



PATHWAYS HORIZON 'Easy Read' Study Description

Puberty Suppression And Transitional Healthcare With Adaptive Youth Services (PATHWAYS) - HORIZON

Who is this article for?

This plain language study description is for anybody who would like to find out more about PATHWAYS HORIZON and what taking part in the study involves. This 'Easy Read' document is a simplified version of the full scientific protocol, which can be [found on the King's College London website](#).

What is PATHWAYS HORIZON?

PATHWAYS HORIZON is a research study that aims to understand the care needs and experiences of young people attending the NHS Children and Young People's Gender Services in England and how these develop and change with time. The study will last for five and a half years and will explore many life experiences, including quality of life, mental and physical health as well as gender identity. These will be explored with questionnaires completed once per year over the course of the study.

Why is this important?

Gender incongruence is when someone's gender doesn't match their sex registered at birth. It can be very upsetting for young people, particularly when they start to go through puberty, developing signs of adult sex characteristics, like breasts, facial hair and voice deepening. In the UK, there are now many more referrals to gender services than there were 10 or 20 years ago. The young people coming forward today are also different from those in the past, for example, they are often older and more likely to be registered female at birth.

It is not known what medical and non-medical support is most helpful for the young people attending the Gender Services, and which kinds of support and care help which young people. Most of the existing research was done a long time ago, so it doesn't explain how young people experience the care that gender services are offering in the NHS currently, or it includes only a small number of people, and so it isn't helpful for deciding what care is best for young people. The PATHWAYS HORIZON study will provide more information about the young people currently attending the NHS Children and Young People's Gender Services and how their health, wellbeing, and experiences change (or not) over time.

How will the study be done?

This is a longitudinal observational study. *Longitudinal* means that the research follows participants over time to find out what changes and what stays the same. Some young people who join the study early on will be followed for up to five times, over five years. Those who join later may be followed only twice, over two years. The study may be extended after this

funding period to follow young people into adult life, but this has not been confirmed yet. PATHWAYS HORIZON is *observational* because the research itself does not include any treatment or intervention (although many young people will be receiving care in the Gender Services and possibly other parts of the NHS).

Who can take part in this study?

All young people attending the NHS Children and Young People's Gender Services will be able to take part. Their parents/ caregivers will also be asked to take part. If they say it is ok to be contacted, they will be given information about PATHWAYS HORIZON. The researchers are not sure how many people will want to take part but are expecting it will be over 3000 young people (with their parents/caregivers).

To be able to take part, the young person must:

- Be under 18 years of age at the time they join
- Have had at least a first appointment at the Children and Young People's Gender Services

Both young people and their parents/caregivers can complete questionnaires. It is also possible for only young people or only their parents/caregivers to take part.

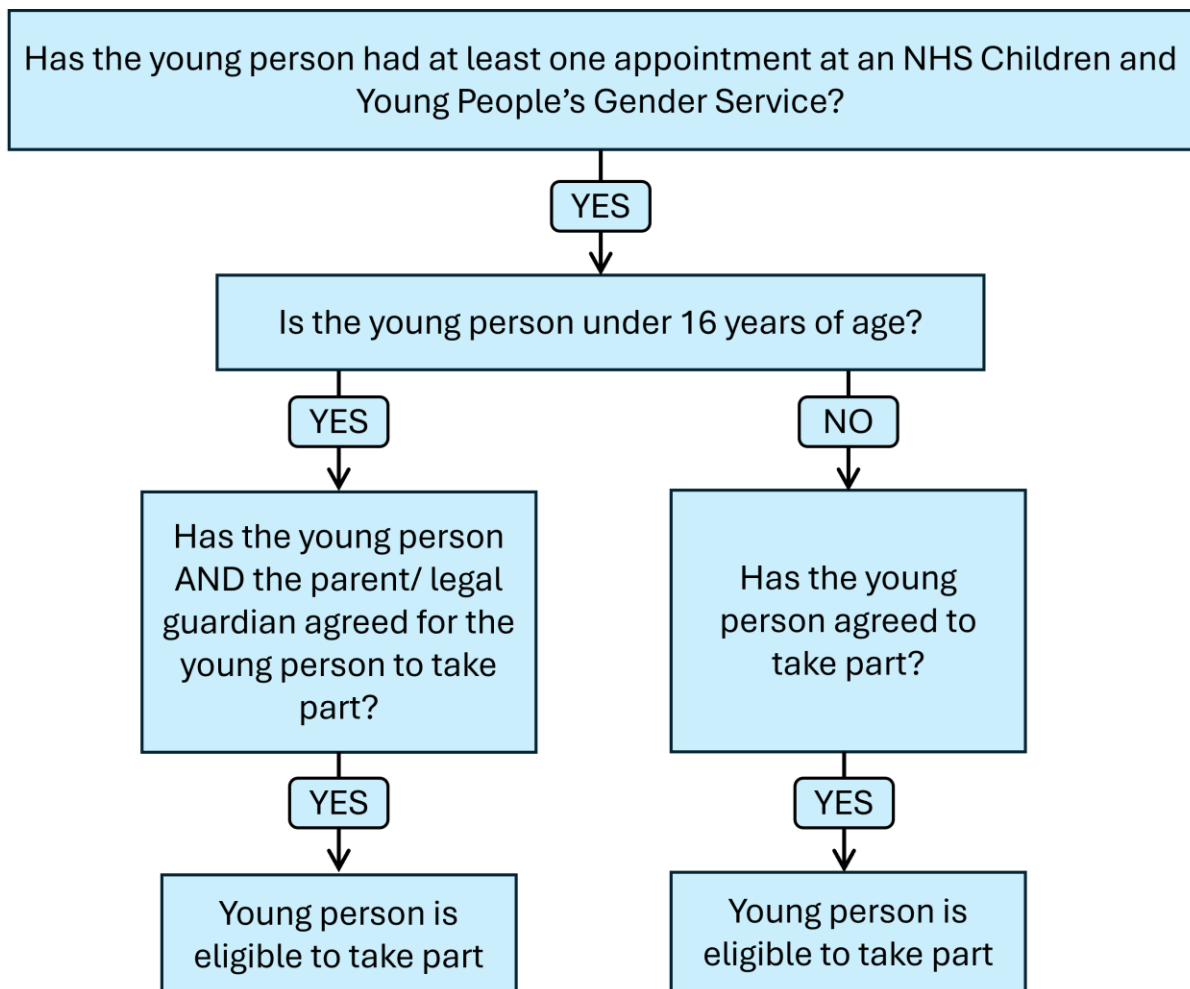
Who can agree to take part?

For young people less than 16 years of age:

- Both the parent/ legal guardian and the young person must agree for the young person to take part.
- The parent/caregiver must agree for themselves to take part.

For young people 16 years of age or older:

- The young person must agree for themselves to take part.
- Both the parent/ caregiver and the young person must agree for the parent/ caregiver to take part.



What will happen if someone takes part?

1. Agreeing to be contacted:

The young person or their parent/caregiver will be asked by their Gender Service if it is ok for a researcher to contact them and tell them more about the study.

2. Finding out about the research:

The young person and their parent/caregiver will be sent information about the study via email.

3. Agreeing to take part:

The young person and their parent/caregiver will be asked to sign a form to confirm that they would like to take part.

4. Time-point 1 questionnaires:

The young person and their parent/caregiver will be sent the first set of questionnaires to complete online, or with the help of a researcher.

They will get a £20 voucher when they complete these questionnaires.

5. Follow-up questionnaires:

The young person and their parent/caregiver will be sent follow-up questionnaires to complete online, or with the help of a researcher. These will be sent once a year.

They will get a £20 voucher every time they complete these questionnaires.

What if someone wants to stop taking part?

If a young person or parent/caregiver no longer wants to take part in PATHWAYS HORIZON, they can stop taking part at any time and they don't need to say why.

If a young person, parent/caregiver, or both stops taking part it will not affect the care the young person gets at the Gender Services, or anywhere else in the NHS.

If a young person is no longer being seen in the Children and Young People's Gender Services, then they and their parent/caregiver can continue in PATHWAYS HORIZON. They can also continue to take part if they turn 18- the study is interested to find out about young people as they enter adult life.

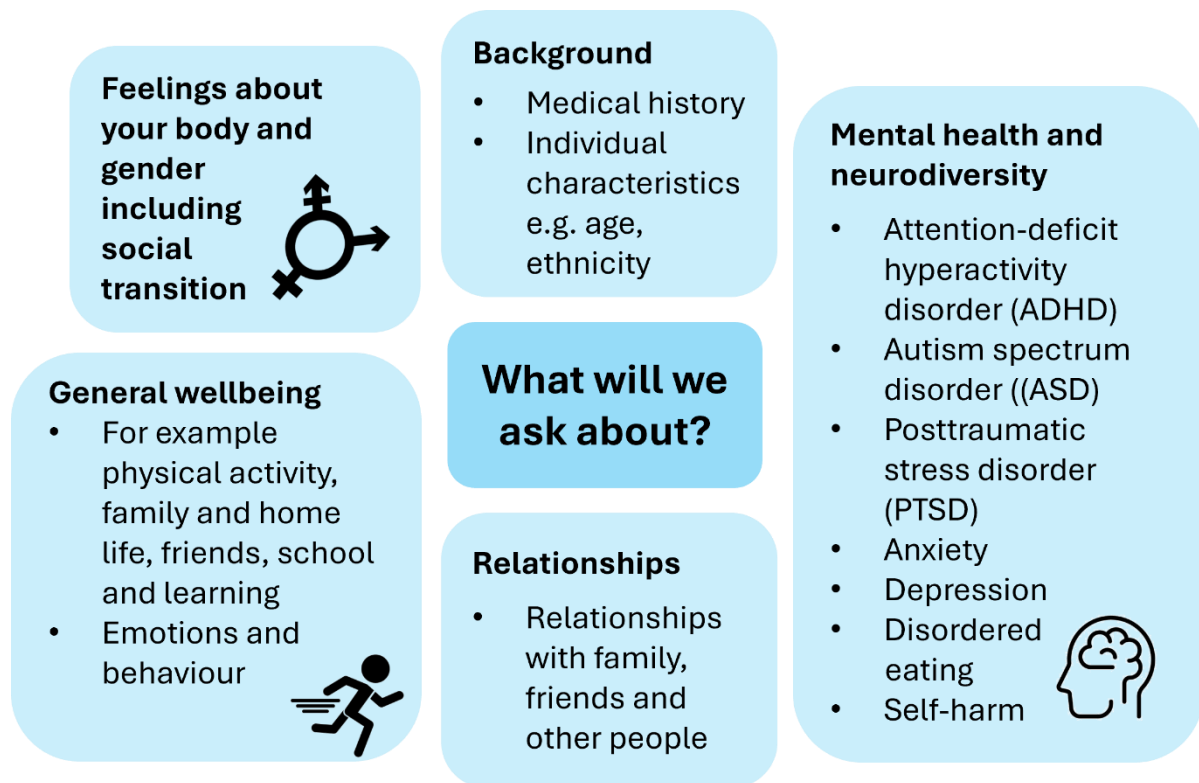
How will the questionnaires be completed?

Young people under 12 years old will complete the questionnaires with the help of a researcher in-person, over the phone, or via video call. The young person can choose how they would like a researcher to support them.

Young people aged 12 years and older and their parents/caregivers will complete the questionnaires online. They can do this on a computer, tablet or phone. Anyone can ask for a researcher to help them complete the questionnaires if they would like extra support.

Young people and their parents/caregivers do not have to answer any questions they do not want to- they can just skip them. They can also take breaks whenever they need. The questionnaires do not need to be completed all at once.

What will PATHWAYS HORIZON ask about?



What else will PATHWAYS HORIZON ask about?

PATHWAYS HORIZON will explore how young people are getting on in everyday life situations. To do this, young people or their parents/caregivers will be asked whether it is ok for the researchers to link their information to UK-wide education and healthcare records. All personal details (e.g. names, contact details) will be removed so that it will not be possible for anyone to know who they are from this information. Young people and parents/caregivers can take part in PATHWAYS HORIZON without agreeing to their information being linked with education and healthcare records.

How will researchers analyse the data?

PATHWAYS HORIZON will describe how young people's wellbeing, mental and physical health, relationships and gender identity change (or not) over time. The study will also look at whether individual characteristics or the type of support a young person receives relates to their wellbeing over time. Right now, it is not known what the results of PATHWAYS HORIZON will be.

Funding and Study Oversight:

The PATHWAYS research study is led by King's College London and co-sponsored by King's College London and the South London and Maudsley NHS Foundation Trust. NHS England commissioned and funded the study in partnership with the National Institute for Health and Care Research (NIHR). The study has undergone a comprehensive review of the science by independent scientists advising NIHR. These include independent academic peer reviewers and NIHR funding committee consideration. It has also undergone review by regulators and received approval from a Research Ethics Committee.

The research is overseen by two groups of people who are independent from the research team and the funders. A Data Monitoring and Ethics Committee will check the data and highlight any concerns they have about the quality of the data (such as the amount of missing information) and any concerns about the safety or wellbeing of people taking part. The Programme Steering Committee will include at least two people with lived

experience, as well as scientists, and will advise on the study's progress overall.