

Participant engagement in longitudinal studies

Date and time: Friday 29 January 2016, 10:30-17:00

Venue: Woburn House Conference Centre, 20 Tavistock Square London WC1H 9HQ

Draft Programme

10:00 Registration and refreshments

10:30 Housekeeping and opening remarks *[Main Hall]*

10:45 **Participant engagement: a review of current practice and what we know about effectiveness** *[Main Hall]*

Alison Park, CLOSER and Lisa Calderwood, Centre for Longitudinal Studies

11:30 **Case study: Participant engagement in the Avon Longitudinal Study of Parents and Children** *[Main Hall]*

Makaela Jacobs-Pearson, Verity Katuszka and Dara O'Hare, University of Bristol

12:15 **Exhibitions, networking and lunch** *[Tavistock room]*

13:00 **Concurrent discussion sessions**

<i>Communicating impact and research effectively</i> <i>(Chair: Emma Saville)</i> UK Biobank, <i>Andrew Trehearne</i> Centre for Longitudinal Studies, <i>Meghan Rainsberry</i> Young Lives, <i>Caroline Knowles</i>	<i>Consent</i> <i>(Chair: Alison Park)</i> Millennium Cohort Study, <i>Kate Smith</i> Growing Up in Ireland, <i>James Williams</i> HUNT Study, Norway, <i>Maria Stuiifbergen</i>	<i>Innovative methods of engagement</i> <i>(Chair: Narayan Sastry)</i> Born in Bradford, <i>Liz Andrews</i> Southampton Women's Survey, <i>Hazel Inskip</i> Understanding Society, <i>Jon Burton/Janine Ford</i>
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14:15 Break

14:20 **Concurrent discussion sessions**

<p>Online communications (social media and websites) (Chair: Emma Saville)</p> <p>Growing Up in Scotland, <i>Judith Mabelis</i></p> <p>Millennium Cohort Study and Next Steps, <i>Meghan Rainsberry</i></p>	<p>Incentives (Chair: Alison Park)</p> <p>Understanding Society, <i>Violetta Parutis</i></p> <p>Born in Bradford, <i>Liz Andrews</i></p> <p>Cork BASELINE Birth Cohort, Ireland, <i>Emma Cobbe</i></p> <p>Panel Study of Income Dynamics (PSID), USA, <i>Narayan Sastry</i></p>	<p>Innovative methods of engagement (Chair: Janine Ford)</p> <p>Lothian Birth Cohort, <i>Robin Morton</i></p> <p>MRC National Survey of Health and Development, <i>Marcus Richards</i></p> <p>Longitudinal Internet Studies for the Social sciences (LISS), The Netherlands, <i>Josette Janssen</i></p>	<p>Involving participants in study design & management (Chair: Emily Gilbert)</p> <p>ALSPAC, <i>Makaela Jacobs-Pearson</i></p> <p>BRIGHTLIGHT, <i>Lorna Fern & Rachel Taylor</i></p> <p>Millennium Cohort Study, <i>Lisa Calderwood</i></p>
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15:35 **Engaging different audience types [Main Hall]**

(round table discussions with refreshments)

Topics:

- Engaging children
- Engaging adolescents
- Engaging older people
- Engaging fathers
- Engaging immigrants and people with English as a second language
- Engaging carers (all ages)
- Engaging people with learning difficulties/SEN

16:45 Closing remarks and discussion on future participant engagement training or events [Main Hall]

17:00 End

Website: <http://www.closer.ac.uk/event/participantengagementkew/>

Google maps: <https://goo.gl/maps/3J7D8RP53LH2>

Detailed programme

- 10:45 **Participant engagement: a review of current practice and what we know about effectiveness**
Alison Park, CLOSER and Lisa Calderwood, Centre for Longitudinal Studies [Main Hall]

This presentation will set the scene for the day by: discussing what we mean by participant engagement; reviewing current engagement strategies across a range of studies, using data gained from a survey of longitudinal and cohort studies; considering the factors that shape how studies are able to engage with their sample members; and reviewing the research evidence about the effectiveness of different engagement strategies.

- 11:30 **Children of the 90s (ALSPAC): a warts-and-all account of participant engagement**
Makaela Jacobs-Pearson (participation worker), Verity Katuszka (participation worker) and Dara O'Hare (communications and participation manager), University of Bristol [Main Hall]

The Children of the 90s participation team will give an honest account of the range of participation activities they've run in recent years, most of which worked but some of which didn't. There'll be laughter, there'll be tears and hopefully there'll be some interesting evidence-based ideas to provide inspiration and stimulate coffee-break conversations.

- 13:00 **Concurrent discussion sessions**

<p>Communicating impact and research effectively <i>(Chair: Emma Saville, Centre for Longitudinal Studies)</i></p> <p>UK Biobank: Engaged - but Will the Marriage Last? Thoughts on a Lasting Relationship</p> <p>Presenter: Andrew Trehearne, Head of Communications, UK Biobank</p> <p>Many scientists spend considerable effort finding and recruiting the perfect partners, only to discover the research relationship sours over time. UK Biobank has been following participants for ten years and will discuss some of the things that have helped keep research</p>	<p>Consent <i>(Chair: Alison Park, CLOSER)</i></p> <p>Millennium Cohort Study: Securing Informed Consent from Children and Young People in a Home Setting: Learning from the Millennium Cohort Study</p> <p>Presenter: Kate Smith, Survey Manager, Centre for Longitudinal Studies</p> <p>The UN Convention on the Rights of the Child gives children rights of protection and participation. In the context of social research, this means protecting their freedom to participate, while ensuring their wellbeing throughout. In developing the approach to gaining consent</p>	<p>Innovative methods of engagement <i>(Chair: Narayan Satyr, University of Michigan)</i></p> <p>Born in Bradford: Chap Books, Twins and Mobile Phones</p> <p>Presenter: Liz Andrews, Senior Research Fellow, Bradford Institute for Health Research</p> <p>These are just some of the strands of work Born in Bradford has worked on with social documentary photographer Ian Beesley and Yorkshire poet Ian McMillan who have worked with BiB since its conception. The work has touched many people; most importantly the families of the children involved in the work. As a form of social documentary the growing archive of the two</p>
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and participants together, and how we might sustain that relationship as the participants age.

Centre for Longitudinal Studies (CLS): Developing Content for Feedback Mailings - Learning from CLS

Presenter: Meghan Rainsberry, Communications Manager, Centre for Longitudinal Studies

The team at the Centre for Longitudinal Studies (CLS) sends annual mailings to its cohort members, which showcase recent research and impact from the studies. Translating the findings for a participant audience brings with it a unique set of challenges, including writing in plain English and treating negative findings sensitively. This presentation will look at the challenges (and opportunities) of putting together feedback mailings to participants in the 1958, 1970 and millennium cohort studies.

Young Lives: Sharing Our Findings and Sharing their Impact: The Virtuous Circle of Research Reciprocity

Presenter: Caroline Knowles, Communications Manager, Young Lives, University of Oxford

We will look at how we communicate findings to our study children, including case studies of feedback to children, their families and community leaders and local politicians. The talk will also briefly cover what

on the Millennium Cohort Study, we sought to facilitate young people's fullest possible informed consent, thus supporting their right to a full say regarding their own level of participation. We developed a structured approach to gaining consent, both to the participation in the study overall and each of the individual elements, which was suitable for standardised administration by interviewers in a home setting.

Growing Up in Ireland: Securing Informed Consent in the Growing Up in Ireland study

Presenter: James Williams, Principal Investigator and Co-Director, Growing Up in Ireland

Growing Up in Ireland has followed the development of two cohorts of children and young people from 9 months to 17 years of age. This presentation considers ways in which informed consent and assent were secured from participants at each round of the study. Child assent was secured from the children themselves from 9 years of age. Parental/guardian consent was also required in respect of the children at all stages in the study. As well as general issues on consent/assent, the presentation also considers how consent was secured for recording information on more sensitive aspects of behaviour

Ian's work with Born in Bradford will assume even greater importance in years to come.

Southampton Women's Survey: Supporting Interventions and Vice Versa

Presenter: Hazel Inskip, Deputy Director, MRC Lifecourse Epidemiology Unit, University of Southampton

The Southampton Women's Survey has led in part to a number of interventions being conducted in Southampton. Some are in pregnant women or those planning a pregnancy, and local knowledge of the SWS has been helpful in recruitment. An intervention in teenagers to improve their diets and lifestyles before they embark on being parents draws heavily on the SWS, and some SWS participants are now engaging in LifeLab independently of the SWS follow-ups. They are excited to see the SWS findings being used, thus supporting both retention in the SWS and recruitment to LifeLab research.

Understanding Society: The Continuous Cycle of Engagement

Presenter: Jon Burton, Senior Research Fellow, ISER University of Essex

We interview the same people each year to build up a picture of change over time in the UK. With a sample that covers the whole of the UK, and the whole age range, Understanding Society must

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we have done to date and our plans for the next round (which starts in the middle of this year).

from 13 years onwards.

HUNT Study, Norway: From Broad, Static Consent to.... What, Actually? Meeting the Public for a Discussion

Presenter: Maria Stuijbergen, Advisor, HUNT Research Centre

The HUNT Study has thus far operated with broad consent, but HUNT researchers wish to explore the possibilities of a more dynamic consent. As a first step to gain insight in participants' thoughts and wishes around a more dynamic variant of consent, we arranged an open meeting discussing: one-off consent versus dynamic and personalized solutions; feedback of results; the desirability of and possible solutions for ongoing contact. The talk will present the debate in our group leading to the need for a conversation with the public, our findings of the discussion with the public, and our plans for moving ahead with involvement and dynamic consent.

engage and motivate sample members, and interviewers, to reduce attrition and improve the quality of the data and the research which uses the data. This presentation briefly covers the different ways in which we engage with our sample members; before, during and after the interview.

14:20 Concurrent discussion sessions

<p>Online communications (social media and websites)</p> <p><i>(Chair: Emma Saville, Centre for Longitudinal Studies)</i></p> <p>Developing webpages for children taking part in Growing up in Scotland</p> <p>Presenter: Judith Mabelis, Senior Researcher, ScotCen Social Research</p> <p>In Growing up in Scotland, children in our oldest birth cohort are turning 11 years old. Since the children are getting older we are starting to engage with them as participants in a longitudinal study. We have done this through a number of different methods (children receive their own letters leaflets; gifts etc). This talk will focus on the work we have done to develop an online quiz for children who take part in GUS.</p>	<p>Incentives</p> <p><i>(Chair: Alison Park, CLOSER)</i></p> <p>Understanding Society: Traditional and Novel Ways to Keep Participants Loyal</p> <p>Presenter: Violetta Parutis, Senior Survey Officer, University of Essex</p> <p>The presentation covers ways in which we incentivise participation in Understanding Society and how the incentives have evolved over time. It discusses the amount, type and conditionality of incentives as well as other (non-monetary) forms of incentivisation. Some advantages and disadvantages of different approaches will be suggested.</p> <p>Born in Bradford: We Love to Shop</p> <p>Presenter: Liz Andrews, Senior Research Fellow, Bradford Institute for Health Research</p> <p>A brief history of incentives used, abandoned and improved upon!</p>	<p>Innovative methods of engagement</p> <p><i>(Chair: Janine Ford, ISER University of Essex)</i></p> <p>Lothian Birth Cohort: Five Ways to Help Your Participants Know How Special They Really Are</p> <p>Presenter: Robin Morton, Communications & Impact Manager, KE Manager Centre for Cognitive Ageing and Cognitive Epidemiology</p> <p>The Lothian Birth Cohorts are special. In fact they are unique, without them we wouldn't have been able to do the research to publish over 200 research papers. But we want them to know they are special, and to keep coming back. We will present some of the ways we engage with LBC participants and show them just how important they are.</p> <p>MRC National Survey of Health and Development (NSHD): Engaging Participants</p> <p>Presenter: Marcus Richards, Programme Leader, MRC Unit for Lifelong Health and Ageing at UCL</p>	<p>Involving participants in study design & management</p> <p><i>(Chair: Emily Gilbert, Centre for Longitudinal Studies)</i></p> <p>ALSPAC: The Benefits, Challenges and Impact of Involving Participants</p> <p>Presenter: Makaela Jacobs-Pearson, Participation Worker, University of Bristol</p> <p>In this session, we will outline some of our current work involving participants in study management and design. We will use two case studies to discuss the benefits, challenges and impact of involving participants: 1) focus group of male participants looking at acceptability and feasibility of a male fertility sub study 2) our long-standing participant panel.</p> <p>BRIGHTLIGHT: the Teenage and Young Adult Cancer Cohort Study</p> <p>Presenters: Lorna Fern, Research & Development</p>
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<p>Centre for Longitudinal Studies: Relaunching a Longitudinal Study: A Comparison of Online Communications in the Millennium Cohort Study and Next Steps</p> <p>Presenter: Meghan Rainsberry, Communications Manager, Centre for Longitudinal Studies</p> <p>The Centre for Longitudinal Studies (CLS) recently relaunched the Millennium Cohort Study (MCS) and Next Steps to participants, as each study had reached a critical stage in its development. The MCS cohort members turned 14, a stage of life when other similar studies had experienced drop-out. It also marked the first time cohort members were the main respondents.</p> <p>For Next Steps, CLS the Age 25 Survey will be the first under CLS's management (having previously been run by the Department for Education). It will mark the first time some</p>	<p>Cork BASELINE Birth Cohort, Ireland: The Cork BASELINE Birth Cohort Study – An Overview of Retention Methods</p> <p>Presenter: Emma Cobbe (Clinical Nurse Manager, INFANT centre)</p> <p>The Cork Babies After Scope: Evaluating the Longitudinal Impact Using Neurological and Nutritional Endpoints (BASELINE) Birth Cohort study is the first birth cohort study in Ireland. We will outline the follow up visits, the retention rates and use of incentives that we feel contributed to the success of our study right up to the 5-year time point.</p> <p>Panel Study of Income Dynamics (PSID), USA: The Use of Incentives in the Panel Study of Income Dynamics and its Supplements</p> <p>Presenter: Narayan Sastry, Professor of Statistical Epidemiology, University of Michigan</p> <p>The Panel Study of Income Dynamics (PSID), begun in 1968, is the world's longest-running household</p>	<p>NSHD has historically high response rates due to a culture of commitment, possibly established early through a sense of civic responsibility and in response to study impact (e.g. policy changes in anaesthetic administration in childbirth; paediatric ward facilities; educational reform). This is maintained today by birthday card with lay summaries of research, study member website, study member events for 65th and 70th birthday, responses to personal enquiries, duty of care for medical and psychological problems. However, concern over possible future increased attrition as the cohort ages; in this context we are reviewing new modes of data capture such as wearables, diaries, mobile phones. We held two focus groups for the neuroscience sub-study, and are considering holding more to tackle the issues addressed above. We have also developed a management strategy for study members who wish to engage with the media about their experiences with the study.</p>	<p>Coordinator, Rachel Taylor, Reader & Senior Research Manager</p> <p>BRIGHTLIGHT is a National Institute for Health (NIHR) funded national evaluation of teenage and young adult (TYA) cancer services in England. Central to the study is a cohort of over 1,000 TYA patients who will be followed for three years. The study design was informed by work undertaken with young people acting as co-researchers. Young people in our Youth Advisory Panel continue to work with researchers advising on study conduct such as recruitment, retention, frequency and content of contact newsletters, and will inform seconding data analysis as well as being central to our dissemination strategy.</p> <p>Millennium Cohort Study: Participant Perspectives on Study Design in the Millennium Cohort Study</p> <p>Presenter: Lisa Calderwood, PI of Next Steps (LSYPE), Senior Survey</p>
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<p>cohort members have been contacted in up to 10 years. Both relaunches involved large programmes of communications work. This presentation will compare the success of the two relaunches, with a particular focus on the use of websites and social media.</p>	<p>longitudinal study. PSID has two major supplements: the Child Development Supplement and the Transition into Adulthood Supplement. The data are used widely in the behavioural, social, and health sciences to investigate many key scientific and policy questions. All PSID respondents receive incentive payments in recognition of the time they contribute. Additional incentives are used to encourage participation by certain hard-to-interview groups, particularly towards the end of fieldwork. This presentation provides an overview of incentives used by PSID and its supplements in recent years.</p>	<p>Longitudinal Internet Studies for the Social sciences (LISS), The Netherlands: A Happy Respondent is a Participating Respondent</p> <p>Presenter: Josette Janssen, Panel Manager, CentERdata</p> <p>Over time respondents stop participating due to personal circumstances, lack of time or interest etc. But what can survey agencies/the panel management do to prevent them from dropping out. After all, panel data become more valuable over time, so actions are necessary to keep the respondents happy and feel valued. This presentation will be about best practices in the LISS panel, conducted in the Netherlands.</p>	<p>Manager, Centre for Longitudinal Studies</p> <p>This talk presents findings from research with Millennium Cohort Study members and their parents and describes how they have been used to inform the design of the study. The research was carried out by the National Children's Bureau and Ipsos MORI for the Centre for Longitudinal Studies, and involved a survey and qualitative work with cohort members at age 12/13 and their parents. The research covered factors affecting involvement to date, the dynamics of family decision-making about participation; experiences of taking part; and views on respondent communications and preferences for future communication.</p>
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Informal round table discussion topics and facilitators: [Main Hall]

- **Engaging children and young people** – Lisa Calderwood, PI of Next Steps (LSYPE) and Senior Survey Manager, Centre for Longitudinal Studies
- **Engaging adolescents and young adults** – James Williams, Principal Investigator and Co-Director, Growing up in Ireland
- **Engaging fathers** - Adrienne Burgess, Joint Chief Executive & Head of Research, The Fatherhood Institute
- **Engaging older people** – Marcus Richards, Programme Leader, MRC Unit for Lifelong Health and Ageing at UCL
- **Engaging immigrants and people with English as a second language** – Gina Crivello, Qualitative Research Officer, Young Lives, University of Oxford
- **Engaging carers (all ages)** – Meghan Rainsberry, Communications Manager, Centre for Longitudinal Studies
- **Engaging people with learning difficulties/SEN invited** – Louise Neil, Research Officer, Centre for Research in Autism and Education