
Self-Experimentation and the Value of Uncertainty

Amid Ayobi

Paul Marshall

Anna L Cox

a.ayobi@cs.ucl.ac.uk

paul.marshall@ucl.ac.uk

anna.cox@ucl.ac.uk

UCL Interaction Centre
University College London
London, WC1E 6EA, UK

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Abstract

Self-tracking technologies have a great potential to transform the ways people understand and manage their personal health and wellbeing. However, studies on self-tracking suggest that people face challenges in gaining self-knowledge because of a lack of scientifically robust self-experimentation systems. In this position paper we focus attention on the value of uncertainty in self-experimentation by drawing on diagnostic tracking practices in multiple sclerosis (MS). In doing so, we illustrate the role of uncertainty and scientific thinking in self-tracking and managing the complex and unpredictable nature of the disease. Based on this understanding, we propose a set of design considerations to motivate discussion of the ways in which the design of future self-experimentation tools could spark scientific thinking and acknowledge uncertainty in everyday life.

Author Keywords

Self-tracking; diagnostic tracking; self-experimentation; scientific practice; uncertainty.

P13: "For me the biggest thing about living with MS is coping with the knowledge that you have something that is going to get worse in time. And there is a lot of uncertainty ahead. And that psychological burden is the biggest one to deal with."

P6: "But actually, if I was able to answer it [reasons for increased symptoms], would I even want to know the answer anyway? Because if I can't do anything about it, then it would make it even worse. So, not being able to answer it and trying to, that, actually, gives me a purpose to explore it!"

P11: "Like any good scientist, I went: OK, I am going to try this experiment now and I am going to record what I measure and see if it [physical exercises] helps."

Introduction

Prior research on self-tracking has paid much attention to understanding the use and abandonment of self-tracking technologies, such as fitness tracking devices [1]. Recent studies have explored the potential of scientifically-grounded self-experimentation technologies to guide people's diagnostic practices more effectively [3]. However, it remains unclear in which ways the design of self-experimentation tools could overcome the tensions between scientific rigour and the uncertainties in everyday life.

Findings

The following sections draw on the findings of an interview study with 15 people living with MS. This study was conducted as a part of PhD project that aims to provide a detailed understanding of the use and experience of self-tracking tools in MS self-management in order to inform the design of future health tracking technologies for people living with MS [2]. Here, we briefly illustrate the role of uncertainty and scientific thinking in diagnostic tracking practices in MS self-management.

Uncertainty

MS is a neurodegenerative disease that causes a wide range of physical, cognitive, and psychological symptoms. It is characterised by unpredictable relapses which typically lead to an increase of symptoms. Adjusting to the uncertain nature of MS is a major practical and psychological challenge (see P13).

To cope with the complex and unpredictable representation of MS, most participants engaged in diagnostic tracking. This form of self-tracking is a common practice in people living with chronic

conditions, which aims to explore "*link[s] between one thing and another.*" [4] Participants in our study reported facing several challenges when engaging in diagnostic tracking, such as experiencing negative feelings because of overly focusing on symptoms, gaps between different self-tracking tools, inaccessibility of personal medical data, and difficulties to identify relationships between symptoms and their health behaviour. Notably, these challenges did not necessarily lead to the abandonment of self-tracking tools, but made room for explorations and speculations (see P6)

Scientific Thinking

Most participants, who engaged in diagnostic tracking, were interested in identifying correlations between their health behaviours, symptoms, triggers, and general wellbeing (see P11). We identified the following methodical practices that involved a varied degree of "*scientific*" thinking:

- Doing research online and reading scientific literature to understand the pathology of MS and to inform self-care practices and diagnostic tracking
- Evaluating the validity of self-tracking devices by, for example, tracking and counting steps
- Structuring, re-designing, and keeping paper-based health diaries which were considered as comprehensive, personal health records
- Reflecting upon and drawing relationships between physiological data of fitness tracking devices, recorded symptoms, mundane actions, and events in everyday life

Design Considerations

In the following sections, we discuss the ways in which the design of future self-experimentation tools could inspire scientific thinking and acknowledge the uncertainties in everyday life.

Sparking Scientific Thinking

Rather than prescribing positivistic, scientific methodologies, the design of self-experimentation tools should mediate different types of knowledge.

Medically-Grounded Knowledge – Self-tracking technologies are primarily designed for healthy people and often do not meet the information needs of specific user groups, such as individuals living with chronic conditions. For example, participants in our study explored medically-informed blog articles and scientific papers in order to inform their self-tracking practices. Self-experimentation tools could mediate pathological knowledge in order to increase the awareness of the medical implications of understanding and exploring one's personal health and wellbeing. For example, considering the pathology of MS, self-experimentation apps for MS could, rather than focusing on unpredictable symptoms and triggers, support people in exploring the relationships between health behaviours and individual wellbeing, such as balancing physical activities and feeling fatigued.

Community-Based Knowledge – *PatientsLikeMe* is one of the few platforms that aim to bridge self-tracked health data and the interaction between community members. However, self-experimentation goes beyond monitoring personal health and there are clearly gaps between self-tracked data, self-experimentation skills, and collaborative sense-making practices. Many existing health communities address best practices how

to identify and cope with symptoms, however, rarely share and discuss best practices regarding self-tracking tools and the involved reflective work. Self-experimentation tools could be collaboratively designed with and integrated in health communities. In doing so, people could share and present their best practices, discuss differences, and help other members how to begin with diagnostic tracking and make sense of the tracked data.

Methodological Knowledge – Self-tracking applications often take for granted that people know what kind of self-tracking tool to choose, what to track, and how to interpret the significance of the collected data. However, studies suggest that people tend to overestimate the potential of fitness tracking devices to encourage behaviour change and our findings confirm that people use different tools and track different aspects, and, in doing so, develop and expand their health expertise and methodological knowledge over time. Self-experimentation apps could be accompanied by or link to interactive learning material that provides an introduction into self-tracking, self-experimentation, and behaviour change techniques, and also mediates knowledge about suitable self-tracking tools and data literacy.

Acknowledging Uncertainty

Rather than ignoring the complexity and unpredictability in everyday life, the design of self-experimentation tools should address people's felt experience and support flexibility.

Felt Experience – Self-experimentation tools should consider the uncertainties in everyday life and manage the expectations of users by speaking a clear language, revealing the limitations of experimental set-ups, and

supporting people's felt experience [4]. For example, many participants in our study reported gaining an increased self-awareness and a sense of control over MS through intertwining self-care practices and self-tracking tools. Rather than only focusing on potential correlations, validity, and reliability, scientifically-informed self-experimentation tools should also acknowledge people's agency, efforts, and feelings in order to support a richer self-tracking experience.

Flexibility – Prior research has highlighted the individual, open-ended, and *lived* nature of self-care and self-tracking practices [4, 5]. For example, our findings illustrate that people had to cope with individual MS triggers and developed very individual, idiosyncratic diagnostic self-tracking strategies. There cannot be a one-size-fits-all solution that can meet people's diverse self-tracking preferences. Storni [5] has explored an adaptable self-tracking application called *Tag-it-Yourself* with diabetics and concludes that there are unexplored avenues for flexible self-tracking technologies. Future research endeavours could explore how, for example, customisable self-experimentation tool kits could bridge and combine fitness data and symptom-related records.

Conclusion

To better support diagnostic tracking in the *real world*, we propose that future self-experimentation tools should: (1) meet individual information needs, involving pathological, community-based, and methodological knowledge, in order to inspire scientific thinking; and (2) consider the felt experience and flexibility in order to support people in coping with the uncertainties in everyday life.

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