Key Insights

This chapter focuses on the development of guidelines for monitoring the activities and emotions of patients with CRC, which also summarizes the results of the previous studies. The chapter presents a view of the guideline's design process, including the initial design, the final design, and potential design outcomes stemming from the guidelines.

5.1

Initial Guidelines

The very first guidelines include four things. The first is what elements to monitor. Guidelines provide a list of elements to monitor. The second is what valuable information can be gained from the data. Here I start with the value to stakeholders and think about what elements provide them with valuable information. Elements can appear individually to provide information or multiple elements can be grouped together as "content" to provide valuable information. It is also a matter of deciding which elements are important. I used "workload" and "importance" in conjunction with the data from the previous study to evaluate these elements, which I summarized into a prioritized list of elements. Finally, the key properties for design from the designers' brainstorm session are also very important when moving towards design.

Basic Element: What to Monitor

When building a remote monitoring system, it is first necessary to define what is being monitored. There are five main sections in this element list. The first section focuses on building the context of the activity using the Five Ws, method, which is the same as the probe used in the diary studies. The second section is about indicators. The emotion and energy levels evaluate the activities and reflect patients' physical, social and mental health. The difference between emotion and Emotion Typology is the level of detail. Emotion refers to only negative and positive, while Emotion Typology contains 60 different vocabularies to describe the emotion (Fokkinga & Desmet, 2022).



Figure 46 Results: Key Properties for Design.

The third section is the statistic that can help provide an overview of the patient's status. Except for the activity and emotion, there's also a" Blank Moment", which means when there's no activity from the patients' side. It may be caused by the patient not recording or not being active. The "anomalies" stands for the unusual situations of patients. For example, they have been in negative feelings or not being active for several days.

The fourth section focuses on patients' profiles, encompassing their background information and self-assessment of their health. Within this section, the "Regular Reflection" stands out as a valuable process that enables patients to review their data over time and contemplate its significance. Through diary studies, I discovered that this process plays a pivotal role in enhancing patients' self-awareness. It emphasizes the importance of patients actively engaging in self-reflection to gain a deeper understanding of their health journey.

Lastly, the inclusion of a "Timeline" section contributes an additional dimension to enhance the overall understanding of the project. Through the monitoring process, the introduction of a temporal aspect enables other elements to generate deeper insights. Of particular significance is the "Doctor's Meeting Cycle," which highlights the duration between meetings with doctors. This information holds crucial importance for both doctors and patients, as it provides valuable insights into the frequency and timing of interactions within the healthcare journey.

Valuable Information

Once all the elements have been identified, it becomes crucial to prioritize them, distinguishing between the essential ones and those that are desirable to have. Throughout this process, I examined the insights that hold value to the patients, based on the findings from the study results. Subsequently, I selected the relevant elements from the box of basic elements to be integrated. It is important to note that an element can also function independently, providing valuable information on its own. Figure 47 shows the process and the results.

The elements outlined in the "Single/Combine Elements" section are important for patients, as they generate information that can be valuable to their needs and preferences. These elements have been carefully identified and selected based on their potential to provide meaningful insights and contribute to the overall patient experience.

In addition to patients, I also see value in this system for other stakeholders. This mainly includes medical experts (Figure 48) and researchers (Figure 49). I, therefore, carried out the same analysis for these three stakeholders.

In particular, a different approach was adopted in the process of defining the elements for the researcher (Figure 49). Rather than starting with values, I initially combined the basic elements and then contemplated potential research directions that would hold value for the researcher. This approach emerged because of the designer's reflection and was driven by the belief that the data collected through the remote monitoring system held substantial research potential. Thus, it made more sense to explore how these data could contribute to valuable research insights and guide the selection of elements accordingly. By adopting this perspective, the goal was to maximize the research value derived from the collected data under the consideration of patients' privacy.

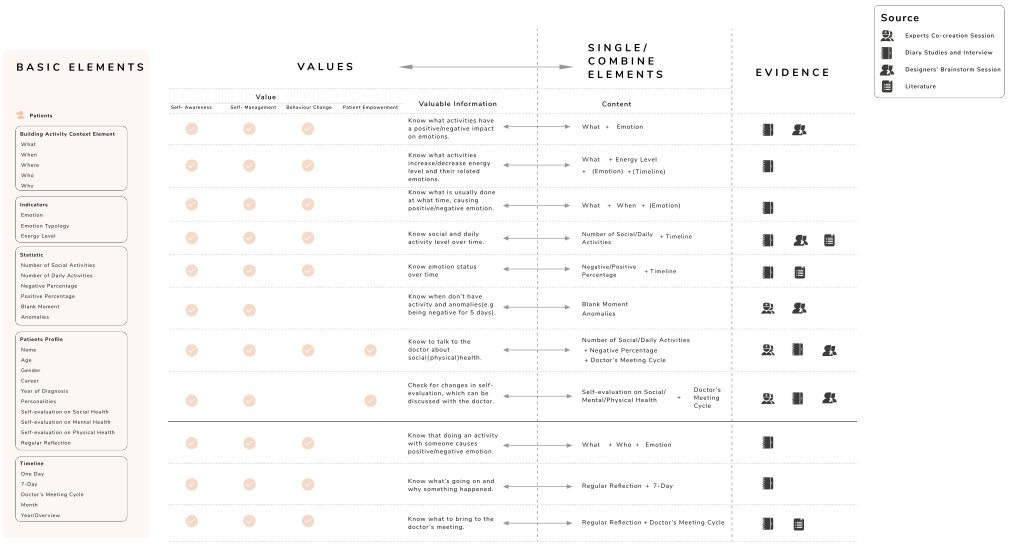


Figure 47 Patients' Valuable Information.

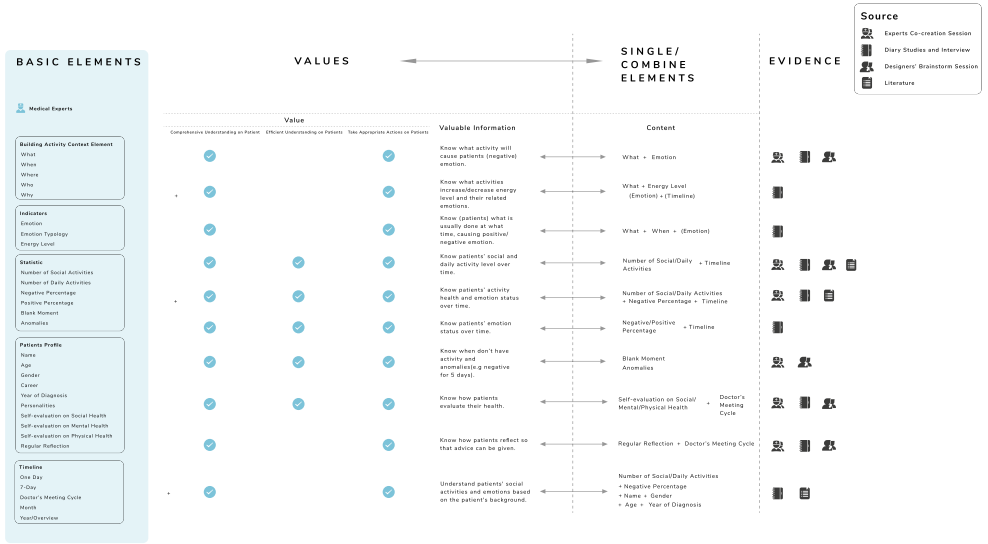


Figure 48 Medical Experts' Valuable Information.

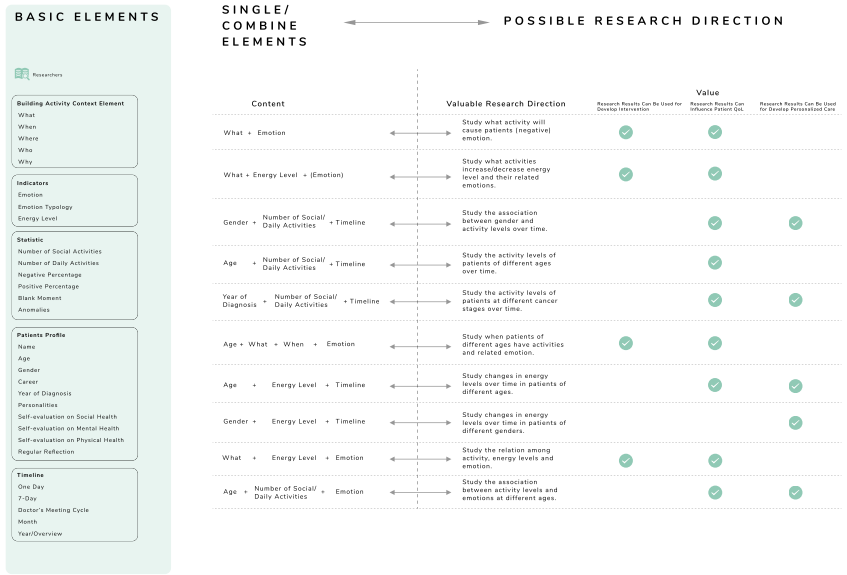


Figure 49 Researchers' Possible Direction.

For Patients

Timely Feedback
Real-time Record
Quick Record
Convenient Record
Visualized Interface
Interesting Interaction
Outline Information
Personalized Product
Periodic but Decreasing Cycles
Afternoon and Evening Interventions
Regular Reflections
Paper and Digital
Instructions on Self-Management
Allow Blank Moments

For Medical Experts

Direct Information
Quick Browsing
Convenient Browsing
Visualized Interface
General overview with details when necessary

Figure 51 Key Properties for Design.

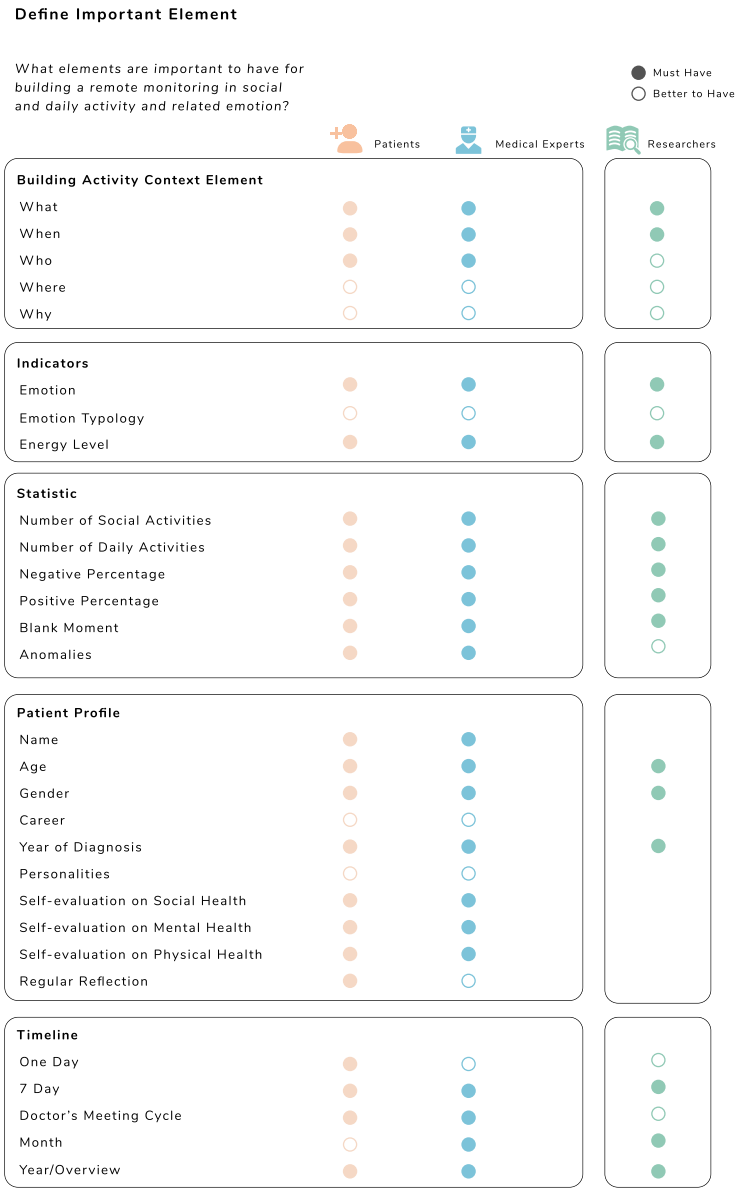


Figure 50 Importance of Elements.

Define Important Element

After the above process, the elements were classified as "Must Have", "Better to Have", and not required (Figure 50) according to the "Importance" and "Workload" of each element.

As shown in Figure 50, both patients and medical experts need to have access to all the basic elements. Colorectal cancer patients can enhance their self-awareness through the information generated by these elements. Medical experts, on the other hand, can gain a comprehensive understanding of the patients, enabling them to provide more personalized care and show empathy during meeting with patients.

Conversely, researchers assume a distinct role as indirect beneficiaries of the system. Their requirements do not entail identifiable patient information, such as names, but rather focus on leveraging the system's big data for quantitative research. By minimizing the storage of personal patient information, the system ensures enhanced privacy protection for individuals.

Key Properties for Design

From the previous study, the list of key properties (Figure 51) that point to the design is also valuable. This list can help designers or researchers who want to develop a system for monitoring activities and emotions to conceptualize what the system should look like.

Evaluation

The initial guidelines were evaluated by three researchers and a designer who gave feedback on the problems they met.

They all said that the guidelines have a lot of details, but it takes a lot of certain time to think about and understand the content. The guidelines with many details, lack an overview or a framework, making it difficult to understand the linkages between them. The second section, "Valuable Information," is rather trivial, making it difficult to grasp the main points. The third section, "Important elements", is more abbreviated and could appropriately show the process of definition.

The list of elements could have a more detailed and clearer categorization. The activity and emotion sections should be emphasized, as they are the basic elements of the monitoring system. Besides, the guidelines should have a visual guide that is easy for users to read and understand.

The feedback from the researchers and designers was reflected and it was used to iterate to produce the final design, which will be presented in the next chapter.

5.2

Final Guidelines

Section 5.2 introduces the final guidelines for developing the RPM in social and daily activity and related emotions for colorectal cancer patients and medical experts. The guidelines include two sections: Elements and Properties (Figure 52). These two sections provide detailed guidance on what data to monitor and the properties for design. When establishing a monitoring system, particularly one that has received limited focus, it is crucial to define the essential monitoring data first. This step enables an understanding of how to collect such data and the benefits it can bring to both patients and medical professionals (Ferrua et al., 2020). Additionally, the identification of key properties, often overlooked by non-design researchers or challenging to access, proves highly valuable in guiding the vision of the final design (Autio & Thomas, 2019). As a result, these two sections constitute the foundation of the provided guidelines.

Here the element can be seen as the data from the system, which also contributes to the content of the system. The properties are the same as the result of the designers' brainstorm session, which is the consensus from the designers when designing the system.

Contents. In the first "Elements" section, there are four parts belonging to elements "Elements" give answers to four questions:

(1) Elements List: What to monitor?

(2) Elements Priority: What is important to monitor?

(3) Valuable information from the elements: What valuable information can stakeholders get from single/multiple elements?

(4) Possible research directions from the elements: What can be possible research directions for researchers from the collected elements?

The primary significance lies in the first and second sections, as they offer direct and crucial insights into the essential data to be monitored (Ferrua et al., 2020). The third section explains how the information generated by elements will provide value to patients and medical experts. It further provides evidence for the elements' priority, as it also reflects which information is more valuable. By considering what values can stakeholders obtain from the elements, the system will be more user-centric, efficient, and sustainable (Kujala & Väänänen-Vainio-Mattila, 2009; User Value, n.d.).

The fourth section presents an indirect approach to exploring potential research avenues for utilizing patient data—a highly valuable resource in the field of research. Through the study and analysis of such data, researchers can often devise more effective solutions to enhance patients' health and quality of life (Cios & William Moore, 2002). However, it is imperative to exercise extra caution and attention to ethical considerations and privacy concerns while working with this sensitive information.

By reading the answers to these four questions,



Figure 52 Contents of the Guidelines.

upcoming researchers will gain insight into not only the specific data of significance for monitoring patients and medical experts but also the methodologies to study the data effectively, thereby enhancing patients' health and overall quality of life.

The second part is the “Properties”, which is the “Key Properties for Design” from the designers’ brainstorm session. The consensus of designers from different fields is also important for the development of RPM because designers often design from a user-centred perspective (Chammas et al., 2015). Future researchers can use the properties to specify what should be kept in mind when designing a system, especially for non-design researchers.

Elements List (1-1)

When building a remote monitoring system, it is first necessary to define what is being monitored. In conjunction with our previous research, I have defined a series of basic elements that can be monitored or collected (Figure 53). These elements are mainly derived from the experts co-creation session, diary studies and follow-up interviews, designers' brainstorm session and the literature, but not all elements are mandatory for developing the system.

There are two categories in the list. One is the "Content", which shows the basic content of the activity and emotion and some additional content. In the basic content, there're two sections for activity. General activity only mentions the two kinds of activity: social and daily activity, while contextualized activity is a more detailed activity with context. The reason is that patients often require in-depth information to aid their self-reflection process (Pezalla et al., 2012), while other stakeholders, like doctors, might not necessarily require such details. Instead, they might seek information about the type of activity involved (Jacobs et al., 2015; Zhang et al., 2013). This distinction facilitates easy differentiation between various scenarios.

The "Emotion" section also offers both simple and detailed versions. Future researchers have the option to collect either positive or negative emotions, or they can opt for a more comprehensive Emotion Typology, comprising 60

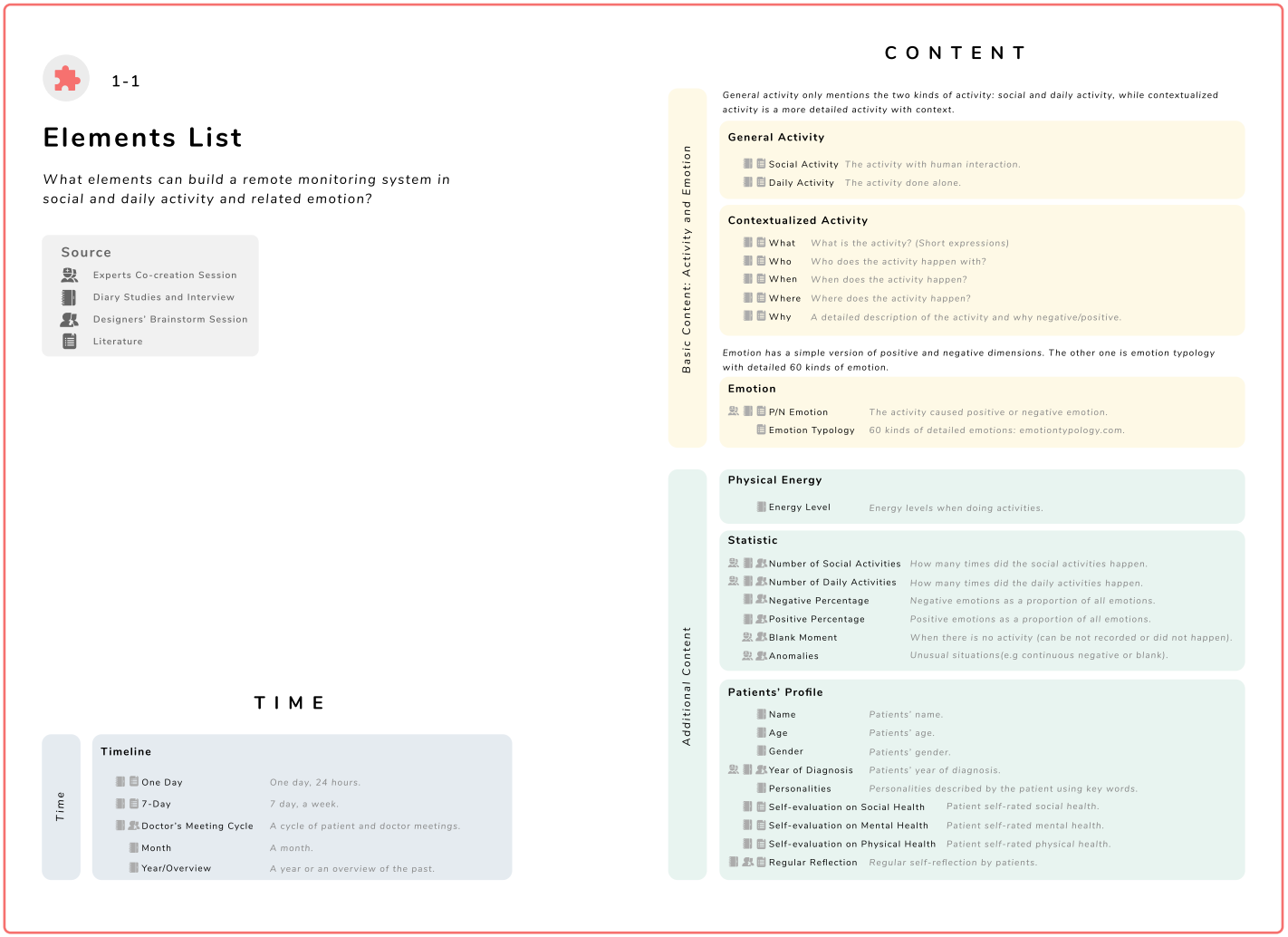


Figure 53 Elements List.

different emotions (Fokkinga & Desmet, 2022). The reason for this choice is similar to the activity section. Patients also emphasized the significance of detailed explanations and descriptions of their emotions during interviews, although they acknowledged that it would entail additional effort.

The "Additional Content" within the Content section encompasses physical energy, statistics, and patients' profiles. Specifically, the physical energy section presents data obtained from prior user research, which indicates the energy levels associated with various activities. Notably, patients found this information meaningful, as it provides them with insights into the energy expended during their activities so that they can rearrange the activities, such as the duration.

Statistics constitute another crucial component. It mainly means doing statistics on the data collected, such as the percentage of negative emotions. In addition to this, there are also Blank Moments and Anomalies. Blank moments, which were mentioned in the designers' brainstorm session, are mainly when there is no data available, especially if the monitoring relies heavily on the patient's self-report. Blank data can indicate whether the patient has lost interest in monitoring, or if there is an anomaly. Anomalies indicate abnormalities in the patient's data, such as when the patient has been in a negative mood for seven consecutive days. Such blank moments or anomalies can signal the need for a doctor's intervention. The statistics serve as valuable indicators for medical professionals, enabling them to promptly identify intervention points and provide enhanced care. The last part of the Content contains the patient's personal information. In addition to basic data, Personalities, Self-evaluation on Health and Regular Reflection are also included. Exploring the aspect of personality can prove beneficial for patients as it enhances their self-understanding, and it also assists doctors in comprehending their patients' personalities, enabling them to establish more personalized communication approaches (Clack et al., 2004; Kallergis, 2008). The Self-evaluation on three aspects of health encourages patients to contemplate their health and recognize its significance cultivates a greater sense of responsibility towards their well-being. This heightened awareness opens up more possibilities for effective communication with medical experts (Hesse & Rauscher, 2019; Shah et al., 2021). Regular Reflection also stands out as a valuable process that enables patients to review their data over time and contemplate its significance. Through diary studies, I discovered that this process plays a vital role in enhancing patients' self-awareness. It emphasizes the importance of patients actively engaging in self-reflection to gain a deeper understanding of their health journey (Hodkinson et al., 2020).

Another section in the Elements List is “Time”. The time element holds significant importance in RPM as it allows for the assessment of the patient's condition at specific moments and over extended durations. (Weinstein et al., 2014). Of particular significance is the "Doctor's Meeting Cycle," which highlights the duration between meetings with doctors, because it provides valuable insights into the frequency and timing of interactions within the healthcare journey (Bhat et al., 2021).

Overall, the Elements List, which includes both content and time components, provides the basic data elements for the development monitoring system in social, daily activity and emotion.

Elements Priority (1-2)

Once all the elements have been identified, it becomes crucial to prioritize them, distinguishing between the essential ones and those that are desirable to have. I classified the elements as "Must Have", "Better to Have", and not necessary (Figure 54).

The right-hand Overview only labels the final prioritized result, whereas the left-hand Detailed section provides insight into the process leading to this outcome. A matrix is predominantly utilized to strike a balance between the importance of elements and the workload for both patients and medical experts. The importance of an element is the most direct indicator of whether or not the element's presence is necessary. The workload required to gather this element considers whether patients need to invest considerable effort in the monitoring system and whether medical experts need ample time to comprehend and analyze it. Given the limited energy of both patients and medical professionals, achieving an equilibrium between the importance of elements and workload becomes crucial (Groenewegen & Hutten, 1991).

This matrix in “Detailed” is divided into four parts. Ideally, for patients and medical professionals, it would be high importance but low workload, so all the elements here are listed as "Must Have". Elements with high importance but high workload were categorized as "Must Have" or "Better to Have", because although some elements are

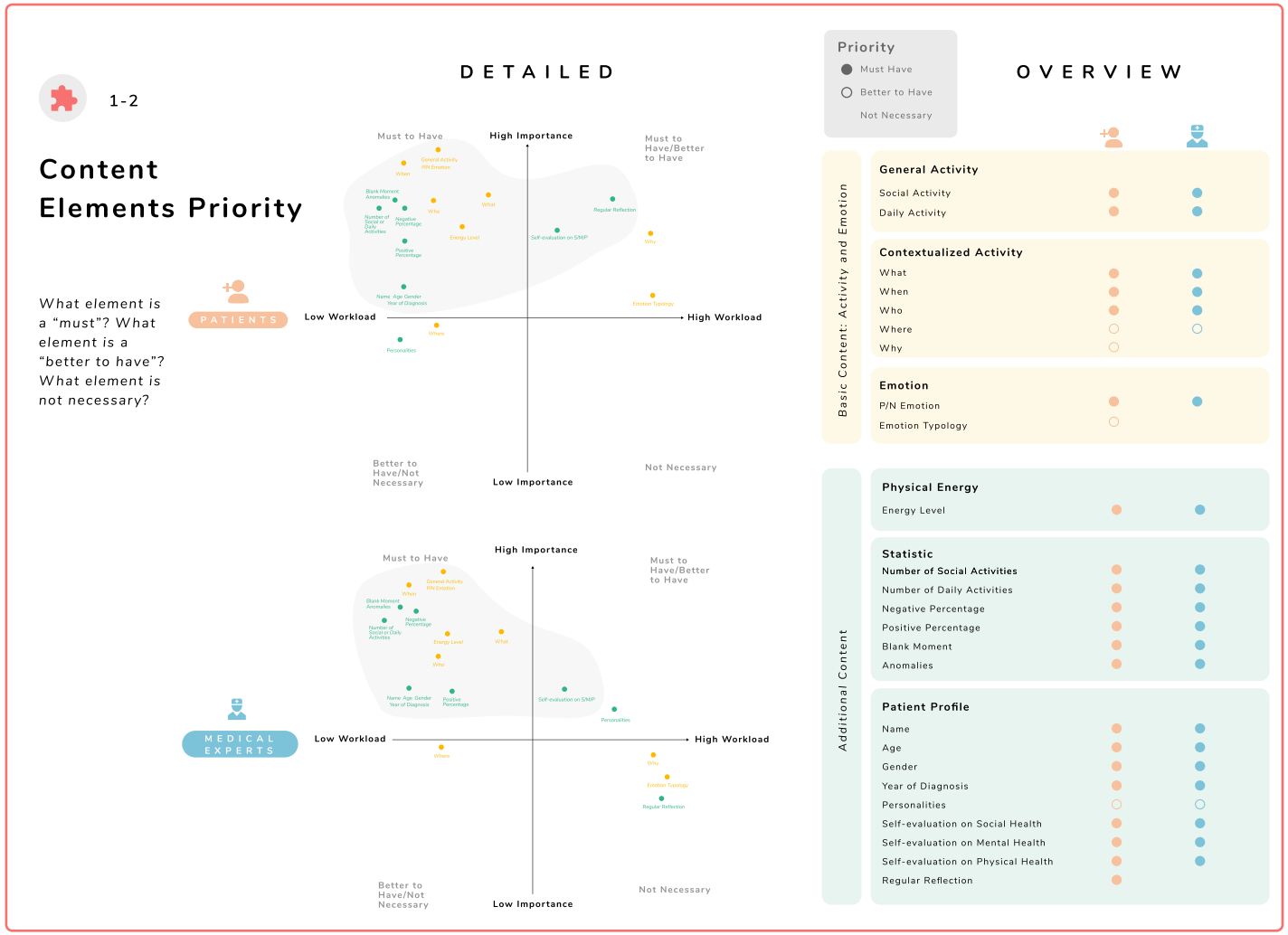


Figure 54 Elements Priority.

important, they are not recommended for mandatory collection due to excessive workload. Elements with low importance but also low workload were classified as "Better to Have" or "Not Necessary", because although they have low workload, they are also not recommended for mandatory collection, e.g., Emotion Typology. Low-importance but also low-workload elements are listed as "Better to Have" or "Not Necessary" because, although the workload is low, they are also relatively unimportant. Elements with low importance and high workload are classified as "Not Necessary" because they are not important yet require a lot of effort to understand or complete. Note that the location of these elements may change dynamically as technology evolves, so this will need to be constantly updated.

In the final result, "General Activity" is mandatory for both patients and medical professionals. Only What, When and Who are required for detailed activity descriptions, while Where and Why are less important, especially for medical professionals. What provides the content of the activity, When provides the temporal element, which constitutes a period, and Who is an essential element in social activity. Where provides the location, but it does not directly affect the property of the activity. Why, on the other hand, favours the process of reflection, a process that allows the patient to think about the activity, but the medical professional doesn't need to know about this element it is too detailed.

Positive/Negative emotion is a must-have because it is judged in a relatively simple and quick way with only two options. Emotion Typology, on the other hand, takes a lot of time to understand and judge although it's meaningful, so Emotion Typology is not a must-have item for patients, while medical professionals don't have to collect and understand it.

In the "Additional Content", Energy Level's importance has been mentioned before and it can be simplified in certain ways, such as giving a percentage or setting only two types of high and low. Statistics can provide a general overview by relying on technology. It is a very efficient way for both patients and medical professionals to understand patients' health. That's why it's a Must Have for both of them. In the Patient Profile, Personalities are beneficial for communication, but it also increases the burden for both patients and medical experts. Regular Reflection is necessary for patients to improve their self-awareness, while medical experts don't have to know the details since includes too many details.

Valuable Information from the Elements (1-3)

To fulfil the expectations of patients and medical professionals, monitoring systems should consider the valuable insights that can be derived from the collected data. When the collected data prompts self-reflection among patients, it enhances their awareness of areas requiring self-management (Gucciardi et al., 2016). Meanwhile, valuable information for medical professionals enables them to intervene promptly and offer personalized treatment and communication approaches (Douglas et al., 2012; Harrington et al., 2004). By emphasizing the acquisition of meaningful data, monitoring systems can effectively cater to the value of both patients and medical experts.

Valuable information can be provided not only by one element but also by a combination of elements. For example, "What" and "Negative Emotion" together reflect that the patient is in a negative mood when doing a certain activity. So, in the first column "Elements Needed", some show one element and some show multiple elements. The second column, "Valuable Information", shows the valuable information that patients and medical professionals can obtain from these elements. The third column, "Evidence Example," provides a rationale example for the previous two sections. It can come from literature or research mentioned before.

1-3

Valuable Information

What valuable information can patients get from single/multiple elements?

PATIENTS

- Improve self-awareness
- Improve patient empowerment during the meeting with doctors

		Elements Needed	Valuable Information	Evidence Example
Basic Content: Activity and Emotion	Must Have (Basic)	General Activity + P/N Emotion	Patients will know what kind of activity will cause positive/negative emotion.	"It (probe) can make you think more about the activities and how you feel about it. For me I am shocked to see how I feel." —— Participant B from Diary Studies
		What + P/N Emotion	Patients will know what specific activity will cause positive/negative emotion.	
	Must Have (Detailed)	What+ Who+ P/N Emotion	Patients will know that doing an activity with someone causes positive/negative emotion.	"It was for me a bad week. I wasn't feeling well and then because of it (probe) I was very aware that my homies were my biggest triggers. So I understand more on what happened between them and me." ——Participant C from Diary Studies
		What+When +P/N Emotion	Patients will know what is usually done at what time, causing positive/ negative emotion.	"I wrap up the day after dinner and it makes me feel satisfied that the day is over."——Participant A from Diary Studies
	Better to Have	Where	Patients will know where they spend a lot of time, such as being indoor or outdoor.	"I like working in the office, it makes me feel back to normal."——Participant D from Diary Studies
		Why	Patients will know the reasons behind the activity and related emotion and start reflecting.	"On the third day, I realized I didn't have my mindful moment like before which made me realized that it is so important to me, so I'll pick up again." ——Participant C from Diary Studies
		Emotion Typology	Patients will know specifically the type of emotion	"The pallet of human emotions is highly diverse, not just in terms of how we feel them but also in terms of why we have them and how they influence our actions." (Fokkinga & Desmet, 2022)
Additional Content	Must Have	What+ P/N Emotion+Energy Level	Patients will know the relationship between the activity, emotion and energy level.	"I have done some activities but they exhausted me...I don't really like the feeling of being exhausted, it makes me frustrated, so probably I need to balance a bit" ——Participant D from Diary Studies
		Number of Social/Daily Activities + Timeline	Patients will know social and daily activity level over time.	A combination of "number of activities" and "timeline" can provide valuable information on how patients are doing in an efficient way (Ali et al., 2021).
		Negative/ Positive Percentage + Timeline	Patients will know how the emotion changes over time.	"When I think I had a bad day, I look back the diary and I think, oh, it wasn't so bad. There were just two bad moments." —— Participant C from Diary Studies
		Blank Moment Anomalies	Patients will know when don't have activity and anomalies(e.g being negative for 5 days).	"I'm experiencing a very low level of social activity just this week ..... This is not good." ——Participant C from Diary Studies
		Number of Social/Daily Activities +Negative Percentage +Doctor's Meeting Cycle	Patients will know they need to talk to the doctor about their health.	"I am willing to share with my doctor, especially when I think I need help." ——Participant D from Diary Studies
		Self-evaluation on S/M/P Health + Doctor's Meeting Cycle	Patients can check for changes in self-evaluation, which can be discussed with the doctor.	"I want to share with doctors to show how I am doing personally because I feel alone when only processing the negative emotion myself." ——Participant A from Diary Studies
		Regular Reflection + 7-Day	Patients will have a reflective information in an acceptable period.	Weekly reflection can help improve self-awareness (Morris et al., 2010).
		Regular Reflection + Doctor's Meeting Cycle	Patients will know what to bring to the doctor's meeting.	Patients' reflections can help them think about what to discuss when they meet with their doctors. This can avoid medical paternalism (Vinson, 2016).
		Name Age Gender Year of Diagnosis	Patients offer the background information to their doctors.	Personal information can help decision-making(Wrobel, 1993).
	Better to Have	Personalities	Patients will think about their personalities and also offer the information to their doctors.	"Doctors knowing patients' personalities will help tailor their interaction styles with patients" (Braman & Gomez, 2004).

Figure 55 Valuable Information for Patients.

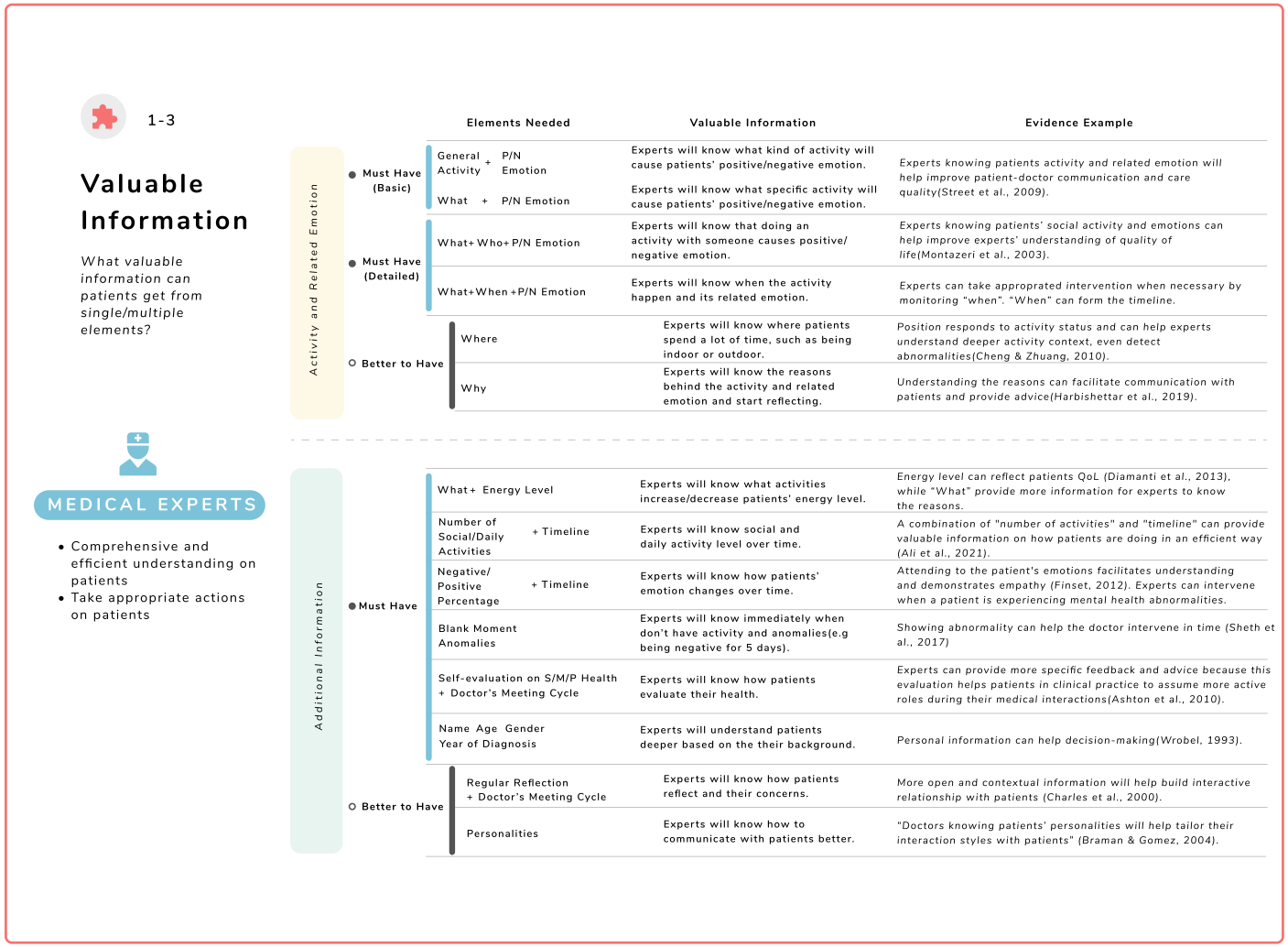


Figure 56 Valuable Information Medical Experts.

The role of Valuable Information, in addition to meeting the values of patients and medical professionals, can also provide some support for the previous Elements List and Elements Priority, justifying the need for these elements to exist.

Possible Research Direction (1-4)

In Elements' final item, I suggested the research value that these collected data might have for researchers (Figure 57). This direction is proposed because research and reflection on patient data can lead to an understanding of patient pain points and targeted efforts to improve patients' quality of life and health (Miller, 1990). Knowing what it's like to be in a patient's shoes can also give researchers an idea of how to intervene (Jensen et al., 2020).

Similar to Valuable Information, multiple elements can make up possible research directions. For example, by collecting social activities or daily activities and emotions, researchers can learn that colorectal cancer patients often have negative social activities. The conclusions that emerge from these studies can enhance researchers' in-depth understanding of the physical, social, and mental health of people with certain diseases.

However, this process requires extra attention to patient privacy. This is why the patient's name does not appear in this and the patient's personal information is not centralized. The study of the collected data should only be done if the amount of data is large enough to ensure that the patient data is blurred. Therefore, it is better for the researcher to conduct the study in a quantitative rather than qualitative way. (Kirilova & Karcher, 2017).

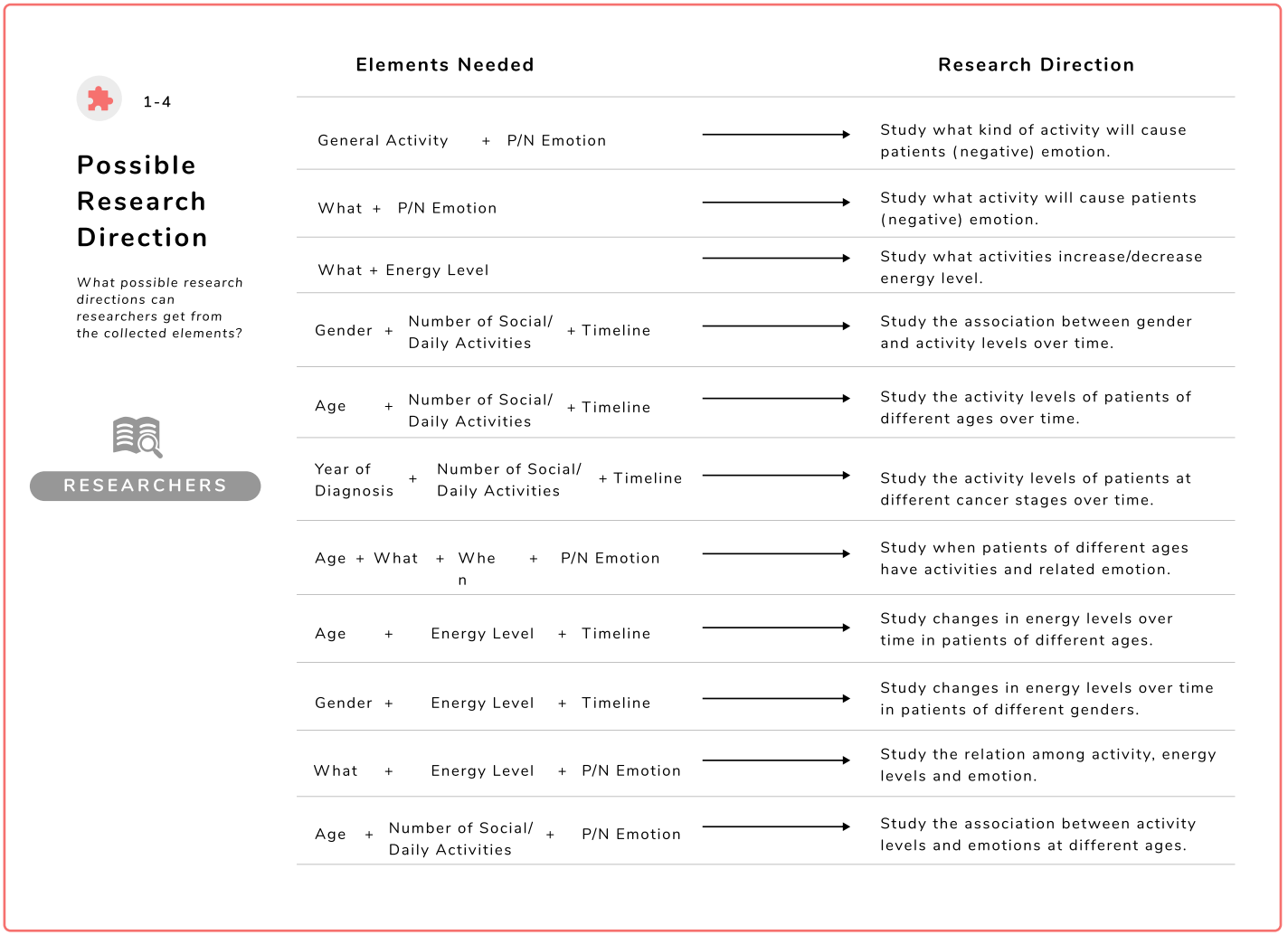


Figure 57 Elements List.

Key Properties for Design (2-1)

This is the part where the designers' brainstorming session comes to a consensus, as known as the key properties. The content is the same as before. The difference is that properties are categorized and presented visually. There are a total of three categories for patients: the process of recording the data, the time of recording the data, and the product form.

The process of recording data consists mainly of the patient's need for easy, real-time and fast records that can be a combination of paper and digital. Multiple forms of recording can also exist, such as photographs, drawings, or the use of technology such as sensors. The timing of the recordings needs to be in cyclical feedback that allows for less frequent monitoring as the patient gradually recovers. Afternoons and evenings tend to be the best times for intervention, as patients are more active and receptive at this time of day.

As for the product, the designers believe that timely feedback is very important. This is the driving force that allows patients to be monitored on an ongoing basis. In addition, the system should be visual and personalized and present clear statistics and interesting interactions. These are important properties that the designers take into account when designing the system from a user-centered perspective. Besides, it should also provide the patient with the opportunity for regular reflection, which can also be in line with the cyclical nature.

For medical experts, properties are relatively centralized, primarily in terms of presenting information. Their quest for efficient access to information can be solved by providing a general overview, but the details should also be available if they want to know more information. Visualizing and providing direct information can help them grasp key information more quickly, such as highlighting patient anomalies. It is important for them to be able to navigate patient data easily and quickly.

Overall, these design properties can help future researchers clarify the characteristics of the system and thus design a system that better fits the user's perspective.

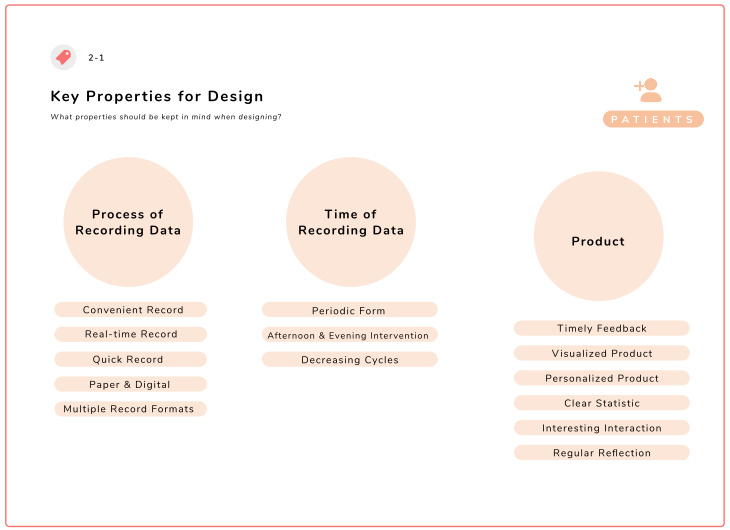


Figure 58 Key Properties for Design (Patients).

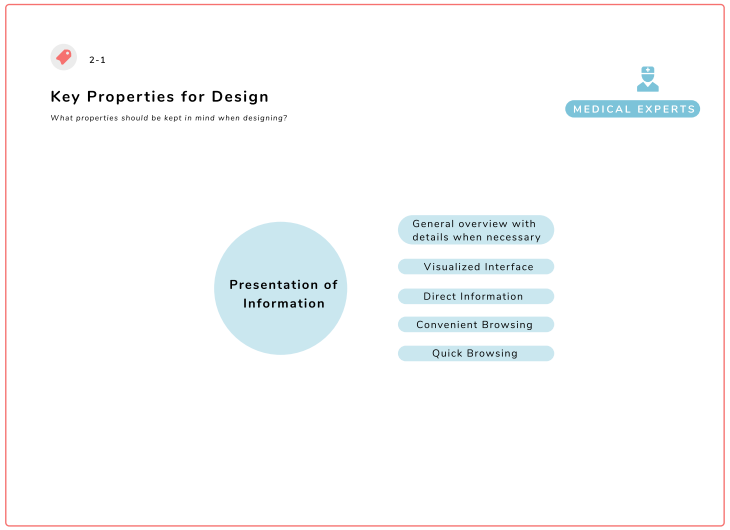


Figure 59 Key Properties for Design (Medical Experts).

5.3

Show Case of Applying Guidelines

To better understand how guidelines can be presented in design, I designed a show case to demonstrate what the product may look like when using the guidelines. This show case is just an example of a possibility for patients and medical experts, but the design from guidelines should not be limited to such possibilities.

There are four parts to this show case (Figure 60). I designed an app interface and some reflection cards for patients and interfaces for medical experts. The flow of these three parts was summarized in the overview of the system. The reason behind the design is from the guidelines, so the last part of this section reflects how these designs fulfil the requirements of the guidelines.

App for Patients

When designing the app for the patients, I used the concept of blooming flowers, with one flower representing an activity. However, the shape of the flower will only appear if the patient fills in the "Where" and "Why" parts, otherwise just the basic information will only show a circle. This whole concept can embody the elements that must and should ideally be present in the first two sections of Figure 54. By allowing the flower to take shape as a bonus, patients are encouraged to fill in detailed information about their activities, but this is not required.

Figure 61-64 shows the application for patient

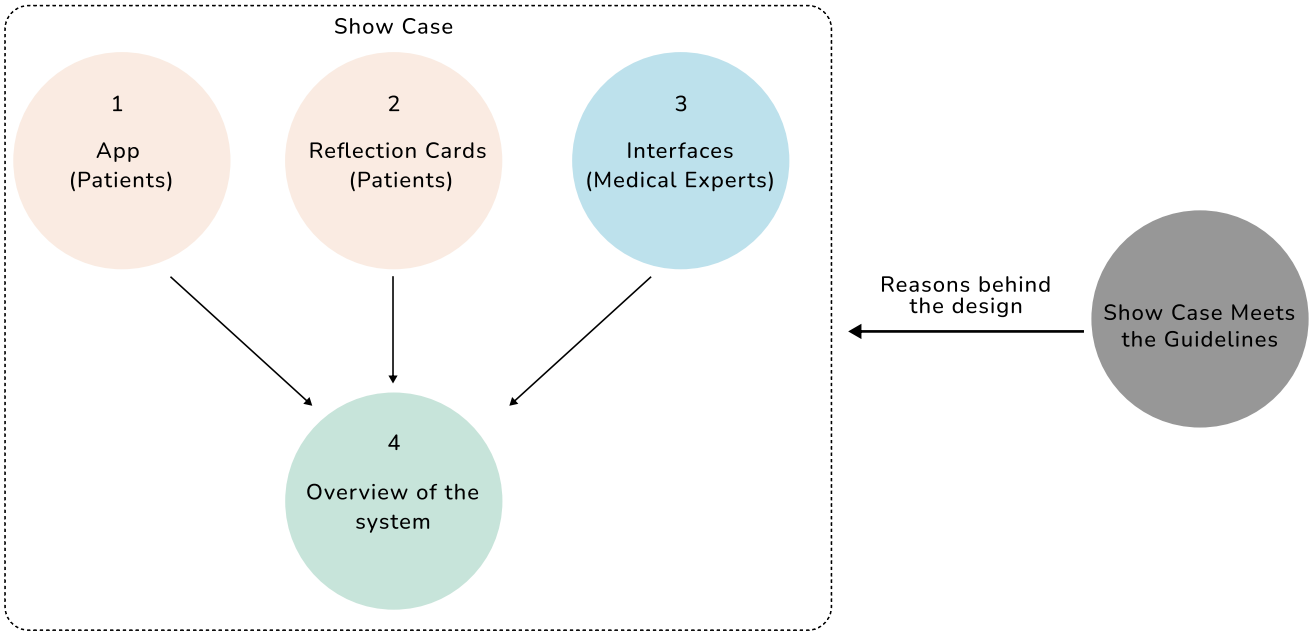


Figure 60 Content of the Show Case.

self-reporting. Patients only need to report activity and fill in the activity details and the technology will automatically perform the functions of data visualization and statistics.

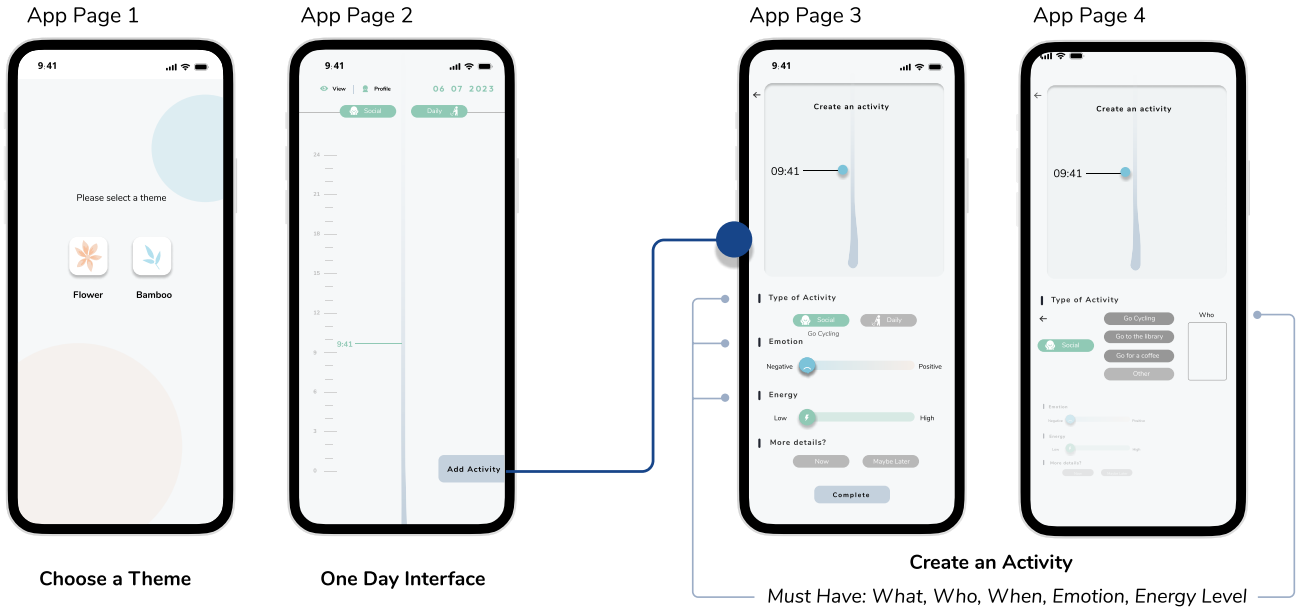


Figure 61 Report an Activity.

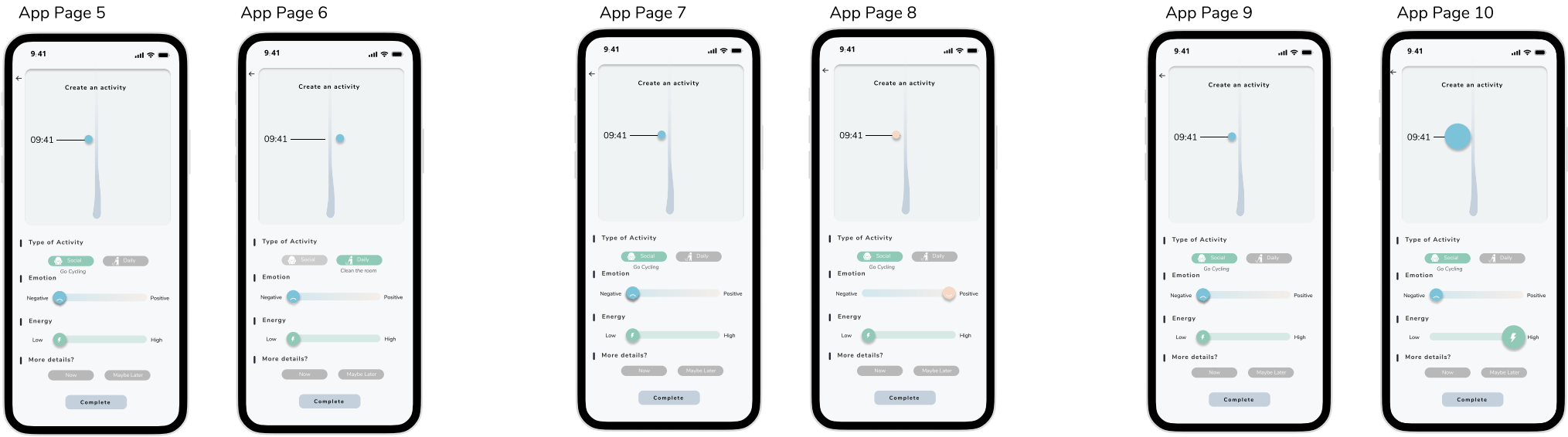
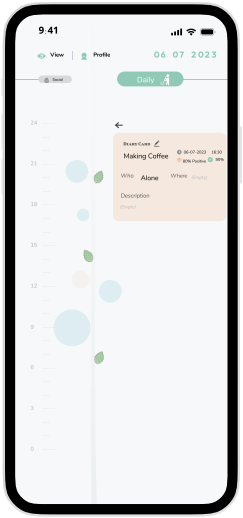


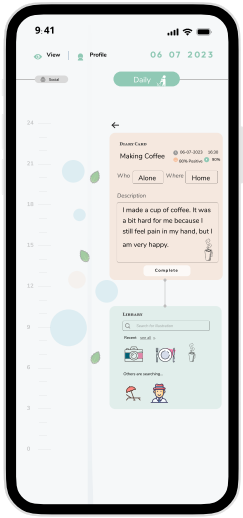
Figure 62 Visualized Process of the Activity.

App Page 15



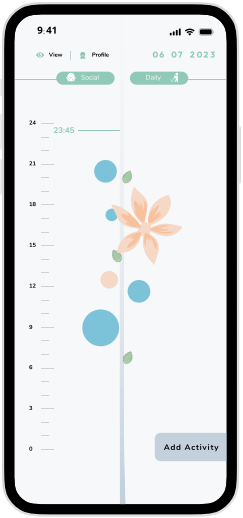
Before Filling in

App Page 16



Filling in the Details

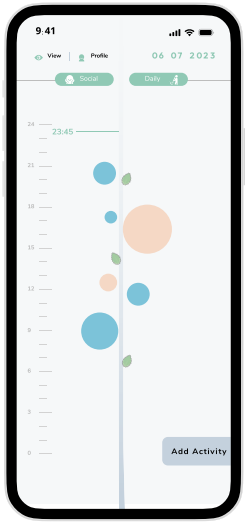
App Page 17



After Finish the Details

Figure 62 Blooming Flower: Fill in the Details for the Activity.

App Page 11



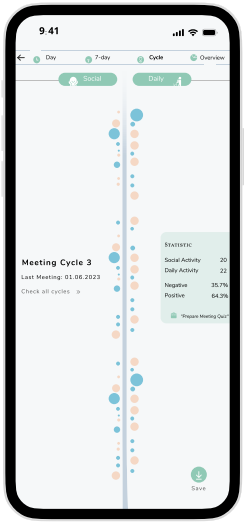
One Day

App Page 12



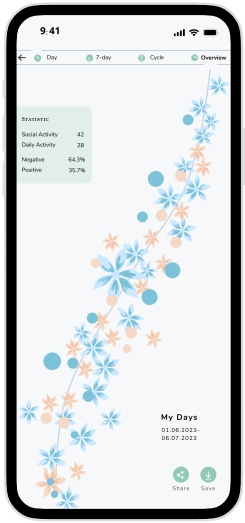
7 Day

App Page 13



Doctor's Meeting Cycle

App Page 14



Overview of All

Figure 63 Overview of the Data on the Timeline.

Statistic: Number of Social/Daily Activities Negative/ Positive Percentage

Reflection Cards

During this process, patients are encouraged to reflect every seven days through the 7-day Quiz Card (Figure 78) and write down their thoughts at the back (Figure 79). I also advise patients to complete the Prepare Meeting Quiz Card (Figure 80) when they are about to see their doctor and write on the back of the card what they would like to share with their doctor (Figure 81).

On the back of both cards is a scale for self-assessment of three areas of health. By answering a series of questions, the patient is able to clearly rate his or her health status.

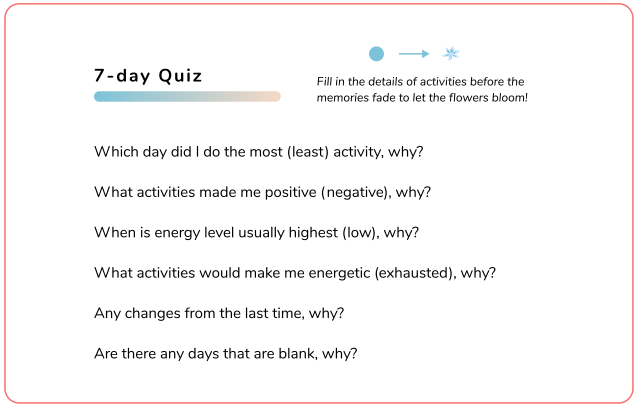


Figure 64 Front: 7-day Quiz Card.

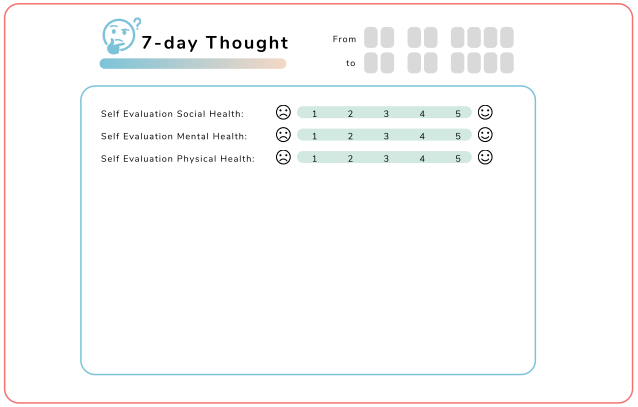


Figure 65 Back: 7-day Quiz Card.

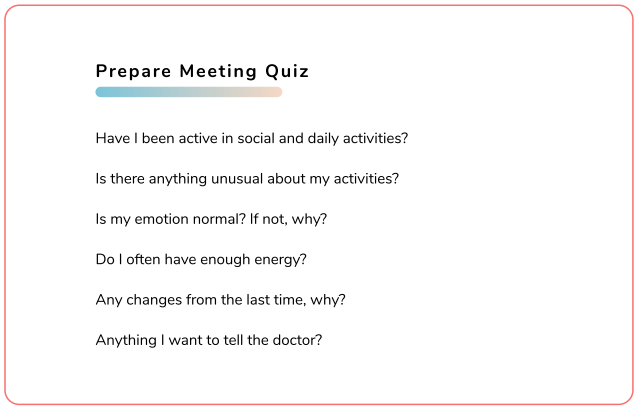


Figure 66 Front: Prepare Meeting Quiz Card.

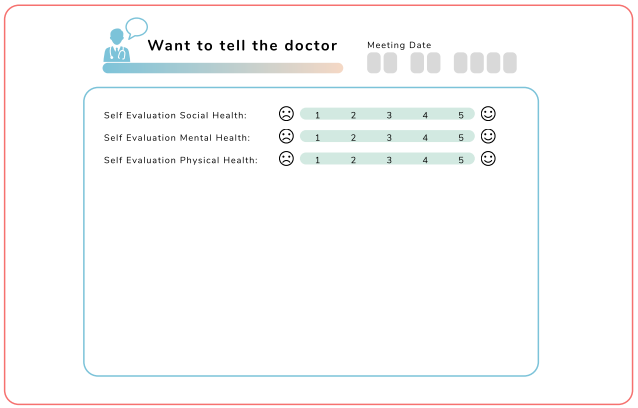


Figure 67 Back: Prepare Meeting Quiz Card.

Medical Experts' Interfaces

The interfaces of the medical experts show the basic information about the patient as well as the main statistics (Figure 68). Taking seven days as an example, the medical expert can see the patient's condition for the seven days, the percentage of social and daily activities respectively and their corresponding negative mood. If there are abnormalities such as blank days or negative moods for several days in a row, they are highlighted in red, so that the medical specialist can directly notice the abnormalities and take action in time.

In addition to this, a certain amount of visualization is possible in geospatial terms (Figure 69). The prerequisite is that the source of geographic information is actively reported by the patient rather than passively tracked. A map showing where the patient has been over time provides a more visual representation of the patient's activity level.

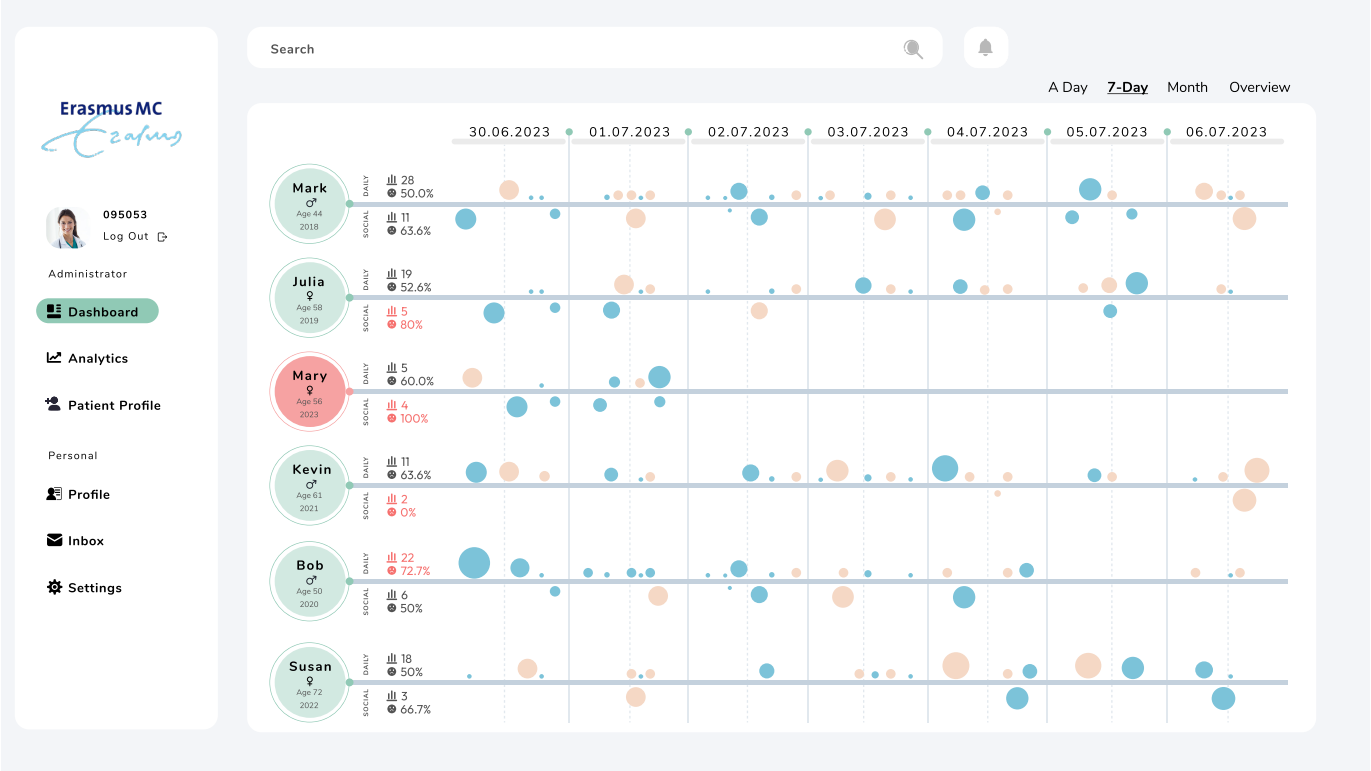


Figure 68 Medical Experts' Interface.

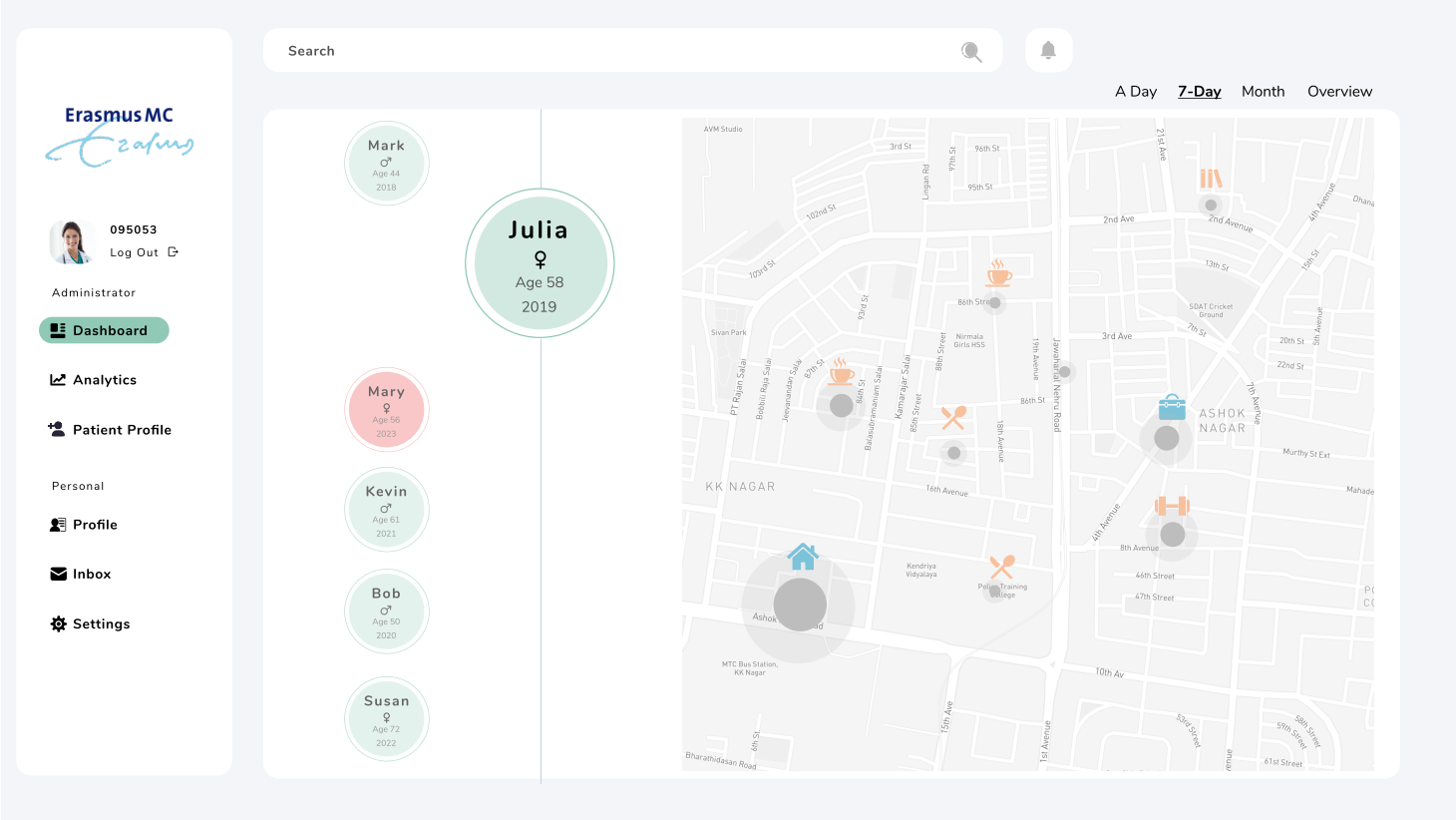


Figure 69 Medical Experts' Interface.

Overview of the System

Combining the previous products designed for patients and medical specialists, I present how the system work (Figure 70).

Patients record data and do a regular 7-day reflection. The different data are transmitted and shared with medical experts and researchers. The medical experts give timely feedback to the patient through the patient data. At the same time, before the next meeting with the doctor, the patients can make certain preparations to clarify their health status and the information they want to share and bring this information to the meeting with the doctors. This can be recorded through the reflection cards. In addition, using the big data collected, researchers can study valuable results and in turn improve patients' QoL and health.

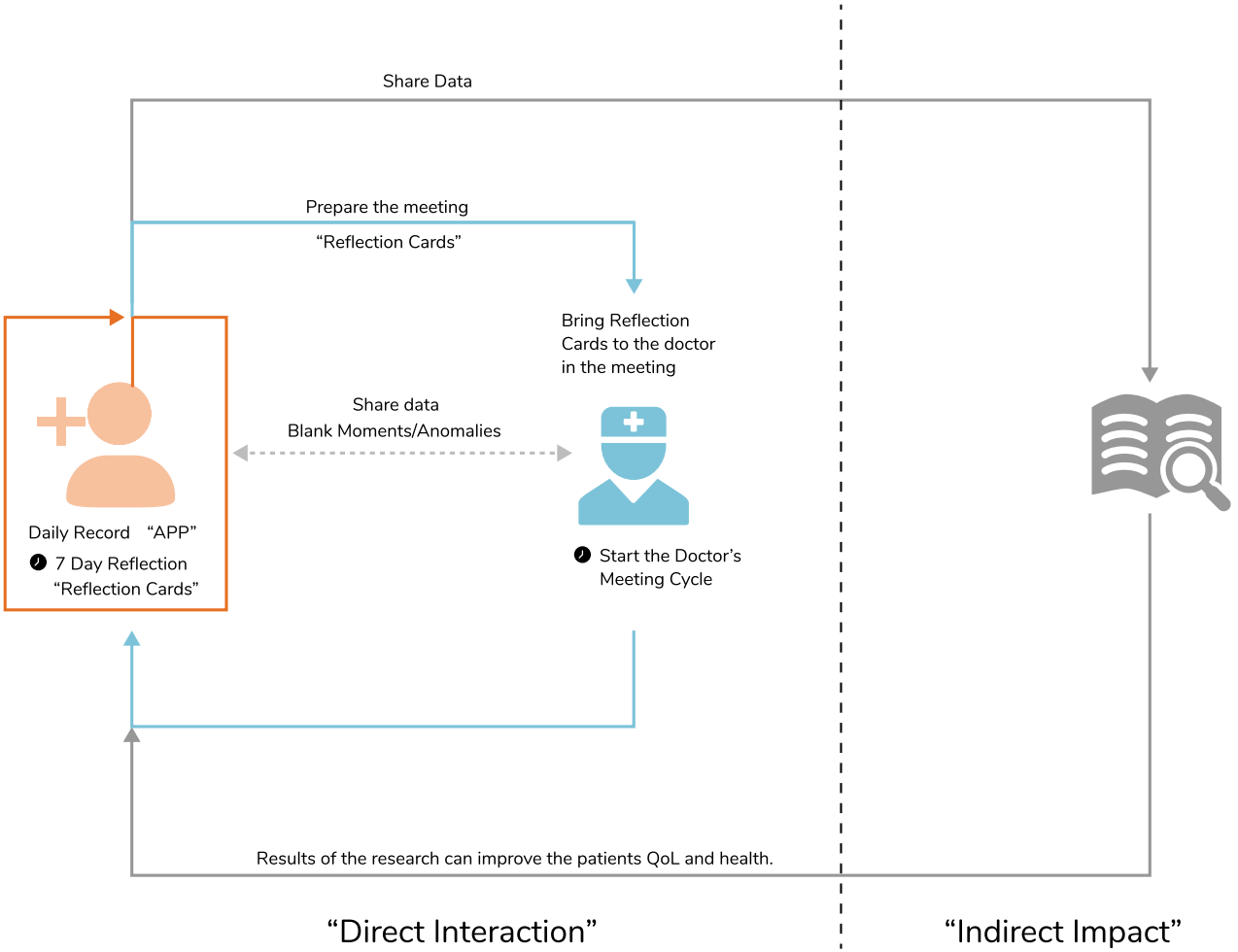


Figure 70 Overview of the System.

Show Case Meets the Guidelines

To clearly represent how the show case corresponds to the guidelines, the content of the show case corresponds to the Elements Priority (Figure 71) and Key Properties (Figure 72). This show case for patients and medical experts almost meets all the guidelines. Although there is still much to be improved or added, for example, afternoon and evening are better times to intervene, this show case provides a possible output from the guidelines. Future researchers and designers can be inspired by it.

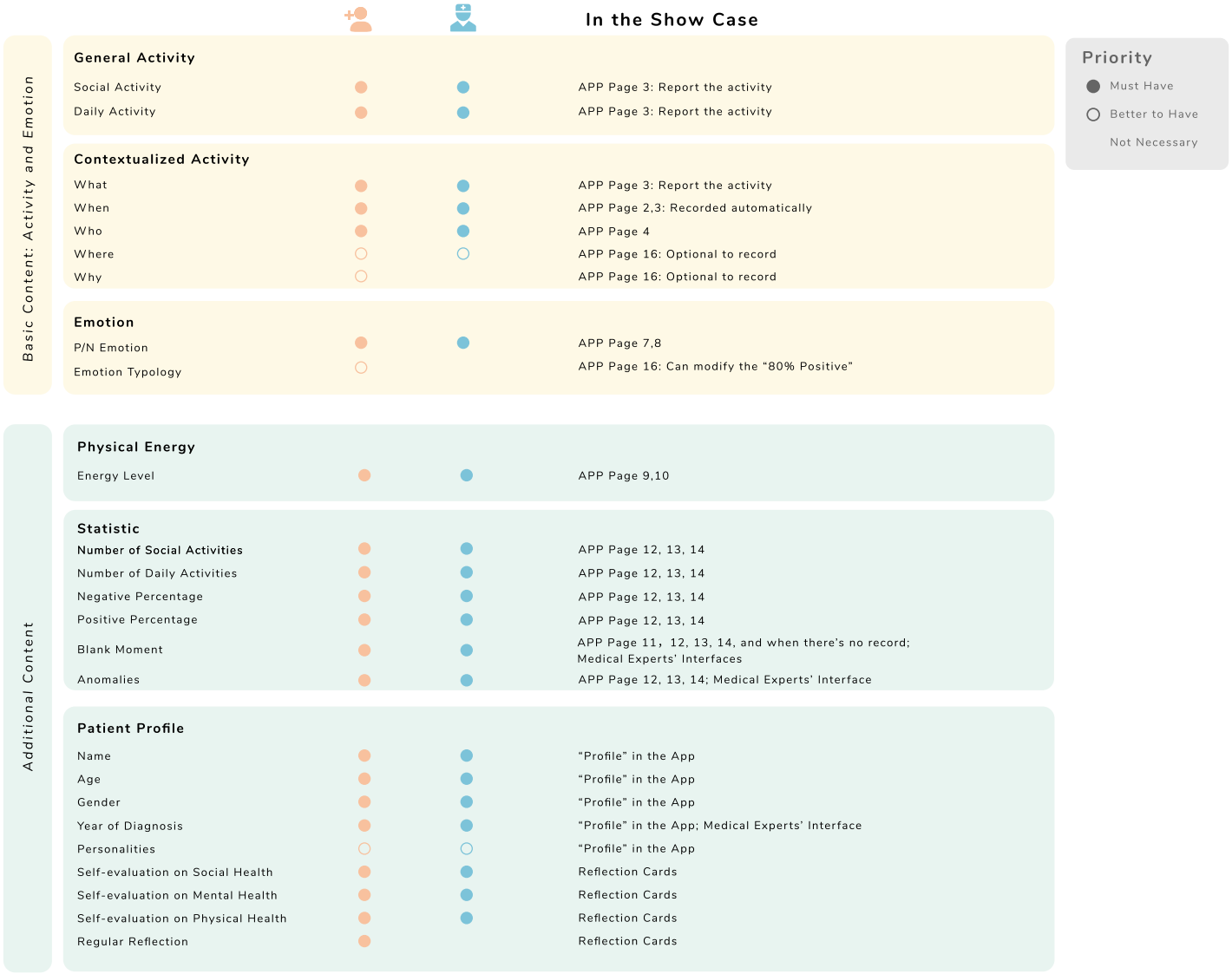


Figure 71 Show Case Meets Elements Priority.

Key Properties for Design

What properties should be kept in mind when designing?

	Properties	In the Show Case
Patients	Timely Feedback	*Blooming flower, Overview of the data, Timely data visualized*
	Real-time Record	*Report activity through an app*
	Quick Record	*Only basic information is needed for record, Record simply by tapping and dragging*
	Convenient Record	*Record simply by tapping and dragging in app*
	Multiple Record Formats	*Provide stickers when detailing the activity*
	Visualized Product	*Flower, circle and timeline visualized, Data visualized*
	Interesting Interaction	*Concept of collecting blooming flowers*
	Clear Statistic	*Shown in the 7-day, cycle and overview*
	Personalized Product	*Record patients' own activities, Have an overview of the data which belongs to their own*
	Periodic but Decreasing Cycles	*Doctor's meeting cycle reduced because patients gradually recover*
	Afternoon and Evening Interventions	*(Not applicable)*
	Regular Reflection	*Reflection cards, Reflect through the statistic*
	Paper and Digital	*Patients can choose not to report*
Medical Experts	Direct Information	*Statistic show in the interface*
	Quick Browsing with Highlights	*Highlight the anomalies, Data visualization*
	Convenient Browsing	*Data visualization, Digital Interface, Location Visualization*
	Visualized Interface	*Medical Experts' Interface*
	General overview with details when necessary	*Show some statistics in the main page, can click for detailed information on each patient*

Figure 72 Show Case Meets Key Properties.

5.4

Summary of Key Insights

1. The guidelines are for developing RPM in social and daily activity and related emotion for CRC patients.

2. The guidelines include two parts: Elements (Part 1) and Properties (Part 2). In Part 1, the four guidelines are Elements List, Elements Priority, Valuable Information from the Elements and Possible Research Directions. In Part 2, there is only Key Properties for Design, which is from the designers' brainstorm session.

3. The show case is only an example of what possible design could be if the guidelines were met. It includes a system, an app and reflection cards for patients and interfaces for medical experts.

Chapter 6

Toolkit for Developing RPM

Final Toolkit Design based on Guidelines

Download: https://sunny990115.wixsite.com/sdae

6.1 Initial Toolkit Design

6.2 Final Toolkit Design

6.3 Toolkit Validation

6.4 Future Vision and Suggestions

6.5 Summary of Key Insights

This chapter shows a toolkit named "SDAE" for developing RPM in social and daily activity and related emotion. This toolkit has an overarching framework that goes back and forth between data collection and data reflection. This toolkit makes the guidelines in the previous chapter extensible, allowing researchers to develop this aspect of monitoring for patients in other contexts besides colorectal cancer patients.

6.1

Initial Toolkit Design

This section describes the very first toolkit prototypes inspired by the initial guidelines. After evaluation and feedback from different designers and researchers, I reflected on the insights obtained and iterated on the toolkit. The final design will be presented in the next section.

Overview

The initial toolkit corresponds to the initial guidelines. The initial design for the toolkit includes lots of contents: (1) Element Cards (2) Define Content with Value Canvas (3) Define Priority Element (4) Key Properties for Design (5) How to Monitor (6) Inspired Blueprint with Timeline (7) Stakeholder System Mapping.

Figure 73 shows the purpose of the contents. Amongst other things, the first three parts were designed for researchers to output their own guidelines. Except for guidelines, there're also some other inspiring materials for researchers to explore. The last part is the key properties for design, which is the same as the result of the designers' brainstorm session.

As shown in Figure 74, the scope of each purpose should be incremental. The outputs of the previous six elements should be used in the final stage towards design, in addition to the final key properties.

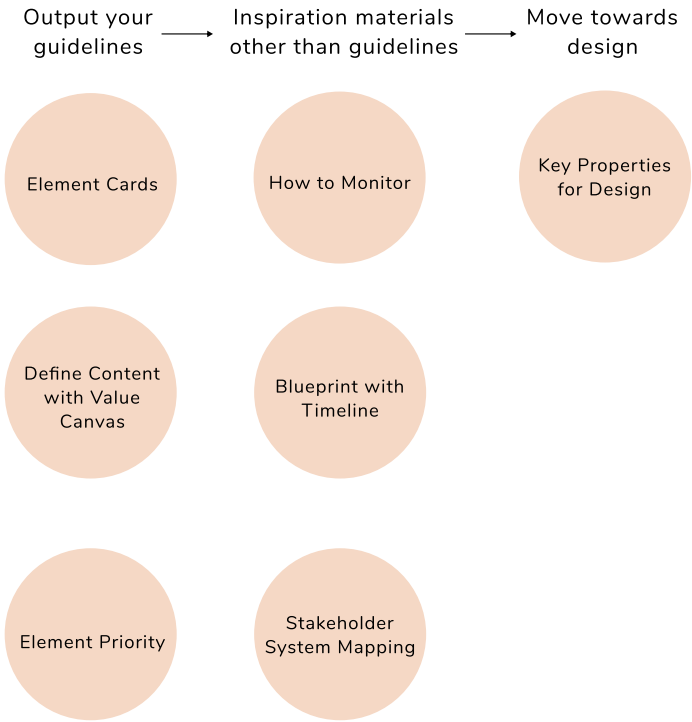


Figure 73 Purpose of the Contents.

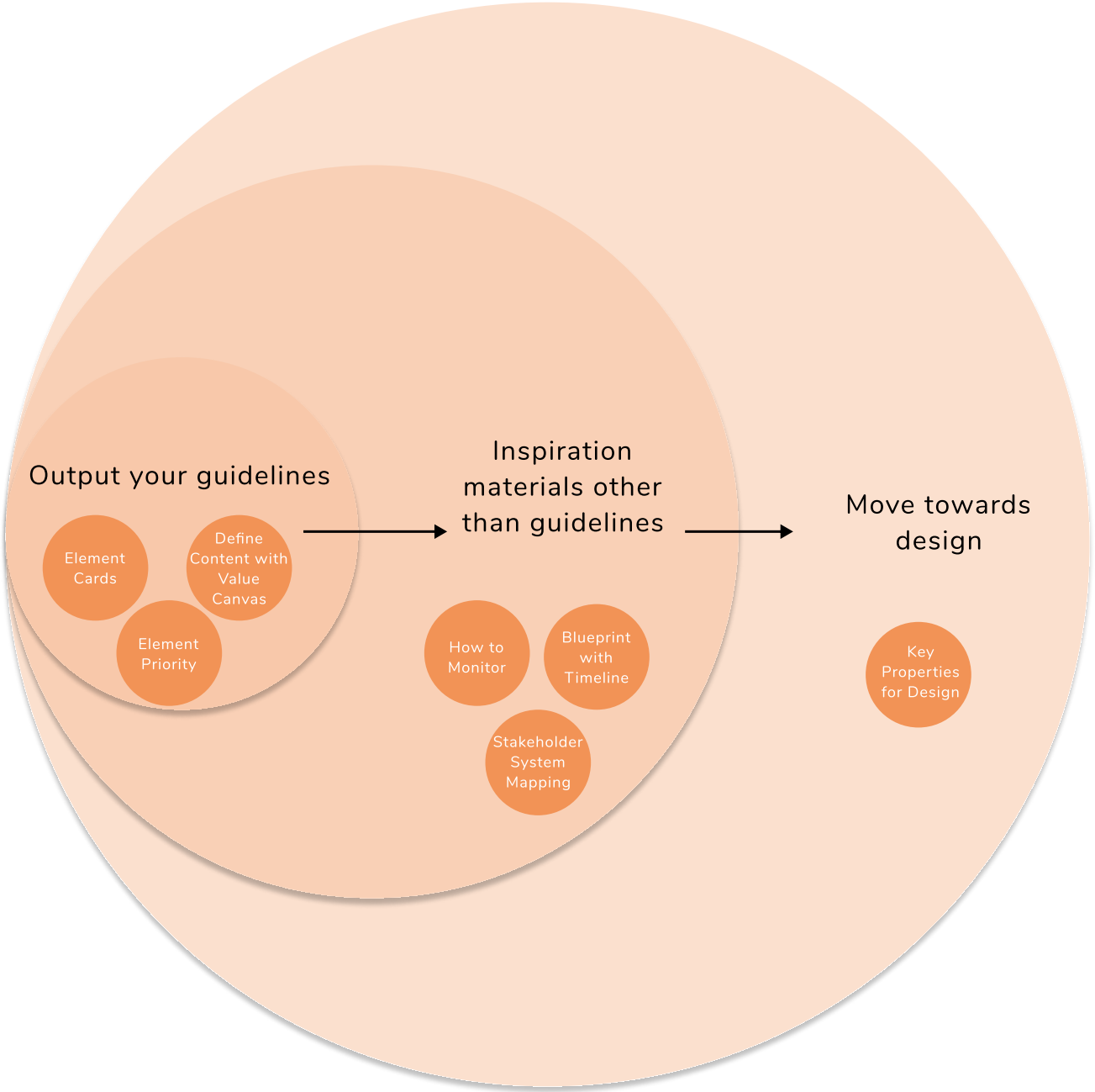


Figure 74 Relationships among Contents.

Contents

Elements Cards. For the element cards (Figure 75), I made cards of all the elements with the name of the element, the description of the element and the section to which it belongs. In addition to this, there are also some designed blank cards. Blank cards can also be used to add elements when the user thinks there is something else, they need that is not in the list.

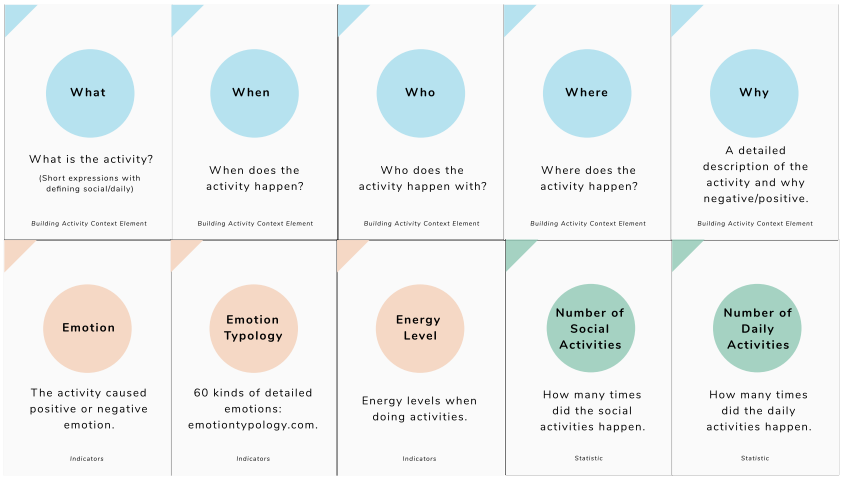
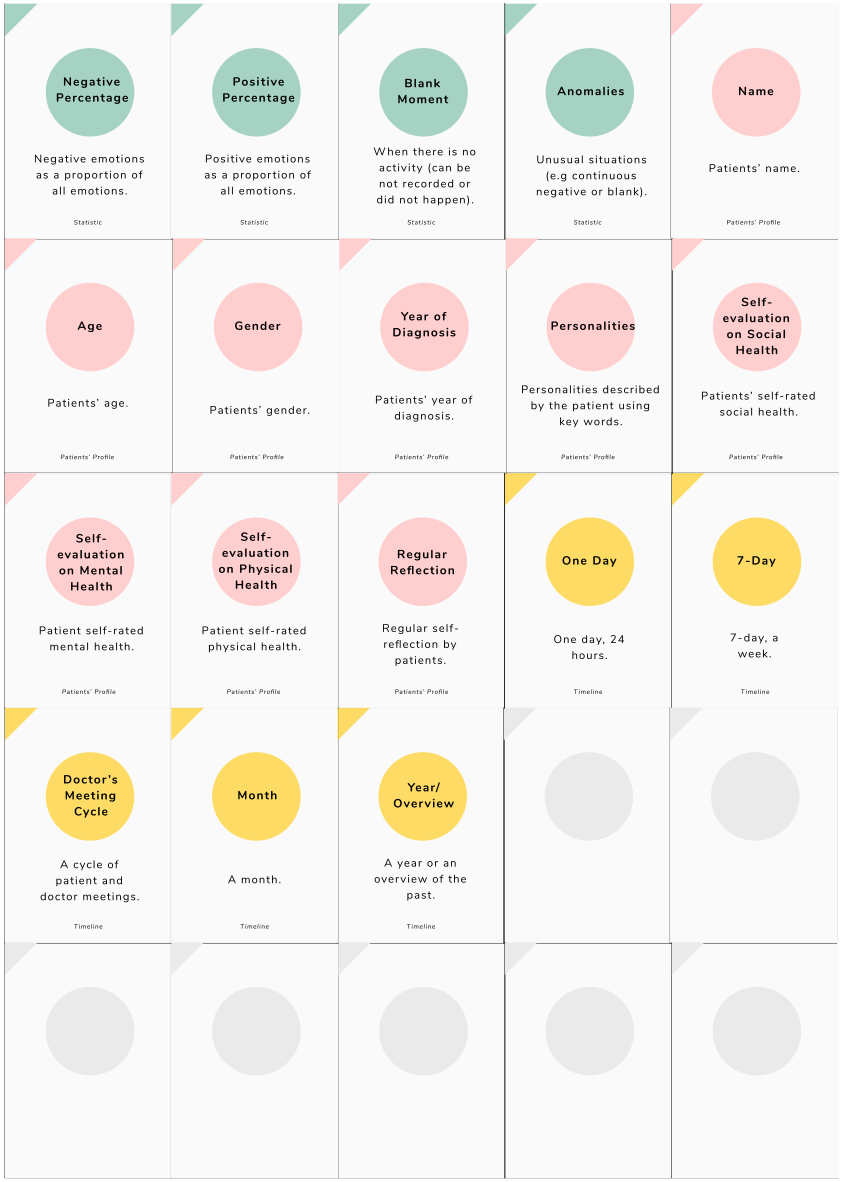


Figure 75 Element Cards.



Define Content with Value Canvas. The second part (Figure 88) defines the specifics of monitoring using element cards. In the image, the element cards are placed on the top, following the content, valuable information, value for stakeholders and supporting evidence on the bottom. Users first need to identify which stakeholder the content is designed for and complete the title. Depending on whether there are already defined values there can be two directions. If there is already a value, it can go from the right to the left. Fill in the Value section first, then think about what valuable information would satisfy the value, and finally select the elements that make up the information from the element cards section.

If there are no pre-defined values, users can brainstorm combinations of element cards, and then think about what valuable information they can provide through the content made up of the assembled elements. Finally, valuable information can be used to determine what value this can bring to the stakeholders.

These processes would be more convincing if they were supported by evidence. Sources of evidence can be theory, literature, research and so on. In addition to this, it is possible to define what is a "must have" or " better to have" after all sections have been completed, giving a clear idea of what information is important.

The canvas allows brainstorming of specific contents to be monitored when considering stakeholder values at the same time.

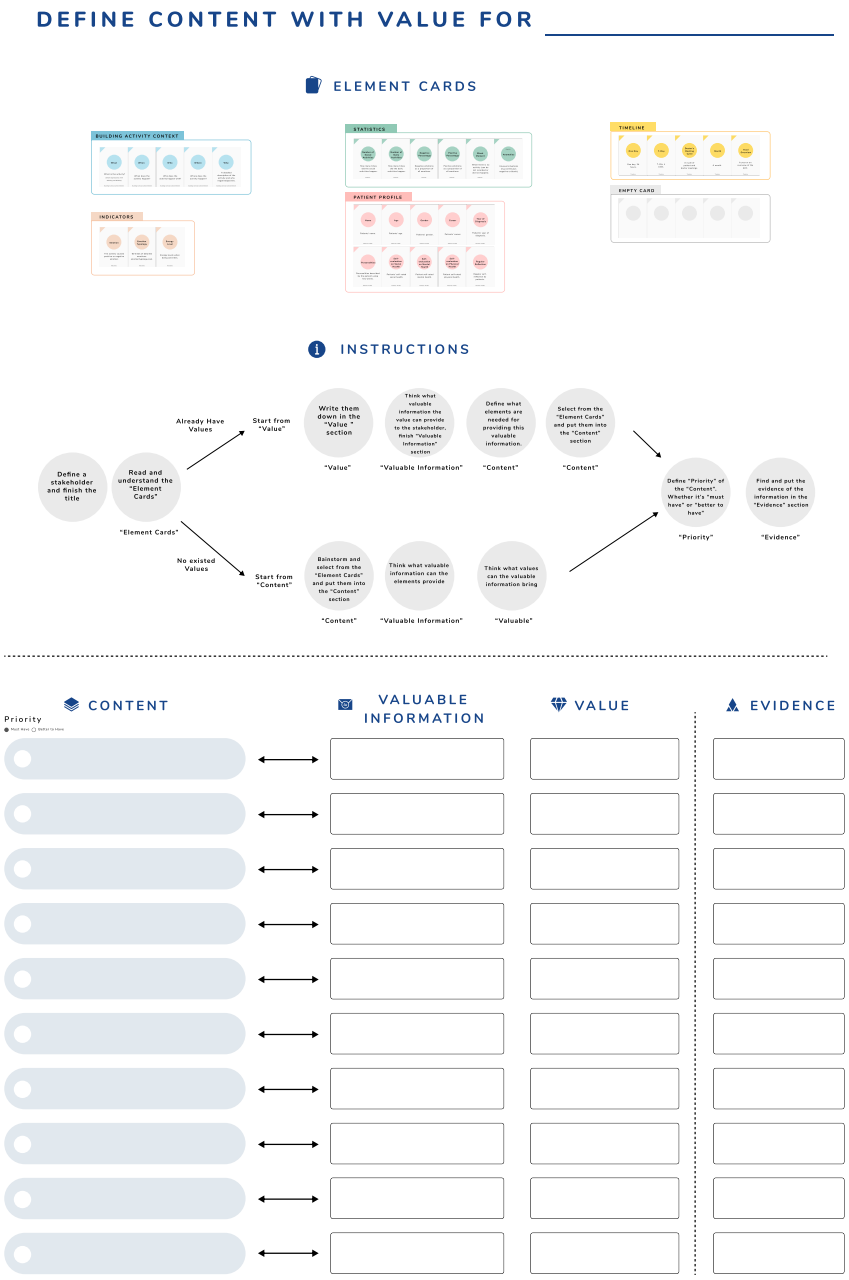


Figure 76 Define Content with Value Canvas.

DEFINE PRIORITY ELEMENT

Define the elements: whether it's "Must Have" or "Better to Have", and whether it's necessary.

● Must Have
○ Better to Have

Stakeholder	Patient				
Building Activity Context Element					
What					
When					
Who					
Where					
Why					
Indicators					
Emotion					
Emotion Typology					
Energy Level					
Statistic					
Number of Social Activities					
Number of Daily Activities					
Negative Percentage					
Positive Percentage					
Blank Moment					
Anomalies					
Patient Profile					
Name					
Age					
Gender					
Career					
Year of Diagnosis					
Personalities					
Self-evaluation on Social Health					
Self-evaluation on Mental Health					
Self-evaluation on Physical Health					
Regular Reflection					
Timeline					
One Day					
7-Day					
Doctor's Meeting Cycle					
Month					
Year/Overview					
Other					

Figure 77 Defined Priority Content.

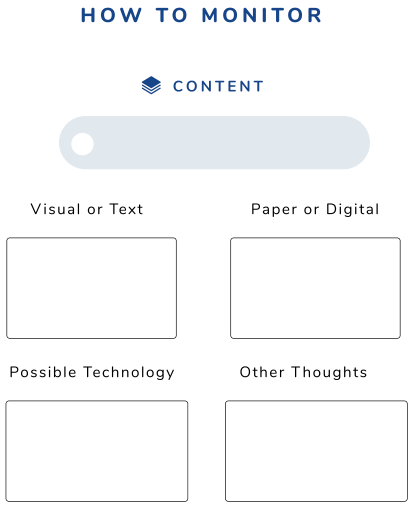


Figure 78 How to Monitor.

Define elements priority. After completing the canvas, the defined elements priority (Figure 77) helps the user to finally define which elements are important. This can be used as a guide for subsequent designs.

How to monitor. How to monitor (Figure 78) is a small section that stimulates the user's thinking about how the content is monitored. I offer three aspects: the use of visual or textual, paper or digital, and the technology that may be required. A blank place is also left to encourage more ideas from users.

Inspired blueprint with timeline. This blueprint (Figure 79) introduced a timeline into this section to help users get a broader perspective and think about the connections between stakeholders. Users can first select from the five timelines above and place them in the 'Timeline' area, and then think about the monitoring content, actions and touchpoints of the different stakeholders according to this timeline. In addition, the "Support Process" helps the user to think about the technologies and judge whether the form is patients' self-reporting or passive monitoring.

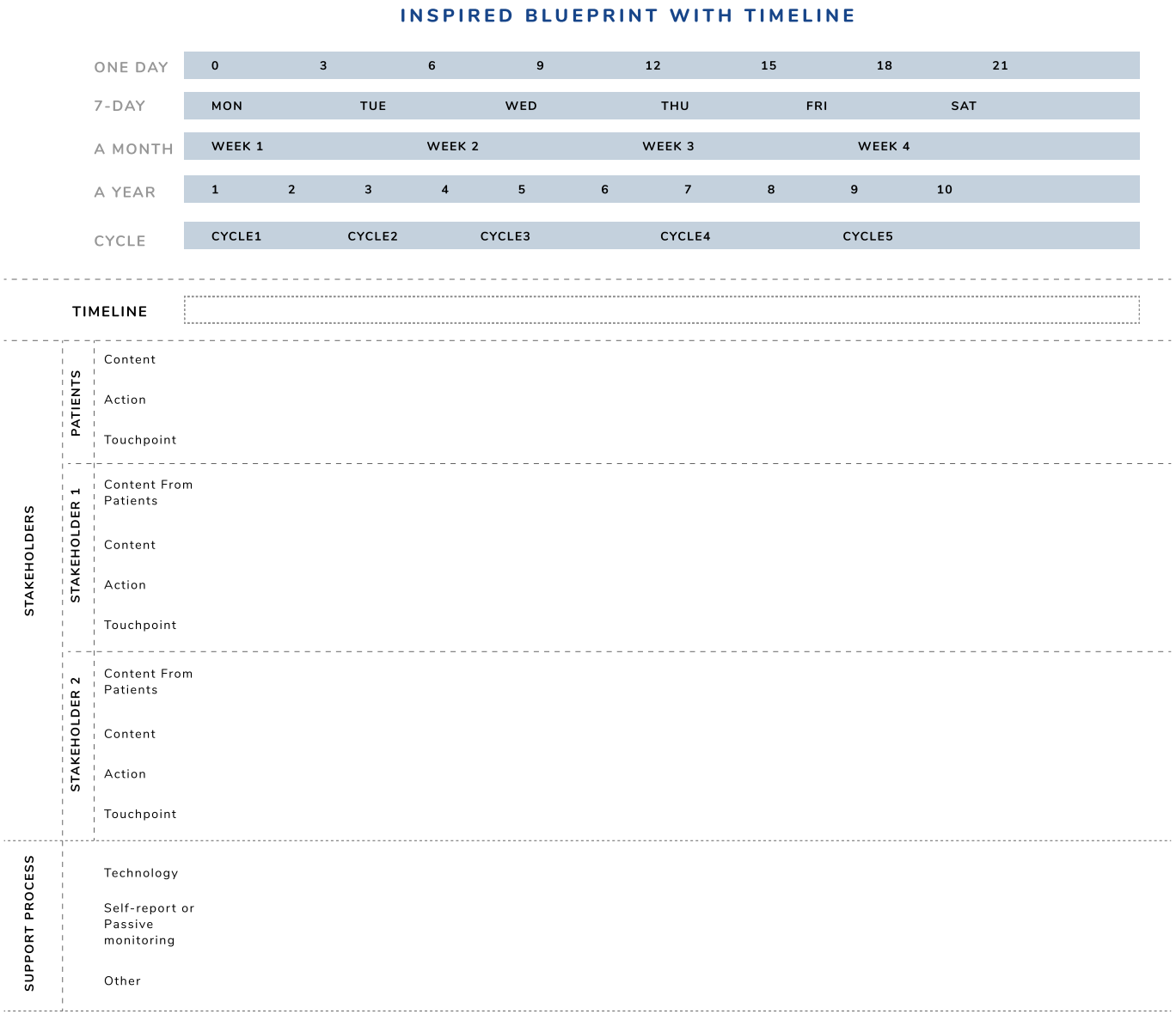


Figure 79 Inspired Blueprint with Timeline.

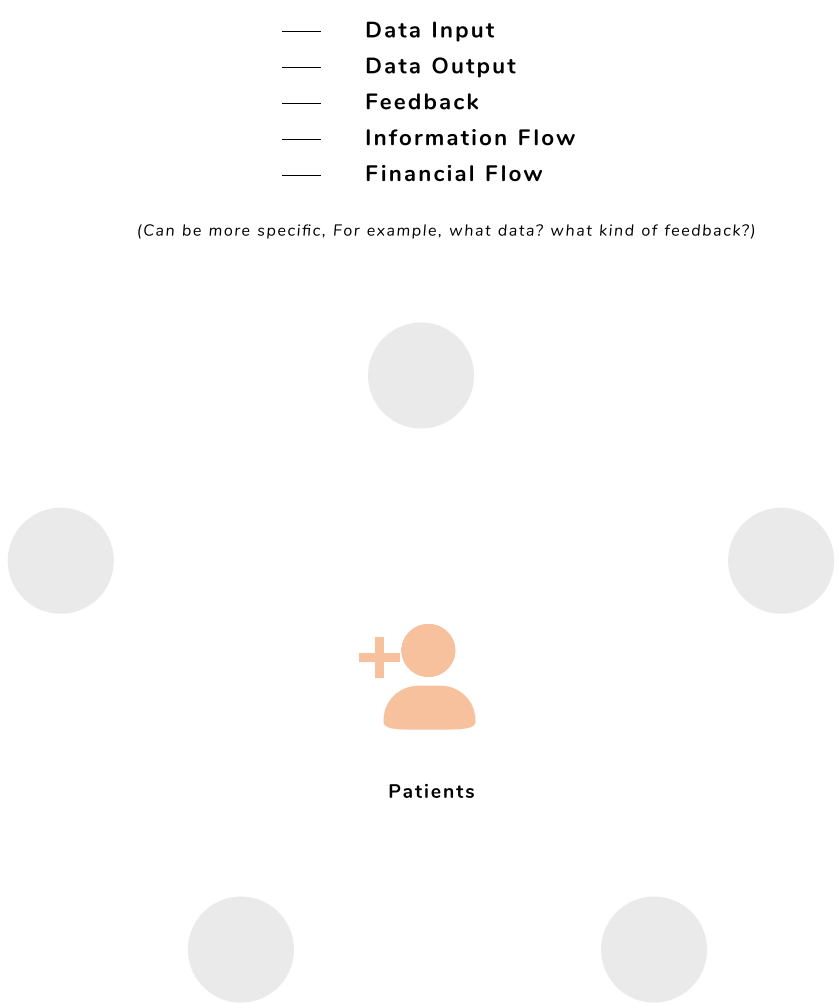


Figure 80 Stakeholder System Mapping.

Stakeholder System Mapping. Finally, users can draw the flows among the stakeholders on the stakeholder system mapping (Figure 80) by thinking about several aspects, including data input, data output, feedback, information flow and financial flow. This process helps the user to sort out the relationships between the stakeholders and summarize all the previous information.

Evaluation

The initial toolkit design underwent evaluation by three researchers and two designers, who provided valuable feedback for improvement.

A main concern raised in their feedback was the lack of coherence in the toolkit's design. The purpose and rationale behind the utilization of each tool remained ambiguous, rendering it challenging for users to comprehend the toolkit's intended usage. Furthermore, the absence of an overarching framework resulted in users struggling to discern the connections between different tools, leading to confusion regarding where to initiate their interaction with the toolkit.

Another critical point of feedback was the fragmented nature of the toolkit. While it contained a copious amount of detail, the organization was lacking. Consequently, users were required to invest substantial time and effort into familiarizing themselves with individual tools without having a holistic overview to facilitate their understanding.

The designers also offered valuable insights, particularly regarding the toolkit's visual presentation. To enhance user experience, a clearer and more unified visual guide is deemed necessary. This visual guide aims to provide users with a lucid indication of each toolkit's respective section and the interrelationships among the various tools.

In summary, the feedback received from the researchers and designers has shed light on several crucial aspects that require attention and refinement in the toolkit design. The final design presented in the next chapter is the result of an enhancement after reflecting on the feedback.

6.2

Final Toolkit Design

Download:
https://sunny990115.wixsite.com/sdae




SDAE
A toolkit for developing remote patient monitoring in social, daily activity and related emotion
Instruction
Elements Processing: Between Patients and Medical Experts
Recommended Participants
Designers,
Patients
Medical Experts
Recommended Duration
60 minutes
New Elements List and Priority

This section introduces the toolkit for developing remote patient monitoring in social and daily activity and related emotion. The toolkit named SDAE (Social Daily Activity Emotion), is the result of my rethinking and redesigning my research process and findings. Since the content of my guidelines is indicative of CRC patients only, plus the lack of remote patient monitoring in this area, I believe that making a toolkit for my research process could help future researchers develop this remote monitoring system for OTHER diseases. This provides a broader answer to my research question "How to develop". In conclusion, this toolkit can extend the guidelines and design to patients having other diseases.

Overview

Toolkit's Framework. The toolkit has a framework (Figure 81) that consists of two parts: data collection and data reflection. The data collection process included diary studies and follow-up interviews with patients (Part A) as well as several co-creation sessions (Part B). Data reflection is modifying my guidelines (Part C) to adapt to the new contexts. This involves constantly reflecting on the results that appear in the data collection and modifying the guidelines. It is not a linear process, but rather a continuous round-trip iterative process. In the end, the researcher will have the guidelines appropriate to

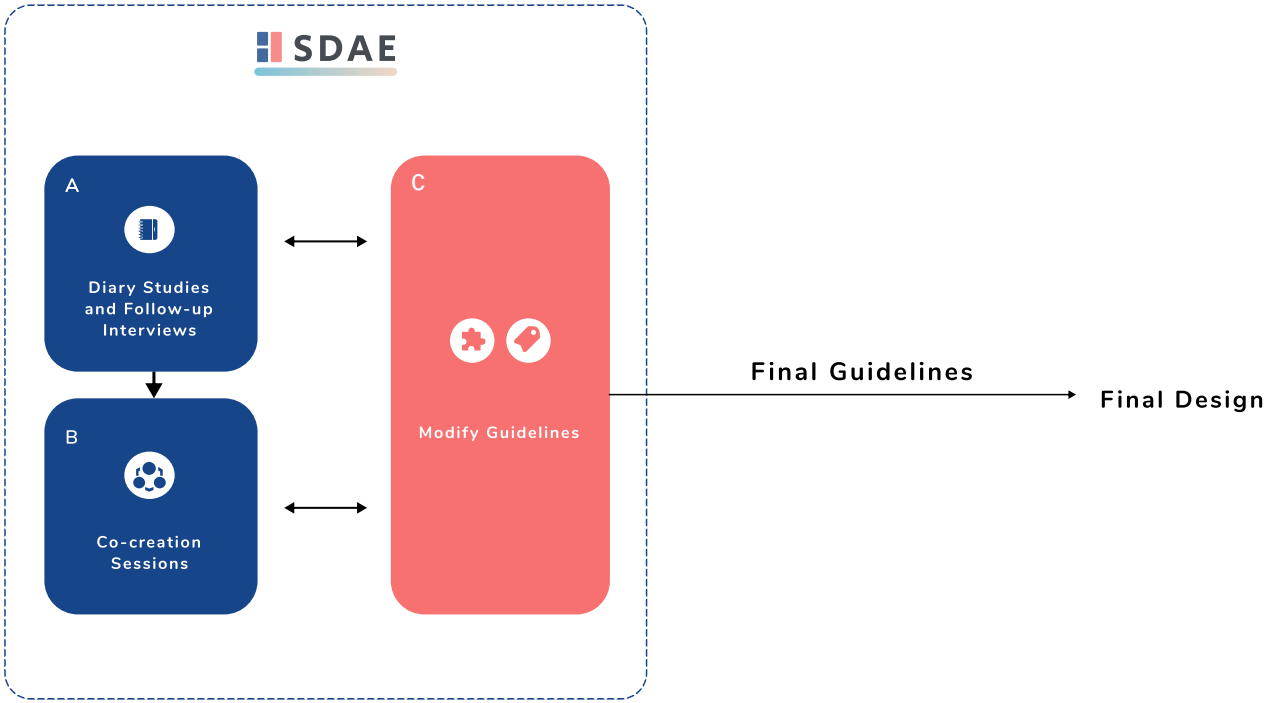


Figure 81 Toolkit's Framework.

their research context and design the final system according to the guidelines.

The reason the framework comprises these two main parts is due to the existence of ready-made guidelines for CRC. Modifying the guidelines based on the data results allows researchers to promptly align the research outcomes. Reflecting on the collected research data through the modification of guidelines also helps researchers slow down their pace and think cautiously (Choe, 2014; Mattimoe et al., 2021). If data is collected blindly without reflection and analysis, researchers are likely to lose direction (Bell, 1998; Pearson & Kayrooz, 2004).

What is in inside the toolkit. Figure 82 shows the contents of the toolkits and Figure 83 introduces the goal and participants for each part. In the diary studies and follow-up interviews in Part A, the toolkit provides two tools: the diary study probe and the interview guide. Researchers can utilize these tools to conduct diary studies with the patients they intend to study. In Part B, four tools are provided for co-creation sessions. This section primarily involves collaborative creation with designers and stakeholders to explore how elements should be collected, translated, and presented, as well as examining interactions among different stakeholders. Researchers can also work together with stakeholders to define the priority of the elements.

When conducting Part A and Part B, researchers need to analyze and reflect on the data and make

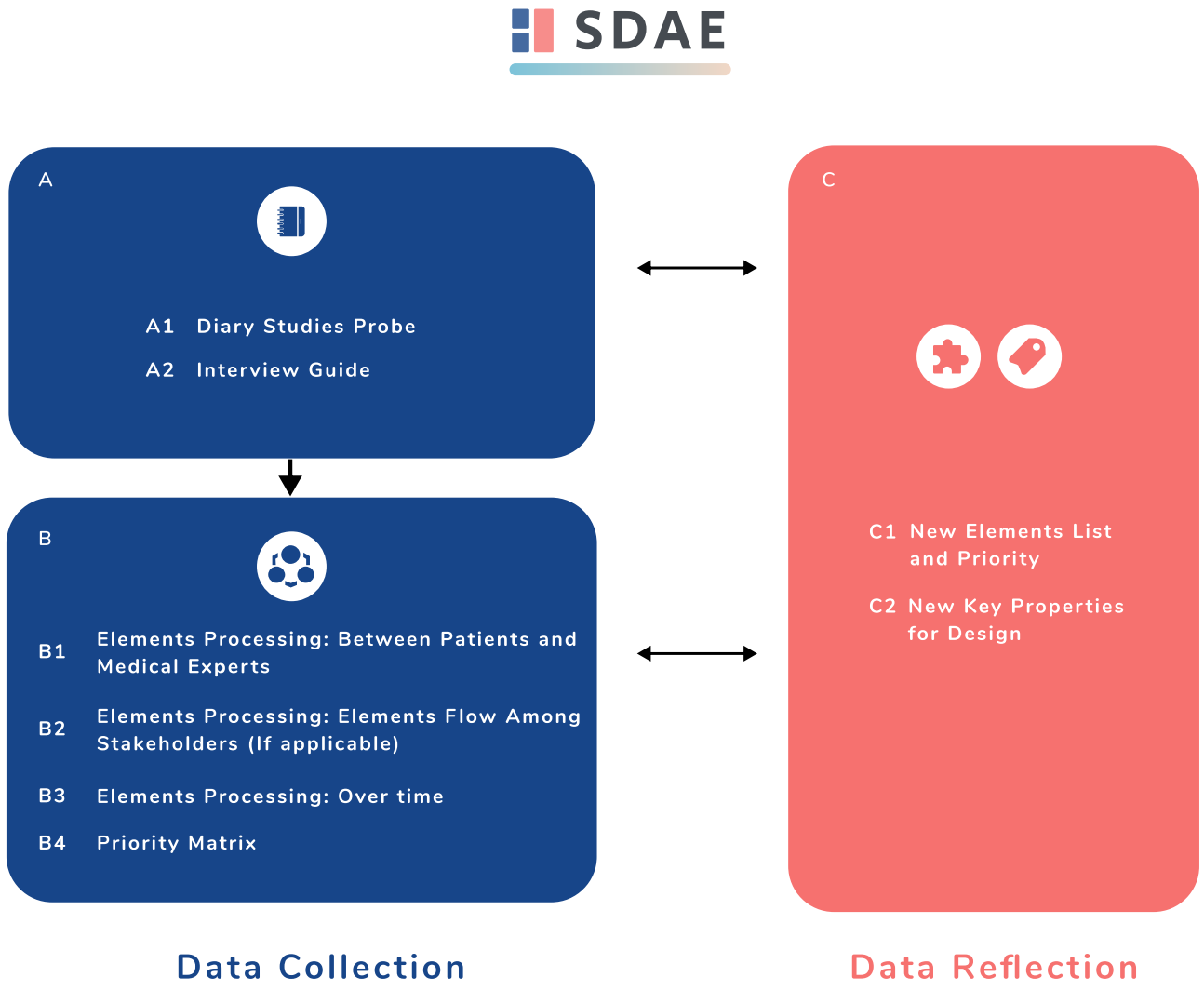


Figure 82 Toolkit's Contents.

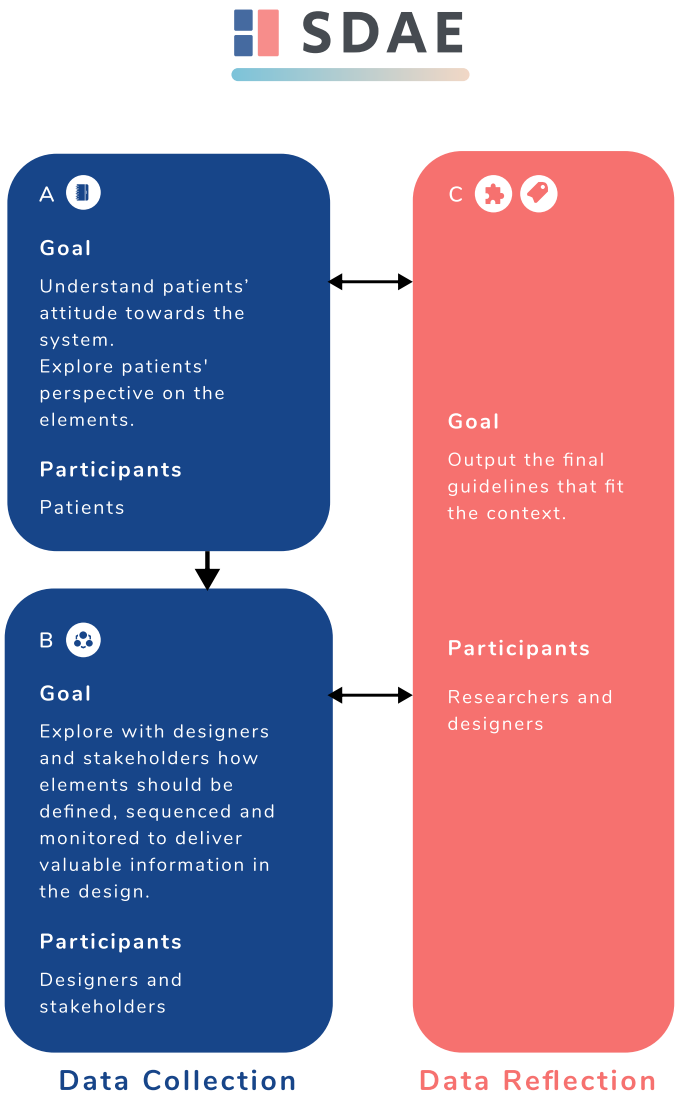


Figure 83 Toolkit's Contents.

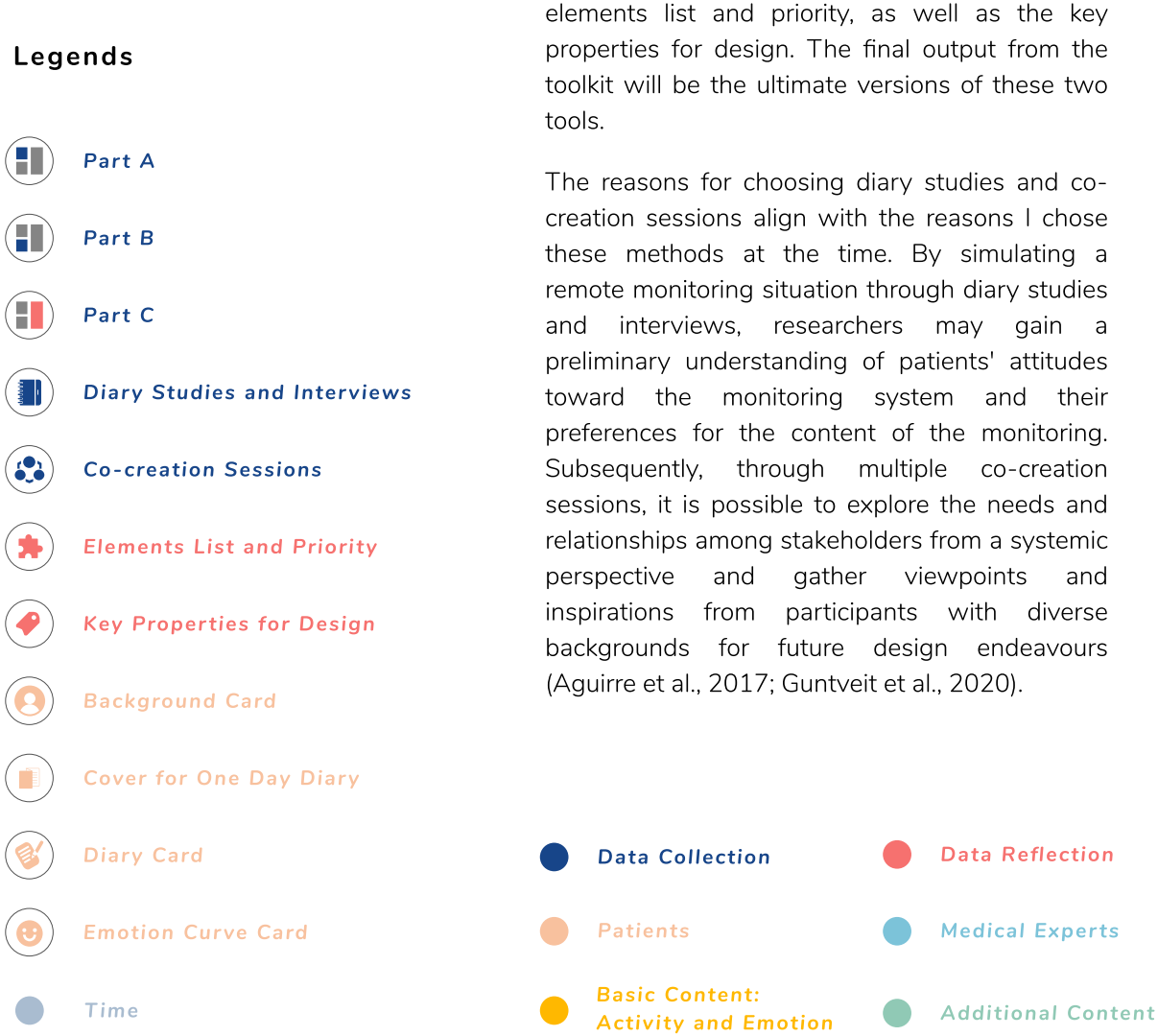


Figure 84 Legends for the Toolkit.

modifications to the guidelines in Part C. The aspects that require modification include the elements list and priority, as well as the key properties for design. The final output from the toolkit will be the ultimate versions of these two tools.

The reasons for choosing diary studies and co-creation sessions align with the reasons I chose these methods at the time. By simulating a remote monitoring situation through diary studies and interviews, researchers may gain a preliminary understanding of patients' attitudes toward the monitoring system and their preferences for the content of the monitoring. Subsequently, through multiple co-creation sessions, it is possible to explore the needs and relationships among stakeholders from a systemic perspective and gather viewpoints and inspirations from participants with diverse backgrounds for future design endeavours (Aguirre et al., 2017; Guntveit et al., 2020).

Toolkit Content: Part A

The probe for diary studies and interview guide in Part A are essentially the same as those used in the user research in Chapter 4. The probe for the diary studies includes:

(1) Instruction (Figure 85)

(2) Background Card (Figure 86)

(3) One Day Diary: a Cover (Figure 87), Diary Card (Figure 88) and Emotion Curve Card (Figure 89)

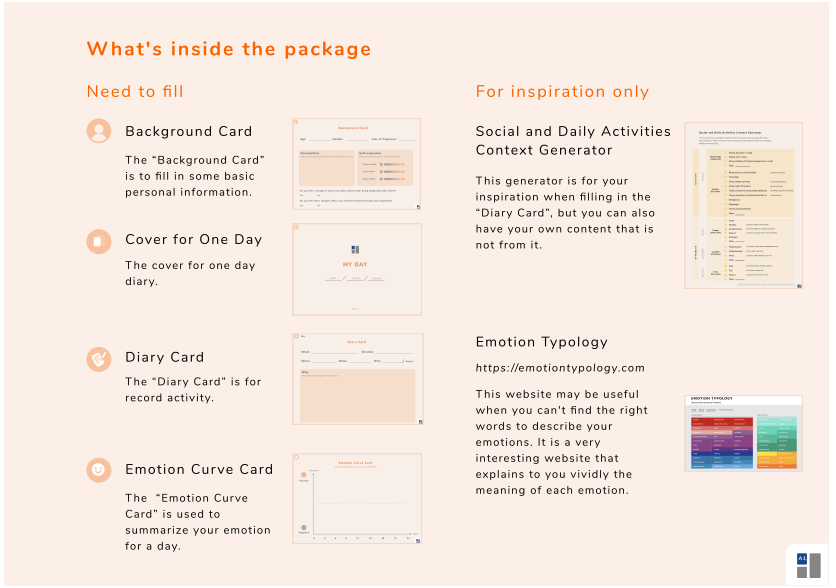
(4) Social and Daily Activity Context Generator (Figure 90)

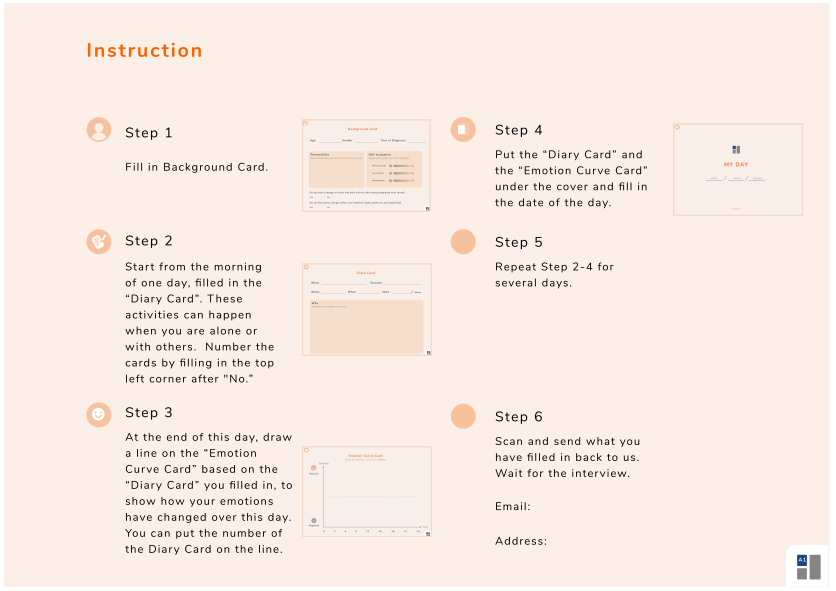
The most significant change is the visual system. All of the materials used for Part A, because they are patient-related, have a light orange colour as the main colour and indicate in the lower right corner that it belongs to Part A to make it easier for the researcher to organize. The tools introduced in the diary studies align with the elements in the guide, allowing the researcher to match them one-to-one. For example, the background card reflects the patient profile, the diary card pertains to activity and emotion, and the process of drawing the emotion curve is also reflective and statistical.

Using the tools from Part A, future researchers can obtain preliminary insights from patients regarding their attitudes towards the monitoring system, as well as their viewpoints on the content and methods of monitoring. After this stage is completed, analysis and reflection should follow, and the findings should be incorporated into the guidelines (Part C).



Figure 85 A1-Instruction.





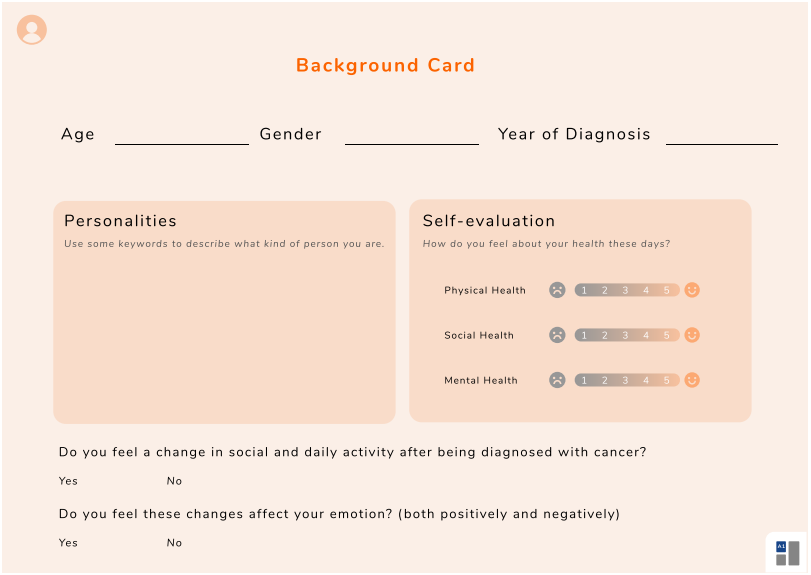


Figure 86 A1-Background Card.

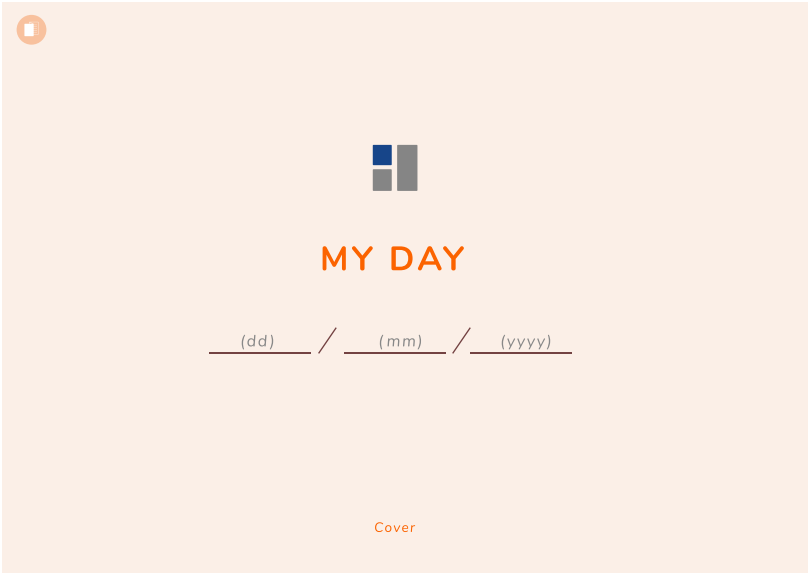


Figure 87 A1-Cover for One Day.

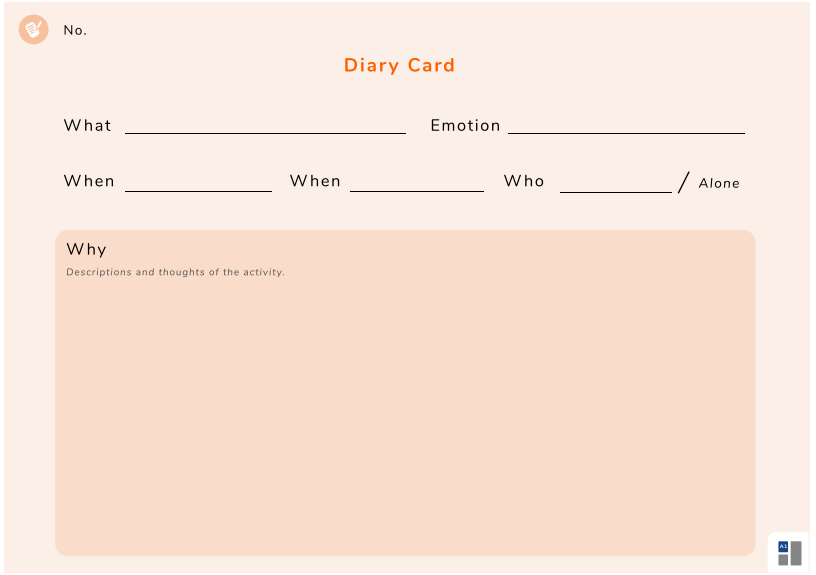


Figure 88 A1-Diary Card.

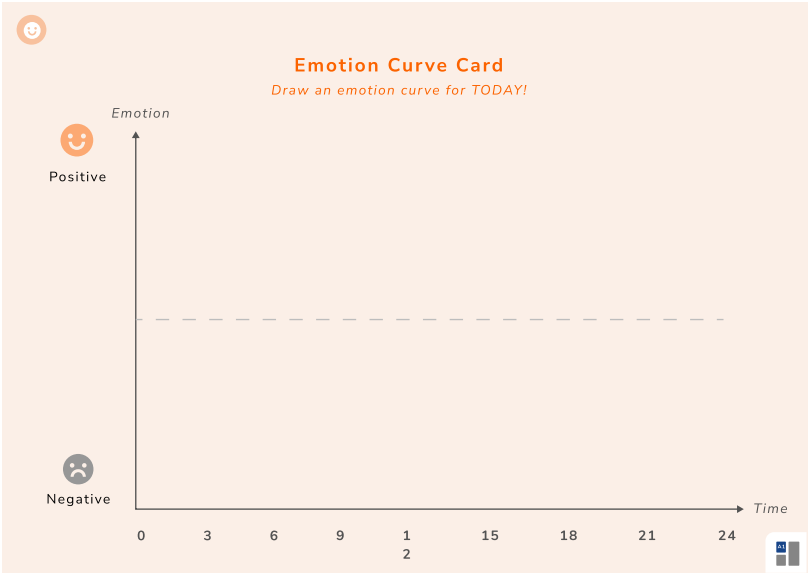


Figure 88 A1-Emotion Curve Card.

Social and Daily Activities Context Generator

This is just for your inspiration. What you fill in the cards is not necessarily from this.
The contents in "What" are from Three-dimensional Theoretical Framework of Health(a), NMF(b) and Bertopic(c).

ACTIVITY

WHAT

Body Image (About me)

- Feeling attractive or not(a)
- Feeling old or not(a)
- Being satisfied with physical appearance or not(a)
- Other _____

Activity (Do what)

- Being active on social media(c) — e.g Facebook. Whatsapp
- Working(a)
- Doing outdoor sports(c) — e.g Horsing, Hiking, Biking
- Doing indoor fitness(b,c) — e.g Work out in gyms
- Feeling of physical functioning/mobility(a,b) — e.g Walking, Lifting, Carrying, Standing
- Having recreation and entertainment(a,b,c) — e.g Planting flowers
- Eating(a,b,c)
- Sleeping(a)
- Having sexual activity(a)
- Other _____

ATTRIBUTE

WHO

People (With who)

- Alone
- Families — e.g Spouse, Children, Parents, Sibling
- Acquaintances — e.g Friends, Neighbours, Colleagues, Classmates
- Experts — e.g Doctors, Psycologist, Fitness instructor, Dietitian
- Strangers
- Other _____

WHERE

Location (At where)

- Public(Indoor) — e.g Company, School, Hospital, Cafe/Restaurant, Gym
- Public(Outdoor) — e.g Park, Beach, Lake, Forest
- Home — e.g Kitchen, Garden, Bedroom, Living room
- Other _____

WHEN

Time (On when)

- Date — e.g Monday, Festivals, Wedding, Graduation
- Day — e.g Afternoon, Evening, Noon
- Season — e.g Spring, Summer, Autumn, Winter
- Other _____

[a] Van Leeuwen, M., Husson, O., Alberti, P., Arraras, J. I., Chirst, D. L., Costantini, A., ... & van de Poll-Franse, L. V. (2018). Understanding the quality of life (QOL) issues in survivors of cancer: towards the development of an EORTC QOL cancer survivorship questionnaire. Health and quality of life outcomes, 16(1), 1-15.

A1

Figure 89 A1- Social and Daily Activities Context Generator.

Interview Guide

Semi-Structure

30-60 minutes

Ice-breaking

How did you feel about filling in the the diary overall?
-How did you feel about the filling in the diary cards?
-How did you feel about drawing the emotion curve?
-Which part is the most interesting and the most difficult, why?

2 minute

Goal:
Ice-breaking and get overview of patients' feeling.

About the diary

Show the emotion curve for a particular day **(Patients can also talk about other days)**
-Which of these activities were easier to fill in and which were difficult, WHY?
-Are there any of these activities that stuck out to you the most?
-Are there any activities on this day that are not written on here and why are they not on here?
-When do you think is the best moment for intervention?
-What types of activities do you think are necessary to be recorded (that may be relevant to your health) and what types are not necessary?
In your past experience, are there any activities/times when you felt you should do something like this diary study, in order to let your doctor know or you think will be important to your health?

Compare to those days when you didn't need to fill in the diary(before/after), do you feel any difference?
-If you do, what's that? Will that be important for you?
-If don't, why?

15 minute

Goal:
Recall patients on the diary they have filled in and find out their feelings and opinions on the process.

Know what they think can be important to their health regarding the content in the diary.

Evaluation on the diary

Any ideas on how to improve? This can be:
-Timing of data collection
-Elements in the diary
-Method of data collection
-Involving other people
-Any other things

3 minute

Goal:
Encourage patients to have opinions on how to improve.

Sharing Data

How do you feel about seeing other patients' activities?
Are you willing to share this kind of data with other CRC patients?
How do you think about letting other people to know your social and daily activities and emotion situation?
How do you think about letting the hospitals (doctors, nurses or other medical experts) to know your social and daily activities and emotion situation.
-Is there anything that is NOT in the diary study, but you feel important for doctors to know?

5 minute

Goal:
Discover the attitude about sharing data with other stakeholders.

Last questions

Any other thing you want to say?

5 minute

Goal:
Give an opportunity for the patient to add.

A2

Figure 90 A2-Interview Guide.

Toolkit Content: Part B

Part B has a total of four tools. These four tools mainly help the researcher to gather ideas and inspirations about the processing of the elements from different stakeholders.

Part B1. Part B1, called Elements Processing: Between Patients and Medical Experts (Figure 91), provides a tool for exploring the process of data transfer between the basic relationship of patients and medical experts. The main question to think about is "How to collect the element?" from the patient's point of view, and "How to translate and present the element?" from the medical expert's point of view (Ferrua et al., 2020).

Due to the complexity of the patient's side, I offer three directions to think about: should the element be collected digitally or on paper? (And if digital, with what technology?) Should it be textual or visual? Should the patient self-report or should the patient receive passive tracking? By thinking about these three questions, the basic form of a remote monitoring system on the patient side can be shaped (Bratan & Clarke, 2006; Ferrua et al., 2020; Sivani & Mishra, 2022). Certainly, there are other ideas that can be written in addition to these three directions. Because the elements in the basic content of activity and emotion are relatively fixed, only this basic content is presented in B1. The other elements can be filled in freely.

This process is recommended to be 1 hour long. It

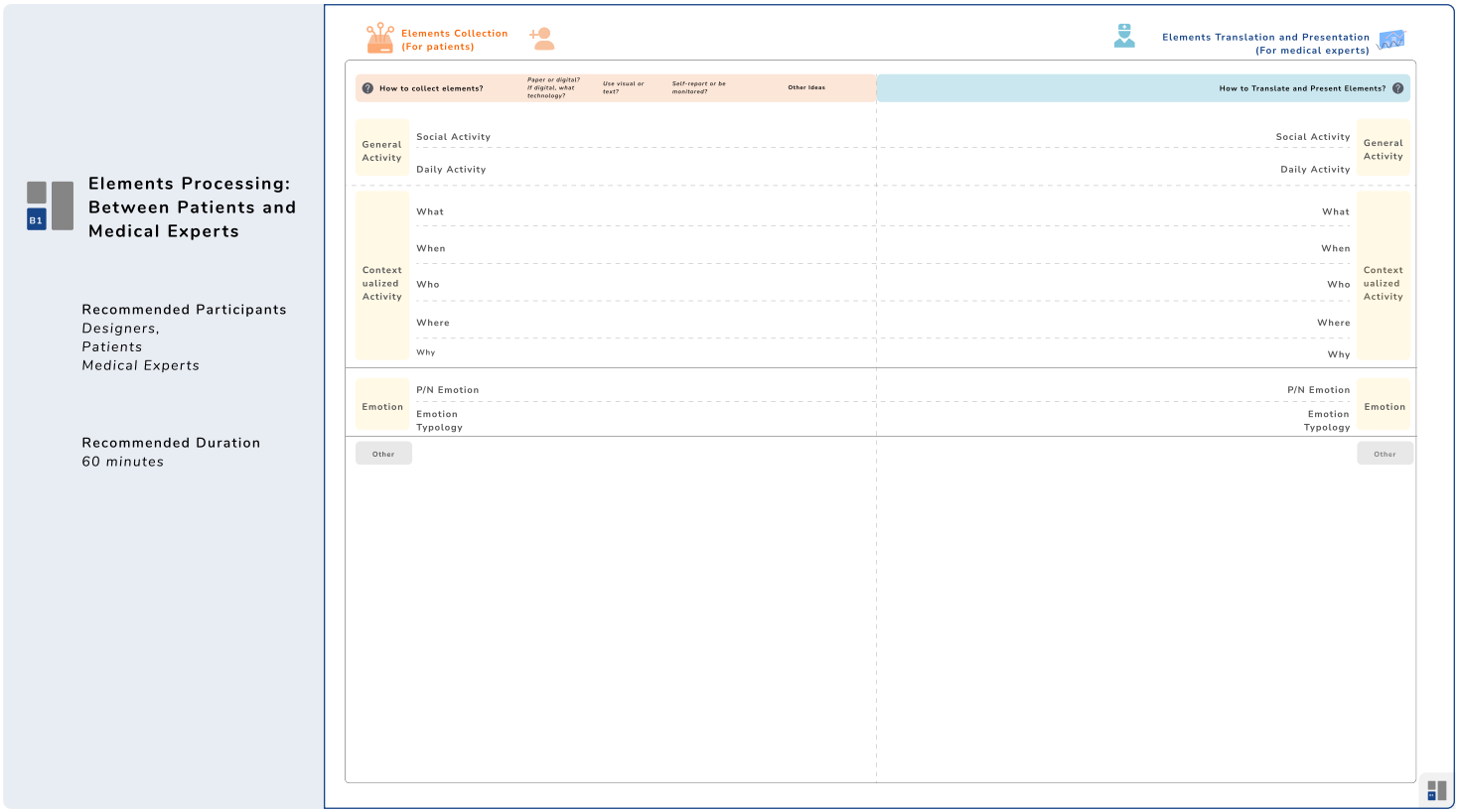


Figure 91 B1-Elements Processing: Between Patients and Medical Experts.

evolves from material from the designers' brainstorm session, which founds that it's important to involve not only designers but also patients and medical experts because bringing the patient and the medical expert together helps to reach a consensus between them and avoids overly favoring the interests of one party (Bhalla, 2011).

Part B2. Part B2, called Elements Processing: Elements Flow Among Stakeholders (Figure 92), provide a tool for exploring the flow of the data among not only patients and medical experts but also other stakeholders, such as lifestyle coaches. This tool is labelled "If applicable" because it is only suitable in a multi-stakeholder context. In other words, if the researchers want to involve other people in the system, then this tool is appropriate.

B2 stimulates participants to think in the first person about the direction of elements' flow by providing a paradigm (What), ways (How), and the reasons behind them (Why). In this way, stakeholders are able to provide valuable insights in the context of their own experiences and needs (Varela & Shear, 1999). An example is also provided below for the participants' reference.

B2 explores stakeholder relationships at a systemic level. It is recommended to have 30 minutes, and relevant stakeholders are invited. As with B1, the purpose of this is to allow for communication, confrontation and ultimately consensus among stakeholders.

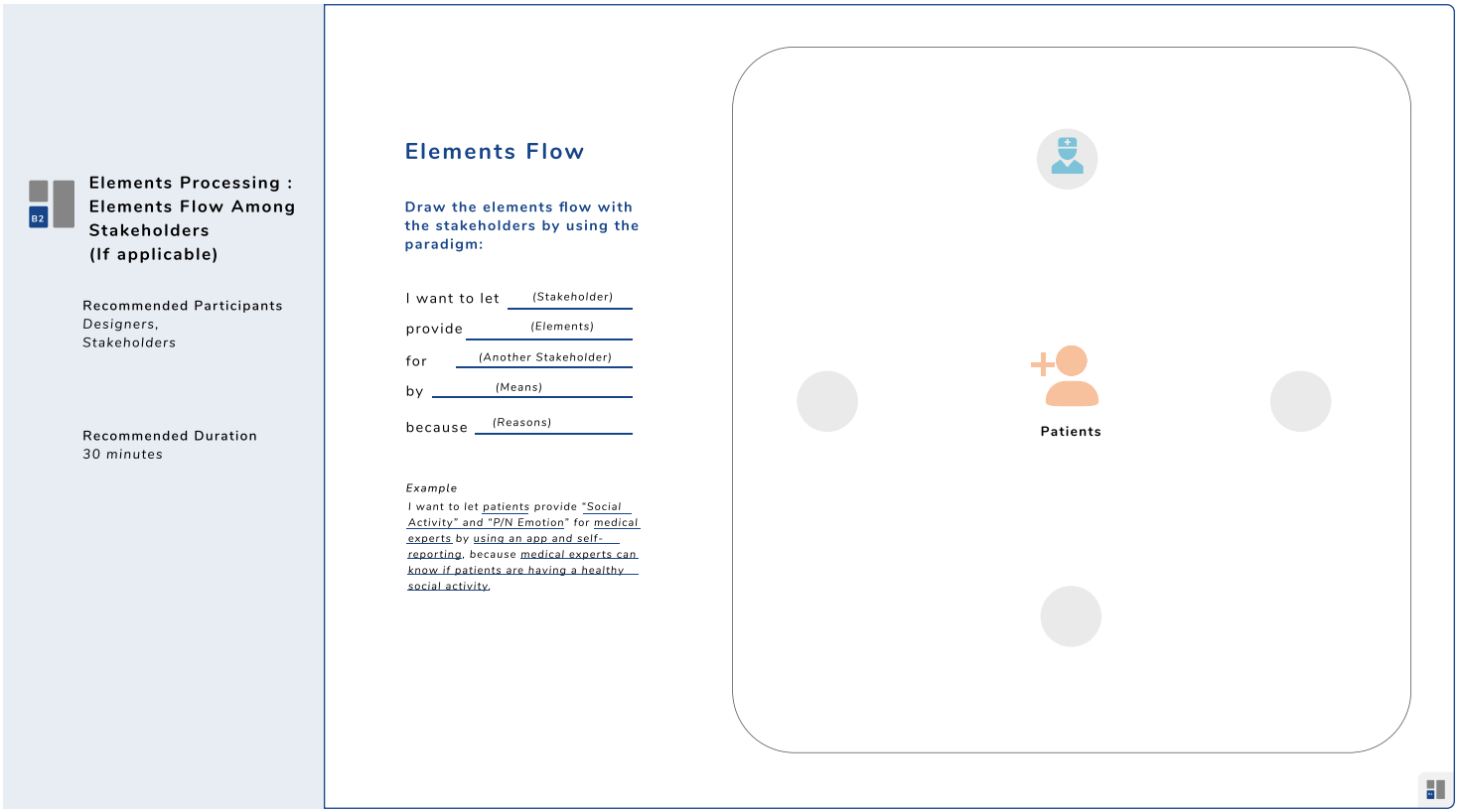


Figure 92 B2-Elements Processing: Elements Flow among Stakeholders.

Part 3. Part B3, called Elements Processing: Over Time (Figure 93), provide a tool for exploring the elements needed over time. Since the monitoring system is a long process rather than an instantaneous one, it also becomes important to explore when elements should appear, for how long, and how often.

The design here draws on the service blueprint approach to service design, thinking about what elements each stakeholder is exposed to, what actions need to be taken, and what the possible touch points are (Bitner et al., 2008). The timeline offers five options: a day, a week, a month, a year, and a doctor's meeting cycle, which aligns with the time element in the Element List. Participants are free to choose the timeline they want to explore.

Through this process, the researcher can gain perspectives that are specific to the characteristics of long periods of time in the monitoring system, thus constructing a sustainable system (Majumder et al., 2017). Therefore the process is also one that requires the involvement of stakeholders and designers and the duration is recommended to be an hour.

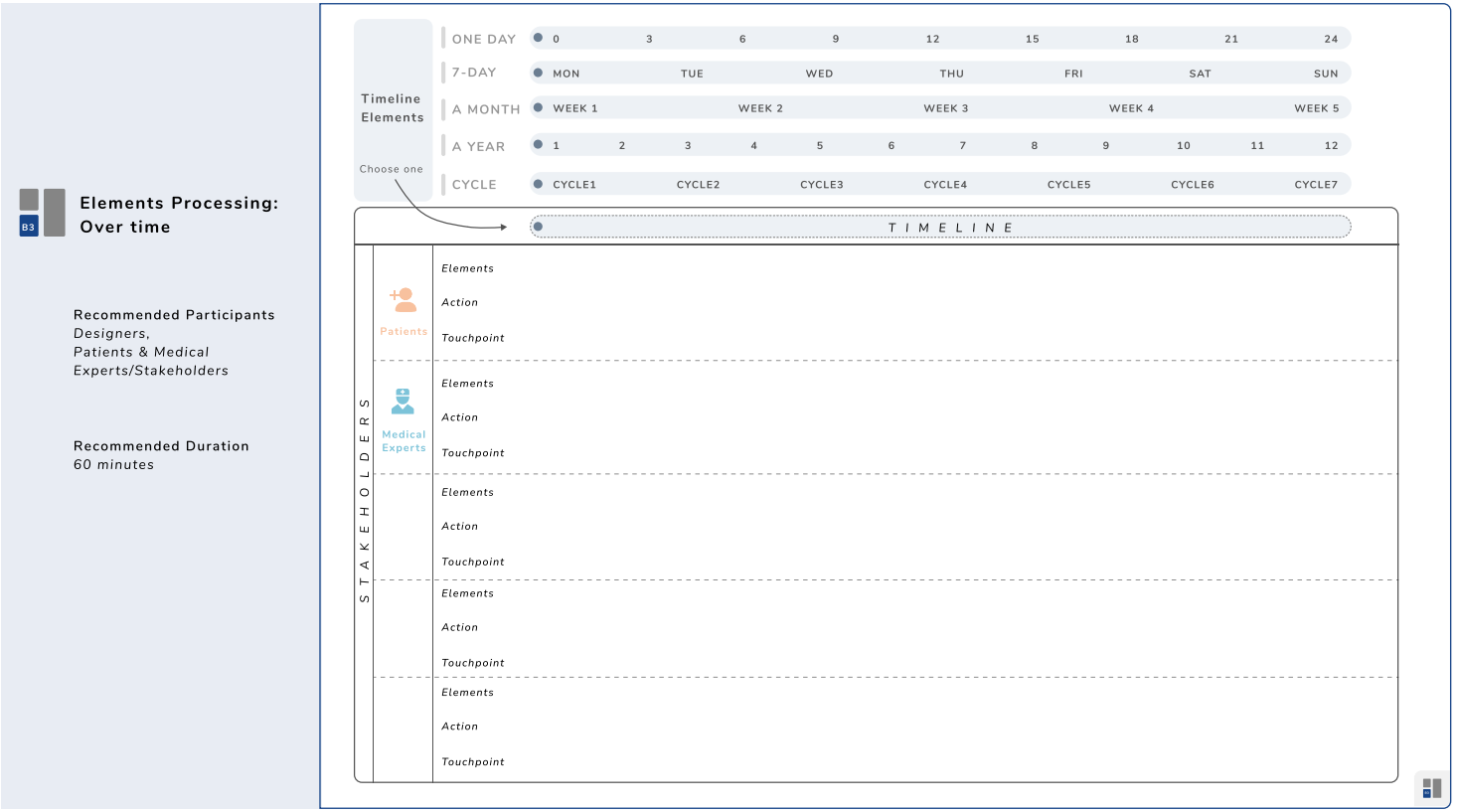


Figure 93 B3-Elements Processing: Over Time.

Part B4. Lastly, Part B4, called Priority Matrix (Figure 94), provide a tool for further defining the elements priority. This is the same matrix used in guidelines, except that this time it requires stakeholders to come together to explore their respective element priorities: which elements do they consider important? Which elements might be too much of a burden for them to collect or understand? This becomes a key step in determining whether an element is "Must Have", "Better to Have" or "Not Necessary".

As mentioned in the introduction to guidelines, the dimensions of importance and workload are often conflicting for stakeholders. Too much workload may mean richer information, but it also means consuming a lot of energy. Balancing these two dimensions is therefore particularly important. By bringing stakeholders together with each other, it is possible to understand each other's demands and compromise to reach a more desirable state as much as possible (Loureiro et al., 2020). This process is suggested to last for 60 minutes.

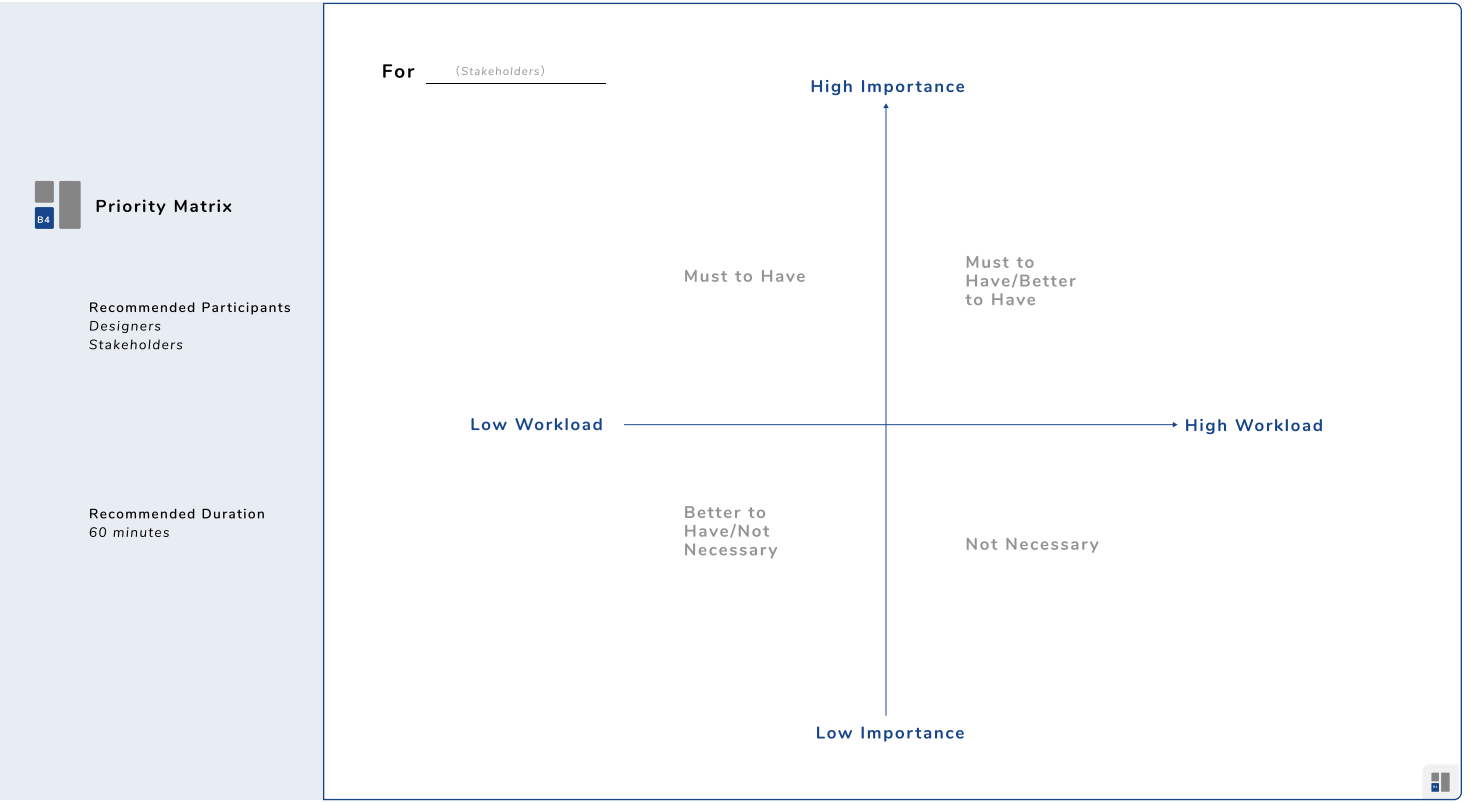


Figure 94 B4-Priority Matrix.

Toolkit Content: Part C

The last part of Part C is about modifying the guidelines provided for CRC patients. While conducting research with the tools in Part A and B, it is suggested to continue to analyze and reflect, and record using the tools in Part C. The guidelines here only include the core parts, which are Elements List, Elements Priority and Key Properties for Design, because these guidelines may be handed over to the designers later. To avoid too many details leading to ambiguous definitions and understandings, I only use these three core components. In addition, I have combined Elements List and Elements Priority into one tool for ease of documentation and transfer.

Part C1. Part C1, which is named New Elements List and Priority, is shown in Figure 95. In this, future researchers can add missing elements in each section or create a new one. This provides them with more freedom to make targeted updates based on their research topics.

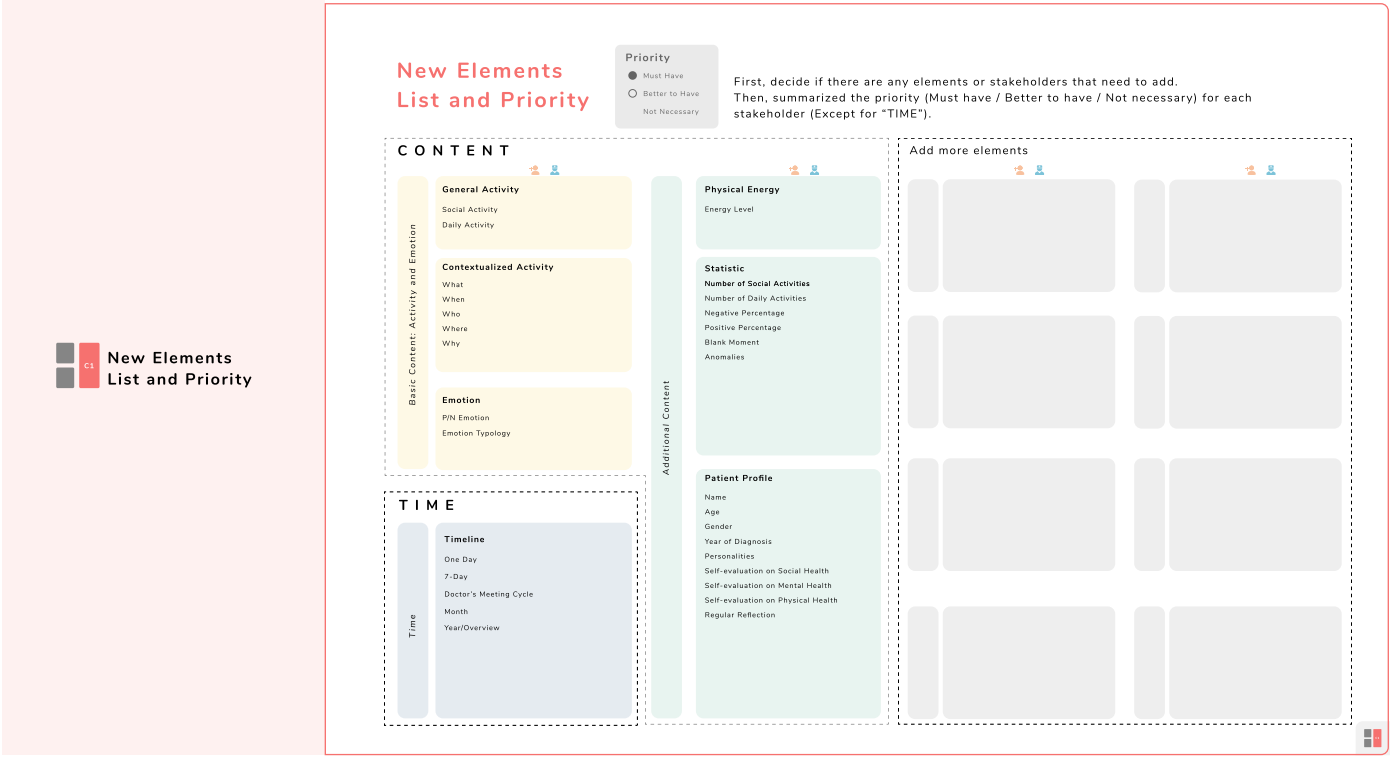


Figure 95 C1-New Elements List and Priority.

Part C2. Part C2 is the New Key Properties for Design. There are already two existing stakeholders: patients (Figure 96) and medical experts (Figure 97). The listed properties are from guidelines for CRC patients. Future researchers can check if they are also suitable for their context. They can also add more properties based on the result from Part A and B. If there are other stakeholders, they can also fill in the blank tool (Figure 98). This process can be decided by the researchers and designers involved in the co-creation sessions, as the designers are able to provide information that is more directed towards the design. The language of the designers can also help the designers who later design the system to understand the properties (Park et al., 2008).



Figure 96 C2-Key Properties for Design (Patients).

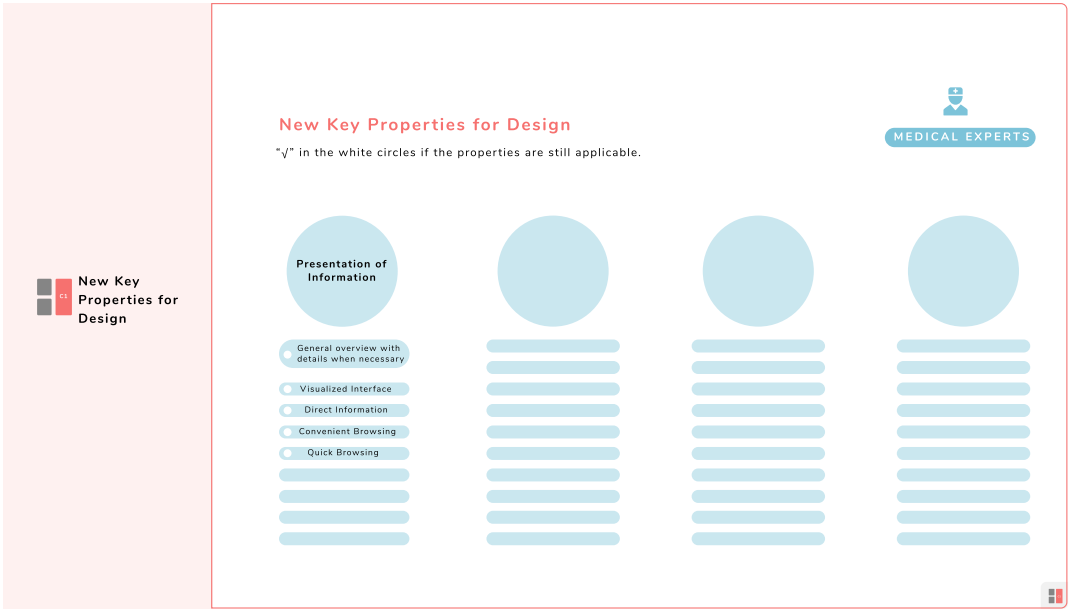


Figure 97 C2-Key Properties for Design (Medical Experts).

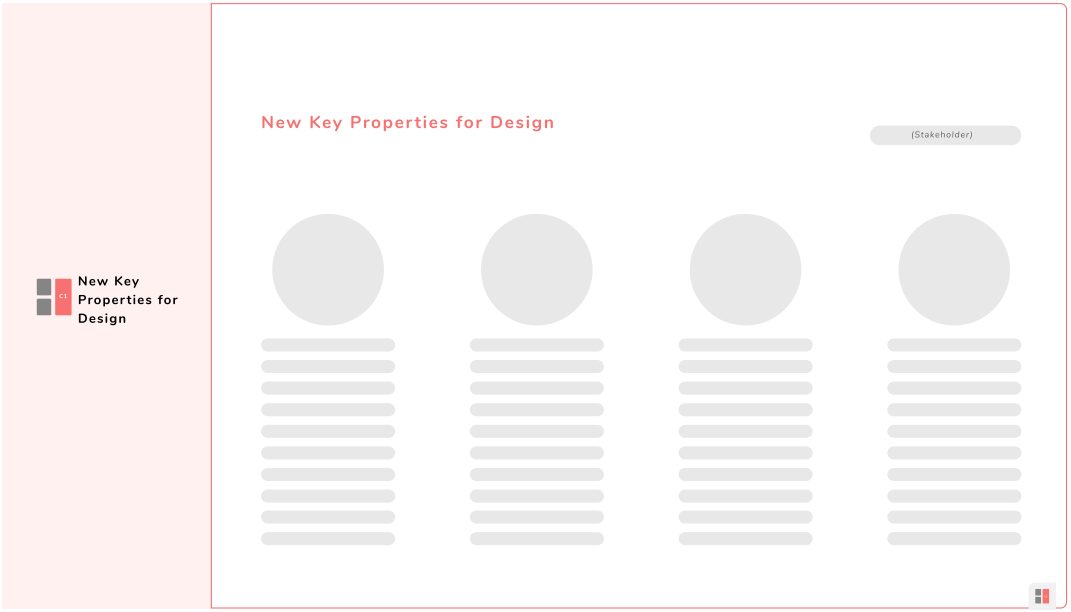


Figure 98 C2-New Elements List and Priority (Other Stakeholders).

6.3

Toolkit Validation

Two healthcare researchers and two designers were invited to validate the final toolkit. They gave some feelings and feedback.

Overall, both the researchers and the designers appreciated the toolkits very much. They expressed that the tools could help them to construct a framework for diary research and co-creation sessions. Since researchers come from a non-design field, it is often more difficult for them to create tools for use in research. These creative tools can increase stakeholders' engagement with the research topic, and stimulate the creativity of stakeholders so that they provide deeper insights. Complex concepts or abstract ideas, especially the diary studies part, can often be challenging for patients to understand. The toolkit clarifies information, making it easier for both researchers and participants to grasp and discuss the subject matter. Designers expressed that it is crucial for them to know what to design, especially what is important to the user. Therefore, the guidelines output by this toolkit provides just the right amount of what the user wants, without being overly restrictive, thus giving them some freedom to design.

Researchers and designers have also made some suggestions. Some felt that more emphasis could be placed on the use of technology in the system. For example, the process of diary studies could be documented by the patient through an app. This enables the patient to experience what it would be like if the data collection was done digitally. In addition to this, the involvement of technology can be made visible in the tools used in co-creation meetings. Because technology is a core component of RPM.

The designers and researchers both suggested that it would also be interesting to have materials that could also support them in some preliminary designs. Because researchers from non-design backgrounds are not systematically trained in design, some creative tools might be able to help them move from research findings to preliminary design. The researcher can have some initial design ideas and the designer is able to understand the researcher's needs and findings. However, it is not necessary to go too far, and this process can be explored with some designers.

The researchers also suggest that when defining the element priority, the Priority Matrix should also provide a blank copy of the axes in addition to the importance and workload of the elements. This is because the results of different studies may lead to different criteria for evaluating the priority of elements in different contexts. Except for that, there are some sections where it is quite possible to add elements, such as Statistics. There are also sections that are largely fixed, such as General Activity, and perhaps it would be good to make a distinction between these two sections. In addition to this, some tools could be made for the list of elements to help the researcher brainstorm what other possible elements could be present. The final guidelines could also add an evidence section for easy tracking by the researcher.

Overall, researchers and designers have approached this toolkit very positively. Possible improvements are intervening technologies, adding tools to aid design, expanding the criteria for prioritizing elements, outlining the ones that could have more chance to add elements or relatively fixed in the Element List and having some brainstorming tools for expanding Element List.

6.4

Future Vision and Suggestions

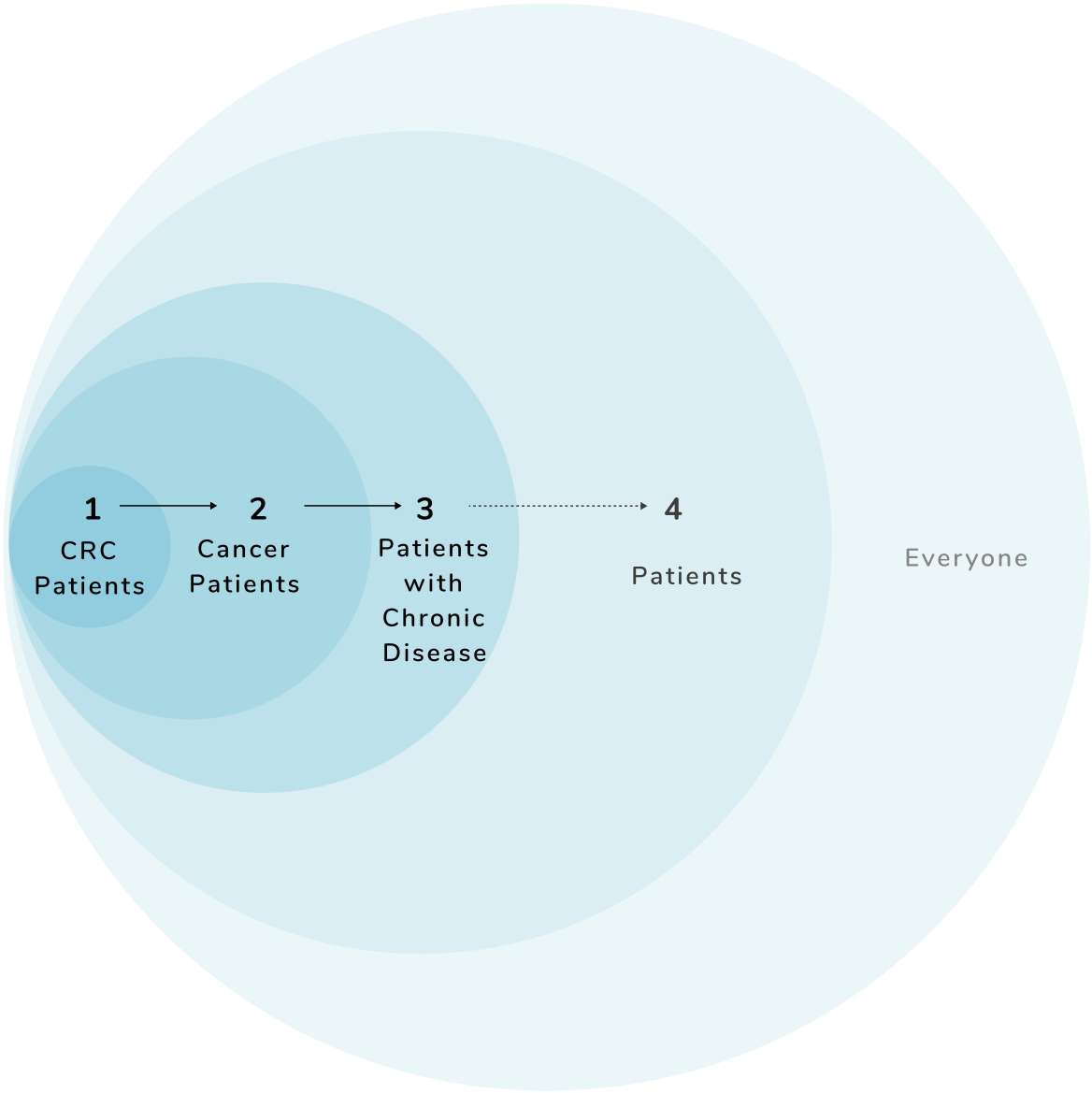


Figure 99 Future Development.

In the future, remote monitoring for activity and emotion should start with CRC patients and gradually expand to cancer patients, patients with chronic disease, and even all patients (Figure 99). Because physical, social and mental health are all equally important, yet now physical health has received the most attention, but social and mental health is still in a relatively neglected position (Hale et al., 2005). Many cancer patients and patients with chronic illnesses suffer long-term impacts on mental health and social health due to the physical aspects of their illnesses, but remote patient monitoring is less focused on these aspects. There is even a possibility that this system focuses on the total health of each individual. However, due to privacy issues, the design for the average person needs to think twice about what elements must be shared with medical professionals and what can be shared without people, for their own self-awareness of their health only.

So that's why this toolkit for extensible contexts was designed. For different contexts, researchers can conduct certain studies and design more personalized monitoring systems to meet the needs of the target group, thus improving their health-related quality of life.

Some suggestions can be taken into consideration to achieve this goal. First, it is necessary to start with colorectal cancer patients and utilize guidelines to design the final product for them and medical experts. This can be a continuation of the iteration and development of the show case from this thesis, or it can be re-designed. This will not only help colorectal cancer patients to improve their quality of life, but at the same time be a reference for future research and design of other contexts. In the meantime, more healthcare researchers and designers can experiment with the toolkit and gather more insights from it to improve its design. Among the suggestions already made in Chapter 6, involving technology in the toolkit is more important. This is because remote monitoring systems need to rely on some degree of digitization rather than purely paper-based (Vegesna et al., 2017) Therefore, providing both paper and digital versions of the probe in the diary studies for a control group experiment might be a good start. In addition, tools for co-creation sessions could incorporate more topics on technology. The rest of the suggestions and the new ones that follow should be used to upgrade the toolkit. After this, the application of the toolkit can start the study of other cancer types, such as breast cancer. This is because the contexts between cancers are more similar, and it is easier to understand the toolkit by starting with other cancers. The slow shift in context also favors the emergence of questions for the toolkit.

In using the toolkit, in addition to focusing on the issue of content, it is also possible to focus on the role of the researcher and designer while doing the research. For example, if there is no designer and only researchers, will this result in the toolkit not working? Would the researcher be able to design the prototype of the RPM themselves through the final output without the designer? Observations on process aspects are also needed, such as whether the researcher was able to successfully produce Guidelines and whether the content of the final Guidelines was sufficient for the designer to constitute a list of design requirements. In addition to this, since the toolkit was developed in the Dutch context, its adaptability to other national contexts requires some exploration.

These steps and questions to think about can help in the continuous iterative upgrading of the toolkit so that it can be adapted to various research contexts. It can also help researchers develop RPM in activity and emotion that is personalized. In promoting the toolkit, the importance of focusing on holistic health is also being promoted.

6.5

Summary of Key Insights

1. The toolkit named “SDAE” is for developing RPM in social and daily activity and related emotion, not only for CRC patients but also for other patients.

2. The toolkit has a framework that consists of two parts: data collection and data reflection. The data collection process included diary studies and follow-up interviews with patients (Part A) as well as several co-creation sessions (Part B). Data reflection is modifying the guidelines (Part C) to adapt to the new contexts.

3. In Part A, the two tools are Diary Studies Probe and Interview Guide.

In Part B, the four tools are Elements Processing: Between Patients and Medical Experts, Elements Processing: Elements Flow Among Stakeholders (if applicable), Elements Processing: Over time and Priority Matrix.

In Part C, the two tools are New Elements List and Priority and New Key Properties for Design.

4. Researchers and designers have approached this toolkit very positively. Possible improvements are intervening technologies, adding tools to aid design, expanding the criteria for prioritizing elements, outlining the ones that could have more chance to add elements or are relatively fixed in the Element List, and having some brainstorming tools for expanding Element List.

5. The future vision for the toolkit is to be able to help researchers develop such RPM in other diseases.

Chapter 7

Reflections

Discussion and Conclusion

Limitation

Other Reflections

Discussion and Conclusion

Beginning with an exploration of the experiences of colorectal cancer patients, this project utilized a variety of methods to define the research question. This research question was ultimately defined as “How to develop a remote patient monitoring system for patients’ social and daily activity and related emotion when they are away from the hospital?” This question is finally answered by a toolkit that can help researchers study developing this system.” This toolkit is derived from reflections on the research process. It aims to extend the context of RPM in activity and emotion, allowing researchers to develop personalized monitoring systems based on their context when studying other illnesses, not just for colorectal cancer patients.

This study highlights the importance of focusing on patients’ whole health for improving patients’ HRQoL, especially social and mental health. This is summarized from the patient community journey map, experts co-creation session, and literature, which matched with some other researchers’ views (Prince et al., 2007; Stuckey, 2013; van Ommeren et al., 2005). But remote patient monitoring has paid less attention to these areas (Sapci & Sapci, 2019; Vitabile et al., 2019). Therefore, it is necessary to master the methods of developing such RPM.

In this study, it was found that patients felt it was essential to be concerned about their whole health and to communicate it to their medical professionals timely. They really liked the probe used in the diary study and felt that it helped them to reflect and focus on their health in addition to physical health, increasing their self-awareness of this aspect. Patients preferred sharing their health data in this way to completing questionnaires. They felt that the probe was very personalized and interesting to track their health. This may be an inspiration for future ways of asking patients about their health. Some studies have also found that questionnaires used in ESM, for example, tend to tire patients over long periods of time because it is repetitive and boring (Brower, 2018; Verhagen et al., 2016), and materials that have been designed may encourage patients to share their data for longer periods of time.

The guidance produced at the end of the study mainly summarizes the content and design attributes of the monitoring, because defining what to monitor is critical in RPM (Ferrua et al., 2020). Overall, the elements of activity and emotion are the most important, as these forms the basic content of the system. Among the additional contents, statistics is also vital as it can help patients and physicians quickly understand the patient's state over time, which is also consistent with other studies (Dhinakaran et al., 2022; Ferrua et al., 2020; Noah et al., 2018; Poncette et al., 2022).

The final toolkit is designed to reflect on the process and results of the research after the research question has been posed. The goal is for the guidelines to expand to other contexts so that the rest of the patients can also have personalized RPM in activity and emotion. The framework of this toolkit is to encourage researchers to go back and forth between collecting data and reflecting on it. The data collected should be used as evidence for modifying guidelines timely. I redesigned and reorganized the materials used in the diary studies and designers' brainstorm sessions to build the toolkits in addition to the final toolkit. The final guidelines can then be handed over to the designers for further design. Both researchers and designers have been very positive about the toolkit, believing that it can help them conduct more framed, deeper, and more creative research, which is consistent with other researchers’ findings regarding the characteristics of the toolkit (Bryson et al., 2011; J. Luca & Ulyannikova, 2020; Schelle et al., 2015).

In conclusion, it’s important to develop RPM in social and daily activity and related emotion, not only for colorectal cancer patients but also for other patients. The toolkit can help future researchers to get deeper research findings and develop such RPM in other contexts.

Limitation

This study has some limitations. At the beginning of the development of the patient community journey map, big data from online forums was used. This can lead to some people who are not active on the internet being excluded. When the diary study was conducted, none of the participants was negative about the diary study because it was stated at the time of recruitment that it was a diary study, whereas there was a high probability that those who were potentially negative would not participate in the study. This also created some bias. In addition to this, the participants were very diverse, ranging from 40s to 60s, with different occupations and many very different answers to questions. The only pity is that all the patients in the diary studies were female. This is a side effect of the fact that women may have had a more positive attitude towards the diary study, but also that the perspective from men was therefore missing. How patients are recruited also becomes important in the next steps of using the toolkit. On top of that, the toolkit was developed in the Dutch context, and it is not clear whether it can be adapted to the context of other countries.

Other Reflections

The workload of this project is large, so the time schedule is relatively compact, and the research has been completed with a certain degree of depth within a short period of time. However, more time can be spent on reflecting on the process and results after each study is completed. This is not necessarily the output of the research results but can be a reflection on the way the activities were organized, the time, the methods used, etc., so that the next time a similar activity is organized, it can be organized more logically.

When writing papers, I often described "what I did" but lacked the rationale to necessarily explain why I did it. I'm also often fuzzy on the hierarchy of information. For example, when I list information, often information that shouldn't belong at the same level is put together, causing the reader to be more confused. There are also times when the lexical properties of the words I list are not consistent, such as putting adjectives and nouns together.

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