

Information Sheet for Parents/Carers (Version 2.0, April 2023)

Study title: Girls growing up with ADHD

If you would like us to send you a hard copy of this information sheet, please email us on:
williamstl6@cardiff.ac.uk.

Invitation

We would like to invite you to take part in our study. This study will examine the experience and presentation of ADHD difficulties in girls and young women, from the perspective of parents/carers of children with ADHD. Before you decide whether or not to take part, it is important for you to understand why the study is being undertaken and what it will involve. Please take your time to read the following information carefully. Discuss it with others if you wish. If you have any questions, please feel free to ask them - our contact details are at the end.

What is the purpose of the study?

- Attention deficit hyperactivity disorder (ADHD) is a common neurodevelopmental condition. However, girls and young women are less commonly diagnosed with ADHD than boys and young men.
- When diagnosed with ADHD, girls and young women often receive their diagnosis at a late age.
- This delay in getting a diagnosis may mean that girls and young women with ADHD miss out on early support for their ADHD difficulties. This could have an impact on their health and wellbeing, their experiences of school and jobs, as well as their friendships and relationships.
- It is important to understand what ADHD is like for girls and young women as ADHD may present differently by gender.
- This study aims to understand the experiences and presentation of ADHD in girls and young women, to identify more gender-diverse presentations of ADHD symptoms.
- This information will be used to develop a new gender-inclusive assessment tool for ADHD for primary school children, alongside research activities that the study team is undertaking.

Who can take part in this study?

Parents and carers of daughters with ADHD, meeting the following criteria:

- Your daughter has been given a diagnosis of ADHD by a doctor or other health professional
- Your daughter is aged 5 – 18 years old
- You live in Wales or the wider UK

Why have I been invited to take part?

We would like to invite you to take part because we feel your views of ADHD in young girls, based on your experiences of having a child with ADHD, would make an important contribution to understanding the experiences of girls and young women growing up with ADHD.

Do I have to take part?

No. It is up to you to decide if you wish to take part in this study. If you decide to take part, you will be given this information sheet to keep and will be asked to sign a consent form. If you no longer wish to participate, you can withdraw at any time without giving an explanation, even after signing the consent form. There will be no disadvantage to you.

What will taking part involve?

If you are happy to be involved in this study, you will first need to fill out an online form so that we can assess your eligibility to participate. If eligible, and there are spaces left in the study, you will be invited to take part in a focus group with other parents/carers that will take around 90 minutes (including breaks). The focus group may take place online via video chat (e.g. Zoom) or in person at Cardiff University, depending on your preference. During the focus group, we would like to ask you questions to stimulate discussion about your views of ADHD in young girls. If the focus group takes place in person, it will be audio recorded. However, if the focus group takes place online via video chat, it will be audio and video recorded. We are only interested in the audio recordings of the focus group; however, the focus groups will be video recorded if they take place online via video chat as video files are automatically created when recording audio on Zoom. The audio recording will then be transcribed anonymously by a professional company.

Opportunity to take part in a future follow up study

You can also choose to be contacted about the possibility of participating in the second stage of this study to help us improve the new ADHD assessment tool that we will be developing using

the results from this study. This is optional and we will provide more information about this follow up study to those who are interested.

Will I be paid for taking part?

Yes. You will receive a £25 Love2shop gift voucher thank you for your time. Additional vouchers are available to cover any travel expenses and childcare costs (if applicable).

What are the possible benefits of taking part?

We hope that you will find the study to be an interesting and useful experience. You will have the opportunity to discuss your experiences of having a child with ADHD. The information you provide will be used to develop a new ADHD assessment tool which may help young people in future.

What are the possible disadvantages of taking part?

It is possible some people may find it difficult or upsetting to talk about certain aspects of their experience of caring for a young person with ADHD. We will make it clear from the beginning of the focus group that you do not have to talk about anything that upsets you and you can take a break or stop at any time.

Will my taking part in this research be kept confidential?

Yes. All information collected about you during this study will be kept confidential, in line with data protection legislation, and will only be used by the study team for research purposes. Any information or verbatim quotes from the focus group that may be used in academic reports or publications will not have your name or any information about you attached that would identify you. In the exceptional circumstance of an urgent concern, the research team may have to disclose information to the relevant agencies if a disclosure is required by law or professional obligation (for example, if we are concerned about your safety or the safety of someone else).

What will happen to my Personal Information & What happens to the information at the end of the study?

This study will use your personal information, including your name, contact details (phone number and email address), age, and some details about your child's diagnosis. Only the study team will have access to this information. Your information will have a study ID for anonymity. The audio recordings of the focus group will be transcribed by a professional company using your study ID for anonymity. We will keep all information about you safe and secure. We will analyse the information for the study and at the end of the study, your information will be

retained securely by Cardiff University in accordance with the University Records Retention Schedule. We will write our reports in a way that no-one can work out that you took part in the study.

Some of your information might be sent from Cardiff University for analysis by researchers who are part of the wider study team and are advising on the project; these are researchers at King's College London, University of Nottingham & Exeter University. Any information we send will be anonymised, so it will not be possible to identify you or your child from this information. They must follow our rules about keeping your information safe.

What are the choices about how my information is used?

You can stop being part of the study at any time, without giving a reason, but we will keep information about you that we already have.

Who holds my information?

We are required to process and store your personal data for up to 15 years in approved archiving facilities (secure computers), following General Data Protection Regulation (GDPR). Cardiff University is the Data Controller and is committed to respecting and protecting your personal data in accordance with your expectations and Data Protection legislation. Further information about Data Protection may be found at <https://www.cardiff.ac.uk/public-information/policies-and-procedures/data-protection>. (Please let us know if you need a paper copy of this).

What will happen to the results of the study?

The results gathered from this study will be written up in a report for publication in an academic journal. This report may include verbatim quotes from the focus group, but the information will be made anonymous, so you will not be identifiable in any way. Further, you will not be identifiable in any other report, publication, or presentation. The results will also be used to help develop a new gender-inclusive ADHD assessment tool.

Who is organising and funding this study?

The study is organised by researchers at Cardiff University. It is being funded by Health and Care Research Wales.

Who has reviewed and approved this study?

This study has been reviewed by the School of Medicine Ethics Committee at Cardiff University [SMREC 23/28] to ensure that it is being carried out in an ethical way.

What if there is a problem?

If you have a concern or feel that you have experienced any harm in any way by the study, you should speak to Dr Joanna Martin (martinjm1@cardiff.ac.uk) who will do her best to help. If you are still unhappy and wish to complain formally, you can contact the Chair of the School Research Ethics Committee Dr Ned Powell (PowellNG@cardiff.ac.uk).

Further information and contact details

The research team:

- Dr Joanna Martin
- Tamara Williams
- Prof Anita Thapar

If you want to know more about the study or have any questions, please contact:

Joanna Martin (martinjm1@cardiff.ac.uk)

Division of Psychological Medicine & Clinical Neuroscience, Cardiff University, Hadyn Ellis Building, Maindy Road, Cardiff, CF24 4HQ.

Thank you for reading this information.

This copy is for you to keep.