Early Life Cohort Feasibility Study

Stakeholder Engagement Event

17th June 2021

Stakeholder engagement event report

FINAL VERSION

1. Background

University College London (UCL) has been commissioned by the Economic and Social Research Council (ESRC) to undertake the Early Life Cohort Feasibility Study which will test a proof of concept of a new national birth cohort study for the UK. If successful, the feasibility study will pave the way to the first new national birth cohort study in the UK for more than 20 years.

The feasibility study will collect rich data on several thousand babies born across the UK in the year 2021, capturing the economic and social environments into which they are born, and their health, well-being and development in their first 9 months. In doing so, the study aims to paint a nationally representative picture of the circumstances of this new generation, and the multi-faceted factors shaping their lives now and into the future.

2. NCB's role in supporting the feasibility study

NCB is supporting UCL to undertake the feasibility study through a series of activities including this stakeholder event, a wider stakeholder survey, and a series of consultation sessions with children and young people, and with families.

This stakeholder engagement event was held on the 17th June 2021. A total of 69 policy and practitioner stakeholders registered for the event, with 54 attendees from 33 organisations attending from across the 4 nations. Approximately two-fifths of the organisations who had staff attending were from Scotland, Wales and Northern Ireland, whilst three-fifths were from England).

The purpose of this event was to bring professionals together to share more information about the Early Life Cohort Feasibility Study and consult them on a range of issues relating to the study's design, implementation and use.

3. Overview and aims of the session

The overall aims of session were:

- To raise awareness of the study.
- To generate interest and buy-in to the study.
- To ensure that the study is informed by the evidence needs of stakeholders.

To meet these aims the session provided an opportunity for UCL to share information on the Early Life Cohort Feasibility study with attendees including its aims, research themes, study design and methods. This was followed by a breakout session to provide an opportunity for attendees to share their views in relation to the following areas:

- The key groups the study should gather data on and the best ways of engaging these groups;
- Their organisation's evidence and policy needs that the feasibility study and the larger one could support; and

- The key content areas the study should explore.

4. Overview of the Early Life Cohort Feasibility Study

Professor Pasco Fearon, Chair in Developmental Psychopathology and Professor Alissa Goodman, Director at the Centre for Longitudinal Studies, both at UCL provided an overview of the Early Life Cohort Feasibility Study.

Since the Millennium Cohort Study (MCS)[1], children, young people and families have experienced dramatic social change in their lives alongside widening inequalities and rapid technological change. In addition, a picture of what the post-pandemic era will look like is becoming clearer in terms of its likely impacts on families and children. Therefore, the timing of this UK study charting the lives of children across the country provides a valuable opportunity to examine the influences and changes impacting children as they grow up in this very different era of British society.

This event provides an important opportunity for policy and practitioner stakeholders to be able to influence the design of the feasibility study and the wider study as the project evolves.

An initial feasibility study has been commissioned to test practical elements of undertaking a wider study and also to make sure the study engages key stakeholders, is supported by them and responds to their evidence and data needs.

UCL has brought together a diverse UK-wide research team and project partners to undertake the feasibility study. In addition to NCB, project partners include: Parent Infant Foundation (PIF), Anna Freud National Centre for Children and Families, ScotCen, Queen's University Belfast, Public Health Scotland and Swansea University.

Core Aims of the Feasibility Study

- To recruit a UK-wide representative sample of babies including families typically under-represented.
- To ensure the voices of people that are not often heard are captured within the study.
- To test the feasibility sampling approach, recruitment, methods of data collection.

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[1] The Millennium Cohort Study (MCS) followed the lives of around 19,000 young people born across England, Scotland, Wales and Northern Ireland in 2000-02. The study began with an original sample of 18,818 cohort members and is due to end in 2022/23 when the final sweep of data collection takes place.

- To test innovative methods of data collection (smart phones) and how administrative data records (e.g. DoE records, NHS records etc.) can be linked in.
- To engage extensively to ensure the main study is informed by the view and feedback of children, young people and families, policy and practitioner stakeholders and academia. Thematic advisory groups will be established to enable stakeholders to feed into the study as it progresses.

Prior to the breakout room discussions, attendees were provided with an opportunity to ask questions of the UCL study team. The questions, and responses from UCL, are summarised below.

Stakeholder questions to the study team and response

Question 1: It is challenging to get high quality data that is consistent across the four-nations of the UK. What approach will the study team adopt to capture outcome data in a consistent way? Is there a need for a common outcomes framework?

Response from UCL: Central to the study will be the use of standardised / core outcomes measurements that are commonly used across the UK and are normed (e.g. for child development). There are likely to be specific data needs for each nation that will also need to be accommodated and that we would be keen to involve local stakeholders in the four nations in discussions about what those priorities might be.

Question 2: A key consideration is how we can use data to develop policy actions / interventions to mitigate the impact of structural and social inequalities that lead to poorer outcomes for women/babies in the long-term. How can this study help to ensure specific groups are boosted to have sufficient sample sizes?

Response from UCL: It is clear this study has to speak to that issue. Addressing the contexts and needs of sub-groups within the study has important design implications for the study and there is also a limit to how many sample boosts we can have. So prioritisation of key sample boosts is a key part of our consultation work, and part of today's discussion. Another important consideration is that there is a trade-off between sample size and richness of the measures and information we can collect, which requires careful discussion to identify the optimal balance. Larger sample sizes allow us to understand more about subgroups, but most likely with limited depth in terms of what is measured. We know that intersectional questions, for example in relation to ethnicity and poverty, are very important and addressing them may require very large samples and potentially sample boosts. We also know there are other key groups of interest, such as infants born extremely prematurely. Therefore, there are challenging constraints and trade-offs to be made, both in terms of the number of subgroups that can be boosted, and the richness with which they can be studied. We want to hear where there are strong policy and practice considerations for boosting samples within particular groups, so that we can bring those suggestions to the funder.

Attendees were then allocated to one of four breakout groups to capture their views on the following areas:

a. The key groups the study should gather data on;
b. The best ways of engaging these groups;
c. The evidence and policy needs that this study and the larger one could support; and
d. The key content areas the study should explore.

The responses from the breakout rooms are summarised under each of these headings and this is followed by some additional observations and comments made by attendees.

a. Who are the key groups the study should gather data on?

The survey will gather information from a representative sample of babies /families across the UK. The study is keen to ensure that certain groups (including those that are hard to reach) are included within the study and their numbers boosted to enable robust analysis to be undertaken.

Attendees at the event suggested that the sample should be boosted for the groups outlined in Table 1 below. It is important to note that the study team may already have planned for boosting some of these groups. Indeed, some of the groups identified by UCL as key were supported by many of the attendees – in particular: young parents (FNP in Scotland was noted), fathers and low-income families.

Table 1: Key groups that the study should gather data on

- Children with SEND/disabilities;
- Minority ethnic groups, e.g. members of Traveller community, gypsy and Roma children;
- Victims of trafficking;
- Low income groups (i.e. 20% most deprived in terms of income);
- Parents/families of premature babies;
- Single parent households;
- Young mothers[2] (in particular teenage mothers / first-time mothers);
- Families in which there is parental involvement in the criminal justice system / pregnant women who are in prison.
- Households where one parent is victim of domestic violence/abuse.
- Recent immigrants / asylum seekers;
- Families where one/both parents speak English as an Additional Language (EAL).
- Mothers with specific perinatal mental health problems.
- Adoptees / Looked After Children (LAC) / Parents who themselves have experience of being in the social care system

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[2] Suggested topics that could be explored include: how their experience of pregnancy & services differs from older parents in terms of their attitudes to the service(s) and whether they believe that the services are patronising. Other areas that could be explored are the perceived benefits of specialist services targeted at supporting new mums, e.g. Family Nurse Partnership.

- The entire family unit- parents, siblings, aunts, uncles, grandparents – recognising the role they all play and capturing their voice
- Carers, childminders, service providers.
- People with no recourse to public funds*

* The impact on families is significant and not only asylum seekers and refugees, but all those with insecure immigration status were highlighted.

b. How can we best engage these groups?

A number of approaches to engaging these groups were put forward by attendees. These have been grouped by thematic area and are illustrated in Table 2 below.

Table 2: Approaches to engaging groups

Engagement themes	Suggested approach
Information/ communication and informed consent	• Clear information to support informed consent. This could include information provided in video format and in alternative languages. • Ensuring that there is a 'continuum of information' to ensure that participants are fully informed about their input and the study. This may include arrangements for sharing key findings and interim reports.
Relationships and trust – importance of working with gatekeepers	• Issue of building trust is crucial in reaching and engaging with certain communities. Attendees highlighted the fact that there is a lack of trust in some communities. Relationships are critical – making an effort to develop relationships to build trust, or working with those who already have trusted relationships. • Using the experiences of participants from previous studies to pass on to potential participants could be a good way to increase levels of trust. • Volunteer-led support can be important in building relationships. • A range of gatekeepers were mentioned including the full range of professionals who support mums pre-birth onwards who will be able to 'drum up' engagement is critical. This included: - Neo-natal health professionals. - Nurseries / professionals working in early years settings. - Working with and through family support hubs and agencies closest to families. - Working with peer supporters/parental champions.

Engagement themes	Suggested approach
	- FNP team for teenage parents. - VCS organisations, including grassroots organisations. • For families where 1 parent/carer is in the criminal justice system, working with community support workers in prison settings was considered to be important.
Incentives	• Offering incentives will be key - although some participants also question whether this could potentially lead to the data being skewed.
Comms strategy and branding	• Communications strategy will be important – a four-nations study needs to have a “local twist”. • Think carefully about the survey branding so it appeals to and reaches the groups that are being targeted. • A sophisticated social media strategy would be needed.
Administration of the survey	Offering flexibility to suit people’s needs should help to engage more people. Therefore, a mix of approaches to administering the survey needed: • Online/virtual meetings can sometimes be less intrusive and more inclusive for some families. • In-home, out of hours visits could support engagement. • It is very important that those involved in outreach or the study itself reflect the groups the study is trying to reach.

c) What are the evidence and policy needs that this study and the larger study could support?

A wide range of evidence and policy needs were put forward by attendees and can be grouped into the following broad areas:

- *Children’s rights and voice*: There is a general challenge of ensuring the ‘infant voice’ is heard – this study could support and push the boundaries by being more experimental in its approach. Capturing the views and experiences of babies and young children and measuring parent-infant relationships is important. There are a range of creative ways to do this, e.g. through play therapy techniques.

- *Environment & society:* attendees raised the followed needs:
    - Understanding how children’s language develops and how development differs according to genetic influences and environmental influences.
    - differences (if any) between parents living in urban vs. rural areas.
    - the extent of social capital that individuals have (i.e. social support networks within the family and wider community) and its impact on parents’ level of engagement in their community.

- *Technology:*
  - Technology in early years – the benefits & challenges e.g. how screen time might potentially impact face-to-face engagement with baby vs social support and information available for new mums via the online world.
  - How parents engage with technology and various apps was also identified as a need, looking at the stresses that these place on parents as well as how supportive they are. In addition, where parents access information and the level of trust they place in particular information sources was also identified.

- *Parents/Carers support delivery mechanism preferences:* A range of evidence and policy needs were identified in relation to parents/carers, including their preferences for face-to-face sessions vs. online/remote support and whether trusting/productive relationships are inhibited by online support (particularly important in light of the pandemic). In addition, a number of attendees would like to know how child outcomes vary in relation to parent's experiences of service(s).

- *Service provision / uptake / impact:* The groups noted a wide range of information needs in relation to service provision, uptake and impact including:
  - Parental knowledge of services available to them.
  - The range of services/interventions that parents access for themselves and their child. This would need to include the variety of service types (early mental health services / peri-natal / children's centres etc.) and cover universal and more specialist provision. Any geographical /socio-economic differences/inequalities in access would need to be explored.
  - Parents' experience of services (from referral through to completing them)
  - The barriers, if any, to accessing these services
  - What impact service provision has had on parental/child outcomes.

- *Social disadvantage / inequalities*
  - Extent of unmet need in general;
  - The impact of child poverty, in particular social security, child welfare benefit receipt and comparison across the 4 nations.

- The impact of multiple adversities (e.g. parental illness/disability, parental substance abuse, and parental mental illness).

- *Measuring outcomes:* attendees reported that this study could provide important outcomes data in relation to:
  - Early social & emotional development (for example, via the administration of the ASQ, Eyberg instrument).
  - Resilience, bonding & attachment.

d) What are the key content areas the study should explore?

A wide range of potential content areas were put forward by participants. These are set out in Table 3 below.

Table 3: Key content areas for exploration

Areas	Content recommended for exploration
Parental income and employment	Employment status of both parents with a particular focus on whether either/both are - working (full or part time). - Have a contract of employment with a range of employment rights or zero hours contracts (Note: focus could be on examining levels of employment security).
Parenting / bonding & attachment	- Early parent-child interactions – in particular, language input children are receiving & parent language (e.g., via family history) and wearable devices could also capture important aspects of this. Participants noted possible risk that wearables could influence parent-child interaction. - Extent and quality of parent/ child attachment and parental bonding. - Parenting styles /capacity and experiences. - Parental attitudes, perceptions and understanding of early years & attachment
Parenting contextual factors	- Level of parental literacy. - Parental relationships, domestic violence and the impact of domestic violence on the child. - Homelessness / parents in temporary accommodation. - Parents in prison, or prison-experienced.
*Services**	- Range/types of information parents receive and which do they actually find useful. - Advice and support available and taken up prenatally (e.g. on attachment). - Parents' experience of the various types of support (e.g. health visitor, BabyBuddy, GP, peer support, extended family) and the perceived benefit of these interventions for families and parents. - Extent of child care available and accessed and whether parents find the quality acceptable.

Areas	Content recommended for exploration
	- Extent of variation, if any, that exists in the quality of access / timeliness of access to services (e.g. dental services) across areas. - Extent of support provided by wider family support networks.
Parental health and environmental context	- Extent of breastfeeding. - Impact of Covid-19 (as a discrete topic within the survey – and focus should be on well-being aspects). - Environmental factors- e.g. access to outdoor space and time spent outdoors with an analysis by socio-economic background - The home learning environment and what parents know about how to create a positive learning environment - SEND & disability and their impact on child & parents alongside any support needed/received. - Social capital including networks around parents and the impact of these networks. - An examination of environment, genomics and stress (acknowledging that this would ideally include a pregnancy sample). The group noted a pregnancy sub-study would be valuable. Also suggested using antenatal book-in records could be considered for sampling purposes (there is a 98% uptake of 20-week scan appointments)). - The early identification of neurological issues and early measurement and identification of speech and language issues. - The impact of screen time on mental health, sleep etc.

***** Children's rights context was mentioned in relation to service provision and uptake more generally.

Further comments

In addition to the four key areas of discussion, attendees also raised the following points:

- *Sampling approach:*
    - The group noted that the sampling approach might be difficult, as birth record samples might be difficult to obtain for some key disadvantaged or minority groups, but there could be linkage going backwards into maternity records.

    - Constraint of 4 months + was of concern to many participants who felt that 0-3 months is a critical stage of development. Attendees asked whether this could be reconsidered via pre-natal consent otherwise the study would exclude neonatal experiences and in utero experiences of parent-child interaction and whether or not support is available or empowering.

- *Sample sizes:* Sample sizes in devolved regions should be addressed through careful consideration of intersectionalities (i.e. how various characteristics overlap in terms of compounding disadvantage).

- *Composition of the expert panel:* The expert panel, researcher & stakeholder groups should be as diverse as possible to ensure adequate representation

5. Next Steps

The event concluded with both NCB and UCL outlining their next steps in terms of future stakeholder engagement activity as outlined below.

NCB activities

NCB will be utilising the findings from the stakeholder event to develop a wider stakeholder survey to test the points raised with a broader policy and practitioner audience. This survey will be administered via NCB's networks in August 2021 with early findings available in September 2021.

NCB will also engage our Young Research Advisor (YRA) group and Family Research Advisory Group (FRAG) to inform and guide the feasibility study at important time points (e.g. design, analysis & reporting phases).

UCL activities

The event was used to gauge interest in the establishment of a policy and practice advisory group for each of the four nations and further wider engagement events over the coming months. A total of 12 individuals (from 11 organisations) expressed an interest in joining this group and these have been shared with UCL.

Separately, UCL will be combining the learning form this stakeholder engagement event with the learning from the Academic and Data Usage session and reporting back to the ESRC with the key messages from both events.

The findings from the engagement events will be published on the Centre Longitudinal Study (CLS) website. In addition, there are plans to create a newsletter to keep stakeholders informed about how things are progressing and provide additional channels for stakeholders to help out and support the research.

At the close of the event, attendees were invited to complete an online evaluation form for the event to provide feedback on the extent to which the session aims were achieved. A total of 94% or more of those who completed the evaluation agreed/strongly agreed that the session aims were achieved and 100% of respondents stated that the content and timing of the workshop and facilitation of the breakout rooms was good/very good. A copy of the evaluation findings is contained in Appendix 3.

Appendix 1: Stakeholder Engagement Event Agenda

2.00pm Introductions and aims of the session (NCB & UCL)

2.05pm Overview of the study and stakeholder engagement including Q & A (UCL)

2.35pm Key areas for discussion - breakout groups (NCB facilitated)

- Who are the key groups the study should gather data on and why?
- What are the best ways of engaging these groups?
- What are your evidence and policy needs that this study and the larger one could support?
- What are your views on the key content areas the study will explore?

3.35pm Break

3.45pm Feedback and Discussion (NCB & UCL)

4.15pm Next Steps (NCB & UCL)

4.30pm Close and evaluation

Appendix 2: Organisations represented at the event

Organisations represented
A Better Start Southend
Aberlour
Action for Children
Anna Freud Centre
Best Beginnings
British Psychological Society
Cattanach
Centre for Early Child Development
Children in Scotland
Children in Wales
Dept of Education
DHSC
Early Years Scotland
Early Years Wales
Home-start UK
London Early Years Foundation
Nasen
National Day Nurseries Association
National Children's Bureau
Nesta
NHS England & Improvement
NSPCC
NSPCC Scotland
Royal College of Paediatrics and Child Health
The Royal College Of Speech & Language Therapists
Save the Children Scotland
Scope
ScotCen Social Research
Scottish Childminding Association
Scottish Government
Swansea University
The Children's Society
The Sutton Trust
University College London (UCL)
Western Health and Social Care Trust

Appendix 3: Feedback from attendees

Feedback was collected through a survey completed at the end of the event. The following presents a summary of the findings.

1. To what extent do you agree with the following statements?

	Disagree	Neither Disagree or Agree	Agree
I felt the event helped me to understand the purpose, design and content of the Early Life Cohort Feasibility study.	0%	0%	100%
The event provided me with adequate opportunity to feed in our organisation's evidence and/or policy needs in relation to this study.	0%	6%	94%
The event provided me with adequate opportunity to contribute my organisation's views on the purpose, design and content of the feasibility study.	0%	6%	94%
As a result of the event I would be keen to understand more about the feasibility study and how I/my organisation could further support it.	0%	0%	94%

2. How would you rate each of the following aspects of the workshop?

	Poor/ Satisfactory	Good	Very Good
The content of the workshop.	0%	25%	75%
The timings/pace of the workshop.	0%	41%	59%
The facilitation of the breakout rooms.	0%	25%	75%

3. Is there anything else you that you would like to add in addition to what was discussed at the event today?

- To reiterate our areas of interest which are healthcare services: Health inequalities that occur at the point of patient contact with healthcare services/settings, e.g.

variation in quality and safety of clinical care by ethnic background. In addition, the study might wish to examine barriers to timely access to early years preventative health services, such as dental care and other areas including Infant feeding and approaches that impact breastfeeding rates in initiation and continuation amongst young mothers and disadvantaged socio-economic groups.

- As usual more time but a lot was covered, great to hear perspectives of others and some shared resources too.
- I have to agree with all or most of what was discussed.
- Thank you for providing so many organisations with an opportunity to input their policy needs!
- It would have been really useful to understand how this differs from the DfE commissioned Children of the 2020s study (and I believe CLS is involved). I understand the geographic scope is different, but an explanation of how the two studies differ, and their unique value, would have been very useful.
- I would emphasise the value of pre-birth data if it was possible to go that far, as discussed by some participants. It would be a pleasure to be involved in the advisory board from a Scottish perspective.
- Clarity over the key research question.