

**Self-Tracking by People Living with Multiple Sclerosis:
Supporting Experiences of Agency in a
Chronic Neurological Condition**

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Declaration

I, Amid Ayobi, confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis. This thesis has not been submitted, in whole or in part, for any other degree, diploma or qualification at any other university.

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Abstract

Multiple sclerosis is a complex neurological condition. It disrupts the central nervous system leading to an individual range of physical, cognitive, and mental impairments. Research has focused on the tracking of primary disease indicators and disability outcome measures to assess the progression of this condition. However, there is little knowledge on how technologies could support the needs of people with multiple sclerosis (MS) in self-tracking their health and wellbeing. Drawing on qualitative research and design methods this thesis provides two contributions.

Firstly, it improves understanding of self-tracking in MS self-management. Interview participants reported regaining a sense of control over MS through intertwining individual self-care practices with different self-tracking tools, including paper notebooks and fitness wearables. They associated experiences of control with their agency to document their health in holistic ways, involving symptom monitoring and life journaling. However, participants criticised that self-tracking apps can impede their capacities, in particular when the user experience is focused on predefined health indicators and the optimisation of health behaviour. These findings highlight the need to support people's individual self-care intentions and agentive capacities through customisable self-tracking approaches.

Secondly, this thesis contributes the design of Trackly, a technology probe that supports people in defining and colouring pictorial trackers, such as body shapes. We identify benefits and challenges of customisable and pictorial self-tracking through a field study of Trackly in MS self-management. Having been able to support their individual self-care intentions with Trackly, participants reported a spectrum of interrelated experiences of agency, including ownership, identity, awareness, mindfulness, and control.

Overall, this thesis provides a qualitative account and design perspective that demonstrate how adapting self-tracking technologies to individual care needs supported experiences of agency. These findings are particularly relevant to the design of technologies aimed at leveraging personally meaningful self-care and quality of life.

Publications

Conference Papers

Amid Ayobi, Paul Marshall, Anna L. Cox, and Yunan Chen. 2017. **Quantifying the Body and Caring for the Mind: Self-Tracking in Multiple Sclerosis**. In *Proceedings of the 2017 CHI Conference on Human Factors in Computing Systems* (CHI '17). ACM, New York, NY, USA. DOI: <http://dx.doi.org/10.1145/3025453.3025869>

Amid Ayobi, Tobias Sonne, Paul Marshall, and Anna L. Cox. 2018. **Flexible and Mindful Self-Tracking: Design Implications from Paper Bullet Journals**. In *Proceedings of the 2018 CHI Conference on Human Factors in Computing Systems* (CHI '18). ACM, New York, NY, USA, Paper 28, 14 pages. DOI: <https://doi.org/10.1145/3173574.3173602>

Amid Ayobi, Paul Marshall, and Anna L. Cox. 2020. **Trackly: A Customisable and Pictorial Self-Tracking App to Support Agency in Multiple Sclerosis Self-Care**. In *Proceedings of the 2020 CHI Conference on Human Factors in Computing Systems* (CHI '20). ACM, New York, NY, USA. DOI: <https://doi.org/10.1145/3313831.3376809>

Extended Abstract Papers

Amid Ayobi, Paul Marshall, and Anna L. Cox. 2016. **Reflections on 5 Years of Personal Informatics: Rising Concerns and Emerging Directions**. In *Proceedings of the 2016 CHI Conference Extended Abstracts on Human Factors in Computing Systems* (CHI EA '16). ACM, New York, NY, USA, 2774-2781. DOI: <https://doi.org/10.1145/2851581.2892406>

Amid Ayobi. 2018. **Informing the Design of Personal Informatics Technologies for Unpredictable Chronic Conditions**. In *Extended Abstracts of the 2018 CHI Conference on Human Factors in Computing Systems* (CHI EA '18). ACM, New York, NY, USA. DOI: <https://doi.org/10.1145/3170427.3173025>

Workshop Paper

Amid Ayobi, Paul Marshall, and Anna L. Cox. 2017. **Self-Experimentation and the Value of Uncertainty**. In *CHI 2017 Workshop on Digital Health & Self-Experimentation*

Impact Statement

Documenting and understanding the individual and fluctuating nature of multiple sclerosis is challenging not only for clinicians but also for people who are living with this chronic neurological condition. This thesis investigates how technologies could support the needs of people living with multiple sclerosis in self-tracking their health and wellbeing. The findings of this thesis have impacts both within and outside of academia.

Within academia, this thesis improves our understanding of self-tracking in multiple sclerosis self-care. Through an interview study, an online ethnography, and a design and field study of a technology probe, this thesis identifies agency as an important self-tracking need in multiple sclerosis self-management and describes experiences of agency as perceived benefits of a customisable and pictorial self-tracking approach.

The contributions of this thesis are transferable. The published findings are cited by not only multiple sclerosis research but also the broader HCI community, spanning self-management, personal informatics, and mental health research. The technology probe Trackly is being deployed as part of an academic project that aims to understand the self-tracking and decision-making support needs of people living with diabetes.

Outside of academia, this thesis is relevant for the software and healthcare industries. The design of the customisable and pictorial technology probe, Trackly, provides guidance on how technologies could be developed to meet the needs of those who are interested in documenting their health and wellbeing in creative and visual ways. Furthermore, this thesis presents best practices that can inform clinicians, nurses, and people who engage in self-tracking, such as combining different self-tracking tools (e.g. health apps and paper notebooks) and styles (e.g. symptom tracking and gratitude journaling) according to personal data collection and visualisation preferences.

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List of Abbreviations

App	–	Application
BuJo	–	Bullet Journaling
HCI	–	Human-Computer Interaction
MS	–	Multiple Sclerosis

1 Introduction

1.1 Motivation

"Insistent, no-matter what you do it will come back and get you; slow, in my case; it's not leaving; gloomy; to some extent I would describe it as partly containable because there are things that you can do; individual, different people have different symptoms; it's unpredictable, you cannot judge by looking at other people how it's going to progress in your particular case; you have to take it every day as it comes and deal with it as best as you can; steadily new." (Participant 11)

The aforementioned description characterises multiple sclerosis (MS), a complex neurological condition. MS affects the central nervous system and typically causes an idiosyncratic range of cognitive, physical, and psychological impairments. Most people with MS receive their diagnosis during young adulthood and experience relapsing-remitting symptoms, such as vision problems, fatigue, pain, spasms, depression, and anxiety (Embrey 2014). Approximately 65% of people with relapsing-remitting MS are diagnosed with secondary-progressive MS, a condition in which the severity of symptoms increases, and the periods of remissions decline (ibid). Considering that the onset and progression of symptoms are highly variable and difficult to diagnose, MS has been described as the disease with 1000 faces (Neuhofer 2010) and characterised as the chameleon of the neurological conditions (Altmeyer, Kröger, and Anton 2003). Understanding and documenting individual and variable signs and symptoms are key challenges in MS management (Embrey 2014; Wendrich et al. 2019).

This thesis investigates self-tracking in MS self-management. Self-tracking involves the documentation of personally meaningful aspects of one's life, such as physical activities, nutrition, and symptoms. Self-tracking is not only associated with health and wellbeing benefits, such as self-awareness and health behaviour change (Dijk et al. 2017), but can also support collaborations with clinicians and inform clinical decision making (Chung et al. 2016). Notably, self-tracking is not a new phenomenon, it likely began with one of the oldest tool sets: pencil and paper. For example, Benjamin Franklin kept a paper diary to document 13 virtues to achieve self-improvement, including moderation and cleanliness (Houston 2011). While paper-based journaling remains a common practice (Fox and Duggan 2013), an explosion of self-tracking technologies on the consumer market has brought about unprecedented opportunities to log health and wellbeing data. Self-tracking technologies aim to support people in documenting and reflecting on personally meaningful information for the purpose of gaining self-knowledge (Li, Dey, and Forlizzi

2010). Typical self-tracking tools are wearable fitness tracking devices (e.g. Fitbit¹), food journaling (e.g. Weight Watchers²), habit tracking (e.g. Loop Habit Tracker³), and symptom monitoring apps (e.g. Symple Symptom Tracker⁴).

The design of self-tracking applications often draws on medically informed and achievement-based approaches. While the former tends to draw on medical models and focuses on the monitoring of disease indicators (Nunes 2019; Mishra et al. 2019), the latter aims to support people in optimising their health behaviour and wellbeing (Elsden, Durrant, and Kirk 2016; Gulotta et al. 2016). However, while medically informed and achievement based self-tracking approaches provide great value to some people, they can impede the physical, cognitive, and emotional capacities of those who have very individual data collection and visualisation needs. For example, people living with post-traumatic stress disorder described perceiving a lack of clarity regarding the purpose of fitness wearables and the meaning of the presented health and wellbeing data (Ng et al. 2018). Vulnerable young adults reported aggravated mental health through social competition features and fading interest in activity tracking over time (Kanstrup, Bertelsen, and Jensen 2018). Women associated feelings of isolation and hopelessness with collecting data related to their fertility (Costa Figueiredo et al. 2017; 2018b).

To address mismatches between the design and experience of self-tracking technologies, researchers have drawn attention to understanding and supporting people's individual self-tracking needs. The term "*lived informatics*" highlights that people are typically neither rational health professionals nor data scientists (Rooksby et al. 2014a): they adapt and intertwine different self-tracking technologies and styles according to their prospective self-care goals and individual circumstances in everyday life. This insight has motivated a special issue journal publication on the "*lived experience of personal informatics*", in which the authors (Cosley et al. 2017) critique research that focuses only on innovation, rational decision making, and self-improvement. In particular, HCI scholars have encouraged researchers and practitioners

¹ www.fitbit.com

² www.weightwatchers.com

³ www.loophabits.org/faq

⁴ www.sympleapp.com

to investigate how technologies could be designed to support people in mindfully engaging in self-tracking and enacting their agency (Cosley et al. 2017; Cox et al. 2016)⁵.

Self-tracking can be characterised as an agency supportive practice, as both self-tracking and agency are associated with goal setting, self-reflection, and behaviour change (Bandura 2006; Dijk et al. 2017). While agency is broadly referred to the capacity of an individual to make choices and act in a given environment (Suchman 2009), this thesis focuses on how people exercise agency to self-manage their health and wellbeing. Concepts of “*self-care agency*” describe underlying capacities of performing agency to maintain personal wellbeing, including attention, physical energy, body control, motivation, decision-making, and knowledge of self-care techniques (Gast et al. 1989). However, it is important to acknowledge that people’s motivations to exercise self-care agency change and that people with changing capabilities can exercise agency in creative and collaborative ways (Boyle 2014). Agency supportive technologies designed to empower people to take an active role in self-managing their health have been shown to support positive experiences, such as a sense of control (Schneider et al. 2018).

Self-tracking practices can not only be associated with self-care agency but also with mindfulness. Langer’s conceptualisation of mindfulness is defined as the “*process of drawing novel distinctions*” (p. 94) that can support people in noticing new things in daily life, adapting to constant changes, and experiencing feelings of control (Pagnini, Bercovitz, and Langer 2016). In particular, mindfulness-based interventions have shown that experiences of mindfulness and agency are intertwined (Allen et al. 2009). Self-tracking can be considered as a mindful practice, as self-tracking is associated with processes that can support people in “*noticing new things*” in daily life (Pagnini, Bercovitz, and Langer 2016) and gaining new self-knowledge (Dijk et al. 2017). Rather than drawing on meditation-based mindfulness techniques (Moore and Malinowski 2009), this thesis draws on prior HCI work that has investigated how technologies could be designed to support mindful use, including design frictions (Cox et al. 2016) and digital wellbeing approaches (Cecchinato et al. 2019). In contrast to automatic and mindless use of technologies, mindful interactions can be defined as deliberate and intentional and potentially support positive health behaviour (Cox et al. 2016).

Here, we take up the call to investigate how self-tracking technologies could be designed to support mindful use and agency by looking at a particular case: self-tracking in MS

⁵ The findings of this thesis highlight the importance of supporting self-care agency and mindful technology use. Here, we define agency and mindfulness and elaborate on how thesis findings relate to concepts of agency and mindfulness in the discussion sections (e.g. chapter 3 and chapter 8).

self-care. The individual and variable nature of MS can cause pragmatic and emotional challenges in understanding and documenting the complex representation of this chronic neurological condition. Self-tracking technologies provide potential to support people in understanding and adjusting to their variable health and wellbeing. For example, wearable fitness tracking devices provide physical and physiological data (e.g. steps and heart rate) that is associated with primary disease indicators (e.g. physical mobility) and symptom triggers (e.g. stress). Commercial and pharmaceutical organisations have recognised the significant potential of self-tracking technologies in MS management. To investigate whether self-tracking devices can supplement the clinical assessment of the progression of MS in home settings, the biotech company Biogen teamed up with the fitness wearable manufacturer Fitbit and the PatientsLikeMe community. Based on a three-week intervention they reported high adherence, positive user experience, and a correlation between number of steps and self-reported walking ability (McIninch et al. 2015). However, technologies that realise manual and automated self-tracking approaches could not only provide real world measures to inform clinical trials and the medical assessment of MS, but also empower people with MS to self-manage their health and wellbeing in everyday life. Moreover, there is little knowledge about how and why people with MS decide to engage in self-tracking, what their self-tracking needs are, and how technologies could support perceived benefits and overcome limitations of existing self-tracking approaches.

1.2 Research Questions

Documenting and understanding the individual and fluctuating nature of MS is important for clinicians who treat MS and for people who live with MS (Embrey 2014). Much attention has been paid to supporting the tracking of primary disease indicators and disability outcome measures to inform the clinical assessment of MS (Morrison, Corish, and Sellen 2014). How technologies could support the needs of people living with MS in self-tracking their health and wellbeing has received much less attention (Wendrich et al. 2019). The objective of this thesis is to improve our understanding of the self-tracking needs of people living with MS and explore how technologies could be designed to support their self-tracking needs. This objective is motivated by the lack of human-centred technology research on self-tracking in MS self-management and the methodological turn to understanding and supporting people's lived experiences and individual self-tracking needs in recent HCI research (Rooksby et al. 2014a; Cosley et al. 2017). To achieve this objective, we investigate the following research questions:

RQ 1 How could technologies support the needs of people living with multiple sclerosis in self-tracking their health and wellbeing?

RQ 1.1 What are the self-tracking needs of people living with multiple sclerosis?

RQ 1.2 How could technologies be designed to support the self-tracking needs of people living with multiple sclerosis?

1.3 Methodology

To address these research questions, this thesis draws on an explorative research approach. More specifically, we apply an ethnographically informed design approach, combining qualitative research and design methods. This orientation is inspired by seminal HCI research methodologies, including ethnographic approaches to design (Blomberg and Burrell 2009) and design ethnography (Crabtree, Rouncefield, and Tolmie 2012). What these approaches have in common is their use of ethnographically informed methods, such as interviews, to gain a detailed understanding of people's practices and experiences with technologies - before iteratively engaging in design work. Based on a detailed understanding of people's needs, ethnographically informed design studies aim to inform and investigate the design of innovative technologies. Ethnographically informed design studies typically draw on ethnographic principles (Blomberg and Burrell 2009). The first principle highlights the importance of considering people's natural settings in which they use and experience technologies. Secondly, ethnographically informed inquiries are holistic as an understanding of human's activities within the larger context is essential to understand technology use and non-use in the real world. Thirdly, design ethnographers strive to take a non-judgemental stance to gain a detailed understanding of people's motivations and needs in their everyday lives (ibid). According to the fourth principle, ethnographic design studies inevitably pursue an understanding from the perspective of research participants to describe the ways in which people conceptualise and perceive their world (ibid). Notably, these ethnographic principles bring along practical and ethical concerns considering the intimate nature of self-tracking and the unpredictable and disruptive representation of MS in everyday life. Hence, this research does not involve traditional, anthropological fieldwork where the researcher delves into people's life worlds (Atkinson 2001). Instead, the described ethnographic principles motivate and guide an interview study, online ethnography, as well as the design and field study of a technology probe to provide a human-centred, non-judgemental, and holistic understanding of how technologies could support the needs of people living with MS in self-tracking their health and wellbeing (**RQ 1**).

1.3.1 Ethnographically Informed Methods

We draw on ethnographically informed methods to investigate the self-tracking needs of people living with MS (RQ 1.1). Blomberg and Burrell describe interviews as “*one of the ethnographer’s most valuable tools*” (p. 970). They are suited to understanding peoples’ motivations to use technologies and their experiences with technologies (Blandford, Furniss, and Makri 2016). We draw on in-depth interviews, a semi-structured qualitative data collection technique that centres on defined research objectives and provides space and time to holistically understand people’s individual experiences and explore unexpected phenomena that interviewees prioritise (Guest, Namey, and Mitchell 2013). In-depth interviews are well suited to investigate personal and sensitive topics and are characterised by open-ended “how” and “why” questions, inductive probing to link interviewees’ responses to research objectives, and interviewers who strive to be open-minded, flexible, patient, and observant (Guion, Diehl, and McDonald 2001; Guest, Namey, and Mitchell 2013). Qualitative interviews can help identify user needs, reveal challenges, elicit visionary ideas, and derive implications for design (Dourish 2006). Moreover, interviews elicit qualitative accounts that can help inform quantitative research (A. Adams, Lunt, and Cairns 2008). However, qualitative data can mask potential differences between participants’ descriptions and their everyday actions, considering the retrospective nature of interview methods and our cognitive limitations to recall situated actions (Blandford, Furniss, and Makri 2016).

We apply online ethnography to examine how technologies could be designed to support the self-tracking needs of people living with MS (RQ 1.2). Online ethnography is an ethnographically informed method that researchers can use to observe and analyse existing practices and conversations in online communities (Daniel 2011). Main advantages of online ethnography include insights based on naturally occurring phenomena and practical benefits, such as being able to collect substantial data sets within a short period of time. However, drawing on publicly available data raises ethical challenges regarding informed consent, anonymisation, and risk of harm (Webb et al. 2017). When people publicly share their data online, it cannot be assumed that they are aware of the fact that their data could be reproduced by different organisations and actors. Best practices for online research are, for example, to obtain permission to reuse photos and comments for research purposes (Townsend and Wallace 2016).

1.3.2 Design Methods

In addition, we utilise interaction design methods to investigate how technologies could be designed to support the self-tracking needs of people living with MS (RQ 1.2). More specifically, we explore the design space by creating sketches and mock-ups, and a prototype application that has characteristics of a technology probe (Sharp, Rogers, and Preece 2007). Similar to ethnographic research, technology probes aim to provide a detailed understanding of people's practices and experiences in the real world. In contrast to ethnographic inquiries, technology probes are design-led interventions involving forms of adaptable technologies that are introduced and used by people in their natural settings (Hutchinson et al. 2003). The method of technology probes has its roots in cultural probes which highlight empathy and reflection. Cultural probes draw on a process of expression and interpretation, in which participants engage in probe tasks typically using a set of tools, including diaries, in order to capture their experiences in everyday life and provide inspirational accounts (Gaver et al. 2004). Technology probes adopt the key features of cultural probes to support researchers in collecting data and pursuing three interdisciplinary goals (Hutchinson et al. 2003): (1) to gain insights regarding the use and non-use of a technology in a real world setting; (2) to investigate the feasibility of a technology; and (3) to motivate both users and researchers to inspire the design of future technologies. Thus, technology probes aim to support flexible use and typically track and visualise data to foster reflection. Technology probes present a suitable strategy to complement ethnographically informed studies, explore sensitive settings, and challenge researchers and designers to critically re-evaluate existing implications for design (K. Huang et al. 2014; Yun et al. 2010).

1.3.3 Ethics

We received UCL ethics approval for applying a human-centred methodology to inform the design of self-tracking technologies for people living with MS, including the iterative use of ethnographic and design methods, such as interviews, diary studies, and prototype evaluations (see appendix 1 and 2). When applying ethnographic and design methods, we aimed to provide flexibility and safeguards for participants considering the variable nature of MS and people's idiosyncratic health and wellbeing needs. For example, participants were able to decide how they want to take part in interviews (e.g. in person, via phone, or online conference system). They could skip interview questions and withdraw from studies at any time. When using Trackly (see chapter 7), participants were able to decide what they want to track, how they want to track it, when they want to track what it important to them, and whether they want to share their data with

researchers. We shared information sheets and consent forms with participants before conducting any interviews to support participants in making an informed decision without time constraints. We provided contact details as part of consent procedures, including the researchers' phone numbers and the helpline of the MS Society UK.

Safeguards were put in place not only for participants but also researchers. For example, the leading researcher obtained permission from organisers before attending any meetups and let the primary supervisor know when he attended MS related meetups. Speaking with people living with MS in person before conducting interviews, helped the leading researcher to gain empathy and sensibility of how people with MS manage their health and wellbeing in daily situations. The leading researcher discussed most memorable insights, interview findings, and ethical implications of applied methods with the supervisory team throughout the course of this research.

1.4 Research Contributions

We have adopted an ethnographically informed design methodology to investigate how technologies could support the needs of people living with MS in self-tracking their health and wellbeing (RQ 1). Our findings identify agency as an important self-tracking need in MS self-management and present experiences of agency as perceived benefits of a customisable and pictorial self-tracking approach. We offer two interrelated contributions based on a characterisation of different types of contributions in HCI research (Wobbrock and Kientz 2016).

1.4.1 Empirical Contribution

The first contribution is a qualitative account that identifies the self-tracking needs of people living with MS (RQ 1.1). We investigate existing self-tracking practices in MS self-management through an interview study. We find that participants regaining a sense of control over MS through intertwining individual self-care practices with different self-tracking tools, such as paper notebooks and fitness wearables. They associated experiences of control with their agency to decide what to track and how to engage in self-tracking. Participants particularly valued being able document their health in holistic ways, involving not only symptom monitoring but also expressive writing and gratitude journaling. Moreover, we identify challenges of self-tracking in MS self-care. Participants reported that self-tracking apps can impede their physical and emotional capacities, in particular when the user experience is focused on predefined health indicators and the optimisation of health behaviour. Based on this understanding, we highlight the need to

support people's individual self-care intentions and agentic capacities through customisable self-tracking approaches.

1.4.2 Artefact and Empirical Contribution

The second contribution entails the design and qualitative investigation of a technology probe. This contribution demonstrates how technologies could be designed to support the self-tracking needs of people living with MS (RQ 1.2). Drawing on the self-tracking needs of people living with MS and paper-based journaling design patterns, we developed Trackly, a technology probe that realises a customisable and pictorial self-tracking approach. Trackly bridges contemporary self-tracking and mindful colouring trends. We identify perceived benefits and limitations of customisable and pictorial self-tracking through a field study of Trackly in MS self-management. Through proactively adapting Trackly to their individual self-care intentions, individuals with MS reported a spectrum of interrelated experiences of agency, involving identity, ownerships, self-awareness, mindfulness, and control. We reveal the importance of pausing self-tracking and retrospectively engaging in self-tracking, especially when experiencing increased severity of symptoms and prioritising everyday life, including quality time with friends and family. Furthermore, we find that customisable and pictorial self-tracking is a reflective learning practice that can require inspiration (e.g. providing examples) and social scaffolding (e.g. involving peers, family members, caregivers, and clinicians).

1.5 Overview of Chapters

To present the investigation of how technologies could support people's individual needs in self-tracking their health and wellbeing in MS self-management, this thesis is structured in the following way (see Figure 1):

2. Background and Related Work - This chapter provides an overview of related self-management and self-tracking research. It shows that self-tracking is an important part of managing chronic health conditions. While medically informed research has focused on the monitoring of primary disease indicators to support clinical decision making, human-centred research has documented people's lived experiences and underscored the importance of supporting their agency and individual self-care needs. This chapter situates our research in the context of MS, a chronic neurological condition that causes an individual range of physical, cognitive, and psychological impairments. Previous work has paid much attention to technology interventions aimed at demonstrating how continuous monitoring of physical mobility and MS relapses can inform the clinical assessment of the disease progression. However, less attention has been paid to the

self-tracking needs of people living with MS: it is unclear why people living with MS decide to engage in self-tracking, what challenges they experience, what self-tracking tools they prefer to use, and how self-tracking technologies could be designed to support them in documenting their health and wellbeing in personally meaningful ways.

3. Understanding Self-Tracking in Multiple Sclerosis Self-Management: An Interview Study

This chapter presents the findings of an in-depth interview study, examining the motivations, self-tracking experiences, and needs of people living with MS. Participants described experiencing a lack of control in everyday life, wrestling with the idiosyncratic, complex, and uncertain nature of MS. Nevertheless, they reported regaining a sense of control over MS through intertwining individual self-care practices with different self-tracking technologies. They associated experiences of control with their agency to document their health and wellbeing in personally meaningful and holistic ways, involving not only symptom monitoring but also habit tracking and life journaling. However, they reported contrary benefits and limitations of existing analogue and digital self-tracking tools. Participants particularly valued being able to customise paper-based self-tracking approaches to their individual needs. However, they found it tedious to find and make sense of their paper-based entries. They appreciated self-tracking apps that empowered them to collect and make sense of their health data. However, participants criticised that digital self-tracking apps for impeding their individual physical and emotional capacities, in particular when the user experience focused on predefined health indicators and the optimisation of health behaviour. These findings highlight the need to support people's agency through customisable self-tracking approaches in MS self-management. However, it is unclear how digital self-tracking applications could be designed to support customisation.

4. Investigating Paper Journals to Inform the Design of Customisable Self-Tracking Applications: An Online Ethnography

To investigate how customisable self-tracking applications could be designed, this chapter looks at paper bullet journaling: a customisable and pictorial self-tracking approach. Drawing on an online ethnography of bullet journaling on Instagram, it illustrates the ways in which individuals adapted bullet journaling systems to meet their individual self-tracking needs. They crafted, combined, and switched between personally meaningful pictorial trackers: custom visualisations that support logging and viewing tracked data in single views. These findings identify design strategies and patterns and, therewith, exemplify how a customisable self-tracking approach can be realised to support people's individual self-tracking needs. Yet, digital research prototypes, that implement such a customisable and pictorial self-tracking approach, do not exist.

5. From Ethnographically Informed Accounts to Design: A Synthesis – This chapter provides a synthesis of the interview study (chapter 3) and analysis of paper bullet journals (chapter 4). Firstly, this chapter highlights three interrelated user needs to support agency in MS self-care: (1) receiving scaffolding when engaging in self-tracking; (2) being able to customise the topic, content, and timing of self-tracking; and (3) experiencing positive affect when engaging in self-tracking. Secondly, this chapter identifies the ways in which these self-tracking needs in MS self-care can be realised by drawing on bullet journaling design patterns: (1) offering examples of pictorial trackers to provide guidance and inspiration; (2) empowering people to customise their pictorial trackers according to their individual self-care needs; and (3) supporting people in flexibly colouring in and viewing their pictorial trackers.

6. Trackly: A Customisable and Pictorial Technology Probe - Based on the synthesis of the interview study and analysis of paper journals, this chapter describes the iterative design and implementation of Trackly: a technology probe that realises a customisable and pictorial self-tracking approach. Instead of being forced to monitor predefined health and wellbeing indicators, Trackly aims to support people in documenting personally meaningful experiences in pictorial ways. Users can define their own tracking parameters, choose from different types of pictorial trackers (e.g. body shapes), and colour pictorial trackers by touch to log personal data. An expert-based evaluation helped identify usability issues and improve the design of Trackly to enable a field study of the technology probe in MS self-management.

7. Understanding the Use and Experience of Trackly in Multiple Sclerosis Self-Management: A Field Study - This chapter presents the findings of a four-week field study of Trackly in MS self-management. It describes the ways in which participants utilised the elements of Trackly designed to support agentic behaviour: they defined personally meaningful tracking parameters in their own words, and particularly valued being able to flexibly colour in and make sense of their pictorial trackers. Having been able to support their individual self-care needs with Trackly, participants reported a spectrum of interrelated experiences of agency, including a sense of ownership, identity, self-awareness, mindfulness, and control. Moreover, participants described challenges, such as remembering to log data, tracking when experiencing increased severity of symptoms, and making sense of changing symptoms.

8. General Discussion - This chapter discusses our findings and contributions. Previous work has focused on the monitoring of predefined primary disease indicators in MS management, including physical activity and symptom relapses. We have investigated how technologies could support the individual self-tracking needs of people living with MS. Firstly, we identify agency and experiences of agency as individual self-tracking needs, including a sense of identity, ownership, self-awareness, mindfulness, and control. Secondly, we demonstrate the potential of a customisable and pictorial self-tracking approach to support people's individual needs in documenting, understanding, and communicating their holistic health and wellbeing. However, our findings also suggest that customisable and pictorial self-tracking can require personalised scaffolding considering that people's individual agentic capacities and social support systems vary. Based on this understanding, we underscore that technologies must support both people's agency and experiences of agency in self-tracking their health and wellbeing. Both views on agency are particularly important considering the individual and fluctuating nature of MS that brings about a loss of control over the body and feelings of loss of control in everyday living. We contribute a qualitative account and transferable design perspective that centre on people's individual self-care needs and experiences of agency rather than persuasion and compliance based on predefined monitoring of primary disease indicators.

9. General Reflections – This chapter provides a reflective account on the research process of this thesis. It covers the researcher's and the participants' views.

10. General Conclusion – The final chapter summarises the findings of our interview study, online ethnography, and the design and field study of Trackly. We have investigated how technologies could support the needs of people living with MS in self-tracking their health and wellbeing. Our findings identify agency as an important self-tracking need in MS self-management and illustrate the ways in which a customisable and pictorial self-tracking approach supported experiences of agency. This chapter motivates future research endeavours that could draw on mixed methods approaches to investigate how customisable and pictorial self-tracking affects experiences of agency and health behaviour over time and across populations.

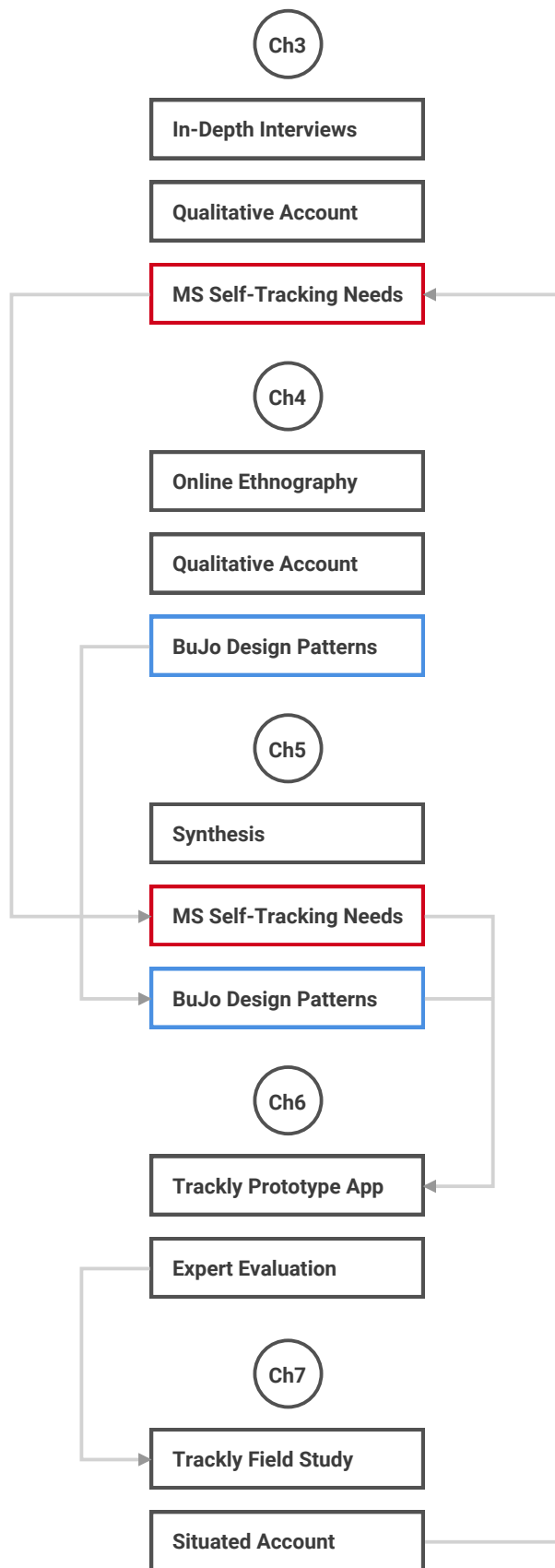


Figure 1. Overview of chapters

2 Background and Related Work

Parts of this chapter have been published in (Ayobi, Marshall, and Cox 2016; Ayobi et al. 2017; Ayobi 2018; Ayobi et al. 2018; Ayobi, Marshall, and Cox 2020).

The structure of this chapter represents the chronology of how we engaged with prior literature and identified the need to investigate self-tracking in multiple sclerosis self-management. We began with reviewing personal informatics research to characterise contemporary self-tracking trends. We found that self-tracking technologies provide new ways for people living with chronic conditions to self-manage their health and wellbeing. We then looked at prior research on self-care technologies in HCI to gain an understanding of the lived experiences of self-managing chronic conditions. Based on this understanding, we situated our research in the context of MS self-management to motivate an investigation into how technologies could support self-tracking in a chronic neurological condition that is relatively little studied in HCI research.

2.1 Self-Tracking with Personal Informatics Technologies

Self-tracking is not a new phenomenon: since the rise of humanity, people have been interested in documenting the manifold facets of life, measuring the body, and obtaining self-knowledge. The Greeks taught philosophical imperatives, such as *"know thyself,"* which claim that we need to seek self-truth and take self-responsibility in order to achieve a meaningful life and gain psychological well-being (Ryff and Singer 2008). In this sense, the Roman philosopher Seneca recorded what he dreamed and Benjamin Franklin's autobiography reveals his endeavours to track 13 virtues, such as moderation and cleanliness, in his everyday life to achieve self-improvement (Houston 2011; Weintraub 2013).

Within the interdisciplinary field of HCI, studies on life logging (Sellen and Whittaker 2010) and self-care technologies (Nunes et al. 2015) have demonstrated in which ways people collect personal information, explore and reflect upon their data collections, and gain self-awareness and self-knowledge. However, there has been a notable increase of both wearable self-tracking devices on the consumer market and related research endeavours in HCI. Consumers have to choose between more wearable health and wellbeing products than ever. For example, smart watches, such as the Apple Watch, compete to own a place on your wrist and incorporate sensors to track sitting, exercise, and calories burned. Within HCI research, Li et al. coined the term 'personal informatics' in 2010 to describe systems that support people in reflecting on personal data in order to

encourage self-reflection and self-knowledge. From then on, researchers have examined use and abandonment (Lazar et al. 2015; Harrison et al. 2015), derived models and frameworks (Li, Dey, and Forlizzi 2010; Epstein et al. 2015), and explored the design space of contemporary self-tracking tools in many ways (Khot, Hjorth, and Mueller 2014; Mauriello, Gubbels, and Froehlich 2014).

However, personal informatics research is an emerging research area lacking an overarching framing and clarity. On the one hand, there has been a strong emphasis on theory guided approaches and persuasive behaviour change strategies (Li, Dey, and Forlizzi 2010; Murnane 2015) and, on the other hand, there has been a shift in focus towards the lived experience and self-reflection highlighting the agency of people within a broader cultural context (Epstein et al. 2015; Deborah Lupton 2014a). At the same time, some lines of research recommend to focus on the design for long-term engagements (Fritz et al. 2014), while others propose to leverage a new type of personal tool specifically designed for short-term interventions (Lazar et al. 2015). Should future personal informatics systems be designed to foster self-knowledge, encourage behaviour change, or support the learning of specific skills to help us reaching our personal self-care goals?

This chapter reviews in which ways self-tracking in personal informatics research has been approached so far. We describe the landscape of personal informatics research and identify psychologically, phenomenologically, and humanistically informed streams. Concluding, this chapter outlines opportunities for future research endeavours: (1) involving populations with special needs, such as people living with chronic conditions; (2) examining the experiential dimensions of self-tracking; and (3) eliciting situated data to improve understanding of self-tracking practices and people's data collection and visualisation preferences.

2.1.1 Research Foci

We identify four self-tracking research foci: (1) lifestyle; (2) mental health; (3) chronic conditions; and (4) women's health. While these research foci appear distinct at first glance, we will find in the next sections of this literature review that people intertwine different self-tracking styles and technologies in everyday life.

2.1.1.1 *Lifestyle*

Research studies have covered a wide range of self-tracking practices, such as activity tracking (Harrison et al. 2015; Khot, Hjorth, and Mueller 2014; Patel and O’Kane 2015), food journaling (Cordeiro, Bales, et al. 2015; Cordeiro, Epstein, et al. 2015), productivity (Ahmed et al. 2014; Collins et al. 2014), sleep tracking (Choe et al. 2015; Liu, Ploderer, and Hoang 2015), and life journaling (Elsden 2014; Pirzadeh, He, and Stolterman 2013). Research studies focused either on a specific type of self-tracking practice or addressed varied types of behaviour, such as physical activity, finances, and sleep, in order to make broader claims (Epstein et al. 2015; Li, Dey, and Forlizzi 2010). Congruent with the availability of wearable self-tracking devices on the consumer market and applications in app stores, most of prior work has examined the self-tracking of physical activity, food intake, and sleeping behaviour. Studies have often involved students and knowledge workers, who were generally young, technologically savvy, and healthy (Spiel et al. 2018). A systematic literature review suggests that self-tracking can primarily support self-awareness and that it remains unclear to what extent self-tracking can support health behaviour change (Dijk et al. 2017).

2.1.1.2 *Mental Health*

A recent systematic literature review found that supporting self-tracking is a core functionality of innovative mental health applications (Sanches et al. 2019). Mental health self-tracking applications typically support people in tracking, reflecting on, and sharing their health data with family members, caregivers, and clinicians (ibid). For example, The Moment is a system that aims to support people with depression and bipolar disorder in documenting their emotional journeys in open-ended ways, including text entries and photos (S. T.-Y. Huang, Kwan, and Sano 2014). MindNavigator is a tailored workshop format aimed at supporting the mental health of college students (K. Lee and Hong 2018). Taking part in the MindNavigator workshops, students were encouraged to create a stress profile, identify stressors and relievers, set personalised goals, track their health behaviour, and adjust their wellness goals to improve their mental wellbeing. Interestingly, a qualitative research study found that students prefer to self-track health behaviour that is related to mental health conditions rather than self-tracking their emotional wellbeing directly (Kelley, Lee, and Wilcox 2017). Self-tracking behavioural proxies for mental health, such as physical activities and sleep, is, moreover, a common approach in clinical mental health interventions to identify stressors (ibid).

2.1.1.3 *Chronic Conditions*

While initial streams of personal informatics research tended to focus on how primarily healthy adults engage with wearable activity tracking devices and food journaling applications, recent research has investigated the benefits and limitations of available self-tracking technologies considering a wide range of different health and wellbeing conditions, including chronic pain (Felipe et al. 2015), human immunodeficiency virus (Bussone, Stumpf, and Buchanan 2016), bipolar disorder (Matthews, Murnane, and Snyder 2017), irritable bowel syndrome (Karkar et al. 2017), migraine (Schroeder et al. 2018), Diabetes (Katz et al. 2018), Parkinson's disease (Mishra et al. 2019), and autism spectrum disorder (S.-I. Kim et al. 2019).

Research on self-tracking in chronic illness management suggests that self-tracking can be an important part of self-managing symptoms and informing clinical practice (Chung et al. 2016). People with chronic conditions seem to focus on documentary (Mishra et al. 2019), goal-directed (Schroeder et al. 2019), and diagnostic self-tracking styles (Karkar, Zia, et al. 2015). Perceived benefits of self-tracking go beyond self-awareness and health behaviour change in self-managing chronic conditions: people highlighted, in particular, affective benefits, such as being able to regulate emotional wellbeing and supporting a positive quality of life. For example, people diagnosed with Parkinson's disease reported that engaging in self-tracking supported them in overcoming denial and coping with the degenerative nature of their health condition (Mishra et al. 2019). Individuals living with migraine explained engaging in self-tracking to answer specific questions about symptom contributors, prevent migraines, and gain social recognition (Schroeder et al. 2018; Park and Chen 2015).

Research has identified not only benefits but also challenges with self-tracking in chronic illness management. Increased self-awareness can potentially cause negative affective states (Vega et al. 2018) and self-tracking symptoms does not necessarily result in new self-knowledge. Symptoms can be ambiguous and symptom triggers unclear (Mishra et al. 2019). Diagnostic self-tracking systems still need to overcome tensions between scientific rigour and the uncertainties of everyday life (Karkar et al. 2017).

2.1.1.4 *Women's Health*

A recent focus in personal informatics research is self-tracking in context of women's health. Studies have investigated the potential of self-tracking technologies to better understand and support the management of enigmatic conditions, such as endometriosis (McKillop, Mamykina, and Elhadad 2018) and vulvodynia (Young and Miller 2019). However, a growing body of research on women's health takes a critical

view on existing self-tracking applications. For example, women with eating disorders use but would not recommend available diet and fitness apps to support recovery, given that the design of diet and fitness apps tends to focus on restriction and optimisation (Eikey, Chen, and Zheng 2019). Menstrual self-tracking apps can exclude minorities and fail to support different life stages, such as pregnancy (Epstein et al. 2017). Accounts of women who engaged in fertility self-tracking revealed a spectrum of mixed experiences with health and wellbeing data, from positive to burdened, obsessive, trapped, and abandoning (Costa Figueiredo et al. 2018a). Critical reflections on self-tracking technologies and menopause focused attention to potential negative outcomes highlighting tensions between medicalised self-tracking approaches and women's lived bodily experiences (Homewood 2019). These issues underscore the need for future work to explore the design of applications that meet people's individual self-tracking priorities and emotions self-care needs.

2.1.2 Methodological Streams

We identify and characterise (1) psychologically, (2) phenomenologically, and (3) humanistically informed streams of personal informatics research. All together these streams reveal the methodological differences and exhibit the growth and expanding context of personal informatics research.

2.1.2.1 *Psychologically Informed Stream: Self-Tracking to Change*

The psychologically grounded stream is typically informed by psychological theories and behaviour change strategies, presents frameworks aiming to provide guidance on how to design more effective and efficient personal informatics systems, and has as central concepts self-reflection and self-knowledge.

Key work in this stream include a stage-based model and identification of different barriers people face when engaging in self-tracking (Li, Dey, and Forlizzi 2010). The technology-centric model is composed of five psychological stages (D. Lupton 2014). At the preparation stage, people determine what they would like to track and decide what kind of tools they would like to use. During the collection stage, people collect personal information about themselves and, afterwards, at the integrations stage, they prepare and aggregate the collected data. At the reflection stage, they reflect upon visualised data and, finally, at the action stage, people "*choose what they are going to do with their newfound understanding of themselves*" (ibid, p. 562). People, for example, adapt their behaviour in order to reach a defined goal.

Epstein and colleagues extend the stage-based model by drawing on prior empirical findings to underscore that people enmesh various tracking devices into their everyday life in many ways (Epstein et al. 2015). Therefore, they propose a lived informatics model and, firstly, divide the preparation stage of Li et al.'s framework into a deciding stage and selecting stage. The former describes that people decide to track because of varying reasons, such as curiosity and reward. The latter builds on the decision to track and mirrors that people select personal informatics tools depending on factors, such as aesthetics, specific features, platform compatibility, and budget. Secondly, they introduce two practices, namely, tracking and action, as an ongoing process of collecting, integrating, and reflecting, which are data dependent and occur simultaneously. Thirdly, the lived informatics model adds the lapsing stage and resuming stage. Lapsing refers to situations, when people lapse using tracking because they forget to use or change their devices, in other cases they temporarily suspend or permanently stop tracking because it is no longer relevant. Resuming refers to situations, when people resume tracking after short- or long-term lapses.

Reflection is a critical part of the stage-based and lived personal informatics model and is conceptualised in the HCI discourse in more detail. In order to gain an understanding of users' self-reflection needs, Li et al. interviewed people who have used different personal informatics tools in their past (Li, Dey, and Forlizzi 2011). In doing so, they identified that people asked questions concerning their current status of tracked activities, history of collected data, set program-level goals, discrepancies between goals and statuses, contextual dependencies, and factors influencing behaviour over the long-term. Additionally, they note that people's information needs changed over time and highlight two phases of reflection that are related to the posed questions, namely, discovery and maintenance. People transitioned from the discovery to the maintenance phase when they explored and learned how to reach their personal goals. Contrary, people also transitioned from the maintenance to the discovery phase in cases such as not being able to pursue personal goals or facing new circumstances and challenges.

In contrast to Li et al.'s empirical based approach, Baumer engages with theoretical and conceptual models of reflection and introduces a conceptual approach consisting of three dimensions of reflection (Baumer 2015): (1) Breakdown refers to situations when people's attention is awakened by striking, disturbing, and doubtful phenomena. For example, the phenomenological concept of ready-to-hand to present-to-hand illustrates breakdown when tools are used unconsciously and at a certain moment become implicit; (2) Inquiry is another dimension of reflection that portrays how people develop, test, and revisit certain phenomena. In educational approaches, for example, the process of

inquiry includes the way people evaluate emerging and existing knowledge, such as ideas, concepts, and theories; and (3) Transformation is the third dimension of reflection and exemplifies a change of fundamental assumptions, attitudes, and behaviour. For example, in cognitive- and system-oriented frameworks transformation changes explicitly the body of rules by which systems behave.

2.1.2.2 *Phenomenological Stream: Self-Tracking as a Lived Experience*

The phenomenologically informed stream seeks to better understand how self-tracking applications are used and experienced in the real world. Here, the focus shifts from the effectiveness and efficiency of technologies to the context of use and the complexity around the system's use. Research studies highlight the manifold ways in which personal informatics is embedded in our lives and aim to address the interactional and social dimensions of tracking practices in more detail.

The use and non-use of self-tracking can be described along human, tracking device, and tracking application related determinants that are interconnected in practice. The human related determinants include individual factors, such as a varied motivation and readiness to change, which affects the adoption and the ways self-tracking tools are used (Fritz et al. 2014).

The term "*lived informatics*" characterise the very personal use of activity tracking devices and to stress the agency of people who are changing their behaviour not because of technologies but rather because they pursue personal goals and aim to change (Rooksby et al. 2014b). In practice, there are five overlapping styles in which tracking devices are used (ibid). During directive tracking people are often pursuing a specific goal such as losing weight or running a marathon in a specific period of time. Documentary tracking reveals that people do not only track in order to change their behaviour but are also interested in documenting their activities because of different reasons: Some start documenting the number of steps at work out of personal interest and curiosity, others document their activities in order to underline their efforts. Diagnostic tracking is a form of tracking that aims to uncover links between different phenomena. People are trying to diagnose, for example, what kind of symptoms correlate with their medication and diet. This kind of tracking is key in the Quantified Self discourse, however, Rooksby et al. additionally note that only a minority of their participants engaged in diagnostic styles of self-tracking. Collecting rewards refers to people's will to score points or receive remunerations. They are keen on, for example, competing with other users of a running app or receiving rewards form health insurance schemes. Fetishised tracking exhibits that a few people are using tracking devices

because they are primarily interested in the appeal and functionality of wearable technologies or the collected data per se.

On the one hand, people keep using self-tracking devices because they develop routines, perceive the device as beneficial and engaging - often because of reaching personal goals - and hope that the gathered data might become valuable in the future (Lazar et al. 2015). Furthermore, a qualitative study that focused on users who have tracked their activities for nearly 15 months found that people tracked not always the same but different activities from time to time (Fritz et al. 2014). They shared their data in the beginning with close friends and family and, later on, with like-minded sports practitioners in dedicated online social networks. Thus, despite changing goals and practices some people develop a strong attachment and engage in self-tracking over many months and even years, which illustrates that it is worth supporting not only behaviour change goals initially but also the development of healthy behaviour in the long-term. Moreover, research has illustrated the move of self-tracking technologies from the consumer to the corporate context by exploring physical activities in an employer-sponsored health program (Vyas et al. 2015). University employees, who participated in the Global Corporate Challenge (GCC), teamed up, used a pedometer to track their steps, and were able to win virtual trophies. Furthermore, participants interweaved the trackers in their work context and home environment, reflected on their lifestyle and recognised patterns in their everyday activities when entering manually their steps in an online system, as well as enjoyed social activities, such as walking and talking together.

On the other hand, recent studies suggest that people face several difficulties in activity tracking and approximately one third of self-tracking devices are abandoned within 6-12 months (Harrison et al. 2015). Expert users, for example, tended to track too many activities at the same time which led to "*tracking fatigue*" (ibid), overlooked triggers and contextual information which obstructed meaningful insights, as well as showed a lack of scientific rigor resulting in unsound results (Choe et al. 2014).

Tracking device related determinants of use and non-use typically include the form and functionality. For example, people are often disappointed that tracking devices are not capable of accurately tracking especially non step-based activities such as doing workouts in the gym or cycling outside (Harrison et al. 2015). While some participants changed their behaviour because of these limitations, others abandoned tracking and would eventually resume only if tracking devices would be capable of accurately recording activities in a holistic manner (ibid). Moreover, users have stopped using activity tracking technologies because they were not able to identify with the devices'

aesthetics, or because of discomfort on the wrist or finding them unmanageable due to short battery life (Harrison et al. 2015; Lazar et al. 2015). Application related determinants typically affect the user experience of self-tracking apps and platforms. Users reported that self-tracking apps were not usable and the represented data non-actionable and useless (Lazar et al. 2015). Furthermore, a lack of competition and opportunities to interact with friends, who used different applications or devices made by other manufactures, resulted in disengagement (Clawson et al. 2015; Harrison et al. 2015).

All in all, individual and contextual factors, such as motivation, expectations, expertise, tracked activities and choice of tracker, as well as personal living conditions and changes in life, together influence the use and non-use of self-tracking technologies. Notably, abandonment results not necessarily from failure. Some people, who abandoned self-tracking technologies successfully achieved their goals, and others wish to upgrade to newer models, and a few people lapse and resume self-tracking over time because of shifting priorities in life (Clawson et al. 2015; Lazar et al. 2015; Rooksby et al. 2014b).

2.1.2.3 Humanistic Stream: Self-Tracking Culture

The humanistically informed stream draws on concepts and perspectives that are grounded in research fields such as digital humanities, media studies, and sociology. This stream tends to take a reflective and critical point of view on the qualified self-movement and especially on technology-centric personal informatics research, reflects on its development by taking a look into the past and present trends, and draws a broader picture by situating fundamental notions such as the individual, society, and culture in the context of contemporary self-tracking technologies.

In the 16th century, the polymath genius Leonardo DaVinci explored the design space of how to measure people's steps and walked distances mechanically in order to construct maps for architectural and military purposes (Tudor-Locke 2003). One of his many solutions was a "wheelbarrow-like" odometer that dropped a pellet into a box after each turn of the wheel (ibid). In order to calculate the distance travelled, the user was supposed to consider the sum of all pellets and the circumference of the wheel. Even though, DaVinci's inventions made initial steps towards measuring step counts, odometers were not meant to and not suitable to track individual physical activity. Only in 1965, Hatano introduced a wearable pedometer called manpo-kei which was manufactured in Tokyo and widely purchased in Japan a few years later. Comparing with contemporary wearable tracking devices, pedometers are capable of accurately counting

steps, but not walked distance. However, manpo-kei pedometers explicitly aimed to support people to achieve a 10000 daily steps count and therefore intended to encourage people in achieving a physically healthier lifestyle.

In their analytical comparison of one of the most effective self-monitoring tool - the weight scale - and contemporary wearable self-tracking devices, Crawford et al. (Crawford, Lingel, and Karppi 2015) illustrate how the physical location and the perceived meaning of the weight scale has changed over the last hundred years. At the end of the 19th century, doctors were privileged to monitor the weight of their patients for medical purposes only. Years later, penny scales moved to public spaces, such as carnivals and large squares, and were initially used because of curiosity and entertainment. Finally, at the start of the 20th century, the weight scale moved to our private bathrooms providing powerful self-knowledge and encouraging us to reach a normalised numeric range. Taking a closer look at early advertisements for weight scales, we can read slogans, such as: *"Here is the simple and pleasant new way to reduce 20, 30, 40 pounds, or more"* and *"Who often weighs himself knows himself well. He who knows himself well lives well"* (ibid, p. 489). A similar picture is drawn by contemporary marketing campaigns for activity trackers which implies that there is a moral and mandatory demand for self-measurement to live a healthy lifestyle. Moreover, it conveys the impression that self-measurement *"becomes the substitute for diet and exercise, transforming the body through a daily interaction with data about the body"* (ibid, p. 490). Furthermore, Crawford et al. argue that there is a lack of control and transparency when using activity trackers. While weight scales (and pedometers) immediately return the measure directly and only to the user, who can compare the results with available height and weight charts, wearable monitoring tools transfer all tracked data to service providers. Only a small portion of the normalised and economically valuable data is returned back to the user and the community resulting in a lack of scientifically credible understanding of physical activity other than the general ten thousand steps per day goal.

The aforementioned literature illustrates that the use of digital technologies is intertwined in our social and cultural life. While the scientific term *"personal informatics"* may lead to the assumption that self-tracking mainly focuses on the individual, the use of personal informatics tools is embedded in people's social life. A few users are taking advantage of social media functionality in order to share their activities, others run in groups or compete with strangers from all over the world, and some even participate in quantify self meet-ups and conferences to share their tracking experiences.

This emerging movement is also reflected in interrelated modes of self-tracking (Deborah Lupton 2014b). Private self-tracking is done purely for one's only purpose in order to gain self-knowledge and reach, for example, personal health goals. Pushed self-tracking occurs when engaging in data collection is encouraged by external actors such as friends, family members, or workplaces promoting wellness programs. Communal self-tracking involves sharing personal data with other people being part of self-tracking communities or citizen science projects. Imposed self-tracking is foisted upon people whose, for example, work practices are recorded and analysed in order to maximise performances and reduce costs. Exploited self-tracking takes place when personal data becomes a commodity and is "*repurposed*" for the benefit of others. For example, in some cases, service providers, such as market research agencies, sell aggregated data of trackers to other business clients.

Furthermore, Lupton takes a sociological perspective on personal informatics and introduces the term "*self-tracking cultures*" in order to highlight that self-tracking is not only an individual but also a social practice which is carried out and endowed with meaning in our cultural context (D. Lupton 2014). More specifically, the understanding of self-tracking cultures draws on topics such as new individualism, data doubles, and social inequalities. Lupton points to the new individualism phenomenon in late modern societies which entail the "*reinvention of the self and body*" for the purpose of individual growth, success, prosperity, and personal health (ibid, p. 80). The use of personal informatics meets also the reinvention paradigm as it focuses on the individual, self-improvement, and requires work to achieve personal health goals. The notion of data doubles refers to people's identity work and self-representation, which have their own materiality, "*apart from the fleshy bodies from which they are developed*" (ibid, p. 82). They are iteratively generated and reconfigured when people use personal informatics tools to record, for example, physical activities, mood, or productivity. Furthermore, they are reflexive as people reflect upon their data doubles and adapt their behaviour which in turn recursively reconfigures the data doubles. This relationship between represented data doubles through technologies and the mediated perception of the self, raises questions such as how people feel and act on the represented images in order to meet the demands of self-tracking tools. Dijk and colleagues point to this direction by addressing unintended and negative effects of self-tracking by drawing on different theories. For example, self-tracking may lead to an excessive self-focus, self-fulfilling prophecies, and data-dependency. Self-tracking could furthermore pressure users to constantly reach new goals and change their behaviour even if it, for example, does not meet their physical conditions.

Personal informatics systems might not only affect the individual emotional experience but might also cause social inequalities when external actors, such health institutions and workplaces, become part of the *self-tracking cultures*. In these cases, failure in self-tracking may be perceived as a lack of self-control, associated with pay and promotion opportunities or result in higher health insurance premiums (D. Lupton 2014).

2.1.3 Research Directions

Based on the identified psychological, phenomenological, and humanistic stream of personal informatics research, this section outlines future research directions: (1) broadening the research context by involving underrepresented populations, such as people living with chronic conditions; and (2) sharpening applied methodological tools by eliciting situated data to better understand the appropriation and use of personal informatics systems in everyday life.

2.1.3.1 *Rewriting Context*

In contrast to technology-centric research, the humanistically informed stream sensitises researchers to data technology driven inequalities which the HCI community should not ignore but actively shape. Prior research has paid much attention to the development of innovative prototypes and a detailed understanding of the use and non-use of personal informatics systems. However, the self-tracking needs of people from minority ethnic communities and individuals living with chronic conditions and mental health impairments have received less attention.

The limited historical account of self-tracking illustrates that people have not discovered self-tracking lately. Contemporary personal informatics research could benefit from using the concept of 'history' as an analytical framework in order to reveal the present nature and inform the future of self-tracking devices. Crawford et al. show in their comparison of wearable self-tracking devices and the weight scale that both have promised and still promise reliable self-improvement through external measurement and numeric accuracy (Crawford, Lingel, and Karppi 2015). However, in contrast to the weight scale, people are facing a lack of control over their data in the context of contemporary personal informatics technologies (ibid). Since consumers are increasingly recording health metrics using wearable devices (Kendall, Morris, and Tan 2015), we could, similarly, take a closer look at the history and use of artefacts, such as paper notebooks, to inform the design of fair and inclusive self-tracking technologies.

A humanistic perspective, furthermore, deepens the personal informatics research context by shedding some light on the relationship between people's data collection practices and their self-awareness. Prior research explored when and what kind of questions individuals ask when reflecting on self-tracked data (Li, Dey, and Forlizzi 2011). Lupton, furthermore, focuses attention on how individuals re-understand their own bodies and develop, for example, data dependencies through the interplay with their data images (D. Lupton 2014). An angle such as this entails further opportunities for explorative and critical design studies on people's reflective work with their data corpuses and, moreover, how self-tracking technologies can affect peoples' emotional experience not only in intended but also unintended ways.

2.1.3.2 *Sharpening Analysis*

On the one hand, previous personal informatics research has mainly drawn on explorative interview studies as well as mixed-method approaches including a combination of questionnaires and semi-structured interviewing techniques in order to uncover people's motivations and individual self-tracking practices. On the other, there are deployment studies of prototype applications that have often focused on the evaluation of a specific range of functionality. They yielded seminal findings, such as the turn to the lived experience of self-tracking (Rooksby et al. 2014b). However, interview studies have rarely covered the situated experience of self-tracking and most of the deployment studies have rarely addressed the effectiveness of the designed applications over the long term. Exceptions are, for example, Patel and O'Kane who conducted a situated study to illustrate the contextual influences on the use and non-use of fitness informatics in a gym (Patel and O'Kane 2015) as well as Gouveia et al. who conducted a ten month in the wild study in order to examine the users' engagement with an activity tracking application in more detail (Gouveia, Karapanos, and Hassenzahl 2015).

Gaining a deeper understanding of the real-world use and informing the design of future personal informatics systems bears several challenges since self-trackers are often mobile, active, and take advantage of different wearable devices, mobile applications, and online platforms across time and space. Screen-capture and wearable camera use revealed in which ways people use iPhones when navigating and searching in the wild (Brown, McGregor, and Laurier 2013). Thus, instead of focusing only on retrospective data, further research studies could draw on rich qualitative accounts and situated data, which are together suitable to coherently uncover peoples' experiences before, during, and after the use of self-tracking technologies. For example, ethnographically informed approaches, technology probe, and experience sampling methods are suitable to describe the immediate and emotional experience of self-tracking.

2.2 Self-Management with Self-Care Technologies

The previous section has reviewed self-tracking in personal informatics research. We found that self-tracking plays a significant role in self-managing chronic conditions. While personal informatics research on self-tracking is a recent research domain within the HCI community (Dijk et al. 2017; Li, Dey, and Forlizzi 2010), there is a related body of knowledge on self-care technologies. This section provides an overview of prior work on self-management and self-care technologies to gain an understanding of what living and coping with chronic conditions in everyday life entails.

2.2.1 Self-Management

The number of people developing chronic conditions, such as cancer, diabetes, and mental illness, increases steadily (Barlow et al. 2002; European Commission 2016). Avoiding risk factors, such as smoking, alcohol abuse, and sedentary behaviour, and pursuing a healthy and physically active lifestyle can support people in self-managing their personal health and wellbeing. Self-management (Barlow et al. 2002) refers to:

“the individual’s ability to manage the symptoms, treatment, physical and psychosocial consequences and lifestyle changes inherent in living with a chronic condition. Efficacious self-management encompasses ability to monitor one’s condition and to effect the cognitive, behavioural and emotional responses necessary to maintain a satisfactory quality of life” (p. 178).

People with chronic conditions are often expected to self-manage their health beyond clinical settings (Blandford 2019). For example, self-monitoring blood glucose levels with medical devices is an integral part of managing diabetes. People increasingly engage in self-care using consumer health technologies to improve their physical performances, nutritional habits, and mental health, including self-tracking technologies, such as wearable fitness tracking devices (Dijk et al. 2017). Research suggests that there are individual and environmental factors that impact whether and how people self-manage chronic conditions and their general health and wellbeing (Wilkinson and Whitehead 2009). Self-care can be viewed as a continuum (Chambers 2006). At the beginning of the continuum, there is the individual person. From an empowerment perspective, adults initiate and regulate self-management activities themselves. They make lifestyle decisions and take risks on daily basis according to their emotional wellbeing and priorities in everyday life. They are likely to gain some self-care expertise over time through experiencing and acting on health changes, which can involve, for example, adjusting dietary habits and medication intake. The everyday realities of self-care are

often described as a challenging task and hard work, that can require guidance and support (Nunes and Fitzpatrick 2018). At the other end of the continuum self-care is shared (Chambers 2006). It is not only a self-centred practice but also collaborative. It can involve support from informal and formal caregivers, friends, communities, and networks of clinicians (Chen, Ngo, and Park 2013).

2.2.2 Self-Care Technologies

Self-care technologies play a central role in supporting people in self-managing chronic conditions. Self-care technologies aim to (1) support the management of chronic conditions and increase people's quality of life; (2) reduce the vast costs of healthcare; and (3) offer opportunities to understand real world self-care priorities and explore the design space of self-care (Nunes et al. 2015). Applied technologies are not limited to medical devices, such as blood glucose meters (O'Kane, Rogers, and Blandford 2015), but include a wide range of different interactive systems, such as dedicated online communities (Liu, Ploderer, and Hoang 2015), smartphone based applications for monitoring symptoms (Storni 2013), web tools for personal data analysis and management (Mamykina et al. 2010), and wearable sensor based systems that are capable of sensing individual and contextual information, such as phone usage (Osmani 2015) or ambient sound (Kusk et al. 2013).

Research on self-care technologies in HCI tends to focus on different methodological strategies, such as eliciting ethnographic data to inform the design of technologies, evaluating prototypes in the wild, drawing on participatory design methodologies, and innovating the hardware and software of technologies.

Qualitative studies of self-management highlight the individual experience, idiosyncratic character, and open-ended nature of self-care practices in everyday settings (Storni 2013). Chen, for example, sheds light on the varied health information management practices of people with diabetes and stresses the need for personalised health technologies (Chen 2010). Ethnographically informed work on self-care practices has documented that type 1 diabetes patients develop unique skills in managing the chronic condition over time (Storni 2013). In this vein, Mamykina et al. report how experienced diabetes patients adopted the self-monitoring application MAHI to track routines, reflect upon their personal stories, and construct their own identities in daily self-management (Mamykina et al. 2010). Their grounded theory analysis of the long-term use of MAHI, which supports unstructured, rich, and personal media recordings in the web, identified people's needs to maintain a positive self-image, demonstrate competence in managing the disease, and sustain the constructed self-image over time (Mamykina et al. 2010).

O’Kane and colleagues shed light not only on the individual use of diabetes technologies but also contextual influences in everyday life (O’Kane, Rogers, and Blandford 2015). Their situated study illustrates that medical technology use in familiar situations shows large individual differences. However, uncertain social situations can lead to actively hiding or purposefully showing off. For example, people tended to conceal their mobile medical devices in romantic situations or encounters at workplaces in order to protect and manage the impression they make on others. Beyond the diabetes context, Park and Chen provide a detailed account of self-management practices performed by people affected by migraines (Park and Chen 2015). They describe how the unpredictability and intermittency of migraines impeded people’s efforts to identify individual triggers and gaining social recognition.

Participatory-design-led projects illustrate ways in which we could build bridges between different stakeholders in order to resolve information asymmetries and provide human-centred care. For example, Kusk et al. involved both health care professionals and hypertension patients in the design of a lightweight system for blood pressure self-measurement at home (Kusk et al. 2013). On the one hand, interviewing general practitioners and nurses helped researchers to learn what kind of methods and devices are used and in which ways the validity of recorded blood pressure measures is evaluated for diagnostic use. On the other, focus group sessions with hypertension patients inspired the design and evaluation of prototype applications. As a result, the BP@Home system is capable of sensing contextual barriers, such as rest time, bodily movement, and ambient sound, as well as provides guidance on the process of self-measuring blood pressure by, for example, displaying a countdown for the recommended rest period. The participatory design study suggests that patients’ acceptance and use of context-sensing support tools is proportional to the severity of the condition.

Moreover, there are lines of research which focus on leveraging technological advances and driving innovative solutions. For example, the COPDTrainer (Spina et al. 2013) is a wearable smartphone-based motion rehabilitation system that analyses motion sensor data and provides real-time acoustic feedback in order to adjust incorrect movements. The evaluation of the system indicates that the COPDTrainer is capable of effectively measuring the performance and quality of exercises in people suffering from chronic pulmonary obstructive disease. The MONARCA system demonstrates the potential of harnessing smartphone sensors for the diagnosis and treatment of chronic mental health conditions (Osmani 2015). The authors point out how the analysis of mobility

data, voice levels, and phone call patterns can be used to detect depressive and manic episodes in patients diagnosed with bipolar disorder.

2.2.3 Lived Experiences and Medical Care Models

Self-care can be positioned on a continuum starting with people's daily lifestyle choices and idiosyncratic self-management practices (Chambers 2006). Moving along the continuum, care becomes increasingly shared involving family members, caregivers, and providers, such as clinicians (ibid). Self-care technologies aim to support people along the self-care continuum and offer a wide range of functionalities, including self-monitoring and patient-provider collaboration features (Nunes, Andersen, and Fitzpatrick 2019). In this section, we highlight tensions between people's lived experiences, clinical practices, and technologies that embody medically informed care models.

Designing self-care technologies is inherently complex. On the one hand, people living with chronic conditions tend to prioritise their emotional wellbeing and quality of life (Nunes et al. 2015). On the other, clinicians tend to focus on the assessment and effective treatment of symptoms according to the pathology of chronic conditions and medical standards (Blandford et al. 2018). These potentially contrasting priorities pose fundamental challenges in the design of self-care technologies (Andersen et al. 2018). Technologies that do not align with the concern of patients and clinicians can lead to frustration, harm, and abandonment (Nunes et al. 2015).

Prior work has documented misalignments between people's lived experiences and medically informed models. For example, diabetes care is typically dictated by standardised blood glucose monitoring and defined lifestyle recommendations (Wing et al. 2001). However, research suggests that the realities of living with and dealing with diabetes can be open-ended and uncertain (Storni 2013). While dementia care is based on disability outcome measures, human-centred research highlights the agency and personhood of those who live with this neurodegenerative condition in everyday life (Lazar, Edasis, and Piper 2017). Social recovery of people with traumatic brain injury is clinically often documented by the frequency of social interactions outside of the home (Struchen et al. 2011). However, Feuston and colleagues illustrate how individuals with traumatic brain injury mindfully disengage from social settings to recover and document how they develop individual goals for social participation to regain social independence over time (Feuston, Marshall-Fricker, and Piper 2017). A critical literature review on the agency of autistic children in technology research highlights a focus on medical and corrective approaches to analyse, assist, and improve behaviour (Spiel et al. 2019). The needs and desires of autistic children are rarely addressed.

Considering these mismatches between people's lived experiences and medically informed care models, prior work has proposed approaches that can help researchers and practitioners to design technologies that prioritise people's subjective health experiences. For example, recent work suggests a shift from "medicalised" to "mundane" self-care technologies. Mundane self-care technologies focus attention to people's agency and quality of life rather than the adherence of medical procedures (Nunes 2019; Nunes and Fitzpatrick 2018). An example of a mundane self-care technology is the mobile self-monitoring app "*Tag-it-Yourself*" that demonstrates how personalised monitoring can empower people living with diabetes to understand and reflect on their conditions in personally meaningful ways (Storni 2013).

Alternative approaches go beyond empowering user interface design. For example, art therapy uses art materials to help express lived experiences. Art therapists focus on supporting people in accepting and living with their health experiences, rather than improving their health status (Piper and Lazar 2018). Their practices demonstrate how researchers and practitioners can take observing and following roles in empowering participants to express their lived experiences (ibid). The creative practice and expressive forms of art therapy contrast with predefined self-report methods and offer new ways of understanding health experiences and designing health technologies.

Other research approaches provide guidance on how researchers and practitioners could bridge the priorities of both patients and clinicians. For example, Anderson and colleagues propose three conceptual properties that can help researchers and practitioners to classify and address emerging concerns in the design of care technologies (Andersen et al. 2018). They distinguish between relevant, actionable, and feasible concerns. Concerns are meaningful if they are relevant to both patients and clinicians (e.g. a patient decides to engage with a system that was recommended by a clinician). They are actionable if clinicians or patients are able to act on the specific concern (e.g. a clinician can use a system to respond to patients' inquiries). They are feasible if they can be realised within the organisational and social setting (e.g. a system supports division of labour, situated clinical workflows, and the local health care infrastructure).

2.2.4 Research Directions

Similar to personal informatics systems, self-care technologies intend to support people in documenting their health behaviour and health experiences. In contrast to personal informatics systems, such as wearable fitness tracking devices and health and wellbeing self-tracking apps, self-care technologies are specifically designed for people living with chronic conditions. Research on self-care technologies tended to focus on empowering people to monitor and manage their disease indicators. While much attention has been paid to support people in self-managing their health and wellbeing with self-care technologies, less attention has been paid to the lived experiences of how people with chronic neurological conditions use and experience emerging personal informatics technologies.

2.3 Multiple Sclerosis

We reviewed prior research on self-tracking and self-care in HCI research. We found that there is little knowledge of how people with chronic neurological conditions use and experience self-tracking technologies, such as wearable fitness tracking devices and health and wellbeing apps. Here, we situate our research in the context of MS, a chronic neurological condition, and motivate an investigation into how people living with MS use and experience self-tracking technologies in everyday life.

2.3.1 Pathology of Multiple Sclerosis

Around 2.5 million people worldwide are living with MS: the most common inflammatory chronic neurological condition in young adults. It affects the central nervous system causing a wide range of symptoms, such as movement and coordination impairment, fatigue, visual complaints, as well as emotional and cognitive changes (Döring et al. 2013). MS is not curable but is manageable. It is assumed that people living with MS can obtain a satisfactory quality of life by, for example, engaging in regular exercise, good nutritional practice, and mental health management (Embrey 2014).

The aetiology of MS remains unclear. However, studies suggest that causes include a combination of genetic and environmental factors (Choices 2016; Döring et al. 2013). Certainly, MS affects the central nervous system, including both the brain and spinal cord. Neurons are the core components of the central nervous system and transmit signals to and from the brain, other neurons, sensory organs, and muscles. MS is an autoimmune condition, in which the immune system mistakenly damages the myelin - the insulating layer of the neurons - and, consequently, disrupts the communication

between the brain and body, leading to an individual complex range of symptoms (Embrey 2014).

There are different forms of MS (Choices 2016). More than eight out of every 10 people with MS develop the relapsing remitting type, which is characterised by periods of relapses, when symptoms occur for a few days or months, and remissions, when symptoms are mild or disappear for several months. Approximately half of the people with relapsing remitting MS are diagnosed with secondary progressive MS, a condition in which the severity of symptoms increases and the periods of remissions decline. One of ten people with MS are affected by primary progressive MS right from the start in which periods of remission do not occur and symptoms gradually become worse over time (Döring et al. 2013). MS leads to increased physical and cognitive impairments over time. Symptomatic treatment for MS symptoms includes both drug and non-drug based therapies, such as physiotherapy and psychotherapy (Embrey 2014).

Several studies suggest that regular physical activity and exercise affect people positively with MS with respect to individual factors, such as age, stage of disease, and degree of disability (Döring et al. 2013). For example, Döring et al. argue that treadmill walking, aerobic training, and habitual exercises lead not only to improvements in walking, muscle strength, and endurance, but also provides neuroprotective benefits (ibid). Furthermore, studies suggest that, in contrast to non-exercisers, physically active people with moderate MS show favourable fatigue, depression and quality of life scores (Stroud and Minahan 2009). There is, moreover, evidence that certain factors are determinants of physical activity, including self-efficacy, functional limitations, goal setting, and enjoyment (Motl et al. 2012; 2006; Suh et al. 2014).

2.3.2 Technologies for Multiple Sclerosis Management

There is a wide range of technologies for MS management that have primarily addressed the assessment of physical activity through different tracking techniques and the development of rehabilitation support tools. For example, research has adapted the consumer vision-body tracking technology Microsoft Kinect for the clinical assessment of motor skills and disability in MS patients (Morrison, Culmer, et al. 2014). They explored technical opportunities and limitation of depth-sensing computer vision for tracking body movements in predefined exercises and explored the design space of audio feedback of what the camera can see when capturing body parts in real time (Morrison, Culmer, et al. 2014; Morrison, Smyth, et al. 2014). Moreover, research has presented a hardware and software based system consisting of a stationary computer, visual display, and a haptic robot arm that serves as an input and output device (Octavia

and Coninx 2015; Octavia, Coninx, and Feys 2012). Through different laboratory studies with the system Octavia et al. demonstrated the benefits of automatically adjusting the difficulty levels in rehabilitation exercises. In addition, their studies demonstrate that collaborative training increases the social interaction and improves the overall performance during training.

Another stream of technologies has explored how wearable activity tracking devices could be used to support MS management. Medically informed studies indicate that 3D accelerometers track changes in disabilities more effectively than clinical measures (Shammas et al. 2014) and might result in improvements in social support, mobility, subjective wellbeing, and mood (Döring et al. 2013). A collaboration between the biotechnology company Biogen and the PatientsLikeMe online community explored the use of consumer fitness tracking devices: 248 people with MS were encouraged to use Fitbit One devices over the course of four weeks and completed a survey revealing the following results (McCaffrey 2015): 89% of the participants believe that activity tracking is important for health management; 55% think that the device helped change their health routine; and 68% reported that the Fitbit One tracker would help them to track and manage MS in everyday life.

Research has investigated how activity tracking technologies could provide personalisation considering the individual range of symptoms people with MS can experience. For example, the app WalkWithMe invited participants to take part in a coaching and personalised 10-week program that supported them in tracking their walking, viewing their progress, and sharing their experiences with their peers (Geurts et al. 2019). Participants valued the audio feedback since it motivated them to reach their weekly walking goals. However, they explained that audio feedback, that encouraged them to increase their pace to meet walking goals, was sometimes counterproductive and impossible. A related study identified barriers to personalised goal setting, such as the unpredictable and fluctuating nature of MS symptoms and personally meaningful measures of physical activity beyond time and steps (J. Lee et al. 2016). A semi-automated tracking intervention investigated the use and experience of an activity tracking device and a smartphone application (Wendrich et al. 2019). The activity tracking devices automatically recorded physical activity, sleep, and heart rate data, and participants logged measures related to their physical and cognitive functioning. While participants reported gaining self-awareness and informing their self-care practices through self-tracking, they experienced challenges, such as making sense of sleep data and test scores. Wendrich and colleagues underscore that self-tracking technologies

need to support personalised lifestyle goals, flexible use, and guidance on how to interpret and act on data to self-manage MS.

We can see that prior research has focused on monitoring primary disease indicators and disability outcome measures in MS management. Exemptions are, for example, studies that looked at how individuals search and perceive information regarding their health conditions. A survey suggests that people preferred MS related information provided by neurologists, but additionally searched health websites and content supplied by MS organisations (Langhorne, Thomas, and Kolaczowski 2013). Participants in this study frequently searched for drug treatment secondary effects, alternative therapies, as well as emerging research projects and promising research findings. An ethnographic study and grounded theory analysis sheds light on role of autonomy in MS self-care (Güldenpfennig et al. 2019). The presented conceptual model illustrates the ways in which people with MS gain autonomy and identifies potential inhibitors. Güldenpfennig and colleagues found that autonomy was associated with people's sense of control in accomplishing short-term goals in everyday life and making future plans, such as maintaining social ties and managing financial resources. Technologies can foster autonomy by supporting people's daily routines, including walking and using bathroom facilities. Autonomy impeding experiences involve technologies that are intrusive and cause trouble by, for example, triggering false fall alarms.

2.4 Conclusion

Self-tracking is not a new phenomenon: people have documented aspects of their lives with different self-tracking tools for centuries. However, an explosion of self-tracking technologies on the consumer market offers new ways of logging health and wellbeing data, such as steps and heart rate (Neff and Nafus 2016). Within HCI research Li and colleagues have characterised self-tracking tools as personal informatics technologies, a new class of systems that aims to *"help people collect personally relevant information for the purpose of self-reflection and gaining self-knowledge"* (p. 558). Typical personal informatics tools are wearable fitness tracking devices, food journaling, habit tracking, and symptom monitoring apps. While medically informed (Nunes 2019; Mishra et al. 2019) and achievement based self-tracking approaches (Elsden, Durrant, and Kirk 2016; Gulotta et al. 2016) provide great value to some people, they can impede the physical, cognitive, and emotional capacities of those who have very individual data collection and visualisation needs, including people living with health and wellbeing impairments (Costa Figueiredo et al. 2017; 2018b).

To address mismatches between the design and experience of self-tracking technologies, researchers have highlighted the importance of supporting people's individual self-tracking needs. The term "*lived informatics*" critiques prior prescriptive self-tracking approaches and underscores that people adapt and intertwine different self-tracking tools and styles according to their prospective self-care goals and individual circumstances in everyday life (Rooksby et al. 2014b). Recent work outlined promising research directions, such as investigating of how self-tracking technologies could support people's individual needs and agency in self-tracking personally meaningful aspects of their lives (Cosley et al. 2017).

A related body of research on self-care technologies in HCI research has documented how people living with chronic conditions use and experience self-care technologies. In contrast to, personal informatics systems, self-care technologies seem specifically tailored to the individual self-care needs of people living with chronic conditions. A systematic literature review on self-care technologies in HCI research confirms that future work should examine how people living with chronic conditions use and experience emerging personal informatics technologies (Nunes et al. 2015).

This thesis draws on the notion of "*lived informatics*" (Rooksby et al. 2014b) to examine how technologies could support the individual self-tracking needs of people living with MS, a complex chronic neurological condition. Since MS affects the central nervous system and typically progresses relapsing and remitting, it can cause an individual range of symptoms, such as mobility issues, vision problems, spasms, and anxiety (Embrey 2014). The individual and fluctuating nature of MS can cause pragmatic and emotional challenges in understanding and documenting the complex representation of this condition. Self-tracking technologies provide significant potential to support people in understanding their variable health and wellbeing, adjusting to MS symptoms, and gaining an improved quality of life. However, prior research tended to focus on monitoring primary disease indicators and disability outcome measures to assess the progression MS in clinical settings (Gulick, Namey, and Halper 2011; Morrison, Corish, and Sellen 2014). There is little knowledge on how people with MS engage in self-tracking, what their individual self-tracking needs are, and how future technologies could support perceived benefits and overcome limitations of existing self-tracking technologies.

3 Investigating Self-Tracking in Multiple Sclerosis Self-Care: An Interview Study

Parts of this chapter have been published as a paper in the Proceedings of the 2017 CHI Conference on Human Factors in Computing Systems (Ayobi et al. 2017). This work was conducted in collaboration with Yunan Chen who took a supervisory role.

3.1 Introduction

The previous chapters have shown that self-tracking technologies provide significant potential not only to inform the clinical assessment of the progression of MS but also to empower people living with MS to self-manage their health and wellbeing in everyday life. Prior MS research has paid much attention to monitoring primary disease indicators, such as physical mobility and symptom relapses. However, people's self-tracking needs in MS self-management have received much less attention. This chapter presents the findings of an in-depth interview study, examining the motivations, self-tracking experiences, and needs of people living with MS. Participants described experiencing a lack of control in everyday life because of the idiosyncratic, complex, and uncertain nature of MS. Nevertheless, they reported regaining a sense of control over MS through intertwining individual self-care practices with different self-tracking technologies, including paper notebooks, wearable fitness tracking devices, and health apps. They associated experiences of control with their agency to document their health and wellbeing in personally meaningful and holistic ways, involving not only disease monitoring but also fitness tracking and life journaling. However, they reported contrary benefits and limitations of existing analogue and digital self-tracking tools. Participants particularly valued being able to customise paper-based self-tracking approaches to their individual needs. However, they found it tedious to find and make sense of their paper-based entries. They appreciated self-tracking apps that empowered them to collect and make sense of their health data. However, participants criticised that digital self-tracking apps can impede their individual physical and emotional capacities, particularly when the design focused on predefined health indicators and the optimisation of health behaviour. These findings highlight the need to support people's agency through customisable self-tracking approaches in MS self-management.

3.2 Method

To investigate self-tracking motivations, practices and needs, 16 in-depth interviews were conducted with people diagnosed with MS.

3.2.1 Participants

Since the goal of this study was to shed some light on people’s experiences with self-tracking technologies and their needs, the study focused on people diagnosed with MS who use or have used any kind of tools (e.g. paper diaries, spreadsheet software, mobile apps, fitness tracking devices, etc.) to track their health and wellbeing. Participants were recruited with the help of charities, including *MS Society UK* and *MS Trust UK*, which published our study advert on their websites. Furthermore, administrators of the online community *shift.ms*, and the MS meet-up group *My Spirited Friends* shared the advert with their members. Sixteen people with diverse backgrounds participated in our study, from individuals who have been newly diagnosed with MS to those with long-term experience in self-managing the disease (see Table 1). Among our participants, eleven were female and four male, which mirrors the 3:1 prevalence ratio of women to men in MS (Embrey 2014). Most participants were passionate about pursuing a healthy lifestyle and all engaged in self-tracking practices of their own volition.

	Gender	Type of MS	Yrs. since diagnosis		Gender	Type of MS	Yrs. since diagnosis
P1	Male	Asymptomatic	13	P9	Male	Primary progressive	4
P2	Female	Relapsing remitting	8	P10	Female	Relapsing remitting	10
P3	Male	Relapsing remitting	Unclear	P11	Female	Primary progressive	7
P4	Female	Relapsing remitting	3	P12	Female	Relapsing remitting	10
P5	Female	Relapsing remitting	1	P13	Female	Relapsing remitting	2
P6	Female	Relapsing remitting	2	P14	Female	Relapsing remitting	1
P7	Female	Relapsing remitting	7	P15	Male	Secondary progressive	2
P8	Female	Relapsing remitting	Unclear	P16	Female	Relapsing remitting	2

Table 1. Interview study: participant details

3.2.2 Data Collection and Analysis

In order to gain a deeper understanding of our participants' experiences of living with MS and their self-tracking practices, in-depth interviews were conducted (Blandford, Furniss, and Makri 2016). Questions covered the following topics: diagnosis; symptoms; relapse experience; lifestyle routines; and self-tracking tools and practices, and focused on attitudes, goals, challenges, and learnings. Participants chose the time and place of the interviews. 13 interviews were conducted via Skype or FaceTime, two interviews in person at the university, and one interview over the phone. Interviews took between 40 and 135 minutes and were audio recorded.

A pragmatic approach was applied to analyse data: we primarily drew on thematic analysis (Braun and Clarke 2006) and selected specific grounded theory techniques, including axial coding and theoretical saturation (Corbin and Strauss 1994). Analysis started after the first interview and guided subsequent interview questions. The qualitative data analysis software *NVivo* (see Figure 2) was used to transcribe the audio recordings and thematically code data (Braun and Clarke 2006). The data corpus was iteratively analysed in an inductive, 'bottom up' fashion drawing on open and axial coding. The analysis focused on the individual experience of each participant who had a unique presentation of MS, individual coping strategies, and particular ways of using self-tracking tools. At later stages, the mind mapping software *SimpleMind* was used to create mind maps visualising emerging themes, associated categories, and sample quotes in order to support axial coding and explore differences in motivations, entanglements between different self-tracking styles, and descriptions covering reflective thinking practices (see Figure 3). To support the data analysis participants were asked to share photos of their self-tracking technologies. As only two participants shared photos of their paper diaries and one participant shared screenshots of their fitness app, the analysis focused on participants' descriptions of how they used and experienced their self-tracking technologies.

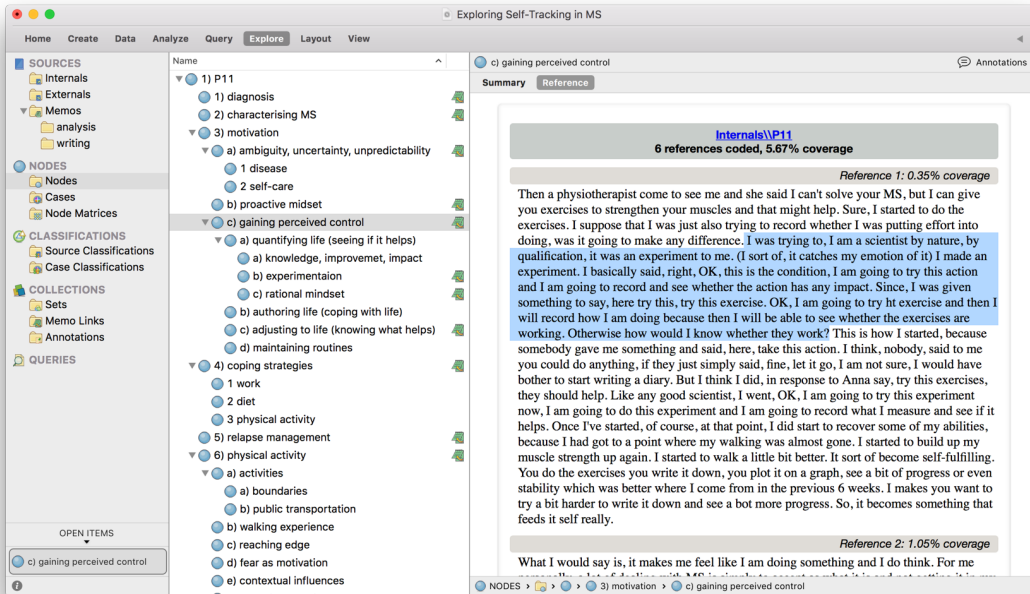


Figure 2. NVivo was used to thematically code the interview data.

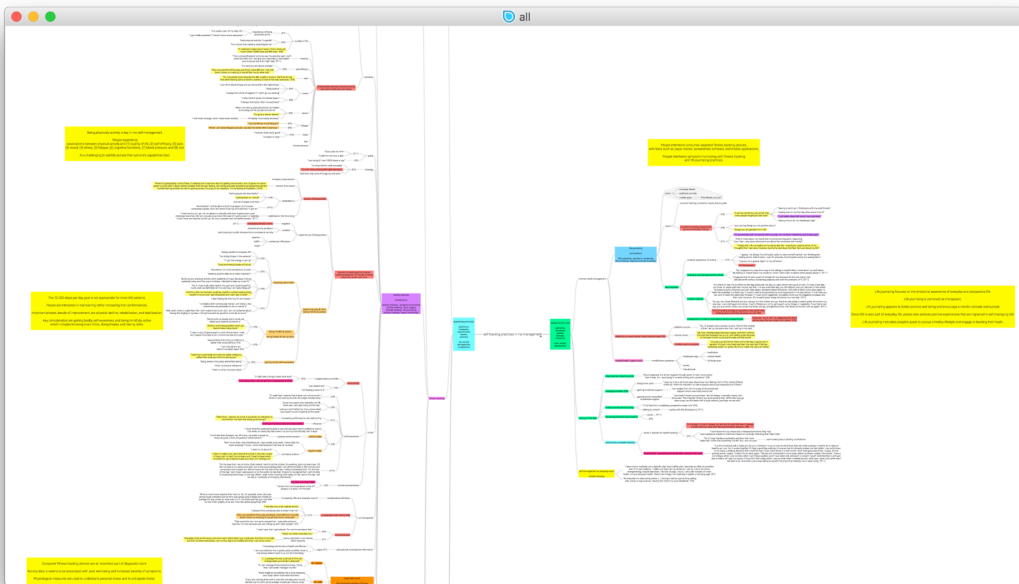


Figure 3. SimpleMind was used to organise themes.

3.3 Findings

This section reports how participants experienced a lack of control over the unpredictable and degenerative nature of MS. Subsequently, it describes motivations for beginning to self-track and illustrates the ways participants regained a sense of control over MS through intertwining individual self-care practices with different self-tracking technologies, namely: (1) gaining knowledge about the pathology of MS and self-knowledge about their own MS through disease monitoring; (2) pursuing a healthy lifestyle and self-tracking physical activities and dietary habits; (3) maintaining mental health management practices involving life-journaling; and (4) engaging in reflective thinking across tracked personal data and health behaviour. In doing so, they reported experiencing not only benefits but also limitations of analogue and digital self-tracking tools, such as findings it tedious to make sense of paper-based entries and experiencing negative feelings when using achievement-based self-tracking apps.

3.3.1 Lack of Control in Adjusting to Multiple Sclerosis

People affected by MS reported experiencing a lack of control when going through unpredictable relapses, coping with the uncertain and degenerative progression of MS, and dealing with the resulting psychological burden.

3.3.1.1 *Dealing with Ambiguous and Unpredictable Relapses*

MS is characterised by unpredictable relapses and remissions. A clinical relapse (Duddy et al. 2014) is defined as *“either the appearance of new symptoms related to MS or very definite worsening of old symptoms, which lasted for at least 24h and occurred after the patient had been stable for at least a month (with the absence of raised temperature, infection, or any other health problem).”* (p. 451)

Identifying relapses was not only important for adapting medication and documenting the progression of the disease, but also for experiencing clarity, assurance, and some degree of control over the uncertainty of the disease, as P8 expressed: *“I think [I track a relapse] for peace of mind. [...] For me it’s important to know. I would prefer to know and deal with something rather than be in ambiguity.”* (P8)

Some participants claimed confidence in their own ability to identify, document, and report relapses. However, newly diagnosed individuals considered recognising relapses to be challenging. In particular, people reported facing challenges when distinguishing between clinical relapses and pseudo-relapses, since both types lead to an increase of MS symptoms. Pseudo-relapses are not caused by new lesions in the central nervous

system but, for example, by heat sensitivity or infections, and can often be resolved within a short period of time. However, pseudo-relapses might also trigger clinical relapses. For example, P8 expressed uncertainty when distinguishing between infections and relapses: *"The answer is: I don't know. I don't think that anybody does [...]. I can never be sure because if I catch things like a cold it will bring all of my symptoms. So, I am never quite sure."* (P3)

Moreover, participants faced a lack of control when coping with the unpredictability of relapses, which can lead to significant physical deficits, as the following examples show: *"And at any point in time, my life could change because I have a relapse. You could lose your eyesight, use a wheelchair; that possibility never escapes from your head. [...] I never know when it's going to strike."* (P7)

"Basically, when I woke up, I couldn't walk in the apartment at all, not because of my legs - because the relapse disturbed my balance. It just knocked off the balance. I was just crying in the shower." (P2)

3.3.1.2 Coping with Mental Health Conditions

MS cannot be reduced to only physical disabilities, but affects people's *"mental health as well. That's equally if not more important."* (P5) Specifically, participants highlighted that the uncertain and degenerative nature of MS depicts a major psychological challenge, as this quote exemplifies: *"For me the biggest thing about living with MS is coping with the knowledge that you have something that is going to get worse in time. And there is a lot of uncertainty ahead. And that psychological burden is the biggest one to deal with."* (P13)

Many participants reported receiving therapy to cope with mental conditions, such as anxiety, stress, and depressive episodes, and managing their fears of losing physical abilities, autonomy, and social life at some point. For example, P5 reported experiencing anxiety, especially when dealing with the constantly changing character of MS: *"So, when something new happens, or changes, or alters, I have to get used to that change. And that's something I can struggle with. And I actually have had CBT [cognitive behavioural therapy] to support me with that."* (P5).

P2 was seeing a psychologist who specialised in the specific needs of MS patients in order to cope with the many mental challenges: *"I felt like a CBT therapist was not good enough; they were overwhelmed when I told them what I've to deal with regarding my MS. I had to apply for a proper MS psychologist to cope with feelings such as anger, loneliness, uselessness, frustration, and sadness."*

3.3.2 Motivations to Engage in Self-Tracking

In order to cope with the lack of control and uncertainties in self-managing MS, most participants developed a proactive attitude and engaged in different self-care practices, such as learning about the pathology of MS, maintaining regular physical activity and good nutritional practices, and caring for their mental wellbeing. Notably, the use of self-tracking tools, such as paper diaries and wearable fitness tracking devices, was enmeshed in their self-care practices. These were motivated by the following factors across all participants: wanting to delay moving to secondary progressive MS and being afraid of losing their physical and cognitive abilities at some later point in life; being proud to be physically active - to be able to walk, run, cycle, swim, and lift - despite having MS; thinking prospectively about the potential effects of a healthy lifestyle and preventing future regret of not having made all possible efforts; as well as wanting to stay as healthy as possible to be eligible for a cure in the near future.

Similar to lifestyle changes, self-tracking often started upon diagnosis, when people tried to grasp the complex nature of MS and to gain some scaffolding by reading about it and using different tools, such as paper diaries: *“I didn’t know what was going on, I didn’t know where I was going next. I suppose that I just started to write stuff down as some sort of record, really, of what was happening to me.”* (P11)

Since presently neither drug-based treatment nor non-drug-based strategies can cure MS, many participants had reservations about clinicians, questioned the ways MS is treated, and in an act of defiance focused on and believed in their own self-care skills to explore and adjust to MS, as the following examples illustrate:

“And they have treatment, but they do not know how to cure it. And they do not really know what causes it. That doesn’t fill you full of confidence, anyway. [...] And they are sceptical of the drugs, and the drugs are not the whole answer, but I decided to take the drugs and do everything I can [to self-manage MS].” (P7)

“So, I feel like I need to have a better idea of what is going on in my body [...] Because I don’t feel like my medical professionals do. That gives me even more motivation to go and find out. I feel like I need to be an expert in myself and be an expert in my condition.” (P8)

3.3.3 Self-Tracking Practices

Participants in this study engaged in a wide range of different self-tracking practices. They used various tools from traditional paper diaries, spreadsheet software, and web applications, to wearable fitness tracking devices and diverse mobile applications (see Figure 4.).

	P1	P2	P3	P4	P5	P6	P7	P8	P9	P10	P11	P12	P13	P14	P15	P16
Disease monitoring																
Symptom monitoring				Paper	Paper	Paper	Paper	Paper		Paper	Paper	Paper	Paper	Paper	Paper	Paper
Medication tracking			Phone							Paper						
Habit tracking																
Activity tracking	Wearable	Phone		Wearable	Wearable		Wearable	Wearable	Tablet	Wearable	Wearable	Phone		Wearable	Wearable	Wearable
Heart rate monitoring	Wearable						Wearable	Wearable								
Sleep tracking	Wearable				Paper		Wearable	Wearable						Wearable	Wearable	Phone
Food journaling				Phone	Phone		Phone	Phone		Phone		Phone		Phone		
Weight monitoring	Scale			Desktop				Desktop			Desktop					
Mental health tracking																
Life journaling		Paper			Paper		Paper	Phone			Paper		Paper			Paper
Meditation					Phone					Phone		Phone				Phone

Figure 4. Participants overview and used self-tracking tools (see description below)

Figure 4. shows that participants used paper notebooks (blue), wearable fitness tracking devices (purple), smart phone apps (dark purple), tablet apps (dark purple), desktop software applications (green), and smart scales (light green). They combined these self-tracking tools to engage in disease monitoring, habit tracking, and mental health management. Eleven of 16 participants decided to utilise the flexibility of paper notebooks to document their symptoms and medication. Furthermore, six of 16 participants preferred to use paper notebooks to engage in life journaling. Ten of 16 owned wearable fitness tracking devices to track their physical activities and 10 of 16 used smart phone apps to track, for example, their sleep and practice meditation. Five of 16 participants reported abandoning wearable fitness tracking devices and smartphone apps, if the apps did not meet their individual self-care needs, physical capacities, and emotional preferences (The coloured text font on white background marks abandonment). The following sections focuses on entanglements between individual self-care practices and self-tracking tools addressing emotional wellbeing and the experience of control.

3.3.3.1 Disease Monitoring: Understanding Multiple Sclerosis

Diagnostic practices were often conducted using paper-based health diaries, mobile food logging applications, and consumer fitness tracking devices. Individuals reported that disease monitoring affected their emotional wellness: sometimes this was in negative ways because of overly focusing on symptoms, and sometimes positively when exploring causal relationships and developing a sense of control over MS triggers and symptoms.

Participants had been encouraged - often over a short, defined period of time - to use structured pain, bladder, and bowel diaries provided by clinicians to document symptoms and inform clinical decision making. Some filled out these types of diaries methodically, others on the fly before appointments. Most participants kept their own paper-based health dairies for their *"own benefit"* appreciating that there is *"no one over [their] shoulder."* (P5) They particularly valued the flexibility of paper notebooks and being able to use their own words in documenting personally meaningful experiences. For example, P16 explained using a customisable system called "bullet journaling" which she adapted to her individual needs. Drawing on our participants' descriptions and photos of symptom diaries, three different types of entries were identified: the first was self-reported descriptions of symptoms, such as *"double vision," "pins and needles types of sensation," "head of cotton wool and porridge," "mood, like anxiety," "energy levels," "spine feels like I have sunburn," and "heavy and useless legs."* People tended to use self-designed scales based on their own words rather than medical scales to define the severity of their symptoms. The second type of entry was measures from external tools. For example, participants manually transferred selected data from weight scales, thermometers, and blood pressure monitors to their diaries in order to visualise, annotate, and compare the recorded metrics with symptoms, medication intake, and life-events. The third type of entry covered narratives of everyday life, including mundane activities and sketched thoughts. Impressionistic notes, such as *"Really struggled today - heat?"* (P11, paper diary) contextualised the tracked actions and helped people to revisit past experiences. Participants also used health diaries to prepare themselves for medical appointments in order to be able to effectively communicate symptoms and demonstrate competence. Challenges that people encountered when keeping paper-based diaries, included: developing a structure, formatting, and finding the *"right words"* (P6), especially, when starting to track; finding specific information in the paper diary; and identifying relationships between different entries.

In addition to paper-based health diaries, people employed food logging apps to monitor and understand MS symptoms and triggers related to their wellbeing. Some participants explored relationships between food intake and symptoms, such as fatigue. For example, P8 explained: *"I am trying to work out what kind of food I need to cut out in order to make a difference to fatigue and general wellbeing."* Others already made some findings, such as P4, who found a relationship between sugar intake and quality of sleep: *"If I have too much sugar it keeps me awake at night and it's not good for my sleep."*

Moreover, wearable consumer fitness tracking devices supported diagnostic practices. Some participants associated physical activity data of fitness trackers with periods of

increased or decreased severity of symptoms. For example, P4 reflected: *"I do wonder at the end of the week: Have I done enough steps? And if I haven't been well [experiencing symptoms], that can really change it."* Others interpreted physiological measures of fitness tracking devices as indicating illness. For example, when reflecting on her heart rate data, P8 considered the possibility that she was getting a cold: *"Actually, my heart rate is up a little bit and maybe I am coming down with something."* Based on her past experience, she explained further: *"If you are coming down with a cold, that two days prior my cold started, my heart rate went up by average 5 beats per minute a day."*

Monitoring MS symptoms and triggers helped especially newly diagnosed individuals to better understand their bodily reactions in everyday life. Notably, a few participants revealed that disease monitoring sometimes led to unintended effects: focusing on a predefined list of symptoms might lead to *"worry unnecessarily about symptoms they don't have"* (P5) and also monitoring symptoms in open-ended ways caused sometimes negative feelings, as P4 describes: *"I guess sometimes, I feel a bit obsessed with it. Maybe, I should not be thinking about it too much and just getting on with life. But I think that could come later on [...]. But I've had MS just since 2015, so I am still learning the ways how my body is."*

Finding a balance between monitoring and an excessive focus on symptoms involved different coping strategies, such as developing a mindful attitude and intertwining different self-tracking styles. Exploring causal relationships between MS symptoms and different factors, such as physical activity, diet, and sleep, provided, all together, a sense of having some degree of control over the disease. For example, P8 explained that using a Fitbit Charge HR device to monitor her heart rate and cope with stressful life events provided a sense of control over MS: *"Because research does say that there is correlation between MS and stress, I am like, well if I manage my stress, I'll be managing my MS. Obviously, this is not a complete truth but in my head it gives me control over something."*

3.3.3.2 *Physical Activity Tracking: Maintaining Physical Abilities*

When using wearable activity tracking devices a few participants reported feeling pressure to perform despite their physical limitations, but many explained having gained an increased bodily self-awareness and a sense of control over the physical symptoms, especially, when identifying short-term improvements and periods of stabilisation in the long-term.

All participants stressed that being physically active was essential in everyday life: it affected mood and energy levels (P1), made people *"feel happy"* (P2), provided *"mental space"* and was a *"stress reliever"* (P8), strengthened muscles, improved balancing (P11),

and helped to reduce fatigue (P4). Using fitness tracking devices (e.g. Fitbit Charge HR⁶) and various fitness apps (e.g. Argus⁷), people tracked physical activities, such as yoga, walking in everyday situations, walking and running defined routes, balance exercises, indoor and outdoor cycling, and weightlifting (e.g. Wendler Log⁸). Furthermore, they also manually captured certain activities, such as sedentary behaviour and meditation.

Participants suggested that wearable fitness tracking devices play a crucial role in maintaining their physical and psychological wellbeing. For example, participants used measures, such as steps and heart rate, in order to gain an awareness of their physical abilities, and tried to avoid overdoing it in order to prevent potential MS symptoms caused by overexertion, such as double vision: *"My heart rate was something like a 195 beats per minute - which is quite extreme - which caused, obviously, my body temperature to go up and I can see double vision."* (P1)

Core functionalities of fitness tracking applications, such as setting goals, receiving rewards, and exploring visualisations of tracked data, led to mixed experiences. On the one hand, goal-setting functionalities were used by three participants who had minimal physical symptoms in order to improve weight lifting, walking, and running performances. Measures of activities made short term achievements tangible and participants felt proud to be physically active despite of being affected by MS: *"Also, as a positive thing, say, you know, I have MS but I can still bench press so many kg."* (P8) On the other hand, many tried to meet well known fitness norms, such as the 10000 steps per day goal, which could cause pressure and be discouraging:

"I also had a Fitbit. It was very rare that I would do 10000 steps a day. It can be quite discouraging when you know that you can only walk so far. So when someone says 10000 steps, you might be saying, let me just walk to France. For someone with MS who has got limitation, not everyone does, but for those who do have limitations it is really discouraging." (P10)

Rather than increasing performances, most participants, especially with physical impairments, were interested in recovering and maintaining their physical capabilities. P9, who used an indoor exercise bike, revealed this attitude in the following way: *"I've found setting a target of exercising every day with MS is not feasible. It just seemed like*

⁶ <https://www.fitbit.com/>

⁷ <http://www.azumio.com/>

⁸ <http://vandersoft.co/>

pointless pressure. Now if I feel like it, I exercise but it's more to do with maintaining flexibility rather than achieving targets."

A few participants were not keen on receiving rewards for their healthy lifestyle choices in fitness apps. They expressed that they *"don't care to get a badge"* (P9) and focus rather on other functionalities such as using heart rate measures to inform diagnostic practices. In contrast to this, many participants stressed the importance of receiving rewards for their effort and work to maintain their fitness. For example, P7 explained: *"Everyday I look at the score card and I want to check that I got a gold star. And then it reminds me that I've done everything I can on that day to be healthy and that I can do no more."*

Charts that visualised low steps counts and negative trends were sometimes perceived as discouraging due to the progressive physical decline that people with MS have to cope with. For example, P10 described: *"The graphs for me are kind of counterintuitive. [...] For someone with MS or for someone has got mobility issues, it can be another sign that you are not the same person you were a few years ago. If you are already feeling like it is an uphill struggle, then having something like that discourages you even more."*

In contrast to this point of view, visual representations of mobility data - recorded over the long-term - could be a helpful tool to cope with the progressive decline of physical abilities. Long-term activity data revealed periods of improvement, stabilisation and stagnation and, in doing so, made people feel more rational, experience hope, motivation, and vindication for their efforts, and a sense of control over the progressive nature of the disease. For example, P11 had recorded her walking performance and balancing exercises in a paper diary for over five years. Reflecting upon her data she explained:

"When it's going badly, I feel, it's helping me to see how fast it's getting worse and it sort of gives me some sense to try to slow it down which is better than the feeling, not having any data; it's going to be hopeless. I can look at the graph and go: actually, over that period of time of five years, I definitely improved my condition. So, I feel some form of vindication that the effort that I put into it, made some difference. [...] For me documenting stuff is being partly about staying in control, knowing what is happening to me."

3.3.3.3 Food Logging: Eating Mindfully for Positive Wellbeing

Participants explored different diets over time and aimed to “avoid food that has been shown by MS research studies to have negative effects on MS,” as P8 representatively explained. They tried to avoid wheat, gluten, dairy, meat, and sugar in order to follow an “anti-inflammatory” diet. People engaged in food logging because of the increased priority “to look after the body” after diagnosis (P5); to lose or maintain weight in order to be “able to exercise better” (P11), and to gain weight because “underweight persons are more vulnerable to infections, which can trigger relapses” (P4).

In the past, participants had used paper-based health diaries to document their dietary practices including detailed information from consumed products to the specific amount of saturated and unsaturated fat which required manual calculation. Many switched from keeping paper-based diaries to food logging apps over time in order to reduce the manual work of tracking. Only one participant switched from using a food journaling app to a lightweight paper diary which she placed in the kitchen in order to collaboratively manage a healthy diet with her family.

Most participants, who tracked their nutritional practices and physical exercises, connected the two: food journaling apps were often linked to physical activity tracking applications to determine the relationship between calorie intake and calories burned (e.g. Weight Watchers⁹). Some registered physical activities manually in food logging apps (e.g. MyFitnessPal¹⁰) because they were not accurately recorded by fitness tracking devices, such as yoga or individual balance exercises.

Compared to the perceived benefits of being physically active, most participants explained that it was not clear to them whether pursuing a healthy diet significantly affected the presentation of MS. However, they emphasised that engaging proactively in good nutritional practices fostered certainly positive emotional wellbeing which “itself is a good thing.” (P11) Both, food and physical activity tracking were considered as “fundamental part[s] of maintaining on a healthy path” (P7).

⁹ <https://www.weightwatchers.com/>

¹⁰ <https://www.myfitnesspal.com/>

3.3.3.4 Life Journaling: Coping with Everyday Life

Most people started to engage in mental health management practices, such as life journaling and the use of meditation apps (e.g. Headspace¹¹), when they tried to cope with the disruptive changes and psychosocial impacts caused by MS. Life journaling involved the use of paper diaries, gratitude journals, and digital smart journals (e.g. Five Minute Journal¹²). They used diaries in order to capture MS-related experiences, non-MS-related thoughts, and specifically positive feelings. Many perceived the process of writing as enjoyable and therapeutic. Keeping a journal helped individuals to cope with and be in control of negative thoughts related to the unpredictable implications of living with MS. For example, P11 perceived her diary as a way to ‘talk to herself’ within a private and protected space: *“I suppose that it’s also a part of escape for me, because it’s the one place I can talk about MS without burdening anybody else with the problems of it.”*

Aside from addressing MS, many other topics and life events were recorded. P7 stated that, in contrast to the fitness tracking and food logging applications, her paper diary is less about the physical, but more about the emotional issues she faced in life: *“I would just capture some of the thoughts that I had about losing my mother and how that feels. Not just about my MS.”* Moreover, some participants recorded specifically *“things you are positive about [...] and grateful for in life”* (P8) or *“something very small that other people might just look over”* (P5), such as having a catch up at Starbucks with friends, learning some new stretches at a ballet class, and taking time to use the Headspace app to meditate. Participants looked back at these captured experiences when they went through the ‘bad days’ of living with MS. Keeping diaries or gratitude journals seemed to help people to cope with everyday life, develop confidence, and gain optimism and hope. P11, who recorded her walking performances, experiences, and thoughts in her diary, explained that the experience and practice of writing can be a motivational coping strategy: *“If you had a bad day, you just write it down, you close that book, and go: all right that’s fine, I am done, tomorrow I will try again.”* In a similar way, P5 reported that having filled out her gratitude journal after her symptom diary, helped her to avoid focusing on symptoms and negative experiences: *“Kind of ending the day on a positive note, rather than thinking about stuff that stresses me out.”*

¹¹ <https://www.headspace.com/>

¹² <http://app.fiveminutejournal.com/>

3.3.4 Self-Tracking and Reflective Thinking

Participants in our study reported engaging in reflective thinking across different self-tracking tools and practices. In doing so, they explored causal relationships between symptoms and everyday actions, dealt with uncertainty in self-tracked data and the unpredictability of MS, and gained self-awareness and health expertise over time.

3.3.4.1 Varied Interest in Reflection

People with MS had a diverging interest and expressed a varying degree of engagement in exploring tracked health data. For example, P8 took a look at the tracked data only occasionally and briefly when there was some time available (*"I don't really look back at it either, to be honest. I roll back on the data when I've got a free couple of minutes, when I am early for a dentist appointment."*) P7 seemed to spend more time exploring her fitness data and was driven by joy and passion (*"And I enjoy looking at it. I love tracking the charts and seeing how I am getting on."*). P11 was keen on conducting self-experiments in order to investigate actions that had a positive impact on her MS in everyday life: *"Like any good scientist, I went: OK, I am going to try this experiment now and I am going to record what I measure and see if it helps."*

3.3.4.2 Connecting Self-Tracking Tools and Practices

Most participants connected different self-tracking styles, such as fitness tracking and life journaling. For example, P11 explained that tracking physical activities helped her to understand and adjust to MS in everyday life, whereas capturing her thoughts motivated her to maintain good physical practices: *"The numbers [of tracked steps] are there to really help me to retain some sort of control and help me to practically manage my condition and trying to do the things that make it less bad. It [life journaling] is the emotional will: it helps you for your motivation to go on and do the things that rationally, probably, I need to do to stay as healthy as I can. So, it works together."*

While making sense of different self-tracking practices and personal health data, most participants experienced a lack of seamless connections and interactions across technologies. Many stressed that they are the ones who are not only connecting but also contextualising tracked data across tools: *"I don't think there are connections at the moment. Other than what I think is in my head, there is no connection between the data. It all comes together to become part of everyday."* (P8)

3.3.4.3 Causal Relationships and Uncertainty

Participants in our study developed causal relationships across individual triggers, symptoms, and mundane actions in order to better understand their unique manifestation of MS and explore how to adjust to MS in everyday life. This was a time-extensive learning process in which people developed their own unique and idiosyncratic 'best practices.' In doing so, they often perceived self-tracked data as evidence for observed phenomena and assumptions they made while being aware of the uncertain and constantly changing nature of MS. P10, for example, expressed the relationships between critical dimensions, such as time and the unpredictability of MS, and emotional factors such as being proactive and gaining a sense of control, when exploring causalities in everyday life in the following way:

"I have also realised that where fatigue happens quite immediately after something, like going of the tube, then I know, there is a more direct correlation between one and the other. When it is something like stress and how busy you are that's harder because the cause and effect is a greater distance in time. I try, I mean, that's the thing, you just don't know. You can't say exactly, hand on heart, that's exactly what it is. You do your best to try and work it out because, I think, if I didn't, I wouldn't be feeling like I was being proactive. If I am proactive, I am more in control and the bully [MS] is less in control."

Notably, inaccuracy, uncertainty, and ambiguity in tracked data did not necessarily lead to frustration, but sometimes made room for speculations and explorations. For example, P6 reflected on the causal relationships she anticipated in the past and the uncertainty of her recently increased symptoms: *"But actually, if I was able to answer it [reasons for increased severity of symptoms], would I even want to know the answer anyway? Because if I can't do anything about it, then it would make it even worse. So, not being able to answer it and trying to, that, actually, gives me a purpose to explore it."*

3.3.4.4 Self-Knowledge and Health Expertise

Participants claimed to have gained bodily self-awareness, self-knowledge, and health expertise regarding how to live with MS. For example, P5 highlighted the importance of *"listening to your body and what it's really telling you rather than what you think it's telling you."* In her experience, taking breaks during the day and attending one half of a ballet class was more beneficial for her wellbeing than pushing oneself and getting *"false energy"* by having sugary snacks.

Furthermore, participants reported obtaining practical knowledge about the disease and self-knowledge through both doing research online and self-tracking, which appeared to make them feel more rational, self-confident, and accountable. For example, before

keeping a bladder diary, P4 thought: *"If I don't drink too much and I am going out, I won't need a toilet just halfway down the road."* After having kept the diary, her thinking was to some extent medically informed and more holistic in terms of the pragmatic implications of being hydrated: *"I've to think of the bigger picture that actually, being dehydrated will irritate my bladder even more. [...] By drinking more water in the morning rather than in the evening, that can stop me from going to the toilet more at night; [...] it flushes away toxins; it can help your immune system."*

However, people with MS explained that they were sometimes not able to find answers for their health-related questions, especially, when medical data was not available or accessible. For example, P7 reported: *"I've been collecting data in my journal and now on my Fitbit, it's not the right data. It's not all of the data."* In addition to fitness data, she was interested in using annual MRI scans or blood values to infer whether her lifestyle had a positive impact on the progression of her MS.

3.4 Discussion

This study has investigated self-tracking practices in MS self-management. Based on this understanding, we discuss the role of agency and the experience of control when self-tracking personal health and wellbeing and motivate the need for customisable self-tracking technologies in MS self-care.

Participants in our study reported facing a lack of control when adjusting to the fluctuating and uncertain nature of MS. Our findings suggest that people regained a sense of control over MS through intertwining individual self-care practices with a wide range of different self-tracking technologies. Perceived control is a seminal psychological construct that refers to the *"belief that one can determine one's own internal states and behaviour, influence one's environment, and/or bring about desired outcomes"* (Wallston et al. 1987). A significant body of interdisciplinary research suggests that perceived control is an important factor in adopting and maintaining good physical and psychological health (Pagnini, Bercovitz, and Langer 2016; Wallston et al. 1987). Within HCI research, Mamykina and colleagues have utilised the Health Locus of Control questionnaire in order to evaluate the application MAHI with diabetes patients and reported an increase of perceived control (Mamykina et al. 2008). MAHI supported individuals with diabetes in changing their diet through self-monitoring and social interaction with diabetes educators. In contrast to blood glucose values in diabetes self-management, there is no primary disease indicator in MS that can be effectively measured and controlled through self-care. The experience of control that participants described appeared to be related to a mindful mindset and faded when experiencing

symptoms relapses. Using self-tracking technologies alone did not support people in gaining a feeling of being in control. Our findings suggest that the experience of control was related to people's agency to engage in self-care and their abilities to adapt combinations of different self-tracking tools to their individual self-care intentions.

Along with paper-based diaries, wearable fitness tracking devices played an important role in empowering people to self-manage MS. For example, participants valued the flexibility of paper notebooks. They, moreover, used the 'novel' physiological data of activity tracking devices, such as heart rate, to not only maintain their fitness, but also to explore symptom triggers, such as stress. By gaining an understanding of their body and exploring how to adjust to these triggers they gained a sense of control over the complex nature of MS. In contrast to prior studies (Harrison et al. 2015), accuracy of tracking devices and uncertainty in personal health data played a minor role. They combined different self-tracking tools (e.g. paper notebooks and wearables) and styles (e.g. documentary and diagnostic) according to their priorities in everyday life.

This lived character of self-tracking practices in MS reveals a critical dimension that needs to be considered when designing self-tracking technologies for self-experimentation and self-diagnosis, which are increasingly explored within HCI research (Karkar, Fogarty, et al. 2015) and beyond (Deborah Lupton and Jutel 2015). Self-experimentation tools have great potential to support self-tracking practices by providing guidance and evidence when identifying not only correlational but also causal relationships between symptoms and triggers (Karkar, Zia, et al. 2015). Designing self-experimentation applications that encourage users to formulate a valid hypothesis, identify independent and dependent variables, and choose a single independent variable to test in the real world, poses not only conceptual challenges. Our findings suggest that pre-defined, dualistic, and deterministic design approaches of diagnosis could violate people's agency and experience of control in self-managing their health.

Research has paid much attention to tracking physical mobility in order to assess the progression (Morrison, Culmer, et al. 2014) and foster physical activity in MS (Octavia, Coninx, and Feys 2012). Indeed, many participants in our study tracked their fitness in order to maintain their physical abilities. However, our findings highlight that there are concerns beyond tracking the performance of primary disease indicators: people living with MS had to deal with enormous mental challenges, such as dealing with the degenerative course of the condition and unpredictability of the next relapse. Our findings illustrate that people with MS were able to cope with some of these psychological challenges when engaging in self-tracking their health and wellbeing. Similar to prior work on journaling (Elsden, Durrant, and Kirk 2016), this study found that

keeping a diary was perceived as therapeutic and supported people in coping with negative thoughts. In addition, our findings suggest that further self-tracking practices affected people's emotional wellbeing in similar ways. For example, some participants perceived documenting and identifying relapses as depressing, while others explained that it was important for their peace of mind. Many who engaged in disease monitoring admitted that focusing on symptoms could be sometimes hopeless but reported being proud and confident when they identified relationships between symptoms and triggers. In some cases, physical activity data revealed periods of stabilisation and enabled people to become more in control, instead of being led by fears about the progression of physical impairments.

These observations suggest that the design of self-tracking technologies should not only consider primary disease indicators but also needs to acknowledge the emotional and mental wellbeing of people who are living with an unpredictable and degenerative condition. In order to avoid dictating and mindless experiences, self-tracking technologies could empower people to proactively care for their health and wellbeing by mediating practice-based health expertise and fostering self-exploration. Rather than focusing on binary outcomes, applications could focus on the self-tracking process itself in order to support people's reflective thinking and opportunities to explore what health behaviour might help to adjust to MS in everyday life. These considerations underpin the need for self-tracking technologies that consider people's individual needs (Choe et al. 2014) and support personalisation (Storni 2013), customisation (Harrison et al. 2015; Lazar et al. 2015), and self-discovery (MacLeod, Tang, and Carpendale 2013).

3.5 Conclusion

This study has investigated the self-tracking motivation, practices, and needs of individuals living with MS, a complex neurological condition that causes a wide range of physical, cognitive, and psychological impairments. The participant's accounts detail that when experiencing a lack of control due to the unpredictable and degenerative nature of MS, individuals regained their sense of control over MS through intertwining individual self-care practices with different self-tracking tools, ranging from paper-based notebooks to wearable fitness tracking devices. In doing so, they documented their health and wellbeing in holistic ways involving disease monitoring, habit tracking, and life journaling to understand their body and care for their mind. However, they reported benefits and limitations of existing analogue and digital self-tracking tools. Participants particularly valued being able to customise paper-based self-tracking approaches and criticised that digital self-tracking apps can impede their physical and emotional capacities, in particular, when the design lacked customisation. These findings highlight the need to support people's individual self-care needs and agency through customisable self-tracking systems in MS self-management. However, it remains unclear how technologies could be designed to support customisable self-tracking approaches.

4 Investigating Paper Journals to Inform the Design of Customisable Self-Tracking Applications: An Online Ethnography

Parts of this chapter have been published as a paper in the Proceedings of the 2018 CHI Conference on Human Factors in Computing Systems (Ayobi et al. 2018). This work was conducted in collaboration with Tobias Sonne who particularly contributed to the quantitative analysis.

4.1 Introduction

The previous chapter presented the findings of an interview study on self-tracking in MS self-management. Participants reported regaining a sense of control over MS through intertwining individual self-care practices with different self-tracking technologies, such as paper notebooks, wearable fitness tracking devices, and diverse health and wellbeing apps. They associated experiences of control with their abilities to combine different self-tracking tools according to their individual self-tracking intentions. They aimed to document their health and wellbeing in personally meaningful and holistic ways, including not only symptom monitoring but also habit tracking and life journaling. Participants valued self-tracking apps that empowered them to collect and make sense of their physical and physiological data beyond clinical settings. However, they criticised that digital self-tracking apps can impede their individual physical and emotional capacities. They explained that, for example, predefined symptoms apps and fitness apps, that visualise low step counts, can be discouraging considering the varied and degenerative nature of MS. Participants decided to utilise the customisability of paper notebooks to document their individual symptoms and medication. P16 specifically drew our attention to bullet journaling, an analogue and customisable self-tracking approach that supports people in documenting personally meaningful experiences in open-ended and pictorial ways. To investigate how digital self-tracking applications could support customisation, this chapter takes a closer look at paper bullet journaling. Investigating paper-based practices to inform the design of technologies is an approach that has been applied in several domains. For example, prior work has examined the use of paper checklists to inform the design of a context-adaptive tablet-based checklist app in clinical settings (Kulp et al. 2017; Sarcevic et al. 2016). Drawing on an online ethnography of paper bullet journaling on Instagram, this chapter illustrates the ways in

which individuals adapted bullet journaling systems to meet their individual self-tracking needs. They crafted, combined, and switched between personally meaningful trackers: pictorial visualisations that support logging and viewing data in single views. These findings identify design strategies and design patterns. In this way, we exemplify how a customisable self-tracking approach can be realised to support the self-tracking needs in MS self-management.

4.2 Method

To investigate how paper bullet journaling practices could inform the design of customisable self-tracking approaches, we analysed posts of paper bullet journals on Instagram that were available publicly. An ethical amendment was not required since the data was freely available in the public domain. Drawing on best practices on using public social media data (Le Moignan et al. 2017; Townsend and Wallace 2016; Webb et al. 2017), we shared a paper draft with those bullet journalists whose photos and comments we present here and obtained permission to present images and comments.

4.2.1 Context

Bullet journaling is an analogue and customisable system for tracking, organising, and planning (Carroll 2016). It consists of different building blocks [ibid]: components for rapid logging, such as short sentences, bullets, and signifiers; and modules, such as the index, and future, monthly and daily logs. Modules help to organise the components, as well as various representations, such as to-do lists, sketches, and diary entries. Instagram is a suitable field site for gaining an understanding of bullet journaling design practices since it is a social network for sharing photos and has an active culture of sharing best practices (Chung et al. 2017).

4.2.2 Data Collection and Analysis

Data collection and analysis were conducted within an interrelated process which involved a thematic analysis of photos and related comments (Braun and Clarke 2006). Microsoft Excel was used for analysing photos, and comments were analysed in NVivo. Firstly, we used the search box on Instagram's public website entering the hashtag #bulletjournal which led to 1,063,790 posts¹³. Using the search feature did not require a login. The first 100 most recent posts were manually included in an Excel sheet, grouped

¹³ <https://www.instagram.com/explore/tags/bulletjournal>

and analysed according to visual similarities and differences. In doing so, we identified the following tags: #habittracker, #foodtracker, #sleeptracker, #exercisetracker, #weighttracker, #moodtracker, #healthtracker, and #symptomtracker. We decided to focus on #habittracker (16,627 posts), and #moodtracker (4,861 posts) because they were most frequently used and because #habittracker was used in combination with other tags, such as #exercisetracker. Although #symptomtracker (104 posts) was less commonly used, we included it because it depicted a contrastive numeric case. (This selection of tags is consistent with the self-tracking preferences described in the previous chapter: people living with MS engaged in disease monitoring, habit tracking, and mental health tracking.) In the next phase, the three hashtags were used to extend our corpus. We excluded photos that had obvious commercial purpose, low quality, insufficient legibility, and did not show pages of a paper bullet journal. All photos were classified by type of tracker (habit, mood, symptom), type of visualisation (e.g. matrix, graph, table), and temporal dimension (daily, weekly, monthly, annual). Data were iteratively coded along visual clusters of trackers which led to descriptions of why and how bullet journalists created different types of visualisations for different trackers. At later stages, axial coding resulted in cross-cutting themes, such as self-reflective strategies. Data collection and analysis ended when we reached theoretical saturation (Corbin and Strauss 1994). Our final corpus comprised 386 photos and related comments, including 54 photos of typical bullet journaling elements, and 152 habit-, 136 mood-, and 44 symptom trackers.

4.3 Findings

Drawing on our corpus of paper bullet journal photos and related conversations on Instagram, we found that individuals extended and adapted bullet journaling systems to meet their individual needs through an interplay between: (1) crafting, combining, and switching between personally meaningful textual, numeric, and symbolic representations of different types of trackers, such as habit, mood, and symptom trackers; (2) engaging in mindful reflective thinking through design practices and self-reflective strategies; and (3) posting photos of paper journals online to become part of a self-tracking culture of sharing and learning.

4.3.1 Evolving and Flexible Journaling Practices

The design of bullet journals varied from functional to artistic. Functional designs were minimalistic and focused, whereas artistic designs included a wide range of design practices involving re-using existing materials (e.g. scrapbook paper), decorating with stickers, creating collages, and digitally crafting, printing, and pasting textual and visual objects into paper dairies. Bullet journalists developed and switched between styles depending on skill, goal, and time available. For example, BJ163 explained:

“Planner Evolution! [F]irst I tried to make every spread very artistic and fancy (.), this just took too much time, so my style has evolved towards more simplistic weekly and daily spreads.”

Individuals appropriated the bullet journaling system as intended using standard elements, such as signifiers and monthly logs. Moreover, they extended the bullet journaling system with different elements highlighting that they liked having control over the design of their paper notebooks. BJ12, for example, reported conceptualising and designing her journal with the help of modules:

“I have had so many #weeklspread layouts over time, I now think of my #bulletjournal as #modular - and every week I pick the bits that I think I'll need. Last week, #moodtracker and #tasklist for the week. This week, #moodtracker and #meditation #quote.”

Bullet journalists explained adding, combining, testing, and switching between different types of trackers: modules used to record personal data over time. We identified 35 different combinations of trackers, and considered a tracker combination as a group of at least two different types of tracker visualisations on a single photo. The top 10 combinations were: habit & mood (n=42), habit & sleep (n=11); habit & symptom (n=7); habit & mood & sleep (n=5); mood & sleep (n=4); symptoms & sleep (n=4); habit & physical activity (n=3); habit & finance (n=3); habit & mood & finance (n=3); and mood & symptom (n=3). In the following sections, we describe the design and use of habit, mood, and symptom trackers.



Figure 5. Example habit trackers

A: Sketched trackers, B: To-do list (matrix), C: Phone app use (list), D: Combination of sleep (line graphs) and habit tracker (matrix), E: Weight tracker (progress visualisation), F: Habit tracker (calendar view)

4.3.1.1 Habit Trackers

Bullet journalists tracked a wide range of habits to document everyday aspects of their lives and to pursue better health and productivity, including fitness activities (e.g. running, weight lifting, meditation), food and nutrition (e.g. water, veggies, home cooking), bedtime routines (e.g. up at 7am, nap time, bed by 11), hygiene (e.g. shower, wash face am and pm), social activities (e.g. phone calls, go out), hobbies (e.g. reading, Nintendo, piano), health (e.g. period, symptoms), medication intake (e.g. drugs, vitamins), mood (e.g. tired, happy), resolutions (e.g. no junk food, no spending, no alcohol, no smoking, no tech after 11pm), and personal development (e.g. creativity, productivity, compassion, courage). In doing so, they documented defined goals with numbers (e.g. +3 fruits, 10mins outside, 10k steps), and when keeping track of fitness routines in paper diaries, many manually recorded data from fitness tracking applications, such as number of steps and sleeping time using similar or alternative types of visualisations.

We identified several different types of textual and visual representations of habit trackers (see Figure 5): matrix (n=89), calendar (n=53), object display (n=18), list (n=18), graph (n=17), table (n=11), progress (n=8), timeline (n=3), and mandala (n=2). Habit trackers were integrated in weekly and monthly logs to structure daily routines, and

combined with other types of trackers to explore relationships between habits and personal wellness. By choosing a specific type of visualisation, bullet journalists crafted certain perspectives on their data. For example, they created matrices to be able to compare several habits in one view or used one dedicated calendar view for each habit to focus on one habit at a time. The temporal perspective also affected people's engagement: for example, BJ54 realised that weekly logs held her more accountable than monthly trackers. Visual progress bars and counters were often attached with a clear statement of intent and created to build motivation in pursuing and maintaining health behaviours (e.g. BJ269: "Tracking my Keto journey has really helped me adapt to this way of eating.")

Visualisations also led to gratifying and sobering insights. BJ95, who documented her media consumption, reported realising that she had lost 3 hours of her life on YouTube and BJ4, who kept track of her app use with her smartphone and bullet journal, explained:

"Last week I spent almost an entire day of the week on my phone. I got an app called Ubhind that tracks how much time I spend on my phone using which apps (...). An entire day! And this is a huge improvement to the week before when I spent a whopping 28 hours on my phone. Eye opening."

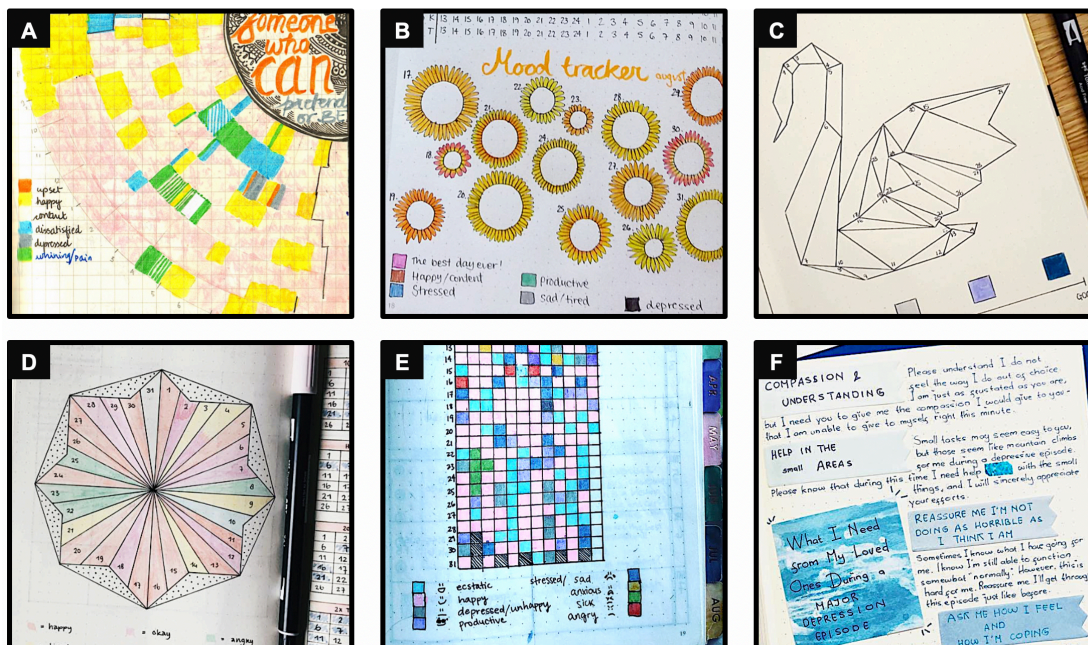


Figure 6: Example mood trackers

A: Matrix, B: Object display, C: Origami, D: Mandala, E: Matrix, F: Text narrative

4.3.1.2 Mood Trackers

Bullet journalists posted that tracking mood was relaxing and therapeutic. It supported them in assessing their emotional wellbeing and coping with everyday life. In contrast to habit trackers, representations of mood were more individualised, decorative, and artistic, and involved the following types of visualisations (see Figure 6): object display (n=65), matrix (n=45), graph (n=16), calendar (n=15), mandala (n=12), list (n=4), origami (n=4), and text narrative (n=4). Most visualisations involved colour codes which were described with more than one adjective covering spectra of feelings, such as *“sad, lonely, disappointed”* or *“joyful, happy, silly, content, satisfied, fulfilled, blessed.”* One bullet journalist used personifications, such as *“frustrated, angry day”* and *“ehhh... day”* transferring the internal emotional state to the given day and focusing the attention on external factors.

Individuals explained having a positive emotional attachment to object displays that depicted geometric shapes, architecture (e.g. houses), vehicles, animals (e.g. cats, owls, turtles), food (e.g. pineapple, ice cream), flora (e.g. tree, flowers, leaves), and household items (e.g. cup). For example, one bullet journalist visualised a camper van, because it was her goal to own a T5 VW Transporter to travel Europe someday, and another one decided to draw and colour her favourite animals, namely, cats:

“🖋️ I'm setting up my #bulletjournal for the month of September. I picked a cat theme, since I obviously love cats and I didn't quite feel the autumn yet. I just created this amazing idea for a mood tracker, where I will just color a cat with my main mood each day 🐱 already looking forward to September!” (BJ63)

On one hand, individuals posted that creating, visualising, and viewing the colourful representations, such as mood mandalas and origami, positively affected their emotional wellbeing (e.g. BJ18: *“I'm really liking how it's turning out, and I love how it reminds me that even the stressful, frustrating days can make something beautiful.”*). On the other, they realised that positive feelings evoked by visualisations might also affect the accuracy of reporting their mood (e.g. BJ297: *“I don't know how accurately I'll be recording my moods since just looking at this makes me cheery! 😊”*).

Mood matrices helped develop understanding fluctuations of mood over a defined period of time. Most bullet journalists tracked their mood daily once or twice (e.g. AM, after work), and created weekly and monthly overviews, while a few documented their mood over one year. When creating and reflecting on tracked mood, one bullet journalist mentioned that it can be *“frustrating to put a lot of crosses down [fill out a tracker]”*

(BJ23). Most comments highlighted that self-tracking supported bullet journalists in recognising and overcoming bad days and gaining emotional strength, as BJ220 said:

“I really feel that tracking my mood for the past year and a half has helped me realise when I've been sinking down, where I would have previously been ignorant to it until it was too late to turn it around. It's not always possible to stop those bad periods, but being able to look back and know that it will only last {so} long is reassuring enough to take some of the hopelessness out of it.” (BJ220)

By combining mood and habit trackers, individuals were able to realise how certain practices can impact their mood, as BJ7 wrote:

“I found that the afternoon at work vs. evening at home could be drastically different, the dates in blue are the weekend, which tend to be better moods 😊”

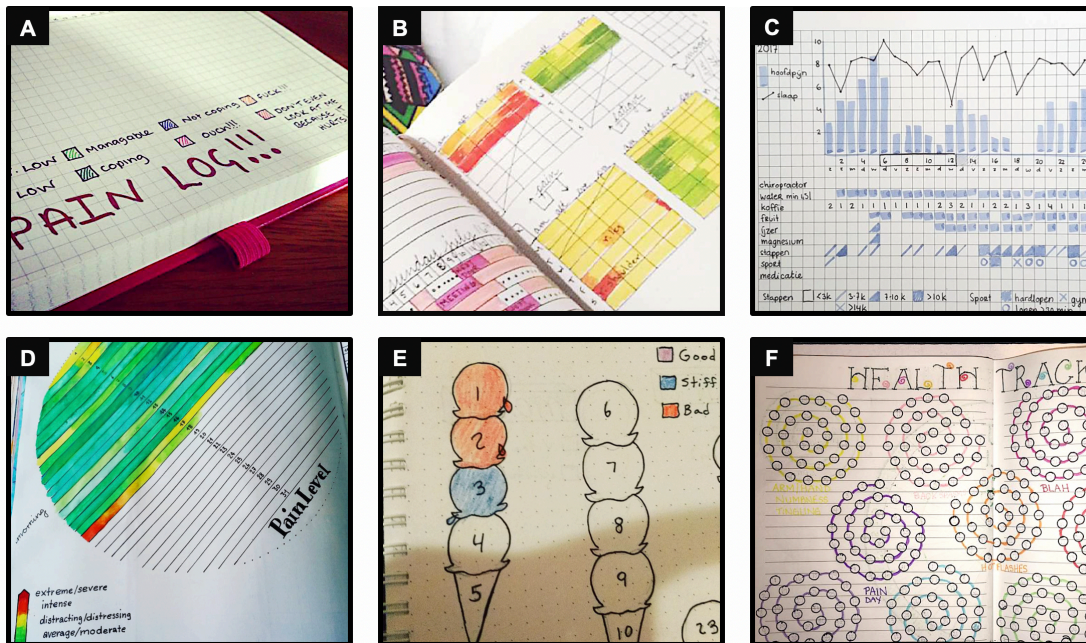


Figure 7: Example symptom trackers

A: Legend, B: Matrices, C: Graphs and matrix, D: Matrix, E: Object display, F: Object display

4.3.1.3 Symptom Trackers

Photos of paper bullet journals including the hashtag #symptomtracker illustrate people's documentary and diagnostic self-tracking practices. They reported engaging in symptom tracking, because it helped in recognising warning signs and relationships between health behaviours and symptoms, and gaining scaffolding in self-managing the complexities of a chronic condition. Furthermore, individuals explained that documenting symptoms supported them in communicating their health and wellbeing to clinicians.

Descriptions of symptoms covered day, time, body site of symptoms, and, in addition, emotional wellbeing, related activities, and everyday events. They documented symptoms using clinically-informed terms (e.g. *"low blood pressure"*), descriptive language (e.g. *"raspy voice, dry eyes, mouth sore, always hungry, scratchy throat"*), comparisons (e.g. *"sick like flu"*), metaphorical constructs (e.g. *"brain fog"*), and brief narratives of related activities (e.g. *"slept bad"*). Individuals captured a wide range of physical (e.g. *"fatigue, nausea, congestion"*) and psychological (e.g. *"anxiety, insomnia"*) symptoms, and described their wellbeing (e.g. *"weak, dizzy, shaky, calm"*).

Most bullet journalists documented the day of symptom onset in monthly overviews and the day and time of symptom onset in weekly overviews (see Figure 7). Timeframes of occurring symptoms were broadly defined as *"am, noon, pm," "am, pm, and evening,"* or *"am, afternoon, evening, and pm."* Most individuals did not track the exact time that symptoms started or improved on a given day. The location of symptoms was tracked by using general terms, such as *"bones and muscles"* or specific human body parts, such as *"base head, shoulder, lower arm, hand, hip, upper leg."* One bullet journalist reported that she printed out and included a printable online template of a body shape in her diary, which she used to mark exact locations of symptoms.

Bullet journalists most frequently created matrices (n=22), followed by text lists (n=14), object displays (n=8), graphs (n=8), calendars (n=2), and mandalas (n=1) to track symptoms. They tracked symptoms in combination with everyday habits and events. For example, matrices were used because they helped identify relationships between habits and symptoms in one single view. Indeed, many bullet journalists suggested gaining valuable self-knowledge over time, such as insights about perceived relationships between medication and symptoms (e.g. BJ219 *"As the chart shows, the pain meds were definitely not causing the headaches."*), and trends of symptoms (e.g. BJ254: *"Sometimes over a long period of time you can figure out Cycles. I usually get warning signs like my hands start to hurt."*).

4.3.2 Mindful Experiences and Self-Reflective Strategies

When engaging in habit, mood, and symptom tracking, bullet journalists expressed not only the challenges of designing paper journals but also described their positive, mindful experiences of colouring tracker visualisations and engaging in self-reflective practices.

4.3.2.1 Effort and Joy in Designing Trackers

Bullet journalists developed a positive, multi-faceted textual and visual language spanning different trackers, symbols, sketches, themes, and narratives. However, they also made clear that the design of bullet journals involved a learning curve and many also posted trackers that included minor flaws, such as false labelling, major mistakes (e.g. BJ47: *"I messed up on the first page and ripped the whole thing[s] out 😊"*), and layouts that might not meet their goals (e.g. BJ150: *"This setup is not going to work for the long run..."*). Furthermore, they reported experiencing challenges in terms of planning, constructing, and extensibility of created trackers and required effort and time. For example, BJ164 expressed the tensions between the static form of created matrices and the unpredictable nature of occurring and disappearing symptoms:

"I still don't have enough room for my #symptom tracker so I have to figure out what else to do there. I don't have some of the things marked at all. Plus, if you have #autoimmune #illness you know this, things pop up that never occurred before here and there throughout your days so you have to have room to add those. Ugh..."

To overcome challenges regarding effort and time required, individuals developed workarounds, such as using alternative visualisations that looked less visually pleasant but that could be constructed more quickly. They also took advantage of rulers, dividers, and paper templates for re-use, as BJ61 expressed:

"Then I traced them around my pages. It was kinda difficult, (I suck at math), and very time consuming (I think I made 4 templates before I got it right), but I LOVE the effect, so it was well worth it!! 💜💜💜"

Despite existing challenges and workarounds, bullet journalists expressed that design practices positively affected their emotional wellbeing. For example, BJ310 decorated her weekly log with owls and made clear she was not the best at drawing but was enjoying the process of drawing. A conversation of bullet journalists revealed the visual aesthetics of using colours and its potential positive, therapeutic effect on emotional wellbeing, as BJ257 wrote: *"Colors make me happy too 🌈;"* and BJ53 explained: *"I love how my habit tracker is always the most colorful page in my bujo 🌈 and filling in the squares is so fulfilling and satisfactory 😊"*

Many expressed their joyful anticipation of filling out, seeing the progress in, and completing visualisations, such as matrices, (e.g. BJ219 *"I am looking forward to filling up the Monthly Chart!"*). Furthermore, they explained that the visual theming can also help in coping with the challenges of setting up the layout of tracker visualisations, as BJ164 described:

"Oh my gosh, my head can't wrap around this [how to construct a flexible symptom tracker]. But at least the #pages are really #cheerful. 😊"

Another design practice and coping strategy that became apparent across the creation of habit, mood, and symptom trackers was the shared use of positive symbols and metaphors. For example, many bullet journalists used the symbol of a cactus to represent endurance, not only in their notebooks but also in the comments sections on Instagram.

4.3.2.2 Self-Reflective Strategies

When designing and completing spreads and trackers, bullet journalists reported developing self-reflective strategies to support mindful, reflective thinking. We identified different self-reflective strategies that focus on the present, past, and future self (see Figure 8).

Firstly, there were reflective practices that concentrate on present experiences. For example, bullet journalists engaged in autobiographical writing, complementing their diaries with narratives of mundane happenings, positive events, such as having a management review and receiving *"nothing but positive feedback, praise & recognition"* (BJ116), and also revealing negative experiences (e.g. BJ147: *"When my fiancé can't deal with my depression, it broke my heart to million pieces"*). Another self-reflective strategy was to incorporate mindful quotes along with mood and symptom trackers, such as, *"Just remember: even your worst day lasts for 24 hours"* (BJ124). Moreover, some bullet journalists created gratitude trackers to write down one good thing about every day to remember or had a dedicated page where they documented stressors to let go of, as BJ225 explained:

"My 'let it go' page: [...] Each day, before I leave work, I am going to choose one major stressor to let go of before leaving for home. Hopefully it helps me be more conscious of my mental well being."

Secondly, bullet journalists engaged in retrospective, reflective thinking, remembering and processing the past by creating documentations of, for example, books read and movies watched. One bullet journalist, made a list of 26 facts about himself which was a

challenging, yet “nice self-reflective practice.” (BJ170), and BJ217 created a “Life at Level Ten” log to evaluate where she is in life rating her health, social relationships, personal development, recreation, and contributions.

Thirdly, they visualised and described prospective thoughts, goals, and intentions about their future self. For example, creating a timeline of “my ideal day” provided orientation when engaging in daily task and habit logging. Bullet journalists also included desirable personal characteristics in their habit and mood trackers, such as being positive at work, and tracked their intentions (e.g. BJ248 “giving back, no fighting, trust, courage, and play”).

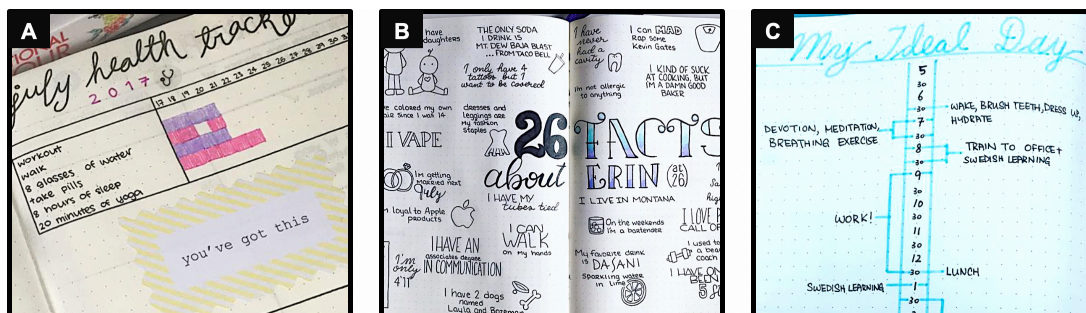


Figure 8: Examples of self-reflective strategies

A: Mindful quote, B: Facts about oneself, C: Ideal day

4.3.3 Social Learning through Online Engagement

Through sharing paper bullet journals online, individuals bridged analogue and digital and, in doing so, reported experiencing additional value in becoming part of an online community, receiving inspiration, citing each other’s works, learning new best practices from peers, and having conversations around and beyond the design of paper bullet journals. Sharing photos often involved staging (e.g. choosing the background), preparation (e.g. blurring sensitive information), and providing descriptions and reflections on how and why bullet journalists designed their notebooks. For example, BJ34 described her graph in the following way:

“So I stopped taking anything on June 1st, and made this chart to keep track. The headache intensity is the blue bar, sleep the black line. I also tracked water and coffee intake, supplements (iron and magnesium), number of steps and exercise (running, hiking, gym).”

Best practices on how to design visualisations and the kinds of tools to use, were also discussed (e.g. BJ310: “I put little guide dots in before drawing the lines so I know where I’m heading, I’ve found it works a lot better than doing is freehand straight away!”). They

also motivated each other providing support and guidance. BJ83, who revealed feeling overwhelmed with tracking too many aspects of her life using different layouts, appreciated BJ82's advice:

"Make it part of your daily routine. Stick with it for at least one month and don't overcomplicate it. If you see that your productivity is increasing because of it, you can slowly start adding fun pages, but don't overwhelm yourself so that it feels like a chore."

Moreover, sharing paper bullet journaling online empowered cooperative practices: individuals teamed up to pursue and document weekly and monthly health challenges. Furthermore, they sent design challenges to each other, for example, *"to create an origami swan as next month's mood tracker"* (BJ64). In doing so, bullet journalists compared themselves with peers. BJ14, for example, found her symptom tracker *"plain and boring"* compared to BJ219's *"pretty January tracker."* While many appreciated the interactions with peers (e.g. BJ386: *"Thank you very much for your support [...]. I'm very happy to be a part of this creative community 🥰"*), BJ257 addressed the negative effects of social comparison: she made clear that although she is not an artist, bullet journaling made her feel happy and has lowered her anxiety. She encouraged other bullet journalists not to compare themselves with the skilled artists but to seek inspiration from them and just enjoy themselves (ibid).

4.4 Discussion

Drawing on our analysis of photos of and conversations about paper bullet journals on Instagram, we have illustrated unique characteristics of paper bullet journaling: (1) being a mindful, visual journaling practice based on subjective experiences; (2) involving not only the organisation of everyday living but also documentary, exploratory, and diagnostic self-tracking styles which cover quantifiable and intangible aspects of the past, present, and future self; and (3) spanning the analogue and digital world through the creative use of pencil and paper, translating digital data into paper journals, and sharing digital representations of paper journals online within a community of practice. Based on these findings, we discuss two interrelated design perspectives: the first motivates maintaining and digitally extending analogue journaling practices rather than replacing the use of pencil and paper; the second highlights how the design practices of bullet journalists might motivate digital self-tracking as a mindful design practice as opposed to passive automation and predefined presentation of personal data.

4.4.1 Digitally Extending Analogue Self-Tracking

The use of paper journals remains common practice, as research studies within and beyond personal informatics suggest (Epstein et al. 2017; Fox and Duggan 2013; Kaye et al. 2014). Material qualities and affordances of pencil and paper provide unique physical values and support experiences of ownership, control, and joy. Prior work has compared affordances of the physical properties of paper (e.g. being “*thin, light, porous, opaque, and flexible*”) with those of digital technologies and explored how paper and digital tools could work in tandem (Sellen and Harper 2003). In this vein, our findings illustrate that analogue journaling can be digitally supported, rather than being imitated or replaced by digital technologies. Bullet journaling on Instagram exemplifies how digital technologies can “*work in concert*” (ibid) with analogue self-tracking tools and, in doing so, extend self-tracking experiences by supporting additional affordances and human values, such as instant communication and social learning. Here, we revisit transitions from analogue to digital and from digital to analogue to map out design spaces for future exploration.

Bullet journalists took advantage of Instagram’s existing infrastructure to participate in an online community of sharing and learning, whilst being able to engage in their offline, analogue journaling practices. Through these transitions from the analogue to digital space, paper journaling - considered to be deeply autobiographical and private - became social and public (c.f. (Chung et al. 2017)). The online conversations between bullet journalists on Instagram remind us of the analogue data drawing project *Dear Data* that exhibits the communication between Giorgia Lupi and Stefanie Posavec, who visualised and shared everyday experiences via physical postcards (Lupi and Posavec 2016). Bullet journaling goes beyond a visual communication between two actors. It has characteristics of a community of practice with a shared language and “*self-tracking culture*” (Lupton 2014) encouraging the sharing of tool-based expertise. The appropriation of Instagram for sharing photos of paper notebooks online suggests that transition work, such as taking and uploading photos, could be extended by new social values, such as collaboration, playful competition, coaching, and augmenting the application with a wide range of digital actions, from copy and paste to edit and share. For example, the design of *Documentary Informatics* tools (Elsden et al. 2017) could facilitate the creation and curation of digital possessions of selected experiences and memories captured in paper journals within more private social settings. The *Bullet Journal Companion* app (Carroll 2016) exemplifies how organisation of, searching in, and reflecting on paper notebooks can be digitally supported.

Furthermore, we observed transitions from the digital to the analogue realm: for example, bullet journalists designed mindful quotes that they printed and stuck into their

paper diaries, as well as translating different types of digital data (e.g. step counts) to their paper diaries. However, they explained experiencing challenges when repetitively drawing layouts of trackers on a weekly and monthly basis and, therefore, used not only tools, such as rulers and compasses but also digitally designed and printed templates for re-use. To support these types of transitions, tailored interfaces could allow individuals to create and manage templates of trackers and use, for example, wearable fitness tracking devices and smartphones solely as data collection tools to import, arrange, and visualise data of interest. In doing so, digital personal data could be printed to gain a physical form able to be incorporated into existing paper notebooks to support design practices, from annotation to bricolage by hand.

4.4.2 Digital Self-Tracking as a Mindful Design Practice

Whilst the use of bullet journals mirrors characteristics of *Lived Informatics* (Rooksby et al. 2014a) and *Documentary Informatics* (Elsden et al. 2017), the design of bullet journals is at odds with the design of current self-tracking applications, especially, consumer self-tracking technologies. Here, we discuss paper bullet journaling as a mindful design practice to provide an alternative design perspective for self-tracking tools.

The notion of “*Lived Informatics*” characterises the use of wearable fitness tracking devices as prospective and enmeshed in everyday life (Rooksby et al. 2014a). In contrast to consumer self-tracking technologies that typically concentrate on automated capture of fitness data to optimise health behaviours, *Documentary Informatics* tools, such as smart journals, focus on the documentation of personal data to support remembering and reminiscence (Elsden et al. 2017). The phenomenon of paper bullet journaling on Instagram illustrates the two notions of personal informatics as a community-driven practice and presents a unique orientation towards mindful design activities: the creative, sketchy, illustrative, and artistic use of pencil and paper to keep track of and cope with felt experiences in everyday life. These design practices focus on the experience of self-expression and self-exploration highlighting that visualising data by hand can be an end in itself. They contrast with the orientation of the quantified self - *self-knowledge through numbers* - and data presentation in self-tracking tools in which data collection and visualisation are predefined (Y.-H. Kim et al. 2017a), aggregated, and separated in different views.

In contrast to separating data collection and visualisation, bullet journalists created trackers and collected data through completing trackers at a glance (e.g. filling out a matrix). In doing so, they were able to view the past, colour the present, and speculate about the future. These practices combine *stages of collection and reflection* (Li, Dey,

and Forlizzi 2010) and mirror Schön's notion *reflection-in-action* (Schön 1983) and lived nature of self-tracking (Epstein et al. 2015). Furthermore, bullet journalists, created overviews to visualise, for example, their mood with the help of symbolic representations that supported a positive emotional relationship to the data being presented (e.g. cats). Here, not researchers, but bullet journalists themselves created their own, personalised "*depictions of data in everyday life*" that go beyond the traditional, analytical information visualisation vocabulary (Pousman, Stasko, and Mateas 2007). In this way, they not only gained visualisation insights (Choe, Lee, and schraefel 2015) but also engaged in mindful, reflective, and therapeutic thinking through designing and completing their visualisations, as previously reported in research interventions on art therapy (e.g. (Smolarski, Leone, and Robbins 2015)).

Prior research has examined the use of organic representations to encourage physical activity (Lin et al. 2006), explored a range of design alternatives to support tailored momentary self-assessments of chronic pain (P. Adams et al. 2017), and empowered individuals to bridge automated and manually tracked data streams (Y.-H. Kim et al. 2017a). We have presented paper bullet journaling as a mindful design practice and illustrated that manual self-tracking is not necessarily a "*burden*" that needs to be overcome with automated capture. It can be an effortful, yet powerful tool for creative and reflective self-expression, self-exploration, and communication. Especially, when manual self-tracking is not forced and when values, such as flexibility and practice-based scaffolding in the form of supporting social interaction and inspiration, outweigh efforts.

4.5 Conclusion

The previous chapter has investigated self-tracking in MS self-care and has highlighted the need to support people's agency through customisable self-tracking approaches. However, it was not clear how customisable self-tracking technologies could be designed to support the needs of people living with MS. This chapter examined the customisable self-tracking approach called paper bullet journaling to inform the design of customisable self-tracking technologies. It illustrates the ways in which individuals adapted bullet journaling systems to meet their individual self-tracking needs. Bullet journalists crafted, combined, and switched between personally meaningful pictorial trackers: visualisations that support logging and viewing tracked data in pictorial views. This chapter identifies design strategies and exemplifies how a customisable and pictorial self-tracking approach can be realised to support people's individual self-tracking needs in MS self-management. However, digital research prototypes, that implement such a customisable and pictorial self-tracking approach, do not exist.

5 From Ethnographically Informed Accounts to Design: A Synthesis

This chapter provides a synthesis of the interview study on self-tracking in multiple sclerosis self-care (see chapter 3) and the online ethnography of paper bullet journaling (see chapter 4). In doing so, this chapter suggests that the self-tracking needs in MS self-management could be supported by a customisable and pictorial self-tracking approach.

5.1 Introduction

Chapter three investigated self-tracking in MS self-management. Interview participants reported experiencing a sense of control over MS through proactively adopting and adapting combinations of different self-tracking tools to their individual self-care needs. This insight underscores the importance of supporting people's agency through customisable self-tracking. To examine how applications could be designed to support customisable self-tracking, chapter four has illustrated the analogue and customisable self-tracking approach bullet journaling. This chapter provides a synthesis of the interview study on self-tracking in MS self-management (see chapter 3) and online ethnography of paper bullet journals on Instagram (see chapter 4). Firstly, this chapter revisits the perceived benefits and challenges of self-tracking with analogue notebooks and digital health and wellbeing apps. We then highlight three interrelated self-tracking needs to support agency in MS self-care: (1) receiving scaffolding when engaging in self-tracking; (2) being able to customise the topic, content, and timing of self-tracking; and (3) experiencing positive affect when self-tracking. This chapter identifies the ways in which these self-tracking needs in MS self-care could be realised by drawing on a customisable self-tracking approach based on bullet journaling design patterns and strategies: (1) offering examples of pictorial trackers to provide inspiration; (2) empower people to customise their pictorial trackers according to their individual self-care need; and (3) supporting people in flexibly colouring in and viewing their pictorial trackers.

5.2 Method

We applied the affinity diagram method to conduct a synthesis of the interview study (see chapter 3) and online ethnography findings (see chapter 4). An affinity diagram is a visual method that is commonly used not only to thematically analyse qualitative data but also to bridge gaps between qualitative accounts and the design of technologies (Harboe and Huang 2015). Firstly, we revisited the findings of the interview study to highlight the perceived benefits and limitations of self-tracking tools in MS self-management. Secondly, we revisited the findings of the online ethnography of paper bullet journaling and identified design strategies and patterns. Thirdly, we associate perceived challenges of self-tracking in MS self-care with bullet journaling design strategies (see Figure 9). In this way, we show how the individual self-tracking needs of people living with MS could be supported by a customisable and pictorial self-tracking approach. In the following sections, the affinity diagram findings are presented in table format and supported by participant quotes.



Figure 9. Affinity diagram: benefits of notebooks could inform limitations of apps

5.3 Findings

In the following sections, we present the affinity diagram-based synthesis. We highlight benefits and challenges of self-tracking tools in MS self-care and suggest how these challenges could be supported by customisable and pictorial self-tracking.

5.3.1 Benefits and Challenges of Self-Tracking Tools

Benefits of Paper Notebooks	Example
<p>Customisability</p> <p>Participants valued being able to document their health and wellbeing in holistic ways:</p> <ol style="list-style-type: none"> 1) they developed their custom systems using their own words, narratives, symbols, and scales 2) they intertwined different self-tracking styles (not only diagnostic but also documentary self-tracking) 3) they enriched their records with contextual information (thoughts, actions, events, and measures from different tools, such as pedometers) to support sense-making 	<p>P8: "If I am feeling fatigued, I just mark the day with a little f. If I am, for example, got loads of energy, I just write an e."</p> <p>P5: "I write down three things that made me happy. Could be anything from, it was bad day, we got clean bad sheets, or the sun was shining. And I find that from a wellbeing perspective really nice."</p>
<p>Sense of control</p> <p>Participants reported experiencing a sense of control through customising their paper notebooks and being able to decide when to create entries.</p>	<p>P11: "I like plotting graphs. I find it interesting; I actually like doing it. It gives me a sense of progress and control."</p>
<p>Positive wellbeing</p> <p>Participants explained that the process of writing down personally meaningful experiences did not only support a sense of control but also self-reflection and positive wellbeing.</p>	<p>P7: "Just the process of writing the words and seeing them. It's therapeutic. It gives me a greater depth to my reflection."</p>

Table 2. Benefits of self-tracking with paper notebooks

Challenges of Paper Notebooks	Example
<p>Expertise and skills</p> <p>Self-tracking required self-awareness and skills of how to structure and document experiences.</p>	<p>P6 revealed that it can be challenging to find the right words when seeing a white page and P4 explained:</p> <p>“I am still learning the ways how my body is.”</p>
<p>Effortful and unpractical</p> <p>Participants found it difficult to:</p> <ol style="list-style-type: none"> 1) remember to create entries 2) maintain paper journaling over time 3) search and find information 4) cross-compare and make sense of different types of entries, including symptoms, medication, and daily activities 5) manually transfer information from other self-tracking tools (e.g. fitness tracking devices and weight scales) 6) share their analogue entries with friends, caregivers, and clinicians 	<p>P7: “It’s really tedious, difficult, time consuming, to collect the data. And also, when it’s in a format which you can’t look at the results easily.”</p> <p>P11: “The only thing is when I go away for a week on holiday. It, sort of, sits in a drawer at home”</p>

Table 3. Challenges of self-tracking with paper notebooks

Benefits of self-tracking apps	Example
<p>Self-care support</p> <p>Participants, who intended to improve their lifestyles, reported that fitness tracking devices and apps (e.g. MyFitnessPal) supported their self-care intentions and health behaviour.</p>	<p>P7: "It (using self-tracking apps)'s a fundamental part of how I mange my health."</p>
<p>Sense of control</p> <p>Self-tracking apps, including fitness tracking and food journaling apps, played an important role in empowering people to self-manage MS in everyday life. By gaining a better understanding of their body and exploring how to adjust to symptoms and potential triggers they gained a sense of control over the complex nature of MS.</p>	<p>P8 explained that using a Fitbit Charge HR device to monitor her heart rate and cope with stressful life events provided a sense of control over MS.</p> <p>P8: "Because research does say that there is correlation between MS and stress, I am like, well if I manage my stress, I'll be managing my MS. In my head it gives me control over something."</p> <p>P4 valued being in control when documenting her symptoms with a symptom tracking app that supported her in visually marking her individual pain levels on a body visualisation.</p> <p>P4: "It was quite good. I could just draw circles where my pains were, and it showed a picture of the front and the back of the body."</p>

Table 4. Benefits of self-tracking with digital apps

Challenges of self-tracking apps	Example
<p>Lack of customisability and negative affect</p> <p>Participants explained that self-tracking apps that lacked customisability can impede their individual needs and agentive capacities. In particular, individuals who experienced relapsing symptoms, intended to rest, or aimed to maintain their physical abilities, reported negative experiences.</p> <p>For example, P10 explained that fitness norms and data visualisations features, that were designed to optimise performances, can be discouraging and counterintuitive. P9 explained that setting goals is not sensible considering the relapsing and remitting nature of MS. P5 highlighted that symptom tracking apps need to be customisable rather than predefined to avoid negative affect.</p>	<p>P10: "I also had a Fitbit. It was very rare that I would do 10000 steps a day. It can be quite discouraging when you know that can only walk so far. They have got these graphs and the graphs for me are kind of counterintuitive"</p> <p>P9: "I've found setting a target of exercising every day with MS is not feasible. It just seemed like pointless pressure. Now if I feel like it, I exercise but it's more to do with maintaining flexibility rather than achieving targets."</p> <p>P5: "It needs to be quite flexible. In the same way as you go onto google and type in MS, it's really easy to say, I got that and that and that. It could lead someone worry unnecessarily about symptoms they don't have."</p>

Table 5. Challenges of self-tracking with digital apps

5.3.2 Informing Self-Tracking Needs in Multiple Sclerosis Self-Care

Self-tracking needs in MS self-care	Bullet journaling design strategies
<p>Scaffolding</p> <p>People with MS reported that documenting personal health and wellbeing can require scaffolding. Beginning with self-tracking was for some individuals challenging. Paper-based self-tracking in particular required health expertise and skills.</p>	<p>Examples trackers</p> <p>Bullet journalists explained that examples of pictorial tracker created by peers can provide initial scaffolding and inspiration of how to begin with self-tracking and how to create and adapt custom pictorial tracker visualisations.</p>
<p>Customisability</p> <p>MS affects different parts of the central nervous system causing an individual range of symptoms. It was important for people with MS to be in control of what, when, and how they self-track. There cannot be a one-size-fits-all self-tracking system. Instead, self-tracking tools need to be customisable.</p>	<p>Customisable trackers</p> <p>Bullet journaling is a customisable self-tracking system consisting of different building blocks including custom tracker visualisations. This customisable system demonstrates how self-tracking technologies could support flexible use and individual self-care needs.</p>
<p>Positive affect</p> <p>Being pushed to document predefined symptoms, reach normative health goals, and reflect on trend-based graphs can cause negative affect. People with MS highlighted that self-tracking needs to be emotionally supportive.</p>	<p>Pictorial trackers</p> <p>Bullet journalists described that keeping track of personally meaningful aspects of their life and colouring in pictorial tracker visualisations can support positive and therapeutic experiences.</p>

Table 6. How journal design strategies can address needs in MS self-care

5.4 Discussion

We have developed the thesis that the individual self-tracking needs in MS self-care could be supported by a customisable and pictorial self-tracking approach. We have reached this thesis by drawing on the findings of an interview study on self-tracking in MS self-care (see chapter 3) and an online ethnography of paper bullet journaling (see chapter 4).

Interview study participants reported contrary benefits and limitations of existing analogue and digital self-tracking tools. They valued being able to document their health and wellbeing with paper notebooks in holistic and personally meaningful ways. They explained that using their own words, intertwining documentary and diagnostic self-tracking styles, and adding contextual information, supported them in engaging in self-care, gaining positive wellbeing, and experiencing a sense of control in everyday life. However, they reported several challenges when using paper notebooks. Keeping a paper notebook required skills of how to structure and compose entries and involved challenges, such as remembering to create entries, findings information, making sense of different types of entries, and sharing entries with friends, caregivers, and clinicians.

Participants, furthermore, reported benefits and challenges of using digital self-tracking apps. Participants, who intended to improve their lifestyles, reported that fitness tracking devices and apps (e.g. MyFitnessPal) supported their self-care intentions and health behaviour. Using fitness tracking and food journaling apps helped gaining self-awareness and a sense of control over the complex nature of MS. However, individuals, who experienced relapsing symptoms and aimed to maintain rather than optimise their health and wellbeing, highlighted mismatches between their individual self-care needs and medically informed and achievement based self-tracking approaches that lacked customisability.

Based on this understanding, we have highlighted three self-tracking needs in MS self-care for more agentive and emotionally supportive self-tracking applications: (1) receiving scaffolding when engaging in self-tracking; (2) being able to customise the topic, content, and timing of self-tracking; and (3) experiencing positive affect when engaging in self-tracking. We have illustrated paper bullet journaling as a customisable and pictorial self-tracking approach and assume that customisable and pictorial self-tracking could support the self-tracking needs in MS self-care because of the following key findings: (1) sharing examples of pictorial trackers providing guidance and inspiration; (2) bullet journaling is a highly customisable self-tracking approach that can be tailored to individual self-care needs; and (3) individuals described that creating

personally meaningful pictorial trackers and colouring in and viewing their pictorial trackers supported positive and therapeutic experiences.

We have discussed different directions for designing self-tracking tools that realise customisable and pictorial approaches (see chapter 4). The first direction detailed how paper bullet journaling could be supplemented, for example, by designing tangible stencils to support people in manually reusing their pictorial trackers. The second direction motivated the design of digital applications that realise customisable and pictorial self-tracking approaches. It seems promising to investigate the second directions, namely, how digital self-tracking tools could be designed to support customisable and pictorial self-tracking, because of the following reasons: (1) interview participants reported that their mobile devices are an important part of self-managing their health and wellbeing; (2) they highlighted the importance of being able to adapt self-tracking systems to their individual range of symptoms and holistically document their health and wellbeing in personally meaningful ways.

5.5 Conclusion

This chapter has synthesised the findings of the interview study on self-tracking in MS self-care (see chapter 3) and the online ethnography of bullet journaling (see chapter 4). We have summarised the perceived benefits and challenges of both analogue and digital self-tracking tools. Based on this understanding, we have highlighted the potential of how the idiosyncratic self-tracking needs in MS self-management could be supported by a customisable and pictorial self-tracking approach. Digital self-tracking applications could: (1) offer examples of pictorial trackers to provide guidance and inspiration; (2) empower people to customise their pictorial trackers according to their individual self-care need; and (3) support people in flexibly colouring in and viewing their pictorial trackers.

6 Trackly: Design of a Customisable and Pictorial Technology Probe

Parts of this chapter have been published as a paper in the Proceedings of the 2020 CHI Conference on Human Factors in Computing Systems (Ayobi, Marshall, and Cox 2020).

6.1 Introduction

We examined self-tracking practices in multiple sclerosis self-care with our first interview study (see chapter 3). People living with MS reported experiencing a lack of control when going through relapses and when dealing with the uncertain and varied nature of the disease. Adapting combinations of different self-tracking technologies to individual self-care needs supported them in regaining a sense of control over MS in every life. Experiences related to a sense of control entailed proactively self-tracking personally meaningful aspects of their life, gaining self-awareness and self-knowledge, adjusting health behaviour to manage MS, and being able to communicate their health status to care givers and clinicians. However, participants abandoned self-tracking technologies when experiencing mismatches between their self-tracking needs and the design of medically informed and achievement-based design approaches. This was in particular the case when they wished to document idiosyncratic symptoms, but MS apps allowed them only to document primary disease indicators based on predefined numeric scales, or when they aimed to maintain their physical abilities, but fitness tracking applications automatically recorded and visualised performance measures to foster achievement-based engagement (see Figure 10). Based on this understanding, we identified the following interrelated user needs in MS self-care: (1) receiving scaffolding when engaging in self-tracking; (2) being able to customise the topic, content, and timing of self-tracking; and (3) experiencing positive affect when self-tracking.

While the interview study provided an understanding of perceived benefits and challenges of different self-tracking tools, it remained unclear how self-tracking technologies could be designed to support the identified self-tracking needs in MS self-care. The analysis of paper bullet journals (see chapter 4) has identified a customisable and pictorial self-tracking approach that demonstrates how the self-tracking needs in MS self-care could be supported: (1) offering examples of pictorial trackers to provide guidance and inspiration; (2) empowering people to customise their pictorial trackers

according to their individual self-care need; and (3) supporting people in flexibly colouring in and viewing their pictorial trackers.

In this chapter, we will utilise paper bullet journaling as an inspirational resource and document the iterative design of a technology probe that is based on the identified customisable and pictorial self-tracking approach. Designing and implementing a technology probe will help (Hutchinson et al. 2003): (1) elicit situated and behavioural data to understand individual data collection practices, visualisation preferences, and information needs; (2) examine the feasibility and perceived benefits and limitations of a customisable and pictorial self-tracking approach in MS self-care; and (3) inform the design of future self-tracking technologies.

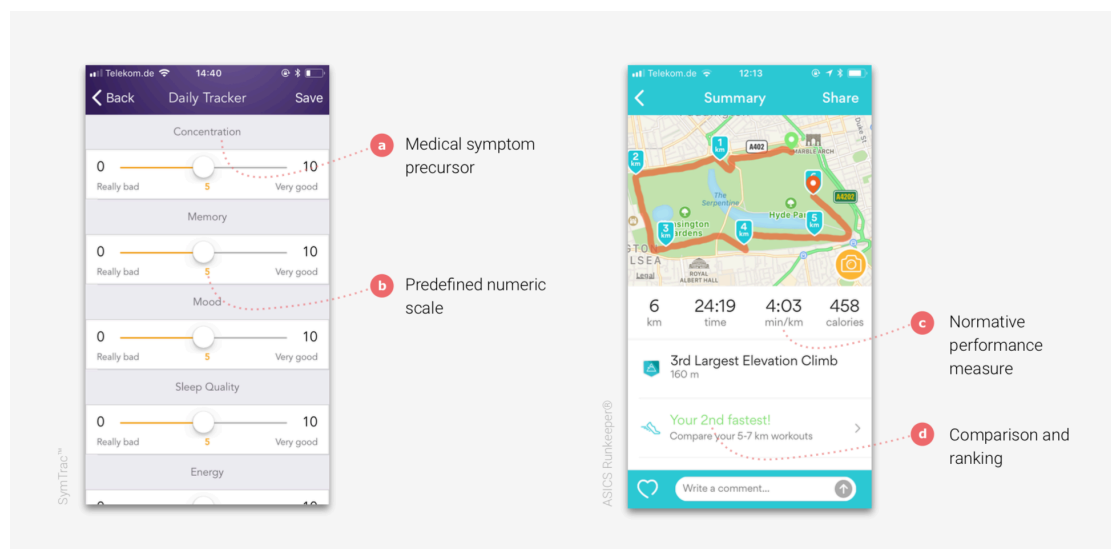


Figure 10. Example health and wellbeing self-tracking apps
Medically informed approach (left) and achievement-based approach (right)

6.2 Design Process

We applied an iterative design approach that centred on the self-tracking needs of people with MS and bullet journaling design patterns. Bullet journaling combines self-tracking with colouring practices. Bullet journaling trackers typically have the following key features: they display pictorial shapes (e.g. flowers or cats); they consist of segments that represent days weeks, or months; they are defined by a name (e.g. mood) and custom parameters (e.g. good, OK, bad) that are associated with a colour scheme (e.g. good: green); and they can be coloured in to log data. In this way, people can colour in pictorial trackers and reflect on their logged data in one view. Based on this customisable and pictorial self-tracking approach, we considered different design directions to support the self-tracking needs in MS self-care: (1) creating a how-to guide to mediate the concept of bullet journaling and best practices of how to create and colour different types of pictorial tracker; (2) building a physical toolkit consisting of customisable stencils to facilitate the manual creation of pictorial trackers with pencil and paper; (3) developing a web-based system to support people in creating and sharing printable template trackers; and (4) designing a mobile app to empower people to define pictorial trackers and digitally explore their recorded data. We decided to focus on the last-named direction. Interview participants particularly valued the customisability of paper-based self-tracking systems and highlighted the importance of being able to holistically document their health and wellbeing in personally meaningful ways. However, they also made clear that they faced challenges when documenting their experiences, findings information, and making sense of their paper notebook entries. Bullet journalists described similar challenges with keeping paper notebooks, including requiring artistic skills and high effort in creating and reusing pictorial trackers. In this chapter, we will explore how digital self-tracking applications could bridge perceived benefits of paper journaling and the potential of mobile devices to support users in collecting and exploring personal health and wellbeing data in pictorial ways.

In the next sections, we illustrate the iterative design and implementation of Trackly beginning with paper-based sketches and visual mock-ups and then moving on to the implementation and expert-based evaluation.

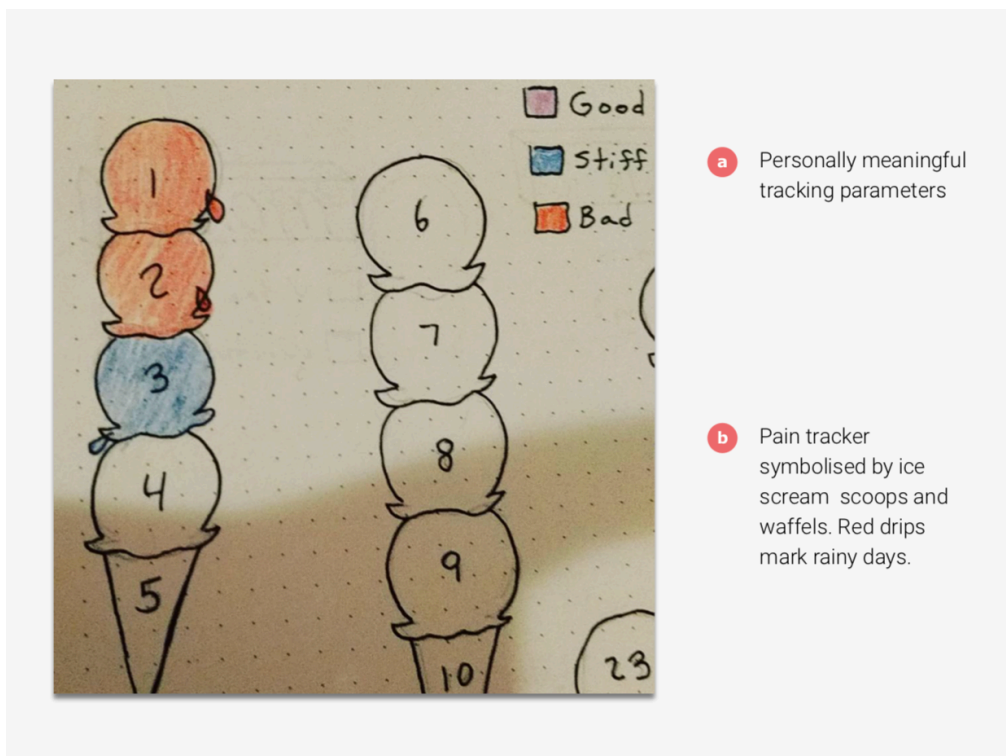


Figure 11. Examples of pictorial bullet journaling trackers

6.2.1 Sketches

Sketches helped explore the feasibility of designing a technology probe aimed at supporting a customisable and pictorial self-tracking approach (see Figure 12). We sketched different interaction variations and the most important views necessary to create pictorial trackers. Sketches, furthermore, fostered decision-making: for example, considering that many apps offer analytical visualisation charts, such as bar and line graphs, we decided to begin with implementing only pictorial trackers, such as mandalas and origami, to examine their benefits and limitations.

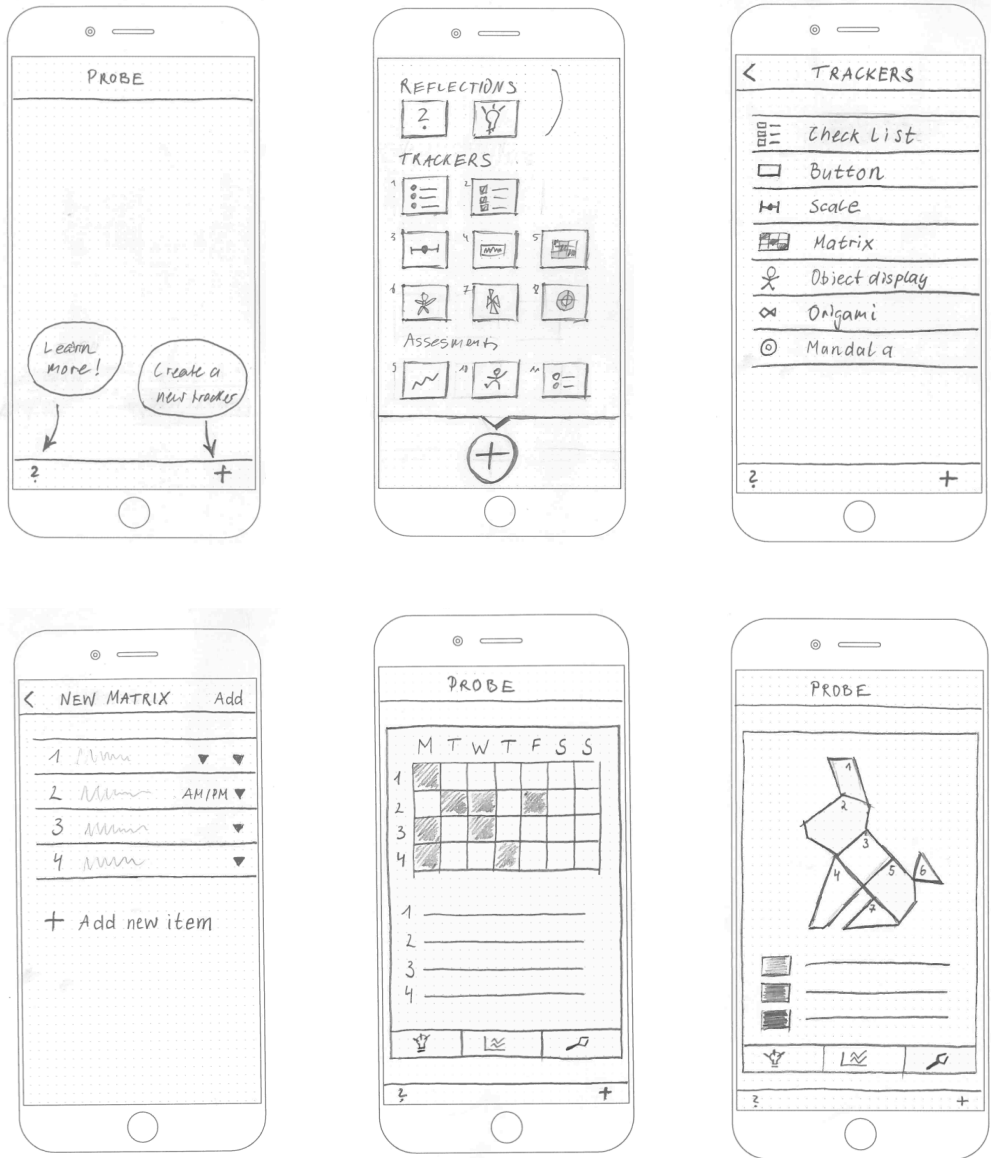


Figure 12: Example sketches

6.2.2 Visual Mock-ups

We created visual mock-ups with the digital design toolkit Sketch to explore different alternatives of how to support the navigation and interaction of a mobile application (see Figure 13). Calendar-based controls are suitable for navigating temporal data that can be aggregated and visualised in traditional charts, such as bar graphs. These controls are also suitable for displaying weekly tracker visualisations. However, there are limitations to displaying monthly and yearly trackers considering the visual segments of trackers and the limited screen real estate of mobile devices. Alternatively, a continuous scrolling list can be used to chronologically display and load trackers.

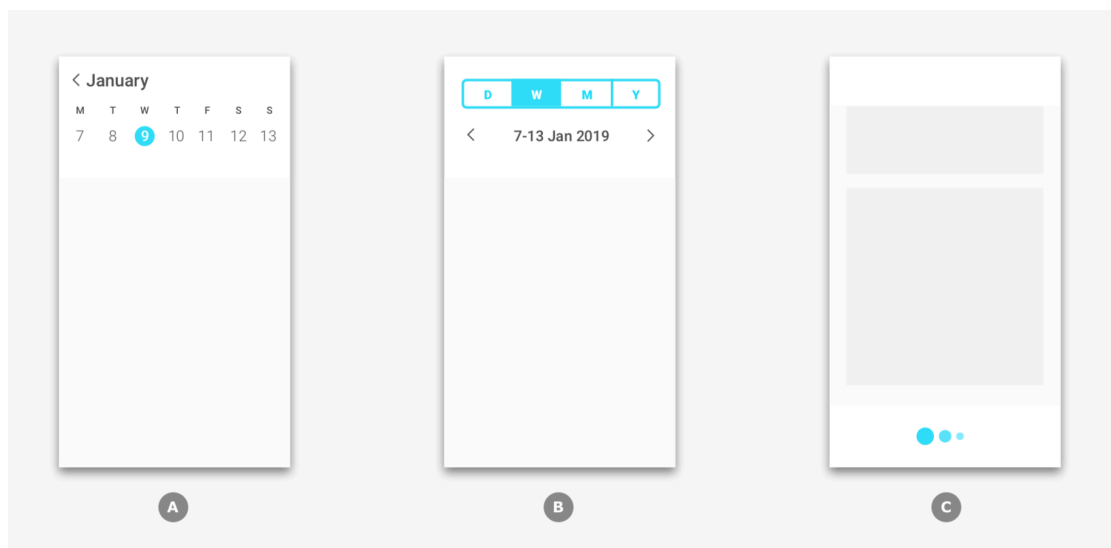


Figure 13: Examples of visual mock-ups: navigation alternatives

Supporting colouring with the help of actionsheets and popover controls is common in the design of mindful colouring apps. However, tracker visualisations are typically accompanied by legends that describe parameter definitions (e.g. the colour yellow symbolises good mood). In this case, a selectable list can help avoid repetition and guide the focus from viewing the legend and selecting a state to colouring a segment of a pictorial trackers (see Figure 14).

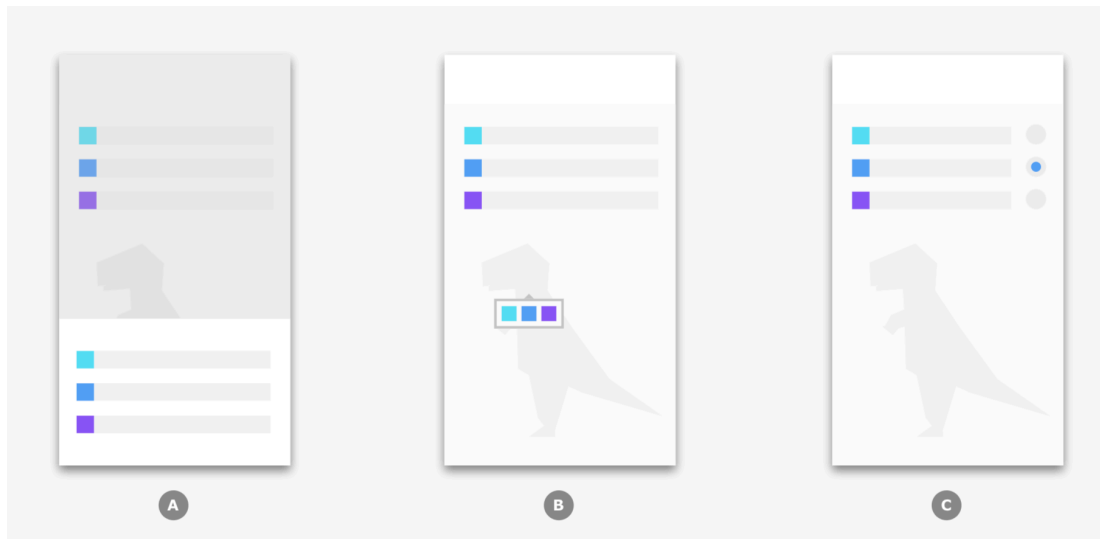


Figure 14: Examples of visual mock-ups: colouring interaction

6.2.3 Customisable and Pictorial Technology Probe

Based on the sketches and visual mock-ups, we iteratively implemented a technology probe that builds on the user needs of people living with MS and the customisable and pictorial self-tracking approach of paper bullet journaling. We aimed to design for experiences of control rather than maximising system automation and minimising user agency.

- Instead of being forced to document predefined primary disease indicators or performance measures, users can document what is important to them by defining and colouring pictorial trackers.
- Rather than interacting with calendar-based controls and automatically renewed trackers each week, users can organise created trackers in a continuous list and decide when they would like to reuse past trackers or create new trackers.
- Instead of collecting and exploring data in separate views, users can colour pictorial trackers and reflect on logged data at a glance.
- Rather than consume automatically generated statistics of trends, users can select what data they wish to view digitally or print and explore physically.
- User log data is not automatically and periodically transferred to researchers. Instead, the data is stored locally, and users can decide whether and when they wish to contribute their data to research.

6.2.3.1 Implementation

We developed the technology probe with Ionic, an open-source development framework that helps developers to build and deploy cross-platform apps (Ionic 2019). The main advantage of the Ionic framework is that developers need to maintain only one single codebase that can be deployed for mobile devices running different operating systems (e.g. Apple iOS and Android). The application logic is coded in TypeScript and the graphical user interfaces are written with HTML-based mark-up. Tracker visualisations were implemented as custom components. They were iteratively designed in Sketch, exported as Scalable Vector Graphics, and embedded in the HTML-based mark-up files (see Figure 15). To allow users to colour pictorial trackers, tap and touch move event listeners were added to the tracker segments and the properties of the segments (e.g. colour and transparency) were bound to the tracker data model. The tracker data model had attributes, such as name, type, tracking parameters, and date of creation. To locally store instances of created trackers, the Ionic Storage wrapper was used. It is based on SQLite and helps developers permanently store key/value pairs written in JavaScript Object Notation format.



```
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132
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139     <defs></defs>
140     <g id="Page-1" stroke="none" stroke-width="1" fill="none" fill-rule="evenodd" sket
141     <g id="mandala-version-7-copy-6" sketch:type="MSArtboardGroup">
142
143         <path d="M59.1185271,4.2986577 C70.0742123,1.22133862 78.5397962,1.6411132
144             id="12" stroke="#313131" stroke-width="1.5" [attr.fill]="p.colors[23]"
145             (touchmove)="this.startColorBody(i, '23')" (touchend)="this.endColorBc
146         </path>
147
148         <path d="M24.2404765,24.5922895 C32.2491416,15.8353361 41.1766921,11.71861
149             id="11" stroke="#313131" stroke-width="1.5" [attr.fill]="p.colors[22]"
150             (touchmove)="this.startColorBody(i, '22')" (touchend)="this.endColorBc
151         </path>
152
153         <path d="M4.17385186,58.7893876 C6.87924835,48.4454614 13.1245699,38.73686
154             id="10" stroke="#313131" stroke-width="1.5" [attr.fill]="p.colors[21]"
155             (touchmove)="this.startColorBody(i, '21')" (touchend)="this.endColorBc
156         </path>
```

Figure 15. Example code of the Trackly implementation with the Ionic Framework

6.2.3.2 Creating Trackers

Users can choose from different types of trackers (see Figure 16). They could, for example, create day trackers, such as a text tracker to record thoughts, a time ring tracker to document fatigue, and a body shape tracker to document pain levels. Furthermore, they could add week trackers, such as a matrix to document habits or a mandala tracker to record their mood. Week trackers consist of seven segments which represent each day. Day trackers consist of seven tracker visualisations: one for each day. Users can choose from six different types of trackers: (1) a text tracker; (2) a time ring tracker that represents 24 hours, (3) two versions of a body shape tracker, one with rounded and one with angular edges; (4) a matrix that can be thought of as a table; (5) origami trackers in the form of a dinosaur and hare; and (6) two mandala trackers, namely a flower and rainbow. The selection of the pictorial trackers was inspired by an analysis of commonly used bullet journaling trackers (see chapter 4) and in line with approaches described in prior studies of people with MS (see chapter 3).

Being able to create and delete multiple trackers is an important feature that is based on best practices we have identified in MS self-care: for example, documenting symptoms and then recording things people liked helped to end the day on a positive note.

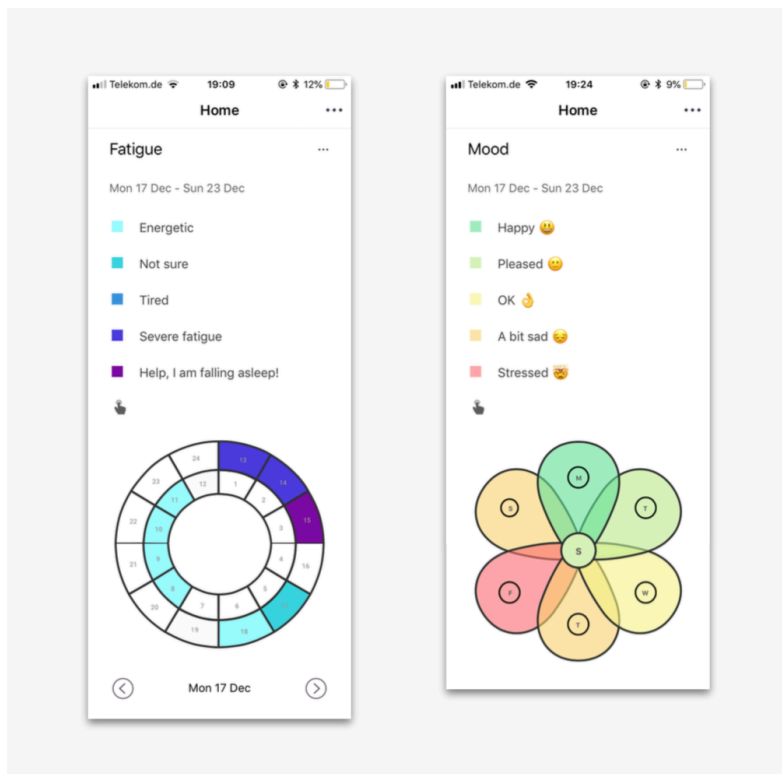
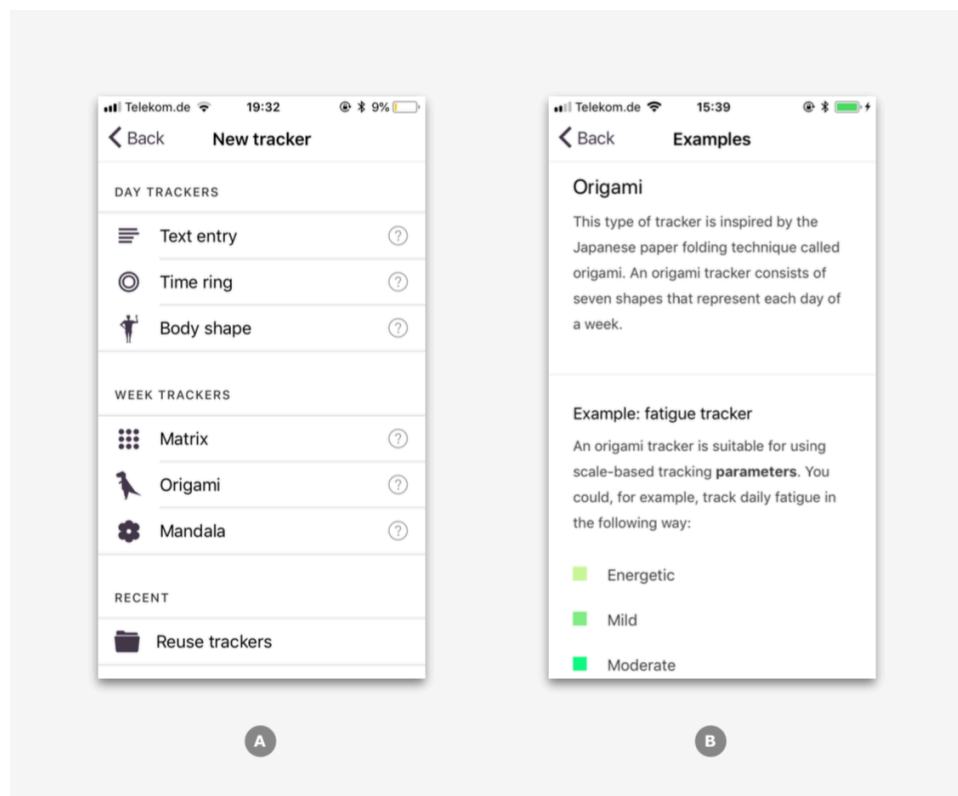


Figure 16. Technology probe: pictorial trackers (time ring and mandala)

Since participants of the interview study revealed that self-tracking in MS self-care can require initial scaffolding, users can learn more about the different types of trackers and how to create tracking parameters by tapping on the question marks (see Figure 17). Each page provides a general description and example trackers which were based on the findings of the interview study including people with MS who, amongst other things, kept track of fatigue levels. The technology probe offers a set of predefined colour schemes, since creating distinct and balanced colour schemes is challenging. Future versions of the technology probe should allow users to mix and add custom colour schemes. Custom parameters can be assigned to a selected colour scheme. Users can enter text and add emojis. Parameters could, for example, represent a scale (e.g. good, OK, bad) or different activities (e.g. walking, swimming, running).



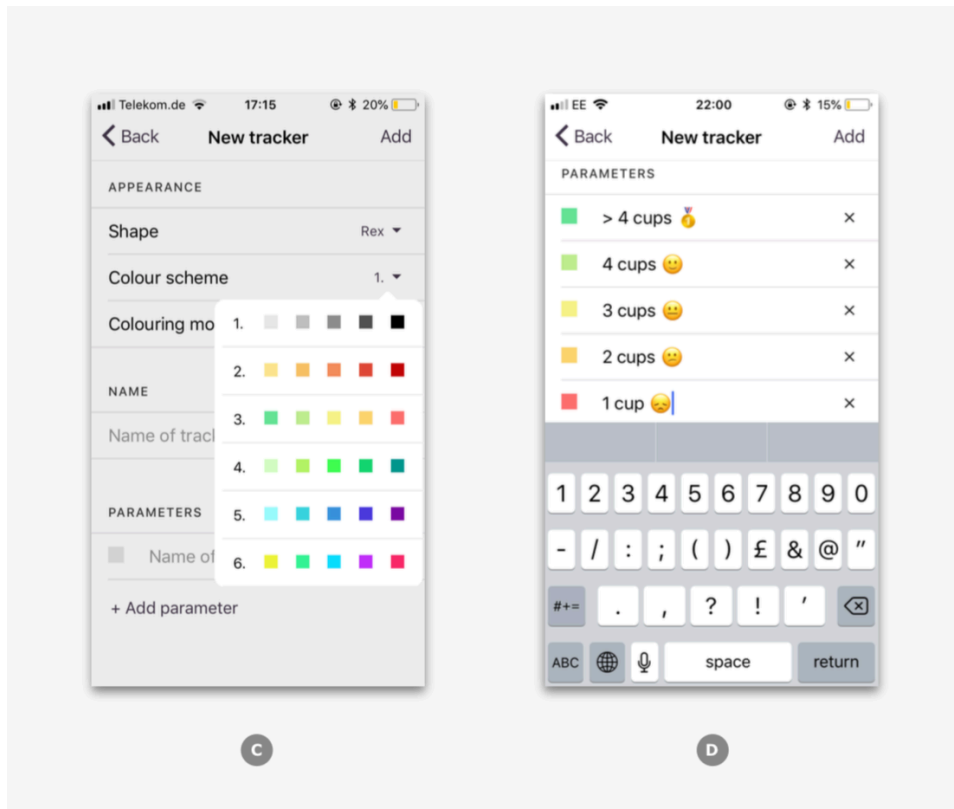


Figure 17. Technology probe screens (A-D): creating trackers

6.2.3.3 Colouring Trackers

The technology probe offers two colouring modes (see Figure 18): tap and touch move. When implementing both colouring modes, our goal was not to imitate the experience of colouring paper notebooks but to implement interactions that feel comfortable despite the limited screen estate of mobile devices. To achieve this, we have implemented the following mechanism (see Figure 19): when users have touched a segment they wish to colour and do not stop touching the screen, they can also leave the selected segment during the touch move colouring gesture. To delete a coloured segment, users can tap on a coloured segment. This works for both colouring modes. A hint will explain the selected colouring mode, only when users tap on a blank segment the first time.

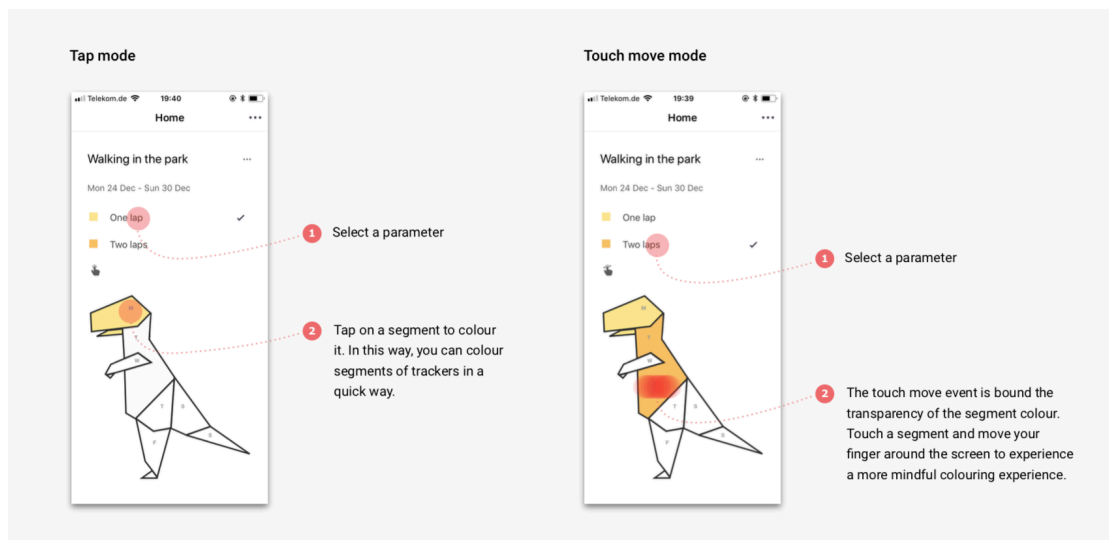


Figure 18. Technology probe screens: colouring modes

```

EXPLORER
  OPEN EDITORS
  MYAPP (WORKSPACE)
    resources
      src
        app
        assets
        components
          graph
            graph.html
            graph.scss
            graph.ts
          matrix
          origami
            origami.html
            origami.scss
            origami.ts
            textual
            textual.html
            textual.scss
            textual.ts
            components.module.ts
          directives
          pages
            add-tracker
            add-tracker.html
            add-tracker.module.ts
  222
  223
  224
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  246

// Double ckeck colouring mode
if (this.t.mode === "touch move") {

// User is colouring a segment
this.colouringOn = true;

// Check whether colour is selected
if (this.currentColor) {

// Increase opacity
this.opacity++;

// Slow down effect based on touch move event
let slowDown = this.opacity * 0.008;

// Make sure that user is not just scrolling
if (slowDown > 0.06) {

// Emit event do freeze scrolling pane
this.interactionWithShape.emit("on");

// Set segment colour
this.t.shapeColors[+day].colors[+shape] = this.currentColor;

```

Figure 19. Implementation code extract: touch colouring mode

6.2.3.4 Exploring Data

Users can explore all the data that they logged (see Figure 20). The exploration view is initially blank and allows users to add and delete data of the different types of trackers they created in the past. Users could, for example, view mood data that was logged with mandala trackers. Considering potential limitations of making sense of data visualisations on mobile devices (Katz et al. 2018; B. Lee et al. 2018), users can receive PDF reports of their tracking data, that they can view on larger screens. Since previous studies have described how people stick printable templates into their notebooks and how they intertwine data from different tracking devices with their paper journaling activities (see chapter 3 and 4), the reports can also be used as materials for creative

data practices: printed reports can be cut, rearranged, and annotated and become part of mindful and reflective design activities.

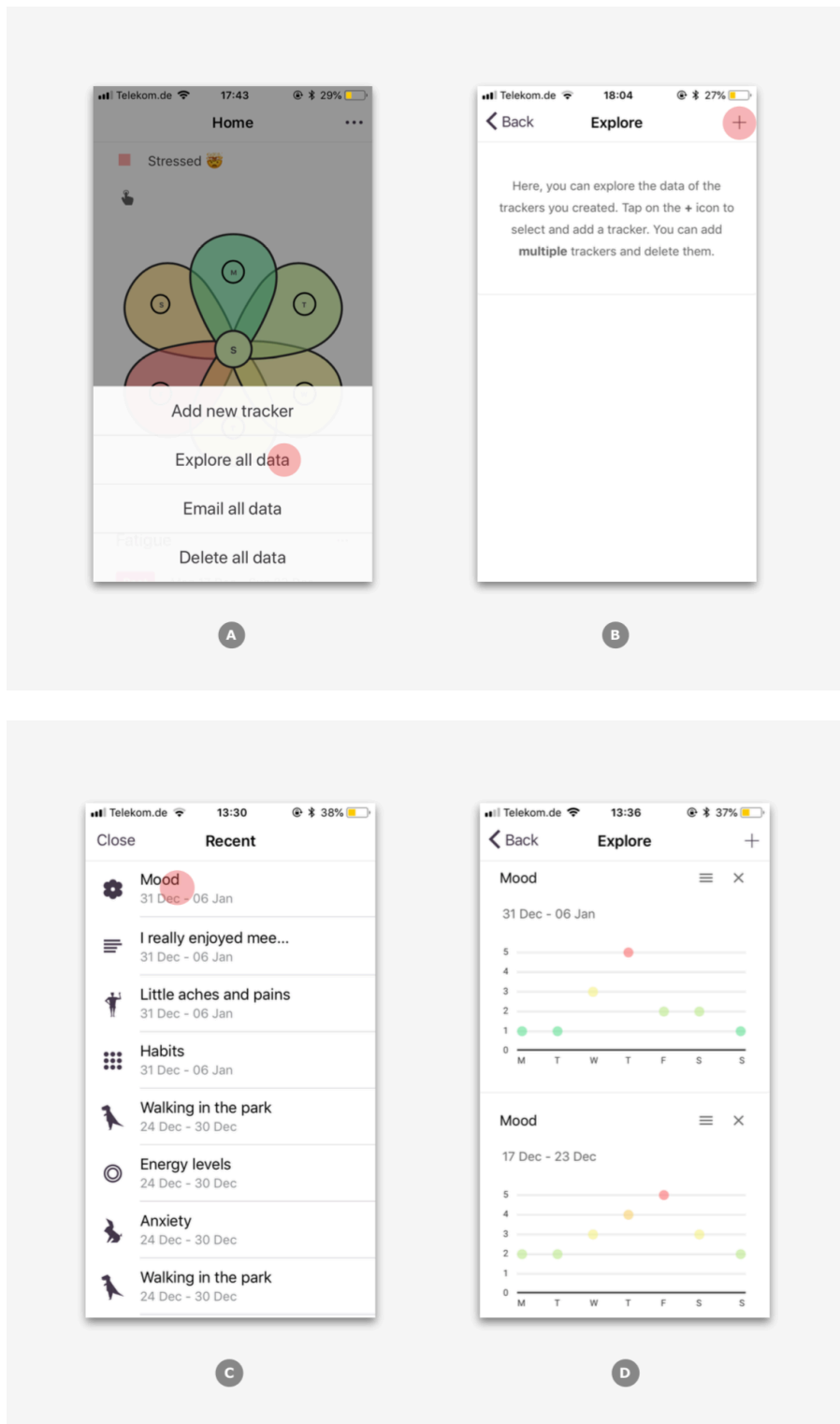


Figure 20. Technology probe screens (A-D): exploring data

6.2.4 Expert-Based Evaluation

The technology probe was evaluated through two informal evaluation cycles to identify usability issues and conduct a “health check,” before sharing the technology probe with people living with MS.

6.2.4.1 Data Collection and Analysis

The leading researcher recruited friends and colleagues in person at the UCL Interaction Centre in London. Participants were PhD students and post-doctoral research fellows and had a background in HCI. As part of their profession they investigated how people use technologies and how technologies could be designed to support people’s needs in different domains, such as health and wellbeing, collaborative work, and workplace productivity. The feedback sessions were conducted in an ad-hoc and rapid fashion according to an iterative and rapid design and implementation process. During feedback sessions participants installed the technology probe on their own device and then freely explored it while thinking aloud. The leading researcher took an observational role and jotted down notes of critical incidents. Notes were summarised according to main steps and functionalities, including installing the technology probe, creating pictorial trackers, and colouring in segments of pictorial trackers.

	Gender	Profession
P1	Female	PhD student
P2	Female	Research fellow
P3	Male	Research fellow
P4	Female	PhD student
P5	Female	PhD student

	Gender	Profession
P6	Male	PhD student
P7	Male	PhD student
P8	Female	Research fellow
P9	Female	PhD student
P10	Female	PhD student

Table 7. Technology Probe feedback sessions: participant details

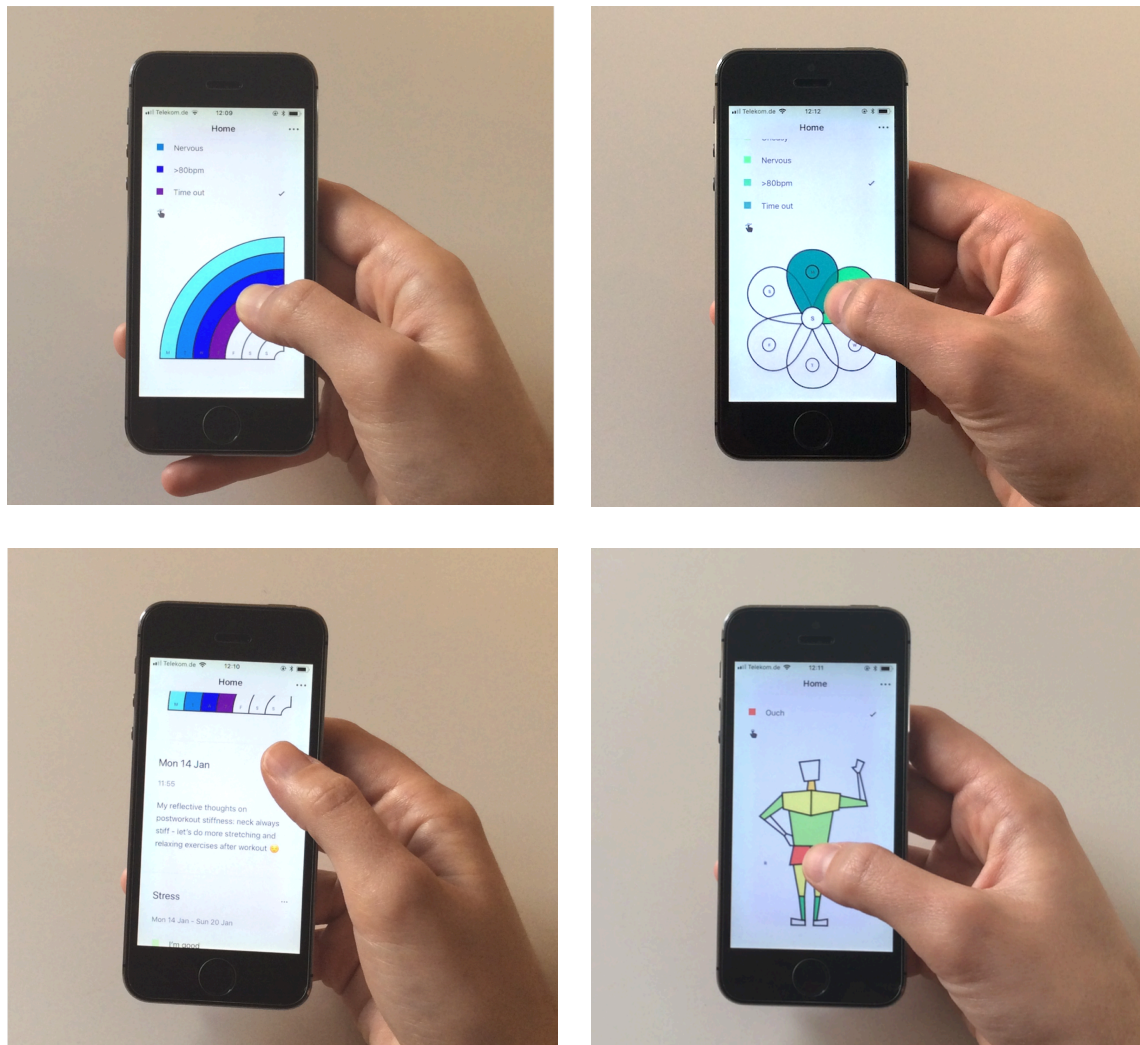


Figure 21. Technology probe screens: participant interacting with Trackly

6.2.4.2 *Installing the Technology Probe*

Participants who owned an iPhone had to install Apple TestFlight, which is a service that helps developers to test apps with users. Once TestFlight was installed, participants installed the technology probe with an installation link that we shared via email. Most participants managed to install the technology probe via Apple TestFlight on their own. Android users needed to make sure that third-party apps were allowed on their device, before they could install the technology probe. Given the variety of Android devices and versions of the operation system, participants had to go to “Security” or “Security and Privacy” or “Lock Screen and Security” or “Advanced Settings”, which caused confusion. When opening the installation link, Android users were, furthermore, confronted with the following message: “This type of file can harm your device. Do you want to keep trackly-

v014.apk anyway?” One participant wished to receive reassurance from the researcher that the file is not harmful. These findings suggest that the installation of the technology probe can be facilitated by offering clear instructions and explanations.

6.2.4.3 *Creating Pictorial Trackers*

The concept of defining custom tracking parameters was well perceived and participants created a wide range of different trackers (e.g. body shape to track hunger and a mandala to log post-workout stiffness). In doing so, participants made the following suggestions which we implemented after the first evaluation cycle: showing newly created trackers at the top of the trackers list, instead of at the end; defining the appearance of trackers (e.g. scheme colour) before defining the parameters; and being able to edit and hide existing trackers. Furthermore, participants sought different levels of scaffolding when creating trackers. Some participants did not realise that the technology probe offers example pages for inspiration and applied a trial and error approach. Others tapped on each question mark chronologically or switched between viewing the examples and creating trackers. These observations suggest that customisation can require tailored scaffolding and multiple entry points.

6.2.4.4 *Colouring Pictorial Trackers*

After implementing hints (see section Colouring trackers), participants seemed to more quickly appropriate how to colour tracker segments. The tap mode was described as effortless and particularly suitable for “lazy people” (P7). When using the touch move mode, participants mindfully observed colour changes while varying the speed of their touch movements. They characterised the use as “straightforward” (P6), “playful” (P8), and “satisfying” (P10). Two participants wished the colouring experience to be more natural by offering, for example, different brushes. During the evaluation sessions, participants identified some segments of tracker visualisations that had a limited target area, which we afterwards increased.

6.3 Discussion

We identified the need for customisable self-tracking approaches in MS self-management (see chapter 3). However, it was not clear how digital technologies could be designed to support people's agency in adapting self-tracking systems to their individual self-care needs. Through an investigation of paper bullet journaling, a customisable and pictorial journaling approach, we identified design strategies to support the self-tracking needs in MS (see chapter 3 and chapter 4). In this chapter, we draw on paper bullet journals as inspirational resources and iteratively designed Trackly, a technology probe that realises a customisable and pictorial self-tracking approach. Our intention in developing a technology probe was not to imitate or replace paper journaling practices, but to explore how we could translate the concept of bullet journaling to the digital realm to investigate a novel self-tracking approach that centres on people's individual self-care needs and agency.

Previous research has explored different customisable self-tracking techniques on mobile devices. For example, the mobile application Tag-It-Yourself supports manual self-tracking and tagging of multimedia data, such as photos (Storni 2013). The flexible self-tracking application OmniTrack allows users to create custom trackers (Y.-H. Kim et al. 2017a): users can combine existing user interface controls, such as buttons and date controls, connect their trackers to automatically recorded data services, such as Fitbit, and reflect on their data by examining different types of data visualisations, such as bar and line charts. Notably, people have different data collection and visualisation preferences. There are not only "*numbers people*" who have a preference for numeric reporting tools but also individuals who prefer interfaces that support pictorial and qualitative self-tracking styles (P. Adams et al. 2017). The tablet-based application called DataSelfie aims to empower people to create their own "*personal visuals to represent their data*" (N. W. Kim et al. 2019). Using DataSelfie people can create a questionnaire, draw visual representations, such as geometric shapes, to assign them to questionnaire options, fill out and submit the questionnaire, and view the generated visuals that represent the responses.

The design of Trackly realises a customisable and pictorial self-tracking approach that supports people in choosing from a set of different types of pictorial trackers, define custom tracking parameters, and log data by colouring in pictorial trackers by touch. It seemed reasonable to reduce the complexity of supporting participants in creating custom pictorial trackers, since it was unclear whether people wish to select from a

broader range of different types of pictorial trackers, adapt existing trackers, or even create custom pictorial trackers from scratch.

Involving people living with MS in the design of the technology probe was unfortunately not feasible at this stage. Based on our experience with the interview study, we were mindful of the practical challenges of recruiting participants living with MS. While two of sixteen participants decided to conduct the interview in person, most preferred to take part remotely. Based on this observation, we realised that it would be important to allow people to engage with a self-tracking technology probe in their natural environment. Hence, we implemented Trackly using the Ionic framework (Ionic 2019) to support both Android and iOS users and iteratively evaluated the technology probe through two informal evaluation cycles with overall ten HCI PhD students and researchers. We decided to conduct expert-based evaluation sessions at this stage to conduct a “*health check*” before running a field study and sharing Trackly with people living with MS.

6.4 Conclusion

This chapter has illustrated the iterative design and expert-based evaluation of Trackly, a technology probe that implements a customisable and pictorial self-tracking approach. The technology probe aims to support people in documenting their health and wellbeing with the help of pictorial tracker visualisations that they can define and colour in by touch. The expert-based evaluation helped identify bugs and improve the usability of the technology probe, so it can be used by people living with MS on their own mobile devices in their natural environment. We found that the technology probe worked on different mobile devices and operating systems (Apple iOS and Android) and that participants successfully created and coloured different types of pictorial trackers. However, the installation and use of the technology probe require different forms and levels of assistance. This can be, for example, a how-to guide with clear instructions of how to install the technology probe and inspirational examples of how to create and colour pictorial trackers.

7 Use and Experience of Trackly in Multiple Sclerosis Self-Care: A Field Study

Parts of this chapter have been published as a paper in the Proceedings of the 2020 CHI Conference on Human Factors in Computing Systems (Ayobi, Marshall, and Cox 2020).

7.1 Introduction

Human-centred research has highlighted the importance of understanding and supporting the individual needs of people who engage in self-tracking (Cosley et al. 2017). This thesis aims to investigate how technologies could support the individual needs of people living with multiple sclerosis in self-tracking their health and wellbeing. Interview participants reported that predefined symptom applications can encourage the documentation of symptoms they do not have, and that goal settings and graphs of fitness wearables can cause “*pointless pressure*” (see chapter 3). As recent research has underscored, people with MS wish to be able to flexibly use and personalise self-tracking applications according to their individual and changing profile of physical, cognitive, and mental impairments (Wendrich et al. 2019).

Our findings highlighted three interrelated self-tracking needs to support agency in MS self-care: (1) receiving scaffolding when engaging in self-tracking; (2) being able to customise the topic, content, and timing of self-tracking; and (3) experiencing positive affect when self-tracking. Based on this understanding, we identified the ways in which these self-tracking needs could be realised by drawing on a customisable self-tracking approach based on bullet journaling design patterns and strategies: (1) offer examples of pictorial trackers to provide inspiration; (2) empower people to customise their pictorial trackers according to their individual self-care need; and (3) support people in flexibly colouring in and viewing their pictorial trackers.

The previous chapter has illustrated the iterative design of Trackly, a technology probe that realises a customisable and pictorial self-tracking approach. This chapter presents the findings of a four-week field study of Trackly in MS self-management. We found that participants utilised the elements of Trackly designed to support agentic behaviour: they defined personally meaningful tracking parameters in their own words, and particularly valued being able to flexibly colour in and make sense of their pictorial trackers. Having been able to support their individual self-care intentions with Trackly, participants reported a spectrum of interrelated experiences of agency. Furthermore,

participants described challenges, such as remembering to log data, tracking when experiencing increased severity of symptoms, and making sense of changing symptoms. These findings demonstrate the importance of supporting people’s individual self-care needs and experiences of agency to foster mindful and personally meaningful engagement with their health and wellbeing data.

7.2 Method

We conducted a four-week field study and follow-up interviews with 14 people diagnosed with MS to investigate their lived experiences of using Trackly.

7.2.1 Participants

We recruited participants with the help of online communities and MS charities. Inclusion criteria were that participants must have a MS diagnosis and own a smartphone. In total, 16 participants signed up for the study. Four participants had taken part in our interview study (see chapter 3). Two left the study within the first week: one because of a lack of time and another because of physical impairments that made interacting with a mobile device difficult. Overall, 14 people with diverse backgrounds completed the study. 11 were diagnosed with relapsing remitting MS, two with primary progressive MS, and one with secondary progressive MS. Among our participants, 11 were female and three male (there is a 3:1 prevalence ratio of women to men with MS (Embrey 2014)). 11 participants had prior experience with paper-based tracking and eight had used consumer health technologies, such as fitness wearables. All participants took part in the study voluntarily without receiving any financial incentives.

	Gender	Type of MS	Yrs. Since diagnosis		Gender	Type of MS	Yrs. Since diagnosis
P1	Female	Relapsing remitting	Unclear	P8	Female	Relapsing remitting	Unclear
P2	Female	Relapsing remitting	3	P9	Female	Primary progressive	4
P3	Female	Relapsing remitting	5	P10	Female	Relapsing remitting	3
P4	Male	Secondary progressive	1	P11	Female	Primary progressive	18
P5	Female	Relapsing remitting	5	P12	Male	Relapsing remitting	10
P6	Female	Relapsing remitting	8	P13	Female	Relapsing remitting	10
P7	Female	Relapsing remitting	2	P14	Male	Relapsing remitting	Unclear

Table 8. Technology probe field study: participant details

7.2.2 Data Collection and Analysis

In the beginning of the field study, participants received a how-to guide which detailed how to install the Android APK file or use Apple TestFlight (see Figure 22-24). It also included descriptions and examples of the different types of trackers and encouraged participants to track what was important to them. We sent weekly emails to participants to ask them to share their data with the research team. All 14 participants decided to share their logged data and 13 took part in the follow-up interview. Before conducting an interview, we shared a summary of the logged data with participants, which included all the pictorial trackers the participant created. The summary helped guide the interview questions which focused on the overall experience, self-tracking intentions, perceived benefits and limitations, visualisation preferences, data sharing, and the use of other self-tracking tools. Eleven interviews were conducted by video conference and two over the phone.

Data analysis started after the first interview. We used the qualitative data analysis software *NVivo* to transcribe the audio recordings and thematically code data (Braun and Clarke 2006). The data corpus was iteratively analysed in an inductive fashion drawing on open and axial coding. We initially focused on the individual experience of each participant and, at later stages, used *Python* to visualise the technology probe log data to support axial coding. This helped understand differences in participants' intentions, self-tracking content, and the temporality of colouring. Visualisation and annotation of the log data, moreover, supported the discussion of interview themes within the research team.

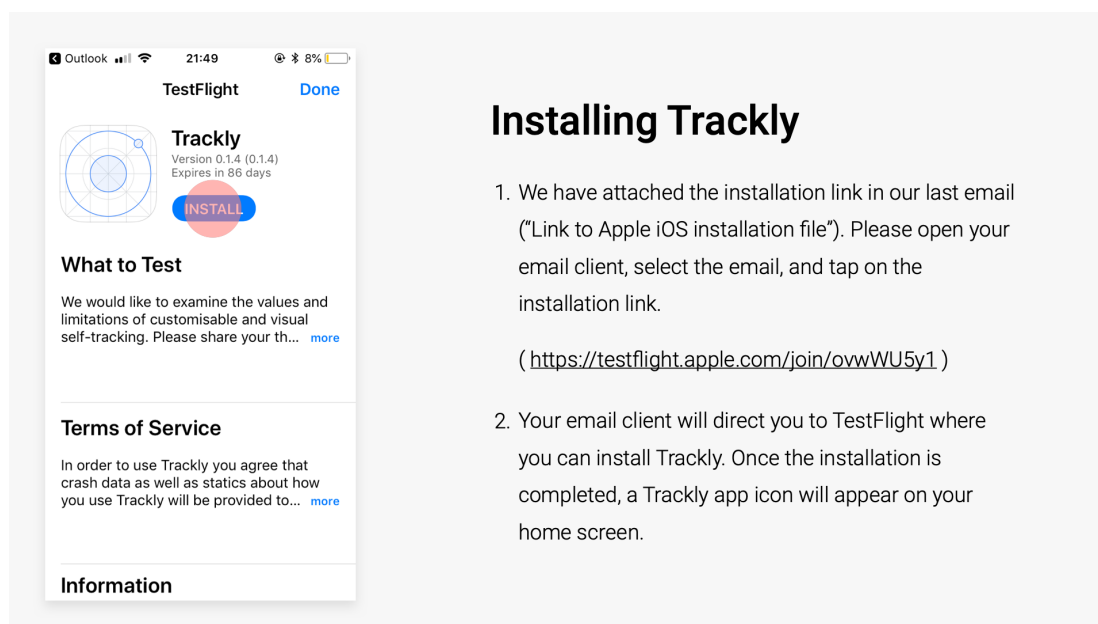
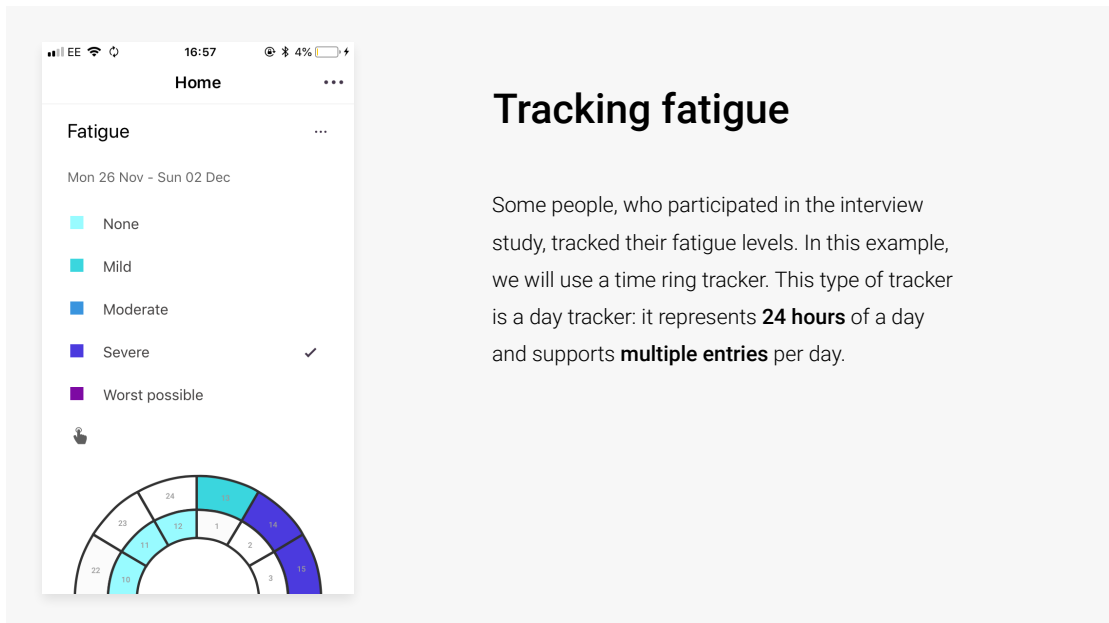


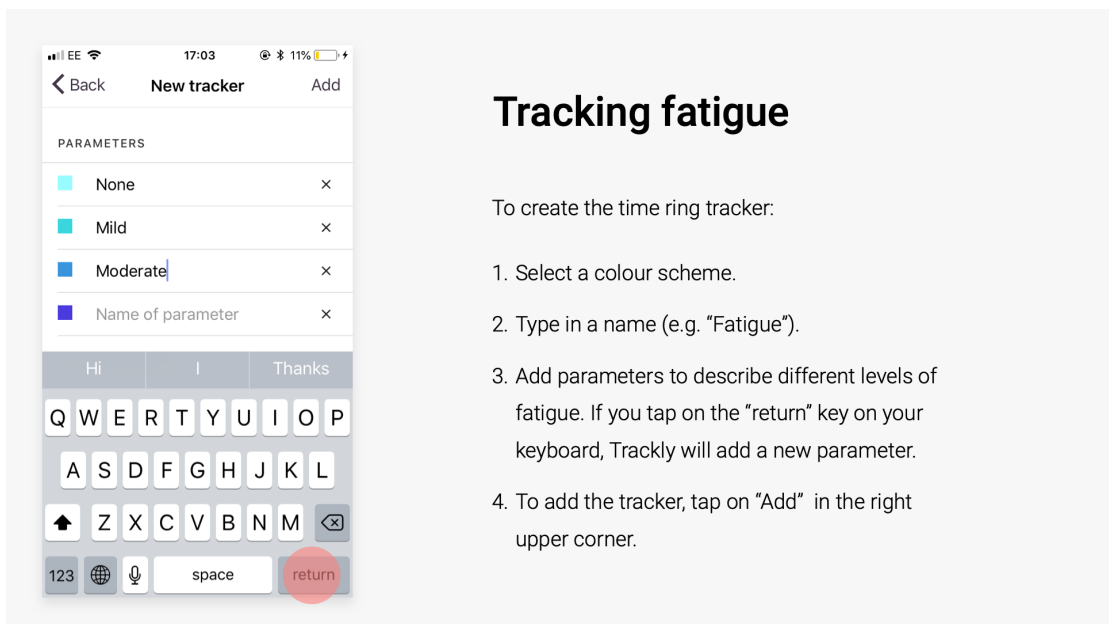
Figure 22. How-to guide: instructions on how to install Trackly



Tracking fatigue

Some people, who participated in the interview study, tracked their fatigue levels. In this example, we will use a time ring tracker. This type of tracker is a day tracker: it represents **24 hours** of a day and supports **multiple entries** per day.

Figure 23. How-to guide: instructions on how to create a fatigue tracker



Tracking fatigue

To create the time ring tracker:

1. Select a colour scheme.
2. Type in a name (e.g. "Fatigue").
3. Add parameters to describe different levels of fatigue. If you tap on the "return" key on your keyboard, Trackly will add a new parameter.
4. To add the tracker, tap on "Add" in the right upper corner.

Figure 24. How-to guide: instructions on how to create tracking parameters

7.3 Findings

Participants' accounts demonstrate that Trackly supported both agentic behaviour and experiences of agency. They particularly valued being able to use their own words in defining tracking parameters, and flexibly colour in and make sense of their pictorial trackers. They defined and coloured personally meaningful pictorial trackers to document their health and wellbeing in holistic ways, including their symptoms, daily activities, and mental health. Having been able to adapt the use of Trackly to their individual self-care intentions and emotional preferences, participants reported a spectrum of interrelated experiences of agency, including ownership, identity, self-awareness, mindfulness, and control. However, participants also described challenges, such as remembering to log data, tracking when experiencing increased severity of symptoms, and making sense of changing symptoms.

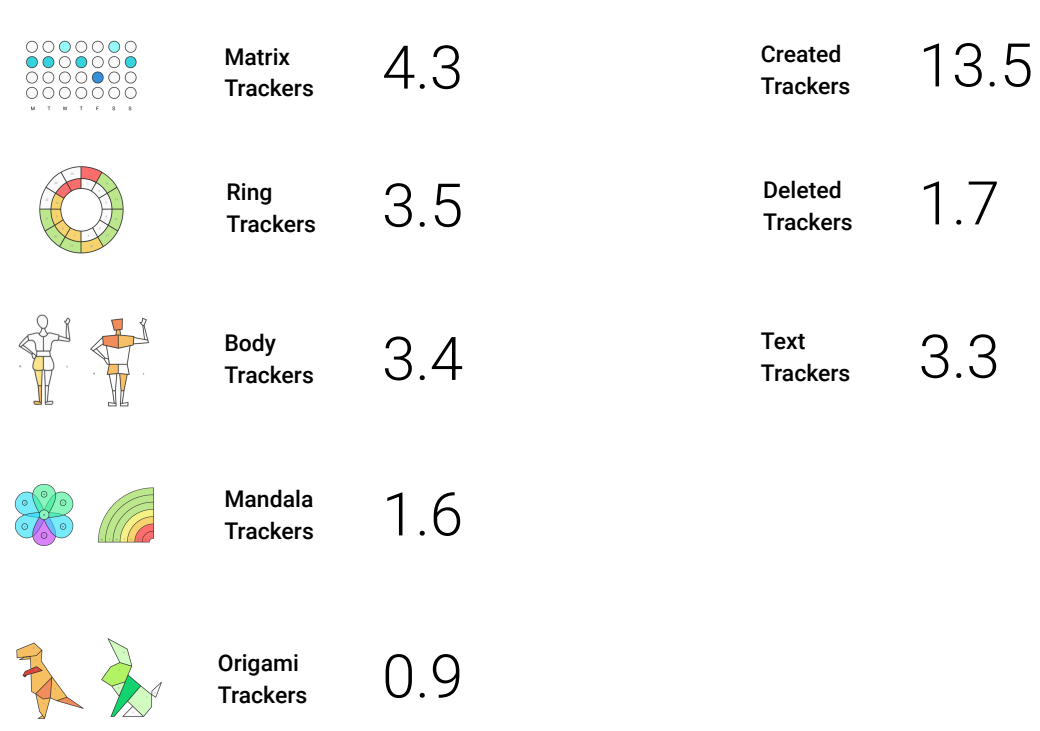


Figure 25. Logging data: each participant created 4.3 matrix trackers on average



Figure 26. Participant report: healthy eating

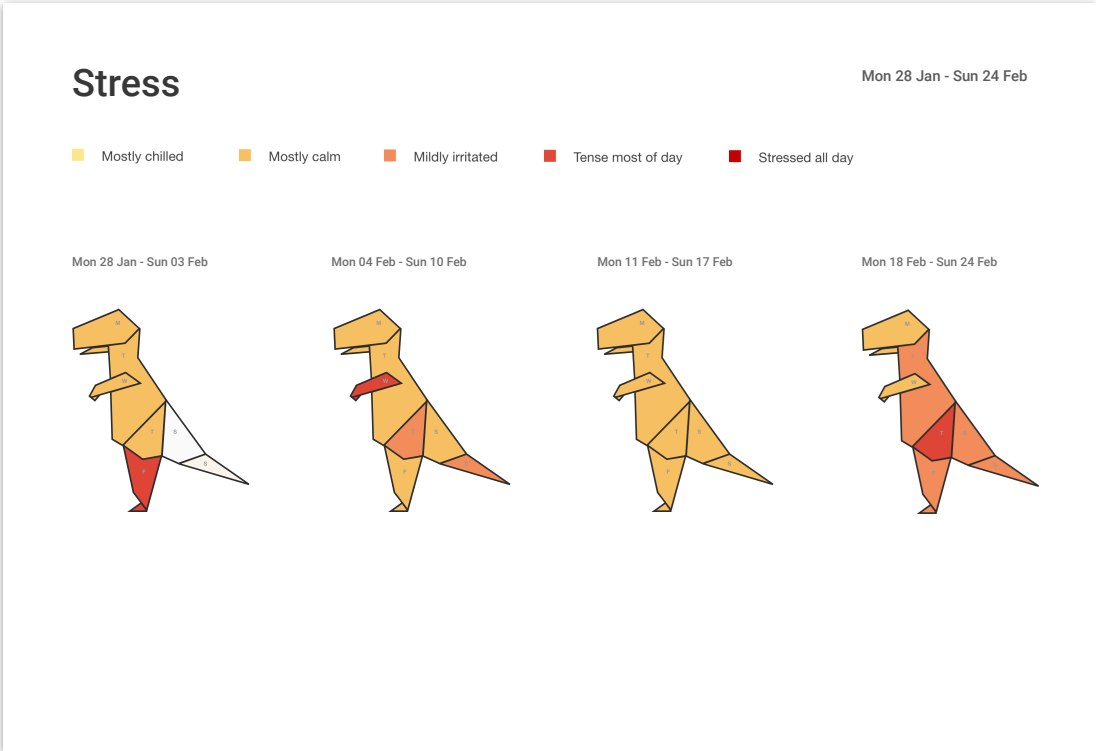


Figure 27. Participant report: stress



Figure 28. Participant report: mood

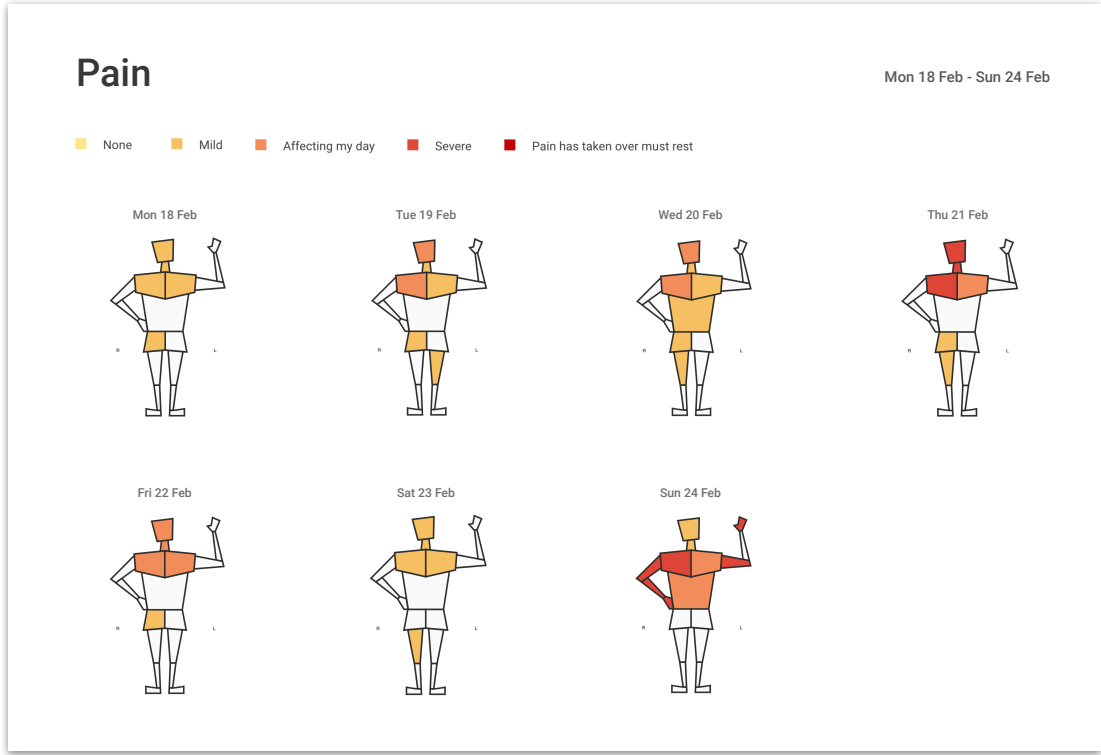


Figure 29: Participant report: pain



Figure 30: Participant report: fatigue

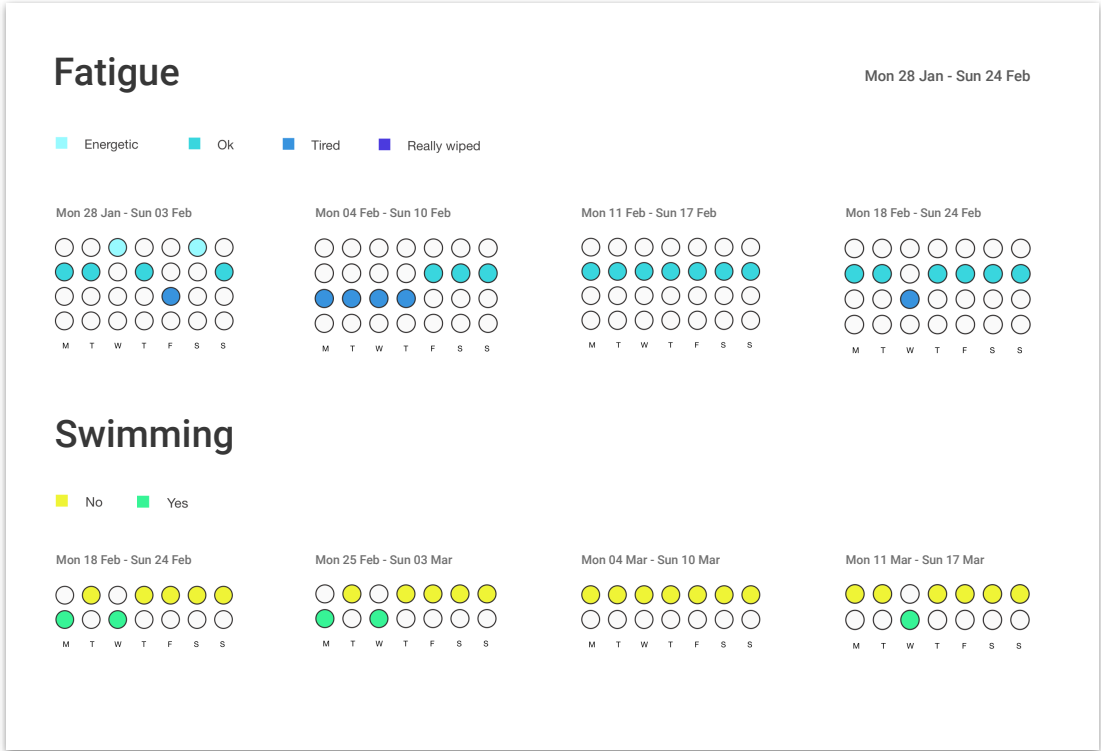


Figure 31. Participant report: fatigue and swimming

7.3.1 Agency and Engagement

Participants utilised the agency supportive aspects of Trackly by adapting trackers to their individual needs: in particular, they engaged in reflective thinking when defining trackers based on their individual self-care intentions and described the reuse and adaptation of trackers as an on-going learning process. They particularly valued being able to retrospectively colour in trackers and intentionally engaged in and paused self-tracking in response to their changing priorities in everyday life (see Figure 32-34).

7.3.1.1 Immediate and Retrospective

Participants created text entries and filled in trackers for 23 days on average (min 5 days; median 27.5 days; max 28 days). However, there is a numeric difference between the total days tracked and the number of days of active use as, whilst 47% of all tap colouring interactions were performed on-time, 53% were completed retrospectively. (We counted logging as on-time if the time stamp of the colouring interaction matched with the corresponding day of the coloured pictorial tracker.) During the 28 days study, participants actively used Trackly on an average of 13 days (min 4 days; median 11.5 days; max 27 days). Active use included adding textual and pictorial trackers, colouring pictorial trackers, and opening the 'help' and 'explore' views. Two participants tracked all their data on-time; three tracked more on-time than in retrospect; and nine tracked more retrospectively than on-time.

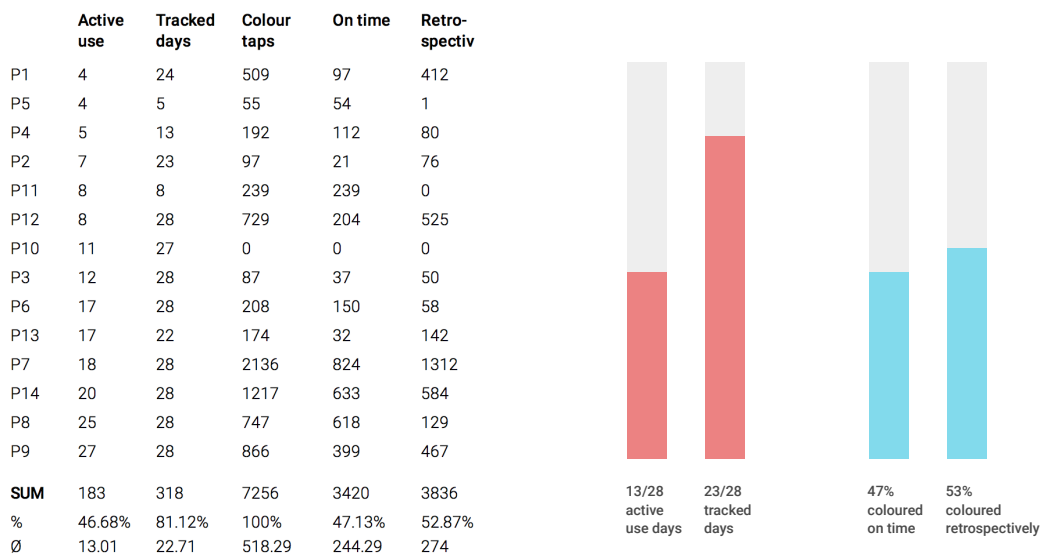


Figure 32. Logging data: user interactions for each participant. P10 created only text trackers.



Figure 33. Logging data: example of one participant who tracked all data on-time

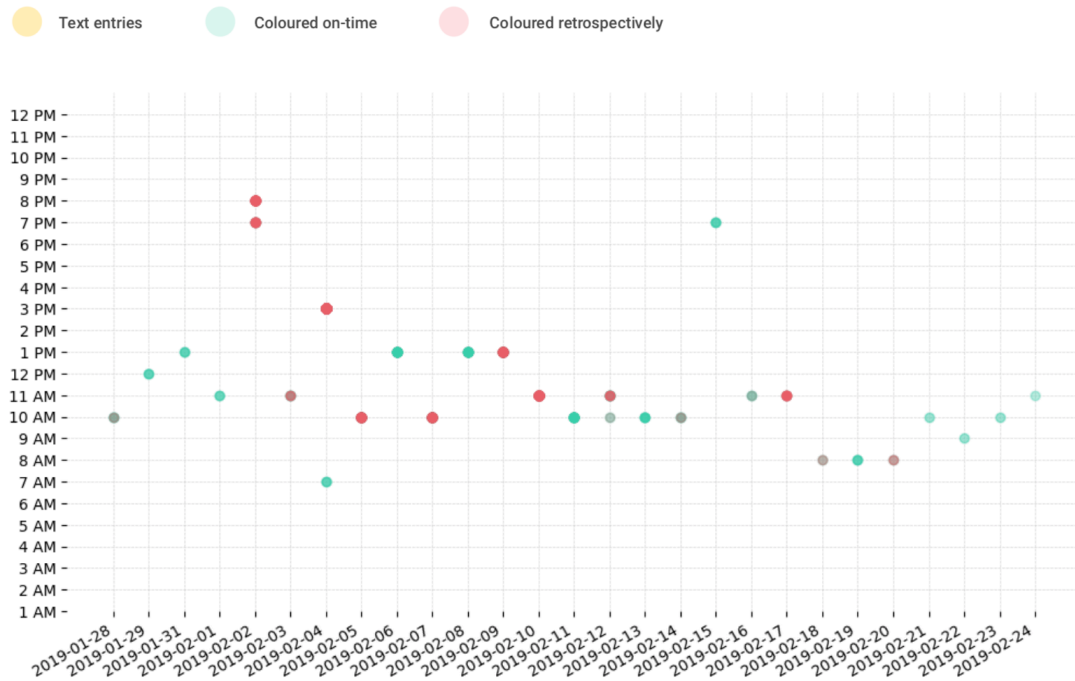


Figure 34. Logging data: example of one participant who tracked data on-time and in retrospect (multiple use per hour intensifies colour display)

Participants' engagement depended on tracking content and scope. For example, the four participants, who used Trackly fewer than eight days, solely focused on documenting the onset of their symptoms, whereas participants with more than eleven days of active use, tracked not only their symptoms but also their moods and daily activities. Participants engaged in retrospective styles of tracking when checking and correcting entries to improve the accuracy of their documentation, given that the severity and perception of symptoms may change. They back filled trackers not only when they simply forgot, but also when they experienced relapsing symptoms and, therefore, mentally and physically were not able to log their health and wellbeing. For example, P9 reported colouring in trackers and creating summaries with text entries of her symptoms after going through periods of severe numbness.

"Basically, for me, your hands are being freezing cold and not having the sensation of touch or anything. So, it's very difficult for me to say for instance go on a phone and click, click. [...] The numbness only last to for 24 or 48 hours of the most. So, I have to choose things, right, this is priority, this is less of priority."

We see that pausing self-tracking was situation-dependent and a conscious decision, where participants prioritised to engage in everyday living rather than documenting it. For example, to minimise engagement, P11 decided to exclude parameters, such as "no numbness", when she defined scale-based tracking parameters, and P6 created parameters, such as "no headache" but decided to colour in only the days she experienced headache. Importantly, participants associated disengagement in the form of pausing self-tracking with positive experiences, such as maintaining a productive lifestyle, quality time with friends and family, and symptom free periods. For example, P1 explained her lapsing with improved wellbeing:

"At first, I was good in completing them but then as the week went on, I did get more lapsed at completing them, I guess. I was probably feeling a lot better."

7.3.1.2 *Intentional and Reflective*

Participants reported creating custom and pictorial trackers based on their individual self-care intentions, which involved: (1) understanding the progression and trends of symptoms; (2) identifying patterns between symptoms and their daily self-care activities; (3) maintaining self-care activities, such as pursuing a physically activate life style and good nutritional practices; (4) managing energy levels in everyday life by balancing

physical activities and resting; (5) investigating and minimising side effects of medications; (6) pursuing positive mental health to cope with the uncertain nature of the condition; (7) supporting collaborative self-care activities with family members and caregivers; and (8) being able to remember and clearly articulate their health status and health history to inform clinical decision-making and improve treatment outcomes.

While participants, who primarily intended to document their health and wellbeing, created new trackers in an ad-hoc way, others, who aimed to gain a better understanding of the relationships between different aspects of their health, tended to create a set of trackers (e.g. fatigue and habits trackers) in the first week which they kept reusing and adapting until the end of the study. According to people's self-care intentions, we identified six content clusters of trackers (see Figure 35): symptoms (n=29); exercises (n=20); non-exercise activities (n=18); mental health (n=10); nutrition (n=9), and medical care (n=2). The most frequent symptom-related trackers comprised pain, followed by fatigue and pins and needles. The most frequently logged exercises included walking, gym activities, and running. Non-exercise activities comprised sleep, combinations of work and chores, and relaxing activities, such as chilling, napping, and reading. Mental health trackers displayed mood, stress, and anxiety levels. Most participants documented specific foods, such as vegetables, meats, and snacks with nutrition trackers, while one participant created a scale-based tracker to capture her healthy eating. Nutrition trackers included also fluid and water intake. Medical care trackers documented things like injection sites and electro-stimulation therapy.

Symptoms	29	Exercise	20	Non-Exercise Activities	18	Mental health	10
Symptoms	2	Exercise	4	Sleep	5	Mood	5
		Walking	3	Chill, Chilling	3	Stress	3
Pain	6	Gym	3	Work	2	Anxiety	2
Areas of pain	1	Running	2	Chores	1		
Shooting pain	1	Steps	1	Admin	1	Medical care	2
Lower back pain	1	Mat work	1	Work/chores	2	Electro-stimulation	1
		Stretching	1	Relaxing/hobbies	1	Injection sites	1
Fatigue	7	Cycling to work	1	Reading	1		
Energy levels	1	Exercise bike	1	Fun	1		
Pins and needles	2	Bouldering	1	Rest/nap	1		
Spasm	1	Swimming	1				
Bladder problems	1	Weights	1				
Eyes	1			Nutrition	9		
Stiffness	2			Selected foods (e.g. veg)	3		
Numbness	1			Healthy eating	1		
Headache	1			Fluid intake	3		
Defecation	1			Water	2		

Figure 35. Logging data: content of trackers

Defining personally meaningful parameters, in particular, made participants think and encouraged creative reflective thinking. Accounts of creative reflections referred to participants' self-care intentions, and how these intentions could be articulated and expressed with the given structure of the different types of trackers and their attributes. Participants described posing questions to support their reflective thinking and decision-making of what to track and how to create trackers. Questions covered not only the wording of tracker names and parameters but also participant's interest in understanding the progression of symptoms and potential relationships between symptoms, daily activities, and medication intake. For instance, P7 was wondering:

"Do I want to know how exercise helps manage my symptoms? Do I want to track I am exercising, or do I want to track what type of exercises I am doing?"

Participants, furthermore, described applying retrospective strategies, such as remembering and tracing back health histories. For P4 it was self-evident that he wanted to document his bodily pain to better support the planning of his daily activities. However, he explained that defining parameters required an iterative thought process of breaking down the topic area "pain" into different facets:

"Having to look at the trackers first [the example trackers] and looking to see what the trackers look like and then trying from there decide what topic area overall that would come under. And once it came under a topic area, trying to define what areas you wanted and then trying to break that down into the subsections of that topic."

Descriptions of introspective reflections referred to observations of emotional and mental states. These thoughts had self-directed, conversational, and evaluative characteristics. For example, P1 detailed how she phrased parameters that supported her in having a dialogue with herself by providing motivational and actionable suggestions (e.g. 'Yeah, I feel great, let's get on with it.'). She reported taking an introspective view, when she reflected on how to use symbolic emojis as visual cues to express her emotions and support her logging:

"I kind of sat there, like what kind of face would I be pulling? It was like a visual cue to what I would say and what face I would show. If I would be describing to someone, like my husband, or if I would say to myself: how has the healthy eating been today?"

Introspective thoughts centred not only on evaluations of emotional and mental states but also on how these self-evaluations fit with the design of trackers. For example, P7

made clear that creating tracking parameters and colouring in trackers “*was challenging, but in a good way*” since it made her question the meaning and, more importantly, better understand the meaning of her own tracking parameters (“*It’s also defining for yourself, what does it actually mean, which I not had thought about before.*”) Engaging in creative and introspective thinking, participants acknowledged the creation and adaptation of their pictorial trackers as an on-going learning process, as P3’s account indicates: “*I was using it more and more, and learning myself, it became easier and easier the more I did it.*” Learning involved iteratively exploring the different types of trackers, as exemplified by P10:

“I was just trying to test some water. Which ways would be better for me, write down text or use a pie chart [time ring tracker] or whatever, for me, the main one, I liked the most, was the segments that you write down the hours, and the picture of the body.”

P13 highlighted that realising that a certain configuration of trackers did not work as expected, was a necessity to adjust his tracking intentions and adapt his trackers on his self-tracking journey. Adaptations concerned both the type of tracker and tracking parameters. For example, P2 used one parameter for her pain tracker in the first two weeks logging her pain in a binary way. Having gained bodily awareness of her pain levels over time, she decided to create a scale to capture two different pain intensities (i.e. mild and moderate) and a temporal dimension (i.e. continuous).

7.3.2 Experiences of Agency

The previous section has described participant’s agentic capacities in adapting and adopting Trackly by describing their self-tracking intentions, reflective thinking and decision making in defining pictorial trackers, and their conscious engagement and disengagement with the technology probe. Based on this understanding, we describe how exercising their agency through engaging in self-care and using Trackly supported a spectrum of interrelated experiences of agency, including ownership, identity, self-awareness, mindfulness, and control.

7.3.2.1 Sense of Identity

Participants reported experiencing a sense of identity through creating personally meaningful collections of pictorial trackers that documented and represented essential aspects of their lives, such as mundane activities, feelings, and personal thoughts. For instance, P11 described recognising herself in and identifying with the visual record she created: “*It’s like a bigger picture, I suppose, a picture of me and what I am doing and when I am doing it.*”

With the use of their personal language, participants shaped and proactively personalised their own app experience in creative ways. Anatomical terminology (e.g. P7: *"Pain in my right rhomboid and trapezius significant."*) mirrored people's medically informed understanding, and MS specific terms revealed a shared language that is common in MS communities. For example, P9 described *"MS hug"* as a symptom that causes feelings of pain and pressure around the chest. Most of the text entries people authored were in stark contrast to the scientific terminology in medical assessments and health apps (Nunes and Fitzpatrick 2018). Participants created personally meaningful entries and expressed their own feelings and understanding of the world by employing a wide range of strategies. For example, two participants used their first names and initials to personalise their body shape trackers. Others created motivational appeals (P1: *"Feelin' fine! - Onwards!"*), combinations of adjectives (P6: *"awake but fussy"*), neologisms (P2: *"tears-in-my-eyes pain"*), metaphorical constructs (P10: *"foggy head"*), comparisons (P9: *"if somebody stood on you"*), contemporary and colloquial terms (P7: *"meh"*), and other personal descriptions (P3: *"funny feeling"*). Many parameters and reflections included emotional expressions of happiness, humour, sarcasm, and frustration, in textual and symbolic representations (P12: *"Went swimming, felt good but headache 🤔 playing up after exercise."*).

7.3.2.2 Sense of Ownership

Participants' feelings of ownership ensued their sense of identity. They appreciated being able to instantly self-track personally meaningful aspects of their health and wellbeing on their own mobile devices and reported experiencing a sense of ownership when recognising their efforts in fitting Trackly to their individual needs, daily practices, and their use of other health and wellbeing technologies. For example, P1 described the names of her trackers as *"my [her] own, kind of, handles"* that allowed her to quickly reach and colour her trackers. Her sense of ownership was evident when she compared Trackly with her Fitbit wearable device, highlighting that she is the one who proactively tailored Trackly and collected the data:

"I quite like that one [Fitbit] it kind of just works for me in the background, and one [Trackly] that I make the efforts to put the data in. Although it's not my app, it's my app by design, because I've defined what I want to track and how I want to track it."

P3's accounts of using Trackly illustrates the temporal and affective dimensions of experiencing a sense of ownership. She conveyed becoming confident using trackers over time, developed a positive attitude towards self-tracking, and eventually, missed using Trackly: *"I actually missed it, once I could not access it anymore. I do miss it."* These

expressions of ownership arose from the omnipresence of smartphones and participants' abilities to adapt Trackly to their individual self-care needs. For example, P1 participated in a fatigue management course and decided to log her fatigue levels with Trackly rather than with the provided paper notebook. For her being able to use her own smartphone had not only practical but also emotional benefits, such as avoiding stigma in public spaces:

"It just felt quite tedious in a notebook. You know, because I have to carry it around with me and then remember to write in it, whereas my phone, I am kind of, like everybody else. You know, I got 5 mins to wait for the train, I will be like, oh, I just have a look on the app and then just add a bit more detail."

Participants, furthermore, described how they embedded Trackly within their existing ecologies of self-tracking tools. For example, P7 detailed how she used Trackly in tandem with her paper bullet journal. Since she perceived manually drawing pictorial trackers as tedious, she preferred to fill in her time ring tracker with Trackly which she used as an *aide-memoire* when reflectively filling in her paper bullet journal at the end of the week.

7.3.2.3 Self-Awareness

Participants reported perceiving a sense of identity and ownership through defining personally meaningful trackers. They particularly valued using their own words in creating parameters and highlighted the pictorial features of trackers, which supported them in making sense of their data and gaining self-awareness.

P10 described MS as a *"crazy old world."* This allegorical comparison expresses the challenges participants experienced in gaining an awareness of their felt symptoms. They considered symptoms, such as anxiety and fatigue, difficult to describe, retrace, understand, and manage. For example, P4 perceived fatigue as counterintuitive, in particular, at times when waking up and being as much tired as before going to bed. For P3, it was *"quite tricky"* to realise the differences between feelings of tiredness caused by physical and mental workload and emerging fatigue symptoms that require rest.

Participants described similar challenges with understanding pain. For example, it was unclear to P2 why there is pain after ten minutes of walking, but cycling did not seem to be a problem at all.

Dealing with the challenges of understanding MS symptoms, participants described Trackly as a helpful *"visual tool"* (P9): the pictorial trackers supported them not only in logging data by colouring in segments but also in viewing and making sense of their logged health and wellbeing data in one view. They described pictorial trackers as *"a*

painted picture" (P2), *"a nice colourful picture"* (P10) and reported enjoying colouring in and making sense of their trackers. For example, P5 used a mandala tracker and expressed experiencing positive feelings when reading her trackers:

"Looking at flowers, it's interesting, and even the fatigue, I can read those very cheerily. It's very visual and it's very easy to see how it's all plotted out. I can see the rhythms going through the results. I find it more interesting to look at it, like the petals going around and the different colours. I can compare against them when I look back at how I felt each day."

The pictorial features of trackers provided a *"shortcut into thinking"* (P10) and an *"instant visual snapshot"* (P6), given that the colour schemes were *"almost like traffic lights"* (P1) that signalled the status of one's health and wellbeing. Similarly, P11 personified pictorial trackers and ascribed them the ability to tell and show the progression of her symptoms and moods: *"It is nice to have it visually, sort of, seeing. It actually tells you; it can actually show you the degrees of how things happened."*

P10, who also used a body shape tracker, revealed the temporal variability and the natural limitations of his reflective self-consciousness and described how the mindful engagement of self-evaluating feelings, colouring in segments, and viewing the pictorial trackers helped him to visualise and perceive his body as a whole:

"Sometimes you feel your leg more, sometimes your arm more. But you are not consciously aware of it. But seeing the entire map kind of makes you think, oh, actually, maybe, there is a little bit more of an issue over here than there. Because you are making that entry and then you are thinking of this part of your body more and then you're seeing the map as a whole, it, kind of, triggers your mind to see what going on."

Similarly, P2 reported gaining an improved bodily self-awareness. She assumed that her pain affected in particular the right side of her body. However, over the course of the study, she was able to *"be very clear"* about the locations of her pain: *"It has given me thought into where the pain is, rather than just saying it's everywhere, which I now don't."*

P9 referred to her rainbow tracker and underpinned the values of its pictorial nature by noting that being able to intuitively make sense of the visualised data supported her not only in becoming aware of the progression of her symptoms throughout the day but also in accepting and taking the changes of her symptoms seriously:

"So, it's good to know that this is happening to me, because it's more visual, because if you can't see it, with me, you don't believe it. You can actually see when you have actually reached the climax. You think to yourself and say stop, because it's sort of the colours on there, it's like an awareness."

In addition to the pictorial trackers, the exploration feature intended to support people in making sense of their data with the help of scatter plots. However, we found that only five participants sporadically used the exploration feature. Participants explained that the pictorial trackers supported a sufficient awareness of the collected data and anticipated that the exploration feature may become useful after a longer period of time to examine more substantial data sets.

7.3.2.4 Mindfulness

Participants reported gaining self-awareness through pictorially documenting their habits, moods, and symptoms. However, they also exposed the challenges of coping with the condition, which highlight self-tracking in MS self-care as a particularly delicate balance: they described worrying about missing a salient relapse, developing anxiety after experiencing a relapse, fearing the degenerative progression of the condition, and perceiving acute symptoms as a reminder of the condition. Remarkably, participants reported adapting Trackly in ways that supported mindful experiences: they described exercising emotional self-awareness and adapting the immediacy, temporality, granularity, and expressiveness of their custom and pictorial trackers to their emotional preferences.

Emotional self-awareness was essential in mindfully self-tracking symptoms. According to P7, it was important to become aware of and acknowledge how documenting different aspects of one's life can affect personal emotional wellbeing. She developed multiple strategies over time, such as linking symptom and habit trackers to focus attention to potential relationships and documenting established self-care activities to maintain positive thinking:

"And you feel better about yourself, when you can give yourself a little tick. So, I added the reading ones [trackers], I picked up my book or magazine, and then tick that one off, and felt a bit better about myself."

P8 reflected on the temporality of self-tracking stressing the importance of immediacy when logging symptoms: rather than recollecting and dwelling on past experiences, she preferred to instantly log and externalise felt symptom experiences. P1 explained that the granularity of tracking can, furthermore, help avoid potential negative affect. Rather than methodically logging the calories of each meal, she felt more comfortable to document her eating with a synoptic set of parameters (e.g. "OK! A bit of a mix"):

"I was kind of giving myself a daily overview. Because if I would do it meal per meal, it would be too much. It's a vicious cycle, I don't do that well, then I feel rubbish, then I eat

bad food, then I get more anxious. I think, if I was tracking that all precisely, it would have gotten me an anxious overdrive."

P5 found it "depressing" to solely document her symptoms with the SymTrack app. She reported being able to channel unhealthy thoughts with Trackly through documenting her mood and, at later stages, mindfully reflecting on her mood levels to reconstruct her symptom experiences:

"I find that quite good, because if I look at my mood, for example, over a week, I can from there extract back to my symptoms and I can think about what symptoms related to that. That's the contrast to SymTrack, where you had to start with your symptoms and then extract a leap from there up to your mood, whereas I find this [Trackly] for me a much healthier way of looking at how I cope with my MS."

Other participants, who deliberately logged their symptoms, reported that data suggesting an increased symptom severity did not necessarily lead to frustration: for some it helped overcome denial (e.g.: P6: *"It was important to acknowledge how bad the pain was, because it's too easy to just carry on."*), and for others logging symptoms helped regulate emotions and manage their self-care expectations. For example, P10 explained how he adopted alternative viewpoints when balancing his fatigue and physical activities:

"I haven't done x, y, and z, because I have no energy to do that, and then you kind of feel less guilty not actually being as active as you think you should be."

Considering the temporality of unmet goals and 'bad days' helped putting things into perspective and adopting positive outlooks. For example, P10 noted that weekly reflections on longer-term data were insightful *"because just because you had a bad week, does not mean that you had a bad month."* P7 revealed that she adopted the role of an outsider when analysing her record of self-tracked data to overcome bias and gain objectivity. A further strategy to mindful and positive engagement was expressive logging. Participants created text entries to document not only symptoms but also positive reflections (e.g. *"It made me smile. Yeah, I had a good day."*) and narratives of mundane activities, such as P2 who logged and appreciated her pain free bike rides.

7.3.2.5 Sense of Control

Experiences of identity, ownership, self-awareness and mindfulness related to experiences of control. This was in particular the case when participants realised and acknowledged customisable and pictorial self-tracking as a way of enacting their agency: which involved exercising control in deciding when and how to document their health and wellbeing, and in utilising their gained self-awareness in structuring self-care activities and impacting social interactions in everyday life.

The experiences of control participants reported gaining when engaging with Trackly were framed by their prior experiences with paper journaling and unmet needs with other self-tracking tools. They valued the flexibility of paper-based journaling highly because notebooks allowed them to document their specific symptoms in personally meaningful ways. P4 expressed being excited about Trackly's customisable and pictorial self-tracking approach: something that she has *"never seen before,"* something that has *"given me [her] the opportunity, and each individual, to track what they needed to track."* The ability to document personally meaningful aspects of their life supported not only feelings of identity but also experiences of control. For example, P8 explained that numeric self-monitoring can be initially meaningless, whereas customisation allowed intentional exertion of control in adapting and adopting the design of trackers to personal needs:

"You are taking more control about how you want to record things, and I think that if you start using boxes and you are trying to rate, for example, pain on a one to ten scale, its arbitrary for the point of noting stuff down, but I am not sure what value that number necessarily is. I like the freer form idea of Trackly, also, to design your own trackers, and that's nice."

Participants' descriptions of experiencing control illustrate how they proactively exercised control in the form of utilising their gained self-awareness in structuring self-care activities, including adjusting medication to symptoms and balancing physical activities and fatigue levels. For example, P4 explained that, similar to people with diabetes who measure their blood glucose levels, he also needs to document his constantly changing health status to adjust and achieve his daily goals:

"It helps you to plan and try to adjust to what you are able to take on and the hopeful part is that it makes it easier for you to achieve what is necessary to be done for the outcome of that day."

Gained self-awareness supported participants' not only in pursuing their self-care intentions but also in defending their own interests when interacting with members of

their care networks. For example, P6 reported showing her pictorial trackers to her family members to raise awareness and gain social recognition, considering that MS symptoms, such as fatigue, can be an invisible to others. P9 reported explaining his pictorial trackers to his partner with the help of the colour legends which made him feel more in control in communicating his health status and, for example, justifying resting breaks. He said:

"I think it was excellent, because it made you feel more in control of being able to define what was going on with you and being able to express it, and being able to be looked at, not just by yourself, actually, but you could show it to like a partner."

Participants detailed using Trackly as a communication tool to share and signal not only their physical but also mental states to family members. For example, P3 characterised her experience of collaboratively setting up Trackly with her partner and developing a shared understanding of her health and wellbeing as empowering:

"As I was using it more and more, I was thinking I can do it now, I don't have to wait until later, I want to write that down. It felt quite empowering actually. I felt like I was doing something that would help me and potentially help my future treatment as well."

P3 unpacked that feelings of control and empowerment were often based on experiences of being used to exercise control in everyday life, losing this control due to a complex range of changing symptoms, and regaining a sense of control through mindfully engaging in self-care activities including self-tracking:

"Well, I think, MS as a disease you feel a lack of, or loss of control. I am a person that always felt in control of so many things, elements of my life. And you feel so completely out of control with MS: you don't know what's going to happen, there are so many ifs, maybes, buts. I actually felt like taking more control for myself for something that might help me and my care providers in the future."

It became evident from the participants' accounts that previous clinical encounters had led to encouraging but also disempowering experiences, where participants felt a lack of control over conversations, decisions making, and outcomes. This was in particular the case when participants were not able to summarise their health history and express their interests during periodic and time-sensitive clinical visits. P6 went through a relapse and discussed that flipping through her weekly text entries during an appointment with her neurologists enabled her to clearly articulate the increased severity of her symptoms. She, moreover, stressed her interest in not only accepting but also understanding the progression of her condition and highlighted her unmet information needs in clinical settings:

“So much goes on and you are not really sure when things started, or you don’t know how long they lasted. So, to be able to keep track of what is going on and also over time. So, to be able to keep a monitor of how you feel things are changing over time is quite a useful tool to have, I think. It’s a good way of keeping an eye on your symptoms because it’s a progressive disease and progression is not something that is talked about in clinical settings. But it can creep up on you without you realising. So, for you being able to sort of go back and think, well, actually, that started to go wrong there and its progressively got worse, I can see a clear change.”

While P6 described her neurologist as a “old dinosaur”, who tolerated the use of smartphones, P11 depicted her experiences of proactively sharing her pictorial trackers as motivational: she reported that her neurologist quickly picked up the visual language of Trackly and recommended that she take rest breaks when colouring in her fatigue trackers with a red colour.

7.4 Discussion

Previous research on MS has examined how technologies can be used to automatically collect health and wellbeing data to assess the progression of MS in clinical settings and domestic environments (Morrison, Corish, and Sellen 2014). Technologies often centred on primary disease indicators and disability outcome measures aimed at advancing the pathology of MS and supplementing clinical decision making (McCaffrey 2015). However, recent human-centred research has begun to explore the quality of life and mundane self-care practices of people living with MS (Bhattacharya et al. 2018; Güldenpfennig et al. 2019).

Informed by self-tracking needs in MS self-management, we have implemented and conducted a field study of Tracky, a customisable and pictorial technology probe. In contrast to prior technology interventions in MS management, Trackly allowed participants to decide what, when and how they want to document their health and wellbeing. We found that participants particularly valued being able to define personally meaningful tracking parameters in their own words, flexibly colour in their pictorial trackers, and make sense of the pictorial representations of their data. They explained being able to support their individual self-care intentions with Trackly and reported a spectrum of interrelated experiences of agency.

These findings confirm the identified user needs and extend the findings of the interview study of self-tracking in MS self-care (see chapter 3). Similar as the interview study, the field study of Trackly has revealed the lack of control people with MS can experience

when adjusting to and coping with the fluctuating and uncertain nature of MS symptoms. In both studies participants highlighted the importance of documenting their health and wellbeing in holistic ways rather than solely quantifying their symptoms. A shared best practice to mindfully engage in self-tracking was intertwining different self-tracking tools and styles, such as symptom tracking and gratitude journaling, to focus attention to positive experiences in everyday life.

The field study of Trackly extended our knowledge on self-tracking in MS. While the interview study findings focused on the experience of control participants gained when exercising their agency in combining existing self-tracking tools, such as paper notebooks and fitness wearables, the participants' accounts of the Trackly field study revealed a broader spectrum of experiences of agency, involving the sense of ownership, identity, self-awareness, mindfulness, and control. These experiences seemed interrelated and enmeshed in people's idiosyncratic self-care efforts.

The field study of Trackly shed more light on participants' self-care intentions and self-tracking priorities. Participants highlighted their intentions to understand the progression and trends of symptoms, manage their energy levels in everyday life by balancing physical activities and resting, and being able to remember and clearly articulate their health status and health history to inform clinical decision-making and improve treatment outcomes. The field study of Trackly, moreover, yielded situated data that revealed the importance of pausing self-tracking and retrospective self-tracking. Participants explained prioritising their momentary health and wellbeing, changing physical and emotional capacities, and everyday life responsibilities over self-tracking.

All in all, our findings demonstrate the importance of supporting people living with MS in adapting technologies to their individual self-tracking needs and offer a design perspective that centres on people's experiences of agency rather than persuasion and compliance.

7.5 Conclusion

We have investigated the use and experience of a customisable and pictorial technology probe in MS self-care. We found that participants utilised the agentic supportive elements of Trackly. They valued being able to define personally meaningful parameters and make sense of their pictorial trackers. Through adapting Trackly to their individual self-care intentions, participants reported a spectrum of experiences of agency, including a sense of identity, ownership, awareness, mindfulness and control. Moreover, participants revealed challenges of using Trackly, including remembering to log data and making sense of changing symptoms. These findings exemplify how self-tracking tools could support the agentic capacities of people living with a complex chronic condition in documenting, understanding, and articulating personally meaningful aspects of their health and wellbeing.

8 General Discussion

We drew on qualitative research and design methods to investigate how technologies could support people living with multiple sclerosis in self-tracking their health and wellbeing. Based on our findings, we discuss the potential of supporting experiences of agency through self-tracking in MS self-management, derive implications for design, address limitations of this thesis, and conclude with outlining the transferability of our contributions.

8.1 Supporting Experiences of Agency

Self-tracking is for many people an important part of managing their health and wellbeing and can involve tools, such as paper notebooks and wearable fitness tracking devices. We investigated how technologies could support the needs of people living with MS in self-tracking their health and wellbeing. Our findings identify agency as an important self-tracking need in MS self-management and present experiences of agency as perceived benefits of a customisable and pictorial self-tracking approach.

Agency and a sense of agency are seminal concepts in HCI research and beyond. Put simply, agency is our capacity to make choices and act in a given environment (Suchman 2009). From a psychological point of view, agency can be characterised as comprising four properties (Bandura 2006): (1) intentionality describes the formation of goals and the development of plans to realise them; (2) forethought involves visualising goals and anticipating outcomes to motivate and guide behaviour; (3) self-reactiveness focuses on the self-regulation of action through adapting intentions and plans during action; and (4) self-reflectiveness is the fourth core property of human agency and describes our metacognitive capacity to reflect on and gain awareness of our goals and actions. People do not act autonomously: our functioning is impacted by interpersonal, behavioural, and environmental determinants. These interdependencies relate to the sociological debate around the influence of “*agency and structure*” (Cockerham 2005), in which structure represents the impact and internalisation of social norms. Applied social research has critiqued theory-driven concepts of agency that centre on action and language determinants. For example, people with dementia have been assumed to lack agency considering the neurodegenerative progression that is associated with mobility and speech impairments (Boyle 2014). However, person- and experience-centred studies

provide evidence that people even with limited physical and cognitive capacities exercise agency in many different ways in their everyday lives. For example, individuals with speech impairment are able to indicate their preferences with their body language and emotions in creative ways (ibid).

In health psychology, the feeling of agency is described as perceived control (Wallston et al. 1987). It is a seminal construct that is defined as the “*belief that one can determine one’s own internal states and behaviour, influence one’s environment, and/or bring about desired outcomes*” (ibid, p. 5). Research suggests that perceived control is an important factor in maintaining good physical and psychological health (Pagnini, Bercovitz, and Langer 2016; Wallston et al. 1987). Within HCI research, the use of technologies and perceived control are associated with empowerment (Schneider et al. 2018). One of the golden rules of interface design is to support perceived control, considering that users desire the sense that they are in control of the system and that the system responds according to their actions (Shneiderman et al. 2017).

However, human-centred research has documented ongoing tensions between technologies that embody biomedical models and peoples’ sense of agency in managing their health and wellbeing (Andersen et al. 2018; Blandford 2019; Cosley et al. 2017; Feuston, Marshall-Fricker, and Piper 2017; Piper and Lazar 2018). For example, recent work suggests a shift from “*medicalised*” to “*mundane*” self-care technologies to focus attention to people’s agency and quality of life rather than the adherence of medical procedures (Nunes 2019; Nunes and Fitzpatrick 2018). In addition, it has been proposed to balance the rigour of clinical methods and the uncertainties of peoples’ lived experiences in the context of self-experimentation (Karkar, Zia, et al. 2015; Karkar et al. 2017). People are typically neither rational health professionals nor data scientists (Elsden et al. 2017; Rooksby et al. 2014a): they adapt and intertwine different self-tracking tools and styles according to their prospective self-care goals and individual circumstances in everyday life. This insight has led to a turn to the lived experience (Cosley et al. 2017; Rooksby et al. 2014a) and is associated with a variety of different approaches aimed at supporting people’s sense of agency, including personalisation (Karkar, Zia, et al. 2015; Karkar et al. 2017), manual tagging (Storni 2013), semi-automated tracking (Y.-H. Kim et al. 2017b), and social scaffolding (Mamykina et al. 2008). Reported benefits of customisation of wearables include a sense of identity (K. Lee and Hong 2017) and open-ended use of tangible self-tracking tools is associated with not only self-reflection and self-awareness but also with self-regulation (van Kollenburg et al. 2018; K. Lee and Hong 2017; Thudt et al. 2018). Human-centred research explicitly encourages researchers to examine how technologies could support

people's agency and individual needs in self-tracking their health and wellbeing (Cosley et al. 2017).

We investigated the self-tracking needs of people living with MS through an interview study. MS is a complex neurological condition that disrupts the central nervous system leading to an individual profile of impairments, such as fatigue, vision problems, muscle spasms, pain, bladder problems, and depression (Embrey 2014). The onset, severity, and progression of MS symptoms are highly variable and individual. People with MS described their lifelong health condition as invisible, constantly changing, and difficult to understand and cope with (see chapter 3). They reported experiencing a lack of control when dealing with enormous mental challenges, such as coping with the unpredictable course of the disease and being afraid of not being able to participate in social life at some indeterminate point. Our interview findings suggest that people regained a sense of control over MS through intertwining individual self-care practices with a wide range of different self-tracking technologies, including paper notebooks, fitness wearables, and mobile health applications. The experiences of control that we encountered here appeared to be grounded in a mindful mindset and positive wellbeing, involved coping with uncertainty when exploring causal relationships, and faded when experiencing relapses. Using self-tracking technologies alone did not support people to gain a feeling of being in control. Our study illustrates that their experience of control was related to their agency of being able to adapt different self-tracking tools to their idiosyncratic self-care practices. Their self-tracking practices involved gaining knowledge about the pathology of MS and self-knowledge about their MS, pursuing healthy lifestyles, engaging in mental health management, and reflective thinking across personal health data and behaviour. They did not conduct experiments like scientists (Rooksby et al. 2014a), but they self-tracked their health and wellbeing in an idiosyncratic, open-ended fashion developing their own personal health data ecologies. They trusted not only in their agency to develop mental connections across tools, tracked symptoms, and mundane actions but also stressed the benefits of the experience of the self-tracking practice itself. Most importantly, they believed in their own interpretations and assumptions they made. Altogether, these key practices empowered people to regain a sense of control over MS.

These interview findings suggest that there cannot be one-size-fits-all self-tracking tool to promote MS self-management and underpin the importance of supporting people's agentive capacities through customisable and emotionally supportive self-tracking approaches. Based on this understanding and informed by paper-based journaling design patterns (see chapter 4), we implemented and investigated the use and experience

of Trackly in MS self-care. Trackly is a technology probe that realises a customisable and pictorial self-tracking approach that centres on people's individual self-care needs and agency. Our findings demonstrate the potential benefits of giving people living with MS the choice to track what is personally meaningful to them based on their own understanding. Instead of being forced to monitor predefined symptoms, Trackly supported people in defining and colouring pictorial trackers to document what is important to them in everyday life, including the felt experiences of their complex health condition. They adapted Trackly to their individual self-care intentions and emotional preferences. In this way, participants reported being able to overcome stigma (P1), avoid potential negative affect (P5), and experience feelings of agency, including a sense of identity, ownership, self-awareness, mindfulness, and control. They did not reduce their experience into a single numeric value (P. Adams et al. 2017), but they pictorially documented and contextualised the funny feeling in the left arm, using personally meaningful key words, symbols, and narratives to express and make sense of their felt experiences (Snyder et al. 2019). These accounts demonstrate that self-tracking does not need to focus solely on primary disease indicators or be driven by scientific constructs to support personally meaningful self-care. It is important to support people's agentic capacities and choices in which ways they want to engage in self-tracking and support them in adapting self-tracking technologies to their individual self-care intentions. Customisable and pictorial self-tracking can become an empowering tool not only in fostering people's creative capacity for enacting agency but also in supporting experiences of agency. Both views on agency are particularly important considering the individual and fluctuating nature of MS that can bring about a loss of control over the physical body and feelings of loss of control in everyday life.

8.2 Design Considerations

Previous work has highlighted and demonstrated design considerations to support people's agency in chronic condition self-management, including supporting personalisation (Storni 2013), fostering creative and artistic practices (Lazar, Edasis, and Piper 2017), and promoting social experiences (Foley et al. 2019). Agency supportive technologies need to empower people in taking an active role in their diagnosis process, learning about their condition, adjusting their medication intake, and collaborating with their carers (Nunes, Andersen, and Fitzpatrick 2019). Based on a detailed understanding of self-tracking practices in MS self-management, our findings suggest two fundamental design consideration researchers and practitioners need to balance to promote experiences of agency through self-tracking: (1) fostering people's individual agentic

capacities and self-tracking needs and (2) providing structure for personally meaningful and mindful self-tracking.

8.2.1 Supporting Individual Agentive Capacities and Self-Tracking Needs

Prior research has paid much attention to the monitoring of primary disease indicators and disability outcome measures to assess the progression of MS in clinical and domestic settings (Gulick, Namey, and Halper 2011; Morrison, Corish, and Sellen 2014). While this approach is particularly important to inform clinical decision making, it might overlook the individual self-care needs of people living with MS. Human-centred studies have highlighted the importance of supporting people's lived experiences and idiosyncratic self-care and self-tracking priorities in everyday life (Nunes et al. 2015; Rooksby et al. 2014a). For example, recent research has underscored that people with MS wish to be able to flexibly use and personalise self-tracking applications according to their diverse and fluctuating nature of their health and wellbeing (Wendrich et al. 2019). Our findings demonstrate the importance of supporting people's individual self-tracking needs and agentive capacities in MS management.

8.2.1.1 Individual Agentive Capacities

We, as researchers and practitioners, need to be mindful of people's individual and fluctuating agentive capacities when designing health and wellbeing technologies. There are different types of MS, from relapsing remitting MS to primary progressive MS. People's agentive capacities are highly variable, including their physical abilities, technology preferences, and metacognitive skills, such as engaging in self-reflection. When people living with MS go through relapses and remissions their individual symptom picture, agentive capacities, and priorities in everyday life can fluctuate within a relatively short period of time.

The customisable and pictorial self-tracking approach of Trackly demonstrates how episodic use (Gorm and Shklovski 2019), temporal lapses (Epstein et al. 2015), and short-term engagement (Lazar et al. 2015) can be supported by design, as opposed to promoting compliance, adherence, and long-term engagement (Meyer et al. 2018). Participants in the field study of Trackly decided to pause their self-tracking practices or colour in pictorial trackers retrospectively, in particular, when they experienced severe symptoms, were not physically or mentally capable to log data, and when they deliberately prioritised their everyday living. Although retrospective tracking can impact accuracy and complicate diagnostic goals, it provided participants temporal flexibility when self-tracking their health and wellbeing. Periods of non-use offer opportunities for

semi-automated (Y.-H. Kim et al. 2017b), tangible (Vega et al. 2018), and voice-based interfaces (Porcheron et al. 2018). However, we need to acknowledge people's deliberate choices and changing agentive capacities to leverage the potential of assistive and flexible self-tracking systems (Caldeira et al. 2017).

8.2.1.2 *Individual Self-Tracking Needs*

We have presented agency and experiences of agency as important self-tracking needs in MS self-care. To support experiences of agency we need to prioritise not only people's individual data collection but also people's individual data presentation preferences, from textual and numeric to pictorial.

Participants particularly valued being able to adapt their self-tracking tools to their individual self-care intentions and self-tracking preferences, which involved different self-tracking technologies and styles. For example, participants explained engaging in documentary self-tracking styles by combining Trackly with paper-based journaling and engaging in achievement-based self-tracking by using wearable fitness tracking devices in tandem. Participants decided to track their health and wellbeing in many different ways: they used custom key words, monitored their symptoms on numeric scales, and particularly valued being able to document and express their health and wellbeing in pictorial ways. As Adams and colleagues have noted there are "*numbers people*" who have a preference for numeric pain reporting tools and individuals who instead prefer interfaces that support pictorial and qualitative expressions of pain (P. Adams et al. 2017). Our findings show that there are also people who prefer to explore and intertwine numeric and pictorial visualisation styles.

Furthermore, we highlight the importance of supporting people in documenting aspects of their lives at a personally meaningful granularity and frequency. For example, participants documented their pain levels in weekly or daily pictorial trackers or combined weekly and daily pictorial trackers, depending on their emotional preferences and intentions, such as understanding the progression of their changing symptoms.

Importantly, people's idiosyncratic self-tracking needs can imply different, but not exclusive, design directions. For example, while the design of Trackly realised a customisable and pictorial self-tracking approach that participants utilised in open-ended ways, further design directions could investigate more focused self-tracking approaches which could support relapse or fatigue management.

8.2.2 Providing Structure for Mindful Self-Tracking

Customisable self-tracking can require structure, given that people's individual capacities and support systems vary. Providing structure could involve the mediation of different types of knowledge and strategies for mindful self-tracking.

8.2.2.1 *Medically Informed Knowledge*

Participants in our study explained reading blog articles and scientific papers in order to learn about the pathology of MS and inform their self-tracking practices. Since knowledge about the complex pathology of MS was for some participants key when engaging in self-tracking and gaining a sense of control over *'the unknown,'* self-tracking technologies could mediate this type of health knowledge. Relevant pathological knowledge, such as scientifically grounded associations between MS symptoms and health behaviour, could be translated from medical models to lay language. This type of knowledge could be iteratively elaborated and evaluated with people living with MS in order to uncover uncertainties and mismatches, surface their hidden health competence, and together co-create informative content for self-tracking technologies.

8.2.2.2 *Community Knowledge*

Participants' accounts suggest that technologies could bridge gaps between communities and individual self-tracking practices. Although self-tracking inherently focuses on the self, it is often informed by knowledge shared within communities of practice. While some participants explained learning from their peers from offline meetups how to begin with self-tracking their health and wellbeing, others reported feeling a lack of support when deciding what to track and how to document their symptoms. In particular, paper-based journaling practices on the online social network Instagram demonstrate the benefits of being part of a self-tracking culture of sharing and learning, where people discuss best practices of creating pictorial trackers (see chapter 4). MS-specific online communities address best practices how to cope with the condition. However, it seems that community members rarely discuss whether and how they engage in self-tracking online. Our participants demonstrated self-tracking expertise that could be valuable for community members with little or none self-tracking experience. Researchers and practitioners could leverage the shift from self-care to community-care, by collaborating with communities and investigate whether there are unmet self-tracking needs.

8.2.2.3 Methodological Knowledge

Participants detailed that they developed their self-care expertise and methodological self-tracking knowledge over time. Knowledge of how to mindfully engage in self-tracking could be an integral part of self-tracking interventions.

The field study of Trackly mediated methodological knowledge in the form of help views with example trackers and a set of different types of pictorial trackers participants could choose from. The post-study interview can be thought of as a methodological tool for self-reflection, since it invited participants to share and reflect on their pictorial records (Slovák, Frauenberger, and Fitzpatrick 2017). Here, we see the potential of pedagogical approaches that are tailored to people's agentic capacities (Foley et al. 2019; Lazar, Edasis, and Piper 2017). For example, collaborations with family members and caregivers could draw on people's pictorial trackers to support them in creating comprehensive summaries, articulating their health, and gaining confidence in clinical encounters.

Mediating methodological knowledge can involve strategies of how to mindfully engage in self-tracking. Participants' accounts suggest that a mindful mindset can help cope with potential unintended effects, such as negative emotional states associated with increased severities of symptoms. Mindfulness, the "*process of drawing novel distinctions*" (p. 94), enables people to develop sensitivity, adopt alternative viewpoints, adapt to constant changes in life and, therefore, fosters the experience of control (Pagnini, Bercovitz, and Langer 2016). In order to avoid dictating and mindless experiences, self-tracking tools could foster engagement with different types of self-tracking contents to foster parallel thinking, such as symptom tracking and gratitude journaling. In this ways, researcher and practitioners could mediate valuable knowledge concerning why, what, and how to self-track and become more in control of "*the bully MS*" (P10).

8.3 Limitations and Future Work

In the following sections, we address the limitations of our work covering the methodology, research scope, and recruitment approach.

8.3.1 Methodology

This thesis focused on an important self-management practice: self-tracking by people living with MS. More specifically, we investigated how technologies could support the individual needs of people living with MS in self-tracking their health and wellbeing. To address this exploratory question, we adopted an ethnographically informed research methodology combining qualitative research and design methods (Blomberg and Burrell 2009). The combination of these methods might be considered a limitation. Arguably, a series of ethnographic studies of existing self-tracking practices could have yielded a richer understanding of how people living with MS engage in self-tracking and what challenges and limitations they perceive. A design-led thesis could have explored the design space of self-tracking technologies for people with MS more extensively and evaluated the effectiveness and efficiency of technology probe more rigorously.

However, we believe that this ethnographically informed design research provides two substantial and interrelated contributions. Firstly, this thesis offers a qualitative account that improves our understanding of self-tracking in MS self-management. We describe the ways in which people living with MS adapted combinations of different self-tracking tools to their individual self-care intentions and identified agency and experiences of agency as individual self-tracking needs. Secondly, this thesis contributes an ethnographically informed implementation of a customisable and pictorial self-tracking approach. We translate a paper-based journaling approach to the digital space by designing and developing Trackly, a technology probe that realises a customisable and pictorial self-tracking approach. We reveal perceived benefits and limitations of customisable and pictorial self-tracking through a field study of Trackly in MS self-management.

The qualitative account of self-tracking in MS self-care was essential in identifying a customisable and pictorial self-tracking approach (see chapter 4) and in implementing Trackly (see chapter 5). On this basis, future mixed methods inquiries could investigate research questions, such as whether customisable and pictorial self-tracking can increase self-care agency and decrease negative affective states in MS management.

8.3.2 Research Scope

We adopted a human-centred approach that focused on people's individual self-tracking needs and their lived experiences of managing their health and wellbeing. This approach focused attention to people's agency and the importance of designing self-tracking technologies that meet the self-care needs of the "*whole person*" (Mount 1993). However, self-tracking does not involve only the person who is living with MS. Family members, care givers, MS nurses, physiotherapists, and neurologist contribute to people's experiences of agency and can substantially inform their self-tracking practices. Future research projects could involve members of participants' care networks, such as MS nurses who are assigned by the National Health System in the United Kingdom to MS patients, taking an important role in managing the neurological condition in everyday life (Embrey 2014). Another promising research direction would be to investigate whether and how self-tracking technologies could leverage collaborative efforts in MS management, involving neurologists who could draw on automatically collected physiological data recorded by wearable devices and manually documented experiences by people living with MS (Wendrich et al. 2019).

8.3.3 Recruitment Approach

Another limitation of this study is our recruitment approach. We recruited participants with the help of MS charities and online communities. Although we did not systematically collect data to quantify people's self-care agency, their qualitative descriptions of the ways in which participants intertwined idiosyncratic self-care practices and different self-tracking tools suggest considerable levels of agentic capacities: they volunteered to participate in this research, learned how to install a beta version of Trackly, manually documented personally meaningful aspects of their lives for four weeks, and reflected on and shared their experiences with us. During the interviews it became evident that it was important to participants to engage in community work and contribute their time and knowledge to research. Supporting the individual needs of people who are motivated to participate in research and self-manage their health and wellbeing is of paramount importance. However, future research endeavours could involve people with different levels of self-care agency to investigate customisable self-tracking approaches and the role of providing structure, such as digital resources and coaching. Researchers could focus on people with diverse cultural backgrounds, social economic statuses, and specific types of MS, such as primary progressive MS which does not cause relapses and remissions but slowly worsening symptoms.

8.4 Transferability of Findings

We have examined self-tracking practices by people living with MS and investigated a customisable and pictorial self-tracking approach in MS self-care by implementing and conducting a field study of a technology probe called Trackly. A customisable and pictorial self-tracking approach is not the most efficient in identifying relationships between health behaviours and symptom triggers, assessing the progression of disease indicators, or informing clinical decision making. However, we identify experiences of agency as perceived benefits of customisable and pictorial self-tracking and exemplify how self-tracking tools could support the agentic capacities of people living with a complex chronic condition in documenting, understanding, and articulating personally meaningful aspects of their health and wellbeing. This thesis demonstrates the importance of supporting people's subjective needs and agentic capacities to foster mindful and personally meaningful experiences with their personal health and wellbeing data.

While the transferability of our contributions needs to be closer examined through further studies, we believe that our findings are relevant to various self-tracking domains. Prior research has highlighted that medically informed and achievement-based self-tracking approaches tend to focus on normative health and wellbeing indicators, such as disability outcome measures, steps, and calories (Nunes 2019; Gulotta et al. 2016; Spiel et al. 2018). While predefined self-tracking approaches provide significant value to some people, they can fail to support the individual needs and agentic capacities of others. For example, self-tracking has been described as meaningless (Choe et al. 2014), burdened (Costa Figueiredo et al. 2018a), oppressive (Orji et al. 2018), forced (Deborah Lupton 2014a), exclusionary (Epstein et al. 2017), and inappropriate (Homewood 2019).

In this thesis, we have investigated a customisable and pictorial self-tracking approach that can complement medically informed and achievement-based self-tracking technologies. We anticipate that customisable and pictorial self-tracking is less suited to foster diagnostic and clinical decision making, since people's pictorial trackers might need translational work to be productive during clinical encounters (Chung et al. 2016; 2019). Considering that the design of Trackly avoided persuasive elements, such as reminders, adherence indicators, and social features, it seems less suited to promote goal-directed (Schroeder et al. 2019) and achievement-based (Gulotta et al. 2016) behaviour change. However, our findings suggest that Trackly can be used in tandem with different self-tracking tools, such as paper bullet journals and fitness wearables. Considering that people's agentic capacities and social support systems vary, customisable and pictorial self-tracking approaches could benefit from personalised

scaffolding and participatory engagement (Foley et al. 2019; Lazar, Edasis, and Piper 2017).

Customisable and pictorial technologies, like Trackly, could be utilised, for example, in mental health contexts to foster emotional self-awareness. Future applications could examine how to support people with different levels of agentic capacity not only in defining but also in creating their custom pictorial trackers (N. W. Kim et al. 2019). Furthermore, research could investigate how to design scaffolded transitions between different self-tracking technologies to support people's evolving intentions from exploratory (MacLeod, Tang, and Carpendale 2013) and documentary (Elsden et al. 2017) to diagnostic self-tracking (Karkar et al. 2017). Applications that merge Trackly's pictorial features and OmniTrack (Y.-H. Kim et al. 2017b)'s semi-automated approach could be applied to conduct mixed methods studies to better understand people's diverse data collection and visualisation preferences and investigate how customisable self-tracking affects experiences of agency and health behaviour over time.

Considering the spectrum of desired and unintended effects of self-tracking tools (Costa Figueiredo et al. 2018a; Mishra et al. 2019; Ng et al. 2018), our findings suggest transferable strategies to promote mindful engagement with health and wellbeing data, such as: (1) prioritising individual data collection preferences, including retrospective tracking, and individual data presentation preferences, from numeric to textual and pictorial; (2) supporting people in documenting aspects of their lives at a personally meaningful granularity and frequency; (3) fostering engagement with different types of self-tracking contents, such as symptom tracking and gratitude journaling; and (4) supporting people in adopting a mindful mindset when engaging in self-tracking by, for example, fostering alternative and longer-term viewpoints.

9 General Reflections

Informed by the reflexive turn in ethnographic research (O'Reilly 2012), this chapter provides reflections on this work.

The initial objective of this PhD project was to conduct an ethnography of self-tracking practices with personal informatics systems. The literature review focused the scope of this research on the chronic neurodegenerative condition multiple sclerosis.

Investigating how technologies could support the needs of people living with multiple sclerosis in self-tracking their health and wellbeing was a complex research endeavour. While the pathology of MS is well documented in the medically informed literature, working with people living with MS revealed particularly the importance of their mental wellbeing and quality of life. Close reading the stream of a public online MS community and searching Twitter for people with MS who publicly shared their experiences of using fitness tracking technologies helped gaining empathy for the challenges people living MS can experience and the best practices they develop to adjust to MS in everyday life. Attending a meet-up group for people with MS and their friends helped the researcher to observe and recognise the individual manifestation of MS. For example, some people had no visible impairments, others had significant disabilities and needed assistance from caregivers. Attending the meetups made clear that living with MS goes beyond assistive and personal informatics technologies. What people particularly valued was being able to enjoy their autonomy and social life. Observing MS online communities and meeting people with MS in person helped gaining confidence in developing a PhD research project that aimed to investigate the self-tracking needs of people with MS.

Rather than applying for National Health Service ethics, we decided to obtain institutional ethical approval and recruit participants with the help of MS charities and online communities considering the iterative and explorative nature of HCI research and design projects. Recruitment was a time extensive process that required patience, confidence, and trust. The researcher was very pleased and grateful that 16 participants took part in the interview study (see chapter 3) and that 14 participants decided to complete the four-week field study of Trackly (see chapter 7).

When conducting in-depth interviews, it was valuable to tell participants about the background of the researcher, clearly explain the objective of the study, and contrast this research with clinically informed studies. This seemed to help manage participants' expectations and supported them to freely speak about the limitations of not only current self-tracking technologies and but also health services. For example, one

participant expressed her frustrations with clinicians in the following way: *"Because they [clinicians] are not interested in my health. They are only interest in do I take my Beta-Interferon or not. No one is interested. The MS nurses are not interested."*

Conducting in-depth interviews and learning about how it is like to live with MS in everyday life was emotional and insightful. Participants were happy to demonstrate and share their expertise with the interviewer. They patiently explained MS specific symptoms (e.g. MS hug) and unpacked their self-care knowledge (e.g. *"It's any exercise that improves your cardiovascular system, so your heart and your lung"*). On the one hand, it was challenging to learn how disruptive and devastating MS symptoms can be and accept the seemingly passive role of an HCI researcher. On the other, it was inspiring to learn about how participants regained a sense of control over MS. Their pursuit to be physically active, maintain good nutritional practices, and manage their mental health was remarkable. They highlighted the importance of resting and having a mindful and grateful mindset to life.

Participants shared their positive experiences of taking part in this research. They explained that it was easier and more pleasant compared with completing clinical trials. Speaking about their self-care practices and their experiences with self-tracking technologies seemed to foster self-reflection. For example, one participant explained realising during the interview that self-tracking is actually an integral part of her life. Another participant described the interviews as therapeutic (e.g. *"You are more than welcome; it was quite therapeutic."*).

Before publishing the interview findings, a paper draft was shared with all study participants who found the descriptions of self-tracking practices useful (e.g. *"Thank you very much for e-mailing me the paper. I enjoyed reading it very much. I found it very practical and useful. I even picked up some helpful tips for myself."*). Moreover, they clarified misunderstandings. A participant emailed: *"I had a read through, and it reads very well. I recognise some of the wording. It may have been interference on Skype so my words may not have been that clear. In the paragraphs about Self Knowledge and Health Expertise I think I would've said: I won't need a toilet just halfway down the road. Being dehydrated will irritate my bladder even more. (rather than blood)."*

Participants expressed their interest in being involved in future research studies. It is the researcher's hope to see upcoming interdisciplinary research projects that explore how technologies could be leveraged to meet the health and wellbeing needs of the people who live with MS, their families, and health care teams.

10 General Conclusion

Multiple sclerosis is a complex chronic neurological condition. Documenting and understanding the individual and fluctuating nature of MS is important for clinicians and people who live with MS. Research has focused on the measurement of primary disease indicators and disability outcome measures to assess the progression of the condition in clinical and domestic settings. Emerging self-tracking technologies, such as fitness tracking devices and symptom monitoring apps, provide significant potential to improve not only clinical practices but also people's quality of life.

We applied an ethnographically informed design approach to investigate how technologies could support the needs of people living with MS in self-tracking their health and wellbeing. Based on an interview study, an online ethnography, and the design and field study of a technology probe, we identify agency as an important self-tracking need in MS self-management and describe experiences of agency as perceived benefits of a customisable and pictorial self-tracking approach. Through adapting self-tracking to their self-care intentions, participants reported a spectrum of experiences of agency, including identity, ownership, self-awareness, mindfulness, and control. These findings demonstrate the importance of supporting people's agentive capacities and their individual data collection and visualisation preferences to foster personally meaningful self-care and quality of life.

We took an explorative research orientation that focused on the self-tracking needs of the person who is living with MS. Future research endeavours could involve members of participants' care networks and draw on mixed methods approaches to investigate how customisable and pictorial self-tracking impacts experiences of agency and health behaviour over time and across populations.

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Appendix 1 Chapter 3

Information Sheet

Information Sheet for Participants in Research Studies	
You will be given a copy of this information sheet.	
Title of Project: Designing Personal Informatics for Multiple Sclerosis	
This study has been approved by the UCL Research Ethics Committee (Project ID Number): 8117/001	
Name	Amid Ayobi, Paul Marshall, Anna Cox
Work Address	University College London UCL Interaction Centre 2nd Floor 66-72 Gower Street London, WC1E 6EA
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<p>We would like to invite you to participate in this research project on the design of future personal technologies for people who are living with multiple sclerosis (MS). Before you decide whether you want to take part, please read the following information carefully and discuss it with others if you wish. Please ask us if there is anything unclear or if you wish to receive more detailed information.</p>	
Details of Study:	
<p>The purpose of this interview study is to explore the ways people living with MS manage their health in everyday life and how we could support these practices with technologies. We would like to ask you questions such as how you cope with your symptoms, what role physical activity plays in your life, and whether you use or have used any tools (e.g. paper diaries, spreadsheet software, mobile applications, fitness tracking devices, etc.) in order to track your health (e.g. physical activity, mood, pain, fatigue, diet, etc.).</p>	
<p>We would like to audio record the interviews and take photos of the tools you use, which will allow us to analyse all information retrospectively. Interview transcripts and photos will be made anonymous. For example, personal data and sensitive information on photos will be blurred out. Your name and personal details will not be used. Only the researchers will have access to the transcripts and recordings.</p>	
<p>The interview can be conducted at the University College London Interaction Centre or in a public space close to your work or home, such as a quiet café. Alternatively, we can conduct the interviews via phone or Skype. After the interview, you will receive a £20 Amazon voucher as a thank you for taking part.</p>	
<p>Please discuss the information above with others if you wish or ask us if there is anything that is not clear or if you would need more information. It is up to you to decide whether to take part or not; choosing not to take part will not disadvantage you in any way. If you do decide to take part, you are still free to withdraw at any time and without giving a reason.</p>	
All data will be collected and stored in accordance with the Data Protection Act 1998.	
Thank you for reading this information sheet and for considering to take part in this research.	

Consent Form

Informed Consent Form for Participants in Research Studies

Please complete this form after you have read the Information Sheet and/or listened to an explanation about the research.

Title of Project: **Designing Personal Informatics for Multiple Sclerosis**

This study has been approved by the UCL Research Ethics Committee (Project ID Number): **8117/001**

Thank you for your interest in taking part in this research. Before you agree to take part, the person organising the research must explain the project to you.

If you have any questions arising from the Information Sheet or explanation already given to you, please ask the researcher before you to decide whether to join in. You will be given a copy of this Consent Form to keep and refer to at any time.

Participant's Statement

I _____

- understand that I must not take part if I am under 18.
- have read the notes written above and the Information Sheet, and understand what the study involves.
- understand that if I decide at any time that I no longer wish to take part in this project, I can notify the researchers involved and withdraw immediately.
- understand that my participation will be audio recorded and that pictures of used tools will be taken and I consent to use of this material as part of the project.
- understand that the information I have submitted will be published as a report and I will be sent a copy. Confidentiality and anonymity will be maintained and it will not be possible to identify me from any publications.
- understand that such information will be treated as strictly confidential and handled in accordance with the provisions of the Data Protection Act 1998.
- understand that I am being paid for my assistance in this research.
- agree that the research project named above has been explained to me to my satisfaction and I agree to take part in this study.

Signed: _____

Date: _____

Appendix 2 Chapter 7

Information Sheet



Participant Information Sheet For Adults

UCL Research Ethics Committee Approval ID Number: 8117/001

Title of Study: Designing Self-Tracking Technologies for Multiple Sclerosis

Department: University College London, UCL Interaction Centre

Name and Contact Details of the Researchers:

Amid Ayobi, Paul Marshall, and Anna Cox
University College London, UCL Interaction Centre 2nd Floor
66-72 Gower Street, London, WC1E 6EA

Email: a.ayobi@cs.ucl.ac.uk, Phone: +44 (0)20 3108 7157
Email: paul.marshall@ucl.ac.uk, Phone: +44 (0) 117 33 1535
Email: anna.cox@ucl.ac.uk, Phone: +44 (0)20 3108 7074

Name and Contact Details of the Principal Researcher:

Paul Marshall
University College London, UCL Interaction Centre 2nd Floor
66-72 Gower Street, London, WC1E 6EA
Email: paul.marshall@ucl.ac.uk, Phone: +44 (0) 117 33 1535

1. Invitation Paragraph

You are invited to take part in a PhD research project. Before you decide it is important for you to understand why the research is being done and what participation will involve. Please take time to read the following information carefully and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part. Thank you for reading this.

2. What is the project's purpose?

The purpose of this research project is to explore the ways people living with multiple sclerosis (MS) manage their health and wellbeing in everyday life and how we could support these practices with technologies.

3. Why have I been chosen?

Anyone over the age of 18 with a confirmed diagnosis of MS can take part in this study.

The study requires a smartphone or tablet running the Apple iOS or Android operating systems.

4. Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and will be asked to sign a consent form. You can withdraw from the study at any time without giving a reason and without it affecting any benefits that you are entitled to. If you decide to withdraw you will be asked what you wish to happen to the data you have provided up to that point.

5. What will happen to me if I take part?

This research project involves an evaluation study of a prototype mobile application (app).

(1) We will share a mobile app with you and you will be able to use it on your own mobile device for one month. The app will support you in documenting your health and wellbeing and any related questions you have. You can document what is important to you (e.g. habits, mood, symptoms). You can use the app whenever you wish. You will be able to share your usage data with the research team. Based on your usage data the research team will create and share a report with you at the end of the study. The report will summarise and visualise what you have tracked.

(2) After one month, we will invite you to take part in an interview. The interview can be conducted at the University College London Interaction Centre or via phone, Skype, or FaceTime. We would like to ask you questions, such as how you used the app, what you liked about it, and what kind of challenges you faced when using it.

6. Will I be recorded and how will the recorded media be used?

The app will locally store data about the things you are tracking and about how you use the app on your mobile device (e.g. times when you open the app, when you create a new tracker, and when you record data). If you decide to share the usage data with the research team, they will create and share a report with you.

We would like to audio record the interviews. Usage data, reports, and interview transcripts will be made pseudonymous (written under a false name). Your name and personal details will not be used.

The recordings of your activities made during this research will be used only for analysis. Pseudonymous quotes and reports will be used for illustration in publications, conference presentations and lectures. Sensitive information will be blurred out. No other use will be made of them without your written permission, and no one outside the project team will be allowed access to the original recordings.

7. What are the possible disadvantages and risks of taking part?

Documenting your health and wellbeing with a mobile app could cause psychological distress. If you feel uncomfortable or distressed using the mobile app, please contact Amid (a.ayobi@cs.ucl.ac.uk), Paul (paul.marshall@ucl.ac.uk, +44 (0) 117 33 1535), or the helpline of the MS Society UK (0808 800 8000).

Interviews could also cause psychological distress, since interview questions will address sensitive topics, such as how you experience MS symptoms and how you manage your health and wellbeing. Interview questions can be skipped, if you feel uncomfortable.

You will be free to leave the study at any time.

8. What are the possible benefits of taking part?

It is hoped that this work will improve our understanding of self-management practices in MS and inform the design of future technologies and services for people living with MS and similar chronic conditions. Prior research suggests that self-tracking health and wellbeing can improve self-awareness and self-knowledge.

9. What if something goes wrong?

If you wish to raise a complaint, please contact the Principal Researcher of this project. If you feel that your complaint has not been handled to your satisfaction, you can contact the Chair of the UCL Research Ethics Committee – ethics@ucl.ac.uk.

10. Will my taking part in this project be kept confidential?

All the information that we collect about you during the course of the research will be kept strictly confidential. You will not be able to be identified in any ensuing reports or publications.

11. Limits to confidentiality

Confidentiality will be respected subject to legal constraints and professional guidelines.

12. What will happen to the results of the research project?

The results of the research will be published in a PhD thesis and in academic publications. You can obtain a copy of the published results. Participants will not be identified in any report or publication.

13. Data Protection Privacy Notice

The data controller for this project will be University College London (UCL). The UCL Data Protection Office provides oversight of UCL activities involving the processing of personal data. UCL's Data Protection Officer is Lee Shailer who can be contacted at data-protection@ucl.ac.uk.

Your personal data will be processed for the purposes outlined in this notice. The legal basis that would be used to process your personal data will be the provision of your consent. You can provide your consent for the use of your personal data in this project by completing the consent form that has been provided to you.

Your personal data will be processed so long as it is required for the research project. If we are able to anonymise or pseudonymise the personal data you provide we will undertake this, and will endeavour to minimise the processing of personal data wherever possible.

If you are concerned about how your personal data is being processed, please contact UCL in the first instance at data-protection@ucl.ac.uk. If you remain unsatisfied, you may wish to contact the Information Commissioner's Office (ICO). Contact details, and details of data subject rights, are available on the ICO website at: <https://ico.org.uk/for-organisations/data-protection-reform/overview-of-the-gdpr/individuals-rights/>

14. Who is organising and funding the research?

This research is organised by members of the UCL Interaction Centre and funded by the Engineering and Physical Sciences Research Council UK.

15. Contact for further information

If you would like to receive further information and would like to participate, please contact Amid at amid.ayobi.14@ucl.ac.uk.

Thank you for reading this information sheet and for considering taking part in this research study.

Consent Form

LONDON'S GLOBAL UNIVERSITY



Consent Form For Adults

UCL Research Ethics Committee Approval ID Number: 8117/001

Title of Study: Designing Self-Tracking Technologies for Multiple Sclerosis

Department: University College London, UCL Interaction Centre

Name and Contact Details of the Researchers:

Amid Ayobi, Paul Marshall, and Anna Cox
University College London, UCL Interaction Centre 2nd Floor
66-72 Gower Street, London, WC1E 6EA

Email: a.ayobi@cs.ucl.ac.uk, Phone: +44 (0)20 3108 7157
Email: paul.marshall@ucl.ac.uk, Phone: +44 (0) 117 33 1535
Email: anna.cox@ucl.ac.uk, Phone: +44 (0)20 3108 7074

Name and Contact Details of the Principal Researcher:

Paul Marshall
University College London, UCL Interaction Centre 2nd Floor
66-72 Gower Street, London, WC1E 6EA
Email: paul.marshall@ucl.ac.uk, Phone: +44 (0) 117 33 1535

Thank you for considering taking part in this research. The person organising the research must explain the project to you before you agree to take part. If you have any questions arising from the Information Sheet or explanation already given to you, please ask the researcher before you decide whether to join in. You will be given a copy of this Consent Form to keep and refer to at any time.

I confirm that I understand that by ticking each box below I am consenting to this element of the study. I understand that it will be assumed that unticked boxes mean that I DO NOT consent to that part of the study. I understand that by not giving consent for any one element that I may be deemed ineligible for the study.

		Tick Box
1.	<p>I confirm that I have read and understood the Information Sheet for the above study. I have had an opportunity to consider the information and what will be expected of me. I have also had the opportunity to ask questions which have been answered to my satisfaction and would like to take part in an evaluation study involving:</p> <ul style="list-style-type: none"> - the use a mobile application; - and an interview 	
2.	<p>I consent to participate in the study. I understand that my personal information will be used for the purposes explained to me. Personal information includes mobile app usage data and interview data. I understand that such information will be handled in accordance with all applicable data protection legislation.</p>	
3.	<p>I understand that all personal information will remain confidential and that all efforts will be made to ensure I cannot be identified.</p> <p>I understand that my data gathered in this study will be stored pseudonymously and securely. It will not be possible to identify me in any publications.</p>	
4.	<p>I understand that my information may be subject to review by responsible individuals from the University for monitoring and audit purposes.</p>	
5.	<p>I understand the potential risks of participating and the support that will be available to me should I become distressed during the course of the research.</p>	
6.	<p>I understand the direct/indirect benefits of participating.</p>	
7.	<p>I understand that the data will not be made available to any commercial organisations and is solely the responsibility of the researchers undertaking this study.</p>	
8.	<p>I understand that I will not benefit financially from this study or from any possible outcome it may result in in the future.</p>	
9.	<p>I understand that the information I have submitted will be published in a report and that I can receive a copy of it.</p>	
10.	<p>I consent that app usage data and interview data will be recorded and understand that the recordings will be: stored pseudonymously, using</p>	

	password-protected software and will only be used for quality control, audit and specific research purposes.	
11.	I hereby confirm that: (a) I understand the inclusion criteria as detailed in the Information Sheet; (b) and I do fall under the inclusion criteria.	
12.	I am aware of who I should contact if I wish to lodge a complaint.	
13.	Overseas Transfer of Data <i>I understand that I will communicate with the research team via email, share mobile app usage data with the research team via email, and receive reports from the research team via email. The researchers' email service provider does NOT transfer data overseas. However, if I use an overseas email service (e.g. Google Gmail, Apple iCloud Mail), the communication with the research team and the shared personal information could be transferred overseas (see Terms and Conditions of your email service provider and/or ask the research team if you have any concerns or questions).</i>	

If you would like your contact details to be retained so that you can be contacted in the future by UCL researchers who would like to invite you to participate in follow up studies to this project, or in future studies of a similar nature, please tick the appropriate box below.

15.	Yes, I would be happy to be contacted in this way	
	No, I would not like to be contacted	

Name of participant

Date Signature