ONCOLOGICAL CONSIDERATIONS FOR THE LGBTQ PATIENT

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@DrAllyCat @DanofChorlton
## Areas Where Being LGBTQ Affects Cancer Care

<table>
<thead>
<tr>
<th>Trust in healthcare staff</th>
<th>Care &amp; support structures</th>
<th>Behavioural risk factors</th>
</tr>
</thead>
<tbody>
<tr>
<td>Treatment side effects</td>
<td>Psychosexual function</td>
<td>Fertility considerations</td>
</tr>
<tr>
<td>Screening needs</td>
<td>Screening provision</td>
<td>Screening uptake</td>
</tr>
<tr>
<td>Physiological differences e.g. hormones</td>
<td>Inherited cancer predisposition</td>
<td>Anatomical differences e.g. surgeries</td>
</tr>
</tbody>
</table>

Sexual orientation and trans status monitoring are poor in health data, so we still lack good quality data on cancer incidence and outcomes.
DEFINITIONS
DEFINITIONS - LGBTQ

LGBTQ stands for:
- Lesbian
  Women who have sex with women (WSW) may be used to talk about sexual behaviour
- Gay
  Men who have sex with men (MSM) may be used to talk about sexual behaviour
- Bisexual
- Transgender
- Queer or questioning

You may also see LGBTQIA+ encompassing:
- Asexual
- Intersex

It is important to distinguish between sexual orientation (and therefore sexual minority populations) and gender identity and trans status (and gender minority or gender diverse populations)
# Definitions – Gender Identity

<table>
<thead>
<tr>
<th><strong>Sex assigned at birth:</strong></th>
<th>Usually based on genitals: “male” or “female” but not necessarily binary e.g. Intersex</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Gender identity:</strong></td>
<td>“How a person <strong>identifies</strong> in terms of being male, female, both, neither, or another identity”</td>
</tr>
<tr>
<td><strong>Transgender/trans:</strong></td>
<td>“A person whose gender identity <strong>does not</strong> match the sex they were assigned at birth”</td>
</tr>
<tr>
<td><strong>Cisgender/cis:</strong></td>
<td>“A person whose gender identity <strong>does</strong> consistently match the sex they were assigned at birth”</td>
</tr>
<tr>
<td><strong>Intersex:</strong></td>
<td>“People born with variations in sex characteristics (chromosomes, gonads, sex hormones or genitals) that, do not fit the ‘typical definitions for male or female bodies’.”</td>
</tr>
</tbody>
</table>
DEFINITIONS – GENDER IDENTITY

Gender dysphoria:

- The discomfort or distress that can be experienced when a person’s gender identity is different from their sex assigned at birth
- May require medical treatment in a specialised gender service
- A ‘Condition related to sexual health’ in ICD-11
  - “HA60 - Gender incongruence of adolescence or adulthood”

<table>
<thead>
<tr>
<th>Trans man:</th>
<th>“Assigned female at birth but identifies as male”</th>
</tr>
</thead>
<tbody>
<tr>
<td>Trans woman:</td>
<td>“Assigned male at birth but identifies as female”</td>
</tr>
<tr>
<td>Non-binary:</td>
<td>“Any gender identity outside exclusively male or female.”</td>
</tr>
<tr>
<td></td>
<td><em>(Non-binary people may have been assigned male or female at birth)</em></td>
</tr>
</tbody>
</table>
THE CONTEXT

American Society of Clinical Oncology position statement: Strategies for reducing cancer health disparities among sexual and gender minority populations

ASCO is committed to addressing the needs of sexual and gender minority (SGM) populations as a diverse group at risk for receiving disparate care and having suboptimal experiences, including discrimination, throughout the cancer care continuum. This position statement outlines five areas of recommendations to address the needs of both SGM populations affected by cancer and members of the oncology workforce who identify as SGM:

1. Patient education and support
2. Workforce development and diversity
3. Quality improvement strategies
4. Policy solutions
5. Research strategies

In making these recommendations, the Society calls for increased outreach and educational support for SGM patients; increased SGM cultural competency training for providers; improvement of quality-of-care metrics that include sexual orientation and gender information variables; and increased data collection to inform future work addressing the needs of SGM communities.

EUROPEAN CONTEXT
RESPECT OF HUMAN RIGHTS, FULL EQUALITY

<table>
<thead>
<tr>
<th>Public funding for:</th>
<th>Psychotherapy available</th>
<th>Hormone therapy available</th>
<th>Vaginoplasty available</th>
<th>Hair removal</th>
<th>Breast augmentation available</th>
<th>Mastectomy available</th>
<th>Hysterectomy available</th>
<th>Phalloplasty available</th>
<th>Metoidioplasty available</th>
<th>Possible to change name only?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Austria</td>
<td>Occasionally</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>No, only after mental health evaluation, real life experience, appearance, hormone therapy required⁰</td>
</tr>
<tr>
<td>Belgium</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
<td>Yes</td>
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<tr>
<td>Britain</td>
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<td>Yes</td>
<td>Yes</td>
<td>No</td>
<td>Occasionally</td>
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<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
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<tr>
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<td>Czech Republic</td>
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<td>Yes</td>
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<td>No</td>
<td>No</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>No, mental health evaluation, permanent sterility required</td>
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<tr>
<td>Denmark</td>
<td>Occasionally</td>
<td>Yes</td>
<td>Yes</td>
<td>No</td>
<td>Occasionally</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>No metal health evaluation</td>
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<tr>
<td>Estonia</td>
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<td>Yes</td>
<td>Unknown</td>
<td>Unknown</td>
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<td>Unknown</td>
<td>Unknown</td>
<td>Unknown</td>
<td>Yes</td>
</tr>
<tr>
<td>Finland</td>
<td>Occasionally</td>
<td>Yes</td>
<td>Yes</td>
<td>Occasionally</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>Yes</td>
<td>No metal health evaluation</td>
</tr>
</tbody>
</table>

⁰See also EU legislation survey ‘Access to treatment and healthcare’;
¹The Council of Europe’s Commissioner, Hammarberg, criticised the Austrian authorities for requiring genital surgery as the only option for legally changing one’s gender. (TGEU 20/12/2007);
²Law designed to decriminalise Homosexuality, also decriminalised Transgender/Transsexuality.
STATISTICS
THE LGBTQ POPULATION

A 2016 pan-European survey\(^1\) estimated around as 6% of the population to be LGBT

- This ranged from ranging from 7.4% in Germany to 1.5% in Hungary
- The proportion of the population with LGB identities increased in younger cohorts

Urban areas tend to have higher LGB population rates than the national average

It is estimated that around 0.9% of the population are transgender\(^2\) but the range is broad across countries

- This estimate rises to 1.2% in children and young adults\(^3\)
- Estimates are higher when the definition “gender diverse” is used

Existing data may continue to underestimate due to ‘prefer not to say’ options and cultural context

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CANCER RISK FACTORS

Some subgroups of the LGBTQ population are at higher rates of:

- Blood-borne virus infection (incl. HIV, Hepatitis B, Hepatitis C)\(^1\)
- Recreational drug use\(^2\)
- Smoking\(^2,3\)
- Alcohol\(^2\)
- Obesity\(^4\)

What is the impact for us as oncologists?

- We may see more sexual minority patients when treating certain tumour types
- There are opportunities here for intervention and reducing risks of second cancers and other health conditions

3. Office for National Statistics; 2018. The odds of smoking by sexual orientation in England, 2016. Available at:
Very little cancer incidence data disaggregated by sexual orientation or trans status

- We are left to make inferences by linking data or due to associating incidence of LGBT status and the cancer

In LGB people:

- Higher rates of anal cancer in MSM, and higher still in HIV +ve MSM
  - Over-representation of other virally driven cancers such as Kaposi’s sarcoma and penile cancers
- Higher rates of cervical cancer in WSW
  - Over-representation of endometrial, oropharyngeal, stomach and mesothelioma

In trans people:

- Alterations to incidence of breast cancer in trans women and trans men compared to cisgender individuals
- Lower rates of prostate cancer in trans women
- Higher rates of virally driven cancers
- Higher incidence and mortality of bladder cancer

TRANS RIGHTS EUROPE MAP 2018

14 countries require sterilisation in gender identity recognition

PATIENT EXPERIENCE
The NHS Cancer Patient Experience Survey (2019) in the UK found longstanding differences between the experiences of LGB and heterosexual people relating to:

- Communication
- Respect
- Dignity
- Timeliness in accessing cancer diagnostic pathway

There were also new differences in the experience of:

- Clarity of explanation of cancer diagnosis and treatment plan
- Always being treated with respect and dignity by hospital staff
- Pain and psychological distress
- Feeling treated as a set of cancer symptoms rather than as a whole person
- Being given privacy when discussing condition and treatment, and when examined or treated
- Teams working well together to give the best possible care

“It isn’t questioned, but it is assumed you are heterosexual until you choose to make them aware of what you thought was obvious. We didn’t always do this as this might add to what was a stressful event by itself. However, the times we did bring it up, it helped us to relax and approach the situation in a much more together way”

“Previously when I saw a nurse, she repeatedly asked me if I was pregnant regardless of the fact I’d told her several times that it was impossible and advised her of my sexual orientation. I found this irritating and disrespectful and it would put me off seeing a medical professional again if I suffered similar symptoms”
INEQUALITIES FACED BY LGBT PEOPLE AFFECTED BY CANCER

The most common source of frustration from participants was the constant assumptions of heterosexuality made by health professionals, which made it impossible for them to feel treated like a whole person.

Participants also resented the additional stress associated with disclosure of their sexual orientation due to the lack of sensitivity from health professionals in being able to deal appropriately with this information.

A lack of targeted information for LGBT people was also identified and this was felt to be particularly important from the gay and bisexual men in the sample who had undergone treatment for prostate cancer.

FERTILITY AND CONTRACEPTION
ASK, DON’T ASSUME

You cannot infer a person’s sexual behaviour from their sexual orientation or their gender identity.

In oncology we have a legal and moral obligation to discuss:
- Potential impact on fertility
- Options for fertility preservation
- Potential teratogenicity of chemotherapy
- Appropriate contraception
- Possibility of pregnancy at the time of imaging or treatment

Gender affirming hormones are not a contraceptive, though transgender patients may be on additional contraceptive medications.

Sanders V, Pedersen S. Radiography (Lond) 2018;24 Suppl 1:S3-S6.
SEXUAL SIDE EFFECTS OF TREATMENT
PROSTATE CANCER CASE STUDY

62-year-old gay man – Diagnosed with locally advanced Gleason 4+3 prostate cancer

Treatment options:
- Prostatectomy?
- External Beam RT + Hormones?
- Brachytherapy boost?

Same sex partner at home
- Sexually active and had other partners
- Had not been given advice prior to PSA check or after biopsy

Concerned about RT effects on rectum
Concerned about hormonal effects on libido
Significant toxicity during radiotherapy

Continued on adjuvant hormone therapy
Relapsed with widespread bone metastases
  - Given docetaxel chemotherapy
  - Advice around anal intercourse required again

SEX WITH AND BEYOND CANCER

Talking about sex can be uncomfortable. If you are LGBTQ+ you may have at some point been on the receiving end of personal questions from others about who does what, with whom and how. This level of curiosity from people outside the community can make the experience of talking about sex feel intrusive. However, talking about sex is important, especially when we think about cancer. Your sex life may be affected by your treatments and it's important that you are able to discuss these changes with your partners and cancer care team.

LIFTING THE LID ON CANCER IN THE LGBTQ+ COMMUNITY

POSSIBLE CHANGES TO ANATOMY AND PHYSIOLOGY

Trans men

Diagrams and photos courtesy of Dr L Seal and Dr J Barrett.

Male chest reconstruction

Hysterectomy

Genital surgery

Only undertaken by 1/3 trans men in UK
POSSIBLE CHANGES TO ANATOMY AND PHYSIOLOGY

Trans women

Diagrams courtesy of Dr L Seal and Prostate Cancer UK. Trans women and prostate cancer. Available at: https://prostatecanceruk.org/prostate-information/are-you-at-risk/trans-women-and-prostate-cancer; accessed Sep 2021.
BREAST CANCER

1 in 7 lifetime risk for cis gender women

Most recent data from Netherlands\(^1\) suggests:

- 3x less common in trans women
- 5x less common in trans men

Implications for screening

- Family history
- BRCA

Photos courtesy of Dr L Seal and Dr J Barrett.
54-year-old trans man
  - On testosterone injections for 2 years
  - Male chest reconstruction

Incidental oestrogen receptor positive breast cancer
  - Advised to stop testosterone
  - Lymph node dissection
  - Commenced tamoxifen
  - Androgen receptor result negative
  - Restarted testosterone

They doctors weren’t quite sure what to do. They had never treated a trans guy before!
Recent study in Netherlands suggests incidence is 5x less than in cis men. Average of 17 years on hormones.

Androgen deprivation and oestrogens:
- Reduce prostate size
- Reduce PSA

Anatomy differs after vaginoplasty:
- Different symptoms
- Different diagnostic work-up

Implications for diagnosis
Implications for monitoring of already diagnosed prostate cancer

   Image from: the MayoClinic.com "Feminizing Surgery". Available at: https://www.mayoclinic.org/tests-procedures/feminizing-surgery/about/pac-20385102; accessed Aug 2021. Used with permission of Mayo Foundation for Medical Education and Research, all rights reserved.
CERVICAL SCREENING

Trans men and non-binary people

Many trans men and non-binary people have a cervix at screening age

- In a US survey\(^1\)
  - 19% of TMNB people did not want a hysterectomy (28% unsure)
  - 33% of non-binary people did not want a hysterectomy (28% unsure)

This population experience inequalities in cervical screening:

- In a US studies\(^2\)
  - 10–15% fewer up-to-date with screening
  - 11x more likely to have an inadequate sample
- In the UK, if registered male with their GP:
  - No routine call and recall
  - Labs frequently fail to process results

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BARRIERS AND FACILITATORS OF CERVICAL SCREENING

ENDOMETRIAL HYPERPLASIA

Incidence of endometrial cancer 17 per 100,000 in cis gender women

- Preceded by endometrial hyperplasia with atypia

No increased incidence reported in trans men but data:

- Not always disaggregated by natal gender
- Not adjusted for previous hysterectomy

Histopathology studies in trans men are conflicting2-5:

- Mixture of atrophic and active endometrium
- Hyperplasia and carcinoma are still rare

Important because:

- Many will retain a uterus, particularly non-binary people or those wishing for pregnancy
- In UK we recommend **ultrasound screening every 2 years in the UK once on testosterone for >2 years**

OTHER CANCERS OF NOTE

Ovarian tumours
Testicular tumours
Anal cancer
HIV-related tumours, e.g., Kaposi’s sarcoma
Meningioma
  - Cyproterone acetate (EMA warning)
Prolactinoma
Oestrogen-dependent tumours, e.g., Desmoid
Colorectal cancer

Impacting dysphoria or sexual function
Related to gender affirming-hormones
Virally driven
Requiring pelvic surgery or radiotherapy

Wagner AD, et al. Ann Oncol 2019;30(12):1914–24. © 2019 European Society for Medical Oncology. Published by Elsevier Ltd. All rights reserved.
OTHER CONSIDERATIONS

“Normal” laboratory values may be different
- And you may have difficulty requesting “sex-specific” tests

Blood transfusion systems may consider only women of child-bearing potential for O negative blood

When requesting investigations it is best practice to seek consent before disclosing trans status
- In your country, it may be a legal requirement to ask to disclose
- Explain that it will help with interpretation

Incidence and mortality data is currently difficult to draw conclusions from because:
- Gender affirming treatments and rates of use can differ between countries
- Most studies don’t disaggregate by sex-assigned at birth
SUPPORTING AND SIGNPOSTING
FIND OUT WHAT IS AVAILABLE TO YOUR PATIENTS!

Cervical screening for trans men and/or non-binary people

PROVIDING GOOD CARE
THE CARE WE PROVIDE

In a UK survey\(^1\)
- 6/10 health and social care practitioners with direct responsibilities for patient care, say they don't consider sexual orientation to be relevant to one’s health needs
- 1/10 say they are not confident in their ability to understand and meet the specific needs of LGB patients
- 1/4 are not confident in their ability to respond to the specific care needs of trans patients and service users
- 1/10 have witnessed staff expressing the belief that someone can be ‘cured’ of being LGB

Feeling safe to disclose sexuality and/or gender identity can improve care\(^2\)
- This can be encouraged by:
  - Posters / leaflets that are representative of the person’s identity
  - Badges / lanyards that are symbols of inclusivity

KNOWLEDGE, ATTITUDES AND BEHAVIOURS OF UK ONCOLOGISTS

Knowledge:
- 8% were confident in their knowledge of LGBTQ+ healthcare
- 75% felt they would benefit from further education

Attitudes:
- 57% felt it important to know a patient’s gender identity
- 29% to know their sexual orientation

Behaviours:
- 5% routinely enquired about sexual orientation
- 3% routinely enquired about gender identity
HOW TO IMPROVE LGBTQ CANCER CARE

Consultation
• Ask preferred
• Ask pronouns
• Ask about support networks
• Explain why you are asking sensitive questions e.g. sexual orientation, gender transition
• Consistent and correct salutation in correspondence

Environment
• Education for clinical & non-clinical staff
• Inclusive posters and imagery
• Avoiding gendered environments
• Be inclusive when inviting patients to contribute to service re-design

Evidence
• Ensure hospital administration systems can record sexual orientation and gender identity appropriately
• Reassure patients about confidentiality and use of data
• Inclusive trials and appropriate monitoring – see SAGER guidelines¹

Heidari et al. (2016) Research Integrity and Peer Review.
WHERE TO LEARN MORE
Review article
How can we meet the support needs of LGBT cancer patients in oncology? A systematic review
R. Webster a, *, H. Drury-Smith b

Editorial
Education to Improve Cancer Care for LGBTQ+ Patients in the UK
A.M. Berner a, *, R. Webster b, D.J. Hughes c, H. Tharmalingam d, D.J. Saunders e

Guidelines for the Primary and Gender-Affirming Care of Transgender and Gender Nonbinary People
Publication Date: June 17, 2016
https://transcare.ucsf.edu/guidelines.
THANK YOU!