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**Article:**

McKinney, P. [orcid.org/0000-0002-0227-3534](https://orcid.org/0000-0002-0227-3534), Peacock, C. and Cox, A. (2024) The self-tracking information literacy practices of LGBTQ+ students: empowerment through self-knowledge. *Journal of Information Literacy*, 18 (1). pp. 182-202. ISSN 1750-5968

<https://doi.org/10.11645/18.1.561>

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# The self-tracking information literacy practices of LGBTQ+ students: empowerment through self-knowledge

## Abstract

This paper explores the self-tracking information literacy practices of LGBTQ+ students, how these are connected to LGBTQ+ identities and whether these practices are perceived as empowering. LGBTQ+ individuals experience particular challenges with physical and mental health, and self-tracking is one way to empower people and support health and wellbeing. Similarly, developing information literacy in a particular landscape can be empowering. Six semi-structured interviews were conducted with students who identified as LGBTQ+ self-trackers. Four previously discovered dimensions of information literacy in self-tracking framed the design of the interview questions: understanding the value of quality in data inputs; the ability to interpret tracked information in the context of the limitations of the app or device; awareness of privacy; and the nuances of sharing tracked data. Collaborative thematic analysis revealed that participants find it useful to monitor their physical health, and tracking supports mental health, which is experienced as empowering. The heteronormative assumptions of apps influenced their perceived usefulness, and what data could be collected. There was some distrust about the way apps used data, but this risk was accepted, typically because the convenience of the app outweighed concerns about privacy. Data sharing took place: restricted due to self-consciousness or fear of being judged, but embraced when there was a feeling of working towards a shared goal. Information literacy in this landscape is related to developing critical awareness of when and how self-tracking can support health goals; the limitations of the apps and devices, particularly for those undergoing transition; privacy implications; and the nuances of social sharing.

## Keywords

LGBTQ+, Transgender, Self-tracking, corporeal information, Data privacy, Data sharing

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## 1. Introduction

This paper reports an exploratory study to understand the self-tracking information literacy practices of LGBTQ+ students. The paper focuses on an under-researched group, the LGBTQ+ community. This refers to lesbian, gay, bisexual, transgender, and queer people, with the plus standing in for a wide range of other identities such as pansexual, asexual and aromantic, and intersex. For clarity, this paper will use the definitions provided by the UK's leading LGBTQ+ charity, Stonewall (n.d). The health of people identifying as LGBTQ+ is a concern as it is generally poorer than the cisgender, heterosexual population, and there are specific challenges with mental and physical wellbeing (Jia et al., 2022). British LGBTQ+ people experience higher incidences of anxiety and depression than the general population, yet avoid seeking healthcare because of concerns about discrimination (Bachmann and Gooch, 2018). Trans people may choose to undergo medical transition, which can involve a range of interventions such as hormone replacement therapy and gender-affirming surgeries, leading to greater healthcare needs (Government Equalities Office, 2018) and therefore greater interaction with a system many perceive as discriminatory. In this troubled landscape of LGBTQ+ health, it is vital to research self-tracking as a method for maintaining health and wellbeing in the LGBTQ+ population.

Many people engage in self-tracking to support their health goals. Self-tracking of physical activity; sleep patterns; heart rate; menstruation; diet and nutrition; and mood and mental health has been made possible through the use of popular mobile apps and devices. Self-tracking facilitates the self-management of non-communicable diseases, behaviour change, and the achievement of

desired health outcomes, such as weight loss (Ernsting et al., 2017; Lunde et al., 2018). A sense of empowerment through information and self-knowledge is often given as an explanation for the rise of self-tracking, in that it enables control of aspects of everyday life (Lupton, 2016; Wieczorek et al., 2022). Empowerment can be defined as a process by which people gain mastery over their lives (Rappaport, 1987). It is variously linked to the enhancement of wellbeing and personal control, improving people's lives and communities, and the achievement of personally meaningful goals (Cattaneo and Chapman, 2010).

However, there are barriers to this empowerment, for example: inaccuracies in data or outputs; the effort required to record some types of data; and fear of becoming obsessed with tracking or fear of surveillance inhibiting the collection of data (Ancker et al., 2015; Attig and Franke, 2020; Baker 2020; Lupton, 2016). In addition, the binary gender assumptions and potential for surveillance from apps and devices could be particularly problematic for LGBTQ+ community and their varied identities (En & Pöll, 2016; Sanders, 2017). This paper will explore these issues of empowerment in the self-tracking landscape to understand the empowering potential of self-tracking for the LGBTQ+ community.

Information literacy is an important dimension of this empowering effect of information and knowledge through self-tracking. Information literacy is defined by UNESCO (2022) as *empowering* people to “to seek, evaluate, use and create information effectively to achieve their personal, social, occupational and educational goals”. This study adopts Lloyd's (2017) theory of information literacy in which it is understood to be a contextual sociocultural practice that connects people with three modalities of information - epistemic, embodied, and social sources - in any given information landscape. In this conceptual positioning of IL, empowerment comes from developing a “way of knowing” and an understanding of the value of these three modalities and how they are constituted by communities in the information landscape (Lloyd et al., 2014). In this study, the self-tracking practices are the information landscape, and this is created from three modalities:

- The **epistemic modality**, characterised by factual information derived from apps and devices, supported by formal health information from trusted sources;
- The **social modality**, characterised by information shared between users and their social circles, either on or offline;
- The **corporeal modality**, characterised by recording and codifying information from the body.

The information literacy of self-tracking has been studied in other communities (Cox et al. 2017; McKinney et al. 2019) and this study extends and develops understanding of self-tracking information practices with this community of LGBTQ+ students. Understanding the value of self-tracking for the LGBTQ+ community and how it can support their health is one way to address the disparity in health between this community and the general population. There is growing interest in the role of bodily information in information literacy and information behaviour research (Bates, 2018; Olsson & Lloyd, 2017), and in extending information literacy research into everyday life. This paper makes an important contribution to the understanding of information literacy in a health context and the value of codifying and recording bodily in the LGBTQ+ community.

The aim of this paper is to explore issues of empowerment in the self-tracking information literacy landscape of the LGBTQ+ community

The specific research questions addressed in this paper are:

1. What self-tracking practices do LGBTQ+ students engage with and why?
2. How do they interpret and use self-tracking information, and what are their attitudes to privacy, sharing, and data quality?
3. What connections do they make between their LGBTQ+ identity and self-tracking information practices?
4. Is self-tracking experienced as empowering?

## 2. Literature review

### *Information literacy and self-tracking*

There is a small body of previous research into information literacy in the self-tracking landscape (Cox et al. 2017; McKinney et al. 2019) that informs the present study. A qualitative study (Cox et al. 2017) focused on practices relating to tracking diet. It identified that self-tracking enables people to create and record epistemic information about their food intake. However, despite the strong relationship between food and the body, the bodily sensation from eating food was muted, with the focus on measuring and controlling body size and shape. The social modality focused on using social networks to select an appropriate app, but information about diet was not shared. This study identified four aspects of information literacy in the self-tracking landscape: understanding the value of quality in data inputs; the ability to interpret tracked information in the context of the limitations of the app or device; awareness of privacy and data ownership; and the nuances of sharing tracked data. A second quantitative survey study (McKinney et al. 2019) drew on these four aspects of information literacy of self-tracking to investigate the self-tracking practices of three groups: people with type 2 diabetes, people who run for pleasure with parkrun, and people with irritable bowel syndrome. Further insights from both studies are integrated below in the literature review.

### *Empowerment and Self-tracking*

Self-tracking is an information practice seemingly driven by the empowerment people feel through gathering information about the self, often to improve health. However, there are a number of barriers to the empowerment through information promised by self-tracking. Both users and experts, such as health professionals, have concerns about the accuracy of the information collected and output by such devices (Attig and Franke, 2020; Baker, 2020). Furthermore, there are concerns about inadvertent human error in recording data, and the possibility of not accurately recording data perceived as unwelcome, or “fooling oneself” (Dennison et al., 2013; McKinney et al. 2019). Health professionals tend to be sceptical about patient-collected self-tracking data because of a perceived lack of diligence in recording accurate data and the propensity of patients to not record or share unfavourable data (Ancker et al., 2015). There is an assumption in the self-tracking literature that “objective” data about the self leads to meaningful insight, however this is not necessarily the case as most people are not “rational data scientists” (Ohlin and Olsson, 2015).

Another source of inaccurate information comes from the abandonment of self-tracking. It seems that users only collect data intermittently or shift between monitoring different aspects of their lives. This can occur due to usability issues; mismatches between hopes of what the device or practice can achieve and the reality; privacy concerns; perceptions that tracking is too much effort or takes too much time, leading to demotivation; challenges in adjusting a daily routine to accommodate self-tracking; and a change in lifestyle or priorities (Attig and Franke, 2020; Shin et al., 2019). However, another major reason for ceasing self-tracking is so-called “happy abandonment”, meaning that an individual has achieved a goal or developed a healthy habit (Attig and Franke, 2020). Developing an awareness of when it is useful to start and stop tracking to align with health goals is one aspect of information literacy in this landscape identified in previous research (Cox et al. 2017).

Another barrier to empowerment through self-tracking information is the fear of obsession and addiction that often surrounds the practice (Cox et al. 2017). There is a discourse in the self-tracking literature about the perceived dangers of becoming obsessed with or addicted to self-tracking, with physicians in particular viewing the collection of too much data, particularly if unrelated to a specific health complaint, as a potential problem (Ancker et al., 2015). This can again lead to the input of only partial information. One side effect of this is that there is less data

available for unwanted surveillance, a phenomenon which Nafus and Sherman (2014) refer to as “soft resistance”. This may have some benefits to the user, but also degrades the quality of the information collected.

There are distinct risks attached to self-tracking that endanger its empowering quality. It is widely understood, at least in academic and professional communities, that apps routinely share data with third parties, but there is little transparency over what personal and identifying data is being shared and with whom (Grundy et al., 2019). Free apps provide services in exchange for access to individuals’ health data, however it is not always clear whether members of the public are aware of this data sharing, or indeed have a well-developed conception of what this “participatory surveillance” can mean for the privacy of their personal data (Healy, 2021). Baker (2020) goes further, exploring the idea that people adopt self-tracking technologies with the expectation of “personalised benefit” because they feel empowered by self-control. However, these technologies offer unprecedented means of exploitation and control by corporations and governments, such as linking tracked data with access to health insurance. A widely found phenomena with social media may be relevant here: the privacy paradox. This observes that while users are troubled by how their social media data might be used, they tend to be fatalistic about avoiding this exploitation and ultimately choose to sign away their privacy (Gerber et al., 2018). Previous research found that what type of data is voluntarily shared, with whom, and through what medium is something that concerns self-trackers (Cifor and Garcia, 2020; Krebs and Duncan, 2015).

### *Information behaviours and practices of LGBTQ+ communities*

A growing body of literature examines the information needs and information behaviour of people who identify as LGBTQ+ (Huttunen et al., 2019; Huttunen et al., 2020; Pohjanen and Kortelainen, 2016). There are many examples focusing on the health information behaviours of LGBTQ+ people, and health information seeking is foregrounded (Delmonaco and Haimson, 2022; Jia et al., 2022). This is often presented in the context of social media activity, where online “safe spaces” offer access to communities for information gathering and sharing (Fox and Ralston, 2016; Haimson et al., 2021; Hawkins and Giesecking, 2017; Karami et al., 2018). There is little research specifically into the information literacy of the LGBTQ+ community, an exception being Hardy (2021: 107) who positions queer information literacy as “a process through which LGBTQ people find, recognize, share, and create information related to their sexual and gender identities”; although this is not well-connected with the theoretical underpinnings of information literacy in library and information science literature. Huttunen et al. (2019) touch on the embodied or corporeal element of transgender people’s information landscape, and Kitzie et al. (2022) take an information practice perspective. The present study differs from this body of literature in that it adopts the practice-theory informed theory of information literacy landscapes (Lloyd, 2017) which highlights the importance and value of embodied information.

### *Gendered self-tracking*

A critical feminist perspective asks questions about the gendered nature and normative character of tracking, which would impact the empowering value of the information it provides. The male is often the assumed norm in the design of technologies: for example, studies of Fitbit show that it wrongly estimates calorie usage for women because assumptions in the calculations are based on male fat and muscle distribution (Criado Perez, 2019). Many apps only have binary gender choices for user profiles, which is alienating for some members of the LGBTQ+ community (Cifor & Garcia 2019; En and Poll, 2016). In their study of one device, Cifor and Garcia (2019) found only limited alterations had been applied to make it suitable for women’s bodies, and the tone of smart coach messaging and the expected competitive social interactions reflected a masculinised world-view. Even apps developed for women make strongly normative assumptions which are not necessarily neutral or benign (Baker, 2020). While individuals may track menstruation for a variety of reasons, such as to be aware of their bodies in different phases of their cycles and to inform discussions with healthcare providers (Epstein et al., 2017), period tracking apps tend to assume that

conception is the purpose for which they are used (Healy, 2021), which is potentially alienating for the LGBTQ+ community.

There is not a great deal of published research into the distinctive nature of LGBTQ+ self-tracking, despite the interest in health information behaviours in this community. En and Pöll (2016) discuss a queer perspective on self-tracking that seeks to challenge normative assumptions about the alignment of bodily characteristics with gender identity. They express a desire for self-tracking app developers to “open up” their apps to facilitate use by people with diverse bodies and more diverse self-tracking motivations, for example, those who are not motivated by competition. Kitzie et al.’s (2022) model of LGBTQ+ information practices makes a distinction between protective information practices that are used to support the self and the community in health matters, and defensive information practices, which are reactive practices developed in response to perceived barriers. Information seeking by trans people is often prompted by a feeling of body dysphoria (Huttunen et al., 2019).

Thus, the self-tracking literature tells us a lot about how people empower themselves through self-tracking, but also about the problems. Many of these, including inaccurate data from devices, information avoidance, and privacy concerns, are also identified as aspects of information literacy in this landscape. As a minoritized social group, it is critical to try to understand how those who identify as LGBTQ+ use the affordances of self-tracking technology. This paper addresses a significant gap in the literature through the exploration of how people with LGBTQ+ identities experience information from self-tracking practices.

### **3. Positionality and motivation for the study**

With research of this nature, it is important to reflect on the positionality of the research team, and how this affects our underlying assumptions and research approach (Kitzie et al., 2022). Pam McKinney is a cisgender heterosexual middle-aged white woman, she is a Fitbit user. Andrew Cox is a cisgender heterosexual middle-aged white male. He self-tracks as a keen runner. McKinney and Cox have a history of research in self-tracking and were keen to extend knowledge of the information literacy landscapes of self-tracking with the under-researched LGBTQ+ community. Corin Peacock was a student recruited to the position of research associate and were able to draw on their identity as a white transmasculine nonbinary individual, who is aromantic and asexual, to support participant interaction, data analysis, and accurate presentation of the results.

### **4. Methodology**

This study investigates an under-researched form of experience; as noted above, there have been very few studies which have sought to understand the self-tracking practices of LGBTQ+ people. As a result, an interpretivist qualitative methodology was adopted. The interpretivist research paradigm acknowledges the complex and multiple realities of the participants (Pickard, 2013). With this perspective it is possible to explore the beliefs, motivations, and reasonings of each participant within their social situation and make sense of their lived experience (Backett-Milburn and McKie, 1999). A qualitative approach is consistent with this worldview, and in this study, semi-structured interviews were used as a data collection method. This enabled the researchers to explore the practices and views of these participants in depth. The study received ethical approval from University of Sheffield Information School, and the principles of informed consent and the preservation of the anonymity of the participants guided the research process throughout.

Participants were recruited using an invitation distributed through LGBTQ+ Facebook groups, mostly those associated with LGBTQ+ societies at British universities. The call for participants invited individuals to register their interest on a Google Form if they self-identified as an LGBTQ+ student who engaged in self-tracking. Due to the limited time available for the study, which took place in the context of a 100-hour Postgraduate Taught Student research internship, it was only

possible to recruit six participants. Summary details of how each participant met the criteria can be found in

Table I. Participants' LGBTQ+ identities are given in their own words.

| Participant | Pronouns | LGBTQ+ identity   | University                 | Tracking device(s) | Tracking app(s)              |
|-------------|----------|---|----------------------------|--------------------|------------------------------|
| 1           | she/her  | I'd just probably say queer. I don't really specifically identify as anything...Well, gender-nonconforming, but definitely female.  | University of Sheffield    | Fitbit             | Fitbit app                   |
| 2           | she/they | I guess the easiest thing to say is that I'm a trans woman.   | University of Birmingham   | Apple watch        | Apple Health<br>MyFitnessPal |
| 3           | she/they | I am bisexual. I do not identify as a woman, but I also don't identify as non-binary. Kind of genderly ambiguous.   | Open University            | Mobile phone       | Flo<br>Lose It!              |
| 4           | she/her  | I identify as bisexual.   | University of Durham       | Mobile phone       | Samsung Health               |
| 5           | she/they | I mainly identify as pan, so pansexual. And then my gender – I'm genderqueer, that's probably the best way to describe it. It's very complex, but genderqueer is probably the best label at the moment. | Birmingham City University | Mobile phone       | Pedometer<br>DBT Coach       |
| 6           | she/her  | I identify as queer or bisexual cis female.   | University of Sheffield    | Mobile phone       | Lose It!                     |

Interviews were approximately half an hour long, and participants were asked a series of nine semi-structured questions about their LGBTQ+ identities and the perceived relationship between this and their self-tracking. Questions about their self-tracking practices, such as what data is collected and why, were included in order to explore and articulate the landscape of self-tracking.

Finally, questions were included that were informed by previous research into self-tracking practices which identified four aspects of information literacy in the self-tracking landscape: understanding the value of quality in data inputs, the ability to interpret tracked information in the context of the limitations of the app or device; awareness of privacy and data ownership; and the nuances of sharing tracked data (Cox et al. 2017; McKinney et al. 2019). The interview schedule can be found in the appendix.

The interviews were conducted by a member of the research team who is queer and trans, and who was a student at the time of the study. This insider perspective facilitated recruitment and helped to put participants at ease, enabling open and frank discussions due to the researcher's understanding of the terminology used and experiences described by participants. Insider research, while not without potential problems to do with consent, confidentiality, and objectivity, has enormous potential to improve understanding of the lived experience of marginalised participant groups, and to contextualise and communicate findings (Devotta et al., 2016).

The interviews were audio recorded and transcribed by the interviewer. The transcripts were thematically coded separately by each member of the research team, who then met to discuss and categorise the emerging themes and sub-themes (Braun and Clarke, 2013). Through writing and discussion, the focus for this paper was collaboratively developed.

## 5. Results

The findings present data related to the purpose and motivation for tracking to establish the self-tracking landscape; the four aspects of information literacy in the self-tracking landscape: data interpretation and use; data privacy; data sharing; and accuracy and data quality. Finally, data related to the link between self-tracking and LGBTQ+ identities is presented.

### 5.1 Tracking purpose & motivation

Participants described a number of motivations for their use of self-tracking apps. These include:

- To lose weight (P1)
- To support a healthy diet (P1,P3 P6)
- To monitor a specific health condition (P1),
- To support mental health (P2, P3, P5)
- To support medical transition (P2)
- To understand menstrual cycles (P3)
- To encourage physical activity (P1, P5)
- To understand sleep patterns (P1)
- To identify periods of stress (P1)
- To feel good about oneself (P2, P4)

Tracking practices focused on understanding their own habits and patterns of behaviour, and observing changes over time. For example, a desire to lose weight through exercise motivated the recording of steps; diet was monitored to ensure proper eating habits during a period of anxiety. These chime with the experiences of many self-trackers and suggest that empowerment is derived through self-motivation to achieve desired objectives. The positive effect tracking can have on anxiety was highlighted: the data provided a concrete record of a factor they were concerned about, and thus was reassuring and grounding.

*“So I track my food to help with my anxiety. Just to get an idea of if I have eaten a good amount of food. Because if I don't track then sometimes it'll get to about 8PM and I'll feel hungry, and then I will freak out thinking, am I allowed to eat, am I not? And this gets rid of that anxiety for me” [P3]*

Participants also emphasised the value of automatic/passive tracking, particularly of steps, because it eased the effort of remembering to input data and reflects a pragmatic approach to tracking. It is a story of effort minimisation, which is a fairly typical tracking behaviour.

Although participants tracked purposively, they revealed that their self-tracking practices were rather fluid and varied significantly over time depending on their needs. This included changes in the apps that were used, frequency of tracking, and factors tracked.

*"It's complicated. I haven't been tracking stuff for the past few weeks, but I have over the past few years, intermittently, I've tracked exercise and calorie intake at different times and sometimes both at the same time" [P2]*

## 5.2 Data interpretation and use

Being able to interpret tracked data is an aspect of information literacy in this landscape. Overall, participants displayed a good understanding of what tracked data meant, and the value it had for them personally in pursuit of their self-identified health goals. Automatic tracking was valued for both for the lack of effort, but also the simplicity of the data outputs. Food tracking was acknowledged to be fiddly and time-consuming, and the outputs were sometimes not particularly meaningful.

*"Lose It! will say, oh, this food helps you keep on track. And what it means by that is that when I'm eating this food, I'm generally having a lower calorie day, which I do not like and is not relevant to me" [P3]*

Some data, for example recording individual ingredients in home-cooked food, was seen to be too complicated, and some expressed a desire for simpler technology that would minimise outputs to just those perceived to be useful.

*"it would be nice to have a simple mode that doesn't show you calories and just says, okay you've moved, or something" [P2]*

Fear of obsession with tracked data also came up as a theme in the data, and the impact this could have on mental wellbeing:

*"I've also found that if I paid too much close attention to it, it ends up becoming something that I spend too much time thinking about....But I still feel like I'm trying to find a balance between paying too much close attention to the stuff that it makes me worry and obsess too much, and then just leaving it and not doing anything at all with it" [P2]*

Two participants described tracking as being like a video game and identified this as both a positive motivator to track and reminder for tasks such as exercise.

*"It is a little bit like a video game, in a positive way. You like scoring higher, and it's good for your body, so I respect that. So, yeah, it's good" [P5]*

Again, the way this experience is described implies a strong sense of pragmatic use and self-control through exploiting the affordances of the tracking device.

## 5.3 Data privacy, data sharing and data quality

Although participants were *concerned* about their data privacy, there did not seem to be an unusually strong sense of *worry*. Indeed, while some participants expressed distrust in the apps they used, all acknowledged that they simply accepted or didn't care about these risks.

Some felt the risk was acceptable because the data being collected was not sensitive:

*"Because the data I have on there is not something I consider personal or important, I'm not at all concerned about the security of my data. I don't feel that anyone could do any*

*damage to me by knowing what I had for breakfast on the 23rd of March, or how heavy my period was last week” [P3]*

From a critical privacy perspective, a willingness to use devices that automatically collect bodily data could also be seen as quite risky, as it tacitly accepts a level of surveillance.

For others, this was because the convenience of the app was experienced as outweighing their concerns about privacy, and it was described as a “trade-off” - one that they were mindful of. Sometimes there was a sense of fatalism about loss of privacy, that this is simply the way things are in the modern world. Several participants did, however, take additional steps to protect privacy, such as providing the minimum amount of information necessary for the app to function, or even giving slightly incorrect information, such as an altered name or birthday. This suggests that participants were willing to take some steps to protect the privacy of their data, but only so long as those steps were simple and did not impact their use of the apps.

Overall, participants had mixed views about sharing the data they collected, although the general trend was towards keeping it private. This was based on two factors: a perceived risk of judgement or competitiveness, and a desire to avoid impacting others.

Several participants mentioned that they would be nervous about sharing data with others – either directly or by using the social media element of certain apps – because of a worry that others would negatively judge them. Similarly, Participant 1 spoke about the competitiveness inherent in certain apps such as Strava and cited this as her reason for not using it to share her data.

*“I don't do - like for example, Strava is a social media thing where people can comment or like your latest run and stuff like that. But I'm not interested in that. I know my some of my family and friends are, and they always ask me why don't you ever put your runs on there? And it's like – because I don't care if you like my time or not” [P1]*

Two participants also spoke about not wanting to burden others – particularly friends – with information gathered through self-tracking for fear that it might make them feel uncomfortable.

*“Usually, I wouldn't with regards to the step stuff because I struggle with an eating disorder. I know that talking about your step count to people randomly can be quite triggering – if I just suddenly went into my friends like, oh my gosh, look at me, I did ten thousand steps today! That's going to make them feel like shit.” [P5]*

When participants did decide to share data with friends, family, medical practitioners, or online, this was highly based on relevance. For example, if the data collection was part of a collaborative effort to run 100 km as part of a team, or perceived as working towards a shared goal, such as with a partner on the same fitness journey. Some participants were more open to sharing in online groups because of the added anonymity or the sense of collaboration if in a specific forum. Others were hesitant about sharing data with strangers online. Similarly, participants had mixed feelings about sharing with medical professionals. While some were happy to give doctors and other practitioners access to tracked data to assist in healthcare – two having even been recommended by professionals to track this data – others were reluctant to share based on previous negative experiences of professionals not listening or not being interested in the data, or a concern about the information being used against their interests.

*“Depending on context – if I was going to the doctors for a physical thing, then yes, I'd be perfectly happy [to share] because that's their job. But if it's anything to do with ED stuff, mental health stuff – I would want to share it, but I also know that I have to be very careful. Because I don't want my bodily autonomy taken away and my autonomy for my entire well-being taken away by professionals because they think they know what I need better than what I know I need” [P5]*

Participants recognised issues to do with accuracy and quality of self-tracked data, and three key areas that affected trust were identified: the accuracy of the technology, particularly with regard to

automatic tracking; the range of input options; and the relevance of the data outputs. Some participants demonstrated a high level of trust in the accuracy of automatic tracking, while others expressed concerns about the technology.

*“Sometimes I feel like I can’t trust the numbers because if I’m just on the bed with my phone in my hand, and I’m just moving my phone around, it counts that as steps sometimes. And I’m like, I haven’t walked anywhere” [P4]*

Other participants commented on the lack of tracking options and the complexity of input, particularly for home-cooked meals, which made the data less accurate.

*“sometimes they didn’t have the food that I was eating, or it was difficult. If I was, let’s say, eating a burger, and it was homemade, then I would have to input the individual ingredients, which was kind of frustrating to have to do that.” [P6]*

As discussed further below, the accuracy and relevance of some tracked data were low for participants going through gender transition.

## **5.4 Self-tracking and LGBTQ+ identity**

Much of what has been reported so far could be found among any population of self-trackers. Indeed, several participants did not see any problems with the apps from the perspective of their LGBTQ+ identity.

*“I think the apps that I use are quite accommodating. I don’t see anything that’s like homophobic, transphobic, or anything like that on it. Like there’s no red flags when I use them, so I think it’s good.” [P5]*

However, other participants did see links between their identity and tracking. The most direct link was Participant 2’s use of tracking apps to monitor physical changes brought about by her hormone replacement therapy, such as changes in body fat percentage. Monitoring this was seen to be supportive of her mental health. As someone who was using self-tracking before they came out, Participant 2 also experienced changes in the way they used apps: not only did they start tracking different things because of physical factors, but her social transition also resulted in her being locked out of her previous account. Here, a pattern of fluid use of tracking is linked to major shifts in identity.

*“I had a lot of stress in my life with various things going on since I transitioned, and changing my e-mail address and my name...I ended up having to log in again, and it wasn’t working” [P2]*

Thus, seemingly trivial technical annoyances can be entangled with major issues of identity.

Participant 2 also expressed a concern that as a transgender woman, the apps she uses do not take account of her particular physiology and this impacts the accuracy of the information received from the app.

*“I do feel like it’s apparent from the design choices of these systems and apps and services that they are designed for cisgender people. And it would be reassuring if it let me explicitly state that I am trans, and I’m taking the hormones that I’m taking, by the method that I’m taking them. So that it could adjust the goals and things, stuff like this, in a more appropriate way that I can feel confident is taking into consideration my physiology and who I am and the hormones I’m taking. Rather than wondering whether or not it’s making assumptions aren’t necessarily accurate. So one thing that I have noticed is that I’ve got certain apps on my Watch that aren’t relevant to me or my needs because of who I am. I don’t know if they’ve appeared there because of the gender picked, but I’m guessing so...I’m talking about the cycle tracking app I have on my Watch. I don’t know if that appears for everybody, or if that’s just something that shows because I picked female as my gender on the Watch” [P2]*

This also relates to a key issue highlighted by Participant 3 about the troubling data outputs they received because their menstrual tracking app assumed they were in a relationship where they could become pregnant.

*“There is not an option to turn off it telling you when you are most likely to be fertile or if you might be pregnant. And neither of these are relevant to me because I am not in a relationship where I could be pregnant, nor do I want to be. Also, neither of them gave me the option to insert my own pronouns. So neither of them actually use pronouns for me, but there is a forum on the Flo app which I do read, I do not participate. And there it assumes gender identity, which I dislike” [P3]*

Here again there is a sense of a troubling experience because of the normative assumptions built into the tracking device. Indeed, the app seemed to have an underlying assumption that if someone menstruates, they must be a woman.

*“I’m just going to check Flo, because obviously having had these for years, my gender identity has changed and it might be that when I signed up for them, that [female] was an accurate representation of my identity. No, there is no option for gender on the Flo app. So I think they are presuming that as a person who is menstruating, that you are a woman” [P3]*

Few of the apps appeared to actively recognise diverse gender identities. Indeed, one of the first actions of signing up to an app would be to be forced into a self-definition based on a gender binary. Another participant felt disappointed that the app had not taken obvious opportunities to represent identity issues:

*“Since using the app, it has not at all included any acknowledgement to LGBT+ identities. Even in June when it was like Pride Month. Companies go all out with their colour schemes and encouragement for LGBTQ members of their company or whatever” [P4]*

A couple of participants identified more indirect links between their LGBTQ+ identity and use of self-tracking apps. Both pointed to the subtle difficulties of using self-tracking when feeling minoritised:

*“As an LGBT person, you get marginalised enough already. For me, I would like to avoid that elsewhere in my life. So to take care of my weight, for example, you can get oppressed because of your weight. And to avoid that, then I would maybe focus on being active because I already get enough stigma as it is” [P4]*

Here, wider social pressures of being in a minoritized group set the context for tracking use. Already feeling stigmatised, the driver for tracking was the pressure to conform in other ways. This gives us a less empowered view of purposive use, pointing to the wider pressures that underlie purposes such as weight loss.

The interviews with these LGBTQ+ self-trackers revealed that they have developed information literacy within their self-tracking landscape. Many of the barriers to empowerment such as concerns of data quality and accuracy, concerns over sharing and data privacy, and fear of obsession that are common to many self-tracking studies apply to this group of participants. In addition, there are some nuances to their self-tracking practices linked to their LGBTQ+ identities that affect whether the practice is experienced as an empowering one. These will be explored in relation to the literature below.

## **6. Discussion**

This study sought to explore issues of empowerment in the information literacy self-tracking practices of LGBTQ+ students. There were some similarities with self-tracking in the general population. However, there are a number of specific challenges for these participants, particularly for those going through gender-affirming transition. Tracking apps only allow a binary gender

choice and this is recognised as a barrier from the moment a device or app is first used (Cifor & Garcia, 2019). Menstrual tracking is a popular motivation for engaging in self-tracking, but these assume a user identifies as female, feature feminised design, assume a partner is a cisgender male, and are oriented towards fertility (Epstein et al., 2017; Healy, 2021). These types of features are identified as alienating or disempowering. At least one transitioning participant saw it as doubtful that the data reflected their specific needs, as it failed to take account of hormone treatments and changing physiology. There were other, more subtle challenges for LGBTQ+ participants to characterise how tracking is experienced and the relationship between their gender and sexual identities, for example through recognizing that there is a masculinised assumption of a competitive aspect to sharing tracked data (Cifor and Garcia, 2020). This prompts us to ask whether specific marginalised groups experience this potential empowerment through information differently.

This study adopts Lloyd's (2017) model of information landscapes, and attempts to understand the three modalities (epistemic, social, and corporeal) of the information landscape of self-tracking, and what it means to be information literate. Embodied information has high value in this context. Olsson and Lloyd (2017) argue that understanding embodied information is a central feature of developing situated understandings of an information landscape, and plays a vital role in individual and collective sense-making, and the nature of practice in a social site. The value of self-tracking is that it enables the monitoring, codifying, recording, and selective sharing of corporeal information in a way that people engaged in the practice find valuable and empowering. Previous studies have highlighted the value and importance of embodied information for queer information practices (Kitzie et al., 2021), and for those undergoing gender-affirming transition, discomfort with the body as a key starting point for information seeking (Huttenen, 2019; Huttenen et al., 2021). Information literacy is developed through understanding the body as an information source and how data about its functioning supports broader health-related goals.

With regard to the social modality, our findings reveal that self-trackers make careful decisions about whether or not to share their tracked data in their social networks. Factors such as whether others in the social network share their world-view and their goals, and a desire to keep some information private, is influenced by LGBTQ+ identities. Understanding the nuances of data sharing is an aspect of the information literacy of self-tracking found in previous research (Cox et al., 2017; McKinney et al. 2019). These participants had a good understanding of the circumstances in which data could or should be shared, and the perceived barriers to and benefits of sharing. However, other studies identify positive aspects of sharing exercise data online as it is seen to be a potentially motivating and empowering practice (Cifor and Garcia, 2020). Online spaces are seen to provide a valuable platform for information sharing for LGBTQ+ people (Delmonaco and Haimson, 2022). For these participants, there are specific challenges relating to the perceived value of sharing data with health professionals, particularly if this was counter-productive to a goal related to LGBTQ+ identity. Additionally, health professionals do not always welcome or value patient-created data (Ancker et al., 2015).

The epistemic modality is a somewhat contested space. Although app and device manufacturers would position tracked information and analyses as objectively accurate epistemic information, both our participants and the wider literature notice inaccuracies in measurement and fallacies in analyses (e.g. Attig and Franke, 2020). En and Poll (2016) question the positioning of tracked information as "true" or "trustworthy", particularly for the LGBTQ+ community whose bodies may not align with the statistical norms of society on which apps and devices are based. They suggest that a queer perspective on self-tracking would support the embracing of multiple selves rather than assuming there is one objective truth in bodily data.

Participants in this study were chosen on the basis that they already engage in self-tracking, and their persistence in self-tracking implies that at some level they did feel it was useful and empowering. The motive for self-tracking was to achieve valued goals, such as fitness or weight control, in common with many proponents of the benefits of self-tracking (Lupton, 2016; Ernsting et al., 2017; Lunde et al., 2018). The value of self-tracking to reduce anxiety seemed a particular

feature for these participants, and this could be of benefit to LGBTQ+ people, who suffer from anxiety at higher rates than the general population (Bachmann and Gooch, 2018).

These participants revealed a fluidity in their adoption and abandonment of technologies and platforms, essentially taking what they felt they needed at any given time. This pattern of quick abandonment is found among other self-trackers (Attig and Franke, 2020). For these participants, tracking changed when a goal had been achieved, or they made pragmatic decisions about the value and worth of self-tracking at any given point in their lives and would adjust practices accordingly. Developing this awareness of when it is appropriate to adjust tracking practices to align with health goals is an aspect of information literacy in self-tracking found in previous research (Cox et al. 2017).

The participants displayed a good understanding of how to interpret their tracked data, but there was a sense that they preferred simpler data collected through passive tracking, and this desire for simpler tracking practices is consistent with previous research (Vaghefi & Tulu 2019). This contrasts with the previous study where some users delighted in collecting complex information or engaged in detailed data creation e.g. of food consumed (Cox et al. 2017).

Tracked information was used to support participant-defined goals. Therefore, even if they do not act as “rational data scientists” (Ohlin and Olsson, 2015), this appears not to be too much of a problem and the experience is still empowering, particularly given the fluidity of practice noted above. The issue of becoming obsessed with any given self-tracking practice or technology did surface in the data, and in common with other studies, this is a barrier to a sense of empowerment in the practice (Ancker et al., 2015 Cox et al. 2017). However, this was balanced by the sense that participants were taking a very pragmatic approach to their self-tracking and were able to recognise when the practice bordered on obsession and take steps to address this, which can be seen as an aspect of information literacy.

Concerns about data accuracy and potential for surveillance or privacy loss were mentioned by participants, but they were not particularly worried. This aspect of information literacy in self-tracking is consistent with previous studies (Cox et al 2017; McKinney et al. 2019). However, there were some signs of “soft resistance” where only fragmentary or false data is being shared as a “protective” information practice (Kitzie, 2021). This implies a certain level of suspicion of the apps and the desire to reduce surveillance (Nafus and Sherman, 2014). However, it was not presented as connected to their LGBTQ+ identity, despite other studies identifying that privacy and anonymity is an important concern in this community, certainly for information-seeking activities (Pohjanen and Kortelainen, 2016; Fox and Ralston, 2016). In some senses, participants displayed a critical awareness of the accuracy of their self-tracking devices and practices, such as when it was obvious that the device was falsely recording movement. The challenges of accurately recording diet were consistent with previous studies (Cox et al. 2017; McKinney et al. 2019). However, they were less critical of other potential inaccuracies in the data that have been highlighted in the literature, such as concerns from experts about the questionable value of tracked data on sleep (Attig and Franke, 2020; Baker, 2020). There was also the adoption of passive tracking practices because they are easy, and not a burden on the user. This could seem to be risky, in that it permits surveillance. There was also evidence of the privacy paradox (Gerber et al., 2018): that users felt uncomfortable with how their data might be used, but felt powerless to stop it and ultimately decided that the tangible benefits of using the app outweighed the somewhat intangible costs. In the UK at least, access to healthcare is not predicated on having health insurance, and these students are not employed by large organisations who might seek to monitor them, and there is free and open access to abortion services, thus the potential consequences of health data leakage are less severe than in the US (Healy, 2021).

The rise of self-tracking in the last decade has been seen as driven by the sense that it can empower individuals through access to information about their own behaviour. This is premised on the reliability of data and confidence in data privacy, and not being discouraged by fear of obsession or surveillance. The participants in this study revealed that there were aspects of their self-tracking that were experienced as empowering, for example because they achieved individual or collaborative health goals, managed anxiety, or were able to monitor physical changes associated with gender transition.

Disempowering features of tracking were often related to LGBTQ+ identities, and the assumptions built into binary gender choices or heteronormative lifestyles. The trade-off between access to self-tracking and privacy was a concern, and Baker (2020) explores some of these issues as the “ironies” of self-tracking, arguing that the feeling of personal empowerment is offset by the potential for the data to be exploited.

## 7. Limitations

This was a small-scale exploratory study with a small number of participants, all of whom were students at UK universities. The study was advertised via student LGBTQ+ groups, which would necessarily limit the study to people who were already confident in identifying themselves as LGBTQ+. Due to the small number of participants, we were not able to explore experiences from a broad range of LGBTQ+ identities.

## 8. Conclusion

Previous research identified four aspects of information literacy in the self-tracking landscape: understanding the value of quality in data inputs; the ability to interpret tracked information in the context of the limitations of the app or device; awareness of privacy and data ownership; and the nuances of sharing tracked data (Cox et al. 2017; McKinney et al. 2019). The findings from this study broadly support the importance of these factors in developing conceptions of what IL means in this landscape. This research extends understanding of the nuances of these factors for self-tracking in the LGBTQ+ community. While participants found value in self-tracking to achieve their health goals and there is evidence that this was empowering, Hicks (2022) cautions against assumptions that empowerment through information literacy in the health arena is a “self-evident good”.

Baker’s (2020) analysis of quantified-self technologies shows that a lack of transparency in the design of these technologies means that decisions made about the interface, what is measured, and the way that information is presented to users are not always with the wellbeing of the user as a primary goal. They note that “*More information does not always result in more knowing*” (p.1485), and that while users might perceive the information as empowering, it is a common mistake to think that these technologies are benevolent in design, particularly if one considers the way that information gathered by self-tracking technologies can be shared with 3<sup>rd</sup> parties without the knowledge of the tracker. If the narrative that self-tracking is empowering is problematic because of the concerns around surveillance and control, which positions self-trackers as “mindless dupes” of technology corporations and data harvesters (Sharon, 2017), then the development of information literacy would seem to be one way in which users can challenge this narrative. By developing information literacy through greater awareness of the issues surrounding both privacy and the potential uses of data, trackers can navigate more safely and effectively through this information landscape. If empowerment is positioned as gaining mastery over one’s life, enhancing wellbeing, and achieving goals (Rappaport, 1987; Cattaneo and Chapman, 2010), then the evidence from this study points to self-tracking as a practice that is empowering, despite the concerns over data privacy.

There are practical implications from this research. There is a clear implication for app designers to reconsider how to design apps reflecting more diverse concepts of gender identity, not just in profiles but more fundamentally in how apps work. For LGBTQ+ self-trackers, as for others, there is scope to offer much more advice on how to use the devices in safe ways. Greater consensus around which form of tracked data are genuinely useful, and how to gather it – led by health agencies – would improve the epistemic modality in this landscape and support the development of information literacy.

As an exploratory study, this paper reveals many opportunities for further research. A wider study would reach out to a larger population of people identifying as LGBTQ+, and beyond students. The results suggest that there is an important relationship between trans individuals undergoing medical transition and their use of self-tracking apps. Further research could explore this and include those undergoing a “masculinising” transition. The data reveals a potential for research into self-tracking for the management of mental health. While the current research was unable to broach this subject in great depth due to the increased ethical considerations, it is likely to yield intriguing and useful results. This could also be studied in conjunction with a focus on LGBTQ+ users, given the high rates of mental health issues among this population (Bachmann and Gooch, 2018). This would require rigorous ethical planning, given the mental health vulnerabilities of this population.

This research explored LGBTQ+ students’ self-tracking information landscape. It found many patterns that have been found in research on other social groups, but there are some specific challenges experienced by members of the LGBTQ+ community that this study has made explicit. This paper therefore makes an important novel contribution to the body of research on self-tracking in specific populations, and also the discourse on LGBTQ+ information practices. Much previous research has focused on health information-seeking practices (e.g. Jia et al., 2022), or the importance of online information-sharing practices in this community (e.g. Fox and Ralston, 2016), but this study differs in that it focuses on information creation about the self rather than information seeking.

## Acknowledgements

We would like to sincerely thank the participants who generously gave their time for this research.

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## **Appendix. Interview questions**

1. Could you describe how you identify as LGBTQ+?
2. What sort of things do you track? For example, exercise, steps, diet, sleep.
3. What apps do you use for tracking? Do you use any devices such as a FitBit?
4. Why do you track the things you described?
5. Have you experienced any challenges with tracking your data consistently or effectively?
6. Do you have any concerns about the security and confidentiality of your tracking data? Do you trust the commercial provider of the app to keep your data secure but accessible long-term?
7. Do you take any measures to keep your data secure, such as using additional privacy features?
8. What data would you share with each of these groups and why?
  1. Friends
  2. Family members
  3. Online communities
  4. Medical practitioners
9. When you were setting the tracking up and since you've been using it, have you felt it has acknowledged and accommodated your LGBTQ+ identity?