"Do you know chronic illness?" The game

Creating a Computer Game to Raise Awareness for Ehlers-Danlos Syndrome

Master's thesis in Computer science and engineering

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Master's Thesis 2025
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Typeset in LaTeX
Gothenburg, Sweden 2025

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Abstract

In this thesis, we investigate how games can be used to raise awareness about living with a chronic illness, specifically Ehlers-Danlos syndrome (EDS). We conducted a literature review, followed by a survey and interview with people with EDS. With the gathered information, we developed a visual novel where the player controls the main character, who has EDS. In the game, the player has to make choices while being careful with their health. Multiple rounds of user testing were done throughout the development, and the feedback was analysed. After the final user tests, we found several game elements that seemed to contribute to the effectiveness of raising awareness for EDS. Among these were the accuracy of the portrayal of EDS, the game asset quality, game mechanics and controls, variation in gameplay, and emotional experiences.

Keywords: Computer, science, computer science, engineering, interaction design, games, project, thesis.

Acknowledgements

We would like to thank our supervisor Pauline Belford for the guidance throughout the entire project. She has been very helpful and always answered all of our questions.

We would also like to thank Riksförbundet Ehlers-Danlos syndrom for their help with sending out our survey to their members. Without them we wouldn't have been able to get as solid of a base for the project as we got.

We are very thankful to our opponent, Simon Truvé, for giving us such thorough feedback and posing some thought-provoking questions.

Finally, a very special thanks to all our friends, family, peers, and teachers for supporting us throughout this project, and throughout our time at Chalmers. The knowledge and experiences we have gained these past few years will remain with us for a lifetime.

Johanna Lahti & Arielle Zaragatzky, Gothenburg, 2025-06-11

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Glossary

cEDS	classical Ehlers-Danlos Syndrome, the second most prevalent type of EDS
Comorbidity	A medical condition that coexists alongside a primary medical condition
EDS	Ehlers-Danlos Syndrome, a collection of 13 connective tissue disorders
hEDS	hypermobile Ehlers-Danlos Syndrome, the most prevalent type of EDS
HSD	Hypermobility Spectrum Disorder

1

Introduction

Video games are a type of media that has grown immensely in popularity over the past several decades. In the early years of video game development, games were simple and primitive due to limited storage space. However, with advancements in technology, today's video games are vastly different from before. Detailed graphics, expansive worlds, and immersive gameplay design have elevated modern games to a new level. Furthermore, video games can also be used as a medium for storytelling. *The Last of Us* and *Life is Strange*, for example, are known for their complex characters and captivating narratives. If done well, games can strongly affect its players emotionally and leave an impression for a long time.

Considering this, it may be possible to raise awareness about various issues through video games. One such topic is chronic illness. By raising awareness of what it can be like living with a chronic illness, especially an invisible one, such as Ehlers-Danlos Syndrome (EDS), it could lead to more understanding for people who are not chronically ill when they meet people who are. Raising awareness could also help show that not all struggles are visible to other people and you never know what someone is going through.

1.1 Aim

The aim of this project is to create a better understanding of life with chronic illness by using EDS as an example. This will be achieved by developing a computer game that follows the everyday life of a person with EDS. Throughout the game, the player has to make decisions that affect the various health levels of the main character. The purpose with this interactivity is to enhance the immersion. This will not only educate the player on the subject, but it may also encourage empathy in them.

1.2 Research question

Based on the defined context and aim of the project, our research question for this thesis is:

> *What are some of the ways a game can be designed to effectively raise awareness about living with chronic illness?*

1.3 Target audience

Since the purpose of the game is to raise awareness of EDS, the main target audience for the game will be people without EDS. Most likely, it will be for teenagers or older audiences so that they are old enough to understand the game and its contents. The game could catch the interest of people who already enjoy playing video games, more specifically story-based games like visual novels. Though, it may be of greatest interest to those who have already heard of EDS, but have little to no knowledge about it and would like to learn more. It could, for instance, be someone with a family member or friend who has been diagnosed with EDS, and they want to understand that person better. Perhaps the game could also be used to educate healthcare workers on EDS.

1.4 Limitations

This project will run over the span of approximately twenty weeks. This means that a clear plan has to be formed to understand what is feasible to accomplish within that time frame. Furthermore, as of now, our budget is rather small, meaning there are also financial limitations. That limits our options when, for example, choosing the software we will work with.

Another possible restriction is the human resources. Data gathering will need to be conducted to find more information on certain topics. We also want to run user tests with other people when a prototype of the game has been developed. One solution for finding willing participants is to contact specific organisations that can reach out to the correct target group. For example, *Riksförbundet Ehlers-Danlos syndrom* (the National Ehlers-Danlos Association) may be able to connect us with some of their members, so that we can gather information about EDS and how it is to live with it.

Furthermore, we understand that we will not be able to produce a polished, fully-developed game by the end of this project. Developing a game often involves many professionals from different fields, and can take a few months or several years [1] [2]. With this in mind, we are aiming to create a simple yet functional game prototype. It will likely be a rather short game, but enough to provide an adequate answer to the research question.

2

Background

2.1 Games to Raise Awareness

2.1.1 Relevant works

The possibility of immersive environments in video games means that they can be used as an additional tool when learning about pressing social issues by having a simplified yet dynamic scale model of reality [3] [4] [5]. Many so-called "serious games" are advanced and require hours of practice before the player becomes skilled at it, but serious mini-games have also been shown to effectively raise awareness [6]. Although we have not found any studies on EDS representation in games, there have been a multitude of studies focusing on other issues.

One study on the effectiveness of using video games to address the refugee crisis identified attitude changes in the participants after playing the games. Specifically, they identified a decrease in denial and an increase in empathy, which supports the idea that perception can be significantly impacted by immersive gaming experiences [3].

Another study focuses on games that address mental health conditions such as anxiety and depression in adolescents [7]. The results have shown that there are many serious games that touch on these issues, and that more research should be done in that area.

2.1.2 Game examples

Other than research, there are also some games that have been created with the purpose of raising awareness for various causes. Analysing each of these may prove useful for determining what makes these types of games effective.

You're just imagining it is a chronic illness simulation game. It is rather short, and the mechanics are simple. Your only goal as the player is to get a diagnosis. On the surface, this may seem like an easy task, but it soon proves to be complicated. Throughout the game, you go to different doctors, who each give you varying diagnoses and medications. Many of these doctors are dismissive of you. One claims that you are not eating well enough without even examining you properly, and only gives you vitamins. Another does not take you seriously when you ask if it could be a certain chronic illness, saying "you're just imagining it". At the same time, you

have to work to make a living, and to afford your appointments and medication. You also have to manage your pain and energy levels, as some tasks are unavailable if these levels are inadequate. After several years, you finally find a doctor who listens to you and helps you get diagnosed. Although this game is similar to the one we plan to make, it lacks in some areas. It does not mention comorbidities, or show any interactions other than those between the main character and the doctors. A more complex game, which takes these factors into account, may show a more realistic view of living with a chronic illness.

In *That Dragon, Cancer*, the story of a young boy named Joel Green was told. He was diagnosed with terminal cancer, and the game follows his four-year fight against this illness through various scenes. Although this game has a very linear story, the point-and-click mechanics offer an element of interactivity, which heightens the immersive feeling. The 3D graphics may also add to this immersion, as well as the clever use of colours and lighting. *That Dragon, Cancer* has received high praise. One reviewer states that "In That Dragon, Cancer, coping is a gameplay mechanic. The fact that it's difficult to do so is deliberate and appropriate." [8] The game is actually an autobiography, developed by Ryan and Amy Green to tell theirs and their son Joel's story. A reason why the game succeeds at evoking empathy in players may be that the developers themselves have lived through the story, and can tell it in a convincing way.

Spent touches on a different subject, but could still be worth exploring, as its purpose is still to raise awareness. In this game, the focus is on poverty. Your goal as the player is to get through one month, starting with only $1000. You have to find a job, pay off your loans and rent, and provide for a child. This quickly proves to be an arduous challenge. You are faced with many difficult choices, and are often forced to make sacrifices just to stay alive. This game was created by *Urban Ministries of Durham*, which is a non-profit organisation working to end homelessness by providing shelter, food, and other necessities to people in need. *Spent* aims to teach people what poverty is like by putting the player in that situation. The organisation is hoping to motivate people to donate or volunteer for their cause, as well as spread the word about its importance.

When examining these games, it becomes clear that they can be very different in terms of art style, mechanics, and the time needed to reach the end. This is interesting, as it could mean that there are many ways to educate players on a given topic and increase their understanding and empathy. Despite their differences, these three games have a couple of common denominators. First, they all qualify as "serious games". Unlike games that are only made for entertainment purposes, these games each carry a more serious message. Second, they all have a strong focus on eliciting emotions from their players. In *You're just imagining it*, the player is treated unfairly by several doctors, which can evoke feelings of frustration and despair. In *Spent*, difficult choices and sacrifices have to be made constantly. *That Dragon, Cancer* consists of many emotionally loaded scenes. It would be helpful to consider these similarities and differences when working on our project.

2.2 Games for storytelling

Although some claim that the first video game was produced in 1962, it is difficult to define exactly when video games first came around [9]. Early video games were very rudimentary due to limitations in disc space, display, and human resources [10]. Some of the oldest arcade games, like *Pong* and *Space Invaders*, are still well-known today.

However, with drastic technological advances, the nature of video games has also evolved [11]. Nowadays, there are large game development companies that create advanced games with stunning graphics, open-world exploration, elaborate gameplay mechanics, and complex stories and characters [12] [13] [14].

Games present a brand new way to tell stories. Unlike traditional forms of media, such as books and movies, video games offer a level of interactivity. The player can be given partial control over the outcome of the story. Based on the choices they make, the areas they explore, and the characters they choose to bond with, the player can unlock different paths that ultimately lead to different endings. This interactivity can heighten the sense of immersion, and make the player feel more responsible for the fate of the main character [15]. There is some scepticism around whether computer games can be considered a form of interactive storytelling, or if they are just explorable worlds [16]. When the player is given considerable freedom, the story that the game intends to tell may not be as evident. Though, restricting the player too much could reduce the immersion that interactivity offers. Perhaps a balance could be found between these two aspects.

Nevertheless, when examining various studies, it seems to be widely accepted among researchers that video games are capable of eliciting emotions from their players [17] [18] [15] [19]. In recent years, more game developers aim to make games with an emotional impact [11]. These emotions do not have to be positive, as even negative emotions in games are appreciated by players [20]. An example is the feeling of frustration and sadness that people often feel when a character they have grown close to dies. In the same study, it was also shown that emotionally difficult experiences in games can inspire players to reflect on various issues. Because of this, it may be possible to develop a game with the purpose of raising awareness for certain topics, such as EDS.

2.3 Visual novels

Visual novels are a type of storytelling media originating in Japan that use images, sound and text [21] [22]. They focus on narrative and often require interactions where players are able to impact the story in some way [23]. The interactions are usually in the in the form of options presented through text boxes. To progress through the story, the player has to click or press a button to see the next part [21]. Some prominent examples of visual novels are *Steins;Gate*, *Slay The Princess*, and the *Ace Attorney* games. Due to their ease of creation, distribution, and accessibility, visual novels are frequently used in academic research [24]. There has been some

debate on whether visual novels should be classified as a game or not [21], with definitions ranging from "interactive textbooks" to "adventure games with multi-ending stories" [24]. In our project, we have chosen to refer to visual novels as games.

One interesting topic that is relevant to visual novels is the study of *ergodic literature*. In his book *Cybertext: Perspectives on Ergodic Literature*, Espen Aarseth defines this term as literature where "nontrivial effort is required to allow the reader to traverse the text." [25]. This can refer to media such as hypertext and adventure games. The term *cybertext* refers to a type of ergodic literature, defined by Aarseth as "texts that involve calculation in their production of scriptons." This differs from traditional forms of literature where the author has full control over the narrative. Arguably, visual novels often fall under these categories, as they usually require the player to explore their surroundings and make choices to progress the story. Visual novels can also have branching narratives, meaning the story changes based on the player's influence. This element of decision-making can be challenging, especially if the choice presented is a moral dilemma, or if the choice could have huge consequences in the story.

Considering the ways in which ergodic literature and cybertext differ from traditional, linear storytelling, some potential pitfalls in our project need to be addressed. In a more traditional non-interactive medium, where the author tells a story directly to the reader, there is little room for deviation from the plot line. Thus, the author can send a clear message to their readers. However, in media such as visual novels, the reader (or player) has partial control over the outcome of the story. Because of this, it may be more difficult to convey information to the recipients in this type of media. As the purpose of our game is to educate people about EDS, it may be detrimental to our cause if we allowed the players too much freedom. Doing this could risk shifting the player's focus away from the message we are trying to deliver. Though, as mentioned in Section 2.2, interactivity can enhance immersion and heighten emotions. By letting players explore and make their own choices in a game simulating what life with EDS is like, it may create a better understanding of the illness than a non-interactive platform could.

3

Theory

3.1 Chronic illness

Chronic illness is the lived experience of those with long-term bodily or health disturbance, such as diseases, conditions, syndromes, or disorders, and how they live and cope with said disturbance [26]. This definition differs slightly from that of *chronic disease*, which only refers to the biomedical disease classification, while *chronic illness* also includes social and emotional effects. The principle of patient-centred care does not just focus on treating the disease itself, but takes into account the specific patient and their socioeconomic status, status of employment, etc.

3.2 The Ehlers-Danlos syndromes

Ehlers-Danlos syndrome is a collection of connective tissue disorders characterised by joint hypermobility, skin hyperextensibility, and tissue fragility [27] [28] [29]. There are thirteen subtypes, with hypermobile EDS (hEDS) being the only one without a known causative genetic variant [30].

Although hEDS is the most common type with an official prevalence of 1 in 5000, which is classified as a rare condition, experts believe it has a higher prevalence. After the term joint hypermobility syndrome (JHS) was dropped after 2017, those who were diagnosed with JHS are now described as having either hEDS or hypermobile spectrum disorder (HSD). JHS had a prevalence of about 1 in 600 to 1 in 900, which means the combined prevalence of hEDS and HSD is likely around 1 in 600 to 1 in 900, it is however not possible to say the prevalence of each of these conditions since it has not been studied yet [31]. However, a recent study has shown evidence supporting hEDS and HSD being classified as the same disorder [32]. This would mean that hEDS would no longer be classified as a rare condition. Despite this, there is very little awareness of EDS among the general public [33], and even among healthcare professionals as it takes on average 10-12 years for people with EDS to get a diagnosis [34] [35] [36].

In contrast, classical EDS (cEDS), while being the second most common type of EDS, has a prevalence of about 1 in 20,000. It is however believed that those with milder manifestations may go undetected as they do not come to medical attention so the prevalence may be higher [37].

Throughout this paper we use person-first language (e.g. person with disability) rather than identity-first language (e.g. disabled person) when talking about people with EDS. While identity-first language is often preferred by the disability rights community [38], there's no satisfying or specific way of using identity-first language for EDS. EDSer feels clunky, and while zebra is often used by the EDS community [39], it comes from the saying "When you hear hoofbeats behind you, dont expect to see a zebra." which refers to rare illnesses and disorders in general rather than specifically EDS which could lead to some ambiguity.

3.3 Research through design

Developing a game in order to research a subject falls under the definition of *research through design*. This is a methodology where an artifact is designed in order to explore possible solutions and generate new knowledge [40]. Rather than being used to test existing theories or seek concrete answers, research through design is used to discover new possibilities. Theories produced by this method are often provisional and aspirational, meaning they are not definitive, but rather aim to inspire future work. This is precisely our goal with the game we are creating. Our research question is a wicked problem, which requires a method like this to find possible solutions [41].

3.4 Ethical considerations

When gathering data about individuals, for example through surveys or interviews, it is of utmost importance to consider their privacy. In the scope of our project, the people of relevance are individuals diagnosed with EDS. The data collected from these people will mainly concern their medical history, symptoms, personal lives, and relationships. This is sensitive information, which can lead to dangerous consequences if misused. Therefore, several ethical considerations are made when gathering this user data.

Firstly, the data collected should be anonymised. Any information that can be used to identify individuals, such as names and addresses, should not be distributed to any third parties. The potential data that will be presented in this thesis, in the form of survey results or personal stories, will be anonymised. Secondly, we need to decide how the data collected will be used. To prevent distribution of the information, it should only be used within this project, specifically as a guideline for what to include in our game. All the sought information will be directly relevant to the project. Lastly, it is important to inform all user study participants about how their data will be used, and how their sensitive information will be protected.

4

Methods and Tools

To explore this topic and try to answer the research question, we need to follow a design process model. There are two options that may be relevant to us: the Double Diamond model (see figure 4.1), and the Game Development process [42]. The first one is commonly used within the field of interaction design to design solutions to specific problems. It contains four stages: *discover*, *define*, *develop*, and *deliver*.

- **Discover.** Firstly, the subject in question is researched. The purpose in this phase is to find as much information as is needed to properly understand the scope of the problem. Oftentimes within interaction design, the problems to be solved are so-called *wicked problems*, which do not have a clear answer and therefore no one way to find a solution [41].
- **Define.** Secondly, once the needed information is found, it is analysed in order to define the problem. This is helpful for designing a solution later. The analysis can be conducted in a variety of ways depending on what data gathering methods were employed in the previous step.
- **Develop.** Thirdly, the development stage is reached. This is where the creation of a solution is attempted based on the needs previously found.
- **Deliver.** Lastly, there is the "deliver" stage, a.k.a the evaluation. Here, the developed artefact is tested in order to determine whether it can solve the given problems. If possible improvements are discovered, these can be implemented before testing the product again.

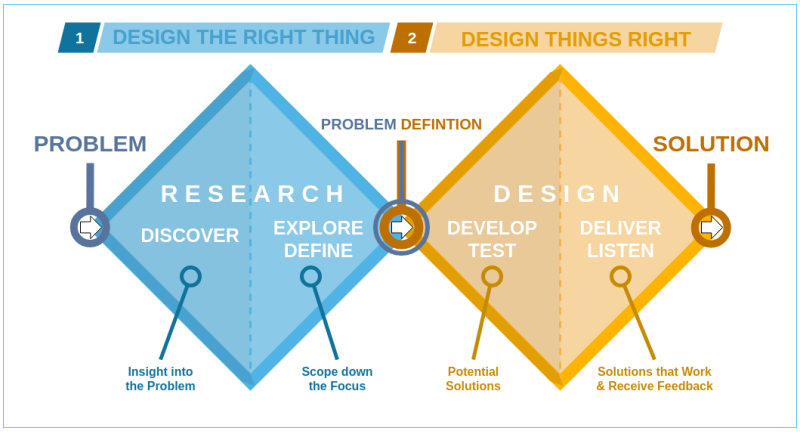

Figure 4.1: The Double Diamond model.

As our goal is to create a game, we may also benefit from partially following the Game Development process [42].

- **Pre-production.** This initial phase includes research and ideation. The market is studied and a target audience is determined. Ideas are formed and envisioned through various means.
- **Production.** Here is where the game itself is developed. A simplified prototype is usually created and tested first. Then, the full game is made through asset creation, coding, and level design. Before moving on to the next stage, the game's quality is tested.
- **Post-production.** This is where the final optimisations are made to the game. This can include improving the controls or removing unnecessary elements. Tests are conducted here as well, and multiple iterations of game polishing may be needed.

4.1 Data gathering

4.1.1 Literature Review

A literature review is conducted by finding relevant literature such as articles, papers, and books, and summarising and evaluating them. This is done to get a better understanding of what the knowledge of the topic currently looks like and where the knowledge gaps are. This will act as starting point for what needs to be found out through other data gathering methods in order to fill those gaps while using the literature as a basis for the other parts [43].

4.1.2 Survey

Surveys are a set of questions that are sent out to a larger group of people, either digitally or on paper, in order to gather quantitative data. It is preferable that many or all questions are multiple choice questions as the longer the survey is and the more people have to write in the survey, the less likely they are to answer it, and since the main purpose of a survey is to collect quantitative data, it is preferable to get as many answers as possible to get a statistically significant result [44].

4.1.3 Interviews

Interviews are meetings with users or experts with the purpose of gathering qualitative data to give a deeper understanding of a certain topic or area. There are different levels of structures for interviews that have different advantages and disadvantages depending on the situation for when they are used and what you aim to achieve with the interviews. There are structured interviews where there is a set of questions that each interviewee will be asked with little to no difference of questions between each interviewee. There are unstructured interviews with little to no pre-determined questions, instead the interviewer has some general or specific

things they want to explore or find out and decides what questions to ask based on what the interviewee answers. Then there's semi-structured which is a cross between structured and unstructured interviews with a set of general questions and freedom to alter the questions or add or remove questions based on the interviewee's answers [45].

4.2 Analysis

4.2.1 Needs Analysis

A needs analysis is a way of figuring out the users needs which can then be used when designing since you know what needs need to be fulfilled. When performing a needs analysis it's important to look for needs rather than solutions since that would close off the possibility of other solutions that might work better [45].

4.2.2 Statistical analysis

Statistical analysis can be applied to quantitative data to find certain trends and patterns in large amounts of information [46]. Data can be visualised in charts and tables. This is a practical way of finding correlation between different types of data. For example, in a survey, it can be discovered that many people with a specific attribute also share some other trait.

4.2.3 Thematic analysis

Thematic analysis is a common method for qualitative data, and can be used to find patterns and themes [47]. To conduct a thematic analysis, the data is carefully examined to find recurring themes. These can then be categorised to find patterns.

4.2.4 Narrative analysis

Narrative analysis is a method applied to qualitative data [48]. Information is collected from people, often through interviews, which is then used to formulate stories. The main purpose of this method is to better understand the lives and experiences of other people.

4.3 Design & Development

4.3.1 Personas

A persona is a fictitious person that represents the target group based on the findings from the data gathering process. It can be helpful to have a specific person in mind when designing something rather than trying to design something for everyone, this is when personas are helpful [45].

4.3.2 Scenarios

A scenario is a situation in which a user uses or interacts with the design. This can be either the current situation of how the user interaction looks, or a future scenario using the persona to show how an ideal interaction with the design would look. This can be useful by taking the design out of the bubble of existing without context and placing it in a context of how it would actually be used and affected by other aspects such as if the user is doing other things at the same time or what is happening around the user [45].

4.3.3 Brainstorming

Brainstorming is a method of idea generation where the goal is to generate as many ideas as possible. During a set amount of time you write down or draw as many ideas as possible regarding a certain topic. Since it's more about quantity than quality, it is important to not critique anyone's ideas during the idea generation process, that can be saved for when it's time to evaluate the ideas and choose a few to continue with [45].

4.4 Evaluation

4.4.1 Heuristic evaluation

Heuristic evaluation is used to find usability problems in a user interface. This is done by having evaluators judge how well it complies with recognized usability principles. A heuristic evaluation is useful for finding major problems as it has a higher probability of major usability problems than minor usability problems [49].

4.4.2 Usability testing

Usability testing is used to ensure that interactive systems are effective, efficient, and favour positive attitudes from the users. To do this, there are three standard approaches when it comes to evaluating user interfaces, those are *Inspection-*, *User-*, and *Model-Based Evaluations* [50].

4.4.3 Participant Observation

During a participant observation, you observe the participant use or interact with the design in order to see how they use it, if there are any unexpected interactions, etc. During the observation, the participant is asked to narrate what they are doing and explain their thought process as this can be helpful in understanding the participants experience of the design, as well as catch the reason for any difficulties they might be having. This is useful since it shows problems you might not have noticed while designing since the participants are coming in with a new set of eyes that are not biased by designing it and already knowing how everything works [45].

4.5 Tools

To create a game, a game engine is usually needed. There are many alternatives on the market, with each engine offering different features and advantages. After searching and examining various game engines, we narrowed our options down to two alternatives:

- **Ren'Py.** Ren'Py is a Python-based game engine that is specifically designed for making visual novels [51]. It is free of charge, even for commercial use. The language and functions can be learned quickly. Creating characters, dialogue, and branching stories is easy and intuitive in this game engine. One downside with Ren'Py is that non-visual novel elements will require coding in Python. This should not be much of a problem, however, since Python is also a rather easy programming language, and both of us already have experience with it.
- **Unity.** Unity is a popular game engine that is widely used by indie developers as well as large companies [52]. It has a free plan, which still offers many features. Its base programming language is C#, which is general-purpose and an industry standard. Unlike Ren'Py, it is rather versatile and can be used to develop a large variety of games. However, as a result of this adaptability, it is also more difficult to learn.

Another tool that can be helpful in this project is *Miro*, a collaborative online platform that can be used for project planning and design work. In Miro, users can create and share boards, and edit them together with collaborators in real-time. We could, for instance, use Miro to sort and analyse data from user studies.

5

Process and Execution

In this chapter, the project work we have done will be described in detail. First, the data gathering phase will be explained, including the survey and interviews. The results will then be examined through statistical and thematic analysis. Then, the game development phase is explained. It consists of an early design, followed by a pilot study, and then the final development. Lastly, the evaluation phase is described, as well as the modifications made to the game after each round of play testing.

5.1 Data Gathering

5.1.1 Literature Review

The first step was to gather information on the most necessary topics. We had a brainstorming session to figure out the topics we needed to read up on to give us an understanding of what has already been done and give us a starting point for the project. We found that the main topics we wanted to review were chronic illness and Ehlers-Danlos syndrome (EDS), games as a tool for storytelling, and games as a tool for raising awareness. Once we had decided on the topics, we went on google scholar and searched for related keywords. First we collected any sources that might be relevant in any way, and then we went through those sources to check which ones might be more relevant for our project and highlighted the most relevant ones to have a starting point for which ones to read first. After that we started writing and looking up more sources when relevant.

5.1.2 Survey

In the data gathering phase, our goal was to collect knowledge that would be relevant for the game we were going to create. In our case, we needed to learn about EDS, and understand the experiences of people who live with it. This is because we wanted our game, for the most part, to accurately portray the reality of living with this illness. One of the data gathering methods we used is a survey. Its purpose was to collect quantitative data from a large group of participants. This could then be analysed statistically to find answers to our questions. To facilitate the following data analysis and to keep the survey short and simple for participants, most of the questions were either checkboxes or multiple-choice. Though, we still had to ask

some questions which required written answers, and therefore a different analysis method.

It was important to us to ensure that all participants really were diagnosed with EDS, to prevent fraudulent responses that could skew the results. To do this, we contacted *Riksförbundet Ehlers-Danlos syndrom*, the Swedish national association for people with EDS. We explained the purpose of our project to the association's committee, and they responded positively, agreeing to send out the survey to their members. However, they first requested that hypermobility spectrum disorders (HSD) be added to the survey, as many of their members have that diagnosis. This was easily done.

5.1.3 Interviews

In addition to the survey, we also used a more qualitative method to collect relevant data. Unlike the quantitative approach of the survey, this method focused on a smaller pool of participants but explored certain topics in more depth. It was helpful for planning the plot and characters in our game. Although the statistical approach of a survey was beneficial for discovering common forms of EDS and symptoms which can be applied to the game, it didn't provide as much insight into the thoughts and feelings of people with EDS, although some participants of the survey gave long and insightful answers to the questions which required written answers. If only the survey was utilised for shaping the story in the game, there would have been a risk of creating shallow characters and oversimplified plot lines, which in turn may not spark as much empathy in players.

The qualitative method chosen was interviews. We met with a handful of people with EDS who agreed to participate in interviews in the survey, and asked them questions that require a more nuanced and elaborate answer. We used a semi-structured interview format, since it let us prepare a set of questions we wanted answers to, as well as allowed for some deviation to focus more on certain discussions. Some of the questions we asked are:

- What does an average day look like for you?
- What does a bad day look like for you?
- What helps you get through the day?
- Describe your close relationships (e.g. family, friends, etc.)
- Do you feel that people have misconceptions about EDS? If yes, what are they?

One important note is that the participants' privacy was a top priority in both the survey and interview. When collecting data from people, it is crucial to protect it from outside parties. In our case it was especially important, since we collected information about people's medical conditions and history, which is sensitive information. The information will only be viewed by us, our supervisor, and examiner. Participants were not required to give their personal information, such as name and

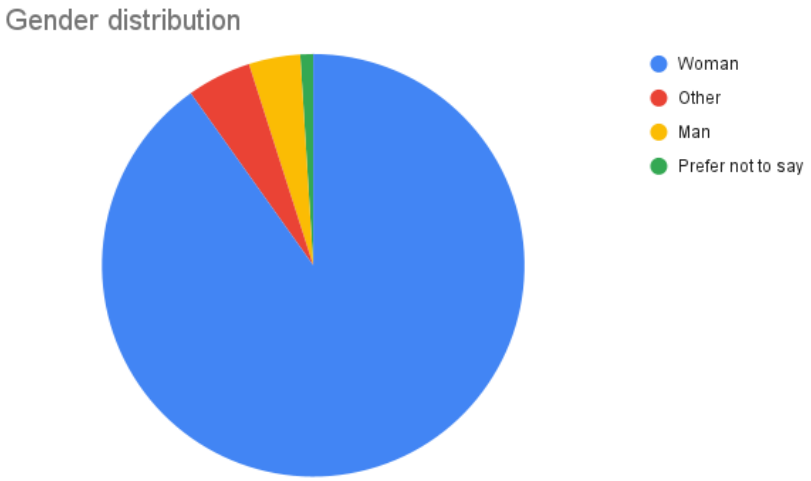

Figure 5.1: Gender distribution of survey respondents

email address. We put this as an optional question in the survey, so that we could contact people who were interested in an interview or user testing, but we made it clear that the question was not mandatory.

5.2 Data Analysis

This next stage focused on analysing the information gathered from the survey and interviews. As these methods of data collection are rather disparate, they needed to be examined in different ways.

For the survey we used two main methods of data analysis depending on the type of answer. For the multiple choice answers we created suitable graphs to visualize the results, for example pie charts for type of EDS and bar graphs for comorbidities. This helped us quickly and easily see the stats for who answered the survey and what the most common comorbidites were etc. For the written answers we read through the answers and highlighted the most common statements, similarly to a thematic analysis, which helped us quickly and easily see how many people mentioned certain symptoms etc.

The survey received 203 responses over the course of one week. Out of those 203 respondents, the most common types of EDS were hypermobile EDS (hEDS) with 65% (132), HSD with 18.2% (37), and classical EDS (cEDS) with 12.3% (25). When asked about comorbidities, only 1.5% (3) reported that they don't have any comorbidities, and out of the respondents who have comorbidities, 93% (186) have more than one comorbidity.

When analysing the responses about what symptoms affected them the most on an average day, some symptoms were mentioned much more than others. Out of 203 responses, 166 (81.8%) mentioned some form of pain. Several people brought up general pain, but the most common areas mentioned were joints, muscles, head,

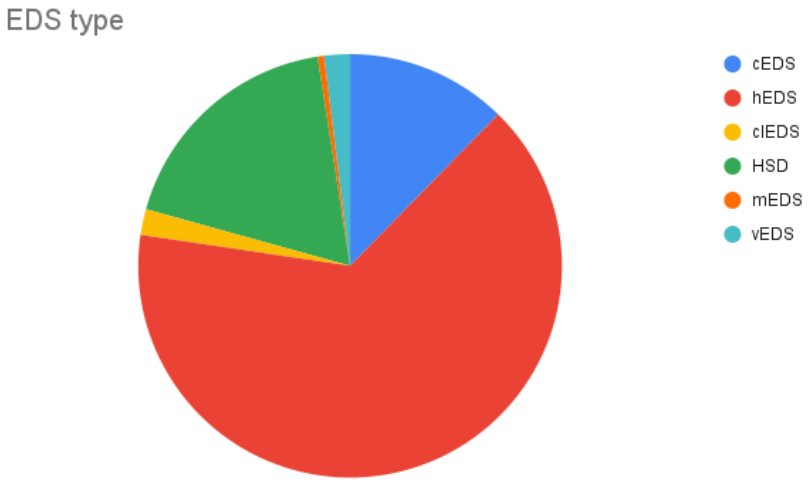

Figure 5.2: Distribution of EDS type of survey respondents

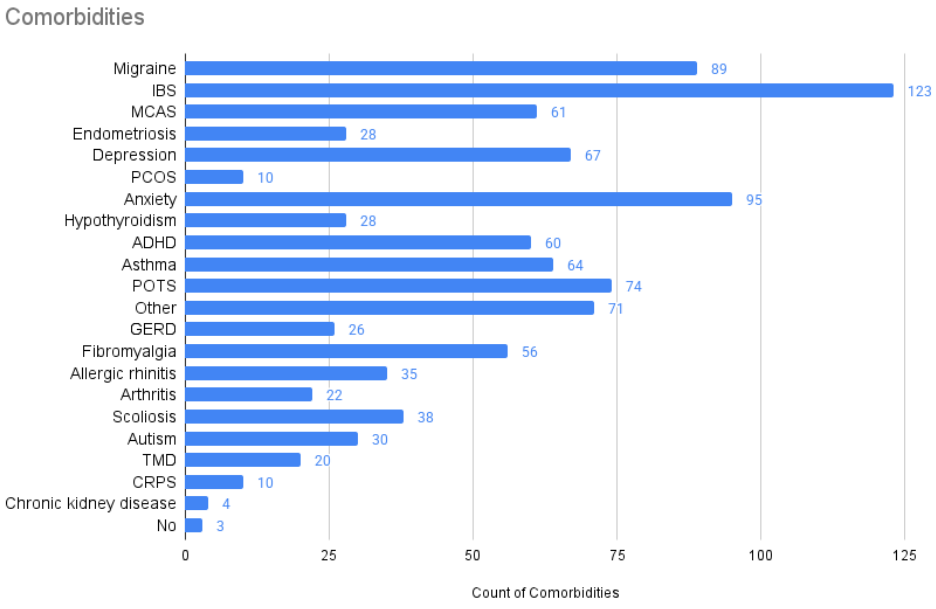

Figure 5.3: Prevalence of different comorbidities among survey respondents

stomach and limbs. Furthermore, 119 (58.6%) respondents stated that they suffered from fatigue. Some mentioned physical and mental fatigue separately, but both of these were brought up by multiple people. Other common symptoms were brain fog, sensory sensitivity (both to light and sound), stomach problems, subluxations, difficulty swallowing food, incontinence, reduced balance, and poor temperature regulation.

When asked what they would like to see represented in the game, pain and fatigue were also brought up here. Specifically, many respondents pointed out how their muscles have to work harder to compensate for their loose connective tissue. As a result, any activity requires energy, even sitting down. This has led many of them to run out of energy early in the day, for example after taking a shower in the morning. Interestingly, multiple respondents mentioned the *spoon theory* when discussing this topic. The *spoon theory* is a metaphor often use to describe how people with a chronic illness have to ration their energy usage [53]. Several respondents also explained that social interaction can be very draining, more than some people think. Sometimes they have had to cancel social events on short notice due to their symptoms suddenly worsening. These are some things that many wanted to see in the game. Furthermore, several people mentioned that EDS can express itself in many different ways, meaning that there is no singular way to represent the illness. This is something that people without EDS may not understand, so the respondents wanted this to be clarified in some way in the game.

Other than the medical aspects, many respondents also discussed EDS from a social perspective. A common problem is that many people do not understand EDS, or are misinformed about it. Some people do not believe that a person has a chronic illness when it is invisible on the outside. This can lead to misconceptions about the illness, for example that the pain is not actually that bad, or that the affected person is just imagining the symptoms. This is not just prevalent in the general public, but also in healthcare. Several respondents described how difficult it has been at times to receive help since many healthcare workers have little to no knowledge about EDS. Some have been met with scepticism when describing their symptoms to doctors and nurses.

For the interviews we did a thematic analysis as it gave us the best overview of what got mentioned a lot by different people and what was mentioned less. This helped us notice patterns and common themes which we could use when designing the game.

Out of the 9 people we interviewed, 5 had hEDS, 2 had cEDS, and 2 had HSD. When asked about how they experience other people's perception of EDS, all nine participants mentioned that a lot of people don't know about EDS or what it is. Some of those who know about it often think it's "just" hypermobility and don't understand the problems it causes. Some people think that hypermobility is a positive trait. As one interviewee told, she has been asked questions like: "Isn't it good to be flexible and agile?" All but one of the participants mentioned that this lack of knowledge is true even within healthcare with doctors not always knowing what EDS is. When describing a normal day, four of the participants mentioned

that there is no such thing as a normal day for them since every day is different depending on which symptoms are worse or better. To quote one interviewee, when she is asked how she feels today, she tends to answer: "Like a roller-coaster." Three of the participants mentioned struggling with feelings of guilt and shame over not being able to do things other people are able to do. Another common theme among the participants was struggling with socializing since they find that it requires a lot of energy.

5.3 Game Development

After analysing the data gathered from the survey and interviews, the next step was to start developing a prototype for the game. Given the time and resources we had, the most reasonable expectation was to create a high-fidelity prototype with certain limits. This would mean creating a fully-functional game that people can play on their own, but without the expected quality of a finished game, which might include advanced graphics and multiple minigames.

5.3.1 Game Design Document

Firstly, a plan was needed to ensure that our goals were feasible within the given time frame. As described earlier, a Game Design Document (GDD), which can be found in Appendix E, was created with the purpose of storing all ideas in one place, as well as ensuring that both of us had a shared understanding of what needs to be done. This document consisted of multiple sections, including a general overview, story, visuals, audio, and gameplay.

- **General overview.** This part presents the core aspects of the game, such as its purpose, target audience, and structure. The game is described as a visual novel, mainly for people who want to learn about EDS, but also for those who simply enjoy visual novels but have little to no knowledge of EDS.
- **Story.** Here, the main story told in the game is outlined. The plot summary describes the length of the game, as well as its "levels" (the levels, in this case, are days in the game). The structure of each day is defined. Furthermore, there is a list of characters or types of people that can appear in the game. There are also examples of choices the player can be faced with, e.g. whether to eat breakfast or not, and notes about how the player's energy, pain and morale is affected by different choices. Finally, some ideas for game endings are given.
- **Visuals.** This section includes all visual aspects of the game, such as backgrounds, character models, and the GUI. There are links to asset packs, and some concept sketches.
- **Audio.** This is where all audio is planned, both background music and sound effects. There are links to sites with royalty-free sounds, as well as examples of some tracks that can be used in the game.

- **Gameplay.** Here, the gameplay features are described, such as the game controls. Since our game will be a visual novel, the controls should not be too complex. It could be possible to incorporate some minigames into the main game.

One of the first steps was to decide which game engine would be most suitable. As mentioned, our game will be a visual novel, which includes branching narratives based on the decisions the player makes. There will be different endings. With this in mind, we returned to the two alternatives presented in Section 4.5 - Ren'Py and Unity. After some discussion, Ren'Py was chosen for this project. Considering the ideas presented in the GDD, this game engine was a good match for our project. As this game engine was especially developed to make visual novels, it would not be too difficult for us to create the game we have visualised in it.

A central part of the gameplay is the main character's health. The player must think through their choices carefully to keep the overall health up. Although many computer games incorporate a singular health bar to represent a character's health level, we realised that this would be too simplistic for our game. As many of the responses to our survey and interviews indicated, there are a multitude of factors affected by EDS. To implement this in a realistic yet feasible way, four variables were defined:

- **Energy.** This was one of the most frequently mentioned keywords in relation to EDS. Many with EDS struggle with fatigue, so we consider this to be a crucial factor for the game. As described in Section 5.2, the respondents of the survey brought up both physical and mental fatigue as common parts of their lives, and while there may be some overlap between the two, these feelings are distinct from each other. However, we felt that it would be difficult to determine the exact effects of various actions on the physical and mental energy, so we decided to create a single variable to represent both.
- **Pain.** Pain is also a common struggle related to EDS. Participants of the survey reported pain in their joints, muscles, stomach, head, limbs, and other parts of their body. This variable represents all forms of pain caused by EDS.
- **Morale.** This variable tracks the general mood of the main character. Various symptoms of EDS can directly affect a person's morale, but the effects can also be indirect, for example if they have to cancel a social event due to pain or tiredness.
- **Money.** The financial perspective is also important. Several participants of the survey/interviews have brought up how it is difficult or even impossible to work full-time. Some are on long-term sick leave. There are also the costs of doctor's appointments, medicine and physiotherapy to consider.

5.3.2 Development of early prototype

To start with the development of the game, a new project was created in Ren'Py. It was given the suitable name of *Ett spel om EDS* ("A game about EDS"). The next

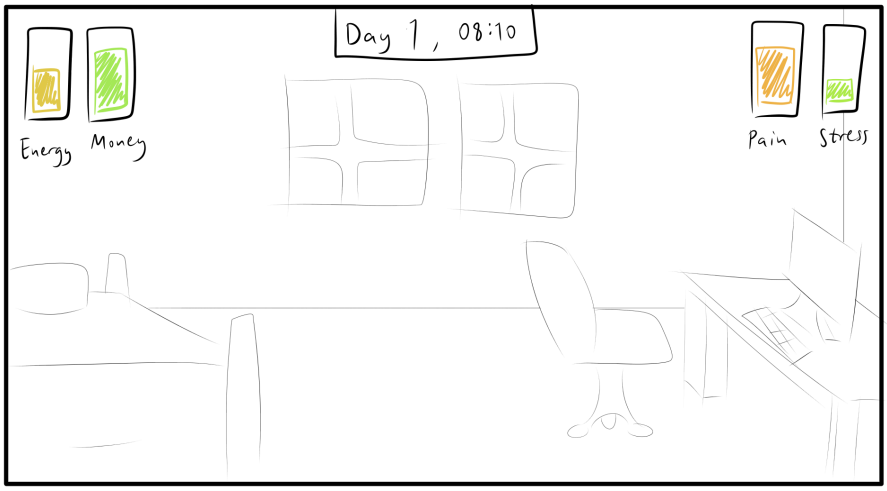

Figure 5.4: Concept sketch of bedroom with bars.

step was to pick the resolution of the project. As there was no specific preference for this, the default value was chosen, which was 1920x1080. This is a standard screen resolution, also known as *Full HD*. Since it is rather common, it made the most sense to create our game with that resolution. Next, the accent and background colors had to be selected. Ren'Py automatically creates many of the necessary assets for a visual novel, including a basic main menu, game menu, and navigation bar. A simple blue colour was chosen without much reasoning, as the colour can easily be changed later. Besides, we wanted to focus mostly on the game itself before concerning ourselves with the design of the GUI.

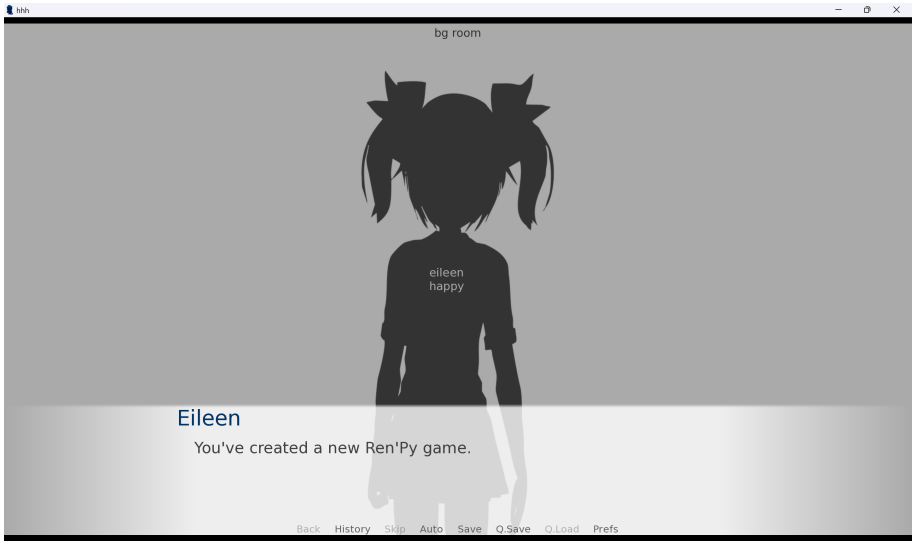

Figure 5.5: What is shown when a new Ren'Py project is launched.

The only part of the UI that was changed at this time was translating the various options from English to Swedish. This was more fitting, as we decided to make a Swedish game. The parts that were translated were the main menu and game menu.

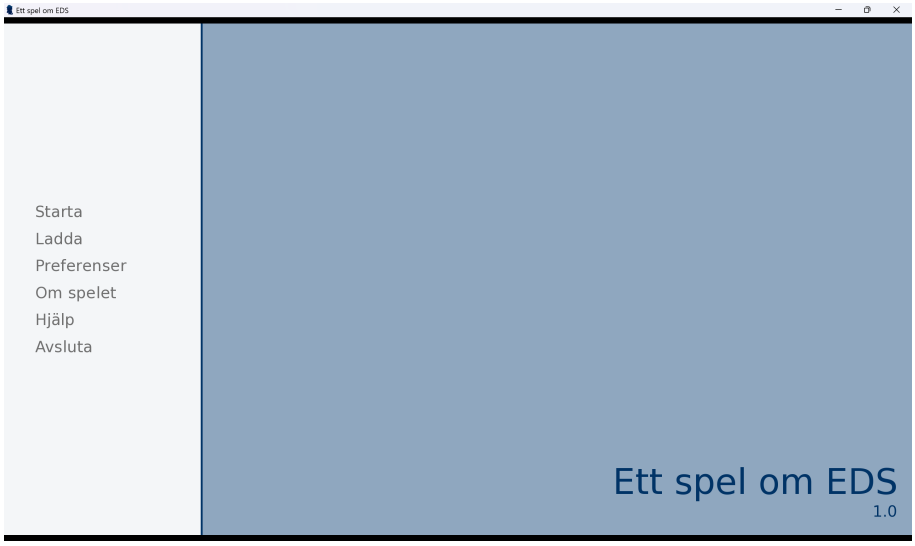

Figure 5.6: The translated main menu.

Once the Ren'Py project was initiated, the script-writing process began. Day one of the game was mostly meant to introduce the player to the game, its controls, and the mundane choices that had to be made throughout the day. The four variables were introduced, i.e. energy, pain, morale and money, which were described in section 5.3.1. They were randomised, within specified limits, at the start of the day. The randomising was meant to represent the unpredictability of EDS. Although the person affected has some control over their energy and pain through the choices they make, it is impossible to know exactly how they will feel when they wake up every morning. The range of the variables was limited to ensure some level of fairness for players, so the difficulty of the game is roughly the same for everyone.

These are some of the choices the player is faced with during the first day:

- Staying in bed for a little longer or getting up right away.
- Taking a long shower, a short shower, or skipping the shower entirely.
- Eating or skipping breakfast.
- Bringing lunch or not.
- Driving or taking public transport to work
- How to spend your break at work (talk to colleagues or stay at your desk)
- What to eat for lunch and where
- Whether to take fika or not
- How to fix dinner
- What to do during the evening (clean, watch TV, etc.)

Because this day mostly acted as an introduction to EDS and the game mechanics, it did not contain much of a narrative. However, the next day was written somewhat

differently. Although the main structure of day two was the same as day one, there was now a possibility for the player to get injured when doing various physical tasks. For example, the main character could subluxate (partially dislocate) their shoulder when taking a long shower. This was implemented to show how EDS can often cause injuries in regular situations, which is something most people do not have to worry about. Another difference between day one and two was the calculation of the variables. Just like at the start of day one, the energy, pain and morale were randomised within limits in day two. Though, these limits were moved based on the energy level the player had at the end of the previous day. If they went to bed with low energy, they were more likely to wake up with medium-low energy and morale, as well as medium-high pain. This mechanic shows that the decisions you make in the game have consequences for your health, as is the case with EDS. Other than these additions, day two had new dialogues in the break room at work and when chatting with someone in the evening.

In the break room, the player gets to hear conversations between some of their coworkers. These are casual workplace discussions, for example about what they did during the weekend. Their purpose is not to teach the player about EDS, but to offer a break from work, which can boost the main character's morale. Unlike these conversations, the evening chats are more personal to the main character and delve more into EDS. The first day, the player can chat with a friend of the main character. They talk about recent happenings in their lives, with the main character bringing up how tired they have been recently and some of their healthcare history. The friend is kind and supportive, so the player's morale goes up after the conversation. The second day, however, the player can chat with the main character's aunt instead. This aunt turns out to be much less understanding, claiming that the diagnosis is fake and is just an excuse to work less. This conversation lowers the player's morale. It is meant to reflect the experience of being met with disbelief and ignorance, which is something that many people with EDS have personal stories about.

After the script for the first two days was developed, some additions needed to be made to the UI, specifically the way the day, time, health and money variables were displayed. In Ren'Py, features like these are implemented as *screens*. Screens contain visual elements, and can be hidden or shown. Multiple screens can be shown at once. Some examples of default screens in Ren'Py projects are the say screen (to display dialogue), the choice screen (to show choices the player can make), and the quick menu screen (displayed constantly in-game at the bottom). As such, one screen was created for displaying the time and day in the game, while another was made for the variables. At this point, we were not sure how we wanted to show the variables. One option was to implement bars to represent each variable. While this is commonly seen in computer games, and could therefore be intuitive for players, we were also unsure how to do this in Ren'Py. A second option was to display the numbers directly. The range for the energy, pain and morale was 0-100, so they could be shown as percentages. This is what we did at this point in time, since it was easier to do than the bars. We also implemented colour changes for the texts based on how high/low the values were. Finally, to make it easier to see how a variable changes during the game, a coloured square appears for a second next to

Figure 5.7: The variables were displayed as coloured text.

the affected variable. For example, if the player makes a choice that lowers their energy, a red square will appear next to the energy value. Similarly, if their energy goes up, the square that appears will be green.

The day-and-time calculation was a bit more complex. We could not simply display the values for the hour and minute, since it turned out as *8:0* instead of *08:00*. To fix this, we created a function that takes the number as input, turns it into a string, puts a zero in front of single-digit inputs, then returns it. We wanted the possibility to change the time easily from the script by adding a specified amount of minutes. This would be useful for calculating the time based on the player's choices, such as taking a long/short shower or skipping the shower. This is the function for that:

```
# calculates the new time of day given how many minutes have passed
def time_calc(plus_mins):
        global minute, hour
        x = minute + plus_mins
        minute = x % 60
        hour = int(hour + x / 60)
        if hour >= 24:
            hour = hour - 24
```

We also needed some backgrounds to distinguish the areas in the game. We drew some simple background images of various necessary areas, including the bathroom, kitchen, bus stop and office.

5.3.3 Pilot study

At this point, we had a functional mid-fidelity prototype. It had a complete script for the first two days, four game variables that were generated and displayed, the time and day calculation, and some temporary backgrounds. At this point, we wanted to test the prototype to make sure we were on the right track, had not missed any major

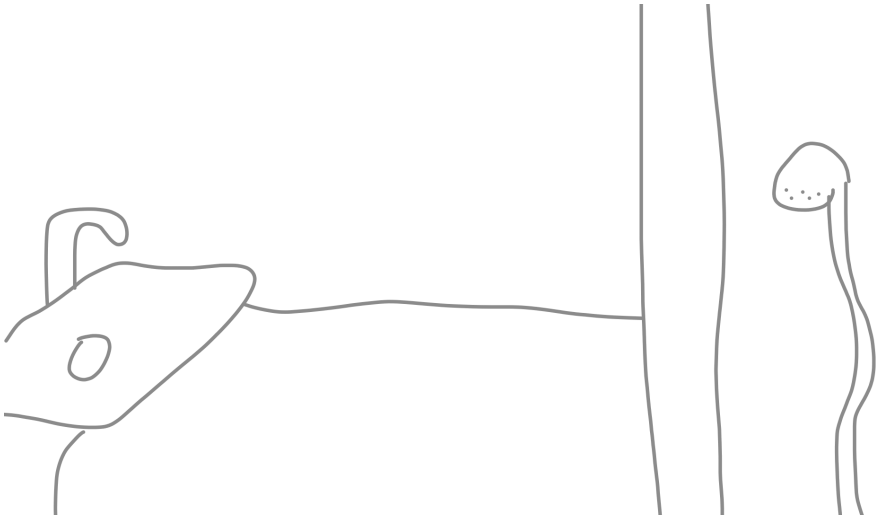

Figure 5.8: Concept background sketch of bathroom.

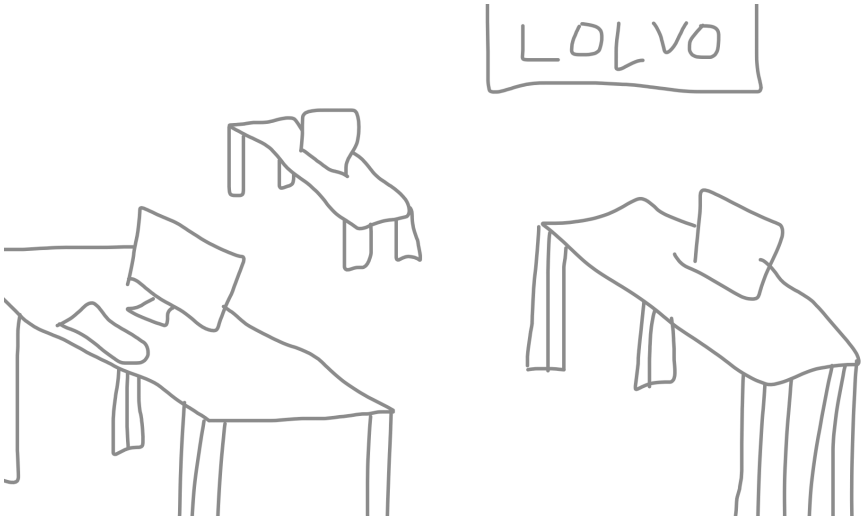

Figure 5.9: Concept background sketch of office.

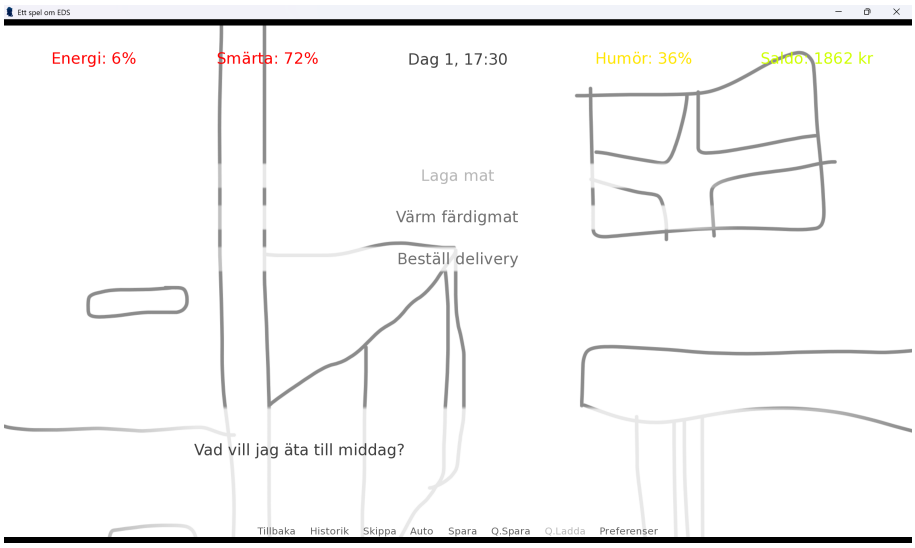

Figure 5.10: When you are too tired to cook dinner, that option is "greyed out".

errors, or made anything too confusing. Additionally, this was also an opportunity to practice evaluating the game, to learn what we wanted to show and ask during the final user tests. Specifically, the attributes we wanted to examine were the game controls and the dialogue. Since this study was meant to be quick and approximate, we only performed the test on two participants.

We asked them to play through the game while thinking out loud, and then we asked them some questions about the experience. The tests showed no major oversight or error in our early prototype. However, we received some valuable feedback on what could be improved.

One point that was brought up when discussing the dialogue was that it could be more detailed. The effects of some choices were unclear, particularly why they had the consequences that they did. Another aspect that caused some confusion were the unavailable options. At this point, whenever the main character was too tired or in pain to make certain choices, those options were "greyed out", meaning they could not be clicked on. An example of this is seen in Figure 5.10. To improve this, we decided to add more elaborate dialogue, especially after making choices, to explain to the player why a decision had a certain effect. Furthermore, rather than immediately "greying out" unavailable choices, we got the idea to leave those options open, but if the player picks them, there is a dialogue that explains why the choice is inaccessible. For example, if the player does not have enough energy to go grocery shopping, clicking that option would give dialogue like "I'm too tired to go out right now." Then the player would be shown the same choice screen again, but with grocery shopping "greyed out".

Another feature that could be refined was the injury risk in day two. At this time, the player could only get injured if they chose to take a long shower in the morning, cook dinner, or shower in the evening. Moreover, the risk of injury for each moment was only one in five. Due to this, and the fact that the player can entirely avoid risk of injury by not picking those options, the total injury risk was very low. One reason

Figure 5.11: You can choose to "borrow" energy from the next day if you run out of energy.

for why we programmed the game like this was to make it more realistic, since not many people with EDS get injured every day. However, we realised that we would have to abandon some of this realism in order to improve the game. Since the game was only planned to have three days, it was already limited when it came to showing an accurate depiction of life with EDS. Our solution was to add more opportunities to get injured in day two, with at least one of the opportunities being unavoidable through choices. The risk for several of these injuries was also increased. Due to these changes, it would be somewhat likely for the player to get injured more than once during day two. Since this is not very realistic, and could also make the game too difficult, we fixed the code so that the player can only get injured once. If they encounter an injury risk but are already injured, that part of the code is skipped.

5.3.4 Refining the prototype

In this stage, the development of the prototype was continued based on the feedback described in section 5.3.3, as well as our own notes in the GDD. The goal was to create a visual novel with proper backgrounds, character models, music and sound effects. It would also show three days in the life of someone with EDS.

An important question that came up was about what happens when the player runs out of energy. It was reasonable to believe that the main character should not be able to do much at that point. However, we wanted to give the player an option when this happens. If they lose all of their energy, they can choose to "borrow" energy from the next day (see Figure 5.11. If they do this, they will receive a small amount of energy, but they are more likely to wake up with less energy the next day. This does not only give players more choices in the game, but also reflects the experiences of many people with EDS. As stated in Section 5.2, some described how they plan out their energy usage. For instance, they may cancel an event if they have another more important event the next day, to save energy.

The next step was to implement day three in the game. This day was planned to have a different structure from the first two days, with more focus on the story and different endings based on the player's choices. The day was scripted to start in a similar way to the other days, but the main character remembers that they have a doctor's appointment today. They can still choose to take a shower and eat breakfast. Then there is a monologue where they contemplate whether they should actually go the the doctor today or not. The limitations of the healthcare system are addressed, i.e. that many people who work in healthcare have little knowledge of EDS. The main character wonders if it is worth going to the doctor, then the player is given the choice to go or stay. Depending on the choice made, the player will see different endings. When they go to the clinic, they will have an interaction with a doctor. The doctor asks about their health, and the main character describes their symptoms. It is also mentioned here that it took a long time for the main character to receive their diagnosis, which appears to be a common experience based on the feedback from the survey and initial interviews. In the end, the doctor is helpful and gives some recommendations to help the main character with their symptoms. Otherwise, if the player chooses not to go, there is a scene where the main character meets with a friend (the friend from day one) at a cafe. The friend asks why they decided against seeing a doctor, and the player is given several choices which give different answers: "It doesn't help", "I was too tired", and "I don't know". No matter which one is chosen, the friend reassures the main character that she is here for them, whether they need support or just someone to talk to. Both the interaction with the doctor and the friend gives a boost in morale. The game ends right after both scenes, showing the credits.

It was our intention to give both choices a "happy" ending. They show two different sides of life with EDS, one focusing more on the medical aspects, while the other shows a more social perspective. Neither answer is necessarily "right" or "wrong" - they are just two possible solutions to the presented problem. Furthermore, we wanted to give every player a hopeful feeling at the end of the game. Although living with EDS can be difficult and feel hopeless at times, the player should understand that it is always worth seeking help or support from people around you. It is better to believe that there is always a chance for the main character's life situation to improve.

Another addition that was made was an intro when the game is started (see Figure 5.12. Its purpose was to explain to the player what EDS is, how it can affect someone's life, and what this game is about. This makes the game appear more polished by not jumping straight into day one without any explanation. It was also done to give the player a basic understanding of EDS before beginning to play, since it may not be clear from just the dialogue and the four variables alone.

At this point the script for the game was fully written. However, when reading through it, there were a few minor adjustments we wanted to make. This included both the dialogue and the way different actions affected the four variables. One more notable change was the chat with the aunt in day two. She was criticising the main character, claiming that EDS is made-up and accusing them of being too sensitive. We realised that this conversation is important, as it shows the player how

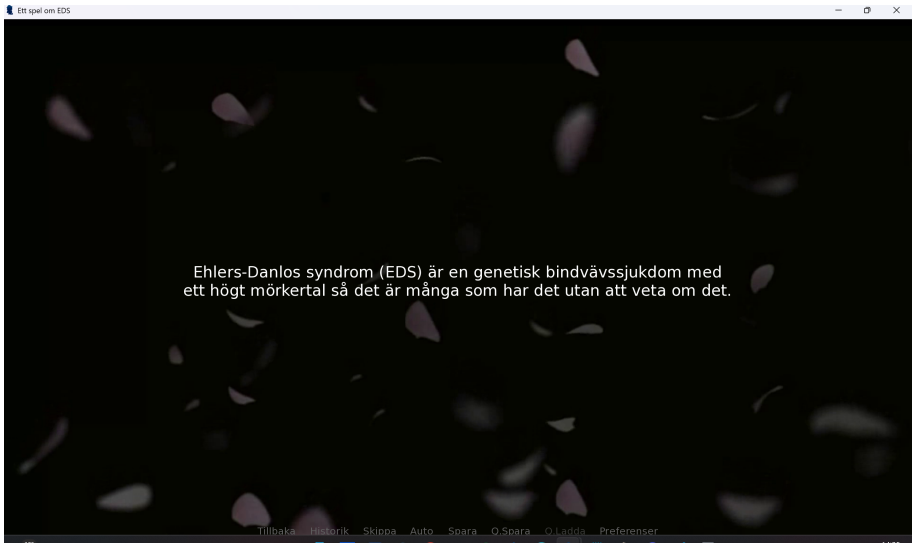

Figure 5.12: The intro explains what EDS is and what the goal of the game is.

some people are closed-minded and prejudiced when it comes to chronic illnesses, and that this negatively affects those who suffer from it. This is also something that was brought up by respondents to the survey, as seen in Section 5.2. Because of that, we wanted every player to experience it, not just those who choose to chat with someone in day two. To solve this problem, the conversation was turned into a phone call from the aunt which happens right after dinner. It always occurs, no matter what choices have been made beforehand. This modification was also made because the conversation with the aunt is mentioned when talking to the friend in day three. We thought that players who do not speak to the aunt but choose to meet with the friend may be confused by this.

Once the script was fully finished, we started improving the visuals of the game. There were a multitude of free assets in different online stores that could be used. For the character art as well as the backgrounds, we found free-to-use images that suited our needs (see Figure 5.14. For some, the creators required credit to be given. We did this for all of the used assets in the end credits of the game. Since the focus of the game was the narrative content rather than the visual content, we chose this route instead of doing original artwork for the game so we could spend the time that we saved on working on the story of the game.

Now it was time to incorporate music and sound effects. As with the visuals assets, free audio was found online, and the creators were credited at the end of the game. For the background music, three tracks were added: one played during mornings, one at work, and the last one was used for the evenings as well as the intro and end credits. During the doctor's appointment and the outing with the friend, there was no background music. Instead, suitable audio was used based on the environment: office-like sounds for the clinic's waiting room, and outdoor sounds like birds singing for the outdoor cafe scene. This was done to differentiate those scenes from the rest of the game, making them stand out in comparison. Other than that, the background music is cut when the main character's monologue about going to the doctor begins.

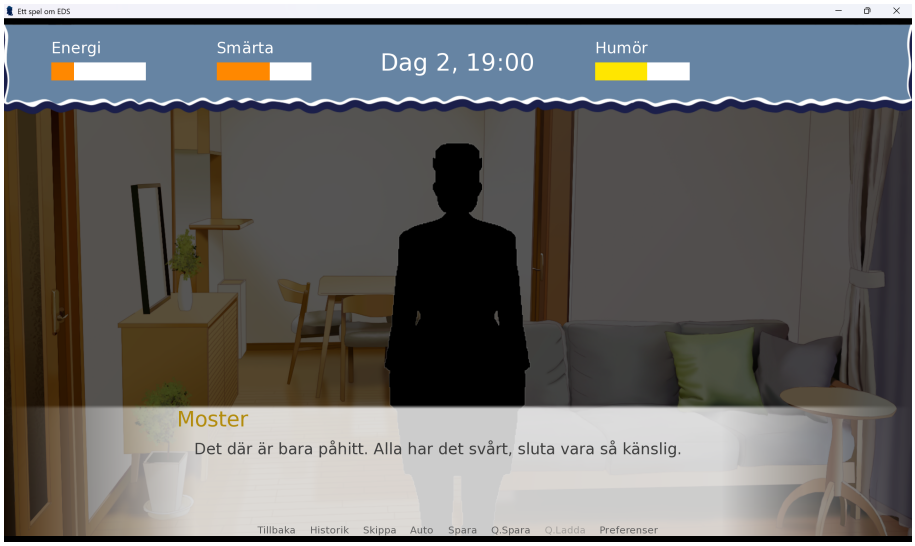

Figure 5.13: The main character gets a phone call from their judgmental aunt.

Figure 5.14: A conversation in the break room between the main character and their colleagues.

The purpose of this was to give the scene a more dramatic feeling. Not many sound effects were added - it was mostly just sounds for the phone call and the notification for the doctor's appointment. A prominent sound effect was a continuous "blip"-sound while dialogue text is written on the screen. There were three variants of this, each one with a different pitch. Each character was assigned one of them, e.g. the main character had the medium-pitch "blips" while the friend had the lower-pitch variant. This was done to simulate different voices.

The final touch to the game prototype was to improve the way the day, time, and four variables were displayed. When they were printed as text directly on top of the backgrounds, it could be hard at times to see the values. That is why we decided to display energy, pain and morale as bars instead. As mentioned before, these three variables work as percentages, so it was easy to translate their values to bars. The colouring was implemented in the same was as before, with the bars changing colour depending on how high or low its associated value is. Text was added above each bar to clarify what they signified. The day and time text remained mostly unchanged, but the size was increased slightly. Finally, a header was created, which acted as a constant background for the bars and text. This made sure that the visibility remained clear throughout the game. These changes can be seen in, for example, Figures 5.13 and 5.14.

At this point, the prototype was ready for another round of user testing. It was uploaded to itch.io, a website for games, so that users could try it on their own computers. At first, we attempted to make the game playable directly in the browser. However, it turned out that some features of the game did not work properly when it is web-based. One issue was the animated background during the intro, which did not work, instead being fully black. We are not sure why this happened, but one theory is that the file type that Ren'Py requires for videos, .ogv, does not display correctly. A more serious issue was with the coloured squares that showed up next to each variable when it changed. These were implemented using Python threads, which ensured that they would be shown for exactly one second before disappearing, unaffected by the state of the game. It turned out that threading does not work properly when the game is made web-based. As a result, these squares did not show up on the screen. Due to these issues with the web-based variant, we uploaded the game as a downloadable version instead. This way, the described issues were eliminated.

5.4 Evaluation

5.4.1 People with EDS

After making changes based on the feedback from the pilot study, adding a third day, and adding visuals and sounds, we conducted a round of play testing with people who have EDS. We wanted to do this before showing it to people who don't have EDS and aren't knowledgeable about it to make sure that the content of the game was accurate. This was very important to us since we didn't want to end up accidentally spreading misinformation about EDS by having the game portray it

inaccurately. After contacting multiple people from the survey who showed interest in play testing, four responded and were able to test it. Though, one person had a friend who joined the test. This friend did not have EDS himself, but had good knowledge and understanding of it thanks to his friend. Due to this, one could say that we had five testers in this phase, but only four tests. This round of testing was conducted similarly to the pilot study with the testers first playing through the game while thinking out loud and then answering questions about it. Because of the way the game branches, especially in day 3, we also showed the tester what would happen if they made the other choice so we could get feedback on both scenarios. The questions in this round of testing focused more on the accuracy of the content in the game rather than the gameplay itself, although that was also discussed and taken into account.

Based on the feedback from these tests (see Section 6.1.1), some changes were made to the game. In the new version, driving takes slightly more energy than public transport (six and four, respectively). However, taking public transport also affects the pain bar. On the first day, the main character cannot get a seat on the bus, getting back pain as a result. On the second day, they can injure their ankle by stepping crookedly when getting off the bus. Additionally, more elaborate dialogue was added to the game, specifically when the player makes choices that affect at least one of the variables. This new dialogue explains the effects in more detail. For example, if the player does not eat breakfast, the following dialogue explains that they will have a more exhausting day. Another part of the script that was edited was the "..." that indicates that the main character is working. As this caused some confusion, it was turned into regular lines of dialogue ("Time to start working," "I have a lot to do today," etc.). Then, the algorithm that generates the variables was modified so that the values are less extreme the first day. This makes the game more fair, and eliminates the possibility of the game being too difficult at the start. Moreover, the risk of injury was increased slightly, since we noticed that few of the testers actually got injured when playing.

One modification we made that was not directly prompted by the user tests was to remove the money variable. The original intention behind it was to show players the financial difficulties that EDS can bring, such as not being able to work full-time or paying for medical care. However, we realised that it was impossible to lose a lot of money in the game. This is because our prototype only shows three days, where there are no large expenses such as rent. Perhaps the money variable would be useful if the game consisted of a few days spanned out over several months, but in the current prototype, it served no purpose.

5.4.2 People without EDS

The final round of testing was conducted after the game was modified according to the feedback from the previous tests. Due to constraints in time and resources, only four people could be recruited for testing. Though, 3-5 evaluators are enough to discover approximately 75% of usability problems [54]. Since these people had not filled in the initial survey, and had thus not given us permission to use their

responses as data, they received a consent form that they filled in before the test started. It can be found in Appendix G. Just like previous rounds of testing, the participants first played through the game, and then were asked questions about the game and their experience playing it. For this round, we focused on getting participants who don't have EDS, and preferably don't know much about it prior to playing the game, so that we could see how effective the game was at communicating what EDS is and what some of the struggles a person who has EDS might experience in their day to day life. To find this out, we asked the participants to describe what EDS is based on their understanding from playing the game. We also asked them about how different aspects of the game were balanced, what they liked and didn't like about the game, how the game felt to play, and whether they thought a game like this could be used to raise awareness for EDS or other chronic illnesses.

6

Results

6.1 User Testing

In this chapter, the results of the two final rounds of testing will be presented. First are the tests with people with EDS, and second are the ones with people without EDS. To better understand the results, a thematic analysis was conducted for each round of testing, where various recurring themes are discussed in detail. Miro was used to convert the feedback from the testers into post-it notes. Then, a board was created for each discovered theme, and the post-it notes were sorted accordingly.

6.1.1 People with EDS

As the main purpose of this round of testing was to discover possible inaccuracies in the way EDS is portrayed in our game, most of the feedback we got was about that. One of the common themes discovered in the following thematic analysis was the game's narrative elements, including the dialogue, visuals and audio. Overall, the response for this was positive. Multiple people (4 out of 5) mentioned that they liked the dialogues, with one tester praising the conversation with the aunt, which was described in Section 5.3.4. She said that it was completely accurate with how some people perceive EDS. Another tester recognised the feeling of constantly being tired, which is shown in the game. However, one flaw that was observed was that there was little explanation behind the effects of some choices. One example was eating or skipping breakfast. Eating always takes some energy right away, but if you eat breakfast, you lose less energy while working up until lunch. However, by skipping breakfast, you save a bit of energy in the moment, but lose more energy throughout the morning. In total, eating breakfast saves more energy. Although this may be intuitive for some people, others may find the effects of that choice unclear. Another example is cooking dinner. While it may be understandable for someone with EDS why this task takes a lot of energy, someone without EDS may need a more detailed explanation.

Furthermore, there was also a lot of feedback related to the health variables (energy, pain and morale), so that was noted as a theme in our analysis. For example, two testers suggested adding ways to gain energy (other than choosing to "borrow" energy from the next day). One tester thought that there should be more ways for the morale to change, since it felt somewhat static. As was mentioned before, EDS can express itself in many different ways. This was also made clear in the

game's introduction. Because of this, some of the testers pointed out how they have different experiences of certain tasks. For example, one aspect that was brought up by two different testers was the choice between driving or taking public transport to work. At this point, both options deducted the same amount of energy (though public transport also cost money). In our discussions, testers argued that the two options take energy in different ways. When driving, you need to be more alert than you are when taking public transport. However, taking public transport can be overwhelming in terms of sensory input, for example when there is a lot of noise. It can also be especially difficult when there is no empty seat, and you have to stand the whole time. One tester said that she preferred driving, while acknowledging that others may feel differently. Another tester suggested giving at least slightly different effects for the choices, so they do not seem too similar. Interestingly, we had the same discussion between ourselves when deciding how much energy each option should take. As a compromise, we programmed the game so that both choices take the same amount of energy. Though, after considering the feedback, we modified the effects. This modification is described in Section 5.4.1.

Although the gameplay was not the main focus in these tests, we also noted the feedback related to this. One recurring comment was about how the health variables were randomly generated. It was possible to start the first day with rather low energy, which made it very difficult to make it through the day without running out of energy. At times, the values were also generated in a somewhat unrealistic way. One tester noticed that she had low energy and high pain, but somehow her morale was rather high. Additionally, the dialogue displayed while the main character works caused some confusion. It was shown as several sequential dialogue boxes with "..." in each, while the in-game time passed. We had to explain what it meant to one of the testers in this round. The code was updated to fix these issues, as described in Section 5.4.1.

6.1.2 People without EDS

When conducting a thematic analysis of the results of the final round of testing, it became apparent that some themes were the same as for the tests with people with EDS. One of these was the narrative elements, such as the dialogue, visuals and audio. Another one was the gameplay, including controls and UI. The themes that were unique to this group of testers were their understanding of EDS, how the medical/social/financial aspects were balanced, and how a game like this can raise awareness.

Focusing on the game itself, the feedback received was overall positive. Two testers said that they liked the backgrounds, with one saying that they "made the game easier to get into". The visuals enhanced the immersion into the game, helping the player see the game as a reflection of someone's life with EDS. The health bars did not just feel like a game feature, but like a part of the main character's life, which helped create understanding and empathy for them. The testers also liked the dialogues throughout the game. Three of them voiced their appreciation for the kind, supportive characters, such as the friend and doctor. They also thought

that the negative interactions, for example the one with the aunt, were helpful for understanding EDS from a social perspective. It showed them how interactions with other people affected the overall health of the main character, just like the physical symptoms of EDS. Two testers complimented the introduction, since it offered a brief but concise explanation of EDS and how the game works. One recurring criticism, however, was about the structure of the game. As stated before, day one and two are rather similar, with only a few differences. Since there are only two days that are so similar, the game did not feel too repetitive. However, we imagined a finished version of the game would cover more than three days to show more long-term effects of EDS. If more days are added in future development, the repetitiveness could become a problem. One suggestion that was made by two of the testers was to diversify the evening activities. For instance, grocery shopping may only be available on some days. There could also be more special events, or days with another structure, such as weekends. Other than this, there were also some minor comments. For example, one tester was confused about the "stay" option on day three. If they choose not to go to the doctor, why are they not going to work? Are they not working that day, or do they work part-time? That could be clarified. Moreover, going out with a friend can also drain your energy, which was not really shown in the game.

From a gameplay perspective, most testers (3 out of 4) thought that the controls were pretty easy and intuitive. As mentioned above, the game intro gave an explanation about the goal of the game, i.e. making everyday choices while being careful with the main character's health bars. Though, this was not the case for all testers. A few of them (one tester with EDS and one without) had to ask about how to proceed with the dialogue. Regarding the health variables, it seems that the testers generally liked how they were displayed as bars. One tester commented that she liked how they were always visible on the screen, so they served as a constant reminder to think carefully about your choices. However, two testers seemed to struggle with seeing the changes in the bars. Although the red and green markers next to the bars gave an indication as to how the bars' values changed, it was difficult to tell how much they moved. One of the testers suggested that the placement of the bars on the screen could be the problem. Firstly, she said that she looked at the bottom of the screen most of the time, where the dialogue was displayed, so it could be hard to see changes to the bars since they are at the top of the screen. Secondly, the bars are somewhat far apart. It may be easier to notice they way they shift if they are closer together. By grouping them, it might also give players a better impression that they are in some ways connected to each other. She suggested putting them on top of one another on one side of the screen. Other than this, another comment from testers was that it would be helpful to see how many days ago the main character last did various tasks, such as showering or cleaning. This was briefly discussed at one point during the game development, but had a lesser priority than other features, so there was not enough time to implement it. Additionally, one tester noticed that their morale went down if they skipped showering in the morning, even if they showered the previous night. This seemed unrealistic, and could be changed, since some people prefer showering in the evenings.

An important question was how well the testers understood EDS based on what

they learned from the game. When prompted, they seemed to have a good basic understanding of it. Everyone brought up fatigue and pain – that people with EDS get tired faster and that everyday activities can lead to pain. Two of the testers, half of the total, got injured. They mentioned the risk of injury during this discussion. Additionally, all testers understood that people with EDS experience harmful social consequences, such as some people not knowing what EDS is, or even having prejudices against it. Two testers specifically mentioned that EDS is a connective tissue disorder, remembering this from either the game's intro or the conversation with the main character's aunt. Another point of discussion was how EDS seems to affect everything you do, both physically and mentally. Furthermore, different perspectives regarding EDS were brought up, mainly a medical, social, and financial perspective. Two testers felt that the financial problems were not very prominent in the game, and could be given more attention. The social elements seemed clear and ample to everyone. One point that was brought up by two of the testers was the representation of pain. They felt that there was little focus on the pain variable, with one tester interpreting it as being less important. Interestingly, the testers who mentioned this were only the ones who did not get injured in the game.

As for the capability of raising awareness for EDS and other chronic illnesses, the testers all had a generally positive outlook. They thought the game was informative and immersive. However, some expressed doubts about how the game could be marketed. If it is meant to be a stand-alone game, how would people find it? What would motivate them to play it? Additionally, one tester thought that the game gives a good overview of EDS, but not a complete depiction. Three of the testers suggested incorporating the game into an educational setting, like in schools. The game could be paired with another activity, such as a lecture or a group discussion after playing.

6.2 Design Recommendations

Based on what we found from making this game and doing play tests, we've developed some guidelines for creating games to raise awareness. First are some general guidelines that will likely apply for any game that is meant to raise awareness about any topic. Then there are some guidelines that are specifically for games to raise awareness for chronic illnesses or other medical conditions. This means that if you are making a game to raise awareness for a chronic illness, you would use both sets of guidelines, but if you are making a game to raise awareness for something else, you would only use the first set of guidelines.

6.2.1 Games to Raise Awareness in general

- **Figure out what type of game would be most suitable.** What type of game would be most effective to raise awareness for the thing you want to raise awareness for? For example open world or visual novel, first person or third person, does it not follow a person at all? For this you might also have

to consider factors such as how much time you have to make the game, what resources you have at your disposal, etc.

- **Determine the scope of the game.** This includes (but is not limited to): How long should it take to play the game? How much time passes in game? How many characters are there? Are there multiple endings? While considering all of this, it is important to keep the thing you're trying to raise awareness for. Is the game going to be effective at raising awareness with a small scope? Will players be able to take in everything with a big scope? To help keep track of all of this, and more, we recommend creating a game design document.
- **Make a prototype.** Make a prototype of the game with the main structure and controls, this could be high or low fidelity depending on how many rounds of user tests you're doing, how much time you have, etc. If you have limited time, focus on the parts that are most important for players to understand what you are trying to raise awareness for.
- **Set up user tests.** Set up user tests to get feedback at various stages of the development. It's important to have user tests at different stages (if you have the possibility to do so) since it shows you if the game is doing what you want it to do, it's much easier to make changes early on than when the game is almost finished, especially if it's big changes that affect many aspects. When doing user tests, make sure to ask questions about what you're trying to raise awareness for. How much do they understand about the topic from playing the game? Are there aspects they wish were more prominent? Are there parts they didn't understand, and if so, why?

6.2.2 Games to Raise Awareness for chronic illnesses or other medical conditions

- **Involve people with the chronic illness/medical condition.** Make sure to involve people with the condition as much as possible since they are the ones who know best what it's like to live with it. Their involvement shouldn't stop at the data gathering process since it's easy for misunderstandings or incorrect assumptions to occur, and these are more easily caught by the people who have the condition.
- **Decide which symptoms should be included.** What are the most common symptoms? Which symptoms affect people the most? Are there any symptoms that should be more or less emphasised in order to make an accurate portrayal? There are multiple ways to figure this out, such as through literature, surveys, or interviews, but we recommend using a mixture of methods since one method might not be able to cover all aspects on its own.
- **Investigate if there are other aspects that should be included.** Are there other ways than symptoms that people are affected that should also be included in the game? Some examples of these aspects are financial aspects and social aspects.

- **Determine if any comorbidities should be included.** Are there any common comorbidities that should be included? How much focus should be put on the comorbidities if they are included?
- **Set up user tests with people with the chronic illness/medical condition.** Before doing any user tests with people who don't have or don't know about the condition you're trying to raise awareness for, do user tests with people who do have it and then make changes if needed. This is to ensure that the game is reasonably accurate before showing it to people who don't have any knowledge about the condition in order to minimise the risk of spreading misinformation with the game. This is especially important when making games about conditions the general public have little to no knowledge about since they most likely won't have another frame of reference, so if the game is inaccurate, they might hold inaccurate beliefs about the condition after playing the game.

7

Discussion

7.1 Process Discussion

7.1.1 Language

Due to most of the survey respondents and interviewees being Swedish and/or having experience of how it is to have EDS in Sweden, we decided to make the game in Swedish rather than English. We considered making the game in English since that would make it accessible to more people since a lot more people know English than Swedish. However, since our data was based on how it is to live with EDS in Sweden, we weren't sure how well it would apply to people living in other countries, especially the part about healthcare. This means that the game might have a smaller reach than if it had been in English, however, it will likely be more effective in Sweden since it doesn't require the players to know a different language.

7.1.2 Gender gap in the survey

While males and females are equally likely to have EDS [55], most people who are actually diagnosed with EDS are female with around 70% being female and around 30% being male [56]. However, this doesn't fully account for the gap between men and women in our survey since around 90% of the respondents were women. Something that complicates this comparison is that the articles talking about the prevalence and diagnosed prevalence both look at it from a point of view of the sex of the the patients while our survey asked about the gender of the participants, so while we know how many women, men, and other responded to the survey, we don't know the amount of participants who were assigned female at birth compared to the amount of participants who were assigned male at birth. The difference could, at least partially, be contributed to women being more likely to respond to surveys than men [57].

The large gap between women and people of other gender identities responding to the survey could mean that the game is more skewed towards showing the experience of having EDS as a woman rather than the experience of having EDS as any gender. While the interviews were still skewed towards women, the gap was smaller than in the survey as we wanted to get several different perspectives to get a wider understanding. When developing the game, we tried avoiding adding things that

are more clearly "gender specific", however, it is possible that there are still parts that are are more skewed toward showing how it is for women specifically.

7.1.3 Additional game mechanics

During the development of the game, there were discussions about the game mechanics. The most basic ones consisted of reading through dialogue and making choices. However, is it possible to add more mechanics to create more variety for players. One idea was to add a mini game at some point in the main game. We even started brainstorming about a potential rhythm game. Though, because of time constraints, this idea was never realised.

7.2 Results Discussion

When doing the final round of testing, due to time constraints, we weren't able to get a very wide spread of testers. We were only able to get other master students of the same or similar masters to test the game. This means that we don't know how effective the game would be for people of different backgrounds such as different ages, different educational levels, different fields of education, or different amounts of experience with games. However, there were still some interesting findings.

One frequently mentioned topic was the game's immersion. As discussed in Section 2.2, games offer a level of interactivity that many other forms of media do not have. When the player's choices affect the outcome of a game, it can strengthen the immersion, which can then invoke feelings of empathy and understanding. Additionally, emotionally difficult experiences in games can leave an imprint on players, making them contemplate the issues presented in the game. This can also be an effective tool for spreading knowledge on various topics. We kept this in mind throughout the game development process, as we wrote dialogue and considered what game mechanics would be most effective for this purpose. Based on the results of the user tests, it seems that our prototype is somewhat successful in that regard. The testers' verbal feedback confirmed this, but it could also be deduced from observing their reactions to various parts of the game. For example, multiple testers had a strong negative reaction to the conversation with the aunt (see Section 5.3.2). One of them was taken aback by her rude attitude, while another one urged the main character to hang up the phone. Likewise, the testers felt positively about the interactions with the doctor and friend, appreciating that there are nice characters in the game too. With more time and resources, the game could be developed further to add more elements to enhance the immersion. This could include improving the graphics, for example by creating animations for the character sprites. Also, with a longer game, there is more opportunity to flesh out the story and make some characters more complex.

Other important factors are the game controls and mechanics. Although most testers figured out how to proceed with the dialogue, a few needed help with that. One possible reason for this may be the player's previous experience with computer games, especially with visual novels. Visual novels often have few, simple mechanics, which

mainly includes clicking through dialogue (see Section 2.3). This is even a default, pre-existing mechanic in Ren'Py games. The testers were told before starting that our game is a visual novel, so perhaps the ones who were more familiar with this type of game did not need as much guidance. As stated in Section 1.3, our target audience is partly people who already play video games, so they may not need an explanation of the controls. Though, it is also unfair to exclude potential players who are not as familiar with visual novels. A simple solution could be to add a visual indicator which shows the player how to proceed with the dialogue. This could be an arrow on the right side of the dialogue boxes, or a message like "right-click or press space to continue".

Based on the feedback and advice from the testers with EDS, it seems that the game overall offers a fairly accurate representation of what life with EDS is like. Though, as was stated in the feedback from the final user tests, the game does not paint a complete picture. This is understandable, as the game is currently an early prototype. One of the shortcomings that was discovered in the final round of testing was how pain is represented. Although pain is one of the health variables, it is not mentioned as often as energy in the dialogues. The pain can go up when taking a shower, if there are no empty seats on the bus, or when the main character's work chair is uncomfortable. Additionally, the pain increases when the main character is injured. As was mentioned in Section 6.1.2, the testers who did not get injured thought that pain was under-represented in the game, while the ones who were injured did not bring this up. This may indicate that the pain variable is currently too reliant on the injury mechanic. One solution could be to add more situations where pain is affected, but the probability of injury could also be reevaluated. On the one hand, it would be unrealistic to make it very high. On the other hand, a small risk can cause more players to view the pain aspect as unimportant. Perhaps, if there are more days in a future version of the game, some days can have a 100% risk of injury while others have little to no risk. This would remove the randomness factor, but may overall give the player a more realistic impression of what EDS is like.

Regarding the feedback on the financial aspects of the game, which some testers believed should have had more attention, changes could be made to improve it. It is possible that removing the money variable is a reason behind this feedback. However, there are other ways to fix this issue. For example, the main character's personal finances could be brought up more in the game's dialogue. They could, for instance, mention how expensive medicine and/or physiotherapy is. If the game covered more than three days, we could also add more factors that affect the player's finances, such as sick leave or rent and other large expenses. As mentioned in Section 5.4.1, the money variable was removed because it served no purpose in the current game prototype, where it is impossible to lose all your money. Though, if the game was developed further and made longer, this variable could be put back in.

Finally, one point of discussion during the evaluation was the target audience of our game. In Section 1.3, we contemplated what groups of people may be interested in a game like ours. These included people who already enjoy playing visual novels, but also those who have already heard of EDS and wish to understand it better.

In the evaluation, one of the testers stated that he was curious about playing our game since he thought he might have undiagnosed EDS and wanted to learn more about it. As mentioned in Section 3.2, there may be a higher prevalence of EDS than current studies show. We may have discovered another target group – people who suspect they have EDS. A game like this could help them learn more about themselves. If they can see themselves in the main character, they may even be encouraged to seek medical advice. Also, we originally thought the game would be for older audiences, but multiple testers said it could be a practical educational tool in schools. We would need to conduct more thorough research to investigate how children would perceive this game.

7.3 Comparison to Other Games

When comparing our game to the games described in Section 2.1.2, there are both some clear similarities and differences. *You're just imagining it* also follows the life of a person with EDS. Some themes overlap, such as the anxiety of going to the doctor or balancing one's work life and private life. Though, the goal of that game is to get diagnosed, while our game is only meant to show what life with EDS can look like. There is also more exploration in our game, with a larger variety of scenes and interactions available. *That Dragon, Cancer* focuses more on individual scenes rather than entire days, but has a strong focus on emotional impact, which is something we also tried to include in our game. *Spent* also puts heavy emphasis on the choices the player makes, but has simpler visual aspects.

Yet another game that can be compared to ours is *Depression Quest*. This is also a "serious game" whose purpose is to spread awareness about an illness, but this game is about depression. Similarly to ours, this game is heavily text-based and follows the everyday life of a person who suffers from depression. The player is presented with various scenes, where they have to make a decision to progress the story. Based on the choices made, the main character's mental health either improves or deteriorates. Additionally, the choices made affect the options of future choices, as some alternatives can become unavailable. One significant difference between this game and ours is the main structure. While both present everyday occurrences, *Depression Quest* does this in the form of specific scenarios where the player has to make a choice. For example, a coworker asks the main character to adopt one of his kittens, which the player can choose to do or not. Furthermore, this game has fewer visual aspects, focusing more on the descriptions of each scenario. Due to the longer texts between each choice, this game becomes less interactive than ours. Because of this, there is a risk that some players may lose interest. In this regard, we believe that our game benefits from incorporating more complex visuals and bite-sized text. Though, the scene-based structure of *Depression Quest* could be an inspiration for us. As mentioned in Section 6.1.2, there is a risk of our game feeling too repetitive if more days are added in the future. Creating more special scenarios may add variation to the game, thus preventing a monotonous structure.

To further study how emotions can be combined with storytelling in games, an interesting game to research is *Alter Ego*. This is a life simulator where the player

can choose between many different actions throughout several life stages. With many of the actions, a mood also has to be selected. Not every combination works, since some moods do not match well with some actions. This game is different from ours in that it does not seem to have a clear message for its players. It focuses more on exploration. Because of this, even though we may take inspiration from the way this game handles emotions and actions, we may have to implement it in a different way for our game. As has been stated before, one of the most important aspects of our game is the accurate representation of EDS. As such, the emotions that come with different actions also need to be portrayed realistically. This could be worth investigating for the future of the game.

7.4 Ethical Aspects

As was discussed in Section 3.4, it was of utmost importance to protect the privacy of the survey participants, interviewees and play testers. All of these groups were informed about how their data would be used, either in the survey or through the consent form. Their data has also been anonymised for the thesis.

When considering the game itself, the greatest ethical risk may be misrepresenting EDS. The purpose of the game is to raise awareness of EDS by informing players about what life with EDS can be like. As such, the way EDS is portrayed in the game has to be as realistic as possible, or else players may get an incorrect view of it. This would contribute to the misconceptions and prejudices about EDS that already exist. For this reason, we carefully noted the misconceptions that were mentioned in the survey and interviews, to make sure the game refuted them rather than affirming them. One point that was frequently mentioned was the belief that EDS is an imagined illness. Some think that it is fully psychological and not physical. While we wanted to include morale as a variable to show the main character's mood, we also made sure to highlight physical pain and fatigue as core factors. The conversation with the aunt was another way to show this harmful misconception about EDS in a realistic setting. Another example is the belief that hypermobility caused by loose connective tissue is an advantage. The energy and pain bars are meant to convey the negative consequences of connective tissue disorders. This is also reinforced by the risks of injury throughout the game.

7.5 Future Work

To get a better understanding of how effective the game is for raising awareness for EDS, there needs to be further user testing conducted with more participants of varied backgrounds. This is to ensure that it is not only people from a certain background that are able to understand the game since the goal of the game is for everyone to be able to understand what EDS is after playing it.

For further development of the game, more days could be added with a bigger variety of things that happen during the day and options for what to do during the evening. This could also include adding weekends to show what a day might look like for

someone with EDS when they don't have to go to work. In order to do this, some more interviews might need to be conducted with a focus on what people with EDS might do on a day off and how different activities affect their body. If enough days are added to the game, it might also be worth considering adding financial aspects as well such as having to pay rent, having to pay for medicine, maybe having to take sick days during a flare up. This would help show how having EDS affects many different aspects of life and not just the body. Another slight improvement to the game would be to implement counters to track how long ago the player last did various tasks, such as showering or going grocery shopping. This would not only give players more useful information, but it could also allow for an improved algorithm for updating the health variables. For instance, the longer a player goes without showering, the more damage each subsequent skipped shower does to their morale.

One idea that was suggested by a survey respondent, and discussed by us early in the development, was the ability to choose one of multiple main characters to play as. These characters would have different appearances, personalities, comorbidities, and life situations. Some may use different mobility aids, which is another aspect mentioned in the survey. This feature would acknowledge that EDS does not express itself in the same way for everyone, but that there are many variations. One character may have classical EDS, while another has the hypermobile variant. It would also let players pick the character they would enjoy playing as the most, perhaps a character whose personality they can relate to. However, this feature would require much work, like changing many lines of dialogue to reflect a character's personality, or create entirely new scenes depending on the character's line of work or family life. We decided that, although this may have been a good idea, it was not feasible to implement within the scope of this project.

Another way to implement showing different experiences and perspectives could be to, instead of having a certain amount of pre-set options for the main character, have a character creation page where the players get to freely choose attributes such as type of EDS, comorbidities, age, gender, ethnicity, and personality. This would allow for the possibility of more nuance with showing more specific difficulties rather than generalized difficulties. However, implementing this would likely take a lot of time since each choice in the character creation process affects what difficulties the character has and how the character interacts with the world.

Another thing that could be added, that we wanted to add but didn't have time for, is a mini game. As an example, a rhythm game could be added during the work day where you have to press random keys on the keyboard while also using the mouse so you can't rely on muscle memory for the keyboard since one hand has to cover the entire keyboard. This could help simulate how people with EDS often have to think more about every move they make in order to avoid pain or injuries. The mini game could also affect things such as energy and performance at work so if you do better in the mini game, your performance at work goes up but your energy also decreases more, but if you keep doing bad at the mini game to save energy, you might lose your job. Adding a mini game would also make the game feel less repetitive by providing a different type of mechanic, as well as increase interactivity.

8

Conclusion

In this thesis, the research question posed was: *What are some of the ways a game can be designed to effectively raise awareness about living with chronic illness?* To answer this question, multiple relevant topics such as EDS, chronic illness, game development and storytelling were studied. Later, people diagnosed with EDS were surveyed and interviewed with the purpose of acquiring first-hand accounts of what living with EDS is like. After analysing that data, a first prototype of a game was developed. This game followed a main character with EDS, who had to make choices throughout their everyday life while considering their health. This prototype was evaluated, first by people with EDS to discover potential inaccuracies in the illness' portrayal, then by people without EDS. Finally, the results were analysed and discussed.

More research can be done on this topic to provide a more detailed answer. Though, in this project, we discovered several game elements that can contribute to how well a game can raise awareness of EDS:

- **Accuracy.** An important part of the project was gaining a good understanding of what EDS is, and in what ways it can affect people. By focusing on the accurate portrayal of EDS in the game, it helped giving players a general understanding of this illness. Several perspectives were included, such as the medical, social, and financial. Additionally, some areas which were lacking were noticed and pointed out by testers, such as the way pain was presented in the game.
- **Quality of game assets.** There was a clear difference in the responses between those who participated in the pilot study and those from the final evaluation. Simplistic visuals and a poorly designed GUI was quickly noticed. However, once the higher quality backgrounds, character sprites and GUI elements were added, as well as the music and sound effects, the responses were more positive. The players found it easier to get immersed in the game's story.
- **Game mechanics and controls.** Most players found the game controls simple and easy to learn. When someone struggled with them, it distracted from other parts of the game. Players would often take time considering the various choices presented to them, and enjoyed seeing different paths in the game. This way, they learned about life with EDS while also being free to explore on their own.

- **Variation.** As several testers pointed out, the first two days could feel repetitive, especially if the game was longer and had more similar days. This could cause players to lose interest in the game. Therefore, we discovered the importance of including days with different structures, as well as different choices each day.
- **Emotional experiences.** Scenes that were more emotionally loaded, both positive and negative, received more attention from the testers than the neutral interactions, for example the conversations with colleagues in the break room. Many discussed these emotional scenes when interviewed after playing the game. They appreciated the nice interactions, but also understood how the negative interactions showed the prejudices against people with EDS.

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A

Appendix: Survey Protocol

Ett spel om EDS/HSD / A game about EDS/HSD

* Indicates required question

1. Vilket språk vill du svara på? *
Which language do you want to answer in?

Mark only one oval.

- Svenska
- English *Skip to question 13*

Ett spel om EDS/HSD

Hej! Vi är två studenter på Chalmers tekniska högskola som gör vårt examensarbete i interaktionsdesign. Vårt uppdrag är att skapa ett spel som visar hur vardagen kan se ut för en person med EDS/HSD. Målet med detta är att öka folks förståelse för livet med EDS/HSD.

Denna enkät tar **ca. 5 minuter**. Dina svar är anonyma (förutom näst sista frågan, som är frivillig).

2. Hur gammal är du? *

Mark only one oval.

- Under 18 år
- 18-29 år
- 30-39 år
- 40-49 år
- 50-59 år
- Över 59 år
- Vill inte säga

3. Vad är ditt kön? *

Mark only one oval.

- Kvinna
- Man
- Annat
- Vill inte säga

4. Vilken typ av EDS/HSD har du? *

Mark only one oval.

- Klassisk EDS (cEDS)
- Klassisk-liknande EDS (clEDS)
- Cardiac-valvular (cvEDS)
- Vaskulär EDS (vEDS)
- Hypermobil EDS (hEDS)
- Arthrochalasia EDS (aEDS)
- Dermatosparaxis EDS (dEDS)
- Kyfoskoliosis EDS (kEDS)
- Brittle Cornea syndrome (BCS)
- Spondylodysplastic EDS (spEDS)
- Musculocontractural EDS (mcEDS)
- Myopathic EDS (mEDS)
- Periodontal EDS (pEDS)
- Hypermobilitetsspektrumstörning (HSD)

5. Hur lång tid tog det att få diagnosen? *

6. Har du några komorbiditeter? *

Check all that apply.

- [ ] Ångest
- [ ] Depression
- [ ] Migrän
- [ ] POTS (postural ortostatiskt takykardisyndrom)
- [ ] IBS (Irritable bowel syndrome)
- [ ] TMD (temporomandibulär ledstörning)
- [ ] Fibromyalgi
- [ ] MCAS (mastcellsaktiveringssyndrom)
- [ ] Artrit
- [ ] GERD (gastroesofageal reflexsjukdom)
- [ ] CRPS (komplext regionalt smärtsyndrom)
- [ ] PCOS (polycystiskt ovarialsyndrom)
- [ ] Endometrios
- [ ] Kronisk njursvikt
- [ ] Skolios
- [ ] Astma
- [ ] Allergisk rinit
- [ ] Hypotyreos
- [ ] ADHD
- [ ] ASD (autismspektrumtillstånd)
- [ ] Nej
- [ ] Other: _____

7. Använder du något mobility aid? Behöver inte vara dagligen *

Check all that apply.

- [ ] Käpp
- [ ] Kryckor
- [ ] Rollator
- [ ] Rullstol
- [ ] Nej
- [ ] Other: _____

8. Vilket eller vilka symtom påverkar dig mest under din vardag? *

9. Vad hade du velat ha med i ett spel som visar hur en dag kan se ut för en person med EDS/HSD? *

   T.ex. något du önskar folk förstod, något som tar mer energi än folk utan EDS/HSD tror, något som är svårt att göra, något som hjälper, etc.

10. Är det något *inte* hade velat var med i ett spel om EDS/HSD?

11. Skulle du vara intresserad av att delta i intervju (februari-mars) eller användartest (april-maj) för det här projektet? Om ja, skriv gärna dina kontaktuppgifter här!

12. Dina personuppgifter skyddas enligt GDPR. Informationen du har gett kommer endast att användas inom vårt examensarbete, och distribueras inte. *

Mark only one oval.

- ◯ Okej

A game about EDS/HSD

Hi! We are two students at Chalmers University of Technology, and we are doing our master's thesis in interaction design. Our mission is to create a game that shows what the everyday life of a person with EDS/HSD can look like. The goal is to raise awareness about living with EDS/HSD.

This survey takes **about 5 minutes**. Your answers are anonymous (except for the second-to-last question, which is optional).

13. How old are you? *

Mark only one oval.

- ◯ Under 18 years
- ◯ 18-29 years
- ◯ 30-39 years
- ◯ 40-49 years
- ◯ 50-59 years
- ◯ Over 59 years
- ◯ I do not want to answer

14. What is your gender? *

Mark only one oval.

- ◯ Woman
- ◯ Man
- ◯ Other
- ◯ I do not want to answer

15. What type of EDS/HSD do you have? *

Mark only one oval.

- Classical EDS (cEDS)
- Classical-like EDS (clEDS)
- Cardiac-valvular (cvEDS)
- Vascular EDS (vEDS)
- Hypermobile EDS (hEDS)
- Arthrochalasia EDS (aEDS)
- Dermatosparaxis EDS (dEDS)
- Kyphoscoliotic EDS (kEDS)
- Brittle Cornea syndrome (BCS)
- Spondylodysplastic EDS (spEDS)
- Musculocontractural EDS (mcEDS)
- Myopathic EDS (mEDS)
- Periodontal EDS (pEDS)
- Hypermobility Spectrum Disorder (HSD)

16. How long did it take to get your diagnosis? *

17. Do you have any comorbidities? *

Check all that apply.

- [ ] Anxiety
- [ ] Depression
- [ ] Migraines
- [ ] POTS (postural orthostatic tachycardia syndrome)
- [ ] IBS (Irritable bowel syndrome)
- [ ] TMD (temporomandibular joint disorder)
- [ ] Fibromyalgia
- [ ] MCAS (mast cell activation syndrome)
- [ ] Arthritis
- [ ] GERD (gastroesophageal reflux disease)
- [ ] CRPS (complex regional pain syndome)
- [ ] PCOS (polycystic ovary syndrome)
- [ ] Endometriosis
- [ ] Chronic Kidney disease
- [ ] Scoliosis
- [ ] Asthma
- [ ] Allergic rhinitis
- [ ] Hypothyroidism
- [ ] ADHD
- [ ] ASD (autism spectrum disorder)
- [ ] No
- [ ] Other: _____

18. Do you use any mobility aids? Does not need to be daily *

Check all that apply.

- [ ] Cane
- [ ] Crutches
- [ ] Walker/rollator
- [ ] Wheelchair
- [ ] No
- [ ] Other: _____

19. What symptom(s) affect you the most in your everyday life? *

20. What would you like to see in a game that shows a day in the life of someone with EDS/HSD? *

    For example something you wish people understood, something that takes more energy than people without EDS/HSD think, something that's difficult to do, something that helps, etc.

21. Is there anything you *wouldn't* want to see in a game about EDS/HSD?

22. Would you be interested in participating in an interview (February-March) or user test (April-May) for this project? If yes, please write your contact information here!

23. Your personal data is protected in accordance with GDPR. The information you have given will only be used within our master's thesis, and will not be distributed. *

Mark only one oval.

- [ ] Okay

B

Appendix: Survey Results

Link to spreadsheet for the results of the survey: https://shorturl.at/bGA8q

C

Appendix: Initial Semi-Structured Interview Protocol

This interview protocol has been translated from Swedish.

- Present ourselves.
- Ask for permission to record the interview. If they do not want that, we will only take notes.
- *What type of EDS do you have? What comorbidities do you have?*
- *What does a normal day look like for you?*
- *What does a more difficult day look like for you? For example when waking up with more pain, less energy, etc.*
- *What helps?*
- *What requires more energy?*
- *Do you feel that people have misconceptions about EDS/HSD? If yes, what are they?*
- *Tell us a little more about your close relationships (family, friends, etc.)*
- Thank them for their help.

D

Appendix: Initial Semi-Structured Interview Thematic Analysis

Figure D.1: Participant 1

Figure D.2: Participant 2

Figure D.3: Participant 3

Figure D.4: Participant 4

Figure D.5: Participant 5

Figure D.6: Participant 6

Figure D.7: Participant 7

Figure D.8: Participant 8

Figure D.9: Participant 9

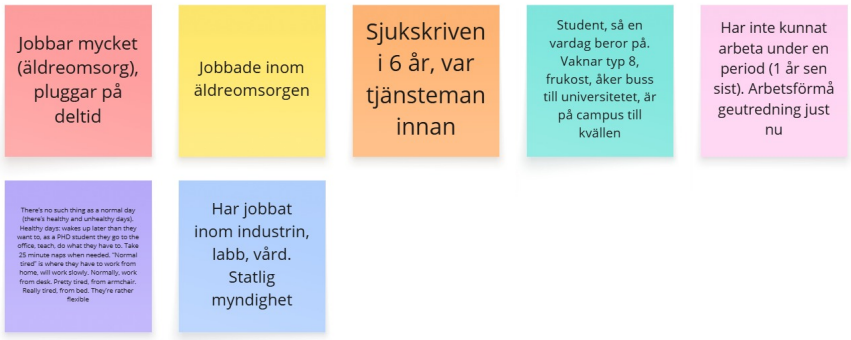


Figure D.10: Job/occupation

Figure D.11: Misconceptions about EDS

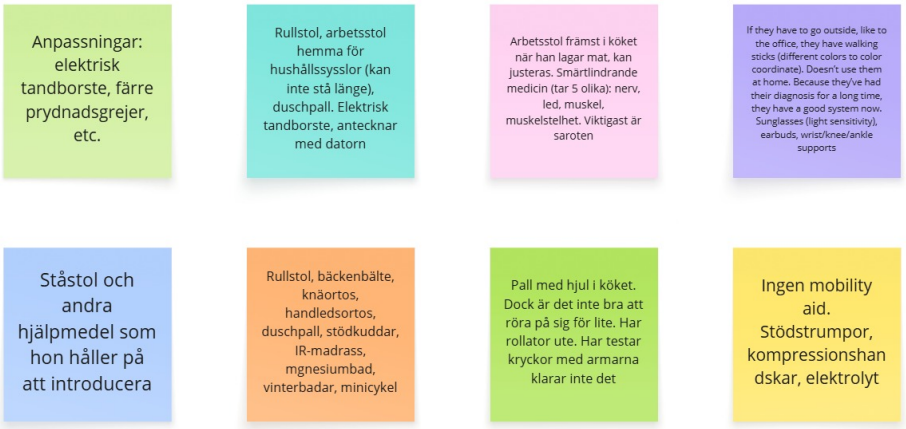


Figure D.12: Mobility aids

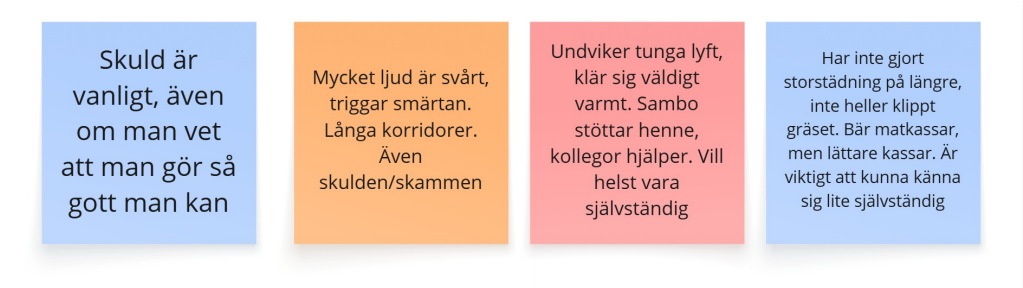


Figure D.13: Guilt/shame, independence

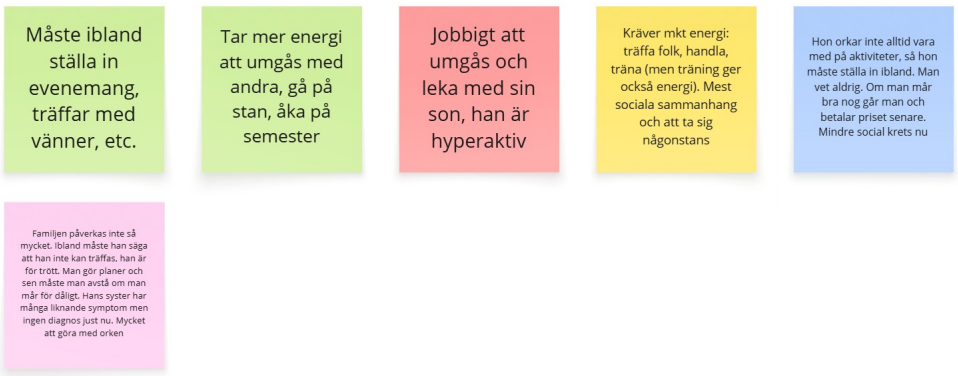


Figure D.14: Difficulty socializing

E

Appendix: Game Design Document

1 Overview

1.1 Game concept

2 Story

2.1 Plot summary

The game will probably be 2-3 days since it's just a prototype, but it should be possible to see what effects choices have across several days. There may be an intro before the game itself starts, where EDS is described briefly, as well as the objective of the game. The game starts with the main character waking up. The first day is normal, with nothing really out-of-the-ordinary happening. They make ordinary choices, go to work, go home, eat dinner, and do something the rest of the evening until bed. The following days are similar, but certain events may happen. The main character may accidentally hurt themselves, or different interactions with various people can unlock different paths. The main objective is to make it through several days with EDS.

Summary, day 1:

- Player wakes up, tone of voice depends on their energy/pain (partly random but maybe not too random so the difficulty level stays relatively the same for everyone).
- Maybe a minigame to get out of bed?
- Shower choice
- Breakfast choice

- Go to work
- Work, break, lunch, break
- Dinner
- Evening activity (could be more than one depending on how long it takes and amount of energy)

2.2 Characters

- Main character (gender neutral?)
- Colleagues
- Friend(s)?
- Family (does anyone in their family also have EDS?)
- Based on one of the interviews: a friend who doesn't understand how difficult it is for the main character, friendship eventually starts turning toxic. Possible choice: should you end this friendship?

2.3 Branching narrative

Choices:

- Shower? (Maybe display days since last shower?)
    - Yes (full shower)
        - Energy down a lot, pain up, takes time
            - Dry hair?
                - Hairdryer
                    - Energy down, pain up
                - Airdry
    - Yes (short shower)
        - Energy down a bit, pain up a bit, takes less time
    - No
        - No effect/mentality down a bit? takes no time
- Breakfast?
    - Yes
        - Energy down immediately, doesn't affect energy after, takes time
    - No
        - Energy slowly down until lunch, delayed start of energy down, takes no time
- Transportation to school/work
    - Public transport
    - Drive
        - fastest
    - Other? (bike, order ride, carpool, walk (if close), etc.)
- During break:
    - Stay at desk
        - No change/mentality down?
    - Talk to colleagues in breakroom (not available if energy low)
        - Energy down
- Lunch

        - Brought from home (alternative to bring earlier during the day)
        - Take out to eat in breakroom
            - money
        - Eat at lunch restaurant
            - money
- Dinner
    - Cook (not available if energy low/pain high)
        - Energy down, pain up
    - Microwave freezer meal
        - takes least time
    - Order delivery
        - takes equal time as cooking? costs money
- Evening activity
    - Clean (not available if energy low/pain high)
        - Energy down, pain up
    - Watch TV
    - Go to bed early
        - More energy next day (if we make it multi-day)
    - Shower (if no in the morning) (not available if energy low/pain high)
    - Grocery shopping (not available if energy low/pain high)
        - Energy down, pain up, money down
    - Text/chat with someone
        - Morale up/down depending on who you're talking to/how the conversation goes

2.4 Endings

If energy runs out, only options that don't decrease energy will be available, and if there are only options that decrease energy for an activity, that activity will not be available at all (for example you'll have to skip dinner if you don't have any energy left because all options decrease energy at least a little) (maybe an option to go into negative energy/borrow energy from the next day and then you'll start with less energy the next day?)

- Maybe a bad ending if all energy runs out
- Main character loses a friend
- Maybe a good ending if all parameters are within certain thresholds? (energy and morale not too low and pain not too high)

3 Visuals

3.1 Environment

- Bedroom (day/night)
- Bathroom
- Kitchen
- Bus stop/outside

- Office
- Breakroom
- Living room (day/night)

Various backgrounds: https://spiralatlas.itch.io/contemporary-vn-backgrounds
https://tainara-p.itch.io/
https://noranekogames.itch.io/yumebackground
https://neeka.itch.io/hospital-backgrounds
Office backgrounds: https://quarkyifu.itch.io/visual-novel-backgrounds-office-bg-set
https://quarkyifu.itch.io/visual-novel-backgrounds-431-mage-bg-set

3.2 Character design

Characters:
- Boring co-worker
- Loud co-worker
- Friend
- Aunt
- Doctor

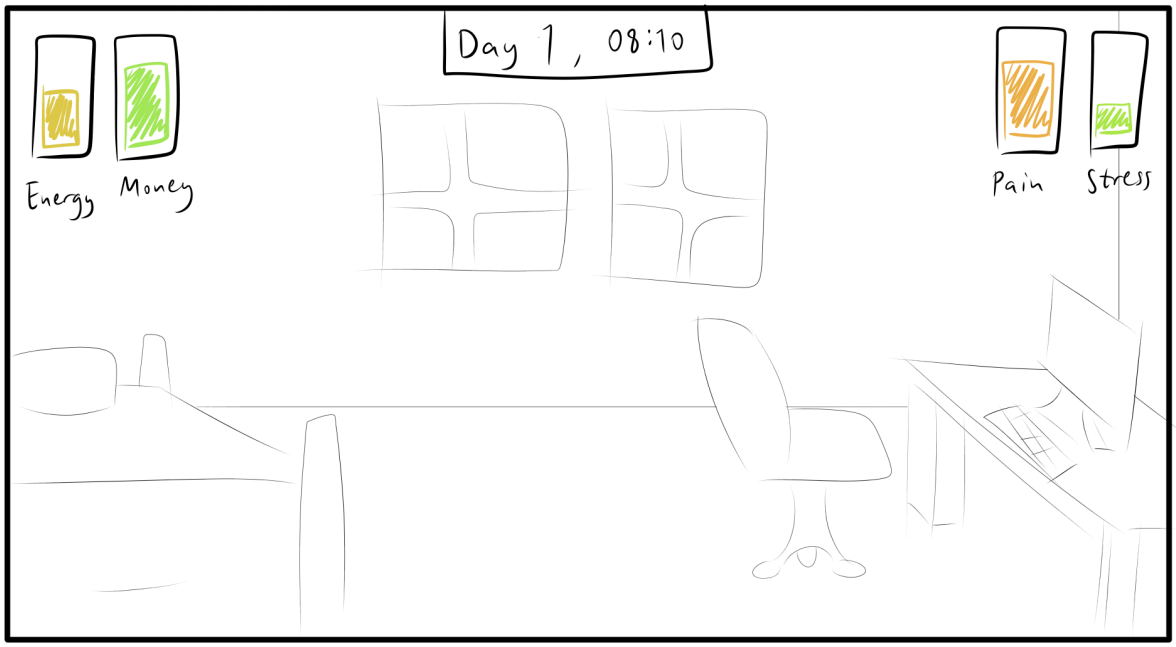
https://itch.io/game-assets/tag-renpy/tag-sprites
Example for assets:
- https://butterymilk.itch.io/sugary-life
- https://potat0master.itch.io/
- https://sraye.itch.io/
- https://witching-metal.itch.io/character-silhouettes-bureaucrats (silhouettes if we want to use for crowds or background characters etc.)

3.3 User interface

Possible bars:
- Energy
    - Can increase when sleeping, resting, eating?
    - Can decrease when doing physical work, exercising, socialising for too long, etc.
    - Decreases faster when pain high
- Pain
    - Can increase when doing chores, physical activity, etc.
    - Can decrease when resting/sleeping, physical therapy?
- Morale
    - Can increase when relaxing, doing something fun, spending time with loved ones, etc.
    - Can decrease when skipping meals, overworking, having bad interactions, etc.
    - Decreases faster when energy low and/or pain high
- Money
    - Increases when working

- Decreases when buying things (food, transportation, medication, etc.)

Example sketches:



4 Audio

4.1 Music

https://incompetech.com/music/

- “Autumn Day” - calm, bright, good for better days
- “Evening Fall (Piano)” - somewhat dramatic, could be used for serious scenes
- “Bittersweet” - calm but sad

4.2 Sound effects

https://pixabay.com/sound-effects/ for example

-

5 Gameplay

5.1 Game controls

- Main gameplay mouse and/or keyboard shortcuts (such as space for next line of dialogue, s for save, etc.)
- Maybe some minigames with different controls to try to imitate why some tasks might be difficult (for example pressing keys that are far apart on the keyboard while also using the mouse) (rhythm game?)

F

Appendix: Pilot Study Protocol

This interview protocol has been translated from Swedish.

- Explain what EDS is and what our project is about.
- Let them try the game.
- *What do you think?*
- *What do you think about the controls?*
- *How well do you think a game like this can raise awareness about EDS and chronic illnesses in general?*
- *Anything else?*
- Thank them for their help.

G

Appendix: Consent Form

Consent form

* Indicates required question

1. Ditt namn: *
   Your name:

2. Dina personuppgifter skyddas enligt GDPR. Informationen du ger under testet/intervjun kommer endast att användas inom vårt examensarbete, och distribueras inte. *
   Your personal data is protected in accordance with GDPR. The information you give during the test/interview will only be used within our master's thesis, and will not be distributed.

   Mark only one oval.

   ◯ Jag accepterar / I accept

H

Appendix: First Test Protocol

This interview protocol has been translated from Swedish.

- Is it realistic? Or close enough to get an okay understanding?
- Is there anything wrong/incorrect?
- Is there anything you think is missing and should be added for people to get a better understanding? Or anything that should be removed?
- Anything else?

I

Appendix: First Test Thematic Analysis

Figure I.1: Controls and gameplay

Figure I.2: Story, visuals, audio

Figure I.3: Energy, pain, mood

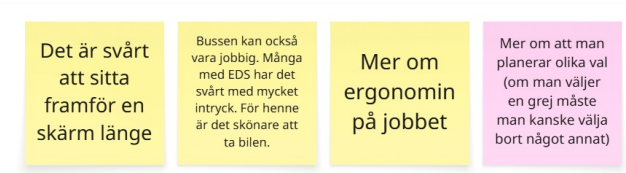


Figure I.4: Other feelings

Figure I.5: Aids

Figure I.6: Went to the doctor or not

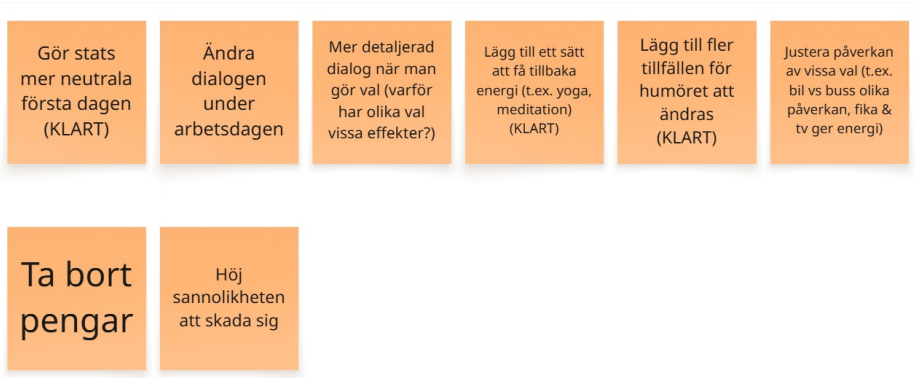


Figure I.7: Conclusions (what should we change?)

J

Appendix: Second Test Protocol

This interview protocol has been translated from Swedish.

Before the test

- Do you know what EDS is?
  - If yes, what do you know about it?
  - How do you know about it?
- Explain briefly what our project is about and how the test will be conducted
- Consent about how the information will be used

After the test

- How did it feel to play the game?
- Can you describe EDS based on what you understood from the game? Do you feel that you know more about EDS now than before?
  - Medical/social/financial aspects: can any be emphasised more/less?
- What did you like about the game?
- What can be improved?
- Do you think a game like this can raise awareness for EDS/chronic illnesses?

K

Appendix: Second Test Thematic Analysis

Figure K.1: Went to the doctor or not

Figure K.2: Story, visuals, audio

Figure K.3: What did they understand about EDS?

Figure K.4: Medical/social/financial

Figure K.5: Gameplay

Figure K.6: Can it raise awareness?

Figure K.7: Conclusions

L

Appendix: The Game Prototype

Here is a link to the prototype after the final changes were made.
https://she-likes-birds.itch.io/ett-spel-om-eds-nedladdning