Proposed revisions to Clinical Reference Groups – response from the National LGB&T Partnership

Introduction

This document provides feedback from the National LGB&T (lesbian, gay, bisexual and trans) Partnership, a member of the Department of Health, NHS England, and Public Health England's Health and Care Voluntary Sector Strategic Partner Programme. The National LGB&T Partnership is an England-wide group of LGB&T voluntary and community service delivery organisations (see below for members of the Partnership) that are committed to reducing health inequalities and challenging homophobia, biphobia and transphobia within public services

The National LGB&T Partnership members intend to positively influence the policy, practice and actions of Government and statutory bodies, in particular the Department of Health, for the benefit of all LGB&T people and communities across England. The member organisations of the National LGB&T Partnership are:

- LGBT Foundation
- East London Out Project (ELOP)
- Gay Advice Darlington and Durham (GADD)
- Gender Identity Research and Education Society (GIRES)
- Health Equality and Rights Organisation also known as GMFA
- Consortium of LGB&T Voluntary and Community Organisations
- London Friend
- PACE
- Stonewall Housing
- Yorkshire MESMAC
- METRO
- Birmingham LGB&T
- BiUK

The National LGB&T Partnership will ensure that health inequalities experienced by LGB&T people are kept high on the Government's agenda and that best use is made of the experience and expertise found within the LGB&T voluntary and community sector. The National LGB&T Partnership has also established a National LGB&T Stakeholder Group which is open to interested groups, organisations, service providers and individuals, giving a direct voice to the LGB&T sector. For more information, see http://nationallgbtpartnership.org.

Consultation Response

2.1 Additional resources have been identified for CRGs to support the work of the groups. Budgets will be allocated for increased administration support, holding meetings, planning engagement events and forming working groups.

The National LGB&T Partnership supports additional resources being allocated to CRGs to support their work.

2.2. The CRG Chairs will become a formal NHS England appointment with remuneration at one Programmed Activity (four hours a week). A recruitment process will be launched refreshing the chair for each CRG. All current CRG Chairs will have the option of applying in competition with new applicants for a three year appointment. All chairs will be accountable to the National Programme of Care Clinical Lead.

The National LGB&T Partnership believes that in the case of the CRG on Gender Dysphoria in adults, continuity of the current chairpersonship would be best as 'refreshing' it may be unhelpful. Testimony from a member of the National LGB&T Partnership states that 'in view of the de-psychopathologising of gender conditions in line with the upcoming removal of 'transsexualism' from the World Health Organisation's section on Mental and Behavioural Disorders in the International Classification of Diseases, it is perhaps more appropriate that the CRG continue to be led by a doctor who is not a psychiatrist, but who has a background in General Practice.'

This testimony suggests that the most appropriate candidate for chairpersonship should have a 'great understanding of the role of GPs. A number of GPs are reluctant or refuse to treat, which is disastrous, especially in circumstances where the GICs have insufficient capacity to provide treatment within 18 weeks; waiting times are now well over a year, and up to 3 years in one clinic. Up-skilling GPs as well as other providers of all services, whether gender-based or not, is a major concern.' The ideal candidate should also be able to work effectively with the specialist VCS to mutually reinforce the important and positive work being done around gender variance.

Furthermore, the Chair of the CRG for Gender Identity Services should have demonstrated their sensitivity to the needs of and genuine respect for gender variant young people.

2.3. Patient and Public Voice members of CRGs will be eligible for involvement payments in recognition of their contribution to the work of their CRG where they are not supported by an organisation. This brings the position for CRGs in line with other strategic PPV roles across specialised commissioning and will initially be subject to a maximum of four days a year per PPV member. Travel and subsistence expenses for PPV members will continue to be paid in line with existing NHS England policy.

Whilst the National LGB&T Partnership believes it is important that individual PPV members are supported to work in the CRGS, it may be most effective and efficient to have PPV members who are supported by an organisation because they can then speak for a wider number of people, rather than just provide a personal view.

In line with this, it is important to recognise that not all organisations will be able to financially support attendance, so where organisations are unfunded, or receive very little funding, financial support should be provided in line with that that is recommended for individuals attending.

2.4. To ensure work dovetails with the revised operating model for specialised commissioning, NHS England will simplify the operation of CRGs. The clinical membership will be reduced from 14 'senate' clinical members to four regional clinical members, and PPV membership will change from four to two individuals. The affiliated membership, including organisations such as Colleges and Societies, will remain at up to four members.

Expertise from within the National LGB&T Partnership strongly suggests that, in the trans field, it could be very unhelpful to reduce the numbers of PPV representatives to 2. In the now disbanded Gender Dysphoria CRG there was no actual representation of non-binary people although provision of treatment to this varied group was discussed.

Testimony from a Partnership member states that 'there is a case for having more than two PPV members not just to match the number of clinicians but also to represent the wide range of services users. There should be at least one person able to advocate on behalf of gender variant young people.'

'Additionally, the work of the CRG for Gender Identity Services should be made fully transparent. This requires utilising the NHS England mechanism

for engaging with the wider trans community for frequent communication about its work.'

The Partnership also recognises that, in the case of the Gender Identity Services, there is an absolute necessity for multidisciplinary working – which includes professionals who are not medical doctors and who play a key role in the provision of care. Consequently representation from the British Psychological Society and the The Royal College of Nursing is vital, as well as from the Medical Royal Colleges.

2.6. NHS England will continue to make use of sub groups and working groups to supplement the expertise of CRG members where further specialised expertise is required (for example when developing a clinical policy for a rare condition).

The National LGB&T Partnership supports the use of sub groups, but it should not be only clinical sub groups, but also PPV sub groups where particular issues may be addressed, e.g. facial feminising surgery, use of the 'real-life experience' and so on.

6 - Do you have any comments on the proposed revisions set out in sections 3 – 8 of the engagement guide relating to the numbers and remit of the CRGs within each National Programme of Care?

It appears that the CRG for Gender Identity Services will cover children and adolescents, as well as adults. This is highly necessary because:

> there is an overlap; adult services can accept people from age 17; the child and adolescent services can continue to treat until the 18th birthday

> the transition from child and adolescent services to adult services is critical but is not currently well managed.

> effective care for the younger patients reduces the cost of treating them as adults

It is appropriate for the Gender Identity Services CRG to be associated with the CRG for CAMHS, which should play a vital role in supporting gender variant children and adolescents but are too frequently not doing so. Health Education England has funded an e-learning resource on caring for these patients: http://www.nlmscontent.nesc.nhs.uk/sabp/gv