

# **Stakeholder Engagement Report for Service Specifications**

Reference Number	E13/S(HSS)/e Specification
Service Specification Title	Gender Identity Development Service for Children and Adolescents
Accountable Commissioner	Bernie Stocks
Lead Clinical Reference Group	Paediatric Medicine
Collaborating Clinical Reference Groups	

development of the service specification?	Key leads from the Paediatric Medicine Clinical Reference Group and stakeholders who attended the 23 July 2015 GIDS Specification Review Stakeholder workshop – which included stakeholders, advocacy, and voluntary support groups, parents of clients of the service, adolescents with GD and health professionals, some of which are from the service provider. Also NHS England commissioning and contracting staff.
	At the 2015 workshop, expressions of interest were invited to contribute to the review of the specification, on the basis that a redrafted version (phase 1) would be created from the notes of the day prior to a series of teleconferences for comment on the redraft.

	There were four teleconferences in all, one in August 2015 and one in September 2015 for the stakeholders and adult members, parents and others, and two others, also in August/September with adolescents who had also been at the event.
	Following the first set of teleconferences, a second redraft was worked on until the version that was circulated for stakeholder comment in February 2016.
Identify the relevant Royal College or Professional Society to the policy and indicate how they have been involved	The British Society for Paediatric Endocrinology and Diabetes have considered the documentation and have no concerns or comments to raise around the GIDS revised specification.
Which stakeholders have actually been involved? State reason for any difference from previous questions	All of the stakeholders above were invited to comment on the document which is the phase 2 redraft.
Identify any particular stakeholder organisations that may be key to the policy develop that have been difficult to engage. Indicate why they have been difficult to engage	The key stakeholder organisations and support groups have commented.

How have the stakeholders been involved? What engagement methods have been used?

In February 2015, the redrafted specification was circulated to stakeholders and the key clinical leads from the Paediatric Medicine CRG who have been supporting the development of the service since 23<sup>rd</sup> July 2015. They were asked for comments on the specification to determine whether any amendments to the specification are required on the basis of stakeholder opinion.

Eight responses were received, one from an individual, six from advocacy/support organisations and one from the British Society for Paediatric Endocrinology and Diabetes.

These all request changes to the document. Please see Appendix A.				
What has happened or changed as a result of their input?	The Policy Working Group considered the responses.  In response to Stakeholder 1 Stakeholder 2 Stakeholder 3 Stakeholder 4 Stakeholder 5 Stakeholder 6 Stakeholder 7 Stakeholder 8			
How have stakeholders been informed of progress with policy development as a result of their input?	This engagement report, along with the updated policy proposition will be circulated as part of the public consultation. Stakeholders will be notified and invited to comment further.			

What level of wider public consultation is recommended by the CRG for the NPOC Board to agree as a result of stakeholder involvement? (see Appendix One)

Public consultation for a period of 30 days as supported by stakeholders.

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Responder	Feedback received	PWG Response	Resulting Action
Stakeholder organisation 1 comments:	<ul> <li>1.1 The service claims to deliver tailored treatment packages (page 12) but does not do so. Instead it applies rigid requirements, which are largely unsupported by any evidence:</li> <li>minimum of 3 assessment meetings prior to blockers (page 16); this contradicts the 2 meetings stated on page 21, where there is also a promise of prompt progress for those approaching puberty or in puberty; however, there is no indication of whether or how this is to be put into effect</li> <li>12 months on blockers before cross-sex hormones (page 25)</li> <li>minimum age of 16 for cross sex hormones (page 25)</li> <li>living in new gender role and education or employment before cross sex hormones (page 30)</li> </ul>	1.1 The PWG noted that the service provider undertakes an assessment of each person which, depending on need, takes place between two and four appointments.	1.1 No action required
	1.2 The triage process proposed (page 28) does not offer fast track care for those in urgent need of treatment; it does nothing to ameliorate risk; it places all responsibility for managing risk on local services, which in many instances do not have the required skills and, in any case, are unable to offer the blockers or cross-sex hormones that may be the best means of reducing stress.	1.2 The PWG notes that at the time of referral, the service will assess the patient according to the scope set out in the specification and will assess risk - where support from local services is not in place, the service provider will contact local services to alert them to the risk.	1.2 No action required
	1.3 It is an overstatement that the international recommendation remains that cross sex hormone treatment should not commence before age 16 (page 3). Moreover, The Endocrine Society recommendation is misquoted. Actually, cross sex hormones can be administered from about age 16. Respectable overseas centres (see the Clinical Commissioning Policy Proposition, E03X16/01 page 9 and the Spack et al article cited	1.3 The PWG noted that whilst there is some variation in international practice, it is noted that the	1.3 No action required

on page14) allow administration from:

- 13.3 years (natal males) and 13.7 years (natal females) in Vancouver, Canada
- 13.9 to 14.9 years in The Netherlands
- 14 years in the USA

1.4 The recommendation in the paper by S. M. Rosenthal also appears to be grossly misrepresented. The actual quote is "Occasionally, some gender-dysphoric youth first come to medical attention when they are Tanner 4/5, but < 14 years of age. Such individuals would be candidates for pubertal blockers (eg, to stop menses in an FTM adolescent), but without supportive outcome data, not currently candidates for cross-sex hormone use under most circumstances." Rosenthal is only talking about patients < 14 years of age and does not state that cross sex hormone medication should be delayed until age 16.

Moreover, Rosenthal states that "not only could delaying such treatment (cross sex hormones) until that age (16) be detrimental to bone health, but keeping someone (receiving hormone blockers) in a prepubertal state until this age would isolate the individual further from age-matched peers, with potentially negative consequences for emotional well-being."

1.5 The proposed research study into lowering the age for cross sex hormones to 15 is merely procrastination. There are ample precedents for case by case assessment and a minimum age of 14.

Endocrine Society
Guidelines make
recommendations
based on the highest
level of evidence which
is that cross sex
hormones should
commence 'from 16'.

1.4 The PWG notes that the single reference in the specification, which reads: 'The international recommendation remains that cross-sex hormone treatment should not commence before the age of 16, although in some clinics in the US there are reports of physical treatments being offered at younger ages (Spack et al 2012; Rosenthal 2014) is appropriate' and no change to the wording is required.

1.5 A clinical trial is being scoped at the current time to develop 1.4 No action required.

1.5 No action required

	more evidence. The	
	clinical evidence	
	review for this policy	
	notes that there is not	
	appropriate evidence	
	to prescribe cross sex	
	hormones from 16.	
1.6 Discharging patients who have accessed hormones privately earlier than the	1.6 The PWG noted	1.6 No action
endocrine service allows (page 26) is punitive and at variance with the practices,	that clients who	required
including "bridging prescriptions", available in adult services	choose to seek	
	physical treatment	
	outside the NHS can	
	access NHS treatment	
	when they meet the	
	scope set out in the	
	specification, at which	
	point they will be	
	referred to the	
	Paediatric Endocrine	
	Liaison Team for	
	evaluation prior to any	
	NHS endocrine	
	treatment taking place.	
	Clients who choose to	
	access private	
	treatment do so at their	
	own risk and cost and	
	the service will	
	continue to provide	
	psychosocial care;	
	staff in the service	
	have all undertaken a	
	range of training and	
	<del>_</del>	

	1.7 The epidemiology section (page 2) overlooks the research undertaken by the	this is ongoing; the scope of the adult service does not include the age of consent and is outside the scope of this document.  1.7 All current available evidence has	1.7 No action required
	Equality and Human Rights Commission and makes no reference to the most recent studies conducted in The Netherlands and Belgium that indicate far greater prevalence.	been reviewed. Please provide references for any other documentation to be reviewed.	
	1.8 The comment regarding the influence of biomedical factors (page 3) overlooks the evidence cited in the latest GIRES paper: <a href="http://gires.org.uk/assets/Research-assets/RCGPbiologicalcorrelations.pdf">http://gires.org.uk/assets/Research-assets/RCGPbiologicalcorrelations.pdf</a>	1.8 The PWG noted that the link is not working and the document could not be on the GIRES website – can the stakeholder please forward the link to the commissioning manager so that it can be considered.	1.8 No action required.
Conflicts:	None		
Stakeholder 2 comments:	<ul> <li>2.1 This document is not fit for purpose.</li> <li>2.2 It would not pass governance, legal or standards provision.</li> <li>2.3 It suffers from amendments superimposed upon an old specification, is out of date, over complex and lacks clarity.</li> <li>2.4 It is poorly drafted, lacks evidence and is based on historic and outdated data and ethos and continues to be placed as a Tier 4 mental health service, which is not in</li> </ul>	2.1- 2.6 The PWG appreciates that there are different views and noted that these comments do not materially add to the	2.1-2.6 No action required

ca im 2.5 Co pro 2.6 co	reping with current thinking and acts as a gatekeeping barrier to the real provider of are which should lie in endocrinology, but even that service requires substantial approvement.  5 The voice of young people or their families is not heard despite the NHS's constitution being one of choice, empowerment and working with the service user to ovide individualised care.  6 Full research references are omitted, appear to be a selection biased toward conservative treatment, and there are errors in the data quoted. We assume the input is the current provider.	specification; confirms that the full range of stakeholder opinion has been sought (recognising that opinions differ widely) and that further views will be sought via the forthcoming public consultation process.	
2.7	7 There is no clear definition of how the pathway manifests.	2.7 The PWG noted that the pathway is set out in the specification. If the stakeholder has a specific query relating to the pathway, please supply this.	2.7 No action required
wit	8 Terms such as psychology, psychotherapy & multi-disciplinary teams are used ithout any objectives and outcomes. How will these teams actually work? What do ey mean by psychotherapy?	2.8 The PWG notes that Interdisciplinary team members are engaged in service delivery; the Endocrine Society Guidelines state: 1.1 We recommend that the diagnosis of gender identity disorder (GID) be made by a mental health professional (MHP). For children and adolescents, the	2.8 No action required

	train adol dever psycometry that apprise changes and asserting and care individuals.	P should also have hing in child and elescent elopmental chopathology. (1 (1 (1 (1 ))) a PWG is assured a staff with propriate expertise hild and adolescent ental health ertakes the essment of gender phoria and ociated difficulties a provide ongoing port to the client a their parents or ers throughout their vidual pathway; the comes are set out the NHS Outcomes mework section of specification and in lition, patient	
	in the standard in the standar	ne NHS Outcomes mework section of specification and in	
2.9 Many young people describe a distinct lack of the seen infrequently for 45 minutes.	assu	The PWG is ured by the service vider that it usual	2.9 No action required

	practice for appointments to be of	
	one hour or more.	
2.10 GP support is not included despite being a vital part of the care pathway.	2.10 The PWG understands that GPs are often the referrers, are copied into correspondence and are essential in supporting the provision of blockers and cross sex hormones.	2.10 No action required
2.11 Work with schools and CAMHS is negligible.	2.11 The PWG understands that the service operates as a network model and convenes visits in schools and with local Child and Adolescent Mental Health Services (CAMHS) where a client has complex presentation/is considered to be a complex case.	2.11 No action required
2.12 Volume issues caused in part by the inefficient running of the service and the lack of progression and sound transfer to adult services are not addressed.	2.12 The PWG notes that issues relating to	2.12 No action required
	the volume of activity	2 4 2 2.

	are a contractual matter between the provider and NHS England, rather than relating to the specification, are dealt with through that process and are out of scope of this document.	
2.13 NHS / National / Clinical / DOH Guidelines are not fully referenced to evidence decisions.	2.13 The PWG is unclear as to the comment and invites the stakeholder to indicate which items in the documents referenced are being suggested.	2.13 No action required
2.14 Assumptions that local services have skills, resources and expertise to pick up risk that emanates from the service provider are made.	2.14 The PWG notes that the service is commissioned as a Tier 4 Mental Health Service, with ongoing management of the patient residing with the GP and local services; the service pathway does include careful management of identified risk; the service provider	2.14 No action required

	annones with loos!	
	engages with local services in terms of	
	training and education	
	as part of its network	
	model.	
	model.	
2.15 The specification should contain the following:	2.15 The PWG notes:	2.15 No action
risk management, safeguarding and suicide prevention strategy	that at the time of	required
• early consideration of blockers and working with endocrinology at the outset and not	referral and during	
creating a barrier to this care	care provision, risk is	
<ul> <li>pubertal young people fast-track and bridging measures and speedy assessment</li> </ul>	assessed;	
equality impact statement.	safeguarding is part of	
SMART quality indicators for outcome based commissioning	standard NHS update	
accountability or governance framework, key as we know that this is weak with the	training; the service	
current provider	provider undertakes	
acknowledgement that it is unlawful and unethical to withhold care from a young	staff training in	
person where clear needs and wishes are expressed	safeguarding, risk	
• no fixed time for blockers to be commenced or maintained -individualised care and	management and	
need is paramount	suicide prevention;	
• cross hormones on individual best interest consideration, giving great weight to the	a referral to the	
young person's wishes	Paediatric Endocrine	
shared care protocols with GP's and GIDS centres worldwide including private	Liaison team for review	
providers so the monopoly is deconstructed, including an explicit directive that the	for hormone blockers	
current provider works with others to achieve this	is made as soon as an	
young people not to be discharged if they access timely care elsewhere	assessment has been	
service designed around the child rather than the clinicians opinions	completed; there is a	
	dedicated Early Intervention clinic	
	offered by the Paediatric Endocrine	
	Liaison Clinic for	
	clients who are in the	
	early stages of	
	puberty; when	
	I puberty, writeri	

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	possible, appointments	
	are offered to expedite	
	the assessment	
	process for clients who	
	are approaching	
	puberty and wish to	
	undertake physical	
	intervention;	
	all commissioned NHS	
	services have regular	
	reporting systems in	
	place; having regard	
	for inequalities has	
	been complied with;	
	the service provider is	
	required to	
	demonstrate the use of	
	specific tools for	
	(HONOSca or CGAS)	
	to improve outcomes	
	and this is embedded	
	into the Quality	
	Schedule of the	
	contract.	
2.16 In addition, currently:	2.16 The PWG noted	2.16 No action
2.16.1 The specification has no regard or reference toward consent (Gillick competency)	that Section 3.2.3 and	required
and human rights of the child	Appendix 6 of the	1
2.16.2 the specification does nothing to hold account, or address how outcomes are	specification relates to	
evaluated	Informed Consent;	
2.16.3 Anecdotal evidence from UCLH has no research base and is there as justification	outcomes are	
for not treating.	evaluated as part of	
	NHS England clinical	
	audit and contract	
	-	

		monitoring; with regard to anecdotal evidence from UCLH - the stakeholder is invited to identify in more details what this comment refers to.	
	2.17 A great deal of ideas raised in many hours of debate and discussion are not reflected in this document, nor the concerns regarding poor leadership and governance of the service.	2.17 The PWG notes that the differing views of the full range of stakeholders have been considered in this process.	2.17 No action required
	2.18 Who is on the paediatric CRG? This should not be the provider. The provider clinicians are conflicted and have indicated many times by word and action that they wish to keep their monopoly at all costs.	2.18 The service provider is not represented on the Paediatric Medicine Clinical Reference Group.	2.18 No action required
Conflicts: Stakeholder 3 comments:	None  3.1 Page 1 Section 1.1  The service will be delivered through a specialist multidisciplinary team (MDT) with contribution from specialist social workers family therapists, psychiatrists, psychologists, psychotherapists and paediatric and adolescent endocrinologists and clinical nurse practitioners (add the following), and other NHS healthcare professionals such as gynaecologists and licenced fertility experts.	3.1.1 The PWG noted this comment and agreed to the amendment, recognising that local licenced fertility experts and gynaecologists may wish to receive advice from the service provider regarding	3.1.1 The specification has been amended accordingly

	particular aspects of gender dysphoria if required.	
3.2 Page 10 6 <sup>th</sup> Bullet point  know what the service can and cannot provide, know how to access help and support from the service between appointments, including online literature and other support from national and local voluntary networks and community groups  I feel that a Helpline should be established within the GIDS service that signposts people to advice and support, and ensures that IF Clients or their families contact the service, that they will get a response, if they call the Service in a distressed state.  This is in addition to any helpline support provided by any of the "Support" groups that support the GD community, as some clients may not want to call one of these support	3.2 The PWG understands that the service provider has in place a rota to respond to enquiries or for families who wish to phone the service for advice.	3.2 The specification has been amended to note that there is a rota to manage enquiries from clients and their families.
groups, such as Mermaids  3.3 Page 13 under the Objective Area "High Quality Care"  The provision of an integrated service which encourages exploration of the mind-body relationship by promoting close collaboration among professionals in different specialties, including paediatric and adolescent endocrinology for consideration of physical treatment with the hypothalamic blocker when the young person is in established puberty, ( should also include ) NHS specialists such as gynaecologists and fertility experts for gamete retrieval advice and support	3.3 The PWG agreed to make this addition.	3.3 The specification has been amended accordingly
3.4 Page 15 3.2.1 The service will be provided through a highly specialist multidisciplinary approach	3.2.1 The PWG agreed to make this addition.	3.2.1 The specification

to the assessment and care of GD in children and adolescents, and will collaboration with local CAMHS, GP's and secondary care paediatric ar (should be added) consultants.	nd gynaecological a	as been amended accordingly.
<ul><li>3.5 Page 17 Figure 2</li><li>"At any stage young people may decide to stop physical treatment or to about treatments"</li><li>3.5.1 These are the words for the box on the right hand side of the diagram</li></ul>	delay decisions to make this addition. s had all all all all all all all all all a	3.5 The specification as been amended accordingly.
3.5.2 There does not appear to be a feedback loop back into the proces young person decides [they] wants to Stop or Delay Physical treatment, THAT [they] WANTS TO START IT AGAIN in a few months time.	· ·	
Please include a feedback loop, This happened to my [child]		
3.6 Page 18		3.6 The specification has been amended
Referral, when appropriate to the needs of the client, to the Paediatric E Team for physical assessment;	h	
Access to other medical specialists such as local secondary care gynae provide advice to clients and their parents or carers when key decisions made, such as when being offered hormone blockers and cross-sex hor	ecologists to a need to be	ccordingly
Needs changing as follows		
Referral, when appropriate to the needs of the client, to the Paediatric E Team for physical assessment; to provide advice to clients and their par		

	when key decisions need to be made, such as when being offered hormone blockers and cross-sex hormones.  Access to other medical specialists such as local secondary care gynaecologists and fertility specialists; to provide advice to clients and their parents or carers when key decisions need to be made with regard to gamete retrieval and eggs storage  3.7 Page 23 3.2.3. Informed Consent  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 (should include) and fertility options, if appropriate.	3.7 The PWG agreed to make this addition on the basis that the service will ask the GP to make a referral to licenced fertility practitioners.	3.7 The specification has been amended accordingly
Conflicts:	None		
Stakeholder 4 comments:	<ul> <li>4.1 I wish to query the underpinning discourse of Gender Dysphoria and knowledge pertaining to this field for the purposes of framing the Gender Identity Development Service.</li> <li>4.2 I am unclear in this document about the criteria for Gender Dysphoria. It would be useful to list the criteria here or at least to refer to its origins. The document states "Children who show gender variant behaviour only, do not fulfil the criteria for a GD diagnosis" but the document does not outline the basis on which clinicians will make a judgment.</li> <li>4.3 How many people are diagnosed with GD in the service and how many aren't and in addition what happens with those who are not diagnosed as such? Referring to Gender Dysphoria as a 'condition' is problematic as it alludes to a pathological model of being transgender. We no longer perceive lesbian and gay people as having a condition. Transgender identification should be seen similarly.</li> <li>4.4 Gender Dysphoria continues to be a rather narrow definition for trans people. Perhaps not all trans people have Gender Dysphoria, but does the service work with all trans people?</li> <li>4.5 Your section around notions of 'persistence and desistance' is a problematic framework to understanding gender identity and gender expression. For instance a persisting non-normative identity can only be measured against a social norm that is</li> </ul>	4.1 The PWG noted that these are very helpful comments and will amend the specification (the version of which will be included in the public consultation pack). The PWG recognises that only a small number of patients wish to undertake endocrine treatments. The PWG notes that the specification includes and supports that individualised care will be provided, including therapeutic	4. The specification has been amended accordingly.

ever changing. If you can identify a persistent non normative gender identity then you must be able to identify a 'normative gender identity'. Persistence and desistence is not the current language used by trans people. It is the language of pathology.

4.6 Earlier on in the document it mentions people not identifying within the gender binary and yet later it's written: "They may identify with the other gender, show behaviours and preferences not typical for the gender they were assigned to at birth, and sometimes strongly dislike their physical sex characteristics." This is a model that reinforces the gender binary and allocates typical gender expression according to social stereotypes and norms according to sex assigned at birth.

4.7 Putting an emphasis on feelings around the body and unhappiness with sexed characteristics is also a reductive model of being trans. Some trans people will wish to undergo medical treatments that will shift or change their bodies, but not all trans people will. It is unclear to me if the service only treats and works with trans people who wish to undergo medical intervention. Does a person who does not wish to undergo changes to their bodies render them a 'desister'? For instance where it writes: "The 'desisters', however, indicated that their desire to have the body of the other sex or the desire to be the other sex, which was considered to be more related to the opportunity to fulfil the preferred gender role, than to a true aversion against their bodies per se" is a reductive understanding of gender diversity and those who identify themselves as trans. If we are to think of gender no longer as one thing or the 'other' (within the binary), these understandings and descriptions of GD are no longer fit for purpose.

4.8 In 1.3 it states: "In a qualitative follow up study, it was reported that two girls who had transitioned when they were in elementary school, had been struggling with the desire to return to their original gender role." My query is: what is an 'original gender role'? This signals the heteronormative starting point that the document makes.

4.9 I find the following section problematic:

"In their writings the Dutch team do not encourage early social transition and explicitly advise parents to proceed with great caution, to seek to keep a balance between the acceptance of cross-gender play and preferences and encouraging activities that are associated with the child's natal gender (Steensma & Cohen-Kettenis 2011)."

Socially transitioning or expressing our gender identity is rich and various ways should be welcomed and celebrated across the masculine and feminine spectrum. To say '[E]ncouraging activities that are associated with the child's natal expression' articulates

work with clients and their families, carers, important others, with or without referral for any physical intervention as it is recognised that some clients will not wish to undertake endocrine treatment. The specification will be amended to ensure this is clear.

	a gender policing that the service could be issuing. Expressing gender in different ways does no harm to society, but discouraging gender expression (even ones that go against social norms) is the sort of thing that impacts on the mental distress of young people. Young people are made to feel ashamed of expressing their gender differently where it goes against social norms and this sentiment reinforces this.  4.10 In general this document suggests that the service supports only those who undergo physical intervention and that there is a one-way straight forward trajectory. Those who do not follow that path will be 'desisters' and not have GD. This is out of kilter with the aims and objectives of the services that are laid out further down the document.  4.11 I am unclear what therapeutic opportunities young people will have. Among other things the document says that the service will provide:  • therapeutic support and care, with a client and family-centred focus  • support for on-going exploration of gender identity and expression  4.12 Our young people and their families need access to therapeutic talking opportunities and facilitated communication opportunities across the family members regardless as to whether they will be pursuing medical intervention or not. However after an assessment phase to diagnose GD the flow chart shows how they are referred to Endocrine Liaison Clinic. My understanding is that from that point the GIDS offer mainly a monitoring exercise. The distinction between psychological service and referral to endocrine team is not clear.		
Conflicts:	I am Director of Gendered Intelligence. Our mission at Gendered Intelligence is to increase understandings of gender diversity. We work predominantly with the young trans community and those who impact on trans lives. We use 'Trans' as a term that describes the broad spectrum of people who feel they are gender variant in some way. Like social models of disability, as well as lesbian, gay and bisexual communities, trans people are developing a positive community identity around being trans rather than figuring trans as a medical condition. Our aims are to increase the quality of young trans people's life experiences; to raise awareness of young trans people's needs, across the UK and beyond; to contribute to the creation of community cohesion across the whole of the trans community and the wider LGBTQI community throughout the UK; and to engage the wider community in understanding the diversity and complexity of gender. We deliver a series of facilitated monthly group sessions and activities across three different cities in England in Leeds, Bristol and London. We also have a BAME trans		

Ctakabaldar	youth group. We work with approximately 400 young people per year (aged 8-25). Our sessions are based around discussion and sharing life experiences, gaining access to accurate, up to date information as well as building confidence through co-delivering the group session and contributing to group discussion. Topics include coping with social anxiety, depression, low mood and managing suicidal thoughts. We also consider coming out as trans to family and friends and managing school/college life including bullying. Young people attending the group sessions have shown that they increase their social networks, feel proud of their gender identity and increase their resilience. In addition we provide educational sessions and workshops for young people in schools, colleges and other settings; mentoring individual young trans people in their educational settings; provide professional development sessions, trans awareness training and policy development consultation for statutory and other professionals, agencies and businesses. Consultant psychologist [x] provides clinical supervision to our mentors.	E 1 E 2 The DWC	E 1 2 No potion
Stakeholder 5 comments:	5.1 Section 3.2.4 Page 26 paragraph 2:- It is understood that some young people may wish to privately access hormone treatments earlier than is considered appropriate in this specification. In such cases, where the young person is a client, the service will provide educational information on the risks of taking products sourced off the internet as they may not be safe. In such cases, the Paediatric Endocrine Liaison Team will be unable to provide ongoing clinical supervision and the client will be discharged from the endocrine team. Psychosocial support will be provided to support the client with any other issues  This paragraph is very worrying and deserves more discussion. If a child has commenced puberty, and is already at the appropriate Tanner stage at referral to GIDS, by the time 4½ months has passed and then another 3 appointments for assessment, it could well be a year before GnRH blockers may be prescribed. The psychological trauma for the child in these cases could be severe and the parent may, as an interim measure, seek treatment in the private sector in order for blockers to be prescribed earlier. This is within the guidelines set by the BMA and the NHS - see references below:-  1. http://webarchive.nationalarchives.gov.uk/20130107105354/http://www.dh.gov.uk/prodconsum_dh/groups/dh_digitalassets/documents/digitalasset/dh_096576.pdf  2. http://www.nhs.uk/chq/Pages/2572.aspx?CategoryID=96  3. https://www.google.co.uk/url?sa=t&rct=j&q=&esrc=s&source=web&cd=1&ved=0ahUKEwjq3J2nnprLAhWJxRQKHXHuAO4QFggdMAA&url=http%3A%2F%2Fwww.bma.o	5.1, 5.2 The PWG noted that following receipt of any endocrine treatment received outside of the NHS, once a client meets the criteria set out in the service specification, they will be referred to the Paediatric Endocrine Liaison Team for evaluation prior to any NHS endocrine treatment taking place; the NHS will provide treatment at a time point which is within the scope set out in the specification, which	5.1,2 No action required

rg.uk%2F- %2Fmedia%2Ffiles%2Fpdfs%2Fpractical%2520advice%2520at%2520work%2Fethic s%2Finterfaceguidanceethicsmay2009.pdf&usg=AFQjCNHoBAztwjg2bAVgwvxAyZc p5HhM4g&sig2=pxWF3By4Fl3fdKlbenOJaQ  5.2 It could well be that the parents can only afford the GnRH blockers for a short period of time and assumed that the NHS would take over these prescriptions after satisfactory assessment of the child by GIDS. To deny this treatment in these circumstances would be both ethically and morally wrong and therefore this provision in the draft service specification should be looked at again.	means that those who choose to access private treatment do so at their own risk and cost; the service will continue to provide psychosocial care; staff in the service have all undertaken a range of appropriate training as part of qualification and ongoing training is in place.	
<ul> <li>5.3 Section 3.4.1 Page 28 paragraph 3:- Criteria for acceptance into the service are as follows: <ul> <li>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.</li> <li>Referrals will be accepted if there is evidence of features consistent with a diagnosis of GD and identified risk is being managed locally;</li> <li>If, after assessment, 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 issues with gender identity development, the case will be closed and the young person referred back to their GP or other referring healthcare professional, with advice regarding appropriate support.</li> </ul> </li> </ul>	5.3.1 The PWG noted that it would be appropriate for voluntary groups to make referrals.	5.3 This change has been added to the specification.
It is well known that some GP's and educational establishments are very resistant to the point of being obstructive to the treatment of transgender people (of all ages). It is therefore vital that other bodies such as selected and approved voluntary bodies be allowed, under these circumstances, to refer a child or adolescent to GIDS for assessment and treatment. Refusal/obstructive behaviour by a GP could lead to psychological harm - including depression, anxiety attacks, self-harming, suicide ideation	5.3.2 The PWG notes that this is the personal opinion of the stakeholder and no action further to that identified in 5.3.1	5.3.2 No action required.

	or even suicide itself.	is required.	
Conflicts:	None		
Stakeholder 6 – stakeholder organisation/ comments:	Many, many thanks for arranging for me to receive the draft service specification. Quite a read! The covering e-mail mentions that this document was developed by a sub-group of the Paediatric Medicine CRG. I hope that you will be able to tell me, please, who were the members of that sub-group and were any of them stakeholders?	6.1 the PWG noted that the attendees for the 23rd July event were invited to contribute to the revision of the specification through a series of teleconferences (a stakeholders from the event – including yourself and b) a separate children and adolescent group) and in addition, to put forward comments by email. We are not able to disclose the names of individual stakeholders for reasons of personal confidentiality. In addition, support has been provided by the members of the Paediatric Medicine Clinical Reference Group in which the commissioning of this service sits as part of	6.1 No action required

		the governance process of NHS England.	
Conflicts Stakeholder 7 – stakeholder organisation/ comments:	7.1 We have no comments to make	7.1 The PWG noted this comment	7.1 No action required
Conflicts Stakeholder 8 – BSPED/ comments:	None The Committee has no concerns or comments to raise around the GIDS revised specification.	8.1 The PWG noted this comment	8.1 No action required
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# Endocrine Treatment of Transsexual Persons: An Endocrine Society Clinical Practice Guideline

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DOI: http://dx.doi.org/10.1210/jc.2009-0345

Received: February 13, 2009

Accepted: June 04, 2009

First Published Online: July 02, 2013

- See more at: http://press.endocrine.org/doi/full/10.1210/jc.2009-

- 0345#sthash.8qLUL6gG.dpuf

The Task Force used the best available research evidence that Task Force members identified and two commissioned systematic reviews (21, 22) to develop some of the recommendations. The Task Force also used consistent language and graphical descriptions of both the strength of a recommendation and the quality of evidence. In terms of the strength of the recommendation, strong recommendations use the phrase "we recommend" and the number 1, and weak recommendations use the phrase "we suggest" and the number 2. Cross-filled circles indicate the quality of the evidence, such that  $\oplus \circ \circ \circ$  denotes very low quality evidence,  $\oplus \oplus \circ \circ \circ$  denotes low quality,  $\oplus \oplus \oplus \circ \circ \circ$  denotes moderate quality, and  $\oplus \oplus \oplus \oplus \circ \circ \circ \circ$  denotes high quality. The Task Force has confidence that persons who receive care according to the strong recommendations will derive, on average, more good than harm. Weak recommendations require more careful consideration of the person's circumstances, values, and preferences to determine the best course of action. Linked to each "recommendation" is a description of the "evidence" and the "values" that panelists considered in making the recommendation; in some instances, there are "remarks," a section in which panelists offer technical suggestions for testing conditions, dosing, and monitoring. These technical comments reflect the best available evidence applied to a typical person being treated. Often this evidence comes from the unsystematic observations of the panelists and their values and preferences; therefore, these

remarks should be considered suggestions. - See more at: http://press.endocrine.org/doi/full/10.1210/jc.2009-0345#sthash.8qLUL6gG.dpuf

conclusions

We recommend treating transsexual adolescents (Tanner stage 2) by suppressing puberty with GnRH analogues until age 16 years old, after which cross-sex hormones may be given. We suggest suppressing endogenous sex hormones, maintaining physiologic levels of gender-appropriate sex hormones and monitoring for known risks in adult transsexual persons. - See more at: <a href="http://press.endocrine.org/doi/full/10.1210/jc.2009-0345#sthash.8qLUL6qG.dpuf">http://press.endocrine.org/doi/full/10.1210/jc.2009-0345#sthash.8qLUL6qG.dpuf</a>

### Summary of Recommendations

## 1.0 Diagnostic procedure

- 1.1 We recommend that the diagnosis of gender identity disorder (GID) be made by a mental health professional (MHP). For children and adolescents, the MHP should also have training in child and adolescent developmental psychopathology. (1  $\oplus \oplus \circ \circ$ )
- 1.2 Given the high rate of remission of GID after the onset of puberty, we recommend against a complete social role change and hormone treatment in prepubertal children with GID. (1  $\oplus\oplus\circ\circ$ )
- 1.3 We recommend that physicians evaluate and ensure that applicants understand the reversible and irreversible effects of hormone suppression (e.g. GnRH analog treatment) and cross-sex hormone treatment before they start hormone treatment.
- 1.4 We recommend that all transsexual individuals be informed and counseled regarding options for fertility prior to initiation of puberty suppression in adolescents and prior to treatment with sex hormones of the desired sex in both adolescents and adults.
- See more at: http://press.endocrine.org/doi/full/10.1210/jc.2009-0345#sthash.8qLUL6qG.dpuf

### 2.0 Treatment of adolescents

- 2.1. We recommend that adolescents who fulfill eligibility and readiness criteria for gender reassignment initially undergo treatment to suppress pubertal development. (1  $\oplus \circ \circ \circ$ )
- 2.2. We recommend that suppression of pubertal hormones start when girls and boys first exhibit physical changes of puberty (confirmed by pubertal levels of estradiol and testosterone, respectively), but no earlier than Tanner stages 2–3. (1  $\oplus\oplus\circ\circ$ )

- 2.3. We recommend that GnRH analogs be used to achieve suppression of pubertal hormones. (1  $\oplus \oplus \circ \circ$ )
- 2.4. We suggest that pubertal development of the desired opposite sex be initiated at **about the age of 16 yr**, using a gradually increasing dose schedule of cross-sex steroids. (2  $\oplus \circ \circ \circ$ )
- 2.5. We recommend referring hormone-treated adolescents for surgery when 1) the real-life experience (RLE) has resulted in a satisfactory social role change; 2) the individual is satisfied about the hormonal effects; and 3) the individual desires definitive surgical changes.  $(1 \oplus \circ \circ \circ)$
- 2.6 We suggest deferring surgery until the individual is at least 18 yr old. (2 ⊕○○○)
- See more at: http://press.endocrine.org/doi/full/10.1210/jc.2009-0345#sthash.8qLUL6qG.dpuf

In summary, neither biological nor psychological studies provide a satisfactory explanation for the intriguing phenomenon of GIDs. In both disciplines, studies have been able to correlate certain findings to GIDs, but the findings are not robust and cannot be generalized to the whole population. - See more at: http://press.endocrine.org/doi/full/10.1210/jc.2009-0345#sthash.8qLUL6qG.dpuf

#### 2.4 Recommendation

We suggest that pubertal development of the desired, opposite sex be initiated at the age of 16 yr, using a gradually increasing dose schedule of cross-sex steroids.  $(2 \oplus \circ \circ \circ)$ 

#### 2.4 Evidence

In many countries, 16-yr-olds are legal adults with regard to medical decision making. This is probably because, at this age, most adolescents are able to make complex cognitive decisions. Although parental consent may not be required, obtaining it is preferred because the support of parents should improve the outcome during this complex phase of the adolescent's life (61).

For the induction of puberty, we use a similar dose scheme of induction of puberty in these hypogonadal transsexual adolescents as in other hypogonadal individuals (Table 9). We do not advise the use of sex steroid creams or patches because there is little experience for induction of puberty. The transsexual adolescent is hypogonadal and may be sensitive to high doses of cross-sex steroids, causing adverse effects of striae and abnormal breast shape in girls and cystic acne in boys.

In FTM transsexual adolescents, suppression of puberty may halt the growth spurt. To achieve maximum height, slow introduction of androgens will mimic a "pubertal" growth spurt. If the patient is relatively short, one may treat with oxandrolone, a growth-stimulating anabolic steroid also successfully applied in women with Turner syndrome (73, 74, 75).

In MTF transsexual adolescents, extreme tall stature is often a genetic probability. The estrogen dose may be increased by more rapid increments in the schedule. Estrogens may be started before the age of 16 (in exceptional cases), or estrogens can be prescribed in growth-inhibiting doses (61).

We suggest that treatment with GnRH analogs be continued during treatment with cross-sex steroids to maintain full suppression of pituitary gonadotropin levels and, thereby, gonadal steroids. When puberty is initiated with a gradually increasing schedule of sex steroid doses, the initial levels will not be high enough to suppress endogenous sex steroid secretion (Table 7). The estrogen doses used may result in reactivation of gonadotropin secretion and endogenous production of testosterone that can interfere with the effectiveness of the treatment. GnRH analog treatment is advised until gonadectomy.

#### 2.4 Values and Preferences

Identifying an age at which pubertal development is initiated will be by necessity arbitrary, but the goal is to start this process at a time when the individual will be able to make informed mature decisions and engage in the therapy, while at the same time developing along with his or her peers. Growth targets reflect personal preferences, often shaped by societal expectations. Individual preferences should be the key determinant, rather than the professional's deciding a priori that MTF transsexuals should be shorter than FTM transsexuals.

- See more at: http://press.endocrine.org/doi/full/10.1210/jc.2009-0345#sthash.8qLUL6qG.dpuf