

Lived experience focus groups Summary report



Context

- Among the underpinning principles of the Review is a commitment that:

“The Review will employ different methods to engage with stakeholders in a manner that makes them feel safe and supported and allows quieter voices to be heard” and that “the Review will balance open access methods with more targeted engagement with those closest to or most affected by the services.”

- As part of the formal research programme, the Review commissioned a participative qualitative research study (conducted by the University of York) to capture young people’s perspectives on their journeys, including into adulthood, and their views on how services could and should be delivered in the future. This has been published as an appendix of the final report.
- Alongside the formal research, the Review established an engagement programme which included weekly listening sessions with people with direct and lived experience of the subject, and regular meetings with support and advocacy groups.
- In addition to these regular activities the Review was keen to understand the thoughts and ideas of former, current and potential future service users and to test emerging thinking with them.
- The focus groups took place at a time when the closure of the Gender Identity Development Service had been announced but the new regional services had yet to open. There was understandable concern about where and how care would be provided in future.

About the focus groups

- The Review worked through support and advocacy organisations who already had a relationship with gender diverse young people (identified through an expressions of interest process) to host a series of focus groups / discussion sessions in a supported environment.
- The organisations that hosted groups were:
 - LGBT Foundation
 - 42 Street
 - Proud Trust
 - Gendered Intelligence
 - Mermaids
 - Kite Trust
- This approach was taken to enable the Review to reach the required audience, so that the young people would feel confident to speak freely and to ensure that they could be supported by youth workers before, during and after participation.
- The hosting organisations were required to:
 - Work with the Review team to agree the format, focus and key questions for the sessions.
 - Recruit appropriate participants, in line with the criteria (see participant profile slide).
 - Provide support to participants before, during and after the sessions as required.
 - Facilitate discussions in an open and non-directive way.
 - Compile and submit to the Cass Review team an accurate and comprehensive written report of the outputs from each focus group, including an anonymised profile of participants – age, expressed gender identity, whether they have accessed GIDs, region that they are resident.
 - Attend a meeting with the Cass Review team to discuss learning from the sessions.
- The Review identified three question sets which all organisations would use. While the support organisations could explore additional questions, it was required that the topics/questions put forward by the Review team remained the main focus of discussion. The young people were compensated for their participation.

Agreeing key themes

- A template report structure was provided to ensure consistency of reporting and so that insights from all the discussions could be compared. We also asked for direct quotes to be included.
- The individual reports are published on the [Review's website](#).
- The Review received transcripts from these sessions – these will not be published to protect the identity of participants.
- After the reports had been submitted by the host organisations the Review team hosted a meeting to review the learning and agree key themes – those that were common across the different groups and survey responses.
- The Review then hosted a round table meeting with representatives of the host organisations and some of the young people who had participated in the groups, clinicians from the phase one providers, members of the Review's assurance group, clinicians who facilitated the GIDS service user group and others to explore some of the key insights and consider how to embed the voice of young people into the new services.

Participant profile

- A total of 18 focus groups were held. Two organisations conducted online surveys and several of the organisations offered one-to-one meetings or telephone interviews.
- The participants of the groups were young people with lived experience, i.e., those who identify as transgender, non-binary, gender fluid and/or young people who have been through a period of gender questioning, ideally, but not exclusively, people who have used NHS gender services, or are likely to use those services in the future.
- The aim was for each focus group to engage with between 10 – 15 people, in the age range of 14 – 30 years.
- The Stakeholder and Advocacy groups were asked to record respondents demographic information including:
 - age,
 - ethnicity,
 - geographical region in which they live,
 - gender expression,
 - GIDs use
 - disabilities, neurodivergence and mental health.

Participant profile: Limitations in the data

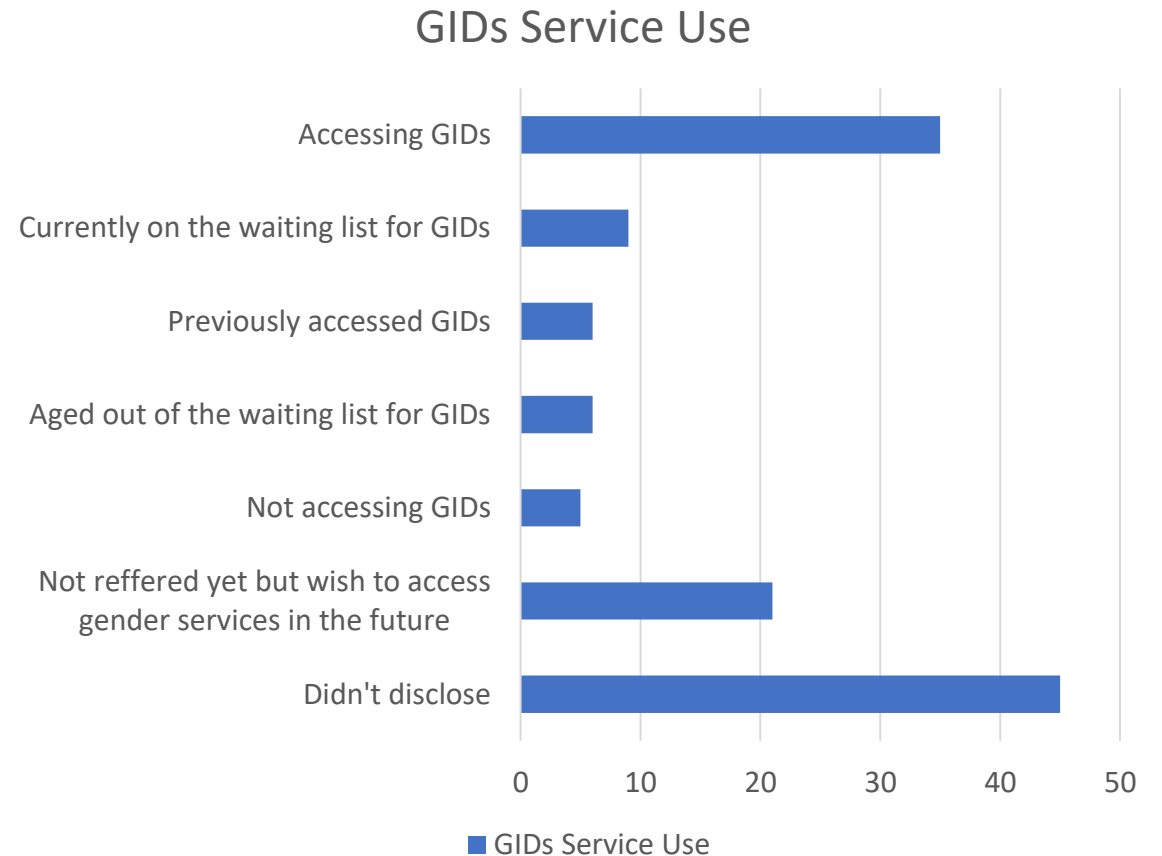
- There are limitations in the demographic data
 - There was a significant amount of missing or undeclared data meaning it isn't possible to understand the participant profile with any accuracy. In the following graphs these have been recorded as 'not declared' this represents an absence of data rather than an active choice of an individual to withhold their demographic data.
 - There was insufficient ethnicity data captured to report with any meaning.
 - Demographic information was captured and reported in a variety of ways with variable amounts of detail. Demographic information was not captured for all the groups or survey respondents.
 - Some host organisations engaged with the same group of individuals across all three focus groups. Other organisations engaged different participants for each of the focus group sessions. This means that the number of "engagement episodes" i.e. the count of people participating in focus groups, is higher than the number of individuals participating.
- There were 127 engagement episodes across the focus groups, 1:1 interviews and surveys

Participant profile: GIDS service use

Data on whether participants had direct experience of GIDs was captured for roughly 2/3 of engagement events.

Of those whose GIDs use was captured:

- 35 were currently accessing the service,
- 9 were on the waiting list,
- 6 had previously accessed GIDS,
- 6 had 'aged out' while waiting
- 5 had not accessed the service
- 22 had not been referred but hoped to be in future.



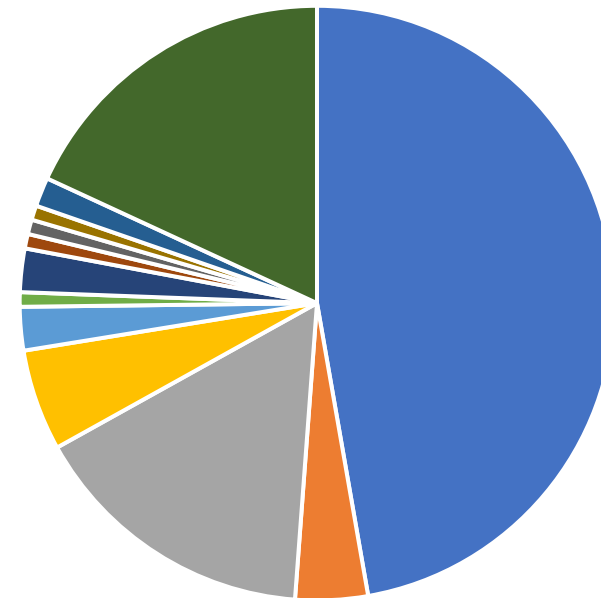
Participant profile: Gender Identity

The data most often captured was the participants self-declared gender identity.

Almost half the participants identified as trans male.

It was noted by a few of the organisations that proportionately only a small number of trans females and femme-identified people participated.

Gender Identity Expressed

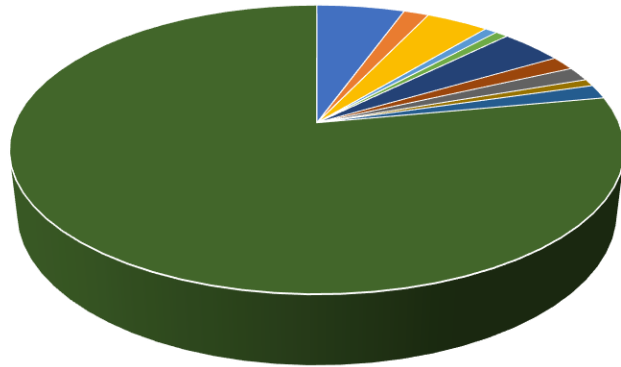


- Trans Male
- Trans Female
- Non Binary
- Gender Fluid
- Transmasculine
- Detransitioner
- Queer
- Demi boy
- A Gender
- Female
- Male
- Didn't disclose



Participant profile: disabilities, neurodivergence and mental health

Disabilities, neurodivergence and mental health



- Autism
- ADHD
- Chronic pain/fatigue
- Multiple disabilities
- Arthritis
- Dyslexia
- Behavioural and emotional
- Depression
- Anxiety
- OCD
- None
- Didn't say

Disability, neurodivergence and mental health was not recorded for many of the participants, However the organisations conducting the groups reported in the feedback session that a majority of participants were autistic or neurodivergent and a high proportion were under NHS care for other conditions/issues.





Overview of key themes

Overarching key messages

- Gender-affirming care needs to be understood as holistic, personal and sometimes complex. This may comprise a wide range of interventions and services, some of which can be delivered outside of specialist services.
- Participants identified a gap in provision of non-medical support. More support around gender expression, social transition, and exploration is wanted – particularly to avoid exclusion of people who are questioning or exploring their gender identity.
- The waiting list is driving people to turn to private healthcare or unregulated sources for medication. Waiting lists need to be reduced significantly so that young people can receive effective care.
- Participants felt very strongly about the need for better communication and support during waiting times and identified that much of the emotional, physical and social support they needed was not met by gender or wider NHS services.
- The transition to adult services can be problematic, some participants suggested having an overlap service for 16–25-year-olds. Some participants queried whether it was necessary or helpful for gender care to be divided by age. It was suggested that this posed an unnecessary barrier to accessing care and seemed like an unnecessary division.
- Increased joint working must be established between local healthcare and gender healthcare services. It would be beneficial for GPs to take on shared care, supporting the administration of HRT and blood tests to avoid unnecessary travel/time constraints/accessibility issues and burdens on the gender healthcare services.
- Participants felt that medical professionals often lack appropriate knowledge and need better training about how to work sensitively and effectively with trans, non-binary and gender questioning young people. Increasing trans visibility, including having trans and non-binary people within the workforce would help support better relationship building and understanding of how to work with trans and gender questioning young people.
- Young people struggle to find trusted sources of information, favouring lived experience accounts over news. Participants would like to see better resources from the NHS that they know they can trust and would be trusted by their parents.
- Resources should be provided for parents, carers and families. Participants particularly wanted the labour of ‘educating parents’ to be removed from them through direct provision of physical resources like leaflets and packs, and the option for parents, carers and families to attend in-person peer support groups.
- Being trans/transitioning should not be considered a negative outcome. Clinicians need to be non-judgmental, respect the young person’s sense of themselves and be open to any and all outcomes. They should ask the young person what they want to achieve from the service.



Session one: Past and Current experiences – themes and quotes

The question set explored participant's views and understanding of gender services based on their own experiences. The questions explored were:

- Why would you / did you go to the NHS for gender-related care?
- What do you think the purpose of assessment in the gender clinic is?
- Is it important to you to have a diagnosis of gender dysphoria?
- What do you think having a diagnosis means in relation to: them personally; parents, family members and carers; healthcare; school; socially?
- What do you expect from the clinicians in the service?

Overview of key themes – Session one

Accessing NHS services

- The NHS is trusted provider of healthcare generally (and especially for parents.) The NHS has the ability to provide shared care / continuity of care. It is free [at the point of care].
- The decision to access private services is presented as a forced choice (because the NHS provision is not accessible in a timely way) rather than a preference. This may be regulated or unregulated sources. It is a significant financial burden and not in reach for many.
- There is no support while people are on the waiting list and no communication of where they are on the “wait journey” – signposting to sources of support and trusted information would help fill this void.

Expectations of clinicians

- Clinicians should have a holistic approach to supporting trans and gender questioning people.
- Clinicians throughout the NHS should be aware of the different services available for gender questioning young people.
- Experiences with GPs are inconsistent and can form a barrier to accessing Gender Services. This may be the first discussion they young person has had with a professional and was largely reported as a negative experience which put people off accessing other care.
- Experiences of CAMHS was very varied and seemed quite dependent on the personal views of the clinician.
- Services and clinicians need to be accessible to autistic & neurodivergent patients.

Overview of key themes- Session one (continued)

Assessment

- There is not a clear understanding of the purpose of assessment, some people believe it is a space to explore while others see it as a barrier to get what they need/want.
- There is a perception that disclosing other mental health issues or trauma would be used to discredit the person's sense of identity. This leads to some people actively not seeking help with their mental health or hiding mental health issues. People feel they can't be honest with their counsellor / health professionals.
- People described the sense that they need to play a role and manage services to get what they need. The system is/ treatment options are very binary and this is particularly an issue for non binary people.

Diagnosis

- There are mixed opinions on diagnosis, for some it is personally important and for others (majority) it feels unnecessary.
- Some consider diagnosis helpful for wider acceptance for the child, young person from parents/families/carers and necessary to access treatment.
- The notion of differential diagnosis concerns people and is viewed as an attempt to find 'any other reason' for the person's distress rather than them being trans. They strongly feel that clinicians should not be actively looking for reasons to "excuse away" how the young person feels. Being trans / transitioning should not be considered a 'bad outcome'.
- Services should be mindful of the level of influence that parents/families/carers have over young people's care, especially for older adolescents.

1.1 Why young people go to the NHS for gender related care

Key themes

Why they seek care:

- To get help / support for gender dysphoria and to have a space to explore their gender identity what action is right for them.
- To build confidence and feel happier and more confident.
- To access gender-affirming medication

NHS vs Private:

- The NHS is trusted provider of [free] healthcare generally (and especially for parents). The NHS has the ability to provide shared care / continuity of care (although this currently this is not happening effectively).
- Extensive waiting lists are the main thing that put people off accessing NHS gender care.
- Private care (which could be regulated or unregulated) would be preferred by some (quicker and easier access) but is not an affordable option for all.
- There is a lack of choice, even in the private sector – if there were more options people may have gone elsewhere.

In their own words:

“I would want to use a gender service to be able to make sure I know exactly what I want when knowing whether I want to transition.”

“To be able to feel more confident in myself and more happy with my body and who I am”

“The fact that I’d feel more like myself would be the main reason.”

“In my case, social transition was a lot more important to me initially, but medical transition was definitely an intended part of my journey. I needed the validation from the GIDS to almost “prove” that I was trans to the people around me.”

“Wanting to get on the list so if you want trans care in future it’s less far away”

“Because the NHS seems like a trustworthy and safe option”

“It is accessible to everyone it is free and also the public sector need to be supported.”

“So I think part of like the main reason was like the NHS is seen as quite, legitimate, like it's got a lot of, regulations and especially my mom, it's a bit of a minefield with, you know, a lot of misinformation and kind of stuff about you know, giving hormones to like 5 year olds and stuff. So I think she was just a bit worried about, something that wasn't properly like regulated.”

“I’ve been on the waitlist for GIDS since 2017, had my first appointment this year (2023) only to be told that I’d have to wait another year-ish to get adult services, then another 6 months for any real treatment. I’m now trying to raise funds for surgery privately because the wait is too long”

“I would go down private route instead if I could.”

“It’s too expensive to go private and it’s easier to get onto a waiting list for it and also most things are through NHS.”

“I don’t have the money to transition privately of my own free will.”

1.2 What young people think the purpose of assessment in the gender clinic is

Key themes:

- There was a general lack of understanding about what the assessment was for and confusion about what was assessment and what was diagnosis. Thoughts on the purpose of assessment included:
 - To support young people to explore their options and access the care that’s right for them
 - To get validation in their trans identity
 - To make the person comfortable and focus on what they’re looking for from the service.
 - Ensuring patients have an understanding of the healthcare options available.
- While some participants felt that the assessment process should be to support young people to explore their options and access the care that’s right for them , others expressed the view that assessment is a means to an end – a step you have to go through in order to access medical treatment.
- Many participants saw the current assessment process as gatekeeping which was there to protect the service rather than help the individual. Several participants described how it felt like you have to “prove” how trans you are.
- A number of participants described the difficulty in accessing care if you do not identify as strictly binary male / female and commented on a sense that you need to give a specific narrative or play a role and hide various aspects of yourself in order to receive treatment.
- Several participants commented that the assessment process is too drawn out, particularly having waited so long to be seen by the service in the first place.



In their own words:

“I think the purpose of the assessment is supposed to be to help you figure out what you want from health care.”

“The purpose of assessment in gender clinic is to determine gender / social / medical, (physical and mental) history.”

“To gauge what pathway you should go down in order to achieve a better quality of life or to be able to present yourself correctly.”

“To help determine and figure out an individual's relationship with their gender and what services they can provide to...help them feel more comfortable in their body....and help use the resources that are available such as hormone therapy and gender affirming surgeries or even helping to figure out the process of socially transitioning.”

“Everyone's needs are different and I think having an open space where it's patient focused and patient-led is essential.”

“I think the assessment should focus on how to make you comfortable, not about whether you’re trans or not because nobody would spend 5 years on a waitlist just for the giggles, and it’s obvious if you get to that point that you’re serious”

“[Assessment could include] trying different clothes pronouns exploring feelings be able to experiment using gender dysphoria devices such as binders or packers or whatever the assessment should be.”

“It should be to help explore gender and expression fully and decide on a transition pathway. Currently it is to diagnose gender dysphoria to prove you're trans at all.”

“Essentially I felt at the time that the purpose of assessment was to sort of scrutinise me and see if I was, quote unquote, really trans...if I was the right sort of trans to be allowed medical intervention...It definitely felt like the purpose was just to kind of hold up hoops for me to jump through”

“You should be finding out with clinicians who you are but instead you’re proving who you are [that you’re trans] to clinicians, not working with them.”

“I even lied about liking girl’s toys as a child, as I felt it would delay treatment. It likely wouldn't have delayed anything but it felt like I had to be perfectly exactly masculine.”

“I'm not fully trans to FTM or MTF...if you're anywhere in the middle, it's a lot more difficult, I think.”

“I felt like I had to perform my gender in an exaggerated way...be male in a very narrow definition of male.”

1.3 Importance for young people and their families to have a diagnosis of gender dysphoria

Key themes:

- There were mixed views on how important it is to have a diagnosis of gender dysphoria.
- Perceived benefits included that it could bring more assurance on whether to transition and can be personally important and validating for the individual.
- For some, a diagnosis was useful to help support explanation to, and acceptance by, families.
- However, the process to get a diagnosis can be distressing and can be a lengthy process.
- Some describe fear or direct experience of ableism, where the presence of other mental health conditions has been a barrier to accessing gender-related care.
- ‘Differential diagnosis’ is understood by some to be trying to rule everything else out until the only answer is that they are really trans (which they believed some clinicians see as a negative outcome). This leads some people to try to hide other conditions.
- There was also some criticism of diagnostic criteria, particularly as dysphoria can manifest itself in so many ways that strict criteria is hard to define. The subjectivity of the diagnostic criteria was questioned with a view that diagnostic criteria were based on outdated stereotypes.

In their own words:

- “I think that it’s important to make sure that’s DEFINITELY the route people want to take, however it can be frustrating because some trans people don’t feel MUCH dysphoria but still know they want to go through with it”
- “Can be comforting/ validating.”
- “Having a diagnosis helps me look into it and have a better understanding of myself.”
- “It helps to ensure people are sure they want to transition and aren’t going to regret it later on, however it slows your transition down as they are very strict with it and it is also the step that takes the longest to complete”
- “It is a good thing because then solutions can be made. However, the way that it is diagnosed is important so that dysphoria is not increased. It is important to be able to make sure people are safe and mentally well”
- “I don’t care personally, but it is important to me that medical professionals understand that I require gender-related medical care, and that diagnosis can function for that. I would prefer that the diagnosis is not a prerequisite for care.”
- “I’m sure it’s important to different people personally but I don’t think it should legally be important.”
- “I think as long as informed consent is given then a diagnosis of dysphoria could be forgone because people’s incongruence can manifest in ways that wouldn’t medically be classed as ‘dysphoria’ I think it’s very subjective and if you’re landed with a bad doctor then they could be the barrier between transitioning and not”
- “Having a diagnosis doesn’t make you “any more trans” than someone who doesn’t.”
- “Some questions [in the diagnosis criteria] are based on old stereotypes of what it is to be trans, it doesn’t feel up to date.”
- “[Educational institution] asked me to get an autism diagnosis so that I can get extra help but I have been refusing in case it affects my ability to transition”

1.4 What young people expect from the clinicians in the service

Key themes

- Participants expected clinicians to display compassion, understanding, and validation and to treat them as an individual, understanding that people will want to transition in different ways – there isn't one way to transition. Some commented that there needs to be more acceptance and understanding of non binary identities.
- Young people want clinicians to listen to them, respect how they feel and work with them to work through their feelings and options. There is a sense that some clinicians may try to convince the young person not to go down a gender-affirming route.
- Medical professionals often lack appropriate knowledge. There is a need for all clinicians across the NHS to receive better training about how to work sensitively and effectively with trans, non-binary and gender questioning young people.
- Clinicians working in gender services should be specifically trained in trans healthcare and have a good level of knowledge about options and different ways to transition.
- Several participants suggested having gender diverse people in the clinical workforce of gender services who will be able to better understand what they are going through and share their own experiences.
- There is a need for clear, open, honest and accurate communication with particular consideration given to providing accessible information including for those with autism and neurodivergence.



In their own words:

"The staff have to be educated and polite and understanding that not everyone is the same or wants the same in terms of care."

"Openness, complete honesty and high levels of communication at all times. However, while clinicians ought to be patient, I would urge them to beware of "babying" patients as everyone deserves respect and autonomy."

"The clinician should be facilitating not dictating, 'I don't know you, you know you and you know what you want.'"

"They should ask what you want to achieve from the service"

"You should be finding out with clinicians who you are but instead you're proving who you are [that you're trans] to clinicians, not working with them."

"To be accepting of who we are and also giving the same level of service as a cisgender person and using the correct name we go by"

"Clinicians should use my name in an affirmative and supportive way, not just by stating my 'preferred name' or avoiding deadname, but by using my name in conversation and making me feel validated. It makes me feel comfortable and understood."

"I'd expect for them to be compassionate and understanding - to listen without an intention of conversion or convincing me not to go down a route of gender affirming healthcare."

"People who are specifically trained in trans healthcare and not people who happen to practice it"

"I'd expect them to be much more accepting than other doctors typically are, maybe for some of them to actually be trans too"

"[If there were actual gender diverse people and different representations being able to share their experiences] clinicians were saying] there's something wrong with me, we're going to figure out what's wrong with you' rather than 'here's all the options, let's figure it out together."



Session two: Future services – themes and quotes

The question set explored participant's thoughts on how services could/should operate in future. The questions explored were:

- How important is the location of the service?
 - What is important in relation to the environment of the clinics?
 - Would you prefer a hospital or community location for the service?
- What do you see as some of the challenges for the new services?
- What ideas do you have to address those challenges?
- Are there any aspects of the current service you think should be built into the new services?
- Do you have a sense of the type of support or treatment you would personally like be offered?
- Do you have any suggestions about what the services should be called?

Overview of key themes- Session two

Location and environment of service

- Generally, young people would prefer a community venue over a hospital setting. Community venues are considered more welcoming than formal clinical / hospital settings, but some participants felt that a more formal setting would make it feel safer and may be more practical.
- Accessibility is important with links to public transport a key consideration.
- Long travel times and the costs of travel acted as a barrier to care. The financial impacts of having to travel long distances to appointments were worsened when appointments were early in the morning, sometimes necessitating a costly overnight stay.
- There was some concern about the safety of the location, sometimes driven by experiences of being caught up in protests against services.
- Consideration needs to be given to make the internal environment as relaxed and youth-friendly as possible with suggestions of having LGBTQ+ reading materials, plants, artwork, comfortable seating and non-harsh lighting to promote a welcoming atmosphere and reduce anxiety.
- The spaces should also be age-appropriate, recognizing the need to be suitable for younger children and older adolescents.

Overview of key themes- Session two

Challenges and ideas for the new service

- The waiting list was the main barrier to care cited. Unless there is effort to address this the problems caused by the waiting list will persist. Action that could help includes being transparent regarding the current waiting times and better communication with those who have been referred. Some suggested that having a mixture of in person, online and telephone appointments could free up some clinical capacity to see more people.
- The nature of the public debate has had a direct and largely negative impact on these young people and has also influenced how parents view the service and the issues being explored. Services should proactively respond to this and be a source of reliable, trustworthy information, particularly for parents.
- There is currently a trust deficit towards NHS gender services. Having clear, non-judgmental information about what the service does, what people can expect and improving communication, resources and sources of support for those waiting to be seen would be a step towards rebuilding trust. This includes resources for families, parents, and carers.
- The wider clinical workforce needs to know about the services, how to refer and what they can do to support the young person in the interim. It was suggested that greater trans visibility - having trans people engaged in the workforce, pronoun badges, building lived experience into training sessions – would help raise awareness of the issues and support better relationship building and understanding of how to work with trans and gender questioning young people.
- GPs are not consistently supporting referral to specialist gender care or entering into shared care arrangements with private providers. This is not people's experience when shared care is needed around other conditions and is viewed as transphobia.
- There are mixed experiences of CAMHs, there needs to be a more consistent approach and CAMHs staff need to be trained specifically on working with gender questioning and trans young people.

Overview of key themes- Session two

Treatment and support

- Gender-affirming care needs to be understood as holistic, personal and sometimes complex.
- It needs to be understood that everyone identifies in a different ways and there is not only one path or one way to transition, the service and treatment options need to reflect that.
- Participants do want access to counselling and spaces to openly explore their gender but this should be alongside, not instead of the option to medically transition.
- For those who are considering a medical transition, there is a strong sense that the NHS should facilitate that but a recognition that there is a need for better information on which to base decisions/consent.
- Gender care shouldn't only be considered "specialist" there are a range of interventions that young people have found helpful in reducing their dysphoria, e.g. support with periods, that can be managed at primary care level.
- There is a gap in provision for those who are exploring / questioning but unsure of what they want. Young people are currently having to do it on their own due to the wait to access services and when they do get seen by the service they feel they need to present exactly what they want (which is currently a binary option currently).
- Ideally people would want to be able to access a range of services under one roof including access to mental health support, advice on binding, voice coaching, laser hair removal and fertility preservation.
- Clinicians working in gender services should have an understanding of the needs of people with autism and neurodiversity and adapt their approach and communication accordingly.

2.1 Importance of the location of gender services for young people

Key themes:

- Gender care needs to be available in more accessible locations. Participants explained that going to clinics in London or Leeds was not possible for lots of people, and that gender care should be available at local healthcare settings. They argued that limiting gender care to a small number of specialist clinics was an unnecessary separation of gender-related care from other aspects of healthcare and made it difficult to access.
- Generally, community-based locations are favoured over formal hospital settings, although there were mixed views on this. Some of this appears to be related to perceptions of community vs hospital settings:
 - Community spaces are seen as more versatile and accessible to a variety of different needs and experiences.
 - Community venues are considered more friendly and less intimidating.
 - Hospital settings can feel quite clinical but may be necessary to have a wider service offer and some suggested a formal setting could feel safer.
 - Hospitals are more associated with physical interventions which some participants did not feel they needed.
 - Some participants felt that hospital settings encourage an over medicalisation of trans identities.
- Geographical accessibility of the service is important particularly for those living in more rural areas.
- Travel time, ease of journey and access to public transport links were considerations in accessing care.
- A combination of face to face and virtual appointments would be useful and reduce the cost and time of travel (although virtual appointments are difficult for some people).
- It was highlighted that having a combined approach with local services would be very beneficial. The need for local healthcare to undertake shared healthcare provision.

In their own words:

“It would be better if there were lots of local places to visit, with a bigger central location in London.”

“Similar to Canada’s services - local services can assess and prescribe for simple cases, more complicated cases can be referred to a larger more central service.”

“I don't think it's that important as long as it's accessible and comfortable for people.”

“A more relaxed community setting would be less stressful, but a clinical setting would make it feel more ‘proper and safe’.”

“I prefer community location for under 18 services definitely, because for me, at least I didn't have any medical stuff to do with the Tavistock, in terms of like you know, physical medicine.”

“Going to a hospital setting would have felt like I'm being cured of something rather than supported through a change.”

“A clinical setting is more practical, but far less comfortable. This setting is too formal and makes folks less likely to feel able to express their own feelings which can be quite difficult.”

“Maybe close to city centres, which are often easier to get to since local public transport goes directly to these places.”

“Some appointments were longer but when it was a short quick one it felt like such an effort and drain for little result, it made my transition feel more difficult.”

“That appointment could’ve been on Skype. I didn’t have any questions [...] I travelled hours for a 10-minute check-in appointment.”

“I don’t feel comfortable doing my appointments over zoom – so location becomes a big barrier to me as I don’t have an alternative when it’s a long journey.”

2.2 How young people would want the environment of gender services to be

Key themes:

- Young people described how they would want gender services to be an accessible and inclusive space, that is age appropriate with a welcoming atmosphere through affable staff and inclusive signage.
- If in a medical setting, there needs to be understanding that these spaces can be triggering for some, and attention paid to creating a more calming environment.
- The waiting area is important to put people at ease with suggestions of having LGBTQ+ reading materials, comfortable seats, and more relaxed layouts. Clear signposting and advertising for related community support groups of activity would also be welcomed.
- Lighting is important – use warmer, less bright lighting to make people feel more at ease.
- Physical access to the clinic was discussed. Several participants commented that having to use a buzzer to access the space was intimidating but others reflected on the need for the clinic to be safe.
- Participants also suggested having service user input into the design of the clinic environment.

In their own words:

"Somewhere where you feel supported and very much at home kind of because this will be a place where you'll most likely be going quite a lot of times and you wanna feel comfortable and feel like you belong there, so maybe a lot of flags [and] a lot of different art"

[The service should be] "a place that feels like it's there to support you rather than "fix" you."

"They have to be easily accessible, well signposted and not hard to find, smiling, friendly supportive staff like receptionists and such would be good too. And not too bright lights in the waiting room."

"Having these things in the waiting room would help me to destress even though these appointments are great there's a lot of anxiety around also just to keep preoccupied."

"Separate seats — like not sofas but singular chairs because in some waiting rooms you have to sit on sofas with strangers."

'[I want] the [service] space not to feel like you're walking in and being told what to do and where to sit'.

"Accessible like with lifts etc would be useful and away from a noisy area or good at cancelling out background noise."

"You want them well to make you feel like you're safe. I want them to wait for me like okay, I can go in and say how I feel and explore if this is what I want and be heard. So, it has to be somewhere spacious as well, so you don't feel kind of trapped."

"Somewhere bright and colourful, somewhere bright and vibrant."

"Kind LED lights Yeah... so it's not quite as harsh and clinical."

"Clinics maybe more accessible so you can show up and get info instead of it being so gated e.g. I had to phone through to get into the building my appointment was in."

"On the outside, maybe not make it obvious it's for trans people since some people don't want others knowing, so it allows some kind of privacy to others."



2.3 What young people see as some of the challenges for the new services and ideas to overcome them

Key themes:

- The waiting list is the main issue cited. Unless there is effort to address this the problems caused by the waiting list will persist. This includes transparency regarding the current waiting lists and better communication with those who have been referred. Also having a mixture of in person, online and telephone appointments.
- The transition to adult services can be problematic, some participants suggested having an overlap service for 16–25-year-olds. Some participants queried whether it was necessary or helpful for gender care to be divided by age. It was suggested that this posed an unnecessary barrier to accessing care and seemed like an unnecessary division.
- General perceptions of gender in wider society and instances of transphobias is having a negative impact on the young people. It also impacts the views of parents. Participants suggested that the new service will need to proactively respond to this through being a reliable and trustworthy source of information for parents.
- There needs to be training and awareness raising among wider workforce. Clinicians don't always know about the service or how to refer to it and young people often experienced a reluctance to engage with the young person about their gender identity.
- There were mixed experiences of engagement with CAMHS with several participants commenting that experiences very much depend on the individual clinician with some with some described as supportive while others were considered openly hostile.
- Reluctance for local GPs to undertake shared care for hormone injections/blood tests etc creates additional access needs. Young people are forced to travel to the main hubs to get routine checks done which is costly, time intensive and presents accessibility issues.
- To encourage the uptake of any education initiatives amongst practicing medical staff, it was suggested that this training was a mandatory part of CPD and that GP practices could have financial incentives for putting themselves forward for additional training on the healthcare needs of trans people.
- Participants suggested that people with lived experience of GIDS or experiencing gender incongruence more broadly should be involved throughout the design and monitoring of the new service. This could involve co-production groups or regular collection of SU feedback.

In their own words:

"For me the biggest challenge is still gonna be the waiting times. I think that will always be the biggest issue and that will have the biggest impact as well"

"We need support during the wait time, I've been waiting 3yrs and I've heard nothing and it's been like awful."

"Communication...both within the team and between patient and clinician... there's so many...stories [of poor communication]."

"These appointments should be available in a mixture of in person, online, phone calls to allow maximum flexibility and comfort for those accessing the service."

"Having more centres where these services [GIDS] can be obtained, it allows for easy and quicker appointments and reduces transportation cost."

'The whole of the service, from questions to environment in general, felt very designed for kids. Leading to 16–18-year-olds feeling like they were falling in-between the cracks.'

"The issue about not having any services for 16-27 year-olds could be solved by having an overlap, so the young people's clinic goes to age 25, and the adults starts from 16, for example, and people switch from the young people to the adult clinic whenever it seems like the right time in that time frame. Alternatively, a third set of services for older teenagers and young adults, say 16-25 year-olds."

"I think for a lot of people there will be an uphill battle with patients trusting the clinicians. Many of us who went through the system do not trust the next one to come so easily, and often warn younger people what to expect."

"Transphobia isn't just existent in strangers, it's also there within families and friends. Transphobia will always be a barrier, but we need to take steps to make sure people can access services in a way that trans people can be protected."

"What would be really helpful is if a specialist gender service could offer support to GP practices. It would be really good if there could be some guidance on what families can do while they are waiting."

"You can create the perfect service but if you don't spread awareness of it, people won't refer you to it."

'you shouldn't have to fight against the system to get the basic thing you need, just to even talk to someone' 'it's been made really difficult to reach the point where you can even talk to someone who knows about it [trans people/gender dysphoria]'

'I had two appointments at CAMHS. The first clinician I saw decided that I wasn't "ready" to be seen by GIDS and it took seeing a different CAMHS clinician who let me be referred to the GIDS waitlist. I should've been referred to GIDS by my GP and not CAMHS, that added a huge delay and meant that I never got to the top of the GIDS waitlist.'

"Don't just focus on the suffering of trans people see our joy in being able to live as ourselves"

2.4 Aspects of the current service young people think should be built into the new model

Key themes:

- There were few elements of the model that participants felt should be built into the new services
- The main point made was that NHS provision of trans healthcare should be maintained.
- Utilisation of existing services like family support, gender education, and mental health resources is recommended.
- Continuing routes and building on communication between the current and new services for patients.
- The practice of counting time waiting for the GIDS service when referring on to adult services is appreciated and should be maintained.
- Referral routes into services should be expanded not contracted.
- Telephone calls and online appointments to increase accessibility, reduce travel time and costs.

In their own words:

“There were no elements of the current service that our focus group agreed should be built into the new services.”

“Education services that children and parents can attend together, and pronoun badges on workers in every professional setting.”

“Not an underground topic that seems to be hidden away or not talked about, more openly talked about”

“I think the idea of a gender specialist isn’t entirely bad or wrong. I think there is a use for them, but they shouldn’t be the only way to access transition care, they should work side by side with medical transition care, not as a blockade to it.”

“Calling by phone regarding appointment for gender treatment should stay in place as an option as some may not be able to come in person or feel anxious.”

“I think it’s more important to have the people who need the service get it rather than gatekeep it to such an extent that no one can actually use it.”

2.5 The type of treatment and support young people would like to be offered

Key themes:

- Gender-affirming care needs to be understood as holistic, personal and sometimes complex. It needs to be understood that everyone identifies in a different ways and there is not only one path.
- Participants do want access to counselling or therapy to tackle challenges related to dysphoria, mental health, and societal pressures and spaces to openly explore their gender but this should be alongside, not instead of the option to medically transition.
- Participants queried the definition of, and focus on, ‘specialist gender services’, explaining that gender-affirming care may comprise a huge range of interventions and services. One participant reported being given hormonal contraception as they found menstruation distressing.
- It would be helpful to able to access a range of services under one roof including access to mental health support, voice coaching and laser hair removal, fertility preservation.
- There is a need to address the specific needs of teenagers through age-tailored services.
- A broad range of supportive and impartial information (including for parents / carers), the chance to ask for information anonymously, and proactive communication.
- Gender services should be aware of community groups and charities that provide safe spaces and support whilst on waiting lists.
- Clinicians involved in this care need to have increased understanding of autism especially given the significant overlap between neurodivergence and trans identities, and the interplay between the two. In addition, gender healthcare services need to be more disability inclusive as a whole and welcoming to all.
- Many participants highlighted how important medical interventions were to their care including puberty blockers, hormone therapy, and surgical options (see next slide)

In their own words:

“Personally, I would love holistic and inclusive care at the new GIDS centres. I would like to have the kind of care that I can without thinking twice recommend to someone struggling with the same thing.”

“I’d say overall support and a clear understanding that everybody identifies in a different way and it affects everybody differently. So that kind of, the way you feel is valid, the way you experience and go through life is valid, and that kind of overall support system and how that can better you as an individual.”

“Community groups, mental health provision that takes into account a whole person, not just one identity or condition, gender care that supplements big decisions like surgery, instead of being an alternative.”

“Deeper discussion of gender expression”

“Having no judgement and fully understanding that trans people can have issues without them being association with being trans.”

“I would like to see them include services for people to adjust their lifestyle to be gender affirming.”

“I just want to have people who understand me to talk to, be able to take medication to stop certain puberty things happening and for it to be easy to access for me and everyone else.”

“A gender focused therapist that you can actually talk to about whatever feelings to have around gender and your body, without the implication that if you aren’t the text-book binary trans person they prevent you from getting hormones.”

“Counselling and support to gender questioning younger children.”

“Something that’s actually been helpful was when I first went there [to the GP], she did put me on the pill, which was helpful.”

“I personally would like to be placed in a group of people that are going through similar treatments to feel less alone.”

“Support in working out what sort of care I’d like best, talking through available options with an unbiased, nonjudgmental professional.”

“GP specialist -- maybe a GP that has more emphasis in gender services and can advise other local GP practices. This GP can also advise where more training is needed.”

“I think autism makes it easier for you to recognise you are trans because you struggle with social cues and gender roles are part of that so you know you are trans it’s not just being gender non-conforming”

2.5 The type of treatment and support young people would like to be offered – medications

Key themes on medications

- Several participants were very clear about their need for medical transition and felt this should be facilitated by the NHS.
- Puberty blockers are seen as providing time to think without the anxiety of the impacts of puberty on your body.
- Going on puberty blockers shouldn't mean that / be seen as you are automatically on a pathway to gender affirming hormones.
- A number of people commented that there needs to be more knowledge about the risks of puberty blockers so that individuals can consent to known and unknown risks.
- Several participants mentioned the need for better shared care including in monitoring blood tests but cited their personal experiences that GPs are reluctant to enter into shared care arrangements, particularly with private providers.



In their own words:

“I just wanted to get my bloody hormones, that was what I was there for, that’s what I wanted, that would’ve been my therapy, all my distress was related to needing to get on hormones and I was expressing this, I had a trans history, I was clearly aware of what I wanted and what care was on offer.”

“I want hormones, I have wanted hormones for a couple of years. Eventually I would like surgery.”

“There's so much anxiety around the ticking clock of puberty- so there's a strong need for blockers to prevent hormonal changes that could happen at any time.”

“Why would we ask for blockers if we really genuinely want HRT? We ask for blockers because we want time before deciding about HRT or typical puberty etc.”

“More neutrality around blockers- this is not a gateway drug to HRT automatically. This is a neutral pause so we can figure things out before permanent changes happen.”

“More specific knowledge around risks for blockers, something that can be discussed by individuals so individuals can consent to known and "unknown" risks.”

“I have ADHD and my GP is compliant with shared care testing around blood tests so I can get my ADHD medication. But they refused shared care blood tests for gender care.”

“GP refuses and local hospitals refuse to carry out my blocker injections, so I have to go to London every 3 months for private medical care.”

2.6 Thoughts on what the new service(s) should be named

Key themes:

- Responses about names for the service were slightly split, participants wanted the service to be recognisable for clarity, but generally wanted the ability to shorten the name to give some subtlety and to avoid having to use 'gender' in shortened versions. For example, an identifiable name for the whole service, with more subtle names that could be shortened for each branch or location of the service.
- There is genuine anxiety around people being attacked or discriminated against if the clinic was too easily identifiable.
- The language around gender changes quite quickly so it needs to be something that isn't going to date or sound overly medicalised.
- Clinic names should underscore inclusivity and accessibility.
- Some people suggested focusing on identity.
- Some people suggested that naming the service after notable trans people would help service users feel respected.
- While some people suggested using location, others advised avoiding location names or names relating to individual organisations.
- Some felt the term dysphoria is problematic while others felt the term 'development' had connotations of having to prove yourself.

townnamegenderclinic phoenix
 childrenandadolescencegendercare genderrelatedcare
 heron lotus
 genderyouthcareforundereighteens
 genderyouthcare youngpeople'sgenderhouse
 genderaffirmativeservicesforyoungpersons
 genderhealthcare
 youthgendercentre

In their own words

"The service name needs to include the word gender, otherwise the gender aspect of the services rendered could be minimized."

"I think the service should maybe have the word gender in it, but the building or clinic be called something else. Children don't want to out themselves by saying they've got an appointment in a particular place."

"The service could be called something that can be easily abbreviated to reveal more or less about the service depending on who they are talking to. For example, 'Indigo Gender Service' can be shortened to 'Indigo' and it still be clear to those aware of the service what they are referring to."

"I think whenever I mentioned I'm with a service to someone I think I get like, a very big wave of anxiety saying it's a gender service. Because sometimes people get sceptical when I say stuff and like, I think there's confidentiality having it as something, like the example that's on there of Lighthouse. But then Lighthouse Gender service so you can just say I'm with Lighthouse without having to say it."

"I think that the name for the gender service shouldn't feel too medical. So it's a service that people feel safe using and saying the name of without getting judgement from people because there's often a lot of judgement when people find out that you're with a medical service group."

"I think small references to trans and gender non-confirming culture would suggest that the developers actually cared about the community and knew them well, as well as providing a subtle space so it is less clinical."

"Maybe naming [it] after significant trans people in the past who have contributed to the medical field, or something would be a good idea."

"Tavistock and GIDS were terms used interchangeably, so any bad press associated solely with Tavistock was then applied accidentally to all gender care services."

"Avoid negative things/problems like "gender dysphoria" since not everyone experiences dysphoria in the first place, and also gender services should be supporting people life-long, even after they no longer experience dysphoria or any problems and are fully settled."

"I can't lie I don't really like the term dysphoria because i think the trans experience is more than just that"

"GIDS -- the focus on development focuses on emphasis on processing. Adding more barriers and more focus on making young people "think about it" more."



Session three: Wider support and information – themes and quotes

The question set explored participants' thoughts on what wider support and information should would be helpful to potential service users and their families / carers. The questions explored were:

- Aside from specialist gender services what other services or support are/would be helpful (both within and outside the NHS)?
- What support should/could be given to parents / families / carers?
- What and/or where are your trusted sources of information if any?
- What general information would be helpful for young people thinking about their gender identity? How would you want this information to be provided?
- What information would you need to know if you were thinking about medically transitioning?

Overview of key themes- Session three

Wider support

- Access to counselling and mental health services is essential but there were concerns about a lack of access to, and support from CAMHS.
- Community forums and group spaces provide a sense of collectiveness and help young people feel less isolated and alone.
- More support around gender expression, social transition, and exploration is wanted – particularly to avoid exclusion of people who are questioning or exploring their gender identity.
- Establishing shared care arrangements with GPs is often problematic, this needs to be addressed so that people who are on a medical pathway are being properly monitored.
- Schools play a key role in supporting gender questioning young people. There should be a more consistent approach across school on how to support gender questioning young people.

Support for families

- Resources should be provided for parents, carers and families but the focus of care should remain the young person – parental needs and views shouldn't be prioritized over the child's.
- Participants particularly wanted the burden of 'educating parents' to be removed from them through direct provision of physical resources like leaflets and packs, and the option for parents, carers and families to attend in-person peer support groups.
- Parents are more likely to trust the NHS as a source of information than other external resources.

Overview of key themes- Session three

Information

- Young people requested a wide variety of information - from general information about LGBTQ+ experiences, to very specific information about the gender service itself.
- The level of mis-information and the public narrative makes it difficult for young people to find trusted sources of information. There is a need for impartial and comprehensive information about diverse gender identities, expressions, and journeys and options for transition.
- There should be clear messages to reassure gender questioning young people that that it is ok to explore and that everyone's experience is different.
- There needs to be an increase in reliable and accurate information about medical transition, particularly around side effects, risks, benefits and long term impacts.
- People would like to see better resources from the NHS that they know they can trust.
- Young people often find online/social media sources the most helpful place to find out information, with varying levels of trust / caution as to the accuracy of information from these sources
- Speaking to people with lived experience was considered the most helpful source of information. Older adults who had been through the process could be engaged to provide peer support / peer education / buddying.
- Other credible information sources include LGBTQ+ organisations, reputable news outlets, and peer-reviewed articles.
- The NHS should signpost to support organisations that are trusted and used by the community, particularly as a source of support while waiting for NHS care.

3.1 Services or support young people would find helpful (aside from specialist gender services)

Key themes:

- Several participants said that access to mental health services and counselling (including long-term therapy) was essential. However, there was also general agreement across the groups about the lack of practical support currently given by CAMHS. There was also concern expressed about NHS England’s proposal that referrals into specialist gender services should go through CAMHs or paediatric services.
- Community forums and group spaces were given as an example of a good resource, as this helped young people connect with their community and learn about how to navigate the service.
- Healthcare needs effective and honest communication and follow-up. Many of the young people who participated in the focus groups reported being given incorrect information, never receiving follow-up communication, and/or being promised referrals that never took place. Participants wanted a greater amount of information about each clinic, including the care available, routes for accessing this care, appointment schedules, a map of the centre, information about the clinical team.
- GP and primary care issues were common. Participants recounted difficulty with securing a referral to specialist care and in instigating shared care agreements between NHS and private providers. They argued that these needed to be made more straightforward and easier to implement, particularly in the current situation where private healthcare is often seen as the only option for accessing gender-affirming care in a timely manner.
- It was suggested that NHS collaboration with established LGBTQ+ organisations would bolster support and resource availability.
- More systematic physical health checkups and a specialist sexual health service for trans people were suggested.
- There was general consensus that more outreach with schools would be helpful, including more comprehensive sex education and specific trans pupil guidance to cultivate inclusive environments for transgender students. A more consistent approach across schools would also be helpful.

In their own words

“CAMHS are completely useless in regard to being trans, my counsellor refused to refer me to the GIDS because I am asexual so ‘there might be something deeper going on.’”

“[CAMHS] just adds another layer of inconsistency when you don’t need it.”

“Good mental health services would have really been a big benefit for me as I was exploring my identity, dealing with things like dysphoria....”

“More accessible therapy (and more accessible long-term therapy) either through charity organisations or the NHS; I spent years actively crawling through hoops to get the NHS to acknowledge that I was even struggling and when they finally decided to listen to me they decided I needed high-intensity therapy, so clearly something went wrong along the process there.”

“Supplementary care for surgery, like mental health support that looks at the whole person and more education about what gender services can provide, community groups ”

“Proper groups to discuss and help with mental health, proper therapy offers to young people (an actual therapist people can see every two weeks).”

“It’s really nice to talk to others like me and to give advice to others who don’t know much about transitioning or even anything about the LGBTQ community.”

“I think that access to informational texts are really important. I did a lot of my research on the internet and got told so much false information because there were so many sources, so some trustworthy informational sources about being transgender, social and medical transitions, etc, would have benefited me a lot.”

“I was my GP’s first trans patient, therefore I had to learn everything myself to teach the GPs how to navigate the system.”

“My GP was super supportive - they just didn’t know how to do it properly or where to send me.”

“My school actually had a lesson about trans people in Year 10 as part of sex ed, and I think that was very helpful for people around me to be understanding when I came out. They were suspiciously progressive for a catholic school, and they were incredibly open regarding the existence of LGBTQ+ people during teaching. I think having that as a more of a commonality in schools would be very helpful for both trans kids and their peers.”

“I find access to services through schools really varies, schools can be really inconsistent with what they tell each person. I don’t know why, I just don’t think they have a good or consistent system in place in schools for gender stuff.”

3.2 Support that should/could be given to parents / families/carers

Key themes:

- Participants discussed the role of families, carers, friends and others in supporting trans, non-binary and gender questioning young people. Although participants highlighted the potential positive role of families, carers and others in supporting their children to navigate transition and related care, other participants spoke of the personal damage that lack of parental support had had on their adult relationships with family.
- Participants suggested that families and others supporting trans young people needed to be able to access information for themselves and also signpost their child/young person towards relevant local services.
- Information needs to both be accurate and come from sources that families/carers can trust and see as legitimate. Participants noted that it can be valuable for families to receive information from medical professionals as this can help them understand that being trans is 'real' and in some cases medical transition is necessary.
- There was a view that parents are more likely to trust information from NHS sources than resources found by the young person themselves and this may help counteract the largely negative media narrative and challenge negative perceptions that parents may hold about trans and non-binary people.
- In-person and online support groups for parents and carers to meet other parents and carers and professionals who can answer their questions and provide mental health support / counselling if needed was felt to be incredibly important.
- Attendees supported the idea of space in which parents could ask questions with trans adults, to challenge existing perceptions of trans and non-binary people and feel more hopeful about their child's future.
- However there were some participants who felt that the focus needed to be on the young person themselves and their care and that needed to be prioritised over parental support. Others also said that while having parental support was important they should not be allowed to act as gatekeepers.

In their own words

"Especially with the current environment for trans people in the UK, having a concrete support system in the NHS for parents of trans people is desperately needed."

"I feel like there is a lack of support for parents who are uneducated and want to learn how they can support their child, and also for ones who have to essentially go through a loss in their life. It may be hard for them to come to terms with the fact that they've lost something and gained another, so a service that could provide support and guidance for parents would be extremely useful."

"The NHS services could perhaps include sessions to help explain the trans healthcare process to parents, counselling/therapy for families of trans people, with or without the trans person being present."

"Information and explanation about transgender 101 stuff, and what options exist for trans healthcare "

"Education nights run online or even online support groups overseen or set up by trained professionals would be helpful"

"General support for understanding having a trans child/family member would be fantastic, and ongoing support for how to advocate for that person, follow their lead and do the right thing for them (e.g. "if they decide they're nonbinary somewhere along the way, don't argue with them, let them explore it and make sure everyone uses their preferred pronouns"

"I feel like if my GP told my parents, yeah, they would trust her more than me. Because I feel like they just don't really get it if I try explaining to them)."

"Counselling and group discussion would be good, so people can talk about their experience with people who understand."

"Support for families should include things like talking therapies for the trans individual and for family members, including group therapies. There should be informational sessions that families can attend to help them to take care of their trans family member, and to attempt to get rid of any stigma that they still hold around being trans."

"A physical pack for family like leaflets and books could be useful as they don't always know how to use online things as well as we do – and they might be confused by negative information from transphobes too."

"Why would the parents get support when we don't get any support? makes no sense that. Come back to me when you support the young people."

3.3 What young people consider trusted sources of information

Key themes

- Participants explained that reliable and accurate information for trans and gender questioning young people can be difficult to find and they had little access to resources which often lead to mis information.
- Young people highlighted the prevalence of misinformation and anti-trans bias in mainstream media and preferred to search the internet themselves or seek information.
- Participants stated that the NHS should have more resources and be a trusted source of information but it is considered lacking currently.
- Attendees were generally more trusting of the information provided by other community members / people with lived experience; however, it was noted that community resources were not always accessible
- Social media was a main source of information. This includes known YouTubers, Reddit forums, and trans people on social media. Participants acknowledged that these sources were not always reliable but favoured these over mainstream sources.
- Other trusted sources included LGBTQ+ support organisations, reputable news outlets, peer-reviewed articles and lived experience of other trans people.
- Participants thought that information about trans identities and experiences should be available within education settings
- Participants would like a choice of formats including podcasts, leaflets, videos, infographics, etc, for both patients and parents and carers of patients.



In their own words

- "I want a lot of trans input on things, I trust it, personal experience is one of the things I trust the most."
- "I've always found that talking to people who have life experience is the best, either on like forums or like places like Reddit or on social media and other places"
- "A lot of trans people make YouTube videos which I think is a [major] informational source for a lot of people, and that's mainly where I get my information from, not so much professional services."
- "I would like the NHS to be more of a trusted source. There are so many places I don't trust who make up things about trans people."
- "A list of accurate checked studies, articles, and research to share with people would be helpful – there's a big thing with misinformation so it's helpful to have something else."
- "Trans charities or helplines like Switchboard have been very helpful."
- "I normally just search it up on the internet and read whatever comes up first."
- "I just searched 'I want to be a boy' and opened a can of worms."
- "I have to spend time picking apart information and assessing it. I feel like I always have to be sceptical of the information I read, and really think about why they are writing it."
- "I go to a lgbtq youth group and its very helpful and nice to be around people that know what they're on about"
- "One of my CAMHS therapists was really helpful, she directed me to a local trans support group."
- "To be fair, my GIC nurse was very up to date in regard to most things and was incredibly helpful with treatment options and side effects."
- "I think generationally...some parents...see the internet as untrustworthy...so I think this is a really important point, having trusted sources of information for young people and for parents, because it's something that definitely caused a lot of arguments in my household."
- "I feel the NHS should have more resources linked on the website to different types of trans individuals, not just FTM or MTF."
- "NHS sources give you standard medical information, but there's so much I've heard from other transgender people that isn't mentioned in any medical sources."
- "I want to be able to get medical information from the NHS website, but they very rarely mention trans-specific stuff."

3.4 General information that would be helpful for young people thinking about their gender identity

Key themes

- Young people requested a wide variety of information - from general information about LGBTQ+ experiences, to very specific information about the gender service itself - including: the building, the staff, how the process worked, what to expect in your first appointment, and more.
- Many noted they had little access to resources which often lead to mis information. This could be addressed by establishing a robust online presence, offering accurate, easily accessible information and peer support forums. This could be in the form of podcasts, leaflets, videos, infographics, etc, for both patients and parents and carers of patients.
- There is a need for impartial and comprehensive information about diverse gender identities, expressions, and journeys (including gender non-conforming cisgender people) and all aspects of, and options for transition, including dealing with transphobia and bullying
- Several participants expressed the need for a clear message to reassure gender questioning young people that that it is ok to explore and that everyone's experience is different.
- Several participants expressed a reliance on other community members who had successfully navigated the service to provide information about what appointments would be like and how to increase chances of being seen by the service quicker.
- Participants also suggested that children and young people need access to information about gender identity and transition as early as they were able to understand it. They explained that better education for all about trans identities and experiences would also support cisgender young people in engaging compassionately with trans and gender questioning peers.
- There needs to be consideration of accessible and inclusive language when generating resources/content.
- Some participants noted that there seemed to be a gap in information aimed specifically at transitioning from male to female.

In their own words

"...really clear message of this is what we do. This is the service we provide. Here's the reason why. Here's where you can find more information. Or here's where you can ask questions, and here's why it's necessary".

"I also think the information you do get the trans experience is very stereotyped and doesn't help and that's probably the thing causing the most people to think they are trans when they are not"

"It would be helpful to show that there is no judgement in experimenting with their appearance such as clothing and makeup. Also to be shown how they don't need to have a specific label to use and should try to feel as comfortable as they can."

"That answers don't have to be concrete and "I'm still figuring it out"

"Knowing its OK to explore gender."

"I think telling them that they aren't alone in this is a big one. When I came out, I thought I must have been the only one feeling like this in my entire area, let alone school at the time. But I slowly realized over time that that is not the case. There needs to be more support in schools that can educate children who don't know a lot about it and how they can become more accepting of their friends at school if they ever came out as trans or gay."

"Knowing that everyone is different and that there isn't a 'set way' they need to be trans or non-binary. Everyone's experience is different, and they don't need to fear that they are not 'trans enough' to be valid. And also that if they change their mind and they are no longer questioning, that it's also ok."

"It's a journey not a race take your time. Through leaflets, online ."

"Information on how many gender identities there are...and how you can identify as gender fluid or non-binary and what each of the gender identities entail"

"Letting them know there's support and further avenues for information out there. They should know where they can go for someone to talk to, whether it be a dedicated staff member(s) at school, or websites, or whatever. There should be anonymised ways of learning things due to risks of being out."

"Leaflets, websites and social media."

"I think talking to older trans people would be a lot of help, doctors honestly do not really know anything, and a lot of trans people end up having to teach their doctors."

3.5 Information young people would need to know if they were thinking about medically transitioning

Key themes

- Participants highlighted a lack of reliable and accurate information about medical transition.
- It was considered important that young people have clear and impartial information about the full range of gender-affirming treatment options and the effects on the body of different aspects of medical transition.
- Participants particularly highlighted the need to know about any known and unknown risks and potential side effects when making an informed decisions about care and treatment. They wanted transparent information about how quickly hormones would have an effect on their body, and a recognition that mental health may still be a concern while they are waiting for changes to take effect. They also wanted information on what to do about any side effects and medical issues (how serious it is, do they need to go to the hospital or just talk to their GP)
- Some participants described wanting information on different medical interventions or aspects of healthcare that they might want to consider in future, even if they were not ready at the time. This included, but was not limited to, hormones/HRT, effects on mental health / mental state as well as physical effects, the impact of fertility.
- Several participants also stated that it is important to inform people that medical transition isn't the only option and that choosing not to go down that route does not invalidate their identity.
- A couple of participants felt there needed to be more information for people wanted to come off the medical pathway. This could be for a number of different reasons from changing your mind to wanting to avoid adverse health impacts or deciding to try to get pregnant.
- Participants reflected that when information was shared with them, it was often based on research carried out with cisgender rather than trans people and so they did not know if/how it applied to them. Individual accounts and experiences available to read/watch from people who have been through different treatments is found to be helpful.

In their own words

“What are the benefits, what have people who've gone through each process thought about it, what are the side-effects, what are the possible drawbacks, what is the time-scale, how reversible is it, what the process actually involves (e.g. not being able to do stuff for several months after certain surgeries), what medical professionals think about it, what everyday people who've done it think about it, what are the things nobody tells you (e.g. post-surgery dysphoria), what is the satisfaction rate (preferably with some stories of people who've done it and loved it, and some who've done it and didn't love it as much).”

“I'd need reassuring about potential risks, statistics relevant to those risks, and knowing how long I can expect to see potential results (in terms of hormones).”

“Common AND uncommon side effects, as well as how likely it is to get them. Information on what to do about any of those side effects and medical issues (how serious it is, do they need to go to the hospital or just talk to their GP)”

“What hormones to take, potential side effects, what changes to expect, effects on fertility, how permanent any changes may be (especially for Trans men since facial hair and deep voices are harder to get rid of), the experiences of other trans people, who to contact if you experience transphobia, how to shave/wax (for both masc and fem people).”

“What treatment involves and the effects in - both short and long-term - and associated risks, and any methods to mitigate said risks”.

“Knowing all the pros and cons of medically transitioning ...on social media, it feels like cons of medical transitions are always downplayed.”

“I think talking about the side effects...wasn't described very well. And similarly, the side effects of hormones aren't described very well”

“I think it's helpful for people to know that there's not only one route or one set way to transition or be trans. They might want just hormones, or just surgery, people are different with different experiences, presentations and bodies. It's fine for that to be the case, it's okay to have different plans for your medical transition.”

“It's good for people to know that it's okay to decide something is not for you....it's good to know that you can start hormones, for example, and then say, 'hmm, this actually isn't the route for me'.”

“To let the clients know that they don't have to necessarily have any medical transitioning and that they are still valid”

“What to do if you want to go off T in future.”