



NUI Galway
OĒ Gaillimh

Parent Information Sheet

Evaluation of the Feeling Better Pain Management Programme for Children with Autism Spectrum Disorder

This research study is examining the suitability of the content of the online Feeling Better pain management programme for children with Autism Spectrum Disorder (ASD). It aims to understand how suitable it is for children with ASD and what modifications are required.

My name is Rachel Fitzpatrick. I am a PhD student in the School of Psychology at National University of Ireland, Galway. I would like to invite you and your child to take part in this study that will examine this online interactive pain management programme for children with ASD who experience pain. I am working under the supervision of Dr. Helena Lydon and Professor. Brian McGuire.

Invitation

You and your child are invited to take part in this research study on the *Evaluating the suitability of the content of an online version of Feeling Better pain management programme in children with Autism Spectrum Disorder*. To be eligible to take part in this study you must be a parent/guardian over the age of 18 years with a child who has a diagnosis of Autism Spectrum Disorder who experiences recurrent or chronic pain and who is aged between 5-18 years of age. Before you agree to take part, it is important for you to understand what the study involves and why it is being done. This *Participant Information Sheet* tells you the purpose, risks, and benefits of this research study. If you agree to take part, you will be asked to consent to the study. Please take as much time as you need to read this information. If you have any further questions, I will be happy to answer them. Contact details are provided at the end of this page. You should only consent to participate in this research study when you feel you understand what is being asked of you and you have enough time to think about your decision.

Taking part- What it Involves

Why do this study?

I would like you and your child's feedback on the content of the Feeling Better online pain management programme. The aim of this study is to make this programme more suitable to children with ASD who experience pain. Your views and personal experiences will be extremely valuable to the modification of this programme. We believe that you and your child are the experts in what works best for you and your opinion, will help us make a better pain management programme for children with ASD who experience pain.

What will happen if I take part?

If you and your child agree to be part of this study, you will be provided with a link that will allow access to the online Feeling Better programme. You will be given a total of 4 weeks to look through the programme (opening modules, watching short interactive videos, exploring the programme).

After 2 weeks the researcher will arrange a short call (no more than 40 minutes). The researcher will ask you some questions about modules 1-4. The researcher will then arrange another call 2 weeks later where questions will be asked about modules 5-9. The researcher will provide the list of questions asked to all participants so that they are aware of the questions being asked. You and your child will be asked about your opinions on the content of the pain management programme (likes, dislikes, suggestions) as well as experiences dealing with pain and problems you may have encountered.

Outline of Study

- After 2 weeks researcher will arrange a call to discuss modules 1-4
- 2 weeks later researcher will arrange a call to discuss the final module 5-9

We hope this conversation will be fun and interactive throughout for your child.

How long will my part in this study last?

You and your child will meet with the researcher through Zoom for approximately as long as it takes to get your views, this could be quite short or as long as 1hr. There will be a total of 2 calls with the researcher (no more than 40 minutes) where you and your child will discuss the modules within the programme. A zoom link will be sent to you once you and your child consent to taking part in this study.

What are the possible benefits of taking part?

The aim of this research is to examine the usability of the online Feeling Better pain management programme for children with ASD and ID and what age range this programme is best suited for i.e. 5-8yrs, 9-12yrs or 13-18yrs. The findings of this research will tell us what age range this pain programme is best suited for and if you child is within the targeted age range.

At the end of the meeting, your child will receive a certificate of achievement.

What are the possible disadvantages and risks of taking part?

The researcher will ask you and your child your opinions on the current programme and ask you to reflect on previous experiences. There, there is a small risk that you may find some of these questions distressing as they relate to experiences of pain. Contact details of helplines are provided if you become distressed. You can also contact members of the research team for advice and support if required. At any time if you wish to stop the conversation with the researcher you can do so without giving any reason.

What happens at the end of the study?

At the end of this study, data will be analysed and prepared for publication. If you would like to know the findings of this research, the researcher will provide you with a short summary of the findings following completion of the study. All data will be kept confidential throughout. You and your child's identity will remain confidential. You and your child's name will be changed for analysing the data, a pseudonym will be used to disguise your identity. Your names will not be published or disclosed to anyone outside the research team. Only the researcher will have direct contact with you and your child. Data will be kept confidential throughout.

What happens if I change my mind during the study?

You are entitled to change your mind about participating in this study at any time. If you decided to opt-out of this study your data will be removed from this study. If you have any questions in relation to the study, please contact the researcher, I will be happy to answer any questions you may have.

Who do I contact for more information or if I have further concerns?

If you have any further questions in relation to this study, please do not hesitate to contact the researcher. I will be happy to answer any questions you may have. Alternatively, you may wish to talk to my supervisors regarding this study. This research does not offer any advice at all and the aim is to capture information on how suitable the Feeling Bette pain management programme for children with ASD and ID. Contact details of helplines are provided at the end of this participant information sheet if you have become distressed.

Researcher:

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Supervisor:

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Telephone: 091-524457

Or

Name: Professor Brian McGuire
Email: brian.mcguire@nuigalway.ie
Telephone: 091-493266

If you have any concerns about this study and wish to contact someone in confidence, you may contact: **The Head of School (Prof. Brian McGuire), School of Psychology, National University of Ireland, Galway at brian.mcguire@nuigalway.ie or 091493266**

Or

If you have any concerns about this study and wish to contact someone independent and in confidence, you may contact The Chairperson of the NUI Galway Research Ethics Committee, c/o Office of the Vice President for Research, NUI Galway, ethics@nuigalway.ie

National Helplines

Chronic Pain Ireland

The CPI telephone support service is available 3 days a week (Tuesday, Thursday & Friday) from 9:30 am to 5:00 pm.

If you would like to talk to someone confidentially call the CPI Helpline on 01 8047567. The staff are here to provide you with information and support. Alternatively, you can email info@chronicpain.ie or visit www.chronicpain.ie for more information.

Pieta House

You can phone for free Pieta House 24- hour helpline on: 1800247247 or, alternatively, text HELP to 51444

Aware

You can phone for free Aware on 1800804848, Monday to Sunday from 10am -10pm or, alternatively email: supportmail@aware.ie

Samaritans

You can phone for free Samaritans on 116123 day or night, 365 days a year. Or, alternatively email on: jo@samaritans.ie

Thank you kindly for taking the time to read this information sheet and I would be very grateful if you would assist me by taking part in this research.