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New technology and novel methods for capturing health-related data in longitudinal and cohort studies

Report from a CLOSER workshop

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Section 1

Executive summary:

Measuring health-related data in longitudinal studies can be a difficult task. However, the recent development of innovative new techniques, such as passive detection of health behaviours using wearables, ambulatory and continuous biosampling, and novel uses of social media data, means we will soon be able to measure a wide range of health-related data in more detail, with better accurate, in less invasive ways than has previously been possible.

On 19th May 2017, a workshop was held in Bristol bringing together researchers and interested parties from the field of longitudinal and cohort health studies to explore and discuss the use of new technologies and methods for capturing health-related data in the context of these studies. This was the third and final workshop in a series of three related knowledge exchange workshops funded by CLOSER (Cohort and Longitudinal Studies Enhancement Resources) - the other two being on the subjects of mixed modes and measurement methods, and new technologies to measure non-health topics. The aim of the workshop was to share knowledge on the current state of activity and developments in new technology for health-related data capture in longitudinal studies, and to define a research agenda and identify priority areas for further research.

This report provides a review of the literature relating to new technology in health data capture, an overview of the existing use of new technology within CLOSER's consortium of studies, and details of the presentations at the workshop. The presentations conveyed experiences of techniques already in use in the CLOSER studies, and presented new approaches to capturing a variety of health data from participants in their day-to-day lives. In addition, many talks touched on future opportunities for use of these new data capture techniques, as well as some of the issues and challenges related to their use. Themes for future work in this area included mental health, physical and cognitive decline, environmental data, biological measures and detailed measurement of physical activity. Issues and challenges were around the themes of security and data privacy, ethics and consent, incentivisation and engagement, feedback to participants and the duty of care, and integration and maintenance of data from multiple sources. The report concludes with a synopsis of these discussions around future opportunities and challenges.

In summary, the availability and accessibility of technology is greater than it has ever been, enabling researchers to build a comprehensive picture of individuals in their natural environment, obtaining contextual data to shed light on the often complex factors underlying their health and behaviour. While techniques based on new technologies face a number of very real challenges, they offer the potential to bring profound, transformative improvements to the study of health in longitudinal and cohort studies.

Section 2

A review of new technology in health-related data capture

This review examines some of the trends in new technology over the past ten years or so and presents examples of how these technologies have featured in (or have potential for) the collection of health-related data, with a view to their use in longitudinal and cohort studies.

2.1 Mobile phones, SMS, and ecological momentary assessment

One of the first serious applications of technology to the capture of health data utilised mobile phones. Short message service (SMS) text messaging has been a feature of mobile phone technology since the early stages of its implementation, and has been adopted by many researchers to carry out a variety of methods for data capture, perhaps most notably ecological momentary assessment (EMA). EMA was pioneered in the 1990s by tobacco researchers Saul Shiffman and Arthur Stone, and is described in Shiffman et al's (2008) review of the subject as involving repeated sampling of participants' behaviours and experiences in real time, in their natural environments. The popularity of mobile phones, and the extent to which they are carried about the person makes them an ideal medium for delivery of EMA testing.

The use of EMA via SMS has since grown in popularity. To give some recent examples, Phillips et al (2014) used EMA to evaluate cannabis use in college students, and found response rates were high (89%) and the results correlated well with a timeline followback reporting method; however, they identified the capacity of the messages themselves (maximum 160 characters) as being a drawback. Garcia et al (2014) developed an SMS-based assessment delivery system for use with adolescents, obtaining high compliance and retention rates, while Axen and Bodin (2016) used it to collect repeated measures of lower back pain and find the optimal frequency for its measurement.

A further development of the technique is 'unobtrusive', or 'context sensitive' EMA, where aspects of the data collection process are driven by data from the sensors on, or connected to, a smartphone. This means data capture can automatically be made dependent on various aspects of the participant's circumstances, such as their geographical location, or environmental conditions. A recent example is a study by van Wel et al (2017), exploring links between radiation exposure and health and wellbeing. A smartphone EMA app was linked to an electromagnetic radiation detector, and data from the detector was used to trigger delivery of questions to the user. Participants reported that the method was convenient and had minimal impact on daily activities.

Reducing the burden of EMA on participants is likely to lead to higher compliance and completion rates, as well as being less distracting for the participant and therefore less likely to result in EMA having an unwanted effect on the participant's behaviour. Intille et al (2016) have developed a modified version of EMA known as microinteraction-based ecological momentary assessment, or μEMA. In this methodology, EMA prompted surveys are reduced to fast, glanceable “micro-interactions” which can be answered within a few seconds by a quick tap on a smartwatch; only one question is presented at a time and a limited set of response options are offered. Although this requires a higher frequency of interruptions, the simplified user interface results in shorter and more predictable interruptions, which participants find more acceptable than those arising from standard EMA approaches, thereby increasing engagement with the data collection process.

2.2 Smartphones

Since the introduction of the Apple iPhone in 2007, the growth of the smartphone market has been extraordinary. A recently-released survey by consultancy firm Deloitte (2017) found penetration in the UK has grown from 52% in 2012 to 85% in 2017, and is predicted to grow to between 90% and 95% by 2022. What makes a smartphone different from the previous generations of mobile phones (often referred to as ‘feature phones’) is its ability to run 3rd party applications – or ‘apps’ as they are now known. This capability, combined with their computing power, data network connectivity, and array of sensors, makes smartphones ideal for collecting research data from participants, particularly in their natural environment.

In a Cochrane review of studies published between 2007 and 2015, Marcano-Belisario et al (2015) found that in both controlled (e.g. clinical environments) and uncontrolled settings (e.g. the home) smartphone apps result in more complete datasets, and improved adherence to sampling protocols compared to paper. As mentioned elsewhere in this review, the sensing capabilities of smartphones also mean these devises can be used for more complex and sophisticated data capture. For example, it is possible to use data from sensors to automatically guide and trigger the collection of data (see section 2.1), and to passively measure complex behaviours without requiring any input from the user (see section 2.5)

However, it is important to note that smartphones are typically expensive devices, which means ownership is patterned by socio-economic status. Ownership is also lower in aging populations, although this is increasing. It is also important to remember that app development requires specialist technical skills, and can be lengthy to implement and test fully. It also requires careful consideration of which operating systems will be supported (e.g. Apple and/or Android?), how compatibility with new versions of operating systems will be tested and ensured, and how systems will be supported beyond the limited lifetime of grant-funded projects. Other issues include how to analyse the potentially large and complex datasets methods using these devices can produce, and ethical issues around data collection in free-living conditions (Miller 2012).

2.3 Activity and fitness monitors

Developments in microelectromechanical systems have enabled motion sensors such as accelerometers (which measure straight line motion) and gyroscopes (which measure rotational motion) to be miniaturised to the extent that they can now easily be incorporated into handheld and wearable devices. Recent years have seen the growing popularity of personal fitness and activity tracking devices that use these sensors. Usually wrist-worn, these devices (a range of which are reviewed by Kaewkannate and Kim, 2016) use the accelerometers and gyroscopes to collect data on physical activity which can either be presented on the device's screen or transmitted to a paired smartphone and processed in an app. They not only give the wearer direct access to personal analytics that can contribute to their health, but they also offer the potential for collection of health-related data on a population scale.

In the last twelve months, however, there has been a shift in buying habits in this sector, with decreased sales of dedicated activity and fitness monitors, and increased sales of smartwatches with activity sensing capability. This is due partly to the flexibility smartwatches have in running 3rd party applications (activity monitors typically just run proprietary applications), and partly to the increased functionality of next generation smartwatches, most notably their mobile/cellular network connectivity (activity monitors typically rely on Bluetooth/wireless data networking).

In addition to consumer activity monitors, research grade activity monitors have also been available for a number of years. These devices (currently available from manufacturers such as ActiGraph and Axivity) use the same types of motion sensors, but are designed and calibrated for use in research, and typically come with dedicated software that enables data to be extracted and visualised. Howard et al (2013) carried out a study of physical activity as part of the REGARDS (Reasons for Geographic and Racial Differences in Stroke) longitudinal study in the USA, and reported a high yield of usable data from these kinds of devices, while Lee and Shiroma (2013) used accelerometer-assessed data on physical activity and sedentary behaviour from another USA longitudinal study (the Women's Health Study) to demonstrate the feasibility of the use of sensors such as accelerometers in large-scale epidemiological studies.

2.4 Smartwatches

Although watches with some form of computing functionality have existed in rudimentary form since the early 1980s, it was not until around 2009 when developments in battery technology, smaller and more precise touch screens, and short-range wireless connectivity to smartphones combined to enable what we know think of as smartwatches. As with smartphones, the distinguishing feature of a smartwatch is its ability to run 3rd party applications. Sony and Samsung were among the first to market with early devices, but it was the release in 2014 of Google's Android Wear operating system, designed specifically for smartwatches, that stimulated market growth. Later that year came the launch of Apple's first smartwatch Apple Watch, followed by the Apple Watch 2 in 2016. Google added mobile/cellular connectivity (via an installed SIM card) when Android Wear 2.0 arrived in early 2017; Apple following suit with the launch of Apple Watch 3 (with eSIM card built in) in September 2017.

Reeder and David (2016) reviewed seventeen studies of smartwatches across a wide range of health applications and reported that these showed encouraging results, although at this point studies were characterised by small sample sizes. Studies in the laboratory tended to focus on validating technical function; whereas field studies demonstrated the feasibility of collecting sensor-based data in natural settings. The most popular sensor-based method of data capture was accelerometry, which was used for a range of different types of activity monitoring. However, studies have also made use of other smartwatch sensors, including the camera, as in the Sen at al (2015) study which used it to capture images of food being eaten for subsequent analysis, and the microphone, which was used by Kalantarian et al (2015) to detect the chewing and swallowing sounds associated with eating.

Looking forward, the growing market for smartwatches means these devices could offer a ubiquitous data capture mechanism that starts to rival the smartphone. The activity sensors already found in the current generation of smartwatches mean they can be used for passive detection of certain behaviours (see section 2.5), while their location on the wrist and the speed with which users can interact with them mean they have been used as the basis of new forms of very low burden EMA (Intille et al, 2016). As mobile/cellular connectivity becomes more commonly available (which means smartwatches can increasingly be used standalone without the need to be paired with a smartphone), and the range of sensors included expands, the appeal of these devices, and their capacity for capturing health data in free-living conditions, looks set to grow further.

2.5 Passive detection of health behaviours

Passive detection involves automatically gathering data from sensors such as accelerometers and gyroscopes, and using this data to identify the behaviour being performed by the individual without requiring any active intervention from that individual. It typically uses machine learning techniques to identify patterns in the sensor data that are the signatures of specific behaviours. This technique has many potential applications in capturing naturalistic behavioural data from individuals in free-living conditions. It is particularly of interest in measuring health-related behaviours that are difficult to record accurately with self-report data. Cigarette smoking is a good example. Self-report data for smoking is known to suffer from reporting biases and recall errors, so mechanisms that can detect and measure this automatically offer the potential for capturing more accurate and reliable data.

Techniques for passive detection of smoking behaviour have included using on-body sensors to measure respiratory rates (Ali et al 2012), and use of proximity detectors to measure hand-to-mouth movements (Lopez-Meyer et al 2012). With the increasing growth in uptake of mobile and wearable digital devices, researchers have begun using the micro electro-mechanical inertial sensing components contained within them to detect and identify the signature gestures associated with cigarette smoking. Parate et al (2014) developed the RisQ system comprising a bespoke motion-sensor equipped wristband paired to a smartphone via a Bluetooth wireless connection. Accelerometer, gyroscope and compass data were combined to provide three-dimensional trajectory data describing hand movements, and these were classified into instances of cigarette smoking by a multi-stage analysis pipeline running on the smartphone. A more recent system, StopWatch (Skinner et al, 2017) uses data from the motion sensors in a commercially available smartwatch and identifies smoking events by applying an analytic pipeline that runs entirely on the watch itself. It does not require the user to wear any specialist sensing devices and there is no need for a networked smartphone running an analytic pipeline.

Other health-related behaviours that have been passively detected include eating. Thomaz et al (2015) used data from the accelerometer in a smartwatch to provide input to a machine learning process for identifying eating gestures. As with the smoking example above, this provide researchers with accurate, detailed measures of behaviour in free-living conditions in the subject's own environment.

2.6 GPS and geographical data capture

Geographic information can be relevant to health data in a variety of ways, for example recording the location of participants in a longitudinal study as they move through their everyday environment, working out where a particular behaviour or item of data was recorded, or the surveying of diseases such as malaria which can be affected by environmental factors that vary from location to location.

The system used to capture geographical location data in almost all instances is the Global Positioning System (GPS). This is a system that comprises a network of satellites that encircle the planet, that transmit data enabling any GPS receiver to identify its location with an accuracy of approximately 5 metres. A detailed description of GPS itself, and its operation, is given by Lange and Gilbert (1999), who also point out the limitations of this technology, such as a lack of accuracy in detection when the GPS receiver is moving, and heavy power consumption.

Burgert et al (2013) provide practical guidelines for the use of the Global Positioning System (GPS) in the collection of data for demographic and health surveys. GPS can be combined with geographic information systems (GIS - which enable the capture and utilisation of large quantities of GPS data for mapping, etc) and accelerometry data to provide a detailed picture of participants' interaction with their environment. For example, in a review of studies combining these technologies, McCrorie et al (2014) show that there is a well-established link between location and engagement with physical activity.

2.7 Bio-sensing

Approaches to bio-sensing can range from consumer products available on the high street, such as blood pressure monitors, through to the latest in specialised measurement techniques, such as the use of spectroscopy for non-invasive blood glucose monitoring for blood-withdrawal-free diabetes screening (Pandey et al, 2017).

One area of interest at present is the application of measurement techniques currently used to monitor specific diseases to measurement in healthy populations. An example is continuous glucose monitoring. This is mainly used at present to monitor glucose levels in people with diabetes as they go about their normal lives, and to alarm if the level goes outside specified limits. However, the glucose measurement data from these systems can be exported, and these same systems can be used to obtain very detailed measurements of glucose levels in healthy users as they go about their normal routines, perhaps during life events such as pregnancy.

In terms of future developments, the growing sensing, processing and networking capabilities of smartphones means these devices could soon become portable and user-friendly bio-sampling and analytical devices. Quesada-Gonzalez and Merkoci (2017) recently reviewed the potential use of smartphones to perform assays in the home or in the field. The phone's camera can be used to carry out colorimetric detection of skin tone, which may provide an indication of the concentration of certain chemicals in solution in the body such as glucose. The phone camera can also be used, with suitable attachments, as an otoscope for examination of the ears, sending images directly to a doctor via a phone app. Additional electrochemical sensors are also available for phones, and include, for example, electrodes to measure skin resistance, and the detection of uric acid in saliva in the mouth. Quesada-Gonzalez and Merkoci conclude that advances in the processing power and communications ability of mobile phones positions them well to be the platform for mobile, personal bio-sensing applications, though their success in this area will depend on the ongoing development and integration of the bio-sensing technology itself.

2.8 Social media

Social media refers to internet-based communication services that enable to create online communities to share information, ideas, and messages. Prominent social media services include (in descending number of users globally as of September 2017); Facebook, WhatsApp, Instagram, Twitter and SnapChat.

In a review of the literature, Shaw et al (2015) looked at studies using social media sites such as Facebook in health research. While social media can be an effective means of disseminating health related messages, they found the quality of data gathered through self-reporting is not always consistent, largely as it is dependent on the level of the user's engagement with the service.

An alternative to using social media for self-report is to use social media data that is in the public domain, and to mine that data using content analysis techniques to infer characteristics (e.g. mood) of populations. Theoretically, social media data that is in the public domain does not require ethical approval from individual users, although some ethical communities would take issue with this. Chu et al (2016) identified Twitter as being a good social media platform for data gathering, with data from millions of users in the form of microblog messages (tweets) and embedded quantitative metadata, and an application programming interface to facilitate the extraction and formatting of the data. In their study, they developed filters to retrieve e-cigarette related tweets from Twitter, obtaining 95% retrieval precision (i.e., how much of the retrieved data was relevant to e-cigarette use) and >75% retrieval recall (i.e., how much of the relevant e-cigarette data was retrieved).

Another current example of the use of social media, which also uses the mining of Twitter data, is the EMBERS (Emotion Monitoring By Electronic Remote Sensing) project being undertaken by Davis and Haworth of the Dynamic Genetics Laboratory (part of the MRC Integrative Epidemiology Unit) at the University of Bristol. This project has so far collected over five million tweets from 2,500 participants in the Twins Early Development Study. In this case, consent was gathered from individual users, and this enabled comparison of the data captured from Twitter with standard questionnaire data to establish the effectiveness of using Twitter data for measuring positive and negative mood in young adults.

2.9 Aggregating data from multiple devices

With the emergence of so many different ways to capture health related data, one growing concern is how to combine disparate sources of health data to make best use of them for research purposes. While it is likely this will continue to require bespoke data processing and management in many cases, some recent initiatives from technology providers may help mitigate some of these issues.

The release of version 8 of the iPhone's operating system in 2014 contained Apple Health, a visual dashboard to display health data collected by a user's iPhone. At the same time, Apple also released HealthKit, an application programming interface (API) framework to enable third-party apps to package up data for presentation in Apple Health. HealthKit allows sensor devices such as smart nutrition scales, blood pressure monitors, wireless body scales, fitness bands, smart watches and others to be made compatible with Apple Health and for a user to be able to view a variety of health data from different sources conveniently in one place on their phone. Shortly after the release of HealthKit, Google announced Google Fit, a health-tracking platform which brings similar functionality to the Android mobile operating system.

While the focus for these systems is integrating health data to enable individuals to visualise combinations of health-related data, subsequent initiatives extended this and focused on capturing and integrating health-related data from populations. In 2015 Apple launched ResearchKit – an open source framework enabling potentially all users of iPhones to share health related data (heart rate, mood, etc) with health researchers. Around the same time a similar offering, called Study Kit, was made available from Google, though this is closely integrated with Google's other health related projects (e.g. Baseline), and is currently only available to partners with a formal agreement with Google.

For more information about Apple's ResearchKit, see Jardine et al (2015).

2.10 Future directions

The technology landscape is fast changing, and making predictions about trends that will shape the way we capture health data in the future is a precarious endeavour. In the medium term, however, we can make some predictions with a level of certainty. The penetration of smartphones looks set to increase even further, with more people from lower income and aging populations moving from feature phones to smartphones, addressing some (though certainly not all) of the social patterning currently seen in smartphone ownership. The market for wearables looks set to increase, though with greater growth in smartwatch sales (driven by the introduction of mobile/cellular connectivity and better applications), and a slowing in sales of activity and fitness monitors. The use of social media is also increasing, with greater uptake among older users. One consequence of this is an occasional shift in the social media services favoured by younger users, as they move away from the services their parents discover and join.

What is also clear is that we can expect the continued emergence of new technologies and methods that will bring new opportunities for capturing health data. To give just a few recent examples:

On-body video camera technology has been with us for a while in the form of helmet mounted cameras from GoPro and other manufacturers for recording first person perspectives of sports activities. As the form factor for these devices shrinks, battery life increases, and data networking capability improves, there will be many applications for using these devices, worn on the body, to capture health data, including information about; specific activates performed throughout the day, food and drink consumed, emotional state of people in environment, and, when combined with similar devices worn by others, the nature of interactions between people, such as between mother and infant (Pearson et al, 2017).

Smart speakers, such as Amazon's Echo and Google's Home, which are equipped with intelligent personal assistant software that can ask questions of people in their home, and respond to questions and request for information, provide considerable potential for collecting data from individuals in the home setting. They can be programmed to ask information about meals consumed, mood, etc., and require very little effort from the user to respond, making participant burden low, so appropriate for use over extended periods of measurement. Because they are voice based, they are also ideally suited to capturing data from people with visual impairments in free-living conditions. These devices also have the added benefit that they can be used to deliver interventions based on information captured from individuals, for example to increase medicine adherence, or to help maintain hydration levels (a leading cause of hospital admissions in older populations).

Innovative smart home projects are demonstrating the capability for collecting longitudinal health data in the natural environment without placing any restriction on the participants' activities and behaviour. A leading example is SPHERE (Sensor Platform for Healthcare in a Residential Environment), a smart home system developed at the University of Bristol, which features an array of sensors for monitoring health and wellbeing in the home, and which is currently in the process of being rolled out to one hundred homes in the Bristol area (Woznowski et al, 2015).

2.11 Conclusion, considerations and recommendations

New and emerging technologies offer huge potential for enabling researchers to gather health related data that are more detailed, have greater accuracy, and can be captured less invasively, with lower participant burden, in free-living conditions, over long periods of time. At the same time, the increased volume of personal data than can be captured with these approaches brings risk of misuse of this data, and concerns about ethics, data privacy and security must be uppermost in the minds of researchers considering their use.

The benefits and challenges of these new approaches have been reviewed and summarised by a number of recent studies, which make some helpful recommendations:

Lu (2010) makes the following general recommendations for data capture using new technology: electronic data capture must ensure superior data quality by following study protocols, corporate guidelines, and good clinical practice rules with supportable technology; must comply with regulatory requirements; must offer flexible, configurable, scalable and auditable system features; and its design, development and support must follow systems development methodology to ensure compliance.

Many of these issues are echoed by Rorie (2017) in a review of 1126 papers in this area: overall, electronic CRF, data capture and IT in general are seen as a cost-effective means of improving health research efficiency and improving data gathering, but clear operational guidelines and best practices are vital, and further work is needed on integration of new technology with current systems (e.g. electronic health records).

Perhaps most importantly, as Franklin et al (2012) point out in an evaluation of electronic data capture, although these new methods offer huge scope for gathering and analysing large volumes of health-related data, ultimately factors such as ease of use and provision of good training materials will be key to the uptake, continued use and success of these approaches.

(References for this review appear in Section 8 at the end of this report)

Section 3

Overview of current use of new technology for health measures within the CLOSER studies

Studies reported:

1. Hertfordshire Cohort Study
2. 1946 MRC National Study of Health and Development
3. 1958 National Child Development Study
4. 1970 British Cohort Study
5. Avon Longitudinal Study of Parents and Children
6. Southampton Women's Study
7. Millennium Cohort Study (Child of the New Century)
8. Understanding Society: the UK Household Longitudinal Study

1. HERTFORDSHIRE COHORT STUDY

(Director: Professor Cyrus Cooper)

Conventional techniques used for capturing study data

NHS birth/infant data recorded by midwife/health visitor; at follow-up, medical and social history, clinical testing, DNA collection.

Use of new technology in the Hertfordshire Cohort Study

Wearable technology has been adopted in this study. Data was collected from 114 men and women using a USB Accelerometer X16-1C (Gulf Coast Data Concepts) as part of the VIBE collaboration. The device is worn on the hip using an elastic belt. This accelerometer uses a low noise digital accelerometer sensor, precise time stamped data logging, micro SD memory storage, real-time data access and USB connectivity. Acceleration is collected in X, Y and Z axes and stored at a selectable rate of up to 200Hz.

Data was also collected from 147 men and women using a GeneActiv device worn on the wrist for one full week as part of a sub-study investigating sarcopenia. Continuous raw data was recorded at up to 100Hz. The device is waterproof and has a near-body temperature sensor that helps to confirm wear time.

2. 1946 MRC NATIONAL STUDY OF HEALTH AND DEVELOPMENT

(Director: Professor Diana Kuh)

Conventional techniques used for capturing study data

Face-to-face interviews (clinic or home), postal questionnaires.

Use of new technology in the 1946 National Study of Health and Development

In their 2006-10 data collection, NSHD used a 7-day accelerometer (actiheart, CamNtech) worn around the chest to measure physical activity and monitor heart rate. In the 2015-2016 data collection a different type of accelerometer (GCDC, Gulf Coast) was used to measure vertical impact. In this data collection, nurse interview data was captured via Computer Assisted Personal Interviewing (CAPI) and additionally use of the iPad was introduced to conduct the Addenbrooke's Cognitive Examination version 3 (ACE-3). Both devices remotely synchronised the data. Lung function data was also captured using the same CAPI laptop. In terms of biotechnology, although not a novel device in itself, a centrifuge was introduced into the home environment which enabled serum samples to be spun prior to posting.

The CLOSER mixed mode workshop held in November 2016 highlighted the use of the internet and this is something that will be explored further. The use of mobile tablets is an area for further investigation as well as remote data capture. One of the main areas of concern is in ensuring that sufficient technical support and data security can be provided to study members who are now aged 70.

3. 1958 NATIONAL CHILD DEVELOPMENT STUDY

(Principal Investigator: Professor Alissa Goodman)

Conventional techniques used for capturing study data

Interview, medical examination, questionnaire, tests of attainment, blood samples, DNA collection, cognitive ability tests, web survey.

Use of new technology in the 1958 National Child Development Study

Computer assisted personal interviewing and computer assisted telephone interviewing has been used. The most recent survey - the Age 55 survey - used a mixed mode approach where participants were first asked to complete the survey online before being asked to do so via telephone if they did not want to complete it online.

There is interest in the potential for using new technologies. The investigators recently met with the main fieldwork agencies in the UK (NatCen, Ipsos-MORI, Gfk-

NOP and TNS-BMRB) to discuss their use of new technologies and potential use in the cohort studies being run. Some examples of the applications discussed were: using smartphones to collect ‘in the moment’ diaries, potentially including photo capture to measure diet or physical activity; conducting regular short mobile web-surveys (in between large survey sweeps) to measure well-being or other topics; passive measurement of internet usage via apps installed on devices to gain deep understanding of ‘digital lives’ and the impact this has on other aspects of life; and using wearable devices to gain detailed measurements of physical activity, sleep quality, and many other aspects of health. At the time of writing there are no concrete plans in this regard, but the investigators are considering these new methods.

4. 1970 BRITISH COHORT STUDY

(Principal Investigator: Dr Alice Sullivan)

Conventional techniques used for capturing study data

Questionnaire, interview, medical examination, educational assessment, activity diary, skills assessment, telephone survey, home interview by nurse.

Use of new technology in the 1970 British Cohort Study

In the current wave of BCS70, respondents are being asked to wear an ActivPal device for the seven days following their visit. This a thigh worn device which classifies an individual’s activity into periods of lying, sitting, standing and moving. The devices are waterproofed before fitting so that they can be worn continuously for the full seven days without any need to remove them for showering/swimming etc.

An online diet questionnaire is also being conducted in which participants are asked to log-in to a web survey on two randomly selected days out of the seven days following in their visit to answer questions about what they ate and drank on the previous day. This is the first use of online data collection within BCS70.

5. AVON LONGITUDINAL STUDY OF PARENTS AND CHILDREN

(Director: Professor George Davey Smith)

Conventional techniques used for capturing study data

Questionnaires (completed by carer, partner, child and school), obstetric and neo-natal clinical records, clinic measurements, biological samples

Use of new technology in the Avon Longitudinal Study of Parents and Children

The ALSPAC birth cohort are now in adulthood and many have their own offspring, leading to the second-generational “Children of the Children of the 90s” study (COCO90s). The following technologies are in use:

1) Head cameras to monitor parent/child interactions - both mother and baby wear head cameras whilst completing a number of short activities, the recordings are then coded to identify specific activities and rate maternal sensitivity.
2) “Early years toolbox” - a series of iPad based games/tests to assess children’s functions such as memory, image recognition, sorting etc.
3) An iPhone app that takes before and after photos of participants’ food as an alternative to using paper based diaries.
4) A web based diet diary.
5) A waterproof wrist worn activity monitor used to measure movement and exercise in pregnant women (swimming is a common form of exercise for this group).
6) The “Atmotube” personal air quality sensor.
7) Continuous glucose monitoring using a “Medtronic” device on the arm or lower back which samples interstitial fluid over 5 days.

Some ALSPAC participants will also be taking part in the SPHERE 100 Homes study. SPHERE (Sensor Programme for Healthcare in the Residential Environment) is a large project to develop a smart home system using sensors to monitor health and well-being in the home.

6. SOUTHAMPTON WOMEN’S STUDY

(Director: Professor Cyrus Cooper)

Conventional techniques used for capturing study data

Clinical measurements, home visits, nurse questionnaire, biological samples, food frequency questionnaire, food diaries, bone scanning.

Use of new technology in the Southampton Women’s Study

The study has used the “Actiheart” device (heart rate monitor combined with accelerometer) to monitor physical activity in both mothers and children. Also, the use of web-based questionnaires in 13-14 year-old children is being piloted, and if this is successful they plan to implement a web-based questionnaire at age 15 years.

7. MILLENIUM COHORT STUDY (CHILD OF THE NEW CENTURY)

(Principal Investigator: Professor Emla Fitzsimons)

Conventional techniques used for capturing study data

Physical measurements, assessments of cognitive ability, DNA samples, questionnaires, time use records.

Use of new technology in the Millennium Cohort Study

At MCS6 (age 14), which has recently finished, the cohort members wore wrist worn accelerometers (“GENEActiv”) for two days. They also completed diaries using their smartphones (using a specially designed app) or via the web. The data has now been deposited at the UKDA.

8. UNDERSTANDING SOCIETY: THE UK HOUSEHOLD LONGITUDINAL STUDY

(Director: Professor Michaela Benzeval)

Conventional techniques used for capturing study data

Interview, self-completion questionnaire, nurse visit, blood sample, anthropometric measurements, blood pressure, grip strength, lung function.

Use of new technology in Understanding Society

Computer assisted web interviewing and computer-assisted telephone interviewing is used in this study. Various mobile technologies tested at the University of Michigan Survey Research Centre are also being used or considered, including GPS, mobile apps, tools that attached to mobile phones to measure distances and sound, Interactive Voice Response to record interviewer observations, and accelerometer-based transportation mode detection on smartphones.

Section 4

Programme of the knowledge exchange workshop on new technology for health measures in longitudinal and cohort studies, Bristol, 19th May 2017

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General discussion

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Section 5

Abstracts of presentations at the knowledge exchange workshop

(Slides of the presentations have been made available from CLOSER and can be obtained from the website www.closer.ac.uk)

1.1 Using wearable technology to measure physical activity in the 1970 British Cohort Study and the Millennium Cohort Study

Matt Brown/Emily Gilbert/Lisa Calderwood (Centre for Longitudinal Studies, UCL)

Measuring physical activity presents methodological challenges for survey research. Most large-scale population based studies use self-reported data to measure physical activity which is subject to both recall and social desirability bias. The use of wearable devices that measure physical activity directly can offer a solution to these problems. Activity monitors, also known as accelerometers, are capable of capturing a wide range of movements as well as the differing intensity of activities. Increasingly, accelerometers are also being recognised for their ability to measure sedentary activities.

The Millennium Cohort Study (MCS) Age 14 survey collected objective measures of physical activity using wrist-worn GeneActiv devices. Participants were asked to wear the device for two randomly selected days in the week following their interview, one day in the week and one day at the weekend. As part of the 1970 British Cohort Study (BCS70) Age 46 Survey, currently in the field, participants are being asked to wear a thigh worn ActivPal device. If participants agree the device is waterproofed and attached to the thigh and the participant is asked to wear it continuously for the 7 days following their visit. In both studies, participants are asked to return the devices via post after wear.

This paper describes the different approaches taken to implement the use of activity monitors in these two large scale studies and will contrast some of the advantages and disadvantages of the two protocols. We will discuss agreement rates, compliance rates and costs and will highlight a number of issues and lessons learned which should be considered if planning similar data collections in the future.

1.2 Adopting new technologies in the MRC National Survey of Health and Development

Andrew Wong (MRC Unit for Lifelong Health and Ageing, UCL)

The MRC National Survey of Health and Development is the oldest of the British Birth cohorts, informing UK health care, education and social policy for more than 60 years. The national representative sample of men and women born in England, Scotland or Wales in March 1946 have been followed up in the course of 24 data collections, which include five face-to-face clinic or home visit based interviews during adulthood. In the neuroscience sub-study, Insight 46, study members are currently undergoing detailed cognitive assessments, and multi-model MRI and amyloid PET neuroimaging, repeated after 2 years. During its history, the NSHD has seen a shift in the methods used to collect health-related data. In this workshop, we will explore some considerations in implementing new technologies, and what this means for longitudinal studies, for example, do new technologies enable better, faster data collections, do they affect response rates and how do we compare data between waves.

1.3 Plans for the Health Innovation Panel in Understanding Society

Meena Kumari (Institute for Social & Economic Research, University of Essex)

Addition of health and biomarker data to the Understanding Society dataset has increased the capacity for research in the social-biological transition by social science and health researchers, a key strategy for the ESRC. Biomarker data were collected from participants at Waves 2 and 3 (2010-2012) of Understanding Society and a re-collection of data will serve to maximise the longitudinal nature of the study however, this needs to be developed appropriately without compromising the study and its participants. Recently Understanding Society has been investigating a move from face-to-face interviews to web-based data collection. However, for the purposes of a future biomarker collection, experimental development is required to ensure that where methods of data collection vary from those previously used in Understanding Society, these provide comparable data in order to allow longitudinal analyses.

The Innovation Panel is a clustered, stratified and equal probability sample of residents in Great Britain, used by researchers as a test-bed for innovative ways of collecting data within Understanding Society through an annual competition. The competition for Innovation Panel 12 will be held for health and related experiments to maximise the use of the resource by the research community.

This presentation described the use of the Innovation Panel to develop methods to investigate the impact of a move from nurse visit to participant led tissue and sample collection. Wave 12 of the Innovation Panel (2019) will be used to a) examine participant characteristics from nurse visit, interviewer directed and participant led collection of biomarker data and b) understand the construct validity of the measurements obtained from tissues that can be collected by participants.

2.1 Using Twitter for high-resolution phenotyping of mood in large samples

Oliver Davis (MRC Integrative Epidemiology Unit, University of Bristol)

Born around the same time as the commercial Internet, today’s emerging adults are the Internet generation, with most engaging frequently with online social networks. These online social networks are integrated with offline social networks of peers, and are an important source of support and interaction. But although offline social networks are difficult to assess and track, online social networks are detailed databases of real-time social activity and its effects on, for example, obesity, depression and psychological wellbeing.

In the MRC Integrative Epidemiology Unit's Dynamic Genetics lab (www.dynamicgenetics.org), we have collected over five million tweets from 2,500 participants in the UK's Twins Early Development Study (TEDS). By comparing scores automatically coded from their tweets with standard questionnaire data collected at the same time, we have been able to establish the effectiveness of Twitter data for measuring positive and negative mood in emerging adulthood. Using these data, we are tracking the dynamics of genetic and environmental influences on positive and negative mood through this important life stage, leading to a better understanding of the complex aetiology of mental health and disorder in young adults.

2.2 StopWatch: a smartwatch-based system for passive detection of smoking

Chris Stone (Tobacco and Alcohol Research Group, University of Bristol)

Introduction: Passive detection of cigarette smoking offers potential for considerable benefits to researchers exploring smoking behaviour and designing precision behaviour change interventions. A number of systems have been developed that either use bespoke sensing technology, or rely on connected smartphones to run analytical software. Here we present StopWatch, a system for passive detection of cigarette smoking that runs on a smartwatch and does not require additional sensing or a connected smartphone.

Methods: Our system uses motion data from the accelerometer and gyroscope in an Android smartwatch to detect the signature hand movements of cigarette smoking. It uses a three-stage analytical pipeline to transform raw motion data into motion features, and in turn into individual drags and instances of smoking. This pipeline runs on the smartwatch, and does not require a smartphone.

Results: We validated the system in daily smokers (n=13) in laboratory and free-living conditions running on an Android LG G-Watch. In free-living conditions, over a 24-hour period, the system achieved precision of 86% and recall of 71%.

Conclusions: StopWatch is a system for passive measurement of cigarette smoking that runs entirely on a commercially available smartwatch. It runs on an Android smartwatch and requires no smartphone so the cost is low. No bespoke sensing equipment is needed, and it uses a mass-market smartwatch, so participant burden is low. Performance is currently lower than other more expensive and complex systems, though adequate for some applications. Future developments will focus on enhancing performance, and validation on a range of smartwatches.

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2.3 Through babies' eyes: practical and theoretical considerations of using wearable technology to measure parent-infant behaviour from the mothers' and infants' viewpoints

Rebecca Pearson (Centre for Academic Mental Health, University of Bristol)

Aim: We will present the utility of first-person viewpoint cameras worn at home by mothers and infants to record behaviour. This approach aims to reduce problems associated with participant reactivity, which represent a fundamental bias in observational research.

Methods: In an initial validation study with 14 mothers and infants, we compared footage recording the same play interactions from a traditional third-person point of view (3^{rd} PC) and using small cameras worn on headbands (first-person cameras [1^{st} PCs]) to record first-person points of view of mother and infant simultaneously. In addition, we left the dyads alone with the 1^{st} PCs for several days to record natural mother-infant behaviour at home.

Results: Codings of maternal behaviour from footage of the same scenario captured from 1^{st} PCs and 3^{rd} PCs showed high concordance (kappa >0.8). Footage captured by the 1^{st} PCs also showed strong inter-rater reliability (kappa = 0.9). Data from 1^{st} PCs during sessions recorded alone at home captured more 'negative' maternal behaviours per min than observations using 1^{st} PCs whilst a researcher was present (mean difference = 0.90 (95% CI 0.5 to 1.2, $p < 0.001$ representing 1.5 SDs).

Conclusion: 1^{st} PCs offer many practical advantages and can reliably record maternal and infant behaviour. This approach may also record a higher frequency of less socially desirable maternal behaviours. It is unclear whether this difference is due to lack of need of the presence of researcher or the increased duration of recordings. This finding is potentially important for research questions aiming to capture more ecologically valid behaviours and reduce demand characteristics.

Future: We are now piloting including the cameras in mothers and infants in the next generation of a large cohort study (ALSPAC-G2). We will present preliminary findings, which further demonstrate that this method captures more natural behaviours including negative emotion, but also 'baby talk' and imitation, which mothers may feel more comfortable displaying without a researcher present.

2.4 Online tools and mobile phone photography for in-depth dietary data capture: reflections from a pilot study

Laura Johnson (Centre for Exercise Nutrition and Health Sciences, University of Bristol)

Traditional methods of dietary assessment rely on self-reported food intake typically using pen and paper diaries, recalls or questionnaires. Such methods are associated with significant volunteer and researcher burden and are prone to error and low response rates. We pilot tested the feasibility of using three novel methods of dietary assessment in a sample of young (aged 23-25), UK-based, pregnant women and their partners. Novel methods tested included Myfood24 (https://www.myfood24.org/web/ an online food recall and diary system), SmartIntake (https://itunes.apple.com/gb/app/smart-intake/id1056300080?mt=8 a smartphone app based on meal photography), and Intake24 (https://intake24.co.uk/ an open-source self-completed computerised dietary recall system).

Participants were invited to record 6 full days of their dietary intake. Data collection began in October 2015 and is on-going. Uptake rates represent the percentage of those agreeing to use a tool out of all those asked. Completion rates reflect the percentage of those that provided data on at least 1 or 4 days out of all those that agreed to use the tool. The quality of the data provided was assessed by comparing estimated energy intakes to expected energy requirements computed from standard equations incorporating weight, height, and gender. Limits on plausible reporting were estimated based on known variability and the % of participants under-plausible- or over-reporting energy intakes was estimated from all that provided data.

Uptake rates varied widely from 18-60%, with low rates relating to the length of training required and perceived inconvenience. The percentage providing data on at least 1 day ranged from 55-64% and those providing 4 or more days of data varied from 26-58% of participants that agreed to use the tool. Overall response rates were low across all tools with just 10-17% of participants invited to use a tool providing 4 or more days of data. As with traditional dietary assessment techniques energy intakes estimated from the novel methods were systematically biased towards under-reporting (42-70% under-reporters). Plausible energy intakes were provided by 22-53% of participants. Researcher burden for data capture varied across tools from sending daily generic email reminders, emailing specific links daily to real-time monitoring of data submission. While nutrient and food intakes were generated instantly for the online tools the photo-based method required expensive and time-consuming expert coding similar to traditional diary techniques.

Novel methods of dietary assessment offer key advantages over traditional methods including automated nutrient estimation, substantially reduced costs and objective assessment of portion sizes. But dietary intake is complex to assess in detail and novel methods cannot overcome the time demands required for participants to provide complete records leading to low uptake and completion rates. Under-reporting of energy intake remains an issue with tools relying on self-report, to which novel technology is not yet a solution. But this is a fast-moving field and updates to the functionality of websites and mobile phone apps mean that continued pilot work to identify the most feasible and accurate method is required.

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Pilot work for dietary assessment was supported by the Elizabeth Blackwell Institute for Health Research. The UK Medical Research Council, Wellcome Trust and University of Bristol fund data collection in this pregnancy cohort. Louisiana State University and Pennington Biomedical Research Centre own the intellectual property surrounding the Remote Food Photography Method and SmartIntake app and C. Martin is listed as an inventor.

3.1 SPHERE - a Sensor Platform for Healthcare in a Residential Environment

Pete Woznowski (Merchant Venturers' School of Engineering, University of Bristol)

The SPHERE project was established with the aim of developing a smart home system, which integrates a combination of off-the-shelf and in-house developed sensors to monitor people's health and wellbeing in the home. Within SPHERE, we are aware that designing effective home healthcare technologies means developing solutions that are flexible and that reflect a sensitive understanding of the diverse users of such systems. To achieve this, the SPHERE system was developed alongside early and sustained user involvement. This talk gave an overview of the sensing technologies used in the SPHERE system and discussed the main challenges of designing and deploying the system in up to 100 homes.

3.2 Current and potential uses of connected health devices for research data collection

Josh Keith (Associate Director, Social Research Institute, Ipsos MORI)

Drawing upon Ipsos MORI's experience across the public and private sectors to explore the potential of 'connected health' technology for health data collection, this presentation explored data on some recent trends in public use of connected health technology, and the opportunities this offers to social researchers in terms of health data collection. The presentation explored some of the challenges associated with utilising connected health technology, and addressed potential future directions in this field.

Section 6

Synopsis of discussion:
Defining a research agenda and identifying priority areas for further research

Discussion at the workshop was framed around the questions of **what data can be captured from the cohorts that has not been possible so far, and what challenges are there in relation to this**. The constantly evolving field of "new technology" encompasses a wide range of areas, as does "health-related data", so the discussion was inevitably broad-based and focused on a high-level view of the subject topic. Within the scope of a one-day workshop it was not feasible to drill down into any one specialist area, but nevertheless a number of areas of interest were identified which could be the subject of further and more detailed discussion.

Areas of interest for health-related data capture using new technology

Mental health emerged as a strong theme, with significant interest around collection of mental health/wellbeing data "in the moment", such as use of ecological momentary assessment, where the participant is prompted to respond to questions (possibly delivered on a smartphone or smartwatch) about mood and affect. There is also scope for data collection initiated by the participants themselves; for example using an app to enable people with mental health disorders to feedback information at times of low mood.

Physical and cognitive decline was also a common area of interest, where changes in patterns of data over time could be used to yield information on this. It was noted that monitoring these can raise issues around duty of care. For example, if data indicates that a participant has had a fall, there will likely be implications for the study investigator around whether they should intervene and notify others.

Environmental data ideas discussed included; using geographical position data from GPS to link to environmental factors such as pollution, noise, and proximity to green space. Although location is captured in cohorts by postcode, this does not account for people's movements as they travel between home and work and interact with their immediate surroundings. Other environmental measures of interest were ambient light, UV exposure, bacteria levels in the home, and energy consumption.

Biological measures such as glucose monitoring, blood pressure monitoring and renal function testing are, as would be expected, topics of interest, and a further requirement was the capability to collect biomarkers without needing the intervention of nursing staff. The facility to link these data to primary care records was also acknowledged to be desirable.

Capture of physical activity yielded perhaps the most diverse and creative ideas, harnessing new and emerging technology for a range of measures - from passive detection of lifestyle behaviour using motion sensors, to "smart shoes" capable of using pressure to identify whether a participant is seated, standing, walking or running. Related to this was a desire to obtain information about the underlying reasons for the activity, for example whether a participant went for a run because their food consumption the day before was at a higher level than usual (perhaps utilising barcode scanning of food packaging or shopping receipts to extract information about what people are eating) – getting at the "why" rather than the "what".

Challenges to effective data capture with new technology

As with the areas of interest for data capture, discussion was at a high level and did not necessarily provide any answers, but nevertheless a number of key themes emerged.

Security and data privacy were quickly identified as being of importance – regular and frequent sampling can generate large quantities of data (particularly if movement data is being collected, which may occur at frequencies up to 200Hz) which has to be securely stored and processed so as to maintain the anonymity of the participant. Any health-related data is likely to be of a sensitive nature and should be handled and stored appropriately.

Ethics and consent are parallel issues to data privacy; concerns around how the data are used need to be addressed. Again taking the example of movement data, there is always the potential for data to be further analysed to obtain more information about the participant's activity, which may particularly be of interest in longitudinal samples. This would either have to be covered by the participant's existing agreement to the use of their data or would necessitate obtaining further consent. In some cases, particularly around the use of research grade measurement devices from certain commercial companies, there was concern those companies may be benefiting financially from any research data captured. The experience of one of the CLOSER studies was that this is not problematic provided participants are kept well-informed and understand the reasons for the research and the use of the data. One of the workshop participants pointed to a survey by the Wellcome Trust which claims that, in general, approximately 20% of participants express concern about the use of their data, a further 20% have no concerns, and the majority are satisfied with the use of their data where they have given consent.

Incentivisation and engagement of participants was seen as a potential problem in capturing data, with issues ranging from how to account for different responses across differing socio-economic status, to how participants might feel about being "pestered" by ecological momentary assessment, being highlighted. Among new approaches discussed for incentivisation were dynamic schemes that use data already generated by individual participants to guide future incentives. This was discussed in the context of factors that can be particularly difficult to measure, such as diet and nutrition. There will be limits to the extent to which incentivisation is practical, cost-effective or ethical, but keeping participants happy is clearly vital to the success of longitudinal studies.

Feedback was another emerging theme, which also touched on issues of duty of care. Basic measures such as height and weight can easily be supplied to participants, but they may sometimes express interest in receiving feedback of potentially more informative data relating to their health, such as blood pressure. In the discussion, there was a feeling that feedback could influence behaviour, and different disciplines take different approaches to it. It was expressed that in ALSPAC, the general approach is not to provide feedback except in certain conditions where there is a duty of care, such as picking up an abnormality from an MRI scan. A red/amber/green system was tried at one time, but GPs tended not to like this as it could alarm their patients. It had been thought that feedback would increase the compliance rate, but experience showed this not to be the case. Participants sometimes make ad-hoc requests for feedback of their data, for example on how cognitive function has declined over the years, and there is a feeling that the studies have a duty of care to provide this.

Integration between studies was raised as a potential issue, including questions such as whether data from different cohorts can be compared together, and whether practical information from focus groups identifying barriers to participation in a study could be better shared between longitudinal studies. The discussion raised the possibility that a way to start addressing these issues could be the identification of facilitators who can assist with cross-cohort communications.

General methodology-related issues it was agreed that there is a need for methods suitable for use with people in lower socio-economic groups who may not be so interested in monitoring their own health, together with the provision of low cost devices and appropriate incentivisation, to establish a simple and reliable way of collecting data. As technology evolves there is a risk that methods may change, although changing the method of data collection as the cohort gets older could degrade the quality of the data. There may also be health and safety implications associated with the methods of data collection; for example, with centrifuging blood in the home.

Among the **concluding remarks** of the discussion was a reminder that, in some circumstances, the most high-tech solution may not be the optimal solution, and paper questionnaires may still be the gold standard. Indeed, the view expressed by a representative of the market research organisation Ipsos-MORI is that response rate to paper questionnaires is often higher than online. Another important point identified was that when writing grant applications for new approaches to capturing health data, these need to consider all of the stakeholders in a project (e.g., fieldworkers), and not just the people who will use the data captured. Also, consideration needs to be given to what we do with the potentially vast quantities of data which may be generated; if not analysed now it could provide an invaluable resource in the future, though this brings issues around data storage and security. The ultimate goal with these new approaches is to obtain detailed measures, over long periods of time, with minimal burden. In practice, there are very complex issues around how data can be combined, and what factors influence what measures. Finally, there was general agreement that data related to health behaviours are among the most challenging to capture, but provided the various issues discussed are addressed, new and emerging technology can offer significant advantages to researchers in longitudinal and cohort studies.

Section 7

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Section 8

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