

Preparing for the future III: Tackling key challenges facing longitudinal population studies in a post-COVID world

Book of abstracts

Tuesday 18 January 2022

15:35 – 16:35 GMT Parallel session A

1A The impact of COVID-19 on longitudinal population studies – Pivoting to remote data collection with different age groups

Session chair: Paul Bradshaw, Growing Up in Scotland

Growing Up in Ireland: Adapting data collection methods in response to the COVID-19 Pandemic

Lisa Kelly, Growing Up in Ireland

Growing Up in Ireland (GUI) is the national longitudinal study of children and young people in the Republic of Ireland. The study includes two cohorts, Cohort '98 who were first interviewed in 2007 at 9 years old and Cohort '08 who were first interviewed in 2008 at 9 months old. Both cohorts are interviewed every 2-4 years with an over-arching objective to provide evidence that will inform government policies to enhance the lives of children and families living in Ireland. Traditionally, GUI data-collection fieldwork has taken place in the study child's family home where the interviewer administers paper and laptop-based questionnaires, conducts a cognitive assessment with the study child and records height and weight measurements from the study participants. However, since March 2020, in-home visits were not possible in light of national COVID-19 restrictions. Consequently, a special Covid-19 survey was conducted completely online for both GUI cohorts in December 2020. In addition, telephone and web-based surveys replaced the traditional in-home interviewing for the Cohort '08 wave six main fieldwork. Many challenges (and opportunities for future research) were realised through these new modes of data collection in terms of training interviewers, contacting families, collecting informed consent and adapting questionnaire content.

Adapting to the times: Collecting data in the CLS cohorts during the pandemic

Matt Brown, UCL Centre for Longitudinal Studies

Description of work: Since the outset of the pandemic, the Centre for Longitudinal Studies has been piloting a range of new 'COVID-secure' methods which aim to replace or supplement traditional face-to-face interviewing whilst retaining some of the advantages of the approach –

including video-interviewing, providing participants with devices to complete surveys and making more use of web and telephone.

Opportunities and challenges: At the time of the outbreak in March 2020, the NCDS Age 62 Survey was in-field; the BCS70 Age 50 Survey fieldwork was about to commence and development of the Next Steps Age 31 Survey was upcoming. All surveys were planned to be conducted face-to-face. Ongoing uncertainty regarding future infection rates and restrictions made it difficult to gauge when resumption of face-to-face visits would be possible. It became clear that more flexibility with regard to methods of data collection and development of COVID-secure approaches would be required.

Learning for the LPS community: The presentation will describe the results of our trials, consider the advantages and disadvantages of the various tested methods, confirm key decisions taken with regard to moving forward with the cohort studies and draw out potential lessons for other studies.

2A Data linkage – Data linkages in regional UK studies

Session chair: Oliver Duke-Williams, ONS Longitudinal Study

All- Inspiring the Development of the Born and Bred in (BaBi) Network of local e-cohorts

Kayley Ciesla, Born in Bradford

Born in Bradford's BiB4All is a longitudinal e-cohort embedded into routine maternity practice in Bradford, UK. The project aims to link routinely collected health, social care, and education data locally to build a picture of child health and development, and use this as a local intelligence tool, to inform and evaluate local policy and practice. Since its launch in March 2019, NHS midwives in Bradford have consented 4099 women and 3395 babies to the study. Following successful implementation of BiB4All, other sites approached the team to develop an e-cohort. As a result, the BaBi Network was established. This multi-site cohort study currently includes Leeds, Doncaster, Wakefield, Nottingham and East London. BiB4All are the co-ordinating centre, providing strategic research support to each BaBi site and developing the process to combine these local cohorts as a meta-cohort over time. Embedding e-cohorts into routine care has highlighted the efficiencies of using existing structures to build a sustainable method to provide a cohort for every generation. Recruitment to the study continued throughout the pandemic, demonstrating its robustness. This presentation will share learning on the process, benefits and challenges of establishing the e-cohort and learning that can be applied to the post-COVID world.

The Challenges of Administrative Data Linkage for Longitudinal Studies of Ageing

Anne Gasteen, Healthy Ageing in Scotland

This paper presents findings from a survey of 14 longitudinal Health and Retirement Studies across the world, exploring their use of data originally collected for administrative purposes, such



as health or tax records. The survey was conducted between June 2020 and June 2021, as part of the ESRC Centre for Population Change project: Linking Longitudinal Studies of Ageing with Administrative Data. It focused on the benefits and challenges of linking longitudinal studies to administrative data: application, approval and access processes, linkage mechanisms, linked data usage and impact.

The main challenges faced by studies centred on building relationships with both data owners and respondents, data protection issues, resources, and fragmented administrative data infrastructures. The development of trust was cited as key to building relationships with data owners and, crucially, respondents. A lack of trust had the potential to undermine the benefit of linkage through poor respondent consent rates.

It is recommended that longitudinal studies should explore whether, given governing data protection legislation, respondent consent is strictly necessary. Further, where administrative data architecture is fragmented, studies should advocate for the establishment of single ID numbers and the development of real time linkage to multiple administrative databases at a single point of access.

Wednesday 19 January 2022

15:30 – 16:30 GMT Parallel session B

1B New forms of data collection – Using innovative technology

Session chair: David Porteous, Generation Scotland

SMS surveys in the Global South: Insights from field studies in Tanzania

Johanna Choumert-Nkolo, EDI Global

In the presentation, we will present our recent experience with SMS surveys in Tanzania. Although phone surveys are usually the preferred alternative to in-person interviews, SMS surveys are progressing. We will present practical tips and best practices for designing and implementing SMS surveys. We will cover the following topics: What should be the length of an SMS survey? What types of questions can be asked in an SMS survey? How to programme an SMS survey? How to choose the type of system to send SMS? How to provide compensation/incentives to survey participants? What should be the timeframe of an SMS survey? How to pilot and test an SMS survey? How to deal with situations where several individuals use the same phone?

“We hope to visit you again soon”: Updating location information from participants of a longitudinal study during COVID-19 in four Low-Middle-Income-Countries

Maria De Los Angeles, Young Lives

Updating participant location information is a crucial process in longitudinal studies for tracking purposes to reduce attrition. Young Lives, a long-standing cohort survey collecting data in Ethiopia, India, Peru, and Vietnam, has previously collected GPS data during the fieldworker’s in-person visits. With in-person data collection interrupted by COVID-19, the study has been conducting telephone surveys: three calls were completed in 2020 and two are planned for 2021, making the acquisition of accurate address data a challenge. We have designed a new mechanism to collect GPS data from participants with access to a smartphone. We will send them a link to submit their GPS location. Only the participant’s name, and birth date must be entered manually, the GPS information is transferred using the device’s built-in GPS support by pressing one button. In this presentation, we explore the opportunities and challenges of introducing remote GPS data collection. Specifically, we discuss the feasibility of collecting GPS data in Low-Middle-Income-Countries, using the participants own smartphones considering i) selection bias, ii) participation rates and associated incentives, iii) duration of the survey, and iv) ethical challenges.

2B The impact of COVID-19 on longitudinal population studies – Remote collection of bio samples

Session chair: Elaine Dennison, Hertfordshire Cohort Study

COVID-19 antibody testing in longitudinal population studies

Andrew Wong, COVID-19 Longitudinal Health and Wellbeing National Core Study

Description of the work: As part of the National Core Studies Longitudinal Health and Wellbeing (NCS LH&W) theme to understand COVID-19, a programme of work was undertaken to obtain serology data. This was achieved through a collaboration with the Department for Health and Social Care (DHSC), who commissioned a blood testing company, Thriva, to provide an [essentially] free end-to-end serological testing service. Over 33,000 antibody results were obtained from the following UK longitudinal population studies: ALSPAC, BCS70, ELSA, EXCEED, MCS, NCDS, Next Steps, NSHD, SABRE, TwinsUK, and Understanding Society.

Opportunities and challenges: Throughout the COVID pandemic, study participants had been asked to complete multiple questionnaires and there was real concern on over-burdening both participants and study teams with a novel form of data collection: finger prick blood testing. Thriva provided a flexible approach to satisfy the information governance and bio-sampling storage requirements of each cohort. Despite the urgency, a shared major challenge lay in protracted contract negotiations.

Learning for the LPS community: This core funded work was successful due to appointing a single key liaison point who co-ordinated activities between the scientific team, cohorts, providers, DHSC and other stakeholders. Additionally, the use of a set of standardised template documents and processes that were scrutinised by the stakeholders streamlined the implementation and delivery of the data collection.

Twinduction: baseline sample and data collection for newly registered twin research volunteers

Taha Bhatti, TwinsUK

The TwinsUK cohort, set up in 1992, is a major epidemiology resource with longitudinal deep genomic and phenomic data from over 14,500 adult twins from the UK, many of whom are highly engaged and recallable. On average, 200 new twin research volunteers sign up to the registry per annum. Following the outbreak of COVID-19 and the media coverage of TwinsUK, spearheaded by the Zoe Covid-19 app – a partnership with TwinsUK, around 800 twins registered their interest to sign up. With clinical visits coming to a halt during the pandemic, Twinduction provides an innovative, rapid and adaptive method for recruitment and data collection by using a remote based testing method. Every pair of twins joining will sign up online and receive a postal box containing equipment to return faecal, urine, saliva and capillary blood samples. Participants will also be provided with an email link to carry out online cognitive assessment and core questionnaires. The samples will be analysed and stored in TwinsUK Biobank. The data will

then be used for further research into common diseases and traits accessible to independent researchers/collaborators who wish to use the enormous potential of the twin design. The structure and rationale for this study paves the way for clinical studies moving forward in this post-pandemic world.

3B Participant and public engagement – Creative strategies to participant engagement

Session chair: Melanie Lewcock, Avon Longitudinal Study of Parents and Children

Involving young people in research during the COVID-19 pandemic: The BRIGHTLIGHT experience

Lorna Fern, BRIGHTLIGHT

BRIGHTLIGHT is the largest longitudinal cohort study of young people (YP) with cancer in the world. Challenges We have involved YP as research partners since study inception through participatory workshop/activities. In March 2020, the United Kingdom Government prohibited face-to-face working which remained in place until May 2021. Aims We set out to rapidly mobilise our patient involvement activities ensuring YP were able to participate in the interpretation of study results, design of secondary data analysis and new survey content. Methods/opportunities We utilised the interactive MIRO platform; a secure National Health Service Clinic Zoom account and google jam-board. We employed an artist to design pre-workshop activities and animate discussions in real-time. Two independent professionals attended each workshop for safe-guarding purposes. Results We held 6 workshops between 09/20 -03/21 each attended by 8-10 participants. YP received pre-workshop packs containing information sheets, consent forms, online workshop policy agreement, activities to assist participation, stationary and snacks. Learning for longitudinal studies The workshops were more accessible to YP compared to face-to-face as they could join from abroad, whilst self-isolating, straight from work, and shortly after giving birth. There were reduced venue and travel costs, however, were also considerably more resource intensive due to preparation time required by workshops facilitators.

COVID-19-safe public engagement

Clare Dolan, Generation Scotland

Generation Scotland (GS) is a family health study which currently has over 24,000 volunteers from 7,000 families recruited across Scotland. We have a wide pool of volunteers who have agreed to be contacted for PPIE activities. The COVID-19 pandemic halted usual face to face engagement. However, as GS was still keen to involve our participants, we pivoted to Covid-19-safe engagement. OurGS is a virtual photography exhibition which will tell our volunteers stories in their own words. We have photographed volunteers across the length and breadth of Scotland, representing rural and urban communities. We are now conducting interviews by telephone or video call. Our interviews are focusing on the volunteers experience of taking part in GS, why



health data research is important to them, and which health issues matter to them most. It is an opportunity for those who volunteer with GS projects to share their perspective on the health challenges GS should be investigating next, and to influence our future work. OurGS demonstrates how to continue public engagement remotely and safely. The high level of uptake by our volunteers demonstrates their enthusiasm for engagement during the pandemic.

Thursday 20 January 2022

13:00 – 14:00 GMT Parallel session C

1C Influencing policy – International and UK perspectives

Session chair: Rushda Khandker, Longitudinal Study of Young People in England 2

Partnerships facilitate policy translation - a case study from Growing Up in New Zealand

Susan Morton, Growing Up in Ireland

In 2019 the New Zealand government adopted a Child Youth and Wellbeing Framework (CYWF) designed to be applied across all policy sectors. The NZ Treasury simultaneously set up a requirement that all agencies must measure fiscal sustainability in terms of impacts on population wellbeing using the CYFW (not just GDP). From its inception the Growing Up in New Zealand (GUiNZ) longitudinal study has utilised a framework that conceptually aligns closely to the CYWF. The study is therefore opportunistically placed to provide context relevant evidence to fill gaps in the wellbeing information available to agencies from the largely actuarial information contained in linked routine administrative datasets. GUiNZ are working alongside multiple policy agencies to provide contextual and strengths-based indicators relevant to the CYWF and providing unique longitudinal evidence to assist with the co-design of strategies to enhance wellbeing. The usual challenges faced in translating GUiNZ evidence to inform policy are reduced by the commitment to policy translation and the credible partnerships established with multiple agencies throughout the longitudinal journey. We will describe the importance of these policy partnerships for impacting population wellbeing as well as for demonstrating the utility of longitudinal studies alongside substantive routine data collections.

Generating policy impact: insights from Understanding Society Policy and Partnerships Unit

Raj Patel, Understanding Society: The UK Household Longitudinal Study

The presentation provides a case study into Understanding Society's strategy for influencing policy. Set within the broader context of maximising the value from the Study, it focus on Understanding Society' policy impact strategy, show cases the work stream under each strand of the strategy, and sets out key challenges. In providing insights into mobilising both data use and published research, it focuses on demand led-activities, knowledge translation and brokerage, and pro-actively stimulating policy research. In particular, it considers the question of 'what next', and set's out what challenges the Study would like to address in the future.

2C New forms of data collection – Experimental designs and clinics

Session chair: Paz Garcia, TwinsUK

Cohort Re-engagement Strategies

Sarah Sullivan, Avon Longitudinal Study of Parents and Children

Description of the work: ALSPAC will run two new clinics in September 2021 for participants and parents. We want to encourage attendance from those who have previously disengaged. We have developed a two-phase re-engagement strategy. We have achieved good progress with phase 1. Phase 2 will follow.

Opportunities and challenges: A successful re-engagement strategy has several important benefits. We will increase the representativeness of our cohort and reduce the amount of missing data. In turn this will reduce selection bias and increase the value of research findings based on cohort data. Challenges include obtaining contact details for participants who have been disengaged for a long time, funding incentive payments for re-engagement of large numbers of participants and running evening and weekend clinics to increase accessibility.

Learning for the LPS community: Our disengaged strategy could provide a valuable toolkit for other cohorts seeking to re-engage participants.

Concurrent, Sequential or Web-Only? Evidence from a mixed-mode recruitment experiment in FReDA

Pablo Christmann, GESIS

The COVID-19 pandemic impacts the operation process of many survey programs, among them the recruitment for the newly established German panel study FReDA (Family Research and Demographic Analysis). Switching from face-to-face to self-administered mixed-modes (web, paper) for the recruitment phase has allowed us to experimentally test the effectiveness of different mode choices based on a gross sample of 108,000 register-based addresses. We investigate how different mode choice strategies affect the response rate, distributions of substantive answers, sample composition, data quality, panel consent and participation in the subsequent wave.

We implemented three different experimental conditions to which individuals were assigned randomly. FReDA deploys an invitation letter and reminders that offer either an access-link/QR-Code to the web survey (CAWI), or containing the paper-based questionnaire and an access-link/QR-Code to the web survey (CAWI/PAPI) in different sequences to contact the target population. Individuals are contacted either with

- (1) a concurrent contact strategy in the sequence CAWI/PAPI, CAWI, CAWI/PAPI, or
- (2) a sequential contact strategy in the sequence CAWI, CAWI, CAWI/PAPI, or
- (3) a sequential contact strategy in the sequence CAWI, CAWI, CAWI, CAWI/PAPI.

By design, the third condition also allows us to simulate and compare how the recruitment would have performed in a web-only mode with one invitation letter and two reminders.

3C Data linkage – Data linkages in national UK studies

Session chair: Rosie McEachan, Born in Bradford

UK Longitudinal Linkage Collaboration

Robin Flaig, UK Longitudinal Linkage Collaboration

The UK Longitudinal Linkage Collaboration (UK LLC) is a new, unprecedented research infrastructure to enable research into the COVID-19 pandemic. We're integrating data from more than 20 of the UK's key longitudinal studies with systematically linked health, administrative and environmental records to facilitate the cross-disciplinary research insights such consolidated data resources can provide. This work is led by the Universities of Bristol and Edinburgh, in collaboration with the Universities of Swansea and Leicester. Since October 2020, we've been developing the infrastructure together with data specialists from our partner studies and experts across the National Core Studies (NCS) programme. We've worked with NHS Digital to create a safe and efficient way of linking multiple longitudinal studies to NHS data in an innovative yet straightforward process. Beta-testing for researcher access commenced mid-2021. Researchers will be able to request access to our Trusted Research Environment to analyse data across multiple longitudinal studies linked with NHS and administrative records with a single application, achieving new research efficiencies and possibilities in a controlled and secure manner. We'll present an overview of the UK LLC and discuss on-going plans for further enhancement of the infrastructure's utility and scope as part of the developing longitudinal research landscape.

Enhancing the birth cohort studies through address-level geographic linkages

David Church, UCL Centre for Longitudinal Studies

Description of the work: The main recent development in geographic data linkage has been address-level geocoding, which will enable analysis at the scale of the individual residence, rather than at the postcode. Linkages to a wide range of datasets have already been made at the postcode level, e.g. to fast-food outlets using Ordnance Survey Points of Interest, and to crime incident-level data from data.police.uk.

Opportunities and challenges: Linkages at the property level will be possible to e.g. Energy Performance Certificate data and to the Land Registry Price Paid data, two rich datasets with GB-wide coverage. The main challenge is replicability/reproducibility since these are large datasets that are continually updated/edited.

Learning for the LPS community: Working with longitudinal data linked to geographic data at the property level should enhance the accuracy of a range of environmental research, where the



calculation of exposure (to, e.g. air pollutants or noise) depends largely on locational precision. Furthermore, it will be possible to run a series of 'natural experiments', i.e. conducting the same analyses on data based on postcode centroids vs building centroids, which will enable the quantification of these locational effects.

Thursday 20 January 2022

14:15 – 15:15 GMT Parallel session D

1D The impact of COVID-19 on longitudinal population studies – Trialling virtual visits

Session chair: Ruth Hogg, Northern Ireland Longitudinal Study of Ageing

The Avon Longitudinal Study of Parents and Children: The role of virtual visits in LPS data collection

Melanie Lewcock, Avon Longitudinal Study of Parents and Children

In March 2020 ALSPAC was forced to stop all face-to-face data collection activities for the ALSPAC-G2 cohort due to the COVID-19 pandemic restrictions. Due to the time critical nature of seeing participants during pregnancy and then at specific time points following birth, the restrictions severely impacted our ability to meet key grant deliverables. ALSPAC developed a virtual visit protocol that enabled collection of a sub-set of variables via video calling platform, this was rolled out from September 2020 and we have completed over 250 data collection visits with adults and children. A participant feedback questionnaire, a small qualitative study and management experiences have provided insight into participant and fieldworker experience of virtual visits and the logistics of running this type of activity. The biggest challenge has been how to validate data obtained and this work is continuing. ALSPAC have identified there is a place for virtual visits as an option alongside traditional face to face visits to provide; an engagement tool, a method to reach those who have never attended face to face visits in the past and to future proof the study against future restrictions.

Video Interviews for Longitudinal Studies During the COVID-19 Pandemic

Alisha Pathania, English Longitudinal Study of Ageing

In this presentation, we will outline how Computer-Assisted Video Interviewing (CAVI) has been introduced for Wave 10 of the English Longitudinal Study of Ageing (ELSA) as an alternative to face-to-face interviews during the COVID-19 pandemic, initially as a CAVI-only pilot and subsequently as a CAVI opt-in alternative for mainstage fieldwork. The unprecedented circumstances we found ourselves facing due to the pandemic led to discussions on how to continue fieldwork on ELSA in a way that would be COVID-secure, encourage respondent participation, and collect high quality data. ELSA comprises a long questionnaire with complex modules, which does not readily lend itself to be adapted to telephone or web modes. CAVI was felt to be a viable option where in-home interviewing was not possible. This presentation will examine the adaptations made to ELSA for CAVI, and the implications for other longitudinal surveys. In particular, it will cover: respondents' willingness to take part in this approach, how well the technology worked, and the length of the video interviews. We will also consider the

advantages and disadvantages of video call interviewing, how useful it may be to other studies, and in which circumstances.

2D Participant and public engagement – Engaging the public and external stakeholders

Session chair: Emla Fitzsimons, Millennium Cohort Study

COVID-19 Impact and Recovery Survey: how COVID-19 fear impacts social, health and economic recovery from the pandemic in people aged over 50

Tamara Brown, Healthy Ageing in Scotland & Generation Scotland

Description of the work: Stirling University has partnered with Generation Scotland to advance Scotland's first comprehensive longitudinal study of ageing. COVID-19 Impact and Recovery Survey is a new Healthy AGEing in Scotland (HAGIS) study exploring how COVID-19 fear may impact social, health and economic recovery from the pandemic in people aged 50+. We have recruited a group of volunteer co-researchers aged 50+ who have co-produced materials for the survey, survey questions, and a co-researcher page on the new website: <https://www.hagis.scot>

Opportunities and challenges: To support team cohesion and engagement we have used a mix of online meeting rooms, phone calls and emails. The plan was to start with a virtual group and then, as restrictions relax, move to more in-person activities but this has not yet been possible.

Learning for the LPS community: Co-researchers have been particularly valuable in identifying key areas of concern, shaping survey questions, and writing recruitment scripts. Co-researchers report benefits with the online group providing support and shared experiences throughout the pandemic. The value of co-production with people that reflect a cohort of interest should not be underestimated and should be built-in to new longitudinal studies.

Engaging Diverse Stakeholders: Strategies from the Environmental influences on Child Health Outcomes (ECHO) Program

Elissa Faro, ECHO Program

The US National Institutes of Health-funded Environmental influences on Child Health Outcomes (ECHO) research program unites 69 diverse longitudinal US pediatric cohorts and enables science to inform policies, practices, and programs related to child health. The ECHO Program views stakeholder engagement as critical to its success. The NIH ECHO Program Office sought public input on the initial protocol via a Request for Information. The ECHO Stakeholder Engagement Working Group (SWG) developed ECHO-wide guiding principles, a participant experience survey, and capacity-building webinars for ECHO investigators. The ECHO Strategic Planning Task Force facilitated solution-oriented research by facilitating an environmental scan of stakeholder organizations, their research gaps, and priorities, to design a research idea evaluation framework. The SWG built upon this by creating outcome-specific resources for ECHO



investigators interested in engaging external stakeholders. The SWG and an ECHO Program Participant Advisory Board co-created policies informing the return of research results to participants, a public-facing website, and communication materials (e.g., accessible research summaries). The ECHO Connector, a bi-monthly newsletter, invites stakeholder representatives (e.g., stakeholder organizations, scientific community, participants) to engage via several channels. The ECHO Program continues to expand its potential to inform policies, programs, and practices by leveraging engagement and building investigator capacity.
