

Appendices

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introduction (continued): space for images

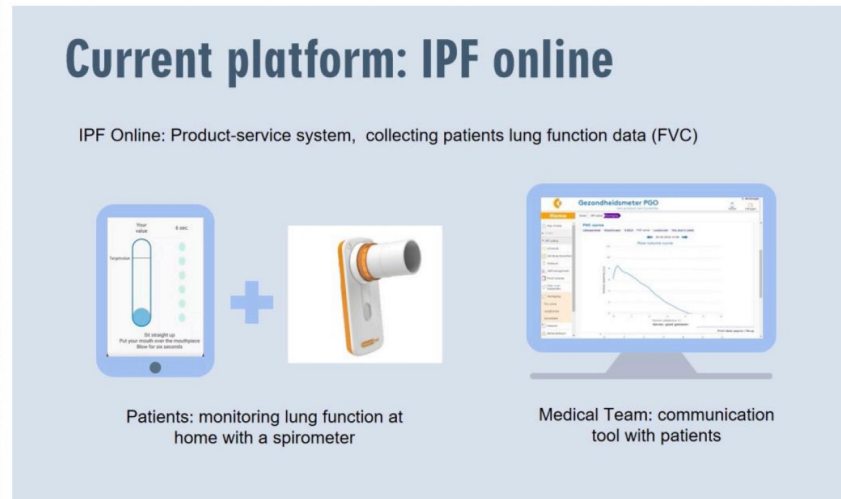


image / figure 1: The current product: IPF-Online

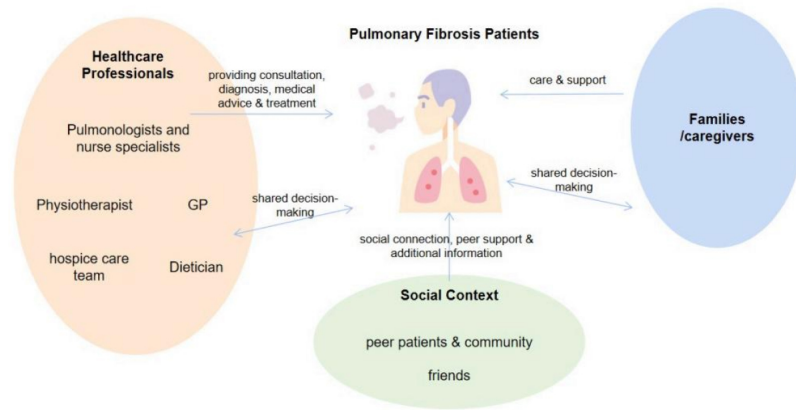


image / figure 2: An overview of the stakeholders involved

Optimizing pulmonary fibrosis patients experience by remote monitoring project title

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

start date 20 - 02 - 2023

20 - 07 - 2023

end date

INTRODUCTION **

Please describe, the context of your project, and address the main stakeholders (interests) within this context in a concise yet complete manner. Who are involved, what do they value and how do they currently operate within the given context? What are the main opportunities and limitations you are currently aware of (cultural- and social norms, resources (time, money,...), technology, ...).

Pulmonary Fibrosis (PF) is a progressive, irreversible, and chronic lung disease that results in lung scarring and leads to a decline in lung function and increasing breathlessness. PF typically occurs in people over 45 years old, with an average age of 65 (Consultation Guide - EU-PF F, 2023). There is a wide range of causes and clinical manifestations of PF, and the most common one is Idiopathic Pulmonary Fibrosis (IPF). Moreover, diagnosing PF is an ongoing process that requires several examination methods and a multidisciplinary diagnosing team. Hence, delayed diagnosis and misdiagnosis commonly occur. The symptoms of PF develop over time, and individual differences exist in patients, while the most common ones are persistent coughing, shortness of breath, and fatigue. Currently, there are two main treatment methods for PF: pharmacology (drug-based) treatment and non-pharmacology treatment, which includes lung transplantation, oxygen therapy, and pulmonary rehabilitation. As the disease is incurable and progresses differently with individual patients, it is necessary to monitor patients' disease courses continuously. Hence, the pulmonologists from Erasmus Medical Center developed the remote-monitoring tool (Figure 1): IPF-online to support patients in measuring their lung functions at home and communicating with healthcare professionals without physical consultations. The aim of my graduation project is to enhance the current platform by investigating and integrating the patients' experience in everyday life, to optimize their health-related quality of life. Several stakeholder groups are included and will be further investigated during my graduation project (Figure 2): 1. Patients themselves are the primary stakeholders since they are in charge of decision-making, keeping track of their disease course, and reorganizing their life to adapt to the changes brought by the disease. 2. Patients' caregivers/families are also involved throughout the journey as they provide care and support the patients. 3. Healthcare professionals are also significant stakeholders to be considered, including primary care providers (general practitioners) and secondary care providers (hospitals), who take the roles in consultation, diagnosis, treatment, and shared decision-making processes. Apart from that, other healthcare professionals are involved in the treatment process, including physiotherapists and dieticians. 4. The social environment surrounding the patients is also relevant, the most relevant are the peer patients and patient communities, which provides peer support and additional information and knowledge. Based on my findings from initial research by journey mapping, currently, there are several challenges that patients are facing during different stages of their care path which can negatively affect their health-related quality of life: 1. Patients experience difficulties in decision-making in different stages of the disease, due to the lack of information and communication barriers with healthcare professionals. 2. The unexpected progression of disease and acute exacerbation could cause patients anxiety and frustration. 3. Treatment plan is constantly adjusted corresponding to the disease progression, and patients need to spend extra time and energy to adapt to the new plan. 4. Patients have to reorganize their daily life to adapt to the tremendous changes in every aspect, such as diet changes, sleeping difficulties, reduced mobilities, quitting jobs, and less social connection. In my graduation project, I want to actively engage in these challenges and identify their reasons, and develop potential solutions.

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MOTIVATION AND PERSONAL AMBITIONS

Explain why you set up this project, what competences you want to prove and learn. For example: acquired competences from your MSc programme, the elective semester, extra-curricular activities (etc.) and point out the competences you have yet developed. Optionally, describe which personal learning ambitions you explicitly want to address in this project, on top of the learning objectives of the Graduation Project, such as: in depth knowledge a on specific subject, broadening your competences or experimenting with a specific tool and/or methodology, Stick to no more than five ambitions.

I am motivated to choose this project because it fits my interest in developing solutions for healthcare contexts involving diverse stakeholders and also helps me finish the medesign specialization. As I have yet to do any project related to data-enabled design, this project is also challenging for me to explore unfamiliar fields. Additionally, I have already done a research elective for the Cardiolab in collaboration with Erasmus MC, therefore, I am already familiar with the context and have developed a great interest in further developing this project. I believe the results of this project will generate great value for the patients and the medical team. Competence I want to approve: - Ability to conduct context research and user experience research - Academic skills, including applying different research methodologies and delivering innovative research findings. - Ability to create meaningful and impactful user experience design - Ability to collaborate with a multidisciplinary team Competence I want to learn: - How to collect and process community data and use it as a tool to understand user experiences? - How to develop a data-enabled design in the healthcare context? - How to make my design align with ethical and medical approval? e.g., how to deal with sensitive data and do research with vulnerable groups? - How to train myself and become a design researcher/PhD student in a healthcare-related field?

FINAL COMMENTS

In case your project brief needs final comments, please add any information you think is relevant.

PROBLEM DEFINITION **

Limit and define the scope and solution space of your project to one that is manageable within one Master Graduation Project of 30 EC (= 20 full time weeks or 100 working days) and clearly indicate what issue(s) should be addressed in this project.

As a progressive and incurable disease, pulmonary fibrosis requires long-term management throughout the patient's life. Moreover, the transition of healthcare context from hospital brings challenges to the patients, which impact different aspects of their daily lives. And this project will address PF patients' difficulties in managing their disease at home and communication with healthcare professionals. Though challenges are identified in different stages of patients' journey, the main scope of this project will be the patients' experiences after diagnosis and living with PF. There are two main research questions that need to be examined in my graduation project: 1. What are the patients' unmet needs during the after-diagnosis stage, meaning how and where patients miss information, skills, and feedback that are demanded to manage their disease effectively? 2. What kinds of data should be continuously collected from the patients to monitor patients' physical and mental experiences apart from the current measurements?

ASSIGNMENT **

State in 2 or 3 sentences what you are going to research, design, create and / or generate, that will solve (part of) the issue(s) pointed out in "problem definition". Then illustrate this assignment by indicating what kind of solution you expect and / or aim to deliver, for instance: a product, a product-service combination, a strategy illustrated through product or product-service combination ideas, In case of a Specialisation and/or Annotation, make sure the assignment reflects this/these.

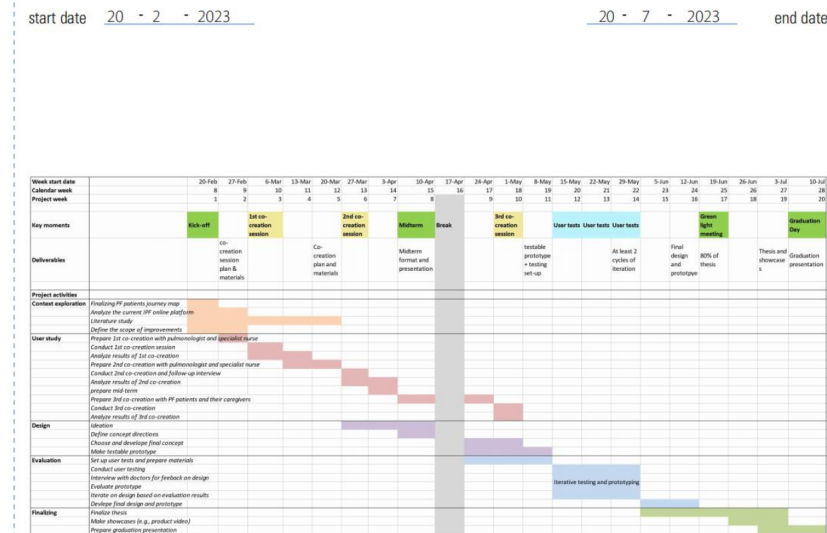
Design a patient-centered product-service system connecting PF patients and healthcare professionals, which supports patients' self-monitoring activities and improves the communication between patients and doctors.

I expect to design a product-service system that enables PF patients to actively keep track of their physical and mental status related to their disease and treatment process in order to better manage their diseases and reorganize their daily lives in a way that is not intrusive or overwhelming, but fits with their context and motivates them continuously use it. Secondly, I will design the interaction of communicating the collected data effectively to both patients and doctors. Since PF patients and healthcare professionals are the target users of this PSS, hence, both of their experiences will be incorporated into the development of effective and relevant solutions for both.

Personal Project Brief - IDE Master Graduation

PLANNING AND APPROACH **

Include a Gantt Chart (replace the example below - more examples can be found in Manual 2) that shows the different phases of your project, deliverables you have in mind, meetings, and how you plan to spend your time. Please note that all activities should fit within the given net time of 30 EC = 20 full time weeks or 100 working days, and your planning should include a kick-off meeting, mid-term meeting, green light meeting and graduation ceremony. Illustrate your Gantt Chart by, for instance, explaining your approach, and please indicate periods of part-time activities and/or periods of not spending time on your graduation project, if any, for instance because of holidays or parallel activities.



The project is planned for 100 days (20 project weeks). It's necessary to apply for ethical approval (HREC) and medical approval (METC) to conduct co-creation sessions, interviews, and user tests with patients. Although a realistic waiting time has already been taken into account, the planning of co-creation sessions and user tests may change due to the waiting time for approval. The detailed planning of co-creations and user tests will be updated once the ethical and medical approvals are received and patients are recruited.

Appendix B: HREC approval letter

Date 11-Apr-2023
Contact person Dr. Cath Cotton, Policy Advisor
Academic Integrity
E-mail c.m.cotton@tudelft.nl



Human Research Ethics
Committee TU Delft
(<http://hrec.tudelft.nl>)

Visiting address
Jaffalaan 5 (building 31)
2628 BX Delft

Postal address
P.O. Box 5015 2600 GA Delft
The Netherlands

Dr. Ir. U. Pesch
Chair HREC
Faculty of Technology, Policy and Management

*Ethics Approval Application: Improving pulmonary fibrosis patient remote monitoring systems through
Community Journey Mapping to increase HRQoL(health-related quality of life) and patient empowerment
Applicant: Zhang, Ruixuan*

Dear Ruixuan Zhang,

It is a pleasure to inform you that your application mentioned above has been approved.

In addition to any specific conditions or notes, the HREC provides the following standard advice to all applicants:

- In light of recent tax changes, we advise that you confirm any proposed remuneration of research subjects with your faculty contract manager before going ahead.
- Please make sure when you carry out your research that you confirm contemporary covid protocols with your faculty HSE advisor, and that ongoing covid risks and precautions are flagged in the informed consent - with particular attention to this where there are physically vulnerable (eg: elderly or with underlying conditions) participants involved.
- Our default advice is not to publish transcripts or transcript summaries, but to retain these privately for specific purposes/checking; and if they are to be made public then only if fully anonymised and the transcript/summary itself approved by participants for specific purpose.
- Where there are collaborating (including funding) partners, appropriate formal agreements including clarity on responsibilities, including data ownership, responsibilities and access, should be in place and that relevant aspects of such agreements (such as access to raw or other data) are clear in the Informed Consent.

Good luck with your research!

Sincerely,

Appendix C: Topic modelling results

Cluster	Meaning	Percentage positive/negative	Total posts
topic 0	Supplement/treatment method: Oxygen therapy: usage of oxygen concentrators	0.526189524	5414
topic 1	lung transplant surgery: decision making, after-care	0.761532447	4240
topic 2	medication: usage of non-traditional medicine (metformin, thalidomide)	0.587243402	2671
topic 3	loss of loved ones, support and sympathy from peer group	0.663209274	1837
topic 4	Symptoms: Coping strategies against coughing: medication, cough syrup, supplements, physical exercises	0.588688946	1250
topic 5	medication: experiences of taking esbriet: usage, effects and side effects	0.369030391	1199
topic 6	medication: experiences of taking ofev: usage, effects and side effects	0.442546584	1127
topic 7	Decision-making: choosing health insurances to cover treatment expenses	0.51826484	1037
topic 8	Diagnosis: Examination - Biopsy: what do patient need to prepare for it? Uncertainty of the experience of biopsy; difficulties in decision-making; Fear of the side effects of the treatment	0.373931624	916
topic 9	Environmental factors: Climatic condition influences on patients' symptoms: temperature, air quality, humidity	0.492727273	850
topic 10	Decision-making: choosing clinic and doctors	0.826086957	837
topic 11	Change in lifestyle: diet change, loss of appetite and losing weight Prepare for transplants surgery: maintain BMI	0.539784946	808
topic 12	Medication: prednisone: dosage of use, strong side effects	0.315914489	744
topic 13	Supplement/treatment method: CBD	0.492877493	706
topic 14	Symptoms: Anti-reflux: medication (omeprazole), keep strict diet, sleep on the bed with angle	0.394805195	704
topic 15	Scam treatment method: stem cell therapy	0.352549889	699

topic 16	Hypersensitivity pneumonitis: different sources of allergen (One of the subgroups of interstitial lung disease is those that are related to)	0.240310078	698
topic 17	Causes: Amiodarone-induced pulmonary fibrosis	0.322033898	685
topic 18	Supplement/treatment method: Enzyme supplements	0.634782609	683
topic 19	Coping strategies against coughing - saline; nasal spray against dry nose	0.492997199	616
topic 20	Indicator of disease progression: diffuse capacity for carbon monoxide and forced vital capacity	0.374015748	614
topic 21	Symptoms: cramps, chest pain For female patients: bras adds extra irritation	0.171232877	598
topic 22	Medication: antioxidant - NAC (N-acetylcysteine) is an antioxidant that may help to prevent lung damage in people with idiopathic pulmonary fibrosis;	0.615969582	545
topic 23	Medication: dosage, usage and side effects of taking all kinds of medication	0.659649123	537
topic 24	Cheering-up and encouragement from peers	0.988235294	535
topic 25	End-of-life: hospice care; palliative care (providing relief from symptoms, optimizing QoL); patients have positive attitude towards it	0.613180516	524
topic 26	Vaccinations are effective tools to prevent infections in pulmonary fibrosis patients, to help stay healthy	0.394736842	492
topic 27	Compassionate allowance from government: Supplemental Security Income (US)	0.377118644	470
topic 28	Complication of PF: arterial hypertension caused by pulmonary fibrosis	0.370731707	443
topic 29	Oxygen saturation: Is it helpful to trace the percentage? Individual differences on patients experiences; Doubts and communication gap with family	0.34375	434
topic 30	Breathing exercise. Physical exercises are experienced as beneficial improving symptoms; Pulmonary rehabilitation is perceived as challenging but also helpful	0.823321555	430
topic 31	Emotion: loneliness, sympathy towards others, fear of the disease when newly diagnoses	0.640243902	412
topic 32	Educating new users & difficulties of finding the needed information	0.565853659	392

Appendix C: Topic modelling results

topic 33	Community support: offline support group, attending webinars, lack of support and attention from national fund	0.866336634	380
topic 34	Emotion: thankful towards peers	0.994382022	362
topic 35	Causes: usage of 'agent orange' (chemical herbicide used in US military)	0.333333333	351
topic 36	Usage of oxygen device; Emotions: frustration of the fact of using oxygen tank; shame and embarrassment of using it in public; Tabu of using oxygen	0.35828877	345
topic 37	Recommendation on doctors and clinics	0.795454545	340
topic 38	Usage of oximeter: choosing the right device	0.653179191	335
topic 39	celebrating	0.961538462	328
topic 40	IPF as an interstitial lung disease	0.270588235	319
topic 41	Best wishes, prayers, congratulations on good news	0.974025974	318
topic 42	Making connections with peers: send friend request	0.859375	310
topic 43	Causes: rheumatoid arthritis (RA) caused complication of PF	0.322033898	273
topic 44	Purchase, pharmacy, online store	0.79389313	268
topic 45	Causes: familial pulmonary fibrosis, tests and doubts towards it	0.205128205	256
topic 46	Oxygen: differences between day and night; difficulties in sleeping at night, sleep apnea; Coping strategies: overnight oximetry, sleep study	0.50877193	251
topic 47	Side effect of medication: sensitive to sun, rashes. Coping strategies: wearing sun screen, stay away from beach	0.28057554	244
topic 48	Purchase medication, from pharmacy, amazon	0.477272727	243
topic 49	Attractions: DIY activities, trips	0.981395349	239

topic 50	Medication: cellcept	0.486956522	234
topic 51	loss of loved ones, grieving	0.468085106	225
topic 52	Diagnosis: misdiagnosis, unsatisfied with the doctor, switching to other doctors and clinics	0.296	224
topic 53	Medication: strong side effects of taking statins	0.214285714	222
topic 54	Medication: antibiotic medicines (doxycycline)	0.342342342	220
topic 55	url	0.827586207	219
topic 56	Medication: thrush caused by side effects of medication	0.352941176	219
topic 57	Changing in life style: becoming sensitive to scents such as artificial fragrances; Doubt of hydrogen peroxide as a treatment method?	0.217687075	218
topic 58	url	0.8	214
topic 59	Changing in life style: singing or participating in choirs is difficult, but it brings people joy and calming; positive attitude	0.546511628	214
topic 60	people not shows up anymore	0.722627737	210
topic 61	Appreciation	1	210
topic 62	Humor, jokes	0.914893617	204
topic 63	Changing in life style: taking shower with oxygen device is difficult; Coping strategy: using cannula and long oxygentubes in the shower	0.534653465	204
topic 64	Changing in life style: give up on keeping pets/plants; unwillingness to be part with their pets	0.627906977	200
topic 65	Changing in life style: daily mobility, using wheelchairs and mobility scooters	0.777777778	199
topic 66	Medication: pirfenidone; discussion on whether it's effective	0.423913043	189

Appendix C: Topic modelling results

topic 66	Medication: pirfenidone; discussion on whether it's effective	0.423913043	189	topic 83	Vitamin supplement; positive attitude towards it	0.526315789	125
topic 67	Influence of smoking: quit smoking after diagnosed; Causes: Asbestosis is a type of pulmonary fibrosis, or lung scarring, specifically caused by inhaling asbestos	0.18699187	188	topic 84	Appreciation	1	122
topic 68	Rehabilitation center, webinars	0.875	184	topic 85	Emotion: anxiety, depression, panic attack; Unclear cause, probably due to side effects of medication. Coping strategies: anti-anxiety/depression	0.421052632	121
topic 69	Medication: morphine (reduce pain), used in final stage of the disease or hospice; Positive attitude towards it: reduce a lot pain, brings comfort	0.5625	175	topic 86	Welcome	0.97826087	119
topic 70	Raising awareness and advocacy about PF	0.554347826	164	topic 87	Influence of COVID-19: fear of contacting with people; reduced opportunities of going out, meeting families and friends	0.14516129	117
topic 71	Changing in lifestyle: difficulties in sleeping; Coping strategy: wedge pillow, adjustable bed to help improve sleep	0.769230769	163	topic 88	Appreciation	1	116
topic 72	Symptoms: clubbing fingers; (<i>The tips of the fingers enlarge and the nails become extremely curved from front to back. Clubbed fingers is a symptom of lung disease.</i>)	0.206185567	162	topic 89	Diary of husband's disease progression	0.851851852	116
topic 73	Treatment: laser therapy; controversial method evokes debates	0.392857143	158	topic 90	Prayers for surgery	0.846153846	114
topic 74	Nonspecific Interstitial Pneumonitis (NSIP)	0.571428571	158	topic 91	Changing in lifestyle / Decision-making: continue or stop working Continue working: challenging but meaningful,	0.565217391	113
topic 75	Changing in lifestyle: hair loss due to unclear causes, possibly due to side effects of medication. Blue streak challenge to support PF research	0.488636364	155	topic 92	Self-protection: wearing face masks to prevent flu, allergens and COVID-19	0.62295082	113
topic 76	Diagnosis: symptoms of lung scarring, doubting if it's PF, looking for medical advices online; misdiagnosis	0.294736842	148	topic 93	Medication: Esbriet (pirfenidone): dosage and usage, individual differences	0.5	110
topic 77	After transplant surgery: fear of organ rejection after surgery; high cost of anti-rejection medicines, lack of information about the cost and whether it's worth it	0.434782609	132	topic 94	Changing in lifestyle: wearing glasses is inconvenient and uncomfortable; Coping strategy: special glasses designed for people who need	0.80952381	107
topic 78	Diagnosis: hard to accept the truth; unexpectation of disease progression	0.511627907	130	topic 95	Medication: Esbriet (pirfenidone): strong side effects, decided to stop taking it	0.434782609	107
topic 79	Causes: scleroderma related PF; Doubts and confuses about lung transplant for these patients	0.441176471	130	topic 96	Appreciation	0.950980392	105
topic 80	Amen	0.88034188	129	topic 97	Appreciation	1	105
topic 81	Fatigue due to side effect of medication;	0.285714286	129	topic 98	Grieving for others' loss	0.4	103
topic 82	sorry	0.481481481	127	topic 99	Waiting list for lung transplant surgery	0.828947368	103

Appendix D: Final re-interpreted categories and topics

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	cellcept (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; Supplement: 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	
	Total		8192	20.50%
Experience on non-pharmaceutical 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	
	Total		9979	24.50%
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	
	72	clubbing fingers; <i>(The tips of the fingers enlarge and the nails become extremely curved from front to back)</i>	162	
	28	arterial hypertension caused by pulmonary fibrosis	443	
	Total		3773	10.40%

Experience around decision-making moments (8)	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	
	Total		7773	21.50%
Experience around their diagnosis (6)	52	misdiagnosis, unsatisfied with the doctor	224	switching to other doctors and hospitals
	31	fear of the disease when newly diagnoses	412	
	76	symptoms of lung scarring, doubting if it's PF, looking for information online; misdiagnosis	148	
	20	Indicator of disease progression: diffuse capacity for carbon monoxide and forced vital capacity	614	
	29	Oxygen saturation: Is tracing the percentage helpful? Individual differences on patients experiences; Doubts and communication gap with doctors	434	
	78	uncertain about the diagnosis results	130	
	Total		1962	5.40%
Describing around causes (7)	16	Hypersensitivity pneumonitis: different sources of allergen (One of the subgroups of interstitial lung disease is those that are related to environmental exposures, referred to as "hypersensitivity pneumonitis.")	698	
	17	Amiodarone-induced pulmonary fibrosis	685	
	35	usage of 'agent orange' (chemical herbicide used in US military)	351	
	40	Unclear causes:IPF	319	
	45	Causes: familial pulmonary fibrosis, tests and doubts towards it	256	
	43	rheumatoid arthritis (RA) caused complication of PF	273	
	79	scleroderma related PF; Doubts and confuses about lung transplat for these patients	130	
	Total		2712	6.00%
	57	becoming sensitive to scents such as artificial fragrances; Doubt of hydrogen peroxide as a treatment method?	218	
	59	singing or participating in choirs is difficult, but it brings people joy and calming; positive attitude	214	
	63	taking shower with oxygen device is difficult; Coping strategy: using cannula and long oxygen tubes in the shower	204	
	64	give up on keeping pets/plants; unwillingness to be part with their pets	200	
	65	daily mobility, using wheelchairs and mobility scooters	199	
	77+99	Receive lung transplant surgery: waiting & after care	235	
	Total			

Appendix D: Final re-interpreted categories and topics

Adjusting lifestyle to adapt to the changes in life(16)	46+71	difficulties in sleeping;	414	
	81	Fatigue influencing daily activities	129	
	75	hair loss due to unclear causes, possibly due to side effects of medication.	155	
	47	Side effect of medication: sensitive to sun, rashes Coping strategies: wearing sun screen, stay away from beach	244	
	11	diet change, loss of appetite and losing weight Prepare for transplants surgery: maintain BMI (weight) in the required range	808	
	94	wearing glasses is inconvenient and uncomfortable when using oxygen tank	107	
	49	DIY activities, trips	239	
	9	Climatic condition influences on patients' symptoms: temperature, air quality, humidity	850	
	87 +92	Influence of COVID-19: fear of contacting with people; reduced opportunities of going out, meeting families and friends	230	
	85	anxiety, depression, panic attack; Unclear cause, probably due to side effects of medication.	121	
Total			4567	11.70%

Appendix E: HPs Co-creation session set up

1st co-creation with healthcare professionals

session work plan

Time: 1.5 hour

Location: Erasmus MC

Participants: pulmonologists (3), specialist nurse (1), designers (2), computer scientists (2)

Research Questions:

1. To scope down the focus: what are the most important challenges that need to be addressed in doctors' perspective to improve HRQOL of patients?
2. What factors are important to optimize for using explainable AI in the context of the medical domain?
3. What kinds of information need to be collected from the patients to help the doctors gain context in these challenges?

The 8 diverse participants in the session with expertise in patient care, design and explainable AI will result in an expert group that is able to validate and generate insights at the intersection of all these research fields.

Time	Activity	Goal	Tasks for participants	Modality
20	Introduction	Share the research methods, limitations (US context), provide schedule for the remainder of the session.	Waiting for everyone to settle down & Quick introduction Jiwon(5min) Give quick presentation about project (10min) Look through and sign the informed consent form (5 min)	PowerPoint C form
15	Validate Journey map (Group)	Help participants to understand the timeline and to validate the Journey map.	1. The participants will first use markers to draw on the main line with their thoughts on the patient journey. (10min) 2. Discuss the changes, what was inspiring? What went wrong? How it is different between Dutch & US context (5min)	Booklet
15	Identify the most	Find the challenges that are most important to improve	Each participant fills in the first page in the booklet.	Map, Cards & Booklet

	important challenges (Group)	on.	Look through the patient topic cards. And each participant picks 2 topic cards that they think is the most important to ask during their consultation with patients; And put them in the Hospital-home spectrum (10min) Discuss about the choices. (5min)	
35		Do they understand, trust the explainability generated by the system and is it useful. Find implicit requirements by using the prototype.	Explain how the prototype system works to the participants using the tutorial page at the start of the system Tutorial shows: an example persona -> posts generated by the persona-> AI processing -> doctor interface. The booklet shows: How a persona would look like Explain the assignment that they must perform in the PowerPoint (5min) Show how to use the system on the screen Each participant gets a separate laptop to use, look through the 3 example patients that were pre-made by us to display the different functions of the system. The participants will use the system to read the main/sub-categories and sentiment generated from the problem posts the pre-made patients are experiencing. They	Prototype & Booklet

			must create in their booklet 3 personas that match the 3 pre-made patients they explore in the system. They can use the explainability for doing this by clicking on the hint button. (10min) From these results we ask them what personas they created and see if they match the ones that we based the messages on. We will hold a structured discussion on if they understood the information presented and if they used and trusted the explainability hints and if they think they needed more hints and how those would look like. (20min)	
5	Closing remarks	Close the session and thank the participants		Cookies

Appendix F: HPs Co-creation booklet

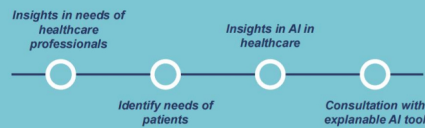
Co-creation session booklet 7th of March

Healthcare professionals co-creation session for designing for Pulmonary Fibrosis patients

Co-creation session goal

The needs and opinions of healthcare professionals in communication with patients in their after-diagnosis stage

Co-creation session outline



Your needs as a healthcare professional

Step 1: Please write your name, position and years of experience below.

Step 2: Write down 2 needs that you experience as a healthcare professional in the communication and interaction with patients.

Step 3: Explain why these needs are important for you.

My needs

My needs

Name _____

Position _____

Years of experience _____

Why?

01

Identify needs of patients

Step 1: Please read through the topic cards on the table, and select two of the cards that you think are important topics to discuss with the patient during their consultation.

Step 2: Write down the topics of these two cards, and could you explain why you choose them.

Step 3: When you finish the first two steps, you can continue with the group discussion.

Name of topic 1:

Name of topic 2:

Why these two topics are important to discuss with the patient?

Your experience with AI

Step 1: Think about your past experience, do you have experience with Artificial Intelligence technologies?

Step 2: How AI can help you as a healthcare professionals?

Step 3: How do you feel towards AI? Please fill in the scale questions in the bottom.

Step 1: My experience with AI:

Step 2: I want to know about AI:

Step 3:

AI should be used in healthcare domain

Strongly disagree Neutral Strongly agree

I have a strong understanding of AI

Strongly disagree Neutral Strongly agree

02

Create patient profile for Mark

Based on your understanding of the information provided by the prototype, please fill in the keywords of questions you will ask Mark in the white boxes.

Mark, 61-year-old, pre-transplant surgery

03

Appendix E: HPs Co-creation booklet

Create patient profile for Jasper

Based on your understanding of the information provided by the prototype, please fill in the keywords of questions you will ask Jasper in the white boxes.



Jasper, 67-year-old,
recently diagnosed

04

Create patient profile for Julia

Based on your understanding of the information provided by the prototype, please fill in the keywords of questions you will ask Julia in the white boxes.



Julia 61-year-old,
diagnosis stage

05

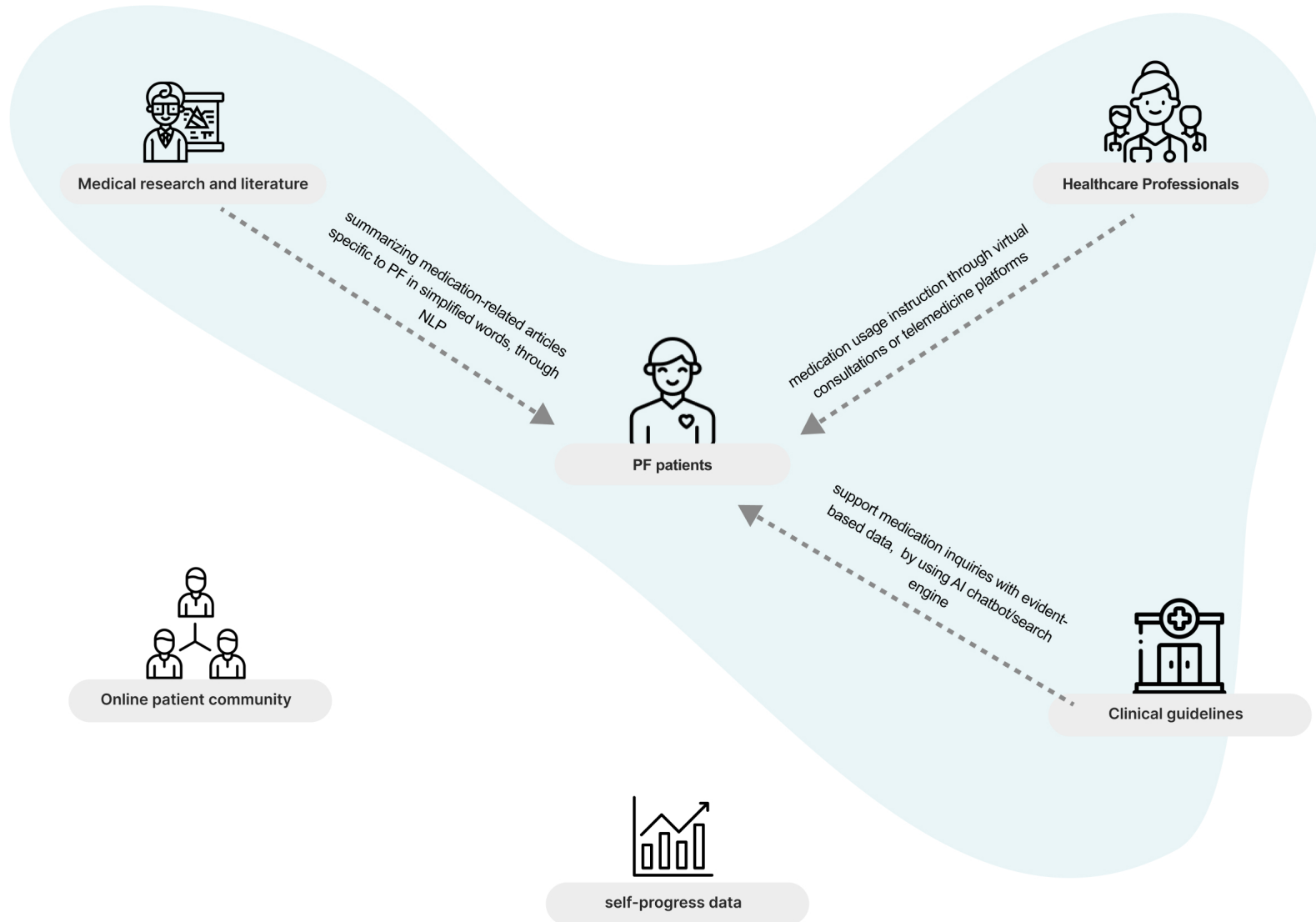
Thank you for your participation!

Your insights are valuable for us to design for PF patients.
This booklet will be picked up by me in the end of this session.

Ruixuan Zhang

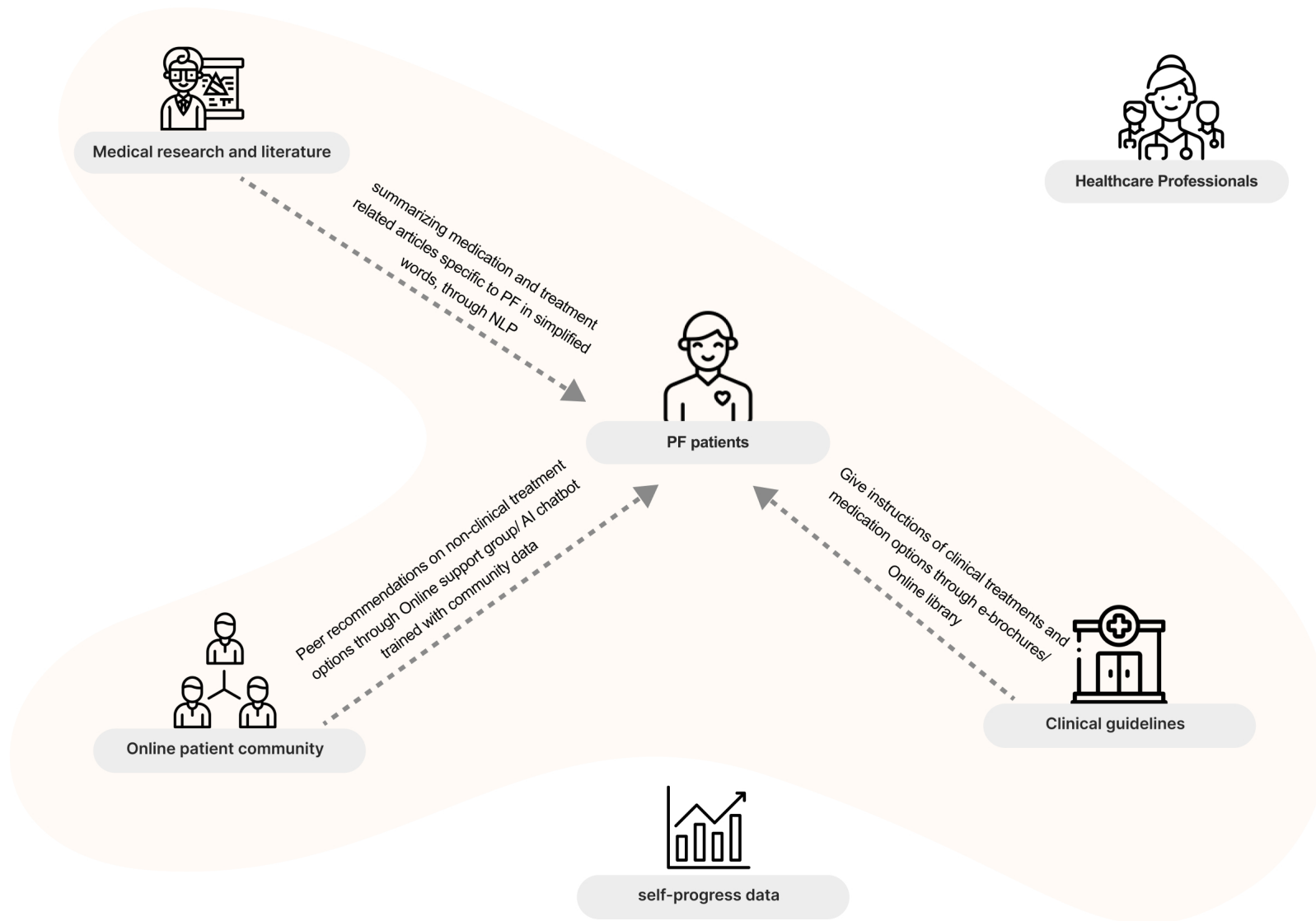
Appendix H: Results brainstorming session with designers

Understanding and management of medication



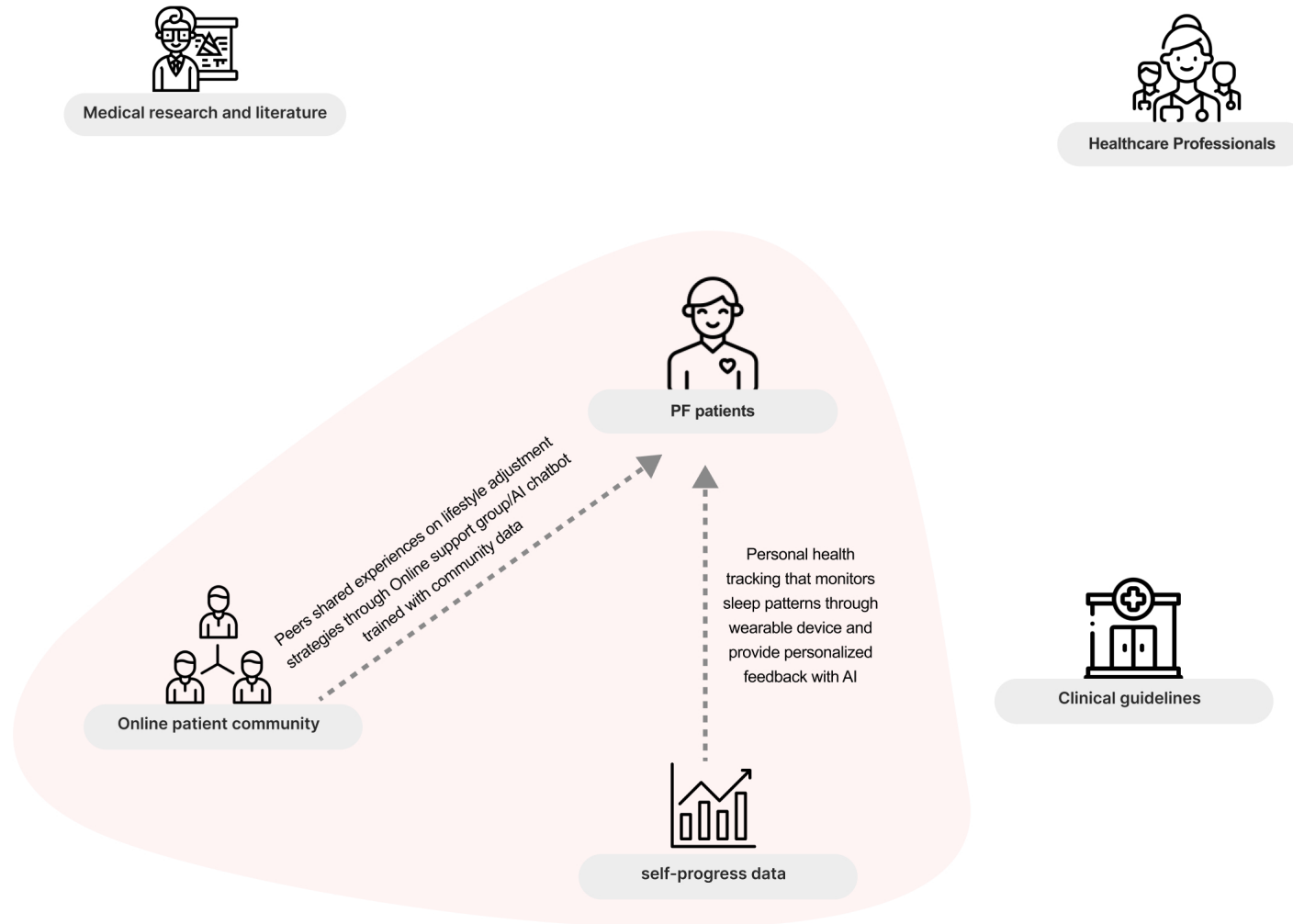
Appendix H: Results brainstorming session with designers

Understanding Treatment and medication options



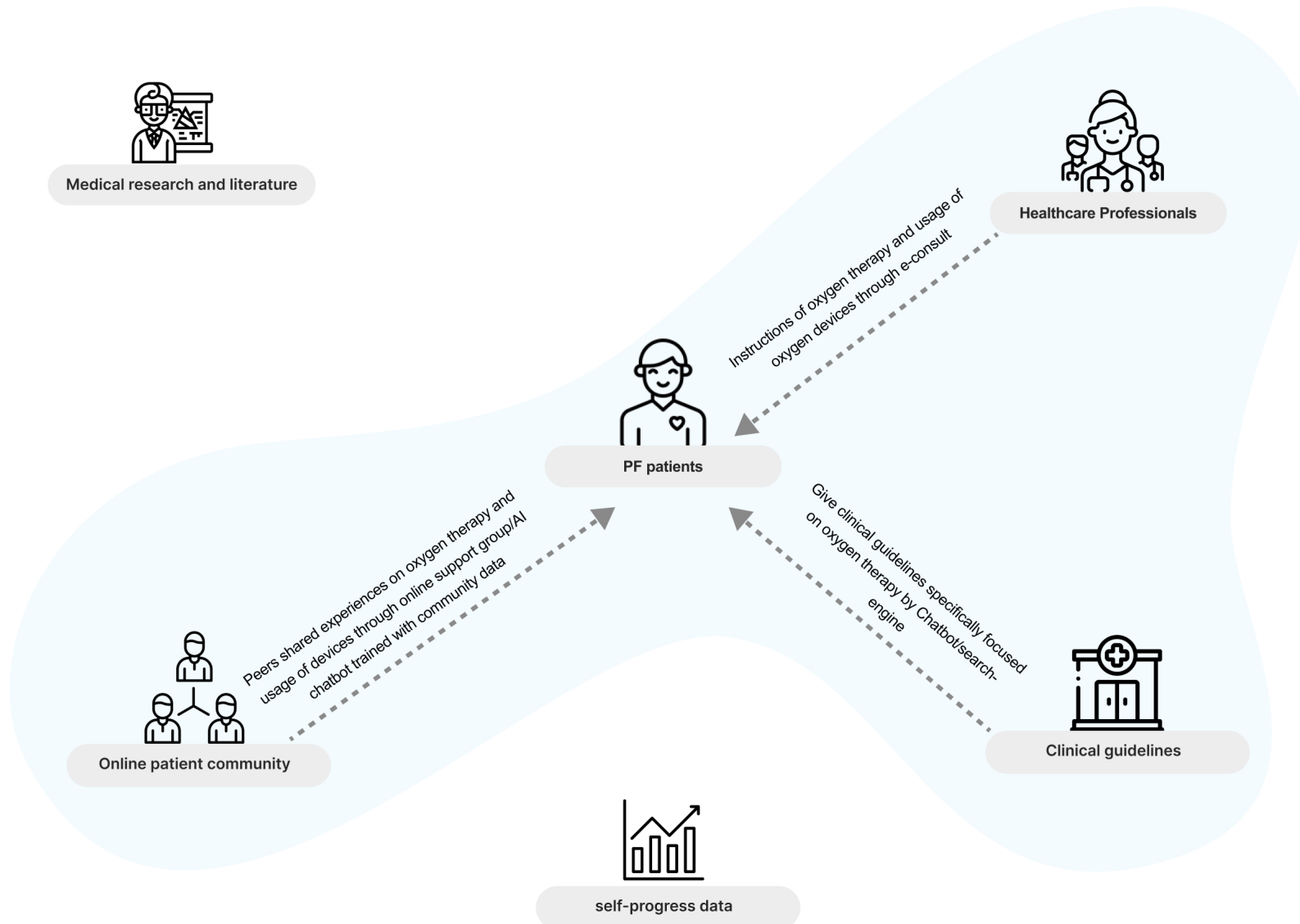
Appendix H: Results brainstorming session with designers

Lifestyle adjusting to adapt to changes in life



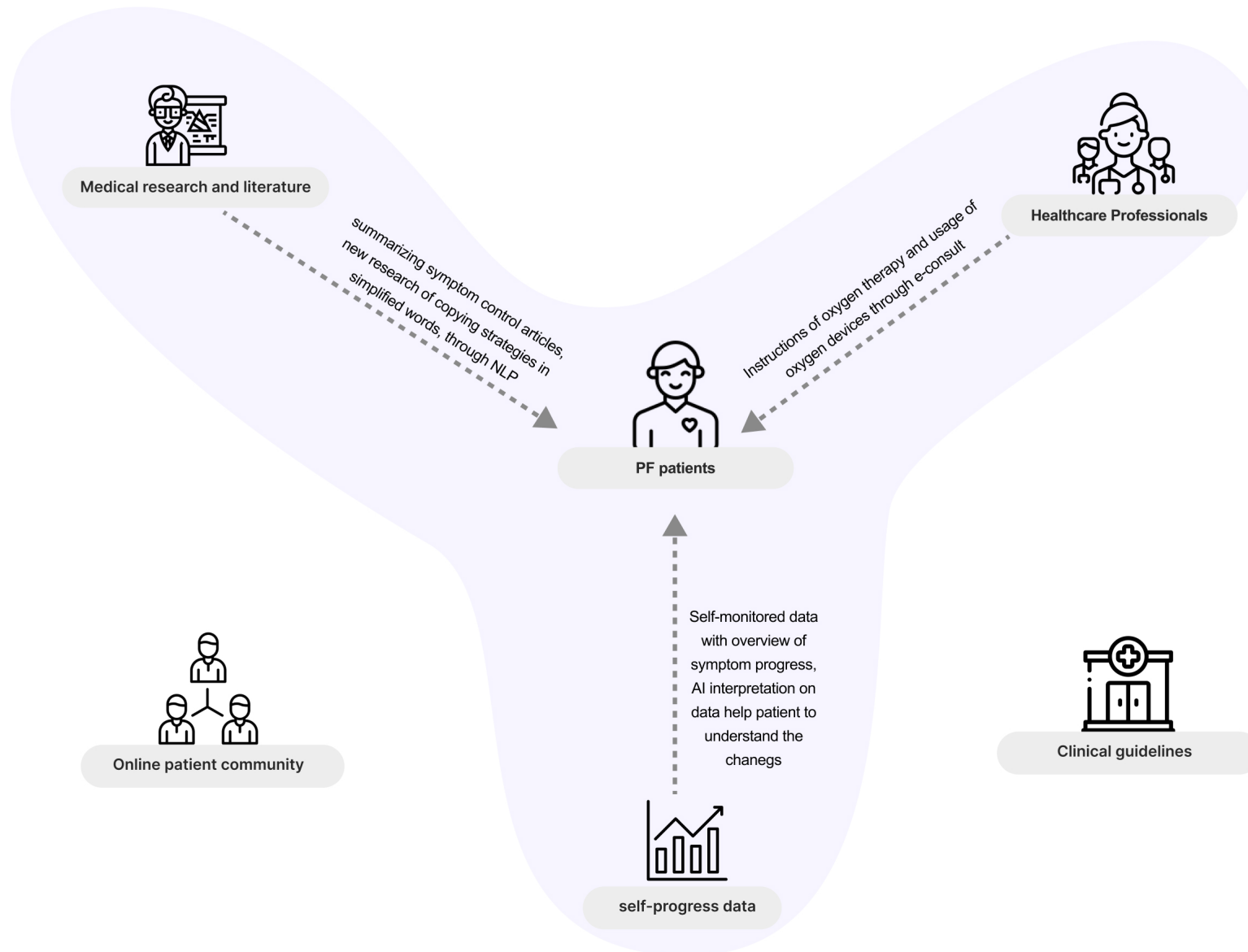
Appendix H: Results brainstorming session with designers

Understanding and management of oxygen therapy



Appendix H: Results brainstorming session with designers

Symptom monitoring and management



Appendix I: Patient validation session set up & questionnaire

1. Introduction [5min]

[Welcome & Explain the project]:

Hi, we're Ruixuan and Rembrandt, and we are researchers from EMC. This interview is about a research project investigating PF patient disease management at home, and we aim to facilitate your disease management and improve the quality of life.

And that's why we designed a new home-monitoring system (a smartphone APP), and we have your feedback by using it, and it would be extremely valuable for us to hear your opinions.

[Recording & Consent form]:

The interview will be audio-recorded, And during the interview, would you allow us to take some pictures of you using the product (without having your face on it), and it will only be used internally within our project team to analyze the test results, not for any other purposes.

You can sign the consent form here! [Read the IC form to patients if he has difficulties reading it]

[Test procedure]:

The whole interview will take around 45min, and the structure of the tests has roughly 2 parts:

- we will start with some general questions;
- Then you will get some small tasks that you can perform in the app, and we will ask several questions after each task.

2. Pre-test interview [5min]

- Can you tell me about your experience with technology, such as smartphones, tablets, or computers? Are you comfortable using them?
- Have you heard of or used the IPF-Online app? If so, how do you feel about it?
- Are there any specific challenges or concerns you have when it comes to using technology or smart devices and healthcare APPs?
- Have you heard of chatbot or voice assistant, like Siri or Amazon Alexa?

3. Testing tasks [30min]

There are 2 small tasks in this test, and it is important to note that we are not testing the actual app but a prototype: a first version that represents the new design as well as possible, which means that not all functionalities are fully working. So don't worry if something may not work as expected! We are testing the prototype, not your skills in the use of it.

And there are no right or wrong comments! Any feedback is helpful for our process, so don't hesitate on what you want to say.

Now let's start the test! I will give you some scenario in disease management which may not be applicable for your case, but you can imagine the situation while doing the tasks.

TASK 1: Navigate to 'my progress' and check the health summary [5min]

[If the patient said he hasn't used the IPF-online before, explain how the spirometer works to him] "You have constantly been doing the self-lung-function tests in the past month, and today you want to view your status and progress, could you check the overview of your lung function in the App?"

[If he can't find it, helps him find it and continue with the test]

TASK 2: Navigate to eConsult and ask a question about the measurements [15min]

"Great! Now you see an overview of your lung function measurements in the past month [Explain that we're just simulating it not using his real data]. And let's take a look at it, **how do you think of this overview? (does he understand what it means)**

"Well, the AI also noticed that your lung function was fluctuating in the first half of May and in some days there are declines, while in the second half, it was quite stable. **What reason do you think causes the fluctuation?**"

[After patient answers] We can also try to find the reason by consulting the virtual assistant! You can now try to find the eConsult and ask about your concerns.

[Rae do the observation and see how the patient interact with chatbot]

[When Rae gives a hint that the participants already tried all the interactions with chatbot, Rembrandt can cut in and ask follow-up questions:]

- (1) About reliability:
 - What do you think of the accuracy and reliability of the information provided by the chatbot?
 - Did you feel that the answers provided by the chatbot were consistent with your practice or what you have learned from other reliable sources?
- (2) Explainability:
 - Did you use the further explanation function when talking with the chatbot?
 - Did the chatbot effectively explain the information and answers it provided to your questions?
 - Did the explanation help you to understand the answers provided by the chatbot?
- (3) Trustworthy:
 - Did you find the information provided by the chatbot to be trustworthy and credible?
 - What factors or features contributed to your perception of the chatbot as a trustworthy source of information?

5 min break for the patient, Rae & Rembrandt discuss next step

Appendix I: Patient validation session set up & questionnaire

TASK 3: Testing resource function

[If the patient is tired or time exceeds this part can leave out]

"Now let's go to the last task. Imagine you would like to stay informed about the latest news and developments in PF research. Try to use the resource function to browse through interesting news or summaries of articles."

[After patient completes it, ask follow-up questions]

- Do you find these resources useful for you to learn more about PF?
- Does the summary help you better understand the latest medical research?

Post-interview survey: evaluate the accessibility of the app

Now I'll give you a questionnaire that include some scale questions [Ask patient why they give certain high/low score in the scale questions]

Vragenlijst

1. Op een schaal van 1 tot 5, hoe gemakkelijk was het om door de verschillende secties en functies van de app te navigeren?
 - 1: Zeer moeilijk
 - 2: Moeilijk
 - 3: Neutraal
 - 4: Gemakkelijk
 - 5: Zeer gemakkelijk
2. Beoordeel alstublieft de duidelijkheid van de lay-out en het ontwerp van de app in het begeleiden van u om de gewenste informatie te vinden of taken uit te voeren.
 - 1: Onduidelijk
 - 2: Enigszins onduidelijk
 - 3: Neutraal
 - 4: Enigszins duidelijk
 - 5: Duidelijk
3. Hoe goed organiseerde en presenteerde de app informatie op een manier die gemakkelijk voor u te begrijpen was?
 - 1: Slecht georganiseerd en moeilijk te begrijpen
 - 2: Enigszins slecht georganiseerd en enigszins moeilijk te begrijpen
 - 3: Neutraal
 - 4: Goed georganiseerd en gemakkelijk te begrijpen
 - 5: Zeer goed georganiseerd en zeer gemakkelijk te begrijpen
4. In hoeverre droegen de lettergrootte, kleurcontrasten en algemene visuele presentatie van de app bij aan de toegankelijkheid voor u?
 - 1: Helemaal niet toegankelijk
 - 2: Enigszins ontoegankelijk
 - 3: Neutraal
 - 4: Enigszins toegankelijk
 - 5: Zeer toegankelijk
5. Hoe intuïtief was de interface van de app in het begeleiden van u om verschillende taken uit te voeren of functionaliteiten te gebruiken?
 - 1: Helemaal niet intuïtief
 - 2: Enigszins niet intuïtief
 - 3: Neutraal
 - 4: Enigszins intuïtief
 - 5: Zeer intuïtief