



Participant Information Sheet for Parents/Carers

(Version 4, April 2026)

Study title: The BEARS study: A new questionnaire about children’s attention, behaviours and emotions

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Invitation

- We would like to invite you to take part in our study. This study will involve completing some questionnaires about your child, including a new measurement scale called BEARS, which stands for: Behaviour, Emotion, and Attention Regulation Scale.
- We have developed this new questionnaire together with many experts, including parents/carers, healthcare and educational professionals, and young people with lived experiences of attention deficit hyperactivity disorder (ADHD).
- The scale asks about attention, behaviours, and emotions, which could be things that children with ADHD find challenging but can also be relevant to all children.
- Children do not have to have a diagnosis of ADHD or even suspected ADHD – we are interested to hear from parents/carers of children with or without ADHD for this study.
- 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 us – our contact details are at the end.

What is the purpose of the study?

- Attention deficit hyperactivity disorder (ADHD) is a common neurodevelopmental condition, affecting about 1 in 20 children and young people.
- Girls and young women are less commonly diagnosed with ADHD than boys and young men.
- Girls and young women with ADHD are more likely to receive their ADHD diagnosis at a later age than boys and young men with ADHD.
- ADHD may present a bit differently by gender. This may result in delayed diagnosis in girls and young women.
- It is important that ADHD assessment tools can identify ADHD symptoms in a more gender diverse group of young people.
- In our research, we spoke to young adults with ADHD, parents/carers of young people with ADHD, and educational and healthcare professionals. We asked them about the ADHD-related difficulties that primary school age girls may experience.
- We combined this information with established ADHD diagnostic criteria and developed a new gender-inclusive ADHD assessment tool for primary school children.
- We then consulted with many experts (including parents/carers, healthcare and educational professionals, and young people with lived experiences of ADHD) to improve and further develop our ADHD assessment tool.
- Our new assessment tool is called BEARS (Behaviour, Emotion, and Attention Regulation Scale).
- We also developed a new measure about masking and support, called BEAMS, which stands for: Behaviour, Emotion & Attention – Masking & Support Scale.
- This study aims to collect information to help us test and validate these new questionnaires.

Who can take part in this study?

- Parents/carers with children aged 9-11 years old (years 5/6 in primary school).
- You must live in the UK.

Why have I been invited to take part?

- We would like to invite you to take part because we feel your personal experience of caring for a child aged 9-11 years old (years 5/6 in primary school) will be valuable when helping us test our new ADHD assessment tool.

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 after reading this Information Sheet you are happy to be involved in this study, you will first need to complete a consent form.
- Following this, you will be asked to complete the assessment pack about your child.
- The assessment pack includes the new gender-inclusive ADHD assessment tool (BEARS), the associated masking and support scale (BEAMS) and additional questions about you and your child.
- The assessment pack will take approximately 60 minutes to complete.
- The assessment pack (including the consent form) can be completed online, via a secure webpage (REDCap).
- If you prefer to complete a paper copy, please contact the study team using the details at the end of the Information Sheet. We will need to know your address to mail a paper copy to you, along with a freepost return envelope.
- We will ask if your child would be willing to complete a shorter self-reported version of our study assessment pack.
- We will also ask your consent to contact your child's teacher to ask if they can complete the same questions about your child.
- You can take part in the study even if your child or their teacher does not complete the study assessment pack.

Optional consent to take part in future research studies

- To help us better understand how well the new BEARS and BEAMS questionnaires work over time, we will also invite a subset of parents/carers who take part in our study to repeat these 2 questionnaires approximately 1-2 months later. Taking part in this follow-up is entirely optional.

Will I be paid for taking part?

- No, you will not receive payment for taking part in this study.

- However, you can choose to enter into a prize draw with an opportunity to win a £20 Love2shop gift voucher. There are 70 such gift vouchers that can be won by families.
- To enter the prize draw, please tick the appropriate box at the end of the survey.
- If your child also chooses to take part, their name will be entered into the prize draw as well, giving the family 2 chances to win a gift voucher.
- If you have more than 1 eligible child and complete the study information separately for each child, you will be entered into the prize draw multiple times, once for each child.
- Similarly, for each child who takes part, their name will be entered into the prize draw, giving the family a bigger chance to win a gift voucher.
- The winners of the prize draw will be informed once all the study data have been collected.
- Parents who take part in our 3-month follow-up study will have the chance to be entered into a new prize draw to win a £20 Love2shop gift voucher (with 10 vouchers available, for this smaller group taking part).
- You will also have the opportunity to receive a copy of an information booklet about ADHD (digital or paper copy) for you to keep.

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 help us test and validate a new gender-inclusive ADHD assessment tool, which may help young people and their parents/carers in the future.

What are the possible disadvantages of taking part?

- The assessment pack contains questions that ask about your child's behaviour, functioning and difficulties. As such, it is possible that some parents/carers may find it difficult or upsetting to reflect on and answer some of these questions.
- We have provided contact details for organisations you can contact that may be able to assist – please find these on the last page of this Information Sheet.
- All questions are optional or have the response option: “Prefer not to say / Not applicable”.
- Also, you can take a break or stop at any time.
- Additionally, we acknowledge that the assessment pack contains multiple questionnaires and is a bit long, with a total time commitment of approximately 60 minutes.
- Although lengthy, the assessment pack does not have to be completed in one sitting. You can complete the assessment pack in sections, saving your progress as you go and returning to it when you wish, before the end of the study data collection. We will send you reminders with your personal link to return to the survey.

Will my taking part in this research be kept confidential?

- Yes. All information collected about you and your child 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 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 Data?

- This study will use your personal information, including your and your child's names, dates of birth, contact details such as phone number, email address, address and postcode. Only the study team will have access to this information.
- This information will be processed during the data collection stage and optional follow-up study (approximately 6-9 months' total time). After this time, the research team will anonymise all the personal data collected from or about you and your child in connection with this research project, with the exception of your consent form.
- The study information you provide will have a study ID for anonymity. We will keep all information about you safe and secure.

Data sharing

- 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 & Cambridge University.
- Any information we send will be anonymised, so it will not be possible to identify you from this information. We will not send any personal data (names, dates of birth, or any contact details like your postcode or email address). They must follow our rules about keeping your information safe.

Data retention

- After we complete analyses for the study, your information (including the consent form) will be retained securely by Cardiff University for up to 15 years after the project ends, in accordance with the University Records Retention Schedule.
- During this time, the information may be accessed by members of the research team and, where necessary, by members of the University's governance and audit teams or by regulatory authorities.
- Anonymised information will be kept for a minimum of 15 years but may be published in support of the research project and/or retained indefinitely, where it is likely to have continuing value for research purposes.

Who holds my information?

- The information will be stored in approved archiving facilities (secure computer storage at Cardiff University), 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>, including information about:
 - Your rights
 - The legal basis under which Cardiff University processes your personal data for research
 - Cardiff University's Data Protection Policy
 - How to contact the Cardiff University Data Protection Officer
 - How to contact the Information Commissioner's Office
- Please let us know if you need a paper copy of this information.

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.
- We will keep information about you that we already have unless you ask us not to.
- It will not be possible to withdraw any anonymised data that has already been published.

What happens to the data at the end of the research project?

- After the research project is finished and the results are published in an academic report, anonymised data about you and your child may be made publicly available via an open data repository and may be used by other researchers for purposes not related to this research project.
- All personal data (names, dates of birth, or any contact details like your postcode or email address) will be removed from this data and it will not be possible to identify you or your child from this anonymised data.

What will happen to the results of the study?

- The results gathered from this study will be used test the final version of the gender-inclusive ADHD assessment tool for validity.
- The results will be written up in a report for publication in an academic journal. Academic journals written may include verbatim quotes from your assessment pack, 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.

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 Research Ethics Committee at Cardiff University [SMREC Reference: 25/39] 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 School of Medicine Research Ethics Committee (medic_rec@cardiff.ac.uk).

Further information and contact details

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

Dr Joanna Martin (martinjm1@cardiff.ac.uk), Division of Psychological Medicine & Clinical Neuroscience, Cardiff University, Hadyn Ellis Building, Maindy Road, Cardiff, CF24 4HQ.

The research team:

- Dr Joanna Martin, Senior Research Fellow & study lead researcher (martinjm1@cardiff.ac.uk)
- Tamara Williams, Research Assistant & PhD student (williamstl6@cardiff.ac.uk)
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- Dr Olga Eyre, Clinical Research Fellow (EyreO2@cardiff.ac.uk)
- Dr Sharifah Shameem Syed Salim Agha, Honorary Lecturer in Child and Adolescent Psychiatry (AghaS10@cardiff.ac.uk)
- Dr Rhys Bevan-Jones, Senior Clinical Research Fellow (BevanJonesR1@cardiff.ac.uk)

Thank you for reading this information. This copy is for you to keep.

Helplines, text and email services for advice on mental and physical health issues:

SAMARITANS

If you need someone to talk to, they listen without judgement. You can phone any time, day or night for free.

Telephone: 116 123 (24 hours every day)

Welsh language line: 0808 164 0123 (7pm-11pm every day)

You can also e-mail them: jo@samaritans.org

www.samaritans.org/england-cy/how-we-can-help/contact-samaritan/



Information service for users of mental health services, carers and other groups.

Call: 0300 123 3393 (9am – 6pm, Monday to Friday)

Text: 86463

E-mail: info@mind.org.uk

www.mind.org.uk

YOUNGMINDS

If you're a young person in a 'mental health crisis', there's messenger service for free across the UK

For urgent help text YM to 85258 (24 hours every day)

www.youngminds.org.uk or <https://youngminds.org.uk/contact-us/>



Information and free, confidential advice and advocacy helping for children and young people up to 25 years old **in Wales**

Phone: 080880 23456; Text: 84001 (8am to midnight, 7 days a week)

Visit: <https://www.meiccymru.org/> or <https://www.meiccymru.org/get-help/>