

# DATADONOR

Crowdsourcing health care through digitalization

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MASTER THESIS  
JORIS HENS

April 2019

## COLOPHON

### DataDonor

Crowdsourcing health care through digitalization

### Master thesis

MSc Strategic Product Design  
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## PREFACE

In front of you is the final deliverable of my graduation project of the MSc Strategic Product Design at the Delft University of Technology, in collaboration with Deloitte Digital. It is a result of a six-month research and design project where I was able to apply the knowledge I gained throughout the past few years. This project enabled me to combine my interest in health care with the dynamic field of design and business while meeting many interesting and inspiring people, visit multiple conferences and learn much more about the cardiovascular domain.

Jeroen, thank you for pushing me in findings solutions beyond the obvious. I often think in obstacles limiting myself in coming up with new solutions. The best advice you gave me which will definitely stick was 'design as if you are God!'

Thank you Maaïke, your knowledge in design-driven innovation in combination with the cardiovascular domain inspired me to dive into the topic and try to design the bridge between these two fields.

Thanks, Tommaso for always being open to discussion and bringing in new perspectives to the problems and findings I found along the way. Additionally, I would like to thank my other colleagues at Deloitte Digital for support and feedback when needed. I appreciated and enjoyed the warm welcome!

A special thanks to all the people participating in the interviews, creative sessions and evaluation of this project. Especially I want to thank the people who were open in sharing their personal stories regarding living with cardiovascular disease. Additionally, I could not have done this project without the help of my fellow students, the client and other experts.

And last but not least I would like to thank my family and friends for supporting me along the way.

Enjoy the read and take care!

Joris Hens



# EXECUTIVE SUMMARY

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## The importance of value-based health care

Worldwide, health care systems are struggling to control costs while improving care outcomes. An ageing population, increase in chronic patients and shortage in care professionals result in high burdens on our health care systems. Current health care systems are organized around delivering quantity. When this is continued, health care costs will rise in an unsustainable pace and the quality of care will be affected. The concept of value-based health care proposes a paradigm shift where we move from organizing care based on volume to value. This concept suggests measuring value of health care based on outcomes achieved for the patient instead of volume delivered.

## Assignment

Value-based health care (VBHC) is an evidence-based approach and can be used to improve individual and public clinical care. Longitudinal and systematic measuring and sharing of health data is essential to be able to track outcomes and improve clinical care accordingly.

Periodic patient health data can be used by care professionals to provide timely treatment interventions to patients. Additionally, patient health data can be used to build predictive models to support care professionals in providing more personalized treatment. For this, patient self-care supported by eHealth services is becoming increasingly important where the role of the patient shifts from being a 'care user' to a 'care contributor'.

However, patients express concerns regarding the safety of eHealth services and are not thoroughly informed on how patient health data can improve both individual and public clinical care. Based on this, this thesis will answer the following research question:

**How can care providers strategically obtain patient health data, in order to improve individual and public clinical care?**

To answer this research question, a theoretical ecosystem which envisions a way of strategically obtaining patient health data to improve clinical care is developed and used during user research.

## A theoretical ecosystem for the cardiovascular domain

Cardiovascular diseases (CVDs) are the main cause of death globally and the number of people living with chronic cardiovascular disease is increasing daily. Providing preventive care to those cardiovascular patients is key to manage the disease properly. Patient self-care, eHealth services and predictive models can have major implications on how cardiovascular care is managed and provided. Because the potential impact technology can have on improving clinical care for CVD, the theoretical ecosystem was designed for this domain.

The ecosystem is designed using insights from extensive preliminary research. It is a product service system which uses patient-generated health data from the telemonitoring service to better manage care and build predictive models to support cardiologists in providing tailored treatment. This ecosystem allows patients to receive personalized treatment and advice, have easier access to care and enables them to contribute to care easier.

## Frisian Health Campus case

The theoretical ecosystem is used during a use case for Frisian Health Campus (FHC), a client of Deloitte. FHC is an initiative that aims to become a pivotal player in developing and supporting care innovations in the northern region of the Netherlands. In order to improve clinical care, they aim to connect various care providers in the region by developing a platform where patient health data is shared for research. Deloitte did extensive research to disclose what FHC is legally allowed to do with patient data on such a platform. However, they did not know what patients and care professionals think of such a platform and what is necessary to let patients share their health data with them. Therefore, the ecosystem that is designed was used to do research on the desirability of FHC's envisioned data sharing platform.

## User research and design challenge

In total 7 cardiovascular patients and 6 cardiologists were interviewed to gain a better understanding of how the theoretical ecosystem addresses drivers and needs of these users. It was found that patients are more than willing to share health data for research if privacy and security are guaranteed. This showed there is not a problem with the willingness to share health. Instead, barriers with keeping up the data flow were identified:

- The desire to measure and share health data fades over time because patients find a balance in medication and lifestyle,
- Measuring and sharing health data remind people they are a patient,
- Patients are unaware of the value of their health data.

Results from user research resulted in the following design challenge:

***To increase adherence of measuring and sharing health data, the design should let patients experience the value of health data and trigger personal drivers to periodically measure and share health data.***

During user research, various alternative drivers to measure and share health data were found and are used to design behavioural interventions in the final concept. Three main triggers were identified. I would measure and share health data to:

- Reassure my family and friends,
- Contribute to care of other people,
- Support my doctor in providing better care.

## DataDonor

The final design, DataDonor, is a digital environment which consists of an informative website regarding the value of health data and a module that can be added to existing telemonitoring services to share health data for research. This way, patients and care professionals can use the initial telemonitoring service. Additionally, the module provides patients

with information regarding the impact of their data donations on their care and that of others. To maintain measuring and sharing adherence, DataDonor adapts to personal drivers to measure and share health data over time.

By repositioning the role of a patient from being a 'care user' to a 'care contributor', patients are not reminded they are a patient when measuring and sharing health data but enable them to be a vital contributor to individual and public care.

## Validation

DataDonor has been evaluated with patients, the client and health care experts to assess the concept on both a user and client level. These sessions resulted in relevant feedback and validation and are shared in chapter 7. However, to fully validate the effect of DataDonor, it should be tested over a longer period of time.

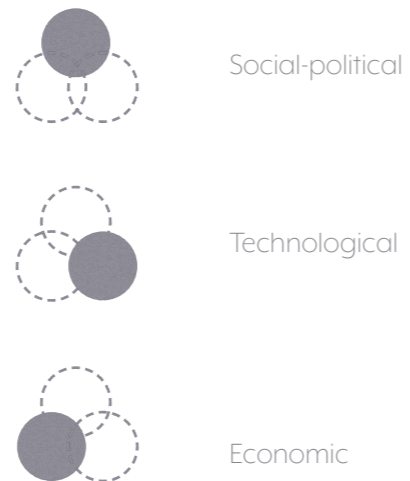
## Conclusion

DataDonor is a digital environment supporting care providers to strategically obtain patient health data to improve clinical care. By guaranteeing secure and anonymous use of patient health data and by enabling patients to contribute to their own care and do good at the same time, patients can be triggered to share health data with their care providers. Additionally, by appealing to personal drivers to measure and share health data, DataDonor provides a solution that fit the needs of the patient, business and organization.

# READING GUIDE

## PEST ANALYSIS

To plan and create a successful innovative strategy it is vital to understand and recognize trends and challenges in the health care sector. Therefore, a PEST analysis is conducted where several challenges and trends in health care from the economic, social-political and technological domain will be discussed. Throughout the report results from this analysis will be presented to support literature and findings. Doing a PEST analysis is a common approach to map the external business environment. The idea of it is that an enterprise should react to changes in its external environment (Gupta, Officer, & Kalan, 2013).



## EXAMPLES FROM PRACTICE

Examples from practice will be presented which illustrate the theory or information provided.

## QUICK OVERVIEW? TAKE-AWAYS!

At the end of each chapter key take-aways will be written. This gives a brief summary of the chapter and will tell how this information will be used for next steps in the project.

“Throughout the project, topics are supported with this colour text indicating a quote derived from expert, client or user interviews and validation sessions.”

## GLOSSARY

DD - Deloitte Digital  
 DHC - Digital Health Compliance  
 EMR - Electronic Medical Record  
 FHC - Frisian Health Campus  
 GDPR - General Data Protection Regulation

MCL - Medical Center Leeuwarden  
 PGHD - Patient Generated Health Data  
 PGO - ‘Persoonlijke GezondheidsOmgeving’  
 TM - Telemonitoring

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# CHAPTER 1

## PROJECT CONTEXT

## 1.0 //

This chapter introduces the project background, assignment and approach. A structured overview of the project is provided and guidelines on how to read this report are shared.

In this chapter:

- 1.1 Project background
- 1.2 Assignment
- 1.3 Project approach
- 1.4 Key take-aways

# 1.1 // BACKGROUND

The Dutch health care system is facing the alarming prospect of controlling costs while improving patient care outcome (World Economic Forum, 2017). An ageing population, increasing number of chronic patients (1) and increasing shortage of care professionals (2) put a high burden on the sustainability of our health care system. If we keep providing care based on quantity (3), health care costs will rise in an unsustainable pace (4) and the quality of care will be affected. As a response, the health care industry is widely exploring and introducing the concept of Value Based Health Care (VBHC).

## VALUE BASED HEALTH CARE

In 2006, Michael Porter introduced the concept of Value Based Health care (VBHC) in his book Redefining Health care: Creating Value-Based Competition on Results. In his book he suggests a health care paradigm shift where we move from volume- to value-based care. This paragraph will explain in more detail the concept of VBHC and how it will be used in this thesis.

### DEFINING VALUE

Michael Porter states: 'value should always be defined around the customer, and in a well-functioning health care system, the creation of value for patients should determine the rewards for all other actors in the system. Since value depends on results, not inputs, value in health care is measured by outcomes achieved, not the volume of services delivered, and shifting focus from volume to value is a central challenge (Porter, 2009).' To make it concrete, in VBHC value is defined as the health outcomes achieved per euro spent (Porter, 2006). A good example of creating value instead of volume is providing eConsult (consult via phone or video-call). If, for example, a patient is living remote or is physically not capable of traveling to the hospital, eConsult makes it possible to receive care in their own home. In addition, patients who do not need to visit the hospital will save time and money for the hospital.

## VBHC FRAMEWORK

A report published by The World Economic Forum, in collaboration with the Boston Consultancy Group (BCG), showcases a comprehensive framework for a value-based health system (figure 1) (World Economic Forum, BCG, 2017). The system can be framed into three main areas which will be explained in more detail on the next pages:

- **Three foundational principles**
  - Track health outcomes and costs
  - Patient segmentation
  - Segment specific interventions
- **Four key enablers**
  - Informatics
  - Benchmark, research and tools
  - Value based payments
  - Delivery organizations
- **Public policy**

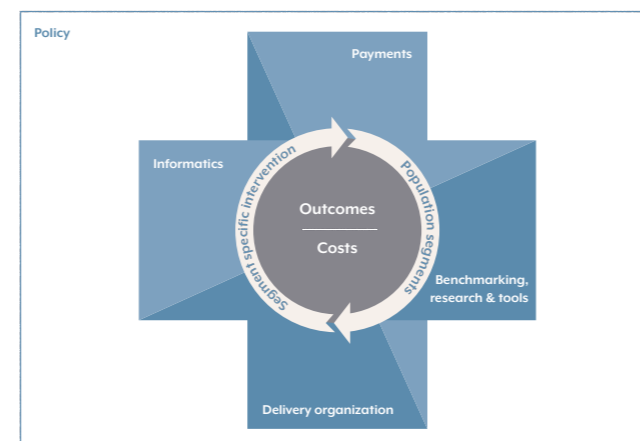


Figure 1 - Framework for a value-based health system

## PEST ANALYSIS

Social-political		<p><b>(1) Chronic disease on the rise</b></p> <p>One in three adults live with more than one chronic condition, or multiple chronic conditions (Hajat &amp; Stein, 2018). In the Netherlands almost 9 million people live with a chronic condition (Volksgezondheidszorg, 2019). This has made prevention and management of chronic diseases a global and local priority (Hajat &amp; Stein, 2018).</p>
Social-political		<p><b>(2) Care professional shortage</b></p> <p>In the Netherlands there is an increasing staff shortage of care professionals (Zorg en Welzijn, 2018). Accompanied with the increasing number of patients, this results in high workloads which have an impact the quantity, and more important, quality of care that is provided (CBS, 2016). eHealth has the opportunity to assist care professionals in managing these workloads because it allows them to remotely monitor patients and provide care only when necessary.</p>
Technological		<p><b>(3) From quantity to value based payments</b></p> <p>In the Netherlands care providers are paid by the quantity of services performed, also called the fee-for-service system. This is a challenge because with this financial structure health care providers sometimes have to deliver quantity over quality. However, Forbes (2019) predicts that in 2019 15% of the global health care spending will be linked to value/outcome-based care concepts. For example, since January 1st 2018, in the Netherlands eConsults are being insured for medical specialists and general practitioners (Federatie Medische Specialisten, 2017).</p>
Social-political		<p><b>(4) Increasing costs</b></p> <p>Health care costs are growing in an unsustainable pace, particularly in developed countries which take up 75% of global health care spending (World Economic Forum, BCG, 2017). In the Netherlands health care costs take up 13,3% of GDP in 2018 (CBS, 2018). This growth puts pressure on health care budgets, constraints potential innovation, and in some cases, it can result in rationing of resources.</p>
Economic		

### Three foundational principles of value-based care delivery

VBHC rests on three foundational principles that together create a health care environment that is continuously learning and improving.

#### Track health outcomes and costs

Value depends on results, which means that value in health care should be measured by outcomes. To be able to improving health care outcomes and reduce costs and it is necessary to longitudinally and systematically measure, report, and compare health outcomes and costs required to deliver those outcomes (Chernichovsky, 2009). VBHC is a evidence based approach to improve care. **For this, patient self-care supported by eHealth services is becoming increasingly important to track health which health care professionals can use to optimize outcomes.** Within the healthcare industry eHealth is referred to as the use of information and communication technologies (ICTs) for health and healthcare delivery services (Hale, Chou, & Cotten, 2018)

#### Patient segmentation

One of the key elements to analyze health care value is to divide individuals into groups that suffer from the same disease or condition, or groups that share similar risk profiles.

A simple way to segment is to group people suffering from the same condition or disease. For example, all people that suffer from high cholesterol. Within a patient segmentation that is suffering from a condition there will be subgroups that have various risk profiles. For example, within the high cholesterol patient population there will be patients suffering from other medical conditions, like diabetes or hypertension, and others will not. These varying groups have different risk profiles and need different treatment plans. The goal is to better understand what treatment works for a specific population segmentation so each segment has its own clearly defined clinical interventions. This way, care providers can better compare health outcomes, track variations in outcomes, and apply

necessary improvement and patients will receive more personalized treatment plans.

#### Segment specific intervention

To improve value for population segments it is necessary to develop customized interventions. When health outcomes are being tracked for population segments, it is possible to learn more about the impact certain interventions have. This can lead to more customized and precise interventions for a specific segmentation or subset of that segmentation.

VBHC focuses on customization in three areas. First, in the traditional care delivery (diagnosis, treatment, recovery and rehabilitation). Second, in timely interventions to stimulate preventive care and the long-term monitoring and management of chronic patients. Third, incorporating behavioural and social interventions in the care continuum. This includes providing patients with life style advice, and trying to increase patients' motivation and willingness to participate in care. The care continuum focuses on delivering an integrated system of care across the entire patient journey, from wellness services to acute care and rehabilitation (figure 2). The adoption of new technologies enable to create a more coherent experience across this continuum (Dimond, 2018).

### Four key enablers of value in health care

There are four enablers that support and facilitate the three foundational principles.

#### Informatics

An informatics infrastructure is necessary to facilitate the systematic collection, analyzing and sharing of health data. This includes a set of data standards, an IT infrastructure, and data analytic capabilities (e.g. machine learning).

#### Benchmark, research and tools

Between care providers there is a widespread variation in medical practices, health outcomes and costs (Kuenen et al., 2015). For example, different hospitals in the Netherlands have varying treatment approaches for the same disease. This is a challenge because, for instance, to increase treatment efficacy

for a specific condition or set of conditions it is better compare and learn from similar treatment plans. Systematic benchmarking of health practices and outcomes is necessary to create alignment between care providers.

Large quantities of health data are generated when monitoring health outcomes. This data can be used for clinical care and research and can contribute to the development of data-driven decision support tools for clinicians. With this new data it will be possible for researchers to analyze large databases off all patients treated for a specific condition. Algorithms can be developed to support clinicians to identify what treatment is most effective in an individual case. These types of algorithms are especially valuable for treating complex patients with various comorbidities. This means that patient health data can be used to manage and improve both individual and public clinical care.

#### Value based payments

Care providers need to look into new ways of how care can be compensated and reimbursed. By creating value-based payment models (e.g. insured eConsult), stakeholders have an incentive to focus on delivering value.

#### Delivery organization

People working in the health care sector are among the most caring and committed in creating and providing value for their customer, the patient.

However, due to high workloads, complex regulatory frameworks, local rules and constraints that evolved over the years, there are often misaligned goals and drivers between stakeholders within the health care continuum (World Economic Forum, BCG, 2017). New pathways, roles and organizational models should provide the opportunity to deliver value to patients easier.

### Public policy

Public policies are an overarching factor since it can influence all enablers. Policies are shaping the legal and regulatory environment of the health care sector. For example, Bruno Bruins, Dutch minister of Medical Care, is advocating for a more aligned digital exchange system for patient data between care providers (NOS, 2018). This could help in benchmarking health practices and outcomes.

### DIGITALIZATION OF CARE

The process of moving into VBHC can also be described as the digitalization of care. Gartner (2018) describes digitalization as the process of moving into a digital business using digital technologies to change business models and create value-producing opportunities. Digitalization is different from digitization which is merely the process of changing from analog into digital.

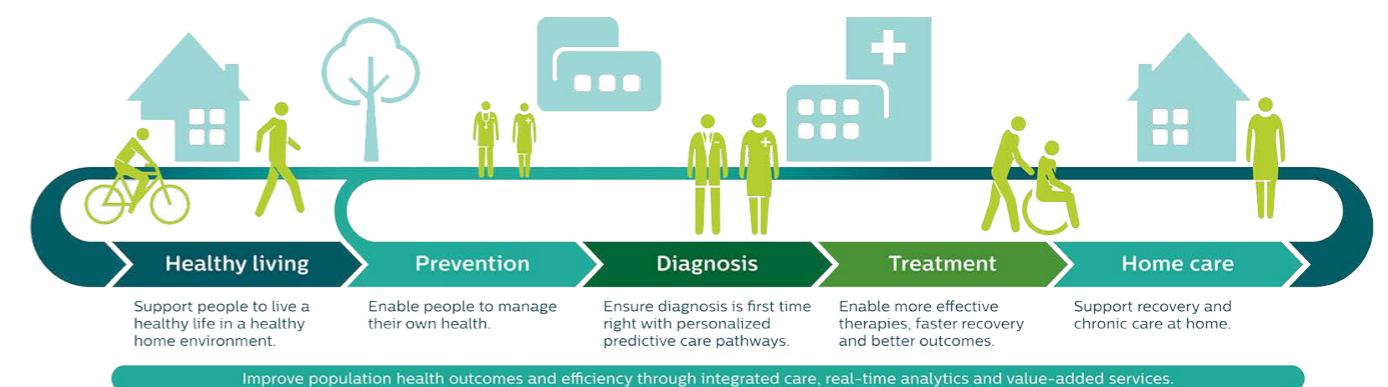


Figure 2 - Health care continuum proposed by Philips



## 1.2 // ASSIGNMENT

The health care industry is widely exploring and introducing eHealth services due to its potential to enhance efficiency, accuracy and availability of health care (Ahern, 2007). eHealth services, and the data that it generates, can support in tracking health outcomes of specific patient segments to create segment specific interventions. eHealth services, like telemonitoring, bring opportunities for patient self-care and better care management by care professionals. This is especially interesting for prevention and management of chronic diseases since they drive up the demand for health care resources (Deloitte, 2019).

Care professionals can use data from telemonitoring services to improve diagnostics, clinical therapy determination and overall care management. Additionally, there is a strong movement to share patient health data for secondary purposes, like clinical research (Emam, Rodgers, & Malin, 2015). The growing availability of Electronic Medical Records (EMR) provide an important opportunity for clinical researchers to have access to larger quantities of data. Researchers can use this data to create a better understanding of disease patterns, treatment efficacy, and the contribution of genetic and other factors in health. In combination with technologies like predictive analytics, more personalized care could be provided (Kankanhalli, Hahn, Tan, & Gao, 2016). This is beneficial for the patient because it can increase the quality and accuracy of treatment and therefor enhance the overall experience.

However, patients also express concerns regarding the privacy, security and integrity of their health data. Studies show that these concerns are sufficient enough to lead people to refuse to share health data or to strictly limit its use (Kim, Sankar, Wilson, & Haynes, 2017). In addition, most patients who share their health data for research are not well informed about the value of their health data and research outcomes derived from using their data. Not enough effort is made to let patients know the results of the research and what the implications are for society, let alone for patients themselves (KPMG, 2015). In addition, research outcomes are not provided as a

service and in an easy-to-understand way (Olson & Downey, 2013). Next to previously addressed concerns, this also influences patients' willingness share health data to improve clinical care.

### CONCLUDING

eHealth can have major implications in how care for chronic diseases can be provided and improved. At the same time, patients express concerns on the safety of eHealth services and are not thoroughly informed on how patient health data can improve both individual and public clinical care. Therefore, the opportunities of eHealth and patient health data are not yet fully utilized to improve the patient experience and clinical care.

### GOAL

The project aims to develop a health data ecosystem which envision a way of strategically obtaining patient health data to improve clinical care. This health data ecosystem will be put into practice with a use case by designing a new proposition that incorporates technology, social and organizational solutions.

This ecosystem will be used to answer the following research question:

**How should care providers strategically obtain patient health data, in order to improve individual and public clinical care?**

## 1.3 // PROJECT APPROACH

In this section, the approach of the project will be presented. Although this report is described chronically, the process the project has been through has been performed iteratively where multiple diverging and converging phases took place. First, a theoretical ecosystem will be created with knowledge gained during a preliminary research. This theoretical ecosystem can be applied to the FHC case. The theoretical ecosystem envisions a way of strategically obtaining patient health data to improve individual and collective care. With the FHC case, the theoretical ecosystem will be put into practice and used as a research tool. Finally, contributions and recommendations for Deloitte and FHC, the outcomes of the FHC case will be evaluated at the end of the report.

### Theoretical ecosystem

To develop the envisioned ecosystem that can be used during the FHC case, the project will first explore the Dutch health care sector, trends, challenges and directions the industry is moving into. Since designing ecosystems involves several steps and is highly iterative, this process is guided by using the model proposed by den Ouden (2012). With the insights gained in chapter 2, the theoretical health data ecosystem will be designed in chapter 3. This process is illustrated by a short discover/define phase during the preliminary research.

### Frisian Health Campus case

The FHC case is introduced in chapter 4 and. The case consists out of three phases; inspiration, final design and implementation. During this use case the theoretical ecosystem is used to guide research, ideation and concept development. The use case of a result of a collaboration between Deloitte and FHC focussing on legal aspects of health data sharing for research. However, the desirability from a user perspective is still unclear. This project uses the Double Diamond model (British Council, 2019) to discover, define, develop and deliver a concept-ready-to-pilot solution to FHC incorporating a user, business and technological perspective on health data sharing for research. This process is illustrated on the right. The graph expands during a diverging phase (discover and develop) and narrows during a converging phase (define and deliver).

On the next page the approach is visualized in more detail explaining per phase what, who and how topics in this project are addressed.



Figure 3 - Approach and chapter overview

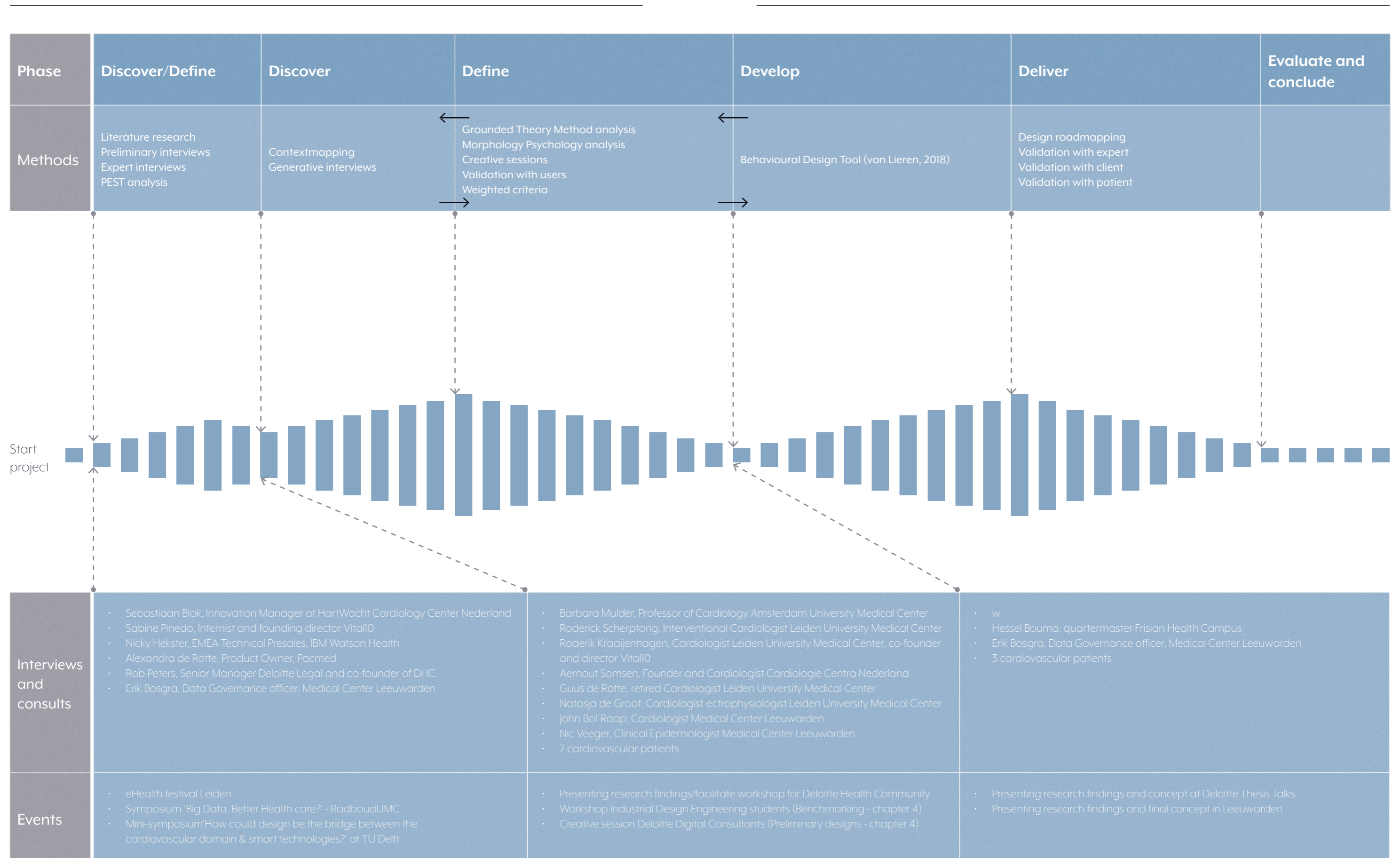
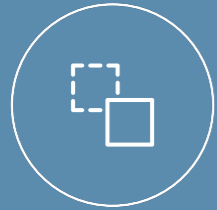


Table 1 - Detailed overview of process



# KEY TAKE-AWAYS CHAPTER 1



## BACKGROUND

In coming years, it is expected the health care industry will shift from volume to value based care. This thesis will use the concept of Value Based Health Care (VBHC) to create a future scenario which envision a way of strategically obtaining patient health data to improve clinical care. Theoretically, this data can be used to manage and improve both individual and public clinical care. Therefore, this thesis will use the three main principles of VBHC; tracking health outcomes of a specific patient segment to be able to provide segment specific interventions.

In addition, more elaborate research will be done on key enablers (informatics, research and tools) supporting these three main principles.

To clarify, this thesis will not look into 'value-based payments', 'delivery organizations', 'public policy', 'benchmarking' and 'tracking outcome costs.'



## ASSIGNMENT

eHealth services are currently being explored due to its potential to deliver value based care. Health data generated by eHealth services can be used for research to improve individual and public clinical care. At the same time, patients express concerns regarding safety of eHealth and are not thoroughly informed on how health data can contribute to improve individual and public clinical care.

Therefore, the project will answer the following research question:

**How should care providers strategically obtain patient health data, in order to improve individual and public clinical care.**



## APPROACH

The project will first build a theoretical ecosystem using knowledge gained from the preliminary research. Thereafter, this theoretical ecosystem is applied in the FHC case. The project uses the Double Diamond model to discover, define, develop and deliver a concept-ready-to-pilot solution to FHC incorporating a user, business and technological perspective on health data sharing for research. The project will close with sharing the conclusion and evaluation, contributions and recommendations regarding the project.

## CHAPTER 2 PRELIMINARY RESEARCH

### 2.0 //

The goal of this phase is to familiarize with the healthcare sector by analyzing healthcare trends and challenges, doing a market analysis, interview experts from industry and explore directions the health care industry is moving into. A framework is used to explain how organizational and technological developments within the industry open up opportunities to improve individual and public clinical care.

This preliminary research is used to build a theoretical health data ecosystem and will be introduced in the next chapter.

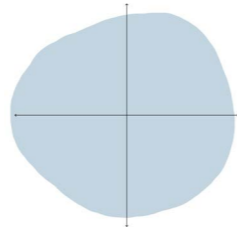
In this chapter:

- 2.1 Preliminary research overview
- 2.2 Moving towards individual care and control
- 2.3 Personalized care opportunities
- 2.4 Key take-aways



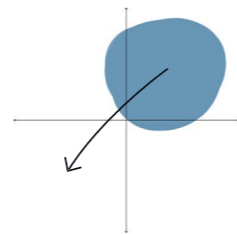
### 2.1.1 EXPLAINING THE FRAMEWORK

The health care framework is introduced briefly which will help to guide the preliminary research that is done.



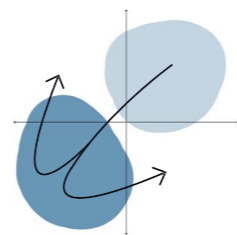
### 2.2 MOVING TOWARDS INDIVIDUAL CARE AND CONTROL

The section explains how developments in the Dutch health care system enable for better self-care and data exchange between care providers.



### 2.3 CROWDSOURCING CARE

The section explains how the changing health care environment opens up opportunities to improve clinical care collaborative.



### 2.1.1 EXPLAINING THE FRAMEWORK

A framework (figure 4) is created which is used to visualize how organizational and technological developments are changing the health care sector. The vertical axis describes the location clinical care is being provided and can be either centralized or remote. Centralized care means that you as a patient have to go somewhere to receive the care needed. Remote care enables patients to receive care from their homes or other distant locations. The horizontal axis describes the individual and public approach to clinical care. The public approach means that improvement of clinical care is based and focused on myriad input and that it is network orientated. The individual approach means that improvement of care is based and focused on individual input and that it is singular orientated. Consecutively, the framework is used in the following paragraphs to illustrate how the health care system is moving towards a more interoperable ecosystem where centralized, remote, individual and public care is merging. Eventually, the framework and all insight gained during the preliminary research are used to build a theoretical health data ecosystem. Additionally, a market analysis is done to show how Dutch health care providers are adapting to the fluid health care landscape. A more detailed version of this analysis can be found in appendix A.I.

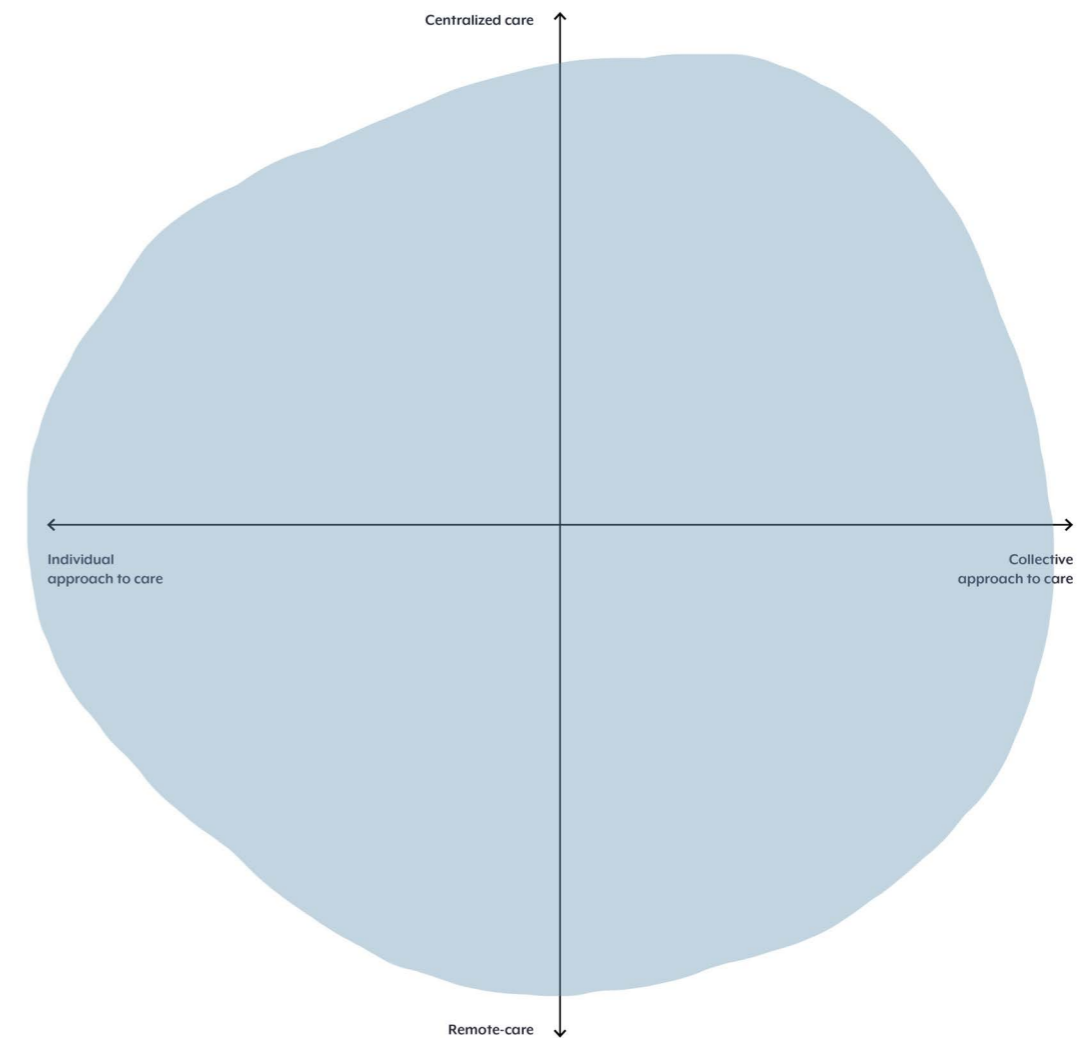


Figure 4 - Health care framework

## 2.2 // MOVING TOWARDS INDIVIDUAL CARE AND CONTROL

### 2.2.1 DRIVING FORCES

Where hospitals and research institutes previously provided more centralized care and research, they are now starting to use and discover a more individual approach to improve and provide clinical care. There are two main indicators for this, the increasing need and availability for self-care and the introduction of the General Data Protection Regulation (GDPR) which give patients more control over their own health data. This paragraph will look into self-care patients and the infrastructure that enables self-care and interoperability of care systems. These findings provide input for the theoretical health data ecosystem.

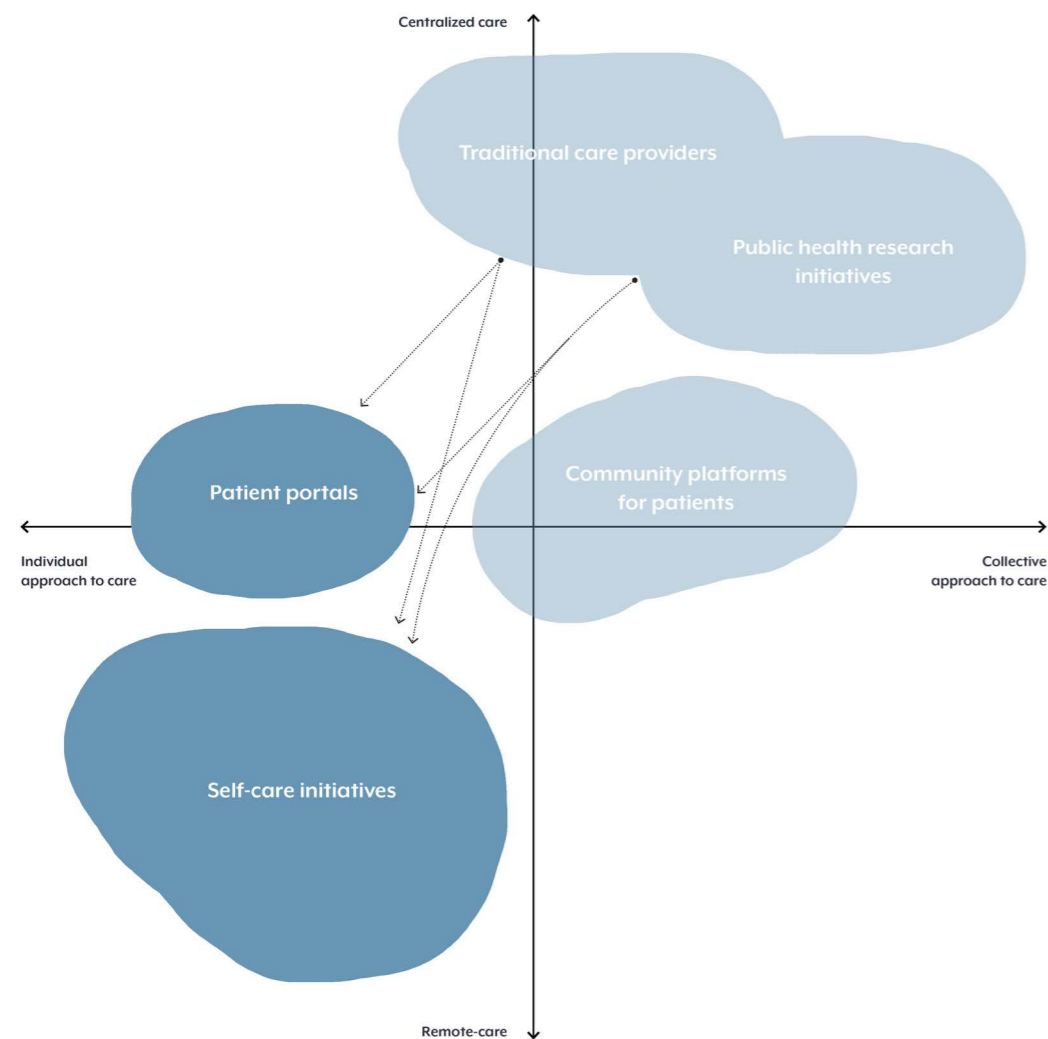
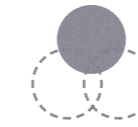


Figure 5 - Visualization of how care providers are moving into individual focused care

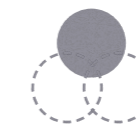
### PEST ANALYSIS

Social-political



Since May 2018 the General Data Protection Regulation (GDPR) is in effect (European Commission, 2018). This law protects and empowers all European citizens' data and privacy and results in people having more control over what happens with their personal data and who could use it. In the Netherlands this law is also called 'Algemene Verordening Gegevensbescherming (AVG)'.

Social-political



Self-care will become necessary to manage the increasing work pressure. Jan Kimpen, Chief Medical Officer at Philips Health states: "We cannot afford to continue to deliver care as we do currently. With increasing numbers of chronic patients and accompanied increasing workloads for health care professionals, patient engagement and self-care of patients will become necessary" (Groenendijk, 2017). In parallel, with more opportunities to find information and measure your own health, patients themselves are becoming more engaged in their health and care (Vahdat et al., 2014).

### 2.2.2 SELF-CARE

To maintain health, and prevent and manage chronic diseases, self-care is fundamental (Riegel et al., 2009; World Health Organization, 1983). Self-care will become increasingly important to manage the increasing workloads for care professionals. In addition, self-care will be important to track health outcomes which care professionals can use to better manage patient care and improve overall clinical care. In this paragraph more will be explained about self-care, the different levels of self-care and how technology creates opportunities in self-care.

#### SELF-CARE EXPLAINED

In the cardiovascular literature, self-care is described as the process where patients maintain health through health-promoting practices (prevention) and managing illness (Riegel et al., 2017). Self-care incorporates 1) self-care maintenance 2) self-care monitoring and 3) self-care management. These three areas combined enable efficient and effective

self-care. When developing self-care solutions, design interventions can be targeted and organized around these areas.

#### Self-care maintenance

Maintenance describes the importance of adherence to actions and behaviours needed to secure a physical and mental stability. These include, for example, taking medication, occasional exercise and a balanced diet. Motivation and capability are important factors which can affect actions and behaviour.

#### Self-care monitoring

Monitoring is the process of observing yourself to identify changes in signs and symptoms. For instance, measuring weight, blood pressure and heart rate can provide a patient and care professional with more information and help in decision making. To properly monitor, tools and a clear reference point are needed.

## Self-care management

Management describes how capable a patient is to responds to changing signs and symptoms when they occur. An active role in treatment planning, implementation and adjustment by the patient is expected.

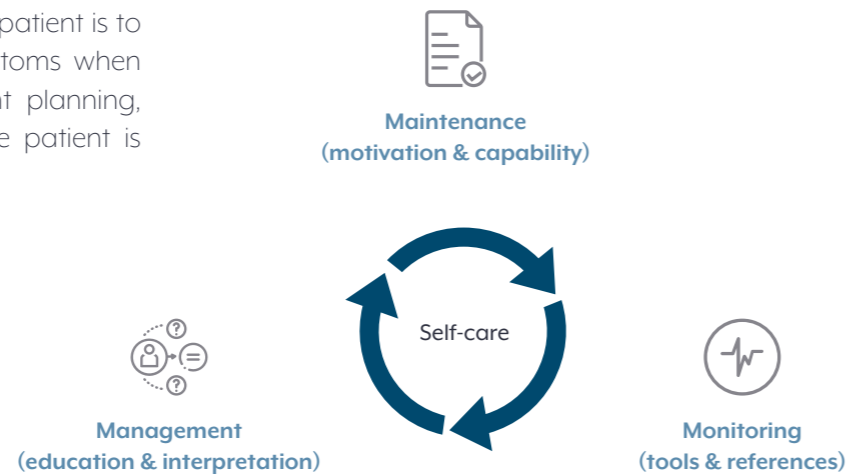


Figure 6 - Visualization of self-care that incorporates three elements

## LEVELS OF SELF-CARE

Often, self-care is seen as merely an individual-level behaviour while in reality it occurs in the individual, family and community level. When developing self-care solutions these different levels should be considered since they can all influence and contribute to the efficacy of self-care (Riegel et al., 2017).

### Individual level

Knowledge, skills, confidence and motivation are necessities for effective self-care at the individual level. Several studies show that knowledge through education is essential for self-care, but knowledge solely doesn't have a significant impact to improve behaviour. In parallel, self-care needs skill to be able to apply the knowledge gained. These skills can be more tactic ('how to') or context ('what to do when') orientated (Dickson & Riegel, 2009; Dickson, et al., 2013).

### Family level (informal caregiver)

Self-care at the family level can be influenced by the social support someone receives. This is amplified by the fact that task-specific confidence or efficacy is usually higher in the informal caregiver than in the patient (Li et al., 2015).

### Community level

The community level provides the opportunity to connect to a network which can provide support, social trust, and information. This can be helpful in achieving health goals in self-care (Lin, N., 2001; Bolin et al., 2003). Several community-based self-care programs show significant enhancement in self-care maintenance and management by participants (Dickson et al., 2014; Campbell & Aday, 2001; South et al., 2010).



Figure 6 - Different levels of self-care

## SELF-CARE SUPPORTED BY TECHNOLOGY

Traditional, face-to-face, self-care programs are proven to be effective (Sol et al., 2005; Sol et al., 2011; Janssen et al., 2013). However, an extensive part of patient's care depends on self-care skills. Many aspects of self-care can be supported by evolving technologies, like telemonitoring devices and smart monitoring. These technologies can increase the reach of delivering more efficient and affordable health care services. In addition, it can provide chronic patients and care providers a tool to engage in active, real-time collaboration regarding clinical care.

Numerous telemonitoring devices are currently on the market which can be used to measure relevant biomarkers of patients (e.g. weight, blood pressure, heart rate). Devices that are being used for clinical purposes first need to be checked and approved by the Food and Drug Administration (FDA) (U.S. Food & Drug Administration, 2018). The FDA assures that these devices are safe, effective and of high-quality for patients and care providers to use.

### Patient Generated Health Data (PGHD)

Data from telemonitoring services is also called patient-generated health data (PGHD). (The Office of the National Coordinator of Health IT defines PGHD as "health-related data created, recorded, or gathered by or from a patient (or family members or other caregivers) to help address a health concern."). This data can provide a broad window into patients' health across the health care continuum (Kilbridge, 2018). PGHD can be used to provide predictive care to patients in two ways. First, when a patient shares generated health data with care providers this data can be screened by a personalized algorithm. When this data deviates from standard data, care professionals receive a notification and necessary advice, interventions or consults can be scheduled or provided. Second, PGHD can be used to improve treatment plans. With this data, predictive models can be created that can be used by care professionals to provide more personalized treatment plans. This will be explained in more detail in chapter 2.3.

## Telemonitoring for work capacity management

As discussed, workloads for care professionals are increasing. Self-care of cardiovascular patients using telemonitoring will be key in reducing workloads and enable care specialists (e.g. cardiologist) to provide care to patients who need it the most. This is illustrated in figure 7 on the next page. From left to right is demonstrated how monitoring health and remote advice and support from care professionals (e.g. a nurse) can distribute the capacity of care. Number 1 illustrates the current way of providing care to patients. Currently, a lot of patients visit their care provider even when they are in good health. Hospital visits of healthy patients are often unnecessary and have an impact on the work capacity of care providers. If patients would monitor their health (e.g. weight, blood pressure, heart rate), as illustrated in number 2, only patients who need advice or support will need to visit their care provider. Often, this advice and support is a medication and/or lifestyle intervention and can be done by a care professional. When these type of interventions are done remotely (e.g. eConsult), the work capacity of the specialist can be used for patients who really need their expertise. Such a telemonitoring service creates value for both the patient and the cardiologist. On page X a visualization of such a service is presented.

### Value of periodic monitoring

There are 8760 hours in a year of which chronic patients spend approximately 10 hours, or 0.001%, with their health care provider (Riegel et al., 2017). Only on these moments care professionals are able to measure biomarkers which they can use to provide advice to patients. However, for care providers to provide the right care at the right time it is often necessary they have periodic insight in the health of a patient. The previous introduced combination of self-care and technology enable for better prevention and management for chronic diseases. Such a telemonitoring service is visualized in figure 8 on the next page.

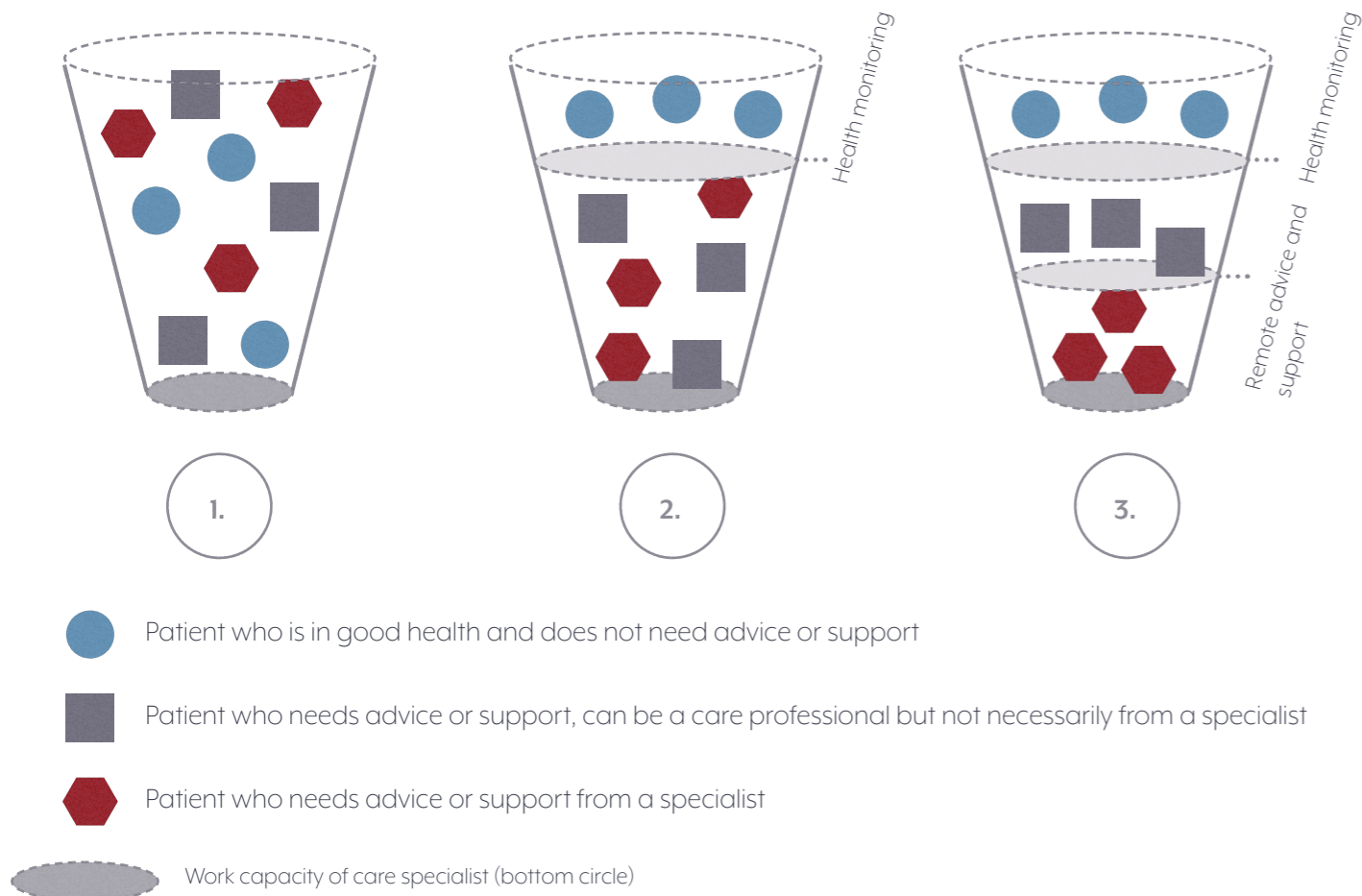


Figure 7 - Impact of a smart telemonitoring service on work capacity of care providers

### Telemonitoring service HartWacht

Hartwacht is an initiative that is created by Cardiologie Centrum Nederland (CCN). With Harwacht, patients are able to measure their blood pressure, weight and heart rate in their own homes with telemonitoring devices. This data is automatically being screened by Hartwacht's platform and when patient data deviates it will send a signal to the patient care provider. The patient can have an eConsult (i.e. phone-/videocall and online chat) with his care provider for information and advice or can visit a care clinic when necessary. This way, Hartwacht tries to limit unnecessary hospital visits. This continues monitoring leads to better care quality because the right care interventions can be provided at the right time.

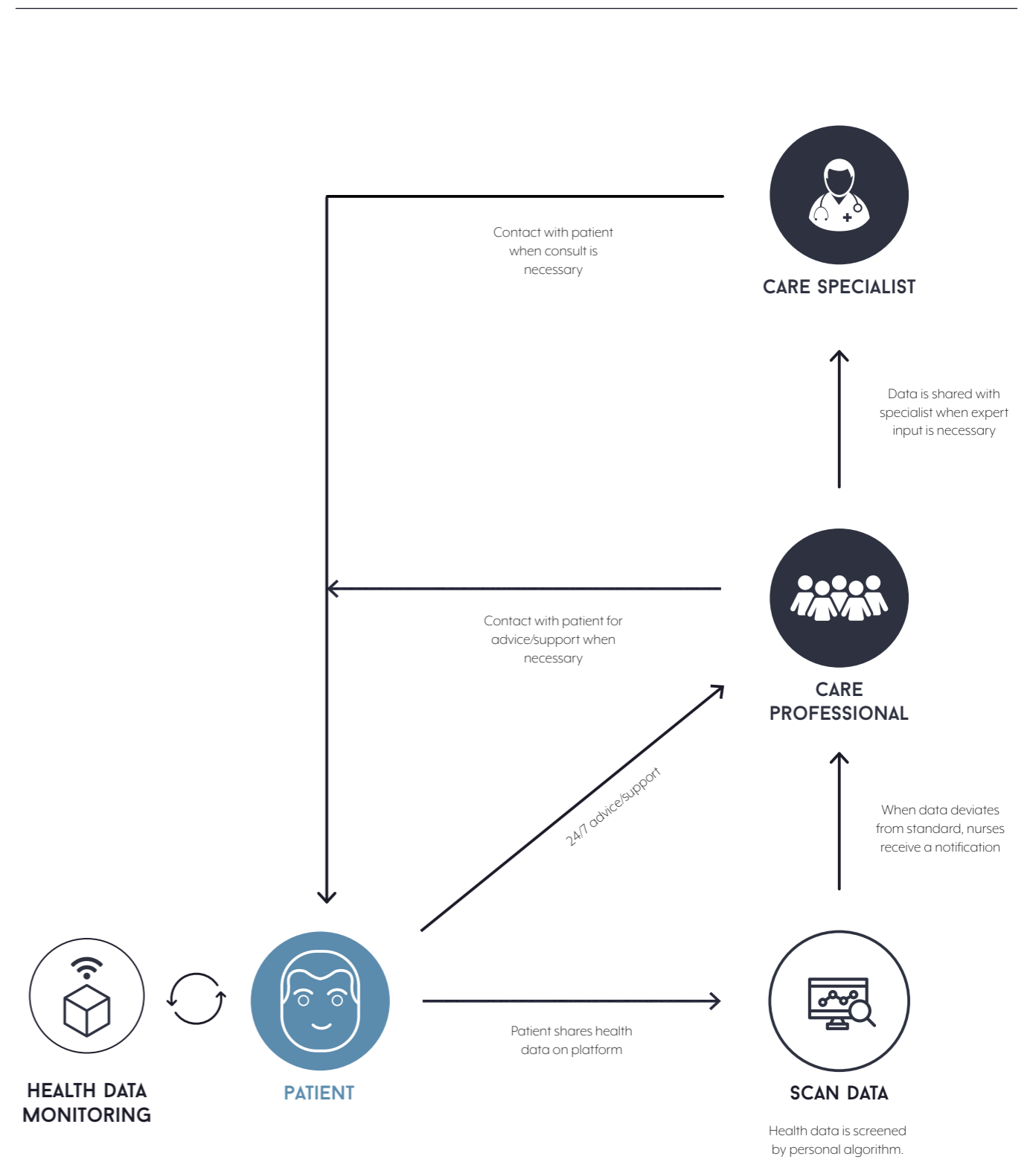


Figure 8 - Visualization of a theoretical telemonitoring service with smart monitoring



## 2.3 // CROWDSOURCING CARE

### 2.2.3 CARE IT INFRASTRUCTURE

To better understand how the theoretical health data ecosystem can be positioned in the Dutch health care system, an analysis of the IT infrastructure is done. These insights will be used to show how patients can control their own health data and how care professionals can use this data to improve preventive and clinical care. It also illustrates the opportunities of interoperable health care systems.

#### Persoonlijke Gezondheidsomgeving

In the Netherlands there are so called 'Persoonlijke Gezondheidsomgevingen (PGOs). These are online platforms which give patients access to their medical data from various care providers portals (Landelijke Huisartsen Vereniging, 2019). This way, patients can better collect, manage and share their medical data (e.g. lab results from hospitals or medication). In addition, these platforms also provide the opportunity to provide eConsults or let patients upload personal generated health data (Patiëntfederatie Nederlands, 2019). These platforms should support the integration of eHealth applications in the health care system (MedMij, 2019) and provide patients the opportunity to have more control over their own health care.

MedMij is a Dutch company that creates regulations for PGOs regarding privacy, security and integrity of data exchange. Each PGO needs a MedMij-label before they can become active. Care providers providing the data to a PGO should also be compliant with MedMij regulations before collaboration is possible (MedMij, 2018).

#### Electronic Health Record (EMR)

Patient health data can be disclosed in Electronic Medical Records (EMR). Currently, most care providers in the Netherlands have integrated such a digital system to keep track of and store patient health data. However, because there are multiple software (e.g. ChipSoft and Epic) companies providing these platforms, care providers cannot exchange EMR when necessary.

#### 'Landelijk Schakelpunt (LSP)'

The LSP is not a database with medical data, it is a secured infrastructure network which connects different EMRs of separate care providers. The LSP is divided in 44 regions. Within a region, care providers (e.i. hospitals, insurances, general practitioners, etc.) are allowed to share EMRs only when the patient explicitly provided permission to do this (due to GDPR).

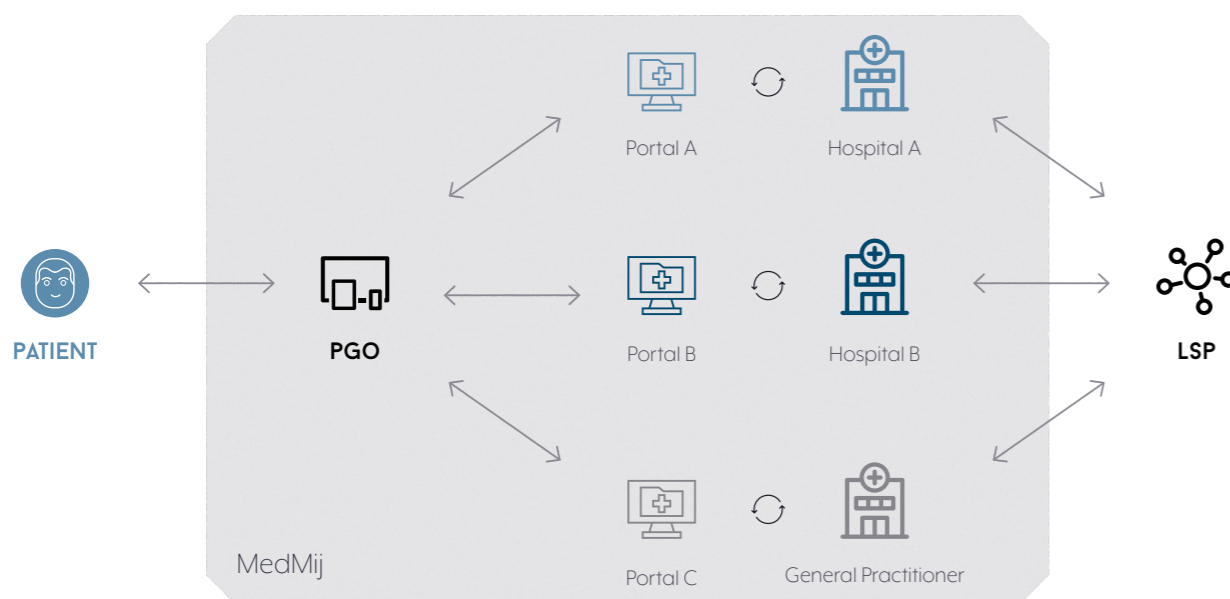


Figure 9 - Theoretical visualization of data sharing infrastructure between patients and care institutes

### DRIVING FORCES

With an increasing number of self-care initiatives and possibilities of interoperable health care systems, new opportunities to improve clinical care arise. Digital technologies, like data mining and machine learning, can use patient health data to build predictive models. These models can be used by care professionals as decision support tools to provide patient specific treatment. This way, an individual patient who generates health data can become an important contributor to improving both individual and public clinical care.

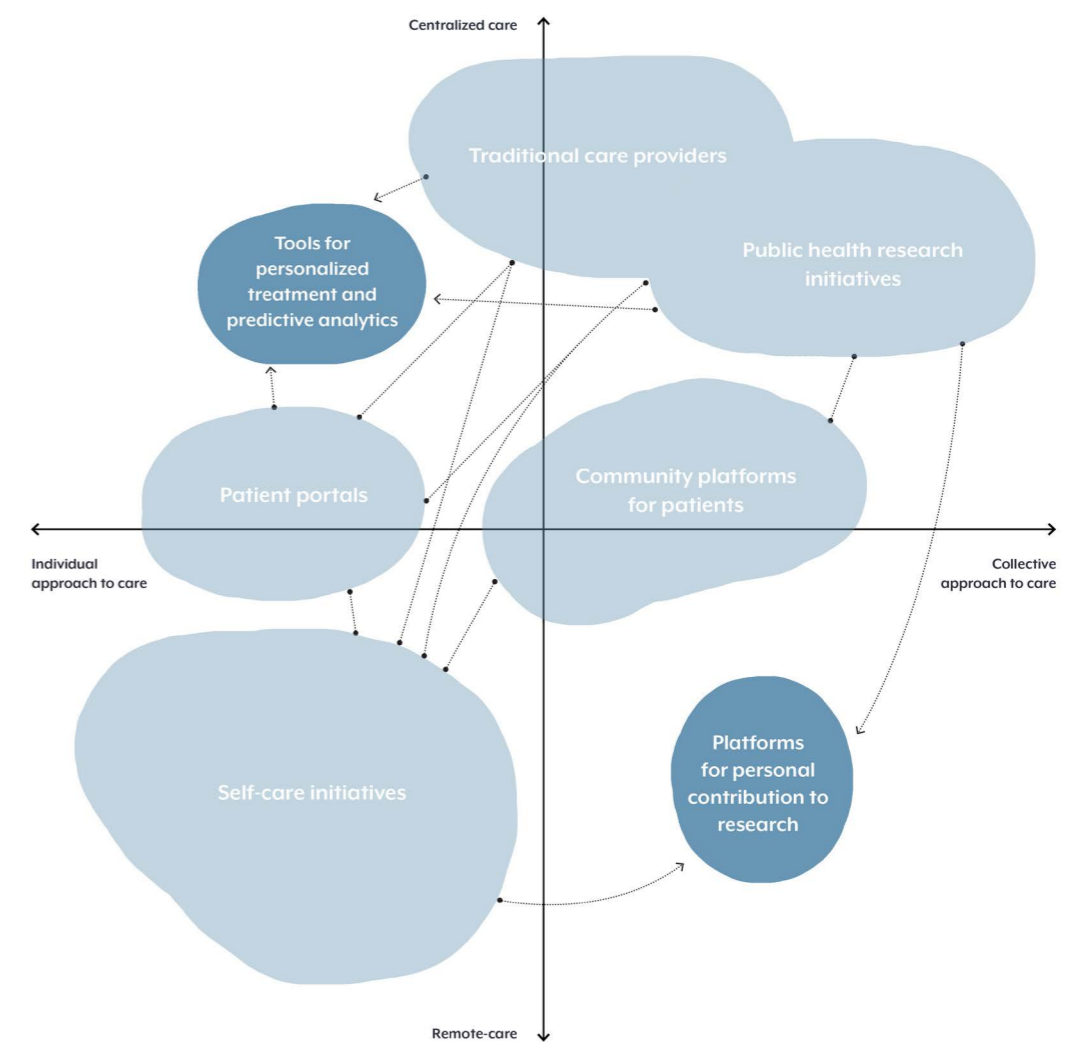


Figure 10 - Opportunity areas for clinical care improvement

### 2.3.1 HEALTH DATA & PERSONALIZED TREATMENT

All previous chapters briefly tapped into the opportunities of using Patient Generated Health Data (PGHD) to provide more personalized care. This paragraph explains what the implications are of PGHD to provide segment specific intervention. First, the current treatment process will be discussed which shows the limitations of providing personalized and predictive care. Then, more will be explained about predictive analytics for segment specific intervention.

#### CURRENT TREATMENT PROCEDURE

Currently, doctors use a trial and error approach to find the best treatment for individuals. When we are treated for a disease we receive treatments based on what worked best for the majority of people, or the statistical average person (Figure 10). These treatments are based on guidelines and evidence derived from scientific research with randomized

controlled trials (Khuc, J, 2018). The problem with these treatments is that the evidence is based on restricted patient populations (little co-morbidity, not including older patients, children, etc.) (Singh, Schulthess, Hughes, Vannieuwenhuysse, & Kalra, 2018). For example, people with high cholesterol can be treated with statins, but the effectiveness of this treatment (using statins) is based on research that is done with people only having high cholesterol. However, in reality, people can have multiple diseases or take multiple medication. In the Netherlands, around 35% of the population aged 50 years and older report they suffer from more than chronic disease, also called multimorbidity (European Commission, 2013). And around 20% of patients older than 65 take more than 5 medicines at the same time. (RIZIV, 2014). For doctors it is therefore very difficult to make treatment decisions because they don't know if evidence derived from one group also work for individuals of another group.



Figure 11 - Visualization of how current treatment is based on the statistical average person. Figure derived from presentation of Wouter Kroese (founder Pacmed)

### MACHINE LEARNING FOR PATIENT SPECIFIC TREATMENT

In chapter 1.1 (VBHC) , it was discussed that value for patients can be improved by developing and providing customized treatment. During the care process of patients, a lot of data is being generated and saved by the care professional for administrative purposes. This data can be patients' DNA, CT/MRI scans, lab values, medication, questionnaires, measurements taken during visits or data generated by telemonitoring devices. These large quantities of data can be used for predictive analytics. With predictive analytics, data predictions are generated using statistical techniques like modeling, machine learning, and data mining. Predictive analytics is the process of examining real-time and historical data and train models using machine learning to make predictions about the future (Kankanhalli, Hahn, Tan, & Gao, 2016). Around the world, it is believed that predictive analytics will be the next revolution in medicine (Winters-Miner, 2014). These models could learn which treatment worked previously for patients with a diverse set of characteristics, medications

and complaints and use this knowledge to provide more personalized treatment. For instance, when a person needs treatment for both high cholesterol and diabetes, treatment will be based on evidence derived from what worked for people with this same set of conditions (figure 12). Predictive analytics can also be used to monitor patients and provide relevant treatment interventions (i.e. lifestyle, medication or other interventions) to reduce unnecessary hospitalizations or readmissions (Kankanhalli, Hahn, Tan, & Gao, 2016). For this, personalized algorithms need to be developed so it can track when certain data of a patient deviates. Predictive models could be used by doctors as a decision support tool when deciding on a treatment plan for a patient and allows them to provide more personalized care along the care process. This thesis will use the concept of predictive analytics for the theoretical health data ecosystem.

Several companies and institutes are doing extensive research on predictive analytics and are building models that can be used by doctors in daily practice. Two of them will briefly be introduced on the next page.

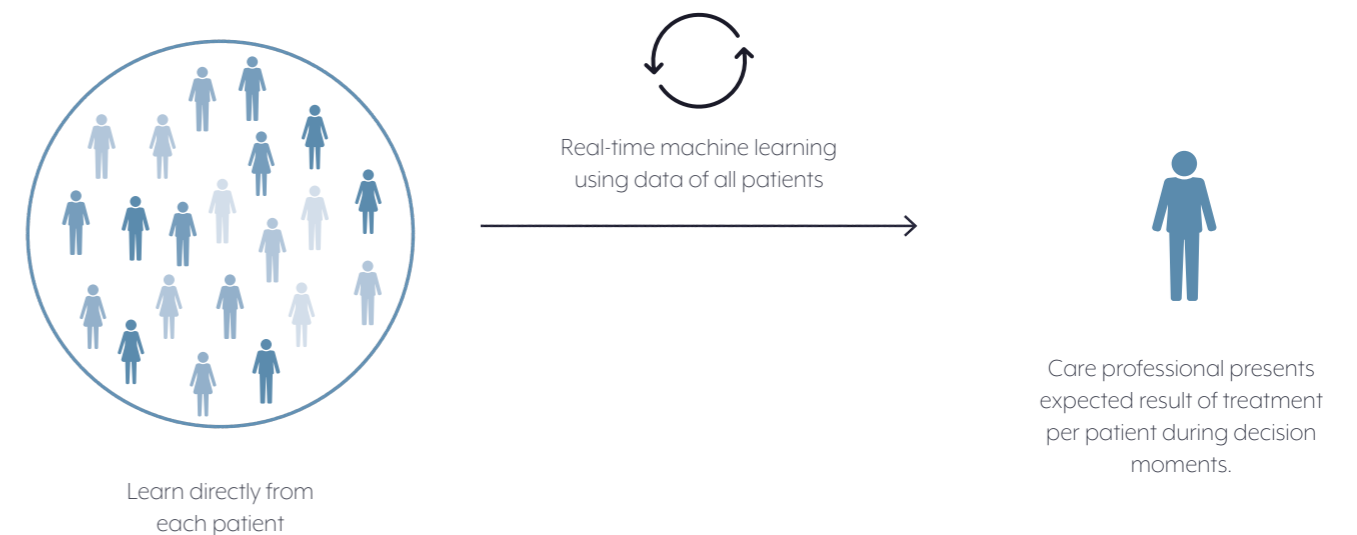


Figure 12 - Visualization patient specific treatment. Figure derived from presentation of Wouter Kroese (founder Pacmed)





### IBM Watson Health

IBM Watson Health is a platform that combines health data, analytics and AI to solve challenging health care problems. The platform aims to turn data and knowledge into actionable insights that can be used by care professionals and researchers to make better informed decision about care for their patients (Watson Health, 2018). One of the platform's capabilities is patient similarity. Kyu Rhee, Chief Health Officer at IBM Watson Health explains: 'patient similarity identifies patients who are similar to a given patient in a clinically meaningful way and identifies a measure of clinical similarity between patients. This allows us to create dynamic patient cohorts, rather than static patient cohorts, and enables an understanding which care path works better for a given group of patients' (Watson Health, 2018).



### U-prevent UMC Utrecht

U-prevent is a tool that is developed by UMC Utrecht and can be used by care professionals to provide patients personalized vascular medicine. By comparing individual patient data (i.e. blood pressure, weight, age, medication, cholesterol levels) with validated big data research models, personal risk profiles can be created. These profiles can support in decision making regarding patient treatment (U-Prevent, 2019). Founder of U-prevent, Frank Visser, professor of vascular medicine UMC Utrecht states: "Worldwide, people use medication to reduce high blood pressure or cholesterol to prevent a cardiovascular disease. Research shows that on average this medication is effective. However, medication does not work the same for everyone. With U-Prevent we can now calculate what the optimal medication is for individual patients" (UMC Utrecht, 2018).

'In the not too distant future not using AI or a Decision Support System will amount to medical negligence'

Demis Hassabis, Google DeepMind Founder

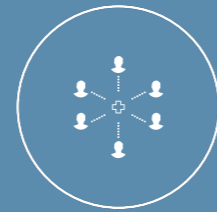


# KEY TAKE-AWAYS CHAPTER 2



## INDIVIDUAL CARE AND CONTROL

Self-care is an important to manage the increasing workload of care providers and create opportunities to improve clinical care of individuals and clinical care in general. In self-care there are three different areas to identify which together enable patients to be more independent; self-care maintenance, management and monitoring. When designing for self-care we should keep in mind that self-care can occur on the individual, family (informal caregiver) and community level and that all levels can influence and contribute to the efficacy of self-care. The growing availability and development of technology has the opportunity to support self-care. Currently, there are interesting initiatives that provide the tools and service for self-care, like HartWacht. However, data that is being generated by patients opens up doors to improve clinical care even more. Therefore, it will become increasingly important to provide patients the knowledge and skills to contribute to individual and public clinical care.



## CROWDSOURCING CARE

Current ways of treatment are based on what worked for the statistical average person of a specific disease. However, a growing number of people are suffering from multimorbidity and take more type of medicine at a time. For care providers it is challenging to provide the right treatment for these types of patients because keeping track of interfering treatments becomes more difficult. Predictive analytics is believed to be the next revolution in health care. This technology can be used by care professionals as a supporting tool to tailor treatments or to provide timely treatment interventions to patients in order to reduce unnecessary hospitalizations or readmissions. Making patients aware of these opportunities is an important step towards improving clinical care together.

This thesis will use Patient Generated Health Data (PGHD) in the following three areas:

- For self-care by patient on their own devices;
- To provide timely interventions to patients by care professionals;
- To build predictive models that can be used by care professionals as a supporting tool to provide tailored treatment.



## ADDITIONAL FINDINGS

A market analysis is done to explore how different actors in the Dutch health care industry fit in the health care framework that is used in this chapter. Results from this analysis can be used in the FHC use case to identify potential partners. The framework with all actors can be found in appendix A1.



## CONCLUDING

The preliminary research and framework show that individual, public, centralized and remote care is becoming more interoperable. This increasing interoperability allows for new ways of how care and research can be organized and designed. Combining insights from self-care, interoperable health care systems and technological developments to provide more patient specific treatment, a theoretical health data ecosystem to improve both individual and public care can be created.

# CHAPTER 3

## THEORETICAL HEALTH DATA ECOSYSTEM

### 3.0 //

In this chapter the theoretical ecosystem is introduced. Designing a new ecosystem involves several steps and is a highly iterative process. First, a target segment is chosen for which the theoretical health data ecosystem will be designed. Second, an initial value proposition is created for the new ecosystem. Third, an operative model will be showed and explains how the ecosystem works. Fourth, the individual and public value the ecosystem provides is visualized and explained. Finally, a value flow model is visualized and explains the offerings and interactions between stakeholders in the ecosystem. This theoretical ecosystem will be used for user the research phase to gain a better understanding of how the value proposition addresses motives and needs of targeted users.

In this chapter:

- 3.1 Target segment
- 3.2 Initial value proposition
- 3.3 Initial interaction flow model
- 3.4 Initial value flow model
- 3.5 Key take-aways

# 3.1 // TARGET SEGMENT

## 3.1.1 CHRONIC DISEASES AND CARDIOVASCULAR DISEASE

A key principle of VBHC is to create population segmentations and track health outcomes which enable segment specific intervention. In this section a segmentation will be chosen where this thesis will focus on. The reason this thesis will focus on a chronic condition and cardiovascular disease specifically, will be explained in more detail below.

### CHRONIC DISEASES

There are two main reasons why this thesis will focus on a chronic disease.

#### High burden on health care system

According to a study on world's mortality done by Wang et al. (2016), chronic diseases attribute to three in five deaths globally. The main contributors are cardiovascular disease, cancer, chronic lung disease and diabetes. Every year, 41 million people die as a result of a chronic disease which take up 71% of global deaths (WHO, 2018). Chronic diseases are also called non-communicable diseases (NCDs). These diseases tend to be of long duration and are result of a combination of genetic, psychological, environmental and behaviour factors. Health care systems are experiencing an increasing burden from chronic diseases as they increasingly take up care resources. This has made prevention and management of chronic diseases a global and local priority (Hajat & Stein, 2018). In the Netherlands 15% of health care expenditures can be linked to chronic diseases. It is expected that this number will increase with 50% between 2007 and 2025, largely as a result of unhealthy Western lifestyles (van Rooijen, Goedvolk, & Houwert, 2013).

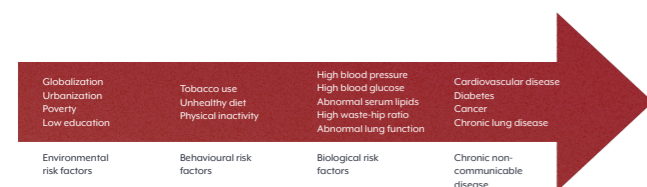


Figure 13 - Factors influencing development and progression of chronic diseases

#### Impact of technology

With eHealth it will become easier to specifically target chronic patients by designing customized sensors, devices and services. This allows for better care management from both a patient and care professional perspective. Additionally, a more engaging and sustainable way of targeting desired behaviour can be realized which can support preventive care to avert costly intervention (Price Waterhouse Cooper, 2012).

### CARDIOVASCULAR DISEASE

Cardiovascular diseases (CVDs) are the biggest cause of death globally. World Health Organization estimated that in 2016 17.9 billion people died from CVDs, which represents 31% of the world's deaths (WHO, 2017). In the Netherlands CVDs are the second biggest cause of death and were responsible for 38.119 (25,4%) deaths in 2017 (Volksgezondheidszorg, 2017).

According to the World Health Organization, high-income countries, like the Netherlands, have invested heavily in prevention and treatment of CVDs. This has led to a reduction of mortality over the years (NOS, 2019). For example, in the Netherlands, in 2016 25% of the people who experience a heart attack survived compared to 10% in the 1990's (Hart- en vaatziekten in Nederland 2017, 2017). However, an increasing survival rate results in more people living with a chronic condition. Both patients and society are burdened with the long-term and costly care that is associated with having a chronic CVD condition (McPhail, 2016) (Mendis, Puska, & Norving, 2011).

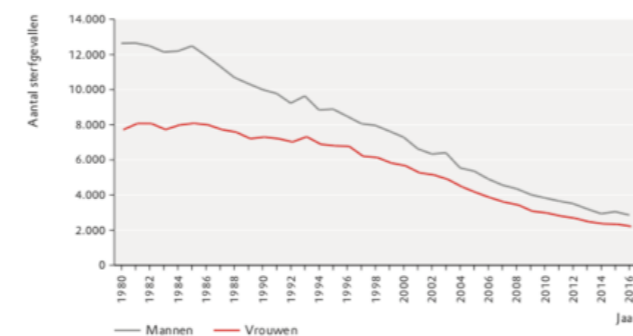


Figure 14 - Trend in mortality rate from a heart attack in the Netherlands between 1980-2016 (CBS, 2016).

### CVD progression and treatment

The term cardiovascular diseases (CVDs) is used to describe a set of conditions that affect the heart and blood vessels. CVDs are a group of disorders of the heart and blood and can be categorized depending on characteristics and section in the human body ( World Health Organization, 2017).

Acute events, like heart attacks and strokes, are mainly caused by a process called atherosclerosis. When a substance called plaque builds up in the walls of arteries, atherosclerosis is developed. This build up plaque can result in blockage that prevents blood from flowing to the heart or brain which can result in heart attacks and strokes (American Heart Association, 2017).

Causes of developing CVDs depend on genetic, psychological, environmental and behaviour factors. This means that developing CVD depends on the specific condition and case of an individual. More accurate, progression of cardiovascular disease depends on modifiable and non-modifiable risk factors. Non-modifiable risk factors include age, gender, ethnicity and family history. However, most CVDs are caused by modifiable risk factors which include behavioural characteristics such as an unhealthy diet, physical inactivity and tobacco and alcohol consumption (Center of Disease Control and Prevention, 2018). CVD treatments depend on the stage and the characteristics of the condition and can vary between behavioural, medical or surgical interventions or a combination of these (Network European Heart, 2017).

### CVD prevention

Several studies show that preventing CVD is humanly, socially and economically superior to CVD treatment using medical interventions (Kottke et al., 2009; Goldman et al., 2013; Goldman et al., 2016). It is estimated that over 75% of premature CVD is preventable and that the growing burden on both individuals and organizations can be reduced by better risk management. This makes self-care an important tool to reduce CVD mortality (World Health Organization, 2016). Because CVDs have different progression phases, there are several types of prevention. Table 2 shows the difference between primary, secondary and tertiary prevention.

This thesis will focus on secondary prevention for the following reasons (Paramie & Upeksha, 2018):

- Primary prevention only focuses on modifiable risks factors like physical activity, eating behaviour or other unhealthy behaviours such as tobacco and alcohol consumption. However, a person can have non-modifiable risk factors which cannot be controlled by an individual. Secondary prevention addresses this by problem by also providing medical interventions (medication, not surgery).
- Secondary prevention has superior benefits to that of tertiary, both from a financial perspective as the effect on daily life and the quality of life. In addition, tertiary prevention comes too late since critical conditions already developed which could result in permanent damage.
- Due to technological development introduced in chapter 2.3.1 , secondary prevention will become more accurate. These technologies can be applied to determine the susceptibility for CVD of an individual case and medication or lifestyle interventions can be provided accordingly. This increases the value care professionals can provide to patients. For example, currently, the right doses of beta blockers for a patient is found by trial and error. This can bring a lot of discomfort to the patient due to side effects of the medication. With these technologies care professionals can determine the right doses for individual cases faster. This will result in less side effects for the patient and thus increases the value of care that is provided.

Aspect	Primary prevention	Secondary prevention	Tertiary prevention
Focus	Preventing the onset of disease, by eliminating risk factors	Reducing the impact of the disease by early diagnosis before permanent damage	Managing pain and increasing life expectancy of the patient
Financial burden	Very low: mainly focusing on lifestyle changes	Medium: medical interventions cost affordable amount	Very high: surgery and other major procedures
Disruption of daily work	Low	Medium	High: requiring constant attention after medical intervention
Examples	Daily exercise, healthy diets	Beta blockers, statin treatment, lifestyle changes	Stent replacement, bypass surgery

Table 2 - comparison of primary, secondary, and tertiary prevention methods

## 3.2 // INITIAL VALUE PROPOSITION

The initial value proposition of a new ecosystem starts from a user perspective. The user is the primary target group of the proposed innovation and without its acceptance the ecosystem will fail (Ouden den, 2012). The initial value proposition will discuss for whom value is created and what value the solution offers for targeted users. The value proposition canvas is used to structure detailed information of the value proposition for the target users. The value map describes the features of the initial value proposition in a more detailed and structured way by breaking the proposition down into products/services, pain relievers and gain creators. The user profile is broken down by describing jobs, pains and gains of the target users. The value proposition canvas per target user can be found in appendix B, the value the proposition delivers to each target group will be discussed in this paragraph.

The value proposition that is created is theoretical and not based on user insights. To illustrate the added value of the theoretical proposition compared to existing solutions, user pains, gains and activities used in the value proposition canvas are derived from the preliminary research and based on how clinical care is currently provided. The value proposition will be used to build an interaction and value flow model and are presented in the next paragraphs.

### PRIMARY TARGET USERS

The theoretical ecosystem aims to create value primarily for patients who are diagnosed with a cardiovascular disease and cardiologists providing clinical care to those patients. When designing ecosystems, value for multiple users of the ecosystem can appear and/or be designed along the way. For now, this thesis will start from a patient and cardiologist perspective.

### ECOSYSTEM DESCRIPTION

The theoretical ecosystem is a product service system which uses patient generated health data from telemonitoring devices to improve both individual and public clinical care. It is a combination of a telemonitoring service and using patient generated health data to build decision support tools for cardiologists. Eventually, care providers are able to provide more personalized care using these decision support tools. This product service system allows patients to manage their care at home, while care professionals and coordinators have vital information that can be used to manage and improve individual and public clinical care. This way, a continuous-learning health ecosystem is created. In new ecosystems, platforms are necessary to connect various stakeholders, technologies, propositions and users (Aarikka-Stenroos, 2016). A simplified visualization of the ecosystem can be found in figure 16.

### VALUE PROPOSITION

For each target user a value proposition is created using the value-proposition canvas.

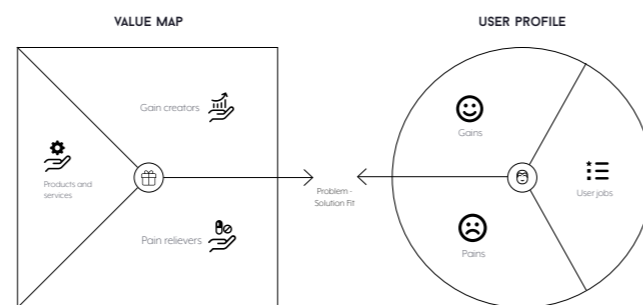


Figure 15 - The value proposition canvas

### CVD patient

*The product service system allows cardiovascular patients to receive personalized treatment and advice, have easier access to care when needed, and enables them to contribute to care easier.*

### Cardiologist

*The product service system allows cardiologists to provide patients personalized treatment and advice, enables them to provide the right care at the right time, and receive additional support during decision moments.*

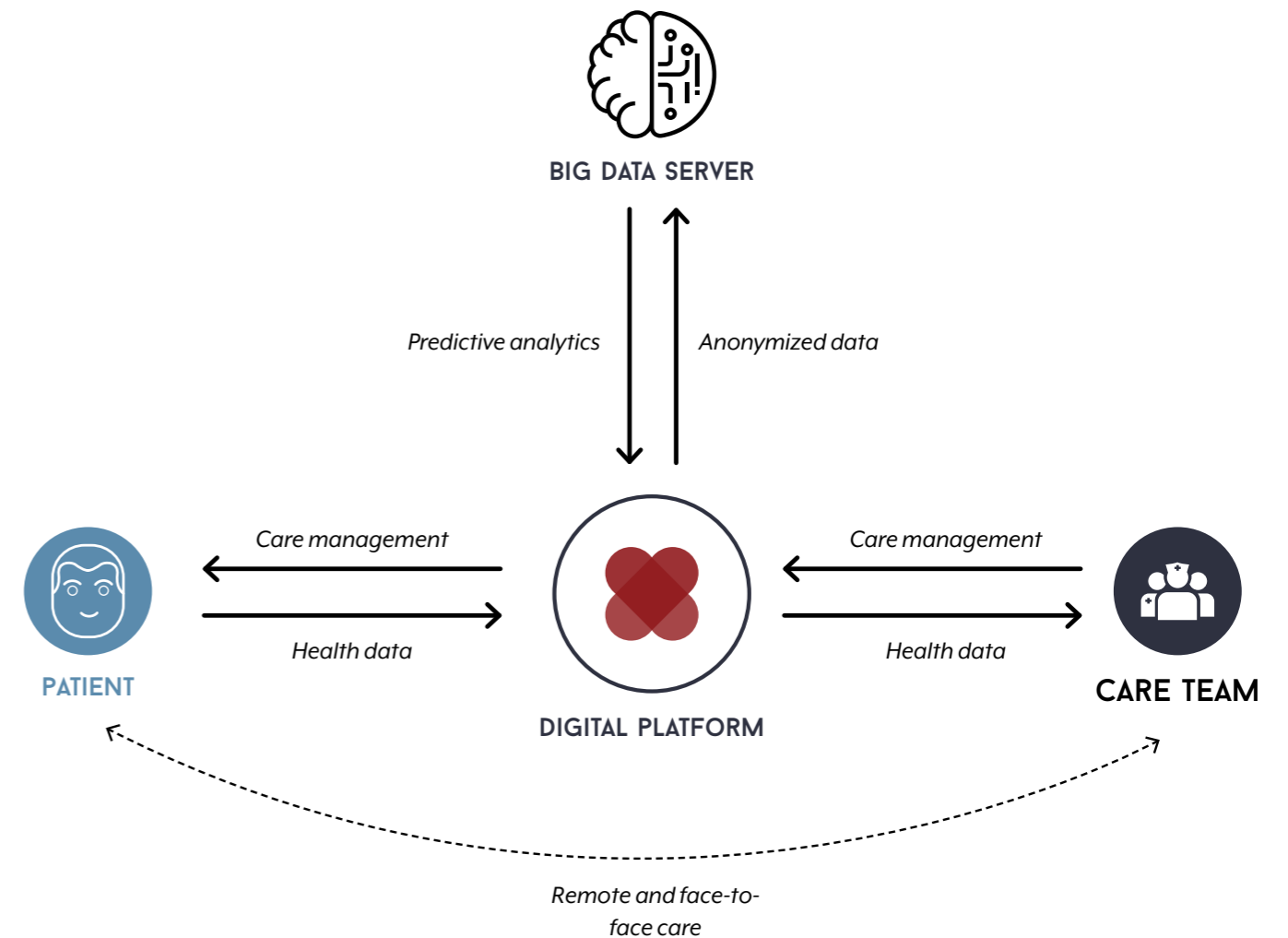


Figure 16 - Simplified visualization of proposition

### 3.3 // INITIAL FLOW MODELS

This paragraph will dive into the operational and value stream side of the theoretical ecosystem. It describes how the ecosystem works step by step. On the next page, a visualization of the interactive model can be found. The interaction flow model will be used during user research to understand how the value proposition addresses motives and needs of targeted users and discover if there is a problem-solution fit.

#### 3.3.1 INTERACTION FLOW MODEL

1. Patients using the service can monitor vital cardiac data with FDA approved devices. These devices measure, for example, blood pressure, weight and heartbeat. The patient can track his health on a platform. The data is shared with care professionals so they can track the health of the patient. In addition, the patient can ask for advice and feedback on their health and data from care professionals via the platform.

2. PGHD runs through a smart system which can detect if the patient's health is stable. If the smart system detects something ordinary it will send an alarm to a team of CVD experts for further investigation.

3. When an alarm comes in a team of cvd experts check the data. When necessary, these experts can contact the patient via phone, video or the platform to provide advice/support (e.g. medication, life style). The team can send patient data to the cardiologists when more expertise is necessary to inspect the data and provide necessary advice or support.

4. When an alarm cannot be solved by the expert team the data will be send to the cardiologist of the patient. The cardiologist will check the data to see if consult is needed change in treatment plan is necessary. If so, the cardiologist can contact the patient to schedule a consult.

5. Additionally, PGHD can be used to build decision support tools. It is important the data is being anonymized, standardizes and harmonized, making it available for further research.

6. Clinical researchers can use PGHD to do research in improving diagnoses, understand chronic diseases and developing better treatment plans. Results can be published and shared with care professionals which they can use to provide more personalized treatment.

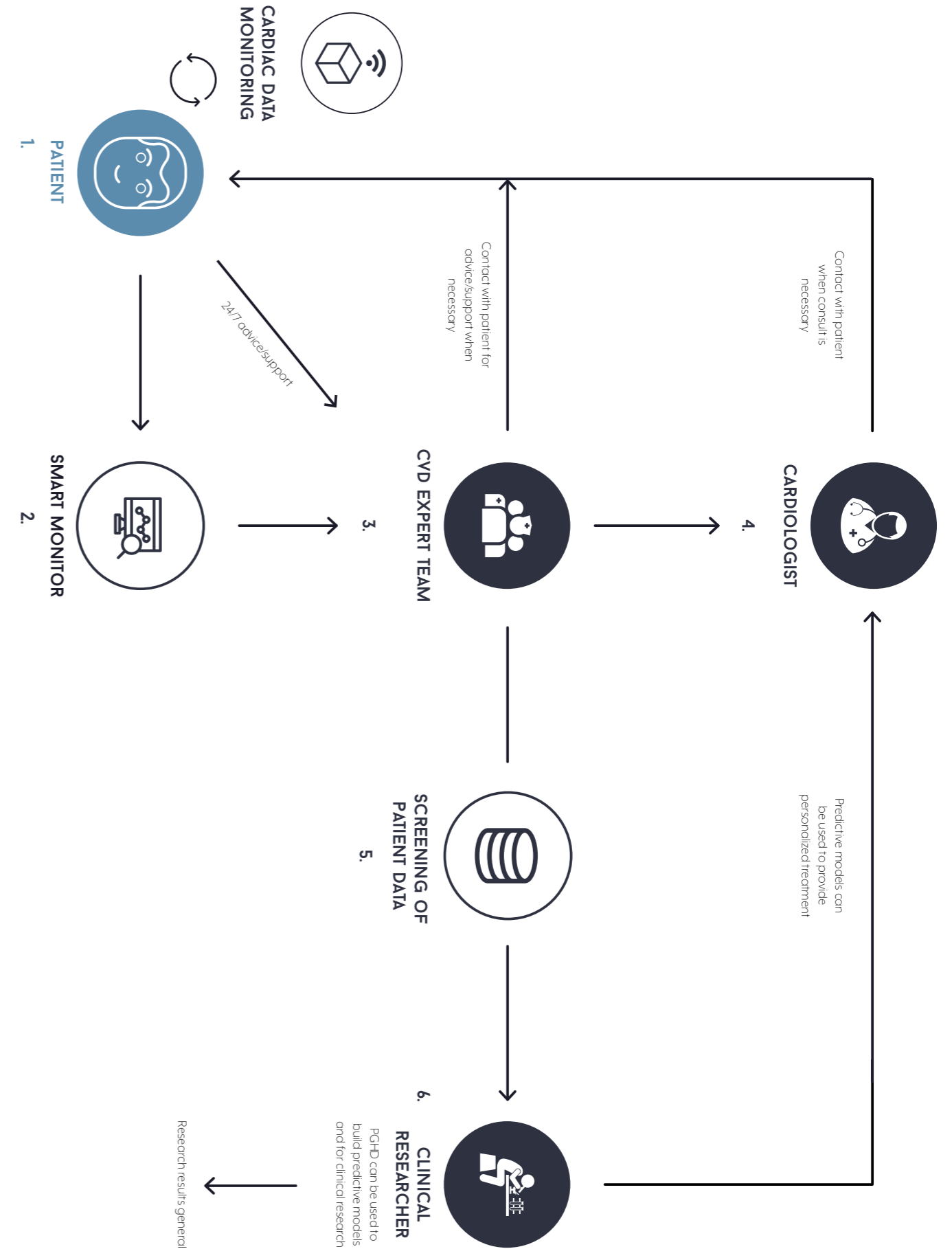


Figure 17 - Visualization of interaction flow model



## INDIVIDUAL AND PUBLIC FLOW IN ECOSYSTEM

As discussed in the introduction of this chapter, the theoretical ecosystem provides patients the opportunity to contribute to their care and that of others. In the theoretical ecosystem an individual and public loop can be identified. When a patient shares health data there can be a direct individual value because care professionals can provide advice and support based on the data. This value flow is visualized with the blue line.

Additionally, patient's health data can be used for clinical research and to build predictive models. This adds value to both individual and public care because an individual can benefit from the predictive models as well. This value flow is visualized with the red line. Especially the public loop has potential to improve both individual and public clinical care by using myriad data.

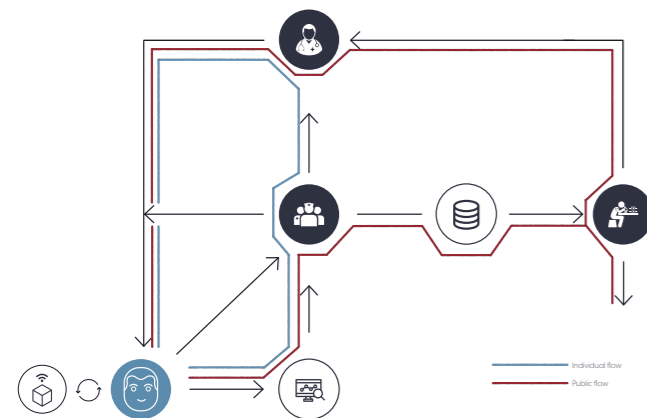


Figure 18 - Visualization of value streams in theoretical health data ecosystem

## 3.3.2 VALUE FLOW MODEL

The value flow model proposed by Ouden (2012) is used to indicate the value of transactions and interactions between stakeholders in the ecosystem. It is used to visualize both tangible and intangible transactions, this way transactions can be converted into negotiable forms of value (Ouden den, 2012). Such a model can be used to link user needs and wants to the resource exchange in the ecosystem and can be used to understand how value is realized. At this point in time, actors and value flows are identified without deciding which person or organization is going to fulfill this role. The use case presented in chapter 4 will look into this. A detailed explanation and description of all value flow elements can be found in appendix C. In this paragraph the initial value flow model is shared.

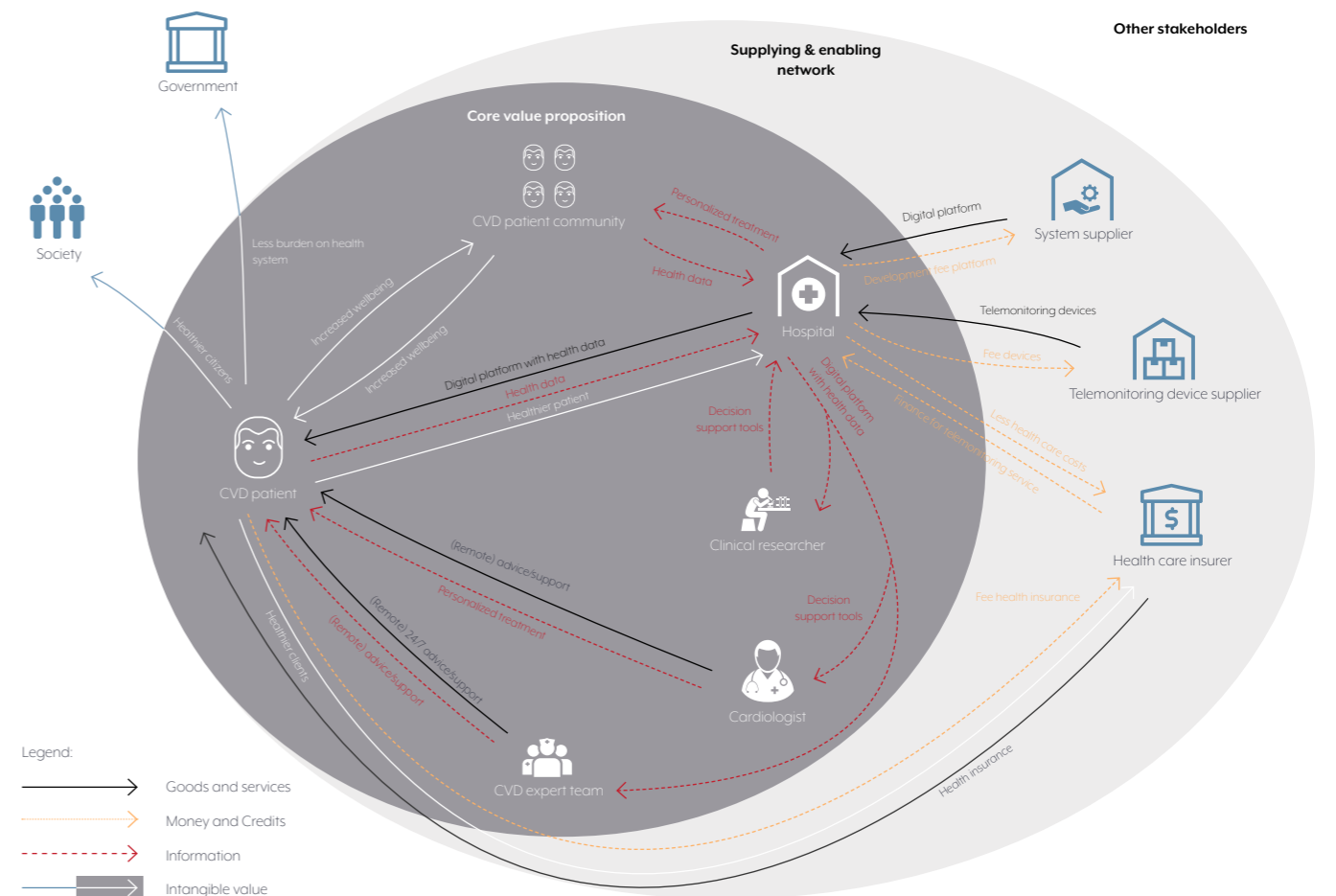


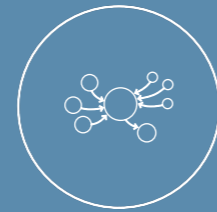
Figure 19 - Initial value flow model

# KEY TAKE-AWAYS CHAPTER 3



## TARGET SEGMENT

Due to the high burden of Cardiovascular Diseases (CVDs) on both health care systems and people, it will become increasingly important to manage this disease. CVD progression can both be the results of modifiable (behavioural characteristics) and non-modifiable (age, gender, ethnicity and family history) risk factors. With secondary prevention both behavioural and medical interventions can be provided and has the highest change of preventing people from developing severe CVD. Another advantage of secondary prevention is that patients themselves can be an important player in managing their CVD. This thesis will focus on people who are diagnosed with CVD and can prevent further progression with behavioural and medical interventions. It will not look into the process of actually diagnosing a person.



## HEALTH DATA ECOSYSTEM

A theoretical ecosystem to improve individual and collective care is designed. This ecosystem consists of a value proposition for targeted users (patients and cardiologists), an interaction flow model to explain how the ecosystem is used and a value flow model to show how different stakeholders within the ecosystem interact and exchange value.

### Initial value proposition

#### *Patient*

The product service system allows cardiovascular patients to receive personalized treatment and advice, have easier access to care when needed, and enables them to contribute to care easier.

#### *Cardiologist*

The product service system allows cardiologists to provide patients personalized treatment and advice, enables them to provide the right care at the right time, and receive additional support during decision moments.



## CONCLUDING

In the interaction flow model an individual and public flow is identified that shows how the ecosystem lets patients contribute to individual and public care. This clearly shows that an individual patient who generated health data can be an important contributor to improve both individual and public clinical care.

In the next chapter the theoretical ecosystem is used during user research to understand how it addresses motives and needs of targeted users and discover if there is a problem-solution fit.





## CHAPTER 4 FRISIAN HEALTH CAMPUS CASE - INSPIRATION

### 4.0 //

During the inspiration phase of the Frisian Health Campus case, the use case and client will be introduced and user research will be conducted. The theoretical ecosystem developed in the previous chapter is used during user research to explore how the initial value proposition of the ecosystem addresses drivers and needs of target users.

Before the design brief is shared, a summary of all key insights from previous chapters will be given. The design brief consists of the design challenge, goals, and a design requirement list. Several brainstorm sessions are held to come up various design directions. To scope the design challenge, one design is selected for further development.

Additional research on behavioural design is done to support further development of the selected design.

In this chapter:

- 4.1 Use case and client introduction
- 4.2 User research
- 4.3 Summary key insights
- 4.4 Design brief
- 4.5 Applying behavioural design
- 4.6 Key take-aways



# 4.1 // USE CASE AND CLIENT INTRODUCTION

## 4.1.1 FRISIAN HEALTH CAMPUS

In 2018, Frisian Health Campus signed up for a collaboration with Deloitte. Frisian Health Campus (FHC) aims to become a pivotal player in developing and supporting care innovations in the north of the Netherlands. FHC is positioned as an independent authority that aims to connect various care providers in the region. The Medical Center Leeuwarden (MCL) (1) took the initiative for developing the FHC and is their first partner. The aim of the collaboration with Deloitte is to conduct research on how FHC can use patient health data to realize its ambition and strategic goals. This thesis is part of the collaboration between FHC and Deloitte. This paragraph will provide background information on FHC and Deloitte and will introduce the use case this thesis will work on.

As explained earlier, FHC has the ambition to become a pivotal player in developing and supporting care innovations in the north of the Netherlands. By bringing together care professionals, patients, universities, schools, students, (international) companies, start-ups and government, they want to combine expertise, data, capabilities and scientific knowledge to create a living health lab (2)

Hessel Bouma, quartermaster (3) of FHC, explains why FHC has this aim: 'due to the changing landscape in the healthcare sector, hospitals need to rethink how they are going to deliver healthcare in the future. Demographic, social, technology and business trends will drastically change the healthcare environment while at the same time they will bring new opportunities to improve it. FHC's services will guide care providers to initiate, accelerate and scale innovative projects.' By developing successful innovative projects and propositions, FHC wants to show and support hospitals in how they could utilize healthcare trends.

### USE CASE

One of FHC's goals is to become future proof for top clinical care. A strategic domain of FHC is therefore eHealth. In order to do improve clinical care, there is the desire to build a platform where patient health data can be shared among care providers in the region. Currently, Deloitte Digital Health Compliance is doing research to disclose what FHC is legally allowed to do with patient data on such a platform. However, FHC does not know yet what patients and

care professionals think of such a platform and what is necessary to let patients share their health data with them.

The theoretical health data ecosystem created in the precious chapter is an example of how FHC could build their envisioned platform and can be used to do research on the desirability of it.

**This thesis will us the theoretical ecosystem to discover if a data sharing platform FHC aims to build is desirable from a patient and care provider perspective. Additionally, a proposition which envision a way of strategically obtaining patient health data to improve clinical care will be designed. This proposition needs to help FHC in showing hospitals how they could support them in utilizing eHealth to improve clinical care (4).**

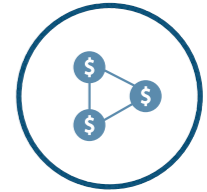
## STRATEGIC GOALS FHC



Become future proof for top clinical care



Act as a facilitator for care innovation and investment



Strengthen the economic structures for health care in Friesland

## CORE VALUES FHC



All research, innovation and other actions initiated and applied at FHC are patient-centered;



All intended results should add value to the entire patient journey, which means they can reach far outside the walls of 'Frieze' care providers.

1 The Medical Center Leeuwarden (MCL) is a hospital in the city of Leeuwarden and provides regional care for the province of Friesland. It is the largest non-university hospital in the Netherlands and provides secondary and tertiary care. It is seen as one of the country's top-clinical hospitals (MCL, 2019).

2 A living lab is a research concept. 'It is a user-centered, open-innovation ecosystem, often operating in a territorial context (e.g. city, region), integrating concurrent research and innovation process within a public-private-people partnership' (Wikipedia, 2019).

3 Originally, a quartermaster is a military term that is used to describe troops that are being sent ahead to prepare the battle ground before other troops arrive. Nowadays, in business, it is used to describe someone who is responsible for preparing and organizing the business ground.

4 FHC is interested in what they need to do to let patients share their health data. Together with Erik Bosgra, Data Governance Officer of MCL, it was discussed this project can be conducted with patients and care professionals nationwide.

## 4.1.2 DELOITTE

To better understand why this project was done within Deloitte Digital Creative a brief introduction about the Deloitte, Digital Health Compliance and Deloitte Digital will be given.

Deloitte Touche Tohmatsu Limited, often referred to as Deloitte, is a multinational professional service provider and is headquartered in New York City, the United States. Deloitte is one of the 'big four' professional service networks in the world, based on their revenue and number of professionals. Currently, it has more than 280,000 professionals and has offices in more than 150 countries worldwide. Deloitte provides services in audit and enterprise risk, consulting, financial advisor and tax.

## DELOITTE DIGITAL HEALTH COMPLIANCE

One of the fastest growing practices within Deloitte is healthcare. In the coming years, the healthcare landscape will radically change due to the exponential growth of new technologies. Healthcare organizations and technology companies will be affected by this, both from an innovation perspective and the legislative and regulatory perspective (Digital Health Compliance, 2019). Deloitte aims to become a big player in the healthcare industry as they have the capability to support a wide range of healthcare providers with digital technology and transformation. Therefore, Digital Health Compliance (DHC) was founded which is a label of Deloitte that helps care providers in their digital transformation. Due to the complexity of the healthcare environment a multidisciplinary team is created to tackle healthcare challenges efficiently and effectively. DHC professionals have expertise in audit and enterprise risk, consulting, financial advisor and tax. Like explained earlier, DHC is currently doing a project for FHC.

## DELOITTE DIGITAL

Deloitte Digital is a service line part of Deloitte Consulting. Deloitte Digital was created because of the increasing digitization in several industries Deloitte is active in. Deloitte Digital is the creative digital consultancy within Deloitte and has three different departments: Creative, Strategy & Advisory and Engineering. By combining different expertise and backgrounds they try to support business in their digital transformation, from building digital strategies to designing and building online platforms. In addition, Deloitte Digital can rely on a broad international network of professionals active in a wide range of industries which differentiates them from independent digital agencies. Regularly, Deloitte Digital brings out publications where they provide insight into digital trend topics such as Digital Leadership, Design Thinking and Digital Customer Experience and Solutions. This shows that they are increasingly active and knowledgeable in the design sector as well.

Together with Tommaso Sarri, Senior Service Design at Deloitte Digital Creative, Erik Bosgra, Data Governance Office at MCL, and Rob Peters, Senior Manager at Deloitte Legal and co-founder of DHC, it was discussed that insights and concepts from a Deloitte Digital Creative perspective can complement the FHC use case.

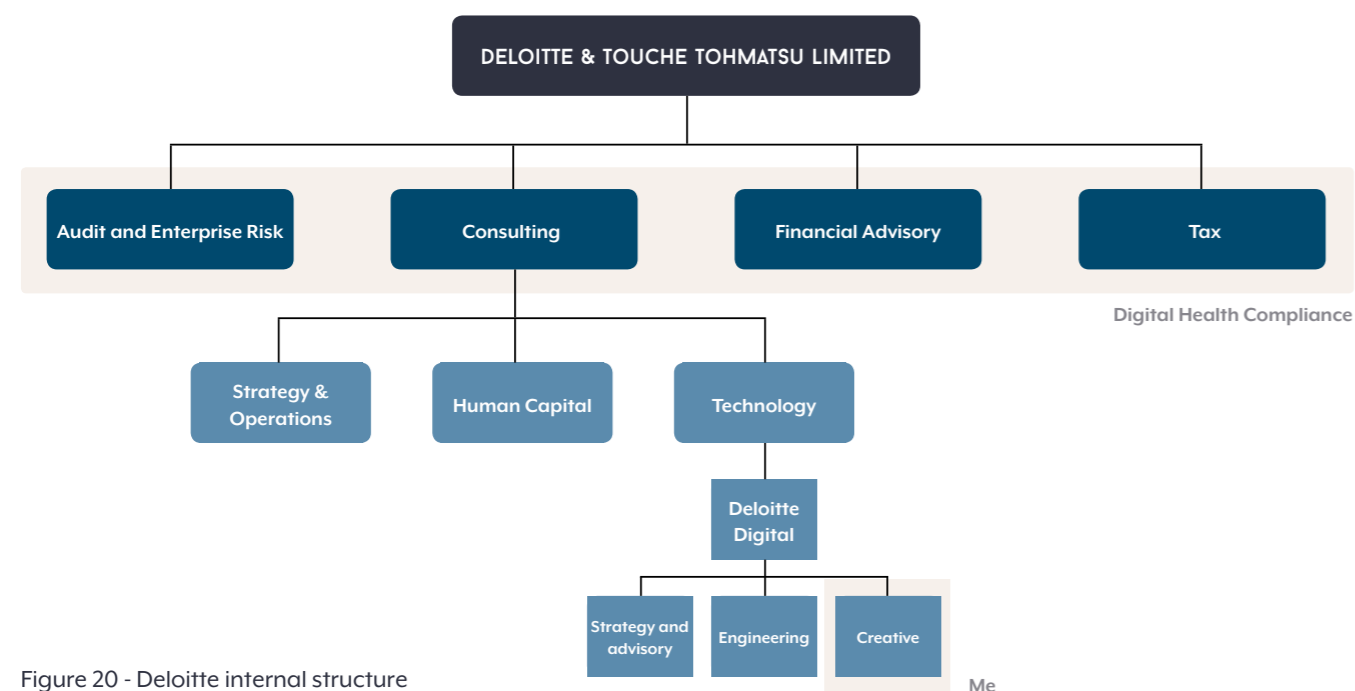
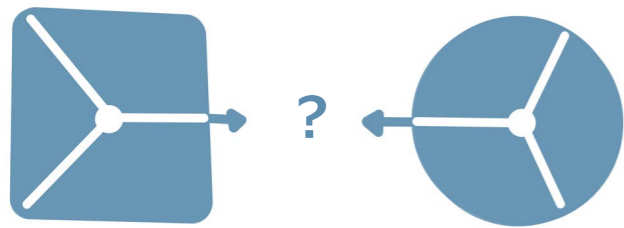


Figure 20 - Deloitte internal structure

## 4.2 // USER RESEARCH

This paragraph will dive into the user research that is done and what its implications are for the theoretical health data ecosystem. To further iterate on the theoretical ecosystem and enrich the initial value proposition user research is done with the two target users. During user research, 7 patients and 6 cardiologists are consulted to define the desirability of the health data ecosystem. The theoretical ecosystem created in the previous chapter is used during generative interviews. Participants prepared the 1,5-hour interviews in advance by filling out a contextmapping booklet. The booklets were analyzed prior to the generative sessions. All interviews were transcribed and analyzed with various data analysis methodologies. This process allows to gain a better understanding of how the initial value proposition addresses the drivers and needs of the targeted users (Ouden den, 2012). The results of the user research can be used to revise the initial value proposition to find a problem-solution fit. First, the paragraph will elaborate on the goal of the user research. Second, most important research findings will be discussed. Finally, potential drivers are identified that could be used to improve the problem-solution fit. A more elaborate description of the research rationale, method, analysis and results of the user research can be found in appendix D. Conclusions derived from this process are discussed in this section.



### 4.2.1 USER RESEARCH GOAL

As discussed in chapter 3.2, the value proposition that is created is theoretical and not based on user insights. The main goal of the user research is to gain a better understanding of the potential value of the initial proposition for the target users and find out if the proposition has a problem-solution fit. Because the value proposition is different for the patient than for the cardiologists, user research is tailored to the specific user. What the main goals of the research per user is will be shared briefly, a more detailed explanation can be found in appendix D.1.

#### Goal patient research

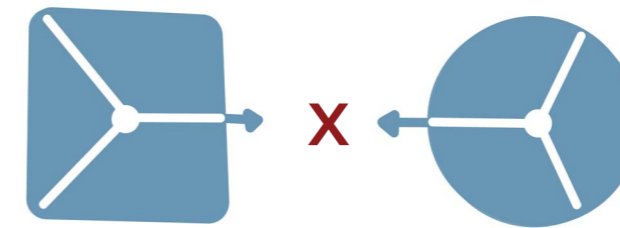
Patient research focused on how a telemonitoring service could potentially add value to their care process, and if so, when this value would manifest itself. Additionally, because sharing health data is vital for the ecosystem to work, patients were asked their opinion on sharing their health data on a platform.

#### Goal cardiologists research

Cardiologist research was focused on what the added value of a telemonitoring is on the care process, both from a patient and cardiologist perspective. Additionally, it was discussed what opportunities, challenges and obstacles are of sharing health data to improve clinical care. Finally, the role and value of a cardiologists in the theoretical ecosystem was discussed.

#### Target user scope

To scope the project, it is decided to focus on revising the value proposition of the patient. This has two reasons. First, the patient is considered the most important user in the ecosystem because without patient health data the ecosystem will not function. Second, more conflicts between the patient's value proposition and research findings were found than with the cardiologist. However, research findings derived from cardiologists are useful and used to iterate on the initial interaction and value flow model. Key findings of cardiologists are shared briefly at the end of this paragraph, more elaborate findings can be found in appendix D.6.



### 4.2.2 VALUE PROPOSITION AND USER CONFLICT (PATIENT)

Research analysis revealed several conflicts between the drivers and needs of the patient regarding measuring and sharing health data, and how the value proposition currently is designed. These conflicts will be discussed and show which areas of the value proposition needs improvement. Only results contributing to these conflicts are discussed, additional research results are shared in appendix D.3, 4 & 5.

#### Open to share health data

To start, it should be noted that patients that were interviewed were all open to share their health data to improve public care. Patients mentioned though that privacy and security are important preconditions for data sharing. This shows that there is not a problem with the willingness to share health data. Instead, barriers with keeping up the data flow are identified.

Patient: "The main reason why I would share health data for research is that it could help other patients in the future to receive better care"

Patient: "I would have no problem with if my anonymous data is mixed with other data to support research"

Patient: "Of course my health data can be used for research, who knows what they can discover with it so in the future they can help other patients better. I am just a small crumb in the system, then let me be a small crumb"

#### Conflicts influencing patient behaviour

In total, three barriers are identified that influence patient's measuring and sharing adherence.

**First**, patients' motive for measuring health data and receive professional advice and support is high once they are diagnosed with CVD. But once a balance in medication and lifestyle is found, patients don't have the drive and don't experience the value of measuring and sharing health data any longer.

**Second**, patients don't constantly want to be reminded they are patient and just want to continue life.

**Third**, the impact of health data is often intangible, this makes patients unaware of the value of their health data.

However, for cardiologists to provide secondary prevention they need periodic patient generated health data in order to provide timely adjustments or recommendations in lifestyle, medication or other interventions. Additionally, the ecosystem needs patient health data to keep improving individual and public care.

Cardiologist: "The whole system you propose depends on collective patient data. If you don't collect measurements, the whole system is worthless."



Figure 21 - Generative interviews using contextmapping



Patients' **desire to monitor health fades** because a balance in medication and lifestyle is found

Patient: "Right after my heart attack I bought a blood pressure device to monitor myself daily. As time passed, I used it less frequent and at one point I did not use it at all anymore and disappeared to the back of the closet."

Patient: "A TM service would especially be nice in the period after the incident where you need security and confirmation. After finding the right medication and everything not anymore."

Patient: "At the start you feel vulnerable, anxious and insecure, having someone or someone to ask questions is very nice at that time. But after a while you start to feel confident again and you know how to cope with your 'disease'".

Cardiologist (using a TM service for patients): "Patients with hypertension often stop measuring because the value it delivers to them is not clear anymore".



The impact of health data is often intangible, this makes patients **unaware of the value** of their health data

Patient: "I believe my health data can be useful for patient in the future, but not for me currently"

Patient: "I don't think my health data would be that useful to improve my care or for research because I feel fine currently"

Patient: "When you put all that data together, what are you going to do with it? What are conclusions you can make?"



Patients **don't want to be reminded** they are a patient

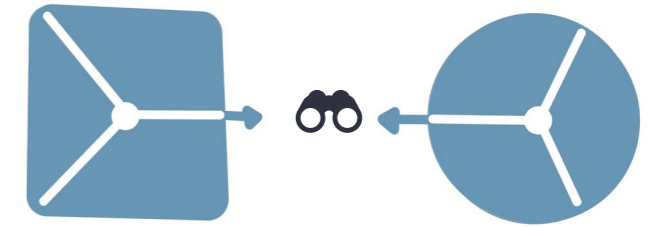
Patient: "After a while you just want to continue life again like before"

Patient: "I think it is not nice if you keep getting reminded you have a cardiovascular disease. But maybe measuring can also become a habit"

Patient: "As long everything goes well I don't have the desire to measure my health or see my cardiologist"

### Individual and public conflict

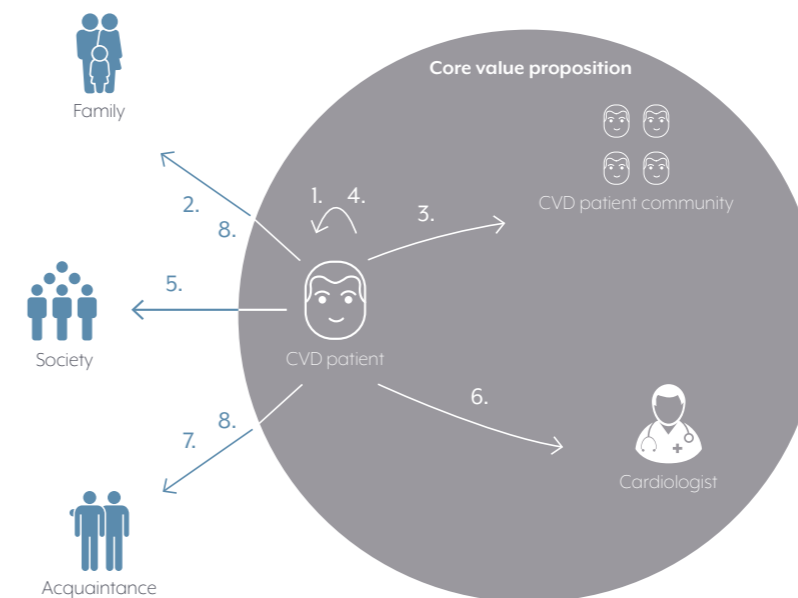
The ecosystem enables patients to contribute to public care easier, additionally, patients' willingness to share health data to improve care is positive. But over time, patient's motive to measure and share health data changes. However, for the ecosystem to provide the intended value (improving individual and public care), periodic data measuring and sharing is essential. This issue shows there is a conflict between the interest of the individual and that of the public. In general, there has always been a natural tension between the interest of the group and the interest of the individual. What is needed for the welfare, safety and security of the group can be in conflict with what the individual wants and what serves its interest (Pecorino, 2001). **Therefore, to find a problem-solution fit that addresses the interest to improve both individual and public care for the cardiovascular domain, the public solution should simultaneously add value to the individual as well (Binkhorst, 2016).**



### 4.2.3 POTENTIAL DRIVERS

#### Patient drivers to share health data

During user research varying drivers for sharing health data were shared after explaining the value of it. These drivers are listed below and are illustrated in the value flow model which can be found in figure 22. This analysis revealed new stakeholders and value flows which could be used to provide patients an additional driver to measure and share data.



Legend:

—> Intangible value

#### I would donate data ...

1. for a medical health check for personal assurance
2. for a medical health check to reassure family and friends around me
3. to help other patients receive the best care as well
4. because gives a good feeling about myself
5. because I believe it is the right thing to do
6. to help my doctor in providing better care
7. because people around me do it as well

Figure 22 - Personal drivers in value flow model



## Potential drivers

### Personal drivers

Patient drivers shared in figure 22 could be used to increase adherence rates of measuring and sharing health data once patients don't experience the value of measuring and sharing data for their own health anymore. User research showed that patients don't want to be seen and treated like a patient after a while. Giving patients a different role/responsibility, data measuring and sharing could be done for a different reason.

**Cardiologist: "When patients don't measure and share anymore, you need to find a different driver for them. That is the crux of eHealth."**

### Complementary drivers

Drivers from complementary offerings can provide a drive to measure and share as well. In appendix C.1 the complementary offering section of the value flow model is explained. For example, receive a discount on your health insurance or gym subscription if measure and share health data occasionally.

### Self-care drivers

Looking at the literature shared in chapter 2.2.1 Self-care, other drivers that could influence measuring and sharing behaviour are social support from family or a community.

To explore the potential added value of additional drivers, preliminary design directions are developed and validated. This resulted in a target direction which will be introduced in the design brief.

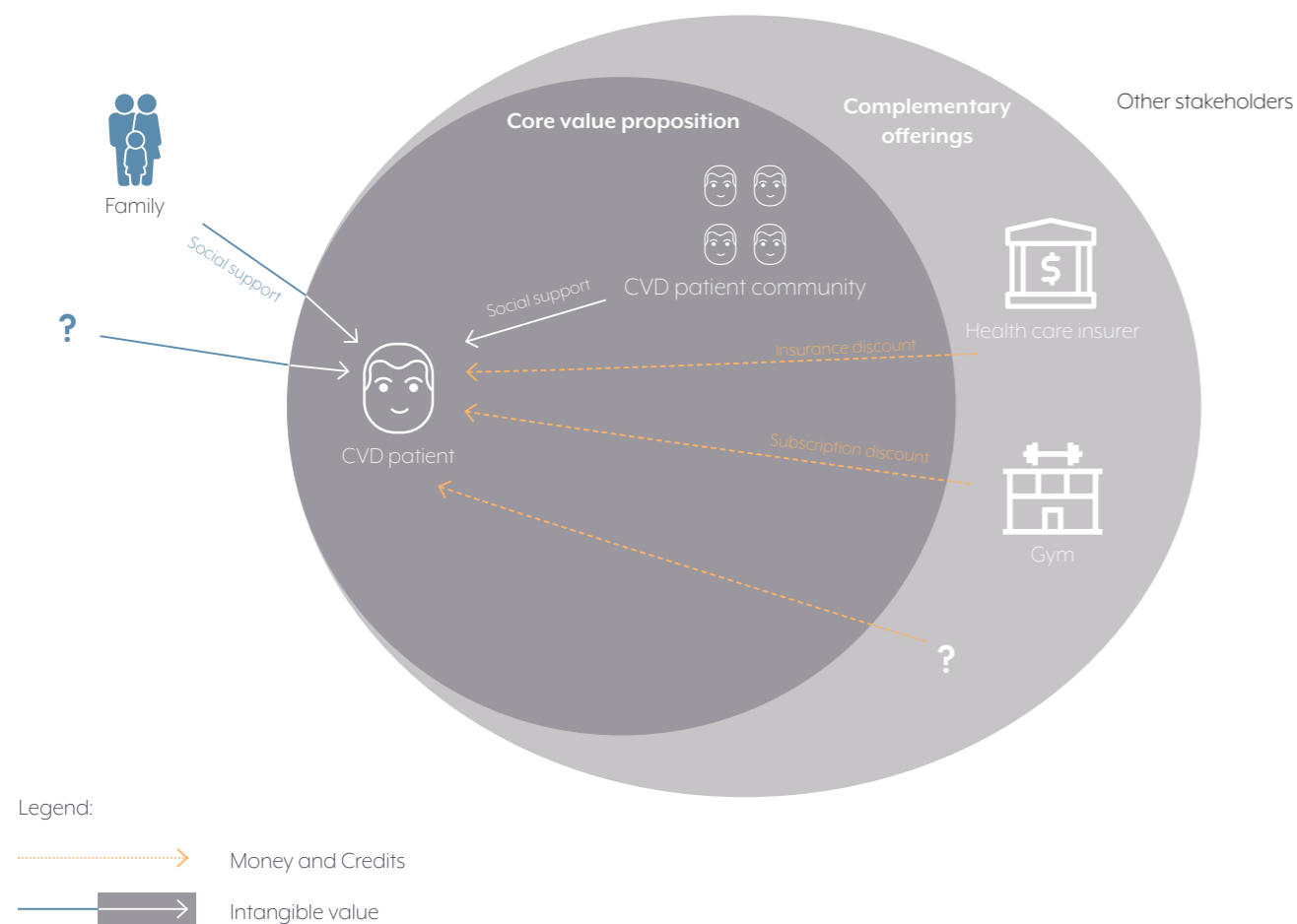


Figure 23 - Potential drivers in value flow model

## 4.2.4 ADDITIONAL INSIGHTS

Next to using the Grounded Theory Method for analyzing user results, two additional data analysis methods are used. First, morphology psychology analysis is used to structure patients' motives and needs for measuring and sharing health data. It was found that patients' drivers and needs regarding measuring, sharing and receiving advice are fluid and respond to time, context and patient's health. A more detailed explanation of this analysis and these fluid needs can be found in appendix D.4. The insights derived from this analysis will be used to create need based persona's. These need based persona's are used to elaborate on the final concept in chapter 5.2. Second, to better understand the potential value of a telemonitoring service for a patient searching for balance in medication and lifestyle, a journey map was created. This was done together with a cvd patients who was experiencing frequent arrhythmia and trying to find the right doses medication for it. This analysis confirmed that a telemonitoring service could add value in finding a right balance in medication and lifestyle faster. A more detailed description of this analysis can be found in appendix D.5.

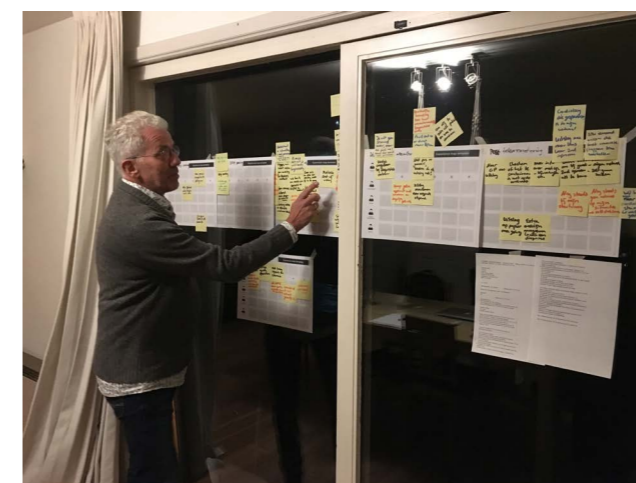


Figure 24 - Journey mapping with patient

### Key findings cardiologists

Overall, cardiologists believe that care management can be improved using telemonitoring and sharing health data for research. They confirmed that having longitudinal health data of patients makes it easier to

timely intervene and adjust a treatment plan before an event occurs. However, good data and service management is essential. Currently, TM services create extra workloads (incoming data that cause an alarm need to be checked manually and put in the EMR of the patient) because the systems are not smart enough yet to do everything automatically. Additionally, when providing a 24/7 monitoring service, patients also expect a 24/7 service.

Cardiologists confirmed that the usefulness of a telemonitoring service depends on the physical and mental wellbeing of a patient and where the patient is in the care process.

**Cardiologist: "Use of sensor data will lead to early detection of changes in the disease process, this can be used to be able to provide timely adjustments or recommendations in lifestyle, medication or other interventions."**

Finally, cardiologists that were interviewed expect that technologies like predictive analytics will not replace them but will support them in their daily work and shift where and how they can deliver care to their patients.

**Cardiologist: "I believe the cardiologist is still the one doing the translation between what the technology tells and what should and is applicable to my patients."**

**Cardiologist: "The role of the cardiologists will stay, but it will change to: 1) passing on information 2) checking quality and validity of the system 3) apply our knowledge to help develop smart systems and 4) the technical acts that are necessary to use the system"**

**Cardiologist: "As a cardiologist you cannot have as much information in your head as computer. Having a computer that supports you during decision moments with grounded information and research and adapts its advice to a specific patient can be very useful"**

# SUMMARY KEY INSIGHTS

Before moving on to the design brief, a summary of valuable insights gained in the precious sections will be given. On this page, an overview of key insights is shared.

1.0 // Project context	<b>Value based health care</b>		The health care system is moving from delivering care based on volume to delivering care based on value
			Tracking health outcomes is vital to be able to improve clinical care
			Creating population segmentations is necessary to better track health outcomes and standardize treatment
			Tracking health outcomes for population segments will result in more personalized interventions
2.0 // Preliminary research	<b>Moving towards individual care and control</b>		Self-care incorporates maintenance, monitoring and management. When developing self-care solutions, design interventions can be targeted and organized around these areas.
			Self-care has three different levels; individual, informal caregiver, and community. These levels can be used when developing the envisioned solution.
			eHealth solutions can provide CVD patients and care providers a tool to engage in active, real-time collaboration regarding clinical care.
	<b>Crowdsourcing care</b>		Patient health data can be used for better self-care and to build decision support tools which care professionals can use to provide more personalized treatment
3.0 // Theoretical ecosystem	<b>Target segment</b>		The design should focus on secondary prevention because both behavioral and medical interventions can be provided and has the highest change of preventing people from developing severe CVD
4.0 // FHC use case - Inspiration	<b>User research</b>	<b>Patient</b>	A patient has the most desire for support and advice when looking for balance in lifestyle and medication
			Patients do not know and experience the value of their own health data
			Patients' health engagement varies over time
			Patients are willing to share their health data if that means contributing to improve health care and help others
		<b>Cardiologist</b>	In appendix D.6 a more detailed overview of research findings of user research with cardiologists can be found.
		<b>Main conflicts</b>	Patients' drive and need for measuring and sharing health data fades because a balance in medication and lifestyle is found.
			Measuring and sharing health data reminds people they are a patient
Patients are unaware of the value of their health data			





# 4.4 // DESIGN BRIEF

The insights gained during the preliminary and user research are used to define the design brief. To scope the project, design goals, a target design and drivers are identified. The direction and drivers will be introduced in this paragraph. Additionally, design requirements are shared.

## DESIGN CHALLENGE

The design challenge is formulated and can be found in the blue box on the next page. Important elements of the design brief will be discussed in more detail.

## Design goals

Three design goals are identified based on the three conflicts found in chapter 4.2.2. The first design goal is the main focus for the design challenge because data is vital for the ecosystem to work. It is expected that the other two goals positively influence the first design goal. And because the whole is greater than the sum of its parts, the final design will focus on all three goals.

To clarify, the third goal aims to reposition the role of a patient from being a care user to a care contributor. This way, measuring and sharing health data does not remind patients they are a patient, but enables them to see themselves as vital contributors to care.

## Target design and drivers

To explore the potential of additional drivers introduced in chapter 4.2.3, preliminary designs are created and validated. These preliminary designs are a result of several individual and collaborative workshops, brainstorm sessions and iterations. In this paragraph the most promising design direction and take-aways from validation will be shared. Additionally, a top three of personal drivers shared in chapter 4.2.2 is made by consulting the patients that were interviewed. Results from these analyses are used to define a target direction and target drivers.

## Target design

In total 5 preliminary designs are created that each provide the patient a different driver to measure and share health data. These directions are evaluated by 7 patients, 4 cardiologist and 15 Deloitte Digital Consultants. The design direction that will be further explored during the conceptualization phase is

'DataDonor'. A more detailed explanation per preliminary direction and how these directions are validated can be found in appendix E.I.

## DataDonor

The DataDonor concept is a platform where patients share their health data with care providers to receive personalized care and can share their health data for research. Additionally, the platform informs patients on the value of their health data and explains how they can contribute to improve health care. A more detailed explanation of the concept will be given in the next chapter.

## Target drivers

In chapter 4.2.2, seven personal drivers to measure and share health data were found. To identify the most important drivers, patients that were interviewed during user research are asked to make a top 3. It should be noted that the driver 'I would donate data for a personal medical health check for personal assurance' is left out deliberately. The reason for this is because user research already showed that over time, measuring and sharing health data does not provide personal value anymore. By leaving this driver out, other important drivers can be identified.

## Design requirements

Insights gained in chapter 2, 3 and 4 are used to create a design requirement list. The requirements are framed in two ways: 1) more general so FHC can use them for additional propositions 2) more specifically for the proposition of this thesis. The categorized and complete list can be found in appendix F. This list will be used to evaluate the final concept in chapter 8.

## DESIGN GOALS



1. Increase measuring and sharing adherence



2. Increase awareness regarding value of health data



3. Change perspective from being a 'care user' into 'a care contributor'

## DESIGN CHALLENGE

To increase adherence of measuring and sharing health data, the design should **let patients experience the value of health data** and **trigger personal drivers** to periodically measure and share health data

## TARGET DRIVERS



1. To reassure family and friends



2. To contribute to care of other people



3. To help the doctor in providing better care

## 4.5 // APPLYING BEHAVIOURAL DESIGN



Figure 25 - Creative session @ Deloitte (preliminary designs)



Figure 28 - Target design DataDonor



Figure 26 - Creative session @ Deloitte (preliminary designs)



Figure 29 - Creative session @ TU Delft (benchmarking)

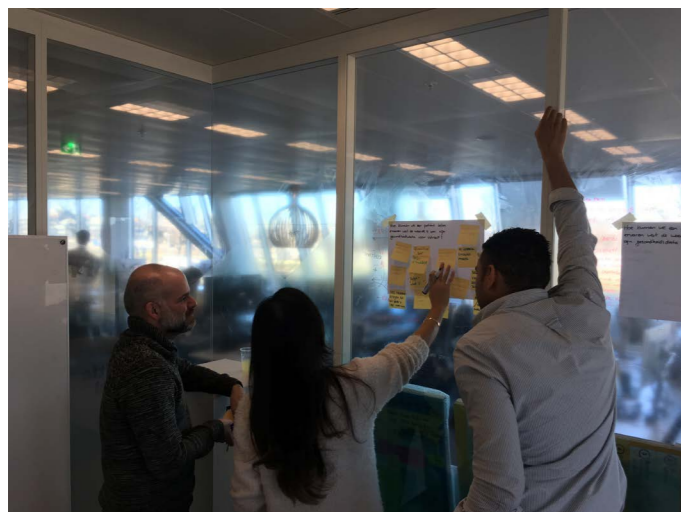


Figure 27 - Creative session @ Deloitte (preliminary designs)



Figure 30 - Creative session @ TU Delft (benchmarking)

### INFLUENCING BEHAVIOUR USING BEHAVIOURAL DESIGN INTERVENTIONS

For the ecosystem to work, the behaviour of periodically measuring and sharing health data is desired. To explain and influence behaviour, we must first understand the underlying decision-making processes that determine if, and how, people will act (or not) (van Lieren, 2018). Therefore, this paragraph will introduce the theory of behavioural psychology and explain how two types of behavioural interventions, namely nudging and rationale override, can be used to elicit the desired behaviour. These insights will be used for the final design. Applying behavioural design in this project complements to the third area VBHC aims to customize in (shared in chapter 1.1): incorporating behavioural and social interventions in the care continuum (i.e. increase patients' motivation and willingness to participate in care).

### 4.5.1 BEHAVIOURAL PSYCHOLOGY

Behavioural psychology is the science of understanding human behaviour and decision-making. According to Lewin (1935), both internal (cognitive) and external (situational) factors should be considered to understand and explain human behaviour. More specifically, the behaviour of an individual can be determined by his or her own personality (cognitive factors, expectations, attitudes) and the physical and social environment. This science can be used to explain the process of individual, cognitive-driven decision-making and how individual's behaviour can be influenced by the environment.

According to the dual-system theory (Kahneman, 2011), the human brain can make decisions using two different systems (visualized in figure 32 on the next page):

**The first system** is automatic and fast and is an intuitive, automatic, experience-based, and unconscious thinking process. Minimal cognitive effort is required and actions that stimulate this system can be influenced by mental shortcuts. Often this type of thinking is used when a routine like situation or familiar information appears.

**The second system** is reflective and slow and is used when more conscious, reflective, controlled, and

analytic decisions and judgments need to be made. This system does not engage when it is not necessary, and when people's motivation and/or ability is lacking. Because high mental effort is required, people use it only when necessary.

#### Nudging

When making decisions, individuals tend to rely on their instinctive sub-conscious system because we do not have the mental capacity to constantly make conscious decision and actions. According to Zaltman (2003), 95% of the time decisions are made using this instinctive subconscious system. To stimulate specific cognitive boundaries, biases, routines and habits of individuals, nudging techniques can be used to influence individual's judgment, choice, and behaviour in a predictable way (Hansen, 2016). Nudging techniques are often used to create frictionless user experiences. This thesis will use the definition of Hansen (2016) to define a nudge:

"A nudge is a function of any attempt at influencing people's judgment, choice or behavioural in a predictable way that is motivated because of cognitive boundaries, biases, routines, and habits in individual and social decision-making posing barriers for people to perform rationally."



An example of a nudge is shown in figure 31. The 'push' sticker provides the user information on how to use the door. This way the user does not need to consciously think about how the door needs to be opened.



Figure 31 - A nudge at one of the doors in the new Deloitte Digital office in Amsterdam

### Rational override

In general, points of friction are removed to create a seamless experience. However, not all service interactions need a frictionless experience. Although friction is commonly thought of as a barrier to achieve a desired behaviour, in some situations it is necessary the user slows down, focus on the decision at hand and understand the options he has (Lieren, Calabretta, & Schoormans, 2018). A rationale override is a behavioural design intervention that can switch a user into this conscious state of mind. With rationale overrides, people are prompted to reassess their beliefs, attitudes and intentions (Frey & Rogers, 2014). Therefore, they can be used to change present behaviour, reassess past behaviour and consider future behaviour. This is supported by Strassheim (2016), who states that using rationale overrides are more likely to result in formation of habits because it can encourage a conscious learning process. Additionally, Keller (2011) states that conscious choices stimulate individual's self-worth, development and ability to engage. This thesis will use the definition of van Lieren (2018) to define a rationale override:

"A rationale override is a small moment of intentional friction that attempts to influence people's behaviour or decision making by intervening automatic thinking and activating reflective conscious thinking."



Figure 33 - The conscious crossing changes its physical pathway over time. This way, the chance that people pay attention and engage with their environment is increased and will result in more conscious road crossing.

## 4.5.2 APPLYING THE RIGHT TYPE OF INTERVENTION AT THE RIGHT TIME

Because different situations require different mindsets, it is important to apply the right intervention for the right situation in order to create successful behavioural change (Lieren et al., 2018). The intended outcome is considered the most important factor to determine if a nudge or rationale override should be used. Typical nudge and rationale override situations are characterized and visualized in figure 34.1 on the next page. These two behavioural interventions can be used to achieve the desired behaviour for the ecosystem (periodic measuring and sharing of health data). Bisset & Lockton (2010) explain that by combining user insights with behavioural psychology, the design process can be supported by more grounded and precise explanation about user behaviour. Therefore, the behavioural interventions should specifically address the three conflicts and target drivers that were found during user research. This way, the unwanted behaviour (discontinue with

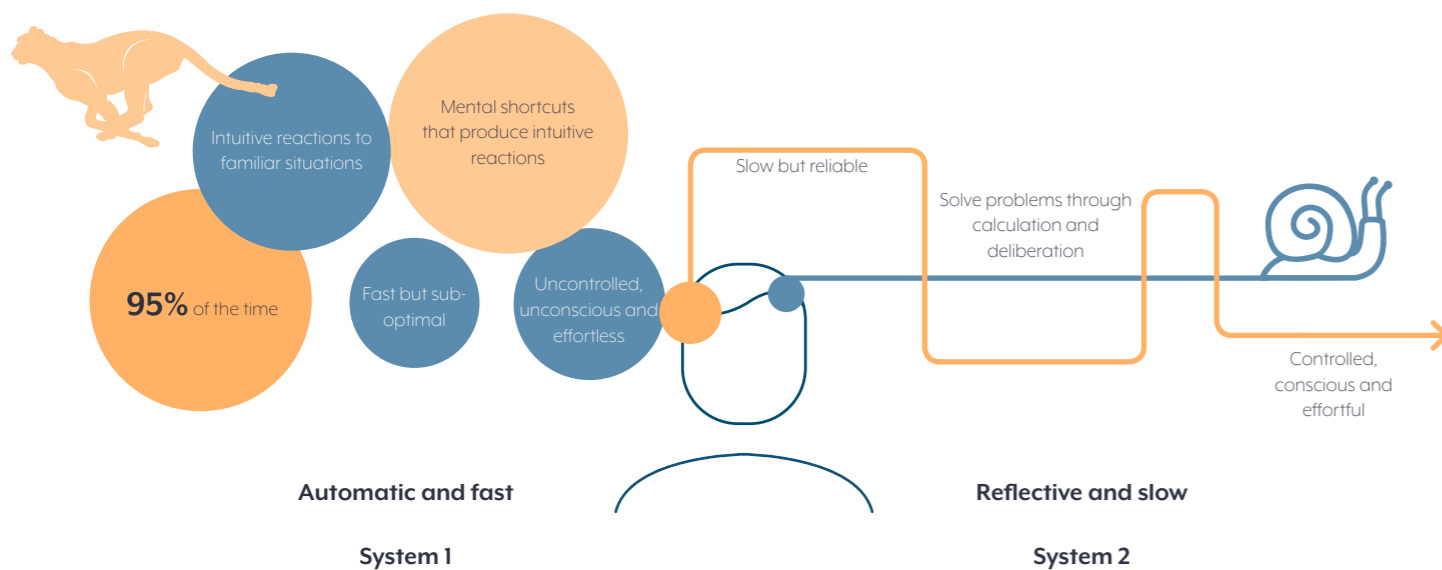


Figure 32 - Differences of thinking processes between system 1 and system 2 (visual derived from van Lieren (2018))

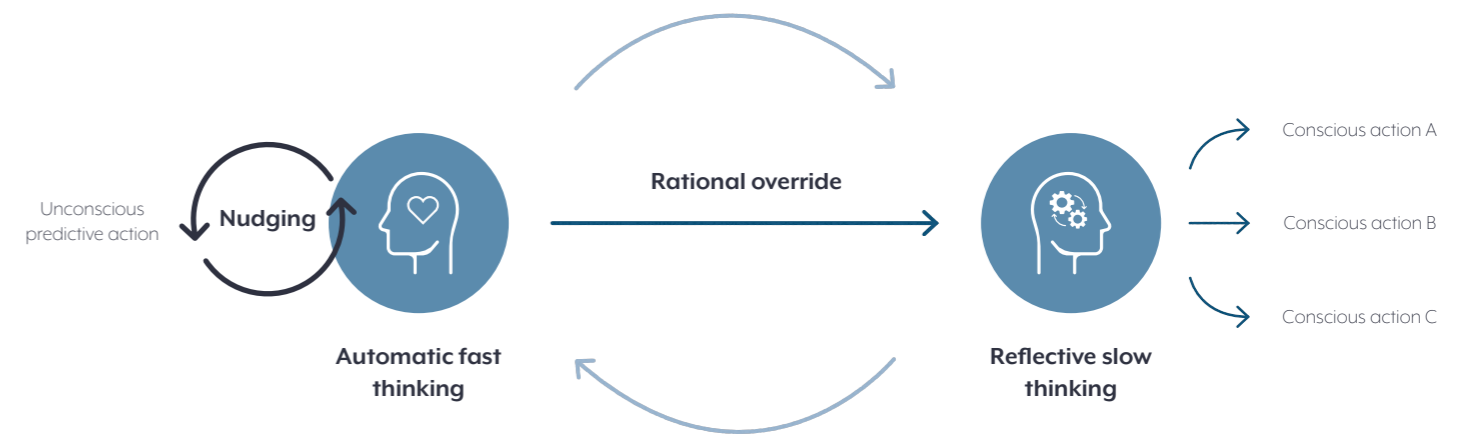


Figure 34 - Two types of behavioural interventions. One for automatic and fast thinking (nudges) and one to switch people to a conscious state of mind (rationale override) (visual derived from van Lieren (2018))



measuring and sharing health data) could potentially be transformed into the desired behaviour.

### Personalized interventions

Similar is in morphology psychology introduced in paragraph 4.2.4, different people can have different mindsets in the same situation. When designing behavioural interventions, these differences between individuals should be considered. The morphology analysis also showed that patient behaviour is dynamic and develops over time. To maximize lasting behaviour, the final design should not use singular, one-off interventions, but use interventions that can adapt to changing patient behaviour.

**Cardiologist:** “The problem with a TM service right now is that over time people are no longer appealed by it. You need to personalize to increase adherence.”

**Deloitte Health Care expert:** “Somehow, you need to reward or trigger people to measure and share on a personal level. You need to stay in touch in a way it is not annoying.”

### Applying the right intervention at the right time in the use case

To guide designers in understanding and designing behavioural design interventions across the user journey, Van Lieren (2018) created a behavioural intervention toolkit. A user journey representing how patients currently experience a CVD telemonitoring service is created. This journey was validated with the Innovation Manager of HartWacht. To identify on which phase in the user journey the design challenge should focus, the toolkit is used. The design goals shared in the design brief are used as the desired outcomes. Two key moments are identified in the journey which have high potential for a behavioural design intervention. These key moments will be introduced briefly, in appendix H, the complete user journey can be found. The final design will focus on the following two key moments:

### During the on-boarding phase of the telemonitoring service.

Currently, there is no awareness regarding the value of patients' health data. To let patients experience the value of their health data, the final design will focus on this moment in the user journey. Increasing patients' knowledge about the value of health data could influence the measuring and sharing behaviour.

### The moment when the adherence of measuring and sharing data fades

To trigger personal drivers to periodically measure and share health data, the final design will create behavioural interventions during these moments. Nudging interventions should be used in the final design to create a seamless experience for the patient. These design interventions should enable patients to measure and share their health data without hassle. However, to remind patients of their measuring and sharing behaviour, rational overrides are more suitable. Measuring and sharing of health data is very appropriate for rationale overrides because:

- Per individual, the desired outcome is different (how often a patient needs to measure and share depends on the type of CVD).
- Measuring and sharing is a routine with varying environments and moments in time (measuring and sharing can be done in different environments (e.g. home, work) and on different moments during the day)
- Enduring engagement and follow-up behavior are required to create a measuring and sharing habit. (for example, if a patient's drive to measure and share health data to help other patients, a rationale override can be used to prompt the patient to reassess its belief (contribute to the care of others)
- User input is required (the patient needs to actively measure and share).

### Examples from practice

Two cases are researched to explore behavioral interventions that are used specifically to influence individual behavior for individual and public good. These are shared on the right in the gray box.



Figure 34.1 - Rationale overrides and nudge situations

### Recycling plastic

It is difficult for us to comprehend the scale of the ocean plastic problem because it is a 'far from our bed show'. The impact of our abundant plastic use is not really tangible in our daily lives. The Tropenmuseum in Amsterdam tried to visualize the actual impact of plastic on our oceans by literally bringing an 'plasticarium' filled with 2,700 liters of Pacific ocean water from the great ocean garbage patch.



### Saving energy in households

In 2015, researchers conducted a preliminary study on how they could let people save energy consumption (Graffeo, Ritov, Bonini, & Hadjichristidis, 2015). They explored different behavioural interventions to influence the energy consumption behavior of those households. One of the techniques they explored was to provide social feedback about what comparable others do and who those comparable others are. The effectiveness of this rationale override was further sharpened and tested in two dimensions: if comparable others come from the same group vs. a different group (own neighborhood or far distance) and if the other group was identified vs. unidentified. The comparative feedback with the best results was the combination of feedback from a household in the same neighborhood without identifiable details.

# KEY TAKE-AWAYS CHAPTER 4



## CLIENT AND CASE

The project is carried out for Deloitte Digital, the internal digital strategist of Deloitte, and one of Deloitte's clients, Frisian Health Campus (FHC). FHC aims to become a pivotal player in developing and supporting care innovations in the north of the Netherlands. By developing successful innovative projects and propositions, FHC wants to support hospitals in how they could utilize eHealth. Therefore, this project is carried out with the help of a case study for one of FHCs clients, Medical Center Leeuwarden (MCL). MCL is a non-academic hospital that is exploring the opportunities of eHealth and how health data can contribute to improve clinical care. With this case study, the desirability from a patient and care professional perspective of sharing health data on a platform to improve clinical care is researched. The theoretical ecosystem designed in the previous chapter is used for this.



## USER RESEARCH

### Goal

The main goal of the user research is to gain a better understanding of the potential value of the initial proposition for the target users and find out if the proposition has a problem-solution fit.

To scope the project, it is decided to focus on revising the value proposition for the patient. The patient is considered the most important user in the ecosystem (without patient health data, the system won't function) and more conflicts between the patient value proposition and research findings were found than with the cardiologist.

### Findings

First, it should be noted that patients that were interviewed were fine with sharing health data for research if privacy and security is guaranteed. Instead, three main barriers influencing patient's measuring and sharing adherence are identified:

1. Patients' drive and need to measure and share health data fades over time because a balance in medication and lifestyle is found,
2. Patients are unaware of the value of their health data,
3. Measuring and sharing health data reminds people they are a patient.

### Opportunities

Additional drivers to measure and share health data are found and will be used during ideation.



## DESIGN BRIEF

To scope the project a design brief is created. Design goals, design challenge, target design and drivers are formulated.

### Design goals

Three design goals are created based on barriers found during user research:

1. Increase measuring and sharing adherence ,
2. Increase awareness regarding value of health data,
3. Change patient's perspective from being a 'care user' into 'a care contributor'.

### Design challenge

To increase adherence of measuring and sharing health data, the design should let patients experience the value of health data and trigger personal drivers to periodically measure and share health data.

### Target design

Several design directions are explored during brainstorming and workshops, eventually the project will iterate on the DataDonor concept.

### Target drivers

Target drivers to measure and share:

1. To reassure family and friends,
2. To help other patients,
3. To help the doctor in providing better care.



## BEHAVIOURAL DESIGN

To achieve the desired patient behaviour of periodically measuring and sharing, behavioural design interventions are used to develop the concept. The Behavioural Design Intervention approach created by van Lieren (2018) is used to identify two key moments in the patient journey of a telemonitoring service. During the on-boarding phase of the telemonitoring service and the moment when adherence of measuring and sharing health data fades. For these two moments, behavioural design interventions (nudges and rationale overrides) will be used.

### Nudging and rationale override

The final design will use nudges to create a seamless experience for the patient. These design interventions should enable patients to measure and share their health data without hassle. To remind people of their measuring and sharing behaviour, rationale overrides will be used to switch the patient's mind into a conscious state of mind. Additional drivers found during user research will be used to design these interventions.

These two interventions combined are used in the final design to get the patient in the right mindset at the right time to achieve the desired behaviour.

# CHAPTER 5

## FHC CASE - FINAL DESIGN

## 5.0 //

All insights derived from previous chapters are combined to design a final concept for FHC. This concept represents an iteration on the target design presented in chapter 4.4. The DataDonor experience is presented in the following pages by a detailed interaction scenario to illustrate how DataDonor is used. Additionally, elements of the concept are presented and explained in more detail.

In this chapter:

- 5.1 DataDonor
- 5.2 Concept detailing
- 5.3 Key take-aways



# 5.1 // DATADONOR

The DataDonor is a digital environment which consists of an informative website and a module that can be added to existing telemonitoring services to donate health data easier. By making use of personalized reminders to measure and share data, the design responds to the dynamic drivers and needs of cardiovascular patients. Because DataDonor functions as a module, patients and cardiologists can continue using the initial telemonitoring service. By adding the module, patients can share their health data easier for clinical research and predictive analytics. Additionally, the module can be used by care professionals as a decision support tool using predictive analytics to tailor patient treatment. This module is complementary to their existing online work environment and can be used during consults.

Because the data donor platform functions as additional module, it could be used to support various telemonitoring services for various diseases. This is beneficial for FHC because they want to establish partnerships with existing telemonitoring services and not build their own. The final design will focus on using the data donor platform for the cardiovascular domain.

In this section, a detailed interaction scenario is illustrated showing how a patient would use DataDonor. The scenario will focus on the two phases that were identified in paragraph 4.5, on-boarding and personalized adherence. It starts with the patient being diagnosed with a CVD and it ends with the patient periodically measure and share health data by receiving personalized triggers. In paragraph 5.2 the concept will be presented in more detail. In appendix I & J the final interaction and value flow model can be found.

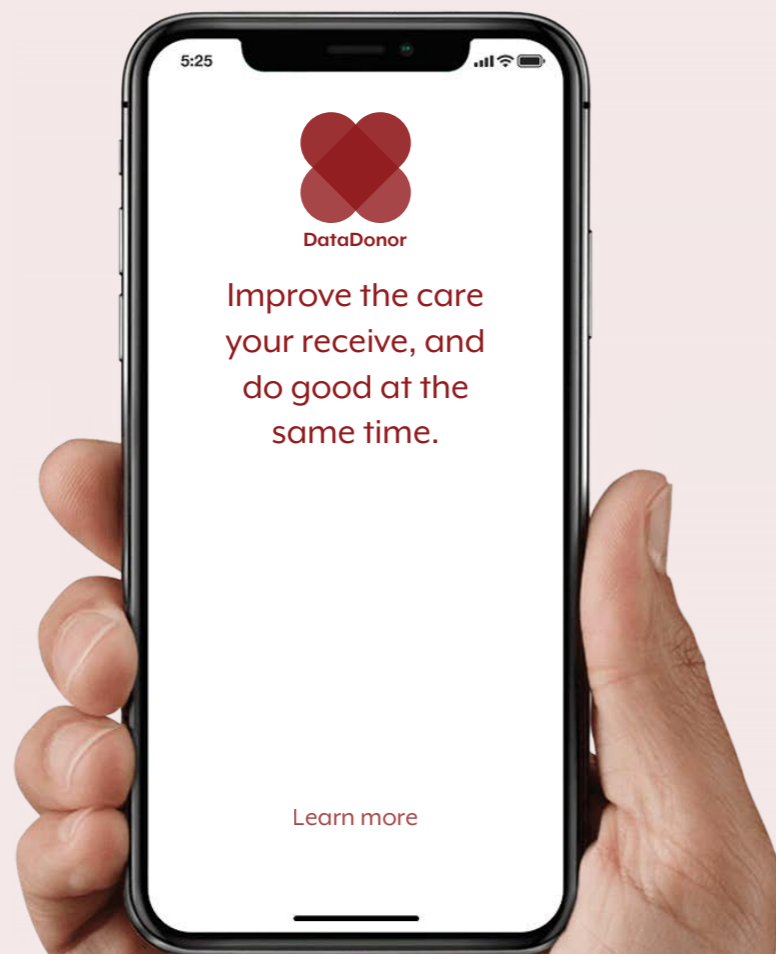
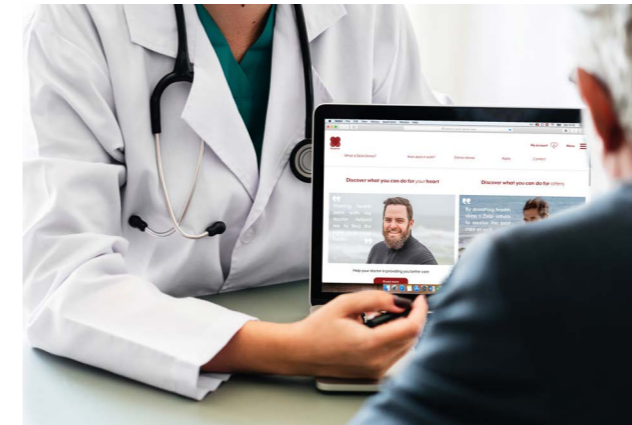


Figure 35 - DataDonor

## 5.1.1 STARTING DATADONOR EXPERIENCE

### 1. DATADONOR INTRODUCTION



*“I don't know what my options are to receive the care I need”*

A patient is diagnosed with high blood pressure and needs to take medication. DataDonor is introduced as an option to receive the right (doses) of medication faster.

- Cardiologist discusses possibilities using the website during consult.

Figure 36 - Introduction of DataDonor during consult

### 2. EXPLORING DATADONOR

*“DataDonor sounds interesting! But I would like to know more before I apply”*

Because there is not enough time during consult, the patient can find more information about DataDonor online at home.

- Information about the value of health data and how it can have an impact on patient's own care and that of others (e.g. interactive platform and donor stories)

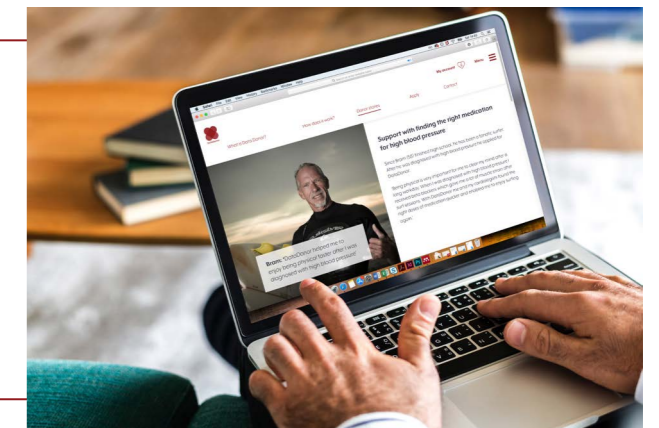


Figure 37 - DataDonor website consulted at home

*“Hmmm, what kind of impact could data have on my own care?”*

The patient can experience what impact data measuring and sharing has via an interactive menu.

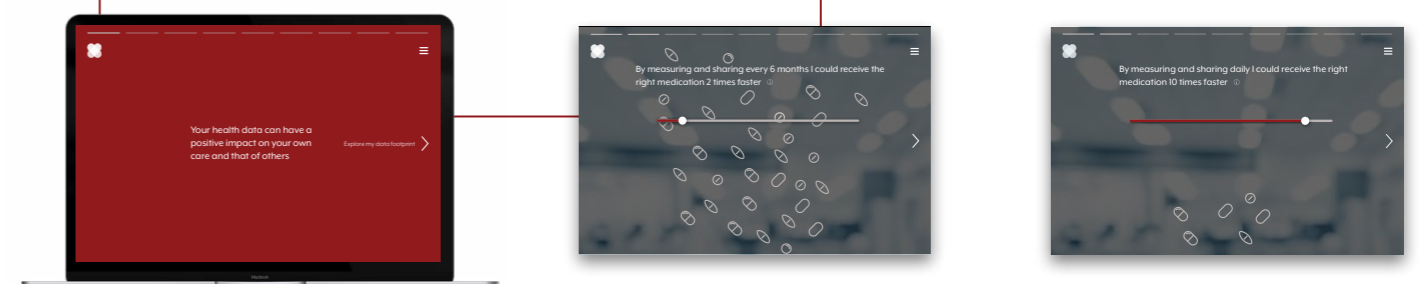


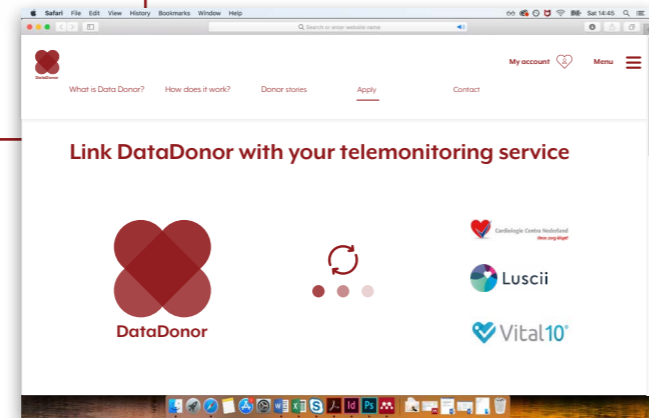
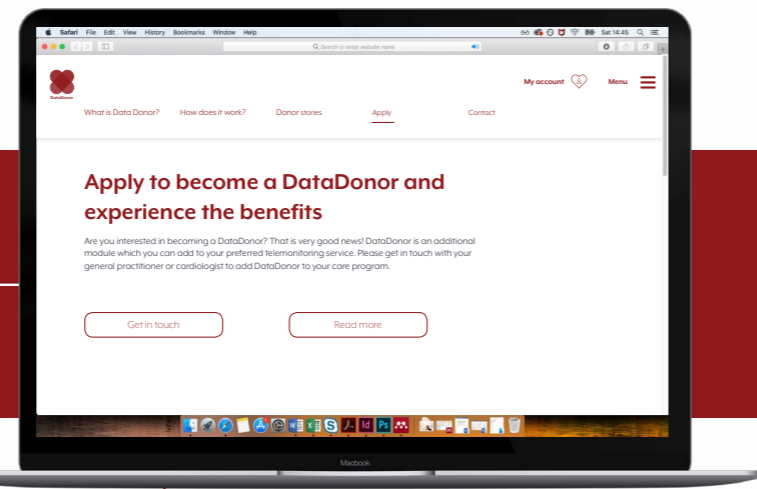
Figure 38 - Data footprint experience (explained more elaborate in chapter 5.2)

Figure 39 - On-boarding of DataDonor

### 3. ON-BOARDING

“Sounds like it can be useful to tailor my care, I would like to apply!”

Together with his caridologist, the patient needs to apply for DataDonor and link the module to the relevant telemonitoring service. What and how often the patient needs to measure depends on the diagnoses.



### 4. TELEMONITORING SERVICE

“I would like to receive remote advice and support”

“I wonder what the impact of my donations has been so far”

The patient can use the initial telemonitoring service (remote care, medication/life style interventions). Additionally, patients can track what impact their data donations has on their care and that of others.

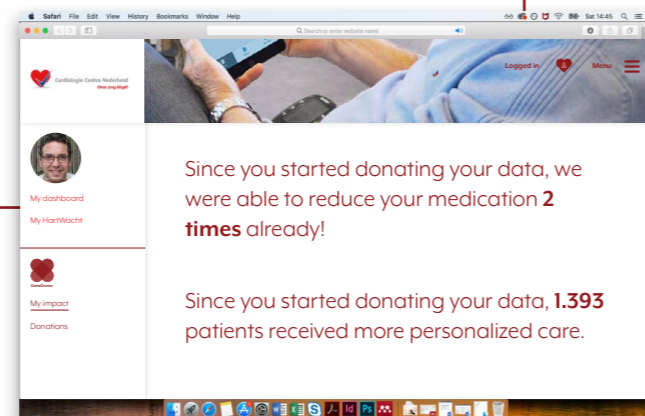
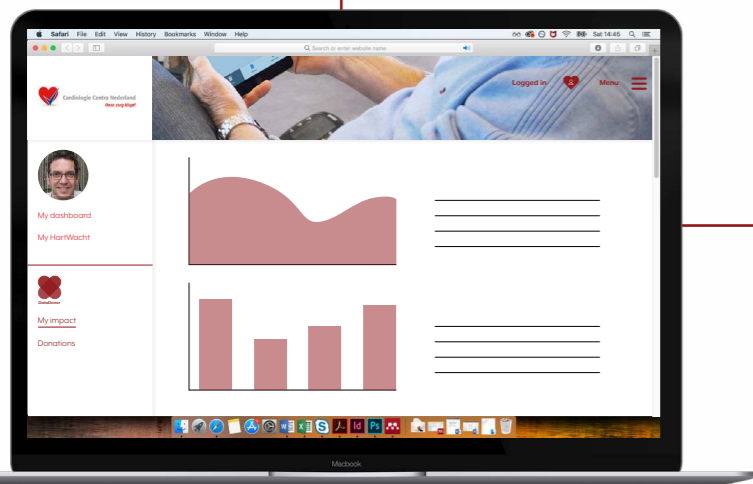


Figure 40 - My Impact overview

### 5. DECISION SUPPORT TOOL DURING CONSULT

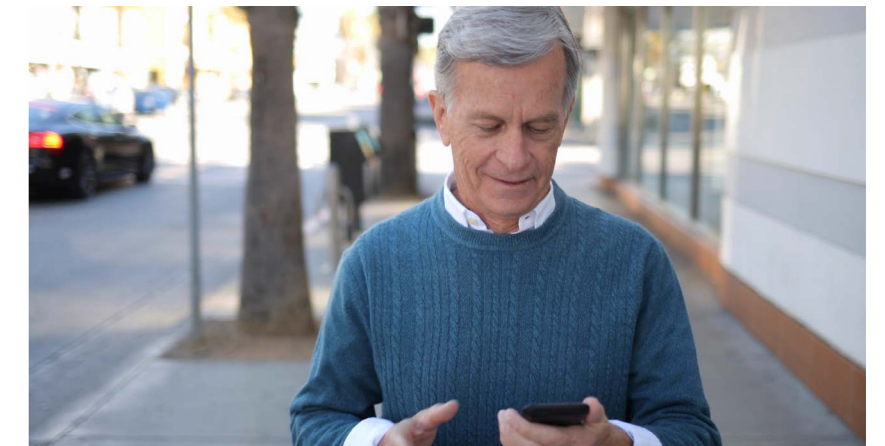


“Is this the right (doses) medication for me?”

The cardiologist can use DataDonor as a decision support tool during consults to provide tailored treatment to the patient. Together they can discuss the best options.

Figure 41 - Receiving personalized care with decision support tool

### 6. PERSONALIZED DRIVERS TO MEASURE AND SHARE



“I would like to know other patients' measuring and sharing behaviour to remind me I have to do it as well”

Over time, the patient finds a balance in medication and life style and needs a different driver to measure and share health data. This way, adherence can be maintained.

- Reminders are patient specific taking the fluid motives and needs to measure and share into account

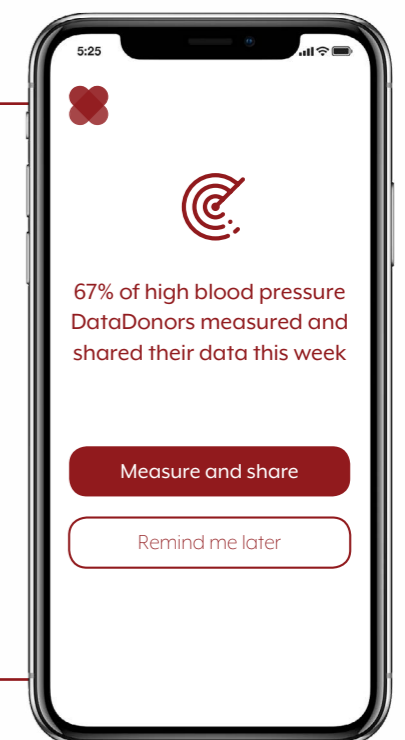


Figure 42 - Personalized reminder



## 5.2 // CONCEPT DETAILING

This paragraph will elaborate on separate elements of the concept and will explain them in more detail. These details help to further break down the concept and explain how behavioural design interventions are used in the concept.

### 5.2.1 DATADONOR HOME PAGE

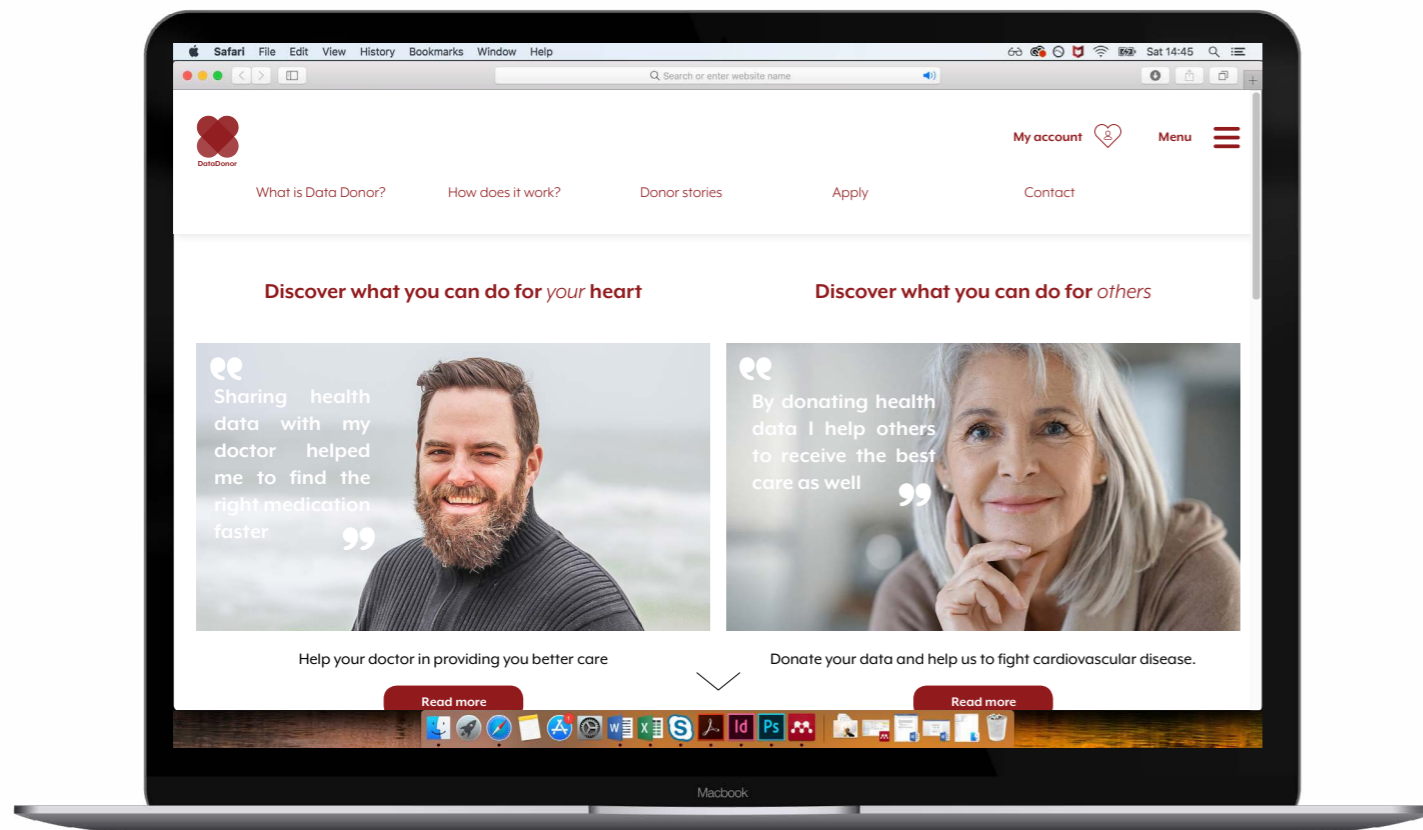


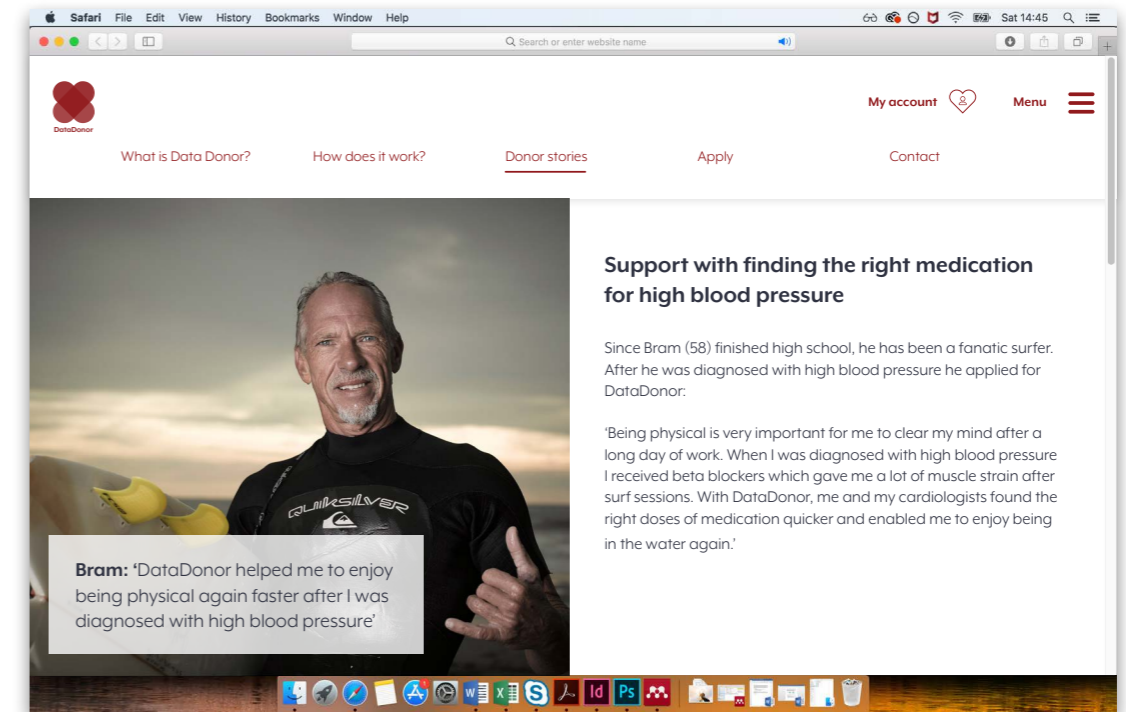
Figure 42 - Homepage of DataDonor

#### Landing page

In the scenario the landing page of DataDonor is visualized in the proposed context. The landing page of DataDonor functions as an informative platform where patients can find more information about the value and impact of health data. Cardiologists and general practitioners can use it to make patients aware of the possibilities of data donation and patients can use it when they are home and want to have more information.

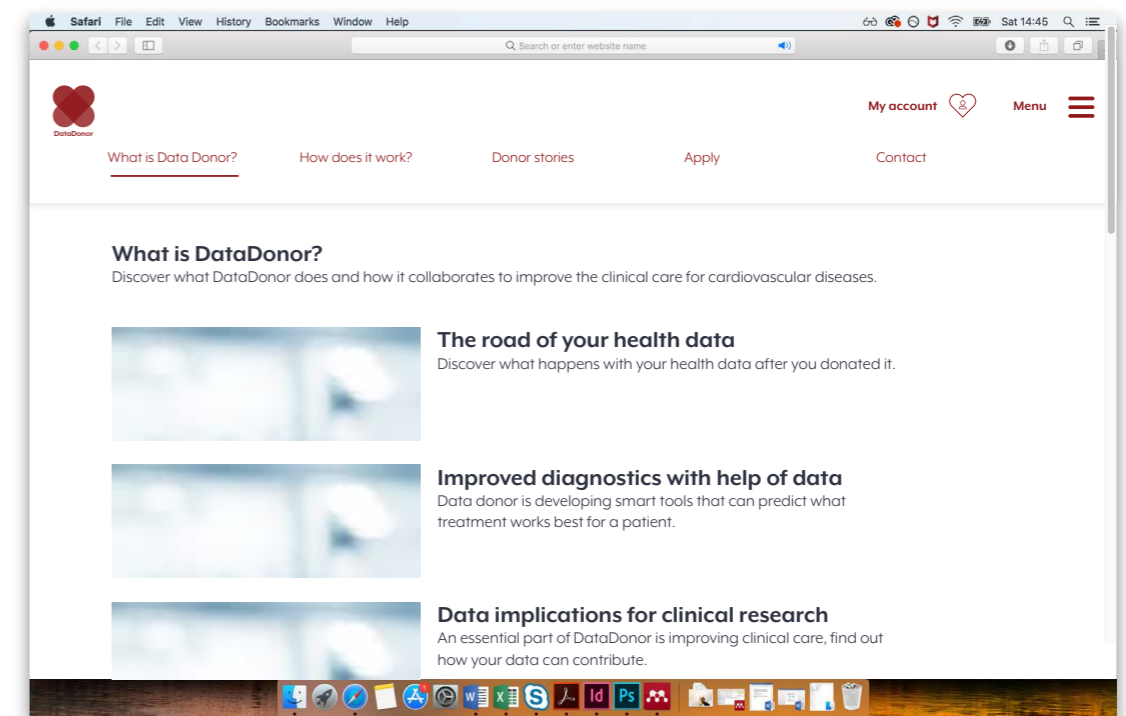
#### Data for personal care

Information is provided where care professionals explain how measuring and sharing health data can improve patient care.



#### Donor stories

To bring the impact of sharing health data to life, stories of patient who received better care because of DataDonor are shared. Potential DataDonors are informed about what the impact of being a DataDonor can have on their care, but also on that of others. This way, the concept makes the value of health data more tangible.



#### About DataDonor

Discover how your donations contribute to DataDonor research. Topics like 'the road of the data', 'new medicine from data', 'improved diagnostics' and 'implications for clinical research' are shared to let show what impact data can have on care. Additionally, publications and year reports that used data from DataDonor are published for the public.

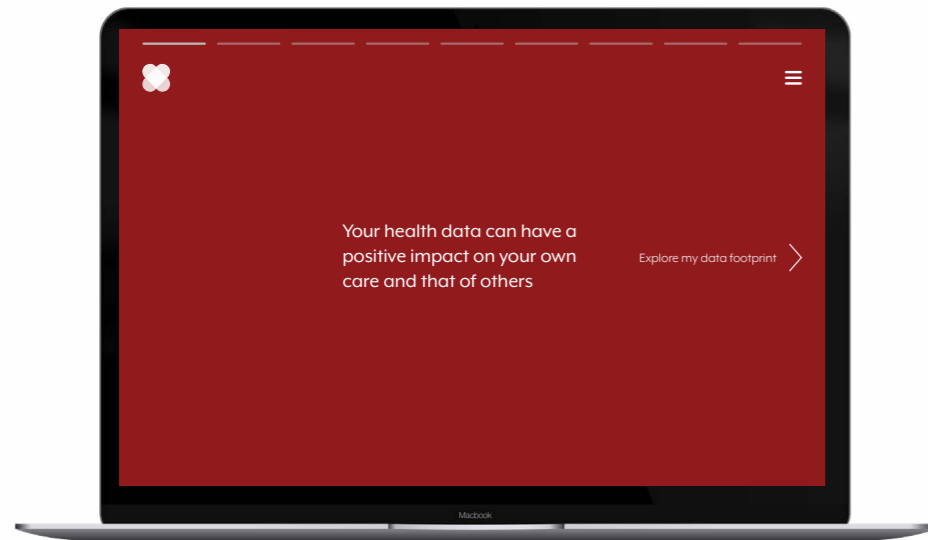
Figure 43 - DataDonor personal stories

Figure 44 - Additional information about DataDonor



## 5.2.2 DATA FOOTPRINT EXPERIENCE

Figure 45 - Data footprint experience



### Interactive experience

To let patients explore the impact of their data, a 'data footprint experience' is created. This is an interactive environment where the patient is guided through the individual, research and social impact of health data. This experience is an example of how the DataDonor could function as an informative environment regarding the value of health data. This way, the potential impact of health data is made more tangible.

It should be noted that information shared in these screens are fictional. When developing and designing this data footprint experience, care professionals should be included to make sure information that is shared is correct and valid.

### Three scenarios

Three scenarios of how health data can have individual, research and social impact are presented to the patient.

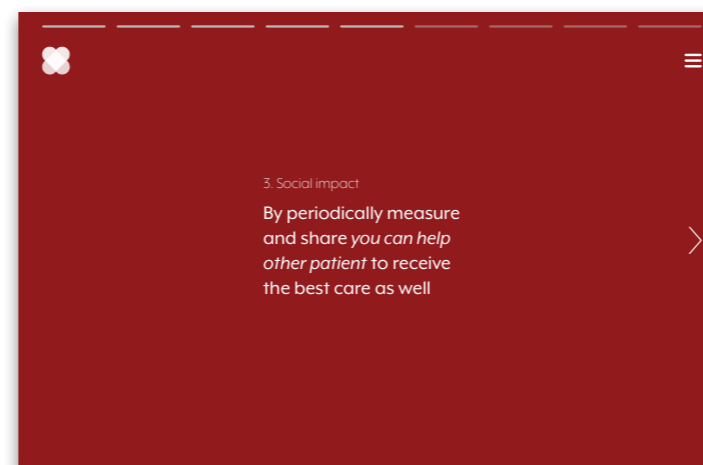
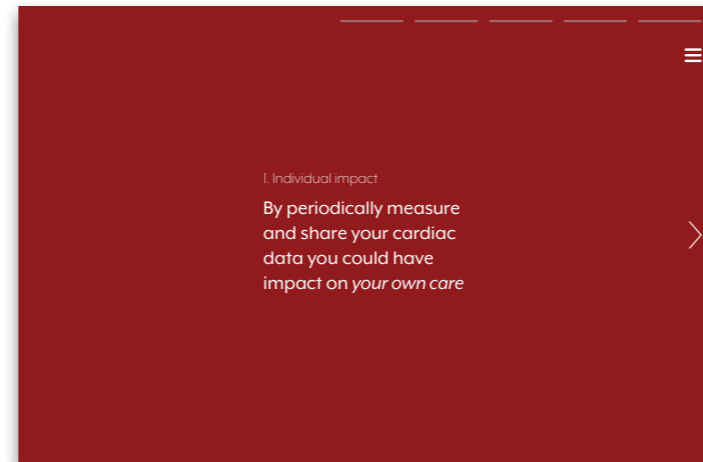


Figure 46 - Data footprint experience overview

### Interactive slider

An interactive page shows you the impact of periodically measure and share health data (slide bar). Below an example of how this could impact the time in which you receive the right doses of medication is given (fictional).

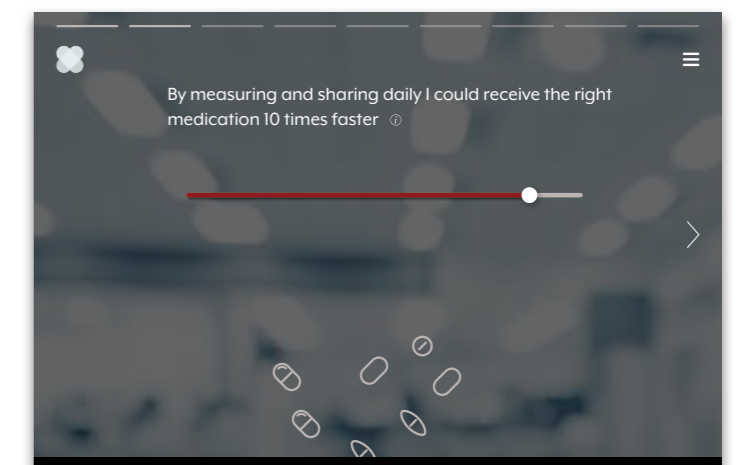
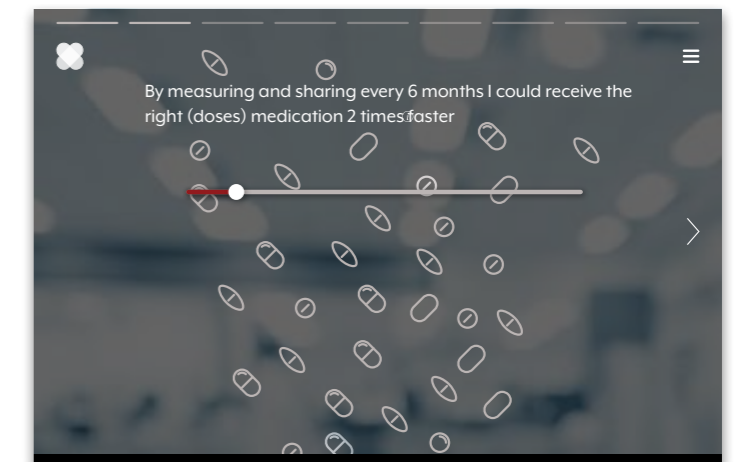
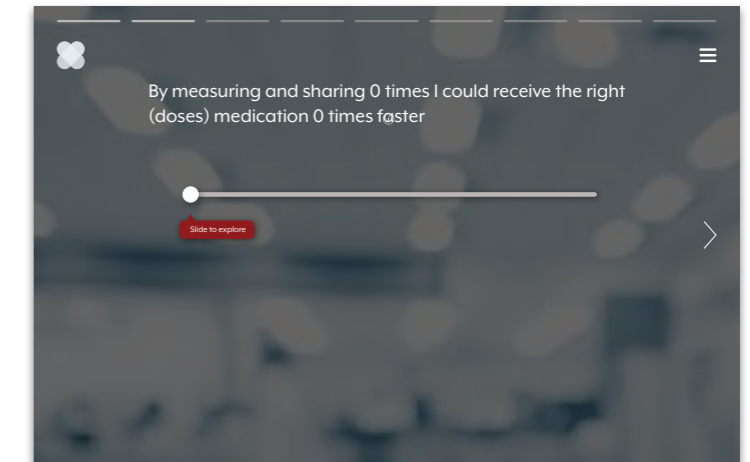


Figure 47 - Data footprint experience interactive screen

## 5.2.3 PERSONALIZED REMINDERS

### Adherence and adaption

As was found during user research, the needs and drive to measure and share health data changes over time. This means that initial drivers to measure and share health data might influence adherence over time. Because of this, the application can change the way it reminds people to measure and share depending on the patient's interaction with the application. These reminders are nudges or rationale overrides and are based on the target drivers that were identified in the design brief or can be created by patients themselves. These drivers include involving family, care professionals or third-party involvement (e.g. community).

### Persona example

To illustrate how reminders will depend on the patient, two personas are created with varying drivers, capabilities and needs. One of the personas is illustrated on the right, the other one can be found in appendix K. The numbers will first be clarified 1) a personal story is shared to understand the background, needs and pains of the patient. 2) A three ax matrix shows the capabilities of the patient regarding self-care, need for advice/support and how digital capable the persona is. 3) Motives to donate data are ranked and show what persona's drivers are to measure and share health data. These drivers are derived from user research. On the right the persona and four optional personalized reminders are presented. The behavioural design interventions that are used are from the toolkit developed by van Lieren (2018) and are explained below. All four made use of rationale overrides (RO). A brief journey is visualized in figure 51 to show how Bram's mindset is aimed to override.

### Behavioural design interventions

1. RO 'relative ranking'. This RO provides the patient his/her relative performance of their behaviour compared to patients with similar characteristics. It provides a reference point.
2. This reminder appeals to the patients drive to help other CVD patients receive the best care as well.
3. RO 'personalized feedback'. This prompts the patient to reflect on his/her previous behaviour.
4. RO 'create commitment'. Patients are more likely to commit to a certain behaviour if they choose it themselves. In this situation, the patient choose to include family to remind him.

Figure 49 - Persona for personalized reminder journey

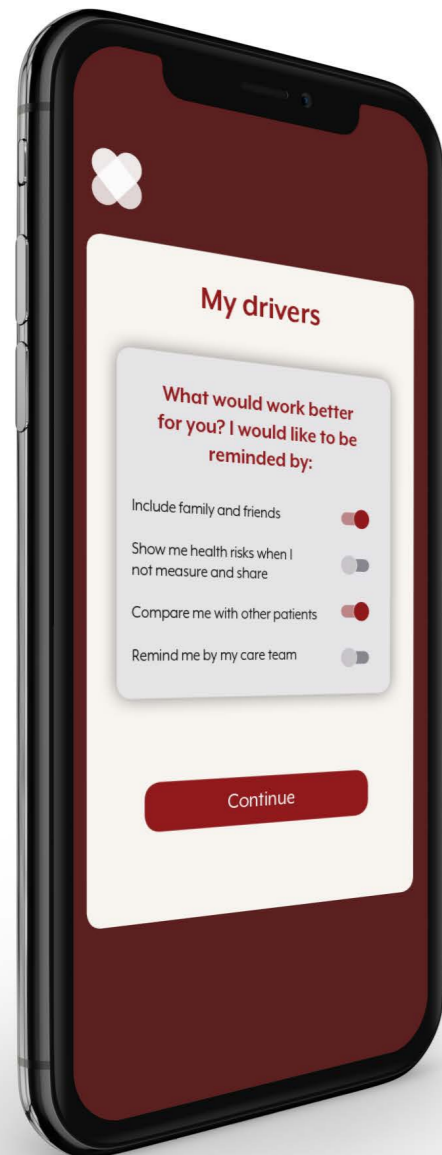
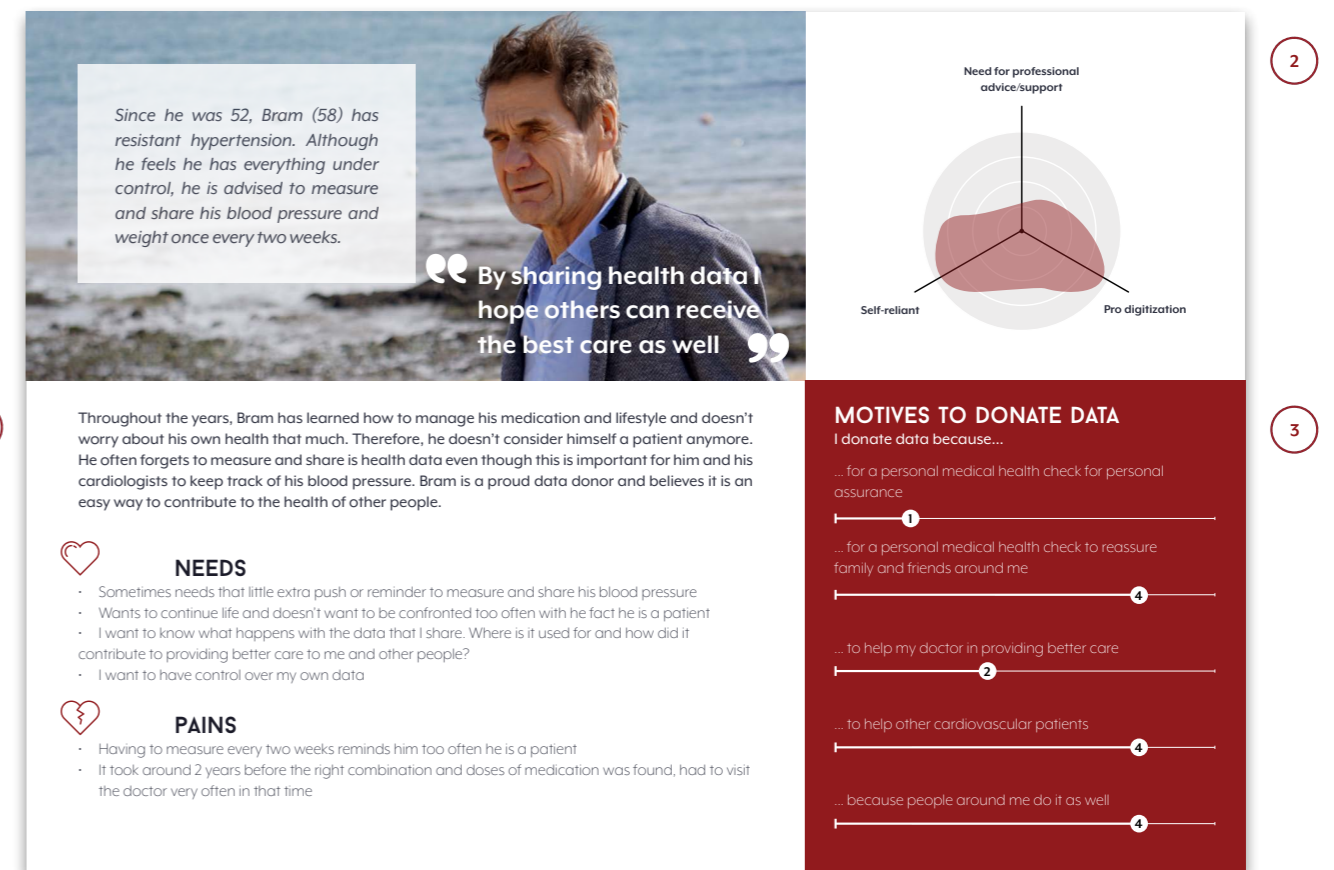


Figure 48 - Setting up personalized reminders

Figure 50 - Personalized reminders

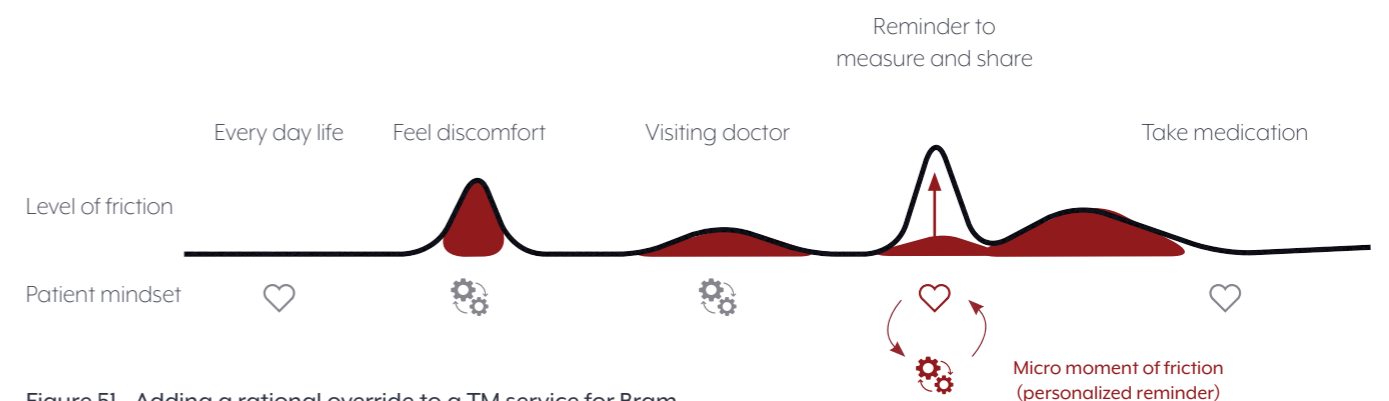
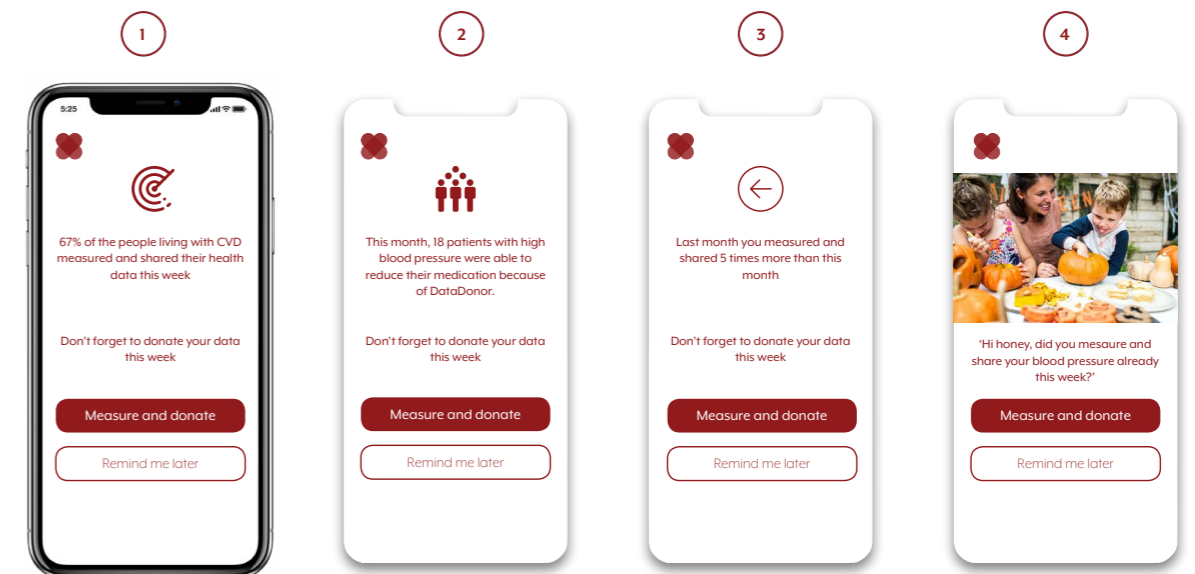


Figure 51 - Adding a rationale override to a TM service for Bram

## 5.2.4 MY IMPACT OVERVIEW

As was found during user research, patients were very curious how their health data actually contributes to their own care and that of others. Therefore, the DataDonor should have an environment where this impact can be found. Figure 52 shows an example of how the DataDonor module is integrated in the HartWacht service of Cardiologie Centra Nederland. In the bottom of the page the menu can be found where patients can see how their data sharing behaviour made impact on their own care and that of others (real-time). It should be noted that the information shared in this example is fictional. The quotes that are shared support the desire of this concept detail and are derived from user research with patients.

Patient: "Receiving feedback could also help to feel reassured. When feedback is provided I see that it contributed to my own treatment and that it is also compared to patients like me feels even more reassuring"

Patient: "Small pieces of information like 'your donation contributed to this research or to improve this diagnostics.'"

Patient: "This whole idea has to do with feeling involved and that my contribution made a difference. If you feel involved with something you do your best more."

Patient: "It would be nice to have an overview with what happened to your data and how it contributed. Something tangible."

Patient: "For me it should feel like my participation is valuable. If I don't know this, there is no reason for me to contribute."

Patient: "Small pieces of information like 'your donation contributed to this research or to improve this diagnostics.'"

Patient: "This whole idea has to do with feeling involved and that my contribution made a difference."

Patient: "Maybe it would be interesting to know how my data deviates from other people. This could potentially influence my behaviour as well if it shows that others are doing better"

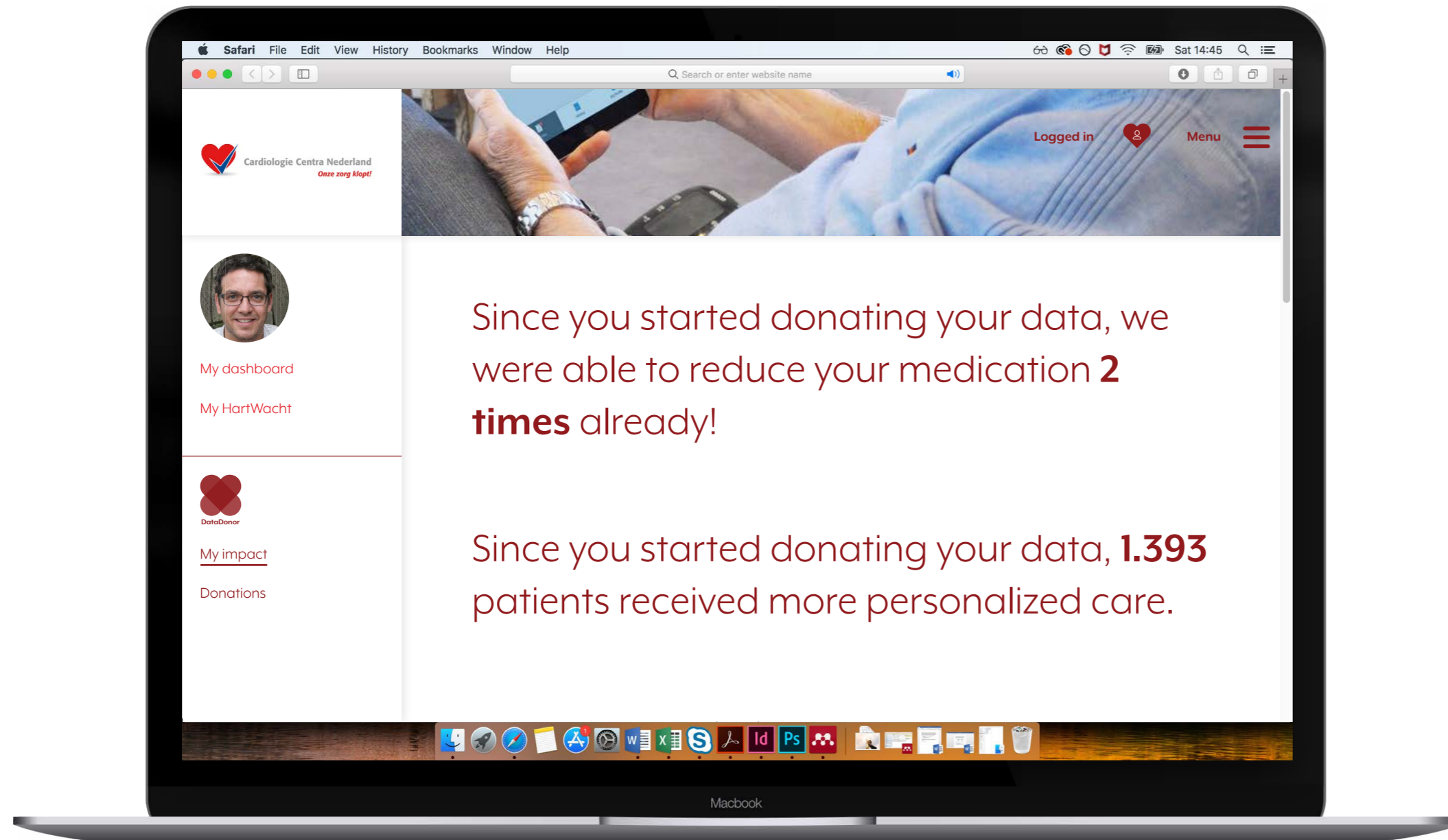


Figure 52 - DataDonor My Impact overview



# KEY TAKE-AWAYS CHAPTER 5



## DATADONOR

Based on the insights that were gathered throughout the project, DataDonor is developed. DataDonor is a digital environment which consists of an informative website and a module that can be added to existing telemonitoring services to donate health data easier. By making use of personalized reminders to measure and share data, the design responds to the dynamic drivers and needs of cardiovascular patients.

By adding the module, patients can share their health data easier for clinical research and predictive analytics. Additionally, the module can be used by care professionals as a decision support tool using predictive analytics to tailor patient treatment. Moreover, it allows patients to better track what impact their data donation has on their care and that of others.

The fact that DataDonor is an additional module to existing telemonitoring services, means that in the future it could also be used for other patient segments as well (e.g. diabetes). The modular characteristic is beneficial for FHC as well, because they do not want to develop their own telemonitoring services, but create partnerships with existing ones.



## CONCEPT DETAILING

DataDonor consists of several elements that together aim to increase measuring and sharing adherence. In chapter 4.5 it was shared that the final design will focus on two key moments in the patient journey of a telemonitoring service. The concept details shared in this chapter are focussed on those moments.

### Data donor homepage

To increase patients' awareness and knowledge regarding the value of health data, an informative website is developed. This website can be used during consult to inform patients about DataDonor and can be consulted by patients when they are home. Information about the following topics is shared:

- Stories about individual care improvement
- DataDonor stories; how did DataDonor impact lives of others?
- Additional information about DataDonor (what happens to my data? How have diagnostics been improved with DataDonor? Implications for clinical research)

### Data footprint experience

Because the value of health data is not well perceived by patients, a data footprint experience is designed. This online interactive experiences shows patients how health data can have individual, research and social impact.

### Personalized reminders

Because patient's need and drive to measure and share health data is dynamic, DataDonor can change the way it reminds people to measure and share data depending on patient's interaction with the application. These reminders are nudges or rational overrides and are based on drivers that were identified in the design brief or can be created by patients themselves.

### My Impact

User research showed that patients are very interested in how their data actually has an impact on their own care and that of others. Therefore, the My Impact overview is created which provides real-time information regarding how patients' data donor behaviour has an impact on their own treatment and how it contributed to research and care of others.

# CHAPTER 6

## FHC CASE - IMPLEMENTATION

### 6.0//

This chapter focuses on what FHC should consider in order to implement the final concept. First, suggestions are given on how DataDonor should be positioned to introduce the concept to MCL and patients. Second, a implementation roadmap is presented to show how to introduce, develop, optimize, and expend DataDonor. Finally, an important part of a health data sharing platform is that it should meet strict regulations, therefore advice is provided on what compliant elements the concept should have in order to start testing and using the concept.

In this chapter:

- 6.1 DataDonor positioning
- 6.2 Implementation roadmap
- 6.3 Compliant on-boarding



# 6.1 // DATADONOR POSITIONING

## Positioning to MCL

In chapter 4.1 it is shared that part of the deliverable for the FHC use case is a proposition which can help FHC in communicating how they can support MCL in utilizing eHealth to improve clinical care. To help FHC with this, a proposition poster is designed. Before designing the poster, Hessel Bouma of FHC was consulted to find out what elements are important to put into the proposition. These requirements are shared in appendix L. The proposition poster introduces the concept and communicates the problem that is being solved, how it works, the targeted users and added value for important stakeholders. This poster can be found in appendix N and will be used during evaluation sessions. These evaluation sessions will be discussed in chapter 7.

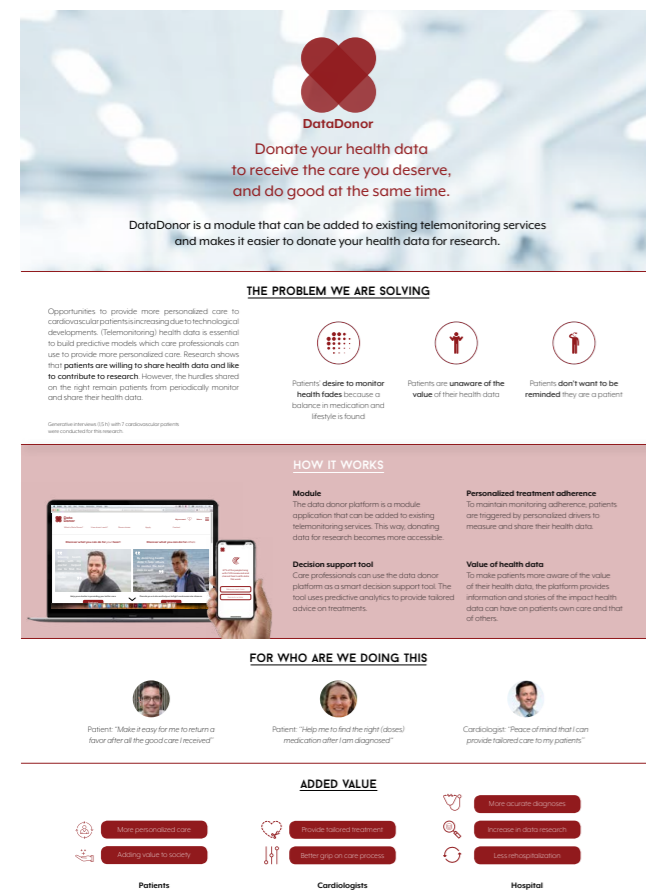


Figure 53 - Final proposition poster for FHC

## Positioning to patients

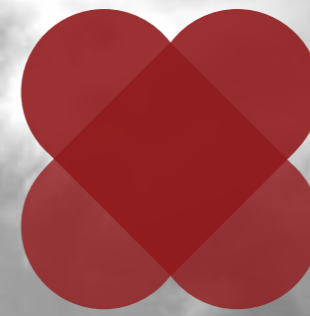
One of the conflicts identified during user research was that patients don't want to be reminded they are a patient. It was found that this has influence on the adherence of measuring and sharing behaviour of patients. What is interesting about DataDonor is that it emphasizes on that patients are not merely patients, but vital contributors to their care and that of others. This could increase the motivation and willingness to participate and improve care and result in higher adherence (vision requirement appendix F).

## DataDonor awareness

An important initial step in implementing DataDonor is to make people aware of the proposition so patients start using it. Therefore, a DataDonor campaign is created. The goal of this campaign is to make people aware of DataDonor and evoke the feeling that patients can become an important contributor to care. By evoking this feeling, the role and meaning of being a patient is repositioned.

The campaign should be distributed across various relevant touchpoints across the patient care continuum. For instance, at hospitals or at GP offices or among existing telemonitoring service platforms.

It should be noted that the picture used in the poster is taken from the Sanquin website. It is not known if the person in the picture has CVD and functions only as an example.



DataDonor

“ By donating health data I hope others can receive the best care as well ”



**Donate your health data**  
 Improve the care you receive,  
 and do good at the same time.

**CROWDSOURCE YOUR HEALTH**



# 6.2 // IMPLEMENTATION ROADMAP

Rome wasn't built in a day, the same counts for DataDonor. Therefore, an implementation roadmap is created which envisions how DataDonor is created and expanded in three main phases. These phases work towards a future vision, namely: *a health care ecosystem where patients and care providers collaboratively improve clinical care and patient wellbeing*. It should be noted that this implementation roadmap is a concept version. Eventually, the roadmap should be created together with FHC making sure their strategic business goals, partnerships, and technological capabilities are aligned and placed along a valid timeline. Below roadmap recommendations are shared and how Deloitte could supervise and support along the way.

### Phase 1 - Local launch

Although DataDonor could be implemented in various telemonitoring services and diseases, it is advised to focus on one disease and telemonitoring service at the start. For example, hypertension patients using HartWacht service. Learnings from this first target group can be used to implement DataDonor more effectively and efficiently for other diseases. Pacmed could be a potential a first partner to build decision support tools since they are currently working on developing such a tool for personalized care for hypertension treatment. FHC aims to bring together multiple care providers, but for the first phase it is recommended to collaborate with MCL since this is their first partner. The first phase consists of doing R&D and piloting at MCL. Along the way, Digital Health Compliance should be consulted to ensure DataDonor meets compliance.

### Research and development

Before developing DataDonor, more research should be conducted regarding the measuring and sharing behaviour of hypertension patients to better understand what causes adherence to fade. These insights can be used to design more accurate behavioural interventions. This type of research can be done by consultants of Deloitte Digital Creative which are specialized in doing user research and turn valuable insight into concepts.

### User testing

The improved DataDonor design should be user tested with patients and cardiologists. Especially how the behavioural design interventions influence patient behaviour should be tested longitudinal. The output of these tests can be used to optimize the design before piloting DataDonor.

### Local piloting and launch

It is advised to first pilot DataDonor with a select group of patients and cardiologists who are interested within MCL. This local piloting enables FHC to validate the concept low key before launching it to a bigger audience and platform. The validations should focus on if the behavioural design interventions result in increased treatment adherence and if the concept increase patient participation in care. The feedback of the local pilot can be used optimize the concept. If iterations are made, the concept could be deployed across all patients with hypertension using MCLs patient portal 'Mijn MCL'. To increase awareness, the DataDonor campaign can be set up locally.

### Phase 2 - Regional launch

At the end of the second phase, the concept specified for hypertension patients could be introduced to multiple care providers FHC aims to collaborate with. Deloitte partnership with SAP Leonardo – Healthcare could potentially be used to deploy DataDonor on a larger scale. Additionally, the concept can be introduced to support other diseases and telemonitoring services.

### Optimization and expansion

#### Optimization

Results and feedback from the local pilot can be used to optimize DataDonor within MCL. It is important DataDonor is continuously being improved so the best patient experience is being delivered.

#### Expansion

When DataDonor is live for patients with hypertension, other patient segments and telemonitoring services could be added. New user research should be conducted regarding behaviour and drivers of

measuring and sharing health data within this new disease category. COPD could be an interesting patient group where telemonitoring can have significant impact on care as well. FocusCura could be a potential partner since they are already providing telemonitoring services for COPD patients.

### Regional launch

The more data is being collected and researched, the better decision support tools will become. That is one of the reasons why FHC want to join forces of multiple care providers. Once FHC learned how DataDonor works within MCL, the concept could be deployed among other parties as well to utilize the potential of the ecosystem. To combine various patient portals

from different care providers, a FHC PGO should be developed (this is explained in chapter 2.2.2. To create more awareness for DataDonor, partnering care providers could use the DataDonor campaign.

### Phase 3 - National launch

It is expected that in the future the Netherlands will have a national PGO. To fully utilize the potential of health data and predictive analytics, combining nationwide databases can result in very strong decision support tools. This will result in a continuously self-learning ecosystem which optimizes care. The DataDonor campaign can be deployed nationwide.

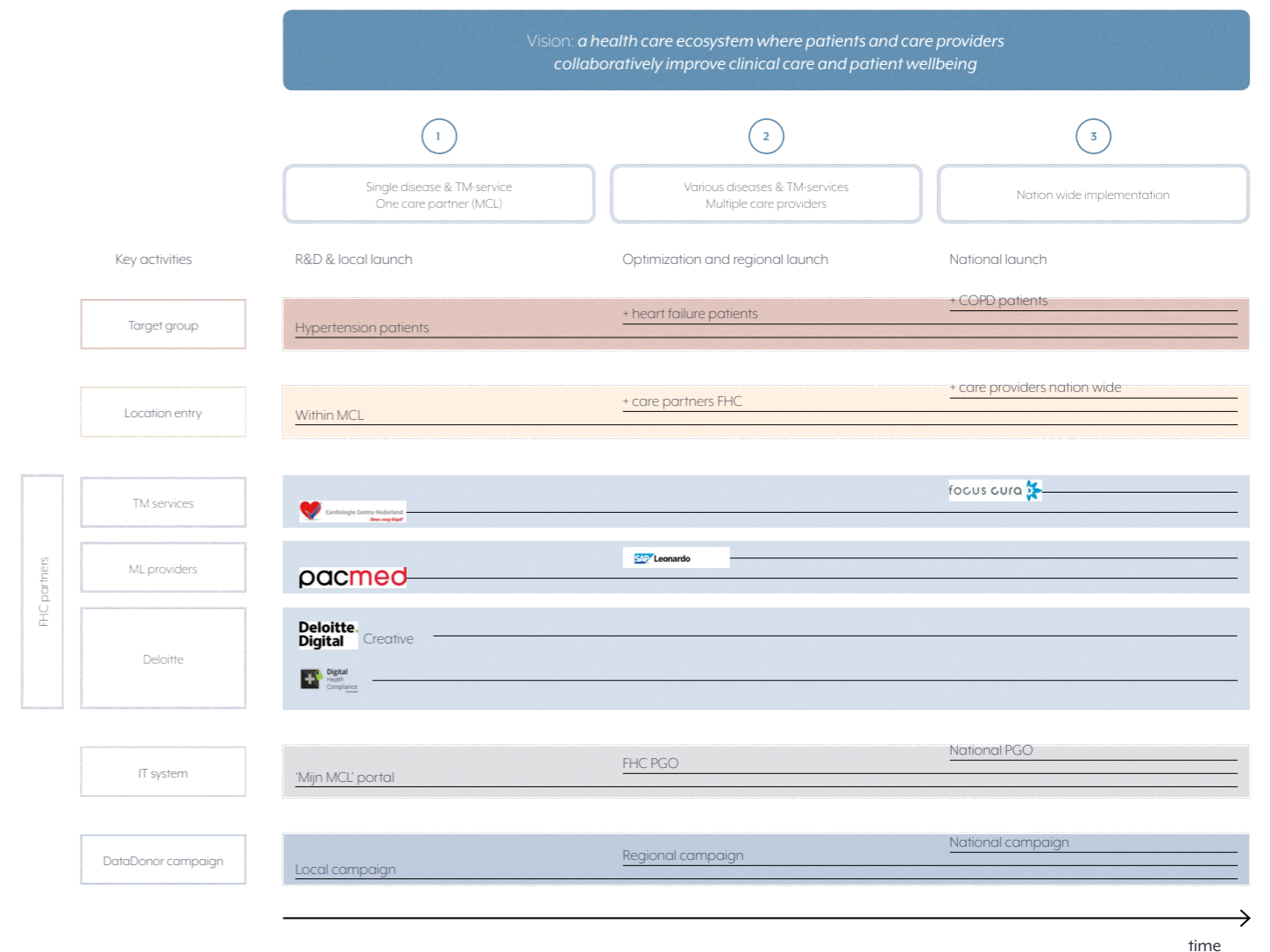


Figure 54 - Concept implementation roadmap

## 6.3 // COMPLIANCE ON-BOARDING

### Consulting Deloitte Digital Health Compliance

An important requirement of DataDonor is that it should be compliant with all patient health data regulations. As introduced in the use case, Digital Health Compliance (DHC) did extensive research on what FHC is allowed to do with data. To make DataDonor compliant, the concept should meet relevant regulations DHC found during their research. Therefore, the final concept is discussed with Rob Peters, Senior Manager at Deloitte Legal and co-founder of DHC, to see which compliant elements should be incorporated into the concept. This resulted in an additional on-boarding step when the concept is going to be introduced to and used by patients. The main focus of this on-boarding is to make patients aware that they control and own their health data and that consent is given consciously and voluntarily. This additional element meets the design requirement 'PGHD must be owned and controlled by CVD patients and consent must be given consciously and voluntarily. This requirement is a result from both new regulations (GDPR) and the trend of patient empowerment. Below, important steps in this on-boarding will be shared briefly.

When the patient is introduced to DataDonor and wants to apply, the concept interface will guide the patient through a compliance flow. Three important elements are identified that need to be incorporated in the flow:

1. A privacy statement where information regarding security and anonymity of data is shared.
2. Information about how the patient can always opt-in and opt-out of DataDonor. It should be clearly communicated that patients control their data.
3. An option menu where patients can decide how they would like to be informed about how their health data is used. One patient prefers to give consent and not to be bothered with information anymore, while the other has the desire to receive information on how his data contributed to research. These fluid needs were also a finding during user research, more information about these findings can be found in appendix D.3.

## KEY TAKE-AWAYS CHAPTER 6

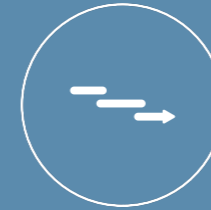


### DATADONOR POSITIONING

In order for FHC to introduce DataDonor to MCL and patients, the concept is positioned using a proposition poster and DataDonor campaign.

The proposition poster introduces the concept and communicates the problem that is being solved, how it works, the targeted users and added value for relevant stakeholders.

To introduce DataDonor to patients and make patients aware of the proposition, a DataDonor campaign is developed. The goal of the campaign is to inform patients and evoke the feeling that patients can become an important contributor to care.



### IMPLEMENTATION ROADMAP

To further develop DataDonor a concept implementation roadmap is created to illustrate how DataDonor is developed and expanded step-by-step. Strategic business goals of FHC, partnerships, target groups, technological capabilities and the DataDonor campaign are aligned over a timeline. The roadmap is divided into three phases:

1. Local launch  
After doing additional user research and updating the concept, DataDonor should be piloted for one specific patient segment (hypertension) within MCL. If pilot results are positive, DataDonor could be used for all hypertension patients of MCL.
2. Regional launch  
FHC's aim is to connect multiple care providers to share health data. After a successful pilot and dry run at MCL, DataDonor could be expanded to other care providers in the region. Additionally, DataDonor could be used to support other patient segments as well.
3. National launch  
In the future, it is likely there will be a National PGO in the Netherlands. Since DataDonor operates best when more patient data is being collected, the platform could benefit from a national database.



### COMPLIANT ON-BOARDING

DataDonor should be compliant with all patient health data regulations in order for FHC to pilot and/or implement the concept at MCL. Three important elements are identified that need to be incorporated into the on-boarding flow of the concept:

1. A privacy statement where information regarding security and anonymity of data is shared.
2. Information about how the patient can always opt-in and opt-out of DataDonor. It should be clearly communicated that patients control their data.
3. An option menu where patients can decide how they would like to be informed about how their health data is used.

# CHAPTER 7 VALIDATION

## 7.0//

This chapter provides an overview of the validation sessions that are done to evaluate DataDonor on both a user and client perspective. The personalized reminders, DataDonor campaign, and MyImpact overview are validated by patients and partly by the client. The proposition poster and implementation roadmap are validated by the client and health care experts from Deloitte.

In this chapter:

7.1 Validation

7.2 Key take-aways



# 7.1 // VALIDATION

To validate the usefulness, desirability and value of DataDonor, different validation activities are performed. Validation with patients and the client are complemented with feedback from Deloitte Health Care experts. These validation activities contribute to evaluate DataDonor on desirability, viability, feasibility on both a user and client level. Figure 55 gives an overview of how the different sessions relate to the validation elements.

## 7.1.1 VALIDATION SET-UP

### Validation with patients

To validate DataDonor on desirability from a patient perspective, four patients are consulted via Skype to provide feedback. Three details of the final design are tested during this validation activity; the personalized reminders, 'My Impact' overview, and the campaign poster. The sessions focused on validating if the target drivers are applied well and if these concept details contribute to reach the design goals shared in chapter 4.4. During the 30/45-minute interviews, concept elements are showed to the patient via a laptop.

### Validation with client

In order to evaluate the usefulness of the proposition built, the final concept is evaluated by Hessel Bouma (FHC) and Erik Bosgra (MCL) after a final presentation was given in Leeuwarden. For this, the final proposition and implementation roadmap created in chapter 6.2 and 6.3 are used. This validation session focused on if the proposition can help FHC in communicating how they can support MCL in utilizing eHealth to improve clinical care.

### Feedback by experts

Finally, Deloitte Healthcare experts, Lucien Engelen (Deloitte Global Strategist Digital Health) and Mathieu van Bergen (Partner Deloitte Consulting - Health), are consulted to assess the final concept on feasibility and viability and how Deloitte could support FHC in developing DataDonor. Both the proposition poster and the implementation roadmap are used during this session.

## 7.1.2 VALIDATION RESULTS

### Validation of concept details

#### Personalized reminders

The four personalized reminders introduced in chapter 5.2 are used to show to patients. Patients perceived the reminders as valuable and a relevant way of reminding to measure and share. What was interesting to see is that all patients that were interviewed chose a different reminder as their favorite. This shows that the trigger to measure and share health data varies per patient like was found during user research and the behavioural design literature. Health care experts agreed that to keep patients engaged reminders should be personalized

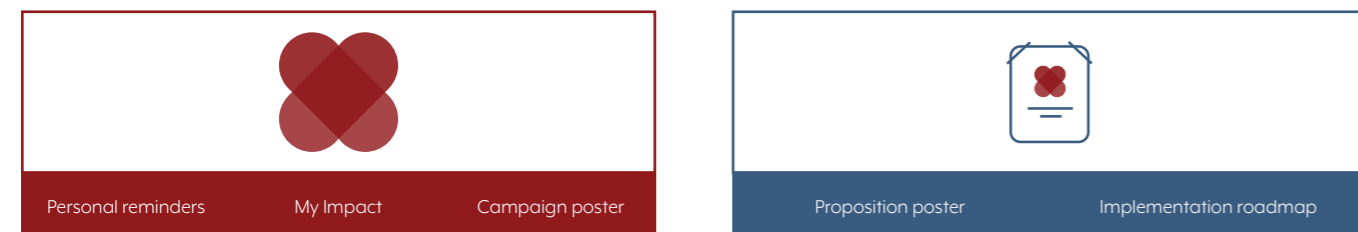


Figure 55 - Overview of different validation session

to increase adherence. This is also in line with what cardiologists stated during user research.

Patient: 'The reminder you can receive from your family really appeals to me, I can hear my husband or children say it to me. It makes it feel like less of a burden. I think it can also contribute in not letting you feel or be reminded you are a patient because someone outside the medical field reminds you'

In chapter 4.3 (user research) one of the health care experts stated that you should keep be

Patient: 'The reminder where you can see the percentage of other people who already measured and have the same condition as me appeals to me. It makes me feel part of a larger community and together we have the responsibility to stay or become healthy.'

Patient: 'For me the family reminder would really work because I am real family person. But I can imagine that someone single or in a different situation finds other things important.'

Patient: 'I think a personal reminder to share your data could be as important as for example a birthday reminder or something else in your agenda.'

Patient: 'Over time, a reminder to measure and share might not be important to me anymore, but it might be important to someone else you keep doing it.'

### Campaign poster

The campaign poster created in chapter 6.2 was showed to patients. Patients were asked what kind of feeling the poster evokes and if it clearly communicates what DataDonor is about.

Patient: 'Crowdsourcing your health appeals to me because it makes you feel like you are part of group and together we will make the best out of it.'

Patient: 'Well, I believe I could have been on that poster. I really like the casual look of it and shows that also the 'regular' guy can have a CVD.'

Patient: 'I think it evokes the feeling that you should do more preventive things for your health. The poster shows that a younger person than me is already doing this so that triggers me to do it as well.'

Patient: 'I notice that it is nice to feel you are part of a larger group of people with the same condition as you. And that you can see how you have impact on each other with sharing health data shows that together you are responsible for your own and each other's health.'

Additionally, Erik Bosgra showed the poster to several colleagues in MCL and said that people understood the concept and message of DataDonor.

### 'My Impact' overview

Patients showed a strong preference for the 'My Impact' overview. During user research it was already found that most patients would like to know what the impact of their data is on their own care and that of others. The results of this validation confirm that this is an important trigger for people to measure and share their health data.

Patient: 'It think it is very good you provide concrete feedback on your data sharing behaviour. At the start sharing data feels a bit like 'black box' because you don't really know how it can contribute. By providing and updating feedback how your donations have an effect on your individual and public health, this medium becomes more tangible which has a positive effect on my relationship with it.'

Patient: 'For me it would really work if I can clearly see what the impact of my data is on my own care and that of others, maybe even more than the personalized reminders.'

**Patient:** 'It would be nice to know more about how DataDonor then actually contributed to the care of others. Not in numbers, but more in a story.'

The patient came up with the last quote by herself without telling that at the DataDonor website there will be datadonor stories that try to give this impact a more tangible form.

## Validation of proposition poster and roadmap

### Proposition poster

Overall, the proposition is well received and could be used to show MCL how FHC can support them in utilizing eHealth to improve clinical care. The modularity of the concept, being able to add it to various telemonitoring services, was especially relevant because eventually FHC wants to focus on more patient segment than solely cardiovascular.

The first thing said after asking how the proposition fits FHC was:

**Client:** 'This proposition is much larger than FHC, it should be aimed for national expansion.'

It is very important to show that DataDonor is compliant with regulations. According to Lucien Engelen, this is on top of mind by people in this field when they evaluate such a proposition. It should also be clear how and where such a module connects to (i.e. EMR or PGO). What could be valuable is to show the future impact of this concept by showing a roadmap where developments and expansion (regional and national) are made more clear. The implementation roadmap could be a good tool for this. However, the current roadmap is a concept version and before putting something like this on a poster information should be valid.

### Implementation roadmap

The implementation roadmap is used to expand in phases and is in line with how FHC aims to expand their data platform. First, the proposition should be implemented in the 'Mijn MCL' portal for initial piloting.

The roadmap then suggests to implement it in a 'FHC PGO' because multiple care providers with different portals would be combined. Currently, care providers in the northern region of the Netherlands are working on a PGO for this region. Hessel Bouma stated:

**Client:** 'This proposition can be an interesting case to use for the northern PGO'.

Additionally, Deloitte could support FHC and MCL with the implementation of DataDonor using their network of health care providers and specialists.

**Expert:** 'Deloitte can help in further development of DataDonor because we know and can bring together the right partners to bring this concept to life. For example, our collaboration with Salesforce could be of value here. Salesforce is a strong player in building user friendly 'cloud-based' platforms and they are very specialized in health care as well. '.

## 7.1.3 CONCLUDING

To conclude the validation part, the three design goals shared in chapter 4.4 are evaluated.

### Increase measuring and sharing adherence

The validation sessions showed that there is potential to increase measuring and sharing adherence because patient felt like they could contribute more to their own care and that of others. Additionally, the personal reminders and My Impact overview were perceived as relevant triggers and drivers to periodically measure and share. In chapter 8.2.3 recommendations are provided how the impact of the design could be measured over a period of time.

### Increase awareness regarding the value of health data

The DataDonor platform and campaign poster communicated clearly what the added value of someones health data on both their own care and that of others. The latter could be amplified with DataDonor stories shared on the website that are created in chapter 5.2.

## Change perspective from being a 'care user' to a 'care contributor'.

DataDonor allows people to take part in their care. By creating a platform where patient input is used and provides feedback on how their input has resulted in an outcome, lets patients feel they are a contributor to their own care and that of others.

# KEY TAKE-AWAYS CHAPTER 7



## VALIDATION

Validation sessions from three different perspectives were conducted to assess the final concept, proposition poster and roadmap created in the previous chapters. Patients, clients and health care experts all provided relevant feedback on different parts of the design and deliverables.

The results of the validation sessions showed that the final concept has potential to reach the design goals that were shared in chapter 4.4. However, more research and validation should be done to measure the real impact of DataDonor. Recommendations are provided in chapter 8.2.3 regarding this.

# CHAPTER 8 CONCLUSION AND DISCUSSION

## 8.0//

The last chapter of this report will conclude the total project. This will be done by evaluating the final concept using the validation sessions from the previous chapter. This is followed by how the final design addresses the research question of this project and how it fits within the concept of value-based health care. Subsequently, limitations to the research and project, recommendations for further development of the concept and further research and contributions of the project for Deloitte, FHC and in general are discussed. Finally, a personal reflection is given.

In this chapter:

8.1 Final design evaluation

8.2 Contributions, limitations and recommendations



# 8.1 // FINAL DESIGN EVALUATION

The concept is evaluated on both a use case and overall project level. First, the final design is evaluated by how it meets design requirements that are found in chapter 2,3 and 4. In appendix M, a detailed description of this analysis can be found. Subsequent, the final concept is evaluated using the results of the validation sessions presented in chapter 7. The outcomes of these validation sessions are used to assess the final concept on its desirability, viability and feasibility. Finally, it will be evaluated how DataDonor assesses the research question of this project.

## 8.1.1 DESIRABILITY, FEASIBILITY & VIABILITY

### Desirability

The desirability of the final design is evaluated from a user (patient/cardiologist) and a client perspective.

#### User desirability

The validation of preliminary designs in chapter 4.4 showed that patients (n=7) and cardiologists (n=4) preferred the data donor direction (see appendix D for these results). Patient think it is 'an easy way to contribute to the greater good' and that 'it can give a rewarding feeling with low effort'. Using the feedback from this validation, the final design was developed. The validation with patients of the final concept showed that the personalized reminders, campaign poster and My Impact overview all trigger the intended feeling of becoming a contributor to care. It also validated that indeed triggers to measure and share are very patient specific and that over time these triggers can change (i.e. at the start you are triggered by your own health, over time you are triggered because you want to ease your family).

#### Client desirability

The feedback received from the proposition presented in Leeuwarden is used to assess the desirability from the client perspective.

As shared in chapter 7.1, the client thinks the concept can contribute to make their offerings more tangible. Several adjustments need to be made to the proposition poster which are shared in appendix N. When these adjustments are done, both Hessel Bouma and Erik Bosgra asked for a final poster which they could place in the FHC office to trigger discussion with MCL and other relevant parties.

### Feasibility

The concept is based on technologies that are being used for telemonitoring services and predictive analytics. Although these technologies are very promising to improve health care, several limitations are important to point out. For instance, during preliminary interviews with telemonitoring service experts it was found that still a lot of 'manual' labor is necessary to provide the service of remote care. When patient health data deviates, an alarm is sent to the system and needs to be checked manually by physician assistants who need to act accordingly. Therefore, it is important a telemonitoring service is managed properly, otherwise it can only increase care professionals' workloads. However, it is expected that personalized algorithms will support data scanning and provide relevant feedback to care professionals and/or patients.

Additionally, predictive analytics is still in its early developments, especially for complex chronic diseases it is difficult to predict outcomes for patient treatment. For example, the Apple Watch 4.0 (ECG) states that it can detect early Atrial Fibrillation (AFib) using machine learning. However, there are cases where patients are labeled with AFib but results are actually false positive (Bharath, 2018). This results in anxious patients and increasing workloads for care professionals who need to deal with all incoming 'patients'. This shows that we should be very careful with incorporating these technologies in delivering care.

Because of these complexities and early stages these technologies are in, it is advised to start DataDonor with a relatively 'easy' chronic disease. Pacmed recently started to support cardiologists with treatment of hypertension and could be a good first use case for DataDonor.

Lucien Engelen commented that DataDonor is techno- realistic but that it takes time and financial resources to develop.

**Expert: "The main challenges to develop such a data sharing platform are cultural and leadership related. Often, the complexity of collaborating with multiple parties is underestimated in these projects".**

Having an impartial party that facilitates the organization can be crucial in managing interest and concerns of various parties, according to Engelen. FHC could potentially be such a party but should be very attentive to manage interest of all collaborative parties.

### Viability

DataDonor probably needs high initial investment due to development of a data sharing platform and predictive algorithms. For FHC or MCL alone these investments would be too high if developments are done internally. Therefore, FHC should look for partnerships with parties that already have sufficient technological knowledge and capabilities. This is another example of why the health care industry is and needs to join forces and collaborate with new relevant parties. In appendix A it was discussed that the commercial IT and health care industry are starting to merge. New entrants, like Apple, Google, Amazon, IBM, Philips and Microsoft, are entering the health care market leveraging their state-of-the-art technologies to make care more accessible and affordable (Forbes, 2019).

Currently, telemonitoring services in the Netherlands are collaborating with health insurance companies to create business models that enable investments for value-based care. These models are partly based on the 'shared saving model' which is a payment strategy that offers incentives for care stakeholders to reduce care spending for a patient segment by providing a percentage of any net savings realized as a result of someone's effort (Bailit & Hughes, 2012). Additionally, remote care makes it possible to move from pay-per-visit to pay-for-availability models (i.e.

subscription to a telemonitoring service). Although these models ask for a high initial investment (i.e. software development, telemonitoring devices), in the long run they should bring down care costs for the patient, the hospital and the health insurer because care can be delivered more sustainable and accurate.

DataDonor is based on the concept of Value Based Health Care which means the success of the concept is based on the value (outcome) it creates for its users. However, for such an ecosystem to operate, financial sustainability is required. Currently, the financial impact of value-based care is being researched in various care fields. It is still hard to determine if this new approach delivers the cost reduction it promises on the long run so if VBHC is managed and applied properly, time will tell.

## 8.1.2 ADDRESSING VBHC & RESEARCH QUESTION

### Addressing value-based health care

In chapter 1.1 the concept of value based health care is introduced. Throughout this project, this concept is used to structure preliminary research, create the theoretical ecosystem and do user research for the FHC use case. This process resulted in a final concept that tracks health outcomes of a specific patient segment to be able to provide segment specific interventions. This shows that DataDonor is based on the three foundational principles of value-based health care.

Moreover, it was shared that VBHC focuses on customizing in three areas:

1. Traditional care delivery (diagnosis, treatment, recovery and rehabilitation).
2. Timely interventions to stimulate preventive care and long-term monitoring and management of chronic patients,
3. Incorporating behavioural and social interventions in the care continuum. For instance, life style advice or increasing patients' motivation and willingness to participate in care.

## 8.2 // CONTRIBUTIONS, LIMITATIONS AND RECOMMENDATIONS

With the technology DataDonor uses introduced in the preliminary research, it is possible to customize the first two areas. However, to be able to deliver customization in these areas, patient participation is and will become essential. Insights found during user research combined with the knowledge of behavioural psychology enable DataDonor to customize in patients' motivation and willingness to participate in care as well. This results in a health care ecosystem where the patient shifts from being a 'care user' to a 'care contributor'.

### Addressing the research question

This section will evaluate how the project addresses the research question that was formulated at the start of this project.

### How should care providers strategically obtain patients health data, in order to improve individual and public clinical care?

To answer this question, an extensive preliminary was done to identify how and what form care providers could strategically obtain patient health data to improve clinical care. This resulted in a theoretical ecosystem. To test the theoretical ecosystem on its desirability from a user and organization perspective, a use case was performed for one of Deloitte's clients focusing on the cardiovascular domain. In total, twenty-five interviews with cardiovascular patients, cardiologists, health care experts and practitioners were conducted, analyzed and integrated.

Along the way, insights from user research combined with behavioural psychology are taken into account as well. This resulted in a final concept which supports care providers in strategically obtaining patient health data to improve clinical care.

DataDonor is a digital environment supporting care providers to strategically obtain patient health data to improve clinical care. By enabling patients to contribute to their own care and do good at the same time, patients can be triggered to share health data with their care providers. Additionally, by appealing to personal drivers to measure and share

health data, DataDonor provides a solution that fit both the patient, business and organization. To conclude, DataDonor is a first step towards strategically using behavioural design interventions combined with state-of-the-art technologies to improve clinical care, and should be interpreted as such.

This section discusses contributions, limitations, recommendations for further research and concept development of the project.

### 8.2.1 CONTRIBUTIONS

#### Contributions to Deloitte

Often, Deloitte Digital needs to design for complex ecosystem to due to digital interactions in a project. The value flow model of Ouden (2012) can be used by Deloitte Digital for these type cases. It is a good tool to map and visualize current and desired ecosystems and can be used to spot innovation opportunities within ecosystems. How the tool was used in this thesis is a good example of how the tool could be applied.

The behavioural design toolkit for service designers created by van Lieren (2018) was used to design behavioural interventions for the final concept. This toolkit could also help Deloitte Digital in their service design projects in two ways. First, the toolkit can be used to explore user behaviours in a service and identify behaviours that need to be researched further. Furthermore, the toolkit could be used for ideation and concept development when designing for behavioural change.

Additionally, since this thesis aims for social innovation it is in line with Deloitte's vision 'making an impact that matters' and could be added to other social innovation projects Deloitte did.

#### Contributions to FHC

The use case that was used for this project originated from the collaboration between DHC and FHC. Initially, DHC did research for FHC to disclose what they are legally allowed to do with sharing patient health data for research. This thesis complements to the deliverable of DHC by doing research on the desirability of health data sharing and designing a concept making data sharing for research tangible. The validation session with FHC shows that this thesis can be used to support FHC in communicating their offerings. Therefore, this thesis both contributes to

FHC and the collaboration between DHC and FHC.

### 8.2.2 LIMITATIONS

This project offers a new digital environment to strategically obtain patient health data. However, several limitations are identified and will be discussed per phase.

#### Limitations in preliminary research

In the first phase, a literature and market study of the health care sector was done. This preliminary research was done to get an in-depth understanding of health care trends and challenges and to explore directions the industry is moving into. The main purpose was to find insights that could be used as basis for user research. Because the field of health care has an astounding amount of literature, information and insights might have been missed.

#### Limitations in user research

User research was conducted to understand how the value proposition of the theoretical ecosystem addresses drivers and needs of targeted users. It should be noted that cardiovascular patients that were consulted do not make us of a telemonitoring service and experienced a heart failure between 5-20 years ago ('fresh' patients might have different drivers and needs). Although contextmapping was used to sensitize with the topic and recall past memories, these limitations can have influence on the insights derived from user research. This was also notified by Lucien Engelen during the validation meeting.

#### Limitations in design

To define the most promising design direction, 5 design directions were validated using the 'weighted criteria' method and by consulting patients, cardiologists and Deloitte consultants using an online questionnaire. This validation resulted in the DataDonor design direction. However, the 'weighted

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criteria' method was done individually and could mean the researcher was biased in selecting the design requirements for this validation.

Finally, parts of the final design (i.e. 'data footprint experience') are currently based on assumptions. We should be very careful with what we promise and show to patients and need to make sure that information that we share don't create wrong expectations.

### Limitations in validation

The validation with patients and health care experts is based on respectively 4 and 2 participants, it is reckoned that this is not yet enough to provide full validation of the concept.

## 8.2.3 RECOMMENDATIONS FOR FURTHER DEVELOPMENT

For DataDonor to be developed further, several recommendations are provided to ensure successful implementation.

### Recommendations in user research

#### Additional user research

To be able to increase the validity and generalize insights, more interviews with patients and cardiologists should be carried out. It is recommended to first start and learn from one patient segment (i.e. hypertension). In chapter 6.3 – Implementation roadmap, it was shared to do more elaborate user research on why patients stop using their telemonitoring service. These insights can be used to design tailored behavioural design interventions. Additionally, I believe it is essential to incorporate care professionals (i.e. cardiologists, physician assistants) into the design process. Their knowledge from daily experience is crucial in making sure the design fits their daily routine and workflow.

#### Additional drivers

Other drivers to measure and share health data could be explored to see how they influence measuring and sharing adherence. For example, receiving a discount on your health insurance or get a discount on healthy

products and services. These are interesting use cases to consider and could add value to the health care ecosystem and care continuum presented in chapter 1.1.

### Data analysis

The data analysis that were conducted enabled the research to gather an abundant amount of insights and perspectives. This resulted in various design requirements and eventually in finding the most pressing conflicts between the theoretical value proposition and user's drivers and needs. However, due to the complexity and amount of data, it was difficult to include other people in the analysis. Because analysis was done solely by the researcher, interpretation biases might have occurred. Additional data analysis by a second and third party should be done to triangulate results and increase validity credibility.

### Recommendations in design

It should be noted that including care providers in the development and design of self-care product-service systems will be essential to create successful solutions (Riegel et al., 2017). Parts of the final design (i.e. 'data footprint experience') include information that is based on assumptions. To be able to validate if the final design meets design goals and can create value for users, information in the final design should be created and checked with care professionals to make it credible.

### Recommendations in validation

After additional research is conducted and insight are turned into an improved concept, DataDonor needs to be user tested with patients and cardiologists. These user tests should assess how the final concept impacts the design goals shared in the design brief (chapter 4.4). Some suggestions are provided in how FHC could do this.

### Patient validation

The success of the design goals can be measured using measuring and sharing adherence rates as a metric. To measure the effect of DataDonor and its

personalized behavioural design interventions, a study could be conducted using two patient groups. One group, a control group, is not informed about the value of health data (website and campaign) and is not provided with personalized behavioural design interventions and the other group is. After the study, participants are interviewed about their awareness regarding the value of health data and if they see themselves as a care contributor.

### Cardiologists validation

For cardiologists the user test should focus on how DataDonor would fit in their daily routine and if it results in a decrease in workloads and more accurate treatment.

### Client validation

The validation session done with FHC provided relevant feedback to improve the proposition poster. Nevertheless, in order to find out the relevance of the final concept for MCL, a final presentation demonstrating the final concept should be given to the board of MCL.

### Additional recommendations

#### DataDonor campaign

Brief suggestions are provided to create awareness around DataDonor for a successful launch. However, a more detailed campaign planning and materials (i.e. posters, social media) need to be created. In the first phase, FHC should collaborate with MCL to look into this and decide on campaign budget and touchpoints. Several suggestions:

- To better scope the marketing campaign, a quantitative research should be conducted regarding the drivers to measure and share health data. Results of this research can be used to strategically target the campaign to a specific audience.
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- The campaign should be built up step-by step. Because patients have a high personal driver to measure and share health data in the beginning, the campaign should focus on the personal relevance at the start. Over time, when patients don't experience

the value of measuring and sharing for themselves, the campaign should appeal to altruism and provide people to opportunity to give back to a system where they also received benefits from at the start.

### Expanding to other patient segments

It is expected that potential drivers to measure and share health data vary between patient segments. Someone living with COPD probably has different motives and needs to measure and share health data than someone living with hypertension or rheumatism. To be able to tailor DataDonor to patient segments it is recommended to do new or additional user research to find patient segment specific drivers to measure and share health data.

## FURTHER RESEARCH

Lastly, suggestions for further research related to the project topic are found.

- Cardiovascular disease is very common among lower income and educated people (Degano et al, 2017). Because an important goal is to increase awareness regarding the value of health data, additional research should be conducted looking into how to communicate this in a clear and comprehensible way.
- Digital skill is necessary for the final concept to use. However, CVD is often found among senior people who lack or are less capable of dealing with digital services. Therefore, further research should be conducted to make the solution more accessible for people with limited digital skills.
- Since the Netherlands has a lot of cultural variety, it is interesting to do more research on the potential differences of willingness to share health data between cultures and how they can be approached.
- Finally, an important topic that this thesis did not look into is around the ethics of using health data to improve clinical care and wellbeing of people.



## 8.3 // PERSONAL REFLECTION

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To start, as a person I have always been very interested in designing for social impact. Looking back on the project, I am very happy with the topic I chose and how I approached the project. I think it was a very explorative project that in the end resulted in a design that makes the future of crowdsourcing health care imaginable, testable and above all discussable.

As an IDE student, you are normally provided with a 'problem'. However, this time I had to find the 'problem' or 'opportunity' myself. This is probably also the reason why I first wanted to do more desk research at the start of the project. I had little knowledge about the health care sector and cardiovascular domain. By suggesting to first do desk research and immerse myself in the topics, I wanted to make sure I felt confident when approaching and interviewing patients, cardiologists and care experts. However, my supervisors pushed me to immediately start talking to people from industry and go out there. In the end I am happy I with this advice because it allowed be to meet interesting care experts and visit learningful events and symposia which is more fun than sitting behind a laptop. However, I still needed to do desk research to be able to understand relevant technologies, trends and how they apply to the cardiovascular domain. In the end, I believe combing this practical and theoretical way of exploring allowed me to provide more accurate and realistic advice on the final design.

*'As designers, we match the revolutionary speed of technological developments with the more evolutionary speed of development of mankind.'*

Ena Voûte

(Dean of Industrial Design Engineering Faculty, TU Delft)

One of the reasons I wanted to do my graduation at Deloitte Digital is because I like to work and do research at the fore front of innovation. This project allowed me to dive into interesting technologies that are starting to show their impact on society. But just as Ena Voûte quotes, matching these technologies with human capabilities and psychology is what I find most interesting. In my project I briefly tap into behavioural design, and if I would have more time this is definitely something I would have dived into.

During the final feedback session at FHC it was said that they would like to receive a final poster because they would like to hang it in their office. Hearing that the final proposition fits their envisioned platform was a nice compliment for me.

What I enjoy most of being a designer is the variety of work and research you do. Driving across the Netherlands to visit patient in their homes, cardiologists in hospitals and other care professionals at their work was something I really enjoyed and gave me energy in this project. I must say that sometimes interviews with patients were quite heavy. To hear people talk about intimate moments and experiences regarding their cardiovascular disease made an impact on me as well. Dealing with these stories felt a bit strange at the start, but I learned how to deal with them along the way. I think knowing how to deal with this kind of interviews is important for a designer, especially if you are interested in social innovation.

Finally, I focused on the cardiovascular domain for a personal reason. The knowledge I gained about CVD enabled me to be more empathic with people around me living with a CVD. Moreover, it provided me more insight and curiosity in my own health and how I should deal with CVD prevention in the future.

I believe that crowdsourcing our health is at the start of having a huge impact on our lives and health and I am looking forward to what the future will bring!



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