

# ***Insight.me***

*Enabling a collaborative use of  
healthcare data.*

Carolina Falcão Duarte

Mentor: Valeria Pannunzio  
Chair: Natalia Romero Herrera

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Carolina Falcão Duarte

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Strategic Product Design

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Faculty of Industrial Design Engineering

Delft University of Technology

Mentor: Valeria Pannunzio

Chair: Natalia Romero Herrera

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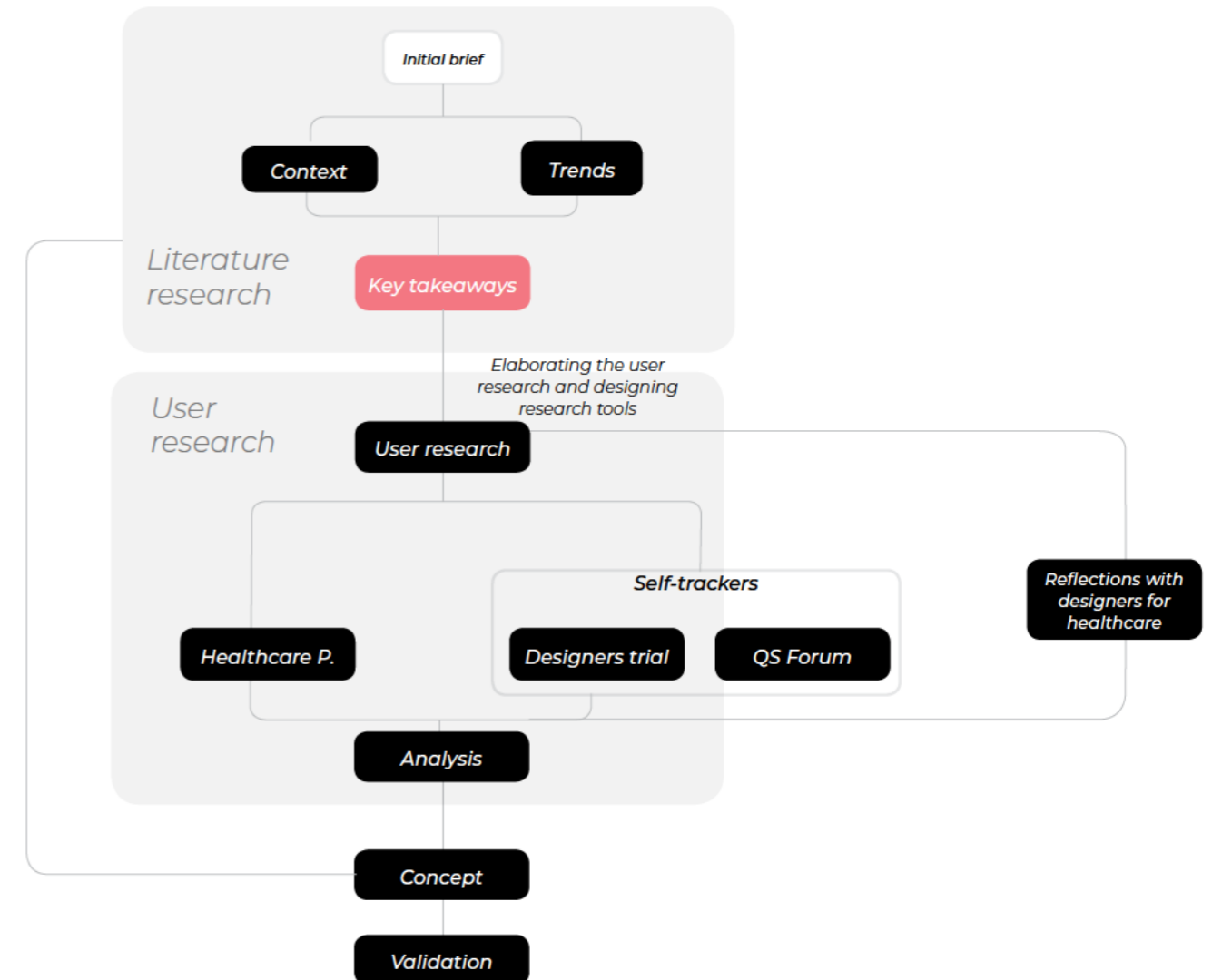
To Pablo for all the exchange of ideas, perspectives and affection.

# Abstract

This thesis presents research on data and healthcare and proposes a design vision that enables collaborative use of self-tracked data. This work was developed within the Cardiolab as a graduation work in Strategic Product Design. It aimed to identify the needs and aspirations of practitioners and patients and, then, embody the findings on a design vision.

To develop the design vision, literature research was carried and user research was done with healthcare professionals and patients. Mixed methods were used to collect and analyze qualitative data. The results have revealed that trust plays a key role in a data-based collaborative system. It enables users and professionals engagements and provides value to other stakeholders involved. Furthermore, the research has revealed that ethical uses of data are critical to unlocking interactions in such a system. Based on that, a platform called "Insight .me" was designed.

From a design perspective, this thesis emphasizes the need for enabling data as material for personal reflection and collaboration, besides, it reinforces the need of designing ethical and trust base businesses to deal with self-tracked and personal data.



# Introduction

*This thesis was developed within the Cardiolab.*

*The design assignment is: to develop a system that enables the collaborative use of healthcare data.*

Nearly half of people with high blood pressure are not aware of it (Chow et al., 2013). It is possible to have High blood pressure through years without even having any idea of the problem. It hardly leaves any traces or symptoms, while it harms the blood vessels and a resulting in cardiovascular diseases, strokes and heart failure (WHO, 2015).

Monitoring it can avoid several diseases, thus, several efforts are being made to monitor this data and to encourage patients to take an active role in managing their health.

The context of blood pressure exemplifies how self-tracking healthcare data can benefit patients by preventing future health conditions and the healthcare system by reducing the occurrence of chronic health conditions. At the same time, the interest in wearables, smartwatches, and self-tracking is gaining momentum among the overall public (K. Costello, 2018), configuring a great opportunity for using self-tracked data in a collaborative manner. However, when it comes to using a patient's healthcare self-generated data for clinical purposes, physicians and patients do not always share the same expectations. This leads to barriers in taking shared data-based decisions and encouraging users to self-monitor blood pressure, among other types of healthcare data.

In this sense, there is a gap between the physician's interests in eHealth systems and patients interests. There are different expectations attached to self-tracked data and different values and attributed to self-tracking. Such differences need to be addressed in order to enable a collaborative use of self-tracked data.

To enable such collaborations, it is necessary to address users and healthcare professionals. Thus, this work explores within the Dutch healthcare system context, the uses, and expectations regarding self-tracked data for both and identifies which values should be addressed in a solution that converges the interest of these two groups.

By taking a strategic design perspective, this thesis argues that a partnership system based on trust is necessary to guarantee ethical uses of data, support users to use data as a material for personal reflections and facilitate data interoperability. As a result, a design vision of a collaborative platform for data management and storage was developed.

# Contents

Introduction 8

## 1. CONTEXT 12

<b>1.1. Blood Pressure</b>	14
· Patient Education	16
· Training	18
· Healthcare Professionals education	22
<b>1.2. E-health</b>	26
<b>1.3. Data &amp; its many uses</b>	31
<b>1.4. Self-tracking</b>	37
· The QS movement and self-tracking practices	40
· Wearables	45
<b>1.5. Self-Experiments</b>	52

## 2. TRENDS 62

<b>2.1. Population trends</b>	63
<b>2.2. Environmental trends</b>	64
<b>2.3. Society trends</b>	65
· Health consumerism	65
· Trust as a key value	67
· Partnerships	70
· Data belongs to the people	72
<b>2.4. Technology trends</b>	74
· AI	75
· IOT	77
· BlockChain	79
<b>2.5. Political trends</b>	82

## 3. RESEARCH 84

<b>3.1. The Process</b>	85
<b>3.2. Healthcare experts cohort</b>	88
· Participants selection	88
· Interviews	90
· analysis	94
· Clustering the information	95
· Key take-aways	108
· Empathizing with the users	110
· setting the ground for the ideation phase	110
<b>3.3. Interview with Designers for healthcare</b>	115
· The interview	116
· Analysis	118
· results	118
· Key takeaways	122
<b>3.4. Designer cohort's self-tracking trial</b>	123
· Selecting the participants	124
· Sensitizing participants	126
· Interventions during the trial	126
· THE generative session planning	128
· Results	129
· Framing the Results and Insights	137
· Key takeaways from the design Cohort trial	137
· Empathizing with the users	139
<b>3.5. Quantified Self Cohort</b>	142
· Collecting Data	144
· Results	144
· Framing the insights	149
· Key takeaways from the qS Cohort	149
· Empathizing with the user	151

## 4. CONCEPT 154

<b>4.1. Problem definition</b>	156
<b>4.2. Ideation</b>	158
<b>4.3. Design vision</b>	164
<b>4.4. Value exchange</b>	178
<b>4.5. Evolution of the system</b>	181
<b>4.6. Validation of the concept</b>	184
<b>Conclusion</b>	<b>186</b>
<b>Reflection</b>	<b>189</b>
<b>Some bits of advice for fellow master students</b>	<b>191</b>
<b>References</b>	<b>192</b>
<b>Appendix I</b>	<b>209</b>
<b>Appendix II</b>	<b>216</b>
<b>Appendix III</b>	<b>219</b>
<b>Appendix IV</b>	<b>234</b>
<b>Appendix V</b>	<b>236</b>
<b>Appendix VI</b>	<b>238</b>

# Context

*This session draws a literature review on the relations of self-tracked data with healthcare. The monitoring of blood pressure is taken as the starting point, moving towards a discussion regarding different uses of data.*

# 01



## 1.1. Blood Pressure

*As previously stated, this thesis has been developed within the Cardiolab. When studying patient-centric design solutions for dealing with Cardiovascular Diseases (CVD) and other Chronic Diseases such as kidney-related conditions, it is necessary to examine how Blood Pressure measurements are taken by users. Therefore, this section explores the state of art of measuring Blood Pressure out of the doctors' office.*

Despite being considered a major risk for several health conditions such as heart attack, stroke and kidney failure, hypertension still lacks control and sufficient treatment. With approximately forty percent of adults above 25 years old diagnosed with Hypertension (World Health Organization, 2013) , an early detection and control of blood pressure values can help preventing the burden of cardiovascular and renal disease (J. D. Cohen, 2009; Constant, Geladari, & Geladari, 2016; Elliott, 2003; Kearney et al., 2005). For those reasons, the development of

cost effective and equitable innovations for managing cardiovascular diseases, its trends and their risk factors have been considered strategic actions in this field. (World Health Organization, 2016).

More and more, such innovations on managing hypertension require the patient to play an active role in managing and monitoring their own condition. In this sense, self-measuring Blood pressure (BP) becomes an important action to be taken (Dart, 2005). Furthermore,

there is evidence that Home BP measurements (HBPM) and Ambulatory Blood Pressure Measurement (ABPM) are more effective to predict the occurrence of cardiovascular diseases than BP measured on the clinic (Daskalopoulou et al., 2015a; Melville et al., 2018; Shimbo, Abdalla, Falzon, Townsend, & Muntner, 2015; Stergiou, Siontis, & Ioannidis, 2010), partly because it can overcome effects such as the White-coat hypertension (Bloomfield & Park, 2017; Filipovský et al., 2016; Franklin, Thijs, Hansen, O'Brien, & Staessen, 2013) and Masked-hypertension (Anstey et al., 2018; Sheppard et al., 2016), besides providing useful data to diagnose related diseases such as diabetes and kidney disease (Mengden et al., 2008; Ushigome et al., 2011).

The HPBM provides the advantage of covering a broader period of time in terms of BP records , while ABPM usually covers 24 hours in the life of the patient (Ntineri, Kollias, & Stergiou, 2018). As a result, the self-monitoring of BP is becoming part of several guidelines to manage hypertension (American College of Cardiology/ American Heart Association, 2017; Campbell et al., 2014; Daskalopoulou et al., 2015b; Egan et al., 2018; Imai et al., 2003; M. Malachias et al., 2016; Nerenberg et al., 2018; Seedat, Rayner, & Veriava, 2014; Sharman et al., 2015; Whelton et al., 2018; Williams et al., 2018). Furthermore, it has been found that just having a BP monitor device

at home is associated with decreases of 3.7 mmHg and 2.8 mmHg for systolic and diastolic BPs (Akpolat et al., 2018a).

However, the use of the data generated by the self-measuring BP at home remains a challenge during the clinical practice (Jung et al., 2015; Logan, Dunai, Mclsaac, Irvine, & Tisler, 2008; Ringrose et al., 2017; Stergiou et al., 2010) and to obtain reliable, accurate and useful data to prevent, manage or diagnose hypertension one needs

to follow a series of recommendations (Celis, Den Hond, & Staessen, 2005). Most recommendations regard the frequency of self-measurements, the correct body posture, arm positioning among other are well established in medical guidelines. On the other hand, protocols regarding the patient education and the healthcare provider approach to implement self-measured BP remain mostly undefined. For this reason, it is necessary to further look into these aspects.

*The use of the data generated by the self-measuring BP at home remains a challenge during the clinical practice*



## PATIENT EDUCATION

With the recent innovations on technologies and devices for measuring BP, the choice of a device can be overwhelming for the patient. However, the correct choice of a device is important for performing valuable BP self-measurements and engaging the user in the process of self-monitoring. The use of a device that provides good measurement and reliable data is not only essential for generating valuable data for medical use (Liyanage-Don, Fung, Phillips, & Kronish, 2019a), but is also essential for doctors and patients successfully adopt a patient-centered monitoring solution (Chiauzzi, Rodarte, & DasMahapatra, 2015).

Automated or semiautomatic oscillometric devices, or devices specifically provided by the health-provider (M. V. B. Malachias et al., 2016), are widely recommended for HBPM (Campbell et al., 2014; Daskalopoulou et al., 2015b; Mengden et al., 2008; Park et al., 2018; Sharman et al., 2015). Those designed to measure the BP in the upper arm are preferred (Stergiou, Parati, et al., 2018; TRUE Consortium, 2017) and they should have been validated according to independent protocols such as, for example, the British Hypertension Society, the Association of Medical instrumentation (Campbell et al., 2014; Celis et al., 2005; Daskalopoulou et al., 2015b; M. V. B. Malachias et al., 2016; Parati et al., 2010; Sharman et al., 2015).

In the case of such devices, the cuff size should match the arm size. As a basic guidance, the length of the bladder should hide from 75% to 100% of the upper arm circumference and its length should be around two times the width size (Stergiou, Kario, et al., 2018), in special cases that involve patients like children or adolescents a specific size guide should be observed (Mengden et al., 2008). Moreover, devices that can transmit BP readings to a data collection centered are pointed as solutions that can overcome the problem of reporting bias (Myers, 2015) and increase the validity of HBPM (Milot et al., 2015).

Recently, some wrist devices have been also validated according to international protocols (British and Irish Hypertension Society, n.d.; dablEducational, n.d.; Medaval, n.d.) and studies have advocated their effective use in special situations (Hoffmann et al., 2018; Melville et al., 2018). However they are still recommended with remarks due to big influence of the positioning of the wrist in obtaining correct measurements (Mengden et al., 2008; Sharman et al., 2015).

It is also important to mention a study that has extended the use of devices, incorporating a chair with sensors in

the self-measurement activity. In this study the sensor chair was able to detect if the user was following the BP measurement recommendations, like for instance, seating with the recommended body posture. The device was paired with a computer and could provide guidance regarding the how long the patient has been seating and when to take the three measurements. Other data regarding body posture, was collected to compare the participants adherence with the protocol regarding the requirements that did not have real time guidance and were informed just at the beginning of the study (Lindahl et al., 2017).

Furthermore, in order to promote successfully the adoption of a wearable device, which is important when it comes to adopt a routine of self-monitoring BP, its aesthetics and design should be also considered. For example, the expression "fashnology" has been created based on the study of users perception of the value of fashion and technology regarding Augmented Reality Smart Glasses (Rauschnabel et al., 2016). This aspect, as well as the service that is paired with the device, are example of features that could be explored and considered when recommending and choosing BP monitors that aim to be

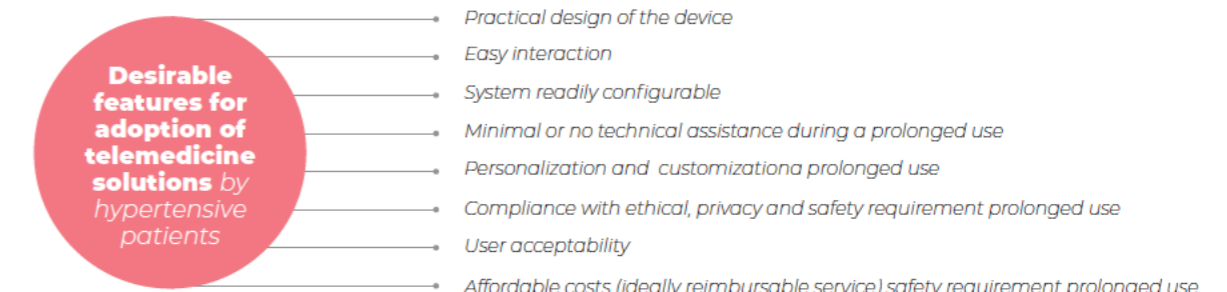


Figure 1 - . Adapted from Extracted from Omboni & Ferrari (2015).

part of the user daily routine, however, although aspects regarding usability are pointed as important factors to favor the adoption of HBPM by patients and clinicians (Wood, Boulanger, & Padwal, 2017), they are ignored in most guidelines provided by the searched medical associations guidelines and consensus (Campbell et al., 2014; M. V. B. Malachias et al., 2016; O'Brien, Waeber, Parati, Staessen, & Myers, 2001; Park et al., 2018; Sharman et al., 2015; Whelton et al., 2018; Williams et al., 2018). In this sense, the work of Omboni and Ferrari stands out by mentioning user-friendly aspect as factors that should be considered on the adoption of telemedicine solutions (Omboni & Ferrari, 2015). The list of features mentioned by the authors can be seen on Figure 1.

## TRAINING

Patient training and education to follow standard procedures (see Table 1) is a requirement for successful self-measurements that can result in valuable medical data (Daskalopoulou et al., 2015b; Liyanage-Don et al., 2019a; Mengden et al., 2008). Frequent problems occur due to the lack of knowledge regarding the correct measurement protocol such as the proper way to position the arm, how frequently the patient should measure the BP, how long he should rest before each measurement, how to position the cuff and choose its size (Akpolat et al., 2018b; Dymek, Skowron, Polak, & Gołda, 2015). Given the fact that HBPM asks for a long-term engagement from patients in self-measuring their BP for weeks or longer periods, following the correct protocol during a longer period of time can be a challenge for many patients (Shimbo et al., 2015). There are no standard guidelines regarding patient education to self-measure their BP at home and approaching these issues (Mengden et al., 2008). However, recent studies involving patient-oriented intervention provide promising indications of approaches that can result in positive outcomes in terms of adherence to the treatment and providing accurate and valuable data.

## Standard procedures for Self-measuring Blood Pressure

<b>Time span</b>	Readings should be performed during 6–7 consecutive days (Mengden et al., 2008).
<b>When</b>	In the morning and the evening,  Two measurements should be taken every time, performed 1–2 min apart. Additional measurements are required only if the first two consecutive readings differ by >10 mmHg.
<b>Where</b>	In a quiet room
<b>Preparation</b>	5 min of rest before beginning BP measurements.  Exercising, eating a large meal, use caffeine, drink alcohol or take decongestants for 30 minutes before should be avoided.  Using the bathroom before taking the BP is advised.
<b>Body posture</b>	Seated with their back and arm supported.  The legs should not be crossed.  The feet should be kept flat on the floor.
<b>Arm posture</b>	The arm should rest at the heart level and be kept stretched out and relaxed.
<b>Attitude</b>	Talking, reading or watching tv during the measurement should be avoided.  Drinking coffee or smoking for at least 30 min before the measurement should be avoided.

Table 1 - Adapted from Mengden et al.(2008); Ntineri et al., (2018) and Million Hearts(n.d.).

Passive interventions, for instance, the use of posters, booklets and handouts reinforcing proper measurement procedures, are pointed as cheap and non-time consuming ways to educate patients and its use is encouraged as an educational tool (American Medical Group Foundation, 2013; Million Hearts, n.d.). However, studies performed (Lindahl et al., 2017; Milot et al., 2015) showed that the single use of passive interventions is not effective in terms of promoting adherence to HBPM guidelines. This suggests that active training and automation could increase the reliability of the collected data and should be promoted.

Some studies support the adoption of active training when promoting Home Blood pressure measurements. When comparing Self-measured BP monitoring with support - such as BP education or pharmacist interventions- against Self-measured BP monitoring without additional support it has been shown that programs with support can help patients to achieve and sustain lower values of blood pressure even after 12 months after the intervention (Uhlir, Patel, Ip, Kitsios, & Balk, 2013). In addition, interventions that provided instructions about the adequate ambience noise level, the importance of not talking and the keeping an adequate leg positioning during the measurement, in contrast with intervention that have only provided a small guidance before the measurement - regarding how long

participants should remain seated and what interval in between measurements should be observed- could contrast the effects of the adherence to such recommendations. The interactive reinforcements during the measurement facilitated the adherence to the recommended procedures (Lindahl et al., 2017).

The use of mobile phones to provide automated communication and prompts to the patients has also been shown to be effective and a feasible solution to encourage patients to self-manage hypertension (Kaplan, Cohen, & Zimlichman, 2017; Pfaeffli Dale, Dobson, Whittaker, & Maddison, 2016; Savard et al., 2018), from self-monitoring to improving diet and exercise habits (Cacciolati, Tzourio, Dufouil, Alperovitch, & Hanon, 2012). This reinforces the vision that technology can provide ways to eliminate errors related to the human factor when measuring BP (Myers, 2014).

Interventions that do not rely exclusively on technology also have shown to be effective in educating patients. A study has shown that community-based education, carried on in groups of participants with hypertension, can result in a better understanding about hypertension and improve participants' skills in clinical anthropometric measurement. The education program has tackled: 1) Hypertension risks factors and complications; 2) Healthy lifestyles and

support towards adopting a healthier lifestyle; 3) How to help group members to achieve realistic goals; 4) Skills to take clinical measures such as weight and BP and 5) Skills to conduct group meetings. The community approach of this study had an interesting outcome besides increasing participants' knowledge, it has found that its participants have also used the acquired knowledge to educate their families, neighbors and friends (Abdel-All et al., 2018).

In addition, populations that are not regarded as technology-savvy can also benefit from self-measuring programs that not rely exclusively on the use of technology. A study carried out with elderly participants ( $\geq 73$  years) has shown that individual supervised demonstrations associated with passive interventions, in this case a booklet with simplified instructions and a log book to record the measurements, can be successful in terms of successfully performing the requested number of self-measurements. However, this was not observed among participants with a low educational level (Cacciolati et al., 2012). These results depict how training programs that do not rely exclusively on patients self-learning skills can provide encouraging outcomes, and corroborate the findings of other studies that used mobile health to improve health behavior, self-efficacy and treatment of the elderly in the case of several chronic diseases (Changizi & Kaveh, 2017).

Another case adds up to such findings. In this study, participants have been divided among groups with individual training, group training, provided by a nurse, and self-learning for education regarding HBPM. Those who have attended the programs that included (individual or group) training retained the principles of self-measurement better than the self-learning group (Leblanc, Cloutier, & Veiga, 2011).

Such studies stress the importance of taking into account the context of the patients when implementing HMBP measurements and the importance of having a healthcare provider actively taking part in the self-measurement instructions (Hanlin et al., 2018). Multi-level and team based interventions have been found to effectively reduce BP (Mills et al., 2018). Therefore, education should also prepare clinicians, medical assistants, pharmacists and nurses to collaborate among each other and with the patients when implementing HBPM. Such collaboration can encourage patients in understanding BP readings and follow the measurement protocol. This will be further discussed in the following session.

*Its important to take into account the patients' context when implementing HMBP measurements.*

## HEALTHCARE PROFESSIONALS EDUCATION

The patient education is fundamental to successfully implement the use of HBPM, however, the health provider education also plays a key role in order to successfully implement the use of valuable self-monitoring. Physicians often choose to rely on office or ambulatory BP readings to take clinical decisions while patients have a positive attitude towards HBPM (Logan et al., 2008). Factors such as lack of use of reliable devices, protocols to be followed and patient education are frequently pointed as reasons for the lack of trust on HBPM. However, it is necessary to recognize the several existing gaps in terms of patient counselling (Jackson, Ayala, Tong, & Wall, 2019) and the need adequate training of healthcare providers to successfully use digital healthcare solutions (Basholli, Lagkas, Bath, & Eleftherakis, 2018) and implement HBPM as part of the process of diagnosis. Health providers also need to be specifically educated regarding self-measurement of BP (Fletcher et al., 2016; Liyanage-Don, Fung, Phillips, & Kronish, 2019b).

A study has made some of these gaps evident by drawing attention on how health care providers, including physicians and nurse practitioners, deal with patients' self-measurements. When interviewing 1590 of these professionals it has been found that someone else in the practice counsel was advising the patient on the correct

cuff size to be used, and 15% answered that they have never touched upon this point with their patients. Furthermore, only 30% have confirmed to validate the patient's BP measurement device (Jackson et al., 2019).

Familiarizing doctors to the advantages and limitations of HMBP, the adequate equipment to be used by patients out of the office and overall guidance can help reducing errors during self-measurements and help in gathering valuable data to support the identification of hypertension (Mengden et al., 2008). One suggestion, for instance, is inviting patients to bring their devices to the doctor's office to demonstrate how to carry on self-measurements and provide feedback (J. B. Cohen & Cohen, 2016). However, such feedback needs to be backed up by measurement protocols.

The Measure Accurately, Act Rapidly, and Partner With Patients (MAP) approach was formulated to fill in this gap and provide some guidance to healthcare providers on how to help patients control blood pressure (Hanlin et al., 2018) whether using HBPM or other methods. This approach is structured to overcome major barriers to achieve optimal control of blood pressure in primary care such as inconsistent care protocols, unproductive care team communication and low patient engagement. It uses different sets of educational materials, tools (Million

Hearts, n.d.) and educational means (e.g. teleconferences) to educate the healthcare professionals on the importance of measuring BP on the primary care and to partner with patients, their families and communities to tackle the problem (Rakotz, 2015). This approach has been shown to improve hypertension control due to successfully established partnerships with patients and accurate measurements of BP (Egan et al., 2018; Hanlin et al., 2018).

Furthermore, Shimbo et al. (2015) have proposed core clinical core competences to use ABPM and HBPM that go beyond knowing the standard protocols to effectively measure BP and tackle factors that regard the interaction with the patient (Table 2). The factors pointed make evident the importance of human factors, besides the technology, as key factors in enabling accurate measurements out of office. Furthermore, by looking at such factors it is possible to infer the multiple roles and skills that are required from physicians when recommending practices such as HBPM.

*Knowing how to instruct the patient on how to use a technology is not enough.*

This raises questions as how do physicians perceive the use of devices by patients? Do doctors and nurses feel comfortable about recommending a particular device? How do they perceive the situation

of patients bringing measurements to the office? Such questions will be further explored in interviews with healthcare providers ( see page 88).

What can be concluded after observing self-measurements of Blood-pressure at home is that there needs to be a collaborative-based relation between healthcare providers and patients. Actively involving healthcare professionals and patients in the digital-health revolution is necessary revolution (Savard et al., 2018) in order to unlock the meaningful value of healthcare innovations.

In overall, best practices on self-measurement can empower patients to self-monitor their BP and manage their own health. Such practices are aligned with ongoing trends of wearable adoption, and changes in patients' attitudes in the healthcare domain. Moreover, there is enough clinical evidence to use HBPM as another source of information to tackle hypertension. However, in order to empower the patient to manage their own health, it is necessary to provide proper training to the health care providers on how to deal with the new technologies and, most of all, foster collaboration between both parties. In this sense, it is necessary to further investigate the e-Health scenario and its impact. Are technologies pushing a shift in the patient-healthcare provider relationships? How do the involved ones perceive this shift? The current

### Proposed clinical core competency in Patient Care and Procedural Skills

- 
1. Skills to integrate clinical data in selecting patients for ABPM and HBPM, including the evidence-base including guidelines that make recommendations regarding ABPM and HBPM
  2. Skills to perform ABPM and HBPM
  3. Skills to prepare patients for ABPM
  4. Skills to instruct patients in how to measure their blood pressure using HBPM devices
  5. Skills to instruct patients in how to properly interpret their HBPM readings
  6. Skills to determine whether an ABPM recording and HBPM readings are valid
  7. Skills to interpret readings obtained from ABPM and HBPM
  8. Skills to calculate blood pressure phenotypic measures from ABPM and HBPM
  9. Skills to instruct patients where to purchase validated HBPM devices
  10. Skills to communicate with patient to bring in home blood pressure readings to visits
  11. Skills to communicate with patient when to call the physician's office about elevated HBPM readings
- 

Table 2 - Adapted from Shimbo et al. (2015)

state-of-art of self-measuring blood pressure at home provides insights and also further questions regarding the future trends of healthcare. While there is a clear perception of the benefits that enabling patients to carry such data based observations, it is clear that high quality devices are not the only factor that contributes to generate reliable and accurate data. Thus, there is the need of further understanding those who are interacting with the devices, how the data that they provide.

*when using new technologies that aim to empower the patient, it is also necessary to get healthcare providers on board.*

## 1.2. E-health

*The previous section has touched upon monitoring and collecting healthcare data out of the doctor's office. This section further explores solutions to provide healthcare in different locations by using communication technologies, the efforts to digitalize healthcare, its promises, and its impacts.*

In 2018, the World Health Assembly has published a resolution on eHealth urging its member states to spread the use of digital healthcare as a way to promote universal Health coverage (World Health Organization, 2018). This makes evident how the use of eHealth products and systems involving digital data, has been portrayed as a solution for dealing with the rising costs of healthcare systems around the world and for promoting a universal healthcare. E-health solutions can bring several benefits to the healthcare domain; however, its implementation still faces several barriers.

Before understanding the promises and challenges around eHealth, the definition of this concept needs to be established. The World Health Organization (WHO) defines e-health as the use of information and communication technologies (ICTs) for health purposes (WHO, n.d.). In other words, e-Health are technologies involved in gathering integrating, communicating an interpreting data (Georgiou & Prgomet, 2019). In addition, it is necessary to define what mHealth, one of the elements of eHealth, is. The WHO define it as an abbreviation for "mobile health", the use of mobile devices such as wireless devices, (e.g. mobile phones, personal digital assistants and patient

monitoring devices) and their technology (e.g. 4G systems, GPS, and Bluetooth) as a support for medical and public health practices (World Health Organization, 2011). This work adopts these definitions; however, it is important to mention how the concept of e-health has been discussed since its early days by authors that took other perspectives rather than the use of technology.

In the early 2000's Eysenbach (2001) has brought up the idea that e-health was more than just using the internet for healthcare purposes. According to the author, e-health encompasses a whole different way of dealing with healthcare, it involves a new mind-set that asks for commitment in a networked system to improve healthcare locally, regionally and worldwide, by taking ICTs as tools. Furthermore, the author points out that several other "e's," can be attributed to the concept as it follows: Efficiency, Enhancing quality of care, Evidence based, Empowerment of consumers and patients, Encouragement of a partnership between the patient and the health professional, Education of physicians through online sources, Enabling a standard of information exchange and communication between health care providers, Extending the scope of health care beyond its conventional boundaries, Ethics and equity (Eysenbach, 2001). His vision on eHealth reveals the benefits that the use of ICT brings to healthcare as it foresees challenges that it brings to healthcare when touching upon aspects

intrinsically related to the use of health-related data, such as information exchange, ethics and equity.

Other authors added to the discussion how eHealth solutions may impact the healthcare domain. Besides empowering patients, Fried et al. (2000) pointed how the use of ICT enables a personalized health promotion and facilitates the access of medical records by physicians. Mittman and Cain (2000) highlighted how such solutions could impact patients' relations with healthcare. It was expected that, by 2005, patients and consumers would be used to seek information regarding health on the web, buy prescription drugs online, and organize support groups for caregivers and patients and that communicate with healthcare providers by email. In other words, there were expectations that patients could become more proactive regarding their own health.

However, back in 2000, the barriers and challenges that could prevent a fast development of an internet based healthcare system had also been noticed. Fried et al. (2000) pointed the dilemma of regulating eHealth, due to security concerns to and, yet, do not put barriers to its development. In addition, there were already concerns regarding the lack of web orientation of several information systems on healthcare organizations, the conservative characteristic of the medical community towards new technologies and

the uncertainty regarding the quality of the information available online (Mittman & Cain, 2000).

Flash forward to almost 20 years later and, while some of optimistic forecasts have become true, there are still several barriers to overcome. Several cases of successful uses of eHealth -especially in chronic diseases management- have been registered. In spite of that, several barriers have not been overcome yet and present new facets to the current scenario. Healthcare is still struggling with fragmented and not unified electronic records, the use of telemedicine and data storage (Farahani et al., 2018; Scott Kruse et al., 2018).

On one hand, in the recent years, eHealth solutions have been successfully used and recommended as a tool to support patients in managing their own condition and deliver a patient-centered care model in various cases (Barello et al., 2016; Duff et al., 2017; Finkelstein et al., 2012; Gee, Greenwood, Paterniti, Ward, & Miller, 2015; Jimison et al., 2008). The diabetes care is a great example of a field that has been experiencing several advancements in using ICT as a tool with promising outcomes (Fatehi, Menon, & Bird, 2018; Fu, McMahon, Gross, Adam, & Wyman, 2017; Hood et al., 2016; Joiner, Nam, & Whittemore, 2017; Mushcab, Kernohan, Wallace, & Martin, 2015; Riazi, Larijani, Langarizadeh, & Shahmoradi, 2015;

Wu, Guo, & Zhang, 2019). In the cardiology domain, even though patients are not so used to self-monitor as diabetic ones, successful experiences have also been registered. Patients with congenital heart disease have benefited out of eHealth interventions (Jaana, Sherrard, & Paré, 2018; Kauw et al., 2018; Triantafyllidis et al., 2015) as well heart failure patients (Fors et al., 2018; Goldstein et al., 2014; Pavneet, Jelani, Sharma, & Kapoor, 2018). Furthermore, as previously discussed (See page 14), when dealing with hypertension, self-tracking Blood Pressure has been encouraged by several guidelines as a way to supply healthcare providers with a better overview of the patient's condition and to improve patients' management of high blood-pressure. Such patient-related benefits are mostly related to an increase in patients' self-efficacy and a better access to information regarding risk factors, symptoms, prevention and treatments of their health condition.

On the other hand, the current scenario presents several challenges to overcome. Healthcare digitalization still faces several barriers regarding infrastructure, data security and analysis. Such barriers impact eHealth acceptance among professionals. For instance, research carried among Finnish physicians' experiences with usability of electronic health record systems in (EHR) has shown a lack of satisfaction of these professionals towards usability issues (Kaipio, Hyppönen, & Lääveri, 2019). While another research

carried in Austria revealed a skeptical attitude regarding the possible e-health improvements in the medical-patient relationship and concerns on dealing with data privacy and safety (Wernhart, Gahbauer, & Haluza, 2019). Furthermore, a study concerning Swedish primary care Nurses perceptions of eHealth has revealed several worries related to its impact on their professional practice. Despite perceived benefits such as reducing errors on medication delivering, preventing patient's allergic reactions and an easier documentation process, they reported feeling stressed about the constants updates in the technologies implemented and the routines required, having a quality decrease in the nurse-patient relationship and a lack of an easy and quick overview of the patient (Öberg et al., 2018). A research carried out regarding the Burnout among physicians in the United States contributes

to the perception of the nurses regarding how stressful technology can be. In this study, cardiologists have pointed "increasing computerization of practice" as the second cause of Burnout out of ten different choices; the first one was attributed to "too many bureaucratic tasks" such as paperwork. In general overview of physicians' causes of burnout, "increasing computerization of practice" occupies

*In which manner  
are e-health designs  
impacting healthcare  
professionals'?*

the third position in the ranking factors contributing to burnout, curiously, "too many bureaucratic tasks" occupies the first position (Kane, 2019). This leads to questioning regarding if EHRs and the use of digital systems are actually helping to decrease the time and effort spent in bureaucratic tasks, and if the data is becoming a burden instead of a helper. Given these examples, it is necessary to acknowledge that the lack of receptiveness or satisfaction regarding e-health cannot be simplified as healthcare professionals' traditionalist attitudes. It is necessary to comprehend and hear these professionals regarding how technology can assist the use of digital data in their professional routines.

Another challenge to overcome is the confusion generated by an overwhelming amount of available devices and apps. In 2017 it has been estimated that 325,000 mobile health apps were available

for download (Research2Guidance, 2017) this adds to the uncertainty regarding the quality of the information available of websites. With such a wide offer of health applications comes the uncertainty regarding the quality of the information provided by such applications and which ones should be chosen to actively help the patient to achieve a certain goal (Hood et al., 2016; Larson, 2018;

Masterson Creber et al., 2016). In parallel, several devices, like the Fitbit, Apple watch, Samsung Fit2 Pro, have been launched into the market, adding confusion regarding which devices can generate accurate and reliable data.

Conversely, this wide spread availability of ICTs solutions, like health related apps and devices, available in the market may reveal a growing and popular interest in healthcare data and lifestyle data. Therefore, it is necessary to explore beyond eHealth solutions and applications and further explore the uses of data in healthcare, what are the promises around it and in which manners it may impacts on users' relationship with their own healthcare and lifestyle.

*It is necessary to explore the uses of data beyond ICTs solutions and understand in which manners it may impact on users' life.*

## 1.3. **Data** & its many **uses**

*This section explores the concept of data in healthcare, its uses and in which manners designers can use data as a material.*

As global expenses with healthcare are expected to rise in the coming years (Deloitte, 2019), the interest in gathering and using data for healthcare is gaining momentum as a possible solution to lower the costs of health-related services. For example, it is estimated that 300 billion to 450 billion dollars can be saved in the healthcare industry by using and implementing Big Data Analytics (Groves, Kayyali, Knott, & Kuiken, 2013). This exemplifies how data can impact healthcare at a populational and organizational level, however, that is not the only impact to be acknowledged. Like any raw material, data needs to be processed to be converted into useful information

(Fernandez-Luque et al., 2019). In this sense, data can have an effect on a personal scale and unlock new practices of working in the design field. This section explores health and personal data as a material by discussing its many uses besides the plain use for interpreting vital signs.

First, it is necessary to understand what data in the healthcare domain is. Data can be a metric or a value such as heart rate. The number of heart beats per minute can be matched with contextual information such as age to acquire meaning and, becoming, then, useful information for a physician (Cooper, 2017). However, since data comes from



## Types of healthcare data.



### Patient-generated health data

Data that is related to health. It includes data collected by patients to address a health or a lifestyle concern, for example, biometric data, symptoms, treatment history.



### Clinical data

Data that is gathered according to a programmed trial by healthcare providers. It can be divided into six subcategories.



### Pharmacovigilance

It concerns data regarding the effects of pharmaceutical products. It is obtained through sharing agreements with patients.

**Electronic health record:** Data generated in the healthcare provider office. It includes personal information like an address to blood tests, insurance coverage, and X-ray reports.

**Administrative data.** Comprises data regarding a patient's admittance and dismissal from a healthcare establishment.

**Claims data:** Data regarding bills and insurance details.

**Patient disease registry:** Data related to diseases such as diabetes and cardiovascular diseases. Includes trends that help policymakers to draw national healthcare plans and policies.

**Health survey:** Concerns data related to an overview of the health condition of a country. Its collected for research purposes.

**Clinical trial data:** Includes information gathered through clinical studies.

Figure 2 - Types of healthcare data. Adapted from Azad et al. (2019)

diverse sources, from the hospital, the clinician's office the patient's house and workplace, (Azad, Arshad, Mahmoud, Salah, & Imran, 2019; Bushko, 2002) defining health data is not a trivial issue. In fact, there is not a consolidated definition of what health data is in the literature (Sonja, Ioana, Miaoqing, & Anna, 2018). In this manner, it is useful to observe the types of health data identified by Azad et al. (2019) to understand how heterogeneous the data used for healthcare purposes can be and how big its volume is (see Figure 2 ). Furthermore, with pervasive technologies (e.g. wearables) gaining momentum, more data is being collected at a higher speed, fostering interest in developing solutions to deal with data and in big data analytics within the healthcare domain (Elhayatmy, Dey, & Ashour, 2018).

Big data analytics has been achieving promising results in providing medicine insights. For example, clinical data has been used for calculating the risk of developing lung cancer (Agrawal & Choudhary, 2016)

while patient-generated data through wearables has been used to understand a population patterns regarding the damages of sleep deprivation (Althoff, Horvitz, White, & Zeitzer, 2017). Moreover, in a rather uncommon approach, Microsoft researchers were able to use web search logs to

predict queries that suggest pancreatic cancer diagnosis (Paparrizos, White, & Horvitz, 2016). Such findings depict the expectations on how data about patients' health state will impact positively on the effectiveness and precision of the healthcare services delivered and improve and enhance the whole healthcare infrastructure (Abedjan et al., 2019; Accenture, 2018b; Chauhan & Jangade, 2016; Koti & Alamma, 2019; Nambiar, Bhardwaj, Sethi, & Vargheese, 2013). Thus, data has become a valuable material to fuel advancements in population healthcare technology.

Moreover, the use of data as material presents impacts on a personal level. From a healthcare professional point of view, dealing with data during their daily practice material

presents several challenges and opportunities. First, the digitalization of medical records demands uses a not always standardized language when inputting digital records. This exposes the healthcare

professional to the risks of ambiguous interpretations by computer systems (Duclos et al., 2014). Second, since patients' data enables a personalized approach to medicine, it generates expectations regarding healthcare professionals delivering a personalized solutions to

*What is the impact of patient-generated data for the healthcare professionals?*

patient's problems (Staccini, Daniel, Dart, & Bouhaddou, 2014; Thomas, 2018). Third, it demands the development of new skills, such as how to manage and interpret digital data (Barnett et al., 2018; Demiris, Irbarren, Sward, Lee, & Yang, 2019); and, finally, it brings concerns on how to deal with the patient's data due to privacy and liability issues (Demiris et al., 2019; Prey, Restaino, & Vawdrey, 2014). Furthermore, the use of data evokes questions that go from the data impact on the healthcare professional's roles to how the possible uselessness and loss of medical identity symbols – like the traditional stethoscope around the neck – may be perceived.

*In which manners can data interactions be designed to foster personal reflections ?*

From a regular user point of view, the widespread use of smartphones and wearables has enabled an easier way to collect personal data. Such technologies have opened the doors for data-driven innovations for personal purposes (Fernandez-Luque et al., 2019; Riazul Islam, Daehan Kwak, Humaun Kabir, Hossain, & Kyung-Sup Kwak, 2015). However, in order to access the value of such technologies, it is necessary to ask what the data means and reflect on its impacts (van der Wilt, Reuzel, & Grin, 2014). Li, Dey & Forlizzi (2011) argue that the data generated by personal informatics can spark several

questions among users and lead to reflections. While Choe et al. (2017) adds that data visualization plays an important role in supporting self-reflection. On the other hand, it is important to consider the impact of such reflections. For example, if the data is used to reveal a degenerative disease it may lead to a better treatment outcome and a better quality of life but, also, to higher levels of anxiety, which may equally harm the patient by a different angle (Tenner, 2018). In this manner, data can be perceived as a tangible material that impacts on personal reflections and actions in a very singular manner.

Furthermore, data can be used as material to foster interaction between different

stakeholders. For example, in a study involving newborn parents, healthcare professionals and designer researchers as participants, a data collection toolkit was provided. In this case, the data has been used as a material to foster dialogue, interactions and creativity (Janne van Kollenburg et al., 2018). This depicts the opportunities of exploring design approaches to work with data as a material.

When discussing design and data King, Churchill, & Tan (2017) introduce three different approaches: Data drive,

data-informed, and data-aware (see Figure 3). The first one regards taking the collected data as the driver of the design decisions. This implies knowing exactly what the problem and the goal is. The second approach considers data as a material that fuels a decision-making process, it does not give a clear answer as an output, but it fosters further interactions and critical thinking. The third approach presupposes acknowledging that, for several questions, there are several types of data that can lead to answers. This implies critical reflections on what are the best approaches to achieve certain goals. Each one of these approaches

building upon the previous one. In addition, there is still a fourth approach to be considered, the Data-enabled design (J. van Kollenburg & Bogers, 2019). This approach enables data to be collected and explored in a continuous manner. This enables the designers to use data as a creative material to be explored and fuel the development of new design interventions. These approaches demonstrate how data can be a useful material for designers in ways that go beyond interpreting data for healthcare purposes only. Furthermore, they exemplify different manners to attribute value to data.

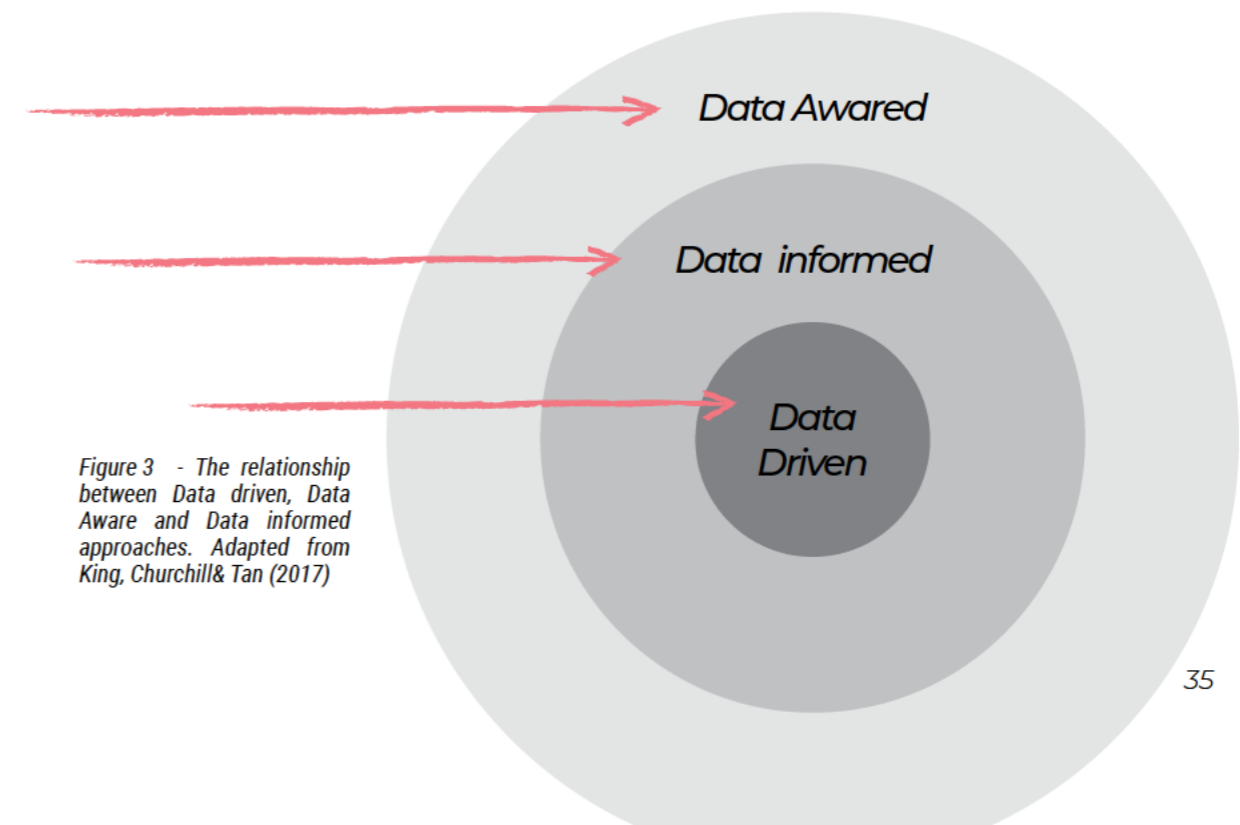


Figure 3 - The relationship between Data driven, Data Aware and Data informed approaches. Adapted from King, Churchill & Tan (2017)

To sum up, health and personal data can be a material that fosters several innovations in different domains. From a strategic design perspective, data opens possibilities to align stakeholders around common goals by taking into account the different meanings and uses that data may present to them in their professional and personal fields. To achieve such a systematic use of data, it is necessary to acknowledge that data is not just an unambiguous material: it is processed and presented to humans who may attribute different meanings to it. This work studies in which manners data may be used regarding healthcare and lifestyle purposes, therefore the next sections further explore self-tracking and self-experimenting as manners of transforming data into meaningful information.

*Data opens possibilities to align stakeholders around common goals. However, it is necessary to acknowledge that data is not just an unambiguous material. At end, it is always interpreted by humans who attribute different meanings to it.*

## 1.4. Self-tracking

*After discussing different types of healthcare data and in which manners designers can deal with it as a material, this section discusses different manners to collect it: the self-tracking practices. This section explores the ethical implications of different practices, and in which manners users are affected. Moreover, it discusses in which manners wearables may support such practices.*

The healthcare domain has been familiar with the act of self-generating data for a long time. For instance, people have been used to track their weight by keeping a scale at home. However, in the last decade, self-tracking has been taking new proportions due to the new technologies available such as wireless sensors (Alemdar & Ersoy, 2010) apps, medical portable devices, and wearables. Self-tracked data is highly personal and sensitive; therefore, it is necessary to observe some aspects regarding self-tracking practices. Firstly, how this kind of data has been accepted as a valuable material in healthcare. Secondly, how self-tracking practices occur and finally, how self-generated data may affect the individuals who have generated it. In this manner, this section discusses self-generated data regarding its uses on healthcare and in everyday life.

In the healthcare domain, self-tracked data is referred to as patient-generated data (see "1.3. Data & its many uses" on page 31). There are several discussions around how patient-generated data, - regarding the data that is self-tracked and reported by patients- might bring several benefits to the healthcare system. For instance, social media platforms such as Patients like me, on which patients openly report and discuss their symptoms, offers a rich source of data for research and better comprehension of patients' experiences (Kallinikos & Tempini, 2014; McDonald, Malcolm, Ramagopalan, & Syrad, 2019). Furthermore, self-tracking data can improve communication with healthcare providers and, encourage the individual's sense of responsibility (Burns et al., 2019). Patients value having access to their own generated data,

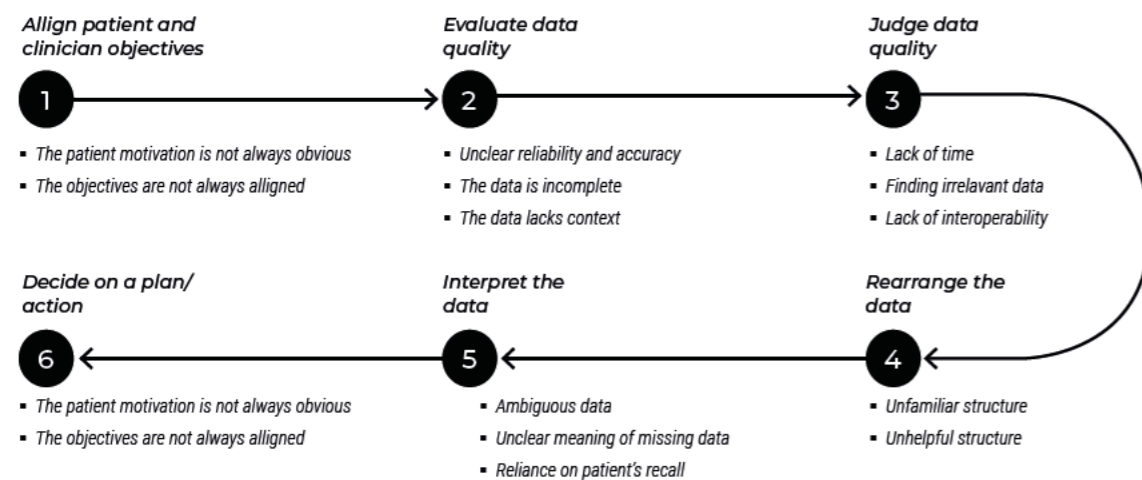


Figure 4 - The six-stages workflow for using patient-generated data . Adapted from West et al. (2018).

sharing it with healthcare providers and using it themselves (Whitney et al., 2018). This implies that patients and non-patients are taking a more active role regarding their own healthcare (Erikainen, Pickersgill, Cunningham-Burley, & Chan, 2019) which can lead to a change in the former paternalistic characteristics of healthcare relationships (Deloitte Centre for Health Solutions, 2014) and healthcare providers feeling like their role as experts might be at the stake (Mehta, 2011).

The creation of this new data pool - collected through methods that transcend the traditional ways of collecting healthcare data- has been sparking interest among the healthcare domain (Tong, Slevin, & Caulfield, 2018). Efforts are being made to develop solutions to unlock the value of self-generated data as a material that enables a better overview of the patient's everyday life.

However, there are some concerns regarding using data generated by patients for medical purposes. For example, in

the case of measuring Blood Pressure, there are concerns regarding if the patient has followed the correct procedure and have used an accurate device to take the measurements (West, Van Kleek, Giordano, Weal, & Shadbolt, 2018). In addition, there is a lack of trust on relying on the use of automated oscillometric BP monitors (AOBPs) and the accuracy of the measurements performed by such devices (Casiglia, Tikhonoff, Albertini, & Palatini, 2016; Filipovsky et al., 2016; Jegatheswaran, Ruzicka, Hiremath, & Edwards, 2017; Myers, 2015). Thus, there are several challenges to overcome when using patient-self-generated data, that goes from the data quality (Codella, Partovian, Chang, & Chen, 2018) to privacy issues. The six-stage workflow for using patient data discussed by West et al. (2018) exemplifies the several challenges that are faced when using patient-generated data for clinical purposes (see Figure 4).

Despite all the challenges of incorporating self-tracked data in a clinical routine, the interest on self-tracking is a growing trend. The wearables device sales is expected to double by 2022 (Lamkin, 2018). This growing interest in devices that can track data has been pushing the development of new wearables which are becoming more integrated into everyday life as accessories. For example, blood-pressure

–an important clinical measurement that is traditionally measured by upper-arm cuffs– now can be measured by smartwatches like the Heartisans and the HeartGuide, a device that provides clinically accurate measures (Food and Drug Administration, 2018). Such novelties in sensors and wearables are providing data that can reveal insights about one's life in an unparalleled manner (Sharon, 2017). In this manner, patient-generated data and self-tracked data regarding lifestyle are starting to overlap (Boll, Meyer, & OConnor, 2018). Such a phenomenon can be seen on the Quantified Self movement, which provides an example of self-tracking practices carried by individuals who do not have necessarily any health conditions but, still, collect

health related data and use it to foster discussions and personal insights. Thus, it is important to examine how self-tracking practices may occur and in which manners the gathered data might be used. The following session

takes how the quantified-self movement practices self-tracking as a starting point and further discusses different self-tracking practices.

*How do self-tracking practices tackle the user's interest on the gathered data?*

## THE QUANTIFIED SELF MOVEMENT AND SELF-TRACKING PRACTICES

There are several expectations that self-tracking data may help users to become more aware of their health condition and, consequently, become more empowered, acquire greater knowledge and a personalized approach to their health and possible changes in harmful lifestyles (Sharon, 2017). The Quantified Self movement embodies such enthusiastic views on self-tracked data as a community. However, in order to access such benefits is necessary to avoid self-tracking practices that undermine the decision power of individuals and put (Sharon, 2017). For these reasons, this section examines the Quantified Self, self-tracking practices and in which manner they may impact individual autonomy.

A lot of interest has aroused around self-tracking and the Self-Quantified movement since Gary Wolf's article Data-Driven Life (2010) has been published. Although the expression "data-driven" might bring an assumption of losing the "self" power to data evidence, in this article, he presents several insights regarding how self-tracked data can be used and transformed in material for reflections and insights by individuals. Further, Wolf (2010) discusses how self-tracking might acquire different meanings that go beyond self-improvement practices. He argues that some

self-trackers do not have a clear goal when self-tracking, in this case, self-tracking is not practiced to achieve efficiency, but rather as a self-exploratory practice that aims to discover new facts using data as the exploratory material. For example, a Quantified-self member might track very minor actions with the help of technology, then explore the data and get insights out of it. In this manner, self-tracking may be a practice that is flexible and adaptable to each individual and carried on with a high level of autonomy. Kristensen & Ruckenstein (2018) add to this practice the idea that self-tracking and self-experimentation enables a complementary structure of the self and the technology, besides enabling a inner-personal communication and reflection. Furthermore, Sharon & Zandbergen (2018), argue that some self-trackers might track memories and thoughts in a manner that data becomes a therapeutic material. In this situation, the individual can reflect on data such as memories and ideas in a practice that the authors call "Self-tracking as a practice of mindfulness". On the other hand, Lupton (2016) discusses that modes of self-tracking that involved the collection of data for self-awareness purposes, any optimization of one's life or even improving the management of chronic conditions can be called Private Self-tracking. Thus, in these cases, self-tracking is a highly personal motivated practice.

In his article, Wolf (2010) also discusses how self-tracking might be done as a reaction to generalities that are imposed on individuals, ignoring their idiosyncrasies. For example, a Quantified-self member might use self-tracking to obtain data and then use such data to ensure that his doctor is observing his particularities when designing a treatment. Thus, self-quantification becomes a manner to understand what works in an individual and personal level instead of knowing what may work on a population level. This overlaps with a practice of Self-tracking for resistance (Sharon & Zandbergen, 2017). Self-tracking as resistance echoes back to the seventies, when the use of personal computers emerged as a reaction to the mainstream computers. Sharon & Zandbergen (2017) argue that this practice is embedded by a will to flourish out of the traditional and oppressive manners to understand and get to know the world in a non-conformist manner, what Sherman & Nafus (2014) calls a "soft-resistance" against industries and scientific production authoritarian modes of operating. Regarding the devices, it is possible to observe such practices when users value devices with open Application programming interface (APIs) and use their coding and data literacy skills to build their own applications on platforms such as GitHub. In this manner, one may ask is self-tracking might be fostering

*Which interests  
may lie behind self-  
tracking practices?*

creativity and innovation as unexpected outcomes.

The Quantified-self movement promotes several meetups in which members present their projects and discuss what they did track, how they have tracked it and what have they learn. Such meetups and the online forums-were members can share their personal experiences and interact with other members- give to the Quantified Self a sense of community. As observed by Sharon & Zandbergen (2017), when describing what they have identified as "Self-tracking as a communicative and narrative practice", in such meetups the members use data to form a kind of digital storytelling. The shared data is highly personal and full of contextual and vulnerable information (Sharon, 2017). Lupton (Lupton, 2016) has also discussed the communal practices of Self-tracking. She argues that community members share their data to learn from each other. Outside from the quantified-self movement, it is possible to see such communal practices in forums where patients discuss symptoms, like the Patients like me among others. When voluntarily sharing data and interacting with other community members the interest and the motivation to self-track remains highly personal and the shared data is taken as a material that can help members to formulate new ideas and interests.

The previously discussed manners of self-tracking give the individuals a high power-of-choice and initiative. However, when self-tracking practices are pushed, imposed or exploited by external actors, the individual power over and ownership over data can diminish and a surveillance situation may take place. The sociologist Deborah Lupton discusses such practices. Lupton (Lupton, 2016) calls “pushed self-tracking” practices on which the user is encouraged to collect his data by an external actor and not in a fully voluntary manner. One example regards companies encouraging employees to join wellness programs like the Fitbit Health Solutions (Fitbit Health Solutions, n.d.) that aims to encourage employees to adopt healthy behaviors and, thus, become more productive and healthy and contribute to lowering cost per employee. Another example is the use of self-tracked data by insurance companies to provide discounts to self-trackers. John Hancock, one of the largest health insurance providers in the United States, for instance, has recently included the use of fitness wearables in all its policies (Wischhover, 2018). One may argue that patients and users may become healthier due to self-tracking, however, it is necessary to take into account that the effects of self-tracking are not the same for every individual. If the user is not interested in becoming healthier, he might cheat the activity tracking system by, for example, attaching the Fitbit to a dog's collar or a drill, and undermine the positive effects of physical activity

(Bachman, 2016). In this manner, to actively achieve health benefits by using wearables, it is necessary that the self-tracker is interested in becoming healthier and gather personal data in the first place. Besides, it is necessary to clarify who is using this data and for which reasons and that, in such cases, the one who holds most interest in the data may not be the person who is actually generating it.

Furthermore, Lupton (2016) defines as Exploited Self-Tracking the cases where self-tracking is stimulated by an external party and the same party treats such personal data as commercial or monetizable material. In some cases, the company does not state clearly how the data is being used and for which purposes and the user is not fully aware that his data is being used for other purposes besides his own interest. A recent example of this situation involves menstrual cycle apps that were selling highly personal data to companies and building a business model around highly sensitive

*If the user is not interested in becoming healthier, he might cheat the activity tracking system by, for example, attaching the Fitbit to a dog's collar or a drill.*

content. The users felt exposed when they started to see adds offering products related to the phase of their cycle on Facebook and Google. As a result, the companies involved suffered a backlash (Kresge, Khrennikov, & Ramli, 2019). In some cases, the users may not even be fully aware that they are practicing self-tracking since the goal of gathering the data might not be explicit. For instance, TWC Product and Technology LLC - a Weather Channel operator in Los Angeles - was suited for selling user location information for third parties. The location data was being monetized for as consumer behavior information while its users were completely unaware of such uses (Keck, 2019).

In the worst scenario, self-tracking can be an imposed practice (Lupton, 2016). For example, wearables can be used at the work to increase the endurance at works and the worker's productivity (Schatsky & Kumar, 2018). In a scenario where more people use ICTs to work from out of the office at different times, wearables might become a tool to measure productivity and provide reassurance regarding the worker's performance from distance (Schatsky & Kumar, 2019). In these situations, the worker is left on a situation in which he can hardly refuse to use such devices

*Why deciding to self-track should be fully in the users' hands?*

without feeling at least uncomfortable. Another example is using wearables for measuring student engagement in class. A study has shown that the heart rate within an-hour class lecture can be an indicator of which students may pass or fail a course, in this manner such data can be used to identify students who are not sufficiently involved and measures can be taken before the student fails (Senthil & Lin, 2017). In such cases, it is necessary to consider what the consequences of feeling surveilled are, in an individual level. Is it possible to state that self-tracking practices are beneficial if they are causing anxiety or any form of constant apprehension to someone? Moreover, the ethics of using highly personal data for purposes which are not personal needs to be discussed and users need to be clearly informed.

Self-tracking practices might bring several benefits for its users. The Quantified Self movement provides several examples of how unusual, sensitive and even qualitative data can be obtained and used for personal purposes. In this manner using technologies such as apps and wearables to track data can bring positive outcomes for the individuals. However, it is necessary to observe that Self-tracking practices should always be an autonomous

decision. If the adoption of wearables is encouraged for any reason, the user's autonomy to make a decision and his will have to be put at the first place (Heikkilä et al., 2018). Furthermore, self-tracking is a highly personal activity that involves highly sensitive data. In the digital context, users are becoming used to share their data with commercial companies to get a benefit in return, however, it is necessary to state clearly and in a transparent manner (Banerjee, Hemphill, & Longstreet, 2018; Lehto & Lehto, n.d.; Paluch & Tuzovic, 2019) how the data is being used, respect the diversity of users' profiles and their intrinsic motivations. Being confronted with personal data has individual outcomes which lead towards the questions: Can a certain user who is not a Quantified Self member feel anxious regarding self-tracking data and achieving goals? Would this person find positive personal outcomes by seeing his own data? How is data used and perceived by users who are having their first experience with wearables? How do users transform personal data into personal insights? In which situations should a doctor be involved? Finally, even self-tracking practices that are a result of a fully autonomous decision can be submitted to unethical uses of data unseen by the user. Systems that involve several uses of data that go beyond enabling personal reflections should involve alliances with commercial and public operatives to assure a great level of transparency and trust among the involved ones (Hardey, 2019). Thus,

self-tracking practices should, above all, benefit the users who generate the data and ensure and present a high level of transparency.

*Self-tracking practices should always be a fully autonomous decision based on a trustworthy and transparent use of data.*

## WEARABLES

Self-tracking practices are frequently assisted by electronic devices with sensors that capture health-related data, the wearables. It is suggested that using trackers might have a positive effect on users' self-reported health and well-being (Stiglbauer, Weber, & Batinic, 2019). Although the interest in such devices keeps growing, wearables still face a high rate of abandonment of use. According to a survey by the research consultancy Garner (Gartner, 2016) the abandonment of smartwatches can get up to 29 percent and up to 30 percent when it comes to fitness trackers. As it has been briefly discussed in the previous section (see page 40), several personal reasons explain the willingness to wear such trackers, in the same fashion, several reasons explain the lack of engagement with such devices. Users who already have higher levels of health awareness or activity are more inclined to use wearables, (Lee & Lee, 2018; Rupp, Michaelis, McConnell, & Smither, 2018; Shin & Biocca, 2017), therefore, it is relevant to understand how to reach those who do not have high levels of health awareness and can highly benefit from the use of these devices. Thus, this section further discussed what can motivate users to adopt wearables, which roles users attribute to wearables and what can influence a sustainable relationship with such devices.

## Roles of wearables

In the previous session, self-tracking practices have been discussed. In a similar approach to the one adopted by Lupton, Lyall and Roberts (2018) have studied subjective experiences of using self-tracking digital technologies such as apps and wearables. The authors have described three different roles of digital technologies in self-tracking practices: tool, toy tutor.

### THE TOOL

The first role, tool, refers to using devices to track data in terms of achieving or observing lifestyle ideas, in other words, the device is a means to an end. For instance, devices (e.g. wearables and smartphones) can be used as tools for observing stepping patterns and track activity patterns. While the wearable collects the data, a smartphone or a personal computer can provide visualizations and an overview of patterns regarding the collected data. In this sense, the authors discuss the importance of the semantics of visualizations as a tool that enables data interpretation. Visuals can help to evoke memories regarding specific moments of the self-tracking experience (e.g.: pictures of meals) and therefore allow users to connect graphs with their narratives about the experience. This role can be identified in Wolf's (2010) article be when he argues

*Using the device as a tool involves connecting data and personal narratives*

### THE TOY

The second identified role, the toy, builds upon visual explorations of data and achievement-based rewards. The device assumes a recreational role. In this case, data visualization plays a very important part in making data interpretation accessible and improves the experience with the use of the device (Lyll & Robards, 2018). For instance, on sleep tracking visualizations, an app may describe a certain "sleep zone" as "deep sleep", which is not the same expression that a specialist would use, however, it makes the information more accessible and insightful for a regular user. Lazar et al (2015) add that users prefer to receive the data from the wearable in an easy to understand and summarized manner, rather than raw data that needs to be interpreted. Also, it is necessary to mention that different users might want different manners of visualizing the information and different levels of details presented.

that self-tracking devices allow users to reconnect with ideas and activities that otherwise, would be forgotten. In this manner, technology becomes an assistant tool to gather data effortlessly and naturally.

For example, when working with individuals with type 2 diabetes Burford, Park and Dawa (2019) concluded that providing participants with personalized and dynamic data visualizations, instead of static diagrams, could lead to richer personal insights. Whereas Zhang et al (2019) have concluded that the use of different sets of colors when presenting data can impact self-empowerment. On the other hand, research has shown that providing textual health feedback might be more efficient (Shin & Biocca, 2017). Therefore, visualizations can enrich the joy of interacting with a wearable, enrich the experience and be a partner with textual information to enable actionable insights. Furthermore, the toy role may involve receiving badges for certain achievements and also engaging in playful competitions (Lyll & Robards, 2018). Such competitions might be a motivational factor for individuals (Rupp et al., 2018; Shin, Feng, Jarrahi, & Gafinowitz, 2019) However, it is important to take into account that introvert and extroverted individuals may be willing to use such features in different

*Visualizations play a part in using the wearable as a toy, by improving the interaction with the wearable and the the data.*

manners and share their data with different groups of people, therefore, the design of a system should consider different profiles and provide users with a possibility to tailor their use (Rupp et al., 2018).

### THE TUTOR

The third role described is the tutor role. It involves using a reflection learning loop (this concept will be further explained in the section "Self-Experiments", see page 52) as a way to keep the motivation for self-tracking and receive feedback. According to Lazar et al. (2015), some users may expect to be coached by actionable feedback and designers should consider that incorporating coaching into devices can benefit some users and increase their motivation to wear the tracker. Users can rely on pieces of advice from the wearable system and engage in programs provided by apps. This implies providing data to companies and, in exchange, having back personalized evidence-based advice. In this manner, it is possible to ask in which ways users attribute value and meaning to personal data and in which conditions are they willing to perform such trades and what influence trust have in such situations. When discussing the roles of wearables, it is possible to perceive that the three categories intertwine and are highly influenced by subjective factors. Understanding better the subjectiveness in using wearables is extremely relevant

for achieving positive health outcomes and sustaining engagement in the long-term, which, currently, is a major challenge. These factors are discussed in the following session.

### Engagement and Abandonment

As previously stated, there is a high abandonment rate of wearables. This can harm the long-term benefits enabled by trackers. Several reasons explain the loss of interest by users such as, for example, the initial motivation level, the perceived usability, the lost of the newness factor, problems in maintaining the devices among others. It is highly relevant to acknowledge such factors to improve the user experience and maximize the benefits of wearing trackers..

*Using the device as a tutor comprises receiving advice from it.*

### PERCEIVED USEFULNESS

The perceived usefulness (i.e. the belief that using a particular system can enhance a certain job performance) of the devices impacts the continued use of it. Lazar et al



(2015) studied a group of users who were invited to choose their own devices and set their goals. Within two months of the study, nearly eighty percent of the participants had discontinued the use of the wearables. When inquiring why the participants had stopped wearing the devices, the researchers found that some participants felt like the data gathered was not exactly useful - either because they already knew the information even without wearing the device or because they did not know what to do with the gathered data. Thus, the way the data is presented (which can be connected with the previously discussed importance of data visualization and the toy role) and the insights that the device provides – or the insights that the user can easily draw from the data- may have an impact on the perceived usability of it. On the other hand, participants who perceived the wearables as useful were likely to keep wearing it. For instance, participants who were able to improve their posture, control anxiety or became more active intended to keep wearing the devices. Also, additional features that were not directly connected to the tracked activity, such as alarm-setting features or watch display features increased the perception of the usefulness of wearing such devices (Lazar et al., 2015).

*How to design for increasing the perception of usefulness?*

To address the perceived usefulness, Rupp et al (2018) suggest providing users with education regarding the activities performed and their possible positive impacts on their well-being can help individuals to internalize and incorporate such activities in their routines. For example, it can be helpful to provide users with evidence of how their heart rate has decreased due to physical activity, or prompt them to rate their mood so they can see how they are feeling due to the new activities that have been incorporated to their routine (Rupp et al., 2018). Lazar et al. (2015) add that personalized suggestions provided by the device system are perceived as more useful. Another factor that needs to be considered is the perceived trust in the accuracy of the performed measurements. Trust in terms of accuracy and validity can increase the perception of usefulness (Rupp et al., 2018; M. Zhang, Luo, Nie, & Zhang, 2017) and, as a consequence, with its acceptance by the user (Trommler, Attig, & Franke, 2018).

#### USABILITY

Rupp et al (2018) discuss how the usability of the devices can influence the motivation and the perception of trust among users. According to the authors, the perceived usability can be influenced by behavioral intentions, the

perception of the motivational qualities of the devices and trust. For example, a person with lower levels of self-efficacy may perceive a device as less usable. In this sense, the authors recommend assisting in the use of wearables. When previous explanations regarding the features of the devices are explained to users, they may be able to successfully use them (Rupp et al., 2018). It is suggested to introduce sets of features that match users' personal goals and later introduce other features. The amount of work invested to make use of the wearables was also identified as a factor that can impact the

*What is perceived as "usability" when it comes to wearables?*

engagement with them. Lazar et al (2015) argue that participants who faced too much extra work to maintain the devices had difficulties to fit their use into their routine and, thus, stopped using them. Also, participants who had to invest too much effort into getting used to uncomfortable devices discontinued their use. Zhang et al. (2017) add that the perceived convenience of wearables can have a positive impact on the perceived usefulness of wearables technology, while Faust et al. (2019) concluded that minimizing participants responsibilities regarding maintaining the devices could be more important to keep participants engaged with the wearables than any other incentives. Therefore, wearables

should take into account features like long-lasting batteries, the need for calibration and also be easily suitable for the users' routines.

#### NOVELTY

The newness factor has also been identified as a motivation to use the trackers. Shin et al. (2018) have identified two stages of use: the novelty period and the long-term use period. According to the authors, the novelty period lasts approximately three months and it is marked by some characteristics such as curiosity towards the data and the technology. For example, users might want to experience how using technology feels like and what it can offer (Epstein et al., 2015). Zhang et al. (2017) add that the newness effect of technical advantages matter, therefore, the hardware and software should be gradually updated to provide users with higher levels of convenience when using it.

When participants finish the novelty and move to the long-term-use period they might lose interest in continuing the use of the devices due to three main reasons: informational, technological and situational aspects (Shin et al., 2019).

*Minimizing the responsibilities regarding maintaining the devices is important to keep participants engaged.*

The "information aspect" resonates with the toy role of the device and the possibility of visually exploring data patterns in different and personalized manners. If users are not provided with different possibilities of exploring their data patterns and make different connections, they might lose interest once they have a good understanding of its repetitions. In this manner, the initial curiosity regarding self-tracking may fade and the device becomes uninteresting (Epstein, Ping, Fogarty, & Munson, 2015). The technological aspect can also overlap with the toy role since users might lose interest in receiving the same badges or maintaining the device (which has an impact on the usability perception). Finally, the "situation aspect" is related to the context of use. Participants who do not feel like the device can offer them a motivation that fits into their context (e.g. someone who is not as active because he does not have enough time) might lose interest on the tracker (Shin et al., 2019). This is related to a lack of perceived usefulness.

### **AESTHETICS**

The appearance and its connection to the user's identity can exert influence on the engagement levels. For instance, Lazar et al (2015) reported that some participants felt

like activity trackers were designed for "health freaks". Therefore, the aesthetics of the device should consider which kind of image the users aim to project (Adapa, Nah, Hall, Siau, & Smith, 2018). Furthermore, the context of use is also important in terms of how the device should look like. In this manner, Pateman et al. (2018) argue that wearables should take into account the do-it-yourself cultures and allow end-users to customize or have a bigger influence on the device's design.

### **SOCIAL ASPECTS & RECOGNITION**

The social aspects of wearables, in terms of playful competitions, have been touched upon when discussing the toy role of devices. However, competitions are not the only motivation for increasing the levels of engagement with wearables. Having other people around wearing trackers might be encouraging in terms of making its use more acceptable (Shin et al. 2019) while having a lot of people discontinuing a

*How to design an ongoing experience of novelty?*

*When the novelty period is over, users may lose the interest due to informational, technological or situational reasons.*

certain tracking activity may be a reason for stop tracking for social-motivated users (Epstein et al., 2015). Furthermore, other aspects that may help users to keep engaged with the trackers in the long term are gamification features and recognition, for example, in the form of badges or feedback as previously discussed on the toy and tutor role.

### **PERSONALIZED GOAL SETTINGS**

Defining personalized and life-style matching goals, in contrast with static predefined goals, is an effective way to keep users interested in the devices (Shin et al., 2019). In addition, personalized goals might help individuals to align the use of the device with their core values and their conceptions of themselves (Lazar et al, 2018), therefore, increasing the perceived usefulness and the engagement levels (Rupp et al., 2018).

In conclusion, in order to promote the use of wearables for a period of time long enough to promote health benefits to users, systems should take into account how different users have different motivations and different profiles. Therefore, a system should be flexible and adaptable to such users in order to help them to have meaningful data-based insights. The following session discusses how self-experimentation and self-reflection loops may play a part to enable such insights.

## 1.5. Self-Experiments

*This section discusses how to attribute sense to data that has been collected by self-tracking. It addresses the relationship between self-experiments and providing meaning to data.*

If self-tracking is not strange to healthcare, neither is self-experimenting. The history of medicine is full of cases of self-experiments that resulted in several innovations in healthcare (Weisse, 2012). One example in the cardiology domain is the experiment conducted by Werner Forssman. He inserted a catheter into his own right atrium and performed Angiocardiology injecting sodium iodide on himself, contributing to several advances in cardiology (Kerridge, 2003; Weisse, 2012). Although such self-experiments were highly risky, today, less dramatic self-experiments are acknowledged as valuable and frequently recommended by practitioners. For example, when a patient aims to identify an allergy trigger, the practitioner advises him to exclude a certain

food from the diet and observe what happens. At the same time, patients have been taking the lead or carrying on self-experiments, having, for instance, the Quantified Self community as a great exponent of such attitudes. Thus, healthcare researchers have been increasingly exploring self-experiment practices and recognizing its contribution to science.

*How is self-experimentation related to healthcare?*

It is common knowledge that certain patients can highly benefit from small self-experiments and observations. Some health conditions like migraines, allergies, and irritable bowel syndrome present a challenging situation for both the patient and the clinician when it comes to identifying what triggers such reactions (Mullin, Swift, Lipski, Turnbull,

& Rampertab, 2010). In these cases, clinical exams can be expensive and fail in presenting clear conclusions. For this reason, self-tracking lifestyle factors such as food intake and experimenting with the elimination of certain foods is a recommended and common practice. However, just self-tracking is not enough to draw conclusions on such associations. Karkar et al. (2016) point out that trackers such as Fitbit make data collection easier but lack on supporting the user in answering questions. For example, one may conclude that there is an association with coffee and lower sleep quality but is not easy to state if the person is drinking more coffee due to poor sleep quality or having a poor sleeping quality due to the coffee intake. In this direction, besides collecting data and observing feedbacks, effective behavioral changes may be achieved by an understanding of the basal process and observations between the current individual state and the desired one (Beute & Ijsselsteijn, 2017). Therefore, it is important to acknowledge that providing answers to personal questions based on self-tracked data is not a simple process, it can take a lot of effort and the mainstream platforms fail in helping the user on this hard work.

*How to enable the use of data as a material for personal reflection?*

Such pitfalls present an opportunity for researchers to structure the self-experimentation process and seek for optimal results for the patients. For instance, Karkar et al. (2017) developed a design that successfully supported patients with irritable bowel syndrome to conduct self-experiments related to a few triggers and symptoms as dependent variables. Headache problems have also been addressed by researchers. Terzimehić et al (2017) have developed an app that allows patients to collect lifestyle data and supports them in reflecting on which factors (sleep, diet, physical activity and weather) and behaviors may trigger headache crises and how to respond to such findings. Both studies have revealed the importance of guiding the participants when conducting self-experiments. In addition, the independent variables selected were grounded on previous research about the possible result, revealing the importance of an expert opinion on the process.

The importance of guiding the participant was corroborated by another study. Dakalova et al. (2017) have conducted a study in which two groups of participants were invited to self-experiment as they pleased. The first group conducted the self-experiment following minimal guidance, and their

experiences have generated guidelines for the second one. The results showed that the group that was provided with guidelines were successfully supported when performing the experiments and experienced less frustration with the process. Therefore, it is important to examine the structure of self-experiments proposed by researchers when designing systems that aim to support self-reflection.

In a broad understanding, a technology-assisted process of self-experimenting involves collecting data and analyzing it while seeking for an answer. In this manner, it is relevant to look into the design of systems to support personal data collection (qualitative and quantitative), self-reflection and self-knowledge, which Li et al. (2010) refer as personal informatics. The authors propose a Stage-Based model of personal informatics divided into the following stages: Preparation, Collection, Integration, Reflection, and Action. Each stage concerns actions and present challenges as it is shown in Figure 5.

### The Stage-Based model

The Stage-Based model presents some properties. First, each stage is iterative, meaning that users can add different types of data, use different tools and so on. Second, the stages can be System-driven, demanding less time from the user, User-driven, demanding more time and responsibility from the user or a mix of both. Third, the system can be either uni-faceted, therefore, depicting only one aspect of someone's life (for example tracking only physical activity or productivity at work) or multi-faceted, for instance, when collecting someone's online search activity and physical activity. Finally, each stage affects the next one in the sense that problems in the earlier stages affect the next ones, what Li et al. (2010) call Barrier Cascade.

Although the Stage-based model presents several design opportunities, Epstein et al., (2015) argue at The Stage-based model tackles primarily users that already have a goal in mind and excludes users with other motivations such as curiosity about themselves. Furthermore, the authors discuss the importance of including a lapse between different self-tracking periods. In this sense, building upon the Stage-Model, Epstein et al. (2015) proposes the Living-informatics Model.

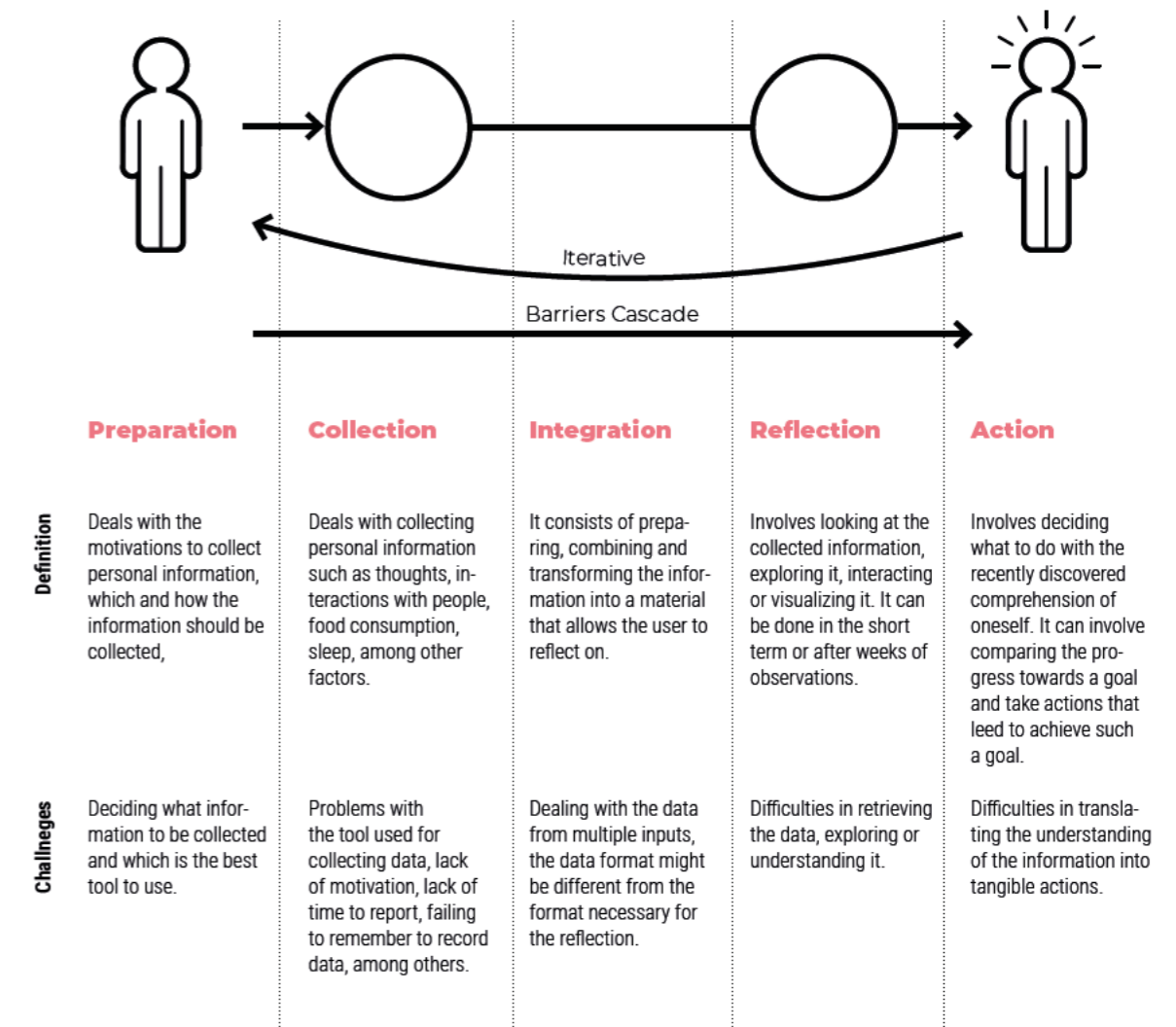


Figure 5 The Stage-Based Model of Personal Informatics Systems and its four properties. Adapted from Li et al. (2010)

## Adding different motivations and lapsing periods to personal informatics models:

### The Living- informatics Model

In this model, the Preparation stage is divided into deciding and selecting. This phase includes users who are self-tracking for the first time and also users who have previous experience with self-tracking and are starting a new cycle. The authors identify three main reasons for deciding to self-track at this stage: a desire to modify behavior, an instrumental motivation that can incorporate social motivation (e.g. sharing activities and seeing others'

activities), getting rewards (e.g. badges or discounts), and curiosity regarding the self-generated data and daily routines, which resonates with a motivation based on the novelty aspect (See page 49).

The *Selection* phase involves selecting a tool to perform the tracking. The motivation for self-tracking can play a role in this phase, for instance, users who are willing to

change a behavior may compare multiple tools, while individuals motivated by curiosity may adopt one tool first, then develop some goal based on the collected data and opt for a different tool to track something directly related to this goal. In this manner, it is advised that a system's design should support the user that changes motivations to switch tools and, in addition, even support the goals changing.

For example, a certain design may help the user to realize the benefits of keep tracking to sustain the goals they have already met and, moreover, to support the setting of new goals. The tracking an acting cycle stage involves collecting, integrating and reflecting. Epstein et al. (2015) understand that these activities are distinct; however, they occur in a single stage. That is one of the main distinctions when comparing the Living -informatics model with previously discussed Personal Informatics Model.

The *Lapsing* stage is another distinct feature that Epstein et al. (2015) bring to the model. It comprises stopping self-tracking temporarily or stopping with no intention of returning to the practice. The authors propose four

categories of lapses: forgetting to self-track, upkeeping (e.g. maintaining the device, charging the battery, etc.) which resonates with the influence of usability in the motivation and engagement with devices (see page 48), skipping (e.g. deciding to not log everything that is tracked, like locations of private appointments or not adding too much details to an entry such as all the ingredients of a meal), and suspending (e.g. not tracking an activity during the holidays or not tracking an activity due to a change in lifestyle).

Finally, the *Resuming* stage can take place after a short-term or long-term lapse. In the first case, the user might not rethink about his decision to track and to use that particular tool, however, in the second case, the user might reflect upon all the collected data and whether keeping a data collection is still necessary or interesting. The system's design should help the user to reflect upon the collected data, and, as previously stated, support eventual migrations to different tools or goals..



Figure 6 The Living- informatics Model  
Adapted from Epstein et al. (2015).

### Thinking about the social interactions while self tracking: the Conceptual model of shared Health Informatics

When discussing personal informatics models used to support patients with chronic diseases, Vizer et al. (2019) add a different perspective to a personal informatics model by incorporating social interactions. The authors have developed the Conceptual model of shared Health Informatics (CoMSHI), which includes tracking activities, how these activities happen in the context of managing chronic diseases and who are the ones involved in such activities.

The model comprises five types of work: communication, information, collection, integration, reflection and, finally, action in which actors collaborate. Communication involves interactions like sharing information regarding a certain illness, sharing tracked data or motivation encouragement. Information work involves providing information to support the tracking activity. The source can be, for instance, the interactions between the individual - and his particular experience with the illness- and the care provider. The collection can be described as the activities to collect data. It includes gathering objective data (e.g. glucose levels, blood pressure) and subjective data (e.g.

perceived discomfort levels). Besides, it includes different types of data, such as photos and videos.

The *integration* phase involves processing the collected data for interpretation. For example, a patient might process the data to further understand the effects of certain medications in a self-experimentation process. Visualization plays an important role at this phase, both in helping users to interpret the data as well as in motivating them to keep tracking (Vizer et al., 2019)

The next type, *Reflection*, comprises the time spent with the data in terms of creating meaning out of it. It can involve having healthcare providers and patients from the same community providing insights collaboratively. In this manner, the data collected may become a material to support shared-decision making. Finally, the *action* type of work consists of what actions self-trackers may take based on reflection and information. This includes adjusting their daily routine according to such insights.

Therefore, the CoMSHI model brings social *interactions*

and *collaborations* to a personal informatics model. Besides, it stresses the importance that care providers, community members, and healthcare providers may bring to a successful self-tracking and data-based reflection process. In this manner, the authors advise that supporting such interactions should be taken into account when designing a self-tracking tool. Also, shared work, interactions, and collaborations between people should be facilitated in self-tracking support systems.

By looking at the different models, it is possible to observe overlaps within the phases described on the models and several design opportunities for each stage of a self-tracking experience, whether it starts immediately with an idea of self-experimenting, or it is motivated by an overall curiosity. Regardless of the chosen framework to self-experiment, self-experiments contribute to healthcare and science. Such experiments may engage a doctor as a partner and expert that guides the patient in this journey safely, avoiding any dangerous outcomes (Mehta, 2011). A successful example of partnerships in self-experiments is a participatory study that has involved self-trackers and their personal projects regarding tracking HDL- cholesterol, and triglycerides. The study was carried out by a professional researcher and the Quantified Self community. It helped individuals to achieve personal learning and also managed to produce valuable general health knowledge (Azure D. Grant & Wolf, 2019). Thus, self-experiments contribute to the public interest in science, its democratization and open possibilities for finding cures or

*self-experiments can engage professional researchers and produce scientific knowledge*

palliative treatments for health conditions that are not met by the formal channels (Kempner & Bailey, 2019). Moreover, small self-experiments contribute to generating new plausible ideas for scientists conducting innovative investigations (S. Roberts, 2004).

## Stages of self-experimentation identified on the literature

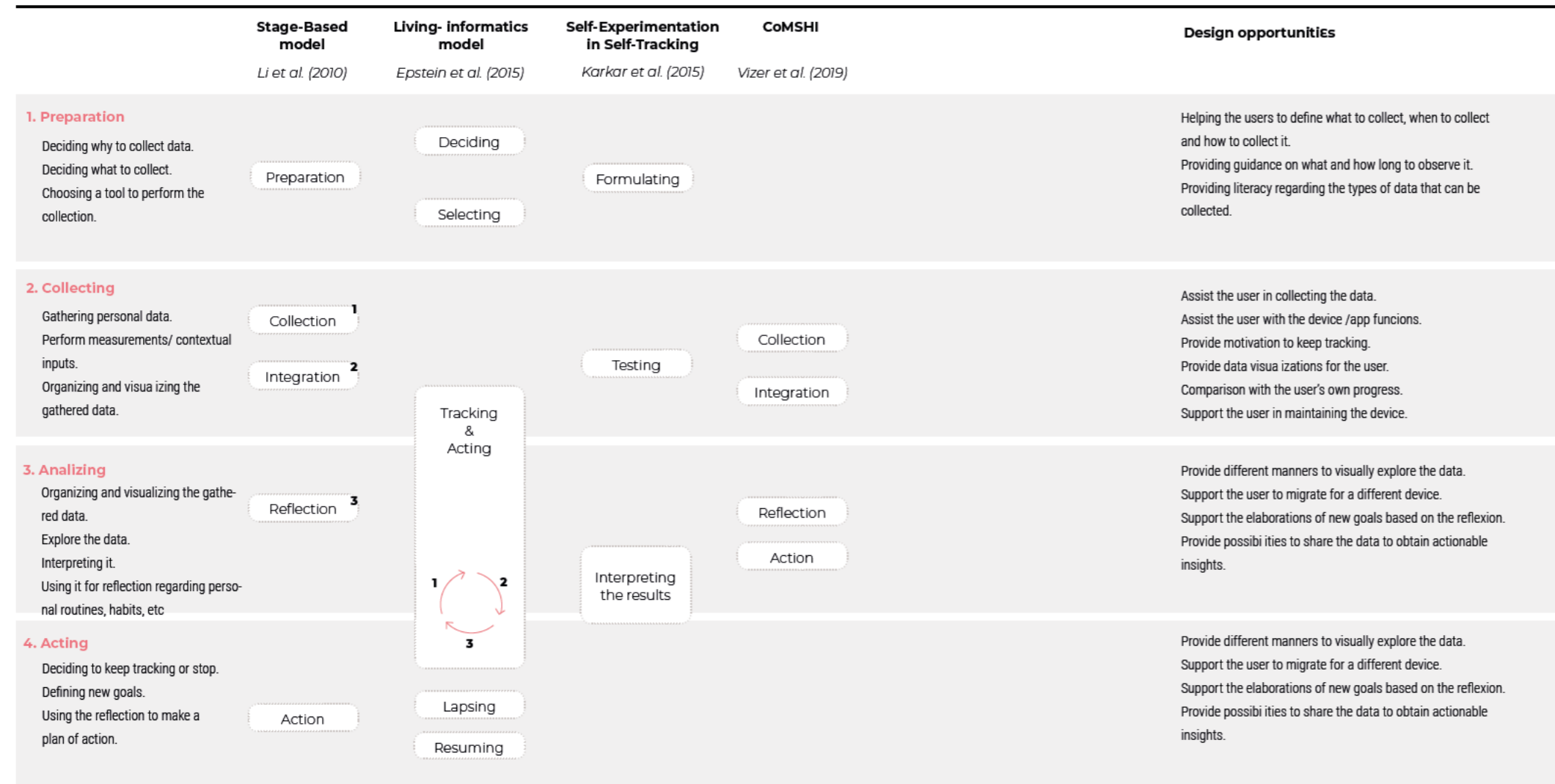


Figure 7- An overview on the Stages of self-experimentation discussed on the literature.

In sum, by taking data as evidential and reflection material, it is possible to state that self-experiments are valuable in helping individuals to draw reflections on their behavior and increase their awareness about the investigated phenomenon. Identifying the phases of self-experiments provides a better understanding of how a data-based self-reflection process can happen and helps to identify challenges in this process. Furthermore, self-experiments are valuable for science and provide opportunities for involving patients in participatory healthcare models by exploring data as collaborative material. Thus, there is an opportunity for designing systems that enable such collaborations and benefit the actors involved such as researchers, users, and doctors.

*Identifying the phases of self-experiments offer a better understanding of how a self-reflection process based on data can occur and help designers to identify opportunities*

# Trends

*This chapter discusses to a greater extent ongoing trends that have an impact on the use of personal generated data in healthcare. A DESTEP-analysis model (Demographic, Ecological, Socio-cultural, Technological, Economic and Political ecosystem factors) has been used to categorize and provide an overview of such trends. The Destep analysis is a marketing tool to map trends that can be used to map future developments that may impact the healthcare domain (Verschuuren, van Oers, Hilderink, & Riley, 2019). Trends that have an immediate impact on the use of data in healthcare, for instance, the use of Artificial intelligence (AI) in healthcare, are further explored.*

## 2.1. Population trends

As it has been stated before (see page 26) the healthcare system under pressure due to demographic and social changes. The world population is not only expected to increase, but also to live longer. In 2025, it is expected that the overall population will increase by 1 billion people, with one-third of the world reaching 65 years old or more (United Nations, 2013). As previously stated (see the section on E-health), this has been pushing the development of several digital approaches to healthcare in an effort to generate accessible health services to the growing population.

As discussed before, (See page 14) chronic diseases represent a burden for the healthcare system. In its 2002 report, The World Health Organization estimated that, until 2020, Chronic diseases will increase by 57% (WHO, 2013). The increase in urbanization contributes to this trend. With a projection of 70% of the global population living in urban areas by 2050, the consumption of unhealthy foods and

the lack of physical activity associated with an urban lifestyle, contribute to the rise of non-communicable diseases (World Health Organization, 2010).

Four non-communicable diseases are accountable for most of the mortality

due to chronic diseases: cardiovascular diseases, cancers, diabetes and chronic respiratory diseases (World Health Organization, 2014). Given the fact that an unhealthy lifestyle harms non-communicable diseases' control, preventive models of care, well-being promotion models and disease management models are gaining momentum (Deloitte, 2019a) to tackle this problem. Thus, promoting health awareness to the population and developing systems that stimulate the adoption of healthy behaviors, can play an important part in controlling such diseases.

*The consumption of unhealthy foods and a sedentary lifestyle is expected to increase*



## 2.2. Environmental trends

Global warming is on the rise and it may contribute to increase healthcare costs (Gaub, 2019). In 2030 the world is expected to be 1.5°C warmer than in pre industrial times (Intergovernmental Panel on Climate Change, 2018). As a consequence, there will be a bigger population exposed to extreme heat waves -that can cause heart failure- and to allergens and air pollution , leading to an increase in diseases like asthma (CDC, 2014). Therefore, providing means to access such changes in the population and monitor the development of new health-related problems is important to prevent. Monitoring population related data can help.

*In 2030 the world is expected to be 1.5°C warmer, increasing the occurrence of several diseases.*

## 2.3. Society trends

The world is getting more connected. Currently, there are 5.117 billion cellphone users and 4.333 billion internet users in the world (Deloitte, 2019b). In countries like South Korea and France, cell phone ownership rates can get up to 90% of the population, besides this fact the connectivity is expected to keep growing in the coming years (K. Taylor & Silver, 2019). In addition, the speed of global connectivity is expected to increase in the next years. Technologies such as 5G and WiFi 6 will enable faster connections in 2020 (Newman, 2019).

As a consequence, users are getting used to online services and, in the healthcare domain, the expectations regarding the availability of digital services and the convenience that they bring for the users are on the rise. For example, an research from the consultancy Accenture has shown that the percentage of patients likely to choose a healthcare provider that gives follow-up reminders by email has increased from fifty-seven percent, in 2016,

to seventy percent in 2019. In addition, more than half of the participants were likely to choose providers who offer telemonitoring (Accenture, 2019b). This leads to the description of the next trend in healthcare: putting the user first.

### HEALTH CONSUMERISM

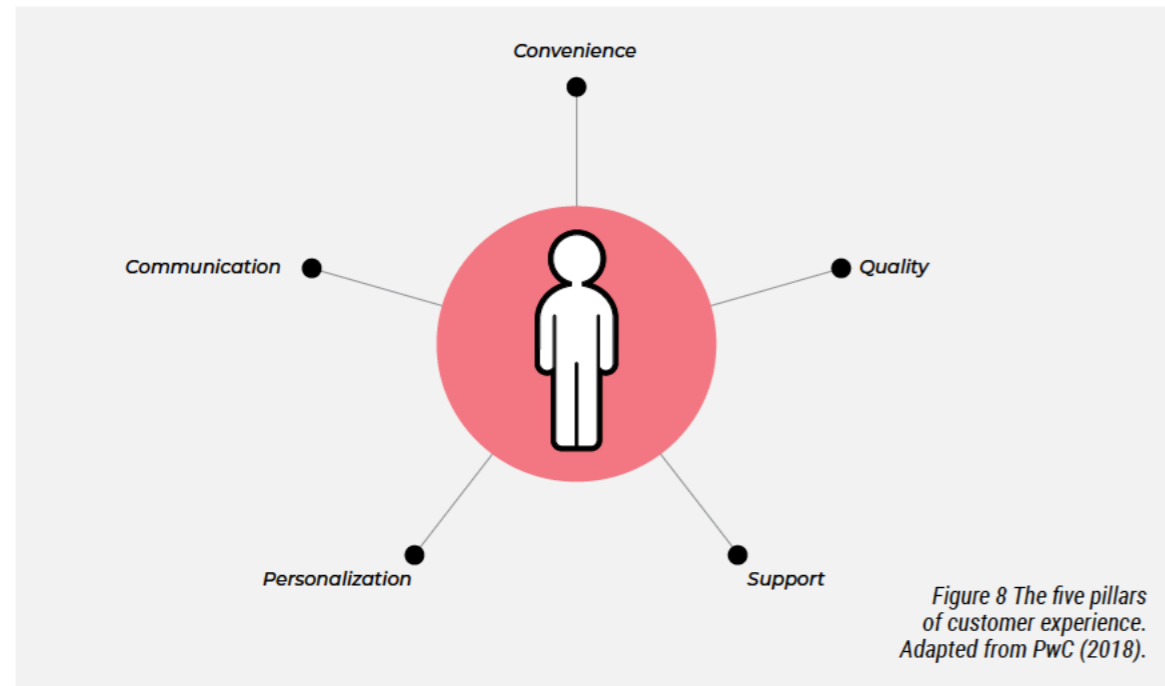
The consumerism in healthcare is growing. The concept of health consumerism has been defined by Black and Gruen (2005) as a social movement that aims to improve and provide representation to users' interests. In a practical sense, this concept is perceived when consumers are aiming for better experiences in healthcare in the same fashion as they experience the digital-enabled convenience with, for instance, banking systems (Accenture, 2019b; EY, 2019; PwC Health Research Institute, 2018). It is expected that consumers will increasingly seek

*How is connectivity impacting healthcare?*

for convenience in healthcare solutions throughout the years (Atluri, Cordina, Mango, Rao, & Velamoor, 2016; RB, 2019) and several movements towards this directions can be already observed in the current scenario.

Non-traditional services that meet users seeking for convenience are growing rapidly and patients are welcoming treatments outside traditional healthcare institutions (Deloitte, 2019a). For example, walk-in/ retail

clinics are gaining momentum as well as virtual care in fields like therapy and mental health (Accenture, 2019b). Furthermore, one of the most unsatisfied groups driving this change are the digital savvy generation Z and Millennials (Accenture, 2019b), which provides a glimpse of what the new generations are aiming for. In this manner, a PwC (2018) has identified five pillars of what users value in customer experience as Figure 8 shows.



Companies are making movements in these directions as a way to generate value to consumers. For instance, Fitbit has partnered with Twine Health, a cloud-based collaborative care platform for chronic disease management, and Google Cloud to provide users with reliable information and professional assistance without the need of physical appointments (Mainwaring, 2019). Furthermore, the company is investing in programs such as Fitbit Care, a membership-based service that provides users with coaching and wearables (Fitbit Health Solutions, n.d.). In this manner, the value offered goes beyond merely the device's technology.

Therefore, providing a great consumer experience is a competitive advantage in the healthcare sector. As it has been described in this session, a great experience has several dimensions to be observed and relies on observing the value exchange between those involved in the healthcare systems.

#### **TRUST AS A KEY VALUE**

Trust in institutions, including the healthcare ones, is globally declining. This raises concerns, given the fact that lower levels of trust are related to lower levels of therapeutic success and asking for second opinions more

frequently (Thom, Hall, & Pawlson, 2004). At the same time, research shows that companies who are highly trusted by consumers perform better than their competitors in the marketplace and in the stock market (Edelman Inc, 2019). These findings have been reinforcing the role of trust as a competitive value for companies entering or already established in the healthcare market.

In order to address trust in organizations it is necessary to establish what does it mean in this context. In this sense, The Edelman institute (2019) provides a definition and overview of this value, that helps to clarify the discussion, by framing Trust in four different dimensions as it can be seen on Figure 9.

Furthermore, it is necessary to state that perceptions of trust within healthcare vary depending on the country and the context. For instance, the Dutch are more likely to trust on the education of their physicians than the Germans, however, when it comes to care services, the Germans show higher level of trust in the system (van der Schee, 2016). Such differences are also perceived in terms privacy (Accenture, 2018b), which has an impact on policies regarding the use of data in healthcare, as it will be further discussed on page 82.



Figure 9 The four dimensions of trust. Adapted from The Edelman Institute (2018).

Despite of the country, health related industries are taking actions to avoid the erosion of trust. Currently, it is possible to see companies making movements towards establishing relationships based on purpose and reinforce an ethical image among the consumers. For example, Fitbit is strengthening its relationship with customers by paying attention to their values. In its campaign Fit for Good, the brand sought to establish connections with consumers by having a positive social impact. The brand has teamed up with charity institutions to promote a competition that would raise support for the causes. The American Diabetes

Association, The American Heart Association, and National Multiple Sclerosis Society were involved in this action. The users could select through Fitbit the organizations they would like to support and, then, instead of donating money, they could walk or run for the chosen institution. The three associations received prizes based on the number of steps taken on their name (Mainwaring, 2019).

One of the most critical factors involving trust revolves around privacy in the health-related industry. Cases that have revealed unexpected uses of personal data (see section 1.4) contribute to raising a lack of trust in having companies managing personal data. The insufficient public trust in data sharing systems, besides organizational barriers like the scarcity of clear rules and scarcity frameworks in this matter, are obstacles to overcome in order to use health-related data as a material to enable further innovations (Microsoft, 2018). In this sense, providing privacy regarding data, while enabling better AI systems, can be considered a value in digital ecosystems that involve personal and health-related data.

Users are aware of privacy issues regarding their own data and they are concerned. In the European scenario, internet users are increasing their awareness regarding the privacy policies offered by companies. Recent research regarding the perception of control over data has revealed that only

fourteen percent of participants who provide personal information online declared they feel full on-control over their own data . In addition, sixty two percent of the respondents who stated having partial or any control over

*Privacy and internet security rate on the top of the list of problems that the respondents want companies to solve*

their generated information, reported feeling concerned about this situation (European Commission, 2019). In addition, consumer research carried on the United States scenario has revealed that privacy and internet security rate on the top of the list of problems that the respondents want companies to solve (Cone and Porter Novelli, 2018).

To meet such users' concerns, organizations such as Data Fund, which stands for ethical uses of data, are emerging. Data Fund offers a protocol to guard personal data based on ethical principles in a decentralized manner (Datafund, 2019) in accordance with the Fair Data Society principles (Fair Data Society, n.d.). Such companies base their revenue streams on donations and contributions in order to keep operating and share such contributions in a transparent way.

Another example of a company who provides users a safe way to store the data and build projects around it is the Open-Humans. The company allows users to upload data from several devices and even genomic tests. Further, it presents to the users' several research projects that they choose to participate by donating their own data or as an active collaborator. The value exchanged, for the researchers, goes beyond the data, participatory research also provides the benefits of generating unexpected hypothesis, sustains a higher level of engagement among participants (Azure Dominique Grant, Wolf, & Nebeker, 2019) enables participants to become actively involved with their own health and results in outcomes that are more connected to the context of the participants (Streuli & Vayena, 2015). Therefore, the company benefits out of the engagement of its users in an ethical and user-centered manner (Greshake Tzovaras et al., 2019).

Further efforts are being made in extracting value from data without selling it for commercial purposes. For instance, Oasis Labs is a blockchain-based platform that makes data unidentifiable and encrypted. In this manner, it enables the use of this training AI without revealing the data to the researchers. Thus, although the data is used, the privacy is fully granted and improvements on AI and Machine Learning systems are enabled (Barber, 2019).

In this manner, providing an ethical, transparent and safe manner to manage personal data is an opportunity to reinforce trust among users in a scenario where innovating to create value for consumers, employers and governments can be a winning factor (Accenture, 2018b; Singhal, Latko, & Pardo Martin, 2018). Brands that are perceived as trustworthy have faster adoption rates and achieve higher levels of loyalty (N. Taylor, 2017). Moreover, being trustworthy improves monetary results, reduces corporate risks and increases the chances of success in the long term (EY, 2017). In terms of achieving higher levels of engagement with digital services and platforms, trust has a pivotal role. For example, research shows that eighty two percent of consumers state that they would not

*82% of consumers state they would not participate in digital platforms that lack ethics in using their data*

participate in digital platforms or ecosystems that lack safety or ethical management of data (Lacy & Cooper, 2016), which depicts the impact that this value has for businesses.

In conclusion, trust is a key value in crisis that needs to be met in personal data applications. Companies who leverage on this value may be successful in personal data-

driven business. It is necessary to prioritize a value-based relationship with users and focus on the long-term results, instead of jeopardizing user's trust by focusing only on short term gains.

## **PARTNERSHIPS**

In order to enable innovative solutions and provide a better user experience to patients and overall user, health systems are increasing the connection and the trades among each other (PwC Health Research Institute, 2018). Public- Private partnerships are growing (Specchia et al., 2017) and so are partnerships among different segments of the society such as communities, institutions and private companies. Companies and institutions across different industries are joining efforts on a network of partnerships. Therefore, new multidimensional ecosystems are being shaped, redefining businesses and building a holistic strategic approach that focuses on a long-term growth (Accenture, 2017b). In such ecosystems service providers seek access to customers, while customers seek for simple decision-making processes. In the healthcare domain, this leads back to the previously discussed trend of users seeking for convenience when looking for health related services.

There are several examples of ongoing successful partnerships. Samsung has partner with Deakin University in Australia and the Greater Geelong municipality to offer a solution to help seniors to remain at the homes and avoid hospitalizations (Swan, 2016). While GE and NVIDIA have joint forces to improve AI applications in healthcare. For example, the Vivid e95 4D Ultrasound system developed by GE, benefits from the NVIDIA CPUs to build visualizations and reconstructions of blood flow and 4D imaging (Altavilla, 2017). Another example is an association between the Blue Cross Shield Association, a United States-based Health federation of health insurance companies, and the Fitbit. Throw a program called Blue365, members of the Association will have access to exclusive Fitbit models that cannot be purchased out of the partnership (Mainwaring, 2019).

Partnerships involving start-ups and governmental institutions also provide opportunities for open innovation to happen in the Healthcare domain. Finland has launched the Upgrade, an associations of several start-ups, researchers and governmental institutions with the motto "No good health innovation should be lost due to the lack of knowledge about it.". The idea is enabling partnerships from different actors with different expertises and foster an environment of innovation (Upgraded, n.d.).

Furthermore patient associations are getting more involved in such partnerships. According to KPMG (KPMG UK, 2017), teaming with patient associations can help companies to better understand patients needs, engage patients as advocates on terms of adherence and lifestyle choices, improve transparency and trust in interactions and communications and, finally, increase the credibility of the company in terms of therapy encouragement. Therefore partnerships between patient associations and companies are growing in the healthcare scenario.

For example Amgen, a biopharma company, has been fostering value-driven relations with several healthcare systems entities, among them, patients associations, in order to improve patient experiences (Fendrick & Chernew, 2018). While Philips has teamed up with Dutch patient organization Apneu Vereniging for conducting a two year research regarding sleep apnea (Philips, 2013).

*Patient associations are getting more involved such partnerships with companies. They can help companies to improve transparency and trust.*

## DATA BELONGS TO THE PEOPLE

The involvement of patient associations in partnerships depicts the trend of creating ecosystems of patient-centered care that integrate community healthcare providers and caregivers (Singhal & Carlton, 2019) enabled by data-sharing platforms. It is expected that consumers will become more empowered through the years (EY, 2019). This means that users will not accept pushed solutions, instead, they will have a saying of future solutions for using personal data (Deloitte, 2019c). By taking into account that sharing data involves a set of values, as it has been previously discussed, platforms that store and allow users to manage their own data and meet such values are on the rise.

Platforms can be described as regulated environments that provide conditions for developers, users and other actors to interact, besides fostering the development of innovations. A platform might be integrated with different sets of platforms or systems assuring an environment of data interoperability (Riso et al., 2017a). Within this concept, users are paving their way to ensure data control and governance in aggregating personal data by engaging in data cooperatives (Blasimme, Vayena, & Hafen, 2018).

Data cooperatives aim to provide their members with democratic decision power of the stored data. For example, members might vote for who should be part of a committee that oversees the data, have a voice on deciding how the revenue should be managed, which partners should be considered and so on (Blasimme et al., 2018). Currently there are interesting examples of such cooperatives operating. The Midata, the healthbank the Taltioni are some of them.

Such platforms, provide data governance in several aspects. For instance, Taltioni allows users to select some applications and customize them to their individual needs. It is maintained by several partner ICT companies who enable more companies to use Taltioni as a sharing platform and use user's records to develop new services (Sitra, n.d.). The Healthbank enables users to profit from their data. Basically participants pay a fee to store their data and, in return, can sell their data to researchers and divide the profits among all users (Healthbank, n.d.). While the MIDATA focuses on protecting users' data and enable easy sharing of specific data with specific groups, besides offering the possibility of deciding how an eventual surplus can be invested in research or improvements of the platform (MIDATA, n.d.).

Most of these platforms are financially funded by research grants, personal contributions and loans in order to ensure their autonomy. Thus, cooperatives open new possibilities to include groups that, by other means would be marginalized from data-related activities such as research (Blasimme et al., 2018). Therefore, cooperative platform models achieve a higher level of perceived trust (Riso et al., 2017b).

This section has discussed how establishing a network of partnerships is necessary to enable services and systems that can match users' needs. Different parties have different roles in a value stream, their engagement is necessary to break data silos and enable innovations on healthcare. In order to break such silos and engage users it is necessary to design interactions and exchanges based on trust.

## 2.4. Technology trends

In the previous session, a better connectivity has been mentioned as an ongoing trend. This has an impact on the use of several technologies. For example, it affects directly the use of Internet of thing (IoT) technologies that may simplify remote monitoring and real-time monitoring (Mordor Intelligence, 2019). Such application may collect valuable and high quality data, which may improve Machine learning and AI systems. In this manner, emerging technologies such as AI, IoT systems, Machine learning, Blockchain and Robotic process automation (RPA) will enable several transformations in the healthcare industry (Deloitte, 2019c; Singhal & Carlton, 2019); 2019 Global life sciences sector outlook). Some expectations regarding the coming years are:

1. Patients data sets - such as financial, healthcare data and lifestyle data- will achieve a higher level of integration;
2. Technology-assisted personalization of insights generation for patients and caregivers will increase
3. There will be a higher level of interaction within the healthcare continuum;
4. Devices will enable and foster patient/user engagement.
5. Individualized care will have real-time assistance.

Within this set of expectations, some technologies are further examined due to their relevance in terms of enabling value for personal-generated data systems. Those are AI, IoT and Blockchain.

### AI

In a larger scale, one of the key technologies that can unlock the value of data in healthcare is AI. It can analyse a vast quantity of data and transform it into applications that can offer assistance to healthcare providers and patients (IBM, n.d.). The healthcare sector has been showing great interest in AI applications. Currently, the healthcare industry is already leading the use of AI when compared with other industry sectors, which highlights the possibilities of this technology for the industry (Accenture, 2018c). Furthermore, there are several expectations regarding the value that AI can unlock in healthcare services.

At the present, there are several successful applications of AI in healthcare domain. Pathologies reports' free text data is being transformed into structure data for AI applications and medical records are being used to predict patients who might be readmitted in the hospital and lower the workload of professionals such as nurses (Prior & McKeown, 2019). AI has been also showing promising results in imaging processing. For example, Google has developed a computer-aided system to screen diabetic retinopathy, which may help to prevent several cases of blindness in diabetic patients (Sayres & Krause, 2018). Furthermore, AI is being used to improve easy access to health literacy, IBM and Johnson & Johnson are using AI

to quickly examine scientific papers and map connections for drug development. Thus, the healthcare domain recognizes the value of AI as an assistant technology and is eager to keep developing new AI-based solutions.

The development of AI in healthcare is important for several reasons. The amount of healthcare data is expected to double every 73 days by 2020.

Therefore, AI might be a crucial tool to help clinicians to explore data quickly and find contextual information regarding patients, design personalized treatments, reduce the costs of treatments and allow healthcare providers to dedicate more time to patients by providing easy tools to quickly explore data (IBM, n.d.).

According to Accenture, the use of AI in healthcare is expected to be 10 times bigger by 2021 in comparison with the 2017 scenario (Accenture, 2017a). At the same time, a integration of AI and sensor based-devices is forecasted to take place in 2021 (Microsoft, 2018). By 2026, AI is expected to have a value impact, in terms of generating benefits, of 150 Billion dollars through applications such

*AI is being used to improve easy access to health literacy*

as Virtual nursing assistants (around 40 billion dollars) and administrative workflow assistance (approximately 18 billion dollars). Furthermore, it is expected that, by the same year, AI will help to address a currently unmet demand for clinicians of twenty percent, besides alleviating the work burden of clinicians (Accenture, 2017a).

As it has been discussed before (see page 42), Insurance companies are stakeholders showing a growing interest in obtaining consumer's data. As a consequence, there is a growing interest in AI applications as well. It is expected that AI systems can, for instance, increase the efficiency of claiming and reimbursement processes (McKinsey&Company, 2017) and help insurance companies to identify unmet healthcare needs in certain areas (Accenture, 2019a). However, in order to unlock such possibilities, insurers need to develop a combination of tolerance and experimentation in order to develop successful pilot applications of AI and scale them up to fully implemented solutions and need to observe ethical concerns regarding AI decisions with the same with the same scrutiny level used in human decisions. Otherwise, AI applications will not be accepted by users (Clifton, 2019).

In the future, new ethical issues due to the use of AI will be observed and will need further discussions. For instance, a promising manner to use patient generated data in a safe

manner is to use a "black-box" system to train algorithms. In such system, the data is kept anonymous and it used for training AI applications. Thus, it generate questions like who should be liable for a decision that is taken by using an AI-based decision. Although it is necessary to keep the data protected, having a good level of understanding regarding such technologies is highly important, given that AI-driven decisions will have an impact in real life. Therefore, limitations and possible biases of AI need to be observed and made transparent (Microsoft, 2018).

*Limitations and biases of AI need to be observed and made transparent*

To address the concerns of using of AI in healthcare, it is suggested to explain its use in terms of four different dimensions: To justify, to control, for improve, to discover. The first dimension, "*explain to justify*". It involves providing information regarding the reason a decision was made. The second one, "*Explain to control*", regards providing understanding and providing visibility regarding the system's behaviors, errors, therefore enabling control over its use. The third one, "*Explain for improve*", comprises iterations on the model with human input with the goal of

making the model smarter. Finally, the fourth dimension, "*Explain to discover*", involves providing information about learned strategies to users and, this, enable learning and further research avenues (Adadi & Berrada, 2018). The key takeaway of these four dimensions is that, for successfully using AI systems, users should be provided with literacy and transparent information regarding what to expect from such systems and the interpretation process of the results (Microsoft, 2018).

*In AI systems, users should be provided with literacy and information regarding what to expect from such systems*

## IOT

The internet of things (IoT) is expected to generate data to enable a higher speed in diagnosis, a higher efficiency in terms of treatments and reduce healthcare costs (Deloitte, 2019a). The use of this technology has been partially discussed in this work (see page 45 ), however this text digs deeper on three future outcomes of IoT in the healthcare field.

The sensors embedded in IoT devices are expected to become cheaper, obtain better quality data and become available to a greater public (Dahlqvist, Pater, Rajko, & Shulman, 2019). For instance, the price of smartwatches is expected to drop from \$223.25 in 2017 to \$214.99 in 2021 (K. Costello, 2018). In the present moment, the Omron Heart Guide currently costs \$499, 00 on its entry price, while the Heartisans, for example, costs \$149,00. Both devices measure blood pressure in an easy manner, and, both, are expected to see a decrease in their prices in the coming years. It is forecasted that more competitors will enter the market and that higher volumes of wearables might be demanded by the overall public (K. Costello, 2018). In this scenario, companies might seek for manners of differentiation that

*the price of smartwatches is expected to drop in the coming years*

go beyond providing clinically accurate data, build stronger trust-based ties with its users and provide integration with other data-based applications (Deloitte, 2017).

The use of IoT technologies is supporting a movement towards a personalized approach to healthcare (Deloitte, 2019a) and precision medicine together with advancements in genomics medicine (World Economic Forum, 2019). Furthermore, the applications of IoT are expected to increase, in the coming years (from three to five years)

it smart-pills and smart clothes might reach a position similar to the one already conquered by wearables and, in the long-term, IoT technologies might be extended for applications such as smart tattoos (PwC, 2018). Moreover, it is expected that IoT devices will enable patients to get more independence from doctors, get healthcare assistance from distance and increase user's level of self-assessment. This will place hospitals in new roles that can help patients to avoid hospitalization, by integrating data and placing such institutions in ecosystems that enable

preventive practices (MckChen, Stepniak, & Wang, n.d.).

To unlock the promises surrounding IoT, it is highly important to ensure integration of the data gathered through IoT technology across the health continuum. Therefore, the conditions to integrate data and the values that motivate data sharing need to be observed. According to Cresswell et al. (2018) there are five priorities to be met in order to fully enable the potential of patient generated data through devices like wearables. First, there a regulatory environment is needed to break the existent data silos. Second, it is necessary to develop a framework that treats sensitive data as such and promotes ethical data sharing while observing data protection. Third, there needs to be definitions regarding which kind of data is relevant for specific health-outcomes in order to guarantee that relevant information generated by patients is used by clinicians. Fourth, healthcare providers should be encouraged to use patients data in their practice, as well as patients should be motivated to generate data that can be useful for healthcare purposes. This is only possible if tools that enable an easy use of data are developed, with flexible and contextual information. Finally, there needs to be collaboration across different stakeholders.

Furthermore, when considering collaboration and data sharing with different stakeholders, it is necessary to

acknowledge that data sharing is not a value-neutral practice (Riso et al., 2017b).

It observes several ethical, political and social goals. In this matter, there are core values to be observed in emerging platforms that enable sharing personal-generated data: scientific value, user protection, an increased user agency (in terms of promoting empowerment and autonomy), Benefits (i.e. providing the outcome and benefits from a research to a certain population) trustworthiness and sustainability (i.e. guaranteeing fairness for the users).

*Data sharing is not a value neutral practice*

## BLOCKCHAIN

Blockchain is a decentralized data technology that was primarily used in criptorrecy to record and store transactions. It has become an appealing technology in the healthcare domain due to its capacity of creating digital identities, its tracing physical objects and, most of all, enabling secure and transparent data exchange while keeping the data control on the hands of its owner (World

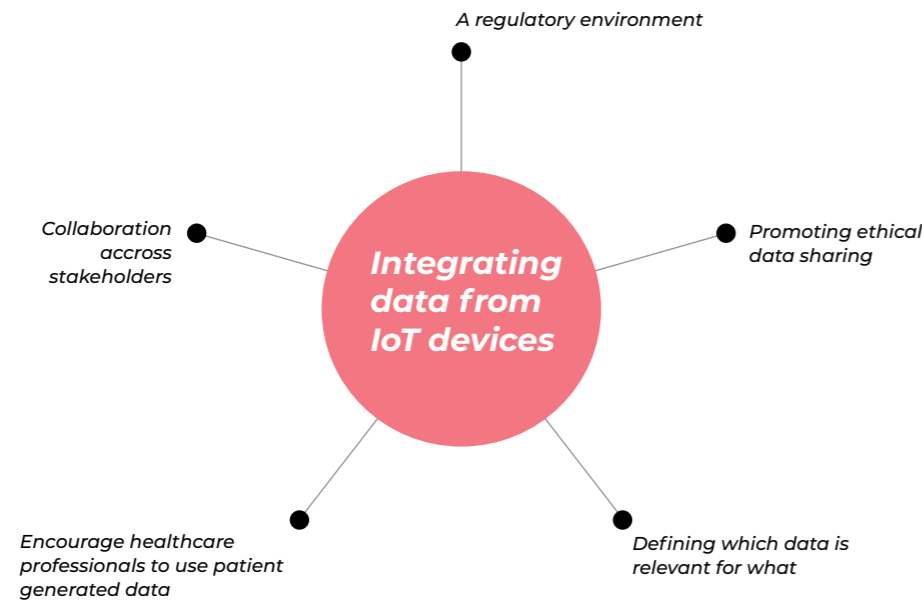


Figure 10 The five priorities for integrating data generated by IoT devices. Adapted from Cresswell et al (2018).



Economic Forum, 2019). This technology has promising applications in healthcare that may enable a safe share and integration of patient's data, however it still faces challenges to be fully mature for applications in healthcare. The applications and the usefulness of blockchain in the healthcare domain are further explored in this session.

When discussing IoT technologies, the problem with data integration across different systems has been touched upon as hurdle to overcome. Blockchain is pointed as one of the technologies that can offer a solution to this problem, besides breaking data silos while keeping a good level of security in terms of accessing patients data

*Blockchain can act as a transaction layer for sharing data*

(Delloite, 2019a; Gordon & Catalini, 2018; PwC, 2018). Blockchain can not solve the problem of fragmented healthcare information, but it can act as a transaction layer for organizations to share data in a safety manner and promote

integration of different data sources. In this manner, the information can be safely stored in a separate location and encrypted links are shared to provide access to it. Once the user gets the proper key to access the block, it will follow the link to the location where the file is stored (Delloite,

2019a). However, there are some technical barriers yet to overcome to enable more applications of blockchain. For instance, a high computational power is required by this technology (Delloite, 2019a). In terms of implementing it in the context of IoT, that is a major barrier. Currently, there are studies that propose a solution to this problem. For instance, Dwivedi et al (2019) proposes a blockchain that eliminate the concept of Proof of Work (which demands high computational power) and implement ring signatures and stores data on cloud servers instead of storing it on the chain. In This sense, the applications are evolving and are expected to increase in the coming years.

Furthermore, blockchain can place the control of the data in the hands of the patient (Gordon & Catalini, 2018).

The technology can provide patients with control over what data is going to be share, who is going to view the data and when (Mackey et al., 2019). Further, Blockchain enables interaction and peer-to peer data exchange in a non-centralized manner (Delloite, 2019a). In this manner its use can point towards a democratization in terms of managing and using data.

However, in order to guarantee a good fit-for -purpose

*Blockchain can provide control over shared data*

use of blockchain, some conditions should be observed. First, there should be a decision in terms of whether the blockchain will be public, private or a hybrid model. Then, it is necessary to have clear and transparent decision process to define which data will be stored in the chain or off the chain, keeping in mind that regulations should be always observed in this process. Further, since blockchain is a decentralized system, it is necessary to define who are the users, peers and validators: are they a consortium of participants? Is there any governmental institution involved? Who regulates the platform? How the general public is involved and in which manner decisions are taken? In addition, there needs to be an easy interface to the blockchain involved to enable features such as smart contracts. Finally, there needs to be a clear agreement and decision on what is the aim of the application of blockchain. It can be making data collection easier, enabling sharing personal data with healthcare providers, among other motivations (Mackey et al., 2019; D. Roberts, 2017).

Besides the discussed conditions, in order to successfully implement blockchain technology for healthcare, it is necessary to meet certain regulations. For example, observing the integrating the Health Care Enterprise protocol is important to ensure the interoperability and access of data and medical records (Delloite, 2019a). Furthermore, policy makers should take into account

possible collaborations with companies in order to enable the use of blockchain in healthcare applications. For instance partnerships and collaborations with start ups and well companies should be considered in order to carry on experiments with such technology. Then, blockchain might be implemented in healthcare in a widespread manner.

To sum up, the discussed technologies might enable safe data sharing and exchange, better prevention systems and convenience for patients. Users might be able to meet their needs without having to go to hospitals or seeing doctors, besides having more personalized treatments (Singhal & Carlton, 2019). However, it is necessary to reinforce that the role of technologies is to assist, not replace, professionals. Further, it is necessary to observe and discuss new ethical challenges that might emerge in their applications. Finally, it is necessary to bring different partners on board to enable the application of the discussed technologies in patient centered solutions.

## 2.5. **Political** trends

Regulations are important in order to guarantee that users are not harmed by technologies on the rise (World Economic Forum, 2019). Regulations play an important role in framing how technologies can be applied in healthcare, how users have their rights insured by the law and in which manners different stakeholders might get involved with innovations in the healthcare domain. New technologies are pushing new discussions regarding its impact and consequently, new laws and policies regarding its use.

Recently, the recent General Protection Regulation (GDPR) has strengthened the data protection laws for all individuals within the European Union. In terms of businesses, the regulation implies that any company that has customers within the EU territory should observe the new regulation, which impact US based companies, for instance (Accenture, 2018b). The EU is not an exception, laws reinforcing personal data protection and security have been approved in several countries around the globe, such as Brazil, India, South Africa and United States ). The

Russian legislation, for instance, establishes a strict use of personal data, specifying who detains the power over data and demanding that a data that belongs to a Russian citizen has to remain physically within its territory. Furthermore, countries like the Netherlands are developing systems to regulate and facilitate the access of patients to their own data, like the Medmij (Delloite, 2017).

The future of regulations is not clear, however, with the increasing concerns regarding privacy and control over personal data and an increasing feeling of distrust regarding its use for commercial purposes (see page 67) it is expected that further discussions will take place in order to protect users (Accenture, n.d.). There are several actors involved when enabling the value of personal data,

*It is expected that further discussions on policies will take place*

and a balance between regulation and an environment that does not put a barrier to innovations in the area needs to be achieved. In this manner, policies to deal with emerging technologies should be structured in partnership with the industry and the academia (World Economic Forum, 2019). In addition, regulations should observe transparency regarding the use of data and data processing technologies (e.g. AI), its supervision and its control, besides promoting mechanisms for incentivizing uses of data that meet societal interests and well-being.

*Regulations should observe transparency regarding the use of data and data*

The explored trends depict a future where technology will become more embedded in healthcare workflows and systems. However, the lack of trust in companies may harm advancements on the use of data that can benefit the overall good.

Thus, designing systems that involve personal data should observe regulations, possible partners, values attributed to data sharing and ethical issues to succeed. Technology will only enable collaboration, if there are trust-based interactions in the system.

# User Research

*The previous sessions have raised several questions and topics to be further explored. In this manner, this session describes an exploratory study that has involved experts of four different cohorts. The main goal was to elicit latent needs and values in order to enable the ideation and conceptualization of the Design Vision.*

## 3.1. **The Process**

The previous sessions have raised several questions and topics to be further explored. In this manner, this session describes an exploratory study that has involved four different cohorts. The main goal was to elicit latent needs and values to enable the ideation and conceptualization of the Design Vision.

An exploratory study was performed involving four groups: (1) Healthcare Experts, (2) Professionals involved in developing services for healthcare (3) Quantified Self members, (4) Designer master students. The data collection and interviews with the first two groups intended to address the attitudes regarding self-tracking technologies and its use in healthcare, including expectations and, further obtain insights on the use of self-tracking devices and its perceived relation to lifestyle and health by users. The data collected from the third

and fourth group aimed to identify insights regarding the process of self-tracking, perceived barriers of self-tracking, the use of the devices, the process of data collection and possible uses of data (see Figure 11).

The interviews and workshops with users (the designers who participated in the trial) and healthcare professionals, were structure to first, identify perceived problems and benefits, and, second, provide the participants with the opportunity of expressing their ideas on how to stress the benefits and solve the perceived problems or barriers.

The studies were planned according to each one of the cohorts, given their idiosyncrasies such as available time, location, professional background and involvement with healthcare. The following sections describe which methods were designed and used in each one of the groups.

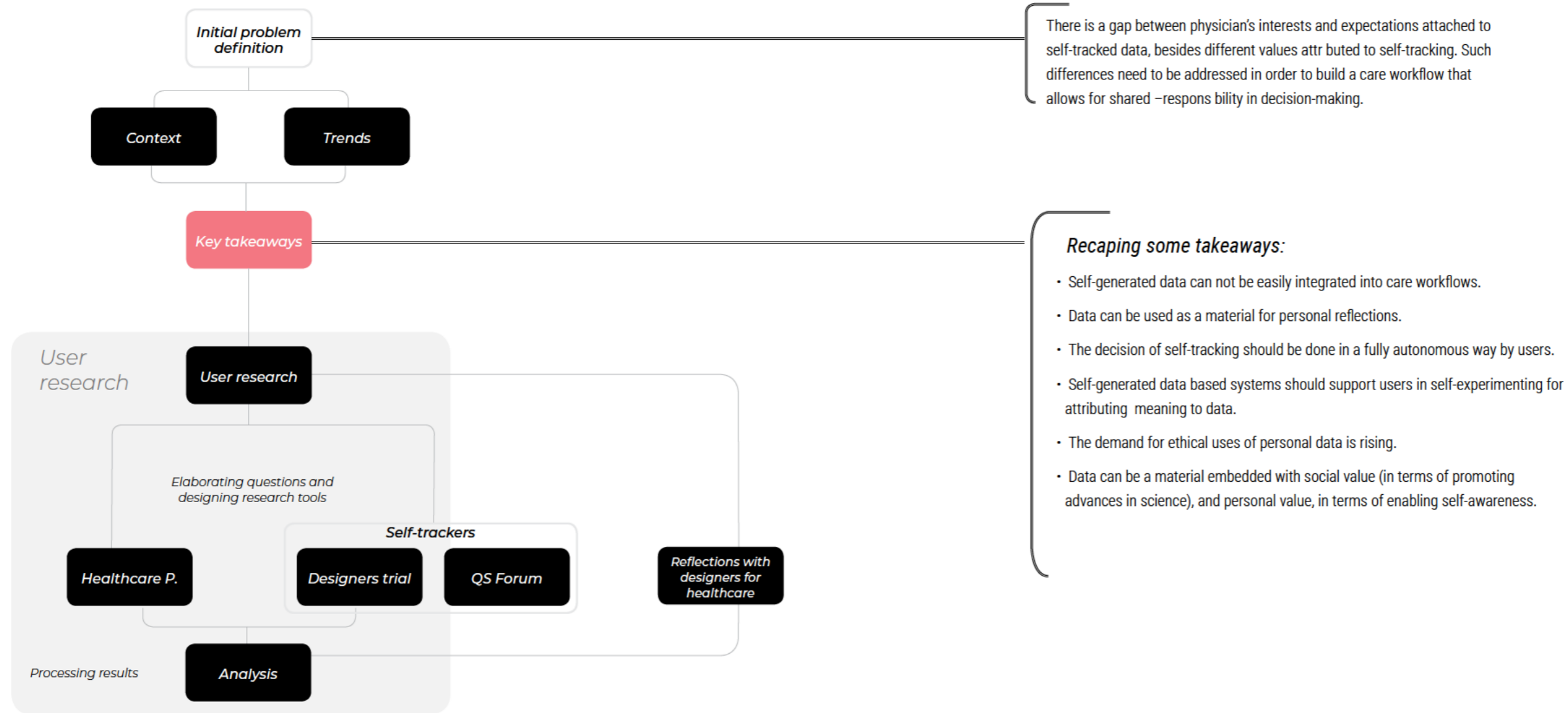


Figure 11 The process towards the user research phase

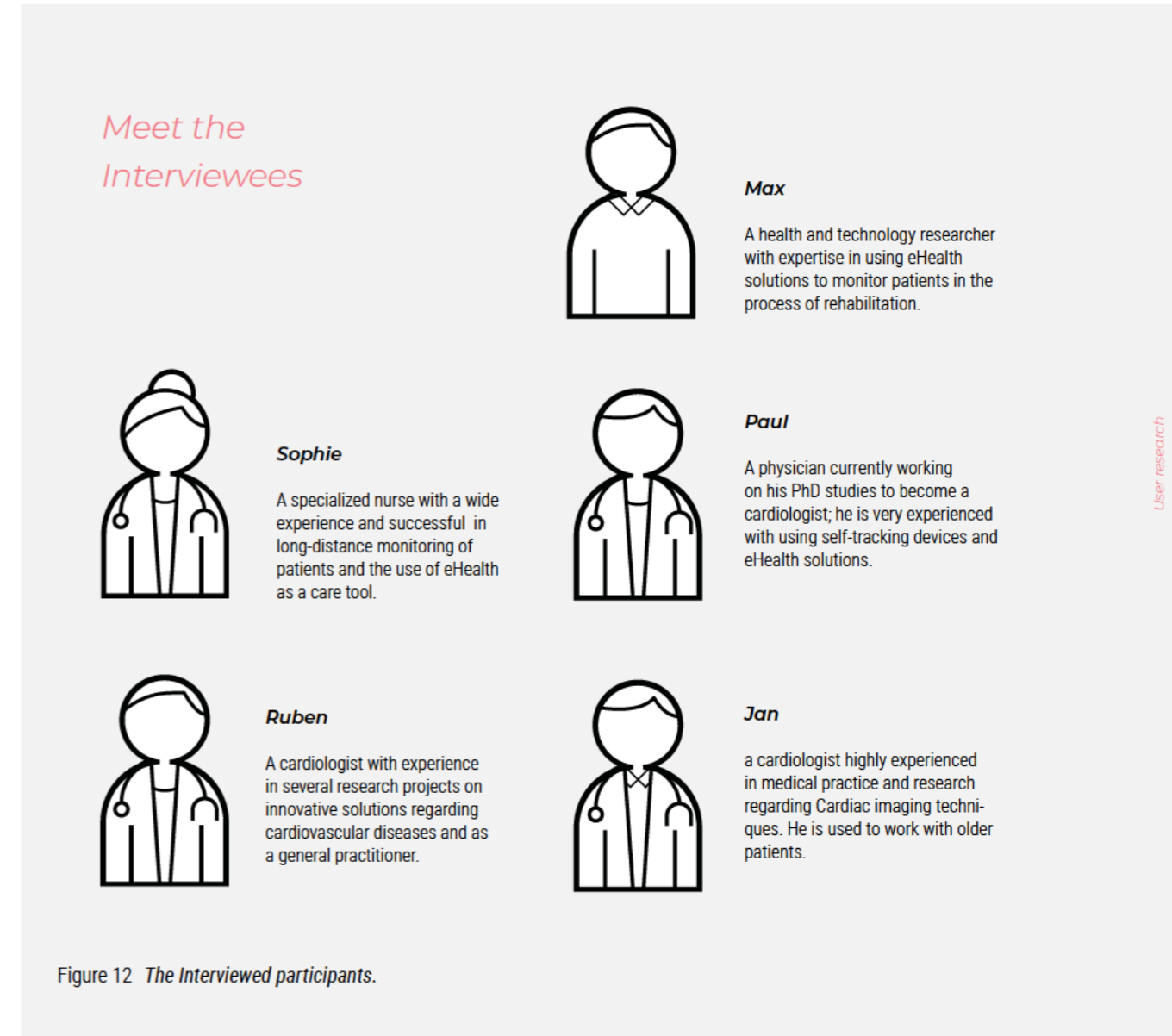
## 3.2. Healthcare experts cohort

Healthcare providers are key partners when developing technology-assisted solutions for healthcare and lifestyle. This session describes the collection of qualitative data regarding these stakeholders' opinions and desires for the future of health-related data used for healthcare and lifestyle purposes.

### PARTICIPANTS SELECTION

Five experts from four different research centers and with mixed backgrounds regarding healthcare were interviewed. The goals of these interviews was eliciting the expectations regarding the use of self-tracking technologies for medical purposes, and discuss the perceived benefits and challenges identified previously in the literature.

The participants' selection criterion was having experience with patients who had experienced cardiovascular diseases or chronic health conditions. A pseudonym has been attributed to each one of them, to prevent any identification. A short description regarding the profile of each participant interviewed can be seen of Figure 12.



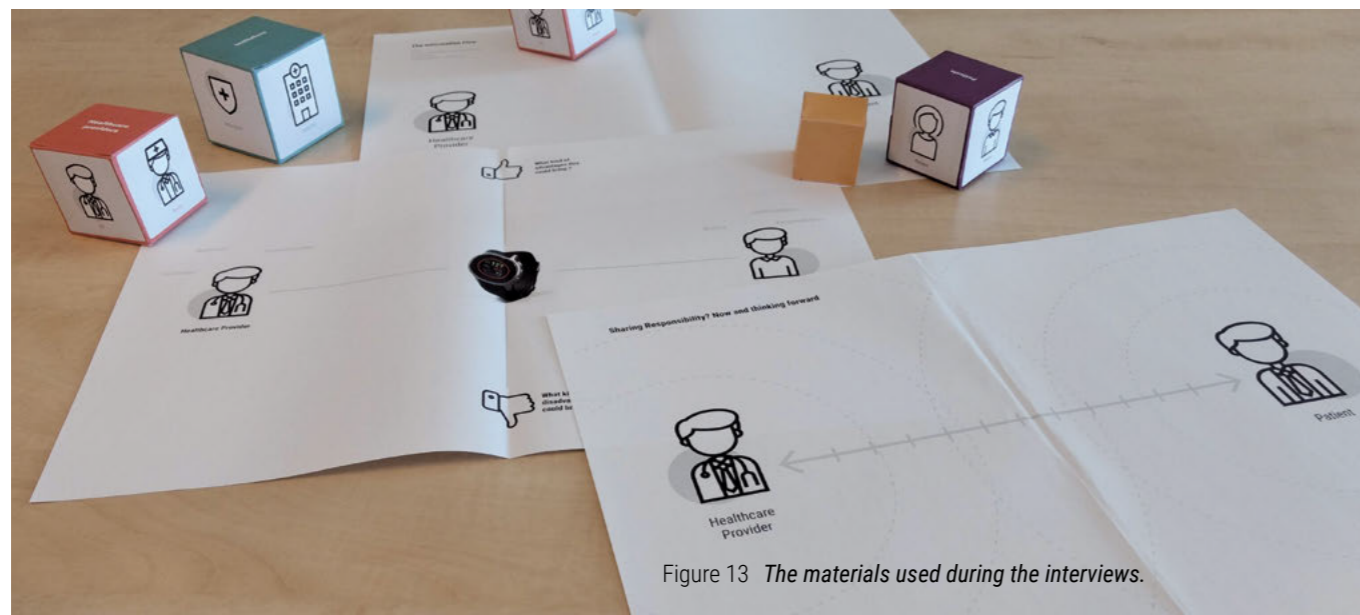


Figure 13 The materials used during the interviews.

## INTERVIEWS

A mixed method approach was used during the interviews. An semi-structured interview guide was designed (Patton, 2002) and three templates with images were presented to the interviewee in order to foster conversation and used as probes (Figure 13). The images have been designed to inspire in depth conversation regarding wishes and aspirations of the participants and to be customized in case the participant felt like expressing his ideas on the paper, taking the use of probes from Context mapping methods

as an inspiration (Sanders & Stappers, 2012; Sleeswijk Visser, Jan Stappers, Van Der Lugt, & B-n Sanders, 2005). In addition, cubes with an icon representing a key stakeholder to be approached were shown to keep the interview touching upon these elements.

The interviewees were contacted by email and asked, informed about the duration of the interview and its goal. They were asked to choose a place where the interview

could be carried out; in all the cases the workplace was chosen. At the beginning of the interview, the participant was informed about the goal of the interview and how the data would be used, in addition, a consent form was provided and permission to record the audio was requested.

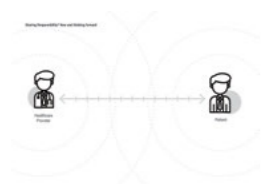
The interviews were held in an individual manner. Despite the fact that it has been very time consuming, individual interviews allowed the experts to express their opinions in depth. Each interview had approximately one hour length and revolved around the questions from the interview guide (Table 4) and templates with images. The participants were invited to draw in the templates, or just talk about

them, pointing at different issues represented in the paper sheets.

The questions aimed to tackle the interviewees experience, opinion, feelings and knowledge and time framed to approach past, present and future thoughts on the topics (Patton, 2002; Sanders & Stappers, 2012; Sleeswijk Visser et al., 2005).

Table 4 - Semi-structured interview guide for healthcare professionals

Topic	Questions	Possible follow up questions
<b>Introduction</b>	Do you have any questions about how the data of this interview will be used?	Do you identify any risk that was not mentioned in the information sheet?
	Do you have any questions about the goal of this interview?	Do you want to receive the final outcomes of this thesis?
	Could you describe your professional experience in healthcare?	Do you have any personal experience with self-tracking devices?
<b>Shared Responsibility</b> +/- 15min	How do you perceived the shared responsibility currently?	Why do you think this happens?  How the different health conditions influence this shared responsibility?



Do you think this scenario is changing? How do you perceive that?

How do you feel this impact a healthcare provider's role?

How this impacts your role as a healthcare provider?

Why do you think this (the responsibility) is changing or remaining the same?

Do you think the new technologies are pushing this scenario?

Do think there is a change in the patient attitude towards his health?

In which ways do you see that happening?

We see frequently people looking for information on the internet. Recently several people have been distrusting basic health recommendations like taking vaccines. Have you come across anything like this?

Which medium do you think influences patients the most?

What do you do when facing such situation?

### Wearables in healthcare

+/- 15min



This is a wearable that is FDA cleared. What kind of advantages do you think this bring to your daily routine as a healthcare professional?

Do you think having more intraday data regarding blood pressure is an advantage?

How do you see yourself using such device for diagnosis/treatment purposes?

Which benefits do you think it brings to patients?

Why do you think that?

Do you have any example?

What do you expect to happen when providing a patient which such device?

Which downsides do you identify?

Do you have any concerns about how the patients will use it?

Which downsides do you think it brings regarding your role in healthcare?

Why?

Do you foresee any negative changes that could happen on your field?

Which downsides do you think it brings regarding your patients?

Why?

Have you seen it happening?

Could you provide an example?

### Information flow, availability and visibility

+/- 15min



When you see devices like this, how would like to see the data that they can provide you with?

What kind of information would you like to have besides the measurements?

How would like to see this information?

When would like to get this information?

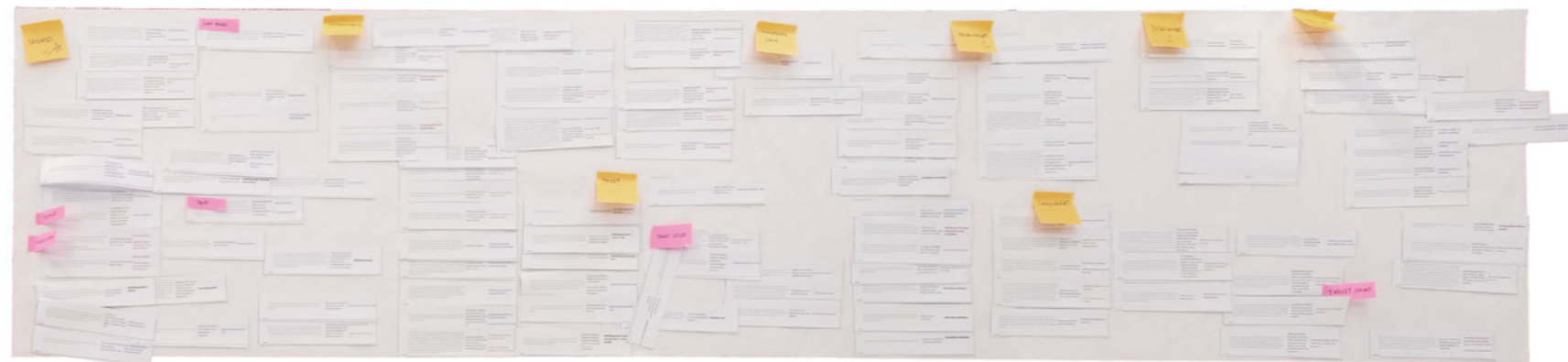
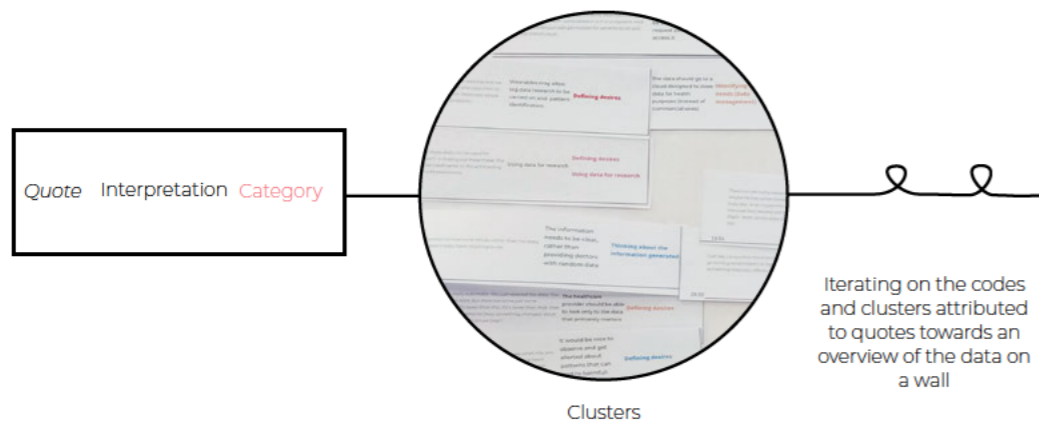
When thinking about the future, in which way do you picture this information getting to your office?

Would you feel reluctant about asking for this information?

How do you picture this information being shared with other colleagues involved in a patient's treatment?

Who should request to view the information?

Who should be able to edit it?



## ANALYSIS

The interviews were transcribed and coded in a mixed-method approach, taking the context mapping method (Sanders & Stappers, 2012) and the grounded theory method (Birks & Mills, 2015) as the main references on how to process the generated data.

First, the most significant quotes have been selected and the interviewer interpretation has been added (Sanders & Stappers, 2012) to identify what was the key insight associated to it. This process has separated each piece of data, and has provided the author with a better connection and reception of all the interviews. In the next step, intermediate coding was done by identifying and attributing

categories to each piece of data previously selected (Birks & Mills, 2015).

The data, the interpretation and the categories were printed, separated and clustered into core categories that were reviewed and iterated (i.e. a second student was asked to look at the codes to check if it could be attributed to a different category). Later on, these core categories were reorganized in order to clearly identify in which ways they were related to each other.

## CLUSTERING THE INFORMATION

The quotes have been coded and discussed with another researcher in order to iterate the coding attribution. Then the information has been clustered. The clusters have been iterated and are presented and further explained in this session.

### Desires: Visions about shaping patient-generated data into healthcare benefits

This cluster depicts Healthcare professional's desires in terms of the use of technologies and also the use of the data. For example, when thinking about the collected data Paul has described his desire to use it to identify patterns that could have a positive impact on the patient's life and

on his practice

*“So if someone who had a heart attack measures blood pressure, you could also see ‘hey, you had a heart attack at this point’. Then you can see changes (referring to lifestyle changes) leading up to the heart attack, and the patient would be alarmed by it. It would be possible to act before it happens. That’s a whole different story.”*

*“I think it (the wearables) shouldn’t not only empower us, but it should also empower the patient. But it should also logically be influenced by us in a supportive manner.”*

When reflecting about desires regarding digital systems, Sophie has added.



“I would like to see more systems that are very human, like this one (referring to the system that she uses in her daily practice). You can see the patient as a human, instead of numbers or data. All pictures of the patients are there and also mine. So you have a feeling of ‘that’s him’. It’s not such a cold platform. It works, I think because it’s a very warm platform. **I want a solution that connects me with patients, not with data.**”

At the same time, there is a concern of a data overload for healthcare professionals. In this manner, there were reflections regarding how the use of the collected data could be done by a professional as Max argues:

“And this could be like, really automatic. You just received the data that matters. You don’t need to look at this data. But there are some just some algorithms. If you that it’s lower than this, if it’s lower than that, then it just sends a message to the patients. At the same time I can know ‘Okay, something changed. What happened? Do we need to do? Can we help?’”

Jan also points the advantage of having evidence recorded to remind the healthcare professional about the decisions taken regarding a patient’s treatment:

“In two years, it would be nice to look back and say, Well, I made that decision because of these values.”

One of the desires that have been stated by all professionals

was an integration of Hospital data bases. In this sense, desires regarding the development of an infrastructure that supports the use of patient-generated data have been identified. One example was voiced by Max:

“The wearable doesn’t fit in the normal care pathways. So we need to develop a new infrastructure or a new pathway where it fits in the usual care program because you need to share data. So patients need to either through an external platform or sharing something. It needs to connect to something that the healthcare provider receives the data that it’s stored safely.”

There was also a common interest in all participants on the value of the data generated by wearables for research.

For example, Ruben stated:

“I imagine how valuable it would be a group of 10,000 patients wearing it. Then we have a 24 hour overview... probably we need computers with algorithm to trust as well. Then you would be able to see this kind of patterns in heart rate, blood pressures, and prognostic for cardiac problems”.

### Shared- Responsibility

This cluster comprises insights regarding the perception of shared-responsibility between patients and healthcare providers.

It was common among the interviewees that the more

experienced the patient is with his own health condition, the more capable he is to take more responsibility in managing his own health. For example Jan states:

“Because of the experience of the patient, they will get more responsibility.”

But he also adds that the device can assist the patients in earning such responsibility

“So the discipline is important in terms of responsibility, but it can also be held by tools, which helps remind you.”

Paul also comments on the relationship between responsibility and patient empowerment.

“You’re can give the patients more responsibility. So it’s empowerment I would say. I would call that (the responsibility moving towards the patient) empowerment because it makes more sense to me.”

All the interviewees have stated that the health condition of the patient plays a part in how much responsibility the doctor has when helping the patient in managing his own health condition. Sophie exemplifies these considerations:

“I think we are more responsible because we have, some patients are vulnerable. So that’s why we need to focus on

that issue, because some of them are not well educated or not well, in writing or reading, so the responsibility is a little bit more in ours ide but they have to agree, and they have to think about what they want to give away and what they do. (...) some people are vulnerable and old. So we have to take that into consideration.”

When involving a wearable in the scenario, there was the vision that the healthcare providers can set the conditions for a patient to use a certain wearable and collect his own data. However, at the end, the health professional take the responsibility for an accurate measurement performance. As Max states:

“The healthcare providers should be the one elaborating this (the plan involving the wearable and the data collection) and telling them, the patient, that it is very important to have accurate data to have an accurate measurement. But in the end, it’s the responsibility of the patients to perform the good measurements, of course”.

In this sense, it is already possible to grasp the role of the healthcare provider as an instructor and advisor. This leads to the next cluster, the definition of Roles.

### Roles: How dealing with patient generated data impacts on the professional parts and tasks.

Paul has identified a change in the role of patients and doctor given the way patients are having easier access to information about their health condition.

*“The patient really wants more stuff from us. They are becoming more talkative, they have an opinion.” (...)* “So they have opinions about certain things we think are important. But then they have a very good opinion about because they can Google it because they can look it up.” (...)

*“But I think that patients still trust us.”*

He elaborates more in his role as someone who needs to understand the context of the patient when designing a treatment.

*“for instance, you have a patient who has smoked 60 years, and he’s 70 now and suddenly has a heart attack... And then, as a doctor, I would say, ‘hey, look, you have had a heart attack. You’ve come through it, you’re okay. But I want to make sure that you don’t have a heart attack again. So please stop smoking.’ ... for the patient is maybe very important to smoke because he goes to play some card games, he’s with his friends or all the friends who are still alive. He drinks some beer and smoke cigarettes. And that’s a daily, daily ritual for him.” (...)* “So, as a doctor, when you’re treating patients, it’s not only about doing the right thing for the right patient. But is also accepting sometimes the things the patient wants, so you want to do the

*right thing for patients, but they have a strong opinion. Maybe that’s wrong regarding your ideas... But, it’s just right for them. So it’s also about understanding that.”*

Sophie explains her perception of the role of healthcare professionals in her work with a mHealth system. She and her colleagues provide reassurance to the patient and, also, transparency in how they work when monitoring them:

*“(...) the patient types in the data, the blood pressure, saturation, oxygen saturation, heartbeat, temperature, their weight. And they all we can see that in the platform. And we (the healthcare team) monitor it every day. And then when I open it, it’s always at a particular time, because we told the patients, that’s the time that we are watching and we cannot do it 24 seven. You are not being monitored on the weekends or in the evenings, then we will not watch. We do it only at that time, and, then we will call you if we see something is wrong. But you can also call us, we have a number, I always carry a phone so they can call me on the spot.”*

This corroborates with other visions on the doctor’s role like the one pointed out by Paul., for instance:

*“There has to be some security for the patient as well. I don’t think you should empower a patient to either to everything and just say, ‘Hey, good luck with it.’ (...) I think there should be some certain intervals or whatever to, to check up on be sure.”*

When considering a scenario in which the patient is asked to self-measure, Max adds the role of being a designer of such treatment in order to guarantee that the patient is also able to successfully perform the measurements:

*“The health care provider has to facilitate that it is possible to perform accurate measurements.”*

In this sense, Jan adds his experience with patients that can adjust their own medication:

*“Some patients can really adjust some few medications. But mostly we have to give the instructions in a way that they are very simple, just one medicine. A little bit more or a little bit less. So I think the self-management, when asked by a doctor, has to be kept simple, it can’t be a burden for the patient.”*

He also adds his role as an educator for the patient, which is also related to previous cluster in terms of managing responsibilities:

*“I think it’s a matter of education. I mean, I tell the patient, what is the purpose of the medicine that I propose. Well, I always say ‘you’re in charge. I don’t have to take the medication, you are the patient, you are in charge of taking it. So I have to convince you that it’s probably a good idea. Yeah. But if you want to stop it, fine.’ So prescribing that it’s a matter of a good informed discussion with the patient.”*

The device’s role has also been touched upon during some of the interviews. Three out of the five interviewees have pointed that the device has the role show evidence about a certain health condition and can be a partner in promoting a healthier lifestyle. Paul’s statement exemplifies this point of view:

*“So think about somebody with diabetes, who’s a smoker and blood pressure and has a lot of weight. So you give him a weight scale, you give him a blood pressure monitor and a pedometer step counter. Like a fit-watch. Then he probably measures every day and see ‘okay, I moved to little I am overweight, my blood pressures way too high’. (...) That makes it conscious for them that something is wrong and they can use it to monitor changes. So you give them a ‘coach’, then this says ‘Okay, that’s fine. But you have to move more.’ Then it gets the patient to move more. So my blood pressure gets better, and my weight is actually declining, becoming less of a problem. That’s, not something a doctor needs to check every day.”*

### Patients’ Profiles: Perceived use of the data by patients

When asked about the use of wearables and sharing responsibilities, the interviewees frequently shared observation regarding the kinds of patient-wearable relationship that they have observed. According to them, there are different profiles of patients, and some of them can develop non-healthy behaviors regarding self-

monitoring as Ruben descr bes:

*“There are some patients, which are always sort of busy with their health. They are so focused on their measurements, and always sort of busy with their health they're more worried about their measurements, then they should be”*

Paul has also pointed out how the device can become a psychological burden for some patients. According to him, some patients experience negative side effects of wearing a device, they became fearful of the device. It is interesting to notice that Paul, as all of his colleagues, perceive the wearable in a similar way of a medication. They feel responsible for “prescribing” it and consider the patient profile in the same way that they would consider a profile when prescribing medicine. For example, Sophie also made an observation regarding the patient profile that overlaps with her perception of her own responsibility as a nurse:

*“I think we are more responsible when dealing with patients who are vulnerable. (...) because some of them (the patients) are not well educated or not good at writing or reading, so the responsibility is a little bit more in our side (the healthcare professionals) (...) Some people are vulnerable and old. So we have to take that into consideration when considering them as patients that will use a system like this (a mHealth solution).”*

There were also several observations regarding how involved patients can be with the wearables and enjoy seeing data as evidence of their condition. For instance Jan points out:

*“Some patients are very intense. So they do measure it three times a day, during weeks every day, and others do it just once a week and others do it once a month.”*

With this information comes the question: how do patients perceive this data? Why they enjoy checking it? In which manner the level of comprehension of the generated data influences the experience?

Frequent measurements can be taken in a healthy way. However, some patients can develop a relationship with self-tracking based on anxiety. The appearance of the devices may reinforce the connection between self-monitoring and having a health problem. For example, Max notices that the most accurate wearables often look like medical devices. In this way, they can be associated with a poor health condition and stigmatize the patient. Furthermore, some patients may associate self-tracking with being sick.

*“So in some cases, they (the patients) had to do a lot of measurements, even when they were feeling good. Then they*

*were thinking ‘Oh, now I do some measurements again, and measurements are related to my sickness and hospital.’”*

In a similar manner, Paul explains his concerns on healthy people using self-monitoring devices:

*“I would be very reluctant to use kind of devices in healthy people actually. (...) So then you have some increasing and anxiety and everything you need to go to a doctor and your health care of your health and change your quality of life is actually declining by that kind of stuff. So I think that's a very important thing to acknowledge with the health and with devices. Yeah, it's not only bringing good to patients, but also a burden.”*

As it is possible to notice, there were several concerns and assumptions stated regarding patients using wearables. This reinforces how self-tracking practices should not be pushed towards users, but a decision based on voluntariness. Such assumptions were further investigated with the Design cohort who performed a trial (See section 3.4).

#### **Challenges: The 'side-effects' of dealing with self-generated data**

The involvement of patients with wearables, as noticed in the previous quote by Jan, and the way and how frequently

they take their measurements leads to several challenges in incorporating wearables in a care flow.

Ruben describes that is challenging to deal with the possibility of having soo much data, given the fact that there is not an existing protocol to deal with it.

*“We don't know what to do with all those measurements yet.”*

Sophie describes how difficult it might be to scale up the use of mHealth and self-monitoring. She reflects on her own routine as a nurse:

*“I think you need a whole job for that. I always joke that I imagine it like a computer room with screens, like an air traffic monitoring setup. And we are sitting there looking at the patients ‘Oh, nice! He's doing well!’.”*

There is also a present challenge in terms of trust in how the patient is performing the measurement. Max voices this concern in the following quote:

*“The provider, the health care provider often used uses his own measurements, because you know, he knows it's a reliable one or if the measurements situation is correct. Like, if he has his two feet on the ground. But he doesn't know that about the measurement the patient made at home. So it's **there's not really a trust in in the data provided by the patients.**”*

Based on this quote it is possible to ask, when self-tracked data is taken to a doctor's office, can such data become a source of disappointment in the relationship between patients and healthcare providers?

Another point that affects the trust in the measurements and makes its interpretation challenging, is lack of context input, as Paul points out :

“There can be many reasons why blood pressure is high in patients. Maybe one has some anxiety attack, or maybe he's stressed, he had a busy day. Then, the other one is pretty low. It can be because he's relaxed or because he's just low on the fluid intake. So *the data burden comes also some insecurities in its interpretation.*”

In this manner, if patients are relying in healthcare providers as health experts, how they perceive such insecurity when they are looking for reassurance?

Jan describes his doubts and lack of trust regarding the data. when a patient brings a list of measurements performed at home:

“And as a clinician, I wonder if all those devices are really reliable... I mean, there are different producers, different vendors, brands... but are they all comparable? That's a big question. So if, someone provides the value, is it really the value?”

In this manner, if the healthcare providers are the experts in healthcare, who should be the expert on advising the choice of healthcare devices? Are healthcare providers willing to take such task and responsibility?

#### Maneuvering data: When data becomes a fragile and sensitive material

Some concerns regarding data management involve its possible commercial use by companies (See Chapter 67). As stated before, some healthcare professionals feel responsible to help patients who self-monitor. This can touch upon recommending a device for the patient to perform self-monitoring. Consequently, this also implies responsibility on how the data is being used. Max explained this concern:

“I already spoke with a lot of hospitals in the Netherlands and also outside, about this problem with for instance, physical activity. How do we measure it accurately? (...) we get it in the hospital without using a Fitbit, which is like the most accurate and reliable device, it also looks nice, which is important for the patient. But there's a problem, if you use Fitbit, then you're actually sending patient data to the U.S., with different

legislation. That's something that we will well, hospitals are not really keen on doing that. ”

“If the data is from the patients, yeah, then it doesn't really have to be that secure. Because, otherwise, maybe, you would use Fitbit as well. But if you use officially if you use this data, in your intervention to change the diagnosis, and to change your, your treatment, yeah, then it is according to the official rules, it's medical data, and then it is not allowed to have it somewhere else then on your own server.”

Jan reinforces the hospital concerns on incorporating wearables and the barriers that come with it:

“The other thing is, as a question for the hospital: do you want to be involved in things like that? So you can also say, leave it to the patient and say, well, you choose whatever you want and you show me only the values. But then you have the question of reliability and multiple devices.”

Paul reinforced how being able to store the contextual information would be valuable:

“It really depends on what this really means. Well, 170, over 90, maybe is a bit high for a marathon Walker, let's say. But you know, it really comes all together when you can answer. 'What does the patient doing at the time?' Yes, you really need that.”

#### Shaping data into benefits

All the interviewees have agreed that wearables can bring several advantages to healthcare in the sense of helping patients to carry self-monitoring practices. There was an overall consensus regarding how wearables might be able to empower patients, avoid hospitalizations and help them to become more aware of their health condition. Paul explains one of the advantages:

“Let's say we have a young patient who has some risk factors, which you can work on, but it's perfectly healthy another way. Maybe it's good to give them a blood pressure monitor and say, Hey, every three, four months, you have some measurements, and we check it and when it's okay, you can stay at home, you don't need to come to the hospital just do that.”

He also exemplifies how that could impact on his own job, in terms of opening opportunities for better care:

“So with everything we do, if you measure it, it can have a positive effect, because we know more about it. We know how we can better apply certain strategies, like 'okay, the blood pressure is rising.' Maybe we should intervene. Maybe should give some more medication, or just ask the patient 'Hey, what's going on?'”

For example, Sophie has described herself as skeptical when she started to use mHealth and work with patients

who are performing self-measurements. However, she tells that today she is very enthusiastic about this practice mainly because she has identified how it has benefited the patients.

*“I see it (telemedicine) as helping people ... I was skeptical at the beginning. But when I see what it brings them, and how happy they are, they are not having to come so frequently to the hospital... That’s also better care.”*

#### Data as a side-effects causing element

The perceived disadvantages were mostly related to the previously stated challenges. However, there was also a concern regarding the appearance of the wearables. For example, Max notices that the most accurate wearables often look like medical devices. In this way, they can be associated with a poor health condition and stigmatize the patient. There is also the problem of the association between performing measurements and a poor health condition.

*“So in some cases, they (the patients) had to do a lot of measurements, even when they were feeling good. Then they were thinking ‘Oh, now I do some measurements again, and measurements are related to my sickness and hospital.’”*

In a similar manner, Paul explains his concerns on healthy people using self-monitoring devices:

*“I would be very reluctant to use kind of devices in healthy people actually. (...) So then you have some increasing and anxiety and everything you need to go to a doctor and your health care of your your health and change your quality of life is actually declining by that kind of stuff. So I think that’s a very important thing to acknowledge with the health and with devices. Yeah, it’s not only bringing good to patients, but also a burden.”*

As it is possible to notice, there several benefits and concerns were stated regarding patients using wearables. These statements have inspired the plan of the generative session, in special the exercises that regarded reflections, in the section "Designer cohort’s self-tracking trial" (See page 123).

Table 5 - Key findings from each cluster

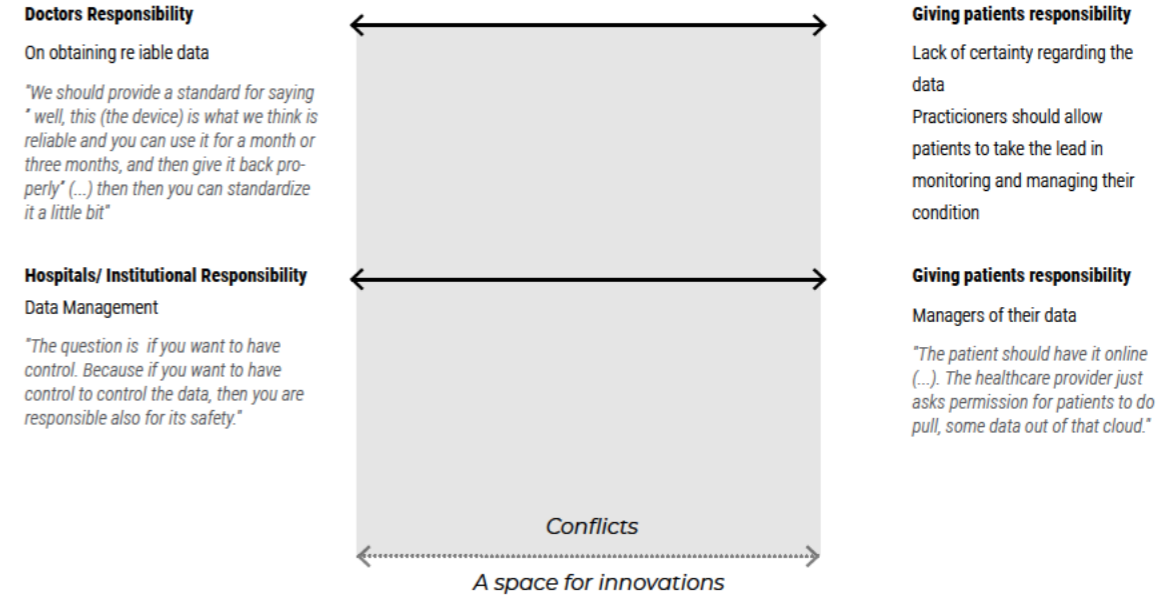
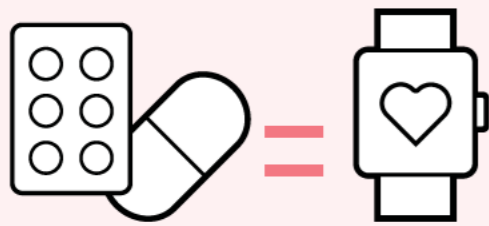
Cluster	Description	Example
<b>Desires: Visions about shaping patient-generated data into healthcare benefits</b>	Data enabling evidence-based medicine	“In two years, it would be nice to look back and say, Well, I made that decision because of these values.”
	Data should be put in context in order to become meaningful information.	“ I want a solution that connects me with patients, not with data.”
	Data enabling a population overview and prevention.	“I imagine how valuable it would be a group of 10,000 patients wearing it. (...). Then you would be able to see this kind of patterns in heart rate, blood pressures, and prognostic for cardiac problems”.
<b>Shared- Responsibility</b>	Responsibility enables empowerment.	“So the discipline is important in terms of responsibility, but it can also be held by tools, which helps remind you.”
	Healthcare providers as instructors	“The healthcare providers should be the one elaborating this (the plan involving the wearable and the data collection) and telling them, the patient, that it is very important to have accurate data to have an accurate measurement.”

<b>Roles: How dealing with patient generated data impacts on the professional parts and tasks.</b>	Patients are changing their attitude	"The patient really wants more stuff from us (...) they have a very good opinion about because they can Google it because they can look it up." (...)
	Healthcare providers as empathic partners	"The health care provider has to facilitate that it is possible to perform accurate measurements."
<b>Patients' Profiles: Perceived use of the data by patients</b>	Some patients feel anxious when seeing their own data	"There are some patients, which are always sort of busy with their health. They are so focused on their measurements, and always sort of busy with their health they're more worried about their measurements, then they should be"
	Patients enjoy seeing their data and incorporate data collection into their routine	"Some patients are very intense. So they do measure it three times a day, during weeks every day, and others do it just once a week and others do it once a month."
<b>Challenges: When data as becomes a burden</b>	There is a lack of protocol on how to deal with wearable generated data	"We don't know what to do with all those measurements yet."
	Too much focus on data may undermine the relationship with patients.	"I think you need a whole job for that. I always joke that I imagine it like a computer room with screens, like an air traffic monitoring setup. And we are sitting there looking at the patients 'Oh, nice! He's doing well!'"
	The lack of context can make data a burden	"There can be many reasons why blood pressure is high in patients. So the data burden comes also with some insecurity in its interpretation."

<b>Shaping data into benefits</b>	Data can enable a better overview of the patient and better conditions for interventions.	"if you measure it, it can have a positive effect, because we know more about it. We know how we can better apply certain strategies, like 'okay, the blood pressure is rising.' Maybe we should intervene"
	Technology can shape data into a better quality of life enabler for patients.	"I see it (telemedicine for monitoring patients' data) as helping people ... I was skeptical at the beginning. But when I see what it brings them, and how happy they are, they are not having to come so frequently to the hospital... That's also better care."
	The lack of context can make data a burden	"There can be many reasons why blood pressure is high in patients. So the data burden comes also with some insecurity in its interpretation."

**KEY TAKE-AWAYS**

1. There are conflicts and dilemmas involving using self-generated data for medical purposes .
2. Trust is a value that enables practitioners to use personal-generated data.
3. Advising the use of the wearable feels like prescribing a medicine: Doctors do not feel comfortable about "prescribing" the use of a wearables, the lack of transparency on how the data is dealt with plays an important and it is perceived as a "Side effects".



**Where can Trust be found in this context?**

*"...those are relations of trust. You can use different methods, but this should be a relation of trust." (Jan)*

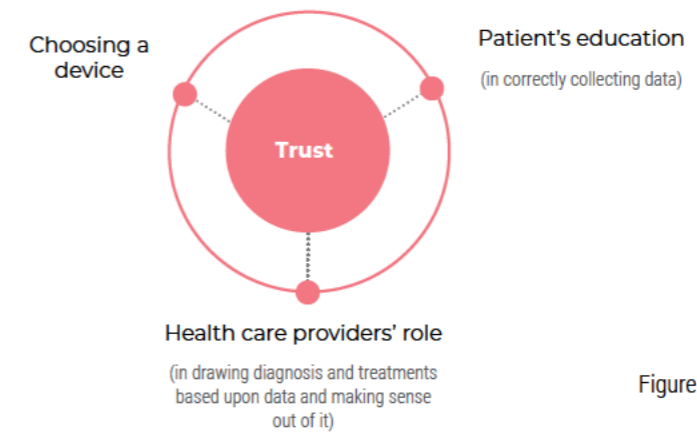


Figure 14 - Identified conflicts and the role of trust..

## EMPATHIZING WITH THE USERS

To empathize with the users, the findings were framed into personas. As a second step, the identified benefits (Gains) and hassles (Pains) were framed.

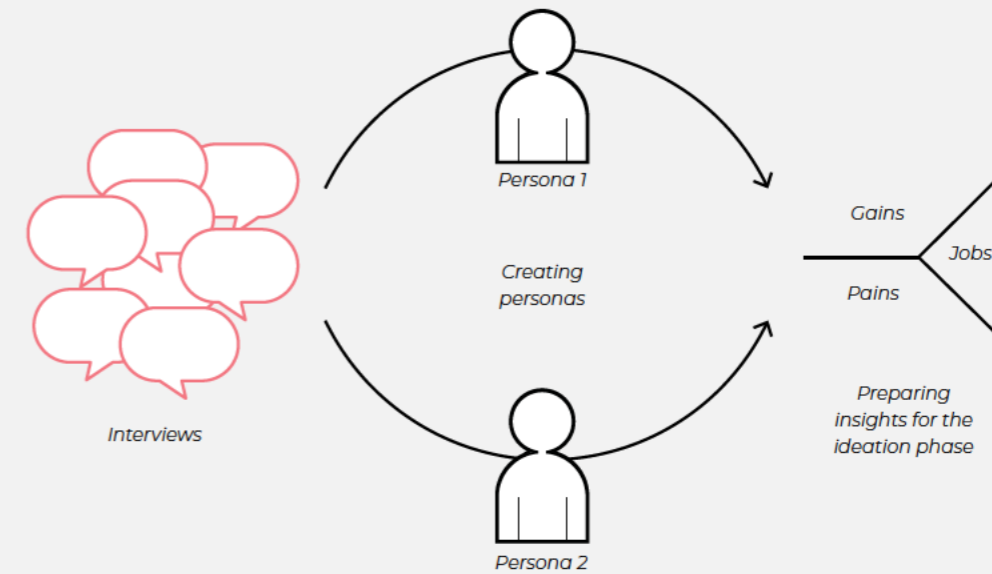
### SETTING THE GROUND FOR THE IDEATION PHASE

The insights were organized in terms of jobs, pains and gains (Osterwalder, Pigneur, Bernarda, & Smith, 2014) as it can be seen on the Figure 6. This framework was used to summarize the findings of the research done with this cohort and prepare it for the ideation phase. In this context:

**Jobs:** refer to tasks that the users want to accomplish, the problems they want to solve or their needs they are trying to satisfy. These "jobs" can have a social or even an emotional function to these personas.

**The Pains:** This section refers to anything that annoys the customers when they are trying to get their job done. Examples are possible identified risks, unpleasant situations that are perceived when they are trying to accomplish a task. For example, when wearables that measure blood pressure are widely available, there might be a data overload for the healthcare professional to look at.

**The Gains:** This describes the benefits that were perceived in the situations of sharing responsibilities, possible benefits perceived on using wearable's data during their practice and also desires that were mentioned, like, for example improving patients adherence.





## The researcher: Simone, 38 years | Cardiologist

### Actions

She always educates patients regarding the measured data. She believes that most of them feel more empowered once they can self-monitor themselves.

She educates patients and believe that, once they have enough information they can take more responsibility regarding their decisions.

She keeps in touch with her patients, however she tries to avoid being intrusive when it comes to propose an intervention

### Conflicts

Although she thinks self-tracking can benefit patients, she does not want to push them into it. Especially because the most reliable devices, are those who look more as a device for someone who is sick. She also don't want to push patients into providing data for commercial purposes just for the sake of generating data.

### Dreams

She dreams about using data of several patients for improving patients lives in a broad scale. She aims to find patterns that can prevent certain cardiopathies before they occur.

She dreams about seeing patients more aware regarding self-tracking devices and their data privacy issues and educated to perform measurements in a reliable way.

### Fears

Not being able to overcome the obstacles to use data for a greater good, such as the lack of unified records in hospitals or a lack of manners to access patients' data.

Seeing data being used for commercial purposes but not for improving lives.



## The rapport doctor: Joseph, 36 years | Cardiologist

### Actions

He believes that responsibility enables empowerment, but that he needs to provide a feeling of security towards his patients.

Therefore, he periodically gets in touch with his patients to have a talk in person, by phone or through skype.

He is also always available on his phone, in case a patient finds himself into trouble. He is always willing to clarify questions regarding health data.

To tries to organize his time to balance personal contact with patients and computer and long distance monitor time.

### Dreams

He dreams about using eHealth to make treatments more efficient and more personalized.

He dreams about a technology that can provide easy ways to visualize data and its context.

### Fears

Spending too much time on the computer analysing data.

Shifting the focus from context to data.

Analysis replacing contact with patients.

Data being used for commercial purposes but not for

at, if eHealth technologies can keep  
tor in healthcare, they will always  
ient. However, he is afraid that the  
generate data, the more time will be  
outer and less on seeing patients in





### 3.3. Interview with Designers for healthcare

*The interview carried with this cohort aimed to provide reflections and further insights on how designers may deal with data as a material. In which manners can designing with data lead towards innovative solutions in the healthcare domain.*

Two professionals involved in designing for healthcare have been interviewed at their workplace. The first professional will be referred as Emma, a design researcher and the second one as Adrian, a data designer. Both of them are very experienced in research projects involving healthcare, design and data. In this sense, the main goal of this interview was collecting insights regarding how to design systems that use data and collect experiences, fueling the ideation and conceptualization stages of this thesis, and

insights to shape the study with the Designers cohort and data collection from the Quantified-Self forum.

## THE INTERVIEW

The contact with these professionals was made by email and they were asked to choose a day and a location for an hour interview take place. Both of them agreed upon having the interview done at their workplace.

An semi-structured interview guide was designed (Patton, 2002) and four main areas were covered, as the plan bellow (Table X - Main questions and topics covered in the Designers for healthcare interview) shows.

Table 6 - **Main questions and topics covered in the Designers for healthcare interview**

Topic	Questions	Possible follow up questions
<b>Introduction and presentation of the Informed Consent Form</b> +/- 5 min	Do you have any questions about how the data of this interview will be used?	Do you identify any risk that was not mentioned in the information sheet?
	Do you have any questions about the goal of this interview?	Do you want to receive the final outcomes of this thesis?
<b>Experiences in the field</b> +/- 20min	Please talk more about your experience working in design projects for healthcare.	Is there anything curious that you remember regarding a user?
		How would you describe your role in a project, besides the obvious researcher one?
	How do you use data as a creative material in research?	How do you bring quantitative and qualitative data together in the projects?
		How do move from data collection to a design intervention?
		How do you communicate an evergreen design during a research project?

<b>Data as a human portrait</b> +/- 10min	In which ways do you think data can tell something about the users?	How do see users attributing meaning to the collected data?
		What is the role of the tone of voice, when telling a story based on collected data?
		Could you provide an example?
<b>Data and healthcare</b> +/- 15min	Patients are usually quite receptive to e-health technologies. However, we can't say the same on the side of the hospitals. Why do you think this happens?	What are the main barriers that you perceived?
		How do you see this scenario changing?
		In which way do believe having a more collaborative attitude is possible?
		In which way do you picture this information getting to your office?
		Would you feel reluctant about asking for this information?
		Who should request to view the information?
		Who should be able to edit it?
<b>Ethics</b> +/- 10 min	What do think are the main ethic concerns for designers working with data?	Have you come across a difficult situation in any project?
		How do you deal with unexpected ethical conflicts that may arouse in exploratory studies?

## ANALYSIS

In a similar fashion to the process used in the Healthcare Experts cohort (see page 94), the interview was transcribed, interpreted and the main identified themes were, then, clustered. However, the focus of this interview was not in understanding a group of users, but to collect practical experiences and insights that could offer the researcher a possibility to reflect of how to design with data.

## RESULTS

The interview has resulted in insights for the Ideation phase and also has validated some previous conclusions from the interview with the healthcare experts. The most relevant topics covered are the following ones:

### From data towards meaning

One interesting fact stated by Adrian was how each study contributes to the next one within the team. This resonates with the practices observed in the Quantified-Self forum where the participants were exchanging knowledge regarding their personal experiments.

*“Different studies can build upon each other, not for participants, but in terms of the tools used by the team.”*

### Trust in a company

When interviewing healthcare experts, there was a lack of trust in the role of commercial companies. However, Adrian and Emma stressed how the company can be present in the whole health continuum in a way that there is an established relationship with the patient.

*“We already have a relationship with the patient. Some babies already start with the baby bottle from us. And then you just move all the way towards meeting the health care provider who is using our tools to do to do the diagnosis and treatment.”*

This has provided insight that a brand that is well established as a trusted brand in healthcare can overcome some concerns regarding the use of data for commercial purposes as stated by the healthcare experts during the interviews.

### Barriers in the healthcare domain

Adrian described how doctors can be conservative when dealing with data. He described one of the frequent problems that he has seen when working with data generated by devices regarding sleep monitoring.

*“It's very easy for the professional to say the device is not at all accurate. (...). So if I give them a sleeper stage data and they will be like 'no, but the Fitbit is for sure not accurate, the patient needs to sleep one day in the hospital. And that's going to be the most accurate night that we can'. Although it's not per se, because you are in a hospital, and that's not really the actual thing that you want to measure. But still, they will omit all the data that's collected at home. Yeah, so very conservative way of saying”*

Emma added her view on how the lack of an infrastructure to work with data in healthcare is a barrier to the use of data and the possibilities that this opens for collaboration with companies specialized in data and healthcare:

*“Nobody really knows how to deal with it. There's no position to cover it. So there's not a role in the hospital that really like*

*is dedicated to that (analyzing data or supporting patients self-generated data). And because you are dealing with life, the physical and mental health of people, you cannot make a mistake.” (...)* *“I think it's really valuable that we as a company also collaborate with them, you know, create and innovate together because we can facilitate them with all the technical stuff.”*

In this case, the company can become a trusted partner that enables innovative solutions to be safely implemented.

### Data, devices and healthcare professionals as partners

Emma points out how healthcare professionals can be hesitant regarding digital solutions until they perceive the technology as a partner that can help them to perform their work in a better way.

*“So, you know, we are transforming the pathology, like the microscopes. We have now a new business. The pathologists in the U.S., some of them were like, fairly, like hesitant about that, like, 'Oh, my God, this is a digital thing and it's gonna do all sorts of analysis on the tissue, I'm going to be replaced',. No, that's not the case at all. It's about making their life like, easier, nicer, and they can do better diagnosis. People are hesitant, but then you see what it delivers and helps them to give better care”*

This resonates with Sophie's experience with mHealth, described in the analysis of the Healthcare Experts

interviews. Although she never felt the fear of being replaced, she described herself as highly skeptical at the beginning and now, an enthusiast of long-distance monitoring.

Adrian pointed out how valuable collaboration with healthcare professionals is in order to give meaning to the data. As he describes a situation that involved the collection of the heart rate during a study:

*“That was something which we were not looking for yet. But then, the expert was directly telling us the meaning of that data. That directly changed our research and how we started dealing with the participants.” (...) “So we really needed this collaboration. Because without, let’s say, the domain knowledge, we wouldn’t be able to deliver the content in a good way.”*

Emma added how a service like a bot could even reinforce the role of a healthcare expert.

*“The bot could play the bad cop and the doctor the good cop.”*

### Data explorations

Emma also added how they had structured workshops in which the data had been pre-processed and then showed to the healthcare professionals. In such studies, there was

data about walking a dog, opening candy bars among other types of data. At first glance, it could be seen as useless data, however, the researchers were able to use it to open conversation about the context of the participants involved. In this sense, Adrian and Emma have described how data could be used to create conversation, create meaning and foster collaboration with different professionals.

They have described how the questions were done regarding the data and how it was explored in different manners. This added valuable insight to vision in which it would be possible to allow the owner of the data to play with it and visualize it in different manners in a collaborative way with a healthcare expert.

### Tone of voice

When asked about the role of the tone of voice of a system, both Emma and Adrian agreed how it has to be adapted during the use. For example, Emma stated

*“Sometimes a participant would say that she would prefer a certain tone of voice and we would design a system like that. then we would hear feedback like ‘I find it annoying’(...) “ It is definitely far from a black and white decision”*

### Ethical conflicts

Emma and Adrian argue that everyone involved in a data system should be aware of the ethics involved. Furthermore, they add how regulation committees cannot foresee all kinds of ethical conflicts that an innovative system may bring. Therefore, the designer has to be committed to ethics in the use of data.

Emma illustrates the situation with an example of a study carried with a family that has revealed that, when the children were left with the father, they were not brushing their teeth as the mother had asked the father to do. Revealing this information to the participant family would bring the discussion among the parents and the children would feel surveilled. If that was not the point of the study, it was not a role of the researchers to bring about this conversation.

*The gathered data can lead to unforeseen ethical dilemmas for designers and researchers. There is not a manual to deal with such issues.*

#### KEY TAKEAWAYS

*for reflecting as a designer*

The interview with professionals who participate in the design of personal data-based solutions for healthcare has revealed interesting insights regarding the roles of researchers and designers. Personal data is highly sensitive as well as the insights that it can reveal. Therefore, participants need to trust that the data they are providing will be used exactly for the purposes that they expect. Furthermore, dealing with personal data implies facing unexpected ethical conflicts. There are no clear rules on how to proceed. Thus, designers need to develop a good sense of ethics to deal with such challenges and discuss such conflicts. As a consequence, this interview has raised the attention given to trust and transparency in the conceptualization phase of this work.

## 3.4. Designer cohort's **self-tracking trial**

*This section describes a study carried on with participants who wore two self-tracking devices and provided insights regarding their experiences.*

A two weeks trial of two devices, A Fitbit Charger HR3 and A Omron Intelli IT was carried with 8 designers as participants. The goal was to see in which ways they would use the wearables, how they would perceive their relation with self-tracking, what kind of conclusions they could draw based on tracking their own data and if they would notice small changes in their routines caused by their interaction with the wearables. The main inspiration for this study was the literature review on self-tracking (see 37) and self-experiments (See page 52) previously discussed.

*In which ways they would the participants use the wearables and attribute roles to them?*

*How the experience of self-tracking is perceived?*

*Can the experience be framed in stages (See page 60)? If so, how which insights can be drawn on each one of them?*

*What kind of ideas and ambitions the participants express based on their contact with self-generated data?*

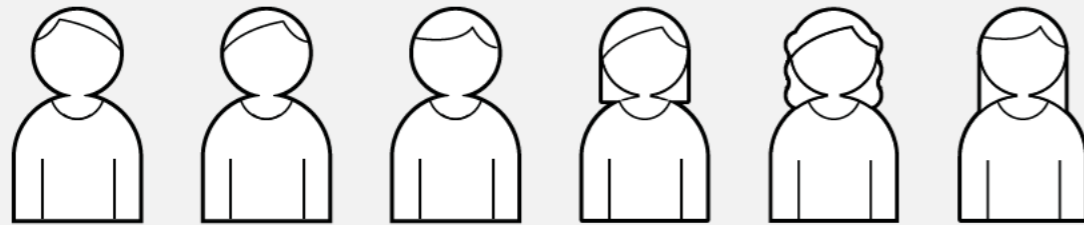
## SELECTING THE PARTICIPANTS

The participants selected were all master students from the Faculty of Industrial Design at Technique University of Delft aged between 24 and 29 years old. The criteria were to be familiar with smart technologies, to be unfamiliar with using self-tracking wearables and have previous experience with the structure of a scientific research. In addition, in order to participate, the participants were asked to return the devices by the end of the trial, performing the

measurements according to the instructions provided and filling in a booklet and be available for joining a three hours generative session (Sanders & Stappers, 2012) or a thirty minutes long interview in person after the two week trial, in case joining the generative session was not possible or in case the participant did not feel comfortable to expose his opinion in front of a bigger group.

## The participants

Eight design master students  
(4 females and 4 males)  
Aged between 24 and 29 year-old



## The structure of the trial

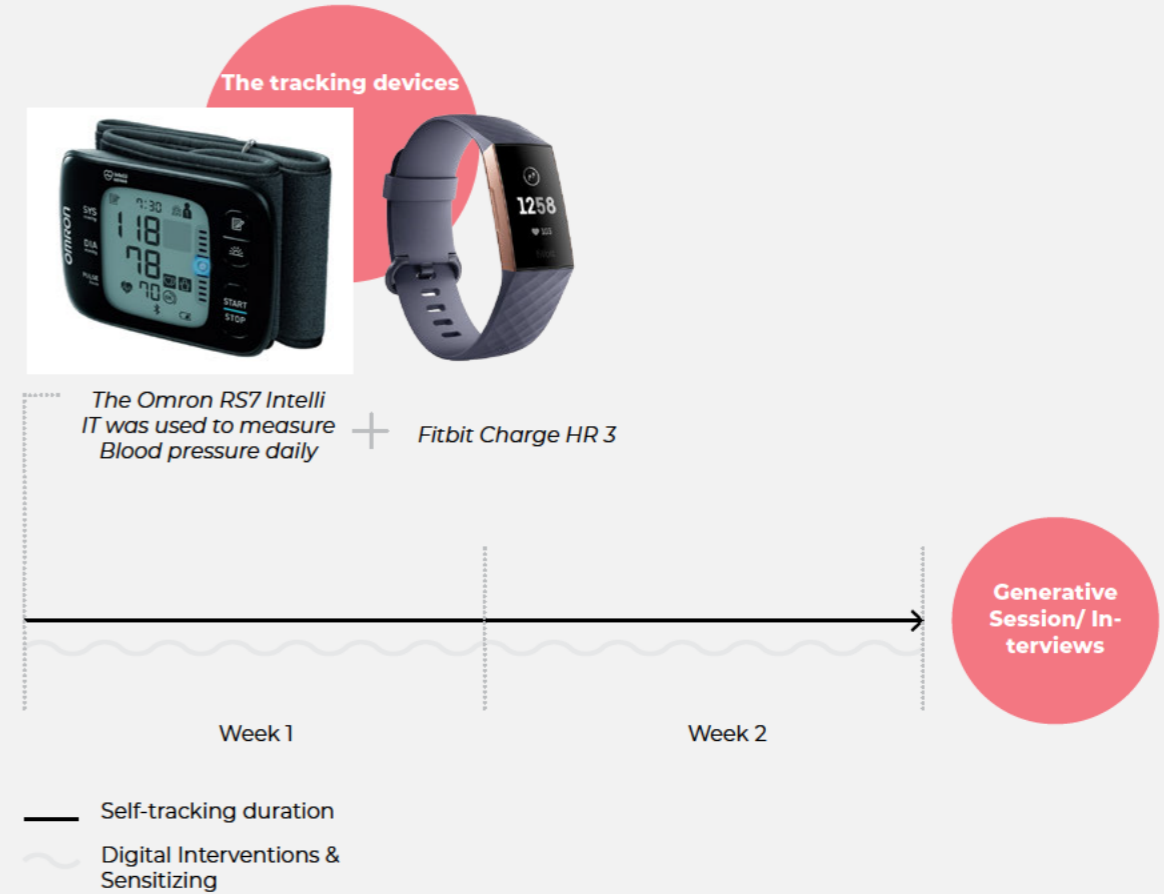
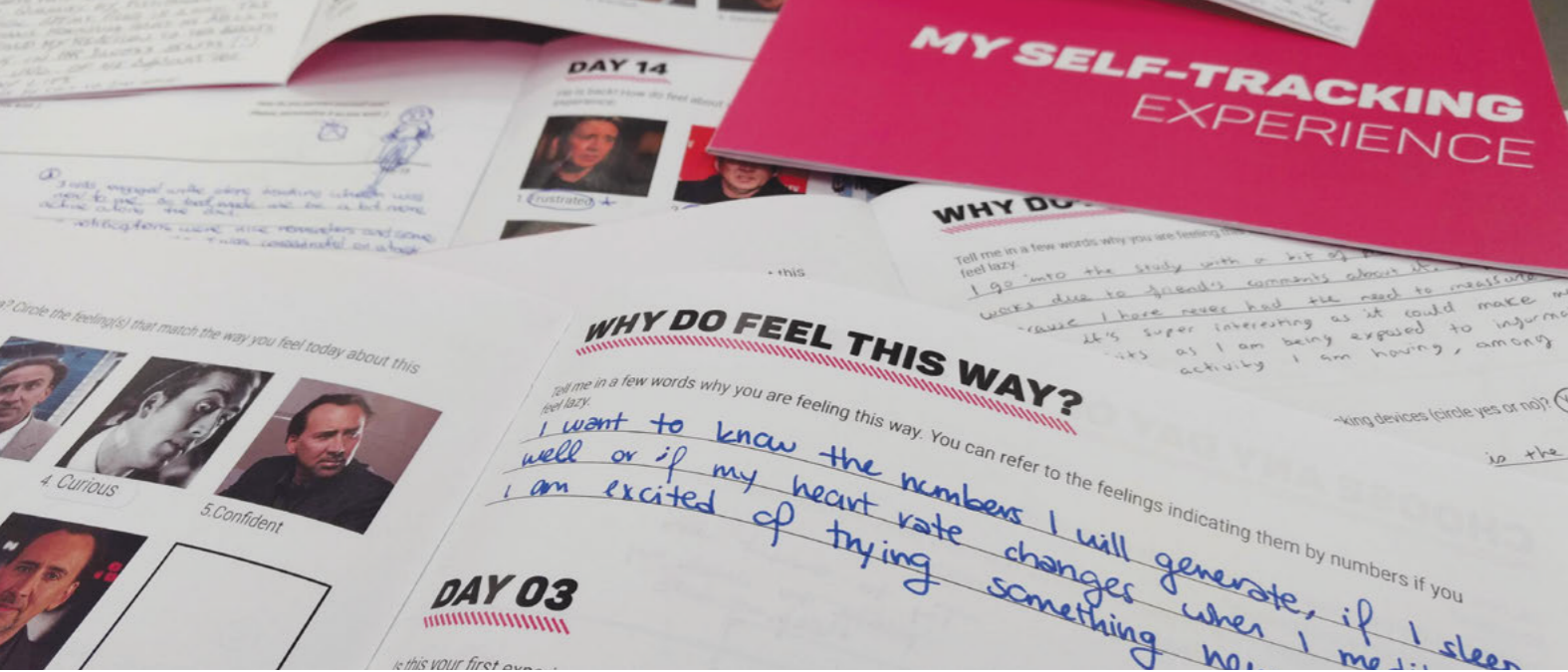


Figure 15 - An overview of the Trial structure.



## SENSITIZING PARTICIPANTS

A booklet was designed in order to provide basic instructions to the participants and sensitize them regarding the topics that the session or the interview would touch upon. The first section of the booklet presented basic information regarding how to correctly perform the Blood Pressure measurements and how to pair the devices with the manufacture's app. The participants were given full freedom to personalize their devices, changing their interfaces. In addition; the material has been designed using a playful tone of voice in order to be used as an ice-breaker during the generative session and help the participants to feel comfortable to expose their opinions regarding their experience with self-tracking.

## INTERVENTIONS DURING THE TRIAL

During the two-weeks trial (see Figure 15) some interventions through the cellphone application WhatsApp have been planned. The goal was to encourage the participants to share their insights during the experience instead of only reflecting on them at the end of the two weeks during the generative session or the interview. In addition, this has opened space for participants to contribute with findings that were relevant to their experience but could be forgotten to be shared in a bigger group discussion. The Table 7 shows the planned interventions.

Table 7 Plan of Interventions during the trial

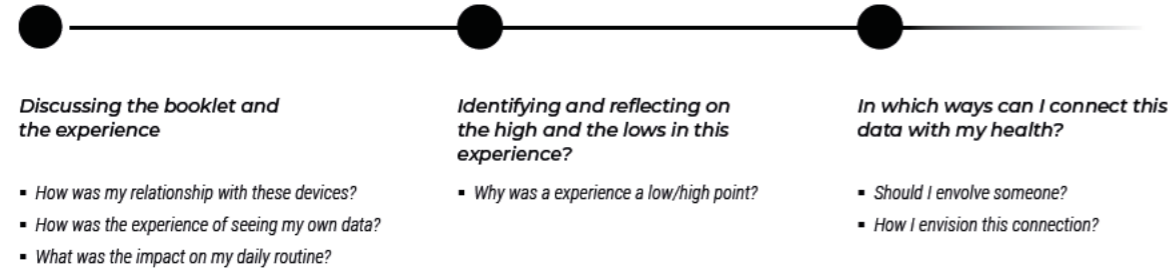
Day	Topic	Questions/WhatsApp interventions
1	Preparation – Setting up the devices	
3	Checking if the setting has been successful.	Have you been able to measure your Blood pressure?  Could you pair the devices with your smartphone?  Ask about any data that they would like to share it.
5	End of the first week trial – Reinforce the request of filling in the booklet.	Please, don't forget to fill in the questions on the booklet.
7	Checking what the participants are changing anything on their routine due to this experiment.	You have just completed the first week of this trial. How are you feeling about it?  Have you changed anything about your behavior because of these devices? Could you tell me more about it?
8	Ask if the participants have anything interesting to share regarding the collected data and why.	How is it going? Did you find something interesting during the last days that you would like to share?
9	Double check the interview day and hour	
11	Reinforce the request to fill in the booklet	
13	Returning the devices	Tomorrow we will meet at the room XX. Please don't forget to bring: <ul style="list-style-type: none"> <li>· The booklet</li> <li>· The Fitbit and its charger</li> <li>· The Omron device</li> <li>· The devices' boxes.</li> </ul>
14	Interview day – send the location again	



## THE GENERATIVE SESSION PLANNING

The generative session was planned in order to cover three main aspects as it is shown on the graph below:

Two participants (Manuela and Daniel) could not join the sessions and were interviewed individually.



## RESULTS

This session involves the information collected during the trial and the generative session.

### Overall experience

Most participants reported feeling curious and excited at the beginning of the experiments. At the end of it, they reported feeling suspicious and curious about some findings showed in the data. In addition, all of them really enjoyed the experience of wearing the Fitbit and reported that they would like to wear it for a longer period of time.

### Data as a social material

During the two week trial, Bart invited other participants to join a competition on Fitbit. One of the invited participants, Liza, decided to not join such competition. She felt like it could draw too much attention for achievements in the Fitbit app in a moment that she was under a heavier workload, due to her work on her thesis. This competition has fostered some playful social interactions between the participants, as Figure 16 shows.

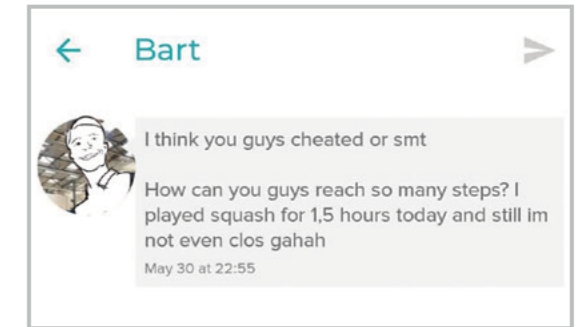
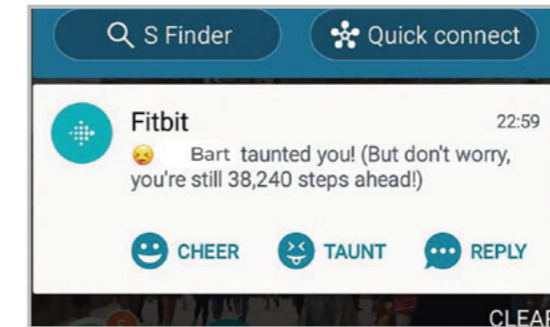


Figure 16 - The screens shared by participants show examples of playful interactions based on data.

## The roles of the devices

The examples on Figure 16 show an use of the Fitbit that can be associated with the Toy role (See page 46). In general, the participants have reported enjoying using the Fitbit and found it easy to incorporate the use of the device in their routine. Conversely, the participants did not feel the same way regarding the Omron device. All of them, with the exception of Liza, have reported that they kept forgetting to perform the measurements, even when they were setting alarms to remember. During the trial, Maria sent an audio message to the researcher reflecting on the reason why she kept forgetting.

*"I have been trying to incorporate the Blood Pressure measurement on my routine, but I keep forgetting it. I think is because I don't have any problem with that and it gives me an isolated data that is there on a different app."*

Liza took the Omron in a boat trip and she told the group how funny the experience was."

*"The Omron catches a lot more attention. I brought the Omron with me during a boat trip, because I am a really good participant (...) then everyone was looking at me with a face like "what are you doing?" (...) People got curious and asked me if they could try it as well. So all of a sudden I was measuring the blood pressure of pretty much everyone around. It was kind of funny."*

Manuela also reported how the device sparked curiosity around her.

*"I took it to the work. During two weeks I was taking the measurements and people were looking at me, probably thinking 'wow this poor girl has a serious issue'. They didn't asked me about what I was doing and I felt like it was because they assumed I actually had a health problem."*

In this manner, it becomes clear that a device can make the user feel stigmatized. In the Fitbit case, the only one who reported a feeling of stigma was Bart:

*"I feel like people who wear Fitbit are usually neurotic."*

Some roles of the devices have been identified. For example, Maria has valued the role of Tutor (Lyll & Robards, 2018) provided by the application associated with the devices and May has reported that the fitbit provided him with some advices regarding his sleep.

*"Add the beginning I've felt a bit lost, but when you download the apps and it tells you what you have to do it helps you to do pair it and take the measurements."*

*"I did get some advice from the app. It says that my sleep quality is pretty low, especially for the deep sleep. Then it says "you might get something like yoga to increase your sleep quality" (...) And I felt quite annoyed of wearing this on my wrist when I was sleeping. So yesterday I took it off to sleep and it felt so relaxing."*

Some participants have synchronized several apps with the Fitbit. Bart for example, has synchronized his phone calls. So every time he was receiving a call his Fitbit would vibrate. Other also used the Fitbit as way to spend time, instead of interacting with their cellphones, in this sense, the device has assumed a Toy role (Lyll & Robards, 2018).

*"I like anything that makes me stay away from my phone for longer periods of time. Even though I am not addicted to my phone, I feel like compulsively checking somethings. And then I check this and, at the most, I can spend 2 minutes going through it."*



Figure 17 - Expressing the experience.

## Reflecting about the experience

During the second exercise, the participants were asked to personalize white balls in order to reflect their journey through the 2 weeks (Figure 17) and explain why they had done such personalization in order to foster discussions about the perceived small changes in their routine.

Lucas described the reason why his personalization had a red dot. He was quite worried about some values regarding his blood pressure at a certain moment. He and Daniel revealed an expectation of the device playing a tutor role in this case:

*“What I missed was some kind of technical support, not in using the device but regarding the meanings of my data. I didn't know if I should go to the doctor or what.” (Lucas)*

*“ sometimes you are seeing those peaks. And then you are concerned like ‘this is wrong somehow, but I'm going to do all I have to do.’ (Daniel)*

He and three other participants also reported that they felt more motivated to exercise and take the stairs in the first week.

*“I felt more motivated during the first week. I've started to run more, sometimes don't take the bike to walk more. But in the*

*second week I was much busier and I couldn't keep up with the same amount of exercise.”*

Some participants like Liza, used the device like a tool (Lyall & Robards, 2018) to exercise in the cardio zone that she was interested.

*“I didn't have this flexion between the first and the second week. (...) During the first week I was looking more at the steps and active time data, while during the second week I've started tracking my exercise in the gym. For example, it tells you when you are in the fat burning area, or when you are in the cardio (...) so I was actively checking if I was in the zone that I wanted.*

## Taking the data to a doctor

In the third exercise, the participants were asked to imagine a situation in which they would take their data to a doctor.

They were asked to think about the following aspects:

- In which situations would like to present a wearable's data to a doctor?
- How would you like data storage to look like?
- What do you expect from a physician that is looking at the data?

When reflecting on the first question, all the participants agreed upon taking the data only when they were finding a discrepant measurement repeatedly. For instance, Lucas found a high value when measuring his Blood Pressure a few times, but after a few days, the levels were back

to normal and he could not understand clearly what had happened.

*“Now that I have these doubts I would like to share it (the Blood Pressure data)”*

One participant that was not present during the session, Manuela, when interviewed and asked about the same topic added

*“I feel like if I take the data and show it my cell phone to the doctor, I would feel like someone who is paranoid. But I would like to tell her ‘ Hey I was a participant in a study and I found through Fitbit that my heart rate was too low for my age, do you think I should be worried about that?’”*

It was a common-sense among the participants that would like to show only the data that is discrepant from the average. For example, Lily explains:



*“I wouldn't like to share all my data with a doctor. If I have all my data and I am visiting the doctor for some kind of issue and he asks me questions then I can share it at that moment.”*

While Bart added:

*“If the doctor establishes what is the criteria I can share the data with the doctor without spamming him, without sharing unnecessary data. I would like to share what is “out of the normal range”*

Lucas pointed out that he would like to bring the data only when he already had specific questions.

Daniel, who was asked the same question, but in a separate interview, added that he if he was in a delicate situation regarding his health, he would give live access to the doctor or the nurse to receive any alerts regarding a “dangerous” data point.

*“I was thinking, you can share directly some readings to your GP or something. And if you are taking a specific medicine for one or two weeks, or whatever program you have, you, can temporarily guarantee their access to your data, so they can also have kind of an active reading over your measure if it points something that is really a priority, or dangerous or whatever, so then they can take action.”*

However, Liza brought to the discussion that she would like to easily share more aspects that she has tracked with other healthcare professionals as well. Something that other participants also agreed that was an interesting possibility.

*“Also, if I am going to a professional such as a nutritionist, it would be nice to have this holistic approach to health care. So if you are tracking all this data it is nice if you can share it with other professionals and they can have this overview of what is going on with you. Because the exercise you do depends on your sleep quality and so on.”*

When thinking about data storage, on question number two, most participants think about data storage integrated directly with data visualization functionality. This adds to Choe et al. (2017) argument that a system that aloud for rich data visualization and exploration supports self-trackers to draw insights about the data.

In addition, there were questions regarding the privacy of the data when using wearables. One of the interviewees, Manuela, shared an interesting statement when questioned why she did not feel uncomfortable of having Fitbit collecting her data, and why she would feel uncomfortable having her data being collected by her cellphone.

### Data as a material that needs further actions to become knowledge

For example, some participants stated that they would like to add their personal context to the data. Lily, for instance, mentioned that she would like to set her own benchmark in the app to remember that once she was looking at the data after sometime

*“I would like to set a normal day and a busy one, so I can compare what happened in a day that I considered to be busy and another one that I have considered to be normal. I may have 10.000 steps on a normal day because I went to the gym, but in another one, because I had to be in many places. If you can easily tag that, it becomes easier to remember.”*

Maria added that she would like to look at the data collected after a while and be able to see in detail the graphs and explanations of the trends in the run.

*“I want to look at the data stored and see what does that means. It would be nice to see it a bigger screen and be able to make connections between types of collected data on a bigger screen.”*

This adds up to the perception stated in the interview with design researchers ( see section 3.3) that the data can be an object of discussion. Furthermore, in the vision of the

participants, the doctor assumes the role of an expert and advisor. For example, Lily states:

*“I expect answers from a doctor, something more specific and medical.” (Lily)*

*“I expect some actionable insights coming from a doctor” (Lucas)*

*“I am thinking about my sleeping quality, it was poor. But I don't know what to do about it and I am lazy to deeply analyze my data, so I would expect the doctor to give me some advice about it.” (May)*

However, it was necessary to clarify where is the threshold between a piece of advice that can be trusted if it is given by a doctor or a bot. In order to understand this issue, the participants were asked in which situations they would trust a bot. Manuela's answer, given in a separate interview, summarizes the perceptions on this matter:

*“I think my son's pediatrician absolutely hated me because I was making all sort of questions since I was a first-time mother. I felt embarrassed about asking him so many things, but my son was a newly born, its a very fragile age.(...) I wanted to hear an answer given by an expert, I would not trust his health to a bot. But I would be fine with getting an answer from a doctor, in a trusted service, even if it was not a live interaction”*

## Privacy concerns

In general the users did not demonstrated elevated concerns regarding the privacy of their data. The informed consent stated clearly that the researcher would not see their data, since this trial's focus was on the experience of self-tracking and reflections made upon the personal data. In order to address this topic a question was made regarding the privacy: In which situations do you feel uncomfortable regarding a device tracking your data. As an answers, participants complained about some smartphones asking them about places where they had been, however no complains were made regarding Fitbit's location tracking. When asked why, Manuela's answer summarizes the overall vision on this matter.

*"I didn't buy a cellphone to track my data. I have it to communicate and I use it for other things like taking picture. So I feel invaded when I see how I am being tracked. But the Fitbit I am using to track my data, that's the purpose of the device and I don't see adds related to what I am doing popping on my browser or my phone all the time because of it. I feel like I am more in control."*

Furthermore, the participants were asked about sharing their data for research. The following answer depicts the mechanism of getting some return for sharing data. All participants were not expecting to get money for their data, but to get knowledge back. Furthermore, sharing data for research was perceived as a contribution for the "greater good".

*" I would share my data for research, but I would like to get back some understanding of the data in a way, can you use it have an impact on my health and also my performance or something So what can I change in order to reach a specific goal, understand something about my behavior, whatever. 'Okay, how does affect that?' "*

## KEY TAKEAWAYS FROM THE DESIGN COHORT TRIAL

In a nutshell, the participants have revealed several experiences that reinforce the findings from the Context research. For example, it is possible to refer back to the stages of self-experimentation, the attribution of roles to the devices and privacy concerns trends. This trial had the limitation of being restricted to two weeks, however, it has revealed several insights for the conceptualization phase of this thesis.

## FRAMING THE RESULTS AND INSIGHTS

In order to better understand the relationship of users with their generated data and the overall experience of self-tracking and reflecting on the data, the insights were organized in phases related to the previously identified steps of self-experiments (See page 60). By looking at the reflections and the generated data from the interviews and the generative session, the following phases were identified.

**Using the device as tool**

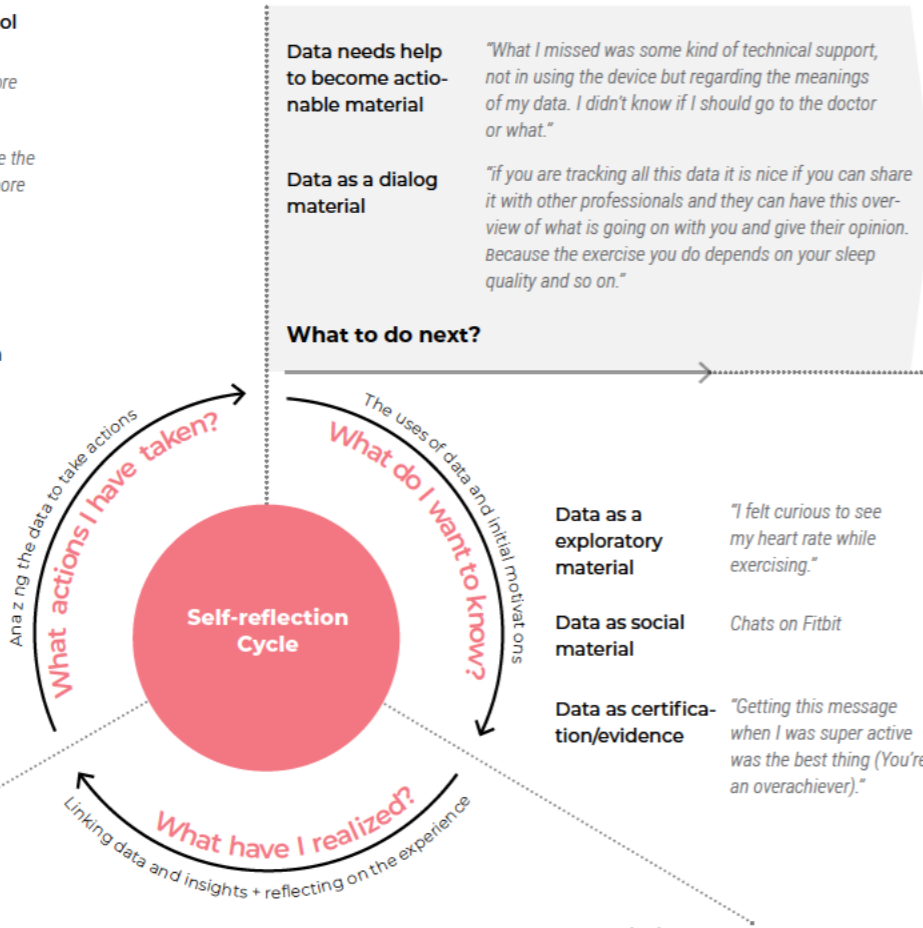
- a) I have started to walk more and take the stairs.
- b) Using the data to improve the exercise routine and gain more control over my goals.

**Evidence-based actions with nuances on motivation**

"I felt more motivated during the first week. I've started to run more and got excited to see the data, sometimes don't take the bike to walk more. But in the second week I was much busier and I couldn't keep up with the same amount of exercise."  
I could take the stairs more often.

**Data as goggles**

Using the data as goggles to see what I can not perceive.  
e.g. Sleep patterns: I don't have a good quality sleep. When I am nervous my blood pressures gets high.



**EMPATHIZING WITH THE USERS**

In a similar procedure taken with the Healthcare Experts Cohort the findings were organized into personas and, then, framed in terms of Pains and gains.

The Pains and Gains framework (see page 110) has been used in order to fuel the ideation phase and foster the identification of possible value streams.

**The focused: Laura 29 years old**

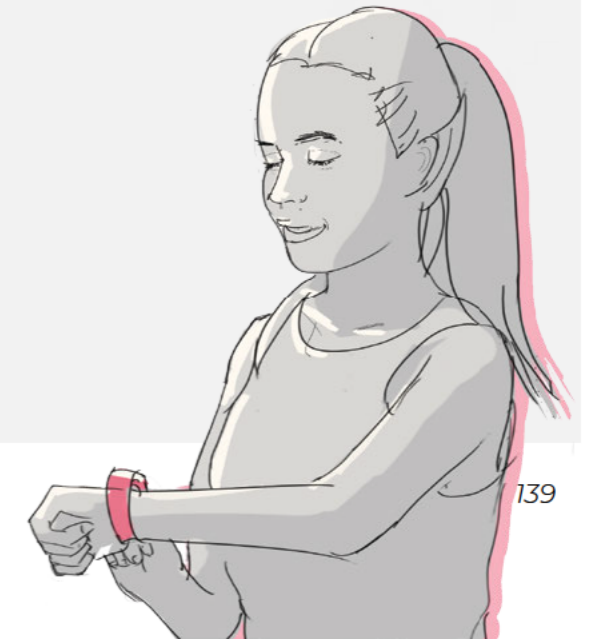
Laura is an architect. She has a very busy schedule, and, one year ago she started to exercise since she started to worry about her health and she aims to achieve a better balance between personal life and work. She likes to feel the benefits of exercising, although sometimes is hard to keep an exercise routine.

**Actions**

She decided to use a wearable as a tool to improve her performance when running. She wants to run her first marathon and she uses the device to achieve this goal.

**Conflicts**

She wants to achieve this goal, but she doesn't want to become addicted to monitoring the data instead of enjoying the running experience.



## The Social: John 28 years old

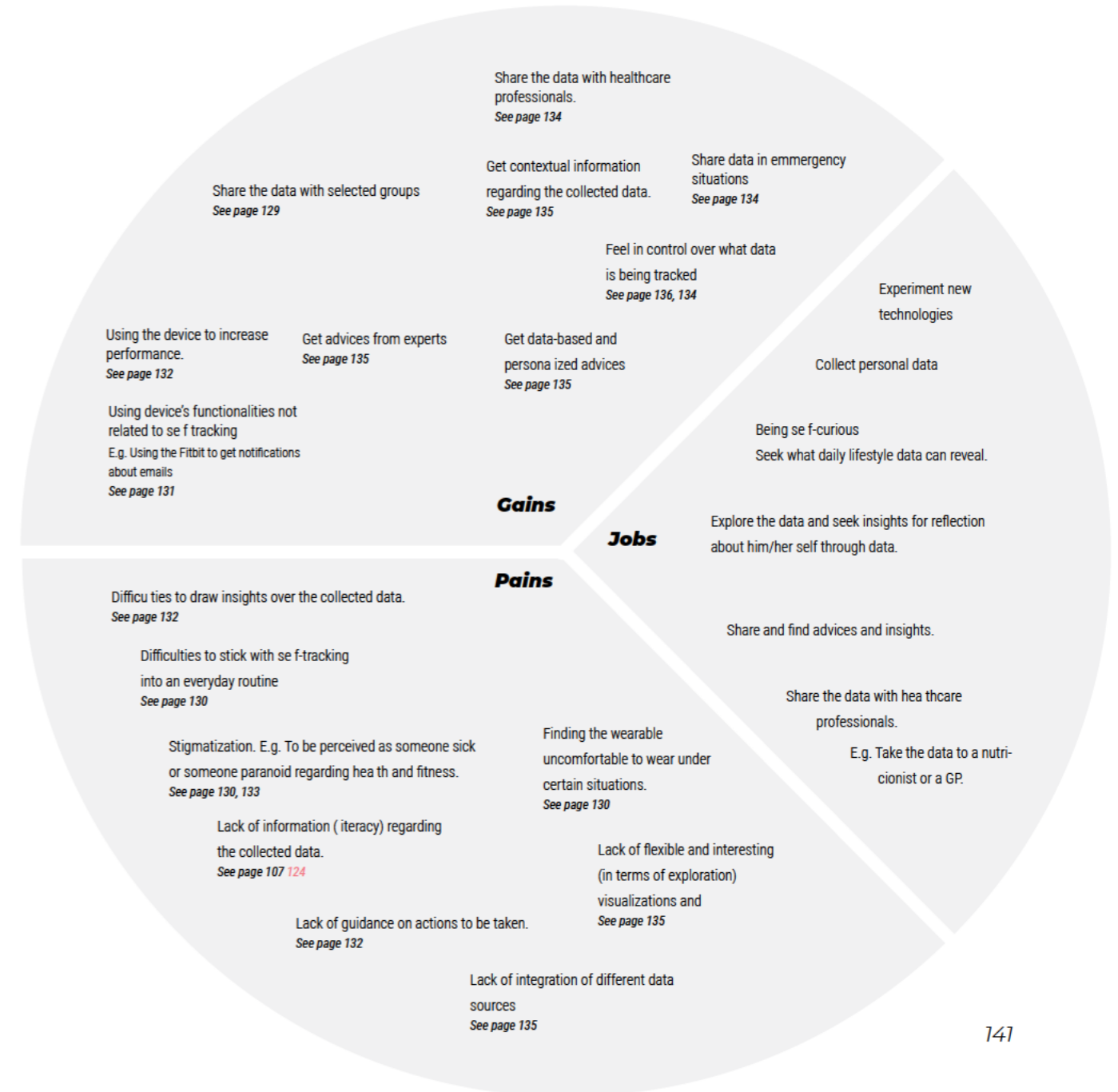
John is a journalist. He has never been into high tech gadgets, but he really appreciates technologies that facilitate communication, not only with friends, but among people in general. As a journalist, he is really interested in how different types of media impact his profession.

### Actions

He is trying to improve his Blood Pressure values since his father has hypertension and he fears that this may be related to his genes. He participates in several forums and does not mind to share his own data with strangers, but he does mind if a company uses his data for profit without his consent. By exchanging information with other people, he feels more motivated.

### Conflicts

He wants to be healthy to avoid the problems that his father had. However, he does not want to be stigmatized for self-tracking his Blood Pressure and being perceived as a "health freak" by doctors or other friends.



## 3.5. Quantified Self Cohort

*The Quantified Self is a highly online active group. The group has originated in 2007 in meetings of people interested in self-tracking and in a website launched by the participants called "The Quantified-Self" (Lupton, 2017). Since then, the Quantified Self community has been tracking and sharing several kinds of data by using technologies such as apps and wearables (Wac, 2018). They can be considered lead-users in this field. Therefore, this community has been studied due to the highly valuable insights they provide to this project.*

The Quantified Self group uses an online forum to share research questions, findings and projects. The Quantified Self was identified as an online community that could successfully provide rich qualitative data by using Netnography methods due to its interactions on its own forum and in other networks such as Github . In addition, it meets some of the recommended criteria for choosing an online community: a focus on questions related to the

research, a high traffic of posts and comments, availability of rich data and between-member interactions that go beyond the scope of this work (Kozinets, 2002).

Netnography uses ethnography research techniques to conduct online research by conducting observations, participations, communications and researching online archives. It studies emerging online cultures

and communities that rely on computer mediated communications (Kozinets, 2002, 2010). Netnography methods can be adapted for a short study that only focuses a single community or involve multiple communities during a longer time span. In addition, it can be used together with other research methods such as off-line interactions with member (Costello, McDermott, & Wallace, 2017). In this study, the methods have been adapted to the short time span available and the focus was kept on the QS community interactions in the forum regarding the questions posted by the researcher and topics covering similar issues like Blood pressure, General Health, Apps and Tools. In addition, two members have been contacted separately by email.

It is advised to have an initial understanding of the community before entering it (Kozinets, Dolbec, & Earley, 2014) In order to understand better the Quantified Self community, the forum was observed from the second week of May until the first week of June. During this time, the researcher had time to get acquainted with the forum "etiquette", the ways of speaking and briefly interact with a few members. In addition, the researcher had been in touch with 3 members of the community who could provide some previous insights about the Quantified Self.

Previously, interviews had been carried with healthcare providers and, in parallel; a study was being carried out with designer who self-monitored themselves for 2 weeks. As a result of these activities and the forum observations, some questions were elaborated to the group and some topics were identified as important and treated like data.

The Quantified Self forum is a public forum online. Although the content is publicly available, its use for research purposes brings ethical concerns. To guarantee an ethical use of the data and follow the recommended practices on using netnography methods (Bowler, 2010), the researcher has contacted the forum's moderators explaining the research and the research goals. Furthermore, it is important to take into account that netnography methods should take the same responsibility in protecting participants identities as ethnography methods (Kozinets et al., 2014), therefore, an introduction of the research was made in the forum and the members of the forum have been kept anonymous in this work.



## COLLECTING DATA

The Quantified Self forum differs from many online patients' communities in the sense that the participants do not necessarily have a health condition as the main motive to engage in a self-tracking activity and exchange knowledge about such experience. As it is described in the Quantified Self official website, the main purpose of the forum is to support the members who seek for answers regarding personal questions (Quantified Self, n.d.). In this sense the focus of the data collection has remain on topics related to healthcare, Blood pressure, wearables, data interpretation, self-learning.

## RESULTS

The question posted on the Quantified Self forum ( Figure X) has received three answers from participants. Although this represents a very small number of the Quantified Self community members, the answers provided have shown some interesting insights.

### Taking the data to a Doctor

One of the participants has reported taking his and his son data to a doctor and has provided a very detailed answer.

*"I've taken my blood pressure and heart rate readings to a walk-in clinic twice in the past. We've also taken medication data to his asthma clinic doctor and to the local emergency.*

*" I took my heart rate/blood pressure readings with me to the walk-in clinic after experiencing an unusual spike in blood pressure as a way of convincing a doctor whom I hadn't seen before that I was not a hypochondriac/wacky (my doctor was on vacation). He only glanced at the data and noted the spike but basically dismissed it and focused on my current vitals and his questioning."*

What is interesting in this answer is how the respondent felt concerned about not being taken seriously and being stigmatized as a hypochondriac. In addition, he posted the data that he took to the doctor. This reflects how open some QS members can be when it comes to sharing their personal data.

*"Part of me expected them to dismiss the data. Though I hoped them to review it and ask related questions, even if it was to ascertain the accuracy of the data, such as, "what device were you using? How did you feel when your blood pressure was spiking?"*

This shows how this participant does not have high hopes of having his data taken into account by a doctor in an insightful manner.

When describing what happened when he took his son's data to the doctors, he wrote that the doctors actually looked into the data and took it as a contribution to understand the health state of his boy:

*"Emergency visit: They glanced at it (referring to the data) long enough to note that his stats had changed recently. Then they focused on his current vitals which weren't good, paged a respiratory specialist and they ordered an x-ray... early stage pneumonia once, bronchial issues the second time. (Background... we've observed when his sleeping heart rate is accelerated and his sleeping spO2 drops below 92 or so for extended periods that he's going to need an intervention. ) "*

He details that he expects Emergency healthcare professionals to look at the data, since they are used to that and he had this experience before. In addition, his answer shows how the data was used as evidence of his son's health status and trust in healthcare team when he adds "then we let do their job".

*"He had pneumonia once since they saw him last and was prescribed antibiotics twice! You dedicated extra years of your life to be a jedi at this stuff and you're acting like I've brought my used Buick in for a tune-up! WTF? At least analyse the data being given to you to decide if you can use it to make my kid's childhood better.*

He describes a different experience when taking his son's data to a Specialist.

*"I took the data in to show that we were diligent about his meds and that we monitored how he was doing on a daily basis. This is a Specialist and we only get a 20 minute appointment every 3 months with her. I expected a specialist to care more about specific and consistent data than a general practitioner or a random emergency/walk-in physician/nurse.*

*" The asthma clinic doctor for my child did not look at the months-long data we kept ("regular" stats were summarized, "spikes and illnesses" were highlighted.) Instead, she just focused on "standard" questions. The questions were general... "How has he been doing?" "Have you been giving him the preventative puffer on a regular basis?" "How often have you given him the intervention puffer?" etc. Well, all the answers to*

her questions were right there in the data but the doctor didn't bother to look...I assume they were tight on time and used to dealing with families who didn't record data.

2) It's my son's breathing! He had pneumonia once since they saw him last and was prescribed antibiotics twice! You dedicated extra years of your life to be a jedi at this stuff and you're acting like I've brought my used Buick in for a tune-up! WTF? At least analyse the data being given to you to decide if you can use it to make my kid's childhood better.

Also... my regular doctor... I don't see him often and when I do, I just summarize the differences in my personal health indicators since last time we visited"

It is possible to notice his frustration with how the doctor used the data. He presented highly personal information and was expecting in return a personalized way of dealing with his son's health. However, the specialist decided to rely on the standard questions only, and did not give much attention to the data chart, which has caused frustration for him. This situation corroborates with the trend of patients expecting more a personalized approach in healthcare (see page 65). When looking at the data graphs, it gets evident that he took the time to process and organizes the data in order to make it easier for the doctor to look into it.

In all his answers describing the different situations, it is possible to notice how the healthcare professional was given the trust to provide insights regarding the data and actions to be taken, as a health expert. In addition,

the notion of a healthcare professional as the expert has remained in all the described situations.

Another member of the forum has answered that he has never taken his data to a doctor. When explaining his reasons he states:

*"I don't expect a doctor to have time to pour over my data. However, I can use my data to prepare for a visit, so instead of saying 'I don't feel like I've slept as well recently', I can be very specific. This is especially important when seeing a doctor who doesn't know you well."*

In his answer it is possible to see that he does not expect doctors to be data scientists, however, he does expect them to provide actionable insights about what to about his findings. Furthermore, he uses data as a tool for understanding his personal condition and for optimizing an appointment with a doctor.

A third participant has also stated that he never took his data to a doctor. In his case, he described that he was not expecting that collected data to be accurate enough in order to be taken into account during an appointment.

*"No. I didn't because I was considering my data just for recreational purposes. Sometimes because I just start running without any app / or watch tracking it."*

*I find very difficult task use this data anyway because the way the data is measured scientifically is different from the way people record."*

He adds that if he takes a data set to a doctor, he expects actionable and personalized insights. This adds to the previous answers and the results from the designer's interviews and generative session.

*"Advices, but based on the data not on just generic good practices. To avoid lesions, cardiac changes, etc and dietary advices"*

### Choosing a device

When looking at the different topics in the forum, it is possible to identify users who are highly experienced in coding and processing their own data and also user and users who are not and seek for advice from these data-expert members.

For example, it is common to find posts asking for advice into what wearable to choose, as the one that follows:

*"What is the best device / combination of devices to measure continuous HRV and sleep?" (...)" Would be great to hear from others if you have any experience or recommendations here?"*

Moreover, there is a popular category just to cover topics related to "Apps & Tools". In such category there are topics related to apps developed by the members, data access and, topics in which the members ask for advice about which device to choose or what app to use.

*"I'm starting QS from scratch."*

*" There are many lists of tools/tests, but I was wondering, based on your experience, what would be the ones you would definitely keep and the ones that are after all not critical." (What are your all time best QS buys?)*

*"I am looking to build a family and extended family medical history ( parents, siblings, grandparents, aunts, uncles, and cousins ) Also I would like to build my own medical history. All in one app would be great" (Personal/Family medical history)*

### Collaborations with Research

There are several posts inviting members to collaborate in studies. The overall attitude of the community is being open and enthusiastic regarding collaborating with scientific research and the development of new devices.

## Reasons for self-tracking

Describing the motivations for self-tracking is not something usual on the QS forum discussions, however, the QS forum has a thread called “What keeps you tracking?” which provides interesting insights on this matter.

Some users track their data in an explorative manner but with a focus in mind like sleep quality, for instance;

*“I started this only as a test to see if I could.” (I track my whole life)*

*“I’m interested in every aspect of QS, no particular focus other than finding things I don’t know about me.” (What are your all-time best QS buys?)*

*“I don’t track steps or spend a lot of time with heart-rate. They just don’t seem that interesting to me. I track my sleep because I think sleep patterns are cool and I like calling my attention to how things like diet and exercise change my sleep quality.” (What keeps you tracking).*

Others track aspects looking for manners to improve their quality of life.

*“I’ve got chronic headache/migraine and fatigue and the mornings are not always easy. I’m looking into things that might have an influence on these chronic distresses and noticed the numbers for my sleeping seem ‘off’. in “Tips for improving (deep) sleep*

Users also exchange ideas about other possible factors to track. In this manner, a system that offers some guidance could help participants to look for possible correlations. The following example shows a participant asking about heart rate. Knowing the meaning of heart rate and how it might be affected by external factors, could spark his interested in tracking it and explore other questions, for example.

*“It’s not that I don’t think that heart-rate tracking is important. It just doesn’t answer any questions that I currently find interesting. What does long-term heart-rate data tell me that’s cool and interesting? That’s not a rhetorical question. If you know of something please let me know. I would totally track it if it was linked to something cool.”*

In this manner it is possible to see how important it is to provide education regarding health related data.

## Taking actions

Participants discuss possible actions to be taken based on their data. This depicts a will of taking control over their own health and manners to organize the self-experimentation. Furthermore, they seek to know how others have experienced a similar issue. This resembles the dynamics on some patients forums.

*“As others on here have said, there are plenty of supplements which can help you sleep. However, you don’t have to jump right in with an expensive sleeping supplement. If you’re really trying to be scientific about it, you will want to start with the most likely candidates for enhancing your sleep and test them out one by one.*

*“In my experience, magnesium is a fantastic, reliable sleep aid. Using magnesium for sleep has the added benefit of leaving you fresh and alert in the morning (melatonin can sometimes leave people drowsy). I recommend using about 100mg of citrate or bisglycinate to start, and the upping the dose as needed.”*

## KEY TAKEAWAYS FROM THE QS COHORT

The interactions on the Quantified Self community reveal in which manners experienced self-trackers look for support in collecting and maneuvering personal data, besides their expectations regarding the use of such data for healthcare purposes. Furthermore, the community reveals how collecting personal data is valuable for addressing self-curiosity and tackling personal goals regarding quality of life. Finally the community regards users who do not necessarily identify themselves as patients but as individuals who seek knowledge through data. Thus it depicts how personal data can be a valuable material also for non-patients.

## FRAMING THE INSIGHTS

The findings were analyzed and organized into a framework that maps the stages of self-reflection as previously done with the design cohort trial (See page 137). This has allowed to enrich the construction of another personas and compliment the identification of pains and gains that can represent the group of self-trackers.

**Using data to have a better care**

*It's my son's breathing! He had pneumonia once since they saw him last and was prescribed antibiotics twice! (...) At least analyse the data being given to you to decide if you can use it to make my kid's childhood better.*

**Seeking and sharing advices**

*"As others on here have said, there are plenty of supplements which can help you sleep. However, you don't have to jump right in with an expensive sleeping supplement. If you're really trying to be scientific about it, you will want to start with the most likely candidates for enhancing your sleep and test them out one by one.*

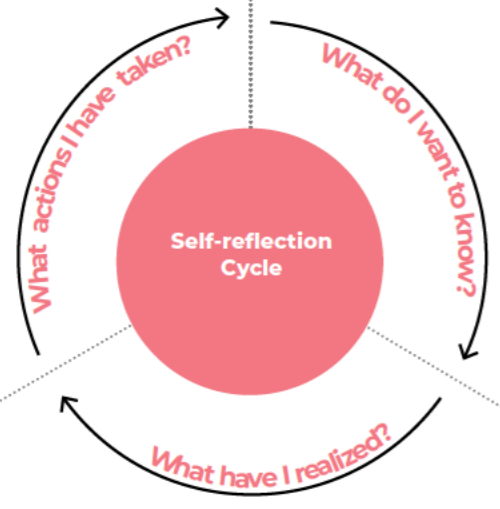
**Connecting different data sets to achieve insights**

*"I like calling my attention to how things like diet and exercise change my sleep quality"*

**Expectations of taking the data to a doctor**  
*Advices, but based on the data not on just generic good practices. To avoid lesions, cardiac changes, etc and dietary advices".*

**Data as a dialog material**  
*"I don't expect a doctor to have time to pour over my data. However, I can use my data to prepare for a visit, so instead of saying "I don't feel like I've slept as well recently",*

**What to do next?**



- Which device to use**  
*There are many lists of tools/tests, what would be the ones you would definitely keep*
- Data as a exploratory material**  
*"I'm interested in every aspect of QS, no particular focus."*
- Data as social material**  
*Chats on the forum, sharing experiences*
- Data as certification/evidence**  
*"I've got chronic headache/migraine (...) I'm looking into things that might have an influence on these chronic distresses"*

**Data as an insight catalyst**

*"I don't expect a doctor to have time to pour over my data. However, I can use my data to prepare for a visit, so instead of saying "I don't feel like I've slept as well recently",*

**EMPATHIZING WITH THE USER**

Based on the findings from the Quantified Self cohort, a persona was created. The idea was to represent a user that is interested in self-tracking, however, does not have a higher level of coding and data literacy. Later, the Pains and Gains framework structured in the section 3.4 (see page 123) was iterated and updated in order to better represent the group of self-trackers. The added insights can be seen in pink.

## Michael 31 years old

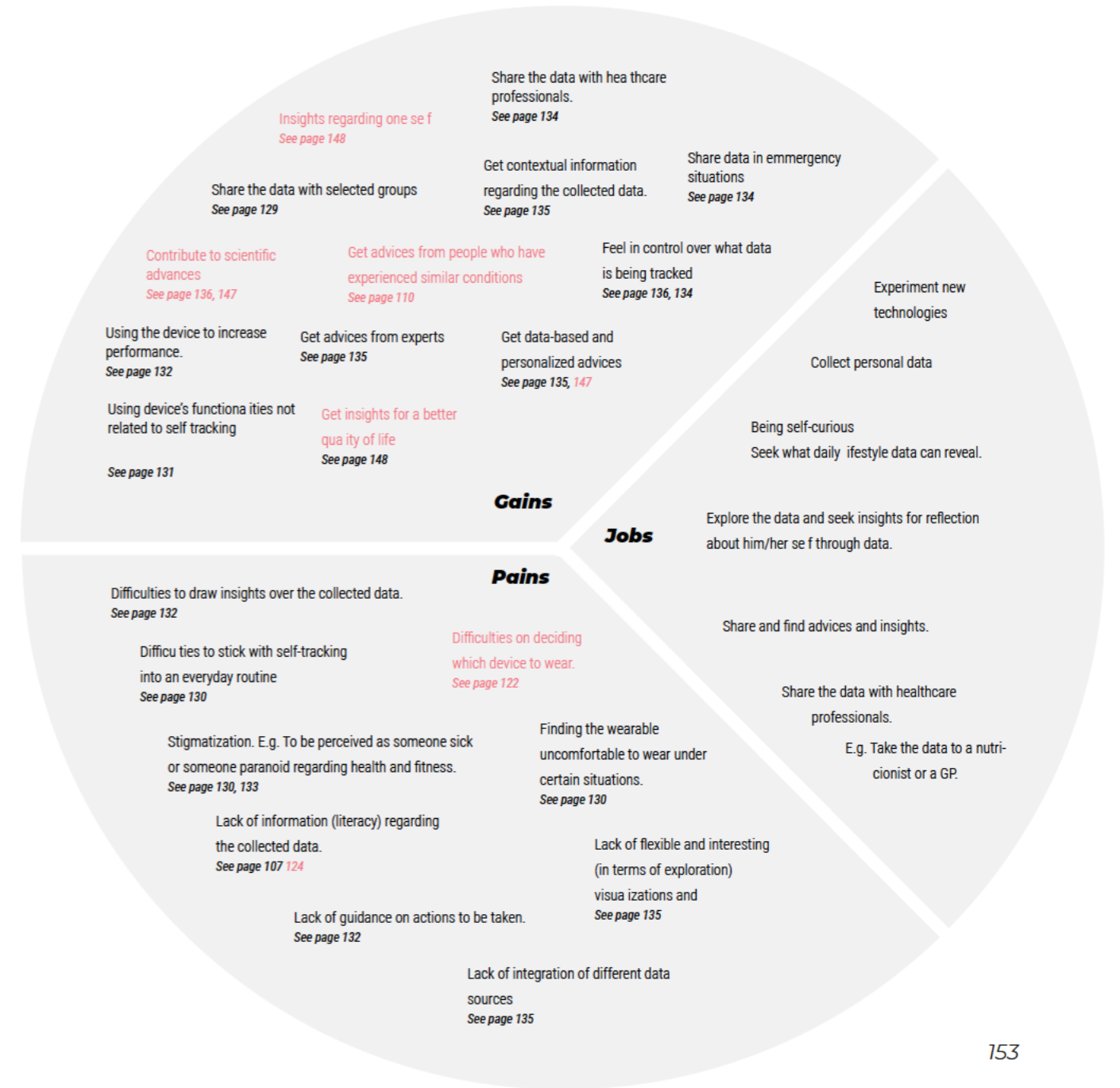
Michael is 31 years-old real estate agency broker. He is used to exploring data regarding the real state market, but recently, he has been feeling curious about using gadgets that help him to get insights about himself. He does not like to code and get deep into technology, he really interested in collecting data about himself and explore what kind of insights he can find. However, he is not sure how long he will keep his interest in using a wearable to invest his money on this. Furthermore, he thinks the downside of any gadget is that it needs maintenance and it may not work do well after a while.

### Actions

He collects data about several  
Mood and stress and the connection  
others data sets interest him a  
evidence of his activities in the

### Conflicts

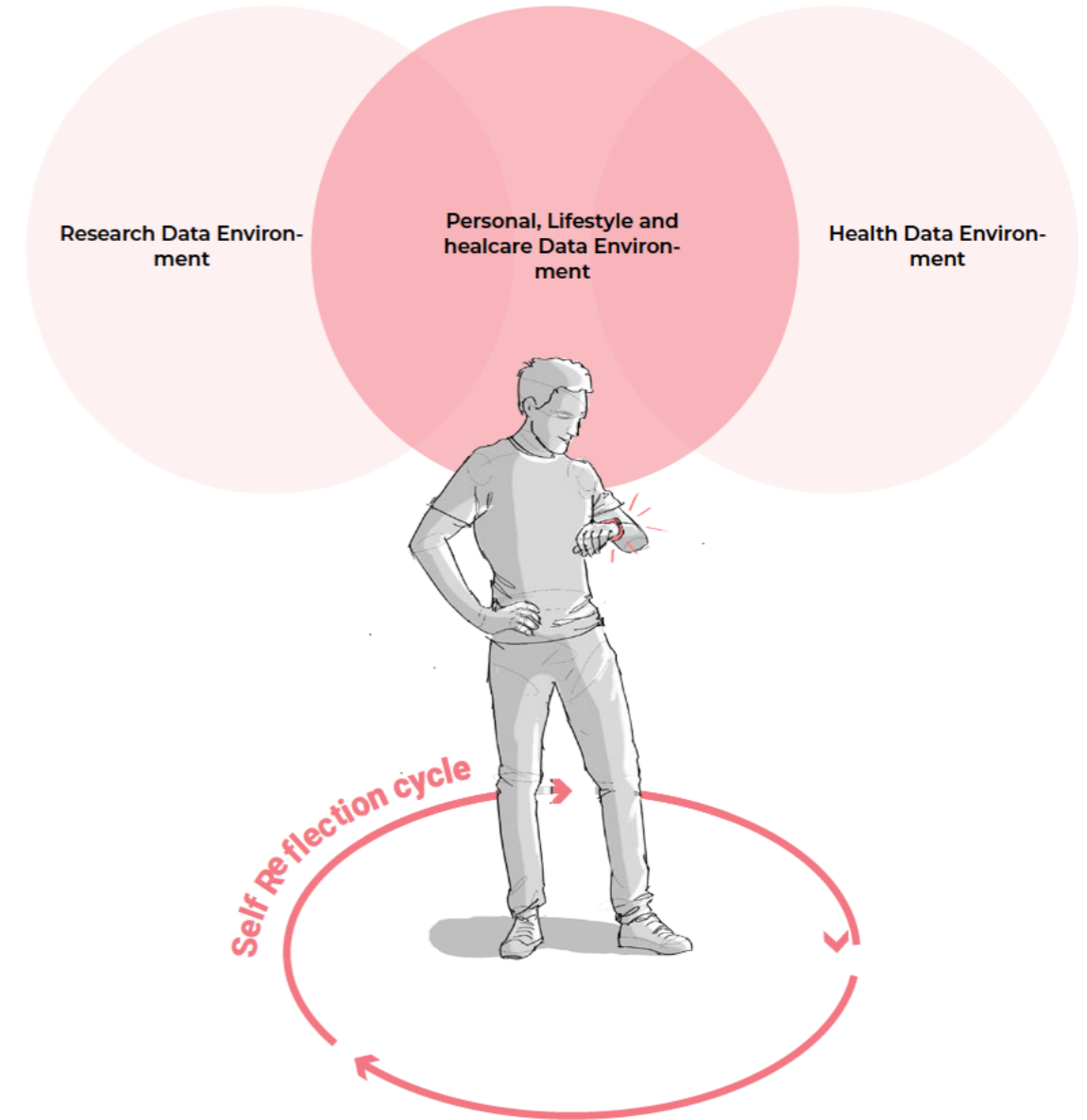
He frequently discovers some  
data that make him reflect on  
his lifestyle. However, he does  
not know clearly what to do in  
order to change somethings  
that maybe could help him to  
have a healthier lifestyle.



# Concept

*This chapter describes the processes of conceptualization. It consists in revisiting the initial identified problem, besides generating and turning insights, ideas and solutions into a concept.*

04



## 4.1. Problem definition

There is a growing interest in using self-tracking practices to encourage citizens to take an active role in monitoring their health. Self-generated data provides an overview of healthcare data in the context of a user's real-life, it can be used for personal reflections, for helping practitioners to provide personalized treatments and detect healthcare problems before they became a disease or a chronic condition. However, currently, there is a lack of perceived trust in ubiquitous technologies and the consequent use of personal data. Besides, their uncertainties regarding devices' accuracy, and if the measurements are correctly performed and drawing conclusions upon self-tracked data is not an easy task for those who do not have access to what the data means and do not have the skills to develop their own solutions for exploring their data. Thus, there is a need to develop a platform that fully provides data ownership and management to the user and

enables collaborative use of data by enabling integration with different ecosystems. This thesis proposes a cooperative data platform in which value exchange is based on trust. Above all, the platform facilitates the use of data as a material for personal reflections by supporting and engaging the user in reflection cycles. Furthermore, he can get some advice on when he should see a doctor, in case it is necessary.

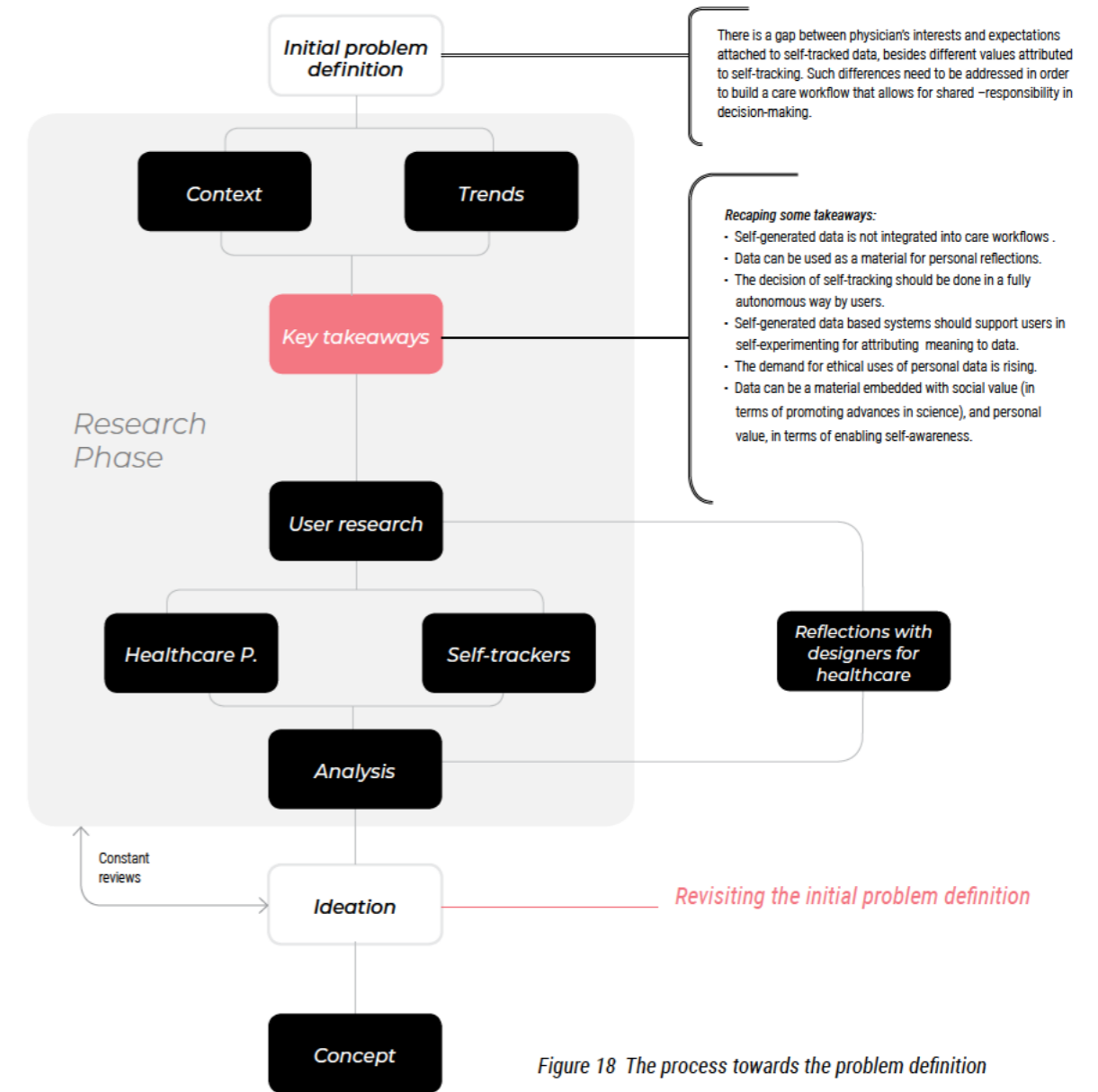
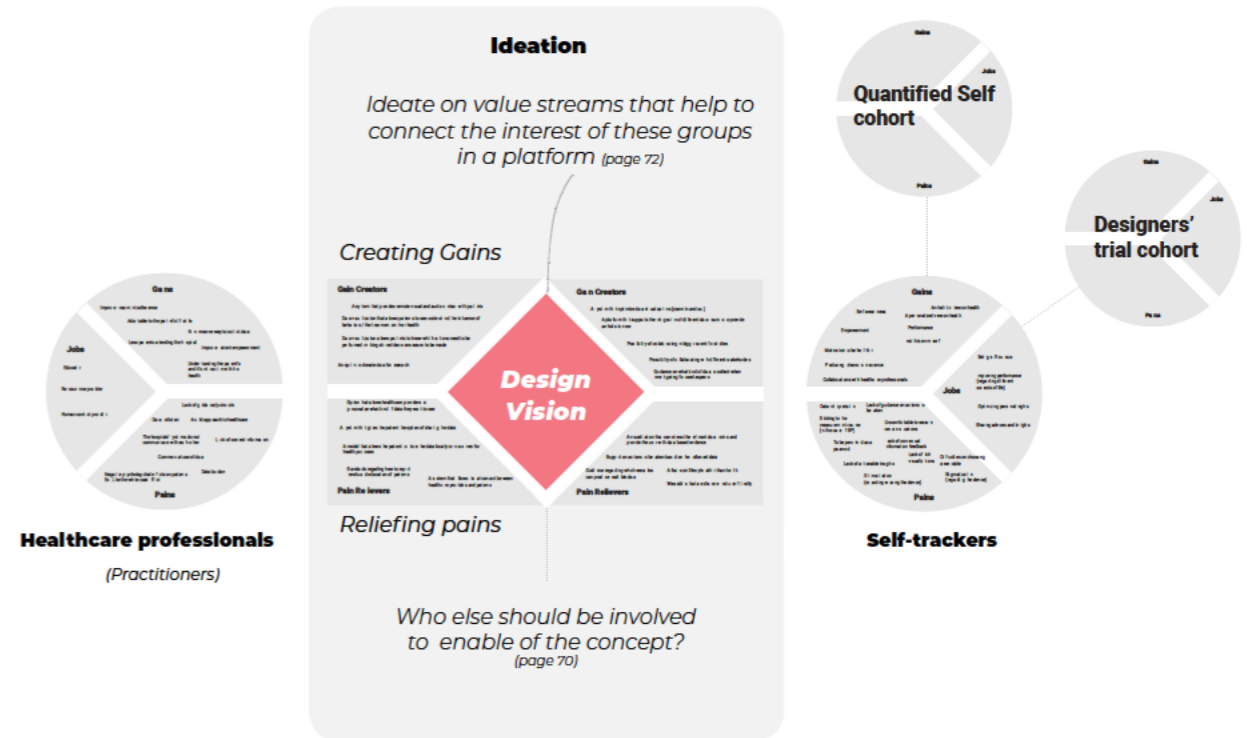


Figure 18 The process towards the problem definition

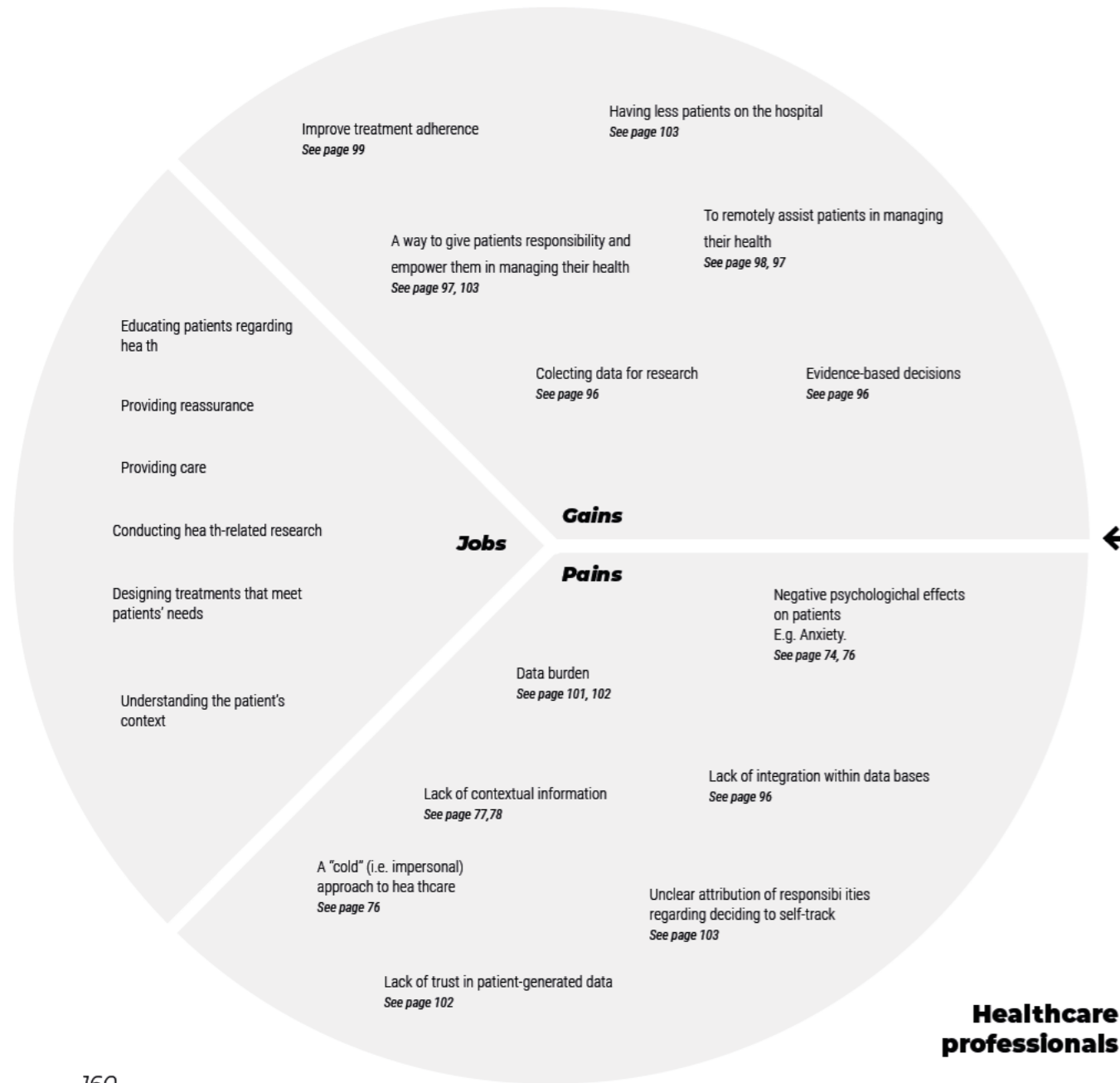
## 4.2. Ideation

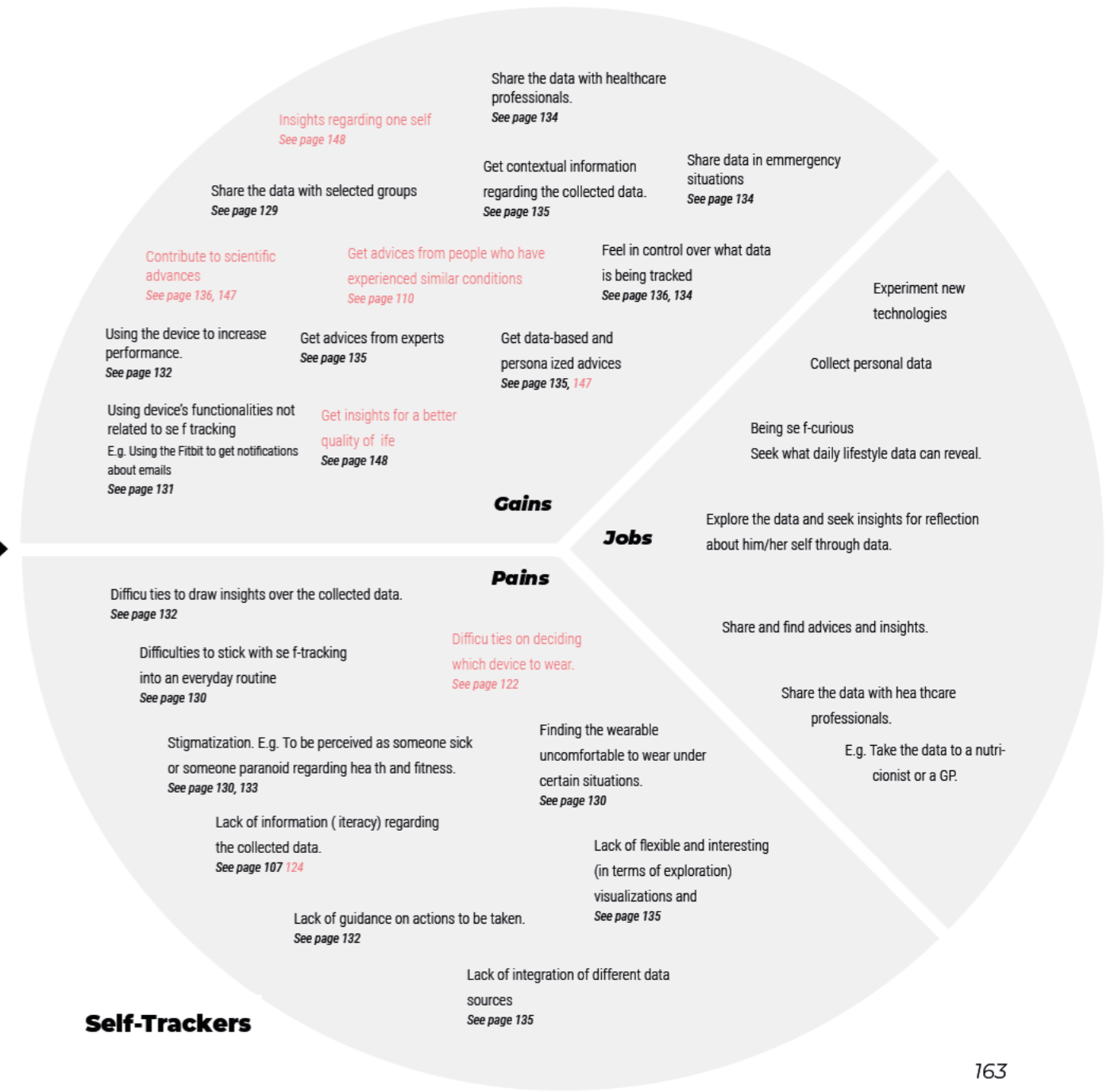
This phase tackles the process of generating ideas for the final outcome. It comprises the how the insights collected during the research phase were used to generate new ideas and how those ideas have been transformed into a concept.

The user research phase has provided several connections between the findings from the Context and Trends chapters. By clearly identifying “pains” as issues to be solved and gains as aspirations to be met and experiences to be enhanced, it was possible to pave the way to reframe the problem definition (see Figure 18), and, thus, move towards the ideating and conceptualizing the design vision.









# 4.3. Design vision

A platform that enables self-tracked data to be used as prevention and dialog material through personal reflections and collaborations.

### 1. An organization level

A level with partners that enable trust based solutions. Involved partners are the government (pg 82), patient associations (pg 71), private companies and insurance companies (pg 70).

### 2. A collaborative level

A level to share data in a collaborative and safe manner

### 3. Individual level

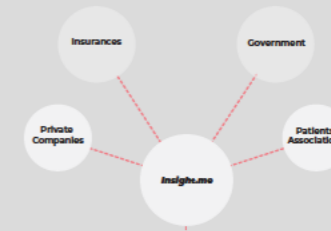
A level that supports personal reflections over data, through rich data visualizations and self-experimentation.

In this level can lease a device and self-track.

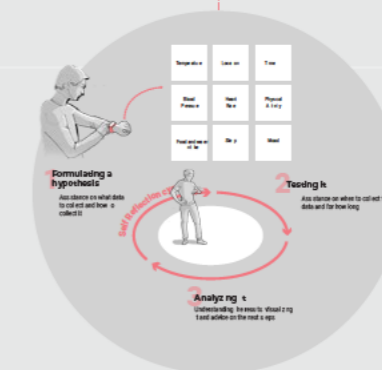
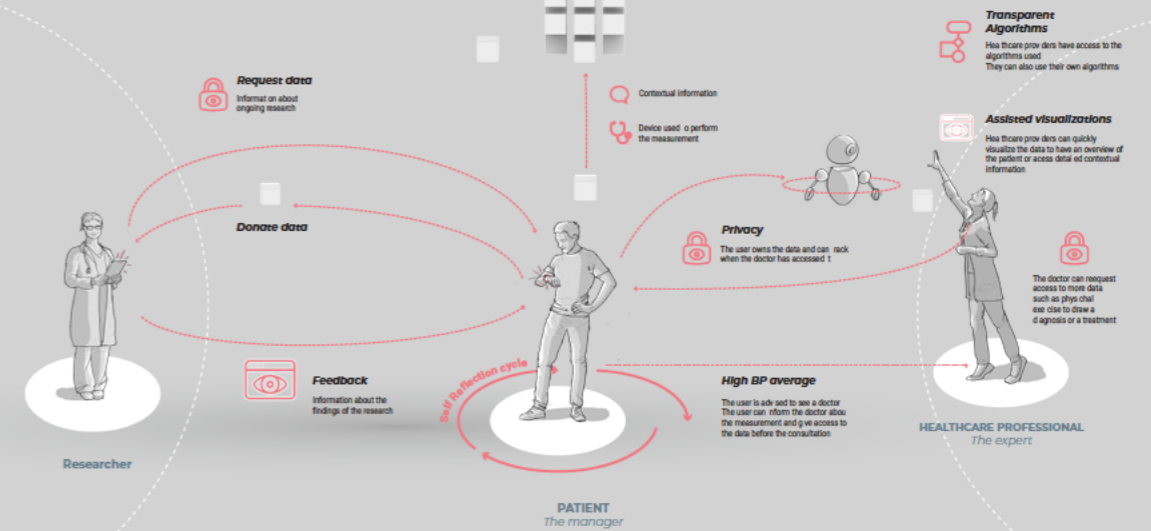
## Insight.me

Insight.me is a *cooperative* data platform. Every participant has a deciding vote in what is done with the revenues of the platform and who should be part of a committee who controls the platform. The platform is designed to protect the data from users from unwanted commercial activities, allow a safe manner to share personal data and, above all, support users in self-reflections based on data.

# Insight.me



A Trust based ownership of the Platform



## Possible future partners of the Platform

Once there is evidence to support the efficiency of the platform in promoting a healthy lifestyle, Insurances could be involved in offering discounts for the members or reimburse a device purchase. This already happens with gym memberships, for example. Their involvement should be always facultative.

### What is in for Insurance Companies ?

Insurances profit more if people are not getting ill. Therefore, if it proved that the platform can promote health benefits, insurances can benefit out of it even if they do not look and do not access the personal data generated by the users.

### What is in for government ?

When there is proof that this Insight.me contributes to preventing conditions such as hypertension, be a partner becomes a valuable investment since preventing is cheaper than treating. By having populational data regarding health and lifestyle the government can understand better why certain health conditions are occurring in certain areas and develop policies. Preventing health conditions can improve citizens quality of life, productivity and reduces health costs.

## Partners

The company provides the technical infrastructure to support such platform. In return, it benefits from the improvements done in the algorithms.

This can generate future solutions for bigger clients such as hospitals.

### What is in for the Private Companies ?

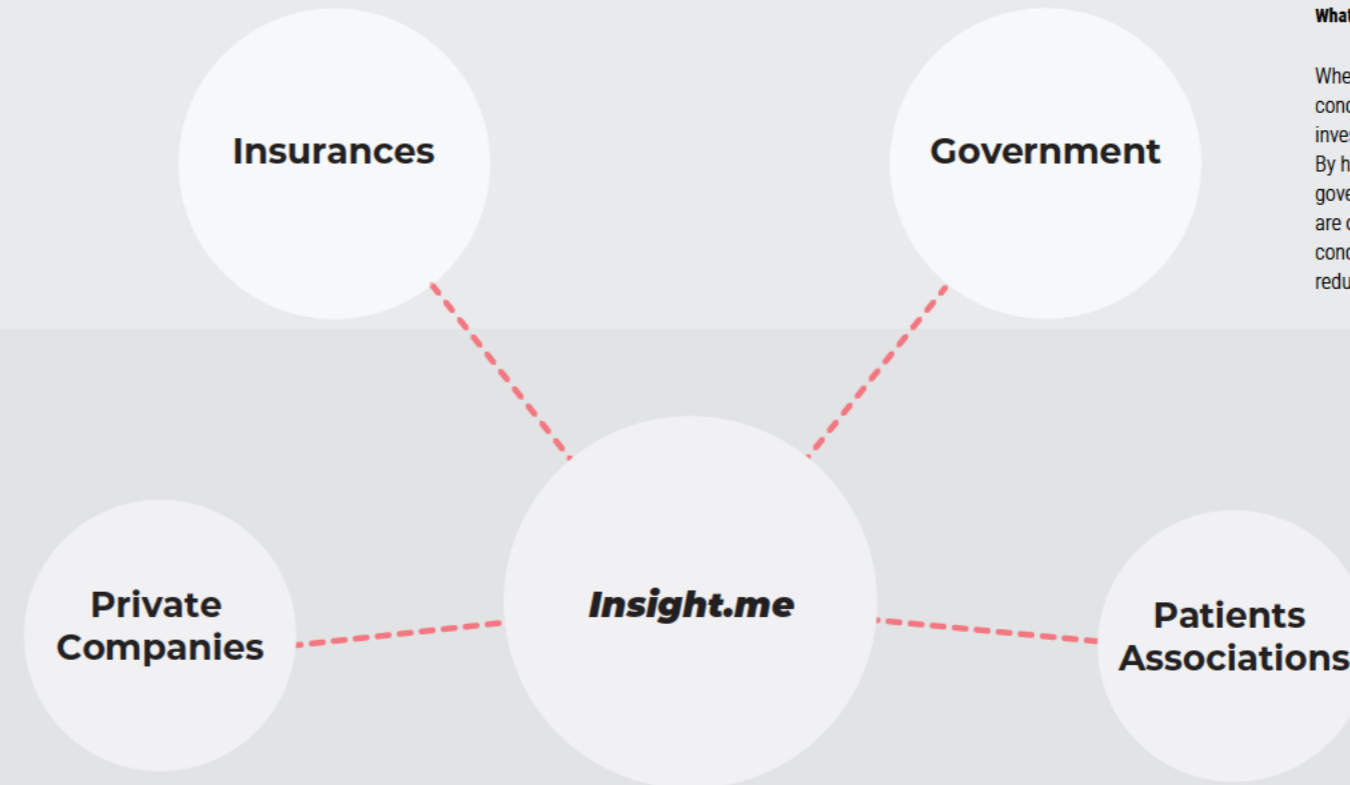
Partners can not use the data for commercial purposes (e.i. sell the data for advertisement purposes). However, they can use the data to train algorithms (pg 72) that can be used in other products and develop a trust based relationship with users (pg67). Furthermore, in the platform they can sell equipments in bulk for leasing purposes, engage in research, have a market for their devices besides fostering brand loyalty.

Also, companies can offer other products or accessories for the public (only in case the privacy criteria established by the cooperative members are met).

### What is in for Patient Associations ?


The patient associations provide guidance and insights on how to cope with certain health conditions and, primarily, on how to prevent them. It guarantees that scientific interests that can benefit a population are met and that the collaboration with users is done transparently.


By partnering with the platform, associations can provide awareness regarding certain conditions and stimulate relevant research for association members. This helps to promote better life quality for its members. Furthermore, by having an active voice on the cooperative, they can ensure that the data and the platform are used for benefiting societal interests.




## Organization level *What is in for the stakeholders?*



 **A trust-based ownership of the platform**  
A cooperative model

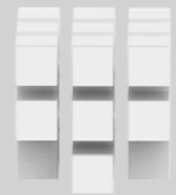
 **Request data/participation**  
Information about ongoing research


 **An option to Donate data for research**

 **Feedback**  
Information about the findings of the research

**Self Reflection cycle**


 Contextual information  
 Device used to perform the measurement




 **Privacy**  
The user owns the data and can track when the doctor has accessed it. Through shared tokens.

The user can define if the doctor can have access to the data for a certain period of time, or an undetermined period.

**Connecting with a doctor**  
*E.g. High BP average*  
The user is advised to see a doctor. The user can inform the doctor about the measurement and give access to the data before the consultation.

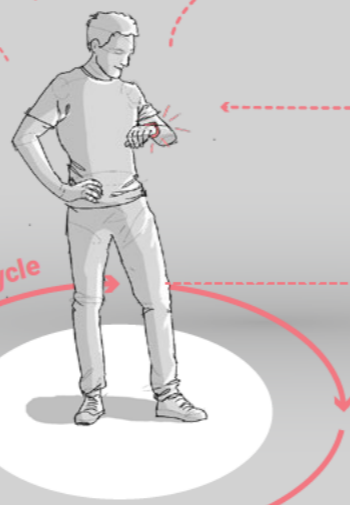
 **Transparent Algorithms**  
Healthcare providers have access to the algorithms used. They can also use their own algorithms and donate them to the system if they want.

 **Assisted visualizations**  
Healthcare providers can quickly visualize the data to have an overview of the patient or access detailed contextual information.

The doctor can re-request access to more data, such as physical exercise to draw a diagnosis or a treatment.

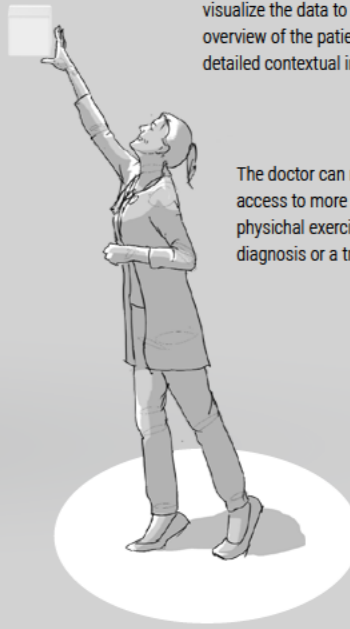
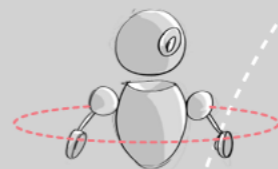


Researcher



PATIENT

The manager and the owner



Healthcare Professional  
The expert

# Collaboration level

## What is in for the stakeholders?



The User /Patient

### What is in for the Users ?

Users can gather different sources of data in one single platform, explore the connections between different data sets and increase their level of health literacy.

A user can join the platform by *signing a leasing plan* and get a wearable from one of Insight.me's partners, this guarantees constant updates on the equipment and easy maintenance (see page 49). Also, the user can upload previously gathered data from one device and pay a fee to join the service. Once the user joins the platform, he can choose if he wants to collect data for a small period and, then, decide to explore connections or if he wants to already carry on a small experiment since the beginning. For example, if the user is interested in exploring more Blood pressure, he can see a list of factors that can influence its values (e.g. physical activity, water intake, perceived stress, etc). Next, he can choose some factors to observe and have some guidance on the experiment.

For instance, a user who is interested in perceiving the influence of a new diet in his blood pressure receives advice on how many weeks he should track it to perceive any impact. The user's baseline is always taken into account to provide feedback.

Finally, the user is provided with flexible manners to explore and visualize the data (pg 46, 135), besides insights based on that. Furthermore, he can get some advice on when he should see a doctor, in case it is necessary.

### What is in for the Researchers ?

Researchers can promote their research to users that have chosen to visualize calls for participants (according to user's pre-established interests). Money for participation is not allowed, however, the researchers need to provide feedback (see page 136) for participants (e.g. how one's data has contributed to the research findings, which insights can be drawn on a personal level from a participant's collaboration). In this manner, they can have engaged participants (see page 59). Furthermore, they can know which device was used to collect data. Participation is ensured by smart contracts in which participants can donate their data.



The researcher

### What is in for the Practitioners ?

The data is made accessible through a link, therefore there is no need to download new software or learn a new system. The data can be explored and visualized in different manners through an AI assisted system. The doctor can request access to the patient to see a bigger time span of data or download it if necessary.

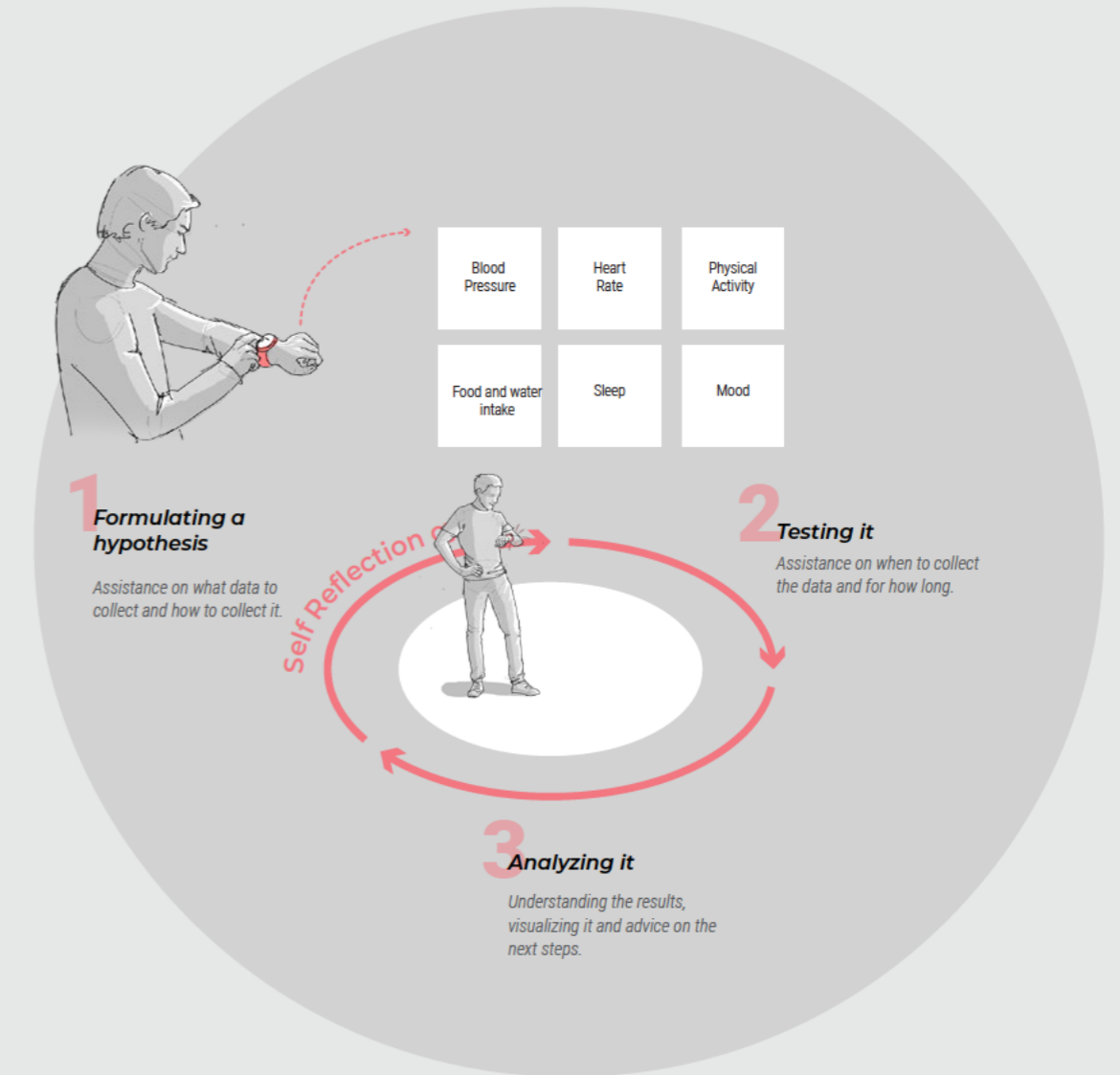
The data can be integrated into different systems when the patient provides authorization. The idea is to use data to provide material for dialog with the healthcare provider and contextual information. In this manner, the data is used to open and foster dialog, rather than foster premeditated conclusions.

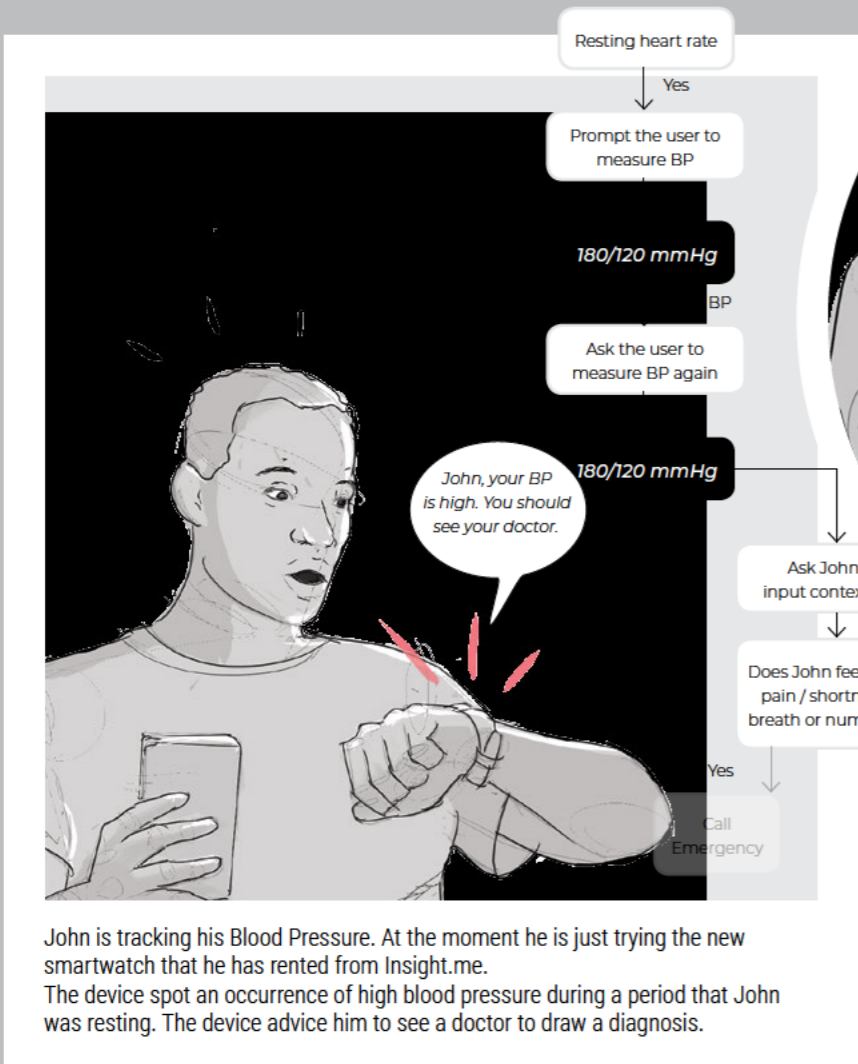


The healthcare professional

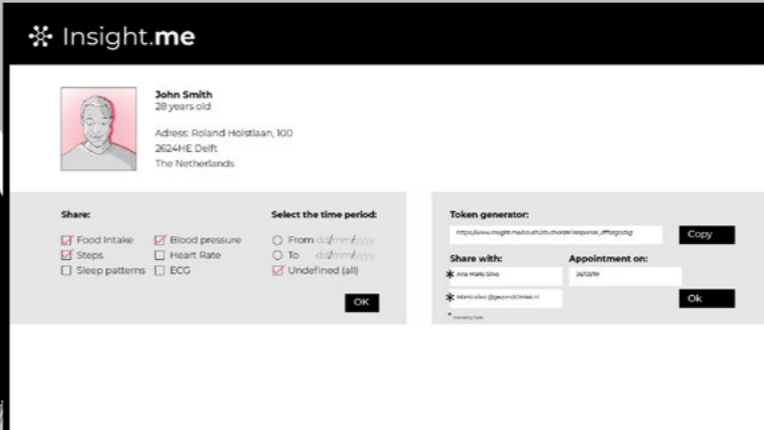
Insight.me assists the user in reflecting upon the self-tracked data (pg. 52, 60). Users can input their interests (e.g. increasing the step count, exercising and monitoring the heart rate) and receive suggestions of other data sets to be observed. Users can also decide to frame their own experiments instead of those suggested by the system. The leasing model allows for updated and, very important, calibrated devices. The data visualization encourages the user to explore his data and engage with the system (pg. 46). The platform also displays ongoing research projects that match the interests of the user. Furthermore, the data is safely stored and the user has power both over the data and the decisions regarding the platform's governance.

## Individual level





John is tracking his Blood Pressure. At the moment he is just trying the new smartwatch that he has rented from Insight.me. The device spot an occurrence of high blood pressure during a period that John was resting. The device advice him to see a doctor to draw a diagnosis.

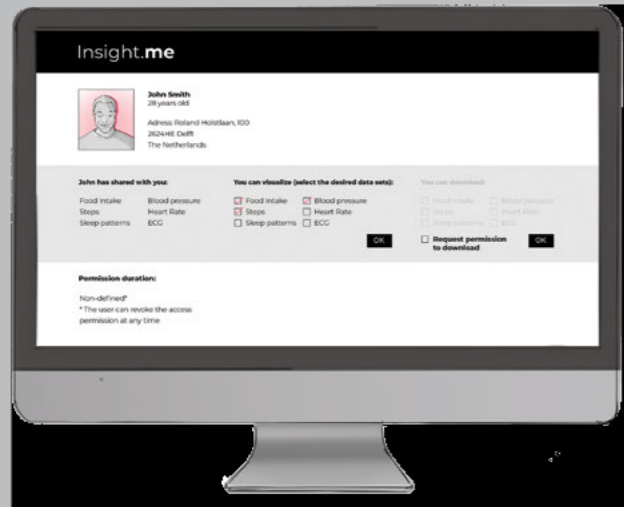


John makes an appointment with the doctor and shares his data. He can choose which data he wants to share and the time frame (e.g.from/until) he is sharing.



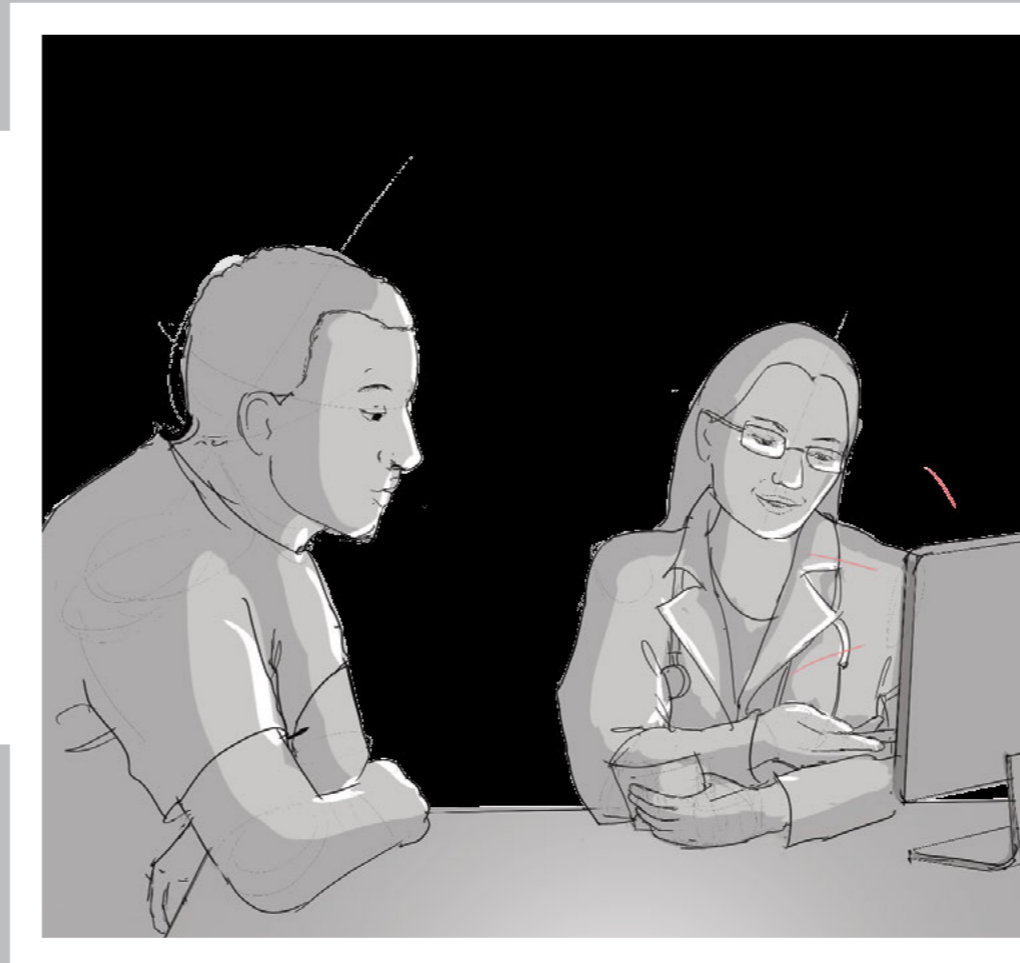
## Scenario (see also Appendix V)





There she can see what John has shared and ask him to share other types of data if she thinks it is necessary...

...and she can visualize the data in her preferred way.



At home, he sets an experiment that tackles the effects of exercising on Blood Pressure at Insight.me. The system suggests him to observe it for 3 weeks.

He keeps tracking his blood pressure. By looking at the visualizations offered by Insight.me, he gets a comparison with his baseline. He sees that exercising is having a good effect on his blood pressure. That keeps him motivated.

He also gets curious to know more about the influence of mood in Blood pressure, that was suggested by Insight.me. He goes to the Insight.me community and looks into other experiments done by owners and check if there is an open request from a researcher at this moment.



# 4.4. Value exchange

To visualizations of the exchange of values were made in order to visualize the exchanges within the system. The visualization shown on Figure 20 has been framed taking the Quadruple aim (Bodenheimer & Sinsky, 2014) as an inspiration.

The visualization shown on Figure 20 shows a value flow that takes into account intangible values on a data sharing platform. It was inspired by the value frameworks proposed by den Ouden (2012).

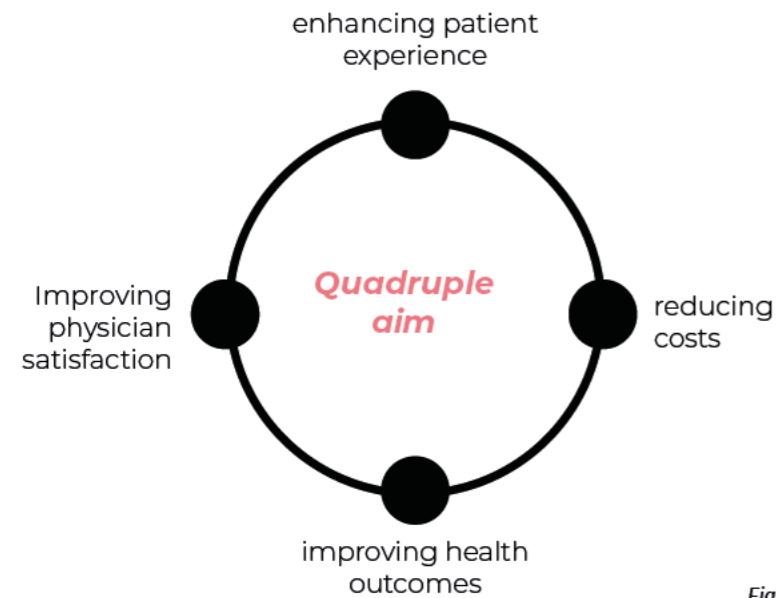


Figure 19 The Quadruple aim. Adapted from Bodenheimer & Sinsky (2014).

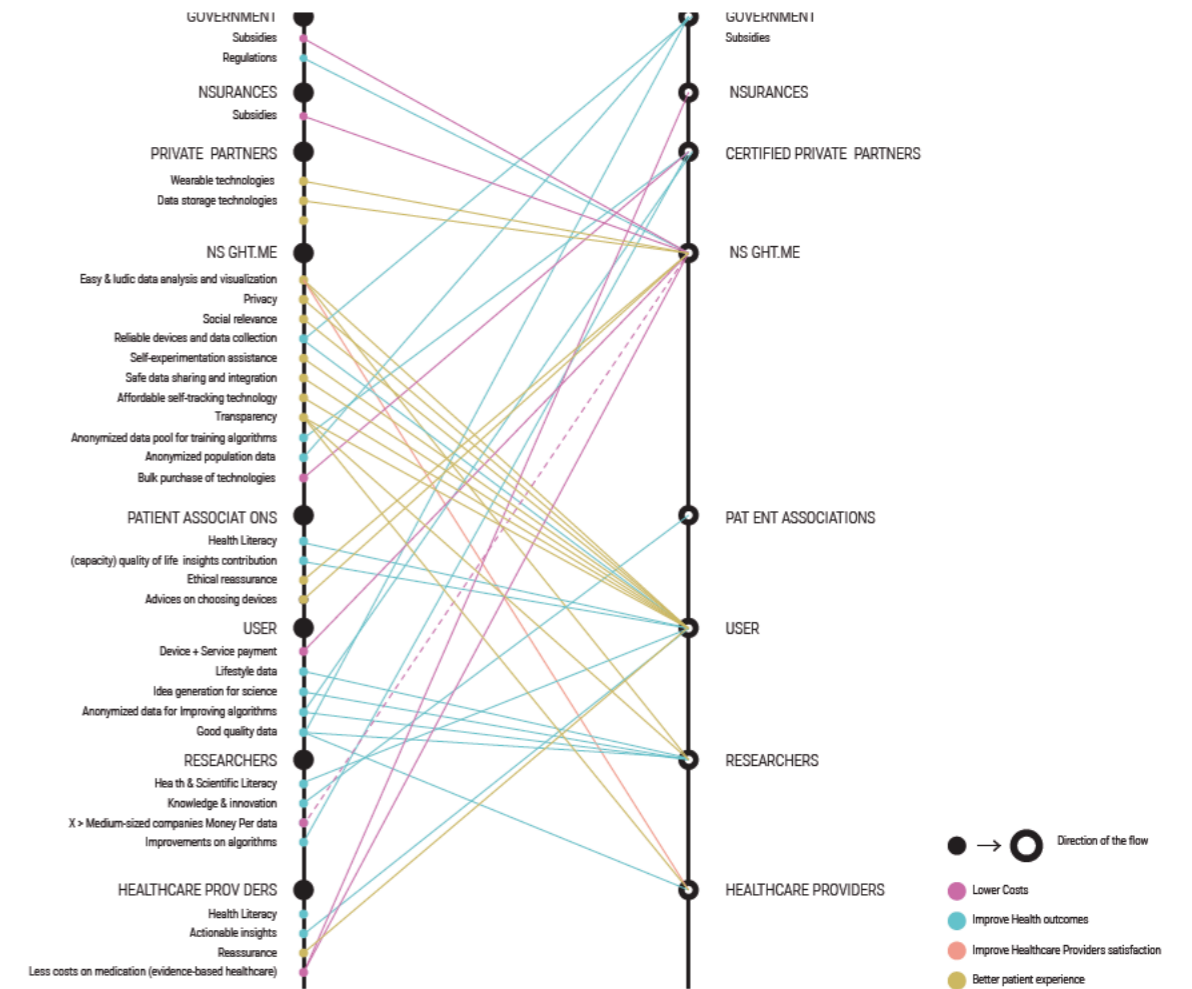
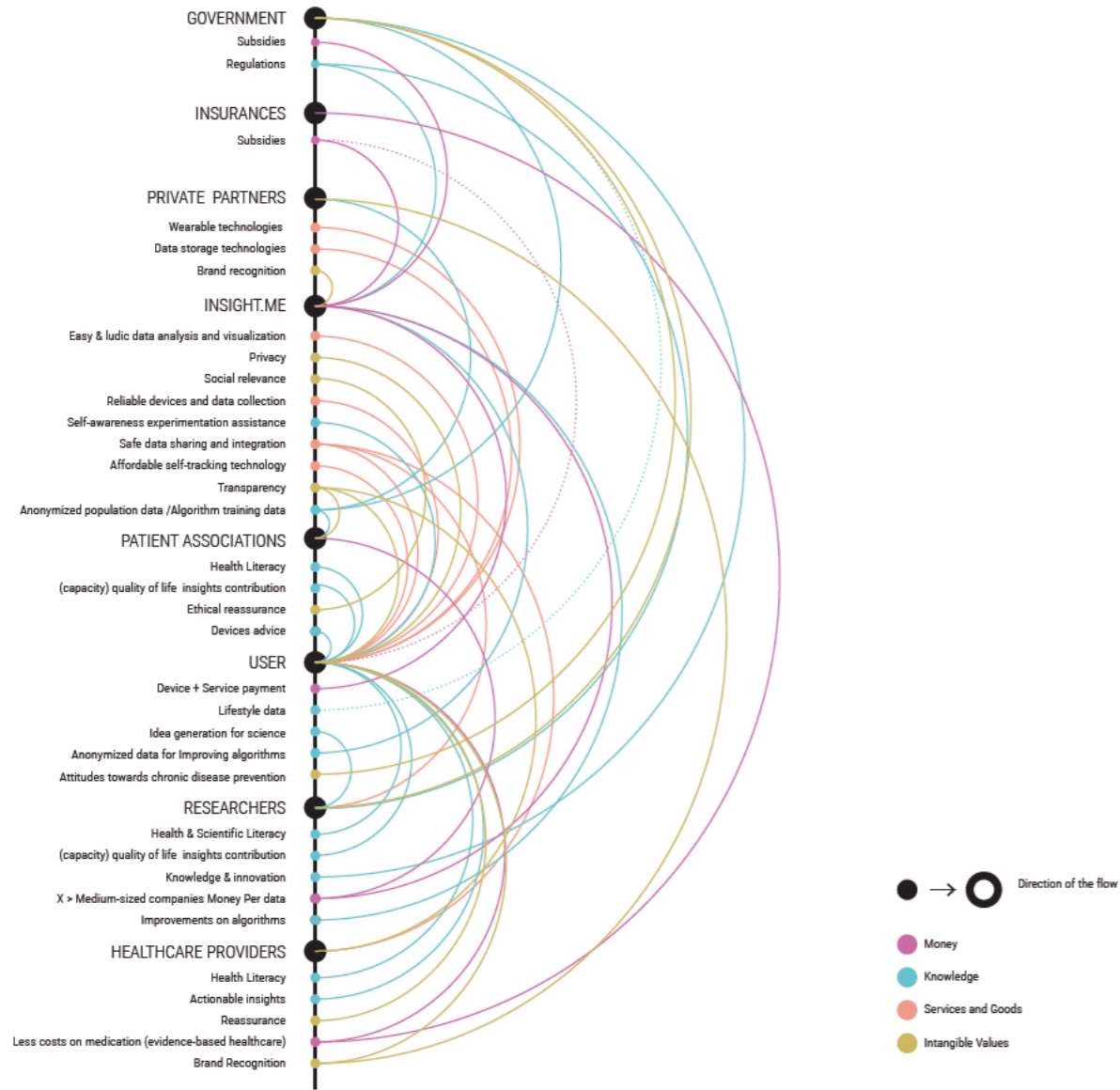


Figure 20 A value flow based on Quadruple aim.



## 4.5. Evolution of the system

A roadmap was developed to discuss the evolution of the platform, in terms of scaling it up and include new partners through time. The roadmap of the following pages uses trends identified in the Trend research chapter to draw how it can look in the future. The time horizons were based in the time needed to collect evidence of the value of patient's data proposed by the United Kingdom's National Health Service study (Spence, 2019).

# Roadmap

Evolution of the platform

## SCALLING IT UP

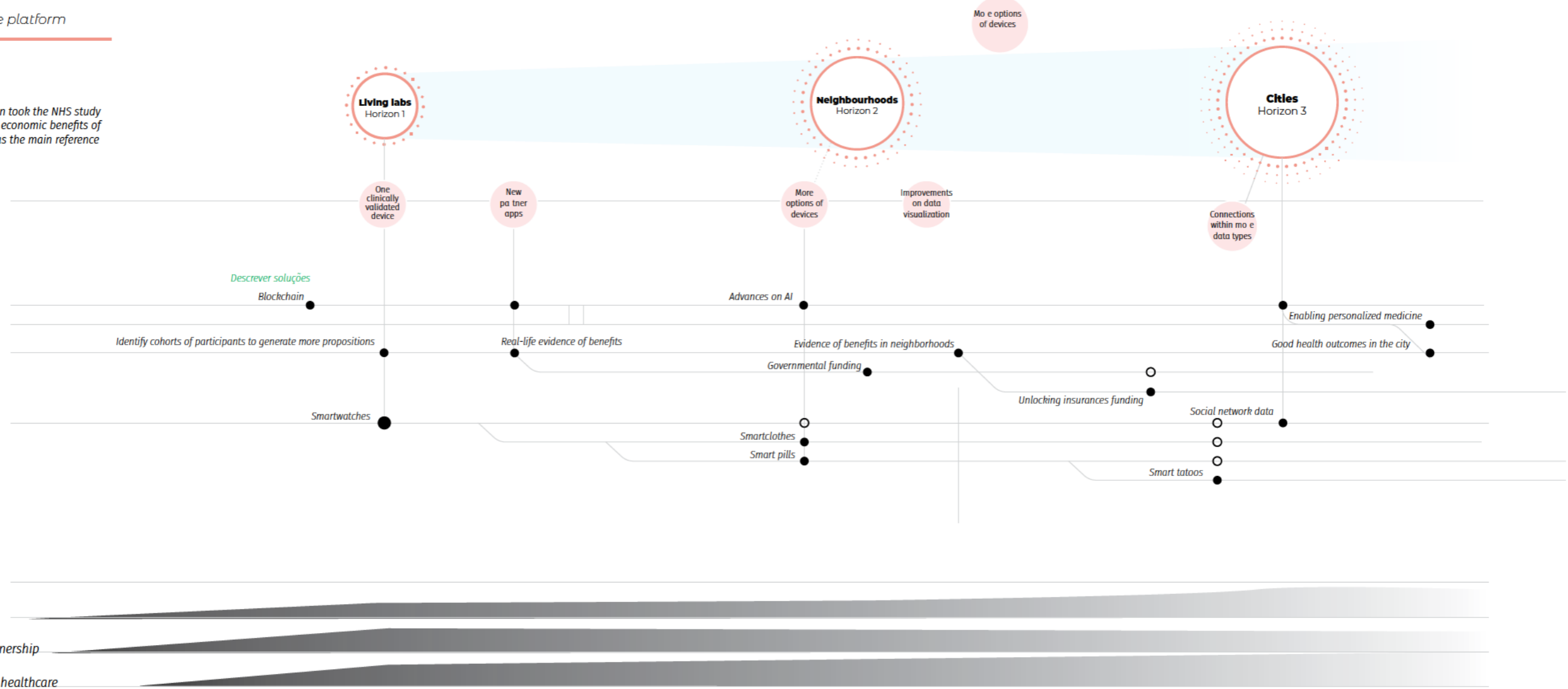
The horizon definition took the NHS study on estimation of the economic benefits of data for healthcare as the main reference (Spence, 2019).

## PLATFORM

## TECHNOLOGIES

## SOCIETY TRENDS

2021 2023 2025 2027



# 4.6. Validation of the concept

The validation was carried in terms of Validity, Feasibility, and Desirability. The diagram below illustrates the process and the outcomes. Given how sensitive information could be shared (for example, patients and corporate information) the names of the participants were kept anonymous.

Insight.me

**Viability**

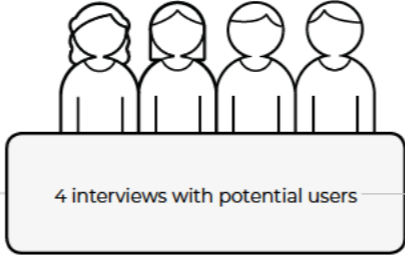
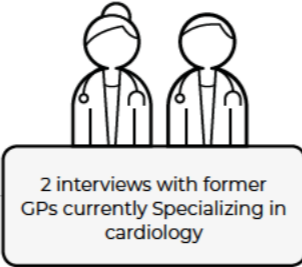
*Is the business model and the value exchange sustainable?*

**Feasibility**

*Is it doable?*

**Desirability**

*Does it solve customers problems?*



The interviews lasted from 30 minutes to 1 hours. All the answers provided positive feedback, validating the solution.

*"It is interesting to involve insurances, they moderate several flows of money in healthcare. For sure they would be interested."*

*"You have managed to get to the conclusion that we got on learning by doing the process. Indeed, people do not trust private companies to share data. I think making it a cooperative makes it feasible and viable."*

*"That's a very complex project. Anything that tackles prevention can save money, but you need time to prove that and involve more partners. So thinking about a Living lab model is valuable to ensure that it can be scaled up"*



*"I really like to see a patient in the center and not just ownership of the data, but also agency over it. I, myself, would like to join a system like this."*

*"This concept is really sharp and clear with a good focus."*

*"We had a patient once. A healthy guy who faded out of the blue. If it was not for the data collected at his wearable, we would not know what the problem was. So this concept, with all this complexity, really can enable these interactions."*



*"I would like to lease a wearable, specially knowing that you need to calibrate them from time to time."*

*"It freaks me out seeing ads based on things that I am not sharing. So this ownership of the platform is really interesting. I would join."*



# Conclusion

This project aimed to explore how design can align the interest of different stakeholders (doctors and patients) in collaboratively preventing cardiovascular diseases. By addressing different perceptions regarding the use of self-generated data in healthcare, this exploration has resulted in a collaborative ecosystem, in which the user has governance over his data.

To address this challenge, a review has been drawn upon the use of data in preventing cardiovascular diseases. I took blood pressure as a starting point, given the importance of this measurement to prevent future health conditions. The context research has revealed how data is being used in the healthcare domain and the impact of ubiquitous technologies in this domain. It has been shown that the forecasts of rising costs in healthcare are adding pressure to explore digital solutions to provide health for a wider public at a lower cost. Given the fact that the design brief aimed for a collaboration-based system, the impact of such technologies on individuals has been addressed. By looking at these aspects, it was possible to understand that technologies on their own can not address problems on health systems, promote healthy lifestyles or prevent chronic diseases. Important considerations regarding the use of digital systems that involve patient-generated data among healthcare professionals, the ethics behind the use of wearables and the use of the data by the users have emerged. Finally, a

framework of self-experimentation, to help users to attribute meaning to the self-generated data was drawn. The following chapter has focused on exploring the future. Trends that impact using data for healthcare purposes revealed societal changes on the rise, such as increasing awareness regarding data privacy and health consumerism. Also, it has shown the need of involving more stakeholders to design collaborative ecosystems and, finally, the importance that trust plays in enabling such interactions and how important it is to address this intangible value when designing for data interactions. To further understand the context and the impact of such ongoing trends, it was necessary to conduct user research to further grasp the perception and the interactions of doctors and users with self-generated data. Thus, healthcare providers and users were interviewed in-depth to further understand their expectations regarding wearables and health-related data in special blood pressure. The interviews have revealed the perception and expectations regarding using self-generated data for healthcare purposes and well being.

A two weeks trial conducted with design students, who tried two different devices that track personal data, explored in which manners the participants were making sense of the data and how they have perceived the experience of self-tracking. The stages of self-

experimentation and reflection previously classified were identified, and the insights were gathered around them. Finally, the quantified self community has been investigated, to further explore insights taken from the context review and the trends chapter. In this manner, the insights from the users were grouped in the form of identified pains and gains.

To ideate on a product service system that matches tackles both groups of interest, the value proposition canvas has been adapted into a framework that brings together the interest of healthcare providers and self-trackers. The resulting proposition has been placed in partnerships and has it been validated. The proposed solution is a platform that embodies the idea of giving ownership and data governance to users and enables easy sharing with doctors, when and if users give permission. Therefore, the data is used as a material for self-reflection and dialogue in interactions with doctors.

One of the main challenges of the conceptualization was dealing with different interests and several moving parts. It was necessary to build a holistic view of the exchanges of values within the system, taking into account values important for business without losing the attention on values that are important, on an individual level, for users. The guiding principle of the designed system is trust.

Finally, this thesis tackles an exploratory future vision concept on a personal-generated data system and foster the discussion regarding data-based ethical prevention systems and what roles should be attributed to different partners, besides exposing the need for the development of a data-driven ethical business model. The concept opens directions for future investigations. For example, the threshold between the advice given by the system and the definition of medical advice needs to be explored. It is necessary to understand the ethical attributions of each stakeholder in this system. For example, if an algorithm makes a mistake when processing the data and it is not spotted by an overlooking human who should be accountable for that? In which decisions would users be willing to take part without feeling overwhelmed by the service? The only certainties are: there needs to be a mutual trust among those involved and the user experience has key importance in enabling a successful use of data for personal reflections in a collaborative manner.

# Reflection

This thesis has investigated how to design for enabling data interactions based on trust. Initially, the solution should involve mainly doctors and patients, however, the research phase has revealed the need for designing a complex system involving several moving parts. This had several impacts on different points of the project.

First, the context research and trend research had to be revisited several times. The conceptualization phase and user research phase revealed the need to explore more topics that were not initially planned. This has generated an extra workload that was essential to enrich the conceptualization phase. Thus, this reinforces that the process of research and conceptualization is not a linear path.

Second, the extra workload had an impact on time management. The research phase has taken more time than it was initially expected. A delay in obtaining the wearables to conduct the trial contributed to holding this phase. Although this unforeseen circumstance was

supposedly covered by a buffer time initially planned to deal with eventual problems, the results from the trial implied in revisiting the literature research. Ignoring this back and forward process after the user trial would have compromised the outcome. Thus, when planning a project it is necessary to pay attention to the cascade impact of a delay in a way that does not consider only the next steps.

Third, tackling a complex problem within the limited time frame, meant that the technologies were not deeply explored. This is a limitation of this work. Also, the validation process ideally should involve more representants of other stakeholders' group. Unfortunately, again, this was not possible due to the limitation of time of this work and the availability of such stakeholders.

Finally, approaching a complex system has contributed to a rich discussion and learning experience from a designer point of view. This work deals with several ethical challenges in designing for personal data. Therefore,

it reinforces the role of designers as those who should embrace these discussions in interactions between humans and technology. Moreover, this thesis has dealt with the exchange of data and values. It has been discussed how data, despite its aseptic and objective nature, it embedded with human values and human context. Those are far from being objective and designers need to be able to deal with his reality in a world where several data-based solutions are being developed.

# Some bits of advice for fellow master students

## **1. Do not lose track of your health.**

When you are working on your thesis and enjoying the topic, you might not notice that your health is in trouble until it hits you. Besides that, the thesis is a time when several concerns came to your mind, you need to find time to find yourself a house, to find a job, manage your financial resources... If you have more things happening in your personal life, that might be too much to deal with. Keep your friends around, that is always helpful.

## **2. Plan some buffer time.**

Delays can happen when you request equipment or need to schedule interviews. The impact is bigger than the actual delay to perform the action, it might freeze your progress for some time and result in an overload of work impossible to meet (especially when it comes to generation of ideas).

## **3. Reserch project**

Do a research project before graduation, this will help you to get familiar with your topic and start at full speed.



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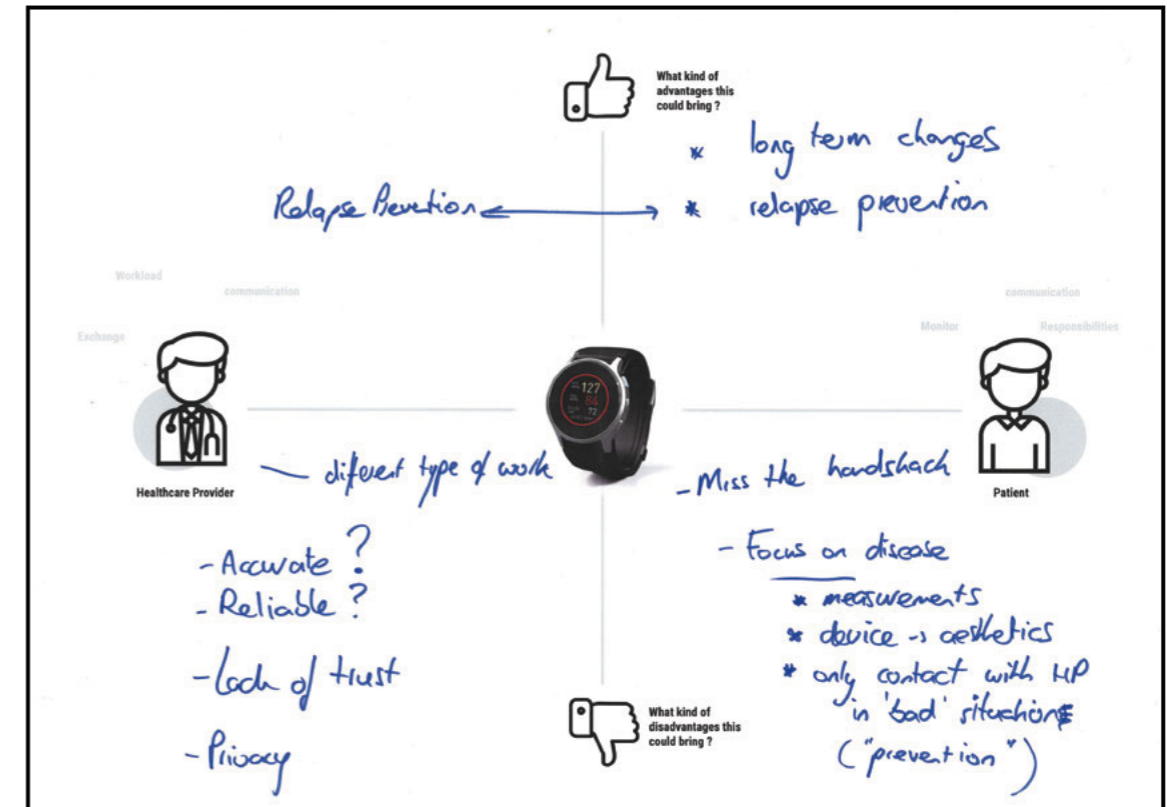
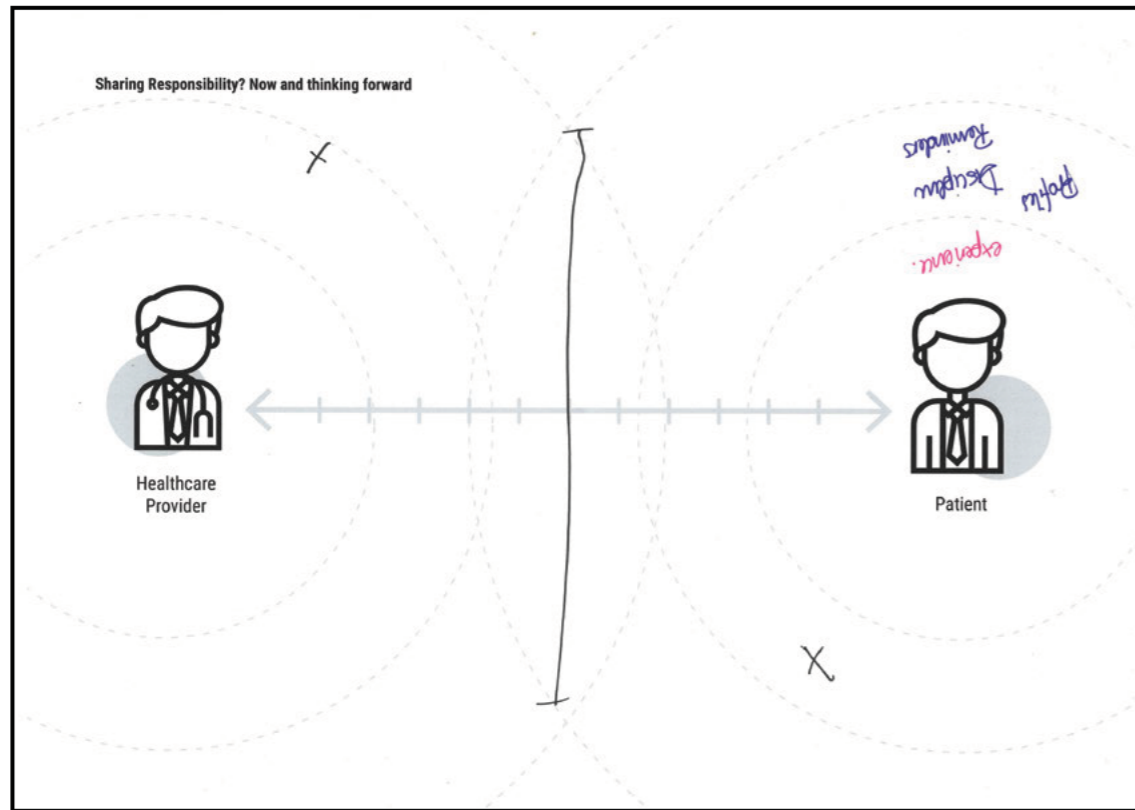
Zhang, Y, Li, D., Zhang, C., & Zhang, H. (2019). Quantified or nonquantified: How quantification affects consumers' motivation in goal pursuit. *Journal of Consumer Behaviour*, 18(2), 120–134. <https://doi.org/10.1002/cb.1752>

# Appendix I

The initial Brief

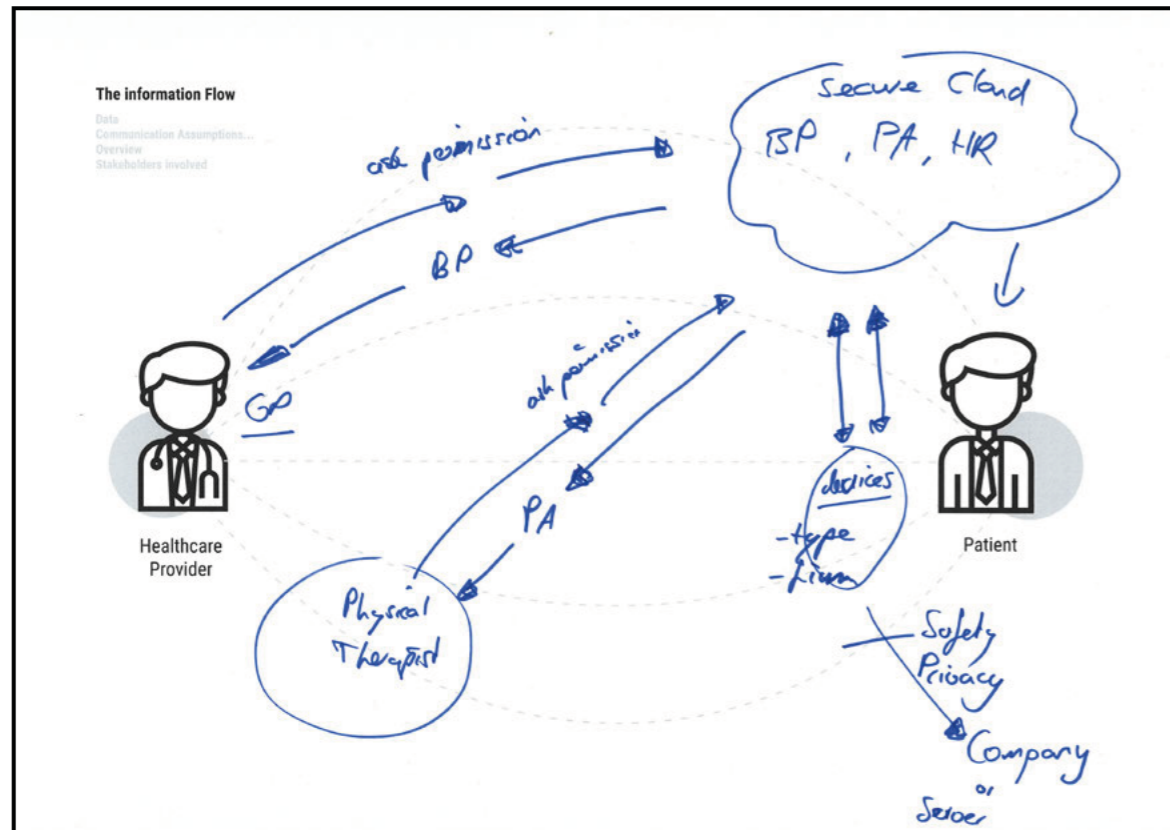
# Appendix II

Examples of filled in materials that were used interviews with the healthcare professionals



# Appendix III

The booklets and examples of filled in pages



**MY SELF-TRACKING**  
EXPERIENCE

This study is part of a master thesis developed in the Cardiolab. You can always refer to the student in case of any questions regarding this material.

You will be referred by a pseudonym in this thesis, you are free to choose another name for yourself. You will not be identified in this thesis.

My pseudonym is: \_\_\_\_\_

You should not use any of the data you obtain by wearing such devices as medical advice. In case you find something that you think is relevant for your health, you should refer to a doctor.

During the next two weeks, I will ask you to measure your blood pressure at least twice a day, during the morning (refer to pg. 6) and in another moment of your own choice, feel free to skip the weekends if you wish. Be honest in case you are forgetting to measure it and comment about it in the booklet. That is also something important to know.

During some moments you will be contacted through WhatsApp regarding this experience. Feel free to send information about your experience, like a screenshot of your phone with some data you think is important and any other thoughts that came to your mind and you feel like sharing.

At the end of those two weeks, I will ask you to return the devices.

By taking part in this study you agree with the conditions above  
Thanks for joining!

## FITBIT

1. Download the Fitbit app from GooglePlay or the Appstore
  2. Create an account and verify your mail
  3. Pair your device with the Fitbit app.
- Done!



## OMRON DEVICE

Download the Omron connect app from GooglePlay or the Appstore

1. Create an account and verify your mail
2. Pair your device with the Omron connect app
3. Run a proof measurement and make sure the results are available on the app (refresh synchronization if necessary - by dragging down the home page screen in the app. Make sure your bluetooth and GPS are on while refreshing).

Done!



## FITBIT

Wear the Fitbit whenever you'd like to have steps, HR, distance, calories, etc. You can check your data on the Fitbit app and compare it with your blood pressure data.

## BLOOD PRESSURE

1. **Some advices:**
  - a) Set up two daily alarms on your phone, one on a moment in the morning in which you expect to have time to take a BP measurement, and one in the afternoon. This way it will be easier to remember to take measurements at the same time.
  - b) Find a suitable spot for the Omron device case; your coat pocket, your backpack, the bag you use at work.. something you usually carry around with you. This way it will be easier to avoid forgetting it.
2. **Take two measurements a day, one in the morning and one in the afternoon**, plus whenever you want during the rest of the day. Feel free to take other measurements besides the regular ones if you want to observe your Blood Pressure under different conditions.

**3. To take measurements, follow these guidelines;**

a) Take 5 min of rest. Exercise, eating a large meal, use caffeine, drink alcohol or take decongestants for 30 minutes before should be avoided. Using the bathroom before taking the BP is advised.

b) Sit in a quiet room with your back and arm supported; the legs should not be crossed, and the feet should be kept flat on the floor.

c) Two measurements should be taken every time, performed 1–2 min apart. Additional measurements are required only if the first two consecutive readings differ by >10 mmHg.

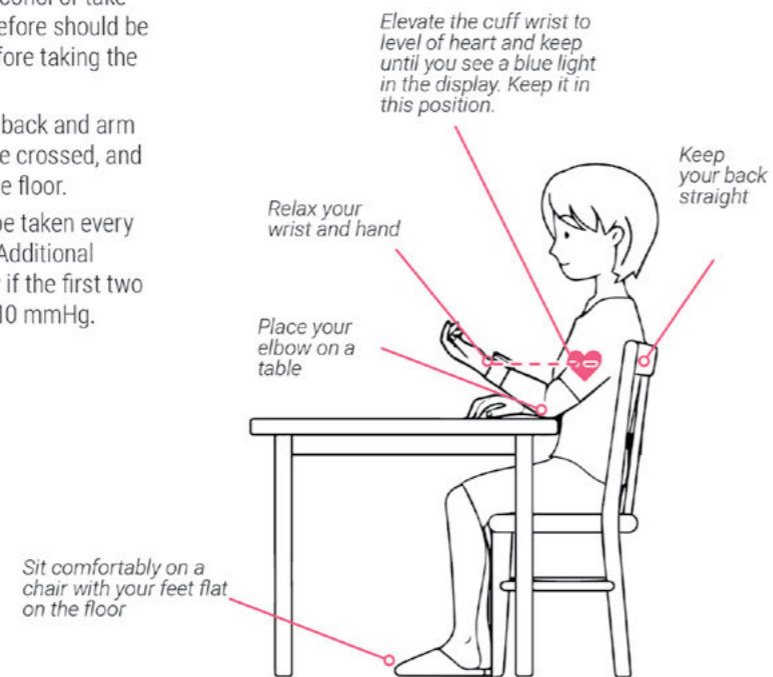
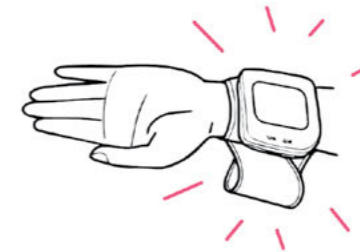


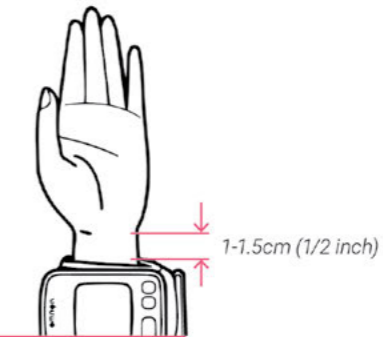
Image adapted from <https://www.healthcare.omron.co.jp/zeroevents/english/bloodpressuremonitor/howtouse.html>

d) Place the cuff according to the following guidelines:

- Wrap the wrist cuff firmly around your wrist. Do not apply the cuff over clothing.
- Wrap it around either the right or left wrist, just make sure to always measure on the same side.



- Position the cuff leaving a space of about 1-1.5cm (1/2 inch) between the cuff and the bottom of your palm. Do not cover the wrist bone.



Instructions and Images adapted from <https://www.healthcare.omron.co.jp/zeroevents/english/bloodpressuremonitor/howtouse.html>

# MY SELF-TRACKING EXPERIENCE

## DAY 01

Circle the statements that fit better your experience with the instructions provided.

- a) The instructions provided on the booklet were clear enough.
- b) I had to read the manual as well to be able to perform the measurement.
- c) I have read the manual because I always read this kind of manuals.
- d) I have searched this Omrom| Fitbit (circle the one you have searched) on google to know more info about it.

e) I'm too cool to fit in standards statements, so I'm gonna write/draw my own answer in the space below:

I have the feeling I miss info and I should research more  
but I am too lazy to read the manuals.  
Thank god the apps explained what to do.

9

## DAY 01

How do you feel about self-tracking your data? Circle the feeling(s) that match the way you feel today about this experience:



1. Frustrated



2. Annoyed



3. Suspicious



4. Indifferent



5. Confident



6. Determined



7. Relaxed



8. Excited



9. Satisfied



10. Other

10

## WHY DO FEEL THIS WAY?

Tell me in a few words why you are feeling this way. You can refer to the feelings indicating them by numbers if you feel lazy.

---

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## DAY 03

Is this your first experience with self-tracking devices (circle yes or no)? Yes/No

If "yes", which device have you used before? \_\_\_\_\_

Why have you tracked yourself? \_\_\_\_\_

---

11



## CHOOSE ANY DAY OF THE 2ND WEEK

Ok, now you have been tracking yourself for a week! Tell me about an average day of your life. When do you usually check your data?

Point out on the line below in which moments do you usually:

1. Measure your Blood pressure?
2. Check something on your Fitbit on your wrist (steps, how many floors you have climbed, etc.)
3. Check something on your Fitbit App (ex. graphs on your cellphone).



I remove my fitbit before showering for 2 reasons  
 → I don't want to dry it, it's uncomfortable  
 → I'm paranoid about getting it wet

I often check on my phone how I slept  
 I check my fitbit on the way to see how much time I have now (I used to do it with my phone)

Point out some things like when do you have your main meals, exercise or anything else you feel it is relevant to describe your day.

12

Add some comments about the **reason** why you check your data! For example:



I struggle to remind myself to check my pressure with OMRON  
 LUNCH TIME!  
 12:00 pm

time to return to my home  
 → 5:00-6:00 pm on the train approx.

dinner time  
 cooking every other day

Daniela you need to take your pressure!  
 (I struggle with it)  
 ; but it's easier than in the morning with so many distractions

it can be later...

13

## DAY 13



Wow! What an accurate portrait of you!  
Please, personalize it as you wish :)

Day 1

Please, Take a moment to reflect.

During this days you have been able to see several aspects of your day in a quantified manner. What did it mean to you? Think about:

1. What impact seeing such things about yourself had on your life? Both positive and negative aspects are interesting.
2. Did you change something on your routine after starting this self-monitoring experience?

14

How do you portrait yourself now?  
Please, personalize it as you wish :)



Day 13

① I was engaged with steps tracking which was new to me, so that made me be a bit more active along the day.

Some notifications were nice reminders and some were distracting when I was concentrated on a task.

I was not longer aware of the bike computer along the day (comparing speed, cadence) but focused on the fat bit.

② I started begin more aware of the daily steps while working. created a blood pressure schedule. Before and after my day.

## DAY 14

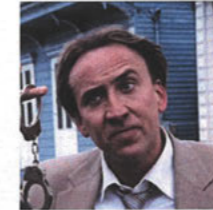
He is back! How do feel about self tracking your data? Circle the feeling(s) that matches the way you feel today about this experience:



① Frustrated



2. Annoyed



3. Suspicious



4. Curious



5. Confident



6. Determined



7. Relaxed



⑧ Excited



9. Satisfied



⑩ Junkie

15

# Appendix IV

Examples of posts collected from  
the Quantified Self Forum

## Service to combine and analyse all your data?

Quantified Self

Jan '17

Is there a (web) service that allows you to upload data/connect APIs from different sources so you can combine, correlate and analyse the data?  
I'm currently doing this in Excel, but that's not very convenient and you might miss (important) correlations and it's a pain to maintain.

1 Like



Reply

Jan '17

I agree with you. I think part of the usefulness of any information system depends on how intimate the user is with the way it works and how it is built. This translates to transparency for the user and transparency = trust. In the area of self-tracking, we are dealing with very personal data, and I feel it is only natural that the system managing this data is personal in similar ways too.

This puts commercial providers at a disadvantage in terms of accessing the full breadth of our personal data (i.e. we have to be willing to upload it). They have an advantage, however, in terms of innovating in the processing and algorithms that make sense and unlock insight from this data. As AI and Machine Learning become more and more prevalent, I suspect even do-it-yourself'ers will be tempted to tap into the insight-generating power offered by commercial personal health and wellbeing algorithms in the cloud.

3 Likes



Reply

16 DAYS LATER

8d

Thanks! That makes sense, if you're tracking something granular like that, it does make a lot more sense! I used a CGM when I had gestational diabetes last year, but mainly just as a rapid feedback mechanism to learn which foods were "safe". I never exported the data.

So... my experiment still isn't started. A couple reasons...

1. I fell off track on food tracking entirely, whoops
2. I really want to try the one-button tracker. In fact, I used it for a day, and the experience of it was interesting! But it's actually a bit broken. @ guessed the GPS chip wasn't connected, so I opened it up - yup, a loose wire. He showed me where it should go, and I've ordered a soldering iron.
3. I'm also really interested in logging data via self-survey, and in particular want to try setting something up using MindLogger. Anisha Keshavan shared an example on how to do this (an example "hangry" survey, haha), and I still want to try setting something up!

Maybe next week. 😊 I'm enjoying exploring tools.

Reply

## Experimenting with diet & diet log / mood / hunger tracking

Quantified Self Project Logs

Hi all! As mentioned by in his own post we have a small, fun group of folks that are exploring self-experimentation.

You're welcome to join! You can read more about the idea & motivation here:  
<http://openhumanfoundation.org/DIYExperiments/>

My upcoming plan is to test this question: "Does intermittent fasting work for me?"

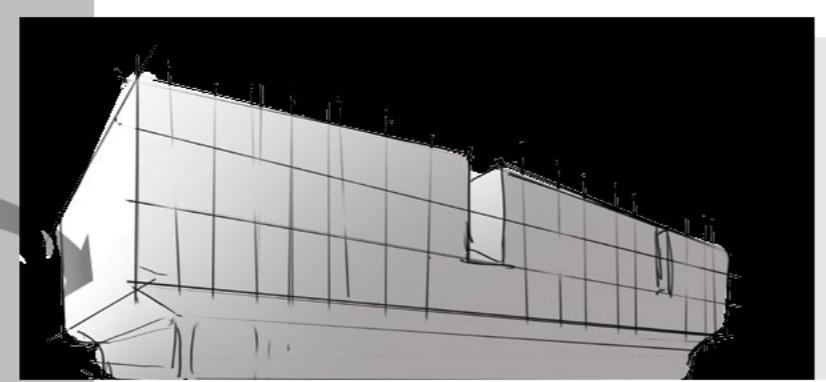
Boring for you, but it matters to me! I've lost points and I'd like it to stick. 😊

### My plan

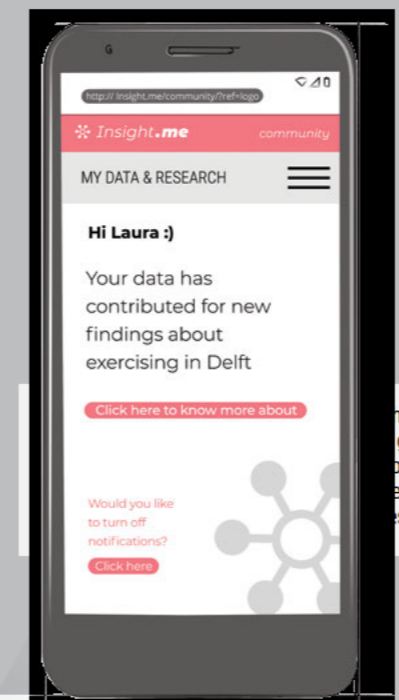
- Test between two conditions:
  - **Condition A:** only eat between 12pm-8pm
  - **Condition B:** have 300-400kcal breakfast
- Alternate every week, a total of 6 weeks: **ABABAB**
- Track "adherence" (sticking to plan) via diet logs (I've been using MyFitnessPal)
- Track "outcomes" via mood tracking, 1-button tracker (distracted/annoyed by cravings), weight logs (Withings scale)



# Scenario of sharing data for research



The municipality has access to her and other participants' data who have to opt for sharing it for population healthcare purposes.



She sees a notification. It gives her feedback about how her data has been contributing for research.



She reads most individuals in Delft South are having a sedentary lifestyle. She is an exception. Thus, she is invited by the municipality to participate in a co-creation session. The session aims to elaborate policies to stimulate physical exercise in the region. She decides to get involved and feels great about participating more in this research.

Using a wearable through insight. She is interested in monitoring her heartbeats per minute and the distance she is able to run. She wants to run in a marathon, thus, it helps her to track her progress.

Attracted by the idea of leasing it, it would be cheaper than buying a new smartwatch to help her to monitor her heartbeats. She finds it interesting that, as Insight.me pointed out, her resting heartbeats per minute have gotten better when compared to her initial mark. In three weeks she got this feedback. It was interesting!

She agreed, when she signed up, to share her data for populational research.



After 4 months, she has run her marathon. Now, she is exploring other features from Insight.me. She checks the open calls to participate in research.

These calls prioritize researches that match the interests she has set up when she joined the service. She can always change those in her profile.



Later on, she decides to explore other types of data in Insight.me. She selects Blood Pressure. The wearable collects this data but she does not know much about it, so she gives it a try.

The system suggests factors that can influence it and she tracks in case she wants to set up an experiment. She is triggered by Blood Pressure and perceived stress. She wonders how blood pressure can be influenced by physical evidence when she is feeling nervous. She decides to experiment it, and Insight.me helps her to form it.

# Appendix VI

TheBusiness  
model canvas

