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The Socio-Technical Imaginary of Citizen-Patient Empowerment in European Healthcare Research Funding: Future Healthcare as Individualized Data Practice

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List of Abbreviations

EC	European Commission
EHDS	European Health Data Space
EHU	European Health Union
EU	European Union
HE	Horizon Europe Work Programm
H2020	Horizon 2020 Work Programm
ICT	Information and Communication Technology
CPE	Citizen-Patient Empowerment
QS	Quantified Self

1 Introduction

As digitization is ongoing throughout all areas of life, the medical field is no exception. Digital technology is not only expected to provide new opportunities to healthcare professionals and researchers but, above all, to patients in the form of Information and Communication Technologies (ICT). Often, this effort, coined as *personalized medicine*, aims to monitor, assess, and treat individuals' health more efficiently. Personalized medicine is referred to as enhancing patient independence through access to data and digital health infrastructures, and allows patients to take care of themselves more autonomously. It is here, in particular, that the terminology of *patient empowerment* of the receiving figure is ubiquitous, transmitting the promise of improved and self-determined care (Prainsack, 2015). This concept is also proclaimed by the European Commission (EC) in their most recent and most extensive research and innovation funding programs, *Horizon 2020* (H2020) and its current successor *Horizon Europe* (HE). In their strategic plan on the overall key orientations of the first four years of HE, the EC states: "The European Union has the ambition of empowering European citizens with digital solutions rooted in our common values and enriching the lives of all of us" (D6, p. 7).

The concept of empowerment is not exclusive nor newly introduced to medical care by the EC but can be traced back to the 1980s (Zimmerman & Rappaport, 1989). Since then, the significance of the term has undergone some changes in reoccurring attempts to define a distinct meaning. Yet, the critique on the lack of clarity regarding what the term means has not lessened (e.g., Acuña Mora et al., 2022; Castro et al., 2016; Karni et al., 2020; Lupton, 2018). Along with criticizing the inaccuracy of theoretical conceptions, there is a gap that results from its practical implementations. This gap is wide enough for researchers to conclude that there is a lack of empirical evidence due to an initial loose theoretical determination, thus making it hard to evaluate empowerment approaches (Aujoulat et al., 2007). Since the increased implementation of patient empowerment through digitization, i.e., ICT-based practices, the concept has been criticized as a *neo-liberalization* of health, framing an ongoing shift of responsibility for well-being onto the individual, detaching health from a broader socio-political level for cost-beneficial motifs. Despite existing critiques and various attempts to refine the significance of the notion of empowerment, not much has changed in the usage of the term.

In light of this critical discourse and the *multiplicity*, speaking with Mol (2002), of notions of empowerment, particularly regarding ongoing efforts in digitization in the medical sector, it is worthwhile to assess the topic explicitly within a massive development framework such as the Horizon programs. This is because research and innovation funding is – not only within Europe – considered a particularly important role in social development:

> Investing in research and innovation is investing in Europe's future. It helps us to compete globally and preserve our unique social model. It improves the daily lives of millions of people here in Europe and around the world, helping to solve some of our biggest societal and generational challenges. (European Commission, 2018, p. 2)

In other words, innovation accounts for a future-making practice as it is integral to the European Union's activities in its conception as a political system. Thereby, while the notion of empowerment itself has also been described as a conception of a future promise, it is taken up by the EC as embedded in the future-directed approach of innovation. *Science and Technology Studies (STS)* have developed various analytical lenses to unpack the regulative power of promises functioning as justifications, and thus shaping current socio-cultural as well as technoscientific practices performing the present implementation of the future aimed towards (e.g., Adam & Groves, 2007; Brown et al., 2000). To analyze the promise of empowerment as innovation-based and implemented as a *co-producing* practice (Jasanoff, 2004) – which means mutually determining its techno-scientific material and socio-structural conception – I make use of the concept of *socio-technical imaginaries* (Jasanoff, 2015), asking my central research question (RQ): *How does the European Commission imagine citizen-patient empowerment in healthcare in their research funding calls for Horizon 2020 and Horizon Europe?*

Addressing the notion of empowerment as a sociotechnical imaginary allows me to unpack its material-practical components, e.g., ICT-based, and its socio-structural determinations as reciprocally reliant upon each other within the particular version stated by the EC. With this work, I aim to add to the well-established and ongoing vital discussion of the development in public healthcare happening within the intersection of the digitization imperative alongside the substantial case of European research and innovation programs. Viewing the notion of empowerment in the wider societal context of innovation and the broader significance of public health within the future vision of the European Union as pursued through research and innovation funding, I adapted the common wording of patient empowerment to *citizen-patient empowerment* (CPE) (Felt et al., 2009). As a result, I stress a) the implications of the notion of empowerment for healthy and fallen-ill persons simultaneously in society, as well as b) the political-structural dimension of how the EC uses the notion of empowerment to describe the individual healthcare receiver´s position within society. This perspective is crucial as I trace the notion of empowerment through funding programs as a signifier of the figure of the (care-receiving) individual within the EC's overall future vision of public healthcare.

Tracing the impact of the funding programs' overall innovation approach onto the citizen-patient through the idea of empowerment means unpacking the impact of the innovation logic pursued by the EC on practices associated with the enactment of *empowered* citizen-patient-ship. To do so, I will address the particular innovation model in two parts. First, I make use of Pfotenhauer et al. (2019) concept of the *deficit model of innovation*, which addresses the narrative of a gap in innovation equating to failing social development. Applying this framework makes the EC´s narrative of "challenges and crisis" in (future) healthcare visible as illustrating such a deficit in innovation, thus justifying an innovation-focused approach. Here, the notion of empowerment is exclusively used to refer to practices that are compatible with ICT-based approaches, which are viewed as not-yet available later outcomes of now-fostered innovation. Second, I will address the practices of empowered citizen-patient-ship using Felt & Fochlers's (2011) concept of *tacit governance through innovation*. While the competence of public healthcare is unique to each individual member state, the EC clearly states its aim to standardize healthcare practices throughout the EU through the impact of its innovation approach. As a result of standardization, the innovation-limited enactment of citizen-patent-ship, referred to as empowered, is not supposed to become a potential option, but a necessity for the individual to participate in public healthcare. Felt & Fochler (2011) outline the limitations of the potential behaviors of citizens based on the innovation model pursued as a *tacit form of governance*.

Having identified the notion of empowerment of the citizen-patients as conducting certain ICT-based practices, e.g., self-tracking and managing data about the self, I end my analysis by focussing on the very description of these practices. Rather than speaking of practices as ICT-based, the EC's innovation approach shifts the focus onto data as the materiality of these practices. These data practices are described in three parts by the EC: as *increased health literacy* informed through data; as *self-conducted data management*, describing data-mining through self-monitoring; and autonomous curation and analysis of the same, resulting in *communication and collaboration* with other actors of the healthcare network mediated through data-sharing. All of these aspects are described interdependently. Together they depict the version of CPE envisioned by the EC.

Having identified the individual components constituting the sociotechnical imaginary of CPE and looking at their complementary dynamics results in a set of determined data practices referred to as *enactments of the figure of the empowered citizen-patient*. Since data practices are simultaneously bodily experiences and practices of knowing, as Hoeyer (2023) recently outlined, I will conclude my discussion by addressing the imaginary of CPE as not only determining participation in healthcare to data practices but also determining the epistemological concept operated within data-based healthcare. As the innovation model

pursued by the EC limits the possibility for citizen-patients to actively co-define practices of healthcare, the final data practices – which *are* practices of knowing – are introduced to citizen-patients as fixed hermeneutical conceptions to be applied in understanding and communicating their well-being. I lastly discuss the exclusion of citizen-patients from determining the hermeneutical conception operated within the healthcare setting they are part of as epistemic injustice (Fricker, 2007), drawing my conclusion in four parts:

1) Keeping the usage of the notion of empowerment multiple and open allows for creating a promissory vision of future healthcare that cannot be pinpointed nor evaluated precisely; therefore it is too big to fail as it can never be proven to be unsuccessful. Integrating this open understanding of CPE in the innovation model – by referring to CPE as both the premise and the outcome – the usage of the notion of CPE does not only refer to itself as fostering potential practices of empowerment but to a broader level, it overall supports the EC's innovation logic.

2) The overall innovation-based approach of the funding programs has a defining impact on the potential meanings of CPE. By referring to the notion of CPE integral to the outcome of innovation, it is incorporated into the innovation logic to a degree that detaches it from other possible understandings of empowerment if these are incompatible with innovation. Thus, since the EC's innovation approach is inherently envisioned as data-based, CPE results in exclusively being envisioned as data-based practices.

3) The EC's vision of empowerment can be understood as tacit governance through innovation (Felt & Fochler, 2011) given that the data practices defined as empowerment are supposed to become standardized and consequently mandatory for individuals if they want to become part of the healthcare network as citizen-patient. Thus the role of citizens with access to health care is made exclusive to people performing the practices of innovation-based empowerment.

4) Citizen-patient empowerment envisioned as data practices entails a fixed hermeneutical conception of health and illness. This exclusively biomedical conception by the EC is closed before citizen-patients can participate in developing the approach to healthcare. The knowledge produced and used by this empowerment approach potentially blocks comprehension and communication of one's experience if not all of the citizen-patient's health aspects are valid from the datafied biomedical perspective. Therefore it leads to epistemic injustice (Fricker, 2007), diminishing the citizen-patients´ agency as a knower of their well-being.

1.1 Overview

In Chapter 2, I trace the genesis of the notion of empowerment in the discourse of biomedical precision medicine and patient sovereignty through the digitization of health. Then I outline the critique on the gap between promises in the theoretical conceptions and the actual practical implementations of empowerment, the latter lacking evidence of having a positive impact (Chapter 2.1). As empowerment is tightly intertwined with digitization and thus the datafication of health, I give an overview on this topic (Chapter 2.2) before summarizing the latest state of critiques on this version of empowerment (Chapter 2.3). While the foremost critiques address individualization of responsibility, there are also critiques addressing the domination of a biomedical lens. This aspect has been discussed already as a rigid hermeneutical conception of health contributing to epistemic injustice (Fricker, 2007). Such rigid conceptions create determining practices of knowing health and result in excluding the possibility to express and understand, e.g., the social conditions and experiences, connected to the health status of a person. Hence, using Haraway´s (1998) term of *situated knowledges*, the *situatedness of health*, being a product of (social) context lacks reflection in the current empowerment discourse exclusively based on a biomedical perspective. I outline this discussion by referring to participatory approaches in medical research (Chapter 2.4), which are integral to some conceptions of patient empowerment, in addition to the discourse on empowerment as a later baseline for my conclusion.

After defining my research questions and building my sub-questions as guiding points in my actual empirical work (Chapter 3), I explain all the mobilized theoretical concepts (Chapter 4). Namely, I use theories on *sociotechnical imaginaries* (Chapter 4.1) as an overall perspective, to aid in understanding and describing the mutual determining impact of the technoscientific-material and socio-structural conception of CPE as a powerful future vision with practical implications for the present. Theory on Innovation (Chapter 4.2) is used as a working tool to unpack the innovation model pursued by the EC: its impact on the potential meaning of empowerment, its function as distributing participation, and the positions in healthcare throughout society.

Chapter 5 is dedicated to the methodology. To identify the imaginary of CPE as entailed in the EC's innovation model, I conducted a *practice-oriented document analysis* (Asdal & Reinertsen, 2022) of the funding call's work programs and additional related documents by the EC. Practice-oriented document analysis allows me to analyze the issue at stake not only as narrative and text but also in its function as communicating the EC's vision to research and refine the meaning of the notion of empowerment by detaching and attaching it from certain contexts (Chapters 5.1 & 5.2). After defining the sample of documents (Chapter 5.3), I give an overview of the structure and status of the work programs as main materials

(Chapter 5.4). Last, in the methodology I outline the analysis approach on information videos provided by the EC as additional empirical material informing the analysis of the innovation model (Chapter 5.5).
The actual analysis (Chapter 6), begins at a macro level in discussing the present context of CPE as presented in the work programs which form a deficit of innovation (6.1). Then I analyze the particular innovation model and its impact (Chapter 6.2) and finally look at the practices of CPE in detail (6.3). After that, I state the conclusion addressing the EC's imaginary of CPE as implicating practical (7.1), socio-structural (7.2), and epistemological (7.3) particularities determining the figure of the citizen-patient within future healthcare. Lastly, I present an outlook for further research (7.4) on European medical research funding and data-based autonomy-aiming healthcare.

2 State of the Art

2.1 Empowerment in the Context of Health

"A conceptual and methodological limbo" (Acuña Mora et al., 2022, p. 350)

On a general basis, empowerment is seen as an individualistic approach connected to the aim of personalized medicine, gained through (information and communication) technology (Felt et al., 2009; Marent & Henwood, 2022; Nielsen & Jensen, 2013). This notion can be traced back to the 1980s (Rappaport, 1981; also see Nielsen & Jensen, 2013; Roth & Bruni, 2021) and has been described manifoldly; hence, this topic is located within an intersection of various areas: biomedicalization, personalized medicine, healthcare, and health economics. Since the inception of empowerment in the health context, its lack of definition has been criticized as contributing to problems in assessing and comparing measurements related to the effectiveness of empowering practices (such as ICTs) (Bravo et al., 2015; Castro et al., 2016; Cyril et al., 2015; Karni et al., 2020; Morley & Floridi, 2019; Rappaport, 1981; Risling et al., 2017). To bring clarity to the concept of empowerment it has been defined according to its components, ascribed attributes, and/or promised consequences, resulting in inconsistencies and overlappings (Fumagalli et al., 2015). Therefore, it has been described from different perspectives, such as from patients, doctors, and/ or from a community level of the healthcare system and society as a whole (Castro et al., 2016; Rappaport, 1981).

To illustrate the inconsistency of definitions: One defining approach by Castro et al. (2016) divides the components chronologically into antecedents (dialogue, patient-centered approach, enhancing patients´ competencies, active participation), components (enabling

process, personal change, self-determination), and consequences (integrated self, sense of mastery and control, quality of life). Similarly, Karni et al. (2020) developed a framework called the *Information and Communication Technology for Patient Empowerment Model* (ICT4PEM), which defines six components of empowerment (control, psychological coping, self-efficacy, understanding, legitimacy, support) as well as their possible consequences (increased quality of life, patient satisfaction, and engagement, adherence, clinical outcomes, health care system effects). Further, the same or similar concept is also referred to by different terms such as: “patient engagement,” “participatory biomedicine,” and “patient activation” (mostly in a U.S. context) (Lupton, 2018).

One current, in-depth analysis by Acuña Mora et al. (2022) identifies 35 different definitions, within which there are 50 overall variables scattered across the definitions, summarizing that “[...] it is not possible to conclude whether all the available evidence on patient empowerment is related to the construct itself.” (p. 354). Their critique mentions missing long-term studies making it impossible to define a sustainable impact as well as discerning which variables may enhance others. Therefore, predictions on what kind of components are contributing to promised versions of empowerment, such as within the models developed by Castro et al. (2016) and Karni et al. (2020), are hardly possible. Similarly, Aujoulat et al. (2007) criticize that patient empowerment is often conceptualized in anticipation rather than measured according to its actual outcome. While the term is inflationary in proposals on health care innovation, neither a definition of what to achieve nor a reliable base for effective measurements exists. Hence, there is a gap between empowerment (in) theory and (in) practice. I illustrate this aspect in the following after giving an overview of the genesis of empowerment in the health context.

2.1.1 A Brief Genesis

The concept of empowerment has been introduced in healthcare since the last quarter of the 20th century (in the 1980s due to Pekonen et al., 2020; in the 1990s due to Fisher & Owen, 2008) and has been traced back to various fields with different foci between the U.S. and European perspective. This differentiation is not absolute but is also mentioned by Holmström & Röing (2010). The former generally refers to psychology as the origin of new models of patient participation (Holmström & Röing, 2010, referring to psychoanalysis Michael and Enid Balint in the 1960s) or stressing empowerment in the health sector as doctor-patient collaboration as in community psychology referring to Zimmerman & Rappaport (1989) (Castro et al., 2016; Agner & Braun, 2018; also see Holmström & Röing, 2010). Here the concept is rooted in the idea of autonomy and self-determination as genuine U.S. American values: “Drawing on the thinking of Giddens (1998), who has been influential

in the assimilation of U.S. libertarian thinking into New Labour's 'third way', social policy has prioritized welfare interventions that promote individual choice and self-management" (Fisher & Owen, 2008, p. 2064; also see Rappaport, 1987).
While broadly speaking, the European perspective is not distinctively different but describes it with a different focus as:

> [...] rooted in social action and the civil rights movement during the 1960s and "self-help" perspectives of the 1970s to promote the rights of ethnic and sexual minorities. In health care, empowerment has increased since the 1980s, especially in patients' care and education with long-term conditions". (Pekonen, 2020, p. 778; also see Aujoulat et al., 2007; Castro et al., 2016)

An early version of distinctively conceptualizing patient empowerment in the health context is Rappaport's conception of a theory of empowerment, developed as applicable in research and healthcare (1981; 1987). Rappaport defines empowerment as a *paradox* of autonomy/freedom and the need to be cared for, viewing collaboration between patients and doctors at the center. He distinctly argues for a bottom-up approach and understands empowerment as a community-based interaction targeting cooperation instead of individualization. This leads him to also criticize other attempts that solely focus on patient autonomy, often done at the expense of the complexity of people's situations. Critiques in the following thirty-five years continued to address similar deficiencies (e.g., Agner & Braun, 2018; Lupton, 2018; Prainsack, 2017).
From psychological patient empowerment, the concept got applied more broadly to "patient-ness" in other contexts (e.g., Agner & Braun, 2018; Castro et al., 2016). Today's established approach of empowerment relates to a shift from individualized drug treatment and gene analysis in the 2000s, which led to the new categorization of people in the aftermath of the Human Gene Project (Prainsack, 2015), to patient-generated data focusing on enhancing healthy behavior as self-management (Prainsack, 2017).

2.1.2 Theoretical Conceptualizations

As said before, empowerment is mostly associated with enhancing people's autonomy and the ability to make healthy lifestyle/behavior changes (Acuña Mora et al., 2022; Funnell & Anderson, 2010) "as a process of personal transformation" (Aujoulat et al., 2007, p. 15) leading to overall improved quality of life (Barr et al., 2015). Here, being empowered is equated with being informed and health-literate. Adaptation is thought of as preventative but

also as making changes like psychological coping, ability to adjust, and *self-efficacy* in adaptation to one's situation with an illness (Agner & Braun, 2018; Aujoulat et al., 2007).
This conceptualization is frequently criticized as deriving from a neoliberal logic of autonomy embodied by the *informed health consumer* (Sturt et al., 2020) and as primarily motivated by the aim to lower healthcare costs instead of focussing on improving the individual's situation (Lupton, 2018; Morely & Floridi, 2019; Odone et al., 2019; Prainsack, 2017; Roth & Bruni, 2021). The notion of autonomy is connected to a vision of democratizing healthcare, giving decisional participation to one's health in opposition to paternalistic treatment (Nielsen & Jensen, 2013; Nielsen & Langstrup, 2018; Rappaport, 1987; Roth & Bruni, 2021). Autonomy can be seen from a solely patient-centered perspective or as collaborative and dialectic (Castro et al. 2016), based on the doctor-patient relationship "[...] as a process of communication and education in which knowledge, values, and power are shared." (Aujoulat et al., 2007, p. 15; also see Funnell & Anderson, 2004; Holmström & Röing, 2010; Risling et al., 2018). Viewing empowered healthcare as interactive can also be focused on the individual's behavior connected to the idea of the need to "activate patients," enabling them to purposefully interact with the healthcare system (Acuña Mora et al., 2022; Castro et al., 2016).

2.1.3 Practice

As said in the beginning, the discourse around patient empowerment is tightly intertwined with the digitization of healthcare. Fischli (2022) argues that "[...] the digital transformation was accompanied by claims to empower the individual from the very start". Hence, the majority of patient empowerment practices are based on the implementation and usage of Information and Communication Technologies (Beck-Gernsheim, 2000; Felt et al., 2009; Lupton, 2018; Marent & Henwood, 2022; Nielsen & Jensen, 2013). Referring to the two main different approaches of conceptualizing empowerment as either focusing on the individual or as an intersubjective process, this implementation varies. Hence, the usage of digital tools can focus on empowering patients by facilitating doctor-patient communication (Karni et al., 2020; Sturt et al., 2020) and/ or exchange with a community (Martinez-Millana et al., 2018) or facilitating particular behavior of individuals.
Referring to the second variant, one major aspect of empowerment is described as the capacity for self-management (e.g., Risling et al., 2017). Castro et al., (2016) refer to self-management as one of the most associated features, addressing e.g., living with post-illness chronic conditions or chronic illnesses (Aujoulat et al. 2007), e.g., diabetes (Funnell & Anderson, 2004; Martinez-Millana et al., 2018); cancer (Kondylakis et al., 2020), respiratory diseases/ asthma (Sleurs, 2019), or psychological illness (Terp et al., 2018). Another aspect of individualized digital facilitated empowerment is the involvement in data gathering for personalized/ precision medicine, hence patient-generated data outside

medical settings about people's everyday life (Odone et al., 2019; Pezzullo et al., 2021) by technology-facilitated self-surveillance (Morley & Floridi, 2019).

This aspect marks a gap in theory and practice, as the narrative on precision medicine still talks about individualized treatment stemming from the discourse on gene testing and individualized drug therapy, as mentioned before by Prainsack (2017), while the technological implementations, such as apps, profoundly focus on self-management and behavior tracking encouraging self-optimization (Prainsack, 2015). In other words, the promise of precision medicine stays consistent while the practice of identifying individual needs gets adapted and shifted onto the individual subject´s behavior.
This discourse on digital health is a huge topic and closely intertwined with the discourse on empowerment by setting the individual up to be responsible for the successful operation of digital possibilities, which associates this practice with self-determined freedom (Lupton, 2018). This kind of individualized practice coined as autonomy is genuinely referred to as “being empowered,” or this kind of behavior being fostered is referred to as “to empower.” Due to the entanglement of the two topics, which the EC particularly emphasizes, it is important to discuss them here.

2.2 Digital Health and the Importance of Data

The increasing shift of practices into a digitized sector simultaneously means intensified datafication of these practices. Hence the generated data points stemming from people's engagement with these digital environments are often handled as objectified information about otherwise inaccessible areas of people's behavior (Van Dijck, 2014). As said, this issue overlaps twofold with the topic of this thesis. On the one hand, the health sector is a particular example of these developments; on the other, datafication of life is referred to with the notion of empowerment beyond the topic of health. Therefore it is important to note that the notion of empowerment does not particularly overlap with digitization in the health sector but is integral to the discourse on digitization altogether. While Swan (2013) identifies three kinds of health data, “[...] traditional medical data (personal and family health history, medication history, lab reports, etc.), ‘‘omics’’ data (genomics, microbiomics, proteomics, metabolomics, etc.), and quantified-self tracking data” (p. 88), the empowerment discourse mostly refers to the third kind of data.

Self-tracking is not new; traditional versions of keeping a diary or later using a scale at home can be traced very far back (Ajana, 2017; Mager & Mayer, 2019; Lupton, 2016). Digitally based self-tracking originated in the 1970s in North America but became bigger in 2007

through the so-called “Quantified Self (QS) movement,” a community project started by editors of Wired magazine (Ajana, 2017; Sharon, 2017). Swan (2013) subsumes the underlying basic assumption: “The individual body becomes a more knowable, calculable, and administrable object through QS activity, and individuals have an increasingly intimate relationship with data as it mediates the experience of reality” (p. 85). It is important to note that the generated data through the self-tracking behavior is viewed as not only providing hidden insights about the body and a person's lifestyle to others, e.g., healthcare professionals but to the data subjects themselves, assuming this knowledge about potentially harmful lifestyle choices will directly induce behavioral changes beneficial to their health (Lupton, 2020). However, these promises of the benefits of self-tracking were quickly accompanied by the promise of a whole new market strand of better devices and apps, provoking a discussion on the ownership of data as an asset and often claiming individualized data(asset)-ownership as an empowering principle (Ajana, 2017; Levina, 2012).

On the other hand, the linkage of these two benefits is not a given. Liddell et al. (2021), for example, argue that the conceptualization of health data ownership as an individual property right is not necessarily motivated by the underlying aim to support autonomy but by the fact that to monetize the data, it has to be *assetized* and therefore owned by someone in a classical understanding of singular property. In other words, to efficiently *use* data as an economic resource, rights and obligations according to the object must be defined. Therefore, an owner is needed, not necessarily the data subject though (Janecek, 2018). Others note that the individual ownership of one's data is falsely equated with control and thereby responsibility for one's health (Ajana, 2017; Kuntsman et al., 2019). What is referred to as empowering in the sense of managing and potentially also owning data about the self, data generated through self-tracking is particularly seen as an “illusion of consumer choice” (Kuntsman et al., 2019, p. 13).

The debate on (health-) data ownership is much more detailed and expansive, and I am only touching on it partially. Still, I do so because it is important to understand how impactful the economization of data defines the societal practices applied and fostered for self-determination of health, referred to as empowerment. The vision of autonomous healthcare being implemented through the neo-liberalization of health data ownership – viewing data as not only an insightful source improving behavior but further monetizable – is a perfect example of *co-production* (Jasanoff, 2004) as both of these characteristics require each other. The notion of empowerment occasionally is used to refer to both and thus results in the ubiquitous usage of the word which also naturalizes this relation. Therefore, in staying within this logic, arguing for the most economical practice is allegedly equated with being the *healthiest*.

As many have already noted, this black-boxed assumption creates an ontological shift in how one's body, health, and individual capabilities of healthiness are perceived through data. Critics have pointed to the false objectification of a supposedly objective embodied truth that now becomes *datafied* as reductionism encompassing human experiences (Ajana, 2017; Sharon, 2017; Hoeyer, 2023). Similarly, Van Dijck (2014) discusses and rejects the objectivity of data: “Metadata relate to human behavioral acts in the same way as MRI scans relate to body interiors: signs of disease never simply appear on a screen, but are the result of careful interpretation and intervention in the imaging process” (p. 201). Instead, data has to be viewed as an entity of ontological multiples, speaking with Mol (2002, also see Hoeyer, 2023), as each participant interacting with the data potentially contextualizes and interprets it differently:

> Data, [...] are so important precisely because people make (or imagine) data function across multiple social worlds. Data are not inherently important or interesting, rather, by definition, data are used to make arguments relative. Put simply, data is only data in the eye of the stakeholder. (Neff, 2013, p. 119)

Hoeyer (2023) recently describes the multiplicity in regard to the various usages, the data practices, and thereby the perceived materiality of data: “[...] people associate the word “data” with what they do in the course of their daily work” (p. 17). Therefore one and the same data point is defined in its meaning not by itself but by the practices it is integrated into while these very practices, such as gathering, managing, and interpreting, become naturalized and rendered invisible, seemingly effortless (Lupton, 2016; 2020). Here, Hoeyer (2023) also notes how in recent developments, data practices not only determine different interpretations of the information carried by data but are particular practices of assetization of data.

Lastly, data practices do not impact the ontology of data itself from a contextual outside, but the data subject and how it is embedded in a social network are also perceived as being determined by these data practices. Mager & Mayer (2019) discuss the fusion of data and data-subject instead of viewing them as separable entities and “[...] define data bodies not as mere digital counterparts of physical bodies, but rather as an indispensable socio-material coupling of data and bodies [...] co-configured from both online and offline data" (p. 96). Also referring to Lupton (2017), who speaks of *lively data*, lively on their own but also containing information about life. Though criticizing the reductionist approach of quantification, Mager & Mayer (2019), as well as Lupton (2020), also acknowledge the togetherness of online and offline bodies; they sense a possibility to strengthen the subject's agency when people

generate new unforeseen practices out of datafication for themself. They can create new “agential capacities" (Lupton, 2020, p. 99). For example, appropriating them for their chronic illnesses needs (e.g., D’Ignazio & Klein, 2020; Sharon, 2017). This positive flexibility in usage is not given, though when treating the data points as objective truth as such leads to (re-)classifications and thereon-based discrimination (Bliss, 2013; Epstein, 2008; Martucci, 2010). Ruckenstein & Pantzar (2017) point to the fact that this practice of datafication not only defines the “knowledge about the self” but also the social practices of how this self interacts with the world.

> Digital data infrastructures not only convey information about the world, but they also make particular worlds emerge as experiential phenomena. […] The social nature of the encounter with data similarly shapes data experiences: With whom do people experience data? At work, in the clinic, or at home, for example? In the course of doing what? (Hoeyer, 2023, p. 122)

According to Hoeyer (2023), this does account for the understanding of society as a collective but not particularly a “governable entity” (p. 20). It is rather to note here that, the data practice creates a feedback loop impacting its source of information (Lupton, 2016; 2020). Proponents of self-tracking, on the other hand, acknowledge this feedback mechanism too but refer to it as an advantage as the potential impacts are controlled by the autonomous individual, able to decide for or against a change in behavior. Often they root their motivation in self-tracking on moral beliefs about an idealized self in connection to ideal citizenship, fulfilling the obligations (Lupton, 2020).

2.3 Critique

In addition to the critique on the naturalization of data practices and the ignorance of the ontological multiplicity of data, citizen-patient empowerment based on digitization has been critically addressed as neoliberal. One point of criticism is the shift of responsibility and (data) work to citizen-patients; less focus on intersubjective aspects changes the understanding of health care in demanding their permanent evaluation of their situation and constant recognition of their health status (Hoeyer, 2023; Sturt et al., 2020). In other words, the critique describes a process of co-production of digital healthcare technologies facilitating individualized tasks such as self-tracking and management – components of patient empowerment.

The vision of technology facilitating patient empowerment is further criticized for being a non-dischargeable promise (Morley & Floridi, 2020). As mentioned in the beginning, the

actual realization of the promise of empowering patients through technologies has rarely been proven so far, nor exists a system to assess the actual impact of, e.g., health managing apps (e.g., Karni et al., 2020). Similarly, the positive impact of datafication lacks evidence (Hoeyer, 2023). For example, Sturt et al. (2020) have addressed that telecommunication between doctors and patients is more concerned with biomedical topics and less with questions about the patients' personal lives, in addition, healthcare professionals are the ones talking more in such settings. Furthermore, such individualized conceptions of empowerment are facilitated through technologies being inoperable due to the increased workload for patients and doctors. Agner & Brown (2018) name the current contradictory relation between what they define as empowering, namely the strengthening of interpersonal care relations, and the current attempts to practice patient empowerment. The conceptions of healthcare and digitally facilitated patient empowerment still have to be adapted one to the other (Meskó et al., 2017; Odone et al., 2019), since the most purposeful usage of such promissory technologies is not yet found.

Another point of criticism stresses the black-boxed concept of ideal and genuine citizenship, ignoring social inequalities and their impact on one's health, autonomy, and freedom of choice (Fischer & Owen, 2008; Prainsack, 2017; Lupton, 2018; Marent & Henwood, 2022). Fischer & Owen (2008) add to this noting that the concept of empowerment is based on “[...] the ideal of the autonomous citizen worker living in the context of a ‘hard working family’ (p. 2064), adding that traditionally the self-efficient working role model is associated with the male figure, being the empowered one. Prainsack (2017) calls this ideal a “[...] discursive alliance between anti establishment activism and libertarian consumerism [...]” (p. 94). Yet again, this genuine ideal is also found in capitalizing on the empowered patient being embodied by the well-informed health consumer enabled to make the right choices (Cairns & Johnston, 2015; Chiapperino & Testa 2016).
Intersectional working analysis criticizes the lack of acknowledging the socio-structural complexity in which health and individual choice are embedded. For example, Valeriani et al. (2020) address that the aim of implementing digital healthcare solutions for more patient participation is not working as such in groups with linguistic and cultural as well as economic barriers (Rappaport, 1981). Hence the digital approach for addressing such groups has to be rethought, for example by thinking about how to use telemedicine technologies to overcome language barriers.

Lastly, the empowered citizen is viewed as genuinely motivated while ambivalent feelings and the connected effort are ignored (Lupton, 2018). However, studies have shown the

hesitancy of patients and discomfort towards using health technologies and practicing such self-surveillance as feeling stressed (e.g., Kondylakiset al., 2020; Terp et al., 2018). Further:

> Some patients expressed the view that they did not necessarily want to be 'empowered' by being able to view all their information; they would rather not know about negative test findings or prognoses, for example, by reading it on the record before being able to discuss this information with their doctor. (Lupton, 2018, p. 96)

Similarly, Hoeyer (2023) quotes an interviewee reporting having "data stress" and sometimes being in need of a "data holiday" (p. 60) from self-tracking. This topic is marked by ambivalence, as other studies report about users feeling de-stressed from having digital support in managing their illness (Schneider et al., 2020; Thomas et al., 2022) and critique by Agner & Brown (2018) also mentions a lack of reflexivity on interpersonal aspects in such studies on patients´ understanding of empowerment.

Hence, critiques of digitally-based empowerment approaches are manifold. Still, they can be concluded as stemming from anticipatory rather than experiential-based definition and thus a mismatch between theoretically-idealistically conception and practical implementation to the fundamental neoliberal approach underlying prevailing empowerment visions in healthcare. Here, the inversion of the argument that being informed about one's health status through digital practices such as self-tracking equates to self-management of data about one's health being the best practice in autonomous health care has been addressed: First, as naturalizing the linear effect of supporting self-tracking technologies and improving data facilities on self-determined healthcare while, second, basing this vision on the false assumption of equal access to possibilities throughout society. Hence, this data-based vision of empowerment practices operates on a particular vision of a genuine citizen, which is important to bear in mind for the actual analysis. Thirdly, the perception of ICT, and generally all self-tracked data-based approaches, has been doubted as being certain in terms of empowerment. Related to this argument, the theoretical lens of epistemic injustice has also been discussed (Fricker, 2007), addressing the limitations on self-determination by confining autonomy in healthcare practices to data practices as knowing practices. As the last point in my thematic summary of the issue of empowerment in the health context, I bring up this topic to successfully critique data-based *self-healthcare* practices and as an additional sensitizing concept for the later interpretation of my findings (Chapter 7.4).

2.4 Epistemic Injustice of Biomedicalization in participatory Health Research

As outlined in Chapters 2.2 & 2.3 on the digitized practices of empowerment in connection to self-quantification, the datafication of human experiences into allegedly objective truths constitutes a particular way of knowing – excluding other possibilities – and thus referred to as reductionistic (Ajana, 2017; Lupton, 2016; 2020; Sharon, 2017). Similarly, Clarke et al. (2010) refer to “[...] biomedicine as a culture per se, as a regime of truth [...]” (p. 49). These voices do not express doubt about the information carried or the value of medical data as such. Rather they criticize its exclusivity as the naturalization of these practices, deemed to be the “best practices,” which creates a certain hierarchy of knowing. Such hierarchy renders the work that goes into gathering, managing, and interpreting data into invisibility and thus cuts off people as knowers who are not able to do this work. Further, the encompassing experience of health and illness – its *situatedness*, speaking with Haraway (1988) – is exclusively made into data points. Here, the way experiences can be translated into information used for decision-making and communicating one’s situation to others, such as healthcare professionals, is predefined within the framework of the technological opportunities developed and provided. These frames are not naturally given to the outcome of decisions made in technological development. Within my thesis, I understand the input given by the EC through the funding programs as a significant determinant in these developments (see Chapter 5.4). It thereby pre-defines what kind of knowing practices are available and acknowledged. In connection to my observation of the standardization process (Busch, 2011, see Chapter 6.1.3), integral to the healthcare vision pursued by the EC, I understand that the fostering of certain digitized practices of knowing in healthcare is not a possibility but obligate. This forms standards of credibility and connects the dependence of credibility to one's social identity. As Dotson (2014) puts it: "It is difficult to impossible to break out of this kind of epistemic exclusion when one’s own capacities to engage in a given epistemic community is compromised to this degree” (p. 25).

In her book, Fricker (2007), traces two types of epistemic injustice: testimonial justice, referring to the belief given into a testionaminal´s account, and hermeneutical justice, referring to a level “when a gap in collective interpretive resources puts someone at an unfair disadvantage when it comes to making sense of their social experiences” (p. 1). In this work, I engage with the latter. While the first one focuses on interpersonal interaction, the second refers to missing concepts in a society that would permit making social injustice visible and being able to address it – or not. Hence, the book looks at how a collective is making sense of everyday social experiences and how these epistemic practices distribute sovereignty of interpretation unequally.

The concept of epistemic injustice has already become a well-established approach used to analyze patients' position as *knowing* subjects. As Carel & Kidd (2014) summarize: “Ill persons are also vulnerable to hermeneutical injustice because many aspects of the experience of illness are difficult to understand and communicate, and this often owes to gaps in collective hermeneutical resources” (p. 529). They distinctly refer to this as “pathocentric epistemic injustices.” Further, ill persons are often less represented in society, and therefore, hermeneutic concepts of their experiences are less distributed (de Boer, 2021). This is particularly the case with illnesses that lack medical research, such as, to give a current example, Long Covid or its *older* sibling chronic fatigue syndrome (ME/CFS), as already discussed under this premise (Bayliss et al., 2014; Blease et al., 2017; Byrne, 2020; de Boer, 2021; Ireson et al., 2022). Further, cases of Fibromyalgia (Heggen & Berg, 2021) and psychological conditions have been interrogated from this perspective (Drożdżowicz, 2021; Harris et al., 2022; Kidd et al., 2022) as well as an intersectional approach of oppression connecting the aspect of gender in health (Bullock, 2023; Shaw & Fehoko, 2022; Tuana, 2006).

Participatory research approaches and working with concerned persons are upcoming attempts to address these gaps. Such attempts are also encouraged and sometimes obligatory on certain subprojects of both Horizon funding programs. Most recently, my colleagues at *Smart4Health* critically reflected on their experience with citizen participation as co-creation in developing a digital health data platform under *Horizon 2020* (Felt et al., 2023). In regard to ill persons in particular, de Boer (2021) also stressed that such approaches in general thought acknowledge the value of insights on experiencing everyday life with an illness, but they nevertheless often do not reflect on the potential limitations in the capacity of ill people to actually participate in these process. Particularly if the very structure of the participatory process is not co-created by the concerned persons – versus e.g., Epstein (1995), Rabeharisoa & Callon (2004), and also Rogers (2022). Further, the stereotypes and accordingly ascribed roles of each part of such research settings may not be overcome resulting in the gathered insights having no substantial effect on underlying epistemic oppression (Dotson, 2014). Still, de Boer (2021), like authors working on the empowerment discourse (see Chapter 2.1.4), argues that such assumptions mostly remain theoretical, missing more empiric interrogation.

Such has been done by Rabeharisoa & Callon (2004) in their work on the involvement of concerned persons organized as patients in the case of the *French Muscular Dystrophy Association.* They precisely outlined the importance of a participatory approach in the generation of medical knowledge and described the practical structures developed to create a setting for “mutual learning” (p. 157) between patients, clinicians, and biologists. They have shown how participation neither only appears in the accumulation of knowledge, i.e.,

data, nor implies some kind of different knowledge. Rather, they argue that ”[...] the production, dissemination and implementation of knowledge and know-how on Muscular Dystrophy requires this form of organization, and would probably be impossible without it” (p. 158). The main takeaway from these studies on participatory research is how participation does not equal emancipation or guarantee *better knowledge* as long as the underlying epistemic system referred to by approaches is kept untouched by the structure of the participatory approach.

Dotson (2014) describes these as: “[...] operative, instituted social imaginaries, habits of cognition, attitudes towards knowers and/or any relevant sensibilities that encourage or hinder the production of knowledge” (p. 121). Hence, the epistemic system operated with potential actually cuts off certain ways of knowing and excludes aspects that would be necessary for fulfilling the promise of increased knowledge transformed into emancipation as partial aspects or synonyms for empowerment. Applying this observation to my topic poses the question about the structure of the epistemic system, the basic premise the EC’s approach is built on. As outlined above, the empowerment approach, if operated with a digital health approach, is exclusively based on a biomedical understanding of health and illness. Biomedicalization accounts for the basic epistemic system these approaches are based on (Clarke et al., 2010). Several works have already discussed the epistemic injustice particularly caused by a solely biomedical approach (Chung, 2021; Kidd & Carel, 2018; Michaels, 2021; Moes et al., 2020). They argue that if the general preference for biomedical knowledge over societal medical insights is not inherently addressed, the possibility to contribute to the knowledge production by ill participants does enable them to go beyond the set frame, hence the set hermeneutic concepts of understanding the illness. In other words, not addressing epistemic injustice in such a research setting not only profoundly prohibits participatory research settings in which participants would offer insights going beyond the biomedical frame but also prohibits the concerned person from developing or using a hermeneutical concept depicting their complex social experience if such is not acknowledged beforehand.

Hence, the biomedical standard causes epistemic oppression beyond the area of evidence-based approaches (Heggen & Berg, 2021; Naldemirci et al., 2021; Wardrope, 2015). This particularly accounts for chronic conditions (Weidmann-Hügle & Monteverde, 2022). In addition to the critique on handling data as objective truth in (self-)healthcare, I will use the described attributes of hermeneutical injustice – the inability to contribute to the conception of knowledge in the data-based knowledge production about the self in my analysis. It allows me to better address the take for the evident connection between the increase in ICT-based self-literacy as an integral part of empowerment and improvement of

health. By using Fricker's (2007) conception, I am able to add a more fine-grained critical discussion on the role of health literacy in the EC's vision of empowerment, aiming to add to the existing arguments on the weak conception of the notion of empowerment.

3 Research Questions

These quite harsh voices of critique in contrast to the optimistic view of the future of healthcare carried by the terminology of empowerment show a complex area of tension. In my analysis, I aim to unpack and work out the particular version of this conflict that empowerment is entangled within the current research funding programs of the European Commission – and thus elucidate the position of the citizen-patient within this setting. I, therefore, ask:

RQ: *How does the European Commission imagine citizen-patient empowerment in healthcare in their research funding calls for Horizon 2020 and Horizon Europe?*

In order to answer this question through my approach, I used the subquestions (SQ) as guidance in my analysis, helping me to determine what to pay attention to in my materials. Hence, they guide what to look for and what particular information to draw from which content.

First, the concept's meaning is not solely mediated by the terminology used but by how it is put into context and how connections are drawn or cut within the work programs´ narration. Asdal (2015) calls this act modifying work. Such does not necessarily describe a change in the meaning of a subject; rather, it describes the creation of a distinct subject through the way it is put in context. SQ1, therefore, helps me to identify this process of modifying the issue of citizen-patient empowerment by contextualizing it.

> *SQ 1: What context is the notion of citizen-patient empowerment embedded in, and how is citizen-patient empowerment connected to its visible context as given in the documents?*

One aspect of the context informs my second SQ. As the EC stresses the "impact-orientated" approach of the funding calls, I expect CPE to be envisioned in structures leading to the anticipated benefits (Fumagalli et al., 2015). I address this future-directed account of impacts, though anticipated in certainty by the EC as narratives of promises, asking:

> SQ 2: *What are the promised benefits?*

Further, in order to analyze the notion of citizen-patient empowerment as a *sociotechnical imaginary* (Jasanoff, 2015), it is essential to understand the "structure-agency" relationship in which the notion is embedded (see Chapter 4.1). With SQ1 and 2, I am looking for the structure forming the concept, constituted by how it is put in context, its future aims and promissory configuration. Identifying the described scopes of CPE (SQ2) informs not only this structure but also the outcome the set agency is tending towards, thereby leading to SQ3. Getting a clear overview of the envisioned enactments of CPE and how it is to be performed informs the aspect of the agency.

SQ 3: How is citizen-patient empowerment imagined to be performed?

The order of SQ2 and SQ3, first looking for the envisioned benefits and then the promoted solutions, refers to the HE works program structure, dividing the individual projects into first, "Expected Outcome" and second, "Scope."

Next, understanding the envisioned notion of CPE can only be done correctly by including its performance *outside* (Asdal, 2015). Identifying such allows tracing the boundaries of the concepts *inside.* This question further corresponds to Jasanoff's (2015) urging to create visions of the future that avoid how a sociotechnical imaginary is to be performed:

SQ4: *What opposite visions of patient empowerment are observable in the work programs?*

SQ4 not only addresses negative visions of disempowered patients but particularly those future scenarios of health that do not care for discussing the role of patients. Hence, SQ4 addresses the sectors they are excluded from as acting subjects.

Lastly, as there exists no clear definition of the concept of CPE while it is used inflationary, I understand the term as a buzzword "only make[ing] sense within its "word collective" (Bensaude Vincent, 2014, p. 243). To get a clear overview of the word collective, I included looking for other expressions to describe the envisioned empowerment.

SQ5: *What descriptions are used to express the notion of citizen-patient empowerment?*

4 Theoretical Framing

As indicated by the wording of my main RQ, the aim of this project is to understand the notion of CPE as used by the EC as a *sociotechnical imaginary* as defined by Jasanoff (2015). In the next chapter, I outline why this concept is beneficial to understand the role of the citizen-patient referred to by the terminology of empowerment within the broader vision of future healthcare. Further, referring to Pfotenhauer & Jasanoff (2017), stressing the

essentiality of innovation approaches in the implementation of *sociotechnical imaginaries*, I outline two theoretical perspectives on the innovation processes. As the EC's funding approach is profoundly based on practices following an innovation logic, also coined as the *Innovation Union* by the EC (European Commission, 2011), both concepts likewise inform my understanding of the practicalities of the sociotechnical imaginary. Pfotenhauer´s et al. (2019) deficit model of innovation helps in defining the guiding logic of the EC's approach, while Felt & Fochler´s (2011) description of tacit governance through innovation allows looking at the practices of empowered citizen-patient being shaped by the innovation logic. I look at the topic at stake through a lens sensitive towards innovation in my approach and understand that it informs the overall interest in the sociotechnical imaginary of citizen-patient empowerment.

4.1 Sociotechnical Imaginaries

The term imaginary describes the vision of a future reality and has been used in various contexts (e.g., Appadurai, 1990; Ezrahi, 2012; Marcus, 1995; McNeil et al., 2017; Taylor, 2004). The concept of sociotechnical imaginaries, in particular, pays attention to the symmetrical influence between the social and how it is regulated through science and technology, looking for the material, practical, and in the end, societal results of such processes. As most pointedly described by Jasanoff (2015), sociotechnical imaginaries can be summarized as:

> [...] collectively held, institutionally stabilized, 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. This definition privileges the word "desirable" because efforts to build new sociotechnical futures are typically grounded in positive visions of social progress. (Jasanoff, 2015, p. 4)

Hence, the concept allows situating technological developments in visions of future society(ies) – visions of optimistic future scenarios or avoiding dystopian ones through technoscientific development.

The concept of sociotechnical imaginary has been used to trace back the history of a presently unquestioned sociotechnical phenomenon on a national level (Felt, 2015; Jasanoff & Kim, 2009, also see Jasanoff & Kim, 2015; Mikami, 2015). Further, it can refer to a transnationally reaching vision (Hilgartner, 2015). In the case discussed here, the European Union is in place of the political entity, or more concisely, the European Commission (EC)

draws a picture of the European Union as an *Innovation Union* (European Commission, 2011). Instead of tracing back the development of a settled imaginary, I am using the concept in means of its other well-established purpose; in looking at an imaginary *in the making*. Hence, this thesis does not re-open the *making* of a certain (nation-state) identity through the enactment of a sociotechnical vision but looks at the current effort to stabilize a potential vision of healthcare in co-production with the sociopolitical context of what has been named the Innovation Union. Here, the concept enables me, in particular, to understand the imagination of a *space*, addressed by the imaginary, as a collective and how the individual is supposed to be envisioned as part of it. Hence, how the collective is imagined through the structure of in- and exclusion of citizens from the collective through the envisioned social and technology-based practices implemented as performing this collective. Jasanoff (2015) refers to this connection between the (sociotechnical) structural setting and the co-production of practices of being an individual within this setting as the *structure-agency relationship*. Thus it is beneficial to understand the role and position of the individual citizen-patient within the imaginary of an ICT-based public healthcare vision – as the imaginary expressed by the notion of empowerment.

The literature review shows that the understanding of patient empowerment is not yet stabilized. Alternatively, it might function as a never-to-be-fulfilled promise, a frame for new input, an instrument of new visions, which keeps it in a constant “in-the-making” mode. Either way, it is unfinished and does not need to be opened up for discussion in the first place as such is ongoingly taking place – though not addressed as unfinished by the EC. Nevertheless, what is in need of such analysis is the very performance of citizen-patient empowerment´s making process within the innovation-driven context.

4.1.1 Four Phases of Sociotechnical Imaginaries: From Imaginations into Practice

To unpack a sociotechnical imaginary, Jasanoff (2015) points to following them along four phases of establishment, starting with *origins* “[...] of new scientific ideas and technologies and the social arrangements or rearrangements they help sustain” (p. 322). In the second step, *embedding*, institutional stabilization happens, followed by a phase of competing versions of a particular imaginary called *resistance*. The last step, *extension*, is constituted by a certain final stabilization of an imaginary and its possible transfer to other sectors and regions. From those four, this thesis focuses on the transition from the moment of origins to embedding. The documents used as reference points in this analysis mark the beginning of the ideas to be spread from there, to be translated into practices generating social and

economic value. It is where the vision is taken further into institutionalized and collective practice, as the EC functions as the source of power to promote and implement a certain future vision. The question is: how does this take place?

In her work on the development of an Austrian national identity as an imagined community defined through the non-implementation of nuclear technology and biotechnology (gene technology) Felt (2015) focuses on the messines and moments lacking consensus marking this development process. Thereby, she argues for the concept of *sociotechnical imaginaries* (Jasanoff, 2015) having the best offering capacity to pay attention to how these processes of closing potential disagreement and uncertainties are practices of techno-politics. Hence, they not only introduce a technoscientific artifact but work in mutual constitution with "[...] preferred ways of living, value structures, and social order [...]" (p. 104). She describes this process, similar to Jasanoff (2015), as happening in four stages, yet paying particular attention to the processual characteristics of the crossover from *origins* into *embedding*. While the moment of *origins* becomes a practice of *assembling* the vision at stake, the discourses and moments constituting the *sociotechnical imaginary*, the following step of *rehearsing* this vision discursively is essential to me here. Felt (2015) distinctly describes the importance of repetition of the vision as a sociocultural practice marked by a social structure, i.e. who is rehearsing in front of whom aiming to stabilize the vision. Focusing on this moment of rehearsal helps to a) understand the performative character of the material I am working with, i.e., the documents continuously repeating in an almost chanting manner the same descriptions; b) the social order of these practices. This allows me to unpack the position of the citizen-patient not only as envisioned within the sociotechnical imaginary at stake but in the messy process aiming to naturalize this vision. This is particularly important considering the connotation of participation and autonomy with *empowerment*.

4.1.2 Power Relations and Sociotechnical Imaginaries

As said, the concept of sociotechnical imaginary helps guide this analysis in taking the enactment of citizen-patient empowerment into account as embedded in a set of power structures. Technoscientific material solutions to a marked problem stem from a certain belief system while they stabilize this very system. The task of this thesis, answering the question of how the EC envisions CPE to be implemented, is not done in understanding the enacted meaning of empowerment through technologies to-be (e.g., what kind of patient behavior shall be facilitated using a certain technology). Yet it also demands as well as helps with understanding the power relations inscribed and restabilized through this vision and its realization. This, of course, connects to the vision of who is (held) responsible for what.

In the case of patient empowerment, this is a crucial point as it appears in two versions. On the one hand, the concept contains the vision of a power hierarchy, putting some actors in the healthcare setting, such as doctors or political decision-makers, in charge of citizen-patients who therefore need to be "upgraded" (i.e., empowered) by some other entity *equipping* them. In other words, to be empowered includes a subject that is not the empowered one but the one that already is in power and who does the empowering. In the case of this analysis, the EC enacts the step of empowering patients through envisioning future empowering practices. Simultaneously this establishes a stabilized set of beliefs the funding calls operate within as well as the power hierarchy between those doing the empowering and those being empowered. In detail, this can be used to ask how revision of responsibilities and how action and behavior of whom are imagined – and by whom. Here, I can note that in this case, this deterministic position is filled out by the EC and enacted through the envisioned technoscientific solutions.
This already refers to the second type of power hierarchies to be encountered in this case: the deterministic power the EC occupies in this arrangement in predefining the vision of empowerment. This deterministic, or discursive, power is conferred to "science" by deciding which project and research team funding is given. Therefore, by using sociotechnical imaginaries as a theoretical lens, this thesis is an example of asking "[...] how actors with authority to shape the public imagination construct stories of progress in their programmatic statements and how they blend into these their expectations of science and technology" (Jasanoff, 2015, p. 25-26).

Following the premise of co-production (Jasanoff, 2004) in the analysis helps to see how the particular envisioned technologies and practices, the *artifacts* of implementing empowerment are not only following the idea of what empowerment means but how it is influenced by the technological capacities and other interest related to these, such as being implementable into a market. Here, the impact of the linear innovation chain logic as an approach to future-making becomes crucial (Pfotenhauer & Jasanoff, 2017). The optimistic imaginary of a technoscientific future is accepted only if it is compatible with current market logic, integrating the improvement steps into a profit-oriented system. As stated throughout the funding calls, this aspect corresponds with the economic interest of implementing an empowering strategy by making the healthcare system more cost-efficient. Unpacking and outlining the entanglements of these aspects in detail is part of the aim of this work. In other words, how the logic of innovation is involved in co-producing the vision and practices of empowerment (see Chapter 4.2).

4.2 Perspectives on Innovation

Pfotenhauer & Jasanoff (2017) understand innovation as a pivot to sociotechnical imaginaries' capacity to perform their envisioned *effect*:

> Imaginaries of innovation can be seen, then, as epistemic and political resources for defining a community that shares a common (and hopefully better) sociotechnical future, and that is on its way to attaining it through innovation. Imaginaries provide a thread of continuity and stability by extending existing frames of reference from the past into the future, thus mitigating the unknown through what is known and taming the disruptive quality of innovation through what is imaginable and permissible in a given social, political, and historical context. (p. 788)

While the concept of innovation has been used as a theoretical lens to analyze the idea of the linear pipeline of research funding seeking industrial development and, preferably finally, commercialization, Pfotenhauer & Jasanoff (2017) described a shift of the concept into practical political application, performing decision making under claim for innovation. This decision-making process is future-directed, hence, performing future visions aiming to construct a path toward it in the present. Thus, studying the development, promotion, and implementation of processes of innovation becomes a fruitful site for investigating the enactment of a sociotechnical imaginary.
Therefore, besides recognizing the EC's clear confession to the innovation model underlying the funding intentions, mobilizing a lens of innovation theory helps identify the sociotechnical imaginary as being performed through the innovation approach in the first place. In other words, to unpack the sociotechnical imaginary of citizen-patient empowerment, it is useful and essential to recognize it as intertwined with the overall innovation approach pursued by the EC as what performs the sociotechnical imaginary at stake.

4.2.1 The Deficit Model of Innovation

To analyze the notion of empowerment as part of the sociotechnical imaginary performed by the innovation approach of the Horizon programs, I make use of Pfotenhauer´s et al. (2019) concept of the deficit model of innovation describing innovation as a political claim for development genuinely based on the identification of a "performance gap" (Pfotenhauer & Jasanoff, 2017, p. 786). Referring to the deficit model of public understanding of science and technology, addressing a negative conception of the public's understanding and attitude towards science as an obstacle to societal progression, Pfotenhauer et al. (2019) look more concretely into how the conception of innovation is constructed as a gap; from the vision of

the absence of innovation. In reverse, innovation is promised to overcome a defined deficit in society and functions as justifying the political decision-making following the linear model – hence, in regards to my case, justifying the funding of certain technoscientific developments. In other words, measuring the ability to perform successfully or failing in an area of social development – such as healthcare – depends on the ability to innovate. This ability is measured by the input given into research and development vs. the output (usually apprehended monetarily by the EC). Using this lens on innovation is crucial for understanding how the imaginary of healthcare referred to under the notion of citizen-patient empowerment is defined as shaped by the innovation imperative, defining possible approaches and cutting off others. Therefore, I use this model of tracing identified deficits as reasoning for citizen-patient empowerment.

Pfotenhauer et al. (2019) outline five dimensions showing the construction of the innovation deficit:

> (1) the kind of deficit that is being diagnosed, (2) the remedies proposed to address this deficit, (3) the forms of expertise considered legitimate in addressing the deficits, (4) the social orders implied by, or co-produced with, the proposed technoscientific solution, and (5) the standards of success and the corollary normative implications of the intervention. (p. 896)

I take up this categorization in different parts of the analysis, addressing the problem diagnosis at the beginning (Chapter 6.1.1 and 6.1.2) and looking at the proposed remedies (from 6.2 onwards). The heart of my analysis is in examining the implied social order and aiming to unpack its manifestation under the notion of empowerment.

Lastly, Felt & Fochler (2011), in their work on regimes of innovation governance, describe innovation with Akrich's (1992) concept of the *script* as "a complex translation-machinery that re-combines techno-scientific knowledge, artifacts, actors, institutions and governance structures to assemble techno-scientific futures" (Felt & Fochler, 2011, p. 312). Thereby, innovation is understood as a co-produced (Jasanoff, 2004) future-directed process, stressing the importance of not only looking at the various components and their entanglement but at how they are made interconnected, how the several components are translated into each other; hence, how the "translation-machinery" is performed. This accounts, for example, when tracing the connection between a certain technological function and the value(s) and future visions meant to be implemented by this function. Such a function could be the possibility to use an app for tracking one's own physical activity.

Analyzing the EC's innovation model by asking what vision or value is being performed by this technological orientation, and how the techno-scientific capacity facilitating self-tracking impacts the connected value, helps to identify the societal component of the imaginary. Therefore, using the concept of tacit governance through innovation (Felt & Fochler, 2011) further allows me to identify the social order implied by the deficit model, its fourth dimension as defined by Pfotenhauer et al. (2019).

4.2.2 Tacit Governance by Innovation

Felt & Fochler (2011) take up on the understanding that in order to have innovation unfold its full potential in a society, it is important to have the public on board, supporting its implementation. Based on the attempt to foster public engagement and thereby endorsement of techno-scientific development, what has been coined the "participatory turn" has been pursued, opening up the classical linear innovation model and involving the public through bottom-up approaches. These are meant to open up the process of decision-making, which is organized within the development of innovations. In short, a process that is linear and solely top-down, or as a network with potential for bottom-up impact. By analyzing citizens' understanding of the connection between innovation and governance, Felt & Fochler (2011) show how these different understandings of how an innovation process takes place impact the governing of a society – imagined as an innovation-driven society. Here, the different imaginaries of development processes differently envision which stakeholders, "techno-scientific knowledge, artifacts, actors, institutions and governance" (p. 312), and the public are involved in the decision-making, thereby envisioning differently who is responsible for what. They refer to these as "regimes of innovation governance" (p. 312).

Felt & Fochler (2011) end their analyses by pointing at the "[...] strong democratic consequences for contemporary knowledge societies [...]" (p. 324) due to the particular way a model of innovation allocates participation and responsibility among society. Further, they refer to these "regimes" as powerful by becoming institutionalized ways of governance, described as *tacit* forms of governance. By tracing the individual steps of innovation underlying the funding approach and how they are put in sequence with each other, I can identify the moment citizens are getting involved in the process and how.
Thinking about the model of innovation the EC follows helps to understand the position of the citizens and their involvement in the innovation process. This helps to understand the notion of empowerment as the term is genuinely used to position citizens and shows how they are entangled in the innovation approach. In other words, analyzing the "regime of

innovation," the imaginary of the very process of innovation the EC operates, tells a lot about the envisioned role of citizens and thereby helps unpack the imaginary of citizen-patient empowerment. It allows me to trace how the EC performs the ability to decide, and the responsibility given to citizens through the way the process of innovation is imposed. Chapter 6.2 is dedicated to understanding citizen-patients' role as defined by the EC´s innovation approach as tacit governance.

5 Methodology

To find out how the European Commission imagines citizen-patient empowerment within the research calls of *Horizon 2020* and its follow-up *Horizon Europe*, I am doing a detailed document analysis of parts of the accomplishing work programs (Table 1) and its corresponding materials (Table 2). This approach echoes Jasanoff's (2015) suggestion pointing to political documents as their argumentation is a great resource for entanglements between the stated aim and suggested implementation, hence the envisioned structure-agency relationship. For the actual analysis, I follow Kristin Asdal's and Hilde Reinertsen's (2022, also Asdal, 2015) practice-oriented document analysis approach, tracing how the issue of patients'/citizens' relation to (public) healthcare is taken up and modified into the "Sache" of citizen-patient empowerment. Within this process, they refer to the documents not only as a medium carrying the information but as crucial subjects in establishing and constituting the issue at stake. To discuss the role of the documents as a source of my research, I am starting this chapter with an explanation of my engagement with practice-oriented document analysis, then a discussion of my material as a performative subject – as an obligatory passage point (Callon, 1984) within the European research funding system. An overview of my sampling follows this before getting into the actual thematic analysis and presentation of findings.

5.1 Why Practice-Orientated Document Analysis?

Documents occupy a powerful position, particularly in a political context. They frame the issue at stake and thereby shape its meaning as well as "[...] eventually induce a change in routinized social practice, material arrangements, and normative obligations." (Felt et al., 2009, p. 25). The power of its impact relates to its scope and utilization (Asdal, 2015). As Chiapperino & Testa (2016) stated: "The pinnacle of this paradigm shift in the political imaginary of empowerment can be found in the vision of [personalized medicine] at the European level" (p. 207). Therefore, the EC's future-directed research programs occupy such a powerful position in being the EU´s key funding program holding a political imaginary

of a reality to-be. Following innovation's linear logic, this future *must* be facilitated through research and funding. The centerpieces applicants have to orient for receiving funding are the work programs documents and their wording also stressed by Jean Luc-Sanne, Policy officer of the *DG Research and Innovation* (V4).

Hence, the empirical focus of this research project is chosen due to documents occupying an interesting twofold position in present developments in European healthcare. First, the context of the documents, their position in creating and carrying a vision of healthcare, and second their textual content and how this modifies the subject of CPE. Asdal & Reinertsen (2022) acknowledge and combine both aspects in their methodology. They acknowledge the documents outside and their position as shaping the content and vice versa as they characterize documents threefold: as being an action, being relational, and being material – setting a certain action into a certain environment, interacting with it, and reacting to it.

5.2 About the Approach

Asdal & Reinertsen (2022) arrange their approach along six steps; six perspectives on how to do document analysis: documents as sites, documents as tools, document work, document texts, document issues, and document movements. As they describe, each of these perspectives allows for different engagement with the document's functions, and so not all apply to each research interest. The six approaches are a toolbox to choose from the best options for answering a particular question. I decided to go with three of them, documents as tools, documents as text, and document issues, particularly focusing on the document's context. These perspectives and methodologies are now used to situate the material before entering the fine-grained analysis.

5.2.1 As Tools

Thinking about the work programs as a tool means asking, "[W]hich world does the document actively seek to establish?" (Asdal & Reinertsen, 2022, p. 53). As the authors point out, one document can function as a tool in multiple ways, implementing various governing steps. In the case of the funding calls, I analyze my material as "tools of knowledge" (p. 45), transporting a certain understanding and specifying the structure of its following research. This aspect is central as "[t]he strength and impact of documents will depend on both their mode of use, their scope of reach and their context" (p. 44).

Hence, the envisioned utilization of documents in implementing CPE can be analyzed as a source of the understanding of the concept itself. The intended utilization is expressed in the documents but even better in the additional materials, the foremost of these being the videos that aim to guide applicants' approach to the documents. However, as Asdal & Reinertsen

(2022) point out, this function can fail. The content of a document reporting certain knowledge can be interpreted differently, and the intended structure for how to work with a certain document may be approached in various ways.
Here, my research is limited since I am not looking beyond the document itself on how the notion of citizen-patient empowerment is transformed when implemented in actual projects. Such would call for a much wider arranged research approach, including investigating the funded projects. Therefore, when I look at the work program documents and trace the contained notion of CPE, I am looking at the intended version, which has to be treated as unstable and momentary. I am looking for the intention implemented by the EC, and the version researchers have to stick to when applying for funding. Nevertheless, as the interpretative freedom of the documents is very limited in getting funding, this intended version is crucial to look at – which leads to the next approach.

5.2.2 As Issue

> Documents [...] contribute to the shaping and formatting of the case and the problem the documents deal with, the issue at stake. This happens in a range of different ways: by establishing and referring an issue, by drawing different elements together in a comprehensive argument, by presenting or not presenting alternatives for action, by what is being described, brought in and addressed, and by lining up how to proceed next with the issue at hand. Thus documents are not simply passively documenting something else. Rather, they are active elements that take part in forming issues – sometimes transforming issues into non-issues, killing them off, so to speak, by deciding there is no problem to deal with. (Asdal & Reinertsen, 2022, p. 104)

The described process of how an issue (*Sache*) is enacted in a document corresponds to the emergence process of a sociotechnical imaginary, as Jasanoff and Kim (2015) identify it. It is crucial that this performance in the case of CPE is organized to denote a problem and shape its solution following a future-directed innovation logic. This structure marks both analyzed work programs and is the main act in defining the subject as it enacts its impact and negates other definitions, stressing one solution and thereby silencing others, which means there is no funding for such approaches. In the case of CPE, this drastically concerns societal perspectives on health and health inequalities. This process can be traced by comparing the analysis outcome with the various understandings of citizen-patient empowerment outlined in Chapter 2.

Referring back to the structure, Asdal & Reinertsen (2022) suggest asking what is made governable by the way the issue is enacted in a document. Further, what may be newly made governable? I adapted this perspective as the working programs have no direct legislative power but rather are part of the process facilitating the definition of an issue and thereby making it integrable in a political structure, in this case, healthcare. Therefore, it is important to acknowledge not only the concept's elements but how they are envisioned to interact with each other. For example, as CPE also describes a certain behavior of patients, this conception can be understood as not only a defining modality of citizen-patient empowerment but also as a modality making people's behavior integrate into a legislative process and thereby defining the behavior.

As document context is one aspect actively shaping the document's topic into an issue, Asdal and Reinertsen (2022) stress taking it into account as a resource. In fact, they point to it as crucial, as taking the stated context for granted leads to the analysis becoming superficial. Not only does the context shape the issue as enacted in the document, but how the issue is contextualized in it also produces its context. Following Asdal & Reinersten (2022), I address this aspect in Chapter 6.1 and outline it briefly for the reader's understanding in 5.4.

For me, this point is a very fruitful source to look at within the work programs and in the complementary material. Further, this is something I, as a researcher, create myself when reading and analyzing my material, I contextualize it and thereby shape the perspective and outcome myself. On the one hand, that is something I cannot prevent; on the other, it is the very matter of my task of analyzing the *issue*. In making this step transparent, I aim to be as open and descriptive of my approach as possible before presenting what I identified as my results.

5.2.3 As Text

As I am interested in the notion of citizen-patient empowerment the documents express, I am very focused on the object of the documents as texts. However, as described in the two primer points, the practice-orientated approach by Asdal & Reinertsen (2022) allows me to pay particular attention to how the document is (intended to be) used, presented, and structured. Looking at the document as text in my case, therefore, also means looking at how the text is crafted, the structural aspect addressed in the layout of the text, such as the order of its subsections as well as the stylistic manner of speech, both forming the argument. Particularly the structure of the work programs is interesting as it is ordered in clearly outlining a problem followed by a proposed solution. This powerful structure creates a distinct future vision, co-producing its context and silencing other versions. This aspect

connects to the imagined audience of the work programs, which potentially applies to scientists for whom the document instead becomes a reference book where they can straitly look into their topic of interest. In other words, the text is not expected to be read as a whole and in one direction like literature.

This “matter-of-fact” writing style is adapted to the perspective of issues I borrow from Asdal & Reinertsen (2022), (p. 109). The authors describe this style as creating trust in the reader. It will be useful to remember when looking at how the concept of citizen-patient empowerment is performed. The structure of this writing style can be found throughout the documents, but I put this sequence here as an illustration:

> Citizens of all ages stay healthy and independent in a rapidly changing society thanks to healthier lifestyles and behaviors, healthier diets, healthier environments, improved evidence-based health policies, and more effective solutions for health promotion and disease prevention.(HE, p. 11).

promise
context
performance

I combine the textual analysis by Asdal & Reinertsen (2022) with Valve et al., (2022), allowing to identify between descriptive sequences containing definitions of what CPE is and sequences alluding to the intentions of the European Commission; the envisioned improvement. The second type includes descriptions of envisioned final changes and the process undertaken to pursue them. In the means of enacting reality, Valve at el. (2022) speak of ordering effects such documents perform, referring to how these documents structure the reality they set up and operate with. Therefore, it is essential to identify the moments and components which work together in creating these orders. The authors mention two such types: (1) legitimation resources, to which documents refer in stabilizing their perspective and (2) ordering concepts, which refer to within the document stabilized relationships between components. This may be the relationship between improved health and digitization or patient empowerment and technological devices.

5.3 Sampling

The sampling process started with the two most current and substantial working programs of H2020 and HE (Tabel 1). From there, several complementary materials that could be found in clear connection to them and/or the EC have been collected and checked for possible insights on CPE. The final selection of complementary material is listed in Table 2.

Table 1: Main material

Document 1: Horizon 2020 Work Programm (H2020): European Commission (2020, 17 June). Decision C(2020)4029 Horizon 2020. *Work Programme 2018-2020: 8. health, demographic change and wellbeing.* Retrieved from https://ec.europa.eu/research/participants/data/ref/h2020/wp/2018-2020/main/h2020-wp1820-health_en.pdf
Document 2: Horizon Europe Work Program (HE): European Commission (2021a, 15 June). Decision C(2021)4200 *Horizon Europe. Work Programme 2021-2022: 4. health. Retrieved from* https://ec.europa.eu/info/funding-tenders/opportunities/docs/2021-2027/horizon/wp-call/2021-2022/wp-4-health_horizon-2021-2022_en.pdf

Table 2: complementary material

Document 3 (D3): PerMed (2015, June). *Shaping Europe's vision for Personalised Medicine strategic research and innovation agenda (SRIA)*. Retrieved from https://www.icpermed.eu/media/content/PerMed_SRIA.pdf
Document 4 (D4) European Commission (2018, 25 April). Communication from the Comission to the European parliament, the council, the European economic and social committee and the committee of the regions: on enabling the digital transformation of health and care in the Digital Single Market; empowering citizens and building a healthier society. Retrieved from https://eur-lex.europa.eu/legal-content/EN/TXT/PDF/?uri=CELEX:52018DC0233&from=EN
Document 5 (D5): European Union (2020, February). Shaping Europe's digital future. Retrieved from https://ec.europa.eu/info/sites/default/files/communication-shaping-europes-digital-future-feb2020_en_4.pdf
Document 6 (D6): Directorate General for Research and Innovation (2021). Horizon Europe: strategic plan 2021 2024. *Publications Office*. https://data.europa.eu/doi/10.2777/083753
Document 7 (D7): European Commission (2021b). Mission on Cancer: implementation plan. Retrieved from

https://ec.europa.eu/info/sites/default/files/research_and_innovation/funding/documents/cancer_implementation_plan_for_publication_final_v2.pdf
Document 8 (D8): Research and Innovation *(2021, 28 September).* Getting fit to fight cancer. Retrieved from https://ec.europa.eu/research-and-innovation/en/horizon-magazine/getting-fit-fight-cancer
Document 9 (D9): European Commission (2022, 12 April). Annex: Annex II to the Commission Implementing Decision amending Commission Implementing Decision C(2021) 4793 final of 24 June 2021 and Commission Implementing Decision C(2022) 317 final of 14 January 2022 on the financing of the Programme for the Union's action in the field of health ('EU4Health Programme') and the adoption of the work programmes for 2021 and 2022 respectively. Retrieved from https://health.ec.europa.eu/publications/2022-eu4health-work-programme_en
Document 10 (D10): Digital Health Europe (2021, July). Recommendations on the European Health Data Space: supporting responsible health data sharing and use through governance, policy and practice. Retrieved from https://digitalhealtheurope.eu/wp-content/uploads/DHE_recommendations_on_EHDS_July_2021.pdf
Document 11 (D11): European Commission (2022, 3 May). Proposal for a regulation of the European Parliament and of the Council: on the European Health Data Space. Retrieved from https://eur-lex.europa.eu/resource.html?uri=cellar:dbfd8974-cb79-11ec-b6f4-01aa75ed71a1.0001.02/DOC_1&format=PDF

5.4 About the Work Programs

The current *Horizon Europe* health cluster has been developed together by the Directorate General for Research and Innovation and the Directorate general health and food safety, as two of the EC's 56 Departments and Executive agencies. First, the EC published its strategic plan, presenting the scoped impacts of the funding program, then translated them into a single defined scope as the destination of all the sub-projects in the work program. This clearly states that the work program is structured and formulated with the aim of communicating what the EC wants to research, innovate, achieve, and develop as an outcome under this funding thus setting a clear stipulation. Besides the two most current funding programs following the ECs cycle of the framework programs, the Commission recently established two more departments delegated with health research funding, the

European Health and Digital Executive Agency (HaDEA) and the *EU4Health program* (€5.3 Billion) (D9) developed to ensure that research outcomes from *Horizon Europe* are getting implemented into the health system(s). It has become the central strand for funding "health innovation," defined by annual work programs.

The commission constituted the HaDEA on 16 February 2021, being in function until 31 December 2028, which has been delegated to managing EC funds in the named areas, supervising a budget of over €20 Billion, subsuming the grant programs under its review – *Horizon Europe* being the most significant part. It focuses on the implementation of the funding programs rather than its legislation, which falls to the EC. In short, while the EC formulates the Horizon work programs, the executive agency has been established to manage the funding money. Having the supervision of the fund health research delegated is a novelty in the EC´s funding structure.

Otherwise, on a more micro level, the two Horizon programs are structured very similarly. *Horizon 2020*, with a total volume of nearly €80 Billion, is divided into nine sections; the third section, "Societal Challenges," lists seven sub-sections, with the first being "Health, Demographic Change and Wellbeing" (Figure 1).

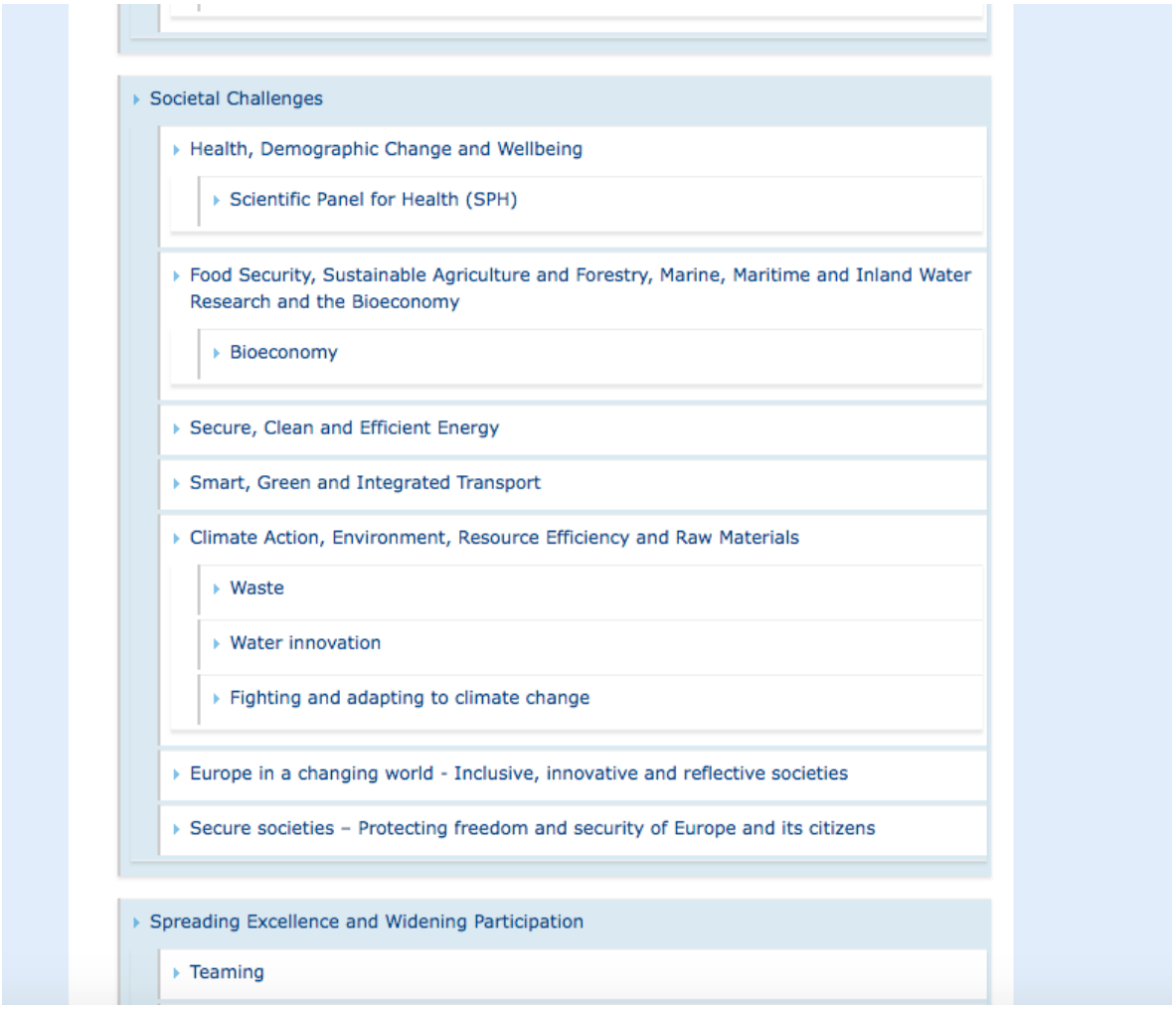

Figure 1: Screenshot of *Horizon 2020* webpage, listing the sections with subsections, https://wayback.archive-it.org/12090/20220124080624/https://ec.europa.eu/programmes/horizon2020/h2020-sections

The webpage of this subsection lists links to all topic-related activities under *Horizon 2020* as well as the work programs. The timespan of *Horizon 2020* (2014-2020) has been divided into three periods, 2014-2015; 2016-2017; 2018-2020. Each period is covered by its own work program document, whereas the most recent one also constitutes the most comprehensive one. The work programs of the subsections are further subdivided into different topics, finally listing the individual sub-projects.

In comparison, the overall structure of *Horizon Europe* (€95.5 Billion) changed and already illustrated the increased emphasis on innovation. The sections have been replaced by three "pillars," where the second one, "Global challenges & European Industrial competitiveness," contains "Health" as its first so-called Cluster (Figure 2). The work programs themselves are further subdivided into "Destinations," referring to different topical focus eras and listing the sub-projects (Figure 3), similar to *Horizon 2020*.

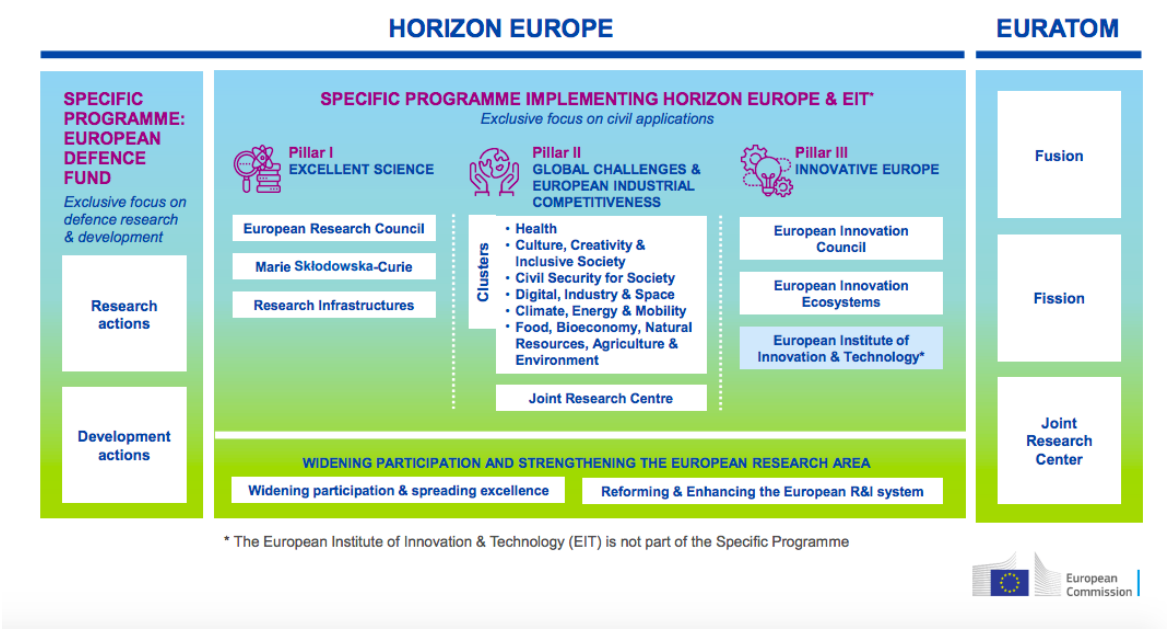

Figure 2: Screenshot of Horizon Europe Structure from Horizon Europe Factsheet, https://research-and-innovation.ec.europa.eu/system/files/2022-06/ec_rtd_he-investing-to-shape-our-future_0.pdf

Figure 3: Screenshot of *Horizon Europe* Work Programme 2021-2022 Table of Contents, showing the document´s internal structure of Destions and Sub-projects (HE, p. 4)

So far (Summer 2023) two work programs have been published, 2021-2022, and in March 2023 the period 2023-2024. At the point in time when I conducted this analysis only the first one was available. To be as accurate as possible with my sampling and the time span I am

looking at, I chose the latest work program of *Horizon 2020* and the first one of *Horizon Europe* available.[1] Still, it is also crucial to stress again that, due to this focus, the observations my analysis is based on are a snap-shot. Nevertheless, as I am looking at the constitution of a particular vision as a sociotechnical imaginary, it has been essential to include several complementary materials, allowing me to trace and compare the notion of citizen-patient empowerment beyond the work programs – as a comparison is also stressed as the methodological approach by Jasanoff (2015). As Asdal & Reinertsen (2022) suggest, paying attention not only to the textual content but to the context and mode of use of a document, how a document connects and detaches from other sites referring to the same topic is crucial for comparing those sites and looking at their interrelatedness.

Beyond the formal embeddedness of the work programs' content, it is essential to acknowledge the context of the work programs as one of the powerful relations. They create realities to which scientists agree and respond as they adopt the one created in the EU Commission document, develop it further in their research, and return their version back to the commission as a means of enacting the reality further into legislation. This intended connection between the work programs' guided research and future policy objectives is stressed, e.g., by John Ryan, Director of DG Health and Food Safety (V1, also see V2 stressing to address policymakers with strategies to improve health literacy). The document's field of action, therefore, is a political one. In detail and referring to Dalglish et al. (2021), the political documents I am focussing on are implementation and working documents.

Prior (2007) defines documents according to their belonging to a field of action. In my case, this field of action is an intersection of interpretational sovereignty and determinative power, in this case being the democratically empowered position to provide money to some research projects instead of others due to their accordance with the EU commission's vision of a promising future. Understanding the field of action (Prior, 2007) as a process, the documents are impactful stages, the stage of *embedding* (Jasanoff, 2015), in the development process of a future imaginary of healthcare and being a citizen-patient, leading the way for a particular vision of empowerment. Therefore, the documents chosen as my sample represent the process of co-production (Jasanoff, 2004) of life science and the law

[1] *Horizon Europe's* work program for 2023-2024 has not been thoroughly analyzed within the scope of this thesis, but – based on skimming – the topics are very similar to HE 2021-2022. The terminology of empowerment is used 21 times (less than HE, more than H2020) where descriptions of various aspects of empowerment in these documents remain the same in support of digital health innovation and data-based approaches. I add this note not as factual but to stress the continuity of the prevalence of this topic.

(Jasanoff, 2011), performing the vision of favored public healthcare by empowering citizen-patients.
On the one hand, they are tools of communication, initiating research schemes feeding back into the set vision of empowerment. On the other hand, the documents themselves are grounded in such research. The process leading into these documents is one of selecting certain imaginaries and continuing them. Therefore, and speaking with Valve et al. (2022), I am approaching them as political documents as they "[...] put governmental intentions into circulation while, at the same time, performing ontological, modifying work [and] materialize governmental intentions" (p. 69-70). The funding calls especially do so by providing well-financed research opportunities. Therefore, the wide reach of power of these documents must be kept in mind when analyzing them.

Last, in this overview of important aspects marking the documents' context, I want to point to the embeddedness of the emphasized future healthcare vision in the context of "[...] the twin green and digital transition [...]" (D5, p. 5). This intertwined approach of transforming Europe and its societies – the green deal and digitalization – is set as a base throughout *Horizon Europe* and when looking into documents sourcing from the EC in recent times in general. Sustainability is acknowledged as a crucial matter of the present and near future while digitization is seen as key to it, also in the Health Cluster: "Enhancing development and uptake of innovative health care services and solutions, including environmentally sustainable ones that contribute to the European Green Deal" (HE, p. 105). The digital transition is marked by the argument that it is needed to improve citizens' lives and strengthen the European economy: "Our future prosperity and well-being will largely depend on it" (D5, p. 5). This constellation is a huge and complex topic in itself, but it is important to embrace this observation as the base from which the EC argues when encountering arguments like: "The European Union has the ambition of empowering European citizens with digital solutions rooted in our common values and enriching the lives of all of us. Horizon Europe will help shape innovative technologies and solutions for healthcare, [...]" (D5, p. 9), or, "[t]he digital transformation of health and care will certainly help to increase the capacity of health care systems to deliver more personalized and effective health care with less resource wasting" (HE, p. 7).
Emphasizing digitization in healthcare and stressing its potentials (such as personalization and better resource efficiency) are arguments in line with framing innovation as the overall panacea, as Pfotenhauer & Jasanoff (2017) have outlined. In other words, these arguments are generalized ones, not case-specific. Hence, they mark a significant position in the context of the documents and technology-based CPE and therefore are discussed in more detail at the beginning of my analysis (Chapter 6.1).

5.5 Videos

Besides the additional material informing the Horizon funding, particularly the health section, I also included video material on the *Horizon Europe* Cluster 1 (Health) section. These videos are provided and accessible by the YouTube channel “EU Science & Innovation." When I speak of videos here, I do so because I encountered this information source in the format of videos. In fact, to be more precise, they are recordings of online hold info sessions held on July 21 and October 28 of 2021, as online meetings with the intention to inform potential applicants about formalities and contents as well as answering their questions.

5.5.1 Materiality: Pieces of Communicating a Certain Reality

Though these recordings include moving visuals of people speaking in front of their webcams and stills of presentation slides, shown via screen sharing (see Figure 4), the technical components of a classical movie, such as zooms, cuts, and camera movement, are neither present nor set by a particular intention. Rather, the material packaging is guided by the intent to facilitate information exchange from *the EC* as *the author* of the funding call to possible applicants. Hence, I am not particularly interested in the layer of the sensory experience (Rose, 2016) of watching the videos, but I am interested in the spoken and material representation of the content. In other words, I adapt my approach in analyzing these materials to their set intention, being set situations and archived materials of communication, working with the tools of speech and slide presentation. What I did not take into account, therefore, were elements such as background or display details and any change of scenery or sound. Still, I pay attention to the visual situation of an argument. Greenwood et al., (2019) work on analyzing visual rhetoric guides my approach as it helps to analyze the graphical processing of the video's narrated content – the slide used in the video presentation. It does so by pointing me to the signs and their usage for communication.

I chose this focus due to the materiality of the videos being presentation recordings. Hence, they are in their material mostly one-directional communication. I say one-directional despite the video calls using *slido.co*, an application making it possible to ask the lecturers written questions, which were then shown via screen sharing and discussed in all the online information meetings. Thus, possible applicants were able to ask questions of understanding, but the structure did not allow for any exchange or discussion of the topics. Rather, the intention was to make sure that applicants understood the intended meaning of the work programs to keep their applications as close to such as possible.

5.5.2 Video Analysis

First, I did a broader sampling of videos in advance and defined the actual relevant material after the first round of coding my central material, the funding work programs. From there, I was able to decide which of the gathered videos were promising. I focused on the general information videos and the ones particularly presenting *Horizon Europe* - Cluster 1 destinations discussing CPE due to the former document coding: Destination 1 (“Staying healthy in a rapidly changing society”), 4 (“Ensuring access to innovative, sustainable and high-quality health care”), 6 (“Maintaining an innovative, sustainable and globally competitive health industry”), as well as destination 3 (“Tackling diseases and reducing disease burden”), and 5 (“Unlocking the full potential of new tools, technologies and digital solutions for a healthy society”) though they only address the topic partly. I have not included Destination 2 (“Living and working in a health-promoting environment “) as CPE is not discussed in this work program chapter. Here it is important to note that the funding of HE is organized in different stages. The analyzed online information only covers the projects funded within the first stage of HE, starting in 2021, hence overlapping with the work program analyzed. I ended up with a sample of 15 information videos, with which I proceeded as outlined in the following.

To keep my approach coherent with the document analysis and treat the video material not as separate but as additional information, I used a similar content analysis approach. As a result, I could stay within my developed set of codes and merge my findings more correspondingly. To do so, I did not transcribe the whole video but first identified sequences relevant to my topic by watching and taking notes. First, because much of the presented content was unrelated to my research interest, and second, transcription does not allow me to see the interpreted content as being co-constructed by spoken word and presented image. Instead, I transcribed selected sequences and included them in my material for coding. I further took screenshots of these sequences, foremost showing presentation slides. When analyzing the coded video materials, I paired them with the screenshots (see Figures 4 & 5) and referred to these materials correspondingly. When finally choosing the most relevant material from the video analysis and including it in the final analysis, I re-watched the particular video to make sure not to miss out on any intentions preceding parts that might impact the sequence I am focusing on. In the end, after several rounds of refining my analysis, keeping only the most significant quotes and snippets, most of the video source has been excluded in favor of more illustrative sequences. Nevertheless, analyzing the 15 videos this way has been an important step to understanding the innovation model the EC is operating on within their funding approach as the connection of visual representation

accompanying the account of the “impact-oriented” approach. Therefore, in the final version of the thesis, I use the video material foremost to outline this aspect in Chapter 6.2.

5.5.3 Video Sampling

Video 1 (V1): EU Science & Innovation. (2021a, 21 July). *Horizon Europe Info Days 2021 | Cluster 1 | Welcome [Video file].* Retrieved from https://www.youtube.com/watch?v=qjSzq7WgOLA
Video 2 (V2): EU Science & Innovation. (2021b, 21 July). *Horizon Europe Info Days 2021 | Cluster 1 | Destination 1 [Video file].* Retrieved from https://www.youtube.com/watch?v=t_BVrog2tLs
Video 3 (V3): EU Science & Innovation. (2021c, 28 October). *Horizon Europe info-days - Cluster 1: Destination 3 [Video file].* Retrieved from https://www.youtube.com/watch?v=iKUDo8Ia5EI
Video 4 (V4): EU Science & Innovation. (2021d, 21 July). *Horizon Europe Info Days 2021 | Cluster 1 | Destination 6 [Video file].* Retrieved from https://www.youtube.com/watch?v=W2jH_QoZQ3U

5.6 Data Analysis

To identify the “issue,” Asdal & Reinertsen (2022) suggest starting at an important point and tracing it from there throughout the connected material. In my case, this means starting with the working programs. After coding those, I was able to identify which additional materials were of interest to me. Either through being referenced in the main materials or due to the topic and position of a document.

Still, in parallel to collecting my materials, I started reading, mostly to decide whether a certain document should be considered in the analysis. Throughout this process of material collection and preliminary note-taking, I also developed my final set of research questions. Proceeding with what Rivas (2018) calls the “zigzag approach” (p. 432) allowed me to get a better overview of the topic at stake and elaborate on my approach. Familiarizing myself with the materials first allowed me to adapt my coding analysis approach in alignment with my materials, understanding how to approach them to best possibly inform my research interest. Consequently, I started coding the two documents at the center of my interest, the work programs, using *Atlas.ti* software, allowing me to mark quotes, and code sequences, write

memos, connect codes, and compile lists of sequences of a certain code very easily. I intended to make this first attempt only doing in-vivo coding. However, while reading, I started to code in an attempt to answer a particular SQ. Hence, coding not only the content of a sequence but its function within the whole text as well. When noting the recurrence of this intention, I immediately decided to develop codes regarding my five SQs: *context, agency/ performance, promised benefits, opposites, and metaphor*. As a result, the coding has been conducted by a mixed approach of marking sections in relation to my SQs and in-vivo coding.

This step has turned out to be very fruitful as it allowed me to identify content from the text addressing patient empowerment as a certain kind of textual structure (referring to Asdal, 2015), fulfilling a particular form of identifying the topic within the text. For example, sections expressing a future perspective, describing certain promised benefits as: “[...] creating a more resilient, inclusive and democratic European society [...].” (p. 11), or sections viewing the context of the measurement are being situated for example when the work program continues to address such as “Europe in times of change” or certain economic stress: “[...] the demand for health care services as well as the budgetary pressures on health care systems are and will keep increasing.” (p. 126), coded as “economic aspects." Therefore I usually applied multiple codes to one sequence, determining its content as well as its structural functionality.

Further, I simultaneously gathered all my notes in a separate document. This also allowed me to compare statements from the videos about the work program with the actual work program. After I finished the first round of coding the work programs, I did the complementary materials. After that, I conducted another round of coding my main materials in a deductive way, looking for sequences fitting the codes generated through the in-vivo coding of the complementary materials. I also started to group my codes according to my SQs and extracted a list of the referring coded citations from *Atlas.ti*.

Groping my coded sequences according to the topics I have defined as an important piece establishing the overall imaginary of CPE when refining my SQs has allowed me to identify which topics (generated through the in-vivo coding) inform which part of the empowerment imaginary. I thereby could identify if sequences on topics emerging in-vivo, like “aging society,” are recurring in regard to promissory future scenarios (promised benefits) or as an evaluation of the current situation (context). Still, when starting to identify particular significant sequences and generating lists of such for my analysis, I based this decision and the ordering of sequences on re-reading the coded section. By picking the most significant quotes, connecting them, and starting to transfer and generate new notes connecting sequences, I realized my final analysis.

5.7 Ethical Considerations

In my research, I only analyze publically available material, such as publications by the European Commission and video material provided via the EC's YouTube channel. These documents are publically available and foremost created for communication, hence directed to a particular public sphere to explain and transmit specific content. On the one hand, this makes it very compatible from an ethical point of view regarding data usage and management. On the other hand, I have to be careful about what material I am considering since my thesis focuses on a sensitive topic. It addresses people's individual and everyday life in regard to health and healthcare but from a specific point of view. Here, it is crucial not to generalize this perspective and mix it up with one of the potentially affected individuals since I am not taking their opinions into account. Further, my materials talk *about* citizens and citizens as patients but, though being publically available, not directly *to* them in a general way but to researchers potentially applying for funding. The work programs should give them guidance on the aims of their application. This content and its structure refer to the "impact-orientated structure" of the EC's research funding, meaning to define research interests according to their scope and scope according to what is identified as needed in the future. This act, defining the impacts which should be aimed for and which should be facilitated with research, is actively set by the EC. Therefore, when analyzing statements from my gathered material, I have to reflect on the position this is coming from as well as the direction these materials are speaking to (being excellently guided to do so by following Asdal & Reinertsen's (2022) approach).

Another point connected to research ethics is my position and perspective. Throughout the process, my thesis has become a piece of criticism, although not intended. This is due to the criticism stated on the topic that I have been referencing. Based thereon, I outline omitted aspects of CPE that have been addressed by former research but not taken into account in the funding calls. I also trace the connection between the EC's economic interests in future public healthcare and how they supersede societal aspects. Still, this intense engagement with the topic has informed my own opinion, and while I base my argumentation on findings from my literature research, it is me who draws the connections and guides the focus of my analysis. Through my work at the Smart4Health project, I was engaged in the topic of European research funding on digital health and the basis for the research process aiming for CPE - all of which is beyond the scope of my thesis. Though my work and thesis were not deliberately connected, both learnings mutually impacted each other. Similarly, my involvement in the patient organization ÖG ME/CFS (Österreichische Gesellschaft für ME/CFS; Austrian Association for ME/CFS) has sensitized me towards patient perspectives on healthcare. Therefore, I aimed to be extra reflexive about my personal opinion at each step. Continuing to reflect on my position within the research process has not only helped

with potential biases in my conclusion but also impacted my methodological approach, hence the adjustment I made throughout the process to build my analysis out of my materials and not based on them. Therefore, reflecting on my positions, my opinions, and my (former) knowledge on the topic has been important in research ethics and further in developing an enhanced approach, allowing me to engage more in-depth with my materials.

6 Analysis

After outlining the current debates around empowerment in the health domain (Chapter 2), defining my research interest (Chapter 3), and how to address it best theoretically (Chapter 4) and methodologically (Chapter 5), I can now start the actual analysis. As presented through my state-of-the-art, the discourse on citizen-patient empowerment is not new but is picked up by the EC and implemented into the work programs. In looking at how this has been done – how the sociotechnical imaginary of future healthcare is approaching the notion of empowerment – it has been helpful to at first gather a better understanding of the backdrop against which empowerment is praised as a need and solution, following the deficit model of innovation (Pfotenhauer et al., 2019). Therefore, in Chapter 6.1, I look at the issue at stake, citizen-patient empowerment, as modified in the documents through how the reality it is embedded in or introduced to is presented. Understanding this, what I refer to as the context of the issue, is important as it modifies the issue by rendering it exclusively (Asdal, 2015). Hence, by attaching empowerment to some contexts through the documents, it is detached from others and thereby defined (Asdal & Reinertsen, 2022).

In Chapter 6.2, I further trace the concept of innovation the EC pursues, coined as impact-oriented. There, I address how the social structure of the envisioned future health care is produced by the very approach to innovation and what role citizens are referred to in it using Felt & Fochler's (2011) understanding of tacit governance through innovation. This further allows me to show how the scope of citizen participation, as an essential aspect of empowerment, is defined as data practices by the premises made for future healthcare through innovation.

Following the imaginary of citizen-patient empowerment from a rather macro (contextual) to a micro (action) level in my analysis, I look at how these promised improvements, displayed as reactions to the identified gaps, are configured in detail in Chapter 6.3 by discussing the different components associated with empowerment in the work programs and how they are envisioned to be performed.

6.1 Context and Surrounding Discourse: Of Challenges and Crisis

Before looking at the detailed understanding of empowerment in the work programs, I want to take a step back and look at the bigger picture by asking: "*What context is the notion of citizen-patient empowerment embedded in?"* (SQ1). I put this step first for two reasons. First, to unpack the vision of future healthcare presented and pursued by the EC, it has been useful to follow the structure of argumentation built into the work programs. This structure does not come by arbitrariness but follows a clear order of defining the problems at stake, followed by the envisioned solutions, stressed as an "impact-oriented" approach. In this structure, the notion of empowerment is introduced as part of the solution. Further, understanding the notion of empowerment within this given structure, the context outlined initially in the work programs functions as a *modifier of the issue* at stake (Asdal, 2015). Here, what I refer to as the context put at the beginning corresponds to Asdal & Reinertsen´s (2022) approach of looking at documents as performing an issue. Tracing the context as a line of argumentation is viewed as the process of modification. De- and attaching the issue at stake to certain contexts and not others is a defining step, helping to identify the boundaries created by the EC on citizen-patient empowerment.

This step is significant since the usage of the terminology of empowerment in the health context has been manifold (Chapter 2) and therefore has been criticized as lacking clarity (e.g., Castro et al., 2016; Cyril et al., 2015; Karni et al., 2020; Morley & Floridi, 2019; Rappaport, 1981; Risling et al., 2017). Hence, as the practice referred to by the term empowerment has not been completely stabilized before being taken up by the EC, this stabilization had to be performed within the Horizon programs to have the term "empowerment" become useful in transmitting the aimed imaginary of healthcare successfully under the usage of this terminology.

This effort is best, but not exclusively, found in the work programs' introductory sections setting the stage for further propositions. These sequences start with a general embedding of the envisioned projects in the presence of "challenges and crises." Here, the EC makes an *inventory* of the crises that *are* and the crises to *become*. Hence, the inner logic performed by the "impact-oriented approach" is grounded in a narrative of futures to be avoided (Jasanoff, 2015). Setting this ground, the work programs stick to this logic throughout the separate sections, not advocating the need and benefit of a specific measurement by possible improvement or desirable but, as needed, as escape mechanisms. In creating this structure, the notion of empowerment is attached to some of the envisioned challenges either as a solution or as an outcome of the solution proposed.

6.1.1 "The Rapidly Changing Society"

The narrative of the challenge as a general context of the EU's healthcare approach goes before the specific funding projects. The Strategic Research and Innovation Agenda for Personalized Medicine (PerMed SRIA) is a "Coordination and Support Action" (D3, p. 2) that has been funded by the EC's 7th Framework Programme for Research, the one before H2020, speaks of five *challenges* (Developing Awareness and Empowerment, Integrating Big Data and ICT Solutions, Translating Basic to Clinical Research and Beyond, Bringing Innovation to the Market, and Shaping Sustainable Healthcare). Compared to using the word in the Horizon programs, "challenges" in the *PerMed SRIA* are defined as possible obstacles within the aimed development and implementation of – what is defined as best – practice in personalized medicine. Hence, challenges are not defined particularly as a lack of health, prevention, or care structures but as hindrances to developing better prevention strategies and care structures.

The deficit logic of innovation, understanding the obstacle to social progression as a lack of innovation, has been performed in a rather classical sense. Hence as described by Pfotenhauer et al. (2019), as with SRIA, the understanding of challenges exemplifies this logic of identifying a deficiency of innovation and further arguing for innovation based on this diagnosis. Compared to the Horizon programs, the outlining of the potential challenges becomes less directly tied to a deficiency in innovation but beforehand depicted as threads, sourcing external and internal of the European society:

> Europe is facing four main healthcare challenges: (i) the rising and potentially unsustainable health and care costs, mainly due to the increasing prevalence of chronic diseases, to an ageing population requiring more diversified care and to increasing societal demands; (ii) the influence on health of external environmental factors including climate change; (iii) the risk to lose our ability to protect the populations against the threats of infectious diseases; (iv) health inequalities and access to health and care. (H2020, p. 7)

While societal and environmental factors are still prominent threads for the population´s health in H2020, they continuously disappear throughout HE. Both spot an increased healthcare demand in the future due to demographic changes, in H2020 it is foremostly aging, and in HE it is foremostly an increase in chronic conditions. In HE, integrated into the narrative of the demographic challenges are several conditions particularly addressed, mainly regarding the rising numbers (either actual or estimated) of affected persons. These include non-communicable diseases (HE:

HORIZON-HLTH-2022-STAYHLTH-01-04-two-stage: Trustworthy artificial intelligence (AI) tools to predict the risk of chronic non-communicable diseases and/or their progression), primarily referring to obesity (HE: HORIZON-HLTH-2022-STAYHLTH-01-05-two-stage: Prevention of obesity throughout the life course), but also mental health (HORIZON-HLTH-2022-STAYHLTH-01-01-two-stage: Boosting mental health in Europe in times of change), and significant cancer and its prevention: “With an estimated 30-50% of avoidable cancers, it is a leading cause of premature death, reducing a country’s productivity.” (H2020, p. 58; also see HE, HORIZON-HLTH-2021-DISEASE-04-01: Improved supportive, palliative, survivorship and end-of-life care of cancer patients; HORIZON-HLTH-2021-CARE-05-02: Data-driven decision-support tools for better health care delivery and policy-making with a focus on cancer; also se D7 & D8).
Exceptions are defined in referring to the COVID-19 pandemic causing “new challenges” and unveiling older ones. COVID-19, and the potential future of unknown challenges are generally situated on a broader scale, to be addressed systematically rather than facilitating individual response, thus viewing citizens as demanding solutions rather than being actively involved in them:

> In particular, the COVID-19 pandemic has highlighted existing structural weaknesses in health and care systems and emphasized areas where not enough effort, planning and resources had been directed to. In addition, rapid technological and societal evolutions call for urgent responses to increasing demands and expectations from citizens. There is a need to accelerate the transition towards more efficient, sustainable, resilient, innovative and accessible health and care systems in Europe. (HE, p. 130)

These cases, located on a meta-societal level, do not operate with the notion of empowerment. Hence, I do not further discuss them within my thesis; while the topic of citizen-patient empowerment is highly present in the Horizon programs, I want to clarify that this does account for a major part of the sub-project but not all of them.
Nevertheless, within the addressed range, the EC lays out a more vague but potential ground for further challenges to be spotted in, what is coined, the “rapidly changing society” (HE). Here, in addition to the known crisis, citizens' behavior is defined as an obstacle and potential challenge, foremost as a forecast of behavior changes in lifestyle categories such as diet and physical fitness, focusing on the “personalized challenges.”

> Moreover, people's health can be impacted by a rapidly changing society, making it challenging to keep pace and find its way through new technological tools and societal changes, which both are increasing demands on the individual´s resilience.
> [...] In this work programme, destination 1 will focus on major societal challenges that are part of the European Commission's political priorities, notably diet and health (obesity), ageing and demographic change, mental health, digital empowerment in health literacy, and personalised prevention. (HE, p. 12)

This narrative creates a double urge for the EC to face change as a potential for improvement as well as a potential crisis to be avoided (Jasanoff, 2015). Simultaneously the source of these "challenges" is situated in a very vague area potentially "out of reach" for the EC; e.g., socio-economic changes throughout society and climate change are *out there* while, in contrast, a home-made threat is observed in the behavior of the "own" society, in citizens' maladaptive lifestyle. In other words, the (potential) challenges stem from a context that is described as disconnected from the EU's institutional performance in the first place. The potential problems are viewed as tasks and by no means as potentially co-produced by other societal circumstances. Put simply, issues are observable, and the EC has to react to them. "Destination 1 – Staying healthy in a rapidly changing society" of the HE program is an exciting point to look for how the EC unfolds these initial logics on how to react. The thread of people potentially becoming sick is responded to with measurements leading to changing behavior – and this is when the notion of empowerment is introduced:

> Citizens adopt healthier lifestyles and behaviors, make healthier choices and maintain longer a healthy, independent and active life with a reduced disease burden, including at old ages or in other vulnerable stages of life.
> Citizens are able and empowered to better manage their own physical and mental health and well-being, monitor their health, and interact with their doctors and health care providers.
> Citizens´ trust in knowledge-based health interventions and in guidance from health authorities is strengthened, including through improved health literacy (including at young ages), resulting in increased engagement in and adherence to effective strategies for health promotion, diseases prevention and treatment, including increased vaccination rates and patient safety. (HE, p. 14)

Here, the context is somehow *absent*. In other words, within the documents, health is completely situated as determined within each individual and their behavior by disconnecting it from broader societal issues. By disconnecting the absence of health from a broader

context but tying it to individuals exclusively, the issue (Asdal & Reinertsen, 2022) of future health and healthcare is based on a lack of citizens´ healthy behavior.
Further, “the rapidly changing society” is not defined precisely regarding how the named changes affect society, nor who is exactly meant by the terminology. Still, what is observable is that the change in the rapidly changing society is partially understood as how the society(s) of the European Union have interconnected through digitization and how this impacts individual behavior, as well as referring to demographic changes. This addresses areas such as citizens who age, get sick, or, worst case, get older while getting sicker, becoming a threat to “society” by increasing the cost of public health care. Compared to the “crisis,” a threat calling for change, the “challenge” here becomes a starting point for introducing potential solutions.

Within the Horizon programs, the deficiency of innovation is less presented as a gap to be filled in favor of general social progression, but moreover, as an urge to act in order to avoid future challenges and crises: “Europe must invest in research, technology, and innovation to develop smart, scalable and sustainable solutions that will overcome those challenges” (HE, p. 7). In other words, though, the “changing” society becomes a threat and a possibility at the same time – a crisis for financing care and a challenge as a possibility for improvement of life through technoscientific innovation, the deficiency of innovation is evermore identified based on the forecast of “futures to be avoided” (Jasanoff, 2015). Still, these potential future crises are identified as a result of deficient innovation approaches in the present. Thereby, the deficit of innovation still is used as a base for stabilizing the claim for innovative approaches, but this deficit is identified as a not-yet-but-future problem. By referring to this “future to be avoided” as a health crisis stemming from citizens' behavior – detaching the problem from broader circumstances – citizen behavior becomes framed as an area within which the deficit of innovation is located. This is when the notion of empowerment becomes introduced as a solution presented as gained by innovation efforts if taken now.

6.1.2 An Economic Crisis

Health Crises are not only, or foremostly, addressed as the threatening quality of life but as an economic challenge of increasing demand and thus increasing cost due to the increasing aging rate and the potential of more co-morbidity. Therefore, the effectiveness of measurement envisioned within the work programs in improving people's health or living with an illness is always connected to being “cost-effective.” The promise made in such expressions is a double logic, reaching two goals at once as digitally based personalized medicine does not only bring more qualitative health care but is “less resource wasting” (HE,

p. 7). In other words, the most “cost-efficient” solution is, in reverse, always referred to as the most effective one in reducing disease burden as well. The common thread between these two is personalized medicine (see Chapter 2.1). The two critical points in this description that define what is meant by such are cost-effective/ cost-efficient/ cost-neutral or even “fiscal sustainability“ (HE., p. 106) and the burden of disease.
Cost-efficiency is either described as a single aim with the potential for future savings of public expenses, for example, through the prevention of disability leading to an inability to work; or the savings made by developing and implementing more convenient digital-based ways of health(care) management; such as “the cost of data curation, a necessary element to foster progress in biology and medicine, also needs to be considered” (H2020, p. 19). The burden of disease is not defined sufficiently, but its meaning meanders between a burden on an individual level and a collective one. For example, as expressed in H2020 “SC1-BHC-22-2019: Mental health in the workplace.”

> Mental health conditions such as depression, anxiety and stress represent substantial financial costs for employers and employees, as well as a significant loss for society at large. An EU-level estimate of the overall costs, direct health costs and lost productivity is more than 450 billion EUR per year. Mental illness is an important cause of absence from work but it is also linked to high levels of presenteeism, where an employee remains at work despite experiencing symptoms resulting in lower productivity. It is important to create mentally healthy workplaces, i.e., promoting and protecting employees’ good mental health and supporting them when they experience mental health problems, and their return to work. (p. 87)

The targeted condition, mental health, is encompassed as becoming a burden for the individual, defined as part of a collective referred to as the employee, i.e., working for and with someone; the employer is also affected by this burden. However, the burden is also a financial stressor for employers and society, threatening the economy by pointing to EU-wide costs for mental health problems. This description of how the individuals and the collective health are connected by healthcare costs is exemplary for the general narrative on disease burden as put in the work programs. For example, in sub-project HORIZON-HEALTH-2022-ENV HLTH-04-01: Methods for assessing health-related costs of environmental stressors:

> Deaths and disabilities resulting from pollution carry a quantifiable economic cost to society, but there are significant uncertainties in the cost estimates methodologies. There is also paucity of data to evaluate the economic benefits of clean

> environments. [...] Proposed research activities should mainly aim to improve the calculation of the socio-economic costs (and/or benefits) of health impacts during the life course associated with environmental stressors, or combinations of these, advance methodological approaches and foster their acceptance as common good practice. (HE, p. 59)

The project aims to weigh the healthcare costs caused by environmental impact on people, for example, when living in areas exposed to toxins, bad air, and water quality, against the costs of implementing pollution control measurements. Alternatively, as put in the work program: ”Development of case studies involving public authorities comparing the costs of action and non-action [...]” (p. 60). Such approaches shift the decision from a public sphere to an allegedly pure reality, dismissing the moral component of such decisions and the actual health benefit within an individual citizen (Busch, 2011).
The metrics to estimate the health impact are the standard measurements *QALY* (Quality-adjusted life years) and the *DALY* (Disability-adjusted life years). The information assessed by these metrics is not foremost the limitation and potential suffering due to being ill but the restriction in one´s productivity, i.e., one’s ability to work, and the burden on the health care system, i.e., the resulting costs. Therefore, they have been considered for turning health into a task to be addressed from an economic perspective (Kenny, 2015; Reubi, 2018). Basing the cost-benefit analysis of environmental measurements on these metrics shows how the potentially gained benefit is only attested by the potential savings. In other words, the cost-benefit analysis measures the invested money against the potential savings due to reduced illness, death, and disability that would result in a diminished workforce – not against, e.g., lived experience due to better or worse quality of life. This subproject is no single example. The benefit of reducing the burden of diseases is known only by its costs within these calculations throughout the work programs. In comparison, none of the sub-projects suggest, e.g., a qualitative approach to people's experience of *health* as an integrated assessment.

What does this have to do with empowerment? First, I assume it to be important to keep this approach in mind as being the back-drop towards which the notion of CPE is stated as positive; as an integral aspect of the *context*. Further, while the health sector is marked by several economic crises and increasing costs, it is also addressed as a new potential digital market, as opportunity. Precisely, the crisis of costs becomes outlined as supporting the claim to foster this market strand as a solutive reaction. Again, framing the crisis (thread) as a challenge (opportunity). Here, the funding programs refer to the outer frame of the “Growth of the European data-driven economy” (H2020, p. 22) and the embeddedness of future

healthcare in the modified circular economy. Health has become envisioned as part of this data-driven economy, as part of the European “Digital Single Market – one of the EU’s key priorities – [...] transforming our economy, our industries as well as our culture and lifestyle” (HE, p. 27). The narrative of the crisis of increasing healthcare costs helps to justify this integration of healthcare into the digital economy – and this is where empowerment enters the stage.

Here, the work programs refer directly to EC communication document COM(2018) 233 final “on enabling the digital transformation of health and care in the Digital Single Market; empowering citizens and building a healthier society” (D4) from April 2018:

> The vision outlined in this Communication is to promote health, prevent and control disease, help address patients' unmet needs and make it easier for citizens to have equal access to high quality care through the meaningful use of digital innovations. It will also strengthen the resilience and sustainability of Europe’s health and care systems. By helping to maximize the potential of the digital internal market with a wider deployment of digital products and services in health and care, the proposed actions also aim to stimulate growth and promote the European industry in the domain. (D4, p. 4)

In short, the argument for making healthcare part of the digital single market is to avoid a future of increasing healthcare costs. Here, the empowered citizen-patient is introduced as a signifier of this vision, as a) the necessary type of citizenship, needed to perform according to the envisioned improvement and b) the beneficial outcome of digitization. This vision of the empowered citizen-patient within the digitized healthcare imaginary is carried further into the Horizon programs.

To bring the aimed benefits for the economy and citizens' healthcare, the single digital market is set to break down boundaries between member states functioning as a unifying measurement. On the one hand, connecting the nation states’ individual digital markets strengthens the EU's digital economy on a global scale and “help[ing] European research and industry remain at the forefront [...].” (D4, p. 8), as part of the “technological race with the United States" (Jasanoff, 2007, p. 77). On the other hand, unifying healthcare throughout the Union by *the force of innovation*. This project was coined the European Health Union (EHU) and represents the promise of unified digital health for all EU citizens, implemented as a unified health data administration. These aims are outlined in three main points: ”[C]itizens' secure access to and sharing of health data across borders; better data to advance research, disease prevention, and personalized health and care; digital tools for citizen empowerment and person-centered care” (D4, p. 3). I touch on the role of health data

several times in later Chapters while the following one is dedicated to the genuine aim for unification as significantly altering the potential meaning of empowerment, showing how it accounts for a distinct modifying context with particular impact.

6.1.3 The European Health Union: a Standardization Project

The attempt for a unified and hence standardized health data administration is referred to as beneficial in the work programs in three ways. First, pan-European certification creates security in this economic strand for investors, thus enhancing the private sector's ability to *innovate* the aimed techniques:

> Standards, standard operating procedures or harmonization strategies are part of the knowledge economy that facilitates innovation and the broader adoption of new technologies by European industry and by the regulatory authorities when approving new medicinal products and/or medical devices. Standards are key elements to facilitate competitiveness of European industry and the success of clinical research. (H2020, p. 28)

Second, citizens benefit from using these qualitatively standardized products and mechanisms, fostering health and equalizing healthcare quality throughout the Union. Third, as presented in the work programs, both points lead to: “Creating a more resilient, inclusive and democratic European society'” (HE, p. 12); labeled the European Health Union (EHU):

> The European Commission is building a strong European Health Union, in which all EU Member States prepare and respond together to health crises, in synergy with national activities in the area of crisis preparedness and response; medical supplies are available, affordable and innovative, and countries work together to improve prevention, diagnosis, treatment and aftercare for any diseases, including cancer. (HE, p. 8)

Overall, the EHU is an attempt to standardize specific points within EU-wide health care. At the same time, the EC has to acknowledge its lack of competence as public healthcare lies within member state responsibility. As the quote shows, the EC understands its role as crucial to reaching this status of resilience by unification through increasing its “input.” Giving this input is understood to be happening by giving funding.

The outlined approach of standardization aiming to lead to unification, therefore, also has to be understood as a workaround for the EC being restricted in its judicial possibility to

regulate healthcare and its administration. Hence, judicial restriction in *doing* politics. Instead of creating unity and strength through law, the EC aims to induce this status by defining standards. The aimed outcome can best be described with Barry's (2006) concept of technological zones, as:

> [...] forms of space which are neither territorially bounded nor global in their extension, yet are of considerable political and economic significance. [...] within which differences between technical practices, procedures or forms have been reduced, or common standards have been established. (p. 239)

Though Barry (2002) argues against observing technological zones by looking at institutions such as the EU, which has a very powerful and determinative position in defining rules for huge territory, this perspective does not allow for recognizing failures and resistance in the actual practical enactments at all levels of the addressed zone. Nevertheless, the unification approach induced by guiding/regulating innovation in healthcare has to be understood not only as an attempt to foster and equalize the quality of healthcare but as doing politics differently than parliamentary. Hence, the observations made in the work programs do not sufficiently account for an existing technological zone but show the attempt to determine a geographical unity strengthened through technology-based practices, i.e., a technological zone in the making. And though the standardization approach does not completely determine the social structures in the addressed territory, the impact it has on the social structure and the connections between all actors within the defined area have to be considered if one wants to understand these social structures. Therefore, in this subchapter, I use literature on standardization (Busch, 2011) to trace the power implications of the way the EC operates its unification approach as a modifying context to the notion of empowerment and the socio-structural determination done through these standardization approaches.

Standards, as Busch (2011) describes them, are an anonymous power as the naturalized modus operandi is the result of sorting out conflicts before a consensus can be reached: "Standards are the rules by which we are told we should live, and the range of possibilities presented to us when we make choices" (p. 24). Participants of this process end up as "winners and losers." (Busch, 2011, p. 33), depending on whose aims achieve standardization. Political institutions having a say might not contradict the genuine understanding of how society is regulated in a democracy such as the EU. Still, the power imbalances in creating standards conduct a different form of rulership due to the invisibility of standards.

As Busch (2011) says: “Standards construct publics since they implicate various persons up and down the value chain, as well as those in networks that surround it” (p. 268). Hence, in the attempt to establish standards for the digital health market the entity of citizenship is constructed as well accordingly. (In the case I discuss here this is done through defining the rights and obligations of citizenship as data practices which are to be performed by individuals to enact their citizenship as well as patient-ship as shown in Chapter 6.2.2). By establishing these practices through standardization with integrated in- and exclusion the standardization approach distributes the ability to decide who is empowered to do what. Therefore, according to Busch (2011), this characteristic of standardization contradicts actual empowerment: “If people are to be truly empowered by quality, audit, and certification, they must be genuinely able to change the goals of the organization” (p. 234). Connecting this observation to Felt & Fochler´s (2011) description of different “regimes of innovation governance”, involving people in the decision about the goals – which are to be envisioned to be reached through innovation – depends on the model of innovation pursued. To empower people, as Busch (2011) defined it, a network-oriented model would be needed: “Network-oriented ideas, on the other hand, allowed for thinking about how societal actors may influence innovation and the future shape of products before the respective objects have been realized” (Felt & Fochler, 2011, p. 325).
In short, both conceptions outline the importance of actively implementing possibilities for the public to participate in development processes on a decision-making level and not only accomplish the decision through or performing a task defined *for* them. Recognizing this determinative power imbalance in the imaginary of future healthcare due to the mechanisms of standardization as inherently contradicting a potential meaning of empowerment is one part of this subchapter.

Another part is looking at the vision of standardization supposed to be performed through a “trickle-down” effect (Joly, 2019), or “downstream” impact as the EC refers to it, of higher-income parts of society's innovation and knowledge towards lower-income groups. The answer to a question on HE sub-project “HORIZON-HLTH-2022-DISEASE-07-03: Non-communicable diseases risk reduction in adolescence and youth (Global Alliance for Chronic Diseases - GACD)” asked in an info session illustrates this understanding:

> So then we have a question to G.A.C.D. topic. Uh can we implement in the middle uh and low and middle-income countries an intervention that has already proven to be effective in the high-income countries? Yes, this is one of the purpose. It has to be evidence-based uh implementation research. So if there is evidence that it works in

> the high-income countries uh there can be also uh uh there can be a tried in the low and middle-income countries. (V3, min 21:56)

The project is dedicated to implementing measurements fostering healthy behavior in people from age 10-24 to reduce the later-in-life potential from chronic diseases associated with lifestyles such as diet, physical activity, smoking, and loneliness. The answer shows that the expression “evidence-based” used in the sub-project description and at many other points throughout the work programs implies this trickle-down effect. Hence, the particular circumstances within an area addressed with measurement may not be acknowledged. This logic is particularly contradictory as lifestyle factors and the health status correlating with it highly depend on the socioeconomic situation of a person – and so does the variety and accessibility of options in lifestyle and behavior.
This constitutes a particular ambiguity in a trickle-down approach to standardization, aiming for equality. On the one hand, (health) inequalities are stated to be overcome by the envisioned measurements:

> Upbringing, income, education levels, social and gender aspects also have an impact on health risks and how disease can be prevented. [...] In order to leave no one behind, to reduce health inequalities and to support healthy and active lives for all, it is crucial to provide suitable and tailor-made solutions, including for people with specific needs. (HE, p. 12)

On the other hand, they are not defined as problems or to be explicitly addressed or taken into account when transferring measurements from one socio-economic setting to another in a “trickle-down” approach. “Tailor-made” here refers to data-based personalized medicine, hence, footing on the unified data gathering and administration approach as premise and panacea. Presenting the same possibilities of behavior to a setting with a different socio-economic structure (as in the case of transferring solutions from higher to lower-income countries) dismisses the different starting points, the different conditions from which an individual is supposed to act as empowered. Socio-economic differences are only one example of dissimilarity in a society dismissed by standardization. At other points in the work programs, the ability and best possibility to take care of one's health is described equally for still-healthy/ not-yet-sick citizens as well as persons living with long-term health issues. Different needs and different technological as well as individual capabilities due to everyday life are simply ignored alongside all aspects potentially shaping the ability to act according to the given vision of empowerment.

To subsume this chapter, empowerment refers to a certain performance, a type of behavior of citizenship, and/ or being a patient. Here, the EC's approach naturalizes this particular performance by setting the goals and its material implementations with a predetermined type of behavior and thus negates other possible behaviors as either inappropriate or unviable. Hence, this materialization of standards cuts back on options. Thereby, the first takeaway of this chapter is that the EC's approach already negates a range of possible understandings of empowerment (see Chapter 2). The aim for standardization functions as a modifying context that has to be taken into account when looking at the aspects of autonomy and freedom of choice – attributes the work programs operate with in connection to empowerment.
Further, by ignoring the impact the individual's situatedness has on one's ability or effort to adopt a certain behavior, the EC promotes performing standardization in a distinctive trickle-down approach. This clashes with the vision of equality as the outcome of empowerment. Therefore, rather than defining empowerment as an outcome of this standardization approach, I argue as a second point to understand the notion of empowerment as a token in the form of a promise that weaponizes ambition to facilitate the adaptation of favored behavior. I see the notion of empowerment used as a promise that stabilizes and thus standardizes a socio-technical imaginary of databased digitized healthcare strengthening the EU and its unity through becoming a strong(er) economic pillar.

To conclude this first Chapter of my analysis: setting the stage in the introduction for the measurement, the notion of empowerment is detached and attached from some areas. These areas are dis- or attached from either individual or structural levels of healthcare. A crucial strand of what I have defined as a modifying narrative is the way healthcare gets presented from an economic perspective, as this narration stresses the need for empowerment as well as defines the area of performing citizen-patient empowerment. The digitization of healthcare and its incorporation into the digital single market is a mutual justifier for empowerment. On the one hand, the envisioned digitized and cost-efficient healthcare needs the empowered individual to work, on the other the empowerment of the individual is viewed as a benefit only to be gained through *cost-efficient* digitization of healthcare. Through this kind of contextualization, empowerment becomes an issue for the EU-wide economy by coining the term of the European Health Union.
To establish this unified approach the EC aims for standardization of healthcare throughout the union by digitization. Here, the notion of empowerment, marking a certain performance, an enactment of being an empowered citizen-patient, becomes a token symbolizing this goal of unification and justifying standardization through trickle-down approaches, which does not take into account the varied socio-economic settings. On a general basis, the standardized

approach to establishing unification contradicts a possible understanding of freedom of choice and autumn associated with empowerment.

Connecting Busch's (2011) claim on empowerment being the ability of people to change the goals of the organization" (p. 234) with Felt & Fochler´s (2011) description of different "regimes of innovation governance," involving people in the decision about the goals differently shows how empowerment can have different meanings dependent on the model of innovation pursued. The next chapter, therefore, distinctively looks at the model of innovation sought by the EC, discussing the potential range of involvement of the public as given by these structures as co-constituting the understanding of CPE.

6.2 The Role of the Citizen-Patient as a Promise of Data-Based Innovation

The EC uses the terminology "impact-oriented" to refer to the innovation approach presented in the work programs, hence, oriented toward creating particular future effects. These impacts are presented in a future-directed narrative of promises. Therefore, to analyze the impact of the innovation approach, I started to look at the promises, asking my second SQ: *What are the promised benefits?*

The work programs promise a lot. They present a future of equally accessible and high-end quality healthcare with many winners. Citizens will profit from evidence-based personalized medicine and are supported in their independence. The healthcare systems will benefit from the "cost-effective" and less "resource-wasting" strategies facilitated through new technological solutions and digitization. The European economy benefits from the reinforcement through innovation in these sections. Ultimately, this also benefits citizens as the whole Union will be strengthened by the growing economy supplying new jobs resulting in "a more resilient, inclusive and democratic European society" (HE, p. 23). According to Pfotenhauer et al. (2019), these are classical promises of innovation that promise to solve the formerly defined crises and challenges, fulfilling a double role of tackling societal problems with a strength of the relative economic strand. They genuinely depict an improved future, not being neutral but creating a material and social impact in the present (Mager & Katzenbach, 2021). In other words, in pursuing this future vision, measurements are taken in the present, aligning with this future imaginary. On a basic level, political decisions are made, deciding for or against such potential alignments. In the case discussed here, it is in deciding what developments are to be funded. Felt & Fochler (2011) stress this aspect when saying: "[T]he question of who participates in shaping these futures is of high democratic relevance" (p. 325). Therefore, the central topic of this chapter is to take a detailed look at the applied structure of the innovation process pursued by the EC to identify the position of

citizen-patients as determined in the present throughout this future-making process. This will offer further information on the dimension of empowerment by clarifying the decisional power of citizen-patients. In a further step, this gained understanding allows me to discuss the dimension of governance and governing the public through innovation as tacit governance (Felt & Fochler, 2011).

Leaning on innovation as the solution is not genuine to the health sector but an overall attempt to subsume as the *"Innovation Union"* (European Commission, 2011). Hence, the logic of innovation – funding basic research, leading into applied research, and ultimately commercialization as a "panacea" (Pfotenhauer & Jasanoff, 2017) – is no naive approach but profoundly declared. In the most current example of *Horizon Europe*, this logic is openly proclaimed and best observable when listening to Irene Norstedt, the Director of DG Research and Innovation, in the video record of the first introductory (V1) explaining the structure and general scope of *Horizon Europe*, speaking of the "impact-oriented" approach.

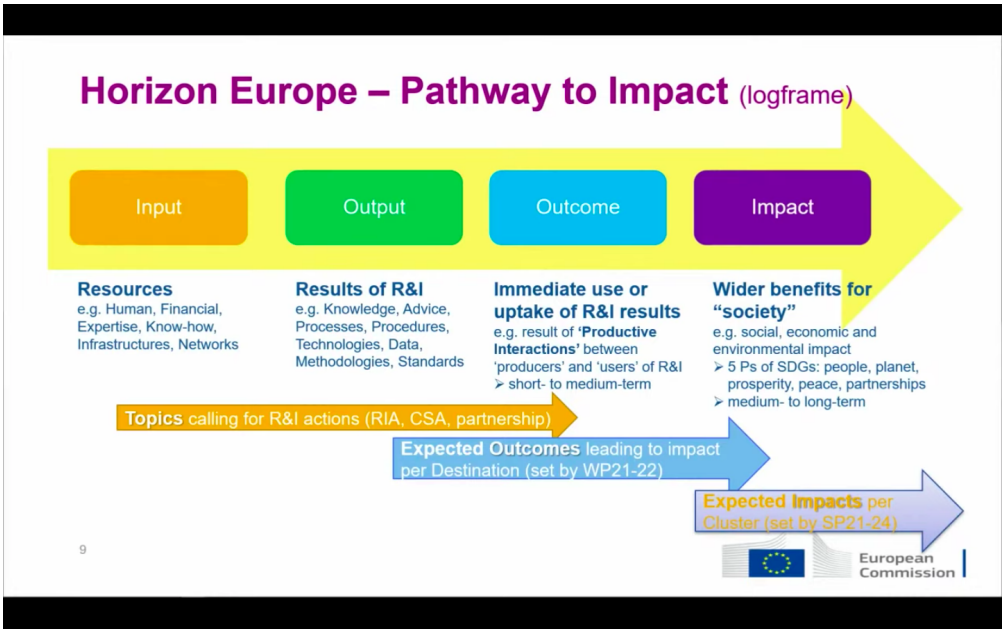

Figure 4: Slide presenting innovation logic under which HE is structured (V1, min 22:14).

This screenshot is taken from the first introductory explanation of *Horizon Europe*'s structure and general scope. The genuine sequence of supporting scientific research through funding, leading to new expertise and technological possibilities resulting in a range of public benefits, is depicted in a one-directional input-outcome order causing the final impact. These public benefits – the "wider benefits for society" as stated on the slide – are distinctly defined as benefits in being commercialize-able: "Public investments under *Horizon Europe* should

deliver research and innovation to create public benefits and this includes the creation of jobs, economic growth, and industrial competitiveness for Europe" (V1, min 4:56), due to Norsted. A more detailed description of the envisioned impact can be found in the *Horizon Europe* strategic plan:

> CLUSTER 1 (Health) will increase Europe's autonomy in delivering health care by contributing to safer, trusted, more effective and efficient, affordable and cost-effective tools, technologies and digital solutions for improved (personalized) health promotion and disease prevention, diagnosis, treatment and monitoring for better health outcomes and well-being, [...]. **It will also contribute to a health-related industry in the EU that is more competitive and sustainable, ensuring European leadership in breakthrough health technologies and open strategic autonomy in essential medical supplies and digital technologies, contributing to job creation and economic growth,** in particular small and medium-sized enterprises (SMEs). (D6, p. 10)

As I have marked in bold, the vision of the promised future healthcare is continuously re-performed as inherently connected to the "health-related" industry – and vice-versa.
Further, the vision of a future society is not vague or possible but presented as an inherently logical result of previous steps and functions as a clear justification for these steps. Details like the arrows used to introduce the funding logic are continuously utilized to depict a straightforward development pointing to the impact as the final step, the syntax, and the terminology of the description of the future. These details, written in what Asdal & Reinertsen (2022) call a matter-of-factual writing style, speak of outcome and impact rather than of e.g., vision or goals. All these mechanisms are repeatedly re-performed through the material provided by the EC. Hence, what I described as promises of innovation are meticulously presented as factual, not as possible. Determining the future in this vigorous way of relying on the suggested measurements supports them immensely in their importance and creates trust in the reader (Asadal & Reinertsen, 2022). Trust is essential to align all actors' actions with the imaginary pursued by the innovation approach and is discussed in more detail in Chapter 6.3.3.
A general consequence of these powerful determinations of measurements needed is the silencing of other potential attempts, not only aiming for different outcomes but resulting in different material and social consequences in the present (Pfotenhauer & Jasanoff, 2017; Pfotenhauer et al., 2019). Looking a level deeper into the structure of the impact-oriented innovation approach depicts the determinative power inscribed into this structure even better. As Felt & Fochler (2011) highlight, the particular innovation process model determines

the position and degree of involvement in decision-making different stakeholders have within the innovation process. On the follow-up slide in the introductory presentation, these different positions of various stakeholders are defined in more detail.

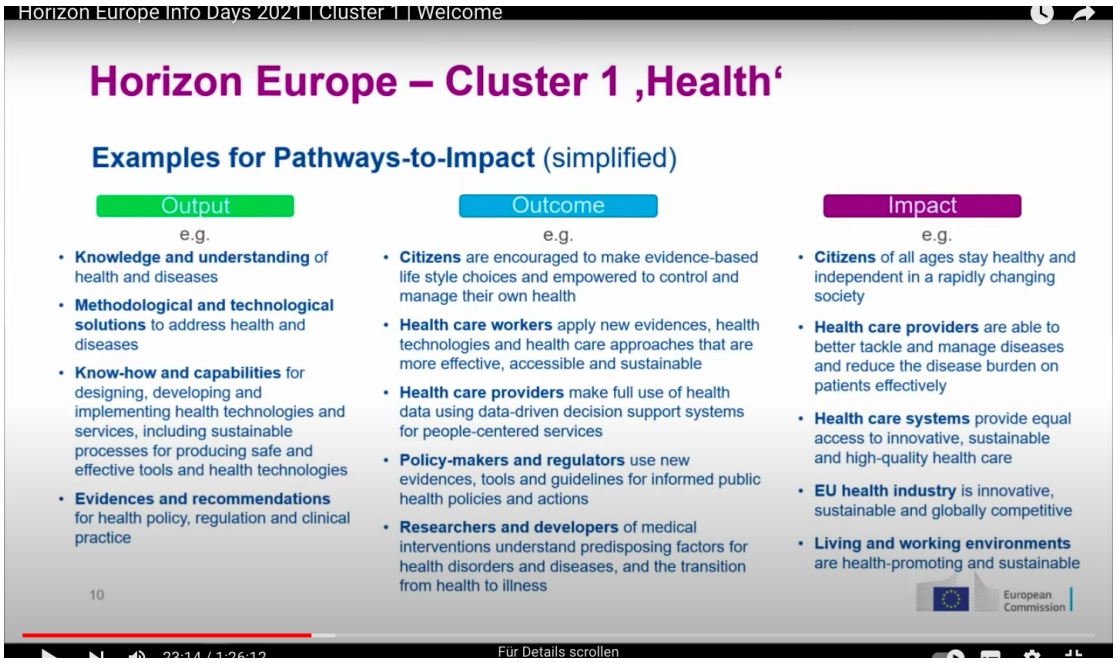

Figure 5: Snipped of a presentation slide, giving an example of how the innovation process is envisioned to plate out on citizens' health (V1, min 23:22).

Here, citizens are stated as one out of five targeted groups impacted by the outcomes besides health care workers, providers, policy-makers and regulators, and researchers and developers. Of course, as stated on the slide, this structure is to be understood as “simplified” and not directly applicable. It is presented as a “bone” to which research shall add “flesh,” expressing the details of how to perform the set outcomes putting the responsibility of the impacts on the funding applicants. Still, it is to be understood as a basic underlying structure already clearly determining the role and position of the various stakeholders. The accompanying speech of the presentation addressing scientists and other potential funding applicants, points out most clearly that citizens are put at the very end of the innovation process: “Regarding the outcome, there, of course, you need to link your research and innovation results to to the user groups, to those who in the end should use the results and I have highlighted that in bold so this can be citizens [...]” (V1, min. 23:34).

Although, the work programs in some passages promote an integrated dialogue between end-users and developers, “[...] promoting patient feedback by providers involved in the procurement of solutions for digital health and care providers, [...]” (H2020, p. 136), the entry point for citizen-patients into the envisioned development process is clearly set as when the outcome shall be performed. Similarly, an approach of co-creation, involving citizens as

end-users in the design and development phase, can be found in the work programs but rarely and not on a profound *“bone”-like level*.
For example, the HE sub-project HORIZON-HLTH-2021-CARE-05-02: Data-driven decision-support tools for better health care delivery and policy-making with a focus on cancer speaks of: “The development of innovations, including tools, processes, and services, should be done together with end-users, i.e., citizens, health professionals, and policymakers, and represent both a support-base and scientific evidence for data-driven innovation” (p. 113). In sub-project HORIZON-HLTH-2022-CARE-08-03: Public procurement of innovative solutions (PPI) for building the resilience of health care systems in the context of recovery, it says:

> Procurers will specify, purchase and deploy solutions addressing their relevant, shared unmet needs, while engaging together in a supply and demand side dialogue, in order for the deployed solutions to deliver sustainable, new or improved health care services and outcomes, always taking into account patient feedback. (HE, p. 123)

Besides these descriptions being rare, the reason why such an approach is suggested to be used, again, nicely depicts the linear innovation model. In the description of the *Horizon 2020* sub-project, SC1-DTH-08-2018: Prototyping a European interoperable Electronic Health Record (EHR) exchange, the connection between pursuing a co-creational approach is foremost aiming for better ensuring the final stage of innovation when the research outcome is implemented and in use. Therefore, the support by citizens, making use of the innovation, and performing as expected is essential: “The design of the prototype should be user-driven as to ensure the early buy-in of final users (from citizens to healthcare professionals and scientists)” (H2020, p. 144). In short, citizens are genuinely not involved in the decisional processes within the innovation model pursued by the EC. If so, the approach aims to increase citizens' “[...] consensus that is supportive of the implementation of certain technologies, [...]” (Felt & Fochler, 2011, p. 326). Hence, it is motivated by fostering the final step of implementing an innovation rather than actual co-creation. The aim to facilitate dialogue is also prevalent in integrating citizens into healthcare by fostering doctor-patient dialogue; this topic will be picked up in Chapter 6.3.3.

What is the “democratic consequence” (Felt & Fochler, 2011) of this? Though citizens on a general level are put into this final stage of the innovation process, their position is not described as passively adopting the outcome of an innovation process. Here, but also throughout the work programs, within the future scenario, citizens are described as

“independent” (e.g., HE, p. 11) and “autonomous” (e.g., HE, p. 51), and “actively engaged” (e.g., HE, p. 17). Hence, they are dominantly presented as not just receiving health care but engaging in it actively, in fact, co-performing it.

These descriptions of patient autonomy overlap with a particular understanding of empowerment in and outside the work programs. They show parallels to a general democratization of healthcare (Nielsen & Jensen, 2013; Nielsen & Langstrup, 2018; Rappaport, 1987; Roth & Bruni, 2021), often standing in opposition to a paternalistic relation between doctor and patient – where strong decisional power lies on the side of the doctors, and not on the patient's side. Still, determined by the underlying structure of the innovation process, primarily cutting citizens off of the process of making decisions – not necessarily in their individual treatment but in defining their role within the overall future health (care) imaginary – the terms of “autonomy” and “independence” are put into a range; a scope, which is not defined by citizens themselves but in this case on a basic level by the EC as the initiator of the innovation process.

Hence, the imaginary of the citizen becoming autonomous and independent, referred to as empowered, here describes a certain behavior of citizens not defined from a perspective of mere citizenship but by the legitimizing impact of innovation – aligning citizens' behavior with the intended future. Here, responding to Hoeyer’s claim (2023): “The most urgent task is to explore what promises do—here and now—in the environments where they circulate" (p. 31), I can conclude that the digitization-based promise of empowerment following a linear logic of innovation is redefining the understanding of citizen- as well as patient-ship in a top-down approach through determining practices of enacting these positions in society. In other words, despite citizens not having – as I call it – decisional responsibility on the innovation impact, they are immensely responsible for keeping the system running as it is partly made dependent on patient-citizens obligated to conduct certain behaviors. This obligation can become invisible and by being framed as an autonomous decision, dismissing the powerful position of the EC as the one who re-distributes *the tasks* in the first place: “If networks diffuse responsibility, they can also depoliticize power by making its actions opaque or invisible” (Jasanoff, 2015, p. 17).

Defining the role of the notion of empowerment in this imaginary, again, using the illustrative example of the subproject “SC1-DTH-08-2018: Prototyping a European interoperable Electronic Health Record (EHR) exchange” (H2020, p. 142-145): As put above, healthcare providers' core duty is to “make full use of health data using data-driven decision support systems for people-centered services” (Figure 2). Throughout both work programs, the promise of health data implies that citizens are engaged in generating this data: “This prototype should be primarily focused on citizens' health data generated by the citizens

themselves, healthcare professionals or sourced from relevant healthcare organizations" (H2020, p. 144). In other words, a particular citizen-patient behavior is needed to reach this imagined healthcare technique work. The impact of facilitating this pursued innovation model has what Felt & Fochler (2011) discuss critically as the tacit approach power of governing through innovation. In light of this assumption, I understand the notion of citizen-patient empowerment used in the funding programs as a mechanism, similar to the arrows above, used with function – re-performing and thereby ensuring a certain imaginary of citizenship and citizen-patient behavior. Before discussing the envisioned practices of empowered citizen-patient-ship, the crucial role of data and datafication in the impact-oriented approach is discussed as it is integral to all the specific enactments of empowerment.

6.2.1 Data and the State: Data Practices as Unification

As already became clear, the innovation promise of the work programs does not come without thinking about data and the other way around. Data is crucial in the EC's innovation model, either aiming to generate new data or to mobilize it better, i.e., facilitating operations with Big Data. This approach is to be implemented through all stages of health care, health politics, science, clinicians, and citizens. Hence the topic spans beyond the empowerment discourse. As Hoeyer (2023) stresses: "Data promises are paradoxical drivers of intensified data sourcing. They are justified by a need for—and promise a future of—decisions based on some sort of 'evidence,' but they are not themselves supported by evidence" (p. 31). Rather, he concludes that the impact of these promises on the present is particularly crucial to be understood when discussing such narratives.

Therefore, in this chapter, I first take a look at the function data has in the future healthcare imaginaries of the Horizon projects on a general level before (Chapter 6.2.2) focusing on the relation between citizens/ patients and *their* data and the thereby determined practices referred to citizen-patients, presented as the premise for the promised future improvement. As the EC's future healthcare vision depicts healthcare as a digitized sphere, data functions as a connector between all stakeholders involved in this healthcare vision. Thereby, the understanding of data and its function and, moreover, the corresponding data practices define the relations between all members of the healthcare network. In other words, the range of citizens' participation, set by the innovation model (see above), is generally defined as data practice. Therefore, looking at the understanding of data the EC operates with is helpful when analyzing how this understanding shapes the role of citizen-patients transmitted by the notion of empowerment.

Throughout all domains of healthcare, the work programs touch upon (research, health politics, clinicians' or patients' behavior), digitization, and thereby data is present as promissory and viewed as underlying any best practice in decision-making. Therefore, it is handled in a classical sense as objective information (Ajana, 2017; Van Dijck, 2014; Sharon, 2017). HE sub-project “HORIZON-HLTH-2021-CARE-05-02: Data-driven decision-support tools for better health care delivery and policy-making with a focus on cancer” (HE, p. 112-115) illustrates this very compactly, focusing on “collection, storage and analysis” of data to better inform political decision making:

> An ever-increasing amount of data is at the disposal of decision- and policy-makers, which, if analysed, pooled and used, could lead to novel data-driven approaches in health care delivery and policy-making, thus improving quality of life, health equity and producing better health outcomes. The collection, access, processing, and (primary and secondary) use of data is still very fragmented across national health systems. The availability and use of structured and unstructured health data represents an opportunity for the implementation of data-driven innovation and it provides new opportunities for developing, monitoring and evaluating decisions, and providing feedback into decision-making processes and policy strategies. (HE, p. 113)

The project description touches on several promised aspects attached to data. Besides the value for policy-making, a similar potential is seen for caregivers' and individuals' decision-making. Still, on a meta-level, the data-based healthcare practice fulfilled another role connected to political decision procedures: It is supposed to unify this approach. As the quote tells, the variety and often nationally handled (health) data approach is viewed as an obstacle in the data-based vision of the EC. Here, another need for standardization, similar to the EHU discussed in Chapter 6.1.3, is proclaimed and promises to overcome this obstacle through a unified data approach that: a) improves health care and puts it on an equal level of quality through the union; here, the handling of data care is equated with health care evidently; b) this unification is necessary if the promise of the positive impacts of the data economy shall be delivered, which feeds into the narrative of the health crisis as an economic crisis; and c) the unification of data practices is supposed to increase pan-European research activities and thereby strengthen the health innovation strand through research activities. These aims have been subsumed as the *European Health Data Space* (EHDS), outlined first in “Digital Health Europe. Recommendations on the European Health Data Space” (D10) and developed with funding of H2020 and used as a point of reference in HE, referring to the “*Proposal for a REGULATION OF THE EUROPEAN*

PARLIAMENT AND OF THE COUNCIL on the European Health Data Space" (D11). These attempts depict how the aim for unification through standardization, which is interpreted as vital in strengthening the economy, is built on data as an essential resource, thereby leading to the *assetization* of data (Birch, 2020) instead of handling it as *objective* information only while the vision of the EDHS is to include evermore "real world data." Hence, data that has been collected "[...] within and outside the healthcare system" (D10, p. 4). Here, inside refers to clinical testing, while outside refers, for instance, to biomarkers tracked in a person's life outside a clinical setting, such as heart rate, and blood sugar, but also tracking of behavior, such as hours of sleep, diet, etc. Including more diverse kinds of data is supposed to increase the accuracy of the information held by this data. In other words, more data provides more objective truth, allowing for better evidence-based decision-making (see Fig. 2). Further, the "real world" data is put as central for the practice of personalized medicine, as the needed information is identified to be coming from outside the classical institutionalized research settings. Hence, the above-described vision of citizen-patient autonomy relies on the availability of this data. Therefore, getting and using this kind of data is when the citizens' role becomes revised.

6.2.2 From "citizen as data subject" to "citizen as key change agent in the health data ecosystem" (D10, p. 6)

The figure of the citizen in the healthcare context has already been described conceptually. For example, *biological citizenship* by Rose & Novas (2007), describes the determination of citizenship according to health information, and the *e-citizen-patient* by Felt et al. (2009), discusses citizenship as understood through the approach of ICTs in health care. In contrast, with the cases I discuss here what shapes the understanding of citizens and citizen-patients particularly are data practices, (a) as behavior ascribed to individuals as well as (b) certain behavior envisioned as a result of these practices. In other words, here I focus on the envisioned practices having a defining power determining what aspect of an individual's life lies inside a governable approach of citizenship and which aspect of dealing with health and illness do not.

As the EC understands "real world data" as data objectively offering detailed and so far unknown information about each individual citizen, the citizens, and their behavior are viewed as the source of this commodity. In order to generate this data, the individual is associated with the particular practice of generating data: "[...], EU citizens contribute data through apps linked to wearable devices and fitness, nutrition and in general healthy lifestyle programs" (D10, p. 6). This idea is uptaken for example, in the HE sub-project "HORIZON-HEALTH-2022-STAY HLTH-02-01: Personalized blueprint of chronic

inflammation in health-to-disease transition" (HE, p. 36-38), which distinctly asks for the development of tracking technologies: "Develop and deploy robust sensors, devices and/or mobile apps and other innovative technologies to monitor dynamically the individual's health status and to identify objective indicators of chronic inflammation correlative to the health-to-disease transition" (HE, p. 37).

With citizen-generated data, the question of data ownership pops up, as citizens are not only the subject of the data but also the creator; they now have to actively engage in sharing the data. The development of an accurate data ownership framework is ongoing, particularly because data generated for and through the personalized medicine approach is viewed and treated as good, having an economic value that "[...] will raise interest from private industry" (D3, p. 12). As noted by Liddell et al., (2021), the question of ownership of health data potentially occurs the other way around, as in means of *assetizing* the very data for economic purposes. Hence to integrate the data into a market-based exchange logic, it has to be owned by an entity – not necessarily the data subject though. In other words, they would argue that data about a living human generated by the same does not call for their ownership over that data but rather the underlying integration of the data-based healthcare system to the data-based economy strand.

On a surface level, the practice of sharing data about the self with other stakeholders through the EHDS is what is defined as strengthening the agency of citizenship: "The enabling agency of the citizen in determining which personal health data may be accessible for which use beyond the primary purpose of data collection (care provision for a given care episode)" (p. D10, p. 7). In other words, by being the data provider, citizens are endowed with a degree of freedom of choice, what data to gather, and with whom to share. This control over data about the self is described as agency already in H2020, where this envisioned mechanism is already to be found as what partially constitutes the notion of empowerment, performing citizens promised autonomy.
Still, having citizens participating in the EHDS through data contribution is not envisioned as being solely enacted by each individual, depending on their personal interest. Moreover, the act of taking the ascribed position in this data-based healthcare network, hence behaving accordingly by practicing self-tracking and data-management, is framed from a moralistic perspective as well as data being viewed as a common good and therefore, data sharing as an act of altruism and self-integration into the *European* society. By adding this moralistic frame to data sharing, the very behavior of doing so loses some of its ascribed freedom but becomes a social duty, an obligation to act as a good citizen. Still, as Hoeyer (2023) states:

> The most common experience when interviewing patients, however, is that they want to focus on their own treatment, not on administering data reuse. Options aimed at data control are likely to serve only the most resourceful citizens. Responsibilization of the individual nevertheless remains the standard response in data politics. (p. 232)

Hence, data sharing and management tasks for purposes beyond immediate individual aims are neither freely done nor practically possible in a general mode so far but can be best described as tacit governance (Felt & Fochler, 2011), making a particular behavior type necessary in order to be counted in as a citizen in the society-encompassing healthcare approach.
Similar accounts occur for induced adaptation of behavior being informed through data. As the citizen becomes a provider of the common denominator of the EHDS data, they also are envisioned as a user of such. This later form of data-oriented behavior is highlighted through the work program, where it becomes annotated with the notion of empowerment. The detailed manifestations are discussed in the next Chapter (6.3).

Both described relations of the individual towards data – sharing and using – have a constitutive meaning in positioning the individual within the healthcare network through the alleged data practice, thereby defining the individual as a citizen or citizen-patient – one who receives healthcare. Here, the position of being a citizen is redefined as a social practice provided as data practices for the citizen to participate in. This understanding of citizenship and the referring behavior are outlined as an active practice performed by the individuals. Still, the ability or even willingness to do so is either naturalized as given or referred to with an ideology of autonomy emphasized as a positive added value to good future health care.
To close this Chapter, the innovation process envisioned by the EC is tied to citizen-patient participation as a crucial function performing the future imaginary. In other words, having the innovation succeed partially relies on having citizens using the developed ICTs, performing the according data practices of gathering, sharing, and lastly, adapting their lifestyles based on the gained information. Analyzing the innovation model shows how participation is not present in all stages and excludes citizens' decisional abilities, hence having a say and impact in defining the future imaginary and, thereby, the steps taken in its directions. By referring to Felt & Fochler (2011), I have described how determining citizens' position and how this position shall be filled /performed can account for a form of tacit governance. This tacit implementation builds on a set of moralities of solidarity, inclusiveness, and altruism – caring for and sharing data as keeping society healthy as a whole – and is framed as given and gained by the capacity to participate.

6.3 Performing Empowerment

After discussing the narrative of challenges and crisis as deficits naturalizing the claim for innovation (Pfotenhauer et al., 2019), a data-based unification and a stronger economization of data as the essential pillar in this future healthcare vision, I have shown how the practices referred to citizen-patients in this imaginary are defined by these very logics. They describe the resulting system as tacit governance (Felt & Fochler, 2011). Thus, I have been able to show why it is important to understand the notion of empowerment in light of the logic of data-based innovation and how empowerment is used throughout the work programs in describing these practices of citizen-patient-ship. In this last chapter of my analysis, I finally take a look at the micro-level of CPE by looking at the actual imagined performance, discussing my third SQ: *How is citizen-patient empowerment imagined to be performed?*

Empowerment has become a keyword, simultaneously vague enough to describe various things and loaded with enough significance to be used in support of a specific meaning (Chapter 2.1). It is used 15 times in H2020, 31 times in HE, and several times in the analyzed complimentary material. The H2020 work program gives a most straightforward definition of how the term is understood within the work programs: “Empowering citizens refers, among others, to enhancing their self-management, raising health literacy, involving people through co-production of care and supporting informal carers” (H2020, p. 113). The HE document describes similarly:

> Patients and citizens are knowledgeable of disease threats, involved and empowered to make and shape decisions for their health, and better adhere to knowledge-based disease management strategies and policies (especially for controlling outbreaks and emergencies). (HE, p. 62)

The described components of empowerment are present beyond the actual term. Paying attention to the description of empowerment and how it is an assemblage of aspects such as “management” and “health literacy,” following Asdal & Reinertsen's (2022) approach by looking at the formation of an issue, allows me to understand the notion of empowerment and its actual range of possible behaviors referred to citizen-patients integrated into the vision of “cost-effective” healthcare. In the following sections, I examine the three prevalent components of health literacy, self-management, and communication and collaboration. These core eras are equally present throughout the work programs and intersect in manifold ways, having to be understood in their various configurations as shaping the notion of CPE. I

look at the material conception of the practices in co-production with the societal structure imagined and the responsibilities of the citizen-patients' position within that structure.

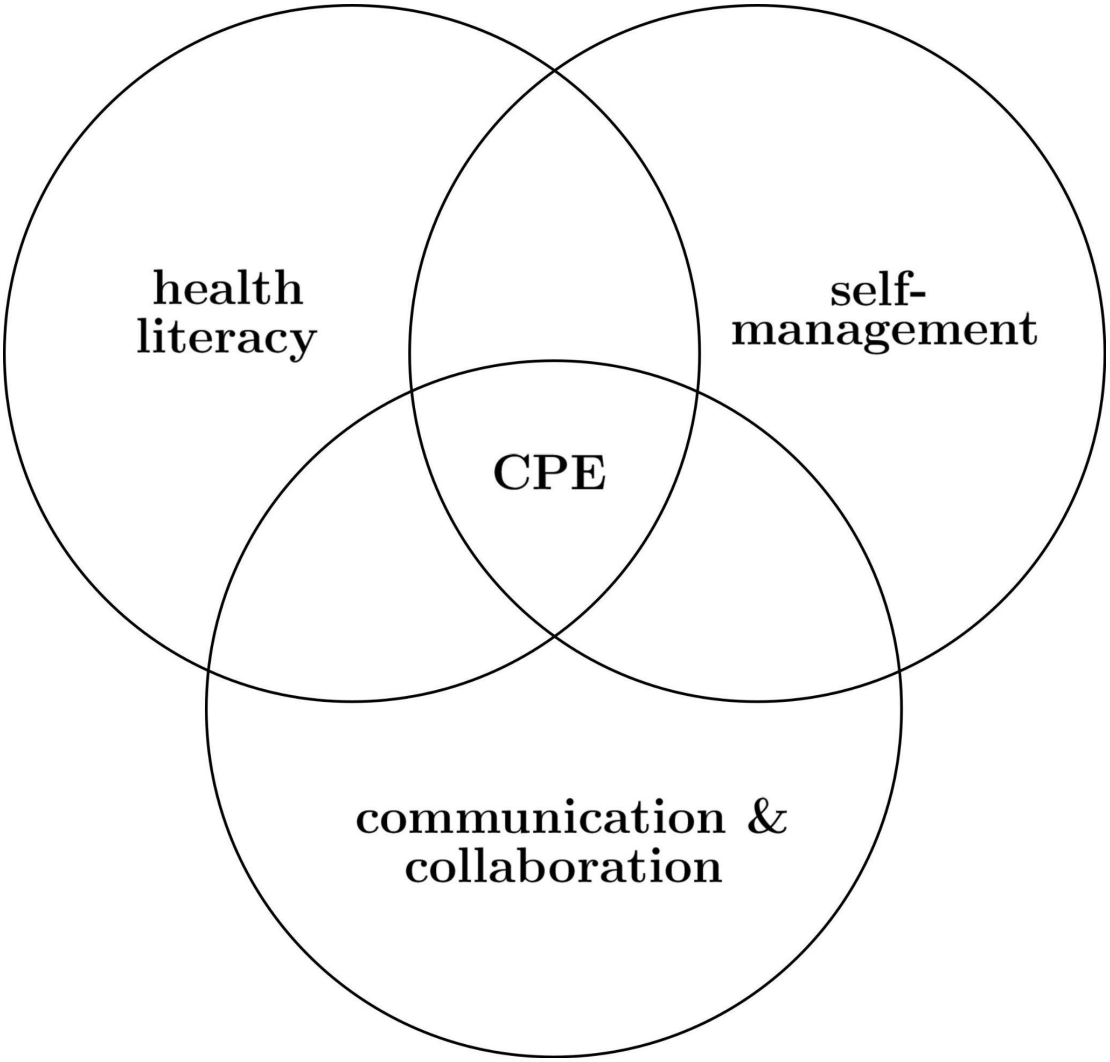

Figure 6: Van-Diagramm, three main co-constituting practices of CPE.

6.3.1 Health Literacy

An omnipresent attribution of empowerment beyond the EC's approach is the increase of citizens' health literacy, stated as a general goal but also a precondition of being health literate is to become empowered: "Health literacy and patient and citizen empowerment are closely linked and have to be supported in a coordinated way" (D3, p. 16). Generally, increased health literacy shows another inversion of an argument as it is supposed to support citizen-patients' autonomy while leading to the intended behavior of citizens as *adherence*. In detail, increased health literacy enables people to make healthier lifestyle choices: "Patients and citizens are more knowledgeable about disease threats and contribute to a patient-centered decision-making process, assuring better adherence to

knowledge-based disease management strategies and policies (including for controlling outbreaks and emergencies)" (HE, p. 99). This logic is expressed several times:

> Citizens' trust in knowledge-based health interventions and in guidance from health authorities is strengthened, including through improved health literacy (including at young ages), resulting in increased engagement in and adherence to effective strategies for health promotion, diseases prevention and treatment, including increased vaccination rates and patient safety. (HE, p. 13)

As with empowerment in general, a more detailed definition of what is understood by the several components of empowerment, such as health literacy, is not given by the EC. Still, its function and impact are indicated when the documents describe how increasing people's health literacy shall be facilitated.

Here, the conception of a lack of knowledge in citizens causing the lack of possibility to behave in the "best possible" way always follows distinctively what has been described as "the deficit model of public understanding of science and technology" (Pfotenhauer et al., 2019, see Chapter 4.2). This aspect is an identified obstacle causing public costs as *the current crisis* (see Chapter 6.1.1). Both work programs view knowledge as one-directional in determining what citizens should be literate about. While this particular obstacle is still also defined to be overcome through communication from the side of professionals towards the public in H2020: "Better informed decision making by patients and the public, due to objective, accurate and transparent communications of the latest developments and actual treatments available in the field in order to avoid misconceptions" (p.47), HE shifts this process of literacy into the range of practices performed by citizens by defining what is worth tracking as to be taken into account. This is a particularly contradictory point as citizens are viewed as lacking awareness of their own health while this kind of "knowledge" is simultaneously supposed to be provided by citizens. What Wynn (1992) referred to as lay expertise, knowledge gained from people's experience, is not denied as valid information but viewed as inexistent yet and in need to be "discovered" through the deployment of new ICTs, allowing individual practiced data-mining. The subproject "HORIZON-HEALTH-2021-STAY HLTH-01-03: Healthy Citizens 2.0 - Supporting digital empowerment and health literacy of citizens" (HE, p. 19-21) is particularly dedicated to facilitating this vision:

> European citizens are educated, motivated and empowered to use digital tools for monitoring and managing their own physical, mental and social health and well-being. As a result, they take on a more active role in achieving their health potential and in adopting healthy lifestyles at home, in the community and at work,

> and they also interact better with their doctors and carers (receiving and providing feedback). Citizens are more health literate, are more autonomous and active, participate more in social life, have better employment opportunities, take on a more active role in achieving their health potential and in turn have a higher quality of life. [...] However, in parallel, it is vital to ensure that online-based patient-centered programmes do not leave behind the very people they are primarily designed to empower. Moreover, citizen's digital health literacy is essential for the successful transformation of health care systems. [...] Accordingly, the proposed activities should address all of the following: Map health literacy research in the EU (and beyond). (HE, p. 19)

Hence, from H2020 to HE, a shift in how increasing health literacy should be implemented is observable in the latter improving health literacy through developing and implementing new ICTs that either function as an internet-based source of information or create further information through self-tracking (catchphrase: creating evidence), allowing users to collect and assess new information. Digital literacy becomes a premise for citizens and professionals: "Citizens and health and care professionals have increased digital and health literacy" (HE, p. 129). While for citizens particularly, digital literacy becomes a premise for practices of self-tracking; self-tracking also becomes a premise for health literacy. This leads to the second component of self-tracking practices, usually referred to as self-management.

6.3.2 Self-Management

In this chapter, I first give an overview of the aspect of self-management presented by the EC before outlining the practical and socio-structural effects of these visions in particular connection to data practices. Similar to increasing health literacy, the practices of self-/ health-management are not entirely defined but always inherently ICT- and data-based: "European citizens are educated, motivated and empowered to use digital tools for monitoring and managing their own physical, mental and social health and well-being" (HE, p. 19). Here, the work programs mostly refer to self-operated monitoring (i.e., self-tracking), and the administration of the generated data for one's own use in being better informed about one's health status (see above) or for health care practitioners and researchers. In H2020, several promises tied to this envisioned data practices are stated, to quote the most significant one:

> Improved level of accessibility, control and portability of health data for citizens; Open, extensible and harmonisation-based citizen health records solution for service

> and app developers; Easy and safe for citizens to provide and donate their health data for research. (H2020, p. 168)

Here, also the above-discussed aim is stated to unify healthcare and health-data administration as good for the digital economy and relying on harmonization of data practices (see Chapter 6.1.3). Further, the importance of this data to inform not only citizen-patients themselves but also research is stated, particularly displayed in the H2020 sub-project "SC1-DTH-12-2020: Use of Real-World Data to advance research on the management of complex chronic conditions" (H2020, p. 111-113). Basing the possible performances of researchers and health care practices also on the practices conducted by citizen-patients marks another shift of responsibilities in health care. Not only is the process of decision-making re-divided but also the matter of who informs whom. This is directly stated in HE as seen below marked in bold:

> Health care providers are trained and equipped with the skills and competences suited for the future needs of health care systems that are modernised, digitally transformed and equipped with innovative tools, technologies and digital solutions for health care. **They save time and resources by integrating and applying innovative technologies, which better involve patients in their own care, by reorganising workflows and redistributing tasks and responsibilities throughout the health care system, and by monitoring and analysing corresponding health care activities**. (p. 106)

Being observable in regard to practices of self-conducted data management creates differentiations according to the EC who also simultaneously equates all of the EU's citizens as "healthy," hence not yet patients. Both groups are viewed as distinguishable while addressed with the same solutive concept. As "[c]itizens are better informed to manage their own health actively, have the tools to maintain their healthy status, improve their health and reduce their risk for developing chronic diseases" (HE, p. 36), the acute care approach for patients is described equally:

> The development of data-driven solutions empowering citizens' and cancer patients' interaction with the health care systems, including feedback mechanisms, guidance on health care pathways and on managing health care data, supporting patients in making health care decisions and treatment adherence; [...]. (HE, p. 191)

Within the work programs, citizens are either situated towards the *good and healthy* end of this range or on the *bad and ill*, any in-between is usually not acknowledged. The observation of being ill as costing money is based on this clear order of society. Therefore, the argument of implementing a solution that prevents public healthcare costs can be viewed as equally a solution for (and prevention of) potential individuals suffering from illness. In other words, where health care costs are being diminished evenly, suffering is also diminished (also see Chapter 6.1.2).

This inversion of the argument for ICT-based health management as beneficial for prevention and treatment is similarly an argument also made in favor of citizens' autonomy. Evidence-based personalized care approaches have earlier been viewed as based on data gathered and evaluated in the setting of health care institutions, hence within doctor-patient interactions, e.g., hospitals and doctors' offices (Prainsack, 2017). As mentioned, in recent years, the emphasis has been put on data gathered outside these settings by individuals, foremost through ICT-based self-tracking. Hence, the vision of the empowered citizen being enabled to act self-determined has been added with the co-responsibility of helping to “mine” this knowledge – referred to as self-management.
The EC connects this behavior to an ideal vision of the Union´s citizens: “European citizens are educated, motivated and empowered to use digital tools for monitoring and managing their physical, mental and social health and well-being” (HE, p. 19). Here, empowerment is referred to as going hand-in-hand with a certain mindset. Acting as empowered is viewed not as a task but as something individuals are keen to participate in. Here, the interconnectedness of management and health literacy also becomes visible again. While, as discussed, data generated through self-monitoring, as an aspect of self-management, is a premise for health literacy, here this literacy is also stated as a premise for self-management:

> Educational material and campaigns targeting the most vulnerable groups, (e.g. children and the elderly), disseminated via the most appropriate and effective media and communication channels, to improve health literacy, skills, attitudes and self-awareness leading to a better (self-)management of wellbeing and/or mental ill health. (HE, p. 28)

Besides showing the messiness of how the various components of empowerment are intertwined in a meaning-transmitting assemblage, the stated target groups of children and the elderly are particularly highlighted in this quote. Yet again, it exemplifies the overarching frame of a one-size-fits-all approach still present within the vision of personalized medicine.

The go-to approach emphasized by the EC is tagged as personalized. At the same time, the definition of what is required is defined in general and thereby still a patronizing, top-down approach. The quote expresses the need for adapted ways of communicating with the “most vulnerable groups.” However, the inherent logic of the EC´s approach, that health literacy can be transmitted unidirectionally and will lead to changed behavior, is maintained for all groups equally. In short, self-management as a premise for health is considered equally possible to achieve and perform for everyone. Healthy, ill, young, and old are demographic categories directly stated in the work programs in connection with self-management, illustrating the understanding of innovation as a generally applicable panacea, as Pfotenhauer & Jasanof (2017) fittingly put it.

Lastly, management is inherently connected to data practices such as mining through ICT-based monitoring, administrating, and sharing. Besides unifying health care quality throughout the union and making it fit for increased demand through facilitating these practices done by citizen-patients, the data managed in these practices are viewed as an asset. This aspect includes the discussion on ownership of citizen-generated data (see Chapter 6.2.2). While this point yet marks another aspect coined as empowering, when the control over one’s self-generated data becomes equated with control and autonomy of one’s health, researchers have pointed to the complexity of data as an asset due to its reproducibility and concurrency of usage (e.g., Birch, 2020; Fischli, 2022; Piasecki & Cheah, 2022; Prainsack, 2019). Thereby, the promise of autonomy, as presented by the EC, lacks operability as control over one’s data is not given. Also, treating data as a personal asset has been criticized as the for-profit direct exchange of individual data that reproduces inequalities, as people with a lower socioeconomic standing or dealing with under-researched illnesses might be more willing to exchange their data for poor conditions. Prainsack (2019) argues against personal control and individual property rights over data but also stresses that public control is insufficient if it does not actively address social inequalities in using and handling data for a broader public good. For example, when fostering specific research areas, such as rare diseases. In the following last Chapter of my analysis, I look more detail into social practices implicated in these data practices referred to as empowerment.

6.3.3 Communication and Collaboration

This aspect is exciting as it depicts how the EC envisions health and healthcare as a collective affair distributed in society while determining the citizen-patients’ position and, thereby, the scope of empowerment. As said in Chapter 2.1.2 on the theoretical

conceptualization of empowerment, the notion can either be defined purely alongside the behavior of individuals as citizens-patients and potential healthcare receivers or as a more collaborative vision. The latter version acknowledges the shared expertise of patients and doctors and focuses on facilitating dialogue between these two. Since this aspect is a crucial feature of the notion of empowerment but can be constituted differently, this chapter examines the version supported by the EC and how this narrative strand is integrated into the innovation imperative (Pfotenhauer et al., 2019) using the terminology of empowerment. Note that the term “collaboration” as such is not taken in-vivo from the work programs but has been applied by me as an umbrella term for various similar things.

Both work programs and the additional materials explicitly express this vision manifoldly, e.g., “Innovative solutions involving digital tools have the potential to improve people-centred care through self-management, goal orientation and shared decision-making” (H2020, p. 114). More illustrative, and as roughly stated before, a general statement that is made several times throughout the HE work program (under Destination 1 and 5) stressing empowerment as dialogue: “Proposals should consider a patient-centered approach that empowers patients/citizens, promotes a culture of dialogue and openness between health professionals and citizens/ patients and unleashes the potential for social innovation” (HE, p. 22; 29; 34; 38; 68; 105; 112; 115; 161; 169).
Overall, whenever a sub-project mentions aspects like “dialogue,” “interaction,” and “shared decision-making” it either refers to the development of new ICTs foremost facilitating the better gathering and usability of citizen-data or better integration of thereby generated data into decision-making processes, i.e., dialogue between patients and caregivers is supposed to be based on and mediated through such data. Therefore, as with other aspects of empowerment, a more collaborative and less paternalistic healthcare approach is always viewed as requiring not-yet-available technological innovation.

Taking a more detailed look shows the entanglement of autonomy becoming involved in healthcare with the development of ICTs, facilitating the envisioned healthcare is scheduled at two points in time of the linear process of innovation. Once, in the future setting of doctor-patient interaction, and secondly in the development process of the potential ICTs: “Encourage an early systematic dialogue between innovators, patients, and decision-makers throughout all regulatory steps to provide guidance and clarity” (D3, p. 32). This emphasis on “integrating people in the design and decision-making, based on expected health outcomes and potential risks involved” (D6, p. 10) is happening in the wider frame of responsible research and innovation (RRI) state as to be approached in the Framework Programmes for Research and Technological Development. Hence, it is not exclusive to the health cluster.

However, in the health section, this approach is crucial to the above-described observation that collaboration is foremost stated in supporting the positive future vision of technological innovation. In other words, this early integration of what could be understood as acknowledged lay expertise (Wynne, 1992) of citizen patients is only emphasized in connection to the development of ICTs in order to secure the usage of those by the envisioned end-users of citizen-patients: “The design of the prototype should be user-driven as to ensure the early buy-in of final users (from citizens to healthcare professionals and scientists)” (H2020, p. 144).

Integrating citizen-patient needs in the development process to secure later usage of the innovation output potentially appears to be a bottom-up design approach. Still, as discussed in Chapter 6.2, the potential behaviors of citizen-patients are not only determined to be ICT-based in the first place but these ICT-based practices are pre-defined as well before citizen-patients are included in the development process. Hence, collaboration in the development process is promoted to ensure citizen-patients will use the results. In other words, the envisioned citizen-patient behavior – broadly described with self-management – is facilitated in a way that is certainly approachable for *end-users* and thereby successful. Hence, the proclaimed performance of this collaborative approach is not put to first and foremost provide space for hearing, gathering, and integrating citizens-patient needs as these needs are already predefined to a certain degree as a need for the described ICT and their ability to facilitate a certain behavior of citizen-patients. In comparison, other definitions of collaborative empowerment (2.1.2) emphasize strengthening the interpersonal doctor-patient relationship based on the possibility and openness to discuss individual needs and values in health and care instead of entering this dialogue with preconceived ideas of improvement. This approach also nicely depicts the described tacit governance (Felt & Fochler, 2011), as the usage of the ICTs is not judicially demanded by citizen-patients but otherwise tried to be implemented as a common standard.

Further, as discussed in Chapter 2.3, so far promises of ICT-based empowerment lack evidence (Hoeyer, 2023; Karni et al., 2020; Morley & Floridi, 2020). Agner & Brown (2018) even describe the current ICT-based approach to empowerment as counter-productive in strengthening actual collaboration if collaboration is understood as interpersonal engagement, as ICT approaches only focus on a limited set of practices. This rather narrow and pre-defined vision is re-performed, i.e., *rehearsed* (Felt, 2015), in the EC’s depiction of the future empowered citizen-patient as the actions emphasized as empowering color this term with meaning within the work program.

Looking at the second moment, the doctor-patient interactions in moments of care, collaboration as empowerment is emphasized by several sub-projects as a necessity for

improved health care and treatment outcomes. Sharing values and aims between those caring and those cared for is stressed as required for the success of “patient-centered care,” for example: “HORIZON-HLTH-2021-DISEASE-04-01: Improved supportive, palliative, survivorship and end-of-life care of cancer patients”

> Prove the feasibility of integrating the proposed interventions in current pain management, palliative, supportive, survivorship and/or end-of-life care regimes and healthcare systems across Europe. The complex human, social, cultural and ethical aspects that are necessarily managed by those care regimes and healthcare systems should be reflected from the patients’ perspectives as well as those of their professional and family caregivers. The views and values of patients and their caregivers (including families, volunteers, nurses and others) should also be appropriately taken into account in patient-centered care decisions. (HE, p. 67)

While the project supports that patients’ perspectives are taken into account in moments of care, a few lines above, it also states that the project is determined to have patients make “use [of] the improved evidence-based and information-driven palliative care decision-making process” as they are higher in quality as they show a better “(cost)effectiveness” (HE, p. 67). Hence, while the complexity of the healthcare setting and the patient's perspective is valued, the project again describes an approach that aims to tune those to an attitude in favor of the EC's intervention-based approach.

My observation here is not about judging the quality and actual outcome of the measurements that potentially follow this subproject, as my analysis focuses on the vision given by EC, not further development or even practical implementations. Still, the work programs show quite a contradiction in valuing the autonomy of those being cared for when the outcome of the project is supposed to bring evidence for the effectiveness of the EC’s suggestion, fostering adaptation of perspective and behavior on the patients’ side toward these suggestions.

The picked example refers to a general topic observable in the work programs popping up regularly: trust. Trust plays a huge role and is referred to as the result of the EC’s approach as well as the premise for success – similar to the notion of empowerment. This is because the solutions focus on the behavior of the individual. Therefore, the success of the measurements relies on the uptake of solutions, hence the usage of the newly developed ICTs and the adaptation of behavior toward the intended usage.

> Citizens’ trust in knowledge-based health interventions and in guidance from health authorities is strengthened, including through improved health literacy (including at

> young ages), resulting in increased engagement in and adherence to effective strategies for health promotion, diseases prevention and treatment, including increased vaccination rates and patient safety. (HE, p. 13)
>
> The scope of this topic is to foster the large-scale pilots for deployment of trusted and personalized digital solutions dealing with Integrated Care, with a view to supporting and extending healthy and independent living for older individuals who are facing permanently or temporarily reduced functionality and capabilities. This in turn is expected to contribute to a patient-centered and truly individualized strategy in order to develop trusted, robust, and financially sustainable services potentially usable in any Member States and the Digital Single Market, and applicable to a very wide range of patient pathways. These approaches aim to enable people to remain independent as long as possible and prevent hospitalization. (H2020, p. 150)

Similarly to the depiction of a deficiency in knowledge about health, causing a lack of healthy behavior, trust in this kind of expert knowledge and the referring knowledge-based practices is viewed as missing in the present society. Therefore, autonomy and independence are favored as people are supposed to enact the envisioned health care more independently. However, the “usage” of this autonomy has to happen in tune with the wider vision of the interplay of society and health care to have the vision of a more (cost)-effective system to be successful. To have people independently adapt their behavior to this vision, the EC goes for “establishing” trust. This observation, as such, would not be diminishing the statement in favor of autonomy, but in connection to the observation made before, the aim to take citizens' perspective actively into account overlaps with the aim to harmonize citizens’ perspective with the EC’s perspective. In short, autonomy is emphasized in having people behave in line with the EC’s suggestion, and the establishment of trust is needed to accomplish this behavior in a way where individuals act autonomously, meaning being enabled to do so by themselves. This ties back into the redistribution of responsibility as “enacting” health care is allocated to the individual ICTs using citizen-patient.

The aspect of trust also marks the overlap between the aim to increase health literacy and strengthening collaboration. Health literacy is defined as a premise for trust in expertise. In contrast, trust is viewed as a premise for patient-citizens' collaboration with experts in the ICT development process or care settings. Noting this underlines the one-directional dimension of collaboration. Though I am focusing on the role of the citizen-patients in my thesis while the EC’s vision addresses other actors as well, it has been remarkable that the most revised role/ position in the work programs is the one of the citizen-patient. This becomes very clear by understanding that collaboration is envisioned through citizens

adapting their perspectives toward that of experts. Citizen-patients are viewed as lacking information and the ability to interact with healthcare professionals by lacking trust, knowledge, or simply willingness – as the work programs occasionally speak of *motivating* citizens through ICT-based practices. The notion of empowerment continuously addressed these deficiencies and functions as chameleon terminology by addressing different things while always expressing this narrative of deficit in a positive speech. In other words, instead of speaking of *"citizens currently lacking the ability to manage their health,"* the documents say: *"Through innovation, citizens will be empowered to manage their health"*. As described by Pfotenhauer et al. (2019), the deficiencies of the public become a deficiency of innovation needed to practically implement a certain socio-technical imaginary (Pfotenhauer & Jasanoff, 2017). The notion of empowerment is integral to this kind of expression as it is used to transmit this practical implementation, always referring to innovation.

7 Discussion and Conclusion

In this last Chapter, I discuss four final conclusions drawn from my research and outline potential areas for further research. While the analysis (Chapter 6) has been structured as discussing the macro level of contexts of the topic at stake before digging deeper into the micro level of practices referred to the notion of CPE, this Chapter is roughly organized the other way around. I start with two takeaways on the notion of CPE as put by the EC and discuss further implications of this very understanding subsequently.

7.1 Too loose to be pinpointed, too narrow to be adapted: Two main Observations

Tracing the notion of citizen-patient empowerment through the EC's current research funding approach has shown two things simultaneously. First, the concept is not yet definitely defined as picked up by the EC: though both Horizon projects give a rough definition at some point and refer to the stated components throughout their texts, the term is used to describe various aspects, overlapping and shaping each other´s meaning in a rather messy way. I depict this in Figure 7, filling the overlapping areas between the three main aspects, increased health literacy, self-management as data management, and collaboration and communication. Summarizing my general findings on "*How does the European Commission imagine citizen-patient empowerment in healthcare in their research funding calls for Horizon 2020 and Horizon Europe?"* is supposed to illustrate the multiplicity of practices referred to empowerment. In other words, let me stress that this summary is the result of my analysis

and not described as such in depth by the EC, which keeps its definition of empowerment rather loose.

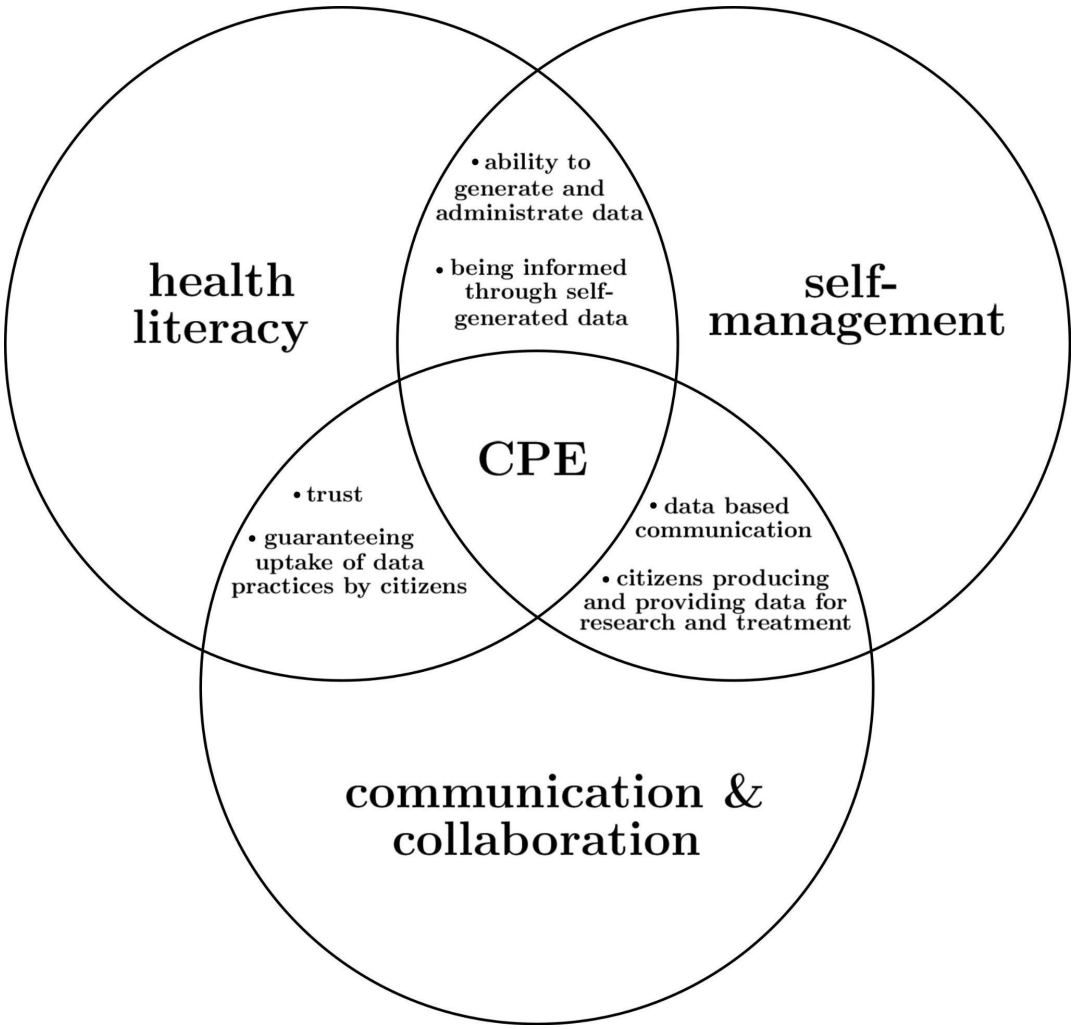

Figure 7: Van-Diagramm, three main co-constituting practices of CPE and their overlappings

Increasing citizen-patients' health literacy, e.g., is expected to enable them to fulfill self-management as data management. While the very component of increased health literacy is also supposed to be implemented through the outcome of self-management, described as self-monitoring and, thereby generation of data. This data about the self is also framed as an informing resource for citizen-patients and an *obligatory passage point* (Callon, 1984) when gaining better health literacy and becoming part of the envisioned public healthcare network.

Similarly to the shared area of literacy and management, collaboration and communication with self-management is solely envisioned as data practice itself or as being about improving data practices. Either citizen-patients are expected to share their data generated through self-monitoring to inform doctors and base, e.g., treatment decisions on this information –

viewed as the most objective and right approach. This aspect of collaboration is particularly coined as improved communication based on patient-generated data. Or citizen-patients are expected to engage in research. Either through sharing their data for future research or by including citizen-patients in the research and development approaches within the innovation process. As I have outlined above (Chapter 6.3.3), this participatory approach is usually underpinned by guaranteeing the later voluntary usage of the developed data technologies; hence, applied in order to match the beforehand defied vision of data practices with the citizen-patient as ensuring the later uptake and usage of the practices in an intended way. How participatory research has eventually been conducted in the funded project and how citizen-patients are actually going to make use of the final results is not answered by my analysis.

The last common denominator between components of CPE is trust; viewed again simultaneously as obligatory for finally *working out* vision and also a result. Particularly, collaboration (in all states) is viewed as motivated and voluntary by citizen-patients as they trust experts and the offered approach. To establish trust, the EC describes a classical deficiency model in public understanding of science (Pfotenhauer et al., 2019), claiming the need to increase citizen-patient literacy in expert knowledge as the base of this very trust.

Let me stress that, similarly to the notion of empowerment itself, the three main components are not defined further than what I describe here. As taken from the information videos, this openness is also given to the funding applicants to a certain degree, while I also would like to stress that this very openness is in itself a substantial component of the notion of CPE, performing a particular implication, which builds my first main result:

1) Keeping the usage of the notion of empowerment multiple and open allows for creating a promissory vision of future healthcare that cannot be pinpointed nor evaluated precisely; therefore it is too big to fail as it can never be proven to be unsuccessful. Integrating this open understanding of CPE in the innovation model – by referring to CPE as both the premise and the outcome – the usage of the notion of CPE does not only refer to itself as fostering potential practices of empowerment but to a broader level, it overall supports the EC's innovation logic.

Second, this very entanglement of the notion of empowerment and the linear innovation model depicts the deficiency logic described by Pfotenhauer et al. (2019) as a non-separable deficiency of CPE and innovation. In other words, the lack of empowered-behaving citizen-patients is defined as a weakness, a threat to the innovation-based economy, and a result of the lack of innovation. Strengthening this entanglement of CPE and linear innovation by putting the missing one as causing a gap in the other also stabilizes the

inverted argument that fostering innovation equates to fostering citizen-patients' health and well-being – as this is viewed as reliant on CPE. Therefore, as I have outlined in Chapter 6.1, making CPE inherently innovation-based through how it is described as mutually integral to the innovation-based economy, stemming healthcare costs, shapes the very meaning of CPE by only connecting it to practices compatible with innovation. As this future economic strength as an outcome of innovation is put as inherently data-based, coined the overall "digital transition [...]" (D5, p. 5), the very practices of CPE, impacted by or being aligned to the innovation approach, are envisioned as data-practices solely. Therefore, my second take-away message is:

2) The overall innovation-based approach of the funding programs has a defining impact on the potential meanings of CPE. By referring to the notion of CPE integral to the outcome of innovation, it is incorporated into the innovation logic to a degree that detaches it from other possible understandings of empowerment if these are incompatible with innovation. Thus, since the EC's innovation approach is inherently envisioned as data-based, CPE results in exclusively being envisioned as data-based practices.

The notion of empowerment being as strongly intertwined with visions of overarching digitization of life is not specific to the EC's approach but common, as particularly the history of the terminology of empowerment in the health context shows (Beck-Gernsheim, 2000; Felt et al., 2009; Fischli, 2022; Lupton, 2018; Marent & Henwood, 2022; Nielsen & Jensen, 2013). Hence, my observation here is giving an in-detail depiction of how this intertwinement is shaped by the overall innovation-based logic and how this plays out – particularly in the EC's case. Still, I also want to stress the shift from describing empowerment this way in the health context, not as ICT based but data-based, shifting the focus of analysis twofold. First, focus on referred data practices. Hoeyer (2023) uses the terminology of data work, acknowledging the effort put into these practices. Viewing the ICT-based empowerment approach this way helps to place special emphasis on the bodily experience of conducting the data practices, i.e., acknowledging that there must be a living body that has to conduct these practices, investing one's time and energy. This effort is usually kept silent and paradoxically, as the example of the EC precisely illustrates, is supposed to be conducted by people throughout all phases of life, health conditions, and other demographic aspects. Addressing empowerment as data practice instead of ICT-based shall help foreground the paradox of expecting equal ability throughout society to conduct the same kind of effort in the digitization of health. Acknowledging this paradox of unequally distributed empowerment and disempowerment, as Hoeyer (2023) has precisely put it, shall help address different capabilities and needs when thinking about digitizing health.

Second, the focus on data instead of ICTs allows focussing on the key overlap of the given understanding of empowerment and integration of individualized healthcare into an economic promise of the “Digital Single Market” which would overall strengthen the EU – as a panacea (Pfotenhauer & Jasanoff, 2017). Here, data is viewed as an evermore promissory asset. Thereby, focusing on data helps trace the defining impact of the innovation approach on the actual given description of empowerment. Making healthcare a pillar in the digital single market is described as equally beneficial for healthcare, as becoming more cost-efficient, and for the EU as an economy generating new assets in the form of citizen-patient data from the newly integrated sector. The often-claimed critique on empowerment, being a neoliberal approach (e.g., Lupton, 2018; Morely & Floridi, 2019; Odone et al., 2019; Prainsack, 2017; Roth & Bruni, 2021; Stuart, 2020), can be understood more precisely when making this intersection visible. Neoliberalization here does not merely mean a shift of responsibility to the individual, but this shift is happening according to the underlying aim of economic growth. Accordingly, in the case discussed here, the datafication and assetization of this data are not motivated by a benefit for individuals’ health but a necessity in a more encompassing logic of benefiting society. In short, focusing on data allows tracing the determining integration of the notion of CPE into the innovation logic and, thereby, the digital single market-oriented outcome of the very envisioned practices of empowerment.

7.2 Empowerment Practices as Practices of Citizenship

Further, my analysis has shown that the EC’s vision of empowerment is not merely a set of practices but that these practices are integral to the overall sociotechnical imaginary in the making. These practices can be described best as part of the structure-agency relationship, a technological-based performance of the agency of individual actors. In this case, the very practices have an ontological impact on the agency of citizen-patients. On their position not only in a care network (as patients) but as conducting the very data practices of staying healthy through staying informed, self-management, and supporting research through sharing self-gathered data – coined as altruistic and “good citizen” behavior. These practices have become integral in constituting one's position in society as a citizen of the EU. In other words, the EC not only refers to the public and care-receiving group in society as empowered if they fulfill such tasks and practices but actually integrates the individual into this healthcare network as both patient and “not-yet-patient figure” (Felt et al., 2009)., leading to my third main observation:

3) The EC's vision of empowerment can be understood as tacit governance through innovation (Felt & Fochler, 2011) given that the data practices defined as empowerment are supposed to become standardized and consequently mandatory for individuals if they want to become part of the healthcare network as citizen-patient. Thus the role of citizens with access to health care is made exclusive to people performing the practices of innovation-based empowerment.

Looking at the determination of the figure of the citizen-patient being enacted through data practices and defining these data practices by how they are referred to by the notion of empowerment, allows me to identify the societal reality as a component of the socio-technical imaginary of empowerment. Here, data as an actor in the healthcare network determines the relation and position one has and the referenced behavior is defined according to the data. Addressing this assemblage as a sociotechnical imaginary with Jasanoff (2015) has allowed me to outline the power structure within this network, showing the defining power of the EC ascribing tasks and practices of enacting a certain position.
Looking at the figure of the citizen-patient in particular, the ascribed data practices have a twofold defining impact. What I have discussed so far describes the component of data practices as just practical; hence they are embodied behavioral experiences and also social. They define behavior to be conducted; here, Hoeyer (2023) defines four types of what he calls data work: "Data production, data analysis, data instruction, data use" (p. 92). This practical multiplicity of data is always paired with an epistemological multiplicity and similarly to the determinative power of the EC, conducts a form of tacit governance by defining a) healthcare as data-based and b) the actual practices constituting this data-based approach, and also c) defines the epistemology of data. In other words, Hoeyer (2023) has shown how data is ontological multiple as data- practices differ due to the context: "Taken together, these musings on the meaning of 'data' show— is in line with Wittgenstein's notion of meaning emerging through language-gameshow people associate the word 'data' with what they do in the course of their daily work" (p. 17). On the other hand, Hoeyer (2023) has stressed the epistemological multiplicity of data as equally context-dependent and consistent with former voices (Ajana, 2017; Sharon, 2017; Van Dijck, 2014), falsely framed as pure or objective truth; it is thereby simultaneously epistemologically multiple. The last observation I draw from my analysis sticks to this particular characteristic of data and discusses it in regard to the determinative top-down approach by the EC, defining data practices also as epistemological practices of knowing health and illness.

7.3 Empowerment as Epistemological Injustice

As I have discussed in Chapters 6.1 and 6.2, the division of possibilities and responsibilities of citizen-patients, participating in (shaping) the future healthcare approach practiced under the linear innovation model of the EC's impact-oriented approach leads to a rather executive position of citizen-patients. Neither are they involved in the development process nor the autonomous usage of the innovation process outcomes in a degree designed to involve citizen-patients' perspective on the conception of health, healthiness, and illness, nor what is accounted as healthy behavior. These conceptions are strictly inscribed (Akrich, 1992, as referred to by Felt & Fochler, 2011) in the process as biomedical and data-based before citizen-patents are supposed to be integrated.

Biomedical approaches as techno-scientific practices of knowledge production have already been discussed as rendering societal aspects of health and illness invisible, functioning "as a regime of truth [...]" (Clarke et al., 2010, p. 49). This has further been addressed as epistemic injustice (Fricker, 2007); if the participation of care receivers in the production of knowledge about their health status is not actively added, the possibility of overcoming the set hermeneutical – biomedical – concepts of health (Chung, 2021; Kidd & Carel, 2018; Michaels, 2021; Moes et al., 2020). Putting this differently, hermeneutical injustice happens when the hermeneutical concept of making sense of a situation that is admissibly applied to a situation does not allow one to grasp the situation. By contextualizing the health status of an individual with their behavior – hence on an individualistic level – foremost and disconnecting it from broader social or environmental influences, as I have shown is the case in the Horizon work programs (Chapter 6.1), the resulting hermeneutical conception of health is not designed for comprehending social dimensions of health. In my analysis, I noted the framing of health as located on an individual level, progressing further from *Horizon 2020* to *Horizon Europe*.

Particularly by making the healthy and the sick citizen evermore a data object while data can only depict certain aspects of health, the EC's innovation approach creates a hermeneutical gap, as Friker (2007) calls it, as it is only applicable to a biomedical perspective. Therefore, the outcomes of the funding processes silence certain realities by making the techniques and practices used to gather evidence noncompliant with them. Tracing the notion of empowerment shows the idea that increasing health literacy, hence knowledge about one's health, is to be gathered and interpreted in a particular database approach. Knowledge about the self is gathered through tracking, translated into data points, and, lastly, supposed to depict one's healthy and unhealthy habits. This behavior is referred to as exclusively going to enable the individual as a knower of one's health and communicate this situation with caregivers while at the same time, the facilitated practice of knowing does not allow for

grasping all aspects of one's health and illness. I summarize this point as my last main observation:

4) Citizen-patient empowerment envisioned as data practices entails a fixed hermeneutical conception of health and illness. This exclusively biomedical conception by the EC is closed before citizen-patients can participate in developing the approach to healthcare. The knowledge produced and used by this empowerment approach potentially blocks comprehension and communication of one's experience if not all of the citizen-patient's health aspects are valid from the datafied biomedical perspective. Therefore it leads to epistemic injustice (Fricker, 2007), diminishing the citizen-patients´ agency as a knower of their well-being.

Therefore, the social dimension of the sociotechnical imaginary of citizen-patient empowerment as envisioned by the EC in the Horizon funding programs does not solely result in a shift of responsibility of taking care and making decisions for one's own health (Btihaj; 2017; Kuntsman et al., 2019; Lupton, 2018; Miyake & Martin, 2019; Prainsack, 2017 Sturt et al., 2020) to be performed by the according data practices, but simultaneously locates the sovereignty of knowing on the position of the caregivers and health professionals. As noted throughout the thesis, such imaginaries and innovation processes can never be 100 percent controlled. How citizens, either by active initiative or just by practice (will) adapt to the possibilities and their usage is an outstanding question, as discussed in the following last subchapter.

7.4 Areas for further Research

When understanding the notion of CPE as a sociotechnical imaginary (Jasanoff, 2015), it has to be understood as an imaginary in the making, particularly as visions the EC aims to establish and stabilize. Further steps in the development of a sociotechnical imaginary are not part of this thesis and are not yet foreseeable. Projects under *Horizon Europe* have not all started yet and will end in 2027. Keeping track of CPE as it is taken up by researchers conducting the funded sub-projects would be one fruitful point in following the notion. Next, it would also be fruitful if the corresponding reaction of the EC integrates the projects' outcome into an overall approach or not. Lastly, the very practices as outcomes would need to be assessed. As techniques of self-monitoring and datafication of health are not entirely new, such works already exist, and the potential outcome of practices by the Horizon projects will not be completely separable from existing practices. Still, how ICTs and their usage will be

implemented in society and used by citizens as other actors in the healthcare network is an ongoing development.
Hence, while I have analyzed a very rigid theoretical kickoff solely from the perspective of the EC, though being a powerful determined, that does not allow forecasting a societal reality of healthcare. It is a firm intention, and whether it will fail or succeed in some points is to be negotiated. Exceptionally, interrogating the final personal experience of citizen-patients with it will be important to assess in regard to the notion of CPE. First, whether a person would describe it as beneficial and thereby empowering, or second if the version of empowerment I have identified in my thesis does not correspond with a person's needs and thus either fails or is modified in an unforeseeable way.
Also, since the very practices of participation are integral to the notion of CPE also include other persons, such as researchers, technicians, and developers, or later healthcare professionals, assessment of their experience with the practices of citizen patient empowerment would be of interest (Felt et al., 2023). Here, Hoeyer (2023) has already done essential work and noted partial skepticism as well as disinterest in the ongoing datafication from the doctors' perspective who have experienced problems with the operability of the system in Denmark.

Certainly, the discussion on digitization and thus datafication of health and healthcare as well as the stronger integration of care receivers into the referring practices reaches beyond the Horizon programs. First, participatory approaches in medical research as well as in care settings and the understanding of the role of the participant, i.e. the care-receiver are genuinely impacted by the aim for digitization. As briefly addressed in Chapter 2.4, the need to reflect on capacities and needs in order to participate in a self-determined manner is particularly delicate when the participants are concerned with a debilitating condition (e.g., de Boer, 2021; Rogers, 2022). Integrating a person with a severe health condition into any participatory approach, either research or care setting, demands different practices as well as epistemic conceptions than addressing a formally healthy person. The question of how to make participation as flexible as needed to allow autonomy beyond the standardized model is yet to be interrogated and in particular, in regard to the participatory approach facilitated through data practices (Rabeharisoa & Callon, 2004). Similarly, acknowledging the epistemic impact datafication has on the understanding of health and illness, in particular, the resulting emerging understanding an ill person has about oneself still lacks empirical work.
To summarize, health is an encompassing public topic with a strong potential to shape a person's life. Therefore, the actuality of how collaboration between patients and caregivers will look in future care settings and how citizen-patients self-understanding in regard to their

well-being will be practiced with or without data as integral are ongoing topics in need of careful analysis, either accompanied by the notion of empowerment in the future or not.

List of Figures

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Abstract

Digitization in medicine does not only envision a future of personalized care and treatment but also heralds a future of increasing autonomy and self-determination, often called "patient empowerment." This controversial term is part of the European Commission's current Research and Innovation Fund programs *Horizon 2020* (2014-2020) and its successor *Horizon Europe* (2021-2027). Understanding these innovation-oriented programs as future-creating practices, I analyze the role of the empowered citizen-patient as a subject of the future of healthcare with material-practical and sociostructural implications for individual citizens as persons with access to public healthcare. Tracing the notion of empowerment throughout *Horizon 2020* and *Horizon Europe's* documents, I identify the practice of empowerment as exclusively data-based. Ultimately I conclude that empowerment determines the citizen-patient's performance as an actor in the network of public healthcare and also determines the epistemic concepts of one's own well-being exclusively through a database method.

Zusammenfassung

Die Digitalisierung der Medizin steht nicht nur für Visionen einer personalisierten Diagnostik und Behandlung, sondern auch für zunehmende Autonomie und Selbstbestimmung, oft bezeichnet als "Patienten Ermächtigung", "Patient Empowerment". Dieser kontrovers diskutierte Begriff ist auch Teil der aktuellen Forschungs- und Innovationsförderprogramme der Europäischen Kommission *Horizion 2020* (2014-2020) und dem Nachfolgeprogramm *Horizion Europe* (2021-2027). Die beiden innovationsorientierten Programme als zukunftsschaffende Praktiken verstehend analysiere ich die Rolle der/s ermächtigten Bürger*in-Patient*in (empowered citizen-patient) als Subjekt einer Zukunftsvision von Gesundheitsversorgung mit praktisch-materiellen und sozio-strukturellen Implikationen für die Rolle des/der einzelnen Brüger*in als Person mit Zugang zu öffentlicher Gesundheitsversorgung. Die durch die Analyse des empowerments-begriffs in Dokumenten zu den Förderprogrammen identifizierte rein Datenbasierte Praxis des Empowerments bestimmt letztlich nicht nur die Performanz der Bürger*in-Patient*in als Akteur im Netzwerk der öffentlichen Gesundheitsversorgung, sondern auch welche epistemischen Konzepte von Gesundheit und eigenem Wohlbefinden diesen zur Verfügung stehen.