

Findings from meetings of
the National Children's
Bureau's Family Research
Advisory Group and Youth
Research Advisors on the
Early Life Cohort Feasibility
Study.

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Findings from meetings of the National Children's Bureau's Family Research Advisory Group and Youth Research Advisors about the Early Life Cohort Feasibility Study.

The National Children's Bureau has two research advisory groups: the Youth Research Advisors (YRA) which is a group of 10-18 year olds from around England who advise on research projects that involve them. Some of the group have Special Educational Needs and Disabilities (SEND) aged up to 25; and the Family Research Advisory Group (FRAG) which is a group of parents and carers from around England who advise on research projects which involve people like them. Both groups receive training on data collection, ethics, research methods and how to interpret findings.

In the first session in Autumn 2021, the ELC-FS study team spoke with the groups to understand participant views on proposed study content, who should be interviewed and answer which questions, perceived costs and benefits of participating, information and engagement needs, and who consents to the child's enrolment. In the second session in early 2023, the ELC-FS study team spoke with the group again to let them know how their advice had been incorporated into the study, and ask some follow up questions on specific engagement areas such as messaging and publicity. These sessions were hosted and moderated by staff from National Children's Bureau. A third and final session with the YRA and FRAG groups is planned for 2024.

Session 1 findings

There were 14 participants in the YRA group, with a mix of ages, those with SEND, male and female participants, ethnicities, and regions from England and Northern

Ireland. There were 12 participants in the FRAG: 2 were from Northern Ireland and the rest were from England, 10 were mothers, and there were a mix of ethnicities.

Study questionnaire and content

The study team asked the FRAG this to understand the likelihood of engagement with different parts of the study protocol, and to understand key issues for families today.

Topics of particular interest to parents included childcare arrangements, return to work, living arrangements, effect of COVID-19, reflections on their own upbringing and parenting experience, parental disability, parental mental health, support networks, use of different services and children's diet and allergies.

The study team asked both the FRAG and YRA for their views on collecting genetic samples from parents and their children. Both groups raised concerns about the purpose of this collection and had concerns about the lack of agency and autonomy from the child in the process. They also had practical concerns about how this collection would work if the child was sick.

The study team also asked parents about the idea of using a baby heart rate monitor, and an app with the option to record videos. For the heart rate monitor, parents felt that clear information about this and being reassured there was no risk would be important. In particular, clear information on purpose of the activity was needed. Regarding the app, parents felt that using this signals an ongoing commitment from parents and queried whether parents would have time to do this. However, other parents/carers suggested that an app could be a quick and easy way for a parent to submit their information. Parents raised that some may not be able to use the app (e.g. those without a smartphone or who are less tech savvy) and that it may feel like surveillance. There were mixed views about filming via the app: some felt that they would feel judged whereas others liked the interactive aspect.

Benefits and barriers to participation

The study team asked the FRAG about what they might like to get out of a study like the ELC-FS, as well as what might put them off participating. This was asked to

inform the study's engagement and incentive strategy. Parents wanted to receive materials that stressed the value of doing something bigger for society and science, demonstrated trustworthiness, and was inclusive of all kinds of families. In terms of a financial incentive, parents thought £10 was a little small, and a gift for the child may be more effective. They thought a branded gift would not be effective and potentially bad for the environment. Other suggestions they had were to disseminate study findings, particularly if they could be individually tailored, and setting up a support group for parents in the study.

In terms of what might put them off participating, the FRAG felt a 60-minute interview would be too long for busy parents. They thought fear of being referred to social services, a lack of trust and fear of judgement would also be issues for some parents.

Recruitment strategy

The study team asked both the FRAG and YRA about how the study should recruit parents to take part. This was done to understand the best ways of reaching and engaging parents, and also to understand the practical considerations of contacting and inviting different parents.

Both groups stressed the importance of an inclusive approach to recruitment – for example they thought step-parents, grandparent carers and other carers should be invited. The FRAG were unsure how recruitment via birth records would work when parents were separated and had some ethical concerns about the use of data in this way. The FRAG thought a social media campaign would aid recruitment.

Deciding to take part

The study team asked the FRAG and the YRA groups who they thought should decide whether the child participates in the study, and what information would be needed to make this decision. FRAG and YRA members broadly agreed that both parents need to agree to enrol their baby to the study to avoid conflict and because it is the right thing to do. FRAG members felt that this was a good idea if one of the parents/carers is not available and if they feel strongly enough, they have an opportunity to opt out. FRAG members also suggested a 14 day opt out period for

both parties in case they change their mind. YRA members felt that the degree of involvement in the child's life should also be a deciding factor.

YRA members suggested that clear information about how the study data would be stored, used and shared would be needed to make this decision. YRA members also felt it would be important for parents/carers to know how long their involvement in the study would be, and also what happens when the baby becomes a young person. Overall, the group believed that unless a parent was not involved in the baby's life, both parents or carers would need to have the same information about the study.

Conducting the interview

The study team asked both groups about how the different parent interviews could be managed logistically. This was asked to understand any practical issues, but also to understand which questions should be asked to which parents, as the proposal was for one parent to do a longer interview about themselves and their child, and for the other parent to do a shorter interview mainly about themselves.

FRAG members raised a number of practical concerns e.g. how to manage an interview alongside looking after children, could there be a quicker/easy read version of the questionnaire, could the interview be broken up over a few visits.

In terms of which parent is asked which questions, the FRAG felt the presumption that the mother is the primary caregiver was thought to be outmoded – therefore families could be asked who they wanted to define in that role. Both groups agreed that a main carer should be identified but also felt that both should undertake an interview that is of the same length and duration if budget allowed. Some YRA members pointed out risk of duplication. Both groups felt the primary carer should do the longer interview; however, this may change over time (depending on family dynamics and circumstances), and this should be taken into account. The FRAG group also stressed that those doing the survey should be determined by amount of care to child, not parenthood status.

Session 2 findings

A second session with the two groups was held in early 2023. Six members of the FRAG attended and eight from the YRA group attended. These sessions were used to feedback how their advice had been incorporated into decisions taken for the study design, and to get additional feedback on some new areas.

Feedback on study website and brand

The YRA were asked for their thoughts on an early design of the participant study website. This was asked to understand whether the group found the page visually effective and engaging, and to understand any issues with navigation and comprehension. Overall, the group liked the colour palette, found the pages easy to read, and thought the layout was intuitive. Suggestions for changes included having more 'realistic' images of parents throughout.

How cohort studies make a difference

The study team asked both the FRAG and YRA group to discuss different examples of how previous cohort studies have made a difference to policy and scientific knowledge. The study team used this feedback to choose the examples to highlight in the study materials and website. The most popular examples related to the development of the world's first universal Child Trust Fund using evidence from the National Child Development Study (though the FRAG noted the scheme no longer existed), extensions made to parental leave in the UK using evidence from the Millenium Cohort Study, and research from the SEED study about differences in children's educational outcomes dependent on the quality of nursery they attended.

Creating an inclusive and accessible study

Both groups were asked to give their thoughts on practical measures the study could take to ensure all parents were able to take part. Suggestions included flexibility scheduling interviews, training interviewers to be aware of accessibility issues, allowing use of interpreters and translating materials, avoiding jargon in communications, having alternative mediums for materials (audio and large print

versions) and screening parental needs prior to interview so adjustments could be made.

Publicising the study

Both groups were asked about their thoughts on how to publicise the study. The study team did this to understand where parents are most likely to get their information from. Instagram, facebook and Mumsnet were suggested as possible outlets. TikTok was not thought to be effective by either group. The FRAG also suggested disseminating information via parent/carer forums, and through health visitors and GP networks. The YRA thought radio may be an effective way of reaching parents, though the FRAG thought visual engagement would be better.

Incorporating children's and young people's voices

During the YRA session, the group were asked how they thought children's and young people's voices could be incorporated into the study. The study team wanted to give the group the opportunity to voice their opinions on this, as they can better speak on the perspective of the study's cohort members than the FRAG participants. The group felt that children should be able to opt-out from the study when they are old enough to verbalise this, that they should be given reassurances about their anonymity and how their data was being used, and be provided with feedback about the study findings and progress.

Keeping in touch

The FRAG were presented with the proposed plans for keeping in touch with parents after the interview. The group suggested there should be clear methods for parents to let the study know they had changed their address or contact details.

Additional feedback on sampling procedure

We received feedback from four members of the FRAG after the session in response to a request for additional feedback from the sample frame data holder in March 2023. The data holder requested additional evidence about the public acceptability of the sampling procedure of providing contact details to Ipsos for the purpose of the study opt-out. None of the responses raised concerns with contact details held by

the data holder being passed to Ipsos for the purposes of issuing the opt-out. The respondents felt that this was acceptable given that the Generation New Era materials would have clear instructions and options to opt-out of the study, endorsement from the data holder for the use of the records to contact participants, and that there was not too long an opt-out period that parents would forget about the study.