

**NHS STANDARD CONTRACT  
FOR GENDER IDENTITY DEVELOPMENT SERVICE  
FOR CHILDREN AND ADOLESCENTS**

**SCHEDULE 2 – THE SERVICES  
A. SERVICE SPECIFICATION**

<b>Service Specification No.</b>	E13/S(HSS)/e
<b>Service</b>	Gender Identity Development Service (GIDS) for Children and Adolescents
<b>Commissioner Lead</b>	Bernie Stocks
<b>Provider Lead</b>	
<b>Period</b>	1.4.2016 to 1.4.2020
<b>Date of Review</b>	30.12.2019

**1. Population Needs**

**1.1 National/local context and evidence base**

**National context**

**1.1.1 About the service**

This specification sets out the deliverables for a highly specialised service for Gender Identity Development (GID) for children and adolescents up to their 18<sup>th</sup> birthday and is for individuals who need support around their gender identity.

The service is commissioned to provide specialist assessment, consultation and care for children and young people, including psychological support and physical treatments, to help reduce the distressing feelings of a mismatch between their natal (assigned) sex and their gender identity. The service will also provide support to the family or carers of clients.

The psychological element of the service is a Tier 4 mental health service which will support children and young people to understand their gender identity.

See here for a description of tiers of mental health care:

[http://www.icptoolkit.org/child\\_and\\_adolescent\\_pathways/about\\_icps/camh\\_service\\_tiers.aspx](http://www.icptoolkit.org/child_and_adolescent_pathways/about_icps/camh_service_tiers.aspx)

Once accepted into the service, individuals are referred to as 'clients'.

The service will recognise a wide diversity in sexual and gender identities. It will be delivered through a highly specialist multidisciplinary team (MDT) with contributions from specialist social workers family therapists, psychiatrists, psychologists, psychotherapists, paediatric and adolescent endocrinologists and clinical nurse practitioners.

Children and young people who have disorders of sex development or intersex conditions and other endocrine conditions may be referred if there are associated concerns with gender identity development. If not, other services are available which local services can refer to.

The service will be delivered in line with:

- emerging evidence for best practice
- relevant national and international guidelines for the care of children and adolescents with GD such as the World Professional Association for Transgender Health Standards Of Care For the Health of Transsexual, Transgender and Gender Nonconforming people, (Version 7 2012) (referred to in this document as WPATH SOC v7) and the Endocrine Society's Clinical Guidelines (2009);
- NICE guidelines specific to the treatment of mental and emotional health and wellbeing including for psychosis, anxiety and depression.

## **Prevalence**

### **1.1.2 Epidemiology**

The incidence and prevalence of GD in adolescence is difficult to ascertain because it includes gender non-conforming individuals in whom the dysphoria subsequently partially or wholly disappears; those in which it evolves into a non-binary identity; those in whom it is the precursor to a lesbian, gay or bisexual identity (with or without a trans identity in addition), and those in whom the GD continues to be experienced.

### **Incidence in the UK**

In the UK, a surveillance study examined the incidence and clinical presentation of GD in UK and Irish children and adolescents aged 4 to 15 years inclusive. New cases were reported by clinicians over a 19-month period (November 2011 – June 2013) and validated against DSM-IV criteria. Unpublished data from this study suggests an incidence (new cases per year) in children and adolescents aged 4-15 years (inclusive) presenting to secondary or tertiary care services of 1.6 per 100,000 in the UK.

This figure only reflects those who presented to NHS paediatric or psychological services and not those who have chosen not to, or who have been unable to access this care. The figure does not reflect the total number who may have accessed their GP regarding their gender dysphoria, or include those who have elected to seek private support.

Average age at presentation reflects referral trends to the GIDS, that is mid-adolescence (median 14.68 years [interquartile range 12.1-15.31 years]). A significant limitation of this surveillance study is that it only captured data for those presenting between their 4th and 16th birthdays - meaning that it is not possible to comment on the incidence of gender dysphoria among 16 and 17 year olds, which referral trends to the service suggest have significantly increased the overall incidence rate.

It is difficult to compare prevalence studies due to different inclusion criteria and potential underreporting. In Belgium, a population-based survey which looked at the prevalence of broader definitions of gender incongruence and gender ambivalence rather than gender dysphoria in the Flemish population, noted that the numbers were much higher than the

prevalence of gender dysphoria in clinical settings. This study identified a prevalence of gender incongruence of 0.7% and 0.6% and gender ambivalence of 2.2% and 1.9% in men and women respectively. (Van Caenegem et al. 2015).

A 2014 Dutch review reported gender dysphoria in 0.6 men and 0.2% women- based on an estimated percentage of men/women reporting ambivalent or incongruent gender identity combined with dislike of male/female body and a wish to obtain hormones/surgery. (Kuyper & Wijsen, 2014).

In the UK, the number of adolescents referred to specialised gender identity clinics for GD appears to be increasing. There also appears to be a corresponding shift in the sex ratio, from predominantly biological/assigned males to predominantly biological/assigned females. Similarly in a study at clinics in Toronto and Amsterdam, there was a significant change in the sex ratio of referred adolescents between two cohort periods: between 2006 and 2013, more assigned females were referred, but in the prior years there were more assigned males. (In Toronto there was no corresponding change in the sex ratio of 6,592 adolescents referred for other clinical problems). Sociological and sociocultural explanations have been offered to account for this recent inversion in the sex ratio of adolescents with GD (Aitken et al 2015).

#### **1.1.4 Evidence base**

The reason why some people experience GD is not fully understood. A review of the evidence supports this view. (NHS England Clinical Evidence Review: Prescribing of Cross-Sex [gender affirming] Hormones as part of the Gender Identity Development Service for Children and Adolescents E03X16/01). It is likely that the development of gender identity is multifactorial and influenced by both biological and social factors.

### **1.2 Gender non-conforming behaviours and continuation of GD**

#### **1.2.1 About Gender Dysphoria**

The language in this area is evolving. Gender identity refers to an individual's subjective sense of being male, female, both, neither or something else.

Gender Dysphoria (GD) describes the distress that is caused by a discrepancy between a person's gender identity and that person's sex classified at birth (and the associated gender role and/or primary and secondary sex characteristics) (Fisk, 1974; Knudson, De Cuypere, & Bockting, 2010b). Assigned sex is classified at birth based on the appearance of the genitals. The term transgender is used where a person's gender identity is different to their sex assigned at birth.

GD can be more distressing in adolescence due to the pubertal development of secondary sex characteristics and increasing social divisions between genders. As a result, adolescents can be at risk of self-harm, despair and can become vulnerable to relationship difficulties, social isolation and stigma.

Gender Identity was originally defined by Stoller (1964) as "core gender identity" which reflects a person's "fundamental sense of belonging to one sex [an awareness of being male or female and]; an over-all sense of identity."

Currently a diversification of gender identifications is taking place. A person may identify with characteristics and behaviours which (their) society may recognise as not being consistent with their experienced gender, or they may identify by another descriptor such as non-binary. Binary implies that an individual identifies exclusively as a man or a woman, however there is a growing recognition that many people do not regard themselves as conforming to the binary male/female classification.

Some children experience anxiety and other forms of distress associated with the difference or incongruence between their assigned sex classified at birth and the gender characteristics and behaviours they identify with. In addition, some may strongly dislike the physical sex characteristics of their biological sex.

The WPATH SOC v7 note that not all gender variant people experience GD and those who do may not experience it persistently (on a continuing basis) throughout their lives. However, if the distress resulting from this incongruence reaches clinical levels, the diagnosis of GD according to the Diagnostic and Statistical Manual of Mental Disorders version 5 (DSM-5) is applicable.

It is recognised that there are some concerns about the DSM-5 classification, although it has a place in supporting the identification of GD. de Vries & Cohen-Kettenis (2012) of the Dutch childrens' gender service state "About one quarter of the referrals in Amsterdam do not fulfil diagnostic criteria for GID and most of them drop out early in the diagnostic procedure for this reason or because other problems are prominent".

In follow-up studies of prepubertal children (mainly boys) who were referred to clinics for assessment of gender dysphoria, the dysphoria persisted into adulthood for only 6–23% of children (Cohen-Kettenis, 2001; Zucker & Bradley, 1995). Boys in these studies were more likely to identify as gay in adulthood than as transgender (Green, 1987; Money & Russo, 1979; Zucker & Bradley, 1995; Zucker, 1984). Newer studies, also including girls, showed a 12–27% persistence rate of gender dysphoria into adulthood (Drummond, Bradley, Peterson-Badali, & Zucker, 2008; Wallien & Cohen-Kettenis, 2008).

In some children, the dysphoria will intensify and body aversion will develop or increase as they become adolescents and their secondary sex characteristics develop (Cohen-Kettenis, 2001; Cohen-Kettenis & Pfäfflin, 2003; Drummond et al., 2008; Wallien & Cohen-Kettenis, 2008; Zucker & Bradley, 1995), in WPATH SOC v7).

In contrast, GD continuing into adulthood appears to be much higher for adolescents. No formal prospective studies exist. However, in a Dutch follow-up study of 70 adolescents who were diagnosed with gender dysphoria and given puberty-suppressing hormones, all continued with gender affirming surgery, beginning with feminising/masculinizing hormone therapy (de Vries, Steensma, Doreleijers, & Cohen-Kettenis, 2010) (in WPATH SOC v7).

According to the DSM-5, rates of GD continuing into adolescence or adulthood vary. In assigned males, this has ranged from 2 to 30 percent. In assigned females, this has ranged from 12 to 50 percent. (DSM-5. American Psychiatric Association, Diagnostic and Statistical Manual of Mental Disorders, 5th edn. Washington DC:American Psychiatric Publishing, 2013, 302.85:455). 'It's clear that, for the majority of gender-confused boys and girls, gender dysphoria desists over time as they enter adolescence'. (Zucker KJ. Measurement of

psychosexual differentiation. Arch Sex Behav 2005;34 (4):375-388.) Early introduction of puberty suppressants may mask these developmental changes.

Many adolescents may experience some disorientation and embarrassment with the physical changes of the body during puberty. Adolescence seems to be important to the way in which an individual's gender identity develops and how it is expressed.

### **1.2.2 Social transition**

Some children state that they want to make a social transition to their preferred gender role long before puberty. 'Families vary in the extent to which they allow their young children to make a social transition to another gender role. Social transitions in early childhood do occur within some families quite smoothly. This is a controversial issue, and divergent views are held by health professionals. The current evidence base is insufficient to predict the long-term outcomes of completing a gender role transition during early childhood. Outcomes research with children who completed early social transitions would greatly inform future clinical recommendations', (WPATH SOC v7). Additional research is needed to refine estimates of its prevalence and persistence in different populations worldwide, Zucker and Lawrence (2009) in WPATH SOC v7.

The age at which adolescents transition socially has decreased in the last decade. Many young people choose to socially transition before any treatment has started, although some more anxious youngsters often prefer to wait until cross-sex hormone treatment actually commences. (Kaltiala-Heino et al. 2015).

Steensma and Cohen-Kettenis (2011) report from a clinical based sample that between 2000 and 2004, out of 121 pre-pubertal children, 3.3% had completely transitioned (clothing, hairstyle, change of name, and use of pronouns) when they were referred, and 19% were living in the preferred gender role in clothing style and hairstyle, but did not announce that they wanted a change in name and pronoun. Between 2005 and 2009, these percentages increased to 8.9% and 33.3% respectively.

Olsen et al. (2016) report data from a community based national sample of 73 transgender pre-pubescent children in the USA, suggesting that socially transitioned transgender children who were supported in their gender identity have developmentally normative levels of depression and only slightly elevated anxiety compared with population averages. They conclude that psychopathology is not inevitable within this group and that, although different samples and methods were used, compared with reports of children with GD; socially transitioned transgender children have notably lower rates of internalizing psychopathology than previously reported among children with GD living as their natal sex." (Olson et al, 2016).

It is notable that the literature looking at social transition is frequently based on a binary model of gender. Young people self-identify in increasingly diverse ways and some question traditional assumptions about stereotypical gender expression associated with gender identities.

### 1.2.3 Associated difficulties:

Various studies show that transgender young people may present with psychosocial difficulties. Yet it is also true that many young people who present to gender services are not acutely distressed. This may be particularly the case for adolescents who are aware of the possibility of gender transition, who live in an accepting environment, and who can have access to puberty suppressing treatments until they are able to take a decision to transition physiologically (Drescher et. al. 2012).

Some empirical studies of the mental health of gender variant young people, mostly from the US, show that adolescents are at high risk of self-harm and suicidal ideation (e.g. Grossman & D'Augelli, 2006). However, it is not helpful to generalise across the whole international population of gender variant young people given the diversity of the specific national, cultural and socio-political contexts in which young people live.

Data from the Netherlands (de Vries et al. 2014) show that there is a group of well-supported, mentally stable young people who cope well with their significant gender incongruence.

In the UK evidence suggests that experiencing GD can correlate with severe distress (Holt, Skagerberg & Dunsford 2014). The service in England identified the three most common associated difficulties which clients encountered in their daily lives were bullying (47%), low mood/depression (42%) and self-harming behaviours (39%), (Holt et al, 2014). In Holland, the Dutch team found that 67% of referred young people had no additional psychiatric diagnosis (de Vries et al 2010) but it was more common for their clients to have coexisting internalising difficulties such as anxiety and depression, than externalising presentations such as oppositional defiant disorder (de Vries et al., 2010).

In Finland, more than three quarters of 49 adolescents who were assessed over a two year period in a gender identity service had needed/or currently needed specialist level child and adolescent psychiatric services due to psychiatric problems other than GD (Kaltiala-Heino et al. 2015). The authors identified five distinctive groups of young people and adolescents amongst 49 adolescents presenting at their service: Group A: Early onset with no significant psychopathology; Group B: Early onset with considerable psychopathological difficulties; Group C: Adolescent onset with no, or very few psychopathological or developmental difficulties; Group D: Adolescent onset with severe psychopathological and developmental difficulties; and Group E: Adolescent onset with identity confused development. This last group was the largest, consisting of young people who were bullied, isolated with few friends, not attending school or not leaving the house, and frequently self-harming; they had a strong conviction that gender reassignment would solve their psychosocial difficulties.

In a more recent study, 24% of the young people referred to a specialist gender service self-harmed, 14% of the young people had thoughts of self-harming, and suicide attempts were indicated in 10% of the young people prior to attending the service (Skagerberg et. al., 2013).

The data for the assigned females and assigned males, showed that thoughts of self-harm were more common in the assigned males than in the assigned females prior to attending the specialist gender service, whereas actual self-harm was more common in the assigned females. These figures for associated difficulties appear to be increasing in line with the rise in the general population; self-harm rates in the general population tripled between 2002 and

2012 (Hawton et al 2014).

In some settings, it appears that social exclusion may be a key causal pathway for the relationship between gender identity and disadvantageous health outcomes (Hendricks & Testa 2012). This can take the form of prejudice; stigma; transphobia; individual, institutional, and societal discrimination and violence.

#### **1.2.4 Autistic spectrum disorder conditions (ASD):**

There seems to be a higher prevalence of autistic spectrum disorder (ASD) conditions in clinically referred, gender dysphoric adolescents than in the general adolescent population. Holt, Skagerberg & Dunsford (2014) found that 13.3% of referrals to the service in 2012 mentioned comorbid ASD (although this is likely to be an underestimate). This compares with 9.4% in the Dutch service; whereas in the Finnish service, 26% of adolescents were diagnosed to be on the autism spectrum (Kaltiala-Heino et al. 2015).

#### **1.3 Physical Treatments:**

It should be noted that the research evidence around the long term impacts of some treatments is limited and still developing and that by no means all clients with GD choose to have physical interventions.

Adolescents with continuing GD will be able to have physical interventions via the Service provided they fulfil the eligibility and readiness criteria for these. National and international guidelines recommend the use of hormone blockers (gonadotropin-releasing hormone agonists GnRH) in adolescence to suppress puberty,. For some individuals, this is followed later with cross-sex hormones, which are sex steroids of the experienced gender, also referred to as gender affirming hormones. If individuals fulfil additional criteria, they may have various types of gender affirming surgery from the age of 18 through adult gender identity clinics.

WPATH SOC v7 note that physical interventions should be addressed in the context of adolescent development. Some identity beliefs in adolescents may become firmly held and strongly expressed, giving a false impression of irreversibility. At the same time an adolescent's shift towards gender conformity can occur primarily to please the parents and may not persist or reflect a permanent change in gender dysphoria (Hembree et al., 2009; Steensma et al., published online ahead of print January 7, 2011).

There has been some debate about the minimum age at which puberty suppression and cross-sex hormone treatment could start. When first introduced, an age of 12 years was recommended for puberty suppression. However, boys and girls enter puberty at different stages. Please see separate NHS England Policy - Prescribing of Cross Sex Hormones as part of the Gender Identity Development Service for children and adolescents for access criteria to cross sex hormones.

In adolescents with GD, psychological support and puberty suppression have both been shown to be associated with an improved global psychosocial functioning. Both interventions may be considered effective in the clinical care of psychosocial functioning difficulties in adolescents with GD (Costa et al: in press).

Engagement in social interaction with other transgender people has been shown to help build resilience: Testa, Jimenez & Rankin (2014) demonstrated this effect empirically.

In the Dutch long-term evaluation study, it has been found that the psychological functioning of selected transgender adolescents tends to improve after a staged programme of puberty suppression, cross-sex hormones and gender reassignment surgery (de Vries et al, 2014). In this series of studies, 55 adolescents with GD were followed up at three time points: i) at intake, before the start of puberty suppression (mean age 13.6); ii) when cross-sex hormones were introduced (mean age 16.7); and iii) at least one year after gender reassignment surgery (mean age 20.7). No adolescent withdrew from puberty suppression, and all started cross-sex hormone treatment. Their psychological functioning improved steadily over time, resulting in rates of clinical problems that were indistinguishable from general population samples (e.g. numbers in the 'clinical' range dropped from 30% to 7% on the Youth Self Report (YSR) and 38% to 5% on the Child Behaviour Checklist (CBCL). Quality of life, satisfaction with life, and subjective happiness were comparable to same-age peers.

In the follow-up cohort study by the Dutch clinical team, young people were only eligible for puberty suppression if they (a) had persistent [continuing] GD from childhood, (b) lived in a supportive environment and (c) had no serious co-morbidities. These were called the 'immediately eligible' group (de Vries et al 2011).

In Holland therefore, those young people who achieve good outcomes are more likely to be those who have experienced lifelong gender non-conformity and who start off with significant social advantages: chiefly, the absence of any serious psychological difficulties and the presence of strong family support. Young people were started on puberty suppression only after a 'comprehensive psychosocial evaluation with many sessions over a longer period of time' (de Vries et al 2014). For the 'immediately eligible' group, the time from starting assessment to starting on the blocker was up to 18 months, with a mean of 9 months. If the young people did not show persistent [continuing] GD from childhood, live in a supportive environment or if they had serious co-morbidities, assessment was prolonged to up to almost two years (1.86 months). Such young people were in the 'delayed eligible' group. This delay in starting the blocker was to ensure they had adequate mental health treatment prior to medical intervention.

Spack, Edwards-Leeper and Feldman (2012), note that all the young people who were seen in the Boston service were reported to be in counselling, and the authors reference studies to show that 'those who do not receive counselling have a higher risk of behavioural and emotional problems and psychiatric diagnoses'.

Safety concerns remain regarding the impact of physical interventions. Although puberty suppression, cross-sex hormones and gender affirming surgeries are generally considered safe treatments in the short term, the long-term effects regarding bone health and cardiovascular risks are still unknown (Cohen-Kettenis & Klink, 2015).

The clinical team in Holland and the WPATH SOC v7 emphasise the importance of informed consent at each stage of treatment. This means that clients need to be informed about the possibilities and limitations of gender affirming interventions and other types of treatment, including psychological interventions. As GD may exist in many forms and intensities, gender affirming surgeries are not the only treatment option to help resolve GD. The broader impact



of gender affirming medical treatments on many aspects of their lives has to be discussed, including fertility.

## 2.0 Outcomes

### 2.1 NHS Outcomes Framework Domains & Indicators

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

The service will impact on the domains in the following ways:

#### **Domain 1: Preventing people from dying prematurely**

Experiencing GD can be associated with acute distress. The service will seek to reduce the distress of clients by providing high quality psychological and medical support, including physical interventions, as required on an individual basis.

#### **Domain 2: Enhancing Quality of Life for people with long-term health conditions**

Experiencing GD can be associated with significant social and emotional difficulties and distress. The service will seek to reduce the negative effects on a client's general development and build their resilience across a range of domains, including family and peer relationships, self-esteem, self-image and education, thereby improving quality of life.

#### **Domain 3: Helping people to recover from episodes of ill-health or following injury**

The service aims to reduce morbidity by providing high quality psychological and medical support through individualised health care pathways.

#### **Domain 4: Ensuring that people have a positive experience of care**

##### **Overarching indicator: patient/client experience:**

To ensure that the client and their family/carer are well-supported during the time they are in contact with the service, each client will be assigned a named Lead Worker.

The Lead Worker will be the primary source of contact for any issues arising between appointments and will be the lead for providing psychological care, supported by other staff as appropriate. Referrals will be made to the paediatric endocrine liaison service when indicated. Endocrine Consultants are the lead professionals for physical care and interventions. Care

decisions related to the commencement and continuation of hormone blockers and cross sex hormones are made jointly with psychosocial and endocrine professionals in consultation with clients and their families/carers.

**As a result of interaction with the service, clients will:**

- feel safe, supported and listened to by the service during their personal gender identity development experience.
- experience a reduction in the level of distress and conflict around their GD
- have an increased ability to function well in daily life in relation to their gender identification
- feel supported as a consequence of clear pathways, the availability of support materials and access to local professionals to gain information and support.
- be able to access care locally, including accessing prescribed hormone treatments by their local GP, with oversight from the Service's Paediatric and Adolescent Endocrine Liaison Team.
- know what the Service can and cannot provide, know how to access help and support from the Service between appointments, including telephone support for clients and their families/carers which are staffed on a rota basis, online literature and other support from national and local voluntary networks and community groups.
- have clarity about how to access local health care services that people with GD may want to be in contact with, for example speech and language and sexual health services. (See Appendix 3 for information on partnership working with GPs and CAMHS and Appendix 4 for more information on referral processes to local services).
- have information on fertility options and be signposted to other specialists such as gynaecologists and licensed NHS fertility experts for gamete retrieval via their GP.
- be offered support when transferring to adult gender services if this is their chosen pathway
- feel that their parents or carers are supported by the Service, so that parents/carers in turn are better able to support them.
- feel that those supporting them locally (e.g. professionals from schools, colleges, voluntary organisations, health and social care) are appropriately included and consulted with by the Service.

The Service will also provide peer support through therapeutic groups which focus on facilitating information sharing, reducing harm and promoting coping and resilience. Family days will bring together clients, families and carers who are facing similar issues, with health professionals to facilitate peer support and a safe environment to explore options and concerns.

Clients will be involved in service improvements, innovations and developments in a variety of ways which may include:

- regular feedback (including with their family/carers) about their experience of the service;
- participation in a Young Person's Stakeholder Group to influence the service based on their personal experience;
- being part of interview panels for new staff of the Service;
- attending wider provider Trust meetings to represent the views of service-users;
- requests to comment on specific issues;
- being involved in events and communications aimed at increasing awareness of needs of

young people with GD and their families and what services, professionals and communities can do to best support them.

### **Domain 5: Treating and caring for people in a safe environment and protecting them from avoidable harm**

The Service will ensure that local systems are in place to track and manage client safety performance, including taking action when agreed standards are not met. Robust reporting of incidents will be undertaken through local procedures and reported to NHS England.

Overarching indicator: Risks will be assessed and incidents reported. Evidence of lessons learnt and subsequent improved patient safety will be required to be provided to the NHS England commissioning team.

#### **2.2 Locally Defined Outcomes for the Gender Identity Development Service**

The Service will use a number of different measures to monitor the clinical outcomes that clients achieve. The measures will capture client wellbeing and GD and hence are a proxy for the change achieved.

##### **2.2.1 Clinically Rated Outcome Measure (CROM)**

Clinically rated outcome measures will be used by the Service to monitor each client's general progress throughout their time with the Service. The Children's Global Assessment Scale (CGAS) will be used to assess adolescent global functioning after psychological support and physical treatment.

##### **2.2.2 Patient Rated Outcome Measures (PROMs)**

Patient/client rated outcome measures involve each client providing feedback on the progress they feel they are making as a result of the interventions provided by the Service. This will include measures of GD and a self-harm questionnaire.

##### **2.2.3 Patient Rated Experience Measure (PREMs)**

The Service will measure the overall experience of clients by routinely using patient satisfaction questionnaires to gauge overall satisfaction with the interventions provided by the service.

## **3. Scope**

### **3.1 Aim and objectives of service**

The aim of the service is to provide a highly specialised service for children and adolescents up to their 18th birthday who are experiencing features of GD or need support to explore their gender identity.

It will do this by fostering recognition and non-judgemental acceptance of diversity in gender identities and gender expression; providing support, advice and treatment to assist in reducing behavioural, emotional and relationship difficulties and their effects; offering options for physical interventions as appropriate, and working to prevent further mental health problems such as anxiety, low mood, self-harm and suicidal thoughts. The service will consider

difficulties associated with gender identity development in the context of general developmental processes.

## Objectives

The service will be provided in a timely way and will deliver the aim by working in a tiered way with other services so that the client can be supported as close to home as possible, accessing the service when specialist expertise and input is required. This will include joint-working, consultation and liaison with local Child and Adolescent Mental Health Services (CAMHS), schools, colleges and others as required.

The service will provide specialist input and consultation for GD experienced by a client. The service is not commissioned to provide care for psychiatric emergencies, as local clinical professionals are responsible for this care, and may include CAMHS, GPs and/or secondary care consultants.

The service is commissioned to improve a client's state of psychological health and social inclusion by delivering tailored treatment packages in a safe environment.

For those clients who decide to undertake physical interventions, the Service will follow a staged approach, including undertaking ongoing monitoring and therapeutic exploration of their gender identity. This approach will ensure that clients have adequate time to fully assimilate the effects of each stage of physical intervention and the different options for gender expression, recognising that the needs of each person will be different.

The objectives of the Service are to provide:

Objective Area	Aim	Deliverables – this will include:
<b>Expert advice</b>	To be the lead clinical service and a source of expert advice for the diagnosis and care of children and adolescents with GD within the NHS, social care and educational system.	Raised awareness and increased understanding across health, social care and educational agencies of the issues associated with GD, thereby enabling those organisations to provide improved support locally to the individual and their family/carers and a more informed, timely and effective response in referral, assessment and treatment.
<b>Pre-referral advice</b>	Provide consultation advice to healthcare professionals, CAMHS, schools, colleges, voluntary sector organisations prior to referral and pre-referral support where there is a complex presentation or when the young	Advice by telephone/email.

	person, parents/family or carers are not yet ready for direct contact with the service.		
<b>Support local services</b>	Ensure excellent joint working and effective monitoring.	Good communication, liaison and support available to GPs, local schools, colleges, health and social care providers to support young clients with GD. Support this via appropriate literature and web-based resources including guidance for schools.	
<b>Improved access</b>	Promote equity of access and choice through the development of satellite clinics where there is a high volume of clients, following consultation and agreement with commissioners.	Ongoing review of need.	
<b>Objective Area</b>	<b>Aim</b>	<b>Deliverables – this will include:</b>	
<b>High Quality Care</b>	<p>Provide expert opinion, therapeutic support and care for clients who have GD to maximise the client's experience of care, improving their long-term quality of life, social inclusion, mental and emotional health and reducing self-harm and suicidal thoughts. The service will do this through:</p> <ul style="list-style-type: none"> <li>• providing therapeutic support and care, with a client and family-centred focus;</li> <li>• undertaking an initial assessment process which will be specific to the person in terms of duration and will typically be over three to six meetings depending on the individual; In some complex cases, this may take longer and interim recommendations for further assessment and exploration will be made;</li> <li>• using the most up-to-date clinical protocols for prescribing, therapeutic interventions, control of symptoms and treatment;</li> </ul>	<p>An assessment report and care plan to include a history of gender development and gender identification, and a description of associated mental health issues.</p> <p>High quality information for clients, families or carers, schools, colleges and healthcare professionals in appropriate and accessible formats and media.</p>	

	<ul style="list-style-type: none"> <li>• supporting the on-going exploration of gender identity and expression;</li> <li>• enabling the client and their parents/carers to make an informed choice of the treatment options;</li> <li>• providing an integrated service which encourages exploration of the mind-body relationship through close collaboration among professionals in different specialties, including paediatric and adolescent endocrinology for consideration of physical treatment with the hormone blocker when the client is in established puberty, (not before Tanner Stage 2) (see Appendix 5 for information on Tanner stages) and with referral via the GP to NHS specialists such as gynaecologists and fertility experts for egg and sperm retrieval advice and storage, and support;</li> <li>• providing a prompt, staged approach to reducing the risk of self-harming behaviour and encourage a positive self-image.</li> </ul>		
<b>Improved functioning of clients in their daily life</b>	<p>Maximise the client's daily functioning by working within the client's relationships with parents and family/carers, school and other social agencies.</p> <p>Help the client and their parents/carers to:</p> <ul style="list-style-type: none"> <li>• understand the nature of obstacles or adverse factors in the development of gender identity and try to minimise their negative influence;</li> <li>• support the client and their parents/ carers to tolerate uncertainty in gender identity</li> </ul>	<p>The client has an improved ability to effectively communicate and make informed choices about their life.</p>	

	<p>development;</p> <ul style="list-style-type: none"> <li>• combat the stigma which is often associated with the experience of atypical gender identity and is at times internalised by the individual experiencing GD;</li> <li>• alleviate feeling of shame that some clients and their parents and family/carers' experience, and enable them to develop skills in handling social interactions and dealing with possible hostility;</li> <li>• promote the development of autonomy.</li> </ul>	
<b>Transfer</b>	Facilitate a secure and seamless transfer to adult services for those clients in whom the GD persists and who therefore require ongoing care and support. Establish effective working relationships with providers of adult gender services and maintain supportive contact with the clients referred to those services until they are securely placed.	Supported transfer.
<b>Audit</b>	Undertake a rolling programme of clinical audit to test current practice and inform the evolution of care and therapeutic intervention for GD.	Audits and publications of findings.
<b>Engagement</b>	Collaborate and engage with community groups which deliver services to clients with GD and their family/carers.	Annual programme of engagement activities.
<b>Service improvement and innovation</b>	Continually develop the specialist experience, knowledge and skills of the Service's MDT to ensure high quality, sustainable provision. Continually develop clinical methods, new aspects of the Service and new ways of delivering care, while increasing the evidence base, in the area of GD.	Annual training and development programme. Attendance at National and International conferences.

### **3.2 Service description/care pathway**

#### **Service description**

3.2.1 The Service will be provided through a highly specialist multidisciplinary approach and include the assessment and care of children and adolescents with features of GD.

It will be delivered through a network model in collaboration with specialists local to where the client lives and the organisations and agencies with whom the client and their family/ carers are interacting, including CAMHS, GP's, secondary care paediatricians, gynaecology consultants, schools and colleges. This will be holistic and tailored to the needs of the individual and their family/ carers. The Service will make recommendations to GPs for onward referral via the GP for input from other NHS healthcare professionals such as gynaecologists and licenced NHS fertility experts.

#### **Referrals**

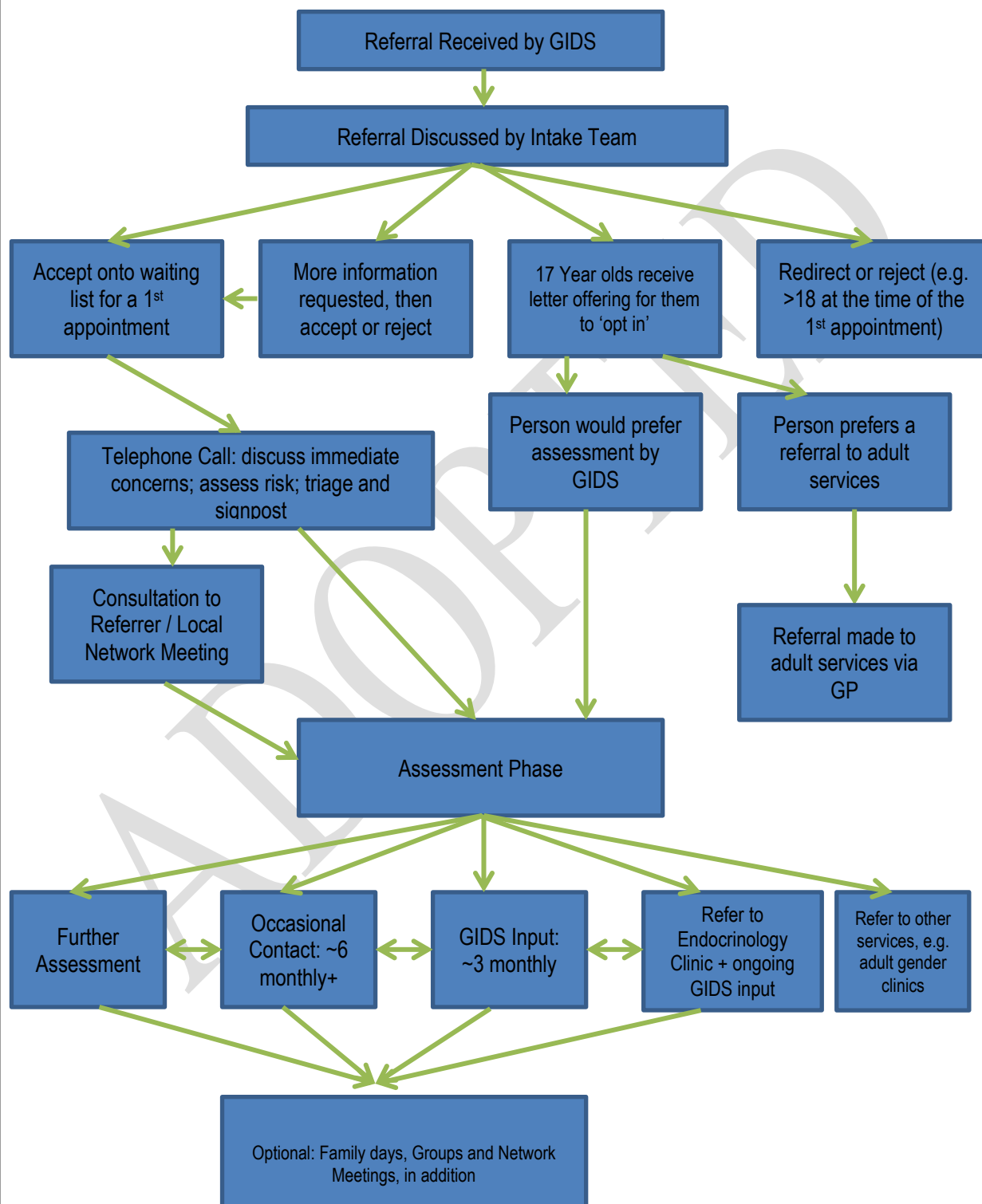
3.2.2 Referring professionals will be encouraged to discuss the referral with the family/ carer and seek their agreement. The Service will only accept referrals for children and adolescents with features of GD which are consistent with the current diagnostic criteria as defined in DSM-5.

Referrals can be made by staff in health and social services, schools, colleges of further education and by people in voluntary organisations who may have concerns about a young person's gender identity development and associated difficulties.



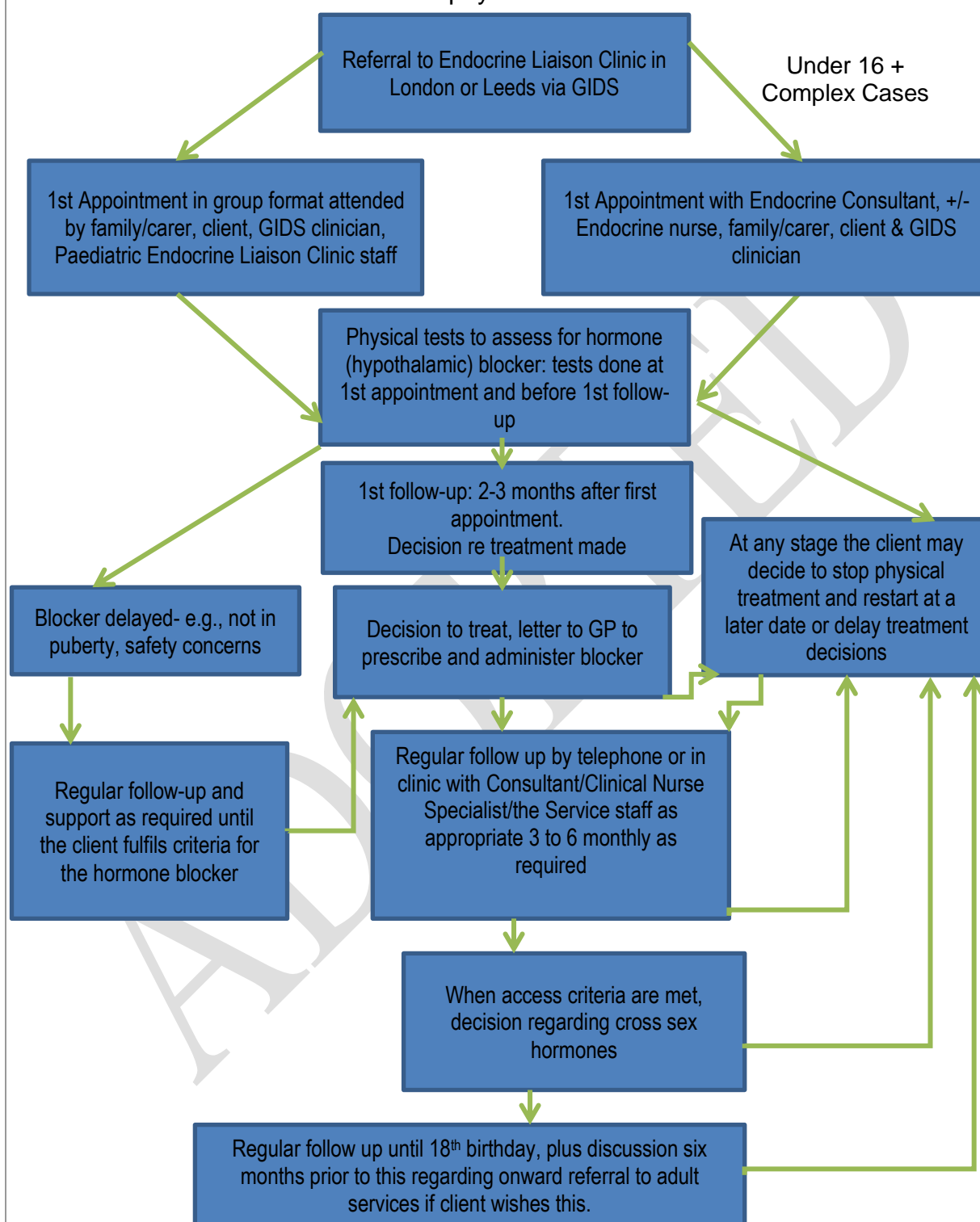
**Figure 1: Indicative Schematic illustration of GIDS Service pathway**

Following assessment, clients follow different and individualised pathways, which may or may not include physical assessment and treatment. (In practice, pathways may be adjusted to meet individual circumstances). In some cases, clients may move between and back and forth from the various aspects of the pathway at any stage.



**Figure 2: Indicative schematic diagram of pathways through the Paediatric Endocrine Liaison Clinic (in practice pathways may be adjusted to meet individual circumstances)**

- For clients who decide to undertake physical assessment and treatment



### **3.2.2 Service inputs:**

#### **The service will provide:**

- psychological/psychosocial support aimed at increasing the wellbeing and resilience of the client;
- therapeutic exploration of gender identity development and gender expression, including in relation to the client's familial, social and cultural situation;
- referral, when appropriate to the needs of the client, to the Service's Paediatric Endocrine Liaison Clinic for the following:
  - an initial physical assessment
  - advice for clients and their parents/carers around key decisions, such as when being offered hormone blockers or cross-sex hormones
  - ongoing review of progress with these treatments once prescribed;
  - access, via subsequent GP referral, to other medical specialists such as local secondary care gynaecologists and licenced NHS fertility specialists to provide advice to clients and their parents or carers when key decisions need to be made with regard to sperm or egg retrieval and storage.

#### **The Service will also provide:**

- consultation and teaching;
- research;
- support to children of transgender parents
- support to children with DSD (Disorder of Sex Development – also known as intersex conditions) who are experiencing GD and to professionals and families/carers making decisions about sex assignment and associated care;
- court reports;
- clinical placements.

### **3.2.3 Tiered model of care**

The model is based on four tiers of care, with the Service managing care at Tier 4 and supporting local provision of care at the other tiers.

#### **This will ensure that:**

- appropriate care is provided as close to home as possible and,
- local professionals caring for children and adolescents can access appropriate information and support between the appointments with the Service.

See Table 1 below

**Table 1: Tiers of Care**

Tier	Description	Detail of support and toolkits/documentation that the Service will make available to this Tier
Tier 1	Local meetings with professionals involved in the care of the client with a diagnosis of GD including: teachers, social workers, school or college staff, secondary care consultants, GPs and others as appropriate, to identify roles and facilitate the recognition and support of the client in their local community.	<p>The Service will support the following staff with advice in local network meetings and advise on any issues that arise:</p> <ul style="list-style-type: none"> <li>• School nurses, teachers</li> <li>• College lecturers</li> <li>• Social workers</li> <li>• GP's (including CCG's and LMC's)</li> <li>• CAMHS professionals</li> </ul> <p>The Service will work with primary care accreditation schemes, which support GP Practices to meet the needs of LGBT patients, and promote greater understanding through training such as the CPD accredited Gender Variance e-learning module.</p>
Tiers 2 and 3	The client will access local generic CAMHS and GPs for general mental health needs. The service will offer advice to these staff.	<p>The Service will support staff as follows:</p> <p>CAMHS – establish communication protocols and close working arrangements to enable local services to better support clients and their family or carers.</p> <p>CAMHS will be asked to review clients who the Service identifies as at risk. This request will be copied to the GP for information.</p> <p>The Service will report to NHS England on its approach to risk assessment and management and other interactions with GP's, local CAMHS teams and secondary care clinicians to provide an understanding of how/whether the issues have been addressed.</p>
Tier 4	The Service will provide specialist assessment and care for children and adolescents with GD. The	<ul style="list-style-type: none"> <li>• On a case by case basis, the service will share care and work with those who support clients locally through information giving</li> </ul>

	<p>Service will support generic CAMHS (Tiers 2 and 3) and other professionals (Tier 1) who are working with children for emergency and urgent care and treatment for mental illness.</p> <p>This will include liaison, and where appropriate joint assessment and co-working in relation to GD.</p>	<p>and providing education and advice</p> <ul style="list-style-type: none"> <li>• promote a wider understanding of GD through: <ul style="list-style-type: none"> <li>○ Creating education materials</li> <li>○ Undertaking and disseminating research</li> <li>○ Creating and taking part in Continuing Professional Development opportunities</li> </ul> </li> </ul>	
--	---	---	--

The Service is commissioned to provide assessment/consultation and the following inputs:

- continuing therapeutic exploration;
- intermittent reviews to monitor gender identity development;
- family therapy, work with parents/carers and support for siblings;
- group work and family days for clients, parents/carers and siblings;
- consultation to the network of agencies supporting the client, with or without further direct involvement with the client and their family/carers;
- network meetings in the client's locality;
- referral to the Paediatric Endocrine Liaison Clinic for physical assessment and endocrine treatment where appropriate;
- referral, via the client's GP, to other NHS healthcare professionals such as gynaecologists and licensed NHS fertility experts for discussion on gamete retrieval;
- referral to adult gender services/clinics.

Input will be agreed on a case by case basis dependent on each client's needs, including focus and frequency of contact. The Service will follow an integrated model of care involving psychosocial support, monitoring of GD and physical interventions as appropriate on a case by case basis. Where clients need more support between appointments and that support is within the expertise of local healthcare teams such as local CAMHS, the client's GP or the local acute or community paediatrician, the Service will make contact with the relevant organisation and request this.

It is recognised that a client's needs may change during their time with the Service. The Service will discuss the level of support needed with clients and their family or carers during clinic visits and other forms of contact. An individualised care plan will be created, agreed and reviewed as needs change.

### **3.2.4 Assessment, consultation and treatment at Tier 4:**

#### **3.2.4.1 Psychological Support:**

When assessing children and adolescents who present with GD, the Service's mental health professionals will conform to the following guidelines taken from WPATH SOC v7. See Appendix 6 for more information. The service will also take into account new guidelines and evidence as they are published.

### **3.2.4.4 How psychological support will be offered**

#### **Pre-pubertal children, children in puberty and post pubertal children**

The Service for pre-pubertal children will include initial assessment together with the family or carers to ascertain the features of GD and the nature of associated difficulties. The Service will facilitate communication in the family about the client's perceptions and behaviour regarding their gender identity to support their ongoing relationships.

In this initial assessment/consultation phase, clients and carers will be seen every one to three months, although this may be more or less frequent as needed. The Service will also provide therapeutic support and liaise with local services where appropriate to help clients and their family or carers manage any relationship difficulties. The Service may meet with parents/carers separately if requested or indicated.

The Service will organise and host Family Days to be attended by clients, their parents/ carers and siblings, and support groups for young people and for parents/carers. The aim of these will be to encourage peer support and discussion of shared experiences.

#### **Children approaching puberty**

For children approaching puberty, children in puberty and post-pubertal children and young people, provision will include the inputs described above, as well as individual sessions for clients.

There will be a multi-factorial assessment to enable the Lead Worker to gain a broad picture of the client's previous and current gender identification, as well as their development across a number of domains (education, family relationships, peer relationships), with a particular focus on any associated psychological difficulties that may impact on future development and response to treatment.

The work will aim to facilitate the curiosity and thoughtfulness of clients and their family or carers about the complex interactions between gender identity, gender expression, gender roles and other aspects of identity. Such conversations might also touch on the impact of living in a social world where negative attitudes towards gender variance are widespread and how these attitudes forces may be challenged.

The exact content and manner of delivery will be dependent on the developmental stage and age of the client. Where the client's situation is complex, that is, has a number of health conditions or psychosocial adversities in addition to the GD presentation, the Service will, as appropriate, undertake joint 'network' meetings with the client, their family or carers, their GP, CAMHS provider, school, secondary care paediatrician and others to ensure the appropriate care.

The Service will take particular care in assessing clients who may have social and communication difficulties or difficulties in learning, with attention paid to the client's understanding of gender and sex development and physical treatments for GD, and any issues regarding informed consent to treatment.

The Service will use a range of questionnaires as part of the assessment process to gather information on the client's gender identification and general functioning and contribute to the evidence base.

The diagnostic criteria for GD (Diagnostic and Statistical Manual of Mental Disorders, 5th Edition) will also inform the assessment regarding the child's gender identity development. The American Psychiatric Association (2013) provides further clarity on defining GD in children.

NHS England has reviewed the available evidence and concluded that as there is insufficient evidence of the long term risks and effects to inform the timing of cross sex hormones, it is appropriate to adopt a routine commissioning policy position subject to each case being assessed on the readiness of the person for further treatment and that they meet the eligibility and readiness criteria set out in the policy.

Changes to current practice should be informed by standardised data collection which develops the evidence base.

The assessment/consultation phase will involve clients and their family/carers being seen together for at least some of the time to facilitate communication about the client's perceptions of their gender identity.

Specialist assessment will take into account:

- the subjective sense of the client's identity over time;
- their expression of gender identity across different contexts over time;
- the client's and their family or carers' wishes, hopes and expectations, and their stance towards the client's gender identification;
- the capacity of the client, and their understanding of gender, puberty and fertility;
- any actual or potential risks (related to the client's physical and mental health) and how these are managed. If the risk of harm is felt to be significant, the necessary steps must be taken (i.e. immediate liaison with, or referral to, relevant agencies);
- the degree to which the client is engaging in school or work, and their experience of bullying or harassment;
- the client's psychosexual development and any sexual experiences;
- the quality of relationships within the family and wider community, and the level of support;
- the family or carers and the client's spiritual, cultural, or religious beliefs.

Factors that could influence the complexity and length of the assessment include:

- the intensity of any associated difficulties;
- on-going risk issues, including self-harm and suicidality, and safeguarding issues;
- concerns with regard to the client's capacity to understand and consent;
- family conflict (especially in a younger child) about how to proceed;
- inadequate support from the local network of agencies and services involved with the young person (where there are any concerns regarding mental health or social functioning).

The Service may liaise with CAMHS, social care and education at the assessment/consultation stage in order to set out specific needs which local services may respond to, now

or in the future, with further psychiatric, educational and inter-disciplinary input.

The clinical work that supports identity exploration involves conversations which are focused on increasing understanding and insight. These conversations can be engaged in during the assessment period and continued subsequently when the relationship with the clinicians in the Service may become more trusting. Exploratory work will recognise the right of a client to self-define their gender identity and to make decisions about their own life and treatment, taking their developmental stage and competence into account.

Issues to do with body dissatisfaction may be broached, and hopes (which may be more or less realistic) for achieving a more settled relationship with the body. The opportunities provided by medical intervention, and the limitations of intervention will be discussed.

The Service may also support thinking about notions of masculinity and femininity and the range of possibilities around identification, whilst helping clients to tolerate the uncertainty associated with the process of exploration. Understanding the unique experience and point of view of each client will be a priority.

All aspects of the care pathways are available for clients who present with other gender identifications, including non-binary.

Liaison with CAMHS, social care, schools and colleges may be conducted at the assessment/consultation stage, identifying specific needs to which local services may respond, now or in the future, with further psychiatric and inter-disciplinary input. If there are concerns about a client's mental health, local services will be asked to provide further psychiatric and multi-disciplinary input.

The Service will take appropriate action if harm, or the risk of harm, is felt to be significant (i.e. immediate liaison with or referral to relevant agencies).

It is noted that not all clients decide or wish to undertake physical assessment and treatment. On an individual basis therefore, clients may prefer only to access on-going support and therapeutic exploration of gender identification and/or social gender expression and not opt for physical treatment. At different times whilst in contact with the Service, clients can move between different elements of the pathway (see Figure 1).

Some children or adolescents who have socially and/or physiologically transitioned in line with their individual needs may decide to de-transition. The service will provide support for this, which may include consultation with schools, colleges and local services to ensure that the process is as smooth as possible. Support will also be provided to the young person and their family/carers in the usual way.

### **3.2.5 Informed consent**

The Service will recognise a wide diversity in sexual and gender identities and will affirm the importance of each person to develop autonomy in relation to treatment decisions, as well as their need for care and support from their family and the professional team.

The Service will facilitate the careful consideration by clients and their family or carers of the



meaning of informed consent, as it is an important aspect of ethical assessment and intervention, including the emotional, social and factual issues, so as to enable them to make informed decisions about the treatment options, benefits, risks, and the alternatives to the treatments proposed (including the option of no treatment). The consequences of treatment decisions can be significant and life-changing.

The Service will support the client and their family or carers to jointly understand the factual information which will enable them to make informed decisions about treatment options, including hormone treatments if appropriate; initial advice about fertility options and, make a recommendation to the client's GP that a referral to a licenced NHS fertility specialist is required.

Age alone does not determine capacity to give consent. If it is concluded that a client has sufficient autonomy and understanding of what is to be offered, plus other key eligibility and readiness criteria have been met, they can consent to treatment.

The term 'competence' means that a person fully understands what is proposed; can retain an understanding of the implications; can appreciate the importance of the information and see how it applies to themselves and can assess the benefits and dis-benefits of their decision. The level of understanding that is sufficient will vary with the complexity and gravity of the decision.

The Service will assess a client's capacity or competence to consent to physical interventions. The evaluation of competence of a client for whom physical intervention is recommended within the scope of the specifications will be undertaken with special care for those under the age of 16 (see the Tavistock and Portman NHS Foundation Trust policy on 'Consent to Treatment').

<http://tavistockandportman.uk/sites/default/files/files/consent-policy-and-procedure-Apr-15.pdf>

All efforts will be made to ensure that clients are aware of the longer term consequences of the endocrine treatments, including implications for fertility, and the decision of the competence of the client will be jointly made by the endocrine and psychological members of the Service's integrated team.

The current context of treatment decisions about cross sex hormones in adolescence is that there is limited scientific evidence for the long-term benefits versus the potential harms of the intervention. There are also concerns that it is uncertain whether or not a young person will continue to identify as transgender in the future, given that some subsequently identify in a different way, (as referenced in Section 1.2).

Please see Appendix 7 for guidance on Informed Consent in the context of the Service.

### **3.2.6 Referral to the Service's Paediatric Endocrine Liaison Team**

Following a detailed psychosocial assessment and consultation, a client may wish to be considered for referral to the Paediatric Endocrinology Liaison Team.

The Paediatric Endocrine Liaison Team includes Consultant Adolescent Endocrinologists and Clinical Nurse Specialists. Physical intervention is one part of the overall treatment offered by

the Service and is not offered in isolation from other aspects of the treatment provided by the MDT.

3.2.6.1 There will be two entry points:

- Early Intervention Clinic
- Standard Clinic

**Early Intervention Clinic:**

Physical intervention in the early stages of puberty is available via the Paediatric Endocrine Liaison Team's Early Intervention' Clinic for carefully selected clients who are at least in Tanner Stage 2 of puberty and are up to the age of 15. The Early Intervention Clinic will continue to follow the Service's 2011 research protocol, which following evaluation, has now become established practice, with the exception that hormone blockers will now be considered for any children under the age of 12 if they are in established puberty.

**Standard Clinic:**

These appointments will be for adolescents referred to the clinic who are aged between 15 to 18 years.

The client and their parents/carers will first attend either an educational group session or a joint appointment with a member or members of the endocrine and psychological/psychosocial care teams. Joint clinic appointments and the educational group will both include an introduction to the work of the clinic, information about physical treatments and issues relating to informed consent.

**3.2.6.2 Assessment process for all clients**

In the first or second Paediatric Endocrine Liaison clinic appointment, there will be a very short, visual and physical examination which will be done with the utmost empathy and respect for the client, in order to:

- provide the clinician(s) with a baseline assessment of the stage of pubertal development (genital stage/testicular volume in natal males and breast stage in natal females),
- enable the clinicians to ensure that the client is in good physical health and determine whether self-neglect or self-harm are present.

The need for this examination will be clearly explained to the client well in advance so that they can prepare for this and ask any questions. The client will be asked to consent to the examination. Following the examination, the client, their family or carers and clinicians will discuss further plans and reach a joint decision about whether to start the use of the hormone blocker if appropriate.

There are two separate categories of hormone treatments available:

- gonadotropin-releasing hormone analogues (GnRHa), (referred to in this document as hormone blockers). These can be prescribed to suspend puberty for clients who meet eligibility and readiness criteria. The Service will liaise with the client's GP and make the referral to the GP to prescribe these, which will be an injection given in primary care according to recommended dosage schedules. These can be taken for a limited time.

- cross-sex hormones. A client who has been on the hormone blocker for a period of time and been assessed as having continuing GD may be considered for cross-sex hormones if they meet eligibility and readiness criteria. Cross-sex hormones can be gradually introduced to mimic the physical and psychological changes of puberty.

It is expected that all treatments will be prescribed and administered in primary care services. The Service will provide support to GP's with any queries regarding this.

Hormone blockers will be considered as an appropriate treatment alongside psychological intervention, and will not necessarily be viewed as the pre-cursor to the prescribing of cross-sex hormones. The next stage of treatment, if any, should be left open for further exploration with the client.

The paediatric endocrinologist's assessment of the biological environment and the client's physical development will precede the prescribing of hormone blockers.

The decision to start hormone blockers is reached after an in-depth discussion involving the MDT. Decision-making responsibility for prescribing the hormone blocker and the physical monitoring of this treatment is with the paediatric endocrinologists, subject to periodic review by the MDT.

## **Fertility**

All clients attending the Paediatric Endocrine Liaison clinic will receive general fertility advice including the possible effects of taking hormones for future fertility.

The Paediatric Endocrine Liaison Team will provide initial information on fertility options and signpost the client and their family or carers back to their GP who can make an onward referral to licensed NHS fertility specialists for expert advice on fertility options including gamete retrieval.

### **3.2.7 Staffing**

The specialist MDT team will include the following professionals, with different levels of seniority providing care in each group:

- family therapists,
- child and adolescent psychiatrists,
- clinical psychologists
- social workers
- child and adolescent psychotherapists,
- clinical nurse specialists in endocrinology
- adolescent endocrinologists

### **3.2.8 Service hours:**

The Service will operate Monday to Friday 9.30-5.30pm. If the Service cancels an appointment, a replacement slot will be booked within a week for the appointment to take place within six weeks. There should be a record kept of the number of times that a clinic appointment is cancelled before it takes place.

### 3.2.9 Discharge planning and possible transfer to adult services:

There are two possible outcomes for clients of the Service who are aged 17 years of age or more:

- for those clients who do not wish to proceed to the adult service for whatever reason, a referral back to the GP will be made, or
- referral to the adult gender service for those adolescents who wish to be referred. Adult gender services will accept referrals from the age of 17 years. For those clients who are being seen in the Paediatric Endocrine Liaison Clinic, the case history will be forwarded to the adult clinic at the point of onward referral, copied to the GP.

In such cases, the Service will ensure as far as is possible, that the transfer between adolescent and adult services is achieved through liaison between these services so that treatments that have been initiated for adolescents may continue without interruption and so that where treatment has not yet been undertaken, it may be started in a timely manner, taking account of the client's clinical and social history.

The Service will ensure effective, safe, smooth and timely discharge (to local services, other NHS professionals or the adult gender service) as appropriate to the client.

To facilitate this, the Service will put in place a discharge plan to ensure that the client's needs are considered from the earliest point of contact. Discharge planning will include the needs and wishes of the client and their parents/carers. The final discharge plan will be agreed with the client and their family or carers. Discharge planning should commence from the 17<sup>th</sup> birthday or as close to this as appropriate, depending on the age at which a client is referred.

A copy of the discharge plan will be given to the client and their family or carers, the referrer, their GP and, with the permission of the family, to any other involved professionals.

The discharge documentation will include a copy of the healthcare discharge plan which is , an 'About Me' hand-held booklet, co-designed with clients to include sections which are important to them and inform other health and social care professionals about key issues, GD experiences and intentions of the person so that they do not have to unnecessarily repeat their personal experience . This should be updatable. For example: identity, pronouns, experiences with dysphoria, any experiences with self-harm or suicide attempts - if the client wishes, as these can often be very difficult to talk about.

Clients may transfer to other services where this is appropriate, such as :

- adult mental health services
- other appropriate services.

At the point of discharge, the Service will collect data on outcomes of GD and their reason for leaving, including transfer to adult service. This will be shared with the commissioners on an annual basis to inform future service development activities.

### **3.3 Population covered**

The Service is for clients who are registered with an English General Practitioner (GP), or who are resident in Scotland or the European Union and eligible for treatment in the NHS under reciprocal arrangements.

Young people who live in Wales and Northern Ireland are not part of this commissioned service and the relevant commissioners will have separate arrangements in place with the service provider for their residents.

This contract includes provision for the Service to treat eligible patients from overseas under S2 and aligned referral arrangements. Providers are reimbursed for appropriately referred and recorded activity as part of this contract.

NHS Trusts performing procedures on patients outside of S2 arrangements and aligned referral arrangements will need to continue to make the financial arrangements directly with the governments involved, separately from their contract with NHS England.

### **3.4 Any acceptance and exclusion criteria**

#### **3.4.1 Referral management**

New clients will be seen within 18 weeks from the date the referral is received.

As a young person may or may not be experiencing distress relating to the social or physiological aspects of their GD, referrals will be assessed to ascertain the level of distress and any associated risk. If the referral is received from a health professional other than local CAMHS or from a voluntary organisation, a letter will be sent to the client's GP and the local CAMHS team to advise them of the referral and the perceived level of risk with the client.

Where the Service identifies that the client is at significant risk, it will communicate this with the GP and local CAMHS to request that the young person is assessed locally as soon as possible and an appropriate risk management plan put in place.

As a rule, referrals cannot be accepted in cases when the identified risk is not being managed locally. In such cases, the Service will liaise with local services to facilitate engagement and the development of a local care plan.

Acceptance criteria are:

- referrals will be accepted from a range of professionals including CAMHS professionals, GPs, secondary care clinicians including paediatricians and gynaecologists, schools and colleges of further education, voluntary organisations.
- referrals will be accepted if there is evidence of features consistent with a diagnosis of GD.

Following assessment, if it is apparent that the young person does not fulfil the criteria for a diagnosis of GD, or it is concluded that there are no outstanding issues with their gender identity development, they will be referred back to their GP or other referring healthcare professional, with advice regarding appropriate support and the case will be closed.

### 3.4.2 Age of access

The Service will be offered to children and young people aged up to their 18<sup>th</sup> birthday. If a new referral is received for a client who is already 17 years of age, the Service will contact the young person to discuss referral options, given that the 18 week timeline to be seen as a new patient followed by the appropriate duration of assessment means that they are likely to have already reached or nearly reached the exclusion criteria for the Service (that is, reached their 18<sup>th</sup> birthday) before they can commence hormone treatment, if this is indicated.

In such cases,

- If the young person's objective is to receive hormone treatment and they would instead prefer a direct referral to adult services, the referrer will be contacted and asked to do this.
- If the young person would like the opportunity to explore their gender identification and options, on their own or with their parents/carers, the Service will offer to assess the young person over two to three appointments. It will then agree an appropriate onward referral if appropriate and the young person wishes.

In all cases, referrers will be informed of the client's decision so that local health professionals can put in place support as required whilst the young person waits to access the adult gender identity clinic.

Referrals for young people who will be 18 by the time of the first assessment appointment will be promptly re directed via the referrer to adult gender services to minimise delays.

### 3.4.3 Criteria for referral to the Paediatric Endocrine Liaison Team for hormone blockers in the early stages of puberty and/or under the age of fifteen.

Hormone blockers will be considered as an appropriate treatment alongside psychological intervention, and will not necessarily be viewed as the pre-cursor to the prescribing of cross-sex hormones. The next stage of treatment, if any, should be left open for further exploration with the client and their parents/carers.

In reaching an overall decision regarding the prescribing of hormone blockers, the multidisciplinary clinical team will, together with the young person and their parents/ carers, consider each individual's case including the outcome of the assessment of the biological environment and the client's physical development.

Clients under the age of 16 should be assessed regarding their ability to give informed consent and whether they have appropriate autonomy to make decisions.

The decision to start hormone blockers is reached after an in-depth discussion involving the MDT, following which the final responsibility for prescribing the hormone blocker and the physical monitoring of this treatment remains with the paediatric and adolescent endocrinologists, subject to periodic review by the MDT.

The criteria for considering a referral to the Paediatric Endocrinology Liaison Team are as follows:

- the adolescent has been presenting with continuing GD and the intensity and distress has

increased with puberty;

- the adolescent presents as relatively stable psychologically as evaluated through clinical observation and questionnaires;
- there is support from the family/carers;
- where there is a need to provide information about physical development in order to allay some anxieties in the adolescent patient and the family;
- to exclude a disorder of sex development (intersex) or other endocrine conditions;

#### **3.4.4 Criteria for considering administering hormone blockers to post-pubertal adolescents over the age of 15 years with GD:**

- there is a substantial history of gender incongruence, lasting more than one year. While a diagnosis of Gender Dysphoria (DSM-5) may be made after six months of dysphoria, a move to physical treatment requires a further period of consolidation.
- the young person is judged to have sufficient understanding of what the blocker will do, and how it works, to be able to give assent, or consent, to treatment.
- if the request for blockers seems driven by a wish for no puberty or no gender, perhaps accompanied by a generalised dissatisfaction with the body, and this motivation has been carefully explored. In such a case, the young person and their parents/carers have an understanding of the limitations of what medical intervention can offer in the longer term.
- similarly, if the request, and any accompanying distress, seem linked to sexual orientation rather than gender identity, and the motivation has been carefully explored.
- there is no intense and prolonged psychological illness on the part of the young person (such as a severe eating disorder, psychotic experiences or major depression) such as might interfere with considered decision-making by the young person.
- there is no ongoing major family disruption.
- one or both parents/carers support the young person's request for puberty suppression treatment and work has been done to develop their understanding of its potential advantages and its potential disadvantages.
- where the parents are separated, it has been established who has legal parental responsibility, and careful thought has been given to involving an estranged parent in the decision-making about the young person's treatment.
- the young person and family are likely to be able to attend appointments regularly. Any likely barriers to attending have been explored prior to referral for puberty suspension.
- the young person is engaged in education and some face to face social interaction with peers.
- the young person is at least at Tanner Stage 2 i.e. 'in puberty'.

#### **3.4.5 The eligibility and readiness criteria for prescribing cross-sex hormones**

This is as set out in the separate NHS England Policy: Prescribing Cross Sex Hormones as part of the Gender Identity Development Service for Children and Adolescents.

### **3.5 Exclusion criteria**

3.5.1 The service is not commissioned to respond to emergencies or offer treatment to associated psychological and psychiatric problems (e.g. school refusal and compulsive

symptoms). The service will, in complex cases, ensure that the client's GP and CAMHS provider are engaging with the client and are aware of any escalation in risk.

### 3.5.2 Care may be suspended where:

- there are abnormalities in the status or timing of pubertal development or there are other physical contraindications that require further investigation.
- the client has not met all the criteria described above.
- the client presents with a severe psychotic or other significant mental health disorder that is not adequately controlled.

In such cases, if the hormone treatments have begun, these may be paused whilst the client is being supported by other services to better manage their condition.

3.5.3 The Service does not offer shared care with private clinicians, although it is understood that some young people may wish to access hormone treatments outside of an NHS prescription or without medical supervision (e.g. from the Internet) at an earlier point than is set out in this specification.

The Service provider will make the young person and their family/carers aware of the risks, contraindications and any irreversible or partly reversible effects of any interventions, but will be unable to provide ongoing clinical supervision for the management of hormone treatments prescribed or accessed outside the service. The Service will still provide holistic psychosocial support with input from mental health professionals.

Once the client meets the access criteria set out in this specification and has been assessed by the MDT, a care plan will be agreed and if appropriate, hormones will be prescribed. If required, the Service will, with the consent of the client and their family/carers, review and evaluate the records of any prior mental health assessments or treatments, and liaise as necessary with any previous provider, to obtain the results of baseline examinations and laboratory tests.

## 3.6 Stopping criteria

Endocrine treatment will be suspended, following discussion with the client and their family or carers where:

- there are any concerns about the client's physical health such as low bone density
- the client and family do not attend regular follow ups at the Paediatric Endocrine Liaison Clinic and/or the GIDS general clinic as agreed in their care plan.
- the client is having a significant psychotic episode or has an exacerbation of a significant mental health condition that is not being adequately controlled with support from other agencies, as this may reduce their ability to manage the emotional issues that may arise from the changes in hormone levels from the hormone treatments and may impact on their capacity to consent.
- there are physical contraindications that require further investigation.
- the client decides to cease treatment for any reason
- gender related medications are taken without an NHS prescription.



### **3.7 Response time and prioritisation**

The Service is required to see clients for the first time and begin the assessment process within eighteen weeks of referral.

The Service will provide equitable care for any child or young person up to their 18<sup>th</sup> birthday from any cultural background, with any protected characteristic and with any illness or disability. Every reasonable effort is to be made to make services accessible. The Service will provide accessible toilets and access for wheelchair users. When required, the Service will use interpreters and translate printed documents

The Service will undertake Equality Impact Assessments with regard to all protected characteristics as a requirement of equality legislation, promoting equality and addressing health inequalities.

The Service will:

- give due regard to the need to eliminate discrimination, harassment and victimisation, to advance equality of opportunity, and to foster good relations between people who share a relevant protected characteristic (as cited under the Equality Act 2010) and those who do not share it; and
- give regard to the need to reduce inequalities between clients in access to, and outcomes from healthcare services and to ensure that care is provided in an integrated way where this might reduce health inequalities.

### **3.8 Interdependencies with other services**

As shown in the Tiers of Care table on page 20/21, the Service provider will be the leader in the NHS in England for the assessment and care of children and adolescents with GD even though the tiered model of care means that interaction with the Service will only be part of the client's experience.

The Service will provide advice and support to referrers and will provide education on GD within the NHS and across the education (schools and colleges), social care and voluntary sectors to raise awareness of gender identity development in child and adolescents.

The Service will form supportive relationships with local education, health, social care providers and the voluntary sector to support optimal care for clients with GD. This will include liaison with healthcare professionals such as secondary care paediatric and gynaecological consultants; GPs; community nurses; school nurses and health staff in colleges of Further Education; academies; staff in Local Education Authorities that have pupils attending the Service in any of its locations; CAMHS staff; social workers; adult gender service providers; adult endocrine services; adult surgical providers; local Clinical Commissioning Groups; helpline providers; and charities.

The Service will engage in two way communication with and seek to have robust working relationships with: local CAMHS, GP's and secondary care healthcare professionals and provide routine feedback to them of client progress, subject to appropriate information governance. This will include:

- direct consultations;

- co-working for complex cases;
- liaison and individual client care planning;
- support for transfer of clients to adult services.

In line with the tiered model of care, responsibility for managing the risk associated with gender dysphoria for all clients will reside with local services.

The Service will work in collaboration with another gender identity clinic in the Netherlands, and others in Europe, Canada and America to share and implement standardised assessments for research and evidence base practice purposes.

The Service will:

- undertake effective two-way communication with adult gender services prior to the transfer of clients to the adult service. This needs to take place with the client and their family or carers.
- provide transfer support to the adolescent in their move to the adult service

Discussions about any substantive potential change to the service model or clinical approach must take place with NHS England commissioners in order that clinical approval can be given and any changes to commissioning policies taken through the clinical governance and approvals processes.

A report to commissioners will be submitted annually on innovation and improvements in the Service.

### **3.9 Audit and Research**

The Service will conduct research and undertake audit projects as part of ongoing service improvement and development. This will build knowledge about the profiles of the young people who are referred, their experiences at different stages in their development and at different stages of treatment and outcomes.

The Service will collaborate with adult services in the UK to follow up the outcomes for clients in a way that respects their privacy. International collaboration will also be undertaken to inform an improved understanding of the most effective treatment pathways for different groups of young people.

## **4. Applicable Service Standards**

### **4.1 Applicable national standards e.g. NICE, Royal College**

The Service will be fully integrated into its Trust corporate and clinical governance arrangements. Practitioners will participate in continuous professional development and networking.

The Service will develop standardised evidence base tools and training programmes, including:

- common risk assessment, care approaches and systems;
- training for gender identity development, clinical skills and specific training related to mental health;
- clinical information systems, reports to commissioners;
- child protection procedures;
- client consultation and advocacy.

## **Education and training**

The Service will undertake a training and education role including:

- training of professionals working within it
- education (including educational materials) for professionals at Tiers 1,2,3
- education for other agencies such as schools, and colleges of further education, CAMHS and social services, voluntary organisations which support young people locally.

## **Documentation and Information Technology**

Following each multidisciplinary clinic, the staff will produce a single clinic letter which will integrate the reports from each clinician. This will be sent out to the client and their family/ carer; the client's GP and CAMHS and other secondary care paediatric specialists.

Clinic notes and correspondence will be stored at each centre (computerised) and included in the organisation's computerised client records of the client. The provider's administrator will have responsibility for ensuring safe storage and adherence to the Data Protection Act (1998) for computerised data. Offsite backup storage will also be arranged.

## **Facilities**

Each centre used by the Service for the provision of care will have clinic space that is appropriate for children and adolescents and suitable for attendance by a number of multi-professional staff at one time.

## **Equity of access to services**

Service access is paramount to success. The Service will be tiered so that care can be provided as close to home as possible, with appropriate geographic access related to demand, agreed in conjunction with commissioners.

## **Managing Risk**

The Service provider must meet the standards set out in this specification. It is the Trust's responsibility to notify the commissioner on an exceptional basis should there be any breaches of the standards.

## **5. Applicable quality requirements and CQUIN Goals (see Schedule 4 Parts A-D)**

There is a requirement to hold national audit meetings on an annual basis.

All parts of the Service must assure that:

- all practitioners participate in continuous professional development and networking
- client outcome data is recorded and audited across the Service
- all centres must participate in the NHS England annual national audit process.

Audit meetings will address:

- clinical performance and outcomes
- process-related indicators e.g. efficiency of the assessment process, prescribing policy, outpatient follow-up etc.
- service issues;
- notable events;
- treatment guidelines
- evidence based practice;
- review of learning from the year
- safety
- stakeholder satisfaction, including feedback
- client, family and carer involvement and engagement and with other stakeholders including voluntary sector support groups
- sustainability
- transfer to adult services
- review of international evidence and benchmarks to inform changes in delivery
- audit activities, service evaluation and research, including future audit programme
- potential new developments, improvements and innovations
- potential improving value schemes

**Measures for monitoring the clinical benefit of the service are:**

- diagnosis rate
- base unit of measurement e.g. feelings of anxiety
- informative problem-based measures
- participation in a research study.
- a minimum defined data set will be collected on all clients.
- clinically rated outcome measures (CROM)
- patient rated outcome measures (PROMs)
- patient rated experience measures (PREMS)

## **6. Location of Provider Premises**

The Service is provided by the Tavistock and Portman NHS Foundation Trust in London and Leeds, with associated integrated Paediatric Endocrine Liaison clinics.

The community outreach service is delivered through a hub and spoke model in London and agreed outreach centres in England to ensure equity of access. The location of outreach clinics will be determined by the commissioner and will be based on referrals and following agreement with commissioners. These are currently Barnstaple, Exeter, Bristol and Bath.

### **Sub-contractors**

The Paediatric Endocrinology Liaison Clinics which are based at the University College London Hospital NHS Foundation Trust and the Leeds Teaching Hospitals NHS Trust: Leeds General Infirmary (LGI) site, are sub-contracted, although the staff are part of the Service's MDT and there is a single, integrated clinical protocol.

## **7. Individual Service User Placement**

Not applicable.

## Evidence Base

- Aitken, M., Steensma, T. D., Blanchard, R., VanderLaan, D. P., Wood, H., Fuentes, A., Zucker, K. J. (2015). Evidence for an Altered Sex Ratio in Clinic-Referred Adolescents with Gender Dysphoria. *The journal of sexual medicine*, 12(3), 756-763.
- Cohen-Kettenis PT & Klink D. Adolescents with Gender Dysphoria, *Best practice & Research Clinical Endocrinology & Metabolism* (2015), doi:10.1016/j.beem.2015.01.004.
- Cohen-Kettenis, P. T., Steensma, T. D., & de Vries, A. L. (2011). Treatment of adolescents with gender dysphoria in the Netherlands. *Child and adolescent psychiatric clinics of North America*, 20(4), 689-700.
- Cohen Kettenis, P (2001); Zucker & Bradley (1995) cited in the World Professional Association for Transgender Health: Standards of Care for the Health of Transsexual, Transgender, and Gender-Nonconforming People v7, (2012).
- Cohen-Kettenis, P. T., & Kuiper, A. J. (1984). Transseksualiteit en psychotherapie. *Tijdschrift Voor Psychotherapie*, 10, 153-166.
- Cohen-Kettenis & Pfäfflin, (2003); Transgenderism and Intersexuality in Childhood and Adolescence: Making Choices (Developmental Clinical Psychology and Psychiatry) Paperback.
- Delemarre-van de Waal, H. A., & Cohen-Kettenis, P. T. (2006). Clinical management of gender identity disorder in adolescents: a protocol on psychological and paediatric endocrinology aspects. *European Journal of Endocrinology*, 155(suppl 1), S131-S137.
- Rosalia Costa, MD,\*† Michael Dunsford, PsyD,\* Elin Skagerberg, PhD,\* Victoria Holt, MRCPsych,\* Polly Carmichael, PhD,\*1 and Marco Colizzi, MD† Psychological Support, Puberty Suppression, and Psychosocial Functioning in Adolescents with Gender Dysphoria 2015 International Society for Sexual Medicine DOI: 10.1111/jsm.13034.
- de Vries, A. L., Noens, I. L., Cohen-Kettenis, P. T., van Berckelaer-Onnes, I. A., & Doreleijers, T. A. (2010). Autism spectrum disorders in gender dysphoric children and adolescents. *Journal of Autism and Developmental Disorders*, 40, 930–936. <http://dx.doi.org/10.1007/s10803-010-0935-9>.
- de Vries, A. L., Steensma, T. D., Doreleijers, T. A., & Cohen-Kettenis, P. T. (2011). Puberty suppression in adolescents with gender identity disorder: A prospective follow-up study. *The Journal of Sexual Medicine*, 8(8), 2276-2283.
- de Vries, A.L; Cohen-Kettenis, P; (2001) Clinical Management of Gender Dysphoria in Children and Adolescents: The Dutch Approach, *Journal of Homosexuality*, 59:3, 301-320.
- de Vries AL, McGuire JK, Steensma TD, Wagenaar EC, Doreleijers TA, Cohen-Kettenis PT. (2014) Young adult psychological outcome after puberty suppression and gender reassignment. *Pediatrics*. 2014;134(4):696-704.
- de Vries, A.L; Steensma; T.D, Doreleijers, T.A; Cohen-Kettenis, P.(2010) Puberty suppression in adolescents with gender identity disorder: a prospective follow-up study cited in the World Professional Association for Transgender Health: Standards of Care for the Health of Transsexual, Transgender, and Gender-Nonconforming People v7, (2012).

- Di Ceglie and Thummel (2006) p56 Experience of Group Work with Parents of Children and Adolescents with Gender Identity Disorder Clinical Child Psychology and Psychiatry Copyright © 2006 SAGE Publications (London, Thousand Oaks and New Delhi) Vol 11(3): 387–396. DOI: 10.1177/1359104506064983 www.sagepublications.com
- Drescher, J., & Byne, W. (2012). Gender dysphoric/gender variant (GD/GV) children and adolescents: Summarizing what we know and what we have yet to learn. *Journal of homosexuality*, 59(3), 501-510.
- Drummond, K.D; Bradley, S.J.; Peterson-Badali, M.; Zucker, K.J. (2008); A follow-up study of girls with gender identity disorder. *Developmental Psychology*, Vol 44(1), Jan 2008, 34-45. <http://dx.doi.org/10.1037/0012-1649.44.1.34> .
- Endocrine Treatment of Transsexual Persons: An Endocrine Society Clinical Practice Guideline (2009) Hembree, W.C.; Cohen-Kettenis, P; Delemarre-van de Waal, H.A; Gooren, L.J; Meyer, W.J. III; Spack, N.P; Tangpricha, V; Montori V.M 1;
- Fisk, 1974; Knudson, De Cuypere, & Bockting, 2010b) in the World Professional Association for Transgender Health: Standards of Care for the Health of Transsexual, Transgender, and Gender-Nonconforming People 2012, (WPATH SOC v7.
- Gelder, M. G., & Marks, I. M. (1969). Aversion treatment in transvestism and transsexualism. *Transsexualism and sex reassignment*, 383-413. Gold, M., & MacNish, M. (2011). Adjustment and resiliency following disclosure of transgender identity in families of adolescents and young adults: Themes and clinical implications.
- GMC [http://www.gmc-uk.org/guidance/ethical\\_guidance/28851.asp](http://www.gmc-uk.org/guidance/ethical_guidance/28851.asp)
- Greenson, R. R. (1964). ON HOMOSEXUALITY AND GENDER IDENTITY. *The International journal of psycho-analysis*, 45, 217.
- Grossman, A. H., D'augelli, A. R., & Salter, N. P. (2006). Male-to-female transgender youth: Gender expression milestones, gender atypicality, victimization, and parents' responses. *Journal of GLBT Family Studies*, 2(1), 71-92; Grossman, A. H., D'Augelli, A. R., Salter, N. P., & Hubbard, S. M. (2006). Comparing gender expression, gender nonconformity, and parents' responses of female-to-male and male-to-female transgender youth: Implications for counseling. *Journal of LGBT Issues in Counseling*, 1(1), 41-59.
- Green, (1987); Money & Russo, (1979); Zucker & Bradley, (1995); Zucker, (1984) in World Professional Association for Transgender Health: Standards of Care for the Health of Transsexual, Transgender, and Gender-Nonconforming People v7, (2012).
- Grossman, A.H; D'Augelli, A.R; (2006). Transgender youth: invisible and vulnerable. *Journal of Homosexuality* 2006; 51:910;111-28.
- Hawton, K., Linsell, L., Adeniji, T., Sariaslan, A., & Fazel, S. (2014). Self-harm in prisons in England and Wales: an epidemiological study of prevalence, risk factors, clustering, and subsequent suicide. *The Lancet*, 383(9923), 1147-1154.
- Hein I.M., De Vries M.C., Troost P.W., Meynen G., Van Goudoever J.B. and Lindauer R.J.L (2015) Why is it hard to make progress in assessing children's decision-making competence? *BMC Medical Ethics* 16:1
- Hein, I. M., Troost, P. W., Broersma, A., De Vries, M. C., Daams, J. G., & Lindauer, R. J. (2015). Why is it hard to make progress in assessing children's decision-making competence?. *BMC medical ethics*, 16(1), 1.

- Hembree et al., 2009; Steensma et al., published online ahead of print January 7, 2011).
- Hendricks, M. L., & Testa, R. J. (2012). A conceptual framework for clinical work with transgender and gender nonconforming clients: An adaptation of the Minority Stress Model. *Professional Psychology: Research and Practice*, 43(5), 460.
- Holt, V., Skagerberg, E., & Dunsford, M. (2014). Young people with features of gender dysphoria: Demographics and associated difficulties. *Clinical child psychology and psychiatry*, 1359104514558431.
- Kaltiala-Heino, R., Sumia, M., Työläjäarvi, M., & Lindberg, N. (2015). Two years of gender identity service for minors: overrepresentation of natal girls with severe problems in adolescent development. *Child and adolescent psychiatry and mental health*, 9(1), 9.
- Kuyper, L. Wijsen, C. (2014) Gender Identities and Gender Dysphoria in the Netherlands, *Archives of Sexual Behavior* February 2014, Volume 43, Issue 2, pp 377-385
- National Society for the Prevention of Cruelty to Children (NSPCC)/ <https://www.nspcc.org.uk/preventing-abuse/child-protection-system/legal-definition-child-rights-law/gillick-competency-fraser-guidelines/>
- Nuttbrock et al (2010). cited in *Diagnosing and Treating Children and Adolescents: A Guide for Mental Health Professionals* Flamez B. Sherperis, C.J. (2016) J wiley and Sons Inc).
- Olson, K.R; Durwood, L; DeMeules, M; McLaughlin, K.A; (2016) Mental Health of Transgender Children Who Are Supported in Their Identities. *Paediatrics*, V137, Issue 3.
- Skagerberg, E., Parkinson, R., & Carmichael, P. (2013). Self-harming thoughts and behaviors in a group of children and adolescents with gender dysphoria. *International Journal of Transgenderism*, 14(2), 86-92.
- Spack NP, Edwards-Leeper L, Feldman H a, et al. Children and adolescents with gender identity disorder referred to a pediatric medical center. *Pediatrics*. 2012;129(3):418-425.
- Stoller RJ. (1964) A contribution to the study of Gender Identity. *J Psychoanal* 45: 220-6.
- Testa, R. J., Jimenez, C L, & Rankin, S. (2014). Risk and resilience during transgender identity development: The effects of awareness of and engagement with other transgender people on affect. *Journal of Gay and Lesbian Mental Health*, 18(1), 34-56.
- Vanderburgh, R. (2009). Appropriate therapeutic care for families with prepubescent transgender/gender-dissonant children. *Child and Adolescent Social Work Journal*, 26, 135–154
- Van Caenegem, E, Wierckx, K, Elaut, E, Buysse, A., Dewaele, A. Van Nieuwerburgh, F. De Cuypere, G. and T'Sjoen, G.(2015) Prevalence of Gender Nonconformity in Flanders, Belgium. *Archives of sexual behaviour* 2015.
- Wallien, M.S.C., & Cohen-Kettenis, P.T. (2008). Psychosexual outcome of gender dysphoria in children. *Journal of the American Academy of Child and Adolescent Psychiatry*, 47, 1413-1423.
- World Professional Association for Transgender Health: Standards of Care for the Health of Transsexual, Transgender, and Gender-Nonconforming People v7, (2012).



- Zucker, K.J; Bradley, S.J (1995), Gender Identity Disorder and Psychosexual Problems in Children and Adolescents, Guildford Press cited in the World Professional Association for Transgender Health: Standards of Care for the Health of Transsexual, Transgender, and Gender-Nonconforming People v7, (2012).
- Zucker KJ. Measurement of psychosexual differentiation. ArchSex Behav 2005;34(4):375-388.
- Zucker, K. J. (2006). Commentary on Langer and Martin's (2004) 'How dresses can make you mentally ill: Examining gender identity disorder in children.' Child and Adolescent Social Work Journal, 23(5/6), 533–555.
- Zucker, K.J; Lawrence, A.A (2009). Epidemiology of Gender Identity Disorder: Recommendations for the Standards of Care of the World Professional Association for Transgender Health.

## Glossary of Terms

	Term	Initials	Description
1	Analogue		See GnRH below
2	Autonomy		Term used to describe a person's ability to give informed consent.
3	Biological sex		See 'natal' sex below.
4	Child and Adolescent Mental Health Services	CAMHS	CAMHS are specialist NHS children and young people's mental health services See <a href="http://www.youngminds.org.uk/for_parents/services_children_young_people/camhs">http://www.youngminds.org.uk/for_parents/services_children_young_people/camhs</a>
5	Child Behaviour Checklist	CBCL	The Child Behaviour Checklist (CBCL) is a parent-report questionnaire on which the child is rated on various behavioural and emotional problems.
6	Cross Sex Hormone [gender affirming] (therapy)	CSH	Hormone replacement therapy for gender variant individuals, where sex hormones (androgens for trans male) and oestrogens for trans female) are administered for the purpose of inducing physical changes which are more in line with the experienced gender identity – also called gender affirming hormone therapy.
7	Diagnostic and Statistical Manual of Mental Disorders Fifth edition	DSM-5	Diagnostic and Statistical Manual of Mental Disorders, 5th Edition, <a href="http://journals.lww.com/co-psychiatry/Abstract/2007/01000/Dimensional_models_of_personality_disorder_.11.aspx">http://journals.lww.com/co-psychiatry/Abstract/2007/01000/Dimensional_models_of_personality_disorder_.11.aspx</a>
8	Gamete		Reproductive or sex cells. Female gametes are called ova or egg cells and male gametes are called sperm.
9	Gender Dysphoria	GD	Where a person experiences discomfort or distress due to a mismatch between their biological sex and the gender as which they identify. Biological sex is classified at birth, depending on the appearance of the genitals. <a href="http://www.nhs.uk/conditions/Gender-dysphoria/Pages/Introduction.aspx">www.nhs.uk/conditions/Gender-dysphoria/Pages/Introduction.aspx</a>
10	Gender Identity		In simplest terms Gender Identity refers to an individual's internal sense of being male, female, both, neither, or something else. A person's "fundamental sense of belonging to one sex [an awareness of being male or female and] an over-all sense of identity." Stoller RJ. A contribution to the study of Gender Identity. J Psychoanal 1964; 45: 220-6.
11	Gender Identity		The emotional and intellectual experiences of a child or young person in seeking to understand

	Development		their gender identity
12	Gender Identity Development Service	GIDS	The abbreviation used for the service that NHS England commissions for children and adolescents with GD.
13	Gender role		<p>Characteristics in personality, appearance, and behavior that in a given culture and historical period are designated as masculine or feminine (that is, more typical of the male or female social role) (Ruble, Martin, &amp; Berenbaum, 2006). While most individuals present socially in clearly masculine or feminine gender roles, some people present in an alternative gender role such as genderqueer or specifically transgender. All people tend to incorporate both masculine and feminine characteristics in their gender expression in varying ways and to varying degrees (Bockting, 2008) in WPATH SOC v7. see <a href="http://www.wpath.org/site_page.cfm?pk_association_webpage_menu=1351">http://www.wpath.org/site_page.cfm?pk_association_webpage_menu=1351</a></p>
14	Gillick competence/ Fraser guidelines		<p>A term used in medical law to decide whether a child or young person up to the age of 16 years is able to consent to his or her own medical treatment, without the need for parental permission or knowledge. Based on the names of cases.</p> <p><a href="https://www.nspcc.org.uk/preventing-abuse/child-protection-system/legal-definition-child-rights-law/gillick-competency-fraser-guidelines/">https://www.nspcc.org.uk/preventing-abuse/child-protection-system/legal-definition-child-rights-law/gillick-competency-fraser-guidelines/</a></p> <p>‘Gillick competency and Fraser guidelines’ refers to a legal case which looked specifically at whether doctors should be able to give contraceptive advice or treatment to under 16-year-olds without parental consent. But since then, they have been more widely used to help assess whether a child has the maturity to make their own decisions and to understand the implications of those decisions’.</p> <p>‘...whether or not a child is capable of giving the necessary consent will depend on the child’s maturity and understanding and the nature of the consent required. The child must be capable of making a reasonable assessment of the advantages and disadvantages of the treatment proposed, so the consent, if given, can be properly and fairly described as true consent.” (Gillick v West Norfolk, 1984).</p>

15	Gonadotropin - releasing hormone (also known as the hormone blocker/s)	GnRH	A gonadotropin-releasing hormone analogue (GnRHa), also known as a luteinizing hormone releasing hormone agonist (LHRH agonist) or LHRH analogue or hormone blocker. This is a synthetic peptide drug modelled after the human hypothalamic gonadotropin-releasing hormone (GnRH). This is designed to 'competitively block' the GnRH receptor and prevent the release of pituitary gonadotropins FSH and LH for therapeutic purposes. It is used by the Service to halt puberty in order that the client can further explore their GD without the fear of puberty progressing.
16	General Practitioner	GP	<a href="http://www.nhs.uk/NHSEngland/AboutNHSservices/doctors/Pages/NHSGPs.aspx">http://www.nhs.uk/NHSEngland/AboutNHSservices/doctors/Pages/NHSGPs.aspx</a> GPs deal with a whole range of health problems and manage the care of their patients, referring onto specialists as appropriate.
17	Multi-Disciplinary Team	MDT	The identified group of professional staff who provide the service.
18	Natal sex (see also biological sex)		The biological sex that a person is born as, which is male - 'natal male', female - 'natal female' or Intersex and is most often based on identification of genitals at birth.
19	Non-binary, agender, Bigender, non-gendered or gender fluid		An umbrella term for any gender identity that does not fit into the traditional gender binary of male and female. Can also be a discrete gender identity. Also: Agender: a gender identity characterised by having no feeling of gender, or a specific identity of no gender. Bigender: experiencing two genders simultaneously. These two genders are often, but not always, male and female, and are not necessarily split evenly. Genderfluid: an experience of gender that is not fixed, but changes between two or more identities. For example, someone may feel female some days and non-binary on others.
20	Tanner Stage		Specialist classification of puberty by stage at which adolescents experience maturation. Used by specialists only. The complex series of biologic transitions are known as puberty, and these changes may impact psychosocial factors. See <a href="http://www.childgrowthfoundation.org/CMS/FILES/Puberty_and_the_Tanner_Stages.pdf">http://www.childgrowthfoundation.org/CMS/FILES/Puberty_and_the_Tanner_Stages.pdf</a>

			For a simpler classification of pubertal development – puberty phases, see <a href="http://www.rcpch.ac.uk/child-health/research-projects/uk-who-growth-charts/uk-growth-chart-resources-2-18-years/school-age#cpcm">http://www.rcpch.ac.uk/child-health/research-projects/uk-who-growth-charts/uk-growth-chart-resources-2-18-years/school-age#cpcm</a>
<b>21</b>	Transgender	trans	A person whose gender identity is different to the sex assigned at birth.
<b>22</b>	US	USA	United States of America
<b>23</b>	World Professional Association for Transgender Health (2012)	WPATH SOC v7	World Professional Association for Transgender Health: Standards of Care for the Health of Transsexual, Transgender, and Gender-Nonconforming People 2012 (WPATH SOC v7) see <a href="http://www.wpath.org/site_page.cfm?pk_association_webpage_menu=1351">http://www.wpath.org/site_page.cfm?pk_association_webpage_menu=1351</a>

## **Appendices**

- Appendix 1: Children's Insert to NHS England specifications –  
(standard NHS England wording/ subject to revision)
- Appendix 2: Quality standards specific to the service:
- Appendix 3: Description of partnership working with GPs and local CAMHS
- Appendix 4: Referral processes and funding arrangements to access associated  
treatments for children and adolescents with Gender Dysphoria
- Appendix 5: Definitions of Tanner Stages
- Appendix 6: Description of the psychological support that the Service will offer
- Appendix 7: Informed consent in the context of GIDS

## **Appendix 1: Children's Insert – Provision of services to children**

### **Aims and objectives of service**

This specification annex applies to all children's services and outlines generic standards and outcomes that would be fundamental to all services.

### **The generic aspects of care:**

The Care of Children in Hospital (Health Service Circular 1998/238) requires that:

- Families with children have easy access to hospital facilities for children without needing to travel significantly further than to other similar amenities.
- Good child health care is shared with parents/carers and they are closely involved in the care of their children at all times unless, exceptionally, this is not in the best interest of the child.

### **Service description/care pathway**

All paediatric specialised services have a component of primary, secondary, tertiary and even quaternary elements.

The efficient and effective delivery of services requires children to receive their care as close to home as possible dependent on the phase of their disease/condition.

Services should therefore be organised and delivered through "integrated pathways of care" (National Service Framework for children, young people and maternity services (Department of Health & Department for Education and Skills, London 2004))

### **Interdependencies with other services**

All services will comply with Commissioning Safe and Sustainable Specialised Paediatric Services: A Framework of Critical Inter-Dependencies – Department of Health (DH)

### **References**

Continuing Professional Development (CPD) matrix level 3

Taking account of the differences in client profiles the principles and standards set out in this specification apply with modifications to the recommendations regarding the following:

- Facilities and environment – essential Quality Network for In-patient CAMHS (QNIC) standards should apply (<http://www.rcpsych.ac.uk/quality/quality,accreditationaudit/qnic1.aspx>)
- Staffing profiles and training - essential QNIC standards should apply.
- Parents/carers are involved in the child/young person's care except where this is not in the best interests of the child / young person and in the case of young people who have the capacity to make their own decisions is subject to their consent.
- Applicable national standards e.g. NICE, Royal College

Children and young people must receive care, treatment and support by staff registered by the Nursing and Midwifery Council on the parts of their register that permit a nurse to work with children (Outcome 14h Essential Standards of Quality and Safety, Care Quality Commission, London 2010)

- There must be at least two Registered Children's Nurses (RCNs) on duty 24 hours a day in all hospital children's departments and wards.
- There must be an Registered Children's Nurse available 24 hours a day to advise on the nursing of children in other departments (this post is included in the staff establishment of 2RCNs in total).

Accommodation, facilities and staffing must be appropriate to the needs of children and separate from those provided for adults. All facilities for children and young people must comply with the Hospital Build Notes HBN 23 Hospital Accommodation for Children and Young People NHS Estates, The Stationary Office 2004.

All staff who work with children and young people must be appropriately trained to provide care, treatment and support for children, including Children's Workforce Development Council Induction standards (Outcome 14b Essential Standards of Quality and Safety, Care Quality Commission, London 2010).

Staff must carry out sufficient levels of activity to maintain their competence in caring for children and young people, taking account of guidance from relevant expert or professional bodies (Outcome 14g Essential Standards of Quality and Safety, Care Quality Commission, London 2010).

Providers must have systems in place to gain and review consent from people who use services, and act on them (Outcome 2a Essential Standards of Quality and Safety, Care Quality Commission, London 2010). These must include specific arrangements for seeking valid consent from children while respecting their human rights and confidentiality and ensure that where the person using the service lacks capacity, best interest meetings are held with people who know and understand the person using the service. Staff should be able to show that they know how to take appropriate consent from children, young people and those with learning disabilities (Outcome 2b) (Seeking Consent: working with children Department of Health, London 2001).

Children and young people must only receive a service from a provider who takes steps to prevent abuse and does not tolerate any abusive practice should it occur (Outcome 7 Essential Standards of Quality and Safety, Care Quality Commission, London 2010 defines the standards and evidence required from providers in this regard). Providers minimise the risk and likelihood of abuse occurring by:

- Ensuring that staff and people who use services understand the aspects of the safeguarding processes that are relevant to them
- Ensuring that staff understand the signs of abuse and raise this with the right person when those signs are noticed.
- Ensuring that people who use services are aware of how to raise concerns of abuse.
- Having effective means to monitor and review incidents, concerns and complaints that have the potential to become an abuse or safeguarding concern.
- Having effective means of receiving and acting upon feedback from people who use services and any other person.
- Taking action immediately to ensure that any abuse identified is stopped and suspected abuse is addressed by:



- a. Having clear procedures followed in practice, monitored and reviewed that take account of relevant legislation and guidance for the management of alleged abuse
- b. Separating the alleged abuser from the person who uses services and others who may be at risk or managing the risk by removing the opportunity for abuse to occur, where this is within the control of the provider
- c. Reporting the alleged abuse to the appropriate authority
- d. Reviewing the person's plan of care to ensure that they are properly supported following the alleged abuse incident.
- Using information from safeguarding concerns to identify non-compliance, or any risk of non-compliance, with the regulations and to decide what will be done to return to compliance.
- Working collaboratively with other services, teams, individuals and agencies in relation to all safeguarding matters and has safeguarding policies that link with local authority policies.
- Participates in local safeguarding children boards where required and understand their responsibilities and the responsibilities of others in line with the Children Act 2004.
- Having clear procedures followed in practice, monitored and reviewed in place about the use of restraint and safeguarding.
- Taking into account relevant guidance set out in the Care Quality Commission's Schedule of Applicable Publications
- Ensuring that those working with children must wait for a full CRB disclosure before starting work.
- Training and supervising staff in safeguarding to ensure they can demonstrate the competences listed in Outcome 7E of the Essential Standards of Quality and Safety, Care Quality Commission, London 2010

All children and young people who use services must be:

- Fully informed of their care, treatment and support.
- Able to take part in decision making to the fullest extent that is possible.
- Asked if they agree for their parents or carers to be involved in decisions they need to make.

(Outcome 4I Essential Standards of Quality and Safety, Care Quality Commission, London 2010)

#### Key Service Outcomes

Evidence is increasing that implementation of the national Quality Criteria for Young People Friendly Services (Department of Health, London 2011) have the potential to greatly improve client experience, leading to better health outcomes for young people and increasing socially responsible life-long use of the NHS.

Implementation is also expected to contribute to improvements in health inequalities and public health outcomes e.g. reduced teenage pregnancy and STIs, and increased smoking cessation. All providers delivering services to young people should be implementing the good practice guidance which delivers compliance with the quality criteria.

Poorly planned transfer from young people's to adult-oriented health services can be

associated with increased risk of non-adherence to treatment and loss to follow-up, which can have serious consequences. There are measurable adverse consequences in terms of morbidity and mortality as well as in social and educational outcomes. When children and young people who use paediatric services are moving to access adult services (for example, during transfer for those with long term conditions), these should be organised so that:

- All those involved in the care, treatment and support cooperate with the planning and provision to ensure that the services provided continue to be appropriate to the age and needs of the person who uses services.

The National Minimum Standards for Providers of Independent Healthcare, (Department of Health, London 2002) require the following standards:

- A16.1 Children are seen in a separate out-patient area, or where the hospital does not have a separate outpatient area for children, they are seen promptly.
- A16.3 Toys and/or books suitable to the child's age are provided.
- A16.8 There are segregated areas for the reception of children and adolescents into theatre and for recovery, to screen the children and adolescents from adult patients; the segregated areas contain all necessary equipment for the care of children.
- A16.9 A parent is to be actively encouraged to stay at all times, with accommodation made available for the adult in the child's room or close by.
- A16.10 The child's family is allowed to visit him/her at any time of the day, except where safeguarding procedures do not allow this (?does not apply)
- A18.10 There are written procedures for the assessment of pain in children and the provision of appropriate control.

There should be age specific arrangements for meeting Regulation 14 of the Health and Social Care Act 2008 (Regulated Activities) Regulations 2010. These require: (we will need to delete those that do not apply)

- A choice of suitable and nutritious food and hydration, in sufficient quantities to meet service users' needs
- Food and hydration that meet any reasonable requirements arising from a service user's religious or cultural background
- Support, where necessary, for the purposes of enabling service users to eat and drink sufficient amounts for their needs
- For the purposes of this regulation, "food and hydration" includes, where applicable, parenteral nutrition and the administration of dietary supplements where prescribed
- Providers must have access to facilities for infant feeding, including facilities to support breastfeeding (Outcome 5E, of the Essential Standards of Quality and Safety, Care Quality Commission, London 2010)

All paediatric clients should have access to appropriately trained paediatric trained dieticians, physiotherapists, occupational therapists, speech and language therapy, psychology, social work and CAMHS services within nationally defined access standards.

All children and young people should have access to a professional who can undertake an assessment using the Common Assessment Framework and access

support from social care, housing, education and other agencies as appropriate.

All registered providers must ensure safe use and management of medicines, by means of the making of appropriate arrangements for the obtaining, recording, handling, using, safe keeping, dispensing, safe administration and disposal of medicines (Outcome 9 Essential Standards of Quality and Safety, Care Quality Commission, London 2010). For children, these should include specific arrangements that:

- They are supported to have a health action plan
- Facilities meet the appropriate requirements of the Disability Discrimination Act 1995

They meet the standards set out in Transfer: getting it right for young people. Improving the transfer of young people with long-term conditions from children's to adult health services. Department of Health, 2006.

## Appendix 2: Quality standards specific to the service:

Quality Requirement	Threshold	Method of Measurement	Consequence of breach
<b>Domain 1: Preventing people dying prematurely</b>			
The Service will seek to reduce distress by providing high quality psychological and medical support, including physical interventions as required on an individual basis.	100% of people accepted into the Service will commence the assessment process within the first one to one appointment.	National database Annual Returns	To be addressed in annual service audit meeting
<b>Domain 2: Enhancing the quality of life of people with long-term conditions</b>			
The Service will seek to ameliorate the negative effects on the client's general development and build their resilience across a number of domains, (including family and peer relationships, self-esteem, self-image and education), including thereby improving their quality of life.	100% of clients will have a personalised care plan which sets out a pathway through the Service, recognising that this may change over time depending on need.	National database Annual Returns	To be addressed in annual service audit meeting
<b>Domain 3: Helping people to recover from episodes of ill-health or following injury</b>			
The Service will help to reduce	See care plan note above	National Database –	To be addressed in annual service

Quality Requirement	Threshold	Method of Measurement	Consequence of breach
morbidity by providing high quality psychological and medical support through individualised health care pathways.		Annual Returns	audit meeting
<b>Domain 4: Ensuring that people have a positive experience of care</b>			
The Service will support the client and their family/carer, which will be led and co-ordinated by a named Lead Worker who will support them during their time with the Service.	100% of clients will have a named Lead Worker who, when possible, will be introduced at the first one to one meeting with the Service.	National database – Annual Returns	To be addressed in annual service audit meeting
<b>Domain 5: Treating and caring for people in a safe environment and protecting them from avoidable harm</b>			
The Service will ensure that local systems are in place to track and manage client safety performance, including taking action when agreed standards are not met. Robust reporting of incidents will be undertaken through local procedures and reported to NHS England.	<p>Risk reporting processes will be in place for all clients.</p> <p>100% of incidents will be reported to NHS England, together with a report of lessons learned and amendments to safety systems, process and clinical practice where appropriate.</p>	National database – Annual Returns	To be addressed in annual service audit meeting

Quality Requirement	Threshold	Method of Measurement	Consequence of breach
Overarching indicator: Risks will be identified and incidents reported. Evidence of lessons learnt and subsequent improved patient safety will be required to be provided to the commissioning team.			

### Appendix 3: Description of partnership working with GPs and local CAMHS

The service will work with General Practitioners (GP's) and local CAMHS to promote clarity about respective responsibilities and good communication on both sides.

When referrals are accepted by the service, it will ensure that both the client's GP and the CAMHS team which is local to where the client lives, are made aware of the referral with the client's knowledge. The CAMHS team will be advised that they retain responsibility for monitoring and managing risk and associated difficulties. Any change in risk will be communicated to the GP and to CAMHS by telephone and/or letter as appropriate.

The service will confirm to the GP and CAMHS team that it is responsible for the individualised care plan that has been agreed with the client (and their family or carer if appropriate).

GPs prescribe and monitor any physical treatments and the Paediatric Endocrine Liaison Clinic will supply a shared care agreement and respond to any queries or concerns around this.

In complex cases, the service will convene local network meetings with CAMHS teams to review and discuss the needs of the client and agree roles. GPs will be kept informed.

If risk is identified with a client at any stage in their time with the service and there is no local CAMHS involvement, the service will facilitate an appropriate referral in order that the risk is understood locally and so that the CAMHS can provide support to the young person.

The service will be as active as possible where there is a client is at significant risk by ensuring that the client's GP and CAMHS are made aware.

The service will respond promptly to enquiries and concerns raised by CAMHS teams.

CAMHS teams will be asked to keep the service informed of their contact with clients by letter and/or telephone as appropriate.

With the permission of the client, the service will copy CAMHS into correspondence including the assessment report.

Work will be undertaken with GPs and local CAMHS providers to build relationships and the support offer from the service.

The service will provide advice to GPs as required with regard to issues in managing prescriptions which have been issued for a young person **in accordance with the GMC's requirements**

**[http://www.gmc-uk.org/guidance/ethical\\_guidance/28851.asp](http://www.gmc-uk.org/guidance/ethical_guidance/28851.asp)**

## Appendix 4: Definition of Tanner Stages

Adolescents experience several types of maturation, including cognitive (the development of formal operational thought), psychosocial (the stages of adolescence), and biologic. The complex series of biologic transitions are known as puberty, and these changes may impact psychosocial factors.

The most visible changes during puberty are growth in stature and development of secondary sexual characteristics. Equally profound are changes in body composition; the achievement of fertility; and changes in most body systems, such as the neuroendocrine axis, bone size, and mineralization; and the cardiovascular system. As an example, normal cardiovascular changes, including greater aerobic power reserve, electrocardiographic changes, and blood pressure changes, occur during puberty.

The normal sequence of pubertal events and perils of puberty are reviewed here. This is within the normal ranges and does not take into account Precocious Puberty or Delayed Puberty. See [http://www.childgrowthfoundation.org/CMS/FILES/Puberty\\_and\\_the\\_Tanner\\_Stages.pdf](http://www.childgrowthfoundation.org/CMS/FILES/Puberty_and_the_Tanner_Stages.pdf)  
See <http://www.rcpch.ac.uk/child-health/research-projects/uk-who-growth-charts/uk-growth-chart-resources-2-18-years/school-age#cpcm> for a simpler classification and explanation of puberty development.



## Appendix 5: Referral processes and funding arrangements to access associated treatments for children and adolescents with GD

There are a range of other services which children and adolescents with GD may require access to, but are funded outside of this specification, commissioned by NHS England Clinical Commissioning Groups (CCG's) rather than the Highly Specialised Commissioning Team.

For clarity, the means of accessing these is as follows:

		Funded by	Requirement
1	CAMHS – Local services	Clinical Commissioning Groups	Where not involved, may be made via the GP or the Service to the local CAMHS team.
2	Fertility advice and preservation	CCGs	GIDS to signpost, via GP, to other Medical specialists such as gynaecologists, and licensed NHS fertility experts who will be able to assist clients in making key decisions regarding gamete retrieval. This will include being made aware of the full facts of the implications of extracting or not extracting the eggs or sperm and what happens, before, during, and after the procedure. Also discussion on subsidiary issues such as storage of gametes, how long they can be kept for, what happens if you want to use these at a future date if you want to use them, and the additional future consequences and treatments required if gametes haven't been extracted before hormone therapy is started.
3	Gynaecological advice	CCGs	GIDS to clarify access routes to other medical specialists, i.e. gynaecologists to assist clients and their family or carers in making key decisions. GIDS to write to GP proposing that a referral is made to local clinician.
4	Occupational therapy	CCGs	GIDS to write to GP proposing that a referral is made to local team.
5	Physiotherapy	CCGs	GIDS to write to GP proposing that a referral is made to local teams.
6	Sexual health services	CCGs	GIDS to write to GP proposing that a referral is made to local teams
7	Speech and language therapy (SaLT)	CCGs	GIDS to write to GP proposing that a referral is made to local team.

## **Appendix 6: Informed consent in the context of GIDS – a description**

Thinking carefully about informed consent is an important aspect of assessing and intervening ethically. The aim is to enhance the young person's and the family/carer's grasp of the available factual information about the interventions they are offered, including hormone treatments, and the emotional and social issues involved in undertaking treatment, so as to enable them to make informed decisions about the options.

Children's competence relies on them having access to good information tailored to their comprehension level: they need to understand fully what is proposed, retain an understanding of the implications, appreciate the importance of the information and see how it applies to them. Therefore young people and their parents/carers are offered a thorough discussion of the treatments offered, the benefits and risks, and alternatives to the treatment proposed (including the option of no treatment). Information sheets are provided prior to attending the service's endocrinology clinics explaining available physical treatments, and Consent Forms need to be signed prior to medical intervention.

Age alone does not determine capacity to give consent: there is no international consensus on the lower age limit for presuming competence.

For young people under 16, consent to treatment should usually be sought from the child and from one or both parents/carers, except under exceptional circumstances. Under the law, adolescents over 16 may consent to treatment if capacity is demonstrated. A clinician(s) should assess a young person's capacity to give consent. While we may think of a young person expressing their 'autonomy' by deciding on their own, with good understanding and without undue constraint, in reality a number of contextual factors are likely to influence a child or young person's decision-making competence.

These will include their developmental stage, the quality of information provided (as discussed above, the influence of peers, parents/carers and their life experience. For instance, young children face cognitive limitations: they may view the world in concrete terms and struggle to reason about abstract or hypothetical problems. In adolescence, new cognitive and social skills are acquired which lead to increased maturity in reasoning about complex issues. Yet adolescents may still find it difficult to restrain impulsiveness and to see a given decision in a larger temporal context.

Competence in children and young people may also be related to life experience: children who have personal experiences with particular kinds of challenge may show greater insight and understanding than children of comparable age who lack this experience. Finally, children and young people are still dependant on their parents/carers (and their clinicians) to define the meaning of the situation they are in, and so the quality of those relationships may also influence the young person's capacity for autonomous decision-making. (See Hein et al 2015).

Reference: Hein I.M., De Vries M.C., Troost P.W., Meynen G., Van Goudoever J.B. and Lindauer R.J.L (2015) Why is it hard to make progress in assessing children's decision-making competence? BMC Medical Ethics 16:1

## **Appendix 7: Description of the psychological support that the Service will offer:**

7.1 When assessing children and adolescents who present with GD, the service's mental health professionals will broadly conform to the following guidelines taken from the WPATH SOC v7:

7.1.1 Mental health professionals should not dismiss or express a negative attitude towards nonconforming gender identities or indications of gender dysphoria. Rather, they should acknowledge the presenting concerns of children, adolescents, and their families; offer a thorough assessment for gender dysphoria and any coexisting mental health concerns; and educate clients and their families about therapeutic options, if needed. Acceptance, and alleviation of secrecy, can bring considerable relief to gender dysphoric children/adolescents and their families.

7.1.2 Assessment of gender dysphoria and mental health should explore the nature and characteristics of a child's or adolescent's gender identity. A psychodiagnostic and psychiatric assessment—covering the areas of emotional functioning, peer and other social relationships, and intellectual functioning/school achievement—should be performed. Assessment should include an evaluation of the strengths and weaknesses of family functioning. Emotional and behavioral problems are relatively common, and unresolved issues in a child's or youth's environment may be present (de Vries, Doreleijers, Steensma, & Cohen-Kettenis, 2011; Di Ceglie & Thümmel, 2006; Wallien et al., 2007).

7.1.3 For adolescents, the assessment phase should also be used to inform youth and their families about the possibilities and limitations of different treatments. This is necessary for informed consent, but also important for assessment. The way that adolescents respond to information about the reality of sex reassignment can be diagnostically informative. Correct information may alter a youth's desire for certain treatment, if the desire was based on unrealistic expectations of its possibilities.

### **7.1.4 Roles of Mental Health Professionals Working with Children and Adolescents with Gender Dysphoria**

Mental health professionals will:

- Directly assess gender dysphoria in children and adolescents (see general guidelines for assessment, below).
- Provide family counselling and supportive psychotherapy to assist children and adolescents with exploring their gender identity, alleviating distress related to their gender dysphoria, and ameliorating any other psychosocial difficulties.
- Assess and treat any coexisting mental health concerns of children or adolescents (or refer to another mental health professional for treatment). Such concerns should be addressed as part of the overall treatment plan.
- Refer adolescents for additional physical interventions (such as puberty-suppressing hormones) to alleviate gender dysphoria. The referral should include

documentation of an assessment of gender dysphoria and mental health, the adolescent's eligibility for physical interventions (outlined below), the mental health professional's relevant expertise, and any other information pertinent to the youth's health and referral for specific treatments.

- Educate and advocate on behalf of gender dysphoric children, adolescents, and their families in their community (e.g., day care centers, schools, camps, other organizations). This is particularly important in light of evidence that children and adolescents who do not conform to socially prescribed gender norms may experience harassment in school (Grossman, D'Augelli, & Salter, 2006; Grossman, D'Augelli, Howell, & Hubbard, 2006; Sausa, 2005), putting them at risk for social isolation, depression, and other negative sequelae (Nuttbrock et al., 2010)
- Provide children, youth, and their families with information and referral for peer support, such as support groups for parents of gender-nonconforming and transgender children (Gold & MacNish, 2011; Pleak, 1999; Rosenberg, 2002).

#### 7.1.5 Psychological and Social Interventions for Children and Adolescents

When supporting clients, the service's health professionals will broadly conform to the following guidelines as set out in the World Professional Association for Transgender Health: Standards of Care V7 (2012):

- help families to have an accepting and nurturing response to the concerns of their gender dysphoric child or adolescent. Families play an important role in the psychological health and well-being of youth (Brill & Pepper, 2008; Lev, 2004). This also applies to peers and mentors from the community, who can be another source of social support.
- psychosocial support should focus on reducing a child's or adolescent's distress related to the gender dysphoria and on ameliorating any other psychosocial difficulties. For youth pursuing sex reassignment, psychotherapy may focus on supporting them before, during, and after reassignment. Formal evaluations of different psychotherapeutic approaches for this situation have not been published, but several counseling methods have been described (de Vries, Cohen-Kettenis, & Delemarre-van de Waal, 2006; Di Ceglie & Thümmel, 2006; Hill, Menvielle, Sica, & Johnson, 2010; Malpas, in press; Menvielle & Tuerk, 2002; Rosenberg, 2002; Vanderburgh, 2009; Zucker, 2006).
- treatment aimed at trying to change a person's gender identity and expression to become more congruent with sex assigned at birth has been attempted in the past without success (Gelder & Marks, 1969; Greenson, 1964), particularly in the long term (Cohen-Kettenis & Kuiper, 1984; Pauly, 1965). Such treatment is no longer considered ethical.
- families should be supported in managing uncertainty and anxiety about their child's or adolescent's psychosexual outcomes and in helping youth to develop a positive self-concept.
- mental health professionals should not impose a binary view of gender. They should give ample room for clients to explore different options for gender expression.
- hormonal treatments are appropriate for some adolescents, but not for others.
- clients and their families should be supported in making difficult decisions regarding the extent to which clients are allowed to express a gender role that is consistent

with their gender identity, as well as the timing of changes in gender role and possible social transition. For example, a client might attend school while undergoing social transition only partly (e.g., by wearing clothing and having a hairstyle that reflects gender identity) or completely (e.g., by also using a name and pronouns congruent with gender identity). Difficult issues include whether and when to inform other people of the client's situation, and how others in their lives might respond.

- health professionals should support clients and their families as educators and advocates in their interactions with community members and authorities such as teachers, school boards, and courts.
- mental health professionals should strive to maintain a therapeutic relationship with gender-nonconforming children/adolescents and their families throughout any subsequent social changes or physical interventions. This ensures that decisions about gender expression and the treatment of gender dysphoria are thoughtfully and recurrently considered. The same reasoning applies if a child or adolescent has already socially changed gender role prior to being seen by a mental health professional.