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

Appendices

David Quijada Fernández

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

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Appendix A

DESIGN FOR our future

*TU*Delft

IDE Master Graduation
Project team, Procedural checks and personal Project brief

This document contains the agreements made between student and supervisory team about the student's IDE Master Graduation Project. This document can also include the involvement of an external organisation, however, it does not cover any legal employment relationship that the student and the client (might) agree upon. Next to that, this document facilitates the required procedural checks. In this document:

- The student defines the team, what he/she is going to do/deliver and how that will come about.
- SSC E&SA (Shared Service Center, Education & Student Affairs) reports on the student's registration and study progress.
- IDE's Board of Examiners confirms if the student is allowed to start the Graduation Project.

USE ADOBE ACROBAT READER TO OPEN, EDIT AND SAVE THIS DOCUMENT
Download again and reopen in case you tried other software, such as Preview (Mac) or a webbrowser.

STUDENT DATA & MASTER PROGRAMME
Save this form according the format "IDE Master Graduation Project Brief_familyname_firstname_studentnumber_dd-mm-yyyy".
Complete all blue parts of the form and include the approved Project Brief in your Graduation Report as Appendix 1 !

family name	Quijada Fernández	6820
initials	D	given name David
student number	5391695	
street & no.		
zipcode & city		
country		
phone		
email		

Your master programme (only select the options that apply to you):
IDE master(s): ( ) IPD (★) Dfl ( ) SPD
2nd non-IDE master:
individual programme: _ _ - _ _ (give date of approval)
honours programme: (Honours Programme Master)
specialisation / annotation: (★ Medisign)
(Tech. in Sustainable Design)
(Entrepeneurship)

SUPERVISORY TEAM **
Fill in the required data for the supervisory team members. Please check the instructions on the right !

** chair	Prof. dr. ir. Goossens, R.H.M.	dept. / section:	HCD
** mentor	Dr. Jiwon Jung	dept. / section:	DOS
2nd mentor	Dr. Venktesh Viswanathan		
	organisation:	Web Information Systems, EWI, TU Delft	
	city:	country:	
comments (optional)			

Chair should request the IDE Board of Examiners for approval of a non-IDE mentor, including a motivation letter and c.v..

Second mentor only applies in case the assignment is hosted by an external organisation.

Ensure a heterogeneous team. In case you wish to include two team members from the same section, please explain why.
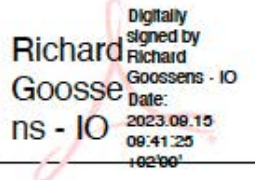
IDE TU Delft - E&SA Department /// Graduation project brief & study overview /// 2018-01 v30

Page 1 of 7

Procedural Checks - IDE Master Graduation

TUDelft

APPROVAL PROJECT BRIEF
To be filled in by the chair of the supervisory team.

chair   Prof. dr. ir. Goossens, R.H.M.   date   15 - 09 - 2023   signature _____

Richard Goossens - IO
Digitally signed by Richard Goossens - IO
Date: 2023.09.15 09:41:25 +02'00'

CHECK STUDY PROGRESS
To be filled in by the SSC E&SA (Shared Service Center, Education & Student Affairs), after approval of the project brief by the Chair.
The study progress will be checked for a 2nd time just before the green light meeting.

Master electives no. of EC accumulated in total: 42   EC

Of which, taking the conditional requirements
into account, can be part of the exam programme   30   EC

List of electives obtained before the third
semester without approval of the BoE

(★) YES   all 1st year master courses passed

( ) NO   missing 1st year master courses are:

name   Robin den Braber   date   19 - 09 - 2023   signature _____

Robin den Braber
Digitaal ondertekend door Robin den Braber
Datum: 2023.09.19 08:04:22 +02'00'

FORMAL APPROVAL GRADUATION PROJECT
To be filled in by the Board of Examiners of IDE TU Delft. Please check the supervisory team and study the parts of the brief marked **.
Next, please assess, (dis)approve and sign this Project Brief, by using the criteria below.

- Does the project fit within the (MSc)-programme of the student (taking into account, if described, the activities done next to the obligatory MSc specific courses)?
- Is the level of the project challenging enough for a MSc IDE graduating student?
- Is the project expected to be doable within 100 working days/20 weeks ?
- Does the composition of the supervisory team comply with the regulations and fit the assignment ?

Content: (★) APPROVED   ( ) NOT APPROVED

Procedure: (★) APPROVED   ( ) NOT APPROVED

- also approved for Medisign

comments

name   Monique von Morgen   date   03 - 10 - 2023   signature _____

Monique von Morgen
Digitally signed by Monique von Morgen
Date: 2023.10.03 11:34:17 +02'00'

Personal Project Brief - IDE Master Graduation

TUDelft

Mapping collective needs for remote patient monitoring service-systems   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   29 - 08 - 2023   15 - 03 - 2024   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, ...).

This graduation project builds upon the previous efforts of three Master's graduation students who created detailed patient journey maps as part of their thesis project (Kicken, H., 2023; Sun, Y., 2023; Zhang, R., 2023). These maps were developed using data gathered from 3 patient communities: colorectal cancer, pulmonary fibrosis (see Figure 1) and sarcoidosis patients. They represent the experiences and perspectives of a diverse group of patients who were undergoing the diagnosis, treatment and post-treatment process of the same condition. The main objective of this project is to identify shared patterns and similarities among the patient journeys of these 3 diseases and extrapolate collective needs that can be used for creating a service proposition for remote patient monitoring system. To achieve this, the project will employ a combination of three approaches: computational analysis, literature review, and design research. The collective needs will represent the common requirements for the 3 diseases and provide valuable guidance for the development of a unified remote patient monitoring system and its transversality could be evaluated in different hospital departments and medical conditions.

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

Nevertheless, health digitalization also accounts for constraints and issues. Privacy regulations are some of the main concerns (Manteghinejad et al. 2021). User consent and transparency of the collected data should be fundamental to ensure innovations that respect citizens' rights and needs for privacy, safety and autonomy (Vayena et al. 2013). Another matter requiring attention is data governance. Governments should protect the data and implement policies that ensure eHealth is safe and held to a standard (World Health Organization, 2017).

Due to the growing demand for care, it is even more imperative that health innovations contribute to meaningful caregiving (Gupta Strategists, 2021). When providing a highly-demanded service such as healthcare the employees' well-being is sometimes overlooked. Workers' happiness and self-development are critical to the quality of their work and, ultimately, how users perceive the service. To align with the Quadruple Aim, health innovations should contribute to some extent or not be detrimental to healthcare professionals' efficiency and well-being at the workplace (Sikka et al. 2015). Health innovations should ultimately contribute to the experience of delivering care. However, capitalistic service design is currently focused on hiding the work of professionals (van Amstel, F., 2023). Within the current service design framework, how can we involve practitioners and patients in transparent and secure data-centric services that contribute to practitioners' wellbeing and sense of meaning in their work?

space available for images / figures on next page
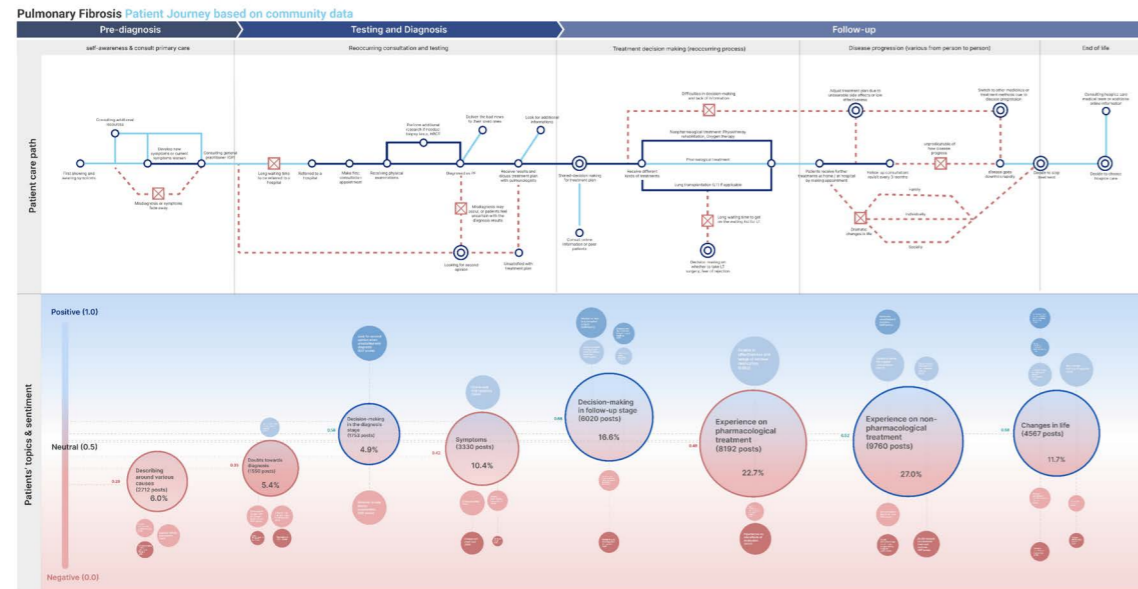
introduction (continued): space for images

Pulmonary Fibrosis Patient Journey based on community data

image / figure 1:   Example of previous outcomes - Master's thesis by Ruixuan Zhang

image / figure 2:

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.

The demand for care has been rapidly increasing in the last decades and it will keep growing to the extent that access to healthcare will be hindered. By 2040, 1 in 4 workers will have to be employed in the healthcare system to meet the demand (Gupta Strategists, 2021). During the COVID-19 pandemic, we could already observe that the number of intensivists and ICU professionals limited the efficacy of hospitals to attend the wave of people with the disease (Gupta Strategists, 2021). Therefore, focusing on innovations that enhance the productivity and efficiency of healthcare professionals should become a top priority.

We already observe developments towards remote patient monitoring systems so that hospitals can provide more home-based care (Gupta Strategists, 2017). These developments are mainly motivated by the potential financial advantages, the improvements in the patient's quality of life and increased efficiency in the practitioners' routines, as patients would perform medical tasks at home by themselves with limited involvement from healthcare professionals (e.g., hemodialysis). The ErasmusMC has been working on several projects with Master's graduation students from TU Delft that address the topic of patient monitoring systems. For my graduation project, we picked the context of three of those graduation projects, for which detailed patient journey maps have already been developed based on patient community data (Kicken, H., 2023; Sun, Y., 2023; Zhang, R., 2023).

Nevertheless, the development of a remote patient monitoring system comes with obstacles and limitations. Acquiring the necessary funding required to develop these systems can be compromised if it will only be applied to one specific disease or medical condition. Moreover, to move care to patients' homes, many stakeholders need to align to responsibly redesign patient journeys. The patient journey cannot directly be translated to the home environment. Therefore, healthcare professionals, engineers and data scientists and designers should come together to reimagine these care journeys.

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.

The project aims to develop a service concept proposition and strategic roadmap on how ErasmusMC can develop a remote patient monitoring system for the follow-up stage of different diseases.

The final design outcome will be a combination of a visualization of the service concept and a roadmap. The project aims to understand the fundamental needs for a remote patient monitoring service system (RPMSS) in the follow-up stage that ultimately benefits efficiency, workforce satisfaction, patients' quality of treatment. The final deliverables should visualize the core service and supporting services of RPMSS for CRC, PF and Sarcoidosis follow-up stage and how the ErasmucMc should work towards it.

1) Service concept visualization: A diagram of the service package or offering. This will illustrate the primary and secondary needs for both users (practitioners and patients) and how they are translated into core and supporting services.

2) A strategic roadmap on how ErasmusMC could develop the service in the coming years which is visualized through a design roadmap.

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.

start date 29 - 8 - 2023   15 - 3 - 2024 end date
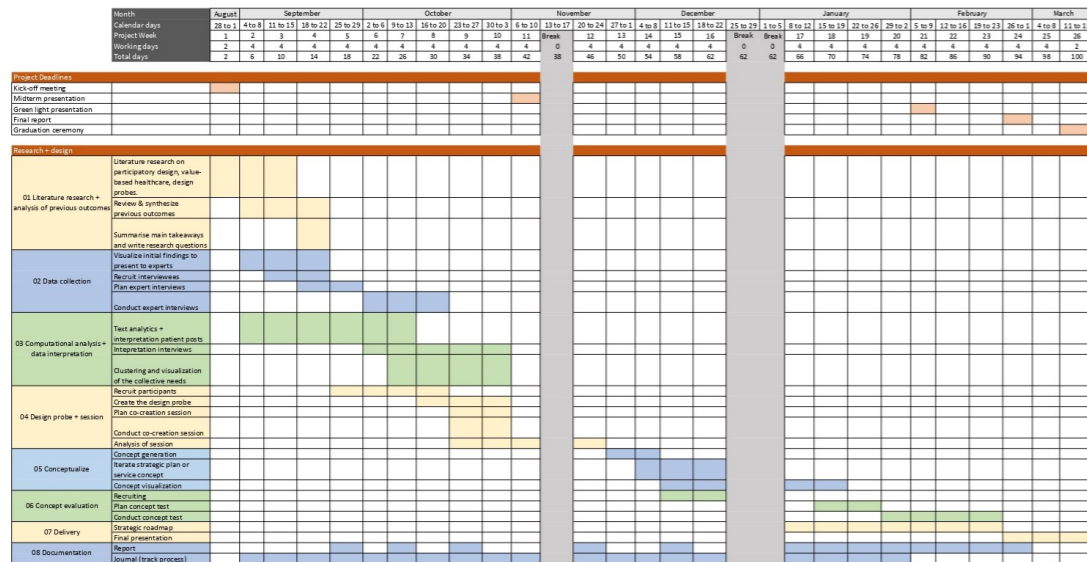
Kickoff: 29/08/2023   Midterm: 07/11/2023   Green light: 07/02/2024   Graduation: 15/03/2024

Phase 1: LITERATURE RESEARCH + ANALYSIS OF PREVIOUS OUTCOMES: The aim is to investigate how to apply value-based healthcare, health psychology frameworks, participatory design and design probes in my project and extract research questions for my graduation project. In this stage, the goal is to throughly review the outcomes from the previous graduation projects and synthesize their work by comparing the datasets from the 3 conditions and their clusters.
Phase 2: DATA COLLECTION: To enrich the data from online patient communities through interviews with physicians and other healthcare experts.
Phase 3: COMPUTATIONAL ANALYSIS + DATA INTERPRETATION: To analyse the main commonalities and patterns in the patient community data and extract clusters that represent collective needs for the three diseases. The main insights will be translated into communicative visuals that can be used for interviews and co-creation sessions.
Phase 4: DESIGN PROBE + SESSION: The objective is to plan a co-creation session for a diverse group of stakeholders. A design probe will be created to support the discussion and reflection.
Phase 5: CONCEPTUALIZATION: To develop a concept of a service that would satisfy the collective needs from the computational analysis.
Phase 6: CONCEPT EVALUATION: To evaluate the service concept with practitioners and other relevant experts in ErasmusMC and extract future recommendations and insights for the strategic roadmap.
Phase 7: DELIVERY: The objective is to prepare a strategic roadmap for future developments and the final presentation of the graduation project.
Phase 8: DOCUMENTATION: Includes the final report and all the materials such as images, blueprints and infographics.

Initials & Name   D   Quijada Fernández   6820   Student number 5391695
Title of Project   Mapping collective needs for remote patient monitoring service-systems

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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.

My personal goal as a designer is to develop context-sensitive tools and services that foster more efficient processes within healthcare systems. In my academic journey at TU Delft, I undertook several electives that have shaped my understanding and passion for creating positive changes in healthcare systems. Through the elective Contextmapping Skills, I delved into the art of immersing oneself in a given context with compassion and empathy. This course allowed me to improve my skills to capture users' considerations, behaviours, and unexpressed needs in a way that could inspire innovative solutions.

The elective Health Psychology sparked my interest in exploring well-being theory and behavioural science. Using theoretical frameworks to map psychological factors and inspire interventions that stimulate positive behaviour change.

In the elective Health Systems Transformation I learned to develop strategic roadmaps to visualize the seamless integration of interaction and service concepts within an organization. This understanding encouraged me to think beyond isolated interventions and aim for comprehensive improvements in healthcare systems.

Armed with the knowledge and skills gained from my Master's coursework in Design for Interaction, I would like to ensure that the tools and services I design are finely attuned to the needs and aspirations of the stakeholders, whether they are healthcare professionals or patients. Furthermore, I would like to expand my knowledge towards service design, strategic design and data technologies. As healthcare is essentially a service, I want to analyse where and how to appropriately redesign interactions that contribute towards more efficient, accessible, and compassionate healthcare systems.

FINAL COMMENTS

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

Initials & Name   D   Quijada Fernández   6820   Student number 5391695
Title of Project   Mapping collective needs for remote patient monitoring service-systems

Appendix B

Date 13-Dec-2023
Contact person Grace van Arkel, Policy Advisor
Academic Integrity
E-mail E.G.vanArkel@tudelft.nl

TUDelft Delft University of Technology

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

Ethics Approval Application: Mapping collective needs for unified remote patient monitoring system for Colorectal Cancer, Pulmonary Fibrosis and Sarcoidosis
Applicant: Quijada Fernández, David

Dear David Quijada Fernández,

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

Thanks very much for your submission to the HREC which has been approved.

In addition to any specific conditions or notes, the HREC provides the following standard advice to all applicants:
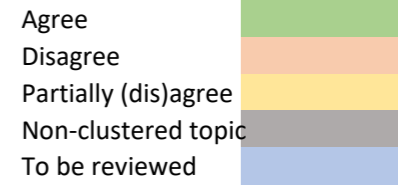• In light of recent tax changes, we advise that you confirm any proposed remuneration of research subjects with your faculty contract manager before going ahead.
• Please make sure when you carry out your research that you confirm contemporary covid protocols with your faculty HSE advisor, and that 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

Column1		
pf_topic,sarc_topic,score		
39,1,0.17601585	Agree	
13,2,0.1662979	Disagree	
4,7,0.21231548	Partially (dis)agree	
83,2,0.2527177	Non-clustered topic	
9,12,0.1284265	To be reviewed	
6,2,0.2974328		
84,13,0.16147228		
24,13,0.17268117		
23,2,0.31367165		
61,13,0.15232457		
0,3,0.119628794		
44,6,0.075582705		
16,8,0.22200014		
11,28,0.21055669		
5,2,0.2944584		
95,2,0.2655714		
21,7,0.25311637	Dealing with symptoms with unclear cause	
82,1,0.09329488		
34,13,0.12830134		
29,8,0.16239052		
86,13,0.11653628		
98,7,0.22138484		
52,8,0.25210595	Recommending where to get more specialised help and more	
71,30,0.1446088	Sleeping difficulties	
27,17,0.16900724	Financial assistance when unable to work (ARBO)	
91,10,0.21125679	Discussing whether to keep or stop working	
20,8,0.2166663	20 is monitoring and measure progression of disease, 8 is diag	
33,8,0.19504249	33 is sharing offline support groups and 8 is doubting on diagr	
68,6,0.109962754		
46,30,0.2073635	Sleeping difficulties	
2,3,0.22164562	Is thalidomide and metformine conventional treatment for PF	
12,2,0.3535269	Literally sometimes discussing the same drug (prednisone)	
57,7,0.13475505	Discussing symptoms with unclear cause and treatment meth	
31,18,0.22709712		
1,8,0.21936125	1 is about transplant procedure and 8 is unsatisfaction with d	
60,13,0.15422198		
18,2,0.23994812		
78,3,0.2449986	78 is about navigating the pessimistic diagnosis and 3 is about	
15,8,0.18303555	15 is talking about scam method and 8 is about complex diagr	
87,8,0.23404805	87 is about the influence of COVID in patients life and 8 is abo	
32,19,0.10326431		
7,3,0.1807298	7 is about financial assistance and 3 is about drug treatment (I	
56,2,0.21020019	56 is about a specific side effect of PF drug treatment and 2 is	
35,8,0.20245802	35 is about a possible cause of PF and 8 is about complex diag	
37,8,0.28170148		
28,8,0.22582965		
40,8,0.2566081	Complex diagnostics	
96,6,0.10868336		

Appendix C

Code	Color	Description
38,15,0.14381248	Disagree	
81,30,0.27092642	Disagree	Sleep-related symptoms
80,13,0.10674065	Non-clustered	
92,24,0.13206594	Disagree	
17,8,0.2589345	Agree	
59,7,0.16473475	Disagree	59 is about participating in choirs and singing, 7 is about uncle
79,8,0.25493532	Partially	
14,7,0.22937316	Agree	dealing with symptoms
54,2,0.24693152		prescribed meds
25,8,0.17726913	Disagree	25 is about palliative care and 8 is about complex diagnosis of
88,13,0.12389838	Non-clustered	
19,2,0.17393726	Partially	19 is about coughing as a symptom and 2 is about treatment r
67,8,0.19224493	Disagree	67 is about deciding to quit smoking after diagnosis and 8 is al
26,31,0.2221964	Agree	vaccinations
10,8,0.20837094	Agree	specialised doctors and clinics for complete diagnosis
8,8,0.2730247	Agree	Diagnosis
30,29,0.2104507	Disagree	30 is brathing exercise to deal with symptoms and 29 is about
75,2,0.15674038	Partially	
47,2,0.21739379	Partially	Side effects of medication
42,19,0.078069724	Non-clustered	
58,19,0.07265723	Non-clustered	
97,13,0.1397251		
65,29,0.09879225	Agree	
69,2,0.25456598	Disagree	
85,2,0.22259606	Partially	
41,13,0.22947447	Non-clustered	
51,8,0.22952788	Disagree	
3,13,0.17002527		
99,13,0.1494424		
43,8,0.2694344	Partially	
50,2,0.28581005	Agree	
22,2,0.2628766	Disagree	
66,2,0.26447853	Agree	
90,15,0.21152586		
64,8,0.10025549	Disagree	64 describes giving up on pets and plants because of IPF symp
36,8,0.19435899		
93,2,0.32038993	Agree	
49,1,0.15550414		
55,6,0.09717073	Non-clustered	
89,8,0.21936256	Non-clustered	
45,4,0.22179022	Agree	Talking about causes and possibility of disease as hereditary c
76,8,0.2631608	Agree	Discussing causes and debating whether the diagnosis is comp
63,30,0.10979658		
62,1,0.13392684		
73,8,0.21686378	Disagree	
77,3,0.17805304		
74,8,0.23378669	Disagree	One if about diagnosis of Nonspecific Interstitial Pneumonitis
72,7,0.17296661		
94,24,0.21032012		
70,8,0.13829695		

Appendix C

Column1	Color	Description
sarc_topic,crc_topic,score		
8,8,0.23509279	Agree	
2,33,0.26815212		
13,47,0.12780552	Non-clustered	
1,35,0.13374293	Partially	
13,19,0.12596714		
13,16,0.17156309	Non-clustered	
13,5,0.16883208		
13,26,0.16260001		
28,17,0.16635156	Agree	
7,27,0.18401365	Partially	
8,49,0.19372922	Agree	
1,37,0.1276098	Disagree	
8,39,0.2007802	Agree	
8,45,0.18538497		
0,24,0.18206061	Agree	
0,0,0.14737192	Agree	Both talk about adjusting to life with the disease
15,36,0.16948122	Disagree	
13,4,0.16187625	Non-clustered	
3,14,0.14543332		
8,43,0.16083291		
13,44,0.1669587	Non-clustered	
13,2,0.17888026		
1,13,0.15830728		
0,46,0.15745349	Agree	Reflecting on life with the disease
2,30,0.16515148	Partially	
13,6,0.1727945		
13,10,0.16627741		
13,48,0.15423071		
1,3,0.17132458	Agree	Talking about money and financial concerns
17,38,0.13218081		
13,12,0.17760174		
2,42,0.23641212	Partially	
7,32,0.2230514	Agree	Experience with side effects
13,7,0.19982545	Non-clustered	
13,29,0.14471899		
13,40,0.13920903		
13,1,0.19407125	Agree	
13,11,0.14530423	Partially	
8,9,0.17248575		
13,41,0.15299363	Agree	
8,25,0.16645196	Disagree	
1,31,0.15992318	Agree	
13,15,0.1464979		
8,18,0.17242281		
2,22,0.18292129	Partially	
2,21,0.16571541		
13,20,0.18389486	Agree	
13,28,0.14654282	Disagree	

Legend	Color
Agree	Green
Disagree	Orange
Partially (dis)agree	Yellow
Non-clustered topic	Grey
To be reviewed	Blue

Appendix C

Column1
pf_topic,crc_topic,score
39,3,0.29526743
13,33,0.17279574
4,42,0.20087585
83,33,0.22115107
9,31,0.11034096
6,33,0.26540568
84,1,0.23542304
24,1,0.30759278
23,33,0.26598123
61,1,0.21635753
0,45,0.10093721
44,4,0.0686613
16,8,0.19682111
11,17,0.17127304
5,33,0.26449794
95,33,0.24331386
21,32,0.2118947
82,5,0.11849393
34,4,0.19173521
29,33,0.1584219
86,1,0.16686663
98,2,0.4083882
52,8,0.24945892
71,34,0.10050145
27,38,0.16450304
91,36,0.2040763
20,8,0.1705201
33,36,0.20873621
68,1,0.15403277
46,42,0.16678455
2,33,0.23094533
12,33,0.26018566
57,42,0.1271387
31,36,0.30024546
1,8,0.25782812
60,1,0.2273595
18,33,0.24157882
78,33,0.26253146
15,30,0.21067165
87,8,0.21118562
32,19,0.13580674
7,38,0.17327616
56,33,0.18619455

Legend:

Agree	(green)
Disagree	(orange)
Partially (dis)agree	(yellow)
Non-clustered topic	(grey)
To be reviewed	(blue)

38,49,0.123527706
81,42,0.19405891
80,1,0.14188959
92,22,0.11155679
17,8,0.26776335
59,2,0.14755285
79,8,0.26589262
14,8,0.22978087
54,33,0.22175147
25,2,0.31030285
88,3,0.1818828
19,42,0.17563489
67,8,0.18822901
26,33,0.20160028
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8,8,0.32425305247306824
30,23,0.1745545119047165
75,37,0.1649719625711441
47,33,0.18610532581806183
42,31,0.11390194296836853
58,19,0.09542927891016006
97,3,0.2026723027229309
65,38,0.09500981122255325
69,33,0.2527095377445221
85,42,0.21221964061260223
41,7,0.38540077209472656
51,2,0.3635491132736206
3,2,0.41317564249038696
99,1,0.224405557334423065
43,8,0.25342127680778503
50,33,0.26422029733657837
22,33,0.23951250314712524
66,33,0.2687309980392456
90,7,0.298749715089798
64,2,0.1629992574453354
36,33,0.1811268925666809
93,33,0.2814306318759918
49,3,0.2158782184123993
55,19,0.10545652359724045
89,7,0.2534100115299225
45,8,0.2079896479845047
76,8,0.27096956968307495
63,22,0.13155628740787506
62,3,0.16328538954257965
73,8,0.2520168423652649
77,8,0.20374678075313568
74,8,0.22482086718082428
72,32,0.16860847175121307
94,8,0.13884180784225464
70,36,0.1704842895269394

Appendix D

Main category			PF Topic No.	PF Topics	Number of topics	Percentage	Sarco Topic No.	Sarco Topics	Number of topics	Percentage	CRC Topic No.	CRC Topics	Number of topics	Percentage	Legend
Sharing experiences on the medical treatment to improve health status or alleviate symptoms (treatment)	Pharmacological treatment		5 & 66 & 93 & 95	Sharing information on taking esbriet (pirfenidone), effectiveness and purpose of the med, weighing side effects and quality of life.	1605	5481	2	Describing the progression of the drug treatment plan: side effects, dosage, reimbursement of medication (prednisolone, prednisone, ritalin, modafinil, etc.)	262	1593	33 *	Sharing regimen, effectiveness and side effects of drugs (folfox, oxaliplatin, avastin, and irinotecan) and natural supports to complement the drug treatment (chemotherapy)	8768	8768	Unsure about topic categorisation
			6 & 23	Sharing experiences on taking ofev and purpose: weighing side effects and quality of life.	1664	12,7426592	3	Sharing their progress, treatment plan and symptoms with Remicade (Infliximab)	241	25,91086532					4,124506663	Topic with disconnected posts
			12	Discussing the dosage of use and side effects of Prednisone.	744		9	Weighing pros and cons of Prednisone, dosage and side effects, doubts about this drug	195							
			53	Sharing side effects from taking statins (cholesterol-lowering drugs)	222		5 & 39	Describing the progress of symptoms and side effects with the prescribed medication (prednisolone, Qvar, Methotrexate) and methods to alleviate their side effects	392							
			26	Understanding which vaccinations to take in relation to treatment and their health condition, frequency and purpose.	492		21	Describing side effects of medication and discussing different drugs to deal with symptoms, weighing side effects and benefitial outcomes (biologicala, prednisone, etc.)	164							
			50	Sharing experiences with cellcept (med to prevent organ rejection following tranplant surgery)	234		31	Mainly discussing about flu vaccinations	179							
			54	Sharing views on dealing with infections and describing experiences with doxycycline (antibiotic med)	220		11	Discussing whether to consume certain vitamin supplements and the correlation between B12 defficiency and Sarco	160							
			69	Understanding purpose and dosage of morphine, and sharing side effects and attitudes towards using it in hospice care.	175											
			83	Discussing benefits and dosage of vitamin supplements with PF and dealing with vitamin deficiency	125											
	Alternative therapies		2	Seeking/enabling clarity about drugs which are not generally prescribed for IPF to avoid scams and harmful side effects (metformine, thalidomide, or senolytic drugs like dasatanib & quercetine)	2671	5462	14	Sharing progress and experiences with the Marshall protocol	144	144	30	Sharing research about alternative therapy options from websites and articles, making a judgement on options.	7854	22809	
			18	Taking enzyme supplements (e.g., serrapeptase), discussing effectiveness to break up scar tissue and improve health status	683	12,6984865				2,342225114	21	Sharing experiences and recommendations for supplements and medication.	2854	10,72945626	
			15	Doubting on the effectiveness of stem cell therapy to treat PF and warning that it seems a scam	699						14	Sharing experiences on using Traditional Chinese Medicine to manage health.	3610		
			22	Discussing antioxidant NAC (N-acetylcysteine) and curcumin supplements to prevent lung damage in people with idiopathic pulmonary fibrosis.	545						48	Sharing information about and holding a positive attitude towards clinical trials of new treatment methods	3732		
			13	Discussing the benefits of CBD oil and THC for various symptom management and emolient cream for dry skin. Disconnected: debating about Vicks as a controversial cause of IPF.	706						10	Debating on alternative methods and conventional western medicine, sharing reflections on the treatment pathway followed and its outcomes	4759		
			73	Debating about laser therapy and warning about lack of proof and research	158										
	Interventional treatment		77	Sheding light on post-transplant care: fear of organ rejection after surgery; worry about high costs of anti-rejection medicines and wether insurance will cover it.	132	4372					25	Sharing experience around RFA (Radiofrequency ablation) for the liver.	4979	14253	
			1	Exchanging experiences/knowledge for better decision-making around transplant procedure, post-transplant life and care.	4240	10,16436891					23	Sharing experiences about resection in liver and lung and the complications happening	4561	6,70467535	
											45	Discussing experiences and preparations to receive a port catheter (Port-A-Cath)	4713		
	Assisted living therapies		0	Sharing knowledge and doubts about (portable) oxygen concentrators and related equipment. Community resourcefulness around oxygen therapy.	5414	6707									
			29	Doubts about oxygen therapy regimen: tracing oxygen saturation, when oxygen is needed. Individual differences on patients experiences and knowledge gap with doctors.	434	15,59296027									
			38	Choosing an oximeter to get accurate readings	335										
			25	Dealing with end of life in a more dignified and comfortable way through palliative and hospice care (relief from symptoms and optimizing QoL)	524										
				Total Cluster 1	22022	51,19847488			1737	28,25309044			45830	21,55863827	
Work capacity and personal finances	Allowance		7	Discussing financial assistance, the choice of health insurance and the extent of coverage	1037	1620				371	38	Confusion about insurance coverage	7912	7912	
			27	Allowance from government: Supplemental Security Income (US)	470	3,766303211				6,034482759				3,721840411	
	Professional career		91	Weighing whether to keep working or stop working: Keep 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	Sharing experiences on managing professional career with Sarcoidosis and dealing with occupational doctors/ARBO services, wishing more recognition and visibility	196						
							17	Communicating with occupational doctors, complaining about ARBO reports and decisions not representing how they feel and dealing with possible loss of job.	175						
Self-management of specific symptoms/side	Pain and discomfort (side effect)		56	Dealing with oral thrush as a side effect of medication	219	6747				1337	32	Experiencing pain and numbness due to nerve damage in various body parts of the body	6275	34570	
	Sleep and rest		46 & 71	Sharing coping strategies to improve sleep and avoid morning headaches and feeling unrested: sleep study, overnight oximetry, wedge pillow, adjustable bed.	414	15,68595541	30	Describing sleep difficulties and how Sarcoidosis symptoms affect sleep. Sharing coping methods to improve sleep.	150	21,74690956				16,26188359	
	Sleep and rest		81	Describing feeling sleepy and sleep apnea/insomnia as a symptom/side effect. Coping strategies: taking melatonin/ambien	130						22	Discussing and sharing tips on how to take care of stoma and avoid infections.	8418		
	Fatigue						26	Dealing with fatigue, shortness of breath, coughing and sensitivity to smokes and environment, being afraid of feeling too tired	156						
	Environment		57	Becoming sensitive to scents such as artificial fragrances; Doubt of hydrogen peroxide as a treatment method?	218										
	Pain and discomfort		4 & 19	Finding methods and meds to alleviate the coughs	1866		7 & 33	Describing symptoms and physical complaints, whose cause is sometimes unclear and unconnected to each other.	365		34	Feeling uncomfortable due to the intestinal blockage	6414		
	Pain and discomfort		14	Dealing with stomach-reflux and heartburn: medication (omerprazole), keep strict diet, sleep on the bed with angle	704		38	Dealing with symptoms and complaints in the lungs	154		42	Sharing their experience on managing the side effects of treatment: drinking water, taking medications, and getting plenty of rest.	8341		
	Pain and discomfort		21	Dealing with cramps. Coping with chest irritation, rib cage pain and shortness of breath, especially while wearing bras or seatbelts.	598		18	Describing complaints and asking for experiences around symptoms with unclear cause and cure (joint pain, struggle to swallow, fatigue, mood swings, etc.)							

Main category			PF Topic No.	PF Topics	Number of topics	Percentage	Sarco Topic No.	Sarco Topics	Number of topics	Percentage	CRC Topic No.	CRC Topics	Number of topics	Percentage	Legend
	specific symptoms/ side effects			Sharing information on taking esbriet (pirfenidone), effectiveness				Describing the progression of the drug treatment plan: side				Sharing regimen, effectivenss and side effects of drugs (folfox,			
		Pain and discomfort	72	Sharing doubts about clubbing fingers: symptom of disease that usually happens because of chronically low blood levels of oxygen	162		34	Discussing effective symptom relief through different medications and their side effects	179						
		Hair loss (side effect)	75	Discussing hair loss due to unclear causes, possibly due to medication.	155						37	Sharing negative feelings of hair loss due to cancer treatments.	5122		
		Environment	47	Describing being sensitive to sun as side effect of medication. Sharing coping strategies to deal with it: wearing sun screen, stay away from beach	244										
		Environment	9	Addressing climate conditions and home environment to boost quality of life and breathability.	850		37	Dealing with feet and joint discomfort and clothing types (e.g., numbness and swelling and wearing socks)	165						
		Symptom relief	30 & 68	Breathing exercise, Physical exercises are experienced as beneficial for improving symptoms; Pulmonary rehabilitatation is perceived as challenging but also helpful	614										
Describing the impact of the disease on life		Pain and discomfort	94	Wearing glasses is uncomfortable when using oxygen tank; so there are special glasses designed for people who need supplemental oxygen. Also discussing eye conditions and IPF: dealing with cataracts operations and addressing the possibility of retina tearing.	107		24	Understand how Sarco manifests itself in the eyes and dealing with the symptoms (black spots, low tear fluid…)	168						
		Mental/discomfort	36	Discussing frustration of using an oxygen tank; expressing the shame and embarrassment of using it in public	345										
		Mental	85	Anxiety, depression, panic attack; Unclear cause, probably due to side effects of medication.	121										
		Diet/weight	11	Improve/refine diet to compensate loss of appetite and weight; maintain BMI (weight) in the required range	808	1599	28	Recommending dietary changes/recipes or quitting certain foods to prevent or stop symptoms (anti-inflammatory foods, red meat, sugar)	163	536	17	Sharing suggestions on diets focused on balanced meals and healthy alternatives	9910	15370	
		Weight				3,717480762	12	Sharing experiences and struggles to control weight and stay lean	191	8,718282368				7,230117178	
		Sports & weight					29	Finding their way to exercise and practice sports with Sarcoidosis, and understanding how to exercise in a sensible manner to not worsen the symptoms	182		35	Sharing experiences and tips on how to deal with daily activities in the follow-up phase in a healthier way (exercise, meditation, bowel movements at work).	5460		
	Lifestyle adaptations (e.g, diet, exercise, etc.)	Habits	67	Decide to quit smoking after diagnosis	188										
		Habits	64	Giving up on keeping pets/plants; unwillingness to be separated from their pets	200										
		Self-care	63	Taking shower with oxygen device is difficult; Coping strategy: using cannula and long oxygen tubes in the shower	204										
		Mobility	65	Discussing daily mobility with PF: using wheelchairs and mobility scooters	199										
			87 & 92	Describing the influence of COVID-19 on their social life: fear of meeting with people; reduced opportunies of going out, meeting families and friends.	230	1011	1	Staying active and spending time outside, dealing with the weather changes and the disease, enjoying the little things in life	245	245	40	Talking about family members' emotional struggle about having a cancer patient in their family	4798	33114	
			49	Organising DIY activities and trip to stay active	239	2,350452189				3,985035784	13	Arguing the importance to spend moments with family members during the cancer journey	6071	15,57697464	
	Social relationships		59	Singing or participating in choirs is difficult, but it brings people joy and calming; positive attitude	214						28	Sharing changes in their family relationship due to cancer journey(both positive and negative)	3189		
											47	Experience on relationships with friends while having cancer	4062		
											31	Sharing ways to stay in a positive mood through planning for a fun weekend, such as a vacation, trip, party, movie or game night	6949		
			39	Wishing blissful celebrations	328						3	Celebrating anniversary and birthday for patients as a big milestone of their lives	8045		
			31	Finding empathy and understanding among peers who are navigating this unpredictable disease, keeping hopes up and fighting loneliness	412	412	0	Trying to find balance in life with Sarcoidosis, dealing with the uncertainty of the disease and trying to accept the living conditions and process.	210	363	0	Difficulties to adjust and adapt to their lives with colorectal cancer.	6332	30001	
						0,957849952	35	Reporting on overall health condition (symptoms, blood test results, etc) and their outlook on the disease	153	5,904359141	20	Staying positive and making life adjustments to their cancer circumstances during the recovery phase	3622	14,11260543	
	Attitude towards living with disease										46	Sharing their positive philosophical thoughts about living with cancer (e.g. taking care of the quality of life, being more resilient in the face of fear and death, and the power of living in the present moment for a more fulfilling life.)	5451		
											41	Sharing how patients can be resilient and positive: always stay strong, laugh and humor, never give up, and be a hero.	4449		
											24	Battling feeling exhausted and weak while sharing hope to feel better and stronger.	4520		
											11	Survivors sharing their attitudes towards living with cancer along with survival rate	5627		
				Total Cluster 2	11389	26,47804152			2852	46,38906962			120967	56,90342125	
			24	Expressing encouragement and hope among peers. Wishing for happiness, positive news and a longer life.	535	3080	13	Sharing state of mind in relation to disease and treatment, expressing a desire to feel better	192	192	7	Expressing happiness for patient peers going back home after surgery and wishing each other to recover quickly	5486	5486	
Expressing compassion and encouragement among peers (emotional support)			99	Sharing encouragement and celebrating while waiting for lung transplant surgery	103	7,160625857				3,122966818				2,580639092	
			33	Sharing offline support group, webinars, and discussing lack of support and attention from national fund	380						36	Expressing mutual support and understanding among community members towards recently diagnosed patients			
			3 & 51	Expressing compassion and support after the loss of loved ones. Honouring the bereaved.	2062										
			40	Talking about the unclear origins of IPF and elusive nature of disease	319	449	8	Describing the complex and confusing diagnosis of Sarcoidosis, doubting on how to demonstrate Sarcoidosis	225	626					
	Doubts on diagnosis and nature of the disease		78	Struggling to accept the discouraging diagnosis, managing expectations on the unpredictable progression of health status	130	1,043870458	6	Asking for knowledge bases and information on the disease	228	10,18217306					
							27	Sharing information on the tests to determine sarcoidosis and other related conditions	173						

Main category			PF Topic No.	PF Topics	Number of topics	Percentage	Sarco Topic No.	Sarco Topics	Number of topics	Percentage	CRC Topic No.	CRC Topics	Number of topics	Percentage	Legend
			5 & 66 & 93 & 95	Sharing information on taking esbriet (pirfenidone), effectiveness and purpose of the med, weighing side effects and quality of life.	1605	5481	2	Describing the progression of the drug treatment plan: side effects, dosage, reimbursement of medication (prednisolone, prednisone, ritalin, modafinil, etc.)	262	1593	33 *	Sharing regimen, effectivenss and side effects of drugs (folfox, oxaliplatin, avastin, and irinotecan) and natural supports to complement the drug treatment (chemotherapy)	8768	8768	Unsure about topic categorisation
Trying to understand the disease: causes, stage and connected conditions (disease analysis & understanding)	Doubts on monitoring and medical opinion		8	Asking for second opinions and experiences on lung biopsy. Expressing concerns and doubts on the need for biopsy.	916	2931					8	Being worried and confused about scan results in the liver, lungs, and lymph	13560	35027	
			20	Discussing how to properly measure progression of disease and the meaning of each lung function test (difusse capacity, forced vital capacity, fev1)	614	6,814218957					9	Discussing the results from diagnostics (tests and scans) and its relation to treatment plan options, sharing indications of satisfaction level with chosen treatment option	3210	16,47685845	
			10	Recommending where to find the right expertise, redirecting to medical professionals.	837						39	Sharing doubts about treatment opinions from medical professionals	5043		
			52	Recommending to hear different opinion on the disease and consult specialised centers for pulmonary diseases	224						15	Sharing negative emotions and experiences to live with colorectal cancer: overwhelmed, confused and scared, especially for the tests and screenings.	3873		
			37	Recommending specialised doctors and clinics	340						18	Sharing their outcomes (clear or not) from scanning and caring about how frequently they scan	4293		
											49	Describing a stressful experience in a blood test; worry about the numbers in the result	5048		
	Causes of the disease and related conditions	Environmental factor	16	Discussing sources of allergens (e.g., mold, hot tubs, chicken feathers) that can worsen the condition of people with lung scarring and result in Chronic Hypersensitivity Pneumonitis (CHP)	698	3142									
		Defficiency				7,304768326	11 *	Discussing whether to consume certain vitamin supplements and the correlation between B12 defficiency and Sarco	160	741					
		Condition	28	Clarifying origin and effects of pulmonary hypertension and recommending meds and coping methods to deal with it	443					12,05270007					
		Disease	79	Scleroderma related PF; Doubts about lung transplant for these patients	130		15	Discussing nerve disorders related to DVN (Thin fibre neuropathy), complaints, test and diagnosis, experimental studies	211						
		Disease	43	Rheumatoid arthritis (RA) caused complication of PF	273										
		Disease	74	Discussing Nonspecific Interstitial Pneumonitis (NSIP): diagnosis, living with NSIP and IPF	158										
		Causes	35	Debating on agent orange (chemical herbicide used in US military) being a direct cause for IPF in US military veterans	351		4	Understanding what causes the symptoms of Sarcoidosis, and detection of other health conditions that affect general health	200						
		Causes	45	Causes: family pulmonary fibrosis, tests and doubts towards it	256		25	Searching for causes and triggers of the disease and trying alternative therapies to treat those possible triggers (nutrition and dietary restrictions, carnitine)	170		43	Being worried about their family members and seeking information on family history (e.g genetic testing)	5273	5273	
		Causes	76	Debating on possible causes for the lung scarring and whether the diagnosis received is definite or not	148									2,480442933	
		Causes	17	Discussing amiodarone toxicity (drug to treat cardiac dysrhythmias) as a cause of lung inflammation and fibrosis, and often confused with chronic heart failure	685										

	Total Cluster 4	6522	15,16285774			1367	22,23487313			40300	18,95730138
	Total of posts	43013				6148				212583	

Non-clustered				
	PF	70	Fundraising and awareness programs	
	CRC	27	Describing negative experience of repeated visits to the hospital due to the infection after surgery	
	Sarco			
	Sarco			
	Sarco	20	Ocular sarcoidosis & random stories	

Co-creation session

Time: 55 min
Location: Erasmus MC
Participants: **medical professionals and/or clinical researcher** who have experience with pulmonary fibrosis, sarcoidosis and/or colorectal cancer patients.

Introduction:

"What patients seek support for" is the result of thorough analysis of posts from 3 patient peer support platforms. The goal was to understand common themes of doubts, tips and concerns throughout the care path of Pulmonary Fibrosis, Sarcoidosis and Colorrectal Cancer. From our analysis of commonalities from the patient community data, we found that the patient community mainly looks for self-efficacy in:

- Treatment coping and management. For Sarco and PF, mainly more information and guidance on treatment expected outcomes (health benefits), its side effects, and about alternative/non-conventional methods. For CRC, diversity of opinions and guidance on the relation between the diagnostics (scans and tests)and their decision making about treatment options.

- Adjust to the life with the disease, mainly in the case of CRC and Sarco.

I propose this study to reduce bias and co-define the problem with the potential end users. The goal is to involve medical practitioners and/or researchers to discuss the outcomes of the research and future directions that contribute to the optimization of their workflows for increased efficiency and shared decision-making.

In the past years, the investment and venture capital on medtech that supports care at home has increased significantly ("No Place Like Home", Gupta strategists). The transition towards home-based care has been boosted by the COVID crisis. The COVID pandemic may seem in the past but the growing demand of care and staffing crisis still alert for the need of productivity-enhancing innovations in healthcare ("Prevent the Next Wave", Gupta Strategists).

Furthermore, based on the Pulmonary Fibrosis patient community (Zhang, R., 2023), due to the high level of education and socio-economic status, most of the PF patients had a significant motivation to seek health information and participate in shared decision-making around care paths. Is that the situation for the other patient communities? Inspired by Rob Baatenburg de Jong's farewell lecture, which I exemplify with the following quote, I have posed some research questions for this study:

"Where should we go now? We need to quantify as much as possible, for example health benefits. Preferably in QALYs...In addition, informed and personalized "shared decision-making" based on real-life data is expected to lead to less treatment. I think that 'augmented intelligence' can help to weigh the 'facts, figures and feelings'. Models and algorithms supplemented with collective intelligence from people with knowledge and skills. And discuss this together with the patient. That is the future."
Source: Farewell lecture by Rob Baatenburg de Jong

Co-creation session

Research questions:

- To what extent our categorisation of the patient data matches the mental models of our target group?

  - To what extent the associations in the table of commonalities align with the physicians/clinical researcher understanding of the disease?

  - To what extent do the clusters generated match the physicians'/ clinical researchers' vocabulary around the disease?

  - How relevant is this data for the clinical research/practice according to physicians?

- How can the collection of patient experience data like the one presented be systematized in a way that it is relevant evidence for clinical research/practice?

  - In which situations can the patient data be collected and analysed with automated ways (e.g., through natural language processing or AI)?

  - In what situations can patient data be collected and analyzed with a semi-automated method (e.g., researcher scrutiny after prior machine analysis?

  - In what situations should data be examined only by medical experts and researchers?

Session planning:

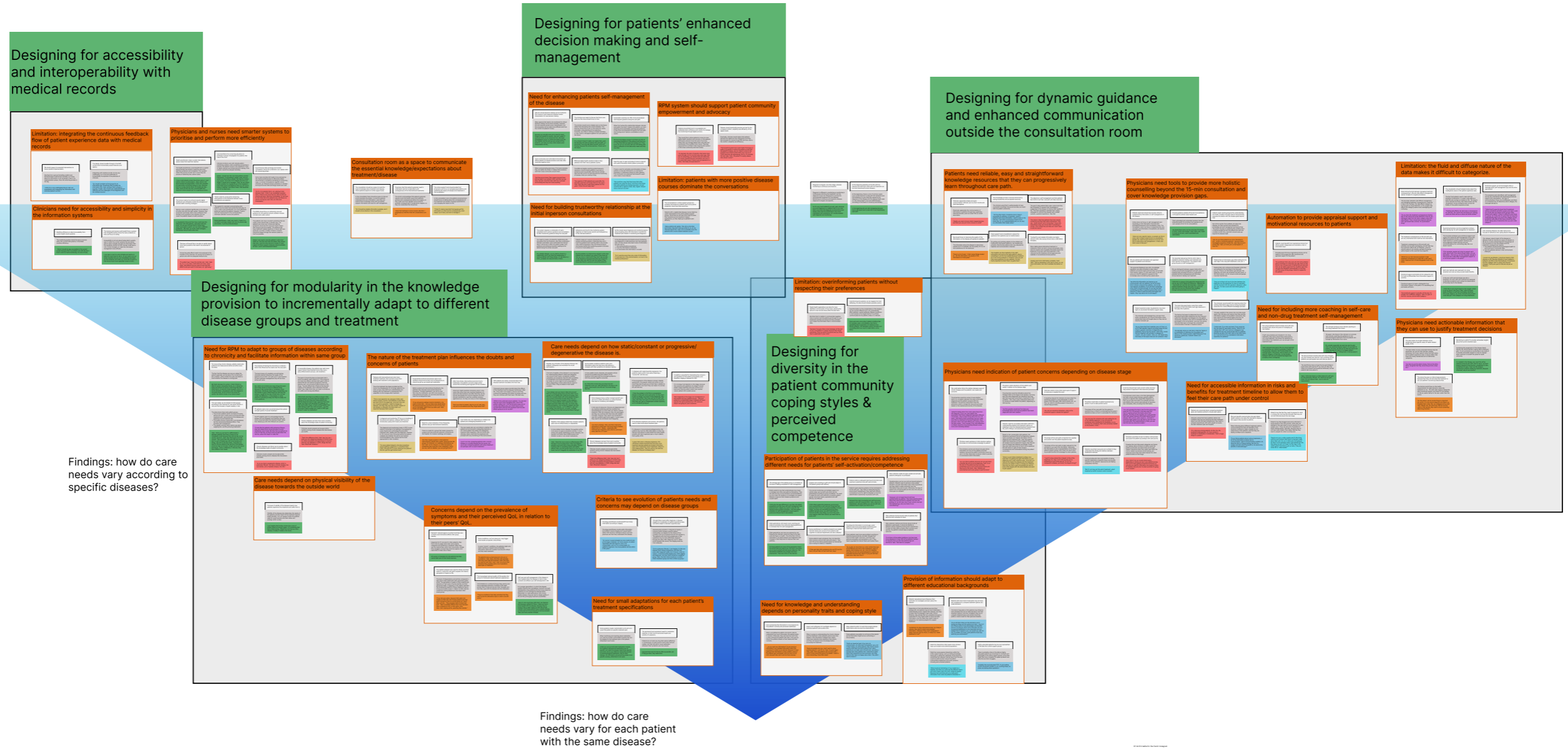| Time	Activity	Tasks	Materials
10	Introduction	Give quick presentation about project (5 min) Participants read and sign the informed consent form (5 min)	• Powerpoint presentation • Consent form
20	Validate commonalities findings To what extent our categorisation of the patient data matches the mental models of our target group? (vocabulary, associations & clarity)	Read the materials and navigate through interactive data visualization (5 min) Use the missing topic cards to co-create the cluster cards (15 min)	• Digital prototype • Printed cluster cards • Printed topic cards

Appendix E

Co-creation session

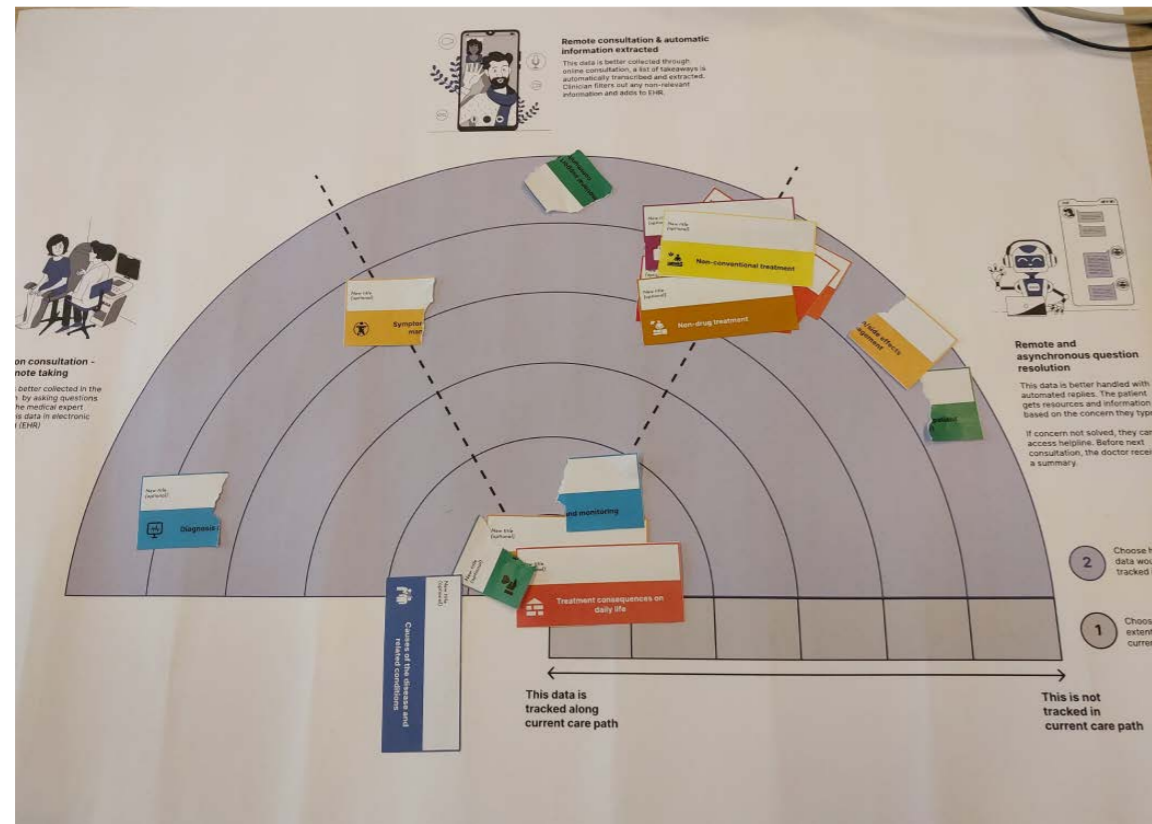| Time	Activity	Tasks	Materials
20	Participate in the data visualization How relevant is this data for the clinical research/practice according to physicians? How can the collection of patient experience data like the one presented be systematized in a way that it is relevant evidence for clinical research/practice?	Participants can distribute the cluster cards around the co-creation value map. Participants are asked questions about the reasons behind their choices.	• Cluster cards with added topics. • Printed co-creation value map.
5	Wrap up and conclusions		

Interview questions

○ What is your general impression after navigating through the results? What is something that you have discovered? What do you think are the possible reasons behind that?

    ○ Did you find anything unexpected or surprising? Is there any topic you found that you thought did not match the category?

    ○ *(With specific categories)* How would you interpret the percentage of posts found for this category compared to the same category in the other diseases?

    ○ *(With specific categories)* Would you like to change the wording of this category or from any topic in this category? Why? Would you like to move any topic from here to another category

    ○ How useful/not useful would you find this data in your everyday practice?

    ○ How clear/unclear was navigating through the data visualization in general?

○ Why do you think this category of data is currently tracked at that level?

    ○ In which situations can the patient data be collected and analysed with automated ways (e.g., through natural language processing or AI)?

    ○ How useful/not useful would you find this data in your everyday practice, if it was tracked more? *(if not asked before)*

○ Why do you think this category of patient experience data should be tracked in that way? Are there any cases in which it could be tracked in a different way?

    ○ Who is usually tracking and analysing this data?/Would there be a job position that would benefit from collecting this data?

Appendix F

Designing for accessibility and interoperability with medical records

Designing for patients' enhanced decision making and self-management

Designing for dynamic guidance and enhanced communication outside the consultation room

Designing for modularity in the knowledge provision to incrementally adapt to different disease groups and treatment

Designing for diversity in the patient community coping styles & perceived competence

Findings: what are the overarching needs for the chronic patient community as a whole?

Findings: how do care needs vary according to specific diseases?

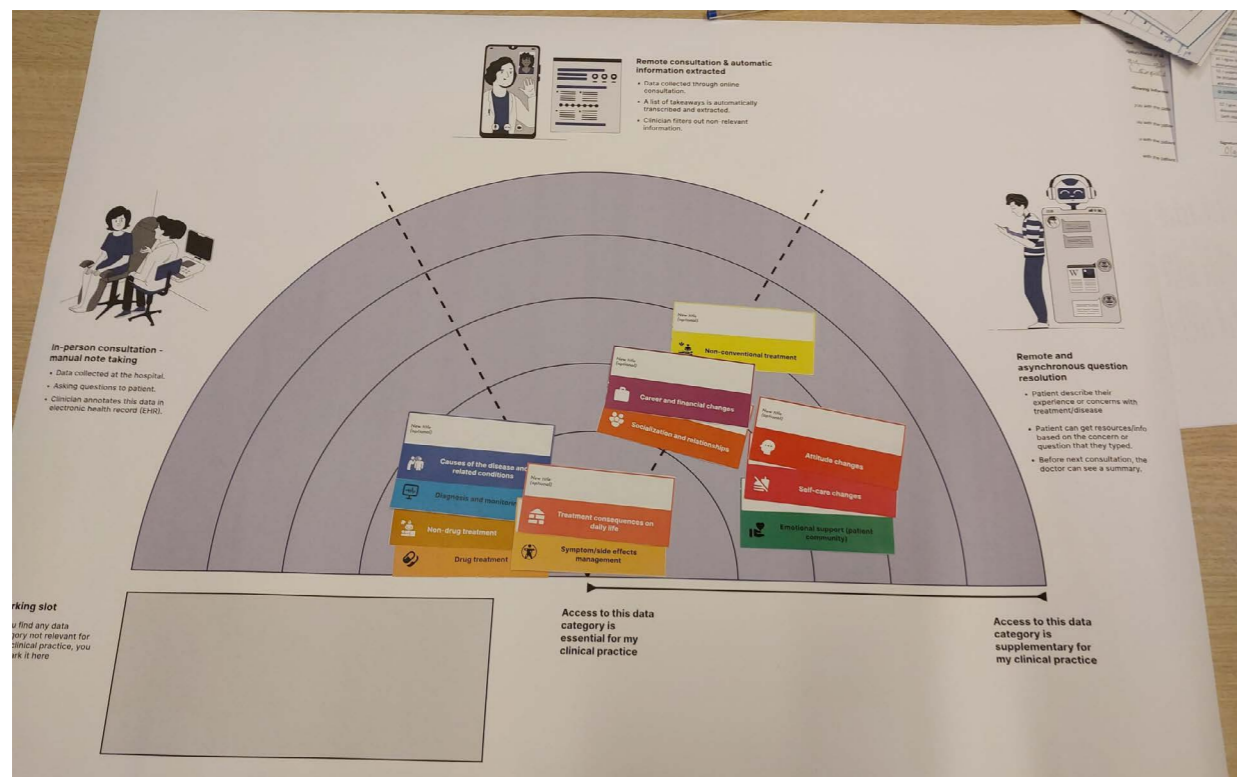Findings: how do care needs vary for each patient with the same disease?

Appendix F

Co-creation session 1
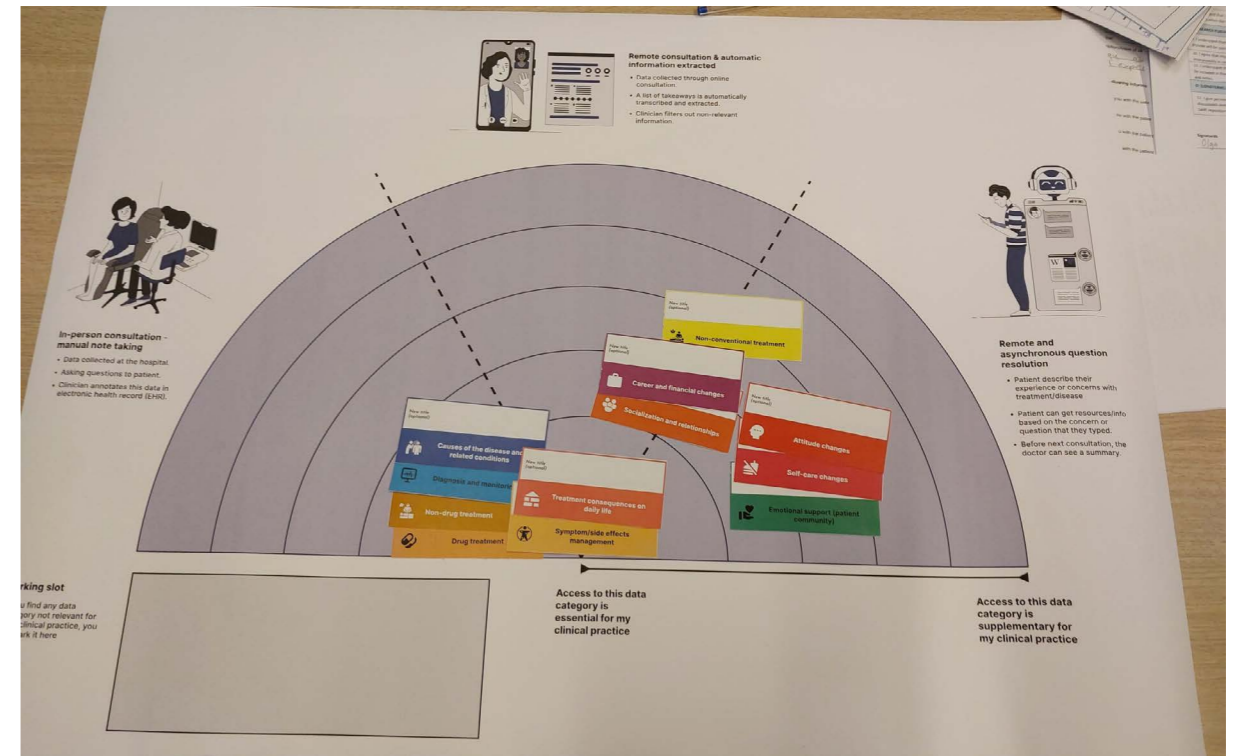
Co-creation session 5

Co-creation session 3

Appendix G

Grid view

#	Service	Data category	Sub-service	Service patterns	Communication patterns
1	Find information on the nature of the condition	Diagnosis and natur…	A. Type question about the disease. B. Select article.	Learn someth…	Self-manage…
2	Vent or complain about diagnosis process	Diagnosis and natur…		Emotional reg… Report a com…	Community fo… Complaint flow
3	Find information about how to avoid complications of the condition	Causes of the disea…		Learn someth…	Self-manage…
4	Find information about possible causes of the condition	Causes of the disea…		Learn someth…	Self-manage…
5	Check the plan for surveillance for their chronic disease	Monitoring and medi…	A. Find personal treatment plan page. B. Display the monitoring checkpoints.	Review some…	Personal details
6	Find guidelines on how to understand the tests and scans	Monitoring and medi…		Learn someth…	Self-manage…
7	Find coping strategies to	Pharmacological tre…	A. Describe side effects/symptoms.	Learn someth…	Self-manage…

	deal with the possible side effects from …		B. Choose and read article.		
8	Reflect on the relation between perceived quality of life and side …	Pharmacological tre…		Reflect on so…	Community fo… Complaint flow
9	Renew prescription	Pharmacological tre…	A. Get notification to renew prescription. B. Click to request a renew prescription. …	Get notification Send a request	Request flow
10	Find scam treatments	Alternative therapies	A. Type treatment. B. Find article about whether it is a scam.	Learn someth…	Self-manage…
11	Find coping methods post-intervention	Interventional treat…	A. Type intervention or question mentioning intervention. B. Find article with …	Learn someth…	Self-manage…
12	Vent about not getting access to transplant	Interventional treat…	A. Find discussion topic. B. Write about frustration.	Emotional reg…	Community fo… Complaint flow
13	Compare different options for hospice care	Assisted living thera…	A. Find the discussion topic with search bar B. Find the best-rated (most helpful…	Compare so…	Community fo…
14	Find tips to manage oxygen therapy at	Assisted living thera…		Learn someth…	Self-manage… Community fo…

	home				
15	Report or complain about specific experienced side effects	Management of spe…		Report a com…	Complaint flow
16	Find active coping strategies to deal with specific symptoms/sid…	Management of spe…		Learn someth…	Self-manage…
17	Find information on dietary recommendations	Lifestyle adaptations	A. Browse through articles. B. Select one to read.	Learn someth…	Self-manage… Community fo…
18	Find information on how to exercise/practice sports	Lifestyle adaptations	A. Browse through articles. B. Select one to read.	Learn someth…	Self-manage…
19	Vent on the struggle to give up personal habits	Lifestyle adaptations		Emotional reg…	Community fo…
20	Request personal information on whether certain habits should not be …	Lifestyle adaptations	A. Describe doubt. B. Send to nurse practitioners.	Send a request	Complaint flow
21	Find financial tips	Work capacity and p…		Learn someth…	Self-manage…

22	Find information on reimbursements and medical coverage	Work capacity and p…	A. Type question/concern. B. Select a resource among the matching ones.	Learn someth…	Self-manage…
23	Report on the misalignment with occupational doctors	Work capacity and p…		Report a com…	
24	Share ideas on how to stay active with friends and family	Social relationships		Learn someth… Compare so…	Community fo… Self-manage…
25	Vent about emotional struggle to take care of relationships	Social relationships		Emotional reg…	Community fo… Complaint flow
26	Venting about general difficulties inside a discussion topic about life with the disease	Attitude towards livi…	A. Read other people's stories inside a discussion topic B. Write about your …	Emotional reg… Reflect on so…	Community fo…
27	Find survivors' stories	Attitude towards livi…		Learn someth…	Community fo…
28	Find motivation and resilience among the community stories	Attitude towards livi…		Reappraisal o… Emotional reg…	Community fo…

29	Share an open doubt			Reflect on so… Report a com… Send a request	Request flow Complaint flow
30	Recommending articles for self-management of symptoms/side effects of medication	Management of spe…		Learn someth…	
31	Recommending articles to stay socially active	Social relationships Attitude towards livi…		Share someth…	
32	Smart search chatbot to help you describe your concern and suggest articles based …			Report a com… Reflect on so… Share someth…	
33	Generate prompts or questions to help you discuss something …	Social relationships		Compare so… Reappraisal o…	
34	Facilitate documentation of medical expenses and reimbursements	Work capacity and p…		Review some… Compare so…	
35	Provide info on risks and benefits of treatment options for current stage …	Pharmacological tre… Interventional treat… Monitoring and medi…		Learn someth… Making decisi…	
	Provide…				

36	Provide matches between more activated patients and less activated …			Learn someth… Compare so… Emotional reg… Reappraisal o… Making decisi…

Appendix G

Grid, Filtered by Service patterns

#	Data category	Service	Sub-service	Service patterns
1	Diagnosis and nature of the disease	Finding support about the diagnosis and the nature of the condition	- Vent about the diagnosis process. - Find information on how to get diagnosed properly. - Find information on the nature of the …	Learn something Emotional regulation
2	Causes of the disease and related conditions	Sharing information to understand possible causes of the condition and …	- Information finding about possible causes of the condition (genetics, environmental factors). - Find information about how to avoid complications of the condition.	Learn something
3	Monitoring and medical opinion	Sharing doubts about medical professionals' decisions and getting different …	- Discuss when and where they can get professional second opinions. - Comparing their plan for surveillance of the chronic disease. …	Making decisions Compare something Emotional regulation
4	Pharmacological treatment	Compare prescribed drugs with others	- Compare regimen, dosage and side effects with other patients. - Learn coping strategies to deal with medication side effects. …	Compare something Learn something Making decisions Emotional regulation
5	Alternative therapies	Learn about non-registered therapies and drugs which are not prescribed for ..	- Learning about scam treatments. - Debating on effectiveness of alternative therapies. - Sharing information on clinical trials an…	Learn something Making decisions Emotional regulation Reappraisal of somethi…
6	Interventional treatment	Sharing experiences with interventional treatment (surgery or …	- Share information about intervention (surgery or radiology) to manage expectations. - Sharing tips for active coping post-intervention.…	Learn something Emotional regulation
7	Assisted living	Share doubts and	- Sharing knowledge on how to manage the therapy.	

#	Data category	Service	Sub-service	Service patterns
		therapies	experiences about prescribed …	- Compare different options to get the most adequate one.	Compare something Learn something Making decisions
8	Management of specific symptoms/side effects	Information finding about managing specific symptoms/side effects	- Sharing tips for active coping with specific symptoms or medication/surgery side effects. - Comparing experiences with specific symptoms/side effects.	Learn something Compare something
9	Lifestyle adaptations	Sharing how they make changes in their lifestyle to improve health outcomes	- Comparing experiences about physical activity with disease. - Sharing dietary recommendations. - Comparing experiences on giving up …	Compare something Learn something
10	Work capacity and personal finances	Sharing experiences about professional career and financial …	- Sharing information about medical coverage and reimbursements. - Sharing experiences about managing professional career and disease …	Learn something Compare something Emotional regulation Making decisions
11	Social relationships	Comparing how different patients deal with social life with their condition	- Sharing experiences on how to stay active socially (hobbies, weekend trips). - Talking about emotional struggle to take care of relationships while having the chronic disease.	Learn something Compare something Emotional regulation
12	Attitude towards living with disease	Sharing experiences for community resilience	- Comparing how to stay resilient and confront life during/post-treatment. - Venting about difficulties and struggles in the life with the chronic disease. ...	Compare something Reappraisal of somethi… Emotional regulation
13	Emotional support	Expressing compassion and encouragement among patient community	- Expressing condolences and compassion. - Expressing encouragement.	Emotional regulation
14				

Welcome to the preparation tasks!

Try to complete the tasks if you have time, otherwise just reading through the reading sections should be enough to prepare you for the co-design session of coming Monday from 10 to 12:30. If this workspace closes, text me and I'll re-activate it! Your progress will be saved.

Day 1
(15-20 min)

Day 1.1

Understanding patient experience data
Before we start, let's understand the data landscape where this project is situated!

Data sources

Online Patient Community Stories

This project builds on the work from three IDE graduation students. Each of them worked around one of the following patient communities: people living with colorectal cancer, sarcoidosis or pulmonary fibrosis.

Together with computer science students, they analysed and clustered thousands of posts from online patient support groups with a machine learning method known as topic modelling.

Topic modeling combines computational analysis and human interpretation to achieve a number of topics of patient community experiences. You can see a topic as a cluster of hundreds or thousands of posts.

Example:

Post

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

Topic where it was clustered

Sharing information on taking esbriet (pirfenidone), effectiveness and purpose of the med, weighing side effects and quality of life.

Links to the patient support groups (if you're interested)

Colorectal Cancer in the Cancer Survivor Network → https://csn.cancer.org/categories/colorectal

Pulmonary Fibrosis in Inspire → https://www.inspire.com/groups/living-with-pulmonary-fibrosis/

Sarcoidosis in WijHebbenSarcoidose → https://www.wijhebbensarcoidose.nl

Project goal

My goal at the start of this project was to:
1. map common themes of needs and concerns among the 3 patient communities.
2. build a concept of a service system for self-monitoring based on this treatment-related patient experience data.

Day 1.2

In the consultation room

Step 1: Think about the last time you went to a doctor's consultation room. What are advantages/limitations of in-person consultations?

Step 2: Think now that you have been diagnosed with a disease that needs to be monitored for a long period. You visit a specialist at the hospital periodically for checking the status of this disease, which advantages and limitations would you add?

Advantages

Example: The doctors can see the symptoms in person.

David Quijada Fernandez

Limitations

Example: Limited time to talk about my problems.

David Quijada Fernandez

Appendix H

Understanding remote monitoring

What exactly do we mean by remote monitoring systems?

Remote monitoring systems

Through remote monitoring system, some medical centers have aimed to train patient communities for the self-management of the disease/treatment and the self-monitoring of their health status, so that they only need to visit the hospital when it is really needed.

One example is the Myocardial Infarction (MI) Box, which has been researched by Ir. Julian Houwen and MSc. Ragini Karki. The MI Box includes a smartwatch, smart scale, blood pressure monitor, and two apps, all provided by Withings. The devices are connected to the Withings Health Mate app (Figure 1). The data collected through this app is transferred to the LUMC Care app (Figure 2).

With this system patients who suffered from myocardial infarction and their families can manage health at home and learn to cope with the changes in their life induced by the disease and the treatment regimen prescribed.

a.

b.

c.
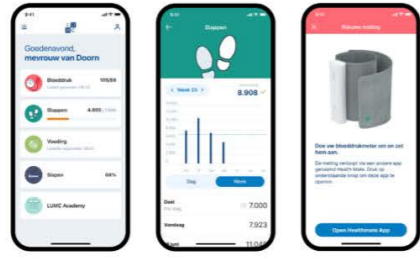
Figure 1: The LUMC Care app
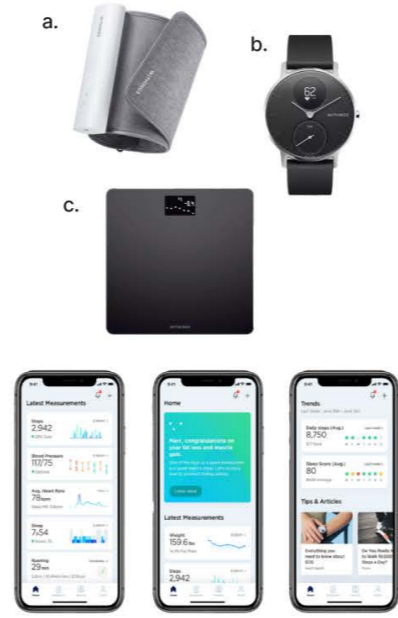
Figure 2: Blood pressure monitor (a), smartwatch (b) and smart scale (c) connected with Withings Health Mate app.

In the consultation room, again.

You have been diagnosed with a disease that needs to be monitored for a long period but there is a remote monitoring system in place. You periodically monitor symptoms, receive information and communicate with doctors when necessary through this system. In this way, your hospital visits are reduced by half. How would the advantages and limitations that you wrote in the page 1.2 change, if at all?

Advantages

Limitations

Appendix H

Day 3.1

Understanding social support

We have talked about patient support groups, but what is social support from the health psychology perspective?

Types of social support

1. Emotional support	provision of empathy, love, trust, and caring.	
2. Instrumental support	provision of tangible aid and services that directly assist a person in need.	
3. Informational support	provision of advice, suggestions, and information that a person can use to address problems.	
4. Appraisal support	provision of information that is useful for self-evaluation purposes—in other words, constructive feedback and affirmation.	

House (1981)

Due to the intangible, online nature of these patient support groups and remote self-monitoring, we will not focus on instrumental support.

After reading some posts from the three patient communities, I could identify the provision of emotional, informational and appraisal support. Some posts offered a combination of different types of support.

The social support diagram

This diagram illustrates that when people face a stressful experience (stressor), having resources both at the individual and community level can improve physical, social and mental health and reduce the negative effects of the stressor.

Following this theory, I asked myself two questions:
- How can services within a remote monitoring system strengthen and coordinate existing/new social network ties?
- What can we learn from online patient support groups to develop patient-centred remote monitoring systems?

Day 3.2

Your metaphor for data-driven support

In 2030, Erasmus MC releases a remote monitoring system for patients of different chronic diseases. In this monitoring system, a machine learning model (ML model) allows for continuous learning about each patient community's quality of life. The algorithm could, for instance, analyse the messages of the patient community reporting doubts an concerns , and then extract takeaways to provide timely summarised information to the clinicians. Or maybe it could track the knowledge articles that they patients read the most or which articles the patients are recommending to each other, etc...

What would be a metaphor to represent how the ML model enables social support? You can use the icons and images on the right or add your own.

Your metaphor canvas

The ML model = Metaphor

Example

The ML model = White Rabbit from Alice in Wonderland

- Guides you to the right information/contacts
- Indicates but does not mandate
- Considers time (=stage of disease)

Appendix I

Diagnosis and nature of the disease

○ ——————————————————————

Vent/share experiences about the diagnosis process.

"I underwent a mediastinoscopy to rule out one and diagnose the other. It was finally ruled out that I had Hodgkin's disease and determined that I have Sarcoidosis. For this, you are put under full anaesthetic and a specialist, in my case a pulmonologist, performs keyhole surgery between the rib cage and trachea/esophagus, at the level of the lymph nodes. A piece of tissue is then removed here, for examination, which should determine which disease you do or do not have."

○ ——————————————————————

Share information on the nature of the disease.

"it can be very confusing. idiopathic pulmonary fibrosis is ideopathic pulmonary fibrosis which is the type of pulmonary fibrosis that has no known cause so no known treatment. interstitial lung disease is interstitial lung disease which generally has an identifiable cause... depending on the cause, there are various treatments meds that a can be effective in delaying the progression. <person>"

○ ——————————————————————

Share/find information on how to get diagnosed properly.

"you are very wise to seek a second opinion! remember idiopathic pulmonary fibrosis is a very rare disease the local pulmonologists most likely havent seen many cases. a center of excellence has. i just got back from <location>, and i am so pleased. they re examined my biopsy slides and ct scans and appear to be heading to a difference diagnosis than the local doctor..."

Causes of the disease and related conditions

○ ——————————————————————

Find/share information about possible causes of the condition (genetics, environmental factors).

"bottom line is that agent orange may be the cause of idiopathic pulmonary fibrosis in many veterans. i am filing a claim with the veterans admin for this. these cases usually go to court on appeal, but recently many have been won"

○ ——————————————————————

Share/find information about how to avoid complications of the condition.

"i agree with your doctor. the feathers are the worst for us. we got scaring on our lungs from somewhere. birds is very high on the list. do what your doctor told you. i would not even visit them but that is just me. good luck."

Monitoring and medical opinion

Share doubts about medical opinion

"i am being seen by a duke pulmonologist at the va hospital in <location> and he thinks that i should have a lung biopsy. i am reluctant as i do not have any serious breathing problems so far. i dont know if it is the thing to do because of chances of infection, bleeding, and just putting a wound in a lung that is not at full capacity...what are the pros and cons of a lung biopsy and should i have one?..."

Find support for the understanding of results of tests and scans.

"SO after reading the reports I am upset that that she never mention nodule in lungs. I feel cheated. I asked what the plan was and if we should start 5-fu and lecouvorin and she NO they are too small and the only thing we do is rescan in another 3 months. So family what do you suggest, besides switching oncologist?? Please what you would do... I do not like the let us wait and approach, I mean what for, to if more nodules pop up??"

Compare with other patients their plan for surveillance of the chronic disease.

"...Fortunately they were all tubular adenomas. None were cancerous but all had some degree of displaysia. I am on two yearly scopes from now on. None of 's have suggested testing for familiar polyposis. I would be asking for two yearly scopes as you are in the high risk category, cheers."

Pharmacological treatment

Compare regimen, perceived progress and side effects with other patients.

"had my third infusion last Monday...Fortunately, my blood pressure, and then my upper pressure, is no longer dropping that much. A good sign...This morning I had an appointment with the pulmonologist about the progress. He again explained perfectly how everything works and how long it will take before I notice anything. After six months there will be another evaluation."

Debate on perceived quality of life and effectivity of medication.

"i was on ofev for <number> months, the side effects just getting worse almost by the day. tried a lower dose still bad. i was exhausted all the time, as in no energy and could sleep most of the day. my quality of life was just not worth the effort. i am glad that some can tolerate ofev as it does seem to slow the progression of pulmonary fibrosis. i wish you the best as we go down this very rocky road."

Share coping strategies to deal better with medication.

"i am <number> years old and been on pirfenidone for one year. my only side affect is severe sun sensitivity. i use the strongest sun screen i can get and i will still burn if i sit in direct sunlight for <number> minutes. so <location> and <location> are pretty much out for me. i basically adjust what i do and where i go to meet my circumstances, but i still do pretty much whatever i wish."

Alternative treatment

Learn about/flag scam treatments.

"thanks. well said. this has all the earmarks of an orchestrated scam. nothing i can find on the internet dares step beyond feel better with no measures. and even then with very vague and weak confidence!"

Debate on effectiveness of alternative therapies and their relation with conventional treatment.

"...TCM (traditional chinese medicine) is not about "seeds", it is about restoring the body: making it well enough to battle it is ills without the use of toxic chemicals. It is about restoring and bolstering the immune system, in effort to thwart cancer,and the ramifications of cancer..."

Share information/experiences with alternative medicines.

"i have been taking nac for <number> months and curcumin for about <number> weeks. the nac is for my cough and i feel it has helped me. i read about curcumin turmeric helping with inflammation and because i have rheumoid arthritis along with pulmonary fibrosis, i thought i might benefit, however i think i might need more time than the <number> wks for any results.."

Interventional treatment

Share stories/tips for better decision making around pre-intervention preparations and post-intervention care.

"Make sure you spend some time well before the operation date to find the exact spot for placement of the stoma. You want to insist on the "spout", the amount the stoma sticks out from your body, is sufficient. With ileostomy, it is 3/4 to 1 inch. The placement of the stoma is very important, especially if you plan to be sexually active..."

Share information/experiences about intervention (surgery or radiology).

"...the microwave ablation is less invasive and more precise. After that heals, he performs a procedure injecting radioactive beads into the right lobe of liver to kill off those tumors. These procedures are supposed to help achieve a disease free period and have been shown to increase survival rates dramatically..."

Vent about the struggles before and after intervention.

"it seems my road to transplant is going to be long and adventurous. i have tested quite high for the pra antibody which makes it quite difficult to find a donor match. apparently im in the <number> percentage range, meaning <number> out of <number> people in my blood type would not be compatible. it is a leading cause in rejection and graft failure..."

O₂ Assisted living therapies

○

Share knowledge/tips on how to manage the oxygen therapy.

"the inogen g3 (oxygen concentrator) gets somewhat heavy when walking as i tend to use the heavier battery more than the lighter one. the g3 is much better on an airplane or at dinner. i have learned to keep it between my legs when dining. i simply forget i am on oxygen and enjoy the meal with no worries about whether it will run out. things look good for <year>."

○

Share experiences with hospice and palliative care.

"...i too use palliative care. they help me with pain management. they are great. a nurse comes to my house once a week and gets updates on how im doing. if im really sick and need help, they will come out and see me and help determine if i need to be admitted into the hospital..."

Management of specific symptoms/side effects

○

Share tips to deal with specific symptoms or side effects from medication/surgery.

"i have found that sometimes i can reduce my tendency to cough by putting the oxygen cannula into my mouth for a few minutes. it seems to overcome that fatal tickle at the back of the throat temporarily. i also make sure that my nasal passages are clear at all times..."

○

Compare experiences with other patients about specific symptoms/side effects.

"A few weeks after finishing chemo I noticed that I had terrible pain in joints throughout entire body. I could not walk up or down the stairs, after sitting for a short period of time not only could not I walk but I could not even straighten up. I also noticed that I had swelling in fingers and toes, on top of the neuropathy in hands and feet..."

Lifestyle adaptations

○ ——————————————————

Compare experiences about physical activity with disease.

"You can keep your spirits up by keeping moving, sure. But I stopped expecting improvements a long time ago. And with physiotherapists or sports instructors who don't know what they're talking about - prednisone and obesity - you need to get out as soon as possible. The last thing you want is misunderstanding.
But yoga, I think I will indeed try to find out..."

○ ——————————————————

Share dietary recommendations.

"I was prescribed a Low after surgery. A low residue diet eliminates coarse fiber and other indigestible material that causes distress to the gastrointestinal tract and designed to reduce the volume and frequency of bowel movements. It is similar to a low fiber diet, but also restricts milk and milk products and prunes."

○ ——————————————————

Share coping strategies to deal with daily activities.

"you may find that barely warm showers with the bathroom door open are much easier to handle than hot and steamy showers. many of us have a great deal more trouble breathing in hot and humid conditions and find that water too hot can be exhausting..."

Work capacity and personal finances

○ ——————————————————

Share information about medical coverage and reimbursements.

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

○ ——————————————————

Vent about the occupational doctors' decisions and work concerns.

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

○ ——————————————————

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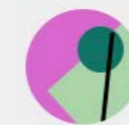
"i was wondering how everyone else is able to juggle working full time and going to doctor visits and test. i was just diagnosed and going through tons of test and my work is not taking it very well. any one have any advise on how to deal with work. its getting financially hard to pay co pays and more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

Social relationships

Share experiences/ideas on how to stay active socially (hobbies, weekend trips).

"the exercise of singing may be beneficial to lung health, but the joy of singing can clearly be beneficial to your spirit and that is enough to recommend it!"

Discuss impact of disease on relationships with partners, friends and family.

"I found this site very helpful for support. But you must also include god and your family in your life as well i found it hard to talk to family about it and easier to talk to strangers but your family mis-interpret you not talking to them and you must try or they think you are angry or depressed."

Attitude towards living with the disease

Discuss how to stay resilient and confront life during/post-treatment.
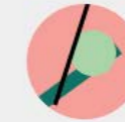
"Hope as others have, there is always, be careful how you read reports, first they are in medical language, second, you are reading them from a personal, emotional point of view and things can seem worse than what they are. I have to admit that I do not wait to hear about a report anymore...the report only states what has been found....not how it can be treated."

Vent about difficulties and struggles in the life with the chronic disease.

"...I was deathly ill right away, so there was no doing this or that, or even putting my child to bed, who was six months old at the time. I had psychosocial therapy (at least I think that's what it was called), but the problem with that was that I was not so much sick in my head, but my body could do absolutely nothing..."

Learn about survivors' stories.

"...He devised a new combination of three older drugs, which eradicated all three cancers in only two cycles. I went on to a stem cell transplant and now have no evidence of cancer. It was 11 years ago now that I had a 3 month average survival. This July, doctor and I toast 12 years together. Sure beats three months. To paraphrase , "It is not over until it is over.""

❤ Emotional support (patient community)

○ ────────────────────────────

Express condolences and compassion.

"i am so sorry you lost your mom. we are all here for you and your family. wishing i could carry some of your pain right now."

○ ────────────────────────────

Express encouragement and positivity.

"Glad You are Home. So glad that everything went well. You get used to your new "normal" fast especially after what you have been through. I actually just came back from the hospital also and this is first post. I am glad you are positive about the new changes...Rest up and you have a speedy recovery."
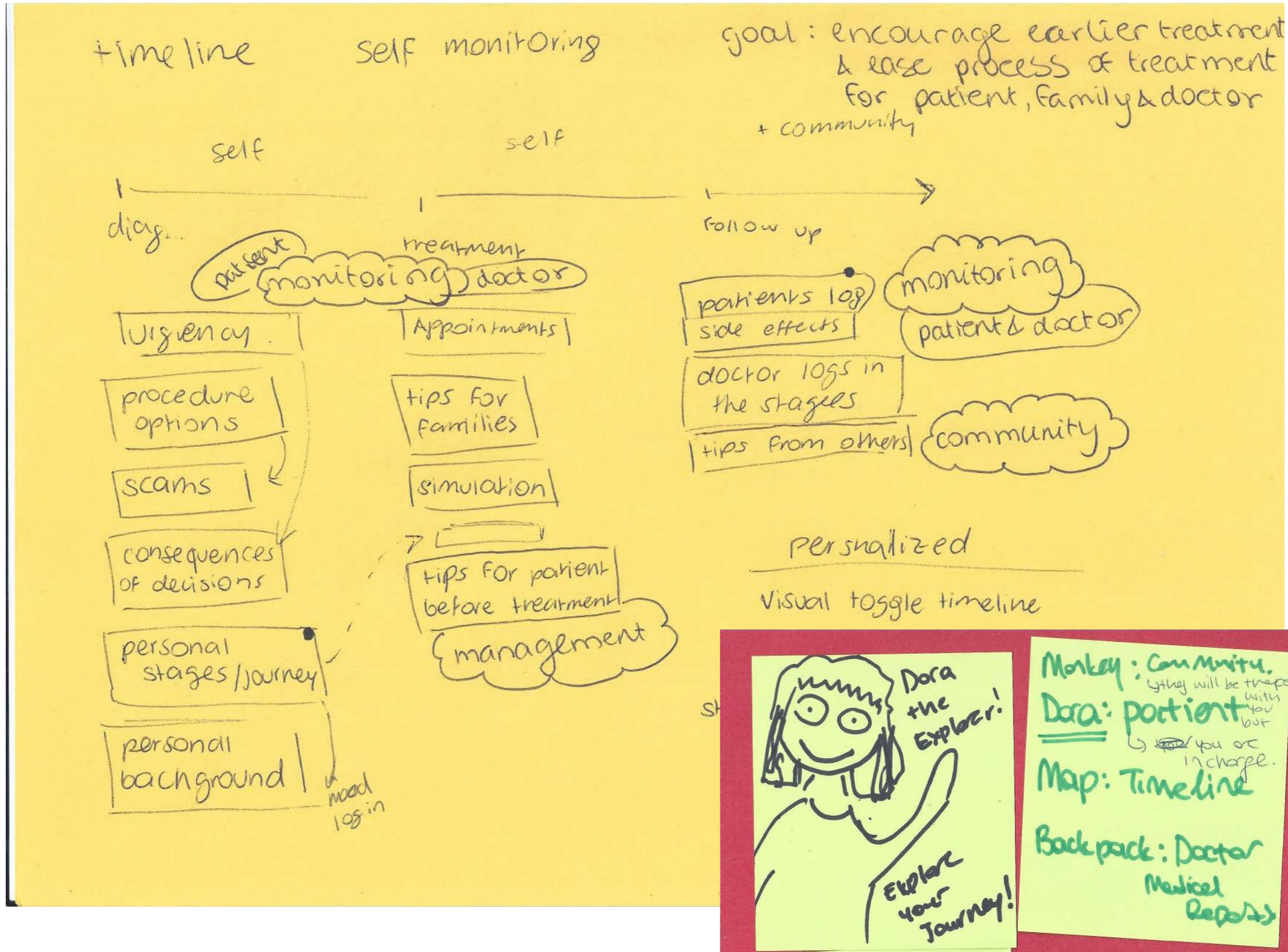
Appendix J

Concept A from Creativity session

PRACTICAL TIPS FOR IMPLEMENTIG LIFESTYLE CHANGES

SELF - MANAGEMENT

- Provided by the hospital
- Sort of manual
- Doesn't include personal experience
- ~~Feels very reliable~~
- Limited content

COMMUNITY DISCUSSION TOPICS

- Integration of community and care team
- System detects data from posts and shows it as tips
- Matching system
  └ system detects similar / complimentary posts and prompts people to connect
- Expert validation of content (only if harmful)
- Ranking by patients

POSTS | TIPS

ext. res.   Doctors

1. Select categories that apply to you (patient
2. Browse through the ti
3. Provide feedback on the tips' quality
4. Share tips with relatives

1. Open "tips" section
2. Select categories
3. Open (tips) you like
   └ by community
   └ by experts
   └ by external resources
4. Rank tips
5. Find new tips every day
6. Add your own

→ Makes it <u>practical</u> and <u>easy</u>

→ Makes you feel <u>safe</u>

→ It's <u>reliable</u> & <u>effective</u>

→ <u>Validates</u> your experience and struggles

Concept B from Creativity session

Session 1: ML expert

The summary of reported concerns should indicate the lack of data during periods of time

When providing a synopsis or summary of the patients' concerns, the doctor and nurses should also be aware of the absence of data, the patients who are not reporting anything after certain questions. This way, they can identify whether they have some hidden issues or be alerted.

"I would say that that absence is also a signal that the doctors can use."

The model should be technically validated and documented after updates

The update of the model should be controlled to ensure the correct functioning of the system after the update. This needs to be technically validated and documented following criteria.

"There is quite some effort that needs to go into technically validating this...Uh, and then especially once the system is deployed and maintained, then you need to update it."

The model should be technically validated and documented after updates

The update of the model should be controlled to ensure the correct functioning of the system after the update. This needs to be technically validated and documented following criteria.

"There is quite some effort that needs to go into technically validating this...Uh, and then especially once the system is deployed and maintained, then you need to update it."

Fine-tuning should involve some validation (maintenance) to check the performance of the model

The fine-tuning of the classifier does not entail just adding more data to train the model and deploy it. It should be validated and reviewed that it is still working appropriately and the parameters of the model have not been affected drastically.

"You cannot just, you know, get a bit more data on it. We deploy it as good because things, uh, like when you do, when you do an update to a model, even if it behaves the same...Yeah, let's say the internal parameters, they might shift like all of them."

The summarization should be designed further and validated and together with clinicians.

The summarization algorithms should validated and documented, so that the next engineers or developers can review that it keeps working correctly. Also it should be verified that it is meeting some criteria for the adequate/desirable performance of the summarization. For instance, that it is not removing important details.

"Be sure that whatever you're using to summarize...Whether it's a model or not... You know, it's proper is what it is proper, in the sense that it works...Like how you expect it to..."

The data should be abundant, widespread and representative of the whole community

To avoid data cross-contamination and a fake illusion that the model is performing correctly, we need a large database to train the model, and the data that we test the model with should be new, the model never saw it before. Then the data has to be widespread and representative of the whole patient community we are seeking to analyse.

"for that one you need to have enough data...Yeah, and the data has to be somewhat representative of the patients that these people are dealing with...So there is also that challenge...It's doable, but there are conditions."

Periodic topic modelling should aim to review the relevance of the existing categories and assessing whether it is necessary or not to update topics.

When conducting periodic topic modelling, doctors should be involved if the results have drastically change or the topics show a lot of differences compared to the previous set.

"And then if those topics have not changed, yeah...Then you know that one might be more of OK...We are set that we don't need to involve doctors and stuff because if doctors do not have major complaints that all these things do not make sense or there is no like a drift like a huge drifting..."

The system seems technically feasible but there are conditions to the development and deployment of the system

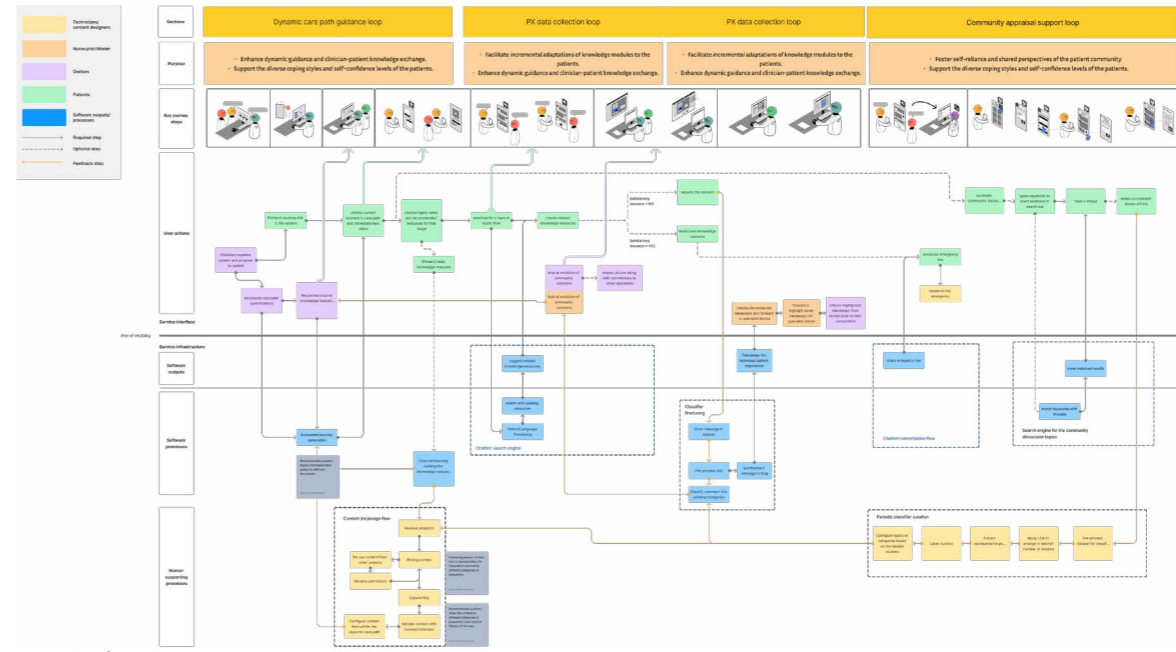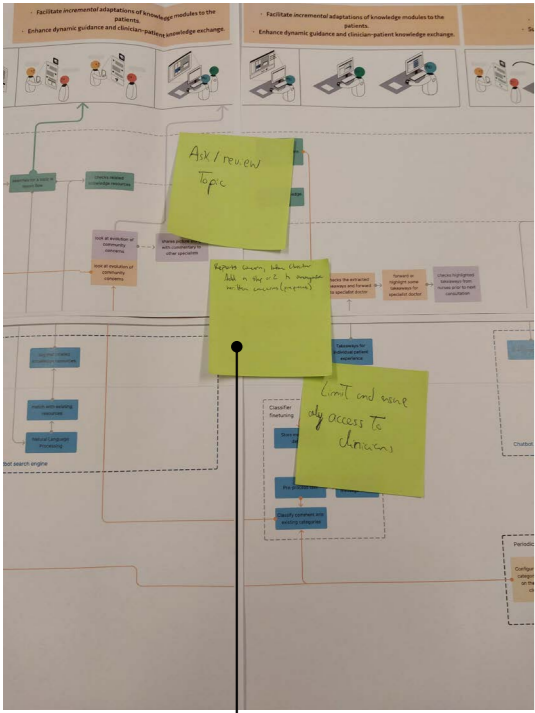The service system seems doable, but it depends on the conditions of gathering enough representative data and involving the necessary stakeholders in this enterprise.

"from an engineering perspective, yeah, sorts of these things like, even when you have like chatbot engine or again like the curation of the classifier or the fine tuning does make sense and they are actually doable..."

The technical feasibility and performance of the model should be documented and verified through established requirements.

The model should align with technical requirements established by well-known institutions, so that medical professionals know they can trust the system and also to prevent any harmful effects.

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

Document to give confidence and reassurance to doctors about the performance of the model

The system should be documented and validated to provide reassurance to doctors that it can work for a specific purpose (which is clear to them) and that it will not stop working unexpectedly (or there is a plan in place to mitigate or fix the system when it breaks).

"I think at least what they're gonna have about is that, OK? Is it gonna be is gonna work properly? Is it gonna give like suggestions that make sense to patients? Umm, it's not gonna...I don't know break, for example."

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Periodic checkups to warrant representativeness of the system for patients' concerns and needs

Periodic updated can be important to verify the relevance and representativeness of the classifier and themes of resources. this could also allow us to notify changes in informational needs due to societal, community changes.

"let's make sure that you know, since we have more and more people using it...we can update and like see how things go... Also, because maybe on a broader societal level, you have shifts those kind of things, maybe, I don't know, eating or like living habits change."

The system should align with the general level of patients informational needs and preserve the general medical materials.

The knowledge and information system should cover the medical best practices and a general estimation of the needs and concerns of the patient community.

"to some extent, you also have like a bunch of, you know, historical practices and like medical knowledge that says, OK, generally no, like on average this is what happens...And I think that as long as this thing this system is like in line with the average...And then it can give more."

Find the balance between being persistent to get the data and avoid annoying reminders.

Notifications and reminders should be designed in a way that they are not overwhelming and intrusive, but they ensure data collection to improve the system.

"I would say this one needs to be, I think, like designed carefully...No, but one way that I can imagine this is that, OK, the patients what a particular patient does not respond to this one"

Indicating lack of data could support doctors' role as investigators of patients' problems and concerns.

Provided that doctors know that these are summarised concerns derived from the self-reported concerns, the system should indicate when patients stopped giving information, so that it can be a conversation starter for opevious consultations.

"If you want to always summarize them, yeah, I would just say OK, summarize is what happens by default...So that doctors get like a how to say some synopsis what the patient said, but at the same time, if the patients like stopped out at some point and like, stopped. giving info or replying to the yes or no questions and stuff...Then it's like, OK, here's the summary...But doctor, you should know that this is incomplete because this patient stopped."

Session 2: ML expert

The generative AI in the future could facilitate adapting the content to different patient profiles.

In the future (perhaps on the long run) content design could be adapted to different literacies or personalized to different patient profiles through generative AI. The content adaptation could depart from a reviewed resource created or validated by medical professionals.

"I have the feeling that these are curated knowledge, right? but it might be difficult for people to engage, right?...For people who are highly educated, they're used to actually reading stuff...how can that content be turned into different formats?...I mean we are not there yet, but if in the future for instance...Videos could be easily generated based on prompts"

To use moderation and content redesign flows to transform patients' tips/experiences as resources for appraisal support

We could ideate further on feedback loops of experiences and stories from the patient community that can be useful for patients' self-evaluation or understanding of the care journey

"even if the Community reports something that well might be not super accurate from a doctor's point of view...It's still a situation that another peer can feel represented by right? Umm, so I think there should be somewhere a loop of verification, so that the comments coming from peers are not dismissed. "

The resources that the chatbot search engine provides should follow a curation/revision process to validate them, before including them in the repository.

The resources included in the repository should be curated/peer-reviewed to enable that the community support does not lead to harmful consequences or misleading other patients.

"I mean so that there needs to be a minimum set of curation...even if there is just a matchmaking tool, the thing that you match the query with still has to be to some extent minimally verified, right?...So the community aspect is important as long as it's it happens within a minimum boundary."

Indicate when to create new knowledge and based on what data.

The classifier should more clearly indicate when to refresh the knowledge and when to create new one, as sometimes knowledge that deals with that issue might not exist in the repository

"So here you are kind of refreshing existing knowledge right?... But there it might be the case that new knowledge has to come in right?"

Allow patients to retain agency over the data sharing by clearly asking them which messages they want to include in the medical reports.

Patients should control which data is gonna be shared with the medical professionals so that the trust the system and they do not feel the system violates their privacy.

"I would add like an if statement... Basically, if the patient wants like the yeah, if patient wants to some extent giving patients the agency...to decide what to share, right decide what to share."

Anonymisation of the patient community concerns is critical.

We should explore how to anonymize the patient community experiences, as it is search information and reported concerns that the patients have not consented to provide with their names.

"Community-level concerns are anonymized, I guess."

Include overlap level mechanism to avoid repetitions of threads.

The community support platform should contain a way to detect threads that overlap when the patient is creating a new thread, so that conversations about the same topic are not happening in two different places.

"In the part where they can actually create a new thread...So I would hearing show match results...I would add like an overlap level...So that you don't open a thread that is basically the same as the previous one."

Alternative recommender system that offers higher personalization to the contents.

There could be an option that if patient logs in more personal details, the system adapts further the content in terms of literacy and lifestyle recommendations.

"So something like lifestyle-related things...Umm, literacy-related things and I don't know...I'm thinking of in terms of literacy...The way you present the app or you make content accessible differs based on how much content accessible differs based on how much people know about the content and how aware they are...it's a matter of adapting the accessibility of the tool to the needs of of the user."

Moderate and control the spreading of misinformation through the community forums.

There could be not-badly-intentioned people sharing misinformation or spreading very personal beliefs that contradicts medical best practices. In that case, some moderators should review and control the topics to observe and stop the spreading of scams.

"I mean so that you know that the community doesn't go crazy and there is always night trolls...that they are sharing scams..."

Consider ethical and technical considerations about data storage and governance in the next phases of design development

We should plan and specify where the data would be stored, the access and review the data storage requirements before the development of the service system to ensure secure data governance and storage

"there would be the practical concerns of, OK, where where is the data stored? Where is the data governance?"

Session 3: ML expert

Anonymization tools or processes are necessary to include a community overview of patients' concerns.

Anonymization processes should be explored to be able to collect patient community concerns and classify them while respecting the sensitivity and personal nature of the data. Anonymization tools and algorithms could be designed to detect set of texts with identifiable data (names, locations, etc.), so the resulting text data is free from personal details.

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

Data management planning to warrant secure storage of the patients' concerns

We should plot a data management plan that specifies how we are storing the sensitive data about the patients' concerns and doubts.

"We have to specify where that's gonna be...Who's gonna have access to and how long it's gonna live?...Yeah. Same thing... you basically apply that same concept there...Who's gonna have access to it?...How long is it gonna be there?"

The social design and engineering is the main challenge to warrant clinicians' adoption of the service

The involvement of clinicians and medical researchers throughout the development, evaluation and implementation of the service system is critical to ensure the adoption of such a system and overcome the issues of reduced data and information to develop the model.

"Even if you had the clinicians willing to give you the time, give you the database, give you get this all up and running, you're gonna need to run some, like, clinical trials with users, with conditions that are low risk."

The ML model could be eventually automated by setting some triggers and indicators that activate the model to reupdate.

Eventually, the ML model can be automated based on some check marks. Some indicators that trigger the model to re-update and then swap the models, once the new model has been completed.

"eventually that technician can be phased out because you can automate, set some check marks that says, oh, this topic of concerns this many things, that means we need to trigger a classifier retuning, keep running this current version fine tune, swap them out."

Users should rate usefulness as the most important is that the chatbot retrieves useful resources effectively.

Rather than rating the relevance, the users should be prompted to assess the usefulness of the articles and resources. To what extent was it useful? How much has it helped?

"I think rather than relevance, I would rate it on usefulness."

Identify a sensible period of time to update the classifier model.

We should identify how often the dataset for the classifier should be fine-tuned with the data that the system is collecting. How often do we need to update the classifier database?

"So you're gonna need to figure out a threshold...How often do I do this fine-tuning and then each time you do that fine-tuning you can just wipe the data set."

The service system seems feasible on the technological side, but challenging on the social aspect.

The service system concept seems feasible with current state-of-the-art technologies and processes, it is more concerning to have the necessary people to build the system.

"But in terms of like implementation and like process and the technology like feasibility of it, yeah, I think it's all doable in today's world."

The chatbot could help to review the accuracy of the model by retrieving the topics.

The chatbot had previously associated the concern to a topic to provide resources that matches those topics. If the provided resources are not relevant. Then the chatbot could ask the patient whether the concern is related to that topic, to analyse whether the model was off.

"you can have the bot say so if they say no, this isn't useful, you can say hey, I looked for information according to this topic, is this topic related to your concern?...And then if they say no, then you ask them to report the concern because that's where you can say, OK, my classifier was off."

Collecting individual patient concerns to allow clinicians to reply to those concerns should follow a rigorous data management plan

A critical aspect would be to ensure that only the clinicians have access to the individual concerns of patients. The data management is highly relevant for this feature.

"I would just caution the aspect of be aware of the privacy concerns to make sure that it's just the clinician and user that are seeing that information ."

An engineer to investigate and determine how often the model needs to be updated in the early stage.

A ML engineer who is familiar with classifiers should be updated or fine-tuned based on the data collected. Ultimately, the system could continue running automatically once the settings/ criteria to fine-tune the model have been defined.

"I mean, in the early going, maybe the technician... like pretty much any running-the-mill machine learning engineer is gonna know how to do this...And the like real value they're bringing is based on this data. How often do I actually have to refine-tune or reupdate this model?"

Limitation of having enough data and stakeholders to build the service system.

The limitation of this service concept to bring together the participation (stakeholders) to build the service system and also collect the necessary data to test, develop and implement such a service system.

"I think it's honestly very feasible the I think the issue is going to be it's almost like a cold start issue, right?...So to get this classifier like off the ground, get the chatbot the ground, you're gonna need really direct connection with the clinicians at Erasmus, which it sounds like you kind of had, but you're gonna have to have their willingness and their time to, like, give you the data to be able to build these things to, like, actually construct all of this... "

Ask users whether they want to flag/ report this doubt to medical team, and then anonymise it after being sent to synopsis.

The system could detect the concern and ask to report this doubt to the clinician. Once it is sent to the individual report of patient doubts, the text is anonymised and classified in the community overview.

"And then in the case of a concern, you have that flag that says, hey, we wanna report this...So in this data set, you now send that off to be part of the report and then in your preprocess you would anonymize and treat."

The service system should be developed through a progressive trial process to warrant the accuracy and effectivity of the model.

The service system should be developed through a sensible development and evaluation plan that combines clinical trial of the technology with actual patients to test that the system does work and there will not be any fatal mistakes.

"you'll want to come up with a good, like, introduction plan...Yeah, of once you have the tool, how are you going to, you know, ease this into the process so that you can make sure that you're collecting these reports of concerns...You're fine tuning this...You're really smoothing out the process, improving the user experience so that you know that when you start going to multiple hospitals, you're like this is a tried and true thing...you know, it's not perfect...it doesn't have the world's knowledge in it, but it's good enough the the chances that there's gonna be fatal mistakes are tiny."

Session 4: ML expert

Augmented retrieval generation enables a chatbot that lists matching resources and explains them to the patients.

Through augmented retrieval generation, the model can generate sentences to summarise or explain the knowledge resources.

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

The Augmented Retrieval generation could summarise the content in a few sentences or provide the initial lines/ subheading information

It could be possible to provide some introductory lines to the matching resources or a summary of the content, so that users can decide whether it is useful or not before checking the entire resource.

"You can summarise the documents or just give the first few lines and then just give the link to the person so that they can read it."

Dealing with the cold start problem through a comprehensive roadmap, and defining stages of implementation.

Developing and implementing the service concept in stages makes sense to deal with the cold start problem, when you lack representative amount of data.

"I think my initial thoughts would be it's good that you're going through stages because especially when you use machine learning, there is always this problem called the cold start problem..."

By identifying themes of the resources/ knowledge provided, we could oversee knowledge gaps.

We could identify themes/topics of the knowledge/resources that they are providing to the patients, to compare with categories of patient concerns.

"For instance, you can extract common themes from all the documents to categorize them to present them to the doctor...that's timely feasible..."

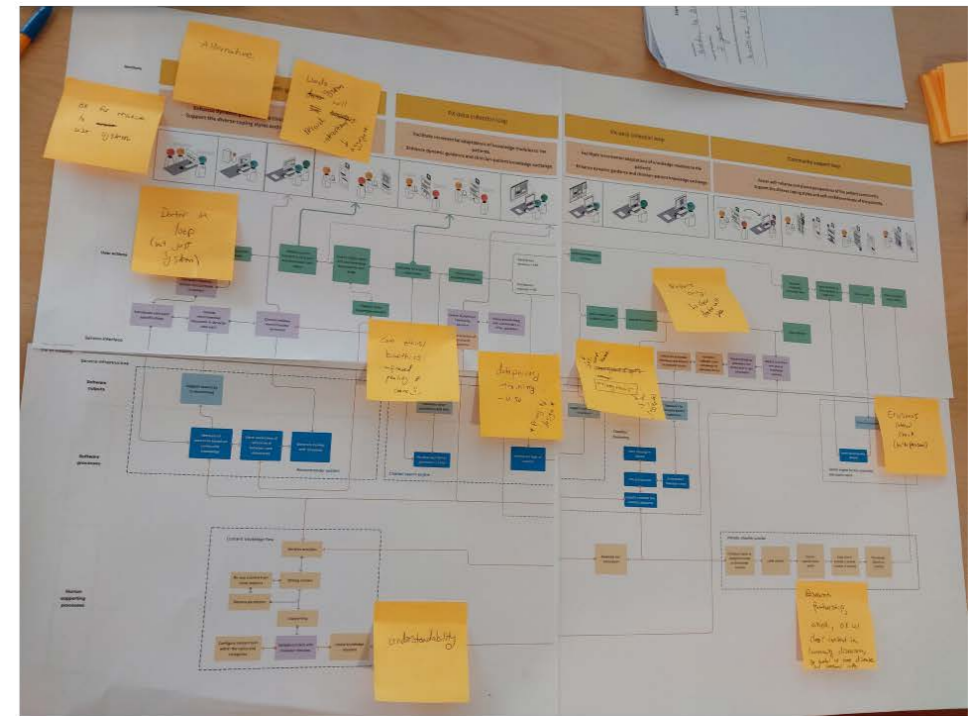By comparing themes of concerns and themes of resources provided, we could identify gaps in the information support.

By extracting and refining the topics of the patient community, and comparing with the topics of the resources provided, we could identify how we are covering information support for specific patient communities.

"...afterwards, for the information you can get from interacting with patients, I was thinking that and what that you would get all these questions?...and so based on maybe you could also like cluster their own questions by themes...So that it's kind of...and you see or you see what themes that are coming from the questions to the themes that you have in your documents..."

The software could combine the searches and the ratings to prioritise the resources that appear in the timeline.

We could use the top searches and the ranking together could improve the results that are provided as "Highly rated by patient community". By combining the searches that patients deemed helpful and the ratings of usefulness of each resource, we could build a more robust timeline of knowledge provision.

"...since you mentioned that you get the questions from the patients and you also know whether they answer that the document is relevant or not...I was wondering also whether you can use both information together to reclassify the documents this way..."

To provide knowledge resources through recommender system that learns from the ratings and themes of concerns.

Considering the themes of questions and concerns and the ratings, we could provide recommendations for the clinicians to include either existing knowledge in the templates or create new knowledge for the repository.

"So based on the documents, the theme of the question and what you know the answer, how relevant is it? I think you could also...So that would be kind of like the same as what recommender systems do..."

To use recommender system algorithms to connect information sources about patient experience and care path, and suggest existing resources.

By considering information of patients care path and the patient experience data collected, the recommender systems algorithms can suggest improvements in the templates of time-based information support.

"some information about their care paths, which brings you information about the...that...you have well some kind of recommender system algorithms...You can match the information of different patients to a different documents and whether those documents would be relevant."

The agency of the recommender system could be modified or adapted to suggest the resources either to the doctor or to the patient directly.

The recommender system could suggest resources to the patients or to the doctors directly. This could be explored further, to what extent the doctors prefer to control that or they would delegate to the bit, model this type of interaction.

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

The system should clearly explain that the data is collected to improve the recommended resources internally.

The recommender system would be beneficial to improve quality of care through the data collected. However, the system should be transparent to the users regarding that the data collected and that it is being used internally to improve the recommended resources.

"I think I would really need to explain to the patient how I would use their data and that I want to use it to recommend to other patients as well and make sure they consent to that too..."

The system should be trained with representative datasets that warrant the right performance for all patient community.

Before deploying the system, we should ensure that the model operates well for a broad range of patients. Having collected enough representative data and appropriate operation of the model.

"Maybe some patients might or not understand what you provide to them, so I think by using the recommender systems algorithms and the several documents that present the several documents that present the content in different ways like more or less difficult, more or less in depth."

The content design might need to be adapted to different patients' literacy

The patient communities may include patients with different literacies so they might need adaptations of the content design to ensure everyone understand the same piece of information provided

"Sure I also think that some of the recommender systems could work to adapt the content...but actually you could ask the doctor to transform this document into several documents that present the content in different ways like more or less difficult, more or less in-depth."

The recommender system concept could suggested to doctors how to adapt the content to different patients.

The recommender system algorithms could be used to suggest to the doctor what content needs to be adapted and to what level of literacy.

"but I also see it maybe that it would inform, I don't know which kind of doctor it proves to create new content bind to add this content to the system."

The service system could indicate the volunteer questions that there are no existing resources for yet.

The service system could enable doctors to refine the time-based information resources they provide to patients, but also to identify uncovered concerns that patients want answers for. Then, they can create new knowledge/materials for those resources.

"but I also see it maybe that it would inform, I don't know which kind of doctor it proves to create new content bind to add this content to the system."

The data inputs that a recommender system algorithm would be trained with could enable relevant provision of resources throughout the care journey.

The service should combine different data inputs. Then, through a recommender system, we can effectively present which resources are most relevant to the patient communities according to their stage in the care journey.

"but I also see it maybe that it would inform, I don't know which kind of doctor it proves to create new content bind to add this content to the system."

A challenge is to orchestrate and showcase the information processes outputs for good usability.

The design challenge when using the recommender system algorithm would be to orchestrate all these information flows and outputs and show them appropriately to the different stakeholders.

"I can just see the challenge for a designer I guess to actually present all this information in a clear way and that's a while users don't get overwhelmed."

Session 5: ML expert

The interfaces should be clear about which resources are automated recommendations and which are directly highlighted by a clinician.

The information support timeline along the care path should be clear about which resources have been highlighted by the doctor, which are highlighted by the patients and which by the system through the patient data.

"it's good to make a difference in the map on the journey to between the article that was like the Doctor put in and the article that recommended by the system and already have a different like layout for articles recommended by patients."

The system could incorporate the clinicians' responses as resources the chatbot/report flow provides when patients ask a question/doubt.

The service system could learn from the responses that the clinicians provide to individual concerns to improve efficiency of the clinicians to answer the patients' questions.

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

The classifier not only needs work to adapt to different illnesses but also to adapt to different contexts.

The classifier needs development to adapt to different cultural contexts and illnesses, the model that has been created for the context of Sarco in the Netherlands cannot be used for Sarco in China.

"there's, like work here in the classifier for the different illnesses and for the different cultural contexts to do, like fine tuning and not just use it out of the box."

A human should assess the classifier performance periodically to spot improvements and fine-tune it.

The service system might need a moderator that controls the classifier's performance periodically or identifies changes that should be made in the classifier. For instance, two topics that might need to be merged or a topic that needs to be split into two.

"It might like need some human also to maintain the database in the back end just so that like...one of the problems is that maybe keeps classifying things that should be in the same category in different categories, but the categories also are very similar...So it should merge a category."

The system to integrate into the clinicians' workflows and organizational structures.

The individual concern-solving flow should be carefully adapted to the nurse practitioners' workflow, so that they can feel that they act upon the information.

"So whatever kind of works for the clinician workflow of when they would like to input this text into the system..."

The chatbot could match the patients' questions with existing resources and progressively overcome the cold start.

A well-trained chatbot could be incorporated in the initial stages to avoid the cold start issues, when your dataset is reduced. In the case of the chatbot, the chatbot learns from you proactively, whereas a recommender system would need to first learn what you care about and then provide the recommended resources.

"I would say like you should have the chatbot from the start because the chatbot doesn't have this problem because it's not like the chatbot proactively asks you for recommendations or tips or recommendations...You go to ask the chatbot questions from the start."

Supervised learning methods to ensure the classifiers consistency and durability

The supervised learning could help to ensure consistency of the system, then the model only would need to be updated periodically.

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

The system to classify the newly added response/tip by the clinicians and then the moderators can add it to the repository.

The system could tag the medical tip/answer so that a human moderator cna review and add it to the knowledge repository, so that the ML model can match it when new concerns are raised in the report flow/chatbot.

"the system can automatically tag it with the classifier and the moderator just adds it to the knowledge base that you have..."

The chatbot fits better when the system has just been deployed in a new patient community.

The chatbot is more efficient at the beginning of the implementation roadmap, as it does not need to collect data from many users to identify which articles are less or more relevant/usefulness to the patient community. It proactively matches the community concerns with existing resources.

"I think the chatbot is a much faster way to Start learning what this user cares about...Than just looking at the implicit feedback from whether or not there is articles, whether or not they like the article, whether or not."

Supervised and prescriptive model that affords easier maintenance of the system

The supervised model would ensure more sustainability and better maintenance of the database than unsupervised techniques.

"It could be here more prescriptive than it would be easier to maintain the database, but someone here...some sort of human should, uh, keep an eye on it and not like, yeah, completely itself."

The system could store clinicians' responses to specific questions to inform the rest of the patient community

The system could request the patients whether it is okay if the system stores their concern and the answer received from the doctor to reuse this medical tip with other patients in the future.

"in that case you can ask patients if that's OK, like the doctor said this, can we save this and keep it somewhere? So other people can also see it."

Prior to including a clinicians' response to a patient concern to the repository, we must consider deleting/generalising details about the patients' profile.

If the question includes information about the profile of the patient, then we should request users' consent to share the clinicians' responses.

"If it's like feeling bloated, this is what you do then you don't care about the patient's privacy, but if it's like this specific patient to like, ask if what if you're having, like super like this with this kind of health profile...Then this is what you should do then that's closer to the actual patients situation is, yeah, and you should be like asking patient if if it's OK to share like the style of the question and the content of the question along with the answer with other people..."

The interface should distinguish between what is a direct information recommendation by a stakeholder and what is recommended by the ML model.

The service interface should clearly indicate what has been selected by a person (even if based on the system's recommendations) and what has not

"you could say like here like the first tab is like curated knowledge should be like...auto-generated knowledge...but then you just need to make a distinction between what is selected by a person and what isn't."

Session 6: ML expert

Identify which resources could be improved in terms of the clarity/written style

The service interface could prompt the patients to rate also the understandability or clarity of the resource...so they can learn which resources to improve/refresh based on the patient community ratings.

"would you ever consider rating the understandability? Just because of these are written by doctors...Sometimes there can be highly too complex jargony words for patients."

Specify the purpose of the report flow and rethink the need for chatbot for the report flow.

The chatbot would need a lot of sensitive data to be trained and afford the augmented retrieving generation. A more simplified search engine could fit the same purpose but in a way that only searching terms need to be protected from data leakages.

"is this chat bot using this particular LLM system going to be better than say a more basic search engine thing gets the same job done but then we only have to worry about protecting searching terms?"

Avoid replacing the individual point of view with community overview.

The community overview should not replace the individual thoughts and considerations. Both should complement each other.

"we shouldn't, couldn't uplift the voices so that we shouldn't, you know, replace personal perspectives with sort of community aggregate data."

The system should clearly indicate at the beginning that interactions will be recorded and anonymised for system improvements.

To inform the patients that the searches will be recorded for system improvements, we could clearly indicate it in the onboarding, and let clinicians also communicate it. We should be transparent that even though anonymised, the interactions will be recorded for learning purposes.

"I was thinking maybe in the beginning of the system you could say all interactions with the system are recorded in aggregate or something, you know, put together."

Before being added to the community overview or classifier, the patient concerns should be anonymised.

All the personal details that medical professionals don't need to make decisions should be anonymised.

"I would definitely anonymize it on the way."

Be clear and loud about the data that will be included in doctors' reports.

The system should repeat several times and be clear about the fact that mentioned reported concerns will shared with doctor, so that patients do not unwillingly end up sharing things that they would not want to share with doctors.

"It's important that they're aware if they're engaging with the system that the doctor will be able to see this...because sometimes we over trust technology and we share things with technology that we wouldn't share with others."

Ensure restricted access to the individual concerns and avoid unwanted slips.

It should be clearly communicated that the doctor will see the data they are reporting and ensure that the access to the data is carefully protected, and only the designated medical professionals can actually see it.

"So I think that's OK as long as you make it clear that their doctor...the doctor will see...And that you stay true to your word like from a data protection standpoint. Yeah, doctorate... like keep it there and treat it like patient data...treat it with the sensitive data protections that it deserves."

Find balance between seamless user experience and reduce data-sharing risks.

We should investigate how to preserve the desired user experience but also ensure data privacy. Perhaps other algorithmic techniques would need less data to train them. The system would be simplified for sustainability and to meet better data privacy regulations.

"does it have to be a chat, but could there be something that's more data privacy preserving that you could also get feedback on like a decision tree like that?...You know that wouldn't require the use of so much sensitive data...I don't know...Like in order to train and set up."

The data technologies should contribute to empathising with vulnerable communities and include their feedback.

The community overview dashboard could help improved quality of care in a meaningful way. So empathising and learning from the patient community concerns to make decisions on how to improve quality of care.

"I just wrote that I liked this...you know, from, like, I care ethics, bioethics, perspective...I mean that's an ethical positive...Yeah, I think it's just about dealing with vulnerable people and trying to meet their needs and to be receptive to their feedback...And this is a nice way of sort of improving quality of care and integrating it into the healthcare system."

Keep alternatives open for patients who are reticent to use the system.

The system should provide alternative communication flow for patients who do not want to participate in this system or share their concerns through this flow.

"I guess I should have said at the beginning there has to be an alternative throughout all of this, do not consent to the system...Yeah, so not to have and still get a good quality of care...to still be like OK, in that case you can still email the nurse practitioners, or you could still do something."

Chatbots afford a more human conversation style which also leads to the data being more personal and sensitive.

Through chatbots, some patients might modify their message to share information in a more human way. They might then share very personal details, so the data protection measures should be more strict.

"They feel safer, but I also say it's a bit "evil" in quotes because people can, you know, attribute human characteristics to they can trust it more, can give more away, which means that we need even more stringent data privacy protections and using responses..."

Consider also the searching data to add to overview that informs about what the patients are looking for.

Including the search terms in the community overview could help to also take into consideration the concerns that patients try to research about, even if they succeed in finding the resource.

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

Enable relatives with given consent from patients, but consider ethical considerations.

If relatives want to use the system, we should afford a way for patients to actively provide that consent and verify that the relatives are not misusing the system to harm the patients.

"are you OK with your relative having access to the system like you know, maybe that's the best we can do at that stage, because otherwise it's gonna get really complicated."

Restrict the system to patients with high cognitive capacity due to ethical considerations.

Patients that also have cognitive impairments or dementia should not be included in the system without carefully assessing their specific needs. Otherwise, the system is not ethically verified to warrant the usability or accessibility of those patients to the system.

"I would restrict this to people who have shown, you know, have demonstrated, you know, still high cognitive capacity. You know that kind of stuff, because I think having it was such a vulnerable population just because the ethical concerns, you know to the roof."

Session 1: Clinical expert

Care milestones can reflect the evolving needs and concerns for diseases with unpredictable progression.

For degenerative diseases with an unpredictable progression, milestones would provide a more relevant overview of the patients' concerns to the clinicians. Since the years does not match the nature of the disease.

Participant: "would you be able to make... to change this to the location of the care path where the patient is in, because...pulmonary fibrosis is a very heterogenetic disease like it's not very predictable how the patients will progress within years...maybe after they started oxygen therapy.

Researcher: "oh, like those milestones?"

Participant: " yeah, milestones...to put in milestones..."

Visualizing evolving care needs should adapt to the behaviour/progression of the disease.

The predictability or the behaviour of the disease, meaning how it progresses, is a relevant factor visualize patients' concerns with the aim of improving quality of care.

"I think per disease you have to see how progressive is the disease? How predictable is the disease?"

Doctors might be more reticent to use these services if they are not integrated within current medical record systems

An adoption hurdle for this type of intervention is the integration of this service within the current applications to monitor the patients progress and keep track of their medical records.

"I think if you provide this as a separate module then it it'll be more difficult to implement than when you put it in these applications and also ErasmusMC is working on its own application. "

Mental models is a prominent hurdle in the adaptation of this service concept to different departments.

One important challenge to adapting this service to different chronic diseases is the different mental models, beliefs and values that the practitioners might hold towards eHealth applications. Fortunately, the society is increasingly accepting those innovations in the medical setting.

"I think it's all depends on how healthcare professionals and what healthcare professionals and patients think of it...Patient and healthcare professionals are getting more used to eHealth applications and uh, it's like a whole cultural change of yeah, of healthcare that we're currently in."

The service is a tool for patients to have longer access to the knowledge support along their care path.

The service would complement the clinicians' role in the sense that it allows patients to revisit the information and the tips that clinicians provide in the hospital.

"when you integrate this machine learning then you'll get specific feedback based on what other patients report in this phase of the disease. For example, when a patient starts with oxygen therapy...but then they'll get specific information about the oxygen therapy there, because they will get this information in the hospital as well, but it doesn't stick always with patients because they'll get a lot of information in one day."

Care path specific information fits the interaction between nurses and patients to fill out their care plan.

Patients are aware of their care plan as they discuss it with the nurses. So this application fits the context since patients are aware of the milestones but the system could guide them in the care path, let get access to specific information according to their stage.

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

Linking self-reported symptom progress with information retrieval for patients for improved quality of life.

Retrieving knowledge resources when patients input new data about symptoms would be quite a meaningful improvements as it would be more connected to the remote monitoring of clinical data.

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

The care path shouldn't be fed per patient all the time by the healthcare professionals but it should be more automatic.

The healthcare professionals do not have the time to be changing the templates all the time, it would need to be periodically, like every 6 months, or when the community overview has been updated or fine-tuned. But the changes should be stored as templates that are reusable and do not be to be changed every time.

"I think the personalization part of adding this knowledge resource based on what patients fill out the symptoms is very nice.....but it shouldn't be like changed by the healthcare professional."

Promote self-management by providing resources based on progress of symptoms.

Patients could be able to monitor their symptoms' progress and get relevant resources based on their worsening of certain symptoms and improve how they are feeling.

"when you are in this phase like starting oxygen therapy that the patient will receive the baseline questionnaires and when and like cough, fatigue, shortness of breath, General well being...that the patient has some worsening of scores there that you'll get specific tools for the complaints he or she reports.."

Valuable to provide resources based on the patients' concerns and keep improving from there.

The idea of having resources per stage of the disease based on self-reported concerns by patients was found very relevant, and especially being able to improve based on the self-reported doubts.

"also the most important...nice part of this is that it's based on reports of other patients...but once you implement it and you have to like improve it...Yeah, based on new reports"

Care path-based information support is highly relevant for the clinical expert, especially according to the milestones.

It would be beneficial if they implement the care path with specific information. Through this interaction, the patients could see which stage they are in right now and understand which resources are recommended by the patient community and the clinicians for that stage.

"I was thinking of this, this was really help in like if we could implement the sort of care path in the application because we don't have it yet...And they will get really personalized information about the phase of the disease they're in right now"

Session 2: Clinical expert

The topics indicate better how to answer collective concerns and they should also be quantified to compare concerns more truthfully

The clinical expert pointed out very sharply that the topic is better at indicating how to curate and expand the knowledge repository since the categories are too abstract. The topics better indicate what to write about.

"I think the topic is more interesting at every step of the way, because that's the question you need to answer...Yeah, doesn't really matter if these are all 4%, but that together makes I don't know 50%...It's less relevant than if there is one question here...That is, for example, this one topic that's 30%."

The topics are more useful to curate new knowledge but the categories provide a sense of overview to interpret community needs.

The category is better to have an overall picture of the community needs, but if you want to create new specific knowledge or resources, then you would be to investigate the topics.

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

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The system should remain as neutral and unbiased possible when recommending knowledge

By recommending different knowledge based on your personal details and preferences, the technology could be stereotyping the patients and missing information that could be beneficial for some of them. This could lead to different patient health outcomes, so maybe some would learn how to manage their symptoms better.

"I'm wondering if maybe the issue with that also is that if you do that, then you're nudging people to...So for example, if women more often look at this page and then more often look at that page and you're offering that page, you're also making the assumption that they want to see more of them and you're not giving patients the same informational content...I don't know if it's a problem because it feels like you may maybe do some stereotyping there and it might lead to differing health outcomes."

Efficient retrieval of documents to respond to specific concerns

It would be interesting to have a feature to let the nurses and doctors efficiently retrieve a resource and document, and share it to respond to a specific question from a patient.

"wouldn't you want here also be able to respond with things from the repository? Because maybe the computer hasn't found it yet, but you know that you that there is a topic about it that you want to select and read this."

Health content expert to manage the creation and implementation of content into specific categories and topics.

There should be a designated health content creator that manages the overview and identifies specific content or resources that should be created to fulfill better the patients' needs.

"because this is more something I would see in a workflow, I mean the the prior thing is more like a popul- group health management...So that I wouldn't fit that in a direct patient care flow..There's one person or two that has a couple hours per week to update the repository and to see what new topics are the most asked question that we don't have information for...So that's more, yeah, a content creator actually like like you would have for for the website or something."

Individual question answering could be integrated into everyday workflow

The dashboard for individual patients' doubts is something that would fit better in the clinicians' workflow, so each health professional knows specific questions that they need to respond on a weekly basis.

"this I would integrate in the direct patient care...For example, the nurse practitioner that has, uh, for example, every two times a day at at lunch or at the end of the day has one hour to answer all these questions.."

Classifying answer from nurses into the topics for future content creation.

The dashboard could visualise the concerns that have been answered and cluster them into a topic, so that the answer from nurses can eventually be combined into a more complete resource.

"you might just be able to click on the topic and see already the questions that have been answered...We combine those answers and we push it to the repository as the answer to this kind of future questions...So you might reuse the messages you sent back to the patient."

Professional that controls everybody's accessibility to the system regardless of literacy or socioeconomic situation.

There should be a professionals that controls that patients can understand the system and that they are not skipped due to low literacy in health-related topics or other socioeconomical factors.

"you would need a very like some sort of safeguard that just looks at how it works for patients with low health literacy or with different socioeconomical classes."