Meeting report

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The future of data collection in longitudinal population studies: during and after COVID-19

Jennie Blows, Rebecca Hardy & Razwana Quadir
CLOSER

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Key insights from the meeting

- Main study data collection sweeps have been either paused (1958 National Child Development Study (NCDS)), postponed (Avon Longitudinal Study of Parents and Children (ALSPAC), 1970 British Cohort Study (BCS70)) or changed approach to focus more on remote data collection (Next Steps and Understanding Society).

- TwinsUK and Delirium and Population Health Informatics Cohort Study (DELPHIC) have been able to continue in-home visits with extra safety and hygiene precautions taken such as interviewers wearing full PPE.

- Sub-studies focusing specifically on COVID-19 and its impacts have been launched by TwinsUK, DELPHIC, Understanding Society, ALSPAC, and the UCL Centre for Longitudinal Studies (CLS) managed studies (NCDS, BCS70, the Millennium Cohort Study (MCS) and Next Steps) in collaboration with the MRC 1946 National Survey of Health and Development (NSHD).

- The Market Research Society (MRS) has produced detailed guidance for undertaking face-to-face (F2F) data collection via doorstep interviews, and the survey agencies, NatCen Social Research and Kantar Public UK have updated their data collection processes and procedures in line with the government guidance.

- Although doorstep interviews were considered unsuitable for conducting F2F interviews for longitudinal studies, the approach could provide useful insights into participants' willingness to take part in surveys during the crisis, as well as delivering packs, instructions and tests to participants.

- There was general consensus that current guidance lacks clarity on when F2F interviews in participants' homes may resume, however a number of studies were tentatively planning to restart in January 2021.

- A number of studies are exploring conducting virtual visits using video conferencing software and plans for pilot studies investigating this approach are underway.

- There needs to be a mixed-mode approach to remote data collection to maximise response rates across all groups and to avoid digital exclusion.

- It is unclear whether or not participants' willingness to invite interviewers into their homes will have been affected by the pandemic, and how this may change going forward. Therefore, decisions made on resuming F2F data collection should be led by the participants and what they are comfortable with irrespective of what the government guidance states.

- There is a need for the longitudinal research community to work together to find solutions with studies and organisations sharing their knowledge, learning and best practice. It was suggested that a central place online be created so that studies can easily access and update this information.

Introduction

The COVID-19 crisis resulted in the suspension of usual F2F data collection which meant longitudinal population studies have needed to adapt their methods for collecting data and samples from their participants. Studies and survey agencies have reacted rapidly to ensure valuable data are collected throughout the pandemic, but they are now facing a new challenge - how can normal data collection - questionnaires, measurements and biological samples - resume?

In July 2020, CLOSER hosted a meeting to bring together representatives of longitudinal population studies and survey agencies to share information and identify solutions to tackle key challenges relating to data collection during and after the COVID-19 pandemic.

The meeting was split into three main sessions: the first session involved short presentations from both studies and survey agencies; the second (optional) session involved participants breaking out into small groups to discuss remote data collection and resuming safe F2F data collection; and the final session involved feeding back key points from the group discussions.

In total, 60 delegates attended the online meeting representing 26 different longitudinal population studies and organisations. Of those 60, 45 delegates joined the optional group discussions session.

This report summarises the content of presentations from five longitudinal population studies and three survey agencies, key messages arising from group discussions and potential ways forward.

Presentations from longitudinal population studies

This section of the report summarises the five presentations from longitudinal population studies who shared approaches adopted during the pandemic and their plans looking ahead at future waves of data collection. The studies were:

- TwinsUK
- Linkage-Camden COVID-19 Study
- Understanding Society: The UK Household Longitudinal Study
- ALSPAC
- NCDS, BCS70, MCS and Next Steps

TwinsUK and the COVID Symptom study: from apps to roving teams

Claire Steves, King's College London

The TwinsUK team worked with the web development team, ZOE, to create the COVID Symptom Study app which asks participants to record their symptoms (or lack of symptoms) on a daily basis. The data collected by the app is available for research through SAIL and HDR UK. It is hoped that the data collected via the app

Of the 4,000 twins taking part in the COVID Symptom Study app, the TwinsUK team has carried out home visits to 517 participants living within 80 miles of London and who had not exhibited any symptoms of the virus for over two weeks. The visits were carried out between April-May 2020 and participants will continue to be followed up every six weeks. This work was carried out as part of the TwinsUK Early Serological study.

The team has also launched the COVID-19 Personal Experiences Study (COPE) which aims to understand the physical and mental health implications of self-isolation due to the pandemic. In April 2020, a web survey, with telephone aided completion for those without web access, was sent to participants. The second questionnaire will be sent out in July 2020 alongside antibody testing.

Linkage-Camden COVID-19 Study

Dr Alex Tsui, University College London (UCL)

The DELPHIC study team developed a COVID-19 sub-study in collaboration with UCL and Imperial College London. The team re-visited all existing DELPHIC participants in Camden and also recruited new participants who had recently been admitted to or had contact with University College London Hospital.

During these visits, participants were asked to give blood samples and subsequently sent weekly follow-up surveys to find out if they had developed any symptoms of COVID-19. The follow-up surveys were carried out either over the telephone or the web using REDCAP. If participants reported any symptoms that could be attributed to the virus, the team visited their homes in full Personal Protective Equipment (PPE) to take a new set of blood samples. If the participant was admitted to hospital, the team visited them there instead.

Remote data collection for Understanding Society during COVID-19: adaptions and innovations

Jonathan Burton, University of Essex

The Understanding Society team have identified three main challenges to moving to remote data collection. The first challenge relates to interviews and moving away from the use of F2F in a mixed mode design. Since 2015, the team moved to a mixed mode design (web first, then F2F, then telephone) and this previous development work meant that when F2F interviews were suspended in March 2020, the team were able to make an easy transition to web-based surveys, with telephone as the follow-up mode.

The second challenge is the collection of biomeasure samples. In Understanding Society’s Innovation Panel Wave 12, the team experimented with self-completion collection of blood spots, hair samples and blood pressure. This experiment was discussed in more detail during Martin Wood’s presentation on behalf of NatCen Social Research. The third challenge relates to the timeliness as each annual survey is spread over 28.5 months meaning a long delay between questionnaire specification and the data being available for researchers, with little flexibility to adapt the questionnaire content. For the current survey however, the team has made some slight amendments in response to the pandemic. A new module on COVID-19 symptoms is also due to be included in Waves 11 and 12 but as this is part of the main survey, the data won't be released for quite a while.

Understanding Society launched new monthly surveys which focus specifically on COVID-19 and its impacts. The surveys are carried out online each month and are supplemented with telephone interviews for those without internet access for two of the months. The first two waves of data are currently available for researchers to download from the UK Data Service, and future questionnaires are currently in development. The information collected in these monthly surveys will be linkable to previous and future annual Understanding Society surveys.

ALSPAC – Adapting to a new normal

Mel Lewcock, University of Bristol

ALSPAC was already utilising postal and online questionnaires and so the team is now looking into other measures that can be collected remotely via virtual visits. Within the G2 cohort of study participants, the team identified three main categories of measures – those that require specialist equipment and so cannot be moved to remote collection (e.g. skinfolds), those that are already carried out as remote measures but require consent or necessary equipment (e.g. teeth), and measures that can be collected with either single use or portable equipment and guidance for participants (e.g. blood pressure).

Virtual visits would involve participants booking an appointment to video conference with a fieldworker. Prior to the appointment, the participant would be sent a virtual visit pack which would include links to any online questionnaires and necessary measuring equipment. During the appointment, the fieldworker would ensure electronic consent was gained, guide participants through the measurement collections, and demonstrate activities. The data would then be collected by courier at a later date.

The team will be carrying out a virtual visits pilot study to investigate data validation, participant's access and willingness to take part, how long the visits will take to complete, and cost effectiveness.

COVID-19 and the CLS Cohort Studies: new online surveys and adaptations to upcoming major sweeps

Matt Brown, UCL

CLS conducted a web survey in May 2020 in which participants of all four CLS studies (the NCDS, BCS70, MCS and Next Steps) as well as participants of NSHD were asked to take part. A second wave will commence in August 2020, and a third (subject to funding) is planned to take place in November 2020. The first web survey was conducted internally using Qualtrics. Operational capacity meant that invites and reminders could only be sent via email. The second web survey will be conducted externally, and communications will be sent via email, post and text message. In the third wave it is hoped that telephone follow ups will also be carried out for non-responders.

The pandemic has led to CLS either pausing or postponing major sweeps of F2F data collection across the NCDS Age 62 survey, BCS70 Age 50 survey, and the Next Steps Age 31 survey. The team is looking into how these sweeps could resume. The NCDS and BCS70 teams are considering switching to a mixed mode approach involving web and telephone, but significant challenges include the length of the interviews, how to carry out cognitive assessments, and how to conduct the planned nurse visits for NCDS participants. The Next Steps Age 31 Survey, which will commence next year, will move from a F2F interview to a web-first sequential mixed mode approach. Interview content for all studies will be adapted to ensure that the impact of the pandemic on people's lives Is fully captured. The inclusion of antibody testing is also under consideration.

CLS is also exploring the use of video conferencing. The advantages of moving to virtual interviews include the ability to retain the human interaction element and capitalising on increased familiarity with using video calling technology during the crisis. However, challenges involve how to share visual content (e.g. showcards or booklets), and how to carry out cognitive assessments. The approach will be piloted with BCS70 cohort members in September.

Presentations from fieldwork agencies

The second set of presentations delivered by Kantar Public UK, NatCen Social Research and the Market Research Society provided an overview of the changes each organisation is in the process of making to their data collection procedures and guidance.

F2F data collection: current alternatives and how it might resume

Hannah Carpenter and Michelle Lewis, Kantar Public UK

In line with current government advice, Kantar is working towards F2F data collection resuming in July 2020, however this would only be in the form of doorstep interviews. Doorstep interviews will ensure interviewers and participants can adhere to the 2-metre social distancing guidance. Interviewers will be given protective gloves and sanitiser to ensure they can maintain cleanliness during the F2F interviews. It has been suggested interviewers will not be required to wear masks as they will be working outside and maintaining the 2-metre distance rule. This will be beneficial in developing a rapport with the participants and means those who may be hard of hearing can still participate in the survey.

There are restrictions to carrying out doorstep interviews. For instance, interviews will need to be made shorter (Kantar suggests 30 minutes or under); it may not be possible to ask sensitive questions in public spaces; and the ability to share prompt materials is hindered. Kantar are exploring the use of single use paper showcards and/or attaching tablets to selfie sticks to ensure participants can see materials on the screen as possible solutions.

It was noted that it is hard to know to what extent participants' willingness to take part in F2F interviews will have changed due to the pandemic. With this in mind, Kantar plan to send an information leaflet to participants prior to their interviews detailing the new safety and hygiene measures that have been put in place. Interviewers will also reiterate this information at the beginning of each doorstep interview.

Practical considerations for the collection of biomeasures during the COVID-19 outbreak: What can fieldworkers do and what can be done remotely?

Martin Wood, NatCen Social Research

As part of Understanding Society's Innovation Panel 12 (IP12) carried out pre-pandemic, the team experimented with remote self-collection of biomeasures such as blood spots and hair. The experiment looked at response rates from online interviews (where participants were sent instruments for self-collection of samples) vs interviewer placed (where interviewers left instruments for self-collection before leaving the home); compared with nurse collection of the biomeasures. While the response rates were encouraging for the self-collection methods, there were a number of limiting factors. These include off-putting complexity of the tasks, burden on the participant, and understanding the purpose of the collection. The complexity of the task could also lead to lower quality samples as participants may get the collection wrong. The cost, size and complexity of the sample collection instrument also needs to be considered.

NatCen has also explored what can be achieved by socially distanced fieldworkers and have found that interviewers at a distance can still help overcome some of the limiting factors noted in the Understanding Society IP12 experiment. For instance, fieldworkers can encourage hesitant participants to take part, explain complex collections, collect samples from the doorstep, and re-use/take care of expensive and delicate instruments. However, limitations to having socially distanced fieldworkers include lack of outside space to distance, poor weather, and difficulty obtaining PPE if required. Close contact is required for many standard biomedical protocols and there is a risk to accuracy and consistency if no-contact amendments are introduced. The importance of participants' informed consent was also highlighted.

COVID-19 Lockdown Guidance: undertaking safe F2F data collection

Debrah Harding, Market Research Society (MRS)

During lockdown, MRS worked with the UK Government to develop guidance on safe working during the COVID-19 pandemic. MRS has also produced guidance for undertaking safe F2F data collection which is being updated in line with changes to government guidance. Local guidelines apply to where the data is being collected and so research practitioners (any individual working in the research supply chain) will need to be aware of different requirements for the devolved nations and potential local lockdowns. The MRS' guidance on safe F2F data collection covers: definitions relating to COVID-19, requirements for before F2F data collection can commence (including design, selection and use of participants), F2F participant recruitment, requirements during F2F, and considerations for in-home and doorstep interviews plus other environments.

Before F2F research can commence, the guidance advises studies to undertake risk assessments, ensure they follow the government's safe working guidance, identify and mitigate risks, consider use of body coverings, identify liability of risks, and carry out robust training for fieldworkers.

In relation to the F2F interviews, the current MRS guidelines dictate that fieldworkers must not enter participants' homes, and therefore interviews must be carried out on the doorstep and in adherence with the social distancing rules. The study teams will need to consider environmental pressures (such as weather and lack of privacy) and participant factors (such as length of interview time, use of support materials, and the collection of sensitive or special category data). The guidance also suggests study teams include screening questions to determine any COVID-19 risks to both participants and any other individuals in their households.

Key messages arising for group discussions

This section of the report highlights the key messages that arose from the small group discussions. Four groups of 10-12 delegates were asked to discuss the following topics:

- What are the best approaches to remote data collection? What measurements, tests and biological samples is it possible to collect by these approaches?
- When, and how, can safe face-to-face data collection be resumed? How can we engage with participants to ensure they feel safe?

Sharing knowledge and best practice

One of the key messages that arose during the group discussions was the need for the community to work together to find solutions with studies and organisations sharing their knowledge, learning and best practice. In sharing learning, studies will be able to make better informed decisions about approaches to data collection going forward.

Delegates suggested it would be beneficial for studies to share their experiences and best practice for collecting remote consent, using different virtual technologies such as REDCAP or Qualtrics for conducting online questionnaires, and using BlueJeans, MS Teams or Zoom for video conferencing. Sharing of findings, including advantages, limitations, and response rates from studies carrying out pilot testing for incorporating remote data collection into data collection sweeps would be extremely valuable.

Delegates suggested a practical solution to aid the sharing of information would be to create a central place online that studies can access to share knowledge, learning and best practices. This will allow the wider longitudinal research community to develop a form of alignment in approaches to data collection within the different studies.

Remote data collection

It was noted that there needs to be a mixed-mode approach to remote data collection to maximise response rates across all groups and to avoid digital exclusion. There is a need to understand how different groups prefer to respond and survey teams need to be mindful that not all participants will have access to the same devices or technologies, such as the internet, due to a number of reasons such as age, poverty or culture.

Participants' personal preference for different data collection methods should be taken into consideration. For instance, it was suggested that some of the more vulnerable or frailer participants in TwinsUK preferred shorter bursts of data collection where specific tasks are carried out in pre-arranged time slots. However, this method may not be as helpful for all participant groups given competing demands on their time.

A number of studies reported already using or experimenting with several remote measures such as accelerometery data, blood and hair samples, and weight/height measurements. It was noted that this sudden need to switch to remote data collection offers studies an opportunity to be more creative with their solutions. It was also suggested that moving more measures to remote collection could encourage participation from cohort members who were previously put off from taking part in traditional F2F interviews or clinic visits. It will be important when moving to more remote measures to find ways to mitigate against potential loss of data quality.

Ways in which sensitive questions could be included in remote visits via video conferencing software, need consideration. Possibilities include moving sensitive questions to a web survey so that during virtual visits interviewers can instruct the participant to answer the sensitive questions privately. Developments in AI technology were also mentioned meaning studies could look into the use of chatbots to record sensitive data.

Many studies are facing the challenge of how the consent process is operationalised and what will be acceptable to ethics committees. Many studies would traditionally have used paper forms to gather consent for biomeasure collection and data linkage but work now needs to focus on the best ways to move towards remote consent such as using electronic consent forms. It was noted that previous research suggests gaining consent via web surveys can prove difficult and having an interviewer present to help explain the process and/or answer questions could improve consent rates.

Resuming face-to-face data collection

The general consensus among the delegates was that doorstep interviews are not a feasible option for conducting F2F interviews for longitudinal studies due to a number of limiting factors such as constraints to the interview length, lack of privacy, an inability to ask sensitive questions, and unpredictable weather. However, doorstep data collection could be useful in indicating public perception to taking part in surveys during the crisis, as well as delivering packs, instructions and tests to participants, and recruiting participants for other data collection methods.

Delegates agreed that there is currently a lack of clarity regarding when F2F data collection in participant's homes or through clinic visits could resume. A number of studies suggested they were planning for F2F data collection to begin again in January 2021 – however plans are tentative. Studies will also need to consider how potential future local lockdowns may affect their F2F data collection plans. It was highlighted that some studies have been able to continue with F2F data collection throughout the crisis, such as TwinsUK and DELPHIC, who were able to collect samples that could be used for specific research into COVID-19 with nurses entering homes in PPE.

Delegates agreed that considerations for F2F data collections in participants' homes need to be based on a risk assessment and whether the measures are too difficult or too sensitive to be carried out in any other way. Delegates suggested studies also need to take public perception into consideration, even once the guidance deems it safe to start F2F again. It is currently unclear how participants' willingness to invite interviewers into their homes will have been affected by the pandemic, and how this may change going forward.

Delegates agreed that decisions on resuming F2F data collection should be led by the participants and what they are comfortable with irrespective of what the government guidance states. Some studies are collecting information from study participants about their willingness to be interviewed and some will be running focus groups to get participants views. Sharing findings from these exercises will provide valuable insight into how participants feel about resuming F2F data collection.

There was consensus that longitudinal studies have a duty of care to their participants and so ensuring their safety and comfort is paramount. It will be key for the studies to maintain the trust of their participants. As well as putting into place the safety measures such as regular testing for interviewers, dedicated participant engagement and communications campaigns detailing the safety measures being taken would be required.

Correspondence:

closer@ucl.ac.uk

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UCL Institute of Education
20 Bedford Way
London WC1H 0AL
www.closer.ac.uk

About CLOSER

The UK is home to the world's largest and longest-running longitudinal studies. CLOSER aims to maximise their use, value and impact both at home and abroad. Bringing together leading studies, the British Library and the UK Data Service, CLOSER works to stimulate interdisciplinary research, develop shared resources, provide training, and share expertise. In this way, CLOSER is helping to build the body of knowledge on how life in the UK is changing – both across generations and in comparison to the rest of the world. CLOSER was funded by the Economic and Social Research Council (ESRC) and the Medical Research Council (MRC) from 2012-17, and by the ESRC from 2017 to present. Visit www.closer.ac.uk.

The views expressed in this work are those of the conference delegates and do not necessarily reflect the views of CLOSER, UCL, ESRC, MRC or the Wellcome Trust.

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Please contact CLOSER:

tel: +44 (0)20 7612 6938

email: closer@ucl.ac.uk