# Student Perspectives on Digital Phenotyping

The Acceptability of Using Smartphone Data to Assess Mental Health

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### **ABSTRACT**

There is a mental health crisis facing universities internationally. A growing body of interdisciplinary research has successfully demonstrated that using sensor and interaction data from students' smartphones can give insight into stress, depression, mood, suicide risk and more. The approach, which is sometimes termed Digital Phenotyping, has potential to transform how mental health and wellbeing can be monitored and understood. The approach could also transform how interventions are designed, delivered and evaluated. To date, little work has addressed the human and ethical side of digital phenotyping, including how students feel about being monitored. In this paper we report findings from in-depth focus groups, prototyping and interviews with students. We find they are positive about mental health technology, but also that there are multi-layered issues to address if digital phenotyping is to become acceptable. Using an acceptability framework, we set out the key design challenges that need to be addressed.

# **CCS CONCEPTS**

 Human-centered computing → Empirical studies in ubiquitous and mobile computing;

# **KEYWORDS**

Qualitative Research; Acceptability; Mobile Health; Mental Health; Mental Wellbeing; Lived Informatics; Sensors.

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#### 1 INTRODUCTION

Student mental health and wellbeing is of concern internationally. Mental health and emotional wellbeing among college students in the USA is in "continued decline" [25, 82], an increasing suicide rate in South Korea is the "hidden price of education" [38], and in Australia there is an "urgent need to better understand the prevalence of mental health problems" among tertiary students [66].

From a UK perspective, mental health problems are increasing among students and young people, and the large majority of students will experience some form of emotional distress [49, 80, 83]. One prominent cause for concern has been an increasing suicide rate [32]. However, there is a much wider problem—students that experience mental illness and mental distress have a lower quality of life, achieve less, and are more likely to drop out from education [16, 58, 80].

Universities have a duty of care to students, and many offer counselling and support services. However, these services are increasingly stretched and many students feel undersupported [11]. Services themselves are turning to new forms of limited counselling and to online services in order to meet demand [15]. A report by the UK Institute for Public Policy Research has recommended: "Universities should not just be helping people in crisis but also concentrating on prevention, early intervention, management of risk and giving low level support" [80].

In this paper we are interested in an emerging form of health surveillance technology, sometimes referred to as *Digital Phenotyping*, that uses passive sensing to identify and monitor problems. Data is collected via smartphones [60, 84], social media [5, 70], wearables [52], eLearning platforms [67] and more, which may then be useful for: (i) Monitoring students known to be at risk or with pre-diagnosed disorders and self reported problems; (ii) Monitoring all students to identify individuals who may be at risk and requiring help; (iii) Monitoring the student body as a whole in order to measure mental health and wellbeing and inform policy and

Table 1: Smartphone sensors previously used in digital phenotyping research

Sensor	Description
Accel./Activity	Movement of device and person
App Use	App launches, installs, etc.
Web History	Websites visited
Battery	Battery level and charging
Bluetooth	Devices seen, plus status
Call Logs	Calls made and received
Camera	Raw images, num photos taken, etc.
Screen	Screen status (on/off)
Keyboard/UI	Event counts, potentially keylogging
Location	Geographical coordinates of device
Light	Light levels detected
Microphone	Sound recordings, decibels, etc.
SMS/Email	Messages sent and received

Table 2: Self reports previously used in digital phenotyping research

Survey	Description
PHQ9	Depression and low mood scale (see [43])
GAD7	Generalised Anxiety Disorder Scale (see [77])
WEMWBS	Mental Wellbeing Scale (see [79])

service provision; (iv) Monitoring students solely for research purposes.

As this area matures and expands, it is timely to explore students' perspectives on the acceptability of digital phenotyping systems for monitoring, assessing and researching mental health and wellbeing. Acceptability is clearly crucial if the technology is to be adopted beyond limited studies. In this paper we will specifically explore the acceptability of *smartphone-based* digital phenotyping. Smartphones are the source for a large part of research in this area, including technologies for students.

#### 2 BACKGROUND

Dawkins [24] argued that the Life Sciences should examine the behavioural expressions of organisms, or what he called "the extended phenotype". This idea has found traction in areas including Psychiatry, where the work of Jain et al. [40] sparked interest in behavioural expressions of mental health and wellbeing. Jain et al. explain that collecting behavioural data in mental health allows for "a more comprehensive and nuanced view of the experience of illness", providing "substantial value above and beyond the physical exam, laboratory values and clinical imaging data—our traditional approaches to characterizing a disease phenotype" [40].

# Digital phenotyping and smartphone data

In Psychiatry, the term digital phenotyping refers to the use of digital technology to measure the extended phenotype [39]. Jain et al. describe the use of interaction data from smartphones and computers, data from wearable sensors, web browsing and search data, and social media data [40]. Many place particular value on smartphone data; for example Torous et al. state "The data generated by increasingly sophisticated smartphone sensors and phone use patterns appear ideal for capturing various social and behavioral dimensions of psychiatric and neurological diseases" [81]. Onnela et al. discuss digital phenotyping with special reference to smartphone data, defining it as: "the moment-by-moment quantification of the individual-level human phenotype in situ using data from personal digital devices, in particular smartphones" [62]. One study has even coined the term "phone-o-typing" [73].

Work to date in this area has focused on several issues including monitoring people already diagnosed with mental health issues such as schizophrenia [7, 10, 86, 87] and depression [17, 18], and monitoring general populations for signs of depression [69] or examining mood [55]. Other work has looked at specific populations and contexts, for example looking at stress in the workplace [29]. Much of the current work has been of limited scale and primarily for research, but wide-scale monitoring is envisioned in this area, such as the systematic, population scale data collections proposed by [2, 50, 75, 81] and others.

Data collected. Typical forms of data collected in digital phenotyping are reported in Tables 1 and 2. The key form in this area is sensor and interaction data (Table 1). These data are generally 'passive' in that they are not actively input by the user, but are generated incidentally during day-to-day life. Unlike much of the personal tracking data discussed in HCI and contexts of the quantified self [59, 68], this data can be more 'raw' in nature rather than something intended to hold meaning to end users, with, for example, accelerometer logs often being collected rather than step counts.

Another important form of data are self-reports. In Table 2, we summarise several standard questionnaires that are often used. These are medical questionnaires and not designed specifically for self-tracking. The point of such questionnaires is often for providing 'ground truth' about the person, with which to then compare with the sensor data. These questionnaires are important for research, but the vision for digital phenotyping is primarily that passive data can be enough to inform assessments and meaningful monitoring. Other forms of self-report data can include demographics, medication logs and schedules or timetables. Several systems have also used Experience Sampling Methods (ESM) [19, 35, 85] in which self-report questions are triggered at

various points in time or associated with contextual factors such as location.

# Digital phenotyping and students

A population of particular interest in digital phenotyping research has been students. The work with students has often been exploratory, collecting data for many purposes, as summarised in Table 3. The table includes the focus (i.e. what the research was monitoring or attempting to infer), and descriptions of what 'raw' data was collected. The table does not show sampling rates, consider how models were constructed, or consider findings—but is intended to characterise the scope and direction of the area.

A widely discussed study of students is the StudentLife project by Wang et al. [84]. The authors developed a "continuous sensing app" that collected a variety of data, as detailed in Table 3. They used this data in order to assess the dayby-day and week-by-week impact of student life on stress, sleep, activity, mood, sociability, mental wellbeing and academic performance. The results from the study are insightful, showing correlations between the data with mental health and educational outcomes.

Data from the StudentLife study was collected from students participating in a computer science class. They were given mobile devices to use, preferably as their primary device. The authors gained ethical approval for the study and gained consent from the students, but it is not clear how the students felt about being tracked by their university, and it is not clear what opportunities they were given to talk through their thoughts. The authors mention gaining consent from participants but in the context of students being "trained to use the app" and shown "how to respond to the MobileEMA system". Similar accounts are given in many other papers from Table 3, where contact with participants is about ensuring they comply with research procedures in order that data of sufficient quality may be gained in order to perform valid analyses. Ensuring compliance is important and reasonable in early stage research, but does not wholly enable exploration of autonomy and acceptability at the same time.

Perspectives in Human Computer Interaction (HCI). The StudentLife study has been influential in HCI research, and has been prominently discussed in papers by Kelley et al. [41] and Lee and Hong [44]. Kelley et al. consider the ways in which tracked data might be put to use by counsellors, and Lee and Hong consider the development of personalised mental health interventions by students. This perspective is characteristic of the wider body of work on activity tracking in HCI which has been human centered but predominantly concerned with facilitating uptake of tracking technology. An exception is Mathews et al. [53], who have called for caution and critical perspectives in mental health tracking.

The literature on workplace tracking [6, 22, 65] is also more cautious. Our own work is highly influenced by Kelley et al. [41] and others, but with a more cautious tone.

Beyond HCI, Lovatt & Holmes [47] have critiqued digital phenotyping from a sociological perspective, praising the creation of new forms of measurement, but worrying it takes a reductive, individualistic stance on social behaviours.

# Acceptability

Acceptability is an important consideration for health technologies and interventions [56, 71, 90]. If an intervention is acceptable then people are more likely to engage and adhere to it. Acceptability is not always the first consideration in intervention development (as has been the case with digital phenotyping), with efficacy often given greater initial priority. Acceptability, however, is an important dimension of effectiveness and one that ought to be addressed early. It also has an interrelationship with ethics, particularly concepts of autonomy and informed consent.

There are several ways in which acceptability can be defined. "Social acceptability" has been one consideration in HCI [61, 89] and health [72]. Another consideration has been the perspective of experts and those delivering technologies and interventions on acceptability; this perspective is evident in ethics research in HCI (e.g [48, 54]). From the perspective of this paper, acceptability is what the user or beneficiary of the technology thinks and feels.

Sekhon et al. [71] have developed a Theoretical Framework for Acceptability (TFA) for health interventions. The framework centres on the user's point of view, and is intended to be applied throughout the lifecycle of intervention development (prospectively, concurrently and retrospectively). We will draw from the TFA later in this paper for a prospective analysis of digital phenotyping.

# Scope of this work

As an important note, the term *digital phenotyping* is not always used in the papers we describe here. For us, the term is primarily a way of referring to a growing body of work. However, use of the term also signifies that there are theoretical perspectives at play, ones that data science work does not always acknowledge. Similar perspectives include *"reality mining"* [26], *"social physics"* [64] or broader medical and sociological concepts of *"health surveillance"* [3, 34].

The work we are describing does have strong parallels with other forms of smartphone sensor-based study, particularly smartphone usage analytics [12, 23, 30, 57, 88], and a growing body of work on occupational stress (e.g. [29, 51]).

# 3 THE STUDY

We report on an in-depth study of the acceptability to students of digital phenotyping of mental health by universities.

Table 3: Papers using sensor data for monitoring student mental health

Authors	Focus	Accel. / Activity	App usage	Battery / charge	Browser History	Bluetooth	Call logs	Camera events	Screen	Keyboard / UI	Location	Light Sensor	Microphone	SMS / Email	Duration	N
Abdullah et al. [1]	Sleep		<b>√</b>		<b>√</b>		✓		✓		<b>√</b>			✓	97 days	9
Asselbergs et al. [4]	Mood	<b>√</b>	<b>√</b>				<b>√</b>	<b>√</b>	<b>√</b>					<b>√</b>	35 days (avg)	27
Becker et al. [8]	Mood	✓	<b>√</b>				✓		<b>√</b>					<b>√</b>	6 weeks	27
Ben-Zeev et al. [9]	Multiple	<b>√</b>							<b>√</b>		<b>√</b>	<b>√</b>	<b>√</b>		10 weeks	47
Boukhechba et al. [13]	Social anxiety						<b>√</b>				<b>√</b>			<b>√</b>	2 weeks	54
Chan et al. [20]	Method / UI	<b>√</b>	<b>√</b>				<b>√</b>		<b>√</b>		<b>√</b>		<b>√</b>	<b>√</b>	12 days (avg)	32
Chen et al. [21]	Sleep	<b>√</b>		<b>√</b>					✓			<b>√</b>	<b>√</b>		1 week	8
Eskes et al. [27]	Sociability		<b>√</b>			<b>√</b>	✓				<b>√</b>				11 days (avg)	10
Farhan et al. [28]	Depression	<b>√</b>									<b>√</b>				14 day blocks	79
Huang et al. [36]	Social anxiety										<b>√</b>				10 days	18
Hung et al. [37]	Depression		<b>√</b>				<b>√</b>		<b>√</b>						14+10 days	18
Lee et al. [45]	Phone overuse		<b>√</b>		<b>√</b>		<b>√</b>		✓	<b>√</b>				<b>√</b>	27 days (avg)	95
LiKamWa et al. [46]	Mood		<b>√</b>		<b>√</b>		<b>√</b>				<b>√</b>			<b>√</b>	2 months	32
Madan et al. [50]	General					<b>√</b>	<b>√</b>				<b>√</b>			<b>√</b>	2 months	70
Nobles et al. [60]	Suicide risk				<b>√</b>		<b>√</b>							<b>√</b>	Historical	26
Singh et al. [73]	Cooperation						<b>√</b>				<b>√</b>			<b>√</b>	10 weeks	54
Singh et al. [74]	Social capital						<b>√</b>							<b>√</b>	10 weeks	55
Stütz et al. [78]	Stress	<b>√</b>	<b>√</b>				<b>√</b>		<b>√</b>			<b>√</b>	<b>√</b>	<b>√</b>	2 weeks	15
Wang et al. [85]	Multiple	<b>√</b>	<b>√</b>			<b>√</b>	<b>√</b>				<b>√</b>	<b>√</b>	<b>√</b>	<b>√</b>	10 weeks	48

Our work has combined focus groups, interviews and deployment of a tracker application. We used focus groups to encourage groups of peers to engage in extended and open discussions, followed up with individual interviews to elicit personal opinions and reflection. Depth of discussion has been important in this work—we spent on average 4.5 hours (268.5 audio recorded minutes, min=236, max=316, sd=25) face-to-face with each student in group and individual sessions, where we discussed issues that were conceptually and sometimes emotionally difficult.

The study gained ethical approval from an IRB at the study site. We have used an "ongoing consent" approach [33], in which we gained informed consent at the outset, and returned to the study information throughout. At the end we showed participants their transcripts and log data for comment and discussion. Participants have also had the opportunity to comment on this paper. This was important because the students' views and understandings were formative during the study. Anonymisation in this paper is a little more stringent than usual because of participant's concerns about what they revealed.

# **Participants**

15 students participated in our study (see Table 4). 11 participants were female and 4 male, 8 were undergraduate and 7 postgraduate. The average age was 23.5 (min=18, max=30, sd=3.6).

We did not recruit people based on whether they had experienced mental distress or mental health problems, our interest being in the general student population. Given that many students in the UK have experienced mental distress (80% of students experience stress and around 50% experience anxiety, problems sleeping and/or feelings of depression [42], 43% experience feelings of isolation and loneliness [58]) it was likely that people with these experiences would attend. Given that 28% of women in the UK have experienced mental health problems by the time they are 25 [80], it was also likely that we would have people with these experiences.

To preserve anonymity, specific ages, course information and device hardware are not given in Table 4. Participants were studying topics including history, architecture, design and art; none were studying computing or medical subjects. Participants were diverse, and included nationals of and/or

Table 4: Participant information for the three cohorts. Notes: (level: UG=undergraduate, M=masters), (times shown are total for focus groups + interview), (sensor data types:  $\sqrt{\ }$  = participant's personalised data recorded and visualised,  $\triangle$  =preprepared non-personal data visualisations shown,  $\triangle$ =discussed only)

	Age	Gender id.	Level	Device	Focus Groups	Interview	Time (FG+Int)	Screen	App Use	Battery	Location	Microphone	Activity	Bluetooth	Call logs	Camera	Keyboard	Light	SMS/Email	PHQ9	GAD7	WEMWBS
P1	≥24	f	M	Android	<b>//</b>	<b>√</b>	5h16	<b>√</b>	<b>√</b>	<b>√</b>	<b>A</b>	<b>A</b>	<b>A</b>	Δ	Δ	Δ	Δ	Δ	Δ	Δ	Δ	Δ
P2	<24	f	UG	Android	$\checkmark\checkmark$	$\checkmark$	5h03	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	<b>A</b>	<b>A</b>	Δ	Δ	Δ	Δ	Δ	Δ	Δ	Δ	Δ
P3	<24	f	UG	iOS	$\checkmark\checkmark$		4h20	Δ	Δ	Δ	Δ	Δ	Δ	Δ	Δ	Δ	Δ	Δ	Δ	Δ	Δ	Δ
P4	≥24	m	PhD	iOS	$\checkmark\checkmark$	$\checkmark$	5h06	$\checkmark$	<b>A</b>	$\checkmark$	$\checkmark$	<b>A</b>	<b>A</b>	Δ	Δ	Δ	Δ	Δ	Δ	Δ	Δ	Δ
P5	<24	f	UG	iOS	$\checkmark\checkmark$		4h20	Δ	Δ	Δ	Δ	Δ	Δ	Δ	Δ	Δ	Δ	Δ	Δ	Δ	Δ	Δ
P6	<24	f	UG	Android	<b>√</b> √	<b>√</b>	4h29	<b>√</b>	<b>√</b>	<b>√</b>	<b>A</b>	<b>A</b>	<b>A</b>	Δ	Δ	Δ	Δ	Δ	Δ	Δ	Δ	Δ
P7	<24	f	UG	iOS	$\checkmark\checkmark$	$\checkmark$	5h01	$\checkmark$	<b>A</b>	$\checkmark$	•	<b>A</b>	<b>A</b>	Δ	Δ	Δ	Δ	Δ	Δ	Δ	Δ	Δ
P8	<24	m	UG	iOS	$\checkmark\checkmark$	$\checkmark$	4h01	$\checkmark$	<b>A</b>	$\checkmark$	$\checkmark$	<b>A</b>	<b>A</b>	Δ	Δ	Δ	Δ	Δ	Δ	Δ	Δ	Δ
P9	<24	m	UG	iOS	$\checkmark\checkmark$	$\checkmark$	4h11	$\checkmark$	<b>A</b>	$\checkmark$	•	<b>A</b>	<b>A</b>	Δ	Δ	Δ	Δ	Δ	Δ	Δ	Δ	Δ
P10	<24	f	M	iOS	<b>√√</b>	✓	4h13	✓	<b>A</b>	✓	✓	<b>A</b>	<b>A</b>	Δ	Δ	Δ	Δ	Δ	Δ	Δ	Δ	Δ
P11	≥24	f	PhD	Android	<b>√</b> ✓	<b>√</b>	4h29	<b>√</b>	<b>√</b>	<b>√</b>	<b>√</b>	<b>A</b>	<b>A</b>	Δ	Δ	Δ	Δ	Δ	Δ	Δ	Δ	Δ
P12	≥24	m	M	Android	$\checkmark\checkmark$	$\checkmark$	3h56	•	<b>A</b>	•	•	<b>A</b>	<b>A</b>	Δ	Δ	Δ	Δ	Δ	Δ	Δ	Δ	Δ
P13	≥24	f	UG	iOS	$\checkmark\checkmark$	$\checkmark$	4h16	$\checkmark$	•	$\checkmark$	$\checkmark$	<b>A</b>	<b>A</b>	Δ	Δ	Δ	Δ	Δ	Δ	Δ	Δ	Δ
P14	≥24	f	M	Android	$\checkmark\checkmark$	$\checkmark$	4h12	$\checkmark$	$\checkmark$	$\checkmark$	$\checkmark$	<b>A</b>	<b>A</b>	Δ	Δ	Δ	Δ	Δ	Δ	Δ	Δ	Δ
P15	≥24	f	PhD	iOS	$\checkmark\checkmark$	$\checkmark$	4h14	$\checkmark$	<b>A</b>	$\checkmark$	•	<b>A</b>	<b>A</b>	Δ	Δ	Δ	Δ	Δ	Δ	Δ	Δ	Δ

people with prior educational experiences in N.America, Africa, Europe, and Asia.

Participants were each given a £50 voucher after the focus groups, before being invited to the optional follow-on.

# Focus groups

We ran focus groups with three cohorts. For each cohort there were two sessions, each of approximately two-hour duration. Five students participated in each cohort, attending the first and second sessions with the same people.

In the first two-hour session, the researcher introduced the concept of digital phenotyping for mental health and then discussed collecting passive and self report data. The data covered in Table 1 was discussed, with the exception of browser history. The information was based upon sensor descriptions for the AWARE logging framework [31]. We also discussed collecting camera images along with camera interactions. The self report data discussed included the items described in Table 2 as well as demographics, medication details, and course related data.

In the second two-hour session we discussed what digital phenotyping technology might seek to infer from the data collected (e.g anxiety, stress, depression) and also what might be done with the data in terms of storage and sharing.

## Tracking and interviews

The final stage of the research was optional. The participants were invited to install a tracking application onto their personal smartphone, which would record data and upload it to our database. This system was built upon the AWARE framework [31]. Based upon outcomes from the focus groups, the software allowed collection of screen, battery, app use (Android only) and location. Each student made an individual choice of which forms of data collection to allow.

We completed the study by conducting one-to-one interviews. In the interview we showed the participants visualisations of their data via a prototype app (Figure 1), and then showed 'raw' copies of their data in CSV format. If a student had not collected a form of data themselves, they were shown a preprepared sample of data not personal to them. In addition we showed them examples of microphone recordings, physical activity and other data (both visualised and raw). Transcripts from the focus groups were also shown and emergent themes from the analysis discussed.

Table 4 shows what data the participants shared, saw and discussed. P3 and P5 chose not to participate in the final stage (one was unresponsive to the invitation and the other "too busy"). The logging application failed on P12's device so no data was collected from him, but he attended the interview.



Figure 1: App prototype showing app launches and battery levels by day. Note: visualisations available to participants only during interview.

The other 12 participants installed the app for between 1 and 7 days, each generating on average 9615 rows of data.

#### 4 FINDINGS

We transcribed the interviews and focus groups and have used thematic analysis [14] to build up an understanding of the data. Initial themes from the focus groups were discussed in the interviews and have been refined for this paper. The body of this findings section represents the key inductive themes that have emerged in the study. Deductive (i.e. pre-specified) themes about the sensor and self-report data also form an important aspect of this work, and these are represented by Tables 5 and 6. In order to produce generalisations for the deductive themes, we have used a technique called charting or matrix analysis [63, 76] (which is appropriate when there are differing opinions, understandings and levels of engagement among participants). The theoretical perspective underlying our analysis is one of "realism", simply meaning that we take the participant's opinions at face value (as opposed to looking for underlying motives or social constructs) [14]. This is appropriate for studying acceptability where subjective opinions are of importance, even if these are mistaken or underdeveloped. This perspective acknowledges that an aspect of making interventions more acceptable may be to educate and explain.

#### Potential for value

Our first theme concerns general opinions on the potential value of digital phenotyping technology. Most participants saw some value in the technology and all saw the need for universities and students to address mental health. P1 explained that the focus at university is on physical health, when mental health can be a bigger issue for students:

P1:"[Physical health] doesn't limit you as much in your University career as much as mental health can do."

The participants all recognised the seriousness of the issues, and had the sense that mental health and wellbeing challenges are widespread. Several discussed personal experiences and most knew at least one person who had faced problems. P5 explained that some forms of mental wellbeing issues are easy to talk to people about at university, but many are still taboo:

P5:"Anxiety and stress are much more prevalent themes in a university so it's less taboo, but if someone were to point blank ask you if you were depressed, you know, then that would be a lot harder to admit to."

However, a key issue participants raised throughout the study was not so much the difficulties of talking to others about mental health, but difficulties of recognising signs and symptoms in the first place, and then knowing what services or resources to turn to:

P2: "You don't really realise until it's really bad and then its, oh! Well what do I do now?"

Based upon this issue, participants thought that digital phenotyping technology may best help with reflection on and awareness of one's own mental health. They thought an important use for the app would be giving information back to the user and signposting to services.

P5:"An app like this ... it could at least point you in the right direction if it picks up on certain things. Cos just by having the app you would then be more aware of what you can take advantage of as a student."

The broader perspective here was that mental health is primarily a student's responsibility. In the first place, students should be supported in recognising problems themselves and deciding if and where to seek help:

P14:"I think it's better for students to give them a chance to improve themselves and then if that didn't work then maybe they can reach out to someone else, professional help in or outside of the university."

Beyond this, some participants (particularly the postgraduates in group 3), saw the value of such a technology in terms of improving research and as a tool for measuring the scope and scale of the problems faced at university to inform policy and services:

P12:"I think the technology does provide an excellent foundation for furthering other research and arguments for better resources for people ... if you manage to design it in a way that the data collection is effective and discreet, and doesn't provide more problems to people or hurt them then it would be fantastic."

Most in group 1 on the other hand did not agree that monitoring technology would be appropriate for informing

Table 5: Overview of the participants' opinions on passive data collection

Sensor	Opinion summary	Example quotes
Accel. / Activity	Some problems understanding what this data is and encompasses. Participants thought walking was relevant to mental health.	P12: "I think at least one of the signs of depression is lethargy and apathy, so if you go from walking your necessary 10,000 steps a day to, like, 2,000 it could be a sign that something's wrong."
App usage	Concerns about tracking specific apps, such as dating and LGBT+ related apps, but others less so. Also concerns about misinterpreting uses of some apps. Communication apps seen as relevant. Interests shown in personal tracking of app use.	P11: "a student at the College of Art might spend hours on Instagram because they document and they promote themselves." P5:"Tinder people might be 'there's no way I'm actually going to let you keep track when I open or close that', but I don't see a problem if you track when I play my games or when I'm on Facebook."
Battery / charging	Participants could not see the purpose of this for mental health, but did not see much privacy concern.	P11: "I don't care if you know about my battery." P14: "I wasn't quite sure what that has to do with the mental status."
Bluetooth	Main concerns raised are for other people's privacy. Students do not think they use Bluetooth often or connect to many devices.	P1 "I might consent for this but if I have my Bluetooth on and one of my friends has their Bluetooth on and they do not consent to this app, you will still get data from her phone."
Call logs	Main objection is on the grounds that few of the students use the telephone. Phone mainly used where there is poor data or for calling companies and services.	P9 "This caused a lot of outcry a few years back, When they realised phone companies do this And here we are, we've become quite tolerant about it." P7: "Most of [my friends] are in WhatsApp and Skype, I don't know. I get contacted from all kinds of apps, but not calling."
Camera	Any collection of content seen as unacceptable. No one would accept automatic collection of pictures, and most would not accept manual uploads (e.g. of selfie). Overuse of camera may be problematic.	P12: "You'd end up putting a piece of duct tape over both cameras."  P8: "I think if it asked you to take a photo. I don't know what you could learn from that."  P13: "I think it's a very unhealthy behaviour to encourage."
Screen	Seen as one of the less invasive ways of seeing interaction patterns and daily routines. Worries about false positives (e.g. screen on due to movement or notification).	P12 "interesting to see if there are correlations between how much screen-time you get versus your ability to sleep and your ability to relax and put it away, because the screen being on and the screen being off, it doesn't bother me for privacy issues."
Keyboard	Highly unacceptable to record keys clicked. Participants do not want their messages or searches tracked. Keyboard events (key press counts etc.) rather than content more acceptable.	P1 "That's a scary one I definitely don't want them to see what I Google."
Location	Mixed opinions: highly unacceptable for some, but others would be happy if there is a need. Limiting tracking to campus seen as more acceptable.	P5 "It's something that drains battery and takes up space." P6 "Unless they show my professors how long I spend in the library I'm fine with that." P14 "if the app will work without me switching location on then I would choose not to."
Light sensor	Seen as relatively acceptable. Light seen as relevant to mental health.	P2 "I was really curious about it, like how does it, do that?" P12 "This one appeals to me the amount of exposure that people have to light can affect your mental health."
Mic.	Recordings very unacceptable. Quantification somewhat acceptable.	P10 "I have to ask for permission all the times whenever I like talk with someone." P14: "it's like an invasion of privacy."
SMS / Msg.	Message counts not generally seen as a problem, but tracking content unacceptable. Participants rarely use SMS.	P12 "I would be okay with a log as long as it didn't have any of the content."

research or decision making, arguing that they themselves and others would not use it unless there was a direct personal benefit. A dissenting voice about the potential value of digital phenotyping was P13, who viewed most mental health technology as a "cop out", a cheap and inferior alternative to counselling and contact.

#### Potential for harm

The reference by P12 to "hurt" in the previous quote is important because even though all but one of the participants were positive about technology for mental health, they were also dubious that monitoring via passive sensing was the correct approach. One of the concerns underlying this was that digital phenotyping would not necessarily mean better support. In the words of P1:

P1: "An app itself is not going to fix it."

The point here is partly that there needs to be some sort of service behind the app; it is not enough just to make assessments, but these would need to be acted on. However, this notion of remote assessment by members of an institution worried people. For example in the words of P13:

P13:"I feel very much like I have to protect myself and only tell them what I feel is necessary to get the support that I need. And even then I feel like it's questioned or dismissed or they just don't have the policies and procedures to properly support me."

This is not just an issue at the study site (which the participants felt was more focused on mental health than many others). Several participants spoke about experiences elsewhere, for example:

P10:"I was in China during my undergraduate ... Our university wanted to know our mental situation, and if the test result is bad, like err some teacher will get a task, this teacher will be responsible for this student's mental health ... So some student really don't like that, so when they fill this form, they will like err do not fill the real situation."

Self determination was important, otherwise the system would be "infantilising" (a word used a lot in groups 1 and 2). The participants referred to going to university as a time to become adults. This was important for some because it meant gaining control:

P6:"[At school they would] just like sort of blame you for it and just like sort of check your body for scars."

The arguments made about mental health care as a personal responsibility, therefore, should not be seen as a moral individualism among the students, but as a response to problematic systems of care. These are systems that students want to artfully navigate or simply protect themselves from.

Another worry was not so much loss of autonomy, but the potential for discrimination based upon labels:

P11: "This app would then give them information or data to make inferences about me that could potentially...discriminate against me as a student perhaps or label me a certain way which I'm not comfortable with."

Strong arguments were built over the sessions about the relevance and problematics of the institutional contexts into which the technology would enter. It became clear that digital phenotyping for student mental health should not be narrowly construed as a technical or computer science problem.

# Privacy concerns

As acknowledged in prior digital phenotyping research, there are privacy issues at play. However, these are not simply issues of data security.

Generally, the participants felt that many of the suggested forms of data collection were "invasive" or at least "sensitive": P9: "This is very sensitive data collection."

Partly the issue was that the data may leak out from the university. Some students felt they trusted their university with their data, but others worried it would be vulnerable to hacking.

The core privacy concerns, however, were whether university staff that knew or taught the student would have access to this data.

P7:"I wouldn't [want] my tutors to know, because if I have an issue which is affecting my work, I'll tell my tutors. I'll email them and tell them. They don't need to know everything that's going on in my life."

One of the participants was worried lecturers might find out that she sets her alarm for 11am. It was not that the students never wanted lecturers or tutors to have access to information, but that release of information should be controlled. One idea that came up in all groups was that data could be released when needing to provide evidence for reasons of absence, or for needing deadline extensions.

# Relevancy of data collected

The students felt that there must be good reasons in order for data to be collected:

P1:"It's like I don't want you to have data that you don't absolutely need."

Importantly, most participants did not understand why a mental health app would need to collect information that is not 'logically' related to mental health. Although it was accepted that data can be used to make inferences, just how seemingly innocuous things could be linked to mental health was not well understood:

P12: "AI totally baffles me now."

Table 6: Overview of the participants' opinions on self report

Survey	Opinion summary	Example quotes
PHQ9	The questions might cause worry or bad	P5: "There's a lot of questions, and at the end you're convinced
	thoughts, particularly the ones about suicide	you're depressed,"
	and self harm. Students were concerned what	P8: "they're not even thinking about it and they read this ques-
	would happen (or not happen) if you say you	tion and ok maybe I'm better off dead."
	are depressed.	
GAD7	The questions might cause worry. Participants	P6: "What's going to happen if I answer that I have been feeling
	thought it was too easy to self mis-diagnose.	super anxious? Is there going to be a team of medics rushed
	Concerns about the consequences of answering	into my room?"
	these questions.	
WEMWBS	Positively framed questions are more appropri-	P9: "The first question is 'I've been feeling optimistic about the
	ate. However, answering negatively may be up-	future', and for me it's like well uh, oh the future, I'm graduating,
	setting.	where will I be? Can I stay here? I want to be in the UK but I
		don't know."

P11:"I guess I don't really see the relevance, when I think in terms of a lot of data that's being collected."

Being able to see relevance (rightly or wrongly) of data to mental health meant that the participants saw the data collection more positively (e.g. the comments about walking or light in Table 5). Even the relatively unacceptable forms of data collection may become acceptable if there is a perceived need, e.g. tracking "trigger words" in text messages or searches would be more acceptable than tracking all words.

Several participants wondered if inferences could be made on the device and then shared, rather than the raw data.

P8: "inferences ... that's the data you can have."

If on-device analytics is possible and participants are able to control and share the inferences, then it seems much more likely that students would accept this.

# Making users worry

Regarding the self-report questions, the participants thought being asked about anxiety, depression and wellbeing may make people worry unnecessarily, or may even cause negative thoughts and feelings. The questions about anxiety and depression were "dark". The positively framed questions in the WEBWBS questionnaire were more acceptable to participants, but even positive questions may cause upset:

P13: "if you were feeling helpless or hopeless and you answered no to ["I've been feeling useful"] I think it would just make your symptoms worse."

A major criticism of the surveys, particularly the depression and anxiety surveys, was that these would be better used in a face-to-face setting with a trained person.

P9: "These questions may be raised by a medical professional more appropriately than through an app."

The participants made suggestions that more abstract mood tracking may be preferable to having to answer these questions, or something such as bullet journaling.

## Effect on device

A key concern about passive data collection was the effect this would have on their device. A fundamental concern for the participants was their device's battery. They argued any app that negatively effects battery life is likely not to be used unless it is of high value. Use of data and storage were also concerns, although less pronounced than battery. The participants all regularly connected to University Wi-Fi, and for some this was their only source of data.

Issues of whether it is right to expect students to have a smartphone and for this to then be used for a university initiative were also questioned. Potentially it would be better to supply students with new smartphones.

### 5 DISCUSSION

This study raises doubts about the acceptability to students of digital phenotyping by universities. However, acceptability is not a simple yes/no question and in this section we will discuss these doubts and identify ways in which they may be overcome.

# Acceptability of digital phenotyping

As described earlier, the Theoretical Framework for Acceptability (TFA) [71] is appropriate for structuring our findings with respect to acceptability. The TFA has seven components, which we will step through here:

Affective attitude. This concerns how people feel about and may be affected by digital phenotyping technology. On the positive side we found that all participants thought that universities and students should take mental health seriously, and that most were in favour of technology-based approaches

such as apps. However, participants pointed out that the proposed technology may cause people worry and anxiety by the questions asked and in terms of what lecturers and tutors may find out. They were also concerned about a loss of autonomy and dignity in navigating systems of care.

Developers of digital phenotyping systems need to be transparent and careful about what data is collected and who has access, and need to consider the affective user experience of having and using the technology.

Burden. This concerns the perceived amount of effort required for using the technology. There was no suggestion among participants that having an app such as this would place specific burden on them, although several did question whether they would make the effort to install an app and answer questions. There were also worries about needing to charge batteries frequently.

Developers of digital phenotyping technology should be aware that low burden characterises digital phenotyping, but this alone will not ensure acceptability.

Ethicality. This is the extent to which digital phenotyping fits with individuals' value systems. The students' key concerns were loss of autonomy, control and dignity. The transition to adulthood was an important aspect of many of the younger students' considerations.

Developers should provide controls over how information is released, and on-device analytics with selective sharing of inferences rather than raw data is potentially fruitful here.

Coherence. This concerns whether people understand the intervention and how it works. Many participants were aware that inferences could be made about them from behavioural data, but wanted to see logical relationships between a datatype and wellbeing. They were not aware of how much could be extrapolated from seemingly innocuous data such as battery charge over time.

Developers need to carefully explain why data is collected and how it holds meanings. Case-based examples might help to ensure that consent is informed as well as address any mismatch between perceived and actual potential threats. Consent that is oriented to inferences rather than just the types of raw data may also be needed.

Opportunity costs. This concerns what is given up to exchange in the intervention. In the case of smartphone-based digital phenotyping, the fundamental concern to students is the effect on their battery. Data, storage and performance costs are also concerns.

Developers of digital phenotyping systems should minimise the effects on participants' devices, particularly battery. Although smartphone penetration is high, it should not be assumed students own new or high-end devices, or can charge

batteries regularly. It may be reasonable to supply students with new devices to use.

Perceived effectiveness. This concerns whether the intervention is perceived by participants as likely to achieve its purpose. The overriding factor here is not whether participants think digital phenotyping will make correct assessments, but how they see it situated within a system of care. The students pointed out that these systems of care need to be navigated in order that students get the help they think they need and to avoid what they do not want.

Designers of digital phenotyping technology need to engage in service design rather than just technology design. Technologies should be appropriate for the artful navigation of care, and/or be part of a reconfiguration of existing institutional approaches.

Self efficacy. This concerns whether users are confident they can make changes. The participants did not report feeling in control of their mental health. They had difficulties recognising when things were wrong or knowing what to do.

Designers of digital phenotyping technology should provide information about mental health and wellbeing and support reflection for self awareness. Supporting know-how for change and expediting human contact may be valuable.

#### **Future work**

Design work in this area should be more user centered; the design recommendations we have outlined above could inform such work. Further qualitative work could involve larger sample sizes and/or could focus on: subpopulations who face additional mental health challenges at university e.g. LGBT+; people with diagnosed disorders; or, surveillance and sharing within clinical, peer, and family contexts.

## 6 CONCLUSION

We have looked at digital phenotyping through the lens of *acceptability* in order to develop a sense of what engenders willing participation by students in data collection. We have uncovered a range of views and beliefs that suggest seeing digital phenotyping not as a technical or computer science challenge of data collection and analytics, but as an interdisciplinary design challenge in which the ways in which students are supported are rethought. There are important technical challenges still to address, but if we are not paying attention at the same time to the contexts of care for mental health and wellbeing, and if we are not putting student autonomy and self determination at the heart of of our approaches, then innovations in this area may be in vain.

### 7 ACKNOWLEDGEMENT

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