Specialised Gender Identity Services Project

Final Report

June 2012

Chair: Mr Daniel Phillips, Director of Planning, WHSSC

Contents

Acknowledgements 3

Executive Summary 4

Introduction 6

Specialised Gender Identity Services Project 6
Methodology 7
Meeting our Public Sector Equality Duties 9
Health Needs Assessment 11

Epidemiology 11
Services in Wales for patients with Gender Dysphoria 14

Models for Specialised Assessment Services 15

Quality and Key Performance Indicators 19

Designation Criteria 21

Key Findings 22

Recommendations 23

References 25

Appendix A – Service Specification 26

Appendix B – Quality Indicators 49

Appendix C – Key Performance Indicators 86

Appendix D – Criteria for Preferred Providers 88

Acknowledgements

The Project Management Group Chair would like to thank all who have contributed to this report. They include the members of the Project Management Group, the Chair and members of the Stakeholder Reference Group, and in particular the Chairs of the two workstreams. Each of the workstream chairs also acknowledges the support provided by service users, clinicians and managerial staff in the development of key documents.

Executive Summary

The Specialised Gender Identity Services Project formally commenced on the 1st September 2011, with the aim of improving the planning and securing of specialised mental health services for patients with Gender Dysphoria and gender confirmation surgical services.

The project comprised of two working groups and a stakeholder reference group, critical to the success of the project has been the involvement of service users, clinicians, the NHS Centre for Equality and Human Rights, and planners.

The key principles of Equality Impact Assessment have been embedded and considered at each stage of the planning process. The key findings have revealed significant gaps in the provision of services to support patients with Gender Dysphoria, as well as a number of equality and human rights themes which need to be considered and addressed by the wider healthcare community. The Equality and Human Rights Commission will be looking for evidence in December 2012 to assess the impact of the Equality Act 2010, and the experiences of the Transgender community will be of particular importance as they are a protected characteristic under the Act.

The working groups have developed a proposed model for service provision, together with care pathways, quality indicators, key performance indicators and criteria for identifying service providers for assessment and gender confirmation surgery.

The report sets out six recommendations for addressing the issues identified, that are considered to be key to improving the planning and provision of services for patients with Gender Dysphoria:

1. Gaps in provision of locally delivered services should be addressed as soon as possible.

2. Specialised assessment – further work should be undertaken to develop proposals for providing regional specialised assessment services within existing resources.

3. Gender confirmation surgery – it is recommended that WHSSC continues to commission the more highly specialised surgical procedures from recognised English centres.

4. Wider consultation should be undertaken with service users and providers to consider whether the proposed Quality Indicators and Key Performance Indicators are fit for purpose of:
    a. Auditing existing assessment and surgical services
    b. Informing the development of proposals for a regional assessment service
    c. Informing the designation of surgical services for Welsh patients.
    d. Informing and improving the equality evidence base including patient experience to ensure that the new pathway complies with the Statutory Equality Duties and promotes fairness.

5. A partnership board should be established to support the development of future NHS Wales strategy for gender identity services and to review the audit of assessment and surgical services against the quality indicators and key performance indicators.

6. The existing planning policy should be amended to incorporate the proposed care pathways developed by the service model group, and should be further reviewed once the work on the specialised assessment services has been concluded and the Joint Committee have reached a decision of the future model of provision.

Introduction

The Welsh Health Specialised Services Committee is responsible for planning:

- Specialist assessment and monitoring of real life experience
- Gender confirmation surgery

Following an internal review of the processes for managing referrals to the specialised gender identity assessment services in London, a number of actions were agreed by the Joint Committee in order to strengthen and improve the process:

1. The development of local gatekeepers to manage referrals into specialised assessment services.
2. A review of the service pathway and model for provision of specialised assessment services, including the role of local services.

Specialised Gender Identity Services Project

Following a series of meetings with service users and representatives from third sector organisations, the project was initiated on the 1st September 2011. The involvement and engagement of service users and third sector organisations, was an essential element to ensuring that the service was designed around their needs, and balanced against the wider constraints of the health service in Wales. The overall aim of the project was to improve the planning and securing of specialised mental health services for patients with Gender Dysphoria and gender confirmation surgical services.

The following objectives were identified.

i. Revise the current policy to reflect the revised planning arrangements within NHS Wales, including an equality impact assessment and a review of existing evidence including performance indicators and outcome measures and monitoring of equality data. This will include clarifying the interfaces between the Gender Dysphoria policy and other WHSSC policies. The project will address the issues relating to the patient pathway, and will not review the access criteria.

ii. Revise the referral pathway and to advise on the definitive model for providing Gender Dysphoria assessment and review for patients resident in Wales – there are three options for this
    a. Procure assessment services from an established English NHS service, under this option all referrals would be considered by the centre and patients would travel to the centre for assessment and follow up.
    b. Develop a peripatetic service in partnership with a specialised gender identity centre - under this option all referrals would be considered by the centre and the patients would travel to clinics hosted within Wales.
    c. Develop a Welsh specialised assessment service, delivered through either a central, regional, local or network service model.

iii. Identify criteria for selecting preferred providers for specialised assessment and gender reassignment surgery – this would be undertaken with key stakeholders including clinicians, service users, and the third sector.

iv. Clarify the role of services within Wales – this could be informed by a survey of services within Wales.

Methodology

In order to facilitate the delivery of the project within the agreed timescales, the role of the Project Board was taken on by the WHSSC management team. A Project Management Group, chaired by the WHSSC Director of Planning, was established to lead and manage the project, and coordinate the work of the two working groups:

Service Model Working Group – This group was chaired by Martin Riley, Principal Psychological Therapist, Betsi Cadwaldr University Health Board. The group was responsible for developing the following documents:

- ***Directory of service within Wales –*** The directory identifies services within Wales for patients with gender dysphoria.
- ***Service Specification and Model –*** The service specification is intended to replace the current commissioning policy for Gender Dysphoria, and will incorporate the access criteria and referral pathway. The service model will specify how patients in Wales access specialised

assessment services. The development of the service model was informed through an option appraisal of potential models for service delivery within the resources available to WHSSC.

Service Quality Working Group - This group was chaired by Dr Kenny Midence, Clinical Psychologist, Betsi Cadwaldr University Health Board. The group was responsible for developing the following documents:

- ***Quality indicators and Outcome measures*** –for assessment and specialised surgical services
- ***Key performance indicators***–for assessment and specialised surgical services.
- ***Criteria for preferred provider*** – to inform the identification of preferred providers for specialised assessment and surgical services for patients resident in Wales.

Both groups had service user representatives, and had further support from Voirrey Manson, Senior Equality Manager, NHS Centre for Equality and Human Rights.

In addition to the two working groups, a Stakeholder Reference Group was established. This group was chaired by Dr Michelle Northcott, a service user, and was responsible for ensuring that key stakeholders are kept up to date on the progress of the project and the development of the key products, and to provide a forum for discussion and feedback. The group was responsible for

- Providing a forum for discussion and feedback through the Project Management Team and the Service Quality and Service Model Working Groups;
- ensuring key stakeholders are kept up to date on the progress of the project and the development of the key products;
- ensuring that the Service Quality and Service Model Working Groups adopt an Equality Impact Assessment approach for the development of their products.

The chairs of the stakeholder reference group and the chairs of the two working groups were members of the Project Management Group.

Meeting Public Sector Equality Duties

A primary consideration was whether this work was relevant to equality and human rights. There is sufficient information, anecdotal evidence and published reports which would support the view that this is highly relevant.

It is recognised that some individuals and groups continue to face discrimination in the way in which public services are planned and delivered, ***Not just another statistic*** (EHRC Wales, 2010), places the Transgender Community firmly in this category.

The Equality Act 2010 has expanded the range of protected groups. Protection is now given on the grounds of:

- Ethnicity
- Gender
- Transgender status
- Disability
- Religion, belief /non-belief
- Sexual orientation
- Age
- Pregnancy and maternity

The Act places a positive duty on public authorities to promote equality for all the protected groups and requires Welsh public bodies to demonstrate how they pay "due regard" to equality when carrying out their functions and activities.

In the context of this work, the commissioning and procurement of services is viewed as a public function. WHSCC is required to pay due regard to the promotion of equality when planning and delivering a service, including the contract criteria, the conditions of monitoring the performance of the contractor and the user experience.

The project management group agreed to use an Equality Impact Assessment (EQIA) framework to anticipate the consequences of decisions on relevant groups. The intention was to make sure that as far as possible, negative consequences were eliminated or minimised, and opportunities for promoting equality and human rights were maximised.

The framework adopted was based on the following principles that underpin the Public Sector Equality Duties:

- Evidence based
- Transparent
- Engagement
- Leadership

This approach has enabled the working groups to design what they feel and believe as service users, planners and clinicians to be a flexible service responsive to the needs and circumstances of individuals undergoing a very personal and unique journey. The EQIA framework, based on the premise of dialogue and engagement, has offered an important opportunity to build respect for the individual, and the protection of human dignity at the heart of policy design.

By engaging service users at the very beginning of service design and listening to their experiences, it became clear that discriminatory attitudes and behaviours are apparent across the health service. The EQIA framework has allowed conflicts and differences to be aired. The decision making has been transparent and has been shaped by those directly affected by the policy. It has built a platform for partnership working that fosters good relations, and has in some way removed the underlying expectation of discrimination that the Transgendered community has long felt in their relationship with health services.

During the course of this work it was evident that there were a number of wider, potentially discriminatory issues, outside of the scope of WHSSC, which need to be addressed. It is important that these are recognised and addressed by the Welsh Government Health and Social Services Directorate, Health Boards, Public Health Wales and Regulating Bodies.

The framework of EQIA has enabled the working groups to think carefully about the likely impact of their recommendations and ensured that they were based on available evidence. It is recognised that there are gaps in our evidence and data and this is highlighted in the recommendations.

Health Needs Assessment

A Health Needs Assessment was undertaken to support the work of the working groups. Principal references were identified through several methods including literature search by Public Health Wales and additional search by Dr Geoffrey Carroll, Medical Director, WHSSC, through PubMed. Professor Kevan Wylie also provided further advice concerning the reference from Belgium.

Epidemiology

The Gender Identity Research and Education Society (GIRES) report (2009) provides substantial information on prevalence, incidence, growth and geographic distribution.

Incidence: In 2007, incidence was estimated to be 3.0 per 100,000 people aged over 15 in the UK, that is 1,500 people presenting for treatment of gender dysphoria. This would correspond to 90 new people presenting for treatment in Wales per year.

In 2007, the growth rate in the number of people who had presented was estimated as 15 %.

Prevalence: The GIRES report estimated that, in 2007, the prevalence of people who had sought medical care for gender variance was 20 per 100,000, i.e. 10,000 people, of whom 6,000 had undergone transition.

80% were assigned as boys at birth (now trans women) and 20% as girls (now trans men). On the basis of 200 per million population, Wales would have 600 people who have sought care with 360 having "undergone transition".

In 2010, HM Revenue and Customs (HMRC) had 7,471 gender variant people who had changed their records, of whom 2,436 had a gender recognition certificate (GRC). The latter figure accords closely with the 2,531 GRCs that the Gender Recognition Panel had issued by that date.

This would represent a prevalence estimate of 370 Welsh gender variant people (in contact with HMRC) of whom 125 may have a gender recognition certificate.

Based on the Scottish data relating to 1998, it was estimated by GIRES that a further 5,000 people were in the medical system but not yet transitioned. This translates as an additional 250 for Wales on top of the 370 gender variant

people: again this figure of 620 is close to the figure of 600 for Wales based on prevalence estimate of 20 per 100,000.

The growth trend from 1998 is reported as 11 % per annum. Hence, the number who have presented would double every 6 ½ years.

A report from De Cuypere et al on the Prevalence and demography of transsexualism in Belgium (2007) includes a table summarising other prevalence studies. Table 1 below is an adapted version where numbers per million population have been calculated for male to female and female to male transsexuals. The results of the Belgium study have been included in the table.

Table 1: Review prevalence-studies

Authors	Country	Year	MF	PMP	FM	PMP	Male/Female
Pauly [10]	VS	1968	1:100,000	10	1:400,000	2.5	4:1
Walinder [15]	Sweden	1968	1:37,000	27.03	1:103,000	9.71	2.8:1
Hoenig and Kenna [8]	England and Wales	1973	1:34,000	29.41	1:108,000	9.26	3.2:1
Ross et al. [12]	Australia	1981	1:24,000	41.67	1:150,000	6.67	6.1:1
O'Gorman [9]	Northern-Ireland	1982	1:35,000	28.57	1:100,000	10	2.8:1
Eklund et al. [5]	The Netherlands	1980	1:45,000	22.23	1:200,000	5	4.4:1
		1986	1:18,000	55.56	1:54,000	18.52	3:1
Tsoi [13]	Singapore	1988	1:2900	344.83	1:8300	120.48	3:1
Bakker et al. [1]	The Netherlands	1993	1:11,900	84.03	1:30,400	32.89	2.5:1
Weitze and Osburg [16]	Germany	1996	1:42,000	23.89	1:104,000	9.62	2.5:1
Wilson et al. [17]	Scotland	1999	1:12,700	78.74	1:52,000	19.23	4:1
De Cuypere	Belgium	2007	1:12,900	79	1:33,800	29	2.43:1

References are listed in the paper by Cuypere G. D. at al. European Psychiatry 22 (2007) 137-141

Olyslager and Conway (2007) have critiqued the prevalence studies in Table 1 and have attempted to challenge the basis of calculation of prevalence of life long conditions taking account of population, demographics as well as the difference between diagnosis of the condition versus treatment including

surgery. The mathematical methods challenge but do not substantiate final conclusions on the prevalence data.

Horton (2008) examined the incident and prevalence of Sex Reassignment Surgery (SRS) for US residents. Estimates of incidence and prevalence of GID, mental health therapy, hormone treatments and Female to Male surgery are derived.

The GIRES report, Horton and also Olsson and Moller (2003), all identify the classic epidemiological problem which is that presentation of the condition has historically been poorly understood with barriers to access not only to psychological support but also to hormone management and in particular to definitive surgery.

Olsson and Moller examined the defined visible identification of patients with GD through applications for SRS in Sweden over 30 years including age at application and Gender ratio.

Combs, Turner and Whittle, (2008) completed a mapping project but provide no analysis specific to incidence and prevalence: There is indirect information concerning legal recognition applications and GID clinic capacity, attendances and annual numbers.

Initial analysis centres on a prevalence figure of 600 people in Wales (2008) with GD but the pathway of care and access to specialised GD services reduces the number above the level of primary care.

Services in Wales for patients with Gender Dysphoria

As outlined in the introduction WHSSC is responsible for specialised assessment services and gender confirmation surgery. At present WHSSC commissions this activity from a small number of providers in England. However, there are a range of support services which are provided at a primary and secondary care level which are intrinsic to the gender dysphoria pathway, e.g. Endocrinology, Speech and Language Therapy. These services do not fall within the responsibility of WHSSC, and are provided and commissioned by Local Health Boards.

The Service Model working group sent a questionnaire to each Local Health Board to seek clarification on the range of services provided to support patients with gender dysphoria. The responses were used to develop a directory of services (Appendix A).

The directory reveals that service provision is inconsistent throughout Wales. There are assessment services in Aneurin Bevan and Betsi Cadwaldr University Health, however neither of these services are commissioned by the WHSSC, and therefore they are only available to patients resident in those areas. Patients in these areas are also able to access local endocrinology support, which is critical for the management of hormone therapy, and in North Wales, patients are able to access speech and language support.

As there are no services in the remainder of Wales, patients in these areas have to access specialised assessment services and endocrinology support from the Gender Identity Clinic at West London Mental Health NHS Trust. This service is commissioned by WHSSC

This current situation is highly inequitable, and needs to be addressed in order to minimise the need for Welsh patients to have to travel out of area. Particularly for those services, such as endocrinology and speech and language, which could be provided locally.

Whilst it is accepted that the specialised assessment services in London have significant experience and expertise in the provision of specialised assessment, the fact that two of the Local Health Boards have been able to develop their own assessment services would support the view that it is possible to develop local assessment services. This covered in greater detail in the next section.

Models for Specialised Assessment Services

The Service Model working group undertook an option appraisal to identify the most appropriate model for delivering specialised assessment services for Welsh patients. As highlighted in the preceding section, some work has already been undertaken in this area as two of the seven Local Health Boards have already established specialised assessment services.

In developing options for the provision of this service, the group first defined the purpose of the service as being to provide an equitable multidisciplinary service across Wales to meet the diverse needs of people with Gender Dysphoria:

"The service will consist of assessment and diagnosis of gender dysphoria, support, guidance and follow up during transition to the person's desired gender and where appropriate preparation and application for funding for Gender Reassignment Surgery (GRS) (where indicated) and in the post-operative period.

The service will assist the patient in an exploration of available options with a specialist clinician. Although GRS is a possible outcome, the patient should be assisted to consider alternative possibilities for dealing with their dysphoria. This may include psychological support to deal with the social ramifications of transitioning and undertaking confirmatory procedures including speech and language therapy, endocrine (hormone) treatments and a period of a real life experience of the desired gender role.

When patients require endocrine therapy and reconstructive surgeries to facilitate living in the opposite gender, or other procedures (such as donor site hair removal in preparation for later reconstructive surgeries) the service will provide or facilitate this in accordance with the criteria set out below

The service aims to ensure that patients leaving this service, with or without the facilitation of surgical intervention, will have a stable gender identity; accepting and confident of the decisions they have been supported to make with regards to their pathway and transition."

The following options were shortlisted as appropriate for the future delivery of gender identity specialised assessment services in Wales:

1. Assessment services provided by an established English NHS service. Under this option all referrals would be considered by the centre and patients would travel to the centre for assessment and follow up.

2. Peripatetic service provided by an established English NHS service. Under this option all referrals would be considered by the centre and the patients would travel to clinics hosted within Wales.

3. Develop a Welsh specialised assessment service. There are three potential sub options:
   - Central
   - Regional
   - Local

Results

The option which scored the highest was the provision of a regional service, with the current service model receiving the lowest score.

Under this option it is proposed that two services would be developed in Wales to cover the whole population, one hosted by BCUHB and the other hosted by a southern Health Board. This model would have the following benefits:

- A Welsh based service built upon existing expertise within Wales
- Ensures that there is equitable access to services across Wales
- Improved lines of communication between General Practitioner and assessment clinic via a simple single pathway.
- Regional multidisciplinary service providing all care up to and including surgical assessment.
- Patients would be seen in Wales and the burden of travel times and costs would be minimised.
- Easier to address local needs by process of networking with colleagues from other disciplines.

This model also would be support the delivery of the care pathways as specified below and the achievement of the Quality Indicators and Key Performance Indicators as set out in the next sections of this report.

Care Pathway

The group also developed and integrated care pathway which reflects each of the various phases in transition:

1. Assessment and Diagnostic Phase

Following assessment which will include a detailed history, medical examination, psychological assessment and if necessary, a period of exploratory therapy, a diagnosis will be made in accordance with either ICD-10 or DSM IV. Where the diagnosis is uncertain a referral may be made to an independent clinician for conformation of the diagnosis. Following diagnosis, a plan for transition including a minimum period of least 12 months living in full time in the gender role with which the individual identifies (the Real Life Experience) will be discussed and the GP will be informed of the details of the plan.

2. Transition and Confirmation Phase

When the patient is ready he/she commences transition which includes regular supportive assessment and monitoring at least every three months. Contact and support with the independent sector is strongly encouraged and information will be provided to assist this. Referral to a Consultant Endocrinologist will be made at an early stage in the transition process to assist adjustment to the patients' desired presentation of gender. Where clinically appropriate, referral for additional confirmatory procedures including Speech and Language Services, hair removal and chest reconstruction will be made during the period of the Real Life Experience.

3. Gender Reassignment Surgery Approval and Preparation Phase

At the end of the transition period which will include a minimum of 12 months living full time in the person's desired gender the option of Gender Reassignment Surgery (GRS) will be discussed with the patient. Where surgery is requested and indicated then application will be made by the GD service to WHSSC for funding for the surgery. Following approval of funding, a referral to a surgical provider for a independent clinical assessment of the patient's readiness and eligibility for GRS will be made, including full review of the different surgical options available.

Where GRS is not indicated or requested, the GD service will continue to provide support and follow up until the patient is ready for discharge (usually after 6-12 months).

4. Gender Reassignment Surgery and Post operative follow up phase.

The GD service will continue to offer psychological support to the patient (alongside relevant transgender voluntary sector organisations where the patient has accessed these) during the process of surgical assessment and following surgery. The GD service will liaise with the GP and the surgical providers and share care in the follow up process after surgery for a period of 6 to 12 months. Further appointments in the GD service will be offered to assist in psychological adjustment until discharge from the service is indicated.

Quality and Key Performance Indicators

The Service Quality working group reviewed the current evidence available on services for patients with Gender Dysphoria, and developed Quality Indicators and Key Performance Indicators for services providing care to Welsh patients.

Quality Indicators

The Quality Indicators were developed to provide guidance to Health Boards, NHS Trusts and other healthcare organisations that provide Specialised Gender Dysphoria services on the standards of care and service delivery. They are intended to support planners in assessing the achievement of specified Quality Indicators and promote consistency between providers.

The indicators are set out under three broad themes:

1. Information and Communication
2. Providing a quality service
    a. Assessment
    b. Transition and Confirmation
    c. Surgery
    d. Care and support
3. Discharge and follow up

Each indicator is as explicit as possible to ensure that interpretation is clear. **Level A** indicates the highest priority that providers should give to achieving compliance. **Levels B & C** will be set to allow time for improvement. Specified within each indicator are the measures of compliance that are necessary for assessment.

Key Performance Indicators

The Key Performance Indicators were developed to provide key performance measures to enable planners to measure the performance of healthcare organisations that provide Specialised Gender Dysphoria services to Welsh patients.

The group identified five KPIs, with measurable criteria:

- All patients have an agreed clearly defined treatment plan
- All patients' treatment plans are reviewed.
- All patients' treatment plans are reviewed.

- Prompt appointment with other specialist services
- Patients will have follow-up assessment and postoperative care.

Designation Criteria

The designation criteria (Appendix E) were developed to support the planners of services in identifying appropriate providers of specialised services for Welsh patients with Gender Dysphoria, including assessment and surgery.

Key Findings

The Project has revealed significant gaps in the provision of services to support patients with Gender Dysphoria. In particular Welsh patients living outside Betsi Cadwaldr University Health Board and Aneurin Bevan Health Board do not have access to local assessment services, or other support services such as endocrinology and speech and language therapy. As a consequence such patients are required to travel out of area to access services provided by the West London Mental Health Trust.

There are a number of emerging equality and human rights themes which must be considered and addressed by the wider healthcare community:

- The role of Primary healthcare in relation to referral care pathways, knowledge of Gender Dysphoria, attitudes towards the Transgender community and improving the experience of service users.
- The needs of people detained under the Mental Health Act; offenders and those with a personality disorder or learning disabilities that might require treatment.
- Discussions with service users revealed a lack of clarity around the level and appropriateness of service provision and support for people under 18.
- The lack of current up to date information and guidance for Health Boards on Gender Dysphoria, the patient experience and the associated equality and human rights issues.
- There is a gap in data around the health needs and experiences of the Transgendered community.
- Monitoring of quality, patient experience must be embedded into NHS Wales/Welsh Government mechanisms for example the Annual Quality Framework.

Recommendations

1. Gaps in provision of locally delivered services should be addressed as soon as possible. In those areas which do not have endocrinology services, arrangements should be put in place to enable patients to access services provided by an adjacent local health board.

2. Specialised assessment – further work should be undertaken over the next six months in partnership with Local Health Boards and WHSSC to develop proposals for providing regional specialised assessment services within existing resources, including the resource mapping of existing local health board funded provision and the out of area services currently commissioned through WHSSC.

   It is recommended that this work is led by Betsi Cadwaladr University Health Board, as the Health Board already has significant managerial and clinical experience in the development and delivery of these services.

3. Gender confirmation surgery – currently there is not a sufficient critical mass to support the development of the full range of gender confirmation surgical services within Wales. Whilst a small number of procedures, e.g. mastectomy, hysterectomy, can be undertaken locally, it is recommended that WHSSC continues to commission the more highly specialised surgical procedures from recognised English centres.

4. Wider consultation should be undertaken with service users and providers to consider whether the proposed Quality Indicators and Key Performance Indicators are fit for purpose of:
   a. Auditing existing assessment and surgical services
   b. Informing the development of proposals for a regional assessment service
   c. Informing the designation of surgical services for Welsh patients.
   d. Informing and improving the equality evidence base

5. A partnership board should be established to support the development of future NHS Wales strategy for gender identity services and to review the audit of assessment and surgical services against the quality indicators and key performance indicators. The scope of the partnership

board should extend beyond the services currently commissioned by WHSSC, and would include primary and secondary care services provided and commissioned by Local Health Boards. The board should have clear terms of reference which ensure that equality and human rights issues and legislative requirements are taken into account for all stages of policy development and review. It is envisaged that the board would be independently chaired, and would be supported by the NHS Centre for Equality and Human Rights.

6. The existing planning policy should be amended to incorporate the proposed care pathways developed by the service model group, and should be further reviewed once the work on the specialised assessment services has been concluded and the Joint Committee have reached a decision of the future model of provision.

References

Reed B., Rhodes S., Schofield P., Wylie K. (2009) Gender Variance in the UK: Prevalence, Incidence, Growth and Geographic Distribution.

Combs R., Turner L., Whittle S. (2008) The 'Gender Identity Services in England' Mapping Project Report. *Prepared for the Department of Health.*

Olyslager F., Conway L. (2007) On the Calculation of the Prevalence of Transsexualism. *International Journal of Transgenderism* .

Horton, M. A. (2008) The Prevalence of SRS Among US Resident. *Out & Equal Workplace Summit.*

Stig-Eric Olsson, and Anders R. M¨oller (2003) On the Incidence and Sex Ratio of Transsexualism in Sweden, 1972–2002. *Archives of Sexual Behavior, 32, 4: 381–386.*

WALINDER J. (1971)Incidence and Sex Ratio of Transsexualism in Sweden *British Journal of Psychiatry. 119: 195-6.*

Equality and Human Rights Commission (2010) Not just another statistic http://www.equalityhumanrights.com/uploaded_files/Wales/not_just_another_statistic_email.pdf

Appendix A – Service Specification

Service Specification and Option Appraisal for Gender Dysphoria Services for Welsh residents

Aim

To present a service specification and an associated care pathway for Gender Dysphoria Services in Wales. The paper also presents Option Appraisal process by which the type of service model was chosen

The purpose of this paper is to

- Detail the specification for Gender Dysphoria Services (GDS) for adults (aged over 16 years) resident in Wales
- Set out the circumstances under which patients will be able to access specialised gender dysphoria services
- Clarify the referral process
- Describe the service model through which services will be provided
- Define the referral criteria that patients must meet in order to receive services

Context

The WPATH guidelines [1]state:

> 'the expression of ... identities that are not stereotypically associated with one's assigned sex at birth, is a common and culturally diverse human phenomenon that should not be judge as inherently pathological or negative'

In terms of diagnostic criteria, WPATH suggests

- Strong and persistent distress with physical sex characteristics, or ascribed social gender role that is incongruent with persistent gender identity
- The distress is clinically significant or causes impairment in social, occupational or other important areas of functioning, and this distress or impairment is not solely due to external prejudice or discrimination

The process of designating providers must be compliant with the Equality Act 2010 and the Human Rights Act 1998. Those ultimately designated as providers will also be required to be compliant with this legislation, and therefore must embody the principles of eliminating discrimination, respecting patient autonomy and ensuring the dignity of the service user.

---

[1] World Professional Association for Transgender Health (2011) Standards of Care for the Health of Transsexual, Transgender and Gender Nonconforming People (7th Version) www.wpath.org . Accessed 14.02.12

.
In Wales people with GD have never had a Principality wide service and only in North Wales has there ever been a local service which stemmed from service provided by a surgeon undertaking genital reconstructive surgery. Consequently people needing a GD service have traditionally been referred to an English provider - West London Mental Health Trust (Charing Cross Hospital, London) although recognition of the diagnosis and funding has often been inconsistent.

Gender Identity issues can manifest in different ways and with different levels of severity. Therefore the therapeutic goal of the service is to work in partnership with the patient to facilitate a clear and realistic understanding of their feelings and wishes. Gender Dysphoria (GD) is a condition in which there is a psychological experience of oneself as male or female, which is incongruent with the external sexual characteristics of the body. Gender identity issues can manifest in different ways and with different levels of severity. Therefore the therapeutic goal of GD services is to work in partnership with the patient to facilitate a clear and realistic understanding of their feelings and wishes.

GD services will facilitate access to specialist mental health provision which initiates appropriate psychiatric and other non-surgical) assessment and treatment for all patients aged 16 years and over who have been referred with a provisional diagnosis of gender dysphoria. Treatments include: specialist assessment and diagnosis, psychological therapies, speech and language therapies, endocrinology (hormone treatment) , hair removal, referral for surgery and psychological aftercare and follow up. The GD service supports any person requiring assessment or treatment for gender identity issues.

Individuals who need help to optimise mental health and to make the transition of status will need intervention from professionals with knowledge, training and experience in the treatment of gender dysphoria. In some cases, gender re-assignment surgery may also be appropriate. This document seeks to specify commissioners' requirements of non-surgical gender dysphoria services. The requirements for gender re-assignment surgery services will be addressed in a separate specification.

The provision of Gender Reassignment Surgery (GRS) will for the time being continue to be provided outside Wales and as such will not be discussed within this Service Specification.

Prevalence of Gender Variance

Estimates of the prevalence of gender dysphoria vary. Many transgendered people do not reveal their gender variance to their GPs, or seek medical treatment, and so their trans status goes unrecorded. An unknown but possibly significant proportion of transgender people obtain treatment outside the specialised NHS and private clinics, self-medicating with hormones bought via the internet or having surgery outside the UK.

In its published guidance2 The Department of Health (DoH) suggest that population estimates for transsexual people based on published research in The Netherlands and Scotland suggest a prevalence ratio of around 1 in 11,500 of the general population which provides a crude means of estimating the likely numbers of pre- and post-operative transsexual people within the working population of NHS organisations. They also cite the Charing Cross Gender Identity Clinic reports that it receives around 500 new referrals every year and has 2,000 patients on its books at any point in time. Ministers have also confirmed to Parliament that 99 NHS gender reassignment surgical procedures were carried out in the last year for which statistics are available.

The DoH report suggests that the 500 per annum figure for gender clinic referrals and the level of 25 gender recognition applications per month are both indicative of the numbers who are likely to present for and complete NHS care in England and Wales each year. *"In practice it means that the average PCT is likely to see few new cases annually. In turn this means that timely and clinically appropriate provision for the needs of such patients is never going to have a significant impact on budgeting. Savings are far more likely to be found through creative approaches to commissioning – especially with a view to making greater use of local resources to cover care needs. Remember that*

[2] Department of Health (2008): Trans: A practical guide for the NHS: http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/documents/digitalasset/dh_089939.pdf. Accessed 14 Feb 2012

innovation of this kind is positively encouraged as part of World Class Commissioning (using strategies to deal with the market and meet demand)".

In 2009, GIRES published a report funded by the Home Office[3] which estimated that in 2007, the prevalence of people who had sought medical care for gender variance was 20 per 100,000, i.e. 10,000 people, of whom 6,000 had undergone transition. 80% were assigned as male at birth (trans women) and 20% as female (trans men). These figures are at odds with the established incidence which was estimated to be 3.0 per 100,000 people aged over 15 in the UK; a figure which suggests that approximately 1,500 people would present for treatment of gender dysphoria.

Data provided to GIRES by HMRC confirm this upward trend. As at the end of March 2010, HMRC had 7,471 gender variant people who had changed their records, of whom 2,436 had a gender recognition certificate (GRC). The latter figure accords closely with the 2,531 GRCs that the Gender Recognition Panel had issued by that date. Based on the Scottish data relating to 1998, and frequently cited by NHS commissioners, it can be estimated that a further 5,000 people were in the medical system but not yet transitioned. Hence, the number who have presented for treatment can now be estimated to be 12,500. The growth trend from 1998 is 11 % per annum. Hence, the number who have presented doubles every 6 ½ years.

Attempts to estimate the prevalence of gender dysphoria in Wales have been undertaken by Dr Julie Baker of Transgender Wales who has been maintaining a personal register of post surgery transsexual patients obtained anecdotally by personal contact and probably understated because they do not include referrals within the private sector or abroad. These figures, re-examined by Welsh county by Dr Michelle Northcott suggest there may be some a further 670 transgender patients awaiting diagnosis or surgery (2008) and contain an increasing proportion of patients who are expected to be younger - during secondary education - than historic average age of transition. These estimates do not take account of patients who are pursuing treatment in the private sector or outside of Wales. Ms Jenny Anne Bishop of the transgender organisation Unique comments on this saying that if "the Population of Wales is 3,006,400 (Welsh Government Figure for Mid 2011) 4.83% of UK Population) thus it is estimated that there are 31,300 Trans people in Wales 6,260 of whom have or will Transition." Ms Bishop goes on to the say that "the figures presented showed that the number of people presenting to the

---

[3] Reed B, Rhodes S, Schofield P, Wylie K. (2009) Gender in the UK: Prevalence, incidence, growth and Geographic Distribution. Gender Identity Research and Education Society, UK.

NHS for Gender Variance treatment is increasing by 12% per annum, so that the number of new requests for treatment doubles every 4-5 years." She also states that anther older survey estimated that 1 in 10 men are gender variant in some away, which would give us a UK Trans population of at least 2.5 million, of whom approx 10% are Transsexual or Latent Transsexual people. This gives us an estimate of 250,000 transsexual people in the UK, 4.83% of whom are likely to live in Wales = 12,075 which is twice the number the GIRES survey would suggest. She adds that *"Because the numbers are almost impossible to accurately collect, we can only suggest a "Scale" of the numbers requiring treatment in Wales. This is approximately 10 x the estimate in the discussion document of 671 (0.022% of the Welsh population) for the whole of Wales, and I feel the 6,000 figure gives a much better estimate of the Scale of people likely to seek some form of treatment. I strongly recommend we use the estimate of 6,000 as the minimum figure for number of gender variant people and plan the TG care pathway appropriately"*.

An update from GIRES in 2011[4] suggests that the incidence of transitioning transsexual people to be 0.2% of the population (6,012 in Wales). Gires also makes the point that commissioners and providers of health care and other services should reconsider the basis upon which they are estimating the likely need to treat people with gender dysphoria. They state that "The only safe assumption is that the present growth rate in the incidence of new people requiring medical and other care is likely to continue, which is usually the basis on which service provision is planned. At a growth rate of 15% per annum compound, the number of new cases will approximately double every 5 years.

Access / Eligibility Criteria

The diagnosis of Gender Dysphoria in an adult requires four criteria to be met:

1. The desire to live and be accepted as a member of the opposite sex, usually accompanied by the wish to make his or her body as congruent as possible with the preferred sex through surgery and hormone treatment; and

[4] GIRES (2011) The Number of Gender Variant People in the UK – an update http://www.gires.org.uk/Prevalence2011.pdf Accessed 14/02/12

2. The transsexual identity has been present persistently for at least two years; and
3. The disorder is not a symptom of another mental disorder or chromosomal abnormality; and
4. The disorder causes clinically significant distress or impairment in social, occupational or other important areas of functioning

The service will be provided for individuals with a preliminary diagnosis of Gender Dysphoria usually (though not exclusively) made by the person's General Practitioner (GP).

The person must be resident in Wales.

The service is for patients over the age of 16. Young people under 16 will be referred to a CAMHS service in the first instance. The provision of services under the age of 16 is outside the scope of this service specification although it should be noted that the Gender Identity Unit at the Tavistock and Portman NHS Trust provides a highly specialised service for young people).

<u>Purpose of Service</u>

The purpose of the service is to provide an equitable multidisciplinary service across Wales to meet the diverse needs of people with Gender Dysphoria. The service will consist of assessment and diagnosis of gender dysphoria, support, guidance and follow up during transition to the person's desired gender and where appropriate preparation and application for funding for gender reassignment surgery (where indicated) and in the post-operative period.

The service will assist the patient in an exploration of available options with a specialist clinician. Although GRS is a possible outcome, the patient should be assisted to consider alternative possibilities for dealing with their dysphoria. Whether or not GRS is agreed upon the patient will be offered psychological support to deal with the social ramifications of transitioning and undertaking confirmatory procedures including speech and language therapy, endocrine (hormone) treatments and a period of a real life experience of the desired gender role.

When patients require endocrine therapy and reconstructive surgeries to facilitate living in the opposite gender, or other procedures (such as donor site

hair removal in preparation for later reconstructive surgeries) the service will provide or facilitate this in accordance with the criteria set out below

The service aims to ensure that patients leaving this service, whether with or without the facilitation of surgical intervention, will have a stable gender identity; accepting and confident of the decisions they have been supported to make with regards to their pathway and transition.

Collaboration with other services

General Practitioner (GP):

The care pathway for individuals with gender dysphoria starts with a referral from a patient's GP. The GP is responsible for ongoing prescribing of endocrine therapy and organising blood and other diagnostic tests as recommended by the specialist consultant. GPs are also responsible for ensuring that the patient's life-long wellbeing is maintained by conducting periodic diagnostic tests and medication reviews as recommended initially by the discharging specialist and thereafter according to extant best practice.

Third / independent sector.

The involvement of the independent sector to offer additional support and guidance to patients, family members and clinicians is a vital part of the process. Providing access to independent offline and online organisations offering information advice and support to transgendered people should begin at referral (facilitated either by the GP or the GD service) and be reinforced throughout the period of transition..Information about support and resources for a patient's family and friends should also be readily available.

Endocrinology service

Once diagnosis has been confirmed at the GD service and a treatment plan commenced, referral to a GD specialist endocrinologist will be made to allow the patient to commence hormone treatment at an early stage. The endocrinology consultant will liaise with the GP and the GD service. GP responsibilities are outlined above.

Speech and Language Therapy service

Referral will be made to a Speech Therapist as part of the Gender Confirmatory procedures undertaken during transition with a view to offering techniques and guidance regarding speech and voice modulation.

Providers of other confirmatory procedures

Other confirmatory procedures include electrolysis / laser epilation, breast augmentation, chest reconstructive surgery, thyroid chondroplasty and lipoplasty as appropriate. The GD service and GP will liaise with appropriate providers and will receive reports of treatment progress and outcomes from those providers.

Gamete Storage

Patients will be offered the opportunity to consider storage of gametes in order to preserve reproductive potential on individual basis in accordance with the local policy on fertility treatment for non-trans people.

Surgical providers:

Where indicated, the GD service will make a referral to an appropriate WHSSC approved surgical provider of the patient's choice at an appropriate time during the patient's transition. Collaboration and communication between the surgical providers, GP and GD service will include details of procedures undertaken post operative recovery and discharge plans.

Equity of access to services

Services for assessment and treatment of gender dysphoria must ensure the accessibility of the full range of help and services irrespective of birth assigned sex, ethnicity, cultural background, disability, sexual orientation or previous history of intersex conditions.

Where service cannot be offered in the language of the patient's choice, interpreters will be provided and relatives are not to be routinely used as interpreters.

The Gender Dysphoria service will offer patients a first assessment within 18 weeks of referral.

The environment within the GD services will meet the needs of people with physical disabilities and sensory impairment and comply with current legislation on disabled access.

Service Model: Options Appraisal

Historically within Wales services for people with gender dysphoria have been limited and have not covered fully the whole population. A scoping exercise to identify services available across Wales was undertaken by WHSSC in November 2011(see Appendix 1) confirms that available services are only provided by Aneurin Bevan and Betsi Cadwaldr University Local Health Boards. An option appraisal was commissioned by WHSSC to identify the appropriate service model to provide services across all Local Health Board areas in Wales. The Option Appraisal process is set out in Appendix 2.

The appraisal process identified the preferred option as the establishment of two regional Gender Dysphoria Services. In order to ensure that there is a consistent model of service delivery, it is recommended that the services are managed as a single service across two sites. This service would build on the existing expertise within the Health Boards that are already providing services and extend provision to all eligible patients.

Each of these services will provide clinical services based upon the care pathway set out in the Gender Dysphoria Care Pathway (see Appendix 3). Additionally the services will meet the criteria and quality indicators set out in the document 'Quality Indicators for Specialised Gender Dysphoria Services' (WHSSC February 2012).

Care Pathway

1. Assessment and Diagnostic Phase

Following assessment which will include a detailed history, medical examination, psychological assessment and if necessary, a period of exploratory therapy, a diagnosis will be made in accordance with either ICD-10 or DSM IV. Where the diagnosis is uncertain a referral may be made to an independent clinician for conformation of the diagnosis. Following diagnosis, a plan for transition including a minimum period of least 12 months living in full time in the gender role with which the individual identifies (the Real Life Experience) will be discussed and the GP will be informed of the details of the plan.

2. Transition and Confirmation Phase

When the patient is ready he/she commences transition which includes regular supportive assessment and monitoring at least every three months. Contact and support with the independent sector is strongly encouraged and information will be provided to assist this. Referral to a Consultant Endocrinologist will be made at an early stage in the transition process to assist adjustment to the patients' desired presentation of gender. Where clinically appropriate, referral for additional confirmatory procedures including Speech and Language Services, hair removal and chest reconstruction will be made during the period of the Real Life Experience.

3. Gender Reassignment Surgery Approval and Preparation Phase

At the end of the transition period which will include a minimum of 12 months living full time in the person's desired gender the option of Gender Reassignment Surgery (GRS) will be discussed with the patient. There are different options for GRS; which Include Vaginoplasty, Orchiectomy, Clitoroplasty, Penectomy. Where surgery is requested and indicated then application will be made by the GD service to WHSSC for funding for the surgery. Following approval of funding, a referral to a surgical provider for a independent clinical assessment of the patient's readiness and eligibility for GRS will be made.

Where GRS is not indicated or requested, the GD service will continue to provide support and follow up until the patient is ready for discharge (usually after 6-12 months).

4. Gender Reassignment Surgery and Post operative follow up phase.

The GD service will continue to offer psychological support to the patient (alongside relevant transgender voluntary sector organisations where the patient has accessed these) during the process of surgical assessment and following surgery. The GD service will liaise with the GP and the surgical providers and share care in the follow up process after surgery for a period of 6 to 12 months. Further appointments in the GD service will be offered to assist in psychological adjustment until discharge from the service is indicated.

APPENDIX 1: Directory of Local Services in Wales

LHB	Person Completing Form	Q1 - Are there any services available for transgender patients within your area? If so, please list;	Q2 - Is there an identified clinician co-ordinating the assessment, management and follow-up of transgender patients in your area? - If yes, please provide details of who and where	Q3 - Do you have a single point of referral where clinicians can direct potential transgender patients? - if yes, please provide details	Q4 - Does that Single Point of Contact Provide;	Q5 - If any of the services are provided within your LHB, please provide details - if no services available, please tell us where you direct patients seeking such services?	Q6 Please include any other issues or comments related to transgender services that may not have already been covered
Betsi Cadwaladr	Martin Riley	Psychosexual Clinic, Grove Road Wrexham Psychosexual Clinic, Craig Y Don Road, Bangor	Martin Riley, Principal Psychological Therapist, Wrexham Dr Kenny Midence, Clinical Psychologist, Bangor	Martin Riley, Principal Psychological Therapist, Wrexham	Assessment - Y Diagnosis - Y Ongoing Management/Care Co-ordination - Y Referral to Endocrinologist - Y Co-ordination of Gender Treatments (hair removal) - Y Referral for gender confirmation surgery - Y Post Surgery (non surgical) follow up - Y	Assessment, diagnosis management carried out within clinics. Endocrinology provided via Dr Stephen Wong at Glan Clwyd Hospital Speech Therapy via Ms Gail Edgely at Glan Clwyd Hospital Referral for surgery via clinic in conjunction with Dr David Crossley (Clinical Gatekeeper) using usual WHSSC channels	Martin Riley & Dr Kenny Midence are currently working with WHSSC to develop an All Wales Policy and Clinical Pathway for Transgendered people. This questionnaire is the first element of the process
Aneurin Bevan	Nahla Jamil	Assessments Diagnosis Endocrinology	There is no identified Clinician co-ordinating the assessment, management and follow-up of transgender patients, however, Dr Jamil is 'gatekeeper' and is able to offer assessments, diagnosis and referral to endocrinology	The single point of referral where Clinicians can direct potential transgender patients is to Dr Jamil	Assessment - Y Diagnosis - Y Ongoing Management/Care Co-ordination - N Referral to Endocrinologist - Y Co-ordination of Gender Treatments (hair removal) - N Referral for gender confirmation surgery - Y Post Surgery (non surgical) follow up - N	Dr Jamil Consultant Psychiatrist is the contact for assessments and diagnosis Dr Oboubie is the contact for Endocrinology	There is no comprehensive service available, what is available is patchy and inadequate

ABM	Nil response						
Cardiff & Vale	Nil response						
Cwm Taf	Dr. Huw Griffiths	None	No. Dr Griffiths acts as a gatekeeper to WHSSC but this only involves checking that the referral criteria is met	No	N/A	Transgender patients are managed by each sector team. If the referral to the Gender Identity Clinic is thought appropriate I gate keep the referrals to WHSSC but the referrals are then made by the sector consultant and I have no further involvement	Numbers are relatively small so development of local specialty services would be unsustainable. Perhaps a regional service would be appropriate?
Hywel dda	Nil response						
Powys	Nil response						

APPENDIX 2: Option Appraisal

Options:

The following options were shortlisted as appropriate for the future delivery of gender identity specialised assessment services in Wales.

4. Assessment services provided by an established English NHS service. Under this option all referrals would be considered by the centre and patients would travel to the centre for assessment and follow up.

5. Peripatetic service provided by an established English NHS service. Under this option all referrals would be considered by the centre and the patients would travel to clinics hosted within Wales.

6. Develop a Welsh specialised assessment service. There are three potential sub options:
   - Central
   - Regional
   - Local

Option 1: Services continue to be provided by an established English GD service.

GD services are provided by established English NHS service. Under this option, GP's would refer to a local Adult Mental Health Psychiatrists for confirmation of the diagnosis. The Psychiatrist then makes an application to WHSSC for funding of confirmation of diagnosis, treatment, follow up and monitoring by a WHSSC approved English service. The English GDS would liaise with the GP to provide ongoing care locally.

Benefits

- Service comes from an established organisation with high service specification. It meets the WPATH Standards of Care.
- Clear lines of communication between GP Psychiatrist & WHSSC and simple single pathway.
- Single service providing all care up to and including surgical assessment.

Option 2: Peripatetic service provided by an established English NHS service to centres in Wales.

This form of service would be similar in referral pathway to Option 1, with the patient's GP making an initial referral to a local psychiatrist who would seek confirmation of funding from WHSSC prior to referral to an established English service. Arrangements would be made for 1 or 2 members of staff from this service

to run clinics at 1 or possibly 2 centres in Wales (perhaps 1 in North Wales and 1 in South Wales) on a monthly basis.

Benefits

- Service comes from an established organisation with high service specification.
- Clear lines of communication between GP Psychiatrist & WHSSC and simple single pathway
- Single service providing all care up to and including surgical assessment.
- Patients would be seen in Wales and travel times and costs would be minimised until the point of surgical intervention.
- Peripatetic service may be used as a platform for the training and education of staff seconded from Welsh health boards with a view to eventually developing Welsh based services.

Options 3: Develop Welsh specialist GID service(s) providing assessment, treatment and follow up.

This option allows for the development of GD service(s) located within Wales. GP's would refer to the service directly where confirmation of the diagnosis, assessment, treatment and follow up would be undertaken by a Welsh based service. Patients requesting GRS could be referred directly to surgical providers. There are 3 options for the development of a Welsh GD service:

a. A central service which is based in one location for the whole of Wales.

In this option one central GD clinic would be developed in Wales covering the whole of the principality. This would require a central location accessible to the whole population, staffed by a senior consultant clinician and at least 3 other WTE's qualified to undertake assessment and manage patient treatment programmes. I .5 WTE secretarial support would also be required. A monthly clinic session provided by a consultant endocrinologist would also be required.

Benefits

- A Welsh based service in which expertise is fostered and maintained in one location.
- Clear lines of communication between GP and relatively local GD service.
- Single service providing all care up to and including surgical assessment.
- Patients would be seen in Wales and travel times and costs would be less burdensome.

b. A regional service - 2 services covering the whole of Wales

In this option 2 GD services would be developed in Wales to cover the whole population. Hosted within a northern and southern Health Board each would be headed by a senior consultant clinician and 1 or 2 WTE staff capable of undertaking assessments and managing patient treatment programmes I WTE secretarial support

would also be required. A monthly clinic session provided by a consultant endocrinologist would also be required.

Benefits
- A Welsh based service built upon existing expertise within Wales
- Problems with the 'North/South' divide are obviated
- Clear lines of communication between GP and GD clinic via a simple single pathway.
- Regional multidisciplinary service providing all care up to and including surgical assessment.
- Patients would be seen in Wales and the burden of travel times and costs would be minimised.
- Easier to address local needs by process of networking with colleagues from other disciplines

c. A local service – each Health Board develop its own GID service.

Under this option a GID service would be provided in each of the 7 health boards. Each service would require it's own clinical lead (0.5 WTE) and at least one other member of staff (O.5 WTE) supported by 0.5 WTE secretarial support. A 2-3 monthly clinic session provided by a consultant endocrinologist would also be required.

Benefits:

- A Welsh based local service.
- Problems with the 'North/South' divide and regional clinics are obviated
- Clear lines of communication between GP and local GD clinic via a simple single pathway
- Local multidisciplinary service providing all care up to and including surgical assessment.
- Patients would be seen in their local area and the burden of travel times and costs would be no greater than for any other.
- Service is highly responsive to local needs and issues and can network with local colleagues and the voluntary sector
- Waiting times for services easy to monitor

Options appraisal:

The options were then appraised by a small group comprising stakeholders, clinicians and a representative from the NHS Centre for Equalities and Human Rights. The process had been previously disseminated and participants were briefed about the appraisal technique.

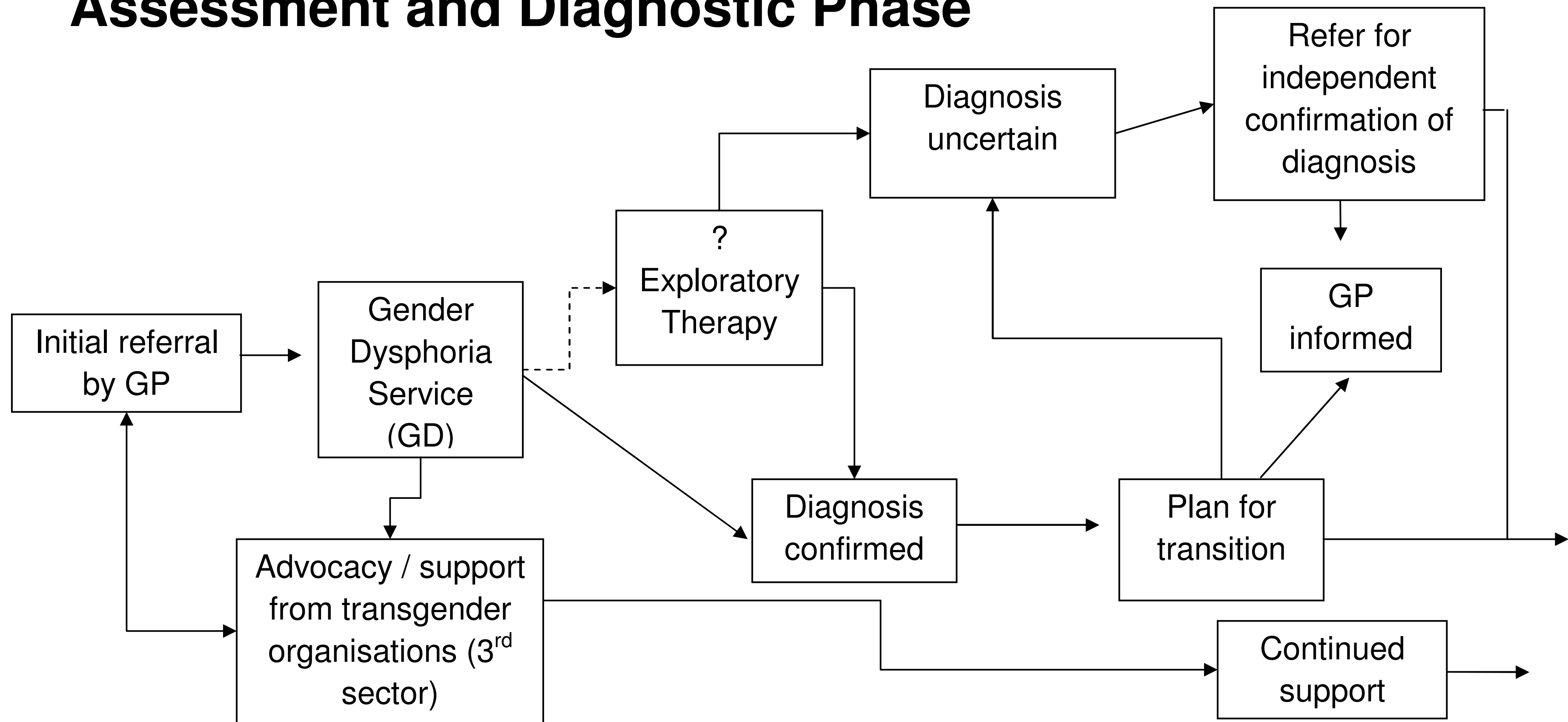
The criteria, the weighting applied to each and the scoring of each option is set out in Table 1 below.

Table 1: Options Appraisal 02/02/12

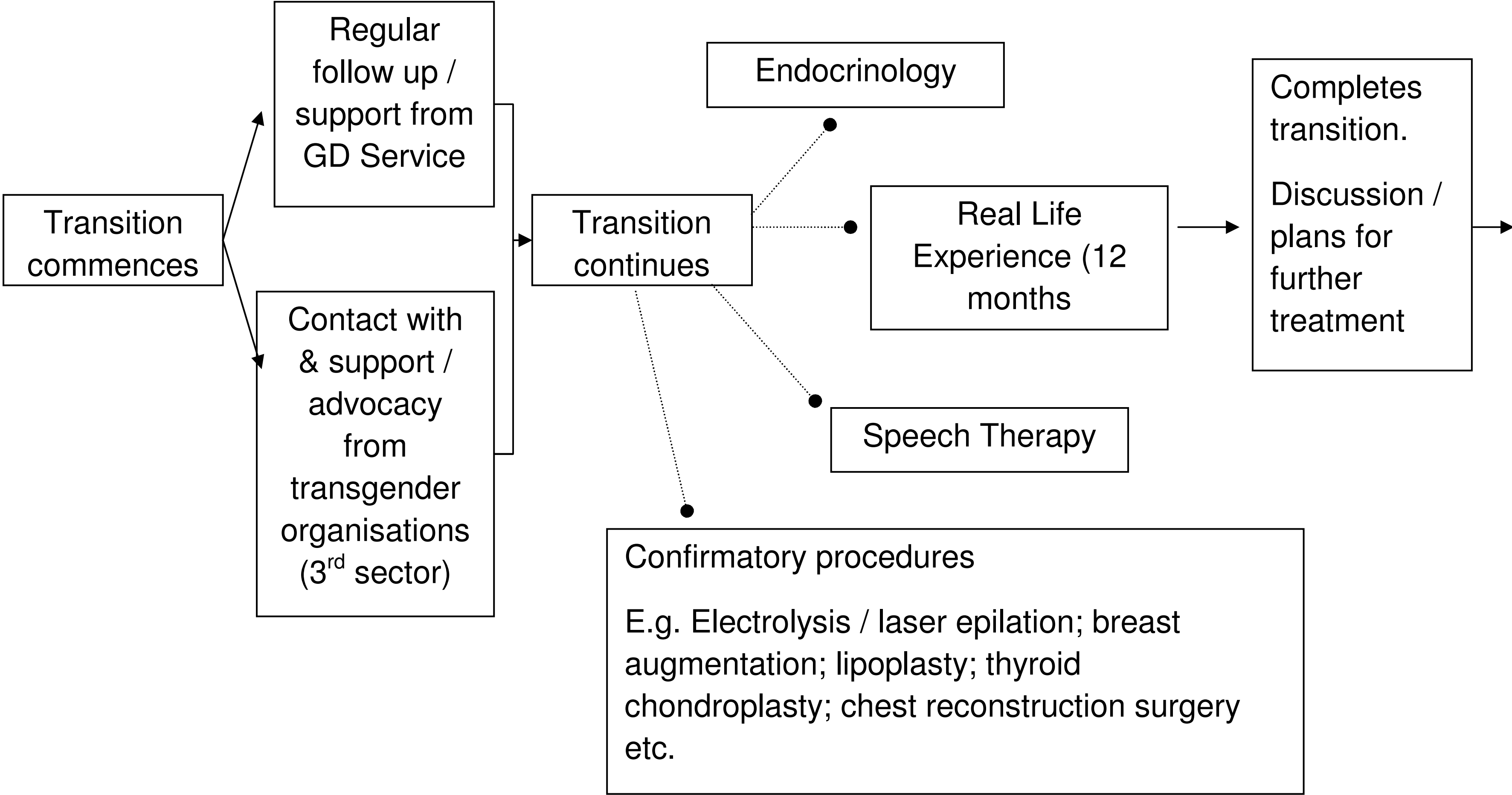
Benefit Criteria	Weight		Option 1: Status Quo			Option 2: Peripatetic			Option 3a: Wales (Central)			Option 3b: Wales (Regional)			Option 3b: Wales (Local)		
			Score	Weight		Score	Weight		Score	Weight		Score	Weight		Score	Weight	
Access	**20**		**1**	**20**		**3**	**60**		**3**	**60**		**4**	**80**		**5**	**100**	
User Acceptab-ility	**20**		**2**	**40**		**2**	**40**		**3**	**60**		**4**	**80**		**5**	**100**	
Provider Acceptab-ility	**5**		**3**	**15**		**1**	**5**		**3**	**15**		**5**	**25**		**3**	**15**	
Achieva-bility	**5**		**5**	**25**		**2**	**10**		**3**	**15**		**5**	**25**		**2**	**10**	

Quality of Care	25		2	50		2	50		4	100		5	125		4	100	
Relevance to Need	25		2	50		2	50		3	75		5	125		4	100	
TOTAL			15	200		12	215		19	325		28	460		23	425	

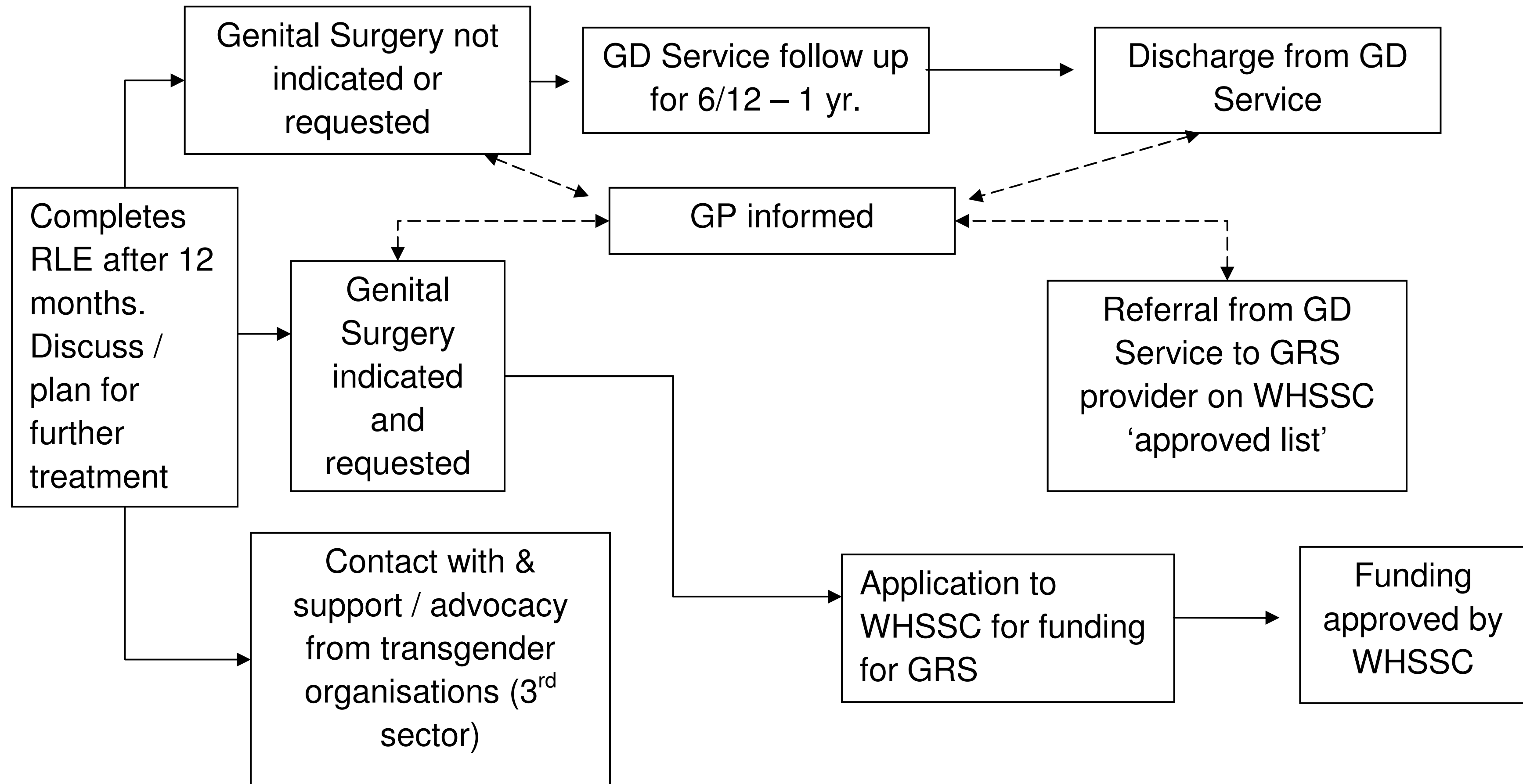
APPENDIX 3: Gender Dysphoria Care Pathway



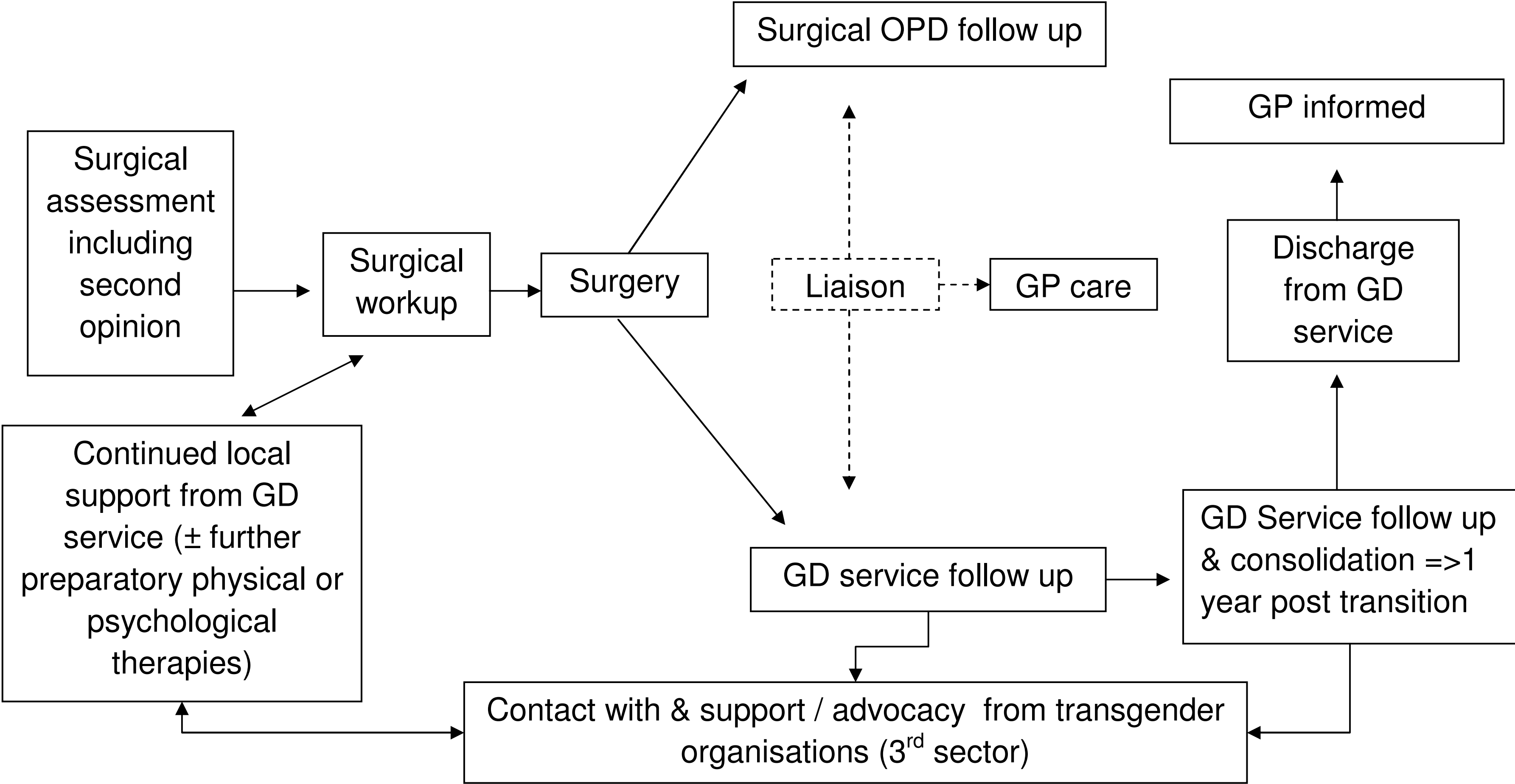
Transition & Confirmation Phase



Genital Surgery Preparation and Approval Phase



Surgical & Follow Up Phase



Appendix B – Quality Indicators

Quality Indicators for Specialised Gender Dysphoria Services

Aim

The Quality Indicators give guidance to the Health Boards, NHS Trusts and other healthcare organisations that provide Specialised Gender Dysphoria services on the standards of care and service delivery. They enable planners of the service to assess the achievement of specified Quality Indicators and promote consistency between providers.

What the Quality Indicators Cover

The indicators are set out under three broad themes:

7. Information and Communication

8. Providing a quality service

    a. Assessment
    b. Transition and Confirmation
    c. Surgery
    d. Care and support

9. Discharge and follow up

Each indicator is as explicit as possible to ensure that interpretation is clear. **Level A** indicates the highest priority that providers should give to achieving compliance. **Levels B & C** will be set to allow time for improvement. Specified within each indicator are the measures of compliance that are necessary for assessment.

Key:

A = Essential, Mandatory, must meet now.

B = To be met in *1-2 years.*

C = To be met in *3-5 years.*

References

The World Professional Association for Transgender Health (WPATH) (7th Edition) *Standards of Care for the Health of Transsexual, Transgender, and Gender Nonconforming People*. Retrieved 26 January 2012, from http://www.wpath.org/documents/Standards%20of%20Care%20V7%20-%202011%20WPATH.pdf

Welsh Government (2010) *Doing Well, Doing Better: Standards for Health Services in Wales*. Retrieved 26 January 2012, from http://www.nhswalesgovernance.com/Uploads/Resources/pWIHKe4fu.pdf and http://www.nhswalesgovernance.com/Uploads/Resources/2bUIH2xHl.pdf

The Equality Act 2010. Retrieved 26 January 2012, from http://www.legislation.gov.uk/ukpga/2010/15/contents

The Data Protection Act (1998). Retrieved 26 January 2012, from http://www.legislation.gov.uk/ukpga/1998/29/contents

The Universal Declaration of Human Rights. Retrieved 26 January 2012, from http://www.un.org/en/documents/udhr

Welsh Government (2006) *Copying Letters to Patients* (WHC 2006 (042).

National Assembly for Wales (2010) *Mental Health (Wales) Measure 2010*. Retrieved 26 January 2012, from http://www.assemblywales.org/bus-home/bus-legislation/bus-leg-measures/business-legislation-measures-mhs-2.htm

Access to Health Records Act (1990). Retrieved 26 January 2012, from http://www.legislation.gov.uk/ukpga/1990/23/contents

Welsh Government (2011) *NHS (Concerns, Complaints and Redress Arrangements) (Wales) Regulations 2011*

1. Information and Communication				
Aim – Patients and all relevant others receive timely and complete information about treatment in an accessible and appropriate format. All information is received in a sensitive and confidential manner.				
Standard		**Cross Ref**	**Priority**	**Measures of Compliance**
Communication and Information				
1.1	Up to date written information regarding service provision for gender dysphoria is available and advertised in GP surgeries, Local Health Boards, NHS Trusts and all other relevant health organisations. The information is written in everyday language, avoiding jargon and acronyms, to make it easier to read. The information is available, on request, in a format to suit the patient's individual needs e.g. • Welsh language • Other languages • Large print • Audio	Standards for Health Services in Wales 2, 7, 8, 9, 18	A	Printed information available

1.2	Information and support for families and carers about gender dysphoria and treatment should be available.		A	
1.3	Staff treat every individual with respect and dignity and address individuals according to the gender in which they present.	Equality Act 2010, Human Rights	A	
1.4	Staff are sensitive to the individual wishes and needs of patients and families of different ethnic, religious or cultural backgrounds. Advice, support and training is available for staff. Where differences arise between the wishes and needs of the patient and their family, the patient needs become paramount.		A	
1.5	Patients receive a copy of letters sent between health care professionals e.g. letters to GPs.	WHC 2006 (042)	A	Copy of correspondence
1.6	Patients are provided with timely and accessible written and verbal information on their condition, care, medication, treatment and support arrangements. The information contains details of self care before, during and after treatment and (where indicated) gender reassignment surgery.		A	Printed information available
1.7	There is a clear procedure for communication between primary, secondary and specialist service.		B	Available pathway
Confidentiality				
1.8	Organisations providing a gender dysphoria service have policies in place which are fully compliant with the Data Protection Act, Caldicott, Gender Recognition Act and the Human Rights Act	Standards for Health Services in	A	Confidentiality/privacy policy in

		Wales 5,18		place
1.9	Patients are able to, on request, access their own records.	Access to Health Records Act (1990)	A	
	Organisations and services treat patient information confidentially		A	
Advocacy				
1.10	Up to date information regarding advocacy is available in GP surgeries, Local Health Boards and all other health organisations.	Mental Health (Wales) Measure 2010	B	Evidence of access to advocacy services
	Patients are informed by their health professional of the advocacy support available.		B	
Concerns including Complaints, Claims and Incidents				
1.11	Information about raising a concern about the NHS, "Putting Things Right", is readily available to patients.	Standards for Health Services in Wales 23	A	Concerns policy in place
1.12	Concerns are handled and investigated openly, effectively and by those appropriately skilled to do so.	Standards for Health Services in	A	

		Wales 23		
1.13	Patients who have raised a concern can expect to be treated without discrimination or victimisation.	Standards for Health Services in Wales 23	A	
1.14	Where the concern involves more than one health care organisation, the organisation to whom the concern was originally raised will not disclose any information without consent of the patient.	NHS (Concerns, Complaints and Redress Arrangements) (Wales) Regulations 2011, Regulation 17	A	
Engagement/Involvement				
1.15	The views of patients, families and health professionals regarding the quality of service are collected as part of clinical governance arrangements at regular intervals (minimum annually).	Standards for Health Services in Wales 1,9,19	A	Survey of patient's experiences

2a. Providing a quality assessment service Aim – Full attention is paid by the service to the quality of care provided to patients using continuous measures of improvement within audit and governance programmes.				
Standard		**Cross Ref**	**Priority**	**Measures of Compliance**
Access to assessment services				
2a.1	Contact details for Gender Dysphoria specialists and the referral pathway are readily available to all GPs, CMHTs and other Health Professionals.	Standards for Health Services in Wales 7, 8, 11, 18	A	Available patient referral pathway
2a.2	Health Professionals are able to directly refer patients to the specialist service, in accordance with the referral pathway.		A	
2a.3	Information regarding the Gender Dysphoria service, provided for patients aged 18 years and over, is available to patients.		A	
	Patients have straightforward and uncomplicated access to the gender dysphoria		B	

	service.			
2a.4	Services are delivered in a way that respects the individual needs and wishes of the patient.		A	Patient satisfaction survey
Referral assessment				
2a.5	Patients are referred to gender dysphoria specialists for a comprehensive assessment including diagnosis or confirmation of gender dysphoria according to the ICD or DSM, and psychological and psychiatric assessment.		A	Available clinical protocol
2a.6	Continuous assessment of patient's gender dysphoria development, sexual, social and occupational history; physical and emotional development; employment and family background and current level of social functioning is undertaken.	Standards for Health Services in Wales 7,8	A	Standards of Care
2a.7	Assessment of the patient's mental health is undertaken.		A	Case not review
2a.8	Patients' expectations of and commitment to treatment are addressed.		A	
2a.9	The patient is fully informed of the outcome of the assessment and informed of the medical and psychological limitations regarding treatment. This is supported with written information. The patient's understanding of the information is assessed.		A	
Care team				
2a.10	A Lead Clinician with expertise in gender dysphoria is appointed to coordinate	Standards for	A	Evidence of

	service and provide treatment, care and support.	Health Services in Wales 7,8		knowledge and experience in gender dysphoria
2a.11	Assessment is carried out by health professionals specialised in gender dysphoria. A full multidisciplinary team is in place which includes, as minimum, the GP, Endocrinology, Speech Therapist and Surgeon.		A	Evidence of membership to professional organisation
Access to other specialties				
2a.12	Patients will have timely access to other specialist services as outlined in the commissioning policy.	Standards for Health Services in Wales 9	A	Treatment pathway
Governance				
2a.13	Patients are provided with safe, effective treatment and care which is based on agreed best practice and guidelines e.g. current WPATH's Standards of Care.	Standards for Health Services in Wales 6,7	A	Standards of Care
2a.14	Patients are provided with a service which complies with safety and clinical directives in a timely way and which is demonstrated by procedures for recording and auditing compliance.		A	Evidence of clinical audit

2a.15	Organisations and services provide all aspects of care including referral, assessment, treatment, transfer of care and discharge in a timely way consistent with any national timescales, pathways and best practice.	Standards for Health Services in Wales 8	A	
Consent for Treatment				
2a.16	Services provide opportunities for patients to discuss and agree the options available.	Standards for Health Services in Wales 10	A	
2a.17	Informed consent is obtained, in line with best practice guidance, and in a manner that respects the patient's autonomy.		A	
2a.18	When seeking consent, health professionals ensure that patients are assessed and care for in line with the Mental Capacity Act 2005 when appropriate.		A	
Information and reporting				
2a.19	Audit data is collected and present to commissioners, patients and providers on a regular basis as outlined in the Key Performance Indicators.		A	Patient satisfaction survey

2b. Providing a quality care and support service				
Aim – The service should pay full attention to the quality of care provided to patients using continuous measures of improvement within an audit and governance programme.				
Standard		**Cross Ref**	**Priority**	**Measures of Compliance**
Access to services				
2b.1	Patients have access to a comprehensive gender dysphoria service, which includes multidisciplinary input from primary care, specialist clinicians, electrolysis, endocrinology and surgical specialities in accordance with the policy.	Standards for Health Services in Wales 7,8	A	Treatment pathway
2b.2	Psychological therapy is offered if gender dysphoria is not confirmed.		A	
Referral assessment				
2b.3	Patients have a thorough medical and psychological assessment before hormone treatment or any other intervention is considered.	Standards for Health Services in Wales 2,7,8	A	Treatment pathway
2b.4	Patients are followed up regularly, and support made available throughout the period of care , in line with the individualise and flexible care pathway.		A	Standards of

				Care
2b.5	Continuous assessment of patients' functioning including social, vocational and psychological functioning is offered.		A	
Care team				
2b.6	A Lead Clinician with expertise in gender dysphoria is appointed to coordinate service and provide treatment, care and support.	Standards for Health Services in Wales 7,8	A	Evidence of knowledge and experience in gender dysphoria
2b.7	Assessment is carried out by health professionals specialised in gender dysphoria. A full multidisciplinary team is in place which includes, as minimum, the GP, Endocrinology, Speech Therapist and Surgeon.	Standards for Health Services in Wales 7,8	A	Evidence of membership to professional organisation
Access to other specialties				
2b.8	Patients receive effective treatment and care that are well coordinated to provide a seamless service across all specialties that need to be involved.	Standards for Health Services in Wales 7,8	A	Patient's satisfaction survey
Governance				

2b.9	Treatment, care and support is patient-centred and recognises the individual's preferences, needs, wishes and differences in circumstances.	Standards for Health Services in Wales 7,8	A	Evidence of competence
2b.10	Patients receive treatment and care that is delivered by health professionals who make clinical decisions based on evidence-based practice.		A	
2b.11	Treatment, care and support allows for patient choice with regard to clinically safe treatment.		A	
Information and reporting				
2b.12	There is clear communication between specialists, GPs and other health professionals regarding the patients' treatment.		A	Care Pathway
2b.13	Letters of communication between specialists, GPs and other health professionals regarding the patients' treatment are copied to the patient in line with Welsh Government guidance *Copying Letters to Patients* (WHC 2006 (042))	WHC 2006 (042)	A	

2c. Providing a quality surgical service				
Aim – Full attention is paid to the quality of care provided to patients using continuous measures of improvement within an audit and governance programme.				
Standard		**Cross Ref**	**Priority**	**Measures of Compliance**
Access to services				
2c.1	Information and advice regarding all surgical options is available	Standards for Health Services in Wales 7, 8, 9	A	Referral Pathway
2c.2	Easy access to surgical services should be offered in line with policies and care pathways.		A	
2c.3	Gender Specialists can directly refer patients for surgery .		A	
2c.4	The Care Pathway clearly specifies the procedure for access of all surgical procedures and referral of patients.		A	Written confirmation
2c.5	All patients and carers have information about and access to the spiritual care service.		A	

2c.6	Patients and their carers have their spiritual and religious needs assessed and addressed.		A	
Referral assessment and patient care				
2c.7	A full assessment of patients' surgical requests is carried out.	Standards for Health Services in Wales 7,8	A	Care pathway
2c.8	A psychological assessment of patients requesting surgical interventions is carried out.		A	
2c.9	The patient's readiness and eligibility for gender reassignment surgery is assessed independently by two specialists in gender dysphoria, in line with the current WPATH's Standards of Care.		A	Standards of care
2c.10	Patients in need of other surgical procedures including mastectomy are assessed by the Care Team.		A	
2c.11	On receipt of a referral, the surgeon confirms with the referring GD specialist that the referral has been accepted and provides details of the timescales for surgical assessment.		A	Copy of corresponden ce
2c.12	The surgeon, ensuring confidentiality, discusses with patients seeking surgical treatment: • The different surgical techniques available (with referral to colleagues, who provide alternative options) • The advantages and disadvantages of each technique • The limitations of a procedure to achieve optimal results; surgeons		A	Consent form

	should provide a full range of before-and-after photographs of their own patients, including both successful and unsuccessful outcomes • The inherent risks and possible complications of the various techniques; surgeons should inform patients of their own complication rates with each procedure • Any other relevant information.			
Care team				
2c.12	A Lead Clinician with expertise in gender dysphoria is appointed to coordinate service and provide treatment, care and support.	Standards for Health Services in Wales 7,8	A	Evidence of knowledge and experience in gender dysphoria
2c.13	Assessment is carried out by health professionals specialised in gender dysphoria. A full multidisciplinary team is in place which includes, as minimum, the GP, Endocrinology, Speech Therapist and Surgeon.		A	Evidence of membership to professional organisation
2.c14	Registered nursing support will be provided based on individual patient need. The support will be reviewed regularly.		A	

2c.15	The surgeon is appropriately qualified and operating within a designated service.		A	Written confirmation
Governance				
2c.16	Treatment, care and support is patient-centred and recognises the individual's preferences, needs, wishes and differences in circumstances.	Standards for Health Services in Wales 7,8	A	Evidence of competence
	Patients receive treatment and care that is delivered by health professionals who make clinical decisions based on evidence-based practice.		A	
	Treatment, care and support allows for patient choice with regard to clinically safe treatment.		A	
2c.17	Quality assurance of service providers is available.		A	Written confirmation and protocol review
2c.18	Patients are able to choose the provider for gender reassignment surgery from a list of designated providers for Welsh patients who have been assessed for clinically safety, quality and surgical outcomes.	Standards for Health Services in Wales 5, 23	A	
Information and reporting				
2c.20	Feedback from patients regarding surgical treatment and the overall pathway is obtained and the information received is used to improve services.		A	Patient's satisfaction

				survey

3. Discharge and Follow-up				
Aim – Agencies will demonstrate a clear understanding of the contribution required for optimum patient care. Care will be delivered and monitored by the appropriate personnel and agencies at each stage of the care pathway.				
Standard		**Cross Ref**	**Priority**	**Measures of Compliance**
Discharge planning - Mental Health Professionals may work with clients and their families at many stages of their lives.				
3.1	Patients are able to re refer themselves to the GI service for further therapy, support or information. An agreed referral process is in place.		A	Care pathway
3.2	A system of follow up outpatient appointment with endocrinology is in place.		A	
3.3	Regular monitoring of patients' functioning is offered		A	Written information available
3.4	The patient should be contacted within 24 hours of an unexpected failure to attend an appointment. The reasons for the failure must be determined before any further action is taken.		A	

3.5	There is clear written communication to GPs/Referrers regarding the patient outcome and discharge process.		A	
	Letters of communication between specialists, GPs and other health professionals regarding the patients' treatment are copied to the patient in line with Welsh Government guidance *Copying Letters to Patients* (WHC 2006 (042))		A	
3.6	There are close links with support services and the primary healthcare team.		B	
3.7	Information regarding support groups is provided in an encouraging manner to the patients .		B	
3.8	Patients are followed up by the GI service after surgery (at a minimum 12 months after surgery), to review and record the outcome.		A	
3.9	On discharge, a detailed discharge plan is provided to enable an appropriate transfer of care from the specialised service back to primary care. The discharge plan includes a recommended programme for periodic diagnostic tests and medication reviews to assure continued wellbeing, based on extant best practice.		A	

Annex (i)

STANDARDS FOR HEALTH SERVICES IN WALES

Introduction

The *Healthcare Standards for Wales*, which were published in 2005, have been updated to ensure that they are fit for purpose to underpin the vision and values and the governance and accountability framework for the new NHS in Wales.

On 1st April 2010, the Minister launched "Doing Well, Doing Better" Standards for Health Services in Wales. The new standards provide the framework to enable organisations to look across the range of their services in an integrated way to ensure that all that they do is of the highest quality. They set out the requirements of what is expected of all health care services in all settings and are at the centre of our drive for continuous improvement in the quality and experience of services that citizens of Wales have a reasonable right to expect.

The Standards should be used as a framework for gaining, and providing assurance to Welsh citizens and others on the organisations ability to fulfil its aims and objectives for the delivery of safe, high quality health services. This involves self assessment of performance against the Standards across all activities and at all levels throughout the organisation.

The standards are not listed in priority order; however an attempt has been made to group them together where they appear to be closely linked.

1. Governance and accountability framework

Organisations and services operate within a clear and robust framework for decision making and accountability designed to achieve successful delivery of their purpose, aims, and objectives, in a manner that:

a) upholds organisational values and standards of behaviour;

b) complies with all relevant regulatory, accreditation, licensing requirements, standards, directions and instructions;

c) secures the efficient, effective and economic use of resources;

d) safeguards and protects all assets, including its people; and

e) ensures good governance when working in partnership with others.

2. Equality, diversity and human rights

Organisations and services have equality priorities in accordance with legislation which ensure that they recognise and address the:

a) needs of individuals whatever their identity and background, and uphold their human rights;

b) rights of children in accordance with the United Nations Convention on the Rights of the Child (UNCRC); and

c) need to challenge discrimination, promote equality and human rights and seek to reduce health inequities through their strategies, policies, practices and procurement processes.

3. Health Promotion, Protection and Improvement

Organisations and services work in partnership with others to protect and improve the health and wellbeing of citizens and reduce health inequities by:

a) having systems in place to identify and act upon significant public health issues;

b) supporting citizens to maintain and improve their health, wellbeing and independence;

c) promoting healthy lifestyles and enabling healthy choices;

d) promoting healthy and safe workplaces;

e) ensuring that needs assessment and public health advice informs service planning, policies and practices;

f) having systems and plans to prevent and control communicable diseases and provide immunisation programmes; and

g) having effective programmes to screen and detect disease.

4. Civil Contingency and Emergency Planning Arrangements

Organisations and services are able to deliver a robust response and ensure business and service continuity in the event of any incident or emergency situation.

5. Citizen Engagement and Feedback

Organisations and services use a range of methods and approaches to:

a) engage with partners in supporting and enabling citizens to be involved in the design, planning and delivery of services;

b) seek feedback from patients, service users and carers about their experiences; and

c) demonstrate that they act on views and feedback in making changes to improve services.

6. Participating in Quality Improvement Activities

Organisations and services reduce waste, variation and harm by:

a) identifying and participating in quality improvement activities and programmes;

b) supporting and enabling teams to identify and address local improvement priorities;

c) using recognised quality improvement methodologies;

d) measuring and recording progress; and

e) spreading the learning.

7. Safe and Clinically Effective Care

Organisations and services will ensure that patients and service users are provided with safe, effective treatment and care:

a) based on agreed best practice and guidelines including those defined by National Service Frameworks, National Institute for Health and Clinical Excellence (NICE), National Patient Safety Agency (NPSA) and professional bodies;

b) that complies with safety and clinical directives in a timely way; and

c) which is demonstrated by procedures for recording and auditing compliance with and variance from any of the above.

8. Care Planning and Provision

Organisations and services recognise and address the needs of patients, service users and their carers by:

a) providing all aspects of care including referral, assessment, diagnosis, treatment, transfer of care and discharge including care at the end of life, in a timely way consistent with any national timescales, pathways and best practice;

b) providing support to develop competence in self-care and promote rehabilitation and re-enablement; and

c) working in partnership with other services and organisations, including social services and the third sector.

9. Patient Information and Consent

Organisations and services recognise and address the needs of patients, service users and their carers by:

a) providing timely and accessible information on their condition, care, medication, treatment and support arrangements;

b) providing opportunities to discuss and agree options;

c) treating their information confidentially;

d) obtaining informed consent, in line with best practice guidance; and

e) assessing and caring for them in line with the Mental Capacity Act 2005 when appropriate.

10. Dignity and respect

Organisations and services recognise and address the physical, psychological, social, cultural, linguistic, spiritual needs and preferences of individuals and that their right to dignity and respect will be protected and provided for.

11. Safeguarding Children and Safeguarding Vulnerable Adults

Organisations and services promote and protect the welfare and safety of children and vulnerable adults by:

a) conforming to legislation and guidance;

b) ensuring effective multi-agency working and co-operation;

c) training and supporting staff to recognise and act on issues and concerns, including sharing of information; and

d) sharing good practice and learning.

12. Environment

Organisations and services comply with legislation and guidance to provide environments that are:

a) accessible;

b) well maintained;

c) fit for purpose;

d) safe and secure;

e) protect privacy; and

f) sustainable.

13. Infection Prevention and Control (IPC) and Decontamination

Organisations and services comply with legislation and guidance on IPC and decontamination, in order to:

a) eliminate or minimise the risk of healthcare associated and community acquired infections;

b) emphasise high standards of hygiene and reflect best practice;

c) support, encourage and enable patients, service users, carers, visitors and staff to achieve and maintain high standards of hygiene;

d) segregate, handle, transport and dispose of waste so as to minimise risks to patients, service users, carers, staff, the public and environment; and

e) handle human tissue and subsequently dispose of it appropriately and sensitively.

14. Nutrition

Organisations and services will comply with legislation and guidance to ensure that:

a) patients' and service users' individual nutritional and fluid needs are assessed, recorded and addressed;

b) any necessary support with eating, drinking or feeding and swallowing is identified and provided;

c) breastfeeding is promoted and supported.

Where food and drink are provided:

d) a choice of food is offered, which is prepared safely and meets the nutritional, therapeutic, religious and cultural needs of all; and

e) is accessible 24 hours a day.

15. Medicines Management

Organisations and services will ensure that:

a) they comply with legislation, licensing and good practice guidance for all aspects of medicines management including controlled drugs;

b) clinicians are qualified and trained in prescribing, dispensing and administering medicines within their individual scope of practice; and

c) there is timely, accessible and appropriate medicines advice and information for patients, service users, their carers and staff including the reporting of drug related adverse incidents.

16. Medical Devices, Equipment and Diagnostic Systems

Organisations and services ensure the safe and effective procurement, use and disposal of medical equipment, devices and diagnostic systems that:

a) conform to health, safety and environmental legislation and guidance;

b) are maintained, cleaned and calibrated in accordance with manufacturer's guidelines;

c) are appropriate for their intended use and for the environment in which they are used;

d) decontaminates reusable medical devices properly;

e) is supported by an ongoing programme of training and competence assessment for staff and users; and

f) there is timely reporting and management of any device, equipment or system faults.

17. Blood Management

Organisations and services ensure that patients have access to a safe and sufficient supply of blood, blood products and blood components, through:

a) compliance with legislation and national guidance on the supply and use of blood, blood products and blood components;

b) the use of schemes and systems to reduce wastage of blood, blood products and blood components;

c) effective planning for blood shortages;

d) an ongoing programme of education, training and competence assessment for all staff involved in the transfusion process; and

e) the reporting of all adverse blood reactions and incidents.

18. Communicating Effectively

Organisations and services comply with legislation and guidance to ensure effective, accessible, appropriate and timely communication and information sharing:

a) internally and externally;

b) with patients, service users, carers and staff using a range of media and formats;

c) about patients, service users and their carers;

d) on the full range and locations of services they provide; and

e) addressing all language and communication needs.

19. Information Management and Communications Technology

Organisations and services support and facilitate patient care and service delivery by:

a) developing and using safe and secure information systems in accordance with legislation and within a robust governance framework;

b) having processes to operate and manage information and data effectively and to maintain business continuity;

c) ensuring data quality is robust and timely;

d) using information to review, assess and improve services; and

e) sharing information with relevant partners using protocols when necessary.

20. Records Management

Organisations and services manage all records in accordance with legislation and guidance to ensure that they are:

a) designed, prepared, reviewed and accessible to meet the required needs;

b) stored safely, maintained securely, are retrievable in a timely manner and disposed of appropriately;

c) accurate, complete, understandable and contemporaneous in accordance with professional standards and guidance; and

d) shared as appropriate.

21. Research, Development and Innovation

Organisations and services will:

a) ensure that the principles and requirements of the Research Governance Framework for Health and Social Care are consistently applied;

b) have an outcome focussed research and development strategy that benefits patients and improves service delivery; and

c) promote research, development and innovation.

22. Managing Risk and Health and Safety

Organisations and services will have systems and processes in place which comply with legislation and guidance that:

a) applies best practice in assessing, managing and mitigating risk;

b) implements policies and arrangements for reviewing and continuously improving all aspects of their activities and environment to protect and improve the health, safety and wellbeing of their patients, service users, carers, staff and the public; and

c) acts upon safety notices, alerts and other such communications.

23. Dealing with concerns and managing incidents

Organisations and services comply with legislation and guidance to deal with complaints, incidents, near misses, and claims - known collectively as 'concerns' which ensure that they:

a) are reported, acted upon and responded to in an appropriate and timely manner;

b) are handled and investigated openly, effectively and by those appropriately skilled to do so;

c) offer patients, service users and their carers support including advocacy and where appropriate redress;

d) provide appropriate support to staff; and

e) learn and share lessons from local and national reviews to improve services.

24. Workforce Planning

Organisations and services work with partners to develop an appropriately constituted and sustainable workforce by:

a) having effective workforce plans which are integrated with service and financial plans;

b) meeting the needs of the population served through an appropriate skill mix;

c) reflecting the demographic profile of its population;

d) promoting the continuous improvement of services through better ways of working; and

e) enabling the supply of trainees, students, newly qualified staff and new recruits and their development.

25. Workforce Recruitment and Employment Practices

Organisations and services ensure that their workforce:

a) have all necessary recruitment and periodic employment checks and are registered with the relevant bodies;

b) are appropriately recruited, trained, qualified and competent for the work they undertake;

c) act, and are treated, in accordance with identified standards and codes of conduct;

d) have access to processes which permit them to raise, in confidence and without prejudice, concerns over any aspect of service delivery, treatment or management;

e) are supervised and supported in the delivery of their role; and

f) are dealt with fairly and equitably when their performance causes concern.

26. Workforce Training and Organisational Development

Organisations and services ensure that their workforce is provided with appropriate support to enable them to:

a) maintain and develop competencies in order to be developed to their full potential;

b) participate in induction and mandatory training programmes;

c) have an annual personal appraisal and a personal development plan enabling them to develop their role;

d) demonstrate continuing professional and occupational development; and

e) access opportunities to develop collaborative practice and team working.

Appendix C – Key Performance Indicators

Key Performance Indicators for Specialised Gender Identity Services

Definition: All patients have an agreed clearly defined treatment plan

Rationale	Measures the number of patients with an agreed clearly defined treatment plan
Implementation	Treatment plan review
Target	95% of patients to have a treatment plan within 2 weeks of their first outpatient assessment appointment. Treatment plan should include diagnosis, frequency of blood test, frequency of appointments during RLE, time scale for referral to specialist service (e.g. endocrinology, speech therapy, surgery); post-surgery follow-up.
Data Source	Information return from gender dysphoria service
Validation	Annual audit
Reporting Arrangements	Quarterly information return to WHSSC

Definition: All patients' treatment plans are reviewed.

Rationale	Measure the level of adherence of treatment plans to a specified Care Pathway for Gender Dysphoria
Implementation	Treatment plans review against Care Pathway
Target	95% of treatment plan will adhere to a specified Care Pathway.
Data Source	File audit. Information return from gender dysphoria service
Validation	Annual audit
Reporting Arrangements	6 monthly information return to WHSSC

Definition: **Prompt appointment with other specialist services**

Rationale	Measures the waiting times to see specialist (e.g. endocrinology; surgery).
Implementation	Data source
Target	95% of patients will be referred and seen within acceptable NHS waiting times.
Data Source	Information from Health Board, Trust waiting times.
Validation	Annual audit
Reporting Arrangements	National waiting list return

Definition: Patients will have follow-up assessment and postoperative care.

Rationale	Measures the level of aftercare patients receive after surgery
Implementation	Information return from Surgery and gender identity service.
Target	95% of patients will have an aftercare plan and follow up including regular medical screening up to 12 months following surgery
Data Source	Information return from Surgery and gender identity service.
Validation	Annual audit
Reporting Arrangements	6 monthly information return

Appendix D – Criteria for Preferred Providers

Criteria for Preferred Providers

1	The providers are able to demonstrate the: a. Success rate in comparison to national data b. Qualifications, competence and professional registration of the multidisciplinary team c. Cost effectiveness of the service d. Location of service and environment e. Referral to assessment times f. Referral to treatment times g. Post operative care h. Arrangements for follow up
2	The provider is able to demonstrate that a patient and public engagement strategy is in place and fully implemented.
3	The provider is able to demonstrate that patient satisfaction surveys are carried out routinely and the results obtained are used to drive service development.
4	The provider is able to demonstrate that clinical outcomes are monitored and used as a measure of performance and development.
5	The provider has a Board agreed quality improvement plan and can evidence improvements in service provision.
6	The provider is able to demonstrate compliance with the agreed patient care pathway which includes assessment, admission and discharge.
7	The provider meet the requirements of the NHS Multilateral Contract.
8	The provider has clearly defined treatment options which can be tailored towards individual needs.
9	The provider can demonstrate compliance the Standards for Health Services in Wales or Standards for Better Health.
10	The provider meets the requirements of currency and remains within cost. The costing relates to all inclusive prices.

11	The provider are able to gather, collate and provide reports on outcome measures as defined in the NHS Contract, Commissioners requirements, Service Specifications and Quality Improvement Plans.
12	The provider meets (as a minimum) all the performance indicators as outlined in current WPATH Best Practice Guidance.