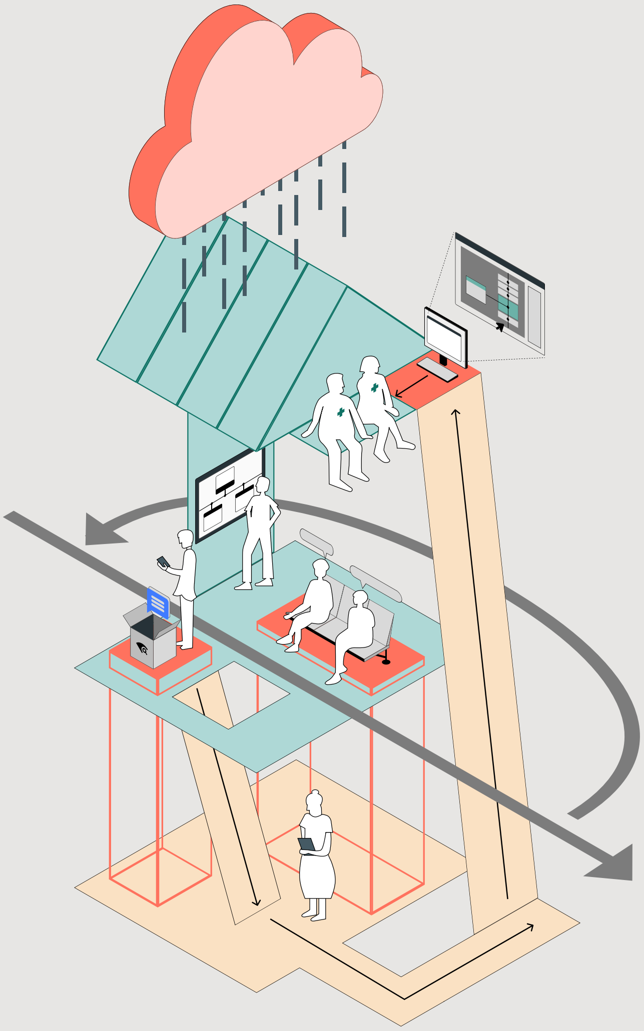

Co-designing data-enabled information support for different chronic patient communities.

David Quijada Fernández

MSc Design for Interaction | Master's thesis |
March 2024 | Delft University of Technology

Master's thesis

Co-designing data-enabled information support for different chronic patient communities.

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Defended on the 15th March 2024

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Executive summary

This project aimed to facilitate information support between clinicians and patients that is dynamic to the milestones in their care path and can be incrementally adapted to different chronic diseases at ErasmusMC. The project strived to envision a foundational service that informs holistically about the doubts and concerns of patient communities throughout their care journey and can be progressively incorporated into clinicians' workflows.

Research was done to find patterns between the online patient stories from community support forums and to identify value opportunities for intervention that align with the clinicians' aspirations, motivations and needs. The research activities included:

- Desk research of relevant literature (Chapter 2).
- Contextual inquiry through a combination of human interpretation of patient experience data and computational analysis (Chapter 3).
- Co-creation sessions to gather information about opportunities for improving information support from a data-enabled design perspective (Chapter 4).

The data categories derived from the contextual inquiry were used to map transactional services in the online patient support groups and ideate on new transactional services for the context of remote patient monitoring. The co-creation sessions inspired a service vision and a set of guiding principles that were used to conceptualise a service system for information support, which could improve the curation of patient support knowledge resources. It was decided to focus on information support among the different types of social support due to the co-exploration of the data categories with clinicians.

Ideation on a service system enabling dynamic and incremental information support resulted in three essential modules or features of the service system:

- The first module, **dynamic guidance**, enables Erasmus MC to use recurrent milestones in the personalised care plan of patients to standardise the provision of information resources in templates. The patient community could progressively rate the usefulness and clarity of such resources to provide recommendations to the rest of the patient community.
- The second module, **PX data collection**, offers the efficient collection of patients' self-reported concerns and doubts for internal system and content improvements.
- The third module, **community appraisal**, discusses how the development and moderation of conversations among peers could not only facilitate patients' self-evaluation and emotional support but also the periodic research of shifting or uncovered areas of concerns, experiences and doubts among the patient community.

The interconnections between these modules have been conceptualised through a service blueprint, which was presented to ML and AI researchers to refine the supporting software processes.

These service features or modules could strategically be developed and implemented within existing eHealth applications within specific departments or in a foundational self-monitoring application for ErasmusMC that is shared by different departments (e.g., surgical oncology, pulmonology).

Outcomes

Thematic categorization of patient experience data has been established, which can be used to cluster results of unsupervised topic modelling for other patient communities and compare the results. A better understanding of guiding principles to design data-enabled services and systems, which facilitate information support for patient communities, has been achieved. A service system is proposed to standardise and incrementally fine-tune resources for different patient communities. Future developments are envisioned which encompass state-of-the-art machine learning techniques and interface/service design.

Abbreviations

RPM – Remote patient monitoring.

CRC – Colorectal Cancer.

PF – Pulmonary Fibrosis.

Sarco – Sarcoidosis.

PX – Patient Experience

ML – Machine Learning

IR – Information Retrieval

AI – Artificial Intelligence

Acknowledgments

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

....to Jiwon, Venktesh and Richard, for your guidance throughout this project. Thanks to Jiwon for her dedication as a mentor and for believing in me for this graduation opportunity. I have learned from your proactiveness and your sharp questions. Thank you Richard for the comfort and calmness you convey in the meetings. Thanks to Venktesh, for sharing your expertise around data technologies from the technical side. Without your contribution, it would not have been possible to achieve the foundation of this project.

...to the Erasmus MC and all the clinicians and researchers who shared their boundless knowledge with me. Your creativity and expertise were the driving force of this project.

....to all the researchers from TU Delft who participated in the evaluation sessions. Thank you for your insights and your interest in the project. Your feedback was a tremendous help in consolidating the research.

...to my family, for being an amazing source of support in every aspect of my life. Muchas gracias por cuidarme y mostrar vuestro apoyo desde lejos. Papá y mamá, vosotros me habéis dado el mayor regalo que podría tener, una educación.

...to Miri, thank you for all the cafesitos, and all your coaching through the project. You brought all the sun to the course of this graduation project.

...to all my friends and my roommates here in Delft (the old and the new ones), with your smiles, discussions, reflections, volleyball....you make my life a fun journey. Also, a special thank to Jeltje, Niza and all the graduation buddies for being there and listening.

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Chapter 1 : Introduction

Data technologies such as machine learning, artificial intelligence and big data have impacted the amount of information at our disposition in all domains and how we design products and services (Giaccardi et al., 2020). These technologies embedded in wearable devices, biosensors and smartphones afford greater accessibility to some health data and increasingly enable the monitoring of health conditions from patients' homes (Manteghinejad & Javanmard, 2021). Beyond the democratization of health data collection, these technologies can facilitate the transition from disease-centred practices towards patient-centred healthcare (Manteghinejad & Javanmard, 2021). AI-based and machine-learning tools could process large databases of patients' medical records and extract patterns and actionable insights.

This project is based on Dr. Ir. Jiwon Jung's research: "Developing Data-enabled Design in the Field of Digital Health" (Jung, 2023) and the author's design exploration to visualize patient community experiences using large datasets of online patient stories. Within this research area, this master's thesis specifically builds upon the previous efforts of Master's graduation students who collaborated with Dr Ir. Jiwon Jung to visualize patient community journey maps and ideate strategies or design interventions in the context of remote patient monitoring (RPM) for three patient communities (Kicken, 2023; Sun, 2023; Zhang, 2023).

The three online patient communities studied are colorectal cancer, pulmonary fibrosis, and sarcoidosis. These patient communities interact within peer support platforms developed and facilitated by medical institutions and patient organizations. These online communities consist of anyone in close contact with the care-path experience of these diseases, which includes not only the patients but also their relatives, partners and even some medical professionals. The members of these online communities ask questions and exchange knowledge with each other, engage in reflections on the disease and treatment methods, and compare experiences (Jung et al., 2023). The previous master's thesis analysed the three online patient communities independently to develop solutions or strategies tailored to those patient communities. However, the present master's thesis zooms out to analyse the commonalities between these three online communities and develop a modular service architecture that can incrementally be adapted to these three communities and even other patient communities and departments at ErasmusMC (collaborating partner for this research).

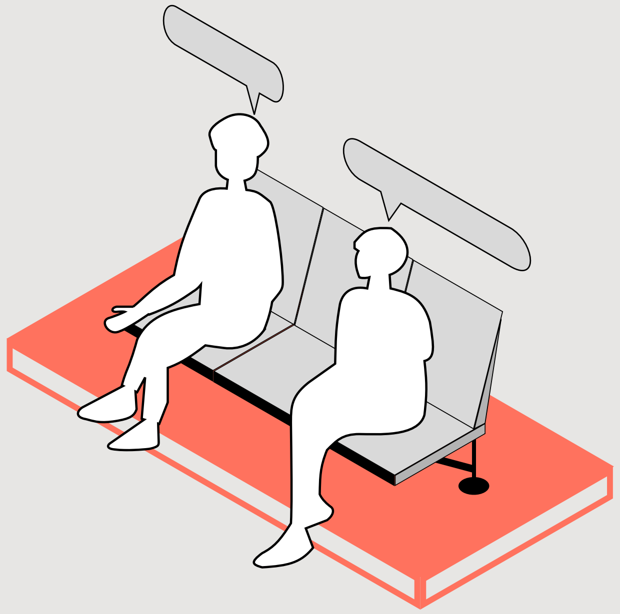


Figure 1.1: Posts from online community platforms as the main source of data.

1.1 The problem context.

Due to the growing demand for care and the shortage of healthcare staff, it has become imperative that developments and innovations within healthcare contribute to more efficient and meaningful caregiving. The increasing demand for care and the approaching crisis of personnel will compromise accessibility to healthcare. To face this societal challenge, we need more improvements in the care delivery processes that contribute to the productivity of health professionals and make their jobs more attractive and pleasant (Gupta Strategists, 2021; Sikka et al., 2015).

To support high-value care delivery processes in healthcare, technological and organizational developments should benefit to some extent clinicians' needs for impact and contribution to society through their jobs, along with the goals of reducing costs in healthcare, enhancing the experience of receiving care and improving the health of the patient populations (Sikka et al., 2015). This sense of meaning in the workplace is currently hindered by large amounts of administrative and reporting tasks, which limit the amount of time they spend treating and coaching each patient (Sikka et al., 2015).

Within this problem context, we can highlight the opportunities for remote patient monitoring, telemonitoring or self-monitoring to substitute check-ups and reduce the burden on clinicians to complete non-caregiving tasks (Gupta Strategists, 2021). RPM strategies have been suggested to collect valuable data for clinical research and foster the patients' self-management, which ultimately allows clinicians to focus on caregiving work and coaching patients, instead of administrative tasks (Ajami & Teimouri, 2015; McManus et al., 2018; Oh et al., 2005; Rakers et al., 2023; Steinhubl et al., 2015). RPM also promises to promote timely and precise health interventions, and therefore contribute to better health outcomes and clinicians' well-being in the workplace (Pevnick et al., 2016; Sood et al., 2007).

Within this complex and multi-faceted context, this master's thesis focuses on the efficient allocation of knowledge resources and self-learning patient coaching systems. It delves into the domain of eHealth and data technologies complementing clinicians' roles as communicators and developing a continuous feedback loop among patients, clinicians and supporting parties, to ultimately, benefit the experience of receiving and providing care.

1.2 Research questions.

To launch the research and design activities conducted during this master's graduation project, I raised three research questions based on the previous outcomes of graduation students (Kicken, 2023; Sun, 2023; Zhang, 2023) and related literature (Chapter 2).

1. *How can patient experience data co-exist with other data types to inform core services and support services in an RPM context?*
2. *What are the common themes of needs and concerns that an RPM service system needs to cover for several chronic diseases based on the data from online patient support groups?*
3. *How can we involve practitioners and patients in data-enabled services within an RPM context that contributes to both stakeholders' well-being and shared decision-making?*

Nevertheless, as I carried out different research and design activities, the research questions broke down into more specific research questions. These incremental research questions are introduced at the beginning of each chapter, and I discuss the outcomes at the end of each chapter to explain to what extent I managed to cover those questions. Similarly, the design challenge that I try to address through this master's thesis also evolves throughout the process, together with the prototypes and conceptual visions developed.

1.3 Stakeholders.

This master's thesis is situated in the Flagship Consultation Room 2030. Within this Flagship, a multidisciplinary community of researchers from Erasmus Medical Centrum, Erasmus University Rotterdam and TU Delft addresses the main challenges that hinder the accessibility and sustainability of healthcare, such as the shortage of staff, financial restrictions, and societal changes.

Figure 1.2: The website page of the Flagship Consultation Room 2030

The end users that this project focuses on are patients and clinicians of three selected patient communities and the knowledge exchange and communication among them. However, this project aims to inform the professionals within the Flagship and their contributions to seamless care experiences. For this reason, the format of the service blueprint is selected as one of the main deliverables as it enables the involvement of a wide range of professionals to discuss how to provide information support to patients through the orchestration of digital technologies.

1.4 Design approach.

The project approach is based on the enhanced data-enabled approach by Jung (2023), which is in turn based on the data-enabled approach used by Phillips (Van Kollenburg & Bogers, 2019). The project process consisted of progressively gathering insights from the data collection activities (see the section on the left in Figure 1.3) and implementing those insights through interpretation and design activities (section on the right in Figure 1.3). Therefore, the research and design phases are highly intertwined, and they function as a continuous feedback loop.

The project approach visualization draws inspiration from contour maps to show how the same types of activities build on top of each other. For instance, on the left side, the desk research contains the inquiry of patient community experience data (Chapter 3). The desk research extends to the whole society since some literature reviewed comes from different domains and disciplines, whereas the inquiry of patient community experience data focuses on the three selected patient communities. On the right side, the theoretical background (Chapter 2) embraces the categorisation and visualization of the patient experience data from the three online communities. My understanding of the literature gathered through the desk research influences the interpretation of the patient experience data and the identification of opportunities for design intervention.

In turn, the patient community experience data encompasses the co-creation session with domain experts since the community-level data enables uncovering the needs and wishes of the experts (clinicians and a clinical researcher). On the right side, the data categorisation and visualization influence the expert insights and design guidelines (Chapter 4), and the service concept ideation (Chapter 5). The interpretation of insights from the co-creation session and the service concept ideation are conducted in parallel.

Finally, in the right section, the evaluation of the service proposition sits on top of the co-creation with experts. On the other hand, the service blueprinting builds upon the service concept ideation and the design guidelines. This is due to the service system concept being evaluated drawing inspiration from the co-creation with experts.

Moreover, the feedback flows between the two main sections are represented by the pathways, the lines connecting the two sections. The first pathway illustrates how the project is continuously based on literature that informs the theoretical positioning of this project. The second pathway shows how the analysis of patient community experience data informs the data categorisation and visualization but also influences the insights from the co-creation sessions with domain experts. Through interactive prototypes and printed cards, the data categories are translated into design probes for co-creation with experts. In turn, the insights extracted from the co-creation sessions will inform:

- Improvements in data categorisation and visualization. These co-creation sessions serve as an early evaluation of the data categories and the effectiveness of the visualization.
- The creation of design guidelines for the service blueprint through the analysis and interpretation of the audio recordings and transcripts from the co-creation session.

Pathway 3 illustrates that after each co-creation session, the improvements made in the data categorisation and visualization influence the next session to iteratively refine the data categories. Pathway 4 exemplifies that the design guidelines and insights from the co-creation session are used to inform the service concept ideation. Finally, the fifth pathway describes that service blueprinting is used as a method to involve clinicians and machine learning researchers to evaluate the service system concept and discuss pain points and opportunities for improvements.

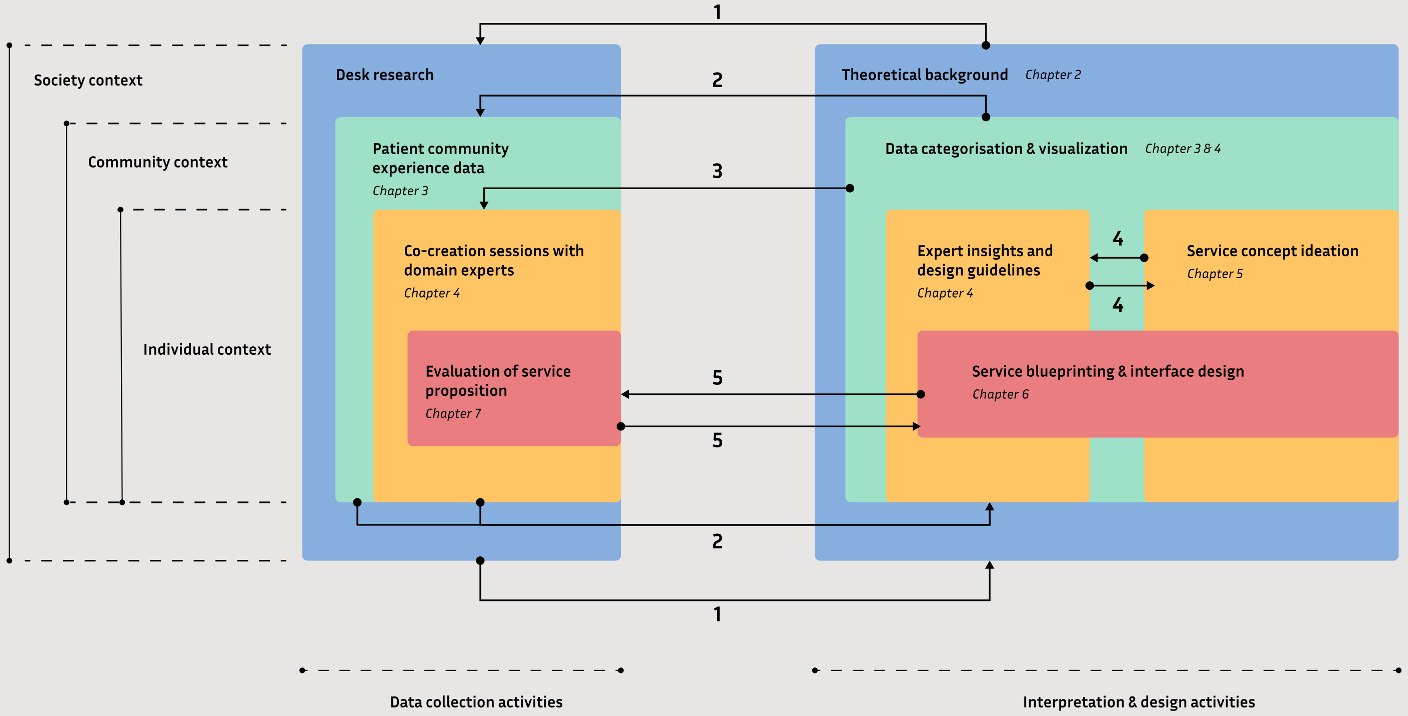
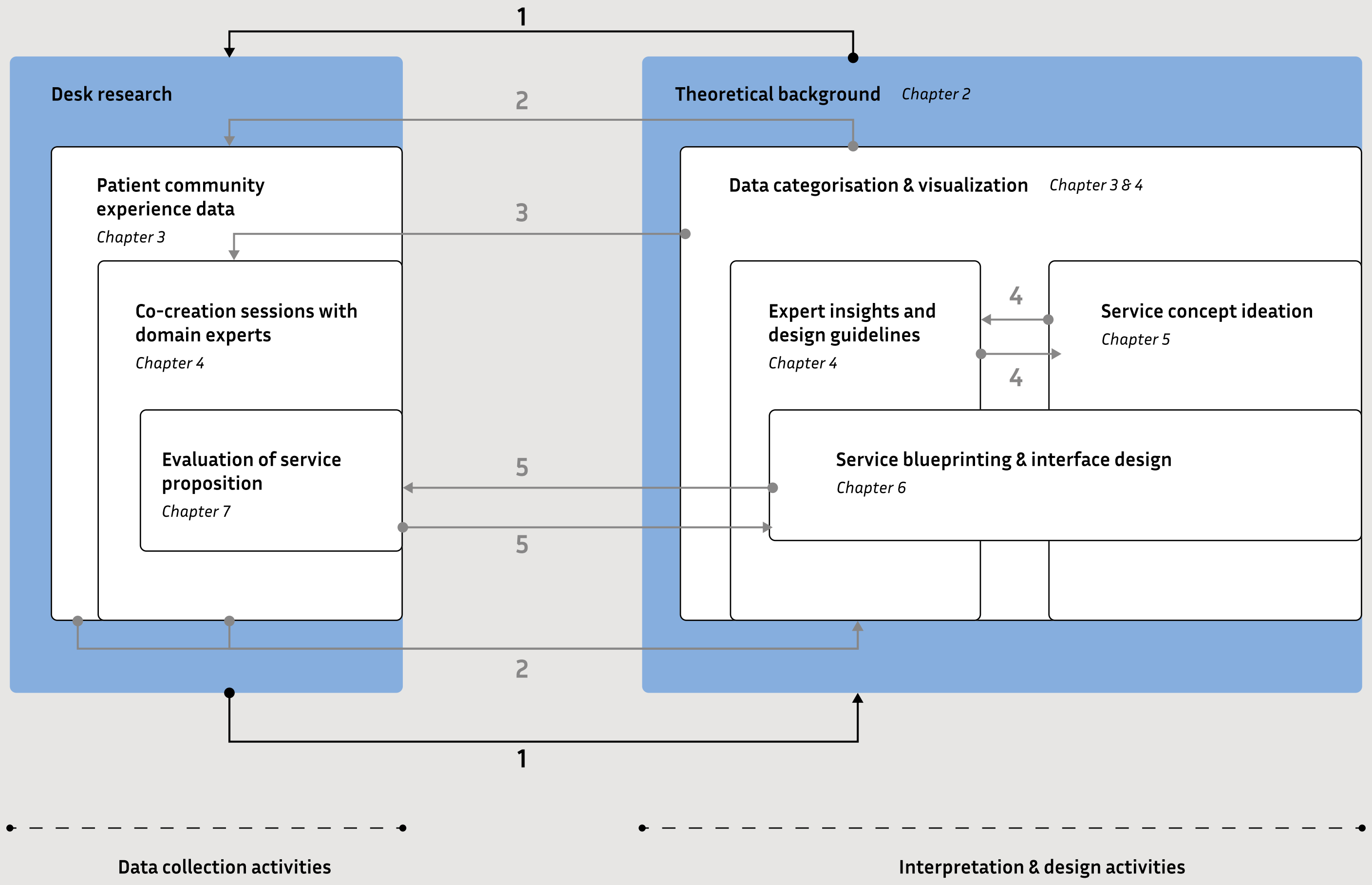


Figure 1.3: Design approach

Chapter 2 : Theoretical background



2.1 Using patient experience data from online patient support groups.

How can patient experience data co-exist with clinical data to inform core services and supporting services of RPM?

This first research question introduced in Chapter 1 connects the main source of data for this project with service design theory. In service design theory (Edvardsson & Olsson, 1996; Secomandi, 2012), a service concept means the package that includes core and supporting services, which in turn respond to diverse customer needs (primary and secondary). These customer needs represent the starting point to specify the requirements for the service system resources and processes. This service package is also known as a "bundle" or "offering" in the literature (Grönroos, 2015; Secomandi, 2012).

Since this project expands upon the research conducted by Dr. Ir. Jiwon Jung (Jung, 2023), the project uses online patient stories as its main data source to inform the primary and secondary needs of the service concept. Online patient stories consist of the posts that the patient community writes on online platforms for peer support (also referred to in this master's thesis as online patient support groups). These online posts represented the raw data that the researcher may use to zoom in on individuals' experiences and doubts.

Throughout the previous work of the master's graduation students (Kicken, 2023; Sun, 2023; Zhang, 2023), the designers together with data scientists grouped hundreds or thousands of online patient stories in topics, which represent another layer of information which will be used in this project. The topics were created through a combination of computational analysis and human interpretation. The data scientist applies a topic modelling algorithm (Sushil et al., 2021) to group the posts into the chosen number of topics and extract several keywords that represent the topic. Once the data scientist student has processed the posts and gathered the requested number of topics, the designer reviews 50 posts per topic along with the keywords that were extracted to define the topic. The designer can then give an adequate description of each topic, a label that informs about the content clustered (Jung et al., 2023). These topics allow us to compare the themes of experiences of each patient community.

	Sarcoidosis	Pulmonary Fibrosis	Colorectal Cancer
Source	wijhebbensar-coïdose.nl	inspire.com	csn.cancer.org
Country	Netherlands	USA	USA
Number of posts analysed	~7500	~30000	~300000
Link	https://www.wijhebben sarcoidose. nl	https://www.inspire.com/groups/living-with-pulmonary-fibrosis/	https://csn.cancer.org/categories/colorectal

Table 2.1: Community forums analysed through topic modelling.

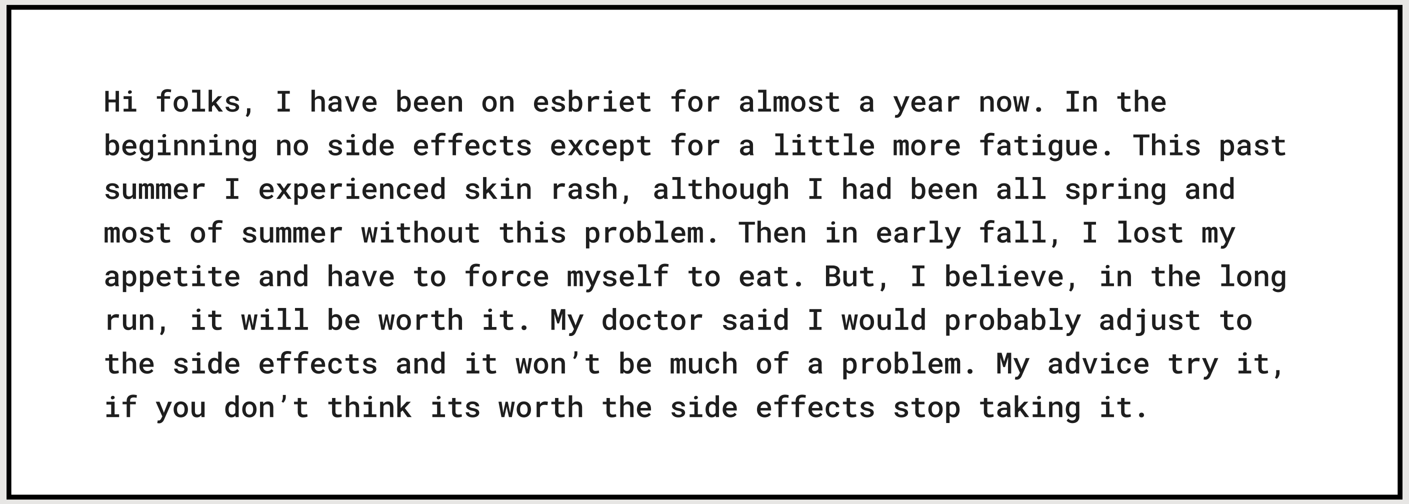

Hi folks, I have been on esbriet for almost a year now. In the beginning no side effects except for a little more fatigue. This past summer I experienced skin rash, although I had been all spring and most of summer without this problem. Then in early fall, I lost my appetite and have to force myself to eat. But, I believe, in the long run, it will be worth it. My doctor said I would probably adjust to the side effects and it won't be much of a problem. My advice try it, if you don't think its worth the side effects stop taking it.

Figure 2.1: example of an online patient story

The resulting topics are plotted in collaboration with domain experts along a patient community journey map, which represents the experiences and perspectives of broad and complex patient populations throughout the care path (Jung et al., 2023). Journey mapping is a tool that has the potential to illustrate opportunities and pain points in specific stages of the care path (Joseph et al., 2023). By interpreting these visualizations in collaboration with domain experts, the designers could draw insights to conceptualise strategies and design interventions tailored to the communities of those diseases. All the projects' design interventions revolved around the advancement of RPM to facilitate patient self-management and reduce workload in medical centres, more specifically, ErasmusMC.

Therefore, the online patient stories represented a largely accessible, affordable, and minimally invasive source of patient experience data that can inspire design interventions in the medical field (Jung et al., 2023; Dellarocas, 2003). The users are dynamically generating content as they have online conversations and debates. For that reason, online patient support groups represent large-scale databases that are continuously growing and changing. Analysed through topic modelling, this source of qualitative data is relatively affordable for such a broad patient population. In contrast, traditional qualitative data collection methods such as interviews require time and effort to recruit participants and transcribe and code the data. Furthermore, once the data is anonymised and patients are adequately informed, we can gain a deep understanding of the experiences of the patient communities without asking them to revisit stressful and traumatic experiences. Moreover, in contrast to traditional questionnaires, this patient experience data is driven by the community (Jung et al., 2023). Through questionnaires, we as researchers decide what we want to know by setting the questions. However, the online patient stories are narrated by the patients themselves, who organically share their concerns and experiences with their peers. Therefore, the online patient stories represent a valuable data source to ideate product-service systems with patient perspectives centre and front.

Online patient stories as patient experience data.

Through analysing the online patient stories, we are processing valuable and inspiring patient experience data, but how can this patient experience data be relevant for meaningful caregiving? How can feedback loops of patient experience data be incorporated in RPM to enhance value in care delivery processes?

Patient experience data has been proposed to co-exist with other types of data to ensure healthcare decision-makers have a holistic understanding of the patient community situation (Rand et al., 2019). The patient experience data may not be evidence of causes and effects as clinical data, but it can inform about the context of the effects that we see through the clinical data. In short, it can contextualise clinical data to better interpret causes and effects.

→ **Patient experience data should co-exist with clinical data to holistically understand each patients' situation and make fair decision over the treatment prescribed (Rand et al., 2019).**

Nevertheless, to serve as a trustworthy and relevant source of information for priority-setting in healthcare, patient experience data should be collected through systematic methodological frameworks that align with the evaluation requirements and quality standards of healthcare technology (Rand et al., 2019). This systematic data-collection framework should also aim to reduce bias and subjective interpretation by involving experts in the field.

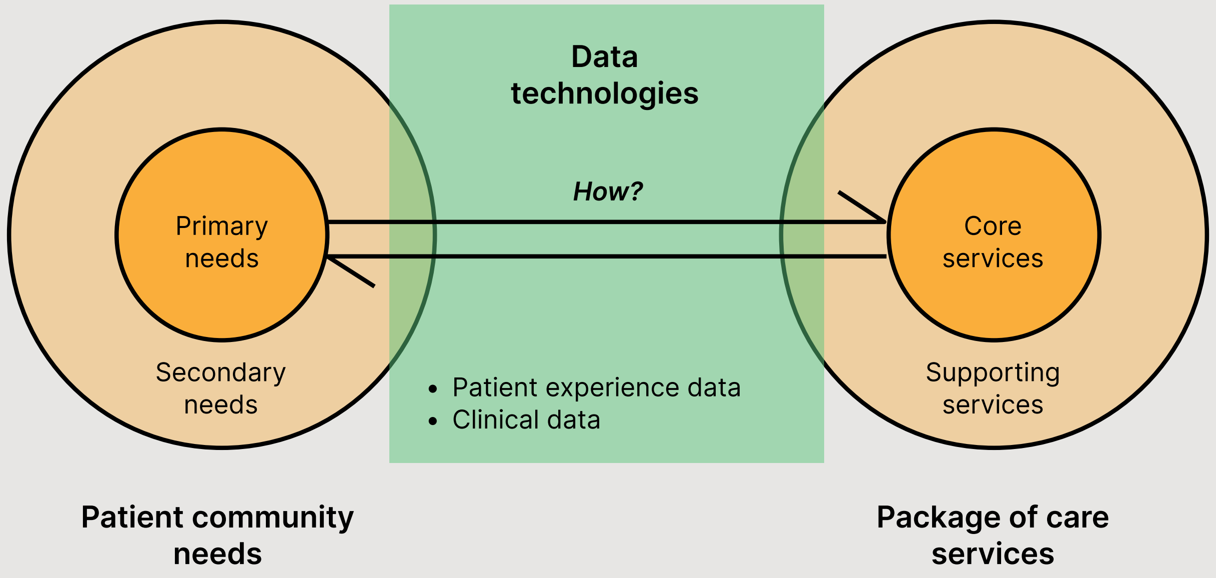


Figure 2.2: visualisation of the first research question, based on definition of service concept by Edvardsson & Olsson (1996).

Even though this master's thesis does not focus on the domain of healthcare priority-setting, it draws from the positioning by Rand et al. (2019) to investigate the possible applications of feedback loops of patient experience data to inform clinical practice. Patient experience data can effectively inform about the nature of the condition, the impact of the treatment and the impact of the treatment beyond health benefits (Rand et al., 2019). From the narratives of patients and caregivers, we can acquire a more nuanced understanding of the needs that arise from living with the condition, and therefore the nature of the disease (Rand et al., 2019; Kinter et al., 2009; Ajayi et al., 2009; Goodman et al., 2011). Moreover, clinical data indicates better direct health benefits, but the patients' experiences can contextualise how the treatment process and outcomes are affecting their lives (Mayer, 2012; Wit et al., 2014; Gillard et al., 2012; Staniszewska et al., 2012).

Provided that the data collection is systematic and meets the quality standards (Rand et al., 2019), patient experience data along a patient journey could then inform the creation and update of services within clinical practice. Data technologies in the form of AI, machine learning or NLP (Natural Language Processing) technologies may enable the constant feedback flow of evidence from clinical research to inform clinical practice and data from clinical practice to inform clinical research (Institute of Medicine (US) Roundtable on Evidence-Based Medicine, 2007; Somashekhar et al., 2018; Friedman et al., 2015; Guise et al., 2018). Through a continuously learning service system, several data streams could also indicate how to improve care service delivery processes (Levine et al., 2019; Joseph et al., 2023). In conclusion, the research question investigates to what extent patient experience data extracted and synthesized by data technologies can inform incremental improvements in service delivery processes within clinical practice.

2.2 Intersecting 3 Patient Communities.

> *What are the common themes of needs and concerns that an RPM service system needs to cover for several chronic diseases based on the data from online patient support groups?*

This research question reflects the goal of this project to map out commonalities and patterns among the three patient communities to inspire an RPM service system that incrementally adapts or muddles through different conditions. The term "muddling through" (Norman & Stappers, 2015) represents the idea that designers are more involved in the implementation phase of their design intervention to ensure their designs will progressively adapt to the contexts for which they were envisioned. Based on this concept, the analysis of commonalities among these online patient groups does not aim to merely distinguish how their support needs differ, but it also aims to look at foundational service systems that incrementally adapt or muddle through to offer high-value care to distinctive patient communities.

Three levels of chronic conditions.

The selection of these specific three patient communities for this master's thesis is due to their common approach (patient community journey mapping; Jung et al., 2023) and their different levels of chronicity.

The design and computer science students applied a common data analysis method (topic modelling; Jung et al., 2023) to analyse the datasets from the three patient communities and they visualized the findings in a uniform format (patient community journey maps). In preparation and throughout their graduation projects, the students collaborated with computer science students to cluster online patient stories into topics through topic modelling and interpretation. This method employs an unsupervised machine learning algorithm, which is known as Latent Dirichlet Allocation (LDA), to cluster the online patient stories into topics following topic similarities (Blei et al., 2003).

Furthermore, the selected diseases represent three hypothetic levels of a chronic disease spanning from chronic and degenerative (Pulmonary fibrosis) to more acute conditions with possibilities for curative treatments (Colorectal Cancer). Sarcoidosis is a transition between those two situations since it is chronic in many cases, but it is most likely not a rapidly degenerative disease.

- **Colorectal cancer (CRC)** is a rather acute disease. If the treatment is successful at stopping the propagation of cancerous cells, the patients are released after a 5-year-long monitoring phase. In this 5-year follow-up phase, the patients visit the hospital for periodic scans to monitor health status and reoccurrences, and they attend meetings with clinicians to discuss health progression and receive the necessary support and information. If the cancer spreads or is considered unresectable, CRC can represent a rapidly degenerative and fatal disease. Nevertheless, technological development in the last decades has allowed boosting the treatment options for these patients and improved the survival rates of this variant of cancer (Dekker et al., 2019; Siegel et al., 2019).

- **Sarcoidosis** is a rare condition, which can be acute and chronic. In most cases, the disease does not compromise the patient's life. Patients with chronic sarcoidosis can suffer from gradual symptom development to the point of even being able to suffer from organ damage. Patients of acute sarcoidosis will experience that the symptoms completely vanish over time. The patients who are more active in the online support groups are the patients with chronic sarcoidosis. For that reason, we will focus on the chronic variant for this project (Baughman et al., 2008).
- **Pulmonary fibrosis (PF)** is a chronic and incurable disease. The disease consists of lung scarring, which leads to progressive loss of lung function until the end of life of the patient. The trajectory of PF is highly fluctuant as the disease worsens with variable speed (Murray et al., 2005). The current treatment has only shown to be effective in slowing the progression, but the scarring is irreversible. The life expectancy is between 3 and 7 years (EU-PFF, 2023).

Towards a common service architecture.

The past master's thesis (Kicken, 2023; Sun, 2023; Zhang, 2023) dove into the 3 patient communities independently and managed to comprehensively examine the patient needs and concerns for each respective condition. The team from the Flagship Consultation 2023 was interested in learning about how to use the insights from each project to develop RPM for these diseases. Nevertheless, due to the need to involve many stakeholders and parties to fund the development and implementation of remote patient monitoring, it was necessary to develop a foundational RPM service system that can be incrementally adapted to the specific context of different diseases. Having this outlook in mind, this project aims to identify collective needs and concerns shared by the three online patient communities that can inform future developments of an RPM service system. On a higher level, this master's thesis aims to contribute to the domains of patient-centric service design in healthcare and RPM systems.

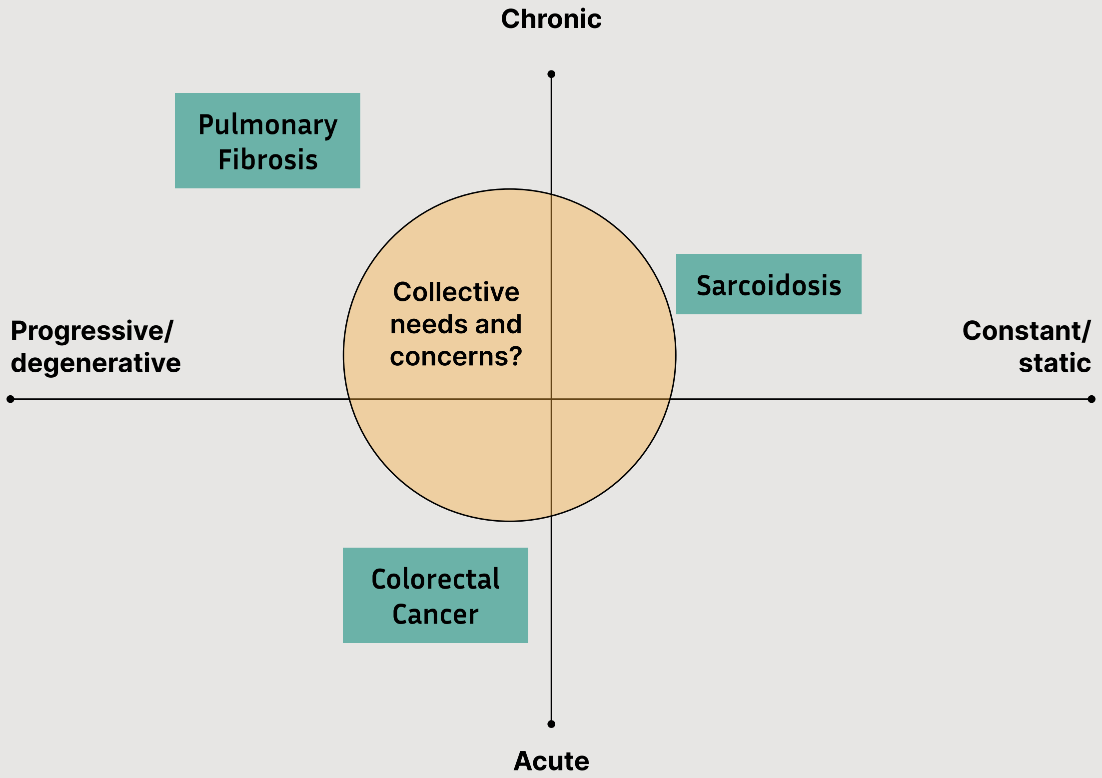


Figure 2.3: Visualisation of the second research question.

2.3 Enhancing the experience of receiving and providing care.

> *How can we involve practitioners and patients in data-enabled services within an RPM context that contributes to both stakeholders' well-being and shared decision-making?*

Quadruple Aim and RPM systems.

To create a healthy and attractive work environment in healthcare, technological innovations should contribute to relieving medical professionals from cumbersome administrative tasks and allow them to feel that they are providing more care with less or the same effort (Gupta Strategists, 2021). The theoretical framework of the Quadruple Aim posits that healthcare innovations should benefit or at least not be detrimental to four overarching goals: improving the experience of receiving care as a patient, contributing to the health of populations, reducing the cost per capita of healthcare, and improving the experience of providing care (Sikka et al., 2015). One aspect that hinders the latter goal is clinicians experiencing an overload of non-caregiving tasks, and as a result, having less time for meaningful care tasks such as diagnosing, treating and educating the patients (Sikka et al., 2015). Since a motivated workforce is the foundation of any effective and efficient healthcare system (Sikka et al., 2015)., the data-enabled services that enhance the exchange of knowledge and information such as an RPM intervention should consider the Quadruple Aim. Specially, the goals of improving the experience of receiving and providing care.

To benefit work satisfaction and well-being, remote patient monitoring should effectively lead to more precise and straightforward consultations, that happen when it is necessary. Remote patient monitoring interventions may contribute to this goal by partially substituting in-hospital check-ups with hybrid systems, which combine at-home care and monitoring with periodic tests and consultations at the medical centre (Gupta Strategists, 2021. This way, the energy-intensive hospital check-ups can be reduced with telemonitoring of patients' conditions with sensors and apps that collect timely data relevant to clinical practice. RPM may also foster the self-management of patients to partially liberate workload from medical professionals (Noah et al., 2018; McManus et al., 2018, Rakers et al., 2023).

Moreover, the data technologies and information retrieval technology within an RPM system could help reduce information overload when clinicians analyse each patient's history and situation, (Sharma et al., 2022; Murray et al. 2021). The data collection

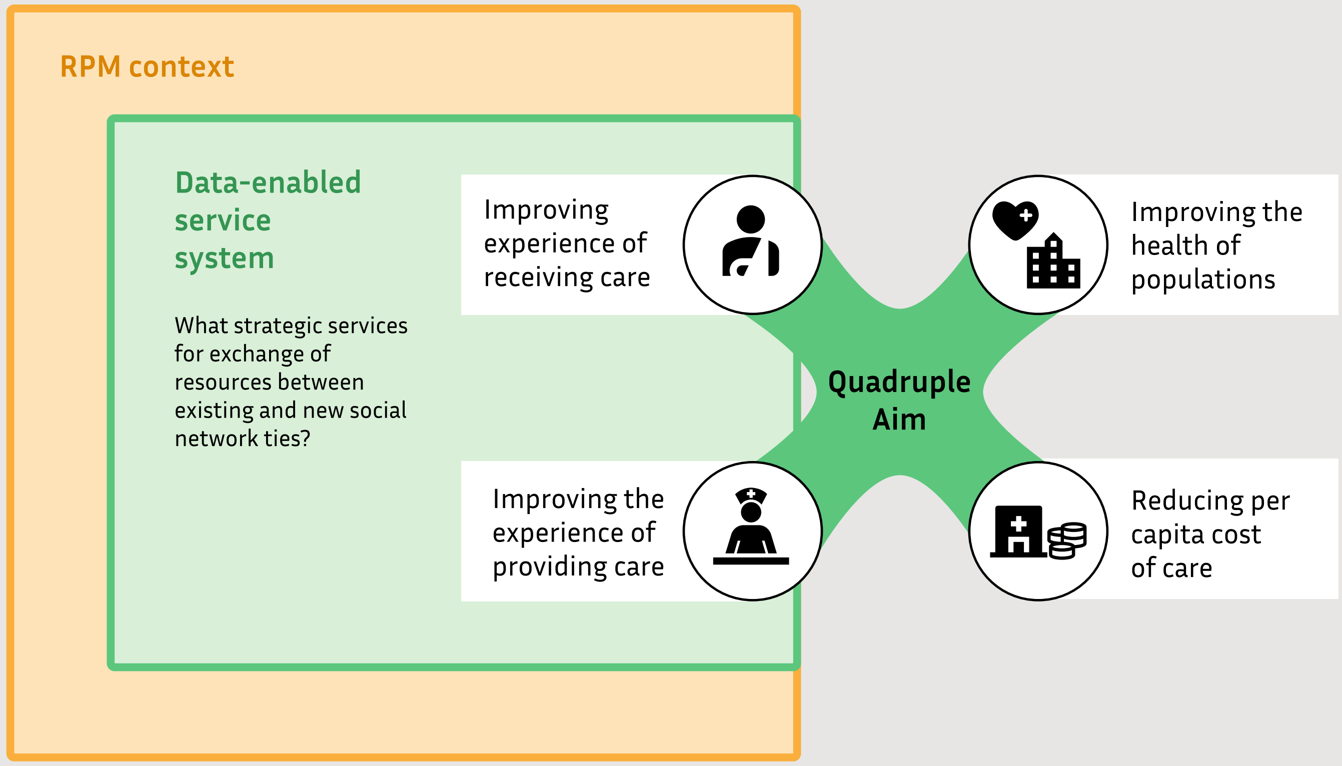


Figure 2.4: Visualization of the third research questions, based on Quadruple Aim (Sikka et al., 2015)

could ultimately lead to clinicians having more time for diagnosing, prescribing treatment and educating the patients. Allowing the clinicians to focus on these tasks could hypothetically lead to higher levels of work satisfaction and finding their jobs more meaningful and fulfilling (Oh et al., 2005, Noah et al., 2018). Considering these technological developments and the future trend towards RPM, this master's thesis aims to explore data-enabled services that benefit both clinicians' and patients' satisfaction and self-development within an RPM context.

Despite all the theoretical benefits that RPM could offer, there is still little evidence of the direct effects of RPM interventions on health outcomes and satisfaction with care (Noah et al., 2018). Many patients seem still reluctant to engage in such RPM systems to monitor their health data (Pevnick et al., 2016). Therefore, this master's thesis investigates innovations that provide value to patients in exchange for their valuable data and experiences.

→ **Self-monitoring interventions should enhance value for patients in exchange for their data to motivate to use and adhere to such systems.**

Social support theory

Based on social support theory (House, 1981), we can distinguish four types of support, which the online patient communities may engage in while exchanging messages: **informational, instrumental, emotional, and appraisal support**. Informational support refers to exchanging advice, suggestions, and knowledge that someone can use to deal with stressful situations. Instrumental support represents offering tangible help and services to assist another person. Moreover, emotional support means sharing compassion, affection, and trust with others. Finally, appraisal support is characterized by comparing information that facilitates self-evaluation. Nevertheless, in practice, it is complicated to distinguish between these types of support. Within the same online patient story, patients may provide the online community with appraisal and information support at the same time. These types of social support will be taken as a reference to interpret service patterns within the interactions in the online patient support groups (Chapter 5).

Heaney & Israel (2008) propose the Conceptual Model for the Relationship of Social Networks and Social Support to Health. The model illustrates social networks and social support as enablers of health outcomes. In the model, pathways 2 and 4 show how both individual and community resources complement each other to allow a person and their social network to manage stressful experiences in a way that buffers the short-term and long-term harmful effects on health and well-being. This means that social interactions through online patient communities can enable the exchange of resources that ultimately benefit the physical, mental, and social health of the individuals. In the online patient stories, one patient may recommend to others coping mechanisms to deal with a treatment side effect and therefore, it will contribute to others' physical health. Patients may also share a philosophical reflection and inspire others to stay resilient while undergoing treatment, and ultimately, contribute to the mental health of other patients. Another patient may share recommendations for weekend activities with the family and this way foster the social health of other peers (Heaney & Israel, 2008) .

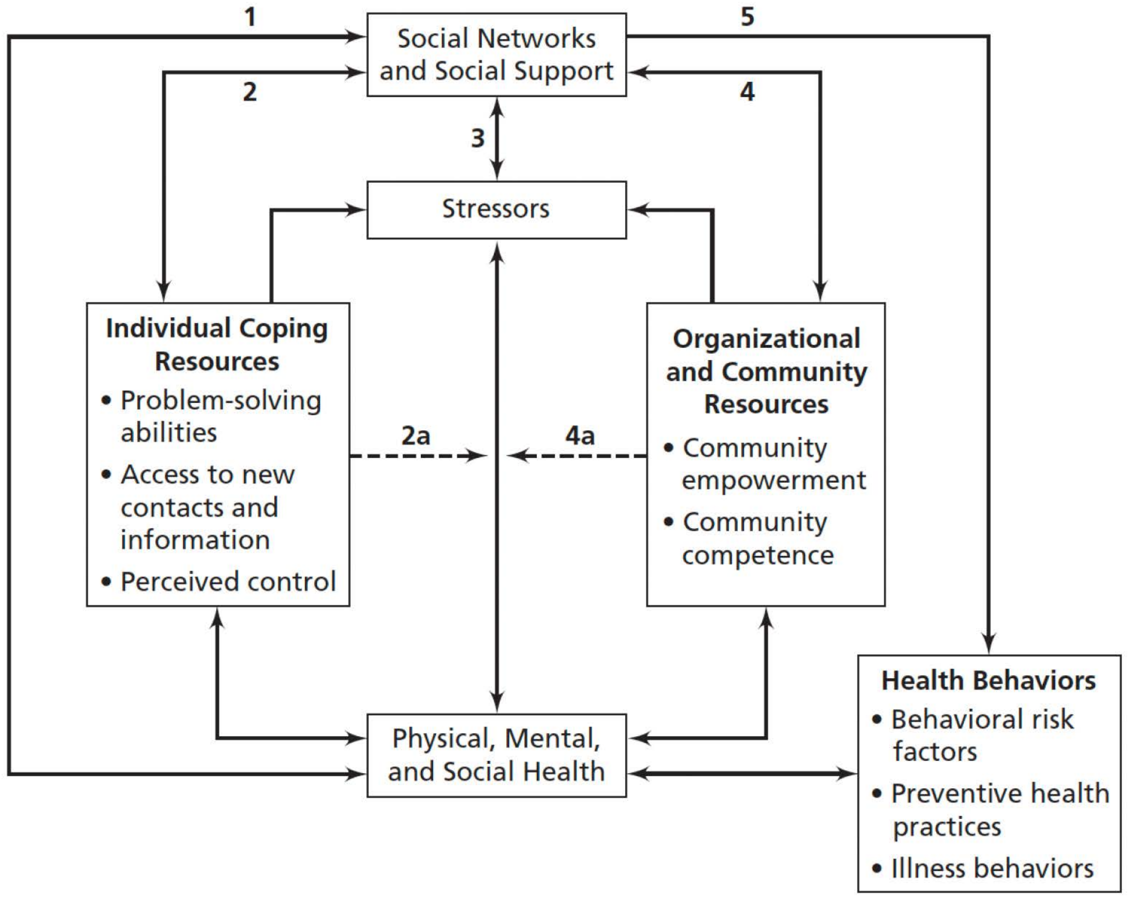


Figure 2.5: Conceptual Model for the Relationship of Social Networks and Social Support to Health, retrieved from (Heaney and Israel, 2008).

→ **Social networks have the potential to contribute to the physical, mental and social health of the patient communities and how they navigate through stressful experiences (Heaney & Israel, 2008). This conceptual model will be used later to ideate on the service vision (Chapter 4, section 4.3).**

In pathway 5, this model illustrates that social networks can influence the adherence of other individuals to behaviours that benefit health outcomes, for instance, through social support, patients from the pulmonology department may stop smoking. Therefore, the patient community may also encourage the individual to adhere to the treatment plan prescribed or to even accept the treatment earlier and with more ease (Heaney & Israel, 2008).

Less close-knit but more widespread and populated social networks may respond better in periods of significant changes and transitions in life (Granovetter, 1983). These particular social networks can better provide more diverse information and resources that help the individual navigate the change in life. This is interesting because it relates to the spontaneous and disseminated nature of the online patient support groups. Therefore, the existing network ties with relatives and clinicians and new network ties with the patient community offer a lot of potential to support attitudinal and behavioural change that contribute to adjusting to the impact of the disease in life. Furthermore, by implementing strategies for community capacity building, communities can deal with a common problem together, be encouraged to turn more to each other for advice and support and avoid isolation.

The social support theory and the mentioned conceptual framework are relevant for the exploration of a data-enabled service system that enhances the quality of the experience of receiving and providing care. In the service conceptualisation, social support through diverse network ties should be investigated to foster patients' self-management through an RPM system intervention.

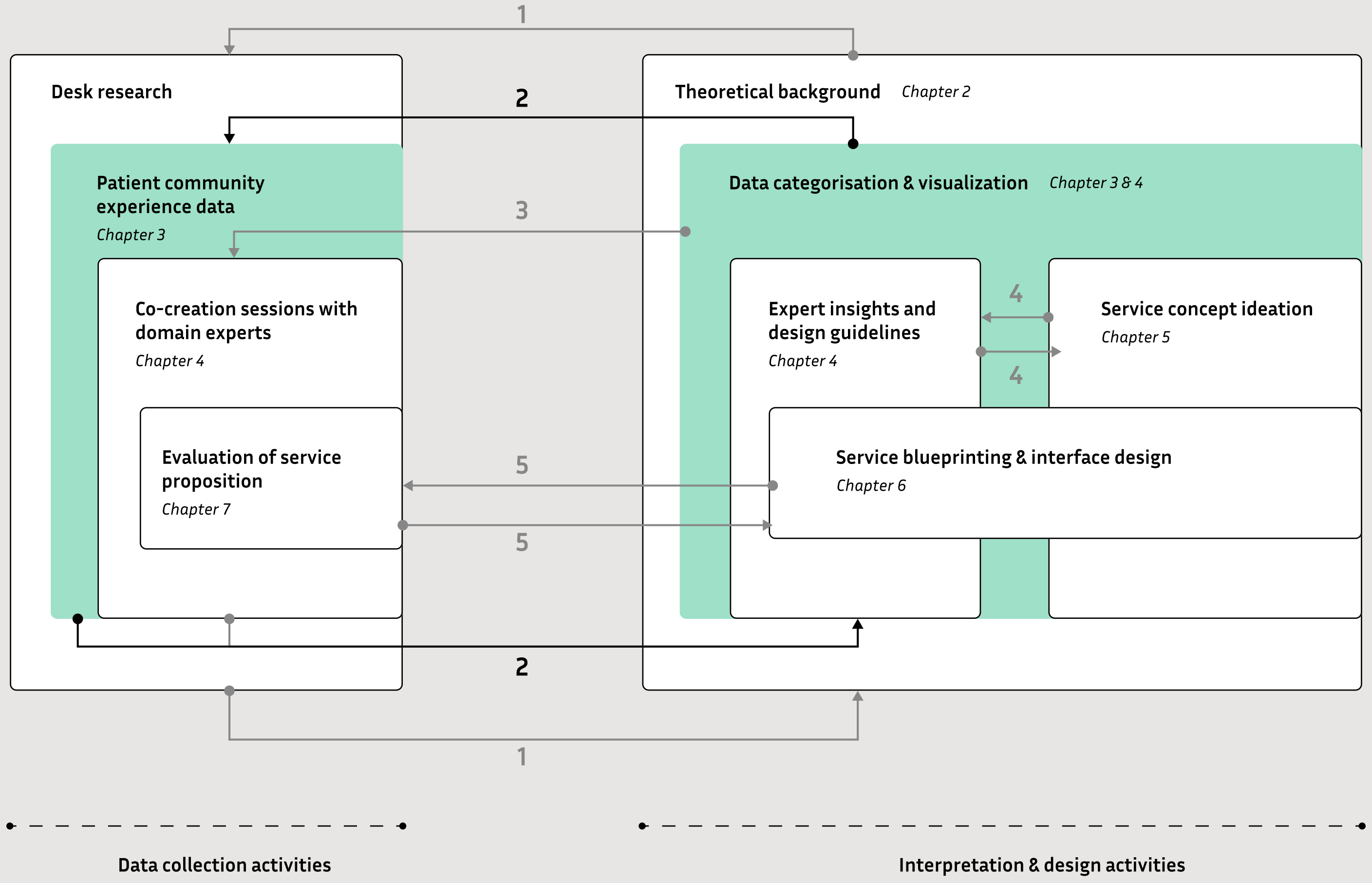
Key takeaways from this chapter

→ Patient experience data can co-exist with clinical data to inform improvements that increase value in care delivery processes.

→ Service design interventions for healthcare should muddle through the context. This way, the can incrementally adapt to specific departments in the hospital and patient communities.

→ Strategic and service design interventions should consider new and existing social network ties to investigate meaningful ways of fostering self-management. This may lead to interventions that ultimately help reduce the workload of clinicians and improve the quality of care for patients.

Chapter 3: Mapping collective needs and concerns



What are the common themes of needs and concerns among the three selected online patient communities?

After setting the project brief, the goal was to find common themes of concerns and needs among the three patient communities selected. This chapter delves into identifying those commonalities through the thematic categorisation of topics from the three databases. The process combines human interpretation and computational analysis to achieve data categories. The computational analysis consisted of a process known as semantic matching (Giunchiglia & Shvaiko, 2003; Liu et al., 2022). Therefore, this chapter deals with processing the previously interpreted and clustered patient experience data to support our comparison and deduction of common areas of concern or doubt.

3.1 Methodology.

To compare the findings from the previous contextual inquiry of the 3 patient communities (Kicken, 2023; Sun, 2023; Zhang, 2023), the team for this master's thesis decided that we should achieve overarching categories. Under these categories, we can then cluster the topics, so that we can discuss the differences and similarities of the 3 selected online patient support groups. The first step in the process involved comparing the topics by reading specific online patient stories and the topic labels to manually classify the topics into common categories. In the meantime, some topics were re-labelled to make the labelling more homogenous among the three databases. As a second step, the results from the semantic matching analysis were reviewed to inform changes in the initial categorisation. The second step used semantic matching to iteratively fine-tune the grouping of topics and the meaning of each category. This method continued until the team for this master's thesis felt confident about the clarity and level of abstraction of the common categories for the 3 selected online communities.

Step 1: Manual classification of topics

The manual classification consisted of revising each topic label and reading around ten posts per topic to intuitively cluster them under a similar theme (the data categories). Reading a few posts provided a more in-depth understanding of the content of the topic and the nuances that the previous designers had wanted to reflect on the topic label. Building on their interpretation, I reformulated some topic labels to make the labelling more homogeneous among the three datasets. Occasional desk research to consult medical vocabulary and understand treatment methods (e.g., medication, medical interventions, symptoms) allowed me to get a better interpretation of the topic and ultimately classify them into the most adequate category. Consult Appendix D to see the final categorisation of topics.

Through this process, patterns emerged, and I could familiarise myself with the care context and the shared doubts and experiences. This thematic categorisation was carried out in an Excel sheet to facilitate grouping the topics and calculating the

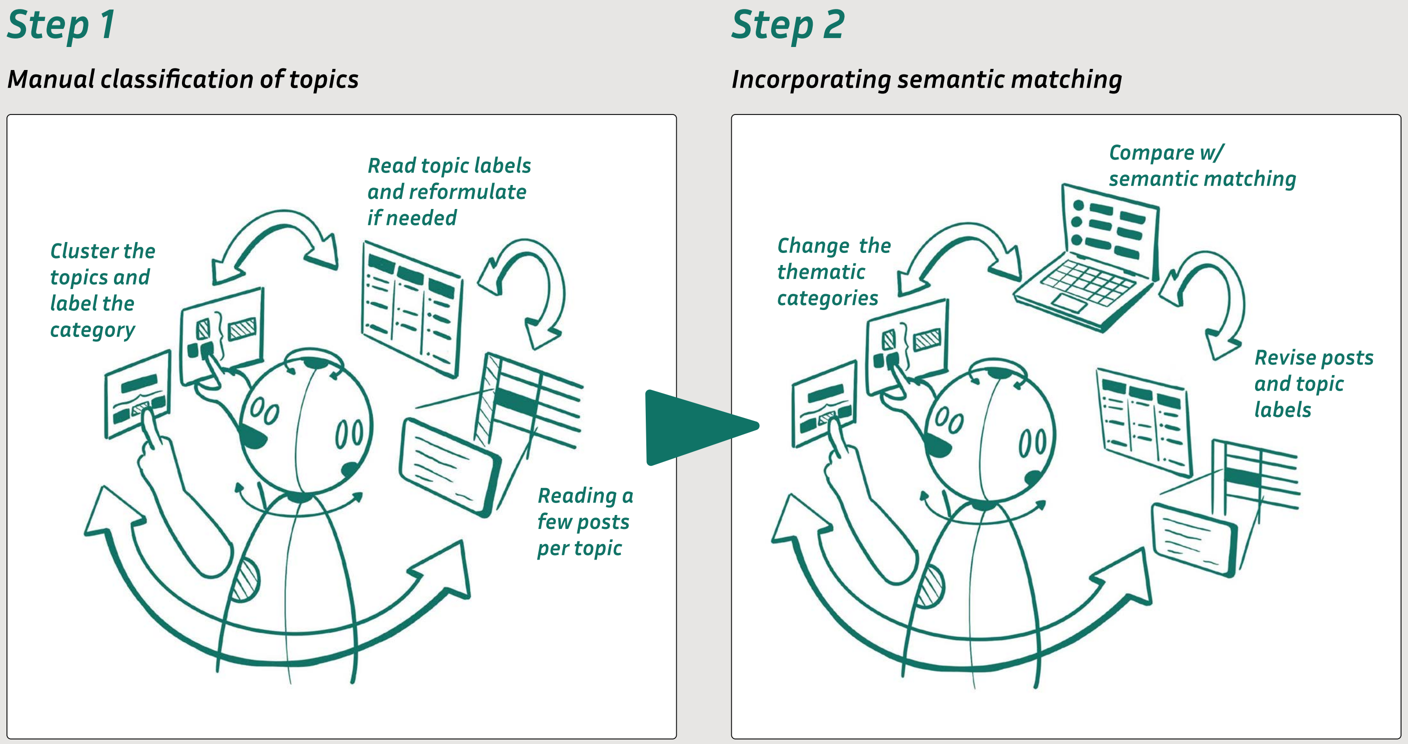
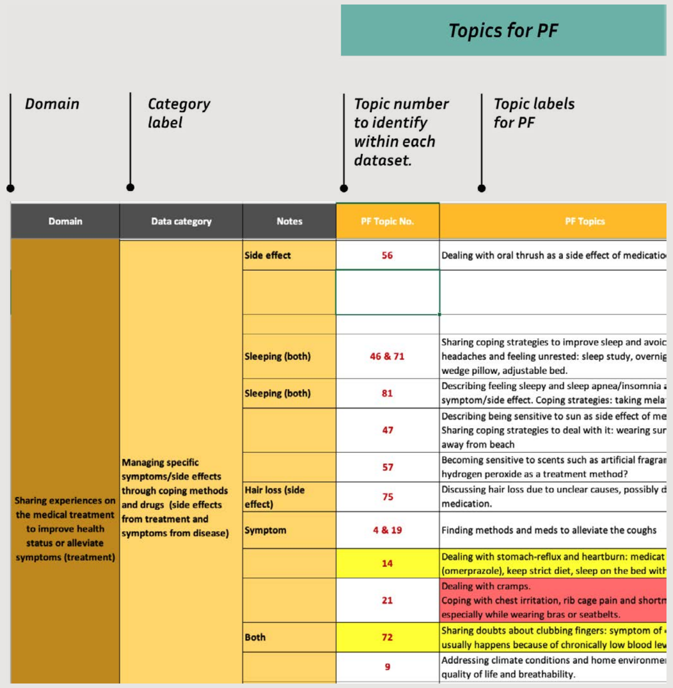
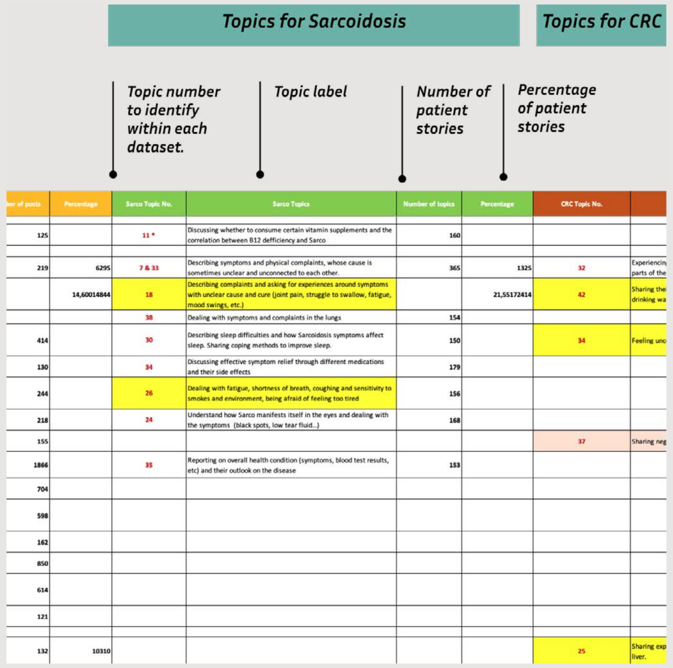


Figure 3.1: process to identify thematic categories among the topics.



Domain	Data category	Notes	PF Topic No.	PF Topics
Sharing experiences on the medical treatment to improve health status or alleviate symptoms (treatment)	Managing specific symptoms/side effects through coping methods and drugs (side effects from treatment and symptoms from disease)	Side effect	56	Dealing with oral thrush as a side effect of medicatio
		Sleeping (both)	46 & 71	Sharing coping strategies to improve sleep and avoic headaches and feeling unrested: sleep study, overnig wedge pillow, adjustable bed.
		Sleeping (both)	81	Describing feeling sleepy and sleep apnea/insomnia a symptom/side effect. Coping strategies: taking mela
			47	Describing being sensitive to sun as side effect of me Sharing coping strategies to deal with it: wearing sur away from beach
			57	Becoming sensitive to scents such as artificial fragran hydrogen peroxide as a treatment method?
		Hair loss (side effect)	75	Discussing hair loss due to unclear causes, possibly d medication.
		Symptom	4 & 19	Finding methods and meds to alleviate the coughs
			14	Dealing with stomach-reflux and heartburn: medicat (omerprazole), keep strict diet, sleep on the bed with
			21	Dealing with cramps. Coping with chest irritation, rib cage pain and shortn especially while wearing bras or seatbelts.
		Both	72	Sharing doubts about clubbing fingers: symptom of usually happens because of chronically low blood lev
			9	Addressing climate conditions and home environme quality of life and breathability.

Figure 3.2: Section of the manual categorisation of topics in Excel



ber of posts	Percentage	Sarco Topic No.	Sarco Topics	Number of topics	Percentage	CRC Topic No.	
125		11 *	Discussing whether to consume certain vitamin supplements and the correlation between B12 defficiency and Sarco	160			
219	6295	7 & 33	Describing symptoms and physical complaints, whose cause is sometimes unclear and unconnected to each other.	365	1325	32	Experiencin parts of the
	14,60014844	18	Describing complaints and asking for experiences around symptoms with unclear cause and cure (joint pain, struggle to swallow, fatigue, mood swings, etc.)		21,55172414	42	Sharing the drinking wa
		38	Dealing with symptoms and complaints in the lungs	154			
414		30	Describing sleep difficulties and how Sarcoidosis symptoms affect sleep. Sharing coping methods to improve sleep.	150		34	Feeling unc
130		34	Discussing effective symptom relief through different medications and their side effects	179			
244		26	Dealing with fatigue, shortness of breath, coughing and sensitivity to smokes and environment, being afraid of feeling too tired	156			
218		24	Understand how Sarco manifests itself in the eyes and dealing with the symptoms (black spots, low tear fluid...)	168			
155						37	Sharing neg
1866		35	Reporting on overall health condition (symptoms, blood test results, etc) and their outlook on the disease	153			
704							
598							
162							
850							
614							
121							
132	10310					25	Sharing exp liver.

Figure 3.3: Section of the manual categorisation of topics in Excel

percentages in the same platform. The manual classification provided an initial framing of themes of doubts, experiences and reflections in the selected online patient groups. To create more robust categories that fully represent the datasets, the next step was to employ the computational analysis method of semantic matching to assess and improve the thematic categorization.

Step 2: Incorporating semantic matching

After the manual classification of most of the topics, Dr. ir. Venktesh Viswanathan (co-mentor of this project) applied a semantic matching algorithm to extract relations between the topics of two different datasets (Zhao et al., 2023). Semantical analysis is an important technique for search engines and recommender systems (Liu et al., 2022) which, in this case, is applied to extract matches of common concerns and experiences among two different patient communities. The result of this process is a sheet with the obtained matches of topics and their corresponding correlation scores (Figure 3.4). Since we had three datasets, we also obtained three data sheets with the lists of matched topics.

Iteratively revising the matches from the semantic matching algorithm and applying changes in the thematic categorisation allowed me to improve the manual classification of topics. Reviewing each match from the semantic matching consisted of reading the labels and some posts from each topic in the match to determine to what extent I agreed or disagreed with the matches by the algorithmic model. Occasionally, the labels were reformulated throughout this exercise inspired by the results of the semantic matching. For matches that sparked more debate, I wrote longer reflections that I called field notes. These field notes allowed me to reflect and justify any significant changes in the classification. In short, by interpreting the results of the semantic matching algorithm, and reading some posts, I could rethink the meaning of each category of topics to achieve the preliminary categories explained in Section 3.3.

Column1		
pf_topic,sarc_topic,score		
39,1,0.17601585	🟩	
13,2,0.1662979	🟨	
4,7,0.21231548	🟩	
83,2,0.2527177	🟩	
9,12,0.1284265	🟧	
6,2,0.2974328	🟩	
84,13,0.16147228	⬛	
24,13,0.17268117	🟧	
23,2,0.31367165	🟩	
61,13,0.15232457	⬛	
0,3,0.119628794	🟩	
44,6,0.075582705	⬛	
16,8,0.22200014	🟨	
11,28,0.21055669	🟩	
5,2,0.2944584	🟩	
95,2,0.2655714	🟩	
21,7,0.25311637	🟩	Dealing with symptoms with unclear cause
82,1,0.09329488	⬛	
34,13,0.12830134	⬛	
29,8,0.16239052	🟨	
86,13,0.11653628	⬛	
98,7,0.22138484	🟧	
52,8,0.25210595	🟩	Recommending where to get more specialised help
71,30,0.1446088	🟩	Sleeping difficulties
27,17,0.16900724	🟩	Financial assistance when unable to work (ARBO)
91,10,0.21125679	🟩	Discussing whether to keep or stop working
20,8,0.2166663	🟨	20 is monitoring and measure progression of disea
33,8,0.19504249	🟧	33 is sharing offline support groups and 8 is doubti
68,6,0.109962754		
46,30,0.2073635	🟩	Sleeping difficulties

Agree	🟩
Disagree	🟧
Partially (dis)agree	🟨
Non-clustered topic	⬛
To be reviewed	🟦

Figure 3.4: Section of assessment of semantic matching results to iterate the thematic categorisation.

3.2 Results: Interim data categories.

The data analysis process which combined manual classification and computational analysis resulted in 12 data categories, which split into 4 overarching domains. The findings discussed in this section represent interim results since, together with clinicians and domain experts, the data categories will get iteratively improved (Chapter 4).

The first domain involves treatment-related experiences. This domain represents the self-narrated experiences that centre around the different therapies and treatment methods. The categories include doubts and stories around the prescribed drug treatment, shared experiences about managing specific symptoms or side effects, discussions, and doubts regarding non-drug treatment (e.g., surgical and radiation interventions), and debates and stories with non-conventional treatment (alternative therapies which may not generally prescribed by a medical professional).

The second domain groups the categories that discuss more directly the impact of the disease on lifestyle, including perceived changes around the personal and professional life of the patient community. This domain involves a mixture of self-motivated changes, and an intrinsic willingness to feel better moves the patient community to try or incorporate new habits in their life. The first category of changes involves career and finances, in many cases, the patient discusses experiences and doubts about how the disease and treatment plan will affect or is already affecting their professional career, and they support each other in financial matters like medical reimbursements and insurance coverages. The next category deals with self-care changes, which consist of new or reformed habits around diet, and sports. The following category is related to the latter since it involves direct consequences of treatment or therapy in daily life. For instance, having problems with taking showers with oxygen therapy in the case of PF patients. The fourth category entails stories about struggles and experiences to maintain a healthy social life and interpersonal connections with a close community. The final category in this domain deals with attitude changes, representing the patients' appraisal and relatively philosophical thoughts on confronting the disease discovery, treatment, and follow-up stages.

The third domain only groups one data category and focuses on emotional support within the patient community. As the literature describes (Heaney and Israel, 2008), emotional support involves nurturing empathy, reliability, and affection within a community. In this case, we mainly find compassionate and encouraging posts between patients and their close circles (relatives and partners).

The fourth domain groups understand and analyse the behaviour and stage of the disease. The first category (Diagnosis and monitoring) focuses on the shared experiences about the initial and gradual testing and assessment process of the disease progression. The second category (causes of the disease and related conditions) centres around discussing possible triggers or drivers of the disease and, in some cases, sharing doubts about co-morbidities and triggers of complications of the disease.

Illustrating the similarities and differences between the three patient communities was challenging since the graphic representation needed to be comprehensive yet simple at the same time. The results and percentages from the three datasets needed to appear together to show the disparities. The choice was to use a Marimekko-style graph, as it seemed to efficiently highlight the different compositions of concerns and needs across one common dimension: the types of diseases analysed. In this case, the data categories act as criteria to show the frequency of the themes of concerns and needs.

Initial interpretation of results

The need for more guidance and a better understanding of the effectiveness and relationships between treatment methods (e.g., medication, surgery, etc) and dealing with side effects seems highly relevant for the three diseases. Especially, for Pulmonary Fibrosis and Sarcoidosis, where the percentage of posts about treatment-related experiences are 63,9% and 49,8% respectively. Furthermore, the most discussed categories were "Non-drug treatment" for PF (22,7%) and "Drug treatment" for Sarcoidosis (25,9%). In the case of "Non-drug treatment" for PF, the category consists of sharing doubts and tips about oxygen therapy and discussing transplant procedures and post-transplant care. In the case of "Drug treatment" for Sarcoidosis, the patient community shares experiences with their perceived health progress, weighs pros and cons, and discusses side effects of specific drugs. This shows the relevance of collecting patient experience data on the effects of the treatment for more holistically informed clinicians, as it seems that patients perceive their lives highly affected by the treatment and need to compare it with others' experiences.

Regarding CRC, the most prominent category is "Diagnosis and monitoring" (18,7%). For CRC, this category specifically deals with concerns about the results from scans and tests, and doubts about the medical professionals' opinion about the test results and treatment plan. The patient community also highlights the importance of getting multiple medical professional opinions to choose the best treatment plan. Within the posts of this category, there is a clear connection between discussing results from the tests and scans and making decisions on the

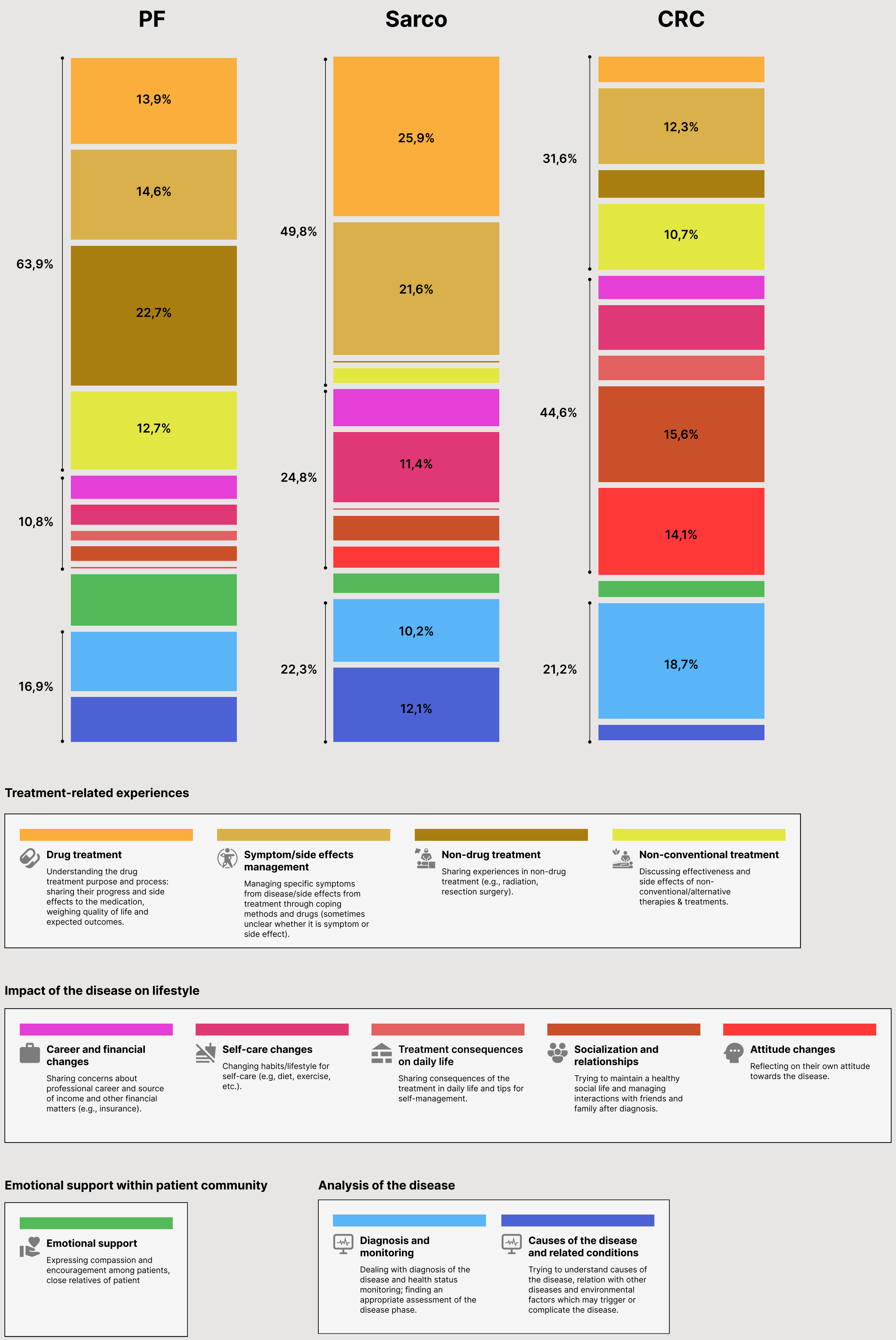


Figure 3.5 : Interim data categories and visual comparison of the three datasets.

best treatment plan accordingly. This may explain the lower percentage of posts in the domain of treatment-related experiences compared to the other diseases.

In parallel, the domain of "Analysis of the disease" is especially relevant in the case of Sarcoidosis and CRC. 12,1% of the posts on Sarcoidosis centre on the origin and causes of the symptoms of Sarcoidosis and discuss seemingly related conditions like SFN (Small Fibre Neuropathy). 10,2% of the posts focus on the process of diagnosing Sarcoidosis and understanding the disease. This is probably due to the complexity of diagnosing the disease due to its systemic nature, and consequent high variation in how the disease manifests (Drent et al., 2021). In the case of CRC, the percentage may also relate to the nature of the condition and treatment. CRC patients in a resectable stage of the disease may undergo combinations of drug (chemotherapy) and non-drug treatment (surgery and radiation) and then are monitored for a few years (Warrington et al., 2015), during this follow-up stage patients are likely worried about the reoccurrence of the cancer. These results might show that Sarcoidosis patients need more social support right after diagnosis and CRC patients may need it more throughout the periodic monitoring of the disease in the follow-up phase.

It is noteworthy that, in the case of CRC, 44.6% of the messages centre on the impact of the disease on lifestyle, whereas, in the case of PF, these topics accounted for 10.8% and 24.8% of the messages, respectively. The two most prominent clusters within this theme, which partly explain this high percentage for CRC, deal with how patients perceive and try to adjust to life with the disease (15,6%) and how the disease impacts their social life and relationships (14,1%). This might mean that CRC patients are generally more concerned about the process of adjusting to life after undergoing treatment, and they need more coaching on this matter. This may be due to the other two patient communities always undergoing treatment since they are more chronic conditions, and consequently not having such a clear post-treatment stage.

In conclusion, the results indicate that the three patient communities differ in the perceived relevance of coaching and information support themes. It seems that there is a tendency regarding the themes of social support that the patient communities engage in (Figure 3.6). Whereas the PF community seems more concerned about managing the treatment and discussing how they adapt to the symptoms and side effects, the CRC community appears to be more motivated to discuss how the disease impacts their life and how they cope with re-incorporating to their previous routines and lifestyles. The Sarcoidosis community seems to be a transition between these two tendencies. It could be that in the PF community, adjusting to life with the disease is more intertwined with treatment in the online patient stories, and therefore more difficult to separate semantically. For instance, when they talk about oxygen therapy, which is part of the treatment, they also discuss how to adapt better to living with oxygen concentrators. Remote patient monitoring that benefits healthcare

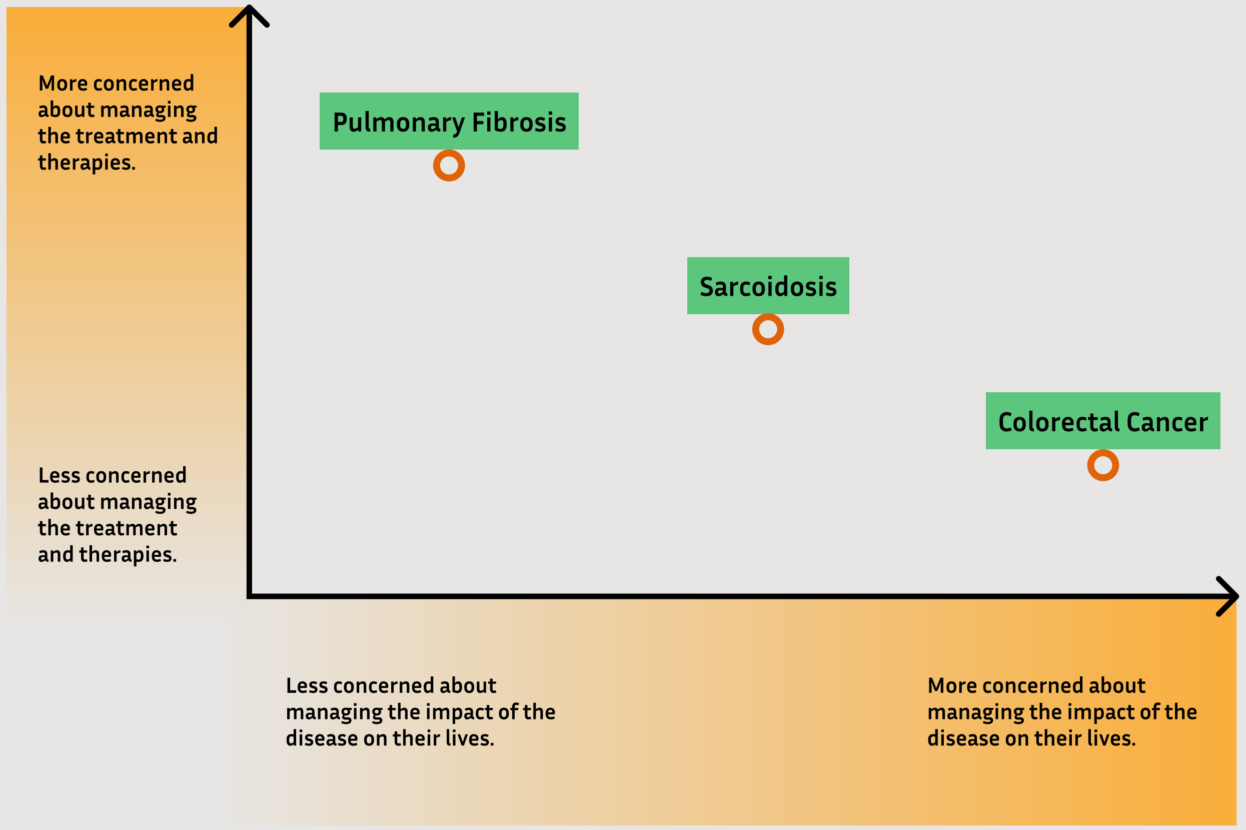


Figure 3.6: Perceived tendencies about the different needs of social support and guidance.

service delivery processes for these three diseases should consider these two tendencies for information support. Later, the implementation of strategies regarding emotional and appraisal support would help to fulfil patient needs.

3.3 Reflection.

Reflection on methodology

Combining manual classification with semantic matching was useful for refining the categories and reducing the selection bias. This bias arises from reading only a few online patient records per topic. With the semantic matching results, I could assess the classification of the topics by reflecting on what extent I agreed or disagreed with the associations made by the algorithm. I perceived semantic matching as an analysis companion which presented strengths and weaknesses. For more information about the topic numbers mentioned in this section check the Appendix C & D.

Strengths

Indicating how to divide larger categories.

By looking at one specific topic from one category in one dataset and how the semantic matching repeatedly connected it to others from another dataset, I could reflect further on if and how I should divide a specific category.

For instance, topic 42 from CRC ("Sharing their experience on managing the side effects of treatment: drinking water, taking medications, and getting plenty of rest") had been matched with topics in the PF dataset that described the management of specific symptoms or side effects (topics 4, 19, 46, 57, 81, 85). For instance, topic 4 focused on alleviating coughing and topic 81 on sleep apnea/insomnia. This finding led to creating a category about coping with specific symptoms or side effects, whether it is through other meds, other products or through exercises. This way I would distinguish it from another category that would centre around the patients debating on specific medications and their side effects.

Pointing out essential connections between topics

The semantic matching seemed to be a more pragmatic researcher that matches the essential semantic connections. For instance, in the case of topic 57 for PF and topic 42 for CRC. Topic 57 was only matched with topic 42. Topic 57 from PF describes “Becoming sensitive to scents such as artificial fragrances”. This topic was clustered in “Adapting to a new sensitivity to the environment". Topic 42 from CRC describes "Sharing their experience on managing the side effects of treatment: drinking water, taking medications, and getting plenty of rest". This topic was clustered in "Discussing side effects and symptoms and coping strategies". This match made me think that all symptoms and side effects impact your daily life to some extent, it does not matter whether they directly involve products in the home environment. In essence, these two topics describe dealing with specific symptoms or side effects, so the decision was to move this topic to the second cluster.

Weaknesses

Different levels of detail in the datasets complicate the comparison of topics.

In general terms, through my manual classification, I realized that the 3 datasets presented different levels of detail when clustering the posts into topics. These discrepancies are possibly due to the independent analysis of the 3 datasets by the previous teams of graduation students, and to the use of different topic modelling techniques. For instance, for PF we had topics talking about specific side effects like oral thrush, whereas for CRC, we got more general topics discussing combinations of side effects from chemo. The online patient stories from the PF community were grouped using the BERTopic (Bidirectional Encoder Representation of Transformer), the CRC online stories were clustered with the NMF (Non-negative Matrix Factorization) model, and the Sarcoidosis team employed the technique LDA (Latent Dirichlet Allocation). Consequently, for the dataset of PF, it seemed possible to reach more specific categories, but the other datasets restricted the level of detail.

Source of tension: prescribed or not prescribed.

The semantic matching sometimes did not distinguish between typically prescribed medication and non-registered medication for each disease, which could be concerning for medical professionals when looking at the results. Due to my lack of education and training in medicine, I could mainly rely on desk research to make this distinction.
For example, the semantic matching algorithm associated topic 18 from PF with topic 2 from Sarcoidosis with a correlation score of 0.24, which is relatively high. In both topics, the patients seem to discuss specific drugs to inhibit inflammation. In topic 18 from PF, the patients discuss the use of enzymes such as serrapeptase. However, the success rates and efficacy of serrapeptase remain unclear and are being researched through only a few studies (Van de Walle, 2023). In topic 2 from Sarcoidosis, patients discuss their side effects, dosage, and reimbursement of drugs like prednisolone, prednisone, Ritalin, modafinil, etc. Prednisone and prednisolone are included in Apotheek.nl as medication commonly prescribed for Sarcoidosis. It is therefore still unclear to what extent these two topics can be matched together. In short, the use of semantic matching algorithms might need some expert supervision, if implemented in information systems for clinical practice and research.

Lack of differentiated matches with more visceral and self-reflective topics.

In some cases, the semantic matching did not show a clear tendency towards one of the proposed clusters or the other. For instance, the algorithm matches topic 13 from Sarco with topics from CRC in the cluster of "Expressing compassion and encouragement among peers" and topics in the clusetr about "Reflecting on their attitude towards the disease". When patients and their relatives share their outlook on the disease, they might often express their compassion towards others too. This may result in the posts having similar semantics. This shows how difficult it is to differentiate between emotional and appraisal support in practice (Heaney and Israel, 2008).

3.4 Conclusion.

As shown in Chapter 1, one of the main research goals of this master's thesis revolves around identifying the common themes of needs and concerns that an RPM service system needs to cover for several chronic diseases based on the data from online patient support groups. By combining manual classification and the semantic matching conducted by Dr Viswanathan, I discovered 12 interim data categories of social support, which seem to some extent relevant for all three patient communities. However, the missing contextual clues in some online patient stories (Jung et al., 2023), coupled with my reduced experience in treating these diseases, limits the interpretation of the data categorization results. It seemed imperative to tackle this knowledge gap by involving experts in the medical field, be they physicians, nurses, or clinical researchers. Together with clinical experts, we can revise the data categories and gain a richer understanding of the differences in support needs along the care path. Based on this, I asked myself the following question:

> *To what extent does our categorisation of the patient experience data match the mental models of domain experts (e.g., clinicians, nurses, clinical researchers...)?*

In an era of accessible digital technologies and designers increasingly working in transitional changes, designers should envision a collaborative way of identifying meaningful technological developments together with experts from other disciplines (Jung et al., 2022). Therefore, the involvement of clinical experts at this stage of the process was essential to identify meaningful opportunities for value creation regarding social support within RPM contexts (Chapter 2, section 2.3).

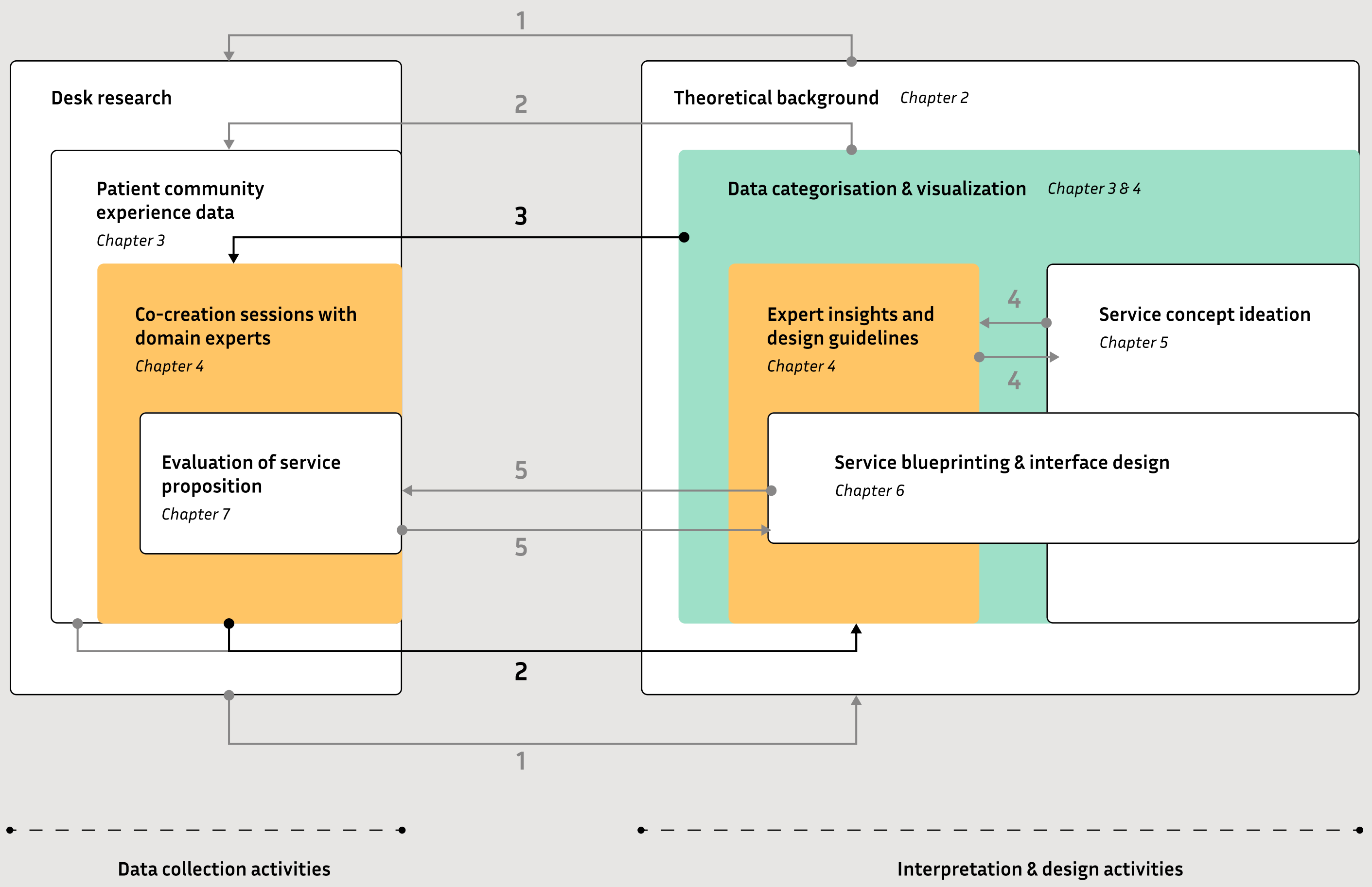
> *How can the collection and visualization of patient experience data be more relevant and actionable for domain experts?*

The next chapter will focus on the co-exploration of these research questions with domain experts to achieve refined data categories and map opportunities to improve care delivery processes considering a future RPM context.

Key takeaways from this chapter:

- The more chronic and degenerative diseases like PF seem to need more support regarding the self-management of the treatment and therapies, whereas the more acute diseases like CRC seem to require more support to adjust to the impact of the disease on the individuals’ lifestyle. Chronic but rather static diseases like Sarcoidosis seem to be a transitional element between these trends.
- The semantic matching algorithm was a useful tool to assess and refine the manual classification of topics.
- The use of semantic matching could be improved with a better understanding of the usual prescribed treatment and alternative therapies, more similarity in the depth and diversity of the topics in each dataset, and more fine-tuning to distinguish between the topics about emotional support and reappraisal of one’s situation.

Chapter 4: Exploring findings and opportunities with clinical experts.



Once the data categories had been distilled from the datasets, the next step had the dual aim of refining the categorisation and exploring opportunities to improve care delivery processes in a future RPM context. Through the involvement of 8 clinical experts (Table 4.1), the objective is to gather insights that inform an adequate strategy or service design intervention that addresses the research questions presented in Chapter 1. To tackle these research questions and based on the learnings from the previous phase (Chapter 3), I posit the following sub-research questions:

1. *To what extent does our categorisation of the patient experience data match the mental models of clinical experts (e.g., clinicians, nurses, clinical researchers...)?*
2. *How can the collection and visualization of patient experience data be more relevant and actionable for clinical practice?*

The first question intends to expand on our understanding of collective themes of needs and concerns that an RPM service intervention should support for different conditions. This question serves more as a premise for revising and improving the thematic categorization with clinical experts iteratively, rather than as a question to be answered in a quantifiable or concrete way.

The second question represents the aim to reflect together with clinical experts on how this patient experience data can become relevant in practice through systematic feedback loops. Therefore, it is a combination of questions 2 and 3 introduced in section 1.2. The patient experience data has been proposed as a valuable source of information about the impact of the treatment and the nature of the condition (Rand et al., 2019), but it remained unclear how to adequately incorporate the collection and provision of this knowledge in a way that aligns with the motivations and wishes of clinical experts.

Through the process presented in this chapter, the findings took the form of 4 key values and one service-system vision of knowledge exchange and social support that could exist within the RPM context (Figure 4.1).

4.1 Methodology.

Initial set-up and materials for co-creation with experts

To address these chapter's research questions, the co-creation set-up draws from the Contextmapping method and generative research tools (Sanders & Stappers, 2012). Contextmapping is a user research method aimed at uncovering tacit needs and wishes through interactive materials and semi-structured interviews. Through the interactive materials, the interactive participants and researchers can engage in a conversation that reveals deeper information about their values and aspirations. As the experts participating are mainly medical professionals their time is highly valuable for the functioning of the healthcare system. Therefore, the interactive materials should be designed to gather contextual insights from the participants without consuming too much time from their work routines.

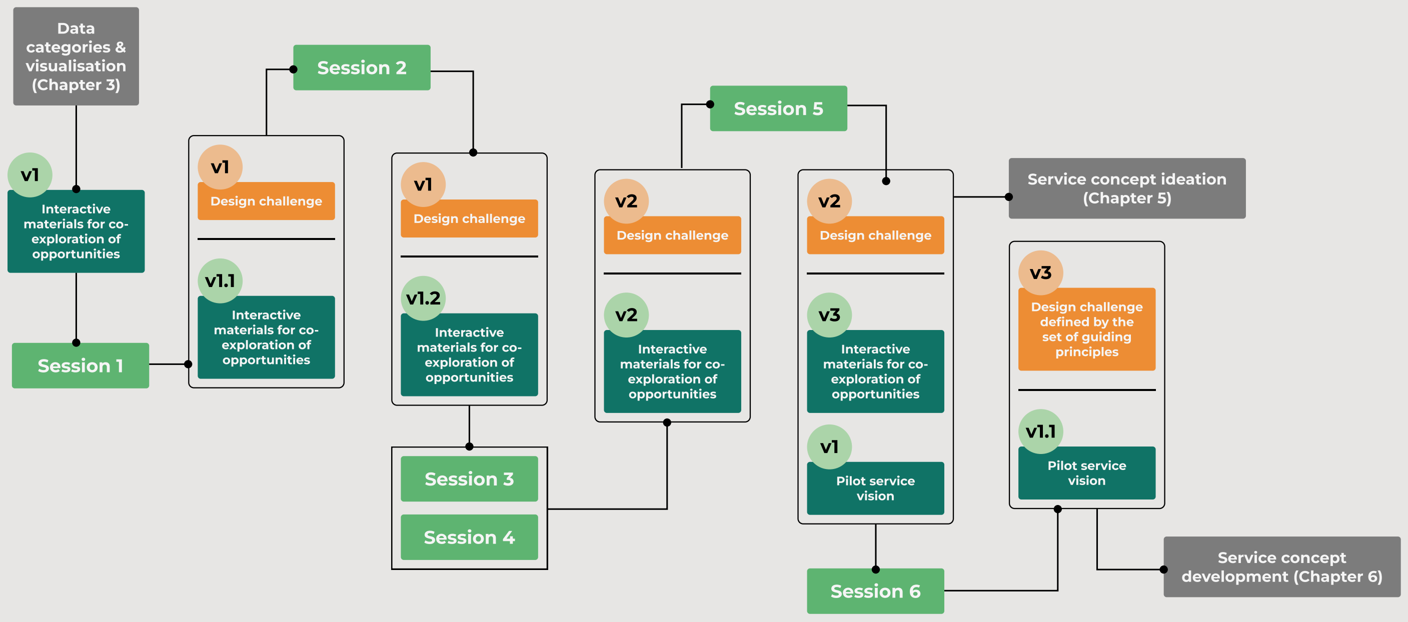
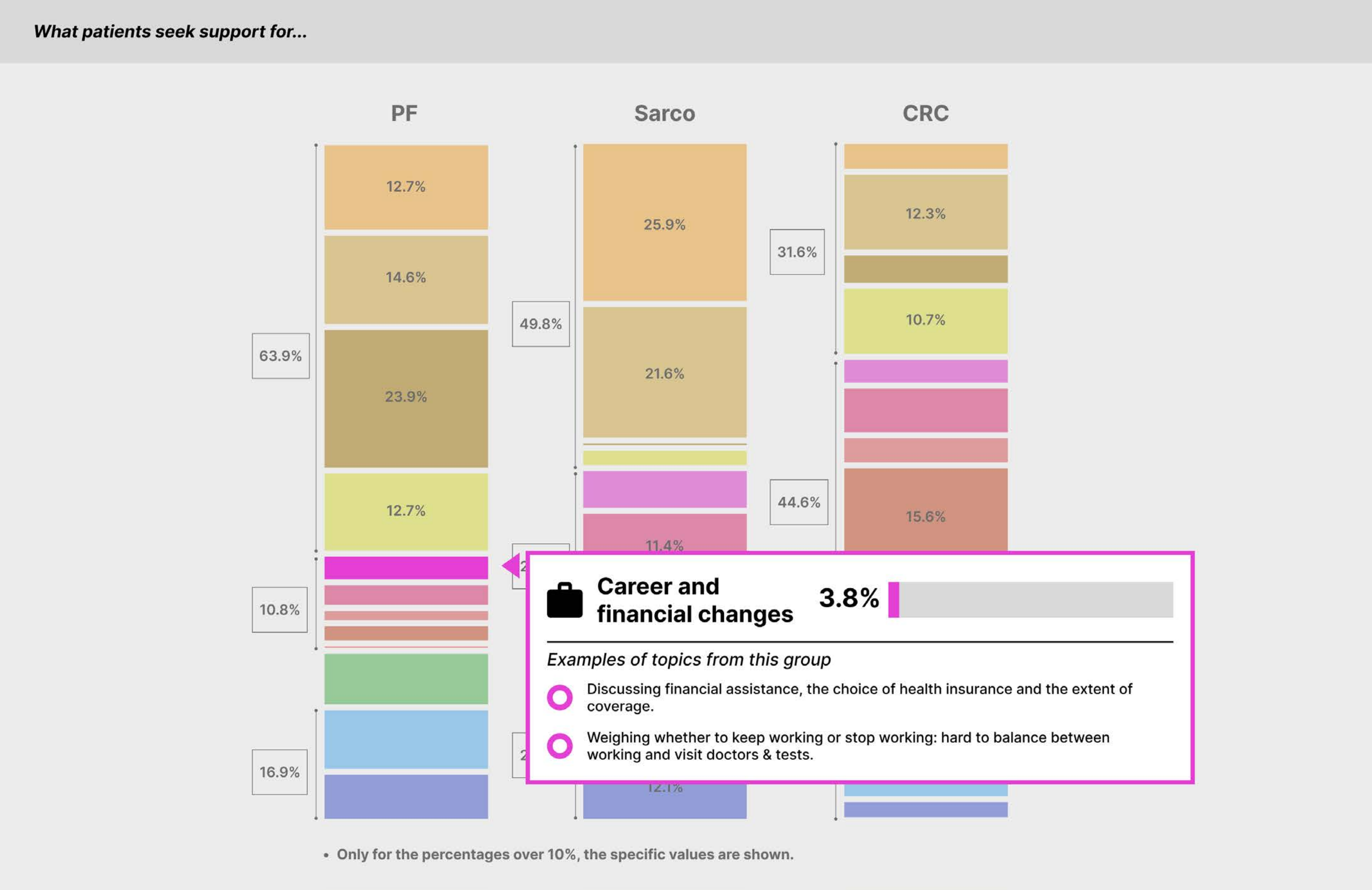


Figure 4.1: Co-exploration with clinical experts of interactive materials and design challenge.

	Session 1	Session 2	Session 3	Session 4	Session 5		Session 6	
Profession	Pulmonologist	Surgeon	Researcher	Vascular Surgeon	Surgeon	Surgeon	Surgeon	Nurse practitioner
Years of experience	17	6	15	10	12	20	>10	32
Expertise Description	Interstitial Lung Diseases	Endrocrine surgery, oncological (soft tissue) surgery	Oncology quality of life, patient experience	Aneurysm, Endovascular treatment, Quality of life	Surgical oncology	Oncology	Pancreato-biliary cancer	Pancreas surgery

Table 4.1: Recruited clinical experts for co-creation sessions.



Examples of topics from this group

- Discussing financial assistance, the choice of health insurance and the extent of coverage.
- Weighing whether to keep working or stop working: hard to balance between working and visit doctors & tests.

- Only for the percentages over 10%, the specific values are shown.

Figure 4.2: Interactive prototype to navigate through the data categories.

Due to the dual aim of this research activity of validating the data categories and exploring opportunities, the participants had to give their views as domain experts but also users. As experts, the participants reviewed and interpreted the categorisation of the patient experience data, whereas as users the participants explored meaningful applications of the data. The participation was open to a wide range of clinicians and clinical researchers, as we are exploring an RPM service system that may function for different chronic conditions. We can divide the planning for the session into two halves, which directly correspond to the research questions mentioned in the introduction to this chapter (check Appendix E for the full planning).

Interactive exploration of data categories and topics.

For the first half of the session, an interactive prototype (Figure 4.2) allowed the participants to navigate through the data categories and the topics.

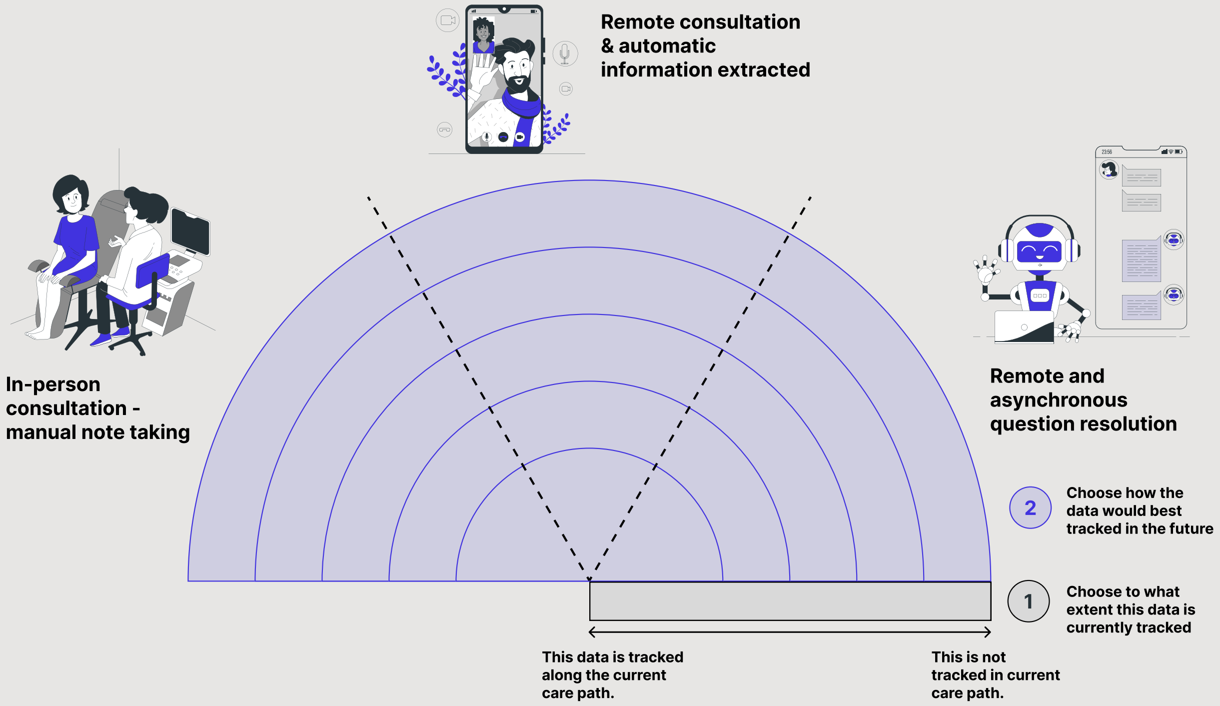


Figure 4.3: Initial prioritisation map. Illustrations created based on templates from Storyset by Freepik.

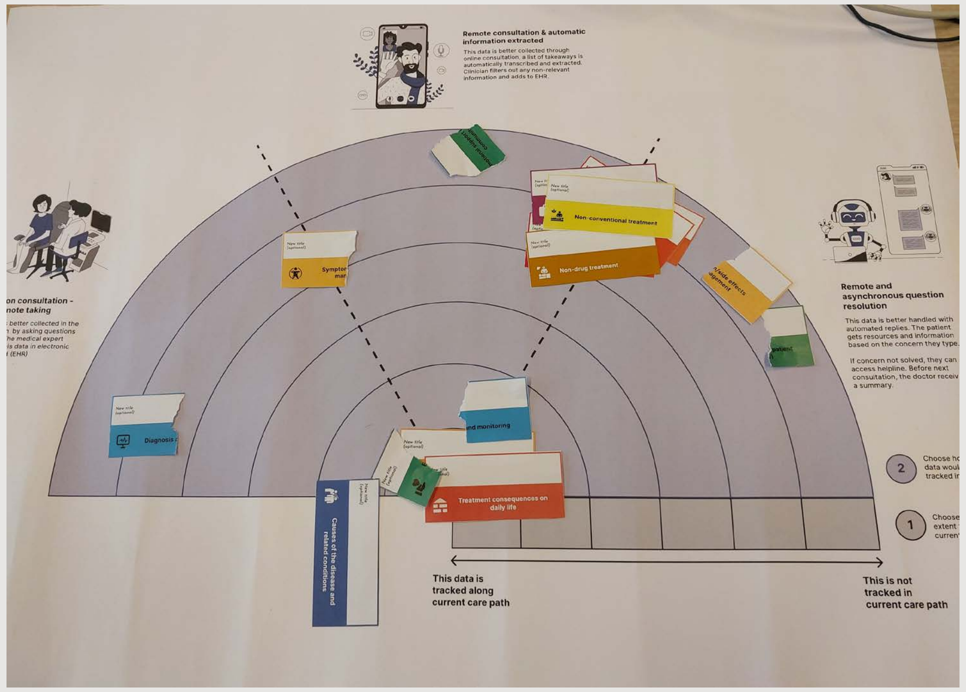


Figure 4.4: Prioritisation map after the discussion with clinical expert in the first session.

The prototype aims to showcase the classification of patient experience data in a simplified and explorative way. While letting the clinicians navigate the prototype, we could discuss how to improve the categorisation to ultimately achieve a minimum viable product of data categories (Link to prototype).

Discussing the value of different data categories and opportunities for data-enabled support.

In the second half of the session, a printed prioritisation map (Figure 4.3 & 4.4) prompted the participants to reflect on to what extent these information categories are currently tracked along the care path and in which contexts the communications should take place. Three scenarios express those different contexts:

- In-person consultation: collecting and communicating the information from that data category through in-person inquiry and face-to-face conversation at the hospital.

- Remote consultation & automatic information extracted: the information is collected through an online consultation. Patient and clinician interact through a video call format of consultation. A natural language processing model transcribes and extracts a list of takeaways from the consultation. The clinician can filter out non-relevant information and include the takeaways in the medical reports.

- Remote and asynchronous question resolution: Patients describe their experience or concerns with treatment or disease in an AI-enabled chat. Resources have been in advance together with medical professionals to cover many of the recurrent areas of concern from patients. This way, the patients can get knowledge based on the questions they type. Before the next consultation, the doctor can see a summary of the concerns they described.

Analysis method

The sessions provided a considerable amount of qualitative data that needed to be analysed progressively through a common process. The raw data consisted of transcripts from the audio recordings and pictures of the printed materials after the participants had interacted with them.

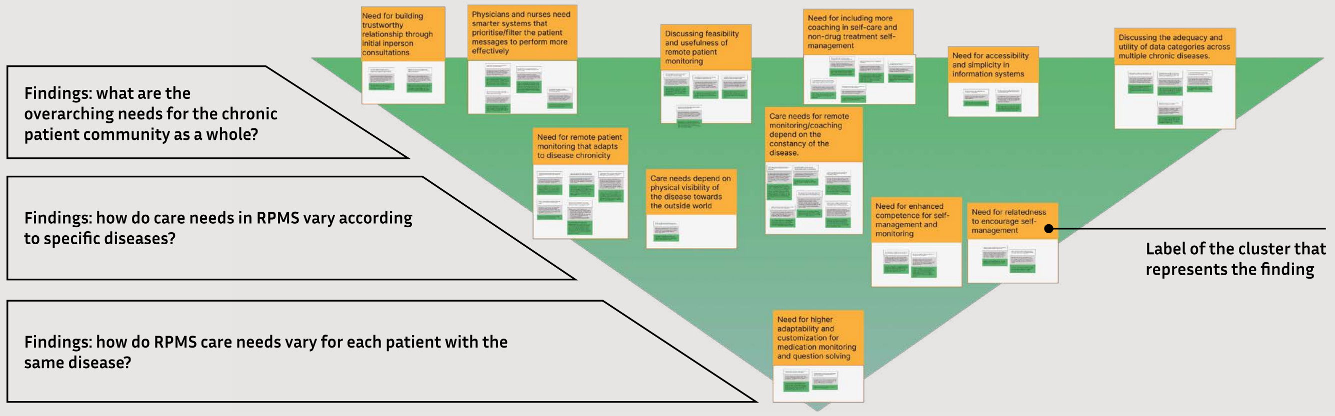
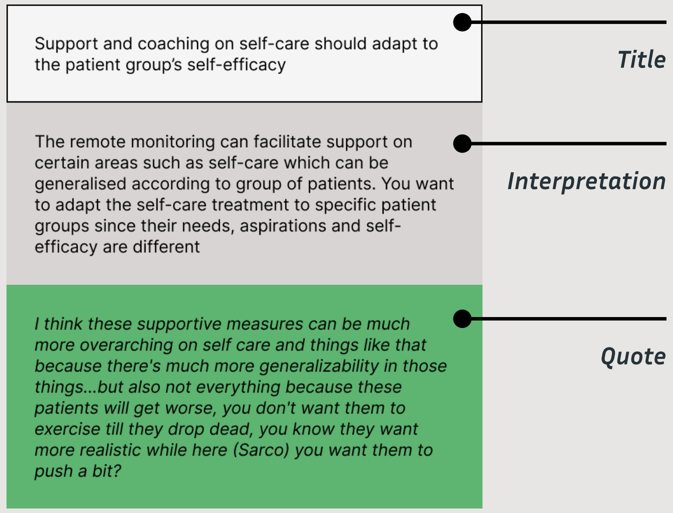


Figure 4.6: Clusters of statement cards mapped in the Iceberg chart.

The sessions were recorded using MS Teams to provide secure storage of the audio recordings and automatic transcripts in OneDrive, which only this master's thesis team had access to. The transcripts were reviewed to correct any notable errors or misinterpretations of the software and to anonymize the speakers. The notes and pictures of the printed materials were securely stored in OneDrive.

Following the Contextmapping method (Sanders & Stappers, 2012), statement cards were used to interpret the quotes from participants in a consistent manner. As shown in Figure 4.5, the statement cards consist of the selected quote, an interpretation of the quote and a title that summarises the insight. The statement cards were grouped in clusters, which represent an overarching finding: a need, challenge, or aspiration.

Later, these clusters were progressively added to an Iceberg-inspired chart as in Figure 4.5.



Support and coaching on self-care should adapt to the patient group's self-efficacy

The remote monitoring can facilitate support on certain areas such as self-care which can be generalised according to group of patients. You want to adapt the self-care treatment to specific patient groups since their needs, aspirations and self-efficacy are different

I think these supportive measures can be much more overarching on self care and things like that because there's much more generalizability in those things...but also not everything because these patients will get worse, you don't want them to exercise till they drop dead, you know they want more realistic while here (Sarco) you want them to push a bit?

Figure 4.5: Example of a statement card from the first co-creation session.

The top area of the Iceberg chart includes the care needs that the three patient communities share. The area in the middle represents how the care needs may change according to each specific disease. The lower area of this Iceberg explores how the care needs may change according to each patient. Through this chart, the findings relate to considering how the system adapts to various levels: the whole hospital, department/disease, and individual level.

Figure 4.6 only shows the results of the analysis of the co-creation sessions can be reviewed in Appendix F.

4.2 Incremental changes in the co-creation materials and definition of design challenge.

Due to the busy schedules of domain experts, it was necessary to progressively conduct co-creation sessions with one or two domain experts at once (Figure 4.1). This had the advantage that I could learn how to make incremental changes in the interactive materials and the semi-structured interview questions. Furthermore, I could progressively reframe the challenge that the design intervention should address based on the interpretations, motivations, and experiences that the clinical experts share through the co-creation sessions.

Changes after session 1

Changes in the interactive materials

> Quote: "Everything is done for a bit, but it's all done now in person...you would probably put it here (in-person consultation)...but I think we can move it...to there (remote consultation) and there all along the care pathway, right, these are nice to have (the group further from the centre) and this is what is done now (the group in the centre)."

Moreover, the clinician reported that data technologies should allow them to cover all these information areas, since the time in consultation with each patient is very limited (15 minutes), making it impossible to ask questions about all these data categories.

Since all the data categories seemed to some extent relevant for the health practitioner, the question pivoted to whether these data categories were essential or supplementary for other domain experts. The scale was changed accordingly to make it a more straightforward prioritisation. Additionally, the new version of the prioritisation map includes a parking spot where the domain experts can place any data categories that is not relevant for their practice.

Evolution of design challenge

After the first session with the pulmonologist, statement cards were elaborated using the most relevant quotes from the transcript. Having them clustered and distributed around the Iceberg chart (Figure 4.6), I could identify some preliminary findings. Some of these preliminary findings were combined to formulate the design challenge.

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co-design of modules of a remote therapy service system which provides an adequate learning environment for patients with chronic conditions and efficient collection of relevant patient experience data for shared decision-making during the follow-up stage.

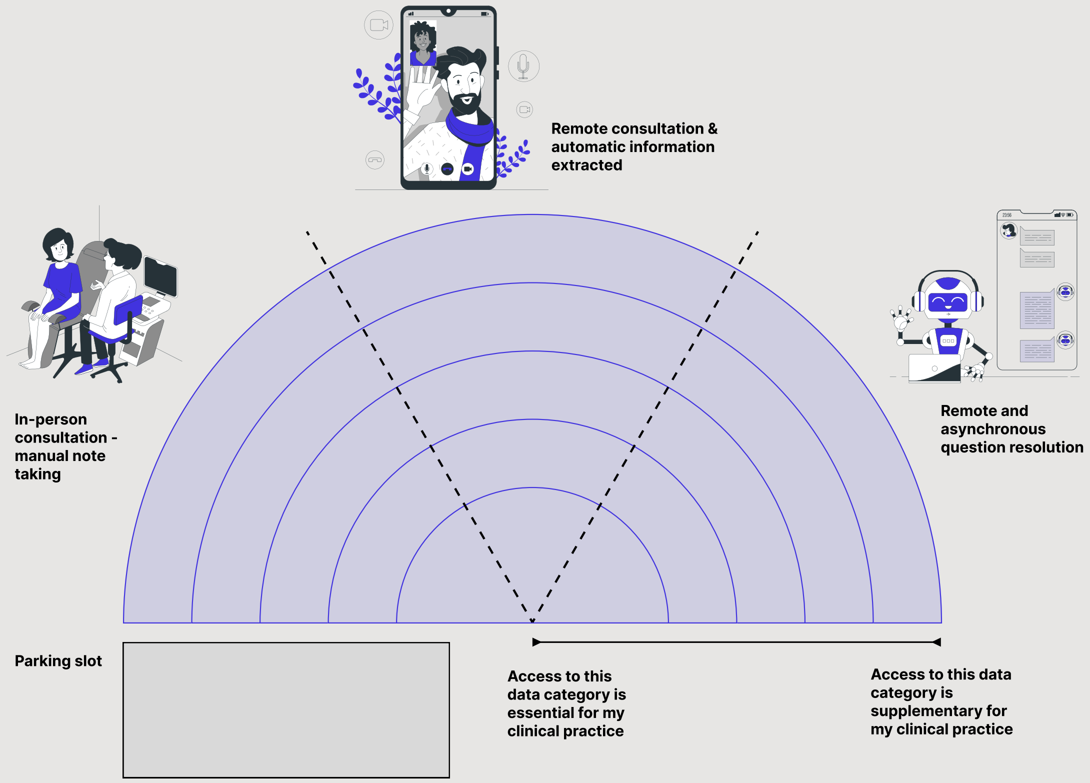


Figure 4.7: Second version of the prioritisation map. Illustrations created based on templates from Storyset by Freepik.

co-design of...

modules of a remote therapy service system...

Findings: clusters of statement cards	*Quotes from the pulmonologist*
Need for adaptability and customization on medication monitoring and question solving	"For instance, because the medications are so specific, you need to anyways make those specific you know...for each disease, the information and everything needs to be specific anyway, otherwise it's not used."
When designing RPM platform for a broad range of diseases, there are 3 parameters that may influence the care needs : 1. Chronic vs acute. 2. Degenerative vs constant. 3. Not so visible vs Highly visible.	"Yeah, I think you just have to differentiate in between patients that have a chance to be completely cured because they will one day not be chronic anymore....Then you'll have the ones that are chronic, but in a sort of stable way with some bumps and things...But will not die from them...And then you have the chronic patients that will die of the disease and know that so that they will get worse and worse and worse...That's a difference, in the end, they have different care needs." "I can imagine that having a stoma has a sort of similar impact as having oxygen...It's something that feels embarrassing...People can see that you have disease, it makes it visible to the world."

which provides...

an adequate learning environment for patients of chronic conditions...

Physicians aspire to expand their coaching in self-care and non-drug treatment self-management	"No, actually especially we want we want to give more non-pharmacological support. So we want to extend...for both, we want to do that..."
System should enhance competence for self-management and monitoring according to disease	"I think also the age difference in my field, the elderly populations are less busy with self-management and empowerment...Maybe you want to look into the literature about patient activation...And the patient activation on self-management is even lower in pulmonary fibrosis than in Sarcoidosis"

efficient collection of relevant patient experience data for shared decision-making during the follow-up stage....

Physicians and nurses need smarter systems that prioritise/filter the patient messages to perform more effectively	"Nurse practitioners...Yeah, very much...I have 5, so our team is strongly related, but now it's phone calls and emails, it can be professionalized."
Physicians need timely information that they can use to justify treatment decisions	"Yeah, but the disease monitoring is directly related to treatment. Because otherwise, why do we monitor?"

Figure 4.8: Description of the first version of the design challenge.

Changes after session 2

Changes in the interactive materials

In the second session, which involved an oncological surgeon, it was discussed that due to the nature of the patient experience data, the data categories could have some significant overlaps. This posed the question of to what extent the visualization of the data categories accurately represents these interconnections and overlaps between categories.

Therefore, in the following sessions, an activity was introduced to transition from using the interactive prototype to the prioritisation map. The objective of this transition activity was to inquire the domain experts about how they would rearrange the data categories, having navigated through the prototype to understand the content of each category. Printed cards of the categories were presented to the participants in a column, in the same order as in the digital prototype. Then, the experts were asked to make any changes in the order of the categories to represent the relationships they could see between the categories. The digital prototype with the visualization was kept near the participants so they could consult again the topics grouped within each category. Figure 4.9 shows the results of this activity in session 3.

Figure 4.9: Printed cards of the data categories to discuss overlaps.

Changes after sessions 3 & 4

Changes in the interactive materials

Sessions 3 and 4 were conducted on the same day, so all the changes had to be applied after those consecutive sessions. These sessions led to more changes in the data categorisation and visualization based on the insights gathered until this point. The intention was to use the upcoming sessions to review whether the changes applied were in the right direction or not. We can distinguish mainly among changes in the wording of specific categories, changes in the topic classification, and changes in the data visualization.

Changes in the wording of categories

In all the sessions conducted so far, the clinicians expressed doubts about the meaning of the category of "non-conventional treatment". Then, it was decided to change the wording of that data category to "alternative treatment". This new label for the category was proposed by the participants themselves:

> "So with non-conventional treatment, is that an alternative medicine?... I think I would mention it, call it like alternative because non-conventional is maybe...new technology".

Furthermore, the clinician in session 4 pointed out that the categories seemed too centred on pharmacological treatment since we split treatment categories between drug and non-drug treatment. The clinician suggested rephrasing the category "non-drug treatment" as "interventional treatment", since this way it could group radiotherapy and surgery. Consequently, the category" drug treatment" was rephrased as "pharmacological treatment" to make it easier to distinguish.

Some clinical experts had a different interpretation of what self-care entails. Due to this unexpected interpretation, the category "self-care changes" was relabelled as "lifestyle adaptations" to make it more specific and connect better to the topics clustered within that category. The clinical experts in sessions 3 and 4 had respectively mentioned:

> "Self-care is obviously like washing yourself and stuff like that. Physical activity is one step above that."
>
> "Self-care is really, can you take care of yourself? So can you wash yourself yeah, that kind of stuff. Can you still walk to the supermarket or that kind of stuff"

The clinical researcher in session 4 highlighted that the categories seemed to reflect changes in life rather than lifestyle. Therefore, the wording of this domain was changed to include all kinds of changes in the patients' lives, beyond the behaviour or habit changes. The clinical researcher commented:

> "I think if I would not say lifestyle, I would say impact of the disease on life. Because lifestyle is more related to behaviour. And life is more than behaviour. It's because... the first category here is career and financial changes. That's just a part of life and not perceived lifestyle".

Furthermore, the clinician in session 4 suggested looking at the WHOQOL questionnaire to assess the wording of the presented data categories. This way, the categories would be more likely accepted by a wider range of clinicians. After some review of the development of the WHOQOL-100 (The World Health Organization Quality of Life (WHOQOL), 2012), it was decided to use as a reference the domains and facets that also the WHOQOL-100 suggest. Based on these domains and facets, the category "Career and financial changes" was reformulated as "Work capacity and personal finances". The category "Socialization and relationships" was changed to "Social relationships".

Changes in the topic classification

One early finding was that patient experience data about diagnosis and monitoring of the condition should not be grouped, this was also supported by the participants in sessions 1 and 2. Initially, this experience data was grouped because of the lack of contextual cues to confirm that the patients were specifically talking about the diagnosis or monitoring processes. However, if we were to use these categories for collecting and clustering patient experience data in a future RPM service system, according to the experts' interpretation these categories should be separate.

> "Diagnosis is a different item in my view that is you know the diagnosis at some time is just ticked, done. But the monitoring is very much interrelated with treatments. So, I would probably split diagnosis and monitoring."

Consequently, I reviewed the topics from the categories of Diagnosis and monitoring and Causes of the disease and related conditions. Then, I regrouped them into three new categories: diagnosis and nature of the disease, causes of the disease and related conditions, and monitoring and medical opinion:

- The category diagnosis and nature of the disease groups the topics that address the discovery of the disease, the complexity of being diagnosed (especially in the case of Sarcoidosis) and understanding the nature of the condition right after being diagnosed. For instance, this new category includes the topic from Sarcoidosis about "Describing the complex and confusing diagnosis of Sarcoidosis, doubting on how to demonstrate Sarcoidosis" and the topic from PF about "Talking about the unclear origins of IPF and elusive nature of disease".
- The category causes of the disease and related conditions involves the discussions about seemingly related conditions and affections, and debates on the possible triggers of the disease. For instance, the topic from PF about "Debating on Agent Orange (chemical herbicide used in US military) being a direct cause for PF in US military veterans" and the topic labelled "Understanding what causes the symptoms of Sarcoidosis, and detection of other health conditions that affect general health". We can perceive some overlap between the previous category and this one, since while debating on the causes of the condition, patients also discuss their experiences around the nature of the condition.
- The new category of monitoring and medical opinion includes worries and doubts about the tests and scans for monitoring the progression or reoccurrence of the disease (in the case of CRC) and the physicians' recommendations concerning the test results. The online stories may involve doubts about the test procedures and the necessity of undergoing that test. For instance, the topic labelled "Asking for second opinions and experiences on lung biopsy. Expressing concerns and doubts about the need for biopsy". The topics in this category may also regard asking for opinions from the patient community on the test results and the medical professionals' recommendations regarding those results. An example is the topic labelled "Being worried and confused about scan results in the liver, lungs, and lymph".

Furthermore, the category of "Treatment consequences on daily life" seemed to slightly overlap with the categories of "Symptoms/side effects management" and "Self-care changes", according to the clinical experts. Since the former category groups very few topics, it was decided to distribute those topics among the two latter categories. For instance, the topic from PF labelled as "Taking a shower with oxygen device is difficult; Coping strategy: using a cannula and long oxygen tubes in the shower" was included within the category "Self-care changes". On the other hand, the topic from CRC about "Discussing and sharing tips on how to take care of stoma and avoid infections" was grouped under the category of "Symptoms/side effects management".

Finally, based on the interpretation by the clinical researcher and previous notes from session 2 and 3 (Figure 4.11), the category "Symptoms/side effects management" moved to the domain of the impact of the disease on life.

Changes in data visualisation and arrangement of categories

To explore further the graphic identity in the data visualisation, the graphic elements in the interactive prototype went through some modifications. The Marimekko style of the graph was adapted to a scale with bubbles to better show the overlaps between categories (Figure 4.10). Link to prototype.

For this visualization, the order of the categories suffered some changes according to the comments from the clinical experts. A couple of experts commented on the overlap between the domain of "Understanding the disease" and the domain of "Treatment-related experiences". For that reason, it was decided that those domains should appear next to each other.

The clinical researcher from session 3 mentioned:

> "I think there is a part where treatment is always very important. So getting the right information on your diagnosis and a clear treatment plan".

Nevertheless, there was also mentioned an overlap between "Treatment-related experiences" and "Impact of the disease on life". Participant in session 1 reported:

> "So the borders between self-care and nonpharmacological are probably pretty overlapping...I don't think it really matters, but just to realize it."

With this statement, the clinician means that the experiences with doing daily breathing exercises could be classified either in self-care changes or in non-pharmacological treatment. Therefore, treatment and lifestyle adaptations for self-care are not a black-or-white matter.

Furthermore, the domain of emotional support should appear connected to the impact of the disease on life. The semantic matching already pointed out this connection since it seemed hard for the algorithm to distinguish between topics in the categories "Attitude towards the disease" and "Emotional support" (see passage Lack of differentiated matches with more visceral and self-reflective topics in section 3.3). Parallelly, both clinicians seem satisfied with the idea of having the emotional support category connected with the categories in the domain of "Impact of disease on life", as you can see in the following results from the activity about rearranging the data category cards.

Evolution of design challenge

After the fourth session, the most relevant findings took the form of requirements. This way, I could describe a new version of the design challenge through a list of requirements based on the insights from the co-creation sessions. The theoretical

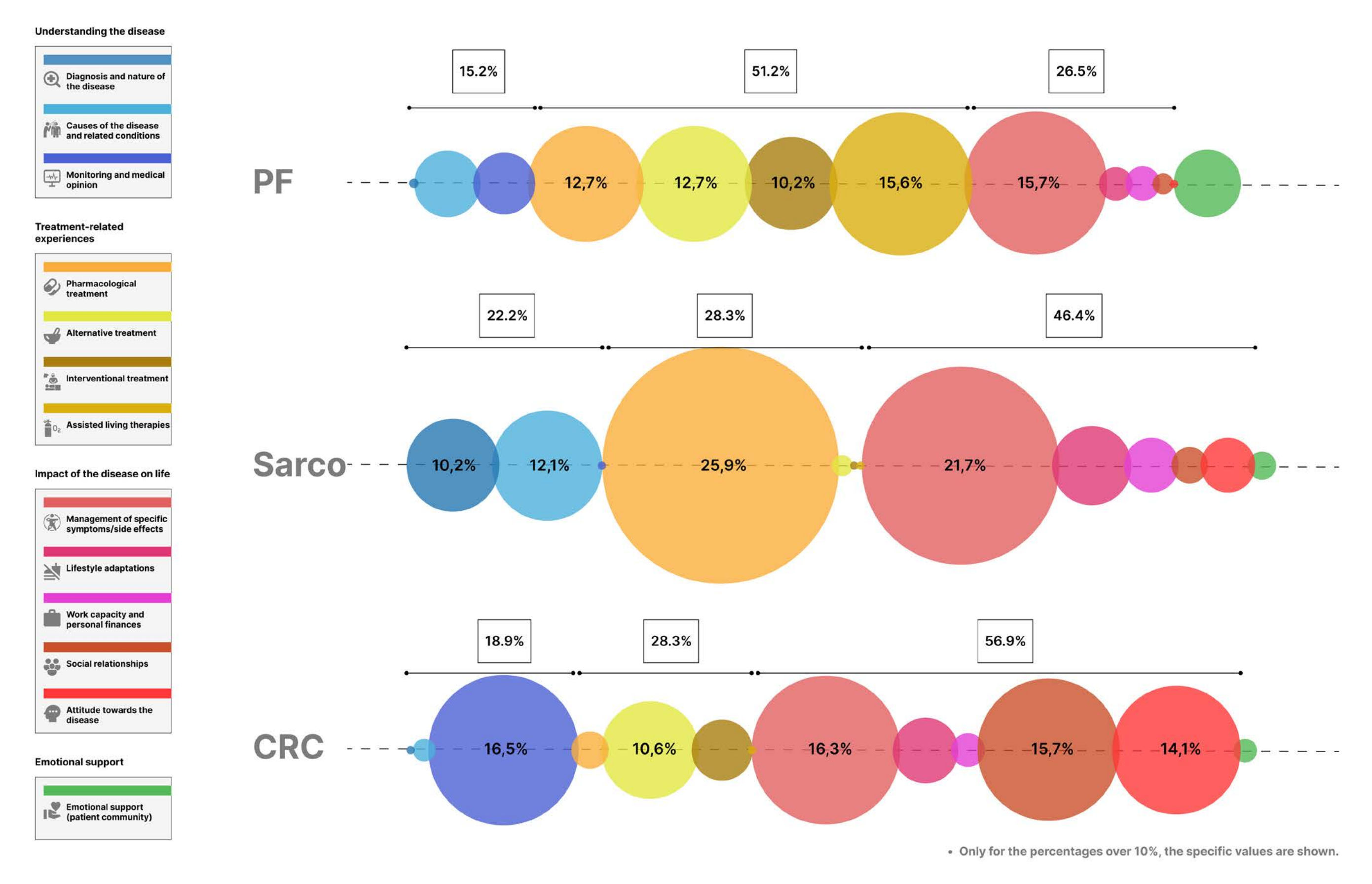
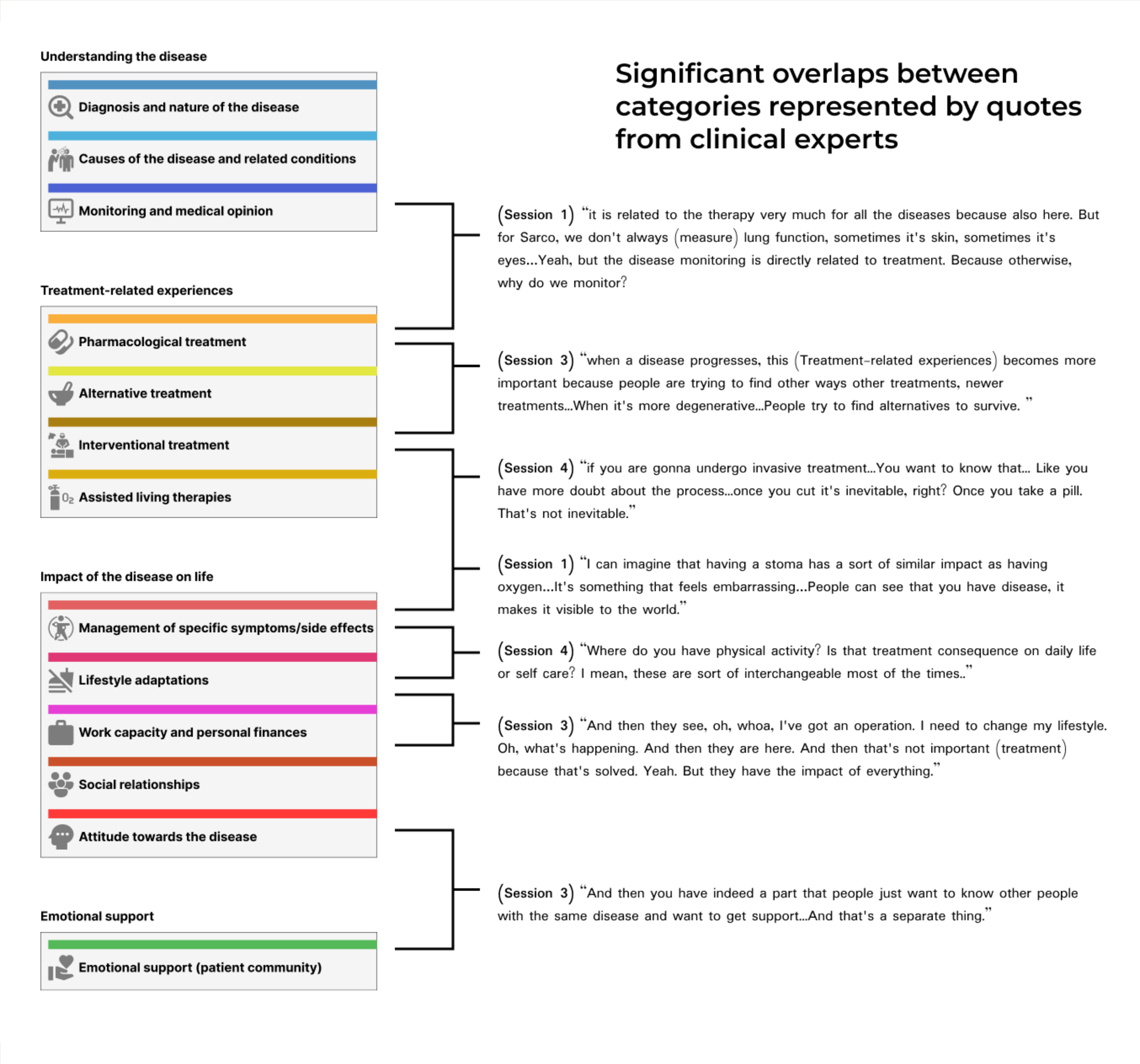


Figure 4.10: Interactive prototype 2 for visualization of the data categories.



Significant overlaps between categories represented by quotes from clinical experts

(**Session 1**) “it is related to the therapy very much for all the diseases because also here. But for Sarco, we don't always (measure) lung function, sometimes it's skin, sometimes it's eyes...Yeah, but the disease monitoring is directly related to treatment. Because otherwise, why do we monitor?

(**Session 3**) “when a disease progresses, this (Treatment-related experiences) becomes more important because people are trying to find other ways other treatments, newer treatments...When it's more degenerative...People try to find alternatives to survive. ”

(**Session 4**) “if you are gonna undergo invasive treatment...You want to know that... Like you have more doubt about the process...once you cut it's inevitable, right? Once you take a pill. That's not inevitable.”

(**Session 1**) “I can imagine that having a stoma has a sort of similar impact as having oxygen...It's something that feels embarrassing...People can see that you have disease, it makes it visible to the world.”

(**Session 4**) “Where do you have physical activity? Is that treatment consequence on daily life or self care? I mean, these are sort of interchangeable most of the times..”

(**Session 3**) “And then they see, oh, whoa, I've got an operation. I need to change my lifestyle. Oh, what's happening. And then they are here. And then that's not important (treatment) because that's solved. Yeah. But they have the impact of everything.”

(**Session 3**) “And then you have indeed a part that people just want to know other people with the same disease and want to get support...And that's a separate thing.”

Figure 4.11: Noticeable overlaps between categories that justify their order in the data visualisation.

framework (Chapter 2) partially informed the formulation of these requirements, as can be seen in the incorporation of some concepts from the reviewed literature like "muddle through" (Norman & Stappers, 2015). This concept represents my interest in developing a service system that incrementally adapts to different departments that treat relatively chronic conditions.

to create service vision and modules for a remote monitoring service system that holistically informs about treatment-related QoL, which can be incrementally incorporated in clinicians' workflows.

The following page expands on the definition of the design challenge at this point, through the formulation of pilot requirements.

Service should be adequate to the clinicians' motivations and needs.

Requirements | **Explanatory question**

1. Service modules should provide actionable information to justify clinical decision making in relation to the stage of disease (years after diagnosis).

How do the service modules muddle through to make patient experience data more accessible in everyday clinical practice?

Representative quote

(Session 2) “You will probably find that in the first five years they have this 10 or 20 percent in the blue area that they're seeking actual information about their disease...And then at the hospital, you could provide them with patient tailored information about thyroid disease, their cancer, what causes it... And then it would be really great if you see that in over the next five years after the implementation of that, you see that the blue box becomes smaller.”

2. The service modules should adapt to:
   - how progressive/degenerative or constant/static the chronic disease is.
   - the perceived QoL in relation to their peers.
   - the nature of the treatment plan (timely/interventional or dosaged/gradual).

How do the service modules muddle through to make patient experience data more accessible in everyday clinical practice?

(Session 3) “This is very logical for me, because I think, well, there's surgery, and for most patients it ends there. But that's just in the beginning...And then they see, oh, I've got an operation, I need to change my lifestyle...And then they are here (cluster: Impact of the disease on lifestyle). And then that's not important because that's solved.”

3. The data retrieved from the service modules should be quickly accessible and interoperable between different medicine specialists.

How do the service modules muddle through depending on the doctors' reporting styles and their area of expertise?

(Session 2) “So you want it sort of easily visualized that you can immediately see these are the problems and what you could also envision is that we put much more specialist nurses on this...”

Requirements for data collection

1. The service modules should be flexible to the patients' self-activation and feeling of competence

(Session 2) “I'm in favour of the patient platforms, but they have to be designed in a way that all the patients are inclined to respond. And not only the patients that are worried or that want to complain.”

2. The service modules should remain flexible to diverse patients' coping styles

(Session 4) “there are people who say: I don't want to know anything about it. Just fix me...(and) there are patients who just say yeah, I want to know everything about the details.”

Figure 4.12: Description of the second version of the design challenge.

Changes after session 5

Changes in the interactive prototype.

> “you can inform patients because we can give them a booklet like this all the beginning. So, at the start of the patient journey and okay, somewhere you’ll, you’ll come around issues and they’re all in this book. Yeah. Patients are overwhelmed and never going to read the book.”

In this session, the clinicians remarked on the importance of identifying what type of information is more relevant for the patient at each stage of the patient journey. Based on the literature, we can understand that clinicians require timely information about the condition and quality of life of the patient to make justified decisions about the prescribed treatment (Sharma et al., 2022). By identifying at what stage each piece of information is more relevant, communications among clinicians and patients can be more efficient and ultimately allow all patients to feel equally heard.

→ **This session highlighted the clinicians' need to provide the patient with timely, efficient educational information and coaching.**

Based on this insight, another version of the interactive prototype was created to substitute the prioritisation map in the discussion of the next steps of the exploration for design intervention (Figure 4.7).

This second interactive prototype includes a community level and an individual level.

- The community level includes a speculative evolution of patients' concerns and doubts throughout the years after diagnosis on a community level (Figure 4.13). This way, the clinicians can oversee how the need for information support changes over time and they can adapt the education and coaching of patients accordingly. This evolution is not based on real data. The style of the visualization goes back to the Marimekko graphs to provide a neater disposition of the emerging windows that show the topics within each category. However, this Marimekko graph has a slight gradient that unites all the categories to symbolize the overlaps between them.
- The individual level shown in Figure 4.14 represents the self-monitoring of each patient individually. The dashboard displays clinical data such as the forced expiratory volume (a measurement of lung capacity used to measure the progression of pulmonary fibrosis) together with individual takeaways from the patients self-reporting their progress and doubts. The individual takeaways represent patient experience data summarised by natural language processing (NLP) technology, which is hypothesized to contextualise the biodata of the force expiratory volume. The team of nurse practitioners or the specialist doctor can then review these takeaways for specific timeframes. The takeaways can then be prioritised to be addressed in the coming consultation or check-up.

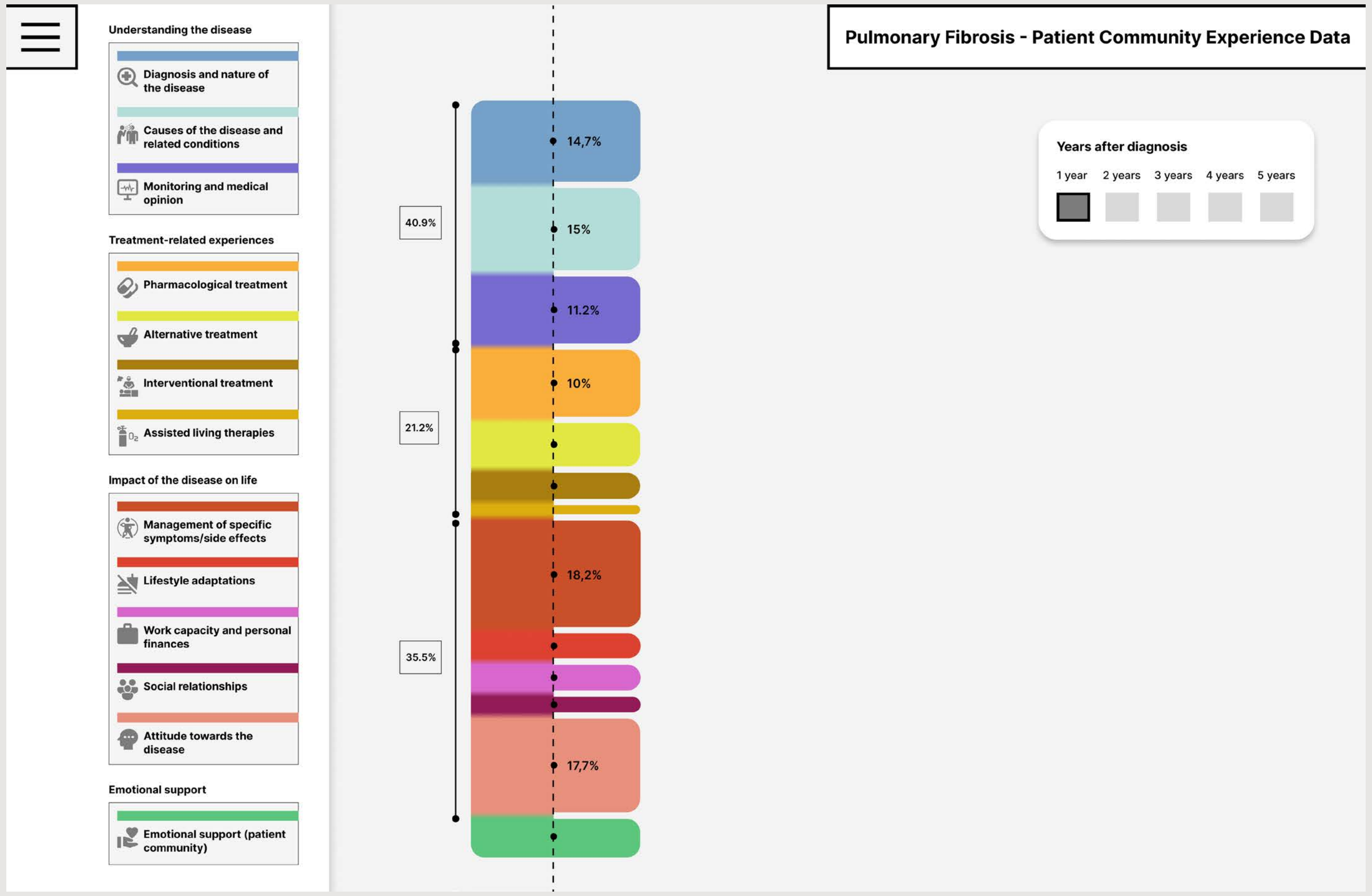
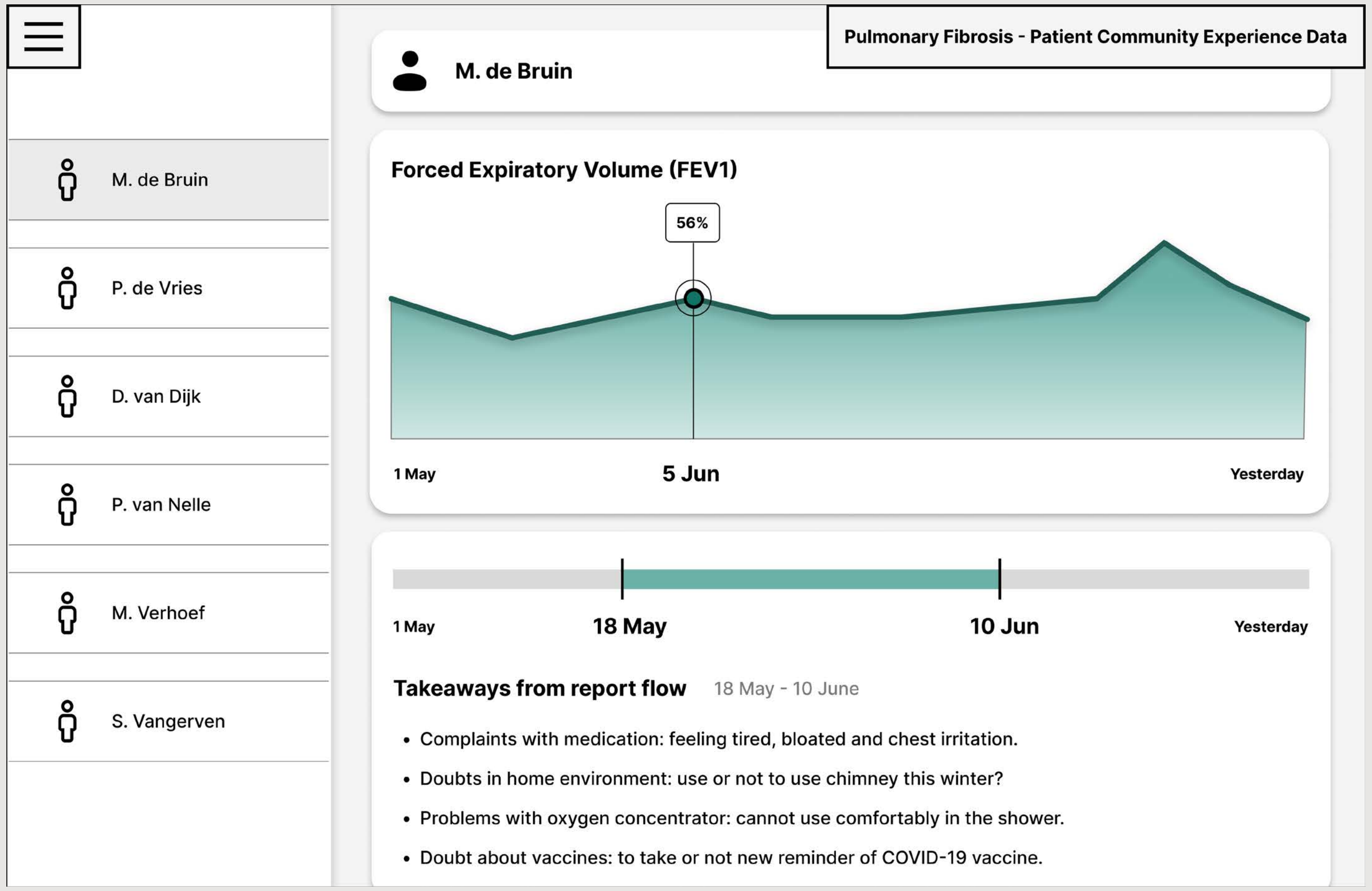


Figure 4.13: Interactive prototype 3 – community level evolution of concerns and needs.



Takeaways from report flow 18 May - 10 June

- Complaints with medication: feeling tired, bloated and chest irritation.
- Doubts in home environment: use or not to use chimney this winter?
- Problems with oxygen concentrator: cannot use comfortably in the shower.
- Doubt about vaccines: to take or not new reminder of COVID-19 vaccine.

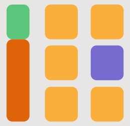
Figure 4.14: Interactive prototype 3 – individual level.

4.3 Outcomes

A set of guiding principles.

After the sixth session and having reviewed literature on value-based care (Porter, 2009), I sought to represent the design challenge through a set of experience principles. These principles consist of key values about how I intend to support care delivery processes and enhance the experience of care for patients and medical professionals. Moreover, these key values should inform the development of a service concept through service blueprint (Chapter 6). Having created the clusters of statement cards (Appendix F), it was possible to connect them to ideate on this set of principles for value creation.

Foster *self-reliance and shared perspectives* of the patient community.



Facilitate *incremental* adaptations of knowledge modules to the patients.

Enhance *dynamic guidance* and clinician-patient knowledge exchange.

Support the *diverse* coping styles and self-confidence levels of the patients.

The identified principles are aimed at guiding the service concept development (Chapter 6) along with the service vision. Each principle includes two opportunities to support value creation and two limitations that problematize the development and measurement of value. The principles represent a value proposition for the RPM service system inferred from the co-creation sessions with domain experts. Using these as design guidelines, we can ensure that the service blueprint and interfaces described in Chapter 6 match the expectations and collective needs of healthcare professionals and the patient community.

The service vision and modules should...

1. Foster self-reliance and shared perspectives of the patient community.

Figure 4.15: Abstract representation of the first experience principle.

Opportunities

Support patient community capacity building.

This could be supported through interventions for community capacity building and coaching among patients. Community capacity building consists of engaging a community to solve or deal with a problem together (Heaney & Israel, 2008). Some session participants described their interest in how digital interactions, whether they are automated or semiautomated, afford patients to coach each other over the care path. As one participant highlighted, to motivate adherence to self-care or self-monitoring activities is necessary to receive coaching. In this matter, the patient community can encourage each other through affordances in the digital platform.

> "This could be a way that they know that other patients are using this forum. And this is the things that other patients are finding important. So that could be also a signal to them, like, maybe I should have a look at it as well."

Support patients' empowerment and advocacy.

Another opportunity in the longer term is to support patients' empowerment and advocacy. The RPM service system should ultimately uplift the voices of patient communities to demand more innovations towards RPM. This opportunity relies on the condition that RPM can enable patients to feel more independent and more quickly integrated back into their daily lives after the curative treatments.

> "That would be great if we could make it that easy or make it so popular or inform the patient so well that the patient is saying, why do I have to come to the hospital every three months? That's what we call empowering, but it's, it's actually the next step."

Limitations

Need for building trustworthy patient-clinician relationship.

Nevertheless, the patient community's self-reliance and shared perspectives are limited by the need for a trustworthy patient-clinician relationship. Until they feel that they can rely on the humans behind the system to take care of their situation, patients might not be willing to engage in RPM systems. For some patients, this may take longer than for others.

> "But the problem is that we've noticed in the clinic that patients are not willing to go online if they have not met you once or twice and if they don't see you like at low frequency because then they don't trust the system. They only start to trust the system if they know that there is someone trustworthy behind it..."

Patents with more positive prognosis dominate the conversation.

The patient community's shared perspectives also count with the bias that patients with a more positive disease course may dominate the conversation. On the other hand, patients with very negative prognoses, who directly get prescribed palliative treatments since their survival is low, may not engage in the system for very long. Therefore, their views will be under-represented. The expectation is that this limitation would be more noteworthy in diseases with very distinct patient groups like in oncology, where some have positive results after curative treatments, and others are deemed incurable after cancer staging.

> "Many patients die rapidly. They die so fast that they don't even go online to be informed about this. So, it's probably more the patients with a more indolent disease course."

2. Facilitate incremental adaptations of knowledge modules to the patients.

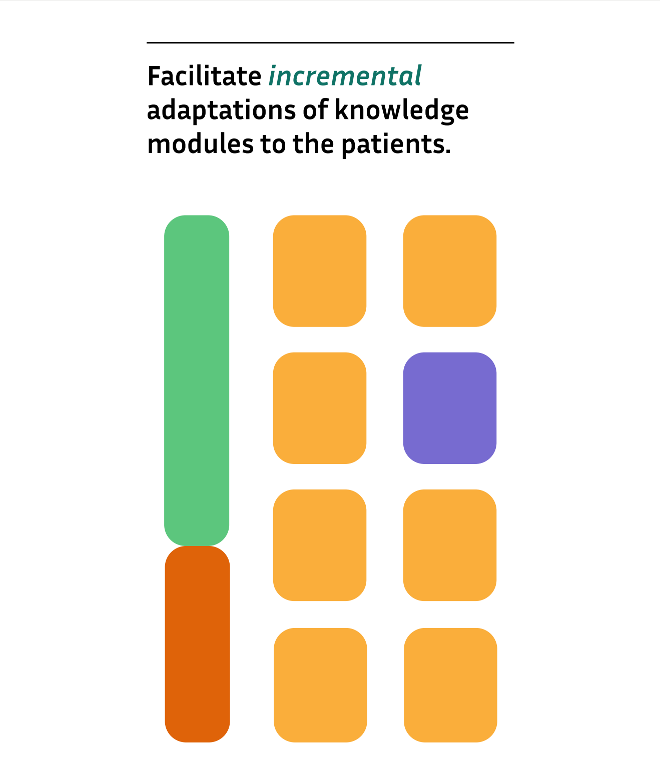


Figure 4.16: Abstract representation of the second experience principle.

Opportunities

Support patient experience data exchange between department or comparable diseases (chronic/progressive/treatable disease).

Another principle for value creation is to create knowledge modules which can be incrementally adapted to each disease. If the anonymised patient data is exported and visualized in uniform formats, patients' needs, and delivery processes can be compared between the specialists that curate the content for each disease. For instance, between pancreatic cancer and colorectal cancer nurse practitioners. This brings the opportunity to reuse coaching content within disease groups (oncology/interstitial lung diseases/rheumatic diseases) or repurpose it by slightly adapting it.

> "...but I think you can categorize diseases as chronic ones. So, I think sarcoidosis will have things in common with let's say diabetes or COPD, things like that, Rheumatic diseases..."

Develop modular support services that can be incrementally implemented.

An RPM service system should also be created in modularity to afford incremental adaptations to each treatment plan. Therefore, a common modular architecture can allow clinicians or nurse practitioners to easily introduce some specifications to tailor the communications to each patient.

> "Because the medications are so specific, you need to anyways make those specific you know, and so you need an overarching module on pharmacological treatments...But for each disease, the information and everything need to be specific anyway, otherwise, it's not used."

Limitations

Distinctive patient groups within one patient community

A challenge is that the patient's needs for coaching and information support may depend on how the disease is behaving and consequently in which patient group within the patient these patients are. For instance, the prescribed treatment for cancer patients heavily relies on the staging and has several patient groups with very different prognoses.

> "But it depends on the stage. So, it all depends on the timeline and your patient journey. Because patients in unresectable stage 4 disease will have I assume the same questions as in PF because they're not going to cure it anymore."

Significant variations in perceived QoL within the same patient community.

Another limitation is that each patient's perceived quality of life also influences their concerns and coaching needs. This parameter is very personal and depends on the patient's context and the peers that they compare with. This complicates the use of the needs and concerns of one community of patients to inform another patient community.

> "Anyways, patients of Sarco, many are very preoccupied with the disease because they're young, it has a major impact on their life at that moment. And these patients have a deadly disease, so they want to live as long and as well as possible...but that's another mindset."

3. Enhance dynamic guidance and clinician-patient knowledge exchange.

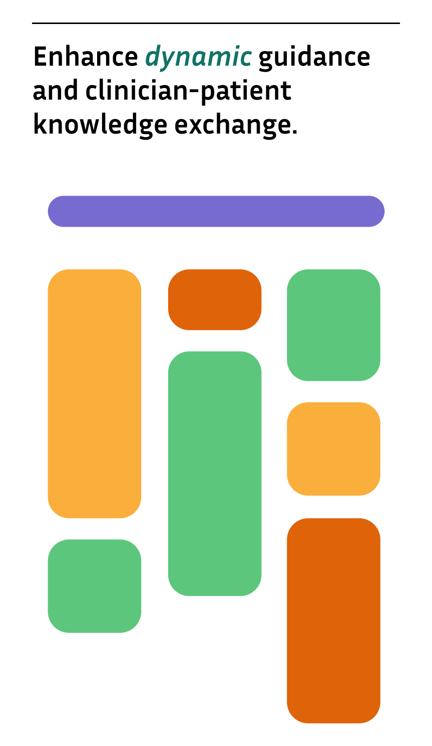


Figure 4.17: Abstract representation of the third experience principle.

The clinical experts reported about the struggle in effectively supporting the knowledge needs of the patients due to the short time they have for each patient and the difficulty of knowing when each information item is needed the most. They also highlighted the importance of tracking and attending to the patient's needs according to the stage of the care journey. Otherwise, providing knowledge to the patient community is inefficient and cumbersome for the clinicians.

Opportunities

Support clinicians' self-improvement in their role as communicators and coaches.

Through data technologies, clinicians could identify information gaps and improve their support to patients.

> "So on the one hand, if you would do this the same for pancreatic cancer, I think it's not unlikely that <name> and I and our colleagues may change the way we communicate with our patients because we learn from that. And on the other hand, it can be kind of as a standalone information repository for patients."

Support clinicians in providing knowledge to patients when it is needed the most.

Moreover, the system can provide patients with timely knowledge along the care path. Since it can be difficult for clinicians alone to identify what information is more relevant at which moment, data-enabled systems can assist the doctor's decision-making and offer specific support when it is needed the most.

> "And I think if we can cluster these topics, depending on where you are in your patient journey, then we're really getting somewhere because you can give you specific information and support where it's needed, but just prior to when we know it's going to be needed."

Facilitate reliable and efficient knowledge resources to patients.

A third opportunity would be to facilitate reliable and efficient knowledge resources for patients. Through a combination of service and content design, clinicians can refer patients to specific knowledge resources where they can delve into a topic that was discussed in the last remote or in-hospital consultation.

> "The hospital can direct patients to the right information and tools to the right platform, there's something to win for the hospital because if patients go to the wrong websites or whatever, then you get even more questions for your patients. So, it's important to direct them, to guide them."

Limitations

Categorising patient experience data is not a black and white issue.

The open-ended and diffuse nature of patient experience data makes it difficult to accurately put each comment in one category. In the same comment, patients may talk about the need for emotional support and coping mechanisms for side effects. For that reason, the categories are only an indication of tendency, but not proof of behaviour.

> "If for example, people are trying to support each other about well, if you drink enough water, you will feel better... How do you, for the computer, decide if that would be a side effect management support or a communal support in the green?"

Support the diverse coping styles and self-confidence levels of the patients.

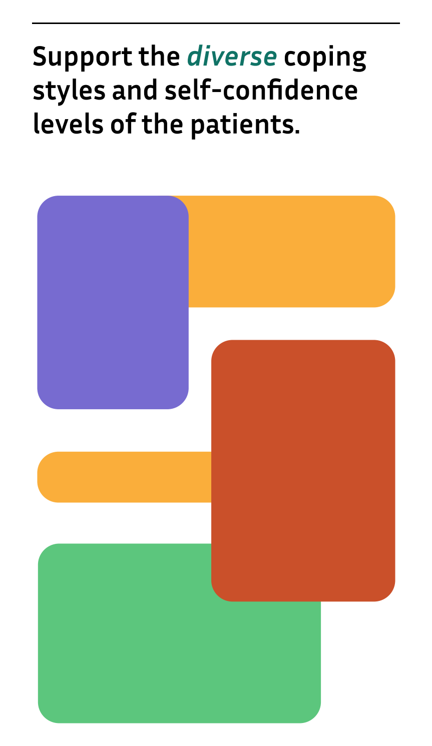


Figure 4.18: Abstract representation of the fourth experience principle.

This principle represents the collective need towards higher personalization in the support system. However, too much personalization is too costly and energy-intensive. Therefore, the opportunities address how to foster personalization on a patient community level.

Opportunities

Facilitate different levels of patient participation.

By including different ways of giving their opinion on the digital platform, the system becomes more convenient for patients with various levels of motivation.

> "I'm in favour of the patient platforms, but they have to be designed in a way that all the patients are inclined to respond. And not only the worried patients or Yeah. That want to complain."

Sustain different coaching styles (Glanz & Schwartz, 2008).

Since patients may demand less or more information depending on factors like educational level, age or social support. The system should allow this accessibility to several depths of topics.

> "So those patients are more of the generation where the doctor tells you what to do. You don't do so much yourself until the doctor tells you. The Sarcoidosis (patients) are younger and more empowered...They look more on the Internet."

Limitations

Adapting to different educational background and information preferences

These opportunities are two-fold since adapting to different educational backgrounds and over-informing the patient community is challenging. More educated patients may feel more competent to voice their opinions and demand shared decision-making, whereas less educated patients may feel that they just want a professional opinion to follow. Similarly, if the knowledge provision does not respect personal preferences and patients do not feel under control, the undesired information may lead to stress and negative feelings.

> "if all of these options have advantages and benefits and it's not obvious which one is the best one and so personal preference is very important. If you explain this to maybe to you, you would say, well, for me, B is better, but most patients would say, what do you recommend?"

Overall, the co-creation sessions with clinical experts represented a very inspiring data collection activity, which immediately stimulated the development of a vision. The next section elaborates on a service-system vision around social support and knowledge provision in the era of data technologies influencing design and innovation activities on a community or society level (Jung et al., 2022).

Pilot service-system vision.

The service-system vision (Figure 4.19) aims to encapsulate the learnings from this stage into an ideation activity, which can complement the set of principles to inform service conceptualisation (Chapter 6). Therefore, it does not represent the final service concept, but rather a step in between analysis of the generative user research and design conceptualization. This vision is situated in a collective computing context, where data technologies are increasingly informing design within complex technological systems, such as healthcare (Jung et al., 2022).

Beyond the findings from the co-creation with domain experts, this vision takes inspiration from literature about social support (Chapter 2; Heaney & Israel, 2008). Having comprehensively analysed the online support groups, we can perceive that these communities mainly engage in informational, emotional and appraisal support. Due to the

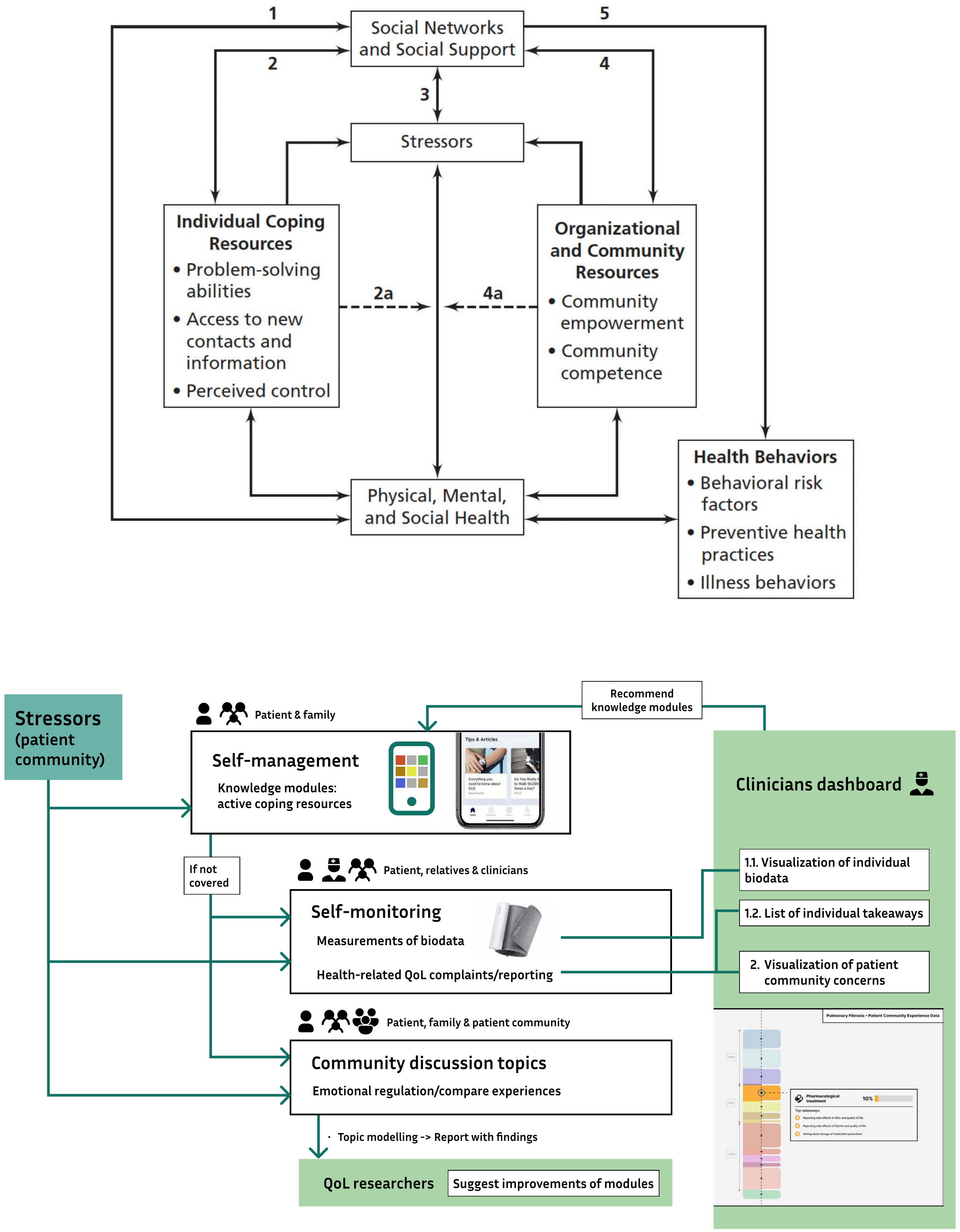


Figure 4.19: Comparison of the pilot service-system vision with the "Conceptual Model for the Relationship of Social Networks and Social Support to Health" (Heaney & Israel, 2008) which draws inspiration from.

intangible, online nature of the patient support groups, it is not surprising that instrumental support is less apparent. Nevertheless, online support platforms can also facilitate instrumental support. The following post serves as an example:

> Online patient story: I will be willing to give you some of my Mucinex if you are near <location>, <location>. I can easily spare a few of either <number> or <number> milligrams. Let me know. The Mucinex helps me so much that I will be glad to share it with you.

However, due to the prevalence of the other types of support and the online nature of RPM, we will include mainly informational and appraisal support as part of the scope of this service-system vision. Therefore, I posit that the service system within an RPM context should:

- Incorporate reliable information support resources curated and recommended by clinical experts. This relates to the experience principles of "Enhance dynamic guidance and clinician-patient knowledge exchange" and "Facilitate incremental adaptations of knowledge modules to the patients".
- Facilitate appraisal support in the community-level interactions to ensure that the RPM provides value to the patients, in exchange for them sharing their valuable experiences and monitoring their condition. This resonates with the principle of "Foster self-reliance and shared perspectives of the patient community".

Furthermore, emotional support should be probably transversal throughout the whole care path and be combined with appraisal support in some key moments in the care journey. As clinicians in session 5 pointed out in the post below, identifying these key moments where emotional support resources are more necessary or urgent for patients could be another relevant topic to investigate. However, targeting emotional support was too much for the time allocated for this master's thesis.

> "(Talking about the domain of emotional support) It is almost... Always related to one of the three subjects, I think (the three other overarching domains: understanding the disease, treatment-related experiences, and impact of the disease on life)...
>
> "No, but you would be interested when is the emotional support needed the highest..."

Considering the "Conceptual Model for the Relationship of Social Networks and Social Support to Health" (Chapter 2; Heaney & Israel, 2008), the service-system vision hypothesizes three data streams according to who is involved in the support/coping process. The stressful experiences (stressors) represent a starting point to ideate on the possible data streams that form the service system. Similarly to pathways 2 and 4 in the conceptual model, my service vision both individual and community resources complement each other to allow a person and their social network to manage stressful experiences in a way that buffers the short-term and long-term harmful effects on health and well-being.

Pathway 5 illustrates that the social network may influence the adoption and maintenance of health behaviours, such as adherence to a prescribed treatment regimen or giving up some habits for health reasons. This resonates with the principles of "Fostering patient community self-reliance and shared perspectives". It would be beneficial to incorporate affordances in the remote monitoring platforms that allow patients to coach each other in the treatment process and active coping strategies. Furthermore, highly educated or more activated patients can become indigenous natural helpers (Heaney & Israel, 2008) who are more involved in the emotional and appraisal support within a platform for community discussion.

The self-management flow is intended to serve as a foundation for the system, a reliable knowledge repository that can be incrementally adapted to specific diseases or disease groups. Whenever a concern is not covered in that knowledge repository, the patient community accesses the self-monitoring or community discussion flow. The self-monitoring represents a support line to receive aid from nurse practitioners or get scheduled for a consultation with a specialist. This stream also collects biodata periodically to inform clinical decisions. These self-reported concerns are progressively added to a community-level visualization. The biodata and extracted takeaways from the complaint/report flow may be visualized in the clinicians' dashboard so they can observe those doubts before each periodic consultation. Based on this information, clinicians can suggest timely knowledge modules.

On the other hand, the stream of community discussion topics focuses on emotional and appraisal support. Patients may need to share a frustration or compare experiences with others outside of the knowledge repository. The data from this stream can be periodically analysed through topic modelling to suggest content design improvements.

4.4 Conclusions

By defining a set-up and interactive prototype to engage domain experts in the interpretation of our findings and making incremental changes in the session set-up, I could on the one hand refine the data categories and identify four principles that respond to the research questions of this chapter.

1. *To what extent does our categorisation of the patient experience data match the mental models of domain experts (e.g., clinicians, nurses, clinical researchers...)?*

2. *How can the collection and visualization of patient experience data be more relevant and actionable?*

Regarding the first question, we could reach data categories that seem to align with the mental models of some experts. The data categories could be further improved and tested with other departments to achieve more acceptance. Nevertheless, the goal of this project was not to achieve definite categories, but a minimum viable product that could be improved in the future. The experts in sessions 5 and 6 were satisfied with the data categories and did not propose any other changes in terms of wording or categorisation of topics, even when asked whether they wanted to suggest changes. For instance, one clinician in session 5 mentioned:

> “I’m really happy with the categories. They make sense. Yeah. I think that the vision between, so the difference that we see in percentages of posts are explainable between the diseases. We’re not sure if we have the right explanation, but I think it is not something that dazzles me. So no, I’m quite happy. I think we’re really curious to see the next step.”

Concerning the second question, to allow more relevant monitoring of patient experiences and health-related quality of life, I posit that we should enhance the values expressed in the set of guiding principles. These values have been derived from the conversation of clinical experts. As the experts recruited are doctors, one nurse and one clinical researcher, most of them are also potential users of this service system. Furthermore, all the clinical experts interpreted the use of this type of data for information support to patients. This is not surprising due to the nature of the data; through their experiences, the patients inform each other in the online support groups. Parallelly, the clinicians have an important role as communicators and guides throughout the care path and the PX data could allow them to reason what information could be more useful to patients.

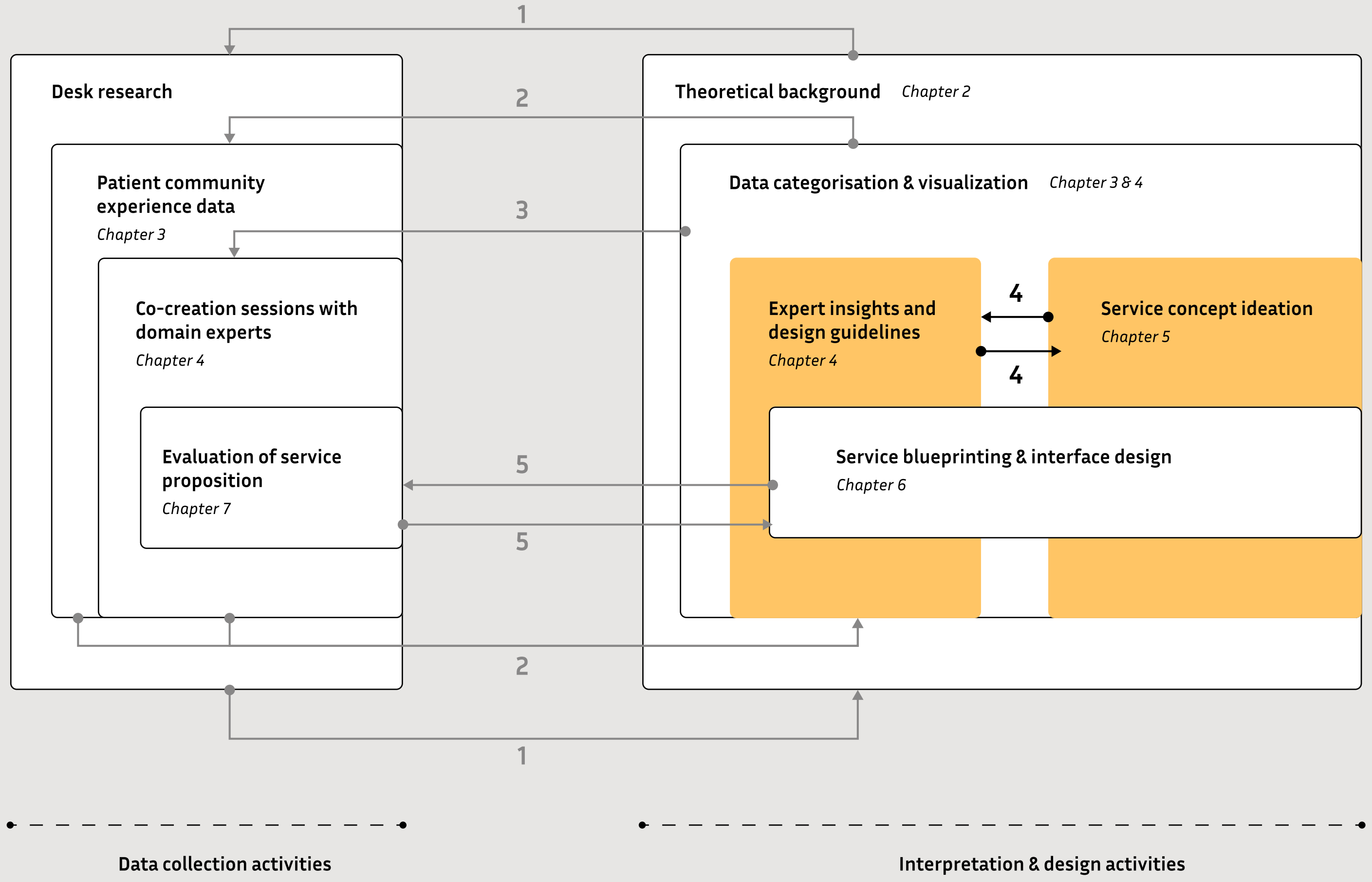
> “We think this information can improve us as communicators with our patients, but at the same time it will be a resource for patients...”

Furthermore, as illustrated in the service system vision, we should enable feedback loops which facilitate different types of patient experience data according to stakeholder engagement. This way, we can provide dynamic or incremental information appraisal support to the patient community. The involvement of community discussion topics in the RPM service system can facilitate the provision of emotional and appraisal support among the community but also ensures that the patients have a safe space to organically inform the developers and medical professionals how to incrementally improve the information support through knowledge resources or other strategies. Data technologies have the potential to analyse this vast amount of data and allow researchers together with medical professionals to suggest information support improvements.

Key takeaways from this chapter

- The data categories can develop into knowledge modules that target the main themes of concerns of the patients and *muddle through* the context of each patient community.
- It would be a meaningful intervention if the service system provided dynamic guidance and information support along the care path and timely captured the knowledge gaps in the system.
- The clinicians would benefit from an information support service system that gets incrementally improved and refined based on the patient community’s wishes and needs.
- In the long term, the service system should uplift the patient community’s voices and empower them to demand more innovations towards RPM systems.

Chapter 5: Service concept ideation



This chapter focuses on the exploration of service ideas based on the interpretation of patients' needs and the clinicians' motivations and wishes compiled in the previous chapter. At the beginning of this project, I was interested in informing the development of RPM from the perspective of service design. It is noteworthy that this service ideation would be based on the categorization of PX data (Chapter 3) and the clinicians' interpretation of the data for relevance in clinical practice (Chapter 4).

How does the patient experience data co-exist with other data types to inform core services and support services of an RPM?

The ideation centred around the service processes and architecture that would support the knowledge exchange and coaching between clinicians and patients. Based on the conversations with clinical experts, I could identify that the service system should contribute to information support and coaching from clinicians to patients. Moreover, the data categories could be extrapolated into knowledge modules. In other words, we could create knowledge modules to fulfil those categories of concerns and doubts. The content in the knowledge modules can be independently adapted to each disease. However, it remained unclear within which service infrastructure and processes those knowledge modules should exist.

1. *What kind of services do the online support groups implicitly provide to the patient communities?*
2. *How to translate the data categories into ideas of transactional services?*
3. *How to unify several ideas into a service concept for the service architecture?*

To investigate these questions, this ideation phase consisted of three explorative rounds that transitioned from exploring underlying service patterns of online patient support groups to conceptualising possible future tools for information information support through a creativity session with designers (Figure 5.1).

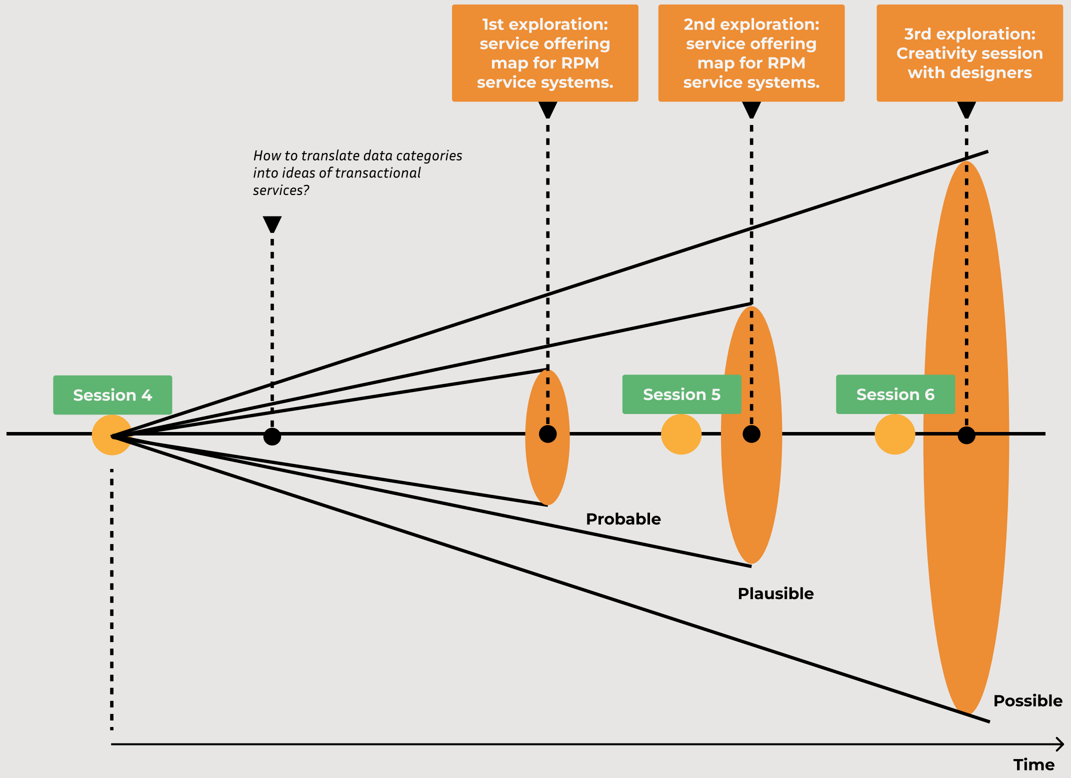


Figure 5.1: Ideation rounds overlapping the co-creation sessions with clinical experts. Visualization based on the The Futures Cone. Hancock & Bezold, 1994.

5.1 First exploration: service offering map of the online patient support groups.

What kind of services do the online support groups provide to the patient communities?

Methodology

The first exploration round involved mapping the service offering of the online support group based on the data categories. This activity was inspired by a case study from the Service Transformation team at the Essex County Council (Ward, 2019). They mapped the transactional services that the council was offering at that moment and created a database where new and past findings could be easily added and retrieved. Most importantly, this activity helped them understand the common patterns among those transactional services.

I conducted a similar activity but, in this case, I would draw on the data categories and the clustered topics to map the transactional services of the online patient support groups. As we can observe in Figure 5.2, the service offering map consisted of the services, sub-services, and service patterns.

The services represent in this case what type of resources the patient communities are exchanging, and what objective or task is the online support group allowing the members to achieve. These are the services that the online support platforms allegedly provide to their members. Since in the online support groups, the community organically creates threads of conversations, there are no formal channels to enable the specific transactional services mapped through this exercise. For instance, the developers do not provide a specific channel for discussing pharmacological treatment and another one for reflecting on resilience during the care path. Those threads are organically generated by the community.

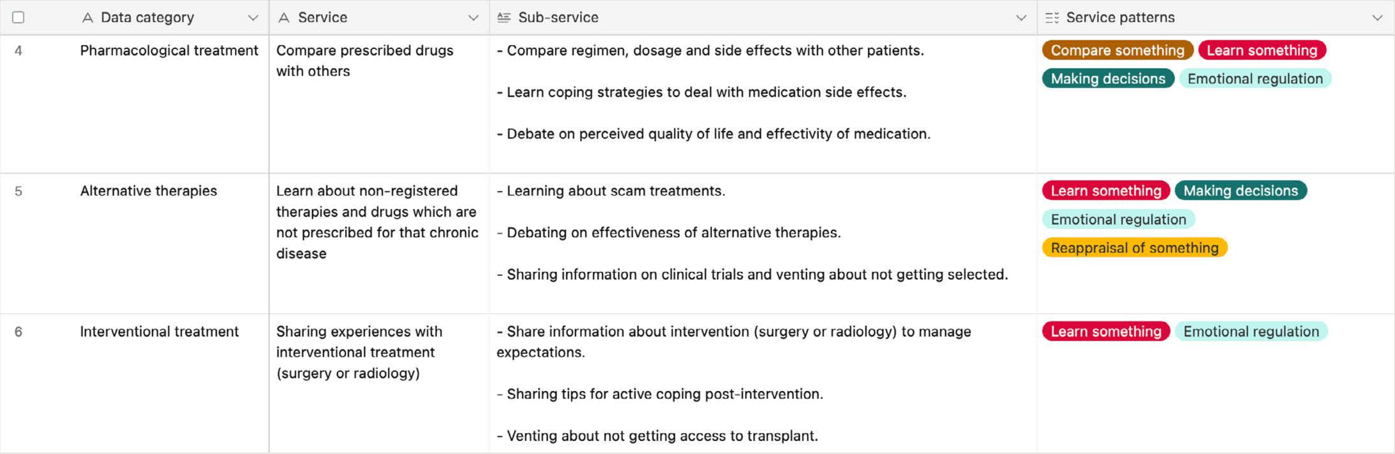
→ **Without the topic modelling and the semantic matching algorithms to identify the data categories, I could have assumed that the online support platform offers the service of "sharing experiences throughout the care pathway". However, that would not have been very inspiring. In this activity, the objective is to use the data categories to formulate more specific transactional services that the support platforms currently provide.**

The sub-services show more specifically how the patient community interacts to complete that service. For instance, for the service about comparing pharmacological treatment with others, the patient community may compare regimen and dosage with other patients, discuss the coping strategies to deal with the side effects, or even debate the relation between perceived effectivity and quality of life with the medication.

These service patterns represent the commonalities among the sub-services regarding the nature of the interaction. For instance, two services may share that the patient community learns something by reading coping strategies from other members. The service patterns have the purpose of reflecting on the role of online patient support groups and inspiring the next stages of ideation and the development of the service blueprint. The complete service offering map can be found in Appendix G.

Results

Through this exercise, I could identify service patterns beneath the data categories and their corresponding topics. The service patterns illustrate what is currently offered by the online patient support groups informally. Figure 5.3 shows the five service patterns that were identified in this exercise.



☐	Data category	Service	Sub-service	Service patterns
4	Pharmacological treatment	Compare prescribed drugs with others	- Compare regimen, dosage and side effects with other patients. - Learn coping strategies to deal with medication side effects. - Debate on perceived quality of life and effectivity of medication.	Compare something Learn something Making decisions Emotional regulation
5	Alternative therapies	Learn about non-registered therapies and drugs which are not prescribed for that chronic disease	- Learning about scam treatments. - Debating on effectiveness of alternative therapies. - Sharing information on clinical trials and venting about not getting selected.	Learn something Making decisions Emotional regulation Reappraisal of something
6	Interventional treatment	Sharing experiences with interventional treatment (surgery or radiology)	- Share information about intervention (surgery or radiology) to manage expectations. - Sharing tips for active coping post-intervention. - Venting about not getting access to transplant.	Learn something Emotional regulation

Figure 5.2: Example of mapping service offering for the online support groups based on the data categories.

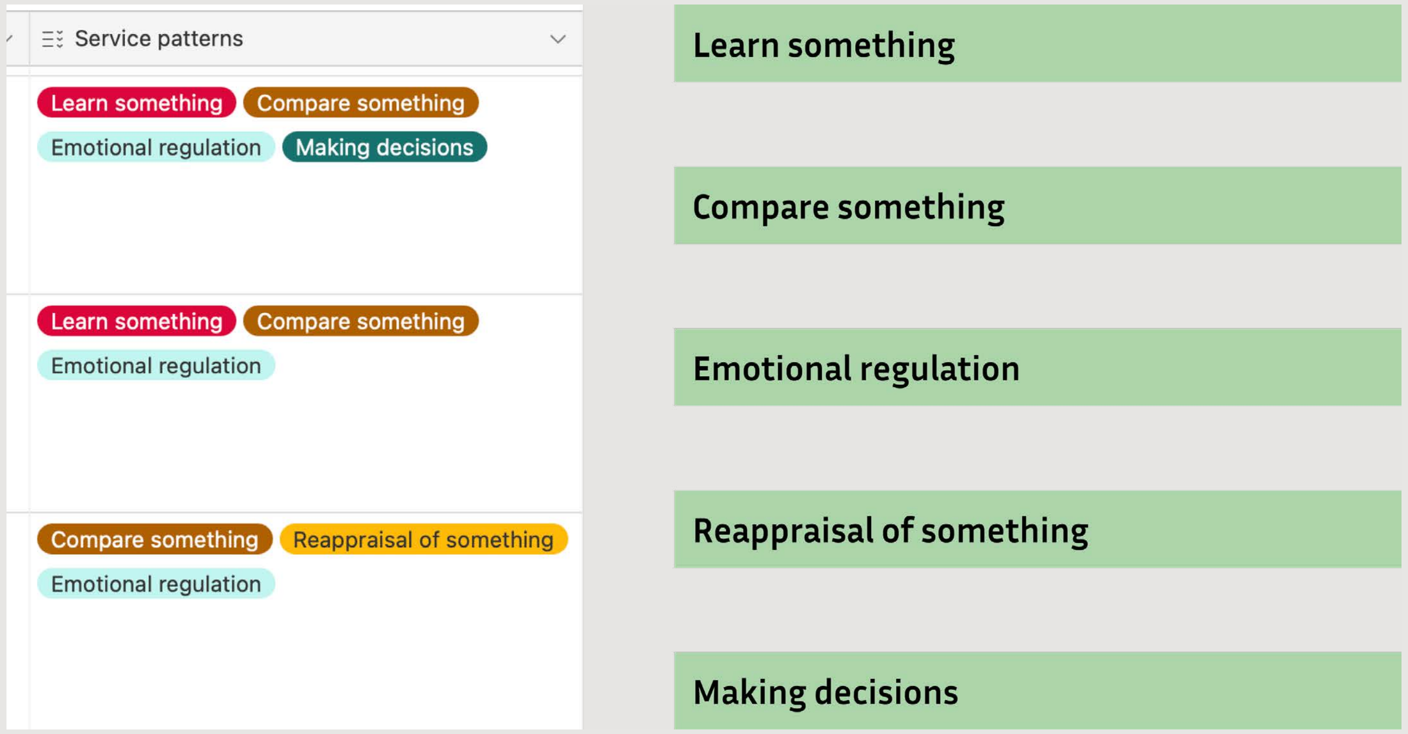


Figure 5.3: Common service patterns of the offering map of the online support groups.

- **Learn something** is the most recurrent service pattern. The patient community exchanges knowledge by sharing information, their coping strategies and tips or online resources.
- **Compare something** refers to the exchange of experiences for the sake of finding affinity within the community and feeling that you are not the only one going through a specific struggle or side effect.
- **Emotional regulation** represents the provision of a channel to vent your feelings and share your frustrations, sometimes to find emotional support.
- **Reappraisal of something** means engaging in conversations to evaluate one's situation or a stressful experience that they are going through. For instance, understanding the results of some scans or accepting to give up on some habits due to the disease.
- **Making decisions** is highly connected to comparing experiences. In this case, the purpose is to directly choose among several options. For instance, when discussing medical insurance, or therapies and institutions for the end of life.

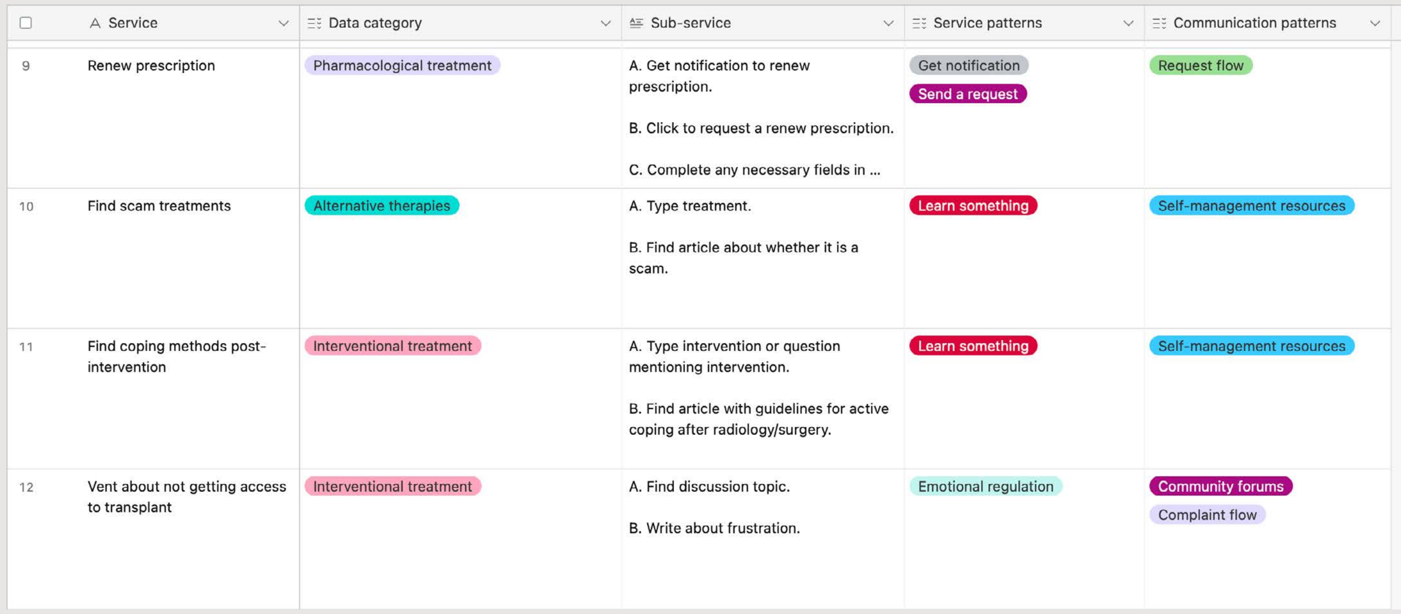
Nevertheless, this service offering could still be professionalised through the RPM system to better meet these collective needs. The second exploration round explained in the next section investigates how the sub-services from this explorative round would exist in the service vision from Chapter 4. Furthermore, it includes new ideas for sub-services that could exist within the RPM system (check Appendix G to see the whole mapping).

5.2 Second exploration: service offering map for RPM service systems.

What transactional services could exist within the RPM context based on my data categories?

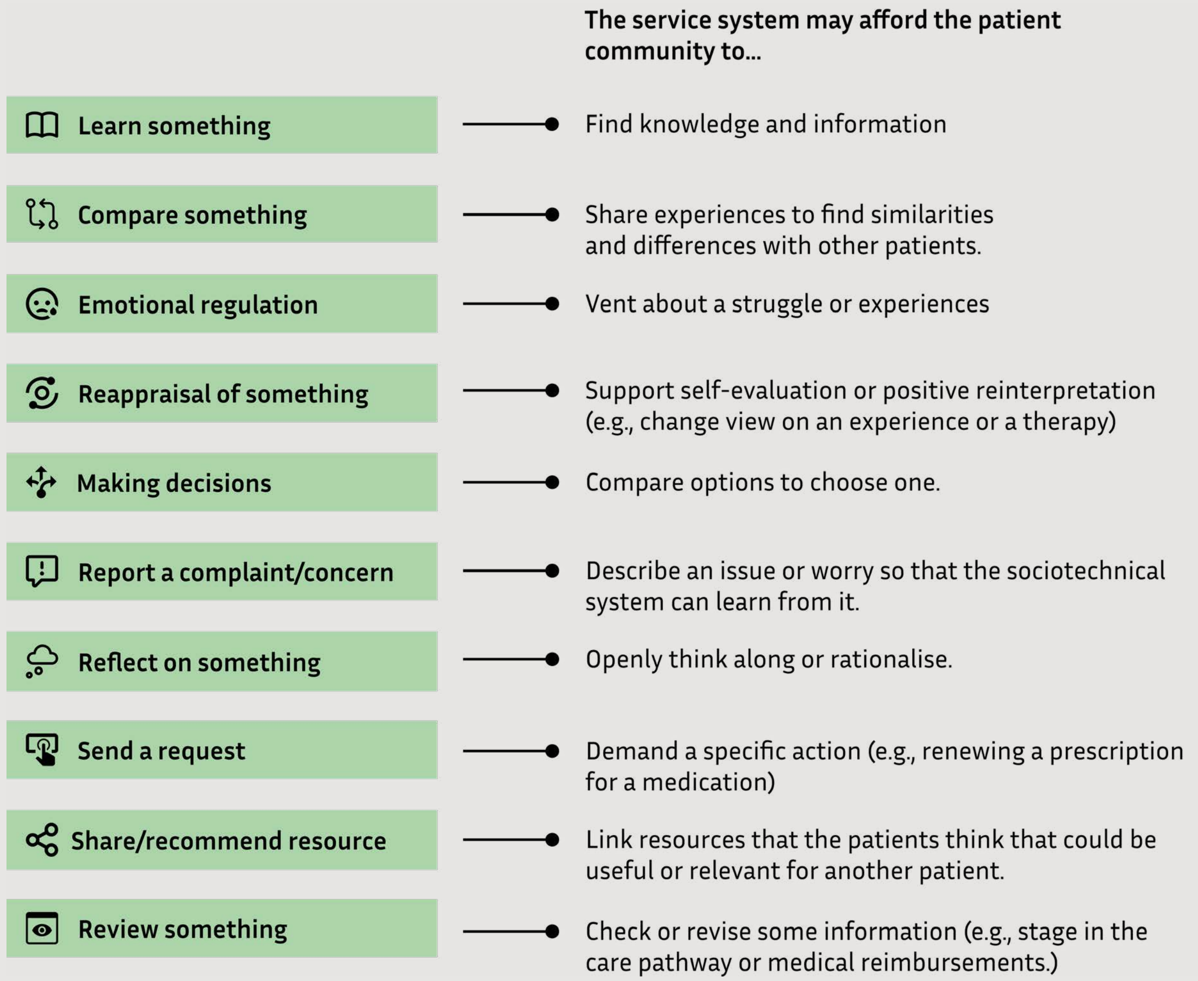
Method

The second exploration round consisted of applying service offering mapping (Ward, 2019) to the fictional context of an RPM service system that has already been implemented in ErasmusMC. This ideation uses a similar format as the previous offering map. Each service idea is related to one of the data categories (Figure 5.4). Then some services are divided into sub-services, which represent the steps the patient community would have to follow to complete their objective. Once again, the service patterns allow for comparing the nature of the interaction between services. The service patterns shed light on what needs the service concept would satisfy from a service perspective. Furthermore, this new offering map includes communication patterns to imagine in which type of channel the service would take place. The communication patterns are based on the service vision introduced in Chapter 4, section 4.3. For instance, the tag of community forums represents the pathway of community discussion topics in the service vision.



☐	Service	Data category	Sub-service	Service patterns	Communication patterns
9	Renew prescription	Pharmacological treatment	A. Get notification to renew prescription. B. Click to request a renew prescription. C. Complete any necessary fields in ...	Get notification Send a request	Request flow
10	Find scam treatments	Alternative therapies	A. Type treatment. B. Find article about whether it is a scam.	Learn something	Self-management resources
11	Find coping methods post-intervention	Interventional treatment	A. Type intervention or question mentioning intervention. B. Find article with guidelines for active coping after radiology/surgery.	Learn something	Self-management resources
12	Vent about not getting access to transplant	Interventional treatment	A. Find discussion topic. B. Write about frustration.	Emotional regulation	Community forums Complaint flow

Figure 5.4: A section of the service offering map for RPM system.



	The service system may afford the patient community to...
Learn something	Find knowledge and information
Compare something	Share experiences to find similarities and differences with other patients.
Emotional regulation	Vent about a struggle or experiences
Reappraisal of something	Support self-evaluation or positive reinterpretation (e.g., change view on an experience or a therapy)
Making decisions	Compare options to choose one.
Report a complaint/concern	Describe an issue or worry so that the sociotechnical system can learn from it.
Reflect on something	Openly think along or rationalise.
Send a request	Demand a specific action (e.g., renewing a prescription for a medication)
Share/recommend resource	Link resources that the patients think that could be useful or relevant for another patient.
Review something	Check or revise some information (e.g., stage in the care pathway or medical reimbursements.)

Figure 5.5: Common service patterns of transactional services that can exist within RPM system inspired by the data categories.

Results

This exercise resulted in a more extensive exploration of sub-services that can exist within an RPM system. The online patient support groups may not provide some of the new sub-services yet, but they could be integrated into the RPM service system. Most importantly, some new service patterns were added to the ones derived from the previous round to show how the RPM system could provide value to the patient community (Figure 5.5).

The overview of service patterns found in Figure 5.5 summarises the recurring types of interactions that the RPM system could provide for different chronic patient communities inspired by the patient experience data from the online support groups.

Nevertheless, this exercise did not show a unified data-enabled service concept but rather resulted in a collection of fragmented service ideas. I also realised that I was fixated with the sub-services mapped in the first exploration and the ideas generated were not very novel. Moreover, there was a lack of understanding of how the ideas could be better integrated into one service system. For that reason, the third and last exploration involves other designers in a creativity session to overcome the design fixation and inspire a more unified service system concept.

5.3 Third exploration: creativity session with designers.

> *How to unify several service ideas into service architecture concepts for the RPM context, based on my data categories and service offering mapping?*

Method

The third exploration round involved students and recent graduates from the faculty of Industrial Design Engineering. The goal was to facilitate the transformation of service ideas based on the data categories into more concrete concepts of service offerings. The creativity session included a sensitizing and ideation phase. Figure 5.7 shows a summary of the activities structure and the planning for the ideation session.

Figure 5.6: Designers developing the service ideas using the service system vision.

The sensitizing activities aimed to allow the participants to discover the research topic through a combination of short readings and practical exercises. The sensitizing activities spanned three days (Appendix H), in which participants were requested to spend 15 minutes each day. The sensitizing activities were included within a digital workspace designed for the quick participation of the designers.

- On day 1, the participants explore the notion of patient experience data in the short reading and think about the advantages and limitations of monitoring a disease and having periodic check-ups with a specialist doctor.
- On day 2, the designers explored the concept of RPM systems in the reading. Then, they reflected on the advantages and limitations of periodically monitoring symptoms and receiving information through digital platforms, so that their in-hospital consultations were reduced by half.
- Finally, on the last day, the designers read about social support theory and created a metaphor for data-driven support. Metaphors are a useful tool for thinking about the relationships between humans and abstract data-enabled systems such as an AI-enabled conversational bot (Alves-Oliveira et al., 2021; Murray-Rust et al., 2022; Dove & Fayard, 2020). The metaphor is intended to allow designers to reflect on the key qualities of an ML model that supports the patient community throughout the care

path and allows caregivers to continuously learn about the community's quality of life. The workspace for the sensitizing activities included a collection of random images and icons that the designers could use to generate the metaphor.

The ideation phase consisted of a 2-hour-long creativity session to translate insights from the data categories into service-offering concepts. After an introduction to the session with slides, the participants engaged in two brainwriting rounds. The participants used ideation cards (Figure 5.9) as inspiration to generate ideas for transactional services based on the data categories. The ideation cards cluster the sub-services mapped in the service offering map from the first exploration round. Each sub-service is represented by a section of a carefully selected online patient story. The aim of using these online patient stories is to allow for different interpretations and ideas. To build upon each other's ideas, we had two discussion rounds after each round of brainwriting. The participants could then discuss their most promising ideas and prioritise them. All the ideation cards can be checked in Appendix I.

The five participants split into two groups to develop two service concepts based on my service system vision (section 4.5) and then present them to the whole group. The designers were asked to use the service system vision as a reference, but they were free to adapt it if they felt the need to.

Sensitizing activities

- 3 days
- 15-20 min a day

Purpose: introduce the context and fundamental theory of the project.

Day 1: Patient experience data.	15 - 20 min
Day 2: Remote patient monitoring systems.	15 - 20 min
Day 3: Social support theory.	15 - 20 min

Ideation session

- 2 hours (ideation)
- 30 min (break/ extra time)

Purpose: generate service ideas based on data categories and offering mapping, and use service system vision to develop a couple of ideas

Introduction to the session	20 min
Energizer	
1st round of brainwriting service ideas	10 min
Group discussion	10 min
2nd round of brainwriting service ideas	10 min
Group discussion & prioritization	10 min
Break	
Introduction to service system vision	10 min
Choose service ideas and develop into concept	25 - 30 min
Create metaphor for ML model	10 min
Present concepts and metaphor	15 min

🟩 Individual activity

🟪 Group activity

🟧 Activity in pairs or trios

Figure 5.7: Planning for the creativity session with designers.

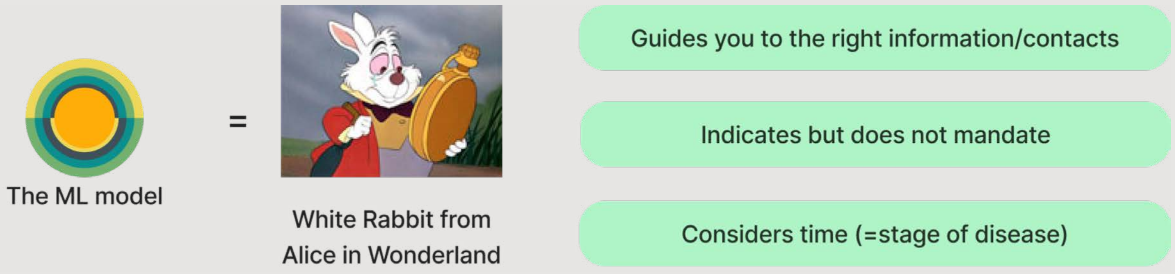
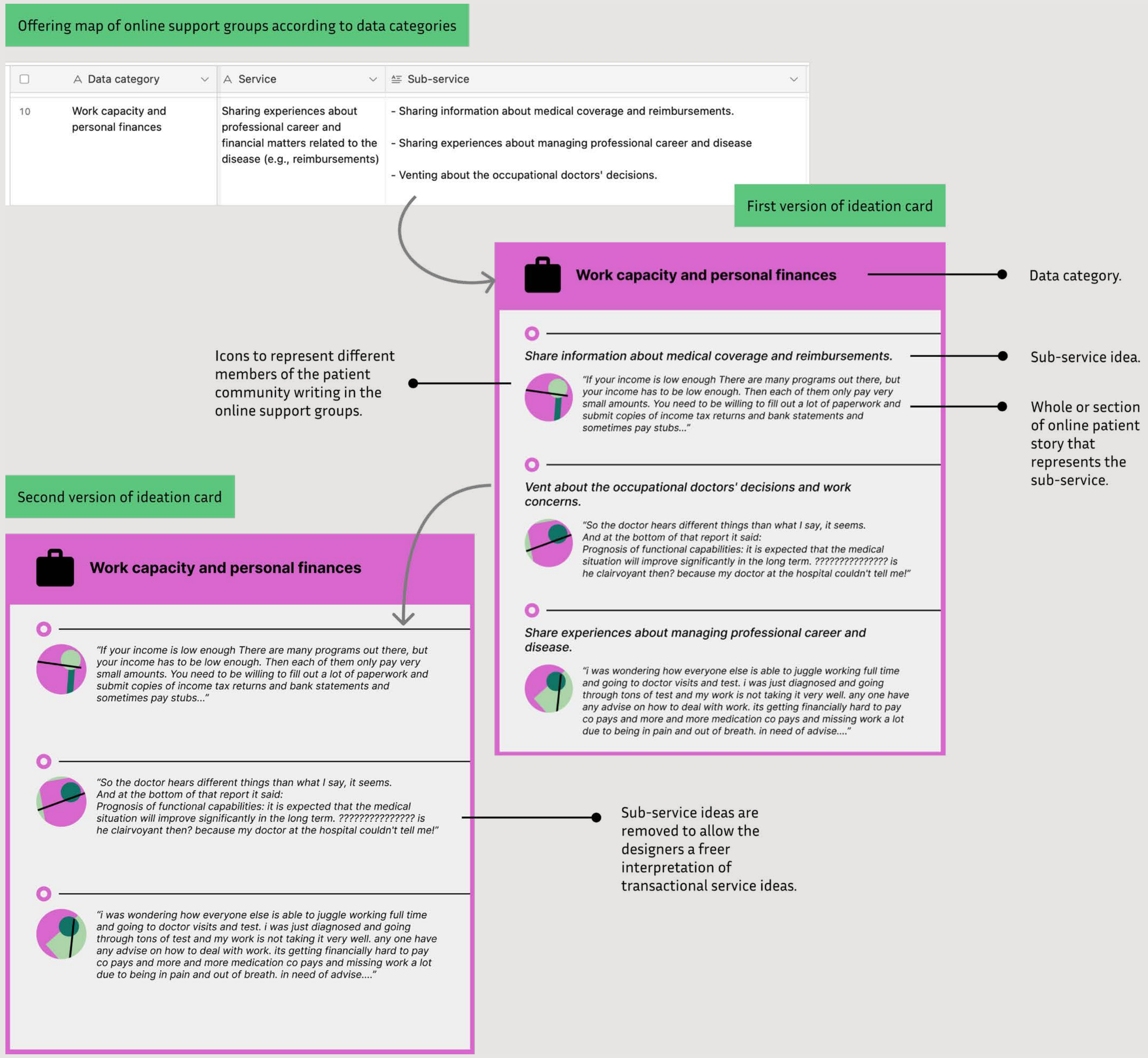


Figure 5.8: Example of a metaphor for a ML model, provided by the author of this master's thesis to the participants in the sensitizing activities.



Offering map of online support groups according to data categories

☐	Data category	Service	Sub-service
10	Work capacity and personal finances	Sharing experiences about professional career and financial matters related to the disease (e.g., reimbursements)	- Sharing information about medical coverage and reimbursements. - Sharing experiences about managing professional career and disease - Venting about the occupational doctors' decisions.

First version of ideation card

Work capacity and personal finances

Share information about medical coverage and reimbursements.

"If your income is low enough There are many programs out there, but your income has to be low enough. Then each of them only pay very small amounts. You need to be willing to fill out a lot of paperwork and submit copies of income tax returns and bank statements and sometimes pay stubs..."

Vent about the occupational doctors' decisions and work concerns.

"So the doctor hears different things than what I say, it seems.
And at the bottom of that report it said:
Prognosis of functional capabilities: it is expected that the medical situation will improve significantly in the long term. ??????????????? is he clairvoyant then? because my doctor at the hospital couldn't tell me!"

Share experiences about managing professional career and disease.

"i was wondering how everyone else is able to juggle working full time and going to doctor visits and test. i was just diagnosed and going through tons of test and my work is not taking it very well. any one have any advise on how to deal with work. its getting financially hard to pay co pays and more and more medication co pays and missing work a lot due to being in pain and out of breath. in need of advise...."

Data category.

Sub-service idea.

Whole or section of online patient story that represents the sub-service.

Icons to represent different members of the patient community writing in the online support groups.

Second version of ideation card

Work capacity and personal finances

"If your income is low enough There are many programs out there, but your income has to be low enough. Then each of them only pay very small amounts. You need to be willing to fill out a lot of paperwork and submit copies of income tax returns and bank statements and sometimes pay stubs..."

"So the doctor hears different things than what I say, it seems.
And at the bottom of that report it said:
Prognosis of functional capabilities: it is expected that the medical situation will improve significantly in the long term. ??????????????? is he clairvoyant then? because my doctor at the hospital couldn't tell me!"

"i was wondering how everyone else is able to juggle working full time and going to doctor visits and test. i was just diagnosed and going through tons of test and my work is not taking it very well. any one have any advise on how to deal with work. its getting financially hard to pay co pays and more and more medication co pays and missing work a lot due to being in pain and out of breath. in need of advise...."

Sub-service ideas are removed to allow the designers a freer interpretation of transactional service ideas.

Figure 5.9: Process of creating the ideation cards.

When the ideas were almost fully developed, I asked the designers to come up with a metaphor that encapsulated how the machine learning model would perform within their concept. This way they could use this metaphor to articulate the presentation to the group and give another layer of meaning.

Results

Through the creativity session, the designers initially brainstormed a large pool of ideas for transactional services, from which they selected the most promising ideas to develop two service concepts in groups. To make a concise explanation of the results, we will only focus on the two final concepts developed. The original sketches can be reviewed in Appendix J.

Concept A: The timeline of risk and benefit communications.

Through their concept (Figure 5.10), the first group of designers dove into how the patients would get access to a timeline of their prescribed treatment to have a sense of overview of the information they need at each stage of the care path. From this concept, it was interesting how the designers attached specific knowledge resources to the care stage through a visual progress timeline. This way, we can better communicate the consequences and benefits of each treatment and adequately inform about every milestone in the care path.

With a timeline of information support, the patient community can get access to curated and standardised articles for each stage in the care journey, which contributes to the patient's experience

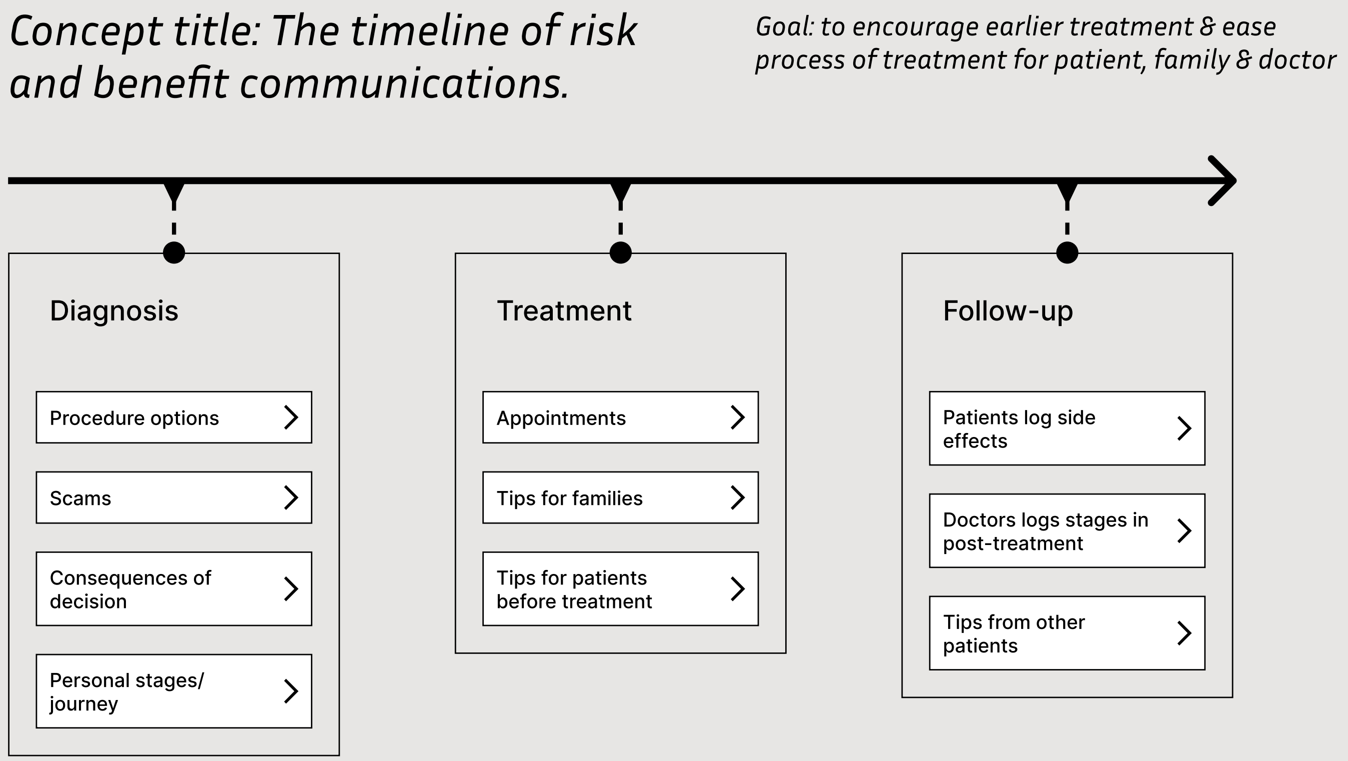


Figure 5.10: Concept A: Digitalised and interpretred by author based on sketches from the designers in the creativity session.

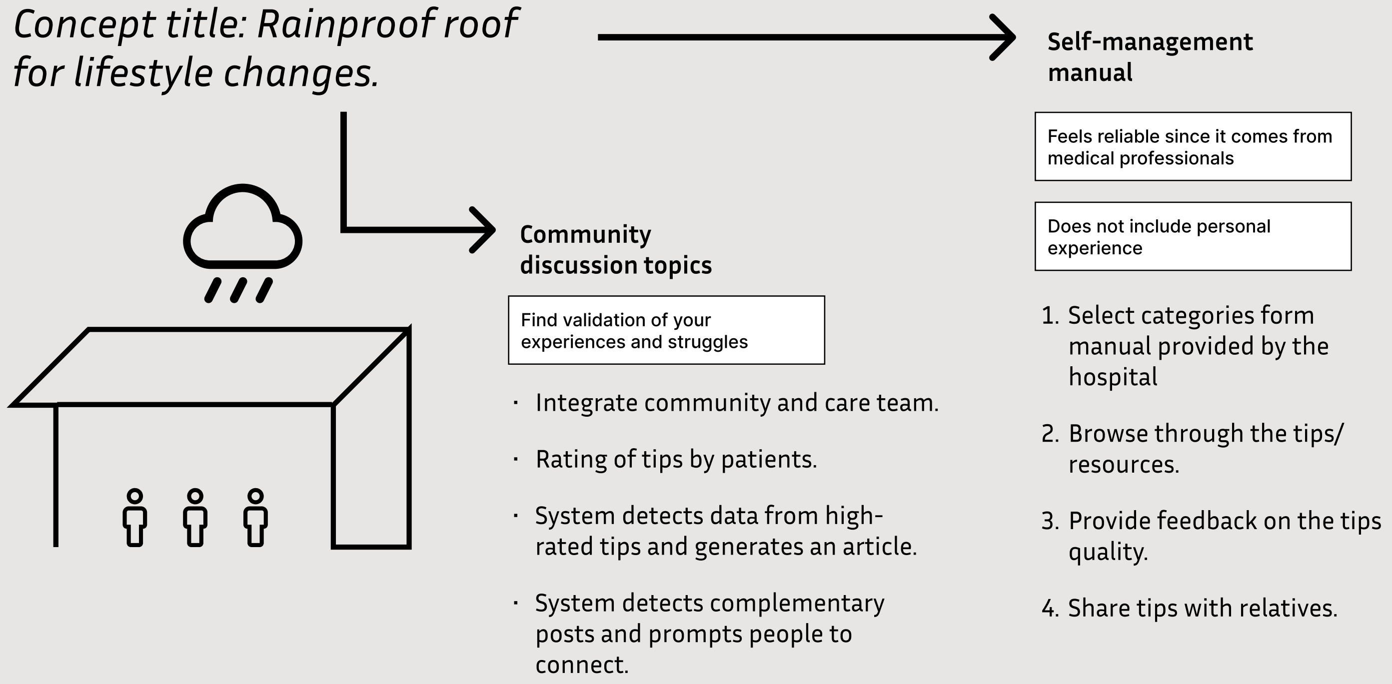


Figure 5.11: Concept B: Digitalised and interpretred by author based on sketches from the designers in the creativity session.

of care but also complements the clinicians' role as communicators and advisors. The clinicians could guide the patients by deciding which resources are included in the milestones of the timeline and updating the timeline based on the online consultations with patients. This result seemed connected with some of the impressions from the clinician and nurse practitioner in session 6:

> (Surgeon - session 6) maybe you would like to look at is, um, because if you inform patients about, um, so the initial part, if you inform patients about, uh, various treatments, a lot of the information is about risk on communication, right? Communicating to a patient what the risk is of doing nothing, the risk of surgery and what the benefit is. So, what is the benefit of chemotherapy?... (Nurse practitioner) But it's not only just the which treatment, which treatment at which moment, which moment.

Concept B: Rainproof roof for lifestyle changes.

Through their concept (Figure 5.11), the designers ideated on how the service system could offer practical tips to improve the self-management of lifestyle changes. It was interesting how the designers used the service system vision to hypothesize about two complementary sub-services.

The self-management flow is a reliable manual with tips and knowledge that have been approved and curated by the medical community. Patients would be able to select the categories within the manual that apply to them. Then they can browse through the tips within specific categories and share the most interesting ones with their relatives.

In the community discussion flow, the patients can share tips concerning specific categories. Then, the system may translate the highest-ranked tips into knowledge articles, which the medical professionals can then review and approve so that it can then be shared as an article or knowledge resource.

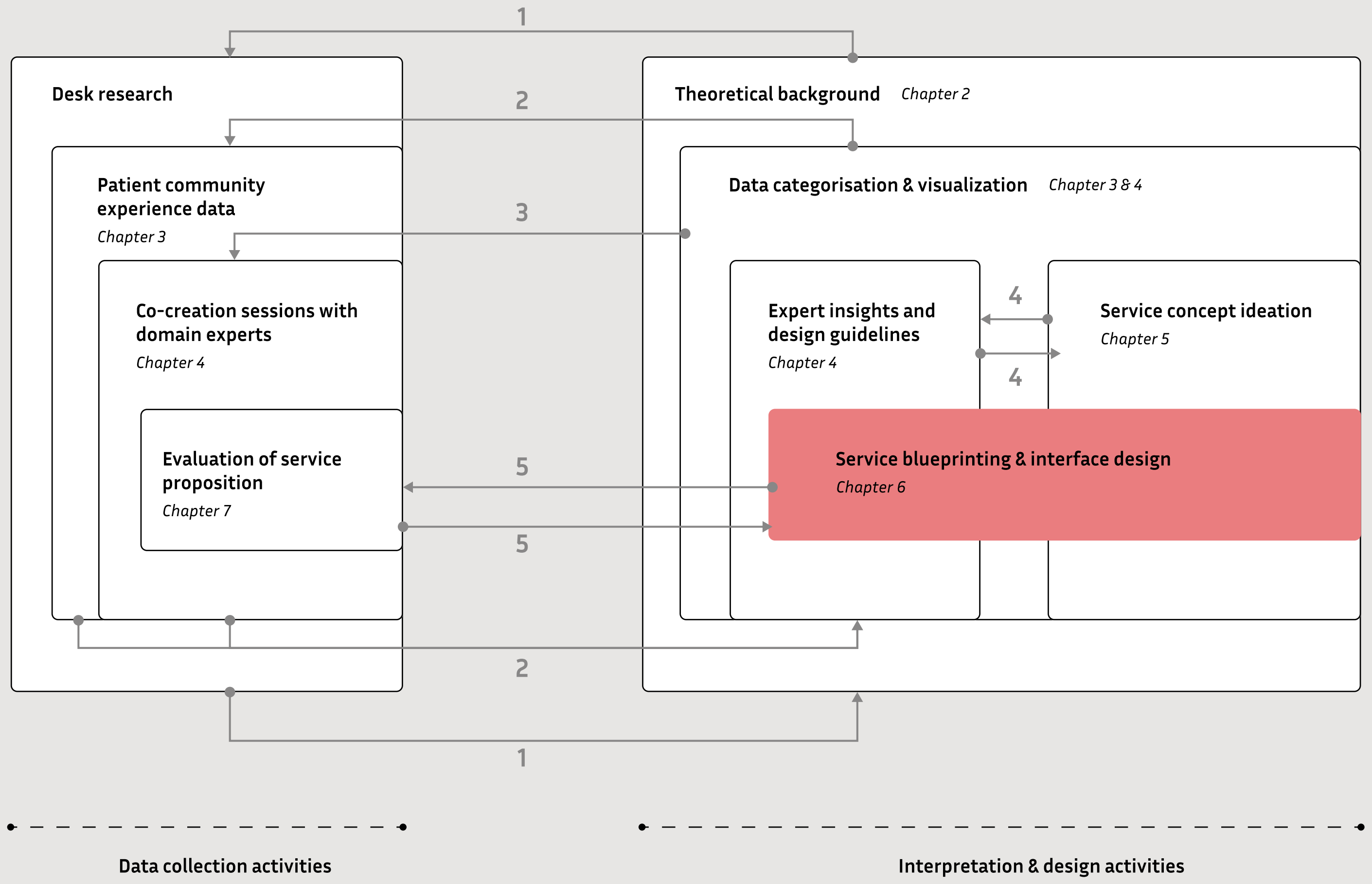
The designers used the metaphor of a rainproof roof to poetically convey the idea of the service system as a safe space place where you can easily step in to consult knowledge resources and exchange experiences and step out whenever you feel ready to continue with the care journey.

5.4 Conclusion.

Key takeaways from this chapter

- → The data-enabled RPM service system could have a module of dynamic guidance that complements the clinicians' task of communicating the risks and benefits of specific treatment plans.
- → The service modules should be organised around the service patterns. A module of community support threads could target the service patterns of "emotional regulation" and "reappraisal of something", whereas a module of dynamic knowledge provision could focus on the service pattern labelled as "learn something". In turn, this module could include knowledge modules based on the data categories that are incrementally adapted according to the patient community and their corresponding concerns. A module of patient experience data collection may cover the service patterns of "report a complaint or concern" or "reflect on something".
- → The service system could employ the metaphor of a small shelter. This metaphorical service architecture should allow the patient community along with their relatives can step in and out to whenever they experience a stressor (a concern or doubt) or when they want to share an experience.

Chapter 6: Service concept development



This concept development stage aims to craft a continuous learning service system for patient-clinician knowledge exchange. The conceptualisation is based the service system vision and the set of experience principles derived from Chapter 4 and the main takeaways from the service concept ideation in Chapter 5. This chapter focuses on the last research question introduced in Chapter 1:

> *How can we involve practitioners and patients in data-enabled services within an RPM context that contributes to stakeholders' well-being and shared decision-making?*

The development of the concept involves plotting a service blueprint that illustrates the supporting software processes and the users' actions to navigate the service system. Furthermore, some service interfaces make more tangible the processes represented in the service blueprint.

6.1 Service system concept.

Service Blueprinting

Blueprinting is the service design method selected to iteratively develop and visualize the service system concept. Through a service blueprint, we can specify how different computational techniques support the incremental finetuning of the service system for different patient communities at ErasmusMC.

Inspired by the work of Magyari & Secomandi (2023), the service blueprint employs the language of flowcharts shared by both interaction designers and machine learning engineers. Through the blueprint, we can identify the different tasks that need to be assigned to the professional with adequate expertise (Magyari & Secomandi, 2023). The interaction and user experience designers can prototype the service interface to showcase the users' actions between touchpoints. ML engineers develop the ML models that support the service system.

The service blueprint can be divided into two halves horizontally separated by the line of visibility. Above the line of visibility, we can find the service interface. This area includes the user actions that both clinicians and patients carry out to navigate through the service system from end to end. The key user actions are represented in a storyboard.

Below the line of visibility is the service infrastructure, which involves the software outputs and processes, and the human supporting processes. The software processes and outputs represent the software architecture to deliver a specific piece of information or outcome to the users. The layer of human supporting processes did not exist in the service blueprint of the digital scribe project (Magyari & Secomandi, 2023). It was included to map the periodic tasks to update and maintain the system, which cannot be completely automated.

Interface Design

To represent the intangible processes of the service, I created wireframes of the service features. These interfaces are kept in greyscale in most of the cases to centre the attention to the service feature proposed. Interfaces become an instrument to let different stakeholders perceive the main features of the service proposition, to make the service "transparent" to users (Secomandi, 2012). This also aims to reflect the idea that the visual style guide would be developed once it is integrated into a more complete eHealth application for remote monitoring.

Three essential processes or modules

The service blueprint contains three overarching modules, which represent three essential processes of this data-enabled service system.

- Dynamic guidance
- PX data collection
- Community appraisal

Dynamic guidance

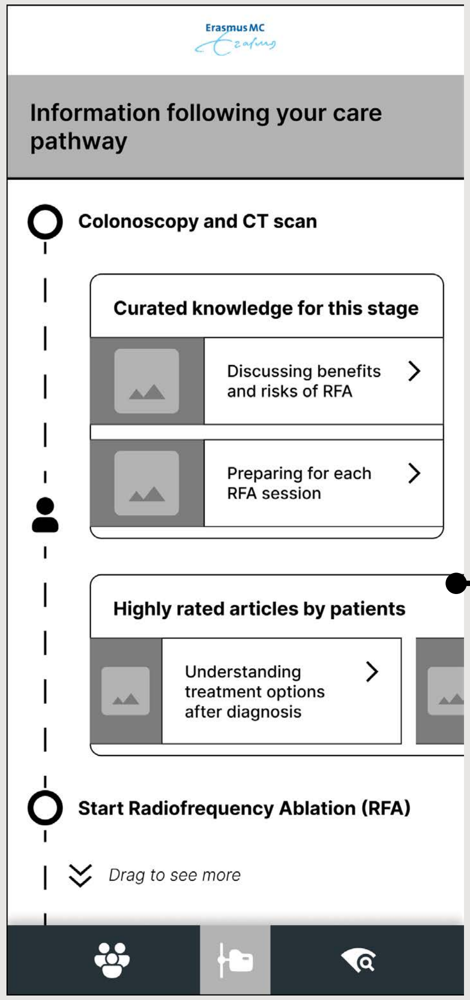
Standardise knowledge provision with templates for care stages.

The first module represents the provision of relevant knowledge resources along the care path (Figure 6.2). The resources are content created based on the data categories and the topics of concerns and doubts of the patient community (Chapter 4). These resources may include videos, articles, or animations.

The resources can be included in templates, which are collections of resources recommended in collaboration with clinicians for the period between a combination of two care milestones. Then, the system can automatically arrange the relevant knowledge resources following the templates when the clinicians specify the care path stages for specific patients (Figure 6.1). The clinicians can also recommend some resources for specific patients based on the discussions in the consultation room.

Highlight resources based on the patients' ratings.

When the patients visit specific resources, they can rate the usefulness of that article. Knowing the milestones in the care journey where the patients are and the ratings, the system can automatically show some highly rated resources for that care path (Figure 6.2), which are not included in the templates co-created with clinicians.



Erasmus MC

Information following your care pathway

Colonoscopy and CT scan

Curated knowledge for this stage

Discussing benefits and risks of RFA

Preparing for each RFA session

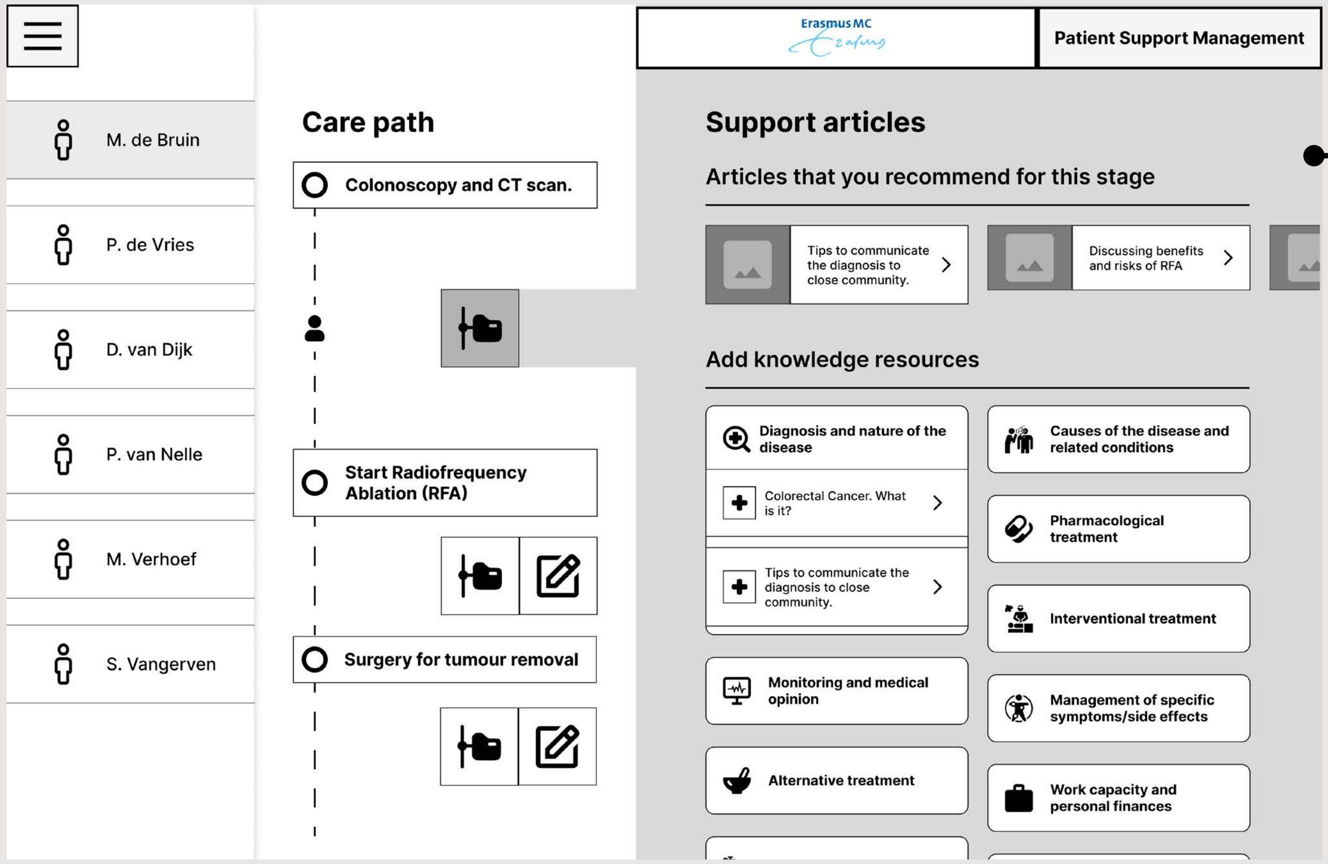
Highly rated articles by patients

Understanding treatment options after diagnosis

Start Radiofrequency Ablation (RFA)

Drag to see more

Figure 6.2: Prototype of dynamic guidance.



Erasmus MC

Patient Support Management

M. de Bruin

P. de Vries

D. van Dijk

P. van Nelle

M. Verhoef

S. Vangerven

Care path

Colonoscopy and CT scan.

Start Radiofrequency Ablation (RFA)

Surgery for tumour removal

Support articles

Articles that you recommend for this stage

Tips to communicate the diagnosis to close community.

Discussing benefits and risks of RFA

Add knowledge resources

Diagnosis and nature of the disease

Colorectal Cancer. What is it?

Tips to communicate the diagnosis to close community.

Causes of the disease and related conditions

Pharmacological treatment

Interventional treatment

Monitoring and medical opinion

Management of specific symptoms/side effects

Alternative treatment

Work capacity and personal finances

Figure 6.1: Clinicians' dashboard for providing knowledge resources

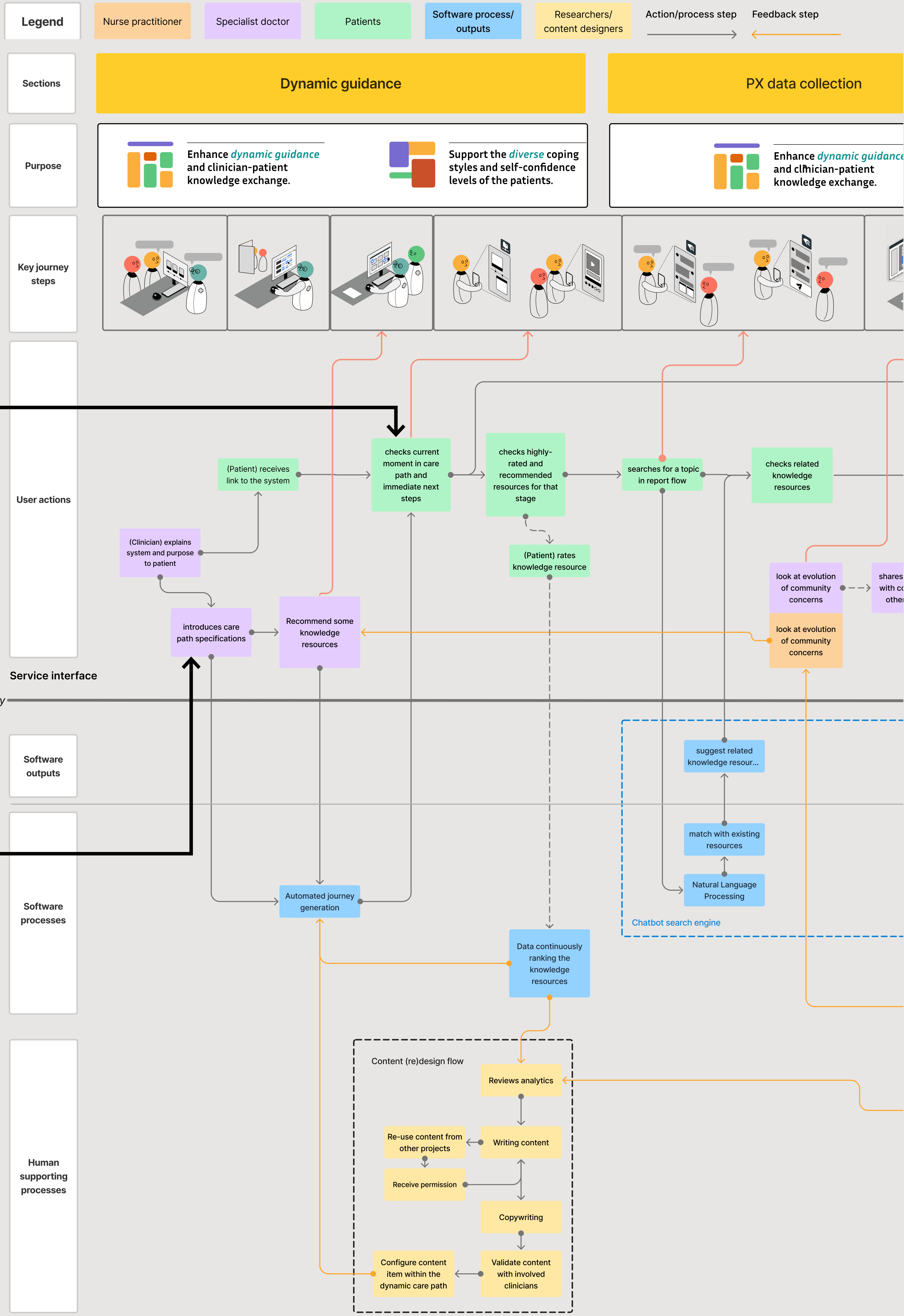


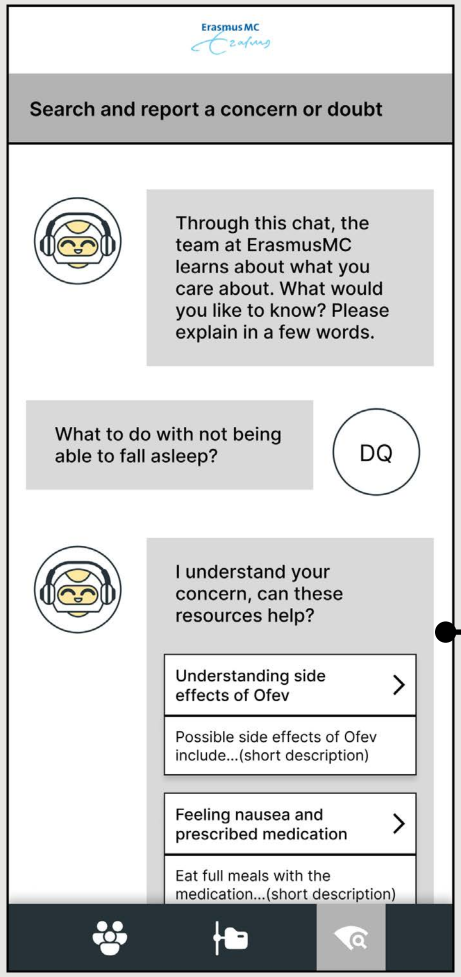
Figure 6.3: Section of the service blueprint about dynamic guidance along the care path

PX data collection

Seamlessly provide resources to concerns and report uncovered concerns.

On the patients' interfaces, the system employs a chatbot tool which guides the patient community to resources in the database and allows the patients to describe a concern or issue that can be later added to a classifier that feeds a dashboard of community-level concerns (Figure 6.4). This chatbot matches the patients' doubts and concerns with existing categories of information or specific articles, depending on the level of confidence.

→ **The data collected through this module directly aims to inform the clinicians as communicators and to improve the knowledge resources provided in the "Dynamic guidance module".**



Search and report a concern or doubt

Through this chat, the team at ErasmusMC learns about what you care about. What would you like to know? Please explain in a few words.

What to do with not being able to fall asleep?

DQ

I understand your concern, can these resources help?

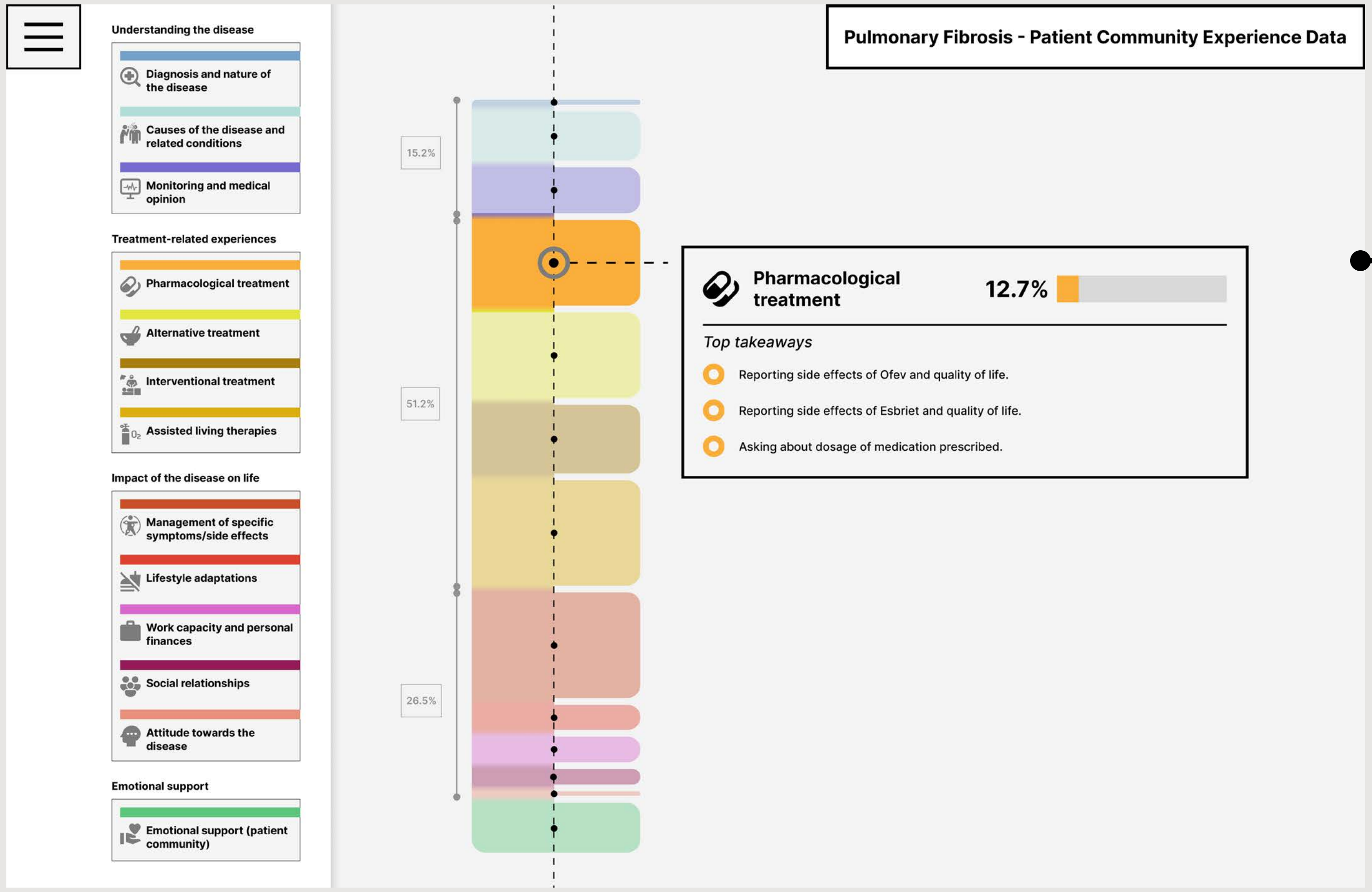
Understanding side effects of Ofev

Possible side effects of Ofev include...(short description)

Feeling nausea and prescribed medication

Eat full meals with the medication...(short description)

Figure 6.5: Prototype of data collection chatbot.



Pulmonary Fibrosis - Patient Community Experience Data

Understanding the disease
- Diagnosis and nature of the disease
- Causes of the disease and related conditions
- Monitoring and medical opinion

Treatment-related experiences
- Pharmacological treatment
- Alternative treatment
- Interventional treatment
- Assisted living therapies

Impact of the disease on life
- Management of specific symptoms/side effects
- Lifestyle adaptations
- Work capacity and personal finances
- Social relationships
- Attitude towards the disease

Emotional support
- Emotional support (patient community)

Pharmacological treatment 12.7%

Top takeaways
- Reporting side effects of Ofev and quality of life.
- Reporting side effects of Esbriet and quality of life.
- Asking about dosage of medication prescribed.

Figure 6.4: Clinicians' dashboard for overview of patients' concerns.

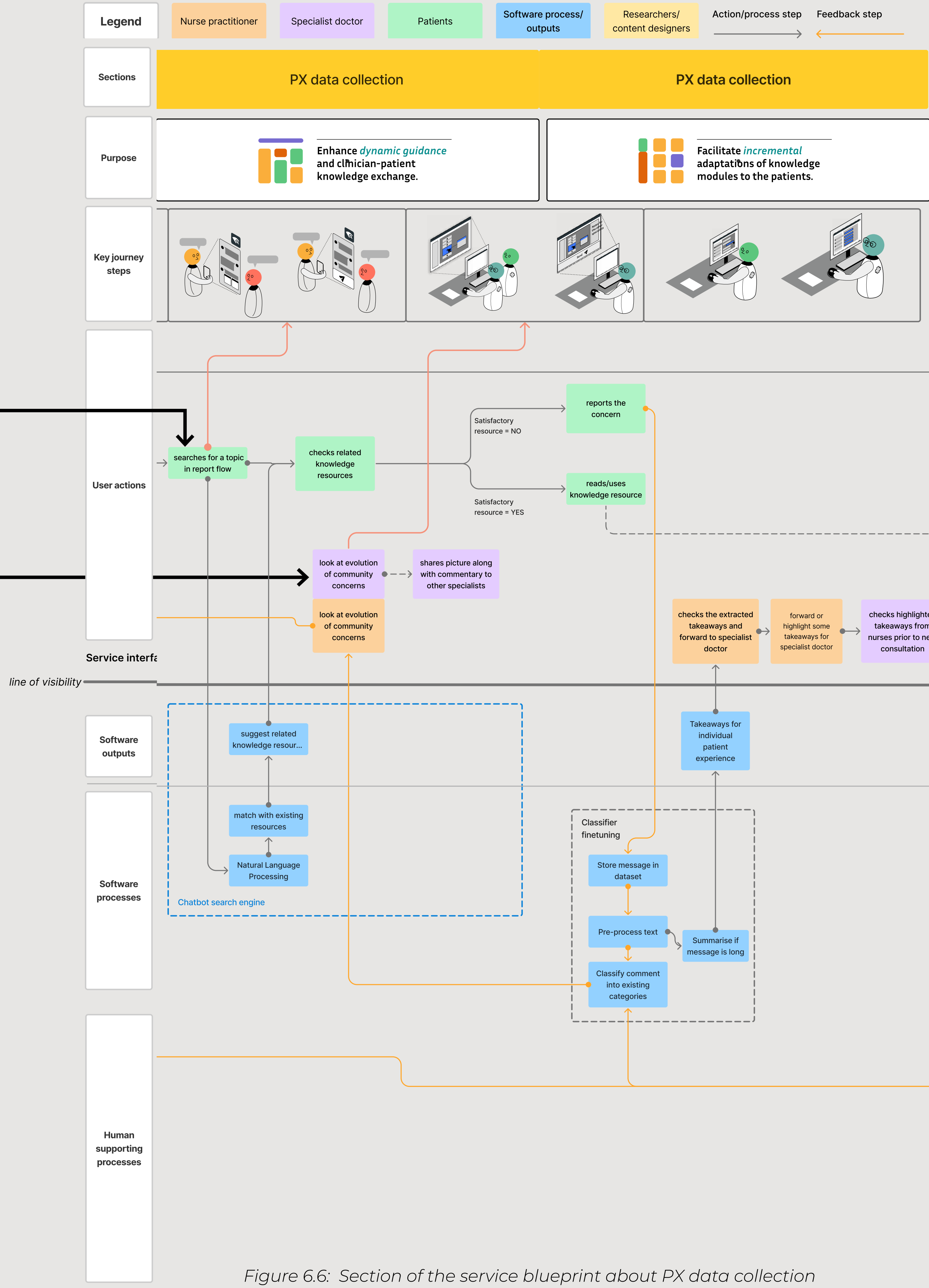


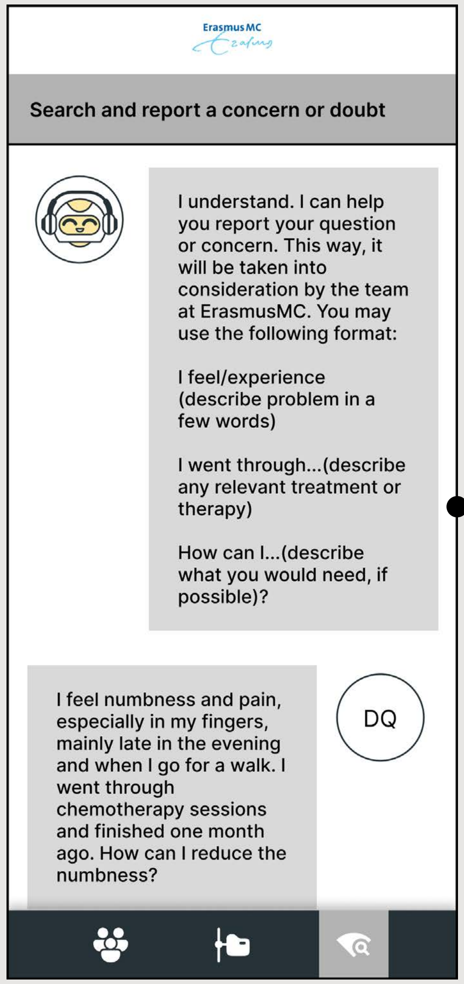
Figure 6.6: Section of the service blueprint about PX data collection

PX data collection

Extract takeaways from individual self-reported concerns.

When patients describe that the resources provided were not useful, the chatbot (Figure 6.8) asks the patient to report their concerns so that they can be added to the community overview.

If the patient accepts, the concern will also be added to an individual report that the specialist nurses and doctors would have access to. ML summarization techniques could be used to extract takeaways. The takeaways should aim to provide the nurses and clinicians with a clearer overview of the reported doubts (Figure 6.7).



Search and report a concern or doubt

I understand. I can help you report your question or concern. This way, it will be taken into consideration by the team at ErasmusMC. You may use the following format:

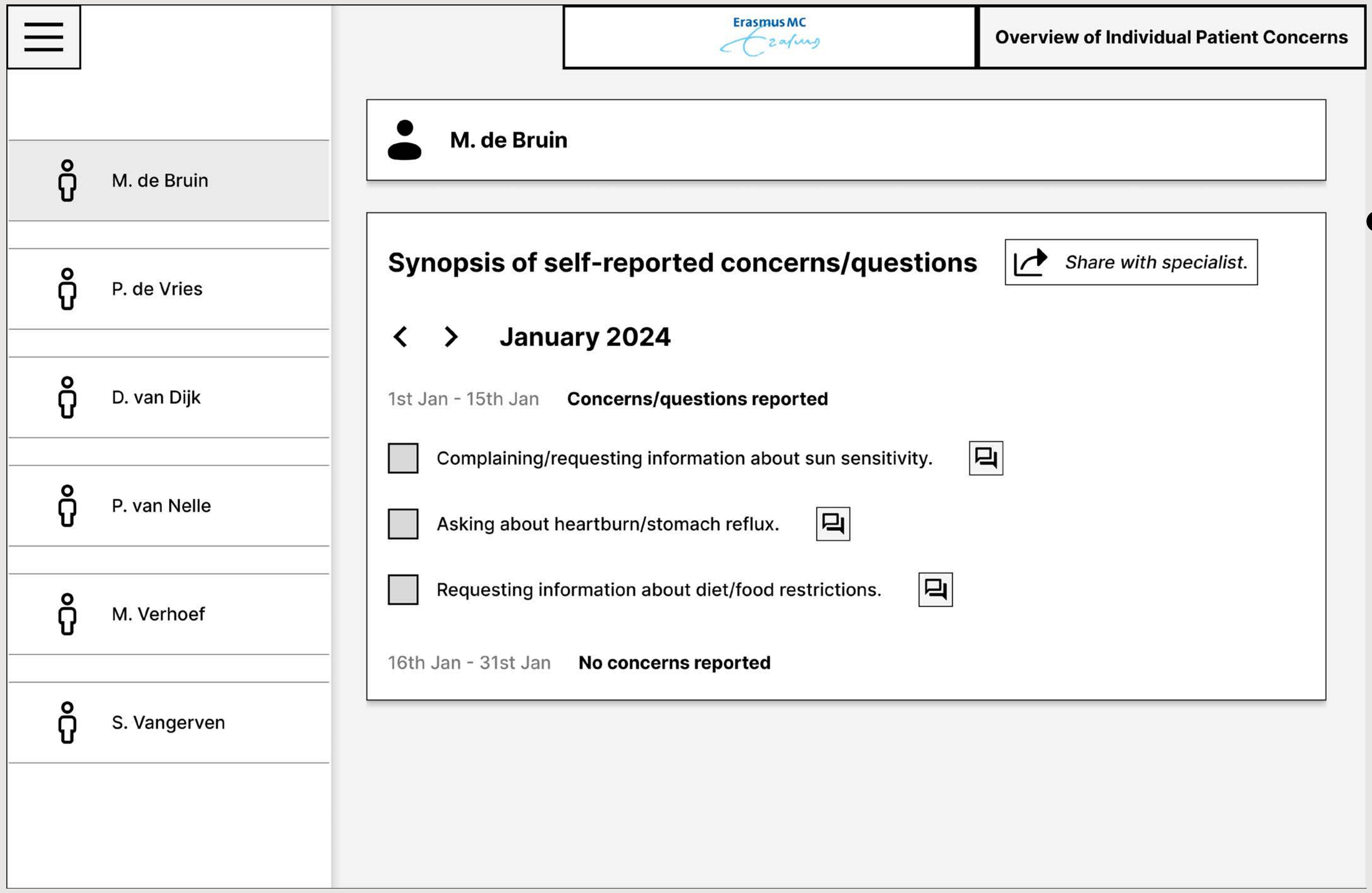
I feel/experience (describe problem in a few words)

I went through...(describe any relevant treatment or therapy)

How can I...(describe what you would need, if possible)?

I feel numbness and pain, especially in my fingers, mainly late in the evening and when I go for a walk. I went through chemotherapy sessions and finished one month ago. How can I reduce the numbness?

Figure 6.8: Prototype of data collection chatbot.



Overview of Individual Patient Concerns

M. de Bruin
P. de Vries
D. van Dijk
P. van Nelle
M. Verhoef
S. Vangerven

M. de Bruin

Synopsis of self-reported concerns/questions

Share with specialist.

January 2024

1st Jan - 15th Jan **Concerns/questions reported**

☐ Complaining/requesting information about sun sensitivity.

☐ Asking about heartburn/stomach reflux.

☐ Requesting information about diet/food restrictions.

16th Jan - 31st Jan **No concerns reported**

Figure 6.7: Clinicians' dashboard for overview of patients' concerns.

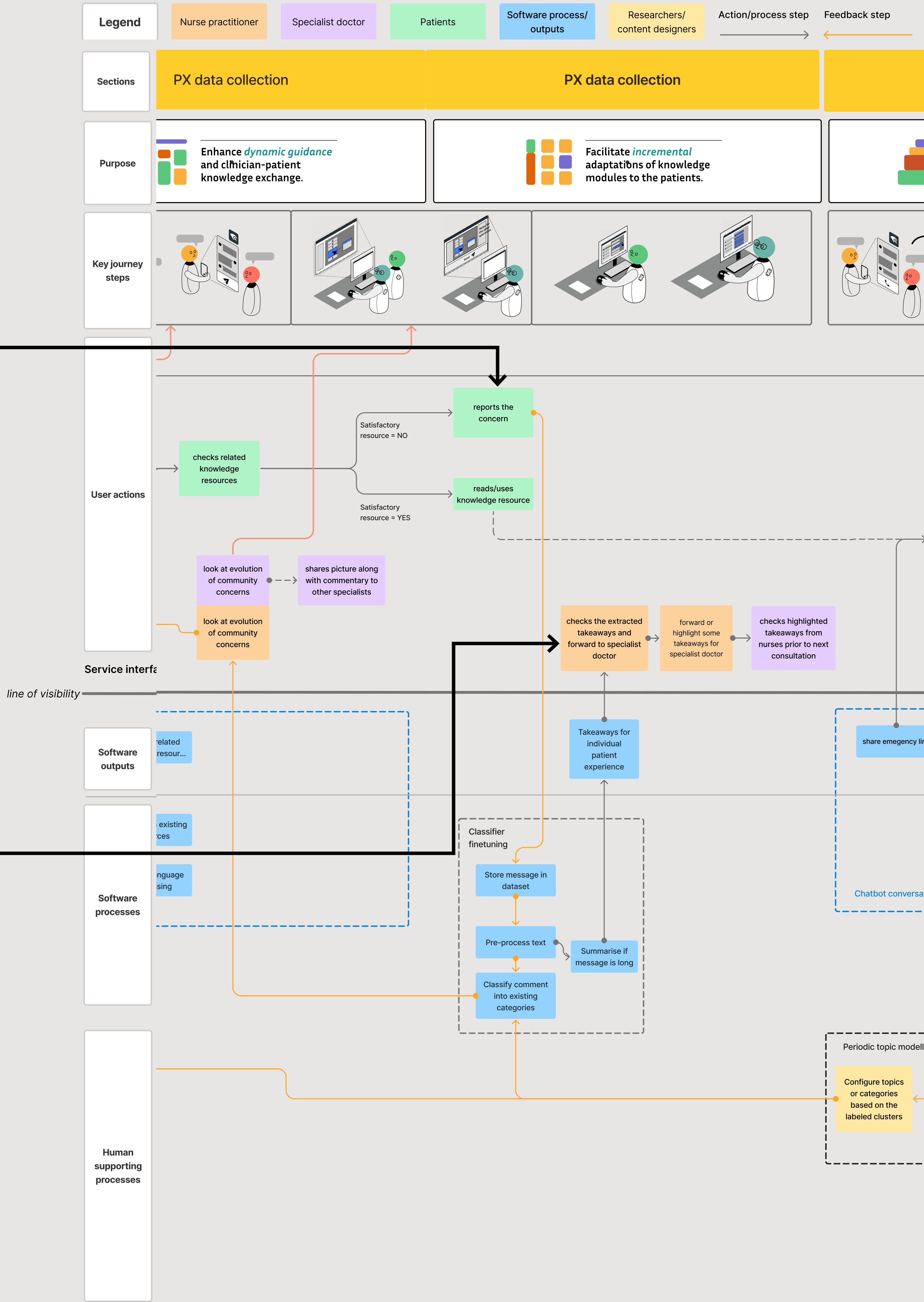


Figure 6.9: Section of the service blueprint about PX data collection

Community appraisal

The third module focuses on the principles of "Foster self-reliance and shared perspectives of the patient community" and "Support the diverse coping styles and self-confidence levels of the patients". This community appraisal module represents a space for patients to compare experiences.

Allow patients to share affinity and find peer-to-peer validation.

The community area should support different levels of participation. When patients read a thread and specific posts within that thread, they may participate by writing a reply or they may also contribute by showing affinity to the posts. This way, the patients can show that they agree with the post, or they have experienced something similar. This also should help to keep the topic modelling free from short messages that only show agreement, but do not provide valuable insights.

Use topic modelling to periodically improve the classifier.

The experiences shared in this module can periodically be anonymised and analysed through topic modelling. Through this technique, we could identify new information support gaps and refine the categories and topics for the classifier in the PX data collection module (Classifier fine-tuning in Figure 6.10). The results of topic modelling of community discussion could indicate new content to create (Content redesign flow in Figure 6.10). This way, the topic contribute to a better understanding of the nature of the condition and the impact of treatment.

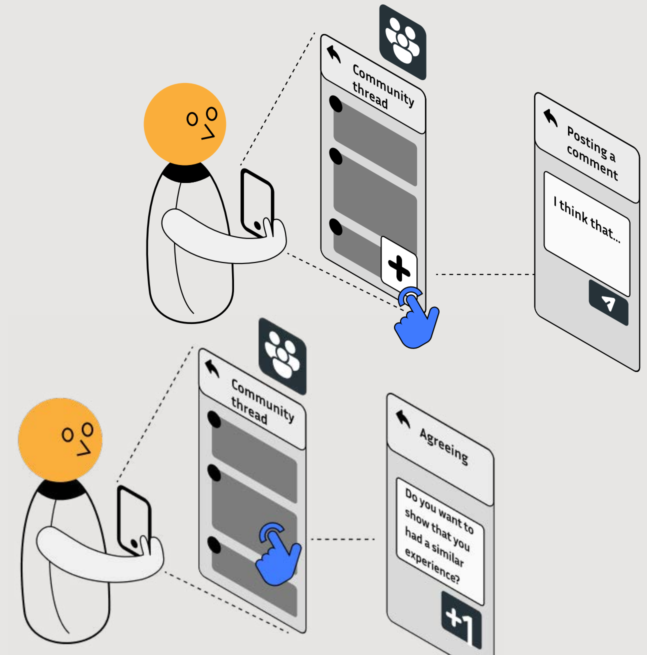


Figure 6.9: Examples of interactions within community appraisal module.

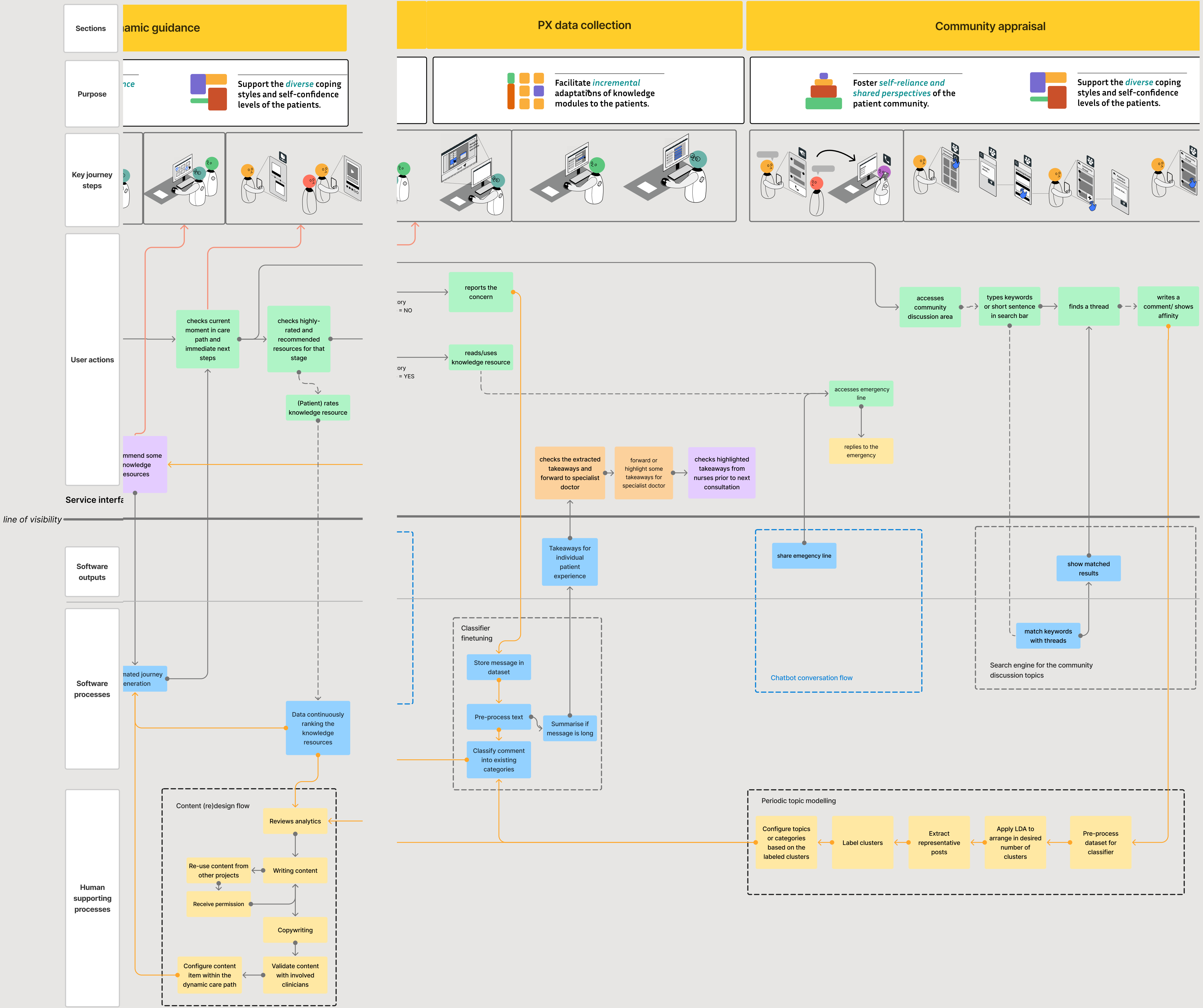
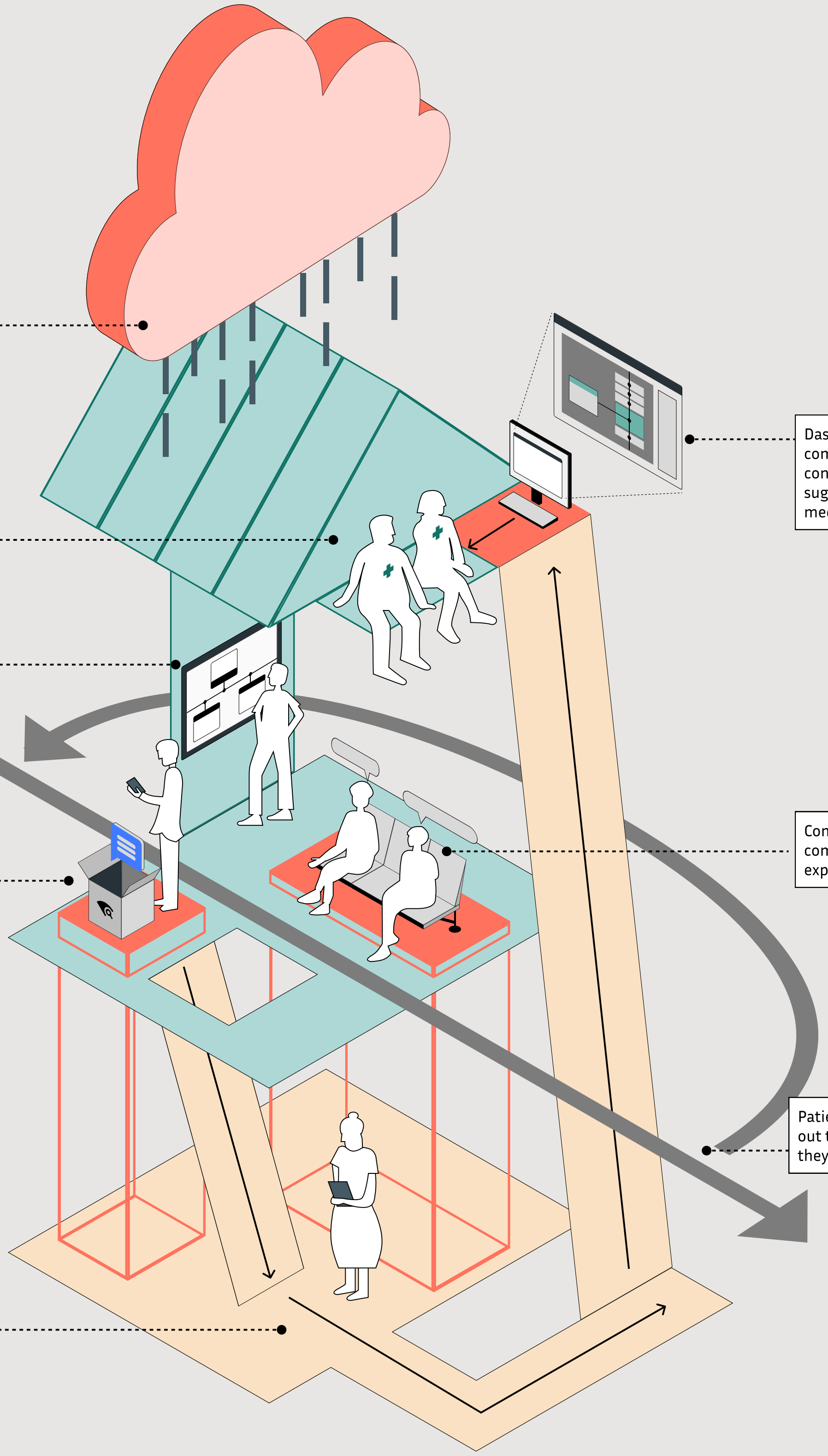


Figure 6.10: Section of the service blueprint about Community appraisal

6.2 Proposal overview.

Digital shelter for informational support and coaching throughout the care pathway



1

Resource repository as a reliable roof for patients to manage their concerns and doubts in the care pathway.

2

Medical team to control and expand the resource repository.

3

Data tech for dynamic resource provision to patients along their care journey

4

Data tech to collect knowledge gaps through self-reported concerns/doubts.

5

Software to monitor and classify the knowledge gaps into a community overview.

6

Dashboard to visualize community and individual concerns and doubts and suggest changes to the medical team.

7

Community threads as a comfortable space to compare experiences.

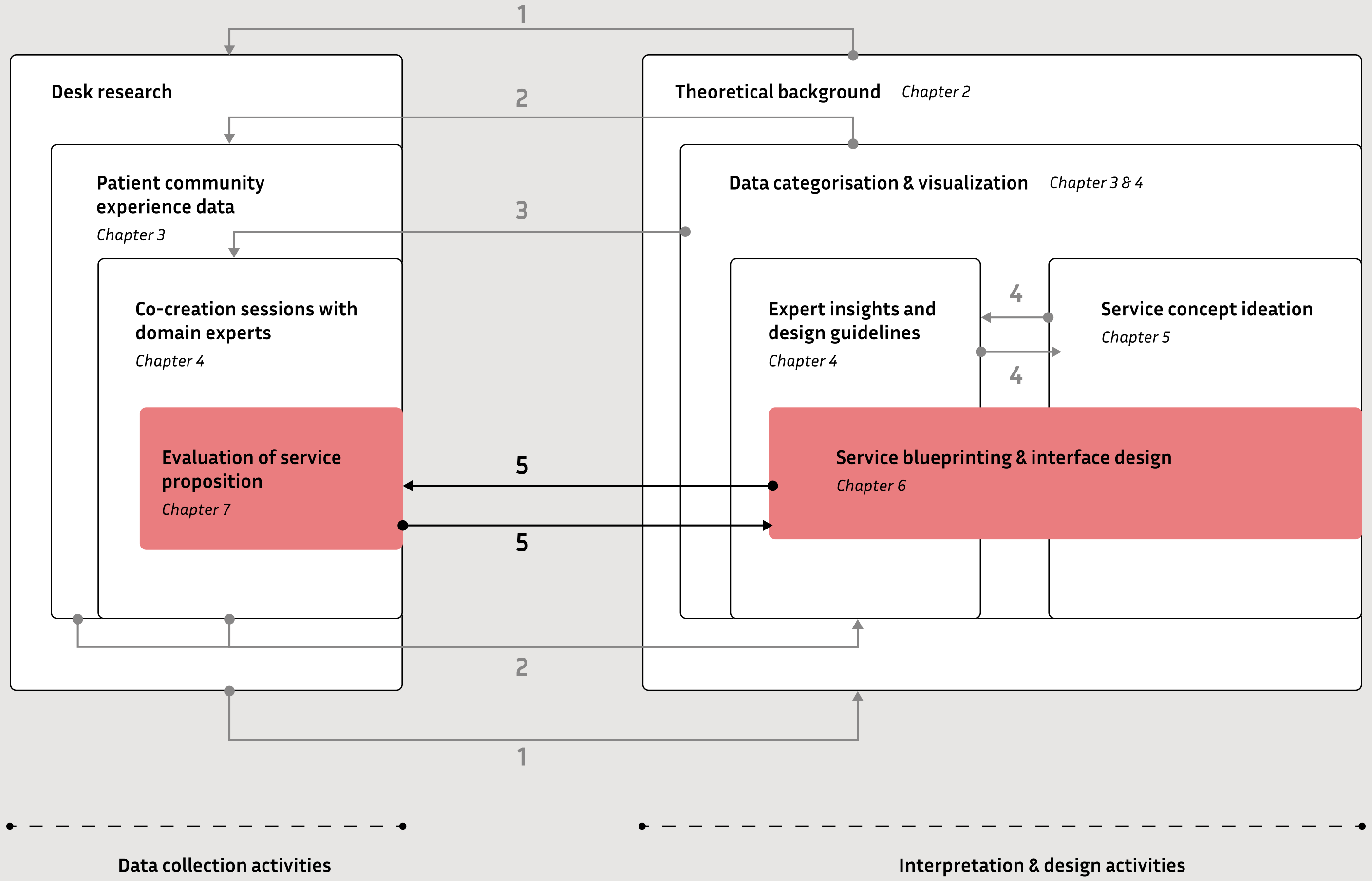
8

Patients can step in or step out the digital shelter when they need.

Figure 6.11: Proposal overview.

- → The service system concept speculates on how the data technologies in a digital service can enhance efficient information support through the involvement of different social network ties: service providers and peers from the patient community, relatives, etc...
- → Through this service proposal, information support for the RPM context can be incrementally adapted to different communities drawing on the self-reported concerns and doubts. This way, the concept aims to favour the experience of care for patients.
- → Through the system, clinicians and nurse practitioners learn about the knowledge gaps and main concerns of patients. This way, they can incrementally improve the knowledge resources they use to guide patients throughout the care path.
- → The system concept involves not only clinicians and patients but also technical managers such as developers and content designers to make progressive improvements in care delivery processes.

Chapter 7: Evaluation and refinements in the service system vision.



7.1 Methodology.

As with any other societal transition, the digitalisation of care delivery processes in healthcare is a long-term challenge. Therefore, the evaluation of the proposed service system has the core aim (Baldassarre et al., 2024) to extract insights for future directions in terms of feasibility, desirability and responsibility. This evaluation of the service concept included two types of semi-structured interview formats with interactive materials. The planning and materials of the evaluation sessions changed according to the experts involved (ML experts and clinical experts).

- Feasibility: the service infrastructural processes were reviewed with ML experts in terms of what is technically feasible with techniques and methods available in today's world.
- Desirability: through the service interfaces, the evaluation sessions analysed how well the service system fits the context that it was envisioned for and how it can complement the information support that clinicians provide.
- Responsibility: both types of evaluation sessions shared the underpinning reflection on how the concept (mis)aligns with what is ethically acceptable for today's society. More specifically, in terms of data governance and AI ethics.

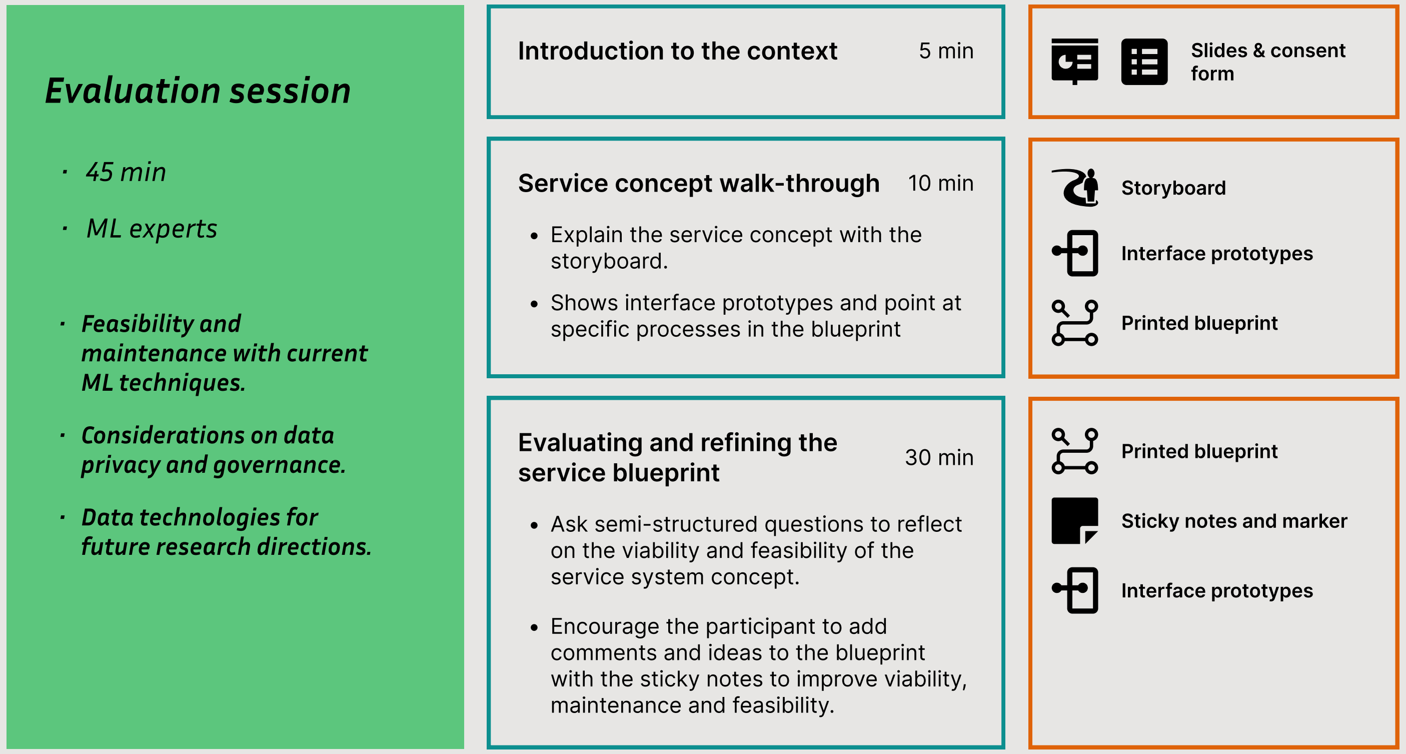
It should be acknowledged that since this intervention is envisioned for clinical practice, a complete evaluation of the proposed service system concept should include a pilot in clinical practice of a functional and validated prototype. However, due to the time constraints of this project, the service concept still would require a lot of technical development to be tested for clinical practice. For that reason, this evaluation focuses on gathering recommendations for future developments grounded on the principles of feasibility, desirability and responsibility (Baldassarre et al., 2024).

Step 1: Evaluation with ML experts

To what extent is the service system concept feasible with current data technologies according to ML experts?

The involvement of ML experts should indicate how the software processes on the blueprint could be simplified for enhanced feasibility and maintenance. The ML experts can also suggest whether the mentioned processes might require the involvement of a lot of specialised staff.

What considerations are to be taken into account regarding the data governance for this service system concept?



Evaluation session

- *45 min*
- *ML experts*

- ***Feasibility and maintenance with current ML techniques.***
- ***Considerations on data privacy and governance.***
- ***Data technologies for future research directions.***

Introduction to the context	5 min	**Slides & consent form**
Service concept walk-through • Explain the service concept with the storyboard. • Shows interface prototypes and point at specific processes in the blueprint	10 min	**Storyboard** **Interface prototypes** **Printed blueprint**
Evaluating and refining the service blueprint • Ask semi-structured questions to reflect on the viability and feasibility of the service system concept. • Encourage the participant to add comments and ideas to the blueprint with the sticky notes to improve viability, maintenance and feasibility.	30 min	**Printed blueprint** **Sticky notes and marker** **Interface prototypes**

Figure 7.1: Session planning for evaluation of service concept with ML experts.

	Session 1	Session 2	Session 3	Session 4	Session 5	Session 6
Profession	PhD Candidate	PhD Candidate	PhD Candidate	Visiting researcher in industry, and guest researcher in academia	PhD Candidate	Postdoc
Years of experience	2	3	3	6	1	7
Expertise Description	Human-Computer Interaction (HCI) and Natural Language Proccessing (NLP)	Human-Computer Interaction (HCI)	HCI, Crowd-sourcing, AI, Information Retrieval	AI, HCI and policy. AI bias, fairness and harmful impact of AI.	HCI in conversational agents	Bioethics, AI ethics, data privacy

Table 7.1: Recruited ML experts for the evaluation sessions.

The system should not compromise the privacy and safety of the patients. By talking with experts with expertise in data science, I aim to evaluate risks regarding data governance and the protection of sensitive data.

Does it support or encourage the development of data technology that is interesting or relevant for ML experts?

The session can also capture ideas for introducing more state-of-the-art technological developments in the blueprint. The ML experts would be encouraged in the session to also suggest ideas that are possible yet advanced. Including these ideas enriches the service blueprint and informs the clinicians in their evaluation sessions about other possibilities that they may not be aware of.

Based on these questions, the pilot session planning followed the three-step process shown in Figure 7.1. The rightmost column includes the materials that were used for each step.

Step 2: Evaluation with clinicians

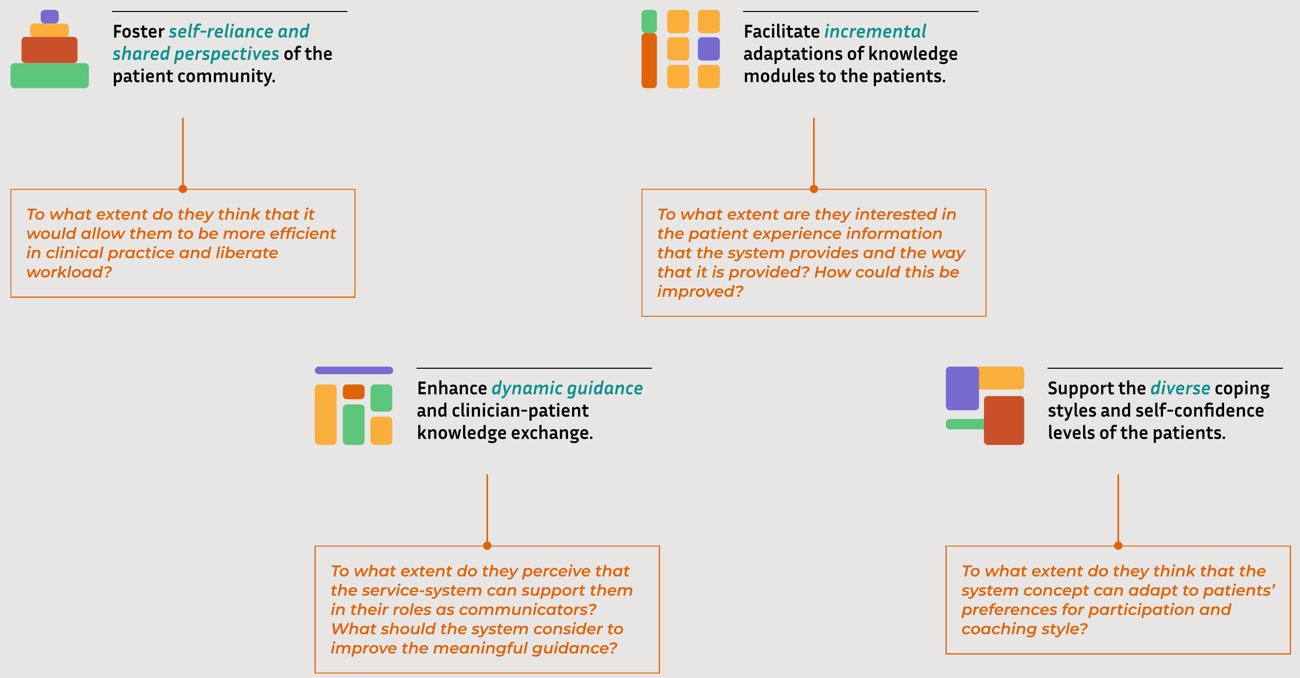
To what extent is the service providing sustainable value for the medical professionals on the short and long term?

The second session explores the desirability and responsibility of the service system concept with 2 clinical experts. These two evaluation sessions investigate the potential of the proposed concept to contribute to the continuous improvement of quality of care for chronic communities like PF, Sarcoidosis and CRC (Porter, 2009).

This session follows the format of a semi-structured interview structured by the set of guiding of principles (Chapter 4, section 4.4). The questions asked throughout the session will stem from the set of guiding principles derived from the co-creation sessions with clinical experts (Figure 7.2). However, the concept evaluation should indicate how other clinical experts perceive those key values from the service interfaces and the proposed service architecture (session planning in Figure 7.3).

	Session 1	Session 2
Profession	PhD researcher (MSc in Medicine)	Postdoctoral researcher in general practice
Years of experience	1	5
Expertise Description	Interstitial Lung Diseases	Technical innovation in general practice. Value-based health.

Table 7.2 Recruited clinical experts for the evaluation sessions.



Foster *self-reliance and shared perspectives* of the patient community.

To what extent do they think that it would allow them to be more efficient in clinical practice and liberate workload?

Facilitate *incremental* adaptations of knowledge modules to the patients.

To what extent are they interested in the patient experience information that the system provides and the way that it is provided? How could this be improved?

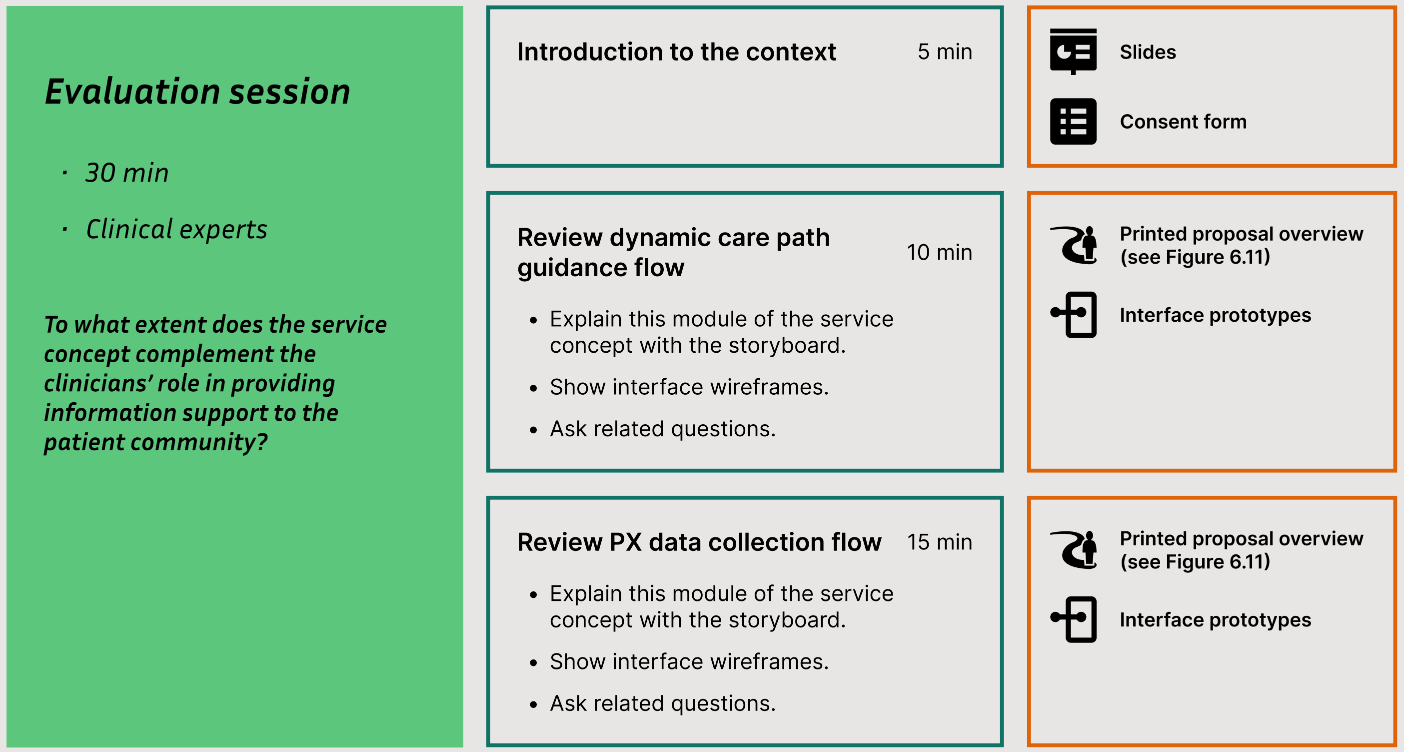
Enhance *dynamic guidance* and clinician-patient knowledge exchange.

To what extent do they perceive that the service-system can support them in their roles as communicators? What should the system consider to improve the meaningful guidance?

Support the *diverse* coping styles and self-confidence levels of the patients.

To what extent do they think that the system concept can adapt to patients' preferences for participation and coaching style?

Figure 7.2: Themes of interview questions for evaluation of service concept with clinicians



Evaluation session

- *30 min*
- *Clinical experts*

To what extent does the service concept complement the clinicians' role in providing information support to the patient community?

Introduction to the context 5 min

Slides

Consent form

Review dynamic care path guidance flow 10 min

- Explain this module of the service concept with the storyboard.
- Show interface wireframes.
- Ask related questions.

Printed proposal overview (see Figure 6.11)

Interface prototypes

Review PX data collection flow 15 min

- Explain this module of the service concept with the storyboard.
- Show interface wireframes.
- Ask related questions.

Printed proposal overview (see Figure 6.11)

Interface prototypes

Figure 7.3: Session planning for evaluation of service concept with clinical experts.

7.2 Discussion of the findings.

Together with the ML and clinical experts, it was possible to identify how to refine the service concept regarding feasibility, desirability and responsibility.

→ **Modifications in the blueprint after the evaluation sessions are marked on the pages 82–83.**

Feasibility

On a general level, the ML experts considered that the proposed service system seems feasible with current data technologies and machine learning techniques.

> “in terms of like implementation and like process and the technology like feasibility of it, yeah, I think it’s all doable in today’s world.”

However, it was also acknowledged that in future steps, the technical feasibility of the service should be more thoroughly validated and documented with technical audits. ML models and information retrieval systems should be developed iteratively, creating and validating functional prototypes with the stringency that the medical context deserves.

> “And then I don’t know some maybe some kind of like, you know, technical audit…just to say this thing, whatever…It’s a collaboration with maybe ErasmusMC or an external company, things were done properly…Things meeting some criteria like exact requirements.

Periodic updates of the classifier by an ML engineer.

→ **Number 1 on blueprint**

The ML experts confirmed that the classifier of patients' self-reported concerns would need an ML engineer who verifies from the backend that the classifier is functioning correctly. Nevertheless, the system should not add the data to the classifier continuously. The ML engineer would have to figure out how often the classifier needs to be finetuned. Once the engineer discovers the markers to update the classifier and provide the best results, the process can be automated. Therefore, the data should be kept in a backlog until the engineer updates the classifier, verifies its accuracy, and can substitute the current classifier with the newly updated one.

> “Because the way I see this in terms of the classifier finetuning, you’re gonna have a loop of how often you’re gonna do that fine-tuning, right? Because you’re not gonna do it every time you get a new piece of information…So you’re gonna need to figure out a threshold…How often do I do this fine-tuning and then each time you do that fine-tuning you can just swipe the data set.”

Specify the use of topic modelling for the community discussions.

→ **Number 2 on blueprint**

The periodic topic modelling of community discussions seemed to cause some confusion among the ML experts. Some thought at first that unsupervised learning would be the main method to train the chatbot (LLM in the PX data collection loop) or the classifier.

> “it would help maybe to have some like already some categories in and tell her to like classify next into one of these categories and yeah, and maybe that will help you…Also, just have more consistent output than just unsupervised learning, because it might be that it’s not very consistent every time.”

Therefore, it is confirmed that the use of a supervised classification to update the community overview of concerns seems a more sensible idea. The ML experts also valued the idea of using topic modelling to review whether there are major changes in the themes of questions within one dataset. Nevertheless, the ML experts also considered that clinicians should only be involved whenever the engineers find noteworthy changes

> “And then if those topics have not changed, yeah…Then you know that one might be more of OK…We are set that we don’t need to involve doctors and stuff because if doctors do not have major complaints that all these things do not make sense or there is no like a drift like a huge drifting…”
>
> “let’s make sure that you know, since we have more and more people using it…we can update and like see how things go…Also, because maybe on a broader societal level, you have shifts those kind of things, maybe, I don’t know, eating or like living habits change.”

In short, the purpose of including the unsupervised topic modelling in the service blueprint was to have a periodic feedback flow from conversations between peers to inspire the stakeholders to include new topics in the classifier or create new content. Some changes were applied in the blueprint to make more explicit this purpose.

Explore the concept of recommender systems for the retrieval of resources.

> “the doctor can include these relevant documents, but with this recommender system, you could also make suggestions to the doctor, or to the patient directly of additional documents.”

If the information resources highlighted between care stages are saved as templates, we can apply recommender systems algorithms to suggest the clinicians' resources to incrementally improve those templates. Through recommender systems, we could efficiently retrieve relevant resources for each patient based on the behaviours of previous users with a similar care path (Rocca, 2021). In this case, the recorded interactions such as anonymised searches and concerns could be used to recommend resources for specific care milestones of new users. For instance, if many Sarcoidosis patients searched repeatedly about Remicade (prescribed medication) after the diagnosis, the algorithm could suggest to the clinicians to include other existing resources related to Remicade after this specific care milestone (diagnosis). The doctors could then validate whether it is sensible to indeed include those resources in the template (Figure 7.4).

The ML experts and researchers anticipated that when developing and validating the ML models within this service system, we should consider the cold start problem, specifically in the case of recommender systems. This issue consists of having limited behaviour data from the communities where we want to implement the service, especially in the pre-deployment stage. In recommender systems, we would need a large dataset of recorded interactions from past patients to accurately suggest resources. This can be particularly concerning in healthcare since missing out on information or not choosing accurate resources when recommending resources to the patient community can directly affect their health outcomes.

> “And then once you have more behavior then you can add like more fine-tuned recommendations and the chatbot tool…I would say like you should have the chatbot from the start because the chatbot doesn’t have this problem because it’s not like the chatbot proactively asks you for recommendations or tips…You go to ask the chatbot questions from the start.”

For that reason, it was decided that the service should first focus on accurate information retrieval based on the patients' questions. Exploring the combination of content design and recommender systems seems more fitting as a promising direction for future research.

Desirability

It is difficult to quantify to what extent the proposed service system is desirable, especially due to the limited number of clinical experts who participated at this stage. However, I could extract some takeaways that elaborate on the desirable aspects of such a service system and what could be improved in future steps.

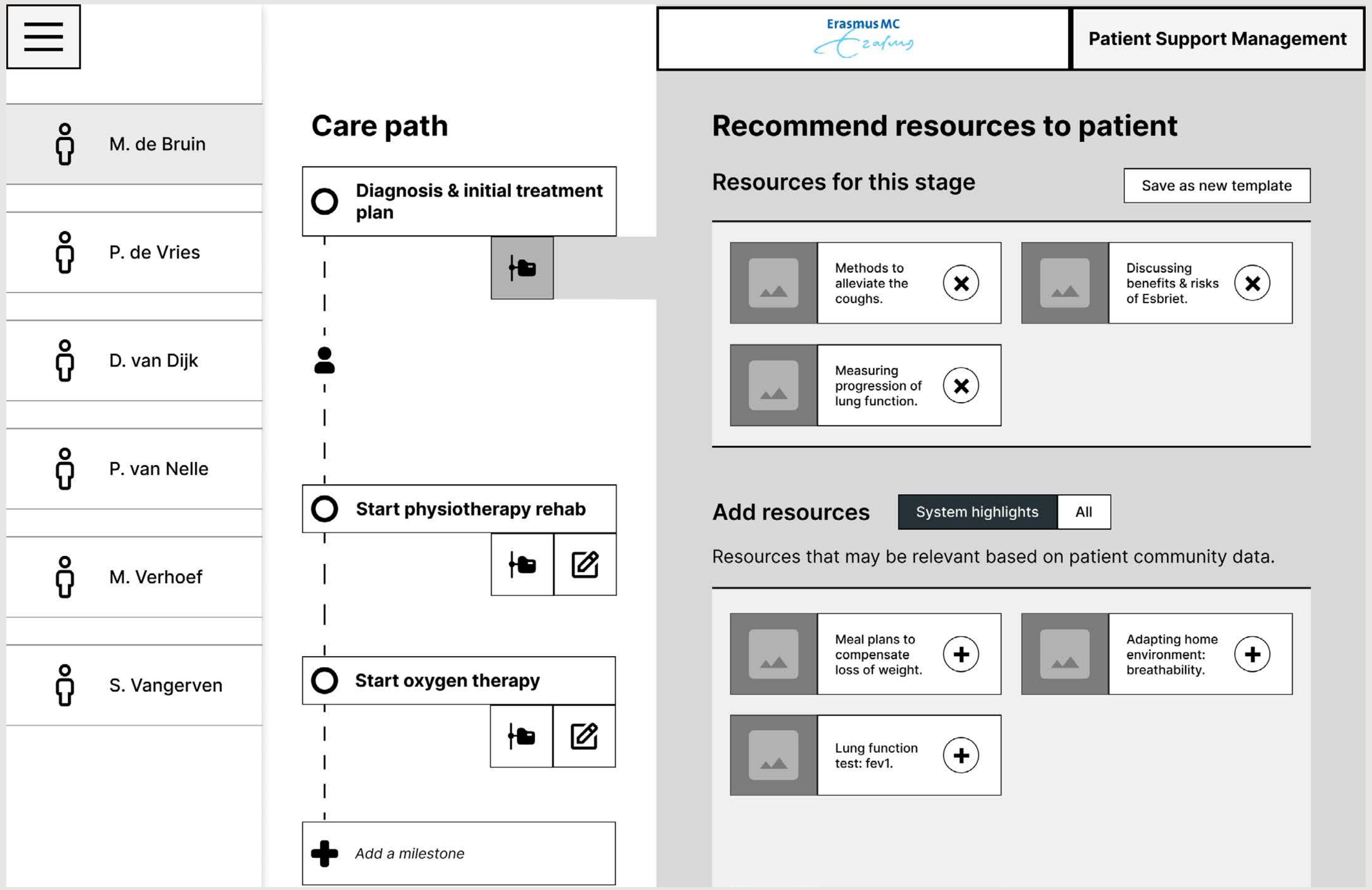


Figure 7.4: Possible future dashboard using recommender systems..

Use care milestones to organize the provision of information support.

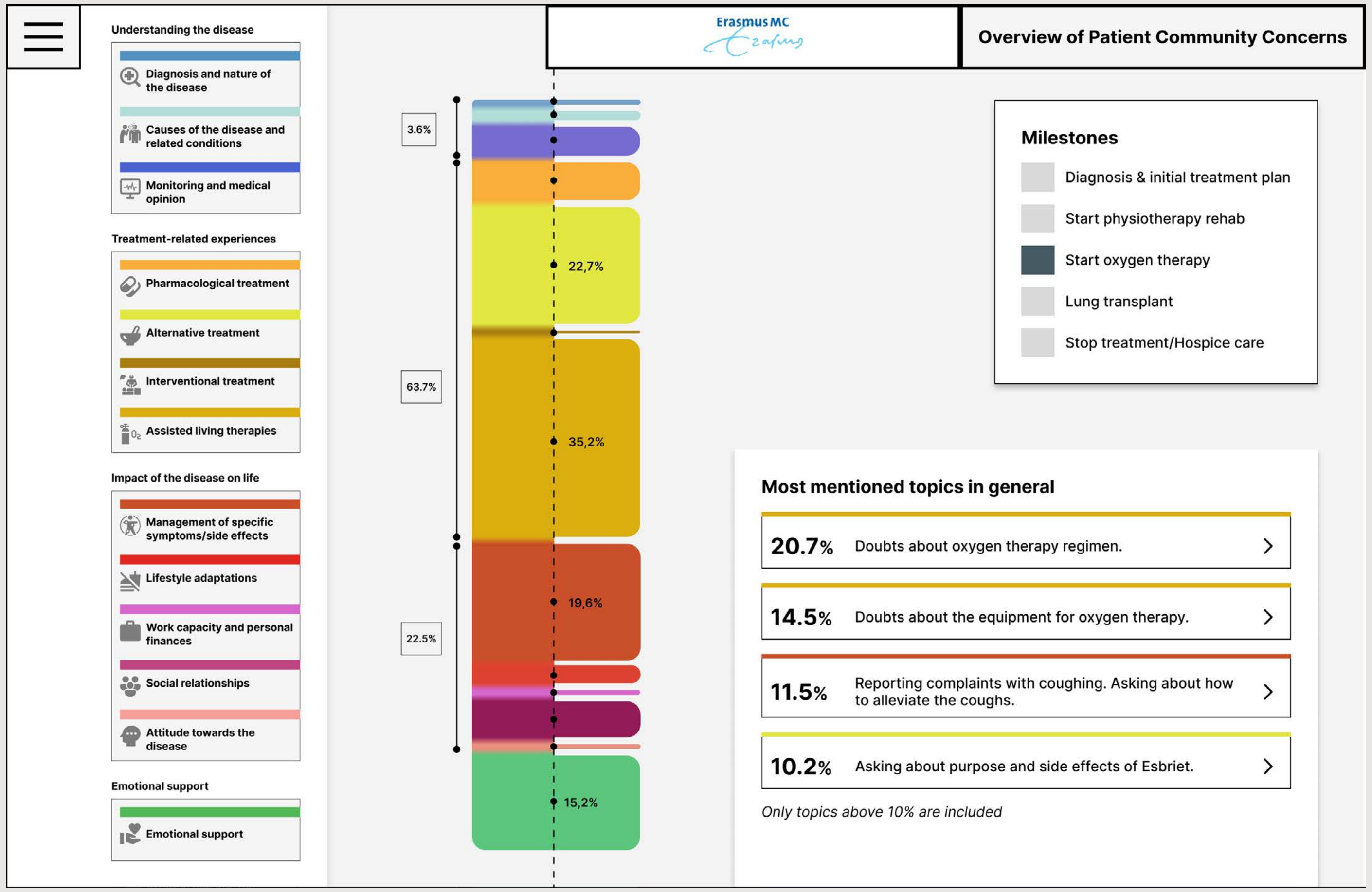
The first clinical expert interviewed in the evaluation sessions found it highly valuable to incorporate the provision of specific information according to the care stages. Since the patients already fill in their personalised care plan together with the nurse practitioners, we could use the recurrent milestones in the care path to highlight different resources throughout the care timeline. It seems that this interaction could fit the current context and complement the eHealth application that the pulmonology department for interstitial lung diseases is already working on.

> Clinical expert 1 - "They have a personalized care plan that they fill out with the nurses and I think you should integrate this all to 1 application and this would be very helpful because patients fill out their personal plan and... if they see from like your care paths that you created where they exactly are in their care path, that they could get specific information out of the tool, based on where they are, in what phase of the disease..."

Regarding the dashboard with the community overview of patients' concerns, the clinical researcher mentioned that the care milestones could be more adequate criteria to represent the evolution of patients' needs and doubts due to the unpredictable nature of the disease. In the prototype that was shown to the expert, I used "years after diagnosis" as the criterion to show the possible evolution of patients' concerns (Figure 4.13).

> Clinical expert 1 - Participant: "would you be able to make... to change this to the location of the care path where the patient is in, because... pulmonary fibrosis is a very heterogenetic disease like it's not very predictable how the patients will progress within years...maybe after they started oxygen therapy.
>
> Researcher: "oh, like those milestones?"
>
> Participant: " yeah, milestones...to put in milestones...Maybe for Sarcoidosis the years would match"

It seems that for more unpredictable and variably progressive diseases it is better to measure the evolution of patient self-reported doubts according to care stages (Figure 7.5). The pancreatic cancer surgeon and nurse practitioner (Chapter 4) also shared that it would be more relevant to distribute the PX data according to the stage of the cancer, which also directly relates to the treatment that they receive. For instance, patients receiving palliative treatment or curative intent. The different preferences for these criteria could be further investigated in future research directions.



Most mentioned topics in general

20.7%	Doubts about oxygen therapy regimen.
14.5%	Doubts about the equipment for oxygen therapy.
11.5%	Reporting complaints with coughing. Asking about how to alleviate the coughs.
10.2%	Asking about purpose and side effects of Esbriet.

Only topics above 10% are included

Figure 7.5: Refinements in the dashboard for community overview of patient concerns.

Combine the dynamic provision of resources with symptom/side effect monitoring.

The clinical expert from the first evaluation session envisioned the opportunity to retrieve relevant resources when the patients report changes in their symptoms. In the current application that they are developing, the patients provide scores depending on the severity of their symptoms (e.g., cough, shortness of breath, fatigue, etc...). We could use this system in future developments to provide specific resources to deal with or alleviate specific symptoms and side effects when patients report that the symptoms or side effects are worsening. This would represent another way to combine patients giving input about their quality of life with the retrieval of relevant resources that contribute to patients' self-management.

> (Clinical expert Evaluation 1) "You could also uhm, put this information out when the patient fills out symptoms about cough, for example, so that methods to alleviate the cough will pop up when a patient has a worsening cough...."

Provided that the data inputs are not conflicting, different sub-services can co-exist together. Following the guiding principle of "Facilitate incremental adaptations of knowledge modules to the patients", the designed service architecture should be flexible to soft launches of sub-services like this one that target the monitoring of a specific data category.

Integrate existing applications and services into a unified architecture.

The clinical expert from the second session valued how the service architecture seamlessly unifies the provision of curated information resources, interactive search engines and a dynamic visualization of the patient needs. Future research could investigate how to unify and integrate better the features from different eHealth applications that are currently being developed at ErasmusMC.

> (Clinical expert Evaluation 2) "I don't know if we need an extra app for that, but I think...we should do something with the idea so the standardized information base which is easily accessible by patients...with linking the question because all the all the distinct parts of this already exists... There's already some chat bots, but this I think it brings it all nicely together and maybe we should see, not really need a different app, but there should be some way to improve patient-(care) provider communication and learn from...what the patients need and what we think the patients need."

Target adequately the individual and community overview in the dashboard.

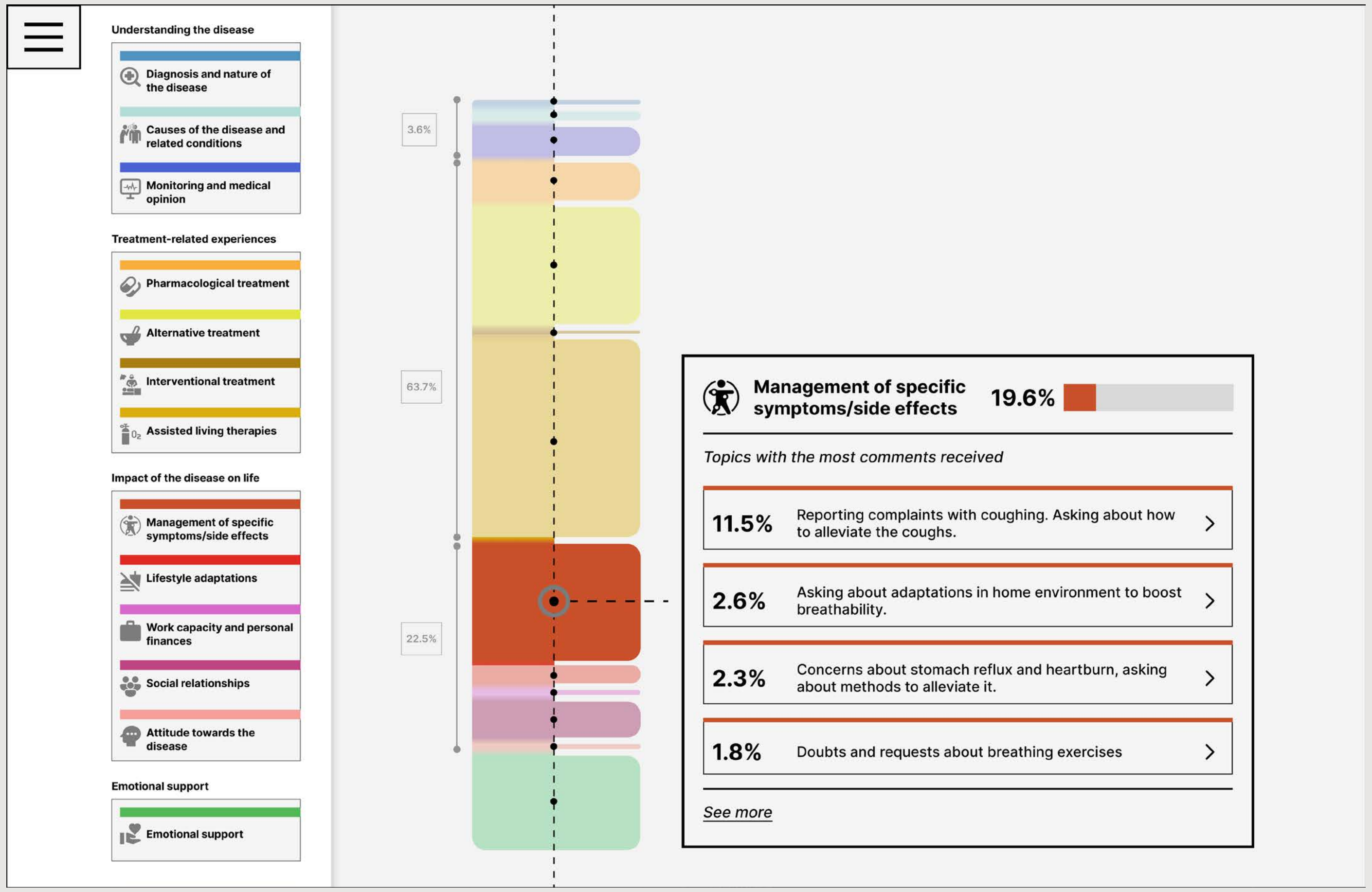
Both clinical experts who participated in the evaluation sessions reported that the individual overview of patients' concerns would fit in the workflows of nurse practitioners since they are the ones who currently answer those questions via phone or email.

Moreover, both clinical experts aligned with the experts involved in the co-creation session on the need for the provision of information support based on the patient's self-reported concerns. However, it should be researched further on how it fits within the work ecosystem of different departments. The clinical expert from the second evaluation session envisioned that a desk manager would control the community overview and update the resources in the repository, since specialist doctors and nurses would be too busy responding the individual doubts. It seems that it would be relevant to create a job position for curating and improving digital health support. This resonates with what a clinician mentioned in the first co-creation session. Alternatively, clinicians could look at it as a periodic meeting, for instance, every 6 months when the ML engineer has updated the classifier.

→ **Number 3 on blueprint**

> (Clinical expert Evaluation 2) - "because this (community overview) is more something I would see in a workflow, I mean the prior thing is more like a group health management...So that I wouldn't fit that in a direct patient care flow.. There's one person or two who has a couple hours per week to update the repository and to see what new topics are the most asked question that we don't have information for...So that's more, yeah, a content creator actually like like you would have for for the website or something...this (individual overview) I would integrate in the direct patient care...For example, the nurse practitioner that has, uh, for example, every two times a day at at lunch or at the end of the day has one hour to answer all these questions..."
>
> (Clinician Co-creation session 1) - "So we see a strong role for nurses here (semi-automated system)...but we need a different profession...We need, you know, desk managers themselves that provide online care."

The clinical expert also described that the topics within each category indicate better how to create or update the content in the repository. This is because the topics show more specific doubts and concerns, and the categories are more abstract. Therefore, the dashboard should also show the percentages of topics as in Figures 7.5 & 7.6. Furthermore, if the professionals are interested in one of these topics, they should be able to access the more representative reported concerns from the patients, which would appear anonymised.



Management of specific symptoms/side effects 19.6%

Topics with the most comments received

11.5%	Reporting complaints with coughing. Asking about how to alleviate the coughs.
2.6%	Asking about adaptations in home environment to boost breathability.
2.3%	Concerns about stomach reflux and heartburn, asking about methods to alleviate it.
1.8%	Doubts and requests about breathing exercises

See more

Figure 7.6: Refinements in the exploration of community concerns.

> "I would break it on topic because they get category is much maybe more interesting to categorize and say something for where are, but if you want to answer those questions, you need the topic..."

Use responses to individual concerns to expand the repository for the community.

→ **Number 4 on blueprint.**

Through data technologies, the nurses could not only answer specific concerns or forward them to the specialist doctor but also save them in the repository to feed the IR system. Then, the information retrieval system could provide those recommendations to other patients to prevent the patients from reporting similar concerns repeatedly when there are useful resources available.

> "Like you're finding out where you don't have enough information, so you have to supplement that information, from now on, so that you are not having always the doctors (answering).."

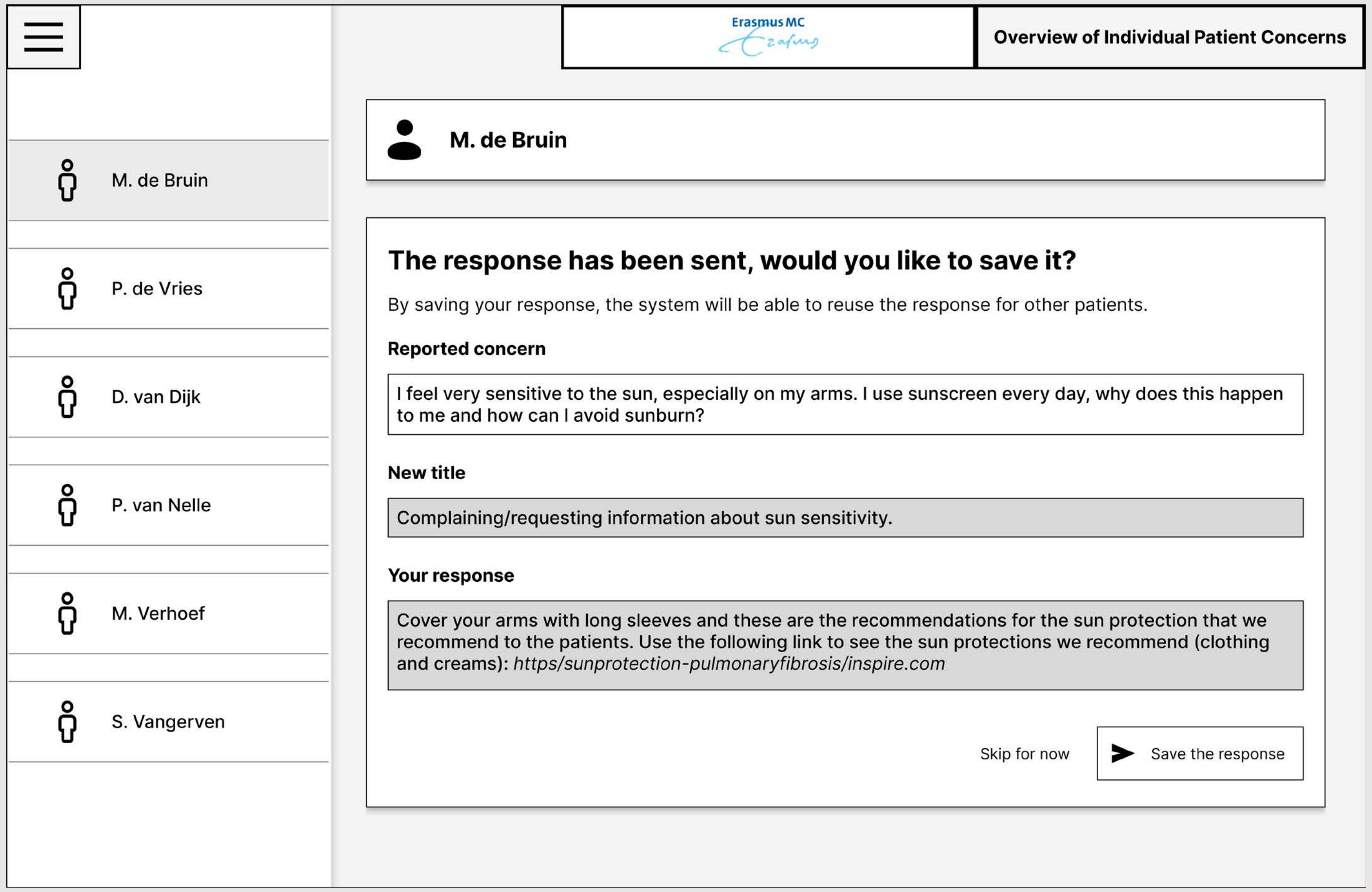
Responsibility

Investigate the anonymisation of self-reported concerns.

→ **Number 5 on blueprint**

Due to the sensitivity of the data and the possibility of containing different types of identifiable data, it would be necessary to explore how to detect sets of identifiable data in the text and delete them through automated ways. The self-reported doubts should be free of personal details that can be traced back to the patient. Future steps could explore computational techniques that warrant the anonymity of the patient's concerns before they are added to the community overview.

> "But the reality is some people vote very high trust in automated systems, and so they will put a lot of details in these reports...And some of those details can be personally identifiable...So you might want to consider a small step in the middle that anonymizes it."



The response has been sent, would you like to save it?

By saving your response, the system will be able to reuse the response for other patients.

Reported concern

I feel very sensitive to the sun, especially on my arms. I use sunscreen every day, why does this happen to me and how can I avoid sunburn?

New title

Complaining/requesting information about sun sensitivity.

Your response

Cover your arms with long sleeves and these are the recommendations for the sun protection that we recommend to the patients. Use the following link to see the sun protections we recommend (clothing and creams): *https/sunprotection-pulmonaryfibrosis/inspire.com*

Figure 7.7: Dashboard interface to respond to individual concerns and save responses in the repository.

Collect search terms for content improvements.

→ **Number 6 on blueprint**

> "the only pro on the other side of collecting all the search terms would be to well system improvement possibly and then also just having this tracking over time of all the different symptoms and other kinds of things...And maybe if there are lots of people researching bloating, you could even, even if they find information about bloating, you could give them even more information about bloating."

The search terms also represent valuable information about the initial concerns or doubts that the patients expressed by patients. Even if they do find appropriate knowledge to solve their doubt, the search terms could indicate what topics the patients do more research about. The content could be then expanded or refreshed accordingly. These search terms could be used, together with the ratings, to rank the resources recommended by the patient community for specific care stages.

Focus on non-generative information retrieval first.

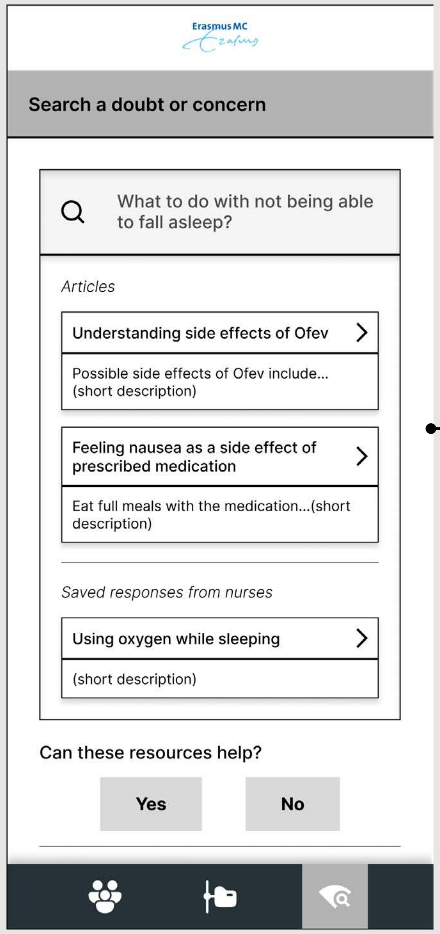
→ **Number 7 on blueprint**

The chatbot in the PX data collection module (Chapter 6) was envisioned as a tool to match the patients' questions with existing curated resources from the repository. ML experts interpreted this as the technique of Retrieval-augmented generation (Martineau, 2023). This technique would be used to ground the responses of a Large Language Model (LLM) on a curated repository of resources (e.g., articles, videos, tips, etc...).

> "instead of having well the user just query documents instead they have a chatbot and the chatbot is powered by chatGPT and more or less they will indeed match the information in the question to documents and the chatbot will then retrieve the document and provide a sentence to provide the document to the user."

An advantage is that it can provide a very seamless or conversation-like user experience where the patient writes a doubt and receives a document along with a generated explanation or a recommendation as if they were talking with their doctor or nurse practitioner. Through the LLM, the system could also justify the suggested resources, so the patients can more efficiently inspect and decide whether those resources are useful or not (Anand et al., 2023).

> Eval. session with 2 ML Expert: "So for somebody who is not super familiar or critical, yeah... Chatbots that generate content to some extent are way more practical, right?...I want to minimize



Search a doubt or concern

What to do with not being able to fall asleep?

Articles

Understanding side effects of Ofev

Possible side effects of Ofev include... (short description)

Feeling nausea as a side effect of prescribed medication

Eat full meals with the medication...(short description)

Saved responses from nurses

Using oxygen while sleeping

(short description)

Can these resources help?

Retrieval of resources based on patients' query.

Figure 7.8: Prototype of information retrieval system after evaluation sessions.

> friction for them to engage with these resources... for them to feel that somebody is helping them or somebody or the system to some extent is... going along with them... but where do you find the balance between making it more seamless, frictionless, but still making sure that the recipient is critically engaging with that content.”

A disadvantage of the conversational agent is that the patient community might overtrust the technology and share very intimate and sensitive data that they would have not shared through other types of interaction, which would have to be more carefully protected than search terms.

> “Is this chatbot using this particular LLM system going to be better than say a more basic search engine thing gets the same job done but then we only have to worry about protecting searching terms?”

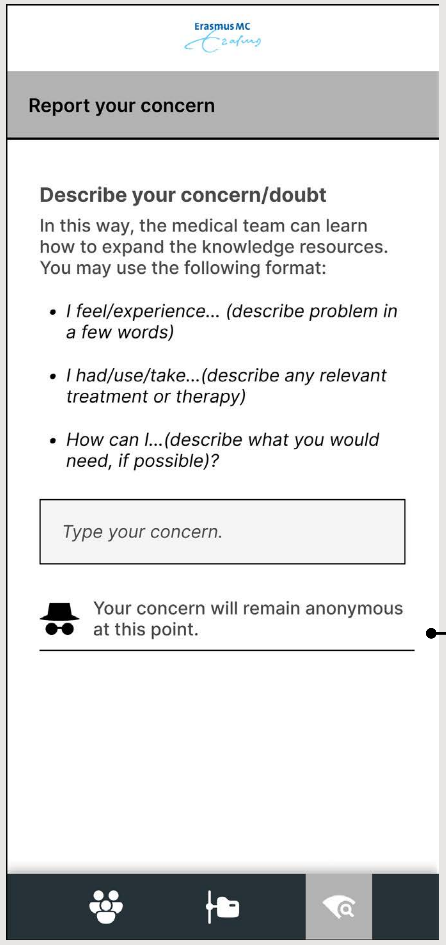
Another disadvantage discussed with the clinical experts is that many clinicians would be reticent to accept a generative search engine. Some clinicians will not trust the responses generated by the LLM, as they would be concerned that the LLM might inaccurately convey the information they intended to communicate through the curated resources.

To avoid misleading the patient about what the chatbot can do, it was decided to transform the interaction into a more explicit search engine (Figure 7.8) with some open-ended questions at the end to identify the missing gaps in the resource repository (Figure 7.9 & 7.10).

Protect patients’ agency over the data shared with medical professionals.

> “it’s important that they’re aware if they’re engaging with the system that the doctor will be able to see this...because sometimes we over trust technology and we share things with technology that we wouldn’t share with others.”

Since some self-reported concerns might be intimate and sensitive, the service interface should allow the patients to clearly distinguish the interactions that will be anonymised and the questions that they want to share in an identifiable way. The interfaces should protect the patients from accidentally sharing some comments (Figure 7.9 & 7.10).



Report your concern

Describe your concern/doubt

In this way, the medical team can learn how to expand the knowledge resources. You may use the following format:

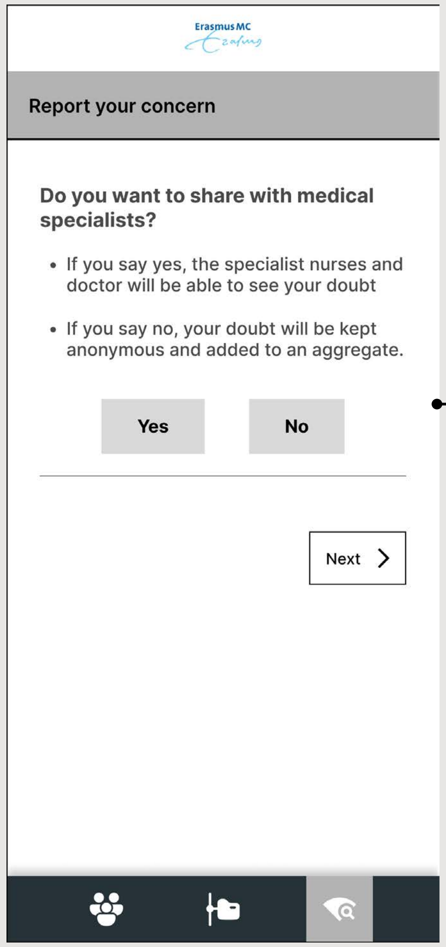
- *I feel/experience... (describe problem in a few words)*
- *I had/use/take...(describe any relevant treatment or therapy)*
- *How can I...(describe what you would need, if possible)?*

Type your concern.

Your concern will remain anonymous at this point.

Reminders of data anonymity.

Figure 7.9: Report a concern anonymously.



Report your concern

Do you want to share with medical specialists?

- If you say yes, the specialist nurses and doctor will be able to see your doubt
- If you say no, your doubt will be kept anonymous and added to an aggregate.

Announce when data will be shared with clinians.

Figure 7.10: Confirming to share the concern.

Design a comprehensive data management plan for the service system.

> “We have to specify where that’s gonna be...Who’s gonna have access to and how long it’s gonna live?...”

The ML experts commented on the considerations regarding data governance for such a service system. They mentioned that we would need to specify the data storing requirements, which include:

- Where is the data stored?
- For how long the data will be stored?
- Who will get access to the data?

The data storage would need to be localised at ErasmusMC and should only be accessible by the designated clinicians or clinical researchers once they have logged in to their work computers at ErasmusMC. Any data sharing with other institutions would raise the data restrictions.

> “I think if you make it hyper-local, which would be the easiest ...Then we would have to see what the requirements are, but for sure across institutions, it becomes more and more complex and very legally, and ethically more complicated.”

7.3 Conclusions.

The ML experts reported that the system seemed feasible with current state-of-the-art technologies. Nevertheless, the ML models should iteratively be developed, tested and validated through technical audits that ensure the performance of the computational model. The system should be investigated further in terms of the exact number of staff involved and expertise, and the period of maintenance that such a service would require.

The desirability for such a system was assessed by 2 clinical experts and they valued how the system standardises information provision along the care path. They highlighted that the service features should be integrated within existing eHealth applications rather than becoming a new application.

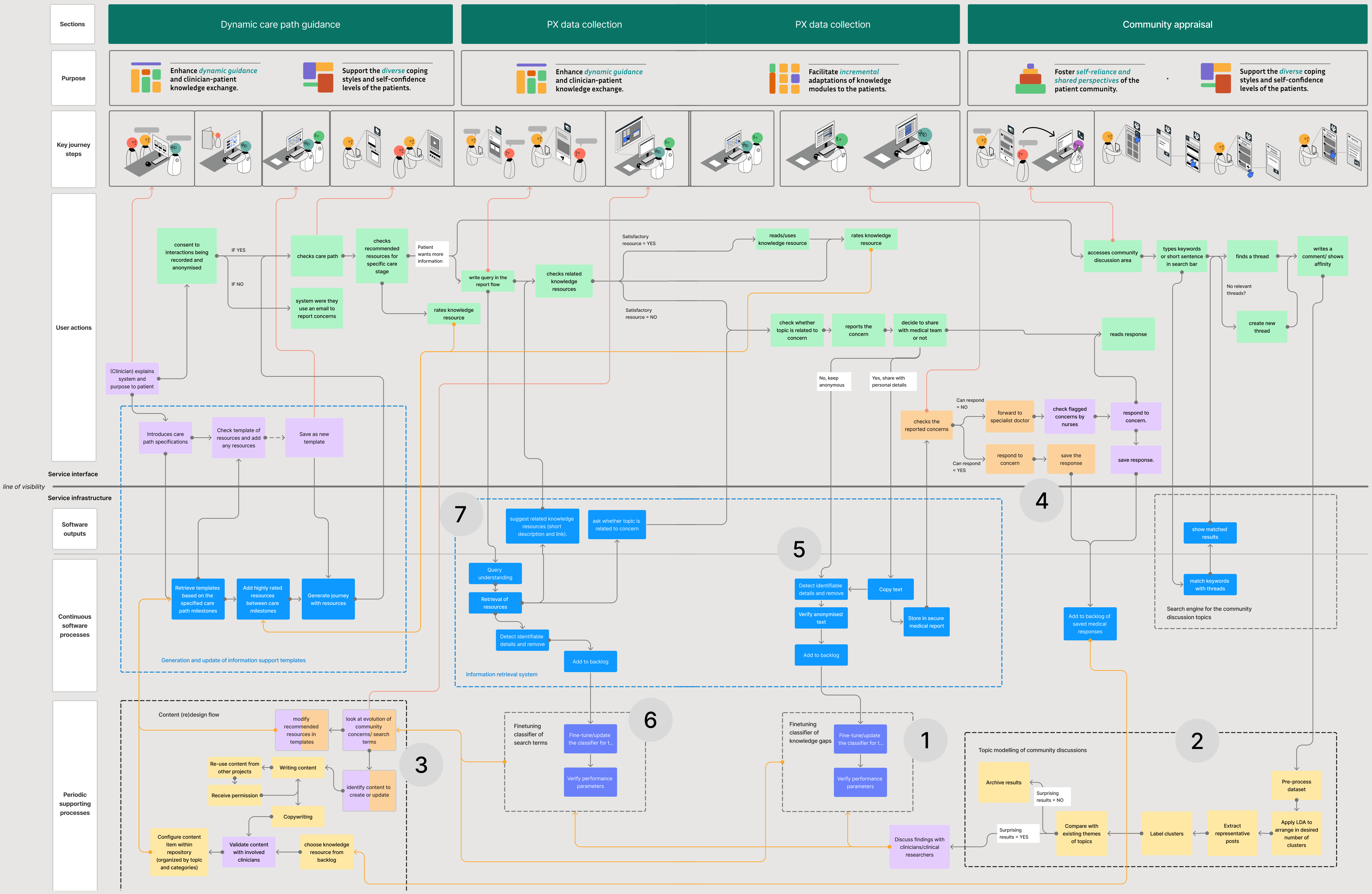
The principle of responsibility was discussed with ML experts in terms of data privacy and governance, and with clinical experts regarding how the system adapts to clinicians' workflow and role as communicators. To comply with ethical considerations around data privacy, the next steps should involve creating a data management plan that specifies how the data is protected following data governance regulations.

Also concerning responsibility, the evaluation sessions showed that the system should focus first on accurate information retrieval and classification of patients' concerns to incrementally improve the content. Then, we could investigate how the information retrieval system could apply generative large language models to make the provision of information more seamless and engaging for patients.

Based on the clinical experts involved, dedicated professionals should curate the content in the platforms, taking into account the nurses' and doctors' observations. This opens new avenues for developing a job position for desk managers that focus on curating and standardising knowledge and resources for patients.

Final service blueprint

Legend
- 🟧 Nurse practitioner
- 🟪 Specialist doctor
- 🟩 Patients
- 🟦 Software process/ outputs
- 🟦 ML engineer
- 🟨 Diverse professionals
- → Action/process step
- ← Feedback step



Sections

Dynamic care path guidance

PX data collection

PX data collection

Community appraisal

Purpose

Enhance *dynamic guidance* and clinician-patient knowledge exchange.

Support the *diverse* coping styles and self-confidence levels of the patients.

Enhance *dynamic guidance* and clinician-patient knowledge exchange.

Facilitate *incremental* adaptations of knowledge modules to the patients.

Foster *self-reliance and shared perspectives* of the patient community.

Support the *diverse* coping styles and self-confidence levels of the patients.

Key journey steps

User actions

(Clinician) explains system and purpose to patient

consent to interactions being recorded and anonymised

IF YES

IF NO

checks care path

system were they use an email to report concerns

checks recommended resources for specific care stage

Patient wants more information

rates knowledge resource

write query in the report flow

checks related knowledge resources

Satisfactory resource = YES

Satisfactory resource = NO

reads/uses knowledge resource

rates knowledge resource

check whether topic is related to concern

reports the concern

decide to share with medical team or not

No, keep anonymous

Yes, share with personal details

reads response

accesses community discussion area

types keywords or short sentence in search bar

finds a thread

No relevant threads?

create new thread

writes a comment/ shows affinity

Introduces care path specifications

Check template of resources and add any resources

Save as new template

checks the reported concerns

Can respond = NO

forward to specialist doctor

check flagged concerns by nurses

respond to concern.

save response.

Can respond = YES

respond to concern

save the response

Service interface

line of visibility

Service infrastructure

Software outputs

suggest related knowledge resources (short description and link).

ask whether topic is related to concern

show matched results

Continuous software processes

Retrieve templates based on the specified care path milestones

Add highly rated resources between care milestones

Generate journey with resources

Generation and update of information support templates

Query understanding

Retrieval of resources

Detect identifiable details and remove

Add to backlog

Information retrieval system

Detect identifiable details and remove

Copy text

Verify anonymised text

Store in secure medical report

Add to backlog

Add to backlog of saved medical responses

match keywords with threads

Search engine for the community discussion topics

Periodic supporting processes

Content (re)design flow

modify recommended resources in templates

look at evolution of community concerns/ search terms

Re-use content from other projects

Writing content

Receive permission

identify content to create or update

Copywriting

Configure content item within repository (organized by topic and categories)

Validate content with involved clinicians

choose knowledge resource from backlog

Finetuning classifier of search terms

Fine-tune/update the classifier for t...

Verify performance parameters

Finetuning classifier of knowledge gaps

Fine-tune/update the classifier for t...

Verify performance parameters

Discuss findings with clinicians/clinical researchers

Topic modelling of community discussions

Archive results

Surprising results = NO

Surprising results = YES

Compare with existing themes of topics

Label clusters

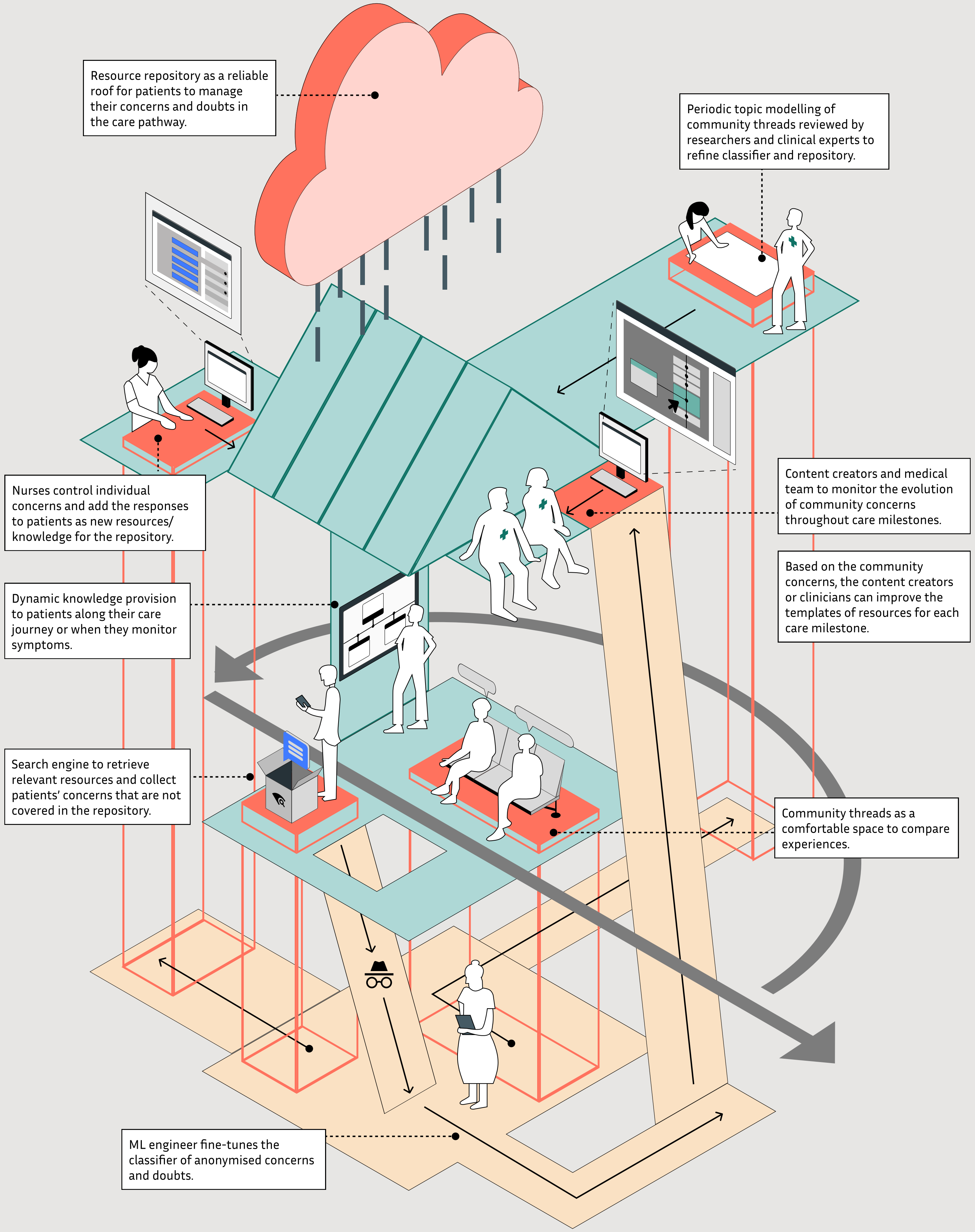
Extract representative posts

Apply LDA to arrange in desired number of clusters

Pre-process dataset

Summary of the refinements in the service system vision.

The following illustration presents the final insights and recommendations of ML and clinical experts reflected in the proposed service system vision. This service system vision is included in the poster uploaded to the TU Delft repository together with this thesis report.



Resource repository as a reliable roof for patients to manage their concerns and doubts in the care pathway.

Periodic topic modelling of community threads reviewed by researchers and clinical experts to refine classifier and repository.

Nurses control individual concerns and add the responses to patients as new resources/ knowledge for the repository.

Dynamic knowledge provision to patients along their care journey or when they monitor symptoms.

Search engine to retrieve relevant resources and collect patients' concerns that are not covered in the repository.

Content creators and medical team to monitor the evolution of community concerns throughout care milestones.

Based on the community concerns, the content creators or clinicians can improve the templates of resources for each care milestone.

Community threads as a comfortable space to compare experiences.

ML engineer fine-tunes the classifier of anonymised concerns and doubts.

Chapter 8: Conclusion

8.1 Discussion

Topics of online patient stories from three different patient communities were analysed through a combination of human interpretation and computational analysis to reach a thematic categorisation of patients' doubts and concerns. The topics and categories were visualized through an interactive prototype to engage clinical experts in a conversation about the findings and discuss meaningful opportunities for value creation. This way, the project iteratively identified, in collaboration with clinical experts, the design challenge: **to create a service vision and modules that...**

- Foster self-reliance and shared perspectives of the patient community.
- Facilitate incremental adaptations of knowledge modules to the patients.
- Enhance dynamic guidance and clinician-patient knowledge exchange.
- Support the diverse coping styles and self-confidence levels of the patients.

The iterative process of research and design with patient experience data resulted in a service system vision that enables the continuous improvement of information support throughout the care path. The envisioned service offering could be incrementally adapted to different departments at ErasmusMC and the eHealth applications that they develop for RPM (Norman & Stappers, 2015). The system aims to proactively learn from the patient communities to curate knowledge support and various resources during the care journey.

Through community discussions, the patients can deal with problems that the clinicians might not have considered before. From the periodic analysis of these community platforms, we can continuously learn about the patients' struggles in their daily lives and provide resources to improve the quality of care. Through this project, I posit that even when patients effectively engage in self-management through RPM, we should afford the patient community to recommend and highlight relevant resources and tips to their peers. Resilient RPM systems should creatively integrate individual and community perspectives to refine the support resources.

The data categories and the topics within those categories could be used to develop the content for comprehensive knowledge modules, which inform the patients along the care path. This research highlights the importance of standardising knowledge support in a way that can be repurposed and adapted for different chronic patient communities and can be incrementally improved based on the self-reported concerns of patients.

Clinical experts highlighted the need for dynamic information support as patients navigate the care journey. Designing and curating knowledge support templates for specific care milestones and stages through ML techniques (e.g., classifiers and explainable information retrieval systems is proposed to enhance the efficiency of clinician-patient communications. The research showed that clinicians also find it relevant to be able to progressively discover the knowledge gaps from the patients' self-reported concerns and improve their role as communicators.

Furthermore, the project highlights the need to make knowledge resources accessible to patients with different coping styles and educational backgrounds. The project envisions that the knowledge is prioritised along the care path so that patients can review only a few simple resources, but if they need, they can prompt the search engine to dive deeper into the repository or explore what other patients rated as more useful.

8.2 Limitations

Creating comprehensive templates of information support for care milestones

From the co-creation and evaluation sessions with clinical experts, it seemed imperative to standardize the content and resources along the care path and to incrementally improve it based on self-reported concerns. However, the project did not thoroughly investigate how the templates of information resources would specifically change for each disease and the specific content that would be included in those templates. Carefully curating the care milestones that the templates should be based on and the content within those templates would require a longer collaboration with clinical researchers and clinicians who have the expertise to validate the quality and accuracy of the content. Nevertheless, the service concept suggests a preliminary way to standardize the provision of information support in a way that can be incrementally adapted and expanded within specific patient communities.

Usability and user experience of the PX data collection module.

Through the service interfaces created, I suggested that the service could connect the retrieval of resources from the patients' queries with a flow to report your uncovered concern, in the case that the resources retrieved were not helpful. This flow and interface design could be investigated further to understand how to adequately engage patients in sharing their concerns. The community discussions in the Community Appraisal module could spark some questions that are not covered in the repository and therefore the patient could reflect that in the PX data collection module. However, there is still a lot of room for research and development on how patients can effectively communicate their doubts in a digital environment and with IR systems.

8.3 Implementation & recommendations.

The proposed service system could be incrementally integrated within different eHealth applications that specific departments at ErasmusMC are developing, or within a self-monitoring eHealth application that ErasmusMC wants to release for the whole hospital. The service system should be initially explored as a new feature for a group of patients from a specific community (for instance, Sarcoidosis) in a controlled trial. Based on the insights from the evaluation sessions with clinical and ML experts, I could derive three phases of future developments.

Phase 1: The next phase of development of the proposed service system should focus on developing an accurate information retrieval (IR) system that provides resources to the patient community based on their self-reported doubts, and a classifier of self-reported doubts and concerns. Throughout this research period, we could investigate how to efficiently engage patients in sharing their concerns and experiences for the continuous improvement of the knowledge repository.

Phase 2: Once a convenient and engaging IR system has been technically validated and meets the relevant data privacy regulations, pilot studies could be carried out to test the performance of the service feature with groups of patients.

If there is a significant number of patients using the system, I suggest the implementation of community support forums and threads, as shown in the module Community Appraisal. This way, we can start learning about what potential topics of content could exist through topic modelling.

Phase 3: Even though more distant in the future, coming research could focus on explainable large language models (Anand et al., 2023). The already precise IR grounded on a highly curated repository could justify its choices for knowledge resources to the patients and engage them in a seamless conversation. Furthermore, it seems promising to explore how recommender system algorithms (Rocca, 2021) could be used to provide new knowledge resources to clinicians to create or include in the templates for each milestone.

Phase 1

Co-design of an information retrieval (IR) for the module of PX data collection.

PX data collection

- Create a functional prototype of an IR system (query understanding and IR of relevant resources for self-reported doubts) & validate in a technical audit.
- Develop and validate the classifier for search terms and reported concerns.
- Automate and technically validate the anonymisation of patients' self-reported concerns.
- Iteratively test and improve the data collection flow through controlled studies to warrant:
  - patients' agency over the data shared.
  - seamless and convenient user experience

Dynamic guidance

- Combine IR system with symptom/side effect self-management.

Outcome

Validated PX Data Collection module for pilot studies.

Phase 2

Improve the repository and classifier

PX data collection

- Launch the IR system through pilot studies to collect representative data (uncovered concerns).
- Update and curate the classifier with pilot data.

Community appraisal

- Develop and moderate the community support module.

Dynamic guidance

- Populate the repository with the responses and recommendations from nurse practitioners to patients.
- Periodically improve topics and content in the repository between pilot studies based on the classified searchers and self-reported concerns (knowledge gaps in the repository).

Outcome

Service can be deployed in the patient community as a large pilot.

Phase 3

Make IR system more personal, explainable and scrutable

PX data collection

- Explore LLM-based IR model that generates short explanations about why the system retrieves a specific resource.

Community appraisal & dynamic guidance

- Improve topics and content based on the results from the periodic topic modelling of the community discussions.

Dynamic guidance

- Research whether recommender system algorithms could be used to suggest to the patient community what resources to read based on searches and ratings.

Outcome

The support resources become highly personalised and understandable.

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Convergence