Early Life Cohort Feasibility Study

Report from a consultation of Data Users held on 10th June 2021

Paper circulated to Early Life Cohort Study Advisory Board for its meeting on 19th July 2021

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1. Introduction

The Early Life Cohort Feasibility Study (ELC-FS) has been commissioned by ESRC to test the feasibility of a new birth cohort study for the UK. The feasibility study will provide vital information to support the design and planning of a future large scale Early Life Cohort, which will paint a nationally representative picture of the circumstances and lives of a new cohort of babies born at a critical time in the UK's history.

This consultation, held on 10th June 2021 had more than 200 registrants, with 172 attending on the day, via MS Teams. (A list of participating organisations and analysis of attendees by academic discipline and geographic region is provided in Annex 2). The purpose of the consultation was for potential data users, from the academic, government and third-sector communities to contribute their views on the feasibility study's scientific purpose, content and design.

The purposes of our consultation work in general, and this consultation event, are set out below.

Our consultation work, general goals:

1. To design the study for maximal public benefit
2. To ensure the design and content of the study meets stakeholder needs
3. To raise awareness across the UK about the study
4. To promote a sense of ownership of the study among different stakeholder communities

This user consultation, specific goals:

1. To ensure that the design and content of the ELC main study meets the needs of data users from academia, government and third sector (defined as people who will use the data or commission research using it)
2. To ensure the study benefits from the best ideas and cutting-edge science
3. To foster collaborations that will benefit the study in the future
4. To help the project to identify key users who could help support the project in an ongoing way, e.g. as part of advisory sub-groups
5. To ensure the feasibility study addresses the most important feasibility questions and unknowns, so that plans for the main study are as robust as possible.

Consultation structure

The agenda for the day is provided in Annex 1. Following an introduction to the study and consultation aims by the study leads, the morning's discussion took place in a total of 26 break out rooms (running both in parallel and in back-to back sessions) according to the following **scientific themes**.

A. Cognitive, social, and emotional development of infants
B. Infant-parent relationships, and the early home environment
C. Infant health, including growth, nutrition and sleep
D. Mental health of parents and the developing child

E. Social, environmental and neighbourhood influences on infant and family
F. Inequality, disadvantage, and social mobility in the new cohort
G. Genomics, early adversity and biological embedding of stress

The main questions the working groups were asked to discuss were:

1. *What are the key scientific questions* within your theme that the future ELC main study should address?
2. *What design features should the study therefore have (e.g.,* informants, age at first visit, mode, sampling strategy, etc?)
3. *Which measures should be used?*
4. *What key unknowns and feasibility questions should the feasibility study address?*
5. What are the group's *top three priority recommendations* regarding the design and content of the feasibility study?

In the afternoon, the consultation covered **how to create an inclusive cohort**, and **study design.** The discussion about how to create an inclusive cohort was again split into parallel break-out rooms (9 in total) discussing engagement of the following population groups:

A. Ethnic diversity and immigrant families
B. Fathers and partners
C. Vulnerable children
D. Diverse families
E. Pre-term, and sick neo-nates

The questions covered within these working groups were:

1. Who do we consider are the priority groups within this theme?
2. What are the most important scientific questions for the main ELC Study relating to these priority groups within this theme?
3. How should we meaningfully engage (raise awareness, consult, recruit, retain) different communities?
4. What key unknowns and feasibility questions are there relating to the recruitment and engagement of these groups? And what methodologies might be most useful in the feasibility study to address them (quantitative? qualitative?).
5. What are the group's *top three priority recommendations* for the feasibility study in relation to these groups?

Structure of this document

The discussions that took place within each of the 35 break-out rooms/ working groups outlined above were very wide-ranging, and given the inter-connectedness of all the themes, the suggestions made were highly overlapping across the different groups. Instead of summarising the discussions theme by theme, or room by room, we have therefore structured this report as follows: key scientific questions raised (Section 2), suggestions

relating to populations to include, and sampling (Section 3), suggestions relating to survey design, and feasibility questions to be addressed (Section 4), topic themes and content (Section 5), biomarkers (Section 6), novel measures (Section 7) and record linkages (Section 8).

2. Consultation messages: scientific questions

- **Capturing the dynamics of childhood poverty, deprivation and adversity**
    - Prior work has primarily focused on risk factors for later life outcomes and insufficient focus has been paid to factors that protect against these (resilience factors e.g. social networks and early intervention programmes and services)
    - What types of adversity matter most for later life outcomes?
    - Which types of adversity do children in the UK experience in particular (e.g. lack of green space, neglect)?
    - What is father's role in modern context in offsetting adversity?
    - To what extent can the effects of early life adversity be reversed and what are the critical time periods for this?
    - Why are some deprivation factors more predictive of later life outcomes than others?

- **How do parents make decisions about work and family life?**
    - What barriers are there to taking parental leave and how much is used by parents? How do couples negotiate who takes leave?
    - How do parents manage relationship dissolutions and conflict? How does this affect their ability to work and care for their children?
    - How does work flexibility and precariousness of employment affect parental decision making about maternity leave and return to work?

- **Capturing a complete picture of parenting across the full diversity of current day families**
    - Role of screens in parenting and technoference
    - How do parents play with their children?
    - What happens physiologically during parent-child interactions?
    - What do parents find enjoyable and difficult about being a parent?
    - Who supports parents with childrearing and who are key figures raising today's children? There was particular interest in the consultation on the role of grandparents.
    - What do new parents think should be affordable for them?
    - How do intergenerational processes (e.g. in social mobility, parenting styles, ethnicity, resource availability, support) affect how parents make parenting decisions?)
    - Disentangling the role of biological and social influences on parents in the child's development, and what kind of relationship the two have with one another.
    - What kind of medication parents give to their children and what are the consequences
    - How does the co-parenting relationship and parental relationship itself influence child development

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- **Enhanced understanding of the early markers for neurological and biological development issues**
    - How does the home and area level environment influence child developmental outcomes?

- What is the effect of being born preterm on cognitive and educational outcomes?
- How do early pain experiences affect the management of pain in later life?
- How do early changes in infant body size reflect changes in underlying body composition?
- What are the long-term consequences of infant regulatory problems, such as infant crying, sleeping or feeding problems, lead to long term dysregulation?
- What role does breastfeeding play in the intergenerational transmission of disease and obesity risk?
- What family and household processes contribute to developmental problems (e.g. household chaos, enrichment environment, parent-infant interactions)?
- What stressful conditions and events result in the biological embedding of stress?
- How does the type of birth (e.g. by caesarean) influence the baby's development?

- **Better establishing genetic influences on child development and outcomes**
  - How can we use genetics to best predict child outcomes?
  - How can genetics best be used to improve child outcomes via modifying their environment?
  - What is the relative contribution of direct genetic effects on the child and indirect genetic effects such as those that act through the parents' nurture of the child?
  - What can genetics tell us about direction of causation between traits, or between the family environment and child outcomes?

- **A more complete understanding of the interrelationship between parental health and child health**
  - How do previous experiences with miscarriages and assisted reproductive technologies affect parents' mental health? Does conception by ART methods affect child outcomes?
  - How do parents' and infants' sleep patterns influence probability of psychosis and mental health disorders?
  - Why is there a link between parental mental health and children's emotional and behavioural outcomes?
  - How does in utero SSRI exposure influence developmental outcomes?
  - What is the emotional impact for parents of having a preterm baby, or a baby with health needs?
  - What internal (e.g. emotional regulation, cognition, behaviour, attachment style) and external (trauma, violence, conflict, neighbourhood environment, support and loneliness) factors influence parental mental health and wellbeing?
  - What informal and formal support and treatment do parents seek for their mental health and well-being?

- **To what extent do parents have knowledge and access to a variety of support services, and how are these services used?**
  - Do racialised identities/'diverse family' identities play a role in difficulties accessing services?

- Where do parents get knowledge and advice from about caring for children? For example, about complementary feeding. To what extent does advice given align with what parents do?
- How do national, regional and local policies influence child outcomes?
- To what extent do people have access to and use green space?

3. Sampling suggestions

Who should the sample include?

- **Parents with disabilities**
- Those in **temporary housing/homeless**
- Children of **prisoners and ex-offenders** (noted that the parents may be too difficult to sample but still find their children)
- Include **parents with drug problems**
- Include **same-sex parents**
- Sub sample of **parents with disabled children/congenital abnormalities**,
- **Re-partnered parents**
- **IVF and surrogate families**
- **Adoptive & foster families** (and plan how to track these children)
- **Children under special guardianship**
- **Roma/Traveller** boost sample (but noted that these may not identifiable via sample frame and less likely to register births)
- **Immigrants from Europe and worldwide**
- **Refugees/asylum seekers/those who have been trafficked** (particularly immigrants from Asia and Africa who are more susceptible to Vitamin D deficiency, and Eastern Europeans) Question raised of how to capture asylum seekers/undocumented migrants who will not be on the sampling frame
- There will be children who are not living with their birth mothers by the time the sample is drawn, either because they have been **taken into care, were born to a surrogate, are living with a relative** etc. How do you 'recruit' these children not living with birth mothers into the study? What are the implications for consent? Are there ethical implications of contacting birth mothers who no longer have the child in their care? In terms of children in care, council records will be needed but the information kept varies between councils. Health Visitor Records could be used but these are likely to be handwritten.
- How to capture **births that are had and registered abroad** (see below, on refreshment samples)
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Boosts

- Oversample or boost for **low-income/disadvantaged** areas, (which also include greater numbers of lone mothers, young parents)
- **Ethnic minorities** boost. Important for the genetics bio-samples study. Suggestion in that sample must distinguish between Bangladeshi, Indian and Pakistani, and between Black African and Caribbean. Suggest qualitative work with these groups first to find meaningful ethnicity categories to encourage participation and prevent top-down assumptions about which groups are important to sample.
- Oversampling **multiple births**
- Oversampling **very preterm births,** as enough preterm babies in general population (8%) to not need an oversample

Other sample design related issues raised

- '*A potential powerful design would be 1) to recruit births over a whole calendar year (e.g., to incorporate seasonal difference which are important – for example for schooling), 2) to have a cohort-sequential design (e.g., births in 2023, 2024, 2025, 2026, etc) to be able to separate age/period/cohort effects and examine effects of policy changes (e.g., regression discontinuity type work), and 3) to move away from "sweeps" to more unbalanced [longitudinal] data that varies by chronological age. These changes may massively increase the power of a new UK cohort*.'
- Advice to build **sample refreshment** into the study. There might be changes to migration patterns to the UK so it's important to keep the study representative. This might also differ in each of the four nations, so a different approach may need to be taken in each nation.
- Sample design should be **stratified by sex, ethnicity and SES status**.
- To ensure sufficient sample size for Wales, Scotland and Northern Ireland (particularly Wales came up a lot as a region that will suffer if there is an over-focus on ethnic minorities which will predominantly come from England and urban Scotland)

4. Survey design suggestions

Sample sizes

- Appetite from some consultees for **larger sample sizes** allowing breakdown of analysis by subgroups of interest (e.g. by ethnicity, region) at expense of greater detail. Also request for large sample size for genetic data collection.
- By contrast, in the general feedback session, several people commented that they would prefer **detailed information on a smaller sample** than less information on a larger sample.

Mode

- Offer as much **flexibility** to respondents as possible to encourage participation. This may include flexibility in **mode and accessibility** (e.g. audio box).
- Online surveys may offer more flexibility and a feeling of more confidentiality if interviewing both parents in the same household. But may lose information (e.g. child safeguarding).
- Need to plan covid safety into interview plans if doing F2F and think about how things like masks might affect interviewer-respondent interactions
- In the general feedback session, face-to-face or face-to-face over video was the preferred mode
- Many studies of time poor families in the US during COVID used text-message questions on mobile phones and found this very effective because they could be put down and returned to

Incentives and engagement

- Both vulnerable children sessions strongly recommend **incentivising vulnerable groups**, but care needed that they don't know that they are being marked out as 'vulnerable' by nature of the increased incentive.
- Importance of **Different engagement strategies** for different hard to reach groups
    - Suggestion to choose top three priority groups and then do engagement strategy well for them**.**
    - Use **expertise of groups** who work with them (charities, political groups, religious groups)
        - Barnardos, Institute of Health Visitors and NSPCC suggested in vulnerable children session
        - Fathers session mentioned North East fathers group
        - Medical Research, Tiny lives and Bliss for preterm births
        - Rob Aldridge could be good source of advice on engaging hard-to-reach populations after Virus Watch project
        - Born in Bradford was very successful in recruiting and retaining ethnic minorities and may be good source of advice. They used community workers to engage with Roma/Traveller communities.
- Build trust – make clear that participation **won't affect their use of public services**
- **Community hubs** could work well to promote the study and engagement, and budget for using voluntary and community service workers to help. Could also advertise and use online communities.

- Undertake **Qualitative work** with groups first to explore barriers/facilitators, what outcomes matter to them and acceptability of new measures/tools/data linkages (particularly ethnic minorities)
- Make sure there is feedback to families **to make experience enjoyable** (e.g. summaries through app that give insights into their children, LIFE study found this to be one of the most interesting parts to parents) and cover issues important to them in survey to promote engagement
- **Parents with mental health difficulties** are going to be more likely to not engage and/or drop out of the study. Extra support will be needed for this group to ensure this doesn't happen as well as ethical protocols about how to support these parents.
- **Difficult to interview parents with very sick children** (e.g. heart problems) or very preterm as will be spending a lot of time in hospital. May need to engage them through healthcare provider and measures need to be appropriate for them (or different measures given compared to rest of sample).
- Important to have training and **guidelines for researchers on how to use this data properly and respectfully**. In turn, this can be fed back to respondents to reassure them that their data are being used properly and they are not being misrepresented.
- Explore what would incentivise **hard-to-reach groups to stay** in the study: need to emphasise value of representative cohort for implementing policy change (with the caveat this may not be a positive for all groups, and will need to work out how to engage with these groups who have been let down previously/see authorities as a threat, and to not mark groups out as 'groups of interest' when they wouldn't see themselves as such)
- Perform a **review of reviews about how to engage with these different groups** and whether measures are likely to perform in the same way between groups (psychometric equivalence and validation).
- May be worth **exploring hiring local interviewers** to reach specific populations (e.g. interviewers of same ethnicity/religion)
- **Include support and guidance for struggling families** into interview strategy
- Need to **translate** participant facing documents/interview into different language
- Materials must be **accessible to parents with poor literacy**
- **National media campaign** and **tailored local campaigns** (potentially through baby box scheme)

Who to interview

- Gathering data from **both birth parents whether co-resident or not and other caregiver figures** (grandparents, stepfathers, siblings). Stepfathers/mothers boyfriend/social parents/key caregivers should be interviewed or have information collected about them. The feasibility study should welcome 'messy data' to work out how to proceed with diverse families in the main study.
- The questionnaire **should not assume that the 'main caregiver' is the mother** and approach as parents/carers who share caring responsibilities equally, particularly given the likely 9 month sampling frames where men typically start doing more care as the mother returns to work
- Recommendation to **ask same questionnaire to mother and father**
- Suggestion **to interview both parents one at a time and not side by side** so that the other can play with child/do something else.
- Decision needed about what to do in situations of **reported domestic abuse**
- If the child is living in more than one household, information on **each of the environments** in those households should be collected

Age at First Interview

Ensure all babies are measured at the same post-conception age rather than post-birth age (relates to pre-term babies in particular).

	Reasons for	**Reasons against**
Pregnancy cohort	Accurate reporting of pregnancy and birth related variables Prenatal diagnosis of conditions means you can follow the journey from identification of a problem to birth and thereafter. There are also differences in care for those prenatally diagnosed with something like a severe heart problem in terms of surgery and medication etc –	These variables can be gathered through maternity record linkage
At birth	Easiest to recruit participants at this stage	Will not be able to identify surrogate births and adoptive parents who are registered later
4 months	Typical first assessment in socio-emotional literature. Visual attention assessment usually done at this age	Feeding and sleeping assessments of behaviour/ development possible at this age
6 months	Infant cognitive literature often includes assessments at 6 and 12 months Some motor behaviours possible to study that couldn't be studied earlier Executive functions best studied at 6 months A priority of the feasibility study is to test new measures/instruments/tools which are more feasible to use from this age onwards	
9-10 months	Alignment with MCS Socio-emotional literature often includes assessment at 4, 9 and 15 months Much broader range of early socio-cognitive skills at this age (joint attention,	Preferential looking easier to assess at younger ages when infants less mobile Return to work may mean it is less easy to schedule interviews at this age

	imitation, gaze following independent play)	Recall about the birth less likely and more difficult to find the father

Sub-study suggestions

- Some interest in **recall-by-genotype sub-studies at a later stage**, e.g. to recall people with high versus low polygenic risk scores for a particular trait for bespoke phenotyping, or to invite them to participate in other studies. Should this be consented at main stage? Would it put people off recruitment and what communications would be needed?
- Interest in the mental health session to have a sub-study of participants in the main stage for **more in-depth analysis of mental health disorders**.
- Sub-study of vulnerable children (children with parents with mental health difficulties, with a social worker, with special educational needs) with more intensive follow up.

Feasibility questions that need to be addressed:

- *Explore what would incentivise hard-to-reach groups to stay in the study*
- *Innovation in data collection methods and assessing their reliability*
- *Assessing **measurement reliability of technological devices** (e.g. body cams, accelerometers) and measurements which are/could be collected by parents outside of interview (e.g. LENA and child's sleep patterns)*
- *Establishing costs of new tools (particularly bio collection & genetics) and the quality of the samples*
- *Feasibility study should be used to **explore concerns** respondents have about genetic/bio data collection so that communications about this can be tailored in the main stage survey (lots of good suggestions about how to do this in session notes).*
- *How to engage with hard to reach groups (e.g. how to incentivise and tailor engagement protocols)*
- *Collecting relevant consents for novel data collection*
- *What is reasonable information to collect from key care providers who aren't the biological parents (e.g. extended family, support networks and institutions), and whether and how to include these carers*
- *Establishing what can be collected via record linkage and therefore what must be collected in the survey*
- *The feasibility of including different data linkages*
- *How do we identify and measure support, social cohesion, trust and social capital*
- *What is the best mode of data collection given the COVID-19 pandemic?*
- *Feasibility of oversampling ethnic minorities and low income families*
- *How could the study be used to test natural interventions/experiments and the efficacy of changes in policies and practice (e.g., nation differences)*
- *How to adequately capture the diverse network of care for children*
- *How does the study perform in the different devolved nations?*
- *How will the primary caregiver be identified?*
- *Who will be missed from the birth registers sampling frame?*
- *How to conceptualise ethnicity in a way meaningful to the participants?*
- *How to engage and recruit own-household-fathers*
- *What issues are important to the families in the surveys and what would be meaningful outcomes to them?*
- *During feasibility study, assess qualitatively the best way to ask sensitive but important questions (e.g., gender of birthing parent, trauma histories, etc. NSPCC*

study of maltreatment was considered a possible gold standard model in this respect).

- *The feasibility of getting a rich assessment of psychopathology/trauma/conflict and treatment history*
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Other

- Advice to diversify project governance for ELC-FS and ESRC commissioning panel, including early career researchers.
- Recommendation to harmonise questionnaire with other international cohorts

5. Topic themes and specific measures

Topic area	Suggestions made in:	Suggested topics:	Specific measures/indexes	Innovative data collection suggestions
Measures of **income, deprivation and social mobility** both before and after birth.	Inequality session	- Income before and after birth - Attitudes towards financial position. - Question on points since birth of zero income and risk of eviction. - Intergenerational management of resources within families - Precarious employment (e.g. zero hours contracts) - Retrospective employment histories. - Whether falls below income poverty threshold of 60% median. - Question on debt and wealth - Informal money flows - Social mobility (grandparents' occupation and education compared to the parents') - Receipt of benefits - Value of house / cost of rent - Individual and area measure of deprivation as can be wealthy individual moving into a cheap area	- Suggestion of simple 'how well are you doing question' (as in COTs and MCS) and comparison to one year ago. - To measure social mobility ask about grandparents' occupation when parents were 14 (Goldthorpe's class schema) - An internationally comparative measure of income, material deprivation and financial strain to that in Family Resources Survey/HBAI - Townsend Index of Deprivation recommended for cross-cohort comparability	- Data linkage for income (but poor information for self employed) - Smartphone app to scan all purchases as expenditure data unavailable
Deprivation/Quality of child's environment	Inequality session Infant health session Infant-parent relationship sessions CSE sessions	- Literacy environment, including quality of the books - Access to toys and books - Screen use and content - Involvement of grandparents in child's enrichment environment and development - Societal attitudes about what should be affordable (of policy interest to Welsh government for their baby bundle)	- Index of home cleanliness and living conditions Confusion, Hubbub and Order Scale of chaotic home environment	- Taking pictures of housing conditions (damp/mould) - Body cameras for child to see what child's lived environment is like - Use an accelerometer to measure air quality

		- Explore deprivation in terms of unmet needs of the child - Who lives in child's household - Living conditions - Does child have their own bedroom - Does family eat all together - Air quality in the home - Whether parents vape at home - Whether access to garden at home - In which households does the child live and how long does it take to go between them?		
Occupation of parents both before and after birth.	Inequality session Fathers session	- Mother's and father's employment status - Highest educational attainment (bearing in mind how to measure overseas qualifications) - Work hours - Contract type - 'Educational journey' - Barriers to work - Measures of precarious/gig economy employment - Decision-making about employment - Flexibility at work - Norms about work - Quality of work - Time spent commuting - Job loss during pregnancy (pregnancy discrimination) - Breastfeeding facilities at mother's place of work	- Suggestion to look at questions from maternity and paternity rights survey - Proportion of time in past 5 years in paid employment/out of work	- May be possible to get occupation linked from birth register
Measures of **social support**, social cohesion, trust and social capital.	Inequality session Environmental and neighbourhood session Infant-parent relationship session Pre-term session	- Who supports parents (informal support networks) - Resources family receives and from and to which countries - How do people conceive social justice - Where do parents get information about parenting from - How long participants have lived in the community		- App about support for mothers - Sandboxing/creative participatory methods could be used for participants to plot their contexts

		- Perception of neighbourhood safety and the safety of outdoor space - Reasons for relocation and moving homes - Where do minority identities (e.g. diverse families, ethnic minorities) feel welcome in their environment? Measures of belonging		
Use of services	Inequality session Environmental and neighbourhood session Infant health session Diverse families Vulnerable children sessions Infant-parent relationship session Mental Health	- Use and access to health visitors, GP use/attendance, services for maternal depression, antenatal classes, childcare support services, vulnerability services - Knowledge of support services and reasons for uptake or not - Perception of access to these services (particularly universal healthcare) in different countries - Experience with these services (including range of health services, antenatal/baby groups, community play groups/church) - National/regional policies and programmes affecting service provision (e.g. Sure Start, Family Nurse Partnership) - Use of early intervention programmes and intensive parenting programmes - Use of Mental Health Services - Use of Charity services - Affordable public transport	- Suggestion to use ALSPAC questions on service use not MCS	
Built environment	Environment and neighbourhood session Infant health session Infant-parent relationship session	- Objective measures: noise, air pollution, green space, urban/rural measure - Subjective measures: use of green space/time spent outdoors by parents and child - Adaptations to climate change - Number of fast food outlets in area - Residential address for last 2-5 years to facilitate data linkage -	Suggestion to use 'perception of environment' questions from Life Study as a starting point	- Could use systematic social observation of google street view images to measure neighbourhood conditions as in E-risk longitudinal twins study - Could ask subset to send videos (walking video diary) of their neighbourhood

				- Suggestion to use GPS tracking device to look at actual movement outside the household and use of green space (although group felt this was likely not to be popular with participants and smartphone tracking more acceptable)
Inequality and COVID-19 in FS but not necessarily main study	Inequality session Vulnerable children	- Employment and furlough; reduced working hours - Home-schooling - Parental engagement with household tasks and childcare - Food security - Long covid - Potential impact of COVID restrictions and behaviours on children (e.g. mask wearing and hand sanitising) - Having to work from home and how this affects crowding in home		
Formal and informal **childcare arrangements and parental leave.**	Inequality session Infant-parent relationship session Infant health session Fathers session Environment session CSE sessions	- Who is providing care, how much and what type - Parental leave (length) and return to work (how does maternity leave connect to quality of maternal employment) - Future childcare plans (particularly for parents still on leave) - Attitudes about parental leave and negotiation of who takes leave in the couple - Attitudes about who should do which tasks and perception of fairness in division of childcare - Barriers to taking parental leave - Kinship care - Sibling care - Who lives in the household - Household division of tasks	- Use Understanding Society or Covid questionnaire questions on household division of labour	- Use of diaries to give detailed picture of care

		- Financial support (regularity rather than amount) with childrearing - 'Mental load' as studied by Heejung Chung		
Parenting styles and how respondents find parenting	Inequality session Infant-parent session Fathers session Pre-term session Environment session	- Parenting style Role of digital devices in parenting (type, purpose, intensity) and technoference - Attitudes and beliefs about parenting styles - Perceptions about society's/parents' cultural background's view on parenting - Intensive parenting - Attitudes about smacking - Perception of parental competence and stress - Co-parenting measures of how care for child negotiated between partners - The parenting style of the parents' parents to explore intergenerational transmission - Financial contributions of each parent to child - Role of the parent in developing healthy nutrition habits - Parents likes/dislikes of parenting	- Overindulgence scale - Suggestion by Bonny about co-parenting measure (Weinburg index of marital quality) - The role of the parent from 0-5 (nb. not clear what this refers to in particular)	- Suggestion by Bonny about audio capture through app of parents thoughts about their child/parenting. Same kind of idea in to do an 'expressed emotion' speech sample
Fertility expectations of both parents	Inequality session	- Expected family size - Expectations about family-work future		
Siblings of cohort member and other children in the household	Inequality session Infant-parent relationship session	- Do siblings share the same environment - Educational attainment of siblings - Resources dedicated to the siblings after birth of cohort member - Birth order - Relationship between infant and siblings - Siblings' temperament		
Child's behavioural development at very young ages to see which children become difficult to manage	Cognitive, social and emotional session Vulnerable children Pre-term session	- Emotional regulation - Executive functioning - Joint attention/attention - Early communication - Socio-emotional interactions - Attachment	- Ages and Stages Questionnaire	- Suggestion to do MRI scans on subsample to look at baby's brain development - Suggestion to use Lab TAB measure of infant temperament (3-5 minute

				observation simulating situations to see emotional reaction)
Measure **interaction** between family and child	Inequality session Infant-parent relationship session Fathers session CSE sessions	- Father's time alone with child - What each parent thinks about the other's parenting capacity and skills - Perception of relationship with child - Parent-child play - preference for interaction measures over resource availability e.g. books in home. - Observe interaction between other key care givers and child - Child's response to interaction	- Fatherhood Institute 'Lockdown Fathers' questionnaire could be used to look at perceived relationship with child - Emotional Availability Scale - MCS used Pianta-Kessler measures of family-child relationship but suggestion that this does not show much differentiation	- Use short videos to identify interaction styles and attachment - Time use diaries for activities - Body cameras for child to see who child interacts with - Heart rate measures of infant and parent in naturalistic interactions (physiological response to interaction)
Cultural and ethnic differences	Inequality session Ethnicity session	- Country of origin - Secondary migration - Self-reported ethnicity - Experience of discrimination (objective and subjective) - Language spoken at home		
Parents' characteristics and relationship	Inequality session Infant-parent session Genetics session Fathers session Diverse families session Mental health session	- Sexual orientation and gender - Whether together or separated - Relationship quality and conflict between parents - How parents negotiated break up - How separation affects ability to work - Experience of domestic abuse during pregnancy (to understand potential patterns of missing father data and to address how forthcoming people are about this information) - Relationship histories - Travel time between parents households if living separately - Parents to support each others mental health e.g. mental health literacy and first aid	- Suggestion to use LGBT foundation questions on self-identification in terms of sex/gender/sexual orientation - Suggestion to use USoc or Growing Up in Australia questions on relationship conflict - Parental Conflict indicator by DWP - MCS questions on relationship quality - Measures of stigma need to be adapted to particular sub-groups and can't be	

		- Perceived stigma/acceptance of 'diverse family' status if applicable, and how it affects service use/feeling of inclusion in community - Gender dysphoria for all parents as may be subject to change around time of having a child	captured by an all purpose scale. - Ask people to complete a genogram of their family and to point out any conflicts/abuse/mental health history in this way.	
Parents' health	Infant-parent relationship session Mental health of parents session Infant health session Inequality session Pre-term session Vulnerable children session	- Parents' disabilities or special needs, including learning difficulties, neurodevelopmental disorders (ADHD, autism, eating disorders) and age of onset - Mental health of mother and father, with the two reporting on each other's mental health - Post-natal depression (whether had and length) - History of mental health problems - Measure traumatic responses/PTSD sxs and PD responses [e.g., interpersonal, self and emotional dysregulation]) for all parents - Experiences of psychosis - Anger management and anti-social personality disorder - Family history of mental health problems - Parents well-being as well as mental health - Mother's diet - Sleep patterns of whole household, including environment of sleep in an in-depth way (where they sleep, noise, light, etc) - Family history and current health problems - Intergenerational changes in healthy behaviours - Factors indicative of poor mental health: overworking, anger, being withdrawn, change in habits of activity, eating, sleep - Alcohol consumption - Drug use/Substance abuse	- Recommended using SDQ and GAD-7 for mental health - Edinburgh post-natal depression scale is validated for mothers and fathers - Suggestion to measure both self-reported mental health/well-being, and an observational measure such as through Experience Sampling Method (ESM) or Ecological Momentary Assessment (EMA) - Changes in behaviour indicative of poor mental health could be done through passive devices	- Body composition of mother and father via DXA or another method (e.g., MRI). - Accelerometery device to monitor sleep or EEG type headsets - Suggestion to collect hair samples to look at cortisol

Child health and physical development	Infant-parent session Mental health session Infant health session Cognitive, social, emotional session Pre-term session	- Pain experiences of child (accidents, vaccinations) - Child's sleep patterns and problems - Crying patterns and duration - Bed wetting - Motor development and milestones - Medication use - Feeding practices and problems (intentions, duration of exclusive breastfeeding, timing of weaning, styles of feeding, responsive feeding techniques, feeding problems, maternal complications (e.g., mastitis), changes in formula use, use of baby friendly initiative etc.) - Visual development – myopia (increasing prevalence), unilateral visual development and family history - Early life adversity – physical/sexual abuse, parents' substance abuse etc perhaps via linkage. - Quality of child play - Child weight (relative to gestational age) and height - Child's body composition and organ development - Head trauma	- Ages and Stages, and Movement ABC suggested as measures of motor development and milestones - Bonny suggests co-TEDs play questionnaire - A helpful report by Early Intervention Foundation on ACE could help with design of these questions - More broad measures of adversity are needed besides the out-of-date Kaiser Permanente and ACES framework - For timing, duration and severity questions ALSPAC is good but could be better	- Time use diaries for sleep - Wrist worn device to monitor sleep - Body composition of infant via air-displacement plethysmography (PeaPod, BodPod) or another method (e.g., bioelectrical impedance or DXA). - Suggestion to use app to collect simple breastfeeding information and give advice/support back - Body cam on fieldworker to observe play, looking at structured free play and probing for key skills (peekaboo, pointing, response, imitation, stacking, objection location, crawling)
Pregnancy and birth	Infant-parent session Mental health session Diverse families session Pre-term session	- Whether birth was preterm - The emotional impact of having a preterm baby for parents - Pregnancy and birth experience - How child was conceived (advised to be more thorough than MCS question) and whether experienced miscarriages (for both parents) previously - Medication exposure (selective serotonin reuptake inhibitors SSRIs) of child during pregnancy		

		- Whether planned to get pregnant - Questions on ART method and whether there was a gamete donor or surrogate. - A question about whether parents intend to inform their child about the mode of conception. - Child's post-conception age - Mothers' alcohol/smoke/drugs/pollution exposure during pregnancy - Does father attend birth - Whether father involved in pre-birth activities		

6. Biosamples

- For bio-samples, the genetics sessions reached a consensus that **saliva was preferable over cheek swabs**.
- **It was suggested that methylation and microbiome studies were not a prioorty** in the feasibility study, however suggestion to get **wide ranging consents/attitudes to the consents** for these samples (or other biomeasures e.g. blood samples) to be collected in future.
- Genetic samples should be collected from **child, mother and father**. Collection from non-biological father and siblings would be interesting but not priority, suggested done at a follow up wave. Collection of samples from OHFs may need special engagement strategy.
- The preference in the genetics sessions was for **genotyping the samples, but if too expensive, checking that the quality of the samples is good enough to genotype**. Most important would be to harmonise phenotypes collected in ELC with other existing surveys (MCS, ALSPAC, TEDS, BiB, MoBa Norway).
- Suggestions to collect other biological samples (e.g., **faecal, blood, breast milk, hair, saliva, and infant fingernails**).

7. Novel Measures

*additional to the specific measures given in Section 5

- Use of technology (e.g. heart rate and brain monitoring devices) to produce more objective assessments of infant development, enabled by machine learning analysis of this data that is now possible (e.g. identification of faces in body cam footage). Also made the point that **these technologies may be more acceptable with harder-to-reach**, as they are familiar with the experience (e.g. taking a picture of their child or social media data).
- Use of an app will **require phone data or broadband** to be used which may be problematic for vulnerable families. If using the interviewer's device, need to ensure they have data package included.
- Suggestion to have an innovation panel like UKHLS in main study.
- New **scales need to be no longer than 3 minutes long**, and advised to do a review of reviews on observational measures.
- In general feedback session, suggestion to look at Parent Ping/Teacher Tapp apps for inspiration, as were successful among people with busy schedules.

8. Record linkages suggested

Suggestion to work out what information can be gained from record linkage in order to free up more space in questionnaire for areas that there is not routinely collected data for. Advised to set up the possibility of future record linkages with consent, and to set up GEOcodes from the feasibility study to easily facilitate later linkages.

Specific records:

- Maternity/antenatal records for more detail about births, which would enhance information from the biosamples e.g. about birth complications.. Warning that the maternal health services dataset for England is not very complete for 2015 onwards but may have improved by the time of our use. Maternity Indicators dataset for Wales is suitable for linkage.
- Tax records
- Benefits records
- DWP records
- "Red book" data on child development, if digitised – in Ethnic Minorities session they mentioned an incoming digital personal child health record (instead of hard-copy red book for <5s health & development)
- Blood spots from heel pricks at birth, if available
- GP/Hospital Episode data for child
- Maternal medication during pregnancy and existing conditions from mothers' GP records
- Linked records on built environment (noise/air pollution/green space)
- National neonate database
- Data linkages to social care records can be done at the national level. E-CHILD in England, SAIL in Wales.
- National Pupil Database. Warning from Alison Macfarlane that TIGAR project struggled to get legal gateway to link to English NPD, but Echild project were successful linking NPD and Household Electricity Survey.
  CAFCAS -Babies in the family justice system who go into care.
  COVID data e.g. testing data/vaccination etc
  ONS infections survey
  Minimum mental health dataset
  IAPTUS data set (NHS improving access to psychological therapies)
  Child in need data could be interesting in getting child protection info, pre-birth info/referrals, any interventions

Annex 1

Agenda

09:15 – 09:20 – Welcome and housekeeping
09:20 – 09:25 – Introduction from Matthew Neale, ESRC
09:25 – 09:40 – Welcome talk by Pasco Fearon

09:45 – 10:45 – Scientific parallel session 1
A. Cognitive, social, and emotional development of infants
B. Infant-parent relationships, and the early home environment
C. Infant health, including growth, nutrition and sleep
D. Mental health of parents and the developing child
E. Social, environmental and neighbourhood influences on infant and family
F. Inequality, disadvantage, and social mobility in the new cohort
G. Genomics, early adversity and biological embedding of stress

10:45 – 11:00 – Refreshment break
11:00 – 12:00 – Scientific parallel session 2

14:00 – 14:15 – Welcome talk by Alissa Goodman
14:15 – 15:15 – Creating an inclusive cohort parallel session
A. Ethnic diversity and immigrant families
B. Fathers and partners
C. Vulnerable children, including born into care
D. Diverse families
E. Pre-term, and sick neo-nates

15:15 – 15:30 – Refreshment break
15:30 – 16:15 – Discussion on study design led by Lisa Calderwood

Annex 2 Participants

Participant analysis

Sector	N	% of total	
Higher Education	155	90%	from 55 centres
Government	12	7%	
Third sector	3	2%	
Private sector	1	0.6%	
Media	1	0.6%	

Location	N	% of total
Greater London	68	40%
South East	22	13%
South West	15	9%
East of England	14	8%
Northern Ireland	10	6%
Wales	8	5%
Yorkshire & the Humber	8	5%
Scotland	7	4%
International	5	3%
West Midlands	4	2%
East Midlands	3	2%
North East	3	2%

North West	3	2%
Republic of Ireland	2	1%

Primary discipline/area of interest	N	% of total
Psychology	37	22%
Epidemiology	30	17%
Public health services	16	9%
Economics	13	8%
Survey methodology	11	6%
Demography	10	6%
Sociology	10	6%
Education	8	5%
Social studies	8	5%
Not applicable	5	3%
Statistics	4	2%
Clinical medicine	3	2%
Anthropology	2	1%
Behavioural sciences	2	1%
Perinatal and infant mental health	2	1%
Speech and Language Sciences	2	1%
Other - Epigenetics/Genomics	1	1%
Ethics and governance	1	1%
Gender studies	1	1%
Genetics	1	1%
Geography	1	1%

Other - Linguistics/ Language policies/Bilingualism	1	1%
Other - Midwifery/Research methods	1	1%
Nutrition and Biomedical Sciences	1	1%
Operational Research	1	1%

Organisations represented

AD Cave Solutions
Birkbeck, University of London
Birmingham University
BookTrust
Born in Bradford
Cambridge University
CASCADE, Cardiff University
Centre for Brain and Cognitive Development, Birkbeck, University of London
Centre for Child and Family Justice Research, Lancaster University
Centre for Family Research, University of Cambridge
Centre for Maternal and Child Health, City, University of London
Centre for Research on Children and Families, University of East Anglia
Department for Education
Department for Work and Pensions
Economic and Social Research Council
Fatherhood Institute
Imperial College London
Institute for Employment Research, University of Warwick
Institute for Fiscal Studies
Institute for Social and Economic Research, University of Essex
Institute of Nursing and Health Research, Ulster University
Ipsos MORI
Kent County Council
King's College London
Lancaster University
Loughborough University
Malawi Epidemiology and Intervention Research Unit, University of Glasgow
Manchester Metropolitan University
MRC Lifecourse Epidemiology Unit, University of Southampton
NatCen Social Research
National Perinatal Epidemiology Unit, University of Oxford
Nature
New York University
Newcastle University
North Bristol NHS Trust

Norwich Business School, University of East Anglia
Population Health Sciences Institute, Newcastle University
Public Health England
Queen Mary University of London
Royal Holloway, University of London
Scottish Government
Sheffield Hallam University
Stockholm University
Swansea University
Swansea University Medical School
Trinity College Dublin
UCL Centre for Inclusive Education
UCL Centre for Longitudinal Studies
UCL GOS Institute of Child Health
UCL Great Ormond Street Institute of Child Health
UCL Institute of Education
UCL Institute of Health Equity
UCL Social Research Institute
Ulster University
Universidade de Lisboa
University College Dublin
University College London
University of Bath
University of Brighton
University of Bristol
University of Cambridge
University of Dundee
University of East Anglia
University of Edinburgh
University of Edinburgh
University of Essex
University of Exeter
University of Huddersfield
University of Kent
University of Leicester
University of Oxford
University of Plymouth
University of Reading
University of St Andrews
University of Stirling
University of Warwick
University of York
Wellcome Sanger Institute
Welsh Government
Wolfson Centre for Young People's Mental Health, Cardiff University
Young Lives, University of Oxford