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# Method Selection and Participant Recruitment in Sensitive HCI Research

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## **INTRODUCTION**

In this paper we draw on experiences from two projects conducting HCI research in sensitive domains. In *EDDA*<sup>1</sup>, we conduct a preliminary exploration of the role of smartphone apps in perceptions of body image and maladaptive eating and exercise behaviours. In *UPP*<sup>2</sup>, we conduct scoping activities to understand behaviours leading to self-harm, and the potential application of mobile technology for support and intervention. Both projects engaged domain-relevant individuals in research, and therefore required careful consideration with regard to method selection and participant recruitment.

<sup>1</sup>Full project title: "Eating Disorders in the Digital Age: considering the safety measures required to prevent the abuse of healthy eating and fitness applications amongst young people".

<sup>2</sup>Full project title: "Understanding Predicting and Preventing non-suicidal self-injury and thoughts amongst adolescents - How can technology help?"

#### KEYWORDS

Eating-disorder; self-harm; mental health.

#### AUTHOR EXPERIENCES

The four authors collaborated to deliver the sensitive research described on page 4. In addition, Clinch conducts research in the area of memory and cognitive failure, include with vulnerable older adults; McNaney's research engages participants with Parkinson's and other chronic medical conditions; Honary's research engages those with mental health conditions; Bell's research centres around body image in adolescents and young adults. McNaney is the co-organiser of a set of long-running CHI workshops (2013-17) on designing with vulnerable people [16] and ethical research in sensitive settings [20, 21].

#### AUTHOR PARTICIPATION

Clinch will attend the workshop. She is keen to develop contacts in related areas of research, and those with ideas and expertise for engaging with sensitive populations that can be applied to diverse research interests. Clinch hopes that the workshop (and her involvement in it) may help to establish a set of documented best practices for sensitive HCI.

#### METHOD SELECTION

At least three broad approaches could be utilized within the context of these projects:

**Data mining** approaches, particularly mining of social media, have previously been applied in both domains [2-8, 10, 12-15, 17-19]. Such methods have the advantage that a wealth of material already exists, removing the need to engage with participants to generate new data – thus bringing benefits in terms of cost, effort, but also participant safety since it avoids potentially triggering unwanted thoughts or behaviours in said participants. However, data mining methods are only useful if data exists to answer the research questions under study. They don't typically enable the researchers themselves to push prompts or other material to participants, thus making dialog impossible.

**Face-to-Face** approaches, including focus groups, interviews and workshops (e.g. [1, 9]). These research methods are relatively costly and labor-intensive in any research setting. In the context of sensitive populations, they also bring additional concerns – for example, the need to ensure appropriate support both during and after. The required support provision, and follow-up contact, further adds to the labor-intensity and cost associated with these methods, with no clear cut-off at which one might consider the researcher to be absolved of responsibility. Finally, use of these methods require small samples, limiting the breadth of perspective gathered; this may be particularly problematic in mental health domains where experiences, symptoms and behaviours are nuanced and varied.

Face-to-face approaches also easily accommodate **group interactions** (focus groups, workshops). These can allow for rich, more diverse coverage of the target domain, and again carry some unique features in a sensitive setting. Firstly, they allow participants to be selective about the degree to which they engage at any point; if active participation becomes overly challenging, they can choose not to contribute to the discussion for a period, only re-engaging when they feel able to do so. In solo settings, participants may feel that such behaviour is disruptive or is detrimental to the research/er; in group settings they may feel that the behaviour could go completely unnoticed. Secondly, as a group of individuals with a shared set of behaviours or thought patterns, it is possible that discussion groups could lead to the formation of group bonds – these may be positive influence (providing a support network when negative situations arise) or could potentially encourage negative behaviours (c.f. pro-ana groups on social media [4, 7, 17, 19]).

**Remotely administered** approaches, most notably **online surveys**. As a research method, online surveys allow for data collection at a scale greater than that accommodated by face-to-face methods. In sensitive settings they can also facilitate disinhibited data collection [11] in which a combination of high private self-awareness (prompted by solitary space to think) and low public self-awareness (prompted by a lack of observation) may lead to high levels of self disclosure.

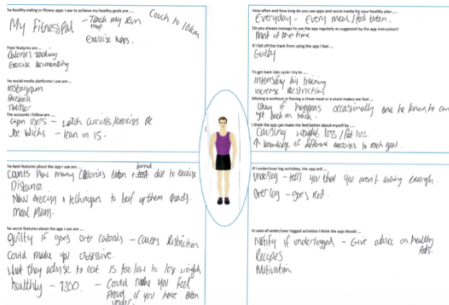


Figure 1: Materials generated during an EDDA workshop with young people with a personal interest in body image.

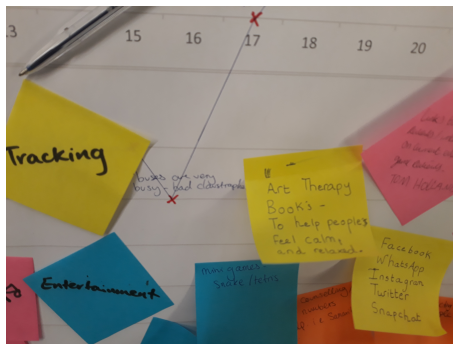


Figure 2: Materials generated during a UPP workshop with young people who had previously having engaged in self-harm behaviours.

## PARTICIPANT RECRUITMENT

Selecting and recruiting appropriate participants for studies in our target domains is a second area of concern. Both projects target populations with mental health concerns: in **EDDA**, these were individuals who engaged in maladaptive eating and exercise behaviours; in **UPP**, the target population was those engaging in self-harm activities.

For preliminary studies, several factors impacted our approach to participant recruitment.

- Both studies were funded under a preliminary funding scheme allowing only minimal staff time (6 months each). Since conducting studies within the context of UK healthcare comes with a substantial ethics process, it was deemed infeasible to recruit within healthcare settings.
- Recruiting participants with a diagnosed eating disorder or other diagnosed mental health condition would have increased both the need to engage in stringent institutional ethics, and the demand for measures to safeguard vulnerable participants.
- An alternative would be recruitment of participants who self-identify as engaging in one of our target behaviours: maladaptive eating/fitness or self-harm (and who explicitly had not received a mental health diagnosis). However, such participants would be at similar risks to those with a medical diagnosis, with the additional concern that they might lack support mechanisms provided to individuals who had a diagnosed condition.
- Existing care structures are likely to be best-placed to support our target populations. Sensitive insertion of researchers into existing support structures would allow us to be sensitive of possible vulnerabilities and power dynamics, whilst simultaneously ensuring participants were well-placed to received any additional support required as a result of participation.
- Onset of both eating disorders and self-harm typically occur during the teens and early adulthood. For this reason, both projects had a particular focus on young people. However, conducting studies with minors (<18) introduces further concerns regarding consent (both their ability to provide informed consent, and a potential expectation that parental consent will be sought).
- Capturing the viewpoints of those with maladaptive eating and fitness behaviours, and those with experiences of self-harm, may be challenging but is critical to conducting research in those domains. Popular media and consciousness may provide some understanding of our target populations and behaviours but this is likely to contain stereotypes and miss important nuances. Broad brush recruitment approaches that target the general population (e.g. mTurk studies) are likely to have limited applicability. Further, use of such approaches may feel lead to a perceived devaluing of the target population and their experiences.
- In addition to the perspectives of those with lived experience, other stakeholders may be able to provide relevant data. Those with, for example, clinical expertise could help to provide a diversity of viewpoints.

## OUR APPROACH

The influence of these factors (and the previously discussed methodological concerns) led to the studies selecting methods and participants as follows:

### ACKNOWLEDGEMENTS

Projects **EDDA** (Eating Disorders in the Digital Age: Considering the safety measures required to prevent the abuse of healthy eating and fitness applications amongst young people) and **UPP** (Understanding Predicting and Preventing non-suicidal self-injury and thoughts amongst adolescents - How can technology help?) were funded by NewMind through their NewMind Plus Feasibility Study Funding scheme (<http://www.newmindnetwork.org.uk/>).

**EDDA** *Data mining* was used to establish a set of popular mobile health and fitness apps (we scraped charts in the Health & Fitness category of the Google Play store to establish the 100 most popular apps whose titles or descriptions made some reference to diet, exercise, or other similar terms). *Face-to-face research activities* (workshops, shown in Fig. 1) were conducted with eight young people to gain an insight into their experiences of engaging with mobile health and fitness apps and to ideate potential safety measures for introduction into such apps. Our young participants were recruited on the basis of their interest in body image, experience of using healthy eating and fitness apps, and who self-identified as being concerned about the impact of these apps on their wellbeing. Individuals with a clinical eating disorder diagnosis (or who had received such a diagnosis in the past) were discouraged from participating. Face-to-face interviews were conducted with experts in the domain of eating disorder and body image, to gain a deeper understanding of the challenges surrounding body image dissatisfaction and its relationship with use/misuse of health and fitness apps. An *online survey* targeted a broader demographic, recruiting adults with experiences of using one or more mobile health and fitness tracking apps, establishing whether app use had led to any positive or negative behaviours; closed questions were supported by free-text to allow rich self-expression.

**UPP** *Face-to-face research activities* (workshops) were conducted with eleven young people aged 18 – 25 who self-identified as “having self-harmed in the past but... not in a current crisis or suffering from current severe mental health or other high risk behaviours” (shown in Fig. 2). These workshops were used to explore the context in which participants experience self-harm including coping mechanisms, support resources, online presence, technology aids, data privacy and trust. Participants were recruited through a charitable organisation that provided support for mental health and emotional well-being<sup>3</sup>. A further set of workshops were conducted with counsellors whose clients had engaged in self-harm activities, recruited through an existing online support platform<sup>4</sup>, in order to gain a deeper understanding of youth who self-harm, their triggers, techniques counsellors use to identify these triggers, recovery plans, interventions and treatment approaches. Finally, an *online survey* targeted those aged 16 – 25 who again self-identified as having some level of interest in self-harm and could answer about themselves or about someone they know who has been affected by self-harm. This survey was used to better understand the young people’s perspectives about a sensor based mobile application which collects data on user’s social interactions. Survey participants were recruited from the platform staffed by the counsellors used in our workshops.

<sup>3</sup><http://42ndstreet.org.uk>

<sup>4</sup><https://www.kooth.com>

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