

UK Trans Info

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Current Waiting Times & Patient Population For NHS England Gender Identity Services

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Contains Information For Up to the End of January 2015

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Foreword

UK Trans Info is a national organisation focused on improving the lives of trans and non-binary people in the UK. One of our main aims is to promote transparency, clarity and openness within public sector organisations. As such we have sent a series of requests under the Freedom of Information Act to all NHS England Trusts which contain an adult Gender Identity Clinic (GIC). The purpose of these requests was to find out more about the waiting lists for accessing gender identity services in England and also to find out more about the current patient population.

These requests are currently being sent on a quarterly basis. This report covers a four month period from October 2014 to January 2015.

First Appointments at GIC

We asked how many patients had their first appointment with the GIC in the four months. Over time this will allow us to make predictions how long waiting lists will take to clear.

Table 1: Number of first appointments October 2014 to January 2015

GIC	Appointments	% (rounded)
Charing Cross, London	382	58%
The Laurels, Exeter	101	15%
Leeds	26	4%
Northern Region Gender Dysphoria Service, Newcastle	0	0%
Northamptonshire Gender Dysphoria Service, Daventry	10	2%
Nottingham Centre for Gender Dysphoria	122	18%
Porterbrook Clinic, Sheffield	21	3%
TOTAL	662	

We also asked how long on average those patients had been waiting for their appointment since they were referred. While this tells us the waiting time for those currently reaching the end of waiting list, it is not necessarily an accurate prediction for those who are just joining the list.

Table 2: Average waiting time for first appointments held October 2014 to January 2015

GIC	Answer Given	Converted to weeks (rounded down)
Charing Cross, London	12 months	52 weeks
The Laurels, Exeter	16 weeks	16 weeks
Leeds	487.54 days	69 weeks
Northern Region Gender Dysphoria Service, Newcastle	N/A	N/A
Northamptonshire Gender Dysphoria Service, Daventry	67 days	9 weeks
Nottingham Centre for Gender Dysphoria	6-8 months	30 weeks
Porterbrook Clinic, Sheffield	38.31 wks Nov, 32.41 Dec & 36.29 Jan	35 weeks

Average waiting times that have exceeded 18 weeks have been highlighted in red and bolded (see later section for details of 18 Week Referral to Treatment Rights).

Urgent First Appointments at GIC

It is known anecdotally that some GICs allow “urgent referrals” to bypass some or all of the waiting list, however there has been little information about which GICs allow it, how often it happens or what classes as “urgent”.

We asked each GIC how many patients had their first appointment with the GIC after bypassing some or all of the waiting list due to an urgent referral. All clinics said that they had not had any patients bypass the list in this manner, and some clinics specifically said that they do not do this.

The Northern Region Gender Dysphoria Service in Newcastle had three patients who did bypass the waiting list, but this was not because they were “urgent”. They said:

“These referrals were not “urgent” but 2 were prioritised due to instruction from NHS England to assess transfers from child and adolescent as a priority. 1 referral was seen after deciding to be discharged from the service. The patient was then unable to access treatment in another part of the country and requested continuation of care within our service. No other referrals were seen.”

These three patients had an average waiting time of 100 days.

Current GIC Waiting Lists

We asked how many patients were still on the waiting list for a first appointment as of the end of January 2015. We also asked how many new referrals had been received over the four months.

Table 3: Patients on waiting list for an appointment at end of January 2015

GIC	Patients	% (rounded)
Charing Cross, London	1296	55%
The Laurels, Exeter	107	5%
Leeds	462	19%
Northern Region Gender Dysphoria Service, Newcastle	199	8%
Northamptonshire Gender Dysphoria Service, Daventry	18	1%
Nottingham Centre for Gender Dysphoria	192	8%
Porterbrook Clinic, Sheffield	103	4%
TOTAL	2377	

Table 4: New referrals received October 2014 to January 2015

GIC	Referrals	% (rounded)
Charing Cross, London	349	40%
The Laurels, Exeter	137	16%
Leeds	104	12%
Northern Region Gender Dysphoria Service, Newcastle	60	7%
Northamptonshire Gender Dysphoria Service, Daventry	23	3%
Nottingham Centre for Gender Dysphoria	169	20%
Porterbrook Clinic, Sheffield	24	3%
TOTAL	866	

It is worth noting that Charing Cross now hold a much smaller percentage of the total waiting list – 55% compared to 71% in September 2014. This is likely due to them increasing their new patient appointments from average of 75 per month between Aug 14 and Sept 14, to an average of 95 per month between Oct 14 and Jan 15 (which includes the Christmas break).

Current GIC Patient Population

We asked how many patients were currently under the care of each GIC. We defined this to include all patients who have had their first appointment but have not yet been discharged from the clinic.

Table 5: Current Patient Population as of End of January 2015

GIC	Patients	% (rounded)
Charing Cross, London	3450	58%
The Laurels, Exeter	698	12%
Leeds	319	5%
Northern Region Gender Dysphoria Service, Newcastle	305	5%
Northamptonshire Gender Dysphoria Service, Daventry	76	1%
Nottingham Centre for Gender Dysphoria	893	15%
Porterbrook Clinic, Sheffield	254	4%
TOTAL	5995	

If we combine this information with the waiting list information in table 3 then we can see how many people are engaging with gender identity services at any stage from referral to discharge. This will not include anybody who has been referred to a local mental health assessment service prior to referral.

Table 6: Current Patient Population (including waiting list) as of End of January 2015

GIC	Patients	% (rounded)
Charing Cross, London	4746	57%
The Laurels, Exeter	805	10%
Leeds	781	9%
Northern Region Gender Dysphoria Service, Newcastle	504	6%
Northamptonshire Gender Dysphoria Service, Daventry	94	1%
Nottingham Centre for Gender Dysphoria	1085	13%
Porterbrook Clinic, Sheffield	357	4%
TOTAL	8372	

We also asked how many patients were discharged during the four months. Over time this will allow us to make estimates about the patient population.

Table 7: Patients Discharged October 2014 to January 2015

GIC	Patients Discharged
Charing Cross, London	316
The Laurels, Exeter	47
Leeds	36
Northern Region Gender Dysphoria Service, Newcastle	15
Northamptonshire Gender Dysphoria Service, Daventry	4
Nottingham Centre for Gender Dysphoria	70
Porterbrook Clinic, Sheffield	24
TOTAL	512

We note also the big increase in discharges from Charing Cross since our last report – moving from an average of 41 discharges per month between Aug 14 and Sept 14, to an average of 79 per month between Oct 14 and Jan 15 (which includes the Christmas break).

Time Between First and Second Appointment

As a one off, we also asked GICs what the usual wait was between a patient's first and second appointments. Unlike our regular questions, we only requested an approximate answer.

Table 8: Approximate average time between first and second appointment

GIC	Answer Given	Converted to Weeks (rounded down)
Charing Cross, London	7 months	30 weeks
The Laurels, Exeter	6 weeks	6 weeks
Leeds	41.2 days	5 weeks
Northern Region Gender Dysphoria Service, Newcastle	190 days	27 weeks
Northamptonshire Gender Dysphoria Service, Daventry	96 days	13 weeks
Nottingham Centre for Gender Dysphoria	2-3 months	10 weeks*
Porterbrook Clinic, Sheffield	6 weeks	6 weeks

**As a range was given, we have used the mid-point of that range*

It is important to note that the 18 week wait legislation states it should be no more than 18 weeks from referral to treatment commencing, not from referral to first appointment. Since no GIC will commence any treatment (such as hormone therapy) on the first appointment apart from in very exceptional circumstances, it is useful to combine the above answer with the average waiting times for the first appointment in table 2. This gives us the average waiting time from GP referral to **second** appointment.

Table 9: Approximate average wait from initial GP referral to second appointment

GIC	Average Wait
Charing Cross, London	82 weeks
The Laurels, Exeter	22 weeks
Leeds	74 weeks
Northern Region Gender Dysphoria Service, Newcastle	More than 41 weeks*
Northamptonshire Gender Dysphoria Service, Daventry	22 weeks
Nottingham Centre for Gender Dysphoria	40 weeks
Porterbrook Clinic, Sheffield	41 weeks

** Only three new patients seen this quarter and they all bypassed part of the waiting list – however their average waiting time was 100 days which is 14 weeks*

Average waiting times that have exceeded 18 weeks legislation at this point have been highlighted in red and bolded (see later section for details of 18 Week Referral to Treatment Rights).

Assessment Periods

Each GIC assesses patients in an entirely different way, and this creates massive discrepancies in patient experience. We asked each GICs how many appointments as a minimum would it usually require before they would consider recommending hormone treatment. This does not suggest that patients **will** be offered hormone treatment, only that in a best case scenario this is the minimum number of appointments before it would be considered.

Table 10: Minimum number of appointments before considering hormone treatment

GIC	Number of Appointments
Charing Cross, London	2
The Laurels, Exeter	5
Leeds*	3*
Northern Region Gender Dysphoria Service, Newcastle	2
Northamptonshire Gender Dysphoria Service, Daventry	3
Nottingham Centre for Gender Dysphoria	3
Porterbrook Clinic, Sheffield	6

** Leeds refused to answer. However their Operational Systems document from September 2014 states that patients who "have already taken steps/changes toward their transition" and can progress through the service "over a shorter term" would still need to attend "a minimum of 2 assessment sessions with a review appointment" making a total of three appointments.*

We find it very unusual that there is so much variation. Why can Charing Cross and Newcastle assess patients in two appointments, yet The Laurels need five and Sheffield need six. If Sheffield adopted Charing Cross or Newcastle's approach, wouldn't it be possible for them to see three patients in the same time that it currently takes them to see just one patient?

In addition, the additional appointments cause extra travel costs for the patient which is made much worse by the fact that these services are not local for many patients. In our survey last year patients reported an average cost of £37 to attend a GIC appointment, which equates to £222 just for the initial assessment appointments at Sheffield.

We asked each GIC how long this assessment period takes. As before, we only asked for an approximate answer.

Table 11: Approximate average time between first and last appointment of minimum assessment

GIC	Answer Given	Converted to Weeks (rounded down)
Charing Cross, London	7 months	30 weeks
The Laurels, Exeter	6-9 months	32 weeks*
Leeds	Not answered	10 weeks**
Northern Region Gender Dysphoria Service, Newcastle	190 days	27 weeks
Northamptonshire Gender Dysphoria Service, Daventry	Not answered	26 weeks**
Nottingham Centre for Gender Dysphoria	4-6 months	23 weeks*
Porterbrook Clinic, Sheffield	3-6 months	19 weeks*

**As a range was given, we have used the mid-point of that range*

***As no answer given, have assumed wait between each appointment is wait between first two appointments as in table 9 above*

18 Week Referral to Treatment Rights

When we released our first report in November 2014 the commonly held opinion within the NHS was that gender identity services are exempt from the 18 week Referral to Treatment legal right. We have always held that there is no exemption, and we are pleased to say that in December 2014 NHS England decided that we were correct. The current position of NHS England is that:

“the 18-week RTT standard applies to both referral to treatment, i.e. surgery, and to referral to first appointment at a gender identity clinic.”¹

NHS England are trying to bring waiting lists down to the 18 week standard by March 2017.

Unfortunately we believe there is still a misinterpretation. The 18 week RTT rules suite² clearly states that the 18 week ‘clock’ stops when “first definitive treatment starts”, which is not usually at the first appointment. The clock can also be paused if a “period of active monitoring” begins, however this can only apply if “it is clinically appropriate to start a period of monitoring [...] without clinical intervention or diagnostic procedures”. This would be suitable where the patient is not yet ready to commence treatment, but not where the assessment has not even been completed.

Hormone treatment is often the first treatment given to those who do not require specialised psychological therapies. This means that the 18 weeks referral to treatment clock will usually stop either:

- a) When the patient receives their first prescription for hormone therapy; or
- b) When the initial assessment is completed and a clinical decision is made that treatment is not yet appropriate.

By combining the initial waiting time information from table 2 with the minimum assessment period information from table 11, we can find out the approximate average time from initial referral by the GP to the end of the assessment period, which is the earliest possible time that hormone therapy could commence.

Table 12: Approximate average wait from GP referral to end of minimum assessment period

GIC	Average
Charing Cross, London	82 weeks
The Laurels, Exeter	48 weeks
Leeds	79 weeks
Northern Region Gender Dysphoria Service, Newcastle	More than 41 weeks*
Northamptonshire Gender Dysphoria Service, Daventry	35 weeks
Nottingham Centre for Gender Dysphoria	53 weeks
Porterbrook Clinic, Sheffield	54 weeks

** Only three new patients seen this quarter and they all bypassed part of the waiting list – however their average waiting time was 100 days which is 14 weeks*

Average waiting times that have exceeded 18 weeks legislation at this point have been highlighted in red.

¹ Letter to Gender Identity Workshop Participants by Will Huxter, Regional Director of Specialised Commissioning, March 2015. Available online: <http://uktrans.info/attachments/article/373/Conference%20follow-up%20letter.pdf>

² Referral to treatment consultant-led waiting times Rules Suite, April 2014, Available online: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/255582/RTT_Rules_Suite_April_2014.pdf

Genital Surgery Waiting Times

For trans men and others requiring surgical procedures such as phalloplasty, the only NHS provider is currently the Andrology Centre. Information about waiting times for this provider is hard to obtain, however in January 2015 it was confirmed by NHS England that the wait was less than 18 weeks.

For trans women and others requiring surgical procedures such as vaginoplasty, there are two NHS providers. The first provider is Nuffield Health Hospital which has one surgeon (Phil Thomas). Waiting time information is difficult to obtain about this provider too, but in January 2015 it was confirmed by NHS England that the wait was about 12 months. It is our understanding that they are looking at training a second surgeon to help reduce these waiting times.

The second provider is Charing Cross Hospital under Imperial College Healthcare NHS Trust. They currently have two surgeons (Tina Rashid and Phil Thomas). As of the end of February 2015:

- There are 387 people on their waiting list.
 - 10 people have been approved for their operation and given a date
 - 76 people have been approved for their operation and are awaiting a date
 - 39 people are 'on hold' as they are not yet fit for surgery
 - 264 people are waiting for an initial consultation with the consultant
- The average waiting time is 69 weeks. This includes delays for hair removal/delays due to the patient being unfit for surgery.

Unfortunately there has consistently been more patients entering the waiting list at Charing Cross than there has been leaving it. It is our understanding that Imperial have started transferring more patients to Mr Bellringer at Parkside to start reducing the backlog, and are discussing with NHS England the option of training up more surgeons.

Table 13: New Referrals and Operations Performed at Charing Cross by Month

Month	New Referrals	Operations	Waiting List Increase
June 2014	27	9	18
July 2014	26	8	18
August 2014	1	2	-1
September 2014	20	10	10
October 2014	22	10	12
November 2014	11	10	1
December 2014	13	10	3
January 2015	21	13	8
February 2015	14	12	2

As mentioned in the previous section, NHS England has now confirmed that access to genital surgery is now covered by 18 week wait legislation, and they are trying to bring waiting lists down to the 18 week standard by March 2017. The way the rule applies to surgery is:

- The clock starts when the surgical provider receives the referral from the GIC. It doesn't matter if they have to apply for funding, the clock ticks while it happens.
- If at the pre-op appointment it is decided that the patient is not yet fit for surgery (due to needing hair removal, weight loss, etc) then the clock stops. A new 18 week clock will start when the surgeon confirms that the patient is fit for surgery.
- The clock ends on the day the patient is admitted to hospital for surgery, even if the actual operation is not until the next day.