

Alder Hey sensory environment project Detailed information for those taking part in the sensory project.

Thank you for your interest in the Alder Hey sensory environment project. Before you decide whether to take part, it is important that you understand why the project is being done and what it will involve. This longer information sheet will explain how we will use the anonymous information you will provide.

Do I have to take part?

No. It is up to you to decide if you want to take part. Taking part in this project is voluntary. You can stop participating in the evaluation at any time, no-one will mind. You can choose how you want to take part. All the information you provide in the survey or activity booklet or large paper sheet or by uploading photos is anonymous (there are no names, personal details or faces). This means that we do not know who submitted or shared the information with us and you will not be identified in anything we write about the project.

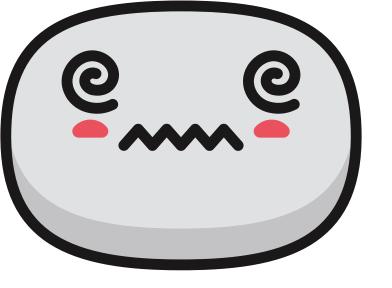
What are the possible benefits or disadvantages of taking part?

You may not benefit directly from taking part, however you will have helped us to better understand how to help other children and parents coming to the hospital. We do not think taking part will be upsetting, but if you do become upset we can tell you about where you can get support, these are listed on the debrief sheet you will have been given at the end of taking part. It is also available here in the figshare area for the project [insert link].

Will taking part be confidential?

All the information shared with us is anonymous so no-one will know who told us anything.

All information will be stored securely on the University One Drive in a shared folder accessible only by the evaluation team and will be retained for a period of 10 years after which it will be securely deleted. The procedures for handling, processing, storage and destruction of data from the study are compliant with GDPR and the Data Protection Act (2018).



Confidentiality will only be broken if you share, or the researcher uncovers, information that suggests that an intention to harm yourself or others, or there is disclosure of poor or illegal practice. We will discuss any action to be taken with you. The anonymous project data will be made available for sharing with other researchers in the future should it be requested.

At Edge Hill, we are committed to respecting and protecting your personal information. To find ways in which we use your data, please see edgehill.ac.uk/about/legal/privacy. The University is committed to ensuring compliance with current data protection legislation and confirms that all data collected is used fairly, stored safely, and not disclosed to any other person unlawfully. The University is a data controller and, in some instances, may be a data processor of this data.

What will happen to the results of the project?

The results of this project will be published in academic journals, be presented at conferences and at events in the Faculty and at Alder Hey. You will not be identified in any publication even if we use your words.

Who has reviewed the study?

The study has been reviewed and approved by Edge Hill University Health-related Research Ethics Committee (REF insert Haplo number) and the audit committee at Alder Hey Children's Hospital.

Is there someone independent I can talk to about the research?

If you are unhappy with the research in any way please tell us. We will try to put things right. If you would prefer to talk to someone outside the research team, or if you are not happy with the way we deal with your problem, you can contact the Secretary of the University Research Ethics Sub-Committee on research@edgehill.ac.uk

The leads for this project are Professor Lucy Bray and Dr Kate Knighting, if you have any questions or concerns please contact us on brayl@Edgehill.ac.uk



