

## Parent-Carer Information Sheet

### Delphi Survey

(Version 2.0, 11.10.2021)

## Resetting Services to Disabled Children

We'd like to invite you to take part in our research study. Before you decide it is important for you to understand why the research is being done and what it will involve. Please take time to read this information carefully. Talk to others about the study if you wish. Please ask us if there is anything that is not clear to you, or you would like more information.

### What is the study about?

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 service changes have worked, which were not supportive for families and their disabled children, 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.

The project has several stages:

1. A review of reports on the effects of changes to services in the UK and abroad
2. Analysis of NHS and social care information on children's contacts with health and social care services before and during COVID-19
3. Interviews with parents and professionals
4. A national survey of the views of families and professionals on how to move forward

We are inviting you to take part in the fourth part of the project. From the previous stages of the study, we have developed a set of recommendations for how services could be remodeled. We want to hear what young people, parents and professionals from across the UK think of these recommendations.

### Why have I been invited?

You have been invited because you are a parent-carer of a disabled child aged 0-19. We are inviting all parents-carers and professionals who registered on the study website to take part in the survey.

Please feel free to share information about the study to any other parents of children with disabilities. If they would like to take part they will need to go to our website and register in the same way as you did to receive the information about the study. Please do not give them your survey link, which is unique to you.

## **Do I have to take part?**

No, you do not have to take part. You can choose not to take part and you can decide to stop at any point in the survey. If your child does not want to take part, you can still take part.

You can change your mind about taking part at any time.

Whether you chose to participate or not this will have no impact on the services your family receives.

## **What will happen if I take part?**

You have been invited to take part in an online survey known as a '**Delphi Survey**'. A Delphi survey takes part in **three** different rounds and is a survey designed to help achieve consensus on a topic between different groups of people. **Each round of the survey will take approximately 15 minutes** to complete. The online link to the survey will have been provided to you in the email where you received this information sheet (please contact us on the email address at the end of the information sheet if you haven't received it or if you would like to talk to a member of the research team about the study).

- 1) Round 1 - The first round of the survey will show a list of practice recommendations developed from the previous stages of the research with children, parents and professionals. You will be asked to rate the importance of these recommendations and you will be able to suggest any additional recommendations you feel are vital but have not been included.
- 2) Round 2 – a couple of weeks after completing round 1, you will receive an email asking you to log-in to the survey for a second time. In round 2, you will be asked to complete a similar task, ranking recommendations. However, you will be able to see your previous answers, and the anonymous scores of others from round 1.
- 3) Round 3 - Delphi survey participants will be invited to volunteer to take part in an online meeting. These participants will be select at random from those who volunteer. There will be a mix of young people, parents and professionals; around 20 participants. You may not be selected for this round

***If you volunteer to take part we would like you to complete round 1 and 2 of the survey so that we can gather meaningful data.***

## **Can my child take part?**

Yes, your child can take part. A child friendly information sheet has been provided as an attachment for you to share with your child and discuss with them.

If you are happy for your child to take part in the survey, please show them the appropriate child friendly information sheet. If your child would like to take part, you will need to register them for the survey with a **separate email** address to the one you use for your survey responses, and ensure they tick 'child' to indicate the group they belong to. This can be another family member's email address, or your child may have their own email address. You can accompany your child when they take part in the survey to help with understanding and instructions. However, it is important that it is the child's opinion that is reflected. Providing the child friendly information sheet to your child and signing them up to take part will be regarded as implied consent from you for your child to take part.

Implied consent is an *assumption* or indication that a person has knowingly agreed to take part in research by performing a research activity or task. In this case, completing the survey will be taken as implied consent.

### **What happens next?**

The link to the online Delphi Survey has been provided to you in the email that contained this information sheet. If you have not received this link, please contact us on the email address below. To take part, please press the link and fill in the registration questions. This will then provide you with a unique log-in I.D. Please then fill out the first round of the survey and submit your responses. You will be sent an email reminder when part 2 is ready to start and you may be invited to participate in round 3 (the online meeting). You will need the unique I.D to log back in, so please keep it safe. If you lose your log-in details, please contact the email address below.

If your child would like to take part separately to you, please provide them with a different email address so that they can also have their own individual log-in for each round of the survey. It's important that your log-in I.D and your child's log-in I.D are kept separate so that we receive the correct information for each person.

### **What happens after the survey?**

We will be conducting an online consensus meeting (round 3) after round 2 of the survey. This consensus meeting will last around half a day and will take place within a month of the final round of the survey. The meeting is to help decide on any outcomes that did not reach consensus round 2 of the survey. The meeting will be video recorded. We would like parents, children and professionals to take part. If you take part in rounds 1 and 2 of the survey you may be eligible to take part in the meeting. We expect to invite 10-20 participants and there will be financial acknowledgement for your participation. More information about the meeting will be sent you after round 2 of the survey.

### **What are the possible disadvantages of taking part?**

Each round of the survey will take about 15 minutes. If you take part in the consensus meeting (round 3), this will take around an hour. We will arrange it for a time that is least disruptive for you.

### **What are the benefits to taking part?**

There are no direct benefits to taking part, but what you tell us could help families in the future and influence future research.

### **Do I receive anything for taking part?**

Your email address will be entered into a draw for one of five £100 vouchers.

If you take part in the consensus meeting for round 3 of the survey you will receive a voucher for £50.00 to reimburse your time.

### **What if there's a problem?**

Cumbria, Northumberland, Tyne and Wear (CNTW) NHS is the Sponsor of this research and holds overall responsibility for the project.

If you have any questions or concerns about the study, please contact Mr Simon Douglas, Research, Innovation & Clinical Effectiveness Senior Manager, Cumbria, Northumberland Tyne and Wear Foundation Trust (0191 223 2338, [simon.douglas@cntw.nhs.uk](mailto:simon.douglas@cntw.nhs.uk)).

## **Who will know that I am taking part?**

We will ensure that your participation in this study is entirely confidential. Only the study team will know that you have taken part. When the research is published there will be no way of identifying anyone who took part in the study.

## **How will my information be used?**

We will need to use information from you for this research project.

This information will include

- your name
- contact details
- your responses in the survey.

We will save your contact details and survey responses in different files on a secure server at Newcastle University.

People will use this information to do the research information to make sure that the research is being done properly. 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.

Once we have finished the study, we will keep some of the data (anonymised survey responses) so we can check the results. We will keep this information for ten years or three years after the youngest person in the study has reached 18 years of age (whichever is sooner). After this time, information will be confidentially destroyed.

People who do not need to know who you are will not be able to see your name or contact details. Your data will have a code number instead. We will keep all information about you safe and secure. We will write our reports in a way that no-one can work out that you took part in the study.

## **What are my choices about how my information is used?**

You can stop being part of the study at any time, without giving a reason, but we will keep information about you that we already have. Should you lose capacity to consent after completing the survey, we will keep your data for analysis, but your data will be fully anonymised and no longer identifiable to the research team.

We need to manage your records in specific ways for the research to be reliable. This means that we won't be able to let you see or change the data we hold about you.

If you give permission, information gathered from this study may be used in future data analyses by us or other researchers undertaking similar research. (Anonymous information from the study will be saved in Newcastle University's data repository data.ncl)

## **Where can I find out more about how my information is used?**

You can find out more about how we use your information:

- at [www.hra.nhs.uk/information-about-patients/](http://www.hra.nhs.uk/information-about-patients/)
- our leaflet available from [www.hra.nhs.uk/patientdataandresearch](http://www.hra.nhs.uk/patientdataandresearch)
- by asking one of the research team
- by sending an email to [DPO@cntw.nhs.uk](mailto:DPO@cntw.nhs.uk)
- by ringing us on Tel: 0191 246 6896

## **What will happen to the results of this study?**

We will report our findings on the project website. The results of this research study may be published in scientific journals and may be discussed at scientific meetings. You will not be identified in any way. A written summary of the study findings will be shared with participants within two months of the study being complete.

**Who is funding the research?**

This study is funded by the National Institute of Health Research (NIHR) Policy Research Programme. Neither the views nor the opinions expressed in this information sheet are those of the NHS, NIHR or the Department of Health.

**Who has reviewed the study?**

This study has been reviewed and given favorable opinion by Preston Research Ethics Committee.

**Can I talk to someone before agreeing to take part?**

If you would like to further information about this study you can contact the director of the study, Dr. Lindsay Pennington, or the researchers Hannah Merrick and Helen Driver (see below). You are welcome to ask us any questions or discuss any worries you may have. In addition, you can ask in general about taking part in research by contacting your local Patient Advice Liaison Service (PALS) on 0800 0320202.

**Thank you for considering taking part in this research project and taking the time to read the information sheets.**

**Dr Lindsay Pennington**  
**Reader in Communication Disorders**  
**0191 282 1360**

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**Researcher**

**Dr Helen Driver**  
**Researcher**

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