



The INSCHOOL project - The school lives of high school pupils living with long-term health condition

Information sheet (16-18 years)

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

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 you 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 I have to take part?

No, you do not have to take part in this project. It's your choice!



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

If you complete the assessment, but change your mind afterwards, then get in touch with me and I will answer any questions you have. Your assessment responses will be anonymous, so nobody will know who you are and we will not be able to remove them from the project data. The only identifiable information we will be collecting is if you choose to give us contact details for you. 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 I take part?

If you would like to take part then click on this link to complete the online assessment:

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

Or click on this QR code:





When you click on the link you will see a short “consent statement” which you will need to agree to before you complete the assessment. If you have any questions about this part of the assessment then get in touch with me.

You will then see some questions about you, your health and your school. After that you will be able to complete the assessment, which will ask you about what your life is like at school. You 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 you have completed the assessment you will have the option to leave your contact details so we can let you know the results of the study and invite you to take part in any of our research in the future. There is also a prize draw where you could win a **£50 GiftPay voucher**.

You can ask for a paper copy of the assessment if you might find it difficult to complete it online, which you can post back to the research team in a stamped addressed envelope.

Then what...?

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



We would like to tell you a little more about how we are going to manage the information and data you give us, so please read the sections below if you would like to find out more.

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 you?

We will need to use information from you for this research project. The only information we will gather from you will be what you choose to tell us. This will include details where you go to school, and what kind of health condition you 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 your records to make sure that the research is being done properly.

People who do not need to know who you are will not be able to see your name or contact details. Your data will have a code number instead. We will keep all information about you 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 you took part in the study.

We would like to keep different parts of your 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 to other parts of the project you might be interested in taking part in.
- 2- We would like to keep your assessment information for longer so that we can look at your answers with all of the other answers given by other young people in the study.



Your name will not be linked to your answers, so nobody will ever know what you 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 choose to give us your contact details at the end.

What are your choices about how your information is used?

- You can stop being part of the study at any time, without giving a reason, but we will keep information about you that we already have.
- We need to manage your 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 you.
- If you agree to take part in this study, you will have the option to take part in future research using your 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 information is used?

You can find out more about how we use your 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/