

# Towards Coherent and Effective Self-Management during the Post-Diagnosis Stage

*An application empowering individuals with Pulmonary Fibrosis*





## Master Thesis

August 2023, in Delft, the Netherlands

MSc. Design for Interaction, Medisign Specialization

Faculty of Industrial Design Engineering

Delft University of Technology

## Author

Ruixuan Zhang

## Supervisory Team

Chair: Prof. dr. ir. R.H.M. Goossens  
Delft University of Technologies  
Department of Human-Centered Design

1<sup>st</sup> Mentor: Prof. dr. Rietjens, J.A.C.  
Delft University of Technologies  
Department of Design, Organization and Strategy

2<sup>nd</sup> Mentor: Dr. J. Jung  
Delft University of Technologies  
Department of Design, Organization and Strategy

## Towards Coherent and Effective Self-Management during the Post-Diagnosis Stage

# Acknowledgement

## Dear reader,

Thank you for reading the report of my Master's graduation project, which has been nourished by all the talented and caring people that I have had the best luck and honor to be supported by. I truly appreciate everyone who has helped, guided, and supported me in making this project possible!

## To my supervisory team:

Many thanks for your support and guidance throughout this project. It is such an great honor and luck for me to be your student. I want to give a big thank you to Richard for all your valuable feedback and suggestions. You always inspired me with new ideas after each of our progress meetings, and I appreciate your cheering and inspiring educational style very much! And Judith, thank you for all the inspirational references and your expertise in public health that you shared with me! And Jiwon, thank you so much for being such a caring and inspiring mentor! I have been inspired by your design methods not only throughout this project but also leading to the next step of my career. To all of you, I have not only learned from your expertise, but I also look up to the way that you are working as excellent researchers. I hope I can follow your steps in my soon-to-begin academic career.

## To the medical team and patients from Erasmus MC:

I want to give a big thank you to all the doctors and nurse specialists from the ILD team in Erasmus MC, and the patients who participated in my research and provided me with invaluable real-life experiences and perspectives, which helped to make this project closer to the real-life and users. I want to thank Dr. Marlies Wijssenbeek for giving me the precious opportunities to observe in your consultation, and helping me recruiting patients for the user research.

## To the data scientist who helped me with the machine learning study in this project:

I would like to thank my 'teammate' Rembrandt for the effort and time your put into the machine learning analysis, and I cannot make this project possible without your help. It helped me a lot that we always worked together and supported each other. You make it feel like a team though we are working on individual projects.

## To my beloved family, my boyfriend, and my friends:

I would never have enough space to thank mom and dad for everything that you give me. Thank you for giving me unconditional trust, love, and motivation all the time.

To my boyfriend Yuyue, thank you for always being there for me, supporting me and calming me down when I was stressed out, and always feeding me with the yummy foods!

And I want to give a big thank you to all my friends, both in the Netherlands and in China. You are always my emotional support no matter how far the distance between us.



Ruixuan Zhang

August 2023

# Abstract

Pulmonary Fibrosis (PF) is a rare and incurable interstitial lung disease, which causes lung scarring, leading to an irreversible decline in patients' lung function and breathing difficulties. In Europe, Pulmonary fibrosis (PF) affects over 400,000 people, and it claims the lives of about 100,000 people each year (EU-IPFF, 2023). In light of the prevailing medical personnel deficit and the stress on healthcare systems, a collaborative synergy between healthcare practitioners and patients becomes indispensable to facilitate the transition of healthcare services from hospital settings to domiciliary environments and to tailor individualized home care.

This endeavor is spearheaded by Erasmus MC, a preeminent specialist center for PF in the Netherlands. In collaboration with the Convergence program and TU Delft, this initiative embarks on exploring the PF patient journey map while develop innovative design solutions. These solutions are aimed at empowering patients to engage in self-management and to enhance their Health-Related Quality of Life (HRQoL).

The overarching methodology of this project adheres to the Enhanced Data-enabled Design (EDED) approach by Jung (2023), which leverages data collected within the community, user, and design contexts and adopts an iterative design process. Firstly, getting inspired

by the online patient community data which contains more than 40,000 of patient stories, the initial problem areas that patients have most struggles are defined.

Subsequently, the insights gained in the community context are further examined in the user context. First, the preliminary patient journey map was validated and refined, and the initial problem areas were scoped down through co-creation and interviews with Healthcare Professionals (HP). Secondly, a user behavior study was conducted to uncover PF patients needs in their self-management process by reusing community data and leveraging the Information-Motivation-Behavioral Skills framework. The result of this study addresses the problem of this project, as the primary needs of PF patients to achieve effective and coherent self-management behavior are to acquire information related to five main aspects:

- Understanding and management of medication;
- Understanding and management of oxygen therapy
- Understanding Treatment and medication options
- Lifestyle adjusting to adapt to changes in life
- Symptom monitoring and management

Therefore, the final design goal of this project is defined as:

***“ How to provide PF patients with required, reliable, and understandable information to support their self-management behavior in their post-diagnosis stage.”***

Accordingly, the user needs in information and the design goal collectively establish the foundation design concept: Vomo, a Product-service systems (PSS) to facilitate PF patient self-management in the post-diagnosis stage. The delivery of Vomo is facilitated through an application that is accessible to its end users. The present PSS has undergone a redesign process, drawing inspiration from the preexisting framework of a PSS known as Erasmus MC's IPF-Online. This project presents a comprehensive analysis of the rationale for the redesign of certain functions and proposes strategies for the future implementation of these revised functions inside the existing product.

# Reading Guide

The reading guide in this sections aims to support the reader to easily to understand the contents in this report.

**The key insights are highlighted in this way in the report.**

*“The quotes from online patient stories or interviews are formatted in this way.”*

## Key takeaways of each chapter

- Takeaway 1
- Takeaway 2
- Takeaway 3
- .....

## Abbreviations used in the report:

AI: Artificial Intelligence

HP: Healthcare Professionals

HRQoL: Health-Related Quality of Life

ILD: Interstitial Lung Disease

GP: General Practitioner

ML: Machine Learning

PF: Pulmonary Fibrosis

RQ: Research question

SMB: Self-Management Behavior

# Table of Contents

|                                                                     |           |                                                                    |           |
|---------------------------------------------------------------------|-----------|--------------------------------------------------------------------|-----------|
| <b>Abstract</b>                                                     | <b>2</b>  | <b>Chapter 4: Self-management Behavior Study</b>                   | <b>41</b> |
| <b>Acknowledgment</b>                                               | <b>3</b>  | 4.1 Study Purpose and Research Questions                           | 42        |
| <b>Reading guide</b>                                                | <b>4</b>  | 4.2 Self-management behavior in PF patient care                    | 43        |
| <b>Table of contents</b>                                            | <b>5</b>  | 4.3 Behavioral-psychological framework of self-management behavior | 44        |
| <b>Chapter 1: General Introduction</b>                              | <b>7</b>  | 4.4 Conclusions                                                    | 50        |
| 1.1 Project background                                              | 8         | <b>Chapter 5: Design Concept Generation</b>                        | <b>51</b> |
| 1.2 The assignment                                                  | 9         | 5.1 Problem Definition                                             | 52        |
| 1.3 Project Approach and structure                                  | 10        | 5.2 Design Goal                                                    | 53        |
| <b>Chapter 2: Context Inquiry</b>                                   | <b>11</b> | 5.3 Re-design directions on the current product-service system     | 55        |
| 2.1 Study purpose and research questions                            | 12        | 5.4 Ideation on the Information Interaction                        | 59        |
| 2.2 The healthcare providers and care path of PF in the Netherlands | 13        | 5.5 Define the technologies integration                            | 62        |
| 2.3 Observational study: the consultation in Erasmus MC             | 15        | 5.6 Conclusions                                                    | 64        |
| 2.4 Patient community journey mapping                               | 17        | <b>Chapter 6: Product-Service-System Final Proposal</b>            | <b>65</b> |
| 2.5 Conclusions                                                     | 28        | 6.1 Modules and sub-modules                                        | 66        |
| <b>Chapter 3: Expert Insights: Co-creation and Interview</b>        | <b>29</b> | 6.2 Information provision mechanism of the Chatbot                 | 67        |
| 3.1 Study purpose and research questions                            | 30        | 6.3 Detailing UI/UX styles: design for older adults                | 68        |
| 3.2 Co-creation with healthcare professionals                       | 31        | 6.4 High-fidelity model of final concept                           | 69        |
| 3.3 Interview with nurse specialists                                | 36        | 6.5 Conclusions                                                    | 74        |
| 3.4 Conclusions                                                     | 40        |                                                                    |           |

# Table of Contents

|                                                     |           |
|-----------------------------------------------------|-----------|
| <b>Chapter 7: Validation and Iterations</b>         | <b>75</b> |
| 7.1 Goal and Methods                                | 76        |
| 7.2 Validation with multi-disciplinary participants | 77        |
| 7.3 Implementation plan and next steps              | 79        |
| 7.4 Conclusions                                     | 81        |
| <b>Chapter 8: Conclusions and Discussion</b>        | <b>82</b> |
| 8.1 Discussion and Conclusions                      | 83        |
| 8.2 Personal reflections                            | 84        |
| <b>References</b>                                   | <b>85</b> |
| <b>Appendices</b>                                   | <b>90</b> |

## CHAPTER

# 1.

# Introduction to the Project

This chapter aims to provide an overview of the project context, the assignment, and the project approaches. Firstly, the background information on Pulmonary Fibrosis and the challenges of home care is introduced in section 1.1. Secondly, it describes the assignment in section 1.2. To conclude, section 1.3 presents the design approach followed throughout the project.



# 1.1 Project Background

The research described in this thesis was conducted during my master's graduation project, which is a collaboration between the Department of Industrial Design Engineering at TU Delft and the Interstitial Lung Disease (ILD) and Sarcoidosis Specialist Center at Erasmus Medical Centre. As part of the Consultation Room 2030, Flagship Convergence, this project aims to shape the continuity of Pulmonary Fibrosis (PF) patient care from hospital to home through digital technologies, to increase patients' Health-Related Quality of Life (HRQoL). Therefore, a smart product-service system is proposed to fit the project vision.

## 1.1.1 About PF

In Europe, Pulmonary fibrosis (PF) affects over 400,000 people, and it claims the lives of about 100,000 people each year (EU-IPFF, 2023). As a chronic and incurable disease, Pulmonary Fibrosis causes lung scarring, leading to an irreversible decline in patients' lung function and breathing difficulties. The underlying causes of pulmonary fibrosis can range widely, including exposure to environmental contaminants, cigarette smoking, usage of certain medications, autoimmune illnesses, and genetic susceptibility. Idiopathic pulmonary fibrosis (IPF) is frequently seen when the precise etiology is yet unknown. However, current treatment can merely slow the progression, and patients with PF have an average life expectancy of 3-7 years.

On the one hand, people with PF typically experience a range of physical symptoms that progressively worsen as the disease advances, commonly including persistent, hacking, coughing, shortness of breath (especially during physical exercises), fatigue, and intense chest pain. On the other hand, the disease also has implications to affect one's mental well-being. Anxiety and Depression can be caused due to people's restricted independence and fear of the future caused by the disease. In conclusion, the disease significantly impacts people's every life and impairs their quality of life. "PF had the effect of 'turning life upside-down' and causing one to 'readjust life goals' and 'refocus their lives.'" (Swigris et al., 2005)

Similar to other chronic obstructive pulmonary diseases, the trajectory of PF (as shown in Figure 1.1) is fluctuant and slowly progressive, with unexpected and often severe exacerbation (Murray et al., 2005). Consequently, to monitor their disease, patients often require frequent hospital visits for checkups and adjustments on treatment plans, which is time-consuming and exhaustive for the patients to travel to the specialist center. On the other hand, considering current medical staff shortages and financial limitations, it also increases the strain on the healthcare system. Therefore, it requires a collaborative effort between healthcare professionals and patients to facilitate the transition of healthcare from hospital to home and personalized home care, as "Professionals

are the expert about the disease, and patients are the experts about their own life" (Bodenheimer, 2002). This is where this project step in.

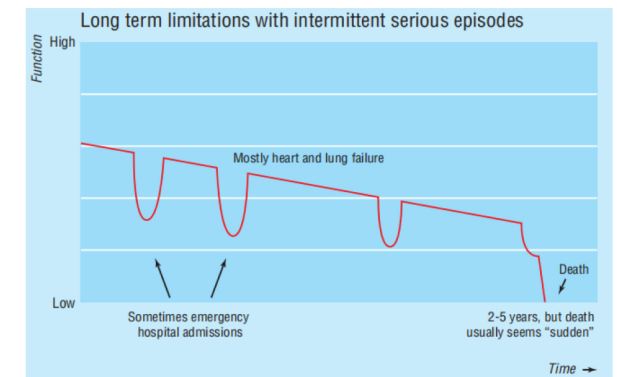


Figure 1.1: Trajectory of heart failure and chronic obstructive pulmonary disease (Murray et al., 2005)

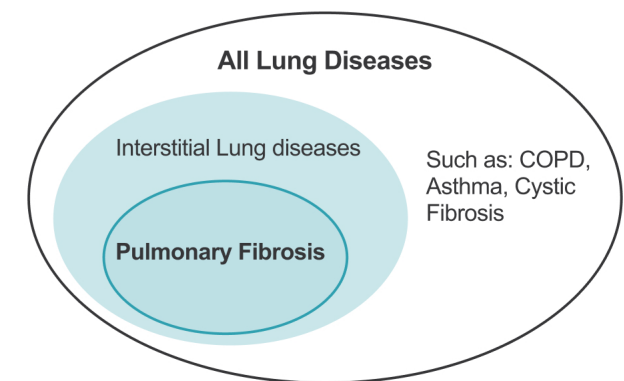


Figure 1.2: Relation between Pulmonary Fibrosis and ILD, Lung diseases



# 1.2 Project Assignment

## 1.2.1 Project aim and scope

The initial project assignment is provided by the Interstitial Lung Disease research group at the Erasmus Medical Center (EMC) and the Convergence program, involving collaboration with TU Delft, EMC, and Erasmus University. The assignment focuses on **"Improving pulmonary fibrosis patient remote monitoring systems through Community Journey Mapping to increase Health-Related Quality of Life (HRQoL) and patient empowerment."** Initially, the project aims to examine the entirety of the pulmonary fibrosis patient journey, from symptom awareness to end-of-life stages, in order to propose design improvements for the existing intervention. The project scope intentionally encompasses a broad range of factors. However, as the project progresses through different stages, the focus gradually becomes more specific. This intentional narrowing down of focus enables a thorough exploration of each stage and facilitates the development of targeted research questions.

Based on the given assignment, the primary objective of this project is to enhance the experiences of individuals diagnosed with pulmonary fibrosis through strategic design interventions. This overarching goal is closely aligned with the Quadruple Aim of Healthcare (Sikka et al, 2015). Within the context of the Quadruple Aim framework, patient experience

holds significant prominence, given its pivotal role in achieving a comprehensive and effective healthcare system. The Quadruple Aim, a holistic approach, seeks to optimize various dimensions of healthcare delivery. This encompasses bolstering population health, enriching patient encounters, curbing costs, and elevating the well-being and job satisfaction of healthcare providers, as visually depicted in Figure 1.3.

In light of the practical considerations, including project feasibility and the constraints of a finite timeline, a strategic approach is undertaken. The central focus remains the enhancement of pulmonary fibrosis patients' experiences, thus constituting the primary aim of this endeavor. Simultaneously, the other three dimensions encapsulated within the Quadruple Aim framework—improving population health, cost reduction, and augmenting healthcare provider satisfaction—are integrated as secondary aims, acknowledging their significance within the broader healthcare landscape.

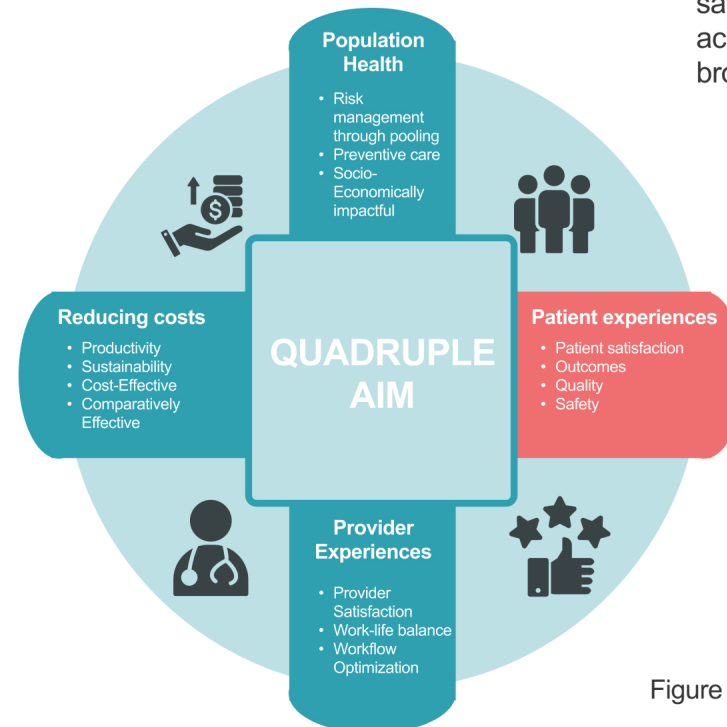


Figure 1.3: The Quadruple Aim of Healthcare

# 1.3 Project approach and structure

## 1.3.1 Project approach

This project utilizes the Enhanced Data-enabled Design (EDED) approach by Jung (2023), which leverages data collected within the community, user, and design contexts, as depicted in Figure 1.X. The EDED approach adopts an iterative design process, wherein the design studios, consisting of the design researchers, continuously receive data from both the community and users. This influx of information provides valuable insights that support the design activities within the studio. Additionally, the user context is actively incorporated during the design process through methods such as co-creation and user interviews.

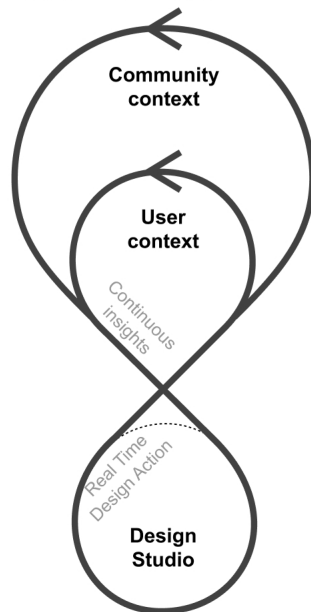


Figure 1.X: Enhanced Data-Enabled Design approach (J.Jung, 2023)

## 1.3.2 Project structure

Adopting this approach, the project is divided into four stages: (1) Contextual Inquiry, (2) User Research, (3) Design and Development, and (4) Evaluation and Next Steps. Figure 1.X illustrates the project's structure and chapter arrangement. In a sequential manner, Chapter 2 engages in a contextual inquiry study, gleaned insights from community data and frames out the initial problem areas. Sequentially, Chapters 3 and 4 delve into user research, involving co-creation sessions, interviews with healthcare professionals, and an analysis of user behavior in

self-management. These chapters merge user and community context insights to frame the problem and design goals. Chapters 5 and 6 concentrate on generating design concepts and prototyping. In Chapter 7, the design concept undergoes validation and evaluation by healthcare professionals, pulmonary fibrosis patients, and design experts, fostering iterative design and an implementation plan. Chapter 8 concludes with overall project conclusions and limitations.

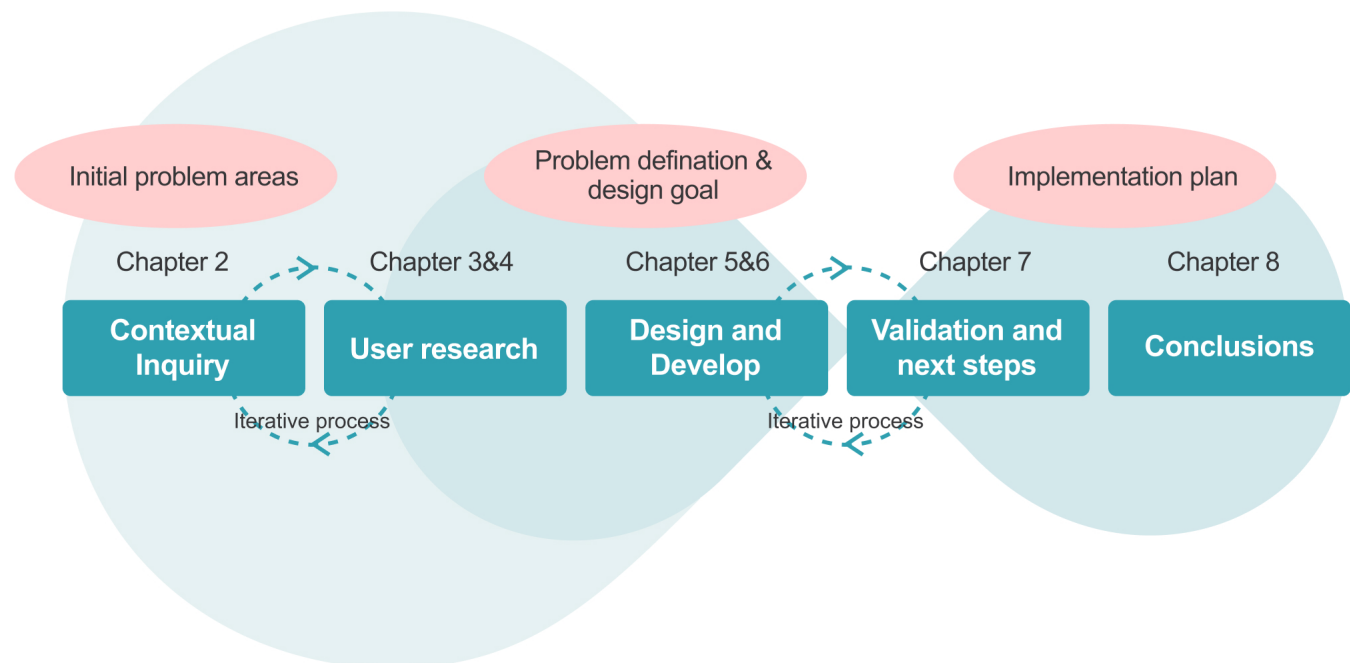


Figure 1.x: Project structure and chapters arrangement

# CHAPTER 2.

# Contextual Inquiry

The purpose of Chapter 2 is to provide an overview of the various research activities carried out during the contextual inquiry phase. The goal of contextual inquiry is to gain a broad understanding of the context of PF patient care from both a domestic (Netherlands) and global perspective, as well as to identify potential barriers in patients' experience with PF by employing mix of qualitative and quantitative research methods.

## 2.1 Study Purpose and Research Questions

Chapter 2 introduces the research activities conducted in the contextual inquiry study, beginning with empirical research on the healthcare providers and the current care pathway of PF patients in the Netherlands, including a review of the EMC care protocol - ZORGPAD, in Section 2.2; followed by an observational study of patient follow-up consultation in Section 2.3. Moreover, Section 2.4 introduces the study of integrating patient perspectives by employing an advanced design method called 'Patient Community Journey Mapping'. Lastly, Section 2.5 concludes the findings from all contextual inquiry studies, which uncover PF patients' experiences and problem areas in which patients face the most challenges in their care path, at the end of this chapter. These findings form the basis for generating design insights and informing subsequent stages of the design process. The following research questions (RQ) are addressed in Chapter 2:

**RQ1:** What is the care path of PF patients in the Netherlands?

**RQ2:** Who are the core healthcare providers in the PF patient care path and what are their tasks?

**RQ3:** What are the barriers and challenges faced by PF patients in their care path?

**Chapter 2 -Contextual Inquiry:** inspired by community data to explore user insights

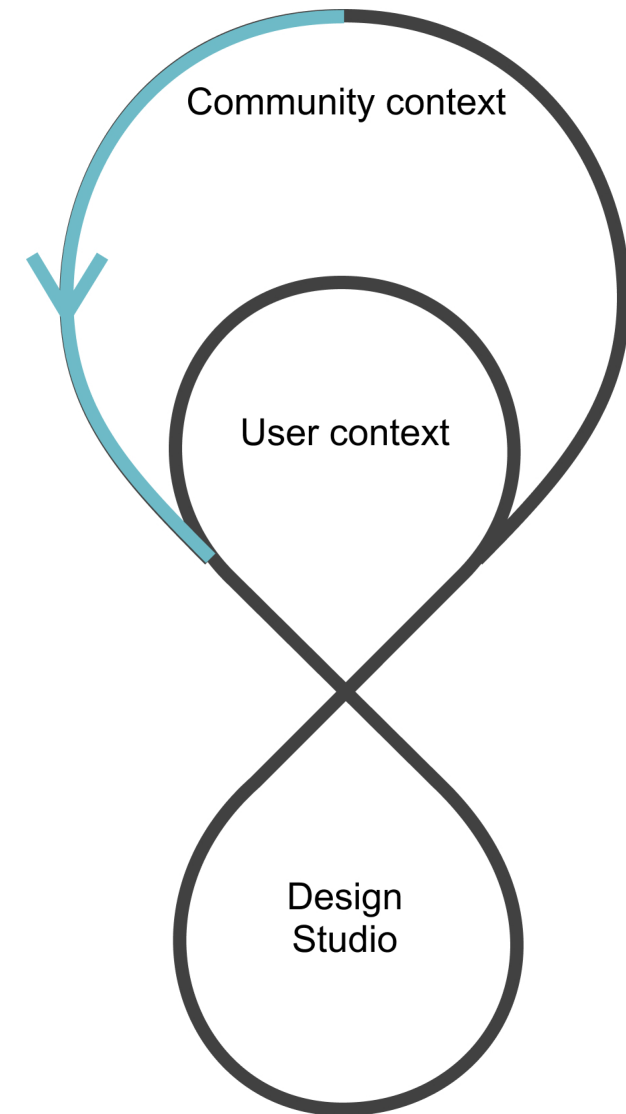


Figure 2.0: DED Approach - from community to user context



## 2.2 The healthcare providers and care path of PF

### 2.2.1 Healthcare Providers of PF

The care path for patients with Pulmonary Fibrosis (PF) involves the active participation of three distinct healthcare providers (as Figure 2.1 shows): the specialist center, treatment center, and general practitioner (GP).

The Erasmus Medical Center (Erasmus MC) Interstitial Lung Disease Group is recognized as one of the Netherlands' leading specialist centers (expertisecentrum) dedicated to the diagnosis and treatment of PF. These specialized centers have a team of healthcare professionals who undergo specific training in PF care, including pulmonologists and specialist nurses. As the primary healthcare provider of the patients who are transferred to the specialist center, their primary responsibilities encompass various aspects, including PF diagnosis, treatment, long-term monitoring of patient disease progression and treatment outcomes, conducting scientific research, and developing guidelines for GPs regarding follow-up care. (Expertise Centra, n.d.)

In addition to the specialist centers, there are also treatment centers (behandelcentrum) that cater to patients' needs in closer proximity to their homes. These treatment centers actively collaborate with specialist centers to ensure they are equipped with the most up-to-date knowledge and advancements in PF care.

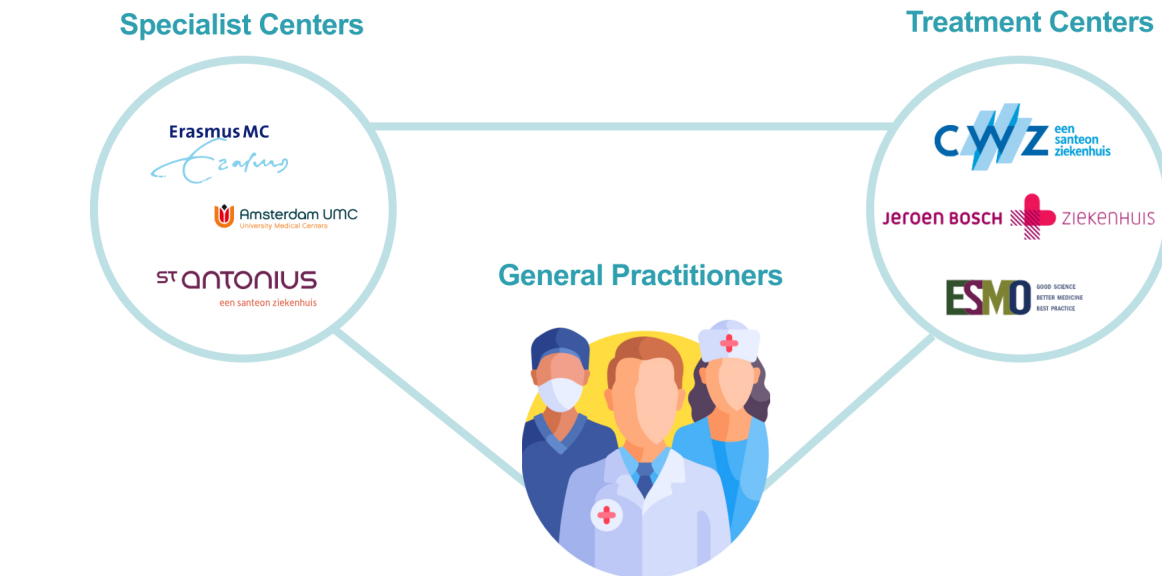


Figure 2.1: Healthcare providers of PF in the Netherlands

Furthermore, GPs assume an important role in the care path, particularly during three key moments, based on the interview results with healthcare professionals (Chapter 4). Firstly, during the initial diagnosis, patients typically consult their GPs when they experience initial symptoms. However, GPs usually encounter only one or two PF patients throughout their entire careers, which limits their knowledge and experience in diagnosing and treating this disease. Secondly, after the diagnosis, GPs serve as the primary point of contact in case of emergency symptoms or complaints, providing initial aid and assessing the patient's condition. If necessary, GPs seek guidance from specialist

centers when they encounter unfamiliar situations. Lastly, during the end-of-life stage, patients often turn to GPs for making critical decisions, such as opting for euthanasia.

By collaboratively working together, these three healthcare providers contribute collectively to PF patient care throughout their disease journey, ensuring that patients receive optimal care throughout their journey.

## 2.2.2 The protocol care path in Erasmus MC: ZORGPAD

To establish a comprehensive and standardized guideline for PF care, the Erasmus Medical Center (Erasmus MC) has developed a care manual known as "ZORGPAD." This manual serves as guidelines for the multidisciplinary healthcare providers involved in PF care. ZORGPAD offers a systematic overview of the diagnosis and treatment procedures for PF, commencing from the initial intake at Erasmus MC and extending throughout the disease's follow-up stage.

While the ZORGPAD was initially formulated based on protocols established at the Erasmus MC, its applicability extends beyond Erasmus MC and is generalizable. Through collaboration with 19 other hospitals, the manual was designed to encompass practices and insights from various healthcare settings across the Netherlands. Thus, it is intended to serve as a generalized reference for PF care nationwide.

The care path for PF patients, as outlined in Figure 2.2, effectively summarizes and visually depicts the key moments and interactions with healthcare providers delineated in the ZORGPAD.

However, it is important to note that the pre-diagnosis phase of care, preceding patients' intake into the hospital, was initially absent from the ZORGPAD. This critical gap was subsequently addressed through a co-creation session involving healthcare professionals from the Erasmus MC, as detailed in section 2.4.

The analysis of the ZORGPAD reveals three distinct stages in the progression of PF: the pre-diagnosis, diagnosis, and follow-up stages, presented in chronological order. It is important to note that the duration of each stage may vary due to the unpredictable nature of PF progression and the individual differences

observed among patients. While the ZORGPAD care path provides an ideal framework that hospitals aim to implement, it is essential to acknowledge potential variations from the actual situation. To bridge this gap, Section 2.4 will delve deeper into understanding real patient experiences, allowing for a comprehensive examination and analysis of the care path.

### Pulmonary Fibrosis Patient Journey based on ZORGPAD

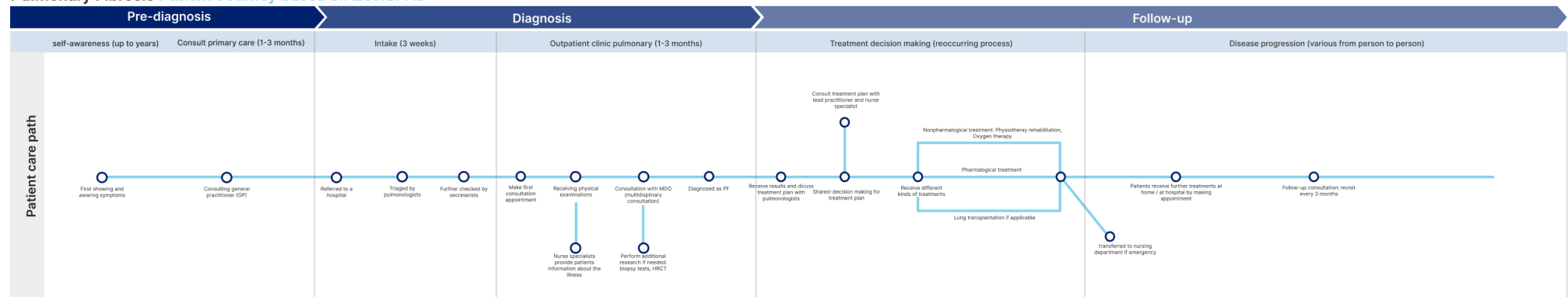


Figure 2.2: ZORGPAD care path with disease stages



## 2.3 Observational study: The consultation in Erasmus MC

In order to gain a deeper understanding of the interactions between patients and healthcare professionals, an observational study was conducted in the outpatient clinic consultations of Interstitial Lung Disease (ILD) at Erasmus MC. This invaluable opportunity was graciously provided by Dr. Marlies Wijsenbeek, the leading pulmonologist from the ILD team. The observation occurred during one afternoon of her consultation day, from 13:00 to 17:00, encompassing a total of seven patients, consisting of a mix of in-person meetings and phone call conversations.

Figure 2.3 provides a visual representation of the standard procedure followed during a consultation session at Erasmus MC. This protocol encompasses three main activities that form an integral part of the consultation process.

Upon arrival at the hospital, patients and their companions, typically family members, are directed to the rest area, where they await their session. Prior to meeting with the pulmonologist, patients undergo a lung function test in the examination room. Following this, they proceed to the consultation, which typically lasts for approximately 15 minutes. The conversation between patients, pulmonologists (occasionally nurse specialists take over), and caregivers revolves around various topics and activities of importance, including:

- Greetings and casual chats: The consultation begins with the pulmonologist extending warm greetings to the patient and engaging in casual conversation about their recent daily life experiences. This initial interaction serves to create a comfortable environment and foster a positive doctor-patient relationship.

- Symptom and medication assessment: The pulmonologist conducts a detailed inquiry into the patient's symptoms, including coughing, breathing difficulties, and other relevant indicators. Additionally, the healthcare professional explores the patient's medication usage, dosage adherence, and any associated side effects.

- Lung function test review: The pulmonologist will review the patient's lung function test and explain the results and implications to them.

- Blood saturation test (only for in-person consultations): The pulmonologist performs a test to determine the patient's blood saturation level by using a pulse oximeter, providing important information about the patient's oxygen levels. Based on the findings, the pulmonologist interprets the results and offers relevant instructions and recommendations in the

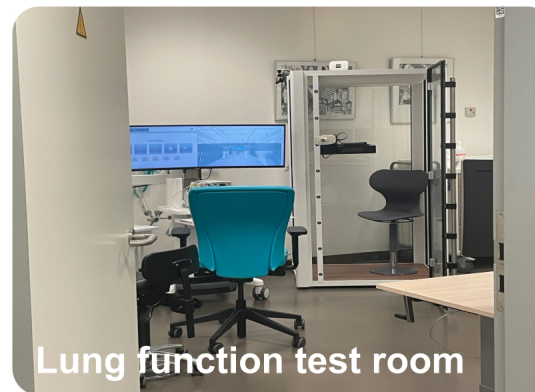
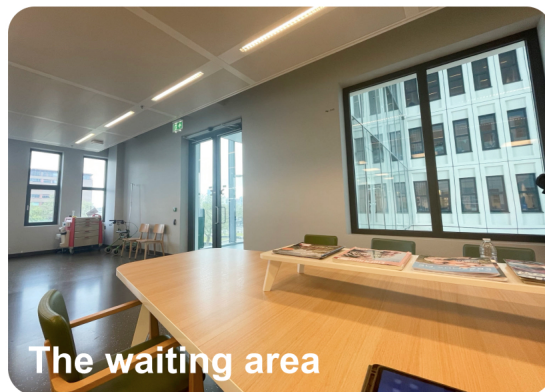


Figure 2.3: Procedure of a consultation session at Erasmus MC (Images were taken with permissions)

patient's daily care, such as the usage of oxygen devices at home.

- When the treatment involves other healthcare providers, such as GP or treatment centers, the pulmonologist needs to make phone calls, write referral letters and give instructions to them.
- Collaboration with other healthcare providers: The pulmonologist takes necessary actions when the treatment plan involves other healthcare providers, such as GPs or treatment centers, including making phone calls to discuss the patient's condition, preparing referral letters for further care, or providing specific instructions to ensure seamless coordination and continuity of care.
- Next consultation scheduling: At the end of the session, the pulmonologist schedules the next consultation with the patient.

In conclusion, the observational study yielded a number of significant findings. The majority of patients arrive at the hospital accompanied by their caregivers (family members). Firstly, during the consultation, caregivers frequently pose more questions about patients' daily care and are more involved in shared decision-making than patients themselves. Secondly, the interaction between patients and pulmonologists is typically unidirectional; the pulmonologist typically inquires about the patient's condition, and the patient simply responds. Lastly, it is observed that pulmonologists have to perform unnecessary tasks during consultations, such as scheduling or submitting referral letters, despite having limited time and barely any break between consultations.

## 2.4 Patient Community Journey Mapping

### 2.4.1 Purpose

In order to address the absence of real-life patient experiences in the ideal care path depicted by ZORGPAD, a contextual inquiry study was conducted to bridge this gap. This study employed an innovative design approach, Patient Community Journey Mapping (Jung, 2023), to uncover the underlying patient perspectives.

Over the past decade, patient journey mapping has emerged as a valuable design tool for effectively identifying and communicating patient needs and barriers within the healthcare system, thereby enabling the delivery of tailored healthcare by multidisciplinary providers and designers (McCarthy et al., 2016). Nevertheless, the current journey mapping methods exhibit noteworthy limitations. Primarily, these methods rely on data collection and analysis techniques such as interviews, ethnographic research, or focus group workshops, which often involve a restricted number of patients from localized areas. Moreover, the demanding nature of these methods necessitates significant labor and time investment for data collection and participant recruitment. Consequently, the current journey mapping methods are considered insufficiently representative for broader target groups and susceptible to bias in the obtained results (Jung, 2023).

In light of these limitations, the research adopts

the Patient Community Journey Mapping, which introduces a novel approach involving worldwide, community-level qualitative patient data. Online patient stories offer rich and valuable insights since it allows the patient to spontaneously express their thoughts about the disease and treatments, by posting their stories and sharing them with peers (Beusterien et al, 2012). Moreover, this approach also allows designers to create evident-based patient journeys, which interpret both qualitative and quantitative insights through computational analysis (machine learning). However, it necessitates a collaborative effort between data scientists and designers. The next section provides a detailed explanation of the method and procedure employed in applying this innovative approach.

### 2.4.2 Method

By following the methods from Jung (2023), the Patient Community Journey Mapping approach consists of three major steps: preparation, analysis, and creation, and each step employs a different design or research method. As the deliverable of the contextual inquiry, an interim result of PF patient journey mapping was created by the designer, following the preparation and analysis, and was refined through the validation and co-creation process

with healthcare professionals (will be introduced in Chapter 3). Figure 2.4 depicts an overview of methods and procedures throughout this study, and each phase will be introduced in the following.



## Phase 1: Preparation

Prior to conducting the analysis, adequate preparation is essential, encompassing two steps: data source selection and ethical considerations.

Several online patient forums from worldwide cater to individuals with PF and their loved ones, ranging from open community websites to Facebook support groups (see Table 2.1 for an overview of diverse online patient forum sources). When selecting the most suitable source, several criteria warrant consideration:

1. **Relevance to PF:** The chosen source should predominantly feature patient stories directly pertinent to PF.
2. **Sufficient Activity and High-Quality Content:** The source should exhibit a substantial number of active users and provide a satisfactory volume of user posts and interactions for robust data analysis.
3. **Open-access:** The selected source should possess an open nature that allows researchers to access it.

## Phase 1: Preparation

## Phase 2: Analysis

## Phase 3: Creation: Interim output

## Validation

## Final output

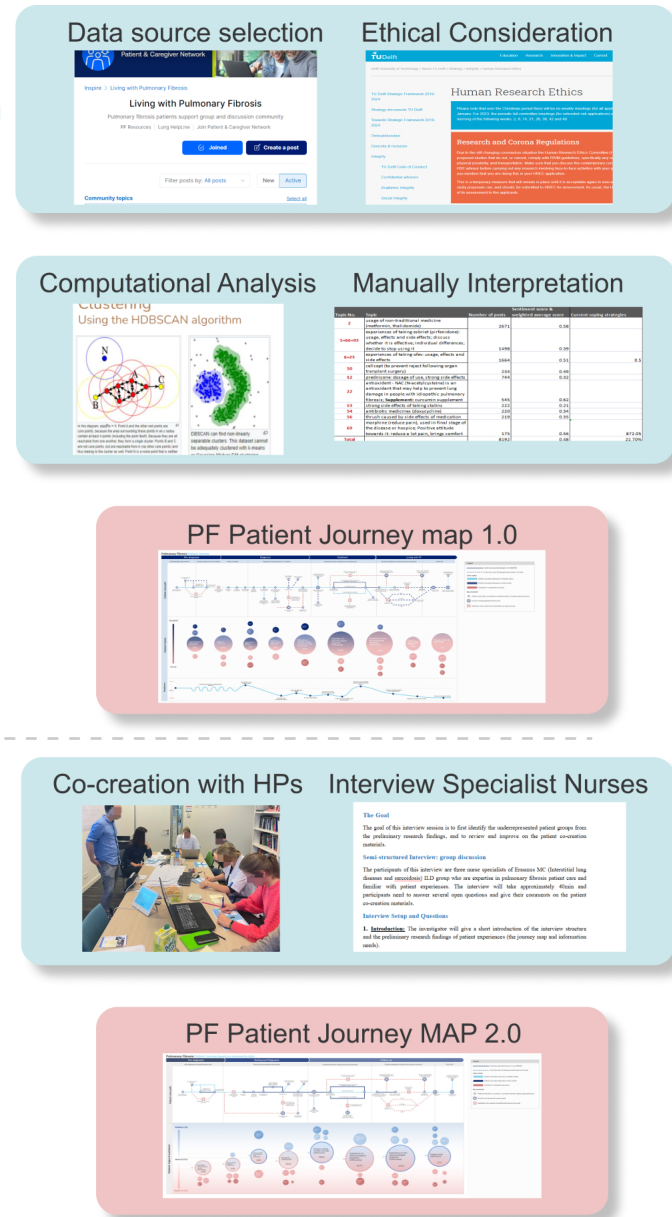


Figure 2.4: Procedures and Methods of Patient Community Journey Mapping

| Name of organization/website                                           | Origin              | Accessibility                            | Total posts | Average sentences per | Main topics                                                                                                                                                                                                   | Extra notes                                                                           |
|------------------------------------------------------------------------|---------------------|------------------------------------------|-------------|-----------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------|
| Inspire.com: living with Pulmonary Fibrosis                            | US                  | open sources, anyone can join and share  | 30,000+     | 3-5                   | News and notes; living advices; Diagnosis and testing; find right medical care team & medication; Supplemental oxygen; Pulmonary rehabilitation; Diagnosis and inheritance; loved ones; forget things;advices | has patients' and their caregivers' community seperately, different topics are shared |
| Smart Patient                                                          | Worldwide community | Needs to be authorized, application sent | unkown      | 2-3                   |                                                                                                                                                                                                               | community for both patients and their caregivers                                      |
| Longforum                                                              | NL                  | Authorized & Joined                      | 20-30       | 3-7                   |                                                                                                                                                                                                               |                                                                                       |
| <b>Facebook groups and twitter</b>                                     |                     |                                          |             |                       |                                                                                                                                                                                                               |                                                                                       |
| Pulmonary Fibrosis Support Group by Breathe Support                    | Worldwide community | Authorized & Joined                      | 10,000+     | 3-7                   | Diagnosis & symptoms; family support;Related to COVID; Supplemental oxygen; Good news & cheering up; Raising awareness;                                                                                       | community for both patients and their caregivers                                      |
| IPF-Idiopathic Fibrosis and Pulmonary Fibrosis PRACTICAL SUPPORT FORUM | Worldwide community | Open group for everyone                  | 10,000+     | 3-7                   | Symptoms & complaints;Moaning for the lost;looking for advice; Hospice/palliative care; Body & Organs donation                                                                                                | community for both patients and their caregivers                                      |
| Pulmonary Fibrosis UK                                                  | UK                  | Private group                            | 50,000+     | unknown               | unknown                                                                                                                                                                                                       | community for both patients and their caregivers                                      |
| Pulmonary Fibrosis NL Support Group!                                   | NL                  | Private group                            | 2,000-5,000 | 3-5                   | seminars, information sharing; raising awareness;includes spmas                                                                                                                                               | community for mostly sharing knowledges                                               |
| Pulmonary Fibrosis NOW Group                                           | Worldwide community | Private group                            | 10,000+     | unknown               | unknown                                                                                                                                                                                                       | community for both patients and their caregivers                                      |

Table 2.1: Online community data sources

Inspire.com has been selected as the data source based on the established selection criteria (Figure 2.5). It is an open-source, global online community that caters to patients with pulmonary fibrosis and their caregivers. The Inspire website is founded upon the American Lung Association, a preeminent global organization that endeavors to enhance the quality of life of individuals afflicted with pulmonary ailments and furnish them with pertinent medical knowledge. The online forum of Inspire.com splits into two parts, the patient community and the caregivers' community. Around 40,000 users actively share their disease-related experiences, looking for health

information, and connect to others through this vibrant community. Moreover, the quality of posts and information are deemed reliable since it is constantly monitored by the website administrators against spam and false information.

Furthermore, in light of the fact that this study entails retrieving and compiling health-related user data, it is imperative to address ethical considerations. This is not only to comply with TU Delft's regulations but also to uphold fundamental ethical principles as a designer. The Human Research Ethical Committee (HREC) and the data steward from IDE faculty

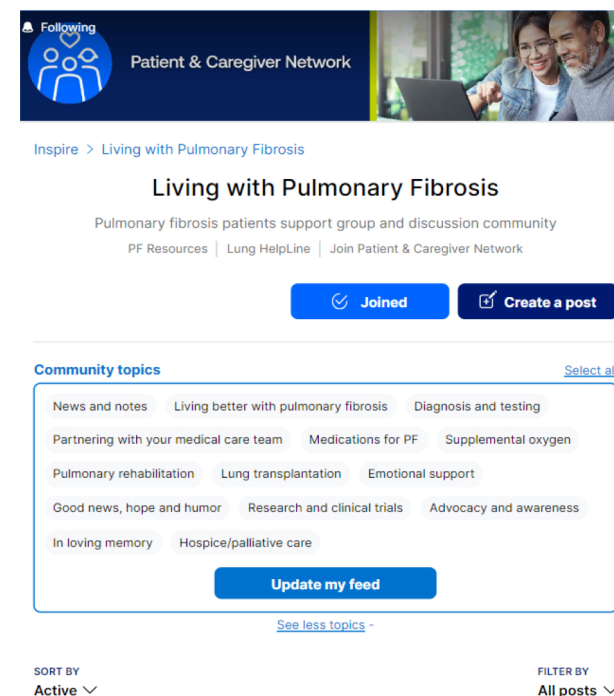


Figure 2.5: Inspire.com homepage

have granted approval for the ethical checklist and a data management plan for the research (Details shown in Appendix B).



## Phase 2: Analysis

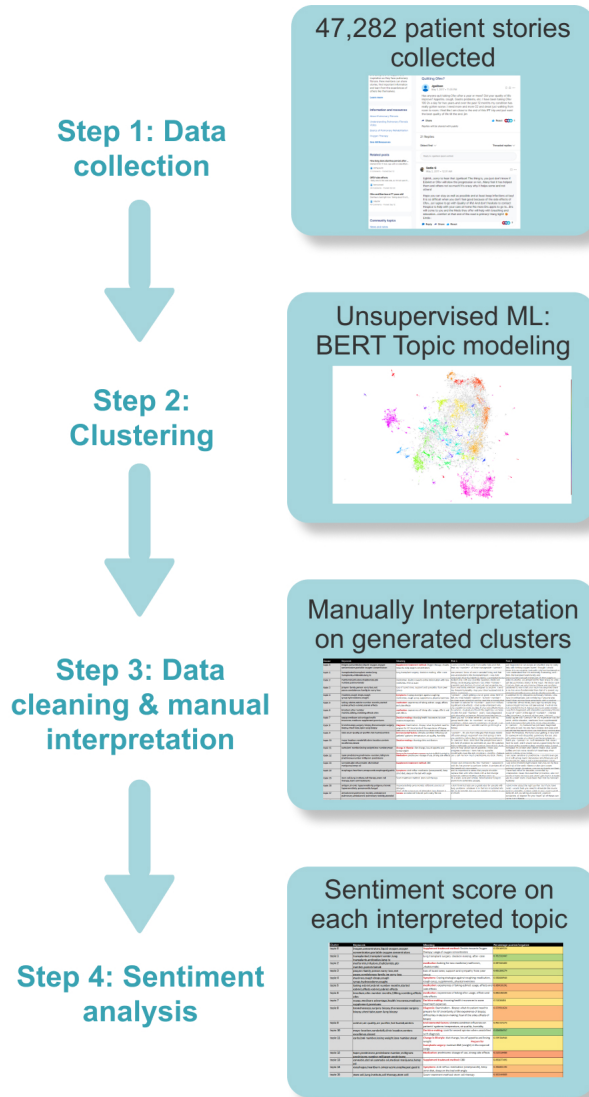


Figure 2.6: Procedure and methods in the Analysis phase

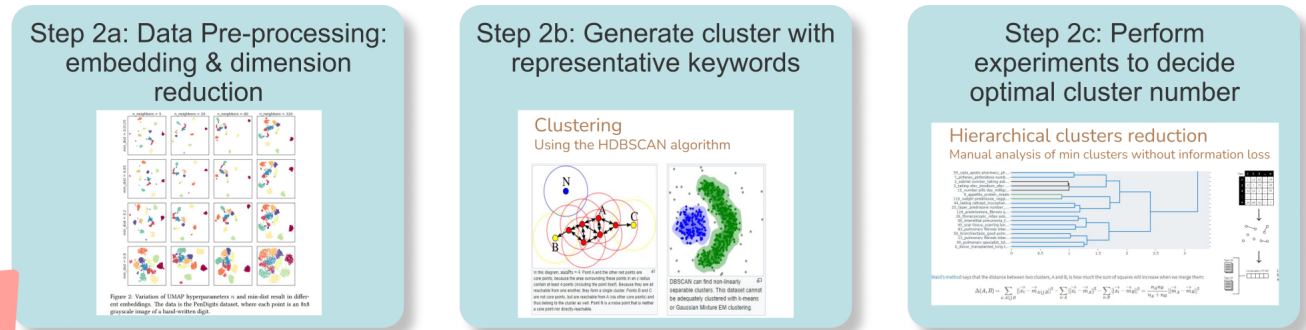


Figure 2.7: Sub-steps of clustering

Upon the finish of preparation, the online patient stories are collected and analyzed through different sub steps involving both computational and manual analysis methods. There are five steps conducted in Phase 2, as shown in Figure 2.6. The following describes each step and its results.

### Step 1: Data collection

In total, 47,282 patient stories (including original posts and replies) from the last five years are collected from Inspire.com. And to prevent data leakage and privacy invasion, all direct and indirect personal identifiers, such as age, gender, location, and user names, are removed to comply with the ethical approval criteria.

### Step 2: Clustering

Given this huge amount of posts, it is impossible to read and analyze them by human force. Therefore, a computational analysis method is adopted in the second step, with the support and

collaboration of a data scientist. This step includes three sub-steps, as shown in Figure 2.7. An unsupervised machine learning (ML) technique is applied to find patterns and structures in a huge amount of unlabeled data. Compared to supervised learning models, which are widely used in text mining and require labeled data for generating quality results, unsupervised learning requires less initial labor and time inputs without data labeling, instead, the topic modeling method is applied to create clusters that contain similar topics. The BERTopic algorithm is chosen by our data scientist, which leverages the state-of-art BERT (Bidirectional Encoder Representations for Transformers) pre-trained language model to create density-based clusters (Sushil et al., 2021).

The procedure starts with the data pre-processing (step 2a), which includes two different actions, namely embedding and dimension reduction.

Firstly, by capturing semantic meaning and contextual relationships, embedding improves the representation of words or texts, resulting in more accurate and meaningful subjects. Secondly, by using the dimension-reduction framework UMAP, the amount of dimensionality of the dataset is reduced to a manageable number that improves computational efficiency while still preserving the most important information.

Subsequently, in step 2b, the HDBSCAN algorithm is leveraged to group similar patient stories together into one cluster based on their embeddings. And to determine the subject matter of each cluster, the most important keywords are extracted to represent each cluster through their class-based numerical statistic (TF-IDF). Continuously, further action is conducted by utilizing a hierarchical clustering structure, with the purpose of organizing the clusters at different levels of granularity, allowing for the exploration and interpretation of topics at various levels.

Lastly, it is imperative to determine an optimal number of clusters generated by the machine learning (ML) model. This step aims to ensure sufficient differentiation among the clusters while allowing for manageable manual analysis by the designer, at the same time minimizing information loss. As this is a trade-off process, the designer and data scientist conducted multiple experiments to determine the most suitable cluster quantity. By reducing the number of clusters from 300 to 50, **it was determined that 100 clusters provided the optimal balance**, affording ample information

| Amount of generated clusters | 50                           | 100                                                              | 300                          |
|------------------------------|------------------------------|------------------------------------------------------------------|------------------------------|
| Clustering Performance       | Significant information loss | Adequate amount of clusters without significant information loss | Too many repetitive clusters |

Table 2.2: Experiments on different numbers of generated topics

for further interpretation without causing a high manual analysis workload. Table 2.2 shows the comparison between different experiments.

### Step 3: Data Cleaning & Manual Interpretation

As a result of step 2, 100 clusters are generated, with the top five representative keywords, the total number of relevant posts, and 50 most-related patient stories, Figure 2.8 exemplifies the result of a cluster with keywords and posts. (See Appendix C for the full topic modeling results). Nevertheless, the clusters are

not properly labeled yet since the keywords cannot well-represent the topics discussed by patients from each cluster. Therefore, this step requires further interpretation by the designers to define the main topics in each cluster. The interpretation step was conducted through manual analysis by the designer carefully reading the top 50 posts of each cluster, combined with the generated keywords, to gain a comprehensive understanding of the prevailing topics and concerns expressed by patients. And each cluster is assigned a summarized topic.

| Cluster | Keywords                                                                              | Post 1                                                                                            | Post 2                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                      | Post 3                                                                                                                                                                                                                                                                                                                                                                      |
|---------|---------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| topic 0 | inogen,concentrators,liquid oxygen,oxygen concentrators,portable oxygen concentrators | i used a swivel that came from salter labs and that kept my <number> of hose manageable. <person> | just happened to run across an excellent way to really help with kinking oxygen hoses i thought i would share. it is on youtube, but sadly i did not bookmark or i would give you the link for it now. you can find it on youtube. very simple quick fix. i put my <number> ft oxygen hose in a mesh laundry bag and put it in my clothes dryer at medium heat for about <number> minutes. be sure and pull it out before it goes into the cooling cycle so it is still warm. anchor or have someone hold one end and unroll flat and straight out all the way. not in a clump chump lays very flat and kink free even after it cools and even as i move around the house. works for me. good luck and have a good one! cheers! found the link. <person> on | ldiothe. thats a good idea. one could use any lengths of sections, ill try that. it appears no company is willing to look at the new data on maximum length of tubing given the improvement in concentrators in recent years and take on the decades old rule of maximum of <number> from the source. maybe someday one of them will take the leap until then ill use tape. |

Figure 2.8: Example of a pre-interpretation cluster with keywords and posts

| Main categories                                             | Percentage of posts |
|-------------------------------------------------------------|---------------------|
| Experiences with non-pharmacological treatments             | 24.5%               |
| Experience with decision-making moments                     | 21.5%               |
| Experiences with pharmacological treatments                 | 20.5%               |
| Experience with modifying lifestyle to adapt to the changes | 11.7%               |
| Describing symptoms                                         | 10.4%               |
| Describing and questions around causes                      | 6.0%                |
| Experience with diagnosis                                   | 5.4%                |

After reading through each cluster, it was found that not all clusters contained meaningful information pertaining to patient care experiences. Consequently, a data cleaning step was undertaken to exclude irrelevant clusters, such as advertisements and URLs. Additionally, clusters that described similar topics were merged together to avoid redundancy and repetition.

As a result, a total of 63 interpreted topics were derived, encompassing various aspects of PF patients' experiences, inquiries, and emotions concerning the disease and daily care. Furthermore, a hierarchical categorization procedure was employed enabling the researchers to discern common themes and

overarching patterns within PF patients' care path. Consequently, seven main categories are defined in table 2.3, including their numerical percentage of posts. And Figure 2.9 shows part of the final outcomes the interpretation step (See Appendix D for the full outcomes).

| Main category                                     | Topic No.    | Topic                                                                                                                                                                                             | Number of posts | Percentage of posts |
|---------------------------------------------------|--------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------|---------------------|
| Experience on pharmacological treatment (10)      | 2            | usage of non-traditional medicine (metformin, thalidomide)                                                                                                                                        | 2671            |                     |
|                                                   | 5+66+93      | experiences of taking esbriet (pirfenidone): usage, effects and side effects; discuss whether it is effective; individual differences; decide to stop using it                                    | 1498            |                     |
|                                                   | 6+23         | experiences of taking ofev: usage, effects and side effects                                                                                                                                       | 1664            |                     |
|                                                   | 50           | celcept (to prevent reject following organ transplant surgery)                                                                                                                                    | 234             |                     |
|                                                   | 12           | prednisone: dosage of use, strong side effects                                                                                                                                                    | 744             |                     |
|                                                   | 22           | antioxidant - NAC (N-acetylcysteine) is an antioxidant that may help to prevent lung damage in people with idiopathic pulmonary fibrosis; <b>Supplement:</b> curcumin supplement                  | 545             |                     |
|                                                   | 53           | strong side effects of taking statins                                                                                                                                                             | 222             |                     |
|                                                   | 54           | antibiotic medicines (doxycycline)                                                                                                                                                                | 220             |                     |
|                                                   | 56           | thrush caused by side effects of medication                                                                                                                                                       | 219             |                     |
|                                                   | 69           | morphine (reduce pain), used in final stage of the disease or hospice; Positive attitude towards it: reduce a lot pain, brings comfort                                                            | 175             |                     |
|                                                   | <b>Total</b> |                                                                                                                                                                                                   | <b>8192</b>     | <b>20.50%</b>       |
| Experience on non-pharmacological treatments (11) | 0            | Doubts towards oxygen therapy: usage of oxygen concentrators                                                                                                                                      | 5414            |                     |
|                                                   | 13           | CBD oil                                                                                                                                                                                           | 706             |                     |
|                                                   | 83           | Vitamin supplements                                                                                                                                                                               | 125             |                     |
|                                                   | 18           | Enzyme supplements                                                                                                                                                                                | 683             |                     |
|                                                   | 15           | Scam treatment method: stem cell therapy                                                                                                                                                          | 699             |                     |
|                                                   | 73           | laser therapy; controversial method evokes debates                                                                                                                                                | 158             |                     |
|                                                   | 30+68        | Breathing exercise, Physical exercises are experienced as beneficial improving symptoms; Pulmonary rehabilitation is perceived as challenging but also helpful                                    | 614             |                     |
|                                                   | 56           | thrush caused by side effects of medication                                                                                                                                                       | 219             |                     |
|                                                   | 36           | Usage of oxygen device: frustration of the fact of using oxygen tank; shame and embarrassment of using it in public; Tabu of using oxygen                                                         | 345             |                     |
|                                                   | 26           | Vaccinations are effective tools to prevent infections in pulmonary fibrosis patients, to help stay healthy                                                                                       | 492             |                     |
|                                                   | 25           | palliative care (providing relief from symptoms, optimizing QoL); patients have positive attitude towards it                                                                                      | 524             |                     |
|                                                   | <b>Total</b> |                                                                                                                                                                                                   | <b>9979</b>     | <b>24.50%</b>       |
| Experience around symptoms (5)                    | 4+19         | coughing & coping strategies                                                                                                                                                                      |                 |                     |
|                                                   |              |                                                                                                                                                                                                   | 1866            |                     |
|                                                   | 14           | stomach-reflux                                                                                                                                                                                    |                 |                     |
|                                                   |              |                                                                                                                                                                                                   | 704             |                     |
|                                                   | 21           | cramps, chest pain; For female patients: bras adds extra irritation                                                                                                                               | 598             |                     |
| Experience around decision-making moments (8)     | 72           | clubbing fingers; (The tips of the fingers enlarge and the nails become extremely curved from front to back)                                                                                      | 162             |                     |
|                                                   | 28           | arterial hypertension caused by pulmonary fibrosis                                                                                                                                                | 443             |                     |
|                                                   | <b>Total</b> |                                                                                                                                                                                                   | <b>3773</b>     | <b>10.40%</b>       |
|                                                   | 1            | wether to take lung transplant surgery                                                                                                                                                            | 4240            |                     |
|                                                   | 7            | choosing health insurances to cover treatment expenses                                                                                                                                            | 1037            |                     |
|                                                   | 38           | Choose the oximeter to have correct reading                                                                                                                                                       | 335             |                     |
|                                                   | 95           | decide to stop taking medication that cause strong side effect and choose quality of life                                                                                                         | 107             |                     |
|                                                   | 67           | decide to quit smoking after diagnosis                                                                                                                                                            | 188             |                     |
|                                                   | 91           | continue or stop working: Continue working: challenging but meaningful, dignity of life; Stop working: disability, huge change to life, hard to balance between working and visit doctors & tests | 113             |                     |
|                                                   | 10           | Look for second opinion when unsatisfied with diagnosis                                                                                                                                           | 837             |                     |
|                                                   | 8            | take biopsy examination: Uncertainty of the experience of biopsy; difficulties in decision-making: Fear of the sides effects of biopsy                                                            | 916             |                     |
|                                                   | <b>Total</b> |                                                                                                                                                                                                   | <b>7773</b>     | <b>21.50%</b>       |

Figure 2.9: Part of final outcomes of topics interpretation



## Step 4: Sentiment Scores

After containing the computational and manual analysis results, a discussion between the designers and the data scientist was undertaken to determine whether the current information is adequate to create the PF patient care path and what other supplement methods can be applied to acquire extra information and insights. And consequently, we decided to apply another computational analysis method: sentiment analysis in our current findings to identify patients' attitudes towards each topic and uncover the barriers and facilitators in their care path.

Sentiment represents an individual's attitude and emotions, which is essential for explaining one's behavior. And sentiment analysis (also known as opinion mining) is a process that leverages natural language processing (NLP) techniques to identify the sentiment of a certain text piece. Similar to the previous step, we applied the BERT model again on the 63 patient topics to predict the sentiment score of each topic. The BERT model looks at the words, the order in which they appear, and the relationships between them to determine whether the sentiment is positive, negative, or neutral (Singh et al., 2021). Accordingly, the sentiment score ranges from 0.0 to 1.0, with specific thresholds for categorizing sentiments. Sentiment scores falling between 0.0 and 0.5 are indicative of negative sentiment, while scores equal to 0.5 (with a threshold of 0.02) are labeled as neutral. Scores above 0.5 are considered positive. However, one major bias we noticed in the sentiment analysis is due to

the sentiment scores being highly influenced by the tone and language of how people express their experiences or opinions. As the following example shows, though it is describing a topic regarding negative disease-related experience, it is predicated as positive by the algorithm since certain keywords of appreciation or expressing feelings arise, such as *"thank you"* and *"helpful"*. One of the quotes from patients' stories shown below, describe the negative feeling of being diagnosed as PF however the sentiment score is positive with a score of 0.63:

*"it is a such very lonely disease and it changes my life completely...but with the support from everyone here, it helps."*

The biases caused by sentiment analysis will be addressed in Chapter 3.

So far, based on the available information, it is deemed that sufficient data has been obtained to proceed with the creation of the PF patient community journey map. The final results of the analysis phase are presented in Appendix D.

## Phase 3: Creation

In order to develop the patient journey map, the integration of patient perspectives is the final phase. This process draws inspiration from a cutting-edge service design method called Metro Mapping, which enables designers to outline the trajectory of patients' diseases, various treatment paths, pain points, and critical decision-making moments (Stiggelbout et al., 2023).

The creation phase consists of four key steps. Firstly, by comprehending the patient topics and referring to the ZORGPAD care path, which encompasses prediagnosis, diagnosis, treatment, and living with PF stages, the four main disease stages are defined. Secondly, the significant moments along the care path are identified based on the generated topics and positioned on the timeline. These moments include patient event points (such as consultations and disease progression), decision-making moments requiring patients to make disease-related choices, and pain points where barriers are encountered during the journey.

The third step involves constructing the Metro Map, which connects the patient event points through three different paths: the hospital context, the home context, and the unwanted or unexpected care path. Together with step 2, this aids in understanding the timing and location of problems that arise during the patient journey. Finally, using sentiment scores, the designer identifies and interprets the underlying emotions associated with the topics related to key moments, and represents them in the journey map as the flow of emotions. The subsequent section will provide a detailed introduction to the interim results of the PF patient community journey map (as depicted in Figure 2.10).



## 2.4.3 Interim Results of patient community journey map

### Pulmonary Fibrosis Patient Journey

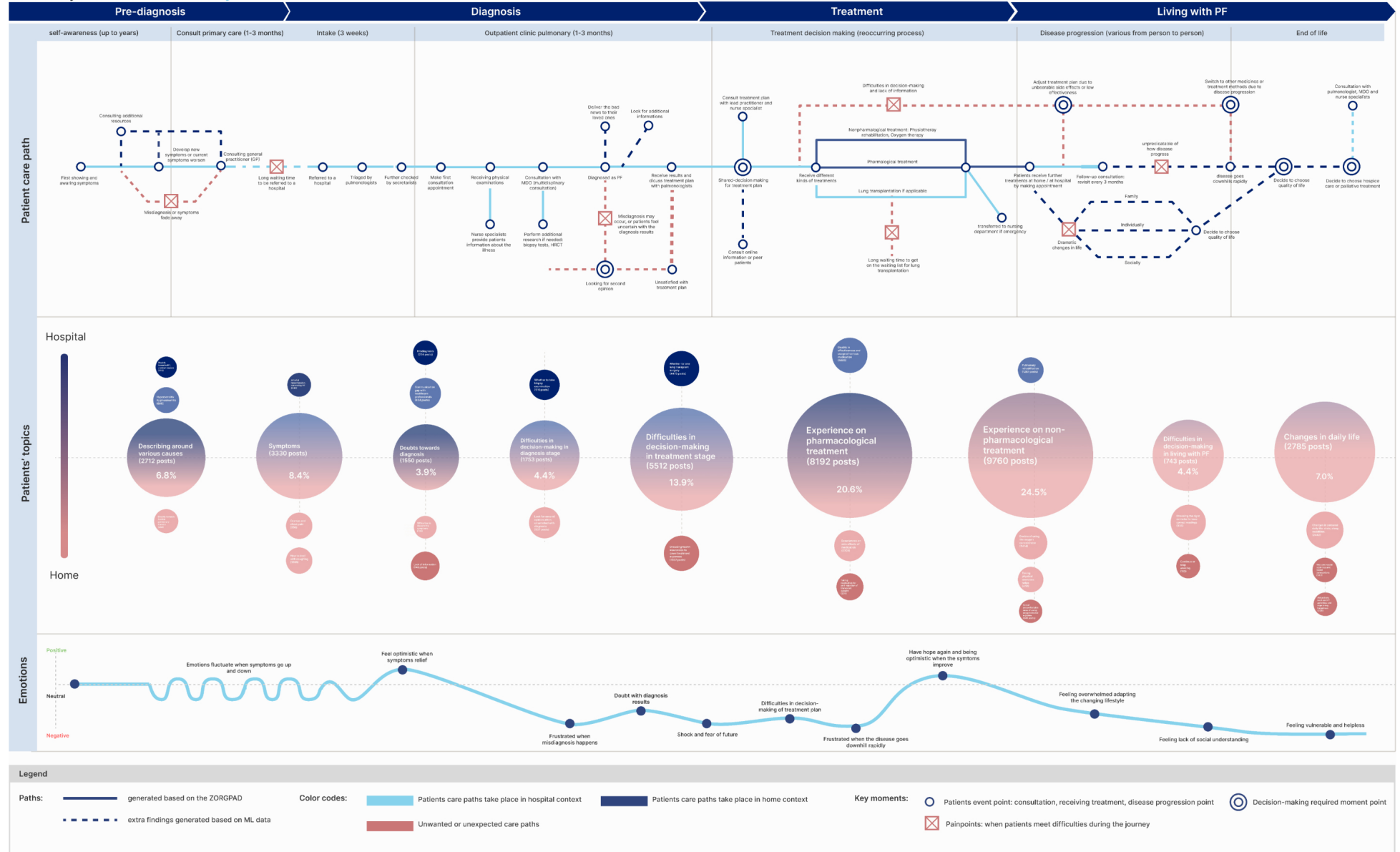


Figure 2.10: Interim results of Patient community journey map

The interim results of the PF patient community Journey Map (JM 1.0), as depicted in Figure 2.10, comprises three essential components: the patient care path generated using community patient data and ZORGPAD, the most discussed patient topics in each disease stage, and the emotion flow diagram based on the sentiment score of each topic (with potential bias in sentiment score).

Firstly, at the top, we have the PF patient care path derived from community patient data and ZORGPAD. In contrast to the ideal linear care path, this new representation reveals numerous deviations and unwanted paths, leading to challenges and barriers in patients' disease progress.

Moving to the second row, it illustrates the most extensively discussed patient topics throughout their disease journey, encompassing both main categories and sub-topics. Furthermore, these patient topics are categorized along a hospital-home spectrum, indicating their association with either the hospital context or the home context. For instance, when patients express concerns regarding misdiagnosis, it is considered a barrier in the hospital context.

Lastly, the emotional journey is presented at the bottom of the patient journey, capturing the emotional changes experienced by patients throughout their disease journey. This diagram is based on sentiment scores and the designer's interpretation.

## Findings from the journey map: 5 initial problem areas in patient experience

Consequently, the patient community journey mapping has shed light on the potential challenges in the patient care path. Specifically, there are five problem areas found in the journey (as shown in Figure 2.11). These problem areas are defined based on the numerical percentage ranking of patient topics and the sentiment scores. Moreover, they will be introduced in chronological order as follow.

The first problem area relates to the **doubts surrounding the unclear cause of the disease and the uncertainty of diagnosis (11.4% of the posts)**, which takes place in the pre-diagnosis and diagnosis stage. The potential reason for it could be from several aspects. Firstly, since PF is a very complex disease with various kinds of disease causes, and in most cases, the cause is unidentifiable, known as Idiopathic pulmonary fibrosis (IPF), it can lead to unlimited patient doubts and powerlessness. Secondly, the symptoms of PF, such as persistent coughing and shortness of breath, are not unique to this condition, which could be found in other respiratory and cardiac diseases. Hence, there are many difficulties in the diagnosis of PF, especially in the early stages with primary healthcare providers (GP), as they are not specifically trained in this rare disease, and misdiagnosis commonly happens, in fact, 37% of PF patients are misdiagnosed at least once (EU-IPFF, 2023). Consequently, delayed diagnosis and negative emotions among patients are prevalent.

The second is the **difficulties in disease**

**-related decision-making (21.5% posts) throughout all disease stages.** If the disease is divided into two main stages, before being diagnosed as PF and after being diagnosed as PF. The decision-making moments during the former one are mostly related to the diagnosis, such as whether the patient should go to another specialist center when a misdiagnosis happens and whether to take a biopsy test when tests haven't diagnosed the condition. On the other hand, in the after-diagnosed stage, patients' decision-making is mainly about treatment and personal lives, for example, whether they should stop taking the medication under strong side effects and whether they should quit their jobs. The factors influencing patients' decision-making can be complex, which are typically summarized into three aspects, including patients' individual factors (socioeconomic status, emotional factors, coping mechanisms), communication between healthcare providers and patients (whether patients are well-informed and guided by the healthcare providers), and the health care settings (access to healthcare resources) (Zheng et al., 2022).

Thirdly, the **experience around disease symptoms is another area that contains many patient problems (10.4% posts).** The progressive nature of PF, characterized by symptoms such as shortness of breath, persistent cough, fatigue, and chest discomfort, significantly impacts patients' quality of life. Among the thousands of patient stories related to the PF symptoms, they constantly mentioned

the negative experience and emotions caused by these symptoms, which can restrict their ability to perform daily activities, engage in social interactions, and maintain a sense of independence. Specifically, based on patients' descriptions, they frequently face emotional distress, anxiety, and depression due to the chronic and unpredictable nature of their condition. The physical limitations imposed by PF symptoms also lead to increased reliance on caregivers and support systems. Moreover, the challenges in breathing and reduced exercise tolerance contribute to a sense of frustration, loss of control, and diminished self-esteem.

Moreover, the fourth problem area focuses on the **experiences related to receiving various treatments, representing the most prominent topic with 49.7% of the posts**. Hence, it is evident to conclude that receiving treatments in the follow-up stage is the biggest concern in PF patients' journey.

The treatment of PF involves pharmacological treatment and non-pharmacological treatment as two main methods, while both methods can merely slow disease progression but they also come with challenges and adverse effects. The negative experiences caused by pharmacological treatment are mostly related to the side effects caused by medication and doubts about the usage and dosage of medication.

The non-pharmacological treatment involves pulmonary rehabilitation, taking supplements, and oxygen treatment, which are more related to home care, and patients are constantly looking for information online with peer patients. Specifically, patients have more positive attitudes toward pulmonary rehabilitation and consider it a useful method. And they have more doubts regarding the usage of oxygen devices and the social uncomfortableness caused by using them in public.

The final problem area concerns the **difficulties in adapting their lifestyle to accommodate the changes brought about by PF (11.7% of the posts)**. Patients experience profound alterations in various aspects of their lives, most notably in their daily routines. These changes encompass dietary adjustments due to loss of appetite, poor sleeping conditions, and reduced mobility. Socially, patients engage in fewer activities and experience limitations in their interactions due to physical constraints and decreased functional capacity. Additionally, a significant number of patients are compelled to give up their jobs, leading to a substantial shift in their roles within the family unit.

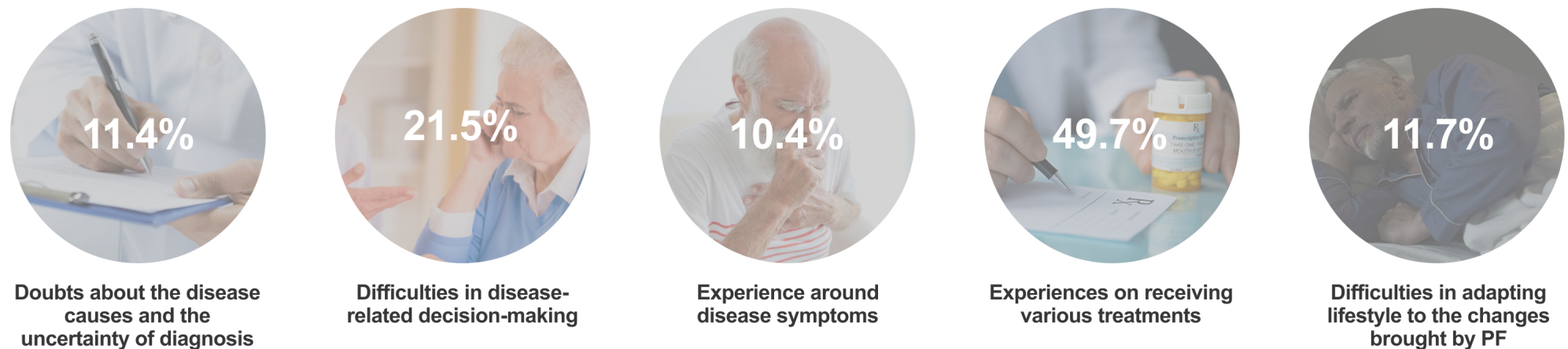


Figure 2.11: Initial problem areas in patient experience

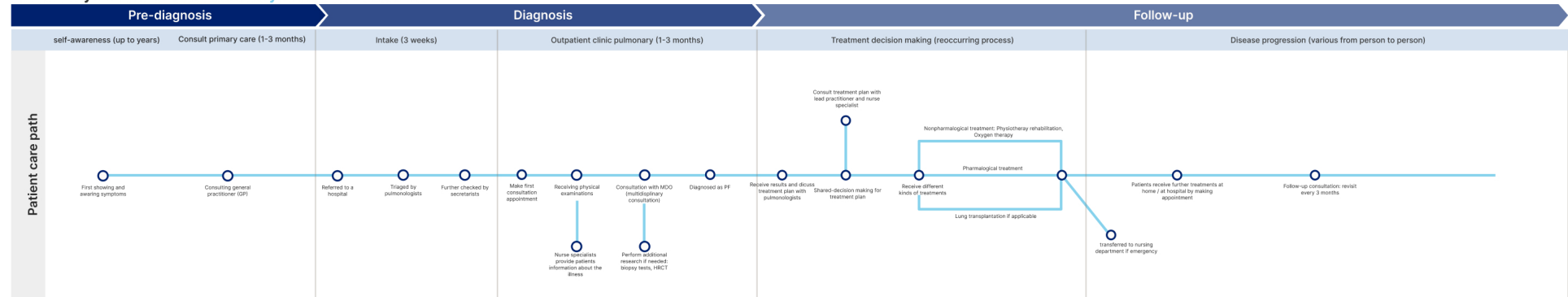


## 2.5 Conclusions of Chapter 2

### To RQ1: What is the care path of PF patients in the Netherlands?

The comparison between the ideal care path and the actual care path experienced by patients with PF reveals significant disparities, as shown in Figure 2.12. The ideal care path is envisioned as a linear process that ensures smooth transitions between various stages of care. However, in reality, patients encounter deviations and unwanted paths that result in challenges and barriers to their disease progression. These deviations may arise from factors in every disease stage, such as misdiagnosis, treatment delays, inadequate support for self-management, or limited access to specialized care. Recognizing these gaps is crucial for identifying areas for improvement, addressing the underlying issues, and developing interventions that align the actual care path with the desired ideal path.

#### Pulmonary Fibrosis Patient Journey based on ZORGPAD



#### Pulmonary Fibrosis Patient Journey based on community data

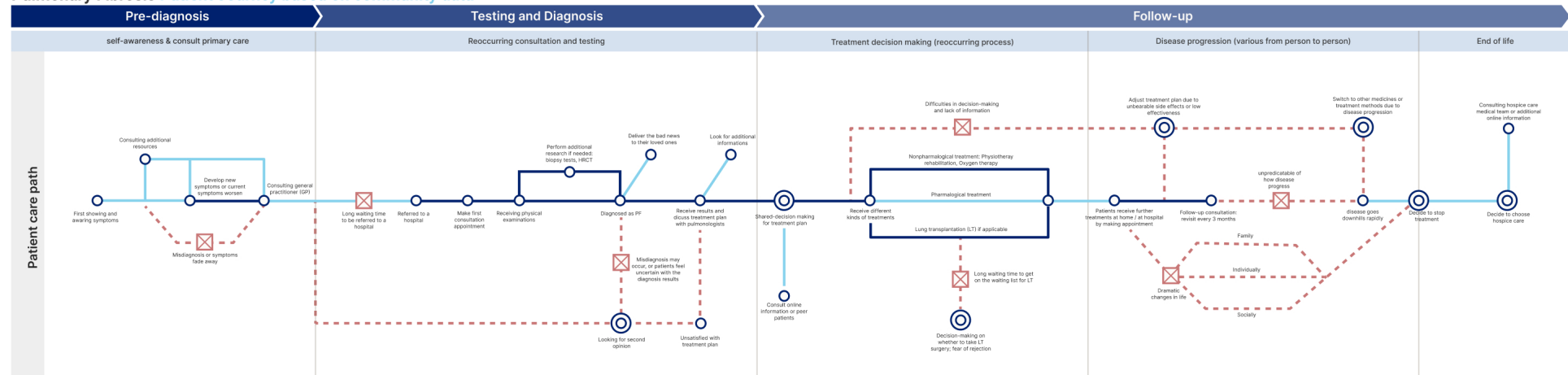


Figure 2.12: Comparison of the ideal and actual PF patient care path



**To RQ2: Who are the main healthcare providers in the PF patient care path, and how do they support patients in their journey?**

The main healthcare providers in the patient care path include the Healthcare professionals from the specialist center (Pulmonologists and nurse specialists), the treatment center, and the general practitioners. Section 2.2 introduced the collaborative effort between these healthcare providers detailly.

**To RQ3: What are the main barriers and challenges faced by PF patients in their care path? And how do patients perceive them?**

#### **(1) Limited communication between patients and Healthcare professionals (HP)**

Based on the findings from consultation observation, it is found that PF patients have limited time and opportunities to communicate with HPs. Supplementally, they frequently disease-related in the online patient community and look for advice from their peers.

Typically, in the follow-up stage, patients only visit the hospital for check-ups and have consultations only every three months to assess their disease courses and adjust treatment plans. However, they often have very complex needs and numerous questions regarding their condition, treatment options, daily care advice, and self-management strategies. And due to the limited time available for consultations, healthcare professionals may struggle to address all of these concerns adequately. This results in a potential gap in information provision

and communication gap between patients and HPs, which can negatively impact the patient's understanding of their condition and hinder their ability and adherence to self-management. To address this issue, more innovative solutions should be induced to provide comprehensive and patient-centered care

#### **(2) five initial problem areas in patient experiences**

Additionally, the findings from the Patient community journey mapping have identified five initial problem areas based on community-level PF patient experiences.

In conclusion, the contextual inquiry study has provided valuable insights into the potential challenges encountered in the care of PF patients. However, it is important to acknowledge the limitations of the contextual inquiry study, including the disparities between the community patient data and the ZORGPAD data, as well as the potential biases introduced by sentiment analysis. Moreover, Furthermore, a bias may be present due to the user groups within the online patient community, as the perspectives of individuals who do not actively share their experiences online have been overlooked. Consequently, validation with healthcare professionals and further research is necessary to solidify the results and draw definitive conclusions. These aspects will be explored in more detail in Chapters 3 and 4.

#### **Key takeaways of Chapter 2**

- There's a significant gap between the ideal and actual PF patient care paths in the Netherlands.
- The collaborative efforts between healthcare providers and patients are crucial but often hindered by limited communication, leading to gaps in information provision and low adherence to self-management
- The identification of five initial problem areas from the Patient community journey mapping underscores the need for innovative solutions to improve the HRQoL of patient.

# CHAPTER 3.

## Expert Insights: Co-creation and Interview

Chapter 3 provides an overview of the co-creation activities and interviews conducted with healthcare professionals. The primary objective of these activities is to integrate the expert perspectives of healthcare professionals, validate the interim findings, and address the limitations of previous studies.

## 3.1 Study Purpose and Research Questions

In this chapter, section 3.2 focuses on the co-creation session held with healthcare professionals from Erasmus MC, which aimed to validate and enhance the interim results obtained from the patient community map, narrow down the focus areas for the follow-up research, and It also explore the specific needs of healthcare professionals in delivering improved care to patients. Furthermore, Section 3.3 presents the interview conducted with nurse specialists, shedding light on an underrepresented user group that was not captured in the online community data. This insight is combined with findings from literature research. Finally, Section 2.4 summarizes the key findings derived from the co-creation session and interviews. The following research questions are addressed in Chapter 3:

**RQ4:** According to the insights provided by HPs, which specific problem areas highlighted in Chapter 2 should be given priority in subsequent research and design activities?

**RQ5:** What are the identified needs of HPs to enhance the quality of care provided to PF patients?

**RQ6:** What are the characteristics of the underrepresented patient groups in the healthcare of PF

**Chapter 3 - Expert Insights:** Gain insights from user context to narrow down focus

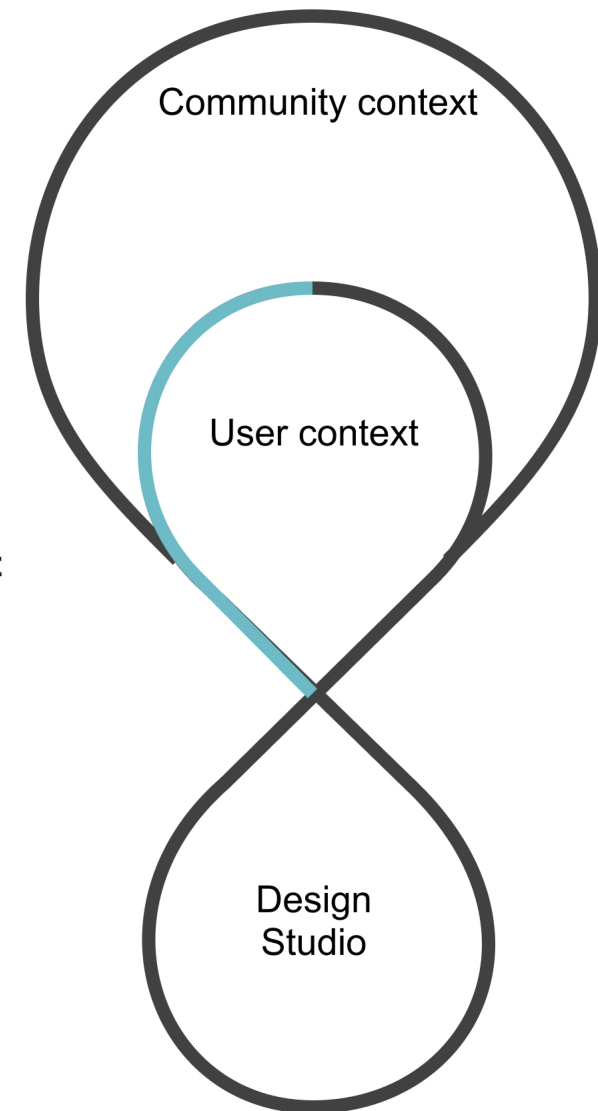


Figure 3.0: DED Approach - from community to user context

## 3.2 Co-creation session with Healthcare Professionals

Previous chapters have underscored the crucial role of healthcare professionals (HPs) in supporting PF patients in different aspects along their journey. As highlighted in Section 2.2, HPs actively participate in PF diagnosis, treatment, and long-term monitoring during the follow-up stage. Therefore, it becomes imperative to integrate the expert perspectives of HPs to gain a better understanding of patient experiences. To achieve this, the chosen methodology for this study is co-creation, which empowers the designer to collaborate with various stakeholders and foster collective creativity by integrating diverse perspectives (Sanders & Stappers, 2013). The co-creation session serves three primary objectives. Firstly, it aims to validate and refine the interim results of the patient community journey map, bridging the existing disparities among datasets. Secondly, the session seeks to prioritize specific focus areas for the next stage in collaboration with HPs, considering that addressing all identified problem areas from Chapter 2 may be impractical within the scope of this project. Lastly, the co-creation process also endeavors to identify the specific needs of HPs in delivering improved care, which sheds light on potential design opportunities.

### 3.2.1 Participants recruitment

The co-creation session involves a multidisciplinary group of participants comprising HPs as the primary participants, a professional designer, and a data scientist (Table 3.1 shows an overview of the participants). The inclusion of a professional designer in the co-creation session enhances the creative environment and brings expertise in user-centered design principles and innovation. Alongside HPs and the designer, the data scientists are also included. It is not only because the co-creation sessions serve as part of the study of the data scientist who helped to create the machine learning algorithm, but their presence also enables generating of data-driven insights during the session.

The participants were recruited using a convenience sampling approach (Stratton, 2021) due to the researcher's limited access to a broader community of HPs beyond Erasmus MC. Email invitations were sent to HPs belonging to the Interstitial Lung Disease (ILD) team at Erasmus MC, the design researcher who has double roles in both Erasmus MC and TU Delft, as well as a Ph.D. researcher of data science at TU Delft.

As the co-creation session involves human participants, each participant signed consent forms, and the co-creation plan was reviewed and approved by HREC TU Delft.

| Organization         | Specialty                |                                           |
|----------------------|--------------------------|-------------------------------------------|
| TU Delft             | Professional Designer    | Post-doc design researcher                |
|                      | Data Scientist           | PhD student in Data Science               |
| Erasmus MC, ILD team | Healthcare Professionals | Pulmonologist with 22 year experiences    |
|                      |                          | Pulmonologist with 5 year experiences     |
|                      |                          | Nurse specialist with 12 year experiences |
|                      |                          | MD, PhD Candidate of ILD team             |

Table 3.1: Overview of participants in the co-creation session



## 3.2.2 Method & Procedure

The co-creation session took place at Erasmus MC and was facilitated by the researcher. It consisted of three main activities within a total duration of 90 minutes, including a 25-minute introduction and closure. Due to the session being divided into two parts to cater to the research objectives of design and data science students, the co-creation activities specifically related to my research lasted 30 minutes.

The chosen method for the co-creation session was contextmapping (Visser et al., 2005), a well-recognized approach for co-creation activities encompassing four main steps: preparation, participant sensitization, generative session, and analysis. However, the detailed activities of this co-creation session were adjusted to accommodate the specific needs of the research purposes and participants' time restrictions. The following section will provide an introduction to the procedures (see the detailed description in Appendix E).

### Step 1: Preparation

The first step involves preparing the planning and materials for the co-creation session. The session includes two planned activities: sensitizing and validation, and the generative session. Three materials are utilized during the session: stacks of topic cards created based on the patient topics interpreted in Chapter 2 and categorized into five problem areas as sensitizing materials; a large-printed patient

community journey map for validation; and booklets distributed to participants for the generative exercises (Figure 3.1 displays the materials).

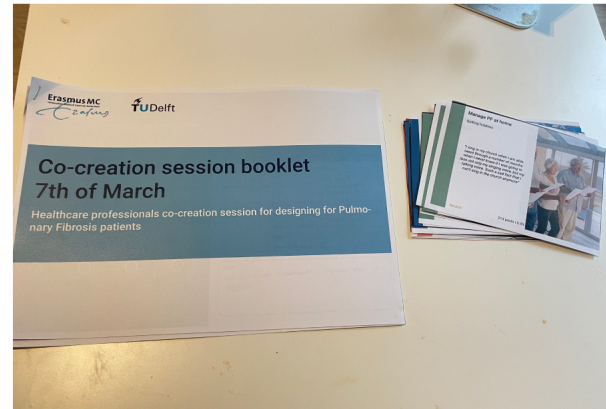


Figure 3.1: Material used in co-creation session

### Step 2: Sensitizing & Validation

The second step involves sensitizing and validation activities. Sensitization serves to familiarize participants with the context before engaging in generative exercises. Typically, this entails providing reading materials or short exercises to participants several days prior to the co-creation session (Visser et al., 2005). However, considering the existing familiarity with the context and the limited availability of HPs, the sensitizing exercises were adjusted to take place on the co-creation day as the first activity in the session.

The sensitizing process commenced with participants browsing the topic cards and the patient community journey map, aimed at inspiring them with the processed data. Furthermore, all HPs were asked to stand up to make changes and write comments on the journey map using a marker, thereby validating the preliminary findings from expert perspectives. Subsequently, a discussion took place between the facilitator and the HPs to delve into the changes and comments they made.

### Step 3: Generative session

Following the third step, the generative session consists of two parts, Figure 3.2 shows the pictures of the co-creation session. Firstly, HPs were asked to individually write down their two most crucial needs for enhancing patient care in their booklets. Moreover, the facilitator initiated a discussion, allowing participants to articulate the significance of these identified needs. Secondly, the participants engage in a group discussion to collaboratively select and prioritize the two most critical patient problem areas from the identified five. Subsequently, they provide rationale and arguments to support their choices.



Figure 3.2: Co-creation session with participants

#### Step 4: Data Analysis

After successfully completing the co-creation session, the subsequent step involved analyzing the collected data from three primary sources. These sources included transcriptions of video and audio recordings, responses obtained from participant booklets, and the printed journey map enriched with comments from HPs. The data collected from the booklets and recording transcripts underwent thematic analysis, identifying patterns in the raw data relevant to the research questions (Braun et al., 2019). Moreover, the data extracted from the journey map incorporating HPs' drawings and comments, along with referring to the discussion recordings, served as the basis for creating an improved version of the patient community journey map. In the following section, the results of the co-creation session will be presented in detail.

### 3.2.3 Results of co-creation

#### Needs of HPs in providing improved care:

After analyzing the collected data from the co-creation session, we have derived three major results. Firstly, the thematic analysis reveals four themes that capture the most crucial needs of HPs. These themes can be summarized as follows:

1. **Understanding Patients' Needs:** Tools for gaining insights into patients' needs.
2. **Automated Data Collection:** More efficient tools for collecting patient data.
3. **Personalized Care:** Tools for delivering customized care to patients.
4. **Information Provision:** Tools for providing patients with relevant information.

#### Narrowed-down project focus area:

Secondly, the group discussion yielded an argument from the HPs that the focus of further studies in this project should be narrowed down to the post-diagnosis stage of PF. While recognizing the importance of the pre-diagnosis stage for early detection and prevention, the HPs emphasized that concentrating on the post-diagnosis stage would have a more immediate impact and allow for effective intervention. Patients who have received a diagnosis require support and assistance to manage their condition effectively. Consequently, it is more practical and feasible to develop design interventions specifically targeted at the post-diagnosis stage. Moreover, from the five

identified problem areas, the HPs collaboratively selected the difficulties in disease-related decision-making and the challenges associated with adapting to lifestyle changes as the two most significant topics to address (as illustrated in Figure 3.3). The rationale behind this selection is that the HPs believe that the other three problem areas, which are more closely related to the hospital context, have already received attention in current research. However, the two challenges selected, which are more closely tied to the home context, require additional interventions and collaborative efforts

#### Improved patient community journey map:

Moreover, based on the feedback and comments received on the patient community journey map (as depicted in Figure 3.4), three crucial changes need to be addressed in order to enhance the map. Firstly, healthcare professionals (HPs) identified inaccuracies in the definitions of disease stages and subsequently made necessary adjustments to the care path. This involved rectifying parts that were either incorrect or not applicable to the Dutch patient context..

Secondly, the HPs emphasized that the merging of ZORGPAD (care path) and online community data in the map should be reconsidered. They pointed out that certain procedures and timeframes in the ideal care path differ from the



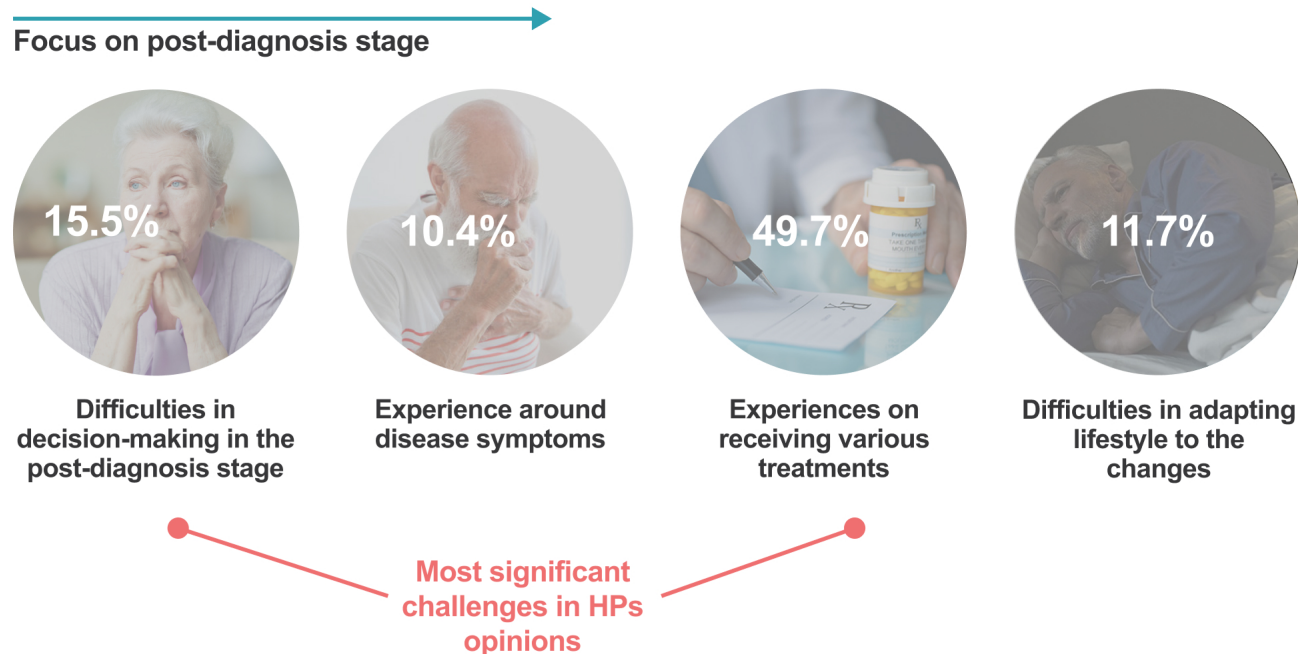


Figure 3.3: Narrowed-down focus areas and specific topics

real-life situation. Consequently, it was deemed necessary to separate the ZORGPAD data from the online community data.

Lastly, the HPs argued that the interpretation of patients' emotional flow in the journey map relied heavily on subjective judgment, which compromised the overall objectivity. Hence, it was recommended to remove human interpretations and solely focus on representing the emotional flow. Consequently, an improved version of the journey map (patient community journey map 2.0) was developed based on the feedback provided by the HPs and a re-evaluation of the data visualization.

As illustrated in Figure 3.4, the updated care path in the patient community journey map incorporates the revisions suggested by the HPs. Additionally, to enhance objectivity and efficiency in data communication, the home-hospital spectrum in patient topics has been replaced with a positive-negative spectrum using sentiment scores.

Pulmonary Fibrosis Patient Journey based on community data

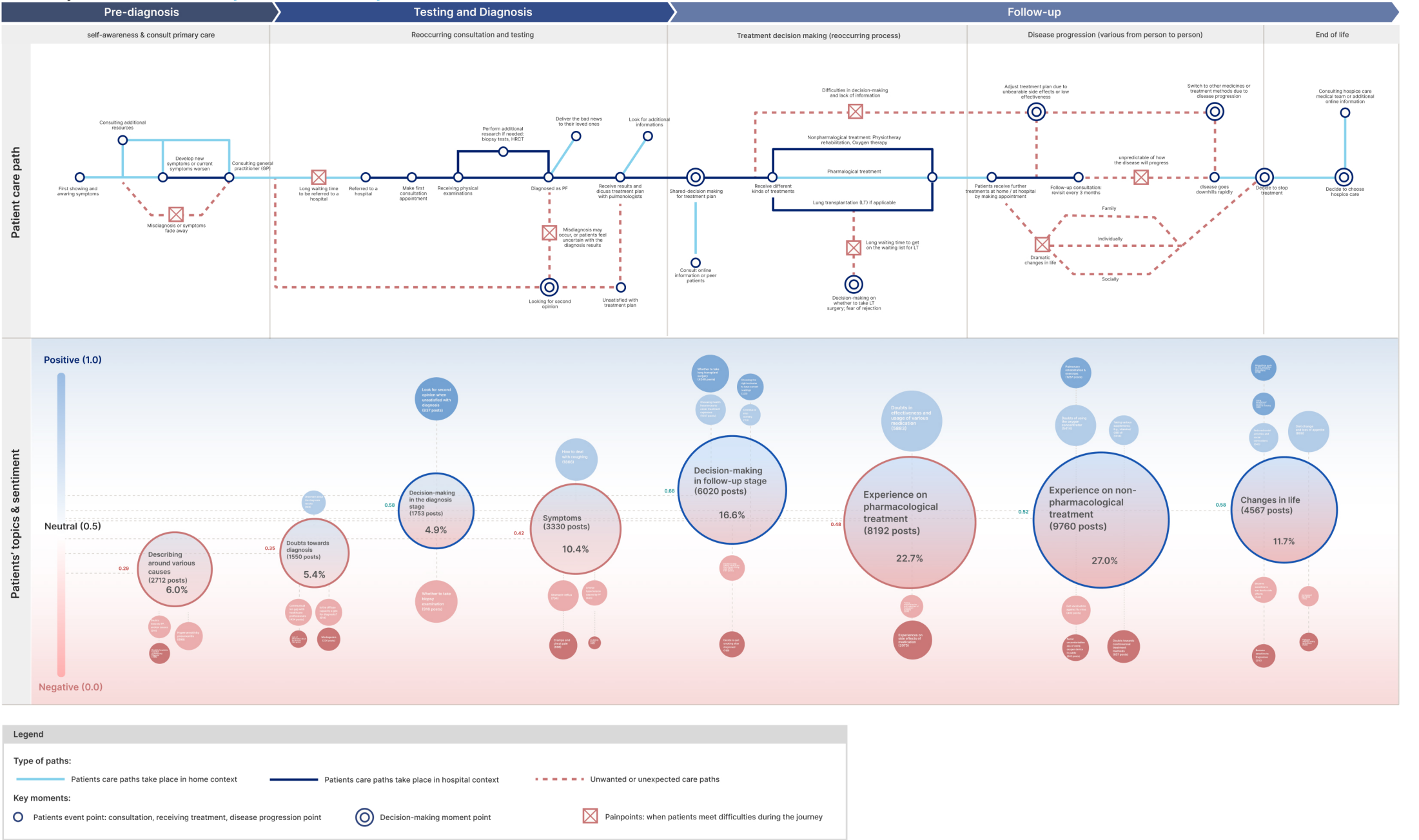


Figure 3.4: Patient community journey map 2.0



## 3.2 Extra Interview with Nurse Specialists

The active participation of patients in online support groups and their pursuit of information tend to correlate with specific demographic characteristics. Previous research conducted by Grande et al. (2006) has demonstrated that support group members are predominantly female, younger, and possess higher levels of education. Additionally, these individuals often seek formal assistance from family, friends, and healthcare professionals (HPs). Drawing from these findings, it is reasonable to hypothesize that similar biases may exist among users of online communities focused on pulmonary fibrosis (PF). However, due to ethical restrictions and limited access to patient profiles on Inspire.com, conducting an additional interview became necessary in order to gain insights into the underrepresented users concerning information acquisition. To address this, two nurse specialists from the Interstitial Lung Disease (ILD) team at Erasmus MC were interviewed.

The nurse specialists have received specialized education and training in the care of interstitial lung diseases, making them highly knowledgeable and experienced in managing PF patients. Their role in the overall care and disease management of PF patients is crucial. Specifically, their primary responsibilities encompass a range of tasks and aspects related to PF patient care, including facilitating in PF diagnosis, treatment planning, medication managements and patient counseling.

### 3.2.1 Interview procedure

#### Interview Questions:

The interview utilized a semi-structured approach, wherein the following key questions were posed:

1. What are the general demographic characteristics of pulmonary fibrosis (PF) patients in the Netherlands?
2. Are there any specific PF patient groups that you perceive as being underrepresented or underserved in terms of socioeconomic status, educational level, gender, etc.? What factors contribute to their overlooked status?
3. What are the roles and responsibilities of general practitioners (GPs) in patient care? (This question was prompted due to the lack of knowledge about GPs in previous research, as explained in Chapter 2, section 2.2)
4. During the interview, these main questions guided the discussion and data collection process, enabling a comprehensive exploration of the subject matter.

#### Data Analysis:

The data analysis method employed for this interview follows a thematic analysis approach, similar to the co-creation session. By thoroughly examining the transcript of the audio recording, four distinct themes emerged from the thematic

analysis. The key findings of the thematic analysis are summarized as follows:

1. Characteristics of general PF patients in the Netherlands
2. Characteristics of the underrepresented PF patients in the Netherlands
3. Patient information-seeking behavior and three different types of patients
4. Role and responsibilities of GP in PF patient care

### 3.2.2 Results

After conducting a thematic analysis of the nurse specialist interview, four key findings emerged. These findings encompass the characteristics of general PF patients, the underrepresented patient groups and their characteristics, the classification of patients into three types based on information acquisition, and the role and responsibilities of GPs in PF patient care. In the subsequent sections, we will present the first three findings, as the last one has already been thoroughly discussed in Chapter 2

#### General PF patients and their characteristics in NL:

Based on demographic research, it has been established that the average age of European idiopathic pulmonary fibrosis (IPF) patients at

the time of diagnosis is around 65 years, with males accounting for a significant majority at 73.7% (Nalysnyk et al., 2012). The nurse specialists in this study validated these demographic characteristics, confirming that the PF patient demographics in the Netherlands align with the broader European statistics. Additionally, drawing from their extensive experience, the nurse specialists provided insights into the occupational and psychological characteristics of PF patients, as summarized in the following.

Notably, **a majority of PF patients in the Netherlands exhibit a relatively high level of education and socio-economic status. These patients actively seek care, and health information, and engage in shared decision-making processes.** Moreover, most patients are Dutch native citizens, and due to their cultural characteristics, they are very independent in daily care and do not want to rely on caregivers or HPs.

Nevertheless, it is important to consider the potential bias that may be present in these findings. The observed patient demographics could be influenced by the proactive healthcare-seeking behavior and heightened symptom awareness among this particular subgroup, leading them to seek care more frequently at specialized centers. As a result, the patient population seen at such centers may not fully represent the broader PF patient population in the country. On the other hand, recent trends indicate a growing diversity in patient demographics.

### **Underrepresented patients' characteristics:**

Firstly, it is observed by the nurse specialists that a minority of patients belong to lower socioeconomic status and possess lower levels of education. This finding aligns with existing research on healthcare disparities, which has consistently shown that individuals with lower socioeconomic status and educational attainment often face barriers in accessing healthcare services and obtaining necessary information (Adler & Stewart, 2010; Mackenbach et al., 2008). These patients may encounter financial constraints, lack of health insurance coverage, and limited resources, which can impede their ability to seek information and actively participate in shared decision-making processes. The influence of socioeconomic factors on health disparities has been well-documented, with studies highlighting the impact of income, education, and occupation on health outcomes and healthcare utilization (Braveman et al., 2011)

Moreover, cultural factors and language barriers are also considered as influencing factors for the underrepresented patient groups. Although the majority of PF patients in the Erasmus MC are Dutch locals, it is noticed that language barriers and information gaps contribute to limited access for international or non-Dutch-speaking patients. Research has shown that language barriers can lead to disparities in healthcare access and quality, with non-English speaking patients experiencing challenges in understanding medical information, communicating with healthcare providers, and navigating the healthcare system (Flores, 2006; Ngo-Metzger et al., 2003).

This is particularly relevant in the context of PF, where clear and effective communication is vital for patients to comprehend their condition, treatment options, and self-management strategies.

In conclusion, these findings shed light on the existence of disparities in healthcare access and engagement. Patients with lower socioeconomic status, lower education levels, and language barriers face challenges in accessing healthcare resources and actively participating in their care. Recognizing the unique needs and experiences of underrepresented patients is crucial for developing targeted interventions to address these disparities. By incorporating their perspectives, promoting inclusivity, and fostering cultural competence, healthcare providers and designers can work towards equitable healthcare delivery and improved patient outcomes for underrepresented populations.

### **Patient information-seeking behavior and three types of patients:**

Health information-seeking plays a crucial role in patient disease management behavior, as it empowers individuals to make informed decisions about their health. Both motivation and abilities influence patients' engagement in seeking health information (Barello et al., 2016).

During the interviews, the nurse specialists identified two significant characteristics of information-seeking behavior among PF patients. Firstly, patients predominantly directed their questions to HPs regarding medication usage, potential side effects, and treatment



plans. Conversely, they were less inclined to seek guidance from HPs regarding everyday care challenges, as they perceived these inquiries to be outside the realm of medical concerns. Secondly, the nurse specialists observed that some patients exhibited hesitation in questioning their diagnosis or treatment plan due to a desire to maintain a positive patient-HP relationship. This hesitation could potentially lead to delays in diagnosis or suboptimal treatment outcomes.

Additionally, the nurse specialists identified three distinct types of patients, each characterized by varying levels of motivation and abilities to seek health information. It is important to delve deeper into these patient types, considering the available evidence and arguments. Figure 3.7, the motivation-ability quadrant diagram, visually represents the interplay between these two factors in patient information-seeking behavior and the position of three types of PF patients.

The first type comprises patients who demonstrate **high motivation and possess the necessary abilities to seek information**. Research suggests that patients who actively seek comprehensive information tend to be highly educated and in the early stages of the disease (Rutten et al., 2005). These individuals may have a greater capacity to process and comprehend complex medical information due to their educational background. Furthermore, nurse specialists have noticed that early-stage patients often exhibit a strong desire to understand their condition, treatment options, and potential outcomes. Their proactive

engagement in information seeking is driven by the sense of control and empowerment in managing their health.

The second type encompasses **patients with limited abilities and motivation to seek information**, which is the most commonly seen based on the nurses' experiences. This majority group faces various barriers, such as low health literacy, limited access to resources, or

or competing priorities in their lives (Gazmararian et al., 2003; Nutbeam, 2008). It is essential to address these barriers and provide tailored support to ensure that patients receive the necessary information to make informed decisions about their health.

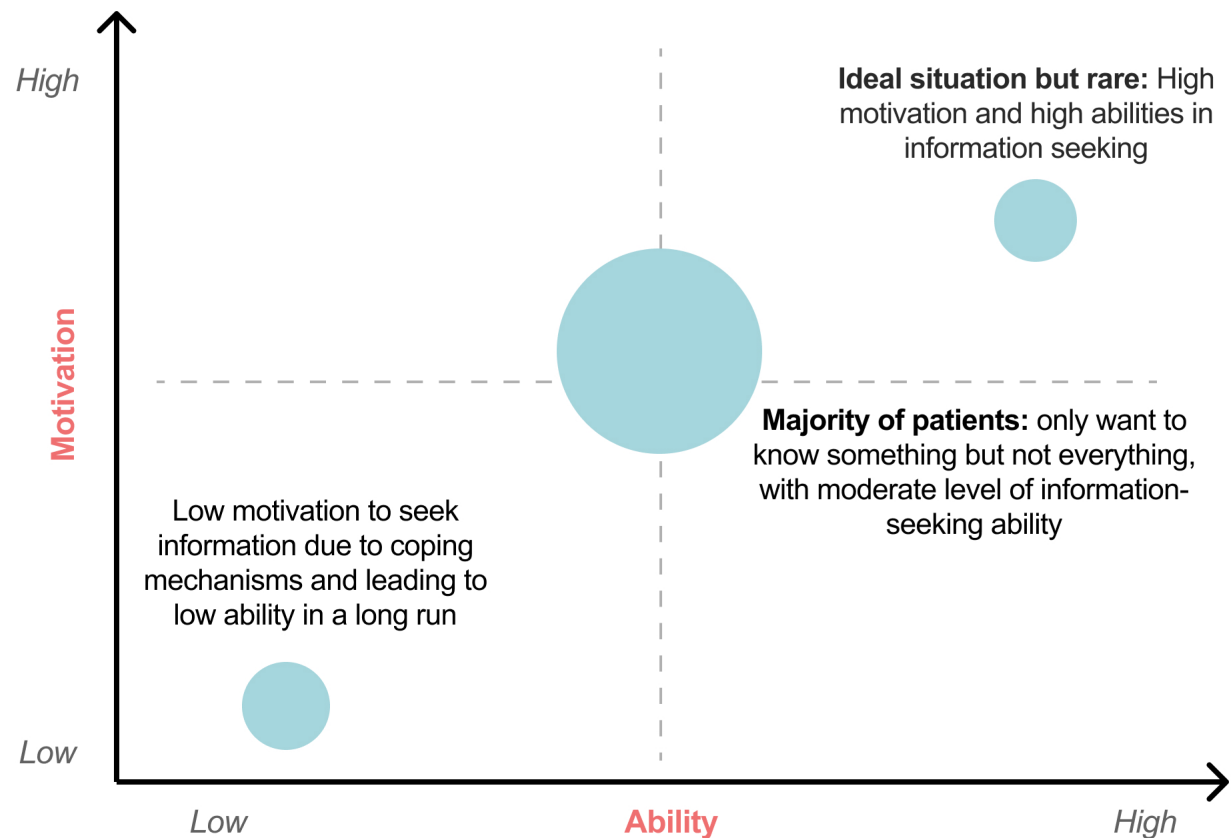


Figure 3.7: Three types of information-seeking behavior in the quadrant

Lastly, **some patients demonstrate a lack of motivation or interest in acquiring any disease-related information.** This behavior can be attributed to their coping mechanisms, as they prefer to avoid potentially negative emotions associated with acquiring knowledge about their condition (Arndt et al., 2017). On the other hand, the lack of received health information can also lead to low information seeking ability. While it is crucial to respect patients' autonomy and preferences, opportunities and resources should be provided for them for communication and education to address any misinformation or misconceptions that may arise due to patients' limited engagement.

In summary, the nurse specialists' observations align with existing research on health information seeking. Understanding the motivations and abilities of patients in seeking health information allows the stakeholders to tailor their approaches accordingly. By recognizing the varying information needs and preferences among different patient types, strategies can be developed to improve health literacy, address barriers to information seeking, and support patients in actively managing their health.



## 3.4 Conclusions of Chapter 3

To **RQ4: According to the insights provided by HPs, which specific problem areas highlighted in Chapter 2 should be given priority in subsequent research and design activities?**

Based on the outcomes of co-creation with HPs, it is recommended that the subsequent studies in this project prioritize the post-diagnosis stage of PF. These studies should particularly concentrate on the four problem areas identified through the examination of patient experiences at the community level during this stage. Specifically, the HPs have expressed a keen interest in exploring the challenges related to decision-making in the post-diagnosis stage, as well as the difficulties in adjusting lifestyle adapting to the changes. However, it remains undetermined whether these two specific problems will be the sole focus of the subsequent studies, as further investigations from the perspectives of patients are still required.

To **RQ5: What are the identified needs of HPs to enhance the quality of care provided to PF patients?**

Through the co-creation and discussion with HPs, four fundamental requirements for enhancing patient care have been identified as follows:

- **Understanding Patients' Needs:** Tools for gaining insights into patients' needs.
- **Automated Data Collection:** More efficient tools for collecting patient data.
- **Personalized Care:** Tools for delivering customized care to patients.
- **Information Provision:** Tools for providing patients with relevant information.

While all four needs are important, the focus of this project is primarily centered on improving patients' health-related quality of life. Therefore, the last two needs, namely personalized care and information provision, are particularly crucial to be addressed. However, it is important to acknowledge that the insights gained from addressing the first two needs will contribute to the future development of the system, facilitating the tasks of healthcare professionals in delivering effective care and achieving positive patient outcomes.

To **RQ6: What are the characteristics of the underrepresented patient groups in the healthcare of PF?**

Two patient groups with different characteristics are underrepresented in PF care, according to nurse specialists' interviews. The first group consists of lower socioeconomic status individuals with lower education levels. The second group comprises international or non-Dutch-speaking patients facing language barriers and limited access to healthcare resources. Targeted interventions are needed to

address the specific needs of these underrepresented patient groups, including financial support, educational resources, and language support services.

### Key takeaways of Chapter 3

- Subsequent studies should prioritize the post-diagnosis stage of PF, including the four problem areas defined.
- Identified most important needs of HPs to enhance care for PF patients which shed light on design possibilities: personalized care interventions, and efficient information provision solutions.
- Underrepresented patient groups: lower socioeconomic status individuals with lower education levels; International/non-Dutch-speaking patients. Targeted interventions needed for these patient groups

# CHAPTER 4.

# Self-management Behavior Study

Chapter 4 presents a comprehensive investigation into the Self-Management Behavior (SMB) exhibited by patients with PF. This investigation builds upon the valuable insights obtained from contextual inquiry, co-creation sessions, and interviews conducted with healthcare professionals. Building on the narrowed focus on the post-diagnosis stage established in Chapter 3, this chapter underscores the crucial role of patient self-management behavior in the follow-up stage care of PF patients. Given the chronic progressive nature of PF and the limitations of healthcare resources, collaborative efforts between patients and healthcare professionals are essential, with self-management emerging as a key aspect of this process.

## 4.1 Study Purpose and Research Questions

Section 4.2 provides an in-depth exploration of the Self-Management Behavior (SMB) based on the findings from an extensive literature review. This section highlights the benefits of effective self-management for PF patients in the disease follow-up stage. Continuing with Section 4.3, various behavioral and psychological frameworks pertaining to SMB are introduced. As a result, the Information-Motivation-Behavioral Skills (IMB) model is selected as the most suitable framework for understanding and enhancing SMB among PF patients. This model is subsequently integrated into the patient community journey map, allowing for a comprehensive assessment of the needs and requirements of PF patients in achieving adherent and effective self-management. Lastly, Section 4.4 concludes this chapter by summarizing the identified user needs derived from the integration of the IMB model within the patient community journey map. These findings provide a solid foundation for informing the subsequent design opportunities and processes in the forthcoming stages. The following shows the research question investigated in this chapter:

**RQ7:** What are the key determinants and barriers that influence the effectiveness of self-management behavior among PF patients?

**Chapter 4 - SMB behavior study:**  
Back to the community data again to find users' needs in SMB

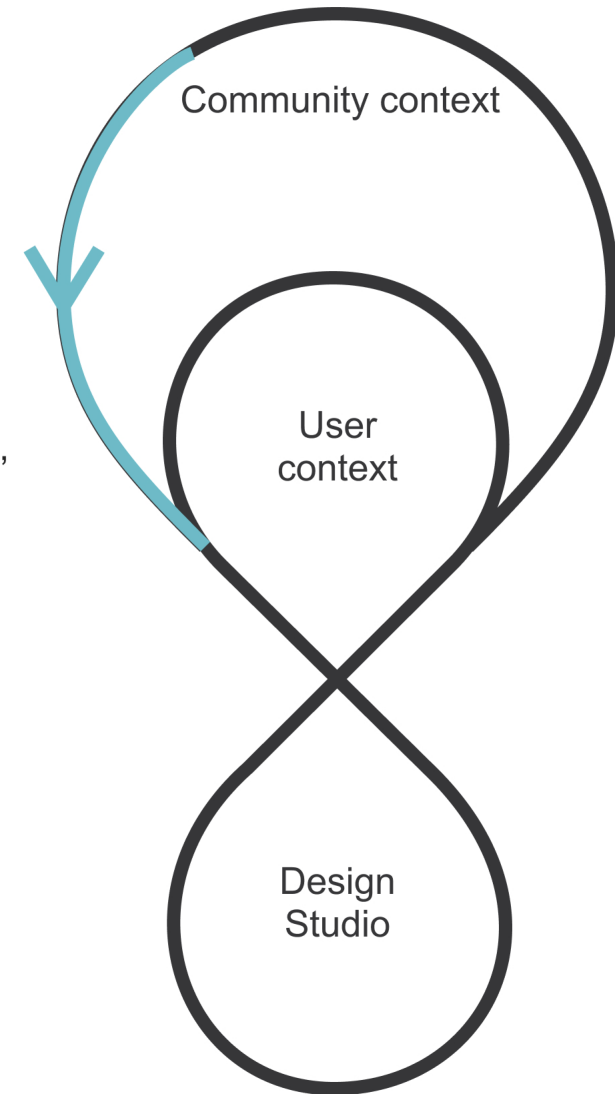


Figure 4.0: DED Approach - back to community data

## 4.2 Self-management behavior in PF patient care

As stated by Barlow et al. (2002), self-management behavior can be defined as individuals' active involvement in the management of their chronic condition(s), encompassing the monitoring of symptoms, adherence to treatment plans, and the adoption of healthy behaviors like exercise and self-care activities.

In the context of PF, self-management behavior plays a crucial role in optimizing patient outcomes and improving their quality of life in the disease follow-up stage. Numerous studies have emphasized the importance of self-management behavior as a key component of chronic pulmonary disease management (Ries et al., 2007; Bourbeau, 2003). By empowering patients to take an active role in their care, self-management behavior enables them to monitor their symptoms, adhere to treatment plans, make informed decisions, and engage in healthy lifestyle behaviors (Effing et al., 2016).

Patients with PF face unique challenges due to the progressive nature of the disease and the impact it has on their daily lives. Engaging in self-management behavior becomes particularly important in the care of PF patients to address these challenges effectively. Research has shown that self-management behavior has a positive impact on various outcomes for PF patients, including improved symptom control, medication adherence, enhanced exercise capacity, reduced healthcare utilization, and

better overall quality of life (Lee et al., 2022). A randomized controlled trial by Monninkhof et al. (2003) revealed that a self-management program tailored to ILD patients led to improved dyspnea, exercise capacity, and overall quality of life. By actively participating in their care, PF patients can gain a sense of control over their condition, which contributes to psychological well-being and improved coping strategies.

Moreover, effective SMB for PF patients encompasses several key components. Based on the recent research by Lee, Tikellis, Khor, et al. (2022), 12 essential components of SMB was defined as shown in Table 4.1. These components can be further categorized into five major themes. The first theme is treatment understanding and management, which encompasses comprehending treatment options, making informed treatment decisions, and adhering to the prescribed treatment plan. The second theme focuses on symptom monitoring, including effectively managing shortness of breath and fatigue, as these symptoms serve as important indicators of disease progression. The third theme emphasizes the importance of lifestyle adjustments, such as smoking cessation and regular participation in physical exercises. Furthermore, addressing mental well-being is a crucial aspect during the disease follow-up stage, as numerous studies consistently highlight the negative psychological and emotional impact experienced by PF patients.

Notably, approximately 31% of patients with ILD, including PF, report anxiety, and 21% report depression (Lee et al., 2020). Lastly, effective communication and connection with others play a significant role in PF patients' self-management behavior.

| Main Category                          | SMB components                                                                |
|----------------------------------------|-------------------------------------------------------------------------------|
| Treatment understanding and management | understanding treatment and medication options                                |
|                                        | understanding and accessing clinical trials                                   |
|                                        | managing medications                                                          |
|                                        | role of oxygen therapy                                                        |
| Symptom monitoring and management      | managing shortness of breath                                                  |
|                                        | managing fatigue                                                              |
|                                        | managing comorbidities                                                        |
| Lifestyle adjusting                    | role and importance of pulmonary rehabilitation and regular physical activity |
|                                        | smoking cessation                                                             |
|                                        | role and importance of pulmonary rehabilitation and regular physical activity |
| Mental well-being management           | managing mood                                                                 |
| Communication and connection           | accessing community support                                                   |
|                                        | how to communicate with others when living with PF.                           |

Table 4.1: 12 components of SMB in PF (Lee, Tikellis, Khor, et al., 2022)



## 4.3 Behavioral-psychological Framework of SMB

The previous section established the understanding of the role of SMB in PF patients' care. To optimize the potential effectiveness of the design interventions to enhance individuals' self-management behavior, it is necessary to comprehend the theoretical models or mechanisms that underpin such behavioral changes (Davis et al., 2014). Therefore, this section intends to examine several health behavioral models that could gain insights into the cognitive, psychological, and social factors that shape patient behaviors related to SMB, which allows us to identify the specific needs, challenges, and barriers that patients encounter in their self-management journey.

### 4.3.1 Model selection

Self-monitoring is considered as one of the most effective interventions in behavioral change to foster adherence to self-management behavior (Homko et al., 2002). It is driven by individuals' self-efficacy, which plays a vital role in shaping their motivation and engagement in self-management practices. Bandura's self-efficacy theory provides a valuable framework for understanding the relationship between self-efficacy and self-management behavior. According to Bandura, self-efficacy refers to individuals' beliefs in their capabilities to successfully perform specific behaviors in order to achieve desired outcomes (Bandura, 1997). In the context of self-management, individuals with higher self-efficacy are more likely to take

proactive measures to monitor their symptoms, adhere to treatment plans, engage in healthy behaviors, and therefore improve their health outcomes. (Fisher & Fisher, 1992). Evidence suggests that self-efficacy is strongly associated with positive self-management outcomes in various chronic conditions. For example, a before-after cohort study by Lorig et al. (2001) demonstrated that higher self-efficacy beliefs were significantly related to better self-management behaviors and improved health outcomes in patients with various kinds of chronic diseases.

While self-monitoring is widely recognized as a significant determinant of self-management behavior, patients' adherence to self-monitoring alone is often low without the support of additional interventions (Mishali et al., 2010). For instance, a systematic review across different health behaviors and populations by Burke et al. (2011) found that the use of self-monitoring technology in chronic disease management reported a decline in adherence over time, with only a subset of participants consistently engaging in self-monitoring activities. Similarly, a meta-analysis by Webb et al. (2010) examining the effectiveness of internet-based behavior change interventions revealed that the dropout rates were significantly higher in interventions that relied solely on self-monitoring compared to those incorporating additional strategies. These findings suggest that solely relying on

self-monitoring as an intervention feature leads to patients' low adherence while additional intervention components are not incorporated.

To address these limitations and further enhance patients' self-manage behavior, it is crucial to implement comprehensive interventions that go beyond individual self-efficacy beliefs and encompass other factors that influence self-management behavior. Furthermore, various health-related behavior models were examined, which are frequently used in research on chronic disease self-management, including the Health Belief Model (HBM) by Rosenstock et al. (1988), the Social Cognitive Theory (SCT) by Bandura (2001), the Information-Motivation-Behavioral Skills (IMB) Model by Fisher & Fisher (1992). Table 4.2 summarizes the comparison between these models.

After a comprehensive understanding of these models, the Information-Motivation-Behavioral Skills (IMB) model was chosen as the most suitable one that covers not only the individual factors that the other two models have but also the external influencing factors such as information acquisition and social support. The IMB model (as shown in Figure 4.1) provides a comprehensive framework that encompasses key determinants of health-related behavior change, including individual's motivation (both self-motivation and social motivation from families, friends, and healthcare providers),

| Behavioral-change model                              | Focus                                                                                       | Influencing factors in health-related behaviors                                                                                         |
|------------------------------------------------------|---------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------|
| Health Belief Model (HBM)                            | One's perceived susceptibility, severity, benefits, barriers, cues to action, self-efficacy | Perceived susceptibility and severity of the health condition, perceived benefits and barriers to action, cues to action, self-efficacy |
| Social Cognitive Theory (SCT)                        | The reciprocal interaction between personal, environmental, and behavioral factors          | Self-efficacy, observational learning, outcome expectations, reinforcement, environmental factors                                       |
| Information-Motivation-Behavioral Skills Model (IMB) | the role of information, motivation, and behavioral skills in driving behavior change.      | Information, personal and social motivations, self-efficacy, behavioral skills                                                          |

Table 4.2: Comparison of three behavior models (Rosenstock et al., 1988; Bandura, 2001; Fisher & Fisher, 1992)

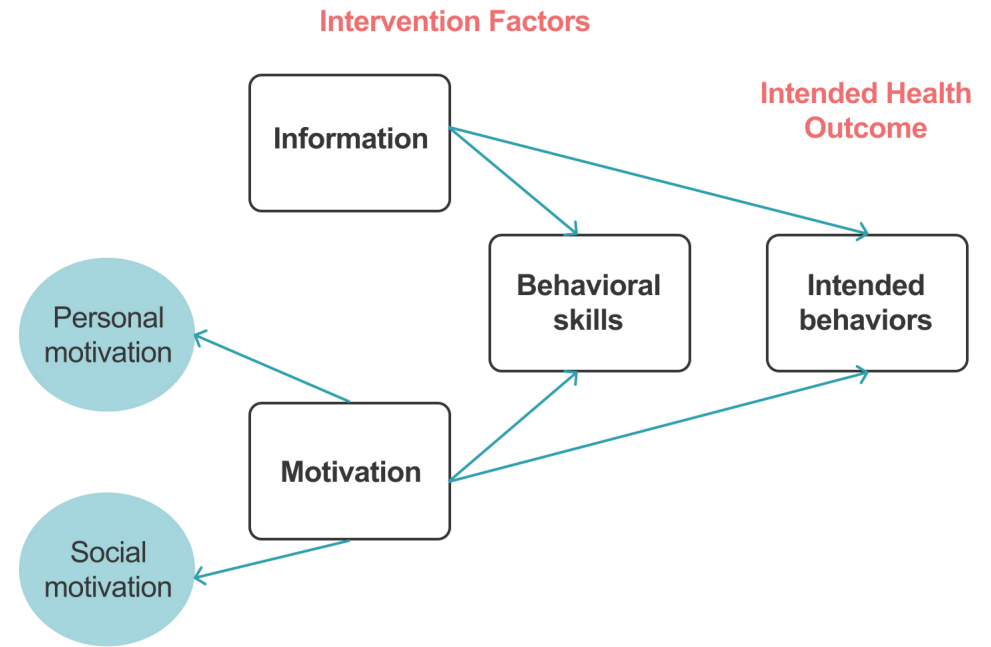


Figure 4.1: IMB model and its constructs (Fisher & Fisher, 2000)

health-related information, and behavioral skills in various self-management behavior. Furthermore, it is found in research that motivation, information, and behavioral skills are correlated with each other (Fisher & Fisher, 2000). Specifically, information and motivation influence health behavior by activating relevant behavioral skills. Individuals express their information and motivation primarily through the application of these skills, which play a key role in initiating and maintaining the behavior. On the other hand, information and motivation can also directly impact behavioral performance, especially when complex or new skills are not required.

One major advantage of choosing the IMB Model is that it demonstrates significant overlap with the HBM model and SCT, including capturing the individual-level factors emphasized by HBM in motivation and information constructs and the self-efficacy component of SCT in its motivation and behavioral skills constructs (Fisher & Fisher, 2000; Misovich et al., 2003). Furthermore, the IMB model has been frequently and widely applied in various research on self-management behavior among different kinds of chronic disease, which has been proven as effective and representative (Starace et al., 2006; Kripalani et al., 2018; Bakir et al., 2021). One

major advantage of choosing the IMB is that it demonstrates significant overlap with the HBM model and SCT, including capturing the individual-level factors emphasized by HBM in motivation and information constructs and the self-efficacy component of SCT in its motivation and behavioral skills constructs (Fisher & Fisher, 2000; Misovich et al., 2003). Furthermore, the IMB model has been frequently and widely applied in various research on self-management behavior among different kinds of chronic disease, which has been proven as effective and representative (Starace et al., 2006; Kripalani et al., 2018; Bakir et al., 2021).

### 4.3.2 Integrating IMB model in the patient journey map: method & procedure

After selecting the IMB model as an appropriate theoretical model, it was employed to analyze and explore the self-management behavior (SMB) of PF patients within the context of the patient community journey map. Based on the understanding of SMB in PF from previous sections, an interpretation was made of the IMB model in PF self-management behavior (as shown in Figure 4.2). The aim of this phase was to investigate the self-management practices exhibited by PF patients at the community-data level and gain insights into their specific needs across the constructs of the IMB model. This examination aimed to facilitate the development of interventions and strategies that promote effective and sustained self-management behavior among PF patients.

To analyze the self-management behaviors within the Patient Community Journey map, a systematic method was employed. The ML-generated topics that belong to the post-diagnosis stages were labeled according to the constructs of the IMB model, including information and (individual/social) motivation, through re-reading the related top 50 patient posts. While the behavioral skills were not labeled, given that they are not directly observable in textual data but are more often manifested through observable actions or demonstrated competencies. Instead, the SMB components are labeled as they can be more easily captured through the topics.

Specifically, the information constructs were

labeled based on what type of information either patients sought or received in the patient posts.

For the motivation construct, a holistic view was taken, and the overarching themes and sentiments expressed in the top 50 patient posts were examined. For individual motivation, the posts were examined by whether the users

expressed personal goals, concerns, or actions related to their health. This included posts where patients discussed their own efforts to manage their symptoms, the research they had conducted about their condition or personal experiences with different treatments. As for social motivation, it was more focused on the interaction between patients, so whether

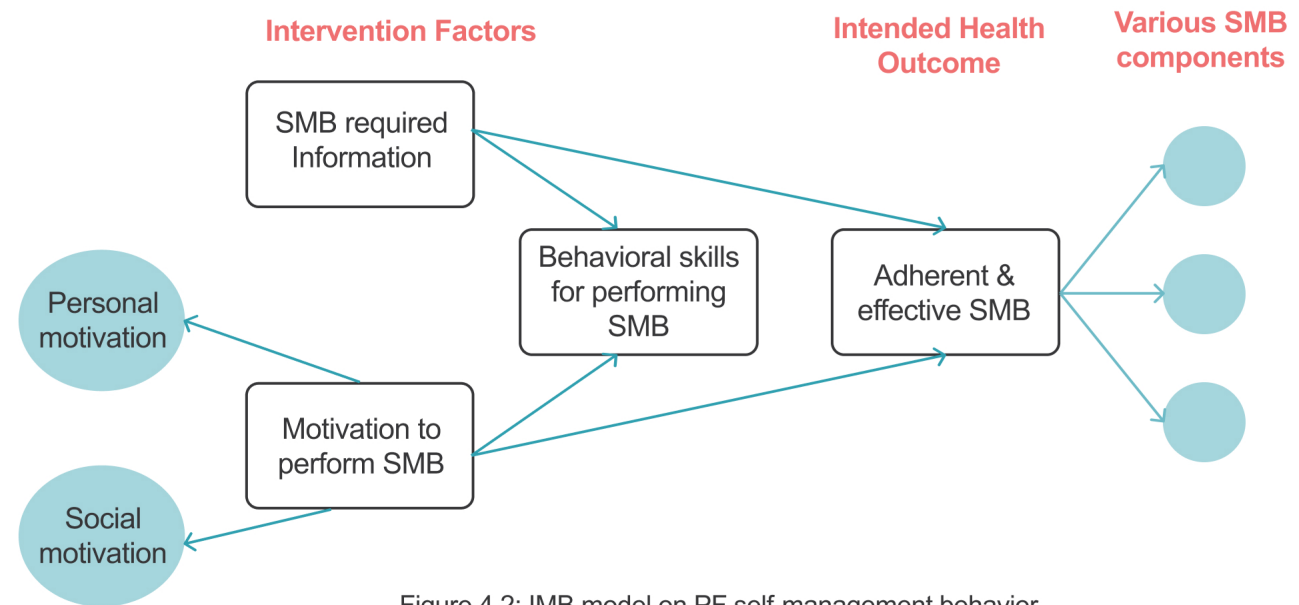


Figure 4.2: IMB model on PF self-management behavior

| Topic                        | Information                                        |                                                                                              | Motivation        |                                                                          | SMB Components                    |
|------------------------------|----------------------------------------------------|----------------------------------------------------------------------------------------------|-------------------|--------------------------------------------------------------------------|-----------------------------------|
|                              | Information seeking                                | Information received                                                                         | self-motivation   | Social-motivation                                                        |                                   |
| coughing & coping strategies | What are the coping strategies to reduce coughing? | Coping strategies against coughing: medication, cough syrup, supplements, physical exercises | Social motivation | Motivated by peer patients, get useful info and recommendation from them | Symptom monitoring and management |

Figure 4.3: Example of how the topics labeled based on IMB model constructs



patients sought or offered advice or shared experiences with each other in the posts, as a judgment basis of motivation from peers, and also including whether they talked about interaction with families and healthcare providers. Moreover, for both of them, the ML sentiment scores are also used as a reference basis.

Lastly, the identified topics were further labeled based on the self-management components in PF derived from the research conducted by Lee, Tikellis, Khor, et al. (2022), as mentioned in Section 4.2, depending on the information type related to the topics and also considering patient posts. Though 12 components provided a comprehensive framework for understanding the specific self-management behaviors relevant to PF patients, the importance of each is not examined yet. By assigning the topics to the appropriate constructs and self-management components, a nuanced understanding of the self-management needs and priorities of PF patients was achieved. This method ensured that the analysis was grounded in the theoretical framework of the IMB model and the empirical evidence provided by the identified self-management components. Figure 4.3 shows an example of how a topic was labeled based on this procedure. The next section will detailly introduce the results of this study.

### 4.3.3 Results

As a result of the integration step, 47 out of 63 ML generated patient topics that are related to experiences during the post-diagnosis stage are relabeled based on the IMB model constructs. The following will introduce the results of each construct, from information, motivation, behavioral skills, and their correlations.

#### Information constructs:

Through the re-labeling process, it was found that all 47 topics involve active information-seeking behavior. Table 4.3 shows the information types that patients were seeking, which topic category it belonged to and the numerical percentage of posts among the 32,641 of the total posts that belong to the post-diagnosis stage. Notably, there are five information types people are constantly seeking that have a high percentage (above 10%) among all, as highlighted in red in Table 4.3). Moreover, a further step is conducted to examine whether a solution is provided for the information seeking among the posts. As a result, it was found that solutions are not always provided, especially for the questions related to pharmacological treatments and symptom control, they are not always recognized by others (in the patient stories, there is not a common solution that can be extracted, and people shows doubts towards them or have different opinions), which means the reliability of these kinds of information provided by the online community is yet to be validated. On the other hand, for questions that are more related to non-pharmacological treatment and home

care advice, such as 'Looking for advice to support lifestyle-related decision-making' and 'How should I adjust my lifestyle to adapt to the changes in lifestyles caused by PF?', the online community provides good-quality solutions (from the patients' stories certain answers can be summarized and people have positive reactions). The inquiries that is provided with solutions is highlighted in Table 4.3 in green. As a conclusion, the community data can provide reliable information or solutions in the following types:

- Recommendations on pulmonary rehabilitation places, effective supplements
- Advices and personal experiences on palliative care
- Advice to support lifestyle-related decision-making based on personal experiences
- Peer recommendations on effective solutions towards changes in life

#### Motivation constructs:

Through reading the patient posts, it was found that in most topics, patients have a relatively high self-motivation, given that they are constantly looking for information and solutions to improve their quality of life. Moreover, social motivation by peers is constantly provided to patients since they are actively engaging with their peers through seeking and providing information, sharing experience,s and encouraging each other. In some topics, they also mentioned motivation by families and healthcare providers. However, these findings



are highly biased by the dataset since the users are already involved in the online community, which means they are dominantly the type of patients who have both motivation and relatively high ability in information acquisition.

### SMB Components:

By labeling the topics based on the 12 SMB components, it was found that 5 components take a dominant role in PF patients' SMB in the post-diagnosis stage, as shown in the following with a percentage of posts related to

1. Treatment understanding and management (Managing medications): 25.1%
2. Treatment understanding and management (Understanding treatment and medication options): 24.1%
3. Lifestyle adjusting to adapt to changes in life: 19.4%
4. Treatment understanding and management (role of oxygen therapy): 18.3%
5. Symptom monitoring and management: 11.6%

### Correlations between Information, Motivation and SMB components:

**Information-Motivation:** Though the motivation cannot be subjectively evaluated, it is found motivation is influenced by the information provided. Previously from the ML sentiment analysis, one of the bias found is that the sentiment score is highly biased that for some topics though they describe a topic regarding negative disease-related experience, the sentiment analysis predict as positive. While comparing the information acquisition and motivation, it was found that when the information needs in the topics are fulfilled - answer are provided by the online community, the ML sentiment score is correspondingly positive even though the overall topic is related to negative disease experience. On the contrary, when information needs are not fulfilled or people cannot judge the reliability of the information, the sentiment scores are negative. Hence, it is hypothesised that when information needs are met, people are motivated, vice versa. This finding also align with the IMB model that, the information and motivation constructs mutually influence each other (Fisher & Fisher, 1992).

| Main Topic category                                            | Information type                                                                              | Number and percentage of posts (32,641 of post-diagnosis stage in total) | Solutions provided or not                                                                                       | SMB category and components                                                             |
|----------------------------------------------------------------|-----------------------------------------------------------------------------------------------|--------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------|
| Experiences on pharmacological treatment                       | Doubts of effectiveness, usage and side effects of medication                                 | 8192 (25.1%)                                                             | Solution cannot be extracted                                                                                    | Treatment understanding and management (Managing medications)                           |
| Experiences on non-pharmacological treatment                   | Doubt about the usage of oxygen treatment devices                                             | 5978 (18.3%)                                                             | Solution cannot be extracted                                                                                    | Treatment understanding and management (role of oxygen therapy)                         |
|                                                                | What are the effective supplements? / Are these supplements effective for PF?                 | 1514 (4.6%)                                                              | Peer recommendations on effective supplements                                                                   | Treatment understanding and management (Understanding treatment and medication options) |
|                                                                | Look for advice and recommendations on physical exercises and pulmonary rehabilitation places | 614 (1.9%)                                                               | Peer recommendations on suitable physical exercises, and good rehabilitation places                             |                                                                                         |
|                                                                | Doubts of controversial treatment methods: is it a scam?                                      | 587 (1.8%)                                                               | Solution cannot be extracted; people have different opinions toward it.                                         |                                                                                         |
|                                                                | Look for peer patients' experiences on palliative and hospice care                            | 492 (1.5%)                                                               | Considered as positive: most peers have positive experience on it and recommend it                              |                                                                                         |
| Experiences on symptoms                                        | Understanding symptoms: are these symptoms (changes) normal?                                  | 3773 (11.6%)                                                             | Solution cannot be extracted                                                                                    | Symptom monitoring and management                                                       |
|                                                                | Looking for coping strategies to reduce symptoms                                              |                                                                          | Some coping strategies are provided, but false information exists                                               |                                                                                         |
| Experiences on decision-making moments in post-diagnosis stage | Looking for advice to support treatment-related decision-making                               | 4268 (14.3%)                                                             | Solution cannot be extracted                                                                                    | Treatment understanding and management (Understanding treatment and medication options) |
|                                                                | Looking for advice to support lifestyle-related decision-making                               | 1772 (5.4%)                                                              | Peers share related-personal experiences, vary from person to person                                            | Lifestyle adjusting                                                                     |
| Difficulties modifying lifestyles adapt to the changes         | How should I adjust my lifestyle to adapt to the changes caused by PF?                        | 4567 (14.0%)                                                             | Peer recommendations on effective solutions towards changes in life, such as weight control, smoking cessation. | Lifestyle adjusting                                                                     |

Table 4.3: Labelled topics in Information needs and behavioral skill components

**Information - other SMB components:** The self-management behavior (SMB) components are directly related to information needs as they encompass the necessary knowledge and understanding required to effectively manage a chronic condition. Information plays a vital role in supporting individuals in their self-management journey by providing them with the necessary insights, guidance, and resources to make informed decisions and engage in appropriate behaviors. For instance, understanding treatment options, medication management, symptom monitoring, and lifestyle adjustments all rely on access to accurate and reliable information. By providing relevant and tailored information, individuals are empowered to engage in self-management behaviors and make informed choices, ultimately leading to improved health outcomes and enhanced quality of life. Therefore, in order to facilitate SMB components, it is essential to provide adequate and accessible information resources to support individuals in their self-management efforts.

## 4.4 Conclusions of Chapter 4

The research in this chapter examines the self-management behavior (SMB) of the PF patients, supported by both literature reviews and interpretation on community data. To answer the research questions presented at the start of this chapter:

**To RQ 7: What are the key determinants and barriers that influence the effectiveness of self-management behavior among PF patients?**

The study identified several key determinants of self-management behavior (SMB) among PF patients, including information acquisition, individual and social motivation, and SMB behavioral skills. Analysis of community-level patient data revealed that the primary need of PF patients in the post-diagnosis stage is information seeking related to the following five SMB components:

1. Treatment understanding and management (Managing medications)
2. Treatment understanding and management (Understanding treatment and medication options)
3. Lifestyle adjusting to adapt to changes in life
4. Treatment understanding and management (role of oxygen therapy)
5. Symptom monitoring and management

However, it was observed that these information needs of PF patients are not adequately fulfilled, leading to barriers in effective SMB. Addressing these information gaps is essential to achieving coherent and effective self-management among PF patients.

Moreover, It is important to note the limitations of the study. The examined needs primarily represent the general patient groups, and the needs of underrepresented users may have been overlooked.

### Key takeaways of Chapter 4

- Information, motivation, and behavioral skills are key factors influencing self-management behavior (SMB) among PF patients.
- PF patients have specific information needs related to treatment understanding, lifestyle adjustments, and symptom management that are yet to be fulfilled.
- The reliability of information varies, and solutions are not always provided, highlighting the need for validation and trustworthy resources.

## CHAPTER

# 5.

# Design Concept Generation

The preceding chapters have extensively explored various aspects of the PF patient context, progressively narrowing down the focus, defining patient profiles, and examining the needs of HPs and patients. Consequently, this chapter aims to synthesize the findings from Chapters 2, 3, and 4 to formulate a comprehensive problem definition, establishing the design goal and direction for the subsequent stages.



## 5.1 Study Purpose

In this chapter, Section 5.2 presents the problem definition for PF patient self-management behavior, encompassing an examination of existing barriers and an exploration of their specific needs. Based on that, the design goal is established, serving as a guiding principle for the generation of design concepts. Furthermore, Section 5.3 provides an overview of the current patient self-monitoring system, IPD-online in EMC, which examines its features and functions, and the design possibilities to improve. Moreover, Sections 5.4 and 5.5 outline the activities conducted to facilitate concept generation, including individual brainstorming and group sessions involving participants from both design and medical fields. Lastly, in Section 5.6, the findings of this chapter are summarized, and the final concept direction is presented.

**Chapter 5 & 6 - Design  
Concept Generation:**  
Use collected insights  
from community and  
user context to generate  
tailored design solutions

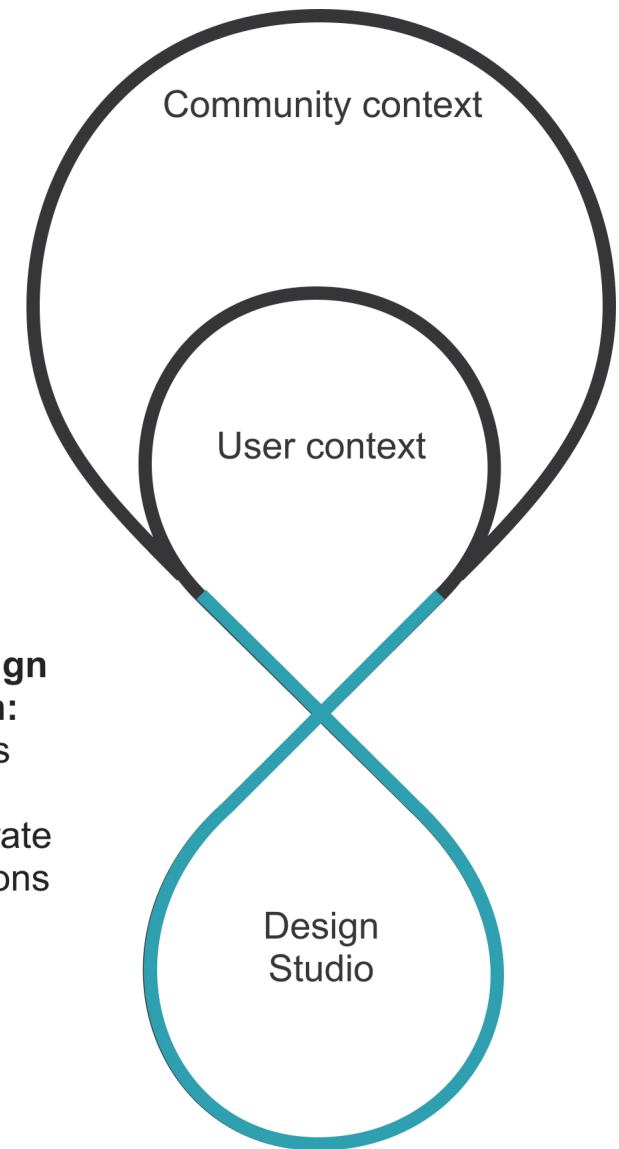


Figure 5.0: DED Approach - towards design stage

## 5.2 Problem Definition and Design Goal

### 5.2.1 Problem Definition

The problem definition of this project revolves around addressing the primary needs of PF patients to support their effective and adherent self-management journey in the post-diagnosis stage. Extensive research activities conducted in Chapters 2 and 3 have identified the post-diagnosis stage as the most challenging phase for patients, where coherent and effective self-management behavior (SMB) is crucial for improving their health-related quality of life (HRQoL). In Chapter 4, it was further explained that while self-monitoring is considered one of the most effective interventions in SMB, relying solely on self-monitoring is insufficient as it is strongly influenced by the acquisition of relevant health information. Furthermore, the five dominant information needs of SMB are defined in Chapter 4.

Firstly, while HPs possess valuable knowledge, it was found during the co-creation session and nurse interview that their limited time restricts their ability to address all patient inquiries comprehensively. Moreover, some patients have hesitation in inquiring their HPs about questions that are more related to home care difficulties.

Secondly, Chapter 4 has found that relying on online communities for information may provide rich information that covers various aspects, but

the reliability and accuracy of the content can be challenging to ascertain.

Lastly, except for the two information source examined in this research, there are also other information sources, such as medical literature and clinical guidelines, that provides reliable health information related to PF. However, medical content from these resources is often written at a higher reading level, making it difficult for patients with limited medical knowledge to comprehend the information effectively. Moreover, self-monitoring progress data, such as lung function test data, is also an informative resource. However, we found in the community data that some patients have difficulties in understanding the measurements and changes without interpretation from HPs.

Overall, each of the above information sources possesses its own strengths and limitations, as depicted in Figure 5.1. In light of these identified limitations, it is imperative to develop new interventions that can effectively address these challenges and provide PF patients with required, accessible, and easily understandable information to support their self-management behavior.

### 5.2.2 Design Goal

Based on the problem definition, a design goal is formulated to provide guidance for subsequent design activities.

***“The design goal of this project is to provide PF patients with **required, reliable, and understandable information** to support their self-management behavior in their post-diagnosis stage.”***

Specifically, each criterion of information is defined as follows:

- **Required:** The information should be provided addressing the specific needs of individuals, covering the five primary information types illustrated in Figure 5.1.
- **Reliable:** The information presented must be reliable, ensuring accuracy and adherence to evidence-based practices. It should be sourced from reputable and trusted healthcare sources, ensuring the credibility of the information provided.
- **Understandable:** The information should be presented in a clear and accessible manner, ensuring ease of comprehension for patients who may not possess extensive health knowledge.

## Information needs



Understanding and management of medication



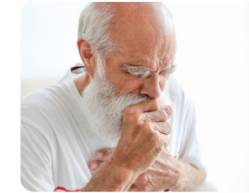
Understanding and management of oxygen therapy



Understanding Treatment and medication options



Lifestyle adjusting to adapt to changes in life



Symptom monitoring and management

## Information Sources

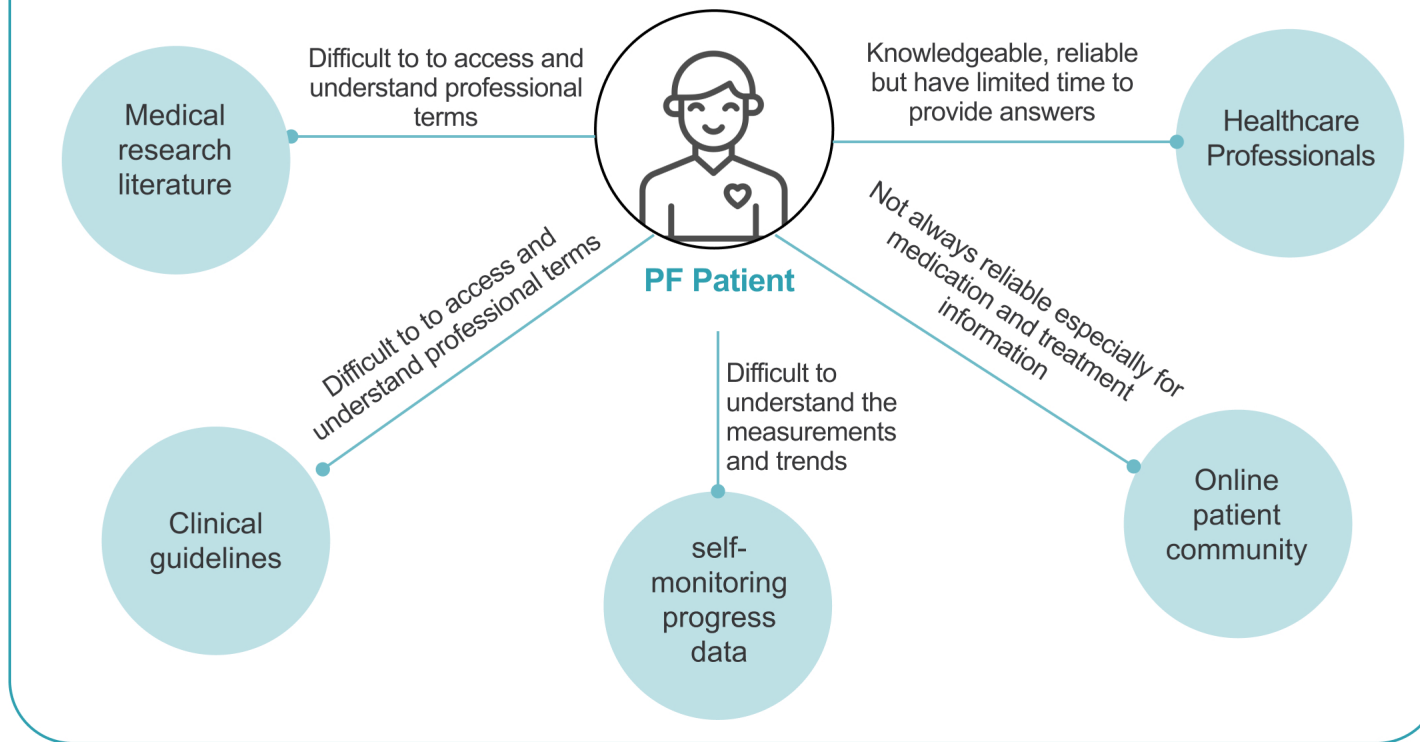


Figure 5.1: Illustration of the problem definition

## 5.3 Generate Re-design direction: build on the current PSS

After defining the design goal, the next step is to ideate on the design direction. As introduced in Chapter 1, there is an existing product-service system in EMC that is designed for the PF patient to support their self-monitoring activities through a smartphone application. Based on the previous finding, it is proven that self-monitoring is an effective intervention in self-management behavior, however, it can be further enhanced by integrating users' needs in information. Considering the development cost and efficiency, a decision was made to continue to develop and improve the existing PSS based on the design goal, specifically, we need to decide which features need to be enhanced, which unnecessary features can be deleted, and which new features need to be added. Therefore, it is necessary to examine the feature and functions of the current PSS, as the focus of the project is to develop patient-end design interventions, we will only discuss the part of the patient system in this PSS. Consequently, an additional interview was conducted with a HP in EMC, moreover, a follow-up brainstorming activity was also conducted with this HP, during which some new design features were proposed.

### Features of current PSS:

Reviewing the current PSS provided a clear overview of its system modules, sub-modules, and features (as shown in Figure 5.2), which allowed us to uncover the problems and improvement possibilities.

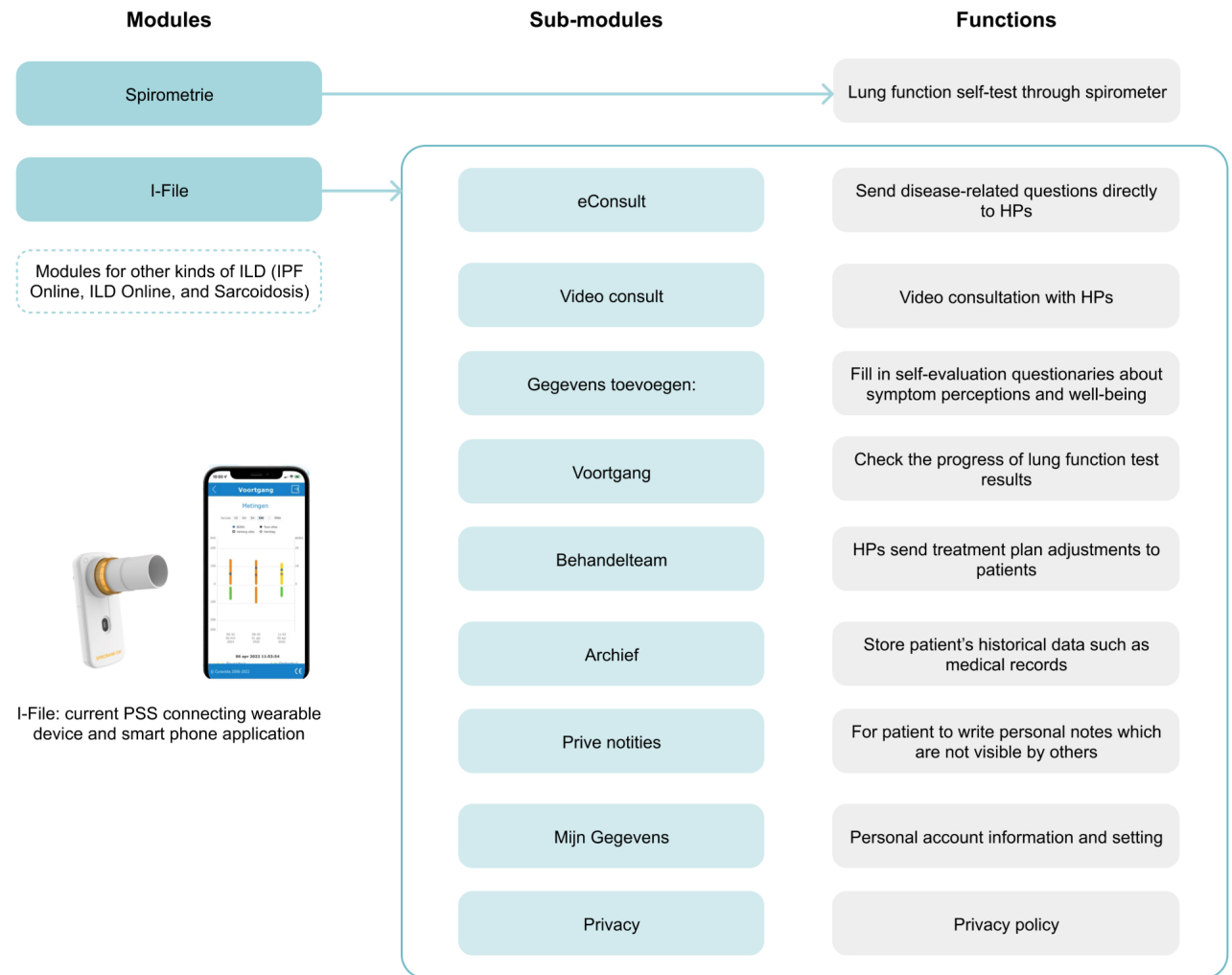


Figure 5.2: Overview of the modules, sub-modules, and features of the current patient application in the PSS



The patient-end system includes two main modules, the 'Spirometrie' and I-File.

**The Spirometrie:** As this PSS is designed for patients with various kinds of Interstitial lung diseases (ILD), the 'Spirometrie' is a common function among all of them. This module allows patients to use a Bluetooth-connected spirometer that measures the total volume of air they can exhale in one forced breath, which allows patients with ILD to monitor their lung functions at home regularly, and the measurements are also shared with HPs enabling them to remote-monitor patients condition.

**The IPF-Online/I-File:** For each kind of ILD, the PSS has different modules towards them, such as I-File (for patients with PF), IPF-Online (for patients with IPF), and Sarcoidose (for patients with Sarcoidosis). Specifically, the I-File and IPF-Online are both for patients with PF, and the only difference between them is the questions in the self-evaluation questionnaires (PF and IPF have different questions), while the rest of the sub-modules and functions are completely the same. Hence, we will only discuss the I-File module in the following. The I-File module has 9 sub-modules in total, as shown in Figure 5.2, and these sub-modules are all integrated into the homepages of the I-File application.

Altogether, the modules in the current PSS for PF patients serve five main purposes:

1. Consultation with HP: 'eConsult' (send questions through the APP), 'Videoconsult' (scheduling a video consultation with HPs).

2. Progress overview: 'Voortgang' (personal progress of lung function test results).
3. Self-monitoring: 'Sirometrie' (objective lung function self-test) and Gegevens toevoegen (subjective self-evaluation questionnaires)
4. Treatment plan communications: 'Behandelteam' (HPs can send treatment plan adjustments to the patient through it)
5. User account management: including 'Archief', 'Prive notities', 'Mijn Gegevens', and 'Privacy', which are functions that are not directly related to patients' disease management but to managing their accounts.

### Information Flow:

After reviewing the features, to figure out how the current PSS serves user needs in information, an information flow map was made to explore the information interaction between PF patients and HPs through the PSS, as shown in Figure 5.3.

### Strengths:

One of the strengths of the current PSS is its self-monitoring functions and progress overview, which are highly valued by patients. These features enable patients to actively track their symptoms and progress, providing them with important information for effective disease management.

Additionally, the treatment plan communication addresses patients' information needs in understanding and managing their treatment, facilitating their engagement in self-management behavior.

### Limitations:

**1. Unfulfilled information needs:** One of the primary limitations of the current PSS is the unfulfilled information needs of patients. The progress overview does not provide sufficient information to help patients understand their symptom changes, which is crucial for effective self-management based on the problem definition. This gap in information may hinder patients' ability to make informed decisions and take appropriate actions in managing their condition.

**2. Solely reliance on HPs as the primary source of information is another limitation.**

Currently, all patient questions are directed to their HPs through the eConsult function. However, as mentioned in Section 5.2, HPs have limited time to address all patient inquiries comprehensively, and this can result in unanswered questions and unmet information needs. Moreover, this increased workload on HPs may have implications for the quality and timeliness of their responses.

**3. Usability and functionality are also areas that require improvement.**

The current PSS includes too many functions on the home page, including some that are infrequently used by patients according to the HP, such as the 'Priva notes' (people barely use it) and 'videoconsult' (they normally do it via phone call). This complexity can create confusion and cognitive load for users, hindering their overall experience with the PSS. Simplifying the interface by consolidating or removing infrequently used functions will enhance usability and streamline the user experience.

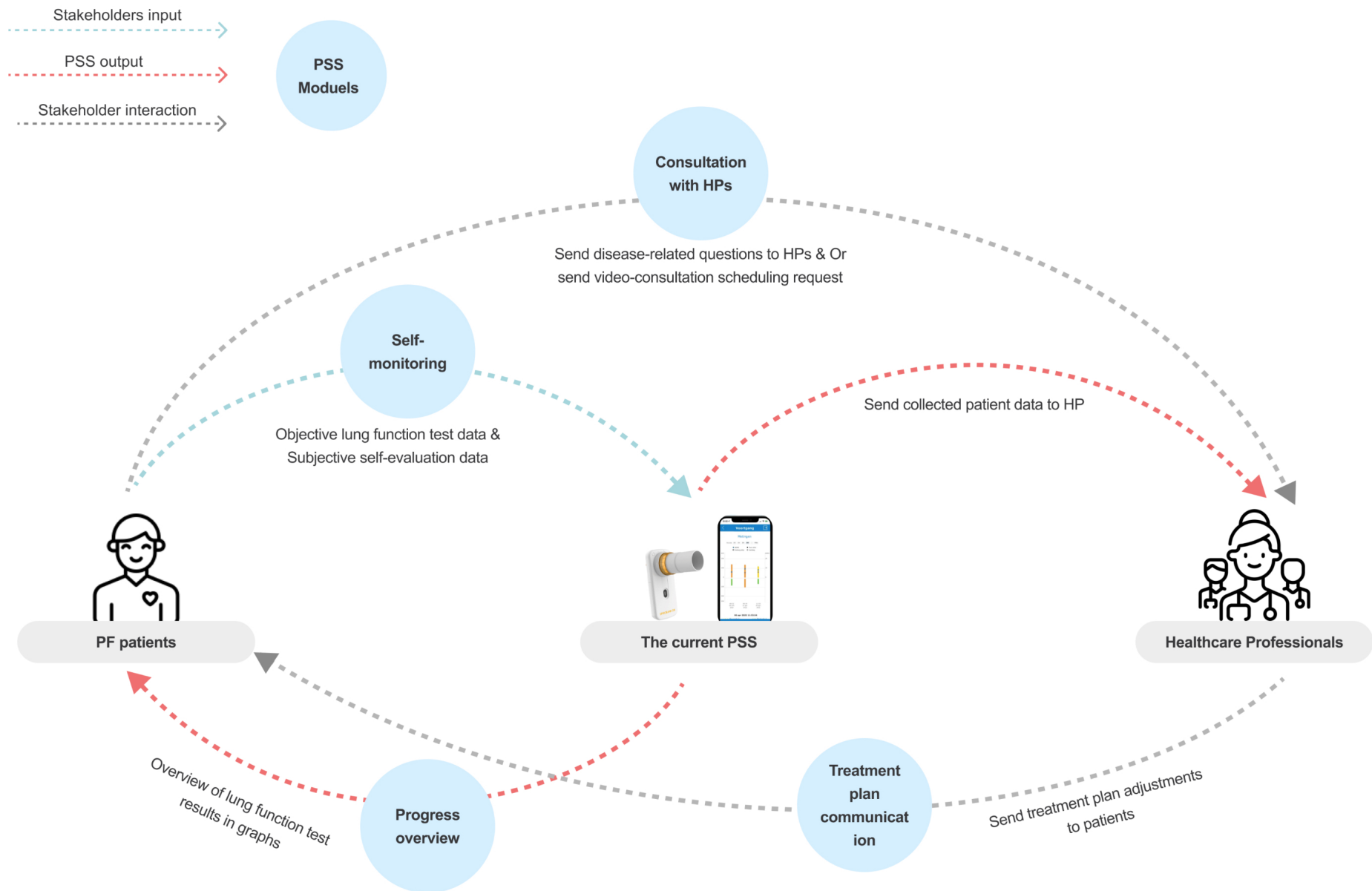


Figure 5.3: Information Flow of the current PSS

## Design possibilities for improvement:

Based on these identified strengths and limitations, a brainstorming was conducted with the HP by using a system map including the PF patients, HPs, and other stakeholders that could be involved, such as peer patients and caregivers. After the discussion, there are several design possibilities for improving the current PSS. These include:

### 1. Enhancing the progress overview:

Incorporate additional information in the progress overview to help patients understand their symptom changes more effectively. This can include visual representations, educational materials, and personalized feedback supported by smart technologies that provide insights into the meaning and implications of symptom fluctuations.

**2. Diversifying information sources:** Expand the information sources beyond HPs by integrating data from online community forums, clinical guidelines, and medical literature. Especially HP mentioned the medical literature as a valuable and reliable information source that patients are highly interested in it. This will provide patients with a broader range of perspectives and information, empowering them to make informed decisions and actively engage in self-management.

**3. Streamlining functionality:** Simplify the interface by prioritizing frequently used functions and removing or folding infrequently used functions. This will reduce cognitive load and enhance the usability of the PSS, making it more intuitive and user-friendly.

By addressing these design possibilities, the improved PSS can better meet the information needs of PF patients, support their self-management behavior, and enhance their overall experience in managing their condition.

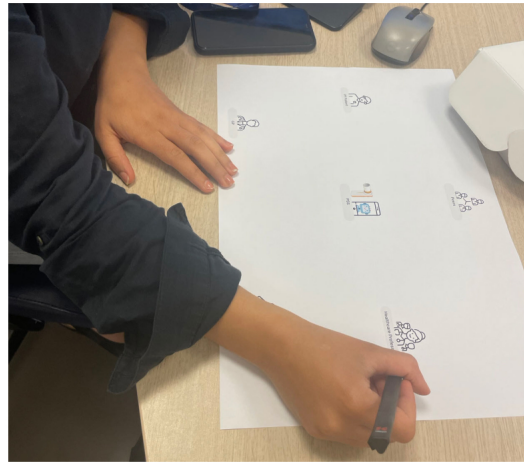


Figure 5.4: Brainstorming with HP on improvement possibilities



## 5.4 Ideation on the Information Interaction with designers

### 5.4.1 Method and Procedure

After defining the design goal and improvement possibilities of the current PSS, to further generate a comprehensive system view of the redesign proposal, a brainstorming session with multidisciplinary designers was organized to gain inspiration (As shown in Figure 5.5). The participants are master students of Industrial Design Engineering at TU Delft, including two interaction designers, two strategic product designers, and one integrated product designer. The main question that is examined in this session is: **“How can the different information sources support the identified information needs of PF patients’ SMB?”**

The brainstorming session was organized by roleplaying and using generative tools, including a system map and five self-management scenarios. These methods are taken from the Delft Design Guide (Van Boeijsen et al., 2014).

The whole session takes around 50 minutes. With a brief project introduction given to the participants, including the self-management behavior and information needs, firstly, each patient was asked to role-play as a PF patient and emerge themselves in the patient perspective. Secondly, five different self-management scenarios with specific examples were given in order, and for each scenario, they had 10 minutes to map out the system interaction maps together to achieve the

self-management goal by utilizing the information sources at the same time, they were asked to also brainstorm on the technologies involved to support the interactions.



Figure 5.5: Brainstorming session with interdisciplinary designers

### 5.4.2 Results

Through an intensive brainstorming session and in-depth discussions, five system maps were generated, representing the five types of information needs in self-management behavior. Figure 5.6 shows the example of the information needs of understanding treatments and medication options (See Appendix H for the rest system maps). These maps provide valuable insights into the interaction flow between patients and information sources, as depicted in Figure 5.7. This serves as a foundational reference for the development of an information system within the PSS.

Furthermore, the brainstorming session resulted in several ideas for implementing various smart technologies to address users' information needs. Among these ideas, two technologies emerged as the most frequently mentioned and considered effective in meeting these needs, namely AI Chatbots and Explainable AI (XAI). The next section will give an introduction to the chosen technologies.



## Understanding treatment and medication options

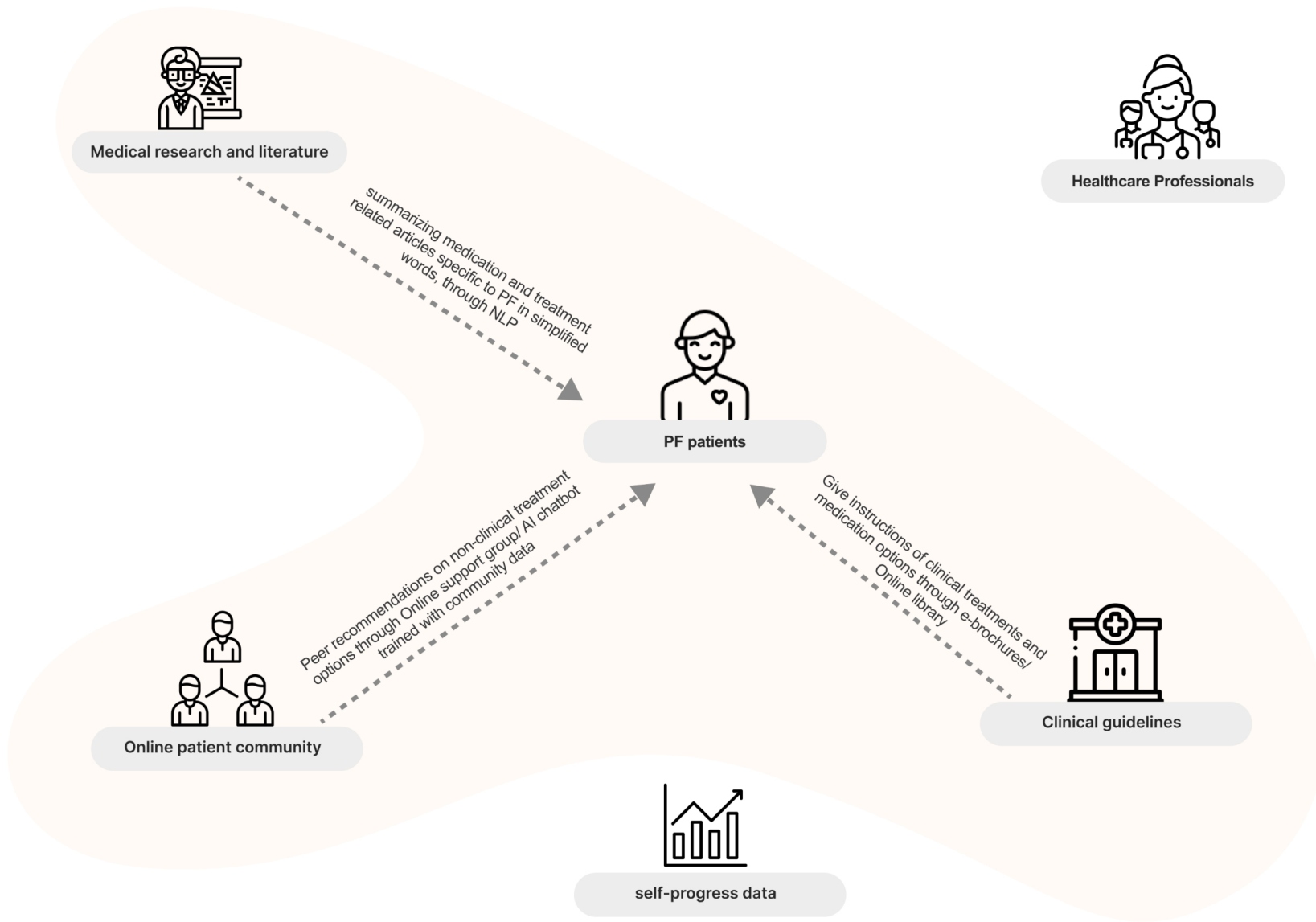


Figure 5.6: System map of understanding treatment and medication options

## Overview of information provision flow



Figure 5.7: Overview of information interaction flow

## 5.5 Define the technologies integration

This section defines the technologies integrated in the PSS, including technology of the delivery channel of the PSS, and the technologies of the information provision system.

### Delivery channel of the PSS:

The delivery channel serves as the medium through which products and services are extended to their end-users. This encompasses the technological, interface, or platform aspects that facilitate users in accessing and engaging with the products and services seamlessly integrated within the operational framework. In the realm of healthcare products and services, various options are available for consideration, including but not limited to applications tailored for smart devices, voice-controlled assistants, smart speakers, and wearable devices. Considering their costs, usability and potential value, the discernment among these alternatives is pivotal. Table 5.1 presents a comprehensive overview of the potential delivery channel options, along with a comparative analysis of their respective merits and demerits. As a result, **the application option stands out as the most competitive and suitable technology** for the delivery channel. Furthermore, given its alignment with the current PSS, utilizing the existing application infrastructure not only ensures cost-efficiency but also convenience in its implementation.

| Technology                        | Accessibility & Convenience | Updates                 | Costs                   | User Engagement |
|-----------------------------------|-----------------------------|-------------------------|-------------------------|-----------------|
| Application                       | High                        | Real-time               | Moderate                | High            |
| Voice assistants & smart speakers | Moderate                    | Limited scope           | Low (development)       | Moderate        |
| Wearable devices                  | Moderate                    | Limited scope           | Moderate                | Moderate        |
| Printed materials                 | Moderate                    | Manual reprinting       | High (reprinting)       | Low             |
| Video conferencing platforms      | Moderate                    | Real-time communication | High (organizing calls) | Moderate        |

Table 5.1: Comparison of various PSS delivery channels

## Technologies of the information-provision system:

**AI Chatbots and XAI (Explainable AI) are the chosen technologies to be integrated into the information provision system**, addressing the complexity of the system and the need to provide patients with accurate information while ensuring their understanding. Here's an expanded version with additional details and evidence:

Continuing from Section 5.4, the brainstorming session with designers identified two key technologies for the information provision system: AI Chatbots and XAI. This section explores how these technologies can be effectively implemented to support information provision for patients.

The selection of the Chatbot function was driven by the system's complexity and the diverse information needs of patients. AI Chatbots have the capability to understand the types of questions asked by patients and provide predicted answers based on training data from various reliable sources. This aligns with the design goal of delivering patients' required information from trustworthy data sources.

Evidence suggests that AI Chatbots can effectively address information needs. Research conducted by Mitzner et al. (2008) highlights the potential of AI-based virtual assistants to provide personalized and interactive support to older adults, indicating the relevance and potential effectiveness of Chatbot technology in the context of information provision for the elderly.

However, traditional AI Chatbots work as a black box, which may lack transparency, as they provide answers without explicit explanations or rationale. To address this limitation and enhance patients' understanding, the integration of XAI into the Chatbot functionality is being considered. XAI can provide patients with explanations and justifications for the answers provided by the Chatbot (Figure 5.8 shows the comparison).

Studies on the importance of explainability in AI systems support the incorporation of XAI. For instance, a research paper by Ribeiro et al. (2016) emphasizes the significance of XAI in building trust and improving human understanding of AI models. By incorporating XAI into the Chatbot, patients can gain insights

into the underlying reasoning behind the answers, ensuring transparency and facilitating their comprehension of the information provided.

In conclusion, the integration of AI Chatbots and XAI in the information provision system addresses the complexity of the system and the diverse information needs of patients. AI Chatbots leverage predictive capabilities to provide accurate answers from reliable data sources, while XAI enhances transparency and understanding by providing explanations for the answers. This combination of technologies enhances the effectiveness and reliability of the information provision system, enabling the PSS to fulfill the design goal.

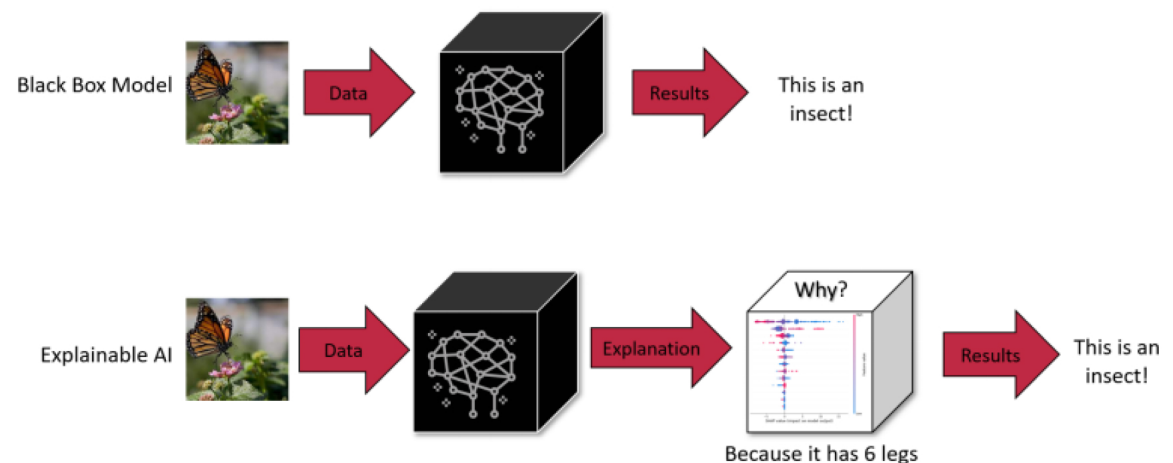


Figure 5.8: Comparison between traditional AI and XAI (Regunath, 2021)



## 5.6 Conclusions of Chapter 5

This chapter establishes the groundwork for addressing the problem and design goal of the information provision system, and reviewed the current PSS, identified its improvement possibilities. The complexity of the information flow and the diverse user needs led to the proposal of integrating explainable AI (XAI) to enhance transparency and comprehensibility.

The next chapter will present a comprehensive design proposal for the final PSS that incorporates AI Chatbots, XAI, and other relevant features that fulfill the design goal - To provide patients with required, reliable, and understandable information in supporting their self-management behavior in the post-diagnosis stage.

### Key takeaways of Chapter 5

- Problem definition: PF patients face challenges in accessing comprehensive and reliable health information
- Improvement possibilities of the current PSS are deprived.
- The complexity of the information flow and diverse user needs to highlight the importance of integrating explainable AI (XAI) for enhanced transparency and comprehensibility.

# CHAPTER 6.

# Product-Service -System Final Proposal

Based on the insights collected from the previous chapters, Chapter 6 presents the final concept of the PSS tailored to the needs of PF patients in self-management. The final PSS, including its modules and sub-modules, are detailly introduced in this chapter. Moreover, a high fidelity interactive model of the PSS is also showcased in the end of this chapter.

## 6.1 Modules and sub-modules of redesigned PSS

The final proposed PSS comprises six modules, which represent the culmination of improvements made to the existing PSS. These modules are further broken down into ten sub-modules, each encompassing various functions or steps. Informed by the findings from Chapter 5, design decisions were made regarding the functions within the PSS. Some functions were maintained, while others were enhanced to align with the design goals. Additionally, certain functions were removed to improve usability and new functions were introduced to address the identified design goals. Figure 6.1 shows the overall structure.

The self-monitoring modules, specifically the 'Spirometrie' (Lung function self-test) and 'Gegevens toevoegen' (self-evaluation questionnaire), along with the treatment planning module, remain unchanged as they effectively cater to patients' needs and are widely utilized.

The eConsult (send inquiries) and Mijn Voortgang (Self-monitoring data progress) functions have been enhanced by incorporating explainable AI, providing patients with more comprehensive and understandable information.

Additionally, a completely new module, the E-library, has been introduced to the PSS, offering patients access to a wide range of educational resources and materials.

Lastly, the infrequently used functions, such as 'archief' (archive), 'mijn Gegevens' (my data), and 'Privacy', have been consolidated into a single module for improved organization and ease of use.

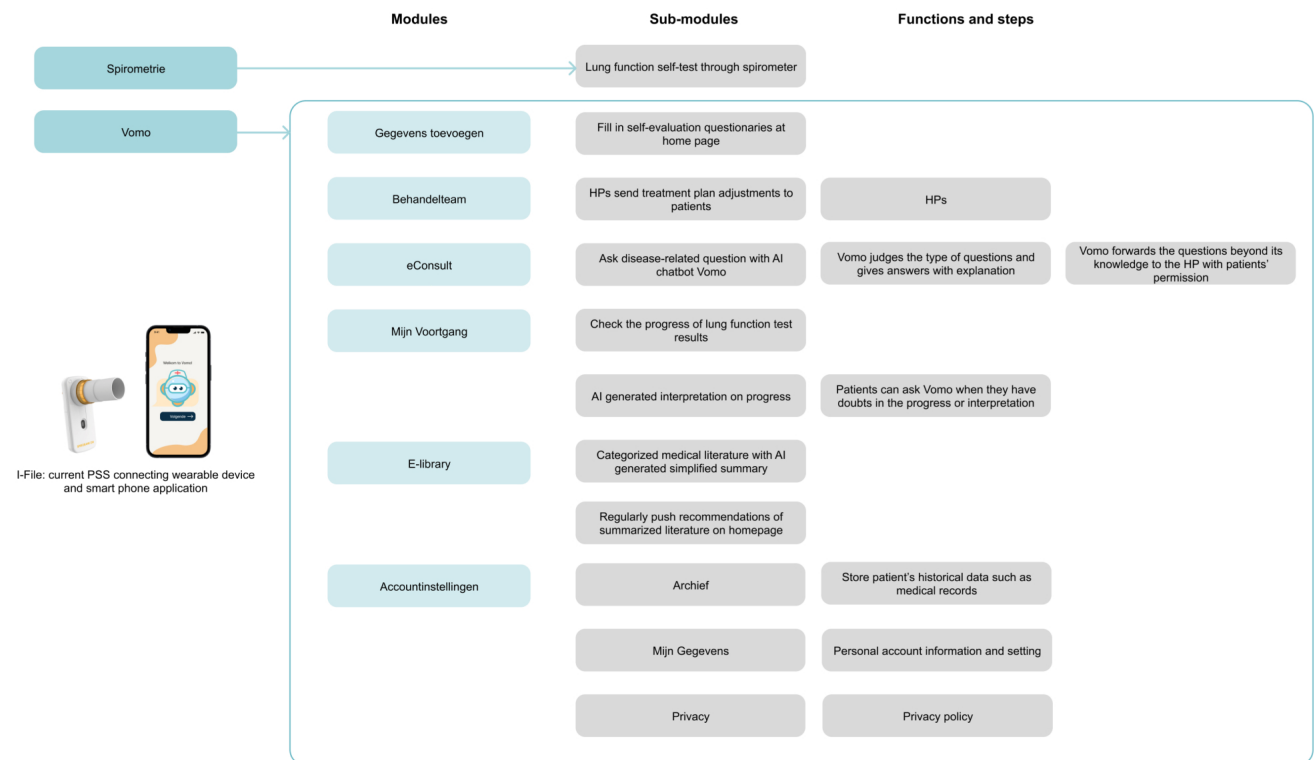


Figure 6.1: Overview of modules of the final PSS

## 6.2 Information Provision Mechanism of the XAI Chatbot

The information-providing mechanism shows the overall procedures of how the Explainable AI chatbot answers patient questions based on its knowledge, as shown in Figure 6.2.

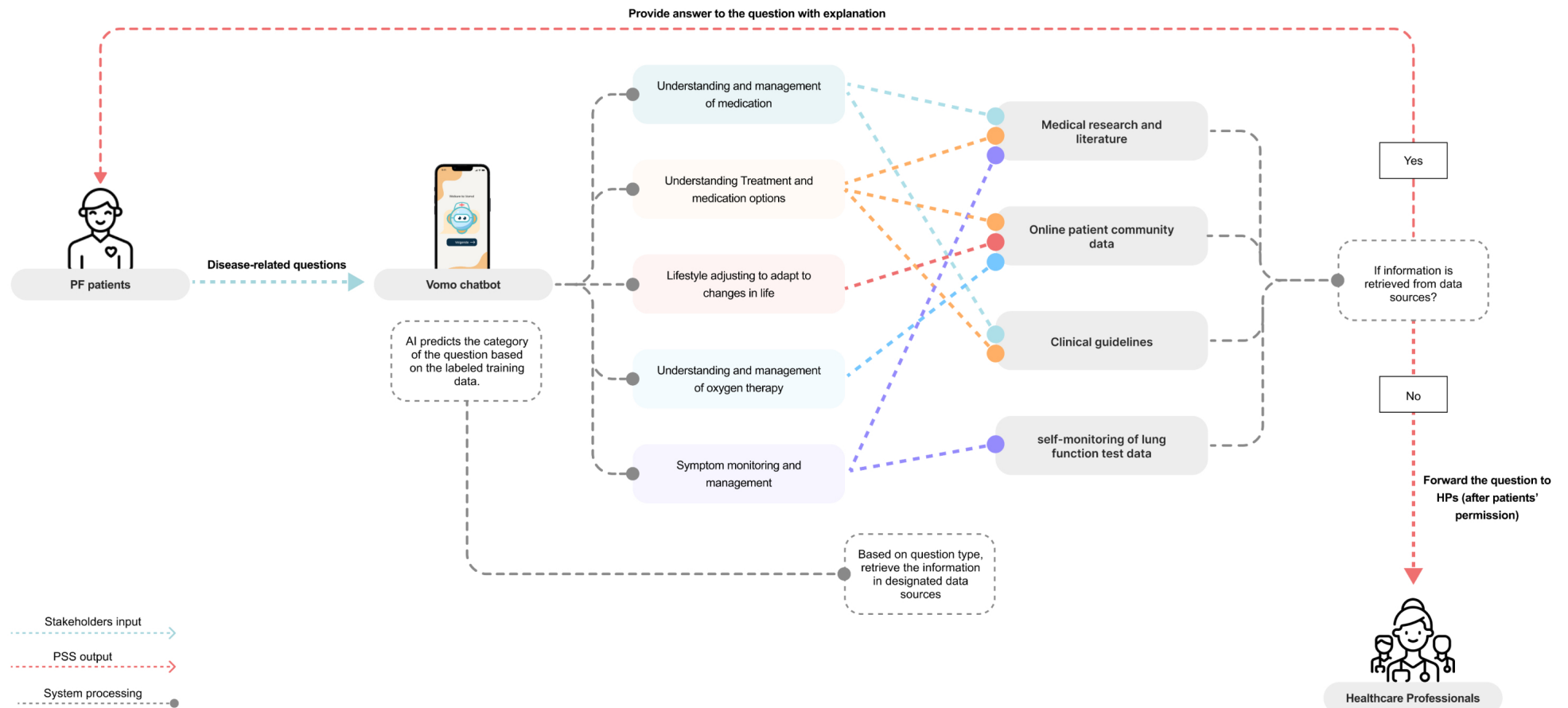


Figure 6.2: Information Provision Mechanism



## 6.3 Detailing UI/UX styles: Design for older adults

This section aims to define the UI/UX styles of the final PSS design. Given the majority of users from the target group are individuals aged over 65 years old, it is necessary to address their specific needs. To achieve this, several UI/UX are taken into consideration.

### Color Usage:

- **Use a high-contrast color scheme:** contrasting colors for text and background elements should be used to enhance readability and visibility. Research has shown that high-contrast colors improve usability for older adults with reduced visual acuity (Morey et al., 2019).
- **Reduce the usage of blue-yellow spectrum colors:** human eyes' ability to distinguish certain colors fades with age. Among people over the 70s, Tritanopia often shows in the blue-yellow spectrum, as shown in Figure 6.3 (Colormax.org - Color Vision Correction, 2019).

Based on these considerations, a color scheme was chosen for the application, as shown in Figure 6.4.

### Clear and Intuitive navigation:

- **Use Breadcrumbs Indicators and avoid hamburger menu:** older adults preferred a straightforward and hierarchical navigation structure. They felt more comfortable and

confident when using apps with a simple and familiar navigation system (Apple UI/UX design guide (Human Interface Guidelines | Apple Developer Documentation, n.d.)).

### Gesture:

- **Use clicking instead of sliding:** Clicking interactions align with the traditional desktop computing paradigm that older adults may be more familiar with. And clicking interactions tend to have a lower cognitive load compared to sliding interactions.

### Readability and Font Size:

- **Bigger and easily readable fonts:** Reading small font sizes for older adults could lead to visual fatigue (Darroch et al., 2005). Based on the Apple UI design guide, a font size of 16 px was recommended for smartphone applications designed for older adults (Human Interface Guidelines | Apple Developer Documentation, n.d.).

### Product Icon: Vomo

Vomo is designed as the product icon (as Figure 6.5 shows), as well as the virtual assistant of the XAI chatbot. In this way, the user can interact with Vomo and ask questions about their disease and doubts.

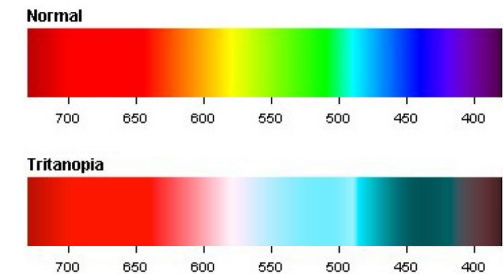


Figure 6.3: Blue-yellow spectrum Tritanopia

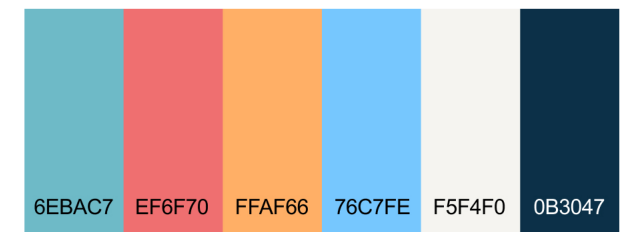


Figure 6.4: Color scheme chosen for the application

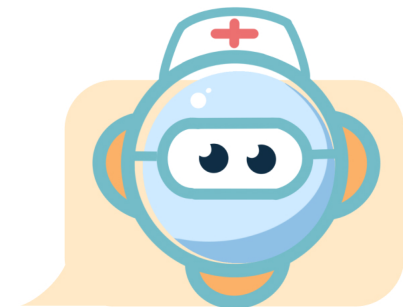


Figure 6.5: Product Icon: Vomo

## 6.4 High-fidelity Model of the Final Concept: Vomo

This section showcases the High-Fidelity model of the Vomo application and introduces each module in the patient application. The interactive prototype was created using the Figma tool, effectively showcasing the application's modules and their interactive features.

As discussed in section 6.1, the final application concept comprises 6 modules and several sub-modules. Nonetheless, the prototype exclusively focuses on the redesigned modules, along with a newly added module meant for evaluation in the subsequent stage. These modules include 'My Progress,' 'eConsult,' and 'E-library.'

Furthermore, aiming to enhance the product's user experiences, the prototype also encompasses a re-designed home page. This redesign serves to facilitate easy navigation and foster personalized user experiences,.

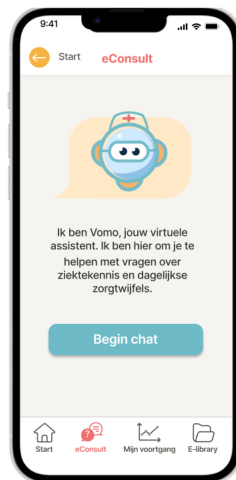
Figure 6.6 illustrates the onboarding page and home page of Vomo. In the next pages, the rest modules will be introduced detailly.



Figure 6.6: Onboarding page and Home page of Vomo

## 6.5.1 Home screen

The home screen includes shortcuts to the other modules pages for the purpose of quick and easy navigation.



### E-library:

By clicking the button here, the user can quickly navigate to the E-library function to check the latest medical papers about PF that are recommended for them.



### Questionnaire:

A shortcut of fill-in self-evaluation questionnaire is on the homepage. The user can click on "Check-in" to go to the questionnaires.

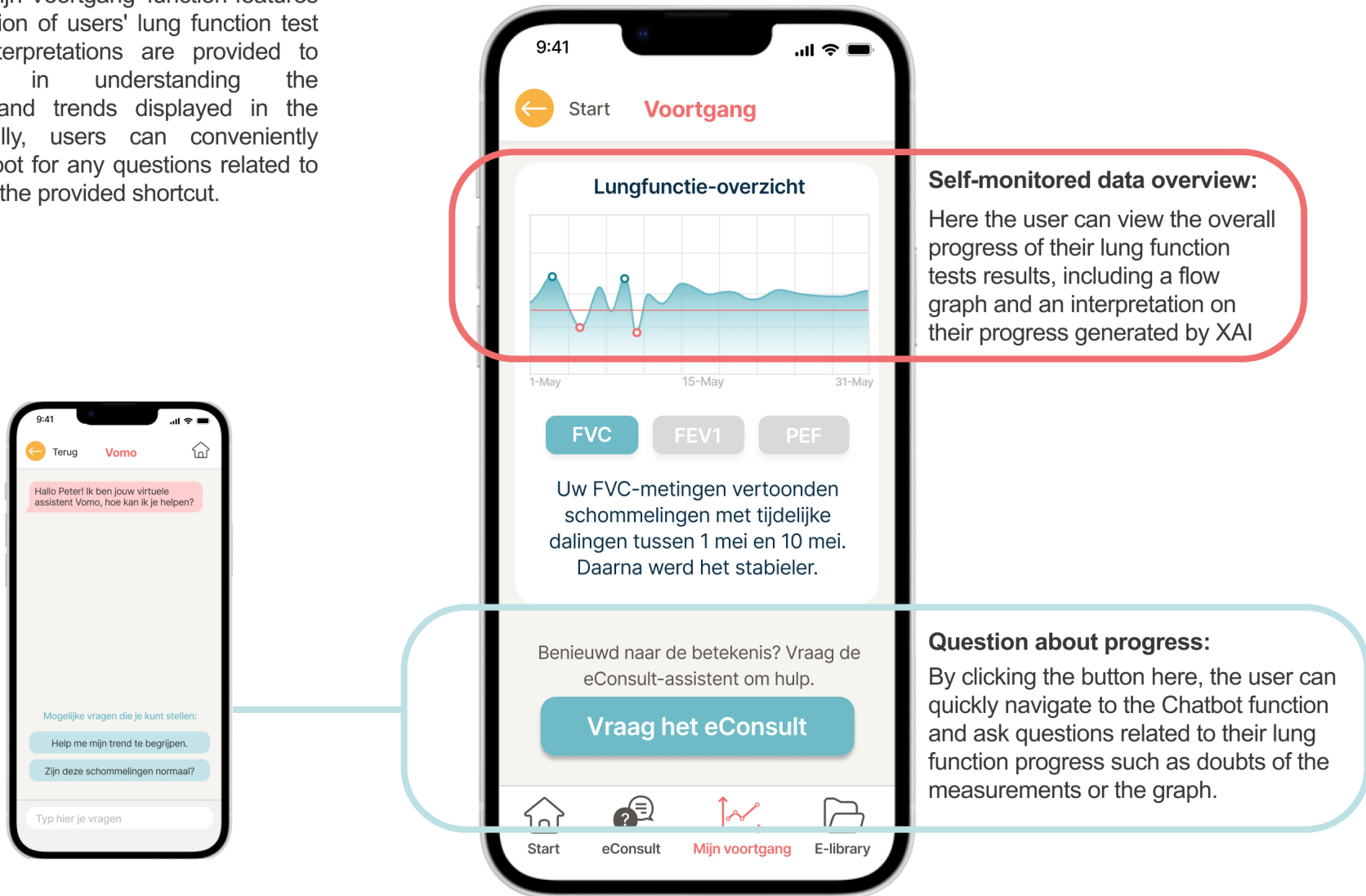
### Chatbot:

Here the user can immediately navigate to the chatbot function to ask questions related to their diseases progresses or treatments.



## 6.5.2 'My Progress' module

The improved 'Mijn Voortgang' function features a data visualization of users' lung function test overview. AI interpretations are provided to assist users in understanding the measurements and trends displayed in the chart. Additionally, users can conveniently consult the chatbot for any questions related to the data through the provided shortcut.



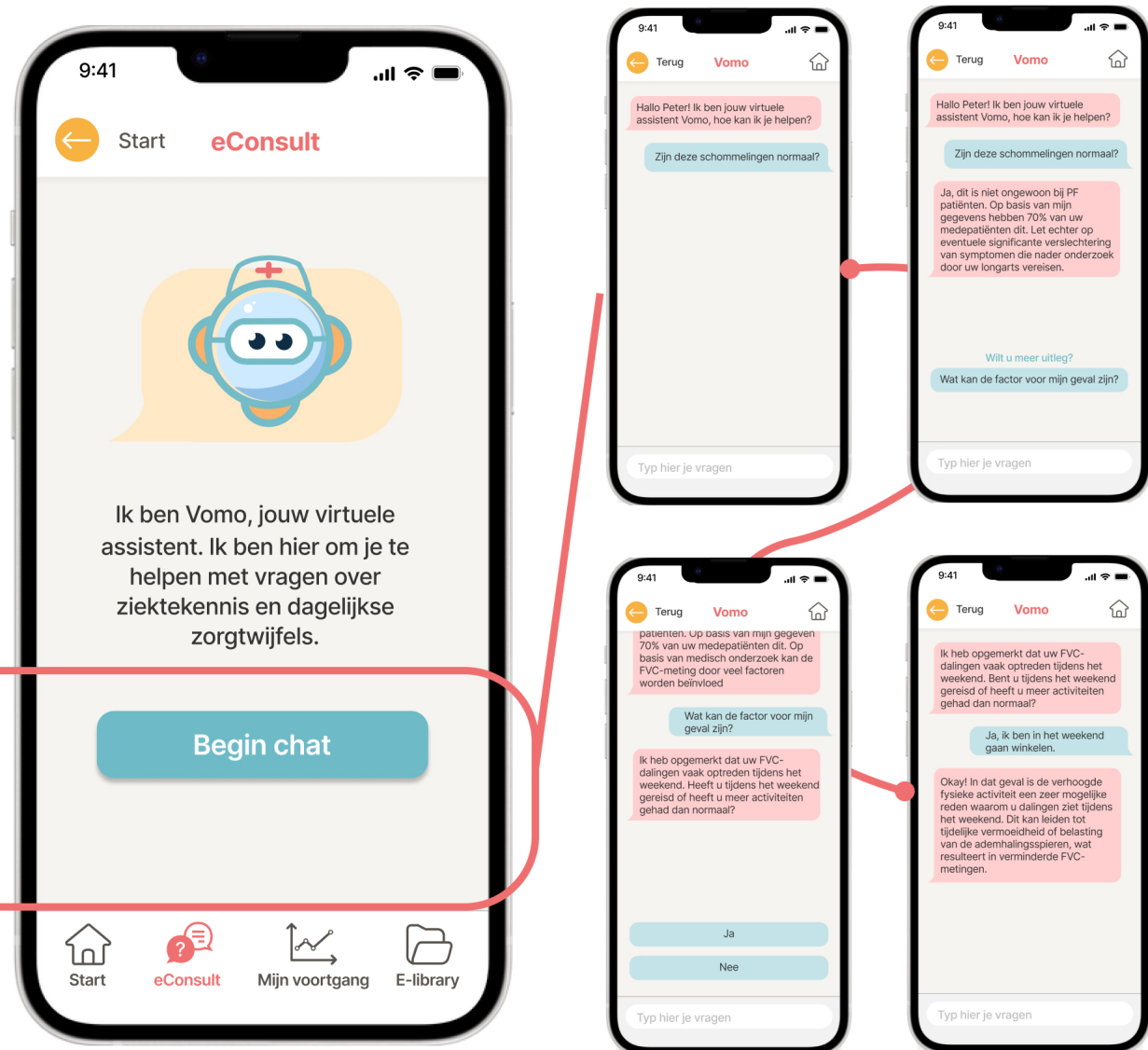


### 6.5.3 'eConsult' module

The improved 'eConsult' function incorporates an Explainable AI chatbot trained on diverse and reputable medical resources. The chatbot uses a step-by-step approach to provide answers with explanations to user questions. Users have the option to request additional explanations if desired. In cases where the chatbot is unable to answer a question, users can choose to have the chatbot forward the question to a HP for further assistance (as section 6.4 introduced). This enhanced functionality ensures that users receive comprehensive and understandable responses while also facilitating communication with healthcare professionals when necessary.

#### Consult AI Chatbot:

By clicking the button here, the user can start consulting with the AI chatbot which will provide answers with step-by-step explanation and reasoning.

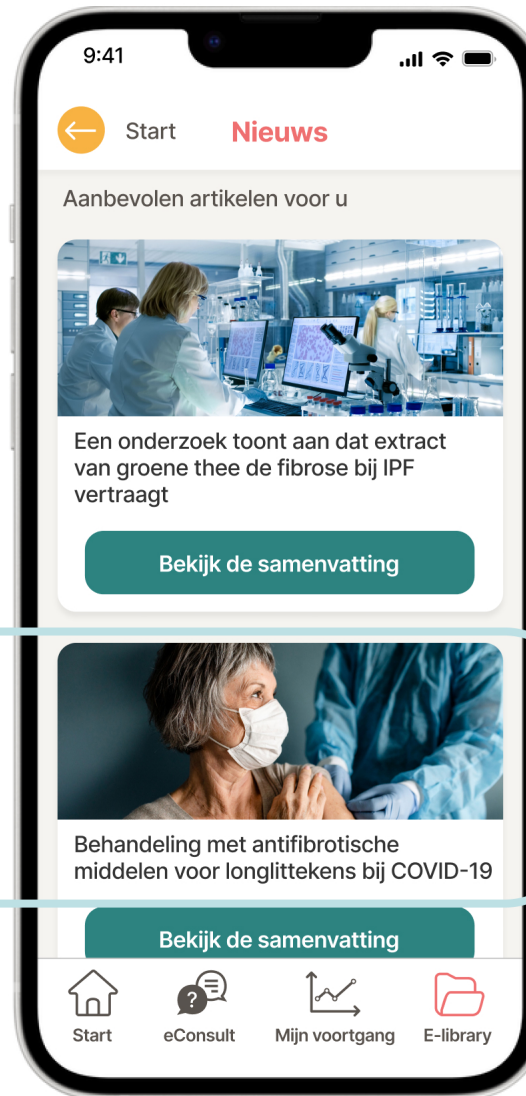


## 6.5.4 E-Library module

The newly added 'E-library' function in the PSS introduces a module that leverages explainable AI and Natural Language Processing (NLP) techniques. This module aims to provide simplified summaries of medical literature for patients to browse. By utilizing explainable AI and NLP, the 'E-library' function enhances accessibility and comprehension of medical literature, allowing patients to access relevant information in a user-friendly format. This feature enables patients to stay informed about current research and findings related to their condition, empowering them to make informed decisions regarding their healthcare journey.

### AI interpreted medical articles:

Here the user can browse through the medical articles related to PF that are re-interpreted and summarized by AI to ensure it is easy-understandable and translated in Dutch



## 6.5 Conclusions of Chapter 6

In this chapter, an overview of the final PSS proposal is presented. The proposed design includes the establishment of various modules and sub-modules within the system, providing a comprehensive structure for effective information provision. Additionally, the information provision mechanism is visualized, illustrating how the system will deliver relevant and reliable information to users. To further advance the design process, a high-fidelity prototype has been developed, which prepares for further evaluation with patients and HPs and iterates on the design.

### Key takeaways of Chapter 6

- Comprehensive overview of final PSS proposal, featuring detailed design and interconnected modules for information provision system.
- Identified PSS Enhancement Opportunities for improvement
- Integration of Explainable AI (XAI) to enhance transparency and user comprehensibility, addressing complex information flow and diverse user needs.

# CHAPTER 7.

## Validation & Next Steps

Chapter 7 presents the validation of the final concept Vomo by the means of organizing validation sessions with multi-disciplinary participants including patients, healthcare professionals, and design experts. In this way, the intended value and overall accessibility of this PSS is preliminarily validated. And insights on iteration direction of the product are collected. And in the end of this chapter, an implementation plan is proposed of how this PSS could be implemented in the user context and community context.



# 7.1 Validation goal and method

## Validation Goal:

In Chapter 6, the final concept of the redesigned PSS is proposed and prototyped. In order to assess the extent to which this concept fulfills the design goal, as well as to gather insights for iterative design improvements, validation sessions and user tests have been organized.

The aim of these validation encompasses two primary aspects. Considering the project primarily aims on enhancing patient experiences, as discussed in Chapter 1, the principal objective revolves around validating the user experiences within the PSS. Given the seven factors of user experiences proposed by Morville (2004), as illustrated in Figure 7.1, this project's validation focuses on **the intended value and overall accessibility of the PSS**. This focus stems from two crucial rationales: firstly, to examine whether the PSS effectively accomplishes the design goal; and secondly, given the target users are dominantly individuals aged 65 and above, the overall accessibility of the PSS holds paramount importance and thus necessitates validation.

The two main research questions of the validation are:

- Does the PSS achieve the design goal - provide PF patients with **required, reliable, and understandable information** to support their self-management behavior?

- Whether the application is accessible to the target users? In terms of its UI/UX elements and navigation flow.

## Validation method:

To gain insights from perspectives of various stakeholders, the validation sessions were held with multi-disciplinary participants. Table 7.1 shows the participations constructs.

Furthermore, the validation sessions adopts two methods:

- **Task-based Testing:** Ask participants to perform specific scenarios within the app to test different functions. Observe their behavior and get feedback on the app's value and accessibility.
- **Questionnaires and follow-up questions:** use questionnaires with scaled questions to evaluate the overall user experiences. And follow-up questions are asked based on their answers.

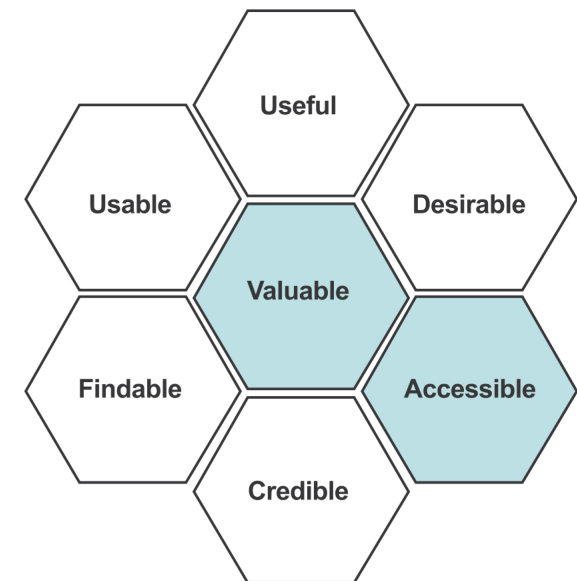


Figure 7.1: Seven factors of user experiences

| Participants               | Description                                                          |
|----------------------------|----------------------------------------------------------------------|
| 2 PF patients              | patients with different information seeking behavior                 |
| 2 Healthcare professionals | a nurse specialist and a pulmonologist PhD student in the ILD team   |
| Design expert              | A post-doc design researcher specialized in health behavioral change |

Table 7.1: Participants of PSS validation

## 7.2 Validation with multi-disciplinary participants

### 7.2.1 Validation with patients

The initial validation cycle is carried out with patients, recruited using a convenience sampling approach (Stratton, 2021) via the patient networks at Erasmus MC. This led to the recruitment of two patients for the validation process.

As previously noted in Chapter 3, patients tend to exhibit diverse information-seeking behaviors. These two participants belong to distinct groups as depicted in Figure 7.2. Consequently, these two validation sessions offer us valuable insights from different user groups.

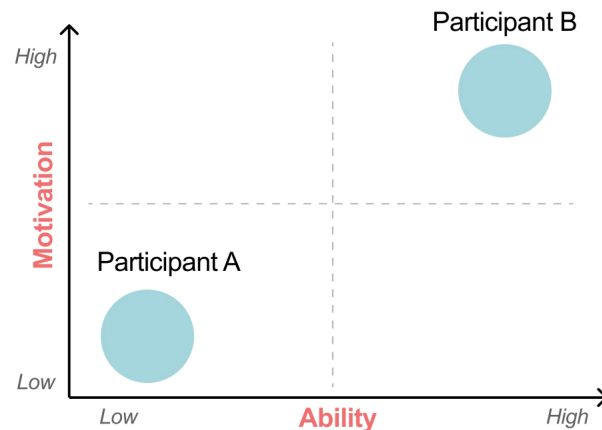


Figure 7.2: Participants information-seeking behaviors



Figure 7.3: Testing and interview with the participant

#### Validation Results:

During the validation sessions, both participants successfully performed the testing tasks by using the eConsult and E-library functions. And the results based on the specific two goals of the validation are:

##### 1. Intended Value:

Both participants deemed the eConsult and E-library functions as valuable to them to learn more about their diseases. However, they showed more interests on the E-library function than eConsult, especially for participant A.

*"This summary function is very useful for me, it's very easy to understand, I used to know very little about my own disease, now I want to know more."* - Participant A

##### 2. Overall accessibility

The overall accessibility of the produced was considered as very high by the participants.

*"The colors and texts are clear enough...and the navigation was very easy"* - Participant B

In conclusion, the redesigned PSS fulfills the design goal and the overall accessibility is satisfactory. However, there are some improvements aspects arose in the sessions.

#### Iteration Directions

1. The eConsult function: **participants exhibited limited trust for Chatbot**, especially for the well-informed patient. They perceived it as "machine" and "non-human". Furthermore, there are reservations about the chatbot's proficiency, especially when addressing medical inquiries.

*"I would prefer to ask my HPs for questions about medications or treatment plan."*

##### Possible iterations:

- **Add human-like interactions and personalized features:** Enhance the chatbot's responses to sound more human-like and empathetic.
- **Implement a feedback mechanism** that allows users to rate the quality of responses and provide feedback on inaccuracies.

## 7.2.2 Validation with healthcare professionals

The second round of validation took place with healthcare professionals from Erasmus MC, including a Post-doc researcher who also serves as the product owner of I-File, and a specialist nurse. Since they had previously participated in the co-creation session during an earlier stage, they were well-acquainted with the progress of the project.

The objective of conducting validation with healthcare professionals was to leverage their expert insights to assess the envisioned value of the PSS and uncover potential directions for improvement.

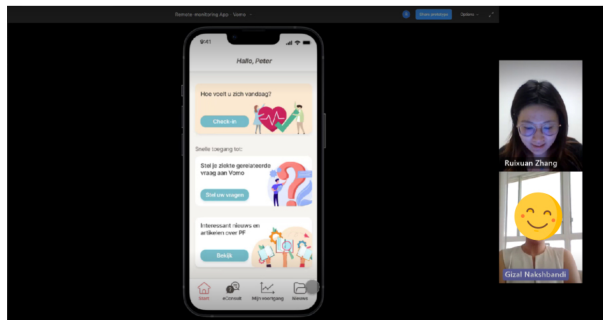


Figure 7.4: Validation session with the HP

### Validation Result:

As a result, the HPs perceived the PSS as highly valuable. They exhibited a specific interest in the E-library function. Moreover, they consider the eConsult function can potentially reduce the HPs' workload in a large extent.

*"I love the E-library function! Patients always want to learn about the updated research on PF, but it's too difficult for them to read, also the language barriers."*

Nevertheless, the HPs provided insights from their expert perspectives that suggest several aspects of the PSS require improvement.

### Iteration Directions:

- **Finalizing the article selection mechanism for the E-library function:** The HPs highlighted that careful consideration should be given to the process of selecting medical articles for the E-library module. Patients might have concerns about how articles were chosen. Involving HPs in this process is essential to ensure the credibility of the resources.
- **Improve the summarization algorithm for the E-library function:** In the prototype, the summary of selected articles was generated using Chat GPT, an existing generative AI tool. However, Chat GPT's training is not specialized for medical purposes. Consequently, the summarization accuracy fell short of expectations. As a result, for integration into the PSS, a dedicated AI algorithm should be developed and trained to ensure precise summarization.

## 7.2.3 Validation with design expert

The final round of validation involved a design expert from the Industrial Design Engineering faculty of TU Delft, specializing in health-related behavioral change research. This validation aimed to acquire expert insights into motivating self-management behavior through design interventions.

Upon reviewing the product, the design expert acknowledged the PSS's potential in driving patients' behavioral change. Furthermore, the expert put forth several suggestions to enhance the PSS.

### Iteration Directions:

- **Personalized elements:** The design expert recommended incorporating personalized elements into both the eConsult and E-library functions, to enhance user engagement and consequently foster greater adherence to using the application. Such as tailored article recommendations within the E-library and integrating human-like chatting into the Chatbot function.
- **Incentives:** The introduction of incentives within the application was also suggested. However, it is crucial to approach this action with careful consideration, as it raises ethical concerns.



## 7.3 Implementation plan

Drawing from the insights gathered during the validation process, the subsequent step involves integrating these observations into iterative development. This will contribute to the refinement of the PSS. Additionally, a macro-level implementation plan for the PSS will be formulated to guide its overall execution. Implementing a complex product-service system necessitates sustained investment and collaboration across various stakeholders, particularly within the healthcare domain. Therefore, this section presents the comprehensive implementation plan for the revamped PSS, encompassing the product itself, development activities, stakeholders' roles, and the requisite technologies across different phases and timelines. Each developmental stage of the PSS is elaborated upon below, while Figure 7.X on the subsequent pages provides a detailed visualization of the implementation plan.

### 1. Research and foundation:

During the initial stage of the PSS development, extensive research and foundational work are undertaken. This phase involves conceptualizing the application's scope, identifying its target audience, and selecting the key technologies that will power the XAI chatbot and the e-library. Stakeholder engagement and thorough market research lay the groundwork for a well-informed and strategic development approach.

### 2. Development:

The development stage focuses on turning concepts into reality. Datasets are carefully gathered, encompassing medical literature, clinical guidelines, and patient data. Leveraging cutting-edge technologies, the XAI chatbot is crafted to provide personalized responses, while the e-library is developed as a user-friendly platform for accessing simplified medical research. This phase involves programming, algorithm implementation, and the creation of a solid technological foundation.

### 3. Testing and Refinement:

User-centricity takes center stage in the testing and refinement phase. The application is put through rigorous user testing, allowing patients and healthcare professionals to provide valuable feedback. This feedback guides iterative improvements, refining the chatbot's accuracy, the e-library's usability, and overall user experience. Regulatory compliance is also addressed, ensuring privacy and legal adherence.

### 4. Deployment and Expansion:

With insights gained from testing, the application is soft-launched to a limited audience. This controlled rollout allows for real-world usage and fine-tuning before broader deployment. During this phase, scaling infrastructure and integration efforts pave the

way for seamless expansion. Collaborations are established with healthcare providers, advocacy groups, and medical institutions, positioning the application for a wider reach.

### 5. Growth and Sustainability:

In the growth and sustainability phase, the application takes its place as a powerful tool in the pulmonary fibrosis ecosystem. The full launch brings the benefits of the XAI chatbot and the e-library to a broader audience. Long-term commitment to updates, ongoing research, and user education ensures the application's continued relevance and impact. Strategic partnerships are nurtured, supporting the application's growth and its role in fostering patient empowerment and informed self-management.



Implementation Plan of Vomo in five years

|                       | Research and Foundation                                                                                                                                                                                                                                    | Development                                                                                                                                                                                                                                                                                                                                                                                         | Testing and Refinement                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                         | Deployment and Expansion                                                                                                                                                                                                                                                                                                                                                                                                                                                               | Growth and Sustainability                                                                                                                                                                                                                                                                                                                                                                                                                       |
|-----------------------|------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
|                       | Year 1                                                                                                                                                                                                                                                     | Year 2                                                                                                                                                                                                                                                                                                                                                                                              | Year 3                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                         | Year 4                                                                                                                                                                                                                                                                                                                                                                                                                                                                                 | Year 5                                                                                                                                                                                                                                                                                                                                                                                                                                          |
| Activities            | <p><b>Conceptualization &amp; Market Research</b></p> <p>Define product scope and validate concepts</p> <p>Conduct market research and investigate on users needs</p>                                                                                      | <p><b>Dataset Acquisition, Chatbot &amp; E-library development</b></p> <p>collect relevant and accurate medical literature and patient data for training the chatbot and e-library AI.</p> <p>Build the XAI chatbot using NLP techniques; Train the chatbot on the collected dataset,</p> <p>Implement the summarization algorithms for E-library; Integrate search and categorization features</p> | <p><b>User Testing</b></p> <p>Invite a group of patients and healthcare professionals to test and provide feedback on usability, accuracy, and overall experience</p> <p><b>Iteration and Enhancement</b></p> <p>Use user feedback to refine the chatbot's responses and improve its performance.</p> <p>Enhance the summarization algorithms to ensure accurate and comprehensible medical paper summaries.</p> <p><b>Regulatory Compliance</b></p> <p>Collaborate with legal and regulatory experts to ensure compliance with medical data privacy laws and regulations.</p> | <p><b>Soft Launch</b></p> <p>Release the application to a limited audience, such as a specific medical institution or patient group.</p> <p>Monitor user engagement, feedback, and usage patterns.</p> <p><b>Scaling and Integration</b></p> <p>Based on the feedback and usage patterns, scale up the application's infrastructure to accommodate a larger user base.</p> <p>Explore integration opportunities with electronic health record systems and other medical platforms.</p> | <p><b>Full Launch</b></p> <p>Launch the application publicly, targeting a broader patient population.</p> <p>Continue to monitor and improve the application's performance based on user feedback.</p> <p><b>Long-Term updates and research</b></p> <p>Continue updating the chatbot and e-library with the latest medical literature and guidelines.</p> <p>Invest in ongoing research to enhance the AI capabilities and user experience.</p> |
| Stakeholders involved | <p><b>Stakeholder Identification</b></p> <p>identify key stakeholders: patients, healthcare professionals, medical institutions, and regulatory bodies.</p> <p>look for third party or product development or negotiate with in-house development team</p> | <p><b>Collaborative team of medical professionals, data acquisition team &amp; designer</b></p> <p>data sources selection with the help of medical &amp; data experts</p> <p>Interface &amp; algorithm develop with designers and programmers</p>                                                                                                                                                   | <p><b>Iterative user feedback from patients and HPs</b></p> <p>consultation with legal experts</p>                                                                                                                                                                                                                                                                                                                                                                                                                                                                             | <p><b>Limited release to specific audiences</b></p> <p>Erasmus MC<br/>Universitair Medisch Centrum Rotterdam</p> <p>Soft release the product limited to the early adaptor patients within Erasmus MC</p>                                                                                                                                                                                                                                                                               | <p><b>Partnerships and Outreach</b></p> <p>Amsterdam UMC<br/>Universitair Medisch Centrum</p> <p>LUMC</p> <p><b>User education</b></p> <p>Offer resources and workshops to help users understand how to effectively use the application for self-management.</p>                                                                                                                                                                                |
| Technologies          | <p><b>Technology Selection</b></p> <p>Choose the programming frameworks, and tools for developing the chatbot and e-library.</p>                                                                                                                           | <p><b>Algorithm and software development</b></p> <p>NLP, XYZ, 101</p>                                                                                                                                                                                                                                                                                                                               | <p><b>Improve chatbot performance and e-library summarization accuracy</b></p>                                                                                                                                                                                                                                                                                                                                                                                                                                                                                                 | <p><b>Integration planning for all developed modules</b></p>                                                                                                                                                                                                                                                                                                                                                                                                                           | <p><b>Transfer learning and re-training ML for other purposes (other diseases)</b></p>                                                                                                                                                                                                                                                                                                                                                          |

## 7.6 Conclusions of Chapter 7

The validation of the PSS meticulously assesses its intended value and overall accessibility across several rounds involving multidisciplinary participants. In summation, the PSS successfully meets the design goal as confirmed by this small-scale evaluation. Given the limited number of participants engaged in the validation, it is recommended that future iterations include larger-scale evaluation rounds to comprehensively test and enhance the product.

Furthermore, this chapter unveils potential avenues for improvement in the PSS, thereby establishing an iterative process of channeling collected user insights into design studios. Lastly, the chapter culminates by presenting a macro-level implementation plan for the PSS, thereby paving the way for its future development.

### Key takeaways of Chapter 7

- The final concept of PSS was validated in a small-scale evaluation, and successfully meet the design goal.
- Iterative design directions was generated from different stakeholders' perspective
- The implementation plan presents future development roadmap of the PSS.

**CHAPTER**

**8.**

# **Conclusions & Discussions**

# 8.1 Conclusions and limitations

## 8.1.1 Discussion and Conclusions

Starting with an explorative study on the pulmonary fibrosis patient journey in the community context, this project leveraged a range of research methods went through user contexts to the design studio, and ultimately defined the design goal as “How to provide PF patients with required, reliable, and understandable information to support their self-management behavior in the post-diagnosis stage?”

This design objective was ultimately realized through the creation of Vomo, a Product-Service-System driven by Explainable Artificial Intelligence. The concluding design concept effectively tackled the information gaps faced by patients through innovative solutions that amalgamate diverse information sources using an AI-driven information delivery mechanism.

Addressing the quadruple aims of this project as mention in Chapter 1, this research not only underscores the importance of enhancing patient experiences by supporting self-management behavior and elevating Health-Related Quality of Life, but also indicates potential improvements on the experiences of healthcare providers in the way of a reduction in their workload. Over the long term, this intervention could also serve as a partial remedy to the strain on the healthcare system by acting as a supplementary resource to alleviate the scarcity of medical staff.

This study also emphasizes the cautious utilization of Artificial Intelligence in the medical domain. Throughout the project, instances arose where AI introduced biases in analysis or generated inaccurate outcomes, posing considerable risks in a medical context. Consequently, the future advancement of the Product-Service-System necessitates collaborative contributions from medical experts, designers, and data scientists to guarantee a meticulous, step-by-step development of the AI tool, as discussed in the implementation plan in Chapter 7.

In conclusion, equipping pulmonary fibrosis patients with requisite, dependable, and intelligible information in an efficient manner is pivotal for fostering coherent and effective self-management behavior. This framework may also have broader applicability for patients grappling with various other chronic conditions.

## 8.1.2 Limitations

This project is subject to several significant limitations. Primarily, during the mapping of the patient community journey, the dataset was drawn from an online patient forum. However, it's important to acknowledge that this dataset is inherently biased. Existing research indicates that individuals who actively share their experiences and pose questions online tend to share common traits – primarily being female, younger, and possessing higher levels of

education (Grande et al., 2006). Consequently, this dataset lacks the capacity to serve as a representative sample for a more diverse and comprehensive patient population.

Secondly, during the co-creation and evaluation sessions with healthcare professionals, an inherent bias emerges due to the concentration of opinions from medical experts within the same context and organization. This homogeneity in experiences and patient interactions has the potential to inadvertently steer the project in a specific direction.

Lastly, it is important to note that the validation session conducted at the conclusion of this project involved a relatively small number of participants. Specifically, the validation phase included only two patients, which was a result of time constraints. Regrettably, this limited scope undermines the representativeness of the validation outcomes for the broader user group. Consequently, the conclusions drawn from the validation session lack a robust level of conviction.



## 8.2 Personal reflections

I have a strong motivation to work on this graduation project since I am intrigued by the data-enabled design technique, and I wonder how I can apply this tool in the medical context, which is the domain that I am enthusiastic about working on in my future career. At the beginning of this project, I wrote down several personal ambitions that I wanted to achieve through this project (See Appendix A). Here, I would like to reflect on these ambitions.

### 1. How to use community data as a tool to understand user experiences?

At the very beginning of this project, I learned about using community data as a design tool for the first time, from my supervisor Jiwon. This is a completely new concept to me, and I barely knew how to actually apply it. However, by conducting the Patient Community Journey Mapping study step by step, I learned about how to be inspired by the community patient stories. At some point, I was stuck there since one of my major weaknesses is converging in the design process. Luckily, I received guidance from my supervisors and explored how to apply psychological-behavioral models to community data to further gain in-depth insights. After finishing this project, I am confident and intrigued to use it in my future research.

### 2. How to develop data-enabled design in the medical context?

Developing design interventions in the medical context is often difficult and many issues can arise related to ethical considerations. Moreover, applying data-enabled design needs to address additional consideration, when smart technologies such as Artificial Intelligences are introduced.

Creating design interventions within the medical context is often challenging, and numerous ethical concerns may emerge. Furthermore, when incorporating data-driven design, there is an added layer of complexity, especially when integrating technologies like Artificial Intelligence.

Through discussions and co-creations with the medical experts, I gained insights into effectively tackling these challenges. This practical experience of working with medical experts in hospital is invaluable for me, as it will be an ongoing learning resource for my future career.

### 3. How to train myself and become an design researcher/PhD student in the healthcare-related field?

During this project, I have learned not only academic research skills but also how to manage my time effectively and work together with data scientists and medical experts. As the project progressed, I received lots of encouraging feedback from the medical experts and patients involved. Looking at the overall outcomes, I feel content with what we have achieved. With these skills honed, I am confident about moving forward into the next phase of my career.

# References

- Adler, N. E., & Stewart, J. C. (2010). Health disparities across the lifespan: Meaning, methods, and mechanisms. *Annals of the New York Academy of Sciences*, 1186(1), 5–23. <https://doi.org/10.1111/j.1749-6632.2009.05337.x>
- Arndt, V., Koch-Gallenkamp, L., Jansen, L., Bertram, H., Eberle, A., Holleczeck, B., Schmid-Höpfner, S., Waldmann, A., Zeissig, S. R., & Brenner, H. (2017). Quality of life in long-term and very long-term cancer survivors versus population controls in Germany. *Acta Oncologica*, 56(2), 190–197. <https://doi.org/10.1080/0284186x.2016.1266089>
- Bakir, E. P., Çavuşoğlu, H., & Mengen, E. (2021). Effects of the Information–Motivation–Behavioral Skills Model on Metabolic Control of Adolescents with Type 1 Diabetes in Turkey: Randomized Controlled Study. *Journal of Pediatric Nursing*, 58, e19–e27. <https://doi.org/10.1016/j.pedn.2020.11.019>
- Bandura, A. (2001). Social Cognitive Theory: An Agentic Perspective. *Annual Review of Psychology*, 52(1), 1–26. <https://doi.org/10.1146/annurev.psych.52.1.1>
- Barello, S., Triberti, S., Graffigna, G., Libreri, C., Serino, S., Hibbard, J. H., & Riva, G. (2016). eHealth for Patient Engagement: A Systematic Review. *Frontiers in Psychology*, 6. <https://doi.org/10.3389/fpsyg.2015.02013>
- Barlow, J. H., Wright, C., Sheasby, J., Turner, A., & Hainsworth, J. (2002). Self-management approaches for people with chronic conditions: a review. *Patient Education and Counseling*, 48(2), 177–187. [https://doi.org/10.1016/s0738-3991\(02\)00032-0](https://doi.org/10.1016/s0738-3991(02)00032-0)
- Beusterien, K., Tsay, S., Su, Y., Corral, M., Gholizadeh, S., & Wagner, S. (2012). Experience with colorectal cancer: Analysis of patient web forums. *Journal of Clinical Oncology*, 30(4\_suppl), 496. [https://doi.org/10.1200/jco.2012.30.4\\_suppl.496](https://doi.org/10.1200/jco.2012.30.4_suppl.496)
- Bodenheimer, T. (2002). Patient Self-management of Chronic Disease in Primary Care. *JAMA*, 288(19), 2469. <https://doi.org/10.1001/jama.288.19.2469>
- Bourbeau, J. (2003). Reduction of Hospital Utilization in Patients With Chronic Obstructive Pulmonary Disease<subtitle>A Disease-Specific Self-management Intervention</subtitle> *Archives of Internal Medicine*, 163(5), 585. <https://doi.org/10.1001/archinte.163.5.585>
- Braun, V., Clarke, V., Hayfield, N., & Terry, G. (2019). Thematic Analysis. In Springer eBooks (pp. 843–860). [https://doi.org/10.1007/978-981-10-5251-4\\_103](https://doi.org/10.1007/978-981-10-5251-4_103)
- Braveman, P., Egerter, S., & Williams, D. R. (2011). The Social Determinants of Health: Coming of Age. *Annual Review of Public Health*, 32(1), 381–398. <https://doi.org/10.1146/annurev-publhealth-031210-101218>
- Burke, L. E., Wang, J., & Sevick, M. A. (2011). Self-Monitoring in Weight Loss: A Systematic Review of the Literature. *Journal of the American Dietetic Association*, 111(1), 92–102. <https://doi.org/10.1016/j.jada.2010.10.008>
- Colormax.org - Color Vision Correction. (2019, July 26). Blue-Yellow Color Blindness | Causes & Treatment. Color Vision Correction. <https://colormax.org/blue-yellow-color-blindness/>
- Darroch, I., Goodman, J., Brewster, S., & Gray, P. (2005). The Effect of Age and Font Size on Reading Text on Handheld Computers. In Springer eBooks (pp. 253–266). [https://doi.org/10.1007/11555261\\_23](https://doi.org/10.1007/11555261_23)
- Davis, R. E., Campbell, R., Hildon, Z., Hobbs, L., & Michie, S. (2014). Theories of behaviour and behaviour change across the social and behavioural sciences: a scoping review. *Health Psychology Review*, 9(3), 323–344. <https://doi.org/10.1080/17437199.2014.941722>
- Effing, T., Vercoulen, J. H., Bourbeau, J., Trappenburg, J. C., Lenferink, A., Cafarella, P., Coultas, D. B., Meek, P., Van Der Valk, P., Bischoff, E., Bucknall, C., Dewan, N. A., Early, F., Fan, V. S., Frith, P., Janssen, D. J., Mitchell, K., Morgan, M., Nici, L., . . . Van Der Palen, J. a. M. (2016). Definition of a COPD self-management intervention: International Expert Group consensus. *European Respiratory Journal*, 48(1), 46–54. <https://doi.org/10.1183/13993003.00025-2016>

EU-IPFF. (2023). The EU-IPFF Consultation Guide. <https://www.eu-ipff.org/about-pf>

Expertise centra. (n.d.). Longfibrose.nl. Retrieved May 31, 2023, from <https://www.longfibrose.nl/>

Fisher, J. W., & Fisher, W. E. (2000). Theoretical Approaches to Individual-Level Change in HIV Risk Behavior. In Springer eBooks (pp. 3–55). [https://doi.org/10.1007/978-1-4615-4137-0\\_1](https://doi.org/10.1007/978-1-4615-4137-0_1)

Flores, G. (2006). Language Barriers to Health Care in the United States. *The New England Journal of Medicine*, 355(3), 229–231. <https://doi.org/10.1056/nejmp058316>

Gazmararian, J. A., Williams, M., Peel, J. L., & Baker, D. (2003). Health literacy and knowledge of chronic disease. *Patient Education and Counseling*, 51(3), 267–275. [https://doi.org/10.1016/s0738-3991\(02\)00239-2](https://doi.org/10.1016/s0738-3991(02)00239-2)

Grande, G., Myers, L. B., & Sutton, S. R. (2006). How do patients who participate in cancer support groups differ from those who do not? *Psycho-oncology*, 15(4), 321–334. <https://doi.org/10.1002/pon.956>

Homko, C. J., Sivan, E., & Reece, E. A. (2002). The Impact of Self-Monitoring of Blood Glucose on Self-Efficacy and Pregnancy Outcomes in Women With Diet-Controlled Gestational Diabetes. *The Diabetes Educator*, 28(3), 435–443. <https://doi.org/10.1177/014572170202800313>

Human Interface Guidelines | Apple Developer Documentation. (n.d.). Apple Developer Documentation. <https://developer.apple.com/design/human-interface-guidelines>

Jung, J. (2023). Developing Data-enabled Design in the Field of Digital Health. TU Delft Repository. <https://doi.org/10.4233/uuid:28c38358-a1ca-423c-97fb-841471138e56>

Kripalani, S., Wallston, K. A., LeStourgeon, L. M., Williamson, S. L., & Mayberry, L. S. (2018). Assessing barriers to diabetes medication adherence using the Information-Motivation-Behavioral skills model. *Diabetes Research and Clinical Practice*, 142, 374–384. <https://doi.org/10.1016/j.diabres.2018.05.046>

Lee, J. Y., Tikellis, G., Corte, T. J., Goh, N. S. L., Keir, G. J., Spencer, L., Sandford, D. G., Khor, Y. H., Glaspole, I., Price, J. W. H., Hey-Cunningham, A. J., Maloney, J., Teoh, A. K. Y., Watson, A. J., & Holland, A. E. (2020). The supportive care needs of people living with pulmonary fibrosis and their caregivers: a systematic review. *European Respiratory Review*, 29(156), 190125. <https://doi.org/10.1183/16000617.0125-2019>

Lee, J. Y., Tikellis, G., Glaspole, I., Khor, Y. H., Symons, K., & Holland, A. E. (2022). Self-management for pulmonary fibrosis: Insights from people living with the disease and healthcare professionals. *Patient Education and Counseling*, 105(4), 956–964. <https://doi.org/10.1016/j.pec.2021.07.005>

Lee, J. Y., Tikellis, G., Khor, Y. H., & Holland, A. E. (2022). Developing a self-management package for pulmonary fibrosis: an international Delphi study. *ERJ Open Research*, 8(4), 00349–02022. <https://doi.org/10.1183/23120541.00349-2022>

Lorig, K., Sobel, D. S., Ritter, P. L., Laurent, D., & Hobbs, M. (2001). Effect of a self-management program on patients with chronic disease. *PubMed*, 4(6), 62–256. <https://pubmed.ncbi.nlm.nih.gov/11769298>

Mackenbach, J. P., Stirbu, I., Roskam, A. R., Schaap, M. M., Menvielle, G., Leinsalu, M., & Kunst, A. E. (2008). Socioeconomic Inequalities in Health in 22 European Countries. *The New England Journal of Medicine*, 358(23), 2468–2481. <https://doi.org/10.1056/nejmsa0707519>

McCarthy, S., O’Raghallaigh, P., Woodworth, S., Lim, Y. Y., Kenny, L. C., & Adam, F. (2016). An integrated patient journey mapping tool for embedding quality in healthcare service reform. *Journal of Decision Systems*, 25(sup1), 354–368. <https://doi.org/10.1080/12460125.2016.1187394>

Mishali, M., Omer, H., & Heymann, A. (2010). The importance of measuring self-efficacy in patients with diabetes. *Family Practice*, 28(1), 82–87. <https://doi.org/10.1093/fampra/cm086>



Misovich, S. J., Martinez, T., Fisher, J. W., Bryan, A. D., & Catapano, N. (2003). Predicting Breast Self-Examination: A Test of the Information-Motivation-Behavioral Skills Model1. *Journal of Applied Social Psychology*, 33(4), 775–790. <https://doi.org/10.1111/j.1559-1816.2003.tb01924.x>

Mitzner, T. L., Fausset, C. B., Boron, J. B., Adams, A., Dijkstra, K., Lee, C. C., Rogers, W. A., & Fisk, A. D. (2008). Older Adults' Training Preferences for Learning to Use Technology. *Journal of Gerontology: Psychological Sciences*, 52(26), 2047–2051. <https://doi.org/10.1177/154193120805202603>

Monninkhof, E. M., Van Der Valk, P., Van Der Palen, J., Van Herwaarden, C., & Zielhuis, G. A. (2003). Effects of a comprehensive self-management programme in patients with chronic obstructive pulmonary disease. *European Respiratory Journal*, 22(5), 815–820. <https://doi.org/10.1183/09031936.03.00047003>

Morey, S. A., Stuck, R. E., Chong, A. L., Barg-Walkow, L. H., Mitzner, T. L., & Rogers, W. A. (2019). Mobile Health Apps: Improving Usability for Older Adult Users. *Ergonomics in Design*, 27(4), 4–13. <https://doi.org/10.1177/1064804619840731>

Murray, S. A., Kendall, M., Boyd, K., & Sheikh, A. (2005). Illness trajectories and palliative care. *BMJ*, 330(7498), 1007–1011. <https://doi.org/10.1136/bmj.330.7498.1007>

Nalysnyk, L., Cid-Ruzafa, J., Rotella, P., & Esser, D. (2012). Incidence and prevalence of idiopathic pulmonary fibrosis: review of the literature. *European Respiratory Review*, 21(126), 355–361. <https://doi.org/10.1183/09059180.00002512>

Ngo-Metzger, Q., Massagli, M. P., Clarridge, B. R., Manocchia, M., Davis, R. J., Iezzoni, L. I., & Phillips, R. S. (2003). Linguistic and cultural barriers to care. *Journal of General Internal Medicine*, 18(1), 44–52. <https://doi.org/10.1046/j.1525-1497.2003.20205.x>

Nutbeam, D. (2008). The evolving concept of health literacy. *Social Science & Medicine*, 67(12), 2072–2078. <https://doi.org/10.1016/j.socscimed.2008.09.050>

Regunath, G. (2021). Explainability AI — Advancing Analytics. *Advancing Analytics*. <https://www.advancinganalytics.co.uk/blog/2021/7/14/shap>

Ribeiro, M. T., Singh, S., & Guestrin, C. (2016). “Why Should I Trust You?”: Explaining the Predictions of Any Classifier. <https://doi.org/10.18653/v1/n16-3020>

Ries, A. L., Bauldoff, G., Carlin, B. W., Casaburi, R., Emery, C. F., Mahler, D. A., Make, B. J., Rochester, C. L., ZuWallack, R., & Herrerias, C. (2007). Pulmonary Rehabilitation. *Chest*, 131(5), 4S–42S. <https://doi.org/10.1378/chest.06-2418>

Rosenstock, I. M., Strecher, V. J., & Becker, M. J. (1988). Social Learning Theory and the Health Belief Model. *Health Education Quarterly*, 15(2), 175–183. <https://doi.org/10.1177/109019818801500203>

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

Sanders, E. B., & Stappers, P. J. (2013). Convivial Toolbox: Generative Research for the Front End of Design. [https://openlibrary.org/books/OL28484092M/Convivial\\_Toolbox](https://openlibrary.org/books/OL28484092M/Convivial_Toolbox)

Semantic Studios. (2004, June 21). [http://semanticstudios.com/user\\_experience\\_design/](http://semanticstudios.com/user_experience_design/)

Sikka, R., Morath, J. M., & Leape, L. L. (2015). The Quadruple Aim: care, health, cost and meaning in work. *BMJ Quality & Safety*, 24(10), 608–610. <https://doi.org/10.1136/bmjqs-2015-004160>

Singh, M., Jakhar, A. K., & Pandey, S. (2021). Sentiment analysis on the impact of coronavirus in social life using the BERT model. *Social Network Analysis and Mining*, 11(1). <https://doi.org/10.1007/s13278-021-00737-z>

Starace, F., Massa, A., Amico, K. R., & Fisher, J. W. (2006). Adherence to antiretroviral therapy: An empirical test of the information-motivation-behavioral skills model. *Health Psychology*, 25(2), 153–162. <https://doi.org/10.1037/0278-6133.25.2.153>

Stiggelbout, A. M., Griffioen, I., Brands, J., Melles, M., Rietjens, J., Kunneman, M., Van Der Kolk, M., Van Eijck, C., & Snelders, D. (2023). Metro Mapping: development of an innovative methodology to co-design care paths to support shared decision making in oncology. *BMJ Evidence-Based Medicine*, bmjebm-112168. <https://doi.org/10.1136/bmjebm-2022-112168>

Stratton, S. J. (2021). Population Research: Convenience Sampling Strategies. *Prehospital and Disaster Medicine*, 36(4), 373–374. <https://doi.org/10.1017/s1049023x21000649>

Sushil, M., Suster, S., & Daelemans, W. (2021). Are we there yet? Exploring clinical domain knowledge of BERT models. <https://doi.org/10.18653/v1/2021.bionlp-1.5>

Swigris, J. J., Stewart, A. L., Gould, M. K., & Wilson, S. B. (2005). Patients' perspectives on how idiopathic pulmonary fibrosis affects the quality of their lives. *Health and Quality of Life Outcomes*, 3(1). <https://doi.org/10.1186/1477-7525-3-61>

Van Boeijen, A., Daalhuizen, J., Zijlstra, J. S., & Van Der Schoor, R. (2014). *Delft Design Guide: Design strategies and methods*. BIS Publishers.

Visser, F. S., Stappers, P. J., Van Der Lugt, R., & Sanders, E. A. (2005). Contextmapping: experiences from practice. *CoDesign*, 1(2), 119–149. <https://doi.org/10.1080/15710880500135987>

Webb, T. L., Joseph, J., Yardley, L., & Michie, S. (2010). Using the Internet to Promote Health Behavior Change: A Systematic Review and Meta-analysis of the Impact of Theoretical Basis, Use of Behavior Change Techniques, and Mode of Delivery on Efficacy. *Journal of Medical Internet Research*, 12(1), e4. <https://doi.org/10.2196/jmir.1376>

Zheng, H., Yang, L., Hu, J., & Yang, Y. (2022). Frequency and Influencing Factors of Shared Decision Making Among Breast Cancer Patients Receiving Surgery: A Systematic Review and Meta-Analysis. *Clinical Breast Cancer*, 23(1), e20–e31. <https://doi.org/10.1016/j.clbc.2022.10.007>