

INFORMATION SHEET AND CONSENT FORM FOR PARTICIPANTS IN INTERVIEW

General Practitioner working with young person with Attention Deficit Hyperactivity Disorder (ADHD)

VERSION NUMBER [1]: DATE [26/08/2015]



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 before deciding whether or not to participate. It contains information about why this study is important and what we hope to show by doing it. It also provides contact details of the researchers.

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.

The project has three strands:

1. Identify how many young people with ADHD who are on medication need to transfer to adult services; to describe this population across the UK and the Republic of Ireland.

2. Interview young people with ADHD, their parents and professionals working with them, to explore their experiences with services and transition between services.
3. Map the services that are currently available for young adults with ADHD and describe what they provide.

The second strand of this research helps us identify factors influencing service use and factors leading to a successful transition. The findings of this study will have the potential to inform policy and practice.

Who do we want to talk to?

We want to hear from practitioners involved in the transition process, including General Practitioners working with young people/adults with ADHD. If you have referred young people with ADHD to adult services to continue their treatment for ADHD, or have managed young adults with ADHD in primary care, we would like to talk to you.

What will you be asked to do?

If you agree to take part in the study we will contact you by email or phone to set a date for an interview. The interview will take place over the phone, at a time suitable to you. During the interview a researcher will ask you questions about your experiences of managing this group and your view of the role of primary care in supporting young adults with ADHD.

Patient confidentiality

We will not talk about individual cases. We will ask you about practicalities related to the transition process (age-boundary of specialist services, existence and use of transition protocol), the management of different groups of patients with ADHD, , key elements of (optimal) transition and personal experiences with good and difficult transition.

Time commitment

The interview will take approximately 30 to 40 minutes.

Can you change your mind and withdraw from the project?

You may withdraw from the project at any time without any disadvantage to yourself or your patients. **Also, you can decide to stop the interview at any time.**

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

The interview will be recorded. The audio-tapes will be kept in a secure storage during the length of the study and will be destroyed once the study is finished. You can ask the researcher not to record the interview, and take notes instead during the interview. Your 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 Ethics Committee has not been able to review the questions as they are asked during the interview.

In case you feel hesitant or uncomfortable about a question, you are reminded of your right to decline to answer any particular question(s) and also that you may withdraw from the project at any stage without any disadvantage to yourself of any kind.

What happens at the end of the study

The findings of this study will be captured in a report, commissioned by the National Institute for Health Research (NIHR). We will also communicate our findings to NHS service providers (clinicians, pediatricians, psychiatrists) and commissioners at various levels, so they gain insight in the transition process of young people with ADHD.

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 about our findings, so they can learn from your experiences.

What if you have any questions?

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. [REDACTED]

Complaints

If you have any complaints please contact the Chair of the University of Exeter Medical School Research Ethics Committee:

Peta Foxall, PhD
[REDACTED]

This project has been reviewed and approved by the University of Exeter Medical School Research Ethics Committee - UEMS REC REF NUMBER: Aug16/D/070Δ1

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CONSENT FORM FOR PRACTITIONER - VERSION NUMBER [1] [26/08/2015] Copy Practitioner

I have read the Information Sheet concerning this project and understand what it is about. All my questions have been answered to my satisfaction. I understand that I am free to request further information at any stage.

I know that:

1.	my participation in the project is entirely voluntary;	Y/N
2.	I am free to withdraw from the project at any time without any disadvantage;	Y/N
3.	that the audio-tapes will be retained in secure storage while in use and will be destroyed once the study is finished.	Y/N
4.	the interview uses open-questionings and therefore the precise nature of the questions is not known in advance. I know that I can decline to answer any particular question and or stop the interview at any time.	Y/N
6.	that I can claim travel costs, and have received documentation what costs I can claim and how to do so.	Y/N
7.	that the results of the project may be published but my anonymity will be preserved.	Y/N

I agree to take part in this project.

Printed name of participant

Date and Signature of participant

Printed name of researcher

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) and the University of Exeter Medical School Research Ethics Committee - UEMS REC REF NUMBER: Aug16/D/070Δ1

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CONSENT FORM FOR PRACTITIONER - VERSION NUMBER [1] [26/08/2015] Copy Researcher

I have read the Information Sheet concerning this project and understand what it is about. All my questions have been answered to my satisfaction. I understand that I am free to request further information at any stage.

I know that:

1.	my participation in the project is entirely voluntary;	Y/N
2.	I am free to withdraw from the project at any time without any disadvantage;	Y/N
3.	that the audio-tapes will be retained in secure storage while in use and will be destroyed once the study is finished.	Y/N
4.	the interview uses open-questionings and therefore the precise nature of the questions is not known in advance. I know that I can decline to answer any particular question and or stop the interview at any time.	Y/N
6.	that I can claim travel costs, and have received documentation what costs I can claim and how to do so.	Y/N
7.	that the results of the project may be published but my anonymity will be preserved.	Y/N

I agree to take part in this project.

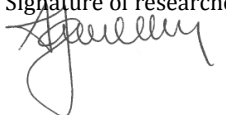
Printed name of participant

Date and Signature of participant

Printed name of researcher

Date and Signature of researcher

Astrid Janssens



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