



The INSCHOOL project - The school lives of high school pupils living with long-term health condition: Information sheet (Parents/Carers)

Who am I?

My name is Simon and I am a researcher from the University of Leeds, but I also work with a lot of doctors and nurses at Leeds Children's Hospital. I have been doing research in young people's health services for over 10 years and have been running the INSCHOOL project since 2019.

If you have any questions, you can contact me – Dr Simon Pini: s.pini@leeds.ac.uk
0113 3436952

What is this project?

The INSCHOOL project is looking at the school lives of young people living with long-term physical health conditions and is funded by the National Institute for Health Research who are a part of the government's health care service. I would like your child to help me with this part of the INSCHOOL project by completing a short assessment (it's like a survey). There are a few things I would like you to know before getting started.

Do they have to take part?

No, they do not have to take part in this project. As a parent/carer of a child under 16, it is your choice whether you are happy for them to take part.

For under 16s in this project we are using an "opt-out" parent/carer consent process. This means that if you are happy for them to take part after you have read this information sheet then you do not need to do anything further. However, if you have any concerns or questions that you would like to raise before deciding if your child can take part, then please contact the research team and we will be happy to talk this through with you.

What if I decide they can take part, but change my mind?

If they complete the assessment, but you or your child change your minds afterwards, then get in touch with me and I will answer any questions you have. Their assessment responses will be anonymous, so nobody will know who they are and we will not be able to remove their responses from the project data. The only identifiable information we will be collecting is if they choose to give us contact details for you or for them. We will be able to remove these contact details from our records up to 31/12/2025, which is when the study will close.

What happens if they do take part?

If you are happy for them to take part then they can complete the online assessment via this link:

<https://app.onlinesurveys.jisc.ac.uk/s/leeds/inschool-needs-assessment-1>

Or click on this QR code:





When they click on the link they will see a short “consent statement” which they will need to agree to before they complete the assessment. I have included a copy of this consent statement below, so if you have any questions about this part of the assessment then get in touch with me.

Consent statement

Thank you for being part of the INSCHOOL project!

Before completing this assessment, please read the ‘participant information sheet’ and contact the research team with any questions. If you are under-16 please make sure a parent/carer has seen the information sheet and is happy for you to take part.

This assessment should take 10-20 minutes to complete and will ask you questions about you, your health, and what life is like at school. The questions are all based on things we have learned from other young people in earlier parts of the project.

We do not want to ask you questions that will make you feel uncomfortable or upset, so you will always have the option to say “prefer not to answer”. You can stop at any time and can let us know if you want us to remove or change any of your answers after you have finished. There are also details of places you can ask for more advice or support if you need to.

We do not believe there are any known risks in completing this survey; however, any online activity has a small risk of information being shared. To the best of our ability, you taking part in this study will remain private. To help with that, we will not ask you for any personal data, so the risks are very small.

You will have an option at the end of the survey to enter your, or your parent/carer’s, email if you would like to take part in other parts of the project in the future or hear about the results of the study. We will store these email addresses separately to the rest of your information, so nobody will be able to link your answers to your email address.

If you have any questions then contact us via email or phone:

Dr Simon Pini: s.pini@leeds.ac.uk 0113 3436952

If you are still happy to take part then tick this box and you can get started

The assessment will ask some basic questions about them, their health and their school. After that the main assessment asks a range of questions about what their life is like at school. They will always have the option to say “prefer not to answer” for any of the assessment questions.

The assessment takes around 10 minutes to complete. Once they have completed the assessment they will have the option to leave contact details for you or them, so we can let you know the results of the study and invite them to take part in any of our research in the future. There is also a prize draw where they could win a **£50 GiftPay voucher**.

You can ask for a paper copy of the assessment if they might find it difficult to complete it online, which you can request by contacting the research team.



Then what...?

Once they have completed the assessment, that's it! You will have allowed them to give us really useful information, which will help us improve the school lives of other young people with health conditions.

If you would like to know a little more about how we are going to manage the information and data you and your child give us, please read the sections below.

Who is monitoring this project?

This project is sponsored by the University of Leeds and overseen by the National Institute for Health Research (NIHR). A research ethics committee have evaluated and approved the project.

How will we use information about your child?

We will need to use information from your child for this research project. The only information we will gather from your child will be what they choose to tell us. This will include details where they go to school, and what kind of health condition they have. It will also include your contact details if you are happy to give them to us. People will use this information to do the research or to check their records to make sure that the research is being done properly.

People who do not need to know who they are will not be able to see your child's name or contact details. Their data will have a code number instead. We will keep all information about them safe and secure.

Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no-one can work out that your child took part in the study.

Any information we collect from you and your child will be stored on secure University of Leeds servers and will only be accessible by the research team. Any paper based information you provide as part of the study will be stored in locked filing cabinets at the University of Leeds.

We would like to keep different parts of your child's data for different reasons.

- 1- If you give us your contact details we would like to keep them for the duration of the research (up to 3 years). This will mean we can contact you to invite you or your child to other parts of the project you might be interested in taking part in.
- 2- We would like to keep your child's assessment information for longer so that we can look at their answers with all of the other answers given by other young people in the study. Your child's name will not be linked to their answers, so nobody will ever know what they have said. We will keep these answers for up to 10 years.

Are there any limits to my information being private?

The assessment is anonymous, unless you or your child provide us with contact details at the end of the assessment.

What are your choices about how your child's information is used?

- Your child can stop being part of the study at any time, without giving a reason, but we will keep information about your child that we already have.



- We need to manage your child's records in specific ways for the research to be reliable. This means that we won't be able to let you see or change the data we hold about your child.
- If you agree for your child to take part in this study, you will have the option to take part in future research using data saved from this study. You can tell us if you are happy with this in the consent form.

Where can you find out more about how your child's information is used?

You can find out more about how we use your child's information

- by asking one of the research team on the contact details provided
- by contacting the University of Leeds Data Protection Officer at: dpo@leeds.ac.uk
- by reading the University of Leeds 'Research Participant Privacy Notice' by following this link: <https://dataprotection.leeds.ac.uk/wp-content/uploads/sites/48/2019/02/Research-Privacy-Notice.pdf>
- by reading the Health Research Association's guidance at www.hra.nhs.uk/information-about-patients/