


Towards Digital Twins in Healthcare:

How would a meaningful Digital Twin for the user look like?


An approach to explore a meaningful Digital Twin
through empathizing with users' perceptions





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Master Thesis I Carla Strasser
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How would a meaningful Digital Twin for the user look like?

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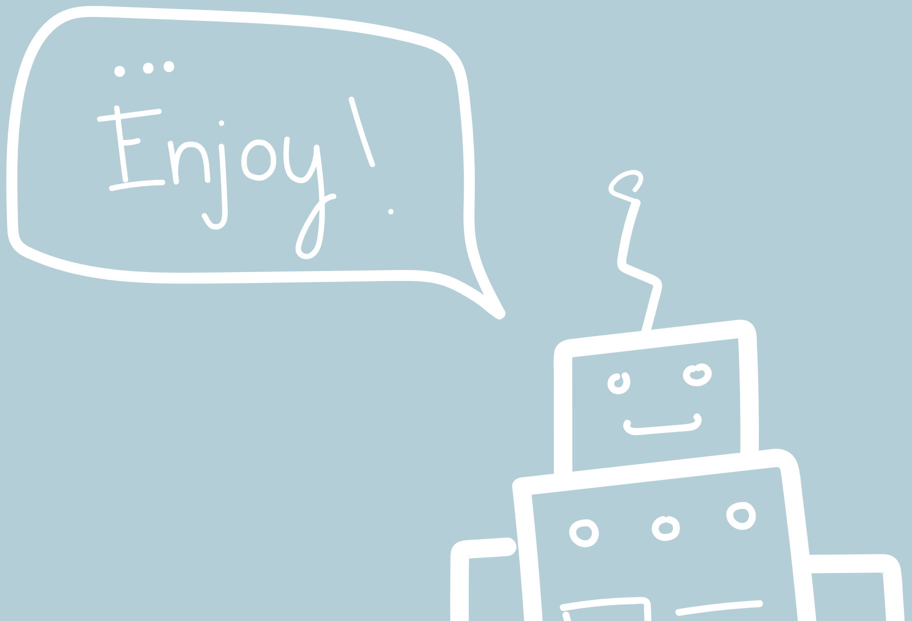


Preface

Dear reader,

In front of you is my final deliverable of my Master program in Strategic Product Design at the Delft Technical University. Looking back, the last two years mark an intense journey with lots of developments not just professionally but also personally. But I have not been alone on this journey, so I would like to thank some people along this way.

I would like to express my gratitude to the people that accompanied me during this graduation. First of all, I would like to thank my graduation supervisors. Marina, I thank you for always challenging me and encouraging me with your constructive criticism to always go one step further while not losing my focus. Bas, I would like to thank you for your constant support with the philosophical approaches of this work and your guidance on valuable interesting ideas and perspectives that guided me and helped to shape this work. Sander, thank you for the constant support that included not only the progress of the work but also my own well-being.

During our bi-weekly sessions, I especially appreciated that you provided a safe space where questions and ideas could be discussed openly and supportively. Even though we could only meet online during the whole time due to the Corona pandemic, I would like to thank you three for your great and consistent guidance, for the fact that I could always count on you for fast and guiding support in moments of uncertainty.

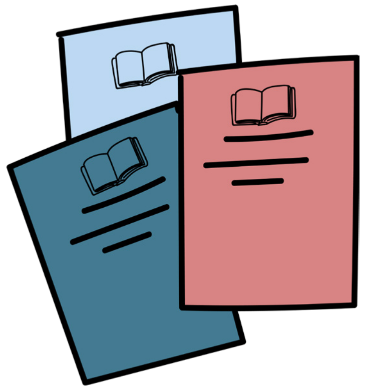
I would also like to thank my family and friends for their support and endless understanding and open door for all my questions and worries. Thank you, Alex, for supporting me in keeping an optimistic mind.

Lastly, I would like to thank all participants that took part in the activities that gave life to this work. Thank you for sharing your professional perspectives, your individual experiences and ideas during brainstorming and validation sessions. I really appreciate your openness and interest in this project, and I am glad I had the opportunity to get to hear your stories and opinions.

Enjoy reading!

Carla

Reading Guidelines

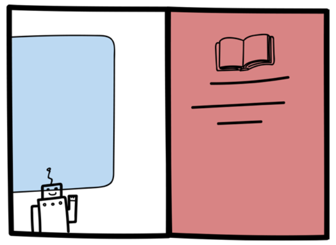


Chapters

The main chapters are distinguished by different colors and numbers.

Key Insights

Some of the chapters end with a colored box where the key findings are summarized.



[...] It even is ready for your death when you are not prepared, thereby it could **normalize the possibility to die even before encountered, it could raise the acceptance for your own faith by normalizing engaging with your end of life.** It could have [...]

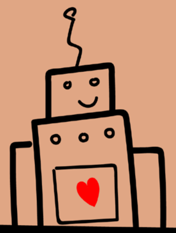
In a hurry?

The main points in the text are highlighted in bold. Thereby it is easier to grasp the essence without having to read the whole text.

Abbrevations

AI	Artificial Intelligence
CVD	Cardiovascular Disease
DT	Digital Twin
IoT	Internet of Things
IPA	Interpretative Phenomenological Analysis
ML	Machine Learning
RRI	Responsible Research in Innovation
TMF	The Medical Futurist
WHO	World Health Organisation

If your are interested in this work and would like to have a comprehensive overview or go on a reflective journey, scan this QR code and explore (format is optimized for computer access)!

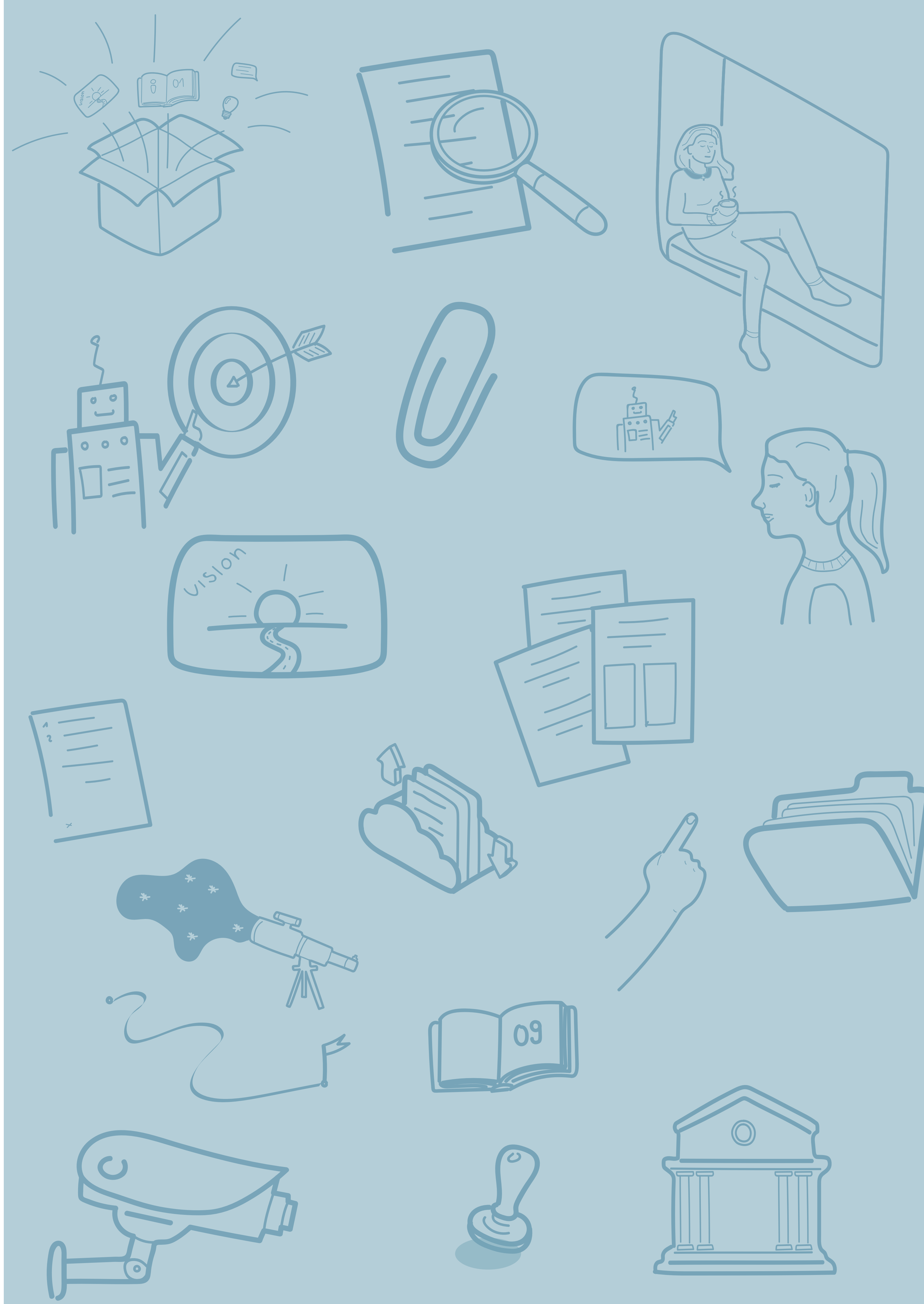


Look out for the robot. He sometimes shows up to give extra information.

Executive Summary

Healthcare is starting to change fundamentally. One of the disruptive technologies that can be seen as an enabler for this change is the technology of a Digital Twin (DT). A DT is widely adopted in the field of engineering for predictive maintenance and testing of parameters of physical objectives such as engines to increase the effectiveness and optimize processes. A DT consists of three major factors: a physical object, its virtual representation and a continuous data stream between the two. In the healthcare sector this could mean to represent not an engine but a whole human with the potential goal for predicting a disease, taking necessary actions for prevention or identifying optimal treatments. This could shift the current underlying paradigm in medicine of curing a disease towards preventing a disease. The extent of representing a whole human body with this technology is still only a vision, but first steps towards this concept have been taken. It becomes clear that this development may come with a lot of responsibility so that a user-centered perspective needs greater attention.
This thesis aimed at unraveling users' values for a meaningful DT as innovative technology. By using the concept of Responsible Research in Innovation (RRI), I addressed the importance of grasping, anticipating, and evaluating the potential impact of a DT on the individual interview partners. In a first step, I identified the field of diagnosis as a central research topic with high importance for the user. The semi-structured interviews were conducted with a focus on the context of diagnosis and followed a practice-based approach of Interpretative Phenomenological Analysis (IPA). This allowed me to explore underlying values from the past into the future of diagnosis with and without DTs. A six-step analysis approach proposed by IPA led to the discovery of values embedded in the (anticipated) experience of diagnosis of the interviewees.
Finally, the findings led to the development of different forms or concepts a DT could take. These are meant to start a reflection. The findings showed that the meaningfulness of a DT may change significantly by age, life situation, preferences or also individual personality. In contrast to current company visions which visualize a DT as dashboard overview of the human, I assumed that this may lead to an objectification of the body with little long-term value, and might rather support the development of an alienate feeling. Furthermore, it might be that the possibility of constant confrontation of one's own objective status of the body might rather have negative effects on the individual. Additionally, time, place and frequency an individual interacts with a DT seemed to play an important role and should be reflected upon.

In order to complement the development of a more user-centered and meaningful DT, I concluded this work with nine guidelines that can be a starting point for further reflection on responsible innovation of a DT. Taken together, I showed that meaningfulness of a DT is highly variable and that it would need a dynamic, personalized approach to create and implement a meaningful and responsible innovation for the user.



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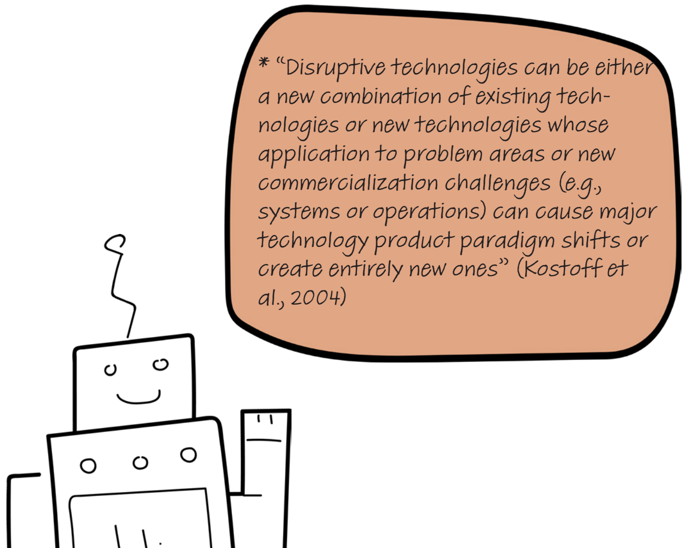
Project introduction

1. Project introduction

Take a look around. How many self-tracking devices do you currently wear or maybe own? As you probably also guess, the number of smart sensors and wearable devices has indeed increased over the last decade and led to a new movement of constant monitoring of one's parameters and tracking of activities. This includes data such as recording one's sleep habits and quality, heart rates, or physical activity, while the users potentially aim at can continuous self-improvement, equally driven by the curiosity in the own body. Many of these measured parameters, may be used to draw direct conclusions about the state of ones own health. With the continuous development of enabling technologies (e.g., smarter sensors, ML or IoT), the application fields, the precision, and the connectivity of such self-tracking devices are increasing. **Leading to a new era of self-tracking, it allows the collection of massive amounts of health data. One of the very early emerging technologies from this possibility of data variety is a DT.**

In general, a conventional DT is a virtual representation of either a process or a product. A connection between the virtual representation and a physical object or process is thereby defined as the constant flow of data between them. Deriving from the engineering context, this technology enables the contextual analysis of captured data. This can be used to ideally predict future events, detect upcoming repairs, minimize downtime and thus increase overall efficiency. Furthermore, **a DT also allows for testing and simulating different scenarios to uncover optimal procedures or process parameters.**

DTs are now paving their way from the engineering field into the healthcare sector. Here, DTs are already used to optimize clinical workflows or for predictive maintenance of costly equipment such as CT or MRI scanners. But a DT holds even more potential. One vision of some players in the healthcare sector is to apply a DT not only to objects and processes, but also to represent a human. By transferring this technology from the engineering to the healthcare field, a DT takes on a completely new, previously unknown context. In this new context, responsibility, ethical and security-related factors must be newly defined. As such, a DT can certainly be seen as a disruptive technology* in the field of healthcare bringing new practices, and changing existing value networks, morals and practices (Rahman *et al.*, 2017). Furthermore, **a DT in healthcare holds the potential to overcome the current paradigm of traditional medicine, namely curing, with the paradigm of prevention. A DT could do so by monitoring, providing predictions and testing of variables for optimal preventive care before treatment on the basis of full personalization for the individual.**



* "Disruptive technologies can be either a new combination of existing technologies or new technologies whose application to problem areas or new commercialization challenges (e.g., systems or operations) can cause major technology product paradigm shifts or create entirely new ones" (Kostoff et al., 2004)

The transfer of a DT technology into the healthcare sector under the existing vision entails also a great responsibility. The technology, when implemented, is likely to potentially interfere with existing values and practices of society. Thereby, a DT may change not only how we perceive ourselves and our bodies through technology, but also how we perceive and understand the world around us. Through confronting us with data of our own body and its virtual representation, our body becomes quantified in the way that we are confronted with objectiveness which might change or even interfere with our subjective perception. These potential issues are not yet fully addressed in literature. Furthermore, **while a DT in healthcare attracts much attention from the technological/engineering angle, there is little attention and almost no research on the desirability or user-centered perspective**. In my understanding, the values of a potential user of such a technology should be understood as early as possible to consider and reflect upon them prior and during the development. In doing so, the development of a DT could be ideally steered in a direction that is meaningful to the user and allows for the identification and awareness of possible impacts of this technology. In contrast, responsible innovation differs from an often practiced consequentialist stand that foresees apologizing for possible unforeseen dangers and impacts afterwards. We need to act preventive to improve the desirability of a DT in healthcare.

Building up on that, I consider it as very important to investigate values and dynamics and involve users in the research and explore their experiences and expectations. Possible risks that the technology of a DT could potentially bring range from asymptotic individuals being exposed to predictions of possible diseases and the associated feeling of vulnerability, to one's body image being potentially disturbed when subjective feelings do not match objective diagnosis, or the feeling of surveillance and invasion of privacy. Therefore, it is important to learn from potential users of the technology on how a DT could be integrated into their lives to meet their value frameworks and to have meaning in its function and form not only for the companies as developers of such technology or the hospitals as drivers, but for the users as such. Therefore, the aim of this project was to uncover what a "meaningful" DT for the potential user in the field of healthcare could look like.

A complete overview of all the stakeholders that were involved in this project can be seen in Figure 1. The general connections between the stakeholder and their relations are shown in blue lines. The white lines describe my connections and interactions with the persons, institutes or projects.

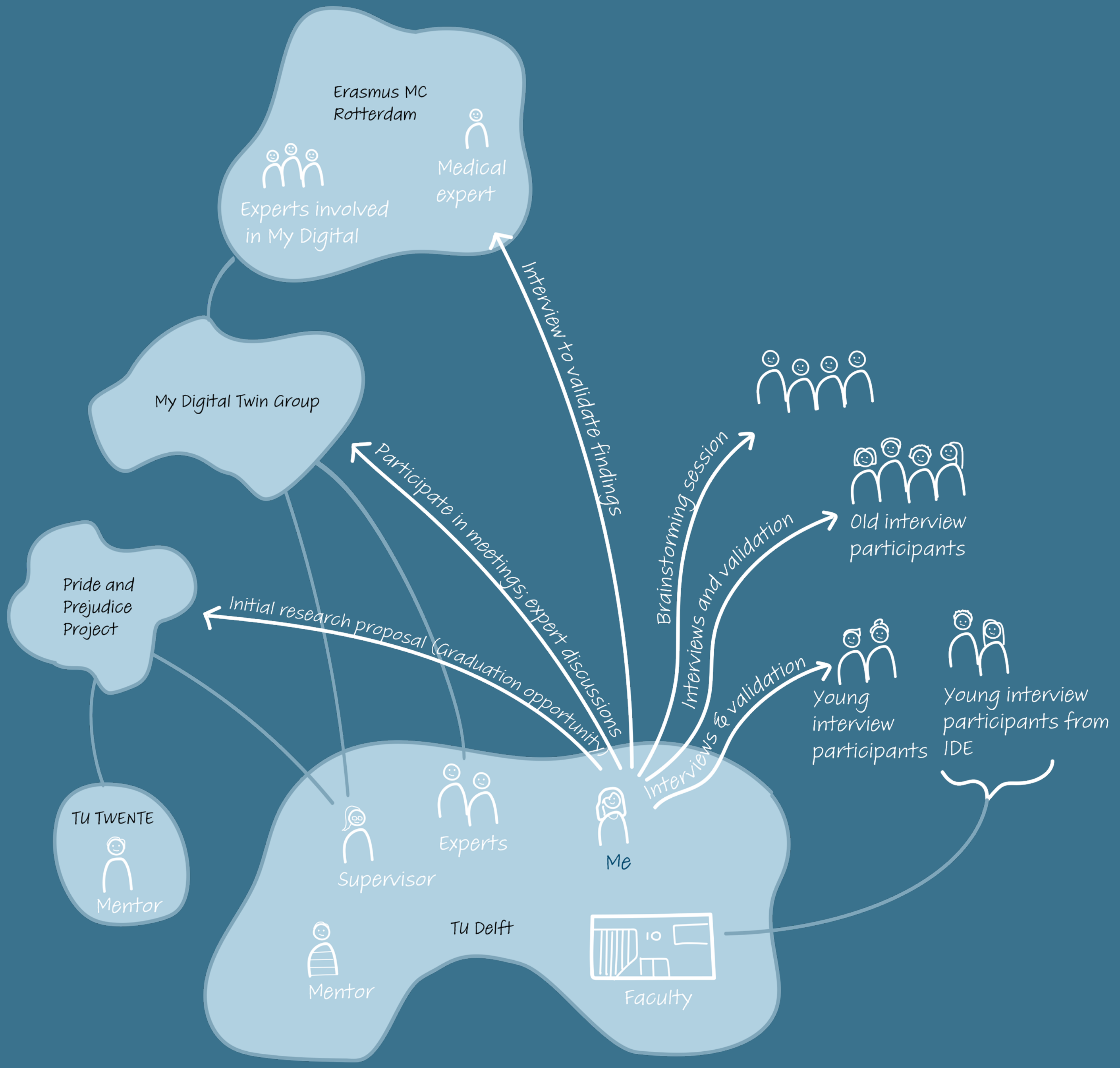


Figure 1 *Overview of stakeholder in relation to their involvement in this project*

1.1. Approach and planning

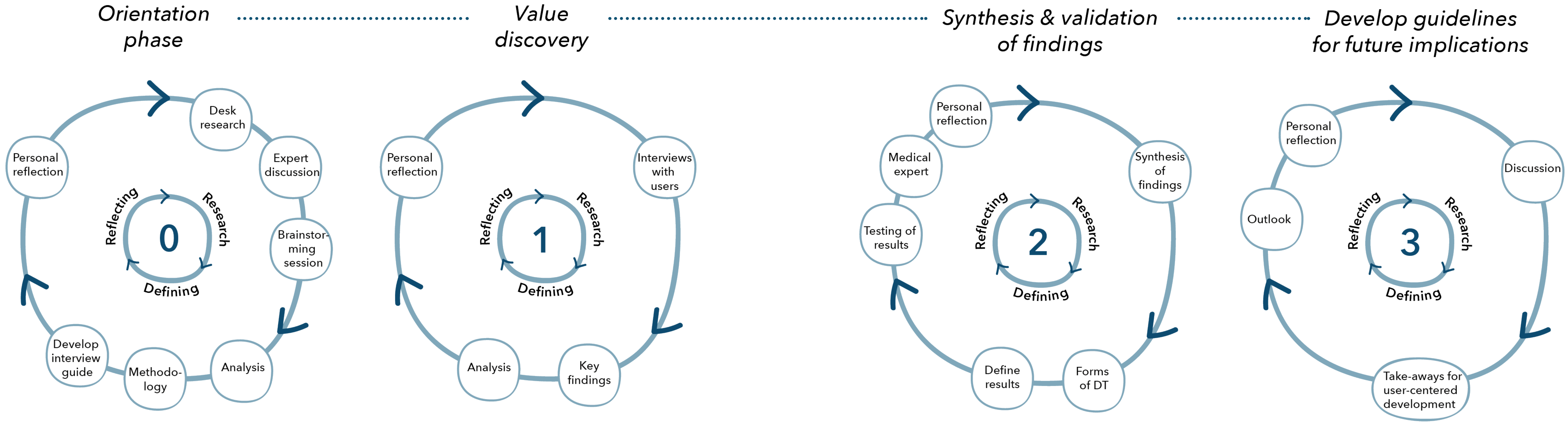


Figure 2 *Overview of process and approach of this project*

The chronological approach of this project can be seen in the overview in Figure 2. This Master thesis was divided into four different phases, namely "*orientation phase*", "*value discovery*", "*synthesis and validation*" and "*development of guidelines for future implications*". These four phases were in turn divided into three different stages that were carried out in each process. Each process started with a research part in which information was gathered. In the next step, "*defining*", this information was analyzed and transformed into actionable next steps or findings. Each of the four phases additionally includes a moment of reflection ("*reflection*"). This took place either alone, with the supervisors in the bi-weekly meetings, or together with others to validate the results. This reflection step was particularly important to check the status and quality of the work and to identify and incorporate necessary iterations. The whole project was scheduled for 100 working days, about 25 days were planned for each of the four phases.

1.2. Pride and Prejudice (4TU)

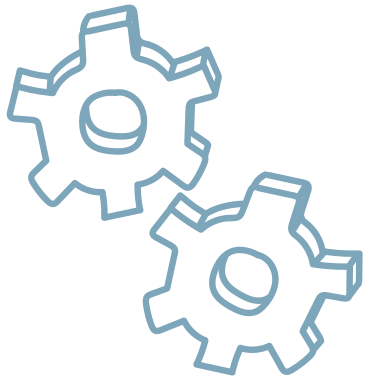
This graduation project was conducted within the „Pride and Prejudice” project which is part of the 4TU collaboration. The “Pride and Prejudice” project has a specific focus on “chronic disease prevention through real-life monitoring and intervention design”, whereas my graduation project contributed to the specific research area “Investigation of health innovations at the systemic level”. This area aims, among other things, to highlight and reflect the differentiating complex values within health innovation and the different ways of understanding and reflecting on health.

This project was also done in close exchange with the experts of “My Digital Twin” group which connects experts from TU Delft and Erasmus MC, working on researching and developing a DT concept. The DT development on which the “My Digital Twin” group is working is also of interest to the various “Pride and Prejudice” researchers, especially Marina as the chair for this project. Furthermore, my thesis is supported by two mentors, Bas and Sander, whereas Bas is also working for the Pride and Prejudice project. Bas and Sanders helped me in bringing in a philosophical perspective towards the development of a DT.

PRIDE AND PREJUDICE 4TU.Federation

Theoretical background

2.1. Digital Twins in engineering



The technology of a DT is highly recognized, in 2018 it was listed as disruptive innovation and as one of the top ten strategic technology trends (Gartner, 2017). In its origin, the concept of a DT was first used during the NASA Apollo program 50 years ago. There 15 computer-aided simulators were heavily used to mirror every aspect of a space vehicle before and during the mission in order to adequately respond to problems encountered on the actual space vehicle. The Apollo mission was a great achievement in the field of engineering and the basic concept of a DT was born (Ferguson, 2020). Over the past years, however, the understanding of DTs has changed. From today's perspective, previous "DTs" were mostly *in-silico* models, that are nowadays rather considered simulators of a physical object. What they were lacking was the smart, continuous and automated interaction (e.g., computational power, wireless connections, high-speed internet, IOT) between them, something that depicts a DT nowadays. During the last years the field of computer sciences and data technology has majorly reshaped the possibilities of a DT, increased complexity and applicability of DTs. This has enabled different movements in the field of DTs. Consequently, a myriad number of definitions are described in literature. To give an overview five definitions where chosen that reflect definitions from different sectors, namely of manufacturing, aviation, and medicine. The overview can be seen in Table 1. The right side of the table gives an overview of the important keywords in the definition. That allows for comparison between the different definitions. What becomes clear, when analyzing different sectors is that most of them have three key components in common which are also reflected in the definition provided by Grieves (2014). **Grieves gives a very clear definition and says that, a DT in manufacturing consists of three central components: a physical product, a virtual representation of that product, and a data connection that feeds data from the physical product to the virtual representation as well as the other way around (2014)**. The closed circle of data flowing between the physical and virtual is what the author calls *"twinning"*, and which is sometimes also referred to as *"mirroring"*. Although some of the definitions propose further key features, for this research this characterization will be sufficient as it delivers a good basic understanding. **Applied to complex systems in the engineering field, the goal of a DT is not just to represent or mirror the physical object, but also to test and develop it based on various variables.** Combined with different data acquisition methods and coupled with AI, ML and software analysis, it is possible to build computer-aided simulation models that are updated in real-time in accordance to parameters or condition changes.

Definition	Field of application	Keywords
The concept of a digital thread/digital twin comprised of advanced modeling and simulation tools that link materials-design-processing-manufacturing (Digital Thread) will be the game-changer that provides the agility and tailorability needed for rapid development and deployment, while also reducing risk. State Awareness and System Prognosis advantages will be achieved through the Digital Twin, a virtual representation of the system as an integrated system of data, models, and analysis tools applied over the entire life cycle on a tail-number unique and operator–by-name basis. Force (2013)	Aviation	virtual representation of a system integrated system of data, models, analytics entire life cycle
"Likewise, Digital Twin represents the digitalization of physical devices and artefacts. This technology has been used in industry, allowing it to simulate physical environments and specific machinery pieces in order to make decisions and assess risks in virtual environments prior to its implementation. This is similar within the context of health care. Patients' body and physiognomy data are monitored on a real-time 24/7 basis with a view to provide more informed and real-time relevant healthcare responses." (Farsi, Daneshkhah, Hosseinian-Far, & Jahankhani, 2019)	Healthcare	Digitalization of physical devices, artefacts Real-time monitoring
"A Digital Twin is a digital representation of an active unique product (real device, object, machine, service, or intangible asset) or unique product-service system (a system consisting of a product and a related service) that comprises its selected characteristics, properties, conditions, and behaviors by means of models, information, and data within a single or even across multiple life cycle phases" (Stark & Damerau, 2019)	Product Engineering	Digital representation Single or across multiple life cycles
Driven by the Industry 4.0 vision and the development of big data analytics, faster algorithms, increased computation power, and amount of available data enable the simulation with ability of real-time control and optimization of products and production lines, which is referred to as a Digital Twin [10], using a digital copy of the physical system to perform real-time optimization. (Zhang, Liu, Chen, Zhang, & Leng, 2017)	Manufacturing	Big data Simulation with real-time control Optimization Digital copy Physical system Real-time
The Digital Twin concept model [...] contains three main parts: a) physical products in Real Space, b) virtual products in Virtual Space, and c) the connections of data and information that ties the virtual and real products together. (Grieves, 2014)	Manufacturing	Physical product Virtual products Connecting data
The concept of a Digital Twin: The physical object in real space provides data to the digital object in virtual space, which analyses the data, learns from it, and then sends information back to the physical object to improve the performance of the physical object. (Hempel, 2017)	Healthcare	Physical object Virtual space Analysis of data Learning Improvement of performance of physical object

Table 1 *Definitions of a DT in different sectors.*

2.2. Digital Twins in healthcare

Originated from the field of engineering, the concept of DTs has become widely adopted in the technical side of healthcare over the past few years. **In the medical context DTs have already been implemented to allow for predictive maintenance of imaging devices, to optimize the clinical workflow and hospital operations** (Polyniak & Matthews, 2016). But there are also different means of application in the healthcare sector which move further away from the engineering background, such as **the aim to build a DT of a human - a virtual model of the human body that is linked to the physical individual**. Although it is still considered a vision, there are proponents that argue that a DT in healthcare can have a great potential and big impact on the quality and effectiveness of everyone's health, such as the early detection and prevention of diseases or the personalization of treatments. Additionally, DTs offer the opportunity what other computational models based on population data will not be capable of; it will represent an individual body and show the uniqueness of it in a digital reproduction. An overview of the three major components of a DT and potential functionalities in healthcare can be seen in Figure 3. In the figure, the first component consists of the physical layer, hereby the individual, the second digital layer, a digital representation of the individual, and the third the closed data stream circle between both layers, i.e., real-world data, biomedical data and contextualized health data and data from knowledge generation, data bank comparison and insights from deep learning algorithm. This concept is adapted from the concept by Grieves previously introduced and modified for its translation into the healthcare sector (2014).

After having defined the concept of a DT, it is interesting to take a closer look at the digital representation, the digital layer. The digital representation can be seen as the core of a DT. Here, multiple scenarios can be performed, adjusted and applied without directly impacting the physical individual. Thereby, it can eventually identify optimal and personalized treatments or medications. In order to arrive there, the digital layer typically runs through four consecutive actions to conclude on ideal measures, as can be seen in Figure 4.
These four actions are not new, and are adapted from four categories classifying modern analytic approaches, for instance ML algorithms or AI. It makes sense to transfer these analytic steps to a DT, as ML and AI can both be seen as enabling technologies of a DT. Starting with the first step of analytics, the descriptive analysis *"What happened?"*, based on the provided data from the physical layer is followed by the second diagnostic step *"Why did it happen?"*. The next action is going more into the future with a predictive step focusing on *"What will happen?"* and is finally concluding with the fourth preventive step on *"What action to do"* in order to make suggestions what action should be done and on what basis. This data could then be shared, in this case with the individual. While in the analytic approach the fourth step is called *"prescriptive"*, I think that for a DT the focus of the last step is better captured by the term *"prevention"* e.g., what action to do in order to prevent a disease.

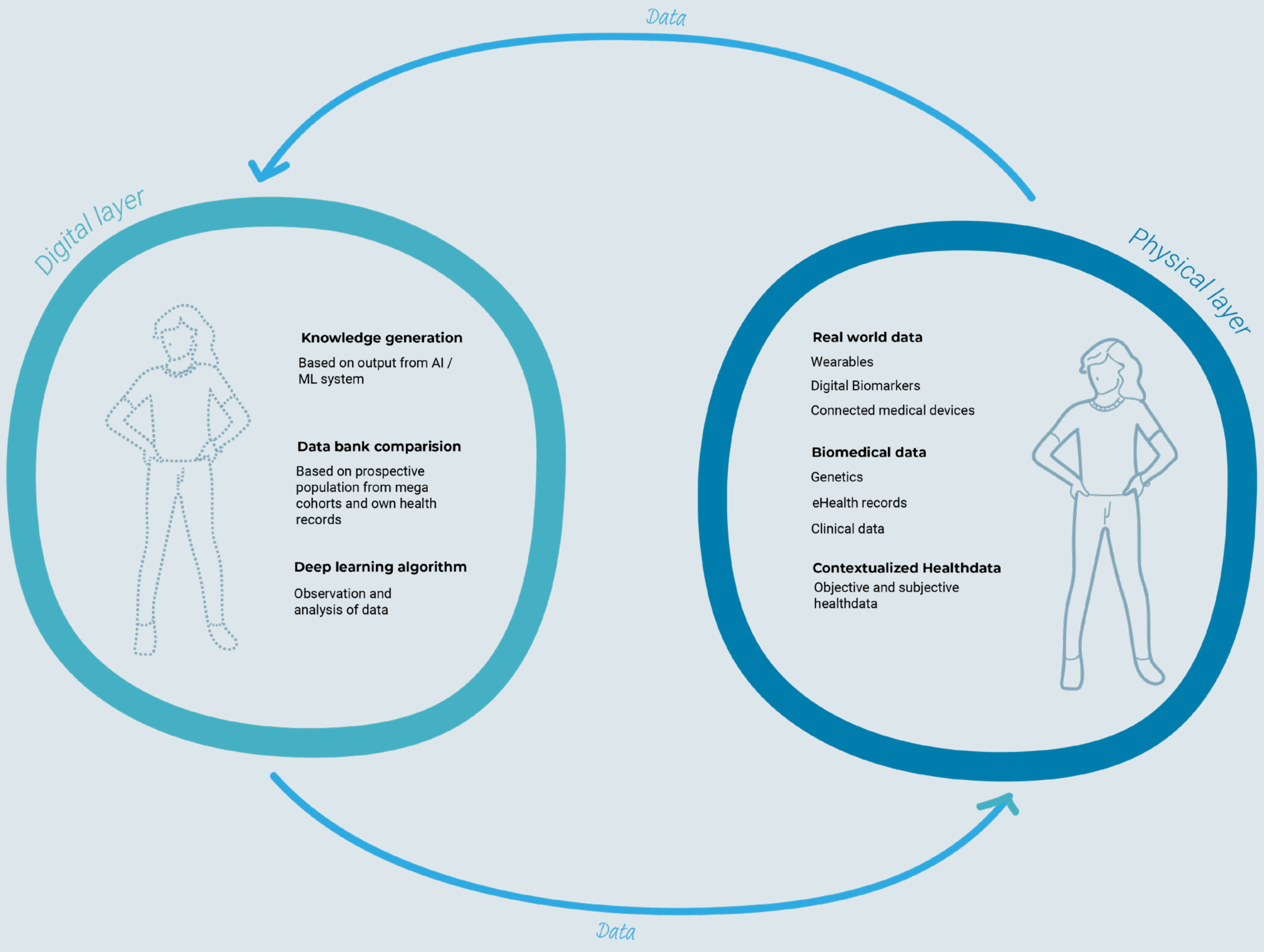


Figure 3 *The three key components of a DT*

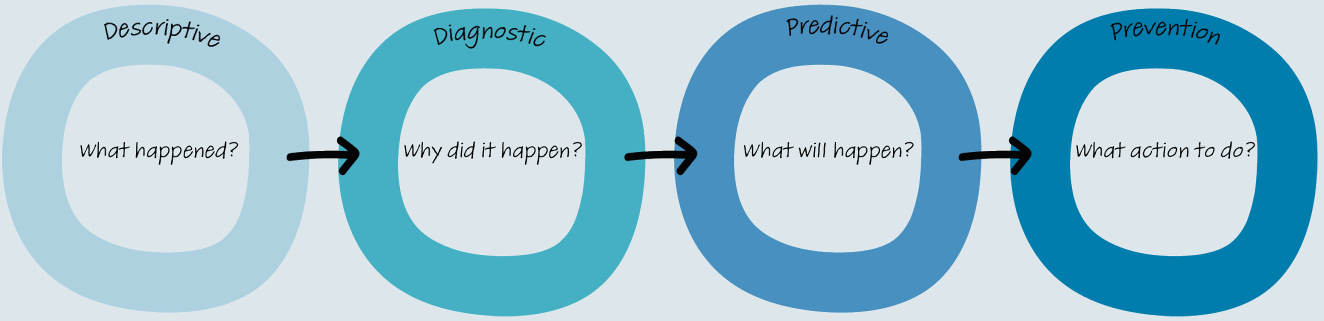
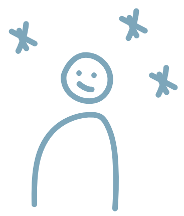


Figure 4 *Four consecutive actions of a DT*

2.2.1. Opportunities and expectations for a DT in healthcare

Visions and expectations for a DT may be likely to change the nature of healthcare and introduce new practices as well as a new paradigm of prevention of a disease instead of curing. Certainly, DTs will not be able to achieve that in isolation but as being part of a broader movement in medicine, which is supported through digitalization, additional innovations and advanced research.

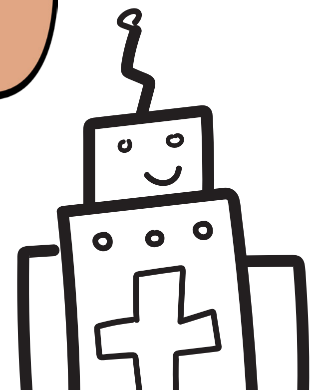
The disruptive technology of a DT and its introduction into today's healthcare environment will most likely act as a catalyst for the ongoing systemic change towards precision medicine. The concept of precision medicine envisages a more proactive and preventive as well as individualized approach to medicine (Duffy, 2016). This approach is also referred to as "*P4 Systems medicine*" under which Vogt *et al.* summarize the movement towards (i) predictive, (ii) preventive, (iii) personalized and (iv) participatory medicine (2016). It is important to note that the authors do not assess the movement as overly positive. They argue that the movement to constant monitoring might lead to a reduction of the individual to mere biological terms. Thereby, it would influence our life-stories and identification to what they call "*technoscientifially*" constituted bio-narratives (Vogt *et al.*, 2016). Furthermore, one's own body feeling might be interrupted leading to the consultation of a computational image to determine one's own health status. Although the authors take a rather critical position warning of the "engineerification" of healthcare, the paradigm move from curing towards the more proactive stand of predicting and preventing can also be seen from a more positive stand. While today patients are classified and treated based on their diseases, the future vision is to create personalized status quo profiles and treat each patient as an individual case. Participating refers to the individual becoming part of and contributing to this movement. The development towards holistic medicalization is largely based on new technological developments such as AI, ML and Big Data which are finding their ways into the medicine of the 21st century.
Movements such as the "Quantified Self"* are not only changing the way people deal with their data and the benefits they see in it but are also having a significant impact on the envisioned possibilities of constantly monitoring one's own bodily functions (Nafus & Sherman, 2014). It might also increase peoples willingness to share personalized data in exchange for information to self-improve.
To feed algorithms of AI or ML, it is particularly important to choose the right data set for the creation and delivery of accurate pieces of information. That the right data sets are crucial can be seen in an example of development programs of drugs for human use. In pharmacy, it seems to be a common practice to solely test therapeutics in male mice, while it became clear that significant differences in the effects of drugs on female and male mice could be occasionally observed (Regitz-Zagrosek & Seeland, 2012). Furthermore, clinical studies are mostly based on male participants, so that the effects of drugs on women are often poorly understood and may be one reason why women have a 1.5–2 fold higher chance of developing an adverse reaction to prescription drugs than men (Zopf et al., 2008). Through personalization and diagnosis based on individual data sets, a DT has an opportunity to address this sex and gender difference in pharmacology and provide new data to promote better inclusion in society. In addition, deviations from typical values do not necessarily have to be pathological. In today's medicine, reference values are determined on the basis of a specific population, which only reflects a part of society. **A DT thus reveals the possibility of individualizing reference parameters through long-term monitoring of various data dimensions such as molecular, phenotypic and behavioral data over the lifetime of the person** (Bruynseels *et al.*, 2018).
In general, a DT potentially opens up new opportunities to advance the paradigm shift of medicine on all of the previously listed points. Through the data-based model that can represent the patient, predictions can be made about possible diseases based on genetic dispositions or population data. Through the early determination, prevention is possible through direct proactive intervention and allows the chance of early detection and early treatment, which is associated with a higher chance of cure for most diseases. Referring back to a DT in engineering, this could be compared to predictive maintenance.
Furthermore, a DT could enable individualized treatment strategies. The digital version of a person may enable the testing of different treatments, medications and can calculate and test the most effective strategy with minimal side effects.



Shift to patient-centered paradigm

It is anticipated by proponents of a DT technology that it will empower individuals through their health data, as it might support the feeling to be actively involved in one's own care. **The empowerment of individuals through their data by allowing self-directed informed decision-making and as such being their own authority could be seen as enabler for more meaningfulness for the user.**
Empowering individuals to participate and regularly monitor their own data, in combination with support by healthcare professionals, can lead to direct detection of deviations from the norm. This combination might support the development of an equal level playing field of patient and doctor (TMF, 2020). A DT might also support increasingly shared responsibility of patient and doctor and might therefore enable the health care professional to focus more on a guidance role for the patient. With a shift in responsibility, the doctor is likely to remain an essential part

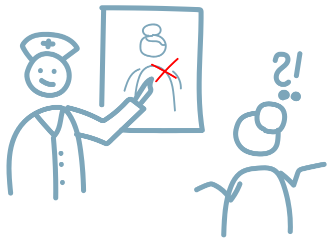
* The Quantified Self movement is an international community of users of self-tracking tools that share the aim to generate knowledge about themselves through acquiring data about their own body. Among other things the aim lies in reflecting on health questions or the curiosity in one's own body.



as decision-maker, while the patient gets the opportunity to better engage with their own health status and take a more self-informed stand (Mesko *et al.*, 2017).

DTs as medical knowledge platform

In recent decades, with the advent of the internet and search engines such as Google, people are increasingly able to acquire knowledge on their own. It is therefore not surprising that over 1 billion queries on health-related topics are researched on Google every day (Murphy, 2019). This translates into about 70,000 queries per minute and about 7% of all daily searches on Google. People want to be self-informed and find out about the questions that are driving them by digital means. This is also reflected in the rise of more and more digital health-oriented platforms that are being created and that give users the opportunity to inform themselves about symptoms, complaints and consequences (MedlinePlus, 2021; Orphanet, 2021; SmartPatients, 2021). In this way, the platform providers are already supporting the development towards an empowered individual in the context of healthcare. **DTs, whereas might offer the opportunity to receive answers and knowledge verified by medical experts and tailored to the individual, so that information gathering about diseases, symptoms, and new treatment methods can be way more accurate and personalized.**



Discrepancy of being diagnosed with what the individual feels

Assuming that the overarching goal of DTs is to achieve and maintain a healthy individual, the question may arise what "healthy" even means. The World Health Organization (WHO) describes health as the: "*state of complete physical, mental and social well-being and not merely the absence of disease or infirmity*" (World Health Organisation, 2021). Whereby the question remains what they mean by well-being. The definition provided by the WHO is opposed to the characterization of traditional medical which rather defines health as the absence of a clinical diagnosed disease. The annotation of well-being by the WHO is not illustrated in a neutral form, rather it refers to a positive state of individual being. The definition builds up on the Ottawa Charter for Health Promotion which sees health as a: "*resource for everyday life, not the objective of living*". Furthermore, they state in the Ottawa Charter that: "*health is a positive concept emphasizing social and personal resources, as well as physical capacities*". This perspective suggests that health and well-being is not limited to bodily functions but also for instance involvement in society. Interestingly, critics of this characterization of health mention that it comes over as a utopian definition, which classifies most of the individuals as unhealthy almost all the time (Smith, 2008). But there are more definitions of how health can be defined. Taking a more philosophical stand it is interesting to take into account the phenomenological concept of health proposed by Svenaeus.

In his phenomenological concept of "*health*", Svenaeus argues that health can be described metaphorically as the feeling of being at home in the world (2011; thereby he builds up on the concept of Heidegger*). Svenaeus characterizes the lived experience of health as being-in-the-world and consisting of a homelike feeling that he describes as an unconscious balancing background mood (2011). Gadamer, one of Heidegger's students, describes health as *"[...] something that is revealed through investigation but, rather, something that manifests itself precisely by virtue of escaping our attention. We are not permanently aware of health, we do not anxiously carry it with us as we do an illness. It is not something which demands or invites permanent attention. Rather, it belongs to that miraculous capacity we have to forget ourselves"* (1996).

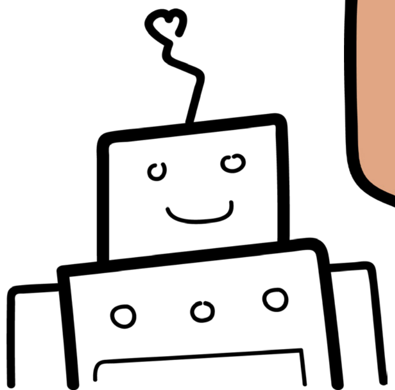
On the contrary, it seems that "*illness*" is easier to grasp in its form. Svenaeus describes illness as the feeling of unfamiliarity or strangeness, which cuts deeper into our daily perception. Illness describes the moment when our self, which gains in meaning and identity through being in the world, loses its transparent sense of being. Furthermore, loses its balance and shifts to a state where there are difficulties in bringing our self-perception into harmony with the world around us (Svenaeus, 2011).

The question is how the constant observation of one's own body by a DT could interfere with the lived perception of health/ill and cut into our own identification of ourselves with the world around us. Through the constant monitoring of the biological parameters of one's own body, this inner balance that Svenaeus described could fall into a state of imbalance. This definition of health is of great importance for this project as a DT might have a great mediating role between objective and subjective body and therefore the feeling of health. **The constant monitoring with which the human might be confronted through a DT could potentially interfere with this transparency of our own objective existence. The confrontation with our body parameters could lead us to disrupt the internal image we have of ourselves and which shapes how we perceive ourselves.** The impact of this could be, among other things, that, instead of achieving the superior goal of a healthy population, the opposite may be caused.

Additionally, the question is how to measure the effectiveness of a DT on health, if there are several competing definitions of what characterizes health.

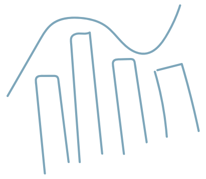
The assessment will certainly depend on the definition of health a DT is evaluated upon. If defined by the absence of disease a DT might be effective. Whereas if healthiness for a DT will be defined as the positive feeling of well-being one may wonder if in relation to the introduced concept of Svenaeus not even the opposite is reached.

Exemplary, if data of an individual, who however sees oneself as healthy, gives a different statistical rating (indicating to



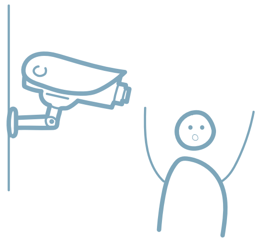
*Svenaeus draws on the concept of being-in-the-world introduced by Heidegger. This concept was first introduced by Heidegger's work "Being and Time" (1996). In this ontological work, Heidegger does not refer to being as a human being as the sum of its individual parts, but to its whole existence and Dasein. The world is not perceived as an external construct to one's own existence, but as an open construct that reveals worldliness to the individual. Thereby, the individual is connected with and to the world, which enables him to live out his own existence through intentional activities and to give it significance through the feeling of being-in-the-world. Svenaeus uses this concept by Heidegger to propose his phenomenological concept of health.

be diseased), which in contrast to lived experience, only refers to the captured biological data instead of the subjective feeling, then it could lead this individual to no longer being able to identify with oneself in this world. Furthermore, if the individual is confronted with a potential future illness, the temporary experience of being could be disturbed and result in an increased number of asymptotically ill individuals. In this sense, a DT could be understood as a mediator between the lived experience and the biological data. This was also captured by Hofmann and Svenaeus by saying that new technologies may not only influence the detection of diseases but also mediate how we perceive and experience them (2018). They argue that through the new experience, the new knowledge that we gain through the technology, a shift can take place in how we perceive our body and what plans we have for our lives. A part of ourselves, how we perceive ourselves and make sense of us in this world is replaced or questioned, which in consequence can lead to emerging feeling of alienation and discomfort, which in turn can initiate a state of illness. A further explanation on the role of technology as mediator can be found in Chapter 2.4. It becomes clear that a medical DT may have a severe impact on society and how we identify us as human. Although these risks can never be fully anticipated steps can be taken to evaluate impacts of this technology which will be further explored throughout this thesis.



The rise and fall with data and prediction accuracy

As already visible today, digital monitoring devices such as self-trackers are generously adopted by society, but they often lack data monitoring accuracy. This disqualifies such devices most often for meeting clinical standards, while their usage is prone for user errors that are not obvious at first glance. **Assuming that a DT will be considered a healthcare device and the monitoring of one's own vital signs becomes a constant companion in the course of a DT, a precise accuracy of the measured data must be guaranteed**. Furthermore, the data processing needs to develop further to increase the accuracy of predictions. A robust data set, and output is a crucial basis for the success and acceptance of a medical DT.



The continuous collection of mass information and the feeling of surveillance

Big Data can be seen as an essential pillar of DTs, the more data individuals share, the better the personalization and the more accurate and predictive the digital models become. However, the input data may need to far exceed only health data. Values and parameters that go beyond biological data may be required for data processing and output generation by a DT. For example, environmental factors such as weather, water, air and nuclear pollution, but also simple geographic data such as location, could be included in a DT. Furthermore, educational data and behavioral patterns might have an influence on the health assessment. **Even if the data collection is done against a supposedly positive background, it can give people the feeling of being under complete online surveillance.** This holds the risk that the population may have a reduced willingness to share data, which is can be seen as an essential factor to the success of DTs.

Legislative restrictions for healthcare data storage

As touched upon in passing in this thesis, legal constraints also fall within the risks associated with medical DTs. The current approach of DT is to cover the entire lifespan of the individual. This long-term data collection would be necessary to create a complete life profile of the individual and to be able to use past information to make future predictions for the individual, but also to build up statistics for the population as a whole. **However, under our current data protection legislation, such long-term collection of individual medical data would not be permissible, as it only provides for a retention period of 30 years** (European Data Protection Supervisor, 2009). As soon as a DT becomes closer to reality, laws and orders need to be revised.

High data security as standard

The digitalization of a person by storing its very personal data in clouds requires strong data governance. This should include to address the requirement for security and transparency of data use (Bruynseels *et al.*, 2018). As Thomas Gebhart, a German politician said, about the digitalization in healthcare, "*[...] we will only be successful if we succeed in creating acceptance among the population. We must ensure that the patient retains control over his or her data.*" (Grätz, 2019). But we may be far away from reaching this stage, as can be illustrated by the example of Google's DeepMind, a sister company specialized in AI. The Royal Free London NHS, one of the biggest healthcare providers and funded by the National Health Service of the UK and paid through taxes, contracted DeepMind in 2015 to develop an application by using patient health care records. The healthcare provider shared 1.6 million files of sensitive personal medical health record data without the consent of the patients. And as DeepMind stored the data on the mother company-related Google servers with US privacy rights, Google gained access to those sensitive data (Hudson, 2016). Hence, data protection should be of highest concern for the success and acceptance of DTs in healthcare.

2.2.2. Medical DTs in today's practice

At the moment, the medical DT is still a vision, but the interest is huge, and many research areas diverge (Gartner, 2017). While many initiatives focus their research and development programs on computer sciences, others investigate what a DT could look like or what the focus and interaction points with the stakeholders could be. Research directions and development plans have a high visibility and recognition, exemplified by position papers and reports, such as "The Digital Patient" funded by the European Union (Díaz *et al.*, 2013). Interestingly the authors of the report specifically personified DTs and referred explicitly to a "Digital Patient". On the one hand, this exemplifies the adoption of the engineering-derived DT into individual healthcare, on the other hand, the name "Digital Patient" already implies that everyone using a DT would be considered a patient; an individual assumed to have a disease or at least being a deviation from the population's average state. **In this thesis, it is assumed that a DT will be used by/for all people that are also not classified as patients undergoing treatments. It can also be assumed that the classification of patients is likely to change with the introduction and widespread implementation of DTs.** This is based on the assumption that the focus will shift from only monitoring in the event of disease to continuous monitoring and perhaps even earlier intervention when a classic disease state and therefore the characterization of a patient cannot yet be identified. In conclusion to that, the term "DT" will be used throughout this thesis to adhere with the terminology of my project partners. At the moment, a DT can be regarded as something that is still in its infancy. **Some emerging concepts are concerned with the analysis and modeling of organs as parts of the individual *in-silico* parts as the lung or the heart** (Sadeghi, 2020) **to then eventually construct the entire body.** However, this bottom-up approach bears the risk of neglecting leading factors compared to the parable of the blind men and the elephant, which examine and describe how they experience parts of the elephant (Figure 5). Each of them has a different part of the elephant that is being touched. The descriptions given by the people do not seem to coincide and lead to unrest - until a wise man comes and tells them that they are all correct but incomplete. This could also be applied to bottom-up approaches in modern medicine such as DTs. The individual areas might become specialized while there is the risk that the whole picture may become out of focus and the development might only concentrating on the technical perspective. A lack of connectivity and data, as well as long-term monitoring might reinforce this issue for the development and especially the accuracy of DTs. **In order to get the big picture of all factors in the body, maybe also outside the body, it could have significant advantages to merge all *in-silico* models into one's individual digital representation. This digital layer might then eventually consist of the integration of organ-specific models into a complete model, that is being fed with valuable information from medical knowledge, environmental factors and others such as genetics, stress and behavior data** (Brown, 2015).

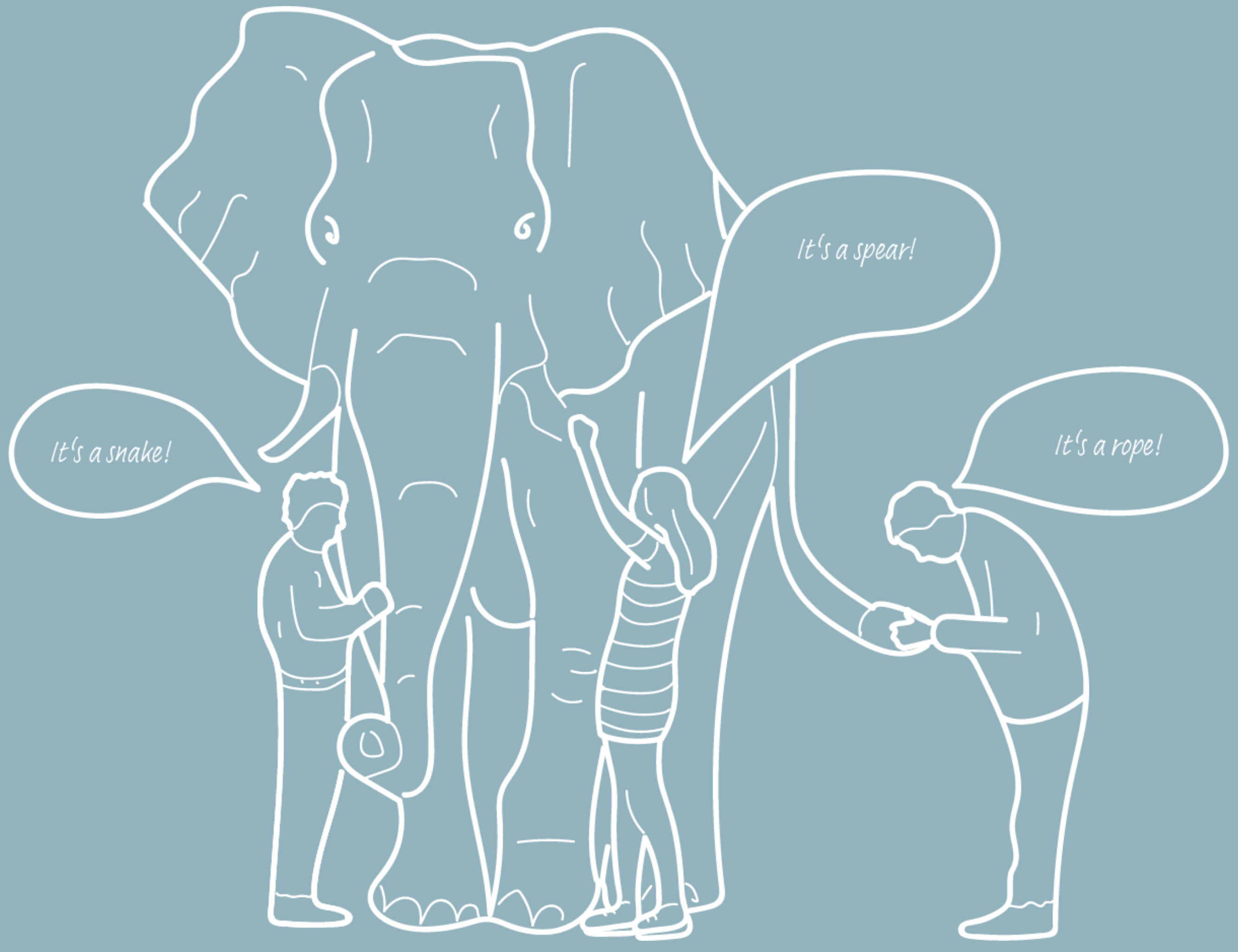


Figure 5 *The blind men/woman and the elephant*

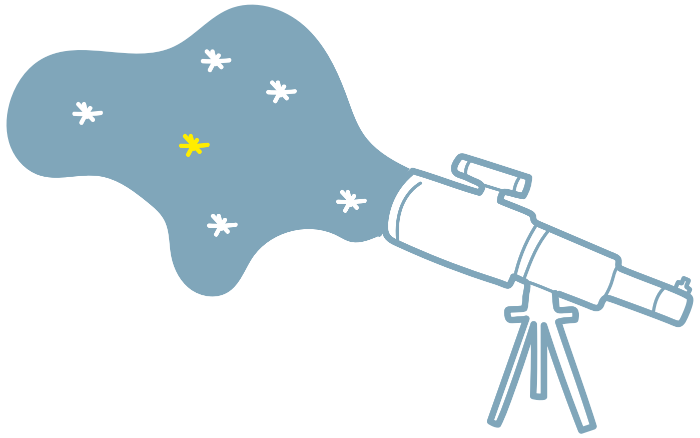
2.2.3. The future vision of medical Digital Twins

Even though the research and development programs of DTs are still in very early days, different visions and goals of the future are shared, especially by key opinion drivers. Medicine and health blogs such as "The Medical Futurist" (TMF) and industry such as Siemens and Philips are aiming to shape the future of healthcare and the implementation of DTs in specific directions.

TMF, for example, presents in their vision of the development of a DT a picture with a perfect dashboard and overview of all vital parameters of an individual. Data points are collected by different portable sensors in real-time uploaded to a central server, which then feeds the digital component of a DT. A potential illustration of the dashboard can be seen in Figure 6. For the interaction, TMF foresees that both the individual person and the doctor will receive feedback on important deviations on measures or tests to prevent certain diseases (2020). TMF imagines a shift towards a more proactive and preventive healthcare setting, where health statuses are monitored seamlessly and where early detection of discrepancies is the norm.

In addition, major industry players are also noticeably active in the field of medical DTs. When investigating Siemens' marketing campaigns and self-representations, it seems that the focus is not on changing to a care that carries the patient in the center of its change, but much more on the clinical flow where the facilitated work of the medical staff can be improved (Siemens Healthineers 2019). According to further publications, Siemens seems to have a specific focus on the development of partial DTs starting with human organs. Thereby, the heart is a major focus and challenge considering that more than 6 million patients and 1.8 million deaths per year are related to cardiovascular diseases (CVDs) resulting in 210 billion Euros in costs (European Cardiovascular Disease Statistics, 2017). **Although Siemens describes a long-term vision of a complete DT, the focus remains to be rather on the clinicians and their improved workflow and their assumption that thereby the patient's well-being itself will improve**. It needs further discussion with Siemens to examine this topic from both sides. Considering the business focus of Siemens, however, it might be considered that Siemens remains to position the company as a provider for clinical tools to their closest stakeholders.

Like Siemens, Philips began developing a DT based on a model of a heart, and in 2015 Philips debuted its application "HeartModel". It allowed cardiologists to "assess several cardiac functions that are relevant to diagnosis and treatment of patients with CVD" (Houten, 2018; Sadeghi, 2020). The heart model consisted of a generic 3D model of a heart based on 1000 ultrasound images. The generic model was then further personalized with individual ultrasound images of the patient's heart and adapted to the target heart it was supposed to represent. Thereby, it was even possible to determine how well blood was pumped by the heart; an important factor for detecting CVD early on. In this way, Philips has succeeded in combining scientific knowledge with advanced data analysis. Certainly, the heart represents only one part of the human, but it can be already seen as the first piece of the big picture of DT development. When looking further at Philips' definition of a DT and their future vision, it becomes striking that most older articles outlined more the high-level management of the patient than taking a patient-centric perspective. A more recent article by Philips and their video which explains their vision of a medical DT more freshly already reflects a shift towards a shared digital model and a patient-centric approach, where not only the physician benefited through increased efficiency and accuracy, but also the patient by gaining insights and increasing responsibility for their data. **In this article and video, Philips introduced the digital patient concept as a long-term vision of an integrated and personalized model that follows a life course approach and is updated in real-time with personal data, including behavioral and genetic data, all synthesized in the digital layer of a person** (Philips, 2018b). **Philips envisions that not only professionals but also individuals will have access to their own twin to inform themselves, insert data and receive lifestyle tips**. Figure 7 displays a part of the video and Figure 8 shows a different image of the visualization of a DT by Philips. **What is interesting to notice about the visualization by TMF and Philips is that they envision a DT in healthcare to look like a direct mirror of the body in form of a objective "map".**



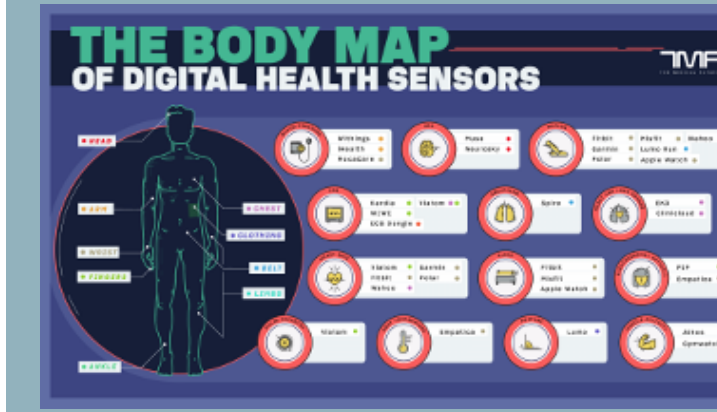


Figure 6 *An illustrated vision of a DT dashboard by TMF*

Figure 7 *Screenshot from commercial video by Philips introducing their DT concept (Philips, 2018b)*

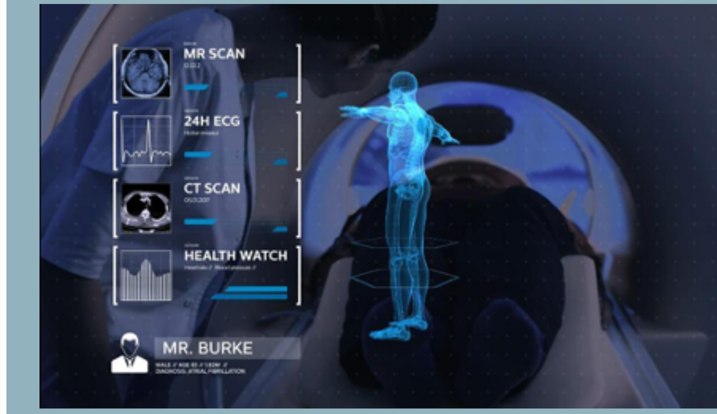


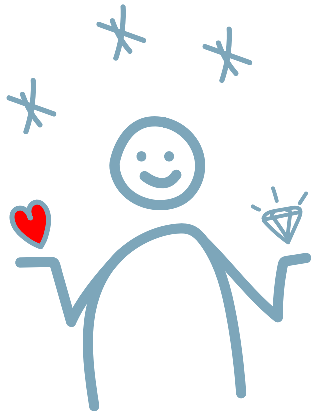
Figure 8 *Concept for a visualization of a DT interface in healthcare by Philips*

2.3. Definition of “meaningful” and values in the context of meaningfulness

As the name of this work already implies this project is concerned to uncover what a meaningful DT for the user could look like. In order to do so, it is important to define and agree on the term “meaningful” beforehand. It quickly becomes clear that this is not an easy task. Although often used, the core of what meaningful describes is not easily grasped. In literature a distinction is made between “*(having a) meaning*” and “*(being) meaningful*” (Martela and Pessi, 2018; Rosso *et al*., 2010; Thomas, 2019). **While meaning can be understood as the act of making-sense of something, “meaningfulness” goes even further as it can be understood as the amount of significance you can get from the sense-making from something** (Rosso *et al*., 2010). Building up on this definition, I argue that in order to define whether and how something can be meaningful, it has to fit the value framework of the person. In “*Meaningfulness as Sensefulness*” the author distinguishes different levels of meaningfulness of a life on the basis of how much meaning they have for society in general (2019). Drawing on that concept of levels of meaningfulness, I argue that meaningfulness of a DT can also have different degrees depending on how much meaning a person can make out of the innovation for themselves. This meaning-making is also not a static process but probably evolves over the lifetime and context. But how to uncover whether something can be meaningful from a user-perspective? **It can be argued, that in order to determine the meaningfulness of a DT, values play an important role.** Diving deeper into the topic of values it becomes clear that there is not a one-fits all definition. Although values and their importance are equally emphasized in various fields, e.g., economics, philosophy, social sciences, just to name a few, there is no consensual definition. **When analyzing the definitions of value contemporary publications, two distinct characterizations are notable. The first determines values in its plural form, as personal guidelines and ideals an individual uses to assess and choose one’s actions and way to determine what they consider meaningful in life** (Cheng & Fleischmann, 2010). **The second characterization defines value, here singular, as the worth of objects or ideas themselves.** Thereby, the value of something is not limited to monetary but can also include social or ecological value. For this work, the definition of values as guidelines and beliefs will be the guiding foundation. This is supported by the definition of value by the Oxford English Dictionary: *“[values are] the principles or standards of a person or society, the personal or social judgement of what is valuable and important in life*”. It is also interesting to take a closer look at how values as guiding principles are different from preferences.

According to Hechter, “*values are relatively and durable internal criteria for evaluation*” (1993). The authors differentiates values from preferences and norms, in the way that although both are internal, preferences are rather liable and with a dedicated focus. Norms, opposed to values or preferences, tend to be external to the actors. Besides their distinction from norms or preferences values are also not stable in the long-term. As they reflect a particular moment in time of what is considered important by the individual or society. Consequently, these values are subject to changes and remain dynamic over time. This dynamic can result from new social circumstances or from the emergence of new technologies that lead to new values, new prioritization or new understanding of these. The interplay of values and technologies is of great importance for the development of DT, due to the fact that the implementation of DTs could significantly change or interfere with existing guiding principles individual have. This will be further elaborated later on. First, we come back to the importance of values for this work. **In order to analyze how a DT could be meaningful from a user-perspective it is vital to determine underlying values that users wish to fulfill by using a DT**. That being the case, a strategy to uncover these values is necessary. Thereby, it is important not to fall into what Boenink and Kudina call the “entity trap” (2020). **In order to uncover values, one should acknowledge their dynamic nature and the hermeneutic work that is required to investigate them.** The entity trap on the other side can be explained as assuming that values are stable entities that are just waiting to be found and reflected upon (Boenink & Kudina, 2020). On the contrary and in order to in-depth uncover value frameworks and guiding principles, it is important to recognize that the meaning of a value might be dynamic depending on the context and that pre-defined values might dismiss the richness and meaning of it. **Values evolve over time through new knowledge, new experiences but can also evolve through new technologies such as a DT, meaning that these values co-evolve with the introduction of new technologies** (Swierstra & Boenink, 2009). In doing so some values are more prone to change than others, especially to a faster change, as they do not interfere with our fundamental principles in life.

That said, how does this relate to the technology of DT? Building up on the definition of Cheng, **a DT as a new innovation may take a meaningful form if it reflects the individuals value framework and guidelines. Therefore, to determine how a DT can be meaningful, the identification of values embedded in the life of the individual is an essential step.** In doing so, it is possible to assess what the individual potential user of a DT values in order to manage the development in a meaningful way. It has to be noted that if we assume that meaningfulness appears to be a matter of degree, the meaningfulness of a DT might evolve and fluctuate with the values of an individual.



2.4. Digital Twin as a mediator

In a previous section of this thesis, it was already introduced that a DT can take a form of mediator between the objective and subject parts of the body (de Boer, 2020). I would like to discuss this concept a bit further and pinpoint the importance for a potentially meaningful DT. In general, products and technologies created in the field of design often focus only on the definition of function and use. Since both products and technologies are designed to serve a specific purpose and must therefore be functional as well as usable, this approach seems fitting. However, it is argued that many of the connections we have to technologies cannot be categorized by pure usability (Verbeek, 2015). By categorizing them purely in terms of function, products are relegated to the role of a mere instrument, while people pursue their own goals that they want to realize with the use of the product. These desires are often directly related to the technology on which they are projected or through which they first arise. **Thus, reducing technologies to mere function would disregard the fact that they have a much greater impact, namely shaping human existence** (Verbeek, 2015). **This shaping of our actions and perceptions is called mediation. Mediation influences how things are revealed to us. In postphenomenology, this term reflects the non-neutrality of technologies, thereby a technology could never be neutral but always mediate how we depict ourselves** (Ihde, 1990). Mediation comes with intentionality. Intentionality can on the one hand be seen as the intention to act, as taking action towards something. On the other hand, it can also be seen as leading our perception towards something. What we do is never detached from the context in which we do it. If we think, we do not just think, we think about something, if we talk, we don't just talk, we talk about something. **Therefore, we cannot understand how a person experiences something without acknowledging one's directedness towards the world, towards reality. Technologies mediate this intentionality not as objects but as being something through which we experience something in a specific way.** In that sense no person is free from this technology mediated intentionality.

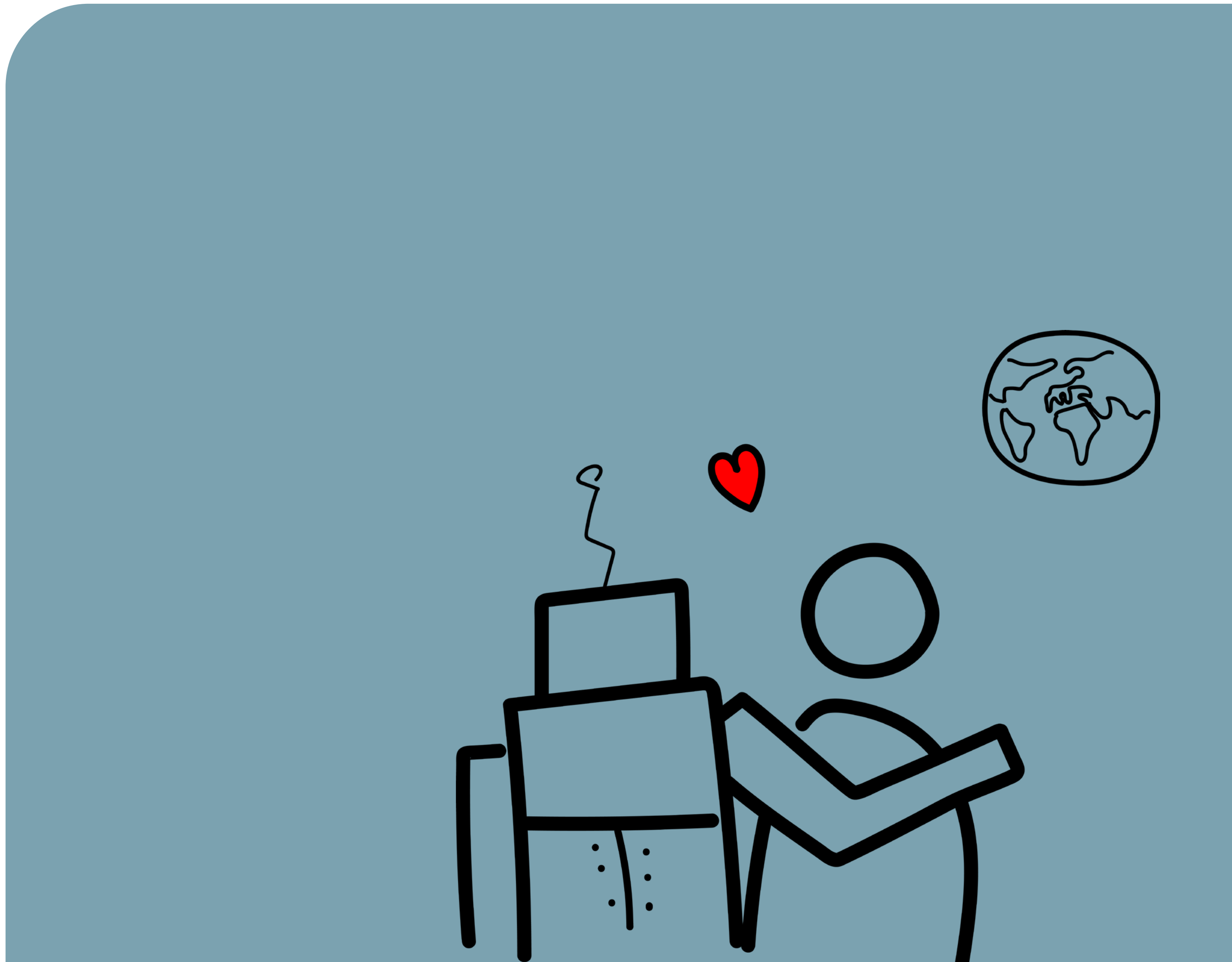
To examine the mediating role of technologies, it is interesting to look at the four realities introduced by Don Ihde and expanded upon by Verbeek in which technology can mediate our sense-making of the world around us (Ihde, 1990; Verbeek, 2015). **Don Ihde introduced four relations namely embodiment, hermeneutic, alterity and background relation** (1990). The first technology relation of *embodiment* can be understood with the famous example of a pair of glasses. If a person is wearing glasses, the attention is not on the object itself. Rather than looking at the glasses we look through the glasses, thereby the glasses become embodied by the wearer. Building up on that the glasses mediate the persons eyesight through amplifying it, while the own presence of the object, the glasses, is reduced. The second technology-relation is *hermeneutic*. Hermeneutics refers to the act of interpretation. While the artifact itself constructs something that has no existence of its own, it gains meaning for the person through interpretation. This can be underpinned with an example of a thermometer. The thermometer displays a number that in itself has no meaning for the user. It is only through the interpretation, for example that the person has to put on a thicker coat when leaving the house, that this number gains a meaning. In doing so, this relation supports a specific interpretation of the world, while the way this interpretation is constructed becomes less relevant. The third technology-relation is the *alterity*. In this the emphasis is on the interaction between the human and the technology. This can be better understood with an example of a coffee machine. We decide to interact with the coffee machine in order to receive a coffee. We interact through actively turning to the object, placing a capsule in the machine and through this interaction receiving our coffee. Thereby our attention turns to the object, while the attention to the world, around is reduced. The fourth and last relation introduced by Ihde introduces the *background* relation. This relation refers to objects that shape our existence while staying in the background and without interaction. In that sense, the technology can be seen as both, absence but present at the same time. As an example, one can think of atomic weapons. Although we do not interact with them, we are aware of their presence in our society, we know their power and the danger coming from them. As a result, their background presence shapes our society. Verbeek builds up on these four relations provided by Ihde with the argumentation that many technologies nowadays do not fit into these categories anymore (2015). He claims that modern technologies "are even more intimate than an embodiment relation, while others have a more powerful contextual influence than the background relation" (Verbeek, 2015). As an example, he refers to brain implants that for instance can be used to treat Parkinson's disease. By actively being placed into the human body, embodiment does not do justice to the technology's mediation approach. Verbeek argues that the in cooperation of the technology into the human body creates a new, as he calls it, "*cyborg relation*". In this relation, the human and the technology merge to a new hybrid being. Additionally, he introduces claims that some technologies might blur the lines between the technology-relations, leading to something what can be seen as a fusion. As an example, he mentions the Google Glass, which on the one side, can be embodied and allow the wearer to experience the world around. On the other side, they also represent the world through an embedded screen. According to Verbeek, this could be seen as a combination of embodiment with hermeneutic relation. As we can see by that example, the way technology is mediating the world around us is constantly evolving. But what does that mean for the technology of a DT? As we could see so far, technologies such as a DT shape how we experience ourselves, but also how we experience and understand the world around us. **The constant monitoring with which a DT is most likely to be featured, comes with a constant awareness of what our actual health status is. Thereby, it creates a demand for persistent attention, drawing our status of health out of its transparency** (Hofmann & Svenaeus, 2018). Building up on that, it means that a DT is most likely to change how we experience our own health. Furthermore, the constant tracking and evaluation of one's own health data is likely to lead to an increased number of times of confrontation with the objective aspect of one's body. It is interesting to think about the influence that may have on a person. **The constant confrontation with one's data in the form of an abstract body representation which might be hard to bring into context with one's own subjective feeling of the body, might come with the inquiry for hermeneutic tasks. Meaning that the experience of having a subjective body moves more into the back, as a DT mostly concentrates on the object of the body as something that can be shaped and intervened.** While turning attention on the objective side is something that might work in the context of engineering, it might be difficult for the human from a subjective side to connect to this experience. This might lead the human to a feeling of detachment from the own objective body presented and constantly analyzed by a DT. **As health can also be understood as the balance between the objective and subjective body and especially the transparency of the first, one could assume that a DT might imbalance the feeling of health through evoking constant awareness**. This brings us back to the importance of defining what a meaningful DT for the user could be. Although one can never be free of the mediation of technology, the mediation of a technology, as Verbeek argues, can be conceptualized and analyzed in order to responsibly design and develop a technology (2015).

2.5. Responsible Research in Innovation

As previously mentioned, the development of DTs in the context of disruptive innovation, and particularly in healthcare, comes with great responsibility. In the modern world, new technologies are often classified and assessed according to the health and security risks they pose to people and their environment. These can also be described as "*hard impacts*", of technologies. Hard impacts are often used as reference points in the scientific community for assessing the safety of new technologies. "*soft impacts*", whereas do not aim at the quantifiability of the results, but rather require an empirical approach and involve how technologies might affect social norms and roles, identities, values, and practices (Swierstra & Boenink, 2009). In practice, these soft impacts receive little to no attention. Therefore, soft impacts are particularly important to complement technological development by, e.g., bringing in users and designers to identify points of application, to reflect on them morally and to define and incorporate social impacts into the design and support of a responsible innovation.

In order to address this responsibility for innovations, the concept of "Responsible Research in Innovation" (RRI) can be applied. In RRI, it is important to first frame the responsibility by setting cornerstones and then identify the responsibility itself. As Owen defined, considering responsibility in the development process is one of the biggest intellectual challenges (2012). The authors argued that currently applied consequentialist responsibility models, in which the effects of one's own actions are only assessed retrospectively, pose a major problem for innovations that are future-oriented and uncertain in their nature. Furthermore, they described that the consequentialist way of acting is limited by the possibility to predict the future and as a consequence produces only one method of acting: A game of chance in which one can only hope "*[..] that we can be excused from moral blame in the fullness of time*" (Owen *et al*., 2012). In reflection and if we deviate from this consequentialist model by involving society in the responsibility that such uncertain foresight brings, attention might move away from established rules towards a constructive discussion.

To translate the concept of RRI into an actionable approach, it is helpful to introduce the practice-based concept of RRI, which states that, instead of proposing external values to minimize the potential harm of an innovation into a potential risk, values should be directly identified and fed into the innovation process in a co-shaping way (Boenink & Kudina, 2020). Furthermore, it is argued that values should be reviewed by the individuals that are potentially impacted by the innovation (Stemerding, 2015). This also implies that values should be uncovered early in the process of developing the innovation (Netherlands Organisation for Scientific Research, 2012; Poel, 2009). The difference between other approaches of RRI and the more practice-based approach of RRI by Boenink and Kudina (2020) is that the emphasis is more on the role of the user in the innovation. In addition, the practice-based approach acknowledges the hermeneutic work requires to uncover these values. **Taken together, I argue that this approach of RRI will support my approach to build a basis to steer the development of a DT in meaningful directions for the user. Building up on that, RRI can be considered as a driver for this thesis, as it could be especially important in the topic of DTs in healthcare as DTs are supposed to affect the perception of people on their own status of health** (Hofmann & Svenaeus, 2018). As a DT is considered a disruptive technology in the healthcare sector, it is likely to not only change the clinical workflow but also the human/technology interactions and morality and societal relations. Furthermore, it is envisioned to open possibilities of diagnosis through predictions or lifestyle advices that serves to prevent an illness before there is even the need for curing it. It is quite important to uncover how such a new technology affects peoples' perception of their state of bodies.



2.6. A phenomenological view of experience

In order to uncover how a DT might be meaningful from a user-perspective, it is important to anticipate how users expect and wish to experience the usage of such a future technology. Therefore, it is important to reveal the user’s experience and the values embedded in the experience of people through empirical studies such as interviews. In order to uncover both, given answers on **the user’s past, current and future experience will contain information on embedded values. To derive to those aspects, the approach of** “*Interpretative Phenomenological Analysis*” (IPA) **can be applied**. In the following, the importance of IPA in this thesis is introduced as well as its relevance for the interview guide.

While IPA is a relatively new concept, it draws up on concepts which have a history reaching far back (Smith *et al*., 2009). The application of IPA started out in health psychology and is now increasingly being applied in other disciplines such as human, health and social sciences. **IPA can be understood as the combination of the three key concepts that are** “*phenomenology*”, “*hermeneutics*” **and** “*idiography*”. IPA is especially concerned to uncover how people make sense of their own experiences. Thereby, IPA aims to obtain descriptive information of how things appear (Smith *et al*., 2009). The goal is to understand the experience of an event from the perspective of the participant.
In IPA, objects or events are ideally given the space “to speak for themselves”, and it is considered that interpretations through the interviewee as well as the researcher are equally important, which will be further explained in the hermeneutic circle. It is assumed that there is no uninterpreted phenomenon (Pietkiewicz & Smith, 2014). Thus, it is assumed that the participants are “self-interpretative” and able to make meaning of the world (Taylor, 1985), just as the researcher is able to interpret the participants’ interpretation of the experience. In the following, I will introduce the three key concepts that influence IPA.

Phenomenology

Phenomenology has a certain track-record in history and can be seen as a study that unites and emphasizes different focuses that all share a special interest in the experience of being human and the things that are important to us and that characterize our lived world (Smith *et al*., 2009). In this project, I will not go into more detail about the history of phenomenology and the different imprints and concepts. **Phenomenology is a qualitative research method aiming at uncovering the lived experience of the participants that are being investigated**. It can be seen as the “*study of one’s immediate apprehensions of an experience as they present themselves to one’s consciousness* “ (Sanders, 1982). Sanders argues that phenomenology is not concerned with presenting “*a “new view“ of observable data. Rather, it presents a “new way“ of viewing what is genuinely discoverable and potentially there but often is not seen*“ (1982).

Lived experience, first-person perspective

We as humans not only have a body as a physical, external shell but we are also able of experiencing ourselves as a body. **Building up on this from a phenomenological perspective we can be a body but also have a body at the same time** (Wehrle, 2019). Thereby, our body is the subject as well as the object of intentionality. It can be distinguished between two completely different ways of human embodiments (Husserl). Namely our *Leib* with which we experience and sense and our *Körper*, as the objective side of something that we experience in the world. By distinguishing these two terms we can both be and have a body. This twofold character of embodiment can be explained with the famous example by Husserl: When touching your left hand with your right hand you can perceive the feeling of touching your hand and attend to the subject of sensing by your right hand, or you can attend to the feeling of the left hand as representing an object (1989). **This differentiation between the subjective feeling of the living body in contrast to objective feeling of a lived body plays an important role to examine the first-person perspective of the lived experience.**
To uncover the lived experience of people, it is important to focus on the first-person perspective, which stands in contrast to the third-person perspective established from theories and explorations of empirical sciences (Svenaeus, 2011). As described in a more recent publication, with an example in healthcare, (contemporary) phenomenology is especially interested in discovering the lived experience from the patient (*first-person perspective*), to supplement the doctor’s causal descriptions when examining the body as diseased (*third-person perspective*) (Svenaeus, 2019). **The starting point for modern phenomenology of medicine was prompted by the observation that modern medicine is too focused on this third-person perspective and therefore on the body as an objective part.** While it might be possible from the third person-perspective (doctor) to examine a human as diseased, only the person (patient) from the first-person perspective, the living body, can experience the disease in the sense of an illness. Exploring an illness addresses the meaning level of illness, the lived experience of it through the person itself, instead of solely focusing on the state of biological malfunction. Therefore, there is the risk of modern medicine only addressing the scientific side of a disease instead of the illness itself. **The introduction of the technology of a DT might come with the risk, that through potentially visualizing the bodily processes of the person, the focus might be placed more on the objective part of the body as being a** ***Körper*****, instead of the lived experience of the individual** (de Boer, 2020). Thereby it is important to for this project to uncover the subjective experience from the first-person perspective when analyzing and reflecting on the consequences, a DT might potentially have on an individual.

Hermeneutics

Hermeneutics, derived from the Greek, means "to interpret" or "*to make clear*" and is an essential part of the IPA approach. The concept of hermeneutics can be dated back to Greek mythologies, referring to Hermes, who is assumed to have translated the god's messages for the humans. To succeed in this task, he had to understand the language and the mindset of the gods as well as those of humankind. This moment of understanding the boundaries between person and text, person and person, and person and the world is where meaning is open for interpretation. This interpretation is what researchers are interested in when using the concept of hermeneutics (Freeman, 2008). Hermeneutic assumes that the researcher must understand a person's way of thinking and the language they use to communicate their experiences in the world in order to interpret their message (Freeman, 2008). Therefore, hermeneutics aim to pursue an open-conversational interview approach and the co-reflection of both the interviewee and the researcher. It can be understood as the researcher interpreting the descriptive experience of the participant, based on the participant's interpretation of its own lived experience. This can also be described as the double hermeneutic approach that IPA takes and will be explained further in the following sections. Taken together, the interpretation through the researcher plays an important role in the analysis phase of the interviews, when the quotes of the interviewees are eventually translated into underlying values. The researcher applies hermeneutics by interpreting the quotes and giving them a meaning of their own by bringing in and acknowledging one's own influence on the interpretation through personal experiences and points of view.

By diving deeply into the particular experience of an individual, IPA focuses on what can be called "double hermeneutics". Smith *et al.* offered the explanation that double hermeneutics is a combination of hermeneutics of empathy and hermeneutics of questioning (2009). This means, on the one hand, that the researcher takes the role of the second person perspective by trying to get an "*insider's perspective*" of the participant (Conrad & Barker, 2010). In order to reach this point and take on the participant's perspective, it is important that the researcher provides empathy. Nevertheless, it is also the goal of the researcher to take on an outsider's role to analyze the participant's experience by asking different questions and looking at the experience from various angles. These two perspectives ensure that the researcher tries to understand what it feels like in a given situation for the person, as well as the analysis and making sense of what is being said. Gadamer argues that the hermeneutic circle can be defined as the uncover of meaning through the researcher (1996). This meaning-making can be achieved by the researcher through in-depth analysis of the researchers own interpretation of the sense-making of the participant (Gadamer, 1996).

Idiography

After having introduced the key concepts of phenomenology and hermeneutics and their influence on the approach of IPA, I will now present the last key concept called idiography.

In general, idiography describes the commitment to the details, and an in-depth analysis of the provided and shared experience by the participant that needs to be conducted in a thorough and systematic way (Smith *et al*., 2009). Thereby details relates to the in-depth study of experiences made by the individual which is opposed to other approaches (e.g., in sociology or psychology) that rather aim at investigating shared experiences of a larger group of people. The focus of IPA is the in-depth understanding of a particular phenomenon from the perspective of the lived experience of particular participants. Therefore, the sample size is usually small and purposefully selected with a focus on homogeneity. Idiography in IPA is more concerned with examining and uncovering the individual's perspectives of the participants in this specific context, in this case diagnosis. The assumption is that these findings cannot be generalized but are dependent on their context.

After the introduction of the three key concepts of IPA, can be summarized with the words of Smith that "*without the phenomenology, there would be nothing to interpret; without hermeneutics, the phenomenon would not be seen*" (Smith *et al*., 2009) and should be further added that without idiography, no details would be revealed. To highlight once again in the end, the phenomenon is something that is accessed by studying the lived experience from the first-person perspective. Therefore, it is important to examine upfront what an experience is. In the following, I will introduce the definition of Husserl in comparison to a more hierarchical understanding of experience.

What is experience?

Husserl can be seen as one of the pioneers of the phenomenological movement. In his proposed concept of intentionality, he defines that our experience can be understood as a consciousness towards an object. Therefore, according to Husserl an experience requires to be conscious of it, to direct one's actions towards it (Smith *et al*., 2009). But defining what "experience" essentially means is not easily explained by itself, neither by the different viewpoints provided by literature (Tomkins *et al.*, 2013). In contrast to the concept proposed by Husserl, experience can also be understood hierarchically from a phenomenologist point of view. As stated by Tomkins, the hierarchy can be divided in three levels, starting with the "*experience*" as something that is rather transparent, unselfconscious, followed by "*an experience*", the turn to a more conscious being-in-the world, and "*an Experience*" the level of consciousness that makes us aware of the significance of the experience itself and its influence on our lives (2013). This hierarchy leads to a differentiation of experiences starting from pre-conscious, to conscious and reflective towards the thetic (Smith *et al*., 2009; Tomkins *et al*., 2013). If we assume that consciousness, in all its different levels, is something that defines an experience, the question remains how people are conscious. The experience of emotions can be seen as a fundamental part of human consciousness (Tye, 2008). This is also supported by a core assumption of IPA which claims that "*emotions are absolutely central to our human understanding of experience*", as well uncovering how humans understand the world around them (Smith *et al*., 2009). Therefore, I argue that, and in order to fully access the lived experience of participants, it is essential to also focus on uncovering the emotions that are experienced by the interviewee.

2.7. Interviews as a method to reveal values

In the following the approach to reveal values embedded in the current and anticipated future experience of the participants through interviews will be further explained.

The concept of RRI can be considered as motivation for the interviews to collect information about participants' experiences in the context of a diagnosis. The aim is to uncover the underlying values embedded in this context in the present, as well as in the future with a potential DT as mediator. Investigating the appropriation of a DT which is more of a technological vision so far demands a certain level of anticipation, as no real-world practice of using the technology has taken place at this point.

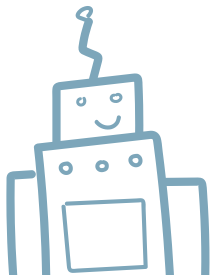
In order to uncover the values of individuals in the specific derived context of diagnosis, it is important to build up on the personal interpretation of their lived experience from the first-person perspective. Therefore, I suggest performing interviews. The questions posed during the interview will mostly concentrate on exploring the *"feeling"* and emotions of people within their experience rather than the *"doing"*; however, these questions of *"doing"* may not be neglected in an introductory part of an interview and a later part by introducing a DT, both aiming at sensitizing the participant and gaining a shared understanding of what the participant perceives as DT.

In order to support the participant, the interview will be built up in a way that helps the participant to reflect on their experience in a chronological order, meaning starting by their past, present and going into the future. Reflection in this context means that the researcher familiarizes the participant with the topic through sensitization and let the conversation build up through time. The interview as a methodological procedure can be seen as a descriptive rather than prescriptive method, as the participant is not given any predefined information, but rather the interviewee indicates the important topics for conversation within the frame of the interview guide. The interview ideally starts with sensitizing the participant by letting one speak and reflect openly about a more general question regarding the healthcare sector to get them into the mood and mindset to reflect on a past experience. Followed by more specific questions concerning the present experience in the context of diagnosis of the participant, it may introduce values as a lived reality. Next, after constituting a shared ground of the context, the participant may be asked to reflect on the current process and its influence on their experience. Thereby, the focus lies on the interactivity of values. Afterwards, the interview may be shifted toward more future-oriented questions, concentrating on the dynamic character of values. In this step the participant may be asked to imagine how the experience might change. Thereby, also the embedded values may change their meaning or importance in the context of diagnoses.

This is followed by an introduction of the concept of a DT in engineering aiming to identify values that might change the context of healthcare through new practices or opportunities envisioned by the participant. Lastly, the interview aims to uncover how the interactivity and dynamics of values might change with a DT embedded in the context of diagnosis. All subtopics will be combined by transitions through the researcher, so that a more conversational approach is facilitated. The questions will be formulated in a way that they are easy to understand, and open-ended to get rich descriptions.

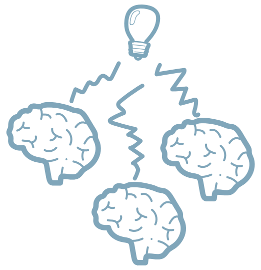
Key Insights – Chapter 2

- Despite the myriad number of definitions, I will concentrate on a DT that is characterized by three key factors: the physical object, the virtual representation and a data stream connecting both of them
- A DT in healthcare that focuses on representing the full human body is not yet developed
- Multiple visions of DTs exist in healthcare that focus on equipment and feasibility
- The impact of a DT in healthcare on the user is only little researched
- Many visions by companies depict a DT as a direct visualization of the physical body
- Technologies have a mediating effect on how we perceive the world around us and influence our practices and moralities
- RRI focuses on discovering user values prior to developing the innovation, in order to steer the development in a responsible way
- Phenomenology is concerned with uncovering the subjective perspective of an experience which is important to uncover how people from the first-person perspective might experience the impact of a DT
- Interviews are a suitable method to discover underlying user values from the first-person perspective

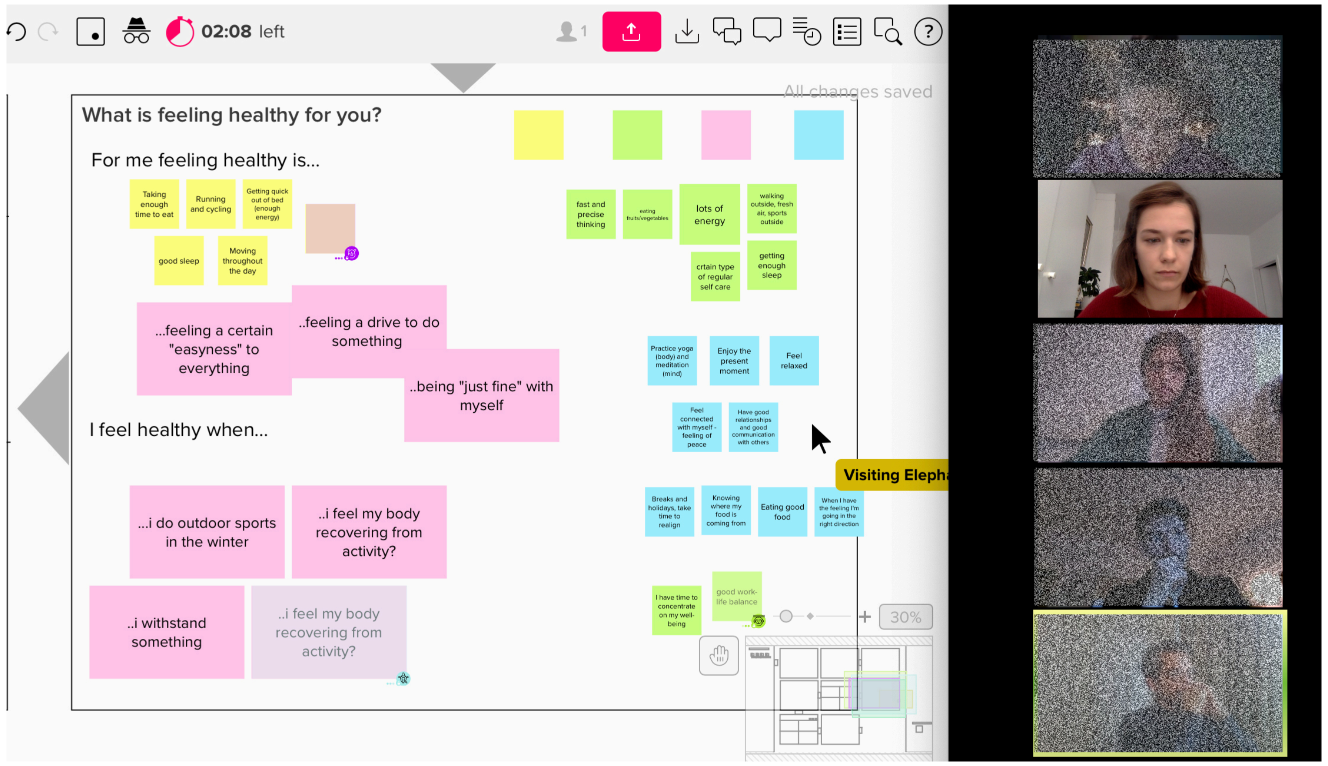


Methodology

3.1. Brainstorming



As a first step a brainstorming session was held to get an initial but differentiated understanding on how people generally perceive the topic DTs and to explore what they identify as immediate potential or risk by the implementation of such technology. This brainstorming session was understood as complementary to the interview with the experts, as it aimed to enrich the first understanding and broadening thoughts, experiences and perceptions of the individual. Therefore, the brainstorming session was held with four participants that were chosen in a conscious way, consisting of two TU Delft Master students, of whom one was already acquainted with the topic of DTs to a limited degree, and additionally to two Master students from Germany of which one was a non-design professional. This specific selection of participants aimed to gain a broad perspective. The brainstorming session had a special focus on examining potential situations assessing the perceived benefits and risks associated to a DT in healthcare. The digital meeting session lasted 65 min and seven questions were asked (see Figure 8). The outline of the discussion guide can be found in Appendix D. For the analysis, I used the affinity diagram method to cluster different quotes and sorted them regarding their thematic coherence with the aim of defining a context in which the perceived influence of a DT on themselves was at its highest (Appendix E).



What is feeling healthy for you?

For me feeling healthy is...

Taking enough time to eat
Running and cycling
Getting quick out of bed (enough energy)
good sleep
Moving throughout the day

...feeling a certain "easyness" to everything
..feeling a drive to do something
..being "just fine" with myself

I feel healthy when...

...i do outdoor sports in the winter
..i feel my body recovering from activity?
..i withstand something
..i feel my body recovering from activity?

fast and precise thinking
eating fruits/vegetables
lots of energy
walking outside, fresh air, sports outside
crtain type of regular self care
getting enough sleep

Practice yoga (body) and meditation (mind)
Enjoy the present moment
Feel relaxed
Feel connected with myself - feeling of peace
Have good relationships and good communication with others

Breaks and holidays, take time to realign
Knowing where my food is coming from
Eating good food
When I have the feeling I'm going in the right direction

I have time to concentrate on my well-being
good work-life balance

Figure 8 *Brainstorming session with four participants to define the context for the research*

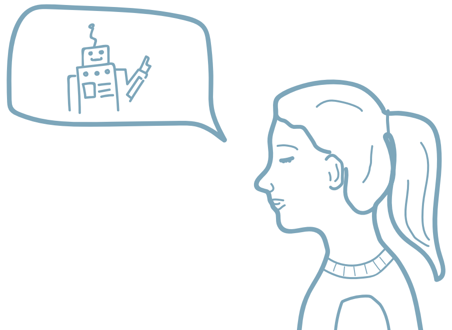
3.2. Interviews

3.2.1. Interviews with experts

The second step was to get a first grasp the topic of DT from the point of view of experts. In order to get first insights into the current development plans and expectations of a DT, two experts from the related “MyDigitalTwin” research group were interviewed separately. **Since the project between the TU Delft and the Erasmus Medical Center was still at its very beginning, both of the interviews concentrated rather on the expectations and perceived potentials of a DT by the interviewees.** The interviews were conducted online, and both had a duration of about 30 minutes in which a semi-structured interview guide was used. The interview guide can be found in Appendix B.

3.2.2. Interviews with potential users

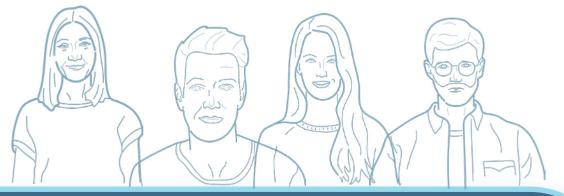
This work is concerned with discovering a meaningful DT from the user-perspective. Therefore, the user interviews can be seen as the core of this work. Thereby, **the aim was to uncover how people experienced the diagnosis in the past and draw a contrast on how they think their feelings might change or evolve in the future when the technology would become an essential part of the diagnosis**. In order to fully access the lived experience of the participants, I used a hermeneutic (interpretative) approach for the interview and the subsequent analysis of the transcript, as it allowed the exploration of values highlighting the importance of interpretation through the researcher.
The discovery of values through hermeneutic tasks was also applied, in accordance to Boenink & Kudina, who proposed a three-part interview, which consists of “*values as lived realities*”, “*values as interactive*” and “*values as dynamic*” coupled with hermeneutic tasks to identify the underlying values (2020). I proposed to adapt these three phases for the purposes of this interview to not only discover the current status, but to derive to values associated to the potential future technology. For this reason, the interview followed the first three suggested steps, and was then extended by the introduction of the new technology. Afterwards, steps two and three of the previous structure were re-applied, namely “*values as interactive*” and “*values as dynamic*”, to test how they would evolve with the DT as a mediator in the context.
After the interview guide was set up according to the five step structure I proposed to follow, a first interview was held to validate the interview guide and check if all questions are open and understandable for the interviewee. After conducting a first interview I made some minor changes on some of the questions to make them more in line with the interview flow and understandable for the participant.



Sample size and participant segmentation

In accordance with IPA, the group samples are conventionally relatively small. Therefore, the aim was to keep the two interview groups small but homogeneous within the groups. It is argued that the users’ requirements for DTs may vary depending on the age. Therefore, **the first group consisted of younger participants, aged between 24 and 28 years**, who have grown up in the digital age and who are very likely to have had only a few long-term problems with illness up to that point.

The **second group was composed of people between 54 to 65 years** who might have been exposed to the world’s digital developments only with the arise of digitalization but would have not grown up with them. At this point in life, it might be realistic, that they have already encountered and experienced a long-term or even chronicle disease(s). In short, the participants were segmented by age expecting the most significant segmentation according to the assumptions that can be found in the blue and orange box underneath.



Group 1 Young

Characteristics: Between 24-28 years old, high educated (Master students), high digital adherence, low chance for chronic disease, lower consciousness about health than group 2

Assumptions: Have different values and potential forms of use of a DT than group 2; younger people might not see value in foresight as much as group 2

Group 2 Old

Characteristics: Between 54-65 years old, highly educated (University degrees), medium digital adherence, high chance for chronic disease, higher consciousness about health than group 1

Assumptions: Higher interest in health; higher intrinsic motivation to use DT; see different purposes for use and value; rather concentrate on more serious life events than group 1

Please note that these illustrations do not reflect the actual interviewees.

Interview procedure

The interviews with both groups were conducted within a period of two weeks. A **digital consent** form was sent to the participants prior to the interview (Appendix C). At the day of the interview, the participants were first given a rough introduction about the following process as a recap to the introductory e-mail. **Due to the pandemic situation, all interviews were conducted online.** The interviews took place in online sessions via Zoom as video conference software. Both researcher and participants used their cameras to create a more natural conversation and pleasant atmosphere. The length of the interview about 40-60 minutes. The participants were informed before the start of the interview that, despite the sensitive context of the diagnosis, they would not need to refer to specific diagnoses nor share any personal information they would not feel comfortable with. This also aimed to guarantee that participants would not focus on actual diseases, but on the experience of the diagnosis and their feelings about it. The semi-structured interview was optionally minimally adapted by the researcher according to the course of the conversation while the main questions were asked in each interview. The interview guide can be found in Appendix F.

3.2.3. The six-step approach of analysis in IPA

A six-step approach in IPA was applied to analyze the interviews in a more structured way (Smith *et al*., 2009). In brief, these six steps consisted of, first, reading of the interview transcript through which the interviewer should gain a second-person perspective. This was followed by collecting initial thoughts, identifying or developing first topics, finding of connections between emerging topics and then potential transitions to new cases that allow to uncover emerging patterns across different cases.

1. **The researcher listens to the interview repeatedly and reads through the transcript,** allowing the researcher to delve deeper into the life of the interviewee and to get a better and more accurate picture of the interview (Figure 9, 10).

2. **Take notes. This step lays the foundation for the researcher's interpretation. Three different steps for taking notes were followed: descriptive, linguistic and conceptual** (Figure 9 and 10). Descriptive comments are designed to reflect and structure the way in which the participant gives their answers and thus the activity of sense-making through the participant. In particular key sentences shall be highlighted. Linguistic comments, whereas, focus on the description between the lines, what tone resonates in the interviewee's narration, are there laughs or are metaphors used to describe certain experiences, as they have a high influence on what meaning is being conveyed through the language of the interviewee. The last of the three comments addresses first emerging concepts. This is the first time that the researcher takes a more distanced role from what is being directly said, bringing in his or her own perspective and experiences. In this step, key moments are interpreted through conceptual comments by the researcher. This is also the moment when the hermeneutic circle described by Gadamer comes into play through the researcher's interpretation of the participant's own sense-making in order to arrive at the respondent's central concerns (1996).

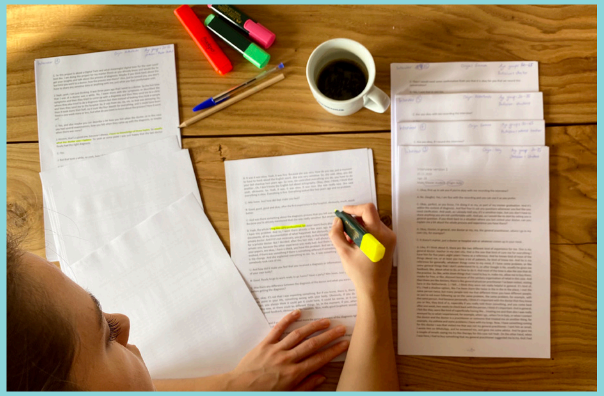


Figure 9 *Researcher taking descriptive, linguistic and conceptual notes on the interview transcripts*

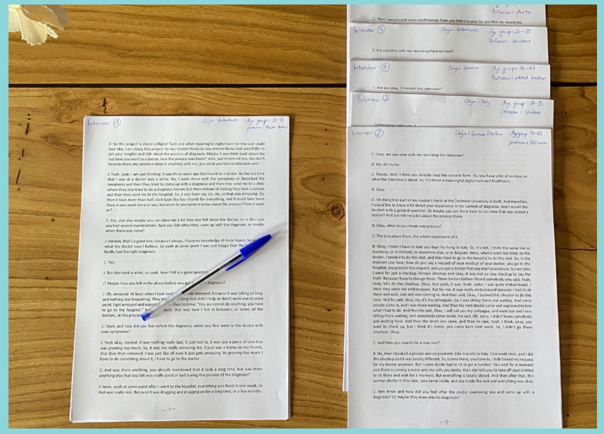


Figure 10 *Interview transcripts*

3. The focus is on identifying emerging themes within the transcribed material. The chronological order of the interview is retained as the structure, hence, emerging themes are listed in chronological order. The emerging themes represent a step towards a more abstract interpretation of the participants' response, but it is important not to abandon the complexity of what is being said.

4. Build on emerging themes that aim to define connections between the individual themes within the chronology of what was transcribed. It is the researcher's perception to exclude topics that do not address the original research question. There are several ways to define the relationship between the topics. Among other things, polarizing themes can be pointed out, the number of occurrences of a certain theme or the focus on certain temporal events such as key moments. Within this project, however, the focus has been on clustering appropriate themes together and linking them under a collective descriptive term.

5. The penultimate step of the analysis is to repeat all previous steps with the other interviews. It is important that the first interview is not used as the basis for the analysis, as otherwise the researcher could be biased in its interpretation and new themes could be neglected. Nevertheless, it is acknowledged that the researcher is never free of one's own interpretation and knowledge gained from the first analysis. For this research I started with the analysis following the chronological order in which the interviews were conducted.

6. In the final step of the analysis, the interview analyses are compared with each other and overarching themes are defined (Figure 11). The visualization of this step plays an important role as it gives the researcher the opportunity to reflect on the process and to reflect on the topic assignment in an iterative process. It is important to note that themes that emerged only within one interview do not lose significance and should not be neglected in the analysis. In order to reliably reflect the broad spectrum of experiences, all topics that arose are therefore presented in the analysis. **In order to get a further perspective and exchange in the analysis, the emerging themes were discussed and validated with an external person outside of this research.** Although IPA theory recognizes the subjectivity of interpretations, this discussion was intended to challenge and reflect on one's own interpretations.

During the identification of the themes 415 quotes in total (e.g., young and older participant group) **were highlighted** that represented themes identified through the researcher. After highlighting the 415 quotes and their underlying themes, this step was used to cluster these and arrive at emerging themes. **In this step, 67 themes emerged from the experiences of the younger participant group and 62 themes emerged from the experience of the older participant group.**

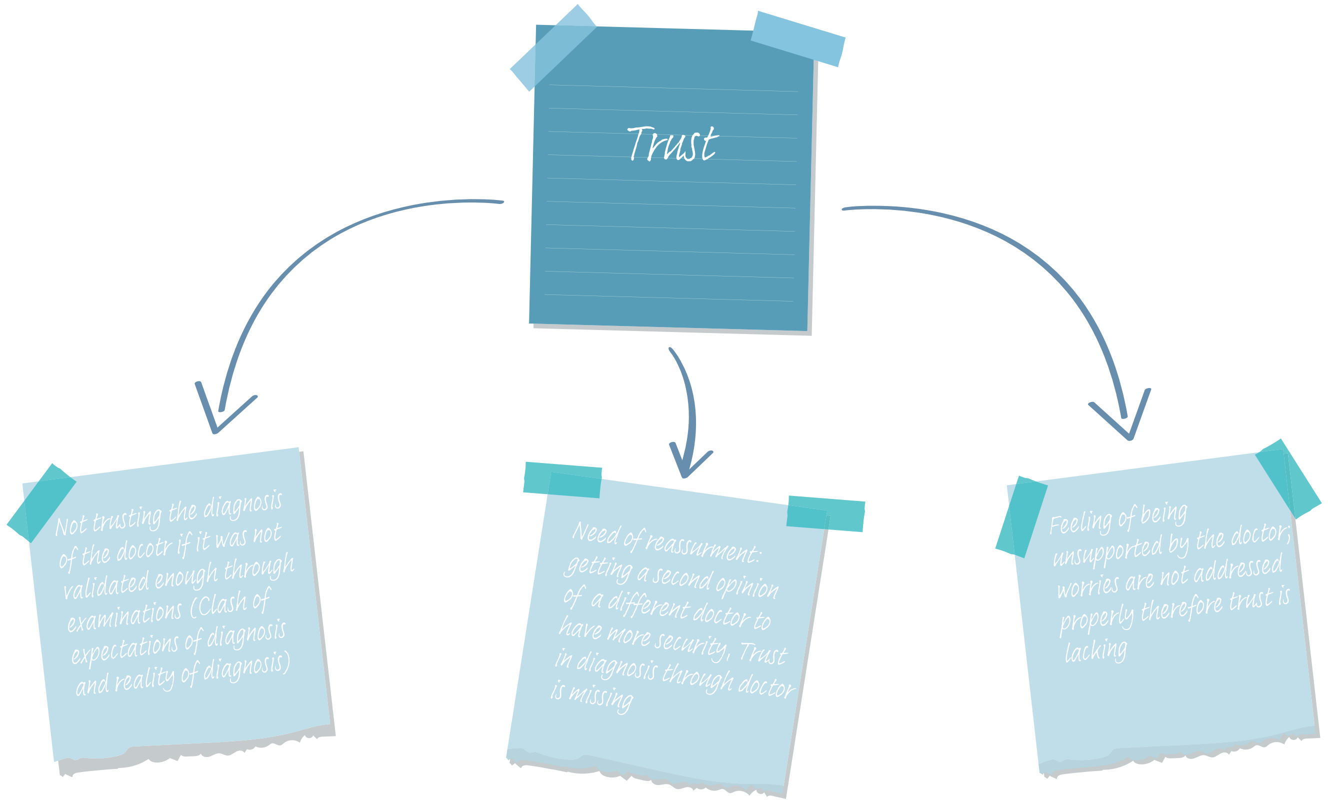
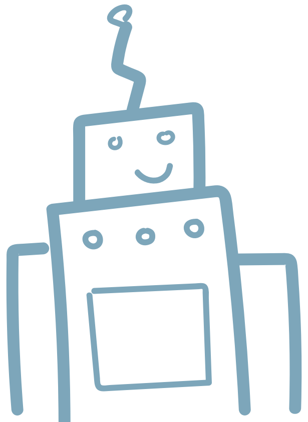


Figure 11 *Themes from the different interviews (light blue) and overaching themes that were uncovered by the researcher*

Key Insights – Chapter 3

- Semi-structured interviews with experts from the "MyDigitalTwin" team were conducted to get a basic understanding of the stand of development and expectations
- Brainstorming session revealed that the context of "diagnosis" is of high importance and therefore defined the scope of this research
- Based on the hypothesis that a meaningful DT may differ depending on the user's age, two participant groups "young" and "old" were distinguished
- The interview guide for the user groups was developed and validated in testing rounds
- Eight interviews were conducted and analyzed on the basis of the six-step analysis approach



Uncovering values that define a meaningful DT

4.1. Building the basis and identifying a focus

In the expert interviews, I grasped, that the development of a DT in healthcare in the “MyDigitalTwin” group is in its infancy. The current focus is starting from “smarter pregnancy” and is in the conceptual phase. **A clear picture of a coherent concept of a DT is currently being identified. Furthermore, there is a discrepancy between the desirability of a life-course approach where a DT accompanies the user from birth until death.** While the interviews with the two experts provided good insights into the expected next steps of development, it also revealed misalignments whether to engage the user prior to development or rather take a consequentialist stand. To my understanding a meaningful DT requires the early involvement of user perspectives and considerations of values. This is needed to steer the development as well as applicability in a meaningful and responsible way.

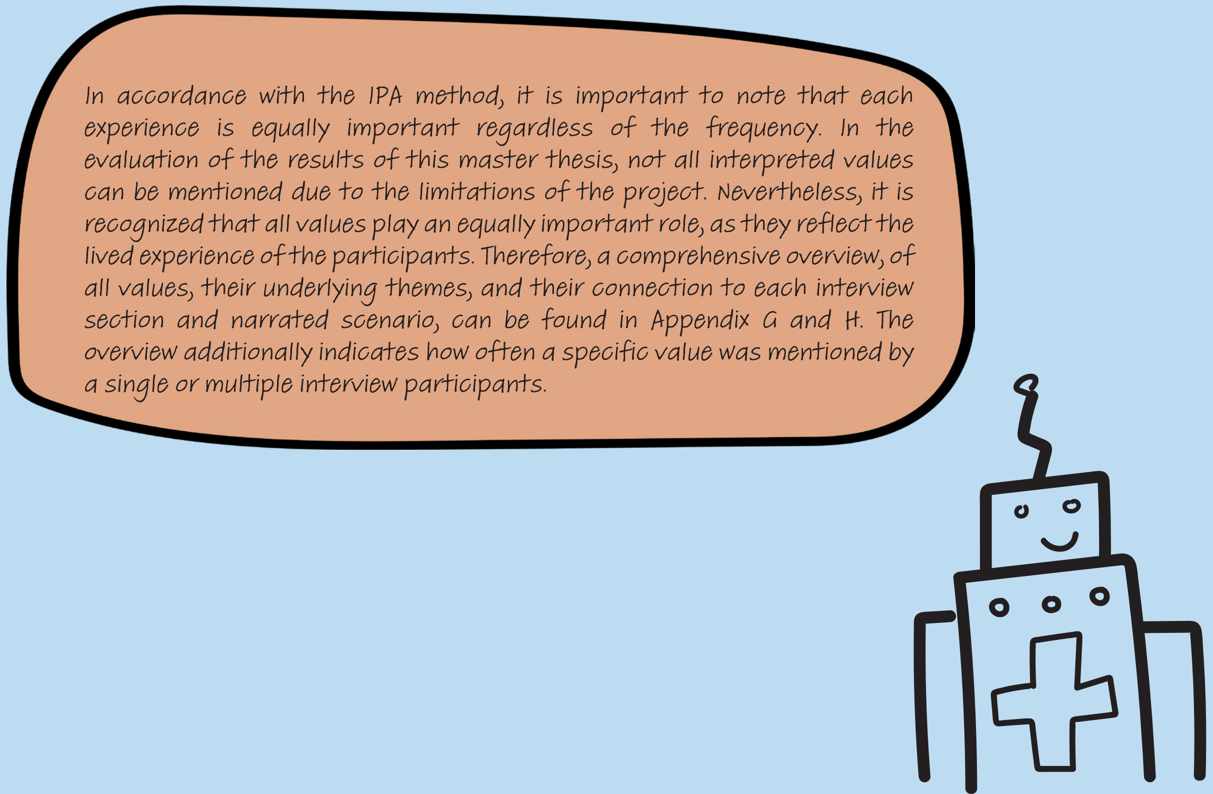
To narrow down the focus of my research, I wanted to understand the context in which a DT in healthcare might have the highest impact on the individual. I organized a brainstorming session with four participants and I found that most participants imagined that a DT could have the highest consequences or pose a potential risk for themselves in the context of “diagnosis”. Therefore, **this research will focus on the context of diagnosis as the lived experience of the participants. This specification towards one context will help to get an in-depth understanding of the experiences and enable more concrete insights.**

4.2. Key findings from the interviews

I made it to the core of my thesis to uncover the values embedded in the experiences of user in the context of diagnosis. Therefore, **I conducted eight in-depth interviews with the aim to derive at important values that could define a meaningful DT.** The analysis of the findings is chronologically structure, reflecting the interview process starting from past to anticipated future experience without and finally with a DT. **Building up on the hypothesis that meaningfulness of a DT for the user changes with age, the interview participants were specifically chosen to fit two age groups.** To ensure that the values do not lose their context but rather remain to be understood in their multifaceted nature, the extracted values are accompanied by quotes from the interviews.

It should be noted that even though I mostly present the values in isolation, most of them may be interconnected and closely related to other values.

It has to be acknowledged, that although the interview guide was structured in five sections (*Past experience of diagnosis, Present experience of diagnosis, Future of Diagnosis, Future of healthcare with DT, Future of diagnosis with DT*), the *present* and *past* often built up on the same shared experience, whereas the past provided richer descriptions. This allowed me to focus on the section *past*.



In accordance with the IPA method, it is important to note that each experience is equally important regardless of the frequency. In the evaluation of the results of this master thesis, not all interpreted values can be mentioned due to the limitations of the project. Nevertheless, it is recognized that all values play an equally important role, as they reflect the lived experience of the participants. Therefore, a comprehensive overview, of all values, their underlying themes, and their connection to each interview section and narrated scenario, can be found in Appendix G and H. The overview additionally indicates how often a specific value was mentioned by a single or multiple interview participants.

Past experience of diagnosis of younger interviewees

Starting with the first part of the interview with the young participants, "*trust*" was mentioned seven times in various forms, whereas it was mentioned five times in a negative context and only two times in a positive context (Figure 12). One example was a lack of trust in the validity of the diagnosis, for which several reasons were given, such as the feeling of not having been sufficiently examined by the doctor, or the participant's own feeling of the body, which was in conflict with the diagnosis:

> *"Usually, usual feelings of my body in this case it was my breathing and kind of my asthma. So, my constriction, I was feeling a bit more constricted. And he (the doctor) was like: "ah, it seems like you have nothing.". So, I was confused." (PY3)*

However, trust can also be expressed in *trust* in the doctor, in the feeling of not being sufficiently informed, or in the feeling of seeing bad intentions in the doctor's decisions. Therefore, *trust* is also closely related to *transparency*. Nevertheless, there remains the distinction about how the participant reported the experience.
While some had a notion of *trust* in terms of missing transparency, some were solely experiencing the exclusion without it leading to a reduced *trust* in the doctor's approach.

Besides trust, the interviews with the young participants also reflected a *lack of empathy* by the doctor. Thereby, *empathy* is referred to as the way the participants perceived the doctor's *empathy* during the diagnosis:

> *"Even though this doctor isn't really good at emphasizing or yeah, to feel with you. [...]". And a lack of empathy, for example, in the communication of the diagnosis." (PY1)*

> *"And he could have also called, since the topic was really sensitive. And the letter just felt really insensitive.". (PY4)*

Another negatively associated aspect in the diagnosis is *security*. *Security* was reported in four scenarios that illuminate different facets of *security* or *insecurity*. One of the ways in which the feeling of *security* was affected in the participants' narratives was that there was a feeling of not having been involved enough in the process of diagnosis, thus, not knowing enough about the consequences for themselves:

> *"[...] I think I also wished for more knowledge around the diagnosis. I think if I would have more knowledge in the moment about the diagnosis they gave me, I would have felt better because I then would know so much more about the consequences." (PY1)*

Furthermore, I noted also positive experiences mentioned by the interviewees in the context of past diagnoses. One of the positive aspects in the participants' narratives is the *enjoyment* about the results of the diagnosis. This joy is based, for example, on the fact that an accurate diagnosis could be found and that this is accompanied by the selection of treatment options, i.e., the prospect for improvement:

> *"I think it was a relief, because then I could get pain killers. And I yeah, I did know that I could take something that would make me feel better." (PY4)*

Enjoyment was also expressed in the fact that a diagnosis gave positive reinforcement of one's own state of health:

> *"Oh, so when I had the results. Ahh that was nice because I knew I was healthy. I was like, hey, go on my body. Because sometimes, yeah, you have no idea if you're healthy." (PY4)*

Furthermore, it seemed as if some of the participants resigned themselves to their *fate* and accepted that no concrete statement or diagnosis could be made at the moment:

> *" [...] well you know this is a topic that is worrying me since a long time. So, there is nothing to do about it. It will stay like this. I will just see at some point in the future if something is going to happen." (PY1)*

Control and *support* resonated both positively and negatively in the experiences shared. Moreover, the negative experiences of *control* were mostly based on *control* over one's own body. For example, one participant reported:

> *"sometimes we feel something and then you don't know if that's normal, because you don't have a reference." (PY4)*

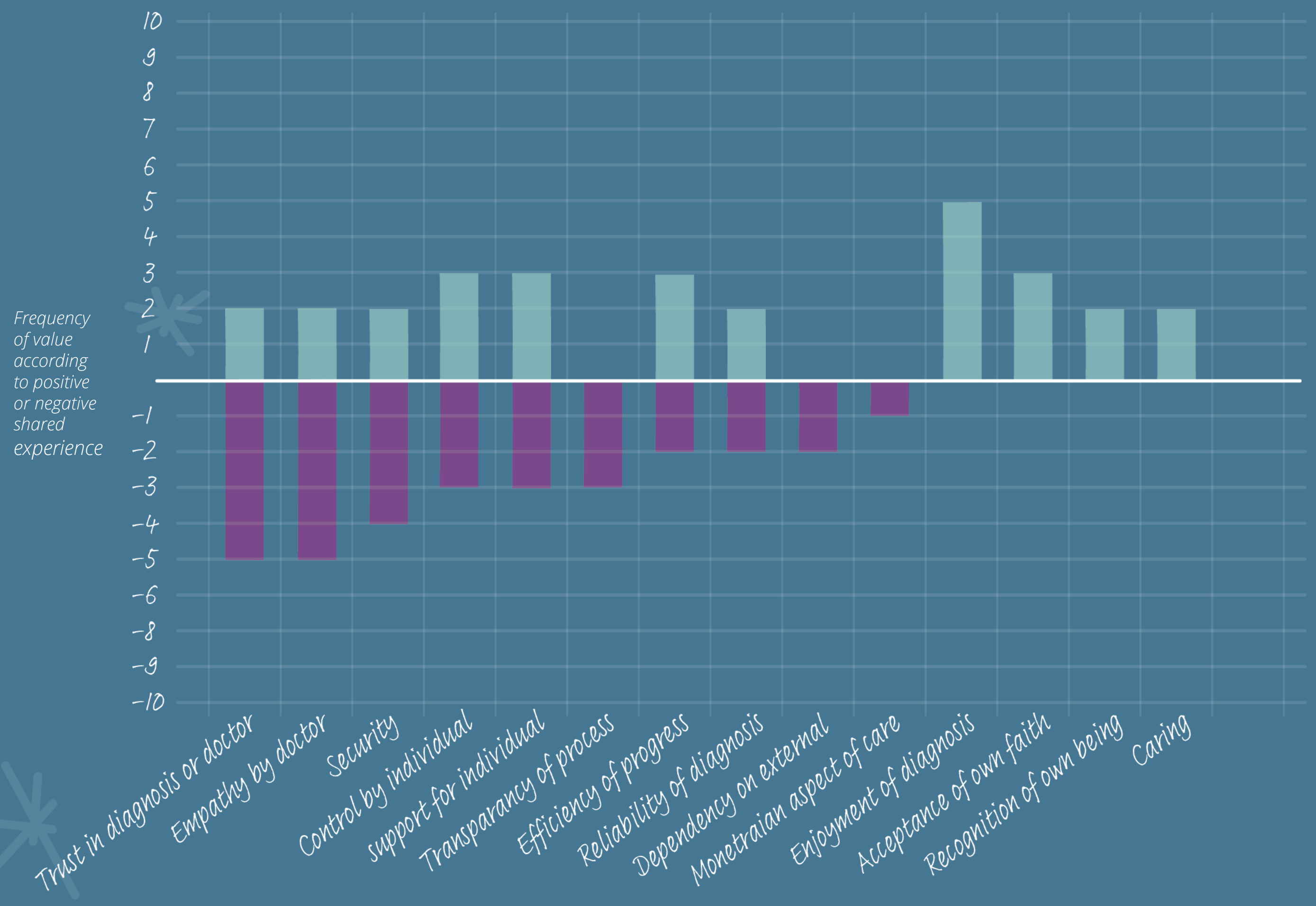


Figure 12 *Values embedded in the past experience of diagnosis by the young participant group. Values mentioned with a positive connotation of the shared experience can be seen in green-blue, values embedded in a negative experience are shown in red.*

Future of diagnosis anticipated by young interviewees

After talking about past and present experiences as well as negative and positive things, the participants were asked to think about how they believed the diagnostic process could change in the future. Overall, the young interviewees mentioned positive aspects 32 times and only two times negative ones (Figure 13). One positive aspect that appeared in various scenarios, but was only represented by two interview participants, was *effectiveness*. For example, one of the participants could imagine that:

> " […] at least with artificial intelligence, you can train, can train a model to recognize certain things. And if the model is able to recognize certain things and certain diagnosis or results, or if it can say with a certain small error margin, that, it could be this, this or this. And maybe then AI can help. Especially when they, they can think a lot quicker and a lot more without needing rest than a normal doctor." (PY2)

This is interesting as an increase of *effectiveness* can be seen as one advantage a DT could bring. The constant monitoring of the individual's parameters would allow a DT to draw faster conclusions on possible diagnosis. Furthermore, the option to test treatments virtually could allow a DT to increase the efficiency not only time wise but also in terms of *effectiveness* in relation to the time. The two other participants did not discuss increase of effectiveness through technologies, but instead focused on *personalization*. They imagined that *personalized* visualization could take place:

> "You can decide, but I think something nice would be an overview like of your body from outside. We need something good like this. These kind of like a body like DaVinci and the man with the open legs, open arms and stuff. I think a body like this, like that one and it itself and you can see it is yourself." (PY3)

This is in line with the way a DT is often characterized. As I explained in the introduction of a DT in healthcare, a DT can serve to visualize the body functions of the individual. This is also consistent with the way how many companies depict the visualization of the virtual part of a DT (see Figures 5 and 6). From a phenomenological perspective, these visualizations focus on displaying the living body of the individual. It is important that this visualization might not only come with benefits, but also lead to an objectification of the own body. I will discuss this aspect in a later stage of this section. Another value that was shared negatively by two participants was (data) security; in more detail, the *insecurity* of using an App for future healthcare inquiries: *"[…] but I wouldn't trust an App, that would feel like self-made […]" (PY1)*. Another participant shared the worry that the point of care could move more into the one's own home in the future and derived to an *invasion of privacy:*

> "And now I think it would be kind of weird that the doctor standing here in my room. So, if he can also see my room? No, that is too personal. But you can only see me then yeah, why not?" (PY4)

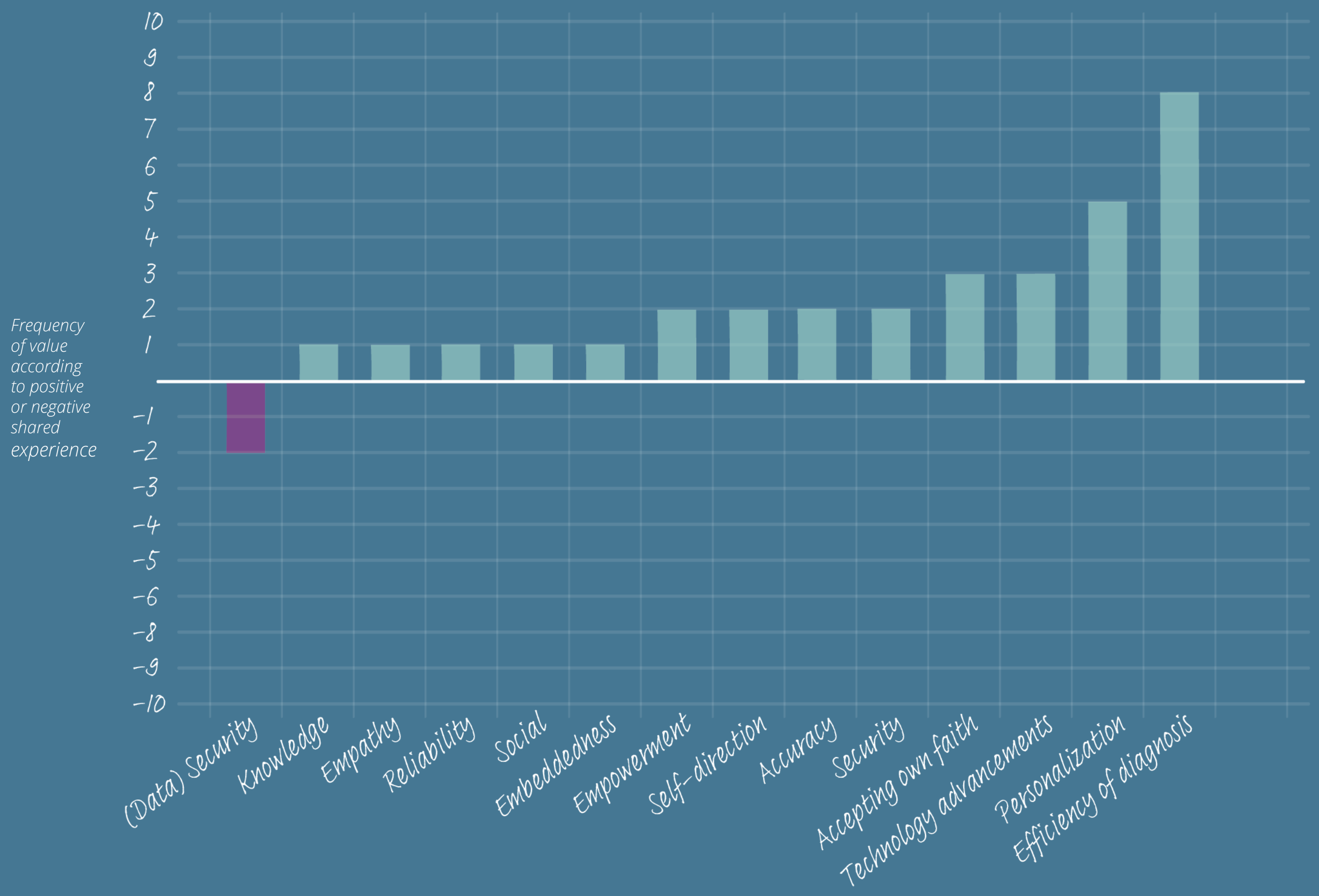
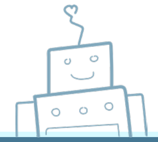


Figure 13 *Values embedded in the expected future experience of diagnosis by the young participant group. Values mentioned with a positive connotation of the shared experience can be seen in green-blue, values embedded in a negative experience are shown in red.*



Future of healthcare with a DT anticipated by young interviewees

After I have introduced the concept of the technology of a DT, participants were asked to anticipate the effect of a DT and what it could mean in the context of healthcare in general (Figure 14). All interviewees shared the expectation that a DT would enable them to get to know their own bodies better. This was expressed by the participants in different ways. For example, one participant considered a DT as an emotional diary that can stimulate the *connection between body and mind* a DT in which "*you can put inside a lot of feelings and things that you have on your own*" *(PY3)*. Another participant stated that the DT could be something you could use as a:

"[...] learning tool for schools to get a more understanding of, because now you have like only one model. And it's like the general way of how it is. But that's not true. Because my body looks different than your body." (PY4).

Additionally, one participant mentioned that:

" it could help smokers for example to confront them with "okay, so if you don`t change your behaviors you will get cancer". Thereby, it would support people to see causes of their behavior on their body and get to know it better." (PY1).

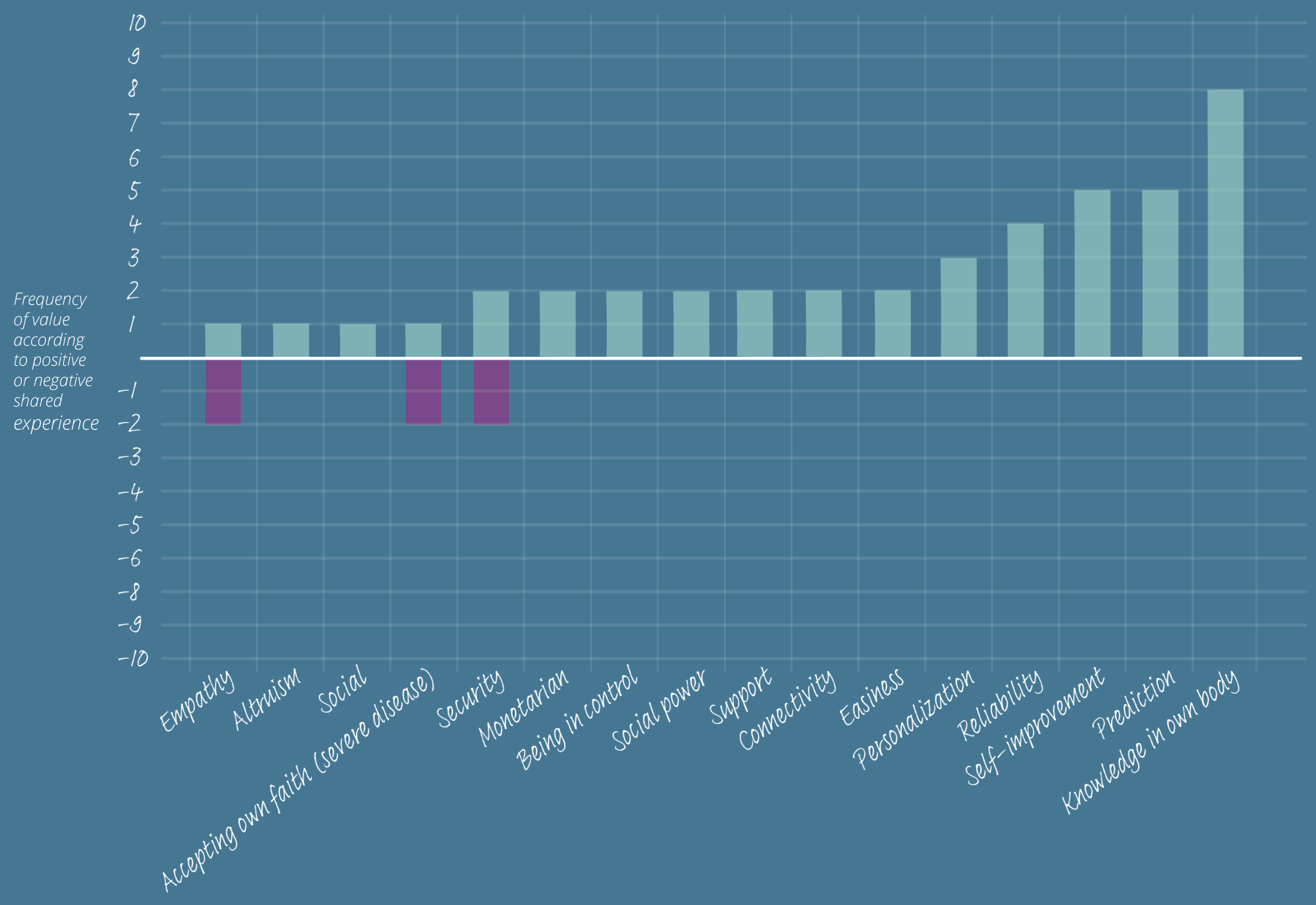


Figure 14 *Values embedded in the anticipated future experience with a DT in healthcare by the young participant group. Values mentioned with a positive connotation of the shared experience can be seen in green-blue, values embedded in a negative experience are shown in red.*

Future of experienced diagnosis with a DT anticipated by young interviewees

In the final step, I asked the participants about the influence a DT might have on the experience of the diagnosis (Figure 15). In the expected experiences with a DT in the diagnosis, one interviewee in particular was especially concerned about the *influence of physical data on emotions* and mental feelings as well as the other way around:

"So, I'm struggling with my health these days, it comes from my asthma, and then something comes from my stomach, maybe the food, and that's really annoying. Because when I'm not well it's my stomach and so I don't drink coffee and when I'm not well I'm not productive. I'm not positive, I'm not active, and that really stresses me out. I want to be active, I want to do something, and when I don't feel good in my body, it affects my psyche, and that drags me down. So, I think that's something I should have known before, more about myself, how to take care and what not to do." (PY3)

This is interesting because it could reflect the focus of traditional medicine that is often rather relying on capturing biological data that is observed from an objective point and does not take into account the *influence of emotions* on these. Thereby, this shows, that there is potential for a DT to make the connection between emotions and the captured data to allow for a holistic view. Another participant strongly focused on the aspect of *self-directedness* and having the knowledge to make a decision for one-self.

"I would like to explain the Digital Twin to me what to do, or what I can expect. Otherwise, I would call a doctor. Yeah, I would not be comfortable watching if the disease will happen. So, the digital twin also has to tell me what I can do, and so I can be informed about this." (PY4)

I think this is important to note, because it correlates with something other participants share. Some interviewees mentioned during the interviews that in the past they did not feel well informed about the consequences of a diagnosis or the actions they could take. Furthermore, two participants mentioned that they are no medical experts themselves, so they were not able to judge the situation or decide for how to proceed. What they explained they would need is more information to understand the diagnosis. I argue that for the DT sharing a plain diagnosis does not sufficiently inform the individual. Rather a DT could communicate a diagnosis with additional knowledge about it and translate it in direct actions for the individual. This way it would support the individual in gaining the fitting knowledge to make an informed decision.

As I mentioned earlier the constant confrontation with the objectiveness of the body through a DT in healthcare might introduce some problems. These concerns were also described by one participant that their own body image could be disturbed by the potential constant information from DT.

"[...] But yeah, on the other hand, I don't know if you always want to check, because when you feel good, you just listen to your own body and you don't always have to check. And you don't always have to control, because then you stop listening to your own body. And that's important too." (PY4)

This is interesting, because it can on the one hand be referred back to what is called an imbalance between *Körper* and *Leib* in literature. The constant confrontation with the own living body, the Körper, can be seen as a shift of the body towards an object of attention. Thereby, constant attention is drawn on the objective side of the body, with consequently pulls it out of its mostly transparent state. This is in line with literature, where this objectification of the body triggered through technology can be seen as an introducing an imbalance (de Boer, 2020). Referring back to the definition of health, it could be argued that this imbalance could be classified as a state of unhealthiness as the misalignment of lived body and information about the living body might create what Svenaeus called a feeling of alienation (2001). On the other hand, it is also in line with the critical stand of P4 systems medicine taking by Vogt et al. (2016). There they stated that the individual might lose connection to the own body feeling and rely on the consultation of a technological representation to determine if one is and should feel healthy. However, it was also positively evaluated by two participants that a DT could help them to better understand the results possibly conveyed by the physician through, for example, *visualization* and to be better informed.

"But yes, make it visible in some way. Because if you have a lot of text, nobody will read it. Right. And you want to see the interaction that's happening in your body" (PY4)

"(How would the DT improve the diagnosis) you understand it better, so maybe you'll be more confident that you have a broader view of what's going on. And also, you see how, it makes it really tangible, not just on your own body, but on, ahh something else that you can see through your body." (PY3)

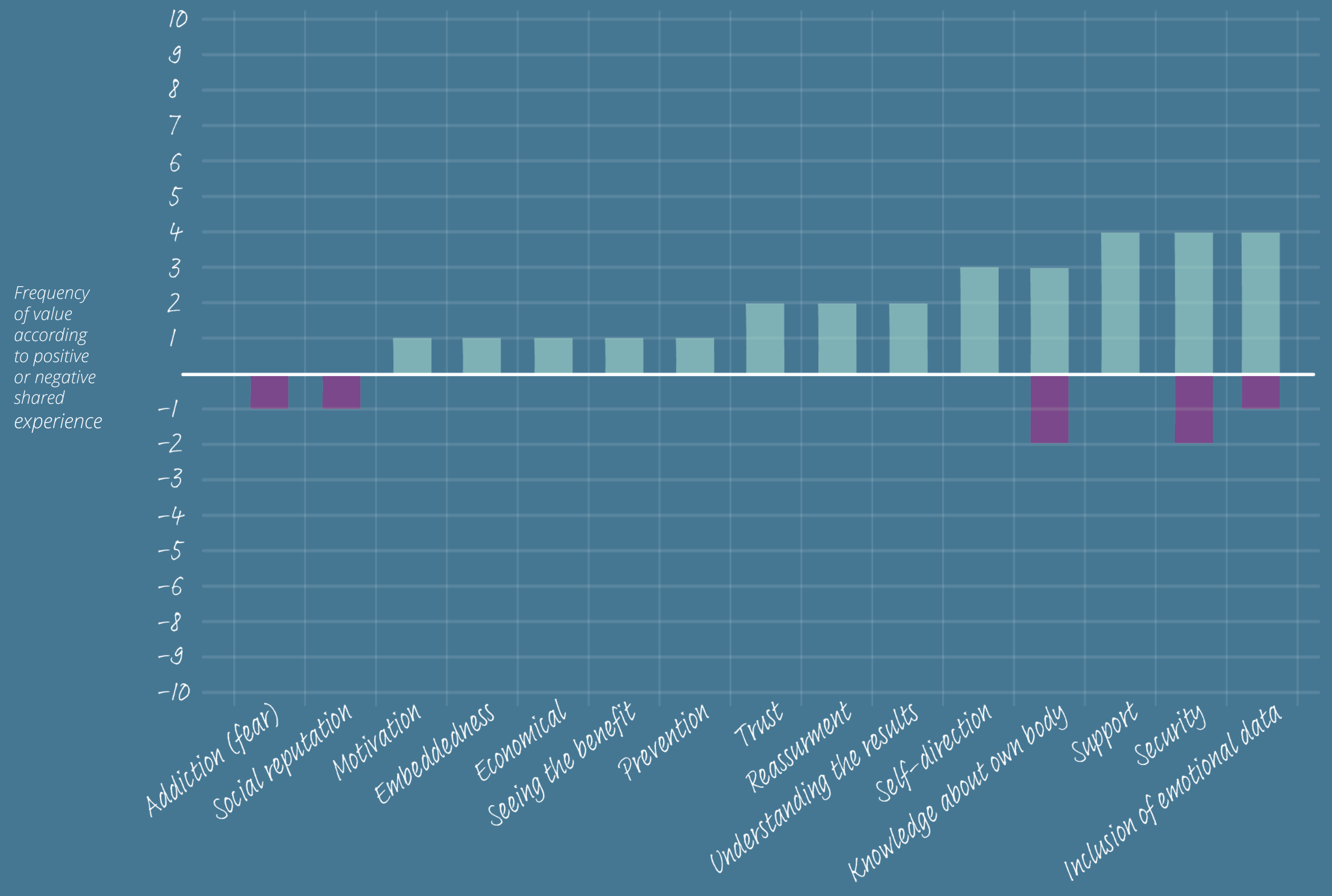


Figure 15 *Values embedded in the expected future experience of diagnosis with a DT by the young participant group. Values mentioned with a positive connotation of the shared experience can be seen in green-blue, values embedded in a negative experience are shown in red.*

Key Insights

Key Insights – Young participant group

The overall results from the interviews I conducted with the young participant group demonstrate two key points.

First it showed that the participants were mostly focused on the aspect of self-improvement and getting to know their own body. This finding is in line with what can be seen as the output of a DT, namely giving life-style advice in order to maintain a "healthy" individual. In line with this vision, the participants were mainly interested in having a DT as a supporter in their daily life. That might focus on self-improvement, improving competitiveness in sports or understanding one's own body. I think this is very interesting as it aligns with what can be currently expected of the output an individual can receive from a DT.

The second key point I observed from the interviews is that the young participants were in general more interested in the predictions of potential diseases through a DT in healthcare than prevention. The participants mentioned that a DT would enable them to plan their lives according to predictions from a DT about their personal future health state. This is important to highlight because the main focus of a DT would rather be on prevention based on these predictions. I argue that this can be derived by the age and life situation as well as prior experiences. One could see this as a naïve way of thinking, nonetheless less serious diseases were established or have occurred yet in a younger age. Therefore, the fear of getting seriously ill is not as high and rather replaced by the feeling of being able to adapt to any news. In general, the young participant group seemed not afraid of the rise of new technologies in the healthcare sector and rather focused on the positive benefits that might arise for themselves.

Now, we will move to the interviews with the older participant group.

Past experience of diagnosis of old interviewees

In the experiences shared by the participants, several scenarios were presented in which control seemed to be an important point of reference (Figure 16). Thereby, it was mentioned five times in a positive scenario and six times in a negative one. Control can be a very broad concept, which in its many facets unites several different experiences described. One participant was concerned that his diagnostic parameters had suddenly changed in a negative way, although neither the doctor nor the patient had suspected this:

"Of course, you have to ask yourself: what does this mean for me now? Where does it come from? Have I now done something completely wrong or is it because of my age? That it's my turn now, so to speak? Sometimes with advancing age the little aches and pains begin, that doesn't suit me at all, lapidary actually and yes, it was a pretty stupid feeling at that moment" (PO4)

In this context, the unpredictability of the change in parameters and the surprise caused by it seemed to imply a feeling of loss of control. In another case, a participant described the *control* of being able to change ones' own situation or the consequences of the diagnosis:

"And of course, there are ways in which I can say "OK, I'm going to have to walk more or change my diet or..." as long as I have the feeling that I can still actively do something. It doesn't get bad until you feel there's nothing more you can do." (PO2)

Interestingly *control* can also be seen as the ability to decide who is performing the examination, as this interviewee shared:

"And the other day I went to see a cardiologist, I had bad experiences in the past, I visited a new one, and I have to say that I am also enthusiastic about the organization of the practice and also listening, which is very important, of course, and willing to explain the details. That's also how I choose my doctors when I have to go somewhere." (PO4)

Furthermore, in the past experiences of the participants it showed that *support* from the doctor in form of clear communication of consequences for one's own behavior was of great importance:

"But in the first moment of course my head cinema runs off, that especially in the moment before Christmas "Oh now you can't even go out to eat like you want or help yourself to any other things like sweets" and for me it was always a horror scenario to have diabetes because I always like to eat sweet. But well, in the first moment it was quite a low blow and of course that pulled you down a bit." (PO4)

In this situation the participant describes the lack of knowledge of the consequences and the resulting fear about the intervention of the diagnosis in his own life. I think this is very interesting because it reflects the different positions between doctor and patient. For the patient this is a completely new situation, probably shocking to some extent. Furthermore, the consequences are unknown as most individuals to not have the medical knowledge themselves but rely on the expertise of the doctor. For the doctor this situation or diagnosis is something they are faced with it every day. Building up on that, I assume that the doctor might not always see the importance of communicating all details because it Is rather a common situation for them. Additionally, the doctor might not always be able to judge the importance of details for the participant in that situation. Another aspect during the interviews was the *enjoyment* of receiving a positive diagnosis and the associated determination of one's own body condition as healthy:

"It's not that I was expecting anything. But if you know, there is, there was a certain point in your life, something wrong with your body. Obviously, if you do these checkups, you always think it could get it could have, it could be worse, or it could be something new, or there could be different things. So, in the moment, if you...where you receive a good feedback, obviously, is like haaahhh. Nice, really good (euphoric sound)." (PO1)

The *enjoyment* of a positive diagnosis was something that I already acknowledged during the interviews with the young participant group. I think that this positive feedback can on the one hand bring a certain relieve but also motivate the individual. I assume that by getting a positive feedback on ones' own health it potentially balances the subjective feeling with the information about the objective side of the body. Thereby, it could lead to a positive feeling about ones' own health.

When I asked the participants about challenges in the current area of diagnosis, two of the participants focused on the factor of *prevention*. One participant described that nowadays the monitoring of one's body parameters only considers the maximum value but does not pay attention to the development over many years. In his experience this ultimately ended in the classification as diabetic, which could have been *prevented* considering the trend of the data:

"That's what they say when warning thresholds or continuous processes point in the direction of a value running away, because I'll soon be in treatment for a longer period of time at the age of 56 and I think that if you hadn't always looked at the maximum value, but had looked at the trend, you could have seen that before. You could have intervened before and would not have come across this value." (PY4)

I consider this to be very interesting because it reflects the traditional paradigm of curing in healthcare. Instead of *preventing*, no attention was paid to the parameters, nor their yearly increase, as they remained under the reference value for diabetics. After the value exceeded the normal reference point actions were taken to cure the diabetic disease. I think this is one of the promises a DT could deliver, through constant monitoring the focus would shift from curing to prevention.

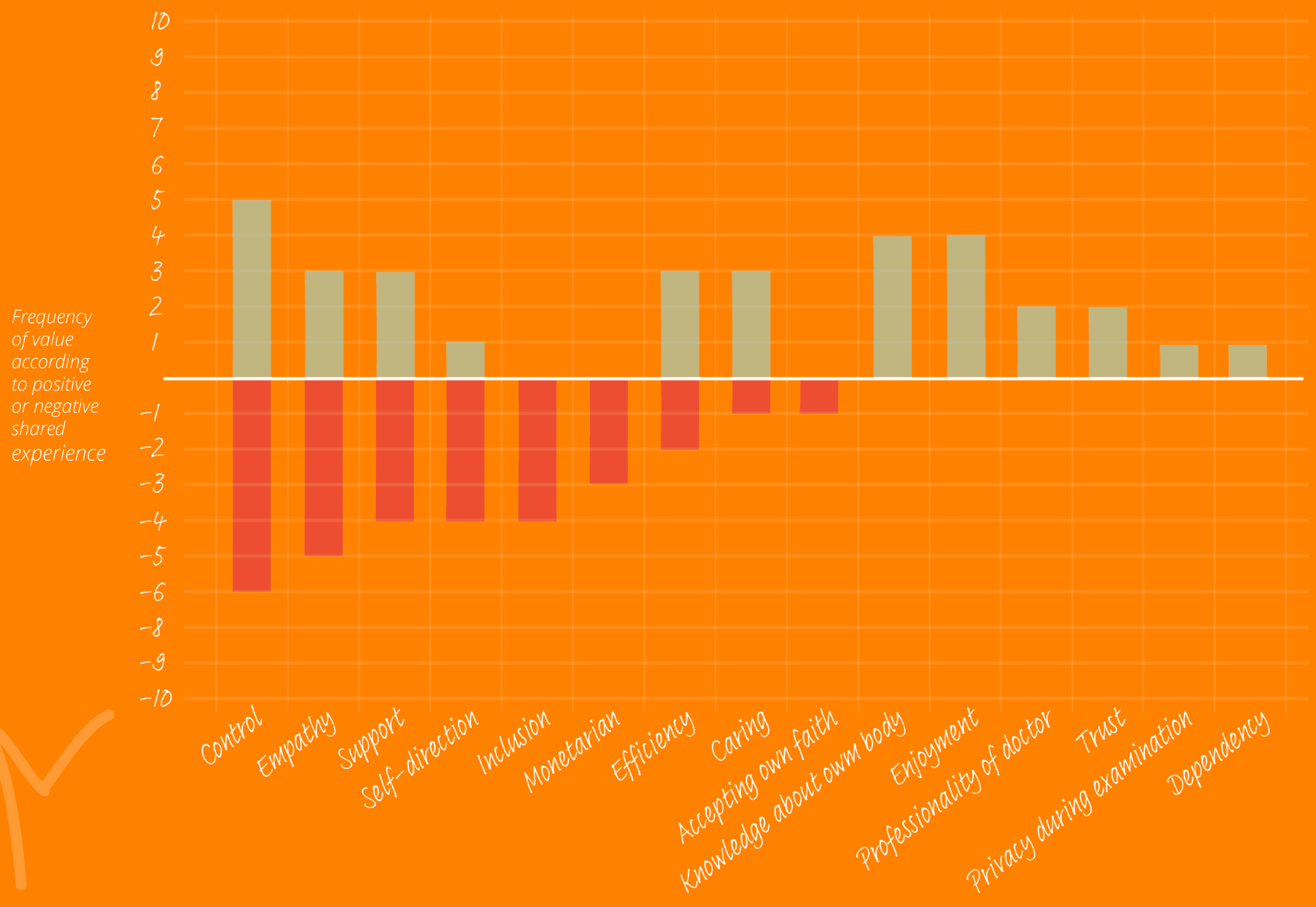


Figure 16 *Values embedded in the past experience of diagnosis by the older participant group. Values mentioned with a positive connotation of the shared experience can be seen in green-blue, values embedded in a negative experience are shown in red.*

Future of diagnosis anticipated by older interviewees

When I asked the old participants how they envisioned the future development of the healthcare sector, frequent statements reflected the assumption of personalization within the healthcare sector (Figure 17). What was interesting is, that the interviewees imagined that diagnostic devices might *move more inside the body:*

"Well, of course you can do all kinds of things, just as I am technically up to date at the moment, of course everything is possible, for example through various implants, even blood sugar with patches that transmit blood sugar values electronically and continuously, certainly everything is already excellent monitoring. The question is to what extent one would like to be equipped with sensors afterwards. Under the skin then an automatic defibrillator, blood sugar values, blood pressure measurement, oxygen content, ECG, EEG monitoring automatically and permanently, then you feel a bit like a guinea pig." (PO4)

It is noticeable that the participant lists the shift of the measurement into the body rather negatively or with distrust. I think this also reflects the critical stand the participant took towards the development of new technologies. In general, the old participants were rather critical towards novel technologies. Although they acknowledged the benefits of past developments, e.g., CT, they remained critically about the future. I think that this is not surprising, as the older participants did not grow up within the digital age and are somewhat more critical towards the consequences and pitfalls of such.
Now let us turn more to the positive aspects. The *personalization* of devices or treatment to the needs of the individual was seen as beneficial:

"In the orthopedic field, for example, more specific machines for the individual or the individual situation or certain muscles or whatever else I know, that more specific things could be developed, also in technically oriented diagnostic processes." (PO2)

Furthermore, the *accuracy* of future technologies was seen as a potential positive development

"you know because nowadays you can do a lot more technically. So, when you compare past ultrasound images with today's, it's a difference between day and night. So mhm that's one thing the technology is just incredibly advanced in that area and you can see much more accurate things and it's a general trend of the time." (PO2)

One point that coincided in many of the shared narratives of the participants was *(data) security*, e.g., one participant expressed the concern that the data could get into the hands of the big companies and that one would become a transparent person

"We already have Big Data and the image of oneself in everyday life enough in the computer for me more or less invisible - for the big companies, of course, they probably know me better than I know myself in many things... I don't know exactly whether I want it to be the same in the medical field or in the medical field." (PO4)

At the same time, *security* can also be seen in terms of misuse or in judging people, which could result in personal disadvantages for the person.

"If such data is disclosed in some profiles by mistake or cracked with criminal energy, it can have a very extreme impact on my everyday life. For example, when changing jobs: "Let's have a look, aha here the data is available. Oh, that doesn't look good, he's got sick so often or the tendencies of what I know is a typical heart attack patient at that age, we don't hire him." That is the danger. Of course, there is enough of dystrophy in literature and movies that also show something like this." (PY4)

I think neither the concern of transparency, nor the fear of misuse is something new. It is rather a concern that is posed since the early rise of digital technologies. Literature offers several dystopian scenarios that reflect the concern that technologies might turn us into transparent individuals (Huxley, 2006; Orwell, 1989).

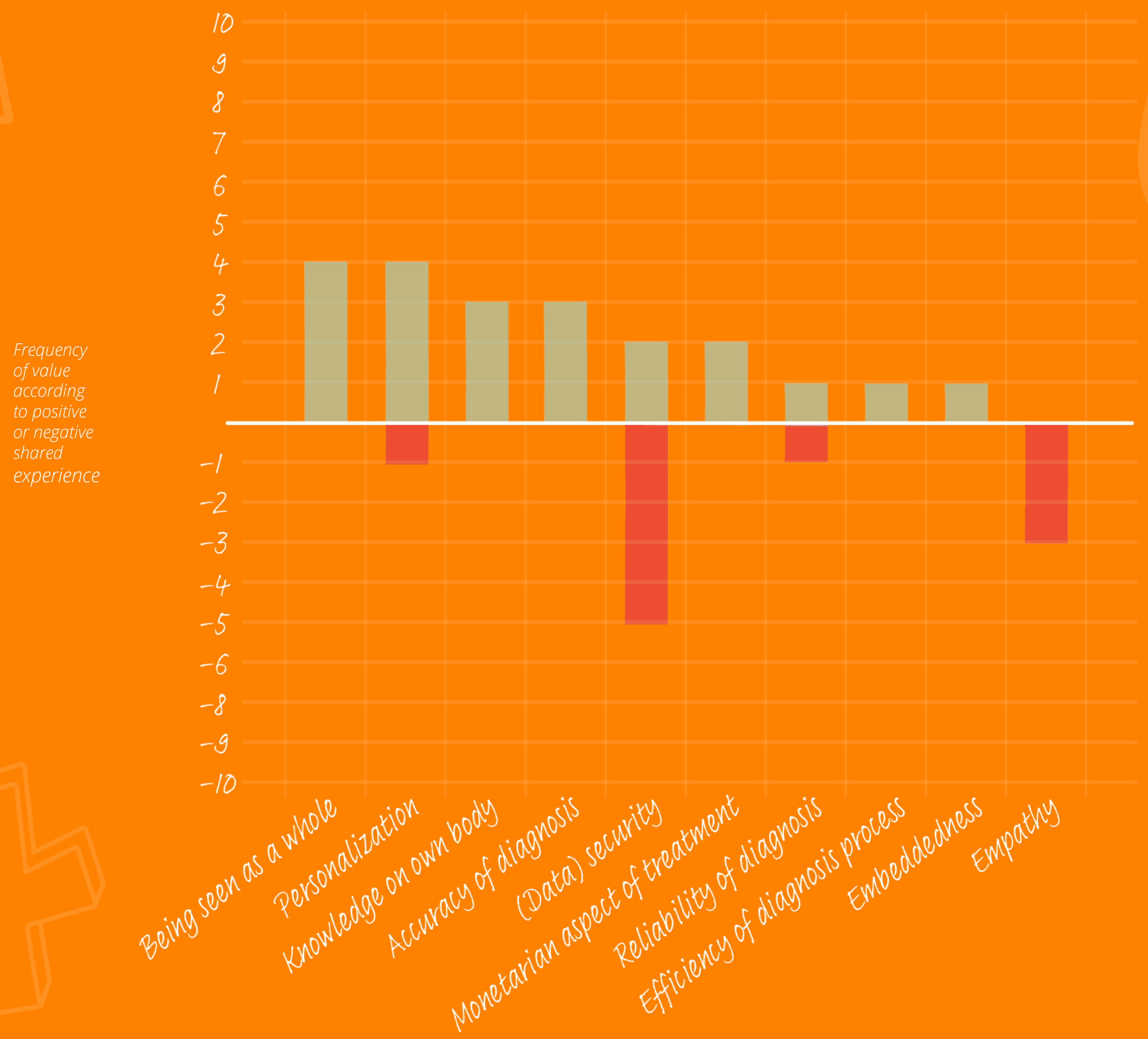


Figure 17 *Values embedded in the expected future experience of diagnosis by the older participant group. Values mentioned with a positive connotation of the shared experience can be seen in green-blue, values embedded in a negative experience are shown in red.*

Future of healthcare with a DT anticipated by older interviewees

After introducing the technology of a DT based on the foundation, I introduced in Chapter 2.1, the participants were asked to imagine the impact of the DT technology on the health care. Often and by all participants, expectations were shared that indicate an appreciation of support from a DT (Figure 18). This was expressed in the interviews, for instance, in the form of help in *optimizing one's own lifestyle*:

> *"If it's just the collected values I can't interpret them myself. If the values are interpreted for me and I understand what I can influence, or not, simple. […] If I get an interpretation for my person, if you continue to sit on the couch every day and only watch series, then it will not end well for you, but you move, then that is something different. Then I profit from it, I only have the values there, of course I can't do much with "what does that mean exactly?" (PO4)*

In this statement, it also becomes clear that the *support* for the interviewee consists not only in having values displayed, but also in having them directly translated into actions. I think this refers back to something we have seen in the findings before. By only presenting the data of one's own body to the individual no interpretation can take place. In contrast to the example of the thermometer introduced in the mediator function of technologies, the individual does not seem to be able to draw concrete consequences from this data. Thereby, I argue this is important to take into account, that the DT additionally has to take on the role of interpreting what this data means for the individual in concrete terms. This might be due to the fact that the complexity and interplay of data embedded in a DT is likely to be far to complex to be interpreted by the human oneself.

It was also interesting to hear one participant say that every diagnosis and thus *knowledge does not pass you by without leaving a trace* but could also have an influence on your own person and personality

> " I think in our life, there are many things that go on let's say when something happens to you, you change your reaction. Because of this, or you change notice reaction, you change because of what has happened. If it's an accident, if it's a sickness, if it's a love story, that finishes I think in everything, what happens in our lives, something inside of us changes." (PO1)

I think this is very interesting to note, because a DT would probably extent the possibilities of predicting the risks for a disease. Furthermore, I argue that the frequency in which a person is confronted with a diagnosis might increase. Thereby, coming back to the quote from the interview, the frequent confrontation with a diagnosis about the objective body might change the subjective feeling of the body creating a state unbalance. In my opinion, the constant possibility of getting a diagnosis, might change the emotional state of the person into a state of constant fear. Furthermore, it could lead to the feeling of alienation of the objective body. Thereby, it could potentially introduce a feeling of illness.

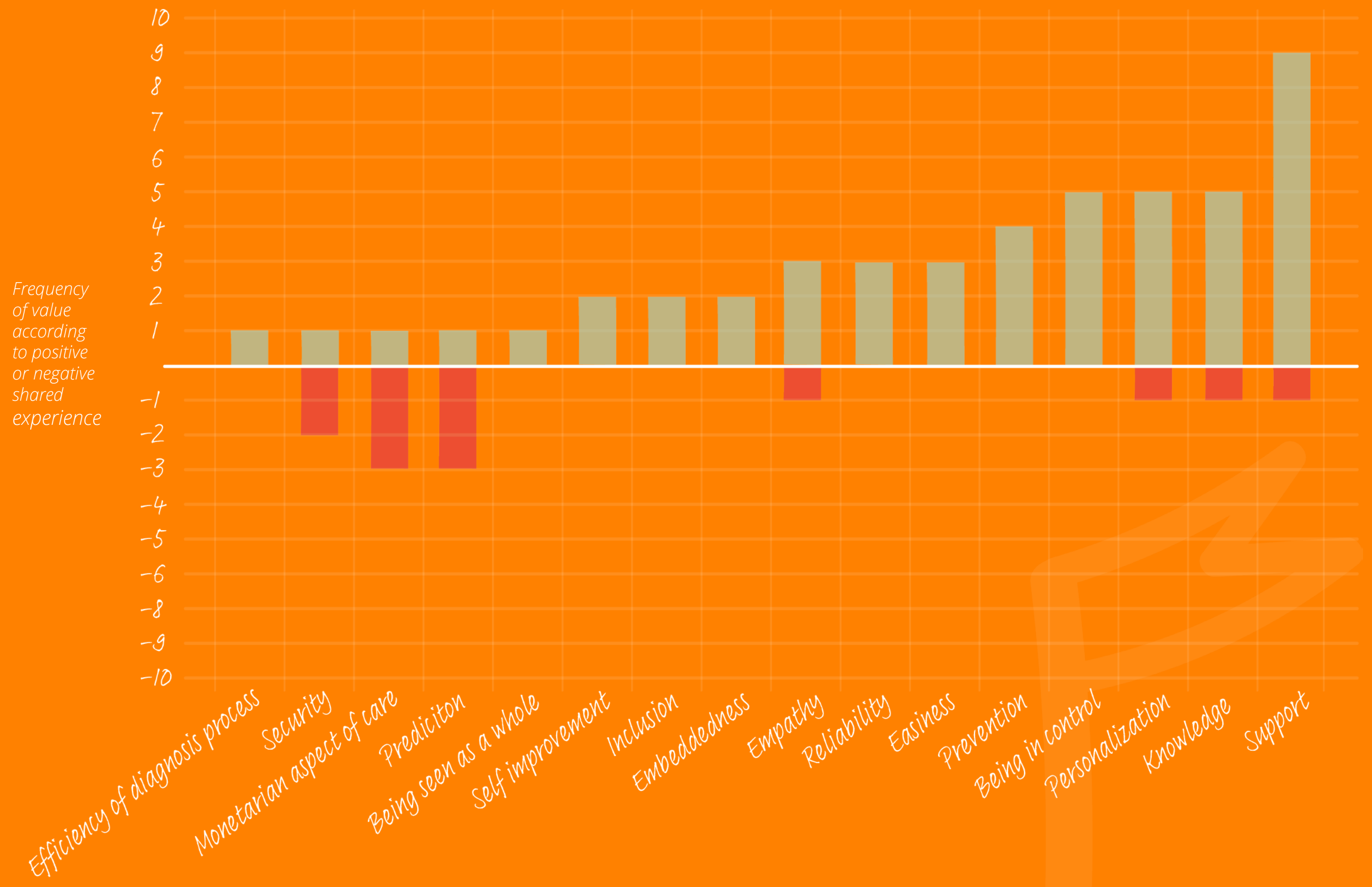


Figure 18 *Values embedded in the anticipated future experience with a DT by the older participant group. Values mentioned with a positive connotation of the shared experience can be seen in green-blue, values embedded in a negative experience are shown in red.*

Future of experienced diagnosis with a DT anticipated by older interviewees

In the last step I asked the old participants to concretely imagine how a DT might change he diagnosis (Figure 19). What become clear for me was that the old participants were really interested in the possibility of *prevention* a DT might offer:

"Or genetic disposition to cancer, you can only hope that you will remain free of symptoms for a long time, that there might be a hope for a cure. But if you can influence it yourself, it makes sense to be pushed in that direction at a young age so that you don't get lost in your habits." (PO4)

This is interesting because it relates with the finding that the interviewees were lacking the *prevention* in their past experiences. Thereby, I want to highlight that they see potential of a DT to fulfill this, which is in line with the potential shift from curing to *prevention* a DT could support. Another point a participant made was that humans get used to certain sensations posed by a potential illness that might evolve. Thereby, it could happen that a disease is not discovered.

"And often you have illnesses that come on gradually and which you actually get used to and which you no longer notice and where the turning point has perhaps already been missed." (PO4)

This is certainly something which I think the constant monitoring of a DT could support. I think it is interesting that some of the interviewees shared the fear of missing an evolving disease because they did not recognize a change in their bodies or because they did not pay attention to it. As one of the interviewees recognized knowing and thinking are two different

"Under certain circumstances, of course. Knowing and thinking are two different things. If he knows because he has direct access to ECG or imaging, because he has direct access to it, which I can't do here, maybe I only have symptoms, but they could have many causes, then you have to see." (PO3)

In that sense I think the participant expects some kind of reassurance and security through a DT. Although I think this might at first sound as a positive addition, I also think this could support the development of constant awareness to one's own objective body and thereby introducing a feeling of a steady imbalance and fear of a potential disease. Another aspect I found during the interview was the aspect of *support* from a DT during the diagnosis from a doctor. It seemed to me that is especially the case if the doctor is not taking the time to effectively inform the patient (which as discussed before might because the doctor takes a rather objective stand on the diagnosis and is sometimes stuck in routines).

"if I don't trust a doctor as much as I do now, because he might be asshole or tell a lot of nonsense or be simply unpleasant, then the twin might help me feel safer. But only under the condition that I should be insecure about whatever, then I would feel safer. I could imagine it like that." (PO2)

I think in this scenario a DT would offer the person the possibility to independent from the doctor gain the information to understand the diagnosis and the consequences more in detail. I think in that sense a DT could serve as an external trustworthy source for information. In that sense I think a DT could replace scheduling a second appointment with another doctor in order to get a second opinion.

The last aspect that caught my interest was the differences in the expectation of empathy during the diagnosis process. For one of the participants, it was important to have a personal contact when receiving a diagnosis that has a high impact on one's life.

"Yeah, it always depends on what it is, of course, certain things you want to know. And you change the offers, I can also change my life, if somebody tells me if there's any information tells me "Okay, if you don't change certain habits or certain things in your life, you can die the next month, okay?" Of course, you change, or you try to find a different way or another solution or whatever to change. And of course, you want to have this information. But that's maybe for me the most important reason why I would need a person where I can talk to and which can understand because I think I would not feel understood by a digital twin". (PO1)

In contrast to that another participant implied that his doctor is not *empathic* when sharing the diagnosis, so why should a DT be. Additionally, there seems to be a difference between a more emotional point of view on the diagnosis and a rather rational perception.

"Because I don't think it is important who communicated the diagnosis, whether it is an MRI result, whether it is the doctor or the digital twins, they do the same thing and communicate a diagnosis to me. How I react to this diagnosis or how I deal with it is my own business, unless of course it is transmitted completely differently." (PO3)

In my opinion this is an interesting observation, because for now it remained unclear to me from the company visions how a DT would communicate with the person. The differences in perception between the art of receiving a diagnosis as well as the different levels of *empathy* needed in the diagnosis, imply that the form and tone of communication could take different shades for a DT. These shades in my opinion would differ depending on the severity of the diagnosis as well as the personality of the receiver.

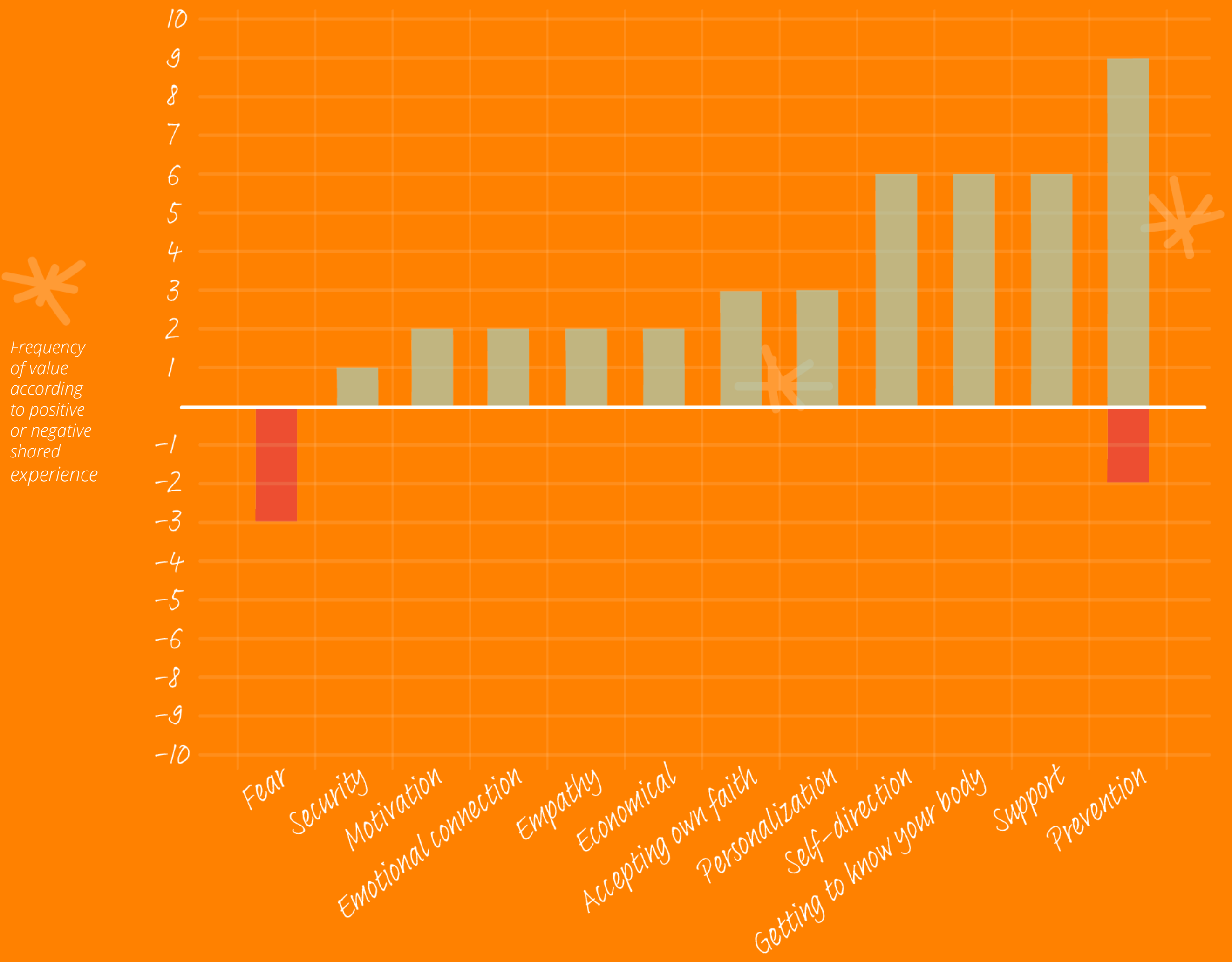


Figure 19 *Values embedded in the expected future experience of diagnosis with a DT by the older participant group. Values mentioned with a positive connotation of the shared experience can be seen in green-blue, values embedded in a negative experience are shown in red.*

Key Insights

Key Insights – Old participant group

Concluding from the second part of the interview, it became clear to me that the older participants where more critical on the impact of technologies.

I think this might be due to the fact that they did not grow up to the same extend as the younger group with these digital technologies. As consequence, slightly little understanding for current and future technologies may already impair their judgment on potential technological impact. Also in this interview group, I could draw two main conclusions.

When the old participants thought about a potential use of a DT they tend to focus on their end of life, e.g., the fear to develop dementia or the own death. Certainly an interesting aspect which was never envisioned by previous studies or literature. Furthermore, this is interesting as the participants could not provide an example for a situation in the past where they would have wished to have access to a DT. I think the focus on the end of life reflects the awareness of an increasing risk for health problems and the feeling of vulnerability of the own body, here a DT might help out.

The second point was that the old participant group had a specific focus on prevention. They mentioned that a DT could potentially allow for better prevention of diseases than pure treatment. Some interviewees wished to have more knowledge on specific diseases in order to change certain behaviors. In addition, the interview partners could have imagined that long-term monitoring allows for early detection and prevention. This is clearly in line with the vision of benefits a DT is thought to deliver. As I already mentioned before, one of the opportunities a DT might bring is to shift the underlying paradigm of healthcare from curing towards prevention. Thereby, it allows to analyze parameters according to their interrelation but also according to changes in relation to time.

4.3. Reflection on findings

Now that I have analyzed the findings of the young and the old interview groups, I want to reflect on the differences and potential consequences on what it means for a DT in healthcare. Thereby, I am especially focusing on two key topics from the findings I derived from the interviews. Firstly, I want to discuss the hypothesis that a meaningful DT would be different for younger people than for older. Secondly, I want to reflect on the intended design of a DT in healthcare and its influence on the experience of people.

Starting with the first, the hypothesis was indeed confirmed. **The results showed that older participants evaluated positively the possibility for prevention, support and self-direction. The younger participants, whereas, were more curious about their body and predictions. Most interestingly, young participants seemed to distinguish** "*prediction*" **from the context of** "*prevention*"; rather, it tended to focus on constant optimization and improvement of oneself. This could be due to the fact that young people are less likely to be affected by long-term and severe, possibly even chronic diseases, as there is a correlation between increase of age and the development of such (Niccoli, 2012). **Because of the young people's low level of confrontation with the vulnerability of their own bodies, I argue that the young participants are more likely to have a sense of immortality, unlike the older group.** This potential difference caused by the age and life context differences was also reflected upon by one of the participants:

> *"Yes, that's right I can imagine that (talking about differences between young and older participants regarding the use of a DT). At that point you are still immortal. [...] You can see with my son; we have a lot of overlapping interests. He really thinks he's still immortal, so I always get him on the ground of facts as a quasi-twin (refers to DT), "well better think about it". So, I can see here, there really is a generational difference, one changes one's view quite clearly (in a later stage of life)."*

I think the finding of the difference in perceived vulnerability of the body between young and old is very relevant because it also connects to the phenomenological insights about the body. If we think back to the differentiation between objective and subjective body (*Körper* and *Leib*), it might suggest that for the younger participants their feeling of low vulnerability is based on the experience of the objective side of the body as rather transparent. Through the low confrontation with potential "dysfunctions" of the body, they did not experience the objective side as much. I think that with the age of the person the experience of the body from an objective side is more prominent. The older participant probably experienced a more severe disease already and were confronted with their objective body moving out of its transparent stage. That is also reflected in the results as "prevention" was an important issue for the old participants while it was not seen as an elemental part for the young participants. I think this builds up in my argumentation of the more transparent appearance of the objective body within the young participants group. In my opinion, this is a very interesting observation as it could be argued that a DT with a sole focus on prevention may not be experienced to the same degree as meaningful by younger users. In comparison with the old participant group, it could mean that the paradigm of prevention by a DT increases in its meaningfulness for the user with age. Moving on to another point, I found for the older group of participants that support was indicated to be important, as well as self-determination, which in parts was also indicated as missing in the experiences of the past. In general, younger people are assumed to be stronger connected to the internet than older people, meaning that they research more but also reflect more critical on information and topics that concern them. It could therefore be that young people do not feel self-determination to be so elementary, since they already have the opportunity to acquire specific knowledge such that may allow self-diagnosis. Older people, whereas, may be more dependent on real-world expertise and opinions of physicians as the preferred opportunity for self-information. In addition, it should be noted that older people have greater problems reflecting on and classifying relevant posts, as well as the truthfulness of information from the internet (Brashier & Schacter, 2020). Therefore, it may actually be more difficult for older people to obtain validated knowledge through internet research. In conclusion, a DT seems to fill this gap in the expected experience of the participants and provide them with more assistance as well as self-determination through accurate knowledge transfer. The need of people to inform themselves and the need for information resources can also be confirmed by the increasing interest in platforms introduced at the beginning of the report which seem to reflect the trend of empowerment of patients to make self-informed decisions. **A DT could therefore provide the opportunity for empowerment of the older participants through personalized and validated health information.** While, on the one hand, young participants reported predictions exclusively in a positive context, the older group reported prediction rather with a negative connotation although prevention received a positive connotation. The older participants associated prediction more with negative examples, such as the prediction of one's own death or an illness that can no longer be prevented; concerns about the limitation of one's own health played a major role. The young participants, on the other hand, saw in the prediction mainly the possibility of life planning and the confrontation with possible events such as infertility, which seem to have a considerable influence on life planning. In this context, the prediction was not seen as negative, but rather as concretizing unavoidable things that are partly uncertain or unknown at the moment. Thus, a DT would give younger people the opportunity to make and plan life decisions through predictions and also comes with acceptance of their own circumstances. For older people, however, the focus is more on prevention rather than prediction. Old participants were more concerned with preventing possible diseases, while knowing about diseases that are not preventable was described as undesirable. This could be in parts due to the observation I mentioned before that younger people do not feel their own vulnerability as much. Therefore, it seems possible that young people feel they can come to terms with any diagnosis and change life plans, while the older participants were more inclined to adapt in consideration of the consequences, as one participant explained:

> *"Because there are some things that I know. I'm 55 years old and I know there are some things that changed and will change even more. And some of them I accept; even I would accept from a Digital Twin but some of them I will not accept. I'm not ready to change anything in my life only because of a Digital Twin. And I wouldn't even change it if I have direct contact (to a doctor). [...] There are some things that will change when you get older and I think there's something, so I think there are some things when being a young person you get a certain diagnosis. And you decide, okay, it's worse to change my life for this. I think if you get older, you decide okay, I can live with this risk."*

A DT also appears to change the possibility of practices and morals. Thus, in the participants' narration, death seemed to be something very daunting and for the young participants something very far from their reality. However, **in several interviews with the old participant group, the option came up that the DT could act as a last support in form of a last will and testament, thus opening up an option that is, to my knowledge, not being currently practiced or considered.** The technology could make it possible to make provisions for one's own death while normalizing the acceptance of the possibility of one's own death. Furthermore, this form of a DT could serve as a uniform and digital overview of wishes and dispositions that should take place after death. This could, as I also argued before, lead to a normalization of the topic and a change in current practices. This change of morality and values over time is not just limited to the topic of death. It can also be extended to the way a DT and its introduction might alter what we perceive as healthy and how we behave to be healthy.

Now moving to the second key point, I perceived from the interviews a difference in the potential use and the perceived meaningfulness of a DT. As the analysis of different company visions of a DT showed, the representation was mainly limited to a static model confronting the individual with its data and consequently giving lifestyle advices on that basis. Based on my insights, however, **I argue that in order to remain meaningful for the user, hereby taking a life-course approach, the form of a DT should change according to multiple underlying factors, such as age, life experiences, preferences, personality and emotions**. It sounds trivial, but in order to be meaningful, a DT should not remain static but become dynamic over the lifetime and situation of the user. Just as the approach of a DT for full personalization, there is no one-fits-all solution for a meaningful DT. Compared to the visions of a DT presented at the beginning, it becomes clear that a DT can take on even more possibilities and forms than envisioned by the intended use design so far. While the major drivers of DT technology in the healthcare sector often envision science fiction-like visualized representations of the individual's body with all associated vital parameters (see Philips), it became clear in the interviews that this picture is only one possibility. Even further, **some of the participants felt uncomfortable with a map or visualization of their own body and envisioned much more of an abstract representation, a kind of external supporter.** More concrete, the pure visualization of vital parameters did not seem sufficient. **Participants reported that a link between emotional data and physical parameters would empower them to better understand their body and the interlink to their own well-being**. In addition, it was interesting to me that the mere presentation of vital signs and predictions did not reflect the main interest, much more the **demand for translating the data into direct consequences or tangible feedback**. Therefore, I conclude that the way a DT is often visualized is insufficient from the perspective of meaningfulness.

The design of different forms for a meaningful Digital Twin

After analyzing the interviews, I observed that the **meaningfulness of a DT might change depending on multiple factors such individual preferences, experiences, life stage and the value framework of each person**. This finding might even differ to the intended use as portrayed or envisioned by a few key companies (see also Chapter 2.2.2.). There, a DT in healthcare seems to be rather limited to a static model that is, e.g., confronting the individual with lifestyle advises or providing medical records. Despite the technological readiness to enable a dynamic nature of a DT, **I suggest that a DT is more complex than this and should be able to take different forms in order to serve different purposes by aligning to the variable and dynamic user's values.** The interviews allowed me to gain many insights into the values embedded in the past experiences of diagnosis and anticipated future experiences with a DT. The values can be a starting point to think about what values should be incorporated in such a development. It aims to help to understand the importance of understanding, anticipating, and assessing the quality of social and cultural impacts of technologies instead of only designing for what they "should" deliver. **In order to make my findings and insights more tangible I propose six concepts of potential forms a DT could take based on the uncovered values.** The forms aim to be a starting point for reflection on what a DT could embody and how it could be used or perceived. Most of the forms are introduced with quotes from the interviews.

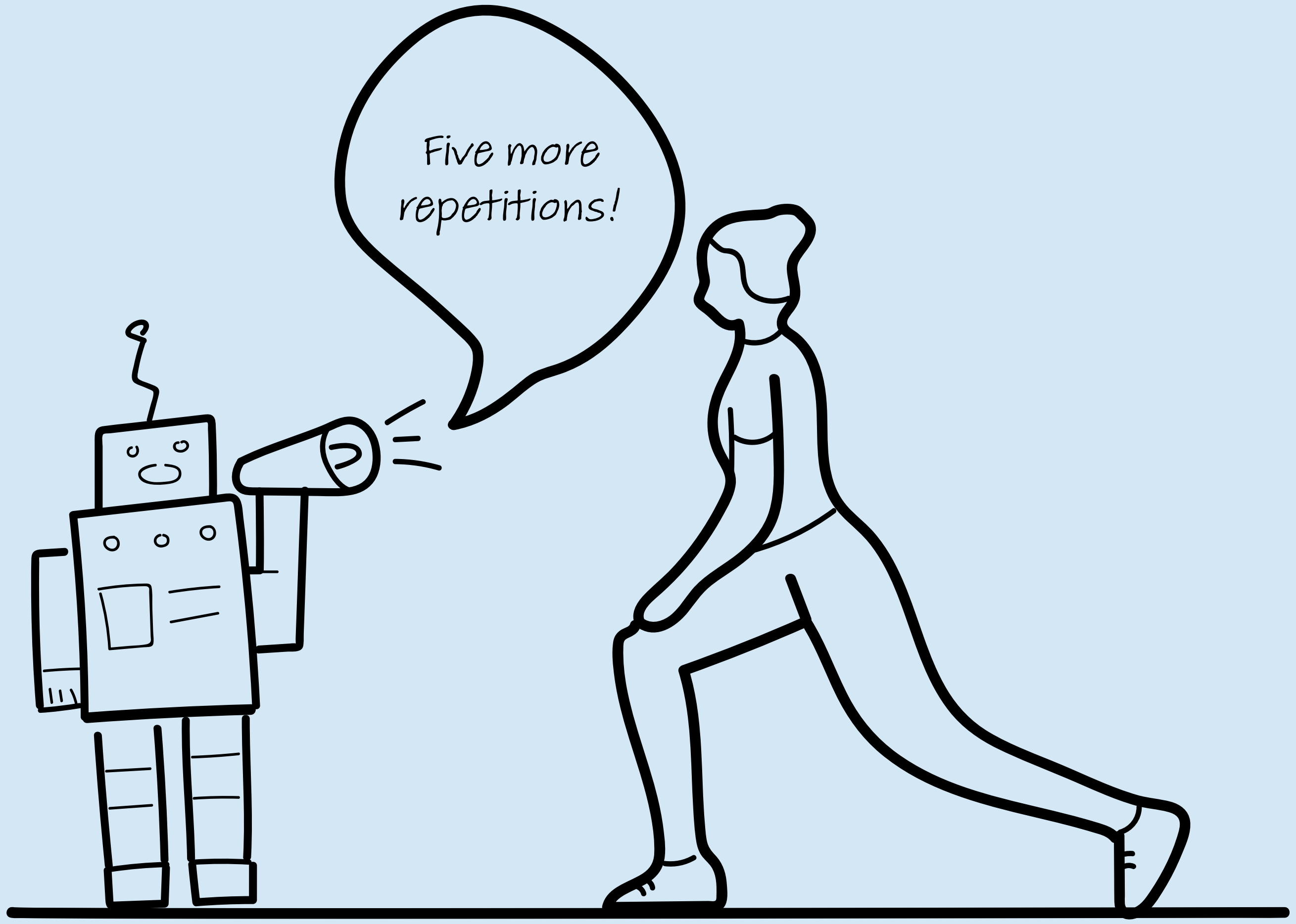
DT as “Coach“

“I think it can be a kind of guide. If it’s the one like saying giving you feedback and suggestions more than the diagnosis on the problem you already have, so maybe having it on a daily basis would be nice, if it’s a helping hand more than just a communicator showing all of your diseases.” (PY3)

“Like I said optimizing your training schedule, for example. So that you can perform better during your contest tournaments.” (PY2)

Values that shaped this concept: Support, Self-improvement, Knowing your body

Especially the younger generation is very interested in *self-improvement* so that a first form of a DT as coach arose. I propose this form that aims at *supporting* individuals in their daily life, from changing habits to supporting the ideal intake of food. This form is particularly positive and tries to transform the user into its better without judging. Recommendations are updated based on parameter changes or change in dietarian knowledge. Thereby, the coach reaches full personalization and offers the individual to pursue goals, which can range from losing weight, competitiveness in sports events, healthier behavior or optimization in terms of cognitive and physical capability. It also shows one’s own body status to increase the *knowledge on the own body* and connections between behavior and parameter change. Thereby, it offers a constant learning curve for the user. While this kind of personalization and optimization is already partially available for professional athletes, a DT as coach will make it available for everyone gaining additional meaning for younger users.



DT as “Diary“

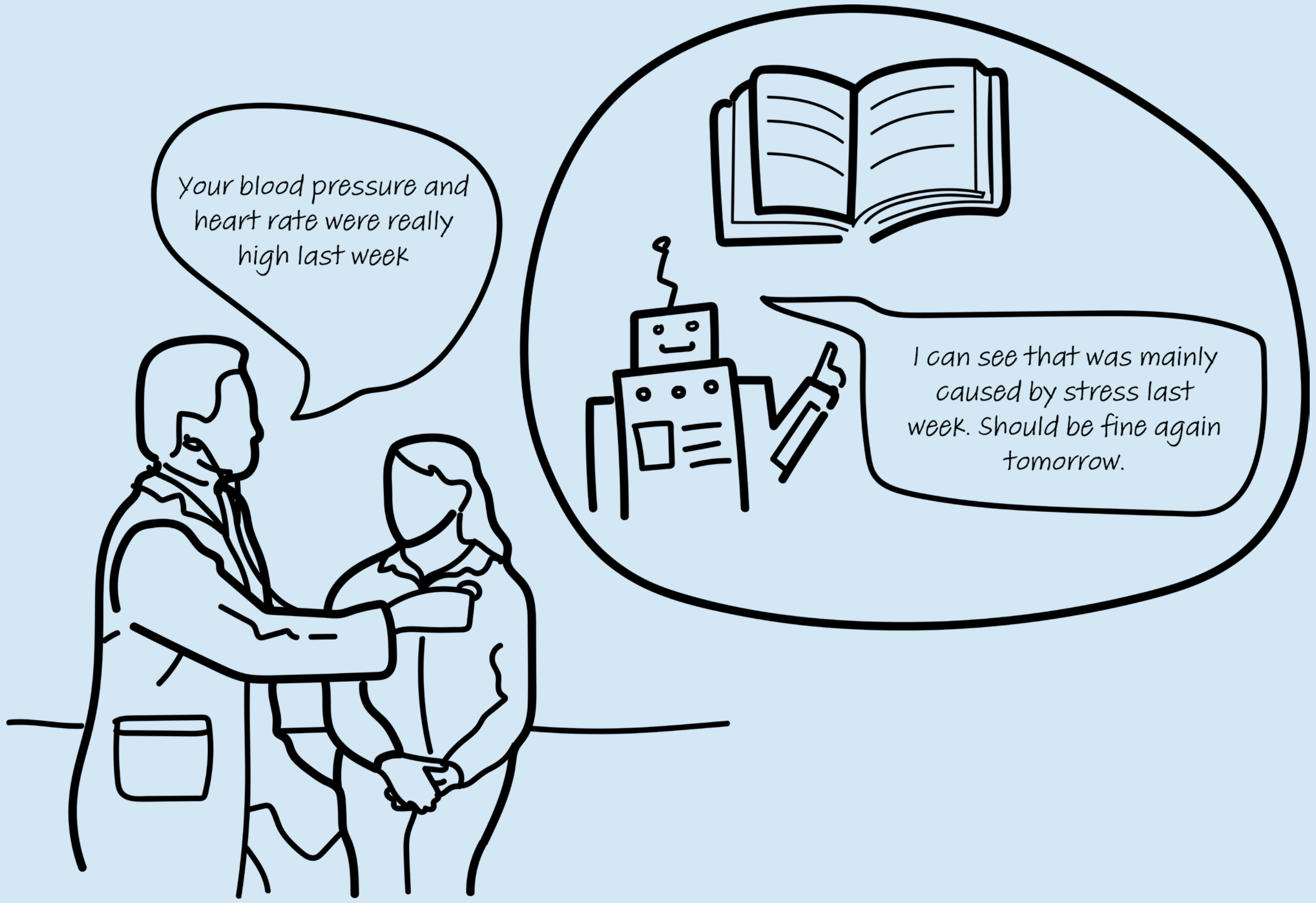
“Yes, in its completeness means: What is the woman like in this case me, (what am I) psychologically terribly afraid of right now? Does she have stress? Does she have big problems? Is she a little depressed? What could it look like under different conditions? What is she willing to do for her body? Is she ready to change something? What are the genetic conditions? What was with her parents? [...] that such things are included and not only an ultrasound picture, like there is a prohibited gall bladder broken and (that is all).” (PO2)

“[...] I could imagine that you find earlier things where you say okay, we intervene earlier simply because the Digital Twin says so. But do you know if the Digital Twin can really capture everything, including your psyche? Well, I can tell you when I’m excited you can see that directly from my blood pressure.” (PO2)

“But if I now have, for example, let’s say psychological problems, then of course it should be sensitive if I have some depressive tendencies of my own and he tells me in the middle of a depressive episode that it doesn’t make sense anymore anyway. Hmm, then of course it can have quite negative consequences. (Says it like is obvious) That this actually pulls you down completely or if you are in a good mood and there comes such information that can of course also knock you out of life.” (PO4)

Values that shaped this concept: Being seen as a whole, Knowing your body, Emotional data

Nearly all interview partners strived towards a DT that could be a great way to track the connection between *emotional* well-being and its connection to the physical stage. Thereby, mechanisms can be in place that support the concentration on behaviors or vital parameters that make the individual feel at ease and emotionally balanced. In this aspect, a meaningful DT combining a diary (focus on emotions) and journal (focus on actions) could offer the chance to the user to be seen as a whole, to get to know the own body and connect to their own emotional data in a way that has not been possible before. The connection of emotions and body data is a new field coming more into the focus of modern medicine. Thereby, drawing a direct correlation and causation between mental and physical data of the individual could lead to new knowledge about their relation and impact. Additionally, the diary/journey could enable the person to *get more knowledge* and the seriousness of parameter deviations from the personalized norm might be easier explained and judged.



DT as “Back-up“

> “And you can see the body and I maybe the time like the Time Machine on your on the computer, like different times for, like when you are young, and when you are old, then you can have like parts of your body, things that you can predict when you can see red spots, when you have more problems or things that happen in this point, pain somewhere.“ (PY3)

Values that shaped this concept: Security, Efficiency, Control

In the event of a serious accident or an unforeseen event that results in the individual suffering serious bodily injury, the DT can step in. I suggest that through the routine creation of full body back-ups, that recorded the patient’s status history as a snapshot, the data can be used to recover the patient. This allows the individual to be reset to the original state before the accident. This increases the *security* of the patient to be restored to the pre-accident state and is considered a safeguard. The procedure in the hospital after such an accident increases the *efficiency* of the recovery because the desired target status is already known. The possibility of making a snapshot of a specific state of the individual by a DT was previously not proposed in literature. The concept reflects the digitalization of the human body, but also captures its dynamic evolution over time. I imagine that offering such back-ups through a specific form of a DT would possibly offer an entirely new practice of emergency care.

DT as “Judge“

“Well, [...] I don’t know if it would happen but theoretically you could say that [...] the parts of the man are all pretty worn out and now he is 78 years old and needs an artificial hip, so it’s not worth it, we don’t do that anymore.” (PO2)

“Okay, if I want to eat 300 grams of chocolate, I don’t want somebody to tell me that tomorrow I’m going to have blood problems because I ate too much chocolate.” (PO1)

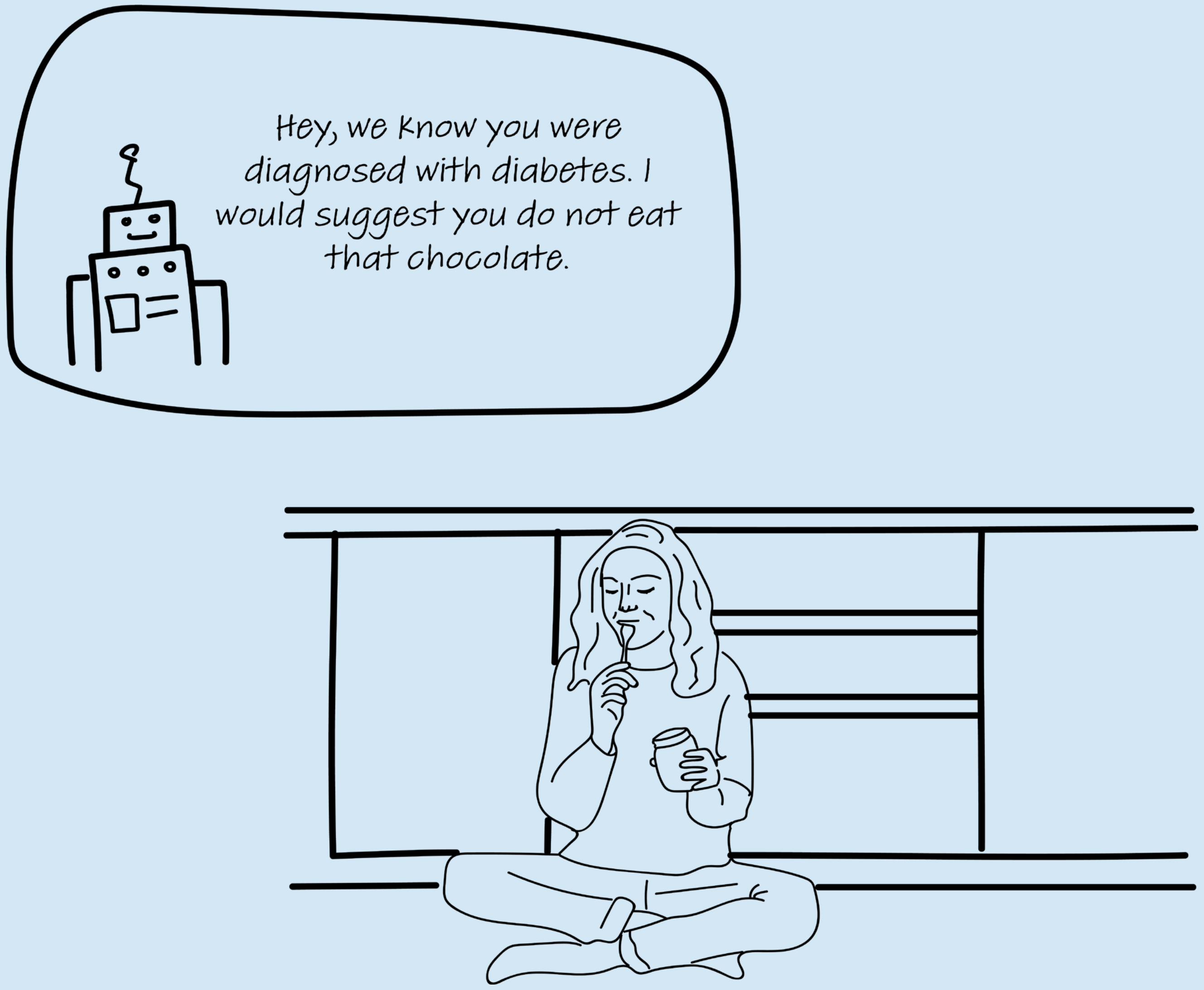
“In the simplest case it could actually be like dialogue in a chat room. You can imagine all kinds of things, like an Alexa. Maybe even as a virtual image - we will certainly experience much more media and augmented mentality; I can imagine something like that implemented. However, I wouldn’t want to have someone telling me: “I’d think about going over the jump hill. The risk of falling is...”.” (PO4)

Values that shaped this concept: Fear of monetary aspect, (Data-) security

A DT may need to interact with the user in some way, e.g. through providing lifestyle advice in order to prevent associated diseases. The concept of a DT as “Judge”, comes with a rather negative connotation. It showed during the interviews that the participants were especially concerned with the tone of voice, and the way and timing a DT would communicate with them. A DT as Judge may take these worries into consideration. In this concept, a DT might criticize or give feedback to a person about negative associated behavior that is being monitored while the individual is totally aware of the negative consequences one‘s behavior might have.

People might be afraid that every action they take is or can be observed and evaluated. With this concept, I want to argue that sometimes people want to actively decide to behave in a way although they know it might not be the right or healthiest thing to do. But as life can be seen as concerned with balance and not perfectionism, I argue a DT should be able to reflect this human behavior; meaning, it should be reflected upon which advice is given at what time and how. Otherwise, I assume that at DT might lead with frustration and anger to a certain resistance for usage.

During the interviews it showed that there was also fear that a DT might concentrate on-profit over humanity. In the form of a “Judge“ this could mean that the worth of an individual is determined and evaluated based on body data.



DT as “Bank“

> “ It’s preparing yourself to face what’s coming next. Because when you have a diagnosis, when you’re at the doctor, is never something for pleasure” (PY3)

> “I would rather have the diagnosis and feedback with an expert at their place and not at home. For me the place is significant.” (PY1)

Finding that shaped this concept: Place is important

I understood during the interviews that one’s emotional constitution becomes particularly important when being confronted with their own health status. The participants argued that the *place where they receive a diagnosis is significant*, as for example the inner prepared mindset and the readiness to face a diagnosis is different at a doctor’s office or in a hospital compared to your home. Uncoupled from a specific form, here, the concept of a DT aims to answer the “where” to derive a meaningful DT. In the following, I want to draw an analogy to a bank. In this comparison, data about the state of health is represented by money. I can choose to open an account, just as I can choose to build my own DT. In addition, I can actively decide to access data about my own condition by asking the doctor about the condition of my DT, just as I can actively decide to go to the bank to withdraw money at the bank. The bank works with my deposited money, which in turn can be used to offer interest to the customer. The more data I feed into DT, the more likely it is that, for example, the health department can work with it to gain new medical knowledge, which in turn benefits a user of a DT. In addition, when you look at your bank account, you may find that it is overdrawn, or that there has been an unexpected receipt of money on the other side. Similarly, my health condition account might be accessed. I will see that parameters may have positively decreased/increased or the opposite. Through my behavior, I can directly influence these data points in real-time, similar to the account balance. The analogy of a DT as a bank draws upon the finding that participants were afraid of the consequences of receiving prompt diagnosis at home. This seemed to pose a high level of intrusiveness in their own homes, which rather reflects a place of privacy and security. Additionally, people were especially afraid of the consequences of receiving a negative diagnosis. This is very interesting, as receiving a diagnosis can be a moment with great and long-lasting impact on the individual and its future. In literature such critical life events or news that impact the memory of the individual can be referred to as flashbulb-memories (May *et al*., 2020). Flashbulb-memories can be seen as commonly triggered by a surprising or even traumatizing event which creates a permanently embedded memory of the event for the individual. This memory does not need to be limited to the news but can also incorporate the emotions, or place where the memory was triggered or the actions that were taken in that moment. (Brown & Kulik, 1977). Building up on that, when the individual would receive an incisive diagnosis by a DT, it could lead to the creation of such flashbulb-memory and therefore have an impaired long-lasting impact on the individual. Thereby, it makes sense that interview partners did not want to receive such critical and perhaps surprising news in their own homes as it might reduce the feeling of security and privacy. Additionally, it could connect the individual experience of their homes to the memory when they received the diagnosis. I am therefore concluding that it is important to reconsider the timing and place when and where the diagnosis from a DT is shared. Maybe it should even be considered that the control to engage with a DT is in the hands of the user.

DT as “Last Will“

“He could take the medication by knowing what I want with my living will and that I might be asked again and that the Digital Twin could then facilitate the medication. [...] (The DT) could also say what other things I need or if it is perhaps time that relatives should join, and the son as he is most important [...]. He has to be informed so that such information can be given if the patient cannot say this anymore.” (PO2)

“I don’t know if I would want to know (talks about an unpreventable disease detected through the DT), let me put it like that: Although I am someone who is good with things and with unavoidable things, but why should I burden myself with something that I cannot really change. Or I would only want to know just before, about four weeks before, I would say. Then you can still say goodbye and you can still regulate many things. That means that you have to be able to program when the Digital Twin says something and what it says.” (PO3)

Values embedded in this concept: Support, Acceptance of own faith

A DT as “Last Will“ arose only in the older participant group and was certainly very unexpected. Thereby, a DT acts as a *supporter* and enables self-directed decisions particularly at the end of life. It could allow people to organize their end of life from everywhere and at every moment. I can imagine that this concept could be used by everyone reaching full age. It would allow easier and more flexible, free choices about death than today. In other words, a DT would be even “ready” for your death even though you are not prepared. It could normalize the possibility to die even before broaching the topic, and it may increase the *acceptance for your own faith*. I can imagine that a DT could have information about your patient decree and information which relatives when to inform. In case the user does not have much time left, a DT can be a supporter for instance for the funeral in the sense that all your wishes and information including the exact place bought on the graveyard were collected beforehand. Overall, it will ease the bureaucracy and the preparation of the funeral while relieving bereaved ones from those tasks. After your death, a DT could inform a notary about the heir before the DT might be shut down. Although for me this pose another highly interesting question of what happens with your DT after your death. This certainly has to be discussed in future research and aligned with legal regulations. Considering a DT serving such a purpose was certainly a surprise. However, in accordance with the user’s live stage, this form is certainly understandable and essential to derive to a meaningful DT.

Validation

During this thesis I posed a strong focus on the validation of the findings and reflected the results with the supervisors and well as with validation groups. This aimed to ensure a high validity and quality of the analysis. Furthermore, the six-step approach of IPA facilitated to derive from the interviews the herein presented findings. Those were discussed with an external person, with no connection to the project. I included this feedback to challenge my own interpretations and gain an unbiased perspective on what the interviewees said and how they said it related to what I found in my analysis. After analyzing all findings from the interviews and after drawing up the first conclusions, I scheduled a meeting with a medical expert situated in the Erasmus MC hospital in Rotterdam. In this meeting, I presented the findings and conclusions, and we critically revisited the interview analysis from a medical perspective. It was equally interesting to hear how the results were retrieved from a medical perspective. Thereby, my view on the results was once again challenged and extended. Last but not least another point of validation took place after presenting the first summary of this work as an interactive PDF. This workbook had the aim to start a reflection on forms a DT could take to be meaningful and at the same time inform about my project and its relevance. For the validation of the PDF, I asked two interview participants from both groups (e.g., young and old) to reflect on whether they find themselves understood in the work and how they rate the accessibility of the provided information with regard to the visualization. What became clear to me during the validation phase was that in some moments the flow of the slides as well as which button to press was unclear to the participants. Furthermore, one person mentioned that one of the presented forms was not yet fully understandable to him. Therefore, I addressed these problems and revised the order and user guidance of the interactive PDF. The other participant worked through the document and reported that she was really glad to have such an overview of the whole project without having to read through everything. She was intrigued by the different forms that were derived.

Recommendations for designing a meaningful DT

Now that I gained thorough insights into the experiences and values of potential users, it not only allowed me to synthesize various forms of DTs, but to conclude on further recommendations that may ideally find their considerations for the conceptualization of a meaningful DT. I must acknowledge that these are only to be understood as guidelines and reflect my personal perception. This perception is based on the empirical study through interviews with experts and potential users as well as literature research. It should also be noted that my suggestions are not to be directly implemented but provide an impulse to consider the development of a DT from other points of view and serve to empower decision-making about the intended design-use or non-use. These guidelines are not meant to be generalizable cornerstones, but hypotheses. As such I argue that they could get more attention to be observed and further researched.

Recommendations for designing a meaningful DT

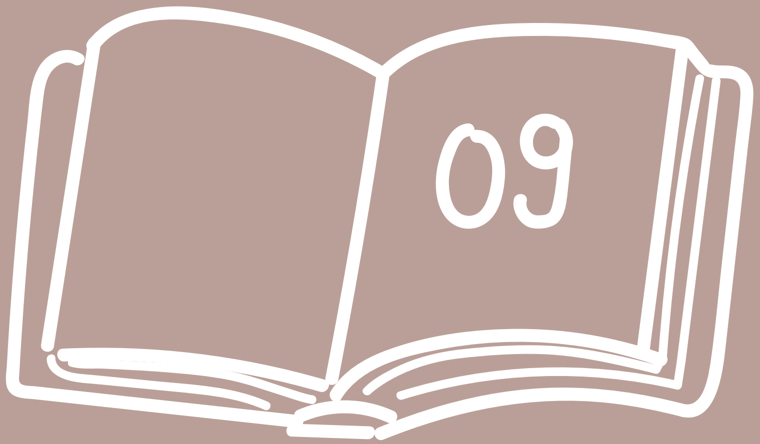
The form of a meaningful DT can and will change. A DT needs to remain dynamic and adaptable to user feedback and allow personalization through the user. In the following are nine recommendations that may support the development of a user-centered DT:

- The form of a DT has multiple layers of application and its use and meaningfulness is likely to change over the life course of the user. Therefore, it needs to remain dynamic. Additionally, the degree of meaningfulness of a DT will most likely change throughout the life of the user.
- A high degree of control of the use of a DT and private data needs to remain in the hands of the user.
- A DT should be inclusive, meaning it needs to be accessible and intuitive for elderly as well as people with low socioeconomic status.
- A DT should give access to a platform that allows people to inform and educate themselves based on personalized verified expert advice.
- A DT should consider emotional data as equally important as physical data.
- Developers and designers of a DT should remain critical with the intended use to meet the desired one by the user. Therefore, I want to highlight the importance to further uncover values embedded in the use of a DT, as well as several iterations to directly translate these values into insights for the development.
- The implementation of a DT should take place in several steps with increasing independence of and gradually increasing control by the user.
- Implementing a system for rewards and positive feedback is as important as warnings and suggestions.
- The place where a diagnosis is received by the user plays a key role, as the mindset might be different. The timing, place and communication when, where and how to inform individuals about their body state, i.e., diagnosis should be taken into account.

Limitations

In the following, I would like to list some points that represent possible limitations of this work. One focus of this work was to explore what unanticipated experiences the interview participants see in a potential DT for themselves. Thereby, the main focus was to remain prescriptive and not to provide the participants with predefined images of a DT in healthcare, but to explore with and through the participant what form and meaning a DT may take from their perspective. This allowed me to get insights into “meaningfulness” and its crucial role for the development of a user-centric DT. However, this approach can be criticized as the participants started the interview from their own different prior levels of knowledge. Without having shared a common definition or vision of a DT in healthcare, it might have negatively affected the direct comparability. Furthermore, the context of the interview was specifically related to the field of diagnosis as identified to be a relative topic in my brainstorming session. I expect that answers and opinions could be different in another context of healthcare and may lead to different interpretations. Thus, the results of this work are not meant to be generalized to different healthcare situations and complementary contexts could be further explored. It must be acknowledged that all topics that emerged during the interviews were interpreted by myself and that even though I involved another person for cross-validation, it still incorporates my own researcher´s views and feelings. Therefore, the study cannot be seen – and is not intended – as a pure sterilized representation of what was said. Furthermore, I want to acknowledge that only a few negative expected experiences for the future of healthcare with a DT were shared by the participants. One reason may be the result that participants gave socially desirable responses, assuming that I was targeting the positive aspects, through my own interest in DT by exploring this topic during this Master thesis.

Conclusion and outlook



In this thesis, I investigated anticipated values of potential users in the future application of a DT in healthcare. To gain insights into how a DT can take a meaningful role from the user-perspective, I have conducted multiple interviews. These interviews provided key findings that will be helpful for the development of potential concepts and for the design of a meaningful DT, as well as further research.

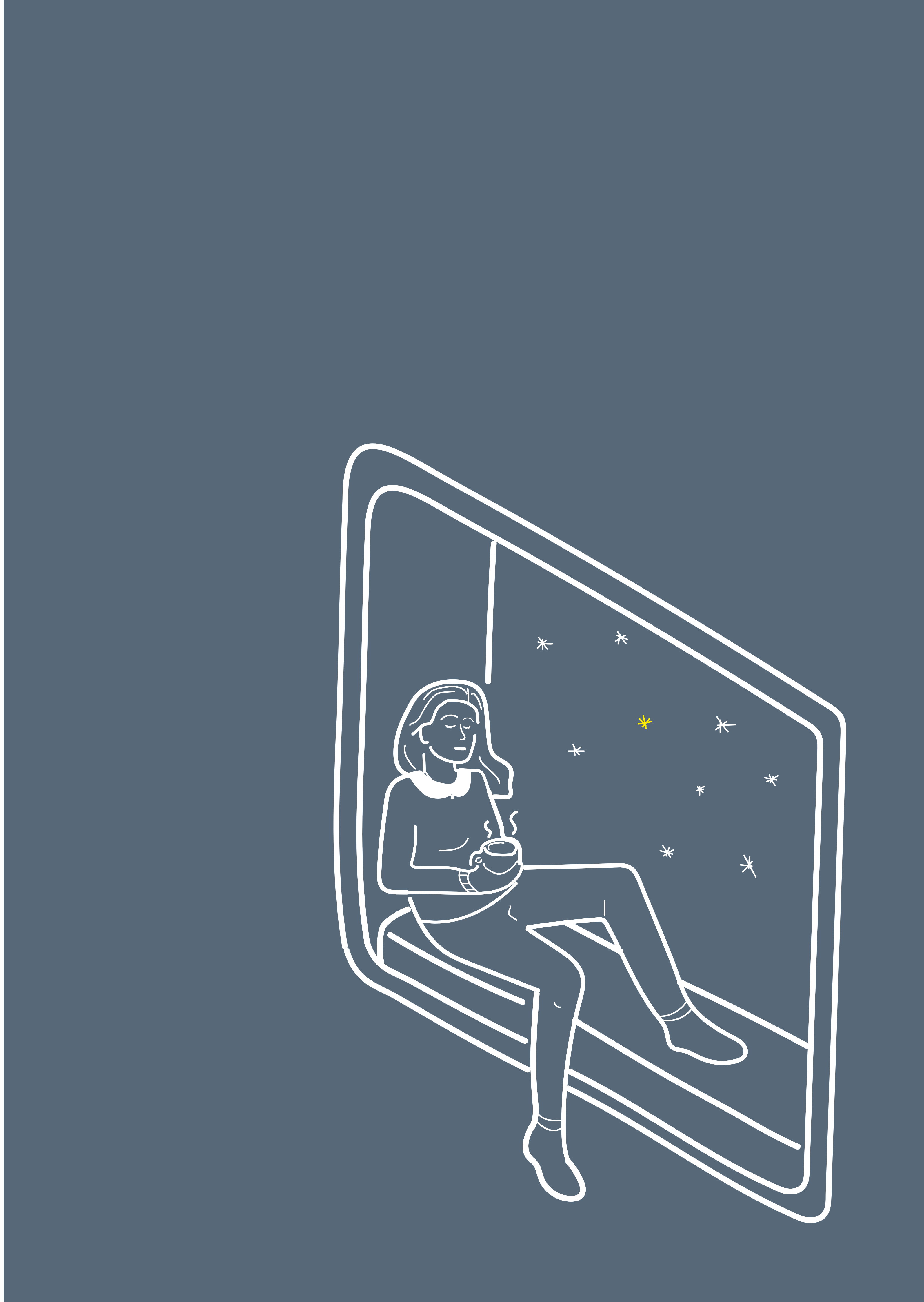
Certainly, the development of a DT will not be immediately launched that allows for the complete involvement of an individual in the interaction process with a DT, but I assume that the full involvement will be the long-term vision of the future. To develop such a meaningful DT, my herein suggested forms will likely differ from the currently intended use as communicated by companies. It becomes clear in this research, that a DT would need to be detached from a static role and change its form according to various factors such as place, emotional balance, life stage and certainly personality and preferences of the user. While the younger participants seem to focus on self-improvement, emotions and prediction of disease or future restrictions posed by health problems, older participants tend to focus on their end of lives and prevention of upcoming diseases. What was certainly common was that all participants considered that a DT needs to be more than just a display of body data in order to deliver meaningful values for the individual. With regard to the end-of-life approach, the form of a DT as "Last Will" may interfere with current practices and moralities, but also normalizes discussions and allows active thoughts about one's own death. This is a particular example reflecting the theory that the introduction of a DT might also change the morality of society through its role as mediator. It becomes clear that many roadblocks are ahead of us and that many unknowns and uncertainties need to be eventually considered. Nevertheless, it should maintain as a central point that initial value frameworks of future users should be constantly taken into account for a responsible innovation, even though related values may be prone for changes over time and by the technology itself. Reflecting on the interviews, I generally grasped a high interest of the participants in a DT, though the interview also showed me that trust in the technology needs to be slowly built up and strengthened over time. To achieve this, it will probably require a stepwise implementation of the technology in the healthcare sector and gradually increasing degree of interaction with the user. Taken together, all findings suggest that the degree of meaningfulness of a DT is likely to change elementary over the lifetime of the user. In consequence, a DT will need to be dynamic and adapt to the user's needs, life contexts and all nuances in order to be and maintain meaningful.

This study is a first step towards an investigation how the technology of a DT can turn to be meaningful for the user in the healthcare context. It ideally gives a first impetus into thinking about a responsible, purposeful development of this technology and should be certainly further investigated. To extend the findings in the context of diagnosis, a future focus may lay in different contexts while maintaining the user-perspective. Additionally, my interview focused on young people between 24-28 and old people between 54-65, meaning that other age groups should be equally investigated to complete the picture of different forms of a meaningful DT. Finally, it will be very valuable if all findings could be brought into a multi-stakeholder perspective including practitioners, software developers and legislators to eventually derive the meaning of a DT from a 360° ecosystem perspective.

Reflection on work and personal development

Reflection on work and personal development

The project in its topicality and scope remained exciting over time and displayed more and more unexpected facets to me. I not only learn a lot about the topic, but also about myself and my way of working. I learned that I appreciate being organized, focused and structured in my work. Writing a thesis in times of Corona pandemics often presented me with its own set of problems. The exchange with others that would be common in the field of design, whether working together or talking in the corridors of the faculty, was often very lacking and made me realize how important this little food for thought and input is, luckily some of this exchange could take place online. Exponentially to the interesting nature of this topic was also its complexity. Conducting this project has shown me that I can overcome even this complexity through perseverance, focus, iteration and input through discussions with others. Before I began this work, I set out to address or improve a few key issues during this master's thesis. Before starting the graduation, I was defining three things that I would want to focus on in my personal development during this six-month journey. The first one was my wish to deepen my research skills. By making interviews the main study focus of my project, I was able to expand my knowledge in developing an interview guide that invites for rich in-depth answers. Furthermore, through conducting interviews with the experts as well as participants I was able to gain more confidence and more calmness. I learned that sometimes silence is the key and that sometimes something what seemed obvious at first glance one can reveal the most interesting insights by asking for elaboration. The second challenge I wanted to overcome in this project is managing the high complexity that lies in the nature of the topic and its uncertainty. This led me to an exploration of philosophical theories and concepts which certainly were a challenge on their own but led to so much more knowledge about human experiences, that I would not want to miss it. My last point that I defined before this project was that I want to explore the impact of future technologies from a user-perspective and thereby adding to my knowledge about user-centricity. I think this is something I managed really well in this project. I was able to gain new perspectives on what user-centered technologies could mean and learned about new approaches to research those.



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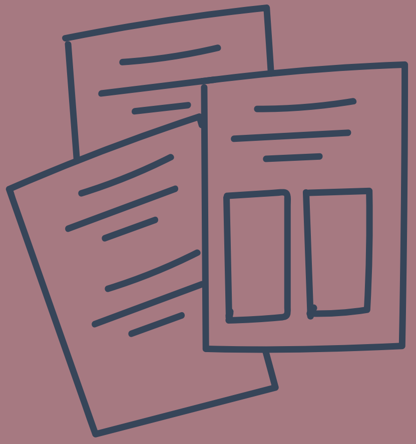

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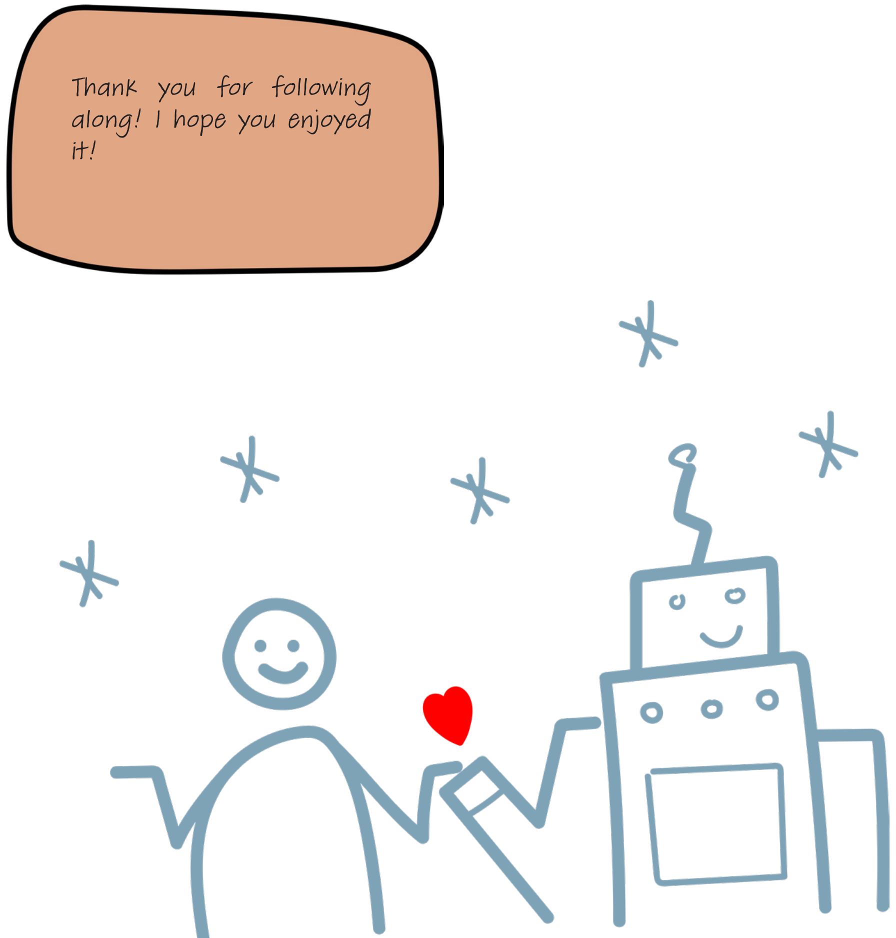
APPENDIX

The APPENDIX for this project can

be found in a separate file.

- APPENDIX A – Project brief
- APPENDIX B – Interview guide for
  “MyDigitalTwin” experts
- APPENDIX C – Consent form for user interviewees
- APPENDIX D – Brainstorming session overview
- APPENDIX E – Brainstorming session analysis
- APPENDIX F – Interview guide – user interviews
- APPENDIX G – Interview analysis young group
- APPENDIX H – Interview analysis old group


Thank you for following along! I hope you enjoyed it!