A BETTER WAY TO LIVE WITH A CHRONIC CONDITION

Envisioning transition kit for women living with endometriosis

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ABSTRACT

This project explores the question of how to support women living with endometriosis in the transition into live with a chronic condition while maintaining the best possible quality of life.

Design process was planned out and exercises in four steps - preparations and background research (outlining well-being perspective, desk research, research online via social media), design research (multiple surveys, interviews, reflections online, co-creation sessions, probing, interviews following probing with co-creation sessions, ideation sessions, analysis), explorations (creation of directions, analysis, initial concepts creation, feedback, synthesis, design proposal, feedback and evaluation sessions, design improvements) and final design proposal. Activities were aiming to repeatedly open up the scope of the project and then through the analysis of each phase narrow it down again following diamond shape.

One important aspect of the process was to engage women living with endometriosis as well as their loved ones throughout the whole process and design together instead of designing for them. Of course, experts were consulted as well to make sure project is following standards of medical care, but the primary focus on the users was important since the product was shaped rather as a lifestyle change facilitator as well as data collection tool rather than a strictly medical solution.

The outcome of the project is a flexible system VEA serving as a transition kit for women diagnosed with endometriosis, but also early detection screening tool and awareness platform for those who haven’t been diagnosed yet. Even though this might seem complicated I’ll try to explain why only this kind of a multifaceted approach can fully support women in their journey toward their best possible quality of life.

VEA allows users to access Habit Nooks supporting them in introducing changes while guided by experts and supported by the community.

Physical tracker allowing to track symptoms together with the Data Dashboard allow users to explore data patterns and make informed decisions. The system gives also an opportunity to get in touch with experts via calls or structured long-term programs.

Beside the design proposal project was closed with a series of reflection touching on the bias in a medical field and how it might affect healthcare design, as well as designer’s experience of working on a project with a personal relevance.
A better way to live with a chronic condition

**TIMELINE**

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### RESEARCH
- Secondary research
- Creation of well-being framework
- Research sprint I (surveys with women living with endometriosis and their loved ones, interviews with experts)
- Research sprint II (interviews with women living with endometriosis)
- Research sprint III (online reflection exercise for women living with endometriosis)
- Analysis of the research phase
- Defining constraints/design opportunities
- Developing design principles
- Reflection

### EXPLORATIONS
- Co-creation sessions
- Ideation sessions
- Directions & first concepts
- Online feedback
- Concept definition I
- Probing I & II
- Interviews + co-creation sessions
- Concept definition II
- Online feedback
- Synthesis
- Reflection

### DEFINITION & DELIVERING
- Final concept definition
- Final prototype
- Storytelling
- Reflection

### EXAMINATION & UID TALKS
- Presentation of the final concept (examination)
- Reflection
- Implementation of feedback from the examination
- Presentation of the concept teaser & exhibition piece (UID Talks)
- Reflection
INTRODUCTION

This MFA Thesis Project investigates how interaction and service design can support endometriosis patients in the management of their condition with a focus on the quality of life.

The proposed solution is a practical answer to the challenges of transition and life with a chronic condition that could be implemented with existing technology and be easily accessible.

The presented design was created not for patients but together with them and their loved ones who were generous enough to share with me their stories and ideas for how to make management and tracking easier, as well as with experts in the field.

Following topics will be discussed in this chapter:

• "Background" introduces main notions regarding endometriosis, challenges linked to living with a chronic condition and shifting perspective in the medical field in the regard to the role of a patient in the decision-making process.

• "Personal perspective" gives an overview of my relationship to the topic of this thesis as well as deeper understanding of the motivation behind it.

• "Well-being perspective" discusses concerns that had to be addressed throughout this project to ensure that participants’ (of the research, co-creation, probing) and designer’s well-being is not going to be in any way compromised by the engagement in this project.

• "Project scope" explains what are the areas that were explored in this project.

• "Summary" present main points and decisions regarding thesis project explained in this chapter.
BACKGROUND

What is endometriosis?

Endometriosis is a condition in which endometrium-like type of tissue grows outside of the uterus and it is experienced by 10% of women in reproductive age (Aggerholm & Kerkisick, 2011) and expressed itself in different forms, but there is no agreement about the underlying cause (Mangani & Booth, 1993; McKillop, English & Elhadad, 2017) or one well-established therapy. Because of that and the fact it is one of the invisible conditions endometriosis is sometimes labeled “the missed disease” (Mastro 2000 as cited in Denny 2004;). Symptoms may vary and can include, but are not limited to, dysmenorrhea (painful menstruation), pain at ovulation, dyspareunia (painful sexual intercourse), abnormal bleeding, chronic pelvic pain, fatigue, and infertility. Moreover the condition is underdiagnosed (Kennedy et al., 2005 as cited in Nnoaham et al., 2011; Simoens et al., 2012; Culley et al, 2013; Giuliani et al., 2016) with the delay in diagnosis ranging from 5 (Sepulcri and do Amaral, 2009 as cited in Culley, 2013) to 8.9 years (Fourquet et al., 2010 as cited in Culley, 2013) depending on a study. There is no cure for endometriosis, but treatment alleviating the symptoms might include analgesics, hormonal therapy, minimally invasive surgery, radical surgery and fertility treatment (European Society of Human Reproduction and Embryology, 2013 as cited in Culley, 2013)

What are the consequences of a chronic condition?

As a chronic condition, endometriosis has a negative impact on the quality of life (Jones, Jenkinson & Kennedy, 2004; Nnoaham et al., 2011; Simoens et al., 2012; Culley et al, 2013; Giuliani et al., 2016) and some patients try to control symptoms not only by medical interventions but also lifestyle choices (Cox et al., 2003c; Huntington and Gilmour, 2005; Gilmour et al., 2008; Markovic et al., 2008 as cited in Culley et al, 2013)

One of the biggest challenges patients struggle with is the feeling of loneliness and being misunderstood - many of them are described as looking healthy and therefore dismissed by their colleagues (Jones et al., 2004 and Gilmour et al., 2008, as cited in Giuliani et al., 2016), family and friends (Jones, Jenkinson & Kennedy, 2004) and even healthcare providers (Barnard 2001 as cited in Denny 2004;). Endometriosis often makes women feel isolated and it is hard to openly communicate all the needs, limitations or expectations to the loved ones, friends or colleagues (McCoy Cohn, 2016). Additionally, some of the endometriosis patients experience patronizing treatment from their doctors (Barnard 2001 as cited in Denny 2004; Denny, 2004; McCoy Cohn, 2016). Pain that sometimes has no physical evidence (or evidence is not easy to be found) is not taken seriously. After diagnosis quite often only one type of medical intervention is presented as a treatment, while other options are not presented at all (Vercellini, 2015; McCoy Cohn, 2016)

Shifting to including patients in decision-making.

At the same time we see a shift in the medicine from treating patients as a body that needs to be fixed toward encouraging patients to be part of the decision-making process and active in their recovery (Forbat, 2009; McCarley, 2009), along with more holistic perspective on the care (Ellis, 1999). Also, the well-being of patients is more and more prominent in the discussion about chronic conditions (Stewart et al., 1989), that might not necessarily need an aggressive treatment at all times, but rather management and monitoring (Vercellini, 2015). Contrasting new trends with the current situation could yield interesting insight into new directions.

PERSONAL PERSPECTIVE

Svedmark (2016) writes in her dissertation that as a situated knower she had “no intention of standing outside” while working on her research and this is also a standpoint I’ve adopted. But in my case, it meant not only discrediting the tradition of claims that an objective perspective is possible in research but also choosing this topic at all. The issues I’m working on are not new to me - I’ve been living with the chronic condition for almost four years now. Research showing high misdiagnosis rate or long time until the correct diagnosis are for me much more than in personal numbers.

I had multiple concerns considering working on a topic that has a personal relevance. Is it professional? Will I cope with the burden of focusing on it for so long? Will I make good decisions? Those questions can be answered only after the project is delivered, but I did ensure I’m well prepared for this process. Obviously, my experience will inform decisions (probably most noticeably in the famous gut feeling that designers refer to), but I do account for that and acknowledge I’m an expert only on my own experience. I have plenty to learn from other patients, their loved ones, and specialists.

In my training as a Social Psychologist, I was prepared to maintain as much objectivity as possible. That is also why getting into this new role was very confronting, but also a valuable learning experience. I decided to think about myself as Insider-Designer: somebody who lived the experience, but has a professional interest in exploring this topic from a design perspective. This decision also meant that I wanted to be transparent with participants of my research and ideation about my personal relationship with the topic. What I haven’t expected is that participants of my research will give me an enormous amount of support and encouragement and become part of that support system themselves. And lastly, I wanted to maintain a good work-life balance to be able to successfully complete project but also set an example that working on thesis does not mean one has to compromise her well-being. 
**WELL-BEING PERSPECTIVE**

Why do we need to care about well-being? This investigation started with a simple question - how can we ensure the well-being of all the parties engaged in the design process? Of course, this question relates to ethics in design, but what is different here is the desire to go beyond “doing no harm” and at the same time include designer herself among those whose well-being is considered. I wanted to engage with real people and their stories but do so in a way that will not have a negative impact.

**Designers in the wild**

In the preliminary exploration and first week of my thesis project, I’ve talked with several designers and researchers engaged in healthcare-related projects, working in academia and in the commercial sector, about ethics in their everyday work (in total four interviews in person and via Skype). There was an agreement that while it is not valid to say that there are no frameworks for the ethical conduct in design there is no comprehensive set of rules that would relate to all aspect of the design process from the early research phase to the usage of the end product. Medical products undergo extensive testing and rules applying to this process are very strict, but it seems fair to say that for example human factor testing is mainly focused on the physical safety of the research participants and future users, as well as mental load of the future users along with the safety of patients, unintended consequences, and misuse. On the other hand, projects carried out in the hospital setting have a deep focus on the anonymity of the patients.

All of my interlocutors mentioned informed consent, the voluntary character of participation and opportunity to opt-out at any given moment of the study as the standard ethically conducted design research should follow. But they see it rather as a part of their design practice than codified rules of conduct. Knowing all that it seemed like there is a missing piece that should be added to my project - guidelines I can refer to making sure that overall comfort of people I’ll be interacting with is not compromised. I did not aim to create a universal set of rules applicable to all design projects, but rather tailor-made guidelines that would help me to navigate within the space of next 17 weeks.

Put your oxygen mask first before helping others

Too often designers forget that design process can be draining not only because of the highs and lows of different phases or long working hours but also due to the topics we are touching upon. Therapists have supervisors that follow them on their professional journey and check if working with patients is not putting too much pressure on them. In the design context supervision is something different and probably is closer to having a mentor or a master. This does not mean that we can wave off the need to take care of our mental health - we might need to look for supervision outside of our field and not to be afraid to do so. To deepen my understanding of this topic I've read the dissertation by Svedmark (2017) where the author describes her own struggles with maintaining a healthy balance when working closely with challenging topics. It led me to believe that it would be good to create a support network for the time of the project - I relied on my tutor from UID, one of my classmates (critical friend) and friend from outside the university who agreed to check-in with me throughout the project.

**Basic principles**

In the course of my research on ethics and practical implementation of rules, I’ve found relevant for this project I’ve realized that ethics are not set in stone, but at the same time they are not coming to interaction. Participants have the right to expect that person conducting research is going to be open, friendly and patient with them. If the designer is not well-rested and very anxious this situation will be out of balance. That is why it is important to take care of ourselves first in order to go into the field with enough resources to be able to complete work.

Even though for the clarity two sets of guidelines above are separated it does not mean that they are not coming into interaction. Participants have the right to expect that person conducting research is going to be open, friendly and patient with them. If the designer is not well-rested and very anxious this situation will be out of balance. That is why it is important to take care of ourselves first in order to go into the field with enough resources to be able to complete work.

It is also important to mention here that those guidelines reflect my approach to transparency and need to include my story into the research. Testing methods on ourselves might not be relevant for other projects and sharing our story might have counterproductive effect in different context.

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**Guidelines relating to the designer:**

1. Put your well-being first
2. Schedule rest time same way as other tasks
3. Plan and create a support network
4. Schedule checkpoints
5. Get participant’s informed consent for interview or workshop (it can be verbal)
6. Give participants an easy way to opt-out at any moment
7. Follow-through with any promises you make
8. Test methods first on yourself (when appropriate)
9. Be mindful of participants mental health and well-being

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**Guidelines relating to people contributing to the design process:**

- Provide full information on the project to the participants
- Share your story (when appropriate)
- Follow-through with any promises you make
- Get participant’s informed consent for interview or workshop (it can be verbal)
PROJECT SCOPE

MANAGEMENT OF CHRONIC DISEASE

How can we improve quality of life of endometriosis patients? The first goal of the research would be to investigate the day-to-day life of patients and gather best practices to build framework supporting them in lifestyle alterations that can improve their quality of life.

BEHAVIOR CHANGE

How can we provide tools for a lifestyle change? In chronic condition, there is a missing link between day-to-day actions and feedback of the body that can be delayed making it impossible for the patient to draw the connection. Finding the best way to support sufferers not only in finding the right information but also strengthening understanding of the impact that lifestyle has on their condition is also part of my research plan.

COMMUNICATION

How can we provide tools helping with better communication? Another big challenge for the patients is the feeling of loneliness and being misunderstood. Researching best ways to help women effectively communicate their condition to different actors. Helping with communication as well as connecting women with each other could possibly help to build a support system.

“The fact that it is not curable doesn’t mean that it is not cope-able”

Participant of co-creation
SUMMARY

This chapter discussed following issues:

• Challenges women living with endometriosis face every day starting with the physical symptoms to social interactions. It also highlighted shift happening in the medical field where the patient is acquiring a more active role in the recovery.

• A personal perspective on this project was presented to underline that my role is best described as Insider-Designer - somebody who has the same experience as a potential user group but also plans to focus on this topic as a professional. Concerns regarding this dual role were discussed.

• Well-being perspective regarding participants and designer was created to ensure that while working on this project nobody will be pushed out of their comfort zone while discussing sensitive topics and their own experience.

• This chapter also explained that project scope will be created around three areas: management of a chronic condition, behavior change and communication.

• Information gathered here were the building blocks for creating the design brief.
This project is motivated by the belief that current situation of endometriosis patients starting with the substantial delay in diagnosis, not being given a full spectrum of treatment options and feeling of isolation is not acceptable. Fixing each healthcare system in each country is not possible, but bringing awareness, contributing to the understanding of problems we are facing and proposing design supporting patients in their journey are within a reach.

To approach this goal design process was planned out and exercises in four steps - preparations and background research (outlining well-being perspective, desk research, research online via social media), design research (multiple surveys, interviews, reflections online, co-creation sessions, probing, interviews following probing with co-creation sessions, ideation sessions, analysis, explorations (creation of directions, analysis, initial concepts creation, feedback, synthesis, design proposal, feedback and evaluation sessions, design improvements) and final design proposal. Activities were aiming to repeatedly open up the scope of the project and then through the analysis of each phase narrow it down again following diamond shape. One important aspect of the process was to engage women living with endometriosis as well as their loved ones throughout the whole process and design together instead of designing for them. Of course, experts were consulted as well to make sure project is following standards of medical care.

Following topics will be discussed in this chapter:
• “Process overview” introduces methodological stand that this project is taking and how did it affect process on a more practical level.
• “Summary” present main points and decisions regarding thesis project explained in this chapter.
A better way to live with a chronic condition

User-Centered Design
It was essential to remember that design decisions should be based on deep understanding of patient’s needs and their view on the condition and as such, it was important to engage them all the way along different phases of the process. In my case, it was challenging since I had limited opportunities for in-person interactions with patients, but to aid this problem I’ve explored opportunities for online research. At every step of the process, patients were actively participating in providing feedback and co-creating solutions. During first co-creation sessions and probing phase followed by interviews and next co-creation, I was collaborating with patients based in Umeå.

This approach does sound very familiar to what we know about User-Centered Design and indeed I was very much guided by this methodology. The difference was that UCD treats designer as an objective investigator of the needs of the users and constraints of the environment. And that was simply not the case in this project as I’ve stated in the “Personal perspective” explaining that I was also one of the potential users. Clearly, I was concerned with my experience informing my design decisions to a degree that would steer the project off the rail. To ensure that I don’t feel silenced and then overcompensate for it with very much persona design decisions I did take part in all research activities (surveys, interview) as well as probing. In that way, my story was acknowledged, but I also made it clear that this is only one of the many voices I need to take into consideration while proposing the final design.

Method
The project followed the process of preparations and background research, design research, explorations and finally presenting final design proposal. The shape and iterative improvements in the proposed concepts were informed by feedback and co-creation with the end users and supported by expert’s opinion. All phases except the presentation of the final design followed diamond shape design process allowing to balance the amount of exploration, analysis and concepts definition. Additionally, design research phase was divided into preliminary phase and three sprints to collect data more effectively and employ new research tools with an understanding of the insights from the previous sprint.

The first sprint was dedicated to the creation of a general landscape of the research area and consisted of three interviews with experts (social worker, researcher, a physiotherapist specializing in pelvic floor therapy) and two surveys (for patients and for partners/loved ones for patients). The second sprint was looking closer at the patient journey and 6 interviews were conducted. The last sprint was exploring pain points and patient’s outlook on their journey in online reflection exercises. In total 83 answers to the survey for patients were collected, 20 answers to the survey for the loved ones and 9 answers to the online reflection exercise.

In the exploration phase, 10 patients took part in the online feedback, 3 patients, and 2 partners were engaged in the first co-creation session and one of the prolings. 3 patients and one partner took part in the interviews and second co-creation following probing. Finally, 3 patients took part in the final feedback round giving an opportunity to finalize the design with their perspective in mind. In total, over 100 patients and loved ones contributed to the project and some of them were taking part in multiple activities.

Additionally, throughout the project social media and in particular Facebook pages of organizations supporting patients as well as support groups were monitored and analyzed to understand the current landscape of the patient’s community and support mechanisms that are naturally occurring in the online sphere. I was an active member of those groups and information about my project were made available there. As a result, members were aware of my presence and some of them decided to support the project by taking part in some of the research activities. It is important to underline that I did not publish any materials from support groups but only talk about the trends that were observed.

SUMMARY
This chapter discussed following issues:

- The User-Centered Design approach was altered and used in this project to include the notion of Insider-Designer (the person running the project is also in a potential user group) - designer contributed to the pool of data in the research phase. That step helped to ensure that design decisions will consider all the collected data as equally important.
- The project followed the diamond-shape process and included research, explorations, and analysis.
- Over 100 women living with endometriosis and their loved ones contributed to this project.
- The importance of online interactions in absence of participants who can be reached to directly was central to this project where many of the steps (surveys, interviews, online reflection, feedback) were carried out online.
This chapter accumulates descriptions and reflections of all the actions taken in this process - starting with understanding the scope of the project, through meetings with potential users and experts in the field, co-creation, ideation, probing and feedbacks. Described activities help to understand how the concept was build and what is behind it, including real stories of people who want to maintain their well-being and simply enjoy life.

Following topics will be discussed in this chapter:

- "Timeline" introduces the list of activities carried out during the project.
- "Identifying design challenges and opportunities" is an invitation to understand the landscape around the condition like the role of the patient, goal of the treatment in case of incurable condition, treatment of women’s pain, language used to discuss women’s conditions and areas that are important to endometriosis patients.
- "Research" presents methods used in the first weeks of the project as well as outcomes of interviews with experts, survey for patients, survey for loved ones, social media immersion
- "Patient journey" combines learnings from steps discussed in "Research" part with information gathered in interviews with women living with endometriosis. Experience as well as pain-points are mapped out throughout the patient journey in a written as well as visual form.
- "Analysis of the research" gives an overview what learnings were the ones that might guide the project to the next phases.
- "Design principles" introduce principles based on learnings from previous steps as a guide for concept creation.
- "Co-creation and ideation sessions" shows methods used in sessions with women living with endometriosis, their loved ones, and designers, as well as outcomes of those exercises.
- "Initial directions and concepts" present three directions emerged from the previous phases and concept illustrating each of the direction (three concepts in total)
- "Feedback" discusses potential users reactions to each of the concepts.
- "Probing of the concept My Journey" gives an overview of the probing of the physical input device.
- "Probing of the concept Empathy Amplifier" gives an overview of the probing of the physical communication device for women living with endometriosis and their partners.
- "Reflections on probing, interviews & co-creation" summarises learnings from both probing sessions as well as interviews and co-creation sessions following them.
- "Design proposal, feedback and synthesis" discusses updated design proposal, feedback from potential users regarding new design as well as decisions made based on potential users’ input.
- "Summary" present main points and decisions regarding thesis project explained in this chapter.

ACTIVITIES
IDENTIFYING CHALLENGES AND DESIGN OPPORTUNITIES

Finding focus
Since the problem area is broad and interconnected with other issues regarding healthcare system and limited treatment options for endometriosis patients, I’ve decided to list design opportunities and challenges that could be touched upon in a 17-weeks project. Below I’ve listed five areas that arise from the current discourse around chronic conditions in general and endometriosis in particular. Those areas will be used as a guide in the further investigation but not necessarily all of them will be included in concept development.

Rethinking patient’s role
The paradigm shift from treating the patient as a set of symptoms into including him or her into the decision-making process, encouraging proactive role and empowered by providing necessary information creates great opportunities for new channels of communication, collecting of data and many more. Patients struggling with chronic conditions will eventually become experts of their own illness and learn how to manage symptoms thanks to being an equal partner in making medical decisions and a feedback loop of data from quantified self devices. Additionally in a near future financial strain at the healthcare system will create a need for more home-care, home-monitoring and more responsibility on the patient’s side. Endometriosis patients are already very proactive (Whelan, 2007) and development of technology will accelerate this trend. In McKillop, Seckin and Elhadad (2016) paper on symptoms tracking using mobile app “Women expressed a range of motivations to track: to better understand their own experience of the disease (i.e., discover and reflect on potential patterns of symptoms throughout their cycle); to explore strategies for symptom management (“what works and what doesn’t”); to help manage their work and personal schedule based on their past tracked data and forecasted flares; and to communicate better with their doctors.” At the same time, Culley et al (2013) point to some interesting consequences: “Becoming an ‘expert patient’ by developing knowledge and engaging in self-management is demanding and has been found to both reduce and compound the stress of living with endometriosis.” Those changes open up new design opportunities like platforms for creating and communicating about treatment plans but also raise questions of the new structures regarding responsibility and well-being of the patients.

Treatment of the condition vs. treatment of symptoms vs. quality of life
Including patients in a dialogue about treatment options will result in a broader discussion about the treatment itself - what is a goal of the treatment? What is the financial strain of the intervention? What is the emotional cost of the invasive procedures? This shift along with the proactive role of patients might result in shaping different treatment plans than the one we’ve seen before. As Vercellini (2015) informs us: “Endometriosis is not a cancer; therefore a paradigm shift from treatment of lesions to treatment of symptoms is warranted. Management should be shaped on the main clinical problem, taking into consideration a woman’s preferences and priorities.” Those changes open up new design opportunities like platforms for creating and communicating about treatment plans but also raise questions of the new structures regarding responsibility and well-being of the patients.
A better way to live with a chronic condition

The body of evidence showing that there are differences in the nature and timing of the treatment administered to patients with the same symptoms and medical history, but different genders are unquestionable. As we can read in "The girl who cried pain: a bias against women in the treatment of pain" women are "more likely to be treated less aggressively in their initial encounters with the health-care system until they prove that they are as sick as male patients" (Hoffmann & Tarzian, 2001). The term "Yentl Syndrome" was coined in the medical community to refer to this type of systemic phenomenon when dealing with heart conditions (Merz & Noel, 2011; Fassler, 2015).

Beside the suggested type of treatment, there are also systematic differences in the wait time between genders. According to A National Institute of Health in USA, "women tend to wait 16 minutes longer than men when they are receiving pain medicine in emergency rooms" (Marthe, 2017). The same study points out that women are "13 to 25 percent less likely to receive opioids when they are dealing with pain." (Marthe, 2017)

As Dusenbery (2015) writes in an article "Is Medicine's Gender Bias Killing Young Women?": "This pervasive bias may simply be easier to see in the especially high-stakes context of a heart attack, in which the true cause usually becomes crystal clear—too often tragically—in a matter of hours or days. When it comes to less acute problems, the effect of such medical gaslighting is harder to quantify, as many women either accept misdiagnoses or persist until they find a health care provider who believes their symptoms aren't just in their head." This voice adds an important perspective to the facts about endometriosis patients: high misdiagnosis rate and extremely long wait time for the correct diagnosis.

Healthcare is a complex system and it is hard to argue that only one factor is responsible for each of the examples presented above, but the message is clear: women are treated differently than men. Since one of the symptoms that might accompany endometriosis is the pain it is likely that patients will experience this systemic bias. Stories posted on private Facebook groups for patients suggest that many of them experience patronizing treatment not only during regular exams but also when visiting emergency rooms. This phenomenon leads to hesitation to visit an emergency room and as a consequence symptom that might be suggesting like appendicitis needing medical intervention might be overlooked.

What does language of diagnosis really tell us?

In the article "Premenstrual Dysphoric Disorder & the Language of Diagnosis" the author argues that: "[... ] some of the terminologies we are accustomed to feel a little like a modern-day counterpart to the Victorian-era "hysteria" - a grossly misrepresented catch-all term for issues that are under-researched and misunderstood." (Tablot, 2018). The text also points out to the issue that is all too familiar for women struggling with endometriosis: "Terms like "mood swings", "tenderness", "irritability", even "cramps" don't do justice to the physical and emotional experience of these things at their most intense. Terms like this that lack a certain weight, lend themselves to normalization of the symptoms which can deter people from seeking help for fear of feeling 'overemotional'." (Tablot, 2018)

Even though it is not a goal of this thesis to investigate psycholinguistics, it is important to keep in mind that descriptions and tone of voice used in the end product (whatever form that product might take) will influence end users. When working on a copy (texts used in an interface, printed materials or in any other touchpoint of the service) I will follow principles of being respectful and inclusive, as well as employ plain English. According to Wikipedia Plain English is language that is easy to understand, emphasizes clarity and brevity, and avoids overly complex vocabulary. Additionally, it is free of cliches and needless technical jargon and should be appropriate to the audience's developmental or educational level and their familiarity with the topic."

I acknowledge that literature on this issue is very rich and I don't even scratch the surface here, but my intention is to rather acknowledge the problem and employ practical measures to guide me in the process than further exploration.

Areas important for endometriosis patients


There is a substantial overlap between topics suggested by different studies. Themes that overlapped and were interesting from the point of view of this project were taken into the first phase of research to be investigated with participants further: Treatment, Management of the condition, Quality of life, Social functioning, Career (Work and Education). This limitation was necessary for narrowing down the scope of the project but even topics not chosen as a focus were considered to make sure that participants of the research can freely and fully express their experience.
RESEARCH

In this part complexity of the topics explored in the research, will be brought to the light to end with an analysis allowing for the narrowing down of the scope and creating the read thread that will be followed in the later phases.

Experts interviews

Expert interviews helped to frame problems described in the literature and where to look for other sources of information (online support groups etc.). It was also an opportunity to understand how social worker supports endometriosis patients in Sweden. However, it is important to underline that this service is not accessible in all locations or to patients with all stages of the condition. The social worker helps with a very broad spectrum of issues patients may encounter like paperwork (for a healthcare provider, workplace), understanding consequences of the treatment options on the future life, pain management, management of the condition and appointments, motivation, sex life, planning, reflecting and discussing infertility issues. In the later phases of my research with patients from around the world it was discovered that those are the services that patients seek, but unfortunately they might not be accessible for them - because of the location, being refused this service due to mild symptoms or financial constraints (in countries where patients have to pay out of pocket for health-related interventions). It was a valuable lesson to see that social worker creates safe space and support network, but the decision what changes or intervention to engage with comes from the patient.

Survey - learning from the patients

In total 83 answers to the survey for patients were collected using online survey consisting of 17 single-choice, multiple-choice and open-ended questions focused around the experience of living with endometriosis, tracking and managing condition, introducing lifestyle changes and seeking support (full list of questions can be found in the appendices at the end of this thesis; it was powered by Google Forms). Participants were between "19 or younger" to their 40s, with experience ranging from being before diagnosis to suffering for 5 or more years. Women who answered to this survey were coming from USA, UK, Netherlands, Sweden, Canada, Austria, India, Australia, Switzerland, Germany.

The most interesting results from the survey described changes that patients introduced to benefit their well-being. 70% or more said that they adjusted Medications, physical activity, diet and social life. At the same time, 60% or more said that they adjusted Intimate relationship and/or sleep. Out of 83 patients, only one hasn’t made any adjustments. This clearly shows that many of the women diagnosed with endometriosis introduce multiple changes in order to feel better. At the same time, 50% of participants said that they are not tracking their condition and more than 60% of patients see managing condition as one of the biggest challenges. Survey also showed that the ones who do track their condition usually use multiple tracking/planning methods like apps, Google Docs, paper-based calendars or notebooks and physical whiteboards. The biggest complaint is that information is scattered, sometimes cannot be easily accessed by the patient.
A better way to live with a chronic condition

As we know more than half of the patients think finding the right healthcare provider (15) and lack of available to endometriosis patients.

In total 20 answers to the survey for the loved ones were collected using online survey consisting of 11 single-choice, multiple-choice and open-ended questions focused around the experience of supporting partner/loved one living with endometriosis, changes and seeking support (full list of questions can be found in the appendices at the end of this thesis). Participants ranged in age between 25-30 to 50 or above, coming from USA, UK, Netherlands, Sweden, Canada, Turkey. The relationship with the person living with endometriosis in 11 cases was described as a partner, in 3 cases as a friend, in 5 cases as a parent and in one case another family member.

Most of the participants claimed that they provide psychological support (19 answers), motivation (16) and helping with taking the mind off of the health-related issues (15). The biggest challenges they perceive is seeing your loved one suffer (17), they perceive is seeing your loved one suffer (17), finding the right healthcare provider (15) and lack of understanding from others (13).

As we know more than half of the patients think that management of the condition is one of the most challenging aspects of their life with a chronic condition but from the survey for partners, we learned that only 6 out of 20 loved ones support them in this area.

Social Media Immersion

Results of general desk research are presented in the background section, however, exploration was not limited to academic sources and included immersion into the world of online resources and social media available to endometriosis patients. One of the valuable sources of information were Instagram profiles and Facebook groups where patients can share knowledge, experience and look for support. It is important to acknowledge that social media do not present a representative image of the patients’ populations and analysis of those sources was not a primary source of information for this project, but particular topics like ways women track their symptoms or ambitions for the future development of care for endometriosis patients were investigated using those channels.

Big learnings that came to surface after analysis and immersion in the online community: The sense of trust - Recommendations are a big part of the online community of endometriosis patients. Some of the group's admins created and manage a list of doctors that are approved by this community as experts in endometriosis. The discussed community is also very invested in sharing the individual experience with healthcare professionals, applications or other tools they use at home (heating pads etc.), discussing symptoms as well as ways their family or partners were dealing with it. Some partners were invited to join the group in order to learn more about endometriosis and understand better what their loved ones are going through. Also, some healthcare professionals are part of the groups giving more legitimacy, although they are not allowed to share professional advice in that context.

Psychological support - This community is very closely bound together and creates a support system that could substantially benefit the well-being of patients. One of the women I’ve talked with started her own online support group believing that this is the only safe place where people are not going to get tired of listening to each other’s troubles, but also can share information. On the other hand, throughout my research, I’ve also learned that some of the patients unfollow support groups on the days when they feel well because of the feeling of guilt.

Motivation - Being part of the group helps to motivate to introduce changes and follow through with them. On an example of a Facebook group where people discuss particular detox protocol, it was observed that members tend to discuss it in advance and start detox on the same day as a group of a certain size. Then WhatsApp group for members of this new group is created where they can follow up with issues like how do they feel, what they’ve prepared to eat, exchange recipes, cheer each other up and motivate to continue.

Education - It is clear that patients want to advocate for themselves, but unfortunately mostly because they had a bad experience with being dismissed or with unsuccessful treatments. There is a strong feeling of distrust toward healthcare providers (especially in a setting where healthcare procedures are not financed by the government). Clearly, a lot of patients active on the forums became expert-patients - following the newest research and having strong opinions about different types of treatment.

Patient journey

The second sprint was looking at the patient journey, support system and topics relevant to interviewee experience using semi-structured interview via Skype/FaceTime, while the last sprint was exploring pain points and patient’s outlook on their journey in online reflection exercises. In total, 6 interviews were conducted with women between mid-20s to their mid-40s with the experience ranging from being recently diagnosed to living with endometriosis for over 20 years. At the same time, 9 answers to the online reflection exercise were collected. Those conversations and materials from the online reflection exercise allowed me to create patient journey map taking into account different types of experience.

Pre-diagnosis

Other events:

Pain Points: symptoms and complaints - doctors visits resulting in no diagnosis or wrong diagnosis

Other events: visit resulting in referral or suspicion of endometriosis and referral for further tests

Big topics & quotes:

(1) Being dismissed:
"I was labeled a hypochondriac, “They all told me it was all in my head”

(2) Fertility:
"My first ever period was incredibly painful. I felt nauseous and kept throwing up my mother told me she had started her life as a woman in the very same way"

(3) Looking for validation:
“It was a trying time because it is not like I wanted another cyst, but I wanted validation”

Diagnosis

Big topics & quotes:

(1) Being dismissed:
"I was given a yellow post-it note that I had endometriosis and the rest I had to google,” “They said you probably have it and they sent me off,” “I really didn’t have any information on what it was. (on a follow-up) doctor explained it to me in 2-3 sentences”

(2) Talking about scenarios, not only symptoms: “Managing expectations would be good. To hear it can go like this, but it can be a lot like this”

(3) Motivation: “Changes, in the beginning, were easy because they were necessary,” “The difficult part was explaining it to my parents (…) they have this approach that you are too young to be sick”,

(4) Changes “Management and learning was difficult in the beginning. I was very dedicated. (…) I’m not sure how ppl who don’t have time do it”

(5) Fertility: “No one ever mentioned fertility to me and that it might be a problem and maybe I should try to have children early”

Post-diagnosis interventions

Big topics & quotes:

(1) Being dismissed:
"I was labeled a hypochondriac, “They all told me it was all in my head”

(2) Fertility:
"My first ever period was incredibly painful. I felt nauseous and kept throwing up my mother told me she had started her life as a woman in the very same way"

(3) Looking for validation:
“It was a trying time because it is not like I wanted another cyst, but I wanted validation”

Diagnosis

Pain Points:
understanding disease, finding the right specialist, decisions on the treatment

Other events:
tests, examinations, visits, confirmed diagnosis.

Big topics & quotes:

(1) Being dismissed:
"I was given a yellow post-it note that I had endometriosis and the rest I had to google,” “They said you probably have it and they sent me off,” “I really didn’t have any information on what it was. (on a follow-up) doctor explained it to me in 2-3 sentences”

(2) Talking about scenarios, not only symptoms: “Managing expectations would be good. To hear it can go like this, but it can be a lot like this”

(3) Motivation: “Changes, in the beginning, were easy because they were necessary,” “The difficult part was explaining it to my parents (…) they have this approach that you are too young to be sick”,

(4) Changes “Management and learning was difficult in the beginning. I was very dedicated. (…) I’m not sure how ppl who don’t have time do it”

(5) Fertility: “No one ever mentioned fertility to me and that it might be a problem and maybe I should try to have children early”

Post-diagnosis interventions

Pain Points:
decisions regarding treatment

Other events:
treatment at the hospital (laparoscopy,
A better way to live with a chronic condition

Big topics & quotes:
(1) Limited treatment options presented: “Hard time finding a doctor who would not suggest surgery as a first choice”, “I asked about the side effect and a lot of stuff and she didn’t give me a lot of the information she [the doctor] should have”

(2) Influence on plans & milestones: “I had to postpone my marriage as well as move to another state we were planning. Also, step down from the promotion”

Transition into the life with a chronic condition

Pain Points:
understanding how life with a chronic condition will look like, saying goodbye to certain plans or dreams or putting them on hold, learning more about changes that might help.

Big topics & quotes:
(1) Uncertainty: “With those conditions where you have flare-ups- how do you navigate in life?”

Life with a chronic condition & Future planning

Pain Points:
planning future, changing goals, infertility issues

Other events:
bad days / flare-ups, changes / non-medical interventions, non-scheduled hospital intervention following a visit to OB-GYN or ER, non-scheduled change of treatment following tests or visit OB-GYN, scheduled hospital intervention, follow-ups, visits, tests

Big topics & quotes:
(1) Am I lazy? “The hardest thing is that I feel like I’m slacking around” (on bad days)

(2) Fear of pain: “More than the pain itself, I have a problem with an anxiety of pain. Because I don’t know when the pain will come,” “I am always afraid that the pain will return, that’s my worst nightmare”

(3) Medication Management: “I used to get confused. I also have a blood pressure so I mixed up all my tablets”

(4) Access: “I have to drive 2 h to meet my gynecologist. So it takes up a lot of space. Don’t have much other. I have to mention I live in the middle of the forest.”

(5) Motivation: “Changes were easier in the beginning when I was feeling really bad, and with time when you are feeling better they are just harder”

(6) Learnings: “Endo taught me that sometimes it is better to make things easier for yourself to have the energy for other, more important stuff”

“What can I know if I can’t know what I am feeling in my own body? How can I remain connected to a world that denies I am in pain, or dizzy, or nauseated, when I myself cannot deny that I am?”

Susan Wendell

Quote above by Wendell (1996) as quoted in “When Doctors Dismiss Women’s Pain” (Dusenbery, 2018);
Photo credit: unsplash.com/@all_who_wander
A better way to live with a chronic condition

**PATIENT JOURNEY**

**PRE DIAGNOSIS**

- Patient experiencing symptoms
- Diagnosed accidentally or as a result of medical investigation

**POST-DIAGNOSIS INTERVENTIONS**

- Symptom and complaints
- Being dismissed by friends & family
- Being dismissed by healthcare professionals

**DIAGNOSIS LOOP**

- Hospital / Clinic
  - Tests & Exams
  - Medical imaging
  - Laparoscopy

**FUTURE**

- Hospital / Clinic
  - Interventions at the hospital

**TRANSITION INTO LIVING WITH A CHRONIC CONDITION**

- Patient experiencing symptoms
  - Diagnosed accidentally or as a result of medical investigation

**LIVING WITH A CHRONIC CONDITION**

- Pain points
- Flare-ups & bad days
- Follow-ups, visits, tests

**Symptoms and complaints**

**Being dismissed by friends & family**

**Being dismissed by healthcare professionals**

**Hospital / Clinic**

- Interventions at the hospital

**Understanding disease**

- Finding the right specialist
- Decisions on the treatment

**Follow-ups, visits, tests**

**Hospital / Clinic**

- Non-scheduled hospital intervention following visit to OB-GYN or ER

**Home**

- Non-scheduled change of treatment following tests or visit to OB-GYN

**Hospital / Clinic**

- Scheduled hospital intervention

**Pains credit:** thenounproject.com/dinosoftlabs/

**Icons credit:** thenounproject.com/vectorsmarket/
ANALYSIS OF THE RESEARCH

Analysis
One of the crucial elements of this project is understanding the importance of time - timeline of diagnosis and treatment, as well as the timeline of the patient's lifetime with their needs, plans, and fears regarding the future. According to Chamberlain & Malvern 1996 (as cited in Denny, 2004) endometriosis is ‘most commonly diagnosed in nulliparous women aged 25–35 years’, which was confirmed by the social worker supporting patients I’ve talked with, and part of this group are patients diagnosed while seeking help with getting pregnant. Understanding how different this scenario is from other situations can help to narrow down the audience of my final design. That is why it was important to me to put emphasis on carefully choosing the final audience of the project as well as design space I want to work in.

Mapping design opportunities
Based on the research described above I’ve mapped seven design opportunity areas on top of the patient journey: looking for information and help (pre-diagnosis), choice of treatment and need for support (first interventions after the diagnosis), transition into life with a chronic condition with the need for information and understanding (transition), daily management (life with a chronic condition), introducing non-medical changes which have a cyclical nature, usually happen in a response to something or as a part of a plan supporting some future goals (life with a chronic condition), planning future and reflecting (future).

Finding focus
After the analysis, I’ve decided to focus on the part of the patient journey regarding transition into life with a chronic condition (including elements of the management of the condition and introducing changes) because I believe that transition time can set patient for a better life afterward. It is also a trying time when not only practicalities need to be taken care of, new knowledge needs to be absorbed, adjustments introduced, but also person going through this needs to come to terms with the diagnosis and communicate it to their loved ones. This is a very multi-layered process and my goal is to help with it in a non-invasive way. During the interview, the social worker told me that she works with changes patients want to work with and don’t stay in their lives forever because at some point they don’t need her anymore. I would like my design to reflect that - to give a safe space and framework to work on what is important for the patient an at some point slowly fade out when a person living with endometriosis reach their balance.

Additionally, I’ve decided to choose one of my research participants as a representative of a group of women I wanted to focus on. As a result I’ll be focusing on Anna because she represents young women who at the time of diagnosis and after don’t have too much of support - they might be ashamed to share this medical information with their family or friends, they might not be in a stable relationship and usually it is the time when their face serious medical decisions for the first time in their life. She also represents the group for whom endometriosis has a moderate influence on their life meaning that they do need to take care of themselves, be under doctor’s control, endure bad days, but do not experience frequent hospitalization or infertility treatment at that time. I felt this is the group that can benefit the most from management tool that would help them to plan activities, understand their body and introduce changes because it might be their first contact with this type of situation and since they don’t have extensive treatment it is mostly their responsibility to take good care of themselves without as much support as might be offered to patients with more severe cases of the condition.

Clustering topics from interviews with experts and women living with endometriosis, both surveys (with patients and their loved ones) and online reflections yielded seven main groups: emotional aspects, support, physical aspects, proactive role, changes, long term changes, short term interventions

Icons credit: thenounproject.com/ale-es/
GIRLS AND WOMEN LIVING WITH ENDOMETRIOSIS (MAPPED AT THE TIME OF DIAGNOSIS)

Independence (in medical decisions)

- Agnes, 23
  University student
  Accidental diagnosis during annual ultrasound

- Anna, 21
  College student
  Living independently
  In a relationship
  Accidental diagnosis during ovarian cyst surgery

- Sophie, 25
  Young professional
  Living independently
  Single
  Accidental diagnosis during annual ultrasound

Support (in medical decisions)

- Elsa, 31
  Professional
  Living with her husband
  Diagnosed when seeking fertility treatment

- Julia, 28
  Living with husband
  Diagnosed after a miscarriage

- Eva, 25
  Young professional
  Living with her husband
  Diagnosed after complains

- Ela, 30
  Professional
  Living with her husband and child
  Diagnosis during exploratory laparoscopy

- Claire, 12
  Middle school student
  Living with parents
  Diagnosed after painful periods

Daily life heavily affected

01

GROUP NEEDING TO NAVIGATE ON THEIR OWN (OFTEN MAKING FIRST MEDICAL DECISIONS IN LIFE)

02

GROUP RECEIVING A LOT OF MEDICAL ATTENTION

03

TEENAGERS

Daily life not affected

Icons credit: thenounproject.com/vectorsmarket/
WHO AM I ADDRESSING WITH THIS PROJECT?

MEET ANNA
She is a master student who was accidentally diagnosed.

ACCIDENTAL DIAGNOSIS BUT FAMILIAR WITH PAIN
“I’ve always had symptoms but they were dismissed by doctors and my family as “normal”

LACK OF INFORMATION
“I really didn’t have any information on what it was, [on a follow-up] doctor explained it to me in 2-3 sentences”

EXPECTATION & TRANSITION
“Managing expectations would be good. Yo hear it can go like this, but it can be also like that”
DESIGN PRINCIPLES

Provide full service wherever and whenever it is needed

Working regardless of location, plain English - no medical jargon.

“I have to drive 2 h to meet my gynecologist. So it takes up a lot of space. I have to mention I live in the middle of the forest.”

Provide transparency and gain trust

No hidden agenda, way to donate your data.

“You are in a vulnerable position where you completely trust the doctors. It’s wrong.”

Adapt to the stage of condition and moment in life

Celebrating your successes and supporting on bad days, Helping you go where YOU want to be.

“I typically unfollow online support group on good days - I start to feel guilty.”

Don’t interfere with every-day life

Not triggering of harmful behavior, working in the background.

“I used apps, but sometimes I don’t know if it makes me too self-involved”
CO-CREATION & IDEATION SESSIONS

In the following parts of this chapter, I’ll be referring to directions, concepts, and probes. In this context, the direction is understood as a general idea and more of an umbrella term for multiple items (for example, “emotional component” is a direction that can include multiple concepts). The concept is a design idea equipped with at least a sketch of the physical form and basic idea about the interactions involved. A probe, on the other hand, is a digital of physical manifestation of a concept or part of the concept that can be tested with real users in environments they would use the final product in the future (ideally it can live with users for a certain period of time).

Co-creation
Two co-creation sessions were conducted at the beginning of the exploration phase: one with endometriosis patient and her husband and one with a person who was recently diagnosed. In both sessions, participants were asked to evaluate big blocks of patients journey that was initially mapped out in the previous phase and adjust it to reflect their own experience. We mapped pain points and workarounds mostly focusing on the transition, management, and changes on top of the journey and treated each of them as a starting point for ideation.

Ideas that came from co-creation included:
- Dietary guide (introducing healthy option tuned to user’s taste, seasoning course to make healthy food better),
- Calendar-tracking (prompting to enter info, seeing patterns from tracking, tangible interactions for recording info - squeezing, shaking, voice input),
- Planning (planning together and separately with the partner or loved ones),
- Accommodating to the pain (informing medical staff before any procedures including physical contact about the discomfort that patient might experience, letting your partner know),
- Community-based friend support.

Ideation
There were three ideation sessions with two participants (me and one other person) utilizing inspiration cards (quotes and findings from the research phase, comparisons to public figures or brands) and “How might we” questions build on research and co-creation sessions. Sessions were built around questions listed below.

1. How might we make tracking symptoms less tiresome?
2. How might we create a ritual around tracking the condition?
3. How might we collect data using tangible interaction?
4. How might we help to decrease cognitive load on the patient?
5. How might we promote reflection and future planning with uncertainty?
6. How might we help to ease the emotional burden?
7. How might we let patient’s partner know how I feel without verbal communication?

After analysis focusing on clustering concepts from co-creation sessions and ideation three components of the transition time emerged: cognitive, emotional and social. Each of those aspects along with concrete ideas developed with participants informed creation of one of the directions and each of the directions was illustrated by one design concept.
INITIAL DIRECTIONS AND CONCEPTS

Directions and initial concepts
Direction I - Cognitive component
Foundation of this direction builds on the idea to create a container for changes that patient wants, allowing for learning in small chunks and providing incentives for tracking.

 - Concept I - My Journey (Cognitive component)
The cognitive component was illustrated by concept focusing on simplifying learning process about the condition and making tracking less troublesome. User would start with deciding on what topics she would like to focus, make changes or learn more about. The system would help to break bigger goals into manageable steps and track changes to make sure that user knows how her body reacts to introduced changes. The information would be broken down into digestible chunks user can absorb even on the go.

Direction II - Emotional component
This direction was responding to the need to process this change/loss characterized by the problem of lack of tools and time to do so. This direction was focusing on processing feelings, working toward deeper change and reflecting over now & future.

 - Concept II - Navigator (Emotional component)
Emotional component was presented as a concept reinforcing reflection and planning for the future. The personalized printed journal would contain inspirational stories of other Endo Sisters (other women living with endometriosis) as well as space for user’s thoughts and tracking. Thanks to electronic pen all of the notes and data would be stored in a cloud for an easy access.

Direction III - Social component
This direction was responding to the need to be understood by loved ones and the problem of lack of support & loneliness that patients experience. The goals of this direction were making others understand and opening up discussion.

 - Concept III - Empathy Amplifier (Social component)
Social component was embodied by a concept focusing on amplifying empathy and helping loved ones to better understand the experience that patient is going through. Small token reflects patient’s level of pain and/or energy levels to keep her connected to the person she has gifted it to.
FEEDBACK

Online feedback
To learn how patients feel about proposed solutions and how would it fit into their life now as well as at the time of the transition into the life with a chronic condition online feedback was collected. In total 10 answers to the survey for patients were obtained using online survey containing video-animation for each of the three directions presented above with one concept representing each direction. The survey consisted of 23 single-choice, multiple-choice and open-ended questions investigating the potential of the proposed solutions to benefit transition time and life of women with endometriosis (full list of questions can be found in the appendices at the end of this thesis; it was powered by Google Forms).

Overall, Concept I (My Journey) was favored by patients in terms how well it fits into their life now and at the time of diagnosis. What is important to note here is that because this idea is a flexible system with many moving parts participants would choose elements they felt they needed at different times. However, feedback around this concept pointed out to problems with creating educational part of the system due to limited well-established knowledge on the condition and disagreements regarding different treatments or even the unknown cause of the condition. As one of the participants pointed out: “Since research regarding endometriosis can have different angles and theories regarding the cause of the disease and treatments, I would be a bit critical of which type of information there would be for the 5 minutes a Day.”

That is why for the time being educational part will be limited to the information that is agreed upon and necessary to deliver as it might have an impact on the future life of the patient (for example that endometriosis might influence fertility). Because of that and also positive reactions to learning about other’s experience in a more narrative format there will be stories of other women added to the project and overall design idea will be rather focused on getting to understand user’s own body, supporting changes she wants to introduce and making sure all that would fit into her life.

Patients also suggested adding other functionalities like sharing data with their doctor (“I wouldn’t change a thing. It’d be especially neat if this data could feed into my health chart at my physicians office.”) or tracking also positive aspects (“The ways to monitor pain. But also to monitor other more positive feelings.”).

Online feedback strongly suggested that Concept II (Navigator) resonated rather with people who already like journaling: “It sounds good, but I don’t think I would keep it up in a regular way which is needed for it to help. I am also a person that more relates to facts and statistics.”; “Not sure I would use it on a daily basis as journaling is not a big part of my life.”

Taking into consideration that there are similar tools on the market that are less condition-specific but can also offer reflection, research around this topic was discontinued. With the exception of the idea to collect and share stories of women living with endometriosis to give recently diagnosed not only a list of symptoms but also scenarios showing different ways that condition can negatively influence future plans but also inspire other choices. This part of the concept resonated with the participants and was transferred to the concept Concept I (My Journey).

Concept III (Empathy Amplifier) got very positive feedback: “In the times where I don’t feel like having a long, drawn-out conversation with my husband when I’m in a tremendous amount of pain, this would be very helpful. I see this being more useful when my husband and I aren’t in the same place […]”; “Being able to send ”real-time” feedback to my husband would be incredible. I get tired of sending him a text message saying, ”I’m in a lot of pain, I might leave work early.”. However, overall it didn’t fit into participant’s life as well as Concept I (My Journey). That is why Concept I (My Journey) and III (Empathy Amplifier) were taken to the next phase focused on probing with women living with endometriosis to discover how well they would work in practice.
PROBING OF THE CONCEPT “MY JOURNEY”

1st Probing - My Journey

The first session of probing was centered around the idea of tangible input device allowing for an easier tracking of the condition and supporting changes enhancing the quality of life included in Concept I (My Journey).

Two patients were living with the probe for 48h and one for 4 days (this discrepancy was due to technical issues; one of the participants who was able to track for longer was me as I’ve followed the idea that all methods are first tested on me). Participants were asked to track different data points (each patient was inputting personalized data point according to their current situation). Probes were made out of little bits components and laser cut plywood casing allowing to use the probe as a portable input device.

Probe A which was fitted with a knob as an input and its output was shown with the brightness of light for the energy level that participant was entering. It also had another input with a button and output was shown with a blink of a led when the intake of the pill was registered.

Probe B was built with a pressure sensor as the input and output were symbolized with a set of LEDs for registering the mood.

Probe C was fitted with a dimmer component as the input and output were shown with a set of LEDs for the tracking of pain level.

For the duration of the probing patients were filling pre-printed journal where they behavior and reflections were noted down. Journal, as well as other topics, were discussed during the interview and co-creation session following probing.

Two of the probings were followed by an interview and co-creation session - in one case it was a meeting with the person participating in probing and in the other case with the participant and her partner. While the interview was focused on the experience of using the input device, co-creation was looking into the usage of the whole system, which features and topics are interesting for patients and what look and feel would they like the input device and the whole system express.

Both interviews and co-creation sessions proven that system would fit very well into lives of the interviewed group and the way they would use it is dependent on the point in time - they expressed the need for a different support just after the diagnosis and a different one later on. Overall the most appreciated feature of the system was its flexibility and ability to adjust to the life of the user, not the other way around.

The experience of using a simple input device in probing was positive for both of the participants. Details of the input type, labels and values were discussed and participants presented they ideas to improve those details by making labels more clear, design of the device sleeker and even more portable and input values more precise (for example not only value numerical presenting severity of pain, but also part of the body impacted by the pain). Some of the feedback was noted in the diary that participants kept throughout the probing. All of those comments were analyzed and taken further into the process. Co-creation sessions gave a clear picture of how potential users react to the idea of the whole system that is being designed and in both cases, feedback was very positive - it was clear that the overall idea is something needed. Exercises with assigning the value to features or topics allowed for an analysis what exactly should be nature of support offered by the system. Interestingly the topic of the community came back as it was needed for support and motivation while introducing changes. At the same time, having a chance to reach out to a specialist was something very needed. This observation leads to the conclusion that there should be a focus on balancing out the support from peers and specialist to create a safe space where all the content can be trusted, but at the same time, there is the element of interaction with other women going through the same experience. Co-creation sessions gave also a clear image of what the input device stands for the participants. One of them referred to it as a “safety pin” and the other one explained that using it gives you the feeling that you are doing something to help yourself and that calms her down. It became clear that it was not seen as a medical device, but rather a personal object that would accompany users on the journey of regaining their best possible quality of life. Both participants brought forward the idea of using materials in a way that shows how the object is aging and becoming something even more personal.
PROBE C
Fitted with a dimmer component as the input and its output was shown with the brightness of light for the energy level that participant was entering. It also had another input with a button and output was shown with a blink of a led when the intake of the pill was registered.

PROBE B
Fitted with the pressure sensor as the input and output were symbolized with a set of LEDs for registering the mood.

PROBE A
Fitted with a knob as an input and its output was shown with the brightness of light for the energy level that participant was entering. It also had another input with a button and output was shown with a blink of a led when the intake of the pill was registered.

Diary kept during probing

MONDAY

How many times did you record information today?
About 3 times

Where the example home, university, work, bus did you
at home.

How well did this way of engaging fit into your day
today?
I had to remind myself - mostly because I was
feeling fine.

Would you prefer it to be an app on your phone? Why?
No specifically.

Additional comments/observations:
I only think of recording into when feeling bad. When feeling bad, I would actively seek out ways to
record - feel like you are doing something.

TUESDAY

How many times did you record information today?
About 30 or 40 times

Where the example home, university, work, bus did you
at work - I decided to leave it at one place (two) what I would do - but
it would be good to have
the anchors I too - or
not very - I even note
the input is counter,
I was feeling quite ok, and
it begins to splinter into orange-red.

How important did you feel your input was?
It seemed like my input was
not 'extreme', not much control.
This I prefer it if I
could be more accurate about
my input - more specific.

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PROBING OF THE CONCEPT "EMPATHY AMPLIFIER"

2nd Probing - Empathy Amplifier
2nd probing was inspired by the co-creation sessions and focus patients gave to the relationship and communication with their partner as well as problems with tracking the condition included in Concept III (Empathy Amplifier). It was a quick exercise to get a feeling of how this design would fit into a regular day of a couple and lasted 24 hours. Patient operated the input device for recording information on energy level and pain level: one probe was exploring tactile aspects of expression and pressure (it was made out of sponge fitted with the pressure sensor) and the other one explored sliding scale built for more control (slider component). Partner received short videos where light and color were representing how their loved ones felt and were based on the input from the devices. Videos represented how the patient has felt - the brightness showed how much energy she had and colors represented pain levels - from green (pain-free) to red (a lot of pain).

Reflections after 2nd probing
The patient was noting reflections along the probing and a short reflection session for the partner followed this exercise.

Patient’s reflections:
The expressive input device (sponge fitted with pressure sensor) - "Quite expressive, seemed better as an input for energy levels. Although if the output device was also tangible sponge would allow for a lot of extra information (twisting it could convey more info about the type of the pain than just applying pressure, poking it would also give an idea about a stabbing pain)."

The precise input device (sliding scale) - "Nice feel for a pain scale - didn’t have to worry about specific numbers, but still had a lot of control. Probably better if the device is used not only as an expression to share with the loved one but also to collect medical data.”

General reflections: ‘At some point, I felt that I don’t want to worry my boyfriend, so I didn’t feel like expressing all the things. There is a need to separate collecting info for medical purposes and to communicate with loved ones since data we input for others to see are biased.”

Partner’s reflections:
How do you feel about the artifact you’ve been interacting with? What emotions did it evoke? "It was nice, I was trying to understand what it meant. Sometimes it was too long [video], and I wasn’t sure what was happening, but after the first one they became shorter and I was curious to see what it would show me.”

Did you feel less worried or did it make you feel more conscious? “I did start relating to the colors, but I felt the green was more of a neutral state so I felt that she was not great but more like OK. It definitely did make me more aware of how she was feeling.”

Do you feel it affected your communication? If yes, how? “I think I was a little busy that day so I didn’t respond immediately, but I can see this affecting what I would say or ask if something was wrong.”

How would you rate intrusiveness of this object on a scale from 0 (not obtrusive at all) to 10 (extremely obtrusive)? ‘Since it was a video that I had to start playing, so only did it when I had time to go through it. Probably in this case as intrusive as any message on my phone.”
Reflections after probing, interviews and co-creation

Overall after analyzing the outcome of the probing sessions, it became clear that in case of endometriosis patients there is an urgent need for basic tools that would help them to navigate through the health and lifestyle-related issues. In the absence of the most elementary solutions, it seemed like those problems need to be addressed first. Even though I do believe that developing design enhancing communication might be beneficial it did not seem as urgent as support on a more fundamental level touching on education, helping to streamline tracking and making changes. That is why Concept I (My Journey) was developed further to create a complete ecosystem supporting women diagnosed with endometriosis in the transition into living with a chronic condition and retaining the best possible quality of life.

“Caring for myself is not self-indulgence, it is self-preservation [...]

Audre Lorde


Photo credit: unsplash.com/@henrihere
A better way to live with chronic conditions

First design proposal
After formulating how the system would work and deciding on the shape of the input device video describing the whole system was created in order to collect feedback from a broader audience. Some of the changes proposed in the feedback from the sessions after probing were already introduced and overall system was described in more details including particular areas of the application and possibilities they open up for the users - elements like the basic interactions with token (input device) were described and illustrated, early mock-ups of the application including data aggregator and filters helping to analyze trends, Habit Nooks introducing changes with a support from the expert and community and opportunity to schedule calls with experts (nutritionists, physicians, pelvic floor therapists, pain management specialists, doctors) to discuss collected data and further plans. This concept was described as focused on making tracking less troublesome and gathered data more meaningful for user's every-day life.

Feedback and final synthesis
Using video described above and online survey consisting of 8 multiple-choice and open-ended questions focused around the issue of how would be presented system fit into potential user’s life feedback was collected (full list of questions can be found in the appendices at the end of this thesis). In total three women participated giving mostly positive feedback with some suggestions for improvements that were implemented in the final version of the design. Topics listed below were the ones that participant brought up and they were in the center of attention when designing the final solution.

Flexibility and personalization
The most important aspect that participants liked was the flexibility of the system and they gave examples of how that would benefit them at different stages of their adaptation to life with a chronic condition: “I like that I can select information that is relevant to me whenever it is needed; (2) Provide transparency and convenient way to communicate data to healthcare professionals.

Summary
This chapter discussed following issues:
• Research reviled that the image of living with endometriosis is full of intertwined problems on many levels: personal, social and systemic. The most important aspects were brought up to create a red thread for the project, inform next iteration of the design brief and emerging in this phase design principles.
• One of the important learnings from the research phase is that many patients introduce multiple lifestyle changes after diagnosis, but only 50% of women track their condition. That means that some of the long-term effects of the changes are not really understood
• Participants of research pointed to problems with tracking like lack of appropriate tools and no convenient way to communicate data to healthcare professionals.
• One of the biggest challenges that patients, as well as their loved ones, pointed to was lack of understanding they face.
• Different groups of patients were mapped out in relation to the severity of the symptoms and amount of support regarding medical decisions they receive. It was decided that in this project the main audience will be patients with mild symptoms who need to manage their condition very much on their own since they see healthcare specialist not too often.
• Patient journey showed how important is the transition time in preparing the patient for life with a chronic condition. As a result transition time (including elements of diagnosis as well as living with endometriosis) was chosen as a focal point for this project.
• Design principles mapped the way toward the solution emerging from the learnings gathered in research: (1) Provide full service wherever and whenever it is needed; (2) Provide transparency and gain trust, (3) Adapt to the stage of condition and moment in life; (4) Don’t interfere with every-day life.
In the last stage improvements and definitions of details were introduced as well as the development of the business perspective creating a cohesive ecosystem supporting women.

Following topics will be discussed in this chapter:

- “Solution for patients” describes how proposed ecosystem (VEA)
- “User journey” illustrates a step-by-step scenario of use of VEA.
- “Solution for patients - Physical input device - Comfort token” looks into detailed interactions with the physical input device being part of VEA ecosystem.
- “Solution for patients - Digital platform” explains how exactly digital platform would work and illustrates it with examples of interfaces.
- “Technology perspective” discusses shortly communication between devices as well as technology used in the physical input device.
- “Business perspective” gives insight into how VEA could become a valuable business partner for healthcare systems, insurance companies, as well as provide services directly to users.
- “Service blueprint” illustrates how the service is provided to the end users at various stages of interaction.
- “Future challenges and contribute to the design field” is a reflection on the problems that VEA as a company and service might face when launched on the market. It also gives insights into how this project contributed to the field of design by the choice of topic and way it was explored.
- “Summary” present main points and decisions regarding thesis project explained in this chapter.
SOLUTION FOR PATIENTS

VEA is a kit supporting women in the transition into living with endometriosis. It is deeply personalized as each of patients has different needs. VEA consists of a physical tracker that helps to record symptoms important for a particular individual and platform helping to introduce lifestyle changes, connect with other women and specialists as well as understand tracked data and make informed decisions. The focus of this system is on helping the user to learn about their own body and achieve the best available to their quality of life.

How does VEA work?
The first face of the service is a free application that can be used without any registration. Its main goal is to provide basic information about endometriosis and screening tool for patients helping them to take steps into seeking appropriate medical care. If the user is diagnosed she can register into the next face of the application and go through onboarding process. This step is essential in preparing personalized experience that will help in the transition. Onboarding process includes inputting information on how condition influences user’s daily life, what activities and topics are interesting for her as well as receiving and setting up the token allowing for easy tracking of the symptoms. While it is possible to use the system without the token it was shown through research that physical object is something not only desired by women living with endometriosis but also something that most likely will make it easier to track their condition on a daily basis. Access to the platform will be paid on a monthly basis and opportunities to use it as a part of national healthcare systems are being explored.

VEA gives access to different aspects of the service:

Habit Nook - Community
Habit Nook is a format uniting group of women who want to follow lifestyle changes in a particular area of life together and start at the same time. Members of the Nook support each other while content is prepared by an expert. There is also a space for chat where members of this particular Nook can exchange experience and motivate each other - this part is moderated by expert-moderator (answering questions, making sure no misunderstanding or wrong information is spread in the chat among participants) and moderator (checking if rules of conduct are followed by the participants). Users can participate in maximum 3 different Nooks at the same time - this restriction allows the participant to find different communities and address a different aspect of lifestyle alterations, but at the same time not be overwhelmed with the amount of work and time that needs to be put into it since that might be demotivating.

Data Dashboard
This part gives an outlook on the data collected using Comfort Token and Habit Nook and provides tools like filters (allowing for turning the visibility of a certain type of data on and off for a more clear view or deciding what period of time should be visible) as well as master-filters pointing out to interesting data patterns or correlations. While the system does show that information it does not propose explanation what this data means and it is understood that this question is answered by the user and can be consulted with her doctor or addressed during a call with an expert. Dataset can be explored in a spreadsheet or PDF format to share with user’s doctor.

Consultation with an Expert
The platform also gives the possibility to schedule calls with experts (nutritionists, physicians, pelvic floor therapists, physical therapists, pain management specialists, doctors) to discuss collected data and changes that user is introducing or planning. The application offers a tool that allows participants of the call to explore data collected by the user and point to a particular moment or place in the dataset. There is a possibility to invite other people for the call so for example partner of the user or her doctor can participate. Length of the call is agreed upon beforehand it and all participants can see remaining time on top of the screen.

Comfort Token
Physical input device providing a simple way
to input set of data that user wished to track in a given period of time. The token is based on a simple interactions od manipulating physical handle and tapping on the top of the device. Shaking device deletes the last recording or in some instances records negative answer (did you take medication? yes-conformation (tap), no - denial (shake). It might seem like confirmation and moving the handle to the top of the device (shown in detail on following pages) is redundant, but this redundancy is meant as a built-in control mechanism for double-checking if recording was correct (recording correct data is essential for this design).

Comfort Token is partly made of wood to change over time (by the change of colour and wear) on this very personal object. It was a suggestion made independently by the participants of my probing to strengthen the personal relationship with the token.

For users who decided not to buy input device or for people who for other reasons don’t have it handy (battery has died, they forgot it home etc.), there is an option to input data via the application.
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During period
During or after intercourse
During ovulation
Low back pain
Heavy menstruation
Premenstrual spotting
Irregular bleeding

Do you experience symptoms listed below?

VEA Screening
9:41
Let’s set up your comfort token

Connect with this phone
Connect with other device
Why is my token not connecting?

3 months later

6 months later

What else can I track?

VEA
9:41

Workspace
My questions & notes

Call with Dr. Hellmund Vega

Lotus Session
15 min Twists
Tuesday

10 min Relax
Thursday

Lee
Do you also find it hard to set aside time for your exercises? Even though I do feel like they are helping with the pain…

😞😞

Month 3

3 months later

My nooks
My Tracking

Stretch Club & Pain Level
There is a link between your activity in the Stretch Club and lower Pain Level.

Ask your doctor

March 2018

5
6
7
8
9
10
11
12
13
14
15
16
17
18

6-Months

My nooks
My Tracking

Pain Level
Energy Level
Bleeding

Suggestions
My nooks
My Tracking

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**SOLUTION FOR PATIENTS**

**PHYSICAL INPUT DEVICE - COMFORT TOKEN**

01. **TURN ON**
   - User: long press

02. **READY**
   - System: blink of all icons

03. **INPUT PAIN LOCATION**
   - User: moves handle

04. **CONFIRM PAIN LOCATION**
   - User: taps

05. **CONFIRMATION**
   - System: shows an icon

06. **GO TO THE NEXT STEP**
   - User: moves handle to the top

07. **READY**
   - System: blink of all icons

08. **INPUT PAIN LEVEL**
   - User: moves handle
   - The same input method can be pre-programmed for energy levels, how heavy is the menstrual bleeding and other values expressed on a scale

09. **CONFIRM**
   - User: taps

10. **CONFIRMATION**
    - System: shows an icon

11. **GO TO THE NEXT STEP**
    - User: moves handle to the top

12. **READY**
    - System: blink of an icon

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**SOLUTION FOR PATIENTS**

**PHYSICAL INPUT DEVICE - COMFORT TOKEN**

13

- **CONFIRM MEDICINE INTAKE**
  - User: taps
  - The same input method can be pre-programmed for menstruation (Yes/No) and other 0/1 values

- **DENY MEDICINE INTAKE**
  - User: shakes device

14

- **TURN OFF**
  - User: long press
  - (can be used at any moment of interacting with the system)

**COMFORT TOKEN - DELETING INPUT**

01

- **DELETE LAST INPUT**
  - User: shakes device

02

- **CONFIRMATION OF DELETING LAST INPUT**
  - System: shows an icon and asks again for the same info

**COMFORT TOKEN - BATTERY**

01

- **LOW BATTERY**
  - Red light from the gap between two parts of the device
SCREENING TOOL

The screening tool is a free first face of the application that doesn’t require registration. VEA Screening is based on an assessment tool that can tell patients if their symptoms suggest they should seek further medical diagnosis connected with endometriosis. This part of the application contains basic information about the condition.
ONBOARDING: SIGN-UP & PERSONALIZATION

Onboarding process starts with a sign-up and payment (it can be a code received as a part of prescription or personal payment for the first month).

Onboarding process contains questions about how endometriosis influences user’s life and what are her preferences regarding activities etc. This process allows creating personalized suggestions for Habit Nooks that might be interesting for the user. In this process, it is also possible to order tracker (comfort token), but it is not required.
ONBOARDING: TOKEN SET-UP

In case user ordered token she needs to set it up when it arrives to decide what to track and connect it to the mobile device. Personalisation process helps to suggest the best parameters to track.
HABIT NOOKS

Habit nook includes a set of different nooks that user chooses from suggestions. Each Nook consists of content created by an expert and support system either created by the community (community-based Nook) or expert actively engaging with the single user (expert-communication Nook).

Each Nook provides support in introducing changes and in combination with the tracking system offers the possibility to check how changes influence user’s mood, energy levels or pain levels (depending on what data user is tracking as indicators of change).

one of the nooks called "Stretch Club" - each card shows one session.

video with a session and contextual educational information for Tuesday. Discussion around this session presented below.
DATA DASHBOARD

Data Dashboard displays data collected by the user via tracking (either with the comfort token or in the app) and inputting information in the Habit Nooks (for example finished session of the stretch exercises).

Within the Data Dashboard filters allow the user to manipulate how long period of time is visible at once (time filters) and what type of data is visible (data filters).

Over time system will also display "Master Filters" showing patterns in data (for example correlations or changes over time) or suggesting what information should be shared with the doctor.

pop-up showing details on the recording of pain (different types of pain, pain level and time of the record).

filters to control period of time displayed (top row) and types of data (bottom row).
CONSULTATION WITH AN EXPERT

Calls with experts can be scheduled to explore data that user collected over time or seek advice regarding a particular area - for example nutrition.

The call can be recorded and video is stored in user’s app as a reference. Data dashboard can be shared during the call on the screen for a better communication.
A better way to live with a chronic condition

This decision was made around the same time when the mobile application would be available for Android and iOS devices to provide service for the broadest possible audience, but at the same time prove to be a safe solution able to protect user’s data. For the same reasons, information stored in a cloud will be encrypted.

Comfort token and communication (input device)

If it comes to the comfort token (input device) initially direct communication between the tracker and the cloud was considered but after consultations with specialist and literature review, it was decided to make input device communicate with the mobile device first which will pass data to the cloud when a stable connection is available. If the connection is not available smartphone or tablet would store data. This decision was made around the same time when it became obvious that mobile application is needed as a dashboard for the system, so using a mobile device for data transfer seemed a logical step. But the main motivation was not to overcomplicate the input device on the technological level as well as make sure that the battery life will be satisfactory. As we can read in “Collection and processing of data from wrist wearable devices in heterogeneous and multiple-user scenarios” (Arribà-Pérez et al., 2016): “A wearable data transfer and direct access between the wearable and the third-party server is possible in theory, but not in practice nowadays. [...] nowadays, this option is only available to connect the wearable to a mobile device (e.g., smartphone) and it does not support the communication to a web service. In addition, the energy consumption is too high. Therefore, this configuration is not a valid option yet.”

Comfort token and display

To prevent glare and make screen easier on the eyes of the user’s who might be engaging in the interaction while in pain the decision to use e-ink paper was made. To be able to use colors as a part of the interface Advanced Color ePaper was the technology of choice. As we can read on the website of the producer (E Ink): “Advanced Color ePaper (ACEP) is a high quality, full color reflective display. In the ACEP system, the ink can produce full color at every pixel” (via www.eink.com). To prevent accidental activation in a pocket or bag device would be fitted with a simple thermal sensor to recognise long-press applied with a finger to turn on the device.

BUSINESS PERSPECTIVE

Shift in distribution of investments in the Healthcare

Changing healthcare landscape welcoming new more efficient proposals that can be distributed on digital platforms was an inspiration to introduce solution that can be financed from different resources - national healthcare system, private insurance and out of pocket.

First Face of the system and subscription

Educational information and screening tool are free, but patients who register into other parts of the service will use it on a subscription basis - for those living in countries with public healthcare providers system this service could be prescribed by GP or OB/GYN and covered by national insurance. For patients using private healthcare, insurance service can be covered by the insurance company or they can pay out of pocket. In that way, barriers to start using this service are minimized.

Layers of the service

Service has three layers - basic application including signing up for up to three nooks and tracking (limitation is not part of the business model, it is restricted not to make patients overwhelmed with too many information and pressure from multiple nooks), individual nooks run by experts (it is a combination of a personalized plan and limited number of calls with this expert included in the nook) and calls with experts. Patients can use a combination of financing methods - for example, their insurance covers the basic usage of the application and up to three calls with experts per month, but the patient would like to have more calls, then they can pay for the additional calls out of pocket.

Comfort token (physical input device) and flexibility

An important element of tracking is the usage of the tracking token that comes in a package as a part of the onboarding process. To make service more accessible it was decided that application would allow tracking without the token for cases like users who forgot their token, lost it, forgot to charge it or countries where the token cannot be delivered. This decision opened up a discussion if there should be an option available to order service without the token. The first intuition I wanted to follow was that by limiting option only to purchasing the full service (access to content via application and token for tracking) would give the best experience. On the other hand it would make the price goes up and make service less accessible while accessibility should be a priority since this service should serve a group that often does not receive the best healthcare care due to the accessibility issues (location, insurance policy, and restriction, financial situation, lack of time or education). That is why the final decision was to allow for purchasing service without the token even though it is an integral part of the service. Shortcomings of not using the token will be presented to the potential users and there will be the possibility to purchase it later, after using the service already. This solution makes also purchasing more transparent since the price of the service and physical token are known to the end users.
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**SCREENING**

- **Online/Physical Evidence**
  - Screening
  - Screening process in the app + tracker sent to the customer (tracker is optional)

**ONBOARDING**

- **Customer Actions**
  - User answers to a set of questions and gets a recommendation
  - Onboarding
  - Sign-up, payment (from prescription or private)
  - Receiving set-up of the tracker (optional)

**TRACKING**

- **Front of Stage Interactions**
  - Receiving package with the tracker, customer service available for the users
  - Tracking
  - Long-term development of algorithm (system learns in the background to allow for smarter tools in the future)

**COMFORT TOKEN**

- **Back of Stage Interactions**
  - Support for the app, updates, bug fixes
  - Data storage, supporting communication and encryption (devices, app, cloud), support for the app, updates, bug fixes

**DATA DASHBOARD**

- **Support Processes & Systems**
  - Data analysis, data storage, supporting communication and encryption (devices, app, cloud), support for the app, updates, bug fixes

**HABIT NOOK**

- **3 months later**
  - Reading data (independently)
  - Using the Habit Nook (also interactions with other users and experts)
  - Call with an expert

**6 months later**

- **Line of Interaction**
  - Preparation of the steps with the experts, app development, development of algorithm (for suggestions tracking pin and instructions design)
  - Customer service available for the users
  - Tools supporting data reading (filters), in-app instructions, exchanging experience with other users (in community module), customer service available for the users

- **Line of Visibility**
  - Preparation of the content by the expert (text, illustrations, videos), updating content, app development, discussions (chat) screening by admins (to ensure rules of conduct are followed)
  - Interactions with the expert running the Nook and other participants, for the users, interactions with admin, customer service available for the users

- **Line of Internal Interactions**
  - Finding and screening new experts, quality control, scheduling calls
  - Data analysis, data storage, supporting communication and encryption (devices, app, cloud), support for the app, updates, bug fixes

- **Icons credit: themounproject.com/vectorsmarket/
FUTURE CHALLENGES & CONTRIBUTION TO THE DESIGN FIELD

Future challenges associated with the usage of the product are always important but even more so when we talk about healthcare landscape. Some of the unintended consequences are at least to some extend safeguarded by the VEA ecosystem itself like engaging two types of moderators (experts and regular moderators) making sure that no negative talk would happen within the Habit Nooks. One of the reasons I wanted to create this safe space for the patient beside the obvious ease of use, is to make sure that nobody would take the advantage of the users. But at the same time, this is one of the unintended consequences for the product I’ve planned as a curated space, so screening program and very clear framework are needed to be put in place before contracting any experts contributing to the platform. Other unintended consequence would be women stopping to seek doctor’s care outside of the online contact. Since the very beginning even in the early concept videos, it was made clear that this product cannot replace medical care, but support self-care and lifestyle changes, but this is something that needs to be addressed throughout the application, but also in calls with experts. It is a quite complex ecosystem so there are more issues we could talk about, but in this short revision, I just wanted to present that this is something that was considered and needs more research and reflection if the product will be intended for the market in the future.

Contribution to the design field

In this project I see the contribution to the design field on two levels.

Insider-designer

The first one is presenting perspective of insider-designer along with an example of design process shaped to be conducted by somebody personally engaged in the topic. This process was carefully prepared to make sure that my experience is not going to color the whole project, but also to allow me to contribute to it in a way that other participants of research or probing did.

Awareness and critical perspective

The other level of the contribution I see is speaking about issues that are underrepresented in the healthcare design field - invisible illness, chronic condition, “women issues”, reproductive health. Pointing out that in the medical field women with chronic conditions are one of the most underserved populations and design can to a certain point improve that situation. Introducing the notion of the bias in medicine (and as a result in healthcare design that supports medicine) or lack of good quality of care for certain groups is not going to change it, but talking about this in a Design School where future designers, managers and decision-makers are listening might.

SUMMARY

This chapter discussed following issues:

• The idea of VEA as a transition kit providing support and motivation to introduce lifestyle alterations for women diagnosed or living with endometriosis was introduced in this chapter.

• VEA is a practical answer to the challenges faced by women living with endometriosis with a focus on maintaining the best possible quality of life. The presented design was created together with patients and their loved ones. VEA supports users in introducing lifestyle changes while guided by experts and supported by the community. Physical tracker allowing to log symptoms and along with the Data Dashboard helps users to explore data patterns and make informed decisions.

• In the first step, the system offers a screening and educational tool and users who have been already diagnosed can register and use the full spectrum of tools starting with the Habit Nooks supporting them in introducing changes while guided by experts and supported by the community.

• Physical tracker allows to track symptoms and together with the Data Dashboard helps users to explore data patterns and make informed decisions. The system gives an opportunity to get in touch with experts via calls or structured long-term programs.

• Physical tracker is communicating with the cloud via mobile application to ensure a long battery life. The screen is produced with e-ink paper to ensure it is not hard on user’s eyes who might be using this device while in pain, as well as help to prolong the battery life.

• VEA company is expected to work with healthcare systems and insurance providers to ensure that service can be refunded to insured individuals. Patients who are not covered can opt to pay for the service out of pocket.

• Even though this project may never become reality it did play its role in spreading awareness about invisible illness, chronic conditions and in particular about endometriosis among future designers and decision-makers.
REFLECTION

Many patients see the experience of living with a chronic condition as a journey, often painful and challenging, but meaningful nevertheless. Work on this project made me realize that true journey is something that each person needs to do by herself but also can find comfort in the togetherness of the community of people who are going through the same experience. My project is trying to honor the fact that transition time is the beginning of a lifelong journey of brave women who not only want to regain the quality of life, but also support each other.

Following topics will be discussed in this chapter:

• “Designer’s perspective” discusses what learnings from this project can be transferred to future projects and kept in my design toolbox.

• “Personal learnings” touch on the discoveries that have been made in regard to human connection and reflections on my role within the process.
I believe that in case of this project the design process and sharing my learnings might be more meaningful than the physical or digital definition of the final solution, for me as a learning experience, but also for bringing the awareness and one more perspective at the issue, I’m exploring (and it is described in more detail in the contribution to the design field chapter). Learnings relating to design that this project brought to me could be divided into categories as I’ve listed them below.

Understanding the future users
Women living with endometriosis who decided to participate in my research gave me the opportunity to gain important insight into the life of my future users. Of course, for each project this part would be quite different but what I will take away from this experience is making sure to talk to the future users using their language and tools they feel comfortable with. Since I had a good understanding of what that might be I’ve learned that for patients setting the right expectations is essential, as well as understanding not only condition but how it will affect their life. Those very basic notions helped me to set tone for my project and what problem I want to tackle. At some point, I was afraid that contacting participants with updates or opportunity to take part in another survey might feel tiresome to them, but actually they were happy to follow the project. This gave me a feeling that at some point this project started to belong to all the people who decided to put their time into it.

Learning about the design process
Planning
I’ve learned to plan rather for flexibility than perfection. Design process is fluid and of course, it is good to rely on a premeditated structure, but it can never be rigid because what is learned today should inform the process tomorrow.

Communication with participants
Experience of the past 17 weeks showed me that different modes of communication will make participants comfortable and help to collect more representative results, especially when working on such a sensitive topic as the one I was tackling. Surprisingly participants of my research and co-creation sessions responded very well to the fact that I was open with them about my personal relationship with the topic we were talking about. I’ve received a lot of support from the online community and all women and loved ones who very generously supported my project with their time, life stories and learnings.
I’m aware that working on topics that have a personal relevance is not something design community is universally supporting. To leave the comfort zone of seemingly scientific and objective discourse and openly talk about engaging with the project that is extremely personal was one of the challenges and learnings of this project. I did see how much I’ve gained by being open with participants of my design process and how much easier it was for me to engage with the community of women living with the endometriosis than it would be to an outsider. Also, it was much easier to stay motivated throughout 17 weeks of work and not lose the focus. This work brings me closer to believing that spreading awareness and showing that there is a need and market for solutions for people living with invisible illnesses might have its impact.

This project developed my sensitivity to social issues within medicine - lack of equality in the quality of the received medical care depending not only on gender, but also age, race, sexual orientation, and income among other factors. I find it especially important since my professional interest lies in the area of healthcare and the way I’ll practice design might help to fight biases or support current status quo. This brings me to the open topic of ethics within design practice that I’ve started this project 17 weeks ago. Back then I was concerned about the consequences that engagement in my design process might have on participants and myself. Now the focus has shifted and I have to ask myself what unwanted or hard to foresee consequences the service I’m proposing might have.

This is a question that I have to carry with me into other projects. Understanding that social constructs and context will influence services we are proposing is essential - that is why reflection and educating ourselves is an important part of design practice.

My last reflection on this project is that I hope it will become outdated as soon as possible. That might not be what designers usually hope for, but in my case, I would like to see standards of treatment becoming better, bias in medicine being reduced, more focus on a holistic approach to improving quality of life, progress in research on new treatments and seeing patients being empowered to choose between many solutions.
REFERENCES


de Arriba-Pérez, F., Caeiro-Rodríguez, M., & Santos-Gago, J. M. (2016). Collection and Processing of Data from Wrist Wearable Devices in Heterogeneous and Multiple-User Scenarios. Sensors, 16(9), 1538.


McCoy Cohn, S. (Producer/Director). (2016). *Endo What?* [Motion Picture], USA

McKillop, M., Seckin, T., Elhadad N. (November, 2016) Qualitative Assessment of Women’s Attitudes Towards a Tracking App for Phenotyping Endometriosis. 2016 AMA Annual Symposium, Chicago


Envisioning tool supporting endometriosis patients

Hello, my name is Joanna and I’m a design student living with endometriosis. I want to contribute my professional skills to create a design empowering women and at the same time spread awareness.

In my Master thesis, I’m focusing on creating a design for supporting life with the chronic condition. In order to do it well, I need your insights and will be thankful for each and every response.

Your responses are going to be anonymous and used only as a part of university project at Umeå Institute of Design. Participation in this survey is voluntary and at any moment you can decide to stop the survey. If you have any questions please contact me at joanna.pruchnicka@gmail.com

If you would like to learn more about the project visit: http://www.joannapruchnicka.com/thesis/

1. Do you use any applications or paper-based tools to manage your condition (tracking symptoms, managing medication, diet, scheduling appointments etc.)? (single choice)
   - Yes
   - No

2. If yes, what tools do you use? (open-ended question)

3. What are the advantages of those tools? (open-ended question)

4. What are the disadvantages of those tools? (open-ended question)

5. What were the areas you’ve adjusted in your life since experiencing the first symptoms of endometriosis? (multiple choice)
   - Sleep
   - Diet
   - Physical activity
   - Supplements
   - Medication
   - Spiritual life
   - Social life
   - Intimate relationships
   - Travel plans
   - Career
   - Education
   - I haven’t made any adjustments
   - Other (text input field)

6. How did you adjust those areas? (open-ended question)

7. What in your opinion are the biggest challenges regarding endometriosis? (multiple choice)
   - Physical symptoms
   - Finding the right healthcare provider
   - Understanding the disease
   - Managing your condition
   - Making adjustments in your life
   - Social functioning
   - Family life (responsibilities at home)
   - Career (work or school responsibilities)
   - Feeling of loneliness
   - Lack of understanding from others
   - I don’t see any challenges
   - Other (text input field)

8. How do you address those challenges? (open-ended question)

9. Where do you look for support when you need it? (multiple choice)
   - Partner
Supporting a loved one/a friend living with endometriosis

Hello, my name is Joanna and I’m a design student living with endometriosis. I want to contribute my professional skills to create a design empowering women and at the same spread the awareness.

In my Master thesis, I’m focusing on creating a design for supporting life with the chronic condition. In order to do it well, I need your insights and will be thankful for each and every response.

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If you would like to learn more about the project visit: http://www.joannapruchnicka.com/thesis/

1. What is your relation with the person living with endometriosis? (single choice)
   - Partner
   - Friend
   - Parent
   - Child
   - Other family member
   - Colleague
   - Other (text field input)

2. Do they seek your support regarding their condition? (single choice)
   - Yes
   - No

3. If yes, what kind of support do you provide? (multiple choice)
   - Psychological support
   - Motivation
   - Taking their mind off the health-related issues
   - Educating myself about the condition and things that might help
   - Going to the hospital/doctor’s visits/other health-related appointments
   - Management of health-related appointments and activities
   - Taking over part of their responsibilities (at home or work)
   - Financial support
   - Other (text field input)

4. Where do you look for support when you need it? (multiple choice)
   - Partner
   - Kids
   - Extended family
   - Friends
   - Support groups of forums (online)
   - Support groups (meetings)
   - My healthcare providers
   - Psychotherapy
   - Other (text field input)

5. Did diagnosis change your outlook on the future or influenced your plans/life goals? (single choice)

6. If yes, how did your outlook on the future or your plans/life goals have changed? (open-ended question)

7. What aspects of your relationship has been influenced by the endometriosis? (multiple choice)
   - Ways we spend our free time
   - How close we are
   - Less conflicts
   - More conflicts
   - I had to take over more responsibilities
   - Financial plans
   - Traveling plans

8. Do you know other people living with endometriosis? (single choice)
   - Yes
   - No

9. If yes, how did you meet? (open-ended question)

10. How often do you need to change or cancel your plans due to endometriosis symptoms? (single choice)
    - Never
    - Couple of times per year
    - Once a month
    - 2-3 times a month
    - Every week
    - 2-3 times per week
    - Every day

11. How would you describe your status regarding endometriosis? (single choice)
    - I’m waiting for the diagnosis
    - I was just diagnosed
    - I was diagnosed up to 1 year ago
    - I was diagnosed 1-4 years ago
    - I was diagnosed more than 5 years ago
    - I do not wish to disclose

12. Where do you live (country and/or city)? (open-ended question)

13. Your age (single choice)
    - 19 or younger
    - 20-24
    - 25-30
    - 31-36
    - 37-42
    - 43-49
    - 50 or above
    - I do not wish to disclose

14. Please leave your e-mail address if you are open to talking with me or would like to learn more about this project. (open-ended question)

15. Comments / Suggestions (open-ended question)
Design ideas (feedback on three directions illustrated by three initial concepts)

Hello, my name is Joanna and I'm a design student living with endometriosis. In my Master thesis, I'm focusing on creating a design for supporting transition into the living with the chronic condition. In order to do it well, I need your feedback and will be thankful for each and every response. If you would like to learn more about the project visit: http://www.joannapruchnicka.com/thesis/

Your responses to this survey are going to be anonymous and used only as a part of university project at Umeå Institute of Design.

Concept I
Video
Description: This concept focuses on simplifying learning process about the condition and makes tracking less troublesome. You would start with deciding on what topics you would like to focus, make changes or learn more about. The system helps you to break bigger goals into manageable steps and track changes to make sure that you know how your body reacts. You are also provided with a 5-min reading or recording per day where information on topics you are focusing are broke down into digestible chunks you can absorb even on the go.

1. How would that solution fit into your life now? (multiple choice)
   - All elements fit very well - I would use it all
   - I would use planner helping me with changes
   - I would use educational instructions (5 min per day)
   - I would use tracker (cube)
   - None of the elements fit into my life
   - Other (text input field)

2. Could you explain why? (open-ended question)

3. How would that solution fit into your life when you were transitioning to living with a chronic condition? (multiple choice)
   - All elements fit very well - I would use it all
   - I would use planner helping me with changes
   - I would use educational instructions (5 min per day)
   - I would use tracker (cube)
   - None of the elements fit into my life
   - Other (text input field)

4. Could you explain why? (open-ended question)

5. What would you change in this concept? (open-ended question)

6. What is good about this concept? (open-ended question)

Concept II
Video
Description: Concept II focuses on self-reflection and exploring stories of other women. After sharing your story with the system your personalized journal would arrive allowing you to write about your daily life, but also read how other women were dealing with similar challenges (those stories are also printed in your journal). The electronic pen attached to the journal allows you to store all your data in the cloud and even track how you feel in the journal and send it for the reference later.

7. How would that solution fit into your life now? (single choice)

- Sex life
- Planning family
- It did not influence our relationship
- Other (text input field)

6. What in your opinion are the biggest challenges regarding endometriosis? (multiple choice)
   - Physical symptoms
   - Finding the right healthcare provider
   - Seeing your loved one suffer
   - Understanding the disease
   - Managing this condition
   - Making adjustments in your life
   - Social functioning
   - Family life (responsibilities at home)
   - Career (work or school responsibilities)
   - Lack of understanding from others
   - I don't see any challenges
   - Other (text input field)

7. How do you address those challenges? (open-ended question)

8. Did diagnosis of your partner/friend/child/parent change your outlook on the future or influenced your plans/life goals? (single choice)
   - All elements fit very well - I would use it all
   - I would use planner helping me with changes
   - I would use educational instructions (5 min per day)
   - I would use tracker (cube)
   - None of the elements fit into my life
   - Other (text input field)

9. How do you address those challenges? (open-ended question)

10. Where do you live (country and/or city)? (open-ended question)

11. Your age (single choice)
    - 19 or younger
    - 20-24
    - 25-30
    - 31-36
    - 37-42
    - 43-49
    - 50 or above
    - I do not wish to disclose

12. Please leave your e-mail address if you are open to talking with me or would like to learn more about this project. (open-ended question)

13. Comments / Suggestions (open-ended question)
- It fits very well
- It fits, but I would use it just from time to time
- I’m not sure - but I would give it a go
- It does not fit into my life
- Other (text input field)

8. Could you explain why? (open-ended question)

9. How would that solution fit into your life when you were transitioning to living with a chronic condition? (single choice)
- It would fit very well back then
- It would fit, but I would use it just from time to time
- I’m not sure - but I would give it a go
- It would not fit back then
- Other (text input field)

10. Could you explain why? (open-ended question)

11. What would you change in this concept? (open-ended question)

12. What is good about this concept? (open-ended question)

**Concept III**

**Video**

*Description:* Concept III allows your loved ones to track how you feel. A small token can be carried by the person whenever they go and by the means of the change of color, temperature or tactile feedback can et them know if you are in pain or feeling well (data is collected from the input you give, for example in a mobile application). This unobtrusive object is meant as a conversation started opening up the possibility to openly talk about your condition with people you love.

13. How would that solution fit into your life now? (single choice)
- It fits very well
- It fits, but I would use it just from time to time
- I’m not sure - but I would give it a go
- It does not fit into my life
- Other (text input field)

14. Could you explain why? (open-ended question)

15. How would that solution fit into your life when you were transitioning to living with a chronic condition? (multiple choice)
- It would fit very well back then
- It would fit, but I would use it just from time to time
- I’m not sure - but I would give it a go
- It would not fit back then
- Other (text input field)

16. Could you explain why? (open-ended question)

17. What would you change in this concept? (open-ended question)

18. What is good about this concept? (open-ended question)

19. Overall rating - Please rate concepts (values assigned to each concept):
- No 1 (best)
- No 2
- No 3 (worst)

20. Where do you live (country and/or city)? (open-ended question)

21. Your age (single choice)
- 19 or younger
- 20-24
- 25-30
- 31-36
- 37-42
- 43-49
- 50 or above
- I do not wish to disclose

22. Please leave your e-mail address if you are open to talking with me or would like to learn more about this project. (open-ended question)

23. Comments / Suggestions (open-ended question)
Feedback for a design concept (refined concept)

Hello, my name is Joanna and I’m a design student living with endometriosis. In my Master thesis, I’m focusing on creating a design for supporting transition into the living with the chronic condition.

In order to do it well, I need your feedback and will be thankful for each and every response. If you would like to learn more about the project visit: http://www.joannapruchnicka.com/thesis/

Your responses to this survey are going to be anonymous and used only as a part of university project at Umeå Institute of Design.

Please watch video on the following page and then give your feedback below.

[Video]

Description: This concept focuses on making tracking less troublesome and gathered data more meaningful to your every-day life.

You would start with deciding on what topics you would like to focus, make changes or learn more about. The system helps you to break bigger goals into manageable steps you can take with other members of the community and track changes to make sure that you know how your body reacts.

You can also reach out to specialists (nutritionists, physicians, pelvic floor therapists, pain management specialists, doctors) to have a call to discuss data you’ve collected and your plans. Of course, this would not replace your doctor’s visits but gave you a broader perspective on your situation.

1. How would that solution fit into your life now? (multiple choice)
   - All elements fit very well - I would use it all
   - I would use modules helping with changes
   - I would use tracker (physical input device)
   - I would use data visualization tool
   - I would use online calls with specialists (nutritionists, physicians, pelvic floor therapists, physical therapists, pain management specialists, doctors)
   - None of the elements fit into my life
   - Other (text input field)

2. Could you explain why? (open-ended question)

3. How would that solution fit into your life when you were transitioning to living with a chronic condition?
   - All elements fit very well - I would use it all
   - I would use modules helping with changes
   - I would use tracker (physical input device)
   - I would use data visualization tool
   - I would use online calls with specialists (nutritionists, physicians, pelvic floor therapists, physical therapists, pain management specialists, doctors)
   - None of the elements fit into my life
   - Other (text input field)

4. Could you explain why? (open-ended question)

5. What would you change in this concept? (open-ended question)

6. What is good about this concept? (open-ended question)

7. Where do you live (country and/or city)? (open-ended question)

8. Your age (single choice)
   - 19 or younger
   - 20-24
   - 25-30
   - 31-36
   - 37-42

9. Please leave your e-mail address if you are open to talking with me or would like to learn more about this project. (open-ended question)

10. Comments / Suggestions (open-ended question)
A better way to live with a chronic condition

TIMELINE

3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 19 20 21 22

JANUARY FEBRUARY MARCH APRIL MAY JUNE

RESEARCH
Secondary research
Creation of well-being framework
Research sprint I (surveys with women living with endometriosis and their loved ones, interviews with experts)
Research sprint II (interviews with women living with endometriosis)
Research sprint III (online reflection exercise for women living with endometriosis)
Analysis of the research phase
Defining contrains/design opportunities
Developing design principles
Reflection

EXPLORATIONS
Co-creation sessions
Ideation sessions
Directions & first concepts
Online feedback
Concept definition I
Probing I & II
Interviews + co-creation sessions
Concept definition II
Online feedback
Synthesis
Reflection

DEFINITION & DELIVERING
Final concept definition
Final prototype
Storytelling
Reflection

EXAMINATION & UID TALKS
Presentation of the final concept (examination)
Reflection
Implementation of feedback from the examination
Presentation of the concept teaser & exhibition piece (UID Talks)
Reflection
THANK YOU

A thesis is never an individual effort even though just one name appears on the cover. I would like to thank all the people who were engaged in this process, supported me and believed in the end result.

I would like to thank over 100 women living with endometriosis and their loved ones who generously shared their story and time with me.

I would like to thank our program director Stoffel Kuenen and my tutors Tara Mullaney (Veryday) and Nicholas Torretta (Umeå Institute of Design), my classmates who were always there for me and especially Piotr Kuklo who supported me with his critical feedback and Yi-Ting Chien who helped me to shape this thesis even before our final year started and Yue Yuan who was my beautiful model.

Friends who helped me to maintain a healthy perspective on the project and my boyfriend who made a point of traveling half a globe to support me.

And last, but also the most important person - I would like to thank my Mom who made it possible for me to study in my dream program.