

 Pwyllgor Gwasanaethau Iechyd Arbenigol Cymru (PGIAC)
Welsh Health Specialised
Services Committee (WHSSC)

Specialised Services Service Specification: CP182b

Gender Identity Service for Adults (Non-Surgical)

March 2020 Version 2.0

Document information	
Document purpose	Service Specification
Document name	Gender Identity Service for Adults (Non-Surgical)
Author	Welsh Health Specialised Services Committee
Date first published	September 2019
Revision Date	March 2020
Commissioning Team	Mental Health & Vulnerable Groups
Target audience	Chief Executives, Medical Directors, Directors of Finance, Chief Pharmacists, Directors of Primary Care
Description	NHS Wales will routinely commission this specialised service in accordance with the criteria described in this document
Document No	CP182b
Review Date	July 2024

Contents

Statem	ent	5
1. Intro	oduction	6
1.1	Background	6
1.3	Epidemiology	7
1.4	Aims and Objectives	7
1.5	Relationship with other documents	8
2. Serv	vice Delivery	9
2.1	Access Criteria	9
2.2	Service description	9
	cilities and equipment	
	affing	
	inical Standards	
2.3	Interdependencies with other services or providers.	
2.3.1	Welsh Gender Team (WGT)	
2.3.2	Local Health Boards	12
2.3.3	Directed Enhanced Service (DES) for Maintenance Treatment in Primary Care	12
2.3.4	NHS England Gender Identity Clinic	
2.3.4	Exclusion Criteria	
2.5	Acceptance Criteria	
2.6	Patient Pathway (Annex i)	
2.7	New referrals	
2.7.1	Assessment process for newly-referred individuals .	
2.8	Requests for transfers of care from the Gender Iden	
	Development Service (GIDS) for Children and Young	J
	People	
2.9	Complex patients	
2.10	Physical examination	
2.11	Shared decision making	
2.12	Capacity and informed consent	
2.13	Loss of fertility	16
2.14	Preparation for surgery for the treatment of gender dysphoria	16
2.15	Conclusion of contact with the Welsh Gender Team on NHS England Gender Identity Clinic	
2.16	Service provider/Designated Centre	
2.17	Exceptions	
	-	

3.	Quality and Patient Safety	18
3	.1 Quality Indicators (Standards)	18
З	.2 National Standards	18
3	.3 Other quality requirements	18
4.	Performance monitoring and Information Requirement	19
4	.1 Performance Monitoring	19
4	.2 Key Performance Indicators	19
4	.3 Date of Review	19
5.	Equality Impact and Assessment	20
6.	Putting Things Right: Raising a Concern	21
6	.1 Raising a Concern	21
6	.2 Individual Patient Funding Request (IPFR)	21
An	nex i: Patient Pathway	22
An	nex ii Codes	25
An	nex iii: New Referrals	26
	nex iv: Transfers from the Gender Identity Development S Children and Young People	
An	nex v: Assessment and Diagnosis	29
An	nex vi: Physical Examination	32
An	nex vii: Arrangements for prescribing endocrine treatmen	ts34
An	nex viii: Quality, Patient Safety and Key Performance Indi	
An	nex ix: Abbreviations and Glossary	39

Statement

Welsh Health Specialised Services Committee (WHSSC) will commission Gender Identity Service for Adults (non-surgical) in accordance with the criteria outlined in this specification.

In creating this document WHSSC has reviewed the requirements and standards of care that are expected to deliver this service.

Disclaimer

WHSSC assumes that healthcare professionals will use their clinical judgment, knowledge and expertise when deciding whether it is appropriate to apply this document.

This document may not be clinically appropriate for use in all situations and does not override the responsibility of healthcare professionals to make decisions appropriate to the circumstances of the individual patient, in consultation with the patient and/or their carer or guardian.

WHSSC disclaims any responsibility for damages arising out of the use or non-use of this document.

1. Introduction

This document has been developed as the Service Specification for the planning and delivery of an adult gender identity service (non-surgical) for people resident in Wales aged 18 years and over. This service will be commissioned by the Welsh Health Specialised Services Committee (WHSSC) and applies to residents of all seven Health Boards in Wales.

1.1 Background

Over the last few years the demand for gender services has increased, this led to the Health Secretary of Wales making a decision that a service needed to be developed in Wales. Up until 31st March 2019, patients within Wales with gender dysphoria had been referred to the London Gender Identity Clinic for assessment and treatment.

This new service has been developed in collaboration with the All Wales Gender Identity Partnership Group and engagement has taken place with service users and stakeholders. Following an options appraisal the gender identity service for adults in Wales has been developed.

The gender identity service for adults in Wales has been designed to reduce waiting times, deliver care as close to home as possible, provide better access to hormone prescribing and improve patient experience.

This service specification updates the WHSSC Specialised Services Policy: CP21, Specialised Adult Gender Identity Services (2012).

1.2 Plain language summary

The term used to describe a discrepancy between birth-assigned sex and gender identity is gender incongruence, this term is preferable to the formerly-used terms of gender identity disorder and transsexualism. Gender incongruence is frequently, but not universally, accompanied by the symptom of gender dysphoria.

The current version of the International Statistical Classification of Diseases and Related Health Problems identifies 'transsexualism' (ICD 10 code F64) as "a disorder characterized by a strong and persistent cross-gender identification (such as stating a desire to be the other sex or frequently passing as the other sex) coupled with persistent discomfort with his or her sex (manifested in adults, for example, as a preoccupation with altering primary and secondary sex characteristics through hormonal manipulation or surgery)"¹.

¹ <u>WHO | International Classification of Diseases, 11th Revision (ICD-11)</u>

The Diagnostic and Statistical Manual of Mental Disorders (v5, 2013) states that Gender Dysphoria is not, in itself, a mental health condition, reflecting contemporary professional opinion².

1.3 Epidemiology

There is no official data on the number of people in Wales who present with a degree of gender variance. Difficulties in assessing prevalence are exacerbated by the limited evidence base.

There is considerable variation in reported prevalence due to factors such as:

- variable data reporting by providers
- differences in diagnostic thresholds applied and inconsistent terminology
- the methodology and diagnostic classification used
- the year and country in which the studies took place.

Thus there is considerable variation in estimates, and the absence of reliable prevalence data exacerbates the challenges in planning and commissioning gender identity services. What is consistent across the literature is a recognition of the significant rise in the number of people pursuing treatment options and the increased incidence of expressed need.

1.4 Aims and Objectives

The aim of this service is to define the requirements and standard of care essential for delivering gender identity services for people with gender dysphoria.

The objectives of this document are to:

- detail the specification required to deliver the gender identity service for adults (non-surgical) who are resident in Wales
- ensure minimum standards of care are met for the delivery of the adult gender identity service (non-surgical)
- ensure equitable access to the adult gender identity service (nonsurgical)
- improve outcomes for people accessing the adult gender identity service (non-surgical)

² <u>https://www.psychiatry.org/psychiatrists/practice/dsm</u>

Welsh Health Specialised Services Committee (WHSSC) March 2020

1.5 Relationship with other documents

This document should be read in conjunction with the following documents:

• NHS Wales

• All Wales Policy: <u>Making Decisions in Individual Patient Funding</u> <u>requests</u> (IPFR).

• WHSSC policies and service specifications

 Specialised Fertility Services Commissioning Policy CP38 <u>WHSSC</u> <u>CP38</u>

• NHS England

 NHS England Service Specification for <u>Gender Identity Services for</u> <u>adults – surgical interventions</u>

• Other published documents

- Royal College of Psychiatrists, <u>Good Practice Guidelines for the</u> <u>assessment and treatment of adults with gender dysphoria</u>
- The World Professional Association for Transgender Health (WPATH) <u>Standards of care for the Health of Transsexual, Transgender and</u> <u>Gender Non-Conforming People</u>

2. Service Delivery

Current Service

The Welsh Health Specialised Services Committee will commission a Gender Identity Service for Adults (non-surgical) for welsh patients with gender dysphoria in-line with the criteria identified in the policy.

2.1 Access Criteria

Equity of access and high quality care will be provided to all individuals who meet the criteria for access to the NHS pathway of care.

This policy recognises and respects diversity in gender identity and its expression. It recognises that there are other identities than the traditional (binary) associated with 'man' and 'woman', and that gender diverse people (who are known by a variety of other names, including non-binary, transfeminine, trans-masculine, Genderqueer, non-gender, intersex and others) who meet the criteria for access to the NHS Wales pathway of care should have access to treatment and described in this document that is equitable to the access available to people with binary identities.

The Welsh Gender Team (WGT) will receive referrals from the registered GP of individuals. The individuals will be 17.5 years of age plus and may have gender dysphoria that is a consequence of their gender identity being incongruent with their visible sex characteristics and/or the social role, typically associated with those characteristics (gender incongruence). Subsequent interventions will only be accessed by individuals who have been diagnosed with gender dysphoria.

2.2 Service description

In addition to the standards required within the Contract, specific quality standards and measures will be expected. The provider should also meet the standards as set out below.

An adult gender identity service has been developed within NHS Wales to provide welsh patients with a:

- non-surgical gender identity service for non-complex cases delivered by a multi-disciplinary Welsh Gender Team (WGT)
- non-surgical gender identity service for complex³ cases delivered by a NHS England Gender Identity Clinic (GIC)
- surgical gender identity service (a new surgical policy is under development)

```
Welsh Health Specialised Services Committee (WHSSC) March 2020
```

³ The complexity of a case is determined by the skills, experience and competency of the Welsh Gender Team to deliver effective treatment for that individual at that point in time. The criteria by which the Welsh Gender Team define a complex case may change as their skills, experience and competency increase over time.

This service is reliant on Local Health Boards initiating and prescribing treatment and on primary care providing ongoing prescribing support for individuals discharged from the WGT and NHS England Gender Identity Clinic. Local health boards and primary care are funded separately for this service. The WGT will provide advice and support to prescribing practitioners to assist them. These interdependencies are further detailed in section 2.3.

In addition to the standards required within the Contract, specific quality standards and measures will be expected. The provider should also meet the standards as set out below.

Facilities and equipment

The WGT will provide the following facilities (in line with forecast demand):

- Consulting rooms
- Gender neutral toilets
- Waiting area
- Space for multi-disciplinary meetings
- Secure access

Staffing

The WGT will have:

- A nominated Senior Clinical Lead, who has the key leadership role for the service overall. The Senior Clinical Lead must demonstrate evidence of appropriate experience and expertise in specialised gender dysphoria practice; significant management experience; and significant evidence of continued professional development.
- A specialist multi-disciplinary team of professionals, with a mix of skills, experience and expertise that is appropriate to ensure the delivery of effective and high-quality services in accordance with the requirements of this service specification.

Clinical Standards

The Welsh Gender Team will:

- Provide a high quality service for adults who have gender dysphoria; and will promote respect, dignity and equality for gender diverse people.
- Provide a timely and sustainable service for adults with gender dysphoria that meets the needs of the population, and incorporates the views of individuals.
- Work with the Gender Identity Development Service (GIDS) for gender variant adolescents and young people to ensure a timely and effective transfer to adult services.

- Achieve an integrated approach to care with local gender teams and ensure close links with other expert centres at national and international levels.
- Ensure timely and appropriate communications with services who are expected to provide other parts of the individual's pathway.
- Increase awareness of best practice in the diagnosis and management of gender dysphoria through active engagement with health professionals; and educate healthcare professionals in the health and support needs of transgender people.
- Collaborate in national and international research projects to increase the evidence base for the commissioning and delivery of specialised services for transgender people.
- Provide support, advice, expertise and training for Local Health Boards.
- Collaborate in sharing best practice, peer review, benchmarking, and in the development of research and innovation.
- Employ consistent and equitable decision-making about the effective use of resources on the NHS pathway of care for transgender people.
- Publicise national and local patient organisations, which can provide invaluable additional information and ongoing support for transgender people and their families.
- Have a robust system of corporate governance with sufficient administrative and managerial support needed for efficient and timely delivery of services.
- Have information and technology systems that enable patient contact remotely.
- Have arrangements in place to ensure that complaints by service users are acknowledged investigated and responded to promptly; and that the means to complain are publicised and accessible.
- Have systems that demonstrate how they will use audit, data management and analysis, service reviews (including peer reviews) and other intelligence to evaluate effectiveness and drive ongoing service improvement.

2.3 Interdependencies with other services or providers

The pathway is comprised of a graduated model of care developed to deliver the entire pathway including referral, diagnosis, transition and ongoing assessment.

2.3.1 Welsh Gender Team (WGT)

The Welsh Gender Team will receive all new referrals directly from the individual patient's registered GP.

The WGT will be responsible for:

- Specialist assessment of the patient after referral from registered GP
- Formulation of management plans including hormone prescribing
- Liaison with other specialist providers if indicated, for example referral to speech and language services
- Referral of complex cases to the NHS England Gender Identity Clinic
- Referral to the NHS England Gender Identity Clinic for gender reassignment or chest reconstruction surgery
- Working with and supporting LHB based Local Gender Teams
- Actively contributing to a service development sub group of the All Wales Gender Identity Partnership Group

2.3.2 Local Health Boards

Local Gender Team

The graduated model of care involves a network of clinicians who will provide an intermediate tier service between the Welsh Gender Team and Primary Care. Their role will be to prescribe, initiate and monitor hormone therapy in line with specialised guidance until the patient is optimised. Each Local Health Board will be responsible for funding and implementing this local gender service. Arrangements for prescribing endocrine treatments are outlined in Annex vii.

Speech and Language Therapy

Each Local Health Board should ensure access to an appropriate level of local speech and language services. The number and frequency of sessions will be variable depending on the individual's needs.

The objective of therapy is to facilitate changes in the individual's voice and communicative profile thereby improving quality of life and alleviating distress related to gender dysphoria.

Hair removal

Hair removal is excluded other than for site preparation for surgery. Please see section 2.4, Exclusion Criteria.

2.3.3 Directed Enhanced Service (DES) for Maintenance Treatment in Primary Care

The enhanced service is designed to support patients who require ongoing hormone therapy after such treatment has been initiated and the patient optimised on treatment by the local gender teams. It will provide the necessary resources to practices to fund the ongoing care to patients with gender dysphoria which does not fall under the definition of essential or additional services. It will support clinicians to prescribe ongoing hormone treatment to patients with gender dysphoria in a safe and supported way, working with support from specialist and intermediate services.

The drug costs and phlebotomy services for these patients are already covered by Local Health Boards and this will continue for both elements of the pathway.

2.3.4 NHS England Gender Identity Clinic

The WGT will make referrals to the NHS England Gender Identity Clinic for complex cases and surgical components. The aim in the longer term will be for the WGT to develop the competency to support more complex cases and provide surgical assessment.

2.4 Exclusion Criteria

Patients resident in Wales but registered with a GP practice in England are not eligible for the service. Refer to England/Wales NHS Cross-border Healthcare Services: Statement of values and principles for further guidance⁴.

Referrals will not be accepted for individuals who are not registered with a GP given the benefits to the individual of ongoing support from their GP, particularly after discharge from the care of the specialist team.

Requests for any procedures which are outside of WHSSC planned services can be considered by the All Wales IPFR panel. Please refer to the All Wales IPFR Policy.⁵

2.5 Acceptance Criteria

The service outlined in this specification is for patients ordinarily resident in Wales, or otherwise the commissioning responsibility of the NHS in Wales. This excludes patients who whilst resident in Wales, are registered with a GP practice in England, but includes patients resident in England who are registered with a GP Practice in Wales.

2.6 Patient Pathway (Annex i)

The key components of the pathway include:

- Direct referral from GP
- Assessment (as part of a MDT and not Mental Health Services)

⁴ <u>https://www.england.nhs.uk/wp-content/uploads/2018/11/cross-border-statement-of-values-and-principles.pdf</u>

⁵ <u>http://www.whssc.wales.nhs.uk/individual-patient-funding-requests</u>

- Psychological support for patients
- Signposting to relevant services
- Assessment for hormone therapy
- Referral to an NHS England Gender Identity Clinic for complex cases and for chest and genital reconstruction surgery assessment
- Central access for support and advice for other professionals

The pathway will support the development of a longer term model that increases capacity, knowledge and competency within primary care so more of the service can be delivered by Local Health Boards. It will also help to progress the development of the Welsh Gender Team to increase the skills of the team and repatriate more patients with the aim of eventually providing a specialised Gender Identity Clinic in Wales.

The delivery model relies on access to specialist Gender Identity Services via primary care, and the principle of multidisciplinary and interdisciplinary teams and networks who work and collaborate in the provision of care.

The Welsh Gender Team and NHS England Gender Identity Clinic will assess and diagnose individuals and arrange for referrals to other services, including for medical and surgical treatments. Access to surgical intervention is only by referral from the Welsh Gender Team or NHS England Gender Identity Clinic that is commissioned by NHS England compliant with this policy.

2.7 New referrals

New referrals will be made directly from the patient's registered GP to the Welsh Gender Team using the online form available on the Welsh Clinical Communications Gateway (WCCG): <u>Welsh Gender Service</u>.

2.7.1 Assessment process for newly-referred individuals

The Welsh Gender Team (WGT) will:

- undertake a specialised assessment for people who may have gender dysphoria
- work with them to identify the most appropriate diagnostic coding
- agree a treatment plan.

If the diagnosis is that the individual does not have gender dysphoria as a consequence of gender incongruence, the Provider will advise the individual and referrer on alternative services that might meet the individual's health and well-being needs (see Annex v).

2.8 Requests for transfers of care from the Gender Identity Development Service (GIDS) for Children and Young People

A request for transfer of care may be made by the designated Gender Identity Development Service for children and young people to a Gender Identity Clinic before the young person's 18th birthday. This may be appropriate where joint working between the two services, including joint consultations with the young person, within a "lead-in" period is beneficial to ensure a timely and effective eventual transfer once the young person has reached 18 years of age.

Both the GIDS and Adult Gender Identity Clinic are provided by the same provider. This enables a seamless transition, with a coordinated approach between the two services at the most appropriate time for the individual. This may vary as it may be more-timely to complete the assessment process within the one before transferring to another. In either case, this will not disadvantage any persons. Joint transition clinics and MDT discussions between two services will take place to aid these discussions and decisions (see Annex IV).

2.9 Complex patients

Patients with complex needs should be referred by the WGT to the NHS England Gender Identity Clinic for assessment and treatment.

2.10 Physical examination

Physical examination, other than the measurement of height, weight and blood pressure will not be performed routinely during the assessment process (see Annex VI).

2.11 Shared decision making

Shared Decision Making is a process in which individuals, when they reach a decision point in their health care, can review all the treatment options available to them and participate actively with their healthcare professional in making that decision. The Clinician will provide individuals with the necessary information so that they may ask questions regarding their care and treatment plans which best suits their needs and preferences, and is clinically appropriate.

2.12 Capacity and informed consent

The Clinician will make all efforts to ensure that individuals are aware of the longer-term consequences of the interventions offered to them. The consequences of treatment decisions can be significant and life-changing.

The process of obtaining informed consent is an important aspect of ethical assessment and intervention, including the emotional, social and factual issues, so as to enable the individual to make informed decisions about the treatment options, benefits, material risks, and the alternatives to the treatments proposed (including the option of having no treatment).

Individuals should be given sufficient time to reflect on the clinical advice and the potential treatment options before deciding what is best for them. Clinicians should be mindful that it is possible that individuals may lack capacity.

2.13 Loss of fertility

The individual should be provided with early advice about the likely impact of medical interventions to physical health. The WGT will provide a general description of the options for conservation of fertility. Where appropriate the WGT with the individual's consent, will make a referral to a fertility service for cryopreservation of eggs or sperm for use in future fertility treatment (gamete storage).

2.14 Preparation for surgery for the treatment of gender dysphoria

Referrals for surgical interventions will be made by the Welsh Gender Team (WGT) in compliance with NHS England's service specification for <u>Gender Identity Services - Surgical Interventions</u> which describes the specialist surgical procedures that are commissioned by NHS England for the treatment of gender dysphoria.

Before a referral for surgery is made, the WGT Clinician will meet with the individual to review current treatment interventions, and to assess the individual's needs and readiness for the surgical intervention. The processes of shared decision making and of obtaining consent (see section 2.12) will provide the individual with necessary information to enable them to make an informed decision on the treatment options, and the associated risks and benefits. This will also allow them sufficient time to ask questions, and to reflect on the advice given.

At this stage the possibility of the need for donor site hair removal, and the likely implications for the timing of surgery, should be explained to the individual.

2.15 Conclusion of contact with the Welsh Gender Team or NHS England Gender Identity Clinic

Individuals will be discharged from the care of the Welsh Gender Team or Gender Identity Clinic:

- at an individual's request
- when the individual and Clinician agree that treatment for gender dysphoria is complete, and not less than six months after completion of the last planned intervention (the purpose of such follow-up is to assess the longer-term impact of interventions)

• in accordance with the Provider's access policy.

2.16 Service provider/Designated Centre

The Service Provider for the Welsh Gender Team is Cardiff and Vale University Health Board. The Welsh Gender Team will be based at:

St David's Hospital Cowbridge Road East Canton Cardiff CF11 9XB

The Local Gender Teams base will be determined by each Local Health Board.

2.17 Exceptions

If the patient does not meet the criteria for treatment as outlined in this policy, an Individual Patient Funding Request (IPFR) can be submitted for consideration in line with the All Wales Policy: Making Decisions on Individual Patient Funding Requests. The request will then be considered by the All Wales IPFR Panel.

If the patient wishes to be referred to a provider outside of the agreed pathway, an IPFR should be submitted.

Further information on making IPFR requests can be found at: <u>Welsh Health</u> <u>Specialised Services Committee (WHSSC) | Individual Patient Funding</u> <u>Requests</u>

3. Quality and Patient Safety

Ensuring that a quality service is provided to patients accessing the service is paramount. The providers of Gender Identity Services must work within the quality measures stipulated in the Service Level Agreement between WHSSC and the provider. In addition they will be required to provide information and data to monitor the quality and performance of the service.

Each centre must ensure that patient experience measures are in place to measure patient satisfaction and ensure that information is provided and easily available to patients to enable them to access outcome and performance data. Provision should be made available for patients with communication difficulties and other additional needs when accessing services.

3.1 Quality Indicators (Standards)

Locally defined outcomes

The Welsh Gender Team will aim to achieve the outcomes and measure performance against the indicators outlined in Annex vii.

3.2 National Standards

• The NHS England providers will be required to share the data that is collected by NHS England Specialised Services as per the service specification.

3.3 Other quality requirements

- the provider will have a recognised system to demonstrate service quality and standards
- the service will have detailed clinical protocols setting out nationally (and local where appropriate) recognised good practice for each treatment site
- the quality system and its treatment protocols will be subject to regular clinical and management audit
- the provider is required to undertake regular patient surveys and develop and implement an action plan based on findings.

4. Performance monitoring and Information Requirement

4.1 Performance Monitoring

WHSSC will be responsible for commissioning services in line with this policy. This will include agreeing appropriate information and procedures to monitor the performance of organisations.

For the services defined in this policy the following approach will be adopted:

- Service providers to evidence quality and performance controls
- Service providers to evidence compliance with standards of care

WHSSC will conduct performance and quality reviews on an annual basis

4.2 Key Performance Indicators

The providers will be expected to monitor against the full list of Quality Indicators derived from the service description components described in Section 2.2.

The provider should also monitor the appropriateness of referrals into the service and provide regular feedback to referrers on inappropriate referrals, identifying any trends or potential educational needs.

In particular, the provider will be expected to monitor against the following target outcomes:

- Waiting times of no longer than 26 weeks (from referral to first appointment). This will not apply to year 1 of the service.
- Referrals acknowledged by WGT within 14 days, with notification sent to referrer and patient.
- Patient letters (including treatment plans) sent within 28 days of the respective appointment.

4.3 Date of Review

This document is scheduled for review before 2022, where we will check if any new evidence is available.

If an update is carried out the policy will remain extant until the revised policy is published.

5. Equality Impact and Assessment

The Equality Impact Assessment (EQIA) process has been developed to help promote fair and equal treatment in the delivery of health services. It aims to enable Welsh Health Specialised Services Committee to identify and eliminate detrimental treatment caused by the adverse impact of health service policies upon groups and individuals for reasons of race, gender reassignment, disability, sex, sexual orientation, age, religion and belief, marriage and civil partnership, pregnancy and maternity and language (Welsh).

This policy has been subjected to an Equality Impact Assessment.

The Assessment demonstrates the policy is robust and there is no potential for discrimination or adverse impact. All opportunities to promote equality have been taken.

In addition, the service provider will be required to complete an Equality Impact Assessment.

6. Putting Things Right: Raising a Concern

6.1 Raising a Concern

Whilst every effort has been made to ensure that decisions made under this policy are robust and appropriate for the patient group, it is acknowledged that there may be occasions when the patient or their representative are not happy with decisions made or the treatment provided.

The patient or their representative should be guided by the clinician, or the member of NHS staff with whom the concern is raised, to the appropriate arrangements for management of their concern.

If a patient or their representative is unhappy with the care provided during the treatment or the clinical decision to withdraw treatment provided under this policy, the patient and/or their representative should be guided to the LHB for <u>NHS Putting Things Right</u>. For services provided outside NHS Wales the patient or their representative should be guided to the <u>NHS Trust</u> <u>Concerns Procedure</u>, with a copy of the concern being sent to WHSSC.

6.2 Individual Patient Funding Request (IPFR)

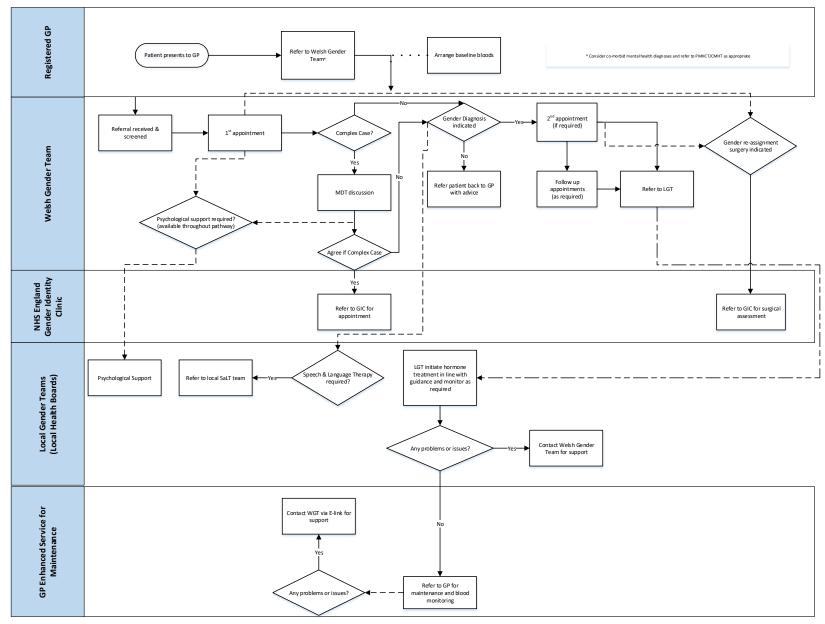
If the patient does not meet the criteria for treatment as outlined in this policy, an Individual Patient Funding Request (IPFR) can be submitted for consideration in line with the All Wales Policy: Making Decisions on Individual Patient Funding Requests. The request will then be considered by the All Wales IPFR Panel.

If an IPFR is declined by the Panel, a patient and/or their NHS clinician has the right to request information about how the decision was reached. If the patient and their NHS clinician feel the process has not been followed in accordance with this policy, arrangements can be made for an independent review of the process to be undertaken by the patient's Local Health Board. The ground for the review, which are detailed in the All Wales Policy: Making Decisions on Individual Patient Funding Requests (IPFR), must be clearly stated

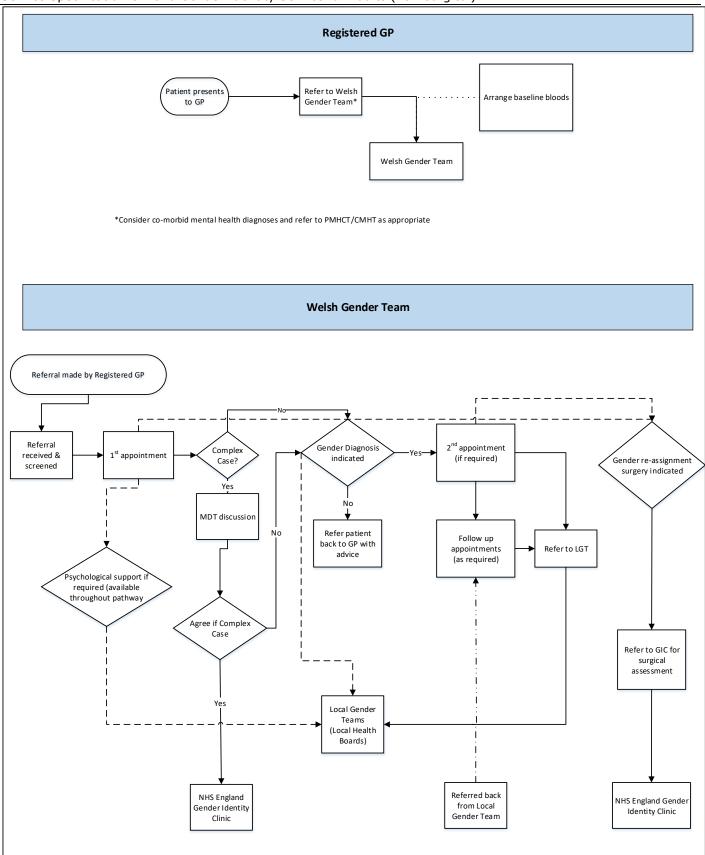
If the patient wishes to be referred to a provider outside of the agreed pathway, and IPFR should be submitted.

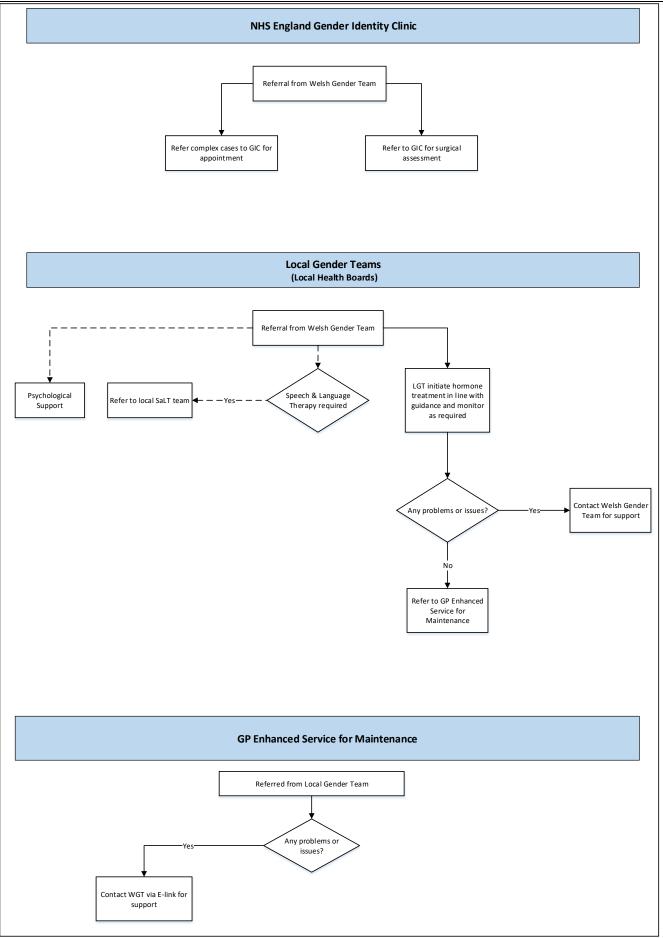
Further information on making IPFR requests can be found at: <u>Welsh Health</u> <u>Specialised Services Committee (WHSSC) | Individual Patient Funding</u> <u>Requests</u>

Annex i: Patient Pathway



Welsh Health Specialised Services Committee (WHSSC) March 2020





Annex ii Codes ICD-10 Codes*

Code Category	Code	Description
ICD-10	F64.0	Transsexualism
ICD-10	F64.1	Dual-role transvestism
ICD-10	F64.2	Gender identity disorder of childhood
ICD-10	F64.8	Other gender identity disorders
ICD-10	F64.9	Gender identity disorder, unspecified
ICD-10	F66.0	Sexual maturation disorder
ICD-10	F66.1	Egodystonic sexual orientation

*ICD 11 has not yet been adopted. On adoption, this specification will be updated to include the relevant ICD 11 codes including the new code HA60 'Gender Incongruence in Adulthood'.

Annex iii: New Referrals

Referrals may be made to the WGT by General Practitioners (GP) using the online form available on the Welsh Clinical Communications Gateway (WCCG): <u>Welsh Gender Service</u>.

Referrals will be acknowledged by the Welsh Gender Team in writing with the referrer and individual within 14 days.

The following is an overview of the type of information required by the referral template:

- A description of the individual's experience of gender dysphoria, including duration.
- A summary of significant physical and mental health history.
- History of substance misuse.
- Forensic history.
- The individual's current medication use (prescribed, self-medication, recreational).
- Details of any other agencies involved
- Basic biometrics (height, weight, Body Mass Index, blood pressure).

Annex iv: Transfers from the Gender Identity Development Service for Children and Young People

The Gender Identity Development Service (GIDS) is commissioned to provide care and support for young people up to 18 years of age and provided by Tavistock and Portman NHS Foundation Trust.

The objective of the transfer is a purposeful, planned movement of adolescents and young adults from a young person's service into an adultoriented service. A well planned transfer should focus on the needs of the individual and should provide coordinated, un-interrupted care and support to avoid negative consequences. The parents, carers and other family members will also value support, information and guidance in the process of transfer. There are therefore compelling reasons for close cooperation, communication and mutual support between the specialist team in the Gender Identity Development Service for children and young people and specialist teams in adult services.

Although the transfer to adult services will not be made until the young person is aged at least 17 years, a request for transfer of care may be made by the young person's service to the adult service before the young person's 18th birthday but they will only be seen by the WGT on or after their 18th birthday. This may be appropriate where joint working between the two services, including joint consultations with the young person, within a "lead-in" period is beneficial to ensure a timely and effective eventual transfer or to determine if a transfer to adult services is appropriate at that time.

Young people who have completed a diagnostic assessment in the young person's service will not be re-assessed for diagnosis in the adult service. The adult service will be provided with the relevant diagnostic codes and agreed treatment plan, including the medical treatment plan if the young person is receiving endocrine interventions, and as part of the process for transfer the adult service will agree arrangements for continued prescribing.

Individualised risk management procedures should be in place and agreed across both services, particularly for more vulnerable young people or those with more complex needs.

In cases where the young person fulfils the diagnosis for gender dysphoria but does not yet have a definitive treatment plan either because they are wanting to explore options more fully, or have related very complex or psychosocial issues that mean physical interventions are not yet appropriate, the process of transfer may be likely to take longer and will require ongoing collaboration and planning between the young person's service and the adult service focused on the needs of the individual. The nature of the individualised plan will differ according to needs, but may necessitate a joint transition clinic in appropriate cases.

By the age of 18 years the different outcomes may be:

• where a diagnosis of gender dysphoria as a consequence of gender incongruence has been made, an agreed plan for transfer to adult gender dysphoria services has been achieved

or

 where a diagnosis of gender dysphoria as a consequence of gender incongruence has not been made, a referral to an adult gender dysphoria service for an assessment of diagnosis, or for access to specific time- limited psychological therapies

or

 discharge from the young person's service and no transfer or referral to adult gender dysphoria services when this is clinically appropriate.

Annex v: Assessment and Diagnosis

The WGT will undertake a specialised assessment for people who may have gender dysphoria, agree with them the most appropriate diagnostic coding and agree a treatment plan. If the diagnosis is that the individual does not have gender dysphoria as a consequence of gender incongruence, the WGT will advise the individual and referrer on alternative services that might meet the individual's health and well-being needs.

The majority of individuals will have two core assessment consultations; at least one of the consultations will be face-to- face. Baseline laboratory investigations and physical measurements (height, weight, and blood pressure) may be requested during the assessment, if these are consistent with the individual's treatment objectives.

First Appointment – Initial assessment consultation

This consultation will be conducted by a regulated health professional (or by a supervised trainee). Information will be collected about:

- the individual's objectives for their engagement with the service
- their gender identity and expression (current and historic), and
- basic bio-psycho-social history.

It is recognised that patients may be at different stages in their transition and it may be appropriate for some patients to also discuss treatment planning during the first appointment or surgical options dependent on individual circumstances and point of readiness.

Second Appointment - Diagnostic and treatment planning consultation

This consultation will be conducted by a medical practitioner or clinical psychologist (or by a supervised trainee). Information from the referrer and the initial consultation, together with any investigation results, will be reviewed and further explored with the individual. Diagnostic coding will be discussed and agreed with the individual. The individual's treatment goals will be discussed and agreed. A general assessment of capacity to consent to treatment will be made.

A written treatment plan, with indicative timelines, will be discussed and agreed with the individual and shared with the GP and Local Gender Team. The treatment plan may recommend that the individual progress to a treatment process. Other outcomes may include a recommendation to the referrer or GP that the individual be referred to other services, or that a referral should be deferred to a later date because of other health or social issues that would prevent the individual from currently benefiting from the interventions. All outcomes will be carefully explained to the individual. It is recognised that some patients may need more/less diagnostic and treatment planning consultations depending on their individual circumstances and point of readiness.

Follow up appointments - additional assessment consultations

A minority of individuals have additional needs such that more than two core assessment consultations may be appropriate. This may include people with co-existing physical or mental health problems, communication difficulties or learning difficulties. In these circumstances, the clinician should explain to the individual the reason for the proposed additional consultations.

Family members

The provider should not insist that the individual gives permission for family members or other people to attend appointments jointly with the individual. If a clinician advises the individual that it would be beneficial for a family member or other person to jointly attend an appointment, the reasoning should be explained to the individual and reassurance given that a refusal to give permission will not prejudice the individual's assessment or ongoing treatment.

Assessment of patients who have been granted a Gender Recognition Certificate

The Gender Recognition Act 2004⁶ enables a trans-person to apply to the Gender Recognition Panel to receive a Gender Recognition Certificate. Individuals who are granted a full Gender Recognition Certificate are considered in the eyes of the law to be of their acquired gender and they are entitled to all the rights appropriate to a person of their acquired gender.

An individual with a Gender Recognition Certificate will already have obtained a clinical diagnosis of gender dysphoria (as that is a requirement for the granting of a Gender Recognition Certificate). As such, the assessment and diagnosis element of the individual's contact with the WGT will be adjusted to reflect the existing diagnosis of gender dysphoria.

Possession of a Gender Recognition Certificate does not in itself provide the multi- disciplinary team with the clinical information that is necessary to assess an individual's suitability and readiness for the medical and other health interventions that are available along the NHS pathway of care. As such, individuals with a Gender Recognition Certificate will be assessed for readiness of interventions, including surgical interventions, as otherwise described in this service specification and will include the individual's:

⁶ https://www.legislation.gov.uk/ukpga/2004/7/contents

Welsh Health Specialised Services Committee (WHSSC) March 2020

- expectations of the interventions and how they will impact upon them socially and psychologically
- health history
- understanding of the interventions and their potential benefits, risks and limitations
- support network and strategies for thriving after the intervention plans for preparation and aftercare following intervention.

Annex vi: Physical Examination

Physical examination, other than the measurement of height, weight and blood pressure, must not be performed routinely during the assessment process. Examination of genitalia and chest is not a routine part of the assessment process. Physical examination may be recommended by the clinical team only if the individual's clinical history suggests that physical examination is likely to result in important benefit to the individual, or is likely to reduce an important risk of harm; or as a response to a specific request by the individual. Individuals must be told that they have the right to refuse physical examination and that refusal will not affect their care with the Provider, unless omission of examination is likely to significantly compromise their safety. In rare circumstances, a refusal of examination (by any medical practitioner in any setting) may increase the clinicallyrelevant risk associated with medical and surgical interventions, to such a degree that it would be unethical to proceed with those interventions.

The individual's views will be sought with regard to who shall examine them and the provider will endeavour to fulfil their wishes with regard to the gender of the examining medical practitioner. Physical examination must not be performed by the medical practitioner involved in the patient's assessment process.

The examining medical practitioner should:

- explain in advance what the examination involves, what information it is intended to yield, and why it is clinically justified
- ensure the examination is held in private, in a secure, quiet and calm environment
- always offer a chaperone (this must be documented in the individual's notes, as must an individual's choice to decline having a chaperone present)
- ask the individual's preferred terms for parts of the body
- defer examination to a later visit, allowing the individual to build a trusting relationship with the medical practitioner.

Chaperones for physical examination 7

A chaperone should usually be a health professional and the examining medical practitioner must be satisfied that the chaperone will:

- be sensitive and respect the individual's dignity and confidentiality
- reassure the individual if they show signs of distress or discomfort
- be familiar with the procedures involved in a routine intimate examination

⁷ Intimate Examinations and Chaperones; General Medical Council; 2013

- stay for the whole examination and be able to see what the examining medical practitioner is doing, if practical
- be prepared to raise concerns if they are concerned about the examining medical practitioner behaviour or actions

A relative or friend of the individual is not an impartial observer and so would not usually be a suitable chaperone, but the examining medical practitioner should comply with a reasonable request to have such a person present as well as a chaperone.

If either the medical examining practitioner or the individual does not want the examination to go ahead without a chaperone present, or if either party is uncomfortable with the choice of chaperone, the examination may be delayed to a later date when a suitable chaperone will be available, as long as the delay would not adversely affect the individual's health.

If the examining medical practitioner does not want to proceed without a chaperone present but the individual has refused to have one, the examining medical practitioner must explain their reasoning clearly, but ultimately the individual's clinical needs must take precedence. The examining medical practitioner may wish to consider referring the patient to a colleague who would be willing to examine them without a chaperone, as long as a delay would not adversely affect the patient's health.

Annex vii: Arrangements for prescribing endocrine treatments

Endocrine treatments may influence central nervous system function and cognition (thoughts and feelings) as well as sex-specific physical characteristics. They may augment physical interventions intended to modify secondary sex characteristics. They may mitigate the unwanted endocrine and metabolic effects of hypogonadism, which follow gonadectomy or the suppression of sex hormones produced by the body.

Endocrine and other pharmacological interventions may be recommended by the Welsh Gender Team or NHS England Gender Identity Clinic where they are essential for the purpose of harm reduction, and where they are in the individual's best interest for reducing gender dysphoria, when assisting the individual in achieving gender expression congruent with their identity and consistent with their treatment goals. It is not a requirement for access to endocrine and other pharmacological interventions to undertake a change in social role.

The recommending medical practitioner will assess the risks, benefits and limitations of pharmacological interventions for the individual, and will ensure that the individual meets the relevant eligibility criteria set out in the <u>World Professional Association for Transgender Health Standards of Care (2011)</u>:

- persistent, well-documented gender dysphoria
- capacity to make a fully informed decision and to consent for treatment
- if significant medical or mental concerns are present, they must be reasonably well-controlled

They will obtain written consent to the interventions under consideration from the individual, and provide a copy of the consent to the individual and their GP.

They will provide the local gender team prescriber with patient-specific 'prescribing guidance', which will consist of a written treatment recommendation, and adequately-detailed information about necessary pre-treatment assessments, recommended preparations of medications, and advice on dosages, administration, initiation, duration of treatment, physical and laboratory monitoring, interpretation of laboratory results and likely treatment effects.

Most recommendations will be for medications to be used outside the indications approved by the Medicines and Healthcare Products Regulatory Agency; the General Medical Council advises primary care prescribers that they may prescribe 'unlicensed medicines' where this is necessary to meet

the specific needs of the patient and where there is no suitably licensed medicine that will meet the patient's need⁸.

Local gender team prescribers will be given advice on dose titration and the introduction of additional pharmacological interventions by the Welsh Gender Team. The Welsh Gender Team will respond promptly to requests by both local gender team prescribers and GPs for advice regarding the interpretation of laboratory results and medication use.

Individuals receiving endocrine and other pharmacological interventions recommended by the Provider will have these reviewed by a medical practitioner from the Welsh Gender Team at least once in twelve months. More frequent review should be provided according to clinical need, particularly after treatment initiation or following significant changes in regimen. The purpose of clinical monitoring during hormone use is to assess the degree of feminisation/masculinisation and the possible presence of adverse effects of medication.

The Welsh Gender Team will provide the GP with written advice when the individual is discharged. They will give advice on the individual's future need for endocrine and other pharmacological interventions, the anticipated duration of treatment (which may be life-long), the regimen recommended for on-going use, its intended effects and possible side-effects, long-term monitoring recommendations, and how they might access further information in the future.

Medication for masculinisation

- Testosterone preparations (includes testosterone injections and transdermal gels)
- Medications to suppress hypothalamic-pituitary-gonadal activity and menstruation

Medication for feminisation

- Estradiol preparations at doses necessary to achieve serum estradiol levels typical of a pre-menopausal woman, (includes oral estradiol, and transdermal estradiol as patches and gels, ethinylestradiol will not be recommended).
- Medications to suppress hypothalamic-pituitary-gonadal activity and endogenous testosterone release (includes gonadotropin releasing hormone analogues and 5-alpha reductase inhibitors).
- Ornithine decarboxylase inhibitors may be recommended as an adjunct to facial hair reduction interventions. An individual being significantly overweight increases their risk of adverse effects and complications related to treatment with estradiol and medications that block the effects of testosterone. There is strong evidence that

⁸ Advice for Doctors Treating Transgender Patients; General Medical Council; 2016

Welsh Health Specialised Services Committee (WHSSC) March 2020

an individual's risk of thrombosis increases as their Body Mass Index (BMI) increases. Consensus opinion amongst specialist medical practitioners is that individuals with a BMI of 40 or more should lose weight before using such hormone therapies. Whilst a BMI greater than 40 is not exclusion to this treatment, hormone therapy should only be recommended following an individualised discussion of risk, possible adverse effects and possible impacts on final treatment outcome.

There is strong evidence that an individual's risk of thrombosis is increased if they smoke, particularly if they are treated with estradiol. Consensus opinion amongst specialist medical practitioners is that individuals who smoke should desist whilst using hormone therapies, and particularly if they are treated with estradiol. Whilst smoking is not an exclusion to access to this treatment, hormone therapy should only be recommended following an individualised discussion of risk, possible adverse effects and possible impacts on final treatment outcome.

Annex viii: Quality, Patient Safety and Key Performance Indicators

Indicator	Indicator Type	Why measure this?
% of referrals received where the diagnosis after assessment is either Gender Dysphoria (as per DSM-V) or Gender Incongruence (as per ICD-11 when available)	Clinical	To inform future planning of services
% of patients receiving more than two assessment consultations before a complete management plan can be made	Clinical	To inform future planning of services
% of patients who do not enter into the treatment programme following two assessment consultations	Clinical	To inform future planning of services
Number of patients open to the service with polycythaemia following endocrine treatment (initiated by the service) needing venesection	Clinical	Patient Safety
Number of patients open to the service reporting DVT/PE following endocrine treatment (initiated by the service)	Clinical	Patient Safety
Number of patients open to the service with cardiovascular complications (e.g. MI or Stroke) post hormone treatment (initiated by the service)	Clinical	Patient Safety
Number of patients requesting chest reconstruction surgery who do not request hormone treatment pre- surgery	Clinical	To inform future planning of services
% of patients attend first appointment within 26 weeks of referral date	Performance	Our aim is for 100% of patients to be seen within 26 weeks of their referral date. This will help to reduce waiting times and align with NHS Wales standards.

% of referrals acknowledged in writing by the provider with the referrer and individual within 14 calendar days	Performance	We understand that the referral process can be an anxious time for patients. Our aim is for 100% of refers/patients to receive an acknowledgement within 14 calendar days.
% of patients receiving letters (treatment plans) within 28 calendar days	Performance	We understand the importance of providing prompt correspondence regarding treatment plans
Patient information provided (paper/online)	Quality	To ensure patients are informed about the service
Patients Feedback Questionnaire	Quality	To ensure patients have a means to feedback on their experience and the service can be continuously improved
There is a Clinical Lead for the service	Quality	To ensure the service is lead in line with the specification
There is a system of corporate governance, including a nominated senior manager who provides guidance, oversight and accountability	Quality	To ensure the service is lead in line with the specification
Patients receiving endocrine and pharmacological interventions are reviewed at least annually by a medical practitioner	Quality	To ensure patients are regularly reviewed. This will apply to all stages including the WGT, Local Gender Team and Enhanced Service.
There is an agreed patient pathway endorsed by the AWGIPG in line with the specification	Quality	To ensure the pathway remains in line with the policy and recommendations of the AWGIPG
There is an agreed transfer between GIDS and the Adult Gender Identity Service	Quality	To ensure the transfer of care of patients from adolescence to adulthood services
The team participates in clinical audit activity	Quality	To ensure the service is being delivered in line with required standards and identify areas for improvement
There is a complaints/concerns procedure in place	Quality	To ensure patients have a means to report complaints/concerns

Annex ix: Abbreviations and Glossary

Abbreviations

AWGIPG	All Wales Gender Identity Partnership Group
WGT	Welsh Gender Team
LGT	Local Gender Team
IPFR	Individual Patient Funding Request
SMC	Scottish Medicines Consortium
WHSSC	Welsh Health Specialised Services
MDT	Multi-disciplinary Team
DES	Direct Enhanced Service
GIDS	Gender Identity Development Service
EQiA	Equality Impact Assessment

Glossary

Individual Patient Funding Request (IPFR)

An IPFR is a request to Welsh Health Specialised Services Committee (WHSSC) to fund an intervention, device or treatment for patients that fall outside the range of services and treatments routinely provided across Wales.

Welsh Health Specialised Services Committee (WHSSC)

WHSSC is a joint committee of the seven local health boards in Wales. The purpose of WHSSC is to ensure that the population of Wales has fair and equitable access to the full range of Specialised Services and Tertiary Services. WHSSC ensures that specialised services are commissioned from providers that have the appropriate experience and expertise. They ensure that these providers are able to provide a robust, high quality and sustainable services, which are safe for patients and are cost effective for NHS Wales.