Trackly: A Customisable and Pictorial Self-Tracking App to Support Agency in Multiple Sclerosis Self-Care

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ABSTRACT

Self-tracking is an important part of self-care. However, predefined self-tracking approaches can impede people's agency in managing their health. We investigated a customisable and pictorial self-tracking approach in multiple sclerosis self-management by implementing and conducting a field study of Trackly: a prototype app that supports people in defining and colouring pictorial trackers, such as body shapes. We found that participants utilised the elements of Trackly designed to support agentive 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, including a sense of ownership, identity, self-awareness, mindfulness, and control. Our findings demonstrate the importance of supporting people's individual needs and creative capacities to foster mindful and personally meaningful engagement with health and wellbeing data.

Author Keywords

Self-tracking; symptom monitoring; mood tracking; bullet journaling; customization; customisation; agency; perceived control; self-reflection; self-awareness; mindfulness.

CSS Concepts

• **Human-centered computing~Human computer interaction (HCI)**; Empirical studies in HCI.

INTRODUCTION

Agency is our capacity to make choices and act in a given environment [74]. Self-tracking technologies provide significant potential to support agency and transform the management of our health and wellbeing [55, 63]. For example, research has documented benefits of self-tracking, including increased self-awareness, health behaviour change, and productive patient-provider collaborations [3, 13, 20, 54]. However, while medically informed [1, 33] and
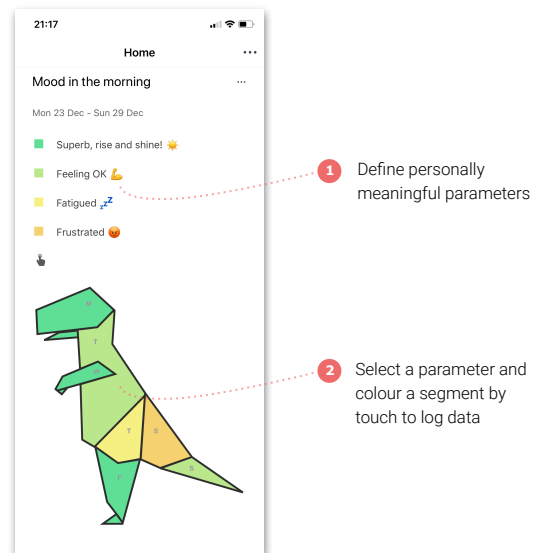
Figure 1. A customisable and pictorial self-tracking approach

achievement-based [34, 65] approaches provide great value to some people, they can also impede agency for others [17, 23, 57]. This is particularly the case for people who have very individual data collection and visualisation needs [5, 18, 64, 67]. For example, multiple sclerosis (MS) is a complex neurological condition that causes an idiosyncratic profile of physical, cognitive, and mental impairments. People with MS have reported that predefined symptom apps can encourage the documentation of symptoms they do not have, and that goal settings and graphs of fitness wearables can cause *"pointless pressure"* ([4]*,* p. 6). In this paper, we investigate how self-tracking tools could support the individual needs of people with MS. Firstly, we contribute the design of Trackly, a prototype app that realises a customisable and pictorial approach, bridging contemporary self-tracking [5] and mindful colouring trends [19, 21, 29, 50]. Secondly, we provide a qualitative account of a four-week field study of Trackly in MS self-management: we establish the ways in which Trackly supported people not only in enacting agency but also in experiencing feelings of agency, including a sense of identity, ownership, self-awareness, mindfulness, and control. Our findings demonstrate a design perspective that centres on people's creative capacities and experiences of agency rather than persuasion and compliance.

RELATED WORK

We investigate how self-tracking technologies could be designed to support agency in multiple sclerosis self-care. To provide background to this research, we unpack the notion of agency, identify the potential to support agency through customisable self-tracking, and situate our work in the context of MS self-management.

Human Agency and a Sense of Agency

From a psychological point of view, agency can be characterised as comprising four properties [6]: (1) intentionality describes the formation of goals and the development of plans to realise them - individually and collectively; (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 a *"a product of a reciprocal interplay of intrapersonal, behavioral, and environmental determinants"* [6]. These interdependencies relate to the sociological debate around the influence of *"agency and structure"* [15], in which structure represents the impact and internalisation of social norms and ideologies. In health psychology, the feeling of agency is described as perceived control, 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"* [77]. Research suggests that perceived control is an important factor in maintaining good physical and psychological health [60, 77]. Within HCI, Schneider et al. [66]'s review associates the use of technologies and perceived control with empowerment, an increasing concern in HCI research.

Customisable Self-Tracking to Support Agency

One of the golden rules of interface design is to support perceived control, considering that users *"strongly desire the sense that they are in charge of the system and that the system responds to their actions"* [70]. 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 [2, 7, 16, 28, 62]. For example, Nunes et al. [57, 58] have recently argued for 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. Karkar et al. [38, 39] proposed to balance the rigour of clinical methods and the uncertainties of peoples' lived experiences in the context of self-experimentation. People are typically neither rational health professionals nor data scientists [23, 65]: 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 [16, 65] and is associated with a variety of different approaches aimed at supporting people's sense of agency, including personalisation [38, 39], manual tagging [73], semi-automated tracking [42], and social scaffolding [49]. Reported benefits of customisation of wearables include a sense of identity [46] and open-ended use of tangible self-tracking tools is associated with not only self-reflection and self-awareness but also with self-regulation [43, 46, 75]. Notably, people have individual data collection and data presentation preferences [5, 40, 64]. For example, Adams et al. [1] distinguish between *"numbers people"* who have a preference for numeric pain reporting tools and individuals who prefer interfaces that support pictorial and qualitative expressions of pain.

Lack of Agency in Multiple Sclerosis Self-Care

MS is a complex neurological condition that disrupts the central nervous system leading to an individual range of cognitive, physical, and mental impairments. Most people with MS receive their diagnosis during young adulthood and experience relapsing-remitting symptoms, including fatigue, vision problems, muscle spasms, pain, bladder problems, and depression [24]. The onset, severity, and progression of symptoms are highly variable. Health informatics studies have focused on the measurement of primary disease indicators to assess the progression of the disease in clinical settings [53, 69]. Complementary, HCI research has highlighted the need for technologies that support people's sense of autonomy and sense of control in managing idiosyncratic MS experiences in everyday life [4, 31, 32, 45]. However, technologies that do not meet the individual needs and agentive capacities of people with MS can impede their self-care agency, such as predefined symptom monitoring apps and fitness tracking devices that focus on optimising rather than maintaining personal health and wellbeing. For example, individuals with MS, who experienced physical symptoms, described charts that visualised low steps counts and negative trends as counterintuitive and discouraging [4]. As Wendrich et al. [78] have underscored, people with MS wish to be able to flexibly use and personalise self-tracking applications.

Summary

Studies on diverse health conditions have documented the idiosyncratic nature of self-tracking, including bipolar disorder [51], migraine [61, 67], autism [41], HIV+ [10], Parkinson's disease [52, 76], and spinal cord injury [11]. These studies have not only described people's varied data collection and visualisation preferences but have also highlighted the potential of customisation [4, 5, 35, 42, 67]. However, it remains unclear (1) how customisable self-tracking tools could be designed to support self-care agency in MS management; (2) how people with MS experience customisable self-tracking in everyday life; and (3) what the transferable implications for health and wellbeing technologies are. To address these questions, we detail how we designed and conducted a field study of a customisable and pictorial self-tracking prototype in MS self-care.
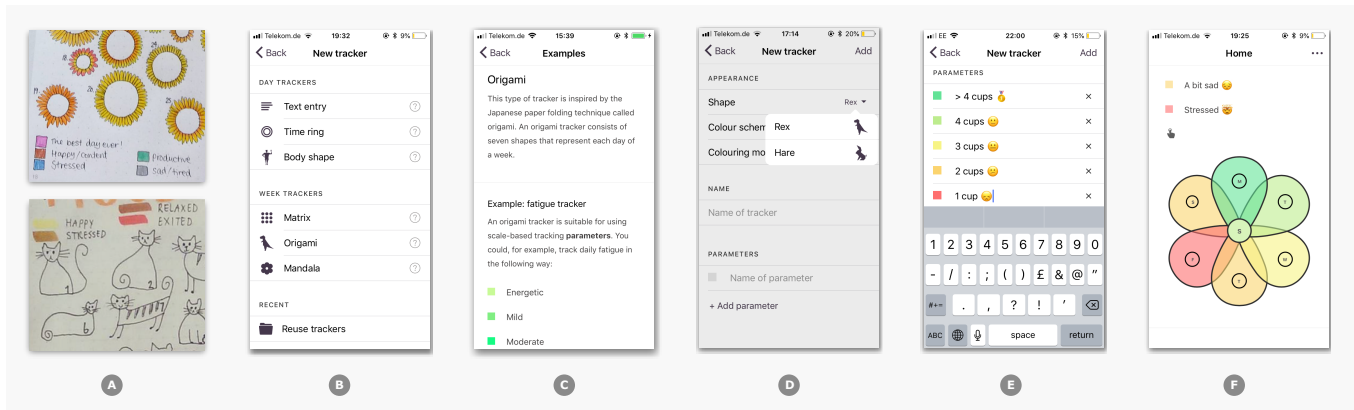
Figure 2: A: bullet journaling as inspiration [3]; B: overview of trackers; C: example; D and E: define trackers; D: mandala tracker

DESIGN AND IMPLEMENTATION OF TRACKLY

To explore how self-tracking tools could support people's individual and agentive needs in MS self-care, we drew on paper bullet journaling, a customisable and pictorial self-tracking approach that allows people to document personally meaningful aspects of their lives in mindful ways [5]. In contrast to previously presented customisation techniques [42, 49, 73], bullet journaling combines self-tracking with mindful colouring [21, 29]. Bullet journaling trackers typically have the following key features (see Figure 2a): 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 pictorial trackers and reflect on their logged data in one view.

We drew on the concept of bullet journaling as an inspirational resource and iteratively designed Trackly, a prototype app that realises a customisable and pictorial self-tracking approach. We implemented Trackly using the Ionic framework [37] to support both Android and iOS users and iteratively evaluated the prototype app through two formative evaluation cycles with overall ten HCI PhD students and researchers. The expert-based evaluation sessions helped identify and fix usability issues regarding the navigation, design of pictorial trackers, and colouring interactions. For example, when iteratively designing and evaluating trackers, we had to balance factors, such as size and number of segments, scope of touch gestures, and the limited display real estate of mobile devices. Trackly provides the following key features (please see the supplementary materials for more details):

Creating trackers: Instead of being forced to monitor predefined health and wellbeing indicators, users can document what is important to them by creating and colouring pictorial trackers. They can define their own tracking parameters, select a colour scheme, and choose from six different types of trackers (see Figure 2b): (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 [5] and in line with approaches described in prior studies of people with MS [4, 32].

Getting inspiration: By tapping on the question marks in the overview of trackers view (see Figure 2c), users can learn more about the different types of trackers. Each view provides descriptions and example trackers (e.g. fatigue) which were informed by qualitative studies that identified the self-care needs in MS self-management [4, 32].

Colouring trackers: Pictorial trackers can be coloured in two ways. The tap mode aims to support a rapid way of logging: users can select a parameter that is assigned to a colour and simply tap on a segment that represents a day. The touch-move mode binds the touch-move gesture event to the colour transparency of a selected segment: users can touch a segment and move their finger around the screen to engage in a more mindful colouring experience.

Reusing trackers: Our design decision to not automatically renew existing trackers each week, but rather to support people in reusing trackers or creating new ones when they wish, was based on the insights that MS symptoms can be relapsing and remitting and that self-care goals can evolve over time [25, 27, 56].

Exploring data: Instead of viewing predefined charts, users can decide what data they wish to explore by opening a list of their existing pictorial trackers, selecting trackers, and viewing generated scatterplots in the exploration view. In this way, users can, for example, view the progression or compare their mood and symptom data across different types of pictorial trackers.

FIELD STUDY 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. The study had institutional research ethics approval.

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 previous research. 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 [24]). 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.

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. 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 [9]. 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 prototype app 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.

FINDINGS

Participants' accounts demonstrate that Trackly supported both agentive 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 a sense of 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.

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.

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.

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.
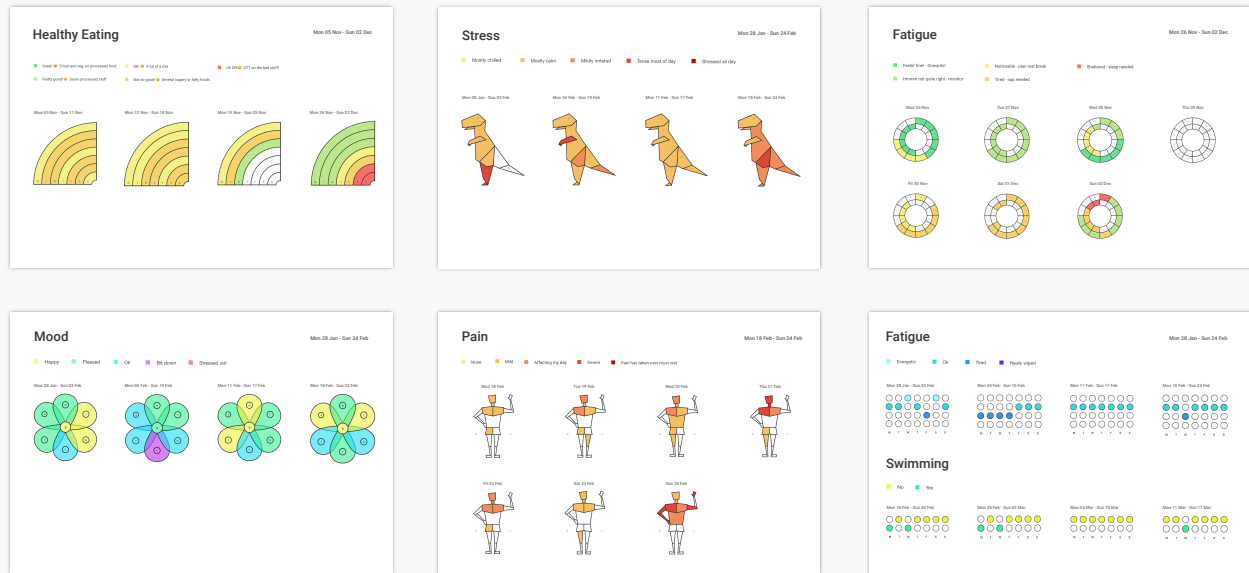
Figure 3: Participants received a summary at the end of the field study, including all the trackers they created.

"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."

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: 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 tacklers, 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.

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).

Experiences of agency
The previous section has described participant's agentive 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 prototype app. 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 a sense of ownership, identity, self-awareness, mindfulness, and control.

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 creatives ways. Anatomical terminology (e.g. P7: *"Pain in my right rhomboid and trapeziums 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 [57, 58]. 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'n fine! - Onwards!"),* combinations of adjectives (P6: *"awake but fussy"*), neologisms (P2: *"tears-in-my-eyes pain"*), metaphorical constructs (P10: *"fogy 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."*).

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.

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 then 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.

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.

Experiences 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 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."

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. 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.

DISCUSSION

Medically-informed [1, 52] and achievement-based [23, 34] self-tracking approaches tend to focus on normative health and wellbeing indicators, such as disability outcome measures, steps, and calories [57, 72]. While predefined self-tracking approaches provide significant value to some people, they can fail to support the individual needs and agentive capacities of others [16, 18, 26, 72]. For example, self-tracking has been described as meaningless [12, 52], burdened [17, 18], oppressive [59], forced [47], exclusionary [26, 72], and inappropriate [36].

We have implemented and investigated the use and experience of Trackly, a prototype app that realises a customisable and pictorial self-tracking approach that centres on people's individual needs and their subjective wellbeing. Our findings demonstrate the potential benefits of giving people living with multiple sclerosis 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 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 *"subjective experience into a single numerical value"* [1], but rather 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 [71]. 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. Customisable 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 particularity 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 [4, 8].

Considering that people's agentive capacities and social support systems vary, customisable and pictorial self-tracking approaches could benefit from personalised scaffolding and participatory engagement [30, 44]. 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 [13, 14]. Since the design of Trackly avoided persuasive elements, such as reminders, adherence indicators, and social features, it seems less suited to promote goal-directed [68] and achievement-based [34] behaviour change. However, our findings suggest that Trackly can complement different tracking approaches and tools, such as paper bullet journals and fitness wearables.

Customisable and pictorial technologies, like Trackly, could be utilised, for example, in sensitive contexts to foster emotional self-awareness (e.g. mental health). Future applications could examine how to support people with different levels of agentive capacity not only in defining but also in creating their custom pictorial trackers [40]. Furthermore, research could investigate how to design scaffolded transitions between different self-tracking technologies to support people's evolving intentions from exploratory [48] and documentary [23] to diagnostic self-tracking [38]. Applications that merge Trackly's pictorial features and OmniTrack [42]'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 and across populations.

Considering the spectrum of desired and unintended effects of self-tracking tools [17, 22, 52, 59], our findings suggest 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 (e.g. alternative and longer-term viewpoints).

CONCLUSION

We have investigated a customisable and pictorial self-tracking approach in multiple sclerosis self-care by implementing and conducting a field study of a prototype app called Trackly. This 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 agentive capacities of people living with a complex chronic condition in documenting, understanding, and articulating personally meaningful aspects of their health and wellbeing. Our study demonstrates the importance of supporting people's subjective needs and creative capacities to foster mindful and personally meaningful experiences with their personal health and wellbeing data.

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