



UK Trans Info

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

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Contains Information For Up to the End of September 2014

Last Updated: 8th December 2014

Available online: <http://uktrans.info/waitingtimes>

Created by UK Trans Info with thanks to: West London Mental Health NHS Trust, Sheffield Health and Social Care NHS Foundation Trust, Leeds and York Partnership NHS Foundation Trust, Northumberland, Tyne and Wear NHS Foundation Trust, Northamptonshire Healthcare NHS Foundation Trust, Nottinghamshire Healthcare NHS Trust, Devon Partnership NHS Trust and Imperial College Healthcare NHS Trust

Foreword

UK Trans Info is a voluntary organisation focused on improving the lives of binary trans people 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 monthly basis. So far we have received information about August and September 2014 from every GIC.

First Appointments at GIC

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

Table 1: Number of first appointments per month

GIC	Aug-14	Sep-14
Charing Cross, London	63	88
The Laurels, Exeter	31	62
Leeds	14	19
Northern Region GD Service, Newcastle	7	3
Northamptonshire Gender Dysphoria Service, Daventry	*	*
Nottingham Centre for Gender Dysphoria	35	39
Porterbrook Clinic, Sheffield	6	7 **
TOTAL	156	218

* Northamptonshire Gender Dysphoria Service has so far refused to answer this question

** Excludes urgent referrals (see below)

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 that month

GIC	Aug-14	Sep-14
Charing Cross, London*	56 weeks	56 weeks
The Laurels, Exeter	17 weeks	17 weeks
Leeds**	60 weeks	62 weeks
Northern Region GD Service, Newcastle	****	****
Northamptonshire Gender Dysphoria Service, Daventry	8 weeks	10 weeks
Nottingham Centre for Gender Dysphoria	19 weeks	21 weeks
Porterbrook Clinic, Sheffield***	49 weeks	40 weeks

* London provided their answer in months. This was converted to weeks and rounded down.

**Leeds provided their answer in days. This was converted to weeks and rounded down.

*** Sheffield provided their September answer in days. This was converted to weeks and rounded down.

**** Figures for Newcastle have been temporarily removed as they have requested time to review the figures.

Average waiting times that have exceeded 18 weeks have been highlighted in red and bolded (see appendix 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. Their response indicates that the use of ‘urgent’ appointments is not commonplace.

Table 3: Number of first appointments per month (urgent appointments only)

GIC	Aug-14	Sep-14
Charing Cross, London	0	0
The Laurels, Exeter	0	0
Leeds	0	0
Northern Region GD Service, Newcastle	0	0
Northamptonshire Gender Dysphoria Service, Daventry	*	*
Nottingham Centre for Gender Dysphoria	0	0
Porterbrook Clinic, Sheffield	0	1
TOTAL	0	1+

* Northamptonshire Gender Dysphoria Service has so far refused to answer this question

Current GIC Waiting Lists

We asked how many patients were still on the waiting list for a first appointment as of the end of the month.

Table 4: Patients on waiting list for an appointment at end of month

GIC	Aug-14	Sep-14
Charing Cross, London	1541	1541
The Laurels, Exeter	47	18
Leeds	302	338
Northern Region GD Service, Newcastle	117	131
Northamptonshire Gender Dysphoria Service, Daventry	7	10
Nottingham Centre for Gender Dysphoria	27	27
Porterbrook Clinic, Sheffield	104	95
TOTAL	2145	2160

We also asked how many new referrals had been received each month.

Table 5: New referrals received per month

GIC	Aug-14	Sep-14
Charing Cross, London	116	113
The Laurels, Exeter	36	42
Leeds	32	37
Northern Region GD Service, Newcastle	21	18
Northamptonshire Gender Dysphoria Service, Daventry	3	6
Nottingham Centre for Gender Dysphoria	37	41
Porterbrook Clinic, Sheffield	7	13
TOTAL	252	270

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 6: Current Patient Population as of End of Month

GIC	Aug-14	Sep-14
Charing Cross, London	3400	3234
The Laurels, Exeter	608	611
Leeds	322	316
Northern Region GD Service, Newcastle	321	321
Northamptonshire Gender Dysphoria Service, Daventry	61	66
Nottingham Centre for Gender Dysphoria	729	725
Porterbrook Clinic, Sheffield	213	230
TOTAL	5654	5503

If we combine this information with the waiting list information in table 4 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 7: Current Patient Population (including waiting list) as of End of Month

GIC	Aug-14	Sep-14
Charing Cross, London	4941	4775
The Laurels, Exeter	655	629
Leeds	624	654
Northern Region GD Service, Newcastle	438	452
Northamptonshire Gender Dysphoria Service, Daventry	68	76
Nottingham Centre for Gender Dysphoria	756	752
Porterbrook Clinic, Sheffield	317	325
TOTAL	7799	7663

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

Table 8: Patients Discharged per Month

GIC	Aug-14	Sep-14
Charing Cross, London	32	50
The Laurels, Exeter	less than 10	5
Leeds	14	15
Northern Region GD Service, Newcastle	4	4
Northamptonshire Gender Dysphoria Service, Daventry	8	2
Nottingham Centre for Gender Dysphoria	8	11
Porterbrook Clinic, Sheffield	1	5
TOTAL	67⁺	92

*Excludes The Laurels, Exeter as they refused to provide a specific answer.

Patient Gender as Recorded by GICs

Finally, we asked the clinics how many of the current patient population are men, how many are women and how many are non-binary people. We expected this to be a simple computer report, but were surprised to learn that this was one of the most difficult questions for the gender clinics to answer. Some answers were offensive.

WARNING: Anybody who is distressed by trans people being misgendered is advised to skip this page.

Charing Cross, London refused to answer this question because it would take them more than 18 hours to answer. This is because they would have to examine each patient's medical notes manually to determine their gender.

The Laurels, Exeter gave us the following answer for August:

- a. Men- (male to female) 407
- b. Women (female to male) 195
- c. Non-binary people Less than 10

Leeds gave us the following answer for August:

- a. Men *196
- b. Women *119
- c. Non-binary people *Nil

* Plus 7 'not recorded / information not collated'.

** Our patient information system records the "biological gender" of our service users, as this is the simplest way to record the gender of service users transitioning through our services. Therefore we do not hold information on non-binary people.

When asked to clarify what "biological gender" means, they said they meant "sex assigned at birth".

Northern Region GD Service, Newcastle gave us the following answer for August:

The following genders refer to 'sex at date of first referral'

Female = 188

Male = 125

Not Specified = 4

Unknown = 4

Northamptonshire Gender Dysphoria Service, Daventry gave us the following answer for August:

Men – 40

Women – 21

Non-binary people – 0

Nottingham Centre for Gender Dysphoria gave us the following answer for August:

Men – 363, Women - 366, Non-binary people – 0

Porterbrook Clinic, Sheffield gave us the following answer for August:

- a. Men 74
- b. Women 139
- c. Non-binary people

The lack of answer after the words "Non-binary people" isn't a mistake in this report and is as provided by Sheffield.

Given the problems and discrepancies between how gender was reported by Exeter, Leeds and Newcastle we do not feel it is safe to assume anything about what Daventry, Nottingham or Sheffield mean by 'men' or 'women'. We also find it highly unlikely that Daventry and Nottingham have zero openly non-binary people between them and suspect this is simply not recorded.

We no longer ask this question.

GRS Waiting Times

In addition to the Freedom of Information requests we have been sending to gender clinics, we have also been sending monthly requests to Imperial College Healthcare NHS Trust (ICHNT) who perform genital surgery such as vaginoplasty at Charing Cross hospital in London.

We asked ICHNT how many people they have on their waiting list for surgery:

Table 9: Charing Cross (ICHNT) Waiting List for GRS as at the end of each month

Stage of Waiting List	Jun-14	Jul-14	Aug-14	Sep-14
Waiting for first pre-op assessment	172	275	278	228
Had pre-op assessment but is on hold as not fit for surgery (eg they need hair removal, weight loss, etc)	30	26	28	28
Had pre-op assessment and approved for surgery Still waiting for a date for surgery	53	49	56	98
Had pre-op assessment and approved for surgery has been given a date for surgery	30	35	35	22
On a waiting list with a private provider	0	0	0	1
TOTAL	285	385	397	377

It's important to note that there are discrepancies¹ in the information they have provided to us. There were 88 patients added to the list in July with no explanation and a further 13 in August. Then in September there were 29 patients who vanished from the list without explanation. ICHNT have not yet been able to explain these discrepancies.

We also asked for the following information:

Table 10: Other Information about GRS at Charing Cross (ICHNT)

Question	Jun-14	Jul-14	Aug-14	Sep-14
New Referrals Received	27	26	1	20
Number of GRS operations performed	9	8	2	10
Average Waiting Time of those who underwent GRS	50.4 weeks	56 weeks	32.4 weeks	67 weeks
Number of pre-op assessments held	8	6	7	14
Number of patients transferred to another provider	10	5	0	0
Number of patients removed from list without surgery	0	1	0	1

It is clear from this information that the number of people entering the waiting list (new referrals) far exceeds the number of people leaving the waiting list (by having the GRS operation, by being transferred to another provider or by leaving the list without surgery).

¹ Full details of discrepancies can be found at <http://tinyurl.com/ImperialFOI>

GRS Future Planning

We asked ICHNT for the number of planned operations they had each month for the next year. There are 166 operations planned over the next twelve months:

- October 2014 - 12
- November 2014 - 13
- December 2014 - 10
- January 2015 - 14
- February 2015 - 13
- March 2015 - 16
- April 2015 - 14
- May 2015 - 14
- June 2015 - 16
- July 2015 - 14
- August 2015 - 16
- September 2015 – 14

As of the end of September 2014 there are 377 patients on the waiting list, yet only 166 operations planned in the next twelve months. Assuming the same number of operations happen each year it would take until January 2017 (28 months) just to clear those 377 patients. Since April 2012 ICHNT has received an average of 22 new referrals per year² which means that by that point there would be an additional 616 patients added to the waiting list.

ICHNT are already breaching the legal right to treatment within 18 weeks of referral (see appendix for details of 18 Week Referral to Treatment Rights) by a long way, and many patients are already seeing waits of over a year. Unless something changes quickly, those who have just been referred are facing a 2-3 year wait and things are only going to get worse.

Summary

The length of time patients have to wait for their first GIC appointment is, in most cases, unacceptable. Those referred to Leeds or London face waits of over a year and those referred to Sheffield face waits of over 9 months. On the other end of the scale is Daventry where patients face waits of only 8-10 weeks, but they are only receiving less than 0.5% of the national referrals and waiting times would likely increase rapidly if this were to change.

The length of time patients have to wait for GRS at Charing Cross is also unacceptable. Those referred a year ago are only just undergoing their operation now and those who have only just been referred are facing a 2 to 3 year wait. This will only increase unless substantial changes are made.

The other two providers of genital surgery (Nuffield Health Hospitals for operations such as vaginoplasty and St Peters Andrology Centre for operations such as phalloplasty) are private hospitals. Due to this we have not yet been able to obtain information about their waiting lists. We would like to see NHS England obtain and publish this information.

² This figure is derived from their four FOI responses and a statement they made in June 2014 (http://www.imperial.nhs.uk/aboutus/news/news_044629)

Appendix: A Quick Note on 18 Week Referral to Treatment Rights

In England, under the NHS Constitution, patients ‘*have the right to access certain services commissioned by NHS bodies within maximum waiting times, or for the NHS to take all reasonable steps to offer a range of suitable alternative providers if this is not possible*’. The maximum waiting time for gender identity services is 18 weeks. This is often known as 18 Week Referral to Treatment (RTT).

We are aware that many people, including some within the NHS, believe that gender identity services do not need to conform to the 18 week RTT legislation, however this is untrue. The Rules Suite³ clearly states that the 18 week RTT right extends to any referral to:

“a consultant led service, regardless of setting, with the intention that the patient will be assessed and, if appropriate, treated before responsibility is transferred back to the referring health professional or general practitioner;”

This is explicitly confirmed by the RTT FAQs⁴:

“A referral to a consultant led gender dysphoria service will start an RTT clock. The RTT clock stops at the start of first definitive treatment, which for most gender dysphoria patients will be the start of initial counselling. If gender reassignment surgery is proposed at a later date, then a new RTT clock would start on the date that the decision is made by the consultant and patient that they are fit and ready for such surgery and they are added to the waiting list for the procedure.”

When a GP makes a referral to a gender clinic they are referring to a consultant led service and an 18 week clock starts. This clock ends at the first treatment, which usually takes the form of counselling given at the first appointment.

Similarly, when the GIC makes a referral to a surgeon they are making a “decision to start a substantively new or different treatment that does not already form part of that patient’s agreed care plan” and as a result a new 18 week clock starts. This clock usually ends upon being admitted for surgery.

In both cases the 18 week maximum waiting time should not be breached, yet it is clear from the data presented in this document that it is breached in the majority of cases.

³ *Referral to treatment consultant-led waiting times Rules Suite*, Department of Health, April 2014. Available online: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/255582/RTT_Rules_Suite_April_2014.pdf

⁴ *Frequently Asked Questions on the Referral to Treatment (RTT) data collection*, Department of Health, October 2012. Available online: <http://www.england.nhs.uk/statistics/wp-content/uploads/sites/2/2013/04/RTT-FAQs-v10-Oct-2012.pdf>