

# Freedom of Information Act 2000 disclosure log entry

## Reference

23-24098

## Date response sent

06/07/23

## Subject

GIDS: Endocrinology, Waiting List Transfers, Staff Leavers,  
Interim Service Specification

## Details of enquiry

I would like you to provide this information in the following format:

- Each answer broken down by referrals per month, and split by age and sex, where possible.
1. How many patients have been referred to the endocrinology team at UCLH or the Leeds General Infirmary by the GIDS service at the Tavistock between 28th July 2022 and 28th June 2023 or the most recent data held?
  2. How many new patients have been referred to the endocrinology team at UCLH or the Leeds General Infirmary by the GIDS service at the Tavistock between 28th July 2022 and 28th June 2023 or the most recent data held?
  3. How many people are currently on the waiting list for an appointment at the GIDS at the Tavistock?
  4. How many patients does the GIDS currently have registered as an ongoing patient?
  5. How many patients will need to be transferred to one of the new providers?
  6. When did NHS England formally tend notice to the Tavistock that its GIDS unit would be closed?
  7. How many GIDS staff have quit since the Cass Review published its interim recommendations?
  8. What was the Tavistock's response to NHS England during the Public Consultation on the Interim Service Specification for a new gender in congruence service?

## Response sent

1. How many patients have been referred to the endocrinology team at UCLH or the Leeds General Infirmary by the GIDS service at the Tavistock between 28th July 2022 and 28th June 2023 or the most recent data held?

**Please read the following notes regarding the data provided for this question.**

- a) This data involves low numbers, i.e. less than five, which have been masked as '<5'. Were we to disclose these exact low numbers they could potentially lead to identification or re-identification of the individual(s) concerned. Although the month and year alone are not personal data, we have also to consider whether other information that is already available, or may become available, to any member of the public, could be combined with the data provided so as to enable identification of the individual(s) concerned. We are, therefore, withholding this information under S.40(2) Personal Information.

Section 40 is an absolute exemption under the FOIA and does not require us to carry out the public interest test.

- b) The data provided below covers the period 1<sup>st</sup> August 2022 to 21<sup>st</sup> June 2023, as when the stats were run, 28<sup>th</sup> June has not yet occurred.
- c) Following a national cyber incident, our electronic patient records (EPR) system was taken offline from 4<sup>th</sup> August 2022 until the new year, and not fully restored until we had finished uploading interim patient data in March 2023.
- d) In view of c) above, the monthly totals may be skewed because the referral form creation date is used by our system as the date referral was made, rather than the actual data it happened.
- e) We can confirm that the overall total for the period 1<sup>st</sup> August 2022 to 21<sup>st</sup> June 2023 was 111 patients.

**GIDS Referrals to Endocrinology Team  
1st August 2022 to 23 June 2023**

Year	Month	Assigned Female	Assigned Male	Total
2022	August	<5	<5	5
	September	<5	<5	6
	October	7	<5	8
	November	<5	<5	5
	December	6	6	12
2023	January	6	<5	9
	February	6	7	13
	March	9	6	15
	April	9	10	19
	May	6	6	12
	June	<5	<5	7

2. How many new patients have been referred to the endocrinology team at UCLH or the Leeds General Infirmary by the GIDS service at the Tavistock between 28<sup>th</sup> July 2022 and 28<sup>th</sup> June 2023 or the most recent data held?

All GIDS patients are required to attend assessment and therapy sessions prior to referral, we cannot therefore classify any patients referred to endocrinology as “new” patients.

3. How many people are currently on the waiting list for an appointment at the GIDS at the Tavistock?  
None

4. How many patients does the GIDS currently have registered as an ongoing patient?

**GIDS Current (open) Patients  
by Age at Referral and Gender Assigned at Birth  
as at 31 May 2023**

Age	Assigned Female	Assigned Male
3	<5	<5
4	9	11
5	16	39
6	26	45
7	39	57
8	42	41
9	50	49
10	63	52
11	82	33
12	134	40
13	82	38
14	32	15
15	10	<5
16	<5	<5
17	<5	

5. How many patients will need to be transferred to one of the new providers?  
We cannot currently provide a number, as this will consist of all current patients still open to the service at the time of GIDS closure
6. When did NHS England formally tend notice to the Tavistock that its GIDS unit would be closed?  
Formal notice has not yet been received
7. How many GIDS staff have quit since the Cass Review published its interim recommendations?  
We can confirm that since publication of the Cass Review in July 2022, 32 staff have left the GIDS service.
8. What was the Tavistock's response to NHS England during the Public Consultation on the Interim Service Specification for a new gender in congruence service?  
GIDS (Gender Identity Development Service) submitted a response to the interim service specification for specialist gender dysphoria services for children and young people. This was as follows:

**Response Submitted to Interim service specification for specialist gender dysphoria services for children and young people – public consultation**

Submitted on 2022-12-04 21:45:12

**About you**

**1 Are you responding on behalf of an organisation?**

Yes

**If yes, please tell us which organisation you are responding on behalf of::**

The Gender Identity Development Service (TPFT)

**2 In what capacity are you responding?**

Service provider

**If you select other, please describe further:**

**Your views**

**3 To what extent do you agree with the four substantive changes to the service specification listed in the supporting documents?**

Neither Agree nor Disagree

**Share any further comments about this::**

We would argue that this is not a substantive change and is about identifying specific specialisms for recruitment. Experts in autism, neurodiversity, and mental health are also likely to be psychologists, clinical nurse specialists, systemic family therapists, psychotherapists, social worker, research psychologists, or psychiatrists who have specialised in these areas and completed additional training in line with these specialisms.

While Appendix B (MULTIDISCIPLINARY TEAM COMPETENCIES AND EXPERIENCE) spells out 'Gender Incongruence and Gender Dysphoria in Children and Young People under 18 years of age' as a key area of expertise, the main references are to understanding the 'wider social context' and the 'contested debate around different management approaches for responding to children and young people who have gender incongruence and the limited evidence base to inform clinical approaches and delivery' and also the 'support needs and support options for children and young people who have degrees of gender incongruence but who do not meet the diagnostic criteria for gender dysphoria' and 'the intended outcomes for children and young people who are seen by NHS specialist gender services'. The wording throughout does not reflect what the GIDS current team feel gender expertise should entail, as per the founding principles of the GIDS service: acceptance and respect for young people's gender identity; not taking a view regarding the outcome of an individual's gender identity development; providing a space for exploration of gender; ameliorating; any negative impacts on general development; working with young people to think through all the options open to them. The core focus should be, as it is at GIDS, child development, and taking a developmental approach to the work, creating links with local networks (such as CAMHS, Social Care, and other care providers) as part of the assessment and support offered. Holistic assessments taking into account all elements of a young person's life, including family, school, relationships, peers, developmental history, mental and physical health, and cultural context.

In the main document, reference to this area of expertise seems to be missing altogether.

The interim service specification details that the Cass Review highlighted a need for research infrastructure and strategy. GIDS has a research team embedded in the service, who, as well as conducting research, lead on regular research and reading meetings to ensure staff are all up to date with the latest research, practice, and evidence in the field. It is hoped something like this would be retained in the new services.

We suggest the interim specification ought to have a structured plan of how data will be collected, by what means, with which questionnaires, in what way, and how this will be completed consistently (and presided over) between multiple sites. This to ensure that data and information is not lost (or not collected) before the 'Future Specifications' can be determined and implemented.

NIHR are briefly mentioned to be the lead in developing these programmes, but there is relevant expertise in the Research Team in the current service who have a wealth of knowledge about data collection with gender-diverse children and young people (who also manage data collection and pathway monitoring of an entire endocrine pathway) who could support this work with insights/what works/what does not. As there is no mention of a research team supporting work in the new services, it is not clear what psychological and behavioural monitoring (via questionnaires) of service users not engaged in medical treatment pathways will be conducted.

The research team in the GIDS presently also act as a research support base, providing research inductions, completing literature review requests, sending the most recent up to date papers in the field, and attending MDT meetings to understand the data they work with from different perspectives. This enriches their knowledge and considerations with the data they work with. There is no mention within these specifications of how integrated research will be in the new services and how the relationship between research and clinicians/clinical work will look. A consideration which bears thinking about should research be conducted through external providers with potentially less subject matter experience.

The interim specification mentions the focus on standardising data sets using a 'Learning Healthcare System'. It is indicated that this work will be outsourced. We recommend there be consultation with current staff who consistently work with data for research, audit, QI, FOIs, and service delivery purposes, who have a wealth of process documents and manuals which are used to systematically collect relevant data, and who could support this work given their considerable experience.

Culturally informed care requires that gender diversity is viewed as an ordinary part of human diversity, and that understandings of gender are acknowledged as culturally situated, with no 'one right way' of viewing gender identity development. A specialist gender service would need to provide truly inclusive care and an environment that feels safe to gender-diverse young people. It is vital that all employed staff are culturally competent and informed with regard to LGBTQ+ identities.

Finally, it is not clear from the spec how the MDT will work and how many members of the team each family may come into contact with. Feedback from service users is that consistency with regards to worker is very important to them. Team members need to be able to draw on each other's expertise without 'passing' the patient around.

Neither Agree nor Disagree

**Share any further comments about this::**

The specification outlines that the majority of the work delivered by the new services will be psychosocial, but will the clinical leadership will be a medic. . Joint leadership between a medical professional and a psychosocial professional would better reflect the staff mix and service delivery being indicated –especially so that all staff can be sure of appropriate clinical supervision. The need for treatment or medical intervention is based on psychological considerations not a medical condition.

The service will be 'addressing a broader range of medical conditions in addition to gender dysphoria' – implying that the service will be providing other kinds of 'treatment'. It

is unclear what medical conditions will also be explored and why these would not be referred on to other services.

There is no mention to the clinical leadership needing experience in gender identity. This is unusual for a specialist service. If the clinical director(s) of this service do(es) not have experience in gender, they may not be able to provide proper informed and containing leadership for a service of this complexity.

Neither Agree nor Disagree

**Share any further comments about this::**

Requirement for a consultation before agreement to refer raises questions both deontologically and operationally. The description of how this will work is very high level, but appears to exclude families from the process, with no evidence of an appeals process in place. Obviously, it also presents an issue of capacity for GPs and the need for a national training programme for GPs in gender diverse presentations and needs. GIDS practice-based evidence suggests that GP referrals tend to be brief, often with critical information lacking. Within social care there is a view that the person who knows the family/young person best, is the person who should make the referral, ensuring that a true picture is shared with the service. GPs will often not have time to gather all the relevant and detailed information to share in a consultation to get a true picture of the young person's needs. Most YP do not know their GP or see the same GP more than once – how will they discuss these complex issues in 10 minutes. And there are many communities who struggle to contact their GP and rely on other support networks. While referrals from other sources are a small minority, they can be the only avenue for some young people.

The specification indicates that safeguarding procedures are to be initiated if families are accessing blockers or hormones from unregulated sources and this should be done by informing GPs. There needs to be a clear definition of what constitutes an unregulated source. While the services would need to consider the potential risks and possible safeguarding issues in some cases, reporting all cases could be problematic. This will be picked up later, but for the purposes of this question, a system capacity question needs to be raised. With long waiting times, a substantial number of the young people we see disclose having accessed or accessing treatments from providers based outside England and Wales.

Historically, our administrative staff have supported GPs and their staff when making referrals. GP admin staff make the majority of referrals, not GPs directly, and often require a considerable amount of assistance. Our staff are also concerned about safeguarding referrals being flagged to GPs who may not be as close to the young person and often do not have capacity to take this on. Safeguarding referrals should be made by the clinician closest to the patient with regards to the reason for the referral.

Neither Agree nor Disagree

**Share any further comments about this::**

Removing the ability to refer for social workers, school counsellors, and other adults who might have sight of marginalised young people is likely to disadvantage vulnerable families the most. Many of our most disadvantaged families have very limited contact with health professionals and face

well-documented systemic barriers in terms of health care access. This could also create regional disparities due to inequities regarding GP availability, capacity and willingness to engage with these issues.

It appears that for every referral (currently 5,000 a year) the referrer will have a meeting or consultation with a service clinician. It is not clear how it is proposed resource will be made available within the new services for this task, or that deployment of resources in this way is clinically useful or efficient. GPs are also very unlikely to have this time available, as it is currently very difficult even to get a 10-minute GP consultation.

An alternative model might be for the new services to run online information workshops that referrers can sign up to, organised by region. These could include answering common questions, giving service information, and signposting to local resources. If a referrer has attended a workshop and deems a referral to be appropriate, then they can make it through the online portal. They can then seek individual follow-up as necessary. Regular regional workshops for CAMHS practitioners could also provide space for consultation in a much more efficient manner. This way, signposting, psychoeducation, and advice can be consistent, and clinician time (and public money) can be best and most efficiently used.

Reducing the accessibility to the service through triage that does not involve the patient or family could increase the clinical risk for CYP excluded from the service. Whilst it may appear to reduce the waiting list, by reducing access, this will not reduce the need for services for gender diverse, gender questioning and trans young people. This need will merely be displaced to young people accessing other services, such as CAMHS, where capacity issues are also present and where they may not meet the thresholds to be seen unless they are quite unwell.

#### **4 To what extent do you agree that the interim service specification provides sufficient clarity about approaches towards social transition?**

Neither Agree nor Disagree

Please expand further::

In the opinion of the current GIDS team, the approach to social transition in the specification perpetuates a reductive, binary, and fixed idea of gender. Children need to be able to explore, and, in some cases, it is only this exploration that can help them to establish their identity or to establish if they can live in their preferred gender.

From a practical perspective, it is extremely difficult to discourage young people and their families from making decisions for themselves. Particularly given current waiting times, it is unrealistic to expect young people to wait to be seen by the service before considering making a social transition. In our

clinical experience, young people and their families regularly describe significant thought and care going into decisions around more serious aspects of social transition e.g. deed poll. No evidence has been provided of early social transition being harmful, and it should be noted that forcing a child to exist in a presentation with which they are unhappy is not a neutral act. The HealthTalk material on this topic is a valuable insight.

Many families now regularly seek advice from third sector organisations because of the long wait and obtain support from them when considering social transition. This section presents as self-contradictory because it states that we do not know the long-term outcomes of early social transition, but then says that young should fully comprehend these outcomes before socially transitioning. We often recommend families think about ways young people might be able to manage distress while they wait, and for some young people social transition may be sufficient and mean they no longer require a service. Furthermore, given these are services for young people experiencing gender dysphoria who need to meet diagnostic criteria, making a social transition would often provide information about their gendered experiences.

#### **5 To what extent do you agree with the approach to the management of patients accessing prescriptions from un-regulated sources?**

Neither Agree nor Disagree

Please expand further::

While we agree with much of this section around the management of prescriptions from unregulated sources and the clinical approach to this risk, it is of concern that the specification indicates that safeguarding procedures are to be initiated if families are accessing blockers or hormones from unregulated sources and this should be done by GPs being informed. Firstly, there needs to be a clear definition of what constitutes an unregulated source (e.g. not under CQC?). Secondly, we should certainly be discussing

the potential risks and considering safeguarding in some cases but reporting all cases is problematic. As well as the clear question of capacity in the system raised previously, safeguarding referrals should be made a) on individual grounds based on an assessment of the individual circumstances and b) by the best-informed professional (rarely the GP in the circumstances described here). Thirdly and most importantly, the notion of an automatic referral would stop families or young people from letting clinicians know if they are accessing these medications from other sources, which would prevent the service or other agencies from supporting them with harm-reduction strategies (e.g. accessing blood tests).

**6 Are there any other changes or additions to the interim service specification that should be considered in order to support Phase 1 services to effectively deliver this service?**

**Please expand further::**

The idea of needing a diagnosis of gender dysphoria in order to access the service may force some young people into feeling they need to make more concrete decisions around their gender identity in order to access the service rather than have an important space for exploration. These criteria may also exclude non-binary identities or people who do not meet the criteria for a diagnosis of gender identity but still identify as trans. They do not recognise the fluidity and complex nature of gender identity or to differentiate gender dysphoria from persistence over time.

In the opinion of current GIDS staff 'Biological sex' should be replaced with 'sex assigned/registered at birth' throughout. This is the most respectful and accurate terminology. Some of the ways in which topics are approached seem to imply a pathologising approach to gender incongruence in children and young people which will concern patients and create anxiety about the nature of the service being proposed.

GIDS initially offered hormone blockers to younger patients under an ethically approved research protocol that has now been rolled out to all patients on the 'early intervention' pathway. Our stepped care approach is in line with international guidance and best practice. It is imperative that the new services continue to collect data on this cohort and in a way which aligns with agreed international collaborations to allow the continued growth of the evidence base. Any gap in these protocols would be a real blow to research.

There is no rationale given for removing paediatric endocrine responsibility from UCLH in London or LGI in Leeds, hospitals recognised internationally for their specialism in this area. There is little mention of how specialist endocrine care will be given.

There is also scant reference to gender affirming hormones or what the pathway or protocol will be for accessing this intervention.

The shift in the referral ratio from predominantly young people assigned male at birth (AMAB) to predominantly young people assigned female at birth

(AFAB) continues to be raised as a point of concern, but without providing a rationale for the concern. A related assumption seems to be that young people who are assigned female are in some way vulnerable to being forced into different ways of being against their will, instead of being credited with the ability to make their own decisions and understand themselves. This is sadly reminiscent of other ways that people assigned female are seen as having less agency than people assigned male.

7 To what extent do you agree that the Equality and Health Inequalities Impact Assessment reflects the potential impact on health inequalities which might arise as a result of the proposed changes?

Neither Agree nor Disagree

**Please expand further::**

Disability



The service specification implies that autistic young people and those with mental health difficulties are less able to understand themselves and their gender identity.

- Gender Reassignment

It is problematic to assume that no children or young people on the waiting list for GIDS would share the protected characteristic of Gender Reassignment. The Equality and Human Rights commission notes that not only are the terms 'gender reassignment' and 'transsexual' outdated, but that in line with the 2010 Equality Act a person does 'not need to have undergone any specific [treatment] to change from your birth sex to your preferred gender'. This means that young people who have undergone a social gender transition (likely the majority of people on the waiting list, and attending GIDS) would have this protected characteristic. A formal diagnosis of Gender Dysphoria is also not a requisite condition for sharing this protected characteristic.

- Pregnancy and Maternity

Nationally commissioned fertility support for young trans people should be explored as it may constitute a barrier to parenthood where this service is not offered.

#### Race and Ethnicity

Removing community referrals may disproportionately affect people from minoritised ethnic groups, as evidence suggests people from BAME groups experience inequalities in healthcare settings.

- Sex

The use of word 'natal' is not preferred by gender-diverse communities. This needs changing to 'sex assigned/registered at birth'.