

Citizens in Search for a Place in the Digital Health Data Space: A Case Study

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Abstract. Background: Digital health solutions have been omnipresent in policy agendas. However, we still need to better understand how citizens experience these developments and, more specifically, how citizens would ideally want such solutions to look like. Objective: We explore the needs and concerns citizens expressed in different phases of the co-creation process for a prototype of a citizen-centred health data platform within a large-scale European project: Smart4Health. Method: We follow a qualitative approach in our analysis of 9 discussion groups in addition to a diverse set of 49 qualitative interviews with citizens and health care professionals. Results: We show how citizens identify the positive potential of health data infrastructures and how they relate digital health to wider developments in contemporary societies. We then outline citizens' concerns that potentially prevent them from becoming users and thus destabilize the policy vision of digital health. Conclusion: Four preconditions need to be met for citizens to find their place within a digital health data environment: transparency/trust, infrastructural literacy, digital justice, and a careful consideration of the distribution of responsibilities.

Keywords. co-creation, trust, transparency, responsibility, data infrastructure literacy, digital justice.

1. Introduction — Creating a place for citizens in the European health data space

In recent years, digital health has been omnipresent in policy agendas in the EU context and beyond. Issues of ageing societies, health crises such as the current pandemic and, more generally, rising expenditures on health and long-term care are all described to be addressable through investments in digital solutions, which allow for data-driven health research and health care [1]. More specifically, the goal is to create a European health data space (EHDS), which “aims at making the most of the potential of digital health to provide high-quality healthcare and reduce inequalities. It should promote access to health data for research and innovation on new preventive strategies, as well as on diagnosis and treatment of diseases to improve health outcomes, while ensuring that citizens have control over their own personal data” [2]. These digital health innovations are thus recognised as a promise “to advance health research by providing the technological means for collecting, managing and analysing the vast and heterogeneous types of data required for data-intensive personalized and precision medicine” [3]. The integration of such solutions can be seen as a re-infrastructuring of existing health care and research arrangements [4], simultaneously aiming to offer improvements while promising not to disrupt existing relations. Yet, there are also concerns that while “digital transformations have the potential to bring [...] enormous long-term benefits [...] to

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many different areas of health and health care”, they could also reinforce existing or even create new power asymmetries [5].

At the same time, these new models of care are often described to be centred on citizens’ needs with the expectation that through digital support, citizens will more proactively engage with their health and invest more time and work into its upkeep [6, 7]. This is much in line with Tamar Sharon’s diagnosis that contemporary understandings of good life are increasingly “framed in terms of the quest for health” [3]. This is not only tied to the expectation that citizens are ready to engage in the collection and maintenance of their health data, but also that they will engage in self-care practices along data-related ideals [7].

While we can see the unfolding of a powerful and highly promising vision for a digital health care system [8], it is also essential that we reflect on the potential challenges citizens might encounter once this vision is realized. On one hand, critical analysts describe the push for digital health as a form of “neoliberal ‘soft’ politics [...] in which laypeople are encouraged (‘nudged’) to engage in practices of self-management and self-care in their own interests” and warn against “victim-blaming” that might potentially occur [9]. On the other hand, the European Public Health Alliance has also raised concerns to the public consultation of the EHDS, highlighting that the main question in realising this digital health data space “is perhaps not so much the *what* but the *how*”. The alliance asserts that “any decisions taken without fully understanding end users’ concerns and real needs will most likely result in an exclusive ‘VIP zone’ rather than an inclusive EHDS – which is why more must be done to reach out to ordinary people, including civil society groups representing them, to build up capacity and identify the real barriers to the EHDS becoming a reality as an integral part of resilient health systems that cater to all. Otherwise, trust will not develop and digital hesitancy may spread” [10].

Engaging with future users should thus be at the core of this digital transformation as data infrastructures must be understood to always encode wider visions and to “become vehicles whereby those [...] are made emotionally real” [11] – in our case, visions of health care and health-related research. We also know from previous health-related studies, how important it is not to limit the alignment of such a health data infrastructure “with people’s attitudes, self-management practices, identified information needs, and the wider care package” [12], but also with the professional health care workers in order to make the data work meaningful for them [13].

In what follows, we will identify and engage with several issues that became visible in the process of building a prototype of a Europe-wide health data platform, i.e., a digital health data infrastructure that would allow citizens to collect, store, and share their health-related and health data. More precisely, we will report on the large-scale Horizon 2020 project *Smart4Health*² and elaborate on some of the key tensions between promise and realisation that citizens identified. *Smart4Health* aims to develop a prototype of an interoperable health data platform for European citizens through a process of co-creation [14-17]. By putting citizens at the core of the development process, the vision is that this data infrastructure would have the potential to empower citizens to engage with their health more proactively. This is expected to create a win-win situation: citizens can become agents in caring for their own health while the pressures on the health care system could also be mitigated. Furthermore, citizens would have the option to provide their health data for research, which would also support the development of new medical knowledge and potentially contribute to personalized treatments and care.

² <https://smart4health.eu/en/>; <https://sts.univie.ac.at/forschung/laufende-projekte/smart4health/>

In the following study we will move away from discussing the promises of digital health and instead address the following **research questions**: How do citizens perceive the tensions between potentials and limitations of such a health data infrastructure? What are their expectations and concerns? And finally, how do they see themselves prepared to engage in this new digital health environment? As we follow a co-creation approach, we can offer in-depth qualitative insights into citizens' perceptions of health data platforms. These insights lead us to argue what needs to be considered if and when a full-fledged digital health approach is implemented to create an inclusive and trustworthy environment – which is of particular importance when it comes to health care.

2. Methods

We have been engaged in the *Smart4Health* project as social science partners, facilitating a citizen-centred co-creation approach in the development and validation of a health data platform prototype. We thus acted as mediators between citizens, health care professionals and tech-developers. Specifically, we embraced a mixture between a value-based and an experience-based co-creation approach [14-17] for a health data infrastructure. As a large-scale Horizon 2020 funded project, *Smart4Health* brings together a variety of project partners from different contexts and from several countries, which each have their own distinct health care systems. In order to make this variety productive, we constructed a methodological toolbox that allowed for adaptability with regard to context, participants, and the COVID-19 pandemic [15]. The co-creation approach followed by us is thus one of the rare cases where co-creation is not applied to well localized or clearly circumscribed problems but instead to the creation of a rather complex, large-scale, and transnational health data infrastructure.

In this paper, we present insights from our qualitative analysis of an international set of engagements. On the citizen end, the sample is comprised of 5 face-to-face and 3 remote group discussions, 9 face-to-face testing sessions and 18 remote interviews; the professional end is comprised of 1 remote group discussion with physiotherapists, 4 face-to-face interviews with medical doctors, and remote interviews with 9 researchers, 5 medical doctors and 4 nurses. The latter set of interviews mainly serves to contextualize the reflections offered by the citizens involved in our co-creation processes. All interviews lasted between 40 and 60 minutes while group discussions lasted 2–4 hours depending on whether they were conducted online or face-to-face.

The interviews were qualitative semi-structured interviews that followed an interview guide with several themes and initial narration-stimulating questions. Further sub-questions were posed only if their content had not already been covered within the response to the initial questions or the ensuing conversation. The group discussions were card-based [18], specifically designed for the project and flexibly allowed for the exploration of either the entire platform and its functionalities or only specific segments thereof. In each setting – both interviews and group discussions – we drew from an exploration of so-called 'situations', i.e., specific hypothetical moments or settings in which users must act or are required to make a decision. To offer some examples, the list of situations comprised elements such as "registering for the platform", "sharing data with the health care professional", "providing data for research" and "deleting data". In that sense, this large abstract topic of digital health was broken down into the exploration of specific and accessible data practices that participants could assess by drawing on their lived experiences.

The qualitative data analysis was conducted based on a constructivist Grounded Theory approach [19] and followed iterations of initial and focused coding. Initial and focused coding are two “emergent processes” that serve distinct yet interlinked purposes. First, assigning initial codes entails an analysis of the material in a way that “remain[s] open to exploring whatever theoretical possibilities we can discern in the data” [19] and supports a sensitivity to action and processes. Through initial coding one assigns codes that are “provisional, comparative and grounded in the data” [19], staying close to the data and ready to identify gaps in the data that need to be filled by further empirical engagements. Focused coding, on the other hand, “advance[s] the theoretical direction” of the analytic work that has been established through initial coding by using the most significant initial codes to “synthesize, analyze, and conceptualize larger segments of data” [19], working out patterns, categories and themes. In addition to these two coding processes, we continuously wrote memos to further develop categories and themes.

On an instrumental level, the results of our analysis were translated into user requirements that describe the performance of the functionalities of the platform. On a more abstract level, the results point to boundary conditions that need to be considered for citizens to find their place in the digital health data space. In the following sections, we will present these conditions.

3. Results

Drawing on the rich material we collected, we want to offer a number of key insights into how citizens perceive a health data platform such as the prototype developed in the *Smart4Health* project. In doing so, we will elaborate on the moments when citizens identify the positive potential of such an infrastructure and how they relate digital health to wider developments in contemporary societies. The main focus here is to identify the constellations under which citizens voice concerns that could potentially prevent them from becoming users of such a platform. These concerns are essential to consider if health data infrastructures, such as those imagined in the European context – i.e., the creation of a European health data space – can be successfully achieved.

Indeed, our engagement with citizens shows that they can, at least in principle, embrace and support the development of such a health data platform and even be able to see themselves using it. Digital health is perceived as a largely beneficial development that has the potential to change current practices of data exchange for the better. Citizens would underline that by using digital means, “*a lot more data could be stored than just on paper*”, highlighting the advantage of being able “*to look them up ... on your mobile phone for example.*” Some even stress that they perceive this development as unavoidable and believe that this “*by and large is the future*” because it “*simply serves the patient.*” Generally, many see the benefit of such a platform, especially if it is “*a Europe-wide effort to assure uniform standards*” as they hope that such an approach would avoid that “*the solution becomes piecemeal again, with no connections between them [the different national systems].*”

However, while many citizens think that they personally – but even more so the health care systems – will simply have to go along with these transformations, they also emphasize that they could “*imagine that many people are afraid of such systems*”, voicing rather specific concerns that must be remedied. Many participants in our discussion groups or interviews were well aware of the potential drawbacks, problems, or moments in which they could lose the power to act or control their data. In actuality,

these conversations about the collection, sharing and provision of data for research were deeply embedded in a larger data discourse – at one point or another, discussions always circled back to questions of data security and protection, and potential consequences of data leaks or hacks. As one citizen put it, there is a high degree of awareness that health data “*have to be stored somewhere*” and that there could always be “*hacker attacks, whether they [the data] are protected or not.*” So, while citizens did ask questions about the security and safety measures put in place, they also exemplified their awareness that the issues at stake were much broader and that any future health data platform should be seen as embedded within a wider web of digital transformation. Thus, citizens were quite aware of the context-dependency of digital health solutions and how such wider transformations could shape the world they live in.

In fact, the omnipresent **digitization of various spheres of our lives impacted the citizens’ reflections on the health data platform.** Through analogical reasoning citizens managed to express their concerns, however, it also shaped some expectations regarding the platform infrastructure and the protection and control of data. Given the already well-entrenched understanding of the high value of health data – expressed through statements such as, “*data equals cash*” – the comparison of the platform and its processes to electronic banking was frequently used. For example, first, to address measures of data security and protection: “*the banks they have a good system. So if you make a copy of those systems, [our data] are safe*”; and, in relation, to assess data handling: “*that is the way that banks are working and it looks like as a safe way.*” Second, to articulate trust in protective measures: “*I fully trust my phone banking app, so I can also see myself in the future, trusting an app like this*”; or, more concretely, that the platform should borrow from electronic banking and “*use automatic logout procedures*” as a protective measure. And third, to explore potential practices of data privacy and management: “*that reminds me of what happens nowadays on the mobile phone when I open the bank account, there is the possibility to hide the amount of money I have.*” These forms of reasoning point to the fact that health data platforms cannot be understood independent from other digital applications: whatever issue citizens encounter in their overall digital experiences will also have an impact on how they will handle health-related and health data.

Access was a key variable for citizens as they assessed the appropriateness of such a health platform both for their own needs and with regard to their own expectations: Who would have access to their collected data and what larger purpose would it serve? Citizens phrased this quite explicitly: “*Who has access to [the data] in the first place? Which institutions are involved? Is it really for my own good, or for the common good, that I am represented on this platform with my data?*” Others went even further, asking: “*who is responsible for the platform? Is there a state structure behind it that can be trusted? Is it a private institution that does business with it or what is it?*” These particular responsibility questions were regularly addressed as citizens wanted to know more about who is responsible for the platform’s protective measures or who would be held accountable if something goes wrong. Citizens wanted assurance that “*there is somebody who is in charge [that] has the responsibility for ensuring that [the functioning of the platform] actually happens*” how it was advertised. They wanted a “*person they could talk to*” in case of concerns and not “*a standardized, computerized system*”.

Transparency, with regard to both the actors and institutions as well as the data access and management processes associated with the platform was thus essential for citizens to perceive a health data platform as trustworthy. Only under specific conditions would they see the platform as an appropriate place for their sensitive health data. This

was particularly important when it came to providing health-related and health data for research. Here, a number of participants underlined that they “*would like to know every time my data is used and what for.*” More generally, citizens underlined the importance of knowing the actors involved institutions that fund the infrastructure and those who control the platform must be clearly stated. Furthermore, they were particularly keen to have transparency about whether there are any connections to pharma or insurance companies. As one interviewee put it: “*It's about making sure that only certain groups of people get access to the data, for example not insurance companies and pharmaceutical companies*”; and he then continued to outline his lack of trust when it comes to those actors. On the other hand, public institutions or national health data platforms were seen to be more trustworthy; for example, when it comes to ensuring that an “*electronic medical record serves [citizens'] health*”, citizens argued that “*the legislator and additional bodies [should] check to make such a secure access option that these organizations [i.e., insurance companies or pharmaceutical companies] do not have access to the electronic record.*” Furthermore, there also needs to be transparency regarding who ultimately decides on access to the data collected by the platform and how citizens can trace that access. Debates on this level generally gravitated towards making the following issues transparent: “*what criteria researchers use when asking for my data*” and “*be explicit that giving data for research means giving away control over them.*” In the end, even the hypothetical location of the servers was addressed with a clear preference for them being located in their home country or “*at least Europe.*”

Knowing the platform’s **exit possibilities** was another relevant issue. Under which conditions would it be possible to leave the platform and moreover, following this process, would they then be able to delete their data and be sure that all traces have been cleared? Well before subscribing to such a health data platform, citizens wanted to get more information about how they could withdraw themselves and their data from the platform. One participant in a discussion group made this very explicit: “*What about deletion? It's always the point: collect, collect, store data – where, how, who has access? But deletion is almost never talked about*”; others inquired: “*what steps does it take to, so to speak, to cancel again, or to, respectively, unsubscribe again*”. This seemed to be a prevalent and important concern for citizens – closely linked to the idea of citizens remaining in control over their own health data.

Beyond these concerns, the **redistribution of work and responsibility** in the health care system was addressed from diverse perspectives. Several participants voiced concerns that the work demanded from citizens to care for their own health data was now put “*somehow into the hands of people who are not trained for it*”, which could dangerously open the door to self-medication. Citizens were also concerned that if the data collection, uploading, or management was not done by health care professionals it would actually be equal to “*outsourcing the medical competence to the patient*”, which for them would signal “*a declaration of bankruptcy of the medical system*”. One citizen synthesised these concerns quite pointedly: “*if people all do it privately, it doesn't work – some can't, others don't want to, they don't know their way around, and so on.*” In short, to make such a health data platform work even for people with lower degrees of data literacy and with little understanding of data infrastructures, citizens would expect automated processes that upload and classify relevant medical information and, moreover, that medical professionals would oversee these processes.

This expectation is all the more important when considering that such a delegation of health data work to citizens would, in effect, also be seen as a **shift of responsibility** – likely changing the perception of their own health. Citizens were eager to understand

who would be able to contribute to the collection of their health data and how. Some of them argued that that primarily trained people, i.e., professionals, should take care of their account as they can select the right data to upload or to be shared. If this work is delegated to them, they fear that, in the end, this shift could reduce the quality of their health care. They were also curious about scope of action that would remain open to them once they entered the data logic. In line with the argument by Peterson and colleagues [8] that technologies supporting digital health are “integral to ‘responsibilising’ citizens, making them accountable (and potentially blameworthy) for health decisions”, our participants underlined the needed transparency about shared and shifted responsibility.

Finally, we encounter a set of concerns that could be related to debates around **data justice** [20, 21], which comes in several different forms. On the one hand, some participants pointed to the fact that while the intention behind such a European health data infrastructure might be good, they see great disparities in the different national health care systems across Europe, which might be further reinforced by the introduction of such a health data infrastructure. This was clearly voiced by some participants, who stressed that while they “*wouldn't be worried*” for the countries involved in the *Smart4Health* project (all from western Europe), they would be for the more South-Eastern European member states that might not have the same support structures. Citizens thus showed concerns that digital divides would persist despite such an infrastructure being built and could also impact health care in important ways [22]. On the other hand, even for nation states with a well-functioning health care system at several points concerns were raised that certain groups in the population would not be able (or willing) to use a health data platform such as *Smart4Health* or invest time and/or attention into this endeavour. Throughout our co-creation engagements we noticed how citizens not only explicate this point but also deliberately deploy different roles through which they articulate their positions. For example, they commonly referenced older family members who might find it difficult to deal with such digital health efforts, or people who lack the basic digital literacy or cannot afford to invest time and financial resources (due to a lower socio-economic status) to raise awareness about a potential exclusionary dynamic. This was seen as of particular importance in the case of older people. For them, the relation of health and illness was addressed repeatedly: while the platform speaks of health data it actually collects information on illness and those who have accumulated illness data are often older people, for whom using the platform might pose an even bigger challenge and hurdle to take. “*How healthy do I have to be, to be able to do this self-management at all?*” would be but one way in which the question of participatory justice was phrased.

4. Discussion and concluding remarks

So far, we have presented a broad spectrum of insights created through qualitative engagements with users (citizens and health care professionals) in our citizen-centred co-creation approach. While these insights could be seen as limited due to the number of participants and to the concrete contexts in which they were recruited (e.g., we mainly spoke to people who had some digital literacy, had time to participate in co-creation activities and some of them were connected to medical activities taking place in the context of the project), we would argue that the advantage of our approach is its ability to allow “multiple readings of the same reality to surface” [23], which ultimately provides in-depth insights into the way citizens value and justify their use (or non-use)

of digital health infrastructures. Indeed, our sample only contains people ready to reflect on digital health in the first place, to give us their time and share their thoughts. However, qualitative engagements of the kind we performed allow for a much more thorough reflection about why citizens demand certain features.

From the results that we presented in the previous section we can summarize the following core points that must be taken into account for health data platforms to become sustainable by allowing citizens to find a place in the generated digital health data space.

TRANSPARENCY & TRUST	... make actors, data flows and the underlying values visible; these are key factors for building sustainable relationships of trust and assure long-term support for the health data platform
HEALTH DATA INFRASTRUCTURE LITERACY	... support citizens' understanding of the infrastructural dimensions, which assures users of their legibility and capacity to navigate the health data landscape and negotiate a position within health data systems
DIGITAL JUSTICE	... assure that both processes of creating the health data infrastructure as well as the potential outcomes are carefully scrutinised to be inclusive and attentive to diversity and the different capacities to handle complex information environments
DISTRIBUTION OF RESPONSIBILITY	... render visible which actions and interactions are required when and by whom; the introduction of health data platforms should not be tied to a shift of responsibilities from the collective to individual citizens

Table 1: Summary of key findings

First, **transparency and trust** are two deeply interrelated key ingredients for a sustainable health data platform. Transparency, as we have shown, is present on several levels as citizens want to know: the actors behind the infrastructure, what information people hold when they engage with the platform, the conditions for data access and how this access can be traced, and how they can withdraw themselves and/or their data from the platform. Being transparent on each of these fronts is essential in order to establish trust towards the health data platform and to have citizens consider using it. As potential users, citizens can only appropriately assess and reflect on this proposed digital health solution once a true level of transparency has been realized, which would allow them to contrast the platform with the other digital applications and services they have become acquainted with in the context of a wider digital transformation. This finding is much in line with other diagnoses that underline “the indispensability of deliberative public engagement on the values being prioritised in health data initiatives [and] the significance of securing social licence in addition to legal assurances” [24]. Indeed, while citizens might assume that the data infrastructure follows all legal provisions, they can still rightfully argue that certain aspects nonetheless breach the set of values they live by.

Second, while there is a lot of debate about data literacy, which is certainly important, we want to underline the role of **data infrastructure literacy**. In line with Gray and co-authors [25], we argue that within discussions about building health data infrastructures it is essential “to include not just competencies in reading and working with datasets but also the ability to account for, intervene around and participate in the wider socio-technical infrastructures through which data is created, stored and analysed”.

Misunderstanding the infrastructural dimensions could lead to constraints when it comes to legibility, capacity to navigate the health data landscape and negotiate one's position within the health data system [25]. This means that we cannot simply demand that citizens invest their own time into this form of literacy but instead we also need those who conceptualise, build, and implement this platform to consider the importance to appropriately disclose the wider embedding of this infrastructure.

Third, citizens showed high awareness for how a health data platform can imply the necessity to be attentive to **digital justice**, a notion which includes data justice but extends further to include the dimension of digital infrastructure literacy. While group discussions and interview participants were mainly invited to reflect on their own use environment, it was critical for them that an unequal distribution of access to health (care) information could lead to ethical and political impacts on health care, and create very concrete differences in patient access to treatments and care. This could potentially create an unfair situation, rendering some well-visible and represented in digital health (care) systems while others would remain invisible [26]. This, in turn, might lead to biases in health care and related research when relying on these data. At the same time, citizens clearly underlined that navigating such a health data platform and being able to invest the work needed to make it a valuable resource for their own health and for the health care system could potentially exclude some members of society while supporting others. Thereby, concerns arose about what kind of entity it is that they would support when deciding to use the *Smart4Health* data platform and how sustainable it could be if 'Europe-wide' only means the inclusion of a finite set of countries.

We want to conclude our discussion by returning to the importance of transparency, particularly with regard to the **responsibilities** of engaging with such a platform. These questions of transparency include: Which actions and interactions are required to be done, when, and by whom? What is the possible scope of choice of actions that remains for citizens? A very clear expectation of citizens is that using a health data platform cannot entail a shift of responsibility to them as this would only make them more accountable than before. This is in fact a call to policymakers and developers to consider that – just as with any new technology – digital health innovations bring a new “geography of responsibility” [27] into being, i.e., a redistribution of responsibilities, which requires careful consideration. Instead of demanding more action *from* them, the actual value of a health data platform only becomes palpable to citizens when it is made clear what the platform can actually take over and do *for* them. To make this happen and to make health data platforms sustainable will require a mutual willingness by health care actors to provide support and by citizens to take up new roles in these digital health environments.

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