



Information sheet for Parent/Guardians

Project title: Understanding the transition to adolescence in girls **with and without** neurodevelopmental conditions (Autism, Attention deficit hyperactivity disorder (ADHD), and/or Developmental co-ordination disorder (DCD)/Dyspraxia): Online Research

We would like to invite you and your daughter to take part in our research study. Before you decide if you want you and your daughter want to take part, we would like to tell you about the research and what will happen if you do take part. Please take time to read this information carefully and to ask us questions if you would like to know more.

WHAT IS THE RESEARCH ABOUT?

This research is being carried out to understand the challenges of becoming a teenage girl. We are especially interested in hearing from autistic girls, girls with ADHD, and/or girls with dyspraxia but also girls without a neurodevelopmental condition are very welcome to take part. Girls have historically been under-diagnosed when it comes to autism, ADHD and dyspraxia. This means there is not a lot of research on them.

We are trying to understand what leads to feelings of anxiety and depression in girls and hear from the girls themselves about what adults can do to help. We will collect information about your daughter's mental health, camouflaging behaviour (i.e. tendency to try to blend in), and physical feelings during her periods, and if/when she has started her period. We are trying to understand differences in the age girls get their periods. We are also trying to understand if girls have different sensory experiences when they are on their period. In other words, do tastes, sounds, noises feel different when they are on their period.

Fifteen adult autistic women, women with dyspraxia, and women with ADHD contributed to the design of this study. We did this so that our project addresses high priority research questions in line with the autistic, the ADHD and the dyspraxic community. It aims to understand experiences of puberty, what leads to mental health problems, and give girls a voice to say what they need to be supported. Equally, if your daughter does not have a neurodevelopmental condition, their contribution will be very valuable and informative for the research about the transition into adolescence.

Findings from this study will be used to create booklets for parents/guardians and school staff to support well-being in girls.

WHY AM I BEING INVITED TO TAKE PART?

To take part, a girl must be between 11 and 13 ½.

To take part, a girl should be able to answer questions verbally with a researcher or complete questionnaires with the help of a researcher.

To take part your daughter can

- have a diagnosis of autism, ADHD, and/or dyspraxia/developmental coordination disorder **or be on a waiting list for a diagnostic assessment for any of these conditions.**
- Or **not** have a diagnosis of autism, ADHD, or dyspraxia/developmental coordination disorder and **not** be on a waiting list for a diagnostic assessment for any of these conditions.

DO I HAVE TO TAKE PART?

No, it is up to you and your daughter whether or not you want to take part. If you do decide to take part, you will be given this information sheet to keep and be asked to complete a consent form. We will also offer your daughter the option of their own information sheet. You and your daughter can decide to stop taking part at any time. You do not need to tell us why. There are no consequences to you or your family if you decide to withdraw.

WHAT WILL HAPPEN IF I TAKE PART?

What does the parent/guardian do?

You will have an initial phone call/text/email with the researcher Ailbhe (pronounced Alva) to arrange a time to meet you and your daughter over zoom, Microsoft teams or the phone. You will be asked to complete four questionnaires about your daughter at the start of the study estimated to take 30 minutes in total. One will ask about background and health-related information about your daughter (age, height and weight, whether they are on medication, any history of seizures). If your daughter has a diagnosis of autism, ADHD, or dyspraxia/DCD, or on the waiting list for an assessment of any of these, you will also be asked about the diagnosis, age of diagnosis, and who diagnosed them. The other questionnaires are about behaviours related to thinking processes, memory, paying attention, social interaction, and motor co-ordination.

What does my daughter do?

There will be two 1 hour video calls with your daughter. There are an additional part to the study: Two short 15 minute video calls. Your daughter can have the camera on or off for these meetings. The parent/guardian can be present for the meeting or not, it is whatever works best for your daughter. We will remind the parent/guardian not to influence their daughter's answers though.

Schedule of the research:

	Meeting 1:	Meeting 2:	Meeting 3: (additional)	Meeting 4: (additional)
When we will meet?	Anytime soon which works for you	1 year after meeting 1	Any convenient time your daughter is having her period	2 weeks after meeting 3
How long it will take ?	1 hour	1 hour	15-20 minutes	15-20 minutes
How will it take place?	Zoom, Microsoft teams, phone	Zoom, Microsoft teams, phone	Online questionnaire (Ailbhe will be available to do it with you if you want on Zoom, Microsoft teams or the phone).	Online questionnaire (Ailbhe will be available to do it with you if you want on Zoom, Microsoft teams or the phone).
What we will be doing?	<p>Quick introduction where the research is explained</p> <p>Girl completes two mental health questionnaires and one questionnaire on relationships with the help of the researcher</p> <p>Parent and daughter together: “Have you started getting periods yet?” “Have you ever had a period?”</p>	<p>Reminder of what the researcher is about</p> <p>Girl completes two mental health questionnaires and one questionnaire on relationships with the help of the researcher</p> <p>Parent and daughter together: “Have you started getting periods yet?” “Have you ever had a period?”</p>	<p>Girl completes a questionnaire about sensory experiences .e.g loud noises</p>	<p>Girl completes a questionnaire about sensory experiences .e.g loud noises</p>

IS THERE ANYTHING I SHOULD BE WORRIED ABOUT IF WE TAKE PART?

Some people may find it difficult talking about their daughter. You and your daughter do not have to answer any questions that you do not want to.

ARE THERE ANY BENEFITS TO US TAKING PART?

You and your daughter's involvement will lead to better understanding of mental health and well-being in girls and the support they need. Findings from this study will be used to create booklets for parents/guardians and school staff to support well-being in girls. We will send you these booklets when they are complete.

HOW DO I HELP MY DAUGHTER DECIDE IF SHE WANTS TO TAKE PART?

Please read this information sheet carefully and then explain the research to your daughter. The Easy Read Information Sheet (attached) and/or the Information sheet for Girls ages 11-13 (see attached) are provided to help explain the study to your daughter.

If your daughter is hesitant to take part, that is completely understandable. A short meeting over Zoom, Microsoft Teams, or a phone call can be arranged with the researcher. On this call the researcher can explain the research to your daughter with the Easy Read Information Sheet (attached) and/or the Information sheet for Girls ages 11-13 (see attached). This will also give your daughter an opportunity to meet the researcher before deciding to take part. The researcher will follow up in three months about participation. If at this point, your daughter still does not want to take part, she will not take part.

WILL THE INFORMATION ABOUT MYSELF AND MY DAUGHTER BE KEPT CONFIDENTIAL?

All the information will be stored on password protected computers . These data will only be accessible by the immediate research team. Any information taken from the questionnaires for further analysis by the research team will be made anonymous. This means that your name and your daughter's name will not be put next to your answers. The research will be written up for publication and be presented conferences, but no individual will be able to be identified from this.

The link to the University of Edinburgh's data protection policy and privacy notice for research participants can be found here:

Data Protection Policy: <https://www.ed.ac.uk/records-management/policy/data-protection>
Privacy Notice for Research Participants <https://www.ed.ac.uk/records-management/privacy-notice-research%20>

If during our assessment with your daughter tells us something that means we're worried about their safety, we will tell you about what your daughter has told us. We will always talk to your daughter about this first.

WHAT IF THERE ARE ANY PROBLEMS?

If you have a concern about any aspects of the study please contact Dr Sinead Rhodes, Email: Sinead.rhodes@ed.ac.uk, Phone: 0131 312 1656 who will do their best to answer your questions.

WHAT WILL HAPPEN IF I DON'T WANT TO CARRY ON WITH THE STUDY?

You and your daughter can leave the study at any time. If you wish for the data collected about you to be permanently deleted on withdrawing from the study please contact Dr Sinead Rhodes and request this and your data will be deleted.

WHAT HAPPENS WHEN THE STUDY IS FINISHED?

We will retain your contact details (if you consent to this) and invite you to take part in further research when appropriate.

WHO IS ORGANISING AND FUNDING THE RESEARCH?

The study has been organised by Ailbhe McKinney (PhD researcher) and Dr Sinead Rhodes and sponsored by the University of Edinburgh. The study is being funded by the College of Medicine and Veterinary Medicine, at the University of Edinburgh.

WHO HAS REVIEWED THE STUDY?

This study has been reviewed and given a favourable ethical opinion by an independent research committee the Edinburgh Medical School Research Ethics Committee. The study is being sponsored by the University of Edinburgh.

WHAT IF I AM UNHAPPY WITH SOME ASPECT OF THE RESEARCH?

If you wish to make a complaint about the study please contact the University of Edinburgh's Academic and Clinical Central Office for Research and Development (ACCORD)

ACCORD

Queen's Medical Research Institute, 47 Little France Crescent, Edinburgh, EH16 4TJ

Email: resgov@accord.scot

HOW DO I FIND OUT MORE?

If you have any more questions, you can speak to Ailbhe McKinney, the lead researcher for this project.

Ailbhe McKinney PhD researcher, Child Life and Health, University of Edinburgh

Phone: 07388454435

Email: a.m.mckinney@sms.ed.ac.uk

Or you can speak to her supervisor Dr Sinead Rhodes:

Dr Sinead Rhodes, Child Life and Health / Centre for Clinical Brain Sciences, University of Edinburgh

Phone: 0131 312 1656 email: Sinead.Rhodes@ed.ac.uk

You can also speak to Dr Karri Gillespie-Smith, an independent contact (not on the research team) if you have concerns

Phone: [+44 \(0\)131 651 3932](tel:+4401316513932)

Email: Karri.Gillespie-Smith@ed.ac.uk