

Evaluating the Family Nurse Partnership in England

Privacy Notice

This research is part of the Population Policy and Practice programme, at the University College London (UCL) Great Ormond Street Institute of Child Health (ICH). It uses information collected from administrative sources to conduct research in order to understand the health of children and their families.

It is led by Dr Katie Harron and funded by the National Institute of Health Research.

1.1 What is this Privacy Notice about?

This privacy notice outlines the purpose of the research and explains how we will collect and use the data for this study. It also describes how to get further information and what to do if you (or your child) do not want to be part of the study.

You have the right to access any personal information held about you, to have your information processed fairly and lawfully and the right to privacy. These rights are upheld by law and outlined in the [Data Protection Act 1998](#).

1.2 What is this study about?

More than 20,000 babies are born to teenage mothers in England each year, but younger mothers often face challenges that put them at a disadvantage compared with older mothers. Additional support for pregnant teenagers may improve outcomes for mothers and their children, but we do not yet know how best to implement services that are available.

We aim to describe how an early support programme called the Family Nurse Partnership (FNP) is delivered across England, and to determine the contexts in which the programme is most effective.

1.3 What is the lawful basis for using this information?

The lawful basis for using information collected routinely for administrative purposes for research is the 'public task'. This is part of the University's commitment to 'integrate research and innovation for the long-term benefit of humanity'.

The public task basis may be found in Article 6(1)(e) of the General Data Protection Regulation, which states:

"Processing is necessary for the performance of a task carried out in the public interest or in the exercise of official authority vested in the controller"

The processing also falls under Article 9(2)(j), which states:

"processing is necessary for archiving purposes in the public interest, scientific or historical research purposes or statistical purposes".

1.4. What information will we collect about you (or your child) for the study?

We will use hospital data for mothers and babies that are collected by the National Health Service for births between 01 April 2010 and 31 March 2017. We will also use information on deaths, collected by the Office for National Statistics. For participants in the Family Nurse Partnership, we will use information that was routinely collected as part of engagement with the programme.

NHS Hospital Episode Statistics are made available by NHS Digital, and include the following personal data:

- Clinical/Management information such as the type of hospital admission – planned/unplanned, speciality of treatment, length of time spent in hospital, the reason for hospital admission (diagnosis);
- Geographical information such as hospital, local authority.

Detailed lists of the management information collected in hospital may be found [here](#) (See 'Data elements'). FNP data are made available through the FNP National Unit and include information from the mother and child collected through the programme (e.g. mother's age, maternal health, baby's birth weight, gestational age) and at regular intervals until 24 months after birth (including child health and development). Information on each visit is also collected (e.g. date, length of visit, family nurse seen, referrals to other services, etc.).

Hospital, FNP and mortality data will be de-identified before it is transferred to the research team. This means that personal identifiers will be removed. We will use date of death, as it is important to take deaths into account as an important outcome measure within these analyses. It will not be possible to identify any individual within the data.

1.5. How will the information be used?

We will use electronic records that are routinely collected as part of health services to compare outcomes for FNP participants with similar families who did not participate. We will look at a range of health outcomes for children and their mothers. Researchers will only access anonymised data and will not be able to identify any individuals from the data.

Finding out whether FNP works better for some families (e.g. the youngest teenagers) than others will help improve targeting of resources and highlight groups in need of alternative support. Findings from the study will help policy-makers decide whether FNP should be offered to families in their local setting. Evidence generated by this study will support commissioners in providing improved services for mothers and children who could benefit most, and lead to increased efficiency through more effective targeting of resources.

Outputs of the analysis, in the form of aggregate data with small numbers suppressed, will be submitted for publication in peer-review journals and presented at national and international conferences. Results will disseminated to healthcare professionals, NHS managers, commissioners and policy makers.

Data in this study will not be used for marketing purposes, shared with or transferred to any third parties. The data provided to the team for research will not be transferred to other countries.

1.6. Where will the data be stored and how long will it be retained?

The study data will be transferred to the University research team in an encrypted form ('scrambled'), where it will be securely stored in the UCL Data Safe Haven. The UCL Data Safe Haven, is a registered data processor under the terms of the Data Protection Act 1998 (ICO Data Protection Registration: Z6364106. See link: [Information Commissioners Office](#)).

The research team have permission to keep the data until January 2022. It will not be used for marketing purposes, shared with or transferred to any third parties. The data provided to the team for research will not be transferred to other countries.

1.7 Access to your (or your child's) information in the study?

It will not be possible to access your study data from the research team data because all the personal information will be removed. Due to this, the right to request access to and rectification or erasure of your personal data, or restriction of processing of personal data, and the right to data portability, is restricted.

1.8 What if I do not want my data (or child's data) to be used in this study?

The research team will not be able to identify you and cannot remove your records from the study directly at your request.

You have the right to tell NHS Digital if you do not want the information you provide to the NHS to be used beyond the purpose of providing healthcare. This is known as a 'patient objection'. Please visit NHS Digital's website for further details: <https://www.nhs.uk/your-nhs-data-matters/manage-your-choice/>.

Your choice will not affect the health care you receive.

1.9 How do I contact the Research team (or Data Controller)?

If you have questions or concerns about the study please contact Dr Katie Harron:

Dr Katie Harron
UCL Great Ormond Street Institute of Child Health
30 Guilford Street
London. WC1N 1EH
Email: k.harron@ucl.ac.uk
Telephone: 02079052101

You may also contact the Data Controller (Prof Ruth Gilbert):

Prof Ruth Gilbert
Professor of Clinical Epidemiology
W5.05 UCL Great Ormond Street Institute of Child Health
30 Guilford Street
London. WC1N 1EH
Email: r.gilbert@ucl.ac.uk
Telephone: 02079052101

You may also contact the UCL Data Protection Officer:

Lee Shailer
Data Protection and Freedom of Information (FOI) Officer
University College London
Legal Services
6th Floor
1-19 Torrington Place
Email: l.shailer@ucl.ac.uk

You also have the right to complain directly to the [Information Commissioner's Office](#), which is an independent regulatory authority set up to uphold information rights.

Additional information/links:

Information Commissioner's Office www.ico.gov.uk

Hospital Episode Statistics <http://content.digital.nhs.uk/hes>