Appendices

Appendices

3 Appendix 1: Project Brief

8 Appendix 2: Initial Journey; Select Platforms for Topic Modelling

9 Appendix 3: LDA Topic Description

13 Appendix 4: NMF Topic Description

18 Appendix 5: Human Research Ethics (HREC Approval)

20 Appendix 6: Expert Survey

21 Appendix 7: Experts' Topic Cards

24 Appendix 8: Experts' Journey Map

27 Appendix 9: Informed Consent

29 Appendix 10: Diary Studies Finished Probe

36 Appendix 11: Interview Material

37 Appendix 12: Designers' Brainstorm Session

41 Appendix 13: Show Case Thinking Process

Appendix 1: Project Brief

Personal Project Brief - IDE Master Graduation

TU Delft

Design a remote monitoring system for colorectal patients after surgery — 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 27 - 02 - 2023 — 14 - 07 - 2023 end date

INTRODUCTION **

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

The development of prevention and treatment technology has led to an increasing number of cancer care survivors. Many cancer patients are able to survive and back to life. However, with an ageing population and a rise in cancer incidence worldwide, access to cancer care is under strain. How to balance the working pressure of medical workers and cancer patients' care outcomes and their satisfaction will be an urgent problem in developing a sustainable healthcare system.

Colorectal cancer (CRC) is a typical example in this context. It is the third common cancer in the Netherlands and 9,411 people were diagnosed in 2021. The whole carepath for CRC patients in the Netherlands includes three parts: (1) diagnosis (2)treatment (3) five-year follow-up. The focus will be on five-year- follow-up stage, because despite the high prevalence, around 90% patients can be cured with treatment and on average, 60 out of 100 people are still alive 10 years after diagnosis. So there are a large amount of patients are trying to improve their long-term health-related quality of life(HRQoL).

In the Netherlands, after the surgery patients still need to go to the hospital back and forth for checking their physical condition, including carcinoembryonic antigen (CEA) test and CT scan. Researches have suggested that repeated trips to the hospital not only cause inconvenience for patients, but also increase their anxiety because of the negative experience they have in the hospital. Therefore, a remote monitoring system is a suitable solution for CRC patients, empowering them to have a better understanding on their own body in a more convenient and comfortable way.

While improving the patients' experience, the medical staff's working experience should also be taken into the consideration. Nowadays doctors and nurses are suffering from a huge amount of caring work, so balancing and designing a better workflow for doctors will be another point.

There is a developed patients community journey map that explains patients' context. The topics are from an online forum and shaped by computer(topic modelling). Topics are divided into two parts: Home and Hospital. The map shows that the topics more to the hospital(home) side, the more rational(emotional) patients are. But in the middle parts, when patients are talking about topics related to both sides, they are being uncertain and confused.

Therefore, the main graduation project research question will be: what is the criteria to designing a remote monitoring for colorectal cancer patients after their surgery considering both patients'(home context) and medical professionals (hospital context). The goal is to develop a remote monitoring system based on the criteria.

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introduction (continued): space for images

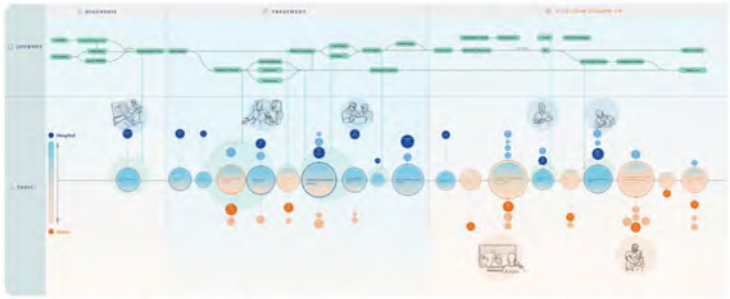


image / figure 1: CRC patients journey map based on an online forum: Understanding patients context

image / figure 2: Research question forming process

Appendix 1: Project Brief

Personal Project Brief - IDE Master Graduation

TU Delft

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.

Colorectal patients need a better living and follow-up experience after their surgery, but doctors' well-being and workload are also very important. The criteria for finding a balance between these two characters is not very clear for developing a sustainable remote monitoring system, which should be beneficial for both patients and medical professionals.

So the main graduation project research question will be: what is the criteria to designing a remote monitoring for colorectal cancer patients after their surgery, considering both patients'(home context) and medical professionals(hospital context). The goal is to develop a remote monitoring system based on this criteria.

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.

To design a remote monitoring system, I will start with doing research for defining a criteria for the system and developing the system based on the criteria. I want to know what is the current situation and research in this topic and try to bring a fresh view to medical system from a design researcher's angel.

I will first do a literature review on the current research on remote monitoring systems, investigate and design a criteria for developing the remote monitoring system. The criteria should be present in a systematic way which include: Atlas of cancer patients in the Netherlands; Patients' pain points and expectations(Home context); Medical professionals' pain points and expectations(Hospital context); The balance between patients and medical professionals expectations(the middle parts) and some evaluation items to help developing design.

The expected result will be a remote monitoring system (mainly a feedback mechanism) which is a product service system including a prototype and service flow behind it. It should be a product that consider both patients' and doctors' benefits and able to create a dynamic interactions between them, bringing fresh knowledge to medical field.

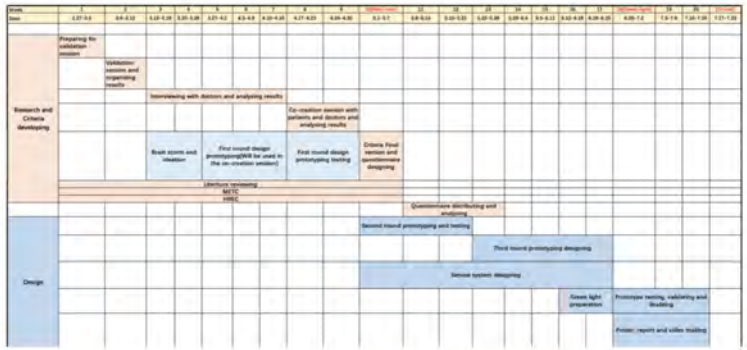
Personal Project Brief - IDE Master Graduation

TU Delft

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 27 - 2 - 2023 14 - 7 - 2023 end date



5 days a week.
Mid-term presentation will be between 5.1-5.7
Green light will be between 6.26-7.2
Final presentation will be around 7.17

Main activities
1. Validating and improve the map to see if it fits the Netherlands context.
2. Shaping the criteria by using the validated journey map and interviewing with doctors.
3. Co-creating session with doctors and patients: validating the criteria, what are the values for them and finding opportunities for the monitoring system.
4. Questionnaires for validating the ideas of opportunities
5. Design monitoring systems and prototypes.
6. Design testing and validating

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TU Delft

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Initials & Name Y. Sun Student number 5514495

Title of Project Design a remote monitoring system for colorectal patients after surgery

Personal Project Brief - IDE Master Graduation

TU Delft

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.

Motivation:
My interest is always medisign. In my master mandatory courses I all choose healthcare related projects or topics (DSP, SPD Research, SPD Media, C&C and so on). My internship is also healthcare related, which is about doing user research and finding opportunity in remote monitoring system. So my graduation project will be medisign related for sure.
Competences:
I have learned a lot through SPD. I always enjoy researching because there is never an end. New things and findings keep popping out and excites me a lot. Therefore I will never stop doing research, and I am trying to improve my research skills. My in-depth interviewing and communication skills also has a great improvement during my learning at IDE, but organizing co-creation sessions still has a long way to go . Therefore I want to shaping these skills in my graduation project.

Goal and ambitions:
1.Try my best to develop the project and make my designs work in practice
2.Sharping my skills that have mentioned above
3.Keep reflecting

FINAL COMMENTS

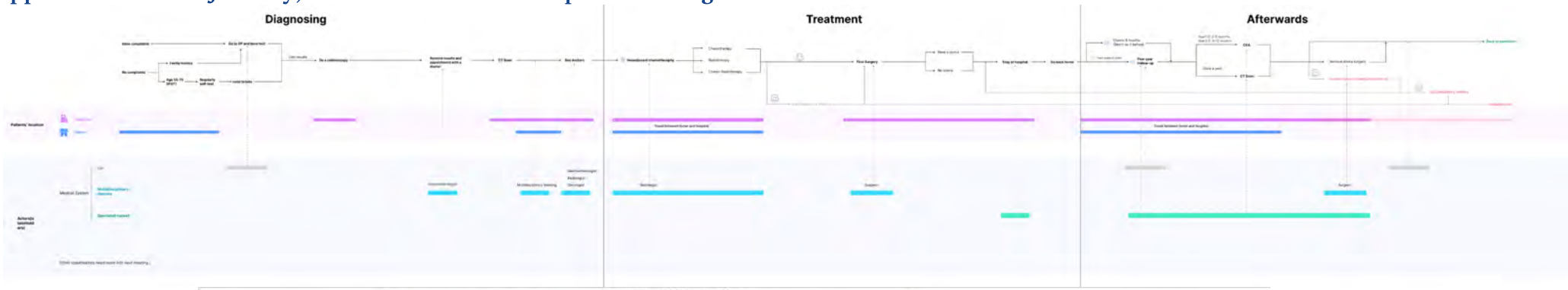
In case your project brief needs final comments, please add any information you think is relevant.

Specify what "criteria" mean.
It is good to start a first round of design before mid-term and use the prototype as a tool for the co-creation session..
Because this is a more research-oriented project, the information should be able to publish. More literature reviews are helpful especially in the current situation of the remote monitoring system.
Deep dive into the dynamics of interaction between doctors and patients will be interesting.

Initials & Name Y. Sun Student number 5514495

Title of Project Design a remote monitoring system for colorectal patients after surgery

Appendix 2: Initial Journey; Select Platforms for Topic Modelling



Name	Country	Number of posts	Average sentences(S)/Responses(R) each post	Characteristic of the posts	link	
Stories						
Kanker	NL	66*10 (blog) Forum--> 738	40 S	#Diary	https://www.kanker.nl/ervaringen-van-anderen/blogs?cancer_type_target_id%5B2720%5D=2720&title=&name=	
Canadian Cancer Society	Canada	4 forum (443)	20 S 5 R	#Support #Consulting	https://cancer.ca/en/about-us/stories?tags=87b638c71b2b43dfad130a3a99a4633f https://cancerconnection.ca/discussions/viewcategory/64#	
Healthtalk	UK	41	20 S	#Challenge #Experience #Advice	https://healthtalk.org/colorectal-cancer/overview	Interviews type
Colorectal cancer alliance	USA	33	25 S	#Diagnosis and curing process #Hope	https://www.ccalliance.org/blog	
Colon Cancer Coalition	USA	around 185	15 S	#Memory	https://coloncancercoalition.org/category/stories/	
Bowel Cancer Australia	Australia	299	30 S	#Diagnosis and curing process #Hope	https://www.bowelcanceraustralia.org/bowel-cancer-stories	
Bowel Cancer UK	UK	5000 posts (2508) 2012 yr	10 R	#Emotion #Daily life #Consulting	https://community.bowelcanceruk.org.uk/forum/living-well-with-bowel-cancer?p=14	
Colorectal Cancer Canada		31	30 S	#Diagnosis and curing process #Hope #Advice	https://www.colorectalcancercanada.com/stories/	
Digestive cancers europe	EU	around 26	30 S	#Diagnosis and curing process #Advice	https://digestivecancers.eu/patient-voices/	
Forum and others						
American Cancer Society: Cancer Survivors Network	USA	forum (200,000)	6 R	#Consulting	https://csn.cancer.org/categories/colorectal	
Cancer support community	USA(Global)	forum		#Support #Emotion	https://www.mylifeline.org/discussionboard?search=colorectal&page=1	
Fight Colorectal Cancer (Inspire)	USA	forum (3206)	4 R	#Consulting #Research	https://www.inspire.com/groups/fight-colorectal-cancer/topic/patient-webinars/?section=All%20Posts&order=active&topics=living-with-cancer https://fightcolorectalcancer.org/resources/?connection%5B%5D=patient-survivor&language%5B%5D=english	
American Cancer Society	USA	5		#Hope	https://www.cancer.org/latest-news/stories-of-hope.html?tag=cancer-types%3Acolon-and-rectal-cancer	
The Ohio State University comprehensive cancer center	USA	6			https://cancer.osu.edu/our-impact/patient-stories?page=1	
American Association for Cancer Research	USA	7			https://www.aacr.org/patients-caregivers/survivor-journeys/?pagenum=11	
Canadian Partnership against Cancer	Canada	3			https://www.partnershipagainstcancer.ca/?s=&post_type=topics&taxonomy=dbt-cancer-site&term=dbv-colorectal	
California Colorectal Cancer Coalition	USA	8(pravite)			https://www.cacoloncancer.org/digital-storytelling/	
Singapore Cancer society	Singapore	7			https://www.singaporecancersociety.org.sg/stories/stories.html	
City of Hope	USA	2(can be more)			https://www.cityofhope.org/patients/patient-success-stories	
PENN Medicine	USA	1			https://communityimpact.pennmedicine.org/drive-walk-mail-text-colorectal-cancer/#	A story related to the black
Company: SYSMEX	EU	3			https://www.sysmex-europe.com/products/life-science/colorectal-cancer.html	Company
Cancer world	EU	1			https://cancerworld.net/beating-the-odds-in-colorectal-cancer/	Magazine
National Colorectal Cancer	USA				https://nccrt.org/resource-center/	Distinguished target audience
MacMillan cancer (UK)		4665			https://community.macmillan.org.uk/cancer_types/bowel-colon-rect	

Appendix 3: LDA Topic Description

topic	keywords	weights	topic_description	AIsummarization	(Jiwon)Hospital can provide information/advice about...	My summarization
0	['chemo', 'work', 'great', 'well', 'insurance', 'pray', 'keep', 'result', 'pay', 'hear']	[0.01897845, 0.015820298, 0.011817918, 0.010751712, 0.0102995215, 0.009541342, 0.009182008, 0.008420595, 0.008191266, 0.00797155]	The LDA discovered topic is about dealing with the financial implications of chemotherapy. The keywords indicate that the topic may be about managing insurance, paying for treatments, and praying for good results. The weights suggest that these are all important aspects of the topic, with paying for treatments and praying for good results having a slightly higher importance than the other aspects.	Chemotherapy, work, insurance, prayer, results.	Home (action point): how to deal with work, insurance, and money related issues during their carepath (context that needs support)	Work, insurance, money related issues
1	['chemo', 'well', 'cancer', 'year', 'day', 'time', 'thing', 'feel', 'treatment', 'really']	[0.012987182, 0.012292476, 0.011061726, 0.010850508, 0.010664458, 0.010017009, 0.009089918, 0.0086251395, 0.0067075994, 0.0064463494]	This LDA discovered topic is about chemotherapy treatments for cancer. The keywords chemo, cancer, treatment, and really indicate that the topic is related to chemotherapy, and the associated weights suggest that this is the primary focus. The other keywords such as well, year, day, time, thing, and feel indicate that the topic may also cover the experience of undergoing chemotherapy, including what to expect and how to cope with it.	Cancer chemotherapy treatment experience.	Home: how to adopt to the changing lifestyle due to cancer	Cancer and treatment can change lifestyles; Questions about some symptoms(side effects); Giving people advice on treatment
2	['well', 'work', 'feel', 'day', 'much', 'treatment', 'help', 'great', 'really', 'time']	[0.013111653, 0.010016038, 0.009783108, 0.009540772, 0.008815336, 0.008180419, 0.007635459, 0.0072563887, 0.007223023, 0.006878718]	Based on these keywords and weights, the LDA discovered topic appears to be about mental health and well-being. The words "well," "feel," "treatment," and "help" indicate that the topic is related to mental health, while the words "work," "day," "much," "great," "really," and "time" suggest that the topic is discussing how to maintain mental health and well-being in day-to-day life.	Well-being through work and treatment.	Home: how to live their daily lives when side effects and when pain exist	Side effects advice; expression of pain; lifestyle changes; life goes on anyway
3	['pain', 'chemo', 'day', 'well', 'start', 'liver', 'first', 'back', 'time', 'bad']	[0.020989977, 0.0151404645, 0.011143439, 0.011014273, 0.010813455, 0.0091864885, 0.008923006, 0.008755577, 0.008728825, 0.008614737]	This LDA discovered topic appears to be about the effects of chemotherapy on the liver. The keywords of "pain", "chemo", "liver", "first", "back", and "bad" all point to this topic. The weights of the keywords also suggest that this topic is about the physical and emotional pain that can come with chemotherapy, the difficulty of returning to normal life after the first treatment, and the overall negative impacts of the experience.	Painful chemo on liver first day.	Home/Hospital: what to expect as side effects	Description of side effects
4	['well', 'time', 'year', 'last', 'day', 'tell', 'really', 'thing', 'back', 'look']	[0.014523212, 0.014168057, 0.011457237, 0.010541823, 0.0091079995, 0.0075202687, 0.0069845185, 0.0065693976, 0.00656768, 0.0058524725]	This LDA discovered topic is about reflecting on the past. The keywords indicate that it is focused on looking back to the last year, day, or time, and really telling or examining what happened. The weights reinforce this idea, as they suggest that the keywords are all important in understanding the topic.	Reflecting on past year.	Home: how to plan for the future (living with cancer)	/exploration of emotional pillars; sharing advice; taking stock of past lives and planning for the future
5	['time', 'well', 'year', 'much', 'cancer', 'day', 'hope', 'thing', 'find', 'help']	[0.022898602, 0.012931456, 0.012621735, 0.011272158, 0.009929297, 0.009774243, 0.009540942, 0.0091705015, 0.009084476, 0.007716314]	The LDA discovered topic appears to be about health and hope, with a focus on cancer. The keywords such as 'time', 'year', 'day', 'hope', and 'thing' suggest that there is a need for hope and for people to find a way to get through difficult times. The keywords 'well', 'much', 'find', and 'help' point towards the need for people to find the resources and help needed to fight cancer. The weights suggest that the topic is centered around cancer, with the other keywords being used to express the need for hope and support in the fight against the disease.	Finding hope for cancer in time.	About what??	Giving gentle advice to peers and sharing your own mindset
6	['help', 'day', 'sleep', 'really', 'well', 'night', 'doctor', 'chemo', 'home', 'find']	[0.0131252445, 0.012977166, 0.009258864, 0.009140706, 0.008073298, 0.008040814, 0.007550902, 0.0075331763, 0.0069359792, 0.0067751226]	This topic appears to be about managing the effects of chemotherapy at home. The keywords suggest that people are looking for help to find ways to cope with chemotherapy, such as getting enough rest and sleep during the day and night, as well as finding ways to feel well and get the support needed from a doctor. The weights indicate that these are all important topics to consider when dealing with chemotherapy.	finding sleep help during chemo at home.	Home: how to manage to live with side effects	Description and management of side effects
7	['family', 'love', 'friend', 'pray', 'time', 'sorry', 'fight', 'much', 'well', 'hear']	[0.026722454, 0.016443139, 0.015317324, 0.014661908, 0.013410516, 0.013117382, 0.012731247, 0.012032617, 0.011384764, 0.010941494]	This LDA discovered topic is about relationships, particularly family and friends. The keywords indicate that the topic is about expressing love and appreciation for those close to us, as well as apologizing for mistakes and making peace after a fight. It also implies that it's important to make time for those we care about and that things will work out well in the end.	Relationships, love, forgiveness.	Home: how to live as family member of patients	A remembrance of a companion, an understanding of love and support for the family
8	['feel', 'cancer', 'time', 'thing', 'life', 'give', 'hope', 'find', 'husband', 'people']	[0.021129148, 0.015668483, 0.014664678, 0.013658396, 0.00885549, 0.008250992, 0.008187036, 0.008083698, 0.007944793, 0.007113854]	This LDA discovered topic is about finding hope and support while dealing with cancer. The keywords 'feel', 'cancer', 'time', 'thing', 'life', 'give', 'hope', 'find', 'husband', and 'people' indicate that the topic is centered around providing emotional and practical support for those dealing with cancer. The weights of the words further emphasize the idea of finding hope and comfort in difficult times, with 'hope' having the highest weight at 0.008187036.	Finding hope in cancer life.	Home: how to keep healthy relationship with family (children and partner)	How to face and deal with relationships and emotions of relatives (especially children), intimacy of partners
9	['post', 'cancer', 'people', 'well', 'help', 'question', 'find', 'answer', 'share', 'year']	[0.016129954, 0.013823704, 0.012748071, 0.0115536535, 0.009842845, 0.008749629, 0.008745365, 0.0079878, 0.00771144, 0.007218795]	The LDA discovered topic is about providing support and resources to people who have been affected by cancer. People can post questions to find answers, share their experiences and help each other. People can also find resources and support from others who have gone through similar experiences in the same year.	Sharing post-cancer wellbeing help.	x	Expressions of gratitude, friendliness, enthusiasm, understanding support, praise for the forum and the people on it
10	['cancer', 'find', 'time', 'year', 'well', 'doctor', 'thing', 'keep', 'hope', 'people']	[0.019032491, 0.009942055, 0.009462788, 0.009108288, 0.008873501, 0.008189765, 0.007997165, 0.007924725, 0.006860665, 0.006804856]	The LDA discovered topic is about the hope people have for finding a cure for cancer in the near future. The keywords associated with the topic emphasize the need for people to be proactive in seeking out medical advice and keeping up to date with the latest developments in cancer research. The weights of the keywords suggest that the importance of finding a cure for cancer is a prominent concern for many people.	Finding hope for cancer people.	Home: how to keep positivity in their lives with cancer	Attitude towards cancer and related matters; encourages learning, growth and positivity
11	['year', 'colonoscopy', 'tell', 'cancer', 'month', 'well', 'time', 'feel', 'scan', 'hope']	[0.032372606, 0.01326794, 0.01258629, 0.012165555, 0.011248989, 0.010007946, 0.008893948, 0.008319609, 0.008137106, 0.007962749]	The LDA discovered topic is about the frequency of having a colonoscopy to detect cancer. The keywords suggest that one should have a colonoscopy every year or once a month depending on how they feel, and the weights indicate the importance of having regular scans in order to detect cancer early and hope for the best outcome.	Screening for cancer with colonoscopy.	Hospital: what to expect and assurance about carepath treatment	Confirmation of diagnosis experienced, sharing of this process of screening and examination processes
12	['time', 'prayer', 'sorry', 'find', 'hear', 'treatment', 'well', 'keep', 'sure', 'thing']	[0.013391955, 0.011422672, 0.010100923, 0.009839174, 0.009143082, 0.00910341, 0.007933883, 0.0075937583, 0.007120087, 0.0066274796]	This LDA discovered topic is about finding peace and solace in difficult times. The words 'time', 'prayer', 'sorry', 'find', 'hear', 'treatment', 'well', 'keep', 'sure', and 'thing' suggest that the topic is focused on taking time to reflect and seek comfort through prayer, understanding, and/or treatment, while making sure to keep well and stay positive. The weights assigned to each keyword suggest that the topic is emphasizing the importance of making sure to take the time to take care of oneself and stay positive in order to find peace and solace.	Prayer, time, sorry, healing.	Home: how to stay as a part of learning process for the life with cancer	Some lessons learned

Appendix 3: LDA Topic Description

13	['cancer', 'treatment', 'chemo', 'surgery', 'tumor', 'patient', 'oncologist', 'year', 'liver', 'colon']	[0.03651799, 0.017155308, 0.012900951, 0.011218661, 0.010876453, 0.008664066, 0.00839003, 0.008038232, 0.0078717283, 0.007397496]	This LDA discovered topic is about cancer treatments, specifically focusing on chemo, surgery, and other treatments for tumors. This can be seen from the high weights associated with words like "chemo", "surgery", "tumor", "oncologist", and "cancer". Other words like "patient", "year", "liver", and "colon" suggest the topic is related to treatments for these specific types of cancer.	Cancer treatment (chemo, surgery, tumor, etc).	Home: what do patients need to know about current research about cancer, their treatments, and future re-occurrence	Research on cancer, treatments, recurrence rates, etc. (citing references, etc.)
14	['cancer', 'week', 'chemo', 'day', 'back', 'time', 'blood', 'work', 'ask', 'doctor']	[0.017337311, 0.015368773, 0.01042048, 0.010067487, 0.00992604, 0.009706893, 0.009672692, 0.009611789, 0.00799708, 0.0073751598]	The LDA discovered topic is likely about managing cancer treatments, including chemotherapy. The keywords and weights suggest that this topic could be about scheduling doctor appointments, managing work schedules around chemo days, and dealing with the emotional and physical side effects of cancer treatments such as fatigue and low blood counts.	Cancer treatment: chemo, blood, doctor.	Home: the place to share their opinion about living with cancer	Personal views on the cancer battle, medications, bodily functions, etc., dealing with relationships, life with and the struggle with cancer
15	['ask', 'time', 'help', 'cancer', 'hear', 'well', 'never', 'doctor', 'hope', 'surgery']	[0.010522235, 0.01009419, 0.009702516, 0.009603259, 0.009206947, 0.009140349, 0.008368339, 0.007639158, 0.0069515, 0.0065352907]	This topic is about medical help and hope. The words 'ask', 'help', 'doctor', 'hope', and 'surgery' suggest that the topic is about seeking medical care for a serious condition. The words 'time', 'cancer', 'well', and 'never' suggest that the topic is discussing the uncertainty of the outcome of the medical care, with the hope that the patient will be well. The weights of the words indicate that this topic is focused on the desire for medical help and hope in the face of uncertainty.	Hope for cancer help through surgery.	H	side effects, cancer and lifestyle management, perceptions.
16	['news', 'hair', 'much', 'love', 'hear', 'treatment', 'chemo', 'day', 'cancer', 'still']	[0.013089909, 0.011214658, 0.011088014, 0.01047955, 0.010116317, 0.009833353, 0.009736595, 0.0096651735, 0.009373942, 0.008802955]	This topic is about cancer treatments, specifically chemotherapy. The words 'cancer', 'chemo', 'treatment', and 'day' suggest this, as well as the relatively high weights of these words in comparison to the others. The other words ('news', 'hair', 'much', 'love', 'hear', 'still') could be referring to the emotional aspects of living with cancer, such as the support from loved ones and the news that can be heard from doctors and others.	Cancer treatment and loving support.	Home: How to live active and self-empowered procedure during the life with cancer	I want to live an active life and [illegible] some side effects as much as a haircut) and I have my own [illegible] understanding and attitude towards cancer
17	['help', 'well', 'time', 'cancer', 'work', 'really', 'feel', 'day', 'tell', 'look']	[0.022519106, 0.01221875, 0.0115995705, 0.010319372, 0.009217651, 0.008954262, 0.0073726813, 0.0073535447, 0.007309984, 0.007293868]	The LDA discovered topic is about offering emotional and practical support to people living with cancer. The keywords associated with the topic point to support-related activities such as helping, working, feeling, and looking. The weights associated with the keywords indicate that those activities should be done in a timely manner in order to really make a difference in someone's life.	Cancer help, work, feeling.		Emotional, family and life related
18	['treatment', 'cancer', 'time', 'year', 'liver', 'chemo', 'work', 'day', 'oncologist', 'drug']	[0.015059285, 0.014055974, 0.009855912, 0.009825009, 0.00969957, 0.009281673, 0.008371198, 0.0071736127, 0.0069992137, 0.006972906]	The LDA discovered topic is about cancer treatment. The keywords and their associated weights show that this topic covers topics such as chemotherapy and drugs, as well as the timeframes of treatment such as year, day, and work. It also addresses the specific kinds of cancer, such as liver cancer, and mentions oncologists who would be involved in the treatment.	Cancer treatment with drugs and chemo.	Hospital: information about research on cancer-treatments	Research and [illegible] on cancer related treatments
19	['find', 'well', 'post', 'cancer', 'link', 'site', 'hope', 'thing', 'help', 'let']	[0.012764171, 0.0123478285, 0.010043645, 0.009048797, 0.008289914, 0.007158441, 0.0063654386, 0.0061118132, 0.005231564, 0.0051805656]	This LDA discovered topic is about finding helpful resources related to cancer. The keywords such as 'find', 'post', 'cancer', 'link', 'site', 'help', suggest that this topic is about searching for websites, articles, and other resources with information related to cancer. The words 'well', 'hope', 'thing', and 'let' suggest that the resources should be positive and encouraging. The weights associated with the keywords indicate the relative importance of each keyword in the topic.	Finding hope and help for cancer.	How to draw expectation still for the life with cancer	/ expectations of life, advice on side effects and recovery; perspectives on life
20	['year', 'still', 'liver', 'chemo', 'time', 'cancer', 'give', 'show', 'back', 'much']	[0.011767267, 0.011566931, 0.010372387, 0.008633298, 0.008259822, 0.0075888135, 0.007556291, 0.007100976, 0.005624607, 0.005505213]	This LDA discovered topic is about the effectiveness of chemotherapy treatments for liver cancer. The keywords and weights suggest that this topic is focused on the amount of time that chemotherapy can give cancer patients, how much it can show back, and how much it can still give even after a year of treatment.	Cancer survival with chemo over time.	Hospital: how to interpret the test results and confirmation about their status	Confused about test results, seeking advice, full of uncertainty
21	['send', 'prayer', 'way', 'tomorrow', 'well', 'awesome', 'fun', 'year', 'hug', 'time']	[0.025701355, 0.022946997, 0.012578837, 0.011705568, 0.01051934, 0.009526905, 0.008970263, 0.008288107, 0.007900231, 0.006995822]	The LDA discovered topic is about sending well-wishes and positive affirmations for the future. The keywords indicate that this topic is focused on expressions of optimism and hope for the future, such as sending prayers, hugs, and having fun. The weights suggest that this topic is weighted towards wishing for a successful and enjoyable tomorrow, and having a great year.	Send prayer for awesome fun year.	How to live still an active life	Living an active life, making memories (and family)
22	['cancer', 'problem', 'colon', 'thing', 'well', 'tell', 'treatment', 'doctor', 'day', 'cause']	[0.011883155, 0.011332601, 0.0076985624, 0.0071317246, 0.0069272122, 0.0063693263, 0.0061967853, 0.00577669, 0.0056184544, 0.005599216]	The LDA discovered topic is about colon cancer, its causes, and its treatments. The keywords in the topic are related to colon cancer and its treatment such as cancer, colon, treatment, doctor, and cause. The weights suggest that cancer and colon are the two most important words in this topic, followed by treatment, doctor, day, cause, problem, well, thing, and tell.	Cancer colon treatment doctor cause	Hospital: how other peers experience their side effects	Experience sharing in dealing with side effects
23	['day', 'time', 'work', 'week', 'well', 'hour', 'chemo', 'port', 'thing', 'way']	[0.030008215, 0.017270122, 0.012068809, 0.010624141, 0.009249922, 0.008990441, 0.008577491, 0.006958122, 0.0068557533, 0.006609574]	The LDA discovered topic is likely about managing time and activities related to work during the week. The keywords "day", "time", "work", "week", "well", and "hour" suggest that this topic is related to managing a workload and balancing it with other activities. The remaining keywords "chemo", "port", "thing", and "way" may suggest ways to manage time, such as using a "port" for tracking tasks or developing specific "ways" to handle the workload. The weights indicate that the components of this topic are important, but not necessarily equally so.	Working with chemo in a good way.	Home: how to deal with negative feelings about side effects	Sharing of side effects (more negative and severe)
24	['pain', 'year', 'well', 'surgery', 'day', 'cancer', 'husband', 'much', 'find', 'tell']	[0.026780108, 0.011508176, 0.011114523, 0.010981531, 0.008807207, 0.00751025, 0.0070161786, 0.0069653606, 0.006371701, 0.006156231]	This topic discovered by LDA appears to be about a person's experience with cancer, either their own or a loved one's. The keywords, such as pain, surgery, cancer, and husband, suggest that the person is dealing with a diagnosis of cancer, and is coping with the physical and emotional pain that comes with it. The weights suggest that this topic is about the struggles of a person over a long period of time, as words like year, day, and much are given higher weights.	Cancer pain, surgery, husband, year.	Home: how to live their lives with side effects	Learning to live with cancer (side effects, attitudes, etc.)
25	['glad', 'wonderful', 'luck', 'hugs_gail', 'great', 'love', 'hear', 'story', 'news', 'hope']	[0.03133872, 0.026585535, 0.016459318, 0.01590005, 0.01437889, 0.0143730845, 0.01320943, 0.013086291, 0.012421671, 0.01202606]	The LDA discovered topic is about positive emotions and news that give hope. The keywords 'glad', 'wonderful', 'luck', 'hugs_gail', 'great', 'love', 'hear', 'story', 'news', and 'hope' suggest that this topic is about feeling good and being optimistic. The weights of each keyword are relatively low, indicating the topic has a general focus on positive emotions and news.	Love, hope, great luck, story.		Expresses gratitude for encouragement from peers, shows support and encouragement to peers and is happy for good things done by peers

Appendix 3: LDA Topic Description

26	['cancer', 'chemo', 'surgery', 'help', 'day', 'time', 'keep', 'week', 'give', 'treatment']	[0.01763877, 0.010200782, 0.009122899, 0.009050425, 0.008740651, 0.008685742, 0.007884835, 0.0075468468, 0.007122417, 0.007102106]	This LDA discovered topic is about treatments for cancer, such as chemotherapy, surgery, and other forms of assistance. The keywords with the highest weights, such as chemo, surgery, and treatment, suggest that the topic is focused on different methods of helping people with cancer. Other words such as help, day, time, keep, week, and give indicate the amount of effort and dedication that is necessary to provide the best possible care and support for people with cancer.	Cancer treatment (help) with chemo/surgery/etc.	How to manage their side effects	How to manage side effects after surgery
27	['chemo', 'week', 'treatment', 'surgery', 'month', 'day', 'time', 'radiation', 'tell', 'well']	[0.053554635, 0.01919705, 0.014452509, 0.013388067, 0.012795798, 0.010610113, 0.010266775, 0.008827875, 0.008677623, 0.008648931]	The LDA discovered topic is about different treatments for cancer, such as chemotherapy, surgery, radiation, and other treatments. The keywords and weights suggest that chemotherapy is the most commonly used treatment, followed by treatments that require less frequent visits or shorter treatment times, such as surgery, radiation, and other treatments that may take place over a week, month, or day at a time. The keywords also suggest that the treatments may have varying effects on a patient's well-being.	Chemotherapy, surgery, radiation, time.	Hospital: what to expect for therapies and medication	The effects of chemotherapy, radiotherapy, stoma and medication on people seeking advice, and how it varies from person to person
28	['feel', 'well', 'hope', 'time', 'day', 'really', 'week', 'treatment', 'much', 'thing']	[0.038709495, 0.023640169, 0.016553354, 0.012278067, 0.010573827, 0.009706971, 0.009227618, 0.009137414, 0.008951305, 0.008941998]	The LDA discovered topic is about the hope of feeling well over time with treatment. The keyword "feel" has the highest weight of 0.038709495, suggesting that the topic is centered around the feeling of wellbeing. The other words in the topic such as "hope", "time", "day", "week", "treatment" and "thing" refer to the idea of improving one's wellbeing over a period of time with some form of treatment. The other words in the list such as "really" and "much" are used to emphasize and increase the importance of the other keywords.	Feeling well with treatment over time.	Home: how to deal with physical and emotional side effects	Physical and emotional side effects of drugs, chemotherapy and coping with them
29	['cancer', 'time', 'work', 'year', 'help', 'positive', 'back', 'way', 'well', 'much']	[0.010802608, 0.009992361, 0.008176207, 0.007874047, 0.007752196, 0.007325805, 0.006228754 8, 0.0057310616, 0.0057230825, 0.005509551]	This LDA discovered topic is about finding ways to help those affected by cancer, with a focus on taking positive steps and making the most of time in order to achieve success. It suggests that work done over the course of a year can have a significant impact, and that it is important to remain well in order to make much progress.	Cancer help over time.	Home: how to adopt to the changing lifestyle due to cancer, hospital: how to deal with problems with medical doctors	Changes in life before and after cancer, complaining about doctors
30	['post', 'read', 'much', 'time', 'really', 'great', 'love', 'give', 'day', 'tell']	[0.044220537, 0.016509585, 0.014908533, 0.012876278, 0.012032085, 0.011413462, 0.009836133, 0.008656431, 0.008126156, 0.008082266]	This LDA discovered topic appears to be about enjoying reading and spending time on it. The keywords such as "post", "read", "love", and "give" suggest that it is a positive topic about the enjoyment of reading, while the words "time", "really", "great", "day", and "tell" suggest that it is about taking the time to read and share stories. The weights for these keywords further reinforce this topic, as the highest weights are for "post" and "read".	Giving time to read great posts we love.	Home: how to live the different life after surgery	Sharing of life after surgery (stoma, extremely side effects, constipation), attitude towards fellow patients
31	['time', 'week', 'surgery', 'walk', 'tell', 'day', 'last', 'feel', 'back', 'well']	[0.027530124, 0.011707773, 0.0113193905, 0.011207531, 0.0090002725, 0.008219337, 0.0076578204, 0.0074725775, 0.006997951, 0.006922872]	The LDA discovered topic is about recovery from surgery. The keywords (time, week, surgery, walk, tell, day, last, feel, back, well) suggest that the topic is about a person's experience after a surgery, and the weights (0.027530124, 0.011707773, 0.0113193905, 0.011207531, 0.0090002725, 0.008219337, 0.0076578204, 0.0074725775, 0.006997951, 0.006922872) highlight the importance of time (0.027530124), walking (0.011207531) and feeling (0.0090002725) in the recovery process.	Recovering after surgery in a week.	Hospital: how to overcome the frustration with recovery phase (bad lab results & busy life with cancer)	/ worries and frustrations during the recovery process; experiences during and after surgery; stress over poor lab results; busy life
32	['wait', 'day', 'week', 'well', 'feel', 'back', 'time', 'work', 'hope', 'thing']	[0.023319935, 0.01579883, 0.012878134, 0.01291461, 0.011371671, 0.009782398, 0.009565367, 0.008558875, 0.007363052, 0.0071732337]	The LDA discovered topic is about waiting and feeling. The words 'wait', 'feel', 'time', 'hope' and 'thing' suggest that the topic is about the emotions associated with waiting, such as worrying, feeling anxious, and being hopeful. The words 'day', 'week', 'well', 'back', and 'work' could suggest that the topic is also about taking a break from work or daily activities and dealing with the emotions associated with it. The weights of the words indicate that the words 'wait' and 'feel' are the most important words in this topic.	Waiting for work to feel better.	Hospital: support for waiting result time	To attend some events; emotional and process issues when waiting for results; stoma and bag use issues and approaches
33	['happy', 'news', 'great', 'well', 'wish', 'hear', 'hope', 'surgery', 'congratulation', 'glad']	[0.06372716, 0.04789402, 0.028646776, 0.02529959, 0.022574022, 0.017605007, 0.01512373, 0.012404106, 0.012241848, 0.010038886]	This LDA topic appears to be about positive news, feelings, and events. The keywords suggest that it refers to topics such as good news, great news, well-wishes, hearing positive news, hoping for something positive, congratulating someone, and being glad. The weights suggest that the most important keywords in this topic are 'happy', 'news', 'great', and 'well'.	Congratulations, hope, glad, great news.	x	Congratulations, encourage, great news, support
34	['surgery', 'cancer', 'work', 'day', 'tumor', 'chemo', 'liver', 'well', 'give', 'time']	[0.01867413, 0.013093677, 0.010603799, 0.009929778, 0.00880814, 0.006777736, 0.0063412124, 0.006297554, 0.006213073, 0.006149816]	The LDA discovered topic is likely about cancer surgery. The keywords and their weights indicate that the topic is focused on issues related to surgery, cancer, and its treatments, such as chemotherapy and liver tumors. Other words, such as work, day, well, give, and time, suggest that the surgery and treatments involve a significant amount of time and effort.	Cancer surgery and treatments.	?	Selection and recommendation of cancer-related products; Description, comfort and encouragement of cancer experience (not very good); Sharing of jokes and interesting things
35	['eat', 'day', 'well', 'time', 'work', 'help', 'chemo', 'thing', 'surgery', 'cancer']	[0.020622265, 0.015999166, 0.014005213, 0.01246269, 0.012009331, 0.011158297, 0.010243947, 0.008324899, 0.008149915, 0.0075030033]	The LDA discovered topic is about cancer treatments, such as eating well, taking time off work, and seeking help with chemotherapy and surgery. The keywords and their corresponding weights indicate that eating well is the most important action to take in treating cancer, followed by taking time off work, helping with chemo and surgery, and other things related to cancer treatment.	Cancer treatment: eating, surgery, chemo, work.	Home: how to eat properly	[illegible]
36	['surgery', 'liver', 'resection', 'surgeon', 'tumor', 'chemo', 'treatment', 'cancer', 'time', 'colon']	[0.043024033, 0.04078143, 0.022969203, 0.015399737, 0.014135231, 0.00994777, 0.009868156, 0.009298648, 0.009192212, 0.008604511]	This LDA discovered topic is about treatments for cancer, specifically those involving surgery and chemotherapy. The keywords 'surgery', 'liver resection', 'surgeon', 'tumor', 'chemo', 'treatment', 'cancer', 'time', and 'colon' all indicate that the topic is related to cancer. The weights show that surgery and liver resection are the most important aspects of the topic, followed by chemo and treatment, then cancer and time, then colon.	Liver surgery, resection, cancer treatment.		Ask other survivors/experts for their opinions; share personal experiences of Live surgery, resection, cancer treatment.
37	['cancer', 'year', 'life', 'time', 'mom', 'well', 'live', 'help', 'thing', 'feel']	[0.03181786, 0.015549807, 0.012995419, 0.011684932, 0.011189908, 0.008601531, 0.0089513855, 0.008667579, 0.0084555205, 0.008128895]	The LDA discovered topic is about the impact that cancer has on a person's life and the various ways that family and friends can help them cope. The words 'cancer', 'life', 'time', 'mom', 'live', 'help', 'thing', 'feel' all point to this topic, with 'year' and 'well' being related words. The weights of the words indicate the relative importance of each keyword to the topic, with 'cancer' being the most important keyword.	Helping mom live longer with cancer.	Home/Hospital: what to encourage their family members and others encourage them	Encourage patients, encourage families, need encouragement

Appendix 3: LDA Topic Description

38	['time', 'well', 'cancer', 'feel', 'much', 'treatment', 'chemo', 'thing', 'year', 'find']	[0.014252007, 0.009479725, 0.009338497, 0.00800342, 0.0078024566, 0.007591262, 0.006469102, 0.0060999724, 0.005448881, 0.0053882007]	The LDA discovered topic is about the experience of living with cancer and undergoing treatment such as chemotherapy. The keywords 'time', 'well', 'feel', 'much', 'thing', 'year', and 'find' suggest that it is about the feelings and struggles of living with cancer and the journey of treatment. The higher weights given to 'cancer', 'treatment', and 'chemo' suggest that this topic is focused on the experience of undergoing cancer treatment.	Cancer treatment and feeling well.	Home: how to overcome the struggles - but what kinds of struggles?	/ about the feelings and struggles of living with cancer and the journey of treatment?
39	['cancer', 'colon', 'stage', 'liver', 'find', 'well', 'lung', 'time', 'surgery', 'tell']	[0.028807547, 0.023227427, 0.014604591, 0.011230107, 0.010947985, 0.0105858045, 0.010360744, 0.00961989, 0.009530403, 0.00927156]	The LDA discovered topic is about the different stages of cancer, specifically colon, liver, and lung cancer. The words with the highest weights (cancer, colon, stage, liver, and lung) indicate the topic is about the various stages of cancer, while the words with the smaller weights (find, well, time, surgery, and tell) indicate the topic is about diagnosing and treating cancer.	Cancer, colon, lung, surgery stages.	Hospital: how to support anxiety during waiting time.	Waiting anxiety; cancer science
40	['hope', 'give', 'well', 'keep', 'picture', 'day', 'year', 'new', 'find', 'cancer']	[0.014392777, 0.011594947, 0.0101645915, 0.00982811, 0.008095216, 0.005459087, 0.005429356, 0.0052243737, 0.0050329864, 0.0049729813]	The LDA discovered topic is about optimism, resilience, and hope in the face of illness, specifically cancer. The words 'hope', 'give', 'well', 'keep', 'picture', 'day', 'year', 'new', 'find', and 'cancer' are associated with the idea of hope and optimism, while the weights indicate that this topic is particularly relevant to cancer. This topic could reflect the idea that despite the difficulties of living with cancer, there is still hope and a future to look forward to.	Finding hope for a new year.	Home: how to go back to normal life	/ trying to get back to life (as a person); sharing experiences
41	['keep', 'prayer', 'hope', 'thought', 'well', 'sorry', 'hear', 'post', 'glad', 'great']	[0.04048259, 0.029330764, 0.016982567, 0.016601792, 0.01624641, 0.012662004, 0.012650008, 0.011390954, 0.011329789, 0.009031446]	This LDA discovered topic appears to be about expressing compassion and hope. The words "keep", "prayer", "hope", "thought", "sorry", and "glad" suggest that the speaker is wishing the best for someone and expressing sympathy and understanding. The words "well", "hear", "post", and "great" suggest that the speaker is also showing optimism and encouragement. The weights of the words show that this topic is primarily centered around expressing hope and compassion.	Prayer, hope, and thought.	Home: possibility for peer-to peer support	Patient-to-patient expressions of encouragement and support; family and patient relationships
42	['birthday', 'happy', 'year', 'day', 'well', 'much', 'drink', 'never', 'time', 'hope']	[0.03331341, 0.021050833, 0.014526392, 0.010583706, 0.008666952, 0.008638978, 0.008333052, 0.0077788066, 0.0064725718, 0.0061686165]	This LDA discovered topic is about celebrating birthdays. The keywords indicate that this topic is related to having a happy birthday, reflecting on the past year, enjoying the day, and hoping for the best in the future. The weights indicate that the most important words in this topic are "birthday," "happy," and "year," which are the main concepts of celebrating a birthday.	Celebrating a happy birthday.	Home: how to stay positive	/ share positive daily life, share coping strategies
43	['cancer', 'day', 'people', 'well', 'chemo', 'year', 'find', 'time', 'keep', 'bad']	[0.013328669, 0.010214197, 0.008557379, 0.007910486, 0.007294853?, 0.006781371, 0.006478656, 0.006276083, 0.005711154, 0.0053422395]	The LDA discovered topic is about coping with cancer, as evidenced by the keywords such as "cancer", "chemo", "keep" and "bad". The weights suggest that this topic is about finding ways to manage the day-to-day struggles of living with cancer, such as finding ways to keep well throughout the year despite the chemo treatments, as well as dealing with the emotional and physical effects of the disease.	Cancer awareness and support.	Home: how to have emotional support	Finding ways to deal with the day-to-day struggle with cancer and treatment, for example, dealing with the emotional and physical effects of the disease.
44	['time', 'cancer', 'tell', 'well', 'pain', 'year', 'thing', 'feel', 'find', 'help']	[0.014381299, 0.010768373, 0.009386196, 0.008852364, 0.008545865, 0.008185013, 0.008170246, 0.008527976, 0.0064611444, 0.0064014816]	This topic appears to be related to coping with cancer. The keywords suggest that people are looking for ways to cope with the pain, tell if they are doing well, and find help. The weights indicate that time and cancer are the most important topics, while the other keywords are less important.	Cancer, time, pain, and help.	hospital: how to overcome the pain	Treatment options and side effects are explored; people are looking for ways to cope with their pain, telling them if they are doing well, and finding help
45	['well', 'happy', 'lung', 'cancer', 'last', 'time', 'new', 'great', 'treatment', 'really']	[0.01288282, 0.0122581385, 0.010809415, 0.009902137, 0.008084532, 0.006984585, 0.00663518, 0.0065811123, 0.0063639493, 0.006362265]	This LDA discovered topic is likely about new treatments for lung cancer that are making people happy. The words "well," "happy," "lung," "cancer," "last," "time," "new," "great," "treatment," and "really" all point to this topic, and the weights of each of the words reflect the importance of each term to the topic.	New great lung cancer treatment.	Hospital: about doubts	/Nodule nodule misjudged, doubts about doctor
46	['care', 'life', 'well', 'look', 'people', 'thing', 'love', 'great', 'much', 'hope']	[0.01606707, 0.01476151, 0.0135806855, 0.012045142, 0.01160299, 0.011598682, 0.0105879875, 0.010279285, 0.009866594, 0.009534576]	The LDA discovered topic is about the importance of taking care of one's life and looking for the best in people and things. It emphasizes the need for love, great things, and much hope in life. The weights indicate that the keywords 'care' and 'life' are the most important in this topic.	Caring for life and hoping for great things.	Home: how to stay positive	Convey a positive mindset and encourage others
47	['cancer', 'cell', 'diet', 'test', 'body', 'well', 'supplement', 'chemo', 'eat', 'food']	[0.030877512, 0.021063143, 0.008452903, 0.0077790613, 0.0074110613, 0.007381035, 0.0071543297, 0.006579332, 0.006571357, 0.0063452017]	This LDA discovered topic is about cancer treatments and diet. The most prominent words in the topic are 'cancer', 'cell', 'diet', and 'test', which suggest that the topic is about treatments and ways to manage cancer, such as chemotherapy, supplements, and changes in food intake. The other words in the topic, 'body', 'well', 'supplement', 'chemo', 'eat', and 'food', all relate to nutrition, which is a key part of cancer management. The weights for the words also suggest that cancer treatment and diet are important topics.	Cancer, diet, body, well-being.	Hospital: cancer research	[illegible]

Appendix 4: NMF Topic Description

						Physical(P)/Social(S)/ Mental(M)	Number of Post	Topic/Cluster	Cluster number	Cluster/Total	Total
Cluster 1: Experience around medical professionals' opinion		39	Doubts about treatment opinions from medical professionals	['doctor', 'oncologist', 'surgeon', 'told', 'patient', 'system', 'cell', 'wrong', 'reason', 'medical', 'asked', 'office', 'immune', 'trust', 'kill', 'testing', 'medicine', 'appointment', 'clinic', 'recommend']	The NMF discovered topic is about trusting your doctor, medical testing, and appointments with your oncologist. The most important keywords are 'doctor', 'oncologist', 'told', 'patient', 'system', 'cell', 'wrong', and 'reason'. These words point to situations where the patient was told something was wrong with their system or cells, and the doctor or oncologist gave them a reason for it. The other keywords, 'trust', 'kill', 'testing', 'medicine', 'appointment', 'clinic', and 'recommend' further reinforce this idea of trusting the doctor, getting medical testing done, and making appointments with the oncologist.	P,M	5043	51.69%	9756	4.48%	217593
		45	Suggestion to look for a second medical opinion; suggestion on dealing port in the best way.	['care', 'second', 'opinion', 'ask', 'port', 'onc', 'put', 'taken', 'nurse', 'center', 'forget', 'top', 'first', 'team', 'comfortable', 'third', 'schedule', 'getting', 'question', 'hospital']	The NMF discovered topic is about getting care and advice from medical professionals. The most important keywords in this topic are "care", "second opinion", "ask", "oncologist", "put", "taken", "nurse", "center", "top", and "first". These words indicate that the topic is about seeking medical advice from multiple sources, such as oncologists, nurses, and medical centers, and getting a second opinion to ensure the best treatment. Other important words are "port", "forget", "team", "comfortable", "third", "schedule", "getting", and "question", which suggest that patients should ask questions and make sure to get all the available information before making a decision about their care.	P	4713	48.31%	9756	4.48%	217593
Cluster 2: Understanding treatment including alternatives and adjunctive therapy		30	Patients share their research about alternative therapy options from websites and articles, making a judgement on options.	['answer', 'information', 'might', 'research', 'alternative', 'therapy', 'study', 'perhaps', 'available', 'patient', 'consider', 'website', 'based', 'benefit', 'article', 'option', 'approach', 'internet', 'current', 'specific']	The NMF discovered topic is about researching alternative therapy options available to colorectal cancer patients. The most important keywords are 'research', 'alternative', 'therapy', 'study', 'available', 'patient', 'consider', 'website', 'based', 'benefit', 'article', 'option', 'approach', 'internet', 'current', and 'specific'. This suggests that colorectal cancer patients should look into doing their own research, such as utilizing websites and articles to find information about alternative therapies that might be beneficial for them, as well as considering a specific approach based on their current situation.	P	7854	24.87%	31577	14.51%	217593
		10	Making treatment decisions for the future with regard to the best outcome and path.	['best', 'wish', 'wishing', 'decision', 'health', 'possible', 'whatever', 'future', 'choice', 'outcome', 'decide', 'path', 'upcoming', 'regard', 'situation', 'advocate', 'choose', 'action', 'simply', 'circumstance']	The NMF discovered topic is about making decisions regarding health and upcoming situations. The most important keywords in this topic are "decision", "health", "possible", "future", "choice", "outcome", "decide", "path", and "upcoming". These words indicate that the topic is focused on making thoughtful decisions regarding health-related matters and the possible outcomes of those decisions. The other words ("wish", "wishing", "regard", "situation", "advocate", "choose", "action", "simply", and "circumstance") help to further explain the topic by indicating the importance of having a plan and taking action, as well as being aware of the current situation and circumstances.	P	4759	15.07%	31577	14.51%	217593
		33	Listing type, side effect, regimen, and effectiveness of drugs (folfox, oxaliplatin, avastin, and irinotecan) and the side effects from them (including rash, cell, and affect).	['side', 'effect', 'drug', 'folfox', 'round', 'cycle', 'dose', 'vitamin', 'week', 'oxaliplatin', 'avastin', 'reaction', 'irinotecan', 'affect', 'rash', 'onc', 'cell', 'regimen', 'session', 'effective']	This NMF discovered topic is about drug side effects experienced by colorectal cancer patients. The most important keywords in this topic are 'side', 'effect', 'drug', 'folfox', 'round', 'cycle', 'dose', 'vitamin', and 'week'. These words refer to the type of drugs taken by colorectal cancer patients (folfox, oxaliplatin, avastin, and irinotecan) and the side effects associated with them (including rash, cell, and affect). Additionally, the topic also refers to the regimen (dose, cycle, and session) and effectiveness of the drug.	P	8768	27.77%	31577	14.51%	217593
	Uncertain	14	Sharing experience on using Traditional Chinese Medicine to manage health.	['well', 'known', 'fairly', 'usual', 'responded', 'recall', 'crc', 'chinese', 'handling', 'version', 'correctly', 'content', 'deserved', 'treating', 'referring', 'nicely', 'handled', 'spelling', 'managing', 'tolerated']	This NMF topic appears to be about managing and treating Colorectal Cancer (CRC). The most important keywords in order are: well, known, fairly, usual, responded, recall, CRC, Chinese, handling, version, correctly, content, deserved, treating, referring, nicely, handled, spelling, managing, and tolerated. This suggests that the patient stories discuss how well known and fairly usual treatments have responded to and recalled CRC, and how Chinese versions have been handled correctly with content that deserved treating and referring nicely, as well as how spelling and managing have been tolerated.	P	3610	11.43%	31577	14.51%	217593
		21	Sharing experiences and recommendations for supplements and medication.	['congratulation', 'definitely', 'tried', 'experience', 'mentioned', 'suggestion', 'type', 'helped', 'mention', 'medication', 'interested', 'speak', 'form', 'help', 'suggest', 'using', 'supplement', 'suggested', 'detail', 'order']	This NMF topic is about alternative treatments for colorectal cancer. The keywords show that people have shared their experiences with alternative treatments such as supplements, medication, and other forms of help. They have mentioned that they have tried these treatments and have had positive experiences with them. They have also suggested that others try them and others have responded with interest and appreciation.	P	2854	9.04%	31577	14.51%	217593

Appendix 4: NMF Topic Description

	48	Sharing information about and holding a positive attitude towards clinical trials	['new', 'find', 'look', 'looking', 'awesome', 'forward', 'trial', 'start', 'working', 'step', 'move', 'hearing', 'hard', 'pic', 'yet', 'clinical', 'finding', 'meeting', 'hopeful', 'totally']	The NMF discovered topic is about finding hope after a diagnosis of colorectal cancer and taking positive steps forward. The most important keywords in this topic are 'look', 'forward', 'working', 'step', 'move', 'hearing', 'finding', 'meeting', and 'hopeful'. These words indicate that the stories shared by cancer survivors discuss the process of looking ahead, taking action, and finding support networks for those affected by the disease. Additionally, the words 'awesome', 'trial', 'start', 'pic', 'yet', and 'totally' imply a sense of optimism, as the survivors are looking forward to new opportunities and feeling inspired by their experiences. Lastly, the words 'new', 'hard', and 'clinical' indicate that the stories reflect the challenges of dealing with a colorectal cancer diagnosis and the importance of staying informed about the latest treatments and research.	P	3732	11.82%	31577	14.51%	217593
Cluster 3: Surgery experience	25	Sharing experience around RFA ablation for the liver	['congrats', 'procedure', 'success', 'huge', 'liver', 'proud', 'shrink', 'treat', 'entire', 'tumor', 'ablation', 'option', 'rfa', 'candidate', 'location', 'status', 'shrinkage', 'inoperable', 'surgical', 'afterwards']	This topic discovered by NMF is about a successful treatment option for inoperable colorectal cancer. The words in order of their importance indicate that the treatment option is radiofrequency ablation (RFA), which is a minimally invasive procedure used to treat tumors. There is huge success in shrinking the tumor, and those affected are proud of their progress. The location of the tumors and the candidate's status afterwards were also taken into consideration. Congrats is used to express the joy of the successful treatment and shrinkage.	P	4979	27.73%	17958	8.25%	217593
	22	Suggesting how to take good care of stoma: a daily process that requires careful attention	['bag', 'problem', 'add', 'colostomy', 'used', 'daily', 'ostomy', 'twice', 'radiation', 'reversal', 'bathroom', 'ileostomy', 'skin', 'diarrhea', 'prep', 'stool', 'stoma', 'rectum', 'careful', 'bowel']	This NMF topic is about colostomy care and bowel management. The most important keywords are 'colostomy', 'ostomy', 'ileostomy', 'stoma', 'rectum', 'stool', and 'bowel', which indicate the use of a colostomy bag. Other important words such as 'radiation', 'reversal', 'daily', 'twice', 'bathroom', and 'careful' suggest that colostomy care is a daily process that requires careful attention. 'Skin', 'diarrhea', 'prep', and 'add' are also used to describe the various aspects of colostomy care, such as skin irritation, diarrhea, and adding ointment to the stoma.	P	8418	46.88%	17958	8.25%	217593
	23	Sharing negative experience about resection in liver and lung: complications happens	['day', 'liver', 'resection', 'mets', 'every', 'met', 'pump', 'lung', 'ahead', 'week', 'couple', 'following', 'open', 'two', 'operation', 'followed', 'throughout', 'single', 'complication', 'section']	The NMF topic discovered is about the process of undergoing surgery for colorectal cancer. It appears that the patient underwent a single open operation followed by a couple of weeks of resection, possibly a liver resection. They experienced some complications throughout the process but were able to continue ahead with the procedure. It also appears that the patient underwent some form of met(s) pump operation, possibly to treat any metastases.	P,M	4561	25.40%	17958	8.25%	217593
Cluster 4: Experience on the test results (including being worried and confused)	9	Being worried about upcoming scans and results	['great', 'result', 'idea', 'scan', 'number', 'option', 'curious', 'present', 'follow', 'considering', 'treated', 'recurrance', 'appendix', 'initial', 'cea', 'mop', 'peritoneal', 'assuming', 'base', 'reliable']	The NMF discovered topic is about treatment of recurrence of colorectal cancer. The most important keywords in this topic are 'treated', 'recurrance', 'initial', 'CEA', 'MOP', and 'peritoneal', suggesting that the stories are discussing treatments such as initial diagnostics, CEA tests, MOP (minimally invasive open pelvic) surgeries, and peritoneal treatments for colorectal cancer recurrence. The other keywords in the topic ('great', 'result', 'idea', 'scan', 'number', 'option', 'curious', 'present', 'follow', 'considering', 'treated', 'recurrance', 'appendix', 'initial', 'cea', 'mop', 'peritoneal', 'assuming', 'base', 'reliable') are likely related to these treatments, as they suggest further exploration of different treatments, the consideration of different options, and the need for reliable results for effective treatment.	P,M	3210	10.71%	29984	13.78%	217593
	18	Sharing their outcomes (clear or not) from scanning and caring about how frequently they scan	['year', 'month', 'ago', 'clear', 'last', 'three', 'two', 'free', 'scan', 'colonoscopy', 'end', 'past', 'every', 'four', 'clean', 'date', 'six', 'safe', 'behind', 'later']	The NMF discovered topic is about preventive health measures related to colorectal cancer. The most important words are 'colonoscopy', 'every', 'year', 'month', 'four', 'six', 'three' which suggests that patients have been getting regular colonoscopies at least every year or every four or six months. The other words ('last', 'ago', 'clear', 'past', 'every', 'free', 'scan', 'end', 'clean', 'date', 'safe', 'behind', 'later') support the idea that patients have been taking preventative measures and staying up to date on their health by getting regular scans and keeping their tests clear.	P	4293	14.32%	29984	13.78%	217593
	49	Describing a stressful experience to a blood test; worry about the numbers in the result	['everyone', 'word', 'blood', 'test', 'kind', 'wait', 'worry', 'fine', 'check', 'waiting', 'count', 'normal', 'wanted', 'level', 'concern', 'checked', 'else', 'low', 'high', 'appointment']	The NMF discovered topic is about the process of having blood work done to check for colorectal cancer. It is a stressful experience for many patients, as they wait for the results, worrying about what the results may be and hoping for a positive outcome. The order of importance of the keywords reveals the steps patients go through: first, they have to make an appointment for the blood test, then wait for the results to come back, and then check for the results. The keywords "low" and "high" indicate that the test results are compared to a normal range, and if the results are outside of the normal range, there is concern and worry about what that may mean. Lastly, the keyword "everyone" reveals that many people have gone through this experience, and it is not unique to just a few.	P,M	5048	16.84%	29984	13.78%	217593

Appendix 4: NMF Topic Description

	8	Being worried and confused about odd scan results in liver, lung, and lymph	['scan', 'tumor', 'liver', 'node', 'lung', 'removed', 'radiation', 'stage', 'lymph', 'spot', 'showed', 'spread', 'small', 'pet', 'biopsy', 'remove', 'mets', 'surgeon', 'recurrence', 'week']	This NMF topic appears to be about the process of diagnosing colorectal cancer. The most important words are 'scan', 'tumor', 'liver', 'node', 'lung', 'removed', 'radiation', and 'stage', which suggest that the diagnosis process may involve imaging scans of the patient's body, including the liver, lungs, and lymph nodes, as well as removal of tumors for biopsy and the use of radiation. Other words such as 'spread', 'small', 'pet', 'remove', 'mets', 'surgeon', 'recurrence', and 'week' suggest that the diagnosis process may also involve further tests to determine if the cancer has spread, or if the patient is at risk of recurrence, and monitoring afterward on a weekly basis.	P,M	13560	45.22%	29984	13.78%	217593
	15	Sharing negative emotions and experiences to live with colorectal cancer: overwhelmed, confused and scared, especially for the tests and screenings	['like', 'sound', 'wonderful', 'plan', 'place', 'picture', 'show', 'meet', 'report', 'looked', 'absolutely', 'really', 'pick', 'button', 'familiar', 'machine', 'pretty', 'smart', 'silly', 'compare']	The NMF topic discovered is about the experience of being diagnosed with colorectal cancer. The most important words in this topic are 'like', 'sound', 'wonderful', 'plan', 'place', 'picture', 'show', 'meet', 'report', 'looked', 'absolutely', 'really', 'pick', 'button', 'familiar', 'machine', 'pretty', 'smart', 'silly' and 'compare'. These words suggest that the topic is about the emotions and experiences associated with being diagnosed with colorectal cancer, such as feeling overwhelmed, confused, scared, and hopeful. The words 'picture', 'button', 'machine' and 'compare' suggest that the stories may also discuss the process of receiving a diagnosis, including medical tests and screenings.	M	3873	12.92%	29984	13.78%	217593
Cluster 5: Experience with side effects	42	Sharing their experience on managing the side effects of treatment: drinking water, taking medications, and getting plenty of rest.	['cold', 'nausea', 'taking', 'help', 'water', 'drink', 'warm', 'pill', 'infusion', 'sleep', 'mouth', 'sore', 'med', 'oxy', 'gave', 'fatigue', 'mum', 'nasty', 'appetite', 'sleeping']	The NMF discovered topic is about managing side effects of colorectal cancer treatment. The most important keywords indicate the need for things like staying hydrated, taking medications, and getting plenty of rest. Other keywords such as 'nausea', 'fatigue', 'mouth sore', and 'nasty appetite' allude to the unpleasant side effects that are often associated with cancer treatment. Lastly, the keyword 'mum' suggests the presence of a caring support system to help the patient cope with their condition.	P	8341	31.89%	26152	12.02%	217593
	37	Negative feelings of hair loss due to cancer treatments.	['stuff', 'hair', 'funny', 'hate', 'bad', 'suck', 'lose', 'cut', 'fall', 'wear', 'crap', 'lost', 'really', 'made', 'stand', 'head', 'weird', 'losing', 'strange', 'air']	The NMF discovered topic appears to relate to experiences of hair loss due to cancer treatments. The keywords suggest that patients feel frustrated and strange with the process, and have a sense of loss and sadness. In order of importance: 'lose', 'losing', 'lost', 'cut', 'fall', 'weird', 'really', 'made', 'stand', 'head', 'wear', 'crap', 'strange', 'air', 'hate', 'bad', 'suck', 'funny', 'stuff'.	P,M	5122	19.59%	26152	12.02%	217593
	34	Feeling uncomfortable due to the intestinal blockage.	['pain', 'control', 'nothing', 'relief', 'med', 'bowel', 'issue', 'breath', 'walking', 'walk', 'scar', 'deep', 'kidney', 'causing', 'blockage', 'problem', 'intestine', 'tube', 'hospital', 'hernia']	The NMF discovered topic is about intestinal issues causing blockage and pain. The most important keywords in this topic are 'pain', 'control', 'nothing', and 'relief', which suggest that the topic is about the physical and emotional effects of having an intestinal blockage. Other important keywords such as 'med', 'bowel', 'issue', 'breath', 'walking', 'walk', 'scar', 'deep', 'kidney', 'causing', 'blockage', 'problem', 'intestine', 'tube', 'hospital', and 'hernia' further reinforce the notion that this topic is discussing the effects of an intestinal blockage and the treatments available to manage it.	P,M	6414	24.53%	26152	12.02%	217593
	32	Experiencing pain and numbness due to nerve damage in various body parts of the body	['hand', 'foot', 'hurt', 'neuropathy', 'bone', 'worse', 'arm', 'pain', 'caused', 'leg', 'left', 'painful', 'problem', 'experienced', 'damage', 'nerve', 'cause', 'related', 'shoulder', 'symptom']	The NMF discovered topic is related to nerve damage caused by Colorectal Cancer. The most important keywords are 'nerve', 'damage', 'pain', 'caused', 'symptom', 'experienced', 'problem', 'painful', 'related', 'arm', 'leg', 'shoulder', 'hand', 'foot', 'left', 'worse', and 'bone'. These words indicate that the topic is about how Colorectal Cancer can cause nerve damage in various parts of the body, causing pain, numbness, and other related symptoms.	P,M	6275	23.99%	26152	12.02%	217593
Cluster 6: Confusion with Insurance	38	Confusion about insurance coverage.	['insurance', 'really', 'sent', 'email', 'needed', 'pay', 'company', 'money', 'state', 'phone', 'cost', 'card', 'mail', 'received', 'hospital', 'address', 'cover', 'attention', 'letter', 'service']	The NMF topic discovered from this dataset is about insurance coverage for colorectal cancer. The most important words in the topic indicate that patients needed to pay for their medical expenses, contact their insurance company, and receive a letter of attention from the hospital. The words also suggest that patients had to contact the insurance company by phone, mail, or email, and provide their address and credit card information to cover the cost of services.	M	7912	100.00%	7912	3.64%	217593
Cluster 7: Experience during recovery phase	27	Describing negative experience of repeated visits to the hospital due to the infection after surgery	['time', 'took', 'full', 'week', 'short', 'last', 'shot', 'infection', 'heal', 'ended', 'went', 'due', 'drop', 'period', 'several', 'stopped', 'hospital', 'started', 'kept', 'taking']	The NMF discovered topic is about recovery from Colorectal Cancer, as it includes words such as 'heal', 'hospital', 'taking', 'went', 'stopped', 'started', and 'ended'. This suggests that the topic is about the process of healing and the amount of time it takes, as the words 'time', 'week', 'short', 'last', 'due', 'period', 'several', and 'drop' all indicate a timeline for recovery.	P,M	5010	35.49%	14116	6.49%	217593

Appendix 4: NMF Topic Description

		20	Staying positive and making life adjustments to their cancer circumstances during the recovery phase.	['way', 'positive', 'sending', 'coming', 'along', 'vibe', 'healing', 'energy', 'half', 'begin', 'rid', 'improve', 'ton', 'complete', 'outlook', 'faster', 'headed', 'toward', 'improved', 'adjustment']	This NMF topic is about the healing process of colorectal cancer patients. The most important words in the order of their importance are "healing", "energy", "improve", "faster", and "headed". These words indicate that colorectal cancer patients are coming along their healing journey in a positive way, sending out a healing vibe, and are beginning to rid themselves of the cancer. They are also seeing an improved outlook and faster adjustment to their circumstances.	M	3622	25.66%	14118	6.49%	217593
	Uncertain	7	Happy for patient peers going back home after surgery and wish each other to recover quickly	['glad', 'everything', 'home', 'went', 'recovery', 'able', 'hubby', 'road', 'quickly', 'fast', 'moving', 'quick', 'speedy', 'successful', 'bet', 'continues', 'crossed', 'recover', 'finger', 'direction']	The NMF discovered topic is about a quick and successful recovery from colorectal cancer. The keywords in order of importance suggest that the patient is glad to have been able to recover quickly and move in a fast and speedy direction. This is further supported by the words "quickly", "fast", "quick", "speedy", and "successful" as well as "able" and "recover". The patient also mentions their "hubby" and the road they have crossed, indicating the support they have received and the progress they have made in their recovery. The fact that the patient is "moving" and "continues" to do so suggests that their recovery is still ongoing. The final keyword, "finger", serves as a metaphor for the direction their recovery is taking.	P,M	5486	38.86%	14118	6.49%	217593
Cluster 8: Mindset-related attitude living with colorectal cancer		24	Sharing their feelings: sick, tired, weak and bad but is starting and hoping to feel better and be stronger	['feel', 'better', 'feeling', 'soon', 'hopefully', 'getting', 'sick', 'felt', 'tired', 'real', 'making', 'really', 'starting', 'bad', 'stronger', 'gotten', 'start', 'expected', 'weak', 'normal']	This NMF topic discovered is about the patient's journey towards recovery from colorectal cancer. The keywords in order of importance indicate that the patient felt sick, tired, weak and bad but is now starting to feel better and stronger. They are getting back to their normal life and hopefully will be feeling better soon. They have gotten back some of the strength they had before they got sick and are making real progress in their recovery. They are starting to feel the way they expected to and are getting back to their life before they got sick.	P,M	4520	14.94%	30252	13.90%	217593
		0	Difficulties to adjust and adapt to their lives with colorectal cancer.	['going', 'time', 'sometimes', 'enough', 'trying', 'probably', 'part', 'really', 'actually', 'course', 'change', 'either', 'pretty', 'different', 'body', 'point', 'never', 'hard', 'anyway', 'whole']	This NMF topic appears to be about the difficult process of adjusting to life after a diagnosis of colorectal cancer. The words in the order of their importance suggest that the speaker has had to try hard, change their whole course of life, and probably never had enough time to accept the diagnosis. They may have also found that their body had changed drastically and that they had to adjust to a different way of living. This topic is likely about the struggles of adapting to a new reality after a cancer diagnosis.	S,M	6332	20.93%	30252	13.90%	217593
		41	Sharing how patients can be resilient and positive -always stay strong, laugh and humor, never give up, and be a hero.	['always', 'stay', 'remember', 'away', 'week', 'next', 'cry', 'laugh', 'sense', 'strong', 'forever', 'matter', 'extra', 'humor', 'staying', 'never', 'whenever', 'hero', 'sweetie', 'corner']	This NMF discovered topic is about the importance of resilience and positivity for cancer patients. The most important words are 'always', 'remember', 'stay', 'strong', 'never', 'forever', and 'matter', which suggest the need for maintaining a positive attitude and perseverance in the face of the cancer diagnosis. Other words such as 'next', 'week', 'away', 'cry', 'laugh', 'sense', 'extra', 'humor', 'staying', 'whenever', 'hero', 'sweetie', and 'corner' emphasize the need for emotional support, hope and courage.	M	4449	14.71%	30252	13.90%	217593
		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).	['life', 'live', 'mean', 'understand', 'people', 'important', 'living', 'world', 'fear', 'time', 'become', 'realize', 'death', 'die', 'quality', 'learn', 'focus', 'illness', 'save', 'allow']	The NMF topic discovered from this dataset is about living life to the fullest despite a diagnosis of colorectal cancer. The most important words in the order of their importance are "life", "live", "mean", "understand", "people", "important", "living", "world", "fear", "time", "become", "realize", "death", "die", "quality", "learn", "focus", "illness", "save", and "allow", which all reflect this concept. The topic emphasizes the importance of living life to its fullest while understanding the gravity of the diagnosis and the fear it can bring. It suggests that learning to focus on the quality of life and the opportunity to save it through treatments and lifestyle changes can allow people to overcome the fear of death and become more accepting of their illness.	M	5451	18.02%	30252	13.90%	217593
	Uncertain	11	Survivors sharing their attitudes towards living with cancer along with survival rate	['story', 'old', 'survivor', 'disease', 'folk', 'site', 'year', 'member', 'cure', 'people', 'recently', 'personal', 'passed', 'woman', 'remission', 'given', 'survival', 'grateful', 'alive', 'lived']	The NMF discovered topic is about Colorectal Cancer survivors and their personal stories. The most important keywords in the order of their importance are 'story', 'old', 'survivor', 'disease', 'folk', 'site', 'year', 'member', 'cure', 'people', 'recently', 'personal', 'passed', 'woman', 'remission', 'given', 'survival', 'grateful', 'alive', 'lived'. This suggests that the stories shared by Colorectal Cancer survivors are often personal, with many of them being grateful to have survived the disease, some having been in remission for many years, while others have recently passed away. The stories also contain accounts of people of all ages, both male and female, of different backgrounds, and from various locations around the world.	M	5627	18.60%	30252	13.90%	217593
Cluster9: Interaction with family & friends		40	Family members' emotional struggle about having a cancer patient in their family.	['husband', 'heart', 'face', 'eye', 'hold', 'head', 'tear', 'dog', 'stop', 'brought', 'hell', 'front', 'putting', 'child', 'soul', 'biggest', 'attack', 'mad', 'horse', 'men']	This NMF topic appears to be about emotional struggles. The most important words in this topic, such as 'soul', 'heart', 'tear', 'hold', 'face', 'stop', 'putting', 'mad', 'hell', and 'brought', all point to an emotional struggle. This could be the struggle of a patient with colorectal cancer, their family members, or even their caregivers. The other words in this topic, such as 'husband', 'eye', 'head', 'dog', 'child', 'biggest', 'attack', 'horse', and 'men', likely describe the people and situations that contribute to the emotional struggle.	S,M	4798	20.51%	23393	10.75%	217593

Appendix 4: NMF Topic Description

		47	Experience on relationships with friends while having cancer	['got', 'friend', 'heard', 'name', 'room', 'semi', 'never', 'bunch', 'forgot', 'hot', 'blue', 'chat', 'surprise', 'joke', 'facebook', 'picked', 'neighbor', 'girlfriend', 'canadian', 'everywhere']	The NMF discovered topic is about connecting with people online, as evidenced by the keywords. The most important terms are "got," "friend," "heard," and "name," which suggest that the topic is about making connections with other people. Other terms such as "chat," "facebook," and "girlfriend" further support this idea. Other terms such as "semi," "bunch," "picked," and "neighbor" suggest that these connections may be made in a variety of ways and contexts, while terms like "hot," "blue," "surprise," "joke," and "canadian" suggest that these connections involve humor, fun, and even exoticism. Finally, the term "everywhere" suggests that these connections can be made anywhere, including online.	S,M	4062	17.36%	23393	10.75%	217593
		28	Sharing changes in their family relationship due to cancer journey (both positive and negative)	['thinking', 'today', 'family', 'anyone', 'call', 'wondering', 'sister', 'called', 'brother', 'visit', 'yesterday', 'talk', 'close', 'else', 'sign', 'talking', 'law', 'wanted', 'concerned', 'appt']	This NMF topic appears to be about family relationships and concerns. The most important words are 'thinking', 'family', 'anyone', 'call', and 'wondering', which suggest that someone is pondering their relationships and considering whether or not to call someone. Other words such as 'sister', 'brother', 'visit', 'yesterday', 'talk', and 'close' suggest that the person is considering reaching out to a family member or someone close to them. The words 'else', 'sign', 'talking', 'law', 'wanted', 'concerned', and 'appt' could indicate that the person is considering seeking help from a lawyer or doctor, or that they are worried about a potential sign of something serious.	S,M	3189	13.63%	23393	10.75%	217593
		43	Being worried about their family members and seeking information on family history (e.g genetic testing)	['mom', 'dad', 'agree', 'mother', 'age', 'never', 'worried', 'father', 'stage', 'breast', 'symptom', 'died', 'diagnosed', 'yr', 'turned', 'happen', 'parent', 'told', 'tested', 'child']	The NMF topic discovered is about the experience of parents with a child diagnosed with colorectal cancer. The most important keywords are 'mom', 'dad', 'mother', 'father', 'parent', and 'child', indicating that the topic is about the parents of a child with colorectal cancer. Other important keywords include 'age', 'never', 'worried', 'stage', 'breast', 'symptom', 'died', 'diagnosed', 'yr', 'turned', 'happen', 'told', 'tested', which indicate that the stories are about the parents' experiences with their child's diagnosis and treatment, including their worries, the stages of the cancer, their reactions when they were told, and the tests their child underwent.	S,M	5273	22.54%	23393	10.75%	217593
		13	Arguing the importance to spend moments with family members during the cancer journey	['night', 'wife', 'daughter', 'kid', 'hour', 'beautiful', 'morning', 'together', 'friday', 'every', 'minute', 'day', 'moment', 'late', 'last', 'bed', 'home', 'thursday', 'gift', 'time']	This NMF topic appears to be about family and spending time together. It reveals that families are spending time together in the evenings and late into the night, cherishing every moment and making memories. It also suggests that families are appreciating the small things in life, like beautiful mornings, gifts, and being together at home or in bed on a Thursday or Friday night.	S	6071	25.95%	23393	10.75%	217593
C10: Daily activities while living with the colorectal cancer		17	Sharing suggestions on diets focused on balanced meals and healthy alternatives	['eat', 'food', 'cheer', 'diet', 'eating', 'juice', 'sugar', 'juicing', 'favorite', 'fruit', 'glass', 'perfect', 'dream', 'green', 'drink', 'red', 'wine', 'meat', 'coffee', 'heck']	This NMF topic is about healthy eating habits. With words like 'diet', 'eating', 'juice', 'sugar', 'juicing', 'fruit', 'red', 'wine', 'meat', and 'coffee', this topic suggests that people with colorectal cancer should focus on eating balanced meals, incorporating healthy juices, fruits, and vegetables, limiting their sugar and red meat intake, and replacing wine and coffee with healthier alternatives like juices and green drinks. The words 'cheer', 'favorite', 'perfect', 'dream', and 'heck' indicate that eating healthy food should be an enjoyable, positive experience, and that it is possible to find healthy alternatives for favorite dishes and drinks.	P	9910	32.64%	30364	13.95%	217593
		35	Sharing experience on being fit again, caring about weight control	['back', 'came', 'weight', 'exercise', 'return', 'set', 'running', 'self', 'track', 'pound', 'door', 'gain', 'lost', 'lb', 'fit', 'buzzard', 'sit', 'key', 'floor', 'put']	This NMF topic appears to be about returning to fitness after a cancer diagnosis. The most important words in this topic are "return," "weight," "exercise," "running," "self," and "track," suggesting that the focus is on regaining physical fitness by running, tracking progress, and setting goals. Other words such as "gain," "lost," "lb," "fit," "buzzard," "sit," "key," "floor," and "put" suggest that the topic is about pushing oneself to achieve goals related to physical fitness.	I	5480	17.98%	30364	13.95%	217593
		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	['going', 'enjoy', 'weekend', 'fun', 'trip', 'ready', 'tonight', 'vacation', 'game', 'watch', 'party', 'drive', 'house', 'weather', 'excited', 'car', 'town', 'near', 'planning', 'movie']	This NMF topic appears to be about planning a fun weekend outing, such as a vacation, trip, party, movie or game night. The words in order of importance are: 'going', 'enjoy', 'weekend', 'fun', 'trip', 'ready', 'tonight', 'vacation', 'game', 'watch', 'party', 'drive', 'house', 'weather', 'excited', 'car', 'town', 'near', 'planning', 'movie'. This suggests that the topic is about making plans for an enjoyable weekend, such as deciding on a destination, booking a hotel or car, and deciding which activities to participate in.	S,M	6949	22.89%	30364	13.95%	217593
		3	Celebrating anniversary and birthday for patients as a big milestone of their lives	['happy', 'birthday', 'dance', 'holiday', 'healthy', 'yea', 'anniversary', 'thanksgiving', 'naked', 'celebrating', 'celebration', 'filled', 'happiness', 'raise', 'dancing', 'cake', 'spongebob', 'ending', 'celebrated', 'scouty']	The NMF discovered topic is about celebrating and happiness. It includes keywords such as "happy", "birthday", "dance", "holiday", "healthy", "anniversary", "thanksgiving", "celebrating", "celebration", "filled", "happiness", "raise", "dancing", "cake", "spongebob", "ending", "celebrated", and "scouty". These words suggest that the topic is about rejoicing in special occasions with family and friends, eating cake, and other activities such as dancing, raising a glass, and celebrating life.	S,M	8045	26.50%	30364	13.95%	217593

Appendix 5: Human Research Ethics (HREC Approval)

Date 22-Dec-2022
Contact person Dr. Cath Cotton, Policy Advisor Academic Integrity
E-mail c.m.cotton@tudelft.nl

TU Delft

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: Developing feedback mechanism for colorectal patient remote monitoring systems (PROMISE) through Community Journey Mapping to increase HRQoL and patient empowerment
Applicant: SUN, Yingtao

Dear Yingtao SUN,

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. We do additionally note/advise the following:

With the methodoly used, there is the risk of using data from unwitting participants. It is advised to pay close attention to the data gathered and ensure patient data is consented to be used in research when entered on the platform. Please also see: Ethics in Social Science and Humanities (European Commission DGR&I 2021) (see section 3 internet research and social media - https://ec.europa.eu/info/funding-tenders/opportunities/docs/2021-2027/horizon/guidance/ethics-in-social-science-and-humanities_he_en.pdf) on this subject.

Good luck with your research!

Sincerely,

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

For making patient community journey map from the online platform.

Date 10-Mar-2023
Contact person Dr. Cath Cotton, Policy Advisor Academic Integrity
E-mail c.m.cotton@tudelft.nl

TU Delft

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: Developing feedback mechanism for colorectal patient remote monitoring systems (PROMISE) through Community Journey Mapping to increase HRQoL and patient empowerment
Applicant: SUN, Yingtao

Dear Yingtao SUN,

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 conditionally approved. Please note that this approval is subject to your ensuring that the following condition is fulfilled:

1) Make sure that any recordings of the co-creation session are deleted after the completion of the research project, or anonymized and stored. In both cases this should be clearly communicated in the Informed Consent.

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,

For Experts Co-creation Session

Appendix 5: Human Research Ethics (HREC Approval)

Date 14-Apr-2023
Contact person Dr. Cath Cotton, Policy Advisor Academic Integrity
E-mail c.m.cotton@tudelft.nl

TU Delft

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: Developing feedback mechanism for colorectal patient remote monitoring systems (PROMISE) through Community Journey Mapping to increase HRQoL and patient empowerment
Applicant: SUN, Yingtao

Dear Yingtao SUN,

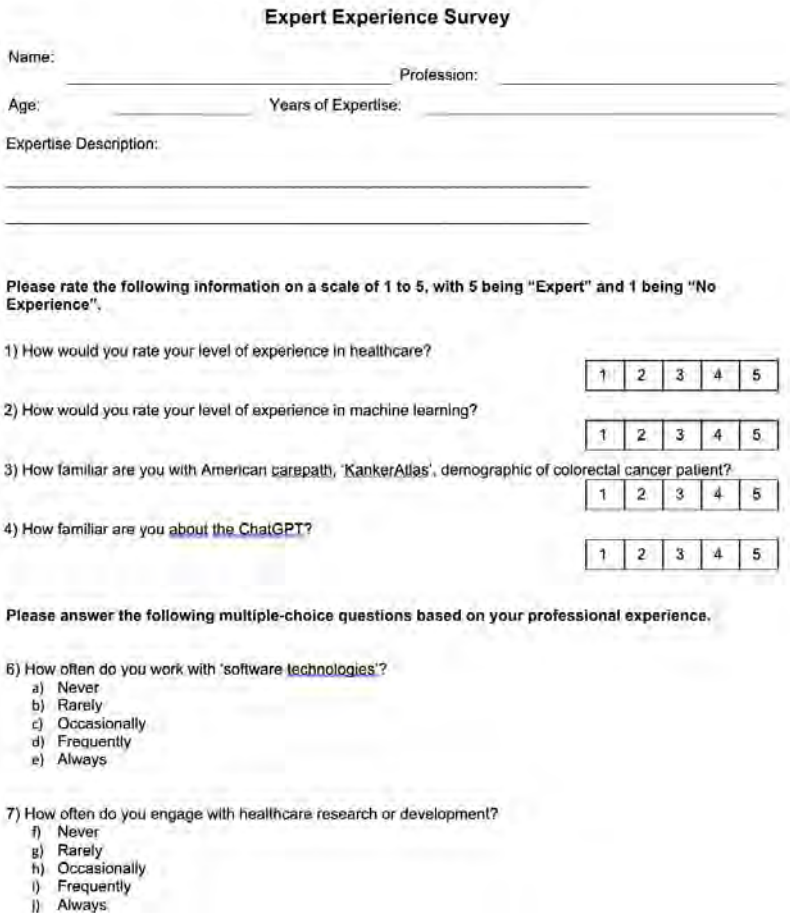
It is a pleasure to inform you that your application mentioned above has been approved.

Thanks very much for your submission to the HREC which has been approved. We do additionally note/advise the following:
please ensure the IC contains the collaboration with EMC. And with the methodoly used, there is the risk of using data from unwitting participants. It is advised to pay close attention to the data gathered and ensure patient data is consented to be used in research when entered on the platform. Please also see: Ethics in Social Science and Humanities (European Commission DGR&I 2021) (see section 3 internet research and social media - https://ec.europa.eu/info/funding-tenders/opportunities/docs/2021-2027/horizon/guidance/ethics-in-social-science-and-humanities_he_en.pdf) on this subject.

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.

For Diary Studies and Interviews

Appendix 6: Expert Survey



Expert Experience Survey

Name: _____ Profession: _____

Age: _____ Years of Expertise: _____

Expertise Description:

_____

_____

Please rate the following information on a scale of 1 to 5, with 5 being "Expert" and 1 being "No Experience".

1) How would you rate your level of experience in healthcare?

1	2	3	4	5

2) How would you rate your level of experience in machine learning?

1	2	3	4	5

3) How familiar are you with American carepath, 'KankerAtlas', demographic of colorectal cancer patient?

1	2	3	4	5

4) How familiar are you about the ChatGPT?

1	2	3	4	5

Please answer the following multiple-choice questions based on your professional experience.

6) How often do you work with 'software technologies'?
- a) Never
- b) Rarely
- c) Occasionally
- d) Frequently
- e) Always

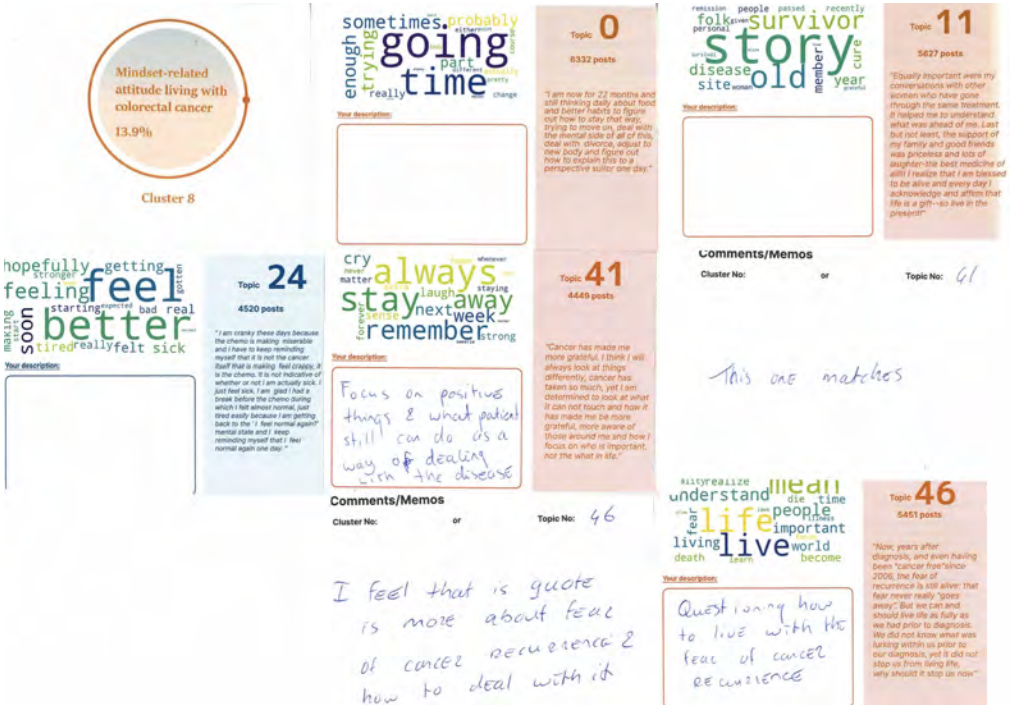
7) How often do you engage with healthcare research or development?
- f) Never
- g) Rarely
- h) Occasionally
- i) Frequently
- j) Always

Expert Survey for Experts Co-creation Session

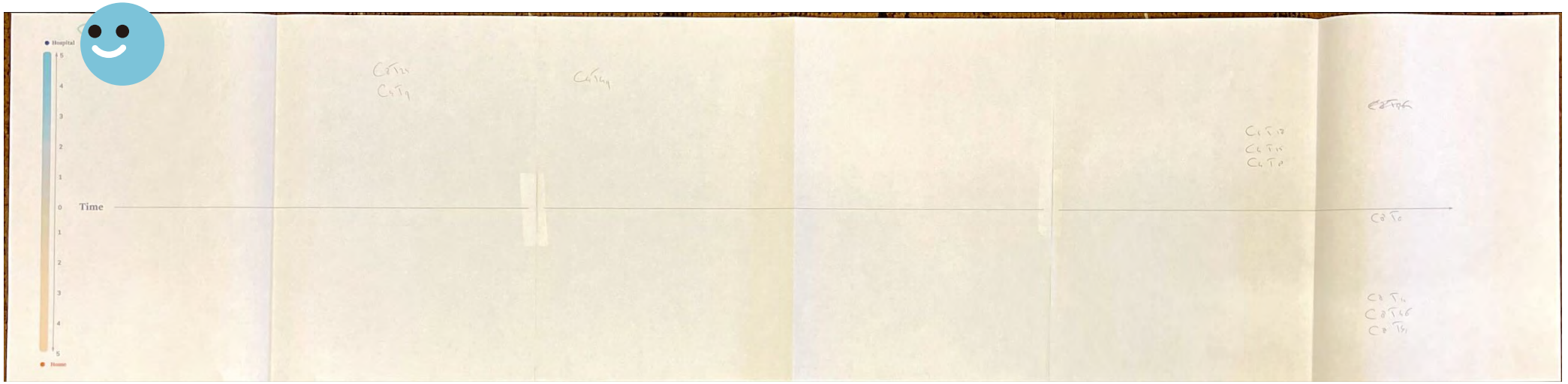
Appendix 7: Experts' Topic Cards

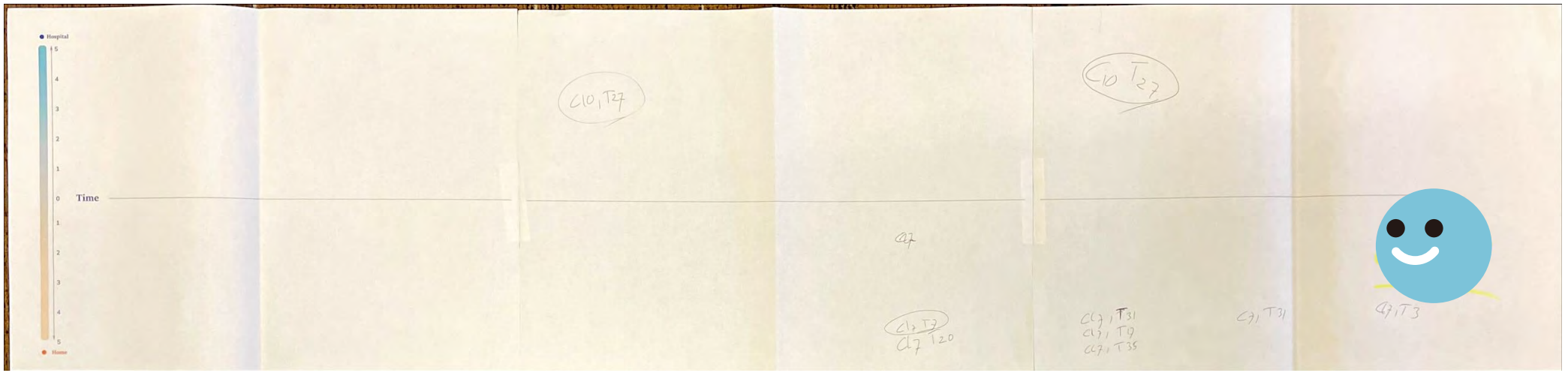
Appendix 7: Experts' Topic Cards

Appendix 7: Experts' Topic Cards

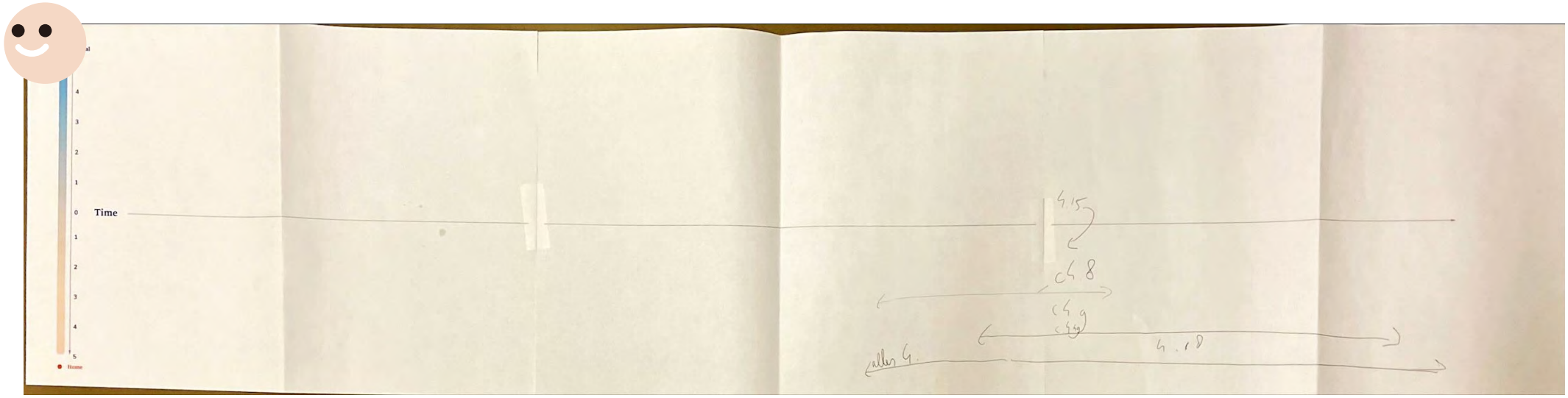


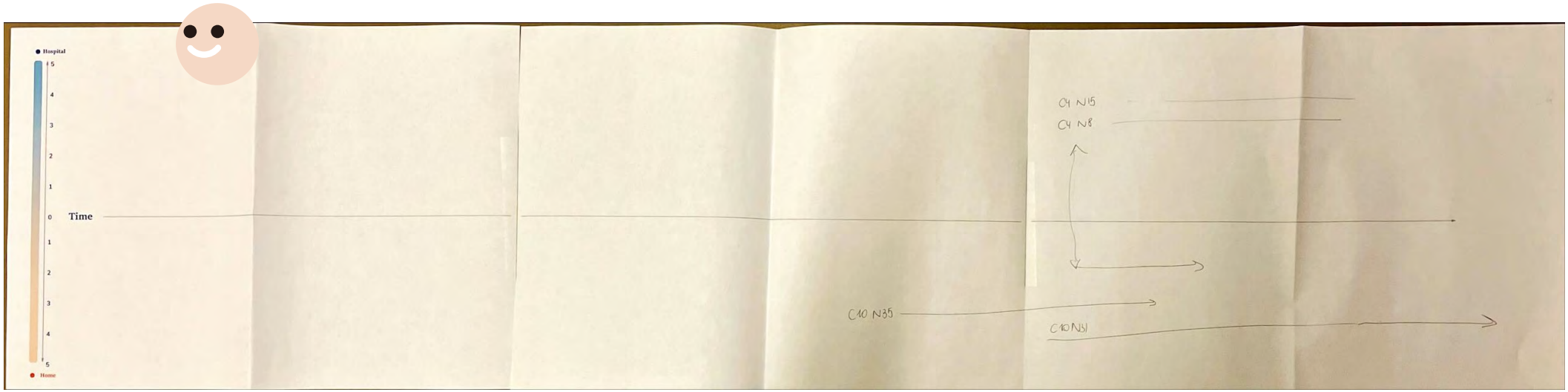
Appendix 8: Experts' Journey Map



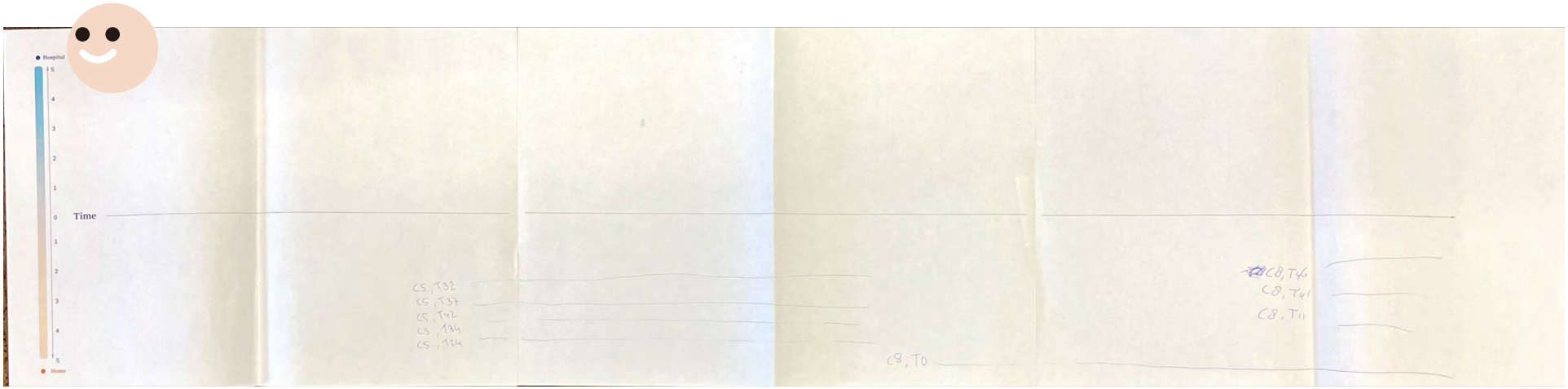


Appendix 8: Experts' Journey Map





Appendix 8: Experts' Journey Map



Appendix 9: Informed Consent

Informed Consent for Colorectal Cancer Co-creation Session

Participant Information
You are being invited to participate in a research study titled "Understanding Colorectal Cancer Patient Experience with Knowledge Discovery". This study is being done by Ayush Patandin and Yingtao Sun from the TU Delft under the supervision of Jiwon Jung. Medical researchers, doctors and their focus groups will be the participants who have knowledge of the Colorectal Cancer disease.

The purpose of this research study is to validate the topics of the Colorectal Cancer Journey Map and to get insights on how to integrate Dutch context into the Journey Map and will take you approximately 90 minutes to complete. The data will be used for validating and improving CRC patient's platform data machine learning analysis research. We will be asking you to co-create which steps to take to further develop the feedback mechanism and to further improve the interpretation of the model output.

As with any online activity, the risk of a breach is always possible. To the best of our ability, your answers in this study will remain confidential. We will minimize any risks by the information and feedback provided by the participants. During the study, we will record the conversations and take some photos with the participants. These recordings will remain confidential and will only be used for the purpose of the study. The photos will be anonymized and used in the papers. Aside from that, there will be no actions taken during the study which can cause the patients to have physical and emotional discomfort. The participants have the right to withdraw from the study at any time.

Your participation in this study is entirely voluntary and you can withdraw at any time. You are free to omit any questions. Data will be immediately removed when a participant denies permission. It is up to the participant if he/she wants to remain anonymous during the study. The participants will cover their own travel costs to be present during this study.

The contact details of corresponding and Responsible Researcher:
Yingtao Sun: y.sun-32@student.tudelft.nl
Ayush Patandin: S.A.S.Patandin@student.tudelft.nl
Jiwon Jung: j.jung@erasmusmc.nl

PLEASE TICK THE APPROPRIATE BOXES	Yes	No
A: GENERAL AGREEMENT – RESEARCH GOALS, PARTICPANT TASKS AND VOLUNTARY PARTICIPATION		
1. I have read and understood the study information dated 08/03/2023, or it has been read to me. I have been able to ask questions about the study and my questions have been answered to my satisfaction.	☐	☐
2. I consent voluntarily to be a participant in this study and understand that I can refuse to answer questions and I can withdraw from the study at any time, without having to give a reason.	☐	☐
3. I understand that taking part in the study involves: co-creating design and development ideas, a survey questionnaire for retrieving Dutch context of the rectal Cancer disease.	☐	☐
4. I understand that the study will end at 10:30PM on 08/03/2023.	☐	☐
B: POTENTIAL RISKS OF PARTICIPATING (INCLUDING DATA PROTECTION)		
6. I understand that the following steps will be taken to minimise the threat of a data breach, and protect my identity in the event of such a breach: the conversations during the co-creation session will be recorded and there will be photos taken during the study. These recordings will not be distributed and will only be used for the purpose of the study. The photos will be anonymized and used in the papers.	☐	☐
7. I understand that personal information collected about me that can identify me, such as my name or where I live, will not be collected.	☐	☐
C: RESEARCH PUBLICATION, DISSEMINATION AND APPLICATION		
8. I understand that after the research study the de-identified information I provide will be used for: Master thesis publication of Computer Science and Industrial Design, reproducibility of the study for future researchers.	☐	☐
9. I agree that my responses, views or other input can be quoted anonymously in research outputs.	☐	☐
D: (LONGTERM) DATA STORAGE, ACCESS AND REUSE		
10. I give permission for the de-identified survey questionnaires that I provide to be archived in the TU Delft SURF Cloud repository so it can be used for future research and learning.	☐	☐
11. I understand that access to this repository is restricted only to the data manager or computer scientist who takes part in the research study.	☐	☐

Signatures

Name of participant [printed]	Signature	Date

I, as researcher, have accurately read out the information sheet to the potential participant and, to the best of my ability, ensured that the participant understands to what they are freely consenting.

Researcher name [printed]	Signature	Date
Yingtao Sun; Ayush Patandin; Jiwon Jung	Yingtao Sun	23-02-2023

Study contact details for further information:
Yingtao Sun: y.sun-32@student.tudelft.nl
Ayush Patandin: S.A.S.Patandin@student.tudelft.nl
Jiwon Jung: j.jung@erasmusmc.nl

Informed Consent for Experts Co-creation Session

Appendix 9: Informed Consent

Informed Consent for Colorectal Cancer Diary Study

Participant Information
You are being invited to participate in a research study titled "Developing a feedback mechanism for colorectal cancer patients in the follow-up stage" . This study is being done by Yingtao Sun from the TU Delft under the supervision of Jiwon Jung. Colorectal cancer patients in the follow-up stage or who have been cured will be the participants.

The purpose of this research study is to understand colorectal cancer patients' social and daily activities based on WWWWWH methods (What, Who, When, Why, How), including how they describe their emotional feelings. The aim is to explore and understand their social and daily activity when patients are away from hospital.

The diary study will last for 3 days, but it is welcome to do more days. The data will be used to further develop a feedback mechanism in the remote monitoring system.

As with any activity, the risk of a breach is always possible. To the best of our ability, your answers in this study will remain confidential. We will minimize any risks through the information and feedback provided by the participants. During the study, you need to fill in the materials and send them back to us. These materials will remain confidential and will only be used for the purpose of the study. The photos being taken during the interviews will be anonymized and used in the papers. Aside from that, there will be no actions taken during the study which can cause the patients to have physical and emotional discomfort. The participants have the right to withdraw from the study at any time.

Your participation in this study is entirely voluntary and you can withdraw at any time. You are free to omit any questions. Data will be immediately removed when a participant denies permission.

The contact details of corresponding and responsible researcher:
Yingtao Sun: y.sun-32@student.tudelft.nl
Jiwon Jung: j.jung@erasmusmc.nl

PLEASE TICK THE APPROPRIATE BOXES	Yes	No
A: GENERAL AGREEMENT – RESEARCH GOALS, PARTICPANT TASKS AND VOLUNTARY PARTICIPATION		
1. I have read and understood the study information. I have been able to ask questions about the study and my questions have been answered to my satisfaction.	☐	☐
2. I consent voluntarily to be a participant in this study and understand that I can refuse to answer questions and I can withdraw from the study at any time, without having to give a reason.	☐	☐
3. I understand that taking part in the study involves: a diary study by filling in the materials and an interview.	☐	☐
B: POTENTIAL RISKS OF PARTICIPATING (INCLUDING DATA PROTECTION)		
4. I understand that the following steps will be taken to minimise the threat of a data breach, and protect my identity in the event of such a breach: the material will be used in research and the materials will be destroyed when the research is finished (on August 1, 2023). What I have filled in will be used in papers anonymously.	☐	☐
5. I understand that personal information collected about me that can identify me, such as my name, age, gender and career, will not be shared outside the research team. It will be destroyed as soon as the research is finished.	☐	☐
6. I understand that the interview will be recorded, and photos being taken. The recording will be destroyed when the research is finished (on August 1, 2023) and the photos will be used in the papers anonymously.		
C: RESEARCH PUBLICATION, DISSEMINATION AND APPLICATION		
7. I understand that after the research study the de-identified information I provide will be used for: Master thesis publication of Industrial Design, journals, and reproducibility of the study for future researchers.	☐	☐
8. I agree that my responses, views, or other input can be quoted anonymously in research outputs.	☐	☐
D: (LONGTERM) DATA STORAGE, ACCESS AND REUSE		
9. I give permission for the de-identified materials that I provide to be archived in the TU Delft SURF Cloud repository so they can be used for future research and learning.	☐	☐
10. I understand that access to this repository is restricted only to the researchers who take part in the research study.	☐	☐

Signatures

Name of participant	Signature	Date

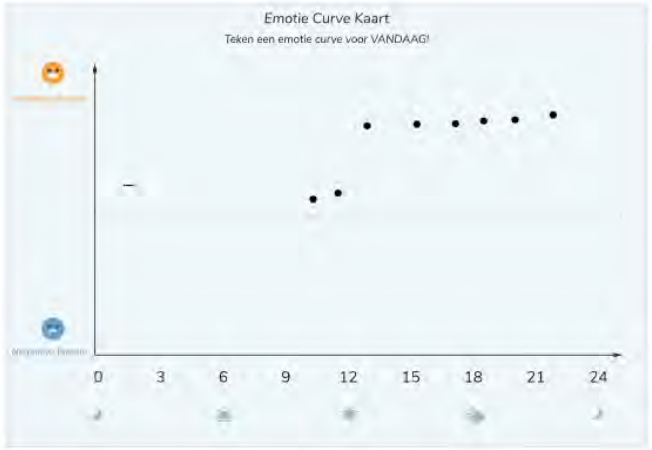
I, as researcher, have accurately read out the information sheet to the potential participant and, to the best of my ability, ensured that the participant understands to what they are freely consenting.

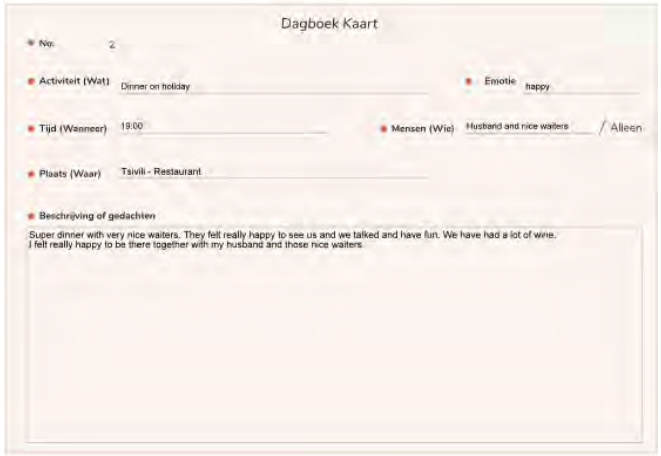
Researcher name	Signature	Date
Yingtao Sun	Yingtao	12-05-2023

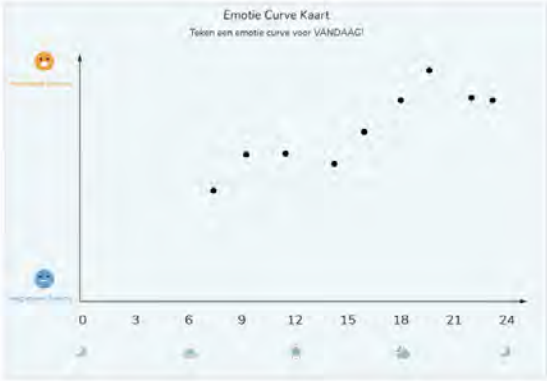
Study contact details for further information:
Yingtao Sun: y.sun-32@student.tudelft.nl

Informed Consent for Diary Studies and Interview

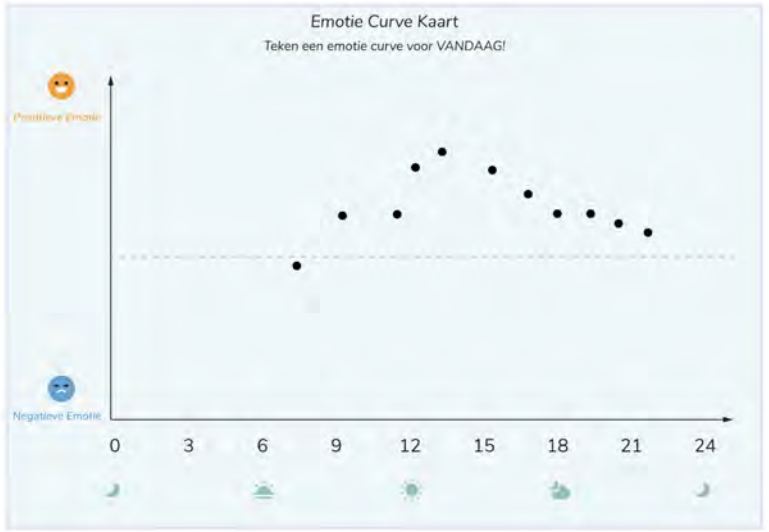
Appendix 10: Diary Studies Finished Probe

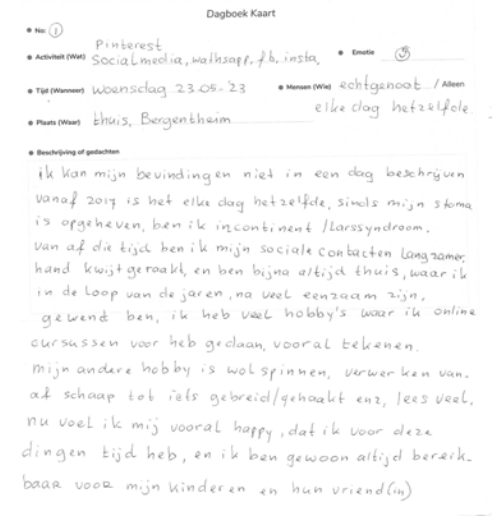


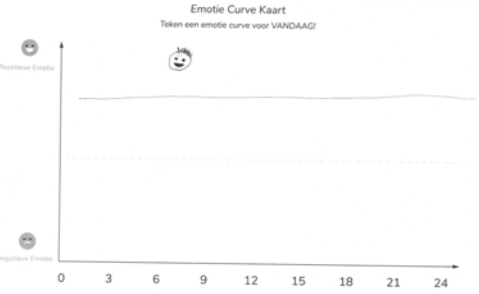




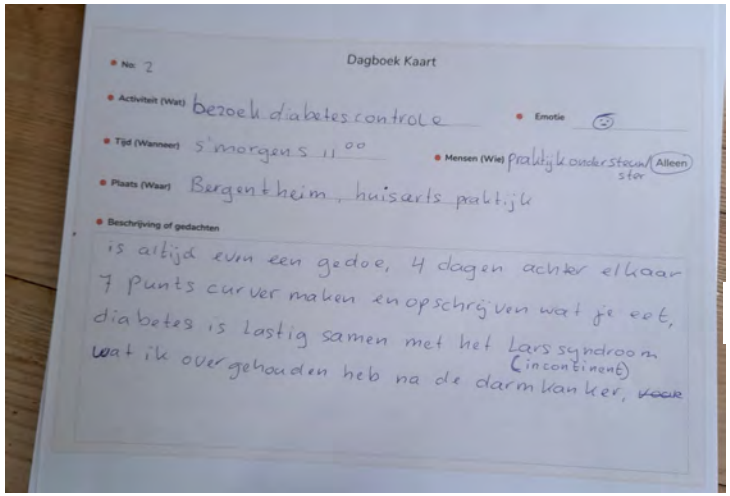
Appendix 10: Diary Studies Finished Probe







Appendix 10: Diary Studies Finished Probe



Dagboek Kaart

No: 2

Activiteit (Wat) bezoek diabetes controle

Emotie

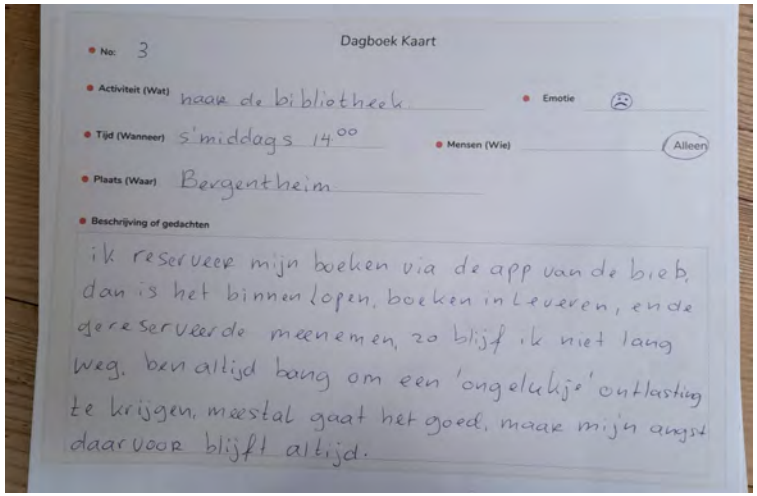
Tijd (Wanneer) s'morgens 11.00

Mensen (Wie) praktijk ondersteun/ster Alleen

Plaats (Waar) Bergentheim, huisarts praktijk

Beschrijving of gedachten

is altijd even een gedoe, 4 dagen achter elkaar 7 punts curver maken en opschrijven wat je eet, diabetes is lastig samen met het Lars syndroom (incontinent) wat ik overgehouden heb na de darmkanker, ~~voor~~



Dagboek Kaart

No: 3

Activiteit (Wat) naar de bibliotheek

Emotie

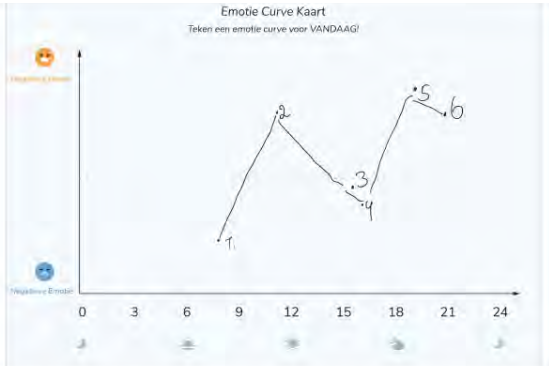
Tijd (Wanneer) s'middags 14.00

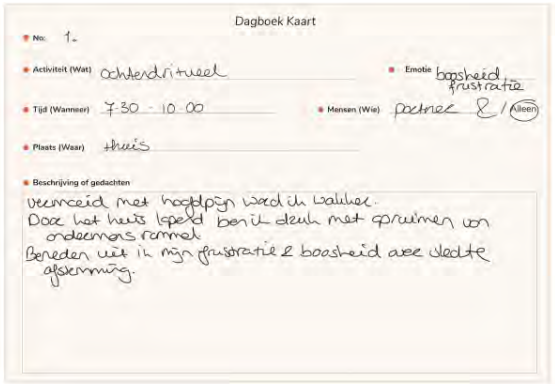
Mensen (Wie) Alleen

Plaats (Waar) Bergentheim

Beschrijving of gedachten

ik reserveer mijn boeken via de app van de bieb, dan is het binnenlopen, boeken inleveren, en de gereserveerde meenemen, zo blijf ik niet lang weg. ben altijd bang om een 'ongelukje' ontlasting te krijgen, meestal gaat het goed, maar mijn angst daarvoor blijft altijd.





Dagboek Kaart

No: 1.

Activiteit (Wat) ochtendritueel

Emotie boosheid, frustratie

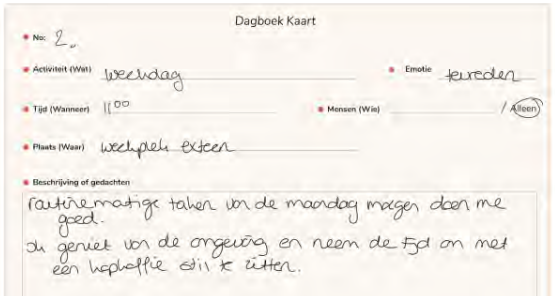
Tijd (Wanneer) 7.30 - 10.00

Mensen (Wie) partner & / Alleen

Plaats (Waar) thuis

Beschrijving of gedachten

vermoeid met hoofdpijn word ik wakker.
Door het huis lopend ben ik druk met opruimen van ondermans rommel
Beneden uit ik mijn frustratie & boosheid over slechte afstemming.



Dagboek Kaart

No: 2.

Activiteit (Wat) werkdag

Emotie tevreden

Tijd (Wanneer) 11.00

Mensen (Wie) / Alleen

Plaats (Waar) werkplek extern

Beschrijving of gedachten

routinematige taken van de maandag morgen doen me goed.
Ik geniet van de omgeving en neem de tijd om met een kopkoffie stil te zitten.

Dagboek Kaart

No: 3

Activiteit (Wat) Gesprek partner

Emotie teleurstelling verdriet

Tijd (Wanneer) 15.30

Mensen (Wie) partner / Alleen

Plaats (Waar) in de tuin

Beschrijving of gedachten

mijn partner vertelt dat mijn bonus er voor heeft gekozen dat ik niet mee ga met het uitje van haar feestje.
Ik voel de teleurstelling verdriet en gevoelens van afgewezen worden.
Om probeer ik de gevoelens van me af te zetten door gedachtes over begrip: de lastige keuze tussen haar moeder en mij.

Dagboek Kaart

No: 4

Activiteit (Wat) boodschappen doen

Emotie zorgenmakend

Tijd (Wanneer) 16.00

Mensen (Wie) partner & bonus/dochter Alleen

Plaats (Waar) onderweg in de auto

Beschrijving of gedachten

mijn lichaam is onrustig pijn & ongemak voel ik
Ik mock me zorgen over wat het zou kunnen zijn.
We zijn opweg om een leuke aanschaf te doen en probeer mijn gedachten daar mee af te leiden, maar dat lukt niet. Ik voel me neerslachtig

Dagboek Kaart

No: 5

Activiteit (Wat) wandelen met hond

Emotie blijdschap

Tijd (Wanneer) 19.30

Mensen (Wie) / Alleen

Plaats (Waar) buiten

Beschrijving of gedachten

Genietend van mijn blije 4-voeter. De zon op mijn gezicht kom mijn partner onderweg naar huis tegen. Blij verrast wandelen we 't laatste stukje samen naar huis.

Dagboek Kaart

No: 6

Activiteit (Wat) Avondritueel

Emotie tevreden

Tijd (Wanneer) 20.30

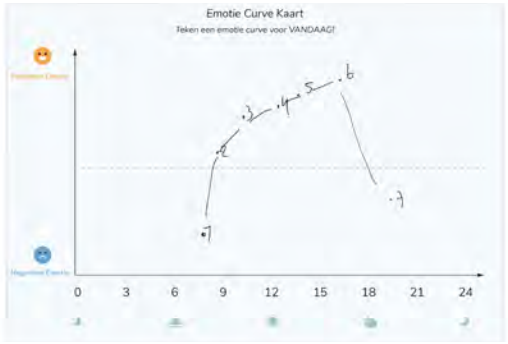
Mensen (Wie) / Alleen

Plaats (Waar) op bed

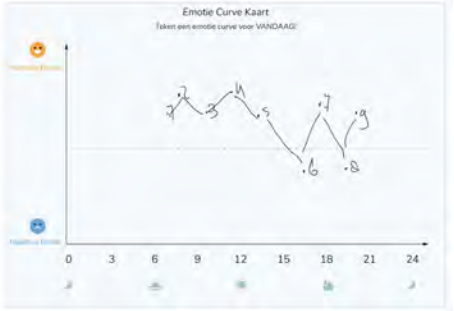
Beschrijving of gedachten

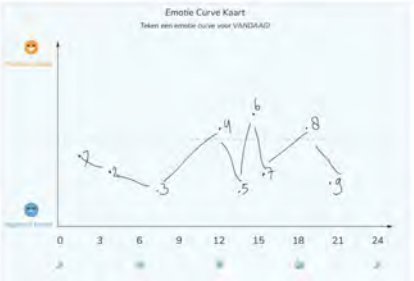
Een korte reflectie over de dag schrijven.
Nu vooral tevreden over de keuze om op tijd op bed te gaan liggen te accepteren dat de dag was zoals hij was en het verder achter me te laten.

Appendix 10: Diary Studies Finished Probe



Appendix 10: Diary Studies Finished Probe





Appendix 10: Diary Studies Finished Probe

Dagboek Kaart
No: 2
Activiteit (Wat) nachtrust
Emotie frustratie
Tijd (Wanneer) 04:00
Mensen (Wie) / Alleen
Plaats (Waar) in bed
Beschrijving of gedachten
Wederom wakker
frustratie wanneer ik op de wekker kijk. Ik dacht dat ik goed had doorgeslapen

Dagboek Kaart
No: 3
Activiteit (Wat) opstaan
Emotie ergernis
Tijd (Wanneer) 8:00
Mensen (Wie) / Alleen
Plaats (Waar) in huis
Beschrijving of gedachten
ook om 6:00 wakker geworden & om 7:00 toen mijn partner ging opstaan.
Ik sta gehoost op, omdat ik denk dat het woensdag is (het is dinsdag).
Ik voel direct mijn hoofdpijn.
Ik erger me aan mijn huisgenoten.

Dagboek Kaart
No: 4
Activiteit (Wat) administratie
Emotie rustig, tevreden
Tijd (Wanneer) 12:00
Mensen (Wie) / Alleen
Plaats (Waar) op de bank
Beschrijving of gedachten
mezelf comfortabel gemaakt : ik 'moet' niks vandaag
muziek - koffie - hondje naast me.
Overzicht creëren in de administratie geeft me rust

Dagboek Kaart
No: 5
Activiteit (Wat) Administratie
Emotie frustratie boos, teleurstelling
Tijd (Wanneer) 13:00
Mensen (Wie) partner / Alleen
Plaats (Waar) thuis
Beschrijving of gedachten
Eén tegenslag en de frustratie / ergernissen zijn er meteen weer en nemen mijn gedachtes volledig in beslag. Ook wat nu niet speelt, maar eerder me ergerde komt ook naar boven: alles op 1 hoop.
Ik projecteer het mn op mijn partner, die ik boos opbel. Wanneer ik me heb geuit en we samen kijken naar wat er werkelijk bij me speelt word ik rustiger en zie ik de teleurstellingen naar mezelf toe.

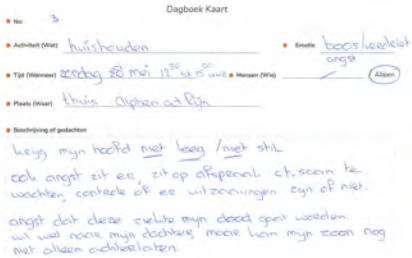
Dagboek Kaart
No: 6
Activiteit (Wat) ophalen van snoer
Emotie warm; blij
Tijd (Wanneer) 13:30
Mensen (Wie) partner / Alleen
Plaats (Waar) de garage
Beschrijving of gedachten
Het 'euvel' is snel opgelost & ik zie mijn partner nog even tussen de afspraken door.
Blij om hem te zien en even vastgehouden te kunnen worden.

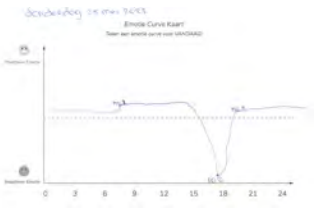
Dagboek Kaart
No: 7
Activiteit (Wat) thuiskomst bonusdochter
Emotie teleurstelling
Tijd (Wanneer) 14:30
Mensen (Wie) bonusdochter / Alleen
Plaats (Waar) thuis
Beschrijving of gedachten
Ze wil al snel zich terugtrekken en alleen iets op haar kamer doen.
Ik vind dat ok en vind 't eigenlijk wel fijn, zo kan ik ook iets voor mezelf doen. Dan vind ik het teleurstellend van mezelf dat ik even niet de energie kan opbrengen om samen iets leuks te doen.

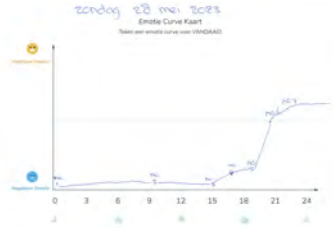
Dagboek Kaart
No: 8
Activiteit (Wat) familie bezoek
Emotie tevreden
Tijd (Wanneer) 19:30
Mensen (Wie) zus, partners kinderen / Alleen
Plaats (Waar) bij zus thuis
Beschrijving of gedachten
Het is fijn om met elkaar samen te zijn.
ontspannen, fijn met elkaar koffie in de avondzon.
Gezellig praten: spelen met de handen

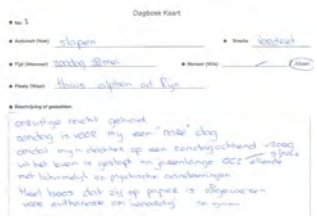
Dagboek Kaart
No: 9
Activiteit (Wat) terugreis
Emotie irritatie
Tijd (Wanneer) 21:00
Mensen (Wie) partner & bonus/dochter / Alleen
Plaats (Waar) in de auto
Beschrijving of gedachten
Het gaat niet zoals ik het bedacht heb.
Ik voel me moe en wil naar huis. Het 'ommetje' valt verkeerd. Ik keer me in mezelf met boze gedachtes over wat mij allemaal ergert en ik binnenkort met mijn partner wil doorspreken.

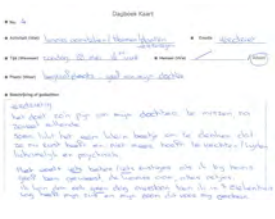
Appendix 10: Diary Studies Finished Probe

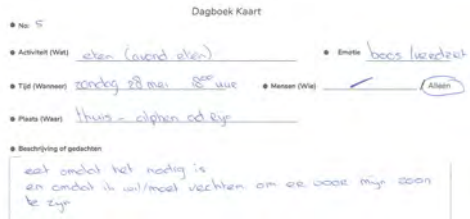




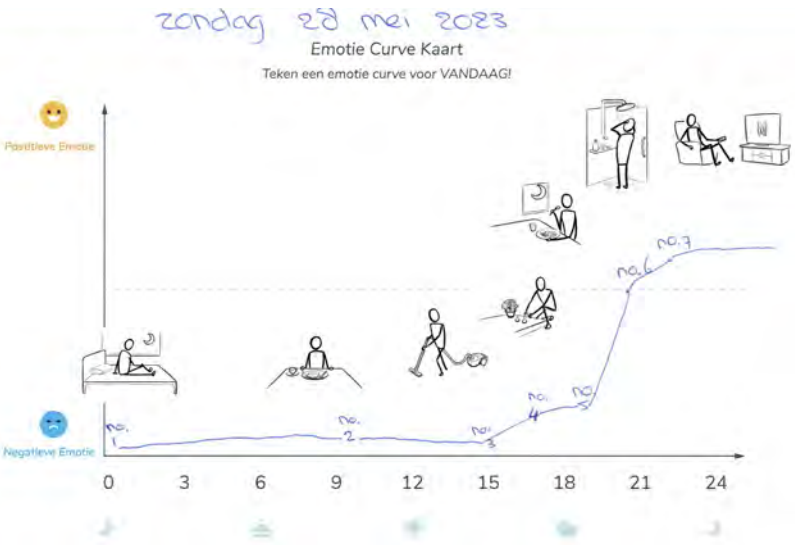


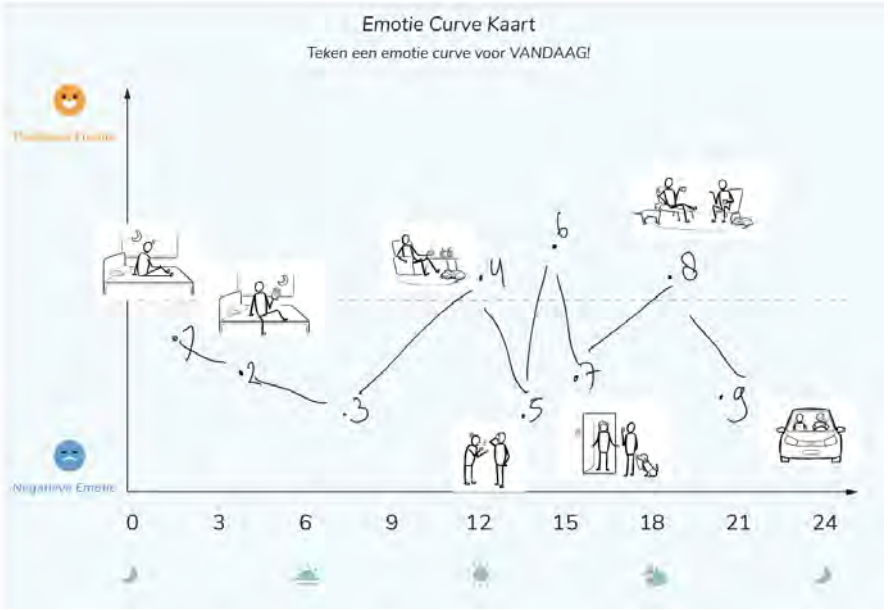


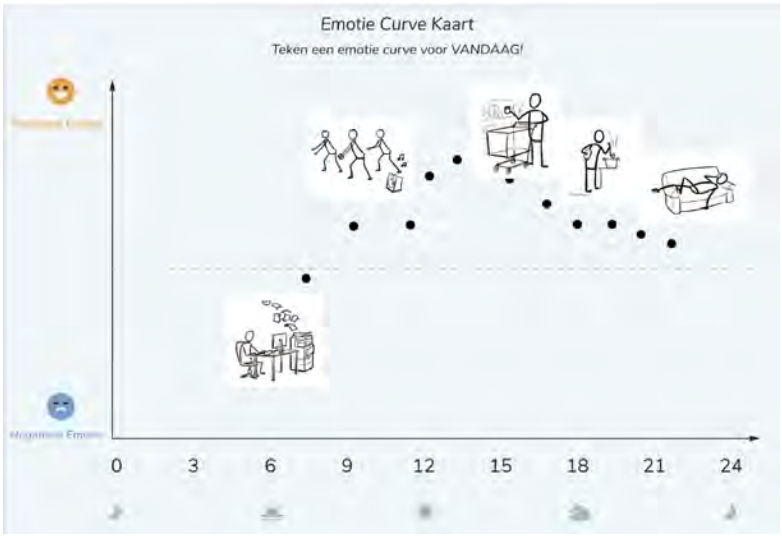




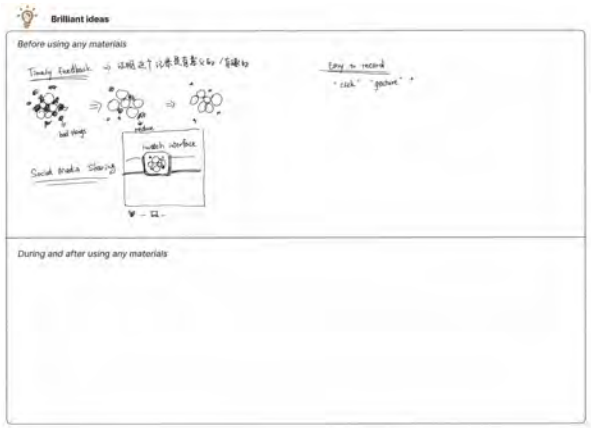
Appendix 11: Interview Material

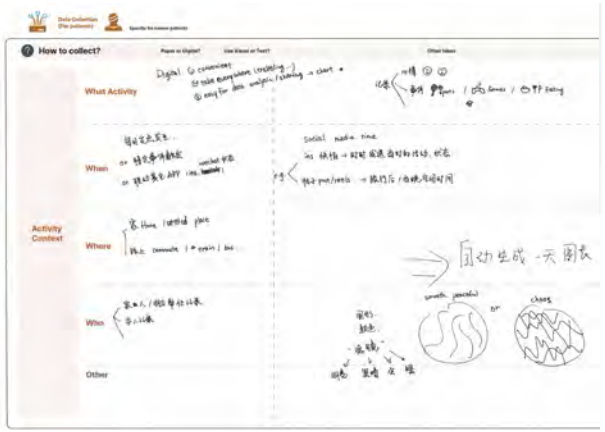


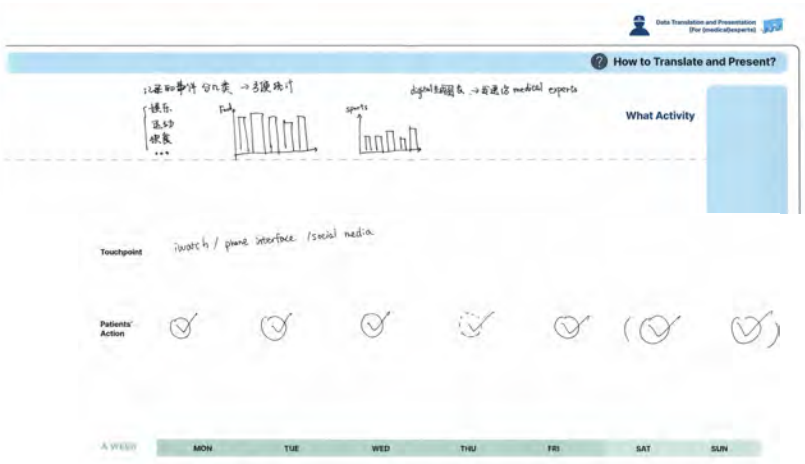


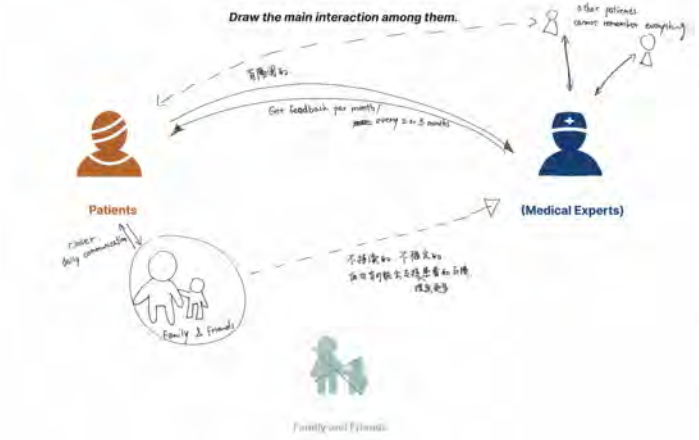


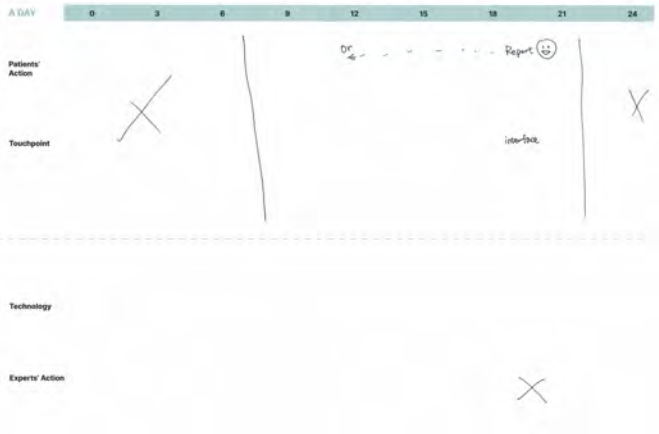
Appendix 12: Designers' Brainstorm Session

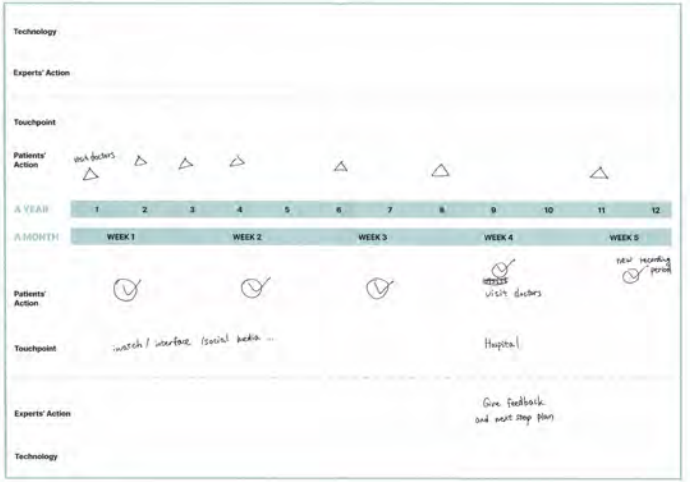












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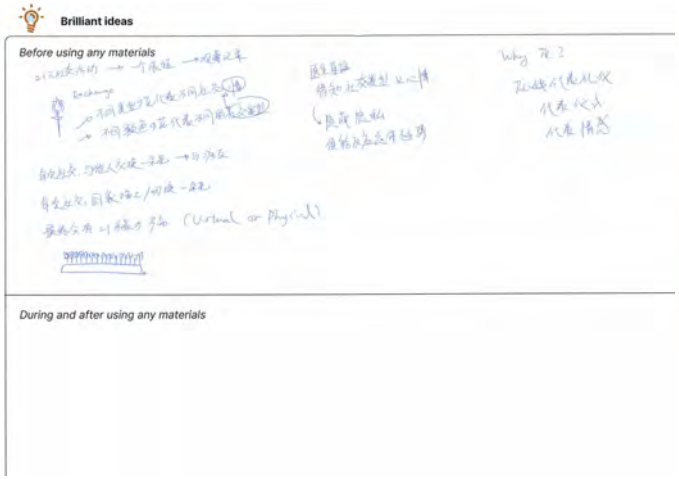
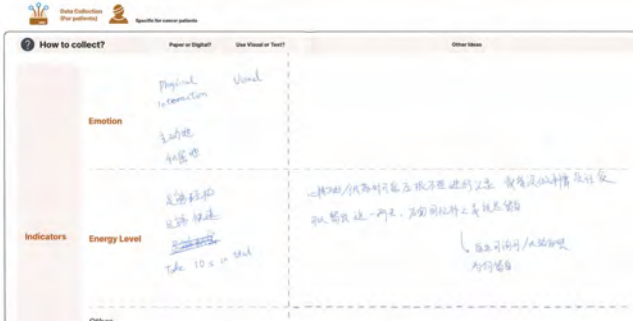
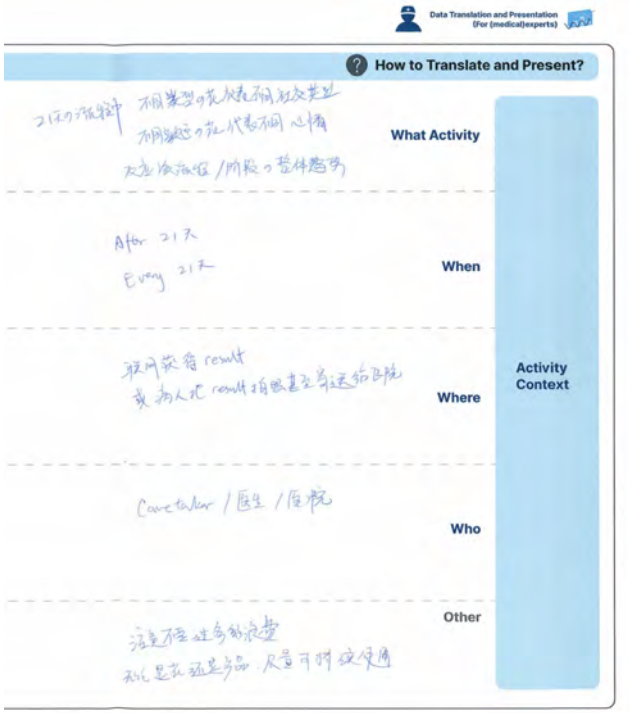
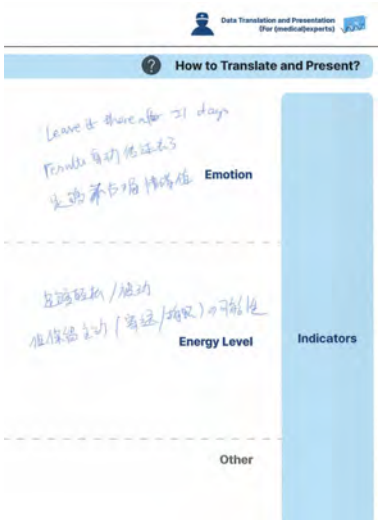
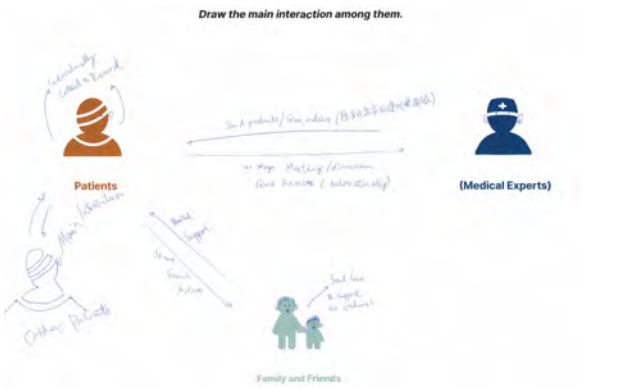


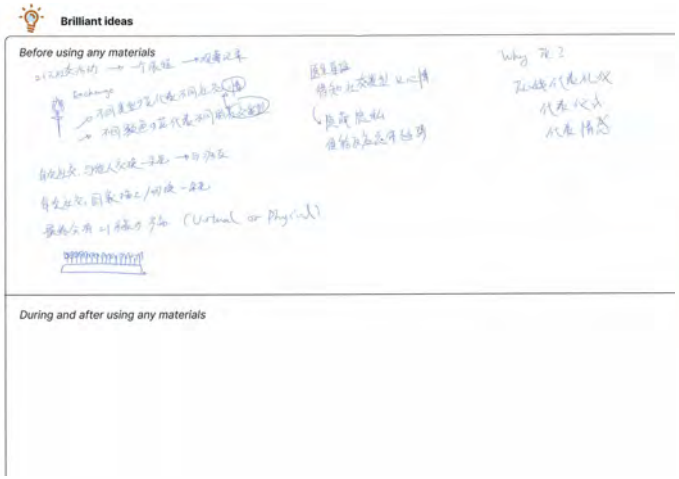


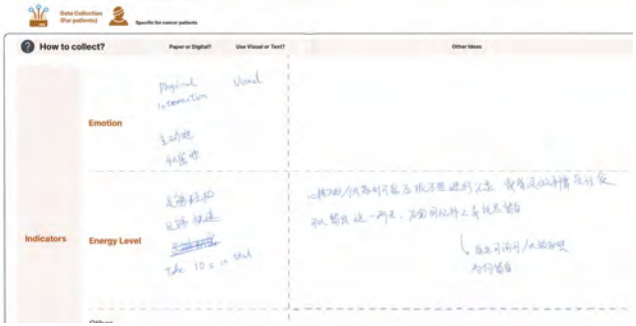


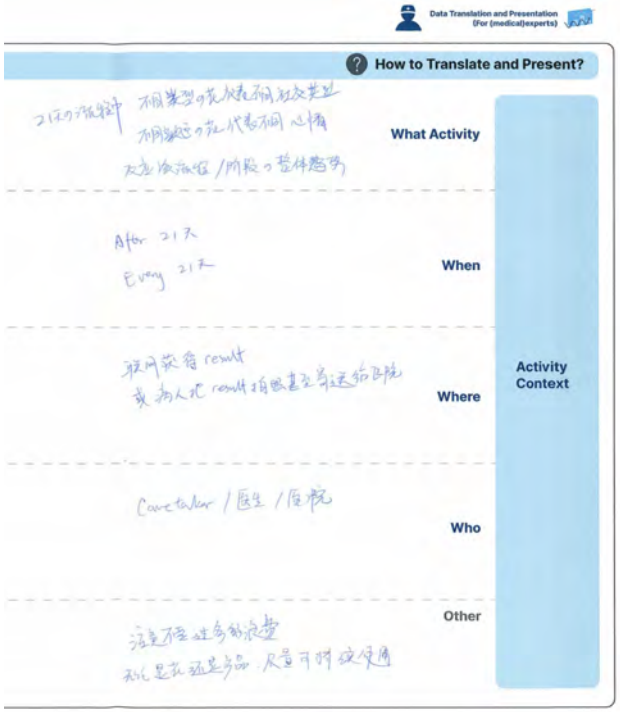


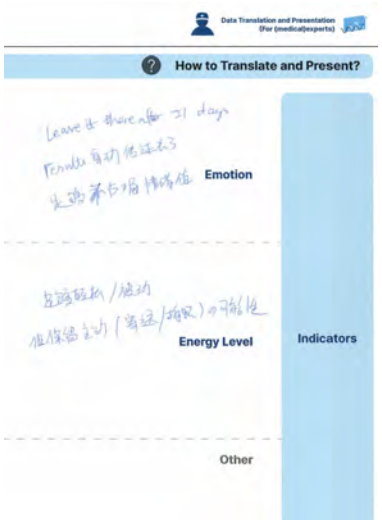


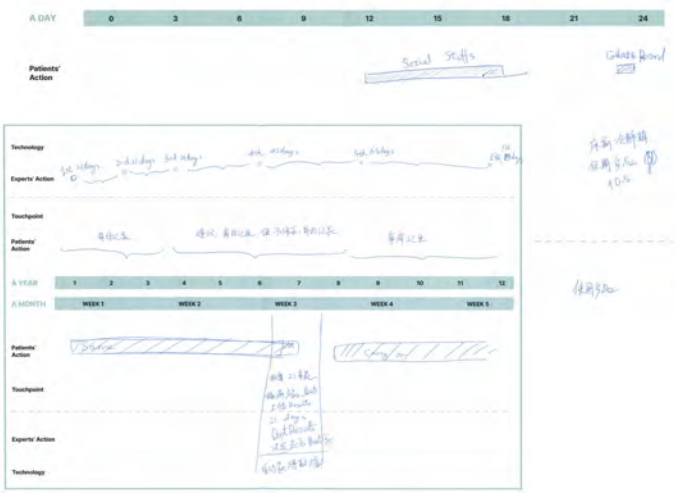
Appendix 12: Designers' Brainstorm Session











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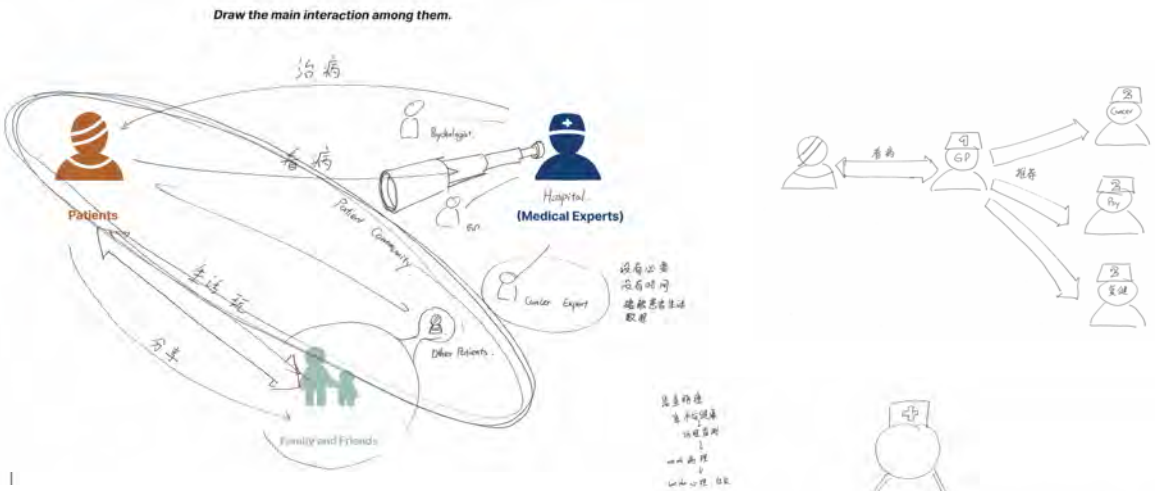
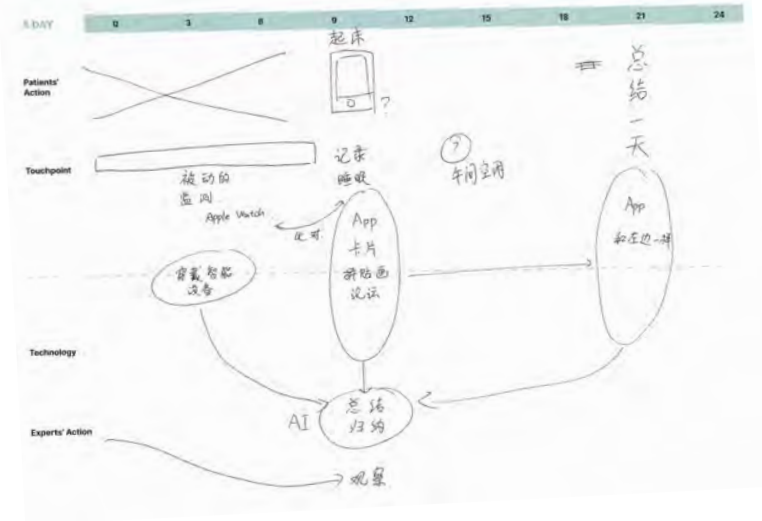
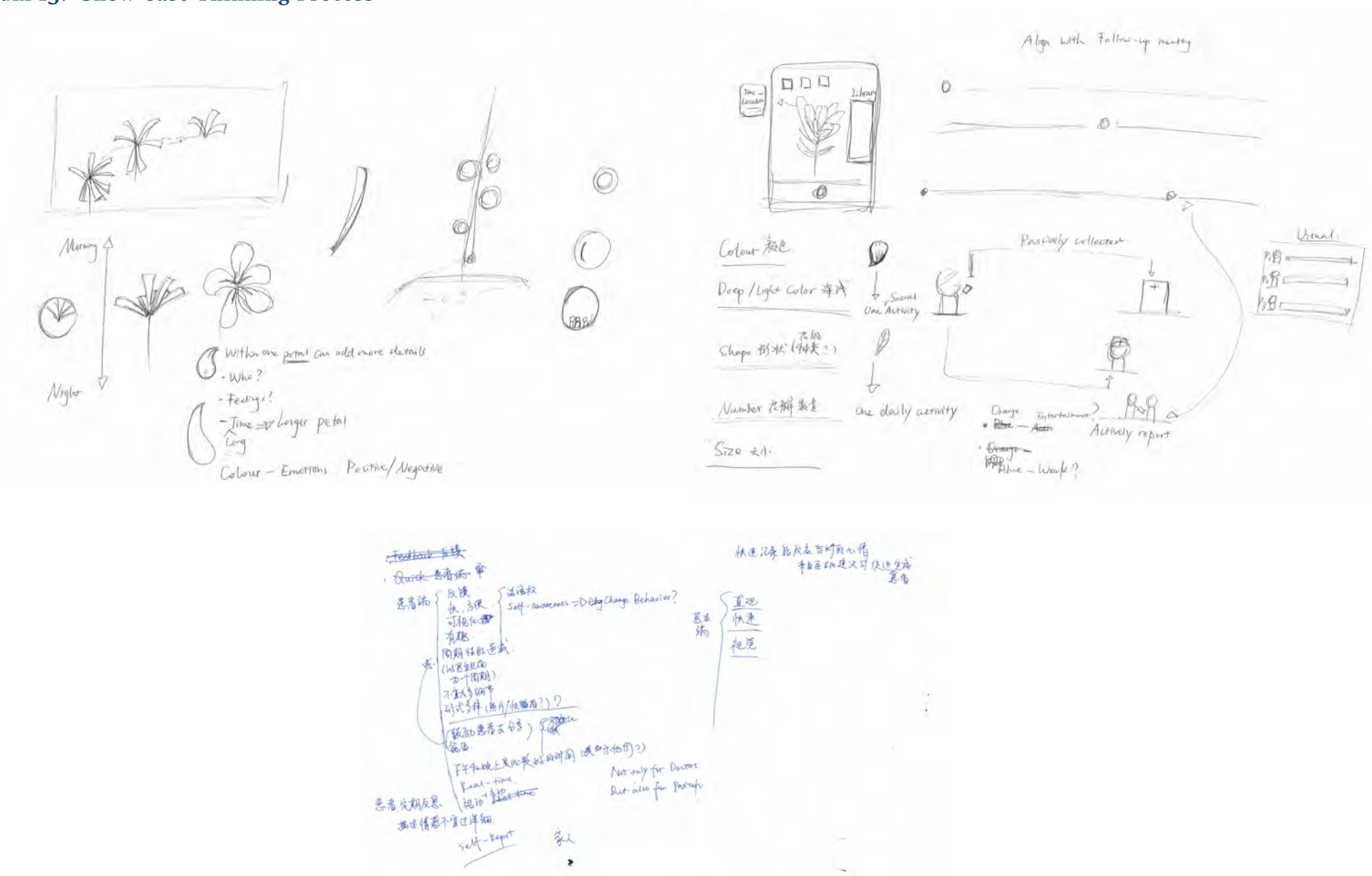
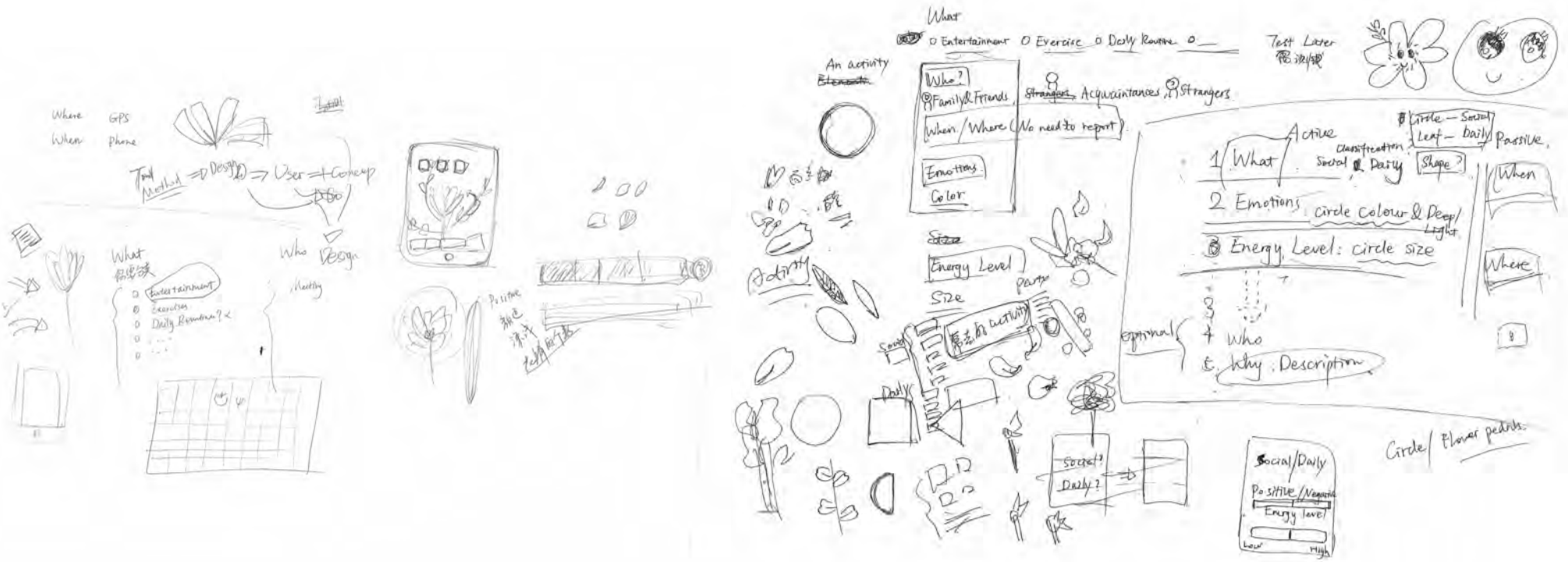




Appendix 13: Show Case Thinking Process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