

Information Sheet for Parents



Title of Study

Parent-child mutual interactions during pain experiences

Invitation

You and your child are invited to take part in a research study to increase our understanding of how children and their parents react to the everyday experience of pain. We are asking families with a child between the ages of 2.5 and 5 years to take part in this study. This Information Sheet will help you decide if it is in your and your child's best interest to take part in this study. If there is anything you are not clear about, we can explain it to you. Please take as much time as you need to read this information.

What is the research about?

Pain is an integral part of children's everyday experience and children mainly depend upon their parents for help and care. We need to understand how parents and their children react to each other during and after their child goes through one of those everyday tumbles or short painful experiences that happen while playing. Specifically, we want to understand how parents and children respond to pain, by asking parents to keep a pain diary for two weeks, of one pain event that their child experiences each day. This will help us understand better how children learn to cope and recover from pain. That is where you and your child come in!

Do I or my child have to take part?

It is your choice and your child's choice whether to take part in this research. You and your child do not have to take part in this study; participating is entirely voluntary. Children can only take part if their parent has first given permission for them to do so. If you decide to allow your child to take part in the research, you will be asked to complete a consent form (as part of the participant details form at the start). It is important to understand that both you and your child are free to withdraw from this research at any time and without giving any reason. This will not affect your or your child's rights. You and your child's participation in the study may be ended if, in the opinion of the study staff, it is not safe or reasonable for you and/or your child to continue. Materials from those who withdraw from the study or who do not participate will be destroyed if you tell us to do so.

What will be involved if my child and I take part?

1. Parents will be asked to complete a short pain diary each day for two consecutive weeks, to report on a pain event that their child experienced that day (14 pain entries in total). This will be completed online, and should not take longer than 5 minutes each day.
2. If families so choose, they can also complete a short assessment immediately after any pain event that occurs. This involves the child answering 2 questions about their pain, and the parent

answering 3 questions about their child's pain (up to a maximum of 5 assessments during the two week period). This will be completed online via the parent's smartphone, and should take 2-3 minutes to complete each time.

Your total participation time for this study is 1.5 hours for the diary across the two week reporting period (plus 15 minutes for the assessments if also completing those).

To thank you for your participation, your child will receive a Junior Scientist certificate, and you will have the option to enter a draw for a €50 One4All voucher, with separate entries for completing the diary and the assessments (UK participants who win a prize will be offered their prize in Pound Sterling instead of Euro).

Are there any potential risks to me or my child taking part?

Although no harms are anticipated during your participation in this study, we realize that sometimes issues may arise. In the unlikely event that completing the questionnaires or observations at home make you or your child feel uncomfortable, you are free to withdraw at any time from the research or you can choose not to answer those specific questions. Should you or your child experience distress, you may wish to discuss this with Grace (the researcher) or with her supervisor, Line Caes (contact details below).

What are the benefits to me and my child taking part?

In being part of this research, you and your child will be helping to increase our knowledge about how children and parents deal with everyday painful experiences. In the past, children and parents have enjoyed participating in studies like this one and have reported that they liked the idea of helping others through research. We plan to publish our group results in academic journals and present it at conferences so that others can learn from this and so that in the future we can improve pain management for children.

What will happen with the information collected?

The information we collect will be used to inform the research questions, which may be presented at an academic conference or published in a journal. However, anything that is learned about you and your child will be kept private. We will never use your or your child's name in any publications of the completed study. Only group results will be given in presentations/talks or reports.

How will the information be kept confidential?

All children and families participating in this study will be given a participant number (e.g. 001). This number will be used to identify all information we get so your name will not be on any of the data forms. The participation evaluation form you complete at the end of the study will not include your participant number; therefore, your answers on these questionnaires will be anonymous and not connected to you or your child's participant number or names. Only the consent form will have your name and signature and this form will be kept separate from all the other materials.

In line with the University's video recording policy, electronic data (including video recordings) will be uploaded onto a secure computer within the University, which will only be accessible to the research team for research purposes. Video recordings will be destroyed after 10 years, in accordance

with University guidelines on data retention and GDPR recommendations. Members of the research team may use group datasets without identifying outside of the university on password-protected computers.

Who are the study researchers?

Grace O'Sullivan is a PhD researcher on this project in the Centre for Pain Research at NUI Galway, supervised by Prof Brian McGuire (NUI Galway) and Dr Line Caes (University of Stirling, Scotland). Several final year Psychology undergraduate students from the University of Stirling will also be assisting with data collection, under the supervision of Dr Line Caes. Grace has been trained for the study and subject to security vetting by *An Garda Síochána* (national police force in Ireland), for the protection of your child. Dr Caes and all the Psychology undergraduate students are approved by the Scottish PVG scheme.

Where can I get further information?

A report with the research findings will be available from the researcher following the research's completion. You may choose to be included on a mailing list to receive a copy of this report.

If you have any queries relating to the research, you can contact Grace O'Sullivan at g.osullivan6@nuigalway.ie; Dr Line Caes at line.caes@stir.ac.uk / +44 (0)1786 467639; or Prof Brian McGuire at brian.mcguire@nuigalway.ie. If you have any concerns about the research and wish to speak to someone in confidence, you can contact the Head of Psychology at NUI Galway, Dr John Bogue, at john.bogue@nuigalway.ie.

Thank you for taking the time to read this information sheet.