Written submission from the Cicely Saunders Institute of Palliative Care, Policy and Rehabilitation (HSC0012)

Executive Summary

- Lesbian, gay, bisexual and/or trans (LGBT) people are at increased risk of life-limiting illnesses, and may therefore have greater need for palliative care.

- LGBT people experience additional barriers and stressors in bereavement, including exclusion around the time of death, lack of recognition of the nature and depth of their relationships, and poor access to bereavement services.

- LGBT people may have different and/or additional needs when facing advanced illness or bereavement. Access to high quality person-centred care is dependent of the knowledge, skills and attitudes of health and social care professionals. Previous experiences of discrimination and exclusion will also affect individuals’ ability to engage with services, and whether they feel able to disclose their relationship and/or gender identity.

- Whilst there have been improvements to support the rights of LGBT people in the UK, experiences for many will be shaped by previous exposure to practices from cultures which discriminate or legislate against LGBT people.

- Ten simple low cost evidence based recommendations have been developed to reduce inequalities for LGBT people facing advanced illness and increase inclusive practice.

- Future research must: strengthen the evidence base with rigorous qualitative and quantitative studies with the LGBT communities; include population based studies beyond the context of mental health and sexual health; include interventional studies to improve care and outcomes for LGBT people; and identify best ways to implement evidence-based resources for quality improvement.

1. This response is for the Women and Equalities Committee inquiry into: whether health and social care provision is adequate for LGBT people; whether discrimination is still occurring; and what more needs to be done to improve LGBT access to health and social care. The ACCESSCare programme of research is led by the Cicely Saunders Institute of Palliative Care, Policy and Rehabilitation, King’s College London. The Cicely Saunders Institute is the first purpose built institute for research into palliative care. We are submitting evidence as leaders in LGBT health research in the context of advanced illness. Our ACCESSCare programme of research includes the first national study of LGBT experiences in the context of advanced illness, and the first population based study of bereavement outcomes for LGB people who have lost a partner or spouse.

2. This summary draws on research from two studies:

- ACCESSCare: advanced cancer care equality strategy for gender and sexual minorities - funded by Marie Curie.
- An appraisal to identify palliative care needs of sexual minorities in Zimbabwe - funded by the Open Society Foundations.

The findings from these studies are presented in the following peer reviewed journal articles:


This work has also informed two further (ongoing) studies: ACCESSCare B (Bereavement, funded by Marie Curie) and ACCESSCare C (Communication, funded by the National Institute for Health Research).

Understanding and addressing LGBT health inequalities

Palliative care needs of LGBT people

3. Lesbian, gay, bisexual and/or trans (LGBT) people have specific health-care needs, including when facing serious illness or bereavement. Our recent systematic review1 of the palliative care needs of LGBT people found that lesbian women and gay men have greater all-cause mortality than heterosexual people. They experience higher rates of certain cancers, are less likely to attend for routine screening (such as cervical screening), and are more likely to present later in the disease trajectory with more advanced illness. LGBT people also have higher rates of alcohol consumption, recreational drug use and mental illness (most pronounced within the bisexual and trans communities), linked to experiences of discrimination and exclusion. These factors mean that LGBT people are at increased risk of life-limiting illness and therefore potentially have greater need for palliative care.

Bereavement needs of LGBT people

4. Our second systematic review2 of the bereavement experiences of LGBT people who have lost a partner also found additional barriers and stressors in bereavement. Alongside the devastation of having lost a life partner, LGBT people describe exclusion around the time of death, lack of recognition of the depth and nature of their relationship, and reduced access to bereavement support services. The bereavement experience for LGBT people is shaped by the degree to which they feel comfortable to share the nature of their relationship with those around them including their clinical team, and to what extent that relationship is recognised and accepted by those individuals (see figure 1)2. Those whose relationship is not spoken about may not be offered the support they need in bereavement, and those whose relationship is not accepted by those around them may not feel able to ask about possible sources of support.
LGBT people have felt excluded from hospice services, in part due to the religious history of many hospices, and also due to the separation of care services for people dying of HIV/AIDS in the 1990s. These factors, alongside the discrimination and exclusion LGBT people describe in broader societal contexts, result in fears of disclosing the nature of their relationship to healthcare providers, which increases the risk that partners may not receive the care and support they need through illness and into bereavement. However, no research has considered outcomes for LGBT people in bereavement outside of the context of HIV/AIDS.

**Discrimination in health and social care:**

6. These systematic reviews informed our first primary research study of the programme, ACCESSCare, funded by Marie Curie, which sought to improve demand for, and supply of, palliative care for LGBT people facing life-limiting illness. The ACCESSCare project was designed to address this inequity through:

- The development and dissemination of evidence-based mass media resources co-designed with the LGBT communities to increase the demand for appropriate end-of-life care
- The improvement of supply of appropriate end-of-life care through development of training resources for integration within existing curricula for health care professionals

7. The project involved in depth qualitative interviews with 40 people from across the UK who identify as LGBT and were in the later stages of a life-limiting illness, their informal caregivers (partners, friends or relatives) as well as with bereaved informal caregivers of LGBT people who died from a progressive illness or condition. This study found that person-centred care needs for LGBT people may require different or additional consideration due for example to differing social support structures and additional legal concerns.
8. Some participants described good experiences of care, feeling respected and that their relationship was recognised and acknowledged. However, others described barriers to accessing person-centred care that were created within consultations due to, for example, assumptions of heterosexuality, homophobia/transphobia, or a lack of recognition of their relationships. They also described barriers at a service level, such as not feeling comfortable to share their identity within the institutional setting. The interviews showed us that experiences for LGBT people are positively or negatively affected by: what is said by healthcare professionals; the services made available to them to meet their needs; and explicit markers of inclusivity by the institution. However participants also described invisible barriers and stressors, including fears and previous experiences of discrimination, which shaped their preferences for disclosing their relationship to healthcare professionals. Access to person-centred care for LGBT people is dependent on: the knowledge, skills and attitudes of health and social care professionals; and professionals’ awareness of these factors, and how they may shape care experiences and access to services (see figure 2).  

[Diagram: Figure 2: Considerations for delivery of person-centred care for LGBT people]

9. Within the ACCESSCare programme of research we have also supported a sister study in Zimbabwe examining experiences of key populations (LGBT people, intersex people and sex workers) accessing healthcare. Individuals described illnesses being blamed on their sexual orientation, having to conceal their sexual orientation, or conform to ‘sexual norms’ to access healthcare, and healthcare professionals’ personal attitudes affecting the care they receive. Whilst there have been improvements to support the rights of LGBT people (Civil partnership Act 2004, the Gender Recognition Act 2004, the Equality Act 2010 and the Marriage (Same Sex Couples) Act 2013) in the UK, experiences for many will be shaped by previous exposure to cultures which discriminate or legislate against LGBT people.

Meeting the needs of LGBT people in health and social care:

**Recommendations to improve care for LGBT people**
10. From the ACCESSCare study, drawing on the positive experiences shared, 10 recommendations were developed to reduce inequalities for LGBT people facing advanced illness and increase inclusive practice (see table 1).

<table>
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<tr>
<th>Individual Level</th>
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<tbody>
<tr>
<td>1. Avoid using heterosexually framed or assumption laden language</td>
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<td>2. Demonstrate sensitivity in exploration of sexual orientation or gender history</td>
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<tr>
<td>3. Respect individuals’ preferences regarding disclosure of sexual identity / gender history</td>
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<td>4. Carefully explore intimate relationships and significant others, including biological and chosen family (friends)</td>
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<td>5. Explicitly include partners and/or significant others in discussions</td>
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<tr>
<th>Service / Institutional Level</th>
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<tr>
<td>6. Make clear statement of policies and procedures related to discrimination</td>
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<tr>
<td>7. Include content regarding LGBT communities in training on diversity and discrimination</td>
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<td>8. Increase LGBT visibility in materials (in written content and images)</td>
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<td>9. Provide explicit markers of inclusion (e.g. Rainbow lanyards or pin badges)</td>
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<td>10. Initiate partnerships and/or engagement with LGBT community groups</td>
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**Table 1: Recommendations to improve care for LGBT people**


**Increasing access to palliative care for LGBT people**

11. The ACCESSCare study was carried out in collaboration with LGBT partners GMFA/HERO. Community engagement was central to the success of this study. The ACCESSCare study data were also used to inform the development of a resource for LGBT people facing advanced illness (see figure 3), co-designed with our community partners, which is free to download.

The resource is designed to help individuals to think about: why sexual orientation or gender identity may be important in relation to care needs, and preferences; the care individuals are entitled to receive; what to do in the event of suspected discrimination during care, due to sexual orientation or gender identity; and where to go for more help and information.

**Improving palliative care for LGBT people**

12. Since the completion of the ACCESSCare study, training on the care needs of LGBT people facing advanced illness and bereavement has been delivered to over 1400 health and social care professionals across the UK. In addition, the ACCESSCare study has contributed to two policy documents, demonstrating the ongoing need to improve care for LGBT people: “Hiding Who I Am”: the reality of end-of-life care for LGBT people\(^5\), and the Care Quality Commission Thematic Review (CQC) ‘A different ending – addressing inequalities in end-of-life care’\(^6\).

**Current research at the Cicely Saunders Institute of Palliative Care, Policy & Rehabilitation, King’s College London**

13. We have two ongoing pieces of research which will build on the above evidence:

- **ACCESSCare B – Bereavement** (commenced summer 2017): Our systematic review of the bereavement outcomes of LGBT people found that, outside of the context of HIV/AIDS, no studies had measured bereavement outcomes for LGBT people who have lost a partner. ACCESSCare B, funded by Marie Curie, is a population based, cross sectional, mixed methods study to compare...
bereavement outcomes and experiences for LGB (lesbian, gay, or bisexual) and heterosexual bereaved partners. This study will also be utilised to estimate prevalence of complicated grief in LGB and heterosexual bereaved partners.

- **ACCESSCare C – Communication** (commenced spring 2018): Despite recent legislative changes in the UK, many individuals still describe discrimination, assumptions of heterosexuality, or insensitive communication within healthcare settings. In addition, healthcare professionals have requested guidance on how to improve their communication with LGBT+ people. ACCESSCare C, funded by the National Institute for Health Research, is a multilevel qualitative study to develop communication guidance for healthcare professionals around exploring sexual orientation and gender history/identity in the context of serious illness to facilitate improved person-centred care.

**Future Research**

14. Alongside the ongoing research at the Cicely Saunders Institute, future research with the LGBT communities must:

- Strengthen the evidence base with rigorous qualitative and quantitative studies with the LGBT communities
- Include population based studies beyond the context of mental health and sexual health
- Involve meaningful engagement with LGBT communities to co-design high quality research and disseminate research findings
- Include interventional studies to improve care and outcomes for LGBT people
- Address care needs of underrepresented minority groups, particularly the bisexual and trans communities
- Examine the care needs of relevant groups not explicitly represented within the LGBT acronym, including intersex, asexual and non-binary communities
- Consider intersectionality to ensure care addresses person-centred care needs of individuals across all of their protected characteristics
- Identify best ways to implement evidence-based resources for quality improvement

For further information on the evidence presented above or the ongoing studies, please contact:

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References