

# Innovations Projects summaries

Funded by ESRC from an award by UKRI Strategic Priorities Fund  
October 2019

This document contains summaries of a series of reports on innovations produced for ESRC in summer 2019. Full reports are available on request.

Authors: Emla Fitzsimons, Marc Bornstein, Alice Sullivan, Heather Joshi, James Williams, Lisa Calderwood, Matt Brown, Kate Smith, Karen Dennison, Danielle Gomes, Nicolas Libuy, Emily Gilbert, David Bann, Praveetha Patalay, Alissa Goodman, Darina Peycheva, George B. Ploubidis, Joseph W. Sakshaug, Richard J. Silverwood, Joel Williams, Erica Wong, Hannah Jongsma, Vanessa Moulton

## Contents

<b>1. STUDYING THE NEXT GENERATIONS: THE CASE FOR FOLLOWING THE OFFSPRING OF MCS AND NEXT STEPS, AND FOR STUDIES OF GRANDPARENTING.....</b>	<b>2</b>
<b>2. NEW BIRTH COHORT STUDY: THEORETICAL SAMPLING DESIGN OPTIONS.....</b>	<b>3</b>
<b>3. CLS COHORTS QUALITATIVE RESEARCH.....</b>	<b>4</b>
<b>4. NOVEL LINKAGES LITERATURE AND SCOPING REVIEW .....</b>	<b>7</b>
4.1 Embedding Centre for Longitudinal Studies cohorts into national linked administrative datasets .....	7
4.2 Review of consent for record linkages.....	8
4.3 Novel Health Record Linkages .....	9
4.4 Geo-linkages scoping review .....	9
<b>5. SURVEY METHODS DEVELOPMENT SCOPING.....</b>	<b>10</b>
5.1 Survey methods research: new technologies .....	10
5.2 Survey methods research on mode and incentives.....	15
<b>6. CALIBRATION OF MENTAL HEALTH AND COGNITIVE ABILITY MEASURES .....</b>	<b>18</b>
<b>7. WEB SURVEY IN MCS AND DESIGN OF ANNUAL WEB-MAILING .....</b>	<b>20</b>

# 1. Studying the next generations: the case for following the offspring of MCS and Next Steps, and for studies of grandparenting

By Emla Fitzsimons and Marc H. Bornstein

This report sets out the scientific merits, design and practical considerations for a longitudinal follow-up of offspring of existing cohorts. The discussion relates to the Millennium Cohort Study (MCS) and Next Steps, whom we recognise are at different stages of their reproductive lives and have differing constellations of data from their childhoods. Nonetheless, the issues pertaining to science, policy and study design are broadly similar and so we discuss them as one and only distinguish between the cohorts where relevant. The report also discusses the grandchildren of the BCS70 and NCDS cohorts.

- Following the offspring of MCS and Next Steps cohort members would provide the unique potential to address a range of important and highly policy relevant scientific questions relating to child development and family well-being among new generations of children being born.
- Births to the cohorts over around the next three decades will be dispersed both in terms of their timing and geography, which leads to important new considerations in relation to study design and measurement. We believe that extensive use of major recent advances in technology to collect data, including remote recordings of child-mother interactions and remote interviews, is key to implementing the offspring studies.
- There are important considerations around which offspring to follow, when to follow them and what developmental domains to measure. We recommend that this is carefully scoped and tested next, but that the below criteria are adhered to:
  - a. **all** offspring of female cohort members are followed,
  - b. they are followed at the same ages as MCS cohort members, using a combination of the same measures as administered to the MCS cohort members, and new measures that have been developed since (and set out in this report),
  - c. two developmental waves are added over and above (b) – prenatally (using maternal report and/or record linkages), and at a point between age 9 months and 3 years, and
  - d. a wide range of administrative data linkages is obtained for the offspring, including from the wealth of health records available from the prenatal and postnatal period.
- Following the offspring of male study members is more challenging and more careful scoping would be required to determine the feasibility of this.
- The scientific justification for following grandchildren of NCDS and BCS70 mirrors that of offspring, allowing for even deeper investigation into the roots of family background and the drivers of transmission across generations. Considerations around design and measurement are also equally relevant. We recommend that the approach to grandchildren studies is hypothesis-driven.

## 2. New Birth Cohort Study: Theoretical Sampling Design Options

By Alice Sullivan, Heather Joshi and James Williams

- A new nationally representative birth cohort study would provide longitudinal evidence on the development and life-chances of a new generation of children in the UK. To maximise its potential to inform science and policies of the future, its content should be broadly based and record details on as many of the main areas of the child's life as possible including, in particular: physical and emotional health and well-being; relationships; and learning.
- There are some advantages to an 'accelerated design' with two cohorts, one to be born in the early 2020s ('the infant cohort'), and one already born in the 2010s ('the child cohort'). In particular this would fill the gap on experiences in a changing context of children born since the Millennium. However with a limited budget, a dual cohort comes at the cost of smaller sample sizes in each cohort, and these considerations have to be carefully traded off. If a dual cohort is commissioned, we recommend recruiting a child cohort in one of the final years of primary school. Age 11 maximizes the period of history recovered and also has points of comparison to previous cohort studies. Surveys from 11 onwards could be at intervals of 3 to 4 years, and under 11 they should occur more frequently.
- Securing a sampling frame from which an opt-out can be operated for the infant cohort will be central to the success of the project. Securing the political will to achieve this at a high level and enthusiasm for the project in the statistical authorities will be essential. Discussions with the ONS and NHS regarding administrative and legal feasibility must be initiated at a high level. Demonstrating public interest also relates to developing public engagement, without which initial recruitment and continuing response in the surveys may not be sustained. Alternatives to an opt-out consent would need to be carefully piloted and participant consent would need to be made very easy and appealing to give.
- While large sample sizes are desirable, these need to be traded off against budgetary constraint. We have considered the case for clustering by geographical ward but have recommended a simple national sampling design would be more straightforward to analyse, and would lead to a more nationally representative, less selective sample. Efficiency savings from geographically clustered designs are likely to be limited in practice.
- The Millennium Cohort Study was geographically clustered by ward, and wards chosen were disproportionately stratified, which added complexity for users. Potential benefits of the clustering included fieldwork efficiency, however in practice these savings would have been limited and short-lived. The over-representation of ethnic minorities added to their sample size, but in a selective way. Since 2001 the proportion of national births to non-white ethnic minorities has risen substantially, meaning that numbers in a random sample would naturally be increased, and could be achieved using data on ethnicity in the national sampling frame.

## 3. CLS Cohorts Qualitative Research

By Lisa Calderwood, Matt Brown and Kate Smith

### Project overview

The purpose of this project was to carry out qualitative research with a sample of cohort members from all four cohort studies to inform the scientific and methodological development of the studies over the next 10 years. The project sought to provide in-depth insight into attitudes towards and the acceptability of new innovations in data collection and participant engagement. Specific topics covered by the research were motivations for participating, new ways to keep in contact with study members, use of incentives, data collection mode and frequency (including conducting major surveys short 'in-between' surveys online), use of new technology (e.g. apps, activity trackers, GPS), novel data linkages (e.g. social media, banking) and collecting data and/or data linkage from partners and other family members.

### Methods

Ipsos Mori conducted 28 in-depth interviews (10 face-to-face and 18 via telephone) and one focus group with study members from each study. Focus groups involved 8 participants so in total 144 study members were involved in the research (112 in-depth interviews and 40 focus group participants). Fieldwork was conducted between 24 April and 11 June 2019.

Study members were approached by Ipsos Mori recruiters who, for the in-depth interviews used quotas including gender, ethnicity, household composition and qualifications to ensure that a diverse range of participants were involved. During recruitment information was also captured about use of technology and confidence with internet use. For the focus groups, study members were approached based on their proximity to the venues to be used (Manchester for MCS and Next Steps, London for NCDS and BCS70).

Discussion guides (with accompanying stimulus materials) for the in-depth interviews and focus groups were jointly developed by CLS and Ipsos Mori. In-depth interviews lasted around 60 minutes. Questions were tailored where appropriate to refer to the specific history and context of each of the four studies. Focus groups lasted around 90 minutes. A £30 incentive was given to in-depth interview participants, and £50 was given to focus group participants.

Ipsos Mori subsequently carried out 30 telephone interviews with family members of those who took part in the initial in-depth interviews (specifically parents of MCS cohort members, resident partners of NCDS, BCS70 and Next Steps cohort members and children over 16 and living at home of NCDS and BCS70 cohort members). The interviews lasted around 20 minutes. Participants were questioned about their awareness of the studies, and their views on potentially taking part in the studies in the future, either by participating directly or by consenting to data linkage. Fieldwork took place between 12th August and 5th September 2019. A £20 incentive was provided to participants.

### Findings

The report from this project provides in-depth insight into study member attitudes towards a full range of new potential innovations for the CLS cohorts. The key findings are summarised below.

- Levels of engagement and motivations for taking part varied between the cohorts. Members of the older cohorts (NCDS and BCS70) were more likely to cite the

societal benefits of the studies as primary motivators for taking part and also a sense of civic duty, whilst members of the younger cohorts tended to be more neutral or indifferent, with MCS cohort members often reporting that taking part was 'just something they did' and Next Steps cohort members often mentioning the incentives received as key motivators.

- Participants from all four studies were keen to receive more information about study findings and for a wider range of modes of contact to be used to provide this information.
- NCDS cohort members did not think that taking part should be incentivised. This was also the strongest view amongst BCS70 cohort members. Next Steps participants have always received incentives. For some these were a major motivator, but others noted they would be happy to participate without. MCS study members would accept incentives but many did not expect them.
- NCDS cohort members were keen for major surveys to continue to be conducted face-to-face and felt these could take place more regularly. Views amongst BCS70 and MCS cohort members were mixed, some expressed a preference for face-to-face interviewing but others were keen on the convenience of being able to take part online (and many MCS participants spontaneously mentioned the participating via an app). Next Steps participants have been able to participate online for some time and were keen to continue being able to do so.
- Participants from all four studies were enthusiastic about more regular short web-surveys in between the major surveys.
- When asked for views on potential new forms of data collection (such as screen-time tracking or GPS tracking) and new types of data linkage (such as social media or financial transactions) participants from all studies had a number of concerns including fears that data could be used for commercial gain, particularly if third parties were involved and the feeling that such requests could feel overly intrusive or like 'surveillance'. It was widely suggested by participants that clear information would be required regarding what data is being collected, why it is needed, and how security will be assured.
- NCDS, BCS70 and Next Steps participants were broadly open to the idea of the studies collecting data from their partners and other family members. However, a consistently expressed view was that study members themselves should be asked for consent before any contact is made with others. MCS participants were positive about the continued involvement of their parents, but made it clear that they would now be expected to be treated as independent adults.
- Family members of the cohort members were asked about their views on participating in the study themselves – either directly or via data linkage. Family members from all four studies were broadly positive about the idea of being asked to provide data to the studies and could see the value that this would bring to the studies. Some hesitancy was expressed around data linkage and despite reassurance around anonymity and confidentiality some expressed the view that they would rather provide information about themselves directly. MCS parents, were keen to both continue to take part and to receive information about the study.

### Next Steps and recommendations

The detailed report from this project provides in-depth insight into study member attitudes towards a full range of new potential innovations for the cohorts, and these findings will be extremely informative and useful for CLS. The findings will be shared with and discussed by

the scientific leads, the survey management team, the cohort maintenance team and communication team and will feed into key decisions around the potential adoption of these novel approaches over the coming years. They will directly feed in to future decisions on mode and incentives for future sweeps, in particular for Next Steps and MCS, and to the ongoing development of our participant engagement strategy. We are also aiming to supplement this qualitative research with quantitative feedback questions on similar topics administered during between-sweep web surveys, and for Next Steps this was included in the short web survey which took place in July/August 2019.

The differences between cohorts are striking and interesting, though not unexpected. The reasons for these differences will likely be multi-faceted and include differences in duration of involvement, generational differences in the importance of civic duty, age of participants and contextual differences between the studies in terms of how participants have been contacted and asked to take part. It is unlikely that differences in levels of engagement are strongly related to differences in data collection mode that have been used in the past.

In relation to new forms of data collection, it is clear that very careful weighing up of the potential scientific benefits and participant burden would be required before decisions were made to move forward with a particular project, as well as appropriate steps to minimise risk and ensure data security. Careful piloting, exploring acceptability amongst study members would be essential, and as expressed by study members in the qualitative work it would be vital to provide full clarity regarding what data is being collected, why it is needed, and how security will be assured. It should also be noted that for the qualitative research, participants were given much less information about the proposed new form of data collection than they would be if they were asked to do this, and the research sought their initial views about a number of different possibilities. The findings are less concerning regarding the future possibilities of collecting these new forms of data in this context.

In general, as the context of each of the cohort studies is very specific, the applicability of the findings to other studies is limited. Having said that, some of the cohort differences, particularly in preferences regarding mode and engagement, are likely to be due to generational differences and as such these findings would be of interest to other studies of similar generations. Additionally, the concerns raised with regard to new forms of data collection will doubtless be shared by participants in a wide range of different research studies, and may in fact be greater in studies which have not had so long to establish trust from participants.

## 4. Novel linkages literature and scoping review

### 4.1 Embedding Centre for Longitudinal Studies cohorts into national linked administrative datasets

By Karen Dennison

#### **Introduction**

In this project we undertook a short scoping review related to a number of strategic aspects of our record linkages programme. This report focuses on opportunities for embedding CLS cohorts into national linked administrative datasets.

#### **Background**

CLS has a programme of data linkage for the four cohort surveys that it runs and which is based on explicit informed consent from cohort members (CMs) to link health, education, economic and crime records into their survey data and to make the linked data available in de-identified form to researchers.

To date, this programme has focused on data linkages where administrative records are linked into the cohort data and the resulting datasets are deposited with the UK Data Service and made available under secure access arrangements. These linkages have so far been limited to single administrative datasets e.g. we have linked Millennium Cohort Study (MCS) data to health records and also separately to education records.

This review looks at the possibility of linking consented cohort data into national linked administrative datasets, meaning that researchers would have access to population level data for a range of administrative data alongside a set of richer information for a subset of that population.

#### **What we did**

We spoke with the Office for National Statistics (ONS), including staff from its leadership team and staff with expertise in the areas of longitudinal, health and administrative data. We also spoke with the Department for Education (DfE) and the Department for Work and Pensions (DWP) in the context of the Longitudinal Educational Outcomes dataset. We also spoke to the Co-Directors of SAIL based at the University of Swansea, and the lead for the Economic and Social Research (ESRC) Council and Health Data Research UK (HDRUK) Administrative Spine Scoping Study. Our aims were to find out what linked administrative datasets are, or will, be available, if there is willingness to embed the CLS cohorts into national linked administrative datasets, any legal, ethical or other challenges around this and how we would go about doing it and making the data available for research purposes.

#### **National linked administrative datasets and interest in embedding cohort data**

There are a number of potential administrative datasets and programmes of work of interest.

## 4.2 Review of consent for record linkages

By Karen Dennison

### Introduction

In this project the Centre for Longitudinal Studies (CLS) undertook a short scoping review related to a number of strategic aspects of our record linkages programme. The review focuses on building a set of recommendations for record linkages in the CLS cohorts. A central part of this project is a review of the consent models currently being used and / or considered within a range of UK studies, especially in light of the new General Data Protection Regulation (GDPR) which enables linkage to be undertaken 'in the public task'. This short report summarises this review which focused specifically on consent for record linkages conducted at the individual level.

### Background

CLS has a programme of data linkage for the four cohort surveys that it runs and which is based on explicit informed consent from cohort members (CMs) to link health, education, economic and crime records into their survey data and to make the linked data available in de-identified form to researchers.

Following guidance from Research Councils, University College London and the Information Commissioner's Office, we have determined that our legal basis for processing (acquiring, linking and sharing) personal data is for a public task under GDPR. In addition, for ethical purposes, we currently continue to seek explicit informed consent from CMs to link specific administrative records to their survey data on an opt-in basis. We seek the consent of CMs for each type of linkage (for example, they can agree to health records but not education records being linked) and they can also withdraw their consent for one or more record linkage types at any time. Being able to withdraw consent is one of the key requirements of 'informed consent'.

Although we gain consent, we are not using consent under GDPR as our legal basis for processing data. Given that consent is not our legal basis, this review explores whether we could take a different approach to the consent we currently seek. Changing our approach could mean fewer or the same number of refusals or withdrawals for records linkage (though this would need to be trialled) alongside efficiency gains in terms of administrative processes and, if it were ethical and acceptable to study members to move to unconsented linkages in certain scenarios, the removal of potential obstacles around the ongoing agreement of consent wording with data controllers.

### What we did

In this project we spoke with other survey organisations to find out more about their policies around consent for data linkages in the context of legal and ethical frameworks, including the form of consent they currently use or are considering using. We also sought their guidance around the legal and ethical issues of changing our existing consent model. We then used this information to consider how we could review future consents for – (i) current CMs in existing studies (ii) a potential new cohort survey (iii) new CMs (for example children of current cohort members that we might bring into the surveys).

### Outcome

The organisations we spoke to had different approaches to consent for records linkage including the use of explicit informed consent, implicit informed consent or no consent.

### 4.3 Novel Health Record Linkages

By Danielle Gomes

- This review scopes health-related data sets at the national/country-level, in order to inform future recommendations for additional health record linkages in the CLS cohorts. It includes health data that are not already subject to linkage applications within CLS. It covers England, Scotland and Wales. Given the difficulties in orchestrating linkages from data held by multiple local authorities into national studies, it considers only linkages to national registers.
- It documents a wide range of data sets covering specific conditions, including cancers (screening, diagnosis, treatment), diabetes, mental health, as well as other types of health-related data such as Child Measurement and Community Services. For each data source it provides information on population coverage, data available, years covered and how to access the data.
- The data in England can be accessed via NHS-Digital or Public Health England; in Wales it can be accessed via the Secure Anonymised Information Linkage (SAIL); and in Scotland, it can be accessed via The Electronic Data Research and Innovation Service (eDRIS).

### 4.4 Geo-linkages scoping review

By Nicolás Libuy and David Church

- We describe and provide examples of geographical methods that can be used to successfully link individual's location through their life with a wide spectrum of exposures, such as environmental and neighbourhood characteristics, physical resources, among others.
- We systematically analysed the linkage potential of twenty-one geographical datasets, according to their duration, and quality, and conclude there is great potential for making valuable geographical linkages with the CLS birth cohort studies.
- A more detailed review of the scientific value of the specific variables within each geographical dataset is needed to prioritize academic research.

## 5. Survey methods development scoping

### 5.1 Survey methods research: new technologies

By Lisa Calderwood, Emily Gilbert, Emla Fitzsimons, David Bann, Praveetha Patalay, and Alice Sullivan

#### Project overview

This element of the project aimed to identify new technologies for data collection that could add scientific value to longitudinal studies including the CLS cohorts. We undertook an in-house literature review (by Emily Gilbert) and also employed 7 UCL PhD students to carry out thematic scoping reviews (whose remit covered data collection innovations and novel linkages related to scientific themes). The PhD students were employed as research assistants on short-term (8-week) contracts in May and June 2019 and supervised by senior academic staff within CLS.

#### New technologies

Technological change has transformed our daily lives in the last 20 years, and advances in technology create important opportunities for collecting data at scale. Smartphones are owned by two-thirds of adults in the UK and there has been explosion in the availability of data derived from people's daily interactions through the internet and elsewhere. CLS studies have used new technologies for data collection in MCS (age 14) which included a time-use diary which was mixed-mode using web, Smartphone app and paper, and in MCS (age 7 and age 14) surveys and BCS70 (age 46) surveys which used a portable activity monitor to collect direct measurements of physical activity. The challenge for CLS, and other longitudinal studies, is how to make best use of these new opportunities in the future to strengthen future research.

#### Literature review

##### Methods

The output covered here is a review of the methodological literature and evidence on the use of new technologies and innovative methods in data collection. The review looked at what major longitudinal studies have already done in terms of collecting data using new technologies and innovative methods, as well as innovation in other academic and market research settings. This covers the opportunities and challenges in the use of new technologies and wearables for both passive and active data collection, including cost, measurement issues and take-up rates.

##### Findings

- There are a large number of opportunities to enhance traditional survey data collected by large-scale longitudinal studies by collecting data through innovative techniques. There are also a number of methodological challenges surrounding innovative data collection, including willingness of participants to take part in non-standard methods of data collection, take up rates and representation, measurement issues, ethics, practicalities for large-scale longitudinal studies, and cost. More research is needed to understand potential biases introduced through these measures, particularly to understand who participates and who does not, to identify exactly what is being measured by different devices, and whether it can be considered a replacement for asking survey questions about certain behaviours, or whether these are complimentary measures.

## Thematic scoping reviews

### Methods

We decided at the outset of the project to take a thematic approach to scoping new data collection opportunities, and that as well as covering new technologies it was also important to scope possibilities for data enhancements through novel linkages. As a result, these reviews are broader than just new technologies for data collection.

Six scoping reviews were carried out in several key scientific areas. These reviews consisted of primarily desk-based research, including grey literature. They were conducted by UCL PhD students who were employed as research assistants on short-term (8-week) contracts in May and June 2019 and supervised by senior academic staff within CLS.

The key domains covered are: mental health, physical activity, cardiovascular health, diet, cognition, digital use, and social media. Each review discusses the opportunities and challenges around novel measurement.

### Findings

- For measuring **mental health**, we scoped out available technology and feasibility of Apps, wearables and momentary assessment tools that have been used to-date, mainly in small scale studies. We discussed the capability of these approaches to measuring mental health and the considerations for scaling these up to population-based cohort studies.
  - We found a number of smartphone apps available that can collect both active (self-report) and passive (device usage information, and location) data, allowing for continuous monitoring of mental health.
  - Wearable technology has been employed for measuring mental health, including the use of technology to infer mental state from breathing rate, heart rate, and EEG sensors.
  - Ecological momentary assessment has also been widely used to assess anxiety and depression in particular.
  - Device standardisation was found to be a particular issue, particularly around the aggregation of data from different types of smartphones.
  - Wearable technology raises some issues in terms of the reliability of devices, as well as the obtrusiveness of some methods of measurement (such as the use of bands worn around the head).
  - User feedback was found to be a useful method of increasing engagement and cooperation in the use of new technologies to measure mental health.
- Wearable **physical activity** monitors continue to advance, and typically decrease in cost, yet yield data which are challenging to process and interpret; novel methods include combined wearable monitors and the use of 'smart' mobile phones which typically passively collect activity data for long periods of time.
  - The most promising approach to a combined wearable system is the combination of heartrate monitors with accelerometers, to improve accuracy of measurement. Combined systems such as this may be better at capturing activities that traditional accelerometers fail to capture, such as cycling or weightlifting.

- o However, combined wearables are more expensive than accelerometers alone, and may also increase participant burden if they involve the use of multiple devices or more invasive devices.
- o Smartphones also provide an opportunity for physical activity measurement, through the use of their in-built sensors. This may be a more cost-effective approach, and reduce participant burden.
- Indicators of **cardiovascular health** have historically been obtained by standard blood pressure and blood draws; novel alternatives include the use of dried blood spots, and tests of cardiorespiratory fitness.
  - o Dried blood spots are a relatively inexpensive method of obtaining biomarkers, as well as being less invasive than venepuncture. Analytical methods are also improving, increasing the range of biomarkers detectable through dried blood spots.
  - o Devices for measuring blood pressure have been developed that do not use a cuff, allowing for continuous monitoring outside of a medical setting. However, these devices are currently costly, making them less viable for population-based research at this stage.
  - o Cardiorespiratory fitness can be measured in-field using shuttle run tests or submaximal step tests. Both of these methods have reasonably strong correlations with direct measures of oxygen uptake measured in laboratory settings.
- Multiple complementary measures of **diet** continue to advance, including means of self-reported intake (paper and electronic) and objectively assessed biomarkers. We discuss these methods, their potential for inclusion in cohorts, and describe a series of available resources to help guide selection of future dietary intake measures.
  - o Mobile phones have been used to collect dietary information, due to their widespread use and the potential for real-time data collection. There are a wide number of commercial apps that track diet. Barcode scanning can also be incorporated through a smartphone, to allow collection of information related to purchased or consumed food.
  - o Web-based dietary diaries are also reasonably common, with a large number of web based tool available.
  - o Camera and tape recorder technologies have been used to measure dietary intake through either visual or verbal records of consumption, along with plate waste, which is then analysed to calculate nutritional intake.
  - o Wearables have been designed to record food intake through cameras, microphones and other sensory methods. The major benefit of wearables, or other approaches that use cameras and sensors, is that there is less reliance on respondent memory.
- Continuous development and increasingly widespread use of technology facilitates the administration of **cognitive** tests in population-based studies. Novel technologies harnessed for enriched datasets on cognition comprise mobile (smartphone and tablet) applications, web-based cognitive testing, wearable technology, smart home systems, and non-invasive neural interface technology.
  - o Smartphones have been used for short-term memory tasks with respondents, enabling collection of this information from participants whilst they are in their homes, reducing burden.

- o Web-based approaches have also been used, again reducing burden by allowing completion in-home. Some batteries of cognition tasks have already been validated for web administration.
- o Wearable technologies can be used to assess physical states, psychological states, social interactions, and environmental context. Several studies have utilised wearables to cognitively monitor and assist the elderly. This data can often come from participants' own devices, reducing burden and cost.
- o Smart home systems have been developed to assist people experiencing cognitive decline. Whilst not designed to measure cognition directly, there is potential to infer cognitive function by observing changes in activities of daily living.
- o Non-invasive neural interface technology can also be used to assess cognition. EEGs and fNIRs have both been used to assess participants whilst they are completing cognitive assessments. Wireless EEG has the potential to be used to assess cognition on large-scale studies.
- **Social media** is increasingly used for research in a range of areas including mental health, politics and social capital. Linking social media to survey data provides the opportunity to validate measures derived from social media with validated survey measures. However, there are a number of methodological challenges to be considered including consent, ethics and data processing.
  - o Social media data obtained from well-known groups (i.e. longitudinal cohorts) can enhance researchers' understanding of human behaviour and, for example, how a person's mental health changes over time.
  - o University of Bristol is currently developing a framework for linking and sharing social media data for high-resolution longitudinal measurement of mental health across CLOSER cohorts.
  - o Few studies that have used social media data have cross-verified their findings with external datasets or captured demographic information. Linking social media data with survey data would add value in terms of representivity, validity and reliability.
  - o Informed consent is a challenge in this space - a key element of asking for informed consent is full transparency over the type of data being linked, the purposes of collection, data security and participants' rights to withdraw their consent.
- It is important for large-scale studies to measure the increasing **digitisation** of lives. Self-reported measures of online behaviours are not able to capture the full range of these activities. There are a number of technological solutions that passively **measure people's online activities, though issues around ethics and data security** need to be considered.
  - o Browser plug-ins utilise a small piece of software installed by the user which tracks how much time is spent on websites visited and which websites are visited. Desktop time tracking software looks beyond websites and gathers information on what's happening with the device operating system (which apps are being used, for how long). In a similar vein, smartphone tracking apps can be installed on a smartphone to track which apps the user is using and for how long.
  - o Cursor tracking can be used to collect the position of the cursor on the screen.
  - o Session replay has the ability to replay a visitor's journey to a website, seeing what the user sees and how they interact with the website.

- o Browser fingerprinting is a technique which collects information about browser type and version, operating system, plugins, language, screen resolution.
- o Tracking cookies can be used to track users' web browsing habits across multiple websites.
- o Deep packet inspection (DPI) is a type of data processing that inspects in detail the data being sent over a computer network (which can then be used to assess which websites the user has visited and how they have interacted with them).
- o It should be borne in mind that technology use is not limited to one device or a specific activity, and user activity is constantly changing, which should drive decisions about which method is best to capture the required information.

## Next steps and recommendations

The findings from this work package will be used by CLS to inform the design of future data collection in the cohort studies. We will also draw on other information, including from the CLS event on large-scale surveys and technology innovation event in June 2019. We will identify and select a set of novel measures in key areas such as screen time, diet, mental health to be trialled in the future for use in the cohort studies. In the forthcoming BCS70 Age 50 Survey, we are intending to pilot collecting data from an app which captures objectively measured smartphone screen time and a second app, a smartphone game (SeaHeroQuest) which will measure cognitive skills. These reports and findings will also be of much wider interest and utility for other large-scale surveys incorporating new technologies for data collection. We summarise the broader implications of these findings below.

There are a large number of opportunities to enhance traditional survey data collected by large-scale longitudinal studies by collecting data using new technologies. The possibilities for more finely granulated and real-time measurement are attractive for research, and it seems feasible that new technologies could be used to collect data in a wide range of topic areas. There is also evidence to suggest that different populations can also be persuaded to participate in data collection exercises using new technologies – from young children to the elderly, lots of different groups have participated in these activities.

Smartphones appear to be a front-running candidate for the collection of data on numerous topics. As well as being able to collect active data, through surveys or momentary assessments, the plethora of sensors built in to these devices offers huge opportunity for data collection. Studies focusing on travel and movement, physical activity, health behaviours, consumer behaviour, and digitisation of lives, to name a few examples, could also be built around smartphone data collection. The fact that smartphone ownership is widespread make them a potentially cost-effective solution for collecting data, as well as possibly reducing burden among participants.

Wearables are also becoming a more common solution for capturing objective data that can be used in a variety of different analyses. There are huge number of commercially available devices which can measure things such as heart rate, physical activity and blood pressure, useful metrics in studies across a broad range of disciplines. Wearables are also able to capture contextual information, such as photographs or audio recordings. These can be used to understand many facets of daily life, as well as validate information captured using alternative methods. In addition, data from participants' own wearable devices may be utilised to answer some research questions in a cost-effective way.

However, more research is needed to understand willingness and compliance. Bias can be introduced through the use of new technologies and innovative data collection methods: who chooses to participate in innovative data collection exercises, and how are they different to the population of interest? We also need more work to identify exactly what is being measured by different devices, and how to aggregate data from different types of device, and devices running different software.

Given the rapidly changing nature of this sphere, the ethics, practicalities and costs associated with innovative data collection are ever-changing. Keeping up with developments will be paramount in ensuring large-scale longitudinal studies can utilise the opportunities offered by new technologies and innovative data collection methods to provide the research community with relevant, high-quality, valuable data.

## 5.2 Survey methods research on mode and incentives

By Lisa Calderwood, Matt Brown, Alissa Goodman, Emla Fitzsimons, Darina Peycheva, George B. Ploubidis, Joseph W. Sakshaug, Richard J. Silverwood, Joel Williams and Erica Wong

### Project overview

The main aim of this strand of the project was to build the evidence base in two key areas of survey methods: mode, and incentives. We produced a combination of literature reviews and novel research evidence on each area, summarised as follows.

### Mode

Most recent sweeps of the CLS cohort studies have used face-to-face in-home interviewing. The main reasons for this are to maximise response rates, maintain longitudinal consistency, to allow sufficiently long interviews to collect a broad range of scientifically valuable information, and to ensure high quality collection of physical measurements, biological samples and direct assessments of cognitive function. Alongside face-to-face interviewing we have increasingly also used the web to enhance our data collections, as part of sequential mixed mode approaches for core interviews (Next Steps and NCDS), or for additional data collection elements (MCS age 14 time-use diaries, MCS age 17 parent and study member web questionnaires, BCS70 dietary diaries). We are considering whether to make use of the web in a mixed-mode content for major sweeps and for shorter between-sweep surveys (see work package 7). The aim of this part of the project was to add to the evidence base in relation to the use of the web, particularly in a mixed-mode context, and to inform our developing forward strategy on mode in the cohorts.

### Methods

There are four outputs in this part of the project. Three are new empirical papers based on recent web collections in the CLS cohorts: mixed-mode time diary on age 14 sweep of MCS, and sequential mixed-mode used on Next Steps age 25 sweep and NCDS age 55 sweep. We have also produced a brief review of the literature and evidence on the use of the web and mixed-mode in longitudinal surveys.

### Findings

- Literature review: The most relevant literature and evidence on the use mixed-mode involving web in longitudinal surveys shows that although mixed-mode can be effective at boosting response rates there is evidence of mode differences on measurement

which are potentially biasing unless appropriately adjusted for by analysts. There is relatively little robust empirical evidence on which to base important design decisions, and the trade-offs in relation to survey errors and costs are different for each survey.

- MCS: A mixed-mode approach to time diary data collection, combining app, web and paper formats, was successfully implemented at the age 14 sweep. Over two thirds of respondents chose to complete the diary using the app. The two online instruments provided data of the highest quality when compared with the traditional paper diary. Differences were observed in the characteristics of respondents choosing to complete the diary in each mode.
- NCDS: A sequential mixed mode data collection, online to telephone, was conducted at age 55 sweep. An embedded experiment shows that relative to telephone-only, the offer of the web increased overall participation rates by approximately 5 percentage points (82.8% vs. 77.9%). Differences attributable to mode of interview were detected in levels of item non-response and response values for a limited number of questions.
- Next Steps: A sequential mixed-mode (web-telephone-face-to-face) design was implemented in wave 8 of the Next Steps cohort study. After controlling for mode selection, we find that a lower proportion of respondents who contribute to item non-response in the web mode than in the telephone and face-to-face modes; and a high-level of measurement equivalence for a multi-item scale across the three modes.

## Incentives

An over-riding objective for longitudinal studies is to maintain study participation, and minimise non-response bias, and the use of incentives is one important tool by which studies can seek to achieve this. CLS studies, with the exception of Next Steps, have not hitherto used monetary incentives paid to participants as part of our response maximisation approach for core survey sweeps. The studies have succeeded in maintaining high response rates without this. However, in the context of declining response rates for surveys, including longitudinal surveys, this is something that it is important to consider going forward. We have a particular concern about maintaining high response rates on the Millennium Cohort Study in adulthood, and incentives may be an important part of minimising any drop-off in participation. Next Steps cohort members have received incentives for their participation throughout the study, and we included an incentive experiment at age 25 survey to boost take-up of the web component of the mixed-mode survey. We anticipate that for both Next Steps and MCS, incentive strategy will be crucial for retention going forward. We may consider targeted incentives for certain groups of cohort members, such as those that are at high risk of drop-out and/or of particular scientific value, such as disadvantaged groups. We are also intending to make greater use of the web for data collection between-waves, and potentially in a mixed-mode context for core sweeps, as well as supplemental data collection using new technologies. It is likely that to secure high participation rates in these additional data collection elements, incentives will be needed.

## Methods

There are two outputs in this part of the project. One is an empirical papers based the recent incentive experiment to boost web response rate at the age 25 survey of Next Steps, and one is a review of the literature on the use of incentives in longitudinal surveys. This includes their effectiveness in boosting take-up to web and mixed-mode surveys and of targeted incentives for encouraging response from marginal groups. This evidence has informed the design an incentives experiment to be implemented in an MCS web-survey later in 2019.

## Findings

- Literature review: Overall, the literature shows that incentives can be effective at increasing response rates in longitudinal studies, with cash (or cash-like, in the form of vouchers) and higher-value incentives being more effective. Incentives especially effective at increasing response rates for survey modes that typically yield lower response rates, like online or mobile web surveys. Incentive experiments in longitudinal surveys do not always find unconditional incentives to be more effective than conditional, and incentives seem to have an enduring, positive effect on response rates in later sweeps.
- Next Steps: An experiment testing the effectiveness of a web-push time-limited incentive was incorporated into the 'soft launch' of Next Steps sweep 8. Participants received a higher value incentive (£20 rather than £10) if the survey was completed via web within three weeks of receiving the survey invite. This was effective in boosting response, and it was subsequently offered to all study members in the main stage. The time-limited incentive was, however, no more effective than the standard incentive on overall response rates at the end of fieldwork for all modes.

## Next steps and recommendations

The three empirical papers will be published as CLS pre-prints, and submitted to appropriate journals for publication. The findings from this work package will be used by CLS to inform the design of future data collection in the cohort studies. These outputs will also be of much wider interest and utility for other large-scale surveys in designing mixed-mode approaches and the use of incentives. We summarise the broader implications of these findings below.

The research suggests that there are benefits to offering the participants the option to complete surveys in more than one mode: mixed-mode design tends to increase overall response rates, important for large-scale longitudinal studies. However, there is also evidence that different people tend to complete surveys in the different modes offered, and mode may affect measurement. As such, more research is needed to understand the implications of these differences for large-scale studies, particularly longitudinal surveys where measurement differences over time are an additional factor.

In terms of incentives, there is evidence to suggest that incentives can boost response rates to surveys, and for longitudinal surveys this boost can be enduring across sweeps. However, the exact combination of the components of an incentive (e.g. conditional versus unconditional, the amount), need to be tested further to understand what is most effective in terms of response, but also most cost-effective, for large-scale longitudinal studies.

## 6. Calibration of mental health and cognitive ability measures

By Emily Gilbert, Hannah Jongsma, Vanessa Moulton, Praveetha Patalay and George B. Ploubidis

### Research question

To assess the comparability of the various measures used to assess adult mental health in the British birth cohorts and to undertake a pilot a study to examine comparability of childhood cognitive assessments administered at age 10/11 across cohorts.

### Methods

For both studies we required ethics approvals from institutional ethics committees and agreements with external fieldwork agencies for data collection, the latter causing delays to the start of data collection.

#### Mental health

We aimed to recruit 5000 adult participants from the general population (not cohort members) across the full adult age range. Participants completed nine different mental health measures used in the cohort studies, measuring both psychological distress and wellbeing. Data was used to examine the correlation between the different measures and will be used to examine the correspondence of the various cut-off scores used in the cohorts, as well as to provide information about their relative utility to inform measure selection for future cohort sweeps.

#### Cognitive ability

We aimed to recruit 100 children aged between 118 and 140 months (year 5/6) from five schools. Children were asked to complete seven cognitive ability tests used in the NSHD, NCDS, BCS and MCS, as well as the British Ability Scales (BAS) 3 core set.

The pilot set-up, fieldwork, data collection and analysis will inform the feasibility of a larger study. Results will be used to construct overall test scores, derive ability and difficulty estimates and, where possible examine measurement invariance between tests. The BAS3 will be used as a Gold Standard to calibrate the remaining measures against.

### Findings

#### Mental health

Missing data was generally low across questionnaires (maximum 5.8%). In general, there was at least a moderate-high correlation ( $>0.60$ ) between all measures. In our initial analyses we have focussed on the correlations between the different measures collected, and in depth calibration analysis is planned next. The highest correlation between different measures of psychological distress was 0.90 (between the General Health Questionnaire-12 item version and General Health Questionnaire -28 item version) and the lowest correlation was between the Malaise questionnaire and the Kessler-6 (0.62). The highest correlation between different measures of well-being was between the wellbeing subscale of the SF-36 health survey and the Warwick-Edinburgh Mental Wellbeing Scale (0.78) whereas the Office for National Statistics life satisfaction measure correlated with both these measures to a slightly lesser extent (0.67 for the SF and 0.69 for the WEMWBS).

## **Cognitive ability**

Four schools have agreed to participate, and fieldwork is ongoing. Collected data will be processed as per the original marking instructions and delivered to CLS in digital format. On the basis of progress to date, the following issues have been noted as affecting the feasibility of a wider calibration project. The set-up time was considerable, including agreement of contracts (two months) with the external agency, recruitment of schools, establishing copyright issues and preparation of test materials. In the pilot, we excluded tests using CAPI or external software, due to set-up time, compatibility of software, copyright and administration issues. In addition, at age 10/11 only a subsample of the cognitive tests that have previously been used in the cohorts could be administered in exactly the same way as in earlier cohorts. This is partly due to length - we needed to identify 2 hours of tests (from 5 hours in total). Some tests were lengthy (>30 minutes) and during fieldwork it was established that the administration test time was greater than the estimated test times. Some tests used outdated language, formulae and visuals. In future work, if full versions of the tests are used, they will need to be updated by expert including educational psychologists, cognitive and language scientists. Finally, using this approach, there is a finite window when one to one administration can be conducted in school, given room availability, school hours, breaks, school holidays and school commitments.

## **Outputs and next steps**

### **Mental health**

Outputs will include one peer review journal article setting out the results from the mental health calibration analyses. We will deposit the data collected for this project in a data repository to permit other researchers to use the data for their research if interested.

The mental health data gathered in this project will be used to examine the degree of correspondence between their respective cut-off scores and will be used to inform decisions on future measures in the cohorts and beyond.

### **Cognitive ability**

The cognitive ability pilot learnings and data in this pilot will facilitate a feasibility assessment of a larger calibration of childhood cognitive ability measures across the British birth cohorts.

Outputs will include one peer review journal article setting out the results from this pilot cognitive calibration. Also, production of a grant application to take forward this project beyond the pilot stage.

## 7. Web survey in MCS and design of annual web-mailing

By Lisa Calderwood, Matt Brown, Emla Fitzsimons, Emily Gilbert, and Darina Peycheva

### Project overview

The main aim of this project was to build the evidence base regarding incorporating further use of web surveys in the CLS cohort studies. It had three main elements: a short web-boost survey within the MCS age 17 sweep in order to increase overall response to the study sweep, the design of an annual web-survey including an incentives experiment for future implementation in MCS, and scoping work on developing the technical capability for CLS to conduct web surveys in-house. All of this work was completed as planned, and we have additionally designed a small web-survey full feasibility test to be carried out on Next Steps as part of the between-sweep mailing in July/August 2019.

We outline the methods and findings for each of these elements separately below, and then summarise the next steps and recommendations arising from this work. Separate reports are provided for each of these three elements.

### MCS Age 17 Web-boost survey

#### Methods

This element comprised of a web-boost survey designed to increase response rates in the MCS Age 17 survey. The main stage fieldwork for the survey finished in March 2019. We designed a web survey to collect data from cohort members who had not participated (N=2506). It was a short survey, approximately 15 minutes, and contained questions on a range of topics as well as collection of contact details, with the content taken from the cohort member questionnaires administered in the main survey. The web-boost survey was implemented successfully in April and May 2019 by Ipsos MORI, the fieldwork contractor the Age 17 survey.

#### Findings

An additional 253 cohort members took part via the web-boost survey who had not taken part in the main stage of the Age 17 Survey, approximately 10% of the target sample for the web-boost. These additional cases increased the final response rate in the Age 17 Survey from 73.3% to 74.4%. These findings show that a web non-response follow-up was an effective way to increase response rates in MCS.

### MCS design of annual web survey

#### Methods

This comprised of the design of an annual web-survey, including an incentives experiment for future implementation in MCS. The initial design work comprised of planning the scope, broad content and timetable for the first annual web-survey in MCS, and designing an incentives experiment. It includes a brief literature review on the use of incentives, and was informed by findings of the two other elements of this work package, and a broader literature review on incentives conducted as part of work package 5 (survey methods).

#### Findings

We provisionally plan to conduct the web-survey in-house using Qualtrics software towards the end of 2019. It will consist of a 20-minute questionnaire, and all cohort members who

were issued for the age 17 survey will be asked to complete it (excluding those who have since permanently withdrawn from the study), approximately 13,500 cohort members. It will incorporate an experiment around incentives, to understand how to maximise response to the survey through their use. We currently expect the incentive to be conditional on completion of the survey, and for the value of the incentive to be the equivalent of £10. At present, our preferred incentive design is to compare the effectiveness of an e-voucher incentive, a charity donation and the option of a choice between these options.

Our planning for this will continue to be developed over the coming months, and the design and planned timetable may change depending on scientific and feasibility considerations.

## **Feasibility review of conducting in-house web surveys**

Note (added November 2019): since time of writing we have completed an in-house web-survey in Next steps using the Qualtrics survey tool, and uncovered a number of issues with using this platform for our future work. We have re-scheduled the planned MCS web-survey for Spring/ Summer 2020.

### **Methods**

Following some brief initial scoping work, we decided that the optimal way to scope the feasibility of conducting in-house web-surveys was to trial this approach in one of our studies. Thus we have adapted the planned annual mailing for the Next Steps cohort due to go out in July 2019 in order to test this approach. The main aim of the survey is primarily to collect updated contact details from study members, but it also includes some other questionnaire items.

### **Findings**

Findings so far indicate that it is feasible for CLS to conduct in-house web surveys, using Qualtrics software. We have successfully programmed a short (5-10 minute) survey for Next Steps, and plan to implement this in July/August 2019. This includes updating and collecting contact information, which is an important requirement. We have also established that this approach meets UCL requirements in relation to information security, another crucial requirement. However, we have not yet actually carried out any data collection using Qualtrics, and though we don't anticipate any major problems, our experience of doing this will have a major impact on our assessment of its feasibility. Although Qualtrics does lack flexibility in some areas, we don't currently anticipate that this will be a major barrier to using this approach for short, relatively straightforward, online surveys between-sweeps.

### **Next steps and recommendations**

The findings from this work package are informative for the design and planning of between-sweep web surveys on the cohort studies, and will also be of broader interest to surveys, in particular longitudinal surveys who are also considering between-sweep web surveys.

The next steps for our work in this area will be to implement the Next Steps web-survey in summer 2019 and to continue to plan, develop and implement the MCS web-survey in winter 2019. The MCS web-survey will be longer than the Next Steps feasibility test and will incorporate incentives, so will provide a first full test of the design we would intend to rollout if successful. In order for us to carry this out in-house, it will require the development of operational capacity to incorporate incentives, likely administered electronically, and we will also investigate the feasibility of incorporating text-message reminders. A key issue will be

whether a sufficiently high response rate can be achieved in a web-only survey for the data to have strong scientific utility.

Depending on the learning in these initial surveys, we will take a decision whether to carry out annual surveys for both MCS and Next Steps, in combination with annual mailing, in years when a major sweep is not taking place. As NCDS and BCS70 are both in the field with major sweeps in 2020, we don't anticipate carrying out a between-sweep web-survey for these studies in the near future.

Additionally, the non-response boost conducted for the age 17 sweep of MCS has indicated that it is feasible to conduct a web survey with this cohort and that a non-response follow-up using another mode can be an effective way to increase response rates. It was successful at engaging substantial numbers of cohort members who refused to complete the face-to-face age 17 sweep, as well as some cohort members who could not be located in-field. Additionally, a number of cohort members who had not participated in MCS in many years completed the web survey. As such, we will look at incorporating non-response follow ups to major sweeps of all of the CLS cohort studies going forwards.