# Parenting with Anxiety: Helping anxious parents raise confident children



# Welcome to the study

Fantastic! It seems like the Parenting with Anxiety project could be a good fit for you and your family. But, before you sign up, we want to make sure you have all the information you need. As this is a research study there might be some things about taking part which are new, or which you have questions about. Below are the key points.

# Parenting with Anxiety: What does taking part involve?

We are inviting you to join almost 2,000 parents to test a new online course developed to give anxious parents skills to raise confident children.

The course contains eight modules and it is all done online, on your computer, tablet or smart phone. You can do it at your own pace and at a time that suits you. Each module takes about 20-30mins and we will ask you try out the skills you learn after each one. It takes most parents 4 to 8 weeks to complete the whole thing. All of this takes place on our secure online computer platform. You will not need to go anywhere or meet with a member of the team. [Find out about the background to the study]

Not all parents who take part in this study will be asked to do the online course. This is because we want to compare two groups of parents, one who does the course and one who does not. Which group you are in is decided by chance. [Find out why we designed the study in this way]

If you don't get access to the course, this can be disappointing. But all parents in the study are playing an important role in trying to improve the lives of anxious parents and their children. The information you give us when you answer our questionnaires is crucial in helping us to understand whether our course works.

We will invite you to fill in a set of questionnaires now, and then two more sets over the next one-to-two years. We will send you a £15 Amazon voucher after you complete the second and third set, as a thank you. [More detail about what taking part involves can be found here]

We will also ask you to suggest a family member or friend to complete some questionnaires as well, although you can still take part if you choose not to do this. [Why am I being asked to do this?]

The study has been ethically approved by the University of Sussex [Access our ethical code].

### Other questions you may have

# What are the benefits of taking part?

If you are in the group which gets the online course we hope you will benefit from developing knowledge and tools to build your confidence as a parent and to support your child.

Even if you do not get to use the course, by taking part and answering our questionnaires you are helping us to understand anxiety. Hopefully, in time, this will benefit many more anxious parents and their children.

# What if I want to stop being part of the study?

Your decision whether to take part is voluntary and you can stop and withdraw at any point during the study without giving a reason. You can withdraw your data at any point by contacting the study team (parents-study@sussex.ac.uk).

## Who is organising and funding the study?

The study is being led by Professor Sam Cartwright-Hatton who developed the original face-to-face version of the course. It has been funded by the KAVLI Trust, a Norwegian charity and the University of Sussex is the sponsor. Brighton & Sussex Clinical Trials Unit will also help coordinate this study.

### What will happen with the results of the study?

We will use the results of this study to decide whether our online course works. Your data will also help us to understand more about how anxiety runs in families.

Some of the information we collect will be published in the form of journal articles and presented at conferences. Any information we use will be anonymised – your name or identity will *not* be published. We will also produce a plain English report of our findings.

# What are the possible disadvantages of taking part?

We do not expect taking part to cause you distress. However, being a parent is stressful and thinking about parenting and children can sometimes lead people to feel upset. If this is the case, you can access support via our website [link to platform help section].

Anyone who takes part will be giving time out of their busy life. Because of this, we have tried to keep the number of questionnaires as low as possible.

# What if there is a problem?

If you have concerns about any aspect of this study or the way you have been dealt with, you should ask to speak to the Trial Manager who will do their best to answer your questions [parents-study@sussex.ac.uk]

If you would prefer to speak to someone not directly involved with the study, Dr Antony Walsh the Research Governance Officer at the University of Sussex can be contacted on 01273 872748 or researchsponsorship@sussex.ac.uk.

The University of Sussex has insurance in place to cover its legal liabilities in respect of this study.

### Will my information be kept confidential?

Yes. All of the information that you give us in response to our questionnaires is completely confidential and will not be shared with anyone outside our team. However, in the unlikely event that anyone in the study tells us something worrying (i.e. that someone's safety is at risk), for example in an email or in a phone call to us, we are required to act on that and to alert the relevant authorities.

# Who can I contact for more information?

The Trial Manager is happy to talk to you about any questions you may have [parents-study@sussex.ac.uk]

# Additional information

# Background to Parenting with Anxiety

Anxiety can run in families: children with highly anxious parents are more likely to develop serious anxiety themselves. However, anxious parents can help their children to grow up free from serious anxiety.

Our team previously developed face-to-face workshops to give anxious parents extra skills to raise confident children. These workshops got good results. However, not all parents can make it to workshops because of work and other commitments, or because they don't live near our base. So, we have made an online version.

Parents and clinicians who developed the face-to-face version of the course have helped us with this online course. The team who run this study also includes two people who have lived experience of anxiety and of being a parent.

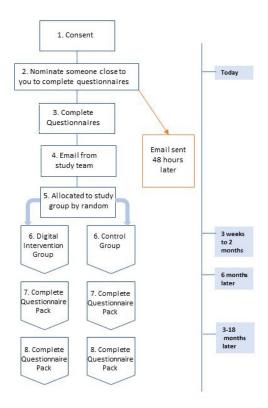
# Why are only half of parents getting to do the online course?

We want to find out whether this online course can prevent serious anxiety in children, by comparing two groups of parents - one group will do the course (called the Intervention group) and the other group will not (called the Control Group). Then we will see if there are differences between how these two groups do.

Which group you are in will be decided by a computer and will be completely by chance, like flipping a coin. This is called a Randomised Controlled Trial. Half of the parents who take part will have access to the online course, and the other half will not. We understand that this could be disappointing and we are very grateful to parents in the control group for the time they give to the study. If we find the online course is helpful then we hope to share it widely in future.

# What does taking part involve?

If you choose to take part in the study you can expect to go through the following stages.



- 1: We will ask you for your consent to take part.
- 2: We will ask you to suggest someone who is close to your child to fill in a smaller number of questionnaires (these take about 10-20 minutes). You do not have to refer someone, or you can choose to suggest someone later on. If you do suggest someone, we will contact this person by email 48 hours after you have completed your own questionnaires. We encourage you to use this time to let them know about the study. During this period, you can cancel your invitation or change the person you invite. We will send you all of this information by email.
- 3: We will ask you to complete questionnaires about you and your child. This will take about 40-45 mins. You can leave and come back to the questions but we encourage you to try and finish the questionnaires within two weeks.
- 4: You will receive an email from us with details about your decision to invite someone to complete questionnaires about your child. It will also include information about how to make a referral/change a referral.
- 5: The computer will put you into the intervention group or control group

6: If you get put into the intervention group, you can begin the online course. We encourage you to do one or two modules (20-30min each) a week and carry out the home practice tasks in-between.

If you get put into the control group we will contact you again in six months. During this time, you should just keep doing what you usually do.

7: Six months later you will be asked to complete some follow-up questionnaires. These are the same as at the ones you completed earlier on. We will send you a £15 Amazon voucher for doing this.

### 8: We will ask you to fill in a third set of questionnaires (between 3-18 months later)

We will ask you to complete the questionnaires again third time. We will send you a £15 Amazon voucher for doing this [Delete when no longer applicable – for participants recruited towards the end of the recruitment period.]

# Why do we want another person to fill out questionnaires too?

We want to understand what your child is like and how they are feeling. Asking more than one person is a good way to increase our understanding of your child. This person can be a family member, or a friend who is not involved in a paid capacity (e.g. nanny). We will ask them to fill out two questionnaires — one about your child's anxiety level and one about their own anxiety level. If they are the child's other parent we will also ask them to fill in a questionnaire about their parenting style (you will have answered these as well). To thank them for their time we will provide them with a £10 Amazon voucher. This other person will not see what you have written in your questionnaires, and you will not be able to see what they have written.

### Do I have to nominate someone to fill out questionnaires?

No. It is completely up to you whether you want to suggest another person to complete these questionnaires. This will not have an effect on which group you are in (intervention or control) or prevent you taking part in the study. The person you nominate does not have to fill in the questionnaires if they decide not to, and this will not affect you taking part in any way.

### Ethical code

The purpose of our research is to advance knowledge of child anxiety and how anxiety runs in families, so we will process your personal data and responses to that end. Your decision whether to

take part is voluntary and you can stop and withdraw at any point during the study without giving a reason. You can withdraw your data at any point by contacting the study team (parents-study@sussex.ac.uk). You can choose not to answer any of the questions that we ask

Your personal data will be handled in accordance with UK data protection legislation and the University's <u>Privacy Notice</u>. We will store your identity and personal data safely, on a protected server and/or password-protected computer, and will not reveal them to anyone outside the research group without first notifying you. From time to time we also re-contact certain people to take part in further studies, but participation is entirely voluntary and you are under no obligation to take part further.

We will not disclose your personal data in any scientific reports resulting from this research (e.g. for a research degree) or in any data repositories for other researchers. Any data that is published will be done so anonymously/statistically. This research program is ongoing and your anonymised data will be held securely until it is no longer scientifically valuable or cannot reasonably be maintained.

This research has been approved by the Sussex SciTec Ethics Committee (C-REC: ref = ER/SC430/1). University of Sussex has insurance in place to cover its legal liabilities in respect of this study. If you have any ethical concerns, please email the project supervisor (parents-study@sussex.ac.uk) or ethics chair (crecscitechchair@sussex.ac.uk).

Contact details of our Data Protection Officer, along with your rights in respect of processing, are found <u>here</u>. You must be over 16 years to consent.