Opportunities for data collection and linkage: mental health

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Introduction

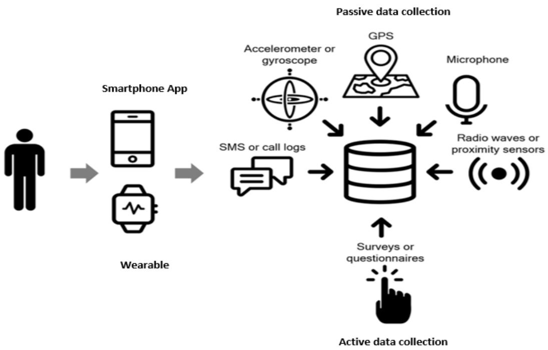
In England one in six people report experiencing a common mental health problem, such as anxiety and depression, in any given week (McManus et al., 2014). Novel technologies provide the opportunity to answer important research questions in mental health including describing behavioural patterns over time; predicting life outcomes; and examining social networks (Harari et al., 2016).

The use of technology to collect data in health monitoring and assessment has grown in recent years (Oliveira and Oliveira, 2018). Passive data collection through smartphones provides less intrusive data capture without additional effort from participants (Ebner-Priemer and Trull, 2009). Physical sensors in smartphones are available through embedded technologies such as GPS, gyroscope, Bluetooth, WiFi, camera, microphone, light and sound sensors. While smartphone data such as usage of applications, calls, SMS and battery can be collected to monitor users health in real-time (Oliveira and Oliveira, 2018).

Previous studies have monitored users typing behaviour and texting speed on smartphone keyboards to indicate current emotional state (Shapsough et al., 2016). Other sensors, such as Bluetooth and microphones have been used as proxy measures of wellbeing through inferring sociability. Smartphone data can support such inferences of sociability through recording communication history with others (Jaques et al., 2015). Physiological measures, such as heart rate can also be detected using smartphone cameras, which can be used to infer an individual's mental state (Huang and Dung, 2016).

Figure 1 presents a visualisation of the technologies used to measure mental health which will be discussed in this report.

Figure 1: Visualisation of technologies used to measure mental health*



**adapted from (Cosco et al., 2019)*

Firstly, mobile applications (Apps) are frequently becoming accessible to users to track and measure mental health. Such apps are referred to in the literature as mobile health applications or 'mHealth' (Marzano et al., 2015). Apps can be used to collect and access data collected from passive data sensing (detailed available in Table 1). Apps also enable active data collection through ecological momentary assessments (EMA). Secondly, research projects have investigated the feasibility of researching a range of emotional symptoms and behavioural disturbances using smartphones and wearable technologies

(Marzano et al., 2015). Wearable technologies can be used be detect physiological measures of stress such as heart rate and breathing (Sano and Picard, 2013).

Data linkage has been identified as a fundamental step to improve data science in mental health care (NHS Digital, 2019a). Big data approaches have been used in several research projects to answer questions on mental health difficulties such as dementia, depression, schizophrenia and autism (Stewart and Davis, 2016). Data linkage is the process of “bringing together two or more sources of information which relate to the same individual… to identify relationships between factors which are not evidence from the single source” (Green, 2015; p.13). The combination of administrative data would facilitate an understanding of a person’s journey through mental ill health, using primary care data to understand pathways to mental healthcare.

Previous published literature have analysed factors such as area of residence and care providers due to their influence on mental health outcomes at local and service provider level (Weich et al., 2018). Data linkages to mental health databases in the UK have also been used to diagnose conditions, such as dementia, in participants of cohort studies (Sabia et al., 2017).

The aims and objectives of this report was to investigate:

1) The opportunity and feasibility of the use of technologies to measure mental health in Centre of Longitudinal Studies (CLS) cohorts.
2) The opportunity and feasibility of linking CLS cohorts to nationally held records on mental health service use.

Methods

For this report, mental health was conceptualised in the broadest sense of an individual’s general mental state. A non-systematic search of the literature was conducted to collate evidence on data technologies and linkages. Google scholar, citation checks and backward searching was used to identity relevant research. Authors in the field of mental health technologies were contacted for transferable learning, while NHS digital was contacted for information on data linkages.

Searches were conducted into ecological momentary assessment in mental health research, smartphone apps using passive data collection to track mental health, and wearable technologies suitable to measure mental health. Information on various technologies was collated in terms of effectiveness, feasibility and user acceptability as attrition is an important consideration for CLS cohorts.

Descriptions of mental health datasets were summarised from information available on NHS websites. Further information regarding data collected in mental health databases was available in technical output specification documents available through NHS digital.

Findings

Part 1: Data collection technologies

Passive data collection

As presented in Appendix 1, the most commonly used sensing technology was GPS to track location of participants (7 examples), followed by physical activity measured by accelerometry (5 examples). Sociability was inferred using audio from microphones in four examples, while light sensors as a measure of sleep was found in three examples. In terms of device data, phone usage was collected in four examples in addition to call logs (2 examples), SMS log (3 examples) and social media use (2 examples). While battery use and phone unlocking were both used as an indication of device use. Some apps within the literature, for example MoodScope and CatchIt, are NHS recommended apps only track symptoms of mental health using self-reported measures without passive sensing. While apps such as Mappiness and UrbanMind, seek to correlate levels of happiness with environment factors using GPS tracking.

The information found in this review supports previous reviews of smartphone based passive sensing for health and wellbeing. Previous reviews reported benefits in all included studies of passive sensing using smartphones including significant correlations with validated measures in mental health studies (Cornet and Holden, 2018). Other systematic reviews focused on effectiveness of mHealth for behaviour change (Han and Lee, 2018), or effectiveness of apps to treat mental health conditions (Donker et al., 2013).

Table 1: Overview of types of smartphone data and behaviours they measure*

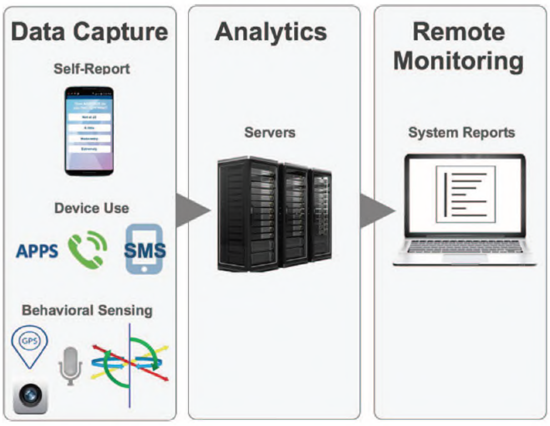
	Features	Behaviour Measure
Physical sensor		
Accelerometer	Coordinates, duration, movement, stationary periods	Daily activity; mobility
BT radio	Number of unique and repeat scans	Social interactions
GPS scans	Coordinates	Daily activity; mobility
Light sensor	Ambient light in environment	Daily activity; mobility
Microphone sensor	Audio recordings in environment	Social interactions; daily activity
Proximity sensor	Proximity of an object to the screen	Daily activity
WiFi scans	Number of WiFi scans, location of WiFi network	Mobility patterns
Smartphone data		
Call log	Incoming and outgoing calls, number of contacts	Social interactions
SMS log	Incoming and outgoing text messages	Social interactions
App use log	Number of apps, frequency and duration of use	Social interactions; daily activity
Battery use log	Battery charge times, battery status	Daily activity

**Adapted from (Harari et al., 2016)*

NB: The studies presented in Appendix 1 are examples of apps available within the literature intended to highlight the feasibility of technologies to measure mental health. This is by no means a comprehensive list of all available apps within the literature.

CrossCheck is an example of a smartphone app used in a research capacity incorporating the elements of passive and active data collection. The study used multimodal data collection for continuous remote monitoring of participants with psychosis (Ben-Zeev et al., 2017). Active assessments were completed through CrossCheck using EMA, where participants respond to questions on smartphones. Passive data continually collected data on device use and behaviour using multimodal sensing. Full details available in Appendix 1. CrossCheck was effective in developing a model of determinants for schizophrenia relapse risk, especially social activity. During the trial research, staff were able to call participants if problems appeared with passive data collection or data integrity, which assisted the collection of data in the context of a randomised control trial. Overall, data collection for CrossCheck lasted 12 months suggesting some people with psychosis are willing and able to engage in multimodal illness monitoring using smartphones for extended periods of time.

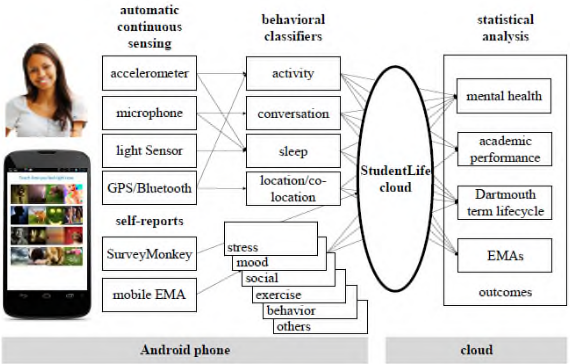
Figure 2: Overview of the CrossCheck System*



**From (Ben-Zeev et al., 2017)*

StudentLife is another example of smartphone technology being used in a research setting over a 10-week period. This study used continuous sensing through a smartphone to track the activity and sociability of 48 students at Dartmouth college (Harari et al., 2017). The study was effective in finding a link between depression scores, location variance and circadian movements (Saeb et al., 2016). In an additional study, prompts from StudentLife to use smartphone cameras to log facial expressions was found to not be an effective measure of mental health due to poor data quality (Wang et al., 2015). Throughout the trial feedback was not provided to students as to not influence behaviour. Despite incentives being provided for participation in the trial, students still reported carrying two phones to be a burden, especially if students did not use Android phones prior to the study. Additional burden was reported as no notifications were sent when EMA was required resulting in participants having to physically check phones to complete measures.

Figure 3: Overview of StudentLife system*



**From (Harari et al., 2017)*

Wearable technologies

Commercially available wearable trackers, often with attached apps or behavioural interventions can be used to measure mental health. Indicators of mental state such as heart rate and breathing have been used in wearables such as Feel and Spire (See Table 2). Transparent and unobtrusive monitoring using wearable sensors including wristbands and smartwatches have been used for participants with depression and anxiety (Seppälä et al., 2019). Information on heart rate, breathing and body temperature can also be collected through a chest band, the wearable AutoSense received positive reactions in exit surveys from participants as not causing discomfort or interfering with daily interactions (Ertin et al., 2011). Smart glasses are another wearable capable of tracking facial muscle activity to indicate emotional responses, EmTeq glasses are currently in beta prototype testing. In some examples, wellness trackers have been developed with wear-ability in mind, as Leaf Nature trackers by BellaBeat are available as a bracelet, necklace or clip, costing £75 per device.

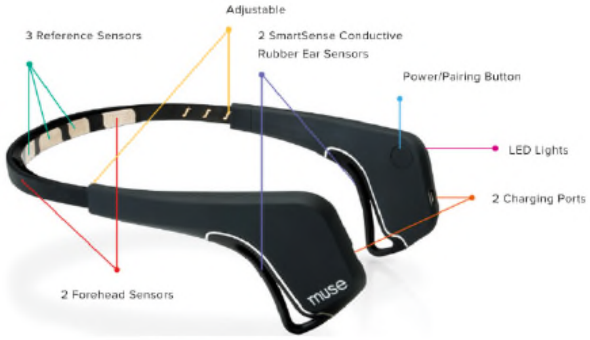
Table 2: Wearable technology mental health data collection

Technology	Aim	Examples
Breathing	Indicate anxiety or stress	Spire
Heart rate monitor	Measure mental state	Feel
Electronic sensor (EEG)	Body temperature and brain activity	Muse

Muse is an example of a consumer headset which produces real-time feedback on brain activity using electroencephalography (EEG), heart rate using pulse oximetry, breathing using gyroscope and body movement using accelerometer. Muse was originally built to use during meditation to improve practice with audio guides. The research team, based on Canada, developed a tool kit providing information on how to record and convert EEG data for research projects. MATLAB codes have been shared by researchers for use in other studies (Krigolson et al., 2017).

Muse costs £239 per device and has been used in several research projects due to its commercial availability. For example, Muse has been used in proof of concept studies to predict and track cognitive state such as anxiety and depression (Bashivan et al., 2016) and has been used in observational studies of focus during lectures (Przegalinska et al., 2018). Although affordable and easy to use, Muse does not continuously monitor activity and only collects data when the headband is on. Muse has been found to only be useable in session-based exercises due to lack of resolution and quality of signal (Bashivan et al., 2016). Muse has been described as being highly portable and unobtrusive (Przegalinska et al., 2018) but reportedly uncomfortable after 30 minutes therefore not appropriate for long term use (Bashivan et al., 2016).

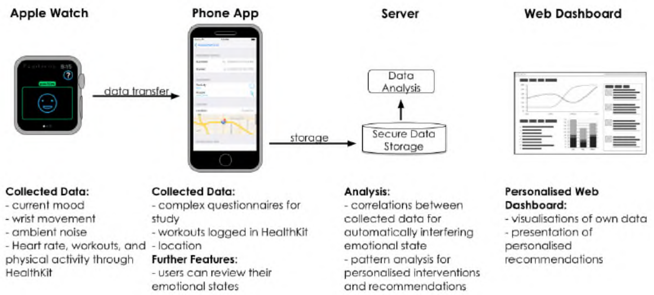
Figure 4: Overview of Muse headband*



**From (Abujelala et al., 2016)*

Another example of a wearable technology is the Apple watch, with corresponding app. This mobile phone and smartwatch application has been used to collect mood experience from participants which is further enriched by mobile sensing data (Hänsel et al., 2016). Users are reminded daily to rate current mood based on a two-dimension approach for affect classification (the Circumplex Model of Affect): valence (positivity) and psychological arousal (activeness) on a 5-point scale. The Apple Watch offers touch sensitive screen to rate mood on the watch, paired with the phone app where scores can be reviewed. Watch based devices have been found to have quicker response times to EMA prompts than head worn devices such as Muse (Hernandez et al., 2016). Researchers wish to develop future algorithms to infer current emotional levels based on the mobile and wearable sensing data (Hänsel et al., 2016).

Figure 5: Overview of Apple Watch App*



**From (Hänsel et al., 2016)*

Ecological Momentary Assessment

EMA is a form of active data collection where participants enter data in real-world environments. Alerts prompt users to complete assessment questionnaires through smartphone apps which then transmit data to the research team. This process increases ecological validity and reduced recall bias (McKay et al., 2016). Such methods have been used in the area of mental health, specifically in the assessment of anxiety (Walz et al., 2014) and depression (Colombo et al., 2019).

EMA has been used in adult populations with emotional difficulties (Ramsey et al., 2016). Varying levels of acceptability have been found in different populations with only 60% of older participants willing to participate in EMA research, and 44% willing to download both GPS and EMA apps (Duncan et al., 2019). EMA involves intensive, repetitive examination of experiences and feelings during daily routine (Wenze and Miller, 2010). There is evidence to suggest that tracking symptoms can make you feel worse through a process called the 'nocebo effect.' This phenomenon is opposite to the placebo effect where expectation of a negative outcome may lead to worsening of symptoms (Benedetti et al., 2007).

MyExperience is an example of EMA using smartphones in research (Froehlich et al., 2007). Completion rates were found to be lower in a sample of people with psychosis, compared to a healthy population, with a completion rate of 28-31%. The study provided participants with phones to ensure standardised formatting and delivery of EMA. Feedback from participants suggested MyExperience would have been better as an app on an iPhone, as participants reported carrying a separate device to be a negative. Participants were compensated for study participation per EMA completion and given monetary rewards were given for completing EMA (Moitra et al., 2017). Participants reported challenges relating to operating mobile device. Reasons for withdrawal included lack of interest, feeling overwhelmed, and losing contact with the research team. Overall, the acceptability of the method was found to be high in sample who reported being satisfied with the experience and willing to use EMA in the future. Suggested improvements included the use of participants own phone when feasible, and limiting EMA to a 1-3 week period.

MoodMonitior is an EMA app designed for people with mild depression which provides notifications when EMA response is required. In a protocol for a randomised control trial, three groups are planned to used MoodMonitor: all three groups will be completing retrospective questionnaire (CES-D) and group 1 completes EMA of mood, group 2 EMA of energy, and group 3 no additional EMA (van Ballegooijen et al., 2016). Effectiveness information is not yet available. System Usability Scale is planned to be completed after week 12 with ten participants completing semi-structured interviews about experience of mood tracking, how the app could be improved and study participation in general.

Part 2: Data linkage opportunities

Mental health datasets

This section provides an overview of available routine mental health datasets and provides the case for the linkage of data with the mental health datasets in England, namely the Mental Health Services Dataset (MHSDS) and Improving Access to Psychological Therapies (IAPT) dataset. For other countries, data is available through The Community Mental Health dataset (Scotland), StatsWales (Wales) and the Mental illness/learning disabilities census (Northern Ireland).

NHS Digital is responsible for standardising, collecting and publishing data and information across health and social care systems in England. MHSDS and IAPT datasets captures information on individuals referred into NHS or IAPT services for their mental health as part of clinical care (NHS Digital, 2019b). The IAPT database provides information on adults in England accessing support for depression or anxiety, while the MHSDS reports information on children and adults in England accessing mental health support from NHS funded services. The MHSDS population is therefore more severe than the IAPT one, also reporting details such as hospital admissions.

NHS Digital have started linking MHSDS and IAPT data to other datasets to gain additional insights and follow up progress. One example would be the linkage of MHSDS to the Maternity Services Data Set and produced a report on new or expectant mothers contact with mental health services in 2017.

MHSDS

The MHSDS provides patient level, output based, secondary user data on people in contact with Mental Health Services in England. The MHSDS collects information from specialist secondary mental health services. Information on services in hospitals, outpatient clinics, and community provide a comprehensive picture of the use of mental health services of both children and adults.

MHSDS records contain a unique patient identifier to link patient care spells across time. MHSDS collates monthly returns from health service providers on all patients in contact with secondary mental health services provided and/or funded by NHS England. This includes voluntary and involuntary inpatient treatment, outpatient attendance, day treatment and other episodes of secondary mental healthcare. MHSDS provides data on a range of patient characteristics, care activities, and outcome measures. Full details available in Table 3.

IAPT Dataset

The IAPT dataset collects national data on IAPT services for people with depression and anxiety, which began in 2012. IAPT have two available services one for adults, and one for children and young people, data for which is reported in separate databases. Information about the IAPT programme is generally based outcomes for depression and anxiety, care activities, and wait times. Full details available in Table 3.

At each contact, the provider completes two questionnaires to assess the severity of condition, either a depression or anxiety disorder specific measure which is issued dependent on problem descriptor. Both measures have a defined caseness threshold which indicates if case is severe enough to be considered a clinical case by IAPT services.

Table 3: Overview of information available on mental health databases

Patient information	**MHSDS** NHS number, birth date, gender, GP Practice, Accommodation, Employment, Disability, Social and Personal Circumstances, Medical History (Previous Diagnosis)	**IAPT** NHS number, birth date, gender, postcode, GP practice, ethnicity, sexual orientation, long term physical health information and disability.
Referral information	**MHSDS** Referral source, reason, team referred to, wait time, medication prescription, care contact/activity, Hospital Provider Spell, Provisional Diagnosis, Primary Diagnosis, Secondary Diagnosis	**IAPT** Referral source, wait time, provisional diagnosis, year and month of symptom onset, previous symptoms, mental health care cluster.
Care information	**MHSDS** Duration of care contact, location, activities, attendance, follow up	**IAPT** Appointment intensity, care professional, attendance, duration of appointment, appointment purpose, consultation medium,

		therapy type, employment status, psychotropic medication usage
Hospital information	**MHSDS** Mental Health Act Legal Status Classification Period, Community Treatment Order, Hospital spell information: Provider, ward stay, assigned professional, restrictive intervention, assault, self-harm, home leave, mental health leave of absence, mental health absence without leave, substance misuse, mental health trial leave	**IAPT** n/a
Outcome measures	**MHSDS** Depression (Patient Health Questionnaire (PHQ-9), anxiety (Generalized anxiety disorder 7 (GAD-7), psychological distress (Clinical outcomes in Routine Evaluation 10 (CORE 10), wellbeing (Warwick Edinburgh Mental Well-being Scale (WEMWBS) and health and social functioning (Health of the Nation Outcome Scales (HoNoS).	**IAPT** Depression (PHQ-9), general anxiety (GAD-7), specific anxiety (Agoraphobia Mobility Inventory, Social Phobia Inventory, Panic Disorder Severity Scale, Impact Events Scale, Obsessive Compulsive Inventory, Health Anxiety Inventory-Short Week) and functioning (Work and Social Adjustment Scale)

Outcome measures are reported in terms of reliable improvement (number of people pre and post treatment who exceed measurement error of questionnaire) and reliable recovery (number of people pre and post treatment exceeding measurement error and score moves below clinical cut off) (Clark and Oates, 2014).

Conclusions

This report summarises a range of novel approaches for collecting data and opportunities for linking data related to mental health. In this conclusion we summarise different considerations for implementing these in large scale population based studies like the CLS cohorts.

Part 1: Data collection technologies

The different considerations for data collection technologies are outlined below:

Device:

In a phone-based approach, whether to use a study specific phone or participants own phone is an important consideration. One research project (CrossCheck) provided participants with a mobile for the duration of the 12-month trial but transferred contents from original phones to the study phone to increase usability. This is an improvement from other trials where participants were required to carry two phones (StudentLife). An important consideration is how to obtain standardisation of devices and how to aggregate data across different models of smartphones.

Prompts:

In EMA studies, various schedules of prompts were found within the literature (examples can be found in Appendix 1). Phone based prompts are most widely used in EMA research however participants have been found to take longer to interact with phone follow prompts compared to if prompted by wrist or head worn wearables (Hernandez, 2016). It is important to consider participant burden when developing prompt schedules to avoid attrition.

Incentives:

Within the literature, various incentives for participation in technological research were found. One study (MyExperience) provided monetary compensation for participants per EMA completion ($0.50 per EMA, overall $60 incentive). The effects of such incentives are important to consider as completion rates were found to be lower in the MyExperience trial than other comparable studies.

Costs of technology/data curation:

Much of the passive data collection used in a research capacity are in a prototype phase therefore cost data is unavailable. The majority of wearable technologies are commercially available and cost data was reported where available. Platforms have been developed to extract clinical insights from smartphone data, for instance, Beiwe is available through collaboration with Onnela Lab at Harvard (Torous, 2016).

Reliability of technology:

Physiological measures can only be taken when the device is in a specific location (e.g. wrist or head), reducing the unobtrusiveness of the data collection method. It is also important to consider natural breaks taken by users from wearable technologies. Strategies to mitigated or minimise disruption have been developed such as open reminders after short breaks, and small nudges for longer breaks (Meyer et al., 2017).

Privacy:

Studies have used microphone data from smartphones as an indicator of sociability (StudentLife). Speech detection software does not record raw speech, but the privacy implications are an important consideration as they may impact participants agreeing to take part in research using such technologies.

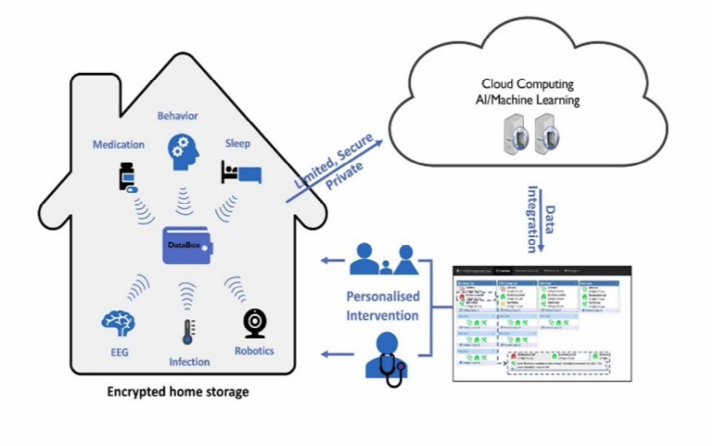
Feedback:

Participants have reported valuing feedback from passive data collection or wearable technologies if it was understandable, timely and relevant to lifestyle (Asimakopoulos et al., 2017). Providing feedback is suggested to be important for longer term adherence and have been found to improve users health (Oliveira and Oliveira, 2018). This may be useful on an individual level however presents challenges to observation study research by changing behaviour. A similar issue occurs in EMA research where a review of mobile mood-monitoring apps found evidence of reduced depressive symptoms following use (Dubad et al., 2018).

Future directions

The future of sensing technologies will be full of innovative ways to identify, track and improve stress and wellbeing. A newly set up research centre is seeking to use sensors in the home to measure heart rate, blood pressure, body temperate, gait and sleep, some of which can be used to provide proxy measures of mental health (see Figure 6).

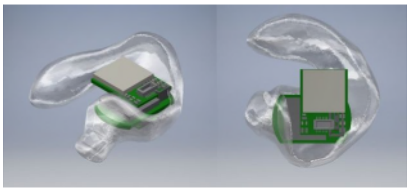
*Figure 6: Overview of Healthy Dementia Home**



**from (Wrighton, 2019)*

Additionally, wearable technologies are being developed to increase usability including an EEG monitor, which can fit in a participant's ear similar to a hearing aid and monitor brain function (see Figure 7).

Figure 7: EEG ear monitor



**(Green, 2019)*

Part 2: Data linkage opportunities

The scientific benefit of data linkages to mental health datasets includes the identification of factors and associations for mental health that would otherwise be difficult to determine. This is possible through combining clinical data with other sources to answer questions a single data set cannot resolve. Examples of such research questions include:

- How many CLS cohort members are accessing mental health services?
- What are the socio-economic and other characteristics of individuals with high symptomology who receive treatment for their mental health?
- Are there lifecourse/early life characteristics that predicts treatment duration and outcomes?
- Investigate the longer-term outcomes of individuals who received treatment.

CLS has already successfully linked different data courses such as Hospital Episode Statistics (HES), education records and registry data. Such linkage has been possible through identifiable variables such as name, age, ethnicity or postcode. The completeness of these variables used for matching is expected to be complete in these datasets (similar to other NHS digital datasets such as HES). In addition, high levels of missing data within the MHSDS have been reported for other patient-level variables such as accommodation status (65%) employment status (75%) (Weich et al., 2017), and these are domains where the cohorts contain detailed information on cohort members, so linkage will allow for a more complete investigation of these variables in the mental health datasets in a subset of that data that overlaps with the cohorts.

NHS digital teams have confirmed that it is feasible to link mental health data based on identifiable features such as names and date of birth. Information about application details is available through the Data Access Request Service (DARS). DARS enquiry reference from HES data linkage will be useful to include in the next stage of enquiry. DARS decides specifics such as timeframes and availability of specific data. The charge for application, data processing and providing access per dataset per dissemination is £2060.

Appendix 1

This table provides a summary of examples of different methods and programmes to collect certain types of data. It is not an exhaustive list of all the different apps, devices and programmes available.

Technology	CrossCheck	StudentLife	MoodMonitor	Purple Robot	iHope	MobiMood	MyExperience	iMonitor	Emotion Sense
Reference	Ben-Zeev (2017)	Harari (2016)	van Ballengooihen (2016)	Saeb (2015)	Hung (2016)	Church (2010)	Froehlich (2007)	Malliaris (2009)	Lathia (2017)
Population	Schizophrenia	Students	Depression	Depression	Emotional state	Mood tracking	Psychosis	Bipolar	Happiness
Operating system	Android	Android	Android	Android	Android	iPhone	Windows	Palm OS	Android
Physical Sensor									
Accelerometer	Yes	Yes			Yes				Yes
GPS	Yes	Yes		Yes	Yes		Yes		Yes
Light sensor		Yes			Yes				
Microphone	Yes	Yes							Yes
WiFi	Yes								
Smartphone Data									
Call Log	Yes				Yes				
SMS Log	Yes						Yes		
Phone Use	Yes			Yes	Yes				Yes
Battery Use							Yes		
Phone Unlock	Yes								
Social Media				Yes	Yes				
EMA									
Frequency	3 times a week	8 per day	Once a day	Pre-post	Based on phone usage	Self-reported	Evening (9pm) or day time (random)	Self-reported	Twice a day
Scale	10-item rating 1-5	Pictures or 5 pre-set answers	Scale 1-10		Visual analogue scale	Microblogging		Visual analogue scale	Grid with two mood adjectives
Measure	Psychosis symptoms	PAM and stress	Mood or energy	PHQ-9	Depression, stress, anxiety	Circumplex Model of Affect		Bipolar symptoms	Happiness

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