

## **Resetting Services to Disabled Children Study**

### **Fair Processing Statement August 2021**

#### **What is the purpose of this study?**

Many disabled children have complex health needs and they and their families receive services from health, social care, and education. During COVID-19 non-essential services paused and then restarted but often in a different way, usually online. Many families have struggled to cope during the pandemic.

We want to find out what impact the changes in services have had on children's health and wellbeing. We want to find out which changes have been helpful for families, which haven't, and why. We aim to work with families and professionals to show how services could be better delivered to provide high quality care to disabled children as the NHS is remodelled. We are also seeking to define minimum acceptable, effective core health service provision for future emergencies and lockdowns.

#### **What is the name of the Data Controller?**

The Data Controllers for this study are:

- Cumbria, Northumberland, Tyne and Wear NHS Foundation Trust. Contact details for the Data Protection Officer are:  
Email: [DPO@cntw.nhs.uk](mailto:DPO@cntw.nhs.uk)
- Newcastle University. Contact details for the Data Protection Officer are:  
Email: [rec-man@ncl.ac.uk](mailto:rec-man@ncl.ac.uk)

#### **What is the lawful basis for processing your data?**

The lawful basis for carrying out this study under GDPR is Task in the Public Interest, (Article 6,1e) as research is cited as part of the University's duties. As we are collecting special categories of personal data the second lawful basis is Scientific Research (Article 9, 2j).

#### **How long will my data be kept?**

Your data has to be kept from the end date of the study for a period of ten years or three years after the youngest person in the study has reached 18 years of age (whichever is sooner). This includes electronic and paper copies of the information. When data is archived the data will be completely anonymized.

#### **What if I change my mind and want to withdraw from the study?**

You are free to withdraw from the whole or part of the study at any time without having to give a reason, **but we will keep information about you that we have already collected.**

To withdraw consent please contact the study research team (details below).

### **Who will you share data with?**

The research 'sponsor', who checks it is done correctly, is Cumbria, Northumberland, Tyne and Wear NHS Foundation Trust. Responsible members of the Cumbria, Northumberland, Tyne and Wear NHS Foundation Trust may be given access to research information for monitoring and/or audit of the study to ensure that the research is complying with applicable regulations.

ONLY de-identified data is shared with approved collaborators whose research aims match or further the goals of this study. De-identified data is data which has had identifiable information removed.

### **Types of data we store**

Personal data held by the study falls into three categories

- (i) Identifiable data collected at the start of the study (name, address, NHS number);
- (ii) Data from interviews (de-identified);
- (iii) Data from surveys (de-identified).

The answers to interview and survey questions will be kept separate from personal information (such as name or address) and will only be identified by a special code number. No individual will be identified or identifiable in any output that arises from the research.

ONLY de-identified data is shared with approved collaborators whose research aims match or further the goals of this study. De-identified data is data which has had identifiable information removed.

### **Will my data be looked after safely?**

Your personal data in the consent forms, names and addresses, are stored in a secure location within Newcastle University with restricted access given only to the Principal Investigator Dr Lindsay Pennington, and the Researcher who has carried out the interview.

All electronic data is stored securely and access is restricted to only those members of staff with a clearly defined need. When data is shared, information is restricted only to that needed to answer a specific research question.

**Who do I complain to?**

You have a right under law to raise a complaint with the Information Commissioner's Office (ICO) <https://ico.org.uk/concerns/>

The ICO is the UK's independent authority set up to uphold information rights in the public interest, promoting openness by public bodies and data privacy for individuals.

**Contact details of Newcastle University Study team**

Dr Lindsay Pennington  
Principal Investigator, Resetting Services to Disabled Children  
Sir James Spence Institute  
Royal Victoria Infirmary  
Newcastle upon Tyne  
NE1 4LP  
Email: [lindsay.pennington@ncl.ac.uk](mailto:lindsay.pennington@ncl.ac.uk)  
Tel: 0191 282 1360