

Rights based standards for children undergoing clinical procedures

Full Information Sheet for Parents/carers

We are asking if you and your child would like to take part in a project. This sheet will tell you all about it.

You are being invited to take part in a research project. Before you decide if you are happy to take part, and if you would like your child to take part, it is important for you to understand why the project is being done and what taking part will involve. Please take time to read this information sheet and discuss it with others if you wish. Ask us if there is anything that is not clear or if you would like more information.

Who is doing this project?

The project is being led by Professor Lucy Bray at Edge Hill University who has worked with an international group of nurses, doctors, play specialists, psychologists, youth workers, children and young people and parents to develop the rights based standards. You can find out more about the team on our webpage.

<https://www.isupportchildrensrights.com/>

What is the point of the project?

If you have used any part of the 'rights-based standards' when your child was having a test, investigation, examination or procedure we would really like to hear what you thought about them and what it was like using them. We are trying to work out if they are useful for children and parents, if anything needs changing or if there are things which make them difficult to use.

We would love to hear from any children aged 7 to 16 years old and their parents/carers.

Do I or my child have to take part?

No. It is up to you to decide whether or not you or your child take part. You and your child can take part separately from each other. If your child would like to share their views, we will just ask you to tick a box at the beginning of their survey to say you have given them permission before they start answering the questions.

What will happen if I take part?

You will be asked to tell us what you thought about the standards and if they were helpful when your child had a test, investigation, treatment or procedure in a short online survey. The survey will take about 10 minutes to fill out, depending on how much you want to tell us. You will not have to answer any questions you do not want to, and you can end the survey at any time. We will not be asking for any information which will identify who you are. Please do not add any identifiable information to the survey.

If you click 'done' at the end of the survey then this means you are happy for us to use your answers as part of the project. As it is anonymous, once you have clicked done or submit then you cannot take your answers back.

What will happen if my child takes part?

If your child decides they would also like to take part and share their views then please read the children's information sheet about the study with them. There is a separate link for the children's survey which has a box at the beginning which we will ask you to tick to say you are happy for them to take part. The survey for children will take about 10 minutes to fill out. We will not be asking for any information which will identify who they are.

Are there any possible disadvantages or risks from taking part?

We hope that taking part will not involve any risks for you or your child. Some of the questions may be upsetting as they may prompt you or your child to think back to the procedure they had. You do not have to answer any questions that you do not want to and at the end of the survey there are some suggestions for places for support, you can skip straight to these if you like. As we cannot identify who has filled out a survey, we will not be able to offer individual help or support.

What are the possible benefits of taking part?

We hope that what we find out from this project will help us work out how the standards are being used and what we need to improve to make sure the standards help make a difference to children having a clinical procedure.

What will happen to the results of the project?

The research team will share the results in articles, presentations and we will also work with parents and children to write a summary of the key findings which will be posted on our webpage. The report from the project will be shared with key organisations across the world.

Who has reviewed this study?

This study has been reviewed and given ethics clearance through the Edge Hill University Health Research Ethics Committee (HREC) Reference:

What if I have a question, concern or something goes wrong?

If you have a question or concern about any part of this project, please contact the lead researcher, Professor Lucy Bray (brayl@edgehill.ac.uk).

If you wish to make a complaint about the project please contact the research office of the University at research@edgehill.ac.uk who is independent to the project team.

Data Protection Notice

Edge Hill University is the organiser for this study based in the United Kingdom. We will be using information from you in order to undertake this project and will act as the data controller for this project. This means that we are responsible for looking after your information and using it properly. Edge Hill University will process your data for the purpose of research. Research is a task that we perform in the public interest. Your rights to access, change or withdraw your information is limited, as you have taken part in the survey anonymously. We are not collecting any information from you which is identifiable.

You can find out more about how we use your information by referring to the University privacy policy: edgehill.ac.uk/about/legal/privacy.

**Thank you for reading this information sheet
and thinking about taking part in this project**

