Findings from the Early Life Cohort Feasibility Study survey component



Summary

- The Early Life Cohort Feasibility Study (ELC-FS) known to participants as Generation New Era recruited a UK-wide representative birth cohort of babies in their first year of life.
- The survey component of the study collected rich data on families from **surveys** and administrative data **linkages**, and also included **saliva collection** for genetic analysis.
- The cohort was based on a representative sample drawn from records of births in all UK countries.
- The sample included boosts of ethnic minority babies and families in low-income areas in England, and the sample was also boosted in Wales, Scotland and Northern Ireland.
- Overall, 1,918 families with 1,959 babies were successfully recruited to the study. This comprises 1,002 families and 1,025 babies in England, 277 families and 286 babies in Wales, 319 families and 326 babies in Scotland, and 320 families and 322 babies in Northern Ireland.
- Across the UK, 49% of invited families agreed to take part (the unweighted study response rate, defined as where at least one parent in the child's main household took part). This was 46% in England, 54% in Wales, 58% in Scotland and 50% in Northern Ireland.
- The study **recruited a diverse range of families**, with over 40% of babies/families recruited in the lowest quintile of the Index of Multiple Deprivation due to the boosted sample design.
- Rich data was also collected on fathers: among productive main households where two eligible parents were identified, 76% of second parents/fathers were interviewed. Fathers who live separately from their child most or all of the time were also invited to take part. While we achieved a low response rate among these fathers (16%), the data provided by those who took part provides important information about a group who are rarely captured in this type of research.

 The study included a number of experiments to test some key design features, including data linkage consent models, saliva collection and incentives.

• Preliminary analyses point to **changing trends in parenting** compared to earlier birth cohorts: for example, 1 in 2 fathers in the study fed their baby more than once a day, and 3 in 4 babies were spending some of their day watching screens (on average 45 minutes per day).

About the study

The Early Life Cohort Feasibility Study (ELC-FS) has tested the feasibility of a new national birth cohort study for the UK. The project aimed to recruit participants into an innovative and inclusive study and to extensively engage with the public to ensure acceptability and value of the study. The study was introduced to participants as **Generation New Era**.

The feasibility study has captured the circumstances and lives of a nationally representative cohort of babies born at a critical time in the UK's history and will help us to understand inequalities in early child development and how they are changing over time.

This briefing paper outlines key innovations and contributions the feasibility study survey component has made for data users and survey methodologists.

Sampling and fieldwork

A key innovation of the study was its sample frame. The project team secured agreements to use birth registrations linked to birth notifications or maternity records in England, Wales and Scotland, and maternity records only in Northern Ireland, as its sample frame, on an opt-out basis. The sample was provided by NHS England (England and Wales), National Records Scotland, and Northern Ireland's Business Services Organisation, with required approvals in each country. Using birth records as a sampling frame for a UK-wide study has the benefit of high population coverage. It enabled direct recruitment of both parents where the birth was registered jointly, even if this was at different addresses, an individual-level ethnic boost using baby's ethnicity, and use of additional sociodemographic information about parents and babies to understand who did and did not take part. The sample design comprised over-sampling at national level in Wales, Scotland and Northern Ireland and, in England, a boost of Black Caribbean, Black African, Pakistani and Bangladeshi babies and a boost of families living in low-income areas (lowest quintile based on Index of Multiple Deprivation).

Survey fieldwork, conducted by Ipsos, ran from **September 2023-September 2024** across all four UK nations. Babies were born in a two-month birth window (in 2022 and 2023), and most parents were interviewed when their **baby was 9-13 months old**.

Fieldwork consisted of a main survey issued by interviewers (different modes were available), followed by an online follow-up survey after a few months for households where no parent had taken part.

Who took part?

Overall, **1,918 families with 1,959 babies were successfully recruited to the study**, meaning at least one interview with a parent was completed in the baby's main household. This comprises 1,002 families and 1,025 babies in England, 277 families and 286 babies in Wales, 319 families and 326 babies in Scotland, and 320 families and 322 babies in Northern Ireland.

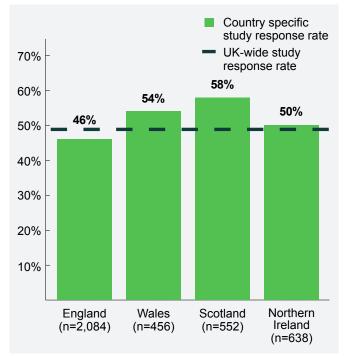
FIGURE 1: SAMPLE NUMBERS IN EACH OF THE FOUR COUNTRIES



87% of parents said they would take part again

These 1,918 families were **49% of the families initially invited to take part in the study** (the study response rate). We found that the proportion recruited was highest in Scotland (58%) and lowest in England (46%). While some variation in response rates between countries was due to over-sampling of particular groups, there were also underlying country differences in willingness to respond, as adding design weights to account for over-sampling of particular population groups in England made little difference to the averages.

FIGURE 2: STUDY RESPONSE RATE



The study was well received by families: participants reported they enjoyed taking part and thought the study was conducted well. Of those asked for feedback after the survey, **87% said they definitely or probably would take part in a second wave**.

Building a picture of families' lives

Questionnaire

The study team consulted widely with academics, policy and practice stakeholders and parents of young children to design the questionnaire. Key scientific priorities identified in the consultation included:

- · The dynamics of childhood poverty and adversity
- · Parental decision-making about work and family
- · Capturing parenting across diverse families
- Early markers of neurological and biological development issues
- · Genetic influences on child development
- The relationship between child and parent health
- · Parents' knowledge and access to services.

Parts of the questionnaire were also cognitively tested with parents prior to the start of fieldwork.

The final questionnaire covered a broad range of topics including:



Baby's health, growth, behaviour, development, sleep, diet and play activities



Parent's work, finances, health and wellbeing, parenting approach and relationship with their baby



Use of childcare and other services



Family's home environment.

The final questionnaire aimed to include content that could be directly compared to other UK-wide birth cohorts to understand change over time. For example, in preliminary data analysis we found that:

- Dads in the study were doing more with their children than in the Millennium Cohort Study (MCS):
 1 in 2 of the dads in the feasibility study fed their baby more than once a day compared to 1 in 4 dads in MCS.
- Allergies were reported as a longstanding health condition for 6% of feasibility study babies. Just 1% of MCS babies had seen a doctor about allergies by the time of the study's first wave in 2002.

The study also included novel content compared to previous cohorts, to answer more contemporary scientific questions. For example, questions were included on parental engagement in play, a range of measures of financial hardship, screen time, vaping and use of fertility treatments for the cohort child. Some preliminary data analyses include:

- 6% of births were conceived using a fertility treatment, the most common being IVF.
- Most babies (3 in 4) were spending some of their day watching screens: the average time spent watching screens per day was 45 minutes (half watched for less than 30 minutes a day).
- The play activities parents did most throughout the day with their children were playing with toys, cuddling and talking. Parents were slightly more likely to do physical or noisy play with their baby if they were a boy.

Administrative data linkages

The study collected consents to add rich data from **health**, education and social care records for both parents and their babies. Consent rates were high (over 75% consent in all countries for each type of linkage). Data about the families' local environments (geo-linkages) will also be added.

Genetic data

An important innovation for the feasibility study was the **collection of saliva samples from both parents and their child for DNA extraction** and subsequent genetic analysis. Around 500 families were randomly invited to provide parent and child saliva. DNA has been extracted from the samples but further genetic analysis will be subject to funding.

Rich data on fathers and mothers

A strength of the feasibility study has been the collection of detailed information from both fathers and mothers. Fathers have typically not been recruited in their own right in previous UK birth cohorts. In the feasibility study, fathers were sampled directly via information on the birth register. This allowed fathers who do not live with their child full-time (own-household parents, OHPs) to be directly invited to take part. Birth registrations suggest that **nearly 20% of UK fathers with a child under one are OHPs, making them a sizeable and important group of parents to include in family research**.

The study was designed to be inclusive of all parents by allowing **up to four interviews per baby** with up to two birth parents and their co-resident partners. Within the baby's main household, a 60-minute face-to-face interview was sought with the parent (mother or father) who spent the most time caring for the baby (the primary informant), as well as (where applicable) a further 30-minute interview, either face-to-face or online, with a co-resident additional informant (this was usually the baby's biological father). This design was innovative for not assuming that the mother was the parent providing most care to the child. The OHP interview was 40 minutes, with an additional informant interview also available for their partner if they had one.

Up to four interviews per baby:

Interview 1: 60-minute face-toface interview with parent who is main carer.



Interview 2: 30-minute interview, either face-to-face or online, with a co-resident carer. parent. Interview 4: 30-minute interview with OHP's co-resident partner.

40-minute interview

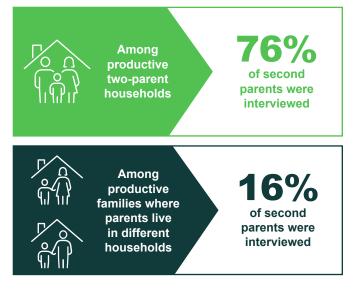
with own-household

Interview 3:

We achieved a high proportion of interviews with fathers/second parents. Of the 1,918 productive main households, where there were two eligible parents, we achieved an interview with 76% of parents allocated to the additional informant interview (typically the father).

Where parents lived at two separate addresses, we interviewed 16% of OHPs among productive households. While this is a low response rate among OHPs, the data provided by those who took part provides important information about a group of fathers whose lives, and their influence on child development, are rarely captured in this type of research.

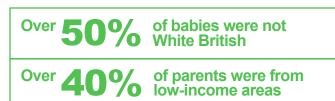
INTERVIEW RATE OF ELIGIBLE RESIDENT AND NON-RESIDENT 'SECOND' PARENTS



Representative and diverse samples for sub-group analysis

In addition to fathers, through the sampling strategy, the study was designed to maximise representation of other less-often-heard groups like ethnic minority and low-income families. The fieldwork protocol, materials, and questionnaire were all designed with inclusivity and accessibility as a priority. For example, the study included a multi-mode design to give participants flexibility in how they took part, and the study materials, engagement messaging and questionnaire wording were rigorously tested with different types of families. We also translated the study recruitment materials and offered translated showcards in 10 languages, including Welsh.

The study recruited a diversity of families: over 40% of the parents recruited lived in areas in the lowest Index of Multiple Deprivation (IMD) quintile, around 10% of parents were under 25 years old and over 50% of babies were not White British, with around 30% from ethnicities other than White (all unweighted proportions). The diverse sample will allow researchers to do analysis with specific groups of policy interest.



Assessing representativeness

The study team have conducted initial work assessing the representativeness of the sample compared to the total population of births in the relevant birth window. The analysis suggests that there was differential response according to a number of characteristics, which is typical for surveys of this kind. For example, babies with mothers under the age of 20 had relatively lower response rates, while families with Bangladeshi ethnicity had higher response rates than families with White ethnicity. Despite these differences in response rates, **the characteristics of the achieved sample are broadly representative of the target population**.

Figure 3 compares the feasibility study's achieved sample (the proportions of the sample with design weights applied) to ONS birth statistics in 2022 for England and Wales (as UK-wide population data is not available) by different sociodemographic characteristics. The differences between the study's population proportions and those in the birth statistics are small.

Despite the fact that the feasibility study had a lower response rate compared to the Millennium Cohort Study, the achieved samples were very similar in terms of overall representativeness compared to their target populations.

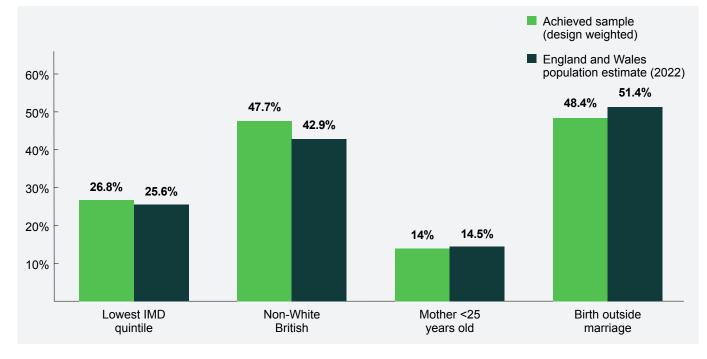


FIGURE 3: COMPARING THE DESIGN-WEIGHTED ACHIEVED SAMPLE TO POPULATION ESTIMATES

Methodological innovations

Lessons from using records of births as a sample frame

The innovation of using records of births as a sampling frame across all four UK countries led to many important insights for future use of these records for research purposes.

- The percentage of births excluded from the sample by the data holder (NHS England) was 12.7% in England which was higher than we had expected based on published data about the National Data Opt-Out in England, which is currently reported at 5.55%. This likely reflects a relatively high level of patient opt-outs in England among the sampled groups.
- We also identified some variation in England in the exclusions by ethnicity (e.g. from 12.8% for Black African to 36.8% for Black Caribbean) and region (from 7.4% in the North East to 16.3% in the South East). We didn't find variation by the area's level of deprivation.
- We learnt important lessons about the quality of the data in the records. For instance, while a comparison of baby's ethnicity on the sample frame and that reported in the survey showed the two to be wellaligned, we also found a lot of missingness on baby's ethnicity in Welsh records.

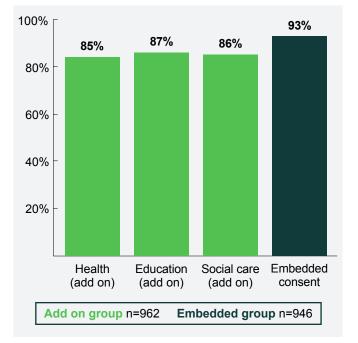
Consent to data linkage

The study aimed to understand more about how to minimise participant burden and improve the likelihood of informed consent for administrative data linkages. Families were randomised to different models of consent:

- 1. 'Add on' consent where participants were asked to consent to each linkage in turn.
- 2. 'Embedded' consent where participants were informed that the study would like to link the records and how to dissent during or after the interview.

We found that the 'embedded' group had higher consent rates than the 'add on' group. Participants and interviewers generally preferred the 'embedded' form of consent in post-fieldwork feedback.

FIGURE 4: CONSENT RATES TO LINK BABY'S ADMINISTRATIVE RECORDS, BY CONSENT MODEL AND TYPE OF RECORD



We found some differences in consent rates by ethnicity, level of deprivation, and mode of data collection. Preliminary analyses suggest that those completing by video call/telephone, from Pakistani/Bangladeshi ethnic groups and from the lowest IMD decile were least likely to consent in the 'add on' group. Variation among the 'embedded' data linkage group was less pronounced.

Consent to providing saliva sample

Saliva samples were received from 43% of babies and 46% of parents asked to consent to give a sample.

Babies' and parents' consent rates varied by country: among parents, **32% in England**, **40% in Wales**, **51% in Scotland and 70% in Northern Ireland consented and sent samples to the lab**.

We found that those in the saliva sub study had broadly similar rates of recruitment into the main study (43.5%) as those who were not part of the saliva sub study (46.1%).

Preliminary analyses show differences in consent rates by ethnicity, age and level of deprivation. Those from Asian ethnic groups, parents under 25 and those from lower IMD areas had the lowest consent rates.

Incentives experiment

Families were randomised into receiving one of three pre-survey unconditional incentives (nothing, £5 cash or a baby's bib) and two post-survey conditional incentives (£10 or £20 voucher). We found that **families who** received £5 pre-survey and £20 post-survey had the highest unweighted response rate (52.8%), and those that received a bib pre-survey and £10 post-survey had the lowest (41.5%).

We also offered an additional £10 for completion of the online follow-up survey in Scotland and Northern Ireland, and an additional £20 for low-income families in these countries. The online follow-up survey raised the final response rates in these countries by 4-5 percentage points, compared to a 3-percentage point elevation to the final response rate in England and Wales where no higher incentive was offered for the online follow-up survey.

Understanding the needs of participants and the public

The study engaged extensively to ensure scientific and policy value, public acceptability, and participant co-production. This included about the use of administrative data, the study name and brand, barriers to participation among parents with young children, parents who do not live full-time with their child and low-income families, and testing the materials and questionnaire. There are learnings from this work which could benefit many different studies. Findings from this engagement can be found on the <u>CLS website</u>.

Small-scale field tests and scoping studies

In addition to the main feasibility study survey, several other studies were conducted to:

- Test the ability of contracted fieldworkers to take a number of specialised objective measures of babies' environments and development, including neuroscience-informed and anthropometric measures (EEG, eye tracking, adiposity), hair samples, and audio-recording of the home language environment.
- 2. Explore the possibilities for recruitment and retention into a longitudinal birth cohort study of very vulnerable children in the early years.
- 3. Scope the feasibility of conducting qualitative research with specific hard-to-reach groups as part of the birth cohort. This was commissioned separately to the main feasibility study survey and led by two study teams at the University of Sussex and the University of York.

Further information on the first two projects and their findings can be read on the <u>CLS website</u>. The reports from the qualitative scoping work will be available from the <u>Economic and Social Research Council website</u>.

Next steps

Researchers will be able to access data from the feasibility study of Generation New Era through the UK Data Service from summer 2025.

The Economic and Social Research Council have evaluated the findings from the feasibility study of Generation New Era and confirmed it will commission a bigger main study. They have invited the feasibility study team to bid to run the main study, as a sole applicant. If funded, this main Generation New Era study would start in 2026.

Study team and advisory groups

The feasibility study was led by the Centre for Longitudinal Studies with an expert UK-wide Scientific Delivery and Leadership Team, including Co-Investigators from UCL, and the Universities of Cambridge, Swansea, Edinburgh and Ulster, and in partnership with the Fatherhood Institute and the Nuffield Family Justice Observatory. The study team also included advisers from Public Health Scotland, Manchester Metropolitan University, ScotCen and Bryson Purdon Social Research. In addition to a Management Board and ELC Advisory Group convened by the funder, the team benefitted from expert advice from an International Cohorts Scientific Advisory Board, a Record Linkage Advisory Group, and also convened a group of methodological experts at key stages in the project.

Acknowledgements

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