

The Northern Region Gender Dysphoria Service (NRGDS) Service User Evaluation 2019.



“My first appointment was extremely comforting and informative. I was treated with respect and care which was great for my mental state at the time”

“(Self-referral would) help a person feel they are taking steps themselves towards treatment pathways - a feeling of control.”

“I have nothing but good comments about the experience that I have had so far and are continuing to receive”

“The help and support provided is amazing, thank you”

“I was worried beforehand, but the lady I saw was lovely and very re-assuring”

Introduction

The Cumbria, Northumberland, Tyne and Wear NHS Foundation trust (CNTW) hosts the Northern Region Gender Dysphoria Service (NRGDS) which is a service for people who experience persistent confusion and/or discomfort as a result of discrepancy between their assigned sex and their gender identity.

In 2019, a qualitative research project was carried out examining service user's experiences of the service.

Methodology

Measures

The “NRGDs service user evaluation” survey was used.

Participants

Service users who were eligible for the survey were all those who had been referred and accepted by the NRGDs in June 2019 and who had an active email address on file. At the time there were 1562 service users open to the service, 1067 of these did not have an active email address recorded and therefore a total number of 495 service users were emailed. The age of all service users in the service at this time ranged from 18-85 years old with a mean age of 29.

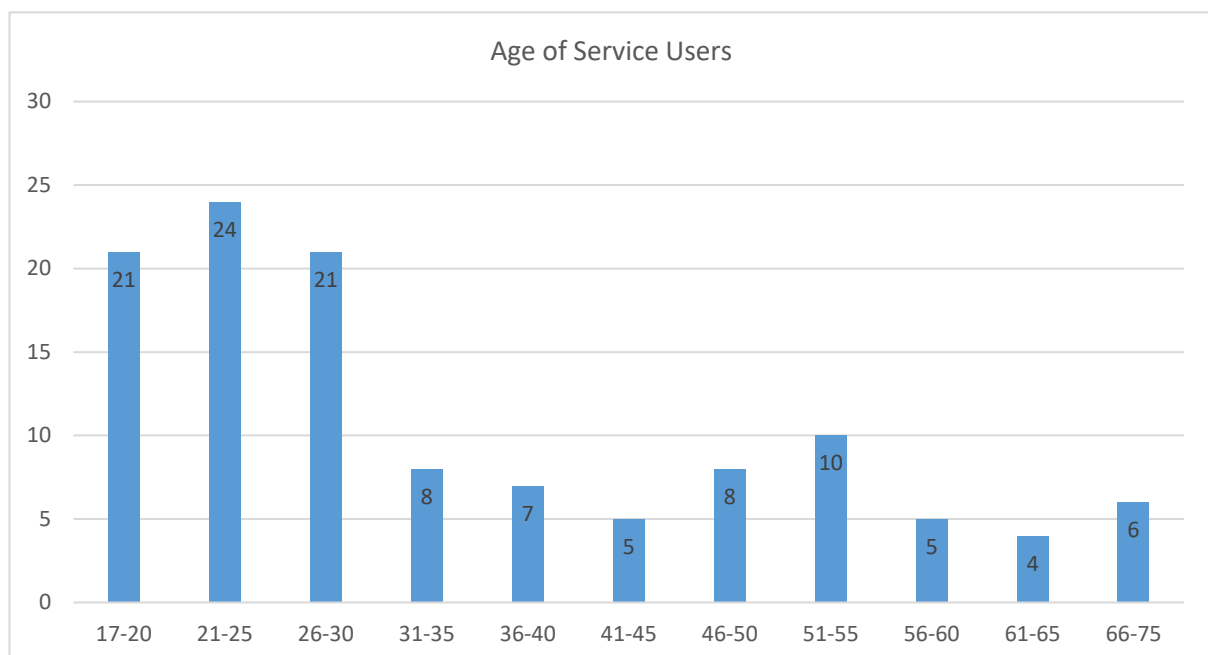


Figure 1 Age of service users

A total of 155 service users participated in the survey. 119 participants placed themselves in an age bracket. The overall age bracket covered ages 17--75. The majority of respondents (55%) were in the brackets 17 – 30 with the highest number in the bracket of 21-25.

Procedure

The electronic record was used to identify all service users who had a referral open to the service and had a recorded email address. A standard email was sent by an administrative assistant outlining the nature and purpose of the service evaluation and outlining assurances regarding the use and storage of responses. A link was provided to allow service users to complete the survey electronically. Responses were anonymised and collated.

Data Analysis

The data was analysed by the assistant psychologist within CNTW but independent to the NRGDS. The qualitative data collected from questions 1, 3, 4, 7, 10, 11, 12, 13, 14, 15, 16, 17, 18, 19, 20, 21, 22, 24, 25, 26, 27, was analysed using thematic analysis. This was conducted according to the guidelines set out by Braun and Clarke (2006), using a data driven approach, meaning the analysis was directed by the content of the data, rather than involving looking for particular themes within the data. The quantitative data collected from questions 2, 5, 6, 8, 9, 23, 28, 29, 30 were analysed using Microsoft Excel.

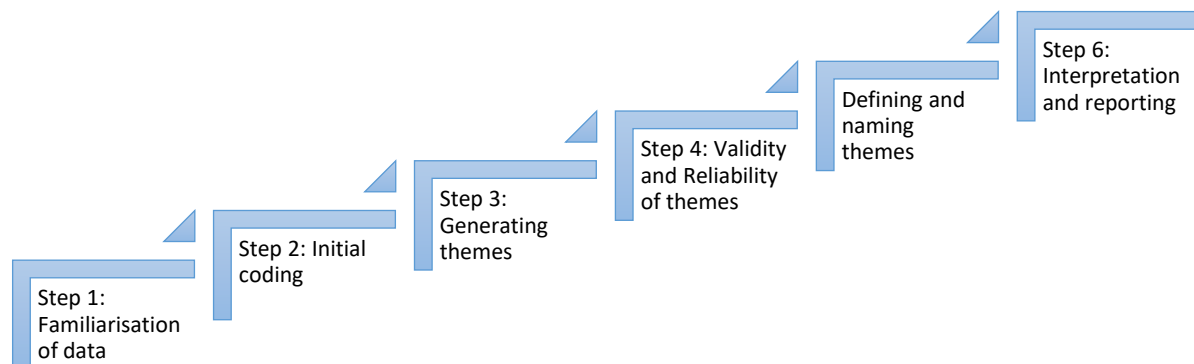


Figure 2 Braun & Clarke's (2006) six phase framework for carrying out a thematic analysis.

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 the first time? (n=141)

141 service users responded to this question. The themes that emerged around what would have helped with the process of waiting, included:

- **Communication** (46) - this included more regular communication (15), waiting list confirmation/place on waiting list (20), mental health check-in (1) and any other communication (10);
- **Managing expectations** (38) - this included helping service users to understand the pathway (3), providing information on place on waiting list (30) and accuracy of information about waiting times (5);
- **Distress** from being placed on a waiting list (57), this included feeling overlooked (7) and other distress (12);
- The final theme was that the service should provide **more information** (38).

“More frequent communication of progress”

“Better communication on the expected length of the list”

“My mood was significantly affected”

Question 2 - In the future, in addition to being able to be referred to our service by a health professional, NHS England has decided that people will be able to refer themselves to gender dysphoria clinics. They will still need to have a G.P. who is willing to collaborate with us in their care. We are designing a system for people to be able to refer themselves to NRGDS. If you had chosen the option of self-referral, how would you have wanted to do it? (n=132)

The majority of service users responded that their preference for self-referral would be through an **online form** (43%). **Email** (21%) was the second most popular choice. 16 service users (7%) would not wish to use self-referral.

Table 1. How would you like to refer yourself?

Option	Number of positive responses	Percentage (%)
<i>By letter</i>	21	9.17
<i>By email</i>	49	21.40
<i>By an online form</i>	98	42.79
<i>By using a form that you print off the NRGDS website and post</i>	33	14.41
<i>I would ask someone that I know to help me make a referral</i>	12	5.24
<i>I would not want to use self-referral</i>	16	6.99

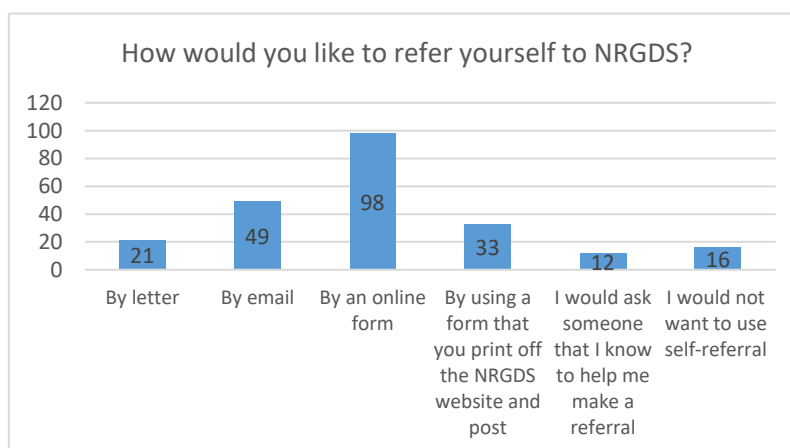


Figure 3. How would you like to refer yourself?

Question 3 - When we start using self-referral a person, or their GP, could contact us to make a referral. If a person self-referred, we would then contact their GP, to let them know that we have received a referral to the service. We may also need to gather more health information at this point. Self-referral will not allow a person to keep their contact with the service secret from their GP, as we cannot provide you with care without the collaboration of your usual doctor. What do you think would be the good things about a self-referral system? (n=125)

125 service users responded to this question. The themes that emerged around what service users thought would be good about a self-referral system included:

- Service users have had **adverse experiences** of the existing referral system (48);
- There is **lack of understanding from GPs** in the current referral system (44);
- Self-referral would **reduce distress** (29);
- Self-referral would create a sense of **empowerment and autonomy** (21);
- It would change **waiting time** (18), most individuals expressed that wait times would be quicker (16);
- The system would be made more **efficient** (13);
- A self-referral system this would **open up GP appointments to others** (4).

“It would be empowering - help a person feel they are taking steps themselves towards treatment pathways - a feeling of control”

“In my experience, many GPs are unaware of the existence of the gender service, so do not refer people”

“Opens up appointments for people with medical problems a GP is better suited to, and helps those with mental health problems such as anxiety or agoraphobia to get on the list”

Question 4 – What do you think would be the problems with self-referral system? (n=120)

120 service users responded to this question. The themes that emerged around what service users thought would be problematic about a self-referral system included:

- Concern that there would be **no screening** for self-referrals (40), leading to inappropriate referrals.
- An increase in **wait time** (37) - including an increase in absolute number of referrals (33) , increased inappropriate referrals (2) and concern about the process underpinning self-referrals leading to increased wait time (2).
- Concern that they would **still have GP involvement** (13).
- There might be **difficulty accessing or using the self-referral system** (15)

“I think it would massively increase waiting lists”

“People who are not sure could refer who may make the list longer for those who really need help”

“It may strain the service, as some people may not need the service”

Question 5 - How likely would you be to use a self-referral system? (n=131)

A significant majority of service users responded that they would **definitely use self-referral** (61%), with 17% saying they **definitely would not use self-referral**.

Table 2. How likely would you be to use a self-referral system?

Option	Number of positive responses	Percentage (%)
I definitely would not use self-referral	22	16.79
I might use self-referral	29	22.14
I definitely would use self-referral	80	61.07

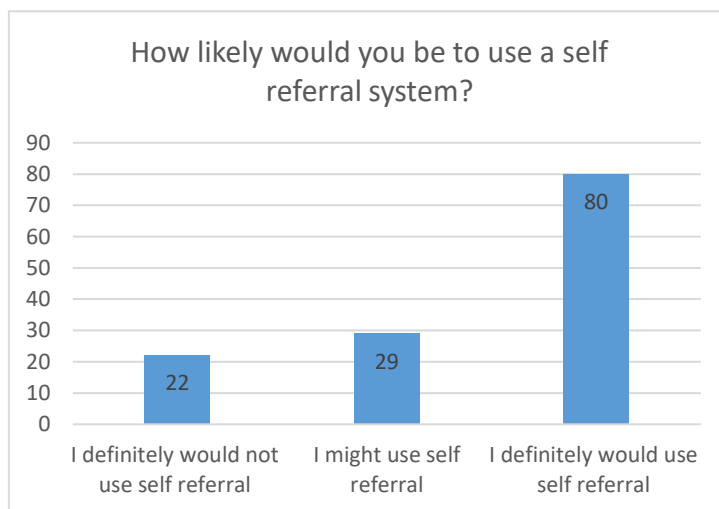


Figure 4. How likely would you be to use a self-referral system?

Question 6 - If you could have self-referred to a gender identity clinic, would that have changed how your referral to NRGD was made? (n=128)

A narrow majority (53%) of service users responded that if the option of self-referral had been available to them, this **would not have changed how their referral was made**.

Table 3. Would self-referral changed how your referral to NRGDS was made?

Option	Number positive responses	Percentage (%)
Yes	60	47
No	68	53

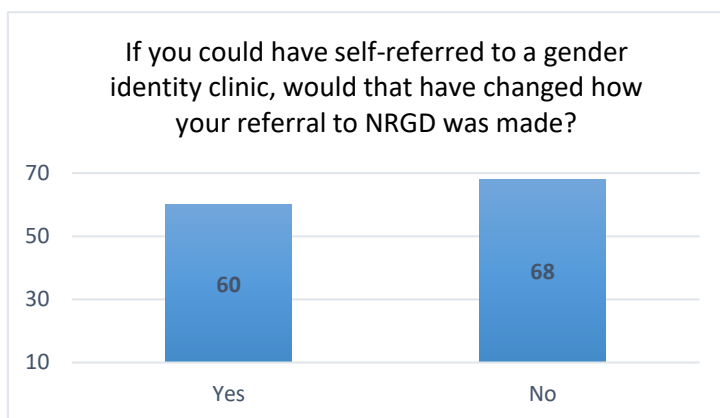


Figure 5. Would self-referral changed how your referral to NRGDS was made?

Question 7 - How would your referral have been different? (n=116)

116 service users responded to this question. The themes that emerged around how services users thought their referral would be different included:

- The referral process would have been **quicker/simpler help** (26);
- It would have helped them to **come out sooner** (8);
- They would have **used the self-referral system** (6);
- There would have been **no difference to their referral** (26) - either because they had a positive experience with GP referral (10) or due to other reasons (16).

"I wanted my GP on board from the start and felt it best to leave referral in their hands"

"I would have bypassed several weeks to months on waiting for my GP to send the referral I needed."

"I would have been more honest about my gender identity"

Question 8 - We would like more regular feedback from people who use our service. What way would make it easier for you to give your feedback more regularly? (n=135, R= 311)

135 service users responded to this question, participants were given the choice to choose multiple options, in total there were 311 responses. The 2 most common responses were for service feedback to be provided through [Survey Monkey](#) (31%) and [Email](#) (24%).

Table 4. What way would make it easier for you to give your feedback more regularly?

Option	Number of positive responses	Percentage (%)
Doodle poll	18	5.79
Survey monkey	96	30.87
Email	76	24.44
Paper survey that you complete and post back	20	6.43
Telephone appointment with a manager	24	7.72
Telephone appointment with a service user who is trained to take feedback	23	7.40
Service user meetings at the weekend	22	7.07
Service user meetings on a week night	17	5.47
Service user meetings during a weekday	10	3.22
Other (please specify)	5	1.61
	Any form of online survey. There is more time to process the question and think of a constructive response.	
	Digital patient participation group where patients have the option of being skyped or conferenced in to meetings as I understand that the patient group covers a wide area and travel may not always be possible.	
	People engaged in the service cannot give honest feedback due to the potential for withheld treatment and delayed access - even medical professionals are susceptible to biases	
	Interview by the Line app	
	After appointment email with link to survey.	
	At appointments	

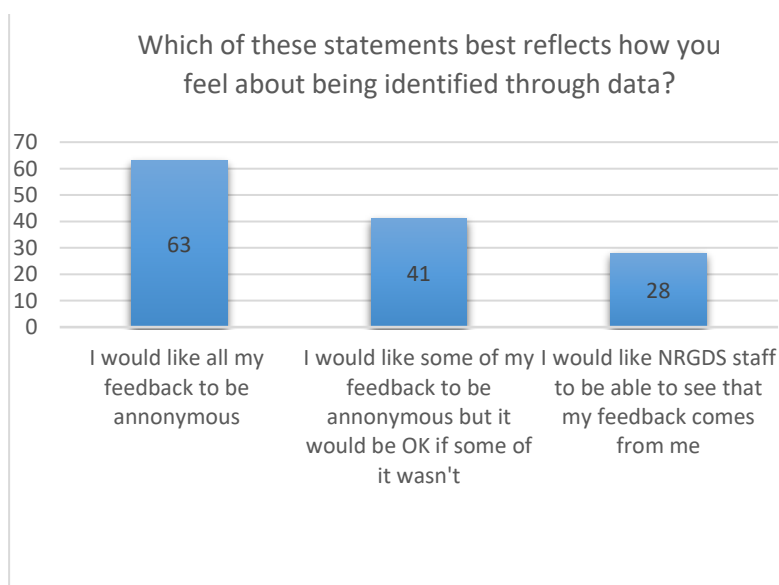
Question 9 - We would never publish feedback from service users in a way that they could be identified. When we collect feedback, we can collect it in a way that it is anonymous, or in a way that you can be identified to relevant staff in the clinic. Which of these statements best reflects how you feel about this? (n=132)

132 service users responded to this question. A clear majority of responses indicated that they would like their feedback to **remain anonymous** (48%). With 31% responding that they would like some feedback to be anonymous and only 21% comfortable with NRGDS staff being able to **see which service user has provided the feedback**..

Table 5. Would you like feedback to be anonymous?

Option	Frequency of positive responses	Percentage (%)
<i>I would like all my feedback to be anonymous</i>	63	47.73
<i>I would like some of my feedback to be anonymous but it would be OK if some of it wasn't</i>	41	31.06
<i>I would like NRGDS staff to be able to see that my feedback comes from me</i>	28	21.21

Figure 6. Would you like feedback to be anonymous?



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

Question 10 – First Assessment Appointment? (n=116)

116 service users responded to this question. The themes that emerged around peoples first assessment appointments included:

- **Poor communication** from the service (17);
- Staff were **comforting and caring** (26);
- The assessment was **helpful and informative** (29);
- The assessment made them feel **uncomfortable** (13);
- The assessment was **unnecessary** (7);
- The **location** (6) - 5 of these responses were negative comments about the location, 1 was positive.
- **Still waiting for an appointment** (5) and therefore could not comment. 10 service users responded about **wait time** (10).

“More details of what to expect rather than an impersonal letter”

“I was worried beforehand, but the lady I saw was lovely and very re-assuring”

“Some very detailed written information to take away, links to resources and support”

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

Question 11 – First appointment with a doctor? (n=113)

113 service users responded to this question. The themes that emerged around service user's first appointment with a doctor included:

- **Positive/at ease** (28);
- **Nervous/uncomfortable** (7);
- **Pointless/unnecessary** (4);
- **Informative** (9) - most responses about information suggested that more information could have been provided about the service to manage expectations (7) and some commented that the information provided was good (2).

“Amazing doctor made me feel so at ease and explained everything to me and answered all my questions”

“Nerve wracking but went well”

“Again felt kind of useless since I knew about the process - lots of wasted time because of this”

“I have no negative feedback”

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

Question 12 – Follow up appointments with a doctor? (n=104)

104 service users responded to this question. The themes that emerged around service user's first appointment with a doctor included:

- The experience was **positive** (caring, respectful, reassuring, excellent, relaxed) (26);
- **Communication** from service (13) – some responses suggested that communication of information could be better (10) and a few suggested that they were happy with the level of communication (3);
- **No complaints** (11);
- **Timeframe** (4) - comments suggested that more frequent appointments would be better;
- The appointment was **unpleasant** (2);
- The appointment was **unnecessary** (2);
- Some responded that the question was **not applicable** as they hadn't had a follow up appointment with a doctor (25).

"The help and support provided is amazing thank you"

"Very enjoyable and useful appointments"

"Occasionally felt like more clarification was needed without me having to prompt though"

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

Question 13 – Follow up appointments with a nurse? (n=104)

104 service users responded to this question. The themes that emerged around service user's experience of appointments with a nurse, included:

- **Not applicable** (51) – the majority of participants had not received a follow up appointment with a nurse;
- **Positive** experience with nurses (31) – personable, good, fantastic.

"The nurses are always fantastic."

"I've not had follow up with nurse."

"Good, effective, efficient."

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

Question 14 – Making appointments? (n=109)

109 service users responded to this question. The themes that emerged around service user's experience of making appointments, included:

- Easy simple and efficient (15);
- Positive experience (13);
- Difficult and problematic (10);
- Negative comments about staff attitude (2);
- Appointments were made at short notice and they were unpredictable (15);
- Service users suggested another method for making appointments (8);
- Long wait times to make appointments (8);
- Their appointments were arranged by NRGDS (7);
- Some responded that the question was not applicable as they had not yet had to arrange appointments (17).

“Very straight forward process, easy to make appointments”

“I felt like I had to chase every appointment”

“We should be able to go online and reschedule appointments”

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

Question 15 – Communicating with the team? (n = 106)

106 service users responded to this question. The themes that emerged around service user's experience of communication, included:

- Positive (44) – including kind people and excellent communication;
- Poor contact (28);
- Not applicable (11) – service users had not communicated with the team yet;
- Admin/reception (9) – including difficult communication and admin team needing better knowledge of the whole process.

“Receptionists need to know more about the whole process.”

“Had little communication between appointments.”

“Easy all really nice and dealt with any issues straight away.”

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

Question 16 – Letters and administrative processes? (n=109)

109 service users responded to this question. The themes that emerged around service user's experience of letters and the administrative process included:

- Delayed/slow/letters have not arrived (33);
- The process is good (31);
- No problems with the process (10);
- The process is efficient and prompt (9);
- There are problems with confidentiality (5);
- Mistakes made within process - (5), including the use of wrong pronouns;
- Some responded that the question was no applicable (5).

“Very slow and annoying”

“Very accurate with processing letters and appointment letters etc.”

“Letters have arrived promptly and all details have been correct.”

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

Question 17 – Therapy and psychology? (n=105)

105 services users responded to this question. The themes that emerged around service user's experience of therapy and psychology included:

- Haven't had therapy (54) – either this was not applicable (45) or they hadn't been offered therapy/psychology (9);
- Experience of therapy was good (30) – this included comments that therapists were kind, respectful and supportive;
- More therapy would be helpful (3);
- Recommended that others should be offered therapy/ psychology (3);
- Experience of therapy was negative (2).

“I have not been offered any therapy or psychological services.”

“Outstanding.”

“Really good, I get on well with my psychologist and really appreciate my appointments with her.”

“What I've had has been very helpful. But would be great to have more of it.”

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

Question 18 – Voice and communication therapy? (n=103)

103 service users responded to this question. The themes that emerged around service user's experience of voice and communication therapy, included:

- The majority responded that this question was **not applicable** (55);
- The therapy was **good/helpful** (23);
- **More should be offered** (9);
- **Not offered any/not received any yet** (6)
- The experience was **negative** (4);
- They would have liked this therapy **sooner** (3).

“More of this type of therapy should be offered.”

“I felt I was given the tools to help improve on my own.”

“Poor. Maybe only my own experience but I felt uncomfortable with the voice therapy, was belittling.”

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

Question 19 – The locations that appointments are offered in? (n=107)

107 service users responded to this question. The themes that emerged from service user's feedback about the location that appointments are offered in included:

- **Good** (23);
- **Variety of locations** (18) – including responses that the locations were too varied (8), there was a good variety of locations (5) and there should be more variety of locations (5);
- **Transport** (23) – including comments about difficulties with transport to reach appointments (16) and comments that transport was good (7);
- Appointments are a far **distance** to travel (17);
- **More local** appointments would be better (10);
- **Facilities** were good (9) – clean, quiet, tidy, private;
- **Finding** (7) – including comments that the locations were easy to find (4) and others that the locations were difficult to find (3);
- **Accessible** (4).

“Way too far for me to travel.”

“Never had any problems with getting to my appointments.”

“A bit difficult to find.”

“Very happy with the location.”

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

Question 20 – The facilities at appointment sites? (n=106)

106 service users responded to this question. The themes that emerged from service users feedback about the facilities at appointment sites, included:

- **Good/neutral** (58);
- **Bad/negative** (10);
- **Good appearance** (10) – comfortable, clean, friendly;
- **Reception** (7) – including negative experiences (4) and positive (3);
- **Catering** (7) – including comments that there were good catering options (4) and comments that there could be more refreshments (3);
- **Parking** is a problem (5);
- **Suggestions** of how facilities could be improved (4).

“Perfectly adequate, no problems here.”

“Availability of coffee/other refreshments would be nice.”

“Staff are lovely.”

Question 21 – What are the things that make you feel welcomed and safe in our service?
(n=103)

103 service users responded to this question. The themes that emerged from service users' feedback about what makes them feel safe and welcomed, included:

- **Staff** (64) – including friendly, pleasant, lovely, kind;
- **Respect/non-judgemental** (24)
- **Patient centred care** (18)
- **Reception** (13) – including nice area and friendly staff.
- **Privacy/quiet** (13)
- **Communication** (10)
- **Staff listening** (7)
- **Community presence** (4)

“Clear celebration of the best in service users and the global trans community.”

“The team I've met so far have been so welcoming and put me at ease.”

“The reception desk staff is efficient, well informed and polite.”

Question 22 – What could we do to make you feel more welcomed and safe in our service?
(n=103)

103 service users responded to this question. The themes that emerged from service user feedback about what could be done to make them feel more welcomed and safe in the service, included:

- **It's all wonderful** (36) – nothing could be improved;
- **More contact/less waiting** (14);
- A better and more private **waiting area** (12);
- **Staff improvements** (11) –less rushed, more transparency and more personal;
- **Location/travel** (4) – including more locations, home visits, better directions.

“More regular contact and updates.”

“I cannot think of anything that could be better.”

“A private waiting area.”

Question 23 – Who would you feel able using Skype for appointments with? (N=113, R=301)

113 service users responded to this question, participants were given the choice to pick multiple options, in total there were 301 responses. 27% felt that they would feel able to use skype for appointments with a doctor, 24% with a psychological therapist, 29% with a nurse and 19% with a voice and communication therapist.

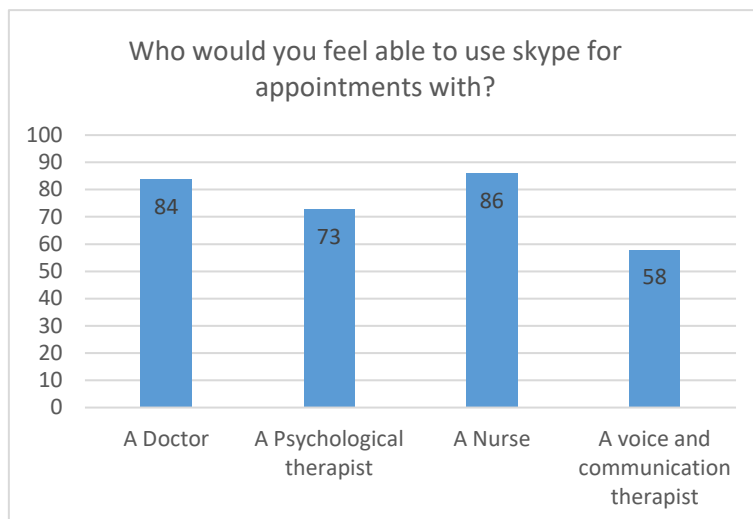


Figure 7. . Who would you feel able to use skype for appointments with?

Table 6. Who would you feel able to use skype for appointments with?

Who would you feel able using skype for appointments with?	Frequency of responses	Percentage (%)
<i>A Doctor</i>	84	27.09
<i>A Psychological therapist</i>	73	24.25
<i>A Nurse</i>	86	28.57
<i>A voice and communication therapist</i>	58	19.27

Question 24 – Are there any forms of technology that you would like us to consider using to improve the service that we offer you? (n=94)

94 service users responded to this question. The themes that emerged around forms of technology that service users would like to be considered for use in the service are displayed in table 7, these included:

- The majority of service users commented that this was **not applicable** as they were happy with the current technology (29);
- **Specific applications** that could be used (27) – including discord, google hangouts, Facebook, FaceTime and Star Leaf;
- **Skype** (9) – most service users said that skype should not be used (7) and a couple saying they would like to use skype (2);
- The remaining responses included – **In person** (5), **text** (11), **email** (6), **telephone** (6), and ability to **book appointments online** (3).

Table 7. What forms of technology would you like us to use?

Option	Frequency
In person	5
Text	11
Email	6
Telephone	6
Not skype	7
Skype is good	2
Book appointments online	3
Specific apps	27
N/A	29

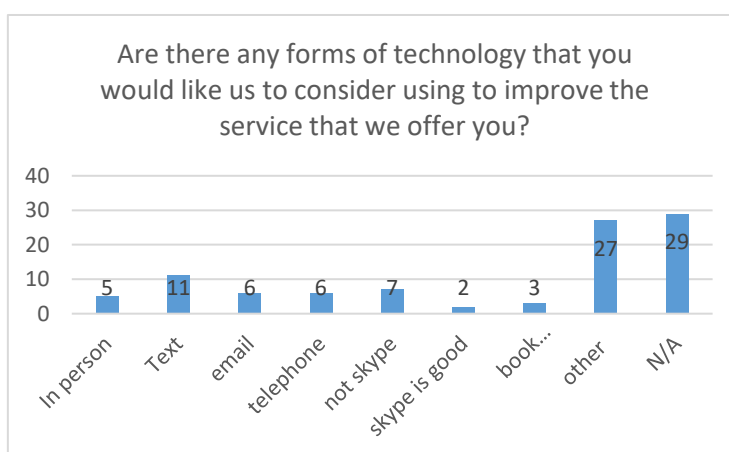


Figure 8. What forms of technology would you like us to use?

Question 25 – 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? (n=113)

113 service users responded to this questions. The themes that emerged around what could help to reduce missed appointments, included:

- Text reminder (26);
- Make those that cancel, wait longer or be punished (17);
- General reminder (14) – the method was not specified;
- Phone call reminder (9);
- Email reminder (7);
- More notice (6);
- There are reasons for missed appointments and this cannot be helped (5);
- More funding (2).

“Nothing can reduce missed appointments. Unforeseen circumstances cause some missed appointment “

“More communication throughout the whole process.”

“Harsher treatment when people miss an appointment for no good reason”

Question 26 – What’s good about the service provided by NRGDS? (n=109)

109 service users responded to this question. The themes that emerged around what is good about the service provided by NRGDS, included:

- The staff are kind (48);
- The service is excellent (17);
- The support that is provided is helpful (11);
- The staff are professional/knowledgeable (9);
- The staff are informative (8);
- The service allows support for transition (8);
- Good communication (3);
- Comments about the waiting list (3).

“It’s very friendly and welcoming and doesn’t feel overly medical, which can be daunting when using medical services.”

“Excellent and highly skilled team with very good specialised knowledge.”

“The service moves at the pace of each patient”

Question 27 – What could be better about the service provided by NRGDS? (n=111)

111 service users responded to this question. The themes that emerged around what could be better about the service provided by NRGDS, included:

- **Funding** (40) – including waiting times and more appointments;
- More **communication** (22);
- Provide more **advice and information** (8);
- Provide a **broader range of services** (7);
- **The service is already good** (5);
- **Better interaction/ relationship** with service users (4);
- More **socialisation** between service users(4);
- **More locations** (4).

“Their ability to see people in a more timely manner.”

“Having a bigger team so that you can do more and see more people.”

“Outreach group appointments at local trans support groups or some form of liason (sic).”

Question 28 – Please indicate your age in years

119 service users responded to this question. The age of participants ranged in the brackets of 17-20 to 66-75, the majority of respondents were in the bracket of 21-25 (20%).

Table 8. Age of service users

Age	Frequency	Percentage (%)
17-20	21	17.65
21-25	24	20.17
26-30	21	17.65
31-35	8	6.72
36-40	7	5.88
41-45	5	4.20
46-50	8	6.72
51-55	10	8.40
56-60	5	4.20
61-65	4	3.36
66-75	6	5.04

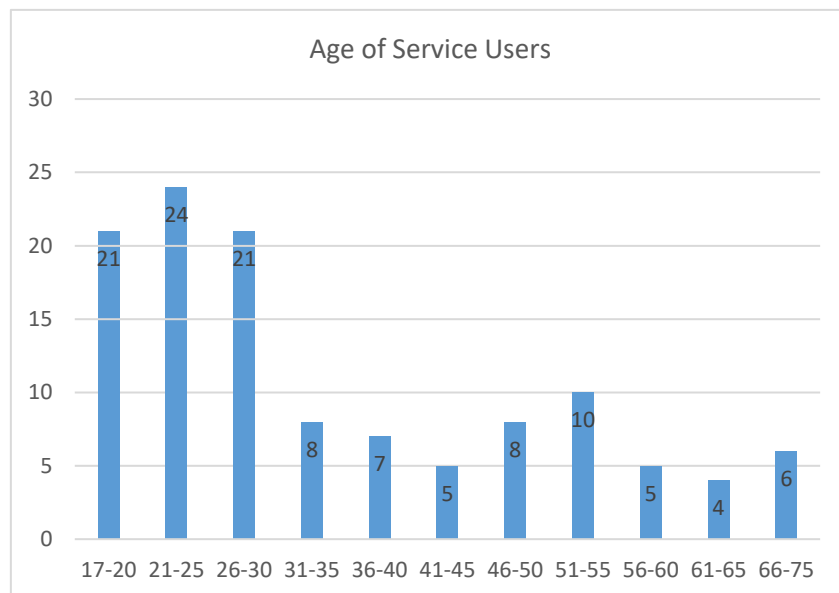


Figure 9. Age of service users

Question 29 – I identify as....

119 service users responded to this question. 47% of participants identified as female, 43% identified as male, 8% identified as non-binary and 2% identified as other.

Table 9. Gender Identity

Gender	Frequency	Percentage (%)
Female	56	47.06
Male	52	43.70
Non-binary	9	7.56
Other	2	1.77

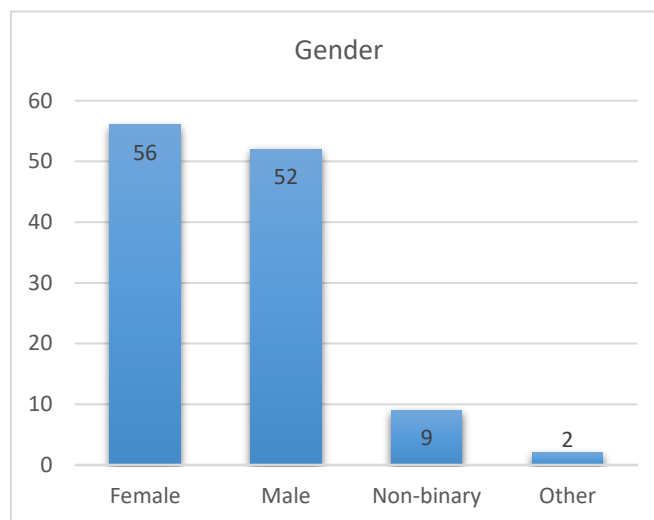


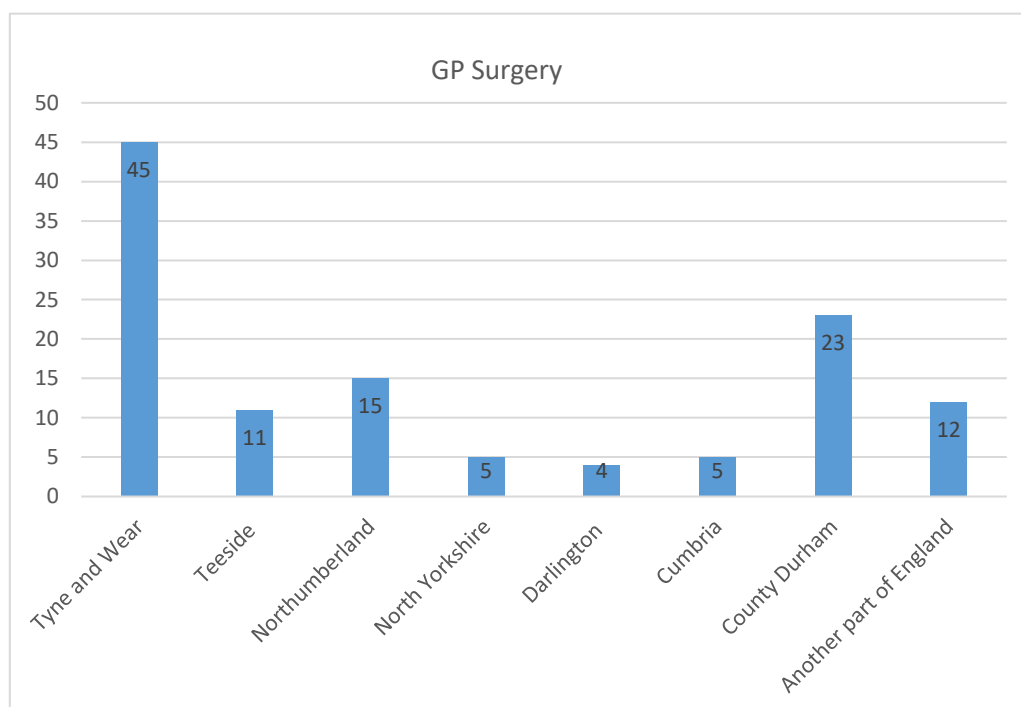
Figure 10. Gender Identity

Question 30 - My GP surgery is in... (n=120)

120 service users responded to this question. The majority of participants responded that their GP surgery was in **Tyne and Wear** (37.5%). With the next most popular response being **County Durham** (19.2%).

GP Surgery	Frequency of participating service users	Percentage (%)	Frequency of total service users	Percentage (%)
<i>Tyne and Wear</i>	45	38	574	37
<i>Teeside</i>	11	9	267	17
<i>Northumberland</i>	15	13	135	9
<i>North Yorkshire</i>	5	4	24	2
<i>Cumbria</i>	5	4	79	5
<i>Darlington & County Durham</i>	27	23	240	15
<i>Another part of England</i>	12	10	243	16

Table 10. Area of GP surgery



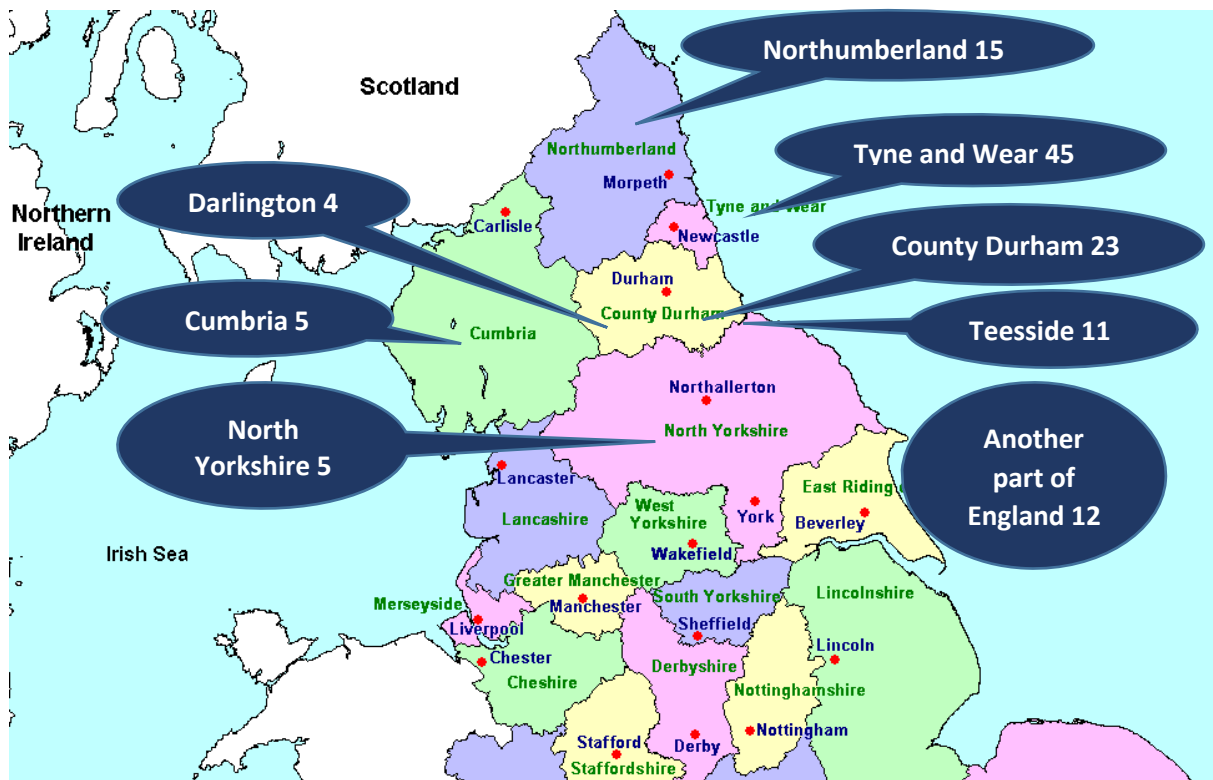


Figure 11. Area of GP surgery

Thematic Map



Thematic Analysis

Overview of themes from qualitative analysis

Care (403)

Overall, 403 comments were made about the care that the service provides. The common subthemes were...

- 1) Kind staff – Participants reported that they had positive interactions with staff. They commented that staff members helped them to feel at ease, reassured, cared for, relaxed and respected. Participants reported that staff went out of their way to make them feel comfortable.
- 2) Respectful - Participants reported that staff were respectful and non-judgemental. They reported that the care was individualised and moved at the pace that they needed. They felt accepted and as though they were allowed to express themselves in a way that they had not been able to before.
- 3) Supportive – Participants reported that they felt as though they had been well supported through their transition. They felt understood and listened to.

Communication (159)

Overall, 159 comments were made about communication within the service. The common subthemes were...

- 1) Managing expectations - Participants would like transparency and honesty particularly when it comes to waiting times. They would like to be given realistic wait times when accessing the service and from then on, regular updates as to where they are on the waiting list. They would like to gain a better understanding of the service pathway, so that they can have an accurate perception of what will be offered from the service.
- 2) Regular communication – Participants would like more frequent contact from the service. This includes updates on waiting times but also 'check-ins' to reassure them that they have not been forgotten about. It was also suggested that more advice should be provided to make the gap between appointments more manageable.
- 3) Speed of communication – Participants reported delayed and slow communication from the service. Some reported receiving letters about their care late or not at all. They would like letters to be sent out promptly, as delayed communication can negatively affect mental health.
- 4) Communication within appointments – Participants reported that within appointments they had received excellent communication. Participants found that service staff had been very informative and knowledgeable. They reported that they had been listened to and their questions had been answered satisfactorily. However, they wanted more of this and earlier on in the process.

Waiting times (179)

Overall, 179 comments were made about waiting times. The common subthemes were...

- 1) Length of wait – Participants reported long wait times to be seen in the service. They suggested that changes should be implemented in order to decrease this. Some of the suggestions that were made included: hire more staff, the service needs increased funding, create a self-referral system and better communication between NRGDS and other services, including GPs and private clinics, in order to reduce repeating procedures/work.
- 2) Accuracy of information – this subtheme also relates to the theme of communication. Participants would like accuracy of information about where they are on the waiting list and how long they will be waiting for. One of the main reasons that participants reported feeling distress was the uncertainty of how long they would be waiting and the disappointment when waiting time is increased.
- 3) Self-referral will increase wait time –. Participants are worried that by introducing a new self-referral system, this would increase the frequency of referrals made to the service and therefore increase wait times.

Uncomfortable/Distress (145)

Overall, 145 comments were made about feeling uncomfortable/distressed, the main subthemes were...

- 1) Lack of understanding – This subtheme relates mainly to the service user experience of their GP but also support staff within CNTW, such as the reception staff. Participants felt as though GPs were uneducated around gender related issues and the services available. They reported that they felt unsupported and unaccepted. It was suggested that increased training for both GPs and support staff within CNTW would be beneficial to reduce the stress of the referral process.
- 2) Unnecessary – Some participants felt as though assessments were unnecessary because they had previously had appointments with other services or private clinics. It was suggested that there should be better communication with other services in order to pass on information. Another suggestion was that advice on coping strategies could be provided to help with the gap between appointments.
- 3) Uncomfortable – Participants reported that parts of their appointment were uncomfortable. They reported that the assessments are very emotionally draining, there are some difficult and uncomfortable questions asked which at times can feel awkward and intimidating. It was suggested that implementing breaks within the sessions could help it feel less overwhelming. Some participants suggested setting up a support group. This could help to process these uncomfortable situations as well as provide a sense of community and support.

Accessibility (113)

Overall, 113 comments were made about the accessibility of the service, the key subthemes were...

- 1) Location - Participants reported that they found the locations of appointments difficult to access. Many participants reported that they had to travel long distances in order to get to their appointments. Many people suggested that more variety of locations would be helpful, although it was acknowledged that there has been an increase in location choice, which has been valued. Participants also reported that each appointment is often held in a different place which can be confusing, it was suggested that more consistency would be better.
- 2) Travel – Participants reported that it is difficult to access the appointments by public transport. The service not being in a central location was reported as the main problem, some had to use several modes of transport to get the location. Those that accessed the service by car commented that it was easy enough to find but they had difficulties with parking, it was suggested that more parking spaces for service users would be beneficial.
- 3) Facilities – Participants reported that the facilities at the services were good. Many reported that the waiting rooms were quiet and private, which allowed them to feel comfortable. Participants also reported that there was a good supply of literature while waiting.

Knowledge/Information (74)

Overall, 74 comments were made about information provided by the service. The key subthemes were...

- 1) Access to information – Participants reported that they would like more information to be provided about the service and about gender identity in general. Several people suggested that it would be useful to have either an information pack or a website containing service information, pathway details, introductions to staff, resources and up to date research.
- 2) Knowledgeable staff – Participants reported that the service provides specialist staff that are very knowledgeable in their fields. The staff help to provide information that otherwise would be difficult to find. Staff provide the information and tools that service users need and ask for.
- 3) Signposting – A recurrent theme in responses was the request for signposting to other services. Participants would like access to information about other services while they are on the waiting list. They would also like signposting to LGBT+ support groups.

Self-referral

A number of questions were specifically aimed at the referral system, so inevitably a large percentage of responses were related to this. Overall, 160 comments were made about self-referral. The key themes related to self-referral are explored below:

- 1) Empowerment – The main benefit of self-referral that participants reported was the capacity to feel empowered and autonomous in their own care. They commented that self-referral would give a greater sense of confidence and a degree of control. Participants reported that currently it can often feel as though you are having to rely entirely on professionals, self-referral would allow more independence.
- 2) Efficient – Participants reported that in the current referral system they often have to repeat information to multiple professionals, they feel as though self-referral will create a more streamlined system. It will also ensure that referral forms are sent, rather than rely on others to do this.
- 3) Accurate – Participants commented that self-referrals would allow a more accurate description of how service users feel rather than a third hand description from the GP. Service users will be able to explain, in their own words, the experiences they are having and anything that they are worried about.
- 4) Reduced distress – Participants reported that approaching a GP about gender identity could be very distressing and anxiety provoking. Participants have had experience with referrers where they have not felt listened to or understood. Self-referral would make the service more accessible for those who feel unable to approach their GP. The pathway would be less stressful in general.
- 5) Inappropriate referrals – Participants were concerned that self-referral would mean that there would be no filter before referrals are sent in. There were apprehensions that there could be a large amount of inappropriate referrals, as well as people ‘spamming’ the system. This links to the theme of waiting time, participants are concerned that by inappropriate referrals coming through the system it will mean longer waiting times for everybody.
- 6) Difficulty accessing/using self-referral – Participants had concerns about the self-referral system itself. Concerns included not knowing what information to provide, difficulties expressing problems through writing, challenging for people who are not computer literate and loss of referrals.
- 7) Waiting times – There were mixed views as to whether self-referral would decrease or increasing waiting times. Some participants felt that self-referral would speed up the process, as they would not have to go through the GP procedure. Others felt it would increase wait times, as there would be an influx of self-referrals, above the capacity of the service.

Not applicable (287)

Overall, 287 comments were made that the question was not applicable to them. The large majority of these responses were because the participant had not been seen within the service yet and were still on the waiting list. Other reasons why people responded 'not applicable' was due to the fact that they had not been offered certain services. Within questions relating to psychology or speech and communication therapy some participants reported that they had not been offered these services but if they had been they would have used them. They wanted these services to be more widely available.

Conclusions:

What service users said – what will be done?

It is important to acknowledge that the sample responding to this evaluation were those who had provided an email address and who responded to an online based exercise. They may not be a typical sample and although the age profile generally matches that of the service as a whole, respondents are likely to be those most comfortable using technology.

In the period following the collection of this data, and during its analysis, unprecedented events in the form of a global pandemic (SARS-CoV-2) resulted in a diversion of resources towards maintaining essential NHS services. NRGDS continued to offer treatment to service users during this period although the ability to take on new assessments was vastly reduced and the way in which appointments were conducted was radically changed.

A significant difference has been the need to offer far more remote consultations using telephone or an online platform (One Consultation). The acceptability and functionality of the technology has been evaluated but the impact on clinical relationships and on clinical decision making is too early to fully ascertain. The majority of service users have accepted remote consultations by phone or online video. In the survey, only 30% felt they would be able to use an online platform whereas the experience has been that a greater proportion have elected to use this. Of interest is that voice and communication appointments were those that the smallest number of service users felt could be conducted online (19%), whereas this has proved to be only deliverable via online video at present, as it is aerosol generating and needs both therapist and client to view each other with their faces uncovered. Early signs are that this is effective and acceptable to service users.

Suitable, adequate clinical and office accommodation for the service has been a longstanding issue, which has been temporarily alleviated by the changed working practices during the pandemic. During the period covered by this study, service users were offered appointments across three sites. Whilst the main satellite site in Middlesbrough was offered to service users to reduce journey times, a second satellite site in Newcastle was utilised purely to manage accommodation demands at the main site rather than being allocated according to service user convenience or preference.

In the period whilst compiling this report, the themes emerging were fed into long-term service development plans and to an extent were able to inform adaptations made due to the pandemic.

Waiting times are being addressed through analysis of the treatment pathways within a new service specification from NHS England with the intention that this will improve flow through the system and focus workforce expansion to where it is needed.

Administration processes have been adapted to allow for more home based working for staff. This has resulted in many paper-based systems moving to electronic format and routine use of email to send and receive documentation with associated efficiencies. The certification of @cntw.nhs.uk as meeting standards for NHS digital accreditation has assisted this change.

Although self-referral has been indicated to be acceptable by around 60% of respondents, fewer, just under 50% thought that they would have used it instead of the means by which

they were actually referred. This suggests that there will still be significant numbers of referrals coming via primary care, which is also the source of prescriptions for hormone treatment and provider of general medical care for service users. Given the key role of General Practice, there is an ongoing programme of working with doctors and medical educators to improve trans awareness and to support medical professionals with training and information.

Communication is a consistent theme alongside access to knowledge and information. It is recognised that there is an overwhelming amount of information available to those with online access but the information provided by the NRGDS website has to compete with many other sources, which are not of consistent quality or reliability. Navigating the sources of online information and accessing information without online access are recognised as problematic for service users. Additionally there is no current identified resource to update the NRGDS website nor is it possible to maintain up to date estimations of waiting times for the service or for other related services such as surgical providers. The latter is being addressed by a pilot project in partnership with the centralised referral system NRSS.

Access to information from NRGDS has been a factor that has occupied administrative time and has previously contributed to delays in administrative processes. There is currently recruitment undergoing for peer supporter posts to support service users and prospective service users to navigate information systems and processes as well as to address questions that might otherwise come to the administrative team. This will be provided in a context that offers greater emotional support and will hopefully reduce distress amongst service users.

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