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Pwyllgor Gwasanaethau Iechyd
Arbenigol Cymru (PGIAC)

Welsh Health Specialised
Services Committee (WHSSC)

AGENDA ITEM 13

27 March 2012

SPECIALISED GENDER IDENTITY SERVICES PROJECT

Report of	Director of Planning
Paper prepared by	Acting Assistant Director of Planning
Executive Summary	<p>The WHSSC Management Team acts as the Project Board for the Specialised Gender Identity Services Project. The Project has now concluded, and the final report is due to be submitted to the next meeting of the Directors of Primary Care, Community and Mental Health Services, prior to consideration by the Joint Committee in June 2012.</p> <p>This report provides a summary of the key findings and recommendations from the review.</p>
Action/Decision required	To NOTE the key findings and recommendations from the review, and to NOTE the timeline for receiving the final report.
Link to Board Committee (s)	N/A

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Link to Standards for Health Services in Wales	2.	Equality, diversity and human rights
	6.	Participating in Quality Improvement Activities
	7.	Safe and Clinically Effective Care
	10.	Dignity and respect

INTRODUCTION

The Welsh Health Specialised Services Committee is responsible for planning:

- Specialist assessment and monitoring of real life experience for patients with Gender Dysphoria
- 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, including a review of the service pathway and model for the provision of specialised assessment services.

Following a series of meetings with service users and representatives from third sector organisations, the project was initiated on the 1st September 2011. 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.

SPECIALISED GENDER IDENTITY SERVICES PROJECT

Objectives

The following four 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.
- ii. Revise the referral pathway and to advise on the definitive model for providing Gender Dysphoria assessment and review for patients resident in Wales.
- iii. Identify criteria for selecting preferred providers for specialised assessment and gender reassignment surgery.
- iv. Clarify the role 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 –responsible for developing the following documents:

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- ***Directory of service within Wales*** – identifying services within Wales that provide support to patients with gender dysphoria.
- ***Service Specification and Model*** – identifying the preferred service model for the provision of assessment services for patients with gender dysphoria.

Service Quality Working Group - 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 the 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 were 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;

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- 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

The Equality Act (2010) 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.

As a subcommittee of the seven Health Boards, 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.

From the outset it was agreed that the project management group agreed would use an Equality Impact Assessment (EQIA) framework to anticipate the consequences of decisions on relevant groups. The NHS Centre for Equality and Human Rights provided support to the working groups and stakeholder reference group with the EQIA framework throughout the project.

The intention was to ensure 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

The approach enabled the working groups to design what they feel and believe as service users, clinicians, and planners to be a flexible service responsive to the needs and circumstances of individuals undergoing a very personal and unique journey.

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. A significant proportion of these issues relate to the experience of patients with primary care and mental health services, therefore the final report will be submitted to the next meeting of the Directors of Primary Care, Community and Mental Health Services. The aim is to ensure that full consideration can be given to the issues raised, at the appropriate level within each of the Health Boards, in order to ensure that Joint Committee members are sufficiently briefed to be able to make decisions on the final report at the June meeting of the Joint Committee.

KEY FINDINGS AND RECOMMENDATIONS

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 any 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.

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

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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.

CONCLUSION

The project has addressed the key objectives as agreed by the Joint Committee in November 2010, and has identified key findings and recommendations for improving planning of services for patients with gender dysphoria.

Further work is required to address the key issues of inequity surrounding access to primary and secondary care services, and to scope the feasibility of developing regional assessment services for Welsh patients.

RECOMMENDATIONS

Members of the Joint Committee are asked to:

- **NOTE** the key findings and recommendations from the review; and
- **NOTE** the timeline for receiving the final report

IMPACT ASSESSMENT

Health Improvement	Implementation of the project's recommendations should lead to reduction in the inequity experienced by individuals with Gender Dysphoria who are unable to access local endocrinology and speech and language support.
Workforce	The project has recommended that further work is undertaken on the models of provision to identify the workforce impact.
Education and Training	The report has identified that there are training and education gaps in primary care services.
Financial	The project has recommended that further work is undertaken on the models of provision to identify how existing resources can be used to develop regional services.
Legal	There are no specific legal issues that arise as a result of the Review.
Equality	The report has identified significant issues

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	relating to the equality act, the implementation of the key recommendations will address the issues raised.
Environmental	The provision of local services will reduce the requirement of individuals to travel out of area, and thus result in a reduced carbon footprint.

RISK ASSESSMENT

Clinical/Service	The implementation of recommendations would be expected to result in an improved service for users in terms of efficiency, quality, equity and user experience.
Financial	The project has recommended that further work is undertaken on the models of provision to identify how existing resources can be used to develop regional services.
Reputational	There has been full engagement with stakeholders from the Transgender community throughout the project.

Acronyms and abbreviations	
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CONSULTATION AND ENGAGEMENT

The Stakeholder Reference Group were involved throughout the project and the development of the key products, and provided a forum for discussion and feedback.

SOURCES OF INFORMATION

A full list of references is included within the final report. Copies of the report are available upon request.