The information literacy practices of LGBTQ+ students self-tracking: attitudes to data collection, data privacy and data sharing

Pam McKinney, Corin Peacock, Andrew Cox
Overview

- The background to the project
- Literature review
- Research questions
- Theoretical underpinning: Lloyd’s (2017) theory of information landscapes
- Methodology
- Participants
- Key findings relating to motivations for tracking, data collection, data privacy, data sharing, data quality and LGBTQ+ identity
- Conclusions about the nature of Information literacy in this landscape
Meet the team

Dr Pam McKinney
Lecturer
Information School, University of Sheffield

Corin Peacock
Subject Librarian
Arts University Bournemouth

Dr Andrew Cox
Senior Lecturer
Information School, University of Sheffield
Background to the project

Dr Robert Caine

• Self-tracking used to be a niche activity in the early “quantified self” movement, but is now mainstream
• Mintel estimates that the market for wearable fitness trackers and smartwatches in the UK is worth £911 million in 2022 (Mintel 2022)
• Self-tracking apps are downloaded millions of times every month from Google Play and Apple App store (Statista 2022)
• People track many aspects of their lives to support their wellbeing: diet, daily steps, mood, menstruation, sleep, heart rate etc.
Social Science PGT research internship

• Hundred-hour paid research internships for PGT students
• Carry out original research with academic supervisors over the summer
• Opportunity to build research skills
• Competitive application process
• Research team led by Andrew Cox, with Pam McKinney and student researcher Corin Peacock
LGBTQ+ what it means & why it matters

• LGBTQ+ refers to the lesbian, gay, bisexual, transgender, and queer community, with the plus standing in for a wide range of other identities

• The health of LGBTQ+ communities is generally poorer than the cisgender, heterosexual population (Jia et al. 2021)

• British LGBTQ+ people experience higher incidences of anxiety and depression than the general population (Bachmann and Gooch 2018)

• Trans people rate their life satisfaction much lower than the rest of the population (Government Equalities Office 2018)

• 23% of LGBTQ+ people witness derogatory or negative remarks about their community from healthcare staff (Bachmann & Gooch 2018)
Literature review: positives of self-tracking

• Self-tracking allows people to take control of aspects of their lives, and provides empowerment through self-knowledge (Lupton 2016)

• Self-trackers like the feeling that they know their bodies better and enjoy “reading” the state of their health (St Jean 2018)

• Self-tracking supports management of non-communicable diseases (Ernsting et al. 2017)

• Tracking enables people to make nuanced decisions about their own health, and often people stop tracking because of “happy abandonment” i.e. they stop because they have achieved a health goal (Cox et al. 2017)
Literature review: issues with self-tracking

- **Data accuracy**: Both users and experts, such as health professionals, have concerns about the accuracy of the information collected and output by such devices (Baker 2020).
- Becoming **obsessed** with self-tracking could be unhealthy, and some trackers worry about this (Cox et al. 2017).
- **Privacy**: Apps routinely share information with 3rd parties, but many users lack a good understanding of the implications of this surveillance (Healy 2021).
- **Gender issues**: apps & devices are designed for men, enforce binary gender choices, and represent a masculine world view (Cifor & Garcia 2019).
Lloyd’s theory of information landscapes

- “Information literacy is a **practice** that is **enacted** in a social setting. It is composed of a suite of **activities** and **skills** that reference structured and **embodied knowledges** and **ways of knowing** relevant to the context. Information literacy is a way of knowing.”

- The **epistemic** modality describes factual sources of information that are objective and reproducible.

- The **social** modality refers to often unwritten norms or conventions of practice and/or social exchange.

- The **corporeal** modality refers to physical information drawn from the body or the bodies of others.

(Lloyd 2017)
Research questions

- What self-tracking practices do LGBTQ+ students engage with, what are their motivations and what data do they collect?
- How do they use self-tracking information and what are their attitudes to privacy, sharing and data quality?
- What connections do they make between their LGBTQ+ identity and self-tracking information experiences?
- What are the characteristics of information literacy in this landscape?
Methodology

- Qualitative interview-based study with an interpretivist, exploratory philosophy
- Received ethical approval from the Information School at the University of Sheffield
- Participants recruited through LGBTQ+ Facebook groups associated with LGBTQ+ student societies at UK universities
- Participants self-identified as LGBTQ+ self-trackers
- Thematic analysis of the data by each member of the research team, with collaborative discussion of the analysis.
<table>
<thead>
<tr>
<th></th>
<th>Pronouns</th>
<th>LGBTQ+ Identity</th>
<th>Apps/devices</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>she/her</td>
<td>I'd just probably say queer. I don't really specifically identify as anything...Well, gender-nonconforming, but definitely female.</td>
<td>Fitbit</td>
</tr>
<tr>
<td>2</td>
<td>she/they</td>
<td>I guess the easiest thing to say is that I'm a trans woman</td>
<td>Apple Health, MyFitnessPal</td>
</tr>
<tr>
<td>3</td>
<td>she/they</td>
<td>I am bisexual. I do not identify as a woman, but I also don't identify as non-binary. Kind of genderly ambiguous.</td>
<td>Flo, Lose It!</td>
</tr>
<tr>
<td>4</td>
<td>she/her</td>
<td>I identify as bisexual.</td>
<td>Samsung Health</td>
</tr>
<tr>
<td>5</td>
<td>she/they</td>
<td>I mainly identify as pan, so pansexual. And then my gender – I'm genderqueer,</td>
<td>Pedometer, DBT Coach</td>
</tr>
<tr>
<td>6</td>
<td>she/her</td>
<td>I identify as queer or bisexual...cis female.</td>
<td>Lose It!</td>
</tr>
</tbody>
</table>
Findings
Findings: Tracking purpose & motivation

Multiple motivations:
• Monitoring a particular factor
• Developing greater understanding of patterns and behaviours
• Understanding oneself

Self-tracking helped reduce anxiety

“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]
Findings: Data collection

Tracking is fluid, changes over time, and is goal-directed

“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]

• The value of automatic tracking was emphasised, participants were keen to minimise effort
• So-called “passive tracking” tacitly accepts surveillance
Findings: Data privacy

- Participants were concerned about their data privacy, but not worried
- Some did not think that the tracked data was 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”

- There is a “trade-off” – the convenience of the app outweighs concerns about privacy
- Some preserved privacy by sharing minimal information or by adding false information
Participants preferred not to share their data for two central reasons:

1. They were wary of judgement
   “I get quite self-conscious about it, especially during the days where I look at the steps at the end of the day, and it's like ten. I don't want anyone else to see that. So I would probably not tell family and friends, just for the fear of being judged”

2. They have no desire to be competitive
   “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”

- Some engaged in collaborative self-tracking activities and did share data
- Mixed feelings about sharing data with health professionals
Findings: Accuracy & data quality

**Three** key areas that affected trust in tracking: accuracy of the technology, the range of input options; and the relevance of the data outputs.

1. Concerns about the accuracy of automatic tracking
   
   “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”

2. Data input in food tracking is complex, particularly for home-cooked meals

3. Data outputs are not always useful
   
   “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”

There was some fear of obsessive tracking, and the impact this could have on mental health.
Findings: Self-tracking and LGBTQ+ identity

- While some did not see any connection with their LGBTQ+ identity, others did
- P2 used tracking apps to monitor physical changes brought about by her hormone replacement therapy e.g. changes in body fat percentage
- Apps have normative assumptions about gender, relationships, and menstruation that are jarring for people with LGBTQ+ identities
  
  ”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”
- Apps only have 2 gender options, and don’t acknowledge diversity in gender
Findings: Self-tracking and LGBTQ+ identity

- Apps don’t take account of diverse physiologies
  “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.”

- Self-tracking can exacerbate negative implications of already being in a minoritised group
Selected findings for discussion

- Self-tracking to **reduce anxiety**: LGBTQ+ people suffer higher levels of anxiety than the general population (Bachman & Gooch 2018)
- **Fluid** use of tracking technologies reflects a nuanced understanding of the value of the practices at any given point
- Participants displayed **critical awareness** of the accuracy of some types of tracked data, but were uncritical of others e.g. sleep (Baker 2020)
- Aspects of “**soft resistance**” with restricted personal data shared (Nafus & Sherman 2014)
- Evidence of the “**privacy paradox**” (Gerber et al. 2018)
- **Lack of data sharing** on social platforms contrasted with other studies that focus on the value of online communities for LGBTQ+ people (Delmonaco & Haimson 2022)
- The **competitive** aspect of self-tracking represents a masculinised worldview and was rejected by these participants (Cifor & Garcia 2019)
- Participants recognized the **heteronormative nature** of the apps and found it alienating (Epstein 2017)
Information literacy in this landscape

**Corporeal modality:** Self-tracking enables the recording, codification monitoring of corporeal information. Information literacy is developed through understanding the body as a source of information and how data supports the achievement of health goals.

**Social modality:** Self trackers make nuanced decisions about sharing information in their social networks, but there are barriers. Information literacy could be enhanced through more socially acceptable sharing of practices and strategies for safe and effective tracking.

**Epistemic modality:** Although app manufacturers position tracked information as objectively true, there are inconsistencies & inaccuracies. Information literacy is related to understanding these, and better advice from health agencies on self-tracking would be an improvement.

Experiencing **empowerment** through information literacy in this landscape is linked to understanding privacy, surveillance, and the social limitations of tracking.
Any questions?

p.mckinney@Sheffield.ac.uk


References continued


