Anticipated Counter-Narratives: How Chronically Ill Patients Expect not to use Digital Self-Monitoring

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Abstract

Technologies in the making are surrounded by visions and promises of developers about how, when, why and by whom the technology should be used. Building upon scholarship of *non-use*, this paper aims to identify why chronically ill patients expect not to use digital self-monitoring once it becomes available. To do so, 21 in-depth interviews were conducted. In line with earlier work, use and non- use was mediated by the 'scripts' encoded in the technology, personal values and wider social networks. What we add, is that use and non-use also emerges in relation to the disease process itself. For example, while technology developers stress the value of controlling disease, for patients good management also implied letting go of control. By eliciting anticipated counter- narratives while a technology is in development, STS scholars can interrogate the visions and promises articulated by technology developers, and show alternatives.

Keywords: Non-use, Digital Technologies, Experiential Knowledge, Anticipation, Counter-Narratives, Patient Participation

Introduction

As research has shown, whether or not people use technology does not so much depend on the technical performativity of a particular device but on how well the technology fits into a given social context (Oudshoorn, 2011; Oudshoorn and Pinch, 2003; Pinch and Bijker, 1984; Pols, 2012). Thus, in order to understand why certain people use or do not use a particular type of technology, scholars recommend examining people's social worlds, i.e. their daily life, which consists of particular practices and routines, e.g., including those involving work, friends and family, as this forms the context from which people assign meaning to a specific kind of technology. Accordingly, amongst others Pols (2012), Oudshoorn (2003, 2011) and Weiner & Will (2018) showed in various works how people 'domesticate' or 'tame' technologies in their daily lives, i.e., transforming a (new) technology from an unfamiliar thing into a familiar object that is useful in their daily context. This process of 'domestication', or building, iteratively, a relation between a person and a technology, can take place in various ways, e.g. by only using particular functions of technology or only using the technology in certain circumstances.

While acknowledging the diverse ways in which people interact with technologies in their everyday, day-to-day life, as well as that people can alternate between periods of use and non-use which will be described in more detail below, for this paper we deliberately chose to focus on expected non users. With the help of in-depth interviews, we inquire into the narratives, i.e. the considerations, doubts and values of chronically ill patients suffering from multiple sclerosis (MS), who expect not to use digital self-monitoring apps when these become available to them.

By doing so, we want to highlight, in line with Wyatt (2003), that non-use is not 'a sign of a deficiency to be remedied' and non -users are also not necessarily future users (cf. Satchell and Dourish, 2009). Instead, non- use of new technologies can be a deliberate, reflective and nuanced act (Wyatt, 2003). As we will show in more detail below, Wyatt (2003) distinguishes between 'voluntary' and 'involuntary' non-use. Voluntary non -use refers to people who deliberately do not want to use a technology, e.g. because they do not experience the added value after a period of use, or a priori resist to use a technology, e.g. because the technology does not fit their preferences or moral values. Involuntary non-use refers to people who are forced to stop using a technology (e.g. because of financial reasons) or were not given the option to use a technology in the first place.

For all MS patients in our interview sample, the non-use of self-monitoring apps was a voluntary decision. Both so called 'rejecters' and 'resisters' (cf. Wyatt, 2003) were identified, i.e. patients who had previously used a self-monitoring app in the context of a scientific study but who had stopped doing so and patients without prior experience digital self-monitoring but who anticipated that they would resist this technology once it would become available to them.

While existing scholarly work on non-use primarily focuses on people's daily experiences with concrete technologies, this paper focuses on a technology in the making, and shows that narratives of non-use can also be anticipated.

Various narratives on digital self-monitoring

Digital self-monitoring refers to the use of digital tools such as smartphones, wearable sensors and activity trackers for the collection of personal health data (e.g. bodily functions, everyday activities and mental wellbeing) to stimulate self-management of health and disease (Lupton, 2013a; Sharon, 2017). Self-monitoring apps that are specifically targeted at chronic diseases can be used by patients to monitor their symptoms and keep track of their disease course (Birkhoff and Smeltzer, 2017).

In this paper we will focus on digital apps developed for degenerative disease multiple sclerosis (MS). As we will show in more detail below, various apps for MS are currently in development. Most of these apps are developed by commercial medical technology companies (e.g. MS Sherpa) or biotechnology companies (e.g. Roche in the case of Floodlight), and sometimes in collaboration with e.g. neurologists via pilot studies (e.g. MS Sherpa). At the time of writing, digital self-monitoring is not playing a significant role in the self-management and healthcare of MS patients (Thomas et al., 2021) as self-monitoring apps for MS are mostly still in the research and development phase. Nevertheless, some patients, including eight out of our twenty-one interviewees, have first experiences with digital self-monitoring as they participated in pilot studies to test apps (see for example Wendrich and Krabbenborg, 2024).

As various scholars already argued, technologies in the making are not just material objects, but embody various visions, values and promises on e.g. what is good health, how to deal with illness or how to establish a 'good life' (e.g. Borup et al., 2006; Aykut et al., 2019). These promises and visions, often voiced by technology developers, like scientists, industrialists, and policymakers that stimulate technological innovation, are not innocent. Instead, they have tangible consequences in the present as these discourses informs e.g. decision making processes regarding e.g. investments and who can or should use the new technologies in the making, when, why, in what way (e.g. Van Lente 2012, Jasanoff, 2015; Aykut et al., 2019; Graminius and Haider, 2025). In the case of digital self -monitoring for MS (see details below), a dominant narrative, containing three main visions and promises, emerges: digital self-monitoring and the quantified knowledge that becomes available is envisioned as empowering patients to take more 'control' and participate in their own care; resulting in better representation of patients' health; and as facilitating more equal doctor-patient relationships (cf. Moerenhout and Gabriels, 2023; Sharon, 2017).

With our empirical inquiry into anticipated non-use, we aim to show alternative narratives on e.g. 'self-management', 'good care' and the value of taking control over ones disease with the help of metrics. As such, the paper aspires to enrich the existing narratives pertaining the development of digital self-monitoring (cf. Borup et al., 2006; Wyatt, 2003; Oudshoorn, 2011), in which voices of non -users, and expected users in general, are less visible. By eliciting the concerns, doubts, considerations and values of chronically ill patients, this paper also adds to existing empirical work in the field of critical digital health studies. Up till now, more attention is paid to healthy people, who deliberately buy and use e.g. lifestyle apps to improve their health (e.g. Lupton, 2017, 2019), as compared to patients who engage in digital self-monitoring as part of managing their disease.

Non-use of digital self-monitoring

To study the meaning-making practices of non-users of these self-monitoring apps, we make use of insights from previous studies aimed at understanding and conceptualising the non-use of technologies. As Oudshoorn argued (2011), while literature on non-use is relatively limited compared to the abundant attention given to user studies, the analysis of non-use has evolved over the years.

Wyatt (2003), who studied non-use of the Internet, developed a conceptual framework in which non-users are divided into four categories, based on whether non-use is voluntary or involuntary and on whether or not people have used the technology before. These four categories are resisters (those who have never voluntarily used the technology), rejecters (those who have stopped using the technology voluntarily), excluded (those who have never used the technology because they have not been given the option to do so, for example because of a lack of resources or limited digital literacy) and expelled (those who were forced to stop using the technology, for example because of financial reasons or physical deficits) (see also Selwyn 2006).

Weiner and Will (2016) have further elaborated the conceptual framework of Wyatt (2003) to characterise the use, non-use and resistance to pharmaceuticals. They have added a group 'want less/different', next to Wyatt's (2003) groups of 'have nots' and 'want nots', to emphasize that there is no strict boundary between use and non-use. The group 'want less/different' refers to people who use the technology, but not as prescribed by e.g. the healthcare provider or the 'script' encoded in the technology, i.e. the material design of a technology prescribing or restricting particular behaviour (cf. Akrich, 1992). Weiner and Will show that people can 'silently resist' prescription of medication (cf. Pound et al., 2015), or use 'voiced resistance' via extensive negotiations with their doctors, resulting in experimenting or altering the 'script' of the technology. Another central characteristic of the framework of Weiner and Will (2016: 290) is the "analytic shift from a focus on the non-user as an identity to non-use as a dynamic practice". They found that people alternate relatively easily between periods of use and periods of non-use, depending on how their circumstances, needs and values evolve (Weiner and Will, 2016).

In her later work, also Wyatt (2014) emphasizes that peoples patterns of use and non-use change over time and life circumstances. But whereas Wyatt (2014) relates use and non-use to decisive moments in one's life, such as a retirement or moving house, Weiner & Will (2016) show that also less eventful periods in someone's life, influence use or non- use, such as negotiations with doctors, or family and friends that can support individuals' use or non-use of technology.

To analyse the non-use of digital self-monitoring apps for chronic diseases, we will build upon the conceptual framework of Wyatt (2014) and Weiner and Will (2016), acknowledging that use and non-use is not a binary distinction, but a dynamic practice. Digital self-monitoring of chronic diseases is thought to facilitate the transition towards a new type of patient: from a passive, minimally informed recipient to a 'digitally engaged patient' who is well informed, proactive and committed to participating in their own care (Lupton, 2013b; Moerenhout and Gabriels, 2023; Sharon, 2017). It is envisioned by app developers and some healthcare providers, that patients, via e.g. activity trackers and smartphone apps, will engage in various new tasks, such as collecting and interpreting health data at home and knowing how to act upon these quantitative data appropriately (Oudshoorn, 2011; Wendrich and Krabbenborg, 2024). Although the assumption underlying digital self-monitoring is that patients have the knowledge, skills and motivation to adopt these new tasks and responsibilities in their disease management (Lupton, 2013b; Prainsack, 2017), previous studies, e.g. in the field of critical digital health, have challenged this assumption.

For example, patients have described the inconvenience of routinely engaging in self-monitoring tasks and the emotional burden of self-monitoring data (Ancker et al., 2015; Hortensius et al., 2012; Reinhardt et al., 2021). Moreover, the prescribed use of a technology might not correspond with people's values, identities and normative beliefs (Lazar et al., 2015; Oudshoorn and Pinch, 2003). For instance, Lazar et al. (2015) found that participants in their study stopped using digital self-monitoring devices because they did not fit participants' conceptions of themselves, such as their perceived needs and personality. And even when people start using digital self-monitoring, this is no guarantee that they will continue doing so. As shown by e.g. Weiner and Will (2018) and Lupton (2013B, 2019), digital self-monitoring may be experienced as uncomfortable, intrusive, restrictive and unpleasant due to the additional tasks and duties that are required from patients, such as performing measurements at certain times of the day and integrating new actions in their daily routines. As among others Birkhoff and Smeltzer (2017) and Shin et al. (2019) concluded, some people discontinue their use of digital self-monitoring technologies when the novelty wears off. And also in our recent study on digital self-monitoring for chronic diseases (Wendrich and Krabbenborg, 2024) we found that patients were primarily motivated to use these digital tools in the context of a scientific study rather than in their private lives to improve their personal self-management practices, as they wanted to contribute to scientific research, i.e. to knowledge production that will benefit the larger community of patients (cf. Dam Nielsen and Langstrup, 2018).

Furthermore, patients might be excluded from digital self-monitoring due to a lack of knowledge, skills or time. Using self-monitoring apps requires for example digital health literacy, i.e. "the ability to seek out, find, evaluate and appraise, integrate, and apply what is gained in electronic environments toward solving a health problem" (Norman and Skinner, 2006: 1). The level of digital health literacy tends to be lower among elderly people and people who are socially disadvantaged, including migrants and people with a lower level of education (Boriani et al., 2021; Kaihlanen et al., 2022; Nelson et al., 2022). This 'digital divide' between people who have the resources, knowledge and skills to use digital health technologies and those who do not may result in health inequalities (Kaihlanen et al., 2022; Prainsack, 2017). Moreover, the use of self-monitoring apps by patients with a chronic disease may be constrained by their cognitive or physical disabilities, such as forgetfulness, a visual impairment or poor dexterity (Griffin and Kehoe, 2018; Simblett et al., 2019). Furthermore, while technology enthusiasts envision that digital self-monitoring reduces work, scholars Oudshoorn (2008) and Prainsack (2017) already argued that it is more likely that it redistributes work. Putting digital self-monitoring to use in patients' daily live comes with additional 'illness work' for the patient, i.e. the actions patients have to perform and the time and energy that they have to invest in order to manage their disease (Corbin and Strauss, 1985; Krabbenborg and Wendrich, 2024).

In our study, we aim to get a better understanding of these factors, including the material characteristics of the technology, that mediate the use and non-use of digital self-monitoring for MS, paying particular attention to the role of knowledge, skills and time investment.

Digital self-monitoring of multiple sclerosis (MS)

MS is a degenerative disease of the central nervous system that is typically characterised by alternating periods of relapse, during which symptoms deteriorate, periods of recovery and periods of disease progression, in which symptoms steadily get worse without recovery. Symptoms include fatigue, muscle weakness, difficulties with walking, cognitive problems and reduced vision (Dobson and Giovannoni, 2019; Kamm et al., 2014). The course of MS differs greatly between individual patients, and there are significant variations in the symptoms they experience, the severity of the symptoms and the pace of the disease progression. The variable and unpredictable disease course of MS results in a lot of uncertainty for patients and a perceived lack of control (Ayobi et al., 2017; Dennison et al., 2016). MS patients are known to already engage in various forms of self-management, which refers to the use of interventions, education or skills by patients, e.g., seeking information online or adopting lifestyle habits, to (learn how to) manage their illness, such as the effects of the disease on their daily lives (Ayobi et al., 2017; Dennison et al., 2010). We will show how the non-use of digital self-monitoring apps for MS is mediated by these existing everyday practices and routines.

In doing so, we compare the motivations and considerations underlying patients' non-use of these apps with the assumptions and visions of technology developers and point out emerging tensions, possible contestation as well as overlap. Several self-monitoring apps for MS are appearing on the market, such as Floodlight, MSCopilot and MS sherpa (Cloosterman et al., 2021; Marziniak et al., 2018). Self-monitoring apps aim to enhance the monitoring of MS symptoms. This is done by tracking longitudinal, real-world data, for example regarding physical activity (e.g. measuring number of steps walked or calories burned), cognitive functioning (e.g. doing cognitive tests multiple times a week) and sleep (e.g. measuring duration and quality of sleep) (Cloosterman et al., 2021; Marziniak et al., 2018; Simblett et al., 2019). While the actual tests slightly differ between the apps, they all expect similar skills, behaviour and responsibilities of users. For instance, it is demanded that users have certain analytical skills in order to understand what the test results means, be able to read instructions and to interpret graphs. The Floodlight Open app for instance indicate that a lower score is better, but does not further specify a number, this is up to the user to interpret. Users also need to be aware of and be able to verbalise own emotions, as the app asks questions about mood multiple times a day, for instance on stress and pain. Moreover, all users need to have discipline to perform and complete the tests, at set timeslots, on a daily basis.

According to the app developers, using these apps on a regular basis will result in better insight into patients' symptoms and disease progression. As such, developers envision a future in which self-monitoring apps support patients to self-manage their health and complement existing clinical approaches to MS, e.g. by adapting treatment decisions to the individual patient or by giving patients and healthcare providers a sign (via the app) that the MS seems to be deteriorating (Marzinaiak et al 2018). The developers of the self-monitoring app MS Sherpa for instance describe: 'By monitoring symptoms frequently over time, both the patient and neurologist can objectively see the progress of the symptoms' (https://www.mssherpa.nl/en/). Moreover, the technology developers also promise that these apps bring unprecedent promises for patients. For example, the developers of the MS self-monitoring app icompanion (https://icompanion.ms) expect it to contribute to "an unparalleled understanding of your MS", "empowerment and peace of mind" and lead to a patient "taking health into your own hands". The developers of other apps envision that they will help patients to "complete simple, everyday tasks" (https://dreams.care/) and to "to become actors of their own disease and their own care" (https://www.mscopilot.com/). These quotes demonstrate the underlying values of digital self-monitoring apps, including the assumptions that quantified data will contribute to more self-knowledge and that patients will be more proactive in the management of their disease (cf. Moerenhout and Gabriels, 2023; Presset et al., 2021).

As we will show, non-users views of these elements are different to those of the developers: they for example value 'experiential knowledge' over the 'quantitative knowledge' that is pursued by developers.

Methods

Recruiting respondents

Non-users were recruited through three different channels. As using self-monitoring apps is not common practice yet for people with MS, we explained to the patients, both during the recruitment process and during the interview, that self-monitoring apps are smartphone apps that people with MS can use to collect personal data on their health, for instance by performing tests or reporting MS-related symptoms. In relation to all three recruitment methods, we explicitly stated that we were looking for MS patients who were not willing or able to use digital self-monitoring apps for MS. The first recruitment method consisted of the second author contacting patients who had previously used a self-monitoring app for MS in the context of a scientific study and who had indicated that they were unlikely to use self-monitoring apps in the future for private self-monitoring (see Wendrich and Krabbenborg, 2024). Five respondents were recruited in this way. The second recruitment method consisted of the second author posting on a website dedicated to scientific research on the Dutch patient forum MSweb (https://msweb.nl/). This resulted in six respondents being recruited. For the third recruitment method, the authors jointly contacted the Nationaal MSfonds, a Dutch patient organisation for people with MS, which copied and pasted their text about recruitment on their Facebook page and on their Instagram page. Twelve patients responded to this call, meaning that 21 MS patients in total were recruited and subsequently interviewed. As no new themes emerged after these interviews, no additional respondents were recruited.

Data collection

With the help of master student Hilde Romijnders, interviews were conducted by both authors between May and August 2021. The interviews lasted for between 37 and 88 minutes, with an average duration of 61 minutes. Due to the Covid-19 pandemic, 19 interviews were conducted online through Google Meet; two were conducted on the telephone because that was the respondents' preference. The first and second author are both experienced in conducting interviews with patients about biomedical innovations. They gave interview training to the student before the interviews began. Both authors collaborated closely to develop a semi-structured interview protocol, which was guided by the literature discussed in the Introduction. To gain insight into non-use as dynamic practice, we asked about respondents' previous experiences with self-monitoring apps, the role of knowledge, skills and time in (not) using digital self-monitoring and whether their non-use of these apps was a voluntary or involuntary decision. By asking about this, we were explicitly paying attention to the norms and values that play a role in patients' reasons for not using self-monitoring apps. Moreover, we wanted to acknowledge that non-use is dynamic rather than static (Wyatt, 2014; Weiner and Will, 2016), so we investigated whether respondents were open to using self-monitoring apps in the future and if so, under which circumstances.

Data analysis

The interviews were audiotaped after written informed consent to do so was obtained from the respondents. This was approved by the Research Ethics Committee of the Faculty of Science (REC19012). Next, each interview was transcribed verbatim in MS Word by the student and second author. Both authors familiarised themselves with the data by reading the transcripts a couple of times. The transcripts were then uploaded to the qualitative data analysis software ATLAS.ti 8 and subjected to a predominantly deductive analysis which was guided by a codebook (Braun and Clarke, 2012, 2022). A codebook was created using deductive codes based on the interview guide. This codebook was refined after both authors, together with the student, had engaged in multiple rounds of discussions. Inductive codes, which were derived from the data, were added to the codebook during this process. The first and second author and the student, coded three, nine and eight interview transcripts respectively, making adaptations to the codebook where necessary, such as adding inductive codes and merging subcodes. These adaptations were discussed with both authors, and final agreement on the codebook was achieved. Subsequently, the authors discussed the (sub-)themes containing a shared idea or concept that had emerged from the interviews. Quotes translated from Dutch are used throughout the Results section to illustrate our findings.

Results

Seventeen women and four men were interviewed, with an average age of 48.6 years (ranging from 29 to 62 years). On average, respondents had received the MS diagnosis 15.8 years ago, ranging from two to 29 years ago.. At the time of the interviews, the respondents were not self-monitoring their MS, either with a digital self-monitoring app or with non-digital tools such as a paper diary. Twelve of the respondents had previously made notes about their MS symptoms using methods other than a self-monitoring app. Most respondents engaged in this self-monitoring of their symptoms in the period just before or after their diagnosis to keep track of their symptoms and find potential patterns, such as identifying factors that might have triggered the symptoms. Eight of the respondents had previously used MS self-monitoring apps, of which five had done so in the context of a scientific study in which they used a prototype of a self-monitoring app (see Wendrich and Krabbenborg, 2024 for more information). The other 13 respondents had never used an MS self-monitoring app. Our findings confirm the notion of non-use as a dynamic practice (Weiner and Will, 2016). Although patients were unwilling to use self-monitoring apps for MS at the time of the interview, most patients could imagine using these apps in the future, albeit less or differently than envisioned by the technology developers. This aligns with the category ‘want less/different’ in the framework of Weiner and Will (2016). As we will show in the next sections, existing self-management practices, the material characteristics of self-monitoring apps, healthcare providers’ support and the process of disease itself, appeared to mediate patients’ practices of use and non-use.

Knowing your body: quantitative versus experiential knowledge

A central assumption of the developers of digital self-monitoring apps is that ‘knowledge is power’, and this leads to the belief that the collection of quantitative health data will contribute to a better understanding of oneself (cf. Sharon, 2017), including the will to ‘better manage’ ones disease. In the discourse surrounding digital self-monitoring, quantified and metric representation of one’s health, e.g. through numeric or graphical representation is preferred and is perceived as more reliable than people’s subjective experiences, haptic sensations and intuitive knowledge of their body and health (Wendrich and Krabbenborg, 2024). For instance, the developers of the app dreaMS state that the data captured by their app is “objective” and “unbiased” (https://dreams.care/). Several patients in our interview sample challenged this dominant discourse and referred to their experiential knowledge. Experiential knowledge is the knowledge that patients have because of their experience of living with a disease on a day-to-day basis, such as knowledge about how their body is functioning or knowledge about optimal strategies for self-managing their disease (Boenink et al., 2018; Pols, 2012).

Characteristic for MS is that symptoms fluctuate throughout the day, or for days or weeks. The respondents explained that over time they had learned to listen to their body and had gained a substantial amount of knowledge about how their body functions, what they can and cannot do and what factors contribute to their symptoms, such as managing their energy levels by prioritising particular activities and avoiding symptom triggers. Many respondents referred to their experiential knowledge and disease course as one reason why they did not perceive that self-monitoring apps added any value to their situation. They believed they did not need the quantitative knowledge provided by digital self-monitoring in their self-management practices:

> I do not see the added value of using such an app. I feel my body well. I do not need an app for that. I know my body. (MS18)

Others also mentioned that they already engaged in offline self-management strategies, such as regular checkups in the hospital, or taking notes.

> I have fine alternatives. And those are (..) actually much lighter than what an app could do. So, it has less impact and gives more freedom. While for me the value is the same – MS8

Some respondents indicated that (digital) self-monitoring might have been valuable for them in the earlier stages of their disease, because at that time they were more uncertain about their bodily functioning and had to gain experiential knowledge on how to manage their MS. Therefore, the respondents believed that digital self-monitoring might be most valuable to patients who have just received their diagnosis:

> Look, I have already had MS for 10 years. I think for someone who is in the initial stage, that this person might be more interested. For that person everything is new. (MS20)

Moreover, patients also mentioned that the different phases of MS, i.e. the relapsing, recovery or disease progression phase, influence the use of self-monitoring apps. At the time of interviewing, one of the respondents for example was in a disease progression phase. He indicated that an app could help to gain more insight into deterioration, as this goes slowly and is more insidious. When this respondent was still in a relapse and recovery phase, the disease course was more obvious: things went well, or there was a relapse. There was no gradual decline. Therefore, this respondent saw more value in using an app during a disease progression phase than in a relapse and recovery phase.

The importance of experiential knowledge for the self-management of MS patients suggests that the quantitative knowledge that comes from digital self-monitoring might ignore the richness and complexity of human experiences and other meaningful aspects of patients' lives that cannot be captured in numbers (Sharon, 2017; Storni, 2014). Digital self-monitoring seems to put the emphasis on 'disease', i.e. on how a condition is biologically defined, which might conflict with how patients identify with their ill health. In fact, as Sharon (2017) argues, the over-reliance on health data produced by digital self-monitoring could lead to a reductionist understanding of the body and health in which the importance of e.g. haptic sensations and intuitive or experiential knowledge is undermined and overshadowed, whereas numbers are privileged (Wendrich and Krabbenborg, 2024: 18). As we will show below, patients are concerned with more than just numbers and graphs and are also interested in establishing a 'good life' that is not dominated by disease (cf. Hoffman, 2016).

Living a normal life: life is about more than being sick

Self-monitoring is not a neutral and value-free endeavour; it can evoke strong emotions and sentiments (Ancker et al., 2015; Lupton, 2019). For example, in a study conducted by Hortensius et al. (2012), diabetes patients said that they want to enjoy life and do not want to focus on their disease all the time. Some patients felt that because of the self-monitoring of their blood glucose they were never free from their diabetes. In a similar vein, our interview respondents indicated that digital self-monitoring apps put too much emphasis on MS, which was an important reason for their non-use of these apps. A common view among respondents was that MS is only a small part of their life and that life is about so much more than their disease:

> For me MS is now a small part of my life, but not the main part. (MS14)

Some respondents also questioned the rationale of continuous tracking, as there is no cure for MS.

> In the way my MS develops, it doesn't make much sense to keep track of it. Because we can't do anything with that (..) I already have the optimal treatment. It's not like I can do things differently to make it better. – MS10

Subsequently, respondents explained that they would be too occupied with their MS if they engaged in self-monitoring. Several respondents stated that digital self-monitoring emphasises illness, i.e. negative aspects, such as symptoms and what is not going well. They do not want to focus on these negative aspects, but rather on health, i.e. what is still possible and what is going well:

> You are already confronted with your disease every day. And if you then also have to monitor the symptoms, then that is yet another thing that you think: shit, actually it is not going well at all. And you do not want to be reminded of that every single time. (MS15)

> Keeping track of how well you walk every day felt like focusing on disease. Keeping track of for instance the number of leg presses in the gym however felt like focusing on health (MS10)

Digital self-monitoring and the continuous stream of information it provides thus appeared to conflict with patients' desire to live a normal life, i.e. a life with not too much focus on (the negative impact of) their MS. This contrasts with the material design of self-monitoring apps, which requires patients to regularly engage in self-monitoring to gain insight into their disease. Whereas technology developers assume that self-monitoring data will result in more knowledge that aids patients in their self-management practices, it is clear that for patients this knowledge can also be a burden and can result in an undesired confrontation with being sick, multiple times a day.

As such, these considerations of patients illustrate, as is already argued by several scholars (e.g Graminius and Haider, 2025; Aykut et al., 2019), that the functionalities of an app, for example the type of knowledge and lifestyle advices that are displayed, are not neutral nor encompassing, but reflect particular views and preferences on e.g. 'good care' and 'living a meaningful life'. Consequently, this raises the question: who can participate in the design of apps including the implementation processes? Whose views, values and concerns are heard and taken taking into account in developing particular 'imaginaries', in this case of future care practices, and which ones are silenced? (cf. Aykut et al., 2019; Jasanoff 2015).

Investing time and energy: digital self-monitoring as illness work

Technology developers position digital self-monitoring technologies as easy to use and requiring minimal effort (Danesi et al., 2020; Hortensius et al., 2012). For instance, the developers of the MS self-monitoring app MSCopilot state: "MSCopilot® can be used in your daily life very easily**"** **(**https://www.mscopilot.com). However, engaging in digital self-monitoring comes with several obligations, such as patients having to perform measurements at certain times of the day, which requires time and energy (Lupton, 2013b; Oudshoorn, 2011; Prainsack, 2017, Wendrich et al (2019). These additional tasks and duties are added to the illness work of patients, which refers to the actions that patients have to perform in order to manage their disease (Strauss, 1982). Our interview respondents were not necessarily willing to invest time and energy in making self-monitoring apps part of their everyday illness work, as they did not perceive that there would be enough value in this investment:

> Well, you need to make time. And because I do not have the motivation for it, because it brings me so little at this moment. Well, then I do not want to invest that time. Then I already know, if I download such an app, then I will do it three days in a row and then I do not think about it anymore. (MS14)

Also here, respondents mentioned that the diseases process itself would influence their non-use or limited use of the apps. Respondents for example they believed that there was little to keep track of, as they only were only experiencing mild or stable MS symptoms. Furthermore, several respondents explained, when their energy was limited because of their MS, they want to decide themselves how to use their energy and not be 'controlled' by an app:

> At a certain point your energy level is so low that you think: I also have to think about myself. And not having to do that [an app] as well. Because it really is something extra. (MS12)

The respondents said that they would rather spend their limited energy on activities that they find valuable and pleasant, such as spending time with friends and family. Moreover, some respondents mentioned that it would take too much energy to use a smartphone:

> I have purchased that phone because of the bank, because I had to do things through an app. I never take it anywhere. That is to protect myself. Because when I go to someone, then I am there. That is already enough. And if you then also have bleeps and things. No way I am going to do that. (MS16)

Interestingly, almost all of the respondents who had previously used MS self-monitoring apps experienced difficulties with the effort required by these apps. They mentioned the complexities of integrating an app into their everyday routines and motivating themselves to perform self-monitoring tasks. Several respondents stated that self-monitoring apps became boring and even annoying when the novelty had disappeared. These findings confirm that digital self-monitoring can be difficult to integrate into daily life routines and that the constant engagement with these technologies can result in boredom, annoyance and frustration (cf. Weiner and Will 2018; Lupton, 2019; Reinhardt et al., 2021).

Giving meaning to digital self-monitoring as a clinical tool

It became clear from the interviews that respondents do not necessarily want to engage in digital self-monitoring for 'private' self-monitoring, i.e. the use of digital self-monitoring for personal health-optimisation purposes (Lupton, 2014). They seemed more positive about 'clinical' self-monitoring, or 'self-monitoring on prescription', in which digital self-monitoring is performed by patients for therapeutic purposes following a recommendation by their healthcare providers (Piras and Miele, 2017). Most of our respondents were open to at least trying out a self-monitoring app if this was recommended by their healthcare provider. In fact, one respondent had previously used such an app following the suggestion of his healthcare provider. Multiple respondents mentioned that they would only use a self-monitoring app if the app added value to their healthcare providers' practices:

> If I really notice that the doctor is going to do something with it. So the moment my MS doctor or my MS nurse thinks that an MS app adds something, I will be the first to participate. (MS7)

> If she thinks that it is necessary, so that she can do her work better, then I would do it. If my doctor deems it necessary for her to do something with the data, to make the conversations easier, then I would do it. (MS13)

Our findings suggest that the interview respondents would primarily engage in self-monitoring to facilitate healthcare providers in their daily work of evaluating patients' health (cf. Piras and Miele, 2017). Also the developers of self-monitoring apps for MS envision a collaboration between patients and healthcare providers; this is clearly illustrated, for instance, in the following quote from the website of the app called Floodlight: "With Floodlight MS, people living with MS and their healthcare providers can work together toward improving clinical conversations and informing decision-making around care" (https://floodlightms-us.com/). Moreover, several MS self-monitoring apps, including MSCopilot and MS sherpa, require patients to obtain an activation code from their neurologist in order to use them.

In fact, as we showed in previous work (Wendrich and Krabbenborg, 2022), also healthcare providers primarily saw benefits when digital self-monitoring was used on prescription. In imagining a future situation with digital self-monitoring, the healthcare providers that were interviewed envisioned a particular type of patient-doctor configuration that might raise tensions with the patient perspectives that we described above. For example, healthcare providers preferred to use a standardized app ('one size fits all') and act as gatekeepers in selecting patients who could (not) use digital apps for therapeutic purposes. Moreover, they envisioned delegating particular tasks and responsibilities to patients via digital self-monitoring. For example patients sharing their health data or acting upon the data if necessary, e.g. by changing their lifestyle or contacting the healthcare provider if deemed necessary by the patient (Wendrich and Krabbenborg, 2022). While healthcare providers acknowledged that not all patients are willing or able to use digital self-monitoring, their future vision on acting as a gatekeeper for example could restrict patients autonomy to decide themselves whether or not to use digital self-monitoring and in what way, considering one's personal situation and disease status. Moreover, as research from amongst others Vasileiou et al (2013) and Krabbenborg et al (2016) showed, it is also not self-evident that patients contact healthcare providers if they noticed e.g. deviations in the self-monitoring data. For example because patients downgrade their problems and anticipate that healthcare providers are busy anyway and they do not want to bother them.

Discussion and conclusion

Just as technologies, in this case digital self-monitoring technologies, can have a broad range of different users, this research shows that there are also different non-users. With the help of 21 interviews, we inquired into the considerations, values and doubts of MS patients who expected not to use digital self-monitoring tools once they would become available to them.

Firstly, in line with Wyatt (2014) and Weiner and Will (2016) we show that use and non-use is not a binary distinction. Instead, some of the MS patients in this study envisioned themselves alternating between periods of use and non-use, which is mediated by the 'scripts' encoded in the technology, personal values, and wider social networks. What we add to the existing literature on non-use, is that use and non-use of technologies also emerges in relation to the disease process itself. How patients experience symptoms of MS, changes over time, varying between severe and mild or no symptoms. And it is exactly the experience of these symptoms that influences whether or not patients see added value in using or non-using digital technology.

Secondly, Satchell and Dourish (2009) have already acknowledged that non-users do not necessarily resist new technologies but that they can be critical about the social changes associated with these technologies. Thus technology resistance does not have to be a technological consideration but can reflect broader social trends or touch upon other aspects of people's lives. Our findings showed that non-users do not necessarily resist digital self-monitoring apps but are critical of the emphasis these apps put on MS and the effort it requires to engage with these apps. Just like the developers of self-monitoring apps, patients are concerned with realising a good life and having good care. Non-users seem to have a different interpretation from that of the app developers of the role of technology in this regard. In fact, as Fletcher et al (2019) already argued, the term self-management is highly nuanced and complex. How the term 'management' is interpreted and put into practice, depends on the position an actor has or can take in relation to a new technology. We saw that for technology developers, better self- management of MS is related to acquiring more quantified data on bodily symptoms. It is envisioned that acting upon this data, for example by getting more sleep or doing exercises, gives people a feeling of controlling the disease. However, our empirical data showed that for patients, good self-management implied, amongst others, letting go of control. In fact, instead of wanting to have more data on their bodily functioning, patients, on occasion, preferred to resist to listen to their body and bodily symptoms as they value living a life that is not dominated by MS. These results are in accordance with earlier work of e.g. Sharon (2017) and Prainsack (2017) arguing that the focus of numbers and monitoring can reduce the complexity of human experiences and other meaningful aspects.

Thirdly, non-users' meaning-making practices also raises the question of what we consider to be 'good care'. One important normative assumption underlying digital self-monitoring, among others shared by technology developers, policy makers and health innovators, is that 'patient empowerment' is desirable (Moerenhout and Gabriels, 2023; Sharon, 2017; Topol, 2015). Patient empowerment is a term that has numerous meanings, including gaining more control over a disease, patients and healthcare providers becoming more equal partners, increased personal responsibility for health, and allowing people to lead more independent lives (Sharon, 2017). These interpretations of patient empowerment hold a specific notion of what is 'good'. This notion is reflected in a question that Moerenhout and Gabriels (2023: 1) ask: "What will a 'good' patient look like in the near future? Someone who closely monitors his or her health and chronic diseases with wearables and apps, and adjusts behavior and treatment accordingly?". Based on our findings, which suggest that not all MS patients are going to use self-monitoring apps, we would like to raise the question how much heterogenous (non) use practices we are willing to allow in care situations. Moerenhout and Gabriels (2023) and Prainsack (2014) claim that freedom of choice is an important prerequisite for empowerment. This implies that not using digital self-monitoring technologies and not adopting a proactive attitude should also remain options for patients. Or as Moerenhout and Gabriels (2023: 1) state, "empowerment may also mean that a patient leans on their care provider or delegates certain decisions to them". When patient autonomy is a guiding principle for good care, technology developers and other actors should consider how to prevent patients who are not willing or able to engage in digital self-monitoring from being excluded from healthcare practices (cf. Prainsack, 2017). Actors could, for instance, deliberate on what alternatives can be provided to people who do not or cannot use self-monitoring apps.

Interestingly, most patients in our study did not fully reject self-monitoring apps and were open to using these apps under certain conditions. This confirms the notion of non-use being a dynamic rather than a static act, with people alternating relatively easily between periods of use and non-use (Weiner and Will, 2016; Wyatt, 2003). Healthcare providers appeared to be important actors enabling or constraining patients' use of digital self-monitoring. Just as it is not self-evident that MS patients are willing or able to use self-monitoring apps, the use of these apps by healthcare providers is also not straightforward. In fact, the adoption and long-term use of new technologies by healthcare providers is known to be a highly complicated process that is influenced by a multitude of factors on different levels (see Greenhalgh et al., 2017 for a comprehensive overview). These factors range from individual perceptions of healthcare providers on what is considered 'good care' including the role of digital technologies, to broader organisational conditions such as (lack of) professional guidelines and (lack of) the reimbursement of the costs of using these technologies (Wendrich and Krabbenborg, 2022). In other words, healthcare providers as well as MS patients might become, for various reasons, non-users of self-monitoring apps. As healthcare providers' actions and behaviours influence the acts that patients can or cannot perform, future research should also turn to healthcare providers as a relevant social group that give meaning to digital self-monitoring apps for chronic diseases. More in particular, in line with e.g. Aykut et al (2019) and Graminius & Haiden (2025), we argue that the development of apps, whether these are meant to track bodily symptoms of chronic diseases or monitor air quality for example, can be positioned, as described by Graminius & Haiden (2025) and Van Driessche et al (2024), as 'anticipatory assemblages'. Assemblages in this case denotes to 'the relationships and complex interplays or materials, representations, technologies, knowledge, practices and values' (Graminius and Haiden, 2025). Together, these human and non-human actors shape new societal practices in the making and influence which actions, roles, responsibilities and values can be easily pursued and which ones are sidelined (cf. Krabbenborg, 2013; Van Driescsche et al., 2024: 209). We showed that developers, patients, and healthcare provides, seem to have different, up to competing, values and ideas regarding the added value of digital self-monitoring for chronically ill patients. Our suggestion for further research, building upon e.g. Aykut et al 2019, is to empirically study the deliberation, negotiation and decision making processes that constitute the making of new technologies, in this case, digital self- monitoring tools. In doing so, scholars can articulate, already in the early stages of a technology development, whose future is envisioned, which problems and solutions are articulated, silenced or remain underdeveloped and why? (cf. Rip and Robinson, 2013; Krabbenborg, 2013). Moreover, building upon the philosophy and methodology of Constructive Technology Assessment, we would like to argue that the role of an STS scholar does not have to stop at deconstructing dominant narratives. Instead, by actively 'moving in and around' the 'different worlds' of e.g. science, policy and industry, and by e.g. asking questions, challenge assumptions and point out discrepancies between various future visions on the role of technology in society, scholars can also become an actor themselves in a technology development and contribute to co-constructing possible other, more encompassing, narratives.

To conclude, as shown, non -use is a dynamic practice, with people alternating between use and non-use. So it might well be that as soon as digital self -monitoring apps become widely available, the first experiences of expected non-users, turns out to be different than what they envisioned when interviewed by us. Nevertheless, our analysis also shows that non-use is not just a coincidence, but the result of, in our case patients, not sharing all the underlying visions, values and use practices envisioned by technology developers. For our study we recruited patients who had either participated in scientific studies or had been active on online patient fora or had been following the social media of patient organisations. Our recruitment strategy thus focused on patients who were digitally active and willing and able to articulate their reasons for non-use. However, our strategy may have prevented the inclusion of involuntary non-users (Wyatt, 2003), i.e. those patients who were unable to use these apps, for instance because they had a low level of digital health literacy. It is recommended that future research also pays attention to involuntary non-users of self-monitoring apps to create a potentially more varied image of non-use, including the role gender for example might play. Melby and Toussaint (2016) bring up the question of how non-users can be reached and can get involved during the development and implementation phases of technologies. Contacting those who rejected an invitation to participate in scientific studies on new technologies or those who have dropped out of such studies, like Oudshoorn (2011) did, might be one potential strategy for reaching non-users. Another option to specifically involve involuntary non-users of digital health technologies would be to actively approach locations where older or socially disadvantaged people gather, for instance community centres (cf. Raap et al. 2024).

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