

# Exploring self-tracking practices for those with lived experience of bipolar disorder

Learning from combined principles of Patient and Public Involvement and HCI

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## ABSTRACT

Bipolar Disorder (BD) is a complex, cyclical and chronic mental illness where self-tracking is central to self-management. Mobile technology is often leveraged to support this. Limited research has investigated the everyday practices of self-tracking for BD, and it is unclear how the normative ontology that is seen in existing self-tracking technology discourses (e.g. the Quantified Self movement) is applicable to the domain of mental health. Combining principles of Patient and Public Involvement (PPI)—a staple research design principle in mental healthcare—with design and HCI-oriented research approaches, we conducted interviews and workshops with people with lived experience of BD to explore reasons and methods for self-tracking, and challenges and opportunities for technology. Our results describe recommendations for the design of self-tracking mental health technology. We also reflect upon the complex role of researchers working at the intersection of emerging mental health technologies, the principles of PPI, and HCI research.

## CCS CONCEPTS

• **Human-centered computing** → Human computer interaction (HCI); HCI design and evaluation methods; Ubiquitous and mobile computing.

## KEYWORDS

self-tracking, bipolar disorder, quantified self, self-management, mental health, patient and public involvement, user-centered design, participatory design, mobile technology

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## 1 INTRODUCTION

Recognized as one of the 10 most debilitating conditions worldwide [30], bipolar disorder is a complex, cyclical and chronic mental illness. The poles of this condition are mania and depression. Mania is a heightened state of mood, more rapid speech and physical and mental activity levels, impulsivity, decreased need for sleep and perceptual acuity [2]. Oppositely, depression is characterized by low mood, decreased speech, activity, energy and an inability to experience pleasure. Self-tracking is a key method that many of those with BD employ to manage their everyday lives, extending into the use of digital devices like mobile phones to support a wide range of self-tracking practices [29]. While self-tracking has received some attention within HCI and DIS research [20, 22]—particularly in the guise of the ‘quantified self’ movement (QS) [5, 7]—self-tracking’s relevance to mental health, particularly in BD, has been examined only in limited ways [26]. Murnane et al. [27] and Matthews et al. [24] explored this in earlier studies and found the process of self-tracking in BD to be inherently complex as the sense of self and emotional state is in “flux, uncertain and unreliable”. Both studies shed light on motivations and methods behind self-tracking however only provided a limited understanding on the internal process of self-tracking, especially on the process of turning a qualitative experience into something quantitative. Our research seeks to extend and deepen this understanding and to explore the nature of self-tracking practices for people with BD—as they are frequently *designing their own* self-tracking methods alongside clinical measures such as lists of ‘early warning signs’ (EWS) [21] to both anticipate and manage conditions.

More specifically our paper attempts to get to grips with three key issues related to work on BD and self-tracking. Firstly, current

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users are not being involved in the design of self-tracking technology for BD as much as they could be, and there are suggestions that HCI and PPI approaches should be hybridised to better empower users in the design and research of mental health technology [23]. Secondly, there are tensions reported in the literature [31] between what participants want, what is theoretically sound, and the practical constraints of what can be measured with tracking-supporting technologies without infringing on confidentiality and privacy. Thirdly, many uses of self-tracking technology draw conceptually from the QS community, but in their nature adopt a specific normative ontology [39]. There are thus questions whether normative QS practices and ontologies are then applicable in the domain of mental health, especially in the context of BD where the sense of self is constantly in ‘flux’. We will return to these issues in our discussion.

To address this, our paper explores reasons and methods for self-tracking, and challenges and opportunities for future mobile technology. To do this, and in line with PPI principles, we designed our study closely with individuals with lived experience of BD where a series of workshops and interviews were performed to explore how and why those with BD self-tracked. As part of this we wanted to understand how this might also inform future technology, paying particular attention to current tensions in relation to some design practices and their limitations, i.e. we wanted to more broadly consider the working environment and researcher experience within mental health technology. If a self-tracking tool was designed which was based on users’ needs, reflective of self-tracking practices as well as being embedded in proven theoretical framework such as early warning signs (EWS) [21], it *could* have capacity to be a very useful method of self-management which is crucial for those BD. Specifically we unpack how those with BD convert their everyday experiences into something quantitative, and investigate the process of what constitutes a ‘count’ in the first place. In doing this, we demonstrate an example of ways to combine the principles of HCI and PPI—a design method of choice in mental healthcare research—in order to better ground research on BD and technology in ways that embed deeper participation. Combining principles of PPI and HCI ensure to not only have users to assist in designing technology (as seen in participatory approaches in HCI) but also in designing and running research (e.g., users co-facilitating design workshops) utilizing end-to-end user involvement

## 1.1 Related Work

To start we will unpack bipolar disorder in more detail. Then, we turn to look more closely at self-tracking as it relates to BD, before we then turn to an examination of the current state of self-tracking technologies.

## 1.2 Bipolar disorder and self-tracking

Self-tracking BD behaviors and symptoms is central to managing this condition. In her book, Emily Martin [25] describes some of the underlying mechanisms of self-tracking, stating that many people are encouraged to keep a “mood chart”. Martin argues that the process of doing so can have dramatic effects for people by making experiences comparable, and to thus understand changes over time. Relatedly, understanding the factors that are being tracked and

their relationship to self-management is also important. Research suggests that individuals with BD look towards life events/life stress as a factor to track however there is a lack of a relationship between tracking this and mood episode initiation [16]. Particularly useful in capturing when self-tracking are clinical Early Warning Signs (EWS). Often referred to as relapse signatures, EWS are a set of 63 unique symptoms and signs that may arise approximately 2-4 weeks before a full manic or depressive episodes and are listed in checklist form [21]. EWS are particular to the individual but—in the clinical view—are reliably similar from episode to episode in the same person. Understanding EWS by self-tracking has been proven to improve time to either episode, decrease the percentage of hospitalization and improve functioning [21].

How people track in general is understood by some of the personal informatics models and tracking styles as seen in the HCI literature. For example, Li et al. [20] describe a five stage process model of personal informatics (preparation, collection, integration, reflection and action) which was extended by Epstein et al. [8] to account for other motivations of tracking beyond behaviour change. There is some, albeit limited literature in specifically understanding self-tracking in BD. Murnane et al. [29] explored self-monitoring practices, attitudes and needs of individuals with BD using a survey with 552 participants. They found that individuals reported that they primarily self-tracked items such as mood, sleep, finances, exercise and social interactions with an increasing trend towards the use of digital self-tracking methods. The study made suggestions towards the design of technology-based methods to be more condition-orientated, intuitive and proactive, including the need for sensing based technology methods. Matthews et al. [26] takes this one step further and used participant interviews (n=10) to explore how and why participants engage in self-tracking, asking how the experience of BD influences self-tracking practices and what role technology plays in supporting this. They found participants use a variety of methods to self-track to identify risky patterns that are indicative of episodes, as well as more positive trends that support recovery. They also found that participants experience considerable challenges in self-tracking as their sense of self and emotional state is in ‘flux, uncertain and unreliable’. This resonates with Rooksby et al. [38] who uncovered the chaotic and complex nature of tracking for activity tracker users.

Both studies report a positive perspective of the role of technology in self-tracking, if designed correctly. Poor usability and difficulty interpreting self-tracking data were the reported challenges in using self-tracking technology. Congruent with the aims of this research, the authors state that “currently, as designers we tend to focus on the quantitative, but as our participants have shown, these numbers have deeply personal and qualitative associations”. In an early paper, Martin and Lynch [24] unpack this process of counting and how we interpret numbers. They argue that how the count is produced is largely dependent on who is doing the counting, what the count is for and the occupational and physical location of the counting event. Furthermore, the process of assigning numbers to “things” requires particular practices to render things accountable. The process of turning a everyday ‘qualitative’ experience into something quantitative has been considered within HCI research with key examples in the case of fitness tracker users [36, 38, 41].

For example, the Tracker Goal Evolution Model described that motivations (which can derive from hedonic/eudaimonic needs) present themselves by qualitative goals. For example, the motivation to *feel* will translate into qualitative goals such as *active lifestyle* or *lose weight*. These qualitative goals, through trust and reflection, are then translated into quantitative goals that can be input into trackers [32]. However, unlike the activities performed by fitness tracker users or other types of tracking in the QS community, it can be suggested that the process of tracking is distinct in the context of mental health. Patients and clinicians often describe the experience of bipolar disorder as “a rollercoaster” [9], where a person can flux between states of relapse, recovery, remission and recurrence [25]. The comparison of the differences in interpretation compared to the QS community were touched upon by Matthews et al. [26], who found that though practices are the same, the reasons and interpretation for QS practices were distinctly different compared to those for BD. For example, Martin [25] describes the concept of a “zero” day. A zero day is a day without change—an unremarkable day—which can actually be an indicator of improvement for those with BD, however this is unlikely to be treated in the same way for non-BD individuals in the QS community. This problem is of course part of a much broader class: for instance, a person’s physical step in the QS community is represented by a set of algorithms that define and detect a particular, normative version of a step [39], but there are questions as to whether such a step applies to ‘everyone’.

In this paper we draw on the idea of foregrounding normative ontologies for BD in and through our study of tracking practices. There are still unanswered questions such as how self-tracking helps people, how important EWS are when self-tracking, and how people feel specifically about mobile-based sensing methods of self-tracking. Although present research establishes that self-tracking is a deeply complex and personal process, the processes underpinning this have not received as much attention. Further, research to date has focused on those with BD “participating” in the research rather than being “involved” in the research such as developing research materials, undertaking interviews with research participants, and identifying research priorities, as seen in much of the PPI literature [18]. It remains unclear whether, by involving individuals with BD, research will produce the same or yield different results.

### 1.3 The current design of self-tracking technology

Using paper-based diaries is a usual practice for tracking, however in the advent of mobile, pervasive and ubiquitous computing, it seems inevitable that such technologies will get leveraged for self-tracking activity for BD. There is a growing body of research in smartphone sensing methods such as capturing the number of text messages [4, 11, 35], number of phone calls [11, 15], number of emails [35], GPS data [15, 33], voice features [13, 19, 27, 28, 40], accelerometer data [3, 12, 40], and app usage [1], and exploring their utility in understanding severity of symptoms in BD. When analyzing consumer perspectives on such apps for BD, Nicholas et al. [31] highlighted two important gaps in the current app marketplace. Firstly, apps are being developed independently of research data, and without reference to clinical guidelines—an apparent *wild west* market. When exploring this in relation to the above, we found

that only a few of the technologies mentioned above had reference to EWS [3, 35], a clinical framework for understanding symptoms and signs prior to mood episodes. The second gap mentioned by Nicholas et al. [31] is the lack of consumer needs being met, which was indicated by the proportion of app reviews which contained user wish list requests.

To follow on from Nicholas et al. [31], one barrier to the adoption of such technology could be the design processes employed. The number of mobile applications for mental health is increasing, it is not clear that existing UX methods and techniques are appropriate or sufficient. Classical focus on usability and the delivery of the application may need to shift towards consideration of the ecosystem that surrounds everyday mental health experiences of the user and how this can be applied to design. Ethical concerns, heightened sensitivities and multiple stakeholder views (such as ‘clinical’ versus ‘patient’) likely require a fine balancing act when attempting design ‘with’ instead of design ‘for’. Goodwin et al. [14] states that there is a lack of parity of user involvement in the design of physical and mental health applications, where, for mental health, users are involved less frequently than for physical health apps. Furthermore, the design of such technology involves an intersection between healthcare and technology development, both of which traditionally have different approaches when involving the user, though there are exceptions to the rule. Patient and public involvement (PPI) dominates as a concept for ‘involvement and engagement’ within healthcare studies and interventions [17]. Key factors of this approach are outlined in Table 1. On the other hand, user-centred design approaches have—historically—been prevalent within HCI or service design more broadly. Participatory approaches that seek more direct user involvement in the design and delivery of digital technologies are also well-established. Thus HCI design and healthcare oriented approaches do have a number of overlaps: 1) they involve ‘users’ in research and development in some way; 2) they focus on understanding and empowering ‘users’; and 3) they make changes based on user responses. However, there are also key differences and limitations [23]. Nevertheless, there is much work to do in blending these approaches, which is our focus here.

Finally, our prior work reviewed the extent of user involvement in the design of self-tracking technology for bipolar disorder [23], which is pertinent here. We found that only a small number of studies reported high user involvement, and that despite the presence of recommended standards for the involvement of the user in the process of design and evaluation, there is large variability in whether the user is involved, how they are involved and to what extent there genuine empowerment of the voice of the user, a purported aim for much healthcare technologies research. Our review developed seven principles for the mixing of methods present in PPI and HCI to ensure integration, which we detail below as they informed our present study described in this paper, and provide key context for this:

- Involve users in all stages of design and evaluation including concept generation and ideation, prototype design and deployment and evaluation stages with a goal to create user empathy and/or empowerment. This process should have an adequate number of participants in order to welcome diversity in thought. Equal representation is also a crucial

**Table 1: Key elements of healthcare-based approaches**

Key elements of healthcare-based approaches
Evidence based in mental health research
Traditionally a linear approach to involvement (from start to finish)
A more standalone ‘event’ of participation rather than integrated into development
Clinicians will often be involved (likely to be leading)
Involvement is on a continuum (high-low) where high involvement is seen less frequently
Users are often paid for contribution
PPI organisers are often authors on works
More commonly used in technology assessment

consideration that needs to be considered when recruiting users.

- Ensure early involvement as this will be cost-effective in the long run (avoid re-design and problems with use and implementation in the later stages).
- Combine principles of PPI and HCI to not only have users to assist in designing technology but also in designing and running research (e.g., users co-facilitating design workshops). Utilizing end-to-end user involvement.
- For academic and industry sectors to establish better mechanisms to access target user groups with lived experience of mental health issues for example by building relationships with existing patient directed organizations such as charities, patient-led community groups etc.
- Increase awareness of HCI and design communities in PPI principles and practices and increase awareness of PPI community in HCI and design methods/skills.
- Encourage use and mixing of formal scientific/design methods with informal experiential and empathic practices to capture richness in understanding dynamic requirements of technology users which are cognizant of use in context.
- Keep the user informed at all stages of the process, including final outcomes, future use, next steps etc which is often forgotten about.
- The current research aims to embed the recommended factors described above to understand self-tracking practices in those with BD and in future to inform the design of mobile self-tracking technology.

## 2 STUDY APPROACH

To ensure user involvement in the research, two individuals (P001 and P002) with lived experience of BD were closely involved in developing the study, via a series of workshops and follow up interviews. P001, P002 and the lead author met on a regular basis to organize the content of the workshops and participant recruitment. P001 facilitated the workshop in one UK location and P002 managed the recruitment and facilitation of the workshop in another UK location, with the lead author being a joint-facilitator. The lead author’s role during the research was largely to be the ‘middleman’ between involvement with lived experience and involvement with research. The study had a consultative and collaborative approach throughout, where the lead author sought to empower those with lived experience to be co-designers and co-researchers in the study.

The findings from the workshops and subsequent interviews were put together in a video presentation (in consultation with P001 and P002) and then shared with participants of the broader study via email, as well as presented to the participants via Zoom. The presentation was aimed at gauging the accuracy of the results and eliciting responses.

### 2.1 Participant Recruitment

Participant recruitment was achieved through the assistance of both national and local charity organizations involved in this study who sent bulk messages to mailing list members who may be interested in the research, as well as other snowballing techniques via an existing PPI team based at the Institute of Mental Health at the University of Nottingham.

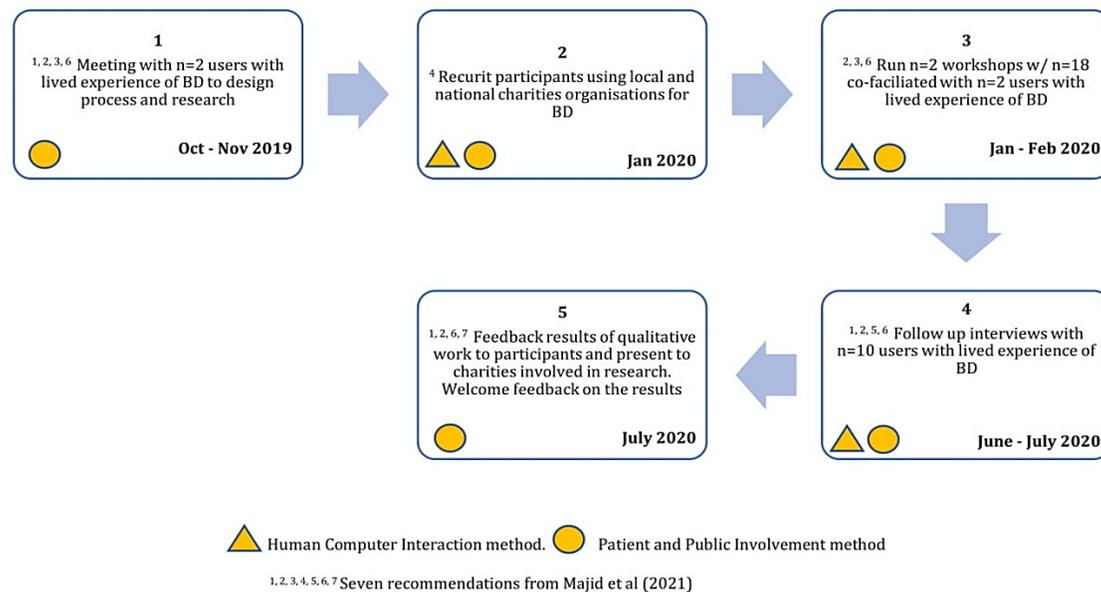
### 2.2 Study Design

As mentioned before, we from principles of HCI and PPI and followed our own list of seven principles of design of mental health technology when developing this particular study. Figure 1 visualizes the study design, indicating where the elements of the study were drawn from (e.g. HCI and/or PPI) and how they relate to the recommended seven principles. The study was conducted between October 2019 and July 2020. By establishing close relationships with two specific BD charities (Bipolar UK and Bipolar Lift CiC) we were able to explore methods that participants would be comfortable with for meeting and sharing experiences. We tried to ensure our methods reflected current practices employed by these organizations. Both organizations run frequent workshops and group events which was the reason behind our choice of data collection. Our two workshops were held at public venues, for example one workshop was held at private meeting venue in a café and the other at a local community centre. Workshops were audio recorded followed by transcription. Subsequent follow-up interviews were conducted with those participants who were willing to share further, to explore the findings specifically in relation to design.

### 2.3 Workshop layout

Both workshops were three hours in total, with a one hour lunch break in between. Workshops started with an icebreaker exercise followed by a three-part structure, which we detail below.

*2.3.1 Exploring reasons for self-tracking.* First, using an affinity mapping approach [10], participants were asked to share their



**Figure 1: Outline of the study method indicating which elements of the process are drawn from HCI and/or PPI and how they relate to the recommendations outlined by Majid et al (2021) [23]. Those elements that are drawn from HCI are indicated by a triangle icon and those that draw from PPI are indicated by a circle icon.**

thoughts on post-it notes to two questions: “how does self-tracking help you?” and “why do you self-track?”. All participants were asked to answer the questions using post it notes and stick them on a large piece of flipchart paper corresponding to each question. Participants were then split into two groups and given all the post it notes for each question and asked to discover and title emerging themes from the responses for the given questions. All participants then had a chance to have a look at all themes and given three dot stickers to indicate which of the themes they found most important, for each question.

**2.3.2 Exploring methods for self-tracking.** Next, participants were given an A4 sheet of paper for use in a rapid sketching exercise [42], where participants were asked to fold the paper until it had eight separate boxes, then were given eight minutes to draw, sketch and/or write the methods they currently use to self-track (spending one minute per box). Subsequently participants were asked to form two separate groups to discuss the following question “how do you count or keep track of relevant factors relating to self-management?”.

**2.3.3 Exploring challenges and opportunities.** Finally, participants were asked get into two groups and have an open discussion about the question “what challenges arise when self-tracking?”. The two workshop facilitators helped to guide the discussion in the two groups at each workshop. Participants were provided an EWS checklist for mania and depression [21] and given five dot stickers to indicate which EWS were relevant for them for depressive and manic episodes. Finally, a scenario was presented about mobile sensing technology which looked at smartphone data to sense EWS.

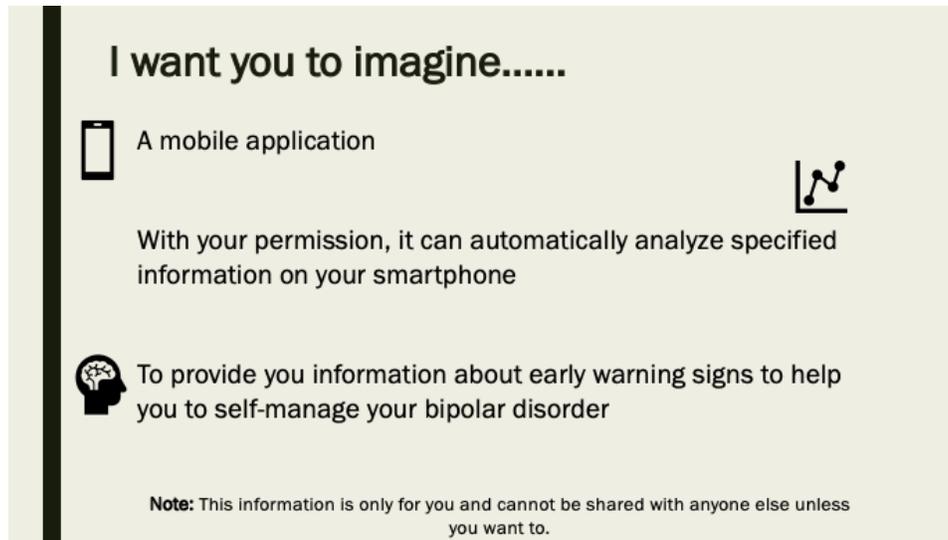
Participants were asked to share their views about this using post-its notes. The scenario was presented in PowerPoint format at the workshop (shown in Figure 2).

## 2.4 Workshop participant sample

In total, we had n=18 participants including the two facilitators with lived experience of BD. One third of participants identified as women, two thirds as men. For age, 25.0% of participants were between 25-34, 31.3% were between 35-44, 18.8% were between 45-54, 12.5% were between 55-64, and 12.5% were 65+. Of the participants, 6.3% had more than three but less than five years of lived experience of BD, 18.8% had more than five but less than seven years and 75.0% had more than seven years. 50.0% had a diagnosis of Type I BD, 43.8% had a diagnosis of Type II BD and 6.3% preferred not to say. Two participants preferred not to answer the demographic questionnaire. Ten participants were willing to take part in follow-up interviews.

## 2.5 Analytic approach

For the first part of the workshop structure (*Exploring reasons for self-tracking*), participants performed analysis themselves: as we mentioned, an affinity mapping was used with participants organizing the answers to questions into themes and indicating importance via dot stickers. No further analysis was performed beyond this, hence results are presented as per the participant discovery. For the subsequent workshop sections, audio data was transcribed by the lead author and then analyzed using Braun and Clarke’s thematic analysis phases [6] using NVivo via the following process: familiarizing yourself with the data, generating initial codes, searching



**I want you to imagine.....**

 A mobile application

 With your permission, it can automatically analyze specified information on your smartphone

 To provide you information about early warning signs to help you to self-manage your bipolar disorder

**Note:** This information is only for you and cannot be shared with anyone else unless you want to.

**Figure 2: Scenario of mobile sensing technology that was presented to participants at the workshops via PowerPoint presentation**

for themes, reviewing themes, defining and name themes and producing the report. During the defining and naming themes stages, P001 and P002 were involved in analysis. For the question “what challenges arise when self-tracking” under the final section of the workshop (*Exploring challenges and opportunities*), themes were ordered in hierarchical format which was dependent on the number of codes belonging to said theme (e.g. the theme with a the highest amount of codes were classified as most commonly described and so on). P001 and P002 also contributed to the understanding and summarizing of the interview data through a series of consultations with the first author in order to understand opportunities for self-tracking technology as presented below.

## 2.6 Ethical Review

This study was subject to ethical review and approved by the School of Computer Science (reference: CS- 2019-R58) at the University of Nottingham, UK.

## 3 RESULTS

In summary, workshops and interviews engaged participants with three main topics: the reasons for self-tracking in BD, which methods were used, and finally a discussion around the challenges and opportunities in self-tracking practices. We discuss these in turn when describing our results.

### 3.1 Exploring reasons for self-tracking

First we want to examine how participants explored questions on “how does self-tracking help you?” and “why do you self-track?”. Figure 3 provides a reconstructed illustrative example of how the post-it notes were organized and using the dot sticker importance ratings for the specific question “how does self-tracking help you?” for all participants. Actual images are not provided to protect the privacy of our participants. Furthermore, participant numbers are

not provided here as these post-it notes were shared openly in the workshop, and participants anonymously wrote answers. The full list of participant discovered themes and level of importance is listed in Figure 4

*3.1.1 Participant responses to how does self-tracking help you.* The most important theme that participants discovered was titled *SOCIAL/COMMUNICATION WITH OTHERS*, where one participant shared on a post-it note that “*sharing triggers with others can help you spot when they may be happening*” when describing periods of relapse. Another participant shared that self-tracking can help them by “*keeping balance with my family*” and that it “*is a tool to share with others to see how I’m doing*”. The second most important theme as discovered by the participants was *PREVENTION*; a participant wrote that self-tracking can “*prevent/work through triggers*”. Further answers include that self-tracking can “*help to intervene before extreme mood changes*”, and that it is “*useful for detecting patterns which are otherwise difficult to notice, for example seasonable mood fluctuations and the impact of significant life events*”. The third most important theme discovered was *BETTER MANAGEMENT OF CONDITION*, an example from an participant here saying that “*knowledge is power*” or another participant answered that self-tracking “*reduced overreliance on medication*” and that it promoted “*discipline*”. The fourth most important theme was *AWARENESS/MONITORING OF CONDITION*, where a participant noted that as a result of self-tracking “*I understand the way I am and why*” and that tracking certain factors such as sleep can “*help me understand what day I’m going to have. Moods vary depending on sleep*” and to “*let me see if my routine is working*”. The least important theme participants discovered was *SELF-TRACKING DOESN’T HELP*, where one participant indicated that self-tracking “*doesn’t help, it can be too much*” and lastly a participant indicated that “*it does not help but I can’t stop*”.

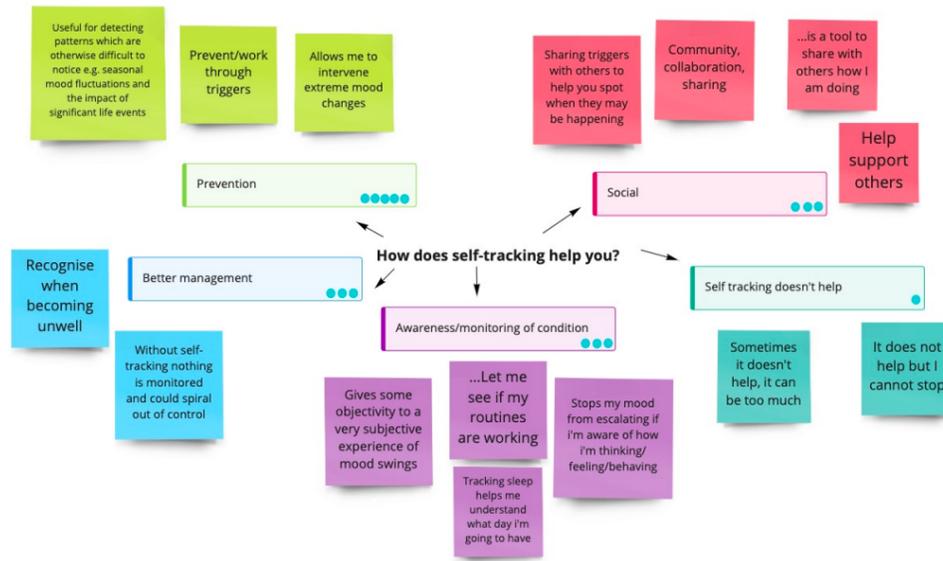


Figure 3: Themes for “how does self-tracking help you”, with indicated level of importance (no. of dots)

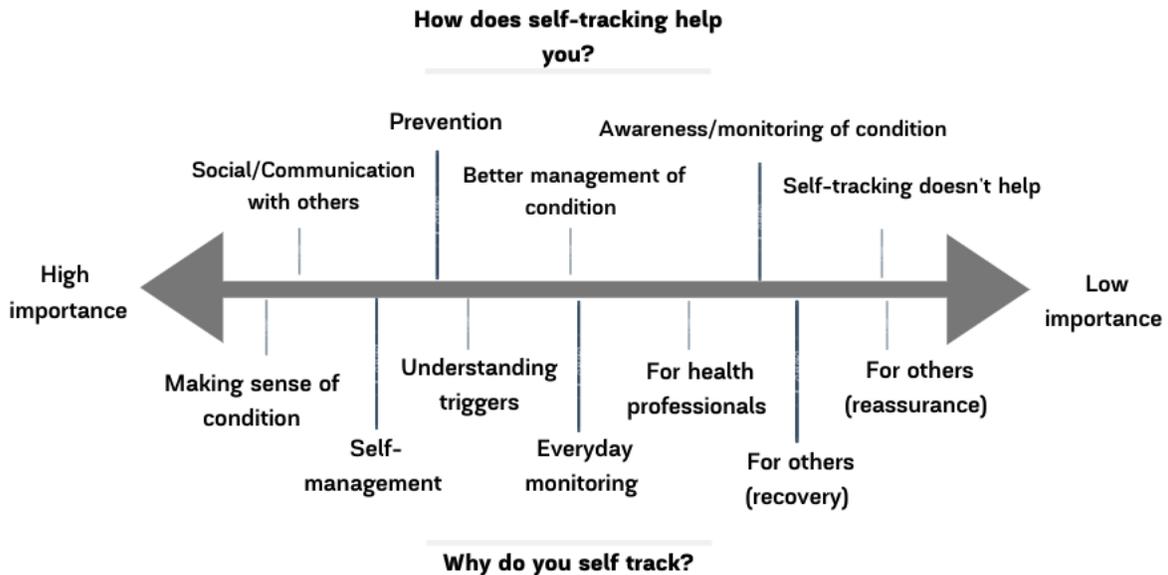


Figure 4: Themes for questions “how does self-tracking help you?” and “why do you self-track?” indicated by level of importance

3.1.2 Participant responses to why do you self-track. Using the same method as above, participants categorized the answers to the question “why do you self-track?” into themes. The theme which was classified as being the most important was *MAKING SENSE OF CONDITION*, which had responses related to how self-tracking can “identify changes in mood” and to “to better understand my condition”.

In line with this theme, another participant indicated that they self-tracked “because it enables me to keep tabs on and consciously monitor my mood. Bipolar (especially Hypomania) has a habit of creeping up on me when I least expect it, so it pays to always be vigilant and not get lulled into a false sense of security. Self-tracking is a practical, straightforward way”. The second most important theme was titled

**Table 2: Summary table of types of tracking, examples of these and how they can be used to count experiences**

Types of tracking	Examples	How it's used to count
Pen and paper	Diaries, lists, calendar, post-it notes, self-made scales, keeping receipts, drawing/art, anniversary of life events	"Looking at number of activities on a calendar and see how they match to mood escalating"
Mental notes	Body scan, mental plan for day, tracking appetite, environment scan, personal hygiene, mindfulness, thought management	"Make a list of 20 things to do... if I get at least 5 done then that's good"
Social feedback	Share with friends/partner/carer	"Your carer or family friend can score your mood too, especially when you're unwell"
Technology based	Mobile apps, wearable technology, online mood scales, phone notes, bank balance, online forums, online research programs	"Use Bipolar UK mood scale. . . number 1-10 with qualitative statements. . . can relate to the qualitative statements and match the number"

*SELF-MANAGEMENT*, which had answers such as to "*be more efficient*", "*maintain balance*" and to "*stop spending all my money*". The next important theme was titled *UNDERSTANDING TRIGGERS*; one participant indicated that they self-track to "*prevent/work through triggers*" and that self-tracking through "*writing feelings. . . helps me to put things into perspective when I calm down, it allows me to see how heavy the trigger was*" and lastly to "*to try and prevent triggers*". The fourth most important theme was titled *EVERYDAY MONITORING/ACTIONS*, where participants provided answers such as they self-tracked "*to not forget*" and that it was part of "*routine*". Another participant indicated that "*I don't really self-track except when extremely low. Then it's more putting it down on paper to be able to read back on it*". The fifth most important theme was titled *FOR HEALTH PROFESSIONALS*, where a participant answered that they self-tracked "*because my doctor told me so*", with another saying "*helps me and my psychiatrist to determine if my meds are working or need adjusting*" and to share "*with doc, shrink and mental health team*". Beyond health professionals, participants split the last theme for others, into *FOR OTHERS (RECOVERY)* which had answers such as "*help support others*" and *for others (reassurance)* which included the following answers "*show those I care about that I am trying to stay well*".

### 3.2 Exploring methods for self-tracking

Table 2 indicates the types of tracking methods participants reported during the workshops, along with examples of how this can be used to count experiences. Overall participants indicated n=50 methods to self-track with multiple accounts of how these are used to count everyday experiences such as mood changes.

**3.2.1 Participant responses to how do you count or keep track of relevant factors relating to self-management. Using numbers to self-track.** Participants indicated that they would use numerical scales such as the Bipolar UK scale [14] and other clinical and mood scales to understand how they are feeling. It terms of helpfulness, one participant indicated that it is "*really helpful to put a number to something that is extremely chaotic*". Participants described that

numbers can be emotional which can be demonstrated with the following quote "*But the thing we have this negative image that between 1-5 your just below average, you're a nothing you're a nobody, and the self-esteem and all that kind of lovely stuff and that's already kind of down at the bottom.. just ends up playing on it more..whereas I'm kind of like ooh I'm a 9. . . Actually I feel better, even though I feel shit.. It's an interesting thing as the number affects me.. that number says something but I'm taking it to mean something different. . . .Because where are all wide in that way*". It was also described how the range of numbers employed differed for individuals: "*1-10 I actually find more helpful. . . if it's just small, like 1-3 I just don't get it. . . it's just not specific enough. 1-10 more options*". Some participants stated that numbers are not for everyone, while others indicated they preferred a combination of quantitative and qualitative tracking: "*it is just a number I think you can be like is it 3 and 4 but it's the statement with the number then you can kind of relate... Relating to it, how to describe that stage.*"

**Using task completion to self-track.** Participants described the process of creating to-do lists and plans as a form of tracking, with the level at which this is completed being indicative of mood state. There were idiosyncratic views of what constitutes success in participants account here. For example, one participant stated "*make a list of 20 things to do... if I get at least 5 done then that's good*", while another participant said "*take three things of this to do list, turn the page over and write those down. . . this is more manageable and if you get one thing of this list today then that's great*".

### 3.3 Exploring challenges and opportunities for self-tracking

Finally we talk about how participants responded to discussions around challenges and opportunities for self-tracking technologies. We will also touch on how participants perceived the EWS checklists combined with their attitudes towards technological opportunities in self-tracking.

**3.3.1 Participant responses to what challenges arise when self-tracking.** Table 3 indicates the key themes that arose from participants when asked about challenges for self-tracking. These responses are presented in hierarchical order including subthemes and quotes. The themes are presented in table format to preserve the detail that was discovered from the thematic analysis, and to provide examples in relation to the subthemes. The most commonly occurring theme (a challenge) that arose from the analysis was about internal factors that prevent tracking. The least commonly occurring theme was related to self-tracking technology tracking more than current technology.

**3.3.2 EWS and opportunities for sensing technology.** For EWS, overall participants engaged positively with the EWS checklists and indicated a number of common signs and symptoms that arose before an episode of mania and depression. A summary of the common EWS reported are described in Table 4. Participants were asked how they felt about a mobile sensing technology to detect EWS via a scenario and asked to share their views via post-it notes. Participants indicated *openness towards this technology* as indicated by the following answers: “*interested to find out how useful it could be*”, “*would give it a go*” and “*it would make what I struggle to do manually, automatic*”. Furthermore, participants shared answers which described *types of personalization and usability features* such as it needing “*simple language*”, “*personalized color layouts/color choice and dark at night mode*”, “*easy to use analytics, archive of stats, records*”. Other things that were uncovered in participants answers were in relation to the *types of data to sense* by the following answers: “*time spent of social media*”, “*measures how many times opening and closing apps*” and “*an app to measure frequency and speech of speech*”. Lastly, participants did describe a series of cautions in their answers such as its “*not for those with paranoia*” or “*what if it got hacked?*” and “*is it safe?*”.

## 4 DISCUSSION

### 4.1 Exploring reasons for self-tracking

We found that the social, communicative aspect of self-tracking was of the highest importance for participants (as per their voting); this was reinforced by responses to how self-tracking helped them, i.e. by making sense of the condition, which was also highly rated in importance. This finding reflects existing research on the social nature of tracking in HCI; for instance, Epstein [9] suggests we reconsider personal tracking as *social tracking*. This also reinforces findings of a similar study [29] that asked similar questions on sociality in self-tracking, where participants described the following themes: made health management more manageable, promoted self-awareness, reflection and empowerment and supported their interactions with clinicians. However, there are some key differences. Firstly, in relation to the detail of the themes that were discovered by our participants around the reasons behind self-tracking compared to the aforementioned three themes in a similar study. Our participants described 5 key themes for the question “how does self-tracking help you?” and 7 key themes for the question “why do you self-track?” with further personal insights via answers to this question. The level of detail in the reasons for self-tracking presented here are all per participant discovery. Given the first-hand

experience of our participants who undertake the self-tracking on a daily basis, we felt as though the opportunity to be the experts here with *little professional research or design influence* will uncover better details for these crucial questions around self-tracking. Conversely, Murnane et al. [29] employed a more traditional approach of a survey method with a large group of participants (n=552) where the researchers themselves uncovered the themes from the answers to these questions.

Another notable difference is the emphasis on how self-tracking can help support interactions with clinicians, also as per Murnane et al. [29]. About two-thirds of the survey respondents in Murnane et al. reported using self-tracking data with discussions with healthcare professionals. However in our findings, though the social communicative nature of self-tracking was a major driving factor, this was more in the context with sharing with family, friends and significant others rather than a clinical interaction. Sharing with health professionals was identified as a theme for “why do you self-track?”, however this was at the lower end of the spectrum of importance for our participants. This comparison may shed light on the importance of the design of research and how it may yield different results, particularly as our study attempted to combine PPI with HCI approaches and thus push more towards participants as co-designers of that research, such as for our workshops and workshop facilitation, where P001 and P002 (with lived experience of BD) co-designed and led alongside the first author. This may have meant that other participants felt more relaxed to share their experiences, away from *probes* connected to a more clinical environment. As mentioned, the Murnane et al. study used a survey approach where participants may have associated this type of research with a clinical setting, which could have influenced the clinical focus in the results to these questions. In contrast, our workshops—sited in a café and a meeting house—avoided a university setting as this can be associated with clinical settings, thus providing a more neutral space for participants.

We think research on BD and self-tracking, and mental health technology in general, can be more participatory using approaches akin to those described in this paper. The benefits to using this are as follows:

- Uncover rich details in findings that are led by the first-hand lived experiences of the participants which can appropriately guide mental health technology research and design
- Create a more neutral, open research and design environment which allows for participants to feel encouraged to share removed from expectations, fear or judgment
- Empower users to guide the research and design by experience

### 4.2 Exploring methods for self-tracking

In terms of self-monitoring practices for those with BD, our findings are congruent with the current research in terms of complexity [26, 29]. From the 18 participant who attended the workshop, 50 methods of self-tracking were indicated which fell into the categories as follows: pen and paper, mental notes, social feedback and technology-based. This too reflects the work of Murnane et al. [29]. Future work should consider to expand these categories beyond these four categories as seen in the work of Rooksby et al

**Table 3: Themes and corresponding sub-themes for question “what challenges arise when self-tracking?” with example quotes**

Themes	Sub-themes	Examples
Internal factors that prevent tracking	Difficulty tracking when unwell	<i>“Self-tracking tends to go out of the window when we’re going on the down”</i>
Personal factors that impact and prevent the process of self-tracking	Being honest with yourself and others when tracking	<i>“I think sometimes I can also skew the results.”</i>
	Poor memory and forgetting to track	<i>“. . . but that pops up, with notifications and ask twice a day about how you’re feeling. I think that’s one of the biggest problems, because I forgot.”</i>
	Lack of motivation	<i>“It’s kind of motivation as well. You know, some days we wake up you think “I don’t want to do it anymore”</i>
	Lack of discipline	<i>“None of is any good if you’re not disciplining yourself to look at the information.”</i>
Experience of tracking can be negative	Reminder of feeling low	<i>“it will highlight that your mood is creeping down”</i>
The process of tracking can be a negative experience and a reminder of ill health	Can become obsessive	<i>“It can become obsessive for some people, which makes it a negative thing to self-track. So you’ve got your 10,000 steps a day goal, but if you may not raise your head by a certain time, you might be like, well you’ve got a go for a run now for yourself”</i>
	Tracking can be counterproductive	<i>“But do I really want a reminder, I don’t know why I was feeling worthless, like a piece of shit. Is that going to trigger me off later on? By looking at it to remember that that’s the time and this happened and you’re going backwards”</i>
	Too much insight is negative	<i>“if you have too much insight, it can actually kill you because you know so much that there’s no end.”</i>
	Tracking can be punishing yourself	<i>“Tracking the moment after the moment and it’s quite like I said painful.”</i>
Mental health stigma and shame	Not wanting to leave a record of your health	<i>“In my case, I’m half Indian and half white and the way I live my life is actually more Indian Asian. So what’s happening Yeah, actually, things like I need to take note, you know, when they’re saying do a journal do a diary, I wouldn’t do any of that. I don’t want people within my family to know that I’m unwell.”</i>
Avoiding tracking to hide mental health struggles because of external and societal pressures	Stigma around mental health	<i>“So the stigma that would then follow my family so my child would not be able to get married, because they’d be seen as being unwell because I’m actually the father and I was unwell, so if you see genetics and things like that, there’s a lot of kind of that whole thing a stronghold in the community behind of it.”</i>
	Shame	<i>“Because I think there’s a lot of shame because well, I know I personally feel a lot of shame.”</i>
Lack of third party support when self-tracking	Lack of support with the results of tracking	<i>“ when tracking they don’t offer you any kind of support within the results or anything like that. That’s all on you. So whilst it’s a good idea to do the self-tracking I think sometimes it’s hard, particularly if you’re not under a secondary mental health team or anything to follow through because you’ve got the information, you got the data, but you don’t know really what to do with it.”</i>
No availability of support from clinicians and services when self-tracking, especially in situations when things are not going well.	Clinicians are not open to the results of self-tracking	<i>“Recently I had an incident where I wanted to share my psychiatrist my sleep tracking on my Fitbit and I showed her, but she wasn’t even the slightest bit interested in it, and thought why am I even bothering. Because I thought that was relevant and if I can evidence that my sleeping is improving then surely that’s a good thing. Either she didn’t have time for it or she wasn’t bothered or you know it felt like it was a bit more wasted time and since then, I haven’t done it”</i>
Self-tracking technology should track more than current technology	No subthemes	<i>“If you could chip us all, and monitor everything, spending, the whole lot”</i>
Self-tracking technology should track as much as possible to monitor health and wellbeing		

**Table 4: Common EWS**

EWS	Common symptoms
Depression	Low motivation/can't get started Difficulty concentrating Low in energy Feeling tired/listless Loss of interest in activities
Mania	Ideas flowing too fast Stronger interest in sex Spending money more freely Racing thoughts More talkative

[38] which considered type of technology such as physical devices, apps, exergames and web apps and also considered type of activities tracked such as walking, physical exercise, food and drink, weight and size and sleep.

Our novel findings are in relation to how these are used to count, turning a 'qualitative' experience into something quantitative. A characteristic example we saw was one participant stating "*make a list of 20 things to do... if I get at least 5 done then that's good*". This shows how situated and particular the perception of a successful day is for individuals, in this instance a 25% completion rate indicated a "good" day. Whereas, for current online to-do lists the model is to set a number of items with a particular deadline, where 100% completion equals ideal productivity. This is similar to the discourse of fitness trackers in the QS community and their particular normativity [39], where an invisible ideal is set without accounting for individual differences; Spiel et al. state that "*technologies do not facilitate a better life: they define it, without oversight, without transparency, using emotional design tricks to engage in a progressive redefinition of what it means to be human*". Being able to set your own level of completion or productivity—an experience of a count—may be more suitable in the case of self-tracking technology for BD, as one's practices of turning experience into quantitative data is likely to differ from person to person. This is further echoed in the work of Rapp and Tirassa (2017) on the Theory of the Self for Personal Informatics [37] who suggest that such personal informatics tools with a focus on behavior change aim to modify specific behaviors (e.g. sedentariness) based on standard that may not be chosen by the user themselves. By placing the user at the heart of the process of change, is more likely to increase wellbeing as the user can find their own goals and ways to "happiness" based on their own *peculiarities*. Further, research looking at data visualization preferences concurs with this, specifically for those with central nervous system disorders, with BD forming a large part of sampled papers in a recent study: Polhemus et al. [34] found absolutely no consensus, where preferences ranged between graphical formats as well as non-graphical and textual descriptions. Polhemus et al. also found there was a large focus on how users valued the ability to provide contextual information when interpreting visualized data, such as annotating to provide "internal context" alongside a numeric score. In addition, Polhemus et al. described that the ability to provide the context behind the

numbers connected the numeric with the qualitative, and was seen as valuable when communicating with healthcare providers, as it enhanced the users' memories of past experiences. We find this is also echoed in personal informatics research where it is urged to recognise that data can be meaningful in the context it is produced, but may lose meaning when it is removed from that context [9]. Future design consideration of self-tracking technology should take into account the complex nature of this 'qualitative-to-quantitative' phenomenon, and accordingly we recommend the following design considerations:

- Provide the user with choice as to whether the self-tracking technology (e.g. tasks and feedback) is quantitative- or qualitative-focused
- Be able to define the quantitative if needed e.g. being able to pick numeric scales (e.g. 1-3 or 1-10), and define what numeric success constitutes (e.g. set a unique and adaptive percentage of success which moves away from a 100% completion model)
- The ability to augment quantitative data with qualitative experience (e.g. being able to annotate quantitative data with 'internal' context).

### 4.3 Challenges and opportunities for mobile technology

In line with [26][29], we found considerable challenges for self-tracking BD, with the most common being personal 'internal' factors that prevented tracking. Participants described that the sense of self is in 'flux', meaning that it is often difficult to self-track during periods of feeling unwell, issues around memory, motivation, or self-discipline. When presented with a scenario around mobile technology that could passively sense clinical factors, such as EWS, participants displayed a degree of openness towards this technology; to sum up, one participant stated such a technology would "*make what I struggle to do manually, automatic*". Relatedly, there is a growing body of research on the utility of sensing various types of digital data as a form of self-tracking for BD severity which responds to this challenge, including sensing factors such as number of text messages [4, 11, 35], phone calls [11, 15], emails [35], GPS data [15, 33], voice features [13, 19, 27, 28, 40], accelerometer data [3, 12, 40], and app usage [1]. In our study, participants responded positively to Early Warning Sign checklists and described a series

of common signs and symptoms, as well as specific symptoms, that arise before a period of relapse. This is in contrast with the ways in which current self-tracking mobile apps for BD tend to be developed without reference to clinical guidelines like EWS [31]. Beyond self-tracking factors suggested by current research, our participants indicated the utility of many factors, outlined in our recommendations below. In our study, participants also expressed caution. The experience of self-tracking can be negative, in that the process of self-tracking can be a reminder of feeling low and that too much insight can be negative, or counterproductive. As one participant stated with reference to the mobile sensing technology scenario: “*it is not for those with paranoia*”. Self-tracking may be detrimental in the context of relapse where it serves as a reminder of deteriorating health.

Future designs of mobile self-tracking technology should consider these factors to support the *self* in self-tracking. In sum we recommend the following design considerations:

Future designers should consider the use of EWS checklists as a clinically validated tool as an underpinning of self-tracking technology for BD

Having passive sensing methods in mobile self-tracking technology for BD responds well to a commonly described challenge and designers and researchers should consider the following factors to sense (presented in hierarchical order): sleep levels, levels of social interaction, medication usage, wearable data, financial data, number of diary entries, food and calorie intake, to-do lists completion and employment information (e.g. sick days)

The experience of self-tracking can sometimes be a negative one for those with BD. The level of user-control over self-tracking tools should be high; sensing streams should be manipulable in a meaningful way, what is collected must be controlled, and disengagement for periods should be easy and available without interactional costs.

#### 4.4 Designing mental health technology: personal reflections of a design researcher

In this final section in our findings discussion we turn to consider the nature of the investigation into BD we conducted, and the ways in which the first author in particular featured within that process. Thus we offer a reflexive account of this, presented in the first person by the first author:

This paper formed part of my doctoral research, where I was part of a multidisciplinary doctoral training course in Computer Science. I have a background in pure psychology (BSc in Psychology and MSc in Psychological Research Methods) with experience of conducting research in the mental health sector. It was a long learning exercise of how to apply the methods and skills I learnt in Psychology and working in the mental health sector, to then develop technology which is something you had to learn “on the job”, as they say. There are huge benefits from having the background in Psychology for the task at hand, as empathy is something that that I was able to cultivate in previous roles and could enthusiastically apply during the process of design to ensure that the users were feeling empowered to shape technology in meaningful ways. My background helped me to build relationships with users and enable roles such as lived experience co-facilitators and co-designers, both at the heart of the methods developed as part of this research. It also pushed me to

notice the current limitations in design of mental health technology, and reflect upon how user involvement is variable and sometimes tokenistic, and that we as designers and researchers need to be better at involving users in mental health technology, even when that can be difficult. The ability to put myself in their shoes, by having spent much time in the mental health sector, meant I became an advocate for user needs and felt dedicated to them being heard. I was invited to peer-to-peer events, formed key relationships with BD charities and also had many users comment on how seen they felt “seen” during talks about the research, even one woman saying “it had brought tears to my eyes” because it is so rarely, genuinely, asked what those with BD want in relation to treatment and management, which unfortunately is the sad reality of severe mental illness.

However, it was the same experience that limited me at times. Often I felt I was a “jack of all trades and master of none” during the course of this research. There were times where I was a psychologist, other times where I was a UX researcher, some other times wearing the hat of an HCI academic and even playing the role of a data scientist. Often I felt like I wasn’t doing any of them well, I was just doing them because that is what the field requires. Mental health technology is such a multifaceted discipline, albeit in its infancy where the requirements of what is needed to create good technology is still being explored. As it’s in its infancy, it lacks precedence for what constitutes good practice as it is the job for us, as current researchers in the field, to create this. The absence of a framework can sometimes be confusing and other times, troubling. For example, working with those with severe mental health issues carries associated risks. When this is being conducted in a more traditional clinical setting, those risks are known and there are associated training and operating procedures to ensure the safety of the researcher. However, when doing the same work in a non-clinical setting, a different approach is needed: operating procedures are not as regimented as those in a clinical setting, for obvious reasons. In the process of empowering those users with severe mental health issues to be co-designers or co-researchers, the therapeutic line which you are trained on in formal clinical training (during my experiences as a mental health researcher), became a lot more blurred. For example, accepting users’ connection requests on social media or giving them access to personal phone numbers, conducting meetings alone, etc., are all things that I would not do in previous research roles prior to my PhD, in line with particular risk procedures in place; however I willingly did during my current doctoral research. Whether it’s right or wrong, risky or not risky is something that is up for debate. But what I do know is that there is huge amount of up-skilling needed in the mental health technology space where contributing disciplines need to be better at sharing practices and expertise to ensure appropriate development, not only to improve the design and deployment of technology, but also to support the development of researchers who are trying to be the “jack of all trades”. More help is needed for them to be the “master of none”. Appropriate supervision is also needed from a multi-disciplinary team, where it’s important to highlight knowledge gaps and work (humbly) towards filling those. Sharing best practice around researcher development, including researcher safety (such as regular debrief and counselling) and wellbeing, is

needed to design this new breed of researcher which is not a psychologist and not even a computer scientist but something along the lines of a computer psychologist.

#### 4.5 Limitations

The data presented here is limited, has a small sample size, and is unlikely to represent the views of the larger population of those with lived experience of bipolar disorder. A large percentage of our participant group were in points of remission, and it is likely that the account of those experiencing relapse is not represented in this research. The participants in this research had existing practices of self-tracking, and were likely to contribute a more detailed viewpoint compared to those who had just started their self-tracking journey. Future work should consider a larger sample with individuals across the spectrum of bipolar disorder severity and self-tracking practices, to account for the full self-tracking experience.

#### 4.6 Future work

To explore how findings and recommendations from this research can be applied in practice, our future works aims to use this research to design and deploy a prototype self-tracking mobile tool which will combine both active and passive sensing to understanding EWS of relapse for BD on a broader spectrum. The findings and recommendations here will be translated into design recommendations and processes to inform future technologies in the BD self-tracking space, and will be subject to further review with BD persons. Beyond this, we think our findings and recommendations could extend more generally to health and wellbeing technology. Future work should consider this. Equally, while we focused on mobile self-tracking, future work should consider beyond this, e.g. other interaction modalities and scenarios, such as those enabled by sensing infrastructures developed for ubiquitous computing or Internet of Things. Though this work shed light on the complex experience of translating qualitative experiences into quantitative, future work should work out how to situate this into models seen in prior HCI research such as the Tracker Goal Evolution Model which describes this process in the case of activity trackers [32]. The categories of and motivations around self-tracking seen in this work (such as pen and paper, mental notes, social feedback and technology-based) could be understood in more depth by relating to the categories seen in the work of Rooksby et al [38]. Furthermore, future work should extend the understanding of reasons behind self-tracking to consider the kinds of questions that people ask about their information such as status, history, goals, discrepancies, context and factors [43] to gain insights about their personal experiences.

### 5 CONCLUSION

We explored reasons, methods and challenges for self-tracking for those with lived experience of BD. Our findings for this differed from current literature, as previous studies indicated a more clinical basis to tracking compared to the more social, communicative basis to tracking we located. Differences of methods in investigating this may explain this, as the current study employed a more participatory method of research combining principles of PPI and HCI to

create a peer-to-peer environment with the ultimate goal of empowering users. Our findings documented a large level of complexity in self-tracking, where 50 methods were described. We suggest that future designers should consider this to create technology with choices to convert these experiences, compared to the blanket normative ontology that is currently seen in the self-tracking space. Self-tracking technology should be designed to account for personal struggles for those with BD experience, and provide users with the ability to have passive sensing methods coupled with increased control, constitution of 'success', and ability to avoid tracking easily. Lastly, we offered a reflexive account of navigating through the emerging discipline of mental health technology, and the intersections that encompass this.

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