

# The Northern Region Gender Dysphoria Service (NRGDS) Service User Evaluation 2023

## **Executive Summary**

The Northern Region Gender Dysphoria Service (NRGDS) carried out a service evaluation seeking the views of those people using the service currently. 11% of those currently on the treatment pathway responded and gave detailed feedback about positive areas of service that they had received and areas where they felt that improvements might be made. Thematic analysis was used to identify themes in the feedback and create a summary of areas to consider for improvements. The summary is given in the table below.

Suggested improvement	Service Response
Consider how to make the facilities more friendly for neurodiverse people	There are limitations in the changes that we can make to building structures, however we are always happy to change things to make individual service users more comfortable.
	We will ask staff to check with service users routinely about their comfort in clinic rooms including lighting, heating and other adjustments as applicable.
	We will co-create a video with our patient involvement bank that supports people who are coming to the building for the first time and aims to reduce anxiety that some people might feel in visiting new places.
Resources about the service made available in reception on a noticeboard	There is a noticeboard in reception that is updated regularly with a range of resources covering a wide geographical area including areas outside of the CNTW footprint. This is supplemented by resources on the website covering all of England and Wales. The noticeboard is in a side section of the waiting area and so some people may have missed seeing it. We will add a notice in reception directing people towards the noticeboard and the website.
Choice of online and virtual appointments	All service users are offered a choice between face to face, virtual and online appointments and most clinicians offer flexibility on the day according to service user need within reason. There are some appointments that must be undertaken face to face for reasons of good clinical governance and this includes at least one face to face appointment each year. Clinicians indicate to the administrative team which appointments must be

undertaken face to face. Service users have free choice over the venue of any other appointments and the administrative team can offer a rationale for why certain appointments need to be face to face at the time of booking. We hope that this helps with increased transparency about the processes and clinicians will be happy to answer questions about any individual circumstances that are relevant to the selection of appointment type. Be able to contact clinicians We appreciate that it can seem as though directly rather than through communicating through the administration team the administrative team puts an extra step in the pathway of communicating with your clinician. However, this step is in place to ensure that clinical enquiries are given to the right person and that urgent queries are dealt with in a timely way. The service receives a very high number of queries and if these were passed to clinicians directly, without reviewing them, it would take clinicians away from clinical work and slow the pathway through the service. Improve connectivity of online We do apologise for times when the connections appointments to the internet interfere with clinical appointments. We appreciate that this is frustrating for both service users and the clinical team, when this happens because of difficulties at the NRGDS sites. Wherever possible CNTW works to reduce connectivity issues with regular updates and infrastructure improvements. Some of these issues are outside the control of the service and CNTW. When service users have difficulties with connections, we endeavour to offer alternative solutions proactively and if they struggle to gain access to the internet we can try and work with them to find alternative methods of meeting or other ways of accessing technology.

Assessments should include fewer questions experienced by some as intrusive and limit the scope of questioning. sensitivity. Increased access to information about pathways and appointments

We recognise that each person comes to an assessment from their own individual perspective and that everyone will experience it differently.

Clinicians in the service care very deeply about ensuring that we offer a respectful, caring and transparent service to the people that we serve.

We always strive to offer clinical excellence and the standardised assessment that the service uses only gathers information that is necessary for the purpose of making sense of a service user's individual circumstances and their eligibility for care and treatment. We do recognise that this is often sensitive information and that each person will have a different story to tell. If a service user is unsure about why a question has been asked we are always happy to explain the rationale.

We have an assessment peer review process through which we aim to always be improving in our practice including in education and cultural

There is a lot of information about what to expect, from the service and the staff, on the service website. Information about this is sent to people at referral. Staff also signpost people to the website as a source of information. In addition to the new sign in reception (see point 2) we will ensure that future service user newsletters advertise the website more clearly.

Increase access to the Peer Support Service to include those in care and treatment. The Peer Support Service was initially commissioned only to support those people on the waiting list. More recently, where the MDT (the team decision making meeting) feels that someone in care and treatment might benefit from individual support from a Peer Supporter a referral can be made.

Those people already in care and treatment benefit from opportunities to speak directly to clinicians, about their personal needs to gain access to support. This is not available to people

	on the waiting list and for this reason, currently, we reserve the Peer Support Service for them alone.
Using an app or online portal to improve ease of booking appointments	We recognise that people who use the service have a wide range of preferences for how they communicate with us and we aim to be flexible in responding according to individual preferences over email, telephone and in writing.
	We will pass this suggested improvement to the CNTW information governance team and ask them to consider whether there might be an option to explore other ways of managing appointment booking.

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### Introduction

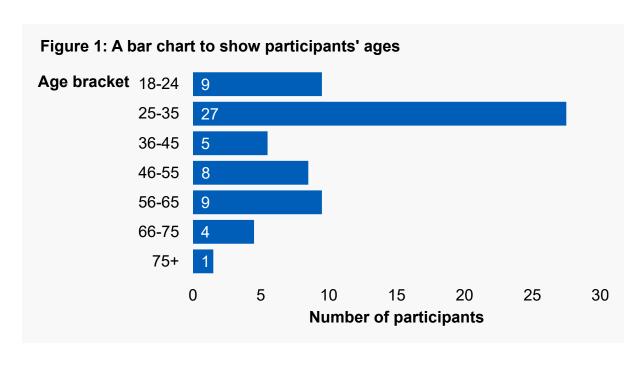
The Northern Region Gender Dysphoria Service (NRGDS) is a specialist gender dysphoria service. The service is part of the Cumbria, Northumberland, Tyne and Wear NHS Foundation trust (CNTW) and is based in Newcastle upon Tyne although it is open to adults throughout England who experience gender dysphoria, including transgender and non-binary people. NRGDS aims to provide support to individuals who are exploring their gender identity by offering an assessment and treatment pathway focused on improving service users' physical, mental and emotional wellbeing. The service caries out periodic service evaluation. In 2022-2023, a qualitative research project was carried out examining service user's experiences of NRGDS. The following report contains the findings of this project.

## <u>Methodology</u>

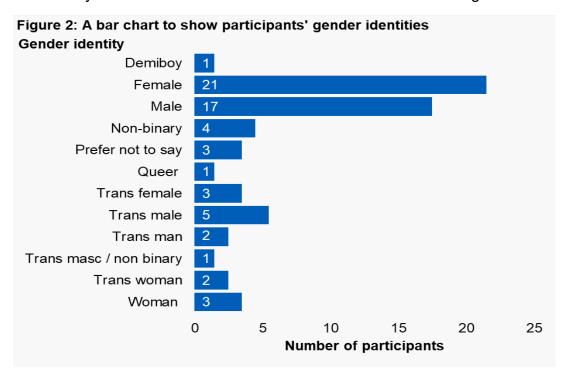
#### **Participants**

Recruitment for the survey took place over 4 weeks. Service users currently in treatment were recruited to take part in the survey via opportunity sampling. For service users who had an active email address on file (532 people) the survey was advertised via 4 weekly emails. A copy of the email invitation can be found in Appendix 1 and a copy of the reminder email can be found in Appendix 2. The survey was also advertised through posters (Appendix 3) in the clinic reception and clinic rooms. Additionally, clinicians asked service users to complete the survey at the end of their appointments whether online or in person (Appendix 4). In total 63 participants responded; no participants were removed, creating a sample of 63.

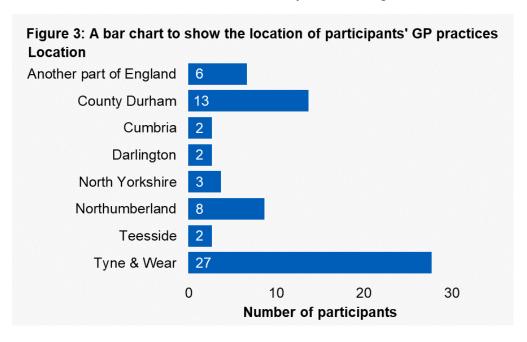
Participants ages ranged from 18 to 75+ with the majority in the 25-35 bracket. Participants' ages are represented below in figure 1.



Participants were asked to write their gender identity in an open text box. Participant gender identities ranged, however, the majority (33.3%) identified as Female, followed by a further 27.0% who identified as Male as shown in figure 2 below.



Participants' GP surgeries were located throughout the northeast and the rest of the UK. However, the majority of participants' GPs (42.9%) were located in Tyne and Wear followed by county Durham where 20.6% of participants' GP surgeries were located. These results are shown visually below in figure 3.



#### **Materials**

Participants answered the survey online via Microsoft forms unless they requested a paper copy. The survey contained 2 multiple-choice questions and 21 open answer questions. A copy of the survey can be found in Appendix 5.

#### **Procedure**

The electronic patient record was used to identify people currently in treatment at the service with an active email address. A standard invitation was sent by email which outlined the survey's aims and purpose. The invitation included a link and a QR code to the survey online (Appendix 1).

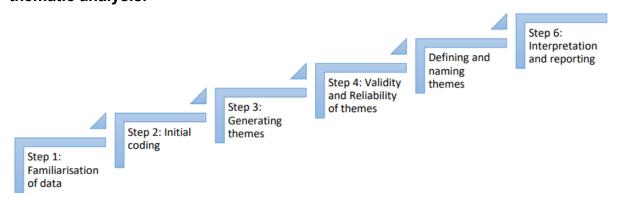
The survey followed a within-subject design where participants answered all the same questions in the same order.

#### Data analysis

Responses to the final demographic questions on gender identity, and multiplechoice questions were analysed using descriptive statistics. Calculating percentages and creating bar and pie charts using Microsoft Excel.

Responses from the open-answer questions and the interview transcripts were analysed using Braun & Clarke's 6-step thematic analysis (2006) by 2 separate researchers, the NRGDS assistant psychologists. The analysis of the dataset was organised by question. The thematic analysis process is shown visually in figure 4 below.

Figure 4: Braun & Clarke's (2006) six phase framework for carrying out a thematic analysis.



Each researcher read through the datasets independently, several times, to familiarise themselves, and then highlighted and coded the data. Codes were sorted into groups and groups were sorted into themes. The researchers met to compare their themes and agreed on collaborative themes, definitions and subthemes. Themes were revised several times to capture the complexity of the service user experience.

## Results

Question 1 - Is there anything that you can think of that would have helped you with the process of waiting to be seen for first and second appointments?

61 of 63 respondents answered this question. The themes that emerged included:

**Lack of funding** – This theme incorporated participants comments on perceived lack of funding and the effect this had on their experience whilst waiting. Namely, service users attributed perceived lack of funding to the length of waiting times and the use by some people waiting of private providers of healthcare.

- "The waiting times are too long. This is not the fault of the NRDGS, but more reflective of a lack of funding for gender dysphoria services in England"
- "I had to go private to get an official diagnosis and to start hormones, I just couldn't wait any longer as I was struggling severely with the waiting times"
- "The people who are still waiting will be severely struggling and this is what those that 'Provide funding' for NRGDS and other GIC services must take into consideration."

**Practical support whilst waiting** – This theme includes participants comments that they believed that bridging hormone prescriptions, better mental health support and practical forms of support, would have helped with the process of waiting. Other participants also mentioned the peer support service, (which is now in place, but was not operating while they waited to be seen), would have helped them to manage the wait.

- "Any extra support whilst waiting, even advice or any information about transitioning."
- "Mental health support, or reminders that I was still on the waiting list and hadn't been forgotten about."
- "Bridging hormones would have helped, or maybe have a team of therapists on hand whose sole role is to caretake for those waiting by giving them some talking therapy? Idk"
- "Access to support groups."
- "Contact with peers, and a professional led group that was able to advise and monitor. Some people need to talk regularly, not suffer in silence."
- "An information pack would be great something that explains the process of getting help and lists do's and don'ts, tips for passing and coping while on the waiting list, so people don't have to get incorrect and potentially harmful information from the internet. Things like don't bind with sports tape, why you shouldn't get testosterone on the black market etc."

**Communication** – Participants stated that better communications would have helped with the process of waiting and reported feeling that they were being ignored and left in the dark whilst waiting. In particular, they reported that more communication about the current length of the wait list and updates on where they were on the waiting list would have helped in the waiting process.

- "Better communication and information of what will be asked before the first appointment would have been helpful."
- "Shorter waiting times, more communication. You basically don't communicate at all until the appointment is available, leaving us completely in the dark as to what's going on."
- "Better communication and information of what will be asked before the first appointment would have been helpful, but my first appointment was in 2017 so things may have improved since in those regards."
- "The ability to at least check you are on the waiting list. Plus, honest answers about wait times made clear in relation to the acceptance date of people currently being offered appointments. Reasons made clear if wait times increase."
- "It would have been helpful to have received updates on where I was in the queue."

# <u>Question 2 - What feedback would you like to give about... first assessment appointment</u>

53 of 63 respondents answered this question. The themes that emerged from feedback about the first assessment appointment included:

**Perceived Pathologising/intrusive process** – This theme describes how some participants reported that the assessment asked intrusive questions or was pathologising the trans experience. Some additionally stated that the assessment served a function to gatekeep access to services.

- "While I understand NRGDS wants to get the whole picture in regards to gender identity it is quite demeaning to have to retell old childhood trauma that is unrelated to my gender and also go over sexual history."
- "It seemed very much centred around my physical appearance and method of presenting myself as my true self. I feel like this is not the best way to go"
- "It felt that I was being analysed, and that I had to justify myself for being referred into the service."
- "Felt like a pointless conversation trying to justify why I was there in the first place to someone else."

**Communication** – This theme, like for question 1, was derived from participants experience of a lack of communication about what to expect in the appointment, next steps, and why some questions were being asked.

- "More information on how to prepare, such as what type of questions would be asked and what we would talk about. The aspect of a first assessment was very daunting and unknown."
- "A more clear and accurate idea of timescales for the 2nd appointment; this would help patients with their expectations."
- "My first assessment was split into two appointments as we had to go over my time with the youth dysphoria services then how things had progressed since.
   I felt it would of been helpful to know in better detail what would happen at that appointment to make it more stream lined"

**Negative experience** – This theme collates all the negative feedback about the services offering of a first assessment appointment, and the negative emotions that came with it.

- "The woman I seen at first her questions seemed very odd and she seemed a little abrupt about certain things made me feel uncomfortable at first."
- "Utterly, utterly pointless."

**Positive experience** – This theme collates all the potential good a first appointment offers, which included feeling heard, accepted, and like it was authentic. It also includes comments about staff which were positive and suggested that staff embodied trust values.

- "my first assessment was fantastic, going back to 2018 it's hard to recall exact feedback, but the nurse was friendly, warm and welcoming from what I recall."
- "I remember being heard, and understood. it was fantastic to have somebody just hear me for once."
- "My initial appointment went very well. I was made welcome by the assessor and quickly felt less nervous. Also to be talking to me as woman certainly helps, especially important considering my own gender dysphoria not helping nerves."
- "They understand my needs right away and assessed me accordingly."
- "Excellent first appointment"
- "I don't have any negative comments about my first assessment appointment, it was quite pleasant. The Doctor that my first appointment was with, was lovely, polite and friendly."

## Question 3 - What feedback would you like to give about... second assessment appointment

49 of 63 respondents answered this question. The themes that emerged from feedback about the second assessment appointment included:

**Positive Experience** – This theme combines all the positive feedback about the second appointment and feedback from participants who reported that their second assessment appointment went smoothly. Participants also praised the clinicians who conducted their appointment and highlighted that they embodied trust values.

- "Went very well again and was assessed quickly to be put onto testosterone."
- "I was very happy, thank you."
- "My second appointment was also, pleasant, no issues that I can think of, different Doctor this time but they were also friendly, polite etc."
- "Second assessment went smoothly."

**Perceived as intrusive or pathologising** – This theme describes how some service users perceived the questions asked in the second assessment where unnecessary, irrelevant or intrusive and the distress that this caused them. Some participants also stated that they had to justify themselves in the second assessment.

- "Again having to justify my own emotions and perspective to another person isn't pleasant and can be quite difficult to convey"
- "As with all these appointments, it is rare for someone to actually understands
  what the trans person experiences and knows about themselves. In many
  ways we are your goldfish and you look in upon our lives."

**Assessment being informative** – This theme combines participant's feedback that the second assessment was informative and helped prepare them for the rest of their care on the pathway by setting expectations, explaining the process and timescales.

- "This went way better. I feel like it was more informative about the route of transition, the process and expectations associated with the journey too"
- "Everything was great. Nice informal but informative chats that made me feel comfortable with everything going on."
- "This was really beneficial as it helped clear up a few expectations and a general idea of next steps."

**Negative experience** – This theme incorporates all of the negative feedback received about the second assessment and the NHS in general.

- "Insulting. I should never have been asked things like whether I liked football as a child."
- "At this time it's 2020 and the Covid restrictions, everything's online, no face to face freedom interactions permitted. Although trying to make the best of this situation of online assessments, I really don't like online assessments and they seem to only serve to extend already very transitioning delays."

**Comprehension of the pathway** – This theme captures some participants' confusion about how the pathway works, namely incorrectly identifying which appointment was their assessment appointment.

- "I didn't have a second assessment, unless that was carried out by the doctor."
- "If this is the second assessment where i had to travel all the way to
  Edinburgh to be assessed by a private doctor, I would say that that was a
  completely unnecessary step when there are many perfectly capable doctors
  in my hometown and absolutely would not be considered under any other
  healthcare circumstance."

Question 4 - What feedback would you like to give about... follow up appointment with a doctor

48 of 63 respondents answered this question and overall the feedback was overwhelmingly positive. The themes that emerged from feedback about the follow up appointment with a doctor included:

**Values of the staff** – This theme encompasses participant's praise of the values and beliefs held by the doctors who manage their healthcare, and it also includes some negative experiences. Overall, the majority of feedback was positive.

- "Same as first and second appointments, pleasant, Doctor was polite and friendly, understanding etc."
- "Good, respectful and knowledgeable"
- "no complaints, drs have felt friendly and informative"

**Negative experiences** – This theme encompasses negative experiences with the wider team, healthcare services, and issues with appointments.

- "I'm sure the doctor meant well but I felt unseen and unheard. I think the outcome was I'd just have to wait around. I left without an idea what the process was for help waiting for the next summons."
- "Felt a little rushed. You can tell they are stressed."

**Positive experiences** – This theme incorporates feedback from participants who had a positive experience. Participants complimented the informative nature of follow up appointments.

- "Quick and very informative"
- "Was a helpful and extensive assessment"
- "Much more relaxed appointment, and discussed the options and treatment."

# Question 5 - What feedback would you like to give about... follow up appointment with a nurse

46 of 63 respondents answered this question and overall the feedback was overwhelmingly positive. The themes that emerged from feedback about the follow up appointment with a nurse included:

**Positive experience** – This theme encompasses staff compliments and the process of appointments with a nurse within the team. The majority of responses showed an appreciation for the nursing staff.

- "she was lovely, really nice, polite, listened to me, showed empathy and care, so no complaints."
- "fantastic, she is lovely, warm and approachable without any judgement"
- "Follow up appointments with nurses for me are frequently and evenly spaces and help with the feeling of worry about any hormone changes or difficulties where my doctors had been reluctant to start my HRT. Talking to the nurse about this helped them send a better stronger worded letter to my doctors"
- "Informative and quite relaxed"

#### Question 6 - What feedback would you like to give about... therapy and psychology

47 of 63 respondents answered this question. The themes that emerged from feedback about therapy and psychology included:

**Access** – This theme incorporates participants who did not access therapy and psychology because they had no need or desire to. It also includes participants who wanted to access therapy and psychology but had not yet done so or were unsure if it was something open to them.

"This was a revelation and a game changer, and the biggest surprise of the
whole transition process. It has become much more important than I thought it
would or could be. If I could go back and give one piece of advice to newlytransitioning me, it would be to do this as soon as possible. As it was, I was

- on the waiting list for three years, I think. I know the service is grossly underresourced, but this is just as important as the medical stuff."
- "i haven't utilised this service as my mental frame of mind has been quite strong fortunately."
- "haven't required any directly from nrgds but the service did guide me towards applying for counselling when i expressed a need for it"
- "Didn't have any even though I asked"
- "Never received any"
- "Was offered by didn't need/want any"
- "That's a new one, not offered at any point to myself so no comment."

**Praise** – This theme summarises participants praise of the therapy that they received and participants commendation for the psychology team in general. It was highlighted that therapy had aided participant's insight, personal growth and anxiety. One participant also mentioned that whilst they had found therapy to be helpful they would have liked to have had more sessions.

- "Brilliant!!!! The psychological therapy I've received under the NRGDS is the best I've ever had ... and I've had plenty. Nothing else to add, keep doing what you are doing."
- "Very positive. I discovered things about myself of which I had no prior knowledge"
- "I had some CBT which really helped me in overcoming my anxiety about transition."
- "After the initial appointment it has been a very good service so far"
- "I had some very helpful counselling sessions via video call though I wish I'd had them more spread out and that I could have had more sessions"
- "fantastic, I've gotten answers to questions I've had since I was a child"
- "Good"

# Question 7 - What feedback would you like to give about... Voice and Communication Therapy?

49 of 63 respondents answered this question. The themes that emerged from feedback about voice and communication therapy included:

**Beneficial voice and language therapy experience -** the overwhelming majority of responses were positive and praised the voice and language therapy that they had received having found it beneficial.

"This was very helpful. It made me feel more comfortable with my voice."

- "Very friendly and positive staff who make exercises fun and enjoyable... makes everything easy to understand, and can answer all of my questions. I like the way they... talk about binding, as I have seen online other professionals who discourage this, whereas they encourage you to practice while binding as that's how you are every day. I can say what I am finding difficult and [they] addressed my issues very individualised treatment."
- "It has been important, And fun! I've discovered the voice is a fascinating instrument. It is also hard work, and I feel I still have a long way to go. At least I have fairly clearly idea of what I need to do."
- "Excellent, began seeing results very quickly and the staff are very nice"

**Suggestions –** Some participants expressed a desire for more appointments, the ability to record feedback sessions to refer back to, more information about voice and communication therapy before referral and the option of face-to-face group sessions.

- "When making the choice between single sessions or group it would have been nice to be offered a similar amount of time for each option. I understand why this is but I feel like solo sessions would have been more beneficial and the option I would have picked if the amount of sessions was not a factor."
- "Voice and communication therapy has been effective and helpful although I was reluctant at first due to misinformation so maybe better information given before referrals to vocal therapy could be helpful"
- "More sessions would be good so I feel better supported, and can check in
  with the Speech therapists on if I'm doing the exercises right. I also feel like
  the group sessions and really beneficial, as I feel surrounded by peers going
  through the same thing, and would love more opportunities for this,
  particularly face to face."

**Disappointment –** This theme developed from the few comments which were negative overall about the VCT offering within NRGDS. It contained quotes such as:

- "Sadly disappointing for me. There were not enough sessions and no real chance to practice. This means I haven't progressed at all with my voice and it leads to me being misgendered."
- "Poor experience with voice therapy didn't really happen and then it just stopped for me with no further communication. The therapy was not enough, more 1-1 sessions needed to support with voice."

Question 8 - What feedback would you like to give about... the relationships you have with staff who manage your healthcare?

50 of 63 respondents answered this question. The themes that emerged from feedback about the relationships service users have with staff who manage their healthcare included:

**Productive and helpful healthcare relationships –** This theme encompassed positive staff feedback, the interactions people have had with staff and different areas of the pathway. Overall, the majority of respondents were very appreciative and agreed that staff were supportive and demonstrated trust values.

- "Getting to know the nurses has been lovely. the two I have seen are really nice and accommodating."
- "My relationships with the staff have been overall extremely positive. They
  have been very friendly and open to listening without judgement. They have
  provided advice where it has been needed, and offered suggestions that I
  hadn't otherwise considered."
- "My main doctor, [is] friendly, polite and always makes sure I'm informed and always gives me the opportunity to ask any questions I may have, not just during appointments but also after appointments (If I have a question but didn't think to ask during our appointment) she says I can email [them] with any questions."
- "been really polite, friendly, caring at every appointment, [they're] lovely"
- "Excellent. Staff are compassionate, caring, open-minded, kind, and willing to work with me on a 1-1 basis to individualise my care to the best the system allows. No complaints."
- "I respect and feel my psychologist respects me"

**Unfavourable relationships –** This theme covered the small minority of people who have had negative experiences with the staff that manage their healthcare.

- "The staff who manage my healthcare have been extremely helpful and I feel I have a good relationship with them and they seem excited to see my developments with transition and family building but again I feel like sometimes they can block things that could help like surgery due to the psychological issues that stem from living in a mostly transphobic society"
- "difficult at times, frustrating, hard to be heard"
- "I had a great relationship with my first member of staff, however she retired mid last year and I have struggled since then, feeling like new staff members don't know me as well. But I'm sure we will get there"

#### Question 9 - What feedback would you like to give about... making appointments

49 of 63 respondents answered this question. The themes that emerged from feedback about making appointments included:

**Straightforward process** – The majority of the participants found the process of managing appointments to be straightforward and easy to do, often just needing to confirm their attendance.

- "I receive appointment letters well in advance, and the admin team on the end of the phone are always very helpful.
- "Making appointments is easy and the admin team is nicer then any other hospital I've had to call"
- "very easy, user friendly, several options of remote appointments for patients who live far, telephone appointments 10/10"
- "The system of reminders sent to my phone is very useful. I've been able to make appointments at times convenient for me, which helps me prepare in advance and get the most out of them."
- "Very easy and convenient via the phone, I have been grateful for the appointments to be given online rather than in person and the process of making these appointments has been very easy."

**Potential improvements –** some potential improvements to the appointment making process included; being given the opportunity to pick between available dates and times, and the majority of responses under this theme covered the wish for an online appointment booking portal, whereby users could manage, cancel, arrange appointments as necessary.

- "Would be improved with an online booking system. Making an appointment is fine though for now, email is easy enough."
- "A greater range of appointment would be good, like more availability of online appointments. Unless paperwork needs to be signed, video appointments should be offered first. This would cut down costs for the service and make the service more efficient"
- "Arranging appointments over email would be useful as your phone number comes up as a private number and a lot of people ignore these"
- "They are a great team and try SO hard to help me, however my help is beyond the N.R.G.D.S. as the [hospital linked with surgery] is not co-operating or even trying to offer any solace what so ever."

**Adverse experience –** some people reported poor relationships with the administration team, feeling that their preferences on how to be contacted had not been kept, for example some participants wanted more notice in appointments, or to be contacted via a different method than the one through which they were contacted.

- "It needs to be CLEARLY recorded in user documents HOW they wish to be contacted, and this passed on to admin people. Too often I've had complaints that I am "non contactable by phone" when I have made it plain on multiple occasions that I should be contacted by email or letter. Why? Because I avoid phones due to the regularity of being misgendered."
- "After some delays and confusion with appointment letters, it is now much easier to arrange by email"

"More notice and ease of changing appointment needed"

# Question 10 - What feedback would you like to give about... communicating with the team

51 of 63 respondents answered this question. The themes that emerged from feedback about communicating with the team included:

**Easy and positive communication –** the majority of service users were happy with the methods and reachability of the team, often commenting that the queries were answered promptly. They often pointed out the friendliness of the team that was involved in their care.

- "This is great, I know that I can ring up with an issue, or email and someone will get back to me within a day."
- "Very friendly and overall extremely positive."
- "The admin team are very helpful and always respond promptly when I have a message for the consultant a while ago I was having issues with some documents, and the admin team and [my Dr] were great, and must have spent a lot of time trying to help me solve the issue. I feel that I can always call and leave a message for one of the staff, and that it will be responded to unlike other services where it is impossible to speak to anyone outside on an appointment time."
- Communication is easy as I get emails or phone calls from a nurse between my main appointments where I can voice my worries and issues and they sort them rather promptly"
- "the team work really well overall as a dept, it is ran with fantastic communication styles and accuracy. the dept model works very well. well done! 10/10"

**Negative experience** – few participants had a negative experience contacting the service highlighting that they did not appreciate contacting a general inbox or the admin team and would prefer to speak to their clinician directly. A minority of participants also took issue with the tone of communication.

- "I don't feel comfortable raising complaints to a general inbox. I can't give my other clinicians a direct contact to my consultant."
- "frustrating having to send all messages via the admin team rather than direct contact with doctors/consultants/voice coaches etc."
- "it took me a good while to understand how i go about getting in touch."

## Question 11 - What feedback would you like to give about... letters and administrative processes

53 of 63 respondents answered this question. The themes that emerged from feedback about letters and administrative processes included:

**Issues with letters** - this theme refers to some participants complaints about communication with NRGDS through letters, namely, that letters take too long, get lost, cause issues with GPs and are inaccessible. However, other participants praised the letters that they had received highlighting their accuracy and clarity.

- "The letters I have received from my appointments have been the most accurate that I have received in over a decade of interacting with different GICs"
- "Sometimes letters go astray or sit around a little too long in someone's out tray, but I do think this issue is improving."
- "Letters post appointment take AGES to come. Apart from that, nothing."
- "A good few times I didn't receive the letters"
- "I'm autistic and the letters from this service are often hard to read"
- "Admin staff always friendly and helpful over the phone, letters always very
  professional and arrive pretty quickly after appointments. Letters cover
  everything we talked about which is good as it helps me remember, and they
  very clearly show what the next steps are and what the plan is, which is very
  reassuring."

**Helpful admin staff** – many participants praised the admin team, particularly their polite and informative demeanour and their demonstration trust values. Participants also praised the admin teams ability to quickly update and amend information, especially in circumstances where it aided the service users transition e.g. a successful application for a GRC.

- "Admin have been very helpful for me to pass on recently sent and amended interview text information. They have also helped by supplying additional letters for processes like applying for my Gender Recognition Certificate GRC. This certificate I did obtain also."
- "Despite the above, admin has been pretty good on the whole. Treat yourselves to a tea and a biscuit, you deserve it."
- "Excellent"
- "10/10 administrative tasks are always accurate, emails get responded to always. I have never experienced any shortfalls with this aspect since 2018 as a patient. letter are adjusted if required to suit the patients specific needs and send out for review before sent to the GP. Incidents more specific aligned with the patients current circumstances or proposal etc."

**Interacting with primary care –** some participants had positive experiences with primary care and stated the letters aided experiences with primary care finding them quite helpful especially with reluctant GPs. However, the other participants were quite critical of the letters sent to GPs.

- "I like that all of the letters between the NRGDS and my GP, or surgeons, are sent to me too. It makes me feel involved in the process and allows me to keep track of what is going on at the time. It also helps when dealing with medication changes for example."
- "I feel the level of detail put into the letters that are shared with the GP is highly inappropriate and only contributes to the pathologisation of trans people at the level - the GPs really only need the recommendation of medicine to be prescribed, they don't need every detail as discussed in private with a psychologist - trans people deserve confidentiality"

# Question 12 - What feedback would you like to give about... the locations appointments are offered in

53 of 63 respondents answered this question. The themes that emerged from feedback about the location appointments are offered in included:

Walkergate Park being inaccessible – some participants stated that Walkergate Park was not an accessible location. In particular participants emphasized issues with lack of parking and that Walkergate Park was far from them, and caused long travel times to appointments. Some participants stated they would prefer more NRGDS locations closer to home. However, some participants mentioned that distance presented less of an issue now that virtual and telephone appointments had been introduced.

- "The locations are a bit difficult. I travel from out of town, meaning I get a 40 min bus and then the metro, and then another 10 minute walk. Even just being more central to Newcastle would be helpful"
- "Due to funding I understand there isn't many locations however there's none for residents in South Tyneside."
- "Sometimes difficult to park."
- "Walkergate is not the easiest place to reach. A base located in Newcastle city centre would be helpful"
- "Pretty far away. Could be closer."

**Walkergate park being suitable –** the majority of participants reported that Walkergate Park was a suitable location for appointments highlighting that it was easy to locate and travel to either by car or metro.

- "Yes Walkergate park is great, easy to find, very handy for me as I am from the area, but could understand how other patients may have to travel far."
- "Flawless options of appointment location choices so far"

- "NO issues. Easy to access."
- "NRGDS. Ensure convenient means of attending any meetings prior to booking."
- "I would normally drive or get the metro to appointments so the locations aren't too bad for me personally."

**Virtual appointments improving accessibility / preferred option –** a lot of participants highlighted since covid the use of virtual appointments has been quite beneficial for those who have to travel further, don't drive, or have other accessibility considerations.

- "onsite, telephone, video are all very accommodating, This approach shows a versatile and flexible approach of meeting the patients needs."
- "online appointments were much easier and accessible especially to people who struggle with travelling. Some users of the service have to travel several hours just to sign a form"
- "Virtual appointments are perfect for everyone, but having to travel 2 hours to get to a hospital, the costs involved and having to schedule a whole day for an appointment really isn't great."
- "Video appointments have saved me hundreds of pounds in transport costs and time I would have had to take off work to get to an appointment. The technology has also worked pretty well from my perspective (I think the clinicians find it more difficult at their end)"

# Question 13 - What feedback would you like to give about... the facilities at appointment sites

48 of 63 respondents answered this question. The themes that emerged from feedback about the facilities at appointment sites included:

**Approval of facilities –** Most participants were satisfied with the facilities at Walkergate Park highlighting that they were clean and functional. Others also highlighted the provision of unisex toilets with changing provisions, accessible rooms and informational leaflets as a positive.

- "Very modern and as you would expect."
- "There's always been an appropriate toilet(unisex) near by to use if needed before/after appointments. There's also usually been a water cooler too which helps. No complaints again"
- "The facilities are clean and have accessible rooms and toilets and it has been easy to take my baby and change them in the changing stations provided"
- "Facilities are clean and functional. Waiting room have useful information."

**Discomfort** – some participants noted a discomfort when attending Walkergate Park for their appointments. Complaints ranged from the temperature of the rooms where

appointments are offered, to the range of literature on display in reception areas. One participant mentioned the fluorescent lighting being inaccessible for those with neurodiverse conditions.

- "Rooms normally too warm for me, like saunas. Very uncomfortable.
- "The waiting area is on the minimal side"
- "Maybe consider non-fluorescent lighting since so many patients are neurodivergent."
- "The chairs in the waiting area get quite uncomfortable. Otherwise facilities have been appropriate. The info on the boards in Benfield house has been helpful, but very specific to the local area. There are a lot of trans folk in the Durham area but there's no info for them at all."

## Question 14 - What are the things that make you feel welcomed and safe in our service?

50 of 63 respondents answered this question. The themes that emerged from feedback about what made service users feel welcome and safe in NRGDS included:

**Staff** – The majority of participants named staff as the main reason they felt welcomed and safe in NRGDS. Participants highlighted that the team as a whole demonstrated trust values and where empathic, helpful and approachable. Moreover, many participants highlighted that staff's desire to help was especially authentic allowing them to feel welcomed and safe.

- "The whole team are very welcoming."
- "General friendliness, lovely staff"
- "All the people I've encountered have been friendly and respectful, putting me more at ease"
- "Very welcoming, good listeners and every effort to help me."
- "The staff are excellent, from the receptionist staff to the dr's and endocrinologist."
- "a huge asset to the service, great listener, very helpful and genuinely wants to help in all aspects"

**Considerate approach** – Participants highlighted that staff's cultural sensitivity and ability to provide care with understanding, compassion and with trans issues in mind was particularly influential in them feeling safe and welcomed at NRGDS.

"support is key, having safe space to discuss anything without any judgement.
patients who are trans get enough abuse in the media. warm, friendly
approachable staff. staff who are equipped with emotional intelligence and
maturity."

- "Following GDPR and nurses are quite understanding and polite."
- "The understanding that staff have of the problems you are having"
- "Being made to feel genuinely welcome by trusting, caring practitioners/clinicians and able to talk freely without fear"

**Building** – Participants also noted that the building and location could add to a sense of safety and feeling welcomed. Participants spoke about the secure doors, the NRGDS using a building used for other purposes added to this sense of safety as it is not easily identifiable why they are using the building, as opposed to a building which would only house the NRGDS.

- "Having trans and Igbt information in the waiting room helps the place to feel safe and welcoming. I also like that the treatment rooms and waiting area are outside of the main hospital."
- "Secure doors. Not in the reception though. Quite fearful of people if they were to intrude."
- "No indication of service on outside of building etc"
- "The posters and information on the waiting rooms are very helpful and not having the services advertised in the hospital signs is comforting even though it means it was hard to navigate to the appropriate building in my first appointment"
- "There's CCTV at all of the facilities and it hasn't been public what the buildings are used for(in case of bigotry etc). I've always felt safe. No complaints here."

## Question 15 - What could we do to make you feel more welcomed and safe in our service?

46 of 63 respondents answered this question. The themes that emerged from feedback about what NRGDS could do to make service users feel more welcomed and safe in the service included:

**Nothing more** – Many participants stated that nothing else could be done to help them feel more welcome and safer in service, going on to highlight that they would like the service to be maintained as is.

- "Nothing, maintain that service!"
- "Nothing you already do enough"
- "I feel very welcome and safe. Nothing more could be added."
- "I am totally happy with the service provided at all times and the effort they make at NRGDS."
- "Nothing comes to mind at the moment, I've only had positive experiences with NRGDS so far."
- "I am not sure because I have been very well looked after."

"Nothing really, you do great"

**Facilities –** Some participants stated that improvements to NRGDS's facilities would help them feel more welcome and safer in the service. A common request was for the service to provide refreshments, specifically coffee and tea. Additionally, some participants reported that Walkergate park felt too clinical and needs more informational leaflets to help prepare themselves for appointments.

- "a cup of coffee;)"
- "Drinking facilities"
- "A cuppa would be nice!"
- "I haven't attended the service since before the pandemic so this may be irrelevant if it's had a makeover. If so, I apologise. More open/brighter waiting area as it feels like I'm being hidden away, almost in shame. I feel like that enough already"
- "Less medical setting, more info about what will happen in the first session, easy read / more accessible or clear definitions about what will happen during appointments"
- "Unsure. It is a hospital. Has all of the available leaflets etc. Maybe a notice board with local groups / information on"

**Additional support –** A minority of participants asked for additional peer support, or links to local support groups to meet more trans people being available for them once past waiting. The NRGDS has a Peer Support Service to help those on the waitlist, but this support does not usually extend past a persons' assessment period. Some participants also indicated that accessibility could be better in creating a safe environment, with some comments directed towards facilities such as the option to wait outside the building. A few comments were also toward staff and being given the space to express themselves without judgment.

- "Maybe a notice board with local groups / information on"
- "Better changing facilities, space. Ability to meet with peers for mutual support."
- "Well trans persons like myself are usually very nervous, maybe a system where you can ask for a call when doctor is ready, so you can wait outside"
- "patience and understanding that I struggle to find the words i need to explain how I'm feeling and or what I'm experiencing and that that can lead to misunderstandings."

Question 16 - Are there any adjustments we could make that would make it easier to manage appointments?

48 of 63 respondents answered this question. The themes that emerged from feedback about adjustments NRGDS could make to make it easier to manage appointments included:

**Nothing to add and praise –** this theme incorporates participants comments that no further accommodations needed to put in place by NRGDS. The theme also incorporates participants who were very happy with the appointment process received so far and praised the appointment process.

- "to be honest, you have manged the appointments so well BC (before covid) and after, you are the best healthcare service I have experienced within the UK, I have experienced many as I have lived in different locations. I truly thank all of your team, for all the hard work, commitment and dedication that goes onto this dept and supporting the diverse range of the LGBT community. THANK YOU!"
- "Can't think of any suggestions for improvement at present"
- "No, do things pretty well"

**Remote appointments –** some participants were unaware that videoconferencing or phone appointments were available. Others asked for more of their appointments to be done remotely due to the location of the clinic.

- "I understand that certain Dr's are only in on certain days, perhaps having the
  option to have video calls with them or telephone appointments on days
  where you cannot get in would help. I missed a few days at college to attend
  appointments."
- "We've had to use a fair bit of IT here and there, and OneConsultation has been poor. It's often dropped out or failed with various practitioners. Using something more stable would help to facilitate remote work more effectively. Contact time is scarce, losing time to IT issues is at times distressing."
- "Don't expect me to answer phone calls or take time off work, offer virtual appointments again."
- "Easier to book appointments. Make online/phone appointments standard

Alternative booking system – some participants suggested that changes to the booking system would help them manage their appointments. The most common request was for an online booking system or app. However, other requests included more notice to be given before appointments, text and email reminders about appointments and for service users to be able to book an appointment within a given timeframe. One participant also suggested that it would be helpful to have appointments with different clinicians booked directly after one another e.g., have a speech and language therapy appointment directly after an appointment with a doctor.

- "Online Portal for appointments (Unless this is already a thing!)."
- "E-booking of appointments would be helpful. Maybe something along the lines of the "Ask mygp" app"
- "Online system. Regular updates about appointments."

- "access to appointment info through nhs app could be useful"
- "Perhaps having the team communicate among themselves to coordinate appointments - so for instance timing speech therapy appointments for directly after a consultant appointment - as it is far for patients to travel and pay for parking etc. and it is difficult to get time off work for multiple appointments; would be easier for a double appointment. Nothing else could be improved"
- "Maybe offer a timeframe to ring up and make appointments rather than just setting one"
- "Give sufficient notice of appointments in case we already have other appointment, including prior sent different NHS appointments. Should appointment schedules change, give service users some flexibility when arranging the new appointment dates/times."

**Explanation of the pathway –** some participants seemed to wish for a bit of additional preparedness before appointments, which included the possibility of videos explaining the different kind of appointments, as well as additional clarity on how to make appointments.

- "Just explain the system so people do not get frustrated."
- "More clarity"
- "Maybe make some videos of the kind of questions that might be asked at different types of appointments, to give context and example. Can be quite daunting otherwise not knowing what to expect."

Question 17 - Are there other forms of technology that you would like us to consider using to improve the services we offer you?

42 of 63 respondents answered this question. The themes that emerged from feedback about other forms of technology that NRGDS could consider to improve the service included:

**App/web portal** – a lot of suggestions focussed on an app being developed which would tie up their care into one portal – somewhere to upload test results, get in touch with clinician/the clinic, book/manage appointments

• "Patients could have an online account or app to access all their records, previous appointments, care received, referrals, surgeries (past and future), medications used previously and currently using. \*Add notifications to remind patients of upcoming appointments/blood tests needed/other information \*Make it possible to book appointments through the patient account \*Add a possible message system to the account so patients can contact their Doctor/NRGDS easily"

- "App with all professionals and test results on. App system to communicate any questions to nurses so it doesn't take an appointment up."
- "A app with appointments would be cool"
- "Online system / portal to review all letters / medical history / communications.
   Personalised account to view these plus wait times and treatment available to me."
- "Be nice to be an app, where I can see all my notes, my next steps and
  messages could be sent between staff and patients. I've found sometimes I've
  needed to ask a quick question but unable to speak with an appointment and
  this could have saved appointments for one questions. Also see blood results
  etc"
- "It would be handy to have the service integrated with my Patient Access app.
   It allows me to request appointments and current medication with my GP when needed."

**Technology to improve integration with primary care** – similar to the above, focus on reducing having to send in blood results manually (more pertinent to those outside of the NE ICB/HIE/GNCR footprint)

- "The only other tech related thing I can think of is some link with GP surgeries and medical records (respecting client preference and confidentiality of course). I've had a very difficult time getting that kind of thing set up with my GP and NRGDS. This has caused wasted appointments, where I've had to use resources I don't have to attend on site to see a doctor to review my meds, who then tells me they've not got results and aren't going to help with anything else. See you in six months!"
- "Add notifications to remind patients of upcoming appointments/blood tests needed/other information"
- "so it doesn't take an appointment up, Chasing bloods, or missed information needing confirmation"
- "use email to communicate letters to gp"

**Technology fine as is –** Around half of the responses said that the clinic shouldn't be introducing new forms of technology as it is fine as it is. A smaller subset of people wanted the clinic to use less technology and go back to face-to-face for most appointments.

- "Fine with what's available"
- "None that I can think of"
- "seems to work well"
- "Face to face first choice."
- "I really don't think online should be used when a service user is prepared to attend a location for a face to face appointment."

- "Not really since you started offering video chat"
- "No thank you. Face to face is best for appointments."
- "no idea, no feedback"

**Technology associated with remote appointments –** Many participants mentioned the technology used in virtual and telephone appointments in their responses. In particular participants brought up issues with one consultation citing previous issues they had experienced due to one consultation's perceived unreliability. Instead, participants offered zoom, attend anywhere and teams as alternative platforms which they would prefer to be used for virtual appointments. One participant also highlighted that they would like to see an increase in the number of virtual appointments offered and more funding provided for better sound technology.

- "I've mentioned the joy that's OneConsultation earlier. We use AttendAnywhere for the same thing, and while it's spotty, it has been more reliable than OneConsultation. It's a possible alternative if you're reviewing tech."
- "Online lessons for the speech therapy would be good. A few 'worked examples', e.g. with Ampitch, would prove useful."
- "Zoom or teams for alternative meeting. Work can be difficult about appointments"
- "more video call availability, with better sound technology for doctors. Also could make use of virtual signatures for certain patients who have use of touchscreen. This again would help to streamline the costs of the service"

Question 18 - Every time that someone misses an appointment at NRGDS without letting us know in good time, this adds an extra period of waiting for those people on the waiting list. What do you think would help to reduce missed appointments?

54 of 63 respondents answered this question. The themes that emerged from feedback about the way NRGDS could reduce missed appointments included:

**Punitive responses –** Responses to this question led to some answers, suggesting that the solution to missed appointments would be a punitive measure, with fines, restricting service access, and being moved down the waiting list for missing appointments being suggested as these. The current policy is if three consecutive appointments are missed without a minimum of 24 hours' notice, a person is discharged back to primary care. Whilst we understand the need to ensure that no appointments are wasted, the service has no wish to take a punitive stance on missed appointments.

- "Gatekeep more, hormones and referrals are up because people often mistake gender dysphoria for something else."
- "If every effort has been made to contact and remind patients of their appointments, then immediately remove them from the NRGDS patient list, they'll have to be referred again if they want to use NRGDS services, they'll have to join the waiting list."
- "Put them back to the bottom of the list as if they are not attending they maybe wavering in where their journey is going"
- "Fine people that don't attend with a good valid reason"
- "Fine people, take them off/move them down the waiting list for hormone replacement/surgery."
- "if people miss the appointment, the NHS should charge them for it. simple."
- "I believe the appointments missed are totally due to the persons with the
  appointment failing to contact the service to cancel. It is their appointment and
  their responsibility. The contact details are always provided perhaps if they
  were refused a further appointment they would think hard about the impact on
  other patients who are in greater need than themselves."

**Processes that are already in place –** many had a good understanding of the current Did Not Attend (DNA) policy, suggesting that the current policy is popular with current service users

- and if people frequently miss their appointments without reason they should be considered for removal of services
- If someone just doesn't show up perhaps they should be kindly warned that if another appointment is missed they will be demoted down the list or referred back to GP?

**Managing appointments through reminders –** The majority of responses indicated that missed appointments could be avoided with reminders on the day before/the day of the appointment. In addition, some users responded that the increase in technology offerings would also make it easier for people to manage appointments and hopefully lead to fewer cancellations such as having to respond to a text to indicate you are still planning on attending for example.

- "Better notifications for when I'm about to have an appointment, as I often get texts almost a week in advance but not on the day before or morning of, when it would be more useful."
- "Texts are brilliant help me to keep track of appointments"
- "Electronic confirmation prior to appointment, e.g. responding to an automated text/email ~24h before appointment to confirm attendance"
- "Reminders by text and email. GP sends these and very useful. Discuss at time of making appointment whether person has any concerns about

attending, cost of travel, social anxiety, etc. Make sure they know they can bring a support person or maybe offer them one from peer support both to help them get there and support them while there. Plus reimbursement of travel costs if applicable."

- "I think an app would be good whereby people can cancel appointments"
- "Text and email reminders a week + a day before the appointment advising of appointment details like if it's with a doctor or a nurse, date and time"
- "Making people aware of the consequences of them missing appointments. Sending out text reminders, which you already do. Some of this is the responsibility of the individual attending the appointment, not NRGDS's."
- "More info on rescheduling appointments, more availability"

#### Question 19 - What's good about the service provided by NRGDS?

54 of 63 respondents answered this question. The themes that emerged from feedback about what was good about the service provided by NRGDS included:

**Staff qualities –** Participant's responses were overwhelmingly focused on praise for the staff involved in their healthcare, highlighting how the team as a whole and individual staff members had a positive impact on them and their care. Participants highlighted that staff embodied trust values and emphasised that NRGDS's passionate and dedicated staff made an effort to empathise and validate service users.

- "Undoubtedly the staff. My previous experience with a gender clinic some 25 years ago was incomparably worse than the support I have received at NRGDS"
- "NRGDS are doing a great service in such an understaffed/ underfunded environment. They always make my issues feel important, even if they would seem very small to standard doctors."
- "The most wonderful team who provides the service is the greatest assets to the excellent service NRGDS offer"
- "It is comprehensive. The speech therapy and psychotherapy proved much more useful than I thought they would. The staff are all very good at what they do. Honestly can't think of a bad experience. Highly professional, perceptive, sensitive and caring."
- "Everything, they are far more approachable and willing to do everything they can to help. Nothing is a problem to the dedicated staff."
- "I truly believe this service saves lives. It saved mine for sure."
- The doctor that I see is very friendly and supportive, and so is the voice therapist!
- "Staff are all brilliant, fantastic service."

Positive experiences – This theme incorporates the praise of staff members detailed above as well as participants positive experiences in NRGDS as a whole. A lot of responses spoke about how much better their care was than expected, and only showed positive change. Indeed, participants highlighted even in situations where they had encountered issues with NRGDS it was taken seriously and quickly rectified. Participants stressed that they valued the service's openness to feedback and proactiveness. Moreover, participants commended the team's ability to provide personalised and individualised care ensuring that service users were understood and received collaborative care. Finally, participants highlighted that staff where supportive when discussing subjects and dealing with issues outside of NRGDS's remit such as surgery and the current climate towards trans people in the UK.

- "They have really helped me feel more confident in who I am, extremely validating whilst also erring on the side of caution when needed (when talking about surgeries)"
- "The staff generally seem to be very understanding of our needs and do their best to fight our corner in whatever wats they are able"
- "everyone seems very well informed and up to date on community matters and have been very understanding of issues that prevent from arriving on time or at all"
- "Everyone is very friendly, there is no push for certain treatments"
- "I've always felt if I've ever had an issues that it will be taken seriously and they're usually quick about responding to emails"
- "They have really helped me feel more confident in who I am, extremely validating whilst also erring on the side of caution when needed (when talking about surgeries)"
- "I feel like the teams are passionate about helping and changing the services to be more proactive and helpful and run smoother"

#### Question 20 - What could be better about the service provided by NRGDS?

53 of 63 respondents answered this question. The themes that emerged from feedback about what could be better about the service provided by NRGDS included:

**Wait lists** – A small majority of comments focussed on all waiting lists within the service, not just the waiting list to initially being seen. This theme includes those who have asked for more availability for surgeries, voice and communication therapy, and psychology.

- "Lower wait times"
- "I know you're sick of seeing this but it's the wait times."
- "We need to push for funds to support service users, increased frequency of assessments and thereby reduce the huge NRGDS backlog."

- "Only that which is impossible, I'm sure more funding would allow for reduced waiting times, but that is an issue seemingly being suffered through by the entire NHS currently. A more serious answer however, nothing. Within the restrictions imposed by waiting times and limited funding, I have found the entire process convenient and beneficial for my HRT and transition process."
- "The waiting times for the various services, to mention the crashingly obvious. I 'only' had to wait a year for my first appointment (Jan '17), but the wait for psycho was more like three years, I think. In retrospect, I wish this could have started sooner."
- "You all know what I'm going to say right? ② (Mainly aimed at NHS England, the only things that could (SHOULD) be better) Ready.. REDUCE. ③
   WAITING. ③ TIMES. ⑤"
- "Faster route to GRS"
- "Black hole of Information related to individual waiting times throughout process of both assessment and surgical treatments. Despite trying to remain positive and focusing as much on distractions as possible, certain elements of life are on hold or in limbo."

**Logistical support –** This theme encompassed suggestions from people pertaining to more contact opportunities with the services, the travel to get to appointments, facilities, and locations. There were few responses relating to this theme, however of the comments, it was clear that people wish to have more contact and be more involved with the service.

- "More communication in a variety of forms such as email, letter, phone call."
- "Longer appointments, more appointments per year, with more communication with doctor about progress and treatment."
- "Also I would suggest that more meetings/contact with the service would have been good during the early part of transition and especially post surgery."
- "Waiting room not very comfortable/ big at Newcastle. Be nice to be able to sit with others if wanted but also sit away from people going to other services
- "More communication between appointments or before the first appointments and lists of resources for the meantime"

**Expanding existing parts of the service –** This theme looks at what the service is already doing and how it could be improved. Some participants asked for an increase in mental health support, more appointments, and a suggestion that the Peer Support Service be expanded in order to provide support to those in treatment also.

- "Things to help well being in between appointments, keeping in touch with patients while waiting – resources"
- "More peer support events that can be attended by active service users
- "Perhaps some type of help(or resources) for those who are waiting for their initial appointments, those between surgeries etc."

- "Whilst many trans folk are not qualified professionally, a peer to peer support group and some face 2 face support meetings utilising GP surgeries with trans folk willing to be vetted and screened, plus receive some basic training would both ensure that folk felt included and that they were valued."
- "More information about different options that are available, like help with name/title changing or speech therapy that people might not necessarily know exists or how to do"

## Conclusions

This survey was conducted to refresh the 2019 Service User Evaluation. It aimed to measure changes in service user priorities and provide goals for new areas of service improvement.

The sample of 63 participants, whilst small, is overall 11.84% of those in treatment. We believe the sample to be representative of those in treatment as a whole as the age sample broadly corresponds to this, as does the mix of genders.

Participants were positive about the care and treatment, and this was evident in the coding and development of themes. The majority of responses to questions about what the service could improve on or introduce were "none" or "n/a", with the exception of wait times which was evidently a theme across.

Further positives relating to care and treatment included the staff. The vast majority of participants praised the clinicians' and other staff's values and how this was demonstrated to the service user in every interaction with the clinic. Throughout the consultation, service users especially praised the sensitivity of staff in incorporating culture, gender and socioeconomic status to personalise their care and make it truly individualised. Accommodations within Voice and Communication Therapy, for example, such as educating trans-masculine individuals about vocal practice when binding and not binding was found to make the sessions particularly helpful.

The administrative processes in the clinic received wide praise for the friendliness of the administration team, how quickly requests are actioned, and how pleasant it is to interact with those in the administration team. In summary, overwhelmingly the respondents were very appreciative of those who work for NRGDS and able to separate the clinicians from the issues within the field, which contribute to the waiting lists.

Similarly, to the staff, NRGDS facilities were largely praised. However, there were a few suggested adjustments relating to accessibility, such as replacing fluorescent lights and making the clinic offices feel warmer. A common suggestion was for refreshments particularly tea and coffee to be provided in the reception area. Finally, some participants suggested that resources could be provided in the reception area either via a notice board or leaflets. There are already these resources in place but some people may benefit from having them highlighted

The addition of remote consultations following the changes due to the COVID-19 pandemic have been very successful. Indeed, in many responses about appointments, technology to meet healthcare needs was praised. There were a few people who reported difficulties with connectivity, or preferred a solely face-to-face service, however the majority were in support of expanding remote consultations where possible as they found it improved flexibility, allowed service users to better manage their time and avoid using leave from work, to attend a short appointment.

Despite the above, there was negative feedback. Throughout the survey there was a running theme about the perceived pathologisation of service users by staff members. Some participants stated that they felt that staff were adding stress to their transition. In particular, participants reported that they felt that there were barriers in their journey, that they felt that they were asked unreasonable questions and were asked to explain themselves to an unnecessary degree. This theme has been covered in detail throughout the report and included the comments of a small minority. Indeed, in contrast the majority of participants praised staff's cultural sensitivity and competency and their ability to individualise care in a way that was not deemed intrusive.

Some participants requested more frequent appointments, more information about future stages, or what to expect from appointments and sought clarity about appointments to help with anxious feelings.

Information about pathways and assessments is available on the service webpage and this cohort of respondents may not have had this in place when they were referred into the service. Some participants were seemingly unaware that NRGDS employed nurses and offered psychological therapy as well as voice and communication therapy. The service could improve signposting to the website and develop a "who's involved in your care document" to support people who struggle to navigate healthcare systems.

Finally, information sheets may help to address comments from participants who wished they had used other parts of the pathway of which they had previously been unaware. Improved signposting to resources may help to improve understanding of the service, staff roles and service users overall experience in NRGDS.

Participants requested improved software for online consultations which is not within the gift of a single service as this is provided trustwide. Some suggestions such as an expansion of the Peer Support Service to include opportunities for those in treatment could be considered in conversation with service commissioners in the future. Further suggestions included expanding Information and Communications Technology with a focus on a potential app/online portal, or new appointment management system enabling better communications with the team. However, this is again dependent on financial and feasibilities studies.

We appreciate and value all of the feedback we receive from service users, and we endeavour to investigate the potential of all participants' suggestions and enact

changes where possible. However, this is only possible within the limitations of funding and commissioning pathways.

In summary, the vast majority of responses were positive and had little to add to what could be done to improve the service. There were a few helpful suggestions outlined above. The clinic is already working on creating information sheets for primary care, in order to improve knowledge. In addition, a training event was recently provided for GPs and others in the healthcare field and it is hoped that this can become a regular event to improve education in healthcare across the region. Information sheets about the pathway have also been discussed and examples of these are available on the service website.

Expanding the role of ICT within the clinic has also been addressed recently, with a redesigned website incorporating suggestions from service users launched in Q3-4 2022, and we are always looking for new ways to incorporate technology to make the experience of the clinic better.

We are extremely grateful for the kindness and support of our service users, especially all those people who gave freely of their time to work with us to improve the service.

- K. Cronesberry, Assistant Psychologist, NRGDS, CNTW
- H. Fleetwood, Honorary Assistant Psychologist, NRGDS, CNTW

#### References

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Laws, A., Matupi, E., & Shaw, M. (2021, May 9). *The Northern Region Gender Dysphoria Service (NRGDS) Service User Evaluation 2019*. Retrieved from <a href="https://www.cntw.nhs.uk/content/uploads/2021/04/The-Northern-Region-Gender-Dysphoria-Service-SUE-2019.pdf">https://www.cntw.nhs.uk/content/uploads/2021/04/The-Northern-Region-Gender-Dysphoria-Service-SUE-2019.pdf</a>

#### **Appendices**

#### Appendix 1: Copy of the service user evaluation invitation email

Hello.

We are contacting you to invite you to give feedback on the service that we at NRGDS provide.

We are interested in hearing your views, both positive and negative.

The feedback you provide will be used to develop and improve the service.

All feedback is anonymous, and will not be able to be linked to you.

From time to time we ask everyone who is in contact with our service to let us know how it can be improved.

The results of the last evaluation can be found on the website here: <a href="https://www.cntw.nhs.uk/resource-library/northern-region-gender-dysphoria-service-service-user-evaluation-2019/">https://www.cntw.nhs.uk/resource-library/northern-region-gender-dysphoria-service-service-user-evaluation-2019/</a>

It is really important to us that you tell us what we are doing well or could improve.

We take your feedback very seriously and always take all feedback to team meetings, where it is discussed and actions are taken, wherever possible, to improve the service.

Sometimes this action is sending the anonymised feedback on, to NHS England, (who are in charge of paying for and creating health services for people with gender dysphoria) so that they can take your feedback into account in the work that they do.

We would be very grateful if you would complete this anonymous online survey to give us your feedback about the service.

We have given space so that you can raise issues that are important to you.

We think that the things that you can tell us, that we haven't thought about, are often the most important for us to know, so do please tell us what matters to you.

In summary, this is

An online survey

- The aim of the survey is to improve the service provided by the Northern Region Gender Dysphoria Service
- We won't know who has answered and who has not
- We won't be able to tell which answer has come from which person
- Choosing to take part or not will not have any impact on your treatment in the service.

We will publish a summary of the results of the survey on our website at:

https://www.cntw.nhs.uk/services/northern-region-gender-dysphoria-service-specialist-service-walkergate-park/

The survey should take no longer than 10-15 minutes to complete. You can complete the survey here:

https://forms.office.com/e/5QaecU5pSx

Alternatively you can scan the QR code below:



We thank you for taking the time to read this email. Your feedback is important to us, and we appreciate you taking the time to give it.

Best Wishes,

The NRGDS team

#### Appendix 2: Copy of the service user evaluation reminder email

#### We welcome your feedback!

The staff at NRGDS would like to thank all the people who have kindly given their feedback on how the service can be improved.

If you have not had a chance to share your views with us yet then please do get in touch using the details below!

A few weeks ago we sent you an e-mail about a survey to have your say about the NRGDS and what we can do better.

The survey should take no longer than 10-15 minutes to complete. Your feedback will be used to develop the service, the report from the last evaluation is on the website

You can complete the survey on any device with an internet connection.

You can access the survey by clicking on this link:

https://forms.office.com/e/5QaecU5pSx

Alternatively you can scan this QR code with a tablet/phone



Best wishes,

NRGDS.

# Do you use the Northern Region Gender Dysphoria Service?



## Would you please complete our online survey to tell us how you think NRGDS could be improved?

- It is an online survey that takes between 10-15 minutes to complete.
- The aim of the survey is to improve the service provided by the Northern Region Gender Dysphoria Service
- We won't know who has answered and who has not
- We won't be able to tell which answer has come from which person
- Choosing to take part or not will not have any impact on your treatment in the service.
- We will publish a summary of the results of the survey on our website at <u>www.ntw.nhs.uk/NRGDS</u>

You can find the survey here: https://forms.office.com/e/5QaecU5pSx



With YOU in mind

#### Appendix 4: Copy of the advertising QR code clinicians used

If you would like to be sent the link by email, please give your email address to your clinician who will arrange for the survey to be sent to you



#### Appendix 5: Copy of the service user evaluation survey

### NRGDS Service User Evaluation - 2023

Thank you for taking part in this service improvement survey.

We estimate it will take around 10-15 minutes to complete.

This survey is anonymous, this means we will not know who has completed it, and who has not.

We will also not be able to see who has given which answers.

Please do not put personal information, like your name, date of birth, or address into your answers.

#### Waiting times

We know that our waiting list is a problem that many people find difficult. We know about how difficult it can be to wait for assessment and treatment and we regularly get feedback from people about this.

We know that people who use our service want to make the waiting time for a first and second appointment shorter. We regularly give feedback to NHS England, who pay for gender identity clinics, about how current staff shortages make waiting times longer.

We work inside NRGDS to try and address waiting times and agree with the people that use our service that this is a problem and would very much like to find a solution for it.

Is there anything that you can think of that would have helped you with the process of waiting to be seen for first and second appointments?			

٠.	,	c 1					
Υ	our-	teed	back	c a	bout ti	he	service.

Apart from reducing waiting times, what feedback would you like to give about...

2.	First assessment appointment
3.	Second assessment appointment
4.	Follow up appointment with a doctor
5.	Follow up appointment with a nurse

6. Therapy	y and psychology?
7. Voice a	nd Communication Therapy?
8. The rela	ationships you have with staff who manage your healthcare?
9. Making	appointments
10. Commu	unicating with the team

11.	Letters, and administrative processes?				
12.	The locations appointments are offered in?				
13.	The facilities at appointment sites?				

#### Meeting with us

14.	What are the things that make you feel welcomed and safe in our service?				
15.	What could we do to make you feel more welcomed and safe in our service?				
16.	Are there any adjustments we could make that would make it easier to manage appointments?				

#### Technology at NRGDS

17.	Are there other forms of technology that you would like us to consider using to improve the services we offer you?

#### General feedback

18.	Every time that someone misses an appointment at NRGDS without letting us know in good time, this adds an extra period of waiting for those people on the waiting list.
	What do you think would help to reduce missed appointments?
19.	What's good about the service provided by NRGDS?
20.	What could be better about the service provided by NRGDS?

#### A bit about you

In order for us to make sure that we have responses from a good range of people who use our service that represents the voices of a wide range of service users, we would like to ask for some general details about you. These will not be used to identify you and you don't have to give us this information if you don't want to.

1. What is your age?		
0	18-24	
$\circ$	25-35	
0	36-45	
$\circ$	46-55	
$\circ$	56-65	
0	66-75	
0	75+	
22. My	Gender Identity is:	

23. My	GP surgery is in:
$\circ$	Northumberland
$\circ$	Tyne & Wear
$\circ$	Cumbria
$\circ$	County Durham
$\circ$	Darlington
$\circ$	Teesside
0	North Yorkshire
0	Another part of England