

Building Blocks:2-6 Privacy Notice

Version 1.0 07NOV2021

1. Study details

Name: Building Blocks: 2-6 Study: Evaluating the medium-term effectiveness, and the cost and consequences of the Family Nurse Partnership parenting support programme in reducing maltreatment in young children.

Address: Centre for Trials Research, Cardiff University, Wales, UK.

Study website: <https://evidencinghomevisiting.co.uk/building-blocks-2-6/>

Data Controller: Cardiff University

Data Processor/s: Swansea University

Sponsor: Cardiff University

Study summary:

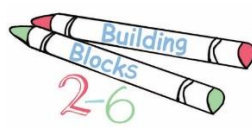
The First Project - Building Blocks: A programme of home visits by specially trained nurses (called the Family Nurse Partnership or FNP) aims to support young mums expecting their first child. The programme was compared to usual health and social care in a study involving 18 English centres and followed children until they were two years old.

The Second Project - Building Blocks: 2-6: This research project followed up these same individuals until that child turned seven. It looked only at routinely collected health and education data—this is information that the GP, hospital and school collect when looking after people. The study looked at this information to explore the long-term effects of extra home visits from family nurses versus the services currently available to families in England. All mothers were given the opportunity to opt-out of this study.

2. The type of personal information we collect for Building Blocks: 2-6

Cardiff University collected and processed the following information on the Building Blocks participants and their child/ren who were part of the trial:

- Personal identifiers:
 - Name
 - Date of birth
 - Address
 - NHS Number
 - Gender
 - Email address
 - Mobile phone number



- Special category data:
 - Race
 - Ethnic origin
 - Health data (including disability)

3. How we get the personal information and why we have it

Most of the personal information we processed was provided to us directly by you for one of the following reasons:

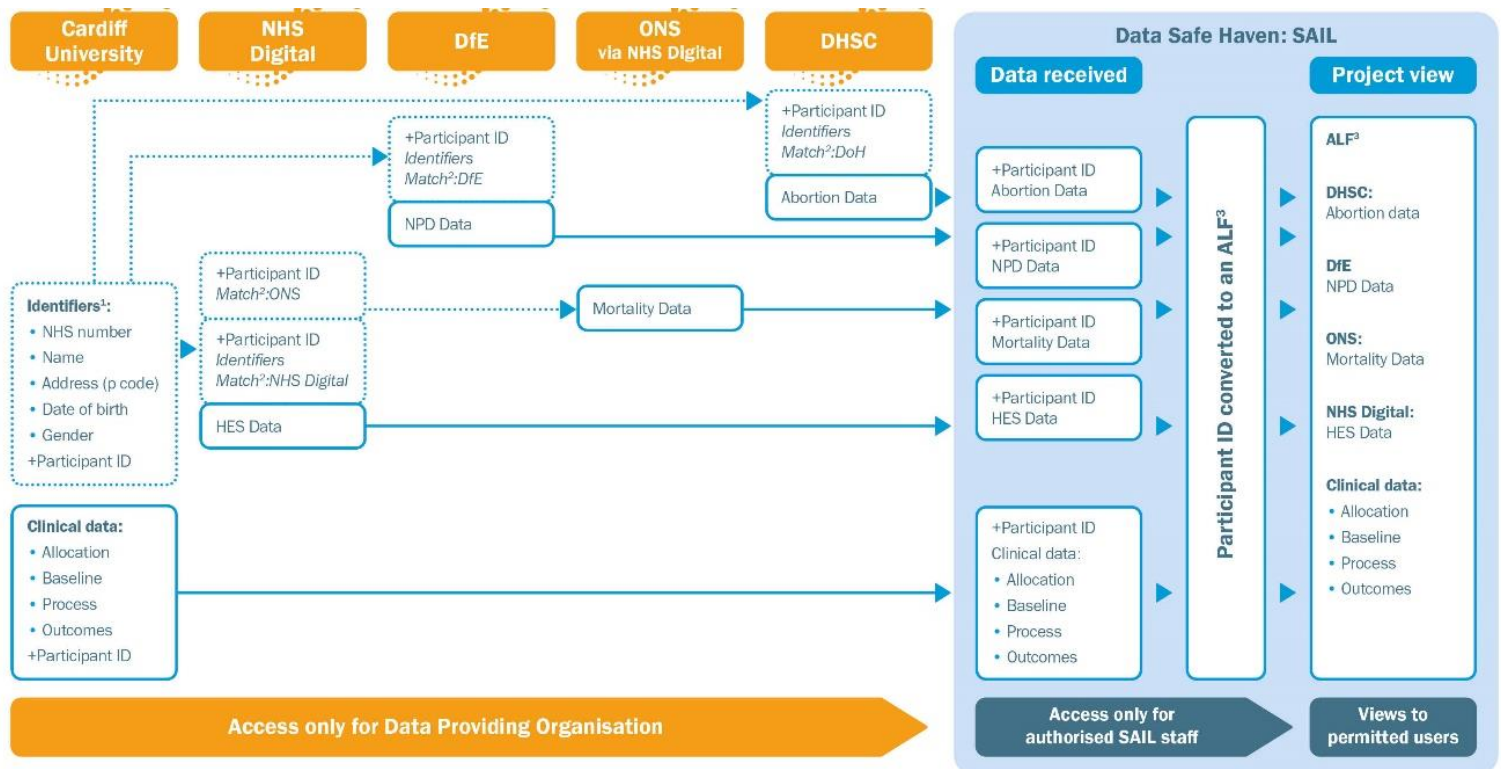
- As a participant of the Building Blocks trial

We also received special category data indirectly, from the following sources in the following scenarios:

- In 2014-2018, for our Building Blocks: 2-6 study, Cardiff University provided details to identify you/your child to the NHS Digital, the Department of Health and Social Care and the Department for Education (DfE) in order for those professionals to provide relevant information about you and your child.
- The details supplied were your/your child's name, NHS Number, date of birth, postcode and gender.
- Data were sent to these organisations at two time points during the study duration:
 - **NHS Digital** provided information on how project participants had used different health services (e.g. how many hospital visits) and for what reasons and also, if applicable, information from the Office for National Statistics related to deaths.
 - The **Department for Education** provided information on how participants had used education services including details of school attendance, free school meals, special education needs and school achievements. For those children who had a record in the child in need or child looked after datasets, information about this was also provided.
 - The **Department of Health and Social Care** provided information that helped identify pregnancies mothers had since the birth of their Building Blocks baby. This included any pregnancies that ended in abortion. As with all other study data, the identity of the mothers will not be known to the researchers.
- These departments provided data to a secure server based at Swansea University. No identifiable data were sent. Instead, a study number was assigned to each individual and was used to join pieces of information together. All data transfers ended in 2018 and since then, no new data has been requested from data providers or sent to the secure server.
- Data viewed by the research team are not identifiable. In other words, when researchers look at the health, education and social care information, all they see is a database containing numbers. When a database technician was sent more data from the sources we mentioned earlier, they used the study number to identify a person and join up the information. We do not know who is who in the database - See the image below for an example of what we see:

PART_ID	TR_7ptype	ART_AS1	CDD_AS2	RdC	RefYN
10652	1	0	1	6455	1
18762	0	3	3	5733	0
45685	2	4	3	0	1
42913	1	2	2	4687	1
10702	4	0	0	2255	1
50194	4	1	3	7484	0
37050	2	3	3	5761	0
40060	0	2	3	6455	0
90760	1	4	4	5733	0
58634	4	0	2	6455	0
57961	3	1	2	0	1
46830	2	2	2	6455	1
40978	4	1	1	4687	0

- Below is a data flow describing how data moved between Cardiff University, the data providers mentioned above and Swansea University:

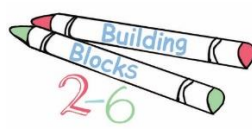


Sensitive person identifiable information

Identifiers: i.e. specifically for linkage

¹ De-identification and Standardisation applied (e.g. date of birth to week of birth)
² Data Providers confirm matching of BB/NHS Digital/ONS/ DfE /DHSC identifiers
³ ALF - Anonymised Linking Field

<http://dx.doi.org/10.1136/bmjopen-2016-015728>



We used the information that you have given us in order to answer important questions about whether the FNP programme made a difference for families over a longer period of time on outcomes such as:

- how many children were referred to social services or needed additional support once they had been assessed
- how many children went to hospital with an injury or having swallowed something
- school readiness
- academic attainment at Key Stage 1
- how many mothers had a subsequent pregnancy

As part of the evaluation, we shared the de-identified data with Swansea University so that colleagues could assess the overall costs of the FNP programme over a longer period of time.

Now that the study has completed, we may share de-identified information with other research institutions. Additional privacy notices will be produced to inform you of this additional research.

Under the General Data Protection Regulation (GDPR), the lawful bases we rely on for processing this information are:

- (e) We need it to perform a public task.

For information on what this means please [follow this link](#).

The lawful bases we rely on for processing special category data are:

- (j) Archiving, research and statistics

For information on what this means please [follow this link](#).

4. How we store your personal information

Your identifiable data is securely stored on a server located at Cardiff University with access restricted only to those working on the study.

De-identified data is securely stored on a server located at Swansea University with access restricted only to those working on the study.

Identifiable data (personal data) collected as part of the original trial and used to contact you is stored separately to the data used for analysis and will be destroyed when it is no longer necessary to keep this information and within 15 years of the study ending.

Special category data held in the de-identified database will be kept until it is no longer necessary and within 15 years of the study ending. We will then dispose of this data following our organisational data destruction policies.



5. Your data protection rights

Under data protection law, you have rights including:

Your right of access - You have the right to ask us for copies of your personal information.

Your right to rectification - You have the right to ask us to rectify personal information you think is inaccurate. You also have the right to ask us to complete information you think is incomplete.

Your right to erasure - You have the right to ask us to erase your personal information in certain circumstances.

Your right to restriction of processing - You have the right to ask us to restrict the processing of your personal information in certain circumstances.

Your right to object to processing - You have the right to object to the processing of your personal information in certain circumstances.

Your right to data portability - You have the right to ask that we transfer the personal information you gave us to another organisation, or to you, in certain circumstances.

You are not required to pay any charge for exercising your rights. If you make a request, we have one month to respond to you.

Please contact us at inforequest@cardiff.ac.uk if you wish to make a request.

To note. Rights in relation to automated decision making and profiling are not relevant in this study (i.e. we do not use automated decision making).

6. How to complain

If you have any concerns about our use of your personal information, you can make a complaint to us at inforequest@cardiff.ac.uk.

You can also complain to the ICO if you are unhappy with how we have used your data.

The ICO's address:

Information Commissioner's Office
Wycliffe House
Water Lane
Wilmslow
Cheshire
SK9 5AF

Helpline number: 0303 123 1113

ICO website: <https://www.ico.org.uk>