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Re-Imagining Healthcare – Developing an Interoperable European Health Data Infrastructure

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List of Abbreviations

ANT - Actor Network Theory

D2D - Device to Device

EC - European Commission

EU - European Union

ELGA - Elektronische Gesundheitsakte

EHR - Electronic Health Record

HCP – Healthcare Professional

IHS - InteropEHRate Health Service

S4H - Smart 4 Health

S-EHR - Smart Electronic Health Record

1. Intro

1.1 Personal Vignette

After returning home from a morning run and getting ready for the day, I find myself feeling inexplicably uneasy. As I move about my apartment the pang of anxiety in my stomach grows until eventually, my chest tightens, I am experiencing an extreme head rush and I urgently sit down. Cross-legged on my bedroom floor, I realise my heart is racing at what feels like a million beats a minute. Suddenly I clue in, I am experiencing for the first time in my life symptoms of a heart condition I have called Wolff Parkinson White syndrome. I look down at my smartwatch to check my heartbeat, it reads 62. Being familiar with monitoring my heart rate during training on the Canadian rowing team I am fairly certain my watch is glitching, a normal occurrence, I remind myself when my heart rate goes above 180. I pull out my Android smartphone, open the built-in health app and place my finger on a sensor to test my pulse. It reads 236 bpm and raises as I leave my finger on the sensor.

So many thoughts are racing through my head; a flashback to when I was first diagnosed with the condition, the doctor telling me there is a small chance when I experience symptoms my heart will simply give out and stop beating, the tests I did in my last check-up. “Okay just breathe,” I tell myself, “Relax this is going to go away”. After what feels like 5 minutes but in reality, maybe 30 seconds, the episode was over. I immediately text my parents who are at home in Canada and call my partner who is living in Vienna with me. My next call is to a heart specialist's office where I get an appointment the next day after telling the receptionist my condition and what I just experienced.

Fast-forward to one day later. I am at the heart specialist’s office. In my backpack, I have a file folder 10 cm thick full of test results, images, scans, and notes from the past 3 doctors who diagnosed me or performed check-ups. We discussed the history of my condition, and the doctor asked me for different test results. I file through my folder and hand over paper copies of each test result feeling very happy that I have them with me and that my tests performed in 2 different countries are also recognized now in this third country I am living in. We then talk about the experience I had the morning prior and the tests that need to be done to determine whether I need a surgical procedure.

1.2 Intro to Research

This one experience I have described above provides an introduction to the themes and topics of this thesis: digital health data and the technologies, uses and practices surrounding it. In this story, there are multiple examples where health data is being collected, stored, generated, and exchanged for me to achieve “good health”. The paper files I bring with me to the doctor are a mix of digital and physical health data coming from multiple Healthcare Professionals (HCP) that I have printed copies of and been responsible for collecting and sharing. I exchange this data generated from previous doctors who have treated me, with the doctor I am now seeing for the first time. This current doctor creates a new digital file that represents me, takes notes, and shares this with the other HCP who will help to perform multiple tests on me, and eventually add more health data. All of this is stored on my Austrian Electronic Health Record (EHR) within Austria’s elektronische Gesundheitsakte (ELGA) which by design will make my health records accessible to other HCPs I encounter in the country in the future.

I was experiencing symptoms of WPW, and my heart was racing. I relied on wearable and sensing devices to monitor my health based on my knowledge and familiarity of my health data in the past. Throughout my 10-year career as a semi-professional rower, I became accustomed to tracking different data points related to my own body. From heart rate, sleeping times, and sleep quality, to hydration level, power output, and perceived effort, at a time in my life, I knew close to everything I could in terms of health data, that I as a layperson with certain technological equipment could have. As a citizen, concerned for my health, in the moments described in the vignette, my awareness through data and technology of what was normal, and what was not, allowed me to determine the next steps in my care journey for this situation. Further still, awareness of this health data that I generated on my own, in addition to the data I had collected and stored from previous encounters with doctors, allowed the doctor I was seeing to gain a better understanding of my circumstance and decide on the next steps forward. There was trust from the doctor in both the data that I generated, and the data I was providing from other HCPs.

This short personal vignette and reflection serve the purpose of showing how data is something citizens encounter constantly in their everyday lives. Health data specifically, and related technology, are becoming more and more prominent within European society. Wearable devices make it possible to track steps, pulse, sleep quality, breathing patterns and menstrual cycles. EHRs allow doctors and patients to store and view medical information such as medical imaging, test results, patient’s vitals, allergies and so on. With the rise of the Global Covid-19 Pandemic test results are constantly being tracked and updated, and information that we never thought of before as health related, such as location and contact tracing, are considered relevant for medical safety. The human body, now more than ever, is being measured, monitored and in some senses made by the health data. The private health and wellness industry has a major lead in collecting, owning, and making use of health data, compared to the public sector, but there is potential for this to slowly change. Governments around the world are currently negotiating between data laws, ethical practices, the efficiency of healthcare and the overall health of populations. Looking specifically at the European Union and the UK, many countries have made or are making the transition to national electronic health record systems.

Especially with the rise of the COVID-19 pandemic, but even before this, the EU emphasised promoting the production of new technology and innovation in the direction of digital health. One avenue that this development has been pushed towards is to create an interoperable system for HCPs and specifically citizens to use. When taking into consideration the huge amounts of data being produced there are infinite possibilities and opportunities that could arise from combining this data and making it accessible to specific groups of people. On the other side, there are of course many potential risks when dealing with sensitive personal data being shared and used for different purposes by varying groups of people. With both the risks and the opportunities, there are many actors involved who all have their own ideas and imaginations of what healthcare can, should or should not look like. With this thesis, I am interested in looking at the entanglement of imaginaries of healthcare and the development of a digital health data platform. More specifically, this research aims to look at the imaginaries that are co-produced with the development of a European digital health data platform that aims to provide better healthcare. Throughout this project, I hope to investigate how the development of a project aiming to build an interoperable health data platform, is developed simultaneously with an imaginary of healthcare that it will afford, and how the different actors involved shape and influence the imaginary during this process.

This thesis is organised into five main chapters. Following this short introduction section (Chapter One), Chapter Two will explore the current state of literature related to the focus areas of this project. The literature reviewed in this chapter comes from multiple areas including medical sociology, critical data studies, surveillance studies, infrastructure studies and Science and Technology Studies (STS). This chapter will give an account of the State of the Art and conclude by situating the research of this project within a gap in the literature. Chapter three will describe the research design and case study used as the site for this project. The first section of chapter three (3.1) will describe the specific questions guiding the research. Section 3.2 will provide a detailed account of the Horizon 2020 project, and the stakeholders involved in building the interoperable health data platform that this thesis is focused on studying. Section 3.3 will discuss the methods and theories of study coming from the STS field that will be applied to the research material, which for this thesis included both interviews and document analysis. The following section of chapter three (3.4) will explain how access to the field of this case site was gained and be concluded with a section (3.5) clarifying the methods used for data analysis. Chapter four of this thesis, makes up the bulk of this project, analysing the different materials collected to answer the research question and sub-questions. The analysis is broken up into four subsections starting with outlining the wider framework of the healthcare imaginary coming from the different groups of actors involved in the project. The second section (4.2) looks deeper into exactly how healthcare is described and imagined throughout the development of an interoperable health data platform. Section 4.3 focuses on looking at the specific aspects of the co-produced view of healthcare that involve technology, or technological solutions that the infrastructure being built aims to provide. Finally, section 4.4 will look at how different users are imagined within this project. Subsequently, this section will also look at non-users and investigate if certain groups are either not discussed or even excluded from the visions of healthcare presented and pushed forward. Breaking the analysis into these four sections aims to give detail to different areas of the project and materials that will answer the research questions set out in Chapter Three. The fifth chapter of this thesis is the concluding chapter which will both aim to clarify the findings of the analysis in the context of the research questions and suggest further avenues for research within this topic.

2. State of the Art and Theoretical Framework

The intro of this thesis has given an overview of the research interests of this project, being the co-production of an imaginaries being developed, alongside the development of a digital health data platform that aims to provide better healthcare. More specifically, the research interest lies in the intersection between imaginaries of users, data practices and healthcare coming from relevant actors involved in the development of an innovative, European digital health data platform and how these imaginaries are entangled and shaped through this development process. Based on these research interests, this chapter will review the current literature in multiple related pre-existing strands of medical sociology, surveillance studies, big data in healthcare and infrastructure studies.

Topics such as the digitization of healthcare and digital health platforms are often looked at through a functionalist lens focused on value creation and how human health can be improved (Lim & Maglio 2018; Maglio, Kwan & Spohrer, 2015). Taking an alternative viewpoint, this literature review will focus on the engineering of digital technologies and services in healthcare (Maglio, 2015), as well as work that looks at big data in healthcare, data bodies and the sociopolitical and epistemological dimensions of data in these senses (Mager & Mayer, 2019; Lupton, 2014). I will give an overview of current work done on the topics of digital health data, big data, digitization of healthcare and infrastructures and their related sociopolitical dimensions. Looking at this discourse will draw attention to arguments made about the use of data in healthcare, the introduction of the data body, ideas about responsibility of care, ownership, and governance in the context of data commodification, or the knowledge economy as well as imaginaries of health data and respective platforms. To organise the many different strands of work coming together in this literature review, the discussion will be guided through four main sections, data bodies and big data in healthcare, the social dimension of data, the politics of data, care, and knowledge economies and finally, imaginaries of digital healthcare and infrastructures.

2.1 Data bodies and Big Data in Healthcare

The notion of data bodies emerged from the framework of Armstrong's (1995) surveillance medicine which can be described as the shift of emphasis from individualised therapy to the utilisation of statistical analyses and broader public health interventions. During the 20th century, the term surveillance medicine referred to the practice of using growth charts, depicting graphs and trajectories of height and weight, to compare children’s measurements and classify normal growth. Later, joining the list of growth charts on what Armstrong (1995) calls “machinery of observation” (p. 396), were sociomedical surveys carried out during World War II, as well as additional post-war screenings. When looking at tools such as growth charts, surveys and screening used to measure and track citizen’s health it is important to note that this meant one's health could only be compared to what was determined as normal and healthy among the general population. This raises questions of what it means to be normal, and what was included or left out when these average metrics of health were determined. The observation of health and pursuance of data collecting that the practices of surveillance medicine drove, translated into the conceptualization of health and illness outside of the individual body and brought these meanings to contexts of larger societies and populations. From this shift in contextualisation from measuring the health or illness of single individuals to looking at the health status of an entire population came the normalisation of two new commonly held beliefs. The first being that bodies should be both monitored and classified and the second being that healthy people are at risk of getting sick (Armstrong, 1995). This second idea that a healthy individual, or body, is at risk of illness introduces a temporal and multidimensional framework in which identities and risks can be juxtaposed with populations and possibilities of illnesses.

The normalisation of classifying what a healthy body is and the idea that all bodies face the risk of becoming ill, resulted in another health-related trend. According to Prainsack (2017), the combination of needing to track and monitor data for health purposes and to avoid the risk of becoming ill, along with wider lifestyle tracking reasons prompted widespread health data tracking habits to emerge. Simultaneously this combination of data tracking for both health and lifestyle purposes has been largely enabled by the increasing amount of health-tracking apps, wearable technologies and smart devices. The wide range of health and or lifestyle technology people use is constantly collecting, storing and displaying information such as (but not limited to) steps, heart rate, workout routines, sleep patterns, menstrual cycles, temperature, mood and location (Lupton 2017a; 2017b). The increased quantification of the human body through data monitoring, or as Prainsack (2017) describes it “hyper data collection” (p.49) can be accounted for by two main factors. The first of these two factors is attributed to the role large corporations and commercial actors played in making not only technology related to self-tracking and monitoring health information but also communities and forums to discuss and exchange this information, so widely available and accessible. Here a transition can be observed from traditional surveillance medicine, as previously discussed, being driven by public health reasons, to more private actors and reasons that are beneficial to them. This shift as well as the widespread technology needed to carry out these practices can be largely attributed to the insurance industry and its development of statistics as a science (Desrosiers, 2002) and a social technology that explains societal structures (Mayer, 2012). The second factor behind the increased quantification of the human body is the interest individual citizens have in personal data tracking and what this practice gives them visibility to and is widely studied. For example, Czerniawski (2007) discusses the intrigue for citizens to be able to assign a numeric value to a person's weight that holds meaning and makes the metric comparable in both societal and medical contexts. In a study, Lupton (2020) asks the question “what can data do” (p.6) and uses the answers provided by participants of the research to display the variety of benefits felt by people who track and monitor metrics on their own bodies. A third facet of this fascination with self-monitoring comes from Igo (2007) who shows citizens are intrigued by how data can depict an image or provide an understanding of the mass society and allow them to situate themselves within it based on a numerical or statistical measurement. Similar to this fascination, Sharon and Zandbergen (2017), discuss how self-trackers, referring to people who are part of the quantified self-movement, are not simply drawn to the objectivity or perceived power of truth that some describe this data to provide. Instead, in this context, self-quantifying practices are argued to be forms of practising mindfulness, used to refrain from conforming to societal norms and can be used to help communicate oneself.

Something important to note when understanding the development and shifts within practices of surveillance medicine, self-tracking and being able to situate oneself or others within a wider population is how large data sets are a necessary factor in making this possible. It is not enough for data to be collected individually whether it be by private or public players, or citizens themselves. For comparisons to be made, and values to be commonly understood, the data needs to be put together and viewable as one much larger picture. These large data sets, and many of the practices used to make sense of them and individual data within them, along with many other practices that have been accepted and used in areas of society, healthcare being one of them, can all be referred to under the blanket term Big Data (Stevens, Wehrens & de Bont, 2018). Stevens, Wehrens and de Bont point out how in addition to the common positive rhetoric and ideals of Big Data and its promised positive capabilities, fields such as critical data studies and STS have pointed out countering problematic and often neglected dimensions. This work points out how within the healthcare domain, the positive ideals of Big Data are often left unbalanced by any critical interpretations or practices. The concept of data bodies is useful when thinking about large health data sets and more generally Big Data because it looks at the role data plays within healthcare as it encompasses the way physical bodies are connected to the virtual, spatiotemporal, and sign dimensions that are created through data sets (Krämer, 2008). Data bodies as a concept also capture the different dimensions, both virtual and physical, that data plays a role in shaping. The word body refers to not only the singular physical human body but also, the connections between individuals and communities, the private and the public, and humans and machines (Apprich, 2018; Berry & Dieter, 2015). Law’s (2007) material-semiotic approach from the classical Actor Network Theory (ANT) (Latour, 2005) has most commonly been used to study the data body. Building on this there are many additional analyses of data bodies done using theories of new materialism (Barad, 2003; Haraway, 2003) and socio-material perspectives from a medical context (Lupton, 2016c, 2018). From this same strand of analysis, Mager and Mayer (2019) frame data bodies as a socio-material coupling of body and data (p.98) and Lupton (2018) refers to this coupling of data and body as human assemblages. Both concepts have prompted questions about what these couplings or assemblages afford (Lupton, 2018) and the thing power (Bennet, 2004) that influences the everyday decisions and actions of individuals. In this line of inquiry, Lupton and others have demonstrated how people and their data are continuously mutually shaping each other.

2.2 Social dimensions of data

Thus far the literature review has given an overview of the frameworks and concepts leading to the concept of data bodies, or those that have branched from the concept to discuss how human bodies and the data bodies that represent them are mutually shaping each other as well as larger sets of data. This next section will continue to look at work done on data bodies, digital health data and Big Data but with a focus on the related social aspects, or notions developed that help explain or discuss how this data moves through and shapes social dimensions. Starting with Haraway's (2003) new materialist perspective, the concept of assemblages between human and non-human actors discussed in the above section also introduces the concept of active data.

> "Digital data about people may be conceptualised as ' lively' in several respects: they are information about human life itself; they have a vitality and social life of their own, circulating as they do between a multitude of sites and being continually repurposed; they have an impact on people' s lives; and, as important elements of the global knowledge economy, they contribute to livelihoods" (Lupton, 2018, p.114).

In her study, Lupton (2018) asserts that data bodies possess a concept known as 'biovalue', which arises from the varying social and political purposes that data becomes useful for on social and political levels when they are transformed, combined, or analysed in specific contexts. This notion of bio value can be understood within the same framework as the concepts of biopower and biopolitics (Rabinow & Rose, 2006). Looking at the cluster of work, as already discussed, on data bodies, through a lens of social dimensions, data or more specifically health data and the many purposes it fulfils from an individual liberation to private or commercial gain to state surveillance and intervention, is never innocent of absent of political or economic agendas (Lyon, 2005). While this is an important fact to make note of on its own, it is also crucial to hold on to this understanding when looking at how data is tracked, measured, stored and transferred for different healthcare practices. What we will see in the remaining sections of this literature review, is there are often multiple intentions behind the face value or readily communicated purposes for health data and practice related technologies and platforms.

As previously explained in the overview of literature above, health and lifestyle tracking practices and technologies through wearable sensors, smart devices and apps have become widely popular over the past 15-20 years. Within society, there are various reasons people decide to take part in one form or another of digital self-tracking almost always in directly or directly related to impacting their own state of health. Some examples of these purposes include individuals with diabetes using sensors to measure their blood sugar levels throughout the day, people who menstruate trying to become pregnant tracking and monitor their cycles to have a clear understanding of when they are fertile and those experiencing mental health issues keeping track of their moods and feelings through digital means to learn more about and hopefully improve their overall wellbeing (Lupton 2017a; 2017b). The reasons linked to each form of tracking or data that is being collected, are of course related to health, but also to some extent social aspects of human life. By far the most common form of digital self-tracking today happens with smart watches track factors including but not limited to sleep quality, steps taken, exertion, heart rate and recovery that is all displayed and tracked over time on an accompanying application usually on a smartphone (2017b). Again, this form of self-tracking has a related societal justification. In this case it is competed largely by athletes ranging from a professional to armature or hobby level. Of course, there also other individuals who are interested in monitoring certain bodily statistics for various reasons. As briefly discussed in the section above, there is also a global population of people who take part in the Quantified Self movement. Citizens who participate in this movement collect physical, environmental, biological and behavioural aspects of their day-to-day activities with the aim of adding a numeric, qualitative account to life (Wolf, 2011). In all of these forms of self-tracking that have been mentioned thus far, and those which have not mentioned, Lupton (2016a) discusses that the process always co-shapes the human body, the data being collected as well as the social relationships of individuals who are taking part in the process.

Unsurprisingly, health data tracking technologies are also widespread within the medical field. Patients have gained new abilities and possibilities to take ownership over their own care practices through self-monitoring. Take the example just mentioned of individuals with diabetes measuring their bloods levels, this allows them to then self-administer a specific dosage of medication according to their doctors' instructions. In this example, what Strauss et al. (1982) call “patient work” is transformed using technology that allows for self-tracking and data collection (Mathieu-Fritz and Guillot 2017). Something else that happens when patients begin to self-monitor and track their own health data specifically regarding a medical condition, is a change in the doctor-patient relationship as patients become in some sense experts on their own condition and symptoms (Baszanger, 1986; Fritz and Guillot 2017).

Similar to the way data tracking practices mutually shape the data being tracked and the decisions or social interactions of the person tracking them, these practices also shape and are shaped by the larger social communities that form around them. Looking at these self-tracking practices ranging from those of members who identify with the Quantified Self movement in pursuit of “self-knowledge through numbers” (Wolf, 2010), all the way to very casual forms of self-monitoring activities, a common by product of all these practices is the formation of social communities. One way this specific social aspect of self-tracking practices gets described within literature is through Hagen’s (2010) notion of biosociality. Hagen claims forms of biosociality are created through platforms, such as 23andme, where citizens share their bio data and contribute to large data sets of information. Initially in 1996 Rabinow introduced the term biosocialitiy which refers to the social exchanges and transformations of relationships that happen when knowledge about human bodies and diseases changes. Rabinow showed how members of communities who shared similar illnesses felt a sense of empowerment and gained expertise through their participation. Social communities are created when individuals use biotechnology platforms such as the ones discussed to share personal health related information (Hagen 2010). As individuals participate in these communities, not only sharing their personal data on their bodies but also ingraining in discussion, expressing concerns or providing feedback and encouragement to fellow members there is a shift from the quantified self to the quantified us.

The benefits and or outcomes of participating in such communities is something many have studied. Some of the more obvious benefits people who participate in these social dimensions of self-tracking Jordan and Pfarr (2014) discuss include the ability to compare data with individuals who you share similarities with, motivation to reach mutual or similar goals, and informed decision making. Additional notable benefits of being part of social self-tracking communities include a sense of belonging (Lupton, 2015) as well as the experience of solidarity that is reported to be felt by individuals who connect with others through sharing or donating their data (Sharon, 2017). Lupton (2015) adds to this list of benefits with the sense of belonging to something bigger than oneself. There are also communities created within this context that are driven by philanthropic purposes. Communities of this type challenge the distrust that is often associated with sharing health data through building and demonstrating positive relationships between the private and public health sectors. Additionally, these philanthropic communities also promote the donation of individual health data for research and the aim to advance a more holistic understanding of public health (Tatevossian, 2011; Nielsen, 2013). This section has provided an overview of the work done and concepts developed to describe how humans, data, and data bodies move through social dimensions by shaping each other and the communities surrounding them. In the next chapter of this literature review, I will build on this by reviewing work that touches on the politics involved in health data and health data practices as well as relationships to care and knowledge economies.

2.3 Politics of Data, Care and Knowledge Economies

When looking at self-data tracking practices mentioned thus far, and the social activities surrounding them, it is important to also be aware of the political implications that are present as well. While the health data tracking, I just discussed is done largely by individual choice, the connection to the original term of surveillance medicine, and how measurements and comparisons of health data were used for public healthcare interventions. When thinking in this context, it is also interesting to look at work done that notices a shift in the responsibility of governance of health and health data tracking away from institutions, onto the individual citizen (Lupton, 2015; Ajana, 2017). Ajana (2017) discusses how self-quantification practices contribute to the development of cultural norms that encourage self-optimization, self-development, and self-investment. These outcomes of self-tracking in some contexts have been compared to neoliberal ideals in terms of how citizens are incentivized to behave in a certain way (Lupton, 2016b; Moore & Robinson, 2016). More specifically, the idea that individuals should constantly pay attention to certain data points and work towards self-improvement of their health and physical body is reinforced through cultural and societal rewards. This phenomenon can be looked at from two sides, the first being the view that assumes under these circumstances, individuals are responsible for their own bodies, and health and therefore have the freedom to make their own choices in how to take care of their bodies. The second viewpoint states that an individual's choices are highly influenced by both the classifications and norms that are built into self-tracking technologies and platforms, as well as societal benefits such as lower health insurance. Related to these two opposing ideas is Mol’s (2008) analysis of the differences between the logic of care and the logic of choice. Within this analysis Mol explores how choice within a healthcare context is often meant to give patients more power or freedom, but this is not always the case. More choice regarding caring for health can be difficult for patients and instead of empowering them, leave them with more responsibility.

Even though the discourse around the responsibility of care in Mol’s Logic of Care is not directly written about digital practices of healthcare, the observation that patients take on the responsibility of care, and choice of care, is well suited to look at how patients gain new responsibilities in their care when digital health data practices are involved. This is even more true when looking at self-tracking practices and the relationship between the responsibility of caring for one’s own health through data. Related to this line of thought, Erikainen et al. (2019), highlight the argument that in the digital era we are currently living in, citizens can no longer be considered as passive recipients of care within digital healthcare systems but are instead active participants taking on multiple roles. The entire patient experience within this digital healthcare realm is analysed in the context of what Lupton (2014) refers to as the digital patient experience economy. Patients are seen to encounter various aspects of this economy including consuming and producing content on related health data platforms and Web 2.0 technologies, the valorising of big data and the commercialisation of affective labour. This work argues that while these platforms offer the opportunity for patients to express opinions and experiences in various extremely accessible formats, this also opens many new opportunities for exploitation.

There are of course multiple different actors within this emerging economy that have different interests when it comes to the exploitation of these types of data. With the increase of individual self-tracking and data sharing and with it the promise to speed up the development of medical research and innovation, tech giants have gained an enormous amount of power in this setting. Google and Apple have developed a monopoly within the health data economy as they are the leading players in developing ways to make sense of the information being tracked and stored, as well as ways to contribute insights that are useful in medical contexts. The power and control that these private companies such as Google and Apple have, are a result of the ownership they have, not only of the data and profiles they collect within their platforms, but also the methods and tools for analysis applied to this data. As a result of gatekeeping the data and insights coming from the analysis of it, these private companies own more private information on individuals than any government in the world (Prainsack 2017).

A number of studies raise issues related to privacy, data security and potential to further social inequalities due to practices surrounding big data in the healthcare and medical realm, and black box algorithmic decision making (Wilbanks & Topol 2018). The political concepts of algorithmic ideology as proposed by Mager (2012), informational capitalism as discussed by Fuchs (2010), cognitive capitalism as explored by Pasquinelli (2009), and the concept of surveillance capitalism as analysed by

Zuboff (2019) all express the capitalist ideologies embedded within the digital health data tracking platforms and related services provided by the privatisation of health data. An issue that arises within this landscape of sensitive health related information being owned by private companies is the little to no privacy and security provided to the users sharing their data. Data is often, by design, transferred between private companies in insurance, banking, advertising, pharma and law enforcement industries (Huckvale et al., 2015). Even in legal contexts there have been instances where personal private data is shared directly with prosecutors by the companies that own it proving this data is not at all secure (Olson, 2014; Crawford et al. 2015). Political values and ideals of innovation are deeply intertwined with the entire topic of health data privacy and security, not only on a private commercial level but on a governmental and institutional level as well.

The updates to the General Data Protection Regulation in the EU since 2018 have increased the protection and privacy over individual's private data. With these updated regulations also came a shift in responsibility to the individual when it comes to making decisions about the use of personal data (Felt, Öchsner & Rae, 2020). The history of the negotiations around data security and digital innovation between the governments of the EU states is long and complicated. While some states are focused more on the protection of data security and legality around the development of innovative technology and argue for this standpoint. Others believe that this is slowing down the progress EU states can make toward future technologies that will benefit society (Mager, 2017). For example, the new GDPR that was passed in 2018 requires the collectors and owners of Big Data produced by consumers to make adaptations to their platforms and practices to comply with these new regulations. In this case, some states would and have obviously argued for this, while other states hold the point that this is slowing innovation. Even though these mentioned updates have been made to the GDPR within the EU, it has been noted that data breaches often go without punishment. As a result, as governmental health bodies are much slower in developing their own health data platforms and infrastructures, the large corporate players who hold a monopoly on the current data economy will continue to maintain this position when it comes to the most valuable data on citizens (Mager & Mayer, 2019).

2.4 Imaginaries of Health Data and Digital Health Infrastructures

This subchapter of the literature review will focus more specifically on two of the core areas of focus of the research being done in this thesis, imaginaries of health data, and digital health infrastructure. What will become apparent when looking at the different literature in STS and related fields on these two topics is that they are in many cases very much intertwined, and in other cases, can at least be seen to impact each other. As already discussed, Stevent, Wehrens and de Bont (2018) performed a literature review on the epistemological claims made about big data and healthcare and found that while STS and critical data fields discuss both the positive and problematic aspects of big data in healthcare, many other fields still only the positive side. Within an STS line of thought, Mager and Mayer (2019) examine the privatisation and individualisation of health data with a more critical approach and suggest three paths of actions to "empower collected endeavours in the public health sector" (p.104). These three suggested paths include "(1) developing solidarity-based legislation, governance models, and institutions, (2) creating and fostering open socio-technical infrastructures instead of black-boxed technologies, (3) building capacities for new skills and literacy grounded in collective expertise" (p104). All three of these suggestions would require major restructuring of the current public health systems, but suggestion two specifically indicates a need for the creation of new infrastructures within healthcare systems. As discussed in the intro of this subchapter, this clearly shows how data and the infrastructure it moves through and is ordered by go hand in hand, and therefore, support and shape imaginaries surrounding what health data can or should do.

Furthermore, Slota & Bowker (2017) explain the importance of studying infrastructures within society through an STS lens as this uncovers imaginaries that stem from or are created with these systems, of what could be. "Interactions with infrastructure govern not just the aesthetic experience of the world, they define imaginaries of what is possible and potentially possible and are presented politically as a pathway to those potentials." (Slota & Bowker, 2017 p. 535). Within this same line of thought Korn et al (2019) discuss the idea of infrastructuring publics, a concept that expresses how infrastructures and the people that are ordered within them or through them, cannot be separated or viewed individually. This work looks at the multiple components that come together, including but not limited to, material, media, data and architecture that all come together to make an infrastructure and then control publics within them. Components of health data infrastructures have also been referred to as the grid, e-infrastructure, e-Research, e- Science and cyberinfrastructure (Edward et al., 2009). Studying these components, or the entire infrastructures means to focus on the systems that encompass codified information, software, hardware, and networks that store and provide access to data (Star and Ruhleder, 1996; Monteiro & Hanseth, 1995; Hanseth et al., 1996). It has been argued that often data infrastructures have been too short term to capture possible social or technical problems, and therefore as a result, also the policies and governing tools relate to them (Pollock and Williams, 2010). Pollock and Williams (2010) have asked questions about the methods used to study infrastructures and emphasised the importance of analysing technologies involved in these systems over longer periods of their use with an approach called the Biography of Artifacts. While all the mentioned literature is not always directly related to health data, it is clear that infrastructures, and the subjects that are organised through them allow for new and different possibilities for citizens, data and society. These new possibilities, or imaginaries turn into real outcomes, sometimes as imagined and sometimes having more negative or unforeseen impacts.

Applying a sociotechnical approach to studying data infrastructures for health purposes shows how problems are presented when infrastructures are built using a one size fits all top-down approach (Ure et al., 2009). This work argues that data infrastructures need to be built with an awareness and inclusivity of all human needs and varying local contexts. Health data infrastructures are also understood to be complex systems constantly adapting to change in relation to asset management, number of agents, data governance and the interdependence between the entire system and its environment (Brous, Janssen & Herder, 2019). When doing research on these data infrastructures it is important to keep this complexity and dynamic nature in mind, and to ask different questions than research might ask of static, single level systems. One example of such research is work done by Goffey, Pettinger and Speed (2014), that looked at the complexities present in the digital interoperable health system used by the UK National Health Service (NHS) using an STS infrastructures studies framework. This framework uncovered many of the often taken for granted or invisible processes of digitization that can be problematic, such as big data being claimed as objective information that is then used for decision making in politics or medical research. While this process can be valid and lead to positive outcomes, the fact that this data could have errors or nuances within it making it subjective is completely overlooked.

Within the EU the entire topic of digitising health and, therefore developing and implementing digital health data infrastructures has a very high political priority. This high political priority is in part a result of the imagined solutions this technology will have to bring to problems many of the EU states' healthcare systems are facing. Digital health infrastructures and the production of big (health) data are imagined to be cost effective, produce new models for improved patient care and provide valuable information for research and innovation (Felt, Öchsner & Rae, 2020). Within the digital health infrastructure used by the NHS the different aspects of promised imagined benefits have been looked at by Goffey, Pettinger and Speed (2014), who also note that the shift to digital healthcare systems is heavily influenced by large private corporations that are often more focused on collecting data than patient care. While there are many imagined and realised benefits of a digital health data infrastructure, Kumar et al., (2002) have also shown there have been instances of resistance to this type of technology and information systems. In their literature review on this discourse, they have found that this resistance and opposing stances can inhibit the imagined benefits promised of the digitization of healthcare.

2.5 Research Gap

In this section I have discussed many of the scholarly discussions around individual health data, data bodies, the ways in which health data permeates through socio political dimensions, aspects of big data practices and how it comes to be through the compilation of small data individually, as well as in the private and public sectors. I then went on to look at work done on the governance of health data, the discourse around data security and ownership and responsibility of care associated with data. Finally, I conclude by discussing literature on the topic of infrastructure and some of the imagined possibilities for the future of society and healthcare that emerging health data infrastructures could be a part of shaping. After looking at all of the works mentioned in this literature review together, it became evident that there is a space for research to be done investigating the imaginaries involved in digital health infrastructure that are currently in the process of being developed. This state of the art also displays room for analysis into how developers and other key stakeholders behind these health data platforms imagine users and view the patient experience in terms of needs and ideals surrounding how individuals should care for their health. Analysing these imaginaries and visions put forward by the actors behind health data infrastructures will also shed light on how futures of responsibility and care are being shaped in this context. Now that this chapter has successfully outlined the landscape of literature and identified an opening where the research of this thesis can fit within, the next section will outline the case study.

3. Assembling a Case Study

In the previous chapters, I have given a general introduction to my thesis as well as a more in-depth account of the state of the current literature surrounding the care that goes into developing, implementing, and caring for digital healthcare practices, the actors involved and their sociological dimensions. I identified a gap in the research on these topics and clarified how my research on the intersection between imaginaries of healthcare through digital healthcare practices, and health data platforms. In this chapter, I will explain the empirical design of my research. This will include the presentation of the research questions, the case site and access to the field, the methodological approach, and data analysis. Each of these sections will not only give more detail into how these methods or approaches were taken but also the reasonings behind each decision throughout the process.

3.1 Research Questions

As described in the state of the art, there is a gap in the literature and research when it comes to looking at the imaginaries of different aspects of digital health infrastructures. More specifically, there is a lack of information on how those involved in the development of digital health infrastructures imagine users or patients, their needs, and the processes involving the use of this technology in the medical field. In an attempt to make the space in this specific area of research slightly smaller, this project presents a case in which a digital health platform is being developed. This project will be explained in full detail at a later point but in short, this case of the project called InteropEHRate, is being funded by the EU Horizon 2020 framework. The focus of the project is to develop a prototype for an interoperable health data platform. Using this project and the stipulations of its funding scheme as a case this research asks the following main question:

Main RQ: How do different actors contribute to, create, support, and stabilise a sociotechnical imaginary of better healthcare through the development of a citizen centred digital health infrastructure supported by the European Commission?

This research question aims to understand the efforts that contribute to the process of the stabilisation of a sociotechnical imaginary of better healthcare through the development of a citizen centred digital health platform. More specifically this question intends to investigate different stages of the development of the sociotechnical imaginary of better healthcare, as well as the contributions that are made to the imaginary by different actor groups. Within the sociotechnical imaginary comes ideas and assumptions about the uses, the different users themselves and how the desired outcome of better healthcare should be achieved through the development of a platform that aligns doctors, citizens, and their health data. The stakeholder groups that are focused on within the scope of this research are the developers in the InteropEHRate project consortium as well as the European Commission (EC) through the project call documents in the Horizon 2020 framework. Because the InteropEHRate project is in the development stage, these actor groups have the most influence and agency on the platform that is being co-produced with the sociotechnical imaginary surrounding it.

It is important to investigate these ideas and assumptions being put forth in the imaginary, as well as the sources they are originating from to be aware of the social and political norms and values that become embedded in the platform used for citizens' healthcare. Considering not only the one stabilised version of the imaginary but also looking at how the separate visions of developers and other actor groups come together throughout the development is very important for this work. Regardless of if the values and imaginations of the people involved are implicitly or explicitly embedded within the platform, these factors not only have an influence on the technology itself but also on the ideas of what the future of healthcare should look like. The following sub questions will be used to break down the main question into more detailed inquiries that go deeper into different aspects of the stabilisation of the sociotechnical imaginary of better healthcare and how the development of a digital infrastructure that aims to deliver it.

SQ1: How do different actors contribute to the assembling of the sociotechnical imaginary of better healthcare through the InteropEHRate project?

This question aims to look at the different actor groups that are involved in the work that is done to assemble, support and stabilise the sociotechnical imaginary of better healthcare within the InteropEHRate project. This sub-question is interested in looking at who the different actor groups involved in the project are and how their visions influence the development of the platform or not. Based on the case this research is focused on there are different ways that actor groups can be analysed. The first obvious actor group that this question will investigate is the developers involved in the InteropEHRate project consortium. As developers themselves will have a large influence on the development of the platform they are building, and therefore that imaginary of better healthcare that is co-produced, this question reflects the investigation into these performances. Of course, the developers will have laden values and ideas that will translate to their work, but this question aims to go deeper and understand how the different visions from developers come together, where they differ and how they are influenced by additional stakeholder groups, and the imaginary of these stakeholders. This leads to the second clear stakeholder group that this question hopes to research, the EC. More specifically, through guidelines provided for this project through the funding documents and more general sentiments of the Horizon 2020 project that have imaginaries embedded within them. These materials will be investigated within the scope of this sub question. Additionally, this question is also interested in determining and investigating these additional actor groups, both internal and externally involved in the

InteropEHRate project, and how the constellations between them influence the stabilisation of the imaginary of better healthcare that should be provided.

SQ2: How do assemblages of technology, data, healthcare, and users emerge within the assembling, rehearsing and stabilisation of the sociotechnical imaginary of better healthcare?

The objective of sub question two is to look deeper into the aspects of the sociotechnical imaginary that aligns users (citizens) and their health data. Investigating how assemblages are made by different stakeholders, between technology, data, healthcare, and users within the imaginaries of the InteropEHRate project will allow for a better understanding of how the ideas of better healthcare are stabilised. This includes understanding the imagined needs of patients as well as how they should be actors involved in their own healthcare, the caring of data and the construction of better healthcare in general. The specific imagination of a user's needs, their assumed capabilities and desire to use a certain technology, as well as the responsibility they are given is influential to the development of the platform and how it will address these needs. This will shed light on who and what is being included or excluded in the imaginary of better healthcare and aims to dig deeper into what the sociotechnical imaginary that is being stabilised entails on a more detailed level.

SQ3: What do the performances that stabilise the sociotechnical imaginary of better healthcare tell about the larger vision of healthcare and who as a user is being included in this vision for the future?

This third sub question is interested in looking at how the visions, assumptions and ideas involved in the work that is done to stabilise the sociotechnical imaginary of better healthcare, come together in hopes of attaining a specific future of healthcare for specific users. In all the efforts involved in creating the sociotechnical imaginary there is a certain future of healthcare catered too and, in a sense, built over others. This sub question aims to consider the visions, assumptions and ideas involved and gain a picture of the specific future that is being tended to through these efforts. This includes looking at components of sub questions one and two to take into consideration the futures that the different actor groups are interested in caring for, as well as how specific assemblages that emerge throughout the imaginary promote a certain idea of what healthcare should be.

3.2 Case Site

Before explaining the methods used to attempt to answer the above research questions, I will give more details into the case site that was chosen for this thesis. As mentioned, multiple times in previous sections, the case site is a project that is funded by the EU within the Horizon 2020 framework called InteropEHRate. Within this research and innovation framework there is a call for projects which are “Prototyping a European interoperable Electronic Health Record exchange” (European Commission, 2018a). As explained in the previous section on the research questions, this thesis is interested in the activities involved in stabilising a sociotechnical imaginary of better healthcare through the development of a citizen centred digital health data platform. While I originally had an idea to study a topic related to digital health data and social technical imaginaries surrounding users and their health data, the specific topic of my thesis was altered many times. When my supervisor introduced me to the Smart4Health (S4H) project that the University of Vienna's STS department was involved in, also stemming from this specific Horizon 2020 project call, the idea for my current research project was sparked. The initial plan was to interview developers from both the InteropEHRate and S4H projects to answer the research questions. Eventually as my research question(s) and plan evolved, the decision was made to focus in more detail on one project, InteropEHRate, as well as use some materials coming from Horizon 2020, the framework in which the project is funded under. More specifically, I chose to focus the research heavily on interviews completed with developers involved in the InteropEHRate project, assisted by materials coming from the InteropEHRate project consortium and the EC project funding documents. This section will give an overview of the structure of the project call and the InteropEHRate project itself as the site of this research beginning with more details on the project call, followed with the InteropEHRate project itself and ending with a brief description of my access to the field.

3.2.1 Developing Interoperable EHR Exchange Infrastructure

Looking at the Horizon 2020, the topic that the case site for this project falls under is Societal Challenges – Health, demographic change, and well-being. Within this topic there are multiple branches of smaller topics that research is funded under all with the main goal of "providing lifelong health and well-being for all" (European Commission, 2014). This topic recognizes various problems healthcare systems in the EU are facing and highlights the importance of using data and technology to provide solutions wherever possible. For example, one solution provided is to improve the sharing of data between silos to learn more about diseases as well as to inform treatment plans. The branch that the InteropEHRate project falls under is the Methods and Data program, which among other calls, is a call for prototyping a European interoperable EHR exchange. The materials outlining and describing this funding scheme are included in the case site because there are already at this level of the case site, efforts towards creating the sociotechnical imaginary that this research is interested in learning about. The title on its own is already an example of a performance that solidifies specific visions and ambitions that the EU has for technological development and healthcare. Additionally, in the project call there are specific instructions for projects to develop and test an extensive European interoperable platform that conforms to all data protection and security regulations. The testing that is performed with the prototype should be wide scale and include citizens, medical doctors, hospitals, pharmacies, and HCPs, and must be able to clearly show its relevance. There are two overarching components within the requirements:

i. citizen-centred implementation of a platform that can be integrated in a federated platform structure, easy-to-use and secure, constantly accessible and portable within any other Member States of the EU (European Commission, 2018b).

ii. a data-driven platform to help the scientific community to benefit from user generated data (health, care, and health-related) going beyond the currently established level of implementation. Social Sciences and Humanities should thereby be considered appropriately (European Commission, 2018).

The project funding scheme also places a large importance on the focus of citizen use and participation through specific recommendations of the strategies to involve citizens early in the development process, the inclusion of health data that is generated by citizens themselves and citizen centred communication or educational programs involving incentives for use. The two key functions that the funding scheme explains the projects need are to 1) empower citizens and 2) promote health through contributing data to research. From these specifications two projects were funded: S4H and InteropEHRate. The following subsections will give more details and background information on the InteropEHRate project.

3.2.2 InteropEHRate

On the InteropEHRate project website, the objective section explains how there are health data silos that store huge amounts of health data but cannot exchange information back and forth without intervention from higher authorities or, in some cases, at all. The website then explains that this hinders the use of data and prevents it from being used to its full potential when it comes to citizen’s own individual health as well as for medical research purposes. InteropEHRate is then among many things, a project that aims to provide a solution to these problems. More specifically, the project consortium aims to, “empower the citizen and unlock health data from local silos, using a bottom-up approach for EHR interoperability” (European Commission, 2020a). Through this platform, the sharing of health data is expected to be controlled primarily by citizens, giving patients ownership of their information and the possibility to share it with other trusted users. Sharing personal EHRs or in the case of this project Smart EHRs (S-EHR), will be tested through three main scenarios (InteropEHRate, 2019):

1. Device to Device → allowing patients to share any data on their S-EHR with a HCP or facility across Europe. This can be done using a mobile phone or desktop app for the patient and a HCP (HCP) app on the side of the doctor or healthcare facility. When a patient chooses to give a HCP access, the HCP can share any data from an appointment or prescription with the patient through Device to Device (D2D) sharing but once the transfer of information is complete the doctor no longer has access to the patient's S-EHR or any of their data.

2. Consultation of S-EHR data from cloud storage in Emergency settings → if citizens chose to, they can upload their data onto cloud storage for emergency situations. This scenario is focused on patients who chose to use this feature. In this case the citizen would carry with them an emergency identity token. HCPs who have been nationally verified could then access emergency S-EHR data stored on the cloud. This access would all be tracked and recorded as emergency use

3.Consultation by researchers of integrated and anonymized data → this scenario is focused on a situation when researchers are doing projects that require citizens' health data. Researchers can request data with criteria and time frames they require through an in-app advertisement. Through this in-app advertisement or notification to citizens, the level of anonymity will also be specified. Citizens can accept or decline to participate. If they accept, the health data being requested will be transferred.

The key elements being developed and tested across multiple countries in the EU with these three scenarios mentioned above are what come together to create the idea of a digital infrastructure being developed that aims to provide better healthcare being examined in this project. These digital and technological components include the S-EHR mobile app, S-EHR cloud, interopEHRate Health Service (IHS), HCP Web app and interopEHRate research services (IRS) (InteropEHRate, 2019). There is a very strong focus in this project both on citizen experience and the secure transfer of data through the different channels. The project, and each of these elements that come together to make the InteropEHRate platform are being developed by the project consortium that includes multiple different partners and developers. The platform is developed based on protocols for apps and software. The protocols are created based on user requirements coming from the EU Horizon 2020 specifications, the expertise of the partners who are developing them and iteration loops coming from the 3 scenarios mentioned above. In order to test the platform and the protocols that come together to make it usable, the developers incorporate the protocol into different apps or software so they can be used. The reason for developing protocols rather than a specific app or software that must be used is to hopefully promote a more widespread and realistic uptake of the platform across EU countries (IntEHRoperate, 2019).

Throughout the project development the partners are responsible for specific components but also collaborate to develop a cohesive product. There are also multiple presentations of the project progress to external stakeholders and the public throughout the development of the project. The Horizon 2020 Framework that pertains to the InteropEHRate project, and also influences its development, as well as the project itself, are the case site for this thesis. Materials from both of these case sites were used as data for research in addition to interviews with developers from the InteropEHRate project. The methods section below will explain how these sources were used to collect data, and then how this data was analysed in further detail. In addition, the following selection will also give an account of how access to the field was obtained and explain how chosen concepts from the field of STS provided an overarching direction.

3.3 Guiding Concepts

The methodological approach for this research was guided by a few sensitizing concepts, that provide a wider direction for analysis but also allow for the application of other approaches or avenues of exploration within them.

3.3.1 Sociotechnical Imaginaries

The first sensitising concept that is used is sociotechnical imaginaries. In the state of the art of this thesis, I discussed many different works that highlight how it is necessary to look at data, infrastructure and the imaginaries that are attached to them. In line with this idea, this thesis attempts to look at the development of a European interoperable health data infrastructure in combination with the imaginaries that are co-produced throughout this process. While the state of the art looked at many different concepts and ideas of imaginaries, this thesis heavily uses the concept of sociotechnical imaginaries when approaching the analysis. In 2009, Jasanoff and Kim first described sociotechnical imaginaries as "collectively imagined forms of social life and social order reflected in the design and fulfilment of nation-specific scientific and/or technological projects" (p.120). Later on, this definition was expanded to include the idea that imaginaries held with any form of society, can coexist, shape each other and be held by individuals or larger communities. This updated description of the concept was defined as "collectively held, institutionally stabilised, and publicly performed visions of desirable futures, animated by shared understandings of forms of social life and social order attainable through, and supportive of, advances in science and technology" (Jasanoff & Kim 2015, p. 4).

This concept affords the ability to recognize the entanglements between technopolitical cultures and emerging technologies as well as the "the multiple ways in which sociotechnical ideas and experiences of different actor constellations matter when making choices about which societal futures are to be attained." (Felt, 2015 p. 3). Research done for this thesis aims to investigate the efforts to assemble and stabilise an imaginary of better healthcare through the process of developing a digital health data European digital health data infrastructure. The concept of sociotechnical imaginaries aids the goal of investigating specific technological and sociopolitical aspects of ideas and the wider imaginary that are co-produced and stabilised throughout the development process of a new health data infrastructure. In addition, this concept provides a framework that allows other concepts from the health data and infrastructure landscape discussed in the state of the art to be used in combination throughout the analysis.

3.3.2 Vanguard Visions

The next main sensitising concept used to assist the investigation of a sociotechnical imaginary being stabilised is Hilgartner's (2015), concepts of sociotechnical vanguards and vanguard visions. Hilgartner describes a sociotechnical vanguard to "designate relatively small collectives that formulate and act intentionally to realise particular socio- technical visions of the future that have yet to be accepted by wider collectives, such as the nation" (p.34). Hilgartner also discusses how these vanguards often position themselves in visionary roles and as holding expert knowledge on the emerging technologies they are focused on, therefore placing more weight and relevance to their imaginaries. The notion that there are individuals or smaller groups within society that have initial ideas about the development, purposes and uses of a technology is relevant to this research because there are different actor groups involved in the InteropEHRate project that can be seen as socio technical vanguards as described above.

Hilgartner highlights two additional aspects of this concept that are also very relevant to the research in this thesis. The first being the fact that the visions held by different vanguards or small collectives of self-proclaimed experts can be simultaneously competing with each other while still sharing some of the same values or factors. The second aspect of this notion that is very relevant to this research is the distinction that Hilgarnter makes between vanguard visions and sociotechnical imaginaries, "To be sure, the visions of vanguards sometimes grow into imaginaries, but following Jasanoff (2015), we will not consider them to have done so unless they have come to be communally held by larger and more stable groups" (p.35). These two clarifying points of the notion of vanguard visions are important to this thesis as they prompt investigation into the different actor groups potentially as vanguards as well as how their vision may have different aspects that are shared while others are contradictors. The actors that could be considered as vanguards within the research of this project include the developers from the InteropEHRate project and the EU Horizon 2020 scheme that this project falls under. Looking at the consortium on a broad level and more specifically how the imaginaries are being co-produced with the development of the health data infrastructure provides an opportunity to ask questions of how some of the vanguard visions are stabilised and brought into a larger sociotechnical imaginary.

3.3.3 Envisioning Users

Finally, the third major guiding concept used to achieve the research aim is that of envisioning users. Hyysalo et al, 2016 explain how whenever a new technology is developed, there is always an intended or imagined user that will influence the actual design process and the way the technology is integrated into society (Hyysalo et al, 2016). "Visions of future products and their usages can further inform the expectations of consumers and other stakeholders, such as regulators and intermediary actors" (Hyysalo et al, 2016 p75). Studying envisioned users is relevant to my research as it allows for an in-depth look into the imagined needs that citizens will have pertaining to their own healthcare and general wellbeing. Together these three leading concepts will be applied to the research materials collected to be analysed. The methods of analysis and data collection will be explained in the following sub chapters.

3.4 Methods and Materials

Following the concepts of sociotechnical imaginaries and vanguard visions, the methods chosen needed to be able to look deeply into how different ideas merged into a shared vision that is being created about how a technological order and social order come together to create better healthcare in the future. This required an identification and investigation into the actor constellations involved in producing and stabilising the vision of better healthcare through the use of an interoperable digital health data platform. It was clear qualitative methods would be best suited for these tasks as they allow for a deeper understanding of individual contexts, experiences and perspectives and are often used to study new ideas or phenomena (Jensen and Laurie, 2016). Quantitative methods are better fitted towards generalising a finding on a large scale, statistical analysis and providing answers to numerical questions (Jensen and Laurie, 2016), as this is not what I aimed to do, an entirely qualitative approach was decided on.

Of the multiple qualitative methods, I originally decided to rely mostly on interviews with developers of two separate projects being funded under the same Horizon 2020 call InteropEHRate and S4H, as well as a minimal amount of document analysis to look closer at the role of the project call itself, and the EC's contribution to the imaginary of better healthcare. After interviews with developers of the InteropEHRate project were completed, I decided to focus all of my attention on this project and do a more thorough analysis of all the actors or stakeholders involved. This led to the use of mixed qualitative methods by including document analysis. The documents used as a source of data included the different materials that guided and were produced by the project partners in addition to the project requirements from the EU.

3.4.1 Interviews

Within the social sciences and the field of STS more specifically, there are multiple different types of interviews used depending on the purpose and objective of the research. There is a range of interview types with very formal, planned interviews on one end and completely open ended, and unstructured interviews beginning with a single general question on the other. Within the range of qualitative interviews there are structured, semi structured, in-depth, survey based, expert based, historical account, and open-ended variations of the method. All of the above were carefully considered for this research. Byrne (2018) , expresses that generally speaking, qualitative interviews used for social science are often loosely or semi-structured in-depth conversations that have a predetermined purpose. The goal is to prompt and encourage the interview partner to speak openly and in detail about their experiences of, or encounters with, a particular subject. Qualitative interviews allow the researcher to gain detailed insights of the world views and social experiences that shape the perspectives of the interview partner (Jensen & Laurie, 2016). This type of conversation aimed towards discussing views and experiences of a specific topic is useful as a method because it allows the researcher to get an account of the interviewee's beliefs, values, ideas, understanding or experiences in their own words. Qualitative interviews require the researcher to come up with a list of themes, topics, and general guiding questions but not a specific questionnaire list or order. This allows the researcher to be flexible during the process and explore interesting or relevant points in more detail as they come up during the conversation.

As stated in earlier sections, in-depth semi-structured, expert interviews was the first of the chosen methods for this research. The first reason for this choice was heavily rooted in the fact that it allows the interview partner to express their own personal experiences, ideas and understanding of different components of the project they are working on. All of which are extremely important to understanding the creation of the sociotechnical imaginary of better healthcare, especially because the developers are considered vanguards who are all seeking to advance their vanguard visions (Hilgartner, 2015), effecting the stabilised shared vision. The second reason I chose this type of qualitative interview was because of the room for flexibility it allows and ease to explore important ideas or topics that fall within certain themes. I wanted to be able to change the order of my prepared questionnaire, go deeper into specific topics that come up or be able to explore new avenues as they arose in the research. This type of interview is also flexible in that it allows for different approaches towards raising themes during the process (Byrne, 2018). To answer my research questions, it was necessary to investigate how developers imagined users, their needs, and the uses of the platform they were working on. In conversations with the developers, I found it was much more fruitful to inquire about their different imaginations about the technology through indirect questions and probes.

As recommended by Ritchie and Lewis (2003), a tentative interview guideline was developed based on themes and questions relevant to the research questions. I created multiple questions that could be asked under each theme and thought about what potential probing questions could be. The notion of retrospecting prospects and prospecting retrospects (Brown & Michael, 2003), was used to formulate some of the interview questions. This concept allowed me to gather data on the changing imaginations of developers from when the project started, to the time they were interviewed and their ideas about the future of it. Changes in the ideas that developers held throughout the process of the project shed light on how the vanguard visions they each held, came together into one sociotechnical imaginary through the development of the digital health platform, how it was stabilised and rehearsed. It is also important to note that interviews themselves can be seen as data generation, as the data is co-produced between the researcher and interviewee (Byrne, 2018). In this case, the interviews could be considered as an instance of the developers of the project rehearsing aspects of the sociotechnical imaginary of better health.

Originally, I planned to conduct the interviews in person but because of the circumstances created by the COVID-19 pandemic this was not possible. Instead, the interviews were conducted over two online video chat tools, Zoom and Google Meet. The audio of the interviews was recorded using my iPhone voice recording tool, so that I could fully engage in the conversation and make sure I was using questions and probes that covered all the necessary themes. The interviews were transcribed later using without any software or AI tools for me to get more into the data and become even more familiar with the responses. The transcripts were the analysed later in methods that will be described below.

3.4.2 Documents

As stated above, after conducting three interviews with developers from the InteropEHRate project it was decided to focus only on the one project and include document analysis as the second main method for research. Within the field of STS, document analysis involves looking at not only the content of the chosen material but also the context around them. In this case, documents refer to "material consisting of words and/or images which have become recorded without the intervention of a researcher as happens in an interview or focus group" (Silverman, 2014 p. 243). By looking at the circumstances in which different documents, as well as the content within them, made it possible to see the beliefs, norms, values, and assumptions that were involved in their creation (Shankar, Hakken & Østerlund, 2017). Priori (2007) explains how documents can be analysed as functioning agents on their own by paying attention to the visions that they are pushing forward or suggesting.

These approaches to documents were useful to answering the research question for multiple reasons. First, looking at certain documents written by the different developers who were interviewed provided more data on the vanguard visions as well as the development of a shared vision that works to stabilise a sociotechnical imaginary of better healthcare. The InteropEHRate project has its own website with information about the project, blog posts from project partners, deliverables written by project partners and video presentations made at midterm public progress reports. These materials provided a different perspective to supplement the information gathered in the interviews. As planned all along, document analysis was also chosen as a method to include an investigation of actors outside of the InteropEHRate consortium, namely visions and imaginaries put forth by the EC. Collecting and analysing the documents of the Horizon 2020 project allowed for a deeper look into the entanglements of the actor constellations involved in the sociotechnical imaginary of better healthcare. Using these documents as a source of data also made it possible to review the rehearsals and beginning of a stabilisation of better healthcare from vanguards outside of the project consortium. To learn about the interopEHRate project and the funding scheme I familiarised myself with the project website, attended one of the midterm progress presentations of the InteropEHRate project (Midterm Public Workshop October 2020 – Part 1 InteropEHRate Scenarios and Data flows), and read the Horizon 2020 funding scheme for the project. I also read many of the partner deliverables to prepare for the interviews with the developers. The documents to be analysed were selected from these materials.

A constructionist analysis of organisational documents as laid out by Silverman 2014 was chosen for the research in this project. This approach aims to become aware of social orders, realities and representations that are put forth by materials in literary societies by paying attention to what they are, how they are created and what they are meant to accomplish. This was achieved by asking questions of the chosen documents such as who created them, how and for what purpose? Who reads them, how and why? What are the outcomes, what is omitted and what is taken for granted? It also required attention to be put on the appearance and layout of the document. This made it possible to look at the visions, ideas and assumptions made within the document that are used as rehearsal, performances, and stabilisation of the sociotechnical imaginary of good health by different actors involved. Additionally, Kristin Asdal and Hilde Reinertsen's (2021) practice oriented focus on the materiality documents have, and the work documents do was used throughout the analysis as well. Through this approach, the richness of documents can be seen through by looking at documents not as static artefacts but by paying attention to their emergence into the world, how they are used, and the work they do. Asdal and Reinertsen explain that "By being set in motion, documents can act upon other things" (p. 5).

3.5 Access to the field

Gaining access to the InteropEHRate project developers was a relatively easy task as my supervisor was connected to members of the project. I began by emailing a colleague of my supervisor at the University of Vienna, who was involved in the InteropEHRate project. It was through this contact that I was introduced to the project supervisors, to whom I explained my research interests. Through the InteropEHRate supervisor's guidance and support I was put in contact with three project partners focused on developing different aspects of the digital health data platform. The interviews I completed with partners involved in developing the InteropEHRate project reveal different instances or vanguard visions and aspects of the sociotechnical imaginary of better healthcare through digital alignment of users, health data and an interoperable health data infrastructure being created. In the interviews, the developers talked about ideas they have about the users, intended uses, potential positive outcomes, benefits to society and citizens, and ideal outcomes of the development of technology. The interviews were conducted with the expert developers working on the health data infrastructure that aims to provide better healthcare. This is why, as briefly mentioned above, their beliefs, ideas and imaginaries can also be seen as vanguard visions (Hilgartner, 2015). It was important to interview developers of different aspects of the technology to understand the multiple visions that contribute to the sociotechnical imaginary being put forward and understand where there might overlap or contradictions between their individual views at van guards within this project.

As stated above, to prepare for the interviews I read the Horizon 2020 documents, the InteropEHRate project call and guidance documents, many of InteropEHRate project deliverables, became familiar with the InteropEHRate website and attended an online live public progress report. After completing the interviews and becoming familiar with recurring themes and topics raised in this data, documents for analysis were selected. I began with the project call and funding requirements from the EU Horizon 2020 website page. This document provided ideas of how citizens, their health data and healthcare systems should be brought together through the digital health data platform. It is an instance of both assembling and rehearsing the sociotechnical imaginary of better healthcare from the perspective of the EU officials. It presents details about the picture of users, uses and healthcare, while at the same time building on or endorsing imaginaries put forward by the EU about how technology, and the collection and use of health data should be, and could benefit society. It also provided a narrative coming from the EU about the direction it’s members countries should be heading regarding healthcare and digital health data to achieve this imaginary of better healthcare. One further reason this document was selected was to analyse what can be assumed to be the most widespread and prominent vision because of the political and societal position of the EU.

The second set of materials chosen for analysis included three documents published online by the InteropEHRate project consortium. The website page “InteropEHRate in a Nutshell” and two blog posts titled “FHIR-based protocols to support a citizen-centric approach” and “Travel Safely with your data” (InteropEHRate, 2021). The website page gives a summary of the entire project. Its aims, its feasibility, reasoning for why it is necessary and beneficial, as well as the three example scenarios that will be used to test and support the use of the interoperable platform. This document was chosen because it provided an example of the vanguard vision held by the different developers being merged into one stronger vision or imaginary. This page is an example of the sociotechnical imaginary of better healthcare being rehearsed and solidified. Additionally, it presents a narrative of how citizens should use the health data platform to care for themselves, care for their data and therefore care for society by allowing their data to be used for research. The blog posts were chosen for analysis as supporting material because they are materials again, written by the project partners but for a more general audience. The blog posts, like the website page, use language that can be easily understood by the wider public. The assumptions made about users, their needs and wants regarding health care, general health and the use of their own health data provided important data for answering the research questions. These materials also presented another example of the sociotechnical imaginary of better healthcare being rehearsed within the constellation included in this research.

3.6 Data Analysis

After collecting data through conducting interviews and selecting the documents related to the project to be used, it was time to analyse the data. This subsection will discuss the approach taken towards data analysis and reflect on decisions made throughout the process. While collecting the data I decided that I would use a thematic content analysis as explained by Rivas 2018. A thematic content analysis is a form of thematic coding that is often used in social science work. This approach aims to make sense of data in a digestible way by dividing it into themes, categories, and patterns through deductive and inductive coding. A thematic content analysis is guided by the sensitising concepts and the research questions. Rivas (2018) explains how this method is useful for looking across the data rather than just at specific cases, but still allows for a detailed analysis through the processes of creating deductive codes, performing open coding, and then grouping and operationalizing the categories. Using both inductive and deductive coding methods was useful because with my research design I had an idea of some of the topics or themes that I would be looking for but could still stay open to details within these ideas (Rivas, 2018). Early in the project I planned to use a zig zag (Rivas, 2018) method to start coding my documents and completed interviews while conducting further interviews and potentially collecting more material to fill in gaps. I did initially begin using this method in the early stages of collecting documents and preparing for the interviews by familiarising myself with the data, creating premade codes related to my research, and developing themes based on these. This approach was altered during my data collection phase due to the decision to focus on only the InteropEHRate project and the availability of the interview partners. I ended up collecting a large majority of the documents I wanted to include in the analysis and completing all of my interviews before completing most of my analysis work and relying on building of networks and themes during this process. In addition to open coding, it was also important to become very familiar with the project documents, website pages and materials. As stated in the document's subsection, this was achieved by a contortionist view of document analysis.

ATAS.ti was decided on as a tool for analysis and coding specifically. Atlas.ti is a data analysis software researchers use to organise and work with qualitative data. The tool has a wide range of functions and resources that support the analysis of research by managing and working with data from multiple sources. As stated on the Atlas.ti website, features of the program include but are not limited to coding, in text memo, content analysis, and networking management. I chose this tool because of its flexibility to perform coding as well as create memos for a document analysis for types of materials including photos, website pages, blogs and or videos from my case site. I also felt like the ease in which the tool allowed me to store all documents, codes, notes, and memos in one space was very advantageous for developing my findings. Later, when it came to grouping my codes and looking at relationships between them, the networking tool which allows for the creation of visual maps of codes and code groups also proved very productive throughout my analysis process.

To begin the deductive part of the coding process I began to brainstorm some of the themes and more specific codes that I would use based on the awareness I already had of my data. In preparing for the interviews and transcribing them I became very familiar with the data specifically coming from the InteropEHRate project and involved developers. From this work I had an idea of themes I would want to pay attention to and specific premade codes I could apply. To create a complete list of premade codes and interesting themes to pay attention to, I went through the material I collected from the Horizon 2020 framework that pertains to the InteropEHRate project making memos and notes. At this stage, I approached the materials collected from the InteropEHRate consortium, the project website and the EC. From these memos I decided on the themes and codes in the chart below that would be important for answering my research questions.

Themes	Codes

• Ideas of better healthcare • New narratives from different actors • Caring for data = caring for healthcare • Care in general, costs of bad healthcare • Better healthcare • Vanguard visions	• Data as a solution for better healthcare • Data not being used effectively for healthcare • Better healthcare needs research • More data = better healthcare • Citizens responsible for their data and their health • Holistic approach for better healthcare • Interoperability and healthcare for better healthcare

I began to apply these deductive codes and themes as well as perform open coding on my data. For the inductive portion of the approach, I thought about using gerund and in vivo codes to avoid reading too much into the data or misinterpreting certain details (Rivas, 2018). I found the gerund technique difficult to apply because very often the materials I was coding did not include action words or specific actions of an actor. Instead, most of the codes I applied, I created to refer to a specific idea, topic, vision, technology, or user as well as some In Vivo codes. What I focused on during this phase was asking questions of the data and paying attention to what these answers were telling me (Rivas, 2018). Very early in the coding process I found it too difficult to apply pre-made codes, perform open coding and categorise the quotes into the premade themes at the same time. This led me to decide to focus solely on coding, and then later grouping the codes into the themes as a second step. I also made the decision to begin with the Horizon 2020 documents from the EU. Because of the nature of the funding scheme, the design of the InteropEHRate project, and therefore the imaginaries surrounding it would be influenced by the contents and visions in these documents. I then moved on to performing open coding on the interview transcripts and the text material from some of the InteropEHRate website pages and blog posts.

Throughout this process I also kept a journal where I would record thoughts during coding and some initial findings. I also would write myself memos for going back to the previously coded material when I found a new theme or concept interesting that I might not have realised earlier. This allowed me to keep making progress with the coding of all sources but at the same time be thorough and look at the data through the lens of different important themes. After going through and coding all the Horizon 2020 documents I selected for analyses, the interview transcripts, and texts from the InteropEHRate project I had over 300 codes. I began to work with these codes by sorting through to see if some of the less frequently used codes could be merged with others or deleted all together. I also looked at the In Vivo codes and decided to use them as open codes and either left them as they were or grouped them with an open code that had the same meaning. This narrowed my list down to about 275 which was still a huge number of codes to work with. The next step in the thematic content analysis was to begin the categorization process.

As I began the categorization process, this is also when I really finalised the sub questions of my main research question. Together as a I began recognizing the potential groupings, I could place the codes into, as well as where my memos and findings from the documents could fit into my analysis it became more clear what the data could really tell me. The final categories that I decided on, which later inspired the sections of the analysis, included both the findings from my constructivist document analysis from website materials and documents, as well as the codes from my interviews. These categories and the structure I placed everything in to answer my research questions are as follows:

1. The EC and InteropEHRate Developers as Vanguards – as the whole project was funded based on the stipulations coming from the EC, understanding the wider frame of how such a project could or should make health care better. Codes and memos coming from the EU Horizon 2020 website, and funding scheme that explained these ideas of what should be included in better health care, and this wider frame as a vanguard vision were included here. To understand and investigate developers and their vanguard visions I looked at codes and memos related to how the members of the InteropEHRate project, on a broad level, see themselves as creating better healthcare through the development of an interoperable health data platform. This category is largely focused on findings from the InteropEHRate website and the project consortium.
2. The Health (care) Imaginary – this section is broken up into three main focuses on different imaginaries present in the data. The first, includes any codes or data in the interviews related to how the health status of citizens is a challenge which future societies will face. The second is related to the idea that health can be captured and represented through data. The final section includes codes and findings associated with the idea put forth that users have to care for their own health, how this is an individual responsibility of a citizen, and how individuals should feel about caring for their data.
3. Technology as part of the Imaginary – this section focuses on data that is related to the idea of how technology, in the form of a digital health data platform, could fix the problem of “bad” healthcare. It also asks questions of the intertwined social solutions, if there are any, and how the problem is framed to position technology as a solution.
4. User Imaginations – this section contains findings centred around the question who is the user and how are they imagined? The way the developers imagine users and their actions shapes the way the platform is constructed, what is included and in turn, what is excluded. Any codes from the interviews related to users being imagined in a way that fits in with the greater ideas of better healthcare are included here.

Creating this structure provided a clearer path into the very plentiful and rich data that was collected and then originally analysed. While before this step of the data analysis, there may have been many alternative paths to dig into the data and observe different findings, this organisation made it possible to tell a story about the development of an imaginary. The structure is not meant to be observed in a chronological order, but rather understood that these developments, performances, and stabilizations of a sociotechnical imaginary of better healthcare were happening in overlapping timelines.

4. Analysis

This chapter will present the analysis of the empirical data collected for this thesis in the frame of the research question, which is interested in understanding how stakeholders, including the Horizon 2020 project funding scheme, the InteropEHRate project consortium, and specific developers involved in the consortium, all contribute to developing a sociotechnical imaginary of better healthcare with the EC. This chapter is structured in a way that attempts to tell a story of the non-linear ways in which both the EC and the developers of the InteropEHRate project (aim to) bring the sociotechnical imaginary of better healthcare to life. This involves understanding the relationship between the two groups and how and why their visions come together, as well as looking into the details of the visions and ideas that can be found in the Horizon 2020 framework documents, materials produced and published by the InteropEHRate project consortium, and the interviews conducted with the individual developers for this thesis. Within all these sources, various instances of the making, rehearsing and stabilisation of a sociotechnical imaginary of better healthcare can be found. As mentioned in the previous section, taking a clear path into the data was an important step to take to recognize connections, and follow different threads throughout the material. The path that was taken into the data, allowed for a clear storyline of the sociotechnical imaginary of better healthcare that is rehearsed and stabilised in this project, to be developed in which there are larger key themes brought up by main stakeholders, that get built on, and co-produced on a deeper level throughout the InteropEHRate project, as well as the work of this thesis itself. Identifying these initial ideas and themes provides a lens to go further and understand on a richer level how certain factors of the imaginary continue to develop as the analysis goes deeper into the development of the InteropEHRate project. The sections of this chapter will use this same storyline, to discuss the findings in relation to the main research questions, and sub-questions.

This chapter is split into four subchapters Based on the decisions used to analyse and understand the data, the first subsection will start by explaining this wider framework as the initial steps of the sociotechnical imaginary being shaped. More specifically, subsection 4.1, will discuss firstly the vanguard visions, as well as imaginaries that are present within the Horizon 2020 project funding documents. Secondly, the visions and imaginaries involved with the InteropEHRate project will be reviewed through looking specifically at the data from website and project materials, as well as on an initial surface level, the overarching ideas from developers within the project. Thirdly, this subsection of the chapter will look at the dynamics between the overarching ideas and themes that are put forward and intertwined in the vision of better healthcare through and interoperable health data platform. The dynamics of these two groups will be sensitizing for the following sections of my analysis into the details of the visions and imaginaries that are present in the development of the InteropEHRate project.

The proceeding sections will be focused on the imaginaries surrounding specific topics identified in the wider framework, that play a crucial role in shaping the larger sociotechnical imaginary that is being brought to life. The second sub-chapter, section 4.2, is focused on the Imaginary of healthcare presented in the case of this thesis. This involves looking at how the health status of societies is viewed as a challenge for the future, the notion that health can be captured and demonstrated through data, and the ways in which citizens are expected to take responsibility for their health. The following sub chapter, 4.3, will discuss the visions and imaginaries related to technology, and the social technological aspects presented in the wider picture. More specifically, how technology is presented as an answer to the healthcare imaginary, as well as social and political aspects that are involved in the technological solutions. Sub chapter 4.4 is focused on analysing the imaginary of users in the case site and how they are thought about in relation to the solution to the healthcare challenges, and efforts to improve healthcare. This section is focused on who is imagined to be a user, what their behaviour should be and how they should care for their own health and the health of society based on the ideas being put forward by different stakeholders within the sources analysed in this project. Inversely, this section also looks at how non-users are imagined and who is left out of the imaginaries.

4.1 The wider framework of Better Healthcare

This first analysis chapter aims to provide an initial entry point for looking at the sociotechnical imaginary of better healthcare co-produced throughout this case site. This starting point aims to provide insights to the wider frame and the beginning stages, or first layer, of the sociotechnical imaginary being co-produced. This includes an analysis of vanguard visions (Hilgartner, 2015) by specific key actors related to, or directly involved in the project, and overarching themes and ideas presented about how an interoperable health data platform can and should achieve better healthcare, from the Horizon 2020 funding scheme as well as members of the InteropEHRate project consortium. This section will begin with a focus on the frame that the Horizon 2020 funding materials provided. Looking at the funding scheme for this project as an actor, or a document that is doing work in the world (Asdal & Reinertsen, 2021) is important because it is involved in developing the sociotechnical imaginary through the details included in the guidelines for any project applying for funding. Through looking at these different resources explaining aspects of the Horizon 2020 objectives, and the specifications of the funding requirements for the InteropEHRate project this section will aim uncover some of the initial ideas being put forward about the aimed future of healthcare through this entry point into the data.

The second actor group being considered in this section as a responsible group for laying out the wider framework of the imaginary is the InteropEHRate project consortium as a whole. This will be done by reviewing website pages, blogs, and some sections of the interviews with the developers involved in the project and asking questions about the goals, stated purpose, and explanation of the project. In addition to this, the constellations, and positions that the developers hold within the project are also investigated.

Throughout this section of the analysis, it will become clear that there are specific ideas about how healthcare is related to the future well-being of populations, how citizens should care for their health and their data, and what the dynamic between health, technology, data, citizens, and HCP should look like to achieve the idea of better healthcare. Observing these ideas and asking question of them will begin to paint the picture of the sociotechnical imaginary that the main research question of this thesis is asking about. The final section of chapter 4.1 will discuss how the answers to the initial questions being asked of the data become intertwined to begin the co-production of the larger sociotechnical imaginary that will continue to be developed.

4.1.1 European Commission as a sociotechnical Vanguard

By analysing the project call documents within the Horizon 2020 framework, the wider framing of better healthcare from the EC is boldly asserted. Due to the nature of the political, and in this case, financial power that the EC has, this group, and the sub actor groups within it, fit into Hilgartner's 2015 definition of a vanguard. Therefore, the ideas formed by the different materials from the EC that are related to the funding guidelines of the InteropEHRate project are regarded as vanguard visions. In my efforts to gain an understanding of the InteropEHRate project itself and the funding scheme behind it, I found it helpful to start with the project description and zoom out one layer at a time until reaching the top overseeing organisation or level within the EC. This allowed me to get an idea of how imaginaries are being passed down from different levels of the EC, and where new visions were introduced by different organisations at different levels. This can help to demonstrate the flow of imaginaries or ideas related to the progress and aims for the EU as a whole, and more specifically the project being looked at in this thesis. While the different imaginaries being presented by the actor groups involved in each of these levels is not linear in the way the image displays below, this approach of looking at the hierarchy or organisation of the EC in separate groups is useful to conceptualise the multiple layers and entanglements of ideals and objectives coming from Horizon 2020 and then how the InteropEHRate project fits within this.

Starting with the very top is of course the EC itself, which decides on goals and focus topics for the EU and then develops strategies to achieve these goals through implementing policies and initiatives. When considering the EC as an actor group, certain values become automatically embedded within the InteropEHRate project. The EC shares and represents the goals and values of the EU. Included in the goals and values are, "to promote the wellbeing of all citizens, offer security, a strong economic market with full employment and social progress, combat social discrimination, promote scientific and technical progress, and enhance cohesion and solidarity among the EU countries" (Innovation Union, n.d.). This list is not inclusive of all goals supported by the EC, but they are ones that have been identified in the analysis as being influential to or supporting new imaginaries of better healthcare.

Looking at the first goal mentioned above to promote the wellbeing of all citizens, through the lens of this research, the initial importance being placed on the health, and therefore healthcare of citizens can unsurprisingly be detected right away. In addition to health status, the wellbeing of all citizens encompasses many aspects of an individual's lives related to physical, social, technological, and economic factors. This begins to paint a picture of a specific vision where healthcare and physical factors are not the only important factors when it comes to a citizen's wellbeing. The second goal mentioned, to offer security, I view as an initial vanguard vision, which we will see translated into a pillar of an imaginary being formed. In the development of an interoperable health data platform, offering security is a guiding factor that affects many aspects within the project. These include, privacy and control of personal health data, providing the security of the opportunity to safe and effective healthcare, and providing secure and reliable ways for HCPs to perform research and care for their patients.

Related to providing security, is the EC's goal to provide a strong economic market with full employment and social progress and combat social discrimination. Again, these goals place an emphasis on social and economic factors of a society that should be considered in the development of any project being funded by the EC. Connected to this research then, the emphasis on this factor begins to paint a vision of a project being developed in a way that is conscious of how it can benefit the European economic market, employment, and social well-being of citizens holistically. Rather than only focusing on the health of EU populations or looking at healthcare in a silo this is viewing the wider constellations and influential factors on society and in a sense beginning to assert that better healthcare through a data infrastructure can provide a solution to multiple issues. Finally, the goal of enhancing cohesion and solidarity among the EU countries, is one that provides a very clear vision without any deep analysis. In this objective importance is placed on a future where EU countries are working together and in relation with one another. Already with an analysis of objectives of the EC actor group presented at this level, the beginning of a vanguard vision begins to form regarding the future of healthcare, and society in general.

4.1.2 Zooming into the European Commission

In magnifying my analysis into the EC towards the InteropEHRate project this led to looking at the department of Research and Innovation. Within this department is the Innovation Union, of which Horizon 2020 was the financial institution charged with implementing its main goals. These three main goals included:

> "1. make Europe into a world-class science performer.
> 2. remove obstacles to innovation like expensive patenting, market fragmentation, slow standard setting, and skills shortages.
> 3. revolutionise the way public and private sectors work together, notably through Innovation Partnerships between the European institutions, national and regional authorities, and business."
> (Innovation Union, n.d.)

An analysis of these goals shows further development of the vanguard vision being put forward by the EC as an actor group. The focus of goal one, “Europe being a world-class science performer”, shows an emphasis on innovation and progress in areas of research as well as technological development. The second and third goals, again place a high importance on innovation. In both of these two goals there is also significance placed on the solidarity and cohesion of EU countries, as well as the need for economic and political market players to work together. These goals are very closely related to those of the first sub actor group reviewed in this section, which work towards the building of a vanguard vision, and add a high importance on the need for innovation, science, and the progression of the EU in general.

At the same level as the Innovation Union, of the different organisations involved in the EC, which is being looked at as an actor group, is the Horizon 2020 framework. This framework has its own goals that build into the vanguard vision put forward by the different departments within this larger actor group. One of the goals particularly important to the research of this thesis stated in the framework is aimed at securing Europe’s global competitiveness (European Commission, 2013). The framework is also seen “as a means to drive economic growth and create jobs” and places emphasis on “excellent science, industrial leadership and tackling societal challenges” (European Commission, 2013). All of these goals and objectives come together to produce a wider framing of European innovation, progress, and competitiveness in relation to healthcare in this case, but also in general which can be seen through their clear relation to the previously mentioned objectives and goals within this actor group. Zooming in even further within EC, an organisation titled, Priority’ Societal Challenges, is the next level that focuses on from the wider Horizon 2020 framework to the more specific InteropEHRate project. The priority on societal challenges is focused on outlining the focus areas for categories of projects that are directly working on the “policy priorities and societal challenges that are identified in the Europe 2020 strategy and that aim to stimulate the critical mass of research and innovation efforts needed to achieve the Union's policy goals.” (European Commission, 2014a). This again supports a vision that places importance on the progress of the EU, innovation, and the overall well-being of EU citizens.

The final two sources for the framework of the sociotechnical imaginary being studied coming from the EC are documents themselves. These documents coming from the EC include the direct project calls and funding schemes for InteropEHRate starting first at the level, *SOCIETAL CHALLENGES - Health, demographic change and well-being* and then moving even more to the specific direction *Prototyping a European interoperable Electronic Health Record (EHR) exchange*. These two documents are extremely rich in data related to almost every section in this analysis chapter and will be included as such. As this section is focused on recognizing the vanguard vision of the EC, as well as teasing out the wider framework for the overall sociotechnical imaginary created in the development of an interoperable health data platform, it is important to first look at how these documents build on what has already been laid out. More specifically, it is clear there is an emphasis on a few broad themes: the well-being of citizens, security, innovation in Science and Tech, and progression of a Unified EU in terms of social, economic, and political areas.

Within the project calls, there are stabilizations of these visions as well as further development. These themes can be seen in the specific project call documents in many areas that are often overlapping. Beginning with the topic of the wellbeing of citizens, there are many data points which show that this must be a large point of focus for any project applying for funding, in more ways than one. The emphasis on the well-being of citizens can be seen in the wider project focus of improving healthcare in ways that are closely tied to the other goals being put forward such as security or social and economic considerations but also through a large emphasis in everything being developed in a largely citizen centred fashion. This approach is put in place with the goal of ensuring that everything being developed is truly beneficial and highly usable by patients themselves and is mentioned or explained many times throughout the project calls. One example of this can be seen in the following quote from the Level 1 project call,

> "Emphasis will also be placed on engaging all health stakeholders – including patients and patient organisations, and health and care providers – in order to develop a research and innovation agenda that actively involves citizens and reflects their needs and expectations." (European Comission, 2014b, p. 4)

This quote explicitly declares that the innovation projects and agendas that are being considered under these requirements should be inclusive of the perspectives and needs of patients which in this case is also referring to citizens. This quote also goes to show how in this vision, patients or citizens are viewed as a key stakeholder in the wider project constellation. A second way in which there is an emphasis being placed on the project being citizen centred by the EC's funding scheme is by requiring an educational aspect to be developed with any projects for users, including patients or citizens.

> "Additionally, a targeted communication and education campaign with key information and tools should be produced to explain the functioning and purpose of the infrastructure (from empowerment of the citizen and promotion of health to the contribution to research) and incentives should be provided to users to accelerate the take-up and sustainability of the platform." (European Commission, 2018, p.3)

This concentration on education in the project calls, shows that within this imaginary being developed different groups of citizens are being imagined as users. This quote shows an understanding for the fact that there will be users who have different levels of technological literacy and will therefore require different levels of support to be able to make use of what is being developed. The later portion of this quote also shows consideration for the different levels of willingness citizens will have to make use of a new healthcare technology. It is also important to mention here that there is at this level a script being built into this initially imaginary of the project, with the reference of an incentivization for use. This can be understood as this actor group imagining that some users will be hesitant or even resistant to using the platform, but regardless of this, they should be pushed to use it to ensure the new technologies success. As will be shown in the remained of this analysis, there are many imagined ways a project funded under this call should benefit society and the EU, and this could be viewed as a reason to ensure its success, rather than focusing only on how users who are patients would like to use technology to take care of their health.

On the other hand, this section of the quote can also be seen as giving different users the opportunity to make use of the most advanced and beneficial technology possible, to achieve and maintain the best health they can as an individual citizen. This aspect of how citizens should take care of their health, is very present as this analysis continues to look at the many ways in which a citizen centred approach is formed into the wider framework of the vision held by the EC as an actor group, and beyond. In addition to the project calls both emphasising that the whole development of what is being built be based on a citizen centred approach, there is also a focus on the actual platform and the technology being concentrated on citizens, and how users care for their health. This is clearly stated in the Level 2 project call,

> “This prototype should be primarily focused on citizens' health data generated by the citizens themselves, HCPs or sourced from relevant healthcare organisations.” (European Commission, 2018, p. 2)

In this quote it is evident that citizens are at the centre of the technology being developed. The statement that the platform should include data generated by citizens themselves shows that there is a focus on the technology being inclusive, and easily usable for all patients, rather than just other stakeholders who will use the platform. It also shows that there is an intention for a dynamic of trust and collaboration to be built between the different users of the platform who will all generate and use health data to achieve a higher level of healthcare. The theme of the citizens' wellbeing is also built on further through the idea that a project being built from these calls need to empower citizens by giving them control of their data and their healthcare.

> “Similarly important is the wide uptake of technological, organisational, and social innovations empowering in particular older persons, persons with chronic diseases as well as disabled persons to remain active and independent. Doing so will contribute to increasing their physical, social, and mental well-being and lengthening the duration thereof.” (European Commission, 2014b, p. 4)

This section in the project call really emphasises the vision that citizens can and should be in more control of their own healthcare, and a new technological innovation will give them the opportunity to benefit their health in all ways possible. All of these data points clearly show the beginning of an imaginary where the health of citizens, and their wellbeing as a whole are thought about from different angles by the EC within the project calls. An importance for citizens' wellbeing can also be seen overlapping with the identified theme of better social and economic factors that are directly related or influenced by the development of an interoperable health data platform.

In both project calls coming from the EU, there are multiple mentions of negative socio economic issues resulting from low functioning healthcare systems. Additionally, there are statements made about how populations in the EU will continue to develop, sometimes in ways that will expose even larger threats in current healthcare systems, or simply render the current systems, technology and infrastructure surrounding healthcare in Europe needing improvement. These statements are based not only on the direct health statistics and or deathrates related to specific diseases and illnesses, but also larger societal and economic factors as well. For example,

> "In the Union, cardiovascular disease annually accounts for more than 2 million deaths and costs the economy more than EUR 192 billion while cancer accounts for a quarter of all deaths and is the number one cause of death for people aged 45-64. Over 27 million people in the Union suffer from diabetes and over 120 million from rheumatic and musculoskeletal conditions. Rare diseases remain a major challenge, affecting approximately 30 million people across Europe. The total cost of brain disorders (including, but not limited to those affecting mental health, including depression) has been estimated at EUR 800 billion. It is estimated that mental disorders alone affect 165 million people in the Union, at a cost of EUR 118 billion. These sums are expected to rise significantly, largely as a result of Europe's ageing population and the associated increases in neurodegenerative diseases. (European Comission, 2014b, p. 1-2)

In addition to these clear numbers, this specific EU document also discusses the increasing burden of an ageing population, drug and vaccine treatments becoming more expensive and less effective, the increasing concern for poverty-related and neglected diseases, the increased social and economic costs of chronic disease and increase of premature deaths. Not only does the first level project call mention many of the problems and related effects of healthcare in its current state, but the second project call also explicitly states how a new project should fix these mistakes. In a list of what the project proposals in this funding scheme should include as indicators to measure progress in certain areas through the development of the project the following points are included:

> "Improved health services and health conditions, enhanced quality and safety; Improved efficiency in terms of health economics such as on timeliness of intervention or measures taken, preventive actions/recommendations; (European Comission, 2018, p. 4)

Looking at all these points made in both project call documents within the sociotechnical imaginary being produced is the idea that there are major issues in the current healthcare systems across Europe and the vision is to improve them. What becomes clear through the points made in these documents, related solely to health, but much larger socio-economic problems, is that poor, outdated or simply inefficient healthcare practices and systems are deemed as the root of these issues. This strand of the overarching imaginary can be directly linked to the importance within the vision placed on citizens' wellbeing as well as the need for innovation.

The theme of citizens' wellbeing and technological innovation through the lens of healthcare is also closely tied to topics of security. As established at the very beginning of this chapter, security of European citizens is an important focus of the EC. This is also demonstrated within the two project call documents, especially related to the topic of data, transferring information and privacy. There are numerous specifications of the way technology should support anonymity, secure and consensual data transfer and simply security. For example in 7 of the 16 bullet points outlining what must be included in any projects applying for this funding these topics are mentioned:

> “Ensure citizens' opt-in processes are properly undertaken in order to allow the secondary use of data for scientific purposes and promoted health;
>
> Provide anonymisation/pseudonymisation capabilities to allow open access to health data for research and public health purposes;
>
> Ensure the proper and legitimate governance of the platform, ensuring the privacy and confidentiality of all citizens/patients/users at all time;
>
> Ensure compliance with relevant EU legislation, in particular REGULATION (EU) 2016/679 on the protection of natural persons with regard to the processing of personal data and on the free movement of such data;
>
> Ensure compliance with the Medical Devices Regulation as appropriate and regarding the specific requirements, such as the need for a unique device identification and proof of cybersecurity;
>
> Consider legal aspects related to data contributions and use, such as portability, data donorship, based on existing regulations on national and EU level;
>
> Compliance or harmonisation with requirements of respective national legislation as appropriate, especially in terms of data protection and regarding electronic patient consent.” (European Comission, 2018, p. 2)

The different specifications mentioned in the above requirements from the project call at this level lay an initial framework for how security, data, and privacy should be viewed and treated throughout the development of the project. Security also then can be viewed as intertwined with the vanguard vision being put forward and a strand that gets developed on further with the co-production of the sociotechnical imaginary of the project.

From the entire EC actor group perspective, in all the stated goals, quotes and examples mentioned, there are very clear values and objectives being spelled out. The goals and clear instruction for how they should be approached, being presented by these different departments within the EC not only provide the outline of one of the vanguard visions within this project, but can also be seen as performances that begin to shape the greater sociotechnical imaginary that this research is interested in.

In terms of the InteropEHRate project there is a clear idea being developed, through performances within these materials, that a change needs to happen within healthcare infrastructures to support the larger goals of citizen wellbeing, innovation, security, and a unified progressing EU. The vision of an interoperable system that collects and exchanges health data from all European citizens, especially for the purposes of research, is often described as important for Europe's competitiveness, as well as the competitiveness of European industries. In addition to the explicit mention of the contributions the development of an interoperable health data platform will make to Europe's competitiveness, there are also visions of how this will improve Europe's progress in terms of innovation, the overall population's health and well-being. The following sub chapter of this section will show how this vision is built on and developed by examining materials of the InteropEHRate consortium itself and some of the specific developers involved.

4.1.3 Visions of Developers

After initially looking at the wider ideas and visions being put forward by the EC, this sub chapter will focus on a second actor group that can also be seen as having vanguard visions within the context of this research, developers. The developers who are partners of the InteropEHRate project come from different countries and organisations, all with sometimes similar but individual objectives related to the technology and projects they are working on in the health field. As stated earlier in the thesis, each developer interviewed is involved in developing a different technological protocol for the InteropEHRate project. The protocols are based on a software or specific technology that the company or organisation they are a part of is privately working with, developing, or has already developed but is then altered to fit with the requirements of the InteropEHRate project. For example, one interview partner has already developed an app that can be downloaded on any smartphone, where patients can store and share their health data with whoever they chose. This app is then used as the basis for this component of the InteropEHRate project that allows citizens to collect, store and share their health data. The other two developers who were interviewed for this project are involved in defining the user requirements for the project and developing the protocol for the HCP app. This means that the work they are doing within the InteropEHRate project also has an impact on their work outside of the results of what the consortium develops. All the developers are viewed as experts within the fields they are working in and bring their unique proficiencies to the work of the InteropEHRate project. Within the framing of this thesis, the developers then can be seen as key people who hold vanguard visions. Some of the visions remain individually held and some become more widely shared development of the imaginaries being investigated.

Each of the developers have their own unique entry point to the InteropEHRate project, but they also have similar roles in that they are shaping the result through the specific features they are responsible for. In a previous sub chapter (4.1.1) vanguard visions as well as initial imaginaries could be identified coming from the EC, the same can be seen coming from the developers. Many of which are closely related to the already determined priorities from the EC of citizens wellbeing, security, innovation and the unification and progress of the EU or in some way building onto, or developing these visions further. It is important to note that the developers are carrying out the development of the InteropEHRate project in accordance with the guidelines provided for doing such. This co-development of the imaginary between the InteropEHRate project, the EC and the developers as individual actors will be investigated in the remaining sub chapters of this thesis (4.2, 4.3, and 4.4).

This current subsection is interested in teasing out again, some of the larger, overarching visions that the developers are bringing into the project with them. The first of these overarching ideas is the high value based on the technology for the project being developed in a way that is multidisciplinary, involving many stakeholders and most of all in a user focused way. This overarching theme that relates closely to the visions coming from the EC as just discussed is also often found in the interview data from the developers. In speaking with the developer's specific ideas about how and why different stakeholder's needs should be considered in the development of this new technology. When asked about their role in the InteropEHRate project when developer answered with:

> “We represent here the voice and the experience of I.T. development, the user experience and user requirements and user functionality on both sides, the HCP, which means that a physicians essentially and patients and InteropEHRate is focused more on the patient side because they plan to provide this kind of platform and that this is an open platform capable to support a certain kind of application that can be executed on a smartphone, but also some other, let's say, devices you just mentioned something just like wearables. And this might be expanded also to some wearable functionality.” (Interview 3, May 21st, 2021, Ln 4)

It is obvious that in the beginning of this answer, the interviewee is of course explaining their role as it is officially determined by the EU project requirements, which will be discussed in a later chapter. Still, the importance of multiple stakeholders, and specifically patients and doctors, is emphasised here. In the second half of the quote the interviewee mentions how the platform should be more heavily focused on patients as users. What is also interesting in this quote is the fact that patients being users is associated with capability of the platform to be used with smartphone applications and wearable technology. Here it begins to become visible that while users are a focus of the development and key stakeholders within the project, a user with specific technological behaviours is being imagined. The importance developers place on involving the users, meaning patients and doctors can also be seen in the following quote. Something important to note from this snippet of the interview is that this developer was not speaking about the InteropEHRate project specifically, but about the development of a healthcare application that will be used and altered to fit the uses and needs of the InteropEHRate project.

> “when you feel like you go to the doctor, you don't know what you have. He doesn't know what you have. So there is first a number of analysis, like maybe blood tests and things. And then finally, gradually you come to a diagnosis. Sometimes you have to revise it because it was not the right one. And so there's a dynamic aspect also. And so

> all of that is quite complex. And then what we had to do very early on is to make choices on how to display that to a patient. Right. It's already super hard to do that for doctors because if you look at EHRs in hospitals, most doctors complain about how difficult it is to use or how user friendly it's not or how un-user friendly it is. And the needs of a gynaecologist are not the same as the need of a radiologist or a family doctor or a nurse. So it's very complex. And so for patients which have less health literacy and then a HCP then it's an even different approach. Right. So we did a lot of work to make it look as simple as it is." (Interview 2, April 16th, 2021, Ln 15)

Speaking to this interview partner about the development of a health data app built before the project, provides insights on the visions that they held and brought with them into the work of the consortium. Within this quote, there are multiple imaginaries present but what's most important for this stage in the analysis is the ideas put forward about patients and doctors as users. The developer is reflexive about the impact that decision making has on the result and use of a technology during the development process. There is an importance placed on both patients and doctors as users, and what their individual and different needs within these two groups are with a clear priority placed on patients.

Within the vision for how development should be handled, and the multiple stakeholder groups that should be involved, this developer also included himself and his personal connections to different user groups.

> "So we have to just to do with it. And so I, there was a strong focus for us initially. How did I decide to build that? Well, in my case, I had a lot of experience, in health IT, and I have been a patient myself and I have been caring for a patient, my son so I have quite a number of views. And I have also very good friends, which are doctors. Right. But I didn't want them to influence too much by building something that would be good for doctor because, you know, they were asking me to put elements that would not make sense for a patient." (Interview 2, April 16th, 2021, Ln 18)

This is only one example of Interview partner number 2 referencing their own specific experiences with healthcare, doctors and medical data. From these three quotes alone, it can be understood that in the vision being brought into the larger imaginary put forward by developers, there is a large focus on multiple stakeholders being involved, with the most focus being placed on users such as doctors and especially patients.

This idea develops even further within the data of the interviews through the notion that not only should the technology be developed in an extremely user-friendly way, but also in a way that gives patients the feeling they can trust the technology and trust data. Without user trust, the technology will not be used in the intended way, or in a way that is in line with the imagined ideal user.

There is a level of awareness from developers that introducing technological and data centred approaches to healthcare will require some level of adjustment and buy-in from users. Based on the interview data the developers expect different levels of buy-in, but they are confident it will happen at a productive level. When asked to imagine the whole InteropEHRate project was finished and successfully implemented across Europe, one developer expressed this expectation of high acceptance from users, "the first results, I expect, and a level of acceptability for the patient, pretty high.*"* (Interview 3 May 21st, 2021, Ln 43). This notion of expected acceptance is common between all the developers. The reasoning behind this being that the use and sharing of data will allow for higher quality healthcare. This idea that is consistent through not only the interview data, but all of the data analysed for this project, ties together many of the overarching visions from the EC and now the developers as well.

> "But I'm not trying to convince them. I'm well aware that, you know, there is that curve of adoption with early adopters and lagers and the mass and so on. And I'm just talking to the ones that are more open to it. It's very clear that young people are less interested in their health because they don't usually have a problem except the ones that have a problem. The diabetes, one on the one that that cancer like my son when he was ten years old. So usually people are interested in their has had some health problem and that's why it's is the trigger. Right. And then you don't need to convince them. Right. They just realise this and they do what's needed". (Interview 2, April 16th, 2021, Ln 65)

In this quote, the developer being interviewed is very explicitly explaining his own view that if a person is interested in being healthy or has a medical problem that requires them to pay closer attention to their health, they will do whatever is needed, and in this instance, "what is needed" refers to using health data. The idea, that making use of health data, and a technological platform that allows for the storing, sharing and translation of data to be used for different medical purposes as the solution to not only better healthcare and a healthier population, but really all of the goals of the EC.

This can be seen by continuing to analyse the visions of the developers, and how these visions are intertwined with those of the EC. The vision that better healthcare can be achieved through technology that makes use of health data being developed in a user centred way is directly related to the wellbeing of citizens. Building on this vision shared between the EC and developers of the consortium, and looking further into the interviews with the developers, this idea is also closely linked to the goals of research and innovation within Europe, the progress of a unified EU and of course, data security and privacy. These connections become very clear when investigating the developers' ideas about how health data can and should be used, what technology is necessary to achieve better healthcare, and the ways in which this technology should be developed. In the previous three quotes from in this subsection, used to highlight the need for user focused development, the theme of citizens and also doctors being responsible for collecting, storing, sharing and caring for health data began to emerge. The assumptions and ideas related to this will be discussed in greater depth later in this chapter, but what is important to take note of as an overarching theme is again the reasoning behind this. One of which, as just discussed, is to achieve better individual healthcare, the second is through research and innovation that can be done with larger sets of health data. Even if this is not the immediate goal of our expected outcome of the

InteropEHRate project as the consortium is only working with small user groups, it is clear this larger vision of larger scale research is something the developers are imagining.

> “And that is a small number. We know haha it is a small number but is capable to scale up up to millions. That starts with, let's say, an expression of a research protocol. That research protocol contains somehow a selection of information that we are aware that the patient have on his or her smartphone. So if we have this, let's say list we will check a few items on this list, then we will publish to another central server, different from the, let's say, back up cloud server.” (Interview 3 May 21st, 2021, Ln 22)

This is only one instance of many in all of the interview data where a developer expresses the large-scale potential for research and data collection. The collection of large sets of health data and intended research uses in the visions the developers have can be seen as very closely linked to the vision of supporting innovation in the EU. Not only is health research connected to this goal of the EC, but it is also related to the goal of the progression of a unified EU. In the many mentions of the ways data can be collected and used for research, the developers place a large emphasis on the importance of collecting and making use of data from citizens across all EU countries. In talking to the developers, it is clear that within the project there is an enormous focus on the translation of data in a way that makes it usable for individual healthcare, research and innovation.

When discussing the idea and importance of data being usable by different actors there are multiple different requirements and implications discussed. The idea of translation refers often to language to ensure that the use of data across borders. For the projects outcomes to fulfil goals of being not only used but also beneficial for the entire EU in terms of unification and innovation, language becomes a key aspect of the technology being built. A form of translation that is slightly less clear, but also very important refers to the format in which data would need to be stored in or corrected to in order to be analysed or transferred to different sources.

> “OK, so the user interface we take care about, the user interface of the HCP App, there is another one, which is in the other layers you have a translation module let's say, which is another partner. OK. Oh. data gatherings can become a task also, it is not really a development by itself, but it is also with task. And it's a technical one because you have to get some, I don't know, patient data, that you anonymize later and for the testing and this task, it is a task is not a development per say.” (Interview 1, April 9th, 2021, Ln 71)

In this quote one of the developers was asked to discuss how different tasks are split up between the members of the partner teams working on different areas of the InteropEHRate project. In explaining this process, the specific example of data needing to be translated in order to fit with the formatting requirements of the HCP app. As the InteropEHRate project is working to build an entire healthcare infrastructure that allows for the storing and sharing of data across many different actors, there are many more instances of this need for data translation. The emphasis being put on both forms of data translation, in order to meet the requirements of many different stakeholders and be used on varying platforms really shows the importance that not only the developers, but all members of the project place on sharing data.

While translation is an extremely important factor in the sharing of health data within this project, a second extremely important factor related is data security and privacy. The interview data shows there is a very clear vision from the developers that for the data sharing process to happen, there needs to be sufficient protocols to “preserve the security and the compliance” (Interview 1, April 9th, 2021, Ln 4). Not only did developers hold this vision that data security and privacy is extremely important in regard to the InteropEHRate project, but in all situations using health data. When discussing a private project related to the collection and use of health data for medical purposes, one of the developers made the comparison to how almost all the Apps people have on their phones nowadays are collecting and even selling health data, but how important the decision to not monetize health data was for him. The emphasis of protecting and securing health data and the privacy of patients seems to be an important issue intrinsically on its own, but also because of the implications it has for the wider infrastructure working and being used by the intended users. This is a vision contributing to the wider imaginary of better healthcare not only by the developers, but across all stakeholders analysed in this research, and will be discussed further in upcoming sections.

4.1.4 Co-development of an imagined better healthcare

The first two sections of this subchapter within the analysis have laid out the overarching vanguard visions coming from two of the major project stakeholders. Taking this path into the data for the analysis of this thesis has, as intended, provided structure through mapping out the beginning of the imaginary of better healthcare being developed through the visions of the main stakeholders. Now that these initial visions from the developers and the EC have been established, this section will look at how these visions are combined and built upon through the InteropEHRate project. More specifically, how the project documents and other materials tie together the visions that have been identified about improving the wellbeing of citizens, unified progress and innovation through a larger imaginary of an interoperable health data platform and infrastructure. Better healthcare has thus far, clearly been identified as a solution to large societal issues pointed out by the ECs. Looking at the materials of the InteropEHRate project that highlight the guidelines of how and what should be developed by the project partners this section in the analysis will discuss how the interoperable health data infrastructure should provide a way for better healthcare to be achieved.

It is through the InteropEHRate project, and the infrastructure that is being developed, that the visions of these two actor groups of the EC and the developers come together to produce one imaginary for better healthcare. The combination of the visions through the negotiation and alignment of objectives, as well as some of the vanguard visions falling away from the larger imaginary happens because both groups are essential to the other and the overall project development. Without the developers working on InteropEHRate, the innovation, progress and objectives set out by the EC would not be attainable. Simultaneously, for the developers of the project to continue working towards achieving their objectives they need the funding and support from the EC. This relationship is what aligns the two groups and results in their visions for a future of better healthcare to come together into one more stabilised imaginary.

Of the materials analysed coming directly from the project, the InteropEHRate Project Description and the website page *InteropEHRate in a Nutshell* are by far the most significant when it comes to the idea of better healthcare being developed through an interoperable health data platform. The information and ideas put forward from the InteropEHRate project materials are in line with essentially all the themes present in the analysis thus far. The notion that better healthcare can be achieved through an interoperable health data platform and infrastructure is supported by multiple different ideas within these documents. The first and most prominent supporting notion within the website page and the project description is that citizens and or patients should be able to easily manage and control their health data. The first line of the first section of the project description states, "Electronic health records made easy for patients to manage", (European Commission, 2020, P. 1). On the website page, the first line reads, "InteropEHRate enables patients to be in full control of the use of their health data." (InteropEHRate, 2019, P. 1). The requirement for patients to be at the centre of what is being developed is consistent throughout all the project materials. The technology being developed in a way that is not only extremely user friendly, but also full of choice for citizens. Patients having access to their data and being empowered to make decisions about who to share it with and for what purpose is very clearly and often spelled out in the project materials.

An interesting point within these materials is how this objective to give patients individual access and control over their health data is often presented as a solution to larger problems that are also sometimes individual but other times on a much larger societal level. For example:

> "Today, citizens moving across Europe have very limited control on their own health data, spread out in different silos. Legal constraints may prevent controllers of these silos from exchanging the managed data, even in an anonymized way, without the intervention of higher authorities. As a consequence, health data cannot be fully exploited for healthcare and research." (European Commission, 2020, P. 2)

The lack of control and data silos being mentioned in this example are very obviously being mentioned in a negative light as issues that need to be resolved. Towards the end of the quote, the idea that these two issues are in fact issues by explaining the negative consequence, that data is then not able to be used for health and research. These two issues are very clearly related to individual use, or prohibitions of individual data use, but the consequences mentioned are very much related to larger societal issues. While there are of course individual consequences to data silos and lack of control over personal data, and the larger societal consequences are in part stemming from individual's data practices, there are many other factors that could be considered. What this phrase indicates is an assumption that if patients become in control of their own health data, they will behave in a way that will allow for the data to be "exploited" for healthcare and research. Within this quote, something that seemingly contradicts the overall strand of the imaginary that citizens should be in control of their data and will benefit from sharing and donating their private information is a peculiar word choice of "exploit" which has a negative connotation.

Often, within the InteropEHRate materials, and really all of the data sources included in this project, there is a much more positive notation around citizens' use of health data, and health data in general always being used in a very safe, secure and private way. In fact, the safety and privacy of data through secure uses is a key aspect built into the imaginary of better healthcare through InteropEHRate. The project description references ideas related to this theme in the project objectives multiple times. The objectives start by claiming, "InteropEHRate aims to empower the citizen and unlock health data from local silos, using a bottom-up approach for EHR interoperability", (European Commission, 2018, P. 2), and continues in each of the five objectives mentioned, discuss how citizens and their choices will be at the centre of the goals, development and intended uses for the outcome of the project. These objectives and the way they are always framed around citizens and or patients can be viewed as a rehearsal that helps stabilise this stance of the project being patient centred to help individual citizens have better healthcare, as well as contribute to an overall healthier population. This is very much in line with the visions of both the EC and the developers. Within the developing imaginary that is being co-produced by these three actor groups thus far, the idea that citizens or patients must be at the centre in terms of involvement in development, as well as the way the end results are intended to be used is extremely important.

In framing the project objectives as being citizen centred and improving healthcare through an interoperable health data platform that is citizen centred, many other aspects of the imaginary that are closely related to the vanguard visions already discussed come through. The first of which being that all stakeholders need to be involved. Even though the strongest focus, especially from the InteropEHRate project materials, is on citizens or patients, there is also an acknowledgement that other users are very important to the development and end uses as well. For the interoperable health data platform and infrastructure to have the intended results, it will require buy-in and specific actions from other stakeholders as well. The webpage that explains InteropEHRate in a nutshell describes how the use of a S-EHR can be used to support the communication of health data. There are three protocols that the S-EHR supports, all of which include at least one stakeholder in addition to a patient.

"An S-EHR supports the following communication protocols:

- D2D (Device to Device) protocol: Exchange of data between patients and healthcare organizations without an internet connection.
- R2D (Remote to Device) protocols: Three protocols for remote access: (1) to EHRs for citizens and to optional S-EHR Cloud for (2) citizens and (3) healthcare providers.

- RDS (Research Data Sharing) protocol: Sharing of health data with research centres without cloud storage." (InteropEHRate, 2019, P.1)

In these protocols the other stakeholders explicitly or implicitly mentioned include healthcare organisations, healthcare providers, HCPs, research organisations and researchers themselves. This shows how even though patients are at the centre of development and are being used as the central actor in the imaginary being developed, there are many other actors within the imaginary that are crucial to the vision of improving healthcare. In these project materials, and even in this quote just used to show the importance of all stakeholders, there are also many other crucial factors to the better healthcare imaginary. These include firstly the idea that better healthcare needs data that should be used for research and innovation projects, secondly the notion that better healthcare requires innovation and technological solutions for multiple purposes including the handling and transfer of data and thirdly, that everyday technology such as smart phones should be used for healthcare purposes and as part of the technological infrastructure being developed.

These three identified features of the imaginary are clearly not only coming from the project material documents. Similarities and connections can be drawn to the different visions and imaginaries coming from the EC and the developers as well. Drawing these connections and looking further into the development of each of these different areas of the imaginary being co-produced will be done in the following sub chapters of this analysis. This will require zooming into the data even further from the key aspects of the imaginary established this far. Looking even deeper into the details of the shared ideas of better healthcare being co-produced through this project is important as these visions contribute to creating and shaping what health and healthcare will look for in this intended future, meaning it also reflects who is cared for and how as well as who is and what is not. In the next sub chapter, the imaginaries will continue to be built upon through looking at the healthcare imaginary more specifically, in terms of how health and care are portrayed currently and how it should look in the future as well as who and what is included in this future.

4.2 The better healthcare imaginary

Now having the wider framework and first view vanguard visions coming from the InteropEHRate project consortium, the developers and the EC, the first more in detail avenue of the imaginary being co-developed by all the actors involved that this analysis will cover is the ideas and visions of healthcare itself. To understand how the project consortium and specifically the developers of the project cultivate a sociotechnical imaginary of better healthcare that will contribute to the larger goals of the EC, it is important to look more closely at what is involved in the healthcare imaginary that is put forward by these actors and what better healthcare is imagined to be. To explore this imaginary, I will break it down into three different aspects that have already been identified as relevant earlier in this analysis. These aspects include the affirmation of the idea that 1) the health status of citizens is a challenge for future societies. 2) Health can be captured and represented through data. 3) Individual responsibility and the idea that citizens should care for their own health. Looking into the details of these three separate aspects will shed light on how the shared ideas of and related to health and the care that needs to be done by different users to have better healthcare are developed. The specific ideas around why and how healthcare needs to be improved that are put forward by those involved in the project influence the shared idea of this, and therefore the technology being developed to carry this out.

To explore the co-development happening between all of the actors involved in this research, chapter 4.2 will be divided into three separate subsections. The first subsection, Chapter 4.2.1, will look into the problems that are identified and discussed with the current healthcare systems and infrastructures in place and how these lead to an intended future for healthcare. The second, Chapter 4.2.2 will look at the very specific idea within the InteropEHRate project that health can and should be captured and represented through data to improve healthcare. Finally, Chapter 4.2.3, will aim to understand how users are expected to participate in this future of better healthcare by caring for data. More specifically, referring to how patients are expected to care for their own health by caring for data, and how doctors and other medical staff are imagined handling data to improve healthcare. Looking at these three aspects gives insights on how specific ideas of healthcare get brought into the imaginary, are rehearsed, and solidified through the InteropEHRate project. Through the unfolding of this section of the analysis it will become evident that the way in which healthcare is imagined in this constellation is co-produced with the infrastructure being built.

4.2.1 Healthcare present past and future

A key layer of the imaginary being investigated here, and as a crucial first step of solidifying an imagined future of better healthcare, are the explanations of why healthcare systems and infrastructures as they are currently running or have been operated in the past are not reaching the current goals of the EC. These highlights of specific problems are significant as they provide a justification for certain decisions made to improve healthcare. At the same time, with the identification of certain issues, also comes a validation of what should be cared for and prioritised in future visions of healthcare. In the data collected there are many identified problems that are referred to directly or through the explanation of how specific technological features, or user practices for example would improve healthcare. This section will focus on some of the larger all-encompassing issues identified, the first of which being the element that in general the overall health of the European population is continuously worsening. Within the data this is by far the most mentioned large issue with healthcare and the related infrastructure in the past and present. In section 4.1 one of the quotes from the project calls regarding how the health of European citizens is becoming a growing issue, in terms of health and well-being, but also in terms of socioeconomic burdens. This quote from a project call emphasises even further that not only is the worsening health of the population an issue, but that the cause(s) of these problems can be attributed to the way healthcare is currently done.

> “If effective health and care is to be maintained for all ages, efforts are required to improve decision making in prevention and in treatment provision, to identify and support the dissemination of best practice in the health and care sectors, and to support integrated care. A better understanding of ageing processes and the prevention of age-related illnesses are the basis for keeping European citizens healthy and active throughout the course of their lives.” (European Commission, 2014b, P.4)

This quote explicitly points out the idea that there are many areas in healthcare across which need attention and improvement. The words “keeping European citizens healthy and active” in this quote assume some level of responsibility on actors who are responsible for implementing healthcare infrastructures. In referencing the decision making, “dissemination of best practice in health and care sectors and in general better understanding of different aspects of care”, this quote in the project call is highlighting very large-scale problems that need to be fixed. This part of the document is also putting emphasis on the whole healthcare cycle of citizens life, taking into consideration especially health concerns of an ageing population and discussing the need to incorporate preventive care into a future system. In doing so, the material highlights the idea that prevention and caring for age related illness within the European population are a key issue.

In addition to pointing out the shortcomings of keeping citizens healthy throughout their lives the project call also addresses solutions for improvement. Looking at these solutions not only provides insights into the ideas being put forward about how healthcare should be done, but also further details of what the issues are.

> “Specific activities shall include: understanding the determinants of health (including nutrition, physical activity and gender, and environmental, socio-economic, occupational and climate-related factors); improving health promotion and disease prevention; understanding disease and improving diagnosis and prognosis;” (European Commission, 2014b, P.5)

This quote is unambiguously referring to issues associated with information and knowledge surrounding healthcare topics that are necessary to care for populations effectively. This is a very common theme throughout the data supported by various reasons. Across all the materials analysed, the effectiveness and efficiency of healthcare can be traced back as the source of all of the different issues with healthcare that are raised.

These issues that can be traced back to effectiveness and efficiency include but are not limited to, the lack of information and data transfer of individual patients between healthcare providers, health data not being used for research, healthcare being increasingly expensive and causing socio economic issues, and healthcare not being innovative or using technology. For example. “However, there is a low level of systems interoperability in Europe since data are collected in different silos and managed under converging security and safety conditions.” (European Commission, 2018, P.1). Many of these issues are connected to each other and compound together to have an even larger effect. Looking at this point of issues compounding together from a different angle, there are ideas being put forward that the connectedness of the issues also means a one size fits all solution is adequate for all of the problems. The personal story below from one of the developers supports this idea of a one size fits all solution quite well. In explaining one experience with the healthcare system there are clear examples of the inefficiencies of the current infrastructure, and how one solution can improve many of them.

> “And then she said [doctor], OK, next step is for you to have a blood test. And then when we have the results of the blood test, a second consultation, you come and see me and we will have the results. Right. So three events, two consultations and one blood test right? At the end of the first consultation, I said, but I am a cancer patient and I have a blood test, every three months isn't that sufficient? Especially because I don't like to be, you know. You know, a syringe, every, its not fun. Yes. But they don't have the results. She said, I said, but I do have the results on my smartphone. Can I take a look? And then I gave her my smartphone she uses her two fingers, you know, because it was very small, of course, right? And she looked at the value that she was interested in and she said, you don't have a problem with Thyroid. So there's no need to have a blood test. And I can already give you the diagnostic. You don't have a problem with your thyroid. Right? So one consultation instead of two consultations plus a blood test so much faster and it's much cheaper for the Social Security. Right. As a patient, I had my results at the first time, I need the doctor instead of one month later, probably. Right. Just because I had the information and that information she trusted because she knew she saw that it was coming from the lab.” (Interview 2, April 16th 2021, Ln 90)

This account of an experience one of the developers had during a doctor’s appointment provides a great example of how the lack of health data and the technology required to transfer it between users, would have created large inefficiencies. If the developer did not have his health data on his phone, a second appointment would have been needed, requiring additional time and financial resources from both the patient, the HCP and the healthcare system they are both using. On the other side, this is a clear example of how these inefficiencies were resolved through the patient having access to his health data and being able to share it using technology. This story clearly shows a rehearsal of behaviours that are solidifying the imaginary of better healthcare through an interoperable health data infrastructure involving multiple stakeholders.

It is also important to recognize the different behaviours involved in supporting this imaginary, and in this specific example, what allowed for the solution to work. In this quote, the reason the doctor was able to provide the health data required of him was because he had previously taken responsibility over this information by collecting it and saving it on his smartphone. The specific behaviour that leads to cutting out the inefficiencies was the trust that she had in health data that the patient provided her with.

As just described, looking at the highlighted problems of the way healthcare is currently done is one way that ideas of better healthcare become justified and lead to the validation for many of the aspects being included within these ideas. Across the data there are several pieces of the imaginary that are intertwined and rely on each other to be effective. As just discussed in analysing the experience of the developer using their own health data during a healthcare appointment two of these aspects include using technology to facilitate data transfer, as well as behaviours that allow for this data to be used and trusted. Additional pieces coming from all actors involved in this study include the idea that healthcare should be holistic, preventive, and as discussed more efficiently. For a healthcare infrastructure to achieve this, as already established, within this imaginary an interoperable data platform and infrastructure is required. What this means more specifically, and as the story above has provided examples of, is that better healthcare requires the transfer and sharing of data, specific uses of data by different users, as well as the use of technology. This quote coming from a developer summarises the point that this imagined future requires the capability to add and use health information and data.

> "In many countries you're allowed to feed information, but not to consult information. And that's a huge obstacle for this kind of a platform, because we need a bidirectional communication between a patient phone, national infrastructure, healthcare providers, also single general practitioner." (Interview 3 May 21st, 2021, Ln 45)

This quote, and the ways in which it is describing data and technology to be used by actors can be seen as focused on improving the efficiency of healthcare on an individual level. The idea of a patient and doctors being able to contribute to this patient 's own health data, and use it to better their individual health being facilitated by a smart phone is being described here. This further develops the notion that an intended outcome of healthcare being done in the ways it is being imagined, will improve the health of each individual citizen. There is also the notion that the health of entire populations should be improved. Of course, if each individual is overall healthier the mass population will by default be healthier as well. In addition to this imagined approach to having a healthier population, there are other ideas as well. One of these ideas, as mentioned is the use of preventive care practices.

> "Personalized medicine should be developed in order to suit preventive and therapeutic approaches to patient requirements and must be underpinned by the early detection of disease." (European Commission, 2014b, P. 3)

Prevention, personalised medicine and early detection of disease, mentioned in the quote above, are all features imagined to be made possible by an interoperable health data platform. Framed in this way, each of these features would all work together to create more effective and efficient healthcare practices as well. A second, but related idea within the larger imaginary of how to increase the health of the wider population involves large sets of data and patient cohorts for medical research.

> "Effective sharing of data, standardised data processing and the linkage of these data with large-scale cohort studies is also essential, as is the translation of research findings into the clinic, in particular through the conduct of clinical trials, which should address all age

> groups to ensure that medicines are adapted to their use." (European Commission, 2014b, P. 4)

In this quote from the project call the large-scale research is clearly very important to improving healthcare and would be made possible through a healthcare system that uses an interoperable data infrastructure. The cooperation and specific behaviour of citizens as patients again is highlighted here. In both of these particular approaches to achieve better individual healthcare, and a healthier population the solutions require trust from all users, specific uses of different technology and of course data. This section has begun to highlight some of the imagined and required uses of behaviours in relation to data and technology and will continue to be investigated on a more granular level in the following chapters. Before this can be done, it is important to recognize and better understand assumptions being made within the developing imaginary of how data is related and used to represent health.

4.2.2 Health can be captured and represented through data

The idea that health can be captured and represented through data. This is a key notion that is expressed in the Horizon 2020 framework documents as it is the basis for many of the other claims that are made about the ways in which the project being developed can and should achieve better healthcare. The stabilisation of the notion that health can be captured and represented through data is made through a process of emphasising the importance of health data, explaining why it is important, and then describing how it can be used to improve health or healthcare. Throughout this process the assumption that health can be captured through data becomes a solidified part of the wider framing. Developers also contribute to stabilising the idea that health can be captured and represented through data within the co-developed sociotechnical imaginary, in the assumptions and visions they have about health data, why it is important and how it is used. This section will discuss the specific examples from the collected data that support these points. Beginning with the EC, and the first step mentioned in the process of stabilising the idea that health can be captured through data is, placing a great deal of importance on health data itself and the collection of it.

> "This prototype should be primarily focused on citizens' health data generated by the citizens themselves, HCPs or sourced from relevant healthcare organisations." (European Commission, 2018, P. 2)

By stating that the primary focus of this EU funded project is to collect citizen's health data, the assumption that this data is valuable and useful to achieving better health is clearly made.

As we have seen in the previous subsection, this project is focused on how the EU can improve the status of healthcare in the future. The prototype that is being developed to carry out this objective, then having the primary focus of collecting all health data from different available sources on individuals, is adding the idea that health data is important for citizens' health and improving healthcare to the wider vision being formed. The message that health data can capture a person's health and should be used in efforts to improve health is being communicated. These assumptions and messages are strengthened through the documents explicitly stating how valuable health data generated on European citizens is. “Large amounts of valuable health data are generated and collected during and between citizens’ medical examinations across Europe” (European Commission, 2018, P. 3). The idea that data on an individual is important because it can capture and be representative of health is also discussed by developers. During one of the interviews conducted for this project, this developer explains that within this imaginary, health data can be many things, and emphasises the fact that any data related to health is valuable to collect.

> “Its health data is not medical data, meaning that it's wider in scope. So for me medical data is something that comes from a doctor or hospital or a nurse. But health data is also activity data, nutrition data, sleep data and genetic data possibly. So everything that has some impact on your health is worth collecting. So that's why I created Andaman as a PHR personal health record. So it's not a medical record it's a health record” (Interview 2, April 16th, 2021, Ln 12).

Through the wider framing from the EC, as well as this idea coming from one of the developers, that health data is important, the formation of the notion that data can capture a person’s health is already being communicated. By looking at why health data is presented as important, this notion becomes even more solidified within the imaginary. Within the Horizon 2020 framework documents, health data is emphasised as being so important because it provides solutions to many problems within healthcare, and can be used to improve the health status of individuals and whole populations. The InteropEHRate project description itself published within the framework spells it out very clearly in the second line of the document:

> “The electronic health record (EHR) collects, systematises and stores patient data in a digital format in order to improve healthcare systems” (European Commission, 2018, P.1)

This justification that storing health data in an EHR is beneficial because it will improve healthcare is not only explicitly stated in the above quote but also supported throughout all three of the related Horizon 2020 documents. This reasoning very clearly implies again that health data can capture the health status of an individual and populations, but in fact should be used for these purposes because it will improve healthcare systems. Under the assumption that health can be a captured through data, developers also discussed the reasoning of why the data is so important.

To strengthen the notion that health can be captured through data even further, the EC as well as developers, have ideas that go beyond the question of ‘why?’ but also communicates the ‘how?’. The question of how health being captured in data will improve healthcare has multiple answers that are represented in the data I analysed for this project. One of these answers, that the EC emphasises is by compiling the data on all individuals to inform health related decisions, to be used as medical evidence and for medical research. This vision is performed by discussing problems related to not using health data to its full potential,

> “Legal constraints may prevent controllers of these silos from exchanging the managed data, even in an anonymized way, without the intervention of higher authorities. As a consequence, health data cannot be fully exploited for healthcare and research.” (European Commission, 2020, P.2)

Then discussing how recognizing that data can capture the health of individuals and populations, and using this data in a specific way can improve healthcare,

> “Effective health promotion, supported by a robust evidence base, prevents disease, contributes to well-being and is cost effective. Promotion of health, active ageing, well-being and disease prevention also depend on an understanding of the determinants of health, on effective preventive tools on effective health and disease surveillance and preparedness, and on effective screening programmes” (European Commission, 2014b, P.4).

In this quote, health data is assumed to be capturing the health of both individuals or populations, and when used in the ways described, are imagined to improve health or healthcare. Looking more closely at this quote, health promotion is being directly linked to solutions that rely on collecting large amounts of health data and using this data as a resource. The second answer of how health being represented by data, can improve healthcare, is the idea that it allows for the more holistic and preventative care that is discussed in the subsection above. Developers also share this idea and expressed it often throughout the interviews. This quote is one example,

> “as patients, but even as doctors and nurses and all the HCPs it is very hard to have a complete picture of your health data and that's because it's so scattered all over the place in several hospitals and in the family doctor’s practice when you were young, the data is with your parents paper files, you know, vaccination stuff when you were a kid and so on. So it's all over the place and it's very hard to have a global view both for patients, which are the more the most interested persons by their own health, but also by doctors.“ (Interview 2, April 16th, 2021, Ln 10)

Here, the developer is discussing the difficulties in having a global view of an individual’s health without having all of the data compiled into one place. This is very clearly expressing the idea that having all of the data on one individual is needed in order to represent their health, and without the full status of their health cannot be represented. The technological aspects of fulfilling these visions will be discussed sub chapter 4.3. The point being discussed in this subsection, the idea that health can and should be captured through data, is strengthened through the way the EC and developers envision health data to be valuable and useful in the overall objective of improving healthcare. One further way that both the EC and developers within the project express the importance of health data being used to represent that status of health is through concern for the reliability and accuracy of data. One developer was conveying how patients not having access to their own health data can be detrimental to a citizens health because there is a possibility for errors within their EHRs that might not be caught, or difficult to fix without access to it, meaning their health would be represented falsely.

> “And also, it's a good way to unfortunately hide the things that they want to hide. Right? If there is a medical error, nobody sees it right. It's very hard to get the data. And there are many cases where patients have obviously had the medical error and it's almost impossible to get access to the data, even with lawyers and so on. Even though GDPR says very clearly this data belongs to the patient, even the doctors enter the data. It belongs to the patient's right, even with that. So there's a number of reasons.”. (Interview 2, April 16th, 2021, Ln 42)

Throughout the data analysed there are differing opinions about what counts as health data, what sources of health data are reliable, how and who is responsible for making sure health data is accurate and how these sources should be used or considered. These topics will be discussed among the themes of the next subsection but are being mentioned here because they also point to how developers and the EC do believe that health is represented through data. The importance of accuracy and reliability of health data is important to these actor groups shows how they already do consider the (health) data bodies to be representative of individuals and their health. It is so important that the data on an individual and groups of people is accurate because it is used to make decisions about the healthcare they receive.

4.2.3 users have to care for their own health

With the previous two subsections I have presented the ways in which the actors involved in the InteropEHRate project co-develop an imaginary about better healthcare through the ideas of what this improves healthcare infrastructure looks like, how it is used, and the importance of data and data as a representation of health is. This final section of Chapter 4.2 will explore the aspect of the better healthcare imaginary that focuses on how the idea that citizens are being made responsible for their health data, and therefore their health in this developing imaginary. The importance of data and certain uses of data have become abundantly clear throughout this analysis thus far.

A more specific script that is getting built into the imaginary specifically for citizens is the notion that as an individual you should take some responsibility in the care of your own health with certain decisions and actions. This is made clear in the ways that healthcare is being envisioned thus far in the analysis but is also explicitly stated as a goal: “Effective health promotion is also facilitated by the provision of better information to citizens which encourages responsible health choices.” (European Union. 2014b, P.4). This quote in the project call is directly stating that while the project which is developed through the grant being offered should help facilitate better health, patients also need to make responsible choices about their health. Individual patients or citizens taking care of their own health is mentioned in the project calls more than once, really emphasising the point, “individual awareness and empowerment for self-management of health” (European Commission, 2014b, P. 4). Within this idea that citizens should be responsible for their health and acting towards being healthier within this framework of this specific imagined future of healthcare are also more specific instructions surrounding being responsible for one's own health data. In line with the very citizen centred approach to development, and goals of user-friendly technology and practices also then translates to an expected level of self-responsibility coming from citizens, especially from the EC.

> "This prototype should be primarily focused on citizens' health data generated by the citizens themselves, HCPs or sourced from relevant healthcare organisations." (European Commission, 2018, P. 2).

Many functionalities that are expressed as empowering citizens and giving people new possibilities to care for their health can also be viewed as a way to place a level of individual responsibility in the hands of patients. Similar to the framing of the EC, developers also share the idea that collecting data that describes an individual's health is important because it will have a positive impact on their health status. One developer explained why individuals should collect their own health data and why it can improve their health status, especially if they are going through medical treatments.

> "You will be in control of your health data. You will see what's happening to you. You will understand your condition and the treatment much better. Right. And you will have a lot more information. You would be more informed. So you have more chances that the treatment goes well. Right. There have been studies about that. Right. Also, you will have a record of everything. Right. So it, in case you have a problem with the medical world. Later, you will be very happy to have some documents and some proof. Right. Well, yeah that's some of the main benefits." (Interview 2, April 16th, 2021, Ln 61)

Within this quote the assumption that specifically individuals can see and express or represent their own health through data and use this to improve their health is being made. Within this quote the developer is expressing the idea that through data, an individual with a medical issue will be able to see and understand the status of their health in a better way than they would without data. It is also expressed that this is not only important for individuals to understand their own health, but also important for them to be able to represent it will to other people, including HCPs, to get better treatment. Understanding the ways in which patients are being allocated new responsibilities within this imaginary of healthcare also requires users to act in a specific way.

Chapter 4.2 of the analysis has now looked deeper into the problems that the actors involved here have identified with the way healthcare is currently being done as well as justifications and imagination of how healthcare can be made more effective and efficient. In these justifications and ideas for improvement through an interoperable health data platform, this analysis uncovered the large overarching assumption that data can represent and capture health of individuals and populations. Finally, this last section, of chapter 4.2, aimed to understand how empowering citizens and placing them at the centre of the imaginary of better healthcare through an interoperable health data platform also shifts responsibility onto individuals as well. The next chapter of this analysis will look into how the collective imaginary being developed within the InteropEHRate project expects to provide specifically technical and social solutions to healthcare.

4.3 Technology Imaginary

Thus far this analysis has aimed to uncover the different intertwined layers of the imaginary of better healthcare being co-produced through the development of a digital health data platform. In doing so, some of the issues with the way the current healthcare infrastructure operates have been uncovered. This chapter of the analysis will set out to look at how the proposed future of healthcare being imagined in this vision provide solutions that are both technical and or social in nature. Looking at different layers of the imaginary through these lenses will allow for an understanding through an alternative perspective. This perspective of identifying the technical and social solutions will provide different insights into the imaginary by uncovering important details that are both assumed about society, and how healthcare should be a part of it. Going back again to the overarching themes of the imaginary; improving citizens' wellbeing, providing safety and security, innovation the progress of a unified EU, it is clear that within this project, there are sociotechnical solutions being imagined support do these goals.

4.3.1 Better future healthcare involves technical solutions.

Throughout the analysis of the co-production of sociotechnical imaginary of better healthcare through an interoperable health data platform technology, and technical solutions have been discussed many times over. The development and use of an infrastructure that stores, translates, and shares data to and from different devices for various purposes of course requires many forms of technology. What this chapter will discuss is how these many forms of technology are framed as the answer to some of the issues that have been uncovered with healthcare being down the way it presently is. These techno solutions or in some cases problems are present throughout all of the materials analysed for this project. In some occurrences the notion of technology itself is discussed as an inherent solution to a very large problem. As if "technology" is one singular thing that can provide a universal fix to any issue. "…reducing health disparities and inequalities by evidence- based decision making and dissemination of best practice and by innovative technologies and approaches." (European Comission, 2014b, P. 5). The need to minimise the inequality among healthcare through evidence-based decision making assumes the use of technology as this quote is referring to large data sets. Moving further into the quote, is where "innovative technologies" is then added into the solution as is.

While there are other instances in which "technology" is simply provided as a stand-alone solution this is not often the case throughout the data. In most instances, technology is discussed in specific ways such as how certain technological aspects of healthcare that are already present can be improved, or how a techno solution can solve a currently non-technical problem. One of the key problems that is mentioned numerous times throughout the data from all sources, and really a key issue in the wider imaginary, is the current lack of interoperability of health data. "However, there is a low level of systems interoperability in Europe since data are collected in different silos and managed under converging security and safety conditions.” (European Comission, 2020, P. 1).

Here we can see the issue of data being kept in silos and being kept under different conditions really highlights a clear example of attention being drawn to a problem that may not seem inherently technical but does have a technical solution within the imaginary. The issue of data silos and the lack of interoperability is framed as something that can be solved through the development of different technological protocols that facilitate data transfers. What is important to note is the second layer of this issue being the varying conditions of security and safety that data is being treated with. This issue also informs the development of the technological protocols being developed.

The security aspect requires the technological protocols for data transfers to different devices and sources to be built in a way that meets the highest level of security and privacy required by the many different stakeholders. The idea that a safe and secure technological solution for interoperability is emphasised very heavily throughout the project calls.

> “However, opportunities to reuse these data for research and better healthcare are often missed because health data continue to be confined in data silos, often not matching semantic standards, quality needs and safe data exchange techniques.” (European Commission, 2018, P.3).

Again, in this quote, the need for a technological infrastructure is being argued for by elaborating on the issues of not currently having this. The explicit mention of the needs for matching semantics also again indicates the need for multiple different technological devices that should be used within the infrastructure being built. Matching semantics are required to have interoperability not only between the different devices that patients, HCPs and medical researchers use, but also including the medical devices such as wearables or more advanced machines used in healthcare settings. Within both last two quotes from the project calls it becomes very visible that the techno solution being imagined is one that can fill the needs of many problems already discussed with the current healthcare system. This idea that a techno solution can be provided for a vast majority of the current inefficiencies or ineffectiveness of healthcare as it is now through interoperability is also held by the developers of the project and often discussed in a more specific and individualised way.

> “So for every encounter we try to solve this difficulty. That is at first that the communication between the patient and the this let's potentially huge data set of healthcare information that is maintained directly on the patient's phone and the health care professional, which is using different kinds of I.T. devices, I.T. platforms, hospital information system, EHR, EMR and whatever. So we need to connect these to work with the something that can be, first of all, open. I mean, this is an open standard, what we are developing. So it might be used by any software developers, any company that would like to develop something to help the patient maintain the information, of the patient of course.” (Interview 3 May 21st, 2021, Ln 6).

This quote from an interview with a developer provides an excellent example of how the wider technological infrastructure being developed improves not only large-scale medical issues such as research, but also individual healthcare moments. Additionally, the quote also provides specifics into who the different users could be involved in the imaginary, as well as all the different devices that are included through the technological solution. It also shows how a technical solution is completely intertwined with the user and how specific devices need to be used in a specific way for the larger picture to become a reality. For example, the assumption that patients do first make use of a smartphone, and second, do store their health data on the device is visible here. Similar assumptions are being made of the technological devices already being used by medical professionals.

Comparable to how the large-scale view of this technological solution included aspects of security and safety, at the individual patient level these aspects are brought in not only through ideas of secure protocols but also through the ability to have choice and control being built into the system.

> "And then they created that exchange platform, which is a way to exchange data between individuals. Like I decided to share my children's file with my wife. I decided to share my files with my doctor. I decide to share with my hospital or the nurse that's coming as well for following up my son's cancer, for example. And so I am in control of exchanging data with whoever I want to. Right. So that's two ways to empower the patient, having access to their data, collecting from all the sources as many as possible, and ideally all of them in the future, and then being able to do whatever I want with my data. But of course, knowing what I'm doing right and keeping the privacy, being able to change my mind if I want to and so on. So that's the goal." (Interview 2, April 16th, 2021, Ln 13).

This is an example of a developer talking not specifically about the InteropEHRate platform, but about the type of technology and uses that are intended for it through the imaginary. In explaining this ideal of how data should be shared in this case by the developer describing himself as a patient, it can be seen how patient uses are connected to the technological solution in a way that gives control. Here, the emphasis on the capabilities that the technology will allow for is very much on the privacy that is afforded through the patient being in control through the solution.

Through all of these examples of techno solutions coming from the quotes in this section it is evident that the technology on its own cannot be the only solution. Instead, the technology needs to be built in way that facilitates specific connections and uses between other technology and human actors. When looking at the technological aspects of the infrastructure being built, the goals for the imagined future that achieve better healthcare would not be reached by technology on their own. This imagined future requires changes in citizen behaviours as well.

4.3.2 Connecting the technical with the social

In discussing the technical solutions involved in the imaginary of better healthcare, it is evident that the social factors cannot be overlooked or disentangled. As has just been discussed, the technology that is being developed requires specific social behaviours and especially in the case of individual healthcare, are embedded within the very social interactions between patients and HCPs. It is crucial to look even further into the social aspect within the imaginary to truly understand the wider context in which the imaginary is being situated. Looking back to the original framework for the imaginary established at the beginning of this analysis, one of the guiding pillars was determined as improving the well-being of citizens. This is clearly a goal coming from a social responsibility that can be seen in relation to the large scale and shared at more individual levels of the actors directly involved or within the imaginary of this project. The mention of many different societal issues such as "Poverty-related and neglected diseases are also a global concern" (European Commission, 2014b, P.2), are something that demand not only a technical response but also a social one. This is something that is recognized and shapes the imaginary,

> "Furthermore, the pertinence of these challenges across Europe and in many cases, globally, demands a response characterised by long-term and coordinated support for co-operation between excellent, multidisciplinary and multi- sector teams. It is also necessary to address the challenge from the perspective of the social and economic sciences and humanities." (European Commission, 2014b, P.3)

This quote from a project call document is expressing this responsibility to attend to the complex social issues that need to be looked at not only at a European level, and with a techno solution, but also using a multidisciplinary approach. It is reflective of the fact that complexity of issues within society related to health and healthcare also require solutions that involve multiple disciplines outside of technical ones to properly be addressed. This is an extremely important influence that can be seen through the project, and therefore in the development as well as the imaginary, factors, experts, and disciplines outside of the strictly technical are heavily incorporated into the development. Building on the ideas of improving societal issues, there is also a level of individual social responsibility being envisioned within the imaginary for citizens. This especially comes through when looking at factors related research that involves both large data sets and specific health data. As has been displayed thus far, there is a very large focus on patients being able to control their data. "And then the patients still have the decision to make on their own" (Interview 2, April 16th, Ln 70) Although this is a focus, there is also an assumption that citizens will be willing to donate their health data for greater good, and to improve medical research.

> "And then will say, OK, you're selecting females with a certain age or with hypertension. This is a male. So nothing happens. That patient will never have a request to to participate to that research protocol. But another patient that, of course, applies, that satisfies those criteria will have a request, a pop up...the phone will ask just like a new message: "oh there is a new research from (example name) Would you like to participate to this research?" And the patient may say, of course, yes, we hope. And of course, we plan to have yes, but this, yes is, let's say, an electronic consent that we are still trying to manage to adjust here in a digital format, because me as a research centre needs to collect the official consent from the patient." (Interview 3 May 21st, 2021, Ln 25).

This is a quote of a developer explaining how a research protocol within the InteropEHRate project could work. On the surface, the idea that users will want to contribute their health data is being assumed simply by the intended development of this protocol. It is also interesting to note the description of how the protocol would work displays very well the vision of medical research and therefore improving healthcare, to be an efficient process. Being able to filter through patients and automatically ask only those that are displaying the correct requirements would result in a very efficient process of data collection. This quote again puts emphasis on the fact that even though patients are being asked, they do not need to say yes. The consent factor of the whole process is clearly very important to the developer and was talked about to an even greater extent than shown here. The social responsibility that citizens are being imagined feeling here can also be linked back to an earlier point in this analysis about how responsibility to take care of data, in order to take care of one's own health is being placed on citizens. Now this responsibility is being extended even further. For this research protocol to work, and for citizens to be able to donate their data, they must also take care of their data and ensure it is accurate. Not only to be in line with the requirements being searched for in citizens, but also because the data will be used in research. It is important to mention there will be additional measures, outside of the patient's responsibility to ensure the data is correct, but without some level of action on the patient's side, this would not be possible.

An additional socioeconomic factor related research that influences the InteropEHRate project imaginary and the way it is developed is the competition of private pharmacy companies. The need for more and more data for medical research required for the growing number of diseases and health problems around the globe is often referred to in the material. As discussed, not having access to health data to complete this research is presented as a large issue. This analysis has already discussed the recognized need for multidisciplinary efforts, and contributions of many different stakeholders. One developer specifically points out the growing need for data to progress with medical research and find new treatments for different diseases or conditions and in doing so also highlights an economic market factor not yet discussed, the private medical industry.

> "And also, there's the second problem is that to find new cures, new treatments pharma companies need new data and need more and more data over time. Right. To make sure that when they find drugs that are efficient, that are safe and no, not too many side effects and so on. And it's hard for them to get data because of privacy, because of security, because of the medical world trying to protect their turf. Right. And so that's a second problem, too." (Interview 2, April 16th, 2021, Ln 11).

This passage from one of the interviews is really the only significant time that this topic of private medical institutions is really addressed as a problem. There is some mention of private companies collecting data through apps such as Facebook, or wearable devices as well as discussion around needing all health data platforms and software's to be able to speak to each other through a protocol being developed. In these instances, and any other involving private actors in the market, there is always either a neutral view of them, or even a view that supports collaboration. In most cases private actors are viewed as any other stakeholder that should be incorporated into the new infrastructure. In the quote above this is not the case. The developer is clearly pointing out how there is a competition between different actors for data, and how this is an issue for the goals that are trying to be achieved within this imaginary. When thinking specifically about the goals of supporting citizens' well-being as well as innovation and the progression of a unified EU, the situation being described by the developer in the above quote is working against them. This can be viewed as a clear performance of not only supporting the goals of the wider imaginary, but also arguing for the need of a truly interoperable health data platform, that should be secure and private, but in a way that still allows for data to easily be used for research.

When discussing the ways in which the technical solutions that can be identified within this imaginary, and how they can be tied to social aspects, translation is a theme that is very present. The translation of health data from the different languages of the many countries in which the citizens who may use it live, in the EU documents, the project material and by the developers. There are many instances that mention how important translation is and how there needs to be a technical solution to translate all the health data that is being collected. Language translation is important not only for patients to be able to use their data and collect new data at medical appointments in countries across the EU, but also again, for the purposes of research. There has been such a large emphasis put on the interoperability of data, especially for the use of research, as well as the different stakeholders' roles in providing and taking care of this data also sometimes for the purpose of research. As mentioned earlier, the translation of data does not always refer to languages but has also been used in the data to refer to translating the data into different formats for it to be usable by different platforms and protocols. A third form of translation that is discussed refers to medical versus “basic” descriptions of medical or health data.

> “Although, of course, we might use this kind of language, a standard language just like English. hahaha. And right now, just like now, we are speaking, we know that there is not, let's say, precise or correct translation of, for a general patient with, let's say, a low level of knowledge for medical English. We are talking about, of course, medical English for or even the current status of the patient, the allergy of the patient, current therapy of the patient. So the patient is not able to express in the correct English many times the basic status, the basic condition for or to let a HCP assess this condition during an evaluation, during a visit, during hospitalisation and so on” (Interview 3 May 21st, 2021, Ln 5).

In this quotation the developer is making a differentiation between two forms of the same spoken language: medical English and standard English. Identifying this difference shows an understanding for the fact that patients will have all different levels of knowledge of their own health and how to describe it. This recognition of how patients communicate their health in different ways takes some level of responsibility off citizens. There is still an assumed responsibility for patients to be able to describe their health status on some level, as well as how there is an assumed responsibility for patients to take care of their health data. Even with that in mind, this quote shows also some responsibility being take on by those accountable for the development of the project to build a technical and social solution that accounts for citizens with all different levels of medical languages, and languages in general.

This subchapter has discussed the technical solutions that are closely intertwined with social factors of the development of an interoperable health data platform in this imaginary. These facts range from social responsibility, socioeconomic circumstances to spoken language and communication. When looking at these solutions, whether they are solely technical, social, or as has been shown, in most cases a mix of both, something that becomes clear is that there is a very specific imagination of how users should act for these solutions to work. The imaginary of users within the wider framework of the entire InteropEHRate project including the EC and the developers will be investigated further in the final subchapter of this analysis.

4.4 Imaginary of Users

As has been discussed so far, there are many different responsibilities being placed on users. Some of these users who are being assigned responsibilities include, but are not limited to, patients or citizens, HCPsre different medical staff, and researchers. This can especially be seen when looking at the three user scenarios provided by the InteropEHRate project that inform the development of the entire project. In these user scenarios, and in many other instances throughout the data, as these responsibilities are expressed, what can be uncovered very clearly is the imaginary of users. How the different users should or could act and the expectations of their behaviours. One of the project call documents spells out explicitly who the users involved in the project should be.

> "The design of the prototype should be user driven as to ensure the early buy-in of final users (from citizens to HCPs and scientists). It should demonstrate tested and validated functionality in exchange of realistic and fit for the purpose EHR datasets exchange bi-directionally between: 1. hospitals, 2. medical doctor practitioners and hospitals, 3. hospitals and citizen, 4. medical doctor practitioner and citizen 5. Cross-border hospitals and 6. Citizen and research database". (European Commission, 2018, P. 5).

In addition to spelling out who the relevant users are for the EC, and therefore for the imaginary being studied here, this quote also again highlights how important buy-in from these different groups is. Without the adoption of the platform, and users behaving in the imagined way, many of the solution discussed in the sub chapter above would not work correctly. It is important then to understand what exactly these imagined behaviours and who an ideal user for this platform is. The following subsections of chapter 4.4 will focus mostly on the ideal patient/ citizen user based on what is found in the data, as well as the ideal HCP user.

4.4.1 The ideal User

Based on the nature of the InteropEHRate project and it's development being so use focused, the use case scenarios that serve the purpose of informing development and validating the entire infrastructure are an obvious place to start when uncovering the ideal user. In Chapter 3 when looking at the case sight the three communication protocols were discussed (1) Device to device protocol, (2) Remote to device protocols and (3) Research and Data sharing. For each of these protocols there is an imaginary user scenario associated to explain how they could and should play out in a real-life situation. Within these descriptions ideas of the ideal user become very clear. In the first scenario "Healthcare visit abroad scenario" the situation explains a Belgian patient who suffers from chronic ischemic heart failure and atrial fibrillation who moves to Greece. "The patient moves to Greece for a 2-year stay during which progressively complains of mild lower limbs oedema, dyspnoea, and reduction in exercise tolerance." (InteropEHRate, 2019, P.1). In setting up the scenario, the description it is not clear whether the patient is assumed to know the medical terms used here for their symptoms or not, but this could be inferred. After providing this background information, the scenario is described as follows,

> "Demographic, consent, and previous history of the patient were already loaded on the S-EHR App. During her stay in Greece, the patient seeks medical care. At the healthcare visit and using the S-EHR App, the patient authorises the HCP to access elements of her health data such as allergies or adverse drug reactions. The clinician accesses this shared data from an HCP App able to make use of the D2D protocol. Treatment is established on these grounds and any prescription is transferred to the S-EHR of the patient's mobile. Once the patient has left, the doctor has no access to further, additional information from the S-EHR. At return in Belgium, the patient will be able to similarly exchange the newly collected health data with other HCPs using the D2D protocol." (InteropEHRate, 2019, P.1).

Here, very basic assumptions are made about the patient making use of the specific technology being developed in this project, namely the S-EHR App, the HCP App, and the S-EHR. What is more interesting is to look one level deeper and understand what might be taken for granted or expected of the patient to make this possible. The first assumption here is that the patient has a smartphone, which is logical as most citizens do use such a device in the EU at this time, but also that using their smartphone the citizen knows how to understand, organise, and decide which part of their health data they want to share and should share with the doctor helping them. This description of the scenario also assumes that the patient again will have a level of understanding of their own health data that allows them to consciously decide which pieces of information from their healthcare appointment in Greece should be securely shared with HCPs at home in Belgium. Not only is a certain level of medical literacy being imagined for the ideal user in this scenario, but also a specific level of literacy with smartphone use. Having the correct Application on a smartphone requires a different level of experience than making use of in this case, the S-EHR App, to an extent that ensures the patients' health data is organised in a specific way and then shares and takes away access with other devices.

The assumption that patients have a smartphone is one that can be justifiably made, as majority of adult citizens across the EU do own such a device. That being said, the levels at which citizens know how to use these devices varies. This is important because proficient smartphone use is a trait that the ideal user has not only as performed by these scenarios, but also by developers. The topic of smartphones and the integration of the use of these devices within the interoperable platform can be found very often in the interview data. For example, "the fact that most of the people have their smartphone to keep the health data on the mobile phone" (Interview 1, April 9th, 2021, Ln 4). This quote shows very clearly the idea and connection being made between users having and making use of a smartphone in their everyday lives in general with the idea that users store and access some form of medical data on their smart devices. The first part of this idea, that most citizens have and regularly make use of their smart devices can be made without questions. Today this is true for much of the population.

The second tier to this idea can be seen more as part of the imaginary of users within this project. There is of course the possibility that users can store their health data on their smartphones, but it is not clear if this really is the case for most citizens or not. This is a very clear example of a user behaviour that could be taken for granted or assumed as de facto within the imaginary. The same developer also recognizes that integrating smartphones into the overall interoperable platform being built is what provides a unique opportunity for this project, which supports the notion that because smartphones present the possibility for citizens to store health data, they simply will.

> "Well the InteropEHRate project is somehow unique and in the European panorama because the leverage on the, let's say, usage or presence in many people's hands of the smartphones" (Interview 3 May 21st, 2021, Ln 2)

These two quotes together, show that even though it might not be as easily assumed that everyone who has a smartphone, also stores their health data on it, an ideal user does complete these behaviours. A second assumption related to the idea that all users will collect their data on their smartphone and provide access to the right data to different medical professionals is that they trust the platform, and the people they are sharing with enough to do this.

> "Everything is on your smartphone, of course, with backup procedures and so on. But still and the power is in the hands of the patients, right? Well, the power, at least the power to collect their health data and to share it with whoever they want. Right." (Interview 2, April 16th, 2021, Ln 12).

Being reflexive about the fact that patients will have the control to not only collect their data, and then making their own decisions about who to share it with, the ideal user is someone who has trust in the infrastructure. Without trust in the platform, the communication protocols and the stakeholders receiving the data from the citizens, no matter what level of technical, data or health literacy the patient has, they could still decide not to share the information. The sharing of health data between patients and HCPs for the purpose of a healthcare appointment is only one scenario described in the communication protocols. The third communication protocol and use case scenario discuss the topic of citizens donating their health data to research. This also requires users to behave in a way that assumes many of the same behaviours of smartphone use, responsibility of data and trust in the system but also adds another layer.

In the "Research data sharing scenario" the InteropEHRate in a Nutshell page explains how "citizens can share health data with research centres without cloud storage enabling decentralised clinical trials." (InteropEHRate, 2019, P.3). The scenario explains a situation of a patient who has chronic hypertension, learns about a study being done at a hospital through the S-EHR App, informs herself of it, and decides she would like to take part and donate her data. In this scenario it is also explained that the study being done is related to the patient's own condition. The fact that the patient's data is anonymous and can be taken back from the study conductors at any time is also mentioned. With these details of the scenario, all the same assumptions as the first user scenario discussed are being made again. Something built on about the ideal user is the responsibility that they are expected to feel about taking care of their own health, as well as the social responsibility of supporting research that has the potential to help other citizen's health as well. The developers also perform the same or similar imaginaries solidifying the idea of the ideal user. Firstly, looking at the idea that users will want to support medical research, especially if it is related to their own health.

> "The final point for the patient is instead that, and this is the one results from the focus group activities, that they are, let's say, much more likely to be involved in the research that involves their condition" (Interview 3 May 21st, 2021, Ln 31).

This quote is from an instance in the interview when the developer was not speaking specifically about the InteropEHRate project of the research data sharing scenario but rather in general about how users will most likely behave. This shows an example of how the visions and requirements of the ideal user are co-produced between the many stakeholders of the project and not only coming from the project, or direct development of it. Within this quote and the whole idea that citizens who have a specific health condition will want to donate their data, is also the idea that these people will take the necessary actions to collect and maintain their health data in a way that makes it usable. When comparing the imagination of the ideal user coming from the developers and coming from the EC there are different levels of details taken for granted. For example, one of the EC documents states the following two points as requirements for the project:

> "Ensure citizens' opt-in processes are properly undertaken in order to allow the secondary use of data for scientific purposes and promote health;
>
> Provide anonymisation/pseudonymisation capabilities to allow open access to health data for research and public health purposes;" (European Commission, 2018, P. 2).

In this document, the requirements are being stated at a more technical level, describing what the technology being developed should allow for. What is taken for granted here is what this requires from users. As just discussed, for this to work, users must be willing to donate their data for it to be used within the infrastructure being built. In the quote just before this one in this analysis, from the developer, a greater awareness for how patients will feel, and act is added into the imaginary providing both technical and social ideas about the ideal user.

Thus far, the ideal user being discussed has been reflective of patients or citizens. A second crucial user who is often present within the data, and often imagined are the HCPs who will be the ones receiving, working with and sharing health data through the platform. Assumptions about HCPs are made in the same way that they are made about citizens. For example, one of the developers explains how health data, and what makes it valid for a doctor and for a patient can be very different things and requires specific behaviours.

> “So the patient requires something that might be stressful for the healthcare profession. I mean, I want to have a translation in the correct language. So this cannot be provided by HCPs. So there are conflicts between some requests of information coming from the patient. The physician might like to know how many times a day the patient is assuming the current therapy is something called adherence therapy. And this is crucial for the care professional. But the patient that doesn't have the time or doesn't want at all to say, yes, I've taken that pill, or every pill during the day. And this is another point that we somehow not excluded but this is something that is out of the project's scope because we are stressing here not the technological platform, but the patient behaviour and the HCP behaviour. (Interview 3 May 21st, 2021, Ln 37).

This larger quotation from the interview points out many expectations being placed on patients and HCPs that are coming from the ideas of how the platform should work within real healthcare settings, and how it should improve healthcare. At the beginning of the quote the developer is explaining how the expectation to be able to provide the health data of the patient in languages that are foreign to them can be stressful. In doing so, the developer is highlighting not only the fact that the translation should be done by a technological feature of the platform, but still that this can cause stress for the HCP who will be viewed as the one providing the information. In this instance then, the ideal HCP is someone who trusts in the translation features of the platform or for some reason or another feels comfortable providing translated health data to patients. A second interesting section of this quote in terms of HCPs' behaviour is the idea that they will want patients to provide or confirm specific aspects of their health data by behaving in a certain way or completing certain actions.

The developer is highlighting an idea in the above quote that not only he has made, but is often present across the material, that HCPs will have different levels of trust in health data coming from different sources, and especially coming from patients themselves. The assumption being made throughout the development of the platform is that the data patients are sharing with HCPs will be accurate and should be trusted the same as data coming from other HCPs. An additional quote from a developer expresses this idea as well,

> “So there's going to be a resistance to all of that which is human, it's normal, then some of the more trusting doctors will say, oh, let's let me take a look at these and I'll compare it. Yes, it looks correct. And, gee, that's interesting when I think of it. And gradually it will become more mainstream. (Interview 2, April 16th, 2021, Ln 88).

This quote is very explicitly explaining the idea that some HCPs, and specifically doctors will have reservations against trusting data that comes directly from patients. It also shows the idea again that the ideal user, who is a doctor, is one who has trust in the data coming from different sources including patients. Something that is very interesting here again is how the behaviour of an ideal HCP to have trust in the data is expressed and thought about differently by the actor groups involved in developing the imaginary being analysed in this project. In the data coming from developers there is a more reflexive view on how patients might feel or act, and what the ideal user will behave like but why this might not be the case.

On the other hand, as we saw, the project call documents stating specific requirements about the technology clearly infer a specific behaviour from the human actors but sometimes take for granted that this may not be the case. The same thing can be seen of the assumed behaviours, feelings, and overall imaginary of HCPs. These different levels of reflexivity coming from the EC or project call documents versus the reflexivity coming from the developers can also be seen when looking at the topic of non-users. This will be explored further in the final subsection of chapter 4.4.

4.4.2 The Non-user

When looking at the sociotechnical imaginary being co-produced within this project, and specifically the ideal users, it is equally as important to pay attention to the non-users. The idea of non-users can be looked at in two different ways. The first way being in the sense that has already briefly been touched upon in the above sub chapter, referring to the people who, for many different reasons will not use the platform and technology to achieve better healthcare to the extent it is intended within the imaginary, or even at all. The second way to examine non-users is by recognizing who is not talked about or imagined at all within the ideas being put forward. There are many instances where this first sense of non-users can be seen within the analysed materials.

Firstly, as already mentioned in the above section, there is clearly an understanding that not all citizens will be willing to use the technology and platform to the same degree, or in some cases at all. One developer very clearly states a recognition for this, “Yeah, well, so first we don't force anybody. If you don't feel like it you just don't do it right.” (Interview, 2 April 16th, 2021 Line 61). In this quote the developer is referring to citizens or users as “you”, and is demonstrating an understanding that individual users can and will need to make the decision for themselves how they chose to take care of their own health, and if that means taking care of their digital health data on their own or not. This understanding of non-users from the same developer goes even further to anticipate many different non-users and how they are interconnected within the platform being built.

> “I'm pretty convinced that it's going to take time before what the project produced gets adopted by a wide, wide range of players because it has to be implemented by hospitals’ software providers, by family doctors' software providers, probably by other players to by medical research players. Right. So, it's probably going to take time unless there are some strong incentives like, you know, that COVID pushed the development of telemedicine like crazy.” (Interview 2, April 16th, 2021, Ln 76).

This quote highlights how different actors are involved in the use of the platform in order to carry out the idea of better healthcare being put forward. The idea of non-users goes much further than simply a patient or citizen deciding they do not want to store their health data on their smartphone, or do not want to share it with different healthcare providers. As shown in this quote, non-users can also be doctors, healthcare providers and researchers, as well as their service providers. Even though the InteropEHRate project is being built in a citizen centred fashion, the complex system being built requires many different actors to be users, which means they can also be non-users. Documents produced by the InteropEHRate project also anticipate non-users and show recognition for the effects this can have on the larger system. One example of this can be seen on the *InteropEHRate in a Nutshell* website page in the explanation of the Infrastructure Building Blocks,

> *“S-EHR cloud: the prototype of a service, managed directly be the citizen, able to store on the cloud the personal health data of the citizen, collected by the S-EHR mobile app. A citizen may choose to use the S-EHR mobile app without using the corresponding S-EHR cloud.” (InteropEHRate, 2019, P. 5).*

When explaining the S-EHR cloud block of the wider infrastructure of the InteropEHRate project, there is anticipation of some level of non-use by at least a portion of patients or citizens. By indicating that users can choose to use the S-EHR mobile app without using the S-EHR cloud this document is showing recognition that some users will not behave as intended, but at the same time shows how there can be varying degrees of use and shows how the platform being built should accommodate this.

Another group of non-users who are discussed, imagined, and tended to within the vision are children. Within the imaginary being co-produced, children are of course imagined as needing healthcare and are included in the benefits that the interoperable health data platform being built should provide. Firstly, they are explicitly stated as non-users because they are until a certain age not capable of using the technology in the required way. Secondly, children, or citizens under a certain age are not able to make decisions about their healthcare, and health data or who to share it with reasons relating to knowledge, responsibility and legality. Still, In the vision of better healthcare being co-produced, even though children are non-users, they are included as their parents or guardians are understood to be responsible for their health and as such, caring for their health data.

One developer describes his own view of parents or guardians being connected to their children's health data,

> "in the family doctor's practice when you were young, the data is with your parents paper files, you know, vaccination stuff when you were a kid and so on. " (Interview 2, April 16th, 2021, Ln 10).

While this quote is describing a healthcare scenario involving health data being stored in a paper rather than a digital system, it gives insight into the origin of the ideas relating to children's health data being stored with their parents' data. Even though the infrastructure is very different in this developing imaginary of healthcare, this same view of how children's health data should be treated and therefore how children are non-users and users at the same time, is tris idea of Children being non-users but considered as users, only through their parents making use of their health data evolves even further by this specific developer and a specific personal experience he shares about a healthcare journey with his health data evolves even further by this specific developer and specific personal experience related to having access to and sharing healthcare data of his family members, including his son.

> "And then they created that exchange platform, which is a way to exchange data between individuals. Like I decide to share my children's file with my wife. I decided to share my files with my doctor. I decide to share with my hospital or the nurse that's coming as well for following up my son's cancer, for example. And so I am in control of exchanging data with whoever I want to. Right. So that's two ways to empower the patient, having access to their data, collecting from all the sources as many as possible, and ideally all of them in the future, and then being able to do whatever I want with my data. But of course, knowing what I'm doing is right and keeping the privacy, being able to change my mind if I want to and so on. So that's the goal." (Interview 2, April 16th, 2021, Ln 13).

In this quote, what is described again is the scenario in which children are viewed as non-users but still connected to the imaginary through their parents or guardians being users. What can also be viewed here is an even larger vision of this developer regarding how users should be afforded control of their health data, and therefore their own, and their children's, healthcare journeys to a certain extent because of this access. Again, in this quote, there is a performance of the importance of data security being shown, and the idea of how the digital infrastructure being built should give many groups of people access to health data, but in a secure, safe way that the patient is informed about and comfortable with.

The second sense of non-users that this subsection will discuss are those who simply cannot use the technology required to be part of this new healthcare infrastructure for one reason or another. This group of non-users are different from those who chose not to use the platform or related technology or are not able to but are still included through other uses participating (children and their guardians), because they are not imagined as users, or being built into the vision being co-produced in the materials being reviewed in this thesis. Within this description of non-users there are different groups or categories of citizens that don’t seem to get discussed thoroughly or even at all. This type of non-user encompasses groups of people who cannot make use of the technology required to participate in a digital health data infrastructure for varying reasons. These groups of people can include but are not limited to citizens with different levels of disabilities, elderly people who also have limited abilities to operate smartphones or devices or simply a very low level of digital literacy, as well as citizens of a lower economic status who do not have access to or own a smart device. While looking at all citizens who fall under one of these categories across the entire EU population, this is by far a small minority.

Still, from an STS perspective, it is important to recognize these non-users and how they are not extensively included into the vision as users being imagined within the InteropEHRate project. It is also important to note that while these groups of people are not discussed as users or heavily considered, there is some discussion of elderly people, people with disabilities and those who are part of a lower socioeconomic status, specifically by the EU documents. When looking back to the overarching goals outlined by the EC for the future of healthcare in general, and specifically for any project receiving funding within this funding scheme, these groups within the population are discussed. This is important, because as stated in sections 4.1, these can also be seen as providing the overarching themes being put forward for the imaginary being developed here. More specifically these goals, and the theme the EU put forward included taking care of the health and wellbeing of the entire population, with a focus on an ageing population (elderly citizens) as well as the growing health concerns specifically those in a lower socioeconomic status. Even though these citizens are in some sense non-users, they are not completely disregarded; they are still imagined receiving benefits as better healthcare should provide widespread improvements for society in a variety of areas even though they might not use the platform themselves in the ideal imagined way.

5. Conclusion

The concluding chapter of my thesis will highlight the 4 key findings made throughout the analysis of these. The findings I will discuss below aims to explain what I learned about through my investigation of the formation of a sociotechnical imaginary surrounding the aim for better healthcare. These findings are broken up into three smaller subchapters. The first of which, discuss the first two findings which look at contributions to the imaginary on a micro and macro level. The second sub chapter discusses finding number three which deals with the ideal imagined user is central to the imaginary. Additionally, the final section of this chapter will highlight further areas for research.

5.1 The co-production of a sociotechnical Imaginary on a macro and micro level.

At the beginning of the analysis process, I completed for this thesis, I looked at the different actor groups I would consider as potential vanguards that held visions around the technology being developed through the InteropEHRate project, and how it should improve healthcare in a neutral way. I first confirmed that both the EC and the developers could be seen as vanguards as they were both smaller groups involved in the project, who have specific ideas about a technological innovation that they hope to push to wider groups within society. In addition to this, both of these groups can be viewed as having expert knowledge as well as an authoritative position in certain situations (Hilgartner, 2015).

Starting with the EC, this actor has an obvious level of power within the EU when it comes to topics of innovation, policies and economics. Looking more specifically at this InteropEHRate project, through Horizon 2020 and the project call documents, the EC has authority over what the project can and should develop in order to receive funding. In terms of the developers, while their authority is not as widespread as the EC as an actor group, they have a great amount of authority over the specific technological aspects of the project they are developing. What's more, the expert knowledge and status they hold in their respective fields from the work they have already or are continuing to develop adds an additional layer of power. This understanding of how exactly these two groups can be viewed as vanguards in their own ways leads to be my first finding:

1) While the EC and the developers of the project can be seen as vanguards holding visions that are in the process of being shaped into the more stabilised sociotechnical imaginary, they don't hold the same wait. By this, I mean that visions coming from the EC held more power when negotiations of what were included in the imaginary of better healthcare, especially at a macro level. Developers on the other hand, very much had to conform and share the visions of the EC when it came to the large goals of the project. Where developers' visions seemed to become more easily transferred into the imaginary where on more of the micro aspects of the project such as a specific use protocol or ideal user behaviour towards the technological aspect of the infrastructure they are responsible for.

This finding is supported by the overarching goals for the InteropEHRate project, and therefore the imaginary of better healthcare it is aiming to achieve, being almost completely dedicated by the goals of the EC on the level of the Horizon 2020 framework as well as the project call. As seen in the analysis, the aim for more effective and efficient healthcare, should not only lead to a healthier population, but also according to the EC documents support solutions for other related issues or social, political or economic ambitions within the EU. This is what I consider the macro level of the sociotechnical imaginary. The micro level is where I found the individual developers had more influence on the imaginary through their vision. Aspects I consider as part of the micro level include for example, the actual steps a user must complete in order to share their data with a HCP within the infrastructure being developed. A second example of a micro level detail of the imaginary that came at least in part from the values expressed by multiple developers is a feature that allows for patients to use the platform and share their data using the cloud, or strictly through D2D protocols. This is just one example of developers being aware that users might have different levels of trust or comfortability with the infrastructure and processes it requires and building this awareness into what they are developing. This leads to my second finding:

2) Aspects of reflexivity built into the sociotechnical imaginary produced throughout the project development and aims are brought in very much as what I previously described as the micro level. It became clear that the EC provided the larger overarching goals that had a heavy influence on aspects of the imaginary describing what better healthcare through a digital health infrastructure should be. These ideas are very idealistic and don't often take into consideration the smaller nitty gritty details that might get in the way. These details were more often brought into the imaginary and shaped it in some ways to be a more realistic vision by the developers and the InteropEHRate project consortium.

I believe the individual developers and the project consortium's contribution to the imaginary being more reflexive and potentially more focused on reality can be attributed to two main factors. The first being the citizen centred approach that the whole project was designed in. While this was a requirement of the EC, it was shared and really brought to life through decisions made during the development processes I observed in the InteropEHRate project. The second factor that leads me to this belief is how I identified the developers to bring their own personal experiences as patients themselves, but also working with patients or citizens and their health data. Through these experiences that developers shared in their interviews it became clear there was a certain level of reflexivity and thoughtfulness being incorporated into their visions, and their work. This thoughtfulness could be seen in ideas about what different citizens might want or be willing to do with their data and individual healthcare decisions, as well as how real world circumstances might affect the way societies use an infrastructure such as the one they are developing.

5.2 A citizen centred Imaginary of better healthcare

User participation and a focus on citizens being a focal point of the development of the InteropEHRate project is highly emphasised, by all actor groups looked at in this project. On the macro level, the EC determined that this was an important factor for the successful development of an interoperable health data platform that could be used in the EU. As discussed earlier, the project consortium and therefore the developers, carried out this requirement by taking a citizen centred approach by among many things, using for example citizen use cases in their development processes. This leads to my third finding:

3) Citizens being placed at the centre of the development design and process has also placed the ideal citizen user at the centre of the sociotechnical imaginary. More specifically, citizens and the intended way for them to take action and responsibility for their health through a digital health infrastructure is crucial to the wider hopes and aims for better healthcare to truly play out. The large goals set out by the EC not only of a healthier population but also on a wider social, economic and political level, would rely on a majority of citizens acting in the intended way. Users are imagined as wanting to care for their health through taking care of their data. This is central to the future of better healthcare being imagined.

While there are different levels of reflexivity when it comes to non-users or small groups citizens who might be against using a digital health data infrastructure, there is a clear notion that a majority of citizens will be able to and interested in acting as an ideal user. If less than a majority of citizens chose to act in the ideal imagined way, specific aspects such as the collection of data sets for medical research, would not be feasible.

5.3 Further research

Completing the research for this thesis using the case site of the InteropEHRate project with the umbrella theme of looking at the sociotechnical imaginary being produced was an extremely fruitful project. Using the three main actor groups to collect the different materials for analysis also provided a great base of information and data to answer the questions that were being asked. As for all research projects a scope must be decided on to find an adequate level of conclusions. With that in mind, outside of the scope of this project, there are many other related avenues or areas of interest that could follow this project. Further research that could be done as a follow up to this master thesis would be to speak with and interview the users involved in the development of the project. As the whole process is centred around users, and user based developmental approach was chosen, these test users would provide an additional perspective coming from a whole new actor group to the research questions. Understanding this whole process of testing and integrating the experience and opinions of the users involved in the project development would allow for an even fuller picture and additional performances and acts that stabilise many of the findings already discussed, and potentially bring up new conclusions within this research framework.

One further route that could be particularly interesting within the STS field on this topic but not necessarily only within this case site would be to look deeper into the ideas of security when it comes to health data and the use of such an infrastructure. There was mention about the security and privacy of an individual's sensitive health data, but this topic could be opened even further. Not only through the lens of security, but also the outcomes of using data in such a way for healthcare might have on individuals and whole populations health. While there are surely many positive outcomes, there are also questions of reliability of the data and issues of furthering biases in healthcare standards for different groups, or worsening the uneven status quo already present within society.

Additionally, while this project was very much focused on looking at the sociotechnical imaginary being developed within the InteropEHRate project within this predetermined scope, the imaginary that is discussed can really only be seen as the very early formation. This sociotechnical imaginary of better healthcare through a digital health data infrastructure will continue to be reworked, added to, and transformed as the InteropEHRate project comes to completion but also as the landscape for this technology within healthcare develops. While this research did highlight some of the initial vanguard visions becoming shared between multiple groups across the project, there are many influences within society that are not at all considered here and will have a large impact on shaping a more matured sociotechnical imaginary. These influences include actual citizens rather than just the imagined citizens or test user groups, policies, and governments across the EU as well as private actors and markets.

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Abstract

Health data being collected and used within healthcare is becoming increasingly relevant within society. The European Commission (EC), and specifically the Horizon 2020 framework aims to harness the power of collecting, organising, and making use of health data by funding projects that set out to build a citizen centred interoperable European health data platform. This research examines how a sociotechnical imaginary (Jasanoff, 2015) of healthcare is co-produced through the development of an interoperable health data infrastructure. The aim of this research is to understand what is being included or left out in this imaginary of technology that aims to provide better healthcare. The methods used to complete this research include analysing EC and Horizon 2020 project documents and the InteropEHRate project materials and conducting interviews with developers working on the InteropEHRate project. Analysis of these materials uncover performances, stabilisations, and ideals of what better healthcare should or could be, as well as what is intentionally left out of the imaginary, or not considered at all. In conclusion, I ultimately find that different actor groups or vanguards are successful (or not) in stabilising their visions (Hilgartner, 2015) within the larger imaginary depending on the level of influence or power they have over aspects of the project. Additionally, I find that the citizen centred approach to developing a health data platform, results in the intended imagined user (Hyysalo et al, 2016) being central to the sociotechnical imaginary.

Zusammenfassung

Gesundheitsdaten, die im Gesundheitswesen erhoben und genutzt werden, gewinnen in der Gesellschaft zunehmend an Bedeutung. Die Europäische Kommission (EK) und insbesondere Horizon 2020 zielt darauf ab, die Kraft der Sammlung, Organisation und Nutzung von Gesundheitsdaten durch die Finanzierung von Projekten zu nutzen, die den Aufbau einer bürgernahen interoperablen europäischen Gesundheitsdaten Plattform zum Ziel haben. Diese Forschung untersucht, wie eine soziotechnische Vorstellung (Jasanoff, 2015) der Gesundheitsversorgung durch die Entwicklung einer interoperablen Gesundheitsdateninfrastruktur ko-produziert wird. Ziel dieser Forschung ist es, zu verstehen, was in dieser Vorstellung von Technologie, die eine bessere Gesundheitsversorgung bieten soll, enthalten ist oder weggelassen wird. Zu den Methoden, die für diese Untersuchung verwendet wurden, gehört die Analyse von Projektdokumenten der Europäischen Kommission und von Horizon 2020 sowie von Materialien des InteropEHRate-Projekts und die Durchführung von Interviews mit Entwicklern, die an dem InteropEHRate-Projekt beteiligt sind. Die Analyse dieser Materialien deckt Vorstellungen, Stabilisierungen und Ideale dessen auf, was eine bessere Gesundheitsversorgung sein sollte oder sein könnte, sowie das, was absichtlich aus dem Imaginären ausgeklammert oder überhaupt nicht berücksichtigt wird. Abschließend stelle ich fest, dass verschiedene Akteursgruppen oder Vorreiter

erfolgreich (oder auch nicht) bei der Stabilisierung ihrer Visionen (Hilgartner, 2015) innerhalb des größeren Imaginären sind, je nachdem, wie viel Einfluss oder Macht sie auf Aspekte des Projekts haben. Darüber hinaus stelle ich fest, dass der bürgernahe Ansatz bei der Entwicklung einer Gesundheitsdaten Plattform dazu führt, dass der beabsichtigte imaginierte Nutzer (Hyysalo et al., 2016) im Mittelpunkt der soziotechnischen Vorstellungswelt steht.