





INFORMATION SHEET FOR PARENT OF PARTICIPANT IN INTERVIEW

Parent or carer of young person with Attention Deficit Hyperactivity Disorder (ADHD)

VERSION NUMBER [1.4]: DATE [17/05/2016]



Children and adolescents with ADHD in transition from children's services to adult services



Thank you for taking the time to learn about this project that focuses on what happens to young people with Attention Deficit Hyperactivity Disorder (ADHD) when they are too old for children's services. Please read this information sheet carefully. We provide you with this information in case your child wants to talk to you about participating in this study. It contains information about why this study is important, what we hope to show by doing it and contact details of the researchers.

No, your child does not HAVE to take part in this study

Whether or not your child takes part in this study, that is up to him or her. Whatever he or she decides, this will not have any impact on the care he or she receives.

What is this project about?

We know little about what happens or should happen to young people with ADHD once they transfer to adult services. Also, which UK areas have specialist services for young adults with ADHD. In this study we will examine how many young people are in need of services for ADHD as adults. We also want to explore how current service users and service providers experience this transition.

Who do we want to talk to your child?

We want to talk to young people with ADHD about the care they receive for managing their ADHD. We want to know what you think about the care they receive and how they see their future.

What will your child be asked to do?

If your child agrees to take part in the study, the person who handed over this form will take your child's contact details. A researcher will then contact your child to set a date for an interview.

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Children and adolescents with ADHD in transition from children's services to adult services

CONSENT FORM FOR <u>PARENT CONSENTING FOR CHILD UNDER 16</u> VERSION NUMBER [1.4] [17/05/2016]

I have read the information sheet and understand what the study is about. My questions have been answered to my satisfaction.

I understand that me and my child can ask for further information at any stage.

I agree that (circle the correct response - Y: Yes, N: No):

1.	Somebody has explained this study to me and my child.	Y/N
2.	My child and I have received the information sheet.	Y/N
3.	My child and I understand what this project is about.	Y/N
4.	My child and I know that he/she can stop the interview at any time, and can refuse to answer certain questions.	Y/N
5.	We know that the interview will be audio recorded; and we know that the recording will be destroyed at the end of the project.	,
6.	We know that the results of the project may be published but names will not be mentioned.	Y/N

Printed name of researcher

Date and signature of participant

Date and signature of researcher

This project has been reviewed and approved by the NRES Yorkshire & the Humber - South Yorkshire Research Ethics Committee (REC Reference: 15/YH/0426)





I agree that my child takes part in this project.

Printed name of participant Date and signature of participant

Printed name of participant Date and signature of participant

Printed name of researcher Date and signature of researcher

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During the interview a researcher will ask your child questions about their experiences with services they use to manage their ADHD.

The interview will take place at a location of your child's choice, for example at your home or at school. We can also do the interview over the computer (e.g. by Skype).

Time commitment

The interview will take approximately one hour. We can stop the interview at any time, to take a break, or we can do the interview in different takes.

To say thank you

for taking part, your child will receive a £10 high street voucher.

Can your child change their mind and withdraw from the project?

Your child can withdraw from the project at <u>any time</u> without any disadvantage. This will not affect your child's treatment.

How will data or information be collected and what use will be made of it?

The interview will be audio recorded using a digital recorder. The recordings will be kept in a secure storage during the length of the study and will be destroyed once the study is finished.

Your child can ask the researcher not to record the interview, and take notes instead during the interview.

Your child's name will never be mentioned, not when we write out the interview, or when we write up the results of the study.

NOTE: We have a list of topics that we want to talk to you about, but we don't have precise questions. As a consequence, the questions will depend on the way in which the interview develops. Therefore, the

Researcher's copy



Ethics Committee has not been able to review the questions as they are asked during the interview.

In case your child feels uncomfortable about a question, your child will be reminded of their right to decline to answer the question and also to withdraw from the project at any stage without any disadvantage.

Will we tell anyone else what your child told us?

Everything your child says to us is confidential. However, we have a duty of care. This means that if we think your child is in danger we will contact their doctor and or other relevant professionals and tell them about this. We would only do this after we have explained to your child that we think this is necessary.

Can I attend the interview?

Your child can choose to bring a parent, carer or friend to attend the interview if that would make him or her feel better.

What happens at the end of the study?

All the things we find out by talking to your child, and other young people with ADHD will be written in a report.

This report is commissioned by the National Institute for Health Research (NIHR). This is the research department of the Department of Health. They aim to improve the health and wealth of the nation through research. This report will help people understand the transition from children's services to adult services for people with ADHD.

We will also communicate our findings to NHS clinicians, pediatricians, psychiatrists and commissioners at various levels, so they gain insight in the transition process of young people with ADHD.



CATCh-uS Children and adolescents with ADHD in transition from children's services to adult services

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I have read the information sheet and understand what the study is about. My questions have been answered to my satisfaction.

I understand that my child is free to request further information at any stage. I agree that (circle the correct response - Y:Yes, N: No):

1.	Somebody has explained this study to me and my child.	Y/N
2.	My child and I have received the information sheet.	Y/N
3.	My child and I understand what this project is about.	Y/N
4.	We know that he/she can stop the interview at any time, and can refuse to answer a question.	Y/N
5.	We know that the interview will be audio recorded; and we know that the recording will be destroyed at the end of the project.	Y/N
6.	We know that the results of the project may be published but names will not be mentioned.	Y/N







We plan to write up guidelines for parents and young people to help them on their journey to adult services, to facilitate the transition process. We will inform professionals and commissioners about our findings.

What if my child has questions after this interview?

If your child has questions about ADHD and or other issues triggered by the interview, we advise him or her to talk about this with their doctor or contact their GP. The researcher doing the interview can not offer treatment but he or she can direct your child to someone who might be able to help.

What if my child has questions about the study I can not answer?

If you have any questions about our project, either now or in the future, please contact Astrid Janssens at the University of Exeter Medical School.

Complaints

If you have any complaints please contact the Chair of the University of Exeter Medical School Research Ethics Committee: Ruth Garside, PhD or Rob Anderson, PhD — Co-chairs of the UEMS Research Ethics Committee.

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