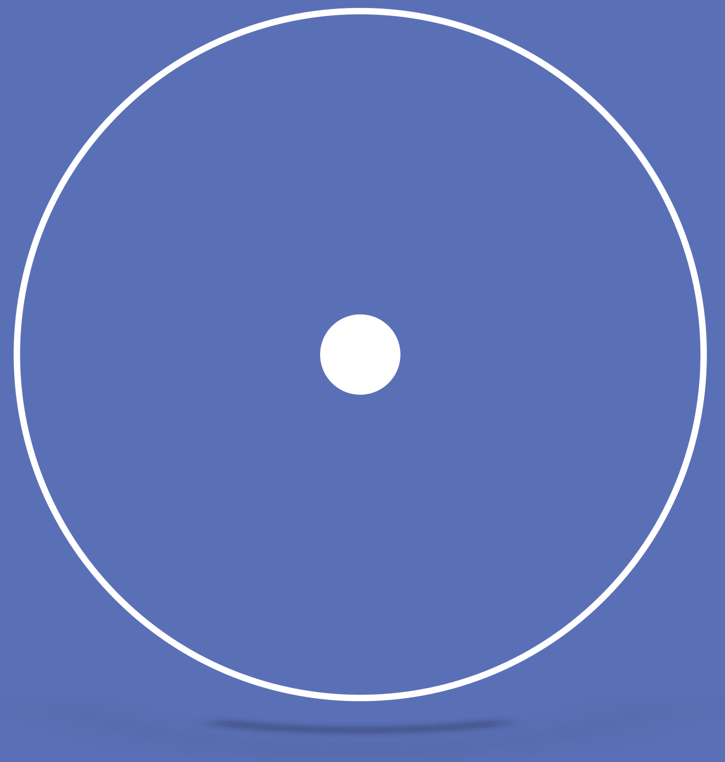
The consultation of the future

A tool to make the communication between patients and specialists more emphatic in the digital world of 2030



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September 2019

Master Graduation project
The consultation of the future: A tool to make the communication between patients and specialists more emphatic in the digital world of 2030

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September 2019

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Preface

Welcome to my graduation report! This report marks the final step of my time as a student. I have enjoyed working on this project as no project before, and I am happy that I could contribute to such a complex problem as this graduation project describes. I could not have achieved this result without the help of many others. Therefore I would like to thank the following people:

Richard, together we have explored the consultation of 2030 and the many opportunities the context has. Thank you for your honest and clear advice and thank you for setting the guidelines of this project. You have given me confidence and trust along the way.

Caroline, what a great support you have been throughout the project. I appreciate your critical questions about the project and your advice at a more personal level. You made me feel at ease with the project and have helped me to bring to project to a deeper level.

Stephanie, thank you for opening up the doors to *the world of care*. With your help, I could talk to different experts in the field. I appreciate your time and advice.

Richard, Caroline and Stephanie, you have been a fantastic team to work with. Thank you for challenging me!

Kris en Eric, thank you for taking the time to have a look at my graduation report and putting things into perspective.

Lara en Maaike, thanks for being a continuous support along the whole process.

To my family, friends, and all others who have helped me throughout this journey: thank you.

Dear readers, enjoy!

Hanneke

Abstract

In the future, healthcare becomes more challenging to reach and less personal. The workload for specialists is increasing (Rossen, 2018), the current health path for patients is extended and long (van Tongerloo, 2019) and more general practitioners do not want to have their own practice which results in lower accessibility (Smit, 2019). Besides, the computer is often in-between the communication of the patient and the specialist when entering the consultation room (Voormolen, 2013). These developments are opposite to the ones of the on-demand society we are currently living in: people have personalised information on-demand and expect companies to understand their needs and wants on the spot (Solis, 2017). However, healthcare is, at this point, behind.

(1) The Erasmus MC has noticed this gap, and therefore, the Erasmus MC wants to implement the value-based healthcare strategy. Within this strategy, the Erasmus MC wants to focus more on the patient experience and the patient's participation in decision making during the consultation (Kimpen, 2019). So how to improve this patient experience, to align the consultation with the value-based healthcare system?

(2) Within this project, the current barriers of positive patient experience, before, during and after the consultation, are defined by an extensive literature and user study.

(3) The concept proposal, the renewed patient portal of the Erasmus MC, aims to translate these barriers into enablers of a positive patient experience. The renewed patient portal exists out of three elements: improve the patient's knowledge around a disease by giving personalised information (1), track the patient's data to get more personalised care (2), and prepare the consultation to start the conversation to the point (3).

A case study for diabetes type 1 patients, focussed on the second element of the renewed patient portal, shows a tangible example of how the patient's data can be used to give more personalised and on-demand care. The final deliverable of the case study is *Mijn Erasmus I.D.*, a visual representation of the patient's mental and physical data. *Mijn Erasmus I.D.* is a digital patient I.D. that is accessible via a platform for the patient and an interactive screen in the consultation room.

(4) An extensive validation study has proven that *Mijn Erasmus I.D.* turns all the found barriers into enablers of the positive patient experience.

(5) The aimed longterm effect is to create a more in-depth and personal conversation, within the same amount of time. *Mijn Erasmus I.D.* allows the specialists to understand the perspective of the patient better within the given amount of time by gathering the patient's information up-front.
An understanding of the patient's perspective contributes to better health outcomes at a physical, psychological and social level (Street, Makoul, Arora, & Epstein, 2009).

The research, the design goal, the concept proposal (the renewed patient portal) and the case study (Mijn Erasmus I.D.) are evenly important to inspire healthcare for future innovation.

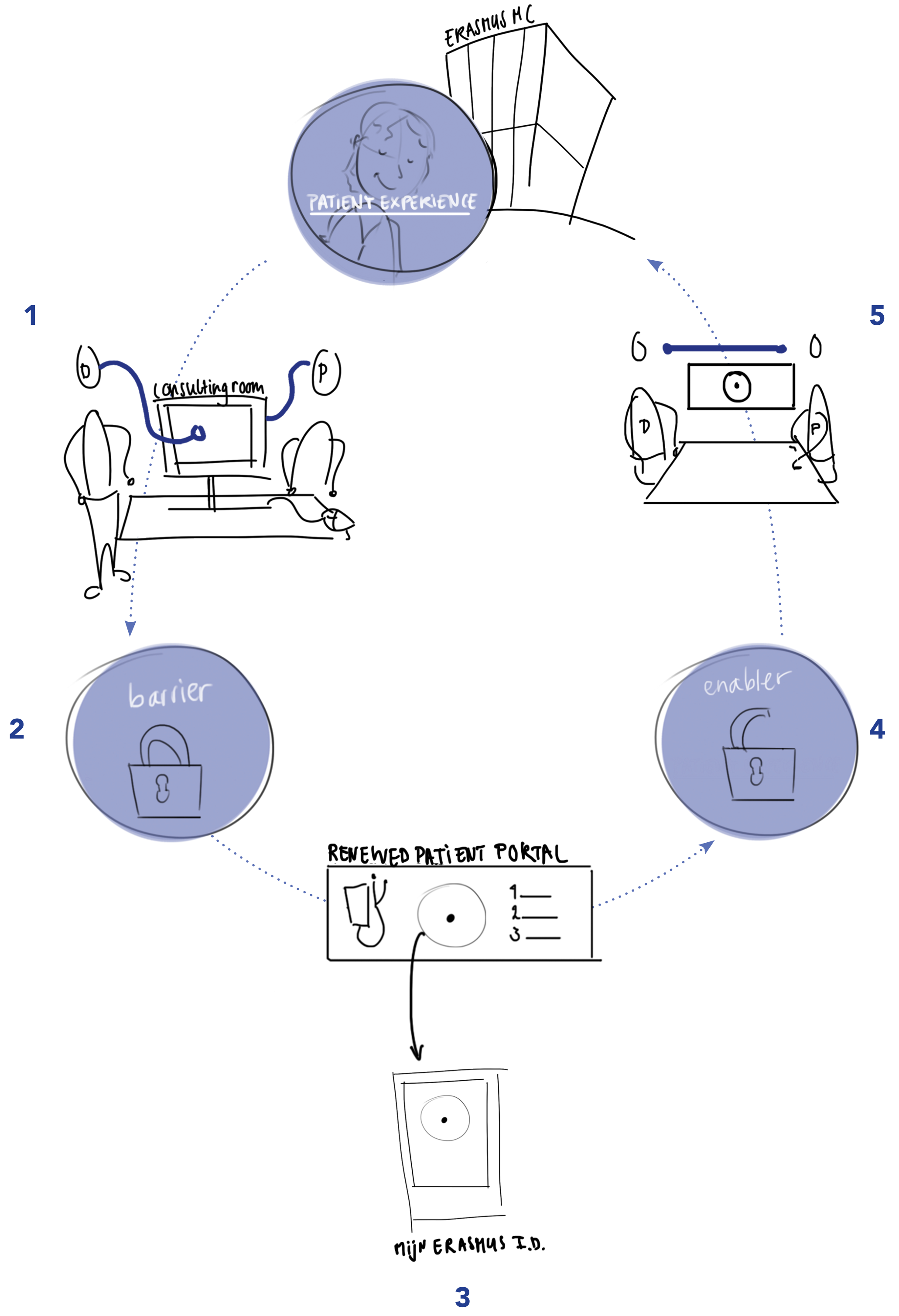
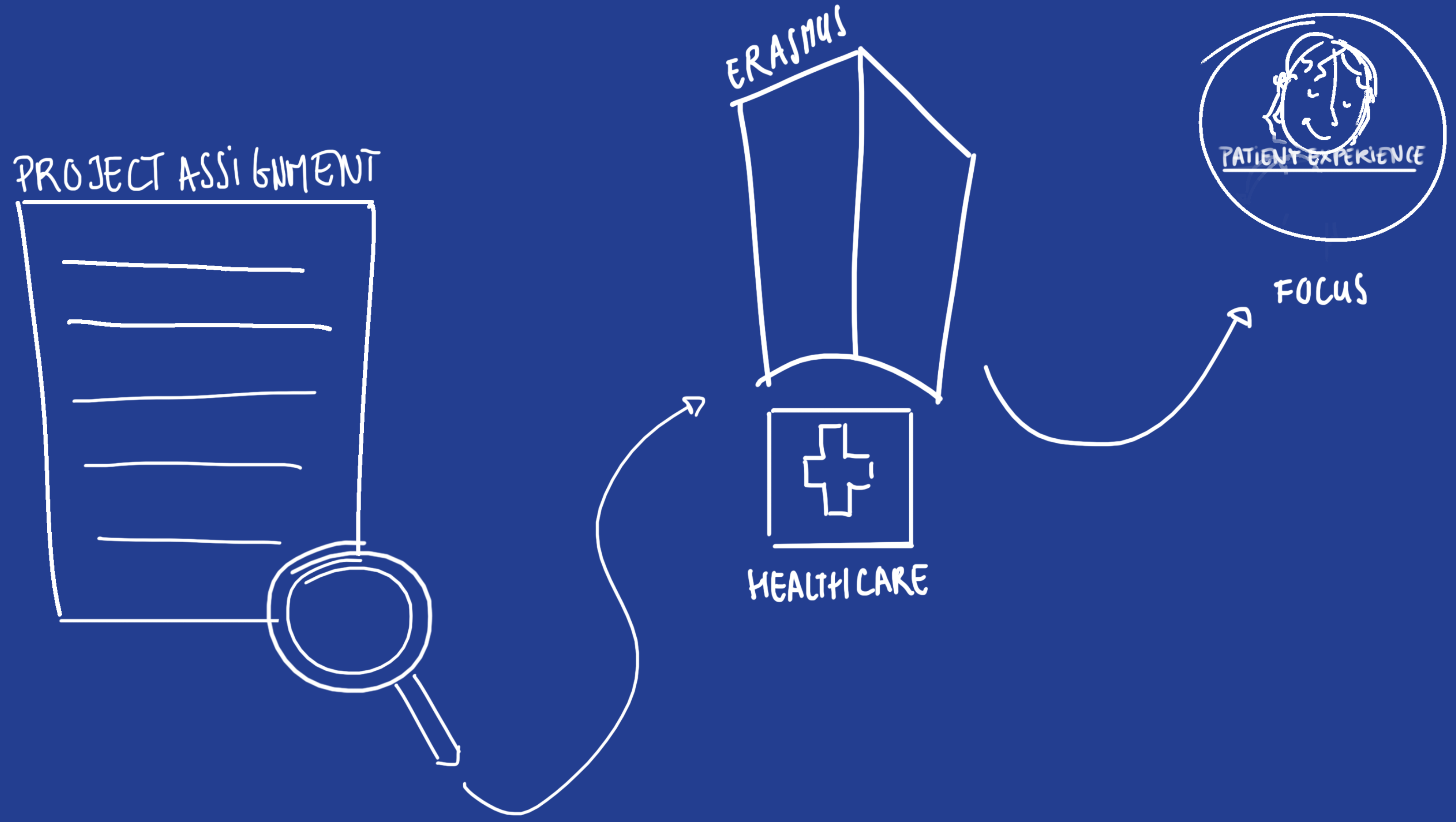


Figure 1: the visualisation of the content

Content

01 INTRODUCTION



This chapter describes the outline of this graduation project: what is the project context, what is the focus of this project, and how did the designer approach this project?

Within this chapter:
- *Project context*
- *Scope of the project*
- *Approach*

1.1 Project context

This project is a collaboration between the TU Delft and the Erasmus MC, and is focussed on the future context of the consultation room. The consultation room is the room in the hospital where the doctor and the patient meet each other to discuss the health path of the patient.

1.1.1 Current context

Healthcare becomes less personal and more challenging to access. The workload of general practitioners is increasing due to the responsibility for more complex treatments and the increase of ageing people visiting the doctor (Rossen, 2018). Specialists are also coping with the problem of increasing work pressure: full hospitals and fully booked agendas make their workload high. The high workload results in the referral of patients to different specialists and makes the health path extended and long for the patient (van Tongerloo, 2019). Besides, more general practitioners are choosing for not having their practice to enjoy their flexibility as an independent contractor. This preference will result in having a decreased accessibility to the general practitioners, especially in smaller villages (Smit, 2019).

The consultation room

The computer is often the jamming agent between the patient and the doctor when being in the consultation room (figure 2). Since its entrance within the consultation room, the relationship between the patient and the doctor has changed. The conversation has become way more 'professional'; the doctor often misses the non-verbal communication of the patient and the patient often stops talking when the doctor starts using the computer (Voormolen, 2013).

From the specialist's perspective, the computer has a negative side effect as well. Specialists are frustrated about the amount of administration they have to do in comparison with the time available for patient care. The current EPD (Elektronisch Patiënten Dossier) is meant to be supportive but is experienced as a burden (van der Mee, 2017). The only technology within the consultation room is threatening the empathic conversation.

These developments suggest that care becomes less personal and more challenging to access in the future, and the continuity of the health path will be harmed. This vicious circle should be broken because not knowing patients well results in more referrals and a higher number of requested diagnostics (van Tongerloo, 2019).

1.1.2 Healthcare is changing

At a higher level, these developments have not remained unnoticed, and healthcare starts to focus more on the patient experience and the patient's participation in decision making (Kimpen, 2019). The healthcare system is making a transition from the 'fee-for-service' to a 'value-based healthcare' strategy defined by Michael Porter (figure 3). This strategy uses the patient's value as one of the factors to measure the success of a hospital. This strategy defines the patient value as the patient-relevant medical outcome divided by the cost (Porter, 2014). The Erasmus MC wants to follow the value-based healthcare strategy to improve the patient experience.

Shared decision making

In line with the value-based healthcare, the Erasmus MC strives for a shared decision-making approach within the consultation room. Lee, Low, & Ng (2013) define shared decision making as:

"… a situation where the physician creates an understanding of the patient's values and beliefs and communicates their medical knowledge in an understandable way, while the patient communicates their values and preferences and has the ability to understand the relevant evidence ."

The patient values *empowerment* and *partnership* are the basis of this communication approach. The Erasmus MC aims to shift from *'what is the matter'* to *'what matters to you'* to improve the patient experience and the patient's participation in decision making within the consultation room (Jan Hazelzet, personal communication, 2019 and Kimpen, 2019).

Unfortunately, shared decision making is often not happening within the consultation room, due to time limits, the inability of patients to understand the medical information and a strong established hospital culture (Jan Hazelzet, personal communication, 2019).

Dokter, kijk eens naar uw patiënt en minder op uw computer

Figure 2: the empathic conversation disappears (image source: NRC)

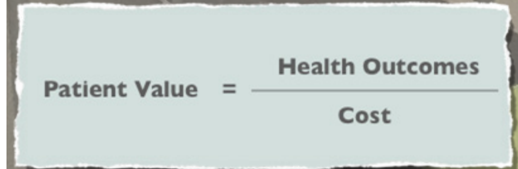


Figure 3: value-based healthcare model (Porter, 2014)

1.2 Scope

In the future, the patient experience becomes more prominent within value-based healthcare, and the Erasmus MC wants to follow this strategy. Unfortunately, the patient experience is not optimal yet due to context developments, time limits and the inability of patients to understand information. Therefore, the focus is on improving the patient experience for the future to align the consultation with the value-based healthcare system.

1.2.1 Barriers

Currently, several barriers make it difficult to establish a positive patient experience:

- Care becomes less personal and more difficult to access
- The usage of the computer during the consultation is interrupting the human, empathic conversation.
- Time constraints and the inability of the patient to understand medical information makes shared decision making difficult, which does not benefit the patient's empowerment and partnership
- The Erasmus MC believes that care should be more extended in the future. Care does not stop at the hospital's doors anymore, but currently, it does stop at the hospital's doors.

1.2.2 Project assignment

This context offers excellent opportunities for future improvement, using technology as a leading asset. It has already been 25 years ago when the first computer was launched and technology has progressed ever since. The starting point for this graduation project is therefore:

How to improve the patient experience before, during and after the consultation, to align the consultation with the value-based healthcare system, using technology as a leading asset?

1.3 Approach

The double diamond model (British Design Council, 2005) in figure 4 visualizes the approach of this graduation project. The project is divided into four steps: discover, define, create and deliver. These steps act as the foundation of the creative process that has led to the final deliverable.

The DISCOVER-chapter describes the analysis phase, where the current and future context of the consultation room and the patient experience are explored by desktop research, literature research, interviews and observations.

The DEFINE-chapter summarizes the findings of the analysis in a design vision, a design goal and an interaction vision.

The CREATE-chapter describes the iterative design process, in which different design techniques, creative sessions and evaluations form the basis of the final proposal.

The DELIVER-chapter describes the final deliverable of this graduation project. The final deliverable is a case study that shows how the chosen working principle works for a specific target group.

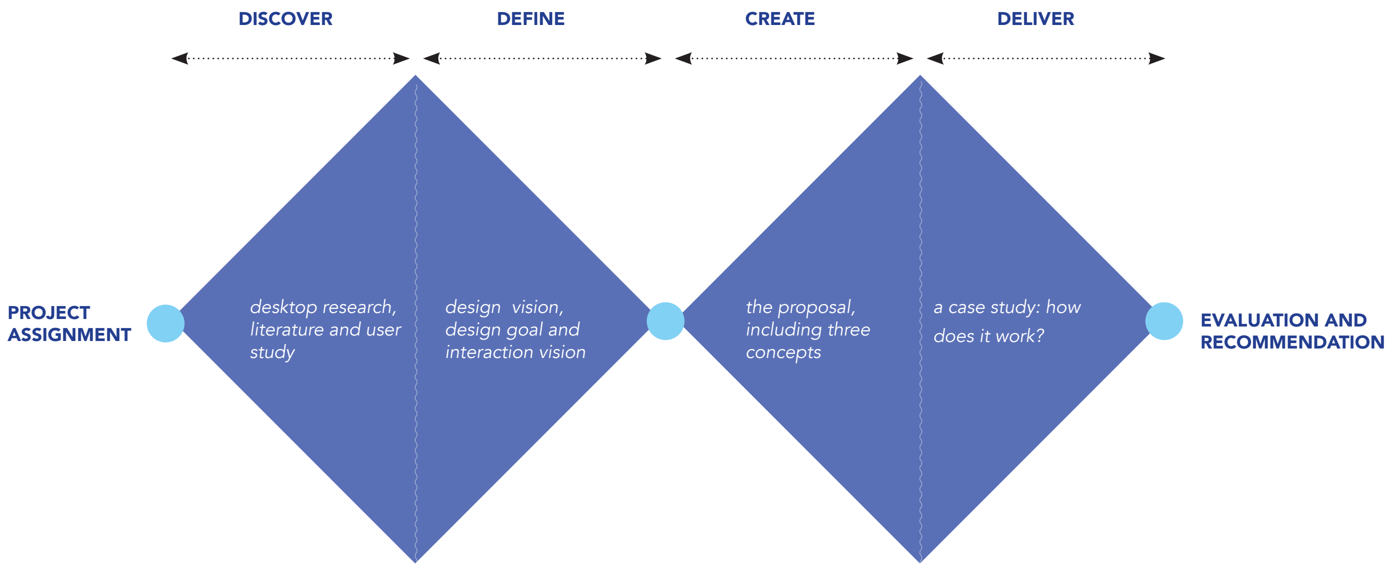


Figure 4: the design approach

02 DISCOVER

This chapter describes the analysis part of this graduation project, focussing on finding the current and future barriers of the patient experience. This analysis contains a literature study, desktop research and an extended user study.

In this chapter:

- *Patient experience*
- *Future context*
- *Touchpoints of experience*
- *Main insights (the barriers)*

2.1 Patient experience

The focus of this project is on improving the patient experience. Therefore it needs to be known which elements define the patient experience and how these elements can be influenced. This paragraph explores and describes the four key elements that define the patient experience.

2.1.1 Defining patient experience

In literature, many definitions are found on what patient experience is. Researchers use different ways to measure patient experience, which results in different factors that influence the patient experience. For this project, the following definition for patient experience is used:

"The sum of all interactions, shaped by an organization's culture, that influence patient perceptions across the continuum of care." - (Wolf, Niederhauser, Marshburn, & LeVela, 2014)

This definition gives an overview of the four key elements that define the patient experience:
1. Interaction
2. Perception of patient
3. Culture
4. The continuum of care

The definition is based upon an extensive literature review between the years 2000-2014, reviewing 18 articles and organizational websites (Wolf, Niederhauser, Marshburn, & LeVela, 2014).

Patient experience exists out of the emotional and physical part of the experience. This project focusses on the emotional part that contains the touchpoints of contact between the patient and the people that cross their health path (the general practitioner, specialists and nurses). The physical patient experience of the complaint, such as the patient's coping's mechanism, is out of scope.

2.1.2 Interaction

The first key element is interaction. Communication acts as the foundation to create a comfortable patient and specialist interaction. Street defined seven pathways in which communication can benefit better health outcomes, at a physical but also psychological and social level (Street, Makoul, Arora, & Epstein, 2009). With this communication model, Street suggests that when the communication between the patient and specialists fulfils these seven pathways, the patient experience is more positive (figure 5). Within the next pages all seven pathways are briefly discussed and placed into the current context.

1. Accessibility of care

For patients, is it essential to have low barriers to access care, but several barriers can be named:

- Economical: can I pay the visit to the doctor?
- Knowledge: is it necessary that I go and see a doctor?
- Logistics: do I know where I can find the correct information (online, offline)?
- Ability: do I have the ability to go to the doctor, or do I need help?

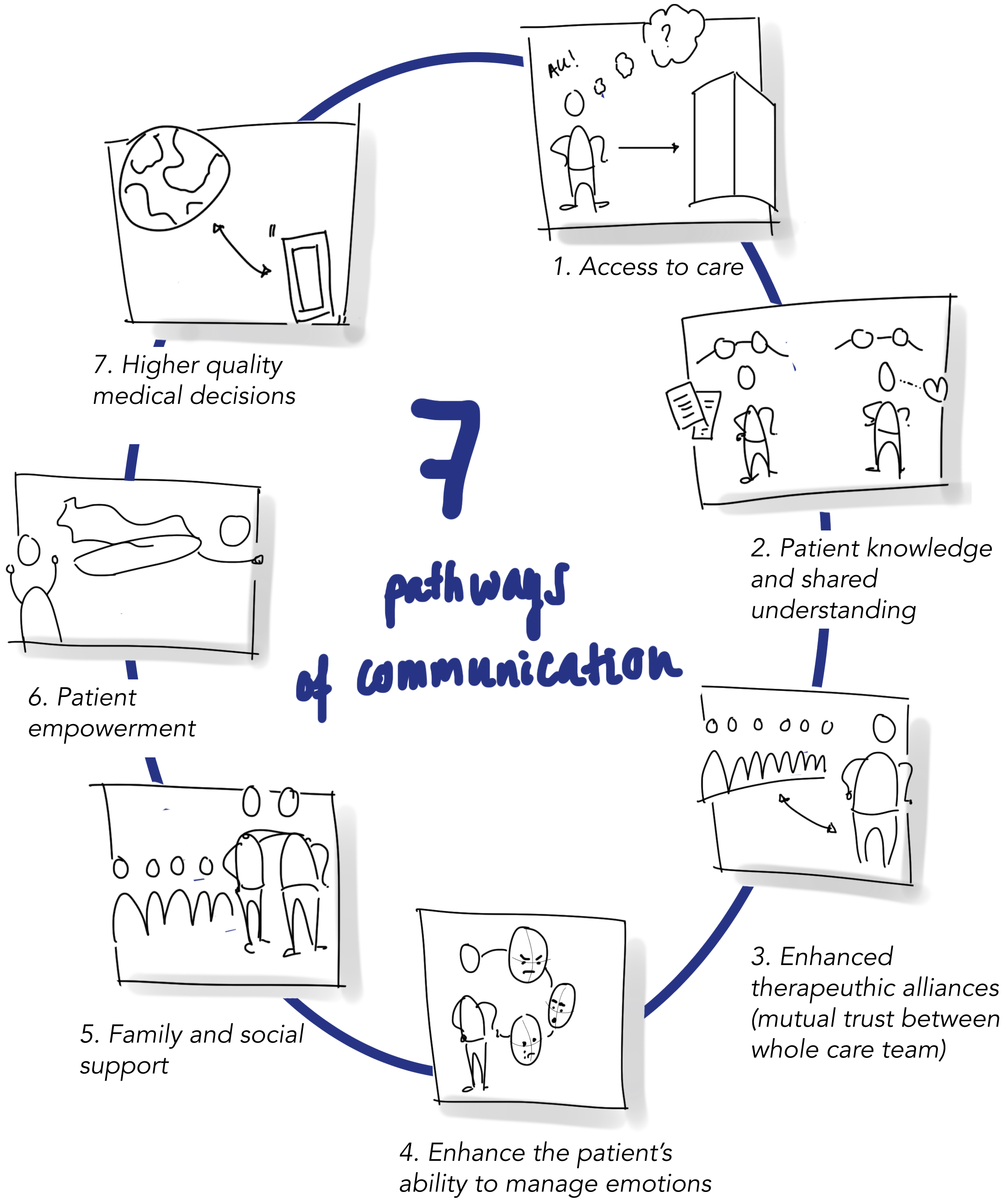


Figure 5: pathways of communication

Nowadays, the internet lowers the barrier of having access to medical knowledge. Unfortunately, it is confusing for patients to distinguish which information suits them the best (Edwards, Davies, & Edwards, 2009).

2. Patient knowledge and shared understanding
In the perfect situation, both the patient and the doctor have an understanding of each other's perspective, which is called shared understanding (Epstein, 2004). Unfortunately, reaching the state of shared understanding is often not happening due to:

- The inability of a patient to understand the information
- The impatience and the lack of time of a doctor to explain the medical information

This gap of non-understanding can lead to a misdiagnosis or a non-acceptance of the treatment method (Luxford & Sutton, 2014 and Edwards, Davies, & Edwards, 2009), which is unbeneficial for the patient experience.

Currently, the Dutch government stimulates doctors to use tools that help to create a shared understanding, but they are often expensive and therefore not used.

3. Mutual trust between the whole care team
The feeling of mutual trust between a medical team leads to a safe and trustworthy environment for the patient (Street, Makoul, Arora, & Epstein, 2009). Unfortunately, trust between the general practitioner and specialists is not optimal yet, and the quality of the communication is not valued mutually (Berendsen et al., 2009). This distrust between the specialists affects the patients the most: patients need to tell their story over and over again. Jelmer Alsma (internist, Erasmus MC, personal conversation) also confirms the distrust between specialists: *"do not trust anybody, not even yourself. Always check the options again."* The distrust makes the health path of the patient extended, long and repetitive.

4. Managing emotions
Negative emotions can have a negative effect on the emotional well-being of a patient. When a patient does not have the ability to manage those emotions properly, the emotions can harm a positive patient experience. Patients can be helped in managing their emotions by giving them control over their situation and providing clear information about their care options. Currently, doctors can not help patients optimally with managing their emotions. According to Patrick Krastman (general practitioner, interview), *"it takes more than 10 minutes to reach an emotional level within a conversation. Doctors simply don't have the time."* The current consultation time is too short to reach the deeper level within the consultation.

5. Improving family and social support
Social connections can act as a safety net for patients outside the consultation. By improving their social support, the feeling of connectedness within the whole health path is enhanced. The internet opens up possibilities to connect with people with similar experiences and complaints (Rozenblum & Bates, 2013), but it also confuses patients since they are not able to distinguish which information suits them the best (Edwards, Davies, & Edwards, 2009).

6. Enhancing patient empowerment and agency
If a patient is actively involved in their health process, they are likely to have better health outcomes and care experiences. Hibbard & Greene (2013) define a higher involvement as having more knowledge and skills to manage your disease, which will contribute to a better level of shared understanding.

Hibbard and Greene have identified three ways to increase patient involvement:

- Give the patient control over their health process by providing them tools to manage themselves (such as knowledge or peer support).
- Make patients aware of the influence of their behaviour on their physical and mental health.
- Adapt the information to patients' needs and preferences — somebody who is low involved benefits more from smaller tasks because those tasks are more likely to be within their reach, than someone who is highly involved.

7. Higher quality medical decisions
Making decisions based on the latest medical evidence will establish a high-quality decision, which benefits the health outcome. Currently, there is no such thing as a world medical evidence database. Therefore, it is happening that different physicians give different advice, based upon the same complaint (Street, Makoul, Arora, & Epstein, 2009). Getting different advice from different specialists is not beneficial for the mutual trust between specialists and patients (point 3). However, when having such thing as a world medical evidence database, challenges specialists to explain the medical evidence clearly, to keep into account the possible medical complications, and to connect it to the patient's needs and wants (see point 2)

Conclusion:
The patients physical and psychological health outcomes can be improved by using these seven pathways as a guideline. This paragraph shows that there is still room for improvement within all seven pathways, concerning the current consultation.

User study insight:
Identify how the current interaction between patients and the Erasmus MC is going, how do both doctor and patient experience the current consultation? Also, is shared understanding reached within the current consultations?

2.1.3 Perceptions

Perception is the second key element of patient experience. Perception is defined as the way somebody understood, remembered and interpreted a specific situation. Perceptions are based on individual values, experiences and beliefs (Cambridge Dictionary).

1. Patient values
As can be read in paragraph 1.1.2, the patient values are a leading factor within the value-based healthcare. Research had identified seven patient values (Bastemeijer, Voogt, Van Ewijk, & Hazelzet, 2017):

- Autonomy
- Uniqueness
- Partnership
- Empowerment
- Compassion
- Responsiveness
- Professionalism

However, these values are changing; patients have more medical knowledge through the internet and doctors have more treatment options due to developing technologies. These different options bring different expectations with them, which results in a higher chance of conflicting expectations and values. When having a conflicting value, it often leads to a miscommunication while having the same values it is often not noticed (Petrova, Dale, & Fulford, 2005). These conflicting values influence the way a patient remembers and understood the consultation.

Research on the possibility of the conflicting values of the patient and the specialist before, during and after the consultation is limited, stated by Bastemeijer, Voogt, Van Ewijk, & Hazelzet in 2017:

"... enriching it with the dynamics between preferences and values and the possibility of conflict between the preferences and values of the patient and those of the professional. "

By understanding the differences between the values of the patient and the specialist, the values can be brought closer together to prevent a miscommunication and thus contribute to better patient experience (Bastemeijer, Voogt, Van Ewijk, & Hazelzet, 2017).

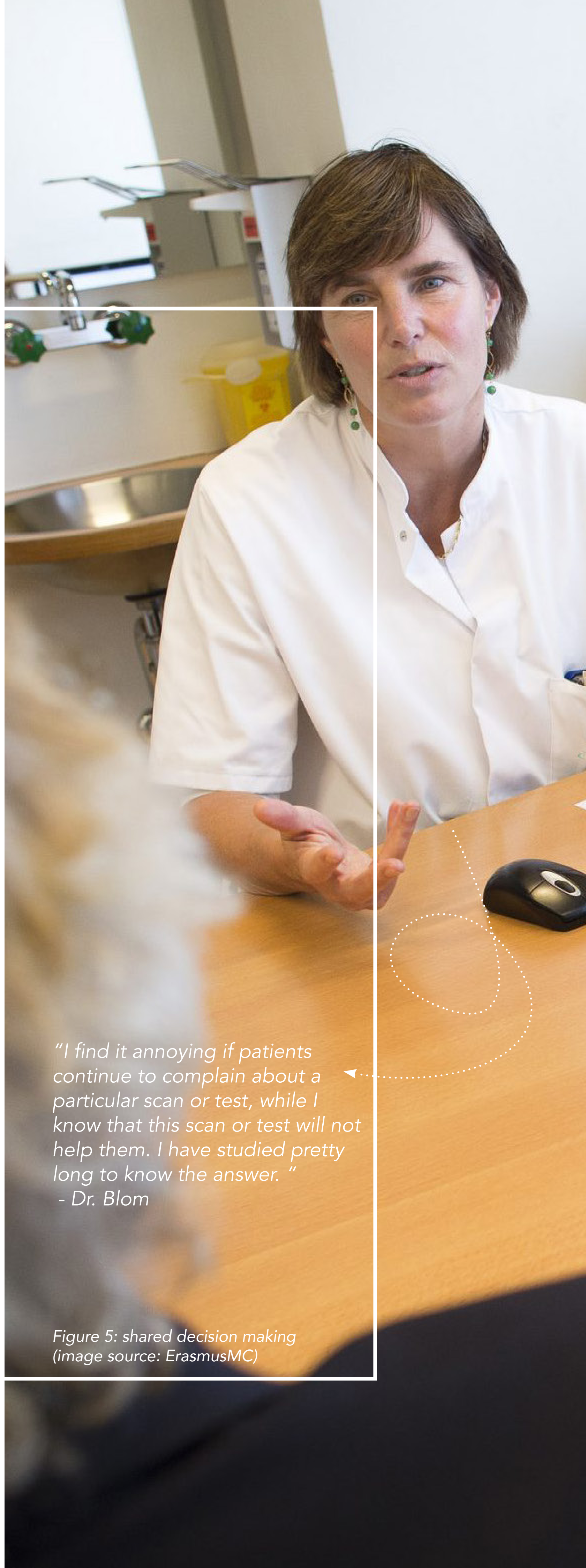
2. Experiences and beliefs
Nowadays, people experience more experiences through others, since more people share their experiences on the internet (García Guaita, 2017). People prepare their consultation by googling their complaint, and they immediately build a context around it. Finding medical knowledge and different experiences and beliefs of other patients on the internet makes the patient-doctor relationship more challenging (Chandra, Mohammadnezhad, & Ward, 2018). Patients are not able to distinguish which information suits them the best, but they often take their medical analysis, based upon their Google results, as a leading asset of the conversation. It becomes more complex to figure out what a patient really needs within the consultation, which costs time (Edwards, Davies, & Edwards, 2009).

Often, the time in the consultation is therefore not spend based upon the patient's preferences which influences their consultation perception. However, spending the time based upon the patient's preferences, has a positive influence on the patient satisfaction (Cape, 2001).

Lastly, physicians tailor their information within a consultation based upon their perception of the patient (Dekkers, Melles, Mathijssen, Vehmeijer, & Ridder, 2018). Unfortunately, this tailored information does often not meet the patient's expectations of the information. The perception of a doctor is, therefore, not a trustworthy starting point for tailoring the information.

Conclusion:
It becomes more challenging to distinguish what a patient wants and needs in a consultation in order to give them quality time. The (future) values, experiences and beliefs of a patient need to be taken into account to establish a positive patient experience. However, in this digital area, it is difficult to know what those values, experiences and beliefs are. The perception of patients is changing.

User study insight:
Identify the conflicting values of the specialist and the patient (knowledge gap according to Bastemeijer, Voogt, Van Ewijk, & Hazelzet, 2017), to bring the values of the patient and doctor closer together. In this way, this project can serve as a first an inspiration of how the value-based healthcare strategy can be implemented.



"I find it annoying if patients continue to complain about a particular scan or test, while I know that this scan or test will not help them. I have studied pretty long to know the answer. "
- Dr. Blom

Figure 5: shared decision making
(image source: ErasmusMC)

2.1.4 Culture of the organization

The change to the value-based healthcare system implies a change within the culture of the hospital. For the Erasmus MC this means that the conversation shifts to '*what matters to you?*', introducing the shared decision-making approach. Three key elements of this culture shift are listed below, the first element being beneficial and the last two being detrimental to the shift:

1. The doctor is not god anymore
Back in the days, the doctor has always been the one 'who knows it all', which automatically means that the patients have a submissive role within the conversation. Within this role division, there is no space for communicating personal needs and values to the specialist (Edwards, Davies, & Edwards, 2009). With the implementation of shared decision making, the role of the doctor is slowly changing to an equal conversation partner. The doctor becomes the patient's supporter, making space for a conversation where the patients' needs and values do have room.

2. No guidance for the patient
The communication model of shared decision making is taught to future doctors. They learn to have a conversation about values, needs and preferences. Unfortunately, there is no guidance for the patients. How do they know that the communication model within the consultation room is changing? The Erasmus MC believes that patients will finally understand that shared decision making is the new standard. It seems that there is a lack of guidance for the patient to facilitate this change to shared decision making.

3. A culture change is difficult
Future doctors will continuously learn from current doctors. The current doctor is taught to have the 'I-know-it-all' attitude. They believe that they are the responsible person within the decision. Since future doctors learn from the current doctors, changing the behaviour is difficult. Also, for doctors, it would be beneficial to have a guiding tool that helps them to establish this change.

" Doctors need to implement this shared decision making without being trained for it. They have learned to act like the one who needs to tell the patient what they need to do." (Jan Hazelzet, personal conversation, 2019)

Conclusion:
The culture within the hospital is changing, but guidance is missing to make this change understandable and possible to both patients and doctors.

Figure 6: operation (image source: Upwellbeing)

2.1.5 Continuum of care

The patient experience hides within all the points of interaction along the whole health path. Two vital takeaways are found concerning the continuity of the current health traject:

1. No continuous system
In Appendix A, the touchpoints within the current health path of a patient can be seen. As stated in the Introduction, the current health traject is not 'continuous and fast'. There are many ways of interaction before the patient has an appointment at the specialist; sometimes, patients need to wait for months. Unfortunately, the waiting times for specialists become only longer in the Netherlands (Kempes, 2019).

2. The patient-doctor relationship is key
Having the same doctor influences the treatment plan, patient satisfaction and the perceived quality of the healthcare (Eustice, 2003). Having the same doctor with whom the patient has a shared history, benefits the feeling of being cared for. This history ensures that a doctor recognizes the change in the patient's appearance and thus in their health. Secondly, it is preferred to discuss emotional problems with a known doctor too.

However, embarrassing problems are preferred to be discussed with an unknown doctor, and for small problems, the patient often does not care to whom they are going to. It is essential to realize that the decision to which doctor they want to go is within the patients' control.

Conclusion:
For improving the patient experience, the patient and a doctor must have a shared history to understand the differences in the health path of the patient better. The shared history will gain trust.

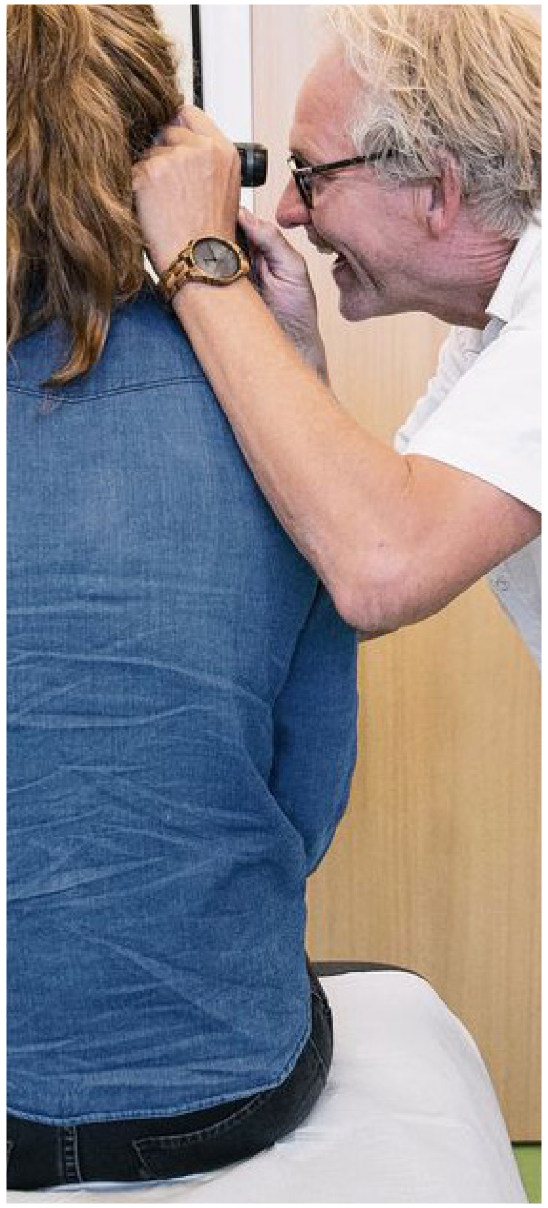


Figure 7: general practitioner (image source: NRC)

2.1.6 Conclusion patient experience

Interaction, perception, culture and the continuum of care are the four key elements of patient experience. Down below the conclusion of the chapter patient experience is given:

Shared understanding can be reached by:
- Increasing the patient's knowledge
- Understanding the patient's perspective (values, needs and preferences)
- Increasing patient involvement (control, awareness, adaptive information)

Currently shared understanding is often not reached due to:
- The inability of a patient to understand the information
- The patience and time of a doctor to explain the medical information
- The lack of guidance in facilitating this new way of communicating

- The internet opens up possibilities for social connections and sharing experiences between patients, but it changes patients expectations and values during a consultation. Patients and specialists 'trade' medical evidence during the consultation. The trade brings the relationship between the doctor and the patient in a disbalance.

- The given information is based on the specialist's perception of the patient. This perception is not always the right fundament for the information stream. Therefore the information does often not meet the patient's information needs.

- The current health process is not continuous and smooth, and the patient needs to wait for long times in order to get an appointment at a specialist. When finally be in the consultation, having an emotional conversation is often not possible due to time pressure.

2.2 Future context

In this paragraph, an exploration of the future context is described, focussing on the society as a whole, the healthcare system and technology developments. The focus is on the year 2030.

2.2.1 Society change

Technology has changed the way people interact with each other, but also the way we live together. Instead of looking around and asking a stranger for the way to go, mobile phones and GoogleMaps are our best friends. In 2030 people will rely more than ever on their mobile devices; they are super connected and will have access to their data through one account. Sharing and having all this data results in people having an online and an offline identity by the year 2040 (Tal, 2019).

By living in an on-demand, always-connected environment, people get impatient. People are craving for instant gratification and fulfilling their needs on-demand, and this also counts for healthcare. For this reason, virtual assistants and interactive wearables are essential for guiding people through the enormous amounts of data they are exposed to, to give them the information that suits them the best (Solis, 2017).

2.2.2 The 2030 healthcare system

According to the Institute of Medicine, four main points need to be taken into account when looking into the healthcare system of the 21st century (Wolfe, 2001).

1. Evidence-based healthcare
In the year 2040, technology makes it possible to shift to a more data-driven, evidence-based online environment for healthcare. Real-time data tracking, healthcare sensors, wearables and a (worldwide) database with evidence-based information make it possible for doctors to track individual patients and patient groups at a distance (Kraft, 2014 and Mesko & Anderson, 2017). The individual data tracking provides the input of the (worldwide) healthcare database on which the healthcare and the users will rely on in the future. Healthcare changes from an individual healing system to a prevention and community-based system (Mesko & Anderson, 2017 and Twillert, 2016).

2. Using information technology
By using the internet combined with smart systems, communication and advice can become more personal and structured. Sharing information via the internet result in automated systems that can react to specific, personalised data (Mesko & Anderson, 2017). Luckily, moving to a more online environment is widely accepted by patients according to the Intel Innovation Barometer. More dan 80 % of the people want to share their health data online (Intel Innovation Barometer).

3. Align payment with the quality of care
The value-based healthcare strategy already covers this point. The payment of care will be linked to the quality of

care, by focussing on the patient values and the relevant health outcomes (Porter, 2014).

4. Taking the doctors and patients into account
The context of healthcare will change, which means that also the relationship between the patient and the doctor will change. In 2030, healthcare will not talk about 'patients' anymore, but about people who manage their health (Bakker, 2016) and the doctor's attitude towards 'patients' will therefore change. Both doctors and patients should be guided towards this change.

2.2.3 Change of the physical hospital

As a result of those four main changes, the physical hospital will change. Due to evidence-based healthcare, fewer patients have to stay at the hospital. The hospital becomes, therefore, smaller, since only the patients that require immediate care need a physical healing environment (Van Namen, 2018).

The way a hospital treats their patients in 2030 will change as well. Instead of having the responsibility as a patient to go to different specialists, the different specialists will cross the patient's health path. There will be one responsible person within the care team that guides the patient through the health traject. This different way of working makes healthcare entirely focussed on the patient's needs (Twillert, 2016 and Jaap Harlaar, personal conversation with Boris 't Hart).

Conclusion:
Healthcare goes to a more personal, continuous and prevention-based system, where technology is an excellent support to the care team. Technology such as A.I. can help specialists to make sense out of all the patient data that is collected. In 2030 technology will not take over the doctor's role, since the vital asset of the doctor is, and will always be, empathy and trust (Ruys, 2019). Figure 8 shows a visual overview of the healthcare system of 2030.

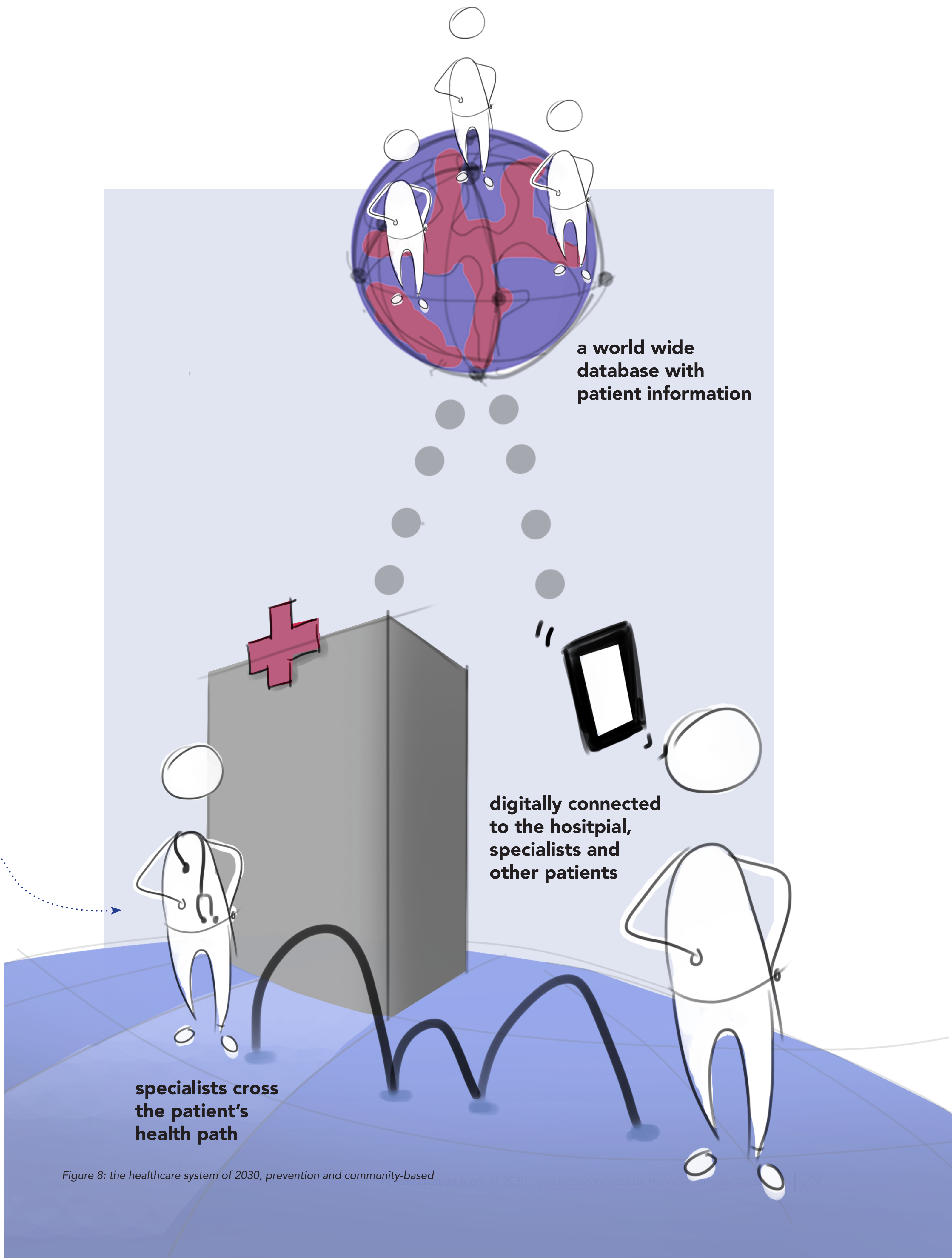


Figure 8: the healthcare system of 2030, prevention and community-based

2.2.4 The role of technology

How does the consultation room fit within this future context? How will the communication between patients and doctors change? Also, what are the new technology developments that can stimulate better communication in the consultation room?

To give a more specific impression of how the consultation can be influenced by technology in the future, a roadmap is made (figure 9). At the beginning of a design process, a roadmap can be used to explore the context of the project and to create opportunities for design. In this way, a solid structure is created that serves as inspiration for design directions (Phaal, Simonse, & Ouden, 2008). This roadmap predicts how the current consultation will develop over the years to reach the future vision of healthcare: *an intimate, continuous and prevention-based environment*, keeping into account the society change (why) and technology developments (how). Horizon 1,2 and 3 explain the change in three steps — the detailed explanation of the three horizons (H1, H2 and H3) is at the next page.

Conclusion:
Based upon the roadmap, three significant opportunities for the future are determined.:

1. The role of the virtual assistant is increasing: people get more impatient and want their information on demand. The virtual assistant helps them to give guidance in the information overload.

2. The interaction with our mobile devices will shift from 2D to 3D interactions: this shift means that VR, AR and holograms will be used when communicating with each other or with devices.

3. The line between the physical and virtual space will disappear: people will meet each other in the virtual space and can even touch elements within the virtual space.

Although technology is going to play a massive role in health care, ethics should not be forgotten. Technology can not replace everything. It should be understood what the possible negative impact of emerging technologies can be, before implementing it.

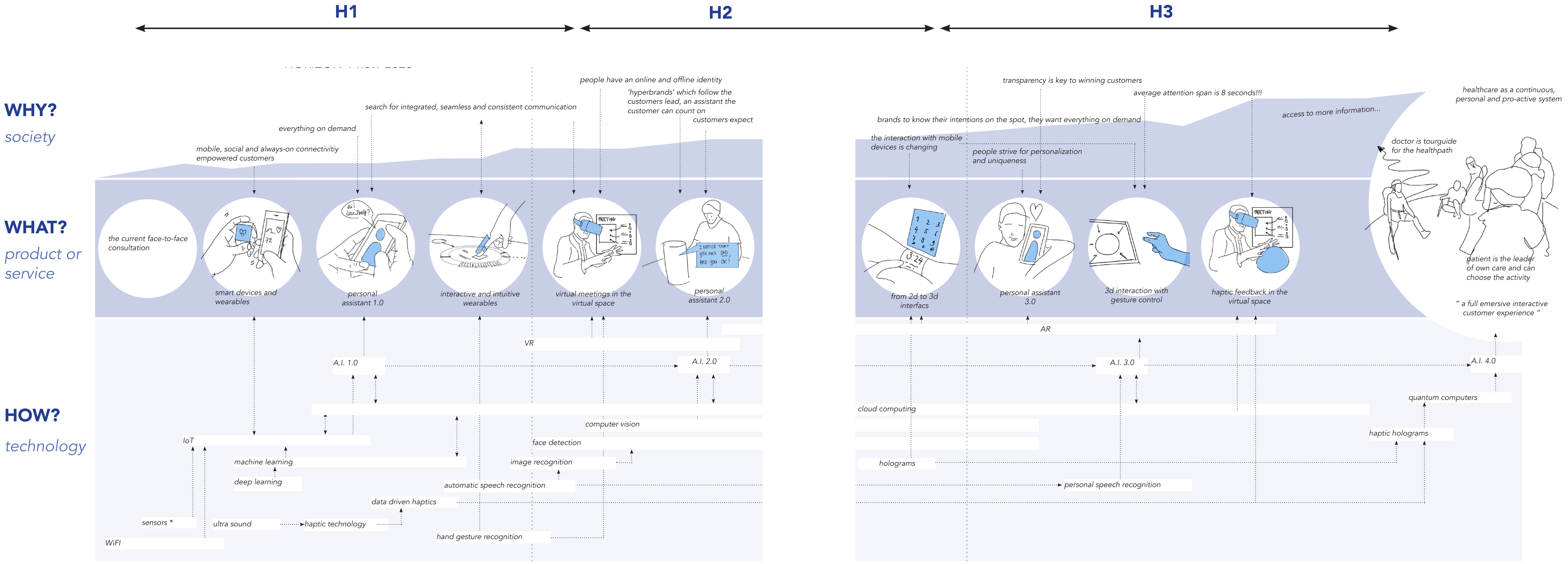


Figure 9: technology roadmap

EXPLANATION OF THE ROADMAP

Horizon 1: now-2025

Wearables to track data - Customers aim for convenience, and they expect brands to understand their needs and wants on the spot. Tracking customer data in real-time becomes a necessity to address peoples needs quickly (Solis, 2017). This data will be collected and communicated by (interactive) wearables, which makes people super-connected. They will have access to their data by having one account, which links to different data streams. In this way, people start creating an online identity, which is as important as their real-life identity (Tal, 2015).

Assistant 1.0 - Living in an online and on-demand community, people get impatient when they do not get what they want immediately (Solis, 2017). Personal assistants, A.I. 1.0, give people the on-demand information they prefer. They give suggestions based on their data, which is collected by their wearables. The development of machine learning, deep learning, IoT and the cloud supports the progress of A.I. technology (Rudin, 2017 and Tal, 2018).

More intuitive interaction - The interaction with devices becomes more intuitive than it is nowadays. Wearables enter the market that can make a surface interactive due to the use of movement, location, orientation and force the user uses. The system understands how the user is behaving, based upon these variables, and acts upon their movement behaviour. Swiping in the air and using hand gestures to interact with a device is 'the' new thing. For this interaction, external devices are necessary (graspable, wearable or touchable) to guide your movement (Olewitz, 2015).

Horizon 2: 2025 - 2030

Interaction between people in the virtual space - People are in search of convenience and on-demand interactions. Therefore virtual meetings become popular (MeetinVR, 2019). Meetings are taking place in the same virtual space without being in the same physical space (Deutsche Welle). It saves time, and it is convenient.

Assistant 2.0 - The increasing amount of data makes people more dependent on their virtual assistant, the A.I. 2.0. Since this A.I. system can make sense of all the data, the assistant becomes an extension of the user. Speech recognition and face detection can make a virtual assistant more human by only reacting to their primary user. This development is in line with the need for people to search for the human side of technology (Forbes Agency Council, 2019). The virtual assistant becomes smarter over time and will learn to understand the needs and preferences of the patients due to data tracking and emotional input of the user. According to Annette Zimmermann, "an A.I. system can recognize the emotional state of human beings in 2022 better than your own family." (Kleber, 2018).

From 2D to 3D interfaces (A.R. + holograms) - 3D holograms and A.R. will be mainstream in our daily lives. The 3D projections can be used to optimize the communication between the patient and the physician. A.R. technology can be used to explore the human body in 3D, which will make the explanation of a certain complaint easier. (Horwitz, 2018). 3D visualizations will also help to communicate better with patients that have a language barrier. Researches expect that A.R. becomes mainstream when "the computational power will be available on A.R. glasses" (Blippar, 2018).

Horizon 3: 2030-2035

Change of interaction - Since people are used to interact differently with their devices (moving more to a 3D interaction), the implementation of gesture control comes at the right time. Due to the development of radar technology, people can control devices more intuitively with gesture control without requiring extra devices. Radar technology is used to track the human hand movement and uses this information to interact with wearables and other devices by interpreting human intent (BristolIG lab, 2017). Hand gestures control devices, enabling the user to move through a 3D space (Tal, 2018 and Underkoffler, 2010). Combining gesture control with the 3D projections, it can mean that patient and doctor can move together through the 3D space, with only using their hands!

Haptic feedback in 3D interfaces - Data-driven haptics make it possible to touch things in this virtual world. "By making use of ultrasonic transducers, soundwaves can be sent to a specific point which creates a pressure level that you can feel" (Hutson, 2018). In this way, haptics can be added to virtual objects, which results in gesture control with natural tactile feedback.


Figure 10: an impression of healthcare in 2030 (image source: Philips HealthSuite)


Figure 11: an impression of healthcare in 2030 (image source: Rawpixel)

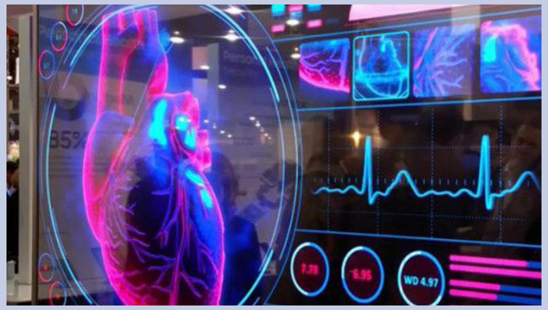


Figure 12: an impression of healthcare in 2030 (image source: Oasis City)


Figure 13: an impression of healthcare in 2030 (image source: Augmented Reality â Applications)

2.2.5 Conclusion future context

- Although technology can do a lot for us, healthcare needs to guard the conversation about the quality of life. Ethics is going to play a huge role when emerging technologies enter the healthcare system: what is the possible negative impact of emerging technologies?
- The patient is more in the lead of their care since they can track their health data, and doctors can follow their patients from a distance. In this way, care becomes more personalised, but more at a distance.
- Personal assistants become mainstream. The personal A.I. devices will become the best friend of their user. The A.I. system is used to give the user a personal and seamless experience, by understanding what people feel, think and like.
- Nowadays people have touch screens, while in 2030 people control their devices with hand gestures in the 3D space. Technology makes it possible to visualize data in the 3D space (V.R., holograms, A.R.). These technologies enable patients and doctors to make their communication more manageable in the future.
- The virtual world becomes a place where people meet each other: being digital in the same space, but physically being somewhere else. The doctor can digitally give a consultation, while the patient is still at home at the couch.

One time the doctor clicked 67 times in 3 minutes of silence!

2.3 Touchpoints of experience

How does the current context work? This chapter describes the results of the user study executed at general practitioners and the Erasmus MC. It has been decided to focus on the non-specific complaints, to unravel the complicated situation within the consultation room. Within this chapter only the conclusions of the user study are shared. The outline and the direct results of the user study can be found in Appendix B.

2.3.1 Goal

The goal of the user study is to identify the current interaction and the implementation of shared decision making within the consultation room (1) and the conflicting and matching values of doctors and patients before, during and after the consultation (2). 8 interviews and 13 observations have given a transparant insight in the current interaction between the patient and the specialist.

2.3.2 Current interaction (1)

The key takeaways of the current communication are listed below The visualisation of the communication flow can be found in Appendix B.3.

- The (digital) system the doctor uses is not intuitive. The doctor uses the system during the consultation, which makes that the physician often misses the body language of the patient.
- In the hospital, the computer had a more prominent place at the table than at the general practitioner.
- There is often unclarity about the medical history of the patient. The medical history of the patient is shattered around different hospitals and is therefore not easy to access. Patients do not remember their medical history precisely, and the doctor does not have access to all the patient information.
- The reflection moment for the doctor and the patient are both at another moment in time. The patient evaluates the impact of the follow-up steps on their personal lives at the end of the conversation. Unfortunately, patients have not thought of the impact before, which makes them feel rushed. The doctor is finalizing the last comments in the computer, and the patient feels the time passing by: have I asked everything?
- The doctor controls the entire conversation. The doctor continuously processes information, while the patient often ‘waits’ during the consultation for the following question. Patients do not have or feel the empowerment for steering the conversation into the preferred direction.
- It is challenging to put shared decision making into practice. The doctor asks if the patient agrees upon the follow-up steps. However, patients do not have enough knowledge to influence the decision.
- Lastly, the first impression of the patient influences the communication technique the doctor uses within the conversation. The doctor books double appointments when they want to come to an emotional level within the consultation. The doctor gives more direct and punctual information when the complaint is easy to handle.

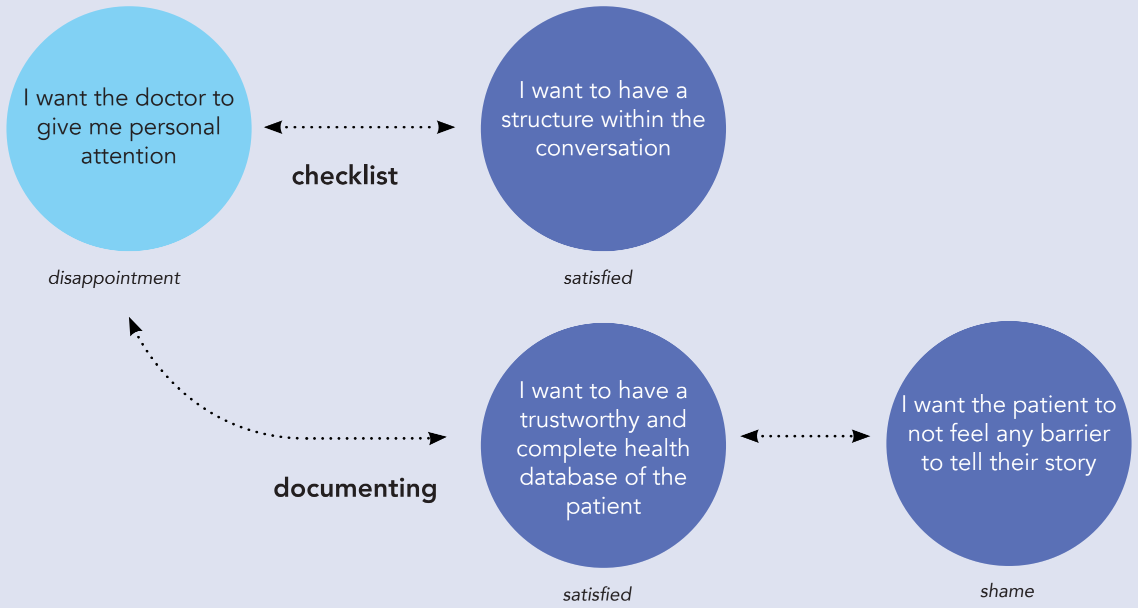
2.3.3 Conflicting and matching concerns (2)

To be sure that the focus is on the most important conflicts and matches, a generative feedback session with future doctors is held (Appendix B.6). As a result of this session, four conflicting concerns and five matching concerns are found within the current context of the consultation room. The arrow indicates the moment of conflict and the circles show the corresponding concern.

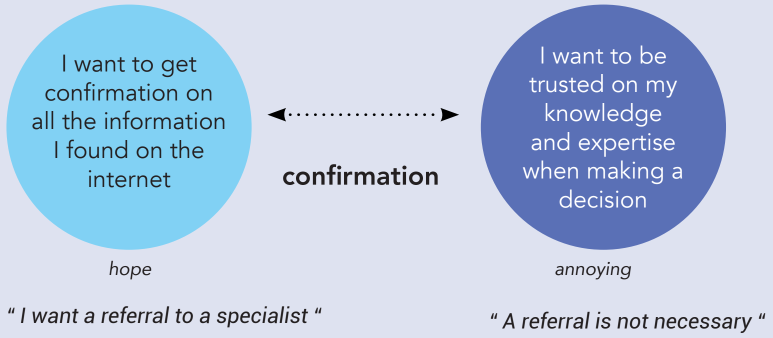
● *specialist*

● *patient*

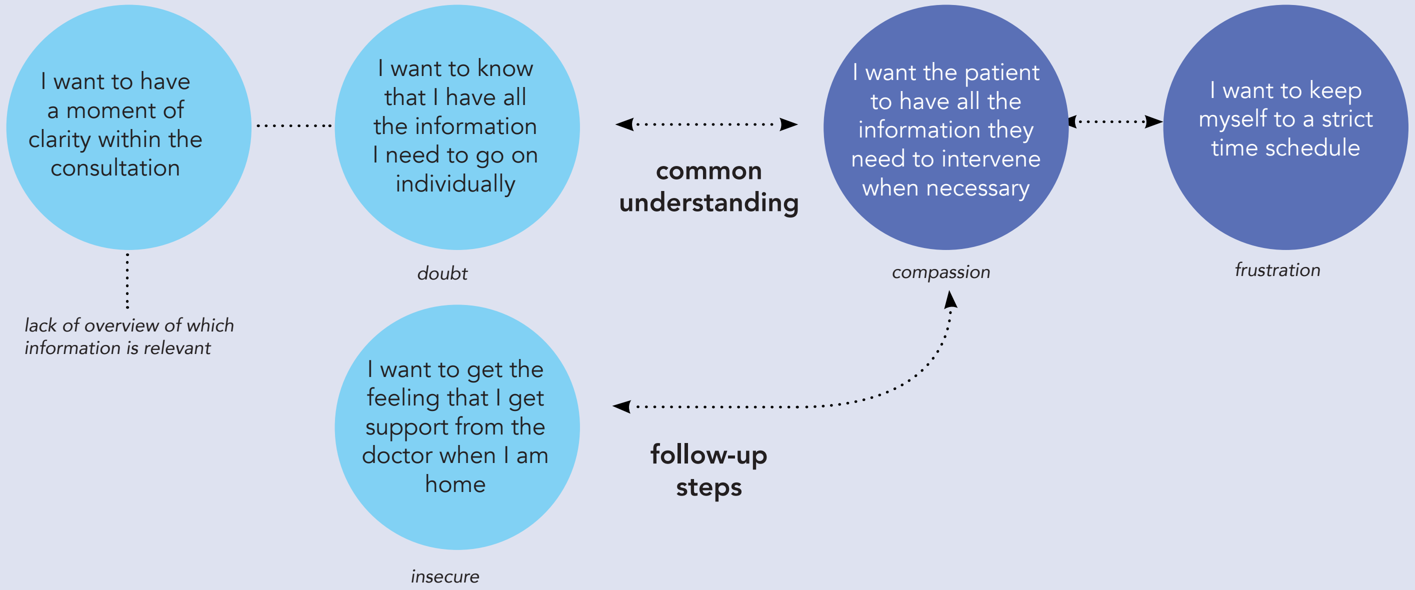
Conflict 1: personal attention vs structure



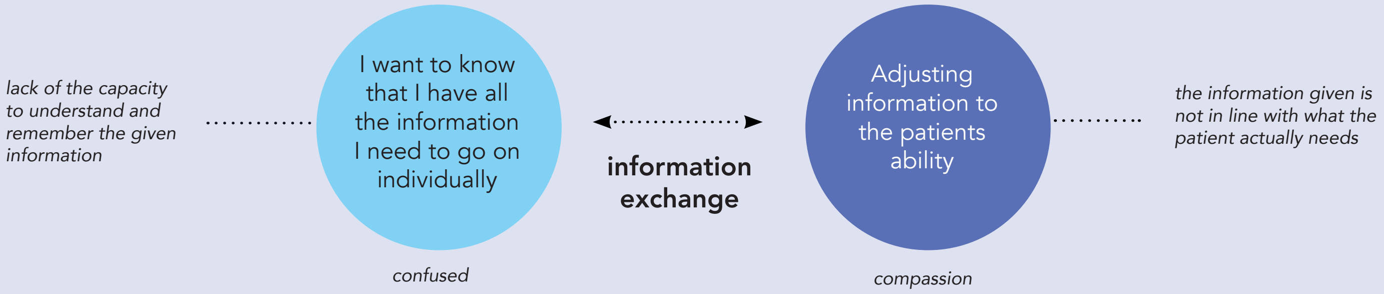
Conflict 2: internet vs expertise



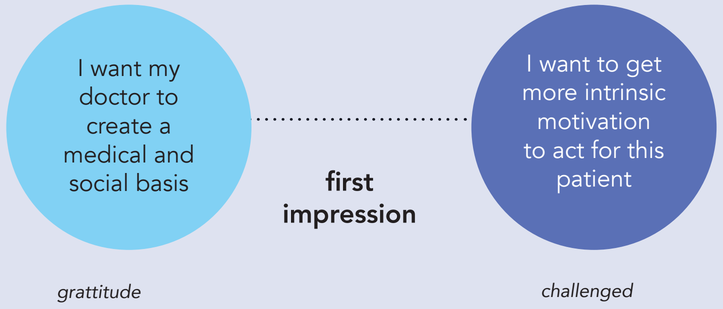
Conflict 3: reaching common understanding



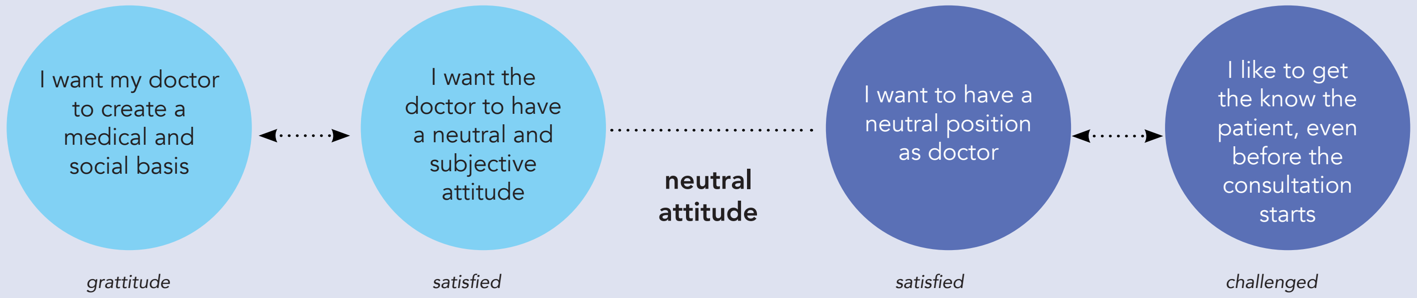
Conflict 4: what a patient wants and what a specialist thinks a patient wants



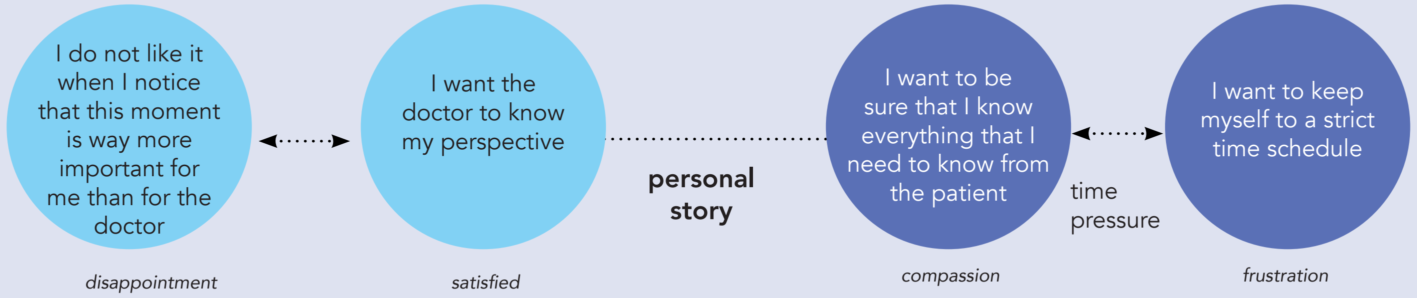
Match 1: personal connection



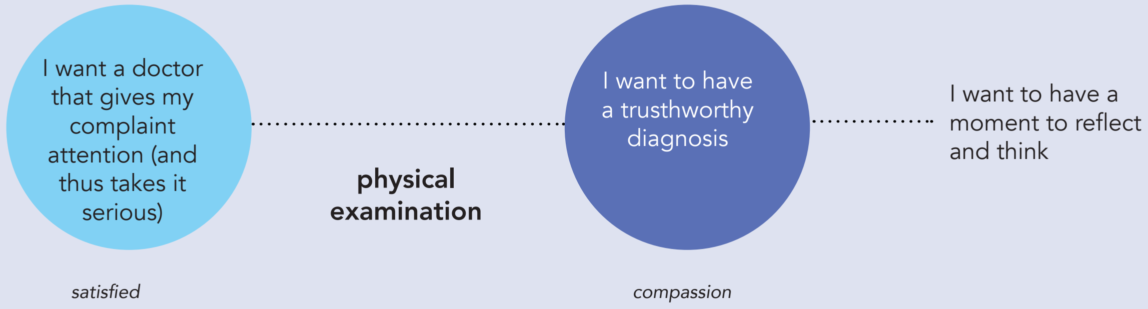
Match 2: neutral attitude



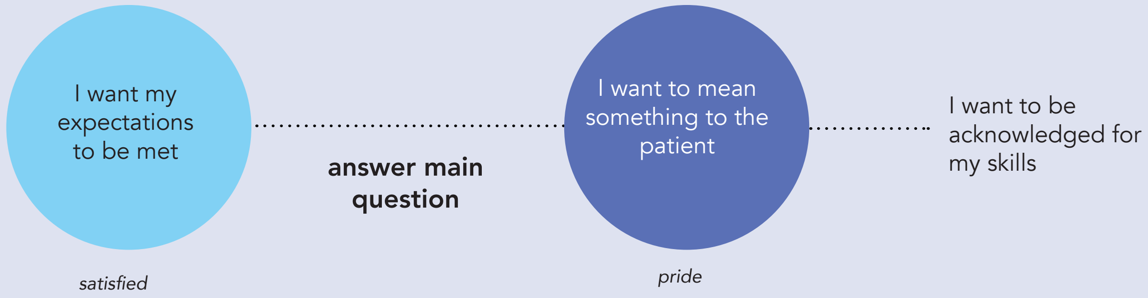
Match 3: personal story



Match 4: physical examination



Match 5: fulfill expectations



2.3.4 Conclusion experience touchpoints

Interviews, observations, creative sessions and validation sessions have given an insight into the current situation. The different concerns and values from the patients and specialist are unravelled and the current information flow is identified.

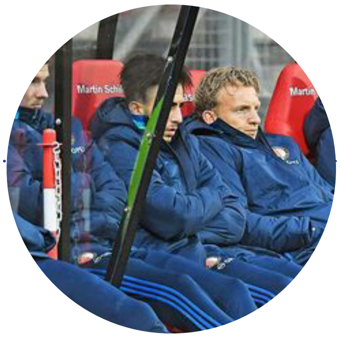
2.4 Main insights

This chapter concludes the analysis, the chapter 02 DISCOVER, by defining seven main insights with regards to patient experience. Six of them can be considered barriers towards a better patient experience and one is an enabler. These main insights are based upon the information from chapter 2.1 patient experience, 2.2 future context and 2.3 touchpoints of experience.

1. The patient as a spectator

There is a lack of structure
There is a lack of structure and overview of the disease and the consultation itself. Therefore, the patient can not process and connect the information found on the internet or given by the doctor. The doctor sends information as efficiently and clearly as possible due to time constraints. As a result, there is no shared understanding of the information, and the time of the consultation is not used optimally (Edwards, Davies, & Edwards, 2009).

The perception of the doctor influences the communication
Doctors adapt their information based on their perception of the patient, while this is often not in line with the information needs of a patient (Dekkers, Melles, Mathijssen, Vehmeijer, & Ridder, 2018). This way of communication creates a situation where the given information by the doctor, with their best intentions, can be confusing instead of clear. In the end, the patient is confused and does not precisely know what to do when they arrive home.



2. The patient's information in the vacuum

The patient is not in control over their health data
The health information of a patient is often spread over different hospitals, and patients do not understand or remember the exact information given by other specialists (user study). The information exchange between different hospitals is slow and cumbersome, which creates an unfavourable situation for the patient, which is out of their control.

Within the conversation
During a consultation, the patient shares personal information but does not see the effect of the given information on the output of the conversation. The doctor follows a checklist and therefore, some questions of the doctor come as a surprise. Patients do not always understand how that question links to their complaint (user study).

3. The feeling of being alone

A circle of distrust
There is a circle of distrust between general practitioners, specialists and patients. The specialist often uses the GP for writing referral letters, while the GP wants to be acknowledged for their skills instead of being an administration office (Berendsen et al., 2009 and user study). This discussion has a negative influence on the continuum of care for the patient (difficult access to care). The patient continually switches around between doctors and responsibilities. It gives the feeling of a low involvement of specialists in their health process, while patients are aiming for relatedness and acknowledgement (user study).

Time for the patient's personal story
The involvement of the doctor is the basis of trust during the health process. When a patient knows a doctor for a longer time, they expect the doctor to know their story. For a new doctor, this means that they listen with all their interest to the patient's story. Due to time pressure, the doctor aims to hear only the essentials of the personal story, which is not always clear to the patient (Chandra, Mohammadnezhad, & Ward, 2018)

4. The doctor as a confirmer

Patients expectations are changing
Patients execute a health analysis on the internet, based on the experiences of others, more and more (Chandra, Mohammadnezhad, & Ward, 2018). Patients go to the doctor with the expectation of getting confirmation on their health analysis, which conflicts with the current role of the doctor. The doctor wants to be acknowledged for their skills and study effort, not to be used to give confirmation. They want to get this acknowledgement from the patient and other specialists (user study).

Shopping doctors
A patient cannot figure out which medical information suits them the best (Edwards, Davies, & Edwards, 2009), and that is why the patient wants the doctor to confirm their thoughts. If a doctor does not agree upon their thought, they 'shop' for other specialists in order to get what they want. This behaviour is in line with the on-demand society we are living in. People start to get impatient (see chapter 2.2 Future context). The access to more medical information results in a disrupted relationship between the doctor and the patient.

5. Less time for patient care

Administration office
The electronic patient files are not linked between different hospitals, which makes sending f.e. an x-ray picture a hassle. The system does not work intuitively and frustrates the doctors during their daily work (van der Mee, 2017). Administration ensures that there is less time for patient care, which is, in the end, the specialist's main priority. Night shifts are therefore experienced as meaningful because that is where patient care is more important than the administrative tasks (user study). Due to the computer and the increased time pressure, a consultation has become routine administrative work. Within the consultation, there is only time for the main priorities at a physical level.

6. Technology as a disabler of human contact

Personal contact disappears
Technology is in the way of human contact during the consultation. Patients often stop talking when the doctor uses the computer (observation, creative session). The computer creates an impersonal approach during the consultation, while the patient wants to have the feeling of being heard (McKay, 2018).

A moment of reflection
Both patient and doctor aim to have a moment of reflection, but this happens at another moment. Since those moments happen at another time in the consultation, shared decision making is impossible within the consultation. Besides, the moment of reflection for the patient is at the end of the consultation when the doctor is processing the information on the computer (67 clicks, 3 min silence). The patient has the feeling of being rushed and out of control. Patient and doctor are not at the same point in time, and technology is blocking their conversation (Street, Makoul, Arora, & Epstein, 2009).

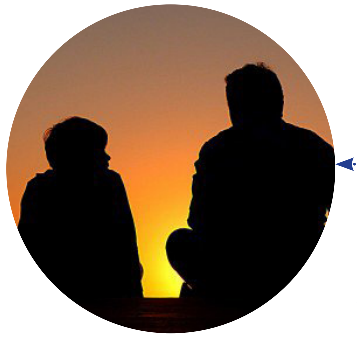
1. Back to the basics: human contact

Creating trust
Both patient and doctor need to have trust in one another to have an open and honest conversation. This trust is the basis for the subjective role of the doctor. A social and medical basis is a necessity for the doctor to process the information within the consultation in a personal way. For the patient, this basis is the fundament to share personal stories without boundaries.

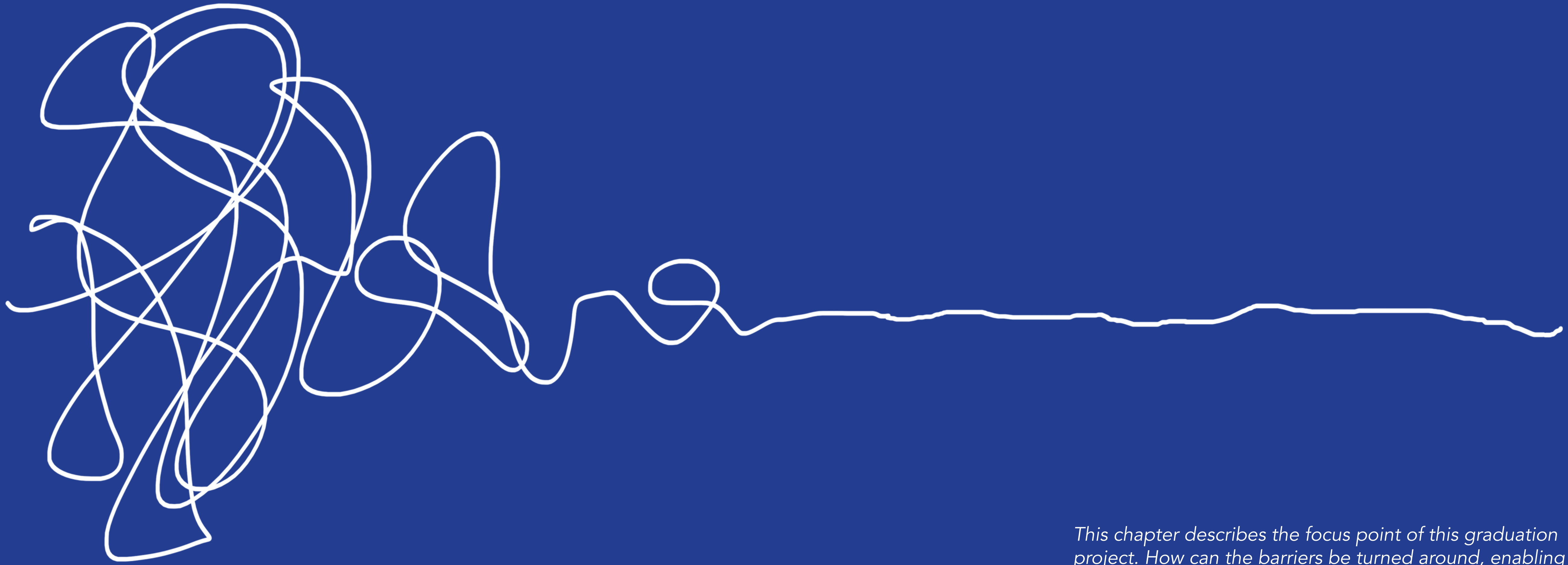
The most important asset
Human contact is the basis of every professional relationship, also within healthcare. This social basis is the responsibility of the doctor, who is leading at the beginning of the consultation. Human contact is *the* essential asset of the doctor. The physical examination is, therefore, one of the elements of the doctor, which is not competing with the internet. At this point, the trust bond between the doctor and the patient is created.

In 2030 technology will not take over the doctor's role, since the vital asset of the doctor is, and will always be, empathy and trust (Ruys, 2019). This physical, human connection is what should be emphasised and preserved for the future.

enabler



03 DEFINE



This chapter describes the focus point of this graduation project. How can the barriers be turned around, enabling a positive patient experience within the consultation room, giving space for the human conversation again? This chapter forms the starting point for the ideation phase.

Within this chapter:

- *Designers' vision*
- *Design goal*
- *Future interaction vision*

3.1 Vision

The vision describes the designers' personal view of the analyzed context, indicating where to focus-on for the continuation of this project. It describes the designer's idea of what should be changed to improve the patient experience.

3.1.1 My perspective

The consultation is on a pedestal; it is such an important, but a short moment. I find the tension around the consultation interesting, and I believe that this moment can, and should be 'stretched'. There is a significant gain in making the consultation more continuous.

A new way of communication needs to be designed to improve the patient experience before, during and after the consultation. This new communication way should fit the future context of healthcare, align with the value-based healthcare system and take the conflicting and matching concerns of patients and doctors into account. I think that the following three pillars are important for future developments:

1. Stretch the consultation
This new way of communication should enable both the patient and the specialist to be aware of each other's perspective to support the shared decision-making approach. Currently, the patient and the doctor have about 10 minutes to establish a shared understanding. In 2030, people live in an always-connected world where services react on-demand. This context offers excellent opportunities to stretch the time of creating a shared understanding, also outside the consultation.

2. Transparent communication
Secondly, the information should be understandable and accessible to different patients. I think that *one* trustworthy information channel, making use of either visual communication or having access to the information from the consultation at a later point in time, can help the communication between the patient and doctor tremendously. Allowing doctors to know what information patients have read and enabling patients to understand and trust the information they receive will bring them at an equal level.

3. Empower the patient
Thirdly, to have an equal conversation, the patient has to become a participant in the conversation. Patients who are more actively involved in their health process can have better health outcomes (Hibbard & Greene, 2013). Increasing the patient's involvement can be done by giving the patient *control* over their process, increasing the patient's *knowledge* and *adapt* the information based upon their preferences (Hibbard & Greene, 2013). These three elements can serve as guidelines to increase the patient's empowerment and thus support the interaction between the patient and doctor to have a better patient experience.

I expect that if the patient and the doctor understand each other's perspective better at the start of the conversation, shared understanding can be reached earlier within the consultation, which shifts the conversation to *'what matters to you?'*. This conversation topic in the goal of the Erasmus MC for the consultation room and is in line with the patient values *empowerment* and *partnership* to establish a positive patient experience. It will enable a conversation that can be more in-deoth and more personal within the given amount of time (the aimed effect).

Therefore I think that the main focus should not be primarily on removing the computer from the consultation room, but on developing a new communication way where the patient is empowered and the time outside the consultation is used to translate the barriers (see Chapter 2.4) into enablers, to make room for the 'real' conversation again.

3.1.2 Critical thoughts

The concept may not interfere with the most essential concerns of the patient and doctor to be successful. A necessity for the patient is being heard as a person and treated uniquely. As I understand, the doctor does not have unlimited time to get to know the patient through-and-through. A balance has been found between the time and personal attention. In the ideal situation, the doctor provides a framework in which the patient feels heard and understood: treated uniquely. The solution should comprise the concerns of both parties. Every patient and every complaint are different and therefore, it is not realistic to design something applicable to every patient and doctor. Sometimes a consultation is not experienced positively due to other context factors than the communication with the doctor himself. I hope to reach a better shared understanding between the patient and the doctor with my concept, which will hopefully lead to a better patient experience for the many concerning patient-doctor communication.

Figure 14: communication between kids (image source: pinterest)

3.2 Design goal

This vision has led to the design goal of this project. The design goal aims to translate the barries into enablers of the patient experience. The design goal is formulated as follows:

I want to create a new, more continuous, trustworthy communication way(1) between the patient and the Erasmus MC, supported by technology as an enabler,

that empowers the patient(2) to communicate their perspective more easily, by making their health process more guided and understandable to them(3),

in which the Erasmus provides the framework where the patient can safely explore their complaint, get structured information and personal support(4) before, during and after the consultation(5), to enable a conversation that puts 'what matters to you?' central (6)

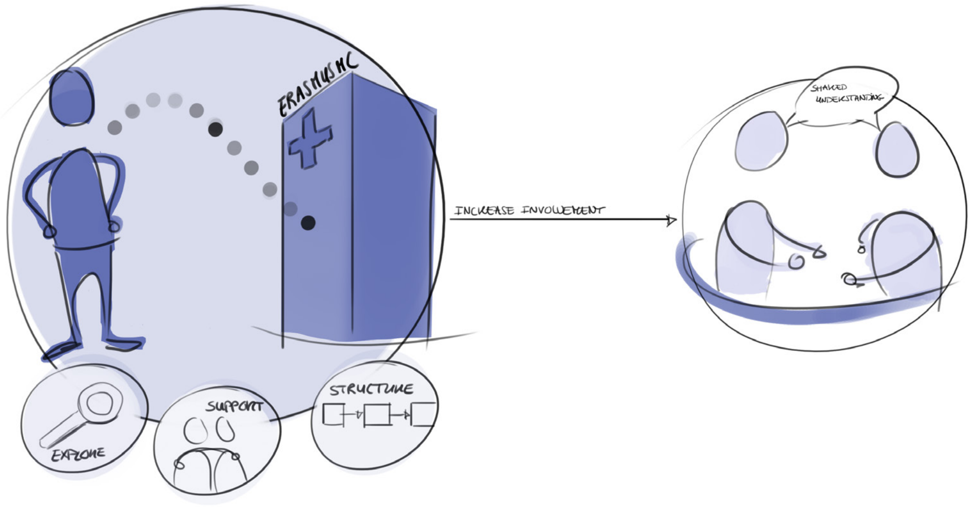


Figure 15: the visualisation of the design goal

1: future context opportunity
translate 'being alone' -> 'more continuous'
2: opportunity for increasing patient experience (literature)
translate 'spectator' -> 'a participant'
3: opportunity for increasing patient's involvement (literature and user study)
translate 'vacuum' -> 'guided information'
4: insights from user study
translate 'confirmer' -> 'supporter'
5: future context opportunity, an on demand society
ranslate 'being alone' -> 'more continuous'
6: the future goal of the Erasmus MC for the consultation room
translate 'technology disabler' -> 'human contact'

3.3 Future interaction vision

As an addition to the design goal, an interaction vision is created. This vision shows the interaction qualities that the final concept should include. It gives a feeling of how the new communication should feel for both the patient and the doctor.

I envision the doctor as the tour guide and the patient as the participant of the tour. The following interaction qualities are essential for the concept:

Personal contact & support
The tour guide takes the participant's personal preferences and expectations into account before they start climbing a mountain. Which mountain does the participant want to climb? How much experience does the participant have? The tour guide will personally support them by walking together to the top of the mountain. In the end, it is the participant's effort that brings them to the top. Nevertheless, the tour guide will provide the participant with tips and tricks in order to reach the top as comfortable as possible.

Guidance and structure
The tour guide knows the route by heart so he can bring the participant to hidden spots that are impossible to reach alone. He gives them guidance and structure along the way. Where does the participant need to go? The tour guide gives tips on how to approach the more challenging parts of the mountain.

Safely explore together
The participant is not walking alone to the top of the mountain. More people follow the same path. Together with the tour guide and the other participants, the journey starts. The tour guide is responsible for the wellbeing of all the participants. However, the participants can support and help each other during the climb.

Conclusion:
The conclusion of the define chapter are a set of guidelines. The design guidelines summarize the requirements the final design must meet in order to be successful. The list is used as a tool to evaluate the proposed concepts to their completeness based upon the analysis, insights, literature study, design goal and the future interaction vision. The guidelines can be found in Appendix C.

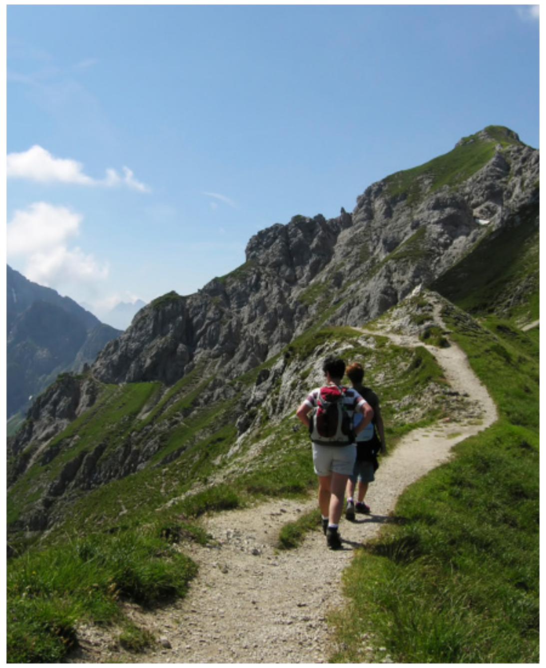
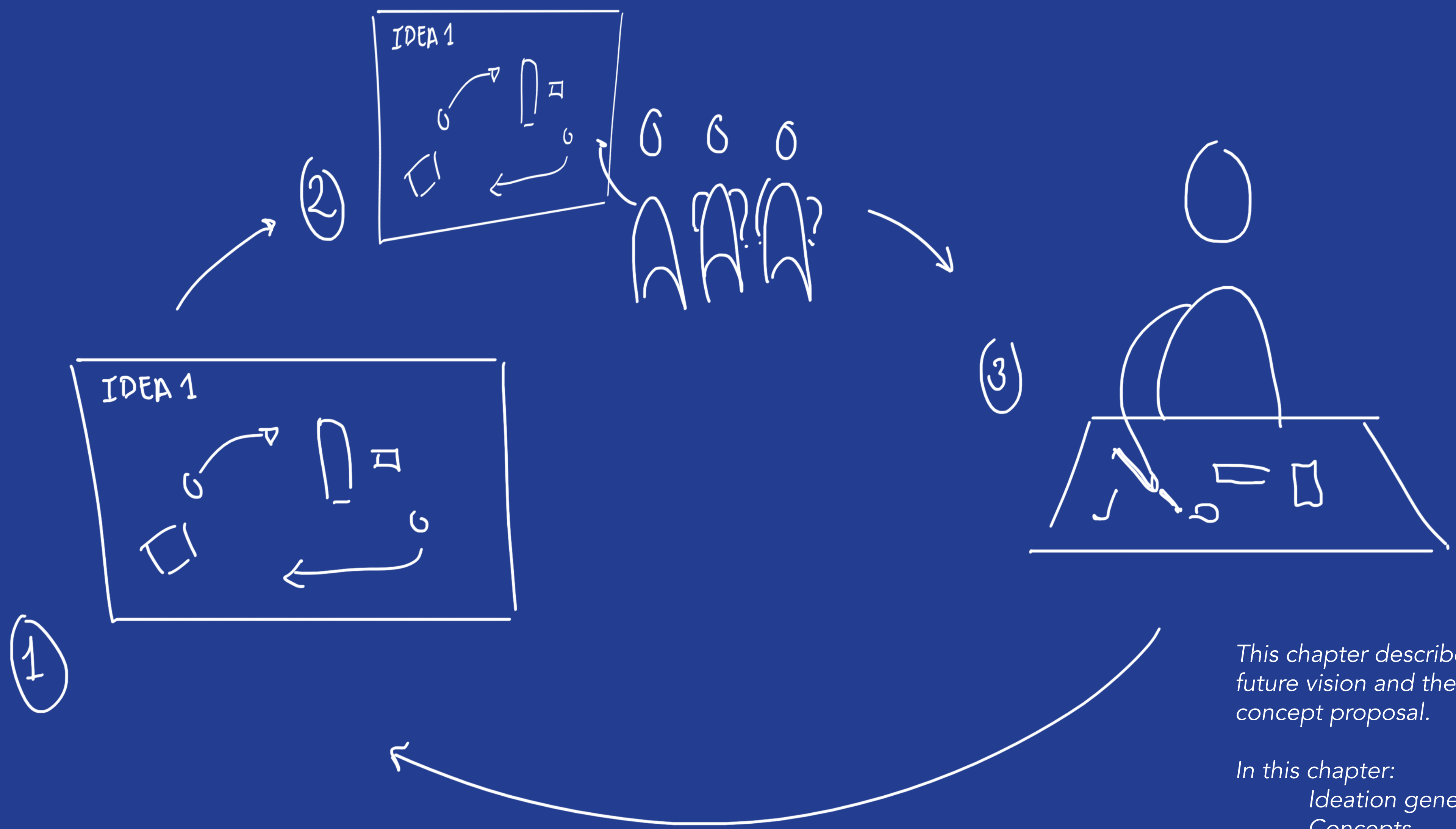


Figure 16: tour guide (image source: consumentenbond)

04 CREATE



This chapter describes how the design vision, goal, the future vision and the guidelines are translated in a tangible concept proposal.

In this chapter:
Ideation generation
Concepts
Concept evaluation
A casestudy

4.1 Ideation

The idea generation process is visualised in figure 17. The design process has been an iterative process where is built upon ideas from previous feedback rounds continuously. The design opportunities, the six search areas and the idea directions can be found in the indicated appendix.

4.1.1 Methods and techniques

During this creative process, various techniques are used to come up with ideas: individual brainstorming, brainwriting, a creative session using 'How can you?' (Tassoul, 2009), analogies, storyboards, metaphors, feedback sessions with the target group and rich experiences (Fokkinga en Desmet, 2012). The explanation of these techniques is found in the Delft Design guide (Boeijen, Daalhuizen, Schoor, & Zijlstra, 2014).

4.1.1 Idea selection

Not all the ideas were immediately suitable for concept development. Some ideas held sub-solutions and others felt out of the scope of this project. The selection of the ideas has happened in steps (figure 17).

First of all three design opportunities, including the first ideas, are presented and evaluated with the Erasmus MC (Appendix D). Instead of choosing for one specific direction, the fruitful elements from all three directions are taken ahead for future exploration. These elements result in six search areas (Appendix E), which form the starting point for the second iteration cycle out of which five ideas are born. Those five ideas are evaluated with patients in a creative session, using a scenario (Appendix F). Stories will allow people to let the design ground in the context of usage, and it will help to explore and define the design without having all the details complete (Quesenbery & Brooks, 2010).

This evaluation led to three rich concepts that are proposed to the Erasmus MC, patients and specialists. In the end, one concept is chosen to develop as the final proposal. On the next two pages, an impression of the ideation process is shown.

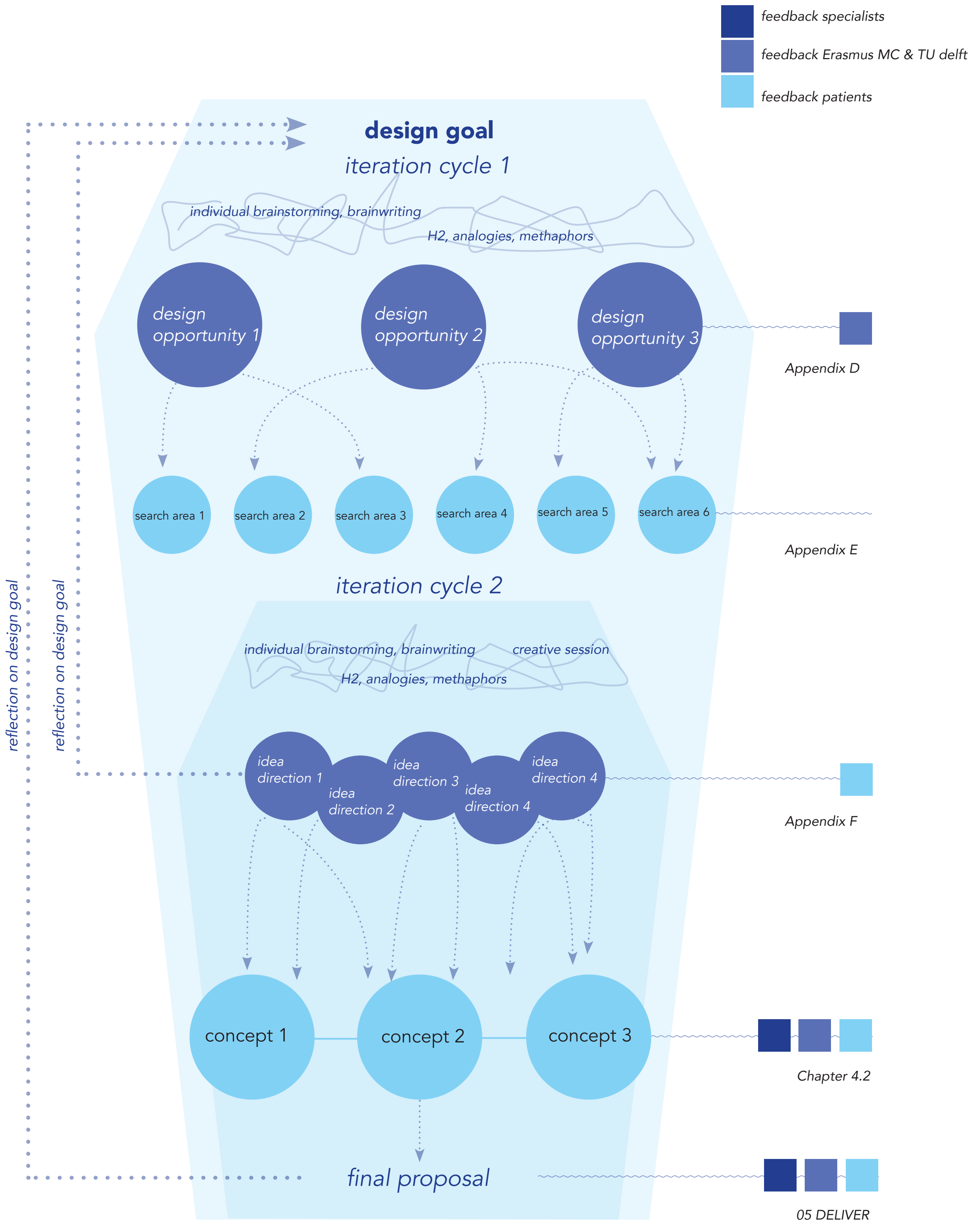
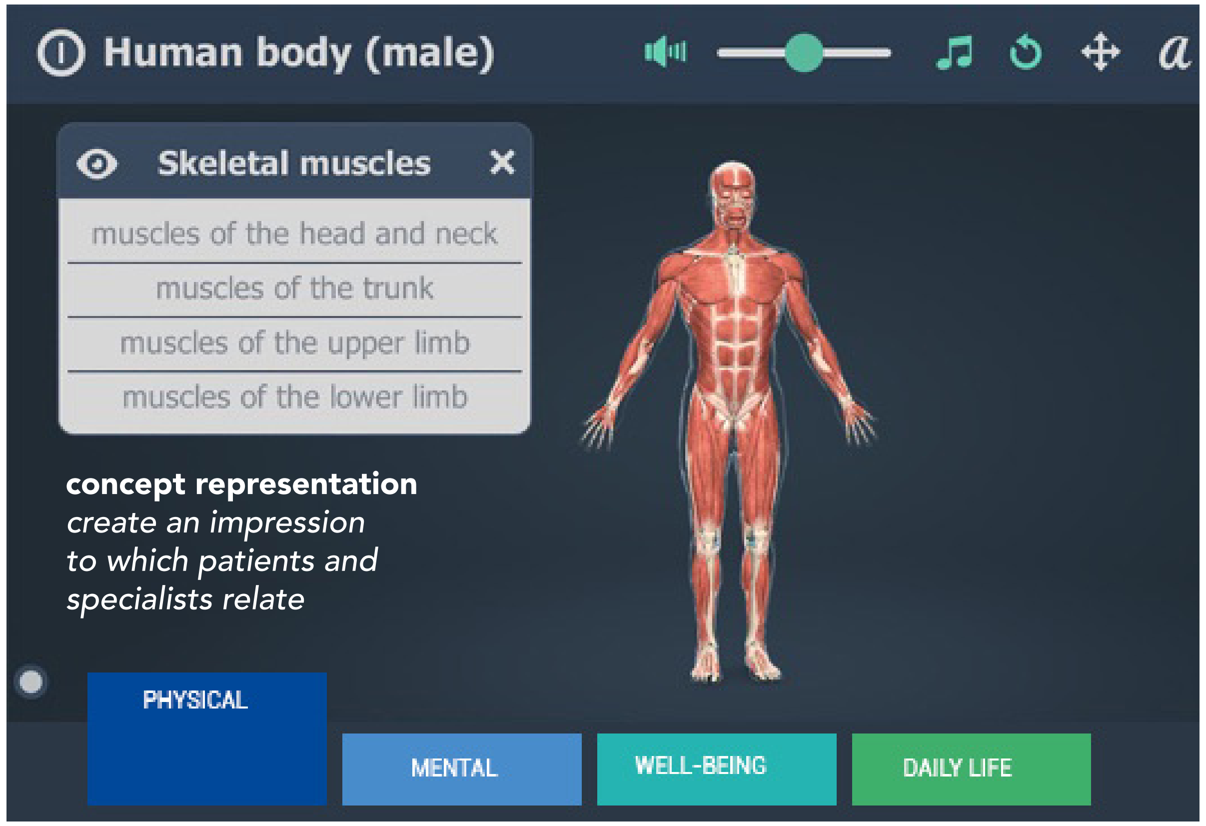


Figure 17: idea generation process

creative session with future doctors
validation of the results and first idea directions

structural overview of the platform
making sense of the different ideas

creative session with design students
first ideas and inspiration



concept representation
create an impression to which patients and specialists relate

Figure 18: a visual overview of the ideation phase

4.2 Concepts

The proposal of three concepts concludes the ideation phase. An explanation and a scenario describe the working principle of all three concepts. The written scenario can be found in Appendix G, and the (visual) explanations are found at the following pages. The scenarios are used for the concept evaluation to allow the participants to place the design in its context.

The Erasmus Academy

4.2.1 The Erasmus Academy

The medical information on the internet often confuses patients since they are not able to distinguish which information suits them the best (Edwards, Davies, & Edwards, 2009). The Erasmus Academy is an online platform where a patient gets structured and guided information, based upon their personal preferences. The patient can learn about the complaint and its context continuously, based upon their diagnosis, needs and wants.

The Erasmus Academy consists of several modules. These modules act upon the patients need in the form of:

- E-learnings to learn about the physical aspect of the diagnosis (f.e. using A.R. technology to explain the physical complaint)
- Podcasts and videos that focus on the mental perspective. The patient can listen to "staged" consultations from a specialist with a patient, talking about the mental part of the disease. It will help the patient to get mental support on demand.

The doctor has control over which modules are opened up within the Academy. In this way, the doctor understands the knowledge level of the patient better, and the patient gets trustworthy information that applies to them. Within the physical consultation, they decide together which modules are essential and which modules are explored. The patient and the doctor use the Erasmus Academy as a shared guideline during the real conversation. Questions as: what does the patient know and where is the patient interested in are already answered before the consultation starts. The Erasmus Academy makes the information around the health process more guided and understandable to both the patient and the doctor. The visualization of the concept is shown on the next page.

Raison d'etre

What does this concept bring to different stakeholders?

The patient:

- By making patients an expert around their complaint, the knowledge gap between the patient and the doctor is decreased. This decrease prevents the occurrence of misdiagnosis or the non-acceptance of a particular treatment method (Luxford & Sutton, 2014 and Edwards, Davies, & Edwards, 2009).
- The platform provides a moment of reflection for the patient to think about what important is to them, in their own time and space. A moment of reflection is beneficial since patients currently have the feeling of being in a rush when the end of the consultation is almost there (user study).
- By giving patients the possibility to have mental support via the platform (f.e. listening to podcasts of other patient experiences), they will feel more open to talking about their emotions during the physical consultation, which has a positive influence on their emotional well-being, contributing to the positive patient experience.

The doctor:

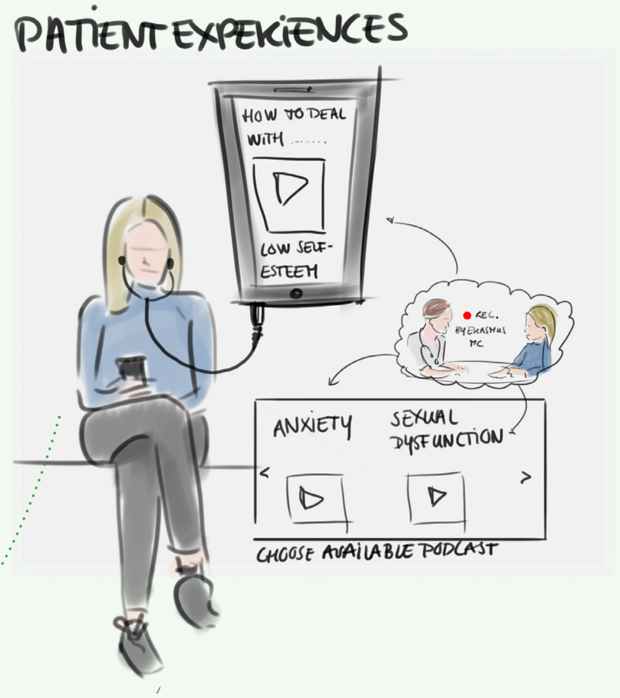
- The doctor can adapt their information on the knowledge of the patient instead of on their perceptions (Dekkers, Melles, Mathijssen, Vehmeijer, & Ridder, 2018)
- The doctor has an equal conversation partner who increases

I expect that when a patient has more knowledge about their diagnosis at a mental and physical level, they are better able to make decisions based upon their preferences and thus have a better patient experience.

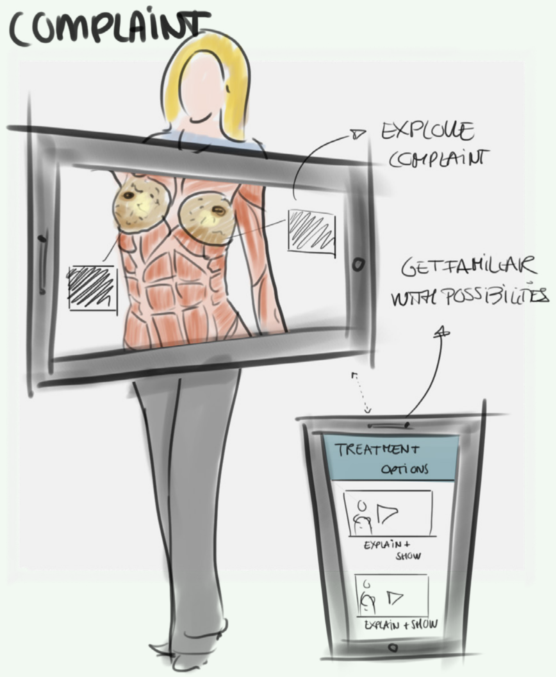
Limitations

- Patients and doctors need to be willing to record the podcasts.
- How to make sure that the podcasts will be supporting and not leading? It is not meant to be as a replacement of the real consultation, but as a mental support to the real consultation.
- The motivation of the patient is key for making it work.
- Is this working for all departments within the hospital?

The Erasmus Academy



1 listen to the experiences of other patients

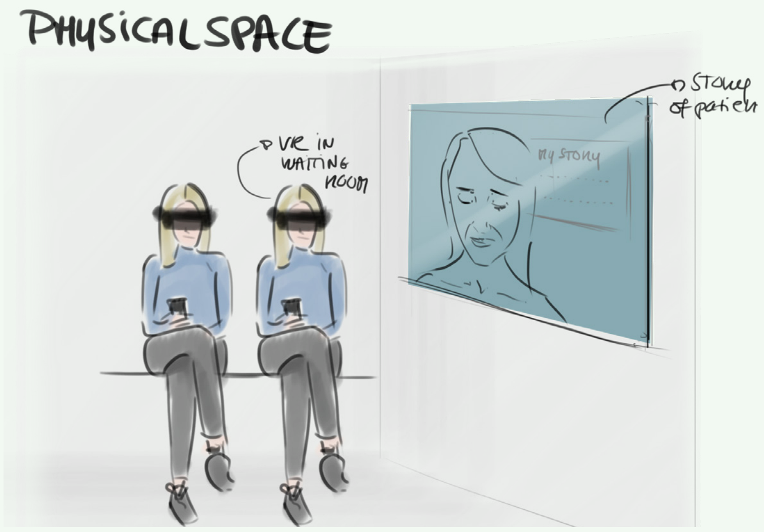


2 explore your complaint

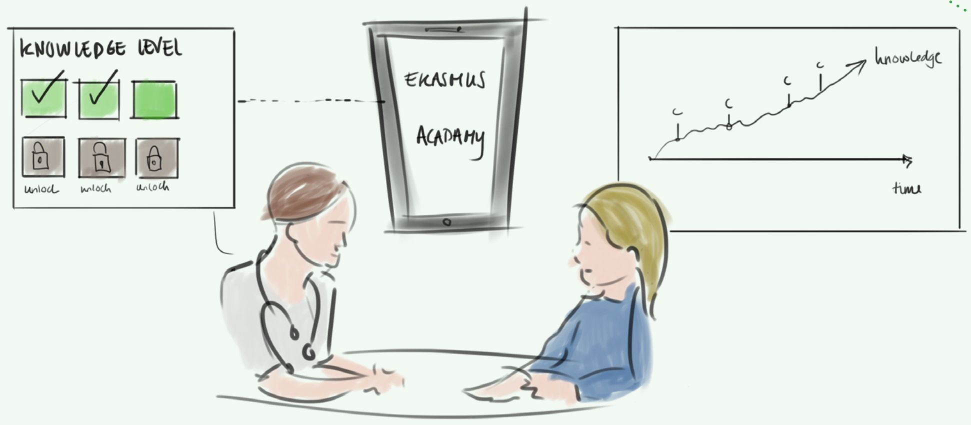
"When you listen deeply to the experience of others, you find yourself standing in front of your own mirror." she said. "It's so powerfully intimate." (Zissu, 2019l)

Figure 19: The Erasmuc Academy

3 spent your time in the waiting room useful



4 use the Academy as a guideline within the consultation



"It is a big advantage that the knowledge is tested, instead of given within the consultation. The conversation can focus on the unclarities." (Jan Hazelzet, personal conversation, 2019)

The Digital Patient I.D.

4.2.2 The digital patient I.D.

In the future, more and more people are tracking and logging their data (Chapter 2.2). The Erasmus MC can use this development to keep track of their patients and give their patients the possibility to have control over their mental and physical health data.

Patients can link their wearables and devices to the patient portal of the Erasmus MC to track and log their data regularly. With this data, they establish a digital patient I.D. With the patient I.D. as the basis, they can:

- get an insight into their health progress over time.
- chat with other patients when they have urgent questions or thoughts. By sharing the patient's data, patient's can help each other.
- get care on-demand and at a distance. By linking the digital patient I.D. to the database of the Erasmus MC, the doctor can have a look at the patients' health data from a distance.

Within the physical conversation, the tracked and logged data can be used as a valuable shared starting point, visualized on an interactive screen. Without losing time, the doctor can see how a patient is doing (mentally and physically) to start the conversation at a deeper level. The patient is up-to-date about their health situation, and the doctor has evidence-based information as a starting point.

The visualization of the concept is shown on the next page.

Raison d'etre

What does this concept bring to different stakeholders?

The patient:

- Patients who have control over their health data are triggered to become more involved and engaged with the information that contributes to the quality of care and their overall care experience (Hibbard & Greene, 2013 and Philips, 2019).
- Symptom tracking is associated with an improved experience, efficiency and health outcomes (Basch et al., 2016)
- Improving peer support can help as a safety net where the feeling of connectedness is enhanced (Rozenblum & Bates, 2013).
- The healthcare is shifting to a more holistic approach, and the conversation goes from: what is the matter? to what matters to you? This tool facilitates such a conversation for the patient and the Erasmus MC.
- Logging and tracking data before the consultation will save time during the conversation. It will help both the patient and the doctor to spend the time within the consultation as quality time, which will lead to a more empathic conversation.

The doctor:

- The doctor can use trustworthy patient data as a starting point for the conversation. The patient creates a shared history for the Erasmus MC, which contributes to the trust bond between the patient and the doctor.
- It gives the doctor more information in a shorter period, which allows them to reach an in-depth conversation (User study, D3).
- By visualizing both physical and mental data, the doctor has tools to be more empathic. The anamnesis is shortened, which allows them to have time for an empathic conversation.
- It gives doctors the possibility to give community-based care and care at a distance. The digital patient profile will help them manage patients with chronic diseases more at a distance (2.2 Future context), which provides them with more time for other patients.
- Previous research has shown that symptom tracking does not increase the number of patient calls to the hospital (Basch et al., 2016).

Technology:

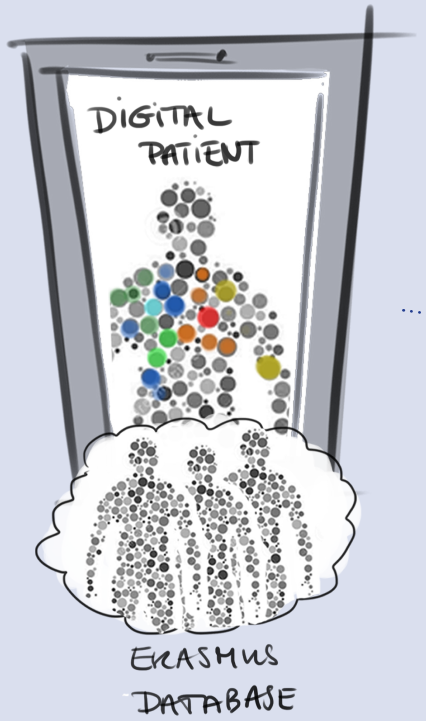
- A. I. technology learns to understand what people want and feel. The service becomes only more accurate when being launched over a longer time: the A.I. becomes smarter and can log and track data according to the patient's behaviour.
- A.I. technology will also help the doctor by controlling their patients at a distance. A.I. technology becomes more accurate over time due to the self-learning mechanism.

I expect that giving the patient control over their data, finding peer support, and having care at a distance will increase their empowerment (one of the patient values) and thus increase their patient experience. By eliminating the 'obvious' doubts, questions and data with this service, the conversation is designed to have a deeper conversation within the set-time.

Limitations

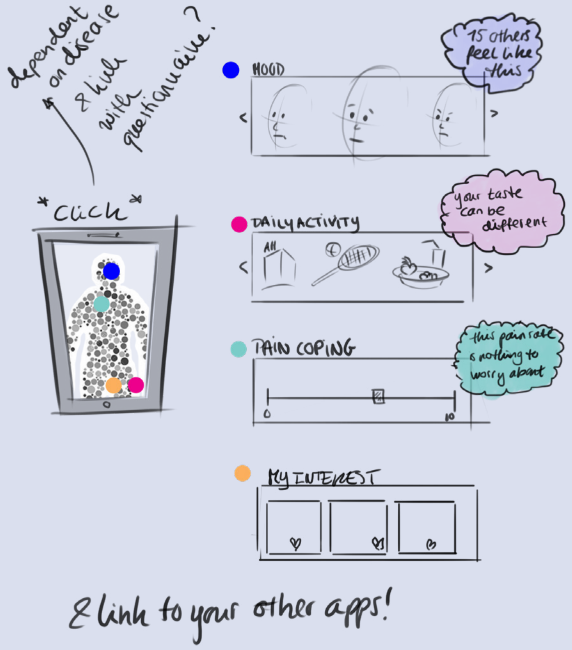
- How to make sure the data is confirming, not alarming?
- How to be sure that patients log the 'true' data?
- The privacy legislation is quite strict; how will the legislation progress over time?
- How much data is needed in order to compare patients in a valuable manner?
- Can the patient decide upon which data is shown to the specialist?

The Digital Patient I.D.

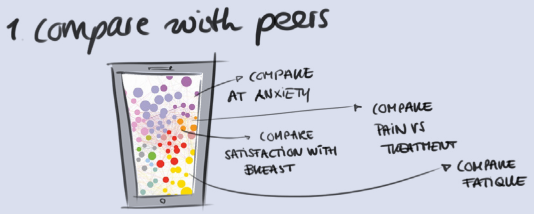


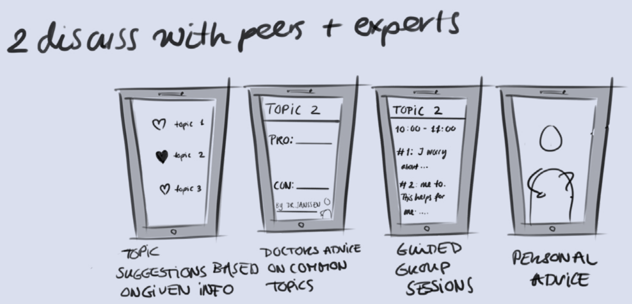
"In the context of a changing health care delivery system, where both population management and patient centeredness are prioritized, symptom self-reporting engages patients as active participants and may improve the experience, efficiency, and outcomes of care." (Basch et al., 2016)

1 track your data to establish your digital patient I.D.

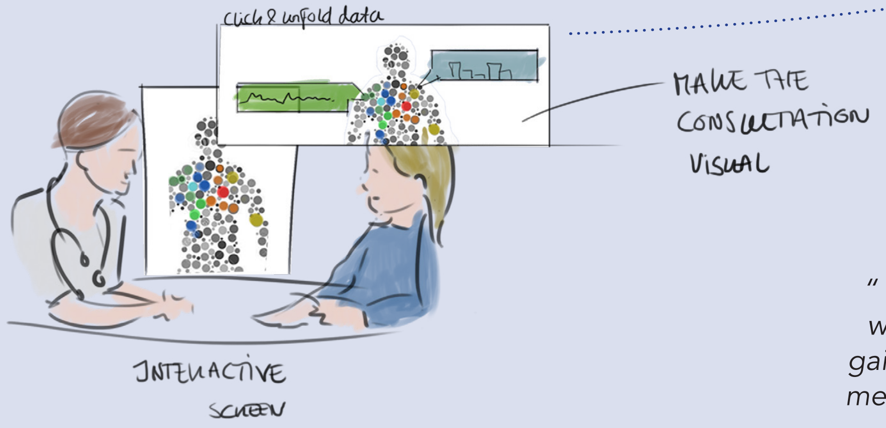


2 create an insight in your health data





3 use the patient data as a shared tool



*" Keeping a digital diary will certainly help me to gain more insight. It allows me to keep care in my own control." -
patient*

Figure 20: The Digital Patient I.D.

Quality time

4.2.3 Quality time

Living in an online and on-demand community makes people impatient. People expect that they are treated on-demand (Solis, 2017). This tool helps the patient to think about what they expect from the consultation; why do I want to go to the doctor? What do I find valuable? And what is my main question?

The patient gives the platform information about their complaint, the impact of the complaint on their daily life, their concerns and finally their main question. The A.I system within the platform will calculate their optimal consultation time-division and type, to establish a conversation based upon their preferences and wishes. The consultation type might be a video call, but this can also be a physical consultation.

When having a conversation with a specialist, the ideal time division from the consultation is visualized on an interactive screen, including the patient's notes. In this way, the patient can use the tool as a cheat sheet during the talk. The visualization of the concept is shown on the next page.

Raison d'etre

What does this concept bring to different stakeholders?

The patient:

- It will help the patient and the doctor to spend the time within the consultation as quality time, which will lead to a satisfied patient (Cape, 2001).
- By giving the patient the ability to think about their preferences and expectations upfront, it will help them to manage their emotions better during the conversation, having a conversation that suits their preferences better. (Street, Makoul, Arora, & Epstein, 2009)
- Increasing control over the health process of the patient will result in a higher involvement in the long term (Street, Makoul, Arora, & Epstein, 2009). Within this concept, the patient is empowered to think about what they find important and to prioritize it.
- It facilitates a way where the Erasmus can ask patients upfront to think about the question "what do I find important", in order to have a valuable conversation (Jan Hazelzet, personal conversation, 2019), which is in line with the goal of the Erasmus MC.
- The platform uses the same colour coding as the tool in the conversation. It makes it easy for the patient to recognize the topics and the structure.
- The patient has their own 'cheat sheet' and thus support within the consultation.

The doctor:

- The doctor knows upfront what the patient wants to know to be able to give more personalized care.
- By visualizing the progress of the conversation, the tool helps the doctor in structuring the conversation. Since technology takes the 'structured and guided' side of the job over, the doctor can focus more on the human side of the conversation.
- At a higher level, the consultations are planned according to the needs and wants of a patient, which in the end will save the doctors time in the physical consultation (optimized calculations).

Technology:

- A. I. technology can match the characteristics of the complaint and preferences with the suitable type and time of consultation: it will learn to recognize the elements.

I expect that when the patient has visual feedback on their input within the conversation, it will increase their feeling of ownership over the conversation. By discussing the topics to their needs, the patient feels treated uniquely (see Perceptions).

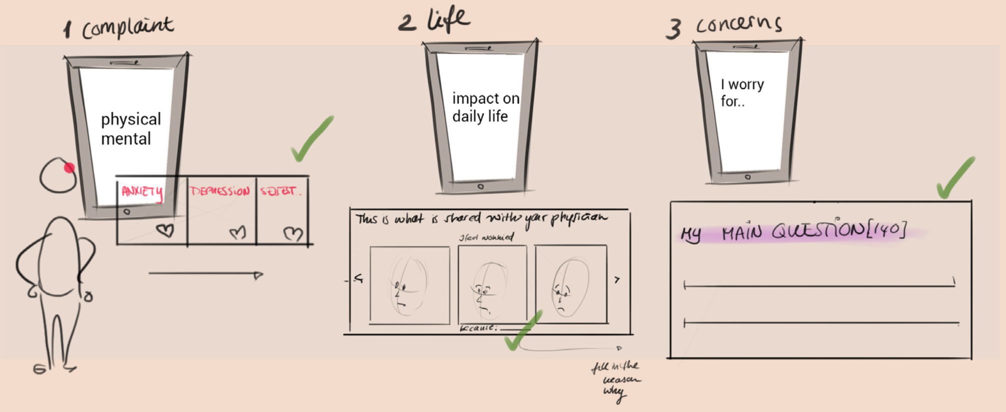
Limitations

- Patients need to have the drive to fill this in to make the concept work.
- Doctors need to be willing to be more flexible in the timeframe of the consultation; every consultation will have another time division, which can become a bit confusing.
- This service does not support a patient before and after the consultation that much, only when making an appointment
- How much flexibility is possible within the structure of the consultation?

Quality time

" Increasing the control over the health process of the patient will result in a higher involvement on the long term. " (Street, Makoul, Arora, & Epstein, 2009)

1 fill in some personal questions



2 get familiair with your personal time division and consultation type

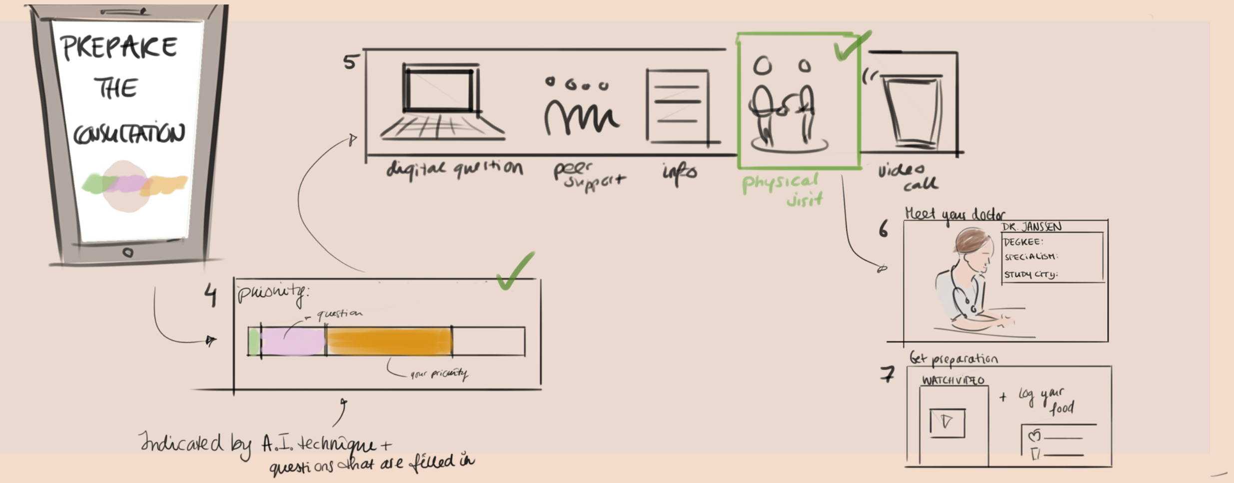
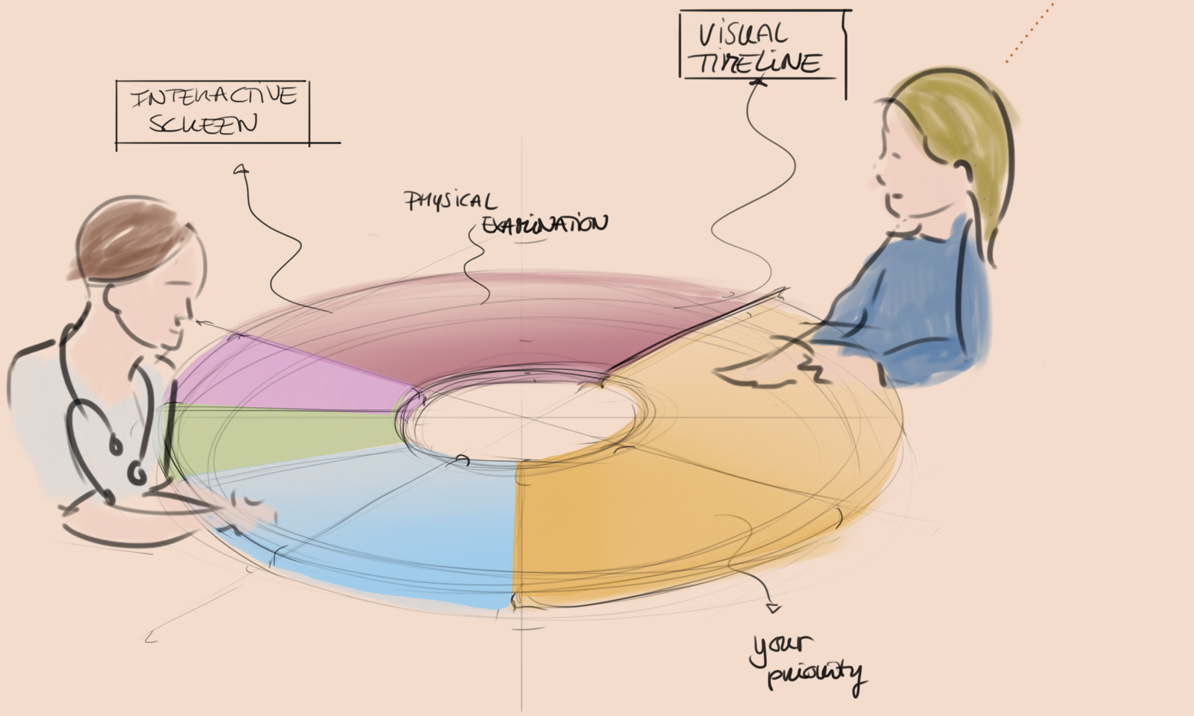


Figure 21: Quality Time

... when a patient beliefs that the perceived time of the consultation is longer than the actual consultation, the patient is more satisfied. This means that doctors can improve patient satisfaction by giving the patient the feeling of quality time. (Cape, 2001).



3 feel ownership over the consultation by seeing the structure of the conversation

4.2.4 The bigger picture

All three concepts aim to empower the patient to make them a more valuable conversation partner that can participate in the conversation: *'what matters to you?'*

The designer sees the three before mentioned concepts combined and working together within one platform: the renewed patient portal of the Erasmus MC. In figure 22, a visual explanation of the platform is shown.

1. Learn and explore (the Erasmus Academy)
When a patient has a complaint, the patient will first explore the severity of the complaint within the Erasmus Academy. The patient gets trustworthy and personal information based on their diagnosis.

2. Track and log (the digital patient I.D.)
If this has not helped the patient solving their doubts or complaint, the patient can have a look into their digital patient profile. Has something changed within their health data? They can talk with peers or get care at a distance. If this still did not clarify their question or complaint, the patient will go to the hospital.

3. Prepare and reflect (Quality time)
In order to have a personalized conversation, the patient will provide the Erasmus MC with the main question and with their preferences and expectations.

When arriving in the hospital, the patient has (1) trustworthy knowledge, (2) a digital evidence-based health profile and (3) a proper preparation of the conversation. The platform as a whole will make the patient an equal conversation partner.

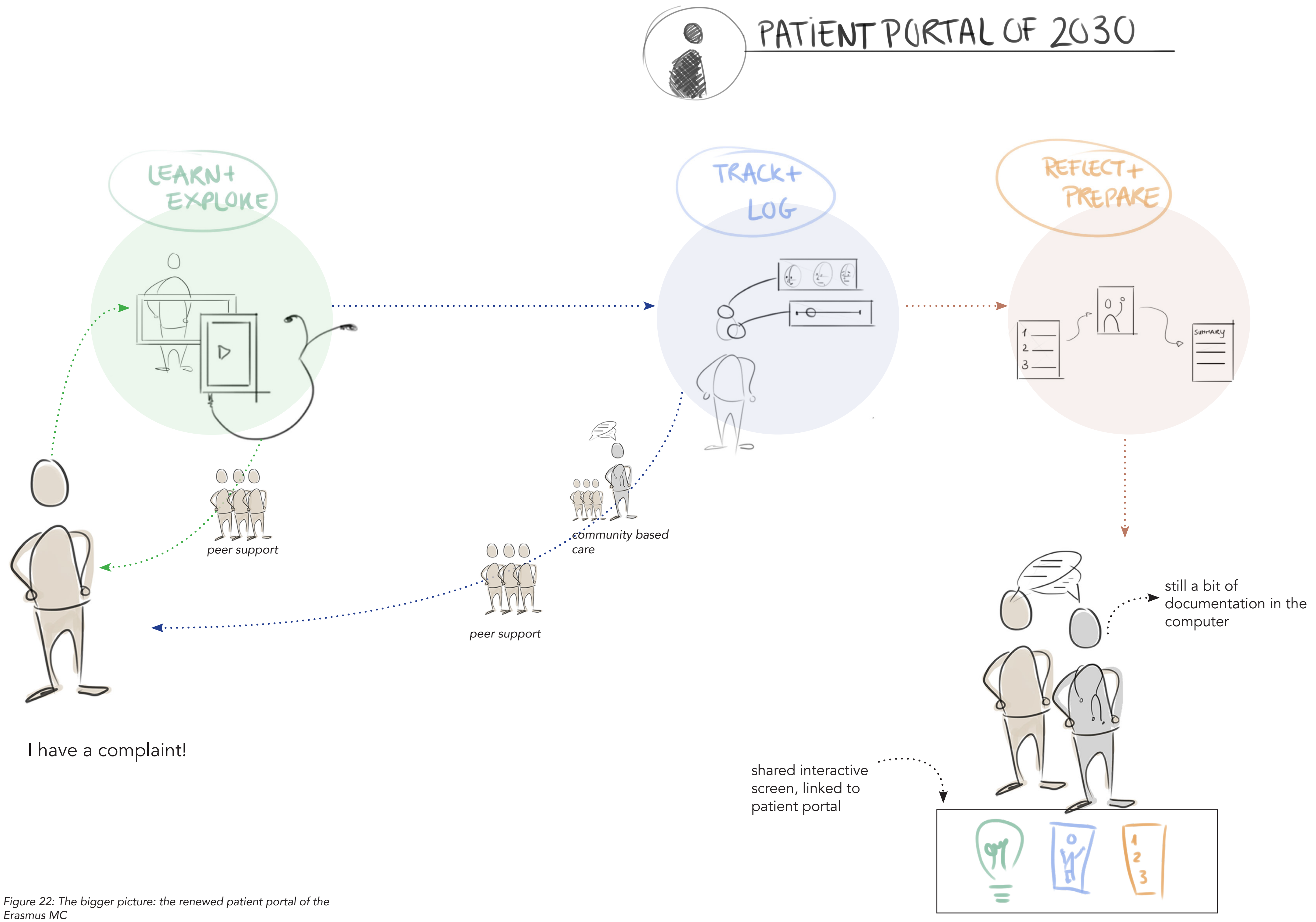


Figure 22: The bigger picture: the renewed patient portal of the Erasmus MC

4.3 Concept evaluation

The three concepts are evaluated with different stakeholders. The goal of this evaluation is to see which concept is the most fruitful to develop further. The test up, the test materials and the test results can be found in Appendix H. Within this chapter, only the conclusions of the evaluation are shared.

4.3.1 Value for the patient

Down below a summary of the valued elements of the patient portal is listed:

- Patients appreciate personalised information based on their health data.
- Patients value the lower threshold for emotional topics since specialists have access to the mental data before the consultation. They find it comfortable that healthcare can extend beyond the physical aspects.
- It is positive to have a cheat sheet within the consultation as support.
- Patients value the fact that all three concepts allow them to prepare a consultation, which brings the conversation to a deeper level.
- The patients find it valuable that all three concepts are linked to the physical environment. In this way, they feel that something useful is happening with their information. It creates ownership over the data within the conversation.

Improvements

- The possibility to evaluate the consultation afterwards is missing.
- Patients want to have to control over what information is shared with the specialist; it should always be a choice.
- Knowing about the time framing within the consultation is undesirable. That is something the doctor should keep track of.
- Communicating with peers is an excellent addition, but it should always be an option.
- The information should not scare the patients; it should comfort them. The visualisation of patient data could harm a patient too.

4.3.2 Value for the Erasmus MC

Down below a summary of the valued elements of the patient portal is listed:

- Focussing more on prevention than on direct care is valuable for the future.
- Visual communication will help for the many (since more than 2 million people do have difficulties with understanding written text).
- The patient's empowerment is vital to establish a shared understanding, that is what all three concepts do.
- Taking the perspective of the patient in the shared decision-making approach is valuable because the Erasmus focusses mainly on the side of the specialist.
- The Erasmus MC wants to focus more on symptom tracking in the future, such as computer adaptive testing, the track and log concept seamlessly fits with this vision.

Improvements

- Adjusting the consultation time based upon the personal preferences and needs of the patient is very difficult. When a computer calculates the time, it also overshadows the side of the specialist: they do not have any influence on the consultation time.
- Tracking and logging data should go systematically, not manually.
- Within the platform, there should be a role for the family since they are significant to the health process.

4.3.3 Evaluation based on the selection criteria

All three concept proposals meet the guidelines (Appendix D). Nevertheless, some guidelines are more important than others to different stakeholders. Eight selection criteria are established, taking into account the opinion of the three different stakeholders (the patient, the Erasmus MC and me as a designer). The choice criteria and the evaluation of the concepts can be found in Appendix H.3). The evaluation shows that the digital patient I.D. is evaluated as the most positive towards the eight choice criteria.

4.3.4 Conclusion

All three concepts have the potential to contribute to a more in-depth conversation sufficiently, but due to time limits, it is not possible to work out the whole patient portal of the future. It has been decided to focus on the second element, the digital patient I.D., due to the following reasons:

- The Erasmus MC: the digital patient I.D. concept fits the ambition level and the future vision of the value-driven healthcare within the Erasmus MC the most. It allows the Erasmus MC to focus more on prevention than on healing due to the continuous data-based patient information.
- Patient: this solution is valued as highly desirable by the patients. Having health data digitally and visually is valued as a great benefit within the consultation. It helps the patients to know, understand and remember how they have felt, which can help them in their communication to their specialist. This concept gives the patients the feeling of ownership and control over their data, also within the consultation.
- Designer's opinion: the development of the digital patient I.D. is in line with my own learning goals: exploring a new field (data visualisation) and inspiring the Erasmus MC with something valuable and new.
- Future of healthcare: Last but not least, this proposal is in line with the future vision of healthcare, where is described how healthcare can expand through services such as health social networks, personalised consumer personalised medicine and quantified self-tracking (Swan, 2009).

A case study is needed, including a target group with corresponding data, to give the Erasmus MC a tangible example of how data can contribute to a more in-depth conversation.

4.4 A case study

In order to give the Erasmus MC a tangible example of how the digital patient I.D. can look like in 2030, a case study is needed. Within this design brief, the case study of the conceptualisation phase is described.

4.4.1 User group

Together with the Erasmus MC is decided to focus on the people with diabetes type 1 to provide the data, information, patients, and doctors to work with due to the following reasons:

- Diabetes type 1 patients have several psychological aspects to deal with.
- Currently, diabetes patients have many unnecessary hospital visits. There is a big gain in giving care at a distance.
- Mostly younger people who are digitally minded and have a good understanding of their diagnosis.
- Diabetes is a disease where patients can talk about easily with others due to the nature of the diagnosis.
- The digital patient I.D. fits the plans for a diabetes type 1 portal of the regional hospitals.

4.4.2 Outline

The structure of the platform of the digital patient I.D. is shown in figure 23. There are four elements of the concept that evoke a change concerning the current consultation: empower, continuous support, understanding and confidence. Those elements are based upon negative moments in the emotional timeline of the patient (Appendix B.5). Due to time limits, it is not possible to focus on all four elements of the concept.

Scope

It is chosen to focus on the link between the patient's preparation and the physical consultation. The elements continuous support and understanding are in scope. The final deliverable will be a combination of a platform for the patient and an interactive screen used in the consultation. The measurement of the data will be out of scope, even as the aftercare.

Design goal

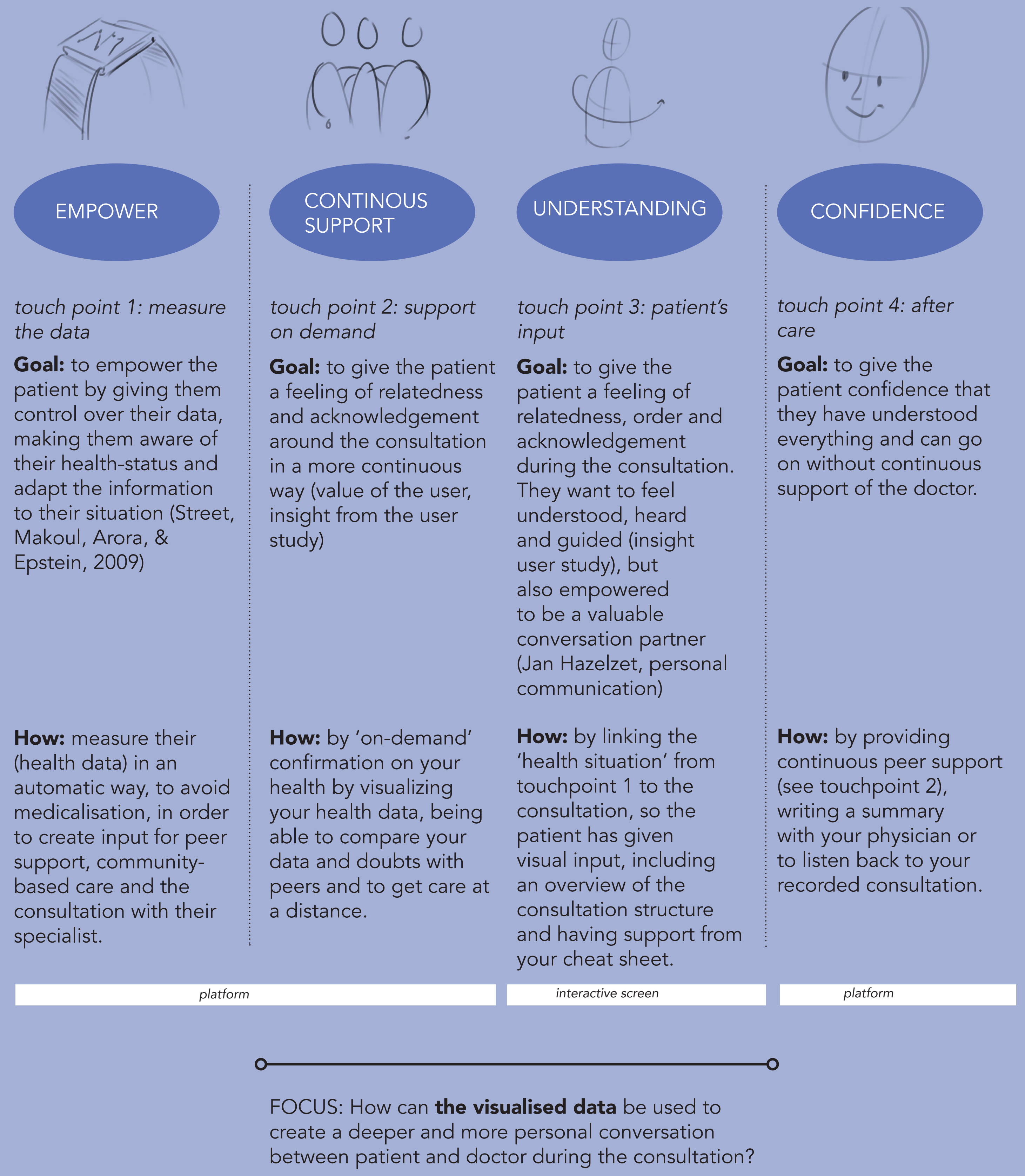
The target group, the outline and the scope of this case study, have led to the following design goal:

How can the visualised patient data of the diabetes type 1 patient be used to establish a more in-depth and personal conversation between the patient and the doctor?

Approach

Within the case study, the design process is repeated in short. The deliverable of this case study has the following structure:

- Discover: exploring the user group
- Define: exploring the essential data
- Create: exploring data visualization
- Deliver: a tangible proposal

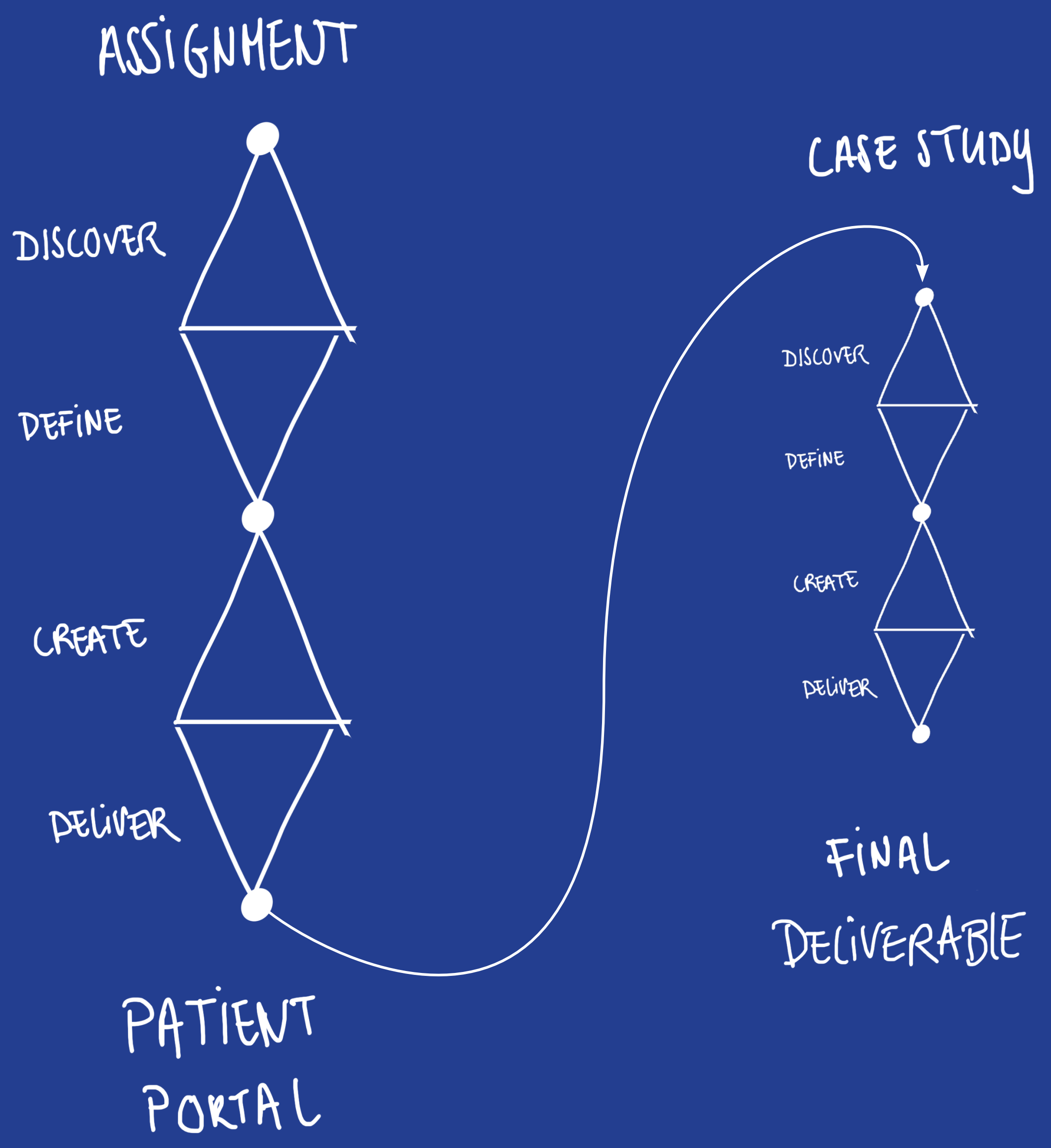


EMPOWER	CONTINOUS SUPPORT	UNDERSTANDING	CONFIDENCE
touch point 1: measure the data	*touch point 2: support on demand*	*touch point 3: patient's input*	*touch point 4: after care*
Goal: to empower the patient by giving them control over their data, making them aware of their health-status and adapt the information to their situation (Street, Makoul, Arora, & Epstein, 2009)	**Goal:** to give the patient a feeling of relatedness and acknowledgement around the consultation in a more continuous way (value of the user, insight from the user study)	**Goal:** to give the patient a feeling of relatedness, order and acknowledgement during the consultation. They want to feel understood, heard and guided (insight user study), but also empowered to be a valuable conversation partner (Jan Hazelzet, personal communication)	**Goal:** to give the patient confidence that they have understood everything and can go on without continuous support of the doctor.
How: measure their (health data) in an automatic way, to avoid medicalisation, in order to create input for peer support, community-based care and the consultation with their specialist.	**How:** by 'on-demand' confirmation on your health by visualizing your health data, being able to compare your data and doubts with peers and to get care at a distance.	**How:** by linking the 'health situation' from touchpoint 1 to the consultation, so the patient has given visual input, including an overview of the consultation structure and having support from your cheat sheet.	**How:** by providing continuous peer support (see touchpoint 2), writing a summary with your physician or to listen back to your recorded consultation.
platform		*interactive screen*	*platform*

FOCUS: How can **the visualised data** be used to create a deeper and more personal conversation between patient and doctor during the consultation?

Figure 23: the structural data framework

04 DELIVER



This chapter describes the final deliverable of this graduation project. The final deliverable is a case study answering the question:

How can visualised data of the diabetes type 1 patient be used to establish a more in-depth, more personal conversation between the patient and the doctor?

In this chapter:
- *Setting the scene*
- *Patient data image*
- *Data visualisation*
- *Mijn Erasmus I.D.*
- *A scenario*
- *Value*

5.1 Setting the scene

What is diabetes? What do diabetes patients discuss within their consultation? Which data is important to them and which data is beneficial to use during the consultation? Two patients and one specialist interview have been conducted to get a brief understanding of the situation.

5.1.1 The medical team

Diabetes is a disease that affects the body's ability to produce or use insulin, which results in having to find a balance in the blood sugar level manually. Figure 24 visualises the medical team of a diabetes patient. The different topics are described per specialist.

In Appendix I more detailed information about diabetes and the consultation can be found.

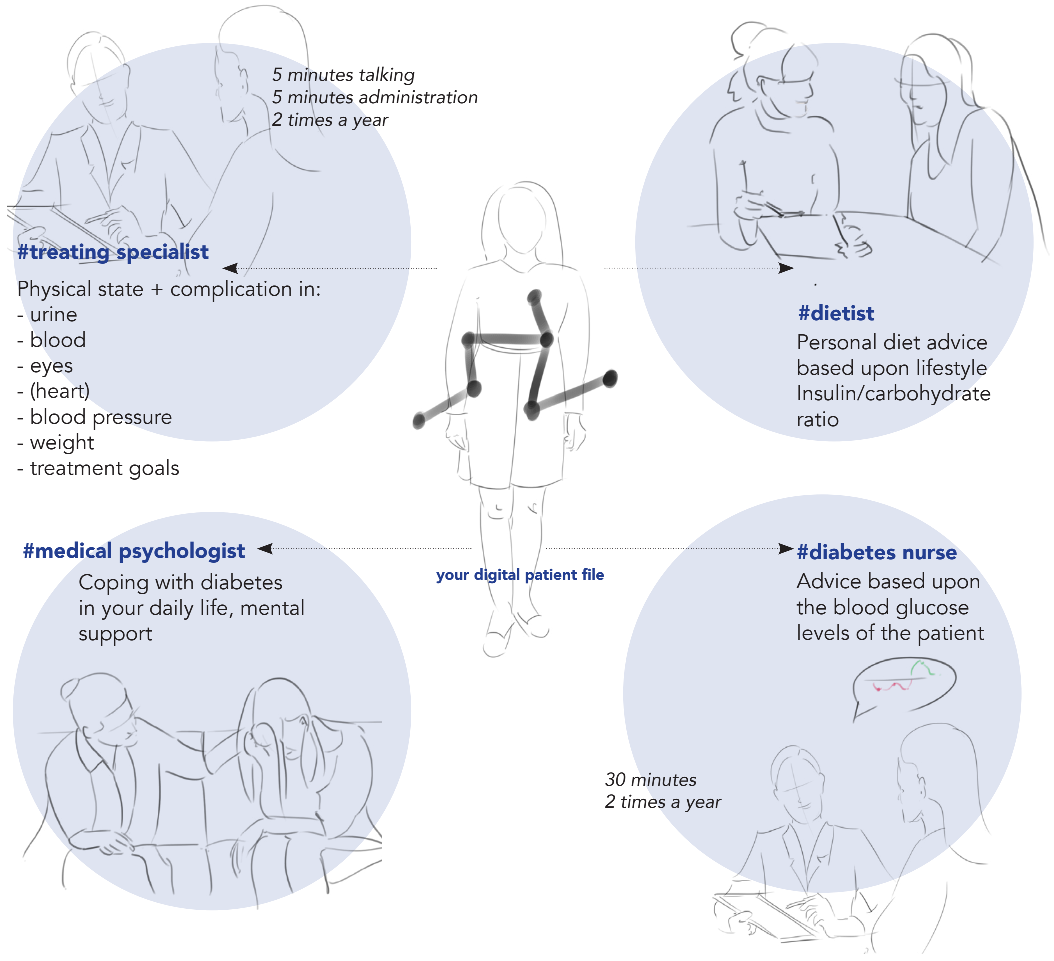


Figure 24: an overview of the medical team

5.2 Patient data image

The ICHOM questionnaire and the institute for positive health (Machteld Huber) are explored to get more specific on which data is used during the consultation. Together with the patient and doctor interviews, the designer established an overview of the relevant information that covers a holistic patient image for diabetes type 1.

5.2.1 ICHOM-questionnaire

Currently, the Erasmus MC measures the physical and mental health outcomes of their diabetes type 1 patients every half a year. The current consultation focusses the physical complications in the blood, urine, eyes, blood pressure and weight. The Erasmus MC also measures the mental aspects of the patient with three questionnaires: wellbeing, depression and diabetes distress. Unfortunately, the results of these questionnaires are often not used or seen by the specialist, due to the intuitive system the specialists use. It takes too much time to search and find these results. (Doctor Oszan, personal conversation, 2019 and ICHOM l Healthcare Improvement l Patient-Reported Outcomes, 2018).

Information needed: physical and mental outcomes of the patient.

5.2.2 Patient's perspective

The goal of the Erasmus MC is to create a shared understanding in the consultation room (Chapter 1.1). The Erasmus aims to take the patient's values, beliefs and preferences into account during a conversation. Patients prefer to have a priority list to communicate their preferences and beliefs: what do they find important and why?

Information needed: patients values, beliefs and preferences (concluded in a priority list)

5.2.3 Institute of positive health

Moving to a consultation where shared understanding is the basis, following a more holistic patient approach is vital for the Erasmus MC. However, which data covers the holistic patient? Not only the physical data defines a patient's wellbeing; care should be taken broader. According to the institute of positive health, being healthy is not only the absence of a disease but also the ability to cope with physical, emotional and social challenges (iPH, 2017).
This strategy focuses on six different elements of health:

- Physical functioning: how do I feel physically?
- Mental wellbeing: how do I feel mentally?
- Meaning of life: How much faith do I have in my future?
- Quality of life: Do I manage to enjoy life?
- Participation: To what extent can I participate in society?
- Daily functioning: how does my daily
- life look like? (iPH, 2017).

Furthermore, topics such as holidays & travels, pregnancy, driving licence, financial aspects, exams are discussed the most on different diabetes platforms (Diabetes trefpunt).

Information needed: the meaning of life, quality of life, participation, daily functioning.

To conclude: to create a holistic, digital diabetes type 1 patient, the conversation should cover the following information:

- *physical and mental outcomes of the*
- *patient*
- *patients values, beliefs and preferences*
- *meaning of life, quality of life, participation, daily functioning*

5.2.4 Structural data framework

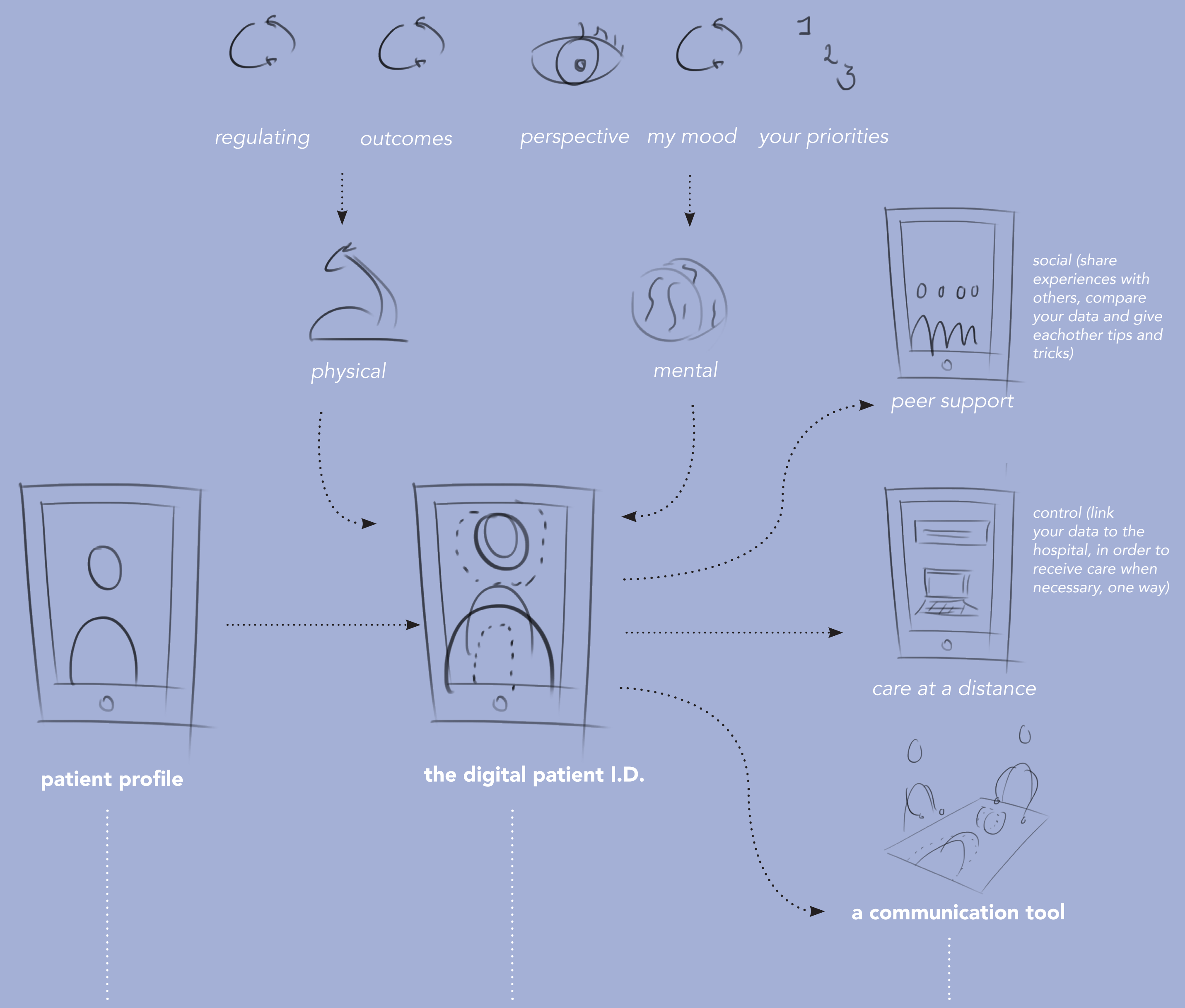
In figure 25, the structural data framework visualises how the holistic patient data is divided over the to-be-designed platform. The aimed effect of the visualised information in the consultation is also listed (data storytelling).

The platform distinguishes static and dynamic information of the patient.

The static information:
In the patient profile, the static information can be found: the type of diabetes or the number of years living with the diagnosis.

Dynamic information:
In the digital patient I.D., the dynamic information can be found. This information can continuously be measured (and therefore does not have to be asked within the ICHOM questionnaire anymore). By having the information already visualised and measured, time is saved within the current consultation and enables doctors and patients to talk about it immediately. The dynamic information distinguishes physical and mental measurement.

Future possibilities:
Within this graduation project, the validated information from the ICHOM questionnaire is used to create a conversation where the holistic patient topics can be discussed. In the future, other information can be linked to the tool to increase the accuracy of the information and personalise the conversation even more. The Erasmus MC wants to move to a more symptom tracking system (Jan Hazelzet, personal conversation, 2019), but then computer adaptive testing need to be applied to the questionnaire. Computer adaptive testing means that the questionnaire can be shortened and are 'smart' enough to know which question is a valuable followup question. This more specific data can be used as input for this platform, which makes the solution valuable for future possibilities. This suggestion is also discussed in Chapter 06 Implementation.



STATIC INFORMATION

Demographic (sex, year of birth, ethnicity, education level)

Diagnosis profile (diabetes type, year of diagnosis, comorbidities, thyroid level (if present)

Diabetes control (treatment, blood pressure-lowering therapy, statin/lipid-lowering therapy, diet advice, exercise advice, blood sugar advice and medication advice)

Health utilization (how often does the patient go to the hospital, discharge diagnosis)

Micro/macrovascular complications chronic (sight-threatening conditions, autonomic neuropathy, heart failure, ischemic heart disease, lower limb ulcer, peripheral artery disease, kidney disease, cerebrovascular disease, periodontal health, erectile dysfunction, lipodystrophy, lower limb, charcot's foot)

Medication
Linked to the pharmacy, so there is a general insight in the medication of a patient

DYNAMIC INFORMATION

Physical
1. Diabetes control (dietary, exercise, blood sugar monitoring, medication adherence, glycemic control)

2. Intermediate outcomes (blood pressure (diastolic, systolic), cholesterol and triglycerides, BMI weight, BMI height, waist circumference)

Micro/macrovascular complications acute (hyper/hypo, stroke)

Health utilization (access to care, access to medicine)

Mental
1. Perspective towards diabetes (coping/manage)
Well-being (Questionnaire WHO-5)
Distress (The PAID)
Depression (PHQ-9)

2. My priorities: what do I find important? Where do my priorities lay? What do I like?

3. My mood: how is my daily mood (A.I.), able to figure out how my mood influences my blood sugar, mood-related to hypo's/hyper's, your daily mood related to physical events (link to agenda f.e.)

DATA STORYTELLING

Data storytelling describes the aimed effect of the visualised patient data: using the data as a shared language between the patient and the doctor to create a conversation about the holistic patient image, covering all the following questions:

Physical functioning: how do I feel physically?
f.e. how is my blood sugar doing?

Mental well-being: how do I feel mentally?
f.e. do I follow my therapy and why?

Meaning of life: how much faith do I have in my own future?
f.e. can I manage my diabetes in the way I am doing now for the next years?

Quality of life: do I manage to enjoy life?
f.e. support of having a chronic disease

Participation: to what extent can I participate in society?
f.e. can I join a hiking holiday with my friends?

Daily functioning: how does my daily life look like?
f.e. can I manage my diabetes at work?

source: mijnpositievegezondheid.nl

Figure 25: structural data framework

5.3 Data visualisation

The deeper layer within the conversation is reached by visualising the patient's mental and physical data. Data visualisation becomes the new shared language between the patient and the doctor within the consultation. This chapter explains the thought behind the working principle of 'data visualisation'.

5.3.1 The relevance of data design

Healthcare is slowly following the developments from the consumer market. The tailored healthcare project of Bob Groeneveld and Tessa Dekkers is one of the first examples, where patient profiles are established inspired by consumer profiles from the consumer market (Tailored Healthcare). Currently, the consumer market is heading towards data-driven personas in order to predict behaviour (Koot, 2019). In parallel, healthcare is moving towards a digital twin to improve care delivery and patient experience (Thotathil, 2019). The first step in creating this digital twin is gathering *valuable data* to establish the digital twin. The second step is understandably communicating the gathered data to specialists and patients. This communication can be done visually. Data visualization is going to play an important role in the future of healthcare (Meyer, 2017).

5.3.2 Data storytelling

According to a different, modern view on the Data Information Knowledge Pyramid (Rowley, 2007), using data at the core of the decision-making process is helping to make wiser decisions (figure 26).

Currently, the consultation mainly focusses on 'trading' information and knowledge, which makes it challenging to reach insights and wise decisions.

For the consultation of 2030, the perspective from figure 26 can mean the following:

- Data: the patient is gathering data over some time, based upon their treatment plan.
- Information: This data is visualised over time, in order to make sense out of this data: bringing information
- Knowledge + Insights: during the consultation both patient and doctor will share their knowledge about the situation with each other, using the visualisation as a common language, trying to create insights in the situation of the patient.
- Wisdom: in the end, the doctor and the patient can make a wise decision together, by linking the insights together (taking into account both perspectives) which contributes to the goal of introducing the shared decision approach in the consultation room.

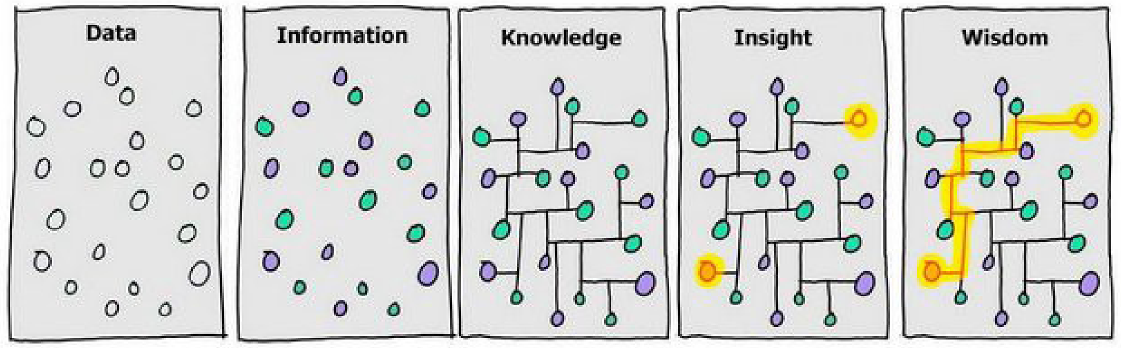


Figure 26: A different view on the DIKW-pyramid (image source: Figueroa, 2019)

in the future A.I systems might be smart enough to create insights already before the consultation starts. The patient and doctor have the time to discuss those insights and to make a wise decision.

Using data, visuals and stories in a combined way is called data storytelling (Dykes, 2018) (figure 27). According to Stephen Few, who is an expert in the field of technology innovation, the success of data storytelling can be summarized in three points:

- Memorize: people remember stories better than single statistics (63% vs 5%), which suggests that this method will let patients remember more from the consultation, linking their stories to their data.
- Persuasive: stories have the power to convey people instead of just seeing the visuals, which suggests that this can give the specialists more insight into the daily life of the patient and thus be more empathic.
- Engage: when listening to stories people tend to trust the bigger picture, instead of focussing on small details, which suggests that it makes it easier understand the holistic patient story, instead of focussing immediately on one specific details.

Validation should confirm if these theories apply to a consultation. If so, the effect of those three pillars will help the patient and the doctor to smoothly go through the consultation, aiming to have a positive influence on the information transfer within the consultation (Dykes, 2018).

This short analysis results in several visualisation requirements for the final design (Appendix J).

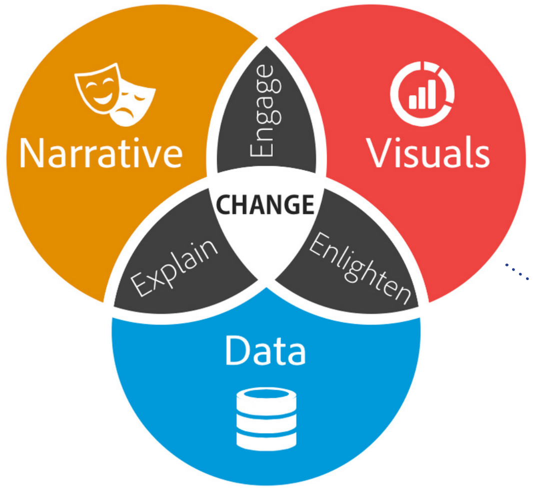


Figure 27: three elements of datastory telling (image source: Dykes (2018))

> *"When data and stories are used together, they resonate with audiences on both an intellectual and emotional level."*
>
> *- Stanford University Professor of Marketing Jennifer L. Aaker*

5.4 Mijn Erasmus I.D.

The final deliverable of the case study is the concept: mijn Erasmus I.D for diabetes type 1 patients. Mijn Erasmus I.D. is a digital patient I.D. that consists of a platform for the user and an interactive screen within the consultation. Both have the same structure of navigating through the data. The structural data framework is used as guidance for the different elements. The iterations can be found in Appendix K and all screens can be found in Appendix L.

5.4.1 The working principle

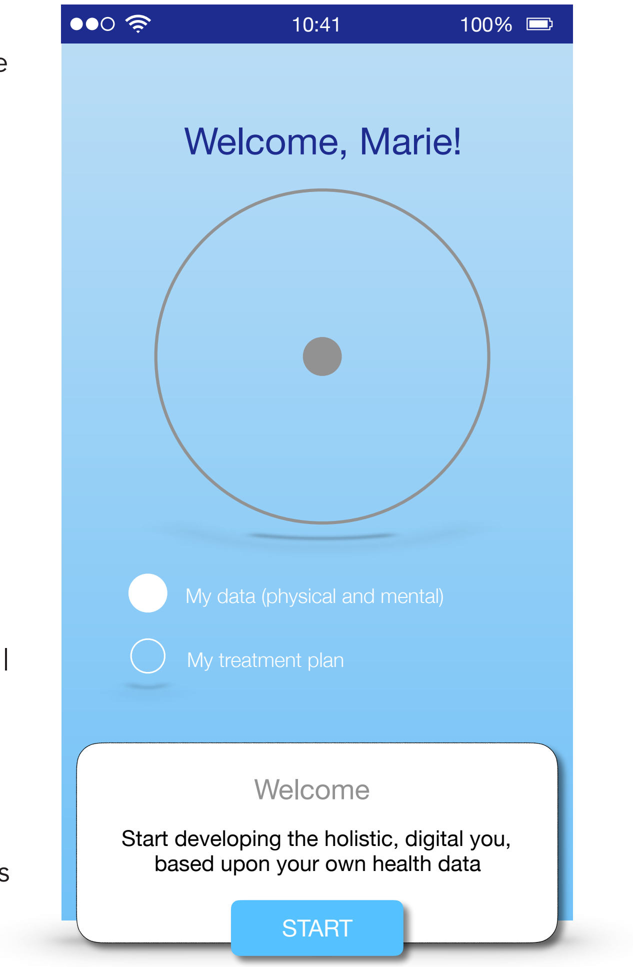
The working principle is the same for the platform and the interactive screen.

When entering the platform for the first time, two circles appear. The inner-circle represents the patient's data (physical and mental), and the outer circle represents their treatment plan. Both circles are in the default mode since there is no data linked to the platform yet.

The user can link their wearables to the platform to create a link between their data and the platform. Together with their specialist, the treatment plan is defined. At this point, the measurement can start, and the grey circle *My data* will grow: the digital patient is born.

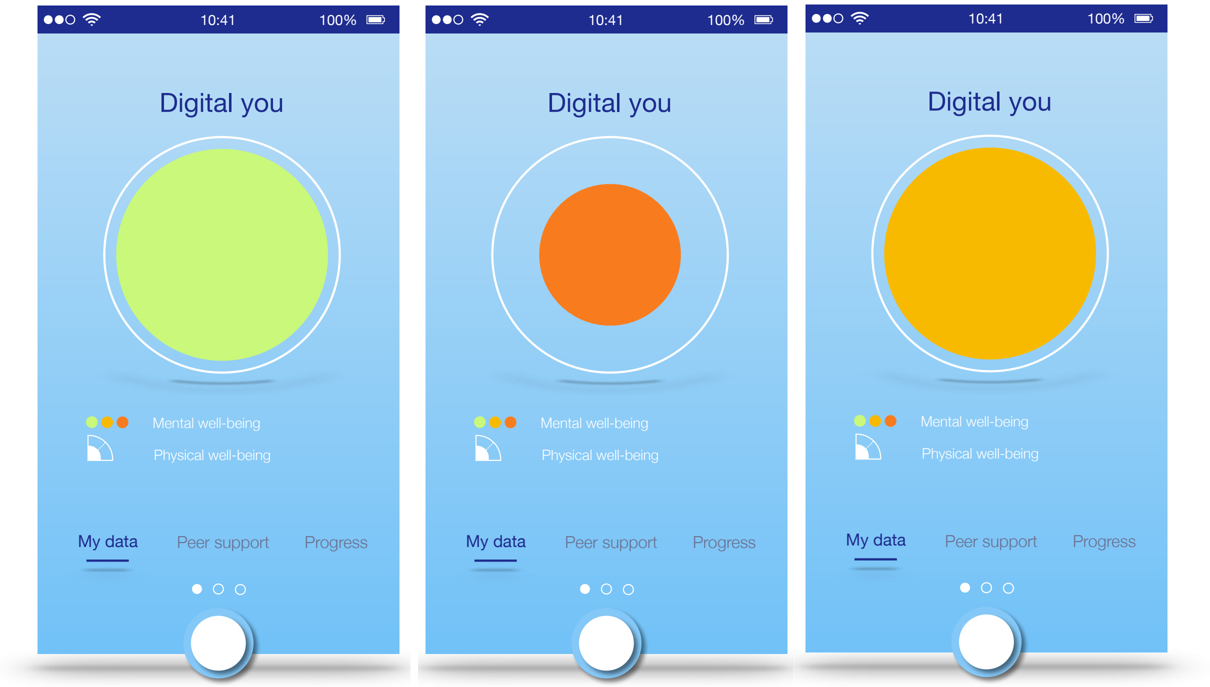
Interpretation

The colour of the circle represents the mental well-being and the width of the circle their physical performance towards the treatment plan. To give some examples of possible patient profiles, see figure 29.



Start developing the holistic, digital you, based upon your own health data

Figure 28: Main screen



The patient is physically doing very well since the distance between the patient data, and the treatment plan is small (the circle is almost full). The patient's mental state is also doing fine because the colour of the circle is green.

The patient is physically not doing so well since the distance between the patient data, and the treatment plan is large (the width of the circle is small and thus far from reaching the treatment goals). The patient's mental state is also not good, because the circle is coloured red.

The patient is physically doing very well since the distance between the patient data, and the treatment plan is small (the circle is almost full), but the patient's mental state is not doing very well. The orange colour of the circle indicates the mental state of the patient.

Figure 29: Interpretation

5.4.2 The main screen

Figure 30 shows the main screen. The legend continuously shows the patient how the visualisation should be interpreted (the colour defines the mental well-being, and the distance to the outer circle defines the physical well-being). By swiping to the left, the patient can navigate in the different tabs of the main screen: *my data, peer support and progress.*

The following page describes the different tabs.

1. My data

The data of the patients is linked to the database of the Erasmus MC. Therefore, the Erasmus MC has an extensive overview of how all their diabetes patients are doing, and continuous care can be given. An A.I. system filters the health data of the diabetes patients and sents automated messages based upon the health data. The A.I. can suggest an appointment (figure 31) or give a compliment when a patient is doing well. When the information from the digital patient profile is doubtful, the A.I. sents the patient's information to the specialist. The specialist than decide how, if and when they want to have contact with the patient. In this way, the A.I system and the doctor work together closely.

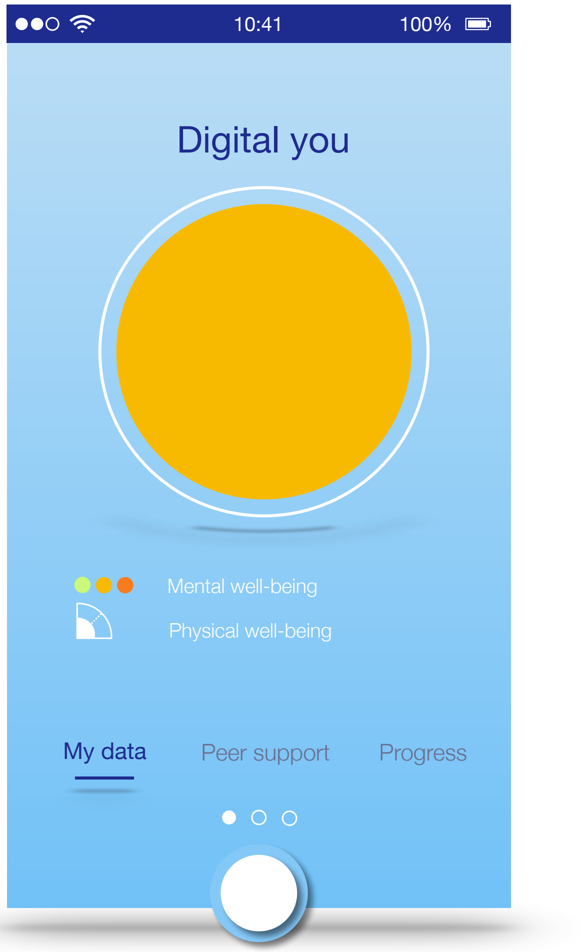
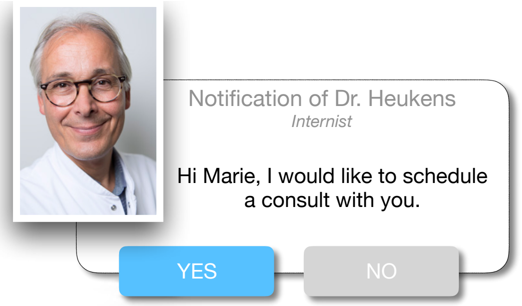


Figure 30: Main screen

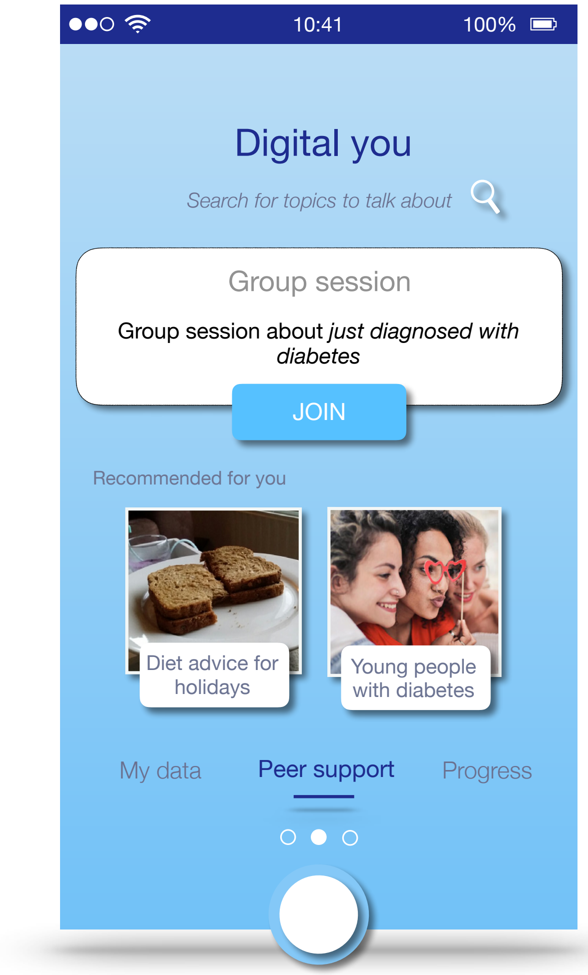


Hi Marie, I would like to schedule a consult with you.

Figure 31: A.I. automated message (image source: Tjongerschans.nl)

2. Peer support

By swiping one screen to the left, the user navigates to *Peer support*. The A.I. system has indicated which topics are attractive to the user, based upon f.e. the Google hits, appointments in the agenda of the patient or the activity in the Erasmus Academy. Those topics will appear in the patient's feed (figure 32). The patient can like the topics that are on top of their mind or join group discussions, after which they will end up in an environment where they can chat with their peers.



Group session about *just diagnosed with diabetes*

Figure 32: peer support

3. Progress

By swiping another screen to the left, the user sees their mental and physical development over time (figure 33). It makes the user aware of their physical and mental development, allowing them to have a moment of reflection. Creating awareness around a 'patient's behaviour and their health outcomes increase patient involvement (Hibbard and Greene, 2013).

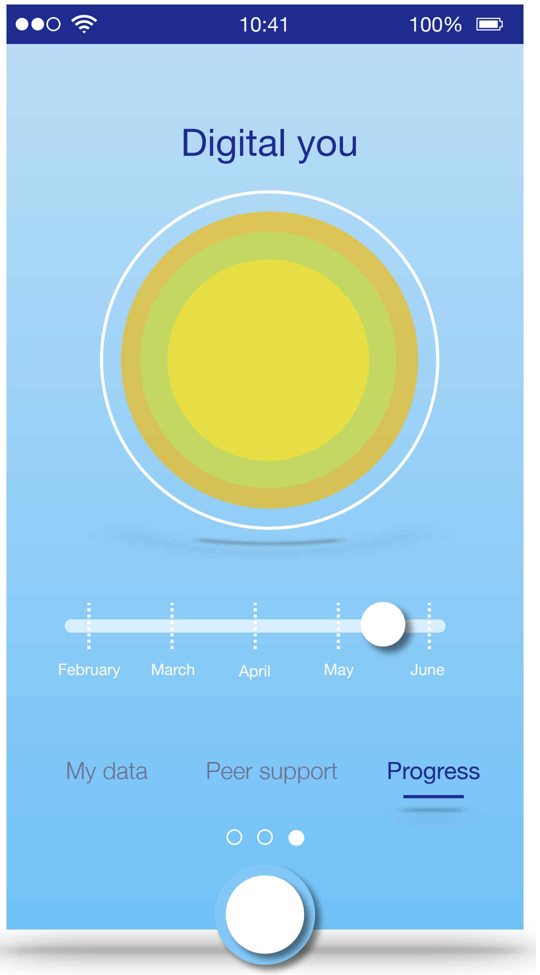


Figure 33: progress

5.4.3. The specified data

The user can navigate to the specified data out of which mijn Erasmus I.D. consists. The user navigates to their physical data by clicking on the outer, white circle 'My treatment plan' (figure 34). Information about the blood sugar level, diet and activity will appear. The detailed screens can be found in Appendix L.2.

Besides the diabetes control data, the intermediate outcomes are linked to this profile (blood pressure (diastolic, systolic), cholesterol and triglycerides, BMI weight, BMI height, waist circumference) (see structural data framework), but this data is not visualised within the scope of this project.

The user navigates to their mental data by clicking on the coloured circle 'How are you?' (figure 35). Information about their perspective, mood and priorities will appear. The detailed screens can be found in Appendix L.3.

Besides the diabetes distress, also the well-being and depression questionnaire should be taken into account to cover the whole mental spectrum of the patient. Within this graduation project, the visualisation of those two questionnaires is out of scope.

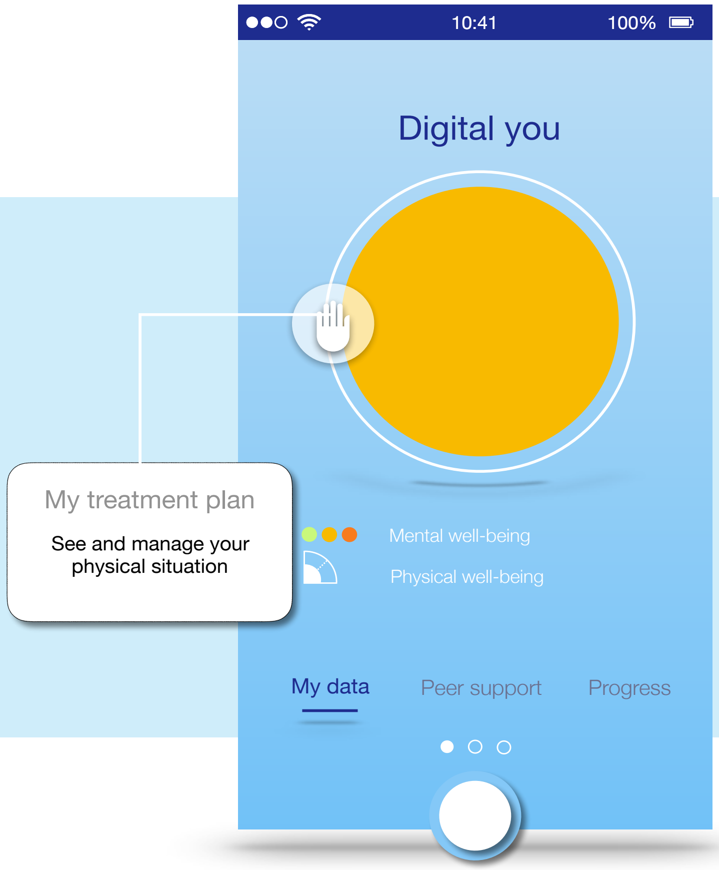


Figure 34: navigation to My treatment plan

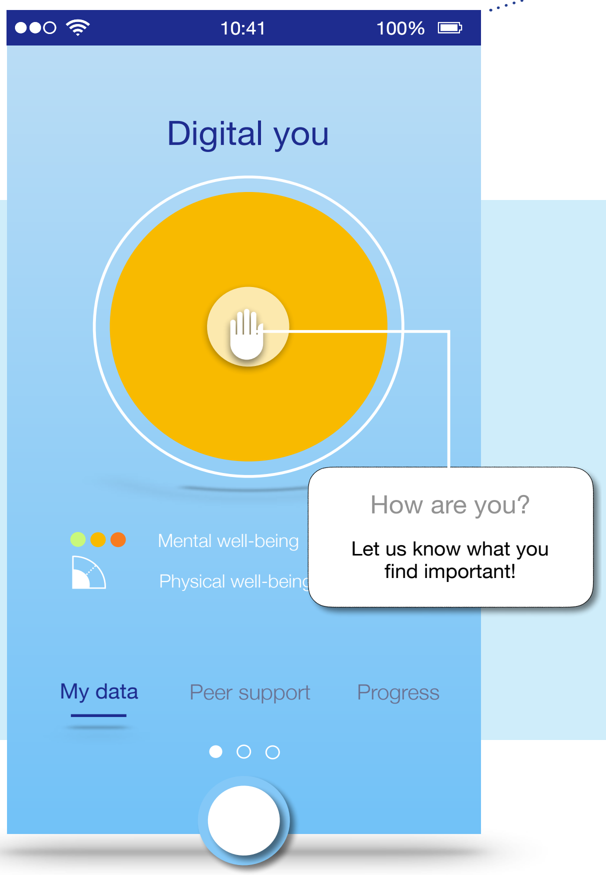


Figure 35: navigation to How are you?

The interactive screen shows the same information and has the same structure as the platform. The specialist sees a brief overview of the progress of the patient's data. The navigation through the data is the same as for the platform. In Appendix L.4, an overview of the screens used within the consultation is shown.

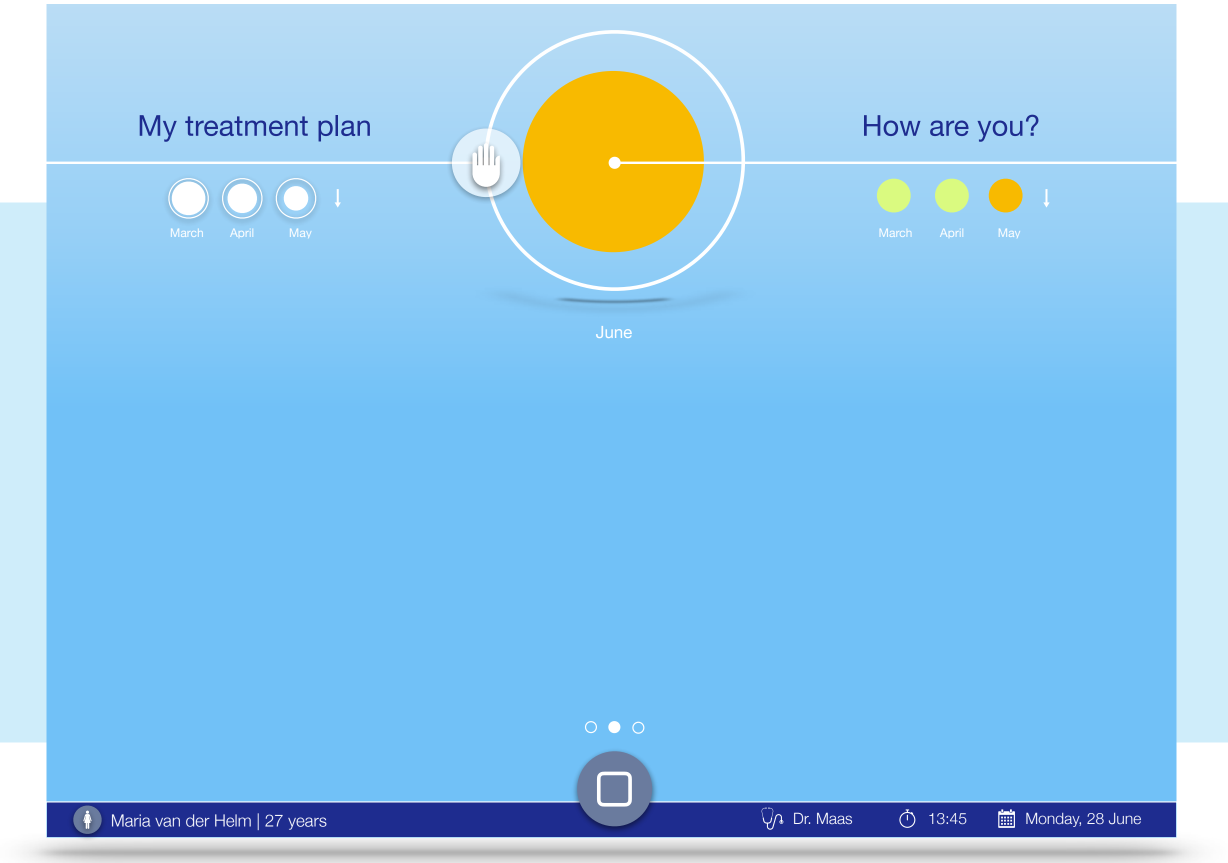
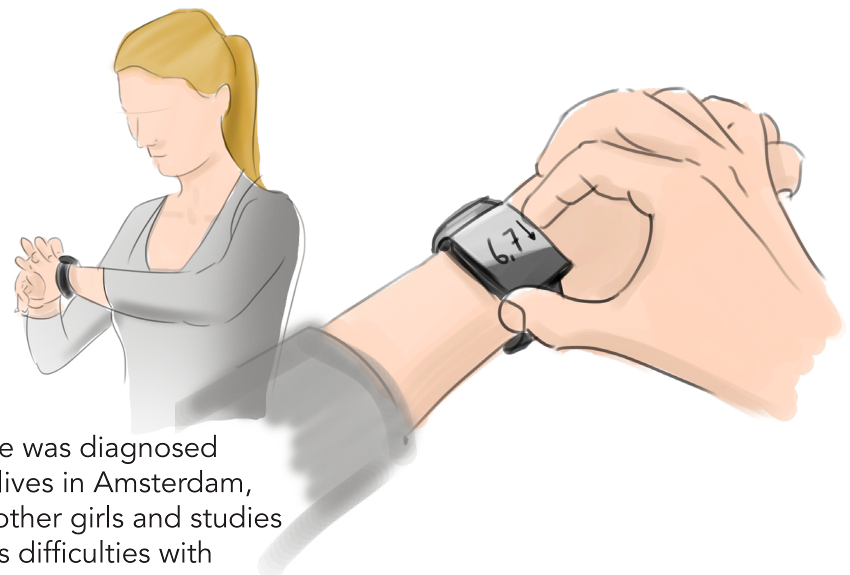


Figure 36: main screen, interactive screen in the consultation room

5.5 Scenario

Stories will allow people to let the design ground in the context of usage, and it will help to explore and define the design without having all the details complete (Quesenbery & Brooks, 2010). Therefore, a scenario is written to communicate the aimed effect of Mijn Erasmus I.D. The scenario is written and validated with the help of diabetes patients.



1

1,5 years ago, Marie was diagnosed with diabetes. She lives in Amsterdam, together with four other girls and studies Economy. Marie has difficulties with regulating her diabetes, and therefore, her urine and blood tests have not been good the previous months.

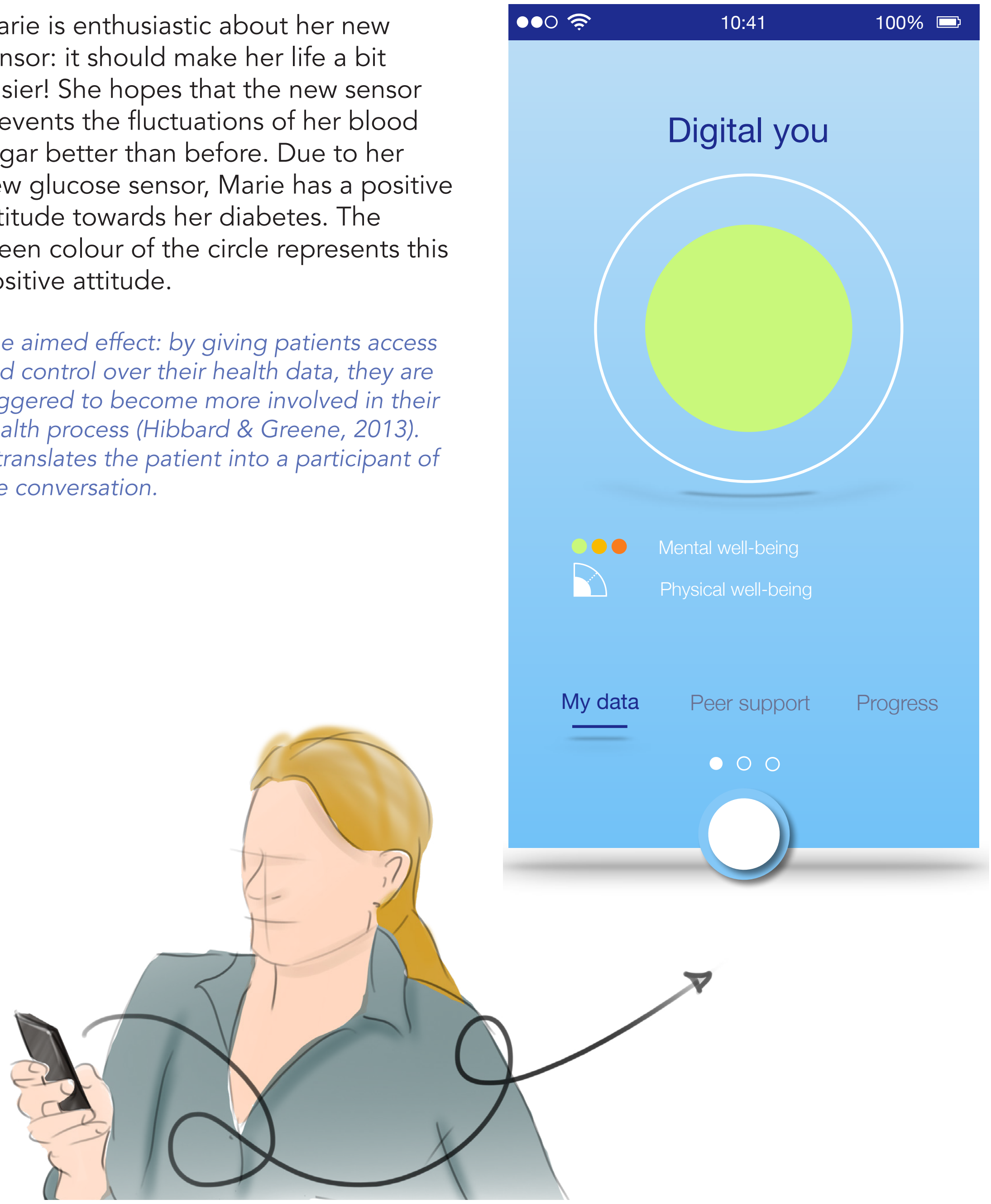
At the 5th of November 2030, Marie has received a new sensor that automatically measures her blood sugar level. The sensor is linked to her Apple Watch. She does not have to measure her blood glucose level manually anymore. Doctor Heukens, Marie's internist and Marie both expect that this will help her to improve her blood sugar levels over the next months.

The aimed effect: by tracking symptoms of patients, the experience, efficiency and health outcomes can improve. Currently, only the data from the ICHOM-questionnaire is measured, but this might be more shortly. (Basch et al., 2016)

2

Marie is enthusiastic about her new sensor: it should make her life a bit easier! She hopes that the new sensor prevents the fluctuations of her blood sugar better than before. Due to her new glucose sensor, Marie has a positive attitude towards her diabetes. The green colour of the circle represents this positive attitude.

The aimed effect: by giving patients access and control over their health data, they are triggered to become more involved in their health process (Hibbard & Greene, 2013). It translates the patient into a participant of the conversation.



3

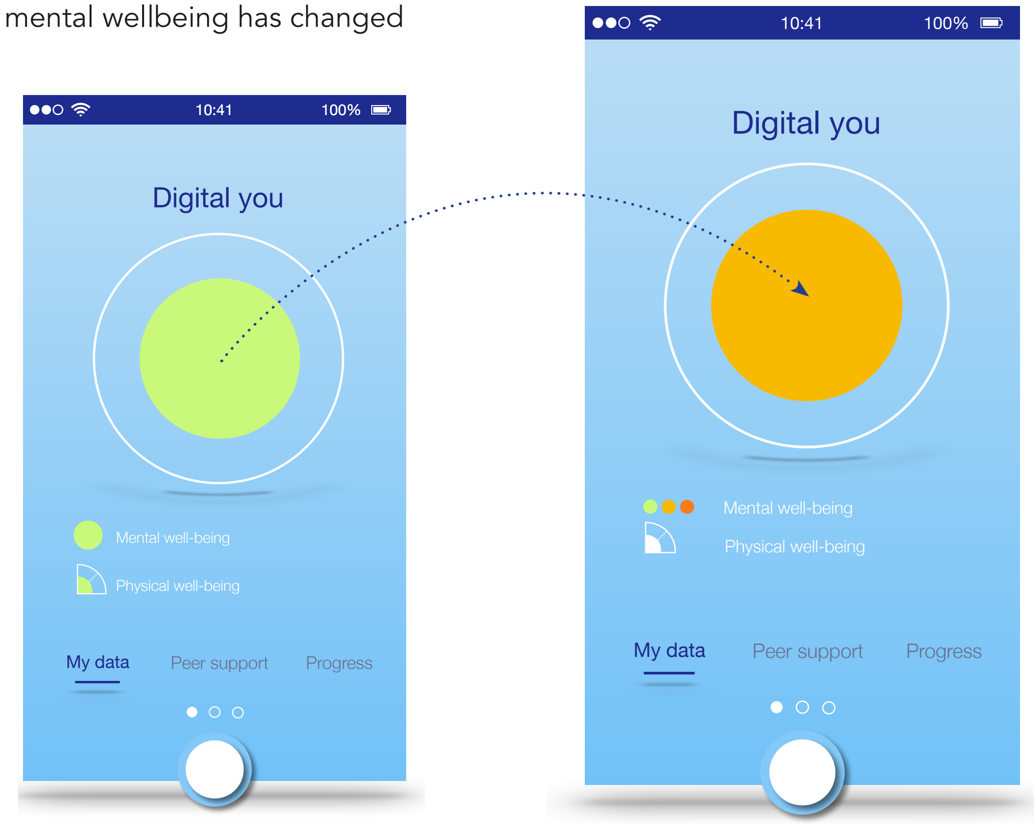
Unfortunately, Marie can not keep up with the positive attitude. Her new sensor does not significantly improve the extreme fluctuations in her blood sugar level. Besides, living in a student house with changing dinner times, make it difficult for Marie to stick to a regular and healthy dinner pattern. It makes it even more difficult that her friends assume that her new sensor is regulating ‘everything’ for Marie.

The A.I system registers the changing mood towards diabetes automatically.

After one month, the A.I system has registered several times a negative mood around Marie. The colour of the mental wellbeing has changed from green to orange. Marie finds it challenging to cope with her diabetes and worries about the future.

Besides, the physical wellbeing has not improved yet although both Marie and dr. Heukens expected this to improve over the next couple of months.

The aimed effect: being linked to the Erasmus MC with the health data, lowers the barrier to have access to care. This link has a positive influence on the patient’s wellbeing ((Street, Makoul, Arora, & Epstein, 2009). The Erasmus MC takes continuously care for their patients.

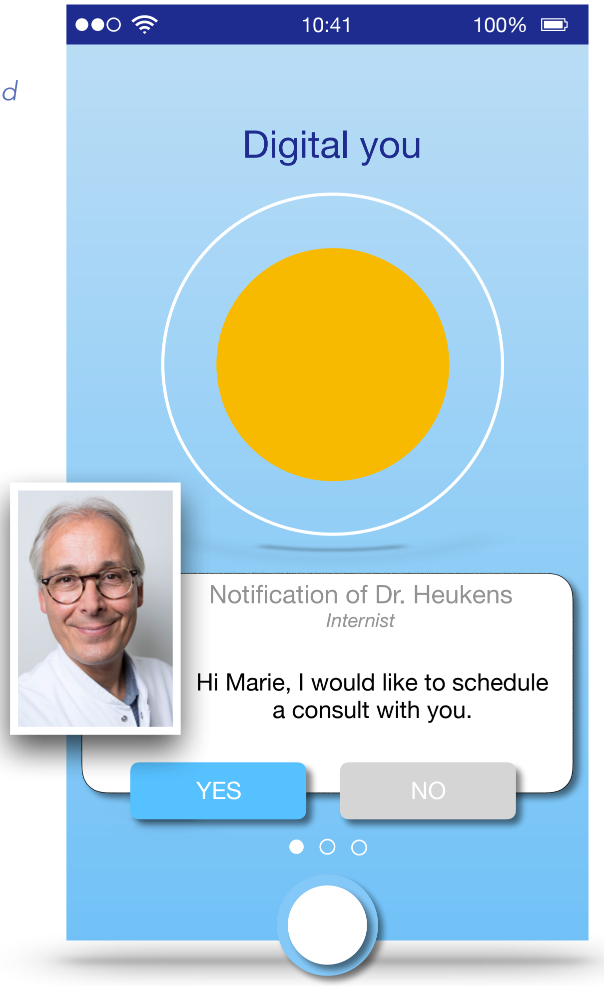


4

After one month, there is still no improvement in the blood sugar levels of Marie. Reason enough for doctor Heukens to schedule an appointment and do a little check-up on Marie’s physical state of well-being.

The A.I system sends an automated message, out of the name of her internist, to schedule an appointment. Before going to this appointment, Marie needs to the hospital for a blood test. Her internist will discuss the results.

The aimed effect: by getting personal messages of your internist, the patient feels continuously cared for. Besides, knowing and seeing your doctor upfront creates already a trust bond before the conversation starts (result of user study).



Hi Marie, I would like to schedule a consult with you.

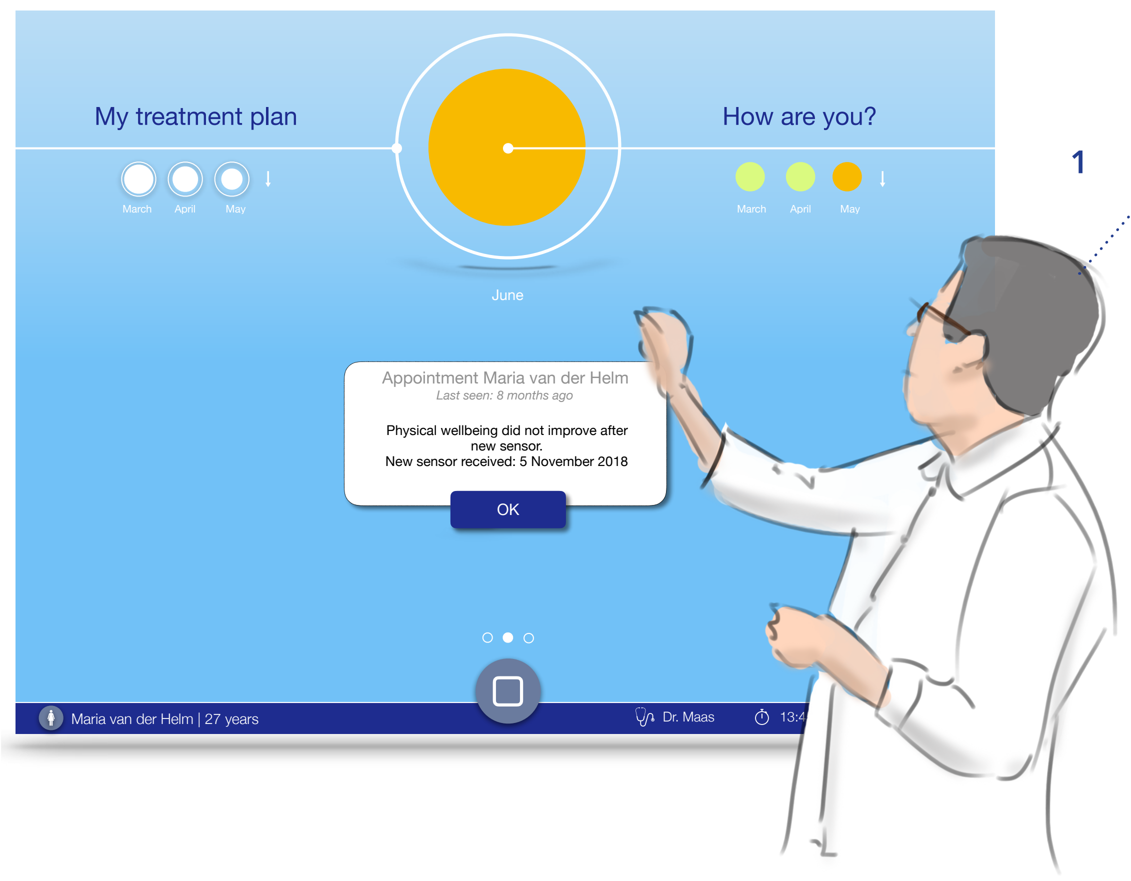
5

Doctor Heukens sees that Marie is scheduled for an appointment because her blood levels did not improve after she received her new sensor. He has a quick look in her data file.

(1) The main screen immediately shows him that Marie has had a mood swing towards her diabetes. He also sees that her physical state did not improve over the past months. In this way, doctor Heukens has a quick, intuitive and accurate overview of Marie.

(2) Doctor Heukense sees that her HBA1c levels have not improved over the last couple of months. Her blood sugar levels are still fluctuating a lot, even after the placement of her new sensor. This smart new sensor gives doctor Heukens a better insight into the progress of Marie's blood sugar level.

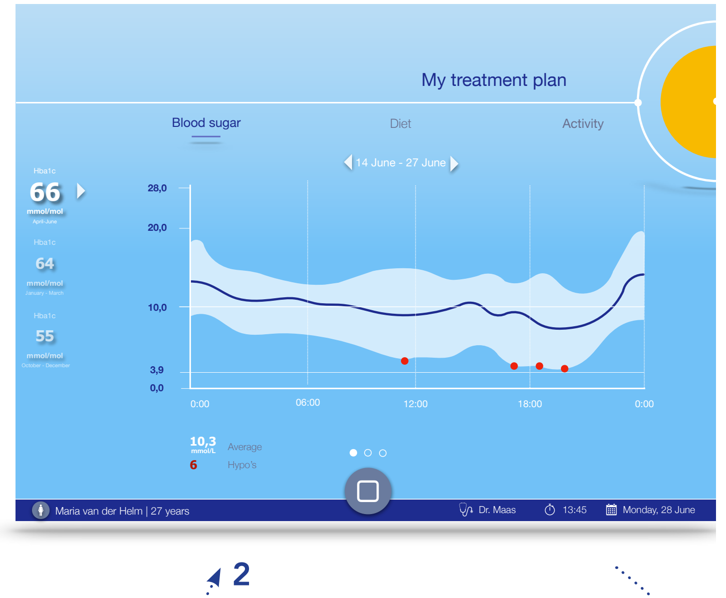
(3) He is also interested in the negative mood of Marie. The results are digitally processed and up to date in the system. Doctor Heukens does not have to search in the HIX system for the diabetes distress scan. The internist can have a quick look at the diabetes distress questionnaire and sees that the diabetes of Marie costs her a lot of physical and mental energy and that she worries about the future. The internist is aware of the emotional load the conversation could have.



Appointment Maria van der Helm
Last seen: 8 months ago

Physical wellbeing did not improve after new sensor.
New sensor received: 5 November 2018

OK



The aimed effect: the specialist gets the opportunity to understand, identify and relate to the feelings of the patient to make the conversation more empathic right from the start.

Furthermore, the platform will contribute to the trust bond between the patient and the specialist. Having a shared history ensures that a specialist can recognize small changes in the health appearance of the patient (Ridd, Shaw, Lewis, & Salisbury, 2009). The platform aims to improve the trustbond by providing this shared history.

6

When entering the consultation room, Marie feels much more comfortable to open up because she knows that doctor Heukens understands her physical and mental situation. This visualisation helps doctor Heukens to understand the patient's values and preferences faster and better, which results in a better experience for Marie.

Marie tells that her new sensor helps her to get a better indication of her blood sugar level, but that her blood sugar level still fluctuates and that it does not improve. Doctor Heukens asks if this situation makes Marie worry about the future more. Marie explains that she finds it difficult to combine her irregular life with her diabetes and that this results in insecurities about her future: how about going on a holiday with her friends, for example? She tells to her internist that she is losing the motivation to put effort into the regulation of her diabetes. Marie feels understood and heard, because of doctor Heukens understands how she is feeling.

Her internist says that he understands the situation and that they need to find a way to improve the situation for Marie: physically and mentally.

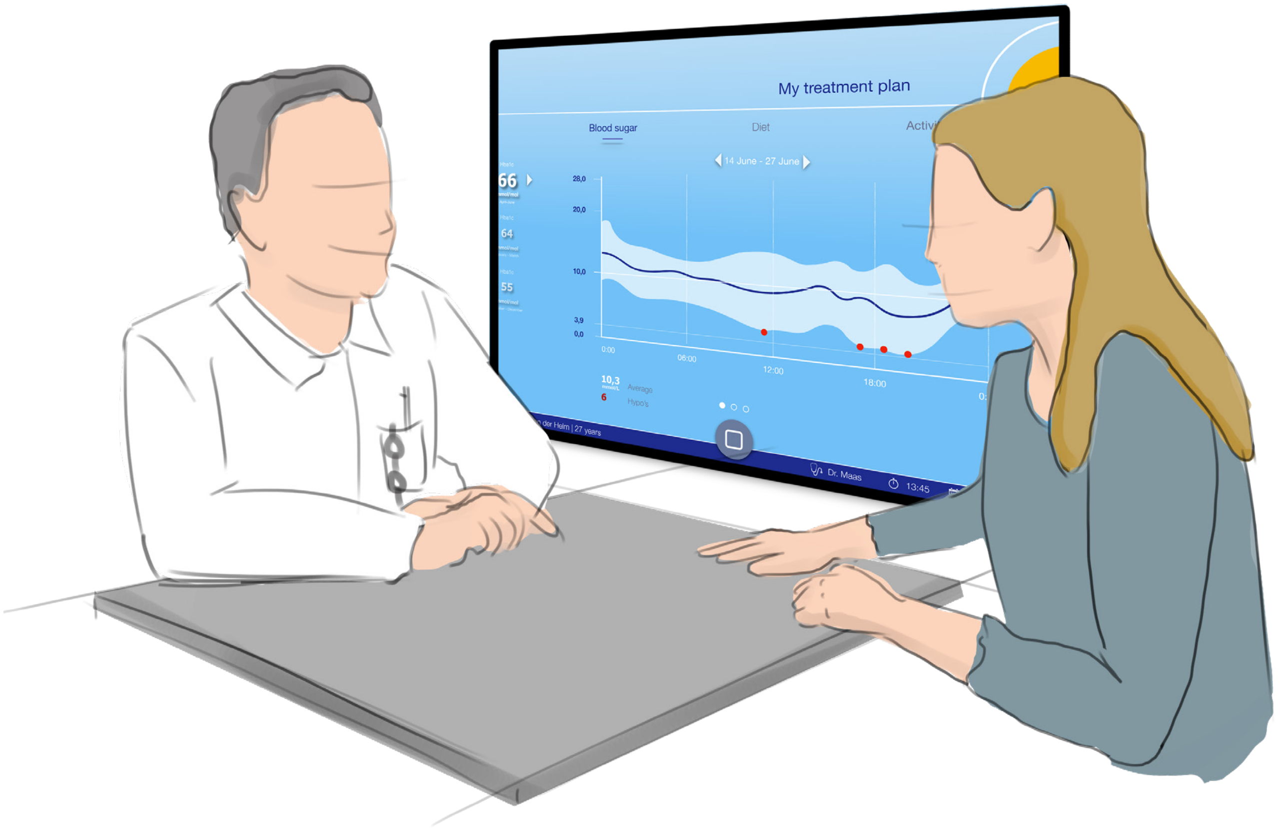
The aimed effect: The platform will help patients and physicians to manage the patient's emotions by being an empathic listener. (Street, Makoul, Arora, & Epstein, 2009). Because the information is gathered automatically, the computer is out of the way of the interaction.

7

They have a look at her previous blood levels, urine tests and fluctuation of the blood sugar levels. Together they create an insight based upon the information (Figueroa, 2019).

Marie explains the moments that she has had her hypo's, based upon the data on the interactive screen. She tells the internist that she thinks that the action time of her insulin is longer than the suggested time of 20 minutes. Marie explains that her hyper's mostly occur just after dinner time. The system measured how many hypo's Marie has had. The data helps her to describe the effects and the occurrence of the hypo's.

The aimed effect: Logging and tracking data before the consultation will save time during the conversation. The information and data will create insights during the consultation to spend time more useful and directed (Figueroa, 2019). Furthermore, it will help both the patient and the doctor to spend the time within the consultation as quality time (Cape, 2001)



8

Based on Marie's data, the internist says that her insulin may have a more prolonged action time. He suggests moving the time to 60 minutes, instead of 20 minutes. Doctor Heukens can create insight into the data provided before the consultation. The system keeps track of Marie's health and the effects of the change in time.

Lastly, doctor Heukens says that he understands that Marie expects her new sensor to improve her physical state immediately, but also indicates that it takes time before the right balance between insulin intake and the carbohydrates is found. He recommends Marie to talk with her friends about her new sensor and to have a look at the peer support app in the portal.

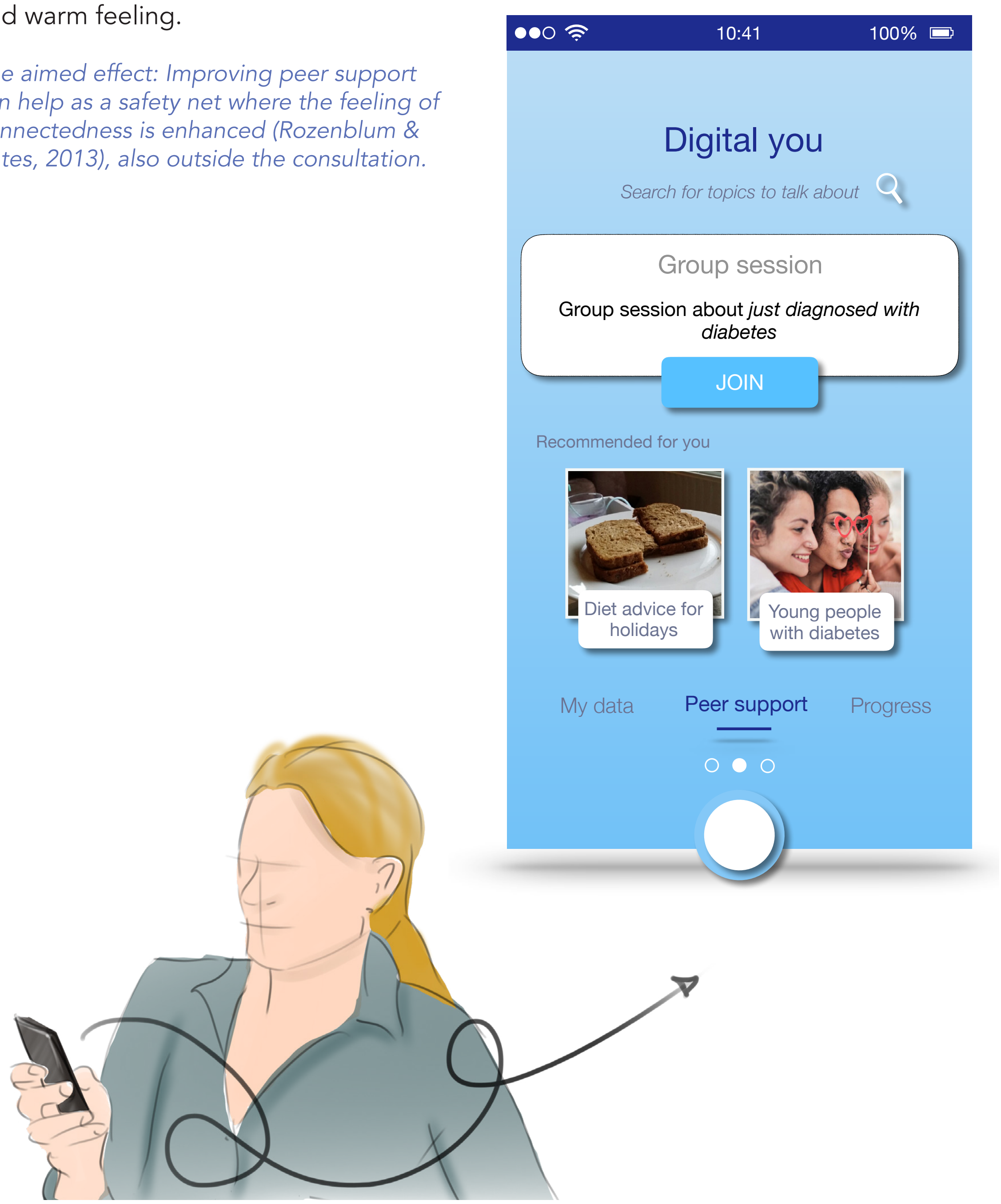
Doctor Heukens says that he will keep an eye on her situation and that he will support her in improving her mental and physical state.

The aimed effect: by providing evidence-based patient information, this intervention closes the gap between what the patients want and what the doctors think the patients, to prevent the occurrence of a misdiagnosis or a nonacceptance of the treatment method (Luxford & Sutton, 2014 and Edwards, Davies, & Edwards, 2009). Marie feels heard and satisfied with the consultation because she feels supported by her specialist. She has the feeling he understands her needs (user study). Doctor Heukens is satisfied because the conversation has become more holistic and in-depth in the same amount of time.

9

In the meantime, Marie finds support in the peer support app by talking to other people with the same problems. She knows that doctor Heukens is keeping an eye on her, which gives her a safe and warm feeling.

The aimed effect: Improving peer support can help as a safety net where the feeling of connectedness is enhanced (Rozenblum & Bates, 2013), also outside the consultation.



Digital you

Search for topics to talk about

Group session

Group session about *just diagnosed with diabetes*

JOIN

Recommended for you

Diet advice for holidays

Young people with diabetes

My data

Peer support

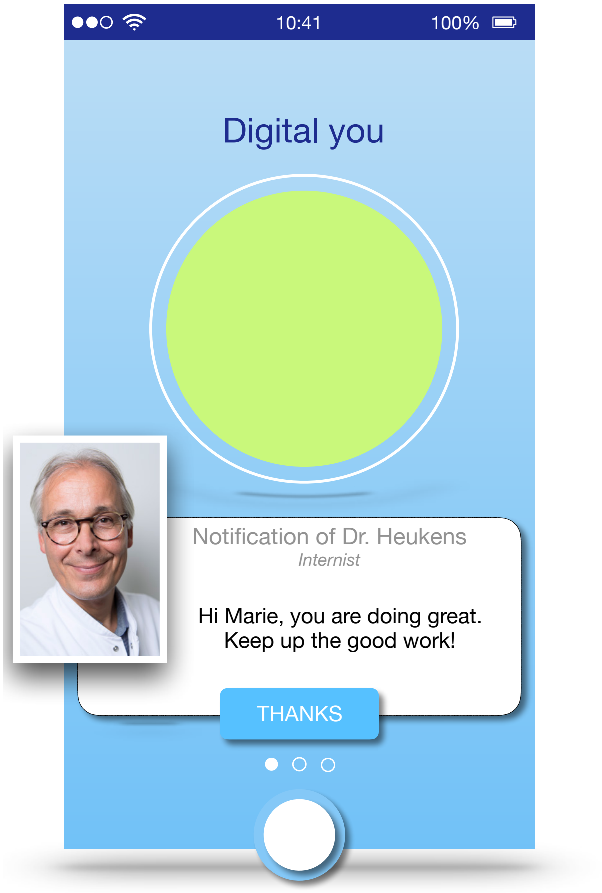
Progress

10

After the conversation with doctor Heukens and getting peer support, the physical and mental well-being of Marie improved. She receives a message from doctor Heukens, who tells her that she is doing great. The compliment makes her feel cared for, and she feels appreciated for her effort.

Six months after her last visit, Marie is still doing very well! Therefore, an appointment with her internist is not necessary at this point. In this way, Marie gets the care she needs at the moment she needs it. Doctor Heukens has now the time for patients that need his time more. Marie does not see doctor Heukens in person, but the A.I system gives Marie the feeling of being continuously cared for.

The aimed effect: having more continuous care due to the A.I assistant, lowers the barrier for patients to have access to care (Street, Makoul, Arora, & Epstein, 2009). This platform gives the patient confidence, also outside the 10 minutes of the consultation time (user study). Lastly, if compliments are linked to positive (health) behaviour, it gives people the feeling of being seen and being worth it, which translates the feeling of 'being alone in the consultation' to doing it together and feeling appreciated ('t Wout, 2015).



Notification of Dr. Heukens
Internist

Hi Marie, you are doing great.
Keep up the good work!

This intervention aims for a conversation that is about 'what matters to you?' focussing on a holistic patient image, able to cover the following questions:

Physical functioning: how do I feel physically?
f.e. how is my blood sugar doing?

Mental well-being: how do I feel mentally?
f.e. do I follow my therapy and why?

Meaning of life: how much faith do I have in my own future?
f.e. can I manage my diabetes in the way I am doing now for the next years?

Quality of life: do I manage to enjoy life?
f.e. support of having a chronic disease

Participation: to what extent can I participate in society?
f.e. can I join a hiking holiday with my friends?

Daily functioning: how does my daily life look like?
f.e. can I manage my diabetes at work?

(paragraph 5.2.4 Structural dataframework)

5.6 Value

Mijn Erasmus I.D. aims to translate the barriers of patient experience into enablers of a positive patient experience (Chapter 2.4). A link between the concept proposal and the research is made to explain the value of the intervention.

5.6.1 Link to main insights

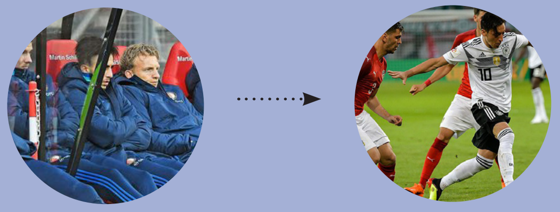
The value of *Mijn Erasmus I.D.* lies in the transition of barriers found in chapter 2.4 Main insights. *Mijn Erasmus I.D.* aims to translate all six barriers into enablers, and is thus likely to improve the patient experience. The translation, based upon information out of the literature, is shown. According to literature, the Erasmus I.D. is a promising solution to translating the barriers into enablers.

The user validation of the concept proposal aims to discover if the target group (patients and specialists) think these barriers are turned around. The evaluation is discussed in Chapter 07.

ENABLERS OF PATIENT EXPERIENCE

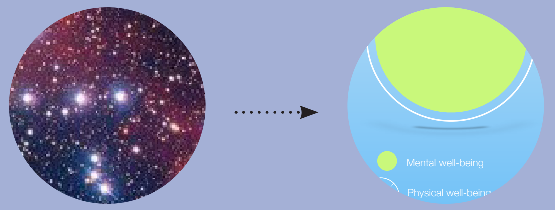
1. Spectator > Participant

The patient becomes a participant of the consultation, by empowering the patient of having control over their own data (Hibbard & Greene, 2013).



2. Vacuum > Visual

Visuals can be understood by the many. Therefore, this solution gives the patient a guided and understandable overview of their health situation, independent from their education level and health literacy. Besides, the information is saved and is, therefore, continuously accessible.



3. Alone > Together

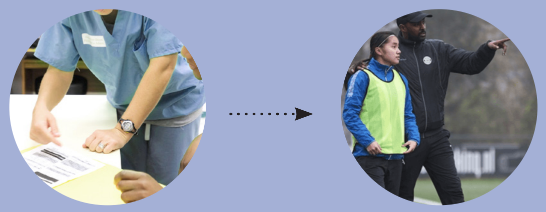
By having a continuous connection with the Erasmus MC, the patient feels connected and related to the Erasmus MC. Easy access to care also improves the physical, social and psychological health outcomes (Street, Makoul, Arora, & Epstein, 2009).

4. Confirmer > Tourguide

The renewed patient portal allows the doctor to be a tour guide: knowing and understanding which information the patient has received. The patient portal allows patients to be involved in a understandable and structured way; they have more insight into their health situation, which helps them to be more aware of the information that applies to them. The interaction between patients and specialists is more transparant, which results in being able to have the specialists as the tourguide.

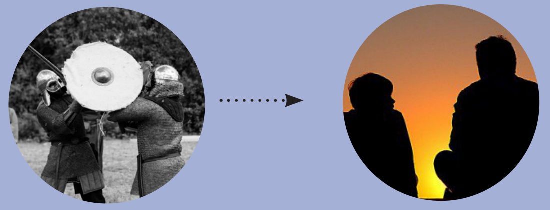
5. Physical > Holistic

Due to administration, there is less time for patient care. Within this proposal, technology lowers the administration workload for the doctor because much data is measured automatically. The digital patient I.D. creates time for specialists to focus on the holistic patient, instead of only on the physical part.

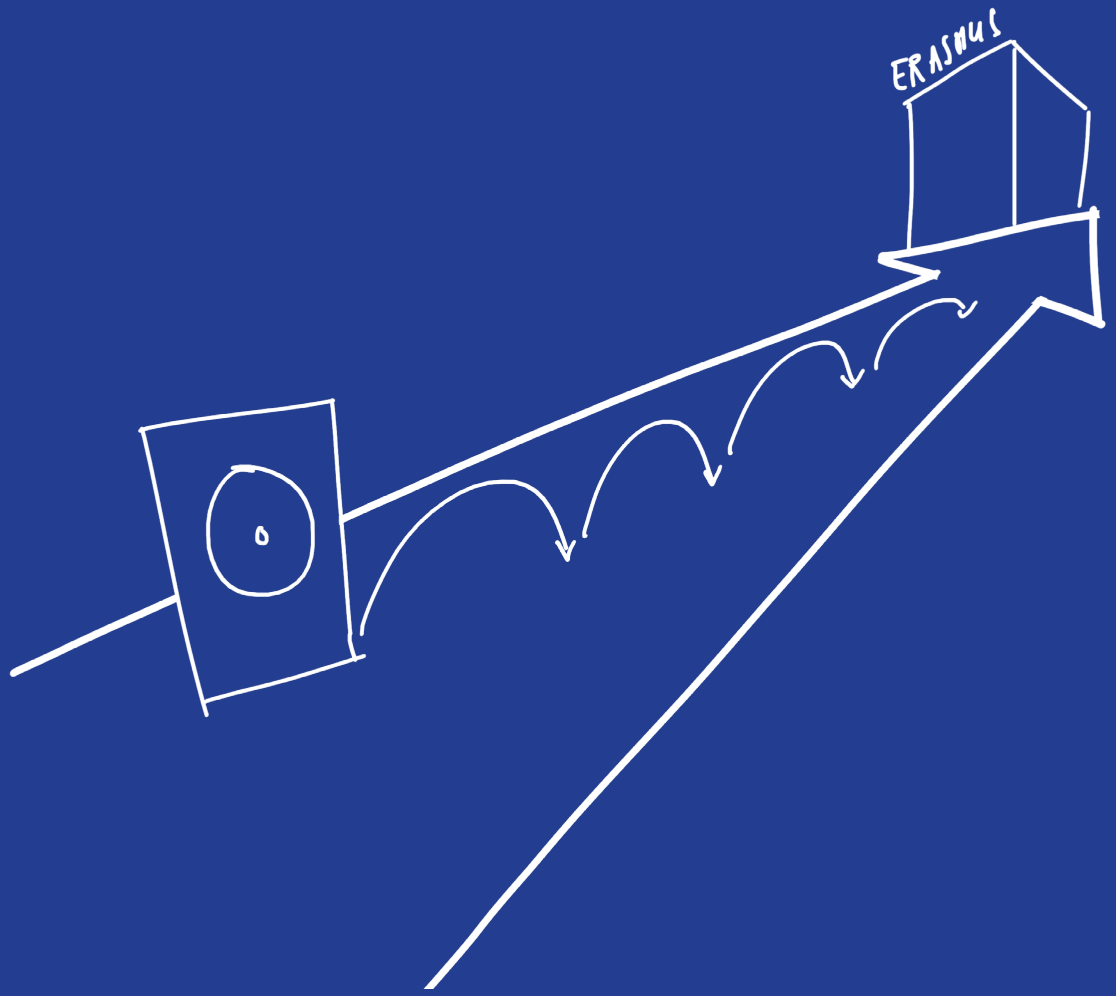


6. Technology > Human

This proposal allows the patient and the doctor to have a personal conversation again, with technology as an enabler of this conversation.



06 IMPLEMENTATION



This chapter describes which steps need to be taken before Mijn Erasmus I.D. can be implemented within the Erasmus MC.

Within this chapter:
Roadmap to implementation

6.1 Implementation

Mijn Erasmus I.D. gives the Erasmus MC an idea of how the future of the consultation room can look. However, how to continue with this project? Besides using roadmapping as a tool to explore the context and to discover opportunities (Chapter 2.2.4), it can also be used as a first step of the visualisation of a project planning (Phaal, Simonse, & Ouden, 2008). Roadmapping is used to show the Erasmus MC which stages are ahead before this concept can be implemented (Figure 37).

6.1.1 Explanation of the roadmap

Mijn Erasmus I.D. aims to create an effect on the long-term. Therefore, the validation of the proposal will be the main focus of the roadmap. The different prototypes describe the five steps that are necessary to validate the concept proposal as a whole.

STAGE 1: VALIDATE AND TEST
1. Desirability patients and specialists
The low fidelity prototype is used within this graduation project to test the desirability of the concept idea. In chapter 07, the results of the test are discussed.

2. Effect during conversation
How patients and specialists experience the intervention during their conversation is dependent on the usage. Therefore, the impact of the concept in the desired context needs to be tested with a high fidelity prototype. A design agency should be hired to design and develop a high fidelity prototype. The prototype needs to cover all the information from the ICHOM-questionnaire. Before testing the high-fidelity prototype, a request to the medical ethical committee needs to be written. Besides, the first test with smart sensors (think about glucose sensors, mood sensors and movement sensors) can start. This data is the basis for the visualisation in the consultation. Furthermore, the possibilities of implementing this intervention in other departments within the hospital are explored.

3. Effect on the long run
The third prototype focuses on the impact on patients and specialists in the long run. A quick and dirty prototype is made to discover the long term effect. The patient is asked to log some data manually, such as the distress questionnaire. However, adaptive computer testing makes it possible to adapt the questions to the patient's needs. The information from the smart sensors is linked automatically. In this way, the effects on the long term can be measured in a relatively easy way. The Erasmus MC will work together with an ISO-14385-certified healthcare design company to conduct this test. This test counts as a go/no-go moment. If this test is successful, the product is going to be developed on a large scale. Lastly, the Erasmus MC should think about which departments are next.

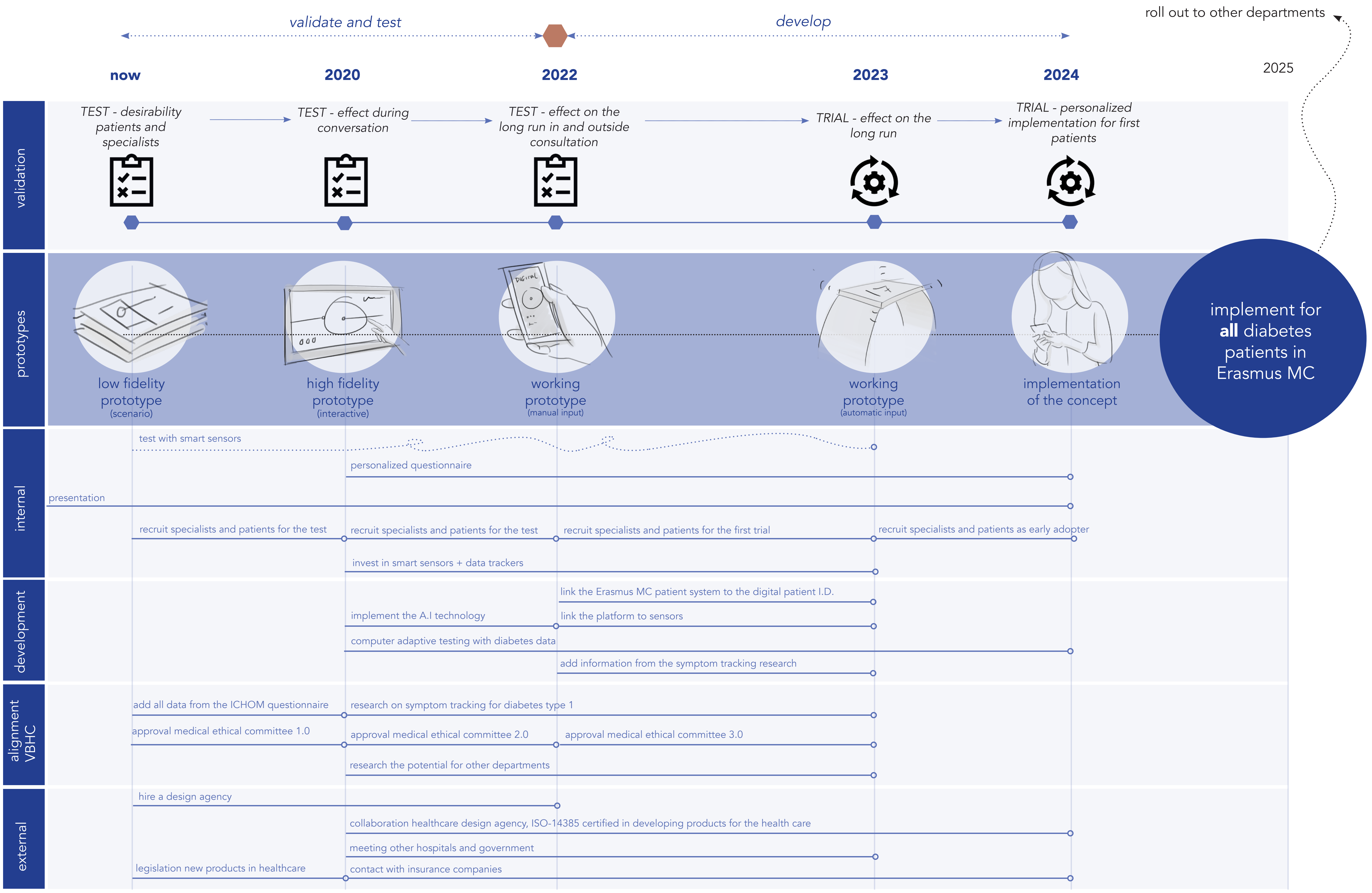
STAGE 2: DEVELOP
4. First trial test
When all legislation, research, approvals and collaborations are set, the ISO-14385-certified design company can test the first version of the digital patient I.D. within a trial test. This prototype works automatically: sensors, smartwatches and other devices are linked to the platform to gather the right information. Because the research around symptom tracking and adaptive computer testing is finished, the prototype is made personalised for the different patients. Lastly, the digital patient I.D. is automatically linked to the system of the Erasmus MC.

5. Implementation
If the evaluation of the first version is successful, the launch of the digital patient I.D. can be planned. Not all diabetes patients will work with the communication tool immediately. It is recommended to continue with the patients that participated in the trial, and with newly diagnosed patients. This approach gives patients, and especially the specialists, the time to get used to the new way of communication. After a while, the concept can be launched for all diabetes patients and specialists.

6.1.2 Important remark

During the validation period, the various stakeholders need to be taken into account:

- Patients: it might be interesting to involve the different patient profiles, established by Bob Groeneveld and Tessa Dekker, into the development of the digital patient I.D. These profiles focus on various communication types within the healthcare.
- Doctors and hospital management: it is recommended to have an internal meet-up with all the specialists and the hospital management regularly. The validation will change the way of working within the hospital. Therefore, hospital management and specialists should be enthusiastic about this project.
- Value-based healthcare department: more research in symptom tracking and computer adaptive testing for diabetes can help to ask the right questions to the right person at the right moment. This information will help to improve the concept proposal for future purposes. Therefore, this research should be done parallel to the implementation of the digital patient I.D.
- Government and other hospitals: When the government and other hospitals are up-to-date about the innovations of the Erasmus MC, several projects can be linked, and different organisations could work together. This collaboration could benefit national legislation around health care to have a national impact.
- Insurance companies: insurance companies could cover the costs for diabetes patients to use an intervention like this in the future (think about the smart sensors they need to have).
- Last but not least, it is essential to have a close look at the legislation. What does privacy legislation say? Also, how does this apply to health care? Several regulations are necessary to take into account when developing this concept further, such as NEN 7510 - information protection within the healthcare, NEN 7512- trust for information exchange and NEN 8028 - quality regulations around telemedicine.



validate and test

develop

roll out to other departments

2025

now

2020

2022

2023

2024

validation

TEST - desirability patients and specialists

TEST - effect during conversation

TEST - effect on the long run in and outside consultation

TRIAL - effect on the long run

TRIAL - personalized implementation for first patients

prototypes

low fidelity prototype
(scenario)

high fidelity prototype
(interactive)

working prototype
(manual input)

working prototype
(automatic input)

implementation of the concept

implement for **all** diabetes patients in Erasmus MC

internal

test with smart sensors

personalized questionnaire

presentation

recruit specialists and patients for the test

recruit specialists and patients for the test

recruit specialists and patients for the first trial

recruit specialists and patients as early adopter

invest in smart sensors + data trackers

development

link the Erasmus MC patient system to the digital patient I.D.

implement the A.I technology

link the platform to sensors

computer adaptive testing with diabetes data

add information from the symptom tracking research

alignment VBHC

add all data from the ICHOM questionnaire

research on symptom tracking for diabetes type 1

approval medical ethical committee 1.0

approval medical ethical committee 2.0

approval medical ethical committee 3.0

research the potential for other departments

external

hire a design agency

collaboration healthcare design agency, ISO-14385 certified in developing products for the health care

meeting other hospitals and government

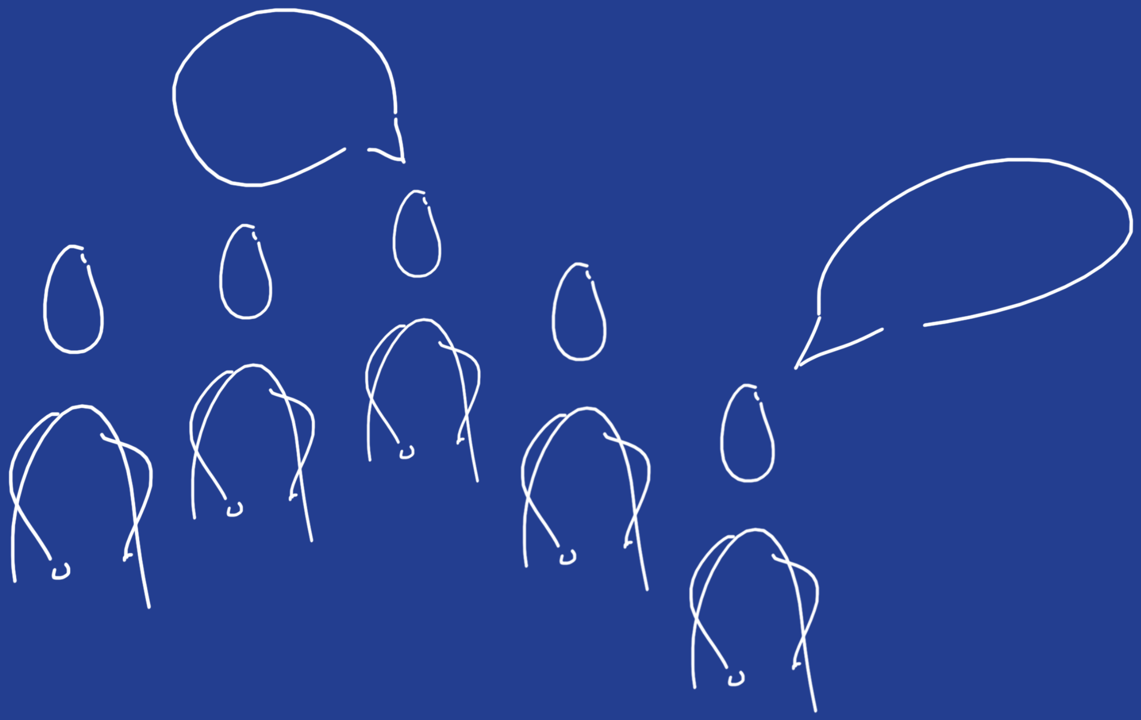
legislation new products in healthcare

contact with insurance companies

Figuur 37: the roadmap to implementation

⬢ *go/no-go moment for product development*

07 EVALUATION



This chapter describes the final evaluation of Mijn Erasmus I.D. How is the concept perceived by the Erasmus MC, diabetes patients and diabetes specialists?

Within this chapter:

- *User evaluation*
- *Recommendations*
- *Relevance to different stakeholders*
- *Personal reflection*

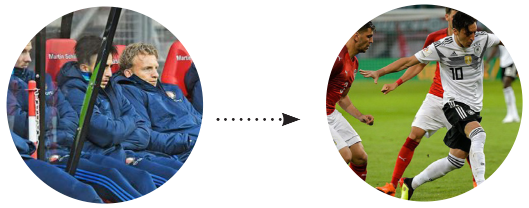
7.1 User evaluation

The goal of the user evaluation is to discover if Mijn Erasmus I.D. turns the barriers around. The research set-up and results per question can be found in Appendix M. This chapter shows the conclusions from the validation session as an average number per barrier. The patients (4) and specialists (9) could rate the different statements from 1 (fully disagree) to 5 (fully agree).

● *specialist*

● *patient*

1. The patient as a spectator



4.1 *I find that this intervention contributes to a better understanding of the patient's perspective.*

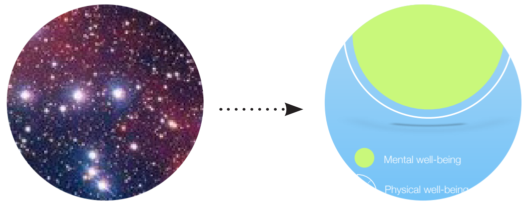
3.5 *When using this intervention, I feel more empowered*

Specialists find it useful to get an insight into the mental state of the patient, being supported with data. They believe that this proposal gives the patient more autonomy in their health process by helping the patient's self-management.

The patients feel more empowered in the conversation because the data can support them in communicating how they feel. Furthermore, they think the data can help the specialists to take the emotional side more into account. Lastly, they expect that the whole care team can communicate better with them since the information is shared within one platform.

" I would give me much trust when this intervention results in a conversation about the link between your physical and mental data. I want to talk about this link, but currently, this is not happening." - diabetes patient

2. Information in the vacuum



4.1 *I find that this intervention supports me in giving structure to the conversation.*

4.5 *When using this intervention, I feel that I am in control of my health data.*

The information is centralized in one system, which gives the specialists an accurate overview of where the problem of the patient lies. The intervention can make the conversation too structured, according to the dietists, but they did not know if this was beneficial or unfavourable in the consultation.

The patient feels more in control of their health data. They do think that the data can be confronting, but they do believe that this confrontation is necessary for regulating diabetes optimally. The patients question the accuracy of an A.I. in defining emotions. Although this doubt, they do think that this is where the future goes to. It is a matter of getting used to being tracked.

"I want to use the overview of 'my progress' as a conversation starter. This progress gives me insight into my health situation over some time." - diabetes patient

3. The feeling of being alone

3.8 *I find that this intervention allows me to be a more involved doctor.*

4 *This intervention makes me feel more continuously cared for.*

Specialists think the intervention makes patients more involved, instead of being more engaged as a specialist. This higher patient involvement will help them to strengthen collaboration and interaction during the consultation.

The participants find it comfortable that all data is linked within one platform; this gives them an accurate overview. Seeing the progress of your data is very insightful. It provides more information about how you felt in a certain period, which can give you valuable information on how to act towards diabetes.

" It feels comfortable when your specialist sents you an invitation for an appointment, then you do not feel alone. It feels supportive when the hospital sents you the message." - diabetes patient

4. The doctor as a confirmer

4.3 *I find that this intervention allows me to support the patient in their health traject better.*

3.8 *This intervention helps me to get insight into my health situation more easily.*

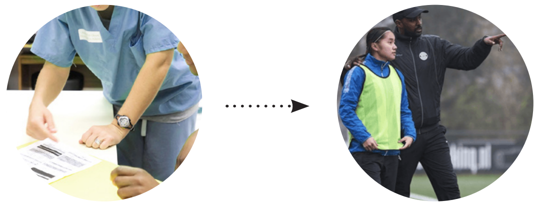
The specialists believe it supports the patient better because patients will come to the hospital when they require care and due to monitoring, they can receive care at a distance. Besides, the data provides a better preparation and will help to see trends in the data to establish concrete goals.

The participants find it comfortable that all data is linked within one platform; this gives them an accurate overview. Seeing the progress of your data is very insightful. It provides more information about how you felt in a certain period, which can give you valuable information on how to act towards diabetes.

" The data can help you giving insight into how you were physically and mentally doing in a certain period. The focus of the conversation can become your progress over some time. " - diabetes patient

" This intervention changes the perspective of the specialist. Instead of focussing on "we should discuss this, this and this, it can greatly help to steer the conversation in the right direction. This guidance is the value. "
- diabetes specialist

5. Less time for patient care

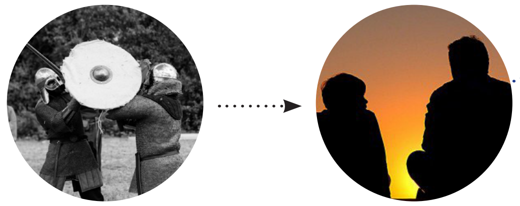


3.7 *I find that this intervention makes the conversation broader: it supports a holistic patient approach*

The tool allows the specialists to spend their time at the more essential tasks. The specialists still miss some data in the proposal, such as diet advice and elements from the positive health institute (Huber). Due to time limits, not the all data is included in the proposal. Only if the information is summarized in the pain points, it is possible to prioritize the conversation. The specialist believe that this tool can help tremendously by guiding the conversation in the right direction. But, if the data is not appropriately summarized, the specialists think this will result in more preparation time.

"I would like to use this intervention to ensure that my specialist understands how I am doing: where are the pain points? " - diabetes patient

6. Technology as a disabler



3.7 *This intervention creates a more in-depth and more empathic conversation between the patient and me.*

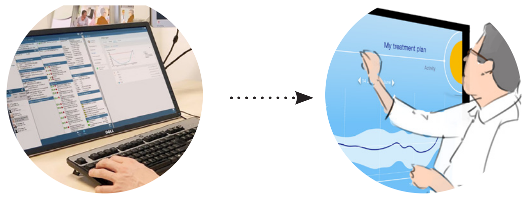
3.8 *This intervention creates a more in-depth and more empathic conversation between the specialist and me.*

Specialist find that this supportes a guided consultation that makes the conversation more equal and guided. The specialist can clearly see where the patient is struggeling.

The participants think that the intervention helps them in communicating better how they feel about their diabetes. They hope that this intervention results into a conversation that links their physical data to their mental data; this is what they value. Furthermore, patients think this intervention could oppose a more empathic conversation when the specialist does not mention anything about their mental state.

"I feel at ease that my specialist receives my physical and mental data... this encourages specialists to take the mental part into account." - diabetes patient

Intuitive to use?



4.2 *I find the visualization of the digital patient intuitive to use.*

5 *I find the visualization of the digital patient intuitive to use.*

All participants find this intervention intuitive to use and want to use this intervention in the future. Patients and specialists find the visualization of the patient data intuitive. The simplicity of shape and colour is something they very much like. However, one patient stated that the 'goal' of the outer circle is challenging to reach, and therefore the patient prefers to focus more on the balance instead of reaching the goal. Furthermore, colour-blindness should be taken into account.

Limitations

- The test set up: the intervention is not tested in the desired context due to regulations and time limits. Therefore, the aimed effect within the conversation is based upon a written scenario.
- Translation of the barriers: the designer translated the barriers into the statements. Therefore, the translation is biased by the opinion of the designer. For example, statement 5 could have been formulated as: "this approach lowers the administration load", while the designer has chosen to go a level deeper by enhancing the possibilities of having less administrative work: "this intervention makes the conversation broader".
- The participants of the test: the interviewed patients are all female and high educated, which, according to doctor Ozcan, most probably result in high involvement. If this is the case, it is expected that this intervention has a higher impact on patients with a lower commitment. Nevertheless, the results, based on this patient-group, are promising already.
- The presentation of the concept: the presentation did not show all the ins-and-outs of the concept. The presentation required own imagination of the patient; therefore, the presentation could have influenced the opinion of the specialists and patients.

Conclusion
Mijn Erasmus I.D. is received highly positive by specialists and patients. All participants want to use this intervention in the future, which validates the desirability of having a digital patient I.D. It can be concluded that *Mijn Erasmus I.D.* meets the needs of specialists and patients. Furthermore, all barriers are turned around, and thus it can be concluded that the intervention contributes to the positive patient experience. The result of the validation shows the potential for the implementation of a digital patient I.D. for diabetes type 1 patients.

Patients
Patients are more in control of their health data (4.5) and have the feeling of being continuously cared for (4). A critical remark is that the visualised data can have a less prominent place in the platform. Patients would like to choose if they are immediately confronted with their health data when opening the platform.

The translation to being a 'participant' gets the lowest score (3.5), which is still quite high. This score can be a result of the highly involved patients that participated in this research.

Specialists
The specialists find that this intervention supports the autonomy of the patient (4.1) and the structure within the conversation (4.1). It is a requirement that the technology within the system is smart enough to filter the information in such a way that it is communicated clearly to the specialist. If this is not possible, they believe that it will cost them more time to make sense out of the data before and during the consultation.

The empathic and more-in-depth conversation gets the lowest score (3.7), which is still quite high. The main reason for this score is the lack of information to make the patient profile complete. Due to time limits, not all data is presented in *Mijn Erasmus M.C.* This decision could have caused the result. However, specialists expect that this intervention supports the conversation by focussing more on the mental part: *"the values and preferences of patients will be easier to discuss."*

7.2 Recommendations

There are still some improvements to be made; these improvements are listed as recommendations for further development for Mijn Erasmus I.D. These recommendations are based on the diabetes type 1 patient group.

1. Confrontation with health data
Patients would like to choose if they are confronted with their health data immediately. The encounter with the health data can be sensitive, especially when a patient is not doing well. With this intervention, ignorance of diabetes is almost impossible; nevertheless, patients believe that being confronted with the data will help them to regulate their diabetes better.

> The designer suggests that the confrontation with the health data becomes less prominent in the following design. The visualisation of the data is received positively; therefore, it is not recommended to change it. The designer suggests that the 'My data' and 'Progress' tab change within the platform (figure 38). In this way, patients will focus more on the progression of their diabetes than on one specific moment. The progress overview can give patients a reality check: "This week, I am not feeling well, but it will be better, like in April." The focus of the data will not be primarily on one specific moment, but on a period.

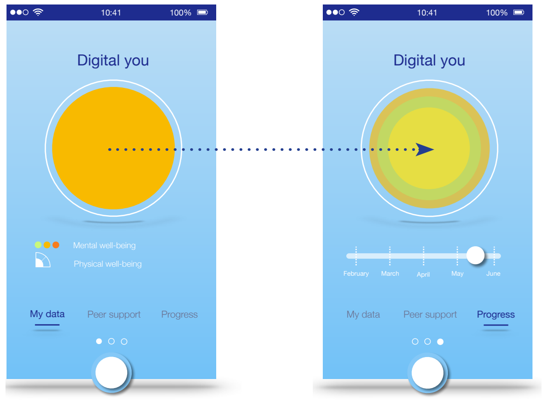


Figure 38: the proposed change of the main screen

2. Reaction time on the data
The system sents an automated message when a patient is not doing well. Specialists prefer to have a fast action time. In this way, they can help the patients at the moment they need it. On the other hand, when reacting too fast on the patient's data, it can result in having more hospital visits instead of fewer visits. Therefore, the requirements for sending a message need to be established.

> The designer suggests to research the following two questions:
- *How sensitive is the data to the transformation of the circle? How fast does the profile of the patient change?*
- *When is a message sent? When a message is sent to a patient who has an off-day, it could lead to more visits to the hospital. However, specialists prefer to have a fast action time to help the patient at the moment they need it. A balance should be found.*

3. Preparation time (specialists)
The system works with an A.I. technology that collects, process and summarises all the patient data in such

a way that the data is understandable to the specialists. However, understandably processing the data is a precondition for the concept to work.

> The designer suggests that the Erasmus MC should work closely together with an I.T. company that is specialised in processing large amounts of data into visualisations. In this way, the 'back-end' for the concept proposal will work properly.

4. Personal approach

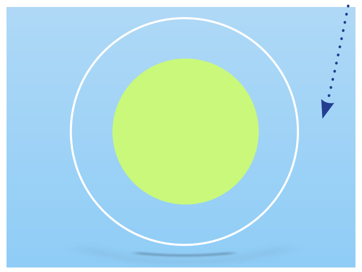
Some patients are in doubt if a personalised message from your internist is enough to feel you appreciated, while other patients are convinced of the working mechanism.

> The designer suggests testing different ways of communication. It is recommended to personalise the messages based upon the results from the Tailored Healthcare Project. Some patients receive a personal note, others receive a phone call or a video message, while other patients receive a text or a WhatsApp.

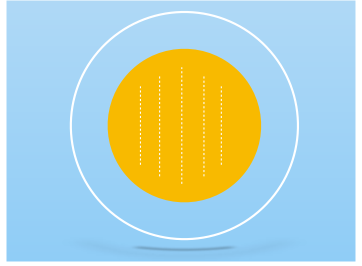
5. Colour

The design did not take into account colour-blindness, which is a limitation of the design.

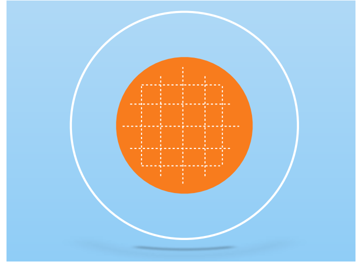
> The designer suggests to find out which colours work for people with colour blindness to make the solution suitable for everybody. However, the deviation from the green, orange and red colours can not be too much because that will lose the psychological effect. Therefore, it is recommended to test if an addition of a pattern could help to communicate the mental state of the patient (figure 39)



no texture means = good



vertical texture means = satisfactory



square texture means = not good

Figure 39: texture and colour

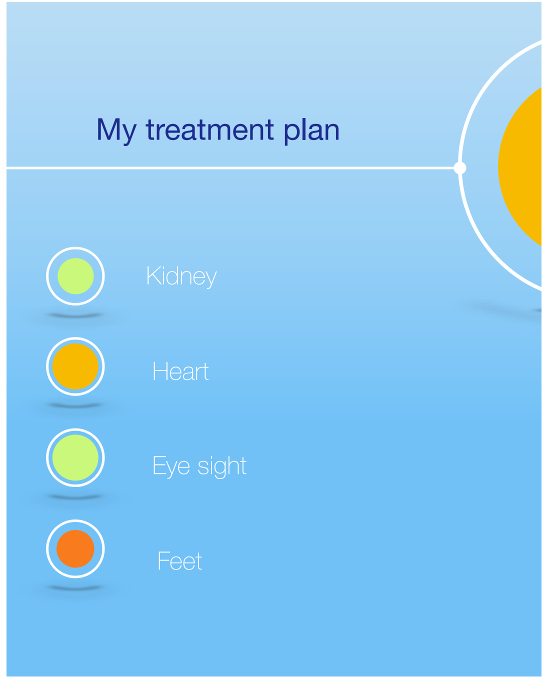


Figure 40: data overview per topic

6. Overview of all the data

Specialists prefer to have an overview of all the data of a diabetes patient, which provides them with a quick and clear overview of the pain points of the patient. The concept proposal does not include all the patient data yet.

> The designer suggests completing the proposal with all the necessary data. All the diabetes data can be incorporated in an overview (figure 40).

7. Moments of visiting the hospital

In the future, patients will only visit the hospital when they do not feel well. Patients will associate the hospital with these negative moments and not with positive moments. On the other hand, specialists will only see patients that do not feel well. Moments of celebration will disappear. However, not all patients find this a problem, but specialists find this a limitation of the concept proposal.

> The designer suggests that positive moments need to be incorporated in the new way of communication. A video call can replace the automated 'compliment'-messages to have more personal contact. However, it should be taken into account that, in the end, this intervention should save time.

8. Trust in technology

Monitoring and logging data manually will be too much effort for the patients, and therefore they will not continue doing this. Thus, the digital patient I.D. makes use of automated data measurement, which results in inaccurate information with a low patient initiative. This proposal implies that people need to trust technology to the fullest to make the concept work: the technology knows how they are mentally and physically doing.

> The designer suggests involving the patients closely when developing the concept. The added value of the intervention should be experienced by the patients, instead of being asked for. In figure 41 an example of the added value of the mobile phone according to people 1998 is visualised. People were asked about their opinion on the mobile phone.

Figure 41: value of the mobile phone (image source: youtube 'mobiel bellen 1998')

9. Implementation

These days, not everybody is as acquainted with a mobile device as others. However, this intervention should be accessible to everyone, and not only to the wizz-kids. A structured and clear implementation of this intervention is therefore crucial.

> The designer thinks that this proposal will fit the future society: everybody will be acquainted with a mobile device. Until then, the designer suggests using this intervention as temporary support as well. People who are not acquainted with the technique can use the intervention on the recommendation of their internist. F.e. when someone requires more guidance and control regarding their diabetes, a specialist can decide to track the patient's data for, for example, two weeks. After two weeks, the specialist and the patient can gain a better insight into the health status of the patient. Instead of continuously gathering information, this approach will help in the short term already. Besides, the patient does not have to use the platform if not preferred. In the future, the designers expect that everyone is known with the technologies described within this concept proposal.

10. Usage

The usage of *Mijn Erasmus I.D.* influences the experience of patients and specialists. Patients hope that the intervention changes the structure of the conversation: they want to talk about the link between their mental and physical data.

> The designer suggests rethinking the structure of the consultation, together with specialists and patients. For patients, it is essential that the structure of the consultation changes in the future. Is this possible from the specialists perspective? What are the vital elements that are necessary to discuss?

Furthermore, the designer suggests having the possibility to switch the screen off when necessary. It should be discovered what the perfect balance is between the screen as support and the human conversation.

Bruins wil verplichte digitale uitwisseling van patiëntengegevens

21 DECEMBER 2018, 08:13 POLITIEK

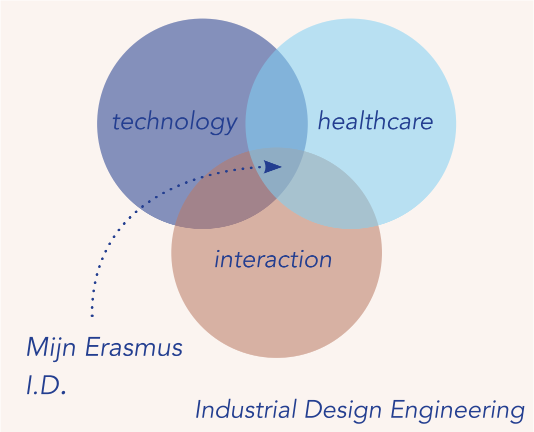
Minister Bruins wil dat in de zorg gegevens over patiënten altijd digitaal worden uitgewisseld. Hij schrijft aan de Tweede Kamer dat nu door gebrekkige elektronische uitwisseling van gegevens vermijdbare fouten worden gemaakt.

Figure 42: desirability of a shared database (image source: NOS.nl)

7.3 Relevance of the project

This graduation project gives a brief look into the consultation of 2030. Within this chapter, the designer aims to describe how this project contributes to the different areas of expertise. What is the relevance of this project? What are the lessons learned, and which elements are useful to explore further?

This project is executed in the field of Industrial Design Engineering, balancing in between three areas of expertise: technology, healthcare and interaction.



7.3.1 Industrial Design Engineering

This project is executed in the field of Industrial Design Engineering. Therefore the relevance of this project is discussed according to its desirability, feasibility and viability. Those three pillars form the basis of relevant design.

Desirability: does it address the user's needs?
All eleven participants want to use *Mijn Erasmus I.D.* in the future. It can be concluded that the intervention is desirable: it meets the user's needs. The intervention improves the overall quality of the conversation, and both patients and specialists are ready for this innovation (7.1 User evaluation). Besides, the Dutch government is ready for such a change.

"This is where the future goes. We need to start working in such a way."
- specialist Erasmus MC

"I would give me much trust when this intervention results in a conversation about the link between your physical and mental data. I want to talk about this link, but currently, this is not happening."
- diabetes patient

This graduation project presents a concept proposal, which means that there are still many things to improve (7.2 Recommendations). Nevertheless, trend experts expect healthcare to go to a more online, personalised and data-driven environment (Kraft, 2014). The designer believes that the concept proposal fits seamlessly within this context (2.2 Future context).

Feasibility: can it be done?
The concept proposal uses technology developments that are already there. However, the implementation of the concept proposal requires technology to be available on a big scale. The hospital and patients need to be willing to share, use and communicate the patient data. Besides, the network should be able to process, save and translate the huge amounts of patient data. The designer expects that the processing of this data will not be a problem by 2030. The recent implementation of 5G supports this expectation.

Viability: will it survive in the long term?
More techniques will be available for measuring data and visualising data. Because A.I. systems are ‘self-learning’ systems, the systems become smarter over time as they understand by 2022 people better than your own family (Kleber, 2018). The designer expects that this results in a system that becomes more accurate and trustworthy over time, which creates a system that grows in value.

Furthermore, data visualisation is going to play a significant role in healthcare (Meyer, 2017). In the future, data visualisation will be used as a promising tool to improve care and patient experience (Thotathil, 2019).

7.3.2 The healthcare sector

This graduation project connects the future vision of healthcare (2.2 Future context) with the future needs of patients and specialists in a tangible example. The project aims to inspire the healthcare of how the future could look like. Therefore, the project can be used as a conversation starter about the future: how to implement value-based healthcare in a hospital’s culture? And how to use technology as an enabler of human conversation?

This proposal can be seen as the first step into exploring the conflicting values between patients and doctor by developing a tool, as described in the paper of Bastemeijer, Voogt, Van Ewijks, & Hazelzet, 2017: *“Further study is needed to validate these findings and to create a possibility for the development of a tool, meter, or questionnaire in the future”*

The proposal is in line with the future vision of the value-based healthcare system the Erasmus MC wants to follow (Jan Hazelzet, personal conversation, 2019). However, it should be explored if the visualisation can be used in different departments and if a combination is possible between different departments. How would the visualisation look like? Can the same visualisation be used within the whole hospital?

The designer expects that the system has the most potential for chronic patients. Those patients visit the hospital multiple times and have the most benefit of a personal conversation. Nevertheless, if technology is smart enough to define the pain points of the patient by itself, the concept could also work for general practitioners. Communication becomes more precise and more in-depth, which results in better referrals (van Tongerloo, 2019). However, it should be thought of how the visualisation communicates the pain points of a patient when not gathering specified data (as been done for diabetes).

7.3.3 Technology

In our society, more and more data is generated. The main question is: how to use this data useful? A discussion about technology, privacy and ethics will unravel. What if somebody does not want to share their data, can this person still get personalised care? What if insurance companies get insight into the patient’s data, will this affect the health assurance premium? The designer believes that this project contributes to this discussion by having a tangible example. This example shows the added value of a solution at the cross-section of technology, privacy and ethics.

7.3.4 Interaction

Technology has changed the way people interact with each other, and this will not stop by the year 2030. This project is relevant in a context where more communication is in the digital world. How to use technology for human interaction, instead of using technology to avoid human interaction?

This project shows how technology can be used to enhance physical interaction instead of digital interaction. The long term effect of the proposal should be tested: does it indeed create a more in-depth conversation on the long term? Also, what is the possible negative impact of the intervention?

Other area’s of expertise
Besides using the principle of data visualisation in the healthcare sector, it can be used in different fields of expertise to communicate complicated information. The designer thinks that the principle can be used by f.e. tax authorities to communicate better with the inhabitants of the Netherlands by using visuals, data and stories to explain complicated information to them, taking into account their situation.

Furthermore, the combination of physical and mental data could be used in the field of top-sport. Using the physical and psychological data of sportsmen and women could help to improve their results by giving insight into their health status.

7.3.5 Cirtical insights for further development

To summarise this project, some critical insights for further development are listed below. These key insights are suggestions for further development.

- Explore the potential of the visualisation at a higher level:

Does the visual add value within different departments? Or is it specific for a particular disease (such as diabetes)?

- Initiate the debate around privacy, ethics and data within the healthcare.

How will this balance look like in 2030? What kind of legislation is necessary to protect patient data? Also, what is the role of insurance companies in this situation? Who can have a look at the digital patient profile? This discussion is necessary for a national acceptance of such an intervention.

- Explore the potential of the national patient I.D.

What is the national opinion about a national patient I.D? Are we willing to share our data with hospitals in exchange for better, more personalised care? How to make the Dutch people enthousiastic about such a change?

- The project structure

The value of this project lays within the whole conceptual idea. The project can serve as the basis for Industrial Design Engineering students to continue working within this topic.

7.4 Personal reflection

The personal reflection describes my personal view on this project: what have I learned? How did I experience the process, and what are my main insights? The reflection is based on the learning goals that are communicated at the beginning of the project.

7.4.1 Reflection on learning goals

1. I want to use the Design for Emotion methods and techniques.

Within this graduation project, I wanted to experience a project whereby the concerns and emotions of a person are the starting point. Just before my graduations started, I have followed the block-course Design for Emotion. Emotion-driven research has given me deep and valuable insights that have contributed to the result of this project. I have learned to look with a different perspective to patients and specialists, and I genuinely believe that this approach has opened up my eyes to look with a broad and objective eye to the whole context. This approach has helped me to unravel the complex project context in a structured way.

2. I want to facilitate a creative session with non-IO participants.

Three creative sessions have taken place (two with patients, one with future doctors), and multiple evaluation meetings. The sessions have helped me choosing with confidence, because the sessions were planned at a moment of a decision. This set-up has given me a relaxed feeling towards choices; the users have given me the reasons for making a particular choice. Having a meeting at a critical moment of making a decision has helped me in making the decision. This reflection brings me by my third learning goal:

3. I want to learn to make decisions faster.

I am very good at overthinking options since I do not want to make the wrong decision. The creative sessions have helped me to make decisions with confidence. Furthermore, just making the decision has given me trust in the iterative and unknown process of an Industrial Designer. Making the wrong choice is not something terrible; it gives you insight on how to continue. This attitude has helped me to make decisions faster, but also to ask for feedback at an early stage, which resulted in open conversations with my supervisors.

4. I want to work very visually. I hope to broaden my drawing skills within this project.

This graduation project is very visual, but not as visual as I hoped for. Within this graduation project, I have mainly used drawings to make the structure of the project clear. When visualising the information that I had found, it became clear on how the situation was linked to each other. Visualisation has given me the guidelines that I needed within this process. The graduation project has shown me that 'visual thinking' is something that I very much like.

5. I want to enjoy the process of this project, rather than focussing on the result.

While writing this reflection, I realise that the previous learning goals have all contributed to the last, most important learning goal. My goal was to enjoy the project and to have an open attitude to learn new things, to make mistakes, and to continue. I continuously explored the context in a way that I liked and I felt comfortable with. I was able to place the project into the context through visualisations. This approach has lead to a project where I was able to combine the overview of the project, with a more detailed level of the project. I have truly enjoyed working on this project, as no project before, together with my supervisors from the TU Delft and the Erasmus MC. Staying close to my own opinion and ideas has satisfied my needs throughout the project.

7.4.2 Overal reflection

This graduation project has helped me to discover what I like doing, where I am good at, and what I find difficult. I like unravelling complex problems, creating structure and visualising my thoughts. I find it difficult to make a decision on my own: do I make the right decision? Throughout the project, I have learned that this something that I can easily overcome by accepting that no choice is the wrong choice.

I hope that my graduation will be used as an inspiration to the healthcare sector by showing my design as a tangible example of how the future could look like. I believe that I succeeded in delivering a project that contributes to a discussion within the healthcare sector: where are we heading?

I am proud and happy with the whole journey, the process, the coaching, and the end result of this graduation project.

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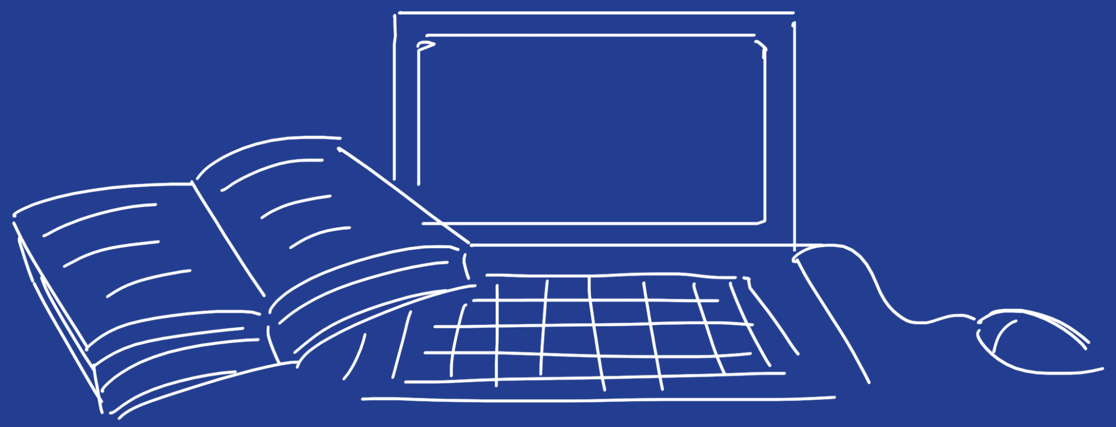

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