



“Printed on Trust headed paper”

Information Sheet for Parents and Guardians

Assessing the impact of children with ADHD on the health and well-being of families.

We would like to invite you to take part in a research study. Before you decide you need to understand why the research is being done and what it would involve for you. Please take time to read the following information carefully.

What is the purpose of the study?

The purpose of the study is to understand how living with a child who has ADHD affects your and your family's health and well-being.

Why has my child been chosen?

We are running this study in a number of locations across the UK. Your child has been chosen because he is attending the ADHD clinic in XXXX.

What will be involved if I agree to take part in the study?

The study will involve members of your family filling out a questionnaire. You may be asked for your permission (consent) for inclusion of older siblings into the study.

There are five sets of questions we would like you to complete. In the brackets is a rough idea of how long the questions will take to do:

- 1) questions about your health and well-being (about 20 minutes)
- 2) if you have a partner who lives with you we'd like them to answer the same questions about their health and well-being
- 3) screening questions for adult ADHD (about 5 minutes); these questions will see whether you have any traits associated with ADHD, this will not diagnose you but will indicate whether you are at low or high risk of adult ADHD. You will be asked if you would like the results of the screening questions.
- 4) some questions which ask about ADHD symptoms for each of your children (about 20 minutes per child with ADHD and 10 minutes per child without ADHD)
- 5) some question for your children to complete about their health and well-being (about 5 minutes)

We appreciate that the research may make a significant demand on your time in total.

Do we have to take part?

No, you do not have to take part. If you don't want to, you do not need to do anything. Your children or partner may also choose not to take part.

If only some of the family wants to fill in the questionnaires, that's fine, we would still very much like those that want to to fill in the questionnaires.

What are the possible benefits of taking part?

There will be no direct benefit to you or your child in taking part in the study. However, the results of the study may help research into ADHD and the impact this condition has upon families.

What are the possible risks of taking part?

There are no risks for you or your family in taking part in the study. Your child's treatment and care at the ADHD clinic will not be affected whether you take part in the study or not.

Is the study confidential?

The information collected in the study will be kept completely confidential. Any information about you or your children will not be stored with your name or address so that you cannot be recognised. If it emerges that there is any possibility of harm to yourself or others from the information you provide then we will inform an appropriate person, for example your GP.

Who will have access to the data and where will it be held?

The data will be sent to the University of Sheffield where it will be stored in a secure area and also kept as a password-protected computer file, both of which can only be accessed by the research team and regulatory authorities. Any personal details will be kept separately to your questionnaire responses and linked only by a research study number.

An anonymous (with any details that might identify you removed) computer file will be retained and made available to other researchers for use in future studies. The anonymous copy of the data will also be retained by the funders, Shire Pharmaceuticals, and may be used in further research studies.

Will my GP be informed?

Yes, with your permission we will inform your GP that you are taking part in this research.

What if I change my mind?

You may change your mind at any point. Your children are free to change their mind at any point.

What will happen to the results of this study?

The results of this study will be used to help understand the impact on health and well-being of living with a child with ADHD. This may provide useful information to health researchers in the future when considering the possible benefits of treatments for ADHD. The results will be presented both nationally and internationally.

Who is funding the study?

This study is being funded by Shire, who is a global pharmaceutical company that makes some treatments for ADHD. This study is not about their products. The study is being run independently by the University of Sheffield.

Has the study been approved?

Yes. The study has been reviewed by Sheffield Research Ethics Committee. The Research Ethics Committee is completely independent from anyone organising the study.

What if there is a problem?

If you have any problems or are worried about anything to do with this study, you should ask to speak to the research nurse who will do their best to answer your questions (**contact name and number TBA**).

In the event that something does go wrong and you are harmed during the research and this is due to someone's negligence then you may have grounds for a legal action for compensation against The University of Sheffield, NHS Trust **NAME**, or **CLINIC NAME** but you may have to pay your legal costs. The normal National Health Service complaints mechanisms will still be available to you. Please contact **THE LOCAL COMPLAINTS MANAGER on LOCAL NUMBER** for more details.

Who should I contact for further information?

If you have any questions about the study or would like any further information, please feel free to ask **THE RESEARCH NURSE** who can be contacted on **LOCAL NUMBER**.