



Building The Kid's Trial: Experiences of the CRAG & PRAG

Parents' & Caregivers' Information Leaflet

Thank you for your interest in our study!

We believe involving the public and patients in the planning and design of trials is an important way to improve research for the people it is meant to benefit. This type of research, where we ask the public and patients for their ideas and opinions, is called 'Participatory Research' or 'Public and Patient Involvement (PPI)'. This is why we formed the Parents' Research Advisory Group (PRAG) and the Children's Research Advisory Group (CRAG) when we started planning *The Kid's Trial*.

What is the Building The Kid's Trial project?

Over the past months, you and your child have been advising our research team on how to design, plan, and improve our online, randomised trial, *The Kid's Trial*. This input has been extremely valuable to *The Kid's Trial* website design, animations, logos, and how we communicate our project to kids and parents.

We would love it if you and your child could tell us what you think worked well about the PRAG and CRAG and how you think we could do better in the future.

Who can take part in the project?

We are only inviting members of *The Kid's Trial* PRAG and CRAG to join this research study since you are the only ones who can tell us what it was like to be advisors for *The Kid's Trial*.

What will taking part mean for me?

Joining this study is entirely up to you. If you decide to join, then we will meet you online for an interview. The interview shouldn't take more than one hour. If you decide your child can join and they agree, we will meet them online for a separate interview. You and your child may decide if you are present during their interview or not.

What information will we collect and what will we do with it?

We will ask you for your email address, gender, and country of residence. We will also ask you for the age, gender, and country of residence of your child.

During the interview, we will ask you what you thought about being part of the PRAG and your experiences throughout the process. We will ask you questions about your perspective of your child's experience as well. Finally, we will ask questions about how you think we could have made it better for parents and caregivers and what we did well. It will be up to you to decide if you share this information.

The interviews will be recorded. This is so that we can be sure we don't leave something out or change your words. We will write a report about what was said in the interviews so that other parents, kids, and researchers can learn how our project worked. Even though we will report on the interviews, your and your child's information and names will stay anonymous. We won't report who said what, and no one will know you even took part in the project unless you tell them. We will delete all the recordings once we have written down what was said.

Risks and benefits of joining the Building The Kid's Trial project

It's important you understand whether being in this project could help you or your child or if it might be hurtful to you or your child. We call this 'Informed Consent'. If you don't understand something or have questions, you can ask us any time.

Could being part of the project help me?

Being part of this project probably won't help you or your child, but we do believe it could help other parents and children who are interested in getting involved in this kind of research by giving:

- you an opportunity to tell us what you thought the good parts of being a PRAG member were.
- you an opportunity to tell us what parts of the PRAG need improvement and if you have any ideas on how we can improve them.
- other parents an opportunity to learn about getting involved in participatory research.

We believe the project could help researchers:

- understand how to do this type of research with parents/caregivers and children better.
- think about what we would do differently in the future.

What are the risks of joining this project?

Joining the study shouldn't be hurtful for you or your child. However, there are some things to think about.

Sharing information can pose a risk that someone else will access it without our or your permission, but we take data security very seriously. You can read about how we protect your data in the next section.

Sharing thoughts and opinions about the project might feel uncomfortable for some people if they didn't like parts of PRAG membership and how it was done. Remember that we want to tell people what really happened and what you thought so it's important that we hear all of it, even the critical feedback.

How is my data and my child's data protected?

We are only collecting the data we really need for the study, and we take data protection very seriously.

- We will not share your information outside of the research team.
- We will handle and store all information carefully behind password-protected servers. We will do this in line with GDPR law and University policies.
- All data will be anonymised before any research reports are written. This means your information will not be traceable to you or your child. After the project is finished, the

anonymous data will be kept at the University of Galway on a password-protected server for seven years, and then it will be destroyed.

Your rights and your child's rights

- You and your child have the right to withdraw from the study at any time. You do not have to tell us why, and no one will be upset.
- You have the right to know what data we are collecting, why we are collecting it, what we will do with it, how we will protect it, and with whom we will share it.
- You have the right to make a complaint with the University of Galway Data Protection Officer or the Irish Data Protection Commissioner if you are not happy with any aspect of how your or your child's data is collected or handled.
- You have the right to object to our using your or your child's data for profiling or automated decision-making (this means making predictions about a participant based on their data).
 - We will NOT do this.
- You have the right to ask that your information be erased and no longer included in the study if you change your mind.
 - We can do this up until the point that it is analysed.

This study has received approval from the following research ethics committee: University of Galway Research Ethics Committee Research and Innovation Centre, University of Galway

Email: ethics@universityofgalway.ie

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Building The Kid's Trial: Experiences of the CRAG & PRAG

Child Information Leaflet

Thank you for your interest in our study!

Before you decide if you want to join this project, it's important you understand why we are doing this and what joining means for you. Please talk about the project with your grown-up to help you decide. If you don't understand something or have questions, just ask us! We're here to help.

What is the Building The Kid's Trial project?

Over the past months, you and your parent or caregiver have been helping our research team to design, plan, and improve our online, randomised trial, *The Kid's Trial*. Your help has been so important to our website design, animations, logos, and how we communicate our project to kids and parents.

We would love it if you and your parent or caregivers could tell us what you think worked well about the PRAG and CRAG and how you think we could do better with this type of research in the future.

Who can take part in this project?

We are only inviting members of *The Kid's Trial* CRAG and PRAG to join this research study since you are the only ones who can tell us what it was like to be advisors for *The Kid's Trial*.

What will taking part mean for me?

Joining this study is entirely up to you and your family. If you decide to join, then we will meet you online for an interview. The interview shouldn't take more than one hour. You can do your interview on your own or have your grown-up with you if you want.

What information will we collect and what will we do with it?

We will ask your parent or caregiver to tell us your age, gender, and what country you live in. During the interview, we will ask you questions about what you thought of being part of the CRAG and what your experiences were in helping to design and plan *The Kid's Trial*. We will also ask questions about how you think we could have made it better for kids and what we did well. It will be up to you and your parent or caregiver to decide if you share your information.

The interviews will be recorded. This is so that we can be sure we don't leave something out or change your words. We will write about what was said in the interviews so that other kids, parents, and researchers can learn how our project worked. Even though we will write about the interviews, we won't write about who said what, and no one will know you even took part in the project unless you tell them. Once we have written down what was said, we will delete all the recordings.

What are the good parts and tricky parts of joining?

It's important you understand whether being in this project could help you or be tricky or hurtful to you. You should talk about the project with your grown-up and decide together if you will take part.

Could being part of the project help me?

Being part of this project probably won't help you, but we do believe it could help other kids who are interested in getting involved in this kind of research by giving:

- you a chance to tell us what you thought the good parts of being a CRAG member were.
- you a chance to tell us what you thought the not-so-good parts of being a CRAG member were and maybe what we could do better next time.
- other kids an opportunity to learn about getting involved in research.

We believe the project could help researchers:

- understand how to do this kind of research with parents/caregivers and children better.
- think about what we would do differently in the future.

Could being part of the project hurt me?

Joining the study shouldn't hurt you. But there are some things to think about:

- Sharing any information about yourself online can be tricky. We don't want anyone to be able to look at it who isn't supposed to, so we do everything we can to protect the information you share with us. We will ask your parent or caregiver to tell us your age, your gender, and what country you live in. This information will be kept at our university and be protected with secret passwords and other protections.
- Sharing thoughts about the project and some of your opinions might be tricky for some kids if they didn't like parts of the CRAG and how it was done. Remember that we want to tell people what really happened and what you thought, so it's important that we hear all of it, even the not-so-good stuff!