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Offbeat: Datafication, Personalization, And Temporalities In Remote Cardiac Monitoring

THÈSE

Présentée à la Faculté des sciences de l’Université de Genève
Pour obtenir le grade de Docteur ès sciences, mention: Interdisciplinaire

Par

Martina Rebecca VON ARX-MAEDER

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Thèse de Madame Martina Rebecca VON ARX-MAEDER

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«Offbeat: Datafication, Personalization, And Temporalities In Remote Cardiac Monitoring»

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To all those who find joy in little things

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Technical Terms and Acronyms

AF: *Atrial Fibrillation*, an irregular and often very rapid heart rhythm that can lead to blood clots in the heart. AF increases the risk of stroke, heart failure and other heart-related complications.

TIA: *Transient Ischemic Attack*, temporary period of symptoms similar to those of a stroke, also called a mini-stroke.

ECG: *Electrocardiogram*, a recording of the electrical signals in the heart to detect heart problems.

ICD: *Implantable cardioverter-defibrillator*, a battery-powered device connected to the heart continuously monitoring the heartbeat and delivering electric shocks, when needed, to restore a regular heart rhythm.

MRI: *Magnetic Resonance Imaging*, medical imaging technique using a magnetic field and computer-generated radio waves to create detailed images of the body organs and tissues.

Syncope: A brief, self-limited, transient loss of consciousness that may or may not be caused by heart arrhythmias.

1 Introduction

After an early morning train ride, a nurse picks me up at the main entrance of one of the university hospitals in Switzerland for an exploratory visit. It's June 22, 2020, and the country is just recovering from the first wave of COVID-19 infections. Public facilities have only recently reopened to the public. Most other preventive measures, except for physical distance and mandatory masks, are lifted.

The nurse hurries ahead, telling me on the way that the day will be busy. At the ward, I am dressed in white clothes. With me disguised as an insider, we join her colleagues in the room where they are preparing the insertion of a cardiac monitor. A short time later, the patient shows up. Before the nurses start with the insertion, I receive a disposable medical cap to comply with hygiene measures. Keeping a large distance from the patient's bedside, I watch in amazement as the two nurses work together. When one of the nurses injects local anesthesia into a patient, a shiver runs through me, even though I am usually not sensitive to syringes or blood. I try to breathe calmly. Nevertheless, my heart begins to beat faster, and I feel hot flushes flowing throughout my body. Although I am terribly embarrassed, I spontaneously sit down on the floor to avoid fainting. Immediately, the nurses focus all their attention on me. They insist that I sit down on one of the empty patient beds and not on the floor. Finally, I do as I am told. They also give me a bottle of water and my body soon calms down.

Thus began my research journey into the world of telecare. It remained my only dizzy spell throughout my fieldwork in contrast to certain patients I met throughout my research. While the cause of my palpitations was most likely due to the anesthesia scene, there are patients whose heartbeat gets out of sync for no apparent reason. Although most arrhythmias are harmless, certain types can make you sick, cause anxiety, or even trigger a stroke. To be treated, a heart arrhythmia must first be detected. However, like earthquakes, heart arrhythmias can occur infrequently, pass quickly, and/or do so without noticeable symptoms (Jones 2013). Since this is the case, they are difficult to detect with conventional examinations such as an ordinary electrocardiogram.

The only possibility to detect the next episode of such an arrhythmia – if there is a next episode at all – consists of continuously monitoring the heart rhythm. This in turn requires that a measuring device accompanies patients everywhere. The hope is that such a device will be able to detect irregularities in the heart rhythm that precedes potentially life-threatening arrhythmias, allowing for timely diagnosis and treatment. Based on this hope, medical device companies began to develop cardiac monitors in the early 1990s. Since then, the devices have shrunk from the size and weight of a lightweight hockey puck to barely the size of a pinky, weighing about a nickel. These cardiac monitors, also called implantable loop recorders, can be inserted under the skin and above the heart with minor surgery. But as the cardiac monitor continued to shrink in size and weight, hopes and expectations for timely diagnosis grew. With this hope came the promise that cardiac monitors would make medicine look ahead. But instead of telling the story of a sophisticated technology, this research will tell several inter-linked stories about how algorithm-based telecare is uncoupling data collection, transmission, and interpretation. This does not only impact how, when and where diagnoses are made but also alters the conditions for doctor-patient relationships. As a result, both cardiologists and patients lack certain contextualization. Cardiologists have more than enough data but miss the circumstances under which they were produced. Patients receive a technology promising high hopes and reassurance but lack medical feedback. Since the script of doctor-patient relationships continues to be shaped by the ritual of establishing a diagnosis (Rosenberg 2002), these changed conditions lead to mutual misunderstandings and sometimes even offbeat scenarios.

According to the Merriam-Webster online dictionary, the term "offbeat" has two meanings. As a noun, it refers to an unaccented beat in music. As a colloquial adjective, it can mean "unconventional, eccentric" (Merriam-Webster Dictionary 2023). Both the reference to a rhythmic pattern and the description of something offbeat resonate well with the research topic of this dissertation. The choice of the term "offbeat" for the title of this dissertation was driven by two intentions. On the one hand, it is a literal reference to the main health problem of the present case study, which is cardiac arrhythmia. In other words, the heartbeat is offbeat, or out of sync. On the other hand, I wanted to make a metaphorical reference to the larger scientific discussion initiated by this study, which seems to indicate that algorithm-based telecare reconfigures, and to a certain extent, depersonalizes traditional doctor-patient relationships, taking it off the beaten path. It requires human synchronization of people and data to bring it back on track and make it meaningful again. This is especially important in the context of medically unexplained symptoms such as suspected arrhythmias, where both cardiologists and patients face the uncertainty of not knowing exactly how life-threatening the unknown risk of a new episode is.

Ever since I started studying sociology, I have been fascinated by everyday technologies and practices rather than extraordinary topics and experiences. During my studies, I was interested in how people choose their seats in trains, how teenagers relate to their smartphones, how families live in multilocal configurations, or how healthcare professionals deal with regret related to clinical situations that did not develop as expected. With cardiac monitors, I once again found a device that, while seemingly sophisticated, is still treated with a certain amount of disregard by both cardiologists and company representatives, especially in comparison to powerful devices such as pacemakers or defibrillators that can intervene and save patients' lives. All the cardiac monitor does is continuously observe the heart rhythm and record all offbeat patterns according to the programmed thresholds. As a result, patients who receive a cardiac monitor because of a suspected arrhythmia are only monitored, and not treated, with the device. In the most extreme case, cardiac monitors could record a person's last, fatal arrhythmia. Whether or not patients suspected of having arrhythmias receive immediate treatment or long-term continuous monitoring with a cardiac monitor is a decision based on risk assessment by cardiologists and patients.

Considering the work of previous researchers who have pointed to an increasing focus on quantifiable risks in medicine (Aronowitz 2015; Beck 1992; Bourrier and Burton-Jeangros 2014; Clarke et al. 2021; Prainsack 2017) the case of remote cardiac monitoring is all the more interesting, because it does not reduce or resolve the risk situation through its implementation.

1.1 What problem does continuous patient remote monitoring solve?

When I arrived at the hospital one morning to conduct ethnographic observations for this study, the nurse excitedly told me that the cardiac monitor of the market-leading medical device company had played an important role in the popular German crime drama "Tatort" ("Krank," episode 1141, October 25, 2020) and had helped the team of investigators solve the case. She also wondered if it had been a product placement. However, as it is commonly portrayed for detective work in popular representations in films and television shows, the simple combination of facts and figures cannot be compared to the approach clinicians use in everyday clinical practice to solve medical mysteries (Groopman 2008). Clinicians' contemporary diagnostic work is based on continuous risk assessment, which makes it a "collective, cumulative, and contingent process" (Rosenberg 2002:256) and not something to be revealed by applying the right instrument at a specific moment of time.

Nevertheless, the market-leading medical device company advertises its cardiac monitor on their website as granting "unmatched accuracy," "reimagined connectivity," and "stream-lined workflow" (Medtronic 2022). More specifically, the company promotes to deliver the "world's most accurate" cardiac monitor which can be "personalised for the patient's lifestyle and customised for the clinician's workflow."

Their promises tie in with the vision of *personalized health* to provide the right medical intervention to the right patient at the right time with the help of large integrated data sets (Erikainen and Chan 2019). Although no clear terminology prevails, several scholars have noted the predominance of quantified biomedical data (Cesario et al. 2021; Hoeyer 2019; Prainsack 2017). The vision of *personalized health* consists of creating an all-encompassing biomedical data conglomerate of every individual to achieve a more tailored healthcare, leading away from the "trial and error" approach of the past. The ideal of such a *technoscientific holism* (Vogt, Hofmann, and Getz 2016) would comprehend and combine all kinds of measurements from birth to death, making them actionable for medicine.

In contrast to treatments, diagnosis has been determined by numbers long before evidence-based medicine brought medical research and practice closer together (Weisz 2005). Although the development of tests and techniques to measure, visualize, and decipher the human body are multiplying, there is no guarantee of a conclusive diagnosis. Medicine is an uncertain practice by nature (Fox 2000), affecting doctors (Groopman 2008) and patients (Nettleton 2006) alike. Hence, doctor-patient relationships have increasingly become guided by probabilistic logics, aiming at preventing potentially adverse outcomes (Aronowitz 2015). These risk-centered approaches cannot be based on a single medical assessment, but must rely on continuous monitoring, re-evaluation, and adjustment. Thus, establishing a diagnosis takes time, especially in the search for rare and elusive heart arrhythmias. It has become clear that determining a diagnosis is a long-term project of knowledge co-construction within patient-doctor relationships. This runs counter to both the imaginary of ever-ready knowledge held within patient bodies and the promise of *personalized health* suggesting that comprehensive measurements are all it takes to establish a diagnosis.

This gap between actual medical practices and patients' expectations seems to be especially salient for digital technologies which have much in common with everyday devices such as smartwatches. Monitoring technologies are generally used to continuously collect information on a specific physiological measurement. With the help of an implanted sensor like the cardiac monitor, patient data are systematically collected and regularly transferred to healthcare professionals. As Lupton noted, scholars do not yet fully understand how such digital technologies transform doctor-patient relationships (Lupton 2017:131). Understanding digital technologies as new forms of connectivity between doctors and patients allows scholars to account for ambivalences in the reconfiguration of these relationships (Henwood and Marent 2019). Like the introduction of the telephone by the mid-twentieth century, patient remote monitoring conveys the idea of a doctor who is always available (Greene 2022). However, unlike the phone, where the connection has to be re-established again and again by dialing the correct number, in remote cardiac monitoring, the automated data connection implies a constant link between the patient and the doctor. Previous research has shown how telecare has reshaped care practices, referring to the new form of connection between patients and doctors with terms such as *asymmetrical digital proximity* (Oudshoorn 2011), *digital intimacy* (Piras and Miele 2019), or a form of *together management* (Pols 2012). However, little is known on how this new form of patient-doctor connection and evolves over a longer period, such as it is the case for the diagnosis of unexplained symptoms.

According to an employee of the market-leading medical device company I interviewed, cardiology units in Switzerland are currently number two in terms of stroke care and patient follow-up in Europe. For syncope patients, Switzerland is among the top 5 in Europe, although telecare follow-up is far more developed in Austria, the United Kingdom, and the Netherlands. The interviewee explained that while the "pretty decent" national reimbursement policies would encourage the implementation of telecare in Switzerland, the decentralized organization of the Swiss healthcare system would be a major obstacle. Hence, studying the case of remote cardiac monitoring in Switzerland is also relevant to better understand implications of algorithm-based telecare for healthcare systems of high-income countries.

Overall, neither the paradigm of quantification nor telecare are recent developments. First, medical expertise has been challenged and advanced by quantified evidence at least since the 19th century (Weisz 2005). Second, telecare has evolved alongside the spread of telecommunication technologies, starting with the telephone network, image, and video transmissions and of course, the internet (Greene 2022). However, the shift from snapshot measurements to continuous monitoring, and from symptom-based to algorithm-based telecare have profound consequences for how, when, and where a diagnosis is made.

1.2 Outline of the chapters

Chapter 2 introduces the theoretical backbone that served to design and conduct the qualitative data collection for this dissertation. The literature review discusses the challenges posed by the probabilistic paradigm of contemporary risk-oriented medical practice. Drawing on the notions of risk, quantification, and uncertainty, this chapter frames the research question about the reconfiguration and (de)personalization of doctor-patient relationships in algorithm-based telecare.

Chapter 3 describes the methodological approach by describing the study sites, data collection, and analysis. It also provides an overview of remote cardiac monitoring in Switzerland. In addition, two subsections are devoted to ethical considerations and the way in which the COVID-19 pandemic influenced the research process.

To give the reader an impression of the importance of the longitudinal perspective on diagnosis, especially in algorithm-based telecare, the result chapters are organized in chronological order. Presenting results this way also allows me to better illustrate how the processes of data collection, transmission, and interpretation become uncoupled in remote cardiac monitoring. Thereby, I want to emphasize the importance of time for the reconfiguration of the doctor-patient relationship. The result chapters will illustrate what happens *simultaneously* in the same place (insertion and removal of the cardiac monitor, Chapters 4 and 8) and what occurs in a *parallel or time-delayed* manner, at different places (at the patients' home and at the hospital, Chapters 5-7). I use the chapters' subsections to regularly contrast cardiologists' and patients' perspectives according to chapter-specific issues.

The patient trajectory starts with the insertion of the cardiac monitor at the hospital. Chapter 4 delivers a description of the insertion procedure and shows how the cardiac monitor becomes a symbol of hope to finally detect the arrhythmia suspected of causing the patient's unexplained symptoms or stroke. Moreover, it discusses the need of the flawless interplay of ordinary infrastructure, business, and medicine to set the stage for such high hopes.

The next three chapters question the nature of digital connectivity in remote cardiac monitoring. Chapter 5 asks to what extent this connection provides reassurance to cardiologists and patients. Most of the chapter is devoted to the reassurance effect on patients, as it seems to be more relevant to them than to cardiologists. In particular, patients' sense of being well cared for was not affected by the ambiguities and doubts that remote cardiac monitoring raised in their minds once they were at home.

Chapter 6 questions the notions of immediacy and urgency in the diagnosis of arrhythmias by asking to what extent remote monitoring provided a direct connection between healthcare professionals and patients. It shows how patients succumbed to the “illusion of the immediacy” conveyed by the idea of being permanently connected to the hospital as they knew it from other data networks. However, while the cardiac monitoring takes place round the clock, data transmission only happens at night and data review and interpretation only during office hours from Monday to Friday. The chapter also discusses the privileged knowledge position of healthcare professionals and how their different perceptions of urgency, in part due to the fine-grained knowledge that tele-nurses had acquired over time, lead to tensions between them and cardiologists as final decision-makers.

Chapter 7 discusses the impact of time on digital doctor-patient relationships. It illustrates how remote cardiac monitoring lost its relevance in patients' daily lives, changing from a fancy, sophisticated tool to a mundane companion. This was largely due to the discrepancy between patients' embodied experiences and the lack of feedback about the measured evidence from the cardiac monitor. This led them to question not only the usefulness of the technology as such, but also its very purpose, demonstrating that the digital connection could not sustain mutual trust between cardiologists and patients.

The final results chapter deals with the removal of the cardiac monitor in the hospital and provides insight into the conclusion of patients’ remote cardiac monitoring journeys. Chapter 8 shows how the cardiac monitor had gone from a symbol of hope to a simple piece of electronic scrap that patients were happy to get rid of. For some, time had done the trick in regaining trust in their bodies, but all patients appreciated the final doctor-patient appointment where they were again declared to be healthy. Thus, the chapter shows that the face-to-face medical contextualization is important not only for diagnosing but also for relativizing the lack of a definitive diagnosis needed to undo patients.

2 *What if…*? Risk, datafication and telecare in medical practice

What if you had decided to see your doctor sooner? What if your doctor had continued to examine your body instead of sending you home with painkillers? What if there was a technology capable of anticipating a bad health outcome independent of patients' own body perception and the doctors' expertise?

Current medical practice revolves around *risk* (Aronowitz 2015). Whereas doctors have always tried to prevent patients' conditions from worsening, medical practice is increasingly dominated by probabilistic risk assessments and preventive treatments. As Aronowitz (2015) argues, most medical interventions which are framed as disease treatments are essentially risk-reducing actions (p. 11), whose efficacy is understood in terms of the "reduction in fear, banishing uncertainty, and reasserting some control over feelings of randomness" (p. 6). Although this orientation is not only specific to medicine (Beck 1992), it concerns a sensitive area of life for all of us, since we all become patients sooner or later in our lives. This is especially true for high-income countries such as Switzerland, the geographical focus of this dissertation, where an aging population with chronic diseases will be one of the major challenges for the coming decades (Prince et al. 2015). This risk-oriented perspective on health has permeated into public awareness. The COVID-19 pandemic has provided a vivid example of how different national governments and population groups have sought to strike a balance between health risks, economic considerations, and individual rights. While preventive care, especially in public health, has done much to improve the health of the population, the risk-centered orientation of medicine also increases uncertainty about how much screening and treatment is medically appropriate and socially justifiable. Risk-oriented health discourses in high-income countries expose doctors and patients to an unsolvable dilemma: How many medical tests are necessary and useful to prevent health deterioration, and how many are too many, provoking more uncertainties or having unexpected or even harmful side-effects? For doctors, these considerations can put into question their role as diagnosticians and bring up the limitations of their expertise (Groopman 2008). For patients, this uncertainty can translate into considerations about when it is appropriate to seek medical help in the first place, and when to become proactive and demand further investigation from doctors or other healthcare providers (Armstrong 2014). Such risk assessments are at the heart of the traditional doctor-patient relationship, no matter how paternalistic these discussions may continue to be (Oh Nelson 2021). In this dissertation I assume that the traditional doctor-patient relationship is characterized by shared decision-making (Charles, Gafni, and Whelan 1997) that occurs in shared space and time. Shared decision-making in medical practice is based on the following 4 key components according to Charles et colleagues (1997:681): "(1) that at least two participants – physician and patient be involved; (2) that both parties share information; (3) that both parties take steps to build a consensus about the preferred treatment; and (4) that an agreement is reached on the treatment to implement." This seemingly linear process of shared decision-making is particularly challenging in the absence of a diagnosis, when physicians and patients must agree on a risk assessment and management, which is often the case with elusive heart arrhythmias.

2.1 Managing the risk of heart arrhythmias

Broadly speaking, an arrhythmia is when the heart beats too fast, called a tachycardia, too slow called a bradycardia, or irregularly (Schweizerische Herzstiftung 2022a). Those who experience them may describe the symptoms of a tachycardia as palpitations or a racing heart, and the symptoms of bradycardia as dizziness, fatigue, or fainting. The latter is medically also referred to as syncope, a term that remains somewhat ambiguous, as a "brief, self-limited, transient loss of consciousness" can have other causes and is therefore particularly challenging to diagnose (Koene, Adkisson, and Benditt 2017:533). Further arrhythmia symptoms can include the sensation of “an irregular pulse, shortness of breath, sweating or pressure on the chest and a decrease in performance” (Schweizerische Herzstiftung 2022; my translation). Other irregular heartbeats are barely noticeable, such as atrial fibrillation, which is the most common arrhythmia in the Swiss population, affecting about 100,000 mostly elderly people (Schweizerische Herzstiftung 2022b). Atrial fibrillation is associated with 1 in 5 ischemic strokes, often with severe outcomes and significant risk of recurrence (Katsanos et al. 2020).

Although certain types of arrhythmias can cause life to end suddenly or be severely disrupted, most types of arrhythmias are not life-threatening. However, the easily recognizably vital sign of the heart rate, or its palpable effect, the pulse, has high symbolic value for many people. European popular, literary, and scientific accounts interpreted the heart as “the source of vitality, the seat of courage, and the embodiment of emotional experience” (p. 8), at least until the end of the 19th century, when the brain started becoming equally important (Jones 2013). But even today, the heart is closely associated with life, and popular medical conceptions associate its malfunctioning with (sudden) death. As a result, the experience of a heart being out of sync or associated symptoms, such as fainting, can be frightening, especially when there is no obvious cause.

At rest, the heart of a healthy person beats between 60 and 100 times per minute. Blood rich in oxygen and nutrients circulates through the body with every heartbeat. But the healthy human body does not always work like a Swiss clock, and the heartbeat can get out of sync for various reasons. Strong emotions or physical exercise might be the cause for short-term changes in the heart rhythm. Such experiences are captured by idioms like “a broken heart” or the heart “racing a mile a minute.” Nevertheless, despite this common knowledge, which we know from experience, it can be difficult for laypeople to know when they should seek medical help. It is also difficult for them to know if it is a legitimate concern. For example, should a patient’s heart palpitations be examined by a doctor? Should he or she worry, or wait and see? Depending on the patient's personal medical history, financial and geographic access to healthcare, moral values, and individual perception of risk or fear of deterioration, answers to these questions vary (Ziebland et al. 2019). Cardiovascular diseases are known to be imbued with disparities in terms of gender, race, and social class. This is true both in the form of epidemiological categories employed by health care professionals and in individuals’ embodied differences, leading to consequential health inequalities (Shim 2014). This is all the more concerning as cardiovascular diseases are among the leading causes for mortality worldwide (Kreatsoulas and Anand 2010).

In addition to the uncertainty around knowing if an arrhythmia requires medical attention, another difficulty is that it is often a temporary, self-limiting phenomenon. This is especially true for arrhythmias that are not immediately life threatening. Consequently, they are almost impossible to detect during routine office or hospital visits. Quite like earthquakes, heart arrhythmias can occur at indefinite intervals of varying duration, and sometimes even without noticeable symptoms (Jones 2013). Cardiologists therefore have no choice but to rely on patient descriptions. Although a patient's medical history can facilitate diagnosis, cardiologists should ideally be able to measure arrhythmias *in situ*, at the moment they occur, to determine if they match patient-described symptoms and to apply appropriate treatments. It is like chasing tornadoes, requiring being in the right place at the right time, or continuous and comprehensive monitoring. Unlike blood pressure or blood glucose levels, which can also fluctuate throughout the day, arrhythmias can only be detected in the very brief and rare moments in which they occur, whereas blood pressure or blood glucose levels in unhealthy people are repeatedly outside the norm.

As a result, standard medical examinations and tests of patients who describe symptoms that could be caused by arrhythmias may be inconclusive. Nevertheless, cardiologists may suspect certain arrhythmias as the cause of these patients' symptoms based on the patients' medical histories. However, these clues may not be clear enough for the cardiologists to suggest treatment options, such as medications, because of their significant side effects (Martínez-Rubio, Tamargo, and Dan 2020). Up to the 2000s, patients were sent home with a follow-up appointment for three months later and instructions to go to the emergency room if acute symptoms would occur. However, in risk-oriented medical approaches, neither cardiologists nor patients are entirely convinced by and satisfied with this option. Cardiologists may feel uncomfortable discharging patients when they do not know if the next arrhythmia episode will be life-threatening (Reyna and Lloyd 2006). Patients, on the other hand, may feel cheated without a medical explanation for their symptoms and may question if their conditions are being taken seriously (Armstrong 2014).

Long-term remote cardiac monitoring is a recent innovation that offers itself as a potential solution for such a situation of diagnostic uncertainty. Since 2010, this option is available as an alternative to regular calendar- and/or symptom-based follow-up in Switzerland. Its main advantage is the continuous follow-up over a long period of time, which makes it possible to detect rare arrhythmias, leading to an increase in clinical recommendations in recent years (Burri and Teres 2015). Remote cardiac monitoring consists of a small implantable cardiac monitor, also called a loop recorder, inserted under the patient's skin over the heart, which is often, but not necessarily, connected to a telemedical home monitoring system (Galli, Ambrosini, and Lombardi 2016).

After introducing the overall challenges of risk management in heart arrhythmias, I will first present the technology of remote cardiac monitoring in more details. This chapter will then outline the relevant sociological literature, drawing on previous work in medical sociology and anthropology, as well as science and technology studies, which guided the conceptualization of this study. Starting from the increasing dominance of quantitative evidence in medical practice, I will show how continuous automated datafication adds an additional layer of complexity to diagnostic work in medicine. Mobilizing the concepts of *quantification, risk, biomedicalization, and uncertainty*, I will discuss how algorithm-based telecare engages physicians and patients in a reconfigured relationship that challenges its traditional operating mode.

2.2 Remote cardiac monitoring: a technology challenges the traditional doctor-patient relationships

The electrocardiograph is a well-established tool to detect heart arrhythmias. Before its invention by Dutch physiologist Willem Einthoven in the early 20th century (see Figure 1), it was impossible to non-invasively measure electrical currents of the heart, leaving physicians with pulse palpitation as the only diagnostic tool (Barron 1950; Fye 1994). The electrocardiograph was so successful that it participated in earning cardiology its place as its own medical specialty (Fye 1994).

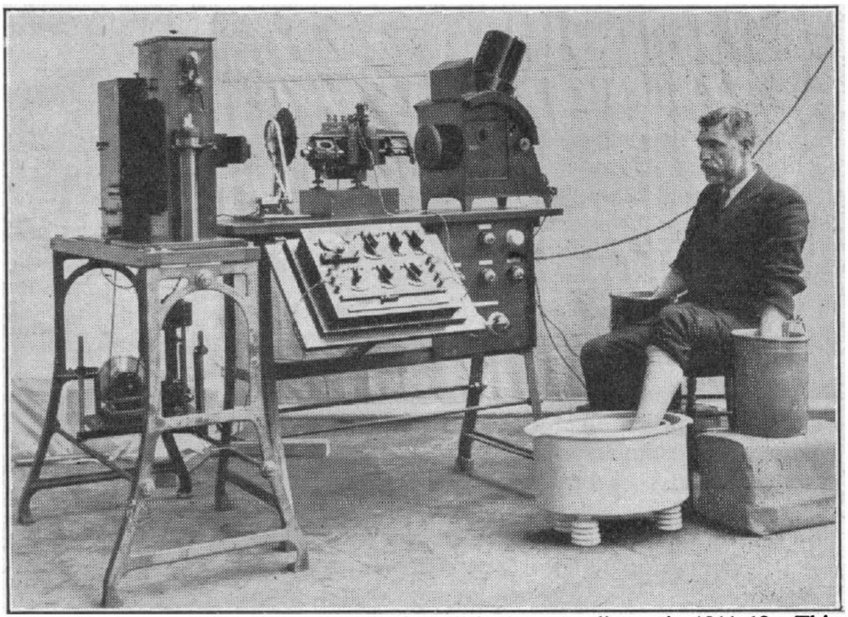


FIG. 3.—The first completed design of English electrocardiograph, 1911–12. This model was the type used by Sir Thomas Lewis (afterwards modified and added to). It may have been the actual instrument delivered to University College Hospital Medical School when he started investigations. Note the arc lamp, electrode jars, time motor, and falling plate camera.

Figure 1: One of the first electrocardiographs built based on Willem Einthoven's invention, 1911-12 (Barron 1950).

Already by the mid-20th century, biophysicist Norman "Jeff" Holter dreamed of a system that would continuously collect, transmit, and analyze all types of physiological data to detect potentially hidden diseases in seemingly normal measurement variations (Greene 2022). Enthusiastic about the emerging broadcast technologies of his time, he developed the first portable cardiac monitor that could record an electrocardiogram "on the go" in 1949 (Kalahasty et al. 2013). Within 70 years the originally a bulky backpack device became smaller and the dream of continuous monitoring more realistic.

Today, beyond cardiac care, wearables and health monitoring applications pre-installed on smartphones are omnipresent, giving third parties access to unprecedented data mining possibilities (Greene 2022). Yet, compared to private providers, clinical applications are still a niche product due to the required scientific validation that accompanies them. In effect, smartphone applications have been criticized by clinicians for their inaccuracy (Jeannot 2017; Lupton and Jutel 2015). Nevertheless, smart wearables are increasingly challenging medical practice as their diagnostic capabilities continue to improve (Campion and Jarcho 2019). We may be at a tipping point, as artificial intelligence (AI)-driven technologies are currently starting to become smaller, cheaper, easier to wear, and accurate enough for large-scale medical use (Maurizi et al. 2023).

Similarly, since the early models of the “Holter” monitor, cardiac monitoring devices have become smaller and lighter. “Holter” monitors are still used for 24-hour, 48-hour, or 7-14-day ambulatory electrocardiograms. Cardiologists often suggest these to patients in the hope of detecting suspected arrhythmias within these time frames. Other conventional diagnostic tests for arrythmias include x-rays, echocardiography, or an electrophysiology study (Deftereos et al. 2016; Schweizerische Herzstiftung 2022a).

If these standard tests or short-term cardiac monitoring strategies do not yield results, cardiologists may recommend implanting a loop recorder (Graf et al. 2007). A loop recorder is a small cardiac monitor with two electrodes on each end that is inserted under the skin and over the heart. The insertion requires minor surgery with a low risk of complications. The implant is capable of storing a single-lead electrocardiogram, which is produced automatically using various algorithms or upon patient activation in the event of symptoms with the help of a remote control (Breitenstein 2018). Current cardiac monitors (see Figure 2) are about the size of a pinky (the hard component; the antenna of the Biomonitor is flexible), weigh about 4 g, and are made of titanium, sapphire, parylene, silicone, or iridium components that protect the electronic devices and make them compatible with human tissue.

Figure 2: Cardiac monitors from the left to the right: BioMonitor III (Biotronik), Confirm Rx (Abbott) and Reveal Linq ILR (Medtronic), approved for use in Switzerland (Schreiber et al. 2022).

In Switzerland, the insertion and removal of cardiac monitors and remote follow-up are covered by the basic mandatory health insurance. This makes Switzerland a rather unique case in Europe, where there is a wide diversity in reimbursement policies regarding remote monitoring of cardiac implantable electrical devices (Boriani et al. 2022). This is not the only peculiarity of the Swiss healthcare system, which is one of the most expensive in the world (Schweizer Monitoring-System Sucht und nichtübertragbare Krankheiten (MonAM) 2021). Depending on the criteria used, Switzerland's healthcare system is most similar to that of the United States, with high universal coverage, mandatory insurance schemes, and a significant amount of out-of-pocket spending (Reibling, Ariaans, and Wendt 2019). According to a typology of OECD-countries looking at long-term care, the Swiss healthcare system has similarities to Belgium and the Netherlands (Ariaans, Linden, and Wendt 2021). Reimbursement policies are one of the main barriers to the adoption of telecare (Boriani et al. 2022). Considering the reimbursement policies in Switzerland, this may explain the increasing use of cardiac monitors as an early diagnostic approach without previously exhausting the full range of standard investigations (Breitenstein 2018; Tomson and Passman 2015).

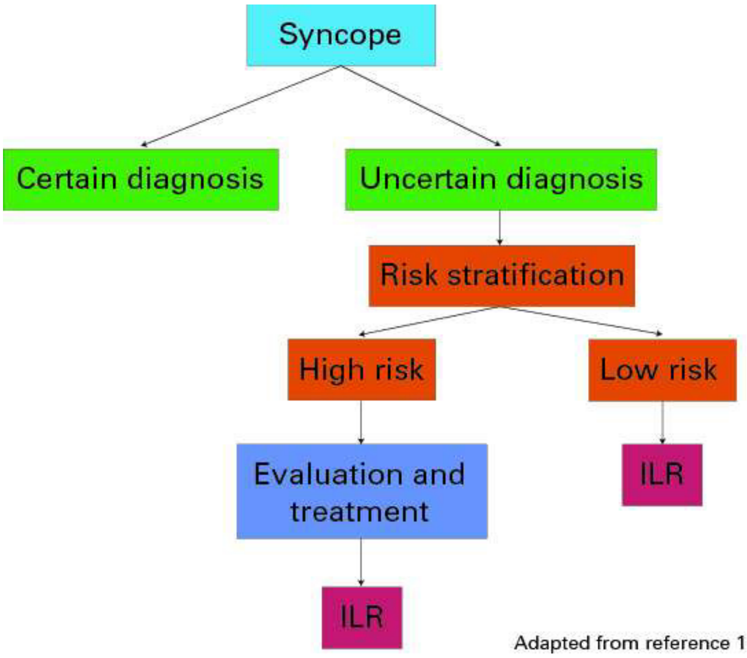


Figure 3: Recommended diagnostic work-up in patients suffering from syncope. ILR = implantable loop recorder, or cardiac monitor (Breitenstein 2018).

The main types of cardiac arrhythmias that qualify patients for the insertion of a cardiac monitor are recurrent syncope of uncertain origin (as shown in the diagnostic work-up in Figure 3), infrequent palpitations, or atrial fibrillation (Galli et al. 2016). The latter is a major risk for ischemic stroke and other thromboembolic events that could be prevented with anticoagulation if atrial fibrillation is diagnosed (Galli et al. 2016).

Once the cardiac monitor is placed under the skin, it is not possible for patients to interrupt or stop the continuous monitoring. Usually, the cardiac monitor is connected to a telecare system automatically transmitting the recorded data once a day. The battery life of the cardiac monitor lasts between 3 to 5 years, depending on the product. The cardiac monitor typically gets removed once a diagnosis is established or when the battery life ends, as the battery cannot be replaced.

However, it is neither the quantification nor the telecare approach itself which make remote cardiac monitoring challenging for traditional doctor-patient relationships. First, quantified evidence has a long tradition of invading the medical sphere (Weisz 2005). At first it usually does so in competition with doctor expertise, only to become indispensable for clinical assessment in a second step, as doctors reclaim interpretative sovereignty. Second, the practice of medicine at a distance was widespread in early modern Europe, with patients and doctors corresponding by mail (Greene 2022). However, continuous data collection over time, as compared to data collected at single time points, coupled with a telemedical follow-up based on algorithmic assessments have profound consequences on how, when and where a diagnosis is made. Thus, the following two sections will be dedicated to these developments in more detail.

2.2.1 From snapshot quantification to continuous monitoring

Starting four centuries ago with weight, then temperature and eventually blood pressure, medical anamnesis increasingly mobilized measurable parameters as the basis for patients' medical histories. For example, the physician Santorio Santorio of the University of Padua invented a weighing chair in the 16th century to quantify the intake and output of food (Sysling 2020). Today, a small model of his machine is exhibited in the museum of history of medicine in Padua. Since then, the quantification of bodily processes or characteristics has continued out of curiosity, scientific interest, or morality (Sysling 2020).

Over time, the aim to understand and differentiate human physiology manifested itself in both an increase in the number of biological variables measured and an attempt to shorten the interval between single measurements. This development was reinforced by a general enthusiasm about quantification starting in the late 19th century (Desrosières 2008). The increased confidence in quantitative measures brought medical science closer to clinical practice over the following decades, which, as a result, allowed it to gain in authority (Warner 1997). In contrast to treatments, diagnostic work quickly became determined by numbers (Weisz 2005).

Today, the sheer volume of results that search engines return in the blink of an eye can fool us to believe that the answer to our suffering must be somewhere "out there." However, when searching for a medical explanation online or in exchange with people they trust, individuals can only rely on their own perception of their body and well-being to circumscribe their symptoms. Knowing that medical technologies can screen our body interior in detail raises hopes and expectations for it to reveal what had been hidden hitherto to our own scrutiny.

The idea that measurements can bring to light and help diagnose what was previously hidden from the "clinical gaze" (Foucault 2003) is not new, but it has come to dominate medical practice in recent decades. In the 1970s, philosopher and historian Michel Foucault formulated the "clinical gaze" as medicine's focus on patient pathologies (Foucault 2003). Starting in the late 18th century, the "clinical gaze" allowed doctors' trained eyes to differentiate between symptoms and distinguish their significance for disease diagnosis. Foucault described the clinic as the necessary environment for the emergence of the "clinical gaze" because it allowed doctors to see pathologies no longer as individual events, but through comparisons among sick individuals. Foucault described how the clinic became an emerging social space, where a multitude of pathologies cumulated, making them countable and comparable. This institutionalized way of classifying the pathological thus placed the clinic in a powerful knowledge position.

Comparison is particularly facilitated by quantified evidence. In the post-World War II period, advances in statistical methods led to a greater demand for evidence-based medical treatments. In the 1950s, randomized clinical trials became the gold standard for evaluating medical interventions to better identify diseases and, over time, establish standards of care and treatment (Meldrum 2000).

Although doctors continued to argue that their personal judgment could never be replaced by numerical assessments, they could not stop the movement toward what proponents of quantification called "objective" expertise. Sooner or later, doctors had to accept the powerful authority of quantification, but adopted “some variant of the cliché that medicine is both science and art” (Weisz 2005:380). It should not be denied that third parties with financial interests in medical treatments, first and foremost insurance companies, further promoted the objectivation of medicine, which contributed significantly to the development of what would come to be known as “evidence-based medicine” (Tomes 2016).

Drawing on Foucault's work, Desrosières (2008) called quantification, and statistics in particular, a tool of governance and a tool of proof, since numbers seem more indisputable than words. Indeed, over time, numbers have been ascribed an almost sacrosanct objectivity (Porter 1995). Daston and Galison (1992) described this form of attributing authority to numbers based on agreed-upon rules of quantification as “mechanical objectivity.” However, quantification’s pure form remains an ideal type. Porter (1995) underlined the importance of other forms of knowledge such as intuition when dealing with numbers, although public discourses often refer to the neutral, or impersonal, nature of objectivity. In line with this claim, quantified evidence is trusted more than other forms of non-quantifiable knowledge, such as an expert’s gut-feeling based on professional experience. As a result, the priority given to evidence-based diagnosis and treatment may constrain doctors’ thinking or even prevent them from considering unconventional options. Physician Groopman (2008) described this in his book *How Doctors Think*:

> *Statistics cannot substitute for the human being before you; statistics embody averages, not individuals. Numbers can only complement a physician's personal experience with a drug or a procedure, as well as his knowledge of whether a "best" therapy from a clinical trial fits a patient's particular needs and values (Groopman 2008:11–12).*

However, with the advent of self-learning algorithms and AI, such a patient-centered approach is challenged again. How much attention does medical practice pay to patients themselves as individuals and how much to their quantified data?

2.2.2 Datafication at the expense of the person

Overall, several scholars have observed the predominance of quantified biomedical data in clinical practice and public health (Canali and Leonelli 2022; Cesario et al. 2021; Hoeyer 2019; Prainsack 2017). This development is referred to with various terms meaning similar things, such as personalized, stratified, precision medicine or healt. The terms and their usage depend on the geographical and political contexts (Erikainen and Chan 2019; Marks, Dosch, and Sprumont 2021). As Prainsack (2017) argued, this shift of what counts as relevant evidence in clinical practice is especially present in current developments of personalized medicine:

> *Medical practice informed by digital, quantified, and computable information about individual patients is now seen as more precise and effective than previous practice based on unstructured data, narratives, and embodied experience (Prainsack 2017:187).*

Driven by advances in molecular biology, the hope for better and more anticipatory healthcare through the systematic combination of different types of data sets has led to the techno-scientific vision of P4 medicine, the 4 Ps being: predictive, preventive, personalized, and participatory (Hood 2013; Topol 2014). Most importantly, these dimensions contain future-oriented expectations around performance (Erikainen and Chan 2019). These expectations are sufficiently strong to generate investments in biotechnologies, putting high-income countries in a privileged position, thus reinforcing the anticipatory and risk-reducing orientation of their healthcare systems (Adams, Murphy, and Clarke 2009; Clarke et al. 2021). Therefore, Erikainen and Chan (2019) recommend that future research directions focus on "how the future as a temporal abstraction is constructed, managed, invested in, by whom and under what conditions" (p.313) in order to understand the meaning and implications of the current dominance of quantified biomedical data.

Although no clear terminology prevails, the notion of "personalization" implies an approach tailored to the individual. However, the approach focuses on patient data rather than on patients themselves (Erikainen and Chan 2019). As such, visions of personalized health or medicine do not envisage more patient-centered care, but improved stratification and timing based on a conglomerate of biomedical data (Schleidgen et al. 2013). To capture this emerging concept, Vogt and colleagues (2016) have coined the concept of the "technoscientific holism," which refers to the idea of systematic and all-encompassing quantification of human life from the time we are born to the moment we die. Consequently, health becomes increasingly defined by quantity instead of quality, thus diminishing "our tolerance for and appreciation of the diversity of human life" (Conrad 2007:148).

Contrary to the argument that quantification is reductionist, Vogt and colleagues (2016) argue that medicine adopts the perspective of the human as a biomedical system. These authors' conclude that this perspective renders all states of health and disease potentially quantifiable, which makes them controllable for medical practice operating within a logic of probabilistic risks.

Since the end of the 20th century, social science researchers have been discussing the causes, unintended consequences, and even harmful side-effects of too many medical tests and treatments (Armstrong 2021; Aronowitz 2015). More recently, sociologist Natalie Armstrong (2021) has called for a macro-sociological approach to better understand the phenomena of overdiagnosis and overtreatment, which do not solely arise from individual interactions. She proposed to think about the phenomenon of overdiagnosis and overtreatment as resulting from the "organizational, financial, and cultural attributes of healthcare systems" (Armstrong 2021:62). Furthermore, she encouraged researchers to collectively question the systemic factors seducing doctors and patients to do more tests and adopt more treatments rather than less. At the same time, it cannot be denied that such an extended risk-reducing medical approaches have the social and psychological effect of "providing reassurance, reducing fear, and signaling responsibility for health" (Aronowitz 2015:6).

Yet, quantification as such and the multiplying possibilities to measure, visualize, and decipher the human body do not necessarily lead to overdiagnosis and overtreatment. These overuses of testing and diagnosis are rather of a social nature and are a result of health system factors influencing how patients and doctors act upon the persistent medical uncertainty and non-conclusive medical results. This is also guided by patients' medical histories and expectations towards medicine or by physicians' clinical and experiential knowledges.

Conrad (2007) noted the paradox of rises in reports of health problems, despite overall improvements in public health. Physician Clifton Meador (1994) had already described this paradox in the 1990s, warning in a short article about the extinction of the "last well person":

> *The demands of the public for definitive wellness are colliding with the public's belief in a diagnostic system that can only find disease. A public in dogged pursuit of the unobtainable, combined with clinicians whose tools are powerful*

> *enough to find very small lesions, is a setup for diagnostic excess. (…) What is paradoxical about our awesome diagnostic power is that we do not have a test to distinguish a well person from a sick one. Wellness cannot be screened for (p. 440).*

In his book on medicalization, Conrad (2007:149) writes that high-income countries have adopted a culture in which "health has become a high-value asset." This valorization created a public hypersensitivity towards health and its potential signs of worsening. Other scholars have described the state of "being sick and healthy at the same time" as the new human condition of the 21st century, as everyone is always on the verge of becoming ill in a risk-oriented approach to health (Bourrier and Burton-Jeangros 2014). Correspondingly, the relentless pursuit of reducing health risks and anticipatory behavior has immeasurably raised patients' and professionals' expectations towards medicine.

Sociologists Roger Burrows, Sarah Nettleton and Robin Bunton (2003) have described how health promotion based on risk calculations is developing in parallel with a consumer culture increasingly focused on "healthism." For Conrad (2007), the commodification of patients into consumers is one of the three main drivers of medicalization, along with biotechnological developments and managed care. In describing these developments, Clarke and colleagues (Clarke et al. 2021) proposed the concept of *biomedicalization*, which does not focus on attempts to control medical phenomena *per se* but rather on how such developments transform medical phenomena "through sooner-rather-than-later technoscientific interventions, not only for treatment but also increasingly for prevention, enhancement and digitized means of monitoring" (Clarke et al. 2021:127).

Continuous forms of medical quantification, such as remote cardiac monitoring, do not enlarge disease categories as such but increase the likelihood of diagnosing a disease or an at-risk-state of a disease. This can justify medical interventions in the name of prevention. Following this line of thinking, remote cardiac monitoring and continuous datafication in general qualify as processes of biomedicalization rather than of medicalization. Still, the concept of medicalization contributes to our understanding of the continuous expansion of available diagnoses (Conrad 2007), and the narrowing down of actionable risk categories for therapeutic interventions (Greene 2007). In this sense, continuous datafication represents a transformation of medical practice which is increasingly "dominated by interventions aimed at warding off anticipated complications" (Aronowitz 2015:11).

Although the overall commodification of health reinforces this transformation, ongoing datafication also introduces a shift in the way knowledge is produced, thereby affecting the interests and values of the actors involved (Aronowitz 2015). This focus on controlling and reducing health risks, rather than treating symptoms or curing disease (Aronowitz 2015:4) has reinforced medical stakeholders' belief that the more extensively and systematically the human body is monitored, the more likely it is that no deviant value will be overlooked. The aim of this form of datafication is not just to observe an individual patient's behavior, but to "continuously track for emergent patterns (…) to know in advance which patients are likely to be risky and expensive" (Ruckenstein and Schull 2017:264).

Since 2010, sociological interest in quantification has been increasing. However, there is not yet a clearly defined study subfield (Berman and Hirschman 2018; Espeland and Stevens 2008). One of the major challenges for the study of quantification is that the study object is difficult to narrow down (Berman and Hirschman 2018). Although the phenomenon of quantification in the form of digital applications and algorithms has started to permeate almost every sphere of life in high-income countries, there is still a lack of shared ideas about the concept of quantification and the methodologies to study it. As such, Berman and Hirschman (2018) propose four questions to orient scholars in their thinking about quantification: (1) what shapes the production of numbers?; (2) when and how do numbers matter?; (3) how should quantification be governed?; and (4) how should scholars study quantification?

In the context of patient-doctor relationships centered around obtaining a diagnosis (Timmermans and Buchbinder 2010), the question of when and how numbers matter is the most relevant. The rapid proliferation of self-tracking technologies, such as the smartwatch (Neff and Nafus 2016), has put pressure on medical practices to also embrace comprehensive and continuous datafication. It is probably only a matter of time before third-party tracker technologies are clinically validated. Nevertheless, more data do not necessarily result in more clarity.

2.2.3 The crux of medical uncertainty

Medicine is and will remain an uncertain practice by nature (Fox 2000), affecting doctors (Groopman 2008) and patients (Nettleton 2006) alike. Already at the turn of the 20th century, Canadian physician Sir William Osler referred to medicine as “a science of uncertainty and an art of probability” (Rysavy 2013:4). Initially, the topic of medical uncertainty was first and foremost studied in doctors and their clinical practice by medical sociologists such as Talcott Parsons and Renée Fox. They underlined that medicine, like other sciences, inherently contains unknown elements which remain out of human control. Additionally, they emphasized that although technological advances might tackle some of these elements, these advances will not eliminate them. Fox (2000) argued how, similar to previous developments in diagnostic technologies, technological advances “change the content of medical uncertainty and alter its contours, but they do not drive it away" (p. 409). As a result, such innovations cannot keep the promise of reducing healthcare costs (Rosenberg 1986).

A recent special issue in *Sociology of Health & Illness* highlighted that the concept of uncertainty continued to provide a valuable framework for studying healthcare (Mackintosh and Armstrong 2020). Research gaps included patients' and families' accounts of living with uncertainty, especially regarding informal modes of knowledge such as intuitions or gut-feelings (Mackintosh and Armstrong 2020). A different qualitative study of parents whose babies had to undergo neonatal surgery suggested that living and dealing with medical uncertainty is a time-consuming process (Hinton and Armstrong 2020). Moreover, it is unclear how doctors might help patients navigate such medical uncertainties by contextualizing the designation of (quantified) health risks or the limited explanatory power of numerical assessment (Gillespie 2012).

The continuous data flow generated by patient remote monitoring may challenge doctors even more than snapshot measurements in learning which "numbers to respect and which to discount" (Groopman 2008:150). Qualitatively studying the interactions between doctors, patients and family members in terminal cancer clinical trials, scholars suggested that although the doctors' probabilistic language might accurately reflect clinical data, it simultaneously complicates patients' perceptions of prognostic certainty (Cortez and Halpin 2020). Nevertheless, it remains unclear whether medical uncertainty in the context of patient remote monitoring could also be employed positively and productively by patients and healthcare professionals, as a qualitative study of snapshot MRI examinations in late pregnancy has shown (Reed, Kochetkova, and Whitby 2016). Results of this qualitative investigation demonstrated how the expert contextualization of the MRI images was crucial for these patients in navigating medical uncertainty.

2.2.4 From symptom-based to algorithm-based telecare

The transformation from symptom-based to algorithm-based medicine requires spatial reorganization. This reorganization primarily affects how, when, and where patient data are collected, analyzed, and interpreted. First, bedside medicine began to map, classify, and assign symptoms to diseases. Second, this process was facilitated by the clinic, which removed patients from their homes and placed them in a seemingly neutral space where signs and symptoms could be discerned through evidence-based medical practice, as described above. Third, "surveillance medicine" has escaped the walls of the clinic inhabiting the public and private spheres of the general public (Armstrong 1995).

This resulted in a spatial and temporal uncoupling of data collection, transmission, and interpretation. Regular, calendar-based medical appointments, which continue to make up the majority of medical follow-ups in healthcare, are based on a distinct moment in time (e.g., every 3 months). During such medical appointments, patients and their narratives, doctors and their expertise, the measuring instruments, and test results are all in one place. This configuration allows patients and cardiologists to immediately discuss potential findings or agree on next steps of action, such as professionals calling patients upon receipt of results. In "surveillance medicine" the processes of data collection, transmission, and interpretation, which were previously part of the common doctor-patient appointment, become uncoupled. In remote cardiac monitoring, for example, the measuring sensor accompanies patients wherever they go, cardiologists work their usual shifts at the hospital, and the ongoing measurements are simultaneously with the patient, in the data cloud, and at the hospital. This kind of spatial and temporal uncoupling has profound implications for how, when and where a diagnosis is made.

Having said that, it is not primarily the spatial uncoupling of data collection, transmission, and interpretation alone that induces this shift. Subsumed today under the term “telecare” (Finch et al. 2006), doctors and patients have always used telecommunications when available and feasible. First, letters and occasionally phials of bodily fluids were used for remote correspondence between doctors and patients in early modern Europe, when healthcare supply and mobility were limited (Greene 2022). While postal exchanges took a certain amount of time, possibilities for remote correspondence were transformed with the spread of the telephone. As Greene (2022) writes in his book on telehealth, the telephone “distorted patients’ expectations” by making medical expertise available regardless of distance and time, transforming patients into “impatient consumers” (p. 25). The telephone became the symbol of doctors always being “on call,” with all the possible opportunities and perils that this development entailed. By 1950, the telephone had become standard equipment within medical practices, clinics, and hospitals, and its use was institutionalized by employing administrative staff to answer the phone, which re-framed the availability of doctors to patients.

Nevertheless, despite the distance, the call remained a distinct moment in time, which connected patients and doctors or other medical staff around a common cause. This is no longer the case with patient remote monitoring. Previous studies have mostly focused on the apparent spatial uncoupling induced by telecare (Oudshoorn 2011; Pols 2012). Adopting a material-semiotic approach, sociologist Nelly Oudshoorn (2011) described how use and meaning of telecare devices are context-dependent. More importantly, she emphasized that the physical separation of healthcare professionals and patients induced by telecare technologies is often replaced by an “asymmetrical digital proximity” (p.206), suggesting that the relationship over the phone is governed by the availability of the telecare workers (only on weekdays) and not by patient demands (p. 176).

Addressing the question of how telecare innovations reconfigure care, anthropologist Jeannette Pols (2012:136) argues that telecare has changed how and by whom medical problems were measured and interpreted. This eventually influenced the values that the respective actors attributed to good care. Like Oudshoorn (2011), Pols stressed the importance to focus on "the place of technology and the relations made with and through it" (p. 150). Drawing on research on patients' use of webcams in the contact of chronic disease homecare support, Pols (2012) noted that telecare technologies might provide a sense of community or "together management" (p. 95f). More recently, Piras and Miele (2019) argued that remote monitoring practices may lead to a particular type of familiarity between patients and providers. They labeled this form of knowing about each other "digital intimacy" referring to a relationship "profoundly entangled with the communications infrastructure" (p. 128).

In the case of patient remote monitoring, the algorithm-based telecare system does not first and foremost reconfigure the care infrastructure linking different places but introduces the imaginary of a medical practice resembling a data network. Contrary to unstructured information, quantified evidence is easier to collect, process, and share remotely (Espeland and Stevens 2008). As Porter wrote in his book *Trust in Numbers*:

> *What is special about the language of quantity? My summary answer to this crucial question is that quantification is a technology of distance (Porter 1995:ix).*

Thinking of medical practice as a data network is not only about the fact that data travels easily. It is also about data being not just in one physical place, but in multiple places at once. Even though data of remote cardiac monitoring used in Switzerland are stored in the Netherlands, France, or Germany by medical device companies, they are accessible from other places if access rights are given (Maillard et al. 2014). Thus, digital data and the knowledge they contain are no longer bound to one place, but are unbound properties of networks (Weinberger 2011).

In addition to the spatial uncoupling of knowledge and actors brought on by telecare, patient remote monitoring creates another reconfiguration of patient-professional relationships which has so far received little scientific attention: the temporal uncoupling. Instead of data snapshots for specific patients, at specific times, at specific places, long-term patient remote monitoring creates a continuous data flow. In my study, the physiological measurement in question – the heart rhythm – is continuously monitored and evaluated with the help of several algorithms. As a result, patient measurements are no longer taken at specific times, such as during blood pressure measurements in a doctor's office or every evening at 7 pm at home, but by programmed thresholds which force the recording of every value that deviates from the norm.

Thus, in remote patient monitoring, physiological measurements no longer show the evolution and diversity produced by measurements taken at regular time-based intervals, but only values that deviate from algorithm-based normative thresholds. Consequently, patient medical records no longer contain physiological measurements which are within the norm, because algorithms only report data outside the norm. Moreover, data are collected without the active involvement of healthcare professionals and patients in the reporting process. Patient remote monitoring is an autonomous system of data collection and transmission, as long as all infrastructure components work as expected (Weiner and Will 2018). Once data have been collected and uploaded to the monitoring system, healthcare professionals can access and review the database when they would like and have the time to do so.

Contrary to healthcare professionals, patients currently do not have access to the reporting system of remote cardiac monitoring. This makes it impossible for them to know if cardiac monitors have detected, recorded, and transmitted an arrhythmic episode or not. On the other hand, healthcare professionals do not have immediate information about patients' embodied experiences when cardiac monitors detect arrhythmic episodes. That said, it is crucial for healthcare professionals to have more details about patients' experiences at the moment of the arrhythmia being measured in order for the individual recording to be clinically meaningful.

According to Armstrong (1995), 20th century medicine began to place illness in a broader temporal context. He argues that hospital medicine analyzes illness from the present by trying to find its cause and make a prognosis. In contrast, surveillance medicine is concerned with the future potential of risk factors to manifest as disease at a later stage. The continuous attention dedicated to a specific physiological measurement puts patients in a permanent at-risk-state in which illness silently lurks at every possible moment. He explains further:

> *Each illness of Hospital Medicine existed as the discrete endpoint in the chain of clinical discovery: in Surveillance Medicine each illness is simply a nodal point in a network of health status monitoring. The problem is less illness per se but the semi-pathological pre-illness at-risk state (Armstrong 1995:401).*

Although continuous remote monitoring of patients may extend the at-risk state in unprecedented ways, Armstrong's argument about the hospital as the place where a disease is finally diagnosed and the patient's case closed, paints an overly optimistic picture of the clinic and the clinicians' diagnostic capabilities. His analysis ignores the existence of general practitioners who have been following-up with their patients over long periods of time. For these doctors, illness has always been a life history, perhaps even a family history. However, what Armstrong's analysis points towards is the continuous form of medical follow-up. The tendency to measure human physiology without interruption is a recent development, as sensors became smaller, more user-friendly, and more affordable. Most importantly, data collection can be outsourced to automated algorithms. These algorithms use evidence-based thresholds designed to help healthcare professionals assess risk.

However, the high sensitivity of these algorithms may increase the amount of clinically irrelevant findings, putting patients in situations where they must wait in periods of uncertainty as medical checks and the expertise of these data remain firmly in the hands of doctors, other healthcare professionals, and are only accessible through healthcare facilities (Clarke et al. 2021; Conrad 2007; Lupton and Jutel 2015). To capture this phenomenon, Timmermans and Buchbinder (2010) coined the term "patients-in-waiting" in the light of the expanding genetic screening of newborns in the United States. They described how improved detection of risk factors can lead to more people becoming potential patients, relentlessly seeking diagnosis:

> *The recent proliferation of patients-in-waiting follows from the incommensurability between the promise and capability of medical technologies and the still-salient motivation of the patient-doctor script centered around obtaining a diagnosis as a turning point in a medical visit (Timmermans and Buchbinder 2010:419).*

Contrary to continuously changing physiological measurements, such as the heart rhythm, there is no need to decipher genetic materials several times. For example, one genetic sequencing is sufficient for DNA data to be consulted many times over (Topol 2014). Such biotechnical developments reinforce patients' hopes and beliefs that the right instrument applied at the right moment can reveal what is wrong with their bodies. In this sense, diagnosis becomes a symbolically significant moment, like an eureka moment, when the data finally reveal the previously unknown disease. However, as Rosenberg (2002) reminded us, diagnostic work often takes time:

> *Even though contemporary diagnosis is ordinarily a collective, cumulative, and contingent process, it is significant that most of us think of it as a discrete act taking place at a particular moment in time (p. 256).*

Due to the raised expectations towards medicine, diagnosis has become all the more important for the doctor-patient relationship as it constitutes the moment in which previous uncertainties are replaced by a medical explanation (Rosenberg 2002). On one hand, a diagnosis allows the doctor to intervene on behalf of the current standards of care. On the other hand, the label provided by the diagnosis gives the patient social permission to be ill (Nettleton 2006).

2.3 Research question

In the case of remote cardiac monitoring, and contrary to traditional medical practice, data contextualization happens in the absence of patients. As such, the present study will examine how the uncoupling of data collection, transmission, and interpretation is reconfiguring and (de)personalizing the doctor-patient relationship in the case of remote cardiac monitoring. This will provide important insights into the implications of these changes in this relationship for future medical practice, especially in light of recent developments in medicine towards the use of large data sets and away from the patient as a person, as mentioned above. This case study is dedicated to a timely discussion of the interplay between daily medical practice and constantly evolving technologies. In particular, it addresses the conditions under which the doctor-patient relationship is established and maintained. This endeavor is all the more difficult in the context of diagnostic uncertainty, as it is the case for risk assessment in heart arrhythmias.

Although today's medical technologies have the ability to measure, visualize, and decipher the human body far more accurately than in the 16th century, one condition remains the same: Data do not speak for themselves. And they "cannot be disentangled from the situation" (Grew and Svendsen 2017). The traditional doctor-patient script of putting together and discussing (a) the experiential knowledge of the patient and (b) the measured evidence in the light of the expert knowledge of the doctor becomes disassociated in algorithm-based telecare. As described by sociologist Deborah Lupton (2017:131), not much is known about "how digital mediation transforms care." For example, we know relatively little about how remote consulting or patient monitoring technologies are transforming doctor-patient encounters, except that scholars expect them to be reconfigured, for example upon the use of smartphone and software applications (Jutel and Lupton 2015). Likewise, Henwood and Marent (2019) identified four key dimensions for future research in digital health: (1) promissory digital health, (2) (re)configurations of knowledge, (3) connectivity, and (4) control. Especially the last three (re)configurations affect the doctor-patient relationship in the ways knowledge is produced, interpreted, and shared, through the impact of different modes of connectivity, and via the production of new, algorithm-based authority. Considering this, the question guiding the research described throughout this dissertation's chapters is as follows:

> *How do long-term experiences of remote cardiac monitoring reconfigure and (de)personalize the relationship between patients and healthcare professionals in Switzerland?*

This research question addresses the long-term evolution of the doctor-patient relationship in the context of diagnostic uncertainty. This is crucial because remote cardiac monitoring induces a shift from symptom-based to algorithm-based medical follow-up, questioning the importance of personal narrative exchange in medical encounters compared to continuous data monitoring through new technologies and subsequent possibilities. New biomedical technologies, such as the implantable cardiac monitor, are often introduced with enthusiasm in the name of progress. However, as Lupton (2017:133) argued:

> *The realities of introducing new digital technologies into the domain of health and medicine are far more complex, messy and fraught with contradiction and ambivalence than is often recognised in initial enthusiasm for their use.*

As a consequence, during my fieldwork (which I cover in further detail in Chapter 5), I paid particular attention to moments when healthcare professionals or patients had to tinker (Mol, Moser, and Pols 2015; Strauss et al. 1985:48f). Tinkering refers here to the practices, decision-making processes, and coping strategies employed when standard treatment protocols or familiar procedures are no longer applicable. In the context of remote cardiac monitoring, I am particularly interested in how the relationship between healthcare professionals and patients evolves over time and how, throughout the process of continuous datafication, other forms of knowledge may alter conditions and mutual understanding for all concerned actors.

Drawing on an interview-study on family doctors' cancer diagnostic, the gut feeling knowledge has great value in the continuity of patient care, as Kristensen and colleagues (2022:578) illustrated:

> *Whereas the logic of guidelines may guide and support clinical judgement in the present, the notion of gut feeling reveals that continuity of care is pivotal to sense change as it unfolds over time for a particular patient and hence to make the fine-tuned distinctions necessary to distinguish a potentially nonthreatening future from a potentially cancerous future.*

However, in remote cardiac monitoring, the processes of data collection, transmission and interpretation become temporally uncoupled. It is therefore especially interesting to examine the role of other forms of knowledge in the continuity of algorithm-based telecare and its potential impact for the relationship between patients and healthcare professionals. Finally, expectations towards remote cardiac monitoring in the light of medical uncertainty might generate emotions such as fear and hope (Petersen 2015) or foster almost magical beliefs in a technical quick-fix solution (Fox 2000; Mackintosh and Armstrong 2020). Time will tell if such ambivalent attitudes have a stabilizing or destabilizing effect on doctor-patient relationships in the context of medical uncertainty. Furthermore, little is known about how new forms of doctor-patient connection evolve over extended periods of time, as is the case of remote cardiac monitoring.

3 Methods

This research was conducted as a PhD thesis realized as a part of the Sinergia project “Development of Personalized Health in Switzerland: Social Sciences Perspectives” (DoPHiS) funded by the Swiss National Science Foundation. The main goal of DoPHiS was to examine the alignments of technical, practical, and scientific components necessary to implement Personalized Health (PH) in Switzerland. Studying the case of remote cardiac monitoring allowed me to get a glimpse of how the doctor-patient relationship may be reconfigured and (de)personalized if healthcare systems of high-income countries start increasingly relying on data, that are automatically and continuously collected by patient sensors.

For this qualitative case study, I conducted ethnographic observations in two hospitals in Switzerland and semi-structured interviews with patients, cardiologists, nurses, and medical device company representatives. This data collection was complemented by the analysis of a purposive selection of documents concerning the technology or doctor-patient interaction (e.g., hospitals’ patient consent forms allowing for the insertion of cardiac monitors).

Data collection was done in collaboration with two university hospitals in different linguistic regions of Switzerland from October 2020 to July 2022. For purposes related to protecting participants and to rendering the reading more enjoyable, I will refer to the university hospital of the French-speaking region of Switzerland as *La Clinique* and to the university hospital in the German-speaking region as *Waldspital*. Moreover, most representatives of the internationally operating companies were native English-speakers. Growing up with Swiss-German as a mother tongue and having mastered French and English well enough for my professional comfort, I was able to conduct this study in trilingual context.

Ethnographic observations were carried out in telemedicine units where nurses and cardiologists analyze and discuss data transmissions and during ambulatory cardiac monitor insertion and removal procedures. I took advantage of the insertion and removal observations to recruit patients for subsequent qualitative interviews.

3.1 Comparing two university hospitals in Switzerland: La Clinique and Waldspital

The Waldspital is slightly bigger than La Clinique. Although both university hospitals are in major Swiss cities, both attract patients from surrounding urban and rural areas. The cardiology unit of the Waldspital is ranked higher than the one of La Clinique in a national ranking of the leading specialties in Switzerland, which was based on a national online survey of medical experts, a patient satisfaction survey, and key medical figures from national statistics (Barmettler, Gross, and Madonna 2022).

However, there is a difference in the way care related to remote cardiac monitoring is organized in the two hospitals. Overall, telecare is less developed in La Clinique compared to the Waldspital. Cardiologists at La Clinique actively seek out and advocate for more financial support, especially for human resources in data processing. During my fieldwork, one nurse and one cardiologist took care of all the data transmissions generated by the telemedical home monitoring systems at La Clinique. In both hospital settings, this task was carried out in addition to professionals' main work activities. The workflow consisted of reviewing data transmissions and forwarding them to the cardiologist in charge (within the hospital or a private cardiology practice) if the data transmission was susceptible to potentially initiate medical intervention.

During my fieldwork, the Waldspital had a separate telemedicine unit with two full-time positions allocated to 3 tele-nurses. Since the end of my fieldwork, the telemedicine unit has expanded to 4 tele-nurses. The telemedicine unit is part of the rhythmology department. Patients can contact the tele-nurses via a direct phone number on weekdays, Monday-Friday, between 8 am and 5 pm.

Another major difference between the two hospitals involves the organization of the insertion and the removal of the cardiac monitor. At La Clinique, patients are generally called in to the cardiology day ward according to a previously agreed upon appointment. On site, they are admitted by the supervising nurse who helps them to settle in the patient compartment and to dress in a patient gown. Once installed on the patient bed, patients must wait until the attending cardiologist is available to perform the minor procedure necessary to insert or remove the cardiac monitor. Waiting time can be up to several hours, as the work schedule of cardiologists, like the work of other clinicians, is rather unpredictable. Thus, appointments for inserting or removing a cardiac monitor were spread throughout the week, and they could be added or cancelled last minute according to the patient availability. Since this was the case, I only knew about the appointments one week in advance. This is why I sometimes was unable to be present for ethnographic observations. During non-pandemic circumstances, this would be a relatively normal occurrence in ethnographic fieldwork in medical settings. However, in the context of the COVID-19 pandemic, this became an additional stressor. I discuss this in further detail below in sub-section 3.2 on field access.

At the Waldspital, there were 3 specialized nurses who were specifically trained to do cardiac monitor insertions and removals. The authorization for nurses to do this began in 2020. Instead of being admitted to the cardiology day ward, patients were welcomed by implant-nurses in a consultation room with a patient bed. Patients simply had to remove the clothing items covering their chests before the procedure and were not required to change into patient gowns. At the time of my observations, insertions and removals of cardiac monitors were always performed on Mondays, with a maximum of 4 implantations scheduled for the day. This made it possible for me to regularly join the nurses for a day of work. At the Waldspital, it was also easier to build rapport and trusting relationships over time than at La Clinique, because the staff always remained the same.

As a result of the different ways remote cardiac monitoring is organized and managed in the two institutions, the number of cardiac monitors implanted per month and the number of patients in telemedical follow-up differ considerably between La Clinique and the Waldspital. From 2019 to 2022, La Clinique inserted 62-79 cardiac monitors per year, while there were about 240-300 cardiac monitor insertions per year at the Waldspital. At any given time during my fieldwork La Clinique had approximately 200 patients involved in remote monitoring, while the Waldspital had about 750.

Proportionally, there are about 5 to 15 data transmissions from cardiac monitors to assess daily at La Clinique, and about 20 to 60 at the Waldspital, with the peak being on Mondays when the data transmissions from Friday to Sunday accumulate in the system over the weekend. However, the number of data transmissions can vary considerably, depending on how well the cardiac monitor is positioned under the skin, how well sensors and algorithms perform, and how well alert thresholds were managed by professionals over time (O'Shea et al. 2021).

Studies show that cardiac monitors transmit a disproportionally high amount of false-positive and high-alert heart rhythm episodes which creates a considerable burden for reviewing data (O'Shea et al. 2021). Among a cohort of 1,470 patients studied for 6 months in 21 American and 2 Australian centers, 14,086 alerts were transmitted over the whole period (1-10 alerts per patient), with 60%

of them being false-positives according to the authors, while only 40% could be considered as true-positives. The largest share of false-positives concerned asystole and atrial fibrillation (about 75% each). These findings bring researchers to propose adapting the management of remote monitoring with the help of third-party review systems or AI to reduce the burden of reviewing data (O'Shea et al. 2021). At La Clinique, cardiologists have the option to include the data transmissions into such a pre-triage program provided by one medical device company with the aim of reducing the data review burden carried out by healthcare professionals. That said, the professionals at La Clinique did not agree about the efficiency of this system in my interviews with them.

Contrary to a standard 12-lead ECG consisting of 10 skin adhesive electrodes for a high quality representation of the electrical activity of the heart (Gregg et al. 2008), the cardiac monitor has only two sensing electrodes at both ends of the device capable of recording a single-lead bipolar ECG (Iglesias et al. 2009). Studies on cardiologists' interpretations skills of standard 12-lead ECGs have shown that interpretations are error-prone, with 33% containing major medical errors (Breen, Kelly, and Kernohan 2022). When working with algorithm-assisted ECG interpretations, cardiologists tended towards overreliance on automated ECG analysis, probably due to time and data volume constraints (Estes 2013; Hongo and Goldschlager 2004; Smulyan 2019). As of July 2023, there are no studies to my knowledge that assess cardiologists' intra and inter-rater reliability in the context of single-lead bipolar ECGs recorded by cardiac monitors. However, there is no reason to assume that results would not be similar to classical 12-lead ECGs, especially since cardiac monitors measure heart rhythms subcutaneously with only two electrodes. This can lead to over- or under-sensing due to the physical positioning of the cardiac monitor (Kida et al. 2022).

For these reasons, the comparative perspective adopted in my study allows me to examine how healthcare professionals from two university hospitals deal with the daily data flow generated by remote cardiac monitoring. This question particularly motivated cardiologists from both hospitals to participate and to assist in the recruitment of the respondents. During the ethnographic fieldwork in the hospitals, I learned that the desire to outperform the other clinic was also part of the cardiologists' motivation to participate. Retrospectively, the decision to conduct the study in two hospitals in Switzerland was not only beneficial from a scientific, comparative standpoint, but unexpectedly also as doctorate-saving strategy during the COVID-19 pandemic.

3.1.1 The configuration of remote cardiac monitoring in Switzerland

Figure 4 illustrates the automated processes of data collection and transmission involved in remote cardiac monitoring in Switzerland. This graphic representation traces the path of data transmission from the moment a patient’s heart beats irregularly to the moment the recording of the irregularity is taken into consideration at the hospital. Moreover, it shows the communication flow which might be activated between tele-nurses, cardiologists and patients depending on the healthcare professionals’ evaluation of a specific recording. The subsequent fictive patient example further demonstrates how remote cardiac monitoring is organized in Switzerland.

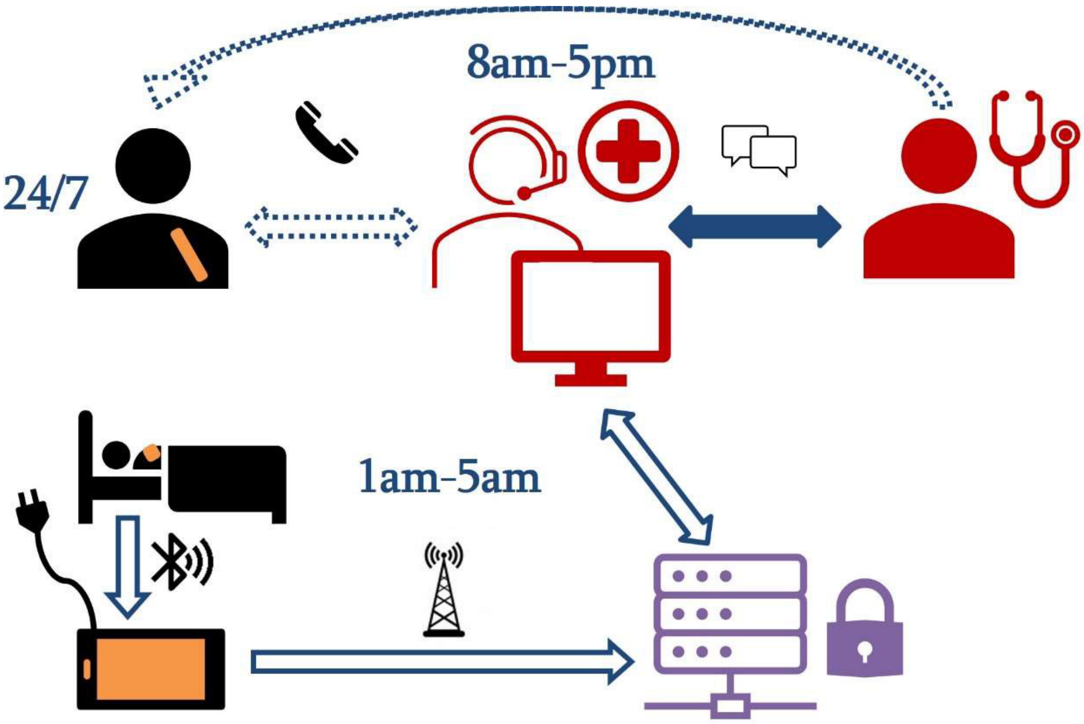


Figure 4: Configuration of remote cardiac monitoring in Switzerland (scheme created by the author); orange = inserted cardiac monitor and transmitter at bedside; red = tele-nurses and cardiologists; purple = protected data server of the medical device company; blue arrows = data and communication flow

Ten months ago, patient Mrs. Schneider received a cardiac monitor after suffering from a stroke of unknown cause. The cardiologist suspected atrial fibrillation to be the cause of it, but this hypothesis needed to be proven before treatment options could apply. After her stroke, Mrs. Schneider continued to work, but with a reduced workload. Today, she had lunch with her colleagues as always. Currently, she is sitting comfortably at a table, while having coffee with them before going back to work. The room is filled with laughter. She feels a bit tired. Unnoticed by her, the upper and lower chambers of her heart beat out of sync for a few minutes. As this occurs, the algorithms in the cardiac monitor detect the irregular electrical signals using the comparison with the millions of heart rhythm sequences in their programming. This sequence of atrial fibrillation is recorded and stored in the cardiac monitor. Mrs. Schneider leaves lunch finishes her workday and goes home. She does not stay up too late because she still feels a bit tired. She is not aware of any potential harm from the unnoticed arrhythmia.

After midnight, the transmitter plugged in next to her bed automatically connects to her inserted cardiac monitor using wireless radiofrequency or Bluetooth. The recording from noon is then transferred to the telephone landline or wireless cellular network to an online server provided by the medical device company. The next day, a specialized tele-nurse logs in to a software program provided by the company and checks the recordings. Recordings coming from cardiac monitors are considered the least important compared to other connected devices such as defibrillators or resynchronization therapy devices. Consequently, and depending on the total daily number of alerts sent, the recordings coming from cardiac monitors are only checked in the afternoon. If considered relevant by the tele-nurse, the recording is transferred to and/or discussed with the cardiologist in charge who then makes a decision to act (or not) to the recorded event. According to the decision made by the attending cardiologist, Mrs. Schneider will be informed by phone, or, if healthcare professionals do not consider it urgent, by mail or at the next appointment with her cardiologist.

3.1.2 The costs of remote cardiac monitoring in Switzerland

The costs for the insertion of a cardiac monitor are about 5,000 Swiss francs (CHF) per patient (~5,495 USD; 1 USD=0.91 CHF as of December 31, 2022). The insertion and removal of the cardiac monitor is covered by the Swiss basic health insurance. Basic health insurance is compulsory for all Swiss residents. Monthly premiums vary depending on the insurance company they choose and the region in which they live. In addition, the higher the deductible people choose (CHF 300-2,500 per year; ~330-2,747 USD), the lower the monthly premiums are. The amount of this deductible defines what people must pay themselves before the insurance begins paying for medical bills and medication. After the deductible has been met, there is also a general additional fee of 10% for each service (up to CHF 700 per year; ~769 USD) which patients must pay out of pocket. Residents in modest economic circumstances can apply to the regional government for a premium reduction (Bondolfi 2018).

Apart from the one-time costs of cardiac monitor insertion and removal, there are recurring costs related to telemedical follow-up. At La Clinique, every data transmission susceptible to require medical intervention is charged to patients for the review of their charts. The cost is set according to the hourly rate of the attending cardiologist. At the Waldspital, patients automatically receive reports every 3 months by mail, a service which is charged to them as a telemedical consultation at the rate of approximately CHF 130 (~143 USD; for an example report, see appendix A). Additional phone call consultations are charged separately.

It is impossible to know how much profit hospitals make for each inserted cardiac monitor because neither cardiologists nor medical device company representatives are transparent in this regard. I overheard during my fieldwork that the medical device companies are in great competition and actively seek out hospitals' attention for further sales. Generally, one medical device company manages to conclude an overall contract in which the hospital agrees to use only its type of cardiac monitors, while the company in return lowers the price for each device. Yet, the cost-benefit ratio may differ depending on the clinical setting in which a cardiac monitor is inserted; in other words, this may differ between outpatient and inpatient settings. This, as well as collaborative clinical trials with medical device companies, may encourage hospitals to enter into different agreements depending on the clinical setting. This could, for example, be a type A cardiac monitor in outpatient settings and a type B monitor for inpatient settings.

In the absence of a national register, it is impossible to know how many patients receive a cardiac monitor in Switzerland per year. In contrast, statistics on annual insertions and removals of pacemakers and implantable cardiac defibrillators can be found on the homepage of the "Working Group Pacemaker and Electrophysiology" of the Swiss Society of Cardiology. When I contacted them to ask about cardiac monitors, the respondent told me that cardiac monitors are counted together with pacemakers. This to me seemed rather odd, as pacemakers are a life-long therapeutic devices directly connected to the heart, whereas cardiac monitors are subcutaneous implants used for diagnostic purposes for a maximum period of 5 years. The market's leading medical device company estimated that they have slightly more than 1 million patients worldwide in remote cardiac monitoring. In general, the interviewed cardiologists and company representatives were convinced that the COVID-19 pandemic had increased the use of telecare technologies. This increase in the use of telecare is supported by other research, which also shows that there are significant variations between medical specialties, and that challenges such as patient distrust and the digital divide based on general access and health literacy remain and need to be addressed (Bestsennyy et al. 2021; Nittas and Wyl 2020).

3.2 Field access during an evolving pandemic

I first met with two cardiologists at La Clinique in October 2019. The contact had been established via a professor of the DoPHiS research project. A senior researcher of the DoPHiS project accompanied me because he was interested in genetic determinants of sudden cardiac death. At the time, I was still deciding between studying two different types of algorithm-based diagnostic technologies. However, since at the time, there were only about 50 patients with the more recent of the two devices, I chose to do a qualitative study on the cardiac monitor so that I could be sure that I would be able to include enough study participants.

As the research design and procedure took shape over the following months, the idea came to me to expand the study to another university hospital in the Swiss German-speaking region of Switzerland. In order to negotiate an entry point with an university hospital in another linguistic area, I relied on the contacts of the cardiologists from La Clinique. Fortunately for me, these already established connections paid off. On March 10, 2020, I had a meeting at La Clinique to discuss potential fieldwork access at the Waldspital.

Not even a full week later, the Swiss government proclaimed strict national health measures to prevent the spread of SARS-CoV-19 and thus avoid excessive cases of COVID-19 (Deml et al. 2021). This major event, which changed everyone's lives in the following months also heavily impacted the conditions of my research. Given that I wanted to conduct data collection in hospital settings with mostly elderly patients who were considered to be de facto at risk of severe COVID-19-related complications, this particularly constrained my field access and data collection. Yet, in spring 2020, I was still rather optimistic, and perhaps naïve, in believing that the restrictions would be temporary.

On April 21, 2020, I presented my research project via videoconference to a cardiologist working at the Waldspital. Luckily, he agreed to participate as well. On June 19, 2020, the state of national health emergency was lifted, which again allowed for public events of more than 1,000 people, but spatial distancing was still recommended. On July 2, 2020, I submitted my study protocol to the local ethics committee ("Commission cantonale d'éthique de la recherche sur l'être humain (CER-VD)"). Shortly before the submission, the commission's secretary had warned me on the phone that there might be a general moratorium for all types of studies in the medical context due to the pandemic, but that I should nonetheless submit my proposal. Fortunately for my doctoral research, the halt on research in medical context did not occur. The ethics commission accepted my proposal after two rounds of revisions on September 16, 2020. Approval by this ethics commission automatically provided ethical clearance for the second hospital as well.

With the ethical green light in hand, I immediately contacted the two university hospitals to plan ethnographic observations and interviews with healthcare professionals. Whereas I was able to start data collection at the Waldspital, it was unfortunately not possible at La Clinique; in October 2020 infection rates began to increase as the second COVID-19 wave hit Switzerland. The French-speaking part of the country was particularly affected at that time. Consequently, La Clinique decided to stop all research activities until further notice. Nationwide, masks became mandatory in all public spaces, and private events were restricted to 100 people by October 28, 2020.

Luckily, my data collection benefited from the fact, that the Swiss healthcare system is organized according to a federal system. This means that the different state-like bodies, referred to as cantons, can implement their own health-related decisions. This led to what I like to call to a "pandemic difference of 100 kilometers." This is the approximate geographical distance that lays between the two university hospitals. Although my access was completely blocked at La Clinique, with no possibility for remote recruitment or videoconference calls, the Waldspital was legally authorized to give me access on the condition that I follow the same sanitary rules as healthcare professionals. This meant that I regularly disinfected my hands, changed my mask, and kept my distance when possible.

Then, as the second wave made its way across Switzerland, my fieldwork began at the Waldspital on October 12, 2020, with interviews of three nurses. Starting with the interviews allowed me to first get a better handle on their perspectives, which I was then able to complement and contextualize through ethnographic observations. Over time, a trusting relationship emerged between the nursing staff and me, especially with the implant-nurses who generously shared their

“Implant-Monday” routines with me. On October 26, 2020, I recruited the first patient for my study during an ethnographic observation of this “Implant-Monday” at the Waldspital. Since it was very unclear at this point how the sanitary situation would develop, the implant-nurses helped me with recruitment by asking additional patients to participate when they did their follow-up phone calls 4 weeks post-insertion. On November 2, 2020, the Swiss government decided to close all non-essential businesses, as well as sports, cultural and leisure centers. Public and private events were restricted to 5 people.

Afraid that my access to the Waldspital could be blocked at any time, I quickly scrambled to maximize the number of ethnographic observations and interviews. I also restricted my contacts in the private sphere to reduce my own risks of contracting the virus and potentially contaminating others. Overall, this was a rather exhausting period for me. To protect the at-risk patients of my study, I did all my interviews remotely, except for a single interview with a woman who insisted on an in-person interview. Her husband had purchased an expensive air filter, and she was convinced that there was no risk of infection. Due to the high workload, it was actually convenient for me that I was able to do almost all interviews virtually without having to spend time on travelling.

As in most European countries, the second wave of coronavirus infections was an intense period in Switzerland. Toward the end of January 2021, the situation started to stabilize, and a cardiologist from La Clinique contacted me on January 25, 2021. Medical research was allowed again as long as there were no study-related examinations for patients. Nevertheless, this hospital site remained closed to outsiders, but two of the hospital’s study nurses agreed to help with recruitment for my study. They distributed study information material and informed consent forms to patients. The nurses asked patients if they would allow their contact details to be transferred to me so that I could contact them. Throughout the months of February and March 2021, I received the contact details from 12 patients. Despite this, all patients but two refused to participate in my study when I called to confirm their participation. On March 1, 2021, pandemic protection measures were reduced. Beginning at the end of December 2021 in Switzerland, particularly vulnerable groups were able to get COVID-19 vaccines. In spring 2021, vaccination became available for all adult Swiss residents older than 16.

I was convinced that participation refusals were due to patients never having seen me in person. In the Waldspital, where I had been present during insertions and removals of the cardiac monitor, refusals to participate had been rare. Curious about this, I asked the recruiting study nurses at La Clinique if I could recruit patients myself. I also still hoped to do some ethnographic observations at La Clinique. During the meeting on April 1, 2021, set up to discuss overcoming the high number of refusals, the study nurses of La Clinique explained to me that this would not be possible since my study was not a clinical trial. Even though the two nurses understood my frustrations about the recruitment process, they said it would be rather difficult to obtain an exemption for me. Access to La Clinique was still restricted to medical staff and patient relatives. At this meeting, I learned that the nurses had been erroneously referring to me as a psychologist, which was probably another reason for the low recruitment rate. I clarified again my role and background as a sociologist and again repeated the aims of my study.

Rather desperate, I asked my co-supervisor Claudine Burton-Jeangros for advice. It was mid-April 2021, and I was running out of time. Field access at La Clinique seemed stuck due the restricted access. Although the study nurses were taking care of patient recruitment, it looked like it was going to take a lot more time than initially planned. After the supervisory discussion, I considered restricting my fieldwork to the Waldspital only and to reiterate another round of ethnographic observations and recruitments there to expand my dataset. In a last-ditch effort, I tried to re-negotiate my access at La Clinique. But, this time, I directly contacted the cardiologist. She understood that I was about to re-orient my data collection. However, she saw no reason why my study should be subject to different conditions than clinical trials and promised me that we would find a solution. As a person with no affiliations to the hospital, it was not possible to give me the status of an employee or an intern, which would have provided me automatic access. It turned out that the solution came in the form of a written certificate, signed by a head cardiologist, confirming that I had an appointment in the cardiology department's day hospital. For every time a patient was expected for a cardiac monitor insertion or removal, a hospital administrator would send me, via e-mail, a dated certificate signed by the chief cardiologist. Before going to the hospital for ethnographic observations and patient recruitment, I had to print it and show it at the security check at the reception of the hospital. It contained only one sentence, which stated, for example, "I, the undersigned, certify that Mrs. Martina von Arx has an appointment on Wednesday, April 28, 2021, from 08h00 onwards, at the Cardiology Day Hospital" (author's translation from French to English). This initiated an active exchange between study nurses, the administrator and myself, especially as medical appointments were sometimes (re-)scheduled at the last minute.

After all this negotiation, I was finally able to observe my first insertion of a cardiac monitor at La Clinique on April 28, 2021. My presence on site helped a great deal with patient recruitment, and I was then able to undertake ethnographic observations at a second field site. Compared to the Waldspital where the surgical procedures mostly took place in a spacious consultation room, there was only little space around patient beds in La Clinique. Accordingly, due to the spatial distance associated with COVID-19 restrictions and/or the preferences of the cardiologists, I was not always allowed to observe insertion and removal procedures at La Clinique. In this setting, I also had to wear a white coat or a surgical gown, depending on who the cardiologists in charge were. In contrast, I always dressed in my normal clothes at the Waldspital, except during my very first exploratory visit when I wore white trousers and a white blouse like the implant-nurses did.

In both hospitals, I always had to cover my hair with a surgical cap during the surgical procedures to reduce infection risks. My access to La Clinique required the above-mentioned certificate until July 2, 2021. In the meantime, I received two injections of a COVID-19 vaccine. By the end of June 2021, the Swiss government relaxed the pandemic protection measures for the second time.

Overall, the pandemic also led to fewer cardiac monitor insertions, as they were considered a non-essential medical intervention. There were several instances of insertions or removals being cancelled or postponed due to the pandemic (fieldnotes, November 9, 2020, Waldspital). This meant that the field was even more unpredictable as usually expected in a hospital environment. Also, it required for me to be highly flexible and sometimes going to the field in vain. These factors also slowed down the recruitment process. To expand my sample of study materials, I decided to do another round of recruitment at the Waldspital.

By September 2021, ethnographic observations and the participant sample were sufficiently saturated (Saunders et al. 2018; Vasileiou et al. 2018) to put an end to the recruitment process. The nurses in both hospitals had become so familiar with my presence that they dared to hand me smaller tasks, such as checking at the other end of the day hospital at La Clinique if the attending cardiologist was already available for the patient. At the Waldspital, I had almost become part of the team. This was illustrated by the nurse's response when a patient told the nurse that he hoped today's procedure would go well in the presence of the sociologist: “Mrs. von Arx and I have been through a lot together. She could actually join us right away” (fieldnotes, September 17, 2021, Waldspital). While the implant-nurses almost counted me as one of their own, the tele-nurses did not think that their work was of any interest to me because they only sat in front of a computer to carry out their tasks. They started questioning my presence towards the end of summer 2021 by regularly asking me how much longer my study would take (fieldnotes, September 29, 2021). The tele-nurses were convinced that I would get bored, and I was unable to successfully negotiate to justify an extended presence in their office.

Overall, the restrictions on field access due to the COVID-19 pandemic protection measures had a major impact on how and what kind of data I was able to collect. Nevertheless, as difficult as it was at times, the pandemic also acted as a door-opener and for serendipitous discoveries in the field (Åkerström 2013).

3.3 Data

3.3.1 Ethnographic observations

To study medical technologies, social scientists of different backgrounds have advocated to primarily focus on practices and uses (Mol 2002; Oudshoorn and Pinch 2003) to avoid the two pitfalls of technological determinism and social essentialism (Timmermans and Berg, 2003). As Timmermans and Berg wrote in their overview of scholarship published in *Sociology of Health & Illness* on medical technologies, the turn towards the study of "technology-in-practice" allows for a more dynamic way of sociological analysis. This avoids the trap of both a deterministic perspective overestimating "the power of technology to change society" and an essentialist perspective underestimating "the role of medical technologies, viewing them as mere tools to be socially situated" (Timmermans and Berg 2003:103).

Observing the insertions and removals of cardiac monitors as well as the daily work at the telemedicine unit allowed me to contextualize patient and professional interview and get a first-hand perspective on the interactions between healthcare professionals *in situ* (Webster and Rice

2019). During my presence in the hospitals, I directly wrote my observations in a small booklet. Whenever this was perceived as intrusive by patients or healthcare professionals who did not yet know me, I closed the booklet. In these instances, I noted what had happened later that day based on my memory. Handwritten notes were transferred to a narrative, digital format on my way home from the hospital or in the days following the observations. I adjusted the focus of my attention for taking field notes during my observations over time. For example, one time I focused on the routine step-by-step process of the cardiac monitor insertion, which allowed me to later concentrate on other practical aspects or discussions which disrupted this known process. The implant-nurses at the Waldspital also agreed that I could document the insertion with a camera. Table 1 summarizes all ethnographic observations that I conducted for this study.

Table 1: Ethnographic observations

Hospital	Type of Observation	Date	Time period of observations	Duration (hours)
Waldspital	interviews with nurses and alongside observation at telemedicine unit	October 12, 2020	1:00pm – 4.30pm	3:30
Waldspital	interviews with nurses and alongside observations	October 19, 2020	11:00am – 3pm	4:00
Waldspital	observation of insertions/removals	October 26, 2020	8:15am – 4:00pm	07:45
Waldspital	observation at telemedicine unit and one insertion	November 9, 2020	8:15am – 4:30pm	08:15
Waldspital	observation of insertions/removals	November 16, 2020	8:15am – 4:30pm	07:15
Waldspital	observation of insertions/removals	November 23, 2020	11:00am – 6:00pm	07:00
Waldspital	observation of insertions/removals	November 30, 2020	8:15am – 3:15pm	07:00
Waldspital	observation of insertions/removals	December 14, 2020	8:15am – 5:00pm	08:45
Waldspital	observation of insertions/removals	December 21, 2020	9:30am – 1:30pm	04:00
Waldspital	observation of insertions/removals	June 14, 2021	10:30am – 12:00am	01:30

Waldspital	observation of insertions/removals	August 20, 2021	9:15am – 4:30pm	07:15
Waldspital	observation of insertions/removals	September 17, 2021	8:15am – 9:45am	01:30
Waldspital	observation at telemedicine unit only	September 29, 2021	8:15am – 4:45pm	08:15
Waldspital			**Total**	**76:00**
La Clinique	observation of insertions/removals	April 28, 2021	8:00am – 2:00pm	06:00
La Clinique	observation of insertions/removals	May 4, 2021	11:30am – 1:30pm	02:00
La Clinique	observation of insertions/removals	May 7, 2021	8:15am – 10:00am	01:45
La Clinique	observation of insertions/removals	June 1, 2021	8:00am – 12:00am	04:00
La Clinique	observation of insertions/removals	June 15, 2021	11:00am – 1:00pm	02:00
La Clinique	observation of insertions/removals	July 2, 2021	9:00am – 11:15am	02:15
La Clinique	observation of insertions/removals	July 21, 2021	9:00am – 11:00am	02:00
La Clinique	observation of insertions/removals	August 23, 2021	8:00am – 9:30am	01:30
La Clinique	observation of insertions/removals	August 24, 2021	8:00am – 9:30am	01:30

La Clinique	observation of insertions/removals	September 15, 2021	7:40am – 10:10am	02:30
La Clinique	observation at telemedicine unit only	December 2, 2021	8:30am – 9:30am	01:00
La Clinique			**Total**	**12:00**

3.3.2 Interviews

All healthcare professionals, patients, and company representatives were interviewed using semi-structured interview guides. In line with the methodological suggestions of Britten (1995), interview questions were elaborated to establish interview guides and were based on relevant literature, two exploratory interviews and one exploratory observation of the insertion procedure of the cardiac monitor at the Waldspital. The interview guide was refined during data collection (Horton, Macve, and Struyven 2004). Adopting a non-suggestive posture during the interviews allowed me to integrate unanticipated elements evoked by the participants (Merton 1948). For example, I added the question “Would you consider yourself in good health?” to the interview guide after I realized how some participants had strengthened the fact that they were well off despite their unexplained symptoms and/or other co-morbidities. Interviews with healthcare professionals (for the interview guide for professionals in French, see appendix B) and patients (for the interview guide of first-round and post-removal patient interviews in French, see appendix C) were conducted in French and Swiss-German or German. Interviews with medical device company representatives were done in English (for the interview guide for company representatives, see appendix D). To prepare, I handwrote the questions from the interview guides into my fieldwork booklet, which I used to guide the interviews.

After each patient interview, I collected socio-demographic characteristics from each participant (age, gender, education, professional trajectory, family situation). The second round of patient interviews was informed by the discussions held during the first round. This interview guide consisted of repeating the questions from the first round, but with a focus on change over time. I always listened to first interview audio files shortly before the second interview, completing the interview guide with questions that had remained open from the first time, questions I forgot to ask in the first round, and patient-specific questions linked to their experience with the cardiac monitor. This longitudinal, qualitative approach in combination with the post-removal interviews contributed to an in-depth understanding of the evolution of patient experiences with remote cardiac monitoring. Due to the prolonged interview data collection, I decided to contact patients a third time to check if their situation had changed since the second interview. However, because of my limited time resources, I could not do another round of interviews. Therefore, I sent a letter to patients to ask them for an update by including sample questions related to a potential arrhythmia detection, technical problems or whether the cardiac monitor had been removed in the meantime (see appendix E). About half of the patients did not get back to me, and those who did (N=7) told me via e-mail, mail, or phone that nothing had changed since the second interview.

Cardiologists and nurses were recruited via the main contact person in each hospital who knew which healthcare professionals were most closely involved in telecare. I then contacted them via e-mail or during fieldwork on site providing them with the information and consent sheets (see appendix F). Data collection included 5 interviews with cardiologists from the Waldspital (1 woman, 4 men), and 4 interviews with cardiologists from La Clinique (3 women, 1 man). They ranged in age between 38 and 57 years old as of 2022 (median = 47 years). Most of these interviews were conducted via videoconference, some in person with cardiologists and me both wearing mask at the hospital, and one without masks on the balcony of the hospital. The median interview duration was 66 minutes (minimum=39 minutes; maximum=76 minutes). As the gender could be used to identify the person in the context of the hospital, I have decided not to indicate the gender at the same time that I mention the institution when I quote cardiologists in the following chapters.

Interviews with nurses included 6 nurses (3 implant-nurses, 3 tele-nurses) from the Waldspital and one tele-nurse from La Clinique. All nurses included in this study are women. Their ages ranged between 30 and 61 years old as of 2022 (median = 53 years). These interviews were conducted in person with masks at the hospital, with the exception of one which took place after the mask was no longer mandatory. The median interview duration was 59 minutes (minimum = 52 minutes; maximum = 71 minutes). Due to the organization and management of telecare, only one nurse was involved in reviewing telemedical alerts at La Clinique. In the Waldspital, three tele-nurses were working in the telemedicine unit of the cardiology ward. The other three were specially trained implant-nurses who were allowed to perform insertions and removals of the cardiac monitor. Similar to the choice I made for the cardiologists, I decided to not specifically mention the workplace of the nurses when quoting data from interviews, unless it was indispensable for comparison.

Initially, inclusion criteria for patient recruitment aimed at including a similar number of men and women, different age categories and different types of medical histories leading to the insertion of a cardiac monitor. However, the access difficulties to the hospitals due to the COVID-19 pandemic (see section 3.2 for more details), made me abandon these criteria in the first months of fieldwork. When I began to complete the patient sample after the first 6 months of data collection, I tried to include patients whose profiles were still lacking in my data collection, especially regarding age and gender.

Healthcare professionals generally gave a helpful hand in patient recruitment. I usually had the opportunity to present my study at the end of patient appointments. When I presented my study to the patients, I was careful to emphasize that I was independent of the hospital. Each time I asked the patient for his or her contact details, I made it clear that I had no direct access to patient records. I left the flyer (see appendix G) and information and consent sheets (see appendix H) for them to read and agreed with them that I would contact them again one or two weeks later to arrange a meeting. However, receiving help from the healthcare professionals for patient recruitment also implied that they sometimes acted as gatekeepers. During on-site recruitment at both hospitals, there were some occasions in which the nurse would tell me, "This is not a good patient for your study." Such assessments usually concerned older patients who were already having trouble keeping up with what was happening to them. Another patient category is underrepresented in my study sample due to this pre-selection: patients whose ability to verbally express themselves following a stroke. While such gate-keeping negotiations took place at the desk before seeing patients at La Clinique, I also observed them during my ethnographic observations at the Waldspital. When implant-nurses had finished providing instructions to patients, they would sometimes signal with their hand or their head that they were not going to present my study. To not jeopardize the trusting relationship with healthcare professionals, I complied with their assessments. Furthermore, I was aware that an interview might be an additional burden for patients who already struggled to understand how remote monitoring worked and what its purpose was, despite implant-nurses' patient and sensitive explanations.

The final patient sample with attributed pseudonyms is listed in **Fehler! Verweisquelle konnte nicht gefunden werden.**. The variables of education, professional trajectory, and family situation are not displayed to protect patient anonymity. Most patients can be classified as Swiss middle-class according to their education and professional careers (Oesch and Murphy 2017), but there are also several interviewed patients from modest (e.g. migrant unemployed worker) and high-income (e.g. nursing home director) economic backgrounds.

Table 2: Patients recruited at Waldspital and La Clinique sorted by gender and pseudonym

Hospital of recruitment	Patient pseudonym	Age (in 2022)	Type of arrhythmia	Interview type
Waldspital	Mr. Ammann	85	syncope	longitudinal (interview with partner)
Waldspital	Mr. Bianchi	62	AF (stroke)	longitudinal - dropout (interview with partner)
Waldspital	Mr. Fontana	53	tachycardia	post-removal (insertion: beginning of October 2020)
Waldspital	Mr. Fuchs	67	syncope	post-removal
Waldspital	Mr. Jansen	65	AF (stroke)	longitudinal - dropout
Waldspital	Mr. Regensburger	72	AF (stroke; TIA)	Longitudinal
Waldspital	Mr. Steiner	60	AF (stroke)	longitudinal
Waldspital	Mr. Tanner	40	syncope	longitudinal - dropout (interview with partner)

Waldspital	Mr. Weber	62	AF (3 strokes)	Longitudinal
Waldspital	Mrs. Christen	68	AF (stroke)	Longitudinal
Waldspital	Mrs. Hasler	82	syncope	Longitudinal
Waldspital	Mrs. Leuenberger	82	AF (stroke)	post-removal (clinical study participant)
Waldspital	Mrs. Scherrer	71	AF (2 strokes)	Longitudinal
Waldspital	Mrs. Schuler	66	AF (TIA)	post-removal (insertion: February 2018)
Waldspital	Mrs. Sommer	23	tachycardia	post-removal (insertion: December 28, 2017)
La Clinique	Mr. Aubert	67	tachycardia	post-removal (insertion: 2018)
La Clinique	Mr. Dubois	56	AF	post-removal (got a second cardiac monitor)
La Clinique	Mr. Fleury	76	syncope	Longitudinal
La Clinique	Mr. Gaillard	45	syncope	post-removal (insertion: 2017)
La Clinique	Mr. Gerber	59	AF	post-removal (insertion: 2017)
La Clinique	Mr. Hoang	21	extrasystoles	Longitudinal
La Clinique	Mr. Pereira	32	tachycardia	Longitudinal
La Clinique	Mrs. Bartoli	61	syncope	Longitudinal

La Clinique	Mrs. Emery	29	tachycardia	Longitudinal
La Clinique	Mrs. Jeanneret	58	tachycardia	Longitudinal
La Clinique	Mrs. Loviat	37	syncope	Longitudinal
La Clinique	Mrs. Rochat	70	AF	Longitudinal
La Clinique	Mrs. Volante	78	AF	post-removal (insertion: circa 2015)

In total, I interviewed 15 patients (6 women, 9 men) from the Waldspital and 13 patients (6 women, 7 men) from La Clinique. Their ages ranged from 23 to 85 years old (median = 66 years old) at the Waldspital and from 21 to 78 years old (median = 58) from La Clinique, as calculated in 2022. A total of 10 patients from the Waldspital and 8 patients from La Clinque were recruited after the insertion of the cardiac monitor and included in the study with a longitudinal interview approach (3 patients recruited at the Waldspital dropped out after the first round of interviews). Finally, 5 patients from each hospital were recruited after the removal of the cardiac monitor and interviewed once.

Patients included in the longitudinal design were interviewed a first time about 6 weeks post-insertion (minimum = 3 weeks; maximum = 11 weeks). The follow-up interview took place about 7 months after the first interview (minimum = 5 months; maximum = 11 months). The large variation in the time lapse was due to patient availability and the COVID-19 pandemic. The very first patient interview took place via videoconference on November 17, 2020, and the last one for this study was conducted in person on April 20, 2022. The first round of interviews took place predominantly place via telephone, except for one older patient who insisted that I see her at home despite the potential risk of COVID-19 infection. Interview durations did not differ much between the first and the second rounds of interviews and the post-removal interviews. Median patient interview duration was about 64 minutes. The shortest interview was during the second round of interviews, and it lasted 21 minutes. With a duration of 181 minutes, a post-removal interview became an outlier as the longest study interview, whereas the second longest interview lasted 93 minutes.

Most patients preferred being interviewed over the phone rather than by videoconference. Once vaccination was available for all age groups in Switzerland in spring 2021, most interviewees chose to be interviewed in person at home. One patient had received the cardiac monitor in the context of a clinical trial, and I decided to keep her interview in the sample as her experience was an interesting addition to my study sample. In three cases, patients' partners joined the interview. In one case, the partner joining the interview had been arranged from the start because the patient's speech was considerably impaired following his stroke. Nevertheless, he contributed to the explanation his wife gave with gestures and facial expressions, as well as with occasional sentences which he sometimes wrote down first. In the other two cases, the partners joined the interview spontaneously, and I perceived their participation more as an opportunity rather than a disturbance.

Despite several attempts to recruit patients who had refused cardiac monitors or had them removed due to dissatisfaction with the devices or remote monitoring, I failed to recruit any. A major obstacle in this regard came in the form of the healthcare professionals who acted as gatekeepers for patient recruitment. During ethnographic observations, I heard about one such case. I then insisted with the cardiologist by explaining that I would like to recruit this patient to have a cardiac monitor refusal in my study. After several e-mails justifying the necessity of integrating such a patient example in my study, the cardiologist finally agreed to put me in contact with the said patient. Even though the patient was initially interested in participating when I called her, she finally refused after I asked her to sign the informed consent form. Another patient who was very skeptical about the insertion of the cardiac monitor, but gave in after a long discussion, was also very suspicious of my presence at the hospital. After explaining to him that I was not affiliated to the Waldspital in any way, he agreed that I could contact him by phone. When I later called him to ask for his consent to participate, he talked to me for 20 minutes on the phone but continued to refuse to participate in an interview and to consent to allow me to at least use what he had told me during the call. These experiences call into question the utility of detailed informed consent forms for study participants who tend to have skeptical attitudes towards medicine and science in general and who therefore may prefer informal exchanges to formal procedures.

Additionally, I tried to obtain interviews with company representatives working at medical device companies that develop and sell cardiac monitors. In total, I conducted 4 interviews with company representatives from two medical device companies. For each medical device company, I conducted interviews with 2 employees. Two had scientific backgrounds, one was trained in business and marketing management, and one had worked as a nurse in the cardiology unit of the Waldspital before being hired by the medical device company. Out of the 4 company representative interviews, 3 of them took place via videoconference and followed a semi-structured interview guide. One was an hour-long informal conversation in a café. Since all official company information was strictly controlled by the marketing department, I did not systematically get answers to all of my questions. In general, the informal conversations and my ethnographic observations helped me best to grasp the challenges and business competition faced by the medical device companies concerning remote cardiac monitoring.

3.4 Data preparation

Following my ethnographic observations, I converted information from my handwritten fieldnotes into narrative, digital accounts. Depending on the field site, I noted observations in French or in (Swiss-)German.

All patients including their partners consented for the interviews to be audio recorded. One cardiologist preferred not to be recorded but allowed me to take notes during the interview. Directly after this interview, I sat down to transfer my notes and what I remembered from the discussion into a Microsoft Word document. Furthermore, an informal conversation with a company representative took place in a café during which I decided to not take out my booklet. Afterwards, I sat down immediately for several hours to reconstruct and write down everything I remembered from the conversation.

Audio-recorded interviews (n=60) were transcribed verbatim in the original languages of utterance: French, Swiss-German, or German. Thus, the dialectical characteristics of the speakers were preserved. Obvious grammatical errors or slips of the tongue were corrected during the transcription process. The following aspects were omitted, unless they were considered relevant in the context of the conversation by the transcriber:

- Active listening expressions: "mmh" / "yes" / "ok"
- Filler words: "uh" / "and, and"
- Immediately corrected formulations or slips of the tongue, unless relevant in the context of the conversation: "I would say" instead of "I think/ I would say"
- Word repetitions that are not reinforcing: "like, like"

Moreover, brackets were used to clarify the quotes:

- Parentheses were used for body language, audible expressions, and hesitations: (laughs) / (shrugs) / (disguised voice) / (seems undecided) / etc.

- Curly brackets were used to indicate incomplete sentences, interruptions, and subsequent omissions: {unfinished sentence} / {deliberate pause} / {…}
- Square brackets were used to replace missing terms, or explain term used by the participants: [transmitter] / [original Swiss-German quote: "Die totali Überwachig."]

Punctuation was inserted as part of the transcription process. For better legibility, periods were preferred over commas, but clearly linked statements were not fragmented into several sentences. I was very grateful to have the opportunity to mandate two French-speaking sociology master students to transcribe the French interview recordings (28 of 60 in total). I transcribed the interviews that took place in (Swiss-)German and English. Quotes used in the result section were transcribed to English by the author respecting the speaker's intentions. Certain expressions or idioms were left in the original language if there was no adequate translation.

3.5 Data analysis

Data was analyzed through use of reflexive thematic analysis (Braun and Clarke 2021). This approach recognizes and values the situated and subjective position of the researcher and requires a reflexive stance throughout the data analysis process. In the following paragraphs, I describe how I engaged with and familiarized myself with my data in various ways, beginning prior to the second round of longitudinal interviews. To prepare the second round of patient interviews, I listened to the audio recordings of the first 9 conversations and mapped recurring topics in the form of a mind map (see appendix I). This mind map from the first round of patient interviews, my fieldnotes, and the interviews with healthcare professionals realized at the Waldspital served to re-orient the interview guide for the second round of patient interviews. This procedure allowed me to become more familiar with my data and to add questions on unexpected topics which emerged in the first period of the data collection. These included for example the (non-)importance of humor to deal with medical uncertainty or patients' self-reported perception of feeling healthy in the face of a potential arrhythmia or recurring, unexplained symptoms.

When transcribing the interviews, I regularly took handwritten notes about what appeared to me as striking, surprising, or fascinating. This served to further refine the analytic scheme of the initial mind map. During a writing retreat, I did another type of mapping of my research by sorting out the main thematic strands of the story based on my preliminary analysis and understanding of the data. This time, my sketch for the dissertation outline was informed by all the data collected and the theoretical framework (see appendix J). Now with a clearer idea about how to present my data, I went back to the preliminary list of topics and transformed them into codes. To establish a first version of my codebook for reflexive thematic analysis, I arranged the list of codes into themes that I thought would compose the chapters of this dissertation. Codes applied simultaneously for the presence and absence of responses or meanings of a given topic, for example, the code "pain" applied for both the presence and absence of pain as described by patients. I tested the first version of this codebook by coding one document of every type of data collection. This coding test was done on a total of 9 documents. This process allowed me to fuse some of the codes, add missing ones and rearrange them within the themes. The final codebook consisted of four themes with 8-13 codes each and 11 non-themed codes. The final codebook therefore had in 52 codes in total (see appendix K). All research materials were coded with the software Atlas.ti. One interview with a scientific nurse was excluded from the analysis because it did not contain any relevant information. Her work tasks were only tangentially linked to remote cardiac monitoring and the data from this interview did not add any meaningful findings to the study results. As I coded, I simultaneously copied and pasted quotes that seemed to illustrate a particular theme into Word documents that I had prepared according to the preliminary dissertation outline. Later, I reviewed them along with my coded data and color-coded the quotations I wanted to use in my chapter. Finally, I translated the final selection of quotes from (Swiss)-German and French into English, taking care to reproduce their meaning as closely as possible.

3.6 Ethical considerations

The study was reviewed and approved by the local “Commission cantonale d’éthique de la recherche sur l’être humain” (Cantonal commission on ethics in human research of the canton Vaud) in September 2020 (see appendix L). Clearance also applied to the second research sit. This clearance was provided by a formal written decision letter. Patients and healthcare professionals provided their written informed consent to participate in this study. This study was conducted in accordance with the submitted research protocol, the ethical principles for medical research of the Declaration of Helsinki (World Medical Association 2022), the Human Research Act (HRA) and the Human Research Ordinance (HRO) (Swiss Federal Law 2022), as well as other locally relevant regulations.

It is imperative that the investigator maintains a reflexive and considerate posture throughout the research process. This helps to identify unexpected ethical issues and handle them appropriately. Participants can experience stress, unease, and discomfort during ethnographic observations or during interviews. When such events occurred, questions causing trouble were left out of data analysis or dissemination. If participants expressed stress about the general situation, I offered participants the opportunity to interrupt ethnographic observations or interviews. I was prepared to hand over necessary information and local contacts provided by the research sites to participants after interviews if participants wished to seek psychiatric support in case of serious distress experienced during the study. Fortunately, this did not happen.

Project data was handled with utmost discretion and were only accessible by me. Participants' anonymity and confidentiality were assured by attributing a code to each participant. The cross-reference table providing links between participants and codes was stored in a separate folder on a protected server which is password protected. Narratives of participants are presented in a way to avoid identification through providing potentially identifying information with contextual information or unique life experiences.

Following the publication of results from this study, audio recordings as well as the cross-reference table indicating participants' real identities will be deleted from all servers, devices, and email programs. Transcriptions of interviews and fieldnotes will be conserved on protected servers (SWITCHdrive at the University of Geneva) of the project DoPHiS for a period of up to 10 years after completion of this PhD thesis. Access to these documents will be protected by a password only known to the PhD candidate and the project leader.

Data restitution is planned in the form of presentations for the involved university hospitals and in the form of an easy-to-understand written summary in French and German for participating patients. Portions of this dissertation are part of an article entitled "The illusion of immediacy: on the need for human synchronization in data-intensive medicine" accepted for publication for the Research Topic "Personalized Health and Precision Medicine in Practice" in *Frontiers in Sociology*.

3.7 The sociologist's personal connection to medicine

Growing up with a stay-at-home mother who had worked as an intensive care nurse for several years, and a father who made his career in marketing and customer support in the diagnostic industry, I am well acquainted with everyday risks and potential hazards. As a result, I was rather protected from such risks as a child. For example, my mother did not want me to take up horseback riding. Instead, I ended up playing badminton which turned out to be quite dangerous for my ankles, which I twisted several times. Otherwise, I am lucky to not have suffered from any major health issues until today. The only rather diffuse health risk that has accompanied me since childhood is a mild allergy of wasps and bee stings. For this reason, I always carry emergency medication that is attached to my key chain.

Overall, I had no negative experiences with doctors or other healthcare professionals and was very fascinated by their role in helping people. My fascination was so strong that I tried to enter medical school after college. However, I did not pass the mandatory selection process, and spontaneously changed my study plans to biology and sociology.

4 Inserting hope: patients receiving a cardiac monitor

The appointment at the hospital for the insertion of the cardiac monitor often marked the end of a long series of other medical examinations. Thus far, the patients had had major or minor incidents, such as a stroke or fainting. Still, other medical tests had failed to detect the cause of these incidents. Even if cardiologists strongly suspected a certain type of arrhythmia to be the cause, treatment only applied if the rhythm disorder could be measured and identified by an electronic recording as it is custom in today's clinical practice grounded in objectivation of bodily signs and symptoms (Weisz 2005). Hence, cardiologists or other doctors, such as neurologists in the case of a stroke, recommended remote cardiac monitoring to patients, while hoping to confirm or reject the hypothesis of the suspected arrhythmia. One cardiologist told me what led to the decision to implant a cardiac monitor in a patient on the morning of the interview:

> *We did an electrophysiological study this morning – which was obviously within the normal range – and so I decided to implant a cardiac monitor, because if there are any major arrhythmias, <u>we</u> can see them. And most importantly, if there's another syncope, like the one he had, we can <u>objectify</u> what's going on. So, I think it's absolutely fundamental (participant's oral <u>emphasis)</u>.*

The above example illustrated to what extent is important for cardiologists to have quantified evidence, especially in the context of the patients' symptoms that they seek to explain. The appointment at the hospital for the insertion of the cardiac monitor is also the moment in which the patient – or, to be more precise, his or her cardiac monitor -– is connected to the remote monitoring system, which allows for patient data to automatically synchronize to other devices in the system. Although it is possible to do, as an alternative, a calendar-based follow-up with regular appointments at the hospital to extract and check the recorded data, cardiologists strongly recommend remote monitoring to their patients. There are only very few who refuse. Generally, patients either accept the remote cardiac monitoring entirely or already refuse having a cardiac monitor in the first place.

This chapter is mainly based on my observations and subsequent fieldnotes at the Waldspital. Its setting allowed me to closely observe all the different stages involved in the insertion process, from patient admission to discharge. That said, my ethnographic observations from La Clinique will also be weaved into the narrative. This chapter contains a detailed description of how patients are prepared for the insertion of the cardiac monitor, about the insertion procedure itself and the technical setup of connecting the patient to the remote cardiac monitoring system. Moreover, the chapter displays the four strategies put into place by nurses or cardiologists aiming at reassuring patients in the handling of remote cardiac monitoring. They told them (1) that the system was completely automatic and that they did not have to do anything, (2) that they could continue their normal life, which would not be changed at all by the heart monitor, (3) that they did not have to pay special attention to beeps or other technical signals emitted by the transmitter, and (4) that they could call the telemedicine unit's helpline at any time if they had any questions. The fourth point was unique to the Waldspital. La Clinique did not offer such a direct phone number to its patients, who were advised to contact their treating cardiologist with any questions.

The act of the insertion itself may take as little as 5 minutes, and patient preparation and providing instructions can last up to 90 minutes. All these processes were affected by individual patient situations and some practical and/or technological hiccups. During the process, previously unthought of uncertainties arose for the patients. For some of them, laughing about these unforeseen uncertainties was a way to cope with the situation. Finally, the chapter introduces the figure of the company representative, who I did not expect to be present in person at a medical appointment such as the insertion of the cardiac monitor. It was the only moment in my fieldwork during which the otherwise hidden entanglement of the hospital's medical sphere and the business sphere of outside interests became obvious.

4.1 "It's no big deal": Welcoming patients for the insertion of the cardiac monitor

Patient care and the hospital staff responsibilities regarding cardiac monitor insertions and removals differed between the two studied university hospitals. Correspondingly, patients will get a different experience of the insertion or removal procedure depending on where they live in Switzerland. This is of particular scientific and practical interest because the Waldspital only implemented restructured patient care at the beginning of 2020 and is the only university hospital in Switzerland with this type of organization. The main difference between the two hospitals was the person in charge of inserting and removing the cardiac monitor. At La Clinique, cardiologists were responsible for this minor surgery, as they would be in any other hospital in Switzerland. At the Waldspital however, three specially trained implant-nurses were allowed to insert and remove cardiac monitors. This reorganization had been developed by a team of cardiologists and nurses to reduce cardiologists' workload by optimizing the daily clinical work schedule and to improve the quality of care (Steinhauer et al. 2022).

Consequently, I was immersed in different realities on site. La Clinique admitted patients to the cardiology day hospital. After being admitted as outpatients, they were assigned to their hospital beds, which were separated from other patients by curtains or walls. A nurse helped patients settle in. Patients were required to change into a patient gown. Cardiac monitor insertions and removals at La Clinique were usually scheduled in the mornings, Monday through Friday. Once admitted to the cardiac day hospital, patients had to wait until the attending cardiologist was available. Due to the unpredictability of the clinical routine, patients sometimes had to wait up to several hours because the cardiologist was stuck in the operating room. One patient had had enough after 3 hours of waiting and left the day clinic in a huff. He had already agreed to participate in my study. When I later contacted him by message to ask if he had already made another appointment for the insertion of the cardiac monitor, he told me that he would let the summer pass and then contact his cardiologist again in the fall to reconsider. In general, however, patients did not complain too much about the wait and remained patient.

Contrary to La Clinique where insertions and removals of cardiac monitors were scheduled throughout the week according to the schedule of the responsible cardiologists and the availability of the patients, the Waldspital had an "Implant-Monday." There, patients were admitted by the specially trained implant-nurses in a conventional consultation room. In one day, implant-nurses usually performed about four cardiac monitor insertions and/or removals. During my presence at the hospital, the consultation room assigned to the implant-nurses and their work changed several times, probably due to the redistribution of the available rooms of the general medical departments and maybe linked to the ongoing construction works according to them. The implant-nurses had no say in the process and had to adjust to the reassignment, which sometimes happened with a week's notice. The last relocation I observed had them working in a very small consultation room where the hospital bed was not adjustable in height or angle. This complicated the surgical procedures for the implant-nurses because they could not adapt the bed to patient comfort and their way of working. Moreover, one implant-nurse had expressed concerns about how they would handle an emergency. As I later witnessed, her worries were not unjustified when a patient suddenly fainted after the insertion of the cardiac monitor.

Before admitting patients, implant-nurses reviewed their medical records and discussed the patient type. They checked the arrhythmia for which the cardiac monitor would be inserted. They also looked at the patient's age, comorbidities, and medication list. The latter was a key indicator for them to decide whether to prophylactically insert a peripheral venous catheter during the procedure. Based on the medical record, they also selected the type of material that they would use to close the wound after the cardiac monitor insertion. In addition, the nurses completed all the paperwork in the hospital's computer system and on paper so that the cardiologists only had to sign the consent form. The following list is an example taken from the fieldnotes of one day of cardiac monitor insertions (fieldnotes, Waldspital, October 26, 2020):

- woman, born 1932, stroke clarification, will be accompanied by her daughter
- man, born 1967, syncope clarification, speaks only Italian, but should bring someone to translate
- man, born 1960, stroke clarification

When the implant-nurse reviewed the medical records of the first patient on the list above, she told her colleague not to make all the preparations for the insertion of the cardiac monitor yet, because they could not be sure that the patient would show up. She based her caution on the patient's year of birth. In her opinion, given that we were in the midst of the October 2020 wave of COVID-19 infections, it could be expected that the patient might cancel this "unnecessary" procedure. This illustrates that the nurse considered the risk of coming to the hospital to insert a diagnostic device at a time when COVID-19 infection rates were high in Switzerland to be higher for this elderly patient than the risk of not knowing if atrial fibrillation might have caused her stroke.

The two implant-nurses at the Waldspital usually split up and regularly alternated their tasks. One of them was the main contact for patients from the beginning to the end of the appointment. I will refer to her as the admitting nurse. The other took care of paperwork and the insertion of the cardiac monitor. In the following sections, I will refer to her as the implant-nurse.

Upon arrival in the consultation room, patients were asked to take a seat. Sometimes they were accompanied by someone close to them, such as a relative or a partner. First, the admitting nurse asked patients if they understood why they would be receiving a cardiac monitor. Most of the time, patients understood the reasons. However, from time to time, the nurse had to explain them again. Because she was familiar with the patients' medical records, she was also able to explain what type of arrhythmia they were looking for. The admitting nurse also took the time to answer other questions patients might have. These questions were often about what the cardiac monitor looked like, how much it might bother them, or whether or not they could continue going on with their normal lives. Many patients were quite nervous about the insertion itself. The admitting nurse often reassured them by saying things like, “It’s no big deal.”

Moreover, patients oftentimes wanted to know if they had to go to their family doctor to have the stitches removed and how long the cardiac monitor would remain in place. Overall, the admitting nurse was careful not to go into too much detail about the remote monitoring part but focused instead on the insertion procedure to avoid confusing patients. If patients had specific medical questions, the nurse told them to ask the cardiologist who would be passing by shortly. If possible, cardiologists tried to see the patients before the insertion procedure began. However, since this was the responsibility of the on-call cardiologists, they were not always able to get there in time. Given that the admitting nurse was occupied with admitting the patients, it was usually the implant-nurse who called the on-call cardiologist as soon as her colleague told her to do so. Some patients were astonished to learn that the insertion of the cardiac monitor would be done by a nurse instead of a cardiologist. Also, most of them were surprised that the intervention would take place on the hospital bed in the consultation room. Inserting and removing a cardiac monitor requires only minor surgery.

Receiving an implant that measures the heart's rhythm inevitably conveys the idea of a procedure close to the heart, which is a symbol of life and death. As a result, patients attached great importance to the procedure and expected a cardiologist to perform it. However, the nurses' explanations, based on their experience, quickly dispelled the patients' doubts. When cardiologists came by before the procedure, they often emphasized what a good job the nurses were doing. In doing so, they legitimized the nurses' work. Overall, the cardiologists found it very convenient that the nurses were doing the work for them, as in the past these minor procedures would have interrupted their daily schedules and been an inefficient use of resources, from their perspectives. My ethnographic observations at La Clinique confirmed their perceptions in the sense that the cardiologists there often arrived at the day hospital in a hurry and the patients had to endure long waiting times. In contrast, the specially trained implant-nurses at the Waldspital were able to welcome patients on time and guide them through the entire process. In addition, "Implant-Monday" was usually the nurses’ favorite day to work, as one nurse enthusiastically confessed. She told me that they very much appreciated their extended responsibilities. It also excluded them from the daily hustle and bustle of the cardiology ward. The calm and quiet environment was also appreciated by the patients.

While many patients were convinced about receiving a cardiac monitor, a few remained reluctant during discussions with the admitting nurse. One day, a patient, accompanied by his wife, was very suspicious about the insertion of a cardiac monitor (fieldnotes, Waldspital, November 23, 2020). The attending cardiologist told me in private that he was an “atypical example.” He went on to tell me that, based on the patient’s medical history, he needed a defibrillator because he had barely survived a heart attack. Although several cardiologists tried to convince him, he categorically refused a defibrillator implant. The patient cited his passion for tinkering with machines in his garage, such as a band saw, which could potentially interfere with and deregulate an implanted defibrillator. He was concerned that he would no longer be able to enjoy his hobby. His wife, on the other hand, feared that her husband would not survive a second heart attack and, like the cardiologists, strongly advocated for the insertion of a defibrillator. Since a defibrillator was not an option for the patient, the cardiologists and the patient's wife thought they had found an *ad interim* solution with the cardiac monitor that might justify the need for a defibrillator. Nevertheless, the patient’s suspicion towards this solution surfaced again during the appointment when he accused the healthcare professionals of trying to trick him into accepting a defibrillator by inserting a cardiac monitor. His distrust was also displayed by his questions about where his data was going and why he had to keep the monitor for several years. The fact that both a company representative and I were there that day did not add to the patient’s trust in the process. After the situation started to heat up, I decided to close my booklet and momentarily put it away. At one point, the patient’s wife could no longer hold back her tears. The company representative offered her a tissue. The attending cardiologist went on to explain the risk of dangerous arrhythmias, telling the patient that he could have another one the following day, in two weeks, or never again, which would be the best thing that could happen to him. Finally, the patient relented and said that at least they would see if he had what they suspected or not. The cardiologist went on by reiterating that the device would not protect him from another heart attack and that he would still have to call the ambulance. His wife was relieved and happy about the decision. Finally, the attending cardiologist, not the implant-nurse as usual, performed the insertion of the cardiac monitor. After the procedure, the patient was in a more conciliatory mood. After the company representative had provided instructions to the patient, I could present my study. Although he was initially suspicious and asked me to explain in detail what would happen to his data, he eventually agreed to give me his contact details. About a week later, I called him to ask if he was still willing to participate in my study. On the phone, he felt comfortable enough to talk to me about his experience for about 20 minutes. Unfortunately, he ultimately refused to sign the consent form to participate in my study, and I was not able to interview him.

Another time, a patient was not feeling well when she was admitted to the consultation room for the insertion of the cardiac monitor (fieldnotes, Waldspital, August 20, 2021). She complained of a severe headache. Although she told the on-call cardiologist that she would rather not have the device inserted, he did not really respond to her doubts. Instead, he said, “But if you want to know something, this is the best thing we can do.” Reluctantly, the patient complied with what the cardiologist said, repeating the reasoning that since she was already there, there was no point in going home. This bad start to the process made for a not-so-good end; this is the above-mentioned patient who fainted shortly after the insertion of the cardiac monitor. This put the implant-nurses in exactly the uncomfortable emergency that they had feared would be difficult to manage in a small consultation room. I gave a helping hand by stabilizing the patient’s head. Once the patient was transferred to a proper hospital bed, I accompanied the nurses as they took the patient to the emergency ward. They assigned me the task of bringing along the patient’s personal belongings. This caused some confusion at the emergency ward as the staff was not sure of my role. At first, they assumed that I was the patient’s daughter or some other kind of relative. Finally, one of the nurses informed her colleagues about the patient’s situation before we returned to the consultation room.

Overall, most patients did not further question receiving a cardiac monitor at the time of insertion appointment. Although the nurses told me that they had sent patients home without a cardiac monitor in the past, this did not happen during my time at the Waldspital. When the patients had no more questions, the admitting nurse asked them to remove the items of clothing covering their upper body and to lie down on the patient bed.

4.2 "It's a bit like at the dentist": Preparing the patient's body for the insertion

Once patients were settled in their hospital beds, the implant-nurse came to introduce herself. With her hand, she felt the patients' chests to determine the insertion spot. By touching the chest with her hand, she could get a haptic sense of the consistency of the tissue, in particular, how much muscle and fat tissue the patient had. For female patients, it allowed her to consider where to best insert the implant in relation to the breast tissue. The guidelines recommended inserting the cardiac monitor between the 4th and 6th rib, about two finger widths from the sternum. Depending on patient body type and gender, the implant-nurse would place the cardiac monitor in parallel to the sternum or at an angle of up to 45º to the sternum. Determining the insertion spot was often easier for men than for women. I observed this during my fieldwork and confirmed it with nurses through informal discussions at the hospital. The challenge with female bodies was to insert the cardiac monitor in a way that would not cause future problems. Generally, the nurses inserted cardiac monitors more in parallel to the sternum and higher up in women than in men. In men, nurses often had to first shave some of their chest hair. They had usually already prepared the razor together with the other materials necessary for the cardiac monitor insertion (see Figure 5).

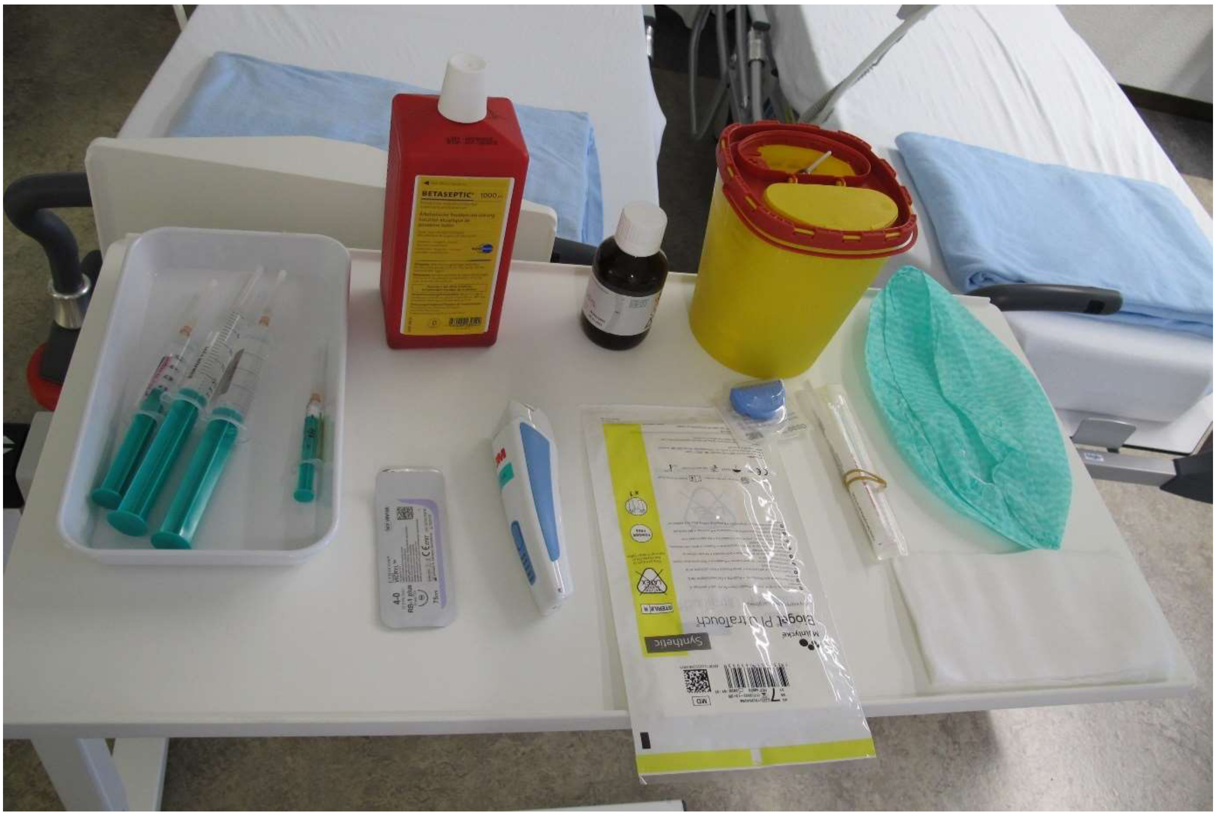


Figure 5: Materials for the insertion procedure; syringe with local anesthetic; pack of surgical needle and thread; two bottles of disinfectant; razor; pack of disposable surgical gloves; medical waste container; surgical cap, and other materials needed for insertion (photograph taken during fieldwork by M. von Arx, October 26, 2020).

Once the location and approach were determined, the implant-nurse then marked the insertion spot by drawing an arrow with a black marker pen. She then disinfected the area using tweezers to apply a cotton ball soaked in disinfectant. Before applying the disinfectant, nurses warned patients that it would be wet and cold. For men with freshly shaved chest hair, nurses sometimes added that it might burn a little. Before taking the next step, everyone had to wait for the disinfectant to dry on the skin. Meanwhile, the implant-nurse put on her sterile uniform. She then prepared the instruments she needed to administer the local anesthetic and insert the cardiac monitor. The latter was in a package along with an incision and insertion tool kit provided by the cardiac monitor medical device company.

Once the disinfectant had dried, the implant-nurse covered the patient with a large sterile fenestrated drape and allowed the incision site to be exposed through a small hole. From that point on, patients could no longer see what was happening below their chin. The admitting nurse stood at the head of the bed and talked to the patients to distract them. Then the sterile-clothed implant-nurse gave an advance warning that the most uncomfortable moment of the cardiac monitor insertion was about to happen. "It's a bit like at the dentist," she explained, referring to the injections of local anesthesia. The anesthetic was injected under the skin at different spots and depths (see Figure 6). Another time, a cardiologist had compared this part of the procedure to a bee sting when explaining it to a patient. This part of the implantation was tricky because there was a risk that patients would lose consciousness due to pain or stress associated with an overreaction of the vagus nerve. Once the local anesthesia was administered, it was only necessary to wait for it to take effect before proceeding with the insertion of the cardiac monitor.

Figure 6: Local anesthesia administered by the implant-nurse at the Waldspital (photograph taken during fieldwork by M. von Arx, October 26, 2020).

4.3 “Gosh! That was quick”: Insertion of the cardiac monitor

To the great surprise of many patients, the insertion of the cardiac monitor itself only took a few minutes. Once patients reported no pain when the implant-nurse or cardiologist tested their pain sensation by gently poking them with a needle or scalpel, they went ahead with making the incision (see Figure 7).

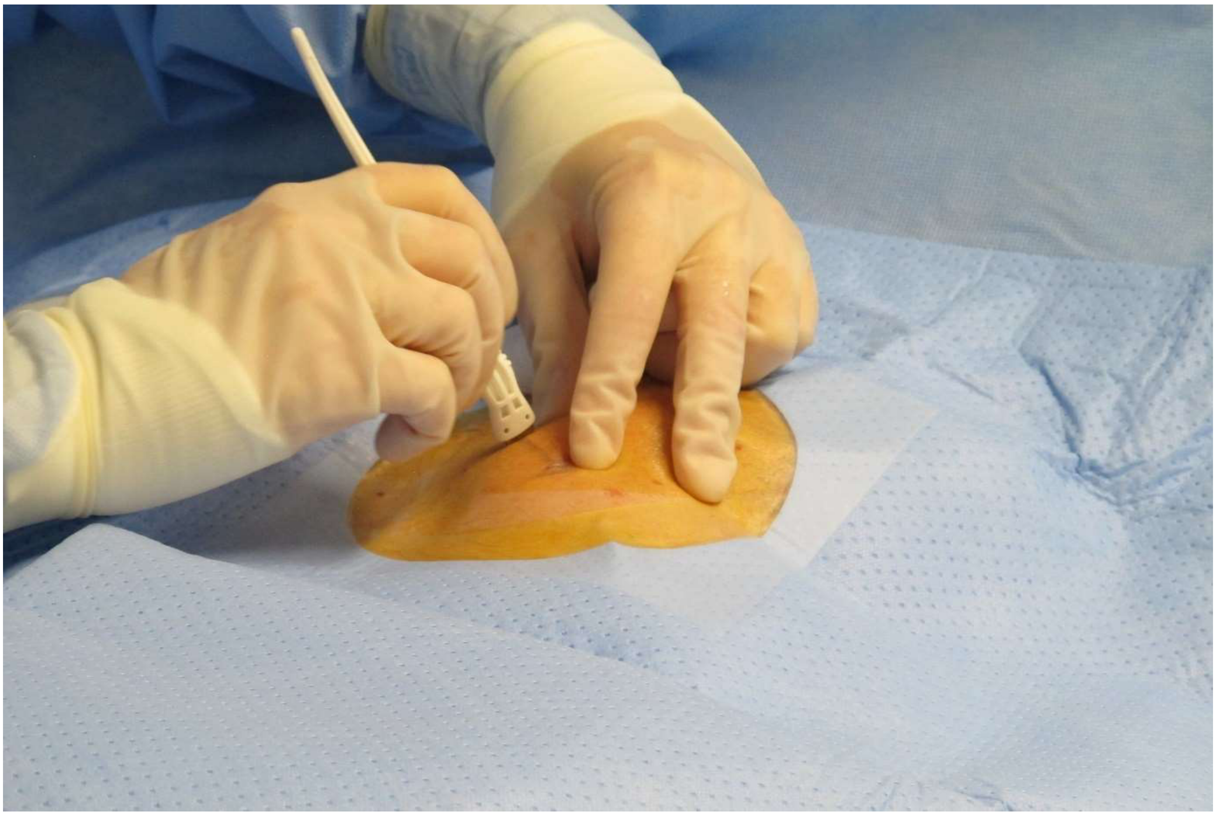


Figure 7: Incision done by the implant-nurse at the Waldspital (photograph taken during fieldwork by M. von Arx, October 26, 2020).

The medical device companies provide a tool kit containing disposable incision and insertion tools. The cardiac monitor is inside the latter and is invisible from the outside. The incision tool is used to make a cut about one centimeter wide in the tissue. The insertion tool is then pushed further under the skin to create the pocket for the insertion of the cardiac monitor (see Figure 8 and Figure 9).

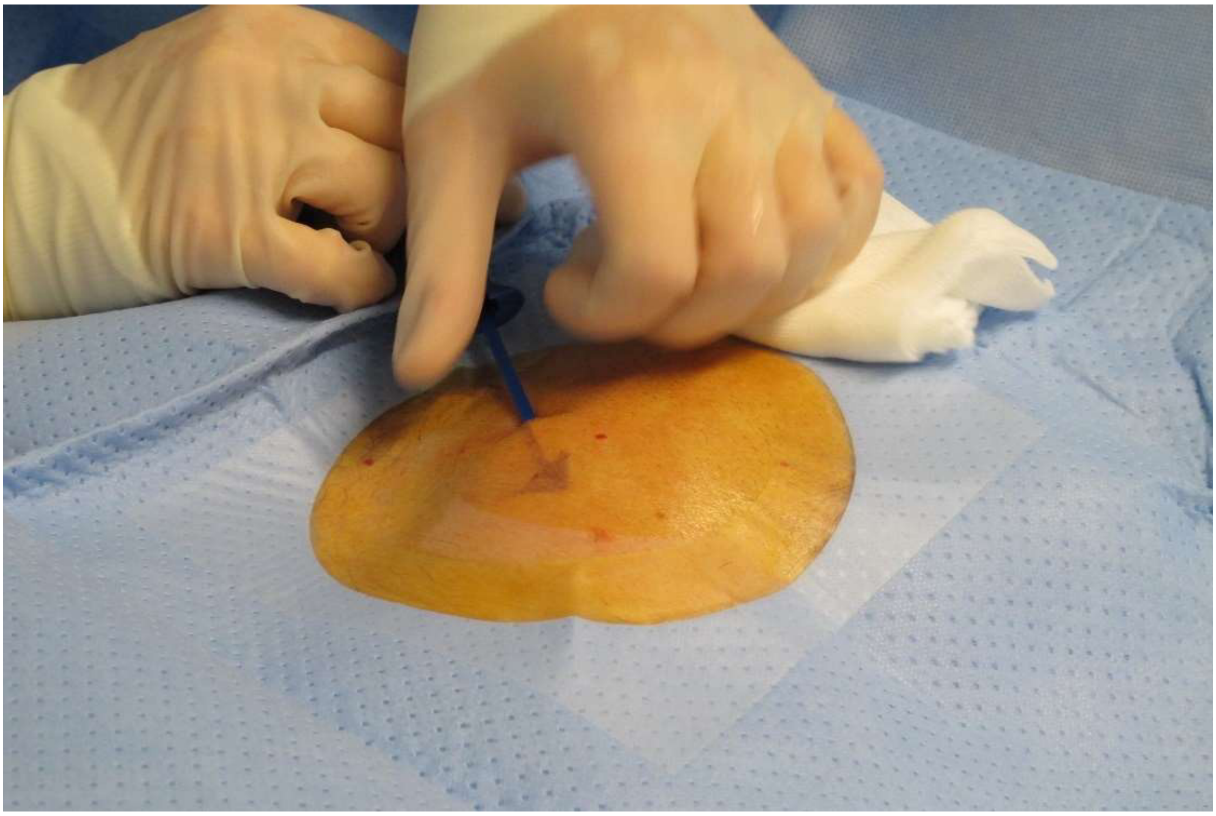


Figure 8: The implant-nurse at the Waldspital creates the pocket for the cardiac monitor by pushing the applicator under the skin (photograph taken during fieldwork by M. von Arx, October 26, 2020).

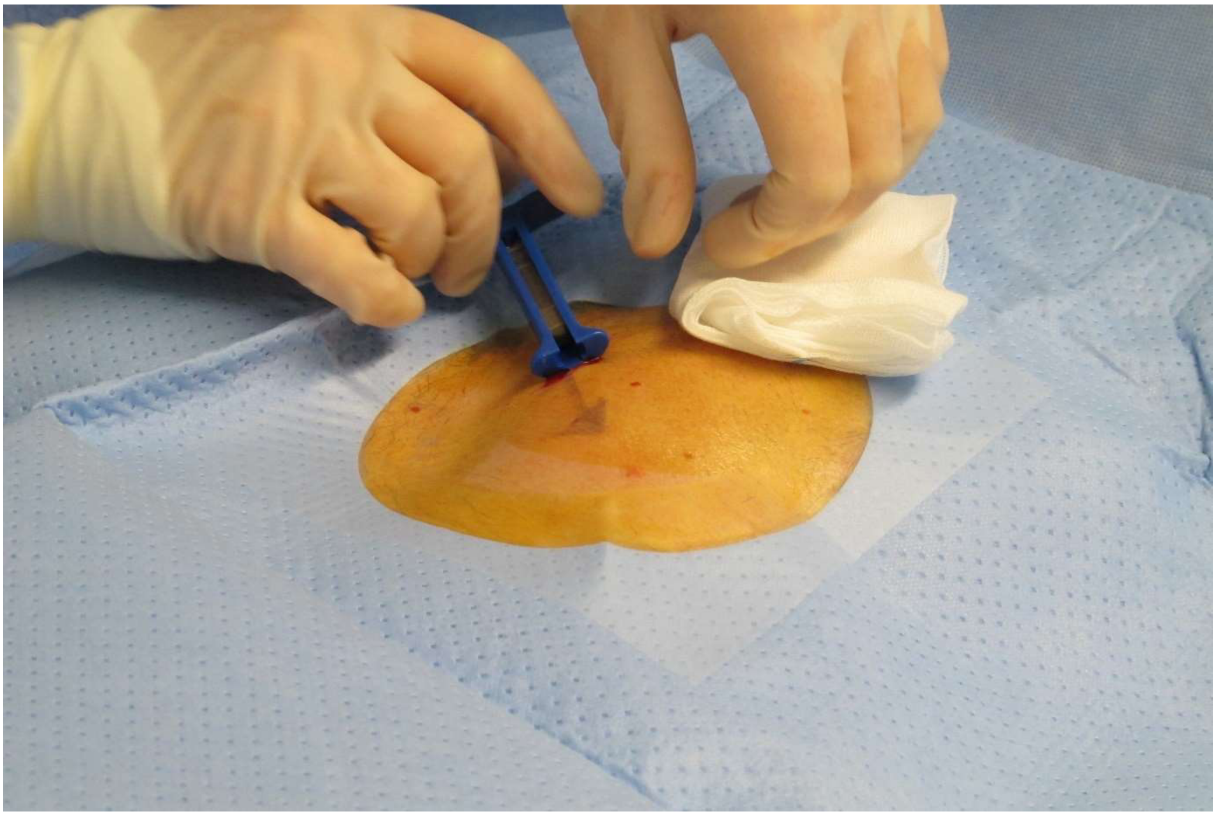


Figure 9: Applicator fully inserted under the skin; cardiac monitor visible before the implant-nurse at the Waldspital turns the insertion tool to inject the cardiac monitor (photograph taken during fieldwork by M. von Arx, October 26, 2020).

The cardiac monitor is then placed under the skin by either injecting it or releasing it from the insertion tool (see Figure 10 and Figure 11).

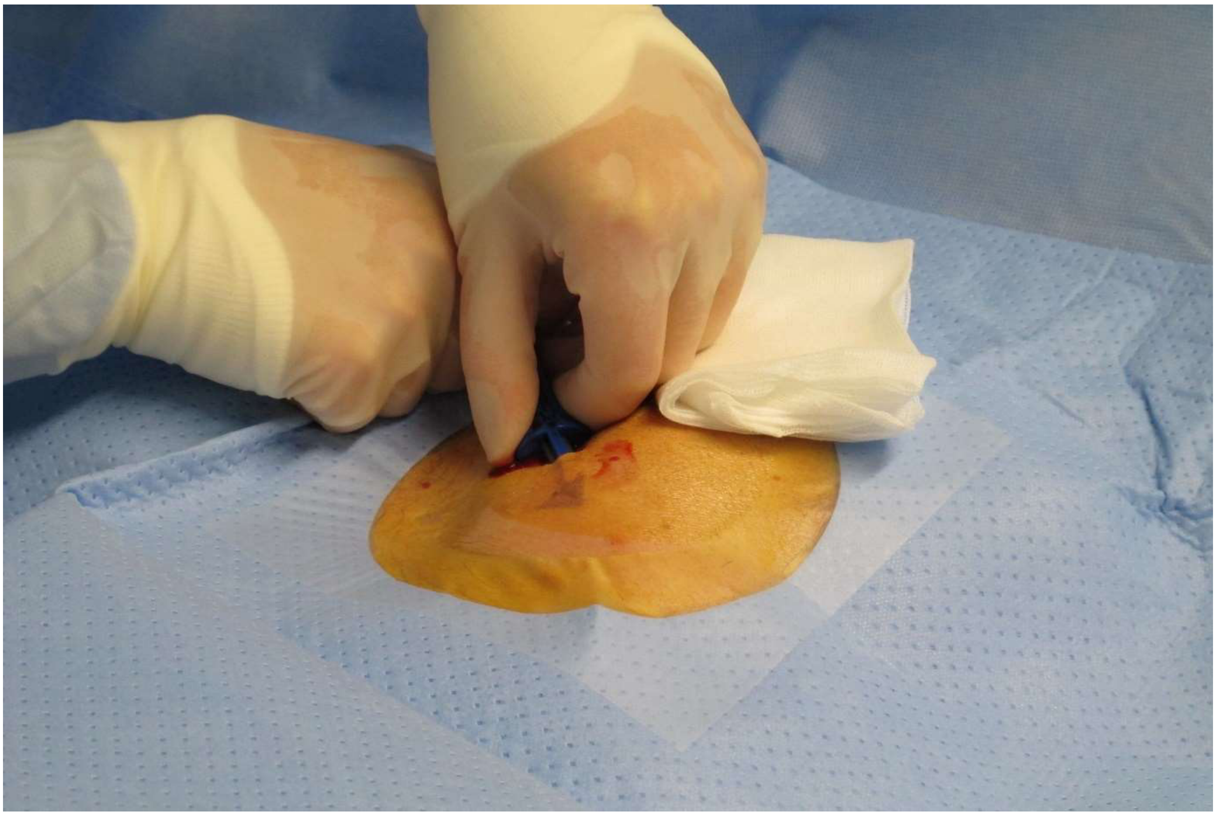


Figure 10: The implant-nurse at the Waldspital pushes the cardiac monitor under the skin of the patient (photograph taken during fieldwork by M. von Arx, October 26, 2020).

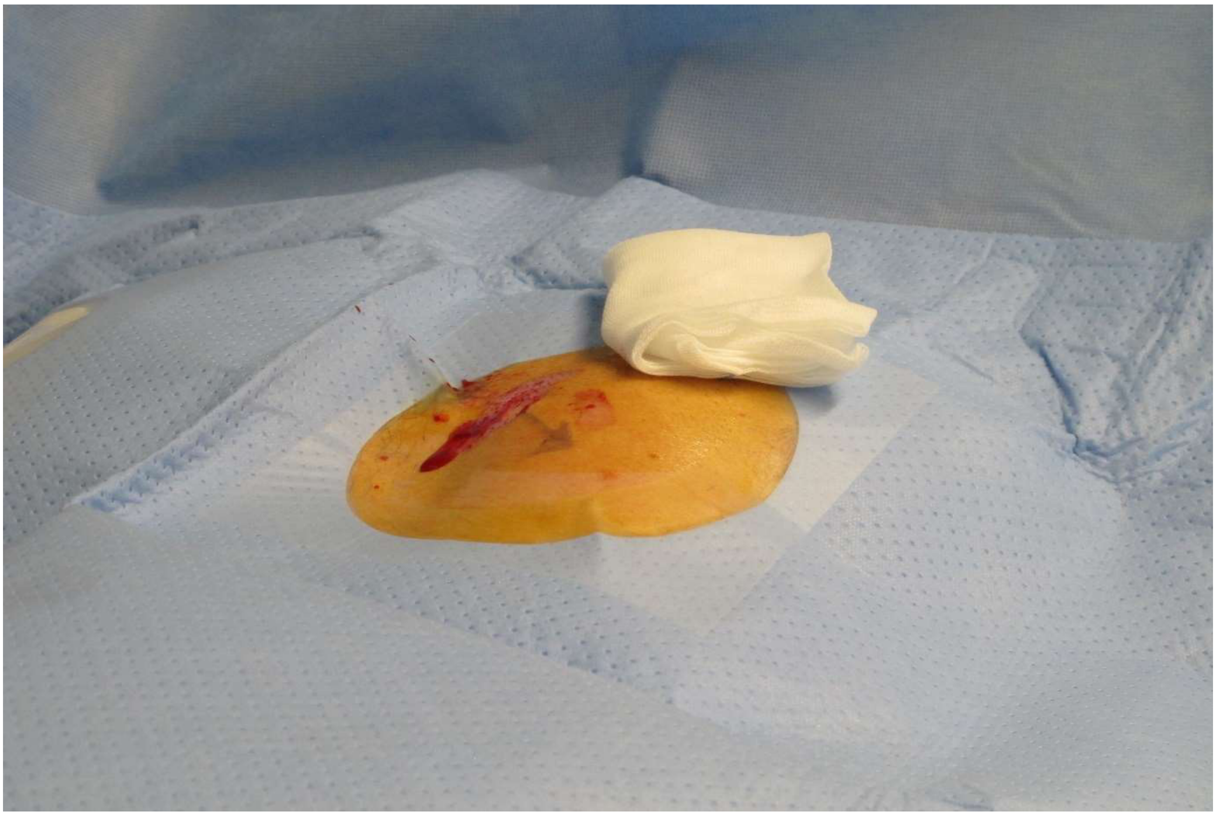


Figure 11: The cardiac monitor is now placed under the skin patient (photograph taken during fieldwork by M. von Arx, October 26, 2020).

Depending on the patients' body type, implant-nurses or cardiologists may need to apply more or less force to insert the tool and place the cardiac monitor. In general, thinner patients and those with well-developed breast muscles appeared to be more difficult for them to insert cardiac monitors. After having placed the cardiac monitor under the skin, the implant-nurses or cardiologists informed patients that the device had been inserted. Patients almost unanimously reacted with pleasant surprise and relief, sometimes by blurting out phrases such as, "Gosh! That was quick."

Once the cardiac monitor was placed under the skin, the implant-nurses or cardiologists closed the incision with one subcutaneous stitch or by applying wound glue (see Figure 12). The choice of how to close the wound depended on the patients' medical record and the hospital's standard procedure. Overall, the incision was sutured rather than glued in athletic patients and those taking blood thinners. This was done to prevent excessive bleeding or to hinder the cardiac monitor from slipping out. Depending on the quality and type of their wound closure, some patients were not allowed to shower for up to two weeks to avoid infection. After wound closure, the implant-nurses or cardiologists dressed the wound with an adhesive skin closure if the wound glue was not sufficient. Finally, they removed the sterile fenestrated drape. Occasionally, they had to act quickly to prevent patients from immediately touching the freshly dressed wound with one of their hands. Some patients also tilted their heads toward the chest to see what their new addition looked like, showing that it mattered to them how their body might have been changed by the insertion of the heart monitor. All materials used in the procedure were then cleaned and disposed of properly. Sometimes the nurse or cardiologist used a damp cloth to remove any remaining disinfectant from the patient's skin. Once the cardiac monitor was in place, all that remained was to set it up for use.

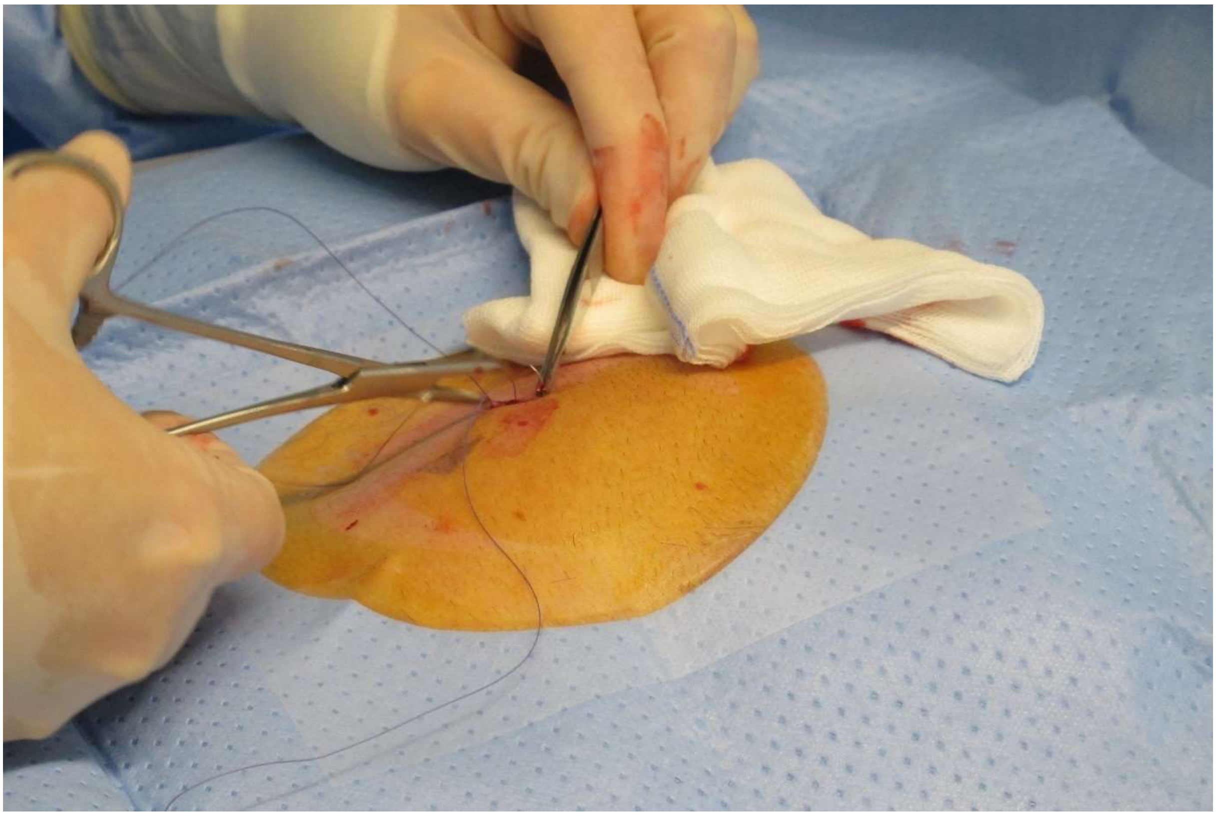


Figure 12: The implant-nurse at the Waldspital closing the wound with a subcutaneous stitch (photograph taken during fieldwork by M. von Arx, October 26, 2020).

4.4 "If it goes up and down, it's fine": Programming the cardiac monitor

By default, cardiac monitors detect any type of arrhythmia. However, depending on patient medical records, cardiologists may want to adjust the default setting to make monitors more sensitive to the type of arrhythmia suspected. Therefore, the implant-nurses or cardiologists had to program cardiac monitors and their algorithms to meet their needs. As I observed during my fieldwork, implant-nurses and cardiologists referred to the standards of care of the local cardiology unit for a particular arrhythmia in order to program the cardiac monitor. For example, they would adjust the duration of the recording or the thresholds at which the monitor would record a particular type of arrhythmia. The implant-nurses at the Waldspital usually used a one-page leaflet to program the cardiac monitor for sensitivity to suspected arrhythmias, such as syncope. The importance of these guidelines was illustrated when, on an "Implant Monday," a company representative recommended leaving a certain parameter "on" to generate more data (fieldnotes, Waldspital, December 14, 2020). The on-call cardiologist disagreed and countered that he did not want the telemedicine unit to be spammed again. Finally, the implant-nurse ended the discussion by saying, “We will program everything the way we used to.”

To program the cardiac monitor, a device similar to a computer mouse was placed on the insertion spot or near it. Newer generations of the technology no longer required it to be on the insertion spot. Then, the implant-nurses or cardiologists verified the patients’ personal data and the set up with the help of a company-specific computer or tablet. It was often the case that hospital staff did not explain much to patients about this step of the programming process in the overall insertion procedure. Most of the time, they just announced to the patients that all that was left to do was to program the device.

Although the companies’ software would allow fine-tuning of the settings for each individual patient, the implant-nurses and cardiologists preferred to stay within the local standard programming for the suspected arrhythmia at this stage. As several cardiologists told me in the interviews, they initially relied on standard programming and almost never adjusted the algorithm settings for individual patients. If they did, they did so at a later stage, primarily to reduce the data load of false-positive alerts generated by the transmitted recordings each time the threshold for arrhythmia detection was reached. When asked if she would use the ability to customize certain settings for patients, one cardiologist replied for example:

> *I do this very rarely. From time to time, we personalize the settings during the follow-up. For example, if patients regularly have pauses of more than three seconds because of phenomena that we already know about. And we are not going to implant a pacemaker because of that. Then we decide that we don't want to get the next 46 pauses, so we set the threshold to only record pauses longer than four or five seconds.*

In general, the cardiologists interviewed did not care much about the many technical possibilities that allowed them to adjust the default settings of cardiac devices. Instead, they had a more pragmatic approach that was essentially aimed at optimizing their daily practice. This calls into question the promises made by medical device companies who promote cardiac monitors as a diagnostic tool of unprecedented accuracy. When asked about the role of algorithms in clinical decision making, one cardiologist bluntly admitted that he was not a fan of all of them:

> *I think most algorithms help us as physicians. The extent to which we improve our diagnosis and therapy ultimately helps the patient. But there is still the question of how good an algorithm is. We always have to look at that very carefully. There are a lot of algorithms and features that we don't want. I actively disable and program some of them out because they don't give good data. They are not that great. Except maybe from the marketing perspective of the companies. Basically, what works is legitimate and should be used because it's supporting us.*

His account shows how much of the personalization discourse surrounding diagnostic tools such as cardiac monitors can be more a marketing strategy of the medical device companies selling them than a practical feature for healthcare professionals and patients.

Overall, the technical specifications appeared to be more profitable for the medical device companies than for the clinical routine, as they could take advantage of all the additional data collected, while the healthcare professionals had to deal with the burden of data review. A company representative confirmed my ethnographic observations of cardiologists who often seemed lost in the plethora of possible settings in remote cardiac monitoring. When I asked him during our informal conversation if cardiologists knew the settings of all the different cardiac devices, he burst out laughing and said, "No, forget about that." However, he agreed with the cardiologists that they should not adjust all the parameters at once, but only two or three at a time, and then review the results after about three months.

When the cardiac monitor was connected to the company-specific computer or tablet, it was possible to view the life graph of the patient's heart rhythm. In addition, there were indications of how accurately the cardiac monitor was capturing the rhythm, for example, by displaying the performance of P-wave detection (Schreiber et al. 2022). This performance could vary depending on the location of the cardiac monitor under the skin. When the cardiac monitor was able to capture the heart rhythm well, nurses and cardiologists often commented that the heart rhythm looked beautiful. Sometimes the nurses or cardiologists would show the patients the electrocardiogram of their heart rhythm by turning the computer or tablet.

As she had done on other occasions, one implant-nurse showed a patient the live heart rhythm that appeared on the screen after programming the device (fieldnotes, Waldspital, December 21, 2020). She commented that his heart rhythm would now be visible and monitored at the hospital. Like most patients I had observed before, he could not do much with this information. When the implant-nurse showed him the emerging graph, he responded, “If it goes up and down, it’s fine.”

His appreciation of the graph was a good representation of other patients' perceptions of the live electrocardiogram. As a widely used symbol of life or death in the medical context, often accompanied by a beep, for example in television programs and movies, many are able to recognize a typical heartbeat graph. However, to the untrained eye, it is almost impossible to tell what the different spikes represent and whether or not they deviate from the norm.

The moment of programming the cardiac monitor was also the occasion for some patients to laugh about the remaining uncertainties regarding their newly received device. The following conversation illustrates one such interaction between a patient and a nurse after programming the cardiac monitor:

> *Patient: Now you can always see where I am. Total surveillance [original Swiss-German quote: "Die totali Überwachig."].*
>
> *Nurse (ironically): Yes, we can now close the front door downstairs when we see that you are coming.*
>
> *(Patient laughs wholeheartedly).*
>
> *Nurse: This device can sometimes do less than we would like it to. But it does what is supposed to do, which is to detect rhythm disorders.*

Joking about the purpose of remote cardiac monitoring helps to alleviate possible fears associated with continuous monitoring. The way it helped patients reassess and cope with their new situation prompted me to ask a question on the importance of humor in relation to their health in the interviews I later conducted with patients. In addition, the nurse's answer and clarification underscored how remote cardiac monitoring can create unfounded expectations and/or fears based on promising assumptions about continuous monitoring.

After programming the cardiac monitor, patients were asked if they felt well enough to sit up and dress themselves. At La Clinique, patients could remain in the hospital bed until discharge. Relieved that the cardiac monitor insertion was over, patients began to ask questions about the inserted device and about the remote connection. Before patients were discharged, admitting nurses or cardiologists provided remote monitoring setup instructions.

4.5 "Just plug it in and forget about it": Strategies for instructing patients about life with a cardiac monitor

Remote cardiac monitoring instructions were mainly given to patients immediately after insertion of their cardiac monitors. However, depending on the hospital, the patient's curiosity, and the staff member performing the insertion, some information was provided before or during the procedure itself. At La Clinique, patients received instructions from cardiologists at the bedside either before or after cardiac monitor insertion. Sometimes the discussion continued during the procedure. At the Waldspital, the standard procedure was to give all instructions after the monitor insertion. This was based on the experience that patients were more receptive once the insertion was complete. This was supported by my observation that patients were often quite nervous before the procedure. Sometimes it was difficult for them to know what to expect, even though it had been explained to them by the cardiologist who had initially recommended a cardiac monitor insertion and again by the hospital staff before the device was inserted.

At the Waldspital, patients were asked to sit at a nearby table after they had finished getting dressed. The admitting nurse offered them tea, coffee, or water, which was very much appreciated by patients who had been advised to have fasted for the period before the insertion of the cardiac monitor. Instructions usually began with unpacking the transmitter from its box. Some patients were astonished that they had to take such a large, additional device home. The transmitter from the dominant medical device company consisted of a base station and detachable device similar to a computer mouse, which I will refer to as a reader. One of the biggest challenges for the admitting nurses at this point was finding an electrical outlet close enough to the table where the patients were sitting. For me as an observer, this was a regular reminder that even the most sophisticated technology would always depend on local electrical infrastructure (Weiner and Will 2018).

Transmitters also took a moment to find the local mobile network. From time to time, the admitting nurses would open the window next to the table a little, explaining to the patients that this would help the transmitter find a connection to the mobile network (fieldnotes, Waldspital, November 16, 2020). The transmitter's display indicated when it had found the local network connection. Nurses usually apologized in advance for the time it took to set up the transmitter. At La Clinique, a staff member usually placed the transmitter next to the hospital bed so that it was ready to connect as soon as the insertion was complete.

The next step was to connect the transmitter to the patients' newly implanted cardiac monitor to ensure that the two devices recognized each other for future data transmission. One admitting nurse once described this step to a patient as the marriage of the two devices. To do this, the reader had to be held over the insertion site. The admitting nurse guided patients about how and where to place the reader for electronic coupling. Most patients had difficulty finding the right spot. Some also thought that they would have to remove their clothes again, not believing that the coupling could be done through their clothes and their body tissue. The gesture was usually accompanied by instructions from the nurses telling them to move it more to the left or right, or more up or down. If the light did not turn green, indicating a connection between the two devices, nurses would give the patients some assistance.

Admitting nurses emphasized the ease of setting up remote cardiac monitoring when explaining to patients how to install the transmitter at home. In general, patients were given the simple advice, “Just plug it in and forget about it.” However, the process of connecting the transmitter to the inserted cardiac monitor often caused patients to ask questions about the connection in general. Realizing that the transmitter would be always plugged in next to their bed, some patients wondered what would happen if they got out of bed in the morning and were no longer near the transmitter as they went about their daily activities. The nurse told them that this would not be a problem because the data transmission would only occur at night.

In addition, some patients were intrigued by the buttons on the transmitter. However, when they asked the admitting nurses about its functions, they usually replied that they did not need to worry about these buttons and that they should just ignore them. From what I could observe at the Waldspital, this was one of four strategies used by the admitting nurses to reassure patients. Although the instructional flow could vary slightly between admitting nurses and depending on the type of patient, the four identified reassurance strategies were used regularly in an attempt to eliminate possible sources of worry in advance.

The second strategy was to tell patients to go about their lives as before. In this strategy, nurses told patients that if they felt well, they could go about their normal lives without restrictions. Often, patients feared that they would have to give up certain leisure activities. When they learned that they only had to be careful until the wound was completely healed, they were very happy. Often, the question of how to live with a cardiac monitor was first raised by the patients, showing that they wanted to do things right.

For example, one patient asked if she could have a small glass of an alcoholic beverage in the evening. "Of course," replied the admitting nurse, who continued, "It really does not change your life at all. You can do everything as before" (fieldnotes, Waldspital, November 16, 2020). Another time, a patient asked already during the surgical intervention, "Can I behave normally at home?" The implant-nurse who was suturing the incision replied with a smile, "That depends on what is normal, but yes" (fieldnotes, Waldspital, October 26, 2020). Overall, nurses emphasized that patients' daily lives were not affected by remote cardiac monitoring, giving the impression that the technology was working smoothly.

The third reassurance strategy was to trivialize any signal the transmitter might give. Nurses sometimes mentioned that the transmitter might occasionally flash or make a noise. An admitting nurse told the patient during instructions that he had absolutely nothing to worry about regarding the transmitter, "even if this device starts glowing in all colors” (fieldnotes, Waldspital, November 16, 2020).

The fourth reassurance strategy involved providing options for future communication. In the context of these potential technical hiccups or other concerns that might arise over time, the admitting nurse gave patients hospital's telemedicine unit’s business card. The card included a phone number that would connect the patient directly to a tele-nurse who could provide help for patients with questions about remote cardiac monitoring. Sometimes the admitting nurse had to explain that this was not an emergency number, but rather a helpline.

In addition, implant-nurses distributed patient implant cards indicating that the patient has a cardiac monitor implanted. They explained that patients should always carry these cards with them, especially when going through airport security or to the hospital for other medical tests, such as MRIs.

When nurses had finished their instructions, it was usually my turn to present my study to the patients and ask if they would agree to participate. On one occasion, the discussion between the patient and me caught the attention of the nurses and the company representative who was present that day (fieldnotes, Waldspital, November 30, 2020). The elderly patient had agreed to give me her phone number and other contact information so that I could later reconfirm her participation and schedule an interview. As I wrote down her number, I explained to her that the first interview would take place via phone or video call as a precautionary measure to avoid unnecessary COVID-19 infections. The patient agreed, adding that the more high-tech forms of communication, such as video calls, would not work because there was no reception where she lived. She explained that this was the reason she didn’t own a cell phone. The nurses' attention was immediately drawn to her comments. One of them carefully jumped into the conversation to ask the patient if she had heard correctly that she had no cell phone reception at home. The patient confirmed this again. At this point, the company representative, who had been present throughout that day, joined the conversation to ask the patient to specify the issue. It turned out that the patient lived in a remote rural area where there is a dead zone for cell towers. The nurses and the company representative seemed confused and somewhat embarrassed. No one had thought to ask the patient about available cell coverage before inserting the cardiac monitor, as it seemed too obvious to not take for granted. One of the nurses speculated that the cellular network might still be sufficient. She then decided and advised the patient to simply plug it in at home, and she would specifically inform her colleagues at the telemedicine unit about the possible lack of connection. In any case, one of her colleagues would call the patient the next day to confirm that everything was working properly and, if not, to discuss possible solutions they could offer her. As an ethnographic observer in the room, I remained skeptical about these exchanges and the ability of the device to transmit data from a dead zone, but it was not my role to speak up. After the patient left the room, the uncertainty about the automated data transmissions continued. I realized that the nurses felt sorry for the patient. One nurse said that in the worst case, the patient would have to come to the Waldspital every three months to read the data from the device. However, everyone was aware that this would be a great burden for an elderly woman who lived far from the hospital. The other nurse said out loud what we were all thinking, "I hope this works for her.” This was not the only time I met company representatives during my ethnographic observations at the hospitals.

4.6 Today, everything is different”: Entanglement of medicine and business

Just as I was about to become familiar with "Implant Mondays", the usual setting changed in an unforeseen way (fieldnotes, November 23, 2020). Due to another professional commitment, I was unable to be present in the first three hours of that specific morning, but the nurses knew that I would join them as soon as possible. When I entered the consultation room, I immediately realized that things were not going to be as usual. The patient was already there surrounded by the two nurses I knew well and a man I had never seen before. One of the nurses approached me and whispered to me in a complicit voice, “Today everything is different.” She explained that they would insert another brand of cardiac monitors than usual. Little by little, I began to understand what the nurse had been trying to signal me by pointing out that everything was different that day. The unknown man was a representative of one of the medical device companies offering remote cardiac monitoring. He had brought with him the latest generation of cardiac monitors developed by his medical device company. It was a different brand than the one I had observed them using in recent weeks. My initial surprise turned to concern when I realized that the patient present was not aware of this change. Due to the presence of the company representative, all patients who had their cardiac monitor insertion appointments at the hospital that day would receive the product he brought with him, and not the type of cardiac monitor they would normally insert. Later observations taught me that the presence of a company representative at an ordinary medical appointment was not exceptional, but part of the close collaboration between the medical staff and the salesmen who promoted their products *in vivo*.

The atmosphere in the exam room was hectic that day. The company representative continued to discuss remote cardiac monitoring with the patient, while the admitting nurse tried to keep up with the situation and began to prepare for the insertion of the cardiac monitor. In addition, the attending cardiologist entered the room and joined the discussion. The patient did not stop asking questions about the nature of the device. She seemed to have informed herself well in advance. She also mentioned that she had expected to receive a cardiac monitor from the competing medical device company that the hospital usually uses. In response, the attending cardiologist explained that she was right and that she would be receiving a different device that day. "But it doesn't matter, it's the same system," he added. As a sociologist with the knowledge provided by other healthcare professionals during study interviews and from my previous observations, I disagreed with him. Although cardiac monitors from different medical device companies are similar, they vary in shape, insertion mechanism, and further technical specifications. When a new cardiac monitor is launched, the medical device company is likely to adapt these dimensions. While the technical specifications may be most important for later diagnosis, the shape of the cardiac monitor and its insertion mechanism have a direct impact on the patients' bodies. If the shape and/or insertion mechanism have been modified by medical device companies, cardiologists and nurses must learn to use these new procedures on the spot.

That day, the company representative demonstrated their new cardiac monitor and its insertion mechanism to the attending cardiologist and the implant-nurse in the back office of the consultation room. With the help of a foam rubber model representing patient skin, he demonstrated the insertion procedure. The implant-nurse and the attending cardiologist then continued the simulation to learn the insertion mechanism through this dry run. Meanwhile, the admitting nurse continued to prepare the patient for the insertion of the cardiac monitor. Finally, the attending cardiologist decided that it would be up to the implant-nurse to do the insertion of the cardiac monitor for this specific patient.

When her colleague was almost finished with the preparations, the implant-nurse put on her sterile uniform and began the insertion procedure as usual. Once the fenestrated drape covered the patient's body, the chief cardiologist entered the room and joined the attending cardiologist. Together with the company representative, there were four of us observing the insertion of the cardiac monitor. First, the implant-nurse applied local anesthesia. After waiting a while, she took a needle to test the patient's sensitivity. On the drawn arrow which indicated the insertion spot, the patient did not feel anything. However, at a point further away from the drawn arrow, the patient indicated that she could feel something sharp. "I'm not going to touch that spot," the implant-nurse reassured her.

Then, with a hand gesture, the attending cardiologist motioned for the implant-nurse to proceed with the insertion. She obeyed, although I could see that she was a little uncomfortable. At first, she could easily insert the front part of the insertion tool, but then she encountered some resistance in the tissue. After applying more force, the insertion tool suddenly slid in. The patient cried out "Ouch!" and writhed under the surgical drape. After that, all I could hear was the patient gasping for air. The attending cardiologist quickly went to the side of the bed to reassure the patient, telling her that it looked good, and that the device had been inserted as it should have been. To me this appeared to be only a small comfort to the patient, but she calmed down.

Before leaving the consultation room, the cardiologist came to see me to ask if I had any questions. I hesitated because on the one hand, I had a lot of questions in my head. On the other hand, they were rather sensitive questions for which it might not be the appropriate time. I tried anyway and asked if this was the first time, they had tried the new insertion technique. My suspicion was confirmed. The cardiologist raised his finger in front of his mouth as a sign that he could not talk about it at that moment.

After the patient was discharged and both the cardiologists and the company representative were no longer in the consultation room, one of the nurses told me that the chief cardiologist had performed the first insertion this morning before I had arrived. "Very kind of him," she commented, in case something had gone wrong. This was not the only situation that made me question whether or not remote cardiac monitoring was for the good of the patient, a lucrative business, or both.

4.7 "This button is for nothing": Who is the user?

Once a cardiac monitor is inserted into the body, it is impossible for patients to interrupt or stop the cardiac monitor from continuously monitoring their heart rhythm until the battery is depleted. Batteries typically run out between 3 and 5 years after insertion. The algorithms are trained to automatically select the most relevant arrhythmia episodes on a rolling basis, according to set thresholds, and in comparison to the episodes already stored. Hence, data are collected continuously, regardless of the cardiac monitor being connected to a telemedical system or not. Accordingly, authors comparing different cardiac monitoring technologies note that "no need for patient collaboration" is an advantage of implantable cardiac monitors (Galli et al. 2016). Indeed, the only alternative technology capable of long-term cardiac monitoring would be a smartwatch. However, when I asked the cardiologists in the interviews about the possibility of smartwatches outperforming the cardiac monitor, one replied:

> *Well, the only disadvantage with smartwatches is that there is a factor that depends on the patient. As individuals living our real lives, we may not think that way, but as doctors, we like to leave as little as possible to chance, especially factors that depend on patients, because patients are not always compliant.*

This quote shows the importance this cardiologist places on the continuity of heart rhythm measurements. By default, patients cannot intervene in the automatic monitoring of their heart managed by algorithms. However, they have the option of self-reporting a symptomatic episode using a remote-control type device, thus forcing the cardiac monitor to record and store their heartbeat at the moment when patients experience symptoms such as fainting or an accelerated heartbeat. Moreover, patients who agreed to be connected to the telemedical system could potentially interrupt regular data transmission by unplugging the transmitter and/or by uninstalling the respective patient app on their smartphones. On a smaller scale, patients can decide if they want to carry the transmitter with them during holidays or any other extended absence from home.

Yet, neither cardiologists nor medical device companies seemed particularly interested in giving patients more access and agency than they felt was absolutely necessary. During a different fieldwork day’s visit, when a company representative was again on site at the Waldspital for cardiac monitor insertions, a particularly illustrative scene occurred (fieldnotes, Waldspital, December 14, 2020). Between patient appointments, the representative was introducing the company's new generation of cardiac monitors and the remote monitoring system that came with them. The box of the new-generation cardiac monitors was shiny and glossy, like any other technological lifestyle gadget one might buy at a consumer electronics store. Its design looked more like the latest smartphone than a medical diagnostic device. The new transmitter was slightly different from the older version, with only one button.

To me, it looked like a device for dummies. One of the nurses asked him what the button was for. The company representative replied, “This button is for nothing.” At first, I thought I had misheard. He continued his explanation, “It lights up. The light turns in a circle, simulating a transmission. But actually, it’s only for defibrillators and pacemakers.” While I could understand the business logic of a medical device company producing only one type of transmitter, this observation showed that the company had not been thinking about active patient engagement in this product’s design. Rather, it seemed to me that it was about automated data transmissions and optimizing patient care from the perspective of healthcare professionals. The same medical device company also advertises remote cardiac monitoring with the slogan of “more time to focus on patient care,” which seems to underline their business orientation towards those who care, and not those who are cared for.

4.8 Discussion: Medical hope relying on infrastructures, networks, and businesses

The insertion of cardiac monitors is accompanied by the hope to finally find the missing puzzle piece necessary for a medical explanation and subsequent treatment for patient arrhythmias. All the hopes of healthcare professionals and patients are placed on a small, lightweight, algorithm-driven sensor. Framed even more drastically, medical uncertainty is being dumped on an artificial entity with two electrodes controlled by multiple algorithms for about CHF 5,000 (~5,495 USD). As such, the technology takes on almost religious characteristics by offering a way to salvation, or in the case of the heart, a possibility to have control over its rhythm and to diagnose potential malfunctions (Petersen 2015). As Petersen (2015:15) writes in his book *Hope in Health*, the construct of hope is mobilized in the absence of experiential knowledge which is the case for the search of temporal, and self-limiting arrhythmias. By referring to the need of evidence-based knowledge, the technology of the cardiac monitor helps both construct "the subject of hopeful expectations and the means by which 'hope' is mediated and marketed" (Petersen 2015:18). Much like religion, to build these powerful hopes and expectations, patients and healthcare professionals need to believe in them. The context of uncertainty provides fertile ground for these beliefs (Fox 2000), as successful doctor-patient relationships continue to revolve around obtaining a diagnosis (Rosenberg 2002). This is well illustrated by the example of the patient who reluctantly agreed to have a cardiac monitor, challenging the beliefs of the healthcare professionals present and his wife, who had a different view and prioritization of his health risks and leisure activities than the patient himself.

However, the hopes of patients and healthcare professionals do not rest on cardiac monitors alone. They were also based on the remote connection between patients and the hospital. Patients went home but stayed connected to the hospital through an invisible data network, conveying the imaginary that the healthcare professionals would "see" the arrhythmia from a distance. However, what remote cardiac monitoring reveals to healthcare professionals is different from what they would normally see during a traditional patient visit. Instead of seeing the patient in person, listening to his or her illness narrative, and having some first medical test results at hand, all healthcare professionals will see is a recorded pattern of a heart rhythm, which was detected as being irregular by the algorithms. Contrary to the "clinical gaze" described by Foucault (2003), which is tightly connected to the institution of the clinic, data collection, transmission, and interpretation happen at different places and times in remote cardiac monitoring. More importantly, the "clinical gaze" is no longer performed by the cardiologists but by an algorithm-based sensor, replacing the expert assessment of the doctor. This has important consequences for diagnostic work. Although remote cardiac monitoring extends the "clinical gaze" to the continuity of the patients' everyday lives, it changes what the cardiologists finally "see." Their clinical assessment is no longer made face-to-face with their proper eyes, but based on what algorithms have "seen," pre-selected, and recorded according to pre-defined thresholds.

This is not insignificant as the cardiac monitor in its present form is the result of myriads of development steps to which a lot of people contributed. The same goes for the transmitter which patients must plug in near the bed. Moreover, the remote connection is based on the telecommunications infrastructure showing that "devices and individuals rarely act alone" (Weiner and Will 2018). The case of the patient living in the rural area of Switzerland was illustrative for this. Like the mobile telephone becoming a mundane tool in healthcare and later in almost everyone's life in high-income countries (Greene 2022) technologies and infrastructures become taken for granted as soon as they are widespread enough to no longer be controversial (Gitelman 2008). Remote cardiac monitoring essentially relies on a working data transmission infrastructure, as it is engaging with healthcare professionals' and patients' hopes.

Additionally, this chapter illustrated that the design of remote cardiac monitoring gives more control to cardiologists than to patients, making cardiologists the primary users of the technology rather than patients (Oudshoorn and Pinch 2003). The configuration of remote cardiac monitoring thus preserves the paternalistic medical model. Patients cannot stop or interrupt the continuous monitoring. The most they can do is unplug the transmitter next to their bed, which would interrupt the remote data connection. Compared to wearable smartwatches, the inserted devices suited the cardiologists I met, who prefer not leaving the continuous monitoring to chance and potentially non-compliant patients. Accordingly, the structure of remote cardiac monitoring provides yet another example of medical power remaining firmly in the hand of the already powerful healthcare professionals, and company representatives. This chapter also showed that medical device companies are not any different from drug companies when it comes to creating sales-enhancing relations with the hospitals (Moynihan 2003). This entanglement is particularly questionable when salesmen were previously employed by the hospital.

Although remote cardiac monitoring was developed with the idea to minimize patients' efforts at home, medical device companies have not taken into account that it would be exactly the hope for diagnosis that would make patients worry about the devices working properly. Consequently, this worry made patients verify regularly that their transmitters were actually transferring their data.

5 A reassuring connection? Alleviated anxieties of healthcare professionals and patients

After the cardiac monitor insertion at the hospital, patients went home and plugged the transmitter in next to their beds. However, the first round of post-insertion interviews showed that, contrary to what patients were told during instructions, they did everything but forget about remote cardiac monitoring. With the healing of the wound, patients became more and more accustomed to the implants. Still, the technological setup triggered questions among patients, who often seized upon the opportunity of the first interview to raise their wonders to me, the sociologist. Besides the uncertainty around how and if, at all, the devices worked, some patients also felt unsure what the cardiac monitor might reveal about their personal feelings or activities. This reflects patients' sensitivity to their heart rhythm and their access to their body through noticeable symptoms. Because patients could not see what the monitor was recording or when it was recording, they could not be sure if their accelerated heartbeats - caused, for example, by normal exercise - were already outside the sensor's thresholds.

Nevertheless, many patients were overly enchanted by the technology of remote cardiac monitoring. Sometimes this enchantment also came to life in form of jokes, with patients referring to themselves as superhumans after having received the implant. Moreover, this fascination for the technology contributed to their belief of being in good hands. The digital connection produced a predominant reassuring effect among all patients. Knowing that their heartbeats were continuously monitored, and that any potential arrhythmia would be noticed at the hospital, made them feel well taken care of. In contrast to the patients themselves, it was more difficult for their relatives to relate to the patients' symptoms from an outsider perspective. Consequently, this reassuring effect was also, if not more intensely, present among patients' relatives who appreciated that their loved ones were under medical control. Interestingly, I identified a similar reassuring effect among cardiologists being on the other end of the connection. For them, remote cardiac monitoring was also a form of safeguarding in a vague diagnostic situation.

While patients felt personally taken care of, cardiologists completely relied on the automatic and impersonal heartbeat monitoring that was controlled by algorithms. What united the two groups was the quest for certainty and for an explanation of the symptoms. Still, some patients were convinced that their hearts were completely fine and described having received the cardiac monitor only because of their cardiologist's recommendation. Others told me that they would be disappointed if nothing was found over time. In general, patients described facing a dilemma about preferring to know the cause of their unease, making it potentially treatable, or preferring no diagnosis at all.

The first six sections of the chapter illustrate how patients experienced the first few weeks of being monitored and remotely connected. The seventh section is dedicated to the cardiologists' perception of remote cardiac monitoring and its role as a diagnostic tool. This uneven division of the chapter is due to the fact that the cardiac monitor and its reassuring effect occupied a much larger place in patients' daily lives than in cardiologists' professional lives. While patients had to adjust to living with a newly implanted device, the cardiologists' daily workload related to remote cardiac monitoring was negligible; the least time amount of daily time dedicated to cardiac monitoring indicated by a cardiologist during my interviews was 10 minutes.

5.1 “I don’t feel anything”: Awareness of the cardiac monitor through intuitive touch

One of the first questions I asked patients when I saw them for the first interview after the insertion was how they felt about the implant. At first, many told me that they did not feel anything special. However, they usually intuitively touched the spot on their chest with their fingers to feel the implant every time we talked about it. Not all of them immediately touched the right spot and had to feel with their fingers where exactly the implant was. Some even pulled down the fabric of their tops to show me the mark on their skin. While some patients had only a small white scar, others had the shape of the device visible under the skin. All patients reported that the insertion site was sensitive for the first few days after the procedure. Then, as the wound healed, this sensitivity disappeared. Most did not feel the implant unless they touched it with their hands. Typically, they were reminded of having an implant when they touched it during personal hygiene routines, such as showering or moisturizing. Similar to others’ narratives, Mrs. Jeanneret (58 years old, La Clinique) explained to me how her perception of the implant had changed since the insertion:

> *So now, now it’s okay. I can touch it more easily. For example, if I put lotion on my body. It’s true that in the beginning, I was always a little bit afraid, because it was still sensitive. I guess, it was the same for the inside too because [the cardiac monitor] was pushed under the skin. I also had a little bruise. So, it took some time for everything to disappear. Afterwards it was beautiful. Now I don’t have any worries. It no longer bothers me at all.*

Mr. Fuchs (67 years old, Waldspital), with whom I conducted a post-removal interview, gave a similar description when recounting his experience after the cardiac monitor insertion:

> *This little wound, it's just such a little cut, right? [The cardiac monitor] was injected into it. In the beginning, I could feel it until the wound was closed. Later on, yeah, every time I would massage the spot here a little bit, or when I was showering or something. That's when I really noticed that there was a kind of "pencil" there.*

Although most patients were able to feel their cardiac monitors at first and described sensitivity around the insertion sites, they usually quickly became accustomed to having an implant under the skin once the wound had healed. From a medical standpoint, the insertion of the cardiac monitor is a minimally invasive procedure. However, there is some risk of infection and poor healing. Except for one hematoma in the first few days, most patients tolerated the procedure, and their wounds healed without problems. Many were even satisfied with the scar. Patients, especially the elderly, often explained during the interview or during the insertion procedure that they had undergone other, more drastic surgeries in the past, making the insertion of the cardiac monitor seem like a necessary evil.

Nevertheless, for a few patients, the wound healing was problematic. This was the case for Mr. Tanner, who had to go to work the day after the insertion. He had been on extended sick leave due to his syncope and other health issues. His commercial truck driver's license had been revoked because of the risk of syncope while driving. This made it impossible for him to continue working in his original job as a truck driver. As a result, his boss assigned him to work in the company's warehouse, where he was required to lift heavy objects often weighing 50 to 60 kilograms. Although the implant-nurses had warned him to be careful and not to lift anything too heavy during his appointment at the Waldspital, he could not afford another sick day (fieldnotes, Waldspital, June 14, 2021). Mr. Tanner (40 years old, Waldspital) told me in the first interview:

> *Now, I feel like I did before the insertion. However, in the beginning it was a bit difficult because of my work. Whenever something would hit against [the insertion spot], I would feel it strongly. It also started to bleed. But this happened because it was relatively new. Now, everything is fine so far. {…} It was because of the weight that I carry from time to time. Big things just hit against my chest at work. That's just the way it is (shrugs). But it worked out in the end.*

Due to his work situation, this patient was not able to handle the wound as carefully as necessary for proper healing. In the end, however, the wound healed, and he no longer could feel the implant. In contrast to his experience, Mr. Weber continued to have problems with the first cardiac monitor he received. His wound reopened several times and never completely closed. He was also experiencing pain, especially in his nipple. As a result, the first implant was removed and he was scheduled for a second implant a month later, during which I was present during my fieldwork at the hospital.

I observed the second insertion, which was also not very easy (field notes, Waldspital, September 17, 2021). To prevent pain, the implant-nurse suggested that the cardiac monitor should be placed more parallel to the sternum, which was approved by the attending cardiologist, who stopped by shortly before the insertion. The implant-nurse finally succeeded in inserting the cardiac monitor, but it took a lot of force to push it under the skin. After the patient had left, the nurse told me that it was difficult to push through the patient's resistant tissue. When I saw Mr. Weber for the first interview a few weeks later, the wound had healed properly. However, he still felt pain from the cardiac monitor when he made certain movements. When asked about it, Mr. Weber (62 years old, Waldspital) said that the cardiac monitor did not bother him, although the pain was a bit annoying:

> *I have no problem with the monitor itself. The only problem is that it continuous [to hurt], although I had the first one taken out again. Because it didn't fit, it didn't fit at all. And this one hurts too. When I pick up my grandchild. When I hug my wife {…} It's uncomfortable, yeah.*

His quote shows that he had accepted the pain as a necessary evil. Although the pain was a very uncomfortable reminder of having a cardiac monitor implanted, other patients mentioned that external pressure made them aware of the implant. However, they did not describe this sensation as painful, but rather as a strange feeling. Mrs. Hasler (82 years old, Waldspital) explained how her cat lying on her chest made her feel the implant:

> *I don't feel anything. What I am a bit sensitive to is pressure from outside. For example, when the cat comes to lie here on my chest. She likes to do that. Then I just feel a little bit of pressure. But I know where it comes from. But other than that, I don't really have anything there, nothing at all, that would bother me in any way or hurt me. I guess it's like a chip. Just like you chip dogs or cats. And then you know where they belong. And yeah, then I think, well, if something is not good, then I hear about it. So, I'm actually quite comfortable with it.*

Most patients got used to the implant after the first few days, when the wound had healed, and the insertion spot was no longer as sensitive as it was at the beginning. As in the examples above, patients also became accustomed to the feeling of external pressure or even some pain. However, some patients described a different type of increased sensitivity that was more associated with a feeling of alienation or a kind of reminder to be careful. Mrs. Christen (68 years old, Waldspital) described to me in the interview how her perception of her body had changed since she received the cardiac monitor:

> *At first, I realized I had something here, you know. It's hard to explain. When I run my finger across my chest like this, sideways, I can feel it very easily. When I run my fingers down here like this [shows hand gesture]. That's a special feeling. Like a foreign object feeling. And a reminder, 'Watch out!' But I had that feeling especially in the beginning. Now I don't really think about it anymore. Well, of course, every evening I see the box next to the bed.*

Again, the perception of the cardiac monitor was linked to the touch by hand and did not occur on its own. Patients who did not experience pain or increased sensitivity tended to quickly forget the implant, as demonstrated by the experience described by Mrs. Loviat (37 years, La Clinique):

> *I am fine. Well, the first few days, I could feel that there was a foreign body. I could feel it. It was actually quite funny. It did not hurt, but it was just that I could feel that there was something inside. And now, I don't feel it at all.*

Although the transmitter placed near the bed could serve as a reminder of remote cardiac monitoring, as Mrs. Christen briefly mentioned. Most patients, like Mr. Regensburger (72 years, Waldspital), did not attach much importance to it:

> *Well, when I want to go to bed, then I see that small box there, but it's just there now. It means nothing special to me. I know what it is for, but I don't let it distract me in any way.*

Although their daily lives soon returned to normal, patients often had questions about how the cardiac monitor, data transmission, or data handling in the hospital worked. This being the case, most of them took the opportunity of the first interview to clarify their questions.

5.2 “Glad you’re here!”: Patients’ questions for the sociologist

Glad you’re here! I heard this exclamation several times when patients opened the door or answered the phone during the first interview after the insertion of the cardiac monitor. For them, it was an opportunity to ask me all the questions that had been piling up since they received the instructions in the hospital. Some began to pepper me with questions right away; others held their questions until the end of the interview. I quickly realized that some of the patients thought I had medical training and worked in the hospital where they had met me. I promptly cleared up the misunderstanding by telling them that my studies did not lead to a doctorate in medicine, but to a doctorate in the sociology of health and medicine. I sometimes added some explanations about the purpose of my study and my work. Nevertheless, it was difficult for some patients to have a clear understanding of my affiliation.

Patient questions often concerned issues of how and when exactly the heart rhythm was recorded, how and if the data was stored and transmitted, and how the data was handled at the hospital. Sometimes the questions were of such a technical or medical nature that I was unable to answer them. Knowing my limits, I recommended that they contact either the telemedicine unit or their cardiologist to find out.

In one case, the daughter of an elderly patient contacted me by e-mail to say that her father did not want to participate in my study. She specified that he otherwise wished to have clarification on three concerns related to the cardiac monitor: (1) whether it would be compatible with a brain MRI, (2) how long he would have to wear it, and (3) who would be responsible for removing it. In my reply I explained my social science background and forwarded the e-mail to my contacts at La Clinique. However, during the interviews, most of the patients naturally expected me to be able to answer their questions because, in their eyes, I was the expert. They knew that I had a higher university-level education, which was by far not the case for most of the patients I interviewed. From fairly simple questions to very challenging ones (often of a complex technical nature), their queries showed that remote cardiac monitoring was not “out of sight, out of mind” once the insertion was over. For me, this was the perfect opportunity to understand and study the initial patient perception of remote cardiac monitoring. The beginning of the following interview with Mrs. Hasler (82 years, Waldspital) shows that even the technical terms associated with remote cardiac monitoring are not everyone's cup of tea:

> *Sociologist: As you’ve already heard, [the interview] is about telemedicine and it’s also about the cardiac monitor which you also received.*
>
> *Mrs. Hasler: Yes, that's one of the things among others. I didn't really know what to call that thing. This implant.*
>
> *Sociologist: Well, what do you call it then?*
>
> *Mrs. Hasler: Somehow, I remember hearing about it when I was [at the hospital] before they did [the insertion]. The doctor showed a little stick that they would then inject under the skin. But at the time, I thought it was something like a pacemaker, but it can’t be. It’s not connected to the heart at all. And that’s why I’ve now looked at all the stuff again, and there I saw that it’s called a cardiac monitor (sounds astonished).*
>
> *Sociologist: (laughs) Yes, it’s not a very common word. That’s right.*
>
> *Mrs. Hasler: Isn’t it? I’ve never heard of it before.*

The discussion illustrates that the term *cardiac monitor* can be foreign to patients' everyday language and may even lead to confusion with other better known cardiac devices such as a pacemaker. The first interview revealed a wide variety of terms used by patients for the cardiac monitor. Most often, they referred to the cardiac monitor as an undefined "it." Other emic terms used by patients were a small rod, a transmitter, a recorder, a thing [original French term: "truc"], a gizmo [original French term: "machin"], a spy, a pencil, a chip, or one of the official brand names of the cardiac monitor such as "Reveal." The type of term used by patients was also influenced by how the device was referred to by healthcare professionals in the hospital. This explains in particular the frequent use of one brand name, even though the implanted cardiac monitor may have been manufactured by another company. The use of the term "chip" to describe a cardiac monitor was also widespread among patients. When I discussed this with a nurse at the Waldspital, she told me that the term "chip" was understandable to many patients because they could relate to the chips implanted in pet dogs and cats to locate them or trigger their pet door mechanism or feeder (fieldnotes, Waldspital, November 16, 2020). Moreover, some cardiologists would use the term in patient instructions, the nurse added. Later, I also spotted the term in the official patient booklet on heart arrhythmias of the Swiss heart association. During the interviews, I tried to adapt and reuse the patients' own term for the cardiac monitor to avoid making them uncomfortable.

Another burning issue that patients were concerned about was what exactly would happen if they experienced their unexplained symptoms again. The above conversation about the correct term for the cardiac monitor continued with me asking Mrs. Hasler (82 years, Waldspital) how she had explained remote cardiac monitoring to her family. She answered:

> *Actually, I did not have to explain very much. I just told them that it should be all right now. Maybe it will be useful for something, and maybe not. But now I*

> *just have it. And how it really works, well, now I have another question for you. I always remember later what else I would have liked to know. There is so much all at once [during instruction], that you can't take it all in, at least not at my age. That's the thing. Now I have it inserted. But I still wonder. Let's suppose I am not well. Then something happens. And what happens next?*

I explained to her that the only thing that would happen was, that the cardiac monitor would observe her heart rhythm, but nothing would happen in terms of an immediate alarm or someone calling her. Therefore, it was important that she still call the national emergency number if, for example, she fell to the floor. Even though healthcare professionals in both hospitals emphasized during instructions that remote cardiac monitoring does not work like an emergency system, some patients still imagined it as a kind of permanent connection to the hospital. In reality, however, the only continuous feature of the system was the cardiac monitoring part, while the remote part consisting of data transmission, review, and interpretation happened at a later point in time. The distinction between continuous monitoring of their heart rhythm and time-shifted data processing was a major source of doubt for patients. Thus, it often became my role to clarify what remote cardiac monitoring was capable of and what its limits were. I caught myself repeating some of the reassurance strategies I had previously observed used by nurses or cardiologists in the hospital (see Chapter 4), emphasizing that the cardiac monitor was a diagnostic tool only and that it would not intervene in an emergency. The following conversation developed when Mrs. Bartoli (61 years old, La Clinique) asked me during the interview if her data was transmitted directly, and I explained to her that the data was transmitted only once every 24 hours during the night:

> *Mrs. Bartoli: But then if there is an alert because I have something at night. [The data] goes [to the hospital], but in the meantime {unfinished sentence, implying doubt, and skepticism}.*
>
> *Sociologist: Yeah, it's not an emergency system. It's just a diagnostic device.*
>
> *Mrs. Bartoli: Okay. Ah, I thought maybe it would still give a... sign.*
>
> *Sociologist: No, it doesn't set off anything, no.*
>
> *Mrs. Bartoli: Okay, so the next day they see it (laughs).*
>
> *Sociologist: (laughs) Well, the next day they see it, but {unfinished sentence}.*
>
> *Mrs. Bartoli: They see it, and then the person has died in the meantime (laughs).*
>
> *Sociologist: (laughs) Yes.*
>
> *Mrs. Bartoli: Okay (laughs).*

In several first interviews I had this kind of conversation making patients aware that the remote cardiac monitoring system would not save their lives in an emergency. This sometimes led to awkward situations during the interviews. Overall, I found less worries and ambiguities among patients from the Waldspital compared to patients from La Clinique. According to my observations and interview data, this difference was most likely due to the telephone follow-up routine adopted by the Waldspital. Usually, the telemedicine unit at this hospital contacted patients within the first days after the insertion to ask them whether everything was working as it should. Often, this phone call was also an opportunity to clarify the first questions patients had and, depending on the situation, to reiterate how the remote cardiac monitoring system worked. With this approach, the Waldspital tele-nurses were able to alleviate some of the patients' initial uncertainties. Waldspital patients told me in interviews that they appreciated this routine follow-up call. They found it very reassuring. It also contributed to their sense of being well cared for. This is illustrated by the answer Mrs. Christen (68 years old, Waldspital) gave me when I asked her if she had already been in contact with the telemedicine unit:

> *They called me the first day. So, the next day after the procedure. They asked me how it was going and told me to call them if I had anything. Later, at some point, they called me again and told me that I had some strange recordings. That was at the very beginning. I don't know if it wasn't transmitting properly. I don't know what happened or if I did anything special. I told them that it was maybe just physical effort. But nothing more. It's true, I am completely monitored. Maybe other people are not used to being called at any time. But they are also very friendly. I really felt like someone really cared.*

In addition, this phone call shortly after insertion served as a confirmation to the patients that the remote connection was working properly and that data transmissions were occurring automatically and regularly. This was an important information for patients, as another major concern they expressed during the first round of interviews was whether or not everything was actually working. Some directly rationalized their concerns by saying that they would have been contacted by the hospital if something had gone wrong. Others thought that I would be able to tell if everything was working as it should. However, I had to disappoint them by telling them that it was impossible for me to know if everything was working as it should. I usually explained that they would have been informed if something was wrong as I had been told by the hospital staff or recommended that they should call the telemedicine unit or their attending cardiologist themselves to verify. In a few cases, I had to look up the contact number of the Waldspital's telemedicine unit to make sure the patients had the correct contact information. For La Clinique, I was not able to help out with a direct contact.

Other ambiguities that caused confusion for many patients were how and when exactly their heart rhythm was being recorded, and how the data transmission and the transmitter next to their bed related to it. Some patients found it difficult to imagine that such a small device could record their heart rhythm wherever they were and around the clock. The following question from Mr. Regensburger (72 years old, Waldspital) illustrates this:

> *What is not quite clear to me is how the transmission works. Does it only record at night when I'm next to the box or does it also record my daily routine?*

I explained to Mr. Regensburger that the cardiac monitor was continuously monitoring his heart rhythm and that the transmission only happened once at night when he slept next to the transmitter.

From what I observed and heard during my fieldwork, one of the reasons for these ambiguities was, that the technical operation of the remote cardiac monitoring was almost completely invisible. The transmitter's display next to the patient's bed shows only a green checkmark and the date of the last successful data transmission. This is important because the date is updated with each data transmission, not each time the two devices connect. This seemed counterintuitive to many patients who expected the devices to update every time they communicated during the night. However, as long as there was no data transmission, the date on the display did not change, which was confusing to some patients who wanted to be sure that their data was being transmitted regularly.

Moreover, the transmitter's display typically remained switched off unless patients pressed the button. However, not all patients dared to press the button for fear of changing the settings. Some of the older patients, in particular, preferred not to touch anything. But when curiosity got the better of them, patients used other strategies to find out what exactly was happening at the time the data was supposedly being transmitted. The following example from an interview with Mrs. Rochat demonstrates this. First, Mrs. Rochat (70 years old, La Clinique) wanted me to confirm that the hospital staff would notice if the system did not work:

> *Mrs. Rochat: Can they see if it's not working?*
>
> *Sociologist: Usually, they can see that, yes.*
>
> *Mrs. Rochat: Yeah, so that's what I was worried about. I would have liked them to confirm about a week later that it was working and that everything was in order. You know, the device is upstairs, you can't see anything, it's turned off. So, I don't know if it's working. Once, I even woke up at midnight, on purpose, to check. Because it's at midnight that it sends the data. I'm an early sleeper, so the transmission could also easily be set from eight o'clock to midnight, no worries. I never go to bed later. But there wasn't even a light flashing or anything.*
>
> *Sociologist: No, there really isn't. There's nothing at all.*
>
> *Mrs. Rochat: Oh, but you're already putting me at ease because I wasn't sure.*
>
> *Sociologist: No, it's true, there's nothing at all.*
>
> *Mrs. Rochat: There's nothing.*
>
> *Sociologist: Regarding this little display. So, it would be nice for you if the date of the last transmission would always show up or something like that?*

> *Mrs. Rochat: Yes, exactly. If the date was updated every time the data was sent at midnight or whatever, I could say to myself, 'Well, it's working. It's fine.' But there's nothing there, so I don't know if they're afraid of waking people up.*

The invisibility of the devices connection and communication left this patient feeling unsettled and led her to wonder if the device was working at all. She also imagined that its design might be meant to be this way to not disturb people's sleep.

Other patients told me that they pressed the button to turn on the transmitter's display in the morning to see if data had been transmitted, i.e., to check if the date displayed matched the calendar date. If the two dates did not match, these patients performed a manual data transmission. To do this, they removed the reader from the transmitter and held it over the inserted cardiac monitor. This forced the devices to extract and transmit the data. As a result, the date on the display was updated to reflect the current calendar date. If the date had changed, they assumed that data transmission had happened and that the remote monitoring was somehow working, although they were aware that they could not be a 100% sure about it. Although the hospital staff had presented remote cardiac monitoring as a simple system, with patients simply plugging in the transmitter and forgetting the rest, patients were uncomfortable with having no clues as to whether the system was working properly. Some of them saw it as their job to regularly check the transmitter's display as it was the case for Mr. Steiner. He was not sleeping well due to chemotherapy for another diagnosis. During the interview, Mr. Steiner (60 years old, Waldspital) explained to me:

> *Mr. Steiner: When I wake up at night, I press the button to check it briefly, and then it connects. Then it does [the transmission]. The last three times, I had to hold [the reader] onto [the insertion spot]. [The transmission] is kind of set*

> *somehow between 12 and 5 in the morning. I woke up too late and did it manually. But that's not a problem.*
>
> *Sociologist: Yes. But did you notice that yourself or did they call you from the hospital?*
>
> *Mr. Steiner: Ah, no, I check it quickly every morning. Whether it has been transmitted or not.*

While patients were concerned that the system was working properly and wondered if anything was happening, they also had questions about what exactly the cardiac monitor could "see." Although it only recorded their heart rhythms, some patients were concerned about what their heartbeat might reveal about their private lives.

5.3 "Do they notice that? Or don't they?": Ambiguities in remote cardiac monitoring

Once patients made the decision to have a cardiac monitor implanted, they also accepted that their heart would be continuously monitored and that their data would be shared. Doubts about data sharing and access, if any, were usually raised during the pre-insertion visit with their cardiologists. Remaining uncertainties about continuous monitoring sometimes resurfaced as jokes during implantation (see Chapter 4). Still, some patients speculated about their habits, intimate life, or emotions being detected. Mrs. Scherrer (71 years old, Waldspital), whose favorite hobby was knitting, told me that she had wondered if the time of data transmission might reveal that she went to bed late:

> *Sometimes I have to remind myself to go to bed, because it transmits between 12 o'clock at night and 5 o'clock in the morning (both laugh). From time to time, I knit until two or three in the morning. Then I think, 'Oh, I should probably go to bed, so it can transmit.' The box is by the bed, of course. And it can only transmit from there. And [transmission] happens until 5 o'clock in the morning. From 12 o'clock to 5 o'clock (shrugs). I don't know what they think. Do they see that I don't go to sleep for so long sometimes?*

Mrs. Scherrer was constantly chuckling as she told me about this, which showed me that the question did not bother her very much. However, she did question what exactly could be deduced from the data transmission, which led her to wonder whether her data would differ from that of other people who would "normally" be in bed at that time.

It was not only the timing of the transmission that led patients to question what their heart rhythm might reveal about their private lives. This consideration of Mr. Jansen (65 years old, Waldspital) showed how the awareness of constant monitoring can also affect intimacy, as he dared to tell me:

> *When I sleep with my wife [original German quote: "Wenn ich mit meiner Frau schlafe."], sometimes I think, 'Well, do they notice that? Or don't they?' The next day. That's a bit strange. A bit intimate. But that's really the only thought I had about how it would be interpreted. In terms of computers, I'm not very afraid of my data being monitored, because I don't think I have that much to hide. {...} Only the small part I described before, but that doesn't bother me too much. Well, if it's like that, then they know about it. But they are professionals, they know how to deal with it. Only the thought is a bit strange.*

The idea that his sexual activities might be made visible through a fast heartbeat detected by the cardiac monitor made this patient feel slightly uncomfortable, even though he expected healthcare professionals to treat such data with due respect. However, the heart rhythm does not only reflect physical activity, but also emotions. For example, the heart may beat faster when people feel nervous. Mrs. Loviat (37 years old, La Clinique) told me that she wondered if the cardiac monitor might occasionally pick up situations of stress or anger. When asked if she was more aware of her heart rhythm now than before she had the cardiac monitor, the conversation went like this:

> *Mrs. Loviat: Yes, it's true. I am much more attentive to it. And then, well, there are always moments in life when…I don't know how to say it… For example, when I'm at work, and I have a lot of stress and everything, then I tell myself, 'Maybe now, how do they see it?' Well, sometimes I think about that. In this case, yes. More than before.*
>
> *Sociologist: Do you mean, how do they see it at the hospital?*
>
> *Mrs. Loviat: Yes, I don't know, I think about it. Or when I get upset, yeah. In ordinary moments of life when life is less calm, let's say.*
>
> *Sociologist: How does it feel for you to be monitored?*
>
> *Mrs. Loviat: Well, fortunately, there's no microphone, but yes, sometimes I tell myself, well, I don't know, I think about it, and then I tell myself, 'Oh, I must calm down,' and so on.*
>
> *Sociologist: Yes, there is a like side effect of telling yourself, 'Oh, I shouldn't get too upset.'*

> *Mrs. Loviat: Yes, I think so, yes. Or if my smartwatch tells me, 'You need to calm down, you're too stressed, relax.' Then I tell myself, 'Oh dear, I must calm down.' How do they see it? I mean, is it normal? Sometimes I wonder.*

Her consideration showed that the awareness of her heart racing occurs on two levels. The first is her own perception. The second is the smartwatch she is wearing, which could give her an additional indication that her stress levels, via heart rate as a proxy, might be outside of what is programmed as normal.

In general, patients were not bothered by the continuous monitoring. Most felt that only their heart rhythms were being monitored, without making the connection that their data might reveal physical activities or emotional states. Additionally, patients did not care about where their data was going. Even though some of them wrongly assumed that the data would be transferred directly from the cardiac monitor to the hospital – without being uploaded to an external server of the medical device companies in the Netherlands, France, or Germany – they had no problems with sharing their heart data. Most patients put this in the context of other technologies or applications they use every day, such as their smartphone, through which they felt they were sharing much more personal data. Moreover, many patients felt that if the technology either helped them get a diagnosis or helped medical research for other purposes, they would be happy to contribute. Mrs. Scherrer (71 years old, Waldspital) mentioned in the interview that she was not concerned about privacy because only her body was being monitored and not her soul and spirit, which remained private. She added, "If it were possible to read minds, I would no longer participate." Beyond the patients' medical and technical questions for me and the ambiguity of what their heart rhythm might inadvertently reveal about their private lives, patients were generally fascinated by the technology of remote cardiac monitoring.

5.4 “It just shouldn't be something too serious”: Dilemmas around hope and (not) knowing

As shown in Chapter 4, the cardiac monitor can be thought of as a "technology of hope" for cardiologists and patients alike, helping to finally find out what, if anything, is causing patients trouble. Generally, the urge of wanting to know the cause for the unexplained symptoms was echoed by the patients and their partners in the first interviews after the insertion. To better understand what patients hoped for, I asked them in the first interview the hypothetical question of whether or not they would prefer to be diagnosed as soon as possible or not diagnosed at all during the entire monitoring period. Then, many had to rethink and hesitated before they knew how to respond. The former truck driver Mr. Tanner (40 years old, Waldspital), whose daily routine was severely disrupted by the fear of another unexplained fainting spell, put it this way in the interview:

> *In principle, it would be good if I had nothing, you know. That's very clear. But then I think I would have been fine all the time in the sense of not having syncope. So, from that point of view, of course, I would prefer that.*

Overall, Mr. Tanner, like probably everyone else, would prefer to have nothing at all. However, for him, having nothing worth diagnosing was synonymous with no longer having syncope, which was of course what he wanted. Like him, most patients told me they would not be disappointed if cardiac monitoring did not lead to a diagnosis, as long as they were symptom-free.

When I further confronted them with the possibility of getting a diagnosis from an incidental finding, most said that whatever was found was good because at least it would have been detected. However, the patients were not very concerned about such a finding and told me that they would deal with it when the time came. Nevertheless, these hypothetical considerations prompted patients to talk about how they cope with the uncertainty of experiencing another episode. Often, they wavered back and forth between the desire for a clear diagnosis that could lead to treatment and the hope of having nothing. The conversation I had with Mrs. Christen (68 years old, Waldspital), who had suffered a cerebral hemorrhage some years before the interview, and more recently a cryptogenic stroke, illustrated this perceived ambivalence in remote cardiac monitoring:

> *Mrs. Christen: Well, actually, I want to know what it is. What triggered it. I would like to know that.*
>
> *Sociologist: Would you say that such a diagnosis would reassure you a bit more? If you knew what it was?*
>
> *Mrs. Christen: Yes, I think it would. Because then you can treat it accordingly afterwards. With medication. Sure, on the one hand it's a bit ambivalent. On the one hand, I don't really want such a diagnosis like atrial fibrillation. On the other hand, it's clear afterwards and takes away my uncertainty. And maybe I just have to live with it. Then again, I also already have a medication. It's one of those platelet aggregation inhibitors. And from that point of view, it reassures me a little bit, although it does not exclude everything. That's what the professor said. That reassured me in that sense.*
>
> *Sociologist: That you are actually already taking something to thin the blood a bit, so to speak?*
>
> *Mrs. Christen: Yeah. But everything is a risk. Somehow. I just have to live with it. {...} Health can never be taken for granted. I've seen that a lot now.*

> *Sociologist: How would it be for you if they would find another arrhythmia than atrial fibrillation? Nothing that had anything to do with the stroke.*
>
> *Mrs. Christen: (sighs) Well, yes. Then on the one hand I would have a confirmation, but the stroke event would remain uncertain. That would be a special feeling. {...} You know, sometimes I really hope that they find something. It just shouldn't be something too serious (both laugh).*

The considerations of Mrs. Christen show how difficult it can be for patients to cope with the risk of another potential health incident, such as a stroke, if the cause of the first one remains unexplained. Moreover, my interview with her revealed the tension between the search for knowledge and the still-present hope that whatever is found will not have further serious consequences. Nevertheless, the hope that remote cardiac monitoring would finally reveal what was hidden hitherto also contributed to an overall enchantment with the technology among patients. Sometimes this enchantment manifested itself in the form of science fiction jokes.

5.5 “I’m a bit like RoboCop”: Patient jokes about remote cardiac monitoring

After observing how patients spontaneously made jokes about remote monitoring during the insertion of the cardiac monitor, I began to systematically ask them about the importance of humor and jokes in dealing with their unexplained symptoms and the technical setup of remote cardiac monitoring. A few patients also mentioned joking about remote cardiac monitoring without my asking. This often happened when I wanted to know from them if they had told anyone close to them about the fact that they were being continuously monitored and, if so, how they had explained it. This was the case, for example, with Mr. Fleury (76 years old, La Clinique), who told me how he had explained to others that he had a cardiac monitor:

> *I said that I'm permanently connected to the hospital. I'm a bit like RoboCop. Well, the latter is more of a joke, but I told them about it, yes.*

Referring to himself as RoboCop, a cyborg police officer from a dystopian science fiction movie from the 1980s, this patient self-deprecatingly shared his fascination with remote cardiac monitoring. Mr. Hoang (21 years old, La Clinique), a young athlete, made a similar comparison when I asked him how he and others perceived his technological companion:

> *I find it quite funny that there is something that accompanies me all the time. No embarrassment, no shame or anything like that. I just find it funny. People often tell me that I'm like Ironman or something like that.*

Unlike Mr. Fleury, who jokingly described himself to others as a cyborg-like figure, Mr. Fleury is seen by those around him as a kind of human-machine superhero. These supernatural attributions are in stark contrast to the fact that the cardiac monitor is not powerful enough to intervene, let alone save the patient's life. The cyborg metaphor was not only used by men. When asked if she was joking about her body being partially technologized after the insertion of the cardiac monitor, Mrs. Emery (29 years, La Clinique) replied:

> *For sure, yes. About the fact that I've been inserted with a chip. That everybody knows everything. I make a lot of jokes about it. Especially with my family. That I'm a robot, all that.*

Born with a heart defect, this young patient was deeply fascinated by medical technologies in general and had no problem giving them a try. Later in the interview, I asked Mrs. Emery (29 years, La Clinique) why she trusted the cardiac monitor and its algorithms:

> *I just want to believe in it. If we manage to create artificial ventricles or completely robotic hearts - well, how far we go after that in an ethical way is another question - but I don't know, I think it's brilliant to make progress on this, to make new discoveries.*

For her, all technological developments would help improve patient care, a belief she held deeply. Although she was the only one in my sample to be so enthusiastic about medical technologies and current developments, many other patients shared her fascination with the cardiac monitor. For example, Mr. Regensburger (72 years old, Waldspital), who was a specialist in radio and television technology, told me about his amazement during the first interview:

> *[The cardiac monitor] is pretty easy to wear, I think. Yes, I feel it when I press on it with my fingers (he touches the spot where the monitor had been inserted). But it's really only such a tiny little thing. Even though I know a little bit about this subject area, I'm amazed that it can record and transmit at that size.*

From what I learned from the first round of interviews, this enchantment with remote cardiac monitoring contributed in part to patient beliefs that they were being well cared for. In general, the reassuring feeling resulting from remote cardiac monitoring was mostly based on their perception of being continuously monitored and linked to the hospital. An exciting discovery for me in this context was that, despite all the ambiguities described in the previous subsections, patients still felt safe and cared for thanks to the remote cardiac monitoring system.

5.6 “Knowing that I was being monitored made me feel safe”: The reassuring effect of remote monitoring for patients

Despite the doubts described above, patients experienced a general feeling of being cared for. This *reassuring effect*, as I will call it, was related to a sense of security and the belief that patients were constantly being cared for from a distance. They were comforted by the fact that the hospital would react if they noticed something unusual. This effect was particularly pronounced for potential arrhythmias that patients believed they would not notice. Patients were convinced that these irregularities would be detected by the cardiac monitor and subsequently addressed by healthcare professionals. On the one hand, this reassuring effect resulted from the perception of constant care by a healthcare professional. On the other hand, it was associated with a reduction in the feeling of uncertainty regarding the unexplained symptoms. Although the cardiac monitor could not intervene to prevent another symptomatic episode of major (e.g., stroke) or minor (e.g., fainting) impact on their lives, patients appreciated the feeling of being monitored. Mrs. Schuler (66 years old, Waldspital), who had received a cardiac monitor for two and a half years prior to the interview after having had two unexplained ischemic attacks, commented on the implant:

> *I would like to say that I was really happy about this thing. It gave me a kind of security for at least two and a half years. This was actually true. Knowing that I was being monitored made me feel safe. There’s someone in the hospital who cares about me [original German quote: “da ist jemand, der schaut auf mich.”]. Even if there wasn't much direct contact.*

Even though patients were not in regular contact with tele-nurses or cardiologists, the digital connection made them feel well cared for. It was the belief that they were constantly linked to the hospital that created the reassuring effect. This effect was particularly strong in the first few months after having received the cardiac monitor. On top of the reassuring effect, Mrs. Emery (29 years old, La Clinique) suggested that the continuous monitoring contributed to a kind of placebo effect that made her less anxious and therefore less likely to experience episodes of arrhythmia:

> *Mrs. Emery: I still feel like I am experiencing some kind of placebo effect or something. Since I've had the cardiac monitor, I feel like I'm having fewer arrhythmias than I used to. So I was wondering if it was possible to have a placebo effect with it.*
>
> *Sociologist: So basically, you're paying almost less attention to [the heart rhythm]?*
>
> *Mrs. Emery: Yes, well, I suppose that maybe subconsciously I'm paying less attention. But let's say there's at least some evidence. Something. If there were to be a slightly dangerous arrhythmia, it would be noticed.*

Convinced that the cardiac monitor would pick the slightest offbeat heart rhythm, she was more at ease than before. Patients have often told me that this reassuring effect of perceiving the cardiac monitor as a device that will detect any potential abnormalities was also present among their loved ones. Interestingly, this peace of mind was sometimes even more intense for patients' relatives than for the patients themselves, as described by Mrs. Leuenberger (82 years old, Waldspital):

> *My sons and my husband said, 'Be happy. If there's anything, [the professionals] will sound the alarm immediately. Even if you don't notice it.'*

Partners and other people living in the same household have sometimes seen their loved ones pass out spontaneously, have seen how a stroke affected their bodies, or know how badly patients have felt at certain times. As a result, family members were often more concerned about a possible recurrence of such incidents than patients themselves. As such, they were reassured that their loved ones were being monitored continuously. Some patients were even annoyed by the worries of their close family and friends because they found it difficult to describe how they felt when their heart was beating out of sync. Mrs. Sommer (23 years old, Waldspital), who used to faint regularly, told me that her parents were more worried about her than she was:

> *Mrs. Sommer: When I told them, 'Well, it's not that bad at all,' they never believed me. They always said (disguised voice), 'Sure, [her first name], you would never say how bad it is anyway.' And like I said, as soon as it's about the heart everybody freaks out anyway. I've always said, 'It's not that bad. And it's okay to live with it. It's fine.' Well, it's a bit of a hassle sometimes. But it's all right. Well, I think it was more difficult for them than for me in that sense. You know, the worries and things like that.*
>
> *Sociologist: Yes. Do you also feel that the monitor has given them a sense of security? In the sense of, 'Ah, now it's okay now. Now she's monitored.' Or don't you think it had such an effect?*
>
> *Mrs. Sommer: I think it certainly helped, that something was being done. That they were able to say, 'Ah, someone cares. It's being taken care of. And then [the cardiologists] can take steps to make things better again. That's for sure. But despite all that, it's still my business. My body. It was good that [the written reports] were addressed to me. So, [my parents] only learned about it later. Sometimes, I forgot to tell them, and then I even got an earful for having*

> *forgotten to tell them (laughs). But I think overall it was helpful that something was being done.*

While the idea of continuous monitoring was reassuring for patients and their loved ones, it was not reassuring enough for some. Knowing that the cardiac monitor would not intervene in a worst-case scenario prompted several participants to take extra precautions in case their symptoms returned. Often, relatives were the driving force behind such precautions; they wanted to prevent their loved ones from suffering again. These patients, or their family members, purchased additional tools to quickly alert specific contacts.

During an interview with Mr. Bianchi and his wife, we discussed the fact that he wore a smartwatch. Due to his limited ability to speak after a stroke, it was usually Mrs. Bianchi who explained the more complex issues. She told me that they had just bought the watch the week before the interview because it had built-in fall detection. They hoped it would provide quick help if her husband (Mr. Bianchi, 62 years old, Waldspital) suffered another stroke:

> *Mrs. Bianchi: Actually, it's supposed to notify three people if he would fall to the ground or simply if the watch hit something hard. Then it would start vibrating on his wrist. And if he wouldn't respond within a minute and stop the vibration, it would notify the people in a pre-set order. Also, with the location services, we would be able to see where he is when something happens. We also had this idea because the last time it happened, he was alone, and he was unable to notify anyone. Well, you don't know if you can notify someone in a situation like that, but there's also an emergency button that you can press. All we have to do is try it all out for once.*

With this purchase, this family had created a backup plan that they hoped would provide timely help in case of an emergency. Another patient, who had suffered a stroke in the presence of her son, purchased a second phone with a simple emergency button on the back. With this option, she and her son hoped to be able to be quickly alerted if she began to experience symptoms similar to the first stroke. She explained this to me during a second interview in a public café. I asked her if she had it with her at the time, and she replied that she did not. She explained that if she fell in the city, people around her would certainly react. This shows how additional precautions can be adapted according to perceptions of safety in particular contexts.

However, there was also a situation where the attending cardiologist, the patient, and his wife did not share the same risk perception regarding his sudden collapses. Although the medical indication for a pacemaker was clear enough according to the attending cardiologist, Mr. Ammann was not very keen on getting one. However, Mrs. Ammann was very concerned that her husband could faint and fall at any time. Finally, they agreed on the cardiac monitor as an interim solution to find and prove the suspected syncope. Four weeks post-insertion, I did the first interview with Mr. Ammann via telephone. A week later, Mr. Ammann sent me an e-mail informing me that he had received a pacemaker the day after the interview because a recording had shown that his heart had stopped for a few seconds. Some months later, I met Mr. Ammann (85 years old, Waldspital) and his wife for the second interview in which she told me that the cardiac monitor hadn't been reassuring for her at all. I then asked her if she felt more comfortable with the pacemaker compared to the cardiac monitor, and Mrs. Amman replied:

> *Rather so, yes. Yes, and the reason is that the other thing, this event recorder, was not tangible for me. It just went "into the ether," somewhere, anonymously. But I myself had no control over it. Did [his heart] stop or didn't it? I didn't know*

> *for sure. And the cell phone didn't tell me either [instead of the transmitter, they had used a phone application for data transmission]. And that was more of an uncertainty factor for me. Maybe it's not true. Maybe it's a subjective feeling, but with the [pacemaker] he got, I feel like it's taking corrective action. And that's the most important thing.*

While it was important to her that the device could intervene and prevent her husband from experiencing syncope or worse, he did not necessarily share her perspective. Mr. Ammann (85 years old, Waldspital) continued to have some reservations towards the pacemaker when we talked about it:

> *Sociologist: How does it feel to have a machine helping your heart now?*
>
> *Mr. Ammann: Well, I guess I've become an old man.*

He went on to explain that, in his opinion, only old people get pacemakers. This had caused a sudden change in his self-image. He added that he might have it removed, a comment his wife acknowledged with an incredulous laugh.

Overall, cardiac monitors had a reassuring effect for both patients and their relatives. Depending on their individual perceptions of the severity of the unexplained symptoms they were experiencing, this sense of security was more or less important to them. A few opted for additional technological tools that they hoped would serve as a backup in case of an emergency. Interestingly, cardiologists also experienced a reassuring effect from placing their patients under remote cardiac monitoring.

5.7 "I've set up everything I could": The reassuring effect of remote monitoring for cardiologists

Although cardiologists today have a myriad of ways to examine patients' bodies, there is no guarantee that the results will be sufficient to make a diagnosis. This can be particularly challenging when dealing with ephemeral events, such as heart arrhythmias. Therefore, cardiologists must find a viable way to deal with the clinical uncertainty of not (yet) knowing how to help patients, for example, by trying to assess individual risks. One cardiologist told me during an interview that her concerns for patients depended on their age and the medications they were already on. For her, remote cardiac monitoring was an option to "not let her patients down." Additionally, cardiologists would usually make extensive use of all available complementary tests to narrow down possible medical explanations. However, if these tests are inconclusive, a simple "wait and see" approach may still be too risky for some patients. Still, the following quote shows, how this cardiologist was aware that she might be indulging in wishful thinking, hoping to find harmless minor arrhythmias before a potentially life-threatening event would occur:

> *We still have a certain anxiety of leaving people with nothing. Especially with pathologies that ultimately require the implantation of a defibrillator. We say to ourselves, 'Well, if it ever goes wrong, at least I'll see that the patient has ventricular arrhythmias.' I think of the cases of several young people I care for who have cardiac histories that make me think, 'I know they must have a mutation somewhere, but it hasn't manifested yet.' So, we're going to wait. And while we're waiting, let's at least reassure ourselves. But I tell them, 'Listen, it may be false reassurance, but at least if {unfinished sentence}. Well, I assume*

> *that the probability of dying of a sudden arrhythmia is preceded by small arrhythmias that we could have seen. But in reality, that is wishful thinking. We might also document the first and last ventricular arrhythmia that occurred.*

Her explanation illustrates well how cardiologists try to deal with the inherent diagnostic uncertainty. Certain parameters allow them to better assess the risk of a fatal event, but ultimately, they must accept and live with the residual risk of their patients suffering a potentially life-threatening event. In addition to the general risk factors associated with patients' medical histories, their level of anxiety also contributes to the decision of whether or not cardiologists recommend a cardiac monitor in an individual case, as one of them told me in the interview. The remote monitoring of their patients allows professionals to have a kind of safety net in the sense that they can choose to continuously monitor their patients' heart rhythms instead of regularly calling them in every 3 or 6 months, as would be the case with traditional calendar-based follow-up. Several cardiologists I interviewed found this reassuring.

Another cardiologist explained in more detail how she thought about the reassuring effect of remote cardiac monitoring. She described the digital connection as a protective tie between cardiologists and patients. Moreover, the simple implementation of remote cardiac monitoring made it a very attractive solution for cardiologists to tackle diagnostic uncertainty. According to this cardiologist, this attractiveness contributed to the recent boom of remote cardiac monitoring in clinical practice:

> *Cardiologist: It's really the ease with which we can offer and deploy this type of system. And then it also reassures doctors in situations that are a little bit complex. They can always say, 'I'm not going to let them go off into the wilderness with just a clinical checkup in a couple of months, knowing that I'm*

> *not going to know what happened in the meantime when I'm treating them.' It's really an easy system to implement, and it's an external system. There are really these positive aspects that are quite - how can I put it? - gourmet for doctors, which make us propose it more and more often.*
>
> *Sociologist: So, did I understand that correctly that this algorithmic technology allows you to say, 'I've done all I could do?'*
>
> *Cardiologist: I don't think you can say that. In our business there is always 0.01% chance of uncertainty. Things that we always look back on and say, 'I could have done this. That's it.' (…) It's reassuring for the doctor to say, 'I've set up everything I could. I keep these ties. Personally, I consider them as ties, like protections for the patients. To reassure the patients but also to reassure yourself, so that we don't lose the patient, as I said, in the wilderness. So, the patient is still being monitored. It's a kind of double psychological effect, but especially for the doctor. It's really something important for the patient, but I think that there is nevertheless a psychological effect on the doctor. Saying, 'I'm not leaving someone without [supervision].' Especially if you have doubts, for example, about a syncope that is still unexplained. To have a certain amount of vigilance over the patients. So, I think it reassures the doctors, who are always in this situation of a little bit of uncertainty, of decisions that are sometimes not easy to make, to be able to keep a certain tie. It's reassuring. It's important.*

Although mentioning that there is a double psychological effect of reassurance for patients and cardiologists, her quote implies that the effect might be slightly more important for cardiologists than for patients. An excerpt from one interview may provide a clue as to why this reassuring effect may be so important to cardiologists. Even though different levels of risk are involved in assessing patient situations, the decision to intervene or wait remains dichotomous, as this cardiologist explained:

> *Arrhythmias can be 100% fatal. Obviously, when it's a young person, we have a very complicated role in stratifying, because we can't give the patient all the anxiety in the world. So, I have to make a choice. Either I'm afraid or I'm not afraid, it's a dichotomy. Most of the time we're afraid when things are not clear. If the diagnosis is clear, we don't ask ourselves 10,000 questions. We have a lot of experience and we kind of follow the recommendations. But in those cases that are in the gray area, we have to tinker a little bit. It's actually tinkering. However, these are [procedures] that reassure us. Maybe wrongly, as I said, but they do.*

Although this cardiologist is aware that remote cardiac monitoring may provide false reassurance because he may not have accurately assessed the risk of a fatal arrhythmia in a particular patient, he must make a decision at some point about how to proceed. Since the cause of patients' symptoms remained unclear, and because most heart medications have serious side effects or can even be counterproductive, continuous monitoring was the only remedy cardiologists could offer their patients. However, continuous monitoring did not seem to be a quick fix for diagnostic uncertainty. On the contrary, when I asked another cardiologist if he thought the cardiac monitor could reduce diagnostic uncertainty, he replied:

> *No, the diagnostic uncertainty is generated (laughs) by the cardiac monitor in the first place. Otherwise, we might not even know about this arrhythmia, you see. We could not detect it on the standard ECG. So it may be an even greater*

> *uncertainty. And if you can record it with a 12-lead ECG instead of a cardiac monitor, then it's also easier to interpret, you know. But it's very difficult, if not impossible, to catch something like that with a 12-lead ECG.*

Again, this cardiologist emphasized that the very nature of how arrhythmias occur makes them difficult to detect and diagnose. Nonetheless, inserting a cardiac monitor does not necessarily narrow down the possible medical explanations for patient symptoms. The human body does not always work like a clock, and the heartbeat can be out of sync for ordinary reasons. Strong emotions or physical exercise can cause short-term changes in the heart rhythm. In addition, the older a heart is, the more likely it is to stumble from time to time, without posing an immediate threat to life. As a result, there is a risk that cardiac monitors detect more arrhythmias than what was previously thought to be the norm, which adds to, rather than reduces, uncertainty in medical decision-making.

5.8 Discussion: Waiting for a diagnosis, but in mutual reassurance

What cardiologists lack to make a diagnosis in an uncertain context is time and the quantified evidence that patients really have what they may suspect to be the source of the arrhythmia. This is especially true for rare and ephemeral arrhythmias, but also for other conditions. Except in the most obvious cases, such as serious injury, it is difficult to determine the cause of a condition from a single measurement taken at a specific time. Contemporary diagnosis in risk-oriented medical practice (Aronowitz 2015) is a process of continuous, cumulative and contingent evaluation and adjustment (Rosenberg 2002). This probabilistic approach has added complexity to the diagnostic process and made it more difficult for healthcare professionals to decide when to intervene. In the case of suspected arrhythmia, both patients and cardiologists are doomed to waiting until the next episode occurs, which would hopefully clarify things. Here, remote cardiac monitoring jumps in with its promise of not missing any irregularities and finally delivering objective proof.

Although cardiac monitors cannot intervene or directly safe lives, patients felt reassured by having them. Knowing that their heart rhythm was continuously monitored and imagining that they were constantly linked digitally with the hospital was sufficient to evoke a reassuring effect. The reassurance consisted in the feeling of being well cared for. Excitingly, in the first few weeks after implantation, this effect persisted, despite all the ambiguities that patients had been wondering about. In the first days after insertion, patients reported that the wound had been sensitive. Afterwards, most of them no longer felt the cardiac monitor unless there was external pressure. Patients knew that the implants were there and often intuitively touched them when I mentioned them during interviews. All that was visible from the outside was a small scar and sometimes a small bulge under which the cardiac monitor was placed. What was visible in patients' homes, however, was the transmitter under their beds, reminding them that they were being remotely monitored. While older patients didn't mind having such a device in their bedroom, younger patients usually hid it under the bed or behind a potted plant to avoid daily reminders and questions from occasional visitors.

While the devices for recording and transmitting data were visible or palpable, the processes of sensing, recording, and transmitting the heart rhythm were invisible to the patients. If they dared to press the button on the transmitter, all they saw was a green check mark and the date of the last successful transmission (automated or manual), which updated if data had been transmitted. This did not happen systematically at every connection between the two devices. This was counter-intuitive for patients, which brought about uncertainties about the system working properly. Some patients checked every morning to make sure their data had been transmitted, and some performed manual data transmissions if the date on the display did not match the calendar date. This suggests that the designers of the transmitter were not thinking of autonomous, engaged, and curious patients who would care about their health and therefore ensure that the data was transmitted, but of patients who would blindly trust the system.

Additionally, having no access to how, when and what data was recorded and transmitted made patients question what exactly the cardiac monitor, and ultimately the healthcare professionals were able to "see." Because the heartbeat and/or the pulse can be easily felt, patients were aware how the heart can adapt to emotional or stressful situations. Furthermore, the heart is still widely regarded as the center of our emotions. Knowing that their heart rhythm was being continuously monitored, some patients wondered to what extent the normal heart rate variability was being detected. They felt uncomfortable because they didn't know how a situation of sexual intimacy or any emotional instability would be reflected in their heartbeat and subsequently detected by the cardiac monitor, which could only detect the irregularity but not its symptomatic cause. This might lead these "digitally engaged patients" as Lupton (2013) would call them, to incorporate self-disciplinary behavior (Foucault 1995) to prevent cardiac monitors from falsely reporting palpitations to healthcare professionals.

While patients correctly assumed that the cardiac monitor was highly sensitive, their worries are in stark contrast with the disproportionally high amount of false-positive alerts in remote cardiac monitoring (O'Shea et al. 2021) which are also due to the proximity of the sensors to the chest muscles and their relative distance from the heart. Nonetheless, the sense of reassurance and fascination with remote cardiac monitoring outweighed patients' doubts and fears in the first few weeks after insertion.

For cardiologists, it was professionally reassuring to integrate patients into remote cardiac monitoring. For them, the reassuring effect was based on the digital tie the system allowed them to keep with patients. Although they were aware that medical practice is never fail-safe, remote cardiac monitoring was a tool for them in uncertain diagnostic situations in which they had to tinker (Mol et al. 2015). Cardiologists knew it might be “wishful thinking” to detect minor arrhythmias before they became life-threatening, but at some point, they had to decide whether to wait and watch or to intervene. With only the patients’ descriptions of symptoms to go on, symptoms which could not previously be measured, cardiologists cannot prescribe a treatment, but must weigh the risks and urgency for a particular patient. In *How Doctors Think*, an emergency doctor puts into perspective his considerations regarding diagnosis:

> *What we try to establish to our comfort, and the patient’s comfort, is that what is bothering them is not going to kill them in the next three days (Groopman 2008:74f).*

Like the emergency doctor in Groopman’s book, cardiologists relied on the reassuring effect provided by remote cardiac monitoring. As shown in this chapter, remote cardiac monitoring has above all a psychological and social effect as Aronowitz has described in the context of other screening routines:

> *Hope may be sustained, patients may worry less about being abandoned, and fear and uncertainty—the doctor’s as well as the patient’s—can be reduced (Aronowitz 2015:150).*

This mutual reassurance could even be beneficial for the patients’ health in general, as anxieties are known to have deleterious effects on the heart (Peacock and Whang 2013). However, patients were faced with the dilemma of either wanting to know what was causing their symptomatic episodes, or wanting the cardiac monitor to not detect anything, meaning that there was nothing wrong with them. Generally, patients preferred – of course – being healthy. The second most-wished-for option involved the detection of a health issue which could be easily treated, even if it would be an incidental finding. Cardiologists, on the other hand, needed a recorded heart rhythm pattern which – in the ideal case – was sufficiently clear to establish a diagnosis. Yet, the high sensitivity of the cardiac monitor to all types of arrhythmias, and not only the suspected type, did not necessarily reduce uncertainty (Fox 2000) but instead shifted it from an symptom-based to algorithm-based assessment.

But, as already indicated in this discussion, data triage and its interpretation were far from orienting themselves at clear-cut thresholds and a technological quick-fix solution (Mackintosh and Armstrong 2020). Instead, my observations in the telemedicine units and my interviews with tele-nurses and cardiologists showed that a large amount of detective work across different types of data sets, in combination with professional gut-feelings, played an important role when dealing with data transmissions created by cardiac monitors. While this seemed not surprising for the healthcare professionals who were used to this type of sense-making through their clinical practice, it could lead to disappointment for patients' whose hearts were being monitored. How these types of misunderstandings linked to the urgency and immediacy in diagnosing heart arrhythmias played out in the first months of remote cardiac monitoring will be the subject of the next chapter.

6 A direct connection? Urgency and immediacy in diagnosing heart arrhythmias

The quest for knowledge and the promise of delivering a timely and correct answer to patient suffering was at the core of daily business at the telemedicine unit. However, data alone are not sufficient to make a reliable judgment. Since the recording of the heart rhythm is based on external sensing of only two electrodes, the electrocardiogram can provide an inaccurate picture of the heart's rhythm. Ordinary heart rate variation, muscle movement, or other vibrations might cause the algorithms of the cardiac monitor to fail to recognize or over-interpret the heart rhythm or parts of it. How accurately the cardiac monitor works can also depend on patient body shape and the position and location of the cardiac monitor under the skin after insertion. In addition to these technical matters, data transmission must be contextualized with patient characteristics, medical record, and if possible, with what was happening when the episode occurred.

The main concern which animated hospital staff at this stage of remote cardiac monitoring was the principle of urgency. Although remote cardiac monitoring is a technology designed for making a diagnosis over extended periods of time, certain types of data transmissions might nonetheless require the hospital staff to intervene quickly. Compared to data produced by other monitored heart devices, such as implantable cardioverter-defibrillator (ICD), data transmissions from cardiac monitor patients were not considered as urgent by cardiologists. However, tele-nurses responsible for the patient follow-up understood that it was up to them to not miss important alerts, putting them in a crucial position within the remote monitoring network. Thus, they had to decide on a daily basis which data transmissions needed further examination by the attending cardiologist and which ones to discard. Moreover, both studied hospitals informed patients by following the rule that “no news is good news.” Additionally, the hospital staff adopted a careful approach for giving feedback to patients. When they were in doubt, they preferred not to inform the patients. This led to misunderstandings for patients who expected immediate care from the setup of remote cardiac monitoring.

For their part, patients were eager to make sure that their data was regularly transmitted and that they always had their remote control within reach to self-report a symptomatic episode. Taking the monitoring of their heart very seriously, they expected the hospital staff to take care of their data transmissions with the same diligence. Although patients were aware that remote cardiac monitoring was not an emergency system, they were disappointed when there was no prompt feedback, especially on self-reported symptomatic episodes. The absence of feedback challenged the promise of total surveillance and thereby also the reassurance effect it produced. Nevertheless, subsequent experiences which met patients’ expectations of how remote cardiac monitoring should work could make up for any initial disappointment. I refer to this patient misperception of temporalities in remote cardiac monitoring as the illusion of immediacy. The illusion emerges from the gap between the imaginary of an automatically synchronized data network and the actual time required for data transmission and interpretation in the hospital, which remains invisible to the patients. Before elaborating on these mismatches, I will first describe how tele-nurses worked in evaluating, classifying, and interpreting the daily flow of heart rhythm data transmissions.

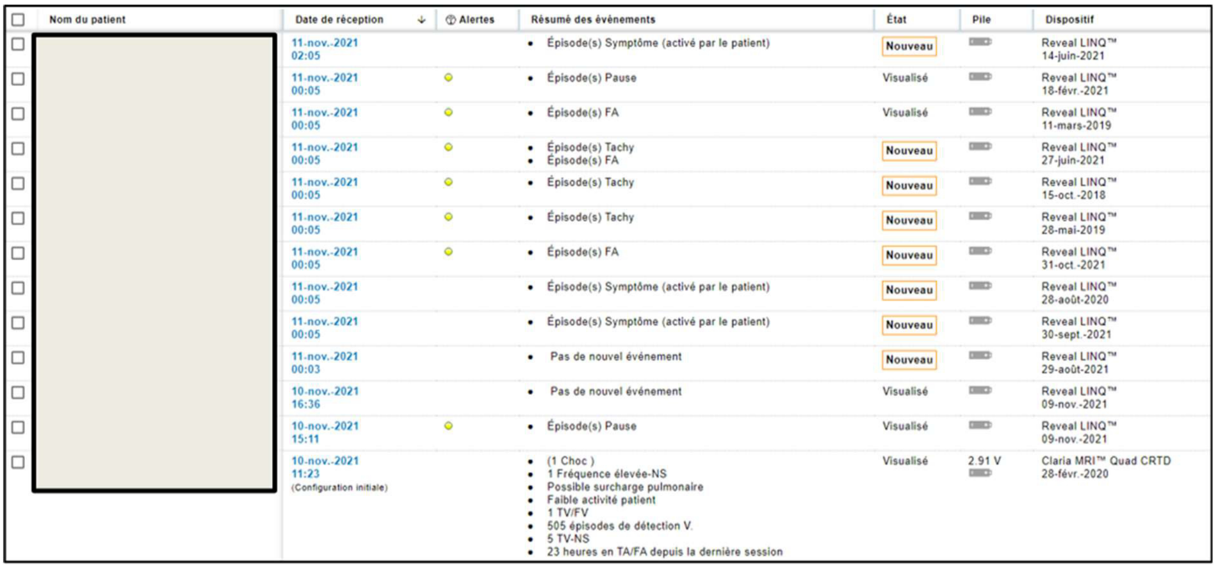
6.1 “What will I catch today?”: Tele-nurses fishing among the data

Every time algorithms detect an irregular heartbeat, or a series of signals cardiac monitors have measured and interpreted as such, an alert is sent through the transmitter to the remote monitoring system. But data do not speak for themselves. Whether or not a particular type of arrhythmia is potentially dangerous to a patient depends on the patient, his or her medical history, and the situation in which it occurred. Therefore, the transmitted heart rhythm recordings must be reviewed by healthcare professionals who are able to interpret an electrocardiogram recorded by a subcutaneous implant. This is all the more difficult because the sensing electrodes are not directly connected to the heart, as is the case with other implanted cardiac devices in telemedicine, such as defibrillators. As a result, other movements caused by nearby muscles, for example, can cause cardiac monitors to detect an arrhythmia that did not occur, which is known as a false-positive or artifact.

Telemedical follow-ups take place during office hours, from Monday to Friday. Based on the fieldnotes from the Waldspital, the following paragraphs provide an example of what this might look like: In the morning, a tele-nurse goes into her office and starts her computer (see Figure 13).

Figure 13: The telemedicine unit of the Waldspital (photograph taken during fieldwork by M. von Arx, September 29, 2021; on the bottom left was my attributed seat during ethnographic observations).

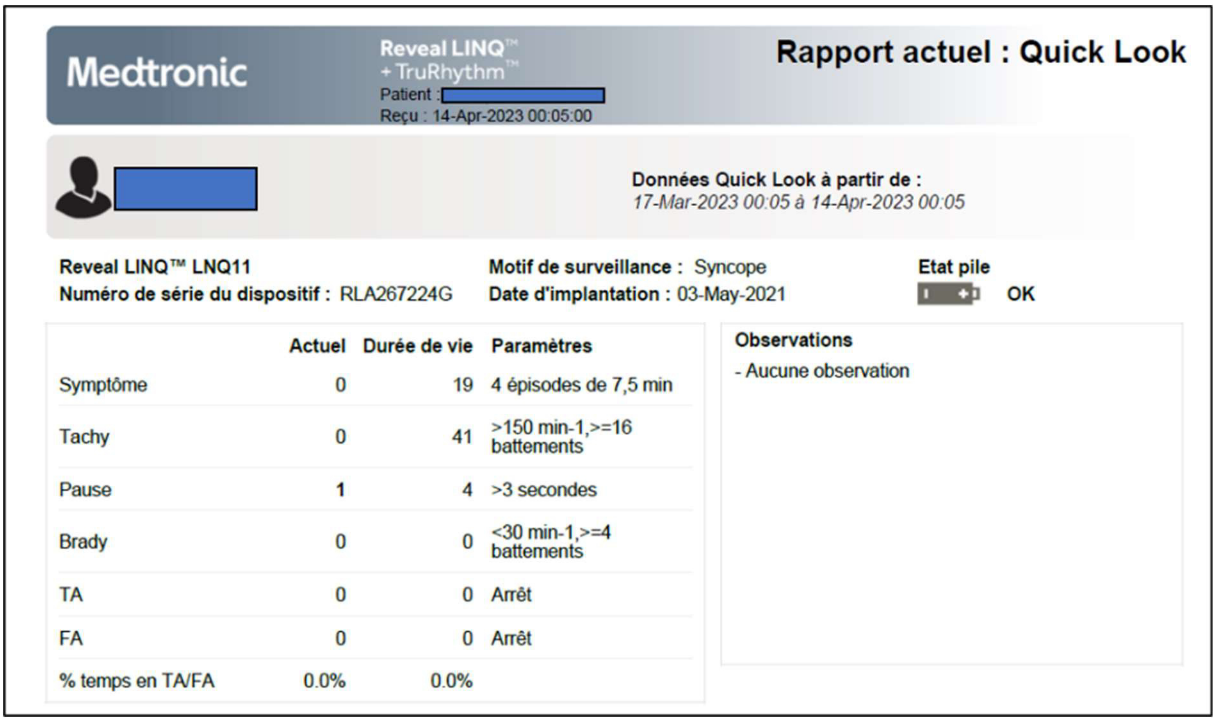
With her personal login details, she has access to the telemedical platforms provided by the different medical device companies. The platforms are similar to an email inbox, displaying the latest alerts from the cardiac monitors and other cardiac devices (see Figure 14 for an example). Some of them can be color-coded, resembling a traffic light system, to indicate the level of importance. These levels are automatically assigned according to the system's settings. The number of heart rhythm recordings to be processed varies from day to day and also depends on the number of devices included in each hospital's remote monitoring system. At the time of my data collection, tele-nurses at the Waldspital were reviewing up to a hundred alerts per day, with a peak on Mondays, as data accumulated over the weekend.



☐	Nom du patient	Date de réception ↓	Alertes	Résumé des évènements	État	Pile	Dispositif
☐	[redacted]	11-nov.-2021 02:05		• Épisode(s) Symptôme (activé par le patient)	Nouveau	🔋	Reveal LINQ™ 14-juin-2021
☐	[redacted]	11-nov.-2021 00:05	●	• Épisode(s) Pause	Visualisé	🔋	Reveal LINQ™ 18-févr.-2021
☐	[redacted]	11-nov.-2021 00:05	●	• Épisode(s) FA	Visualisé	🔋	Reveal LINQ™ 11-mars-2019
☐	[redacted]	11-nov.-2021 00:05	●	• Épisode(s) Tachy • Épisode(s) FA	Nouveau	🔋	Reveal LINQ™ 27-juin-2021
☐	[redacted]	11-nov.-2021 00:05	●	• Épisode(s) Tachy	Nouveau	🔋	Reveal LINQ™ 15-oct.-2018
☐	[redacted]	11-nov.-2021 00:05	●	• Épisode(s) Tachy	Nouveau	🔋	Reveal LINQ™ 28-mai-2019
☐	[redacted]	11-nov.-2021 00:05	●	• Épisode(s) FA	Nouveau	🔋	Reveal LINQ™ 31-oct.-2021
☐	[redacted]	11-nov.-2021 00:05		• Épisode(s) Symptôme (activé par le patient)	Nouveau	🔋	Reveal LINQ™ 28-août-2020
☐	[redacted]	11-nov.-2021 00:05		• Épisode(s) Symptôme (activé par le patient)	Nouveau	🔋	Reveal LINQ™ 30-sept.-2021
☐	[redacted]	11-nov.-2021 00:03		• Pas de nouvel événement	Nouveau	🔋	Reveal LINQ™ 29-août-2021
☐	[redacted]	10-nov.-2021 16:36		• Pas de nouvel événement	Visualisé	🔋	Reveal LINQ™ 09-nov.-2021
☐	[redacted]	10-nov.-2021 15:11	●	• Épisode(s) Pause	Visualisé	🔋	Reveal LINQ™ 09-nov.-2021
☐	[redacted]	10-nov.-2021 11:23 (Configuration initiale)		• (1 Choc) • 1 Fréquence élevée-NS • Possible surcharge pulmonaire • Faible activité patient • 1 TV/FV • 505 épisodes de détection V. • 5 TV-NS • 23 heures en TA/FA depuis la dernière session	Visualisé	2.91 V 🔋	Claria MRI™ Quad CRTD 28-févr.-2020

Figure 14: Screenshot of a patient remote monitoring software (Medtronic CareLink™), received from a cardiologist at La Clinique; from left to right: patient name, alert receipt date, color-code, event overview, processing status, battery status, device type, and insertion date.

Manually, there are several things tele-nurses can look for in the data. For example, they can scrutinize the alerts for false-positives. To do this, they had to click on alerts they received to visualize the corresponding recording and check its parameters (see Figure 15 for an example). Often, they would zoom into the recorded waveform and try to assess if it represented a real electrical irregularity or if the cardiac monitor had misinterpreted or missed certain signals (see Figure 16 for an example). If necessary, they used the parameters to manually calculate context values, such as the heart rate per minute.



Medtronic Reveal LINQ™ + TruRhythm™

Patient : [redacted]

Reçu : 14-Apr-2023 00:05:00

Rapport actuel : Quick Look

[redacted]

Données Quick Look à partir de :
17-Mar-2023 00:05 à 14-Apr-2023 00:05

Reveal LINQ™ LNQ11
Numéro de série du dispositif : RLA267224G

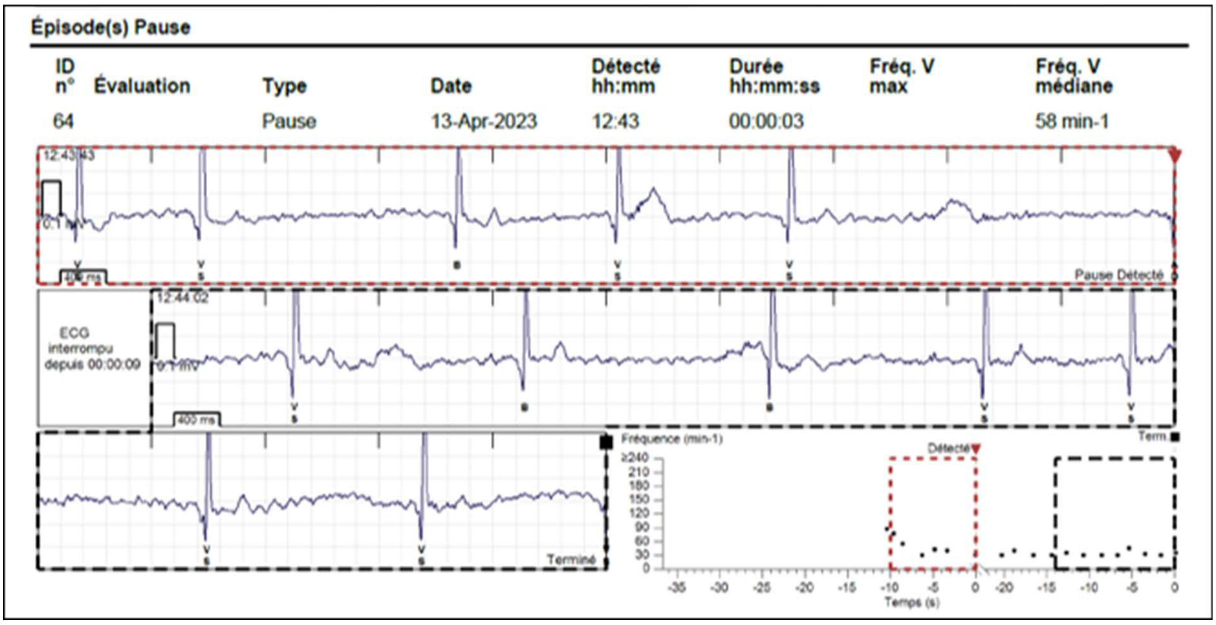
Motif de surveillance : Syncope
Date d'implantation : 03-May-2021

Etat pile OK

	Actuel	Durée de vie	Paramètres
Symptôme	0	19	4 épisodes de 7,5 min
Tachy	0	41	>150 min-1,>=16 battements
Pause	**1**	4	>3 secondes
Brady	0	0	<30 min-1,>=4 battements
TA	0	0	Arrêt
FA	0	0	Arrêt
% temps en TA/FA	0.0%	0.0%	

Observations
- Aucune observation

Figure 15: Screenshot of a quick look of an alert indicating a cardiac pause of >3 seconds, received from a cardiologist at La Clinique.



Épisode(s) Pause

ID n°	Évaluation	Type	Date	Détecté hh:mm	Durée hh:mm:ss	Fréq. V max	Fréq. V médiane
64		Pause	13-Apr-2023	12:43	00:00:03		58 min-1

Figure 16: Screenshot of the cardiac pause of >3 seconds visualized as a graph corresponding to the alert of Figure 15, received from a cardiologist at La Clinique.

Tele-nurses also had to decide whether or not an alert needed to be investigated further by the cardiologists or if it might be alarming enough to require immediate medical intervention. Although tele-nurses did not consider their work very interesting for a sociologist like me to observe, I was intrigued by how they proceeded to treat different alerts with different levels of prioritization. I quickly realized what a tele-nurse had meant when she told me in the interview that they needed a "trained eye" who knew how to interpret electrocardiograms recorded by external sensors. But ECG reading skills alone were not enough. Tele-nurses also relied on their experience and professional knowledge acquired over time. One tele-nurse described to me in the interview how she would get an initial overview of all transmitted arrhythmias when logging into the different telemedical systems of the companies:

> *There are systems where the most important ones are at the top, marked with a red flag. With another system, you have to click through four or five pages to see what you have. Over time, you start to know a little bit (sighs) about what a correct indication really is and what isn't. We have some patients where it says asystole, but you already know that they have little spikes that do not count. So, you might have 20 asystole on a Monday morning, you know? In a single system, in this big system. And then I cannot immediately look at all of them individually. So, at some point, I just look at the names, if there is one that does not seem familiar to me, you know? Over time you start to remember them. The ones that keep coming up, even though there is nothing there. Sure, throughout the morning, I look at everything. But just with the help of my experience, I want to be able to look at the most important ones first. And unfortunately, not all systems are equally well-arranged.*

Some of the telemedical systems were more helpful than others in providing an initial overview by automatically highlighting important alerts. However, when there were too many alerts, the tele-nurses had to rely on other selection criteria, as it was impossible to review every alert in detail in the first round. Over time, the tele-nurses began to remember the names of patients for whom they repeatedly received false-positive alerts. As a result, they began to classify these recurring alerts as less important in a first round of review. After the initial review, the tele-nurses reviewed all alerts individually according to their initial prioritization. During this second review, tele-nurses again face the technical difficulties of an externally recorded ECG and patient-specific ambiguities. During an interview, I discussed with one tele-nurse how she dealt with uncertainties in data interpretation:

> *Tele-nurse: With the cardiac monitors, it often happens that they do not identify it correctly. For example, asystole. If the QRS complex changes during the night or something like that. It just doesn't see that. And then it sends it as asystole, and we have to check if it's really asystole or not. Atrial fibrillation is sometimes difficult as well. That it's just a false-positive. But that's why we need to look at it very carefully. And if we are not quite sure, then the doctor comes to look at it. And sometimes they're not sure either (laughs). Yeah, it's not always easy.*
>
> *Sociologist: And then what happens? If you are still not sure?*
>
> *Tele-nurse: Well, if it's nothing, then we just keep observing. And maybe tomorrow's episode will be better recorded, you know. So, with asystole, you can see if it really is asystole. With atrial fibrillation, sometimes it's a little bit {unfinished sentence}. Depending on the recording, depending on where the cardiac monitor is. These cardiac monitors see the ECG a little bit differently,*

> *you know. But we already know from the long-term ECGs that sometimes they are a little bit difficult [to interpret]. Because they are always moving.*
>
> *Sociologist: But how do I imagine that? Can you take a closer look at the curve? Zoom in a little bit? And that way you might see inconsistencies that would otherwise not be visible.*
>
> *Tele-nurse: Yeah. For example, you can increase the amplitude so that you can see the P-wave a little bit better. You can make the whole thing bigger, of course. And then we still have the overall picture, you know. Yes, it's rare that you don't see it well. But then it's good that we can ask (laughs).*
>
> *Sociologist: (laughs) But overall, do you think the algorithm works well, the way it sorts?*
>
> *Tele-nurse: Actually, it does. Yeah. Just the asystole, they are often false-positives. But it's always the same people, so you know that in advance. And yet that's the dangerous thing about it. When you know, oh yeah, it's that person again.*

This interview excerpt illustrates the daily challenge of interpreting data. While recognizing patients' names could help make the data transmissions more effective over time, there was a risk of missing something important because of this specific knowledge. Throughout the day, tele-nurses reviewed each transmitted heart rhythm episode and made decisions about whether or not they should discard it or investigate it further. If a closer look at the data still did not clarify if the alert was a real one or a fake one, nurses might ask their colleagues or the attending cardiologist to review the recorded event in greater detail. The responsibility for correctly interpreting the recorded data made their job exciting, but it also positioned them as a critical node in the remote monitoring system. One tele-nurse explained this challenge as follows:

> *It's really never boring. Every day, there's the suspense: What will I find today? Between [colleagues], we say, 'What will I catch today? {...} But if you don't see it, it will be lost.*

By the last sentence, she meant that if she misjudged the relevance of an alert for a patient, no one else would notice, because she was the only person who reviewed it. Her quote illustrates how the unpredictability of remote monitoring makes the tele-nurse's job both exciting and critical to subsequent medical care, as it is their job to correctly assess the incoming data transmissions. During my observations, I learned how tele-nurses also relied on contextual data, such as the time at which an episode was recorded. They also relied on normative assumptions such as patients sleeping at night and being active during the day. Accordingly, they tolerated more deviation from the normal heart rhythm at night than during the day. For example, a pause of four to five seconds at night was considered less worrisome than if it had happened during the day. I asked them what happened when a patient's lifestyle or commitments, such as shift work, deviated from common assumptions. Tele-nurses told me that they would learn about it over time and make notes in the patient chart for reference when following-up.

When data transmission first came in from newly connected patients, their data was evaluated in relation to data transmissions from other patients. This might imply that tele-nurses paid more attention to that particular data transmission as the patients' names were not yet familiar to them. However, over time tele-nurses acquired fine-tuned knowledge allowing them to triage the data transmissions more efficiently. For example, tele-nurses learned which cardiac monitors tended to send false-positives. These alerts could then be classified as false-positives either by analyzing the received heart rhythm episode for false sensing or through the exchange with patients via phone. Accordingly, this knowledge of the patients' health status and often also of the patients' everyday lives and hobbies helped tele-nurses to contextualize a recorded heart rhythm episode without having to closely look at it each time.

One ethnographic observation provided an illustrative example. Once, when I was sitting in the telemedicine unit, a specialized nurse showed me an episode of palpitations. The episode indicated 180 beats per minute. Recognizing this patient by name, the tele-nurse told me that in this specific case, the arrhythmia episode was nothing serious. I asked her how she could be sure about that. She drew my attention to the time the episode was recorded and said, "Look. Here, he was cycling again. At this time of day, he always uses his stationary bicycle. We know that. It's normal if you are doing sports" (fieldnotes, Waldspital, October 12, 2020).

Nevertheless, the algorithm of the cardiac monitor systematically marked this episode as potentially relevant due to the faster heartbeat. The tele-nurse told me that this is typically an alert to be discarded. She went on in her explanation, telling me that the main challenge of her everyday work involved distinguishing between relevant and irrelevant episodes, contextualizing them with patient background knowledge, and not missing any potentially important indications. If tele-nurses miss a decisive alert, there is a delay in diagnosing a potentially life-threatening condition. This being the case, one nurse referred to the task of re-assembling, linking, and interpreting different types of data to understand the transmitted episode as "detective work." The fine knowledge of how to examine recorded episodes or learning which cardiac monitors regularly recorded false-positives was acquired over time. Consequently, they were able to directly discard an alert according to a name and/or a type of arrhythmia without further investigation if they recognized it as a repeated artifact.

In a few cases, the remotely monitored heart might also reveal potentially sensitive information. One example involved the data transmission of a younger patient showing a tachycardia episode from the previous weekend. During my ethnographic observation, the tele-nurse commented that this patient had taken “something” again. She explained to me that the patient was known to take drugs. Through the long-term follow-up of remote cardiac monitoring, she was also able to determine that it had happened again for the first time in a while. She therefore saw no reason for further examination and marked the alert as addressed.

One tele-nurse admitted in the interview that they sometimes also joked about certain data transmissions. They did not do so in a disrespectful way. Rather, jokes arose from situations that left them puzzled and which led them to ask themselves what the patient had been up to. She mentioned that there were patients who added certain supplements when using the sauna. Such remedies however would often not be the cream of the crop for the heart rhythm. In other words, even though only heart rhythm data was transmitted, they might reveal more than intended. Thus, tele-nurses developed what other scholars have called “digital intimacy” over time (Piras and Miele 2019).

Although cardiologists are responsible for the final medical decision, it is the tele-nurses’ responsibility to signal events from data transmissions that they deemed to be worthy of further investigation by cardiologists. Thus, the extent to which a heart rhythm recording is relevant or not in the clinical context becomes the core issue of the relationship between tele-nurses and cardiologists.

6.2 “Maybe I will show it next time”: Uncertainties in assessing cardiac data

The tele-nurses were able to clearly distinguish between clinically relevant and irrelevant alerts after reviewing what the telemedical system automatically flagged as important. This distinction was often supported by the tele-nurses' accumulated experiential knowledge. However, there were always a certain number of alerts whose clinical relevance was not clear. As mentioned earlier, the tele-nurses would first consult their colleagues or decide to ask the cardiologists for further investigation and discussion. However, the decision to ignore a data transmission or to follow up with the cardiologists depended not only on the tele-nurses’ experience, but also on their gut feelings (Kristensen et al. 2021). From the cardiologists' point of view, it was the tele-nurses' on-the-job experience that informed their gut-feelings. For cardiologists, this made the difference in how well they were able to deal with unclear data transmissions. In an interview with a cardiologist, we talked about how tele-nurses deal with uncertainty in triaging data transmissions on a daily basis:

> *Cardiologist: [The tele-nurses] have a few guidelines on what to look for. What they must report in any case. And whenever they’re not sure, they report it. That is, they report it to us and discuss it with us.*
>
> *Sociologist: What kind of uncertainties do you encounter? What’s the most difficult thing?*
>
> *Cardiologist: It always depends a little bit on the experience of the person doing it. Those who have been around for a long time and are very experienced report almost only what’s relevant. And for those who are not so experienced, you*

> *might have to show them some tips and tricks. And depending on the situation, if it's difficult to interpret, you look at it together and show them how we do it or how it's done. Especially with cardiac monitors, there are actually two or three things that are difficult. One is identifying whether or not there's atrial fibrillation. That's sometimes difficult. Then if it's a rapid tachycardia, a broad complex tachycardia, whether it's a ventricular tachycardia or a bundle branch block. However, that is often not trivial for us either. And the third situation is if it's a narrow complex tachycardia, whether it's atrial flutter or some other supraventricular tachycardia. That's something that is very difficult to identify. Other than that, pauses, blockages, bradycardia in general are relatively clear and hardly a problem anymore.*
>
> *Sociologist: And what are your strategies to sort of eliminate or deal with these uncertainties?*
>
> *Cardiologist: Well, that's the doctor's job to evaluate. And to make the decision. And if he or she is not sure, he or she often asks one or two other colleagues and then they decide by consensus what's most likely. But we don't have a clear procedure on how to do that. This isn't a trial; this is daily clinical practice. The attending doctor decides whether or not he or she can do it safely enough or whether or not he or she should ask someone else to do it. This is how it usually happens in the clinic, you know.*

Although this cardiologist argued that tele-nurses' level of expertise and ECG-reading skills were the only critical elements to make the cardiac data transmissions meaningful, my ethnographic observations and interviews with tele-nurses revealed that everyday clinical practice depended on more than just sophisticated data interpretation. One tele-nurse told me about a young male patient in remote cardiac monitoring who she knew to have fallen down the stairs. She was concerned about the tachycardia episodes, which were not bad in and of themselves, but their recurrence caught her attention. The tele-nurse explained this to me:

> *I have a young patient who fell down the stairs. He's often so tachycardic. Every time I have to bring myself to not tell the doctor, because I always feel that he's often so tachycardic, but it's nothing, nothing special. It's just supraventricular tachycardia. But maybe I just need to show it once. Even though every time I have the feeling that it doesn't matter, that's not why he fell. However, I also think that every time I see a transmission coming from him, I somehow feel... (she makes a gesture with her hand as if there is something unknown behind the episodes, expressing her uncertainty). That's a special feeling. Maybe I will show it next time, just because I always have that feeling (gesture with hand again). Even though I don't really see anything.*

In contrast with cardiologists, tele-nurses had the complete overview of all data transmissions over time. Consequently, they noticed repeated data transmissions from the same patients, even if they were individually considered irrelevant. However, their intuition was not only dependent on their gut-feeling related to the data transmissions and the background of a specific patient. As another tele-nurse specified during an interview, her reporting also depended on the attending cardiologist she was working with. Moreover, she wanted to make sure not to miss anything relevant when leaving her desk in the evening. The tele-nurse explained:

> *If something is really urgent, then of course you report it, you know. And the rest, you just have to weigh it a little bit. What to report. It depends on the*

> *patient's medical records or if someone is transmitting the same thing over and over again. Then you just keep observing, or you ask [the cardiologist] again at some point. Then they might say, 'Yes, keep observing like that.' It always depends on their decision, and sometimes on the doctor in charge. One might say, 'Yes, we will continue to monitor. But another would say, 'No, call the patient in immediately.' There are individual differences like that. Sometimes it's not easy, even for us. But for us, the situation is such that we actually report for our own [protection], you know. If we feel like we should report something now, even if it's not something urgent, just so that we can go home at night with a clear conscience. Not that you miss something that you should have acted on.*

While the tele-nurses wanted to report to the best of their knowledge and gut feelings, interviewed and observed cardiologists described their attitudes as overly cautious. No cardiologist I interviewed could recall a time when a tele-nurse had failed to report a relevant episode. On the contrary, the majority of episodes reported to them by tele-nurses did not require medical attention in their opinion. A cardiologist working at the Waldspital described her professional relationship with the tele-nurses:

> *My role is to contextualize. To tell them to call the patient to check or not. Or if my alarm bells are ringing [figuratively] and you need to call the patient in immediately. But most of the time it's possible to decide remotely without calling the patient in. {Deliberate pause}. [The tele-nurses] have the tendency to report anything that's not quite clear. I don't think I have ever seen them not report something or us miss something and realize too late that we should have acted on it. No, I cannot think of an example. They tell us nine out of ten things,*

> *which, however, have no consequences. It's more of a relief for them and, of course, a protection. At the end of the day, we [cardiologists] have more know-how. It's a matter of experience until you dare to not report something.*

This point of view was shared by cardiologists at La Clinique who told me during interviews that tele-nurses often sent them data transmissions that were not clinically relevant. However, the nurses never failed to send clinically relevant heart rhythm recordings. The independent position of the tele-nurses in reviewing the remote monitoring data prompted them to report even the slightest doubt. Although they knew the cardiac monitor was not intended to be an emergency system, they feared missing a potentially life-threatening arrhythmia.

During my ethnographic fieldwork, it became clear that the different perceptions of how urgent a data transmission needed to be further investigated led to some resentment between the tele-nurses and the cardiologists. This was often due to the fact that the cardiologists at the Waldspital who were responsible for handling unclear data transmissions were on call. As a result, their time resources were very limited, and they had to deal with much more urgent cases of patients coming to the hospital. Thus, these different interprofessional perceptions of urgency ultimately led to tensions in their daily collaboration. However, when asked about this during interviews, both tele-nurses and cardiologists described their professional relationships as good. One cardiologist briefly admitted that his relationships with the tele-nurses was sometimes strained. According to him, it was not due to the different sense of urgency that I had observed. He explained that it was due to technical difficulties with the various home monitoring systems. He explained this:

> *Cardiologist: It's a step-by-step scheme. The algorithm, which prescreens, then the nurse, who is the finer filter, and then we, who are in the stupid situation that we must make a decision at some point. Even if we don't know for sure. I*

would describe the cooperation as good. {Deliberate pause}. We may have integrated it a bit poorly into the daily process, but you have to be self-critical in clinical routine. It's more something that runs as a sideline. Then the people from telemedicine call and you must go, have a look at something and make a decision. Yet, you just don't have time. And then you go down [to the telemedicine unit] and you are annoyed, when you sit next to your colleague, because you must log back into the software. The software is slow. So there may be some tension, but it's not because we are now facing the same problem together, or because I think the other person should have done a lot more. The tension comes from the shortcomings of the data presentation or the platform itself. I think that's probably the area of tension that's developing in this collaboration. But there's no doubt that the tele-nurses take a lot of work off our shoulders and make it easier. And it helps tremendously, especially in our contact with patients. The bottom line is that the relationship is good.

Sociologist: To what extent does the nurses' knowledge of the patients influence your subsequent decision?

Cardiologist: I would say considerably. They're closer. Especially with patients who regularly transmit something. They call them. They have a notebook in which they write down everything that might come out of these conversations and what comes out of the preliminary decisions. Since someone else from our team [of cardiologists] is responsible for reviewing the alerts every day, this contributes significantly to improving patient contact and probably also to increasing the consistency of clinical decisions.

His account shows that the work of the tele-nurses was essential to cardiologists' subsequent decision-making. Although tele-nurses play such a central role in remote cardiac monitoring, they do not have a specific job title related to these tasks. Nor do they receive a higher salary than other nurses, although some have received additional training (Oudshoorn 2008). In the Waldspital, within the cardiology team, the tele-nurses were referred to as "tele-fairies." This refers to the figure of the fairy godmother in various children's stories, who is a caring figure who protects people from danger or helps them out of hopeless situations. In addition, she often has the magical power to make things happen quickly and effortlessly for the people in question. In the world of fairy tales, the role of the tele-nurse is perhaps best described by the task given to Cinderella by her stepmother, "The good in the pot, the bad in the harvest." Unlike the Cinderella story, tele-nurses did not have animal friends to help them triage data transmissions into relevant and irrelevant findings.

This section has demonstrated the central role of the tele-nurse in processing remote monitoring alerts. Although the data flow could not be managed without their intervention, the different sense of urgency sometimes led to tensions between nurses and cardiologists. Beyond the professional relationship, tele-nurses were also in regular contact with the patients with remote cardiac monitors. However, making decisions about whether or not to contact patients was far from easy and effortless. After overcoming technical uncertainties and checking patient medical records, calling patients was sometimes the only way to find out what had been happening when the arrhythmia occurred. However, this decision was also characterized by a trade-off between the need for certainty and the goal of not causing anxiety to patients.

6.3 “They’re not very sick”: Determining urgency in contexts of uncertainty

In general, cardiologists agreed that patients should be updated as much as necessary, but as little as possible. As mentioned in the previous section, cardiologists did not consider patients with cardiac monitors to be urgent cases. After all, the cardiac monitor was a diagnostic device. As such, the time horizon was more long-term. In addition, patients were given clear instructions that the cardiac monitor was not an emergency device. They were told that if they felt unwell or had severe symptoms, they should call the emergency services immediately. As a result, cardiologists were reluctant to call patients for arrhythmias that they may not have even noticed. Several parameters influenced whether or not cardiologists would call patients immediately after reviewing their data transmissions, whether or not the feedback could wait until the next medical appointment, or whether or not patients would be informed of the recorded episode at all. When asked how they dealt with diagnostic uncertainty as doctors, one cardiologist explained it this way:

> *For example, one of the arrhythmias that we look for the most is atrial fibrillation because of the risk of embolism. If we see that there’s one, but that the patient is already anticoagulated, for example, we aren’t going to panic, or call the patient at home, because it’s very anxiety-provoking for patients to be called at home. I don’t know if all doctors take this parameter into account. I personally don’t like to call patients at home to tell them things like this, because, well, if I call them on Friday evening, they are going to spend the whole weekend worrying, whereas it’s not going to change anything if they’re anticoagulated anyway. So, sometimes we just pass on the message to their*

> *attending cardiologist to tell him or her, 'We found this arrhythmia in your patient.' If it's a patient who's not anticoagulated, for example, we'll call him for a consultation to introduce anticoagulation, because it's not a matter of a week anyway. It's really a matter of risk in the medium- to long-term. But a difference of a few days will not really change anything. However, there are other arrhythmias that are more malignant, and for these, yes, sometimes we must call the patients and tell them to go to the emergency room.*

However, this cardiologist estimated that such urgent situations occurred only about once a month. In addition, the episodes that were reported were never reviewed in real time. As a result, even the hospital's most immediate response always lagged behind what was happening to the patients. This illustrates that the core business of diagnostics is to monitor and classify, not to act on what is monitored and classified. For example, one tele-nurse told me that she did not consider patients with a cardiac monitor to be very sick compared to patients with other therapeutic implants and who are remotely monitored:

> *Well, these cardiac monitor patients, they're not very sick in that sense. We are just looking for something. It's not like a defibrillator or something.*

Unlike therapeutic cardiac devices, such as a defibrillator, which can actively intervene in the heart rhythm by delivering an electric shock, the cardiac monitor has only a monitoring function. As a result, the tele-nurses prioritized checking data transmission from therapeutic cardiac devices over those from diagnostic cardiac devices because it's important that they are properly programmed and function properly to avoid unnecessary shocks. Accordingly, tele-nurses typically started reviewing the recordings from other cardiac devices first in the morning and did not look at alerts from the cardiac monitors until they were finished with the higher-priority devices, unless a cardiac monitor alert had been flagged automatically by the system. Thus, on a day with a heavy data load, alerts from cardiac monitors were checked only in the afternoon. The non-urgent nature of cardiac monitors within the clinical context of the hospital was also illustrated by a cardiologist's comment during an interview. When describing his career, he told me:

> *I've a lot to do with telemedicine. Rather on the level of ICD, pacemaker. We also have ECG recorders, but these are almost the most "boring" (shows quotation marks with hands) of the devices for us.*

After a few other questions about his job and his role in the context of remotely connected devices in cardiology, I asked him why he had described the cardiac monitor as boring in comparison to other technologies. He explained his response:

> *Well, it just gives us an electrocardiogram. That's so far so good, but with all the other devices we have that too. Plus, we have nicer signals because [they are] intracardiac. We have impedance measurements. We have measurements for patient activity, for arrhythmias. The arrhythmias are recorded as with the cardiac monitor, but the quality of the signals and the amount of information is much more comprehensive. Of course, we know that with these other devices, with ICDs, it's not just about the patient. It's also about the function of the device itself, which is a large part of the information that is transmitted. And we're not interested in that with a cardiac monitor. The battery just runs out at some point, and otherwise it works. To put it a bit casually, it doesn't do anything therapeutic compared to a pacemaker.*

While certain dangerous arrhythmias may require an urgent response, remote monitoring of patients with therapeutic devices and their proper functioning is a priority. All of the cardiologists

I interviewed stressed the importance of not having to contact patients every time their cardiac monitor sends an alert. This cardiologist put it this way:

> *I believe that it's very important that patients are not always aware that there has been an alert. Otherwise, we would be bombarded with phone calls to reassure them, asking us if it's important or not. We get alerts regularly. Either alerts about things that were already known, or alerts about things that may deserve a discussion, but they aren't dangerous. They aren't urgent, and they will not change the therapeutic approach in any significant way. In this case I usually wait until the next time I see the patient. And then, last but not least, there are things that really deserve a different approach, and in that case, well, we get active, and we do something.*

This strategy of informing patients about recorded arrhythmias only when more information was needed about the situation in which it occurred or when the cardiologist decided to adjust treatment was used in both hospitals. Cardiologists emphasized that it depended heavily on patient medical history and medications. If there was no immediate risk for patients, the data transfer simply accumulated as clinical information without patient knowledge. Overall, cardiologists adopted a "no news is good news" communication strategy.

However, tele-nurses' and cardiologists' perspectives on how feedback should be handled were not entirely aligned. The Waldspital provided its patients with three-month written reports summarizing the cardiac events transmitted during this period. Since telemedicine services in Switzerland can only be billed for in the form of medical consultations or reports, these three-month reports also served to finance the telemedicine unit.

One nurse showed me what such reports looked like during a visit to the telemedicine unit. It concerned the case of a young patient whose heart was known to occasionally stop beating for three to four seconds during the day. The tele-nurse opened the event-recordings showing the respective asystole. Theoretically, she explained, she would now have to tell the patient about it in the three-month report. She then switched to the letter she was preparing for the young patient. No arrhythmias were noted in the appropriate field. The tele-nurse continued and said, "However, the cardiologist in charge does not want anything noted." Then, in a somewhat quieter, conspiratorial tone, she leaned towards me and said, "Personally, I'm not comfortable with that. I want to write down, 'known regular asystole.' This is a burning issue for me. I would like to write that down, but the cardiologist is our boss, so we do it as he wishes" (fieldnotes, Waldspital, September 29, 2021).

Although it was contrary to her intentions, the tele-nurse accepted the restrained way of communication imposed by the cardiologist. During the interview she laughingly told me another anecdote. When she had started working at the telemedicine unit, she had assumed that everything that had been found through remote monitoring would be noted in the report for the patient. Accordingly, she had written down the findings related to supraventricular tachycardia. After these reports were shared with the concerned patients, the phone did not stop ringing with patients wanting to know what this meant for them. After this incident, she was told not to record harmless arrhythmias such as self-limiting ventricular tachycardia or ventricular extrasystole, as mentioning them to patients would be unsettling.

Still, tele-nurses' and cardiologists' daily work remained a tightrope walk between two different approaches: (1) wait-and-see and (2) emergency. I got to know the extent to which healthcare professionals' learning about the context of cardiac episodes can dispel initial concerns induced by the alarm system. This was made clearer to me in the following two examples. The first example came to me from a cardiologist during an interview. She told me of an episode of atrial fibrillation that had occurred at 3:30 pm. The tele-nurse had informed her about it and she had decided to call the patient to verify. On the phone, she asked the patient what had happened to him at that time. The patient replied that he had been walking fast on a paved sidewalk with a full shopping cart because the parking ticket was about to expire. In this case, the alert turned out to be an artifact due to vibration.

In the second example, the data transmission showed an asystole which turned out to be a real one, which meant that the patient would need a pacemaker. However, the phone call changed this medical indication by revealing what caused the asystole. A tele-nurse described this case to me in the interview:

> *I had this patient with asystole. Then the cardiologist passed by and said that this is a clear indication for pacemaker. He told me to call the patient immediately to inform her. She was only given the choice of having it done in this hospital or another. So, I called her. That was funny. At first the patient said, 'Oh, okay. If that's what you were looking for.' I explained to this cardiac monitor patient that, yes, that was what we were really looking for because of her syncope. At the end of the phone call the patient suddenly asked, 'What day did you say?' So, I repeated it again. Then she said, 'Ah, but that's when I had a gastroscopy.' (Laughs). Then we realized that the asystole had happened while she was under sedation when her heart paused. So, this pacemaker could be crossed off right away (both laugh).*

These two examples show how important it can be to re-evaluate a heart rhythm recording by calling the patient. Nonetheless, tele-nurses and cardiologists were cautious about contacting patients in order to preserve the reassuring effect that most patients perceived from remote cardiac monitoring. Overall, they assumed that the majority of life-threatening arrhythmias would be associated with severe symptoms, so that patients would still notice anyway and call the emergency services immediately.

Still, I was fascinated by the inherent uncertainty of false-positives either generated by the superficial sensing of the cardiac monitor, like the example of the shopping cart artifact, or generated by special circumstances, like the example of the asystole due to another medical exam. While some of the transmitted episodes could be clearly identified as false-positives, there must be others which elude clear interpretation. When asked about how he dealt with the uncertainty related to this type of borderline heart rhythm episodes, a cardiologist explained his approach:

> *We keep our fingers crossed. We assume that human nature is tough, which is true, right, because we expose ourselves to all kinds of toxins all the time, and we're all still alive. To a certain extent. Look, if there's any doubt, we consider the context, as soon as we have any doubt, we will call the patient. We'll tell him, well, your heart rate was at 150 beats per minute, which is a bit unusual. What were you doing at that time? If he would answer, he was shoveling snow in La Chaux-de-Fonds [Swiss town 1,000 meters above sea level], and it was -10º Celsius. You understand that the patient is at 150 beats per minute. However, if he tells me, he was watching the news in front of the television, I'll be more worried. So, we'll weigh the information with the other clinical information given by the patient. Moreover, we also have patients who are on medication that prevents the heart from beating too fast, because they already have a known arrhythmia. We have a lot of them in cardiology, beta-blockers of course, and*

> *other types of anti-arrhythmic drugs. Some of the patients who already are under anti-arrhythmic treatment do not exceed 100 beats per minute no matter what you do. So, if they're at 150, we know it's not good. It doesn't tell us exactly what type of rhythm disorder it is, but we'll consider these different parameters to know if we need to do more or not. And sometimes we're not able to answer that question. Then we wait for the next one. We ask ourselves if this is a phenomenon that reproduces itself over time and so on.*

As in a calendar-based follow-up of medical appointments at the hospital, cardiologists may decide to wait if the evidence does not clearly point to a diagnosis and/or potential preventive treatment. However, unlike calendar-based follow-up, patients are not automatically kept up to date as they would be in a face-to-face meeting with the cardiologists. Tele-nurses had some autonomy in deciding when to call patients. However, they gave different answers about the appropriate level of data feedback to provide to patients. One tele-nurse who had recently joined the unit told me about her more experienced colleagues:

> *One [of the tele-nurses] does not call them often. And one much more often. The reasoning of the one who calls them frequently is, 'I just want to know what happened.' And the other colleague's reasoning is to say, 'I don't want to scare them.'*

Later in the interview, she told me that she was not sure what approach she would take once she settled into her new job. After all, she added, remote cardiac monitoring was also a kind of service that the hospital offered to patients. The dilemma between providing a service and unnecessarily frightening was also familiar to cardiologists. During one of my visits to the telemedicine unit, one cardiologist told me:

> *You see, it is important not to overtreat, not to overcare. That's the reason why you shouldn't call the patients too often, but I think they're still very happy with the phone contact (fieldnotes, Waldspital, November 9, 2020).*

Although this cardiologist emphasized that patients should not be regularly reminded of their condition, she was aware of the importance of personal contact for patients. In fact, patients appreciated regular feedback on their cardiac monitoring, especially in the first few months after implantation. There was a large discrepancy between patients' expectations and the feedback that was considered appropriate by the tele-nurses and cardiologists. In contrast, some patients considered their perceived arrhythmia to be an urgent matter and expected immediate feedback from the hospital.

6.4 "I would have liked someone to call": Patients' expectation of immediate care

Whereas cardiologists and tele-nurses assumed that patients with a cardiac monitor were not very sick, patients themselves took the continuous monitoring seriously. As a result, they watched over their data transmissions as I have described in the previous chapter. Moreover, patients with noticeable symptoms had the possibility to self-report symptomatic episodes using an app or a remote-control device. Since patients made sure that they were "doing the right thing," that everything was working on their end by meticulously reporting their symptoms, they expected the hospital to take the same diligent care of their data transmissions. Patients took their task of self-reporting symptomatic arrhythmias so seriously that the remote control became their constant companion (Lupton 2016). Some of them came up with ingenious strategies to make sure it was always with them. When I asked Mrs. Bartoli (61 years old, La Clinique) how she made sure she never forgot it, she told me:

> *It's in my handbag. And since I often change my handbag according to the way I'm dressed, well, I automatically take it with me when I change the handbag, or I take the stuff out. It's there and I change it with everything else. Yeah, I rarely forget it. It's kind of like the keys, I always have it.*

It was important for patients to always have the remote control with them in case of a recurrence of their symptoms. For most patients, the symptoms did not occur in a specific pattern (e.g., always during exercise), so patients made sure that the remote control was with them whenever and wherever they might experience the symptoms again. Like the woman quoted above, other patients developed strategies to avoid losing or forgetting the remote control. Mr. Pereira (32 years old, La Clinique) told me that he lost the remote control shortly after receiving it. When he was given another one, he attached a bracelet to it. This was only visible when he took it out of his pocket to show it to me just before I left his apartment after the first interview. Mrs. Rochat (70 years old, La Clinique) pulled her blouse aside during the interview to show me how she had attached the remote control to a strap on her bra. This was her way of making sure that she always had it with her and would not forget it in the pocket of another garment.

Patients made great efforts to help the cardiologists find the suspected arrhythmia by making sure to self-report moments in which they experienced the symptoms in question of diagnosis. Given all of their efforts to be good patients in the context of remote cardiac monitoring, patients also expected the hospital to give them immediate feedback about any irregularities.

Two patients told me during a study interview how they began to question this mode of collaboration when they had marked symptomatic episodes but received no feedback in days after sending their alerts. Mrs. Jeanneret (58 years old, La Clinique), who felt regularly disrupted in her daily life by the sensation of extrasystoles, told me about her disappointment at the lack of feedback:

> *So, I set off alerts precisely because of those [extrasystoles]. And then, well, what annoyed me was, that I never got any feedback. In fact, yes, later [the cardiologist] reassured me by telling me that it was nothing serious. Still, it would have been reassuring for me to be contacted when I sent an alert. Not within an hour, because it is true, it has happened quite often on weekends. After I had been in contact with the other doctor. I often sent off alerts to show how frequently it happened. He told me to do so every time I felt something. So, I did it, but then I did not get any response. I would have liked someone to call to tell me that there was nothing, nothing to report, nothing serious, you see. Just to reassure me. So, afterwards, I asked myself, 'Well, what's the point of having this, if, when setting off an alert, I have no news, no follow-up?' So they actually told me, 'If there's no problem, we won't call you.'*

The lack of feedback was unsettling for Mrs. Jeanneret because she felt left alone with her symptoms. Since her recordings did not show anything serious according to clinical criteria, the hospital staff did not contact her. This illustrates well how tele-nurses and cardiologists rely primarily on what the cardiac monitor records, often completely ignoring whether the alerts are self-reported or not. They focus on the clinical relevance of the heart rhythm pattern and do not contact patients as long as measurements do not deviate from the norm. Patients are contacted only when tele-nurses or cardiologists choose to do so, with these professionals living by the imposed rule of "no news is good news." Thus, there is no follow-up for manually recorded episodes that show no irregularities. However, several patients I interviewed emphasized the importance of such feedback. They often felt cut off from the feedback loop. What the lack of feedback can do to a patient is illustrated by the case of Mrs. Loviat (37 years old, La Clinique), who told me how she reacted when her heart started racing again at home:

> *Mrs. Loviat: It happened in November. I felt, I don't know how to say it, like a buzzing and all that, and I couldn't hear very well anymore. Suddenly I felt like I, I don't know, I couldn't hear what was going on around me. Then it got worse. I basically got hot and then it happened.*
>
> *Sociologist: So, you sat down on the floor or?*
>
> *Mrs. Loviat: Well, fortunately I was at home, but I was over there, and I just managed to hold on to the sofa. So I sat down on the couch. But my heart rate went up so fast that, well, when I felt it start to go up, I took this key. Well, this thing, the remote control, and I told my husband to press the button. So he did.*
>
> *Sociologist: Ah, so he's the one who pressed it? And then it calmed down? Let's say it went back to normal?*
>
> *Mrs. Loviat: Yes, yeah. Well, with every fainting spell. Well, after that I lost consciousness for maybe 10 seconds. And then I regained consciousness.*
>
> *Sociologist: And how does it make you feel that you haven't heard anything? Are you perhaps a little disappointed to have no feedback?*
>
> *Mrs. Loviat: Yeah, it's true that afterwards, when we had activated the system and everything, I had asked myself in the days that followed, whether they had seen it. And my husband said it's not normal. They should react by saying, 'You*

> *have triggered the thing. We're going to analyze it.' And tell me what, well, get feedback on all that.*
>
> *Sociologist: So that would be an expectation that you have to get some feedback, either by phone or by {unfinished sentence}.*
>
> *Mrs. Loviat: Yes, yeah, an email or {unfinished sentence}. Well, just to say, 'We saw that you activated [the device].' Maybe they cannot check it right away, but that they will do what is necessary and keep us updated, because that's what it's all about. For sure, it's more important for them, but we have the right to know, too, especially if they've noticed anything abnormal.*

I showed her my understanding of this difficult situation in which she had fainted and made sure that her heart rhythm was recorded at that moment. However, under the "no news is good news" communication policy, patients must assume that there's nothing wrong with their heart if the hospital doesn't contact them, even if symptoms are present. Ultimately, this can make them question the whole idea of remote cardiac monitoring as shown by the reconsideration of Mrs. Loviat (37 years old, La Clinique):

> *What's the point of having this if we're not up to date? Well, I guess when I have my appointment in May, [the cardiologist] could tell me. I don't know. But I tell myself, 'Yeah, I don't have any news, so I don't think it's too serious. But maybe even for them to find out, to really know what happened, how it happened. Because in the end they just see the data, well, that's it, the cardiac data. They don't really know how it happened, under what circumstances and so on.*

She went on to explain that the reason for getting a cardiac monitor was to understand why she was suddenly fainting without any particular circumstances, such as intense physical efforts. Although her cardiologist had told her that there was not always a medical explanation, it was important for her to know what was wrong with her body. And while Mrs. Loviat was able to reassure herself that her cardiologist would have contacted her if a self-reported episode had indicated a serious problem with her heart, she continued to feel a bit let down by the system. Although I tried to encourage her to clarify the issue and communicate her disappointment to her cardiologist during the interview, she did not dare to do so.

From what patients said in the interviews, the hurdle to contact the hospital was higher at La Clinique than at the Waldspital. Because the latter provided a direct phone number to contact the telemedicine unit, patients at the Waldspital were less reluctant to call and discuss their concerns about remote cardiac monitoring. The direct contact also allowed tele-nurses to reassure patients that their self-reported episodes were completely normal, without patients having to wait for their next appointment with their cardiologists.

In addition to the lack of feedback following self-reported data transmissions, technological hiccups were a major source of uncertainty for patients. Tele-nurses at the Waldspital told me that patients often called them because their transmitters were beeping or flashing in the middle of the night. Laughing with embarrassment, a tele-nurse told me in the interview about the case of a patient who went straight to the emergency room after the transmitter had started flashing during the night. Again, in most cases, the direct phone number of the telemedicine unit at the Waldspital allowed such uncertainties to be resolved in a timely manner.

Mrs. Loviat (37 years old, La Clinique) also told me about another unsettling experience in the second interview. This time, it was of a technical nature. The transmitter beside her bed had started beeping for no explainable reason in the middle of the night:

> *It did some little, how shall I say, unexpected things to me during the night. I don't know. It was so weird. One time it was marked that [the reader] needed to be picked up. I picked it up and put it back on the base station. Then it beeped. And every half hour it would beep. I don't know. It did that to me a couple of times. I had to turn it off and on again. I don't know. And then [the display] flashed in a blue light. I looked it up in the manual, but it was like the display froze. It was so weird.*

She also told me that she didn't dare unplug the transmitter at first. However, the transmitter kept making noises and flashing during the night. Her husband also thought that there must be a technical problem because the display became very strange. Again, she checked the manual several times without finding anything. It took a couple of nights before she finally worked up the courage to unplug and reconnect the transmitter, which finally solved the technical problems. After that, it was as if nothing had ever happened. Still, the experience made Ms. Loviat wonder what had caused the technical problems and whether or not the remote monitoring was still working as it should. She told me that sometimes when she presses the button and sees the little green V on the display, she thinks everything is fine. However, even in this case, she was not contacted by the hospital, nor did she contact the hospital on her own initiative to clarify things. This situation illustrates how such an experience can cause patients to question whether or not there is something wrong with the remote cardiac monitoring setup. Depending on their ability to rationalize such unexplained technical events, patients may be more or less frightened. Again, it is not easy for them to continue to trust technology blindly after such problems when left on their own. How frightening it can be to be awakened by the transmitter suddenly turning on in the middle of the night was also illustrated by this quote of Mr. Fleury (76 years old, La Clinique):

> *The transmitter that sends the data to the hospital turned on one night and woke me up. It's right next to my bed. And it showed me on its little display that I should pick up the reader and put it next to my heart, and then put it back down, and so on. At first, I tried to ignore it because I was still sleepy, but it came on a second time. And then I did what it told me to do. Then I was awake. It really scared me. I wondered what had happened to me. Then I did the steps it told me to do. You know the device, right? (Sociologist nods). Then it turned on a third time, but then I just let it go. I finally said to myself, maybe they are doing an update. I have no idea. Maybe downloading a new version or something. But it was two o'clock in the morning. When I went to see my cardiologist, I said to her, 'Something happened.' She told me, 'Yes, indeed, I can see that. But actually everything was normal.' That incident, you know, made me anxious. For me this thing was frightening.*

Even though Mr. Fleury was very distressed by the unexpected incident of the transmitter turning on in the middle of the night for no apparent reason, his trust was restored by a subsequent event when the cardiologist called him while he was on vacation in France. The following interview excerpt of Mr. Fleury (76 years, La Clinique) details this:

> *Mr. Fleury: We were driving to Avignon when suddenly my wife's phone rang. She recognized the number and said it was the hospital. It was my cardiologist calling and asking her, 'What happened to your husband on Tuesday?' It must*

> *have been Thursday, and they couldn't get in touch with me. You know, in our little village, the cell phone doesn't work, and I hadn't given him my French number. My wife said to him, 'Wait, he's next to me. I'll give him the phone.' In fact, I had a recording of 8 seconds during which my heart was beating wildly. I asked him at what time it happened on Tuesday, and he said two in the afternoon. Then I said, 'But that's strange, because I was taking a nap at two o'clock in the afternoon.' Especially when we are in the south. 'I must have had a nightmare,' I told him. But he said, 'No, no. You had arrhythmias during the nap. Your heart was beating wildly.' It went up to 150, I think, at two o'clock in the afternoon, for seven seconds. So, it works. So, the thing works. The transmission was even made from the device in France. That's good.*
>
> *Sociologist: But didn't you notice anything about this episode?*
>
> *Mr. Fleury: No, no. I didn't notice anything. I was very surprised, but it's possible that it happened while I was sleeping. I don't know. This story has reassured me. I told myself, 'It's not useless because he sees it. That's it.' While this reassured me, the night incident made me anxious.*

Comparing the two incidents illustrates how the reassuring effect of remote cardiac monitoring depends on the system's ability to live up to patient expectations. Moreover, un unsettling experience can be compensated by another which went as expected. This was also the case for Mr. Jansen (65 years old, Waldspital), who complained when he was not informed immediately, and how the second time it went as expected. He described his experiences:

> *The first episode was recorded on October 11, but I didn't receive the [written] report until October 21, when I was asked to see my cardiologist. I had already*

> *called my cardiologist to report the incident. Then she apologized. The next time, my cardiologist called me directly about an episode that had happened the day before. That was the confirmation for me, 'Okay, it can work right away if needed. The first episode probably got stuck somehow. {...} It was probably a unique situation. I work in healthcare myself and I know how it works with accounts and reports. It falls on the staff, who then has to deal with all of that.*

His experience shows that he, like other patients, understands the strained working conditions of hospital staff. However, the idea of being constantly connected to a telemedical monitoring system led to the expectation of individualized care among patients. This contrasts with the daily challenge of triaging and interpreting the data flow faced by tele-nurses in the telemedicine unit. The algorithms of cardiac monitors are sensitive by default to not miss a relevant beat that is out of the normal range. As a result, cardiac monitors record numerous false-positive rhythm patterns and artifacts because the sensors are not directly connected to the heart's nerves but are located above the muscle tissue. Over time, the tele-nurses got to know the cardiac monitor patients better because they were in contact with them by phone. At the same time, patients became familiar with the capabilities and limitations of remote cardiac monitoring.

6.5 Discussion: The ambivalence of immediacy and urgency in algorithm-based telecare

First, the tele-nurse has a central position within the data network of remote cardiac monitoring (see also Chapter 3, Figure 4). Her role is crucial, because data do not speak for themselves, but must be interpreted in relation to the patient’s lifeworld (Gitelman 2013; Grew and Svendsen 2017). Although the data recorded by cardiac monitors are automatically transmitted and synchronized through the telemedical system provided by medical device companies, they need to be further synchronized with other data types, such as the last visit to the hospital, co-morbidities, and/or the actual situation in which the recording was produced. Hence, this chapter suggests that the use of big data technologies for diagnosis increases the need for human synchronization. Synchronizing different temporalities is a crucial feature of "timing" in general (Elias 1992). Unlike traditional doctor appointments, where the simultaneous presence of healthcare professionals, patients and their data are given, these elements must be manually synchronized as they were previously separated. This requires "detective work" as the interviewed tele-nurses called it. However, this did not only include consulting the right documents to gather the relevant information. Far from being a Sherlock Holmes story where it is enough to find and connect the right clues, medical practice is much more often characterized by uncertainty that cannot be resolved (Fox 2000; Groopman 2008). The temporal uncoupling of data collection, transmission, and interpretation also creates a delay between (A) the moment when the cardiac monitor detects and records an arrhythmia, which may or may not be accompanied by noticeable symptoms, (B) the moment when this recording is uploaded into the remote monitoring system, and (C) the moment when the recording is reviewed and interpreted by healthcare professionals. Thought through to the end, this means that even if the data was continuously uploaded via a smartphone, for example, the human review effort to process it in a useful timeframe for timely intervention would be gigantic and certainly very expensive.

Over time, the tele-nurses acquired a fine-tuned knowledge about patient habits, which helped them to faster process false-positive alerts. A way of knowing about the patient to which Piras and Miele (2019) referred to as "digital intimacy." For example, they knew that a certain patient always used his stationary bicycle at a certain time of the day which resulted in an alert of an abnormally high pulse. Consequently, they always dismissed this alert without further examination.

Accordingly, over time, they were able to classify certain transmissions better and more quickly according to name and arrhythmia type. This suggests that a certain form of intimate knowledge is indispensable for medical decision-making. In this way, tele-nurses took a personalized approach to reviewing patient data, but it was their expertise, not the conglomerate of biomedical data (Schleidgen et al. 2013) that helped them improve stratification and timing.

Moreover, the way remote cardiac monitoring is uncoupling the processes of data collection, transmission, and interpretation excludes patients from being involved in the feedback-loop on their data. This privileged access to patient data shifts the knowledge power balance towards healthcare professionals, questioning the promise of the participatory dimension of "personalized medicine" (Erikainen and Chan 2019; Hood 2013).

This was all the more frustrating for some patients, who had understood that all the cardiac monitor would record was a heart rhythm pattern, and who did not receive any feedback on their self-reported symptomatic episodes. However, regardless of data transmissions consisting of an automated or a self-reported recording, what counted for healthcare professionals were the numbers. They only contacted patients if they needed further information to better contextualize a recording or when it showed serious abnormalities. Normal heart rhythm patterns remained uncommented upon. Some patients expressed their disappointment around this, either when they did not receive immediate feedback, or when there has been no feedback at all. Similar to when telephones were introduced to medical practices, remote cardiac monitoring conveys the imaginary of a 24/7 connection between patients and medical institutions (Greene 2022). In contrast to traditional follow-ups during which simultaneity is given by a shared space, the network-like character of algorithm-based telecare can only produce meaningful knowledge if the links between the different types of data are correctly put into sync by humans (Weinberger 2011). However, healthcare professionals still need time to accurately link and interpret the recorded data to produce meaningful knowledge. This gap between the imaginary of a data network in sync allowing for prompt feedback after an alert of an arrhythmia, and the above-described human synchronization work, which takes time, led to what I call an “illusion of immediacy” among patients.

What constituted a normal heart rhythm recording depended on the patient, the suspected arrhythmia in the context of the patient's medical record, and the attending cardiologist. In addition, the perception of how unsuspicious a recording was could change over time, as the section on tele-nurses' uncertainty about the review process showed. The different perceptions of the relevance of a heart rhythm recording were primarily based on different attitudes towards its urgency. Patients considered self-reported symptomatic episodes as very urgent to be reviewed. Yet again, it was impossible for healthcare professionals to know in what type of situation patients used the remote control for self-reporting purposes. The only thing they could learn over time was which patients reported frequently and which ones did so rarely or never, often leading them to believe that those who reported frequently did so for every minor, and probably clinically irrelevant, incident.

Moreover, tele-nurses were the only ones who had an overview of the bigger picture of the patients included in remote cardiac monitoring, which influenced how they reviewed and assessed the alerts over time. The absence of peer-review made them cautious in triaging the alerts, sometimes leading to tensions with cardiologists. Cardiologists relied on the tele-nurses’ fine-grained knowledge for the final medical decision about how to proceed further. The deliberative attitude of healthcare professionals in data interpretation could be described as an in-between strategy composed of quantified and intuitive elements (Zinn 2016).

Ultimately, the different attitude towards immediacy and urgency is based on the individual and professional risk tolerance. This chapter suggest that the lack of contextualization in the case of healthcare professionals and the lack of feedback in the case of patients might lead to higher levels of anxiety and thus lower risk tolerance thresholds pushing them towards overcautious behavior. Thus, remote cardiac monitoring might create favorable conditions for overdiagnosis and overtreatment (Armstrong 2021). Some of these are conditions about which certain cardiologists might be more aware than others. Additionally, the temporal reconfiguration and the division of roles regarding data triage and medical decision making might also impact the role and value of the gut feeling in everyday clinical practice (Kristensen et al. 2021).

Over time, patients' initial fascination for remote cardiac monitoring made room for banalization, disenchantment, and sometimes even suspicion when it couldn't keep up to their expectations. This was especially the case for the lack of (immediate) feedback as this chapter has illustrated. The next chapter will discuss the emergence of this new understanding and show how it impacted the initial reassuring effect remote cardiac monitoring had provided to patients.

7 A long-term connection? Temporalities in doctor-patient relationships

The extent to which remote cardiac monitoring continued to be meaningful to patients over time also depended heavily on whether or not devices could provide the expected diagnosis. This was also because cardiac monitors had been “sold” to them by healthcare professionals and/or company representatives as a way of finally getting a medical explanation for their symptomatic episodes. As a result, the initial reassuring effect that patients felt from remote cardiac monitoring began to wane. As important as this feeling was to them in the early stages, over time they no longer needed such reassurance. If their symptoms did not return, their anxieties and worries disappeared over time as well. For most, remote cardiac monitoring became background noise in their daily lives, or they forgot about it altogether. Some were diagnosed with an arrhythmia and received appropriate treatment. Many who had not received a diagnosis were resigned to the fact that there was nothing wrong with them, at least as far as their heart rhythm was concerned. They learned to live with their symptoms and/or the absence thereof. Nevertheless, they were reminded that they had an implant by intuitive touch, occasional discomfort, keeping their remote control within reach, and regular written reports from the hospital. Time led them to reevaluate the performance and usefulness of remote cardiac monitoring as such. Some even suspected that it was serving the cardiologists more than themselves.

However, some patients and healthcare professionals were challenged when long-term remote monitoring did not yield any results. The main thing that complicated their relationships in the long run, both real-life and digital, resulted from mismatches between patient symptoms and algorithm-based measurements. The two most complicated situations involved patients continuing to experience symptoms with no detections from cardiac monitors and patients being symptom-free with cardiac monitors showing no abnormalities. In both cases, patients started questioning the utility of keeping cardiac monitors in the absence of medically relevant recordings. In both cases, cardiologists usually advocated for making the most of the implant as long as patients were not massively bothered by them. A third possible situation consisted of the algorithm-based assessment producing a lot of false-positive alerts or detect clinically irrelevant arrhythmias without patients noticing them or having any symptoms. This was obviously especially burdensome for tele-nurses. For patients, this may be equivalent to a complete lack of detection, as they were usually not informed of this. In these cases, the data flow became a flood of alerts that needed to be processed by professionals at the hospital. This high amount of irrelevant heart rhythm recordings was also the reason why healthcare professionals were reluctant to give patients full data access to remote cardiac monitoring.

7.1 "It's like a little unobtrusive house pet": The disenchantment with the devices in patients' lives

While many patients were initially fascinated by remote cardiac monitoring, this fascination faded over time. Disillusionment with the lack of timely feedback and random technical hiccups led patients to question the very establishment of remote cardiac monitoring, as described in Chapter 6. Over time, this disenchantment with the capabilities of this diagnostic technology continued. Whether or not patients remained convinced of the value of remote cardiac monitoring depended not only on how well their uncertainties and concerns were addressed by tele-nurses or cardiologists, but also on its ability to detect arrhythmias. Many patients equated good remote cardiac monitoring with a diagnosis for their unexplained symptoms. Failing to do so risked making remote cardiac monitoring less meaningful for patients. This was even more likely to happen when their symptoms had not reappeared. Patients who were being monitored for atrial fibrillation after a stroke were particularly affected by these doubts, as the suspected arrhythmia itself was barely noticeable. Subsequently, the importance of remote cardiac monitoring in patients' daily lives declined significantly between the first and second interview rounds.

Most of the patients for whom nothing was found before the second interview shrugged, when I asked them during my second interview with them, how they lived with the cardiac monitor. They told me that they went about their normal daily lives as they did before receiving a cardiac monitor. They usually told me that they had completely forgotten that they had an implant. It was rather my question about the device that reminded them that they had one. Sometimes patients intuitively touched the insertion site, as they had done during the first round of interviews. The quote of Mr. Regensburger (72 years old, Waldspital) illustrates how having a cardiac monitor had become trivial to most patients:

> *I don't really think about it. Now and then, I feel it somehow. When I somehow {unfinished sentence}. (Touches the insertion spot with his fingers). But that's just it. It doesn't bother me at all.*

He explained that he usually felt something under his skin when applying soap in the shower but otherwise forgot about it. However, for other patients, remote cardiac monitoring was more noticeable in their daily lives for a variety of reasons. For example, always having to carry remote controls in order to self-report potential symptomatic episodes became burdensome for some patients over time. Initially, they wanted to make sure to always carry them around to be able to self-report at any time. However, when their self-reported episodes remained inconclusive, and no arrhythmias were otherwise detected, patients began to resent the task of self-reporting. Mrs. Rochat (70 years old, La Clinique), who had developed the habit of attaching the remote control to one of her bra straps told me during the second interview that it was starting to bother her. The following excerpt shows our discussion after I asked her to summarize what had happened since our first interview.

> *Mrs. Rochat: At the doctor's office, well, everything was normal. The only thing that bothers me is that I have to {unfinished sentence}. I put it here, you know, my tool (shows remote control attached to a strap of her bra). I tried to put it in my pockets, but I forget. I have no idea what distance I should always keep it, so I put it here. But it's becoming a nuisance. Now it will be a year. And after a year, if nothing has happened, it's not worth keeping it.*
>
> *Sociologist: Well, no. You can keep it, but there are two things: the implant and this little remote control. Normally you don't need to have the remote control near you. Well, it's just to mark an episode.*
>
> *Mrs. Rochat: If I need to press it, it has to be close enough to me, but otherwise I don't need it.*
>
> *Sociologist: That's right, but in general, if the rhythm is abnormal, the device will be able to record it without your help. Actually, the remote control is more for when you have symptoms. And then {unfinished sentence}.*
>
> *Mrs. Rochat: Yes, but if I don't have any symptoms, the important thing is that I know where it is. But not that it's always with me, right?*
>
> *Sociologist: Yes, I think so.*

> *Mrs. Rochat: I'm going to check with the cardiologist because it's eating me up inside. For example, where I live, there are two floors. So at 7 o'clock I put on my nightgown and everything, and then I have my bathrobe. And I put it in the pocket of the robe, and then I lost it. Because the robe pocket is not like a pair of jeans, it fell into the chair. So, I felt bad because I lost it. Where was it? And so on and so forth. So if I could leave it near the box, that would be fine with me. But I'll check with the cardiologist because it's annoying to have it all the time. It doesn't bother me as such, you know. But thinking about putting it on, thinking about taking it off, it's really about that. And then when it's been a year and nothing's happened? Well, I pressed it twice. One time I was in pain, so I pressed the button. They told me there was nothing there. So what's the point? They still cannot see anything.*

This exchange with Mrs. Rochat shows how she still wanted to be able to self-report a symptomatic episode. Yet, always remembering to have the remote control with her began to irritate her, especially because she saw no worth in keeping it if it did not yield any results. Again, it became my role to try and explain to her that it was no big deal if she forgot to have the remote control with her from time to time. However, she continued to perceive it as important to be able to immediately report potential symptoms. Thus, she wanted to make sure she always knew where to find her remote control.

Unlike cardiac monitors, which are mostly invisible to outsiders, the associated remote control might make others wonder why someone is always carrying it around. This visibility and the unpleasant experiences with carrying the remote control around started bothering Mr. Gaillard (45 years old, La Clinique) over time. The following interview excerpt shows this.

Mr. Gaillard: At first, I was surprised that there was no way to trigger a recording from a smartphone, for example. Because it's true that, well, the remote control, it's a kind of garage remote. You always have to have it with you, but you might forget it. And when you have it with you, people always ask questions. They wonder why you are walking around with a remote control. So, in the beginning, when I didn't want to talk about it too much, I told them it was my garage remote. But then people kept asking me questions, even making fun of me. I had a colleague who said to me, 'But why are you always walking around with your garage remote?' Later I explained it to them. I told them it wasn't a garage remote. After that, I stopped taking it with me for that reason. You know, everyone has their smartphone at hand all the time or not far away. It's true that it might have been a bit more convenient to have that instead of a remote control. But otherwise, I had a very good experience with it.

Sociologist: It was the only kind of visibility.

Mr. Gaillard: Yes, exactly. In fact, one time, I remember it very well, it was right at the beginning, and it really bothered me. I was in a restaurant with my wife and some friends, and I had put the remote control on the table. Someone came up to me in the restaurant. It was someone who worked at Medtronic [a medical device company]. He came up to me and said, 'Ah, I see you have this. May I ask you what kind of device you have implanted?' And so on. I thought it was so inappropriate. I thought it was crazy. It really bothered me. He really came without being, well, he was polite and all that, but I wondered how he could think it was going to be okay. It was a nuisance. In the context of a pathology,

> *you don't feel like talking to strangers at the table between cheese and dessert to tell them what model you have implanted. I thought it was totally inappropriate. So, I ended the conversation with this man. It was one of the rare times when I said to myself, 'Well, the remote control, at the end of the day, even though most people would think of a garage remote, there are people who know very well what it is.' I don't want that to be known, so I'm going to hide it rather than show it.*

In the end, the company employee apologized to Mr. Gaillard before leaving him to finish his meal. Newer generations of remote cardiac monitoring technologies allow for self-reporting via smartphone applications. This would better respect patient privacy rights by allowing them to more easily choose whether or not to make their patient identity public. Furthermore, it illustrates the context-dependency of "what a technology means and how it is used (or not!)" (Oudshoorn 2011:205). In addition, medical device companies continue to develop smartphone applications that would perform all phases of remote cardiac monitoring. Their goal is to integrate all data transmission and patient self-reporting into a single patient smartphone application. However, this endeavor remains challenging. Current efforts are limited to specific smartphone models due to data security issues. Generally, the oldest and newest models, as well as certain brands are not supported. In addition, each country's privacy laws make it difficult to implement the same patient application internationally. Finally, my observations in the field show that patients are much more reluctant to accept data transfer via a smartphone application than via an external device. When given the choice, most of them preferred to have a transmitter plugged in next to their bed rather than an application. In fact, many people told me that they thought it was far too risky to install a data transfer application on their smartphone. They thought it was way more vulnerable to data leakage than a separate device designed for that purpose. Mrs. Emery (29 years old, La Clinique), who had a smartphone application instead of a remote control to self-report her symptomatic episodes, admitted in the second interview that she had never used it and couldn't tell me exactly how it worked. She spontaneously pulled out her smartphone to show me. However, she needed to install the latest update because she hadn't used the app in several months. It was only my question that prompted her to explore the app further. This illustrates that even replacing the remote control with an app will not necessarily get patients to adhere to self-reporting, as it is less a question of technology and more a question of individual risk assessment.

Although patients began to question the importance of always having the remote control with them, a few patients also mentioned how their cardiac monitor insertion sites would sometimes hurt out of the blue for no apparent reason. Such sudden pain or discomfort was another reason why some patients found it difficult to entirely forget about remote cardiac monitoring. Mrs. Loviat (37 years old, La Clinique), for example, told me that it always happened when she was at rest, but that she would not describe it as painful. Rather, she described it as a sensation of the implant rubbing against the internal tissues. She told me that the sensation did not bother her *per se*, but it was like a reminder that she had a foreign body implanted. Mrs. Jeanneret (58 years old, La Clinique) had a similar feeling. She added that she could tolerate it and had gotten used to it, but that these prickly sensations would always remind her that she had a cardiac monitor. She also felt the monitor when she made certain movements or touched the implant site. Mrs. Emery (29 years old, La Clinique) did not really feel bothered by the implant itself but mentioned that a sudden, unexpected blow to her breast made her aware of the implant, which brought her to worry that it might be damaged:

> *I'm thin, [the cardiac monitor] is visible, it's perhaps a little more exposed or I don't know. Sometimes, when I'm doing sports, I might have doubts such as, 'Oh*

> *yes, I could break the antenna.' But it's not something that I think about a lot, I would say. It's more like if I really get a shock at some point, I'm like, 'Oh damn, is it broken?' But it's not something that really affects me.*

Even though most of the patients did not regularly think about having a cardiac monitor at all, there were still uncomfortable moments when they were reminded of it. Mr. Weber, whose implant had caused him pain from the beginning, continued to feel some pain around the insertion site. No arrhythmia had been detected by the time of the second interview. Although he had accepted the pain as a necessary evil, I asked him if he had considered removing the cardiac monitor before the battery died. Mr. Weber (60 years old, Waldspital) explained:

> *Well, yes, maybe (seems undecided). If the pressure of suffering is great enough. But right now I think I'm going to keep it until a year from now when I have my next appointment. And then I might say, 'If they haven't found anything in a year and a half or two years, then I can check it off.' At some point you have to. Life is life-threatening.*

Although the cardiac monitor continued to cause Mr. Weber pain, he preferred to keep it for at least the next few months until his next medical follow-up concerning his previous strokes. However, he was aware that the cardiac monitor did not guarantee absolute safety, knowing that life itself was not without risk, as he had wryly pointed out. His comments illustrate how patients began to accept that medicine could not explain some events or symptoms and that they had to move on. This acceptance became even greater at the moment of the cardiac monitor removal and will be discussed further in the next chapter.

During the second round of interviews, most patients continued to be driven by uncertainty about cardiac monitors' ability to detect anything in the future. However, the initial reassurance that was present in the first few weeks of remote cardiac monitoring diminished over time. Both patients in the longitudinal and post-removal interviews described a fading reassuring effect over time, regardless of how much they had initially hoped that the new configuration would bring answers and more certainty. How quickly and how strongly this feeling of being cared for diminished was related to individual experience with the setup, outcomes of remote cardiac monitoring, and symptom evolution. As a result, patients were sometimes torn between the continued need for reassurance in an uncertain situation and the general banalization of the technology of remote cardiac monitoring over time. This is illustrated by the example of Mrs. Christen (68 years old, Waldspital), who, when asked during the second interview if the reassuring feeling was still as present as it was during our first interview, responded as follows:

> *Yes, that's a good question. I was thinking about that today. I thought you would ask me that (both laugh). It's true I have said in the beginning, 'Now, I'm totally monitored.' It also gives me a good feeling. Yes, it's still a bit there in the sense of which I've talked about before. If I had [another stroke] now, maybe I'd see it differently. Or maybe there's something [like an arrhythmia] that I don't know about. In fact, that's probably what is preventing me from having [the cardiac monitor] taken out.*

The unpredictable and not always noticeable nature of arrhythmias prevented Mrs. Christen from having the cardiac monitor removed before the battery died. In addition, this quote shows that the feeling of being closely monitored had not completely disappeared but had changed over time. Instead of feeling constantly cared for, her perception of the cardiac monitor was reduced to the hope that it could provide additional information in the event of another stroke. The awareness that she was living with some residual risk of another stroke, and that the cardiac monitor might still be useful in that case, was the deciding factor to not have it removed.

While most patients were still more or less convinced of the benefits of remote cardiac monitoring during the second interview, a few told me that they would decide against the insertion of the cardiac monitor in hindsight. This was the case, for example, with Mrs. Hasler, who had decided to accept remote cardiac monitoring at the advice of her cardiologist. Interestingly, I had already noticed during ethnographic observations in the hospital that she had questioned the intervention because she considered herself to be too old at the age of 82. She had told the nurse how she had raised this issue with her cardiologist, but the cardiologist did not accept her objection, telling her that women today can live to be 90. In the second interview, she again explained why she had been advised to have a cardiac monitor after several fainting spells. The following is an excerpt from my exchange with Mrs. Hasler (82 years old, Waldspital) on this subject:

> *Mrs. Hasler: I had these collapses. Like blackouts. It always happened to me in restaurants, strangely enough. After eating, I would just faint. Then they examined and looked at everything, but in the end, they couldn't find anything. And then they recommended this. But if I'm honest today, I don't think I needed it. I didn't need it. Absolutely not (shrugs). But, well, they just thought that since I was living on my own, it might be necessary. It was nice for them that I had something.*
>
> *Sociologist: Well, okay, but it still doesn't work like an emergency call. It's just {unfinished sentence}.*

> *Mrs. Hasler: It's not an emergency call. There's just an alarm afterwards, somehow. Now I have a device on the bedside table that I have plugged in. And I have one in my handbag that I need to activate. I don't think I will ever need that.*
>
> *Sociologist: So, until now, you have never used it?*
>
> *Mrs. Hasler: Never. No. So, it wasn't really necessary. But at the time, the doctor just said that even if nothing was found, we should maybe do it anyway. But we could have left it out in the first place. You're always wiser in hindsight. I probably should have said at the time, 'Well, I don't need this.' But anyway.*

In retrospect, this patient can no longer see why a cardiac monitor is of interest to her. This conversation developed after she showed me some of the three-month reports that had been sent to her from the Waldspital, indicating that no arrhythmia had been detected during that period (for an example report, see appendix A). However, each report was accompanied by a bill for approximately CHF 130 (~143 USD; 1 USD=0.91 CHF as of December 31, 2022). Although the Swiss basic health insurance covers most of the costs, there is a 10% personal contribution (up to a maximum of CHF 700 per legal year; ~769 USD) that must be paid out of pocket, in addition to the co-payment that must first be paid (ranging from 300-2,500 CHF/year; ~330-2,747 USD). For someone with a lower socioeconomic profile, it is not surprising that this patient had little desire to pay this amount every three months for a technology that she considered useless.

While the second round of interviews remained a specific moment in the patients' trajectories, the post-removal interviews allowed me to ask patients more specifically about how they remembered the gradual process by which the cardiac monitor became less important in their daily lives. Mr. Aubert described how he gradually became less concerned about remote cardiac monitoring as we discussed the reassuring effect of the cardiac monitor. He explained to me how the remote cardiac monitoring and the remote control had been an integral part of his life at first, but had slowly and quietly become less important over time. The following exchange with Mr. Aubert (67 years old, La Clinique) illustrates this process:

> *Mr. Aubert: Let's say, to simplify things, that I kept [the cardiac monitor] for three years. The first two years, I had my remote control with me like my keys, all the time in my pocket, in my jacket, or on my bike in my jersey, that comes with a pocket. All the time. It was something that was an integral part of me. I wouldn't have been able to get around, to go anywhere without it. And then, at some point, in the third year, I didn't even know where [the remote control] was anymore. I had to look for it, when I had to go back [to the hospital] to take [the cardiac monitor] out, because I had already moved on.*
>
> *Sociologist: Okay. Was there a particular moment that made you move on or was it a bit of a fluid process?*
>
> *Mr. Aubert: No, there was no {unfinished sentence}. For me, it was my feeling. I felt so good, so fit. Gradually, one or two times, it started. I forgot [the remote control] once, and then I thought, 'Never mind. I'm not going to go back and look for it.' And then I thought about it less and less, and then it went out of my life. The remote control, not the cardiac monitor, because I still had that with me. It reminded me that there was something there.*

The example of this post-removal interview illustrates how the patient wanted to make sure during the first two years that he would be able to self-report a symptomatic episode whenever and wherever he was. However, after forgetting to take the remote control with him once or twice, he began to reevaluate his body awareness. Since he felt like he was in good shape, he stopped taking it with him. However, the cardiac monitor under his skin continued to remind him that he had once had an episode of arrhythmia while cycling.

For Mr. Gerber (59 years old, La Clinique), the banalization of remote cardiac monitoring was also associated with regaining body confidence, but additionally with the realization that the technology did not keep up with his initial expectations. We discussed this issue during the post-removal interview:

> *Mr. Gerber: In the beginning, I held on to [the cardiac monitor] a lot, mostly to reassure myself. And in the end, you know, I think I became a little bit more objective. Maybe I had less anxieties, and it automatically lost a little bit of importance. In retrospect, I think now that I have the confirmation that it's not being followed up as much as I would have hoped. I mean, this device isn't a lifesaver.*
>
> *Sociologist: Yeah, that's true. And I also understand that sometimes it can be difficult to have a device that is, as they say, diagnostic.*
>
> *Mr. Gerber: Yeah, at first, I thought, 'Hey, you know, I'm permanently connected to the hospital.' I'd joke about it a little bit. On the other hand, I would say to myself, 'It's a little bit scary. It's a little bit weird.' And finally, as I went along, I realized that it was actually not as... invasive into my privacy and my everyday life as I had thought at first. But then it automatically lost a lot of its high-tech aspects. At the same time, it became a little less important.*

> *Sociologist: Are you a little disappointed? Can we say that? Are you a little disappointed with the device?*
>
> *Mr. Gerber: No, I'm not disappointed, but I would say that if somebody were to talk to me about it now in retrospect, I would say, 'Yeah, it's nice, but it's not going to determine whether you should or not make a decision. And it's not going to stop the arrhythmia. And I don't think it's something that's going to make it easier to accept surgery. It's not the trigger to say, 'Yes, I'm going to have the surgery.' It was really my own feeling and the experience of these arrhythmias that were not stopping and were still affecting my quality of life a little bit that made me decide in the end. The device had no effect.*

Although the system initially gave him the reassurance he needed, his attitude changed over time. The cardiac monitor became so much less important that it no longer played a role in his decision for or against cardiac ablation. Moreover, Mr. Gerber (59 years old, La Clinique) initially feared being under continuous monitoring. His fear turned out to be not supported by reality, as the following metaphor he employed demonstrates. He explained, "In the end, it became a little, very uninteresting buddy. Well, it's like a little unobtrusive house pet. But I could also live without it."

Over time, remote cardiac monitoring gradually lost its initial magic, its reassuring effect, and sometimes even its meaning for patients. For some of them, this development led patients to question if cardiologists were more interested in reassuring themselves with data or scientific findings than in their own well-being as patients.

7.2 “What am I, a guinea pig?”: Patients’ suspicions about the actual purpose of remote cardiac monitoring

For both cardiologists and patients, remote cardiac monitoring was a convenient and reassuring technology, as described in Chapter 5. Nevertheless, patients were initially convinced that their cardiologists were recommending remote cardiac monitoring with the best of intentions to finally find out what was wrong with them. If the hoped-for answer did not materialize over time, or if patients did not feel sufficiently involved in the feedback loop, this conviction was challenged and eventually took on a sour taste. For example, Mr. Weber had disagreed from the beginning with his doctors who suspected that atrial fibrillation had caused his three strokes. He felt that his suspicions were confirmed when the cardiac monitoring failed to produce any conclusive results. We discussed this as Mr. Weber (60 years old, Waldspital) referred to his most recent appointment with his doctors:

> *Mr. Weber: They said, ‘Nothing has been seen yet.’ From that point of view, [the cardiac monitor] could be removed, but it’s just the way it is. They’re waiting. It could be that... It’s still unclear why it happened and how it happened.*
>
> *Sociologist: But am I right in thinking that this bothers you a little less than it does the doctors? Or is that not quite right?*
>
> *Mr. Weber: (clears throat) Yes, yes, that’s true (both laugh). I take it relatively easy. It’s clear that an incident makes the doctor always ask, ‘Where did it come from? Why did it happen?’ That’s for sure the right thing to do. I let him take care of it. Then I don’t have to. {...} It’s like a car. The windshield is much bigger than the rearview mirror. You have to look forward.*

His perspective illustrates that finding the cause of his strokes was less important to him than it was for his doctors. What was important for Mr. Weber was to look forward and let the past remain in the past. Mr. Fontana also questioned the actual benefit of the cardiac monitor in hindsight. During the post-removal interview, he told me of his ambivalent feelings about the fact that his heart rhythm was being monitored continuously, but that it was still up to him to respond in case of an emergency. Mr. Fontana (53 years old, Waldspital) elaborated on this:

> *I could have said I didn't want it. Then the matter would have been settled. But they recommended it and I think it was good. They know what's going on, so from that point of view it's okay. If there was something, I'm sure they would have contacted me. But if something was going on, I would have called them first and said, 'Do something!' I mean, I would feel it in my own body. I'm not sure what they're hoping for. Well, maybe they see what's going on. I don't know.*

For many patients, it was this reprioritization of what they felt versus what the cardiac monitor could detect that led them to question the purpose of remote cardiac monitoring. Mr. Fleury told me how he had regained confidence that nothing would happen to him. Since he had not had an episode in six months, the matter was settled for him. This led Mr. Fleury (76 years old, La Clinique) to tell me that the cardiac monitor was implanted more for the doctor's benefit than for his own:

> *I completely forgot about it. You know, I never take my remote control with me, because if something happens to me, if I feel something, even now I'm really sure that – well, you can never be sure, but – that nothing will happen to me. This device was implanted to satisfy the doctor. It was a condition for me to get my driver's license back. And I got my license back because I had nothing for 6*

> *months. Well, there was just this little malaise one morning that had no consequences, that's all.*

In the absence of worrisome symptoms of unexplained origin, most patients' lives returned to normal. As such, their anxiety about another event and their need for reassurance diminished over time. Mr. Gerber, who described the cardiac monitor as an unobtrusive household pet in the previous section, mentioned again at another point in the interview that his feeling was the decisive factor in the final medical decision. On the other hand, he stated that the cardiac monitor was primarily reassuring and suggested that its real use was for the hospital's scientific research. Mr. Gerber (59 years old, La Clinique) explained this idea:

> *Yes, perhaps it was reassuring to know that 'big brother is watching you.' There's someone taking care of you. On the other hand, I found it kind of intrusive. I'm a little bit under surveillance. They might always know where I am or things like that. Maybe that's the negative side of it, but otherwise, it's rather reassuring to know that if things get worse, someone somewhere will get an alarm that's going to go off. After a while, I felt it a little less. That means it's less annoying. You suddenly manage to deal with it. You may not even notice that you have these arrhythmias or atrial fibrillation. And that's reassuring. And when we realized it, when the professor realized it, and I realized it too, that it didn't stop despite the beta blocker that I was taking every day and that I didn't want to die with that going on. I was already a bit fed up with the anticoagulant I had to take because of the transient ischemic attack [a mini-stroke]. And that's why I decided to have the surgery. But the device itself, I think it was probably more to collect scientific data for the hospital than it was really useful for me. Other*

> *than that, it was a little reassuring for me. There are people who watch it, who can see it from a distance.*

Although Mr. Gerber seemed more concerned about the continuous monitoring in general than about the possibility that his data might be used for scientific purposes without his knowledge, I was struck by the fact that two other patients expressed similar suspicions without my asking. It came up a lot when we talked about the lack of feedback, which is inextricably linked to the feeling of being cared for with good intentions. When I asked Mrs. Jeanneret (58 years old, La Clinique) to what extent she still felt reassured, she told me about the following during the second interview:

> *Well, I tell myself, 'If they insert a device like that, well, it must also go both ways.' Later, I even wondered, 'I don't know. What am I, a guinea pig? Are they doing a test on me?' I kind of wondered about that.*

In addition to becoming suspicious about the real purpose of remote cardiac monitoring, Mrs. Jeanneret was also disappointed that the system focused on information flowing from patients to the hospital, rather than the other way around. The assumption that remote cardiac monitoring had been proposed to them for scientific rather than medical reasons was sometimes also voiced behind closed doors. In one interview with a patient, I was ordered to turn off the audio recorder when we began discussing the purpose of remote cardiac monitoring. I understood that this patient didn't want cardiologists to know that he or she would have liked to receive a different medical procedure and got the cardiac monitor despite this reluctance. It is noteworthy that I did not have any observations of reluctance on the part of this patient at the time of insertion.

Overall, remote cardiac monitoring is a black box for patients. They have no access to the nature and date of their data transmissions, nor to their medical interpretation. This brought them to speculate about the real use of the technology. Although the cardiac monitor follows the patient home, it preserves the expert position of healthcare professionals who have privileged access to data transmissions. Despite many patients mentioning in the interviews that they would like to have access to their data transmissions or regular feedback from the hospital, cardiologists were reluctant to change their professional practices in this regard.

7.3 “We don’t treat the ECG, we treat the person”: The general challenge of screening technologies

Cardiologists were reluctant to contact patients after receiving data transmissions and only did so when they needed more contextual information to interpret data or when patients needed to be treated following arrhythmia detection (see Chapter 6). However, this mode of operation was disappointing to most patients, who expected to be updated immediately with each data transmission, knowing that their heart was being continuously monitored. Both cardiologists and company representatives were very critical of giving patients direct access to their data. Although both types of actors justified their stance with the inaccuracy of data transmission, their explanations differed slightly. Cardiologists feared that patients would not be able to sort out the data transmissions, for example, if they received too many red-flag alerts that did not match how they were feeling at the time. One cardiologist explained this:

> *It makes little sense for the patient to have access to such data. He or she cannot interpret them. It’s more likely to make them feel insecure and raise questions. {…} Also, the diagnostic tool as it is will probably be used less well. The patient will no longer trust the information he or she gets. For example, if a big red light appears for the fifth time in a row, even though the patient is perfectly happy*

> *reading the newspaper and having a good life. When it comes up the sixth time, he or she will think, 'What a load of crap! Let's drop the whole thing' (Smiles).*

This cardiologist thought that too much information, and especially false-positive alerts, would cause patients to lose confidence in remote cardiac monitoring. This is an intriguing assumption, as I have previously shown that the opposite - no or too little feedback - has exactly the effect that cardiologists feared from providing such data, causing patients to lose confidence in remote cardiac monitoring. In any case, according to the few interviews I was able to conduct with company representatives, they were not ready to give patients access to all data generated in remote cardiac monitoring. One marketing manager explained this to me:

> *We're not at the point yet, where we're showing the patients all the data that's coming through. I think that would be a vision for the future. When the devices are truly, you know, very, you know, a 100% accurate.*

Although she did not specifically mention it, her statement might imply that the need for accuracy could also be linked to legal issues in healthcare, in particular liability in case something goes wrong. Moreover, shortly before we discussed patient data access and personalized care, she made no secret of the fact that *specificity* is the toughest nut to crack in cardiac rhythm management:

> *The sensitivity isn't hard. The specificity is hard. So, this idea of, you know, not sending false readings or false-positives. So, you know, it's like we can send a lot. We can record a lot. Easily. The challenging part is to record only the true episodes. Because, you know, the device isn't 100% accurate, 100% specific. And so that's where we're working on. Like I said, we're doing everything we can with the algorithms. I mean, you know, making them more specific.*

Given the various technical and contextual hiccups I observed during my fieldwork, the chances of remote cardiac monitoring one day becoming 100% specific are very low. This assessment was shared by a cardiologist who shared during an interview that there is not yet an algorithm that can do the job of data triage and interpretation. According to him, there has not been much progress in this area in the last decade:

> *The algorithms contained in the implantable devices have made great progress. Especially with regard to atrial arrhythmias, such as atrial fibrillation. The devices have made great progress in detecting these. Then, on the level of transmission from the device to the transmitter and how it continues afterwards, I have seen little progress in the last few years. Maybe I'm not close enough to the matter, but for me it's still the same 'garbage' [original term] that comes out of it that it was 10 years ago.*

In addition to the challenge of dealing with false-positives and artifacts, continuous screening technologies are also prone to incidental findings. When I mentioned the risk of overtreatment with continuous monitoring, the following cardiologist explained how he deals with incidental findings:

> *That's always the problem with screening. You have incidental findings that you have to draw conclusions from, and you are not sure if that is necessary or in the best interest of the patient. Yet you're faced with findings that you can't ignore. You must discuss them and take action to the best of your ability. This's also the case with screening for other things, that you always have some background noise. But we're already aware of the fact that it's a random finding that we don't value in the same way that we would if it was a finding that we suspected in*

> *someone for some reason. So, we are more cautious in our actions. But sometimes you still have to take it into account, and there's a certain uncertainty that you might be doing too much, yes.*

The mere fact that the heart rhythm was continuously monitored for three or more years increased the likelihood of incidental findings. Moreover, the likelihood of finding an unanticipated arrhythmia increases with the age of the patient, the cardiologists confirmed. As a result, cardiologists have to carefully weigh "which numbers to respect and which to discount" (Groopman 2008:150). At a later point in the interview with the same cardiologist who told me about the uncertainty of doing too much in the quote above, he told me how the entire team involved in remote cardiac monitoring had to learn to deal with the fact that continuous monitoring produced an increased number of clinically relevant alerts that would not have been detected otherwise. It was a learning process for them over the years to know which numbers to give more weight than others. I asked this cardiologist if he thought algorithmic technologies would change clinical practice. The following is an excerpt of this discussion:

> *Cardiologist: Since we started using telemedicine, we are seeing a lot more arrhythmias in patients. Some of them are short episodes that haven't yet had any consequences. In the beginning, we had to learn that we don't have to inform the patients every time or call them because it makes them anxious. Instead, we have to find a balance between what's really relevant, what we need to act on, and what we see in addition to what we didn't see before, and what didn't have any bad consequences before without our intervention. So you have to be aware that you see episodes earlier and you see them more often or you are*

> *informed about them. And that we don't have to set the same standards as we do with the conventional model. That was something [we had to learn], yes.*
>
> *Sociologist: You just said you had to learn it. So did you sort of {unfinished sentence}?*
>
> *Cardiologist: Well, the whole team had to learn, you know, that we should not upset patients unnecessarily. Also, that we have to make the right decision about when to react and when not to react. We have to be aware of the patient's psyche so that we don't scare them too much. And not to remind them too often that they [might] have a disease, you know.*

This account illustrates how he and his team had to learn to measure the results of continuous monitoring differently than by using conventional methods. Once again, it was the overall context that set the tone for how the cardiologists dealt with the findings. His colleague summed it up nicely when she said, "We don't treat the ECG, we treat the person." She told me further during an interview that, as a cardiologist, she could not lose sight of the big picture in her search for the cause of a patient's suffering. In her opinion, the temptation to give patients the runaround is also due to the universe of a highly specialized university hospital, which potentially offers a remedy for every ailment. In particular, this cardiologist was critical of extensive diagnostic testing of the elderly:

> *I have a hard time with too many measurements at the end of life. It's better to let people drink a coffee in peace than to measure I don't know how many parameters.*

Furthermore, she added that cardiologists should pay attention to not over-medicalize their patients' suffering as this would prevent them from leading a normal life. In her experience, the insertion of cardiac monitors often led to an increased patient awareness of their heart rhythms:

> *We really have to be careful that we don't turn people into heart neurotics or heart phobics. That's why I always say, 'Hands off the pulse!' (She presses her index finger against her wrist artery) It's important that patients don't check themselves all the time.*

She continued by explaining that most patients are worried at first. However, if they did not hear from the hospital for a year because nothing was found, their anxiety would fade and give way to the belief that it was good that nothing was found. Contrary to what she thought, I could show that this evolution did not happen as linear and smoothly for all patients. However, discrepancies between what patients can feel and what the two electrodes of the cardiac monitor can detect is key for this issue. There are arrhythmias that undoubtedly require clinical treatment but are not noticed by patients. At the same time, there are arrhythmias that patients can experience and actually feel in their bodies but that do not require medical treatment. When asked about this difference between discrepancy, a cardiologist explained:

> *We always have that in rhythmology. Completely independent of the cardiac monitor or telemedicine. This can also happen with a long-term electrocardiogram. It's not always easy to get patients to understand that the objective reality is not necessarily the subjective reality. That's a problem that we have in general in doctor-patient communication. These are things that are difficult to resolve over the phone, you know. You need the trust to see each other face-to-face. To look at something together on a heart model, to study it,*

> *to have a little time out to think about it, etcetera. I prefer to do it that way. You cannot try to solve it on a technical basis over the phone.*

If the patient's perception and the data did not match, the best course of action, according to this cardiologist, was to schedule an appointment and discuss the issue in person. However, the tele-nurses also played a key role in solving the everyday challenges posed by remote cardiac monitoring.

7.4 “For them it’s bad”: Care in the absence of diagnosis

By regularly reviewing data transmissions and being at the forefront of contextualizing data or clarifying patients’ ambiguities, tele-nurses had privileged and intimate access to patients’ everyday lives. While tele-nurses got to know their patients over time, some patients, in turn, needed to learn that not every offbeat heart rhythm is life-threatening as described in previous sections. Because both hospitals used the “no news is good news” approach for patient communication, patients had to actively seek out explanations. It could be especially unsettling for them when they felt their heartbeat getting out of sync but did not hear back from the hospital in the following days, as described in Chapter 6. When I asked tele-nurses about the main reasons why patients called the telemedicine unit, they told me that it is mostly to get reassurance, either because of a technical glitch with the equipment or because they had experienced an unusual heart rhythm.

In the Waldspital, where patients could directly call the telemedicine unit, it was also the task of tele-nurses to contextualize the absence of findings to patients. During interviews, these nurses explained how they received phone calls from dissatisfied patients at the telemedicine unit who complained about professionals having “not yet seen anything,” but that their services regularly cost them money. This was especially challenging when patients continued to suffer from symptoms. Tele-nurses tried to explain to patients what was possible for them to see and what they could not see. Oftentimes, patients could have inflated expectations that led to disappointment or annoyance over time. One tele-nurse explained:

> *I think that in the beginning, people's expectations are much, much higher, especially with the cardiac monitor. People have the feeling that they're receiving something that will solve all their problems. As time goes by, they realize that they still have the same problems, but we didn't find anything. These people can become a little bit annoyed over time.*

Depending on whether or not tele-nurses are able to reassure patients over the phone, they might propose that patients schedule a consultation with the cardiologist for a check-up and discuss early removal of the cardiac monitor. Nevertheless, in many cases remote cardiac monitoring only ended once the battery of the cardiac monitor was dead. Cardiologists, and oftentimes patients as well, adhered to a risk-minimizing medical approach of keeping the cardiac monitor as long as possible, because 'one never knows.' Thus, cardiologists encouraged patients to not remove cardiac monitors before their batteries ran out.

Some patients used the Waldspital direct number more often than others. One tele-nurse told me that sometimes patients were just happy to have someone to talk to. They knew that the phone number connected them directly to the telemedicine unit, as opposed to a general phone number for a hospital department. With a sigh, another tele-nurse explained during an interview that the telemedicine unit sometimes degenerates into a general help desk for all kinds of medical problems. Other patients just wanted to get the latest news and see if everything was working as it should. Some also asked if the tele-nurses had observed anything that might explain what they had felt earlier in the day, before their call. This was especially true for certain types of patients who were enrolled in remote cardiac monitoring to check if the abnormalities they felt were clinically relevant. The following exchange between a tele-nurse and me provides insight into this:

> *Tele-nurse: Certain people always feel something that just bothers them and they suffer from it. They feel something again and again, so we try to find out what it is they feel. Is it something bad. Because it feels bad for them, you know. It may be that somebody is experiencing extrasystoles all the time. We have people like that. Every time they call again and it's always the same. These are just extra beats that they feel. And for them, well, they are just frightened because they don't know what it is.*
>
> *Sociologist: So how do you calm them down?*
>
> *Tele-nurse: Yeah, sometimes it's not that easy. We might call them in for a consultation to discuss it together. To tell them that it's nothing dramatic. They just feel it, but maybe they can learn to live with it. These are also the people who call us again and again. But they have our phone number, and they can ask anytime. And then we tell them every time that it's still the same, that it's nothing bad. And with the cardiac monitor, they still have the remote control that they can take with them wherever they go. When they're walking and they feel exactly what they want to show us, they can press it and we can check what they felt. Sometimes it's nothing and sometimes it's something.*

As the interview continued, I asked the tele-nurse if she could estimate how many patients would end up getting a diagnosis and how many would not. She told me that she was not able to answer that question because the rate of diagnosis was completely random. Throughout the monitoring period, sometimes they would find one arrhythmia episode, sometimes several, and sometimes none. This was confirmed in interviews with other healthcare professionals. I asked the same nurse if some patients were disappointed when nothing was found over time, and she responded:

> *Yes, some may get fed up with it over time. They say, 'I've had it for so long and nothing has ever happened.' They want to take it out now even though the battery lasts about 3 years. Yes, that happens from time to time. And then we often call them in for a consultation to discuss it with them. If it doesn't bother them, they can actually leave it in. At least until the battery runs out. And when the battery is gone, you can always discuss if it's still necessary, if they need a new one. Yeah, I don't think it's the cardiac monitor in particular that bothers them, it's more the box on the bedside table. A lot of people are bothered by that. Because it might flash, that's true. We get calls all the time about that. Especially from people with a cardiac monitor.*

Contrary to what the tele-nurse told me during our interview, some patients were also bothered by the implant. All interviewed patients told me that they wanted the implants removed at the latest when the battery was empty. Furthermore, post-removal interviews showed that the moment of having the device taken out was perceived as an important step for patients to move on with their normal lives (see Chapter 8). However, cardiologists did not encourage early removal of the cardiac monitor. Rather, they advocated with patients to make the most of monitors' battery life. One cardiologist explained how she always tried to convince her patients to keep cardiac monitors with the aim of getting as much information as possible:

> *I have had to remove cardiac monitors whose batteries had not yet died, but only after I had protested several times. I told [the patients], 'You've already had your procedure, what difference does it make, if you have it for two or four years if it*

> *doesn't hurt you? And then it will give information. The longer you have it, the more information it will give us.' But there are people who can't be convinced. I had one patient who said that [the cardiac monitor] hurts and that it absolutely had to be removed. That happens, but it's rare.*

There is a contrast between what cardiologists perceived as useful for diagnostic purposes and how time affects patient perceptions of remote cardiac monitoring. While cardiologists strove to make the most of a diagnostic tool that is already in place, many patients began to doubt whether they still need the cardiac monitor when the expected results failed to materialize.

7.5 Discussion: The digital doctor-patient connection is not designed for long-term care

Patients' initial high hopes they had placed on the cardiac monitor slowly dissipated over time. It turned out that these hopes had been more of a magical belief than realistic expectations (Fox 2000; Mackintosh and Armstrong 2020). This disillusionment was due to the fact that the cardiac monitor never detected anything. Or more accurately, patients were led to believe that this was the case, as healthcare professionals would only inform them if the transmitted recording was clinically relevant and required intervention. This asymmetry forced patients into a waiting position (Timmermans and Buchbinder 2010). Consequently, the medical control and expertise was preserved and remained with healthcare professionals (Clarke et al. 2021; Conrad 2007; Lupton and Jutel 2015). Being a patient in waiting sometimes tested patients' patience.

Some patients even considered the proper functioning of remote cardiac monitoring as tantamount to being diagnosed (Aronowitz 2015). When that did not happen, they began to question the technology's usefulness. This is in line with what Aronowitz (2015:31) describes as the "social efficacy calculation," which suggests that false-positive screening results no longer make patients feel harmed or skeptical, but instead make them more engaged in the screening program by asserting control over their anxieties. Having no feedback at all deprived patients of those triumphant moments that no news or fake news really is good news. While remote cardiac monitoring could provide reassurance to patients solely through the materiality of the inserted cardiac monitor and the imagined direct connection to the hospital, these assets were not sufficient to sustain the reassuring effect in the long term. The complete absence of a measured risk assessment regarding their heart rhythms made it difficult for some patients to estimate their "personal buffer between health and illness" (Gillespie 2012:205).

Patients' doubts were reinforced if there was a discrepancy between the symptoms or (harmless) arrhythmias that patients could experience, such as extrasystoles, and the absence of findings by the cardiac monitor. This discrepancy between the embodied knowledge of the patients and the technical knowledge produced by cardiac monitors (Henwood and Marent 2019) was not always easy to accept and live with for patients. For cardiologists, however, this inconsistency between what patients noticed and what their instruments measured was not an uncommon challenge in rhythmology. However, the long-term continuity and the remote component made remote cardiac monitoring more challenging than occasional testing or screening.

In particular, the continuous nature of the monitoring over a long period of time made it difficult for patients to believe that the cardiac monitor never detected anything, given the lay knowledge that their heartbeat varies naturally. This was not true, of course, but because they did not have access to their data and because healthcare professionals did not inform them about false-positives or harmless alerts, they began to lose trust or even became suspicious about the real purpose of this endeavor. Healthcare professionals on the other hand also struggled with the continuity of the cardiac monitoring as they faced important amounts of data to process. This illustrates that there is a misunderstanding between what patients expect and hope for and what healthcare professionals really can offer. Although continuous monitoring appeared to be "more thorough and with reduced probability of missing an actionable sign" (Aronowitz 2015:232), it appeared to be more difficult to manage risk perceptions and to maintain reassuring effects in the long term.

Additionally, the remote component moved the doctor-patient relationship from a face-to-face space to a digital one. While this seemed not to be a problem at first glance, the face-to-face contact, or at least a personal contact via telephone, appeared to be irreplaceable to address the above-mentioned misunderstandings related to the absence of clinically relevant findings as time went on. The Waldspital offering patients a direct phone number to their telemedicine unit could better address patients doubts and worries which emerged over time. Advantages were two-fold. On one hand, it was a low-threshold contact method that patients could use whenever they had questions. On the other hand, tele-nurse developed a form of digital intimacy (Piras and Miele 2019), as they grew very familiar over time with the patients' habits through the daily handling of their data transmissions and telephone contact in case of questions. This makes them excellent correspondents, but it also makes them the primary people responsible for restoring the personal relationships which have not been taken care of in remote cardiac monitoring (Oudshoorn 2011). This form of caring often goes beyond traditional relationships between healthcare professionals and patients, which includes articulation and affective work (Oudshoorn 2011:206) being more akin to risk management (Aronowitz 2015) than nursing. This "together management" (Pols 2012:96) between tele-nurses and patients is maintained over the phone. However, as I have shown, it was sometimes necessary to schedule a medical appointment between patients and cardiologists to put patients' experience with remote cardiac monitoring into perspective and restore trust.

Such face-to-face appointments not only restored patient trust in the technology and healthcare professionals. It also maintained the feeling of being (well) cared for and allotted professionals the opportunity to explain to patients that there were things that medicine could not explain. Depending on individual patient history, patients had more or less a hard time to learn and accept this. However, this chapter suggests that digital doctor-patient relationships are not sufficiently trust-filled to accompany this transition. Face-to-face encounters remain indispensable for long-term, high-quality doctor-patient relationships.

At some point, patients began to accept living with their health conditions and the associated residual risks. However, in order to move on, cardiac monitor removal was an important step for patients. This final stage of patient journeys in remote cardiac monitoring is the subject of the next chapter.

8 Removing scrap: undoing patients and the future of telecare

Although most patients experienced cardiac monitor removal as a liberating moment. What mattered most to them was the presence or absence of a diagnosis after so many years of monitoring. Either of these two outcomes allowed patients to go on with their normal lives, reassuring them that a cause had been found and treated, or that their risk of suffering from a potentially life-threatening arrhythmia was very, very low. With this in mind, the first section of this chapter takes a closer look at patients' different diagnostic trajectories. Ideally, cardiac monitors are able to detect arrhythmias, allowing for diagnosis and appropriate treatment. The first section illustrates how patients learned to accept the lack of a definitive diagnosis. Although some patients were frustrated when their monitors failed to detect anything after several months, cardiologists encouraged them to keep their devices implanted until there was no more battery life (see Chapter 7). It was only when the batteries had run out that most cardiac monitors were removed.

Overall, patients were happy to be rid of the cardiac monitors. This was a key moment for both patients and cardiologists. Patients could see themselves again as ordinary people, with the usual number of aches and pains for their age, but generally healthy. Thus, I argue that the removal of patients' cardiac monitors resulted in the process of the undoing of the patient. For cardiologists, the removal was the end of close follow-up, leading either to subsequent traditional calendar-based appointments or to no follow-up at all. Many patients would have liked a final report to close this chapter of their medical history. In particular, they wanted final reassurance that everything was fine with their heart.

In the light of this and the findings from the other chapters, this chapter's final section discusses possible future directions for telecare. Companies are pushing for remote care and digital feedback solutions. They are also trying to improve existing technologies with more biosensors and interactive patient feedback, which promise to better assess whether or not patients need to seek care in a medical setting. Cardiologists, for their part, saw these technological developments as increasingly transforming their clinical practice into data management, replacing classic auscultation and patient narratives. Nevertheless, they stressed the importance of personal interaction with patients and the beneficial effect of non-medical chit-chat during consultations. However, the elephant in the room remains the ever-increasing volume of data in medical practice, which challenges the way patients, doctors and companies interact. Ultimately, these conflicting perspectives raise important political questions around how and by whom healthcare should be provided and about the costs of prevention in the form of screening technologies.

8.1 "It's not fatal unless you're walking on the edge of a cliff": Acceptance of ordinary residual health risks

Ideally, remote cardiac monitoring should provide evidence everybody was looking for. This proof would come in the form of a recorded arrhythmia detected by a cardiac monitor, which could lead to a diagnosis and a treatment. However, instead of immediately removing cardiac monitors when evidence was found, cardiologists encouraged patients to continue remote cardiac monitoring for better follow-up on treatment options, thereby maximizing monitoring time until the battery ran out.

Because of the unpredictable nature of arrhythmias, neither tele-nurses nor cardiologists could estimate the average time it would take for cardiac monitors to detect an arrhythmia and lead to a definitive diagnosis. One tele-nurse told me in the interview that the shortest time it took to detect an arrhythmia had been one day. In this case, a young patient was suspected of having an atrioventricular block, but it had never been documented. Therefore, she received a cardiac monitor. One day after the insertion, the monitor detected a long pause in her heartbeat. The monitor was then removed, and she immediately got a pacemaker. “We hit the bull's eye right away,” said the tele-nurse.

The same tele-nurse told me in the interview that the moment of being able to tell patients what was wrong with them was crucial for her professional motivation. She illustrated this with another anecdote about a patient whose cardiac monitor had detected a sinus arrest a year and a half after its insertion. Moved by the news the tele-nurse was able to give him over the phone, he said, “Now you've finally found something! I've been waiting for a year and a half.” The tele-nurse explained that the recorded episode showed that the patient's heart had stopped for about 20 seconds. Knowing that there were, as she said, “living people” behind the data made it even more impressive to her. Over the phone, she learned from the patient that he had been eating breakfast when his heart stopped and had found himself on the floor after losing consciousness. The patient had experienced similar episodes before, but it was necessary to have the recording of the heart rhythm at the time of the symptoms to make a clear diagnosis. Later that day, at lunchtime, the tele-nurse showed the recorded arrhythmia episode to the attending cardiologist who decided to call in the patient immediately. That same afternoon, the patient went to the hospital's operating room to have a pacemaker implanted.

Overall, most patients found it difficult to accept that their cardiac monitors were not providing results. As argued in the previous chapter, this contributed to general disenchantment with the technology over time and renewed body awareness among patients. Cardiologists, on the other hand, did not care whether or not a diagnosis was made. From their perspectives, both outcomes were equivalent medical findings. With this attitude toward diagnosis, the cardiologists I interviewed struggled to assess the overall ability of cardiac monitors to aid with diagnosis. One of the issues concerned how to define diagnostic performance. From the cardiologists' point of view, cardiac monitors may allow for a definitive diagnosis to be made, or they may help to rule out possible life-threatening causes without providing a definitive diagnosis. Cardiologists considered both outcomes as helpful, and thus successful, for patients' healthcare trajectories. On the other hand, the evaluation of diagnostic performance can vary according to the type of the arrhythmia. Small success rates might be relatively good when the arrhythmia is hard to detect, as it is the case for atrial fibrillation, which may potentially contribute to stroke prevention. Likewise, if cardiac monitors do not detect any arrhythmias for several years, cardiologists assume that the probability that patients' hearts might beat out of sync in the future is insignificant enough that they no longer need continuous surveillance.

However, cardiologists were aware that the absence of a diagnosis can be stressful for most patients. In these cases, personalized feedback from cardiologists to patients is all the more important. While scientifically trained cardiologists considered the lack of a diagnosis as an equally relevant finding as a detected arrhythmia after several years of monitoring, patients did not always share this risk assessment, especially when they were still experiencing the same type of symptoms for which they had received a cardiac monitor. It was therefore even more important for cardiologists to be able to put findings and the risk of recurrence into context. One cardiologist told me during an interview how she explained to her patients that having no diagnosis is good news overall:

> *It's true that the absence of a diagnosis stresses patients out. They want to know, but I try to explain to them that we don't actually know. Most of the time, it's fine. It's not that we're missing out on something important. Medicine focuses on things that are treatable and things that are very dangerous. So, if you have neither one nor the other, that's good news overall.*

Placing the lack of results in the context of the bigger picture was an essential contextualization for patients so that they could have a better understanding of the end result and that the monitoring had not necessarily been in vain. As I have shown in Chapter 4, the cardiac monitor was presented to patients as a manifestation of the hope of finally finding an explanation for their suffering. However, unlike patients, healthcare professionals were more aware that there was no guarantee of a definitive result and that certain health incidents remained without medical explanation. Another cardiologist explained during our interview how he jokingly told patients that the fact that he had not found a cause for their syncope in four years led him to conclude that there was no serious problem with their heart:

> *'Listen, we don't have a cause, but what I can tell you is that it's nothing serious. We know that about 40% of the population will experience syncope at least once in their lives. So, you're one of those 40%. It's an occasional phenomenon, a reflex. It's not fatal unless you're walking on the edge of a cliff.' That's reassuring.*

Situations in which patients would ask him to insert a second cardiac monitor were rare. Among the patients I interviewed, there was only Mr. Dubois who had experienced symptoms without there being a recording of that moment available because cardiac monitor battery had already died. He thought that it was stupid not to have the data from that specific moment. Subsequently, he had asked to have the device replaced with a new one since he found it convenient to know that the cardiac monitor would be able to record a potential arrhythmia whenever he felt unwell. This way, in the eventuality that he would be admitted to a hospital, healthcare professionals would be able to review the recordings and examine if his heart rhythm might be the cause of his symptoms. Nevertheless, his case appears to be an exception and not the rule. Most patients were happy to hear from their cardiologist that nothing had been found during the entire monitoring period, which meant they no longer had to worry about their hearts.

Generally, cardiac monitors allowed patients to regain confidence in their hearts, alleviating some of the uncertainties and anxieties created by their unexplained symptoms. This effect occurred both when patients received a clear diagnosis and appropriate treatment, and when no definitive explanation was given. This is illustrated by the following four examples.

The first example involves Mr. Gaillard, who told me that it was reassuring to know that the remote cardiac monitoring system had been able to record what he was feeling to make sure he wasn't imagining it. Although his arrhythmias were not clinically relevant, it was important for Mr. Gaillard that his cardiologist took him seriously and was able to later explain that these events were not life-threatening. Mr. Gaillard (45 years old, La Clinique) explained:

> *I understood that in any case I was not at risk, that there was no treatment, no surgery, and that as long as it stayed within that range, these were just arrhythmias that I felt in an unpleasant way, but that did not put my life in danger.*

He also said during our interview that the cardiac monitor had been psychologically important in helping him to overcome his doubts. Unlike Mr. Gaillard, 23-year-old Mrs. Sommer's syncope was not immediately taken seriously by healthcare professionals, providing a second example of a patient who received a medical explanation for her sudden fainting episodes. During our interview, she told me how her blackouts had initially been dismissed by healthcare professionals who offered other explanations. They had told her that it was normal for a young woman to faint from time to time, probably due to circulatory problems such as low blood pressure. When medical tests were inconclusive, her doctors thought her blackouts were perhaps psychological in nature. After another fainting episode, she finally received a cardiac monitor. A few months later, she was diagnosed with second-degree atrioventricular block, which means that the electrical signals between her heart's chambers are not working properly and could, in the worst case, lead to sudden cardiac arrest. The condition was then treated by ablating the faulty part that was causing the arrhythmia. However, the treatment was not entirely successful. Although a second ablation was possible, it could incur additional risks, including the possibility that she might need a pacemaker. Mrs. Sommer (23 years old, Waldspital) explained to me how she coped with her heart going out of sync during exercise:

> *I can feel my heart beating fast as hell. I feel that, and then I get dizzy. If I then keep pushing myself, which I used to do a lot, because I just thought it was exercise, it's exhausting, so, I used to faint. But if I don't push myself, I don't faint most of the time. So, after two or three minutes, it's over again. {...} [The cardiologists] told me that if it bothers me, and I can't manage it, they could try to ablate it a second time, so that it works this time. That way, it won't happen again. I might reconsider it, especially in terms of pregnancy or when I get older. But if it doesn't bother me, if I can live with it, then it's okay the way it is, they told me.*

Her narration shows how, over time, she gained a new understanding of her individual risk situation and how to deal with it to prevent fainting. That the cardiac monitor played an important role in this process is illustrated by the sentence Mrs. Sommer (23 years old, Waldspital) used to summarize her experience at the end of our interview, “It's actually almost the same life I lived before, only with more certainty.”

While this reassurance was partly related to the fact that Mrs. Sommer had received a physical explanation for her condition, a third patient example showed that the cardiac monitor could also reassure patients over time, without detecting an arrhythmia or finding a cause for past symptoms. Mrs. Schuler (66 years old, Waldspital) told me how her anxieties about experiencing another transient ischemic attack, also referred to as a mini-stroke in common parlance, had diminished over time:

> *In 2012, I had my second transient ischemic attack. In 2017, I got the cardiac monitor implant. I was really scared for many years. Every time I had a headache, I would immediately panic and think I was going to have another stroke. Those are fears I wouldn't wish on anyone. Now I know that I have to test if I can touch my nose with my finger (laughs) and if I can shake my husband's hand properly. I have learned through this self-examination how I can determine for myself if I’m well or not. I have gained confidence over the years that it is something else, but that it’s not another transient ischemic attack, a small, short-term blockage of a small vessel in the brain. And certainly, no major blockage. But the main reason why I really gained that confidence was from having this cardiac monitor.*

Mrs. Schuler’s example shows how cardiac monitors can serve as a form of support during the transition period when patients reassess the extent to which they need to worry about their health. In this sense, the device helps them to learn to live with their condition, to manage possible symptoms and to gain more autonomy over their bodies. Nevertheless, Mrs. Schuler continued to search for a possible cause or explanation for her mini-strokes. She explained to me that a doctor she was seeing had suggested that what she was experiencing was not a mini-stroke, but a specific type of migraine. As a result, she began to believe in this hypothesis and told herself that she was not going to have another mini-stroke and that it might be just a migraine attack. However, she was aware that she might be fooling herself. During our interview, she asked herself the rhetorical question, "Am I lying to myself? Maybe I am. But I live better with it." As mentioned earlier in this chapter, some patients found it difficult to accept that their symptoms had no medical explanation.

For others, remote cardiac monitoring was a way of accepting that they might never have an explanation for their symptomatic episodes. This is illustrated by the fourth example of Mr. Aubert. In the post-removal interview, he told me how his medical journey started with him experiencing symptoms similar to a heart attack while bicycling, one of his regular leisure activities. After a medical examination, the suspected heart attack was not confirmed. As he had not given up cycling, he continued to experience an accelerated pulse, usually when he was exerting himself. He described it to me as a desynchronization between his heartbeat and his breathing. Whenever this happened, he would have to stop for about 10 to 15 minutes and wait for his heart to calm down. What worried him a bit was that he was not able to manage these events and prevent his heartbeat from becoming erratic. After some other medical tests, his doctor prescribed blood thinners, but the tests did not reveal a real cause for his arrhythmias. However, he wanted to know and further investigate the issue. All the other tests showed that everything about his heart was perfectly normal. Finally, the cardiologist suggested a cardiac monitor to him. At first, Mr. Aubert was reluctant because his symptoms had since disappeared and he was able to put his heart to work again, like he used to do when cycling. As a result, his anxiety had also diminished. Despite his reluctance, he eventually agreed to remote cardiac monitoring. After three years of monitoring, he had the device removed because nothing had been found, and the monitor was just a reminder of a difficult time in his life. When I asked him how he felt about the fact that nothing had been found during those three years of remote cardiac monitoring, Mr. Aubert (67 years old, La Clinique) told me that he could now accept and live with the fact that there was no explanation for that symptomatic period:

> *I'm happy. Afterwards, I thought of other explanations. Maybe it was stress, maybe anxiety. Well, my wife tells me that it was certainly the fact that my daughter was pregnant in March, and as I tend to worry about the people I love. Maybe that made me worry. As soon as our granddaughter was born, I had no more symptoms. I'm not saying that this is the explanation, you know. It's so complex. None of the specialists I've seen have been able to give me an explanation, so I'm not going to allow myself to find one either.*

Later in the interview, Mr. Aubert told me how he had joked about this possible explanation with his daughters, and one had made fun of him saying that he might have suffered from a pseudo pregnancy. In rare cases, cardiologists took advantage of this long-term reassuring effect of remote cardiac monitoring by offering a cardiac monitor to patients for whom they had been certain that the heart rhythm was just fine. An example of this strategy was given by a cardiologist who offered cardiac monitors to a few of her patients because she wanted to prove to them that there was nothing wrong with their hearts. Although the cardiologist was convinced about this, she was not able to persuade such patients. She explained:

> *I give the implant to some people because I wanted to demonstrate that their symptoms were not related to arrhythmias. This is something I am already convinced of, but it is difficult to prove. There are people reporting their*

> *symptoms, and I know that this has nothing to do with an arrhythmia, but they still tell me about palpitations or fainting spells. Or they have pseudo-fainting-spells. They have them very often, and they always end up seeing a cardiologist. Nevertheless, it will be the thing that will allow us to determine, to stop these episodes of paroxysmal arrhythmias by saying, 'Well, there you see, there is nothing.' This has already happened to me three or four times.*

This cardiologist's example illustrates how cardiac monitors are also used to support experts' initial assessments with additional data to show these patients that their heart rhythms are within norms, despite their experienced symptoms. Irrespective of the presence or absence of arrhythmias in patients and the subsequent assessment by cardiologists, cardiac monitors are used for more than just data collection. As shown in the previous chapters, it creates a reassuring effect among patients and cardiologists, which can serve to lull them into the security of mutual care. From the point of view of another cardiologist, this additional cardiac monitor effect is made possible by the fact that the technology digitally connects patients and cardiologists. He explained:

> *This device is really a link. It's a bridge between the patients and his or her doctor. It's a physical link through the device and a digital intermediary through the information it transmits. {…} It's like a connection between them and us. So, it creates a relationship of trust, and we see a lot of situations that are de-dramatized with the help of this type of device. It goes beyond just being an electrocardiogram recorder if you like.*

According to this cardiologist, and as will be shown in the next section, cardiac monitors are more than a screening tool for arrhythmias. Although patients' experiences may vary depending on how their symptoms evolve and whether or not an arrhythmia is detected, cardiac monitors play an important role in reassuring patients and cardiologists in uncertain diagnostic contexts. For patients, the most important thing was to reassess their health and regain autonomy over their bodies. Particularly in the absence of a definitive diagnosis, it was up to cardiologist to make patients aware of residual risks and to reassure them one last time before ending their remote cardiac monitoring. The next section will show how cardiac monitor removal was a key moment for patients and cardiologists, breaking their digital connection once and for all.

8.2 "They leave the family nest": Hospital appointments and the undoing of patients

In general, preparation for cardiac monitor removal consisted of the same logistical procedures as for insertion. Patients were admitted to the day ward or the consultation room. In contrast to the insertion procedure, there were few questions from the patients, as nurses or cardiologists could easily refer to the first insertion procedure to give the patients an idea of what to expect. Often, professionals explained that they would make the incision in the same spot as a few years earlier to avoid additional scarring. Preparations were also very similar to the insertion procedure. As patients were lying on the hospital bed, professionals felt the cardiac monitors through patients' skin by touching them with their hands to assess where and how deep the devices were. Over time, cardiac monitors had become encapsulated by human tissue. The challenge of removal was to work precisely through the tissue fibers to open the encapsulation with an incision of only 1 to 2 centimeters. As there was no special removal material provided by the medical device companies, the implant-nurses or cardiologists used a standard scalpel as their main tool. Removing the cardiac monitor was much more difficult than inserting it and required a great deal of skill and patience. Implant-nurses and cardiologists always warned patients that removal would take much longer than insertion because of the difficulty of prying the device out. Although medical device companies have invested in the design and engineering of the insertion process, they had not provided specific tools for removal, suggesting that this last stage was of no interest to them.

Technically, it would be possible to leave cardiac monitors under the skin, even though they would no longer function without battery power, as long as patients were not bothered by their implants. Only a few patients agreed with this option, telling me that they would leave the devices under their skin as long as they did not hurt or bother them in any other way. However, most of the patients I interviewed were certain that they would like to have the implants removed one day, because they considered cardiac monitors to be foreign objects in their bodies. Another argument that some of them mentioned was that they would not want to keep a no-longer-functional device under the skin. What at the moment of insertion had been a symbol of hope, had become a piece of ordinary electronic scrap. Mrs. Leuenberger (82 years, Waldspital), who had received her cardiac monitor for a one-year clinical study also wanted to get rid of the device for convenience, even though the battery would have lasted for another two years. She explained, “Depending on what I'm doing, I always have to say that I'm still wired. That's a bit annoying.” She was happy to be able to get back to her normal life without having to worry about informing others that she had a device implanted, for example when she travelled or had other medical appointments. Mrs. Sommer, on the other hand, was concerned about what the insertion site would look like as she aged. Although she knew it would be an uncomfortable procedure to remove the device, it was also an important moment for her to come to terms with remote cardiac monitoring. Mrs. Sommer (23 years old, Waldspital) described this:

> *I don't know what it will look like in 50 or 60 years (laughs). Maybe I don't even want to know. But at that time, I have to say, I was a bit pissed off. To go [to the hospital]. Just because I knew the local anesthetic would hurt. And then you're there. And they rip it out. As with any surgery, it's a bit annoying and a bit uncomfortable. But now I know that I won't feel it anymore. The whole thing is over.*

Other patients felt similarly about the removal of their cardiac monitor. Mr. Aubert described to me in the post-removal interview that his daily life changed not when the cardiac monitor was inserted, but when it was removed. Knowing that the cardiac monitor tended to remind him of his symptomatic episodes, I asked him if his life had changed after the removal of the device. Mr. Aubert (67 years old, La Clinique) replied, "I feel freer. In fact, I feel liberated. Such a little feeling of freedom, not having a foreign body inside me all the time, reminding me of bad memories."

For him, the cardiac monitor removal was the final step in moving on and no longer worrying about his heart rhythm. Although he had been symptom-free for the entire three years of monitoring and no arrhythmias had been detected, it was the removal of the monitor that finally set him free. The same was true for Mrs. Schuler. For her, the removal of the cardiac monitor 17 days before the interview was a defining moment, signaling the end of an uncertain period in her patient trajectory. Mrs. Schuler (66 years old, Waldspital) described it this way:

> *I've been really well for 17 days now. Now I say I'm healthy. {...} Yes, you know, at 66, eh, (laughs) of course you have this or that little pain. But I feel healthy now, yes. Everything I have is, I would say, under control. That sounds so stupid. But I can deal with it, that's what I meant.*

Having cardiac monitors removed could symbolically stand for the conclusion of a period of uncertainty, as Mrs. Schuler and others described during our post-removal interviews. Moreover, the removal marked the moment in which patients considered themselves to no longer be potentially ill. In this sense, the removal of the cardiac monitor could be interpreted as the moment in which the status of patient was undone and patients could become people again (Gotzsche and Berg 2010).

Since the removal of the cardiac monitor marked the end of what was in many cases a years-long journey, patients repeatedly mentioned in post-removal interviews they would have liked to have received a final report covering the whole period of their long-term monitoring. Some of them, like Mrs. Schuler, had specifically asked for such documentation during their hospital appointment. In the interview, Mrs. Schuler emphasized that her only disappointment with remote cardiac monitoring was that the hospital had not yet sent her the three-year summary she had asked for.

Mr. Aubert also complained about the lack of explanation. He told me that he had a similar experience with the insertion and removal of his cardiac monitor. He described how his cardiac monitor was still active when it was removed, but he had not received any final feedback about what had appeared on the computer screen, when the nurse had positioned the computer mouse-like reader over the insertion site before removing the device. He said he would have liked a final confirmation that everything was fine. Instead, Mr. Aubert (67 years old, La Clinique) described the removal as follows:

> *They put a sheet on my face, opened me up and removed it. It was perfect, just a small scar. So, I have nothing to say about the medical act itself, but I would have liked to have been told something else, something extra.*

Continuing the discussion, I asked him if he regretted not asking for a final report. He justified his inaction by saying that he had always had the impression that the hospital staff did not have the time and that they were already overworked. He explained that it was not like his family doctor who usually listened to his patients. Continuing my questioning, I asked the patient if the lack of information was the only disadvantage of remote cardiac monitoring. Mr. Aubert (67 years old, La Clinique) then highlighted another contrast, which for him was related to the lack of personalized feedback: "It's very impersonal. At the same time, it's very intimate, because they're putting something external, foreign, into you, and you have to live with it." This echoes what Blaxter has called the "vanishing" of the patient behind high-tech medical images (Blaxter 2009). Similar to Blaxter's arguments, in the case of remote cardiac monitoring, it was not the high-tech methods in themselves that were alienating to patients, but the way in which cardiologists were able, or not, to explain them to the patients.

While for patients, the removal of the cardiac monitor was a liberating moment allowing them to put their problems to rest, there was also a rupture in the links, whether they be digital or relational, between patients and cardiologists that had been created by remote cardiac monitoring. One cardiologist compared the moment of removing the cardiac monitor to young birds flying away from the nest of the medical system by putting it this way:

> *After four years, well, there's a little break. I tell the patients that I'm going to remove it. I suggest that they continue to follow up regularly with their cardiologist. I won't be seeing them anymore, but I'll be available if they need me. It's a bit like children. They leave the family nest. It's a similar way of working.*

The cardiologist's comparison illustrates how he sees remote cardiac monitoring as a period of closer attention to patients whose symptoms seem a little suspicious. However, once this period is over, patients are discharged and left to their own devices, assuming that the risk of a life-threatening arrhythmia is sufficiently low or has been detected and treated.

After having their cardiac monitor removed, but before leaving the hospital, many patients wanted to return their transmitter and/or remote control to healthcare professionals. Often, they had brought these gadgets with them in their original packaging. Mr. Fontana explained to me during our interview that he had wrapped the remote control in a plastic bag to protect it from wear and tear. Despite taking good care of their devices, these patients were faced with the harsh reality that their devices would be disposed of with other electronic waste at the hospital. All patients were shocked and could not understand why their devices could not be reused by other patients. However, when they received their cardiac monitors, they or their health insurance companies had purchased all necessary devices like they would any other electrical appliance, such as a television. Since the devices would be thrown away anyway, no one at the hospital asked patients to bring them back. Healthcare professionals told patients that they could either take them to a recycling center or return them to a pharmacy or other store that is required by law to take back and recycle electrical equipment. Mr. Fontana had finally chosen to return his transmitter box to a pharmacy and asked the staff to dispose of it for him as he did not have the heart to do it himself. In contrast to these environmentally conscious patients, others forgot to return their devices because they had become so unimportant that they no longer knew where they were. Mr. Gaillard told me that his remote control was probably still at the back of his drawer, where he had put it after no longer taking it with him as part of his daily routine.

As Greene and colleagues have written about medical waste, the high proportion of disposable items in medicine is not based on scientific evidence of sterility, but on the economics of industrial production (Greene, Skolnik, and Merritt 2022). Rather than valuing reusable items, healthcare supply chains have been organized in an unsustainable way because of the promise of short-term financial gain. It may therefore be worth reconsidering this mode of operation in order to avoid unnecessary medical waste. However, this waste of resources caused by the disposability of medical devices was not the main problem of waste in telecare, according to medical device companies. How their view and the ones of cardiologists and patients regarding the future of telecare differ, is the subject of the final sub-section of this chapter.

8.3 “That entire visit, it's just a waste”: The (ir)replaceability of personal contact in future telecare

When asked about the role of telecare in the future, the following interviewee, who is responsible for diagnostics and digital health in a medical device company, said eliminating unnecessary hospital visits are a key factor in reducing the burden on healthcare systems. For him, the biggest waste was the traditional follow-up appointment, where patients and doctors chat without patients really needing medical attention. He told me:

> *Basically, the further away you can keep a patient from a hospital, the more cost-effective it is. And I believe telemedicine is going to do a big contribution of being able to do that safely and effectively. {…} Currently, the standard of care is this. You've got a device implanted. It's calendar-based. So, every three months, you come in, you have a check-up, scan it, ‘How are you feeling?’ Often the patient is fine. That entire visit, it's just a waste. So, if you can monitor those*

> *patients remotely and just wait until the system brings up an alert and says, 'You should pay attention to these patients.' That would be tremendously cost saving and time saving for both the patient and the clinician. {...} And I think the tricky part is spreading that awareness. To all doctors. Because right now, the standard of care is still calendar-based follow-up. That's the way medicine is practiced. And we have to {...} change that mindset.*

However, patients were usually happy to visit their cardiologists and discuss how their situation was progressing. One cardiologist described how the informal, calendar-based appointment system contributed to a mutual understanding of the doctor-patient relationship:

> *I build a relationship. I see my patients regularly. I say, 'Hello, how are you?' We also talk about other things. We can shoot the breeze, as I say, you know. That is, we talk about something other than medical problems. By coming in, there is a certain interaction, a mutual understanding that develops.*

What was described by the company representative above as medical cost gouging is praised by this cardiologist as an opportunity to build mutual understanding. As I have shown in the other chapters, there is clearly a lack of feedback and contextualization in telecare when patients are left alone with only a digital connection to the hospital. Of course, both cardiologists and company representatives have enormous financial interests in how they portray the future of telecare. Biomedical companies stand to gain from selling cardiac monitors and other devices that promise to reduce costs. Cardiologists, on the other hand, are paid to 'shoot the breeze' and, of course, to provide specialized care.

Some cardiologists also questioned the overall affordability of remote cardiac monitoring. One cardiologist explained to me in an interview that cardiac monitors would be an expensive and most-times unaffordable device in many countries. In her view, the most important question in healthcare is still how much it can cost. According to her, it would also be possible to introduce regular, opportunistic pulse screening. This would probably be just as effective, but cheaper, because it could be done in pharmacies. Nevertheless, she was convinced that overall, "There is no need to look for something that's not going to be treated." Although long-term cardiac monitoring helps to minimize the risk of a fatal event due to arrhythmia, it remains a relatively expensive screening technology reserved for high-income countries.

While there is currently a coexistence of remote and calendar-based patient follow-up, cardiologists are facing a change in their clinical practice. In general, they have been critical of medical device companies' plans to base medical follow-up solely on data alerts in order to save time and money. In addition to the importance of the informal exchange with patients mentioned by her colleague, this same cardiologist underlined the relevance of patients' general impressions in her clinical work. When I asked her about the importance of telecare in the future, she replied:

> *I think less than the industry would like. It has its place, but it should not replace face-to-face contact. Even talking to patients on the phone is not the same as seeing them in person. When I see them in person, there are moments when I get the impression that the person is saying 'yes' to everything without understanding what I'm saying. And I can see it. I can see it in their face, I can see it in the way they position themselves, but I can't see it on the phone.*

Although seeing patients directly to better assess overall well-being remained important to cardiologists, they had to admit that classic medical examination by touch had almost completely disappeared from their everyday clinical practice. While discussing this topic with another cardiologist, I asked her if she thought her job was increasingly becoming that of a data scientist. She replied, “Absolutely! I see it in my own practice. I touch the patients less and less. The clinical assessment itself, auscultation as we learn it in medical school, is something that’s becoming increasingly rare.”

Although medical device companies are aware that doctors do not need more data, but more efficient ways to process, analyze and combine the vast amount of data they already have, they may say in the same breath that they hope to add more sensors in the future. Paradoxically, they want to cure the lack of accuracy in current data sets by adding more data in the hope of creating better patterns and clusters. They are already trying to do this by highlighting certain alarms from remote cardiac monitoring with traffic-light colors that symbolize the urgency of the episode recorded.

With the growing burden of chronic disease, medical device companies are directing telecare developments towards patient management rather than diagnostics. However, diagnostics indirectly benefits from the strong prevention orientation of chronic disease management. Nevertheless, patient feedback loops remain essential to improve data-review burden and interpretation. As the case of remote cardiac monitoring illustrates, human contextualization of data is an essential component of a well-functioning telemedical system. Medical device companies are therefore working to develop tools to integrate patient feedback into remote patient monitoring applications. The head of diagnostics and digital health at a medical device company talked about their plans of future technical refinements in telecare devices:

> *We're actually trying to extend that capability by making it even more bidirectional and interactive. Maybe [patients] can call the doctor directly. Add in more surveys, questionnaires about their status, and tie it in with machine learning. To make it more specific. To different types of diseases, like heart failure, maybe diabetes management. And also to provide the patient with education, tools, webinars, or things that they can use, and maybe hopefully integrate into their daily life to change their behavior. And just improve their condition.*

His statement makes it clear that the time and cost savings would be shifted to the patients, who would not only manage their condition, but also their health data. Some patients are already doing this by voluntarily wearing smartwatches. According to most of the cardiologists I spoke to, smartwatches are cardiac monitors' biggest technological competitor. Some cardiologists also admitted in interviews that they sometimes asked their patients if they already owned a smartwatch before suggesting a cardiac monitor because the sensor of one brand has a rather good accuracy in detecting arrhythmias. A cardiologist told me about a patient who was reluctant to wear a cardiac monitor. When the patient had symptoms at work that were suspected to be caused by an arrhythmia, her colleague lent the patient her smartwatch. The patient then sent the recording to the cardiologist, saying that the name on it did not match, but that the electrocardiogram was recorded during her symptomatic episode. The recording was sufficiently clear to establish a diagnosis. However, compared to medical device companies, the big tech companies that produce smartwatches have a bad reputation regarding data privacy.

8.4 Discussion: Is time a good healer?

The removal of cardiac monitors allowed patients to finally close their medical chapter on arrhythmias. According to cardiologists, after such a long period of monitoring, every result was a valuable diagnosis, whether the cardiac monitor had detected the suspected arrhythmia, had produced an incidental finding, or had remained without conclusive results. For them, three or more years of monitoring was long enough to conclude that there was a very small risk, if any, that patients would develop dangerous arrhythmias in the future.

Compared to cardiologists, it was more difficult for some patients to accept the absence of a definite diagnosis. This implied that patients had to learn to live with ordinary, residual health risks. A task that was especially challenging for stroke patients who feared that a second attack would consequently impair their quality of life. Thus, cardiologists had to explain to patients that not knowing the cause of a medical incident was nothing extraordinary. Although their symptomatic episodes would remain unexplained, it was likely nothing to worry about. It meant that there was no serious problem with their hearts, not that they were missing something that was there but had not been detected. As one cardiologist put it in a nutshell, “Medicine focuses on things that are treatable and things that are very dangerous. So, if you have neither one nor the other, that’s good news overall.”

This raises an old question about what medicine can and should provide. The answer is all the more difficult to give in risk-oriented medical practice that operates on probabilities and places a high value on health (Conrad 2007). This form of medicalization might also reduce patients’ overall risk tolerance resulting in an higher demand for medical explanations. Moreover, while risk factors and deviations can be quantified, wellness cannot (Meador 1994). Since health cannot be measured or screened, the only way for patients to reclaim the label is either to ascribe it to themselves through self-assessment or to have it ascribed to them by a doctor who can qualify the absence of a diagnosis. This personal contextualization happening in the doctor-patient relationship is all the more important in a medical context dominated by quantified biomedical data (Cesario et al. 2021; Hoeyer 2019; Prainsack 2017).

The absence of clinically relevant findings was also used to back up the cardiologists' initial suspicions that certain patients only suffered from pseudo-arrhythmias, illustrating that for some patients, the expert assessment without a data basis was not sufficient. While some patients were able to accept that there would never be a medical explanation for what they had experienced, others sought other medical or non-medical explanations to frame their illness narratives. For them, it was important to make sense of what happened to them, as they were uncomfortable living with an enigma (Nettleton et al. 2004). Nettleton and colleagues (2004) proposed to use the "chaos narrative" of Frank (2013) to analyze narratives of people living with undiagnosed illness. According to Frank (2013) there are three types of illness narratives: (1) restitution, (2) quest, and (3) chaos. The restitution narrative represents the ideal type of a patient trajectory with a defined illness, appropriate treatment, and recovering. The quest narrative consists of assigning the illness a greater sense for patient identity. The chaos narrative consists of unstructured bits of suffering without closure. However, contrary to people living with medically unexplained symptoms, remote cardiac monitoring helped most patients to put their symptoms into perspective. Hence, this chapter suggests that the removal of the cardiac monitor including the final doctor-patient appointment allows patients to turn their chaos narrative into a restitution narrative. However, contrary to the classic restitution narrative of receiving a definitive diagnosis, they were given the clinical absolution that their heart rhythm was absolutely fine. This resonates with the old sociological argument of medicine as being an institution of social control and place of final judgements (Zola 1972).

Patients were glad to be free of their cardiac monitors. For both patients and cardiologists this was a key moment marking the final ritual of this "collective, cumulative, and contingent" diagnostic journey (Rosenberg 2002:256). After removal, patients again considered themselves as normal people with the common number of aches according to their age, but healthy overall. Thus, this post-removal process can be described as the undoing of the patient. For cardiologists it was the end of a close follow-up leading to either a classical calendar-based appointment scheme or to no follow-up at all. The fact that many patients would have wished for a final report as a kind of written confirmation shows the importance of this moment for their personal illness narratives.

The diversity of patients' disease trajectories and narratives also illustrates that for some patients, a symptom-free period was a good enough cure, while others relied on the evidence-based feedback combined with monitoring data and cardiologist expertise. This suggests that cardiac monitors are much more than a data-collecting sensor. As a constant companion, they shape patient disease experiences from the moment of uncertainty as they make their way back to normal.

9 Discussion and conclusion: The offbeat effects of remote cardiac monitoring

Medical practice is increasingly shaped by big data sets and less by patient narratives. Algorithm-based medicine promises to connect patients directly with the clinic. Instead of medical examinations taking place at the bedside and at specific moments, sensor-based technologies continuously monitor a certain physiological value and automatically transmit data via a remote monitoring system. While previous studies have mostly focused on the spatial separation of data collection, transmission, and interpretation, the different temporalities involved and their potential consequences for doctor-patient relationships have received less scientific attention. This dissertation has therefore aimed at addressing this gap. Continuous monitoring offers the imaginary of patients being in sync with clinics. Although this is technically feasible via data networks, healthcare professionals need time to accurately link and interpret recorded data to produce meaningful knowledge which requires human synchronization. Without this, big data medicine cannot work. These developments challenge traditional doctor-patient relationships, which are centered around diagnosis making. The reorganization of data collection, transmission, and interpretation primarily affects how, when, and where diagnoses are made. To examine how these challenges are unfolding, I chose to explore the case of remote cardiac monitoring in Switzerland. Therefore, this study has responded to the following research question:

> *How do long-term experiences of remote cardiac monitoring reconfigure and (de)personalize the relationship between patients and healthcare professionals in Switzerland?*

The empirical material included ethnographic observations and semi-structured interviews. The qualitative study was conducted at two university hospitals in different linguistic regions of Switzerland from October 2020 to July 2022.

9.1 The illusion of immediacy in algorithm-based telecare

According to informed consent forms given to patients in hospitals, cardiac monitors are devices that provide automated, algorithm-based heart rhythm monitoring (Rosman et al. 2018). However, as I have shown with this qualitative study, cardiac monitors are much more than simple devices with two electrodes that continuously collect data. Inspired by the work of Nassehi (2019) on digital societies, I here raise questions about the true purpose of remote cardiac monitoring. I align my critiques with Nassehi's argument that research on digital phenomena should question their social function without assuming their absolute necessity.

From my interviews, observations, and conversations with healthcare professionals, company representatives, and patients, a solution-oriented narrative of finding a diagnosis was omnipresent. However, in the interviews, both cardiologists and patients emphasized another effect of remote cardiac monitoring that was most important to them. This monitoring system allowed for the creation and maintenance of a digital connection between patients and professionals. It was this digital connection that made cardiologists feel that they took good care of their patients and that brought patients to feel like they were well cared after by their cardiologists. I call this a mutual reassuring effect. The need for reassurance arose from a context of medical uncertainty affecting both cardiologists and patients (Groopman 2008; Nettleton 2006). While medical practice has always been characterized by uncertainty, the inability to determine the cause of unexplained symptoms affects the core of the doctor-patient relationship (Rosenberg 2002). This can be an unsettling experience for doctors and patients alike, as it calls attention to the limits of medicine. Even worse, it prevents cardiologists and patients from performing their respective roles of providing care and being patients. Furthermore, confronted with patient narratives of symptomatic episodes and information documented in their medical records, cardiologists still suspected that patients might once again suffer from an arrhythmia. However, to offer appropriate treatment and avoid unnecessary side effects, the arrhythmia must first be recorded. This is not an easy task for a possibly rare, temporary, and self-limiting phenomenon (Martínez-Rubio et al. 2020).

As I showed in Chapter 5, remote cardiac monitoring offers cardiologists the possibility to continuously monitor patient heart rhythms at a distance. This reassures them that the next arrhythmic episode will not go unnoticed. Patients, on the other hand, feel taken seriously and reassured in their quest for a medical explanation. Nonetheless, cardiologists and patients did not base this reassuring effect on the exact same ideas. On the one hand, cardiologists counted on cardiac monitors to report any clinically relevant arrhythmia. Knowing that cardiac monitors overly report false-positives (O'Shea et al. 2021) and that patients know to seek medical attention for severe symptoms, cardiologists saw the technology as a safety net that would prevent them from otherwise potentially abandoning their patients.

Patients, on the other hand, relied on remote cardiac monitoring as a kind of direct and constant connection to the hospital. This imaginary of remote cardiac monitoring as a synchronized data network (Weinberger 2011) emerged in patients' minds because they were only able to see or touch the devices (cardiac monitors, transmitters, and remote controls) but had no direct access to the processes of data collection and transmission. As this was the case, patients were not necessarily aware that the processes of data collection, transmission, and interpretation happened with a time delay. The invisibility and opacity of how exactly their hearts were monitored masked the fact that although cardiac monitors observed and evaluated their hearts around the clock, data transmission only happened once a day, and tele-nurses only assessed cardiac monitor data during their office hours from Monday to Friday. Nevertheless, the reassuring effect helped patients to overcome their anxieties linked to what might be wrong with their heart (Aronowitz 2015). Building upon previous findings from Pols (2012), this reassuring effect persisted even if there was not much personal contact between patients and tele-nurses or cardiologists.

However, the primary purpose of reassurance was put to the test over time, as the imagined data network of remote cardiac monitoring did not play out as patients expected. While cardiologists were reassured by having delegated the task of rhythm monitoring to cardiac monitors, patients expected to receive regular and prompt feedback from the clinic. The idea of a synchronized data network conveyed the possibility of an uninterrupted connection and 24/7 availability of cardiologists. This could be compared to the introduction of telephones to medical practices in the beginning of the 20th century (Greene 2022). Similarly, with remote cardiac monitoring, the imagined availability of medical feedback independent of place and time shifted patients' expectations, turning them into "impatient consumers" (Greene 2022). Instead of being automatically synchronized, as patients would expect from other data networks, the simultaneity or "closeness" (Pols 2012) of the elements required for data interpretation must be brought into sync by a human.

Indeed, data do not speak for themselves (Gitelman 2013) but must be interpreted in relation to patients' lifeworlds (Grew and Svendsen 2017). Although the data recorded by the monitor are automatically transmitted and synchronized through telemedical systems provided by medical device companies, they need to be further synchronized with other data types, such as the last visit to the hospital, co-morbidities, and/or the actual circumstances in which the recordings were produced. Hence, one major finding of my study suggests that the use of algorithm-based technologies for diagnosis increases the need for human synchronization, a process which Elias (1992:131) identified as essential for human coordination. Unlike traditional follow-ups, where shared space ensures that processes are automatically in sync, the network-like character of algorithm-based medicine (Weinberger 2011) can only produce meaningful knowledge if the links between the different types of data are correctly put into sync by a human. A task called "detective work," by the interviewed tele-nurses. This did not only include consulting the right documents to gather the relevant information. It also mobilized the fine-tuned knowledge that tele-nurses acquired about patients' habits over time. This form of "digital intimacy" (Piras and Miele 2019) helped them to process false-positive alerts more quickly. For example, nurses knew that a particular patient used his stationary bicycle at a certain time of the day, which often resulted in an alert for an abnormally high pulse. Consequently, they dismissed this alert without further examination. This suggests that some intimate knowledge is indispensable for medical decision-making. However, the way remote cardiac monitoring is uncoupling the processes of data collection, transmission, and interpretation re-consolidates the power position of healthcare professionals (Clarke et al. 2021; Conrad 2007; Lupton and Jutel 2015).

This disjuncture between a promissory, imagined in sync data network allowing for prompt feedback after an arrhythmia alert and the actually required human synchronization work, which takes time but is invisible to patients, led to what I call an "illusion of immediacy" among them. This shows that digital connection is as much a social construction as a physical infrastructure. Therefore, to make it function as it was initially intended, the digital connections of remote cardiac monitoring need to be maintained through human interactions. Remote cardiac monitoring and its reassuring effect are not self-sustainable in the long run if the connected actors do not actively contribute to it. Their active contribution essentially consists of medical feedback from cardiologists commenting, contextualizing, and qualifying the ongoing monitoring to and for patients. Although one of the two hospitals, the Waldspital, would send patients reports every three months, patients were not satisfied by this form of impersonal communication, which often reduced the reporting to "no arrhythmias detected to date." This suggests that the lack of regular, personal feedback may impact the mutual trust in doctor-patient relationships over time. In addition, doctor-patient relationships might become fragile if remote cardiac monitoring does not provide results within what patients perceive to be a reasonable timeframe.

9.2 Good news is better than no news

For many patients, the proper functioning of remote cardiac monitoring was tantamount with receiving a diagnosis (Aronowitz 2015). If cardiac monitors did not detect any arrhythmia within the first months of monitoring, some patients started to question the usefulness of the implant or even became suspicious about being used as "guinea pigs" for clinical trials. These doubts also arose from the fact that patients had no access to their transmitted data. Knowledge about what type, if any, of recorded irregularities was reserved for healthcare professionals. From the professionals' point of view, this was a reasonable configuration. Due to the high amount of false-positives, they justified this arrangement by saying that they wanted to avoid unnecessarily frightening patients. Nevertheless, this asymmetry preserved their already privileged position of power and knowledge (Zola 1972). Moreover, due to the algorithm-based assessment of the cardiac monitor, data alerts only consisted of heart rhythm patterns that deviated from the norm. As a result, measurements of normal heart rhythms were no longer part of the clinical assessment in algorithm-based telecare, as they had already been automatically filtered out. This changes the type of evidence that doctors deal with on a daily basis, compared to calendar-based follow-ups, where clinical values were determined by the time of measurement rather than standard thresholds.

In addition, healthcare professionals in both hospitals adopted the communication strategy of "no news is good news," meaning that they only informed patients of irregularities if professionals needed more information to better understand a recorded heart arrhythmia or when they thought it might require clinical intervention. Patients were unaware of any data transmissions other than those they self-reported. This gave tele-nurses and cardiologists complete control over what, how, and when they wanted to contact patients. This resonates what scholars have described for other medico-technological developments (Clarke et al. 2021; Conrad 2007; Lupton and Jutel 2015; Zola 1972). It meant that patients were left with no other choice than to wait for news from the hospital. This turned them into "patients-in-waiting," which was produced by the incommensurability of remote cardiac monitoring to deliver an instant medical explanation and the continued rootedness of doctor-patient relationships in obtaining a diagnosis (Timmermans and Buchbinder 2010).

As a result, if hospitals did not report any news or simply stated that no arrhythmias had been detected, patients perceived it as if the cardiac monitor had found nothing at all. However, the extensive and continuous monitoring made it difficult for patients to believe this, given the lay understanding that there are natural fluctuations of the heartbeat. Patients' doubts in the absence of tangible results is in line with what Aronowitz (2015) described for other early preventive screening technologies, such as those used for cancer detection and prevention. He interpreted the finding that Americans become more invested in these screenings after learning of false-positive results as a way for them to experience victory over disease or to gain some control over their disease-related anxieties (p.31). Receiving results that are not medically worrying can help alleviate patients' anxieties by giving them a greater sense of control. However, the design of remote cardiac monitoring and the decision of the healthcare providers to stick to the motto of "no news is good news" deprived patients of these triumphant moments in their patient trajectories. To them, receiving "good news" in the form of qualified expert feedback contextualizing the absence of alerts or false-positive alerts could be a beneficial long-term coping mechanism in a context of medical uncertainty. While healthcare professionals did not consider the absence or presence of a definitive diagnosis to make a difference as long as the patients' health did not worsen, having good news rather than no news made a difference to patients.

The lack of feedback was all the more challenging for patients who continued to have symptomatic episodes or who regularly experienced their heartbeat as out of sync. In the beginning, they made sure to make the cardiologists aware of their symptoms by self-reporting them with the help of the remote control. However, when they never heard back in cases of transmitted data showing clinically irrelevant results and thus no need for contact from professionals' point of view, patients started to mistrust the technology and question cardiologists' intentions with the cardiac monitoring technology. Some wondered if the devices had any diagnostic value and were concerned about simply being cogs in the machinery of big data. On the other hand, a common challenge for cardiologists was the discrepancy between how patients perceived their heart rhythm or symptoms and what medical instruments could actually detect that was clinically relevant. While this challenge could be addressed in a timely manner in regular medical appointments, it remained unaddressed and unsolved by the digital connection of remote monitoring. As such, mutual understandings which typically emerge in a traditional, calendar-based and/or symptom-based follow-up, were lost in algorithm-based monitoring. This also affected levels of trust within doctor-patient relationships. This illustrates the importance of face-to-face cooperation in diagnostic work (Mol 2002). In her work on atherosclerosis, Mol (2002:23ff) argued that diagnosis is not possible without a patient body present at the doctor's office and without patient cooperation. My study suggests that the simultaneous presence of doctors and patients is also essential to undo the patient in the absence of a definite diagnosis, so they can get rid of their patient status.

To get such face-to-face feedback, patients often had to wait until the cardiac monitors' batteries had run out and then have the devices removed, unless they had requested an appointment beforehand. Nonetheless, it was not only the lack of personal feedback which made remote cardiac monitoring a challenging diagnostic tool for the doctor-patient relationship, but also its long-term nature.

9.3 From inserting hope to removing scrap: the disenchantment of a digital connection

The insertion of the cardiac monitor was accompanied by high hopes associated with finally detecting the missing piece to explain the symptomatic episodes patients had experienced or with finding the cause of a cryptogenic stroke. Thus, cardiac monitors became a beacon of hope serving to assuage cardiologist and patient uncertainties (Fox 2000). This resonates with risk management approaches (Aronowitz 2015) that orient medical practice increasingly towards an abstract future and that attempt to prevent bad outcomes (Adams et al. 2009; Clarke et al. 2021; Erikainen and Chan 2019). To do so, medicine increasingly relies on big sets of biomedical data aiming at quantifying every aspect of life (Vogt et al. 2016). This vision promises to improve quality, timing and personalization in healthcare (Prainsack 2017; Schleidgen et al. 2013). In this sense, remote cardiac monitoring can be described as the "datafication" (Ruckenstein and Schull 2017) of, until recently, symptom-based cardiac rhythm management. Although their default settings can be adjusted, cardiac monitors can detect all types of arrhythmias and not only the suspected ones. This thereby contributes to the biomedicalization of arrhythmia diagnoses. In other words, this transformation results from how the medical specialty of cardiology has come to deal with arrhythmias by delegating the diagnostic task to cardiac monitors, which represents a new "social-organizational-technological" arrangement (Clarke et al. 2021:127).

In addition, the narrative that there must be a medical explanation for everything as long as the right tool is applied in the right moment, fuels patients' expectations that it would only be a question of time until the continuous monitoring of their heart rhythm would do the trick (Aronowitz 2015). As a result, the continuous digital connection of remote cardiac monitoring puts patients in a constant state of alertness. Over time, however, they came to realize, sometimes with quite some frustration, that their individual feels of immediacy and urgency were not shared by healthcare professionals. For professionals, remote cardiac monitoring was a tool to keep a digital connection with patients they consider to be low-risk, but not low-risk enough to leave without supervision. However, most patients were genuinely frightened by their symptoms and the possibility of a potential arrhythmia diagnosis. That said, for some patients who did not receive any conclusive news over time, remote cardiac monitoring started to lose meaning and purpose. In this process, the state of alertness gave way to an overall banalization and disenchantment with the technology. Thereby, the digital connection lost its symbolic imaginary of closeness (Pols 2012) and immediacy. What at the moment of insertion had been a symbol of hope, had become a piece of ordinary electronic scrap at the moment of removal.

That being said, the attitudes towards immediacy and urgency also differed between tele-nurses and cardiologists. Compared to cardiologists, tele-nurses began to "know about the patients" (Piras and Miele 2019) over time, which helped them process the daily data transmission more efficiently (Groopman 2008). This gave them privileged access to patients' habits and private lives, especially at one of the two hospitals in which patients had a direct phone number to contact the tele-nurses. However, the final medical decision of how to proceed for an individual patient was still up to cardiologists. Interestingly, both cardiologists and tele-nurses made decisions by using an "in-between-strategy," which meant combining quantified evidence and gut feelings (Kristensen et al. 2021; Zinn 2016). Future studies on algorithm-based telecare should investigate how professionals' gut feelings differ in situations where patient bodies are physically present in the clinic compared to situations where they make decisions only based on patient data collected as a distance (Grew and Svendsen 2017).

In general, this illustrates how diagnoses are not just hidden in patient bodies waiting for sophisticated instruments to detect them. Rather, they are socially constructed entities (Jutel 2014). These study findings also contribute to literature showing that diagnostic work takes time. Far from resulting from a flash of genius, establishing a diagnosis is often a long-term process (Blaxter 1978), without the guarantee of finally obtaining a definite medical explanation. As Rosenberg (2002:256) argues, "Diagnosis is ordinarily a collective, cumulative, and contingent process," which continues to be at the core of every doctor-patient relationship, whether mediated by an algorithm-based technology or not.

9.4 My position in the field: on anxiety, reassurance, and laughter

During my presence at the hospitals, I agreed with the nurses at the Waldspital that they should introduce me to patients and ask them if they approved of my presence. Even though I was not wearing a white coat, I only encountered one situation in which a patient was very skeptical of me and the notes I was taking. I then closed my booklet, but stayed in the room because I thought it was an interesting scene for my study because it brought to light the arguments that healthcare professionals and patients use for and against the technology. Generally, the context of remote cardiac monitoring represented a special moment for patients, some of whom were very nervous and sometimes even anxious.

At La Clinique the context was more complicated because there were several healthcare professionals involved with the insertions and removals of the cardiac monitors, and the attending staff changed quite often. Consequently, I had to constantly re-evaluate the conditions to determine the best time to introduce myself to patients and the cardiologist in charge.

During patient interviews, I sometimes adopted the role of reassuring patients or answering their questions regarding remote cardiac monitoring, if I felt competent enough to do so. I found this to be difficult to navigate and had to make decisions about asking critical or provocative questions. I did not want to further unsettle patients, especially if they were already anxious or unhappy, either with the technology or the healthcare professionals looking after them.

Another challenge for me involved moments when healthcare professionals or patients would laugh away a serious issue to brush it aside. For example, a tele-nurse jokingly told me how they had realized at the last minute that a patient did not need a pacemaker at all because the recording in question was a false-positive. According to Jerak-Zuiderent (2015), such laughter may be an interesting entry point to further examine what made this person laugh and what this says about the research topic. For her, laughing away serious issues indicates that the interviewee might fear the interviewer's reaction. She writes:

> *The interviewees 'laugh away' what they consider alter from quality and safety in healthcare: laughing away the sense of having no control over what is actually going on, laughing away a state of polyglotism, and laughing away a state of inaction and taking one's time (Jerak-Zuiderent 2015:18).*

This was clearly the case of the example stated above. Besides the emotions I was confronted with by interviewees, there were also situations before, during or after the surgical interventions at the hospital which made me feel rather uncomfortable or even worried for patients' well-being. I was also sometimes worried about implant-nurses, who had to deal with cardiologists' questionable or insensitive attitudes.

9.4.1 Limitations

This study has three major limitations. First, patient recruitment depended on my trusting relationships with healthcare professionals on site. As a result of this, if professionals determined that a patient was not being "good enough" for my study, I did not get a chance to attempt to recruit them. Additionally, professionals were very reluctant to help me get an interview with patients who refused cardiac monitor insertions. This is why non-users are absent in my study. Second, for privacy reasons, it was not possible to disclose the gender of the cardiologist respondents in combination with the institutions where they were employed. I therefore could not take this into account in the presentation of my data analysis. Third, it was very difficult to obtain interviews with representatives of medical device companies due to the secrecy around the competitive market of remote cardiac monitoring. I got a glimpse of this during my ethnographic observations, as described in Chapter 4. Therefore, company perspectives are underrepresented, and their accounts served more as a supplement to the data I collected from patients and professionals.

9.5 Algorithm-based telecare changes the conditions, but not the core of doctor-patient relationships

Overall, this study suggests that there is a major blind spot in current developments in "personalized medicine." My analysis of remote cardiac monitoring in Switzerland provides a stimulating case study into personalized medicine’s under-investigated collective, time-consuming, and socially anchored efforts to establish a diagnosis. Contrary to the visions of “technoscientific holism” (Vogt et al. 2016), more and more comprehensive biomedical data sets alone will not lead to better tailored, more timely, and cheaper healthcare. The case of remote cardiac monitoring in Switzerland shows how algorithm-based telecare leads to a spatial and temporal uncoupling of data collection, transmission, and interpretation. Unlike traditional, calendar-based medical appointments, patients and their narratives, cardiologists and their expertise, measurement devices and the use of test results are no longer in sync in the context of remote cardiac monitoring.

The datafication of continuous monitoring outside of the clinic has changed what is visible and perceptible to both cardiologists and patients and has reorganized different parameters for their relationship. In traditional medical appointments, cardiologists and patients are in the same room, perform data collection (e.g. ECG or blood test) and interpret their results together if they are immediately available. If results are not immediately available, traditionally, doctors and patients then agree on the next steps to be taken. Mol (2002) showed how this form of “cooperation” is essential in establishing a diagnosis.

In remote cardiac monitoring, patients must rely on their embodied experiences, as they do not have access to the data collected by the algorithms. Although they have the possibility to self-report symptomatic episodes, the data themselves remain invisible to them. Cardiologists, on the other hand, have to rely on data transmissions that are automatically preselected by the cardiac monitor's algorithms, with deviations first being triaged by tele-nurses. The circumstances under which recordings are triggered remain invisible to cardiologists. Although the system flags self-reported data transmissions, cardiologists still do not know whether patients triggered recordings because of a slight chest pain or because they suddenly fainted in the street. In a nutshell, there is a tremendous amount of trust that both cardiologists and patients must place in the technology to perform flawlessly in line with their expectations and hopes.

Additionally, there is a considerable time delay between what the patient feels or what the cardiac monitor detects and what cardiologists see. At the earliest, data interpretation happens the day after an arrhythmic episode is recorded. This adds another dimension of invisibility for patients, namely the uncertainty of whether their data transmission has been seen and addressed at the hospital. Overall, hospitals have adopted a "no news is good news" communication strategy with patients. However, as I have shown throughout this dissertation’s chapters, this lack of feedback challenged the overall utility of remote cardiac monitoring and ultimately the trustworthiness of doctor-patient relationships in this remote configuration.

The temporal uncoupling of data collection, transmission and interpretation sets a different stage for the doctor-patient relationship to which patients are accustomed. However, the digital connection alone is not enough to create a meaningful relationship, neither for patients’ illness narratives, nor for doctors’ data interpretation. The digital connection in algorithm-based telecare depersonalizes the doctor-patient relationship, introducing more distance and misunderstandings between healthcare professionals and patients than what is offered in traditional doctor-patient configurations. In the end, patients’ and cardiologists’ accounts, coupled with my observations, showed how face-to-face encounters remain indispensable for medical practice because only shared space and time allow for genuine cooperation.

9.6 Future directions: The expensive thing of big data medicine is interpretation

Often, big data technologies are met with either exuberant enthusiasm or exaggerated criticism. However, this study suggests that independently of an enthusiastic or critical public attitude, their successful implementation into medical practice mainly depends on how data and feedback are communicated and transmitted between healthcare professionals and patients. While data collection, transmission and even its integration into bigger data sets becomes less and less complicated and more and more cost-effective, their meaningful interpretation remains challenging for all involved actors. Lomborg et al. (2020) called interpretation in the context of self-tracking a "luxury." Indeed, algorithm-based telecare is only cost-effective as long as the data review burden and the human synchronization work to render data meaningful does not exceed the saved expenses generated by the automated remote monitoring. Thus, algorithm-based telecare is more likely to be adopted in countries in which the service is covered by the national health insurance, which applies more generally to high-income countries.

Correspondingly, future research should take a closer look at the digital divide in telecare, as it seems to rather increase than close the gap between those who benefit from healthcare those who don't (Greene 2022:242f). Furthermore, it is likely that third-party providers will enter the market, raising questions about who will ensure the quality of data interpretation independently of economic interests. Ultimately, these confronting perspectives lead to political questions about how and by whom healthcare should be provided and how much prevention in form of screening technologies might cost. More importantly, my dissertation shows that the doctor-patient relationship remains a matter of human trust that must be established and maintained no matter how many technologies, data, and digital connections co-exist. Accordingly, it must be continually adapted as the delivery of medical care changes with the advent of innovations and novel approaches. Despite the growing push for datafication and the hype around the opportunities big data might bring to society, there are still areas that cannot be quantified. Especially in the context of medical uncertainty, which is not going to disappear but rather become more complex, the joint consideration and discussion of risks and treatment options require more than a simple diagnostic label and corresponding remedy. We need to consider patients as whole individuals, not just as a data conglomerate. The case of remote cardiac monitoring in Switzerland illustrates that, despite the increasing focus on health risks and offbeat vital signs, we should ensure that healthcare does not get out of sync.

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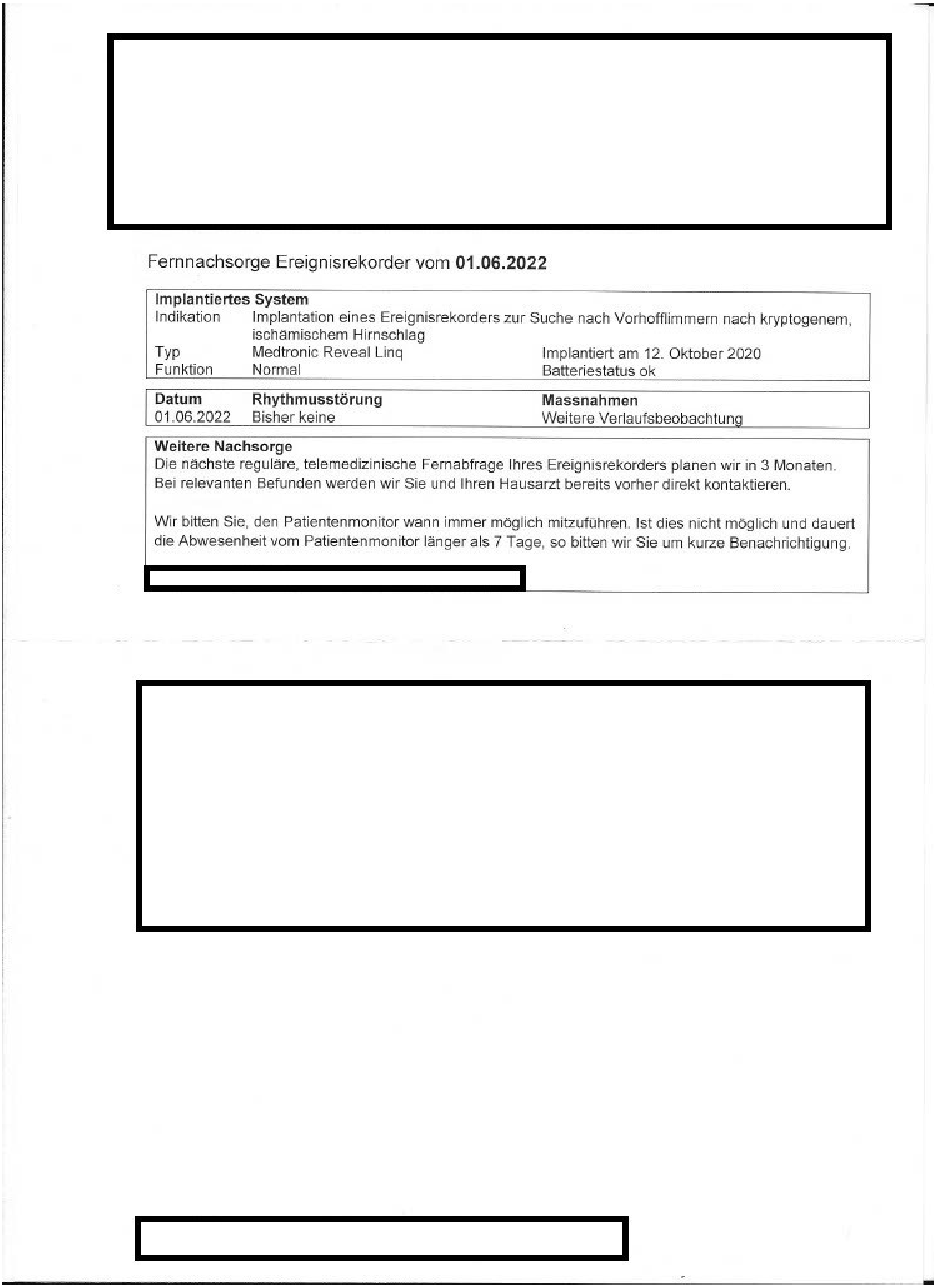
Appendix A



[redacted]

Fernnachsorge Ereignisrekorder vom **01.06.2022**

Implantiertes System		
Indikation	Implantation eines Ereignisrekorders zur Suche nach Vorhofflimmern nach kryptogenem, ischämischem Hirnschlag	
Typ	Medtronic Reveal Linq	Implantiert am 12. Oktober 2020
Funktion	Normal	Batteriestatus ok

Datum	**Rhythmusstörung**	**Massnahmen**
01.06.2022	Bisher keine	Weitere Verlaufsbeobachtung

Weitere Nachsorge

Die nächste reguläre, telemedizinische Fernabfrage Ihres Ereignisrekorders planen wir in 3 Monaten. Bei relevanten Befunden werden wir Sie und Ihren Hausarzt bereits vorher direkt kontaktieren.

Wir bitten Sie, den Patientenmonitor wann immer möglich mitzuführen. Ist dies nicht möglich und dauert die Abwesenheit vom Patientenmonitor länger als 7 Tage, so bitten wir Sie um kurze Benachrichtigung.

[redacted]

[redacted]

[redacted]

Appendix B

La télémédecine cardiaque comme une forme de gestion personnalisée de la santé : perspectives de patient.e.s et de professionnel.le.s de la santé

PROTOCOLE D'ENTRETIEN : Professionnel.le.s de la santé

1) Début de l'entretien

- ✓ Je vous remercie d'avoir accepté de participer à cet entretien.
- ✓ Je m'appelle Martina von Arx et je suis doctorante à l'Université de Genève. Pour ma thèse, je mène une recherche sur la télémédecine et plus spécifiquement sur les enregistreurs de rythme cardiaque de longue durée (ex. Reveal LINQ) dans le cadre d'un projet de recherche s'intéressant aux développements de la santé personnalisée en Suisse. Cet entretien me servira à mieux comprendre l'expérience des professionnel.le.s de la santé avec la télémédecine et ce dispositif en particulier.
- ✓ Cet entretien a une grande valeur pour cette recherche.
- ✓ Il n'y a pas de bonnes ou de mauvaises réponses dans cet entretien. Seul compte votre vécu et votre point de vue personnel.
- ✓ Les données récoltées pendant cet entretien seront traitées de façon anonyme.

Détails sur la codification, si l'interviewé.e demande, répondre:

- ⇨ Les données collectées seront codées et les informations contextuelles reconnaissables seront remplacées par des notions universellement applicables. L'identité des participants ne sera connue que par Martina von Arx.
- ⇨ Toutes les données brutes (fichiers sons, documents Word de retranscription, et résumés) et le tableau de correspondance (nom/prénom ⇔ code d'identification) seront sécurisés sur les serveurs dédiés protégés (SWITCHdrive UNIGE[1]) du projet DoPHiS. Le tableau de correspondance sera stocké dans un dossier séparé sur le serveur SWITCHdrive et ne sera accessible qu'avec un mot de passe et uniquement par l'enquêteur principal (M. von Arx). Une fois la thèse terminée, les fichiers sons et le tableau de correspondance seront effacés. Ce processus permet d'anonymiser les transcriptions et les résumés. Ces dernières seront conservées sur SWITCHdrive pendant 10 ans, protégées par un mot de passe.

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[1] SWITCHdrive est un service non commercial de stockage dans le nuage pour les établissements d'enseignement supérieur en Suisse. (…) Toutes les données sont stockées et traitées exclusivement dans les deux centres de données de SWITCH à Zurich et Lausanne, qui sont reliés au réseau national de recherche et d'éducation de SWITCH. SWITCHdrive est une alternative pour un stockage sécurisé des données en Suisse. Les données enregistrées ne sont ni analysées ni traitées et les données des utilisateurs ne sont pas transmises à des tiers.

https://help.switch.ch/drive/faq/ (Accédé le 27 mai 2020; traduction anglais-français de l'auteure)

- ⇨ Correspondance mail effacée de l'ordinateur de M. von Arx après finalisation de la thèse.

2) Entretien

Bloc I : Télémédecine et santé personnalisée

1. Pourriez-vous me présenter votre parcours professionnel ?
   - ⇨ Depuis quand travaillez-vous dans le domaine de la télémédecine ?
   - ⇨ Avez-vous fait des formations ou recherches spécifiques en télémédecine ?

2. Comment vous expliqueriez la télémédecine à une personne qui s'y ne connaît pas, par exemple une patiente ?

3. Selon vous, quels sont les points forts et faibles de la télémédecine ?
   - ⇨ Précision : Pour quel problème la télémédecine est-elle la solution ?

4. Selon vous, est-ce que la télémédecine fait partie de la santé ou de la médecine personnalisée ?
   - ⇨ Expliquez-moi pourquoi (pas).

5. Pourriez-vous me donner plus de détails sur ce que vous entendez par « santé personnalisée » ?
   - ⇨ Comment différenciez-vous « santé personnalisée » et « santé digitale » ?
   - ⇨ Depuis quel moment dans votre parcours professionnel ces termes ont-ils surgi ?
   - ⇨ Diriez-vous que le télé-monitoring par un enregistreur cardiaque de longue durée (par ex. Reveal LINQ) est une approche de santé personnalisée ? Expliquez-moi pourquoi (pas).

Bloc II : Enregistreur de rythme cardiaque de longue durée (Reveal LINQ)

Après avoir parlé de manière assez générale de la télémédecine et de la santé personnalisée, je voudrais maintenant aborder une des technologies plus en détails, c'est donc l'enregistreur de rythme cardiaque de longue durée (ex. Reveal LINQ de Medtronic). Néanmoins, n'hésitez pas à faire des comparaisons avec d'autres technologies de monitoring, si cela vous semble utile.

6. Comment fonctionne un enregistreur de rythme cardiaque de longue durée (ex. le Reveal LINQ) et à qui est-il proposé ?
   - ⇨ Quels examens médicaux sont fait avant de proposer un Reveal LINQ ?
   - ⇨ Quels sont les bénéfices du dispositif en termes de connaissance d'une pathologie, ou encore d'aide au diagnostic ?
   - ⇨ Quel rôle joue l'algorithme ?
   - ⇨ À quel point est-il possible de personnaliser le dispositif pour chaque patient par exemple par la programmation des seuils d'alarme ?
   - ⇨ Le télé-monitoring permet-il de mieux cerner un diagnostic présupposé ou est-il possible de trouver d'autres irrégularités imprévues ?

- ⇨ Le télé-monitoring permet-il toujours de trouver un diagnostic ?
- ⇨ À quel point le dispositif permet-il une individualisation des risques et conditions de santé ?
- ⇨ Quelle plus-value a le Reveal LINQ comparé avec d'autres dispositifs sur le marché ou des anciens modèles ?

7. Comment se déroule la prise en charge des patient.e.s obtenant un Reveal LINQ ?
   - ⇨ Précision : **qui** est impliqué et à quel degré ? [implantation ; monitoring ; rendez-vous de follow-up ; distribution des charges ; coûts ; administration]
   - ⇨ Qui peut accéder aux données des patient.e.s ?
   - ⇨ Avec qui sont partagées les données enregistrées ?
   - ⇨ Ou sont stockés les données des patient.e.s ?
   - ⇨ Collaboration / coordination avec Medtronic ?

8. Pourriez-vous me décrire le flux de données pour le Reveal LINQ ?
   - ⇨ Comment sont les données produites, gérée et interprétée ? Où ? Par qui ?

9. Pourriez-vous me décrire plus en détails votre charge de travail au quotidien en lien avec le Reveal LINQ ?
   - ⇨ Précision : Quelle est votre vécu quant à la gestion des données et la gestion des patient.e.s ?

10. Quelles sont les questions ou incertitudes récurrentes évoquées par les patient.e.s concernant le Reveal LINQ ?
    - ⇨ Surveillance ?
    - ⇨ Rayonnement ?
    - ⇨ Système d'urgence ?
    - ⇨ Alertes faux-positives ?

11. Quelle participation est demandée de la part de la / du patient.e ?
    - ⇨ À quel point la transmission active des données est-elle utilisée par les patient.e.s ?

12. Comment le télé-monitoring cardiaque par le Reveal LINQ influence-t-il le rapport entre professionnel.le.s de la santé et patient.e.s ?
    - ⇨ Quelle importance accordez-vous à un échange régulier en personne entre professionnel.le.s de la santé et patient.e.s ?

13. Comment le télé-monitoring cardiaque par le Reveal LINQ influence-t-il le rapport entre différents groupes de professionnel.le.s de la santé ?

Bloc III : Fin et ouverture

14. Dans quelle mesure les technologies algorithmiques comme le Reveal LINQ ont-elles changé votre pratique clinique ?
    - ⇨ Quelles incertitudes rencontrez-vous en travaillant avec des enregistreurs cardiaques de longue durée comme le Reveal LINQ ?
    - ⇨ Pourriez-vous positionner le dispositif dans votre travail de diagnostic en termes d'efficacité et gain de temps ? Efficacité et gain de temps pour qui ?
    - ⇨ Quelle influence prennent les technologies algorithmiques comme l'enregistreur de rythme cardiaque implanté dans la prise de décision médicale ?

- ⇨ Craignez-vous une utilisation extensive des technologies algorithmiques comme le Reveal LINQ dans votre domaine ? Expliquez-moi pourquoi (pas).
- ⇨ Selon vous, quelle influence ont les technologies algorithmiques sur votre statut d'expert ?

15. Quel rôle accordez-vous aux technologies algorithmiques comme l'enregistreur de rythme cardiaque implanté dans la production du savoir médical ?
    - ⇨ Pourriez-vous positionner le Reveal LINQ parmi les autres outils diagnostic dans votre travail quotidien ?
16. Quelle place accordez-vous à la télémédecine dans la prise en charge médicale du futur ?

3) Fin de l'entretien:

- ✓ Cet entretien touche à sa fin. Avant de terminer, y a-t-il un point qui a été dit au cours de cet entretien sur lequel vous souhaiteriez revenir ? Ou auriez-vous un élément supplémentaire, nouveau, en tête, que vous souhaiteriez ajouter ?
    - ⇨ Si oui => relances éventuelles
- ✓ Merci beaucoup encore pour cet entretien riche et intéressant et le temps que vous m'avez accordé.
- ✓ Il est tout à fait normal d'oublier l'un ou l'autre aspect important auquel on pense qu'en rétrospective de l'entretien. S'ils vous viennent d'autres choses à l'esprit liées à votre expérience avec le télé-monitoring cardiaque qu'il vous semble pertinentes, n'hésitez pas à me contacter, ça m'intéressera beaucoup. On peut se revoir pour en parler, ou régler cela par téléphone ou par mail. Voici mes coordonnées pour me contacter (donner une carte de visite).
- ✓ (Éventuellement : qui dans votre équipe s'occupe aussi des patient.e.s implanté.e.s avec un Reveal LINQ) ? Il serait super, si vous pouvez me mettre en contact avec cette personne.)
- ✓ Avant de terminer, j'ai encore quelques questions très courtes à vous poser, pourriez-vous m'indiquer :
    - o Votre année de naissance
    - o Votre formation
    - o Votre titre professionnel
    - o Votre genre
- ✓ Merci bien !

Appendix C

La télémédecine cardiaque comme une forme de gestion personnalisée de la santé : perspectives de patient.e.s et de professionnel.le.s de la santé

PROTOCOLE D'ENTRETIEN : Patient.e.s

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https://help.switch.ch/drive/faq/ (Accédé le 27 mai 2020; traduction anglais-français de l'auteure)

2) Entretien

Bloc I : Historique et implantation

1. Comment se fait-il que vous ayez reçu un enregistreur de rythme cardiaque ?
   - ⇨ Pourquoi vous a-t-on suggéré d'utiliser un enregistreur de rythme cardiaque ?
   - ⇨ Quels examens ont été effectués au préalable ?
   - ⇨ Avez-vous eu d'autres problèmes cardiaques auparavant ou est-ce la première fois ?

2. Comment s'est déroulée l'implantation de l'enregistreur de rythme cardiaque ?
   - ⇨ Quelles informations avez-vous reçues avant et après l'implantation ?
   - ⇨ Ces informations vous ont-elles été communiquées de manière compréhensible ?
   - ⇨ Comment avez-vous vécu la situation de conseil ?

Bloc II : Lived experience

3. Comment allez-vous depuis l'implantation de l'enregistreur de rythme cardiaque ?
   - ⇨ Votre vie quotidienne a-t-elle changé depuis l'implantation de l'enregistreur de rythme cardiaque ? De quelle manière ?
   - ⇨ Votre sensation corporelle a-t-elle changé depuis l'implantation de l'enregistreur de rythme cardiaque ? Pouvez-vous sentir l'implant ?
   - ⇨ Si la personne ne vit pas seule, comment l'entourage a-t-il réagi à l'enregistreur de rythme cardiaque et à la télésurveillance ?

4. Comment expliqueriez-vous le fonctionnement de l'enregistreur de rythme cardiaque à une personne qui n'en a jamais entendu parler, par exemple à votre voisine ?

5. Y a-t-il des questions ou des incertitudes concernant le télémonitoring qui vous préoccupent ? [Surveillance ? Radiation ? Système d'urgence ? Alarmes fausses positives ?]

6. Avez-vous déjà appelé l'unité de la télémédecine ?
   - ⇨ Pourquoi (pas) ?
   - ⇨ Si oui, comment l'unité de télémédecine a-t-elle pu vous aider ?

7. Etiez-vous déjà contacté par l’unité de la télémédecine ou l’hôpital ?
   - ⇨ Comment ça s’est passé ?

8. Avez-vous déjà utilisé la possibilité de transmettre activement votre rythme cardiaque ?
   - ⇨ Pourquoi (pas) ?
   - ⇨ Si oui, à quelle fréquence et dans quelles situations ?
   - ⇨ Si oui, à la maison ou sur la route ?

9. Où avez-vous placé le moniteur ?
   - ⇨ Préféreriez-vous l'avoir dans un autre endroit ?

- ⇨ Si cela est possible (via le zoom) et approprié : Pouvez-vous me le montrer ou le prendre en photo ?

10. Avez-vous déjà été absent pour une longue période et décidé d'emmener ou non le moniteur avec vous ?
    - Pourquoi (pas) ?

11. Avez-vous déjà rencontré des problèmes techniques avec votre système de télésurveillance ?
    - ⇨ Par exemple, que l'appareil a été mal engagé ? [Animaux domestiques, dépoussiérage]

12. Avez-vous déjà débranché délibérément votre moniteur patient ?
    - ⇨ Pourquoi ?

13. Aimeriez-vous pouvoir voir les enregistrements de votre rythme cardiaque ?
    - ⇨ Pourquoi et sous quelle forme ?

14. Combien de fois par jour pensez-vous à avoir un enregistreur de rythme cardiaque implanté ?

15. Souhaitez-vous être diagnostiqué prochainement ?
    - ⇨ Pourquoi (pas) ?
    - ⇨ Seriez-vous frustré si un diagnostic ne pouvait être établi avant la fin de la durée de vie de la batterie (environ 3 ans) ?
    - ⇨ Que ressentiriez-vous s'ils trouvaient une autre arythmie de celle qui a été recherchée ?

16. Vous décririez-vous comme étant en bonne santé ?

17. Utilisez-vous certaines applications ou agendas pour documenter votre santé ?
    - ⇨ Si oui : Pourriez-vous me raconter un peu plus de votre expérience ?
    - ⇨ Si oui : Est-ce une chose que vous faites depuis longtemps ou avez-vous commencé récemment ?

Bloc III : Approche et santé personnalisée

18. Êtes-vous à l'aise avec cette approche numérique de votre santé ?
    - ⇨ Pourquoi (pas) ?
    - ⇨ Souhaitez-vous voir votre médecin régulièrement ?

19. Décririez-vous le télémonitoring comme un gain de temps pour vous ?
    - ⇨ Dans quel sens ?
    - ⇨ Trouvez-vous facile de répondre aux exigences qui vous sont imposées en tant que patient ?

20. Quels avantages et inconvénients voyez-vous dans le télémonitoring ?
    - ⇨ Pensez-vous qu'il est normal que l'unité de télémédecine ne vous signale que les arythmies pertinentes ? [Pas de nouvelles, bonnes nouvelles.]

21. Les termes "santé personnalisée" ou "médecine personnalisée" vous disent-ils quelque chose ?
    - ⇨ Si oui, pouvez-vous les expliquer ?
    - ⇨ Pensez-vous que l'enregistreur de rythme cardiaque implanté et le monitoring à distance en font partie ? Pourquoi (pas) ?

22. Seriez-vous favorable à l'extension de ce type de télémonitoring à d'autres domaines de la médecine ou êtes-vous plus inquiet à ce sujet ?

3) Fin de l'entretien :

- ✓ Cet entretien touche à sa fin. Avant de terminer, y a-t-il un point qui a été dit au cours de cet entretien sur lequel vous souhaiteriez revenir ? Ou auriez-vous un élément supplémentaire, nouveau, en tête, que vous souhaiteriez ajouter ?
    - ⇨ Si oui => relances éventuelles
- ✓ Merci beaucoup encore pour cet entretien riche et intéressant et le temps que vous m'avez accordé.
- ✓ Il est tout à fait normal d'oublier l'un ou l'autre aspect important auquel on pense qu'en rétrospective de l'entretien. S'ils vous viennent d'autres choses à l'esprit liées à votre expérience avec la télémédecine ou l'enregistreur de rythme cardiaque qu'il vous semble pertinentes, n'hésitez pas à me contacter, ça m'intéressera beaucoup. On peut se revoir pour en parler, ou régler cela par téléphone ou par mail. Voici mes coordonnées pour me contacter (donner une carte de visite).
- ✓ Il serait très utile pour mon étude que je puisse vous interviewer une deuxième fois. Le deuxième entretien aura lieu 6 à 7 mois après l'implantation ou dès que le diagnostic aura été établi. Pouvez-vous me tenir informé à ce sujet ? Dans tous les cas, je vous recontacterai dans six mois pour fixer le prochain entretien.
- ✓ Avant de terminer, j'ai encore quelques questions très courtes à vous poser, pourriez-vous m'indiquer :
    - o (Votre année de naissance ; voir consentement)
    - o Votre formation
    - o Votre titre professionnel
    - o Votre situation familiale
    - o (Votre genre ; voir consentement)
- ✓ Merci bien !

Appendix D

Telemedicine as a form of personalized health management: perspectives of patients, healthcare professionals and the industry

INTERVIEW GUIDE

MEDICAL DEVICE COMPANIES

1) Beginning of the interview

- ✓ Thank you for agreeing to participate in this interview.
- ✓ My name is Martina von Arx and I am a PhD student at the University of Geneva. As part of my dissertation, I am interested in perspective and vision of Medtronic regarding current developments in cardiac diagnostics and monitoring. My PhD thesis is part of a larger research project looking at developments in personalized health in Switzerland. This interview will help me to better understand the point of view of the industry.
- ✓ Therefore, this interview is very valuable for my research.
- ✓ The data collected during this interview will be treated anonymously.

Details on anonymization if the participant asks, respond:

- ⇨ A code will be assigned to the collected data and recognizable contextual information will be replaced with commonly applicable terms. The identity of the participants will only be known to Martina von Arx and possibly one other trusted person who will be paid for the transcription.
- ⇨ All raw data (audio recordings, transcriptions and summaries) and the correspondence table (last name/first name identification code) will be backed up on specific protected servers (SWITCHdrive UNIGE) of the DoPHiS project. The correspondence table is stored in a separate folder on the SWITCHdrive server and can only be accessed with a password and only by Martina von Arx. After completion of the dissertation, the audio recordings and the correspondence table will be deleted. This process will anonymize the transcriptions and summaries. The latter will be kept password-protected on SWITCHdrive for 10 years.
- ⇨ Any email correspondence will be deleted from Martina von Arx's computer after completion of the dissertation.

2) Interview

Part I: PERSONALIZED MEDICINE

1. How would you describe Personalized Medicine?

2. To what extent is remote monitoring part of Personalized Medicine?

3. How is data-driven medicine changing the healthcare system in Switzerland and Europe?

Part I: CARDIAC DIAGNOSTIC & MONITORING SYSTEMS

4. What makes the insertable cardiac monitor exceptional as a device?

   - ⇨ How does the latest model compare to its previous models?

5. How would you explain home monitoring system to someone who has never heard of it?

6. What does the algorithm detect?

   - ⇨ Subcutaneous ECG?

7. What does TruRhythm-Detection mean?

8. What does the Pause Detection algorithm do?

9. How many algorithms are working together?

10. How is the algorithm trained?

11. Does the algorithm learn, meaning adapt to its patient?

12. How can the algorithm be personalized?

13. How do you imagine your customers?

14. Can patients demand their own data?

15. For whom is remote cardiac monitoring a saving in time?

Part III: TARGETED QUESTIONS

16. What happens to the different devices once they are no longer used by the patients?

Part IV: Future

17. What is the biggest challenge in cardiac monitoring and diagnostics?

18. Which arrythmia is the most difficult one to detect? Why?

19. How do algorithmic technologies impact medical decision make?

20. How do algorithmic technologies interfere with the expertise of cardiologists?

21. Can we hope for an increasingly automated diagnostics in the future?

22. Where do you see telemedicine in the medical care of the future?

23. What are the visions of our company in relation to Personalized Medicine?

3) End of the interview

We are soon at the end of the interview. Before we conclude: Is there anything that came up in this interview that you would like to come back to? Or is there an element that you would like to add?

- ⇨ If yes => perhaps follow up again

Thank you very much for this rich and interesting interview and the time you took to do it.

Appendix E

UNIVERSITÉ
DE GENÈVE

Genève, le 24 juin 2022

En avril de cette année, j'ai réalisé le dernier entretien pour mon étude.
Au total, 13 patient.e.s du [redacted] et 15 patient.e.s de [redacted] ont participé à l'étude.
Je vous remercie encore une fois de votre participation !

Avant de clore la collecte des données, j'ai encore une petite question à vous poser :

Est-ce que d'autres événements ont eu lieu depuis notre dernier échange en rapport avec votre moniteur de rythme cardiaque implanté ?

Par exemple :

a) Un trouble du rythme a-t-il été constaté ou avez-vous reçu un diagnostic ?
b) Avez-vous rencontré des problèmes techniques avec l'implant, le moniteur du patient sur la table de nuit ou l'appareil d'activation noir ?
c) Est-ce que le moniteur de rythme cardiaque a-t-il été explanté entre-temps ?

Je serais heureux que vous me teniez au courant à ce sujet. Bien entendu, vous pouvez également ajouter d'autres éléments ou anecdotes qui vous semblent importants.
Merci de me contacter avant le **29 juillet 2022** via :

- Courriel : martina.vonarx@unige.ch
- Téléphone : [redacted]

(Ma-Me-Je de 10h-16h ; sauf 1ère semaine de juillet)

- Courrier : Martina von Arx, [redacted]

Un grand merci d'avance !

Pour l'instant, j'évalue les résultats. Ensuite, l'ensemble de l'analyse sera rédigé sous la forme d'une thèse de doctorat. Je la soutiendrai en juin 2023 à l'Université de Genève devant un comité d'experts. C'est avec plaisir que je vous enverrai ensuite un résumé de l'étude.

Je vous souhaite un bel été et je vous adresse mes meilleures salutations,

Appendix F

La télémédecine comme une forme de gestion personnalisée de la santé : perspectives de patient.e.s et de professionnel.le.s de la santé

Informations destinées aux professionnel.le.s de la santé et déclaration de consentement

Madame, Monsieur,

Nous vous proposons de participer à notre projet de recherche portant sur la vie professionnelle quotidienne des professionnel.le.s de la santé en télémédecine.

Objectifs du projet de recherche

Nous voulons mieux comprendre l'expérience quotidienne de travail dans le domaine de la télémédecine, en particulier avec des patient.e.s ayant un enregistreur de rythme cardiaque implanté.

Sélection des personnes pouvant participer au projet

La participation est ouverte à toutes les personnes qui travaillent dans le domaine de la télémédecine.

Informations générales sur le projet

Nous mènerons des entretiens avec des professionnel.le.s de la santé. Ces entretiens nous permettront d'explorer comment les professionnel.le.s de la santé perçoivent la télémédecine et comment ils gèrent les patient.e.s et leurs données de santé recueillies dans leur travail quotidien. Ces récits personnels amèneront une perspective précieuse à l'étude de la santé digitale en Suisse. La durée approximative de l'entretien est de 45-60 minutes.

De plus, la doctorante Martina von Arx assistera à plusieurs reprises à des consultations entre patient.e.s et professionnel.le.s de la santé. Elle sera également présente à plusieurs reprises à l'unité de télémédecine lors du suivi téléphonique des patients. Ces observations permettront de mieux comprendre le dialogue entre les patient.e.s et les professionnel.le.s de la santé dans le domaine de la télémédecine.

Nous effectuons ce projet dans le respect des prescriptions de la législation suisse. La commission cantonale d'éthique compétente a contrôlé et autorisé le projet.

Déroulement pour les participant.e.s

L'entretien se déroulera en fonction du rendez-vous convenu avec la doctorante Martina von Arx. La participation aux consultations entre les patient.e.s et les professionnel.le.s de la santé, ainsi que la présence dans l'unité de télémédecine, se feront également sur rendez-vous.

Les entretiens et les observations seront documentés avec des notes manuscrites, des photographies, des enregistrements audio et/ou vidéo. Cette documentation sera adaptée en fonction des recommandations de protection concernant la pandémie de coronavirus et des souhaits des participant.e.s. Les photographies ne montreront jamais les visages des participant.e.s.

Bénéfices pour les participant.e.s

En participant à cette étude, vos récits personnels amèneront une perspective précieuse à l'étude de la santé digitale en Suisse. Les résultats de l'étude ont le potentiel d'améliorer considérablement la future prise en charge des patient.e.s en télémédecine.

Droits des participant.e.s

Vous êtes libre d'accepter ou de refuser de participer au projet. Si vous choisissez de ne pas participer ou si vous choisissez de participer et revenez sur votre décision pendant le déroulement du projet, vous n'aurez pas à vous justifier. Cela ne changera rien à votre relation d'emploi. Vous pouvez à tout moment poser toutes les questions nécessaires au sujet de cette étude. Veuillez vous adresser pour ce faire à la personne indiquée à la fin de la présente feuille d'information.

Quels pourraient être les effets indésirables liés à la participation à cette étude ?

Aucun effet indésirable n'est attendu.

Confidentialité des données

Pour les besoins de l'étude, nous enregistrerons vos données personnelles. Les enregistrements audio et vidéo seront transcrits mot pour mot. Les données recueillies à des fins de recherche seront codées lors de leur collecte. Le codage signifie que toutes les données permettant de vous identifier (par ex. le nom, la date de naissance, etc.) seront remplacées par un code. Les personnes ne connaissant pas ce code ne pourront pas lier ces données à votre personne. Seul un nombre limité de personnes peut consulter vos données sous une forme non codée, et exclusivement afin de pouvoir accomplir des tâches nécessaires au déroulement du projet.

Dans le cas d'une publication, les données seront agrégées et ne vous seront donc pas imputables en tant que personne. Votre nom n'apparaîtra jamais sur Internet ou dans une publication. Toutes les personnes impliquées dans l'étude de quelque manière que ce soit sont tenues au secret professionnel. Toutes les directives relatives à la protection des données sont respectées et vous avez à tout moment le droit de consulter vos données.

Retrait du projet

Vous pouvez à tout moment vous retirer de l'étude si vous le souhaitez. Les données personnelles recueillies jusque-là seront tout de même analysées, ceci afin de ne pas compromettre la valeur de l'étude dans son ensemble.

Financement du projet

L'étude est intégralement financée par le Fonds National Suisse de la recherche scientifique. Il s'agit d'une thèse de doctorat intégrée dans le projet intitulé « Développement de la santé personnalisée en Suisse : Perspectives de sciences sociales ».

Interlocutrice

Pour vos questions pendant ou après l'étude, vous pouvez vous adresser à tout moment à l'interlocutrice suivante :

Martina von Arx (doctorante)

022 379 33 54

martina.vonarx@unige.ch

Déclaration de consentement

Déclaration de consentement écrite pour la participation à un projet de recherche

- Veuillez lire attentivement ce formulaire.
- N’hésitez pas à poser des questions lorsque vous ne comprenez pas quelque chose ou que vous souhaitez avoir des précisions.

Numéro BASEC du projet : (après soumission à la commission d’éthique compétente) :	2020-01735
Titre de l’étude : (titre scientifique et titre usuel)	Remote Cardiac Monitoring as a Form of Personalized Health Management: Perspectives of Patients and Health Professionals --- La télémédecine comme une forme de gestion personnalisée de la santé : perspectives de patient.e.s et de professionnel.le.s de la santé
Institution responsable : (adresse complète) :	Université de Genève Prof.Bruno Strasser Université de Genève Section de Biologie Citizen Sciences group 66 Boulevard Carl-Vogt 1205 Genève
Lieu de réalisation du projet :	
Directrice du projet sur le site : (nom et prénom en caractères d’imprimerie) :	von Arx Martina
Participant / participante : Nom et prénom en caractères d’imprimerie : Date de naissance :	☐ femme ☐ homme ☐ autre

- Je déclare avoir été informé, par la personne soussignée assurant l’information, oralement et par écrit, des objectifs et du déroulement de l’étude ainsi que des effets présumés, des avantages, des inconvénients possibles et des risques éventuels.
- Je prends part à cette étude de façon volontaire et j’accepte le contenu de la feuille d’information qui m’a été remise sur le projet précité. J’ai eu suffisamment de temps pour prendre ma décision.
- J’ai reçu des réponses satisfaisantes aux questions que j’ai posées en relation avec ma participation au projet. Je conserve la feuille d’information et reçois une copie de ma déclaration de consentement écrite.

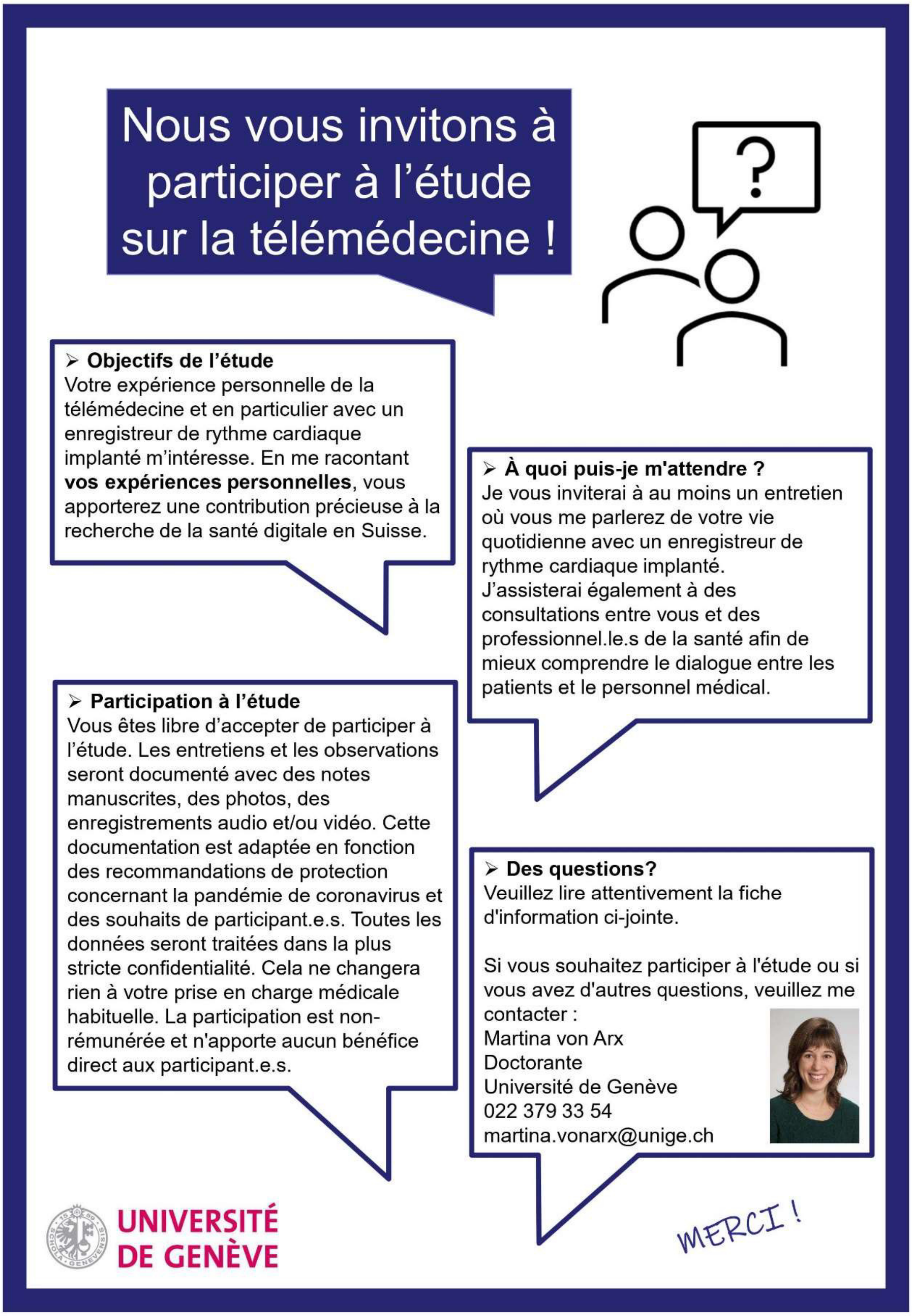
- J’accepte que les spécialistes compétents de l’institution, du mandataire du projet, de la Commission d’éthique compétente pour cette étude, puissent consulter mes données brutes afin de procéder à des contrôles, à condition toutefois que la confidentialité de ces données soit strictement assurée.
- J'accepte que les entretiens et les observations soient documentés par des notes manuscrites, des photos, des enregistrements audio et/ou vidéo.
- Je peux, à tout moment et sans avoir à me justifier, révoquer mon consentement à participer à l’étude, sans que cela n'ait de répercussion défavorable sur la suite de ma prise en charge médicale usuelle.
- Je suis informé que la responsabilité civile de l’Université de Genève couvre les dommages éventuels imputables au projet que je pourrais subir.

Lieu, date	Signature du participant / de la participante

Attestation de la personne assurant l’information : Par la présente, j’atteste avoir expliqué au participant / à la participante la nature, l’importance et la portée du projet. Je déclare satisfaire à toutes les obligations en relation avec ce projet conformément au droit en vigueur. Si je devais prendre connaissance, à quelque moment que ce soit durant la réalisation du projet, d’éléments susceptibles d’influer sur le consentement du participant / de la participante à prendre part au projet, je m’engage à l’en informer immédiatement.

Lieu, date	Nom et prénom de la personne assurant l’information aux participant.e.s en caractères d’imprimerie. Signature de la personne assurant l’information

Appendix G



Nous vous invitons à participer à l’étude sur la télémédecine !

- **Objectifs de l’étude**

Votre expérience personnelle de la télémédecine et en particulier avec un enregistreur de rythme cardiaque implanté m’intéresse. En me racontant **vos expériences personnelles**, vous apporterez une contribution précieuse à la recherche de la santé digitale en Suisse.

- **À quoi puis-je m'attendre ?**

Je vous inviterai à au moins un entretien où vous me parlerez de votre vie quotidienne avec un enregistreur de rythme cardiaque implanté.
J’assisterai également à des consultations entre vous et des professionnel.le.s de la santé afin de mieux comprendre le dialogue entre les patients et le personnel médical.

- **Participation à l’étude**

Vous êtes libre d’accepter de participer à l’étude. Les entretiens et les observations seront documenté avec des notes manuscrites, des photos, des enregistrements audio et/ou vidéo. Cette documentation est adaptée en fonction des recommandations de protection concernant la pandémie de coronavirus et des souhaits de participant.e.s. Toutes les données seront traitées dans la plus stricte confidentialité. Cela ne changera rien à votre prise en charge médicale habituelle. La participation est non-rémunérée et n'apporte aucun bénéfice direct aux participant.e.s.

- **Des questions?**

Veuillez lire attentivement la fiche d'information ci-jointe.

Si vous souhaitez participer à l'étude ou si vous avez d'autres questions, veuillez me contacter :

Martina von Arx
Doctorante
Université de Genève
022 379 33 54
martina.vonarx@unige.ch

UNIVERSITÉ
DE GENÈVE

MERCI !

Appendix H

La télémédecine comme une forme de gestion personnalisée de la santé : perspectives de patient.e.s et de professionnel.le.s de la santé

Informations destinées aux patient.e.s. et déclaration de consentement

Madame, Monsieur,

Nous vous proposons de participer à notre projet de recherche portant sur le vécu personnel de patients et patientes porteurs.euses d'un enregistreur de rythme cardiaque implantable de longue durée.

Objectifs du projet de recherche

Nous voulons mieux comprendre l'expérience quotidienne des patient.e.s bénéficiant d'un télémonitoring cardiaque, en particulier celles et ceux avec un enregistreur de rythme cardiaque.

Sélection des personnes pouvant participer au projet

La participation est ouverte à toutes les personnes qui étaient, sont ou seront porteurs.euses d'un enregistreur de rythme cardiaque de longue durée, ainsi qu'à celles qui ont refusé une telle implantation.

Informations générales sur le projet

Nous menons des entretiens avec des patient.e.s. Ces entretiens nous permettront d'explorer comment les patient.e.s concerné.e.s vivent et gèrent leur télé-monitoring cardiaque au quotidien. Ces récits personnels amèneront une perspective précieuse à l'étude de la santé digitale en Suisse. La durée approximative de l'entretien se situe entre 45 et 60 minutes.

De plus, nous assistons à des consultations entre patient.e.s et professionnel.le.s de la santé. Ces observations nous aideront à mieux comprendre le dialogue entre patient.e.s et professionnel.le.s de la santé concernant le télé-monitoring cardiaque.

Nous effectuons ce projet dans le respect des prescriptions de la législation suisse, avec l'autorisation de la commission cantonale d'éthique compétente.

Déroulement pour les participants

Un premier entretien se déroulera 1 à 2 mois après la pose de l'enregistreur de rythme cardiaque ou après qu'un diagnostic ait pu être posé. Le deuxième entretien sera mené 5 à -6 mois après le premier entretien. Entre ces deux entretiens nous assisterons au minimum à une consultation de suivi, qui a normalement lieu 3 mois après la pose de l'enregistreur de rythme cardiaque. Cet ordre peut être amené à changer dans le cas individuel.

Pour les participants dont l'enregistreur de rythme cardiaque a été enlevé sans qu'un diagnostic soit posé, ou qui ont refusé une implantation, un seul entretien sera demandé.

Les entretiens ont lieu au domicile des patient.e.s. Si la situation de la pandémie de coronavirus ne permet pas une rencontre en face à face, l'entretien sera mené par vidéoconférence ou téléphone.

Les entretiens et les observations sont documentés avec des notes manuscrites, des photographies, des enregistrements audio et/ou vidéo. Cette documentation est adaptée en fonction des recommandations de protection concernant la pandémie de coronavirus et des souhaits des participant.e.s. Les photographies ne montreront jamais les visages des participant.e.s.

Bénéfices pour les participant.e.s

Cette étude n'apporte pas de bénéfice individuel aux patient.e.s. Néanmoins, votre participation à cette étude et vos récits personnels amèneront une perspective précieuse à l'étude de la santé digitale en Suisse. Les résultats de l'étude pourraient améliorer considérablement la future prise en charge des patients en télémédecine.

Droits des participants

Vous êtes libre d'accepter ou de refuser de participer au projet. Si vous choisissez de ne pas participer ou si vous choisissez de participer et revenez sur votre décision pendant le déroulement du projet, vous n'aurez pas à vous justifier. Cela ne changera rien à votre prise en charge médicale habituelle. Vous pouvez à tout moment poser toutes les questions que vous jugerez nécessaires au sujet de cette étude. Veuillez vous adresser pour ce faire à la personne indiquée à la fin de la présente feuille d'information.

Quels pourraient être les risques liés à la participation à cette étude ?

Aucune conséquence indésirable n'est attendue de la participation à cette étude.

Confidentialité des données

Pour les besoins de l'étude, nous enregistrerons vos données personnelles et médicales. Les enregistrements audio et vidéo seront transcrits mot pour mot. Les données recueillies à des fins de recherche sont codées lors de leur collecte. Le codage signifie que toutes les données permettant de vous identifier (par ex. le nom, la date de naissance, etc.) sont remplacées par un code. Les personnes ne connaissant pas ce code ne peuvent pas lier ces données à votre personne. Seul un nombre limité de personnes pourra consulter vos données sous une forme non codée, dans le but exclusif de pouvoir accomplir des tâches nécessaires au déroulement du projet.

Durant son déroulement, le projet peut faire l'objet d'inspections. Celles-ci peuvent être effectuées par la commission d'éthique qui s'est chargée de son contrôle initial et l'a autorisé, mais aussi être mandatées par l'organisme qui l'a initié. Il se peut que la direction du projet doive communiquer vos données personnelles et médicales pour les besoins de ces inspections.

Dans le cas d'une publication, les données seront agrégées et ne vous seront donc pas imputables en tant que personne. Votre nom n'apparaîtra jamais sur Internet ou dans une publication. Toutes les personnes impliquées dans l'étude de quelque manière que ce soit sont tenues au secret professionnel. Toutes les directives relatives à la protection des données sont respectées et vous avez à tout moment le droit de consulter vos données.

À la fin de la cette étude, les enregistrements audio et vidéo ainsi que le tableau de codage seront supprimés de tous les serveurs et appareils utilisés, ce qui rendra de fait les données anonymes. Les transcriptions des notes de terrain et des entretiens seront conservées sous forme anonymisée sur des serveurs protégés jusqu'à 10 ans après la fin de la thèse de doctorat.

Retrait du projet

Vous pouvez à tout moment vous retirer de l'étude si vous le souhaitez. Les données personnelles et médicales recueillies jusque-là seront tout de même analysées, ceci afin de ne pas compromettre la valeur de l'étude dans son ensemble.

Rémunération des participant.e.s

Aucune rémunération n'est prévue pour la participation à ce projet.

Réparation des dommages subis

Les dommages de santé que vous pourriez subir du fait de cette étude relèvent de la responsabilité de l'Université de Genève qui est en charge de sa réalisation. Les conditions et la procédure sont fixées par la loi.

Financement du projet

L'étude est intégralement financée par le Fonds National Suisse de la recherche scientifique. Il s'agit d'une thèse de doctorat intégrée dans le projet intitulé « Développement de la santé personnalisée en Suisse : Perspectives de sciences sociales ».

Interlocutrice

Si vous avez des questions pendant ou après l'étude, vous pouvez vous adresser à tout moment à l'interlocutrice suivante :

Martina von Arx (doctorante)

022 379 33 54

martina.vonarx@unige.ch

Déclaration de consentement

Déclaration de consentement écrite pour la participation à un projet de recherche

- Veuillez lire attentivement ce formulaire.
- N'hésitez pas à poser des questions lorsque vous ne comprenez pas quelque chose ou que vous souhaitez avoir des précisions.

Numéro BASEC du projet : (Après soumission à la commission d'éthique compétente) :	2020-01735
Titre de l'étude : (Titre scientifique et titre usuel)	Remote Cardiac Monitoring as a Form of Personalized Health Management: Perspectives of Patients and Health Professionals --- La télémédecine comme une forme de gestion personnalisée de la santé : perspectives de patient.e.s et de professionnel.le.s de la santé
Institution responsable : (Adresse complète)	Université de Genève Prof.Bruno Strasser Université de Genève Section de Biologie Citizen Sciences group 66 Boulevard Carl-Vogt 1205 Genève
Lieu de réalisation du projet :	
Directrice du projet sur le site : (Nom et prénom en caractères d'imprimerie)	von Arx Martina
Participant / participante : (Nom et prénom en caractères d'imprimerie) Date de naissance :	☐ femme ☐ homme ☐ autre

- Je déclare avoir été informé.e, par la personne soussignée assurant l'information, oralement et par écrit, des objectifs et du déroulement de l'étude ainsi que des effets présumés, des avantages, des inconvénients possibles et des risques éventuels.
- Je prends part à cette étude de façon volontaire et j'accepte le contenu de la feuille d'information qui m'a été remise sur le projet précité. J'ai eu suffisamment de temps pour prendre ma décision.
- J'ai reçu des réponses satisfaisantes aux questions que j'ai posées en relation avec ma participation au projet. Je conserve la feuille d'information et reçois une copie de ma déclaration de consentement écrite.
- J'accepte que les spécialistes compétents de l'institution, du mandataire du projet, de la Commission d'éthique compétente pour cette étude, puissent consulter mes données

brutes afin de procéder à des contrôles, à condition toutefois que la confidentialité de ces données soit strictement assurée.

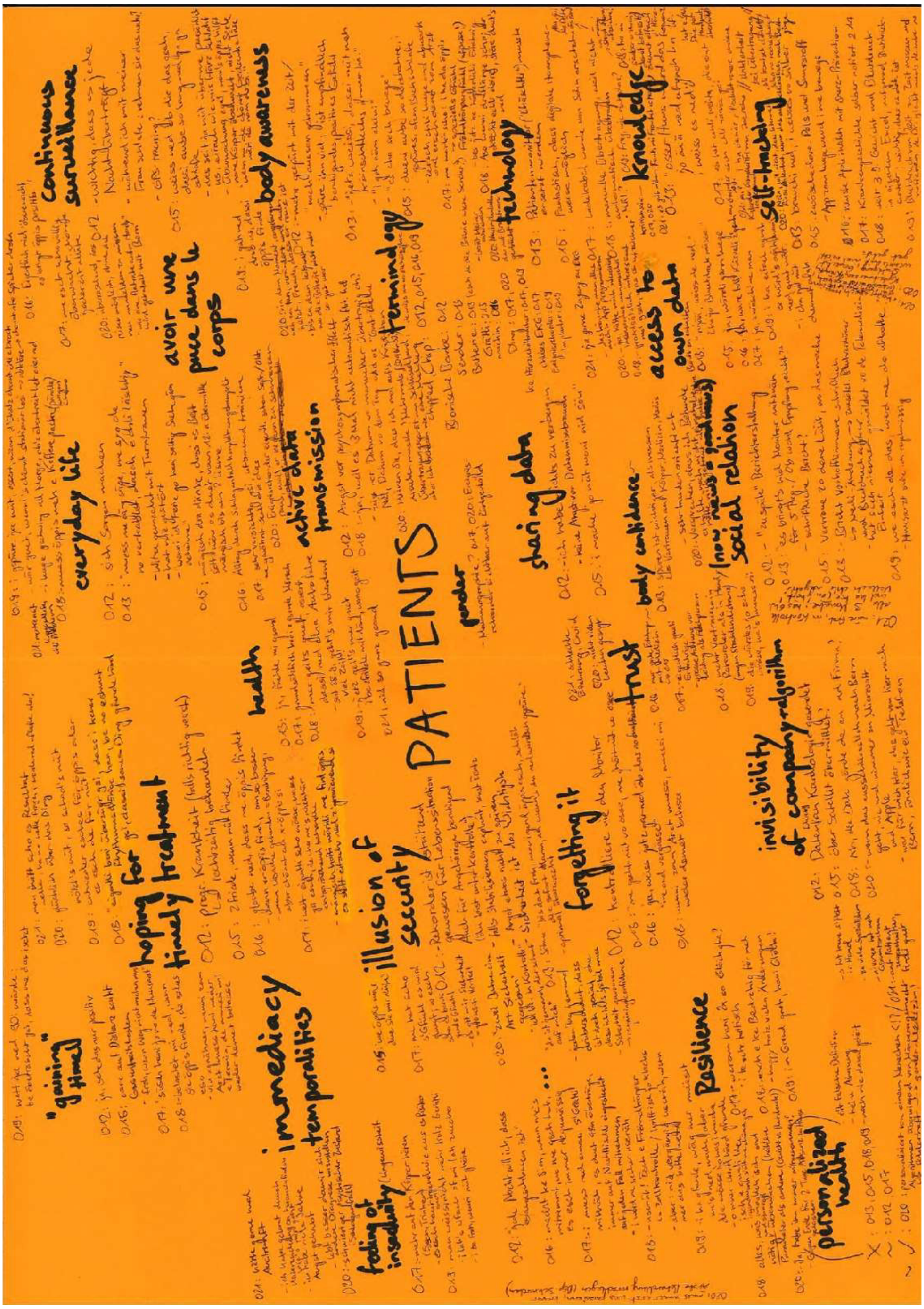
- J'accepte que les entretiens et les observations soient documentés par des notes manuscrites, des photographies, des enregistrements audio et/ou vidéo.
- Je peux, à tout moment et sans avoir à me justifier, révoquer mon consentement à participer à l'étude, sans que cela n'ait de répercussion défavorable sur la suite de ma prise en charge médicale usuelle.
- Je suis informé.e que la responsabilité civile de l'Université de Genève couvre les dommages éventuels imputables au projet que je pourrais subir.

Lieu, date	Signature du participant / de la participante

Attestation de la personne assurant l'information : Par la présente, j'atteste avoir expliqué au participant / à la participante la nature, l'importance et la portée du projet. Je déclare satisfaire à toutes les obligations en relation avec ce projet conformément au droit en vigueur. Si je devais prendre connaissance, à quelque moment que ce soit durant la réalisation du projet, d'éléments susceptibles d'influer sur le consentement du participant / de la participante à prendre part au projet, je m'engage à l'en informer immédiatement.

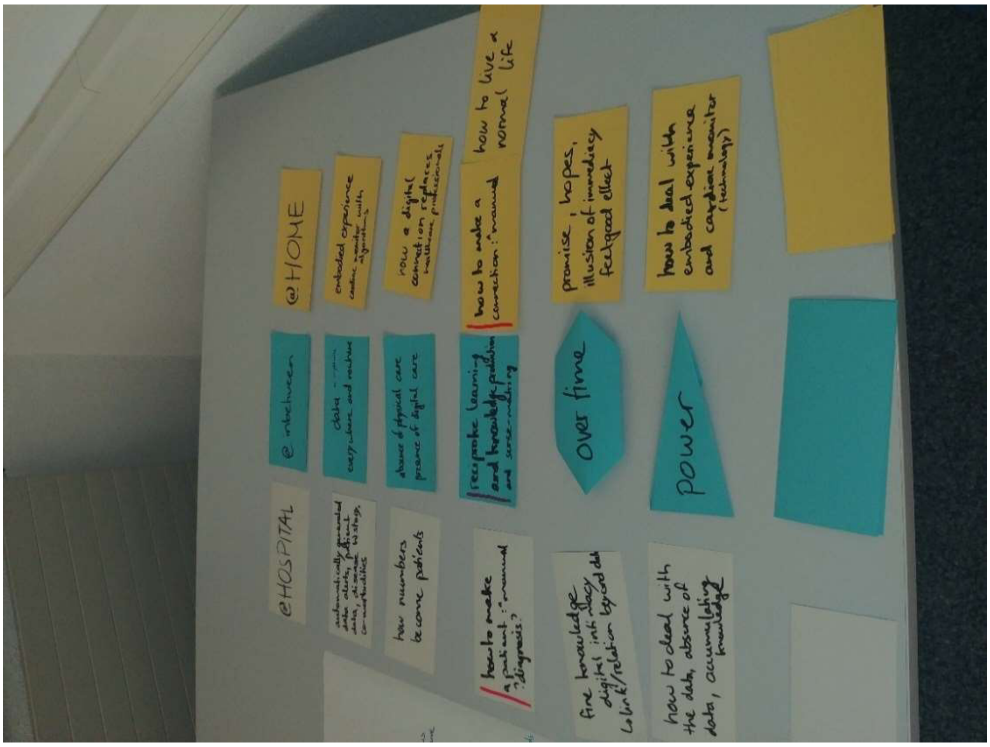
Lieu, date	Nom et prénom de la personne assurant l'information aux participant.e.s en caractères d'imprimerie. Signature de la personne assurant l'information

Appendix I



Preliminary data analysis based on first wave of patient interviews (May 2021).

Appendix J



Data analysis (Photograph taken by M. von Arx, writing retreat Bienenberg, December 12, 2022)

Appendix K

Codes of the theme: Implantation as assembling the body to a data network (8 codes)
easy_technology
implantation
implantation_instruction
implantation_preparation
implantation_questions
implantation_wrap_up
sense-making_quest_knowledge
surveillance_joke_other

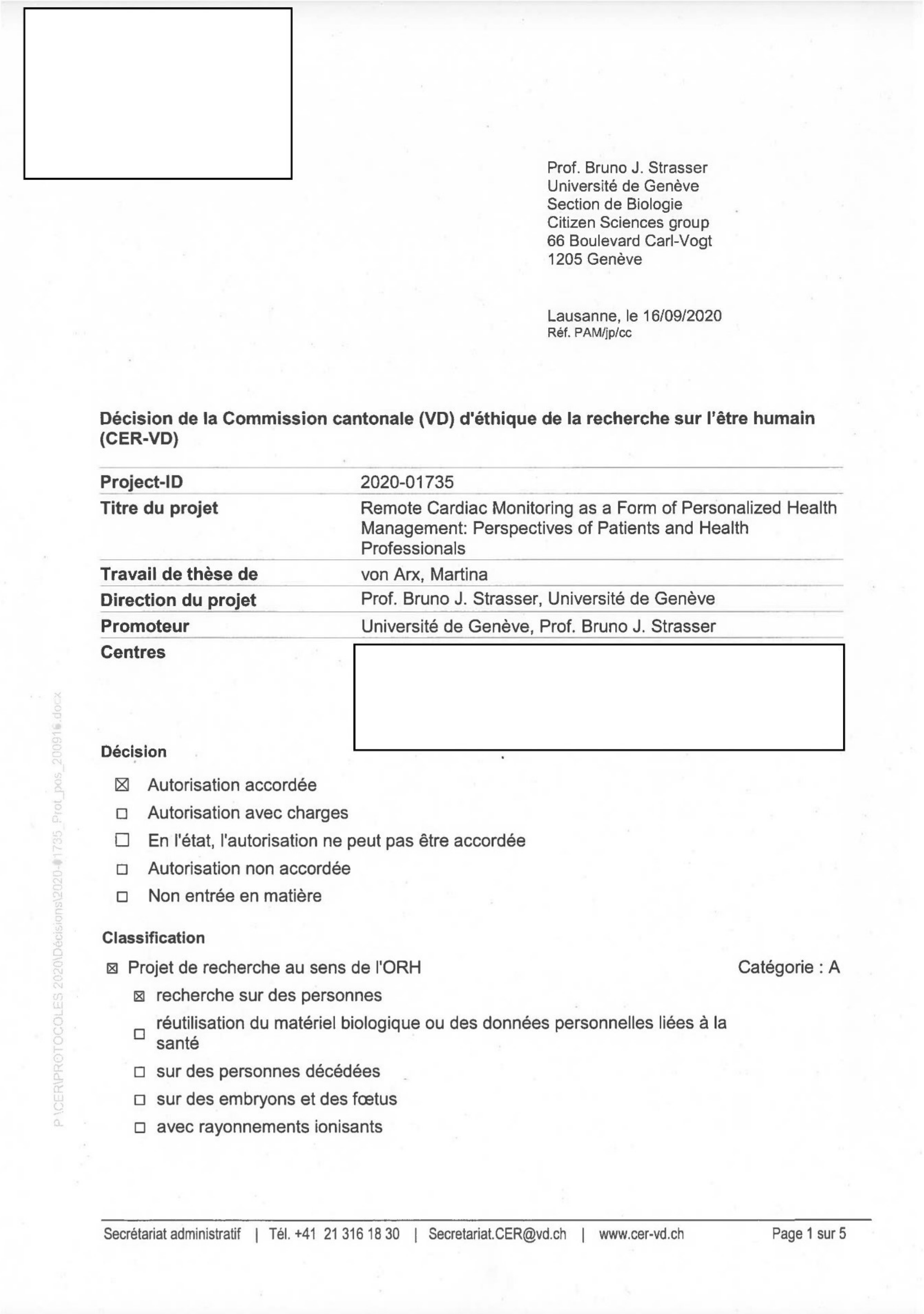
Codes of the theme: Remote cardiac monitoring as a data network (8 codes)
active_data_transmission
invisibility_company
make_sure_patient
perception_implant
sense-making_hope
surveillance_feel-good
surveillance_feel-good_relatives
term_chip_thing_other

Codes of the theme: Two realities colliding – patients' expectations vs. data detective work (13 codes)
being_in_touch_digital
diagnosis_expertise
diagnosis_random
feedback_expectations
feedback_no_news_good_news
relation_nurses_cardiologists
self-monitoring_heart_other
sense-making_data
sense-making_symptoms
sense-making_technical_problems
trust_professionals
trust_technology
wait_and_see

Codes of the theme: Reciprocal learning over time – timing – synchronization (12 codes)
being_in_touch_personal
diagnosis_elimination
diagonsis_gut_feeling
digital_intimacy
forgetting_about_monitoring
resilience_feeling_healthy
resilience_normal_life
resilience_uncertainty
sense-making_diagnosis
sense-making_over_time
surveillance_over_time
trust_over_time

Unthemed codes (11 codes)
data_access
diagnosis_prevention
help_researcher
pain
personalized_precision_medicine
removal_cardiac_monitor
saving_costs
saving_time
scar_aesthetics
telemedicine
telemedicine_future

Appendix L



[redacted]

Prof. Bruno J. Strasser
Université de Genève
Section de Biologie
Citizen Sciences group
66 Boulevard Carl-Vogt
1205 Genève

Lausanne, le 16/09/2020
Réf. PAM/jp/cc

Décision de la Commission cantonale (VD) d'éthique de la recherche sur l'être humain (CER-VD)

Project-ID	2020-01735
Titre du projet	Remote Cardiac Monitoring as a Form of Personalized Health Management: Perspectives of Patients and Health Professionals
Travail de thèse de	von Arx, Martina
Direction du projet	Prof. Bruno J. Strasser, Université de Genève
Promoteur	Université de Genève, Prof. Bruno J. Strasser
Centres	[redacted]

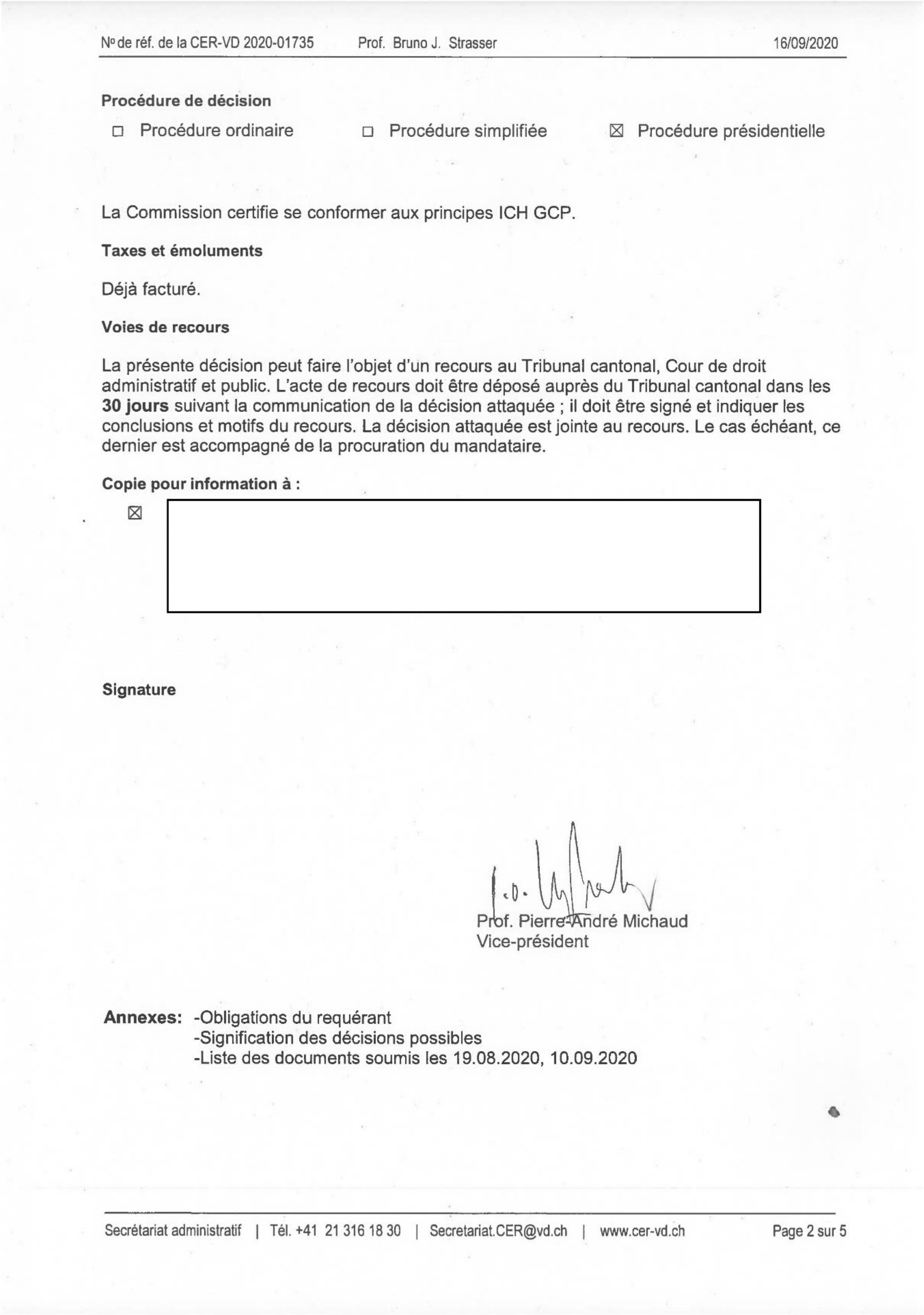
Décision

- ☒ Autorisation accordée
- ☐ Autorisation avec charges
- ☐ En l'état, l'autorisation ne peut pas être accordée
- ☐ Autorisation non accordée
- ☐ Non entrée en matière

Classification

☒ Projet de recherche au sens de l'ORH Catégorie : A

- ☒ recherche sur des personnes
- ☐ réutilisation du matériel biologique ou des données personnelles liées à la santé
- ☐ sur des personnes décédées
- ☐ sur des embryons et des fœtus
- ☐ avec rayonnements ionisants



Procédure de décision

☐ Procédure ordinaire ☐ Procédure simplifiée ☒ Procédure présidentielle

La Commission certifie se conformer aux principes ICH GCP.

Taxes et émoluments

Déjà facturé.

Voies de recours

La présente décision peut faire l'objet d'un recours au Tribunal cantonal, Cour de droit administratif et public. L'acte de recours doit être déposé auprès du Tribunal cantonal dans les **30 jours** suivant la communication de la décision attaquée ; il doit être signé et indiquer les conclusions et motifs du recours. La décision attaquée est jointe au recours. Le cas échéant, ce dernier est accompagné de la procuration du mandataire.

Copie pour information à :

☒ [redacted]

Signature

Prof. Pierre-André Michaud
Vice-président

Annexes: -Obligations du requérant
-Signification des décisions possibles
-Liste des documents soumis les 19.08.2020, 10.09.2020

Annexes

Obligations du requérant (promoteur ou investigateur) :

Soumission de documents : les documents modifiés et les nouveaux documents relatifs à l'étude/au projet de recherche sont soumis via le dossier existant. Les documents qui ne sont plus valides sont effacés et remplacés par les nouveaux. Les documents révisés doivent être soumis une fois en mode « suivi des modifications » et une fois en mode « modifications acceptées » (« track changes » et « clean »). Les documents d'information et de consentement ainsi que le protocole doivent être transmis dans un format permettant la recherche (PDF navigable) ou scannés avec une fonction OCR (Optical Character Recognition). Le cas échéant, les documents révisés sont également mis à disposition des autorités compétentes pour approbation.

Remarque: La commission d'éthique compétente examine, dans le cadre du processus d'autorisation, les feuilles d'information et déclarations de consentement dans une des langues officielles suisses: allemand, français ou italien. La commission d'éthique ne fait qu'accuser réception des feuilles d'information et déclarations de consentement écrites dans d'autres langues. Le promoteur ou la direction du projet est responsable de la traduction correcte des documents.

Obligations d'annonce : Les obligations d'annonce (p.ex d'évènements indésirables, d'interruption d'étude) et de soumission pour autorisation des modifications essentielles obligatoires s'appliquent (Ordonnances). Le rapport final est à remettre à la commission d'éthique compétente dans un délai d'une année à compter de la fin ou de l'arrêt de l'étude.

Devoir d'enregistrement : Le promoteur d'un essai clinique doit procéder à l'enregistrement dans un registre primaire reconnu par l'OMS ou dans le registre de la bibliothèque médicale nationale des Etats-Unis d'Amérique (clinicaltrials.gov) puis indiquer le numéro de l'étude sur le portail BASEC. Le transfert des données vers le Swiss National Clinical Trials Portal (SNCTP) est effectué automatiquement suite à l'autorisation de l'étude par la commission d'éthique, sous réserve de l'accord du requérant. Les données relatives à l'essai clinique figurant sur les deux registres sont accessibles au public. Swissethics publie également sur son site des informations sur chaque étude ayant reçu une autorisation, à l'exception des essais cliniques de phase I.

Signification des décisions possibles

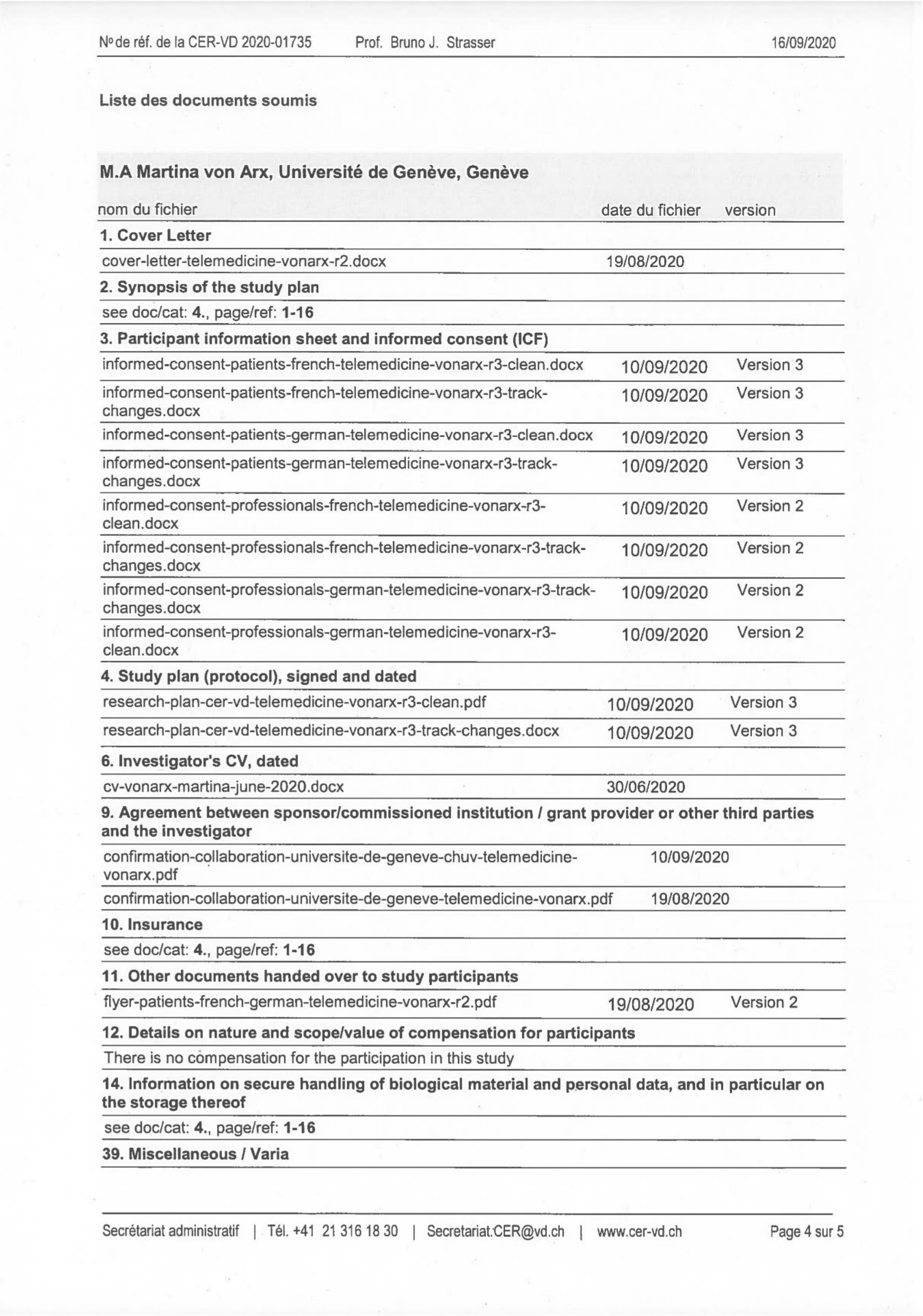
Autorisation accordée : L'étude peut commencer selon le plan de recherche accepté. Elle doit être menée dans le cadre des dispositions légales en vigueur. D'autres obligations d'autorisation (Swissmedic/OFSP) doivent être respectées.

Autorisation avec charges : L'étude peut commencer selon le plan de recherche accepté. Elle doit être menée dans le cadre des dispositions légales en vigueur. Les charges doivent être remplies dans un délai de 30 jours. Les documents modifiés seront réévalués en procédure présidentielle. D'autres obligations d'autorisation (Swissmedic/ OFSP) doivent être respectées

En l'état, l'autorisation ne peut pas être accordée : L'étude ne peut pas commencer. Prière de répondre point par point aux conditions de la commission d'éthique et de nous faire parvenir les documents révisés avec les modifications apparentes et la mention de la date de la nouvelle version.

Autorisation non accordée : L'étude ne peut pas commencer dans sa forme actuelle. Une nouvelle soumission reste possible.

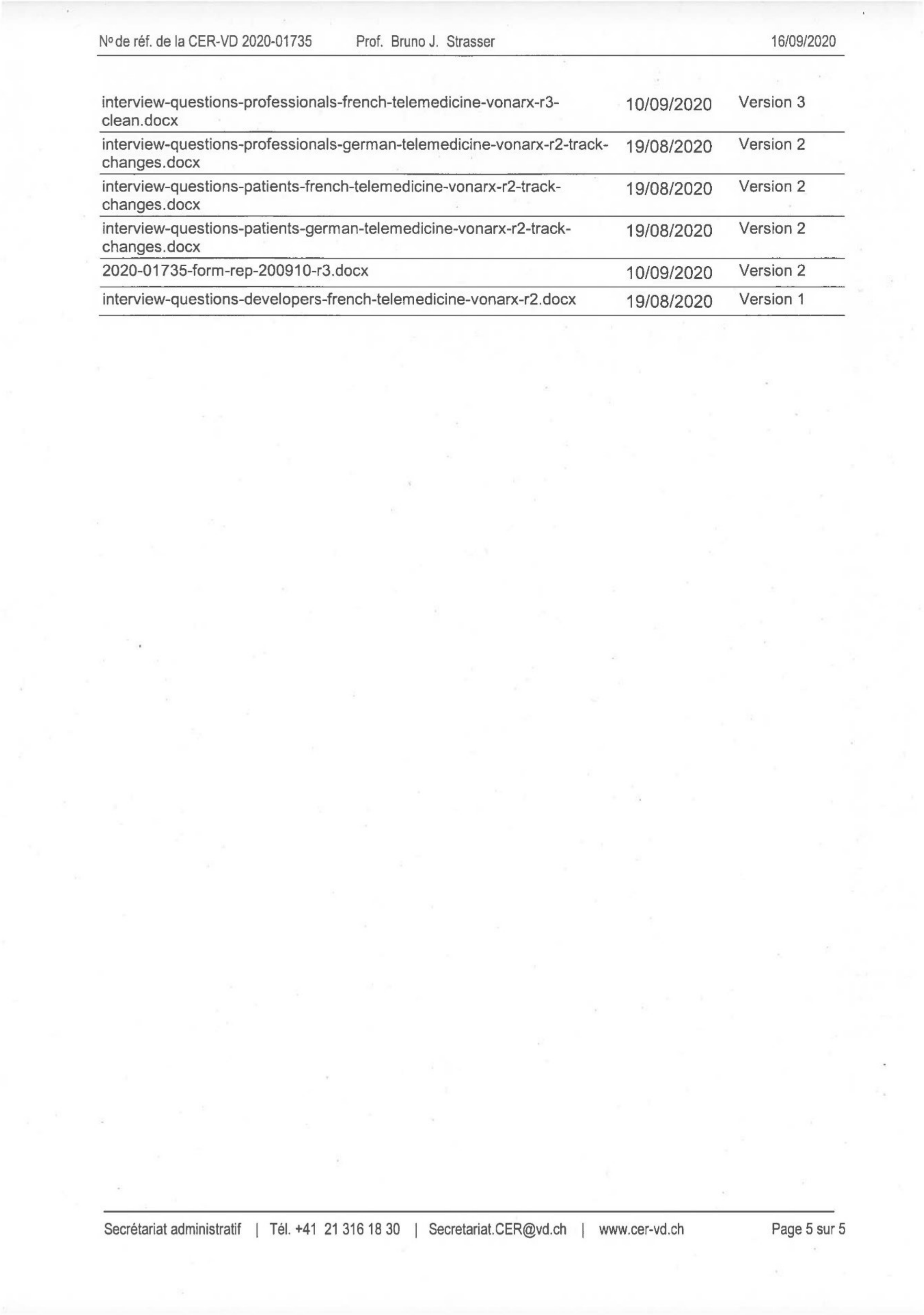
Non entrée en matière : Justification, voir ci-dessus, par exemple la commission d'éthique n'est pas juridiquement compétente pour accorder une autorisation ou l'étude ne nécessite pas d'autorisation



Liste des documents soumis

M.A Martina von Arx, Université de Genève, Genève

nom du fichier	date du fichier	version
1. Cover Letter		
cover-letter-telemedicine-vonarx-r2.docx	19/08/2020	
2. Synopsis of the study plan		
see doc/cat: **4.**, page/ref: **1-16**		
3. Participant information sheet and informed consent (ICF)		
informed-consent-patients-french-telemedicine-vonarx-r3-clean.docx	10/09/2020	Version 3
informed-consent-patients-french-telemedicine-vonarx-r3-track-changes.docx	10/09/2020	Version 3
informed-consent-patients-german-telemedicine-vonarx-r3-clean.docx	10/09/2020	Version 3
informed-consent-patients-german-telemedicine-vonarx-r3-track-changes.docx	10/09/2020	Version 3
informed-consent-professionals-french-telemedicine-vonarx-r3-clean.docx	10/09/2020	Version 2
informed-consent-professionals-french-telemedicine-vonarx-r3-track-changes.docx	10/09/2020	Version 2
informed-consent-professionals-german-telemedicine-vonarx-r3-track-changes.docx	10/09/2020	Version 2
informed-consent-professionals-german-telemedicine-vonarx-r3-clean.docx	10/09/2020	Version 2
4. Study plan (protocol), signed and dated		
research-plan-cer-vd-telemedicine-vonarx-r3-clean.pdf	10/09/2020	Version 3
research-plan-cer-vd-telemedicine-vonarx-r3-track-changes.docx	10/09/2020	Version 3
6. Investigator's CV, dated		
cv-vonarx-martina-june-2020.docx	30/06/2020	
9. Agreement between sponsor/commissioned institution / grant provider or other third parties and the investigator		
confirmation-collaboration-universite-de-geneve-chuv-telemedicine-vonarx.pdf	10/09/2020	
confirmation-collaboration-universite-de-geneve-telemedicine-vonarx.pdf	19/08/2020	
10. Insurance		
see doc/cat: **4.**, page/ref: **1-16**		
11. Other documents handed over to study participants		
flyer-patients-french-german-telemedicine-vonarx-r2.pdf	19/08/2020	Version 2
12. Details on nature and scope/value of compensation for participants		
There is no compensation for the participation in this study		
14. Information on secure handling of biological material and personal data, and in particular on the storage thereof		
see doc/cat: **4.**, page/ref: **1-16**		
39. Miscellaneous / Varia		



interview-questions-professionals-french-telemedicine-vonarx-r3-clean.docx	10/09/2020	Version 3
interview-questions-professionals-german-telemedicine-vonarx-r2-track-changes.docx	19/08/2020	Version 2
interview-questions-patients-french-telemedicine-vonarx-r2-track-changes.docx	19/08/2020	Version 2
interview-questions-patients-german-telemedicine-vonarx-r2-track-changes.docx	19/08/2020	Version 2
2020-01735-form-rep-200910-r3.docx	10/09/2020	Version 2
interview-questions-developers-french-telemedicine-vonarx-r2.docx	19/08/2020	Version 1