



Study Title: PATHWAYS HORIZON

Information Sheet for Children or Young People aged 12- 15 years

Ethical Clearance Reference Number: 25/LO/0251

What is this study about?

We are doing a research study called PATHWAYS HORIZON. PATHWAYS stands for Puberty suppression And Transitional Healthcare with Adaptive Youth Services. The PATHWAYS HORIZON study aims to understand the feelings, health and experiences of young people attending the Gender Services in England and how these change (or not) as young people grow up. If we understand what's going well and what's difficult for young people, we can make the Gender Services better for everyone.

Why have I been invited?

You got this invitation to join the study because you have an appointment with the Gender Service or you've had an appointment with the Gender Service.

Do I have to take part?

No, it's up to you whether you join or not and it won't affect your care in the Gender Service or anywhere else in the NHS. This includes being able to join any other studies run in the Gender Service, if they are right for you.

What will happen if I take part?

You will need to fill in some questionnaires. These will ask about:

- Your feelings and behaviours
- How you feel about your gender and body
- Your relationships with others
- Your daily life with friends, family, school and other activities

The questionnaires will take about 30-40 minutes. You can do them all at once or take breaks. You don't have to answer any questions you don't want to. Just skip those.

You can do this on a computer or tablet, alone or with a member of our team. We can also do this at one of your visits to the Gender Service, over the phone or by video call.



After you finish, you might want to talk about your thoughts and experiences. You can email the research team [\[Insert local PATHWAYS researchers' email\]](#) if you would like to discuss your thoughts and experiences with a researcher.

We'll ask you to complete these questionnaires again once a year, for up to 5 years.

What happens when I have completed the questions?

When you're done press the 'submit' button to send the answers to us. We'll send you directly a £20 voucher to thank you for your time. We'll send you a £20 voucher every year that you complete the questionnaires.

What might be good about taking part?

The information you give us will help us understand how to support children and young people at the Gender Service better. We hope this information will be used to improve care for other children and young people in the future.

What might be bad about taking part?

Some questions might be difficult or upsetting. If you get upset, we can talk to you and arrange for your care team to help. You don't have to answer any questions which make you uncomfortable.

What else will I be asked about?

If you agree to take part in this study, you'll have the option to take part in future research using your data saved from this study.

We're interested in finding out how you're getting on in everyday life. To reduce the amount of information we need to collect from you directly, we'll seek your parent or guardian's consent to:

- Link your data to UK health and education databases, held on secure platforms, once your personal details (e.g. name) have been removed.
- Share your data with other researchers who have a valid research question, once your personal details (e.g. name) have been removed.

In both these instances, your identity will always be kept safe. This data will be separated from your personal details and confidential.

We'll also seek your parent or guardian's consent to contact you about other studies in the future.

- One of those studies is about making a new questionnaire to find out what is most important for young people in the Gender Service.

Please discuss this with your parent or guardian and let them know your views. You can just complete the questionnaires without agreeing to any of the above.



Who else will know that I have taken part in PATHWAYS HORIZON?

Your GP will be told that you're taking part in this research, and if you're under the care of the Children and Young People's Gender Service, they'll also be informed. The questionnaires you complete are routinely used in the Gender Service. To save you repeating the questionnaires, we'll share your responses with the Gender Service, so they can see whether they are helping you and other young people, unless your parent or guardian tells us not to.

How will my information be used?

We'll need to use information from your questionnaires and the Gender Service for this research project. People will use this information to do the research or to check your records to make sure that the research is being done properly. We may need to use information from your medical records for this research, to check any other health conditions for example.

This information includes your:

- Initials
- Name
- Contact Details (phone number & email address)
- NHS Number

People who don't need to know who you are, won't be able to see your name or contact details. Your data will have a code number instead.

King's College London and SLaM NHS Trust are the sponsors of this research, and it is their job to look after your information. We will keep all information about you safe by:

- Following strict rules about the use and storage of personal information, compliant with the General Data Protection Legislation (GDPR) in UK law, to keep the information that you provide safe and private.
- Unless you tell us it is okay to, your information will not be shared with anyone outside of the research team.

We'll tell your GP and clinical team that you are a part of this research. If your answers make us worried about your safety, we may contact your care team, but we'll talk to you first.

The research team may have to share information with your GP or clinical care team if we think that your safety is at risk.

Once we have finished the study, some of your data will be stored safely (without your name or personal details), so we can check the results. We'll keep this type of information for up to 25 years.

We may let other researchers from outside of the UK see your data. If you would like to find out where and how your data will be used outside of the UK, here is some more information:

Your data may be used outside of the UK for research related reasons to:



- Conduct research with others
- Create bigger sets of data to explore other research questions
- Make the impact of the research bigger
- Improve the quality of research on this topic around the world

If this happens, we will only share the data that is needed. We will also make sure people can't tell who you are from the data that is shared where possible. Sometimes, this may not be possible – for example, if you have a rare illness, it may still be possible to know who you are. If your data is shared outside the UK, it will be with the following sorts of organisations:

- Non-commercial research organisations
- Higher education institutions (universities)

We will make sure your data is kept safe. Anyone who sees or uses your data outside the UK must do what we tell them so that your data has a similar level of protection as it does under UK law. We will make sure your data is safe outside the UK by doing the following:

- Some of the countries your data will be shared with have an adequacy decision in place. This means that we know their laws offer a similar level of protection to data protection laws in the UK.
- We use specific contracts approved for use in the UK which give the same level of protection to personal data it has in the UK. For more information visit the Information Commissioner's Office (ICO) website: <https://ico.org.uk/for-organisations/uk-gdpr-guidance-and-resources/international-transfers/>
- We do not allow those who see and use your data outside the UK to use it for anything other than what our written contract with them says.
- We make sure other organisations have the right security measures to protect your data, the same as what we have in the UK. This includes having the right measures to keep your data safe against accidental loss and unauthorised access, use, changes or sharing.
- We have steps in place to deal with any suspected use of your data which is not allowed. We will tell you and applicable regulators if your data has been used in ways which are not allowed when this is legally required. For more information about UK breach reporting rules visit the Information Commissioner's Office (ICO) website: <https://ico.org.uk/for-organisations/report-a-breach>

What are my choices about how my information is used?

You can stop being part of the study at any time, without giving a reason, without your care being affected.

If you would like to stop being part of the study, please tell the team at the Gender Service or one of our researchers.

You have the right to ask us to remove, change or delete data we hold about you for the purposes of the study. We might not always be able to do this if it means we can't use your data to do the research. If so, we'll tell you why we cannot do this.



Where can I find out more about how my information is used?

You can find out more about how we use your information using the following:

- our leaflets: <https://slam.nhs.uk/personal-information-gdpr>,
<https://www.kcl.ac.uk/research/support/rgei/research-ethics/kings-college-london-statement-on-use-of-personal-data-in-research>
- by emailing your local research team:
 - [Insert local PATHWAYS researchers' email]
- by sending an email to the data protection officers:
 - Olenka Cogias, info-compliance@kcl.ac.uk (KCL)
 - Claire Delaney-Pope, informationgovernance@slam.nhs.uk (SLaM).
- by ringing us on: 0207 848 7816

What if something goes wrong?

If you have a concern about any aspect of this study, you should ask to speak to your local researcher team who will do their best to answer your questions [Insert local PATHWAYS researchers' email]. If you remain unhappy and wish to complain formally, you can do this through the local Patient Advice and Liaison Service (PALS) on tel: (insert local PALS tel), email: (insert local PALS email). In the event that something does go wrong, and you are harmed during the research, you may have grounds for legal action for compensation against King's College London and/or SLaM NHS Foundation Trust, but you may have to pay your legal costs. The normal National Health Service complaints mechanisms will still be available to you (if appropriate).

Next steps

Please share this information with your parent(s), carer(s), or another trusted adult.

- If you want to take part, you will need to sign a form to say that you agree to take part. Your parent or legal guardian will also need to sign this form to say that they agree for you to take part.
- If you're not sure, you can talk to a researcher who can answer your questions and help you find out more. To talk to a researcher please email your local research team at [Insert local PATHWAYS researchers' email].
- If you're not ready to decide, you can go to your Gender Service appointment first, if you haven't already. You can take as much time as you need to decide.
- If you don't want to take part, there is nothing else you need to do.

Thank you for reading this information sheet and for considering taking part in this research.