The Parent Carer Empowerment Project

Developing an intervention to support the empowerment of parent carers of children with neurodisability

Phase 2: Part A

Participant Information Leaflet for Parent Carers

Invitation:

We are a team of researchers sponsored by the **University of Exeter,** working in collaboration with East Kent Hospitals University Foundation NHS Trust.

We would like to invite you to participate in the Parent Carer Empowerment Project. The aim of the project is to develop an intervention which helps families to feel more in control of decisions and actions about their child's healthcare.

Before you decide if you would like to participate, it is important you understand why the project is being conducted and what is involved. Please take time to read the following information carefully and discuss it with others if you wish. If anything is unclear or you would like further information, please contact Jim Reeder, who is the project lead.

Email : jr898@exeter.ac.uk

Phone : 07815649202

Why is this study needed?

Improving health and social care for children and their families remains high on the national agenda. It has been prioritised in UK legislation, NHS policy and by national research priority setting partnerships.

Previous research tells us that when parent carers are supported to take control of the decisions and actions surrounding their child's care, there are measurable health and social benefits for them and for their child. The World Health Organisation call this process 'empowerment'.

The aims of this project are:

- To better understand the current barriers to parent carer empowerment.
- To produce a practical and acceptable intervention that will support parent carer empowerment in a clinical setting.
- To offer recommendations to health policymakers and commissioners

Why have I been invited and am I eligible?

We are inviting all parent carers of children with neurodisability who access healthcare services from East Kent Hospitals University Foundation NHS trust.

You are eligible to take part in this project if:

- You are a **parent carer.**

  A parent carer is any person aged 18 or over who provides care for a disabled child for whom the person has parental responsibility.
- Your child has a diagnosis in the category of **neurodisability**.

  Neurodisability includes any condition that involves an impairment to the brain and/or its connections that limits an individual's ability to do everyday activities. Examples of neurodisability include, but are not limited to, cerebral palsy, autism and learning disability.

Do I have to take part?

No, it is completely up to you. Also, if you do decide to take part and then change your mind, you are free to withdraw from the project at any time, without giving a reason. Your decision will have no influence on the services you receive or on the care of your child.

What would taking part involve?

Before you decide to take part in the project, you will be given the opportunity to talk through the information on this form and ask any questions you might have to a member of the research team. If you are happy to take part, you will be asked to complete a consent form. This will include deciding how you would prefer to take part. You can chose between:

- participating in a focus group with other parent carers and health professionals

OR

- attending an individual interview.

What will happen in my Focus Group or Interview?

- Before your focus group or interview, you will be given some information about what is already known about parent carer empowerment.
- We will discuss what parent carer empowerment means to you and explore what the barriers to successful parent carer empowerment might be.
- The focus group will be made up of other parent carers and health professionals
- The focus groups or interviews will be conducted either online or face-to-face, depending on your preference.
- The focus groups/interviews will be facilitated by two members of the research team who have been appropriately trained.
- The focus groups will last a maximum of 90 minutes and interviews will last a maximum of 60 minutes.
- The focus groups/interviews will be recorded on a secure audio recording device and field notes will be taken by one of the facilitators.

Are there any costs associated with taking part?

No, there will be no cost to you when taking part in the project. Any travel costs or child care costs that may be incurred due to your participation in the project will be paid for by the research team. In addition a £15 voucher will be given as recognition of your contribution.

If you wish to take part in a focus group or interview online, but do not have access to suitable IT, this will be provided by the research team.

What are the potential benefits of taking part?

There will be no direct benefit to you or your child from taking part in the project. However, it is hoped and expected that participation will help you to understand your experience as a parent carer in different way. In addition, your contribution to the project should benefit to parent carers accessing healthcare services for their child in the future.

What are the potential risks/disadvantages of taking part?

It is not expected that there will be any significant risks or disadvantages to you taking part in the project.

There is a small risk that issues discussed in focus groups and/or interviews may cause you some distress. If this does happen it is hoped and expected that you will be supported by the facilitator

who is experienced in discussing sensitive topics. If necessary, you will also be supported to access additional support services from the NHS trust.

What information about me will be collected and how will it be used?

We will need to use information from you for this research project. If you decide to take part in the study, you will be asked to complete a consent form with a member of the research team. At that time some personal information will be taken so that we can keep you informed about the progress of the project. This personal data will include your:

- Name
- address,
- telephone number
- email address

We will also record some demographic data. Demographics describe various characteristics about you. We will use the demographic data to ensure that the people involved in the project are from a diverse range of backgrounds. It is hoped that this will mean we will hear a broad variety of different views, opinions and experiences. This will ensure that our project produces an intervention that is useful for everyone.

The recording of your focus group/interview will be transcribed and then deleted. This transcription, together with the field notes and transcriptions from other focus groups and interviews, will be analysed by the research team to produce a report. This report will be used to inform the next phase of the project, which will involve designing the new intervention.
No member of the research team will have access to your medical records or the medical records of your child at any point during the project.

How will information about me be kept confidential?

- All information about you collected in this study will be kept strictly confidential and stored in a secure location on NHS trust computers. This will only be accessed by the lead researcher and the lead from research and innovation in the NHS trust.
- Your personal information, including your name, address, telephone number, email and completed consent forms, will be stored separately from all other project data. Personal information will only be kept for a limited time (6 months), after which it will be securely destroyed.

- Project data (focus group/interview transcripts) will be stored using a unique participant identification number. It will not include any personal identifying details; therefore, researchers working on this data will never know your identity.
- Your rights to access, to change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally-identifiable information possible.
- Once we have finished the study, we will keep some of the project data so we can check the results. We will also write our reports in a way that no-one can work out that you took part in the study.

It is important to note that, during the project, the research team can only offer conditional confidentiality. This means that, whilst it is our intention to protect your privacy at all times, there may be rare instances that we need to share information about you with a third party. Specifically, in instances if disclosures are made, either deliberately or accidently, that may lead to potential harm to you, your child or any other person, the research team have a professional and statutory responsibility to report these to relevant agencies.
You can find out more about how we will use your information at the following website: www.hra.nhs.uk/information-about-patients/

What happens to information about me after the study ends?

Your personal information (name, address, telephone number and email) will be securely deleted from NHS servers within 6 months of the end of the study.
Your anonymised project data will be stored securely for up to 5 years by the University of Exeter.

How can I withdraw from the project if I wish to?

Yes, you can withdraw from the project at any time without needing to give reason to the research team. You can do this by emailing the research lead jr898@exeter.ac.uk. You will then be contacted to discuss your concerns and to determine the desired level of withdrawal from the following two options:

- "No further contact" – This means that the research team will no longer contact you, but still have permission to use any project data collected up to the point of your withdrawal.
- "No further use" – This means that the research team will no longer contact you and any of your project data will not be used in further analysis (e.g. interview recording/transcript). It should be

noted that, if you have taken part in a focus group, it will not be possible to remove your data from focus group transcripts.

Will the use of my information meet UK-GDPR rules?

Yes. In 2018 regulatory changes in the way that data is processed came into force, with the EU General Data Protection Regulation 2018 (GDPR) and the Data Protection Act 2018 (DPA 2018). Since the UK left the EU, the key principles of EU GDPR have been adopted in the UK GDPR (a 'UK-only' version) and the DPA 2018 still applies.

The University of Exeter terms its lawful basis to process personal data for the purposes of carrying out research as being in the 'public interest'. The University continues to be transparent about its processing of your personal data and the participant information sheet should provide a clear explanation of how your data will be collected, processed, stored and destroyed. If you have any queries about the University's processing of your personal data that cannot be resolved by the research team, further information can be obtained from the University of Exeter's Data Protection Officer via the web-link; https://www.exeter.ac.uk/aboutoursite/dataprotection/dpo/

If you have any concerns about how your data is controlled and managed for this study, then please contact the Sponsor Representative: Dr Anthony Walsh, Head of Research Ethics, Governance and Compliance. (Contact details are at the end of this information sheet)

Who is organising and funding the project?

The University of Exeter are acting as sponsors of the project. This means they are responsible for overseeing the management, safety and integrity of the project.
The project design has been supported by the Peninsula Childhood Disability Research Unit (PenCRU) at the University of Exeter in collaboration with the University of Kent and East Kent Hospitals University Foundation NHS Trust. The project is also supported by a team of parent carers who are fully involved as decision making research partners in the research team.

The project is being undertaken as part of a National Institute of Health Research (NIHR) funded Doctoral Clinical Academic Fellowship of the lead researcher (Jim Reeder).

Who has approved the study?

All research in the NHS is reviewed by an independent group of people, called a Research Ethics Committee which is there to protect your safety, rights, wellbeing and dignity. This project has been reviewed and was given a favourable review by ……. Research Ethics Committee on (date).

What happens if something goes wrong?

The risk of participants suffering harm as a result of taking part is minimal. However, the research team has insurance in place to provide compensation for any negligent harm caused by participation.

Who can I contact if I have concerns?

If you have any concerns or complaints about anything to do with the project you can contact the sponsors at the University of Exeter either by telephone, by email or in writing.

Dr Antony Walsh – Head of Research Ethics, Governance and Compliance
University of Exeter, Research Ethics and Governance Office, Lafrowda House, St Germans Road
Exeter EX4 6TL
Tel: 01392 726621
Email: res-sponsor@exeter.ac.uk

If you have a specific concern about how your data is being managed, you can contact the Data Protection Officer at the University of Exeter either by telephone, by email or in writing.

Brenda Waterman – Information Governance Manager and Data Protection Officer
The University of Exeter
Compliance, Governance and Risk
Lafrowda House
St. German's Road
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