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‘I Do Take the Number Seriously, but I Don't Let My Moods Depend on It’: Negotiating Self-Tracking Data With People Living With Long COVID in the Netherlands, Austria and Switzerland

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ABSTRACT

For many people living with long COVID (PWLC), self-tracking has emerged as a valuable practice to monitor their illness. An examination of self-tracking practices can, therefore, shed light on the ways in which individuals navigate their care, make sense of their experiences and advocate for their needs. This study investigates how PWLC engage in self-tracking practices and how they utilise and negotiate the data generated. Based on 33 semi-structured interviews with PWLC in the Netherlands, Austria and Switzerland, we found that PWLC use self-tracking to recognise patterns and identify limits, triggers and effective interventions. The insights drawn from this are used to make informed decisions about health management strategies. Yet, self-tracking may also reify symptoms and negatively influence the subjective illness experience, exacerbating stress and anxiety. Although PWLC themselves negotiate and question their tracking data, they find a variety of responses from healthcare providers in clinical interactions. Using the concept of ‘trading zone’ (Kjærulff and Langstrup), we argue that although self-tracking cannot replace treatment and good care, its integration into the healthcare experience as a valuable form of patient knowledge may improve the patient–provider relationship.

1 | Introduction

The term long COVID was first coined by patients who reported ongoing symptoms after their SARS-CoV-2 infection (Al-Aly et al. 2024). Long COVID, also known as post-COVID or post-acute sequelae of SARS-CoV-2 (PASC), describes a complex multisystemic illness that can have varying manifestations affecting nearly every organ system. The Patient-Led Research Collaborative has defined over 200 symptoms, including fatigue, brain fog and post-exertional malaise (PEM, a profound worsening of symptoms after physical or mental exertion) (Davis et al. 2021). Estimates suggest that 400 million people are affected by long COVID worldwide, impacting their social life, work and well-being (Al-Aly et al. 2024).

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As the number of individuals experiencing long COVID continues to rise, there is a growing need for treatments and effective self-management strategies to deal with the debilitating effects of the condition on the quality of life. However, care for people living with long COVID (PWLC) varies significantly and is characterised by a general lack of understanding and recognition (Al-Aly et al. 2024). A lack of care and support for PWLC often leads to feelings of invisibility; their illness experiences are underacknowledged or even denied (Ireson et al. 2022). Consequently, PWLC have to spend what little energy they have to fight for recognition, diagnosis and treatment (Mullard et al. 2024).

PWLC have adopted a myriad of self-management techniques to deal with the debilitating symptoms they are suffering from (Day 2022; Heaton-Shrestha et al. 2022; Hossain et al. 2023). Self-management is the day-to-day management of chronic conditions by individuals over the course of an illness (Clark et al. 1991). A key element in their self-management is self-tracking or monitoring the details of one's bodily functions and sensations, such as diet, weight, medication or exercise habits, in an attempt to achieve good health or manage illness and disease (Lupton 2018). This can be achieved using traditional ways of using pen and paper or relying on memory or, increasingly, by using digital technologies, such as health apps or wearables available on the market.

When patients take up self-tracking on their own accord (Weiner et al. 2023), challenges in the patient–provider interaction may arise. Especially with lesser-known or understood conditions, care providers tend to dismiss or simply ignore patient experiences (Augst et al. 2024). On the other hand, when healthcare providers are receptive to discussing and valuing patient knowledge and data, consultations may become more collaborative (Kjærulff and Langstrup 2023).

This article examines the self-tracking practices of PWLC, asking how PWLC use and negotiate self-tracking data and how it shapes their everyday self-management. Based on qualitative interviews exploring the informational practices and aspirations of PWLC in the Netherlands, Austria and Switzerland, we show the ambivalences surrounding self-tracking and underline the complexities of managing chronic illness with digital self-tracking technologies. We map out people's self-tracking practices, including recognising patterns, identifying limits and triggers, finding effective interventions, embodied experiences of self-tracking and negotiating data validity, as well as the limits of self-tracking, and look at how their self-tracking practices co-shape their healthcare experience.

Research has so far mainly focused on specific self-management interventions or co-creation of tools (Chopra et al. 2024; Hausberger et al. 2022; Heaton-Shrestha et al. 2022; Sas et al. 2023; Schmid et al. 2023). By centralising everyday experiences of self-tracking, our findings contribute to an understanding of the role of self-tracking as an important tool in everyday self-management for PWLC. Based on our findings, we argue that its integration into the healthcare experience as a valuable form of patient knowledge may improve the patient–provider relationship.

1.1 | Self-Tracking and Chronic Illness

The rise of mobile health (mHealth) applications and wearable devices has transformed health self-management, enabling individuals to track, monitor and quantify their bodies, leading to new forms of self-awareness (Lupton 2013a, 2019; Samper-Pardo et al. 2023). Self-tracking has been examined for chronic illnesses, such as diabetes, multiple sclerosis or myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS), showing how it supports autonomy, health monitoring and communication with healthcare providers (Davies et al. 2019; Tunis 2023; Wendrich and Krabbenborg 2024). Individuals with chronic illness engage in self-tracking practices using a variety of digital and nondigital tools to manage their conditions. These practices include monitoring various health indicators, answering questions about their conditions, predicting and preventing symptoms, and seeking motivation and social recognition through tracking data (Davies et al. 2019; Jiang and Cameron 2020; Schroeder et al. 2018). However, challenges include the need to make sense of the data collected, tracking too many or the wrong factors, misinterpreting data and personalising tools over time (Schroeder et al. 2018).

In the case of long COVID, various health technologies, such as telemonitoring and the use of apps and wearables, are now being employed (Romaszko-Wojtowicz et al. 2022; Schmeelk et al. 2022; Khondakar and Kaushik 2022). In a review of mobile apps, including two apps on long COVID, the authors concluded that 'mHealth apps that track long COVID-19 symptoms could play a significant role in helping to manage [symptoms] more efficiently and gather additional data about how this disease is affecting patients over a long period of time' (Schmeelk et al. 2022). Moreover, Khondakar and Kaushik (2022) reviewed various wearables, focusing on early detection, real-time monitoring and post-therapy, concluding that wearables are aiding in the management of long COVID.

Although there have been several studies on the design and effectiveness of long COVID apps and technologies more broadly (Blanchard et al. 2022; Chopra et al. 2024; Hatcher et al. 2022; Hausberger et al. 2022; Kübler et al. 2023; Nehme et al. 2023; Ruckser-Scherb et al. 2022; Sas et al. 2023; Schmid et al. 2023), there is limited research on how PWLC actually use self-tracking in practice and how it shapes their subjective illness experience.

Homewood's (2023) autoethnographic account demonstrates how wearables, typically used for activity tracking, can be repurposed for long COVID by specifically focusing on pacing. Pacing entails limiting or slowing down activity consistently, thereby reserving physical or mental resources to prevent the exacerbation of symptoms and crashes (Homewood et al. 2024; Sanal-Hayes et al. 2023). Moreover, qualitative studies investigated how PWLC utilise self-tracking technologies to manage their symptoms and make sense of their condition (Homewood et al. 2024; Jayadeva and Lupton 2025). Self-tracking provided a sense of control and validation, allowing users to track their health and correlate activities with symptom fluctuations, while also potentially being an emotional burden (Jayadeva and Lupton 2025). Based on participants' experiences, Homewood et al. (2024) suggest customisable pacing technologies that adapt to individual user experiences and support self-experimentation. Sas et al. (2023) suggest designing lightweight and nuanced tracking tools, possibly augmented with machine learning analytics that predict the worsening of symptoms.

1.2 | Self-Tracking Data and Patient–Provider Interaction

Because there is a general lack of understanding and recognition of long COVID (Al-Aly et al. 2024) and the feelings of invisibility (Ireson et al. 2022), PWLC may attempt to use their self-tracking data as a testimony of their condition. Yet, based on research on patient-generated data in clinical encounters (Augst et al. 2024), care providers are unlikely to treat these as 'hard evidence'.

Interestingly, a study by Chopra et al. (2024) showed some interest in self-tracking data on the part of care providers in the treatment of long COVID patients as a means to validate patient input with more 'objective' data and to monitor patients' care plan adherence through tracking data. This indicates that the role of tracking data in healthcare settings may differ and become more contested, as the self-tracking is self-initiated and uninvited (Weiner et al. 2023). Patients' uninvited self-tracking may create challenges in the patient–provider interaction; especially with lesser-known or understood conditions, care providers tend to dismiss or simply ignore patient data (Augst et al. 2024). Building on Kjærulff and Langstrup (2023), this can create a 'parallel world' where patients and care providers lack common ground. Kjærulff and Langstrup (2023) argue that when healthcare providers are receptive to discussing and valuing patient knowledge, consultations can evolve into a collaborative space for negotiating knowledge (Kjærulff and Langstrup 2023).

In this collaborative space, called 'trading zone' (Galison 1999; Kjærulff and Langstrup 2023), expertise from disparate social spheres—patients' self-tracking data and healthcare providers' biomedical understanding—is exchanged. Although a collaborative encounter between patient and provider improves healthcare provision, as the patient's knowledge and concerns may be taken more seriously, navigating healthcare encounters productively requires skills, competences and knowledge on the side of the patients. In other words, patients need cultural health capital to navigate and capitalise on a possible trading zone (Shim 2010). Those patients with more cultural health capital may be able to mobilise their self-tracking as digitally engaged patients (Lupton 2013b), whereas patients without such capital may not.

Based on previous research, a trading zone as a collaborative space between provider and patient is unlikely to exist in the case of uninvited long COVID self-tracking (Augst et al. 2024; Mullard et al. 2024). Yet, with conditions that are difficult to detect and manage with a biomedical approach, a good patient–provider relation is even more important, whereas patients with these conditions tend to be dismissed and disbelieved (Lian and Robson 2017). In the case of ME/CFS patients, Lian and Robson (2017) even speak of 'a fundamental breakdown of doctor–patient partnerships' because consultations with care providers are often not productive.

2 | Methods

We used an exploratory qualitative research design investigating practices, requirements, challenges and aspirations of PWLC regarding information practices, including self-tracking. Two interviewers (EA & ACM) conducted 33 qualitative semi-structured interviews between November 2023 and April 2024 in the Netherlands, Austria and Switzerland. These locations were chosen pragmatically; the researchers involved in this project are based in these locations, facilitating access to participants. Although there are no exact data available on long COVID cases, the three countries had similar incidences of COVID-19, and the WHO estimates that 10%–20% of people infected with SARS-CoV-2 develop long COVID symptoms (WHO 2022). The countries have different health systems and different levels of support for PWLC. The Netherlands has a centralised healthcare system that relies on GPs and provides nonmedical assistance to PWLC through C-support, a governmental support organisation advising PWLC,[1] whereas in Austria and Switzerland, healthcare is organised regionally, and specialised physicians are more commonly consulted. In addition, at least some specialised outpatient clinics for long COVID have been available at the time of data collection—though participants reported various levels of healthcare support received. Even though the healthcare systems of our sample countries differ, the PWLC share the experience of frustration and uncertainty due to the lack of care knowledge and awareness.

Participants were recruited through social media support groups and online platforms, as well as snowball sampling. Sampling from online forums yielded participants who were particularly invested in digital technologies, who allowed for detailed data collection on the use of digital tools for long COVID self-management. This was particularly the case in the Netherlands, where an online group specifically on digital self-tracking was an important source of participants. Details on the sociodemographics of the interview participants are shown in Table 1. Participants were infected with COVID-19 at different times in the pandemic between 2020 and 2023. People who self-identified as having long COVID were included in the sample; a long COVID diagnosis by a medical professional was not required. We also included one healthcare professional, a physiotherapist, working with wearables and had informal discussions with patient organisations.

Semi-structured interviews took into consideration the health needs of participants and, therefore, lasted between 20 and 60 min (M = 42 min, SD = 8) and allowed for breaks. Conversations centred on information seeking and digital technology usage. Questions revolved around participants' long COVID journey, their information-seeking behaviour, information sources, if and how they track their symptoms, activities and/or treatments, and if so, how this influences their self-management. The interview guide (see Supporting Information S1: Appendix) was informed by following discussions in long COVID social media groups, as well as existing literature on long COVID self-management practices (Day 2022; Heaton-Shrestha et al. 2022; Hossain et al. 2023; Ireson et al. 2022).

Interviews in Austria and Switzerland were held in German, and in the Netherlands, they were held in Dutch. All

TABLE 1 | Overview of participants.

Pseudonym	Age	Gender	Nationality
Andrea	46	Woman	Austrian
Bianca	31	Woman	Austrian
Daniela	41	Woman	Austrian
Julia	30	Woman	Austrian
Louise	29	Woman	Austrian
Martina	52	Woman	Austrian
Melanie	33	Woman	Austrian
Petra	58	Woman	Austrian
Sabrina	36	Woman	Austrian
A1	29	Woman	Austrian
A7	78	Woman	Austrian
A10	70	Man	Austrian
A11	37	Woman	Austrian
A13	55	Woman	Austrian
A14	53	Woman	Austrian
Amber	38	Woman	Dutch
Celeste	53	Woman	Dutch
Hetty	57	Woman	Dutch
Ineke	58	Woman	Dutch
Janne	46	Woman	Dutch
Katja	53	Woman	Dutch
Koosje	57	Woman	Dutch
Laurens	63	Man	Dutch
Loes	47	Woman	Dutch
Paula	50	Woman	Dutch
Sophie	45	Woman	Dutch
Claudia	47	Woman	Swiss
Jan	47	Man	Swiss
Katharina	37	Woman	Swiss
S2	48	Woman	Swiss
S3	62	Man	Swiss
S5	51	Woman	Swiss
S6	55	Woman	Swiss

interviews were audio-recorded, and all—except two interviews for which the audio recording was lost—were transcribed verbatim and de-identified. The two interviews lacking audio recording were recorded in field notes. Quotes used in this article were translated into English, and participants were given pseudonyms.

Two researchers (EA & ACM) carried out thematic analysis (Braun and Clarke 2021) to identify key themes and patterns in the data using ATLAS.ti qualitative data analysis software. This involved coding the interview transcripts, grouping codes into themes and interpreting the findings in relation to existing literature (Braun and Clarke 2021). Together, the two researchers decided on a few initial codes based on transcription and the interview guide but mainly used inductive coding to come to an initial code list. After both coding one interview, the researchers compared their code lists and created a shared list. Subsequently, they coded one of each other's interviews to refine the code list and code categories before proceeding to code the remainder of the interviews. The researchers continued coding the interviews after saturation was reached. Continuing coding was motivated by a feeling that interviewees sacrificed the little energy they had to be interviewed and expressed a strong sense that they wanted to be heard. An in-person data analysis workshop with all authors was conducted in Amsterdam to verify and finalise the data analysis results.

The Ethics Advisory Board of the Amsterdam Institute for Social Science Research approved this study. Data were stored according to the research data management guidelines of the University of Amsterdam. Participants received participant information prior to the interview. Informed consent was provided by all participants. For in-person interviews, the consent form was signed on paper; for online interviews, consent was given digitally.

3 | Findings

We found that in the face of limited medical understanding and support for long COVID, individuals turned to self-tracking as a strategy for managing their condition. We describe this path to self-tracking in the following subsection.

Turning to their everyday use of digital technologies, we go into the following practices participants described around their self-tracking:

1. Recognising patterns and finding out what works
2. Negotiating the validity of self-tracking data
3. Considering the limits of self-tracking

Finally, we present findings on how the self-tracking practices of PWLC co-shape their healthcare experience and their relation to their care provider.

3.1 | The Path to Self-Tracking

PWLC expressed engaging in self-tracking practices in the context of uncertainty. Participants described being thrown into the deep end when confronted with symptoms that persisted after a COVID-19 infection. They describe experiencing a variety of symptoms, most commonly fatigue and PEM, with the so-called ‘relapse’ or ‘crash’ after activities that are mentally or physically exerting. When these symptoms did not subside, they tried to find healthcare support and used online information to make sense of their symptoms as a first step.

Participants expressed that in this search for answers, healthcare providers often did not have enough understanding of and recognition for their condition. As there continued to be a lack of scientific understanding and treatment, participants reported trouble finding the right support and care provider(s) and a need for practical advice on how to deal with their daily life with long COVID.

As Katharina from Switzerland described: ‘But of course what I do online is somehow look for answers to my questions where the doctors can't answer. Or you get some blood work, and the doctor doesn't know anything’. Knowledge and information provided through online support groups appeared highly valuable for their practical everyday life:

> Yes, especially practical information, it's relatively well known anyway that doctors often find it difficult to imagine what it looks like in everyday life. They're familiar with the functions, but they can't really imagine what it means in everyday life. So it's good to have other people affected who can tell you how they've solved things.
>
> (Julia, Austria)

Through the use of digital technologies, including social media, online platforms or podcasts, PWLC received emotional support and practical information, such as information on off-label medication, management techniques and approaches to try to alleviate their symptoms, as well as self-tracking options. Information on different self-tracking methods often stemmed from support groups, most often organised online. Some participants were also advised to engage in self-tracking by healthcare professionals, including occupational therapists or specialists in rehabilitation and long COVID consultations, being provided with protocols for activity tracking or suggested to use a wearable.

Participants used a variety of tools for self-tracking, including digital technologies such as wearables and apps, as well as Excel sheets, digital and handwritten agendas and diaries. Multiple participants reported using a Garmin watch and the corresponding app Garmin Connect, as well as other wearables including Fitbit, Apple Watch or Android devices. Participants using the Garmin watch often mention a specific function called the Body Battery,[2] which shows a numerical value on the watch that represents how much energy they have left. Although the exact calculation of this variable was unclear to many, participants found the numerical depiction of their energy helpful and clearer than other methods, such as activity timetables or self-rated assessments. In addition, some participants also use various apps for self-tracking, for example, Visible, Welltory, Long Covid Tagebuch and Garmin Connect (for an overview of the functionalities of apps, see Supporting Information S2: Appendix).

Participants reported using apps and wearable devices to monitor their pulse, heart rate variability, oxygen levels, sleep and other vital signs daily. Heart rate variability (HRV) was seen as an important variable to monitor.[3] In addition, some participants tracked their symptoms, activities or medication as well as dietary supplements they take.

3.2 | Self-Tracking Practices

3.2.1 | Recognising Patterns and Finding Out What Works

Participants expressed that they used self-tracking in order to recognise patterns and insights into their condition and to make decisions about their health management strategies. Ineke, a Dutch woman in her 50s, used a myriad of tracking technologies and documentation methods to keep track of her activities. Throughout the day, she noted down how much energy her tracking device told her she had after her activities. She explained how she documents being interviewed as an activity in her calendar but will also write down how many ‘Body Battery’ points the interview had cost her when the interview is done. This supported her in understanding ‘what caused the complaints’, as she has trouble remembering her activities due to memory issues. Participants noted that compared to manual tracking methods sometimes recommended by health professionals, self-tracking devices appeared easier to use and more straightforward for their day-to-day management.

To support pacing, some wearables have an integrated alarm when the pulse reaches a certain pulse threshold, indicating to participants that they must rest to prevent a potential crash. Paula, a Dutch participant, went to a sports physician and determined a maximum heart rate that she should not go over:

> I measure my heart rate with a [smart] watch, and so I can stay under that threshold. And this turned out to work very well, to prevent a physical relapse, in any case. [...] And if I have a day with more stress, indeed [then] I see a little more orange [on the wearable—which signals physical exertion] than otherwise. Then I just know: okay, now take it down a notch and slow down.
>
> (Paula, the Netherlands)

Laurens, another participant from the Netherlands, used the smartwatch to walk at a slow pace. The watch notified him when his heart rate went above 110 bpm. Through this, he learnt a new type of walking, much slower than he was used to. After some practice, he was able to keep the right pace without his smartwatch to alarm him (field notes).

Another added benefit of self-tracking with a wearable, according to participants, is the enhanced ability to identify for themselves which activities trigger potential deterioration in energy levels. An example comes from Melanie, an Austrian woman in her 30s:

> When I spent time with my little two-year-old niece during the vacations, especially since I've been fitter, I didn't always think about it and picked her up. And I really didn't notice it acutely there. But then at night I felt extremely bad... but then I seemed to have regenerated to some extent by midday the next day. And it took me a long time to recognise the connection.

> And I did because of the watch, which documents when you've really exerted yourself a lot. Because it was such a quick action, I didn't even realize it. And it took me a long time to realize that, and then I didn't lift her for a day and I felt much better.
>
> (Melanie, Austria)

Moreover, by monitoring the impact of various interventions, such as medication, dietary changes and breathing or relaxation techniques, participants could determine what worked best for them. Sophie, a Dutch woman in her 40s, for example, used the watch to figure out that being active in nature recharged her more than reading a book in the garden. One of the main lessons self-tracking taught her was that 'I don't have to sit still to recharge'. Similarly, Julia, an Austrian woman in her early 30s, identified that cold baths work better for her than meditation, and she was able to integrate other management techniques that her detailed Excel analysis, shown in Table 2, revealed were beneficial. She noted all the details of the intervention she did, the required time and observed changes in pulse and heart rate variability in an Excel sheet to then calculate the average change in stress for her.

Participants stressed that the interventions that alleviate their symptoms are very individual. Meditation may work for one person, whereas others swear by acupressure mats or a weighted blanket. By recognising patterns and identifying limits and triggers, participants found effective interventions or activities that help to manage their symptoms. Although this can be tedious, self-tracking serves PWLC as a tool to assist them in their daily life living with long COVID.

3.2.2 | Negotiating the Validity of Self-Tracking Data

Participants describe losing physical awareness because of living with long COVID and having to relearn feeling and listening to their bodies. As Claudia described: 'Before, I had an extremely good bodily feeling [...]. And [with having Long COVID] that [body feeling] was gone'. (Claudia, Switzerland).

Like Claudia, Amber described the unpredictability of living with long COVID:

> That's what's difficult about LC, sometimes you're ok and then you have bad days and sometimes I just don't know why. For example, I've done something and it actually went surprisingly well, while I would expect a relapse. And sometimes it's completely different than you expect. So it's very difficult to [...] to really predict completely, say, if I do this, then that will happen. It really differs per day.
>
> (Amber, the Netherlands)

Both Claudia and Amber thus attributed the loss of awareness to a changed bodily experience resulting from the unpredictability of everyday life with long COVID. They both explain how their wearable helped them deal with this unpredictability and loss of embodied awareness. Amber described not feeling well after breakfast:

> [and] then I thought, no, I'm going to go back to bed and then then my heart rate will go down. But it stayed high all day. So then I know, higher than normal, then I know, I'm in a relapse. [...] So I know I just have to give in to it [the relapse] and a [smart]watch like this makes it easier for me to do that.

The smartwatch thus helped Amber verify the relapse based on her heart rate and as well as provided clarity on what to do (lie down) in the face of the erratic nature of the condition.

Participants addressed how their tracking data and their embodied experiences correlate or differentiate at different times. They negotiate and question the validity of the data in relation to their situation. Although wearables helped participants with their physical awareness, they stress it did not replace feeling the body. For example, Sabrina, an Austrian woman in her 30s, said about the Garmin Body Battery function, 'It's not bad, it doesn't replace the feeling, but it mostly aligns with the feeling'. Simon, a 62-year-old Swiss participant, also

TABLE 2 | Analysis of activities by Julia (Austria).

Type	Quantity	Total length	Average length	Average pulse beginning	Average pulse end	Pulse change	Average pulse	Average change in stress
Focus meditation breathing exercise	93	19:56:40	12:52	76	75	−0.32	75.87	0.29
Mindfulness meditation	7	01:07:12	09:36	82	81	−1.43	81.57	−1.86
Feldenkrais	1	00:25:00	25:00	96	88	−8	93	0
Control: Television	3	00:52:14	17:25	75	75	0	76	8.33
Control: Insta	3	00:47:34	15:51	77	77	0	77	9.67
Yin Yoga	7	03:29:36	29:57	77	78	1.29		16.86
Control: Podcast	9	02:37:20	17:29	79	79	0.11	79.00	−2.00
Tens	29	02:22:06	04:54	74	74	−0.76	74.34	−2.45
Bathing	16	04:09:58	15:37	82	70	−12.19	72.63	−28.75

said he felt like he was not controlled by the wearable but saw it more as a tool that helps him. He thinks 80% of the time his wearable is accurate, but he really tries to listen to his body. Katharina, a 37-year-old from Switzerland, explained that the watch was 'a kind of body signal', whereby the smartwatch served as a comparison between subjective perception and measurability.

At the same time, seeing numerical data influences the course of their day. Numerical feedback on sleep quality may give a sense of how much energy has been 'recharged'. Dutch participant Laurens checks 'how much energy he has' when he wakes up and tries to divide that energy well over the course of the day. Other participants would cancel appointments or completely clear the calendar if the smartwatch showed a low score upon waking.

Tracking data can also elicit bodily responses, adding a layer of complication to the dynamic. Participants sometimes felt stressed or negatively impacted by self-tracking. Bianca, an Austrian woman in her 30s, told us: 'And I realised relatively quickly that it really stressed me out. Like, I woke up in the morning and the first thing I realised was how much Body Battery I had'. Similarly, Katharina explained how the self-tracking data have had an emotional impact:

> The numbers still trigger a lot in me, and tends to influence an exaggeration of my feelings afterwards. Like, when I read that my Body Battery only 30, I then have the feeling that I'm now really weak or something… So I already realise now that it can definitely have a negative influence.
>
> (Katharina, Switzerland)

Looking at the data can thus trigger bodily responses that are often negative when the numbers are low.

The stories of participants illustrate entanglements between body and device and how trust in the wearable and self-tracking data is not a given but rather negotiated through the practice of using the device. Ineke from the Netherlands illustrated this negotiation:

> Well, in the beginning I must have thought that if the Body Battery says I'm at 40, I am at 40. And now, now that isn't the case anymore. […] Now I say: well, it [the Body Battery] may be low, but I see that if I lay down, it [the reading] becomes blue [indicating recovery]. So my body is actually performing really great. At the moment I lay horizontally, I get into a rest mode.
>
> (Ineke, the Netherlands)

Hetty similarly described how a low number when waking up no longer determines how she feels for the rest of the day:

> I do take the number seriously, but I don't let my moods depend on it, [the reading] 5 percent [indicating the lowest energy]. Today I'm also starting with 5 percent. Well, then I just know that I shouldn't want too much and what I really have to do, [I will plan it] more at the end of the day [so] that I don't suffer from it for so long.
>
> (Hetty, the Netherlands)

Although at the start of the condition, PWLC have trouble relying on their embodied experiences, as their sensations and assumptions seem less reliable than they were before; self-tracking data help people regain a lost understanding of their bodies. In this sense, self-tracking provides a form of guidance in a situation where embodied guidance is missing.

However, although the data provide this guidance, PWLC also constantly negotiate the validity of the data. Self-tracking data are not taken at face value but are rather negotiated. Sometimes, embodied experiences do not align with the tracking data, causing a challenge in decision-making around activities. Moreover, tracking data may elicit affective and bodily responses, adding a layer of complication to this dynamic.

3.2.3 | Considering the Limits of Self-Tracking

Because of the influence of self-tracking in daily life and the constant negotiations involved, a certain amount of anxiety can accompany self-tracking. As a result of such frictions, participants moved away from self-tracking. As one participant illustrated: 'I've also stopped doing it for a bit now, because sometimes it's just mentally more pleasant not to track everything' (Melanie, Austria). Another participant hinted at the way in which constant attention to the symptoms through self-tracking possibly made the symptoms feel worse: 'Yes, well, I've just had the experience that the whole Long COVID issue in general is a huge topic that is extremely related to the nervous system. And I have the feeling that the more focus I put on these symptoms, the more they are there' (Bianca, Austria).

Initially, wearables served as a useful tool in learning how to pace and how to feel your body again, as described in the previous sections. As time progressed, participants did not rely so much on self-tracking anymore. Some participants found that the constant tracking of variables, symptoms and activities could also lead to more stress and the continued preoccupation with 'being an ill person'. This has led to some participants focusing on more positive aspects of their life by, for example, writing a gratitude journal.

> Of course, I spent six months, I think, looking at all my symptoms and what was there. And taking my blood pressure and pulse, and describing the pain in my limbs, and the hoarseness and the dizziness, and what I was doing all day. But if you do that for six months, you become even more depressed. And then we just had to look on the bright side, yes.
>
> (Petra, Austria)

Next to the stress and anxiety self-tracking could cause, another reason for the abandonment of digital self-tracking technologies relates to the lack of customisation that these technologies offer.

Many require much work inputting data and lack the necessary user-friendly features to accommodate the needs of PWLC. Participants instead started using hand-written diaries or agendas, as well as self-made Excel tables, either complementary to or instead of digital technologies. Moreover, many PWLC have issues with looking at screens and therefore limit or do not use digital technologies. As Daniela (Austria) noted: 'a piece of paper or an analogue diary really is easier to deal with'.

Participants overall expressed that digital self-tracking technologies need to be customisable to fit individual needs and consider the different target audiences with long COVID. Participants suggested customisable overviews, the ability to choose which variables (e.g., sleep, activities, mood, symptoms) to track and including everyday activities beyond fitness into tracker functionality. However, when asked about their desires, rather than another digital platform, participants expressed that they preferred improvements to the medical care for PWLC and political action to improve their situation. In the absence of proficient care and support and treatment or cure, self-tracking (as well as other self-management techniques) is helpful to manage daily life, but it will never replace good patient-centred care and a collaborative patient–provider relationship. As Daniela, who was quite critical about the idea of digital interventions, summarised:

> It's a serious illness and there's simply no substitute for a doctor sitting next to you. Because the responsibility you bear for your medical care alone is so stressful if you're really left alone with it. And an app can't solve that either, that's just the way it is.
>
> (Daniela, Austria)

Although self-tracking serves as a self-management technique for long COVID, participants ultimately stressed the need for better care and support, knowledge and recognition.

3.3 | Self-Tracking Data in Medical Consultations

During interviews, participants often recalled providers' misunderstanding of long COVID and the trouble they had communicating their condition and needs to their providers. Several participants recalled going on a search to find a provider able to address their needs, and providers having varying understanding and acknowledgement of self-tracking health data. Although some healthcare providers suggested using a wearable or helping patients work with the tracking data to fine-tune, for example, their pulse threshold, participants also described care providers who would disregard tracking data. Hetty, for example, reported her experience:

> The Body Battery is viewed very sceptically by the medical world, you know? [...] You end up at a general practitioner [who says]: 'Yes, but those things are not reliable.' And then you end up at the ENT and they say: 'Yes, those things are not reliable.' I said no, I believe that [...] they may not be good enough for medical data yet, but I do think that supports how you get through the day. [...] You just have to stand your ground when you [say to your provider] my Body Battery says this [...] you are then uncertain and overwhelmed [by their dismissal] that is a shame in a way. I also think that even though it is not evidence-based, that you can still [use it].
>
> (Hetty, the Netherlands)

Although Hetty stressed that the self-tracking data are not 'evidence-based', it still functioned as a practical tool to manage her daily life. Being confronted with providers' scepticism was overwhelming, as Hetty explains.

Ineke linked the dismissal of data with a dismissal of herself and her illness experience by the providers. She described how she relies on keeping track of her activities and symptoms; she documented everything as she can no longer rely on her memory. She became emotional when she recounted a care provider's response:

> She saw me grab my phone and her reaction several times was: 'Gee, why are you on your phone? I told you to calm down! And that you just had to pay attention to your body!' And at that moment that… such a reaction is WAY too intense for me. She didn't ask what I was doing. What I was going to do was just write down what had happened, because I know that if I don't do that half an hour later, I won't remember.
>
> (Ineke)

Ineke was emotionally affected by her providers' dismissal of her self-tracking. She summarised it as a situation where someone 'doesn't check in with me, and doesn't want to think along with me, especially [someone who] doesn't ask questions, but makes assumptions'.

In contrast, 47-year-old Jan (Switzerland) used the tracking data from his wearable to prove to his doctors what he had known all along:

> I was always advised to exercise for the first year and a half, it was always explained that it couldn't be that you get so weak, it couldn't be that your oxygen saturation drops. And I then pointed this out to the doctors with the pulse curve, so you can print it out and pass it on. And then I showed the doctors what my watch was showing and then I was able to convince the doctors to do a long-term ECG, they had always refused before, they said it wasn't necessary. And the long-term ECG actually showed the same thing that I had recorded on the watch [...] and I passed all the statistics on to the doctor.

In this situation, Jan presented his tracking data to convince his doctor that something more is going on. Consequently, the doctor provided him with certain diagnostic tests that he believed he needed to understand his condition.

Discussing data in medical consultations can also take on a more collaborative form. For example, Ineke recounted a conversation with her new physiotherapist, where they together negotiated the self-tracking practices, acknowledging the advantages and drawbacks. Ineke acknowledged the limitations of depending on her devices, as she is occupied with monitoring her complaints and energy levels all day, every day. At the same time, Ineke needed the devices to function as her memory to be able to prevent crashes. The physiotherapist who engaged with Ineke's tracking practices, questioning them in conversation without dismissing them, made her feel safe and understood, she explained to us.

Similarly, one physiotherapist we interviewed in Austria recounted how many of her patients used wearables, and, in her consultations, she worked with them to personalise the tracking:

> I often have people come to me and say that they use a heart rate limit of 110 for pacing and (…) the limit often doesn't fit because their symptoms still occur. Which tells me that they do go above their anaerobic limit, because it's much lower. Then we look to adjust it [lower the limit], because if you ask more closely, you often realise, well, that's right, from a heart rate of 90 I notice things are off.
>
> (Louise, physiotherapist, Austria)

In this case, the physiotherapist used the wearable data to adjust and guide her patients in their everyday activities. By reflecting on their symptoms in relation to their wearable data, she helped her patients in pacing productively and avoiding crashes.

In summary, PWLC referred to care providers' dismissal of tracking data. Dismissal was understood as triggering and overwhelming. Engaging with their data together with their provider, even exploring and questioning their value and validity, helped them to feel acknowledged.

4 | Discussion and Conclusion

In this study, we examined the different self-tracking practices of PWLC in the Netherlands, Austria and Switzerland. In the face of limited medical understanding and support for long COVID, individuals turned to self-tracking as a strategy for managing their condition. The patient communities that have emerged, mostly online, provided PWLC with a kind of resource for practical knowledge, including self-tracking (Day 2022). Our participants often started their self-tracking journey by reading about wearables online and/or receiving a suggestion from another PWLC. Self-tracking, most often with wearables, plays a vital role in enabling PWLC to manage their symptoms, particularly at the beginning of the long COVID journey when symptoms first appear. By meticulously documenting and tracking their symptoms, daily activities and health variables, PWLC seek to recognise patterns of correlation between activities or situations and symptoms. In interpreting these patterns, they identify limits and triggers and experiment to find effective interventions to better manage their condition and regain bodily awareness. This aligns with prior work on wearables used for long COVID management (Homewood 2023; Homewood et al. 2024; Jayadeva and Lupton 2025), which emphasises the role of self-tracking in enabling PWLC to regain control and provide recognition of their illness experience in the context of biomedical uncertainty.

However, our analysis draws attention to the ambivalences in the use of self-tracking and its impact on people's sense of self—living with illness. Our results reveal the emotional burden and negotiation in the self-tracking practices of PWLC. The entanglement of data and embodiment also introduce new uncertainties when negotiating digital self-tracking data in relation to embodied knowledge. Like other forms of self-tracking (Algera 2023; Lupton 2016), PWLC use tracking data to (re-) gain a bodily awareness, which has often been impaired by their condition, while also questioning and negotiating the data with their bodily feeling. Although individuals can gain valuable insights into their condition and use these to navigate life with long COVID, self-tracking can also reify the symptoms and influence the subjective illness experience, creating stress and anxiety by focusing on negative feelings. However, with experience and time, self-tracking data are eventually understood in a less absolute manner; data are negotiated or reassessed in terms of data validity and embodied experiences.

Moreover, we contribute a deeper understanding that providers dismissing or rejecting the validity of self-tracking practices and self-tracking data contribute to a sense of not being seen or heard by their care provider. In line with Jayadeva and Lupton (2025), our analysis shows that self-tracking can be seen as a form of recognition for long COVID patients—making their reality visible through self-tracking—thereby validating their experience. In the absence of proficient care and support, as well as treatment or cure, self-tracking serves as a helpful tool to manage daily life. In a context where the experiences of PWLC remain unacknowledged, leading to a sense of invisibility (Ireson et al. 2022), a collaborative patient–provider relationship is even more important. Although healthcare providers often dismiss or undervalue self-tracking data, a collaborative engagement with self-tracking data may help provide a sense of validation and support to PWLC. Ultimately, self-tracking serves as both a coping mechanism and a form of self-empowerment in the face of medical uncertainty. For a collaborative patient–provider relationship, we argue, the practical and embodied knowledge of PWLC, including their self-tracking data, are in need of recognition. By mobilising the concept of 'parallel world' and 'trading zone' (Kjærulff and Langstrup 2023), we propose such collaborative engagement with data in consultations. When healthcare providers challenge the value of self-tracking information, as illustrated by the examples in our data, they are maintaining a 'parallel world' where patients' experiences are disconnected from the clinical consultation (Kjærulff and Langstrup 2023). This misrecognition can be harmful (Mullard et al. 2024). Conversely, as illustrated by the example of the Austrian physiotherapist, the creation of a 'trading zone', a collaborative engagement with self-tracking in the consultation process, can facilitate a productive discussion. Dismissing self-tracking may contribute to the general feeling of dismissal that PWLC experience and push it into a parallel world that makes people feel more invisible (Ireson et al. 2022), further eroding patient–provider trust.

Discussing self-tracking between patient and provider in a 'trading zone' serves as a point of negotiation between scientific knowledge and the lived experiences of PWLC (Kjærulff and Langstrup 2023). Healthcare providers engaging with patients in their negotiation of self-tracking data (Augst et al. 2024) can foster dialogue and a collaborative relationship between healthcare providers and patients where different kinds of expertise are considered. Integrating uninvited self-tracking (Augst et al. 2024; Weiner et al. 2023) into clinical discussions can enhance understanding and treatment approaches, possibly through collaborative tinkering with interventions (Algera 2025). This way, self-tracking may serve as a tool for navigating and translating health experiences for PWLC, generating data and giving legitimacy to the long COVID illness experience in the face of medical uncertainty and scepticism.

Further research is required to deepen our understanding of the long-term impact of self-tracking and to develop tailored interventions in co-creation with PWLC that support their health and well-being. Future research should include providers' perspectives and analyse consultations with a particular focus on how healthcare providers engage with patient self-tracking data. Exploring how uninvited self-tracking data (Augst et al. 2024; Weiner et al. 2023) can be incorporated into the management of long COVID may help create a 'trading zone' in clinical consultations. Ultimately, although self-tracking can help PWLC to cope emotionally and physically with their illness experience, it can and should never replace professional care.

Author Contributions

Ellen Algera: conceptualization (equal), data curation (lead), formal analysis (lead), investigation (lead), methodology (equal), writing – original draft (lead), writing – review and editing (lead). **Anna Christina Maukner:** conceptualization (equal), data curation (lead), formal analysis (lead), investigation (lead), methodology (equal), writing – original draft (lead), writing – review and editing (lead), **Jade van Dorth:** formal analysis (supporting), writing – review and editing (supporting). **Monique Alblas:** formal analysis (supporting), writing – review and editing (supporting). **Jonathan Sobel:** conceptualization (equal), formal analysis (supporting), funding acquisition (lead), writing – review and editing (supporting). **Daniel H. de Vries:** conceptualization (equal), formal analysis (supporting), funding acquisition (supporting), investigation (supporting), methodology (equal), project administration (equal), resources (equal), supervision (equal), writing – original draft (supporting), writing – review and editing (supporting).

Ethics Statement

The Ethics Advisory Board of the Amsterdam Institute for Social Science Research at the University of Amsterdam approved this study.

Consent

Participants received participant information prior to the interview. Written informed consent was provided by all participants.

Conflicts of Interest

The authors declare no conflicts of interest.

Data Availability Statement

The data that support the findings of this study are not shared due to privacy or ethical restrictions.

Endnotes

[1] see https://en.c-support.nu/.

[2] For more information on the Body Battery, see https://www.garmin.com/en-US/garmin-technology/health-science/body-battery/.

[3] HRV describes the variation in duration between heartbeats and is used to assess the state of the autonomic nervous system (Asarcikli et al. 2022).

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Supporting Information

Additional supporting information can be found online in the Supporting Information section.
Supporting Information S1: shil70102-sup-0001-suppl-data.docx.
Supporting Information S2: shil70102-sup-0002-suppl-data.docx.