

# The Family VOICE (Work package 3) Privacy Notice

Version 3.0 NOV 2023

## 1. Study details

Study Name: Family VOICE

Work package title: Comparison of service use in Family Group Conference participants and a comparison group after 2 years using a natural experiment.

Address: CASCADE, Cardiff University

Phone Number: 02922 510324

Study E-mail: [family-voice@cardiff.ac.uk](mailto:family-voice@cardiff.ac.uk)

Study website: <https://cascadewales.org/research/family-group-conferencing-for-children-and-families-evaluation-of-implementation-context-and-effectiveness-family-voice/>

Data Controllers for study data: Cardiff University, Oxford University

Data Processors for study data: Birmingham, Devon, Islington, Kent, Stockton, Camden, Warwickshire, Central Bedfordshire; Department for Education; University College London (E-CHILD); Office for National Statistics Secure Research Service.

Sponsor: Cardiff University

**Study summary:** A Family Group Conference is a meeting when wider family (and maybe some friends) come and talk about a child who is in need of help or support and decide on a plan for them. The goal of the study is to better understand of how well they are carried out and what the benefits are for children and their family in family group conferences. This privacy notice relates only to one part of the study, work package 3 (WP3), however the wider study asks four key questions:

1. How widely are family group conferences offered in England and Wales and what are they used for?
2. What do families and practitioners think affects how successful family group conferences are?
3. How does the quality of family group conferences and variation in how they are used affect families' experience and what happens to the family over the next year?
4. What happens over the next two years to families who have had a family group conference? Is there a difference in their use of health, social care or education

services, compared with families who have not taken part in family group conferences, and what does this cost?

This part of the study answers question 4 and involves following up children and their mothers, for 2 years after a family group conference, using data already collected by services from social care, education and health records. This information will be compared with other families with similar difficulties who have not taken part in a family group conference, because this was not offered in their local authority. For information on the study as a whole, please see the study website (link above).

The study team will access only de-identified data. This means they will not have access to information that could be used to identify specific individuals.

## 2. What type of personal information will we process for Family VOICE WP3?

The following information will be processed for this study:

- Personal identifiers:
  - Date of birth
  - Local Authority ID
  - Unique Pupil Number
  - Name
  - Postcode
  - NHS Number
- Special category data:
  - Ethnic origin
  - Health data

## 3. How will we use information about you?

The personal details collected for this study **will not** be shared with the study team at Cardiff and Oxford University.

Instead:

Personal Data will be processed by participating local authorities between November 2023 and April 2024 to:

- Identify children aged less than 18 years old who were referred to Children's Social Care Services and received a family group conference at participating local authorities between 1.1.17 to 31.12.19.
- Securely transfer child identifiers (date of birth, sex, local authority ID and Unique Pupil Number) from participating local authorities to the Department for Education.

Each participating local authority is the Data Controller for the social care records that will be accessed by local authority staff for the purpose of this project.

Personal Data will be processed by the Department for Education between April 2024 and June 2024 to:

- Identify children aged less than 18 years old who were referred to Children’s Social Care Services and did not receive a family group conference at participating local authorities between 1.1.17 to 31.12.19.
- Identify children aged less than 18 years old who were referred to Children’s Social Care Services within comparison local authorities between 1.1.17 to 31.12.19.
- Link identified children to information held by the Department for Education National Pupil Database (Child in Need Census, Child Looked After Census, School Census).
- Securely transfer child identifiers (date of birth, sex, postcode, name) from participating the Department for Education to NHS Digital.

The Department for Education is the Data Controller for data about individuals in the children’s services and education in England. Through their data request service, approved projects can securely access these data. For more information see their guidance here: <https://www.gov.uk/guidance/data-protection-how-we-collect-and-share-research-data>

Personal Data will be processed by University College London / E-CHILD between June 2024 and July 2024 to:

- Link identified children to information held in the E-CHILD database, including education, social care data and NHS England healthcare data (Hospital Episode Statistics, Improving Access to Psychological Therapies, Mental Health Services Dataset, Mental Health and Learning Disabilities Data Set and Mental Health Minimum Dataset).

E-CHILD is a project run by University College London, that joins together existing health, social care and education data for all children in England. Through their data access request service, approved projects can securely access these data. For more information see their privacy notice: <https://www.ucl.ac.uk/child-health/research/population-policy-and-practice-research-and-teaching-department/cenb-clinical-4#ECHILD>

The following Special Category data will be requested from the Department for Education:

- Ethnicity of children
- Special Educational Needs of children

Local authorities will give personal information to by the Department for Education to identify a group of children in a de-identified called the E-CHILD database. This database has information about children's education, social care, and health, but it doesn't include any details that would reveal who these children are. The researchers want to see if there's a difference in the way services are used by children and families who are involved in Family Group Conferences compared to those who are not. .The research team will get to this information without any personal details through a secure system run by the Office for National Statistics. This system, known as the Secure Research Service, lets approved researchers safely study anonymous data. The ONS uses a strict set of rules called the 'Five Safes' to make sure the data is handled in a secure and responsible way. More information can be found here:

<https://www.ons.gov.uk/aboutus/whatwedo/statistics/requestingstatistics/approvedresearcherscheme>

The study data flow can be found at the end of this document. This shows how the data will be used and moves through the study.

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 information will be kept safe at the local authorities taking part in the study and securely sent by local authorities and the Department for Education.

Once the data have been safely sent and used for the study (within 3 months), any files that could identify you will be securely deleted following organisational secure deletion procedures.

#### **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.

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).

The ECHILD team are not able to identify you and so cannot remove your records from the ECHILD database directly at your request. You have the right to tell NHS England 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' and 'opting out'. Please visit NHS's website for further details of how the NHS uses your information and opt out: <https://digital.nhs.uk/your-data>. You do not need to pay any charge for exercising your rights. If you make a request, they have one month to respond to you.

Please contact the relevant Data Controller if you wish to find out more:

Participating Local Authorities: Birmingham, Devon, Islington, Kent, Stockton, Camden, Warwickshire, Central Bedfordshire.

Department for Education: <https://www.gov.uk/contact-dfe>

UCL / E-CHILD: [ich.echild@ucl.ac.uk](mailto:ich.echild@ucl.ac.uk)

To note. Cardiff and Oxford University do not directly have access to your personal data.

## **6. Where can you find out more about how your information is used?**

You can find out more about we use your information:

- At the study website: <https://cascadewales.org/research/family-group-conferencing-for-children-and-families-evaluation-of-implementation-context-and-effectiveness-family-voice/>



Centre for  
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- Our leaflet at <https://www.cardiff.ac.uk/public-information/policies-and-procedures/data-protection/research-participants-data-protection-notice>
- By sending an email to the research project lead. Professor Jonathan Scourfield: [scourfield@cardiff.ac.uk](mailto:scourfield@cardiff.ac.uk)
- By sending an email to Cardiff University's data protection officer: [LaneA5@cardiff.ac.uk](mailto:LaneA5@cardiff.ac.uk)
- By ringing us on 029 208 74164 (research project lead, Professor Jonathan Scourfield)

## 7. Who can you contact if you have a complaint?

If you have any concerns about our use of your personal information, you can make a complaint to Cardiff University as study Sponsor at [inforequest@cardiff.ac.uk](mailto:inforequest@cardiff.ac.uk). Alternatively, please contact the Data Controllers as listed above.

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

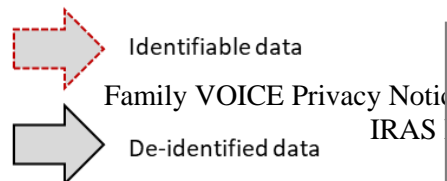
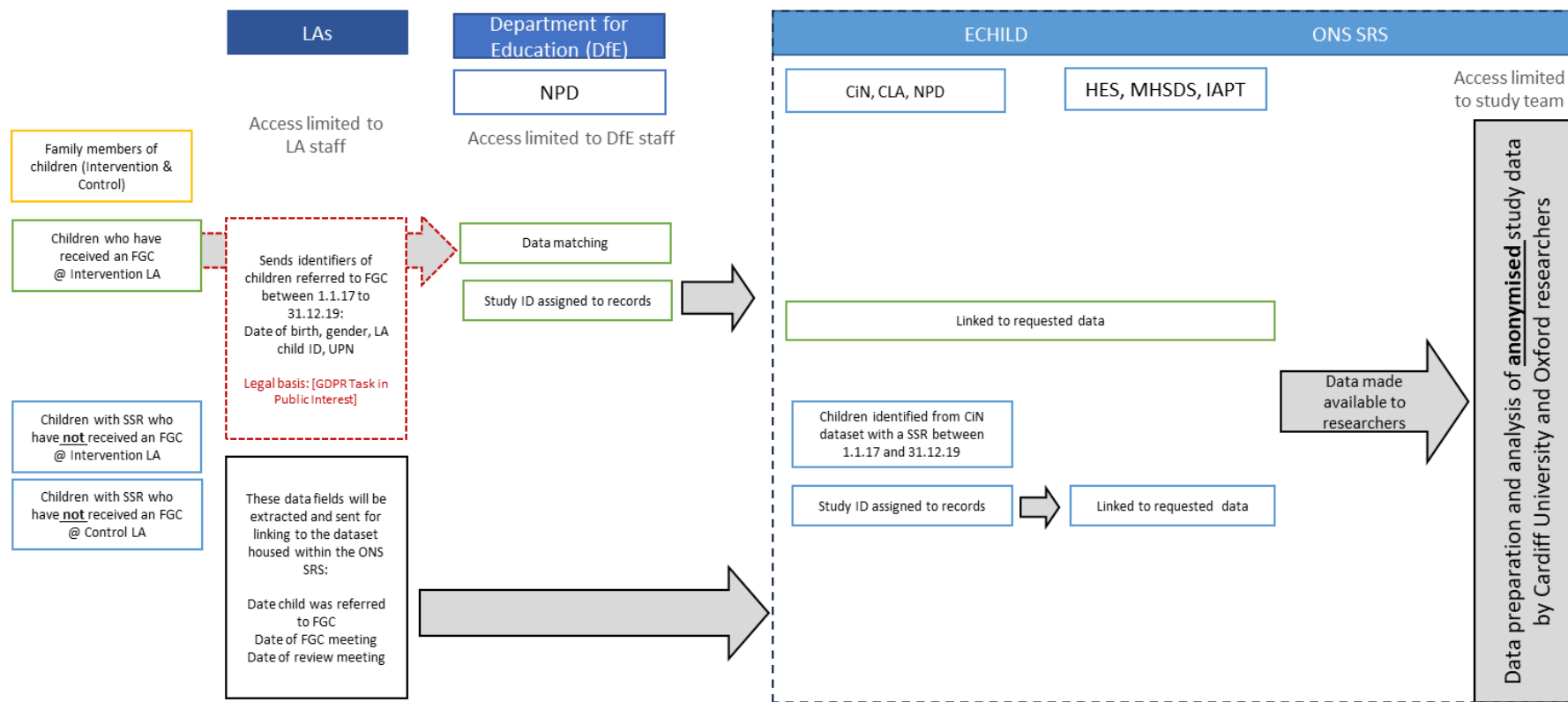
The ICO's address:

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

Helpline number: 0303 123 1113

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

# Family VOICE WP 3 ECHILD Data Flow



LA – Local Authority  
 UPN – Unique Pupil Number  
 SSR – Social Services Referral  
 CIN – Child in Need  
 NHS – National Health Service  
 MHSDS – Mental Health Services Data Set  
 ONS SRS – The Office for National Statistics Secure Research Service  
 FGC – Family Group Conference  
 GDPR – General Data Protection Regulation  
 NPD – National Pupil Database  
 CLA – Child Looked After  
 HES – Hospital Episode Statistics  
 IAPT – Improving Access to Psychological Therapies