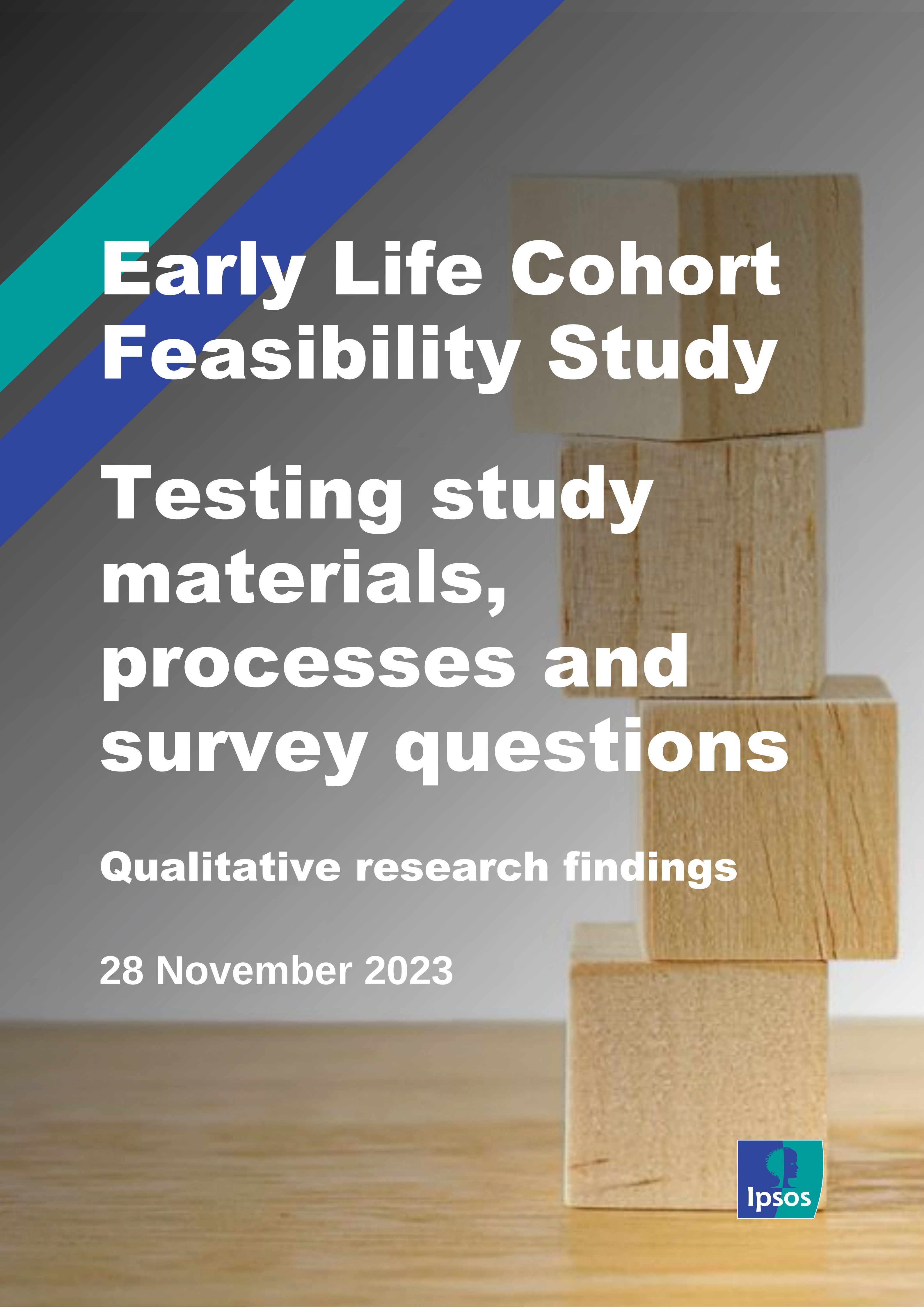


Early Life Cohort Feasibility Study

Testing study materials, processes and survey questions

Qualitative research findings

28 November 2023

Contents

1 Executive Summary

1.1 Background

The Early Life Cohort Feasibility Study (ELC-FS)[1] will collect data (focusing on health, wellbeing and development) from a new generation of UK-born babies in their first year of life. The study will test the feasibility of sampling and recruiting a UK-representative cohort as well as survey processes.

This report details findings from qualitative research that set out to understand views towards the study engagement materials and key study processes to contribute to their development. The qualitative research involved online or face-to-face individual depth interviews lasting up to 1 hour each. Participants were sent study materials to review in advance of their interview.

The research sample was designed to include mothers and fathers with a child aged under 2 years old from a mix of family backgrounds and circumstances with quotas set for: age, gender, social grade, region, ethnicity and household type to include mother only households, own household fathers[2] and two parent households.

Two stages of interviews were carried out. This enabled testing and refinement of study materials as they were being developed. Sample size and interview coverage for each stage are summarised below.

Stage	Stage 1	Stage 2
Sample size	32 interviews	12 interviews with participants re-contacted from the stage 1 sample
Interview coverage	Testing of opt-out letter, advance letter, advance booklet. This included exploration of study opt-out processes. Cognitive testing of new questions, questions for own household parents, and those that could potentially be sensitive.	Testing of advance booklet sections focusing on data linkage, geo-linkages, DNA samples and confidentiality and data security. This included exploration of study consent processes.

1.2 Motivation and comfort in participation

Across the research eight key factors were identified as important in influencing both comfort and motivation to participate in the ELC-FS.

1. **Social value:** highlighting that the study could improve the lives of other people, particularly children. Participants were keen to learn more about the societal benefits of the study.

---

[1] The ELC-FS is managed by the Centre for Longitudinal Studies (CLS) at University College London. It is funded by the Economic and Social Research Council:https://cls.ucl.ac.uk/cls-studies/early-life-cohort-feasibility-study/

[2] Own household fathers are defined as fathers currently residing in a separate household to their child and their child's mother for some or all of the time.

2. **Understanding a new generation:** highlighting to respondents that the study is interested in their child's specific generation with reference to personally relevant issues such as the pandemic and cost-of-living crisis.

3. **Sharing my opinions and experiences:** presenting the study as an opportunity to share experiences as a parent with the study collecting experiences of both mothers and fathers.

4. **Including diverse families:** making clear that the study is seeking engagement from families from diverse backgrounds and circumstances. There were suggestions to clarify the inclusion of specific groups e.g., families with disabled children, families with parent/s who are not British citizens.

5. **Financial incentive:** views regarding the use of incentives (for taking part in an interview, providing a DNA sample and receiving the gift of a baby's bib) were mixed. A financial incentive was particularly appealing to those who reflected on the current economic climate and tight household finances but the sum of £10 could feel low and lack appeal.

6. **Time:** those who anticipated lack of time would impact availability to participate in the study suggested clarifying the time commitment required.

7. **Trust and reassurances:** trust in the study and how data would be used was considered crucial. Participants identified a range of ways in which reassurances around this could be provided including clear information about confidentiality and anonymity.

8. **Choice and control:** choice and control were identified as key to building trust in the study. Participants felt that it was important to be clear that taking part is optional, what taking part involves and why data is sought. Being mindful of potential sensitivities for example regarding parental relationships and study topics was raised as important.

Reflecting these eight factors, a number of changes and steps[3] were implemented in the final study approach and materials:

- Ensuring that choice is made clear throughout the advance materials with clear statements regarding the voluntary nature of taking part in the study and participating in different study elements.

- Offering a flexible approach to participation by offering different interviewing modes, providing opportunity to complete the survey over more than one session and ensuring interviewers make multiple attempts to contact and schedule a convenient time to speak to parents.

- Recognising the role of incentives in encouraging participation and conducting experiments regarding form of incentives.

---

[3] It is important to note that whilst the qualitative research findings played a key role in informing changes and steps described throughout this report, other factors and learnings during the development phase of the ELC-FS will have also influenced these.

- Including reference to different motivating factors and providing reassurances for potential barriers within the study materials.
- Including study impact examples on the participant-facing study website[4].
- Including clarification on queries raised across study materials. For example, clarifying involvement from parent/s who are not British citizens in an FAQ on the participant-facing study website.
- Reviewing the images used in advance materials to ensure a diverse use of family images throughout.
- Interviewer training covered:
    - Who is and who is not eligible to take part in the study so that clarification could be provided if needed.
    - Detailed information about confidentiality and security and study elements such as data linkages and DNA samples so that they could provide further reassurances if required.
    - Guidance on navigating different family circumstances or study topics that may be sensitive in nature.
- Reflecting sensitivities of family dynamics, the study offers a range of options for contacting own household parents (e.g., one parent passing on information to another; parent checking whether they can share contact details for the other parent) and recognises that it won’t always be possible to contact the other parent.

1.3 Processes for taking part

A number of study processes were explored in the research and key reactions to these alongside changes and steps implemented in the final study approach and materials are summarised below.

Sending an individually addressed opt-out letter to each parent in the household.
• Whilst two-parent households felt this approach clearly gave both parents opportunity to take part in the study there were queries around whether this was necessary. Environmental and cost concerns were also raised. • Those living apart from their baby’s other parent noted that the information within the letter about ‘What if I live apart from my baby’s other parent’ was important and reassuring given the different relationships and sensitivities amongst parents not living together. • Overall, the study materials tested felt aimed at both mothers and fathers and participants did not expect different versions.
Changes implemented: • Individual opt-out letters were sent to parents living in the same household in separate envelopes to illustrate the importance of both parents taking part. Individual advance letters were also sent

---

[4] https://gnestudy.info/why-take-part/making-a-difference/

(the second mailing) but packaged together in the same envelope to reflect environmental and cost concerns.

The opt-out process.

- The opt-out process as described in the opt-out letter was not always clear to participants often due to low recall amongst those who skim read the letter.
- When prompted to read the opt-out letter in detail, participants felt that the letter including the information regarding opt-out was long and wordy and the opt-out information not always clear and easily navigated.
- There were mixed views on individual opt-outs for parents living in the same household. The key benefit of this approach was that it offered flexibility where only one parent in the household may be able to take part. However, there were suggestions that a household level opt-out could be simpler and would be preferrable where the reason for opting out was lack of comfort with the child being part of the study.

Changes implemented:

- The opt-out letter was shortened, with detailed Q&As provided on the reverse.
- A process was introduced where parents were able to opt-out individually, but when doing so asked if they were opting out personally or on behalf of both parents.

Consent processes for adding information from administrative records (participants were asked for their views on both opt-in and opt-out approaches).

- Overall participants reported a preference for an opt-in approach as they felt they would receive more detailed and transparent information via this approach which would support decision-making. However, it was noted that this information was lengthy which prompted concerns about potential take-up for the study.
- Those who preferred an opt-out approach typically felt confident that they understood what adding information from administrative records would involve. Benefits of this approach were also raised including having time to decide (avoiding the potential feeling of obligation to give a positive response to the interviewer during the interview) and feeling that the process was simpler.
- Whilst participants did not feel that an opt-out only approach would deter them from taking part in the study, they anticipated that they would be likely to have questions about which records were being accessed and the type of data shared.
- When prompted to consider what would happen around administrative data over time it was clear that participants had not fully considered this, or what would happen if they lost touch with the study. There were suggestions that this be further clarified in study materials.

Changes implemented:

- The study is testing both opt-in and opt-out approaches and the consent wording was reviewed to ensure transparency of the opt-out approach and information provision is commensurate with the level of detail provided for the opt-in approach.
- The script regarding data linkage for both approaches includes detailed information about the records being accessed and details are also provided in the website and interviewer FAQs.

Consent processes for adding information about where you live.

- Information about where you live felt less sensitive to participants when compared to information from administrative records. They typically felt comfortable with the suggested approach to these geo-linkages, particularly where they had noted information within the study materials noting that ‘*these geographical data are publicly available*’.

Changes implemented:

- For adding information about where participants live, the study informs participants this will happen, and lets them know they should contact the study if they do not want this to happen.

Consent processes for the child.

- Participants noted that giving consent for their child’s data linkage was an important decision and not all felt comfortable about making it.
- Overall, there were mixed views on who gives consent with varied views about whether consent should be given by one or both parents. Family dynamics influenced these views, reflecting the diversity of experiences across the research sample.

Changes implemented:

- The study only asks one parent to give the child’s data linkage consents, but study materials encourage parents to discuss this in advance to come to a joint decision.
- Interviewers are briefed on the process should parents disagree on this during the interview itself.

The provision of confirmations.

- Participants were positive towards the idea of receiving a confirmation for both data linkage and the provision of DNA samples. This was considered to be a transparent approach and a clear record of what had been agreed.

Changes implemented:

- Confirmation letters/ emails of data linkage consents will be sent to all participants with information about how to change permissions if respondents change their mind.
- A leaflet will be left at the end of each interview to remind respondents of the study elements, what will happen to their data and how to change permissions in the future.

The approaches for keeping in touch with the study.

- Participants felt comfortable sharing their phone number and email address for the study to contact them. However, they were less keen on sharing details of family and friends, feeling that they should not be playing a role in their decision to keep in touch with the study.
- There was negative reaction to tracing participants through the use of administrative data without notifying families first.

1.4 Design of research materials

This qualitative research tested the following research materials: opt-out letter, advance letter, advance booklet, and advance booklet sections focusing on data linkage, geo-linkages, DNA samples and confidentiality and data security. This included exploration of study consent processes. Overarching feedback and changes resultantly made included:

Length and layout

The length of study materials was considered important. Whilst positive towards the 1-page length of the advance letter, it was noted that the longer opt-out letter, the advance booklet and advance booklet sections could feel daunting. Removing repetition, using layout features such as clear section headings, bullet points, bold text to highlight key information, FAQs and ‘question and answer’ formats and use of shapes to highlight key information (in the advance booklet) were all considered ways to make materials clear and easy to navigate. Building on these findings, the following changes were implemented:

- Where possible materials were shortened and condensed including the use of more visual elements to ensure key messages stand out.

- The advance booklet section regarding DNA samples was shortened to a paragraph with an additional Saliva Information booklet developed to provide participants with more information whilst avoiding overwhelming readers with detailed information in the advance booklet.

- Information in study materials has been structured to support navigation of content for example, use of FAQs and use of colours and headings to identify sections of information.

Tone

Whilst the opt-out letter felt ‘friendly’ in tone, with welcoming content and phrases or words placing active choice on the reader regarding participation, in comparison the advance letter felt ‘direct’ and ‘assumptive’. Making clear that the latter was a follow-up letter was considered key in mitigating the impact of this tone. The booklet was considered inviting in feel, with the use of images creating an inclusive feel.

Content and clarity

Whilst the study materials were considered easy to understand there were suggestions for ways in which clarity could be improved.

- For both the opt-out and advance letters, participants suggested that the focus of the research (e.g., the types of questions that would be asked in an interview and the main aims of the study) could be made clearer. It was further noted that the opt-out letter and advance letter could clarify frequency of participation over time.

- Participants liked the fact that their interviewer's name and number was included on the advance letter. This made the interviewer visit feel less like 'cold calling' and gave them a clearer idea of what to expect next. Interviewers were briefed to include their name and (if possible) telephone number with the advance mailing, and why this would benefit them in making contact with respondents.

- Participants queried some of the phrases in the letter, such as 'your family has been specially chosen' to take part in the study, when the letter elsewhere explained they had been randomly selected. The phrasing of the letter was refined to remove/clarify phrases that seemed confusing or contradictory.

- Participants reacted positively to mentions of motivating factors (as detailed in section 1.2) within the advance booklet but raised queries around the content explaining rationale for, and processes regarding the data linkages, DNA samples and geo-linkages in the additional advance booklet sections. Reflecting the potential for queries, the interview script was developed to check the participant had read and understood material where this was crucial for giving informed consent. Interviewers were also briefed to be aware that participants might have questions or varying levels of familiarity with the survey materials and able to answer questions that may be raised.

Colours and imagery

Colours used in the advance booklet were positively considered bright and friendly. There were suggestions that colour contrast could be improved for those who were colourblind and/ or dyslexic.

Whilst images showing diverse families in the advance booklet was appreciated it was suggested that this could be improved by including images of disabled people. Building on these findings the colour palette was expanded and tested to ensure colour contrast of text met Web Content Accessibility Guidelines (WCAG) – Level AA standards[5].

Logos and signatures

The inclusion of NHS or Public Health agency related logos signified the importance of communications and provided reassurance that the study was professional in nature. Reflecting this, health agency and university logos were included on the letters to signal credibility and university logos added to external envelopes to encourage recipients to open these.[6]

1.5 Cognitive question testing

Cognitive tested was carried out to explore ease of answering questions, whether information requested was easy to recall and comfort in being asked questions. Survey questions for cognitive testing were divided into seven sections as shown below.

Question section
Section A: Screener questions
Section B: Service use questions
Section C: Parental engagement
Section D: Own household parent questions for main respondent
Section E: Own household parent questions for own household parent
Section F: Vaping
Section G: Sensitive questions

Participants were shown sections most relevant to their household and not all participants reviewed each section.

A number of changes were made to the questionnaire specifications as a result of the cognitive testing; specific changes are outlined in the main body of this report. These changes included:

- Clarifying questions that had caused confusion, including introducing reference periods (or more appropriate reference periods) so that questions were more specific. In some instances, help screens or additional text to clarify terminology or answer codes were introduced.

- Simplifying questions where participants reported finding it difficult to recall precise answers – for example, allowing respondents to provide a range rather than the number of times they had used particular services since their child was born.

- Adding more information before and within sensitive questions to stress the confidentiality and voluntary nature of the study, reminders of the ability to skip questions, and explanations about why information is being sought. Some questions about the respondent’s partner have been removed, partly as a result of participants expressing uncertainty about responding on behalf of someone else who may not be taking part in the study.

---

[5] https://www.gov.uk/service-manual/helping-people-to-use-your-service/understanding-wcag

[6] Health agency logo was added for Scotland only (Public Health Scotland), but not in England and Wales, based on the permissions granted to the team to use health agency logos in each country.

2 Introduction

2.1 Background

The Early Life Cohort Feasibility Study (ELC-FS)[7] will collect data on a new generation of UK-born babies in their first year of life. The focus will be to gather data regarding their health, wellbeing and development and their economic and social environments. The goal of the study is to test the feasibility of sampling and effectively recruiting a UK-representative cohort and to test other fundamental survey processes for a new, large-scale UK-wide birth cohort study.

Representativeness and inclusivity are key design features of the study. As well as drawing from a nationally representative sample, the study includes sample boosts of groups who comprise a smaller proportion of the population and/or who are typically under-represented in large studies: families in Scotland, Wales, and Northern Ireland; ethnic minority babies from Bangladeshi, Pakistani, Black African and Black Caribbean backgrounds (in England); and families in low-income areas of the UK.

The study is also inclusive in its approach to fathers and mothers. Each parent is considered a respondent in their own right; fathers and mothers are recruited individually and with equal importance even if they do not live with their baby all or most of the time, and regardless of the relationship with the other parent. This is possible because fathers' names are included in the sample frame (where this is available on the birth registration), whereas other studies have had to rely on mothers as 'gatekeepers' for providing contact details for the fathers. Effectively engaging fathers, and specifically 'Own-Household Fathers' (fathers who live apart from their babies) will therefore be a significant innovation.

Another key aim of the study is to test the feasibility and take-up of consent to administrative linkages and saliva collection for parents and their babies, and how these elements might influence overall recruitment rates. The study will be seeking to link data from parents' and babies' health, education and social care records, and will also be informing participants about its intention to link data about where people live ('geo-linkages'). The study also aims to link genetic information to participants' survey data. For a sub-sample of families, participants will be asked to provide saliva samples for DNA extraction for themselves and their baby. Collecting genetic information at the start of the study will enable new scientific insights into children's health and development in the early years. Saliva samples have been collected from children and adults in previous cohort studies, but not from babies, and not at the first wave of the study.

As part of the recruitment approach, the study is also testing various incentive values and types to assess the impact on overall response rates to the study as well as rates of agreement to saliva collection.

To note, the participant-facing name of the study is 'Generation New Era'. 'ELC-FS' and 'Generation New Era' may be used interchangeably throughout this report to refer to the study; however, only 'Generation New Era' was used with participants in this qualitative research.

---

[7] https://cls.ucl.ac.uk/cls-studies/early-life-cohort-feasibility-study/

The ELC-FS is managed by the Centre for Longitudinal Studies (CLS) at University College London. It is funded by the Economic and Social Research Council. Prior to this qualitative research, the CLS study team have engaged extensively with young people and parents from a wide variety of socioeconomic and ethnic backgrounds to inform the design of the ELC-FS study and ensure a diverse set of participant voices are considered. This feedback from young people and parents was incorporated into every aspect of the ELC-FS, including the design of the questionnaire and materials that was tested in this qualitative research. Further detail on engagement work carried out by CLS is provided in the appendix.

The aim of this qualitative research was to understand people's opinions of the engagement materials, as well as the study content and processes that related to the core objectives mentioned above. The findings from the research influenced the development of these. Two stages of qualitative research were carried out to explore this. The first stage focused on initial recruitment materials and cognitive testing of survey questions, and the second stage focused on information provided around data linkage, saliva collection, and data privacy. The specific objectives for each stage are detailed below, including discussion of the qualitative method employed.

2.2 Stage 1

There were two key objectives for the first stage of research:

1. Materials testing

A number of materials will be used as part of the invitation and engagement approach for the ELC-FS including:

- **An opt-out letter**. The opt-out letter is the first letter potential participants receive. It introduces the survey and informs the reader that they have been selected to take part. The letter briefly covers why they have been selected and what would happen if they took part. It also provides information about how to opt out of further communications.
- **An advance letter.** The advance letter will be sent shortly before the interviewer calls at a potential participant's address. It reminds the reader that they have been selected to take part and reintroduces the survey. The letter will explain what taking part involves and reiterates the opt-out process.

An advance booklet. The advance booklet accompanies the advance letter and provides detailed information about what the study will involve, why taking part is important, as well as information about data protection and ethics. Specific sections of the advance booklet tested included those covering *‘What is Generation New Era’*, *‘How will it make a difference’*, *'What sort of study is Generation New Era’* and *‘Why are these studies important’*. Full copies of the materials tested can be found in the appendix. The materials tested were early drafts of the materials based on initial thoughts regarding layout, branding, use of logos and colours. The images included in these were stock images taken from photo libraries.

This stage of the research set out to explore initial reactions to materials, which messages people found engaging, and what might discourage people from taking part in the ELC-FS. It also explored whether participants felt that the materials were aimed at both fathers and mothers, and overall views on the length, clarity and design of the materials.

2. Cognitive testing

A number of questions for potential inclusion in the ELC-FS survey were identified for cognitive testing. These included questions on the following topics:

- Screener questions
- Service use questions
- Parental engagement
- Own Household Parent questions for primary informant
- Own Household Parent questions for Own Household Parent
- Vaping
- Potentially sensitive question areas

The aim of this cognitive test was to explore whether questions were understood, acceptable to ask and whether people felt able to answer them. This testing was needed as some of these questions were newly written for the ELC-FS survey.

Stage 1 method and sample

A qualitative approach was identified as most appropriate for the Stage 1 research objectives, enabling participants to be open in their views and responses to the materials and questions tested. Individual depth interviews were carried out to ensure the research captured views from participants in a range of circumstances that would be likely difficult to convene in a group setting.

Overall, stage 1 comprised 32 individual depth interviews. Each lasted around one hour. 10 took place face-to-face and 22 took place online via Microsoft Teams. Interviews were carried out during November and December 2022.

Interviews were structured with the first half focused on the materials testing, and the second half focused on the cognitive testing. Participants were sent the materials to review in advance to ensure they had time to engage with these before the interview itself. With this in mind it is useful to note that:

- Participants often compared the different materials received (e.g., made comparisons between the opt-out letter and the advance letter).
- The extent to which participants had read materials in advance varied.

Time restrictions for the cognitive testing element of the individual depth interview meant that each participant saw a selection of question sections to be tested most relevant to their situation. All sections were covered across the 32 interviews.

People with children aged under 2 years old were invited to take part in the research. The ELC-FS is likely to engage families when the child is around 9 months old and therefore it was important to include parents with children around this age. A sample structure was developed to include a range of parent demographics and circumstances that would reflect the diversity of ELC-FS participants. In particular, the sample aimed to ensure inclusion of parents in different household types:

- Mother-only households
- Own household fathers (those currently residing in a separate household to their child and their child’s mother for some or all of the time).
- Two parent households.

Table 2.1 summarises the sample structure and achieved quotas.

Table 2.1: Quotas and achieved sample for stage 1 fieldwork

Quotas	Target	Achieved
Overall	32	32
Mode	At least 16x online Up to 16x face-to-face	22x online 10x face-to-face
Gender	16x female 16x male	17x female 15x male
Social Grade[8]	16x BC1 16x C2DE	15x BC1 17x C2DE
Region	16x England 6x Wales 6x Scotland 4x Northern Ireland	16x England 6x Wales 6x Scotland 4x Northern Ireland
Household Type	4-8x Mother-only households Up to 4x Own household fathers (OHFs) Up to 24x two parent households	5x Mother only households 5x OHFs 22x Two parent households
Ethnicity	At least: 2x Black African 2x Black Caribbean 2x Pakistani 2x Bangladeshi	4x Black African 3x Black Caribbean 3x Pakistani 1x Bangladeshi

2.3 Stage 2

The second stage of fieldwork focused on testing additional sections within the advance booklet regarding different study elements:

- Adding information from administrative records (data linkage).
- Adding information about where you live (geo-linkages).
- Adding information about your and your child's genes (DNA samples).
- Looking after your information (confidentiality and data security).

Specific areas for exploration included:

- Initial reactions to the additional advance booklet sections including views on layout and length, clarity of content and any arising questions.
- Views on who gives consent for the child to participate in study elements.
- Views on an opt-in or opt-out consent model for adding information from administrative records and how long this data linkage takes place for.
- Gathering views towards the use of administrative data for contact tracing.

---

[8] Social grades are a system of demographic classification used in the United Kingdom. The grades are often grouped into ABC1 and C2DE; these are taken to equate to middle class and working class, respectively. Their definition is now maintained by the Market Research Society.

Stage 2 method and sample

Follow-up individual depth interviews were carried out to explore views towards these additional advance booklet text sections. A total of 12 interviews were carried out in February 2023. Interviews were conducted via Microsoft Teams.

Participants were sampled from the 32 participants that had taken part in stage 1 of the research.

Engagement in these follow-up depth interviews was challenging. Due to low response, a shorter interview was offered to some participants to encourage uptake. All full interviews lasted around one hour, with the two shorter interviews lasting 30 to 45 minutes. This and broader time constraints during the interviews meant that not all participants discussed each of the objective areas above, but all were explored across the interviews as a whole. Table 2.2 below details the sample set and achieved.

Table 2.2: Quotas and achieved sample for stage 2 fieldwork

Quotas	Target	Completed
Overall	16	12
Gender	Provide a mix	5x Female 7x Male
Social Grade	Provide a mix	8x BC1 4x C2DE
Region	Minimum of 1 interview in each	1x Wales 2x Scotland 2x Northern Ireland 7x England
Household Type	2-3x Mother-only households and OHFs	2x Mother-only households 2x OHFs 8x Two parent Households
Ethnic minorities	At least 6	7

2.4 Recruitment

Recruitment of participants was carried out by specialist recruiters Criteria Fieldwork Ltd. Recruitment and engagement materials were designed by Ipsos and submitted to the UCL Institute of Education Research Ethics Committee who approved this qualitative research. Copies of the recruitment materials are included in the appendix. The recruitment protocols included:

- **Carefully designed recruitment materials:** we designed a recruitment screening questionnaire which clearly covered the sample criteria while avoiding a lengthy process which could risk deterring people from taking part in the research.
- **Clarity around the purpose and value of the research:** we developed participant facing recruitment materials which clearly explained why we were inviting them to take part in the research and what taking part would involve.
- **Ensuring informed consent:** we provided participants with an Information Sheet which explained the voluntary nature of taking part, the process for withdrawing consent if they changed their mind, and data confidentiality.
- **Offering incentives:** as a gesture of appreciation for participating in the research we offered a financial incentive provided via BACs transfer. The incentive amount was £45.

2.5 How to read this report

When considering these findings, it is important to bear in mind what a qualitative approach provides. Qualitative research is illustrative, detailed, and exploratory. It explores the range of attitudes and opinions of participants in detail, and it provides an insight into the key reasons underlying participants' views. When analysing the data, we were not seeking to understand prevalence but rather the values and experiences which underpin people's attitudes and opinions. The findings presented in this report reflect only the perspectives of those interviewed and cannot be generalised to the wider population.

Please note that there are two accompanying appendices for this report. Appendix 1 provides:

1. An overview of previous engagement work carried out by the Centre for Longitudinal Studies study team which informed the design of the Early Life Cohort Feasibility Study, including the study engagement materials.

2. Copies of the research materials used in the qualitative research described in this report.

Appendix 2 is a table that provides a log of the questions explored during cognitive testing including a summary of findings from the cognitive testing and changes subsequently made to the questions tested.

2.6 Reporting conventions

Across the report we have brought together findings from both stage 1 and stage 2 of the qualitative research. Where findings are from one particular stage, this is clearly noted.

Throughout the report we have referred to 'participants' and included verbatim quotes to illustrate findings. To protect participant anonymity these quotes are attributed only to gender and household type as reported by participants.

Reflecting the public-facing name of the study, we have referred to the ELC-FS as 'the study' or 'Generation New Era' throughout.

The research explored views towards a number of activities that will be part of the ELC-FS:

- Taking part in an interview.
- Adding information from administrative records (data linkage).
- Adding information about where you live (geo-linkages).
- Adding information about your and your child's genes (DNA samples).
- Looking after your information (confidentiality and data security).

These are referred to as 'study elements' throughout the report.

Throughout the report we have detailed the design implications for study materials, processes and questions identified through the qualitative research. Alongside this there is a summary of changes made to these throughout the study development phase. It is important to note that whilst the qualitative research findings played a key role in informing these changes other factors and learnings during the development phase will have also influenced these.

2.7 Reflections on the research process

Below we discuss some of our reflections on the research process and, where relevant, the impact that this may have had on the research findings.

Amenability to participating in research: although it is difficult to determine the impact of this factor, it is important to recognise that those who agreed to participate in this qualitative research may be intrinsically more amenable to participating in research in general. It is therefore plausible to assume that those who took part in this research may be more open to participate in future research such as the ELC-FS.

Incentivisation: the research explored participant views towards the incentive that will be provided to those who take part in an ELC-FS interview (£10 per interview) and those who provide a DNA sample (£5 per sample). It is useful to note that the higher incentive payment offered for taking part in this qualitative research (a £45 incentive for participation in a 1-hour long interview) may have influenced participant expectations for study incentives or informed how they felt about taking part in a study like ELC-FS, which plans to offer a smaller incentive payment for participation. It is difficult to know the extent to which this informed how they felt about the ELC-FS incentive, but the higher incentive for this research may have had a priming effect.

Participant engagement with study materials: the level of engagement with the study materials sent to participants to review prior to taking part in their research interview varied significantly. Whilst some skimmed the materials, barely reading them at all, others read them in detail and annotated the documents with their thoughts. In some instances, participants had not read materials in advance, which led to interviews needing to be rescheduled to provide them with more time to read the materials. In instances where materials had only been skimmed through, more time was needed during the interviews for participants to revisit sections of the materials to provide a view on their content. It is difficult to say whether a similar approach would be taken by those who will receive the materials when invited to take part in the ELC-FS. However, it is useful to note this variance, and this should be anticipated by interviewers.

Recruitment challenges: recruiting participants to take part in a follow-up interview (for stage 2 of the research) proved particularly difficult. Whilst we set out to carry out 16 individual depth interviews, it was only possible to arrange 12. It is difficult to know exactly why this was the case. However, it was clear across stage 1 interviews that participants were time-poor, particularly noting childcare responsibilities. With this in mind, participants were offered a shorter stage 2 research interview lasting 30-45 minutes. Two participants took up this offer.

Fieldwork challenges: two key factors generated challenges for fieldwork:

- **Participant schedules**: throughout both stages of the research, a challenge to fieldwork was participant no-shows and the need to reschedule interviews. Being flexible in rescheduling interviews was essential to the success of fieldwork completion. Own household fathers in particular often asked to reschedule interviews at short notice.

- **Posting study materials**: time was built into the fieldwork schedule to ensure that participants could be sent, receive and review paper copies of the study materials in advance of a stage 1 research interview. The aim was to enable participants to engage with paper copies to reflect the way in which materials will be sent to those invited to take part in the ELC-FS. However, fieldwork coincided with Royal Mail strikes in Autumn and Winter 2022. Materials often didn’t arrive in time or had to be resent. This impacted the scheduling of interviews. For a small number of stage 1 interviews, materials were sent via email and all materials shared in stage 2 were sent via email.

3 Motivation and comfort in participation

This section brings together findings from across both stages of qualitative research interviews to understand how, based on reading the study materials shared, people felt about participating in Generation New Era and specific study elements.

3.1 Overview of factors influencing Generation New Era participation

When reviewing the content of the study materials, participants were asked to consider how comfortable they would feel participating in the study and study elements. They were also asked to consider what might encourage or discourage their participation. Overall, eight key factors emerged as important in influencing both comfort and motivation to participate. These are listed in figure 3.1 and discussed in the remainder of this chapter.

Figure 3.1: Key factors influencing attitudes towards study participation

Social value	Understanding a new generation	Sharing my opinion/ experiences	Including diverse families
Financial incentive	Time	Trust and reassurances	Choice and control

3.2 Social value

Where social value emerged as a motivation, the idea of taking part in a study that could improve the lives of other people, particularly children, was appealing. Participants reflected that they would like to know more about how the study would benefit society and wondered if this type of information would be provided to those who took part as updates throughout their involvement.

> “Give really good, strong examples of how this research has benefited that person, that's relevant to their locality if possible. So, you know, how did this study benefit people in Northern Ireland or even-, the more local you can get to where I live, the more I'm going to be involved.” (Male, Two Parent Household)

When thinking about the societal benefits of taking part, there were some queries around the benefit at a local level, with participants interested to understand the link between wider societal benefits and benefits at a local level that could directly impact their family.

> “When you have got a child and life is busy, you sort of think, 'If this is only something voluntary, do I really want the hassle of this?' And that's going to be a very hard thing to overcome no matter how good the letter is, I think. I think maybe it misses putting a little bit more weight and example on exactly how this study could benefit children, and I know sometimes we're a bit inward thinking when we're busy with our own lives and our own family, we think about our own children first before the wider society. It's probably only natural. So I think people need to see what locally that's going to do for them, for their children, to really put some weight on that.” (Male, Two Parent Household)

3.3 Understanding a new generation

Information across the study materials that highlighted why the research was interested in their child's specific generation was appealing to participants. This was particularly the case where this identified key issues such as the cost-of-living crisis and the COVID-19 pandemic. Participants recognised that these were likely to impact their children and these issues held personal resonance.

More broadly, there were mentions of how parenting differed across generations. Where mentioned, participants noted that they themselves were interested in this, and felt the study would be looking at these types of issues.

> "Even looking at how my mum raised us and how I'm raising my daughter, it's all the generational difference is quite immense, so that was probably the main thing." (Female, Lone Parent)

3.4 Sharing my opinion and experiences

Where the idea of sharing opinions and experiences was appealing, participants described welcoming the opportunity to share their experiences as a parent. As part of this, they recognised the value of the study gathering views and experiences from both mothers and fathers.

> "Doesn't take too much time, it's just a chance to talk to somebody. I think, you know, sometimes I don't have people to talk to if we haven't been doing a playgroup or whatever it might. So, it's just nice to have a chat to someone about what life looks like and if it's, you know, going to inform things for children, it's always a good thing. It's interesting." (Female, Two Parent Household)

> "Being a parent if you hear anything that takes an interest in your child you're going to be quite intrigued to know what else is coming, you know?" (Female, Two Parent Household)

3.5 Including diverse families

Participants positively reported that the research materials made clear that the study was looking to include families from diverse backgrounds and circumstances. This was considered important, and participants were encouraged to see this approach to the study, often noting that they would be interested to learn about different families in study updates.

> "I thought it was quite interesting, I didn't actually know that these studies were a thing, which I think is quite good because you get so many different family types and different experiences through family types, so I thought this was really good. And you can gauge what's needed the most-, in views of supporting families and just work through how everyone lives differently especially because with different backgrounds, that can really play a major impact in that, so I thought it was really cool. I didn't realise that things like this were happening." (Female, Lone Parent)

Key elements of the study materials that signified the importance of including diverse families included:

- The offer of receiving information or taking part in another language. Participants from an ethnic minority background were particularly likely to identify this as important for those with English as a second language.
- Images used across materials depicting the diversity of different families.
- The inclusion of information about parents who live separately. This signified to participants that the study was interested in hearing from different family environments.

Making clear the inclusive nature of the study was also considered important. There were instances where participants felt that the study materials could use text and images to better clarify whether families with a disabled child, or with parent/s who were not British citizens, were eligible to take part.

3.6 Financial incentive

The study materials included the following information about incentives for participation in Generation New Era:

- There would be a £10 incentive for each interview carried out.
- There would be a £5 for each DNA sample provided to the study.

Participants were asked for their views on these as well as views towards the study providing a bib as a thank you for taking part.

It is useful to reflect that participants received £45 for taking part in each research interview. This may have influenced their views towards the incentive amount offered for those taking part in a Generation New Era interview.

3.6.1 Incentive for taking part in a Generation New Era interview

There were mixed views on the role and amount of the incentive offered to those taking part in a Generation New Era interview. In some instances, it was anticipated that the incentive would be greatly appreciated, particularly considering the current economic environment and tight household finances. However, others suggested that £10 felt like a low sum for an hour of time. These attitudes influenced views towards the prominence given to information regarding the incentive in the study materials. In particular, those who felt that the sum of £10 was unlikely to be personally appealing suggested that including this information in bold text in the opt-out letter was unlikely to be motivating. In some instances, participants queried whether there was any value in mentioning the incentive.

Overall, there were some aspects of the incentive that participants felt could be clarified in the study materials. This included specifying what type of voucher the incentive would be provided as, and making clear that the incentive was £10 for each interview.

3.6.2 Incentive for providing a DNA sample

Views regarding the provision of an incentive for each DNA sample provided were varied, ranging from concerns that an incentive could be coercive through to the suggestion that the incentive was not large enough to encourage participation. There was a suggestion from one participant that the study information should make clear who was providing the incentive, to address any potential concerns that the incentive would be provided by an organisation who were keen to collect DNA samples for a reason beyond the research purposes.

3.6.3 Baby's bib as a gift

Views towards the gift of a bib for the baby were also mixed. Overall participants felt that it was a nice touch but was not a strong motivator to take part in Generation New Era. Not all felt that they would be likely to use the bib if they were to receive it, and there were queries regarding what the bib would look like and what type of fabric would be used, noting that parents may prefer to use certain fabrics for their babies.

3.7 Time

Those raising lack of time to participate in the study as a concern reflected that they had busy lives and would therefore find it difficult to find a suitable time slot for the study. There were some queries regarding what the time commitment for participating in the study would be in the longer-term with suggestions for the study materials to clarify this.

3.8 Trust and reassurances

Trust in the Generation New Era study was central to whether participants felt comfortable to participate and emerged as an important part of the advance booklet text across both stages of research.

Existing awareness and attitudes towards personal data use could influence views. This was particularly the case across stage 2 interviews. When speaking about sharing information from administrative records and sharing DNA samples there were instances where participants mentioned:

- Existing awareness of GDPR and consent approaches. Knowledge of these was typically reported amongst those who had come across these in their work. There was also recall of the change to an opt-out system for organ donation in Northern Ireland which took place in March 2022.
- An awareness of the different ways in which organisations may use data. Participants had come across examples of organisational use of data in different places.
- Hearing about issues with data sharing. Where participants had heard about issues such as data breaches or personally had decided not to share their data e.g., use social media, they typically described heightened caution in how personal data was used.

Where expressed, awareness and attitudes tended to provide context for participant views and could lead to either support for, or concern regarding data sharing, particularly for DNA samples. For example, one participant noted that they read research reports and, based on this, felt that they understood the benefits that personal data could bring to studies and would personally feel comfortable sharing their data. Another participant, who described how they avoided sharing personal data and had made an active choice to avoid activities such as ancestry DNA tests, noted that they would be uncomfortable sharing this personal data with the study.

Regardless of existing awareness or views regarding data sharing, it was clear across both stages of research that trust in the study and how data would be used played a crucial role.

> "I think again, it comes down to trust and underlying that's [data linkage is] all confidential."
> (Male, Two Parent Household)

Participants cited a range of reassurances as important in building this trust including:

- Confidentiality of participation and any data shared including reassurances around the anonymity of the data, who has access to the data and how the data will be used. Participants who had previously heard of misuse of data also suggested providing information about how data would not be used e.g., by advertisers, police, or solicitors. This was particularly noted when thinking about the use of DNA samples.
- The authenticity of the research - for example, participants noted the importance of being able to check online that the research was legitimate.
- Who is carrying out the research and which organisations are involved. Participants were reassured to see links to the NHS and Public Health organisations across the research materials as well as details regarding universities involved.
- Clear information and protocols regarding the interviewer visit, including provision of the interviewer's name, ID number and coverage of any COVID-19 procedures.
- Making clear that there would be no impact on the parent or child by sharing the personal data requested. This was raised specifically when discussing comfort in taking part in different study elements including adding information about your and your baby's genes.
- The optional nature of taking part. Choice and control emerged as a key factor influencing comfort in participation and is discussed fully in section 3.9.

Whilst participants generally felt that these types of reassurances were provided in the advance booklet text, it was noted that many of the queries they had around issues such as confidentiality were largely addressed in the 'Looking after your information' part of the booklet. This part of the booklet appears after booklet text regarding 'adding information from administrative records' and 'adding information about your and your baby's genes'. Participants suggested that this information could be provided earlier in the booklet.

3.9 Choice and control

Feelings of choice and control over Generation New Era and study element participation was driven by four factors.

1. Being clear that taking part is optional.
2. Providing clear information about what taking part involves.
3. Providing clear rationale for why the data is sought.
4. Recognising sensitivities.

These are discussed below.

Being clear that taking part is optional

Clarity of the optional nature of participation in the study as a whole, as well as specific study elements, emerged as a key building block for creating trust in the study and ensuring that participants felt in control of their participation.

> “The fact that taking part is completely up to you. I like the fact that you get the option, once you can opt out any time that you wish.” (Female, Lone Parent)

Participants felt that the advance booklet text made it clear that taking part in the overall study was optional. Also, making clear that taking part in study elements was optional was particularly important, as participants felt that if this was not clear it could impact their likelihood to take part in the study overall.

> “[…] when I read that [information about adding information from administrative records] I thought 'Oh flipping heck, that's a bit extra.' […] But, then I thought it's your choice on which records to add to it, I thought, 'Okay that's fair, that's actually fair.'” (Male, Own Household Father)

Providing clear information about what taking part involves

Whilst participants felt that this choice regarding study elements (including the option to change your mind) was clear in the booklet text, some queries emerged.

Queries around the study element ‘adding information from administrative records’ focused on the clarity of which records and what type of information would be accessed. As discussed in section 4.3, participants felt that detailed information about records and information helped clarify what this study element would involve. This also helped make clear that it was possible to ‘pick and choose’ which records were accessed, something that participants reflected was not clear in the booklet text. There were also queries from participants about whether they would be able to take part in Generation New Era if they did not consent to sharing information from administrative records.

Queries and comments regarding the study element ‘adding information from your and your baby’s genes’ were often raised by participants at the outset of the stage 2 interviews, suggesting that this element of the study was something that stood out to participants. These spontaneous views were mixed with some expressing interest in the idea of participating whilst others expressing uncertainty about this study element. Regardless of views, clarity of choice was important.

> "This section I won't consent. It's great that you provide the information and it's fully transparent but as you said, it states it clearly that you have a choice in this. So, the information is there." (Female, Lone Parent)

> "It's nothing by force. If you want to do this, you can do this. If you don't want to do that you don't want to do that. That made me feel 100% comfortable because you're not jamming it down my throat." (Male, Own Household Father)

Providing clear rationale for why the DNA data is sought

Queries regarding DNA samples were varied. There were questions regarding whether participation in this study element would be useful if the parent and/or child did not have a health condition, and whether ultimately it would still be useful for the study for a family to participate in Generation New Era if they did not agree to the DNA sample element. Participants suggested that the booklet text could clarify these points. Other queries were raised by participants who were not always convinced about the benefit of DNA samples for this study, or who expressed wider concerns about data security and the anonymity of DNA samples. Clear information about choice for participation alongside rationale for why the data was sought and how it would be confidentially handled emerged as important. Participants felt that it was not always entirely clear why the study sought this data.

> "You guys have been doing this [cohort studies] since the 1970s and you've been able to track everybody successfully. Why now do you also want my child's DNA?" (Female, Lone Parent)

As noted in section 5.4, participants felt that the reason and benefit for the study seeking this data was not always front and centre in the booklet text.

Recognising sensitivities

Two key potential areas of sensitivity emerged across the research: sensitivity around the parental relationship and sensitivity around the topics for exploration in Generation New Era.

Parental relationship: participants including lone parents and own household fathers noted that relationships varied, and some situations could be sensitive. They felt that it would be important for the study to recognise and reflect this. In particular, participants suggested that it would be important to make clear that taking part in the study was optional and how to contact the study if there were concerns about a partner taking part. Sensitivity of participation particularly emerged for own household fathers, reflecting previous research with this group[9]. For example, an own household father noted how the breakdown of the relationship with their partner could mean particular sensitivities around terms such as '*interview*'.

> "When I think interview, interviewed what? At a police station? A job interview? In the court of law? Come on, again, if I'm having issues with my partner. I'm not saying she's going to take me to court, I'm not taking her to court, but if we've had times where. It's just again, 'Each parent will be interviewed separately.' I know it's not your intention, I know it's open for interpretation, and what you say is clear, but I just don't like the word, 'Interviewed', 'Each parent can contribute separately,' yes? not interviewed separately." (Male, Own Household Father)

Study topics: participants noted that some of the topics for discussion in the Generation New Era survey could be sensitive depending on participant experiences and circumstances. These are further

---

[9] https://the-sra.org.uk/common/Uploaded%20files/Social%20Research%20Practice%20Journal/social-research-practice-journal-issue-13-spring-2023.pdf

discussed in chapter 6 which reports on findings from a cognitive testing element of the stage 1 research.

3.10 Implications and considerations

Insight into the factors likely to drive motivation and comfort in participating in Generation New Era raises a number of implications and considerations for both study communications and processes. These, alongside steps taken to date to reflect these, are summarised below.

Implications and considerations for study communications

- Given the range of factors likely to influence study participation, it will be important to ensure the study materials reference this range.
- Where social value is a motivator for taking part, additional examples of study impacts are likely to further engage people.
- Trust and reassurance are important and therefore the positioning of information on this topic for the advance booklet (Looking after your information) should be carefully considered.
- It will be important to ensure that choice and control is clear across study materials.
- It will be useful to consider how participant queries and suggestions for improvements to the clarity of study materials can be reflected in revisions to study materials going forwards.
- Clarifying the inclusive nature of the study and who is able to participate (e.g., disabled people, those who do not hold British citizenship) is important.

Steps taken to reflect these implications and considerations included a review of study materials:

- Ensuring that choice is made clear throughout. The advance materials all include clear statements that participation in the study and study elements are voluntary: e.g., in the advance booklet *'You can skip any questions that you don't want to answer'*; *'It is your choice'; 'If you don't wish to do this, you can still take part in the study'*; *'It's completely up to you'*; *'We hope both parents take part, but it's up to each of you to make your own decision'*.
- Ensuring that materials appeal to the different motivating factors, and provide reassurances on the potential barriers, raised by participants. Examples from the revised advance booklet include:

  a. **Social value**: *'By being part of Generation New Era, you can help shape the future for UK families'*; *'Study will help researchers, governments and service providers to improve the lives of children and families in the UK'; 'Opportunity to be part of this important scientific research'*.

  b. **Understanding a new generation:** *'Babies born today belong to a one-of-a-kind generation. The pandemic and the cost-of-living crisis have brought unique challenges for mother and fathers like you, your children and your futures.'*; *'First UK-wide study of its kind for over 20 years'*.

  c. **Sharing opinions and experiences: '***We want to understand your experience of being a parent'; 'Knowing what your life is like and how you are experiencing being a parent is vital to building a full picture of your baby's life'*.

  d. **Including diverse families***:* *'For the study findings to help all kinds of families, we need to hear from all parents, in all nations and regions of the UK, including yours.'*; *'Every family chosen for the study is unique and we can't replace you with anyone else.'*

e. **Incentives:** *'Everyone who takes part will receive a high street voucher as a thank you for their time.'*

f. **Time:** *'If you're out or it's not convenient, the interviewer will come back at a better time'; 'The interviewer will arrange a day and time that works for you for your interview.'; 'This can be done either in person with the interviewer or online, whichever suits you best.'*

g. **Trust and reassurances:** *'It will always be up to you to decide whether you want to take part'*; *'The information is used for research purposes only'*; *'Your study information is treated in strict confidence and kept securely.'*

- Further examples of study impact have been included on the participant-facing Generation New Era website. Examples of the impact of similar studies that are featured on the website can be seen here: https://gnestudy.info/why-take-part/making-a-difference/.
- Consideration was given to whether areas where greater clarity was sought could be addressed through clarification either within the advance booklet text or as a study FAQs on the study website. For example, an FAQ about whether parents who are not British citizens could take part was added to the website. In the advance materials, information about how participants were selected was moved earlier within the materials to avoid confusion.
- Ensuring the materials highlight that the study wants to talk to a diverse sample of parents and families. This included ensuring a diverse use of family images throughout the revised advance booklet. The study website and interviewer training also covered who is and is not eligible to take part in the study.

Implications and considerations for study processes

- A flexible approach to participation will help engage those concerned about time to participate.
- An incentive will be motivating for some.
- It will be useful to consider the role of the interviewer in building trust in the study, providing reassurances and recognising the potential sensitivities.

Overall, it should be noted that the study design aims to meet the challenges of interviewing a time-poor population. For example, the study offers different interviewing modes (f2f, web, telephone, Teams) and the opportunity to complete questions over more than one session, and interviewers will make multiple attempts to try to contact and schedule a convenient time to speak to parents. The study team also recognises that incentives are likely to support participation in the main study and are conducting experiments about the best forms of incentive (including unconditional, conditional, and cash vs. gifts) to help inform the best use of the incentives budget for the main study.

Steps taken to reflect the potential role of the interviewer include reviewing interviewer processes and training to ensure they consider:

- Equipping interviewers with detailed information about confidentiality and data security so that they can provide further information and reassurances if needed.
- Equipping interviewers with detailed information about study elements with a specific focus on adding information from administrative records and adding information from your and your baby's genes so they can provide further information and reassurances if needed.
- Providing interviewers with guidance on navigating different family circumstances or study topics that may be sensitive in nature.

4 Processes for taking part

Across both stages of research interviews, participants were asked for their views on potential processes related to taking part in Generation New Era. This chapter describes participant views towards the following:

- Sending the opt-out letter: where parents live in the same household, sending the opt-out letter to each parent.
- Opt-out process for Generation New Era: implementing an individual parent opt-out for participating in the study where parents live in the same household.
- Consent processes for adding information from administrative records: implementing an opt-in or opt-out approach for this data linkage, and continued linkage over time.
- Consent processes for adding information about where you live: informing participants about this linkage and what to do if they do not want this to happen.
- Consent processes for the child taking part in data linkage and DNA samples.
- The provision of confirmations for both adding information from administrative records and adding information about your and your baby's genes.
- The approaches for keeping in touch with Generation New Era participants including the use of administrative data to trace people.

4.1 Sending the opt-out letter

When exploring reactions to the opt-out letter, participants were asked for their views on sending an individually addressed letter to each parent in the household.

Views towards receiving an individually addressed letter were mixed. Participants living in two parent households noted that the benefits of this approach were that it clearly gave both parents the opportunity to take part in Generation New Era, and that it could help make it clear that there was a separate opt-out required for each parent. However, not all felt that separate letters were necessary, particularly where participants noted that they read their partner's post. Concerns regarding the environmental impact of sending multiple letters to a single household, as well as queries around whether this would be a cost-efficient approach for the study were voiced.

Participants living apart from their baby's other parent noted that the information within the opt-out letter detailing '*What if I live apart from my baby's other parent'* was important. They found this information reassuring, particularly noting that there were likely to be different relationships and sensitivities amongst parents who did not live together. With this in mind, they were reassured to see how the research was explained to both parents, and that there was a way to request that the child's other parent not be contacted if needed.

Overall, participants felt that the study materials (including the opt-out letter) felt aimed at both fathers and mothers and did not expect different versions. It was noted that the study materials, including the images shown in the advance booklet, made it clear that both fathers and mothers were being invited to participate in Generation New Era.

> "Yes, I think so. I don't think it, sort of, creates any bias towards one or the other. I think it's sort of gender neutral." (Male, Two Parent Household)

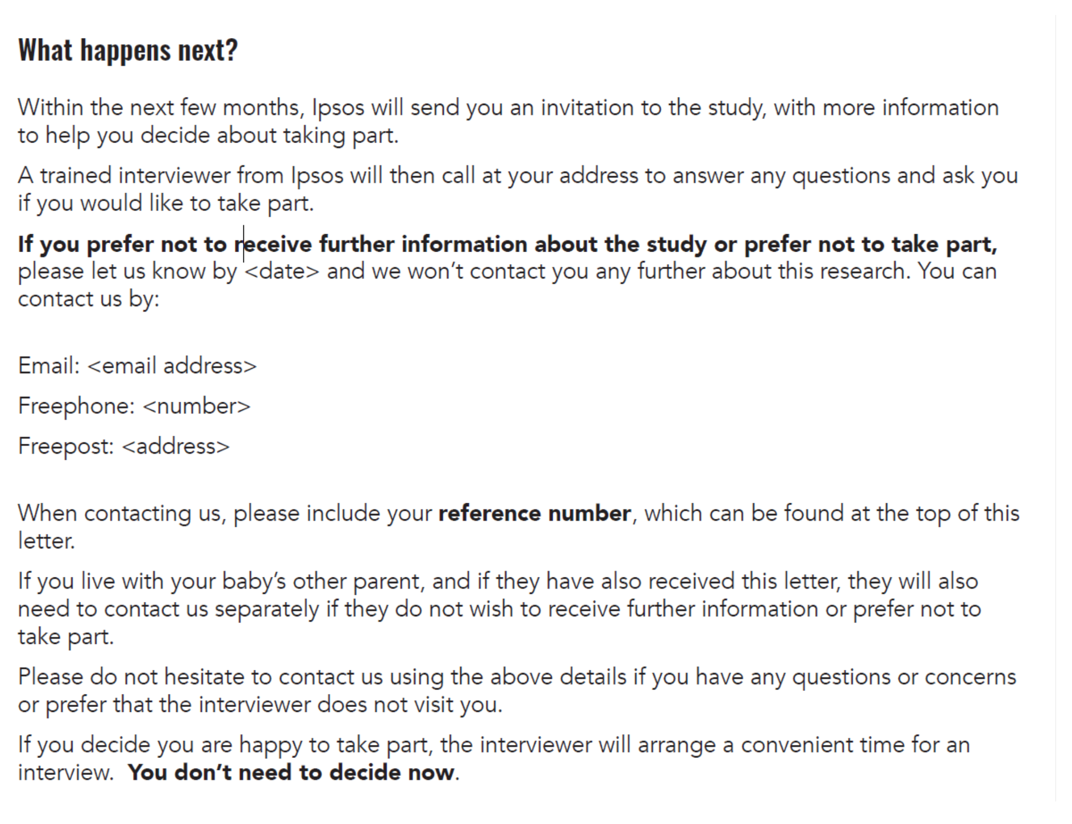
4.2 Opt-out process for Generation New Era

Participants were asked for their views on the opt-out process for Generation New Era as described in the opt-out letter.

Across the stage 1 research interviews, some confusion and uncertainty around the Generation New Era opt-out process emerged. This confusion was in part driven by lack of recall from participants about the opt-out process. It was clear across the research that participants read the opt-out letter (and other study materials) in varied depth. Those who reflected that they had ‘skimmed’ the content were not always clear how the opt-out process would work.

Participants were specifically asked for their views on the ‘*What happens next*?’ section of the opt-out letter (see figure 4.1). This section details information regarding the opt-out process.

Figure 4.1: Opt-out letter: What happens next? section



What happens next?

Within the next few months, Ipsos will send you an invitation to the study, with more information to help you decide about taking part.

A trained interviewer from Ipsos will then call at your address to answer any questions and ask you if you would like to take part.

If you prefer not to receive further information about the study or prefer not to take part, please let us know by <date> and we won’t contact you any further about this research. You can contact us by:

Email: <email address>

Freephone: <number>

Freepost: <address>

When contacting us, please include your **reference number**, which can be found at the top of this letter.

If you live with your baby’s other parent, and if they have also received this letter, they will also need to contact us separately if they do not wish to receive further information or prefer not to take part.

Please do not hesitate to contact us using the above details if you have any questions or concerns or prefer that the interviewer does not visit you.

If you decide you are happy to take part, the interviewer will arrange a convenient time for an interview. **You don’t need to decide now**.

Whilst participants felt that the text made clear that there were a range of ways for people to opt-out, they felt that this section, as well as the opt-out letter overall, was long and wordy (further discussed in section 5.1). This, alongside comments around the different topics covered in this section (e.g., what if you do not live with the baby’s other parent, and information about arranging an interview), suggested that the opt-out information provided was not always clear and easily navigated.

Participants were asked for their views on an individual opt-out for participating in the study where parents live in the same household. Views were mixed. The individual opt-out approach was felt to provide flexibility for situations where only one parent may be able to take part (e.g., may have time during maternity leave, or may lack time due to working patterns such as night shifts). However, there was also a sense that it could be simpler to provide a single opt-out.

> “I think I would just assume that, because you're talking about the 1 child, that there would be 1 letter per child, rather than 1 letter per parent. In this letter, each parent has to opt out individually, as well. Again, I can see why that is the case, but I think, as a two-parent household, we might think, 'Why do we have to do it separately? Why can't we just do it together?'” (Male, Two Parent Household)

Comfort in individual opt-outs was influenced by the overall reason for wanting to opt-out. In instances where a parent was seeking to opt-out because they were not comfortable with the child being a part of the study, a single opt-out was often suggested. However, where the family were likely to seek flexibility of involvement (e.g., a parent was opting out due to time constraints, but the other parent was happy to participate), then the individual opt-out approach was recognised as useful.

4.3 Consent processes for adding information from administrative records

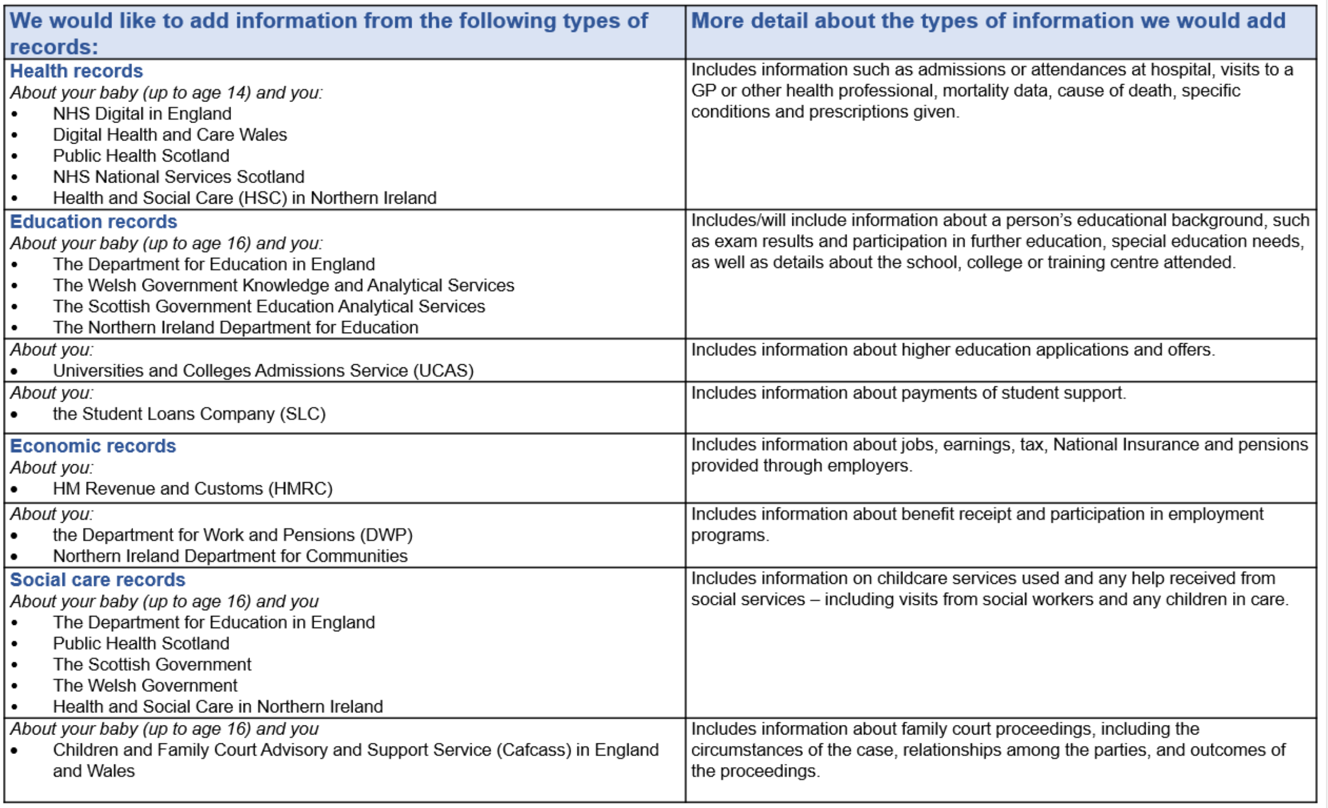
Stage 2 research interviews explored participant views towards the consent process for adding information from administrative records. Two consent approaches were presented to participants – opt-in and opt-out.

Opt-in approach:

Interviewers read out the following explanation: *if you agreed to take part in the study, then an interviewer would arrange a time for an interview which would take place at your home. During the interview the interviewer would ask for your permission for information held in administrative records for you [for non-own household parents only: and your child] to be added to your survey response – they would go through each record in turn.*

Participants were then shown the stimulus below – see figure 4.2.

Figure 4.2: Research interview stimulus: Example of information provided to respondents for an opt-in approach to adding information from administrative records



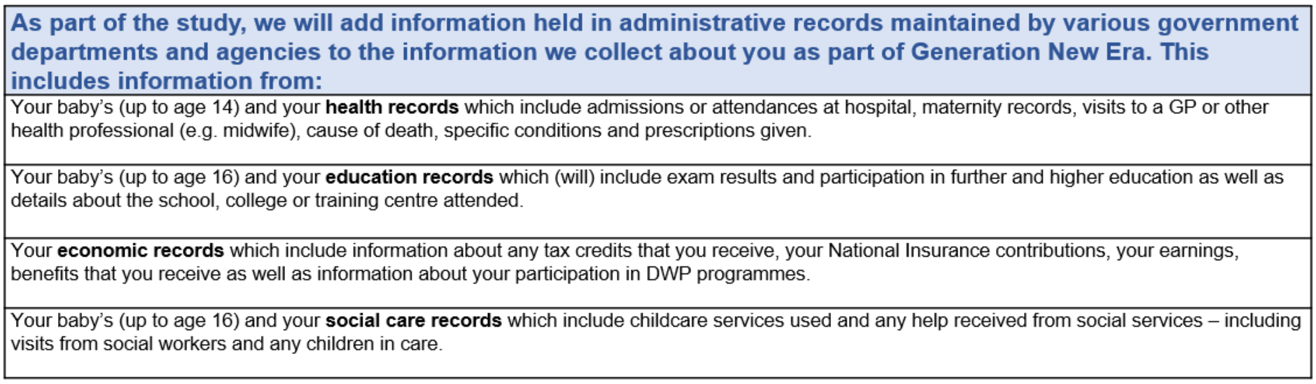
We would like to add information from the following types of records:	More detail about the types of information we would add
Health records *About your baby (up to age 14) and you:* • NHS Digital in England • Digital Health and Care Wales • Public Health Scotland • NHS National Services Scotland • Health and Social Care (HSC) in Northern Ireland	Includes information such as admissions or attendances at hospital, visits to a GP or other health professional, mortality data, cause of death, specific conditions and prescriptions given.
Education records *About your baby (up to age 16) and you:* • The Department for Education in England • The Welsh Government Knowledge and Analytical Services • The Scottish Government Education Analytical Services • The Northern Ireland Department for Education	Includes/will include information about a person's educational background, such as exam results and participation in further education, special education needs, as well as details about the school, college or training centre attended.
About you: • Universities and Colleges Admissions Service (UCAS)	Includes information about higher education applications and offers.
About you: • the Student Loans Company (SLC)	Includes information about payments of student support.
Economic records *About you:* • HM Revenue and Customs (HMRC)	Includes information about jobs, earnings, tax, National Insurance and pensions provided through employers.
About you: • the Department for Work and Pensions (DWP) • Northern Ireland Department for Communities	Includes information about benefit receipt and participation in employment programs.
Social care records *About your baby (up to age 16) and you* • The Department for Education in England • Public Health Scotland • The Scottish Government • The Welsh Government • Health and Social Care in Northern Ireland	Includes information on childcare services used and any help received from social services – including visits from social workers and any children in care.
About your baby (up to age 16) and you • Children and Family Court Advisory and Support Service (Cafcass) in England and Wales	Includes information about family court proceedings, including the circumstances of the case, relationships among the parties, and outcomes of the proceedings.

Opt-out approach:

Interviewers read out the following explanation: *the study team would let people know that information from administrative records will be added to their survey responses unless they tell the study team they do not want this to happen.*

Participants were then shown the stimulus below – see figure 4.3.

Figure 4.3: Research interview stimulus: Example of information provided to respondents for an opt-out approach to adding information from administrative records



As part of the study, we will add information held in administrative records maintained by various government departments and agencies to the information we collect about you as part of Generation New Era. This includes information from:
Your baby's (up to age 14) and your **health records** which include admissions or attendances at hospital, maternity records, visits to a GP or other health professional (e.g. midwife), cause of death, specific conditions and prescriptions given.
Your baby's (up to age 16) and your **education records** which (will) include exam results and participation in further and higher education as well as details about the school, college or training centre attended.
Your **economic records** which include information about any tax credits that you receive, your National Insurance contributions, your earnings, benefits that you receive as well as information about your participation in DWP programmes.
Your baby's (up to age 16) and your **social care records** which include childcare services used and any help received from social services – including visits from social workers and any children in care.

The order in which opt-out and opt-in approaches were discussed across the interviews was rotated to help mitigate any order bias in participant responses.

Both the opt-in and opt-out approaches were viewed as acceptable as long as they involved the provision of clear and transparent information about the use of data, and choice and control over data linkage. However, overall, when comparing the two approaches, participants reported a preference for the opt-in approach to adding information from administrative records. This preference was typically driven by views towards the information (figure 4.2) provided for this option. This information was considered more detailed and transparent, clearly noting which records would be accessed and what type of information would be shared. There was a sense that this greater detail resulted in participants feeling more informed about this study element which helped support their decision-making.

> "I don't really know what information is held about me, to be honest with you, unless you tell me. So I would like to know where the information is going to come from and then I can decide right there and then." (Female, Lone Parent)

Participants felt that this clear choice would be particularly important for families that may not be comfortable sharing more sensitive data e.g., health data.

Whilst typically preferred, it was noted that the information provided for the opt-in approach was lengthy and would therefore be a lot to read. There were also broader concerns about the impact that the opt-in approach would have on levels of uptake for the study with participants anticipating that fewer people would opt-out compared to opt-in.

Where participants voiced preference for an opt-out approach, they typically felt confident that they understood what adding information from administrative records would involve and that they did not need detailed information about this. These participants were likely to note that they were familiar with the idea of sharing this type of information either through work or personally. For example, one participant who had moved country noted that they had needed to share administrative data as part of that process. However, these participants reflected that other people may need more detail and that an opt-in approach might be better suited for others.

A number of benefits related to the opt-out approach were raised. This included greater time to decide about personal comfort in taking part and avoiding any potential feeling of obligation to give a positive response to the interviewer during the interview. There were also comments that the information for the opt-out process was simpler and more streamlined when compared to the information for the opt-in process. It was also noted that an opt-out approach could lead to more data for the study, as fewer people were likely to actively opt-out. However, this benefit was often tempered by participants with concerns that people might not fully engage with what was being asked if an opt-out approach was employed. Participants also felt that the reduced amount of information provided for the opt-out approach could lead to less informed decisions and interviewer questions about records and information sought.

> "I mean you'd probably get a bigger uptake of people doing it then [with an opt-out]. It seems like that could be easily missed if I was someone that wasn't being quite on the ball and then later down the line I'd be like 'wait, when did I consent to this'?...you wouldn't get as much information as you're giving there [opt-in stimulus] and I think morally that's [more information] nice." (Female, Two Parent Household)

Overall, participants did not feel that an opt-out only approach would deter them from taking part in the study. However, they often anticipated that they would be able to opt-out then and there during the interview itself and may want to ask questions about which records were being accessed and what type of data shared. They noted that regardless of approach taken, time should be allocated during the interview for questions. Participants suggested that if the opt-out information (see figure 4.3) were to be used, interviewers should have the more detailed information (see figure 4.2) available to share. It was also suggested that the request to add information from administrative records should not come as a surprise during the interview and that it would be important to include information in the advance booklet, flag the request at the beginning of the interview (even if not specifically discussed until later), and ensure there was a clear pre-amble to explain this study element.

When asked to consider how they would prefer to opt-out if this approach was taken, participants suggested a mix of options including email, webform, telephone, QR code and via an app.

Use of administrative data over time

During stage 2 interviews participants were asked for their views on the use of administrative data over time. They were asked about two scenarios for what would happen if they lost touch with the study or stopped taking part in future waves:

1. What they thought would happen to the administrative records they had given consent for.
2. What they thought about the study team continuing the add information from administrative records they had given consent for unless they contacted the study team to stop this.

Overall, it was clear that participants had not considered or understood how long data linkage would take place for, and what would happen if they could not be reached or decided not to take part in the future. They suggested that this be clarified in the study materials by providing a timescale or making it clear that this would be collected indefinitely.

When prompted to consider what would happen in these situations, participants expected that if they opted out or lost touch with the study that this would extend to their permissions for using administrative records. They felt that in these cases their administrative data should be deleted, or future collection of administrative data should be stopped.

4.4 Consent processes for adding information about where you live

Participants were asked for their views on letting the study team know if they did not want information about where they live to be added to their survey responses.

Participants reflected that information about where they lived felt less personal and sensitive when compared to information from administrative records. With this in mind they typically felt comfortable with the proposed approach to this data linkage, where information would be added unless participants objected to this.

> "This is nothing compared to my personal records […] the first one's more sensitive. This is not." (Male, Own Household Father)

Where recalled, information in the 'adding information about where you live' booklet text that detailed that "*these geographical data are publicly available*" was reassuring. Participants also noted that the example provided regarding how information on air pollution had been used in the past stood out to them and made the benefits of this type of data clear. However, there was some lack of clarity reported regarding whether information about where you lived referred to local data or data specific to your actual house or building. Participants noted that the latter felt more personal.

4.5 Consent processes for the child

Participants were asked for their views on who provides consent for the child for both adding information from administrative records and adding information about the baby's genes.

Overall, participants reflected that giving consent for their child's data was an important decision. Whilst some reflected that this type of decision was part of parenting, others noted that it was a decision that they did not feel comfortable about.

> "You're taking a risk to say did your child really want you to do that? But that's always just parenting and you've to make decisions for them for a long time." (Female, Two Parent Household)

> "It's very unfair in my opinion to make that decision for my child without their consent. Because they're not old enough to know or even have a choice in this." (Female, Lone Parent)

Across the interviews there were mixed views on who gives consent for the child and participants noted that family dynamics would likely influence preferences.

Participants were asked for their views on consent being provided by one parent. There were mixed views towards this. Those comfortable with this idea anticipated that they would discuss the child's participation with the other parent or felt comfortable making the decision and informing the other parent. Those not comfortable with this approach felt that the child's participation in these study elements should be a joint decision. There were also queries around what would happen if parents did not agree, and how this would be dealt with if it became apparent during an interview.

The role of family dynamics was particularly highlighted by the thoughts of own household fathers regarding who gives consent for the child to participate. Diverse participant experiences demonstrated the impact of the relationship with the mother of the child on this process. For example, one participant described how they would discuss the decision with the mother of their child but ultimately would feel comfortable with the mother's decision feeling that they were likely to have similar views on the topic.

> "If it was something that's going to help the child, then I would trust in her as she won't make any negative decisions." (Male, Own Household Father)

Another participant described how they were not in contact with the mother of their child. The idea that they might need to make contact was a key concern. Suggestion of this or a sense of feeling pressured to make contact was noted as something that would not be met with positively and would result in quick disengagement from the study. They recognised that this dynamic presented a challenging situation around consent. This participant reflected that if he did not feel comfortable getting in touch with the mother then he would ultimately need to accept their decision about the child's participation.

> "I'm not in control of what she does over that child, I can only be in control of what I can do, so if she does that then so be it. Would I be happy about it? No, but again that's on her." (Male, Own Household Father)

A query was raised by an own household father about what would happen in a situation where an own household father was not on good terms with the mother of the child and was not comfortable with their child's data being shared. This participant expected that there would be a way for the father to contact the study to voice this concern.

4.6 The provision of confirmations

Participants were asked for their views on the provision of confirmations for both adding information from administrative records and adding information about your and your baby's genes.

Participants were positive towards the idea of receiving a confirmation for both data linkage and the provision of DNA samples, and for both confirmations felt that it would be useful and transparent to include information about what to do if you changed your mind.

When thinking about a confirmation for adding information from administrative records, participants felt that it would be useful to have a record of what had been agreed.

When thinking about a confirmation for adding information from their and their baby's genes, there were differing suggestions for what this could contain. This included confirmation of what had been agreed to (e.g., what had been provided and how it would be used) and confirmation that the DNA samples had been received and processed.

> "Just to make sure, just to reassure you that's it's definitely in their hands." (Female, Lone Parent)

There were mixed preferences for receiving confirmations by post or email and this was typically driven by an individual's preferred way to file the document.

4.7 The approaches for keeping in touch with Generation New Era participants

During stage 2 interviews participants were asked for their views on study contact approaches that could be taken following participation in the first interview. They were asked for their views on:

- The study keeping in touch via email and telephone and through a friend or relative (identified by the participant).
- The use of information from administrative records to find people that the study had lost touch with.

It should be noted that due to timing challenges during interviews, only four participants commented on these approaches.

Participants felt comfortable sharing their phone number and email for the study to contact them, but they did not want to share the details of friends or family. This was because they did not think that others should play a role in their decision to keep in touch with the study.

> "I don't really feel comfortable with [sharing a friend or relative's details]. Because, again, you've taken that control away from me and put it in the hands of somebody else, when this is about me and my child."
> (Female, Lone Parent)

When thinking about how they could be prompted to update the study with change of contact details participants reflected that people very rarely changed their email address or phone number. They therefore felt that calling or texting, and emails seemed like good ways to keep in touch with people.

There was a negative reaction to tracing participants through the use of administrative data. Participants did not think it was appropriate to trace families without notifying them first. For example, one participant suggested that explicit consent should be sought for this. Participants noted that people would likely become suspicious of how the study had been able to find them after moving address if they had not shared this information directly.

> "Yes, I definitely think that [notifying people you are tracing them through the NHS] should be the case because then it just leaves people in limbo, wondering 'Well, I've moved house since taking part in this study and now magically they've found out where I live'. So, you would automatically want to know how these people have obtained your address again to get in contact with you, even though you have moved."
> (Male, Two Parent Household)

4.8 Implications and considerations for study processes

Participants' thoughts and reactions to study processes raise a number of implications and considerations. These, alongside steps taken to date to reflect these are summarised below.

- Changes to the opt-out letter could support improved engagement with this material. Examples include shortening the letter to improve clarity of content, and considering the environmental concerns related to sending individual copies to each parent in a two-parent household. Building on this, mixed reactions to individual parent opt-outs for Generation New Era suggest that there may be an expectation for a household-level opt-out.
- Whilst not universal, there is a preference for an opt-in consent model for adding information from administrative records. Alongside this, it is important for the study to consider how to provide enough information about records and data sought and reflect that people may seek further information and ask questions about this. There is clear indication that if employing an opt-out approach, there will be an expectation of being able to opt-out then and there during the interview. It will also be important to be clear about how long data linkage takes place for, what happens with data linkage if a participant loses touch with the study and how data linkage is used for contact tracing.
- The proposed approach for adding information about where participants live (i.e., informing the study team if you did not want information about where you live added to your survey responses) is considered acceptable.
- Mixed views towards whether consent for the child can be sought from one parent suggests that there may be some discomfort or unease around this. Building on this, it will be important for the study and interviewers to recognise different sensitivities relating to family dynamics, especially for own household fathers who may not want to make contact with the mother of the child.
- Confirmations of what has been agreed to (both for data linkages and DNA samples) is likely to build a sense of control for Generation New Era respondents regarding what is happening to their data and that their data has arrived at the correct place/has not gone missing.

Steps taken to reflect implications and considerations regarding the opt-out letter included:

- Individual opt-out letters were sent to parents living in the same household, but the advance mailing included individual advance letters packaged within the same envelope with a single copy of the advance leaflet. This aimed to balance environmental/ cost concerns about duplicate mailings, while stressing that the study would like to speak to both parents.
- The length of the opt-out letter was significantly reduced to provide a short letter and more detailed Q&A on the reverse.

- Ensuring flexibility with the Generation New Era opt-out process. Parents are still able to opt-out individually, but a process is used to check whether parents who are contacting the study team to opt out are opting out personally or on behalf of both parents.

Steps taken to reflect implications and considerations regarding data linkage consent processes included:

- The study tests both opt-in and opt-out approaches for adding information from administrative records across the sample. The consent wording was critically reviewed to ensure the opt-out approach is fully transparent with a commensurate level of information to that of the opt-in approach and that adequate detail on the linkages is provided in the study materials and website. Those who are part of the opt-out approach sample are able to spontaneously refuse/ opt out of data linkage at the start of the interview when this is mentioned (without needing to change consents at a later stage).
- Participants in both groups have the chance to modify their choices through a range of methods, including an online form which will be signposted in the interview and study materials.
- The script regarding data linkage for both opt-in and opt-out approaches includes full details about the records being accessed which respondents can access/ query. Further details are also available in FAQs (via the website and/ or interviewer).
- The study website FAQs ‘Looking after your information Q&A’ includes information about what will happen if the study loses touch with the respondent.
- For adding information about where participants live, the study informs participants this will happen, and lets them know they should contact the study if they do not want this to happen.
- For practical purposes, the study only asks one parent to give consent for their child’s data linkage, but materials/ interviewers encourage parents to discuss this in advance and come to a joint decision. The parent giving consent must have legal parental responsibility and live in the child’s main residence. Interviewers have been briefed on what the process is should parents disagree on this point during the interview itself.
- Reflecting sensitivities of family dynamics, the study offers a range of options for contacting own household parents (e.g., one parent passing on information to another; parent checking whether they can share contact details for other parent) to reflect these sensitivities, and recognises that it won’t always be possible to contact the other parent.
- Confirmation letters of data linkage consents will be sent to all respondents, with guidance around how to change permissions if respondents have changed their mind. Participants receive an automatic email confirming their choices if they update their permissions online.
- A leaflet is also left with participants after the interview is finished to remind them of the elements of the study, what will happen to their data and how to change their permissions in future.

5 Design of research materials

This chapter brings together findings from across both stages of the qualitative research interviews to understand how participants feel about the design of research materials. Feedback is provided for the following research materials (full copies are provided in the appendix):

- Opt-out letter
- Advance letter
- Advance booklet
- Additional advance booklet text for: adding information from records, adding information about where you live, adding information about your and your baby's genes and looking after your information.

The chapter specifically explores the following design elements of these materials: length and layout, tone, content and clarity, colours and imagery, use of logos and signatures.

5.1 Opt-out letter

Length and layout

Participants found the layout of the opt-out letter easy to digest and thought that it had good spacing and clear section headings. They particularly liked how sections were laid out in a 'question, answer' format. However, there were suggested improvements. This included suggestions to refine the order of information to better reflect when each stage of the survey process would unfold - for example, to move the '*What happens next?*' section to the end of the letter. There were also suggestions for greater use of bold text in the letter to highlight and draw the eye to important headings or information. This was noted as particularly effective when used in the advance letter (as discussed in section 5.2).

Although participants appreciated the information included, the opt-out letter felt long and wordy. They commented that a shorter letter would feel less daunting and could also encourage people to read the letter in its' entirety. Participants identified the first paragraph as key in determining whether they would read the rest of the letter.

When prompted to consider the potential for FAQs to be included in the letter, participants felt that these would be a good way to condense the information as well as highlight the most essential content. Other suggestions to reduce the length included using bullet points to summarise content and overall streamlining of any repetition.

Tone

Participants felt that the letter had a friendly tone based on the welcoming and informative nature of the introduction, the mention of the benefits of taking part, as well as the phrases or words placing active choice on the reader. Words and phrases mentioned included: '*it will always be up to you*', '*you don't need to decide now*', '*we hope very much that you'll be able to*' and the word '*opportunity*'. The tone of the opt-out letter was often compared to the tone of the advance letter which was considered more 'direct' and 'assumptive'. This comparison typically strengthened participant views that the opt-out letter felt friendly.

Content and clarity

Overall, the letter was considered easy to understand, but there were suggestions for greater clarity and information regarding two key points:

1. The focus of the research. Participants were not always sure what the research was about and wanted to see the types of questions that would be asked in an interview or more information about the main aim of the research.

> "That was the only question that stood out to me. In my mind I was like, 'Okay, so it's about the new generation,' but I was wondering what the, I don't know how to put it, like, what the actual research was about."
> (Female, Two Parent Household)

> "'The aim is to follow the lives of several thousand children as they grow up.' Brilliant, why? Why are we following their lives? Why is it vitally important? What is it you're doing? What's the actual objective?"
> (Male, Two Parent Household)

2. Frequency of participation. There was uncertainty around the frequency of interviewer visits during the study over time. The word 'longitudinal' could feel like 'jargon' and was not understood by all.

> "How often are they going to be contacting me? Because I'm thinking I really don't want to be contacted every month for, it doesn't say how long, it just says as they grow up."
> (Male, Two Parent Household)

Overall participants felt that greater use of FAQs could further support the clarity of the letter noting the usefulness of the existing 'Q&A' structure in signposting the reader to useful content.

> "I think certainly as a parent, sometimes I can't take lots of information in one go, so, kind of, FAQs is probably a quick way to write, 'What do I need to do if I was going to be involved in this?' Like, short sharp, idiots guide to being involved in this research, I suppose."
> (Female, Two Parent Household)

Participants suggested that FAQs could include guidance on the following: how they were selected, how to opt out, how to request that the child's other parent is not involved, and time commitment/frequency of visits.

5.2 Advance Letter

Length and layout

Participants were positive towards the length of this letter noting that the one-page format would make them more likely to read it (when compared to the longer opt-out letter).

> "I would be more likely to read something that was shorter." (Male, Two Parent Household)

Whilst shorter than the opt-out letter, participants felt that it provided a good amount of detail and there were positive comments regarding the use of bold text to highlight key content. Providing the advance booklet alongside the letter was also noted as a way to ensure the recipient has easy access to further detail.

Tone

Views regarding the tone of the letter were mixed. Positive comments focused on the more succinct and 'to the point' feel of the letter when compared to the opt-out letter. However, participants felt that if this was the first piece of communication they were to receive about Generation New Era (for example, if they had missed or forgotten about the opt-out letter), this letter could feel ‘sharp’ in tone. These participants felt that the more directive tone felt less welcoming. In particular, there were comments from those who were generally less comfortable with the idea of an interviewer coming to their door that the directive feel of this letter alongside information about the next stage of the process felt ‘abrupt’ and ‘assumptive’.

> “Some of the language I think turns me off a little bit, you know, about saying, it seems a little but presumptuous in some cases, and I think that's a little bit aggravating. If that were a little bit aggravating, that would make me sort of say, 'Well, no, I won't have to let anybody in I don't want to.” (Male, Two Parent Household)

There was suggestion that to help mitigate this, the letter could make clear that it was a follow-up letter rather than the first attempt to make contact.

Content and clarity

Overall, the advance letter was considered easy to understand but there were some suggestions for how clarity could be improved. As reported for the opt-out letter, there were suggestions for more information about the study’s purpose and the types of questions that would be asked in the interview itself.

> “So maybe a few example questions on it, you know…I understand it's going to be ground-breaking scientific research that will benefit the lives of families and children, but what is it specifically that you’re looking at? Are you looking at what they eat for dinner or, like, their social schedule? Things like that. Just a clearer understanding of the types of questions.” (Female, Two Parent Household)

Specific queries after reading this letter included: how it is decided which parent does the longer and shorter interview, the time commitment/frequency of visits, whether the interview needs to be face-to-face, and whether they should assume the child’s other parent had already been contacted by the time they read the letter.

Participants were asked for their views on the phrase *'specially chosen'* (which was included in the introductory part of the advance letter see figure 5.1) to explore the clarity and impact of this phrase.

Figure 5.1: Paragraph including the phrase ‘specially chosen’

Generation New Era is the first study of its kind to be launched across the whole of the UK for over 20 years. Your family has been specially chosen to be part of this ground-breaking scientific research, that will benefit the lives of families and children for many years to come.

This phrase generated an initial feeling of warmth, but its inclusion often led to questions about how recipients of the letter had been ‘*specially chosen’*. Participants reflected on information provided in the opt-out letter which explained how their contact details had been obtained and stated ‘*Your family has been chosen at random from records of births held by NHS Digital’*. They felt that the phrase ‘*specially chosen*’ was at odds with this.

> "I think there are, like, two sides to that. So specially chosen can, kind of, give you that, 'Oh, that's nice.' Like, I've been chosen to take part. Like, specifically me and my family. Like that's really nice because it's quite individual. But then on the flip side, when you know that you've only been selected from a database, from an NHS UK digital whatever it was. I can't even remember what the wording was but yes. It makes you think, 'Well, I haven't really been specially chosen, because I've literally just been populated from a database." (Female, Two Parent Household)

The phrase '*specially chosen'* was also associated with familiar marketing ploys used in communications from a range of companies. This led to a sense that this was disingenuous and included simply to convince people to take part. This phrasing could also trigger some concerns from participants around why their family was worth studying and whether their family would be judged in any way.

Across the stage 1 interviews there were participants who noted that the adjoining phrase '*ground-breaking scientific research*' had stood out to them. Where this was the case, there were mixed views on the inclusion of this phrase. In some instances, it felt motivating. Two key reasons for this were cited:

1. **Emphasising the value of taking part.** This included comments that the phrase made taking part feel important and reinforced the idea that it had societal benefits and would benefit other people in the future.

2. **Creating intrigue**. Participants who reported this noted that they were interested to know more about what the research would cover. These participants often had a broader interest in science or research in general.

> "It's just sparked a level of interest is all, it intrigued me. "Okay what's so ground-breaking about this?" So, that's what probably led me to me on to wanting to read a bit more." (Female, Two Parent Household)

However, the phrase '*ground-breaking scientific research'* could also generate queries such as what 'scientific research' involved and what might be included as part of the research.

5.3 Advance booklet

Length and layout

Participants felt that the advance booklet provided comprehensive information about Generation New Era and this was positively received. They also felt that the booklet was generally appealing and easy to read. Focusing specifically on the layout of the booklet, participants expressed positivity towards:

- The use of bold headings and clear sections which enabled the reader to skim and target key information.

> "Skimming through it you can still gain what exactly is happening, whether or not you read it in depth or not, you gain the general consensus of what the study is about." (Female, Lone Parent)

- The FAQ format, with section headings posing useful questions which were then answered.
- The inclusion of key information in circles. Participants felt that these drew their attention to useful information.
- The presentation of information in a flow chart (as on page 6 of the advance booklet). Participants felt that this structure made the information presented clear.

Whilst positive about the layout of the booklet, participants felt that it was long and that there was a lot to read. Section headings were considered a good way to support with navigation of the booklet but there were also suggestions that a contents page could help the reader find relevant sections. There were also suggestions to further build on the FAQ style format of the booklet, with shorter paragraphs and more subheadings.

Tone

The booklet was considered to have an inviting feel and generated interest in the study. Participants particularly noted the use of images as creating an inclusive feel and this is further discussed later within this chapter.

Content and clarity

Participants felt that the booklet largely addressed the questions they had about Generation New Era after reading the opt-out and advance letters. They also felt that it clearly communicated the desire to include families with different circumstances in the study.

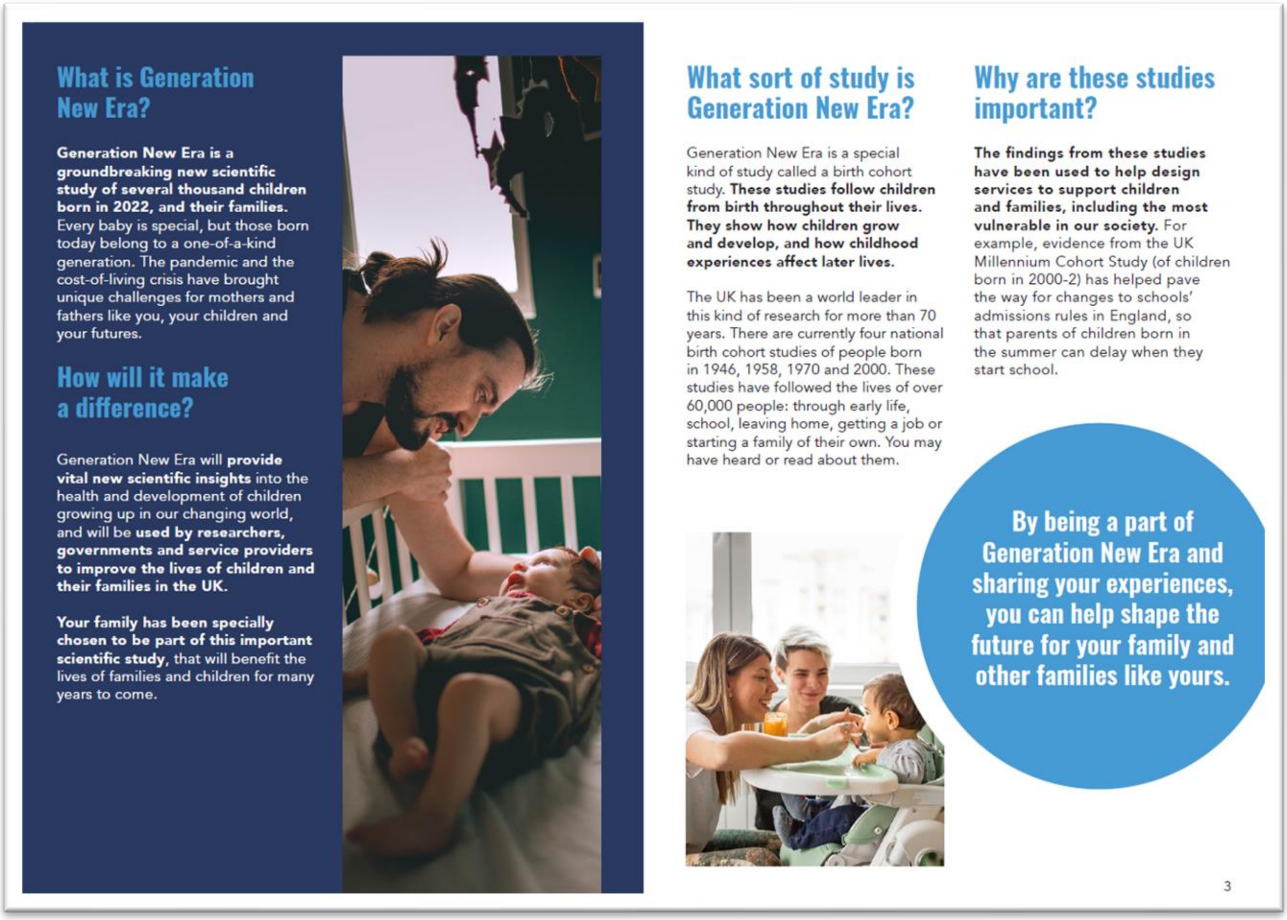
> "I think to be honest, I think the booklet is more inviting than the letters, so I definitely would be more involved and more into taking part." (Female, Lone Parent)

However, there were remaining queries around the long-term time commitment, how often they would be contacted about the study and for how long the study would run.

Across the stage 1 interviews there were suggestions that the booklet could include quotes and examples from people who had previously taken part in a similar (cohort) study. They felt that this content would be helpful and could encourage people to take part. They also suggested that links to previous findings from similar studies could provide reassurances around the types of questions that were asked, and also about how their data would be used e.g., data anonymity.

Participants were specifically asked for their thoughts on the first two pages of the booklet which covered the following content: '*What is Generation New Era?', 'How will it make a difference?', 'What sort of study is Generation New Era?',* and *'Why are these studies important?'* This was to help understand the role they played in motivating participation and whether any changes were needed. Booklet pages 1 and 2 are shown in figure 5.2 below.

Figure 5.2: Booklet pages 1 and 2



What is Generation New Era?

Generation New Era is a groundbreaking new scientific study of several thousand children born in 2022, and their families. Every baby is special, but those born today belong to a one-of-a-kind generation. The pandemic and the cost-of-living crisis have brought unique challenges for mothers and fathers like you, your children and your futures.

How will it make a difference?

Generation New Era will **provide vital new scientific insights** into the health and development of children growing up in our changing world, and will be **used by researchers, governments and service providers to improve the lives of children and their families in the UK.**

Your family has been specially chosen to be part of this important scientific study, that will benefit the lives of families and children for many years to come.

What sort of study is Generation New Era?

Generation New Era is a special kind of study called a birth cohort study. **These studies follow children from birth throughout their lives. They show how children grow and develop, and how childhood experiences affect later lives.**

The UK has been a world leader in this kind of research for more than 70 years. There are currently four national birth cohort studies of people born in 1946, 1958, 1970 and 2000. These studies have followed the lives of over 60,000 people: through early life, school, leaving home, getting a job or starting a family of their own. You may have heard or read about them.

Why are these studies important?

The findings from these studies have been used to help design services to support children and families, including the most vulnerable in our society. For example, evidence from the UK Millennium Cohort Study (of children born in 2000-2) has helped pave the way for changes to schools' admissions rules in England, so that parents of children born in the summer can delay when they start school.

By being a part of Generation New Era and sharing your experiences, you can help shape the future for your family and other families like yours.

3

Participants typically found these first two booklet pages interesting, although some noted that they had only skimmed it on their first read of the advance booklet. Information in these pages highlighted the social value of the study to participants, which was often a motivating factor (as discussed in chapter 3). The content also helped make clear why the research was focusing on their child's generation. Mentions of events such as the cost-of-living crisis and the COVID-19 pandemic resonated with participants and helped them understand why the research was looking at this '*one of a kind'* generation. Even when they were less engaged with the content around the value of the study participants felt like this page provided good context and background for the study.

Focusing specifically on the second page, participants already interested in the social value of the study expressed interest and appeal in learning more about birth cohort studies and their importance. There were suggestions for more examples of the impact of similar studies to help bring to life the value of taking part.

> "It was the fact that there were already 4 national birth cohort studies, and this is the next one…I quite like that you were part of a bit of history by taking part in it." (Female, Two Parent Household)

Colours and imagery

The colours used across the booklet were considered bright and friendly. Participants in Northern Ireland were asked for their views on the use of orange for the Generation New Era logo, as the colour has strong political connotations, and these participants reported no concerns. Participants who were colourblind and/or dyslexic, or knew others who were, suggested that some of the contrast between colours used could be improved. This was particularly noted where a turquoise and white contrast was used or for pages with completely coloured backgrounds.

> “There's a lot of information in there or there's a lot of text in there that's all, sort of, jumbled up. And there are different colours. I'm colour blind and I'm dyslexic and it's actually quite hard to read.” (Male, Two Parent Household)

The diversity of the images used in the booklet was positively noted with reference to images showing fathers and mothers, families from different ethnic backgrounds and families with two mothers or two fathers.

> "I like again the fact that there's pictures of different nationalities, different races and religions in there which I think is really key for inclusion purposes, especially when doing research." (Female, Two Parent Household)

To improve diverse representation, participants suggested including images of disabled people.

5.4 Additional advance booklet text

In stage 2 of the research, participants were asked to review additional advance booklet text relating to:

- Adding information from administrative records
- Adding information about where you live
- Adding information and your and your baby’s genes
- Looking after your information

Length and layout

Whilst the information provided across the additional advance booklet text was considered long and wordy, it was also felt to be relevant and important given the potential sensitivities of the content. With this in mind, participants felt that there was a balance to strike in reducing and simplifying the text length whilst retaining the important content.

> “It was very in-depth and informative which I think is great because I appreciate that it is all very necessary information. However, [there’s] lots to read, I was just concerned that some people may lose interest and not read it all." (Female, Two Parent Household)

Suggestions included the removal of repetition, further use of sub-headings, text boxes, bullet points and bold text across the additional advance booklet text to help people navigate the content and skim it to identify what they felt was most relevant to read.

> “The highlighted areas I thought were great because for someone like me who is always on the go, I don't always have time to read everything.” (Female, Lone Parent)

Content and clarity

Participants were asked to comment on two specific phrases and terms to explore the clarity of these:

‘Administrative records’ (included in the additional advance booklet text ‘adding information from administrative records). This phrase was not always clear to participants. Those most familiar with it, or most able to interpret its meaning were those who used similar terms at work. However, others were not always sure what constituted ‘administrative records’. They expressed uncertainty about which types of information would be included, and from which data sources.

> "I was looking for a first section at the beginning…about what…administrative records are, where they get them from." (Male, Two Parent Household)

‘Oral fluid’ (included in additional advance booklet text ‘adding information about your and your baby’s genes). Participants were specifically asked to consider this phrase, and whether they preferred ‘mouth swab’ instead. Whilst participants overall preferred the phrase ‘mouth swab’ there were spontaneous suggestions that the word ‘saliva’ would work well.

Focusing on the **content** provided across the additional advance booklet text, participants felt that the information provided was clear and informative. However, there were some specific comments, queries and suggestions for how content could be improved. These are summarised in the table below.

Additional advance booklet text section	**Views**
Adding information from administrative records	Participants commented on the phrase ‘*build a fuller picture of your lives’* included in the pull-out box in the sub-section ‘Why is adding information important’ on page 2 of the additional advance booklet text. This phrase often resonated and was considered a good summary of why the study sought this information. However, overall, there were some queries around how data linkage would work in practice including whether participants would be required to actively provide the information themselves. Additional information detailing the different records accessed and information shared provided as part of the consent process (see section 4.3) was considered beneficial in clarifying data linkage.
Adding information about where you live	The research example provided in this section regarding exposure to air pollution stood out to participants and helped make clear the benefits of taking part in geo-linkages.
Adding information about your and your baby’s genes	Two key aspects of adding information about your and your baby’s genes emerged as particularly important to participants: why this was required, and how data would be treated and collected. **Why:** The reasons and benefits for collecting DNA samples were not always clear. Participants garnered two key benefits of sharing DNA samples from the additional booklet text. Firstly, they recognised a greater, societal good in providing data that could lead to benefits for children and communities. Secondly, they recognised that providing samples enabled the research to understand how things are passed down from parents to children. However, participants noted that this information was not ‘front and centre’ in the booklet text.

	“It’s just giving us a definition of what most of us know about what DNA is, coming from both parents and the significance. You get to like, the 50th sentence ‘well this is why we’re looking at complex conditions such as asthma and obesity and diabetes’…I feel as though they’re kind of like, passively going around and not answering the question…tell us exactly what you want it for.” (Male, Own Household Father) There were also queries around why the study needed this information. For example, it was unclear why the study needed DNA if they already had information about health (e.g., from NHS records). Another participant queried why reference to the role of environments did not mention culture and ethnicity; they anticipated that the study would look at this and therefore felt it should be mentioned. **How**: Participants noted that confidentiality, anonymity of data and how the data would be used were all key pieces of information that would help people decide whether to share DNA samples. Whilst participants felt that this information was included in the booklet text, some of the reassurances they sought were included later in the ‘Looking after your information’ section. Individual queries were raised including whether people would receive their DNA data back. There were also queries around how easy it would be to collect a sample from the baby with participants recalling difficult COVID-19 tests. “COVID testing, trying to do that on a toddler is a nightmare…I think people are probably a bit scarred from that and don’t want to put their kids through that.” (Male, Two Parent Household) There were suggestions to include a diagram in the booklet text or make clear that you could carry out the test with the interviewer present if there were concerns around completing the test properly.
Looking after your information	Participants felt that the information in this section was clear and important; it felt relevant and reassuring. With this in mind there were suggestions that this content be provided earlier in the booklet. In particular, participants felt that information regarding how data will and will not be used, who will use the data and who will be responsible for the data were important. Given the importance of this information, there was a suggestion that this content could be made clearer by including a table summarising each organisation involved and what data they would have access to. There was also a suggestion for more clearly laying out the steps taken to look after and protect data. The sub-section titled ‘*Worried about any of the issues covered in Generation New Era?*’ included in this section of the booklet typically attracted a neutral response from participants who often felt it was ‘nice to have’ but did not feel strongly about its personal relevance.

	“It was really nice to say ‘if you have concerns talk to your GP or health visitor’. So, personal to me at the time of reading it, but I'm not taking part in the research, I didn't have worries, but other people, I thought it was good, yes. Other people might go 'As I'm answering this on my child here, I'm a bit concerned of A, B or C.” (Female, Two Parent Household) However, there were comments around why this sat within the ‘Looking after your information’ section of the booklet, and whether ending with this could feel like a negative way to end the booklet.

5.5 Use of logos and signatures

The letters shown to participants in stage 1 of the research included logos and signatures from different organisations.

	Advance booklet		Opt out letter		Advance letter		
Region	Logos	In text mention	Logos	In text mention	Logos	In text mention	Partner University*
England	Generation New Era UCL Ipsos	UCL/CLS Ipsos Swansea University University of Edinburgh Ulster University ESRC NHS	Generation New Era NHS Digital/Public Health Agency (NI)/NHS Scotland (by country) UCL Ipsos	CLS Ipsos Economic and Social Research Council	Generation New Era Ipsos UCL	CLS Ipsos Economic and Social Research Council	-
Wales							Swansea University
Scotland							University of Edinburgh
Northern Ireland							Ulster University

*These organisations are included in the letters in the form of in-text mentions, signatures, and logos. There are no country-specific versions of the advance booklet.

Participants reported that the inclusion of NHS or Public Health logos signalled the importance of the communication. Whilst there was low recognition of NHS Digital, overall inclusion of a logo associated with the NHS or Public Health bodies was felt to increase the likelihood of recipients reading the materials.

> "…it'd be about having the NHS logo and I think that'd make it more official. And get like 'Oh, better read that'." (Female, Two Parent Household)

Whilst not always spontaneously noticed, signatures related to universities alongside these logos were felt to convey the importance of the study and provide reassurance that the study was 'professional' in nature.

> "Because you, sort of, associate universities with professors or researchers, so you know that the research is going to be properly carried out, I suppose."
> (Male, Two Parent Household)

Whilst the logos of universities were not included in the advance booklet, they were listed. Where noticed, this list sometimes caused confusion. For example, one participant noted the list of universities in the booklet and queried why this was different to the one university specified in the letters.

5.6 Implications and considerations

Participants' thoughts on the design of the research materials raised some key implications and considerations. These, alongside steps taken to date to reflect these, are summarised below.

- Shortening the study materials is likely to support improved engagement with these and improved clarity of content. There is indication that FAQs could be used to help achieve this.
- Clear signposting of content within the study materials is important and will help time-poor people identify the information that is most personally relevant. Use of clear subheadings, bullet points to make information clear and concise and generally streamlining the content will be important.

Steps taken to reflect these implications and considerations included:

- Wherever possible, materials were shortened and condensed. The content of the leaflets has been reduced to about half the length of the tested materials, for example, and more visual elements have been incorporated to make sure key messages stand out and the leaflets can easily be skimmed. This included reducing the DNA sample information to a short paragraph in the advance booklet and creating an additional Saliva Information booklet given to participants closer to the interview to avoid overwhelming participants with information at the point of the advance mailing.
- Including health agency and university logos on the letters as participants commented this signalled credibility. The university logos were added to the external envelopes to encourage parents to open the mailing.
- Where appropriate, information has been presented to allow for skimming and quicker location of relevant information. For example, the opt-out letter was reformatted to include a short introduction to the study on the front page, and Q&As on the back with further information. The advance booklet was also redesigned to better use colours and headings to identify sections of information.
- Interviewers were briefed to be aware that participants might have questions or varying levels of familiarity with the survey materials. The research highlighted varying preferences for the amount of information and reassurances respondents would want, and interviewers will be briefed to be equipped to answer the questions different groups of respondents will have. Where understanding of the materials was crucial for giving informed consent, the interview script checks the participant has read and understood the material.

- The colour palette for the study was tested to ensure the colour contrast of text met Web Content Accessibility Guidelines (WCAG) – Level AA standards[10]. Where this was not the case, the colours were adjusted by the branding agency.
- Interviewers were encouraged to add their name and telephone number to the advance mailing before posting it, as participants indicated this helped to build trust in the survey process and would feel less like ‘cold calling’ when the interviewer started to visit face-to-face.

---

[10] https://www.gov.uk/service-manual/helping-people-to-use-your-service/understanding-wcag

6 Cognitive question testing

A key element of the stage 1 qualitative research was to cognitively test a selection of Generation New Era survey questions. The survey questions for testing were divided into seven sections, as shown in table 6.1. The table also shows the intended Generation New Era respondent group for each section.

Table 6.1: Cognitive question sections

Question section	**Respondent group**
Section A: Screener questions	All
Section B: Service use questions	All except OHPs
Section C: Parental engagement	All
Section D: OHP questions for main respondent	Lone parents only
Section E: OHP questions for OHP	OHPs only
Section F: Vaping	All
Section G: Sensitive questions	All

Participants did not see every section of questions in the research interviews. Instead, the sections were rotated across interviews due to time constraints and to ensure participants only saw the sections relevant to their household type. When introducing the cognitive questions, participants were told that the aim was to check how easy they are to answer for parents in different circumstances and that they would first be asked the question itself and then follow-up questions to determine what they thought of the questions.

In the remainder of this chapter, we report the participant feedback for each section of survey questions. We give a broad summary of the key changes made to the questions based on the feedback.

6.2 Section A: Screener questions

Four questions were tested within this section of survey questions. All questions were designed to be asked as part of the screening process to be carried out when the interviewer is seeking to arrange a Generation New Era (GNE) interview. At that point, potential respondents would have received both letters and the advance booklet.

The main aim of testing these questions was to gauge how easy these questions were to answer, as well as how comfortable people would feel answering these with an interviewer before the main interview.

Section A question 1

CHILDINHH. Please can you confirm whether [BABY NAME] **who was born in** [MONTH], **is living at this address?**

INTERVIEWER: IF BABY SHARES RESIDENCE BETWEEN THIS AND ANOTHER ADDRESS, OR IS ONLY TEMPORARILY OUT OF THE HOME, E.G. IS IN HOSPITAL, PLEASE USE CODE 1 OR 2.

1. Yes (named baby at address AND D.O.B. correct)
2. Yes, but some details (spelling of name or D.O.B.) slightly wrong
3. No, this child lives elsewhere
4. No, this child has died
5. No, I don’t know this child

Participants generally felt that this first question was clear and easy to answer. Their main concern was how comfortable they would feel answering the screener questions on their doorstep, when first talking to the interviewer. Participants had mixed views on this.

There were suggestions that they would feel more at ease if the interviewer referenced the study letters, showed their ID, and introduced themselves and their link to the study clearly. Participants recognised that identifying the interviewer as belonging to the study would strongly depend on their level of engagement with the letters, and therefore whether they were expecting an interviewer to call at their address.

Participants who felt less comfortable with the idea of someone showing up at their address often mentioned a general dislike of having someone show up at their door without an appointment. It was noted that if the interviewer was not expected, and had knowledge of the child's name, this could cause concern. There was also discomfort amongst those who felt that the screening questions could feel too private to discuss on the doorstep where neighbours may be able to overhear the conversation.

> "[If] I hadn't read the letters, probably a bit unnerved, I think if I'd read the letters and I was understanding that that was what was going to happen next, then I suppose I'd be expecting it in some ways […] So if somebody was asking about my child, I'd be thinking, 'This doesn't feel great,' just because, you know, they're your child and I don't want everyone having all her information, especially if it's on my doorstep." (Female, Two Parent Household)

Section A question 2

ASK IF BABY LIVES AT THIS ADDRESS ('YES' AT CHILDINHH)
MAINCM. Does [BABY NAME]/ **the baby mainly live here or do they also live somewhere else?**
INTERVIEWER PROBE: IF THE BABY ALSO LIVES SOMEWHERE ELSE, PROBE WHICH IS THEIR MAIN RESIDENCE OR WHETHER THEY LIVE EQUALLY BETWEEN THE TWO

1. Yes - this is the baby's only residence
2. Yes - this is the baby's main residence
3. The baby lives equally between this residence and another
4. No - the baby mainly lives elsewhere

Whilst participants felt that this question was clear, across interviews the first two answer options for this question were frequently used interchangeably. Participants rarely distinguished between whether the address was the child's main or only address.

> "She only lives here, so mainly lives here, yes." (Male, Two Parent Household)

Section A question 3

ASK ALL

MAINRESP. Is this your main residence?

1. Yes - this is the respondent's only residence
2. Yes - this is the respondent's main residence
3. The respondent lives equally between this residence and another
4. No - the respondent mainly lives elsewhere

Similarly to question 2, the difference between 'only' or 'main' address was not always clear to participants. The potential for additional confusion arose when participants considered how they would answer this question if they owned a second home, such as a holiday home used only rarely.

Participants also brought up uncertainties around how travelling for work or working away from home a lot would factor into their answers.

Section A question 4

ASK ALL
PCHECK. Are you the parent who spends the most time caring for [BABY NAME]**?**

1. Yes – Respondent is the primary caregiver
2. Yes – Respondent has shared/equal caregiver responsibility
3. No – Respondent is not the primary caregiver

When thinking about how to answer this question, participants thought about each parent's working patterns, any arrangements that may exist between parents not living together, and whether one parent might be on parental leave. This information typically helped them determine how they would respond.

Alternative wording was tested: '*Are you the parent who spends substantially more time caring for the baby?*'. Both versions of the question could feel sensitive to participants, particularly fathers, who felt uncomfortable about the suggestion that they were not a primary caregiver for their child.

> "That's quite difficult actually because I still see myself as a primary caregiver but I don't spend the most time with [child]. So I would say that it's shared by I don't spend the most time with [child] if that makes sense? But when I'm there it's equal. So, I feel uncomfortable saying that I'm not a primary caregiver." (Male, Two Parent Household)

With this in mind, there was an overall preference for the first question text (as shown in the box), since this felt less like a value judgement on each parent's involvement with the child.

> "I think that [question - are you the parent who spends the most time caring for child] is better because the other one seems as if you're less significant, as a parent." (Male, Two Parent Household)

Implications for and changes made to Section A

The cognitive testing of the screener questions emphasises the importance of further consideration of the context and introduction provided when the interviewer first talks to participants at their door. During the main interviews, interviewers will take care to allow enough time introducing themselves and the study to put participants at ease. This will be stressed during the interviewer briefings, to ensure all interviewers are mindful of the potential sensitivity of the situation.

The questions regarding the main residence of the child and the participant (questions 2 and 3) have been simplified.

Question 4 will be further contextualised to ensure participants are aware of the purpose of the question. This is to determine which parent will be the primary informant and do the longer interview, and the question is not intended to present any judgement of the family's childcare arrangements.

6.3 Section B: Service use questions

Section B included four questions and was asked to half of the participants, excluding own household parents. This section asked about use of different services, such as GP appointments. The main aim was to test whether the questions were easy to understand, the information was easy to recall and whether any services were missing from the answer options.

Section B question 1

ASK ALL EXCEPT OHPS. OHPS SKIP TO NEXT SECTION.

MSEUSE1. The following questions are about professionals you may have seen since your baby was born. ADD IF NECESSARY: **This includes in person, virtual or telephone appointments.**

First, please tell me which, if any, of the professionals listed you have seen since your baby was born.

Showcard A:

1. Midwife
2. Health visitor
3. General practitioner (GP)
4. Family nurse (including Family Nurse Partnership (FNP) Nurse)
5. Social worker
6. Family Support Worker / Early Help Worker
7. Paediatrician
8. Consultant/ hospital doctor
9. Paediatric physiotherapist

Participants were asked what type of appointments they had considered when answering this question, specifically whether they had considered face-to-face and/or remote appointments. Participants typically reported that they had considered both. However, they suggested that the question itself could make it clearer that both modes should be included in the answer.

When answering this question, participants differed in their ability to recall which professionals they had seen and which healthcare professional had been responsible for different procedures. This was especially true for fathers.

> "Family nurse. Is the family nurse the one that gives them the injections as well? Would that be classed as the family nurse? Or is that just classed as general practitioner?" (Male, Two Parent Household)

It is useful to note that recall may have been influenced by the age of participants' children (up to 2 years old); children will be around 9 months when this question is asked in a Generation New Era interview.

Mentions of professionals not listed in the question included: allergy specialists, radiographers, dieticians/paediatric dieticians, dentists.

Participants noted that some of the services mentioned, such as social services, could feel more intrusive than others. They suggested that recognising the sensitivity of these questions, including provision of reassurances that there would be no further probing following on from this question, could help put people at ease.

Section B question 2

INTERVIEWER ASK THIS QUESTION ABOUT EACH PROFESSIONAL MENTIONED AT PREVIOUS QUESTION. IF NONE MENTIONED, GO TO NEXT QUESTION.

MSEUSE1FR. Thinking about the [INTERVIEWER INSERT PROFESSIONAL NAMED AT PREVIOUS QN] **you saw…**

How many times have you seen the …. [INTERVIEWER INSERT PROFESSIONAL NAMED AT PREVIOUS QN] **since your baby was born?**
INTERVIEWER NOTE – RECORD NUMBER OF TIMES 1-10; If more than 10, code ‘10’.

1. Midwife
2. Health visitor
3. General practitioner (GP)
4. Family nurse (including Family Nurse Partnership (FNP) Nurse)
5. Social worker
6. Family Support Worker / Early Help Worker
7. Paediatrician
8. Consultant/ hospital doctor
9. Paediatric physiotherapist

Similarly to section B question 1, answering this question was more difficult for those who struggled to distinguish between the different healthcare professionals and their specific roles. This made it challenging to determine how often they would have seen the professional.

Those who saw a variety of professionals or who had a high number of appointments struggled to recall the exact number of visits for each healthcare professional. It was suggested that allowing participants to provide a ‘ballpark’ figure (e.g., ‘5 or 6 times’) could make it easier to answer the question.

Section B question 3

ASK ALL.
MSEUSE3. Since your baby was born has your family used any of the following services or types of support from any kind of provider?

Showcard B:

1. Breastfeeding support
2. Infant feeding/weaning/nutrition support
3. Infant weight and growth support
4. Infant sleep support
5. Baby and infant health advice and support
6. Playgroup or play sessions (e.g. stay and play groups, one o'clock clubs, baby singing groups, messy play groups)
7. Baby Classes (e.g. Baby massage, baby yoga groups, Baby swimming, Signing groups, Sensory groups)
8. Advice and services for your baby’s disability or learning needs
9. Parenting support/parenting classes
10. Mental health support
11. Family relationships support
12. Money or debt advice and support
13. Housing advice and support
14. Jobs and training advice and support
15. Parent fitness classes
16. Drug and alcohol support
17. Other (please specify)

Some of the answer options for question 3 were considered more sensitive than others. In particular, asking about services related to mental health, drug and alcohol support, and financial wellbeing brought up concerns. Those who voiced concerns mentioned that if they struggled with one of these issues, they might feel embarrassed or concerned about being judged. It was noted that reassurances about why this question was being asked and how the data would be used could be useful to put participants at ease.

Participants were generally clear on what was asked of them and how to answer this question. However, it was not always clear to participants which healthcare professionals to include for code 5. 'Baby and infant health advice and support'.

Section B question 4

ASK ALL

MPAGP. Over the last 12 months, have you had problems accessing…
A GP?

Showcard C:

1. Yes, and it was a big problem
2. Yes, and it was a minor problem
3. Yes, but it was not a problem
4. No
5. Not applicable
6. Don't know
7. Prefer not to say

When answering this question, it was not always clear to participants whether they should be thinking about GP access for both themselves and their child. It was noted that greater clarification was needed in this regard. This was considered particularly important because participants felt that ease of seeing the GP often differed depending on who needed access to the GP; it could be easier to get an appointment for the baby.

> "Is it for me or is it for the baby? Because if it's anything for [baby] I'm seen straight away, anything for me, and I have to wait for a phone – that's a bit harder." (Female, Two Parent Household)

Participants also pointed out that it was often easier to get an online consultation or telephone appointment, whereas face-to-face appointments were typically harder to access. It was suggested that the question text could offer further guidance on how to take this into consideration. There were also queries around how nuanced experiences (e.g., multiple occasions of varying severity over the last 12 months) should be taken into account.

Lastly, participants were not clear on which health issues might be classed as 'big' or minor', as these are subjective terms and are not clearly defined.

Implications for and changes made to Section B

The feedback participants provided showed a range of points that were unclear or confusing. Where participants expressed confusion, additional help text or answer codes were added to the question to ensure participants could answer the question as accurately as possible. For example, the question asking how often participants had had problems accessing a GP was reworded to account for the fact that participants might not have tried contacting their GP in the last 12 months. When asking how often participants have contacted healthcare professionals, ranges were introduced to simplify recall.

6.4 Section C: Parental engagement

Section C included nine questions and was rotated to be asked to around half of the participants. This section included questions about the participant's involvement with their child as well as questions about the other parent.

The aim was to test how easy the questions were to understand and answer as well as to gauge how sensitive the questions were and how comfortable participants felt disclosing information about their child’s other parent.

Section C question 1

ASK ALL

MCCTa. How often do you look after your baby on your own?

Showcard D:

1. More than once a day
2. Once a day
3. A few times a week
4. Once or twice a week
5. Less than once a week
6. Never
7. Don’t know
8. Prefer not to say

This question was generally easy to understand for participants and it was clear that ‘*on your own’* meant that the other parent was not present for a considerable time period. For two parent households there was potential for confusion around whether the other parent being in the same house but not looking after the baby at that time would count. However, when left to make their own decision on answering the question, participants tended to not count these situations.

Across the interviews, some confusion arose around answer code 1 ‘more than once a day’, as participants were unsure whether looking after their baby all day would count as once a day or more than once a day, especially if there were small interruptions in between.

When answering this question, own household fathers tended to struggle more with estimating the time spent with their child, as this could vary between weeks. It was suggested that providing a timeframe or asking participants to consider the time spent with their child ‘in a typical week’ would make this easier to estimate.

Section C question 2

Please look at Showcard D again

MCCTd. And how often do you get up in the night for your baby?

Showcard D:

1. More than once a day
2. Once a day
3. A few times a week
4. Once or twice a week
5. Less than once a week
6. Never
7. Don’t know
8. Prefer not to say

When answering this question, participants considered various timeframes ranging from the previous night to any time since birth. They also noted that the answer could vary depending on the child’s stage of development or factors such as illness. There were suggestions for a timeframe to be included.

As with question 1 of this section, participants felt that the distinction between ‘once a day’ and ‘more than once a day’ might not be clear cut when considering instances in the same night. Additionally, it was pointed out that by using the same showcard as for question 1, the answer options referred to ‘day’ instead of ‘night’.

Where time spent with the child varied greatly, especially for own household fathers, it was difficult to give a meaningful estimate.

Lastly, there was a comment from a participant that the question did not reference how often the baby woke or cried, fearing that answering ‘*Never’* could give the impression that they ignored their crying child.

Section C question 3

MWORK1P. Which of these best describes what [PARTNER NAME] **is currently doing?**

Showcard E:

1. Employee – in paid work
2. Self-employed
3. In unpaid voluntary work
4. Looking after family
5. Found a job, waiting to start it
6. Out of work and looking for a job
7. On unpaid traineeship/government training scheme
8. On paid apprenticeship scheme
9. Full-time student
10. Part-time student
11. Retired from paid work
12. Not in paid work, reasons of poor health
13. Not in paid work for some other reason
14. Don’t know
15. Prefer not to say

Participants were overall willing to share this information about the other parent of their child, especially if they anticipated that the other parent would also be taking part in the survey. Own household fathers were less likely to be comfortable answering or to feel confident in the accuracy of their answer. This depended heavily on their relationship with the other parent.

Section C question 4-5

ASK IF PARTNER IS WORKING OR SELF-EMPLOYED AT MWORK1P. OTHERS GO TO METHNICP.

PUSLA. What is [PARTNER NAME]**’s usual take-home pay after tax and any other deductions? You can give a weekly, monthly or yearly amount or an amount covering another period.**

IF PARTNER IS SELF-EMPLOYED: **It is sometimes difficult for self-employed people to give an exact figure for their income but please think about** [PARTNER NAME]**'s take home pay in the last 12 months. That is, the amount they personally have taken home after all taxes and costs.**

INTERVIEWER READ OUT IF NECESSARY: **If they have more than one job please tell us their total take-home pay from all their jobs.**

About how much was this?

INTERVIEWER-HELPSCREEN: What if respondent doesn't know or want to answer? **Please provide best estimate.** If respondent really doesn't know or doesn't want to answer, choose don't know or prefer not to say.

Enter £ (from 0 to £9,999,997)

1. Don't know
2. Prefer not to say

PUSLP. What period does this cover?

1. One week
2. Calendar month
3. One year
4. Other period (specify)
5. Don't know
6. Prefer not to say

Views towards answering this question were mixed and it was often perceived to be more sensitive than most other questions in Section C asking about the child's other parent.

Two parent households were most likely to be willing to answer this question and to feel confident in their answer. Lone parents and own household fathers were less likely to know the answer or to feel comfortable sharing this information.

Participants were generally more reluctant to answer this question when imagining that the other parent had opted out of the survey. Where participants conversely imagined that the other parent would take part in the survey they queried why this question could not be asked directly of them instead.

> "I'd definitely be answering that one 'Prefer not to say,' because it would be down to (partner) to answer that question" (Male, Two Parent Household)

Ease of answering this question was impacted by the type of work the other parent did. For example, it was difficult to answer accurately where those paid hourly may have different income each month for example, through seasonal work.

Section C question 6-7

ASK IF PARTNER IS EMPLOYED
MLEAVE4P. Has [PARTNER NAME] **taken parental leave for your youngest child?**

INTERVIEWER ADD IF NECESSARY: **This includes statutory maternity leave, shared parental leave, workplace leave agreements and any unpaid leave from their job.**

1. Yes
2. No
3. Don’t know
4. Prefer not to say

ASK IF PARTNER IS EMPLOYED

MLEAVE4P. Are they currently on parental leave?

1. Yes
2. No
3. Don’t know
4. Prefer not to say

Participants found this question generally easy to answer and it rarely caused discomfort. Two parent households had often made the decision regarding parental leave together and were both affected, which meant they rarely had any issues answering questions regarding their partner’s parental leave. Own household fathers were less likely to know the circumstances of whether the other parent had taken parental leave and less likely to feel comfortable answering the questions.

> “…but I just don't feel as though, that's not my right to answer that question” (Male, Own Household Father)

Participants noted that the interviewer prompt includes a specific reference to maternity leave but not to paternity leave. It was suggested that this should also be included to clear up any confusion around whether paternity leave should be taken into account when answering.

Section C question 8

ASK ALL

METHNICP. Which of the groups on this card do you consider [PARTNER NAME**/your partner] as belonging to?**

Showcard F:

1 White - English/Welsh/Scottish/Northern Irish/British
2 White - Irish
3 White - Gypsy or Irish Traveller
4 White - Roma
5 Any other White background
6 Mixed/multiple ethnic groups - White and Black Caribbean
7 Mixed/multiple ethnic groups - White and Black African
8 Mixed/multiple ethnic groups - White and Asian
9 Any other mixed/multiple ethnic background
10 Asian/Asian British - Indian
11 Asian/Asian British - Pakistani
12 Asian/Asian British - Bangladeshi
13 Asian/Asian British - Chinese
14 Any other Asian background
15 Black/African/Caribbean/Black British - African
16 Black/African/Caribbean/Black British - Caribbean
17 Any other Black/African/Caribbean background

18 Other ethnic group – Arab
19 Any other ethnic group

Overall participants were comfortable answering this question and confident in their answer. They also thought that their answer would correspond with the answer their partner would give.

Section C question 9

ASK ALL

MPGH3. Does [PARTNER NAME] **have any physical or mental health conditions or illnesses lasting or expected to last 12 months or more?**

1. Yes
2. No
3. Don't know
4. Prefer not to say

This question was perceived as more sensitive than most of the other questions in Section C. Participants noted that they would be likely to feel less comfortable with this question if the answer was 'yes'.

Reflecting the overall sensitivity across own household fathers regarding questions about the mother of their child, there was general discomfort with the idea of answering this question and it was noted that they were unlikely to know the answer.

Implication for and changes made to Section C

As for section B, help screens and additional answer codes were added to clarify questions that participants struggled to answer. This affected for example the definition for looking after your child 'on your own' (question 2) or providing an answer option to say the baby never wakes up in the night (question 1). Where relevant, timeframes were added to ensure participants are answering questions in relation to a similar time period. For example, a reference period (the last two weeks) was added to question 1 about the number of times babies wake during the night.

The questions regarding the partner's pay were removed.

6.5 Section D: OHP questions for primary informant

Section D was made up of 13 questions and was asked of mothers in single parent households only. Questions focused on the other parent's involvement with the child. The aim was to understand how sensitive these questions felt to participants and how likely they were to feel comfortable and confident in their answers.

Section D question 1

NRBIOP. Is your baby's other biological/birth parent involved in your baby's life?... READ OUT…

INTERVIEWER ADD IF NECESSARY: If there is more than one other birth/biological parent answer about the parent you consider to be most involved

1. Yes –has contact with the baby

5. Yes –does not have contact with the baby but is involved in some other way (e.g. financial support)
6. No –not involved
7. No –parent has passed away
8. SPONTANEOUS: parent is not known
9. SPONTANEOUS: donor who respondent does not consider to be a parent

This question was generally clear to participants, and they felt comfortable answering.

However, some queries were raised regarding answer option 2, *‘Yes – does not have contact with the baby but is involved in some other way e.g. financial support’.* This answer option was met with mixed reactions, as interpretations of ‘involved’ differed. Providing financial support, for example via a Child Support Agency Agreement, was not always considered to constitute ‘involvement’.

Section D question 2-3

ASK IF BABY/IES OTHER PARENT INVOLVED IN THEIR LIFE
OHPFNAME. Could you tell me their first name?

INTERVIEWER ADD IF NECESSARY: This is only to help me ask the following questions. It is not used in the analysis of the survey data.

INTERVIEWER: IF RESPONDENT WOULD PREFER NOT TO SAY, ASK FOR A PSEUDONYM E.G. “Other parent”, SO THAT WE KNOW HOW TO REFER TO THAT PERSON.

OHPDOBD. What is [NAME OF OHP]**’s date of birth?**

INTERVIEWER: ENTER DAY [Range: 1..31]

INTERVIEWER: ENTER MONTH [Range: 1..12]

INTERVIEWER: ENTER YEAR [Range: 1915..2024]

Participants had no concerns or reservations providing the other parent’s name as requested for this question. The options of providing a pseudonym or referring to them as ‘other parent’ were appreciated.

Participants were more reserved about providing the other parent’s date of birth. Whilst they felt this question was clear, and they knew the answer, their willingness to share this information depended on whether the other parent had consented to be involved or to share their data with the study. Participants were especially apprehensive about answering this question if they did not have a good relationship with their child’s other parent.

Section D question 4-5

OHPREL. Just to double check, do you consider yourself and [NAME OF OHP] **to be a couple?**

1. Yes
2. No

IF RESPONDENT DOES NOT CONSIDER THEMSELVES TO BE IN A COUPLE WITH OHP
OPHRELEVER. Have you ever been in a relationship with [NAME OF OHP]**?**

1. Yes

2. No

Although participants were generally open to sharing information regarding the status of their relationship with the child’s other parent, these questions felt more sensitive. This was especially the case for participants where the relationship breakdown was recent or had been particularly difficult.

> “We were married, and now we’re not. So it does feel a little bit…sensitive. But not sensitive enough for me to withhold that information”. (Female, Lone Parent)

Section D question 5-6

ASK IF RESPONDENT IS OR HAS BEEN IN A COUPLE WITH OHP
OHPRELL.

IF RESPONDENT IS NO LONGER IN A COUPLE WITH OHP: **At the time your relationship with** [NAME OF OHP] **ended, how long had you been together as a couple?**

IF RESPONDENT IS CURRENTLY IN A COUPLE WITH OHP: **How long have you and** [NAME OF OHP] **been together as a couple?**

INTERVIEWER ADD IF NECESSARY: **Please include time as a couple whether or not living together**

INTERVIEWER: ROUND ANSWER TO NEAREST NUMBER OF WEEKS, MONTHS OR YEARS, E.G. IF 5 YEARS 3 MONTHS, ENTER 5 YEARS. IF DK, ENCOURAGE AN ESTIMATE/BEST GUESS.

1. WEEKS
2. MONTHS
3. YEARS

ASK IF RESPONDENT IS NO LONGER A COUPLE WITH OHP
OHPRELENDM. Could I check what month and year you separated?

INTERVIEWER: IF DK, ENCOURAGE AN ESTIMATE/BEST GUESS.

INTERVIEWER: ENTER MONTH

INTERVIEWER: ENTER YEAR

Similarly to questions 4 and 5, these questions were regarded as sensitive in nature. This was true especially where the relationship had ended recently. Those who were hesitant to answer noted that knowing why this information was relevant could help make them more comfortable answering these questions.

> “I want to understand the relevance of these questions, why do they want to know this information? I thought the whole premise was this is a single-parent family and it’s about the children. Why are we then delving in to how long was the mother and father together. Going in to the dynamics of our relationship takes away from the whole purpose of the child-focussed study” (Female, Lone Parent)

Section D question 7-12

ASK IF NON-RESIDENT PARENT EVER SEES BABY
OHPSEE. On average, how many times a month does your baby see [OHP NAME] **in person?**

INTERVIEWER: IF THEY SEE THEM MORE THAN ONCE A DAY CODE AS ONCE PER DAY (I.E. TYPE IN 31).

1. TYPE IN: RANGE BETWEEN [1-31] days
2. Once every few months
3. Less often than once a month
4. Never

ALTERNATIVE:

Thinking about [OHP NAME] parent, on how many days a month does [BABY NAME] usually see them (i.e. in person), for a whole day or a part day? Think of what actually happens in a typical month rather than an agreed or set pattern.

ASK IF NON-RESIDENT PARENT SEES BABY
OHPSEEHR. On a day that your baby sees [OHP NAME] **how many hours do they typically spend together?**

INTERVIEWER ADD IF NECESSARY: Please do not include any hours they spend overnight

Range: 0..24

ASK IF NON-RESIDENT PARENT SEES BABY
OHPON. Does your baby ever stay overnight with [OHP NAME] **at their place?**

1. Yes
2. No

ASK IF OHP SEES BABY
OHPONT. On average, how many times a month does your baby stay overnight with [OHP NAME] **at their place?**

1. TYPE IN: RANGE BETWEEN [1-31] days
2. Once every few months
3. Less often than once a month

ALTERNATIVE:

About how many nights each week, fortnight or month does [BABY NAME] **usually stay overnight with** [OHP NAME] **at another address – for example, at** [OHP NAME’S] **place?**

INTERVIEWER: code or ask if necessary: What period does that cover?

INTERVIEWER: if there is no ‘usual’ or ‘typical’ pattern please ask the respondent to answer for what happened during the most recent month [or fortnight].

ENTER NUMBER OF NIGHTS:

….. Week

…. Fortnight

…. 4 weeks/calendar month

ASK IF OHP SEES BABY
OHPSTAY. Does [OHP NAME] **ever stay overnight at your home?**

1. Yes
2. No

ASK IF OHP EVER STAYS OVERNIGHT AT RESPONDENT'S HOME
OHPSTAYN. On average, how many times a month does [OHP NAME] **stay overnight at your home?**

1. TYPE IN: RANGE BETWEEN [1-31] days
2. Once every few months
3. Less often than once a month

These questions did not present any problems to participants. They generally understood why these questions were relevant to the study, were willing and able to provide an answer.

Section D question 13

ASK ALL.

MDISF. **How often do you and** [PARTNER NAME] **disagree over issues relating to bringing up** [BABY NAME]**?**

Showcard G:

1. Very Often
2. Quite Often
3. Sometimes
4. Rarely
5. Never

This question led to hesitation where participants did not have a close relationship with the other parent. Additionally, confusion arose around the broad nature of the question. There might be different types and severity of disagreements and it was not clear what should be considered when answering this question.

> "There's disagreements, then there's disagreements" (Female, Lone Parent)

Implications for and changes made to Section D

In response to feedback, answer code 2 for Section D question 1 was changed to 'Does not have contact with the baby but is involved *or contributes* in some other way (e.g. financial support)'. This was done to be more inclusive of the different types of engagement parents might have with their children.

Throughout the entirety of section D, the voluntary nature of these questions is stressed due to the sensitivity of these questions. Where possible and appropriate, explanations of the rationale for asking the questions has been added, as participants felt more comfortable answering questions if they understood the benefit to the study.

6.6 Section E: OHP questions

Section E included 7 questions asked to own household fathers included in the research. The questions largely mirrored those asked in Section D about own household parents' involvement with the child. The aim was to understand how comfortable participants felt answering the questions and how easy these were to answer accurately.

Section E question 1-2

OHPSEE. On average, how many times a month do you see your baby?
INTERVIEWER: IF THEY SEE THEM MORE THAN ONCE A DAY CODE AS ONCE PER DAY (I.E. TYPE IN 31).

1. TYPE IN: RANGE BETWEEN [1-31] days
2. Once every few months
3. Less often than once a month
4. Never

ALTERNATIVE TO PREVIOUS QUESTION

On how many days a month do you usually see [BABY NAME] **in person, for a whole day or a part day? Think of what actually happens in a typical month rather than an agreed or set pattern.**

WRITE IN NUMBER OF DAYS 0-31

ASK IF RESPONDENT SEES THEIR BABY
OHPSEEHR. On a day that you see your baby, how many hours do you typically spend together?

INTERVIEWER ADD IF NECESSARY: Please do not include any hours they spend overnight

Range: 0..24

Participants were comfortable answering this question. As it asks about their relationship with their child, it was clear to participants how this question was relevant to the study.

Where the time spent with the baby varied greatly, participants struggled to arrive at an answer representing a 'typical' day. Some own household fathers saw their children for full days at a time or overnight, which additionally made it difficult to estimate the number of hours spent with the baby.

> "If it is the weekend, I will be seeing him the whole day. If it is for a couple hours…I would say 6 hours." (Male, Own Household Father)

Section E question 3-5

ASK IF RESPONDENT SEES THEIR BABY
OHPON. Does your baby ever stay overnight at your place?

1. Yes
2. No

ASK IF RESPONDENT SEES THEIR BABY
OHPONT. On average, how many times a month does your baby stay overnight at your place?

1. TYPE IN: RANGE BETWEEN [1-31] days
2. Once every few months

3. Less often than once a month

ASK IF RESPONDENT SEES THEIR BABY
OHPSTAY. Do you ever stay overnight at your baby's main residence?

1. Yes
2. No

ASK IF RESPONDENT STAYS OVERNIGHT AT BABY MAIN RESIDENCE
OHPSTAY. On average how many times a month do you stay overnight at your baby's main residence?

1. TYPE IN: RANGE BETWEEN [1-31] days
2. Once every few months
3. Less often than once a month

Overall, participants found these questions relevant, straightforward and easy to answer. Similarly to questions 1 and 2, participants struggled to provide an estimate where time spent with the child varied from month to month.

Section E question 6

ASK ALL.

MDISF. **How often do you and** [PARTNER NAME] **disagree over issues relating to bringing up** [BABY NAME]**?**

Showcard G:

1. Very Often
2. Quite Often
3. Sometimes
4. Rarely
5. Never

The findings for this question mirror the findings for Section D question 13, which was asked of lone parents. Similar feedback was given by own household fathers to this question, including hesitation where participants did not have a close relationship with the other parent. Confusion arose around the broad nature of the question, as participants were unsure which severity of disagreements would fall under the scope of this question.

Section E question 7

ASK ALL.

MPLAYFa / MPLAYFk.

The next few questions are about your [BABY NAME]**'s activities.**

How often do you do these activities with [BABY NAME]**?**

a) Physical play—for example, lifting or swinging your child, throwing up in the air, rough and tumble

b) Talk to [BABY NAME] **about what you, or they, are doing**

Showcard H:

1. Never
2. Less than once a week
3. Once or twice a week
4. Several times a week
5. Once or twice a day
6. Several times a day
7. Prefer not to say

When answering the first part of this question regarding physical play, participants were hesitant to say they were ‘throwing’ their child or playing ‘rough and tumble’ with them. Those who felt uncomfortable with these terms expressed apprehension at being viewed as uncaring or a fear of being seen as behaving inappropriately. Although these participants reported playing with their children, they shied away from using such physical language.

> “It’s my first kid, and you feel very protective and you don’t want to hurt them because they’re very small and soft. It’s a very closed question – you are kind of putting words in my mouth.” (Male, Own Household Father)

The second part of this question regarding talking to the baby gathered mixed responses, as participants did not always perceive the children to be old enough to talk to. This suggests that the statement could be reworded to sound less formal.

Implication for and changes made to Section E

The changes to section E included the changes made to section D in corresponding questions.

Beyond that, Section E question 7 was changed to put own household parents at ease. The example of ‘throwing the child up in the air’ was removed and statement A was split into two statements:

- Active physical play – lifting or swinging, rough and tumble
- Gentle physical play – tickling, moving child’s limbs, playing finger games such as ‘this little piggy’

6.7 Section F: Vaping

This section was made up of only one question and was asked to all participants. The aim was to gauge whether the question wording and the explanation provided would be sufficient to ensure participants understand which type of products are being referred to.

Section F question 1

ASK ALL RESPONDENTS
VAPE1. The next questions are about electronic nicotine products, such as e-cigarettes, vape pens, personal vaporizers and mods, e-cigars, e-pipes, e-hookahs, and hookah pens. Some common brands include Vuse, Blu, Logic, MarkTen, JUUL, NJOY, eGo, and iTaste.
Now thinking about electronic nicotine products, would you say that…

Showcard J:

1. ...you've never used them
2. …you used to use them but don't at all now
3. …you now use them occasionally but not every day or
4. …you use them every day?

And can I just give you a bit more information about these products? These products are battery-powered and produce vapor or aerosol instead of smoke. Some electronic nicotine products can be bought as one-time, disposable products, while others can be bought as reusable kits with cartridges or a tank system. They typically use a nicotine liquid called "e-liquid", although the amount of nicotine can vary and some may not contain any nicotine at all.

Participants did not have any issues answering this question and felt it was clear regardless of whether they personally used these products or not. Participants felt that the question was clear even without the examples of brands (e.g. Vuse, Blu, Logic) provided. The additional information provided in the second part of the question was rarely needed to clarify the question further.

> “I think a lot of people would know what vaping is, and I don't think anybody…would be confused. If anything, it's most probably a little bit too long, how much detail it involves.”
> (Male, Two Parent Household)

Instances where the further information had been useful included lack of clarity around whether the question referred only to disposable products or only to products containing nicotine.

Implications for and changes made to Section F

The word ‘nicotine’ was removed from the question text. The question info text does reference nicotine and is only provided as an optional ‘help screen’ text that will be read out by interviewers if necessary.

6.8 Section G: Sensitive Questions

In this last section, all participants were asked how they would feel about answering questions on a range of topics. Rather than testing specific questions, the aim was to gauge comfort in answering different topic areas that could be perceived as sensitive. Participants were informed that questions in these subject areas would be self-completed, meaning the interviewer would give a tablet to the respondent to answer privately. The topic areas participants were asked to provide feedback on are listed below.

- Parent-baby bonding: feelings when you are caring for your child or away from your child
- Parent-baby bonding: worry or stress experienced as a parent
- How managing financially
- Conditions in home (e.g. mould, pests, appliances, etc.)
- Affording food or essential baby items
- Respondent physical health, longstanding illnesses
- Adverse life events: illness, injury, deaths, relational issues, employment issues, legal problems
- Abuse or attack because of race or religion
- Social support- support and care from others
- Overall life satisfaction
- Experience of loneliness
- Relationship quality with partner
- Disagreements with other parent (including those not living in your household)

The topics noted as being especially sensitive were:

- Abuse or attack because of race or religion
- Relationship quality with partner

- Adverse life events
- Mental health/treatment for mental health
- Alcohol and smoking
- How managing financially/conditions in home/affording food or essential baby items

Participants mentioned a range of concerns that could arise regarding these. Many of these were thought to particularly affect those who were struggling financially or had experienced hardship in their lives. It was anticipated that people could feel embarrassed or judged by the interviewer when answering questions on these topics. Additionally, it was noted that questions could bring up sensitive or triggering memories for participants. There was also concern about any possible negative implications of answering questions on these topics, such as the involvement of social services. Again, participants felt that this fear could lead to a reluctance to answer questions.

When thinking about the topic ‘relationship quality with partner’, participants mentioned discomfort at the idea of talking about the relationship quality with their partner while the partner was in the house. It was important to them to be certain that their answers would not somehow become known to their partner.

Reflecting on these sensitivities, participants generally preferred the idea of self-completion for these topics. It was noted that reassurances around confidentiality and anonymity would be crucial.

Implications for and changes made to Section G

When asking questions on the sensitive questions listed above, the confidentiality and voluntary nature of the study will be stressed. Additionally, help texts explaining the purpose of collecting this data will be added to ensure participants know how their answers will be relevant. Given participants’ concerns about the sensitivity of the information, and the fact that judgements may be made about their situation, a planned ‘Interviewer Observations’ module about the household environment (not covered by the testing) was removed from the survey.

Sensitivities regarding ‘relationship quality with partner’ were reflected in the following approaches:

- Where a partner is helping the respondent answer survey questions (e.g., due to the need to translate), they are routed out of questions about the partner relationship.

- The script includes the recommendation for the respondent to answer questions about the partner relationship in a private space if possible.

For more information

3 Thomas More Square
London
E1W 1YW

t: +44 (0)20 3059 5000

www.ipsos.com/en-uk
http://twitter.com/IpsosUK

About Ipsos Public Affairs

Ipsos Public Affairs works closely with national governments, local public services and the not-for-profit sector. Its c.200 research staff focus on public service and policy issues. Each has expertise in a particular part of the public sector, ensuring we have a detailed understanding of specific sectors and policy challenges. Combined with our methods and communications expertise, this helps ensure that our research makes a difference for decision makers and communities.