Participant Information Sheet: Interview with Caregivers

PARTICIPANT INFORMATION SHEET

Interviews with Caregivers – E-PAtS

Version 1.5 11.10.18

Title of Project: Early Positive Approaches to Support (E-PAtS) for families of young children with learning disability (sometimes referred to as developmental delay or intellectual disability): Feasibility study

Name of researcher(s): *Professor Richard Hastings and Dr Nick Gore*

Introduction

You are invited to take part in an interview, as part of the E-PAtS study. Before you decide, you need to understand why the interview is being done and what it would involve for you. Please take the time to read the following information carefully. You can talk to others about the study before you decide whether or not to take part.

(Part 1 tells you the purpose of the E-PAtS study and what will happen to you if you take part in the interview. Part 2 gives you more detailed information about how we will carry out the study)

Please ask us if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

PART 1

What is the E-PAtS study about?

As you will remember, we have developed a caregiver programme for families of young children (18 months to 5 years old) with learning disability (sometimes referred to as developmental delay or intellectual disability). This programme is called Early Positive Approaches to Support (E-PAtS). In E-PAtS, family caregivers are supported in a group by a trained parent and professional working in partnership over 8 sessions. E-PAtS helps caregivers look after their own emotional wellbeing, access services and learn practical strategies to support their child’s development and behaviour. We want to find out if E-PAtS helps parents of children with learning disability. To do this, we would need to run a big study and ask a lot of parents to be involved. However, before we can do this, we need to run this smaller study, which is called a feasibility study. We will check out if the research works well so that a much bigger study can be planned in future.

As part of this study your family were invited to take part in an E-PAtS group and complete some questionnaires. We want to find out about the experiences and views of people whose family was invited to an E-PAtS group. This includes people who attended the programme themselves and people who had a family member who attended. It also includes people who were invited to attend but who later either chose not to attend or who were not able to attend for any reason.

We would like to interview family caregivers about their experience of participating in the study and the E-PAtS group. You are being invited to take part in an interview in this way.

Why have I been approached?

You have been invited to take part in this study because you took part in our research by completing questionnaires, were invited to attend an E-PAtS group, and you said that it was OK for us to contact you to take part in an interview study. We are inviting other family caregivers who were selected to take part in an E-PAtS group in the same way.

Do I have to take part?

No. It is entirely up to you to decide. This information sheet should help you make your decision and you can ask any questions you need to. We will ask you to either sign a consent form or give verbal consent over the telephone to confirm that you have agreed to take part. You will be free to withdraw at any time, without giving a reason and this will not affect you or your circumstances in any way.

What will happen to me if I take part?

If you agree to take part, a researcher will arrange a time to interview you either in person, over the telephone or in a convenient place. Interviews will take around 30 minutes. The interview will focus on your views and experiences concerning the E-PAtS programme and your experience of being in this study. We want to find out about things you think might have worked well and things that you think were more difficult and gain your ideas on how E-PAtS could be used and researched in the future. All interviews will be audio recorded and later transcribed to support analysis. When the interview is transcribed your name and any identifying details will not be used. Direct quotations from your interview may be used in future presentations or publications, but all quotations will be published anonymously. We will send you a summary of findings at the end of the study.

What are the possible disadvantages of taking part in this study?

Taking part in this study does require some use of your time. We do not think that taking part in the study will pose any risk to you. Should you have any concerns, please contact the research team on the telephone numbers at the end of this document.

What are the possible benefits of taking part in this study?

The E-PAtS programme has been designed with input from multiple organisations, researchers, clinicians and family carers across the country who can offer expertise on each area that is covered and how the programme is delivered. By gaining further views and hearing the experiences of more caregivers, professionals and organisations we hope to be able to further develop E-PATS and design future research to test its effectiveness.

Expenses and payments

We cannot pay you to take part in this study. However, we will provide you with a £20 high street voucher for taking part in the interview.

What if there is a problem?

If you have a concern about any aspect of this study, you can speak to the Study Manager or Chief Investigators who will do their best to answer your questions (contact details on the last page). If you remain unhappy and wish to complain formally, please contact the University of Warwick (contact details can be found on the last page).

This concludes Part 1.
If the information in Part 1 has interested you and you are considering participation, please read the additional information in Part 2 before making any decision.

PART 2

Who is organising and funding the study?

The study is being led by researchers at the University of Warwick and the University of Kent and is being conducted with the Centre for Trials Research at Cardiff University and other team members at the University of Glasgow and the Challenging Behaviour Foundation. The study is being funded by the Public Health Research (PHR) programme of the National Institute for Health Research (NIHR).

What will happen if I don't want to carry on being part of the study?

You can withdraw from the study at any time, without giving a reason, and without affecting you in any way. If you do decide to withdraw from the study, we will use the data collected up to that point but we will collect no more data. You can additionally request that all data previously collected also be withdrawn. If the study is stopped for any other reason, we will inform you.

Who should I contact if I wish to make a complaint?

Any complaint about the way you have been dealt with during the study or any possible harm you might have suffered will be addressed. Please address your complaint to the person below, who is a senior University of Warwick official entirely independent of this study:

Head of Research Governance
Research & Impact Services
University House
University of Warwick
Coventry
CV4 8UW
Email: researchgovernance@warwick.ac.uk
Tel: 024 76 522746

Will my taking part be kept confidential?

Yes, all information about you will be handled in confidence and will only be seen by the research team. Study data stored at the University of Warwick, University of Kent or Cardiff University will be kept separate from personal information (names and addresses). Only members of the research team will have access to view identifiable data. However, in some instances, officials from regulatory authorities may need to access data for checking the quality of the research. All members of the research team and regulatory bodies are trained in data protection issues and bound by the terms of the Data Protection Act 1998. Study information will be kept securely for up to 15 years in line with Cardiff University's policies.

What will happen to the results of the study?

A report of the research results will be completed and sent to the National Institute for Health Research who are paying for the study. Results will be published in scientific journals and presented at scientific meetings. You will not be identified in any report, publication or presentation. Once the research study is complete, we will send you information about the results of the research.

Who has reviewed the study?

This study has been reviewed and given favourable opinion by the University of Warwick's Humanities and Social Science Research Ethics Committee (HSSREC): 30/17-18

What if I want more information about the study?

If you have any questions about any aspect of the study, or your participation in it, not answered by this participant information sheet, please contact:

Thank you for taking the time to read this Participant Information Sheet.