

Service specification: national referral support service for specialist service for children and young people with gender incongruence

1. Service name	Gender Dysphoria Services (children and adolescents) Referral Pathway for Specialist Service for Children and Young People with Gender Incongruence
2. Service specification number	
3. Date published	7 August 2024
4. Accountable Commissioner	NHS England

5.	Population and/or geography to be served
5.1	<p>Population covered</p> <p>The referral pathway defined in this specification relates to children and young people where it is considered appropriate to refer into the Children and Young People's Gender Service. It defines who is included, how the referral is made, how a national waiting list is managed and how transfers are made from the waiting list into the service. Referrals may be made of children and young people up to the 18th birthday. As an interim arrangement until waiting times are reduced, when a young person who is on the waiting list reaches 17 years and 9 months and who will not be seen by the time of their 18th birthday, they will be removed from the waiting list and advised to discuss with their GP whether a referral should be made to an NHS Gender Dysphoria Clinic for adults.</p> <p>For newly referred individuals the defined patient cohort of this specification is children and young people who are:</p> <ul style="list-style-type: none"> • Registered with a General Practitioner in England or who are otherwise the commissioning responsibility of NHS England; or • Registered with a General Practitioner in Wales or who are otherwise the commissioning responsibility of NHS Wales; or • The commissioning responsibility of a UK Overseas Territory and who are referred to the service in accordance with agreed contractual arrangements; and • Referred to the Specialist Service for Children and Young People with Gender Incongruence because gender incongruence concerns may be present and which exceed the scope and expertise of local services.

Terminology

Gender incongruence of childhood (ICD11 HA61)

“Gender incongruence of childhood is characterised by a marked incongruence between an individual’s experienced/expressed gender and the assigned sex in pre-pubertal children. It includes a strong desire to be a different gender than the assigned sex; a strong dislike on the child’s part of his or her sexual anatomy or anticipated secondary sex characteristics and/or a strong desire for the primary and/or anticipated secondary sex characteristics that match the experienced gender; and make-believe or fantasy play, toys, games, or activities and playmates that are typical of the experienced gender rather than the assigned sex. The incongruence must have persisted for about two years. Gender variant behaviour and preferences alone are not a basis for assigning the diagnosis”.

Gender Incongruence of Adolescence and Adulthood (ICD11 HA60)

“Gender Incongruence of Adolescence and Adulthood is characterised by a marked and persistent incongruence between an individual’s experienced gender and the assigned sex, which often leads to a desire to ‘transition’, in order to live and be accepted as a person of the experienced gender, through hormonal treatment, surgery or other health care services to make the individual’s body align, as much as desired and to the extent possible, with the experienced gender. The diagnosis cannot be assigned prior to the onset of puberty. Gender variant behaviour and preferences alone are not a basis for assigning the diagnosis”.

5.2

Eligible patient cohort

There are two cohorts: the individuals already on an established waiting list now collected into a single national waiting list; and future new referrals to the service.

For young people aged 17 years and 9 months on the established waiting list, they will discontinue on the waiting list and, if in continued need for clinical assessment, they will need to consider with their GP whether a referral to an NHS commissioned Gender Dysphoria Clinic for adults is appropriate. In such cases, the Gender Dysphoria Clinic will honour the original referral date to the children and young person’s service for the purpose of access into the adult service.

For young people aged 17 years and 9 months at the point of referral they will not be added to the waiting list for the Children and Young People Gender Incongruence Service. These individuals will need to consider with their GP whether a referral to an NHS commissioned Gender Dysphoria Clinic for adults is appropriate.

In view of historic long waiting times that are not expected to stabilise until significant additional clinical capacity is built, the providers of the Children and Young People Gender Services will not directly accept new referrals until at

least 2026. Until this time, referrals are made to a National Referral Support Service (NRSS) commissioned by NHS England, and the NRSS will hold and manage a national waiting list.

6. Service aims and outcomes

6.1 Aims

The specification defines:

- a) the pathway of referral into the Children and Young People’s Gender Service;
- b) the function of the National Referral Support Service (NRSS);
- c) the transfer of the referrals into the clinical service.

NRSS aims

- Maintain and update the NRSS Information Hub (microsite)
- Support parents/carers and CYP who need assistance completing the Gender Experience Summary (GES)
- Support referrers who need assistance with the referral pathway, and provide appropriate guidance
- Deliver a service where referral information of those on the existing waiting list is screened and reviewed
- Coordinate a desktop referral review to ensure the referral details are adequately captured and determine whether children and young people should be referred to other appropriate service
- Communicate directly with the referrer, child or young person and their families whether:
 - Further information is required for the referral
 - Recommendation for referral to another service (e.g. CYP Mental Health Service, Social Services, Neurodevelopmental Service)
 - The child or young person has been added to the waiting list
 - The child or young person has not been added to the waiting list

6.2 Outcomes

NHS Outcomes Framework Domains and Indicators

Domain 1	Preventing people from dying prematurely
Domain 2	Enhancing quality of life for people with long-term conditions
Domain 3	Helping people to recover from episodes of ill-health or following injury
Domain 4	Ensuring people have a positive experience of care
Domain 5	Treating and caring for people in safe environment and protecting them from avoidable harm

	<p>Service defined outcomes/outputs</p> <ul style="list-style-type: none"> • Monitoring of patient experience of the referral pathway • To provide continuing high-quality activity data • Published waiting time data • Response times to patient questions • To provide high quality information and support to service users, parents and carers, and referrers • Evidence of engagement with children, young people, families and referrers in the design and review of the NRSS • Collection and reporting of CYP, parents and carers, and referrers experience of NRSS <p>Reporting and data collection</p> <p>The NRSS will hold a database of all patients on the waiting list. Data reporting will include:</p> <ul style="list-style-type: none"> • Total number on the waiting list • Length of time waiting • Age and sex and ethnicity profile • Looked After status and Child Protection Status • Waiting list by Region, Integrated Care Board • Numbers in open CYP Mental Health case load • New patient activity by provider • Referrals received (CYP age, location, referral source) • Contacts with NRSS (CYP, parents/carers, referrers) • Referral consultation service activity • Referral reviews undertaken <p>As individual patient data will be held a robust data governance process will required to ensure the security of data held. Data can only be used for research purposes if individual consent is given.</p> <p>Service provision must follow the NHS 2021 Records Management Code of Practice and relevant retention schedule contained within. Data is categorised for the purpose of this Agreement as a Care Record. No data or information will be stored or processed outside of the European Union.</p>
7.	Service description
7.1	<p>A. The pathway of referral into the Children and Young People’s Gender Service</p> <p>A referral onto the waiting list for the specialist Children and Young People’s Gender Service can be made by an NHS-commissioned secondary care level paediatric service or CYP mental health service. Other agencies including social services and schools cannot refer directly onto the waiting list for the Children and Young People’s Gender Service. These agencies will need to consider</p>

whether a referral to the primary care service is appropriate or, having regard to local arrangements, directly to secondary healthcare services having taken steps to discuss with the young adult and/or parents/carers.

Primary care

Although GPs cannot refer directly into the waiting list for the Children and Young People Gender Incongruence Service it is likely that the first point of contact with healthcare services is through primary care. Clinicians in primary care are not expected to have expertise in the management of gender incongruence but should have the skills to identify a potential presentation of gender incongruence as described in 5.1 above, to identify co-existing other health needs, and to determine whether the degree of distress merits referral into the local secondary healthcare services with potential onward referral to the specialist service, following appropriate clinical assessment by the local service.

To support the initial discussion with primary care, young people aged 16 years and over, and the parents/carers of children under 16 years, are encouraged to complete a national standardised *Gender Experience Summary*. This form will be made available by the NRSS as a digital form and a downloadable paper form.

To consider a referral for gender incongruence a limited set of information is needed. The Gender Experience Summary (GES) places the child in the centre to record the information needed for a referral and discuss their experience with parent/carer. It is not a requirement to complete this form, but it is recommended the young adult or parents/carers of children completes the form and takes it to their primary care and/or secondary healthcare service so key information is identified. Although the GES is not a required form for a referral, it will improve the completeness (and ownership) of the information provided and reduce the likelihood of further information being requested.

At the discussion with primary care service options are considered with the child and parent/carer (where appropriate) using the GES if completed. Primary care teams are supported by the [MindEd modules](#) and a guidance document.

[\[NHS England to include guidance document as an appendix once agreed\]](#)

NRSS will also support those who require assistance completing the GES.

The following outcomes come from the initial discussion at primary care:

- Decision with child and parent/carer (where appropriate) not to refer onward with or without subsequent primary care review.
- Referral to Children and Young People mental health services if needs are identified using standard local arrangements for referral.
- Referral to general paediatrics if specialist mental health needs are not identified using standard local arrangements for referral.
- Referral to autism or neurodevelopmental healthcare service (usually within CYPMHS or Paediatrics) according to local arrangements.

- Joint referral to Children and Young People mental health services and Paediatrics if required.

Secondary care - children and young people mental health services

Children and Young People Mental Health Services (CYPMHS) will offer access to their services as defined in local arrangements.

The CYPMHS will review the GES with the child or young person and parent/carer (where appropriate) and determine any co-existing mental health or wider needs and coordinate onward care. CYPMH will make an assessment as to whether the CYP is experiencing gender related distress in the context of their holistic needs. In addition, consideration should be given whether a referral is needed for neuro-diversity services.

The CYPMHS will be supported by the [MindEd modules](#) and a guidance document. A shared decision is made with the child or young person and parent/carer (where appropriate) whether to refer into the waiting list for Children and Young People Gender Incongruence Service. The referral is a national referral to the NRSS through [a digital referral form available from the NRSS website](#). It must be noted that the NRSS is a non-clinical service that holds the referral up to the point the referral is transferred to the clinical service. If the child or young person is discharged from CYPMHS the NRSS and GP must be informed.

Secondary care - paediatric services

It is expected that local community paediatric services general paediatric services will play a key part in the future service model working in a networked fashion with the specialist service based in regional tertiary paediatric services. In the absence of mental health needs access to the specialist tertiary services is through paediatrics.

The community paediatric service or general paediatric service will review the GES with the child or young person and parent/carer (where appropriate) and determine any change in experience and define the health needs and coordinate onward care. Community paediatric services or general paediatric services will not make a diagnostic determination of whether there is gender incongruence or dysphoria but will make an assessment as to whether the CYP is experiencing gender related distress in the context of their holistic needs.

Community paediatric services or general paediatric services will be supported by the [MindEd modules](#) and a guidance document. A shared decision will be made with the child or young person and parent/carer (where appropriate) whether to refer into the waiting list for the Children and Young People's Gender Service. The referral is a national referral to the NRSS through a [digital referral form available at the NRSS website](#). It must be noted that the NRSS is a non-clinical service that holds the referral up to the point the referral is transferred to the clinical service.

The development of additional educational materials will be commissioned by NHS England in collaboration with professional bodies to support the role of the

paediatric and CYPMH teams building confidence and competence. The scope of this future role has been defined by the Cass Review¹.

Referral consultation service

From 2025/26 the providers delivering the new Children and Young People's Gender Service will offer a referral consultation service to help referrers (from community / general paediatrics and CYPMHS) support their patients considering access to the waiting list.

The aim of a consultation, advice and liaison meeting is to facilitate timely understanding and care of children and young people referred to the waiting list, including if they may otherwise benefit from specialist advice or targeted local care whilst spending a potentially extended period waiting for direct care. Specifically, the consultation, advice and liaison meeting will provide the opportunity to,

- Offer early, expert advice to referrers, local professional networks and indirectly, parents and carers and young people themselves
- Develop an improved understanding (a working formulation) of the child or young person's situation and the options to support them, including in respect of co-occurring needs
- Facilitate and mobilise local support for the young person and their family
- Improve the care available and long-term outcomes for young people on the waiting list for the specialist service
- Clarify gender identity concerns that could be and, may benefit from being addressed by local professional systems and by parents, carers and young people
- Reduce the likelihood and/or impact of adverse outcomes whilst remaining on a potentially extended waiting list
- Improve the referral information available to the Children and Young People's Gender Service

A consultation, advice and liaison meeting is an important opportunity to support local services in developing their confidence and expertise in this work (alongside targeted professional resources as these are made available) and to promote care closer to home.

The Children and Young People's Gender Service will agree with the referrer the outcome of the consultation, advice and liaison meeting, including an initial formulation of the young person's needs and risks and a local care plan to support the child or young person.

The local system and the Children and Young People's Gender Service will agree a written summary record of the consultation, advice and liaison meeting, and the care plan and actions. Clinical responsibility following a consultation advice and liaison meeting will always continue to remain with the local referrer and local healthcare system as appropriate until and unless the specialist service commences direct assessment and intervention.

¹ [Cass Report, April 2024](#)

Where the outcome of the consultation, advice and liaison meeting is that the child or young person does not meet the access criteria for the Children and Young People's Gender Service at this time, the child or young person will not be added to the waiting list - but the family and professional network will have been assisted to develop their formulation of the child or young person's needs and a local care plan and will be advised of other resources for support that are appropriate for individual needs. In some cases, a further consultation for referral may be appropriate following further local assessment and intervention and/or a process of watchful waiting.

B. The function of the National Referral Support Service

All referrals will be held by the [NRSS](#) in a secure database. Referrals will only be accepted from two sources – CYPMHS or community/general paediatric services (which will include local specialist neurodevelopmental assessment services) – using standardised digital referral forms. Completed GES forms will be collected by the NRSS. The NRSS will require the initial date of primary to secondary care referral to be included and used at the start point for waiting times for access to the specialist Children and Young People's Gender Service.

Children and Young People's Gender Services will receive all new referrals for vetting before inclusion in the waiting list coordinated by the NRSS. This is a desktop exercise reviewing the digital referral and the GES (where submitted). The outcomes of the vetting review include:

- Add to waiting list.
- Further details sought but enough information to add to the waiting list.
- Further details sought but not enough information to add to the waiting list.
- Add to the waiting list but recommend referral to other services in parallel.
- Recommend referral to other services and do not add to waiting list.

A series of standard letters will be used by the NRSS to complete the vetting process.

The NRSS will send confirmation to the young person or parent/carer (where appropriate) confirming the addition to the waiting list, the confirmed date for clock start, the current estimation of waiting time and supply the details of the information resource. The referrer will be included within this communication.

C. The transfer of the referrals into the clinical service

All commissioned providers of the Children and Young People's Gender Service will be required to identify to the NRSS the capacity they have to see new referrals for each month, 4 months in advance.

The NRSS will validate that those at the top of the waiting list still wish to be seen, are ready to be seen, and have identified a preferred provider where this is practicable. Where possible an updated GES will be secured if older than 12 months.

	<p>3 months in advance each provider will receive the details of the patients transferred to their Service for the planned month. The patient/parent/carer and referrer will be informed of the transfer by the NRSS. From this point the Service takes responsibility to communicate with the patient/parent/carer and referrer.</p> <p>Patients will be allocated to providers on a strict chronological basis, this may mean that individuals are given the opportunity to be seen by the Service not in their geographical area. Patient choice will be facilitated where this is practicable while the services build clinical capacity over time.</p> <p>The Service provider must inform the NRSS of the completed date of the first assessment at which point the child or young person will be closed on the NRSS record.</p>
<p>7.2</p>	<p>Clinical networks</p> <p>As the new services develop into regional services over time, regional clinical networks will become increasingly developed in line with the recommendations of the Cass Review. Once all regional services are in the place the function of the NRSS will be reviewed to build greater autonomy for networks to manage their regional population (not expected at least until 2026).</p>
<p>7.3</p>	<p>Essential staff groups</p> <p>General Practitioners and their primary care teams supported by guidance and educational materials to build confidence in their role in the pathway.</p> <p>Clinicians in the CYP Mental Health Services supported by guidance and educational materials to build confidence in their role in the pathway.</p> <p>Clinicians in General Paediatric Services supported by guidance and educational materials to build confidence in their role in the pathway.</p> <p>Clinicians in targeted neurodevelopmental healthcare services (usually within CYPMH and general paediatric services), supported by guidance and educational materials to build confidence in their role in the pathway.</p> <p>Administrative team managed by the CSU appointed to run the NRSS.</p> <p>Nurse specialists to make direct contact with children and their parent/carers in the phase of preparing for the first appointment.</p> <p>Clinicians from the specialist service to be part of the vetting process of new referrals.</p>
<p>7.4</p>	<p>Essential equipment and/or facilities</p> <p>The administration and management of the NRSS is entirely virtual. Staff groups as defined above will need IT equipment and a working environment to all confidential discussions with patients.</p> <p>The CSU will utilise an electronic referral management system which will contain details of all referrals and communication into the service will be carried</p>

	<p>out via secure nhs.net email. Patient letters and text messages will also be sent using a specialist mail provider.</p> <p>Provision of microsite containing information and guidance for patients and referrers, the GES and digital referral form. The microsite information will be regularly updated and maintained.</p>
7.5	<p>Interdependent service components – links with other NHS services</p> <p>Data sharing agreements and Memorandum of Understanding will need to be in place between the CSU and the providers of the Children and Young People’s Gender Service for the purpose of transferring patient information related to a referral.</p>
7.6	<p>Additional requirements</p> <p>The NRSS function will be reviewed once all regional services are in place and have been running for at least one year, not expected to be before 2026.</p> <p>Patient identifiable data will be held securely by NRSS, and transfers of data to providers will be made in compliance with Data Protection Act requirements including the need for appropriate Data Sharing Agreements. All staff will be trained in the processing and handling of data in compliance with the Data Protection Act.</p>
7.7	<p>Commissioned providers</p> <p>NHS Arden and Greater East Midlands Commissioning Support Unit have been commissioned to host the NRSS on behalf of NHS England at least until 2026.</p>
7.8	<p>Links to other key documents</p> <p>Interim service specification for Specialist Service for Children and Young People with Gender Incongruence which supersedes service specification E13/S(HSS)/e Gender Identity Development Service for Children and Adolescents (2016)</p> <p>Other key documents:</p> <p>The Cass Review Interim Report, February 2022</p> <p>The Cass Review Final Report, April 2024</p> <p>NHS England Statement: “Implementing the Recommendations of the Cass Review”, July 2022 (updated April 2024)</p>