

# FNP Mechanisms Privacy Notice

Version 1.0 07NOV2021

## 1. Study details

Name: FNP Mechanisms

Address: Centre for Trials Research, Cardiff University, Wales, UK; Department of Economics & Social Research Institute, University College London, England, UK.

Study website: <https://evidencinghomevisiting.co.uk/>

**Data Controllers:** Cardiff University, University College London

**Data Processor/s:** Swansea University

**Sponsor:** Not Applicable

### Study summary:

**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.

**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.

**FNP Mechanisms:** We are now doing some more work looking at how the benefits families received from taking part in the programme were achieved. We will do this by looking at different FNP processes and mechanisms that lead to change. This study is being carried out by both Cardiff University and University College London. Researchers from both universities will be granted access to data that are de-identified, held on a secure server.

## 2. The type of personal information we collected 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:

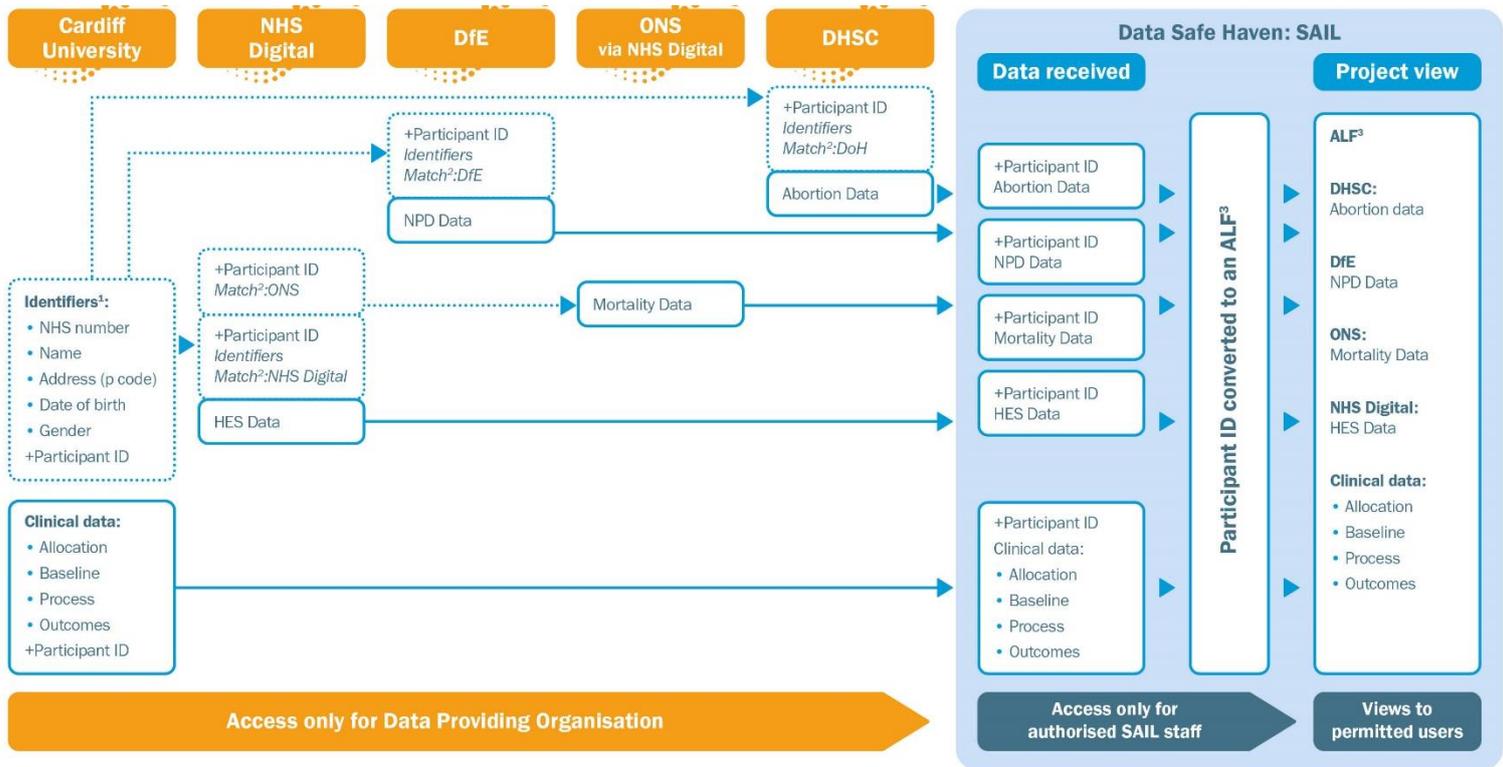
- In 2014-2018, for our Building Blocks: 2-6 study, Cardiff University provided details to identify you/your child to the NHS Digital, the Department of Health and Social Care and the Department for Education (DfE) in order for those professionals to provide relevant information about you and your child.
- 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

- In 2019, the new work on FNP mechanisms started. These researchers are based at the University College London and work closely with the study team in Cardiff. Like the Cardiff team, they will not know who is who in the database. All access is remote, through the secure servers, so nothing can be downloaded onto their own computers.
- No new data has been sent for this mechanisms study, instead researchers are working with the data that are already collected and available through the Building Blocks: 2-6 study. As researchers are working with de-identified data, no further ethical approval was required.

- Below is a data flow describing how data moved between Cardiff University, the data providers mentioned above and Swansea University for the Building Blocks:2-6 study:



Sensitive person identifiable information

Identifiers: i.e. specifically for linkage

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

Now that the Building Blocks: 2-6 study has completed, we have made de-identified information available with University College London. This is to look at how the benefits families received from taking part in the programme were achieved by looking at different FNP processes and mechanisms that lead to change.

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 Building Blocks: 2-6 study. No identifiable data is held, accessed or processed by University College London.

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

**Data retention:** As the data was sourced from NHS Digital, Department for Education and Department for Health and Social Care, data sharing agreements held with these organisations will be maintained for the duration of the study. It will be requested to maintain these agreements for the duration of the FNP mechanisms study, which is planned to end in January 2023. At this point data will be destroyed.

## 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 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](mailto:inforequest@cardiff.ac.uk) or [data-protection@ucl.ac.uk](mailto:data-protection@ucl.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](mailto:inforequest@cardiff.ac.uk) or [data-protection@ucl.ac.uk](mailto:data-protection@ucl.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>