

Incorporating public  
engagement findings on the  
use of administrative data  
into the design of the Early  
Life Cohort Feasibility Study

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# Incorporating public engagement findings on the use of administrative data into the design of the Early Life Cohort Feasibility Study

To inform the design of the Early Life Cohort Feasibility Study, in 2021 the study commissioned Kantar Public (now Verian) to undertake stakeholder interviews and a public dialogue. The findings from this research were discussed in a stakeholder activation workshop held in October 2022, also run by Kantar Public. The purpose of this workshop was to inform the study team's decisions about how to incorporate the findings into the study design. Stakeholders were consulted on – (i) Recruitment models (ii) Use of administrative data for non-response analysis and adjustment and (iii) Consent models for administrative data linkages.

Following the workshop, the study team decided to incorporate the findings into the study design in the following ways –

## Recruitment models

Parents preferred a two-step recruitment approach, where an initial opt out letter is sent to the selected sample by the data controllers prior to the sample being passed to the fieldwork agency, followed by an invitation letter from the study's fieldwork agency a few months later. The alternative would be a one-step approach in which families would receive only one mailing before being approached by an interviewer. In Northern Ireland, the data controllers required this and a two-step recruitment approach will therefore be used. In England, Wales and Scotland, the data controllers informed the study that they were not able to do this themselves, so the initial opt-out letter would need to be sent by the fieldwork agency, after they have received the sample. The England, Wales and Scotland data holders had approved either a one-step or two-step approach. Therefore, in the stakeholder activation

workshop, discussions around the two models focused on whether potential participants would prefer/ respond differently to receiving one or two letters ahead of their first visit from the interviewer. **Based on the stakeholder discussions the study decided to issue two sequential letters, one to inform participants of the opt-out process and one as an advance letter.** This means that a layered approach to providing information about the study can be used, there are two opportunities for people to decide to opt out of the study (in addition to being able to opt out at any time) and it is less likely that participants would miss two letters and therefore less likely that the interviewer visit would be unexpected. The study also found support for this model in further public engagement, including materials testing with parents and from the National Children's Bureau Families Research Advisory Group.

Stakeholders flagged the importance of transparency and of providing certain information in participant materials, including the legal basis of data sharing, the scrutiny applied and data privacy, a compelling narrative regarding how and why the study team has people's data and explaining what the interviewer visit will involve. **The study team incorporated all this information,** including information about approvals from relevant ethics and privacy committees, **into participant materials in a transparent and accessible way** and materials were subject to extensive testing with parents from a range of different backgrounds. The Appendix includes some relevant excerpts from the participant letters and leaflets.

Some stakeholders felt that the first letter should be branded as and/or signed by the data controller, provided this did not give the impression that the letter was being sent by the data controller. Materials testing work also shows that people are reassured by the use of the data controller logo to help signal that the study has been approved by appropriate trusted bodies. This approach was supported in Scotland, where the first letter **included the Public Health Scotland logo.** However, in England and Wales the data controller preferred not to take this approach. **In Northern Ireland,** the first letter (to be sent by the Health and Social Care Business Services Organisation) **was signed by, and included the logo of, the relevant Health and Social Care Health Trust.**

The participant letters and leaflets can be found on the Generation New Era website at <https://gnestudy.info/letters/english>.

## Use of administrative data for non-response analysis and adjustment

Parents had mixed views about the acceptability of using data of those who do not respond to the study team's invite letter or later recruitment attempts. However, stakeholders recognised the necessity of analysing opt-out data for non-response bias and, given the low risk of potential harm to individuals of using deidentified data, viewed it as a suitable use and acceptable trade off. **The study will therefore use administrative data for this purpose, only accessing it for as long as needed** (where physically held by the study, the data will be deleted once it is no longer needed).

Stakeholders agreed that using the privacy notice to highlight the use of deidentified administrative data for non-response analysis was appropriate. However, stakeholders raised concerns about the potential to 'bury' information in the privacy notice. **The study has added clear, easy to understand and transparent information to the privacy notice** (<https://gnestudy.info/privacy/>), including details about the specific information that the study will receive from administrative data, why the study will receive this, how the information will be used and how people can opt out of their information being used for this purpose. **To further address concerns about transparency** and that information in the privacy notice could be missed -

- the **guide to the study/advance booklet**, explains that if people choose not to take part, the study will use the information from their records to understand who does and doesn't take part (see excerpt from Study Guide - 'Looking after your information' in the Appendix).
- Information about how the study will use the data of those who do not take part is provided on the study website, in a **Q&A about looking after people's information**. This includes how people can inform the study if they do not wish their information to be used in this way.

## Consent models for administrative data linkages

In the public dialogue, **parents had mixed views** towards opt-in and opt-out consent models for administrative data linkages but with an understanding of their benefits and constraints. Regardless of approach, there was consensus around principles of **transparency, minimising participant burden**, and providing reassurances to **build trust**. Although overall **stakeholders felt that opt-in consent was needed** for data linkages, there were **mixed views** on which consent model should be used. There were key concerns about **data controller requirements** and **ethical considerations** for an opt-out approach. However, stakeholders appreciated the need to balance these concerns against the **scientific needs** of the study and considerations around **response rates** and **participant burden**.

Given these mixed views, the study went on to test the acceptability of both the opt-in and opt-out approaches in materials testing with parents – both approaches were viewed as acceptable if the proposed linkages and use of the data were made **clear and transparent** to participants and as long as they had a **choice and control** over whether or not their records will be linked. The study is therefore testing both approaches in the field, and study families have been randomly assigned to either an ‘opt-in’ or an ‘opt-out’ approach. The study is doing this to assess which approach works best, in terms of how participants react to the approach, how interviewers find administering each approach, and which ends up with higher consent rates.

The study approaches, website content and materials have been carefully designed with **transparency** and **choice and control** in mind, emphasising to participants that **it is their choice** whether or not these records are linked and that participants can change their mind about their permissions at any time. For both approaches, parents are given the same information about the proposed data linkages in the study guide/advance booklet and also during the interview.

For the opt-in group, they are asked during the interview to give their permission (yes/no) for their own data linkages for each type of record (health, education, social care). A parent with legal responsibility for the child is asked to give their permission (yes/no) for their child’s data linkages for each type of record (health, education, social care).

For the opt-out group, they are informed during the interview of how they can opt out by using an online form after the interview. They can do this for themselves and / or their child and the form includes structured yes/no responses.

Both groups also receive the same 'what happens next' leaflet after the interview with reminders about how to change their choices about data linkage using the online form.

Both approaches have received approval from a Research Ethics Committee and the study will also seek approval from data controllers for both approaches.

## Appendix – excerpts from participant letters and leaflets and consent wording

### Excerpt from 'How was I chosen for this study' from notification letter in England and Wales

Your family was **chosen at random from records of births** held by NHS England for England and Wales, and the National Records of Scotland and Public Health Scotland. These organisations provided your name, address and additional information about you and your baby.

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### Excerpt from notification letter in England and Wales - 'Your confidentiality'

#### Your confidentiality

**The information you give the study will be kept completely confidential and used for research purposes only.** UCL has a legal basis for processing your personal data because it is for 'a task in the public interest' under the General Data Protection Regulation. We also have special approval to receive information from birth records in order to contact you from the NHS Health Research Authority's Confidentiality Advisory Group, NHS England's Independent Group Advising on the Release of Data, and the NHS Scotland Public Benefit and Privacy Panel for Health and Social Care. This has been granted following a careful review of the information the study will collect, and how we will ensure that your data and privacy are protected. Full details about how we will look after your information, including what happens to your information if you decide not to take part, are in the **Privacy Notice** on the study website [gnestudy.info/privacy](https://gnestudy.info/privacy).

## Excerpt from Study Guide – ‘Looking after your information’

# LOOKING AFTER YOUR INFORMATION

### Who has approved this research?

This research has been reviewed and approved by an **NHS Research Ethics Committee**. This is an independent group of people committed to protecting your safety, rights, wellbeing and dignity.

### What will happen to the information you give?

The information is used for **research purposes only**. Your survey responses will be put together with the answers from all the other people who are interviewed and made securely available for research via the UCL Data Safe Haven, UK Data Service and other secure research environments. Sometimes this may include commercial organisations using the data for approved research purposes. This research data does not contain any names, addresses, or other personal details that could directly identify individuals in the study.

#### **Your study information is treated in strict confidence and kept securely.**

It is used in accordance with the General Data Protection Regulation (GDPR) and will be retained until no longer required by the study. Generation New Era has strict security rules and secure systems to protect your information.

The information you give will be kept entirely confidential from other members of your family and from organisations who provide services or administer benefits that you or your baby may use or receive.

In very exceptional circumstances your confidentiality may be broken, for example, if something you tell us indicates that someone is at significant risk of harm.

### What if you choose not to take part, or withdraw from the study?

You do not have to take part in Generation New Era if you do not want to, and you have the right to withdraw from the research at any stage, without having to give a reason. If you do withdraw or if we lose touch with you, **we will retain and continue to use your study information for research unless you tell us not to.**

If you choose not to take part, we will use the information from birth records to understand who does and doesn't take part.



## Excerpt from 'How will we get in touch with you' from the 'What Happens Next' Leaflet

We will also apply to the NHS to receive up-to-date contact details - for example, the address at which you are registered with your GP - and for notifications about study participants who have moved out of the UK or who have died. In the future, we may also apply to other government departments for addresses that they may hold. We may also use data checking services and information that you've made publicly available online to get in touch with you.

## Advance Booklet spread on adding information from administrative records and about where participants live

### ADDING INFORMATION

#### Information from administrative records

Government departments and agencies, such as the NHS, routinely collect administrative records about all of us to help plan and provide services.

**We would like to add information from administrative records about you and your child to your study responses.** This makes the study even more useful for researchers and policymakers, who will use this information to improve public services for everyone.

**Adding information will help Generation New Era build a more complete picture of your lives.**

#### Which administrative records would we like to add?

We would like to add information from **health, education and social care records** for you and your child. To find out what these records cover, please visit the study website.

The information relates to your and your child's past, present, and future circumstances. We would like to add information from these records on an ongoing basis for the duration of the study.

#### Who decides about adding administrative records?

**It is your choice** which of these records are added to your study responses. **The interviewer will tell you more about this,** and you can change your mind at any time.

You may wish to discuss adding information from your child's records with their other parent. We will only ask the parent who does the longer interview about this.

**If you don't wish to do this, you can still take part in the study.**

#### How will information from administrative records be used?

It will be used for research purposes only. Adding information from administrative records will not affect your or your child's services, rights, treatment or any health insurance. It will not affect your benefits or tax.

Scan this QR code to watch our video about adding information from administrative records.



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### Information about where you live

We will also add information about the **local area or property** where you live. This could be information such as air pollution levels, green spaces, local amenities or the energy efficiency of your home. Where we live has a huge impact on many aspects of life, so understanding more about where you live and your local area is very useful for research. Frequently, these geographical data are **publicly available**. We plan to do this for everyone who takes part in the study, but if you prefer that we don't do this, please let us know using the details on the back of this booklet.



**Find out how Generation New Era will look after your information in the next section of this booklet and on the study website.**

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## Extract from ‘What Happens Next’ booklet reminding participants about their permissions to add information from administrative records and about where they live

The survey responses from everyone in the study will be made securely available for research via the UCL Data Safe Haven, UK Data Service and other secure research environments. This research data does not contain any personal details that could directly identify individuals in the study.

Ipsos will also send the information about you and your baby from records of births, and other information you’ve given as part of the study, for example your address and other contact details, securely to UCL.

Your survey responses will always be kept and transferred separately from information that could identify you (such as your name and address). **All of your study information is treated in strict confidence and used in accordance with the General Data Protection Regulation (GDPR).** It will be retained until no longer required by the study. Generation New Era has strict security rules and secure systems to protect your information.

Find out more about how Generation New Era will look after your information, and the study’s privacy notice, at [gnestudy.info/privacy](https://gnestudy.info/privacy).

### What about adding other information to your survey answers?

The interviews covered **adding information from your and your baby’s administrative records to your survey responses.**

You will receive a thank you letter in the post with a further reminder about this, and there is more information on the study website: [gnestudy.info/adding-information](https://gnestudy.info/adding-information).

The information we would like to add relates to your and your child’s past, present and future circumstances. If you have chosen for us to do this, we will continue to add information from these records on an ongoing basis for the duration of the study. **This includes if you decide not to take part in future interviews or if we lose contact with you.** If you change your mind about this at any time you can let us know by completing our online form: [gnestudy.info/update-your-permissions](https://gnestudy.info/update-your-permissions).

In the booklet we sent to you before the interviewer visit, we let you know that we will be **adding information about the local area or property where you live.** Frequently, these geographical data are **publicly available** and adding this information does not usually require us to share any of your personal information with any other organisations. We did not ask your permission to add this kind of information because the data is not individual level information about you. We plan to do this for everyone who’s taken part in the study. **However, if you prefer that we don’t do this, you can let us know using the contact details of the Generation New Era study team at UCL on the back of this booklet.**

## Opt-in consent wording

### **LINKINTRO1**

We would like your permission to add information from administrative records held by various government departments and other agencies to the information we collect as part of Generation New Era. This covers:

- Information from your baby's/babies' health, education and social services records.
- Information from your health, education, and social services records.

The information we would like to add relates to your baby's/babies' and your past, present, and future circumstances. As this study aims to follow children over time, we would like to add information from your baby's/babies and your records on an **ongoing basis for the duration of the study**.

Before continuing, please make sure that you have read the 'Adding Information' section in the study guide which explains more about this.

#### **HELP SCREEN: How is this information added?**

To add this information, we will securely send your name, sex, address and date of birth and a unique study identifier to the named government departments and agencies that hold your records, or to another organisation acting on their behalf. These personal details are only used to find your administrative records. Once identified, the information from your records is made available with your unique ID only.

Neither your child's nor your name or address will be included in the data used by researchers, which ensures that no one can be identified.

1. Next

### **LINKINTRO2**

At the next few questions you can choose whether or not to give us permission to add information about you and your baby/babies from administrative records. You can change your permissions at any time after the interview, without giving a reason.

#### **HELP SCREEN: Where can I find more information about this?**

The 'Adding Information' section of the study guide explains more about this. Further information can also be found on the study website [gnestudy.info](http://gnestudy.info), or you can contact us using the details found on the last page of the study guide.

1. Next

### **LINKNHS**

We would like your permission to add information from health records about you and [child/children's names] until they are 14, held by the following organisations to your survey information:

- NHS England
- Digital Health and Care Wales
- Public Health Scotland
- NHS National Services Scotland
- Health and Social Care (HSC) in Northern Ireland

These health records include information such as admissions or attendances at hospital (including maternity records), visits to a GP or other health professional (e.g. midwife), mortality data, cause of death, specific conditions and prescriptions given.

**HELP SCREEN: Why are we asking to add these records?**

Adding this extra information will mean more detailed research can be done on things like:

- Which factors are linked to particular illnesses
- How some illnesses impact children's wellbeing and how they get on in school"

1. Next

**LINKNHS\_CH**

Are you willing to give this permission for the health records of [child/children's names]

1. Yes - for [child 1's name]
2. Yes – for [child 2's name]
3. Yes – for [child 3's name]
4. Yes – for [child 4's name]
5. No [EXCLUSIVE CODE]

[MULTICODE]  
[NO DK/REF]

**LINKNHS\_R**

Are you willing to give this permission for your own health records?

- 1 Yes
- 2 No

[SINGLE CODE]  
[NO DK/REF]

**LINKEDU**

We would like your permission to add information from your education records and for [child's/children's names] until they are 16 held by the following organisations to your survey information:

- 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 and the Northern Ireland Department for the Economy

These records will include information about education such as exam results and participation in further education, special education needs, as well as details about the schools or colleges attended. These records also cover use of childcare services.

**HELP SCREEN: “<b>Why are we asking to add these records?</b>”**

Adding this extra information means more detailed research can be done on things like:

- How children’s experiences when they are very young affect how they do when they start school
- Which childcare services are being used
- How parents’ education influences their parenting and educational choices for their children “

1. Next

**LINKEDU\_CH**

Are you willing to give this permission for the education records of [child's/children's names]?

1. Yes - for [child 1's name]
2. Yes – for [child 2's name]
3. Yes – for [child 3's name]
4. Yes – for [child 4's name]
5. No [EXCLUSIVE CODE]

[MULTICODE]  
[NO DK/REF]

**LINKEDU\_R**

Are you willing to give this permission for your own education records?

- 1 Yes
- 2 No

[SINGLE CODE]  
[NO DK/REF]



## LINKSC

We would also like to add information from social care records about you and [child's/children's names] until they are 16 held by the following to your survey information:

- The Department for Education in England
- Public Health Scotland
- The Scottish Government
- The Welsh Government
- Health and Social Care (HSC) in Northern Ireland”}

These records include information on any help received from social services – including visits from social workers and experiences of social care.

HELP SCREEN: “<b>Why are we asking to add these records?</b>”

Adding this information will help increase our understanding of how families’ use of these services has affected things such as how well children do at nursery and school. This will be used to help improve public services for everyone.

Adding this extra information will mean more detailed research can be done on things like:

- how social services can affect how well children do at school
- how social services can affect children’s and parents’ wellbeing as they grow up. ”

1. Next

## LINKSC\_CH

Are you willing to give this permission for the social care records of [child’s name/children’s names]?

1. 1. Yes - for [child 1’s name]
2. Yes – for [child 2’s name]
3. Yes – for [child 3’s name]
4. Yes – for [child 4’s name]
5. No [EXCLUSIVE CODE]

[MULTICODE]

[NO DK/REF]

## LINKSC\_R

Are you willing to give this permission for your own social care records?

- 1 Yes
- 2 No

[SINGLE CODE]  
[NO DK/REF]

## **LINK\_OO**

As a reminder, if you change your mind at any point, you can let us know using the contact details on the last page of the study guide. You can also contact the study team if you have any questions.

You can find out more about adding information from administrative records, including what will happen if you change your permission and how long the administrative records will be added, in the 'Adding Information' section in the study guide and on the study website.

1. Next

## Opt-out consent wording

### OPTOUTINFO

As part of the study, we would like to add information from administrative records held by various government departments and agencies to the information we collect as part of Generation New Era.

This covers:

- Information from your baby's/babies' health records until they are 14 and education and social care records until they are 16.
- Information from your health, education, and social care records.
- **Health records** include admissions or attendances at hospital (including maternity records), visits to a GP or other health professional (e.g. midwife), mortality data, cause of death, specific conditions and prescriptions given.
- **Education records** include exam results as well as details about childcare used and schools attended. For parents, further education is also included.
- **Social care records** include any help received from social services – including visits from social workers and experiences of social care.

The information we would like to add relates to your baby's/babies' and your past, present, and future circumstances. As this study aims to follow children over time, we would like to add information from your baby's/babies' and your records on an ongoing basis for the duration of the study.

If you **do not** wish to have information from one, some, or all of these records added to your survey responses, **please let us know** using the contact details in the 'Be Part of Generation Era' Study Guide or using this web form. It is your choice. You can change your mind at any time, without giving a reason. You can still participate in the study if you choose not to add any of your records.

You can find out more about adding information from administrative records in the leaflet and on the study website. You can also contact the study team to ask any questions you may have.



1. Next