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Cancer Care for the LGBTIQ Community: Addressing Inequalities

INSIGHTS FROM THE FIRST OFFICIAL MEETING OF THE LGBTIQ WORKSTREAM OF THE EUROPEAN CANCER ORGANISATION

Contents

Acknowledgements

We extend our sincere gratitude to all individuals and organisations whose contributions made this workshop and report possible. We extend our special thanks to the President of the European Cancer Organisation, Dr. Csaba Dégi, the co-chairs of the LGBTIQ workstream of the European Cancer Organisation, Dr. Nicolò Battisti and Stewart O'Callaghan, the co-chairs of the Inequalities Network of the European Cancer Organisation, Dr. Nicolò Battisti and Sarah Collen. We thank the Inequalities Network[a] and the LGBTIQ workstream of the European Cancer Organisation for organising the workshop and providing a platform for discussion and collaboration. We also express our appreciation to the LGBTIQ advocates, clinicians, researchers, and policymakers who participated in the workshop, sharing their insights and expertise. We acknowledge the valuable contributions of Prof. John de Wit from Utrecht University (UU), Prof. Henny Bos from University of Amsterdam (UvA), Stewart O'Callaghan from OUTpatients UK, Cianán Russell from International Lesbian and Gay Association-Europe (ILGA-Europe), Jana Hugo from the Organisation Intersex International-Europe (OII-Europe), Deekshitha Ganesan from Transgender Europe (TGEU), Dr. Alberto Giovanni Leone, Dr. Saverio Cinieri, Dr. Francesco Perrone, and Dr. Filippo Pietrantonio from Associazione Italiana Oncologia Medica (AIOM), and the representatives from the Sexual and Gender Minority Group of the American Association for Clinical Oncology, Dr. Charles Kamen, Dr. Shail Maingi, Dr. Chunkit Fung and Dr. Janette Merrill. Their dedication to addressing healthcare inequalities for the LGBTIQ community is instrumental in advancing equitable cancer care for all.

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a For more information about the activities of the European Cancer Organisation's Inequalities Network, visit: https://www.europeancancer.org/topic-networks/7:inequalities.html

Suggested Citation

Battisti, N., O'Callaghan, S., Dégi, C., Venegoni, E., Parker, Z. et al. (2024). Cancer Care for the LGBTIQ Community: Addressing Inequalities - Insights from the first official meeting of the LGBTIQ workstream of the European Cancer Organisation. European Cancer Organisation. Brussels

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1. Introduction

In the wake of increasing recognition of inequalities affecting healthcare, addressing inequalities in oncology for LGBTIQ identities is a topic that has only recently received attention within the healthcare sphere. This report presents outcomes from a workshop organised by the Inequalities Network of the European Cancer Organisation, dedicated to exploring and addressing the inequalities faced by LGBTIQ individuals within the realm of oncology. The workshop, attended by LGBTIQ advocates, clinicians, researchers, and policymakers, aimed to shed light on the unique challenges encountered by this community in accessing equitable cancer care and to strategise ways to mitigate these disparities. Different European and international organisations contributed to the event with presentations, including Utrecht University (UU), the University of Amsterdam (UvA), OUTpatients, the International Lesbian and Gay Association-Europe (ILGA-Europe), the Organisation Intersex International Europe (OII Europe), Transgender Europe (TGEU), the Italian Association of Medical Oncology (Associazione Italiana Oncologia Medica - AIOM) and the American Association for Clinical Oncology (ASCO).

Context

The LGBTIQ community continues to confront significant disparities in healthcare access and outcomes, with cancer care being no exception. Historically, LGBTIQ individuals have faced barriers such as discrimination, lack of culturally competent care, and limited access to healthcare services. Moreover, societal stigma and marginalisation have contributed to delayed diagnoses, inadequate screening, and suboptimal treatment options for LGBTIQ individuals with cancer. For example, a recent publication from the European Union Agency for Fundamental Rights[1], showed that both mammography and cervical smear tests are taken up at a lower rate among LGBTIQ people, compared to the general population, with only 10% of the LGBTIQ population declaring to have had a mammography in the previous year in 2023 (vs. 36% for the general population) and 27% of LGBTIQ people reporting to have undergone a cervical smear test in the previous 12 months, compared to 36% of the general population. Additionally, the report showed that the rate of intersex people who said they were diagnosed with cancer in the past year was 2%, which is higher than for the general population, which was 0.6%.

The data show that LGBTIQ people are indeed at risk of experiencing inequalities in cancer care, from the very starting point of the cancer care pathway. Nevertheless, despite this recent publication, the majority of data produced come from North America, with the European region lagging behind when it comes to quantifying and tackling the issue[2]. The persistence of systemic challenges in healthcare, including within oncology, conflicts with the European goal of ensuring that each individual, regardless of sexual orientation, sex characteristics, gender expression or gender identity, receives equitable and compassionate care. Failure to address these disparities not only perpetuates injustice but also undermines efforts to improve health outcomes and reduce the burden of cancer within the LGBTIQ community.

Consequently, it is essential that the oncology community in Europe improves its awareness of inequities faced by the LGBTIQ community, as well as for inequities faced by other marginalised communities. This will ensure more equitable cancer care for all.

2. The challenges: perspectives from the workstream meeting

The meeting brought together several contributions, that drew data on the topic of inequities faced by the LGBTIQ community in cancer care, which reflects inequities experienced in the entire healthcare system.

Research issues

Through searching the literature on LGBTIQ health inequalities, **Prof. John De Wit** from Utrecht University and **Prof. Henny Bos** from the University of Amsterdam outlined what had already been done in this remit and gathered evidence on the topic. Among the 21,792 records reviewed, 9,378 were eligible for further analysis, but only 275 publications were related to cancer, mostly addressing disparities in burden and risk factors, while neglecting areas like the psychosocial impact or responses to diagnosis. Breast and cervical cancer were among the most studied, followed by prostate and penile cancer. Overall, data on inequalities in cancer care for the LGBTIQ community are extremely lacking within the European landscape. As of now, the majority of studies on the topic were conducted in North America, with data not entirely generisable to the European landscape. For example, the American Society of Clinical Oncology (ASCO), which includes a Sexual and Gender Minority task force (SGM), has outlined strategies for reducing cancer health disparities, including the improvement of education and support, the increase of workforce diversity and development, the clear definition of research strategies and policy solutions. ASCO first detailed their goals in the position paper 'American Society of Clinical Oncology Position Statement: Strategies for Reducing Cancer Health Disparities Among Sexual and Gender Minority Populations', published in 2017[3]. The SGM task force was subsequently convened and completed a quantitative study published in 2019[4], the results of which underlined the importance of having a comprehensive approach, including the creation of safe spaces for SGM patients, improving patient navigation for SGM individuals, and increasing cancer prevention education of SGM individuals. Similar exercises are lacking in the European landscape, highlighting a critical gap in addressing the unique needs of SGM individuals within the realm of oncology.

In the European landscape, there is also a lack of intersectionality in the development of research. Intersectionality means accounting for how overlapping social barriers can create unique forms of oppression, even within the LGBTIQ community. This is rarely done in research and when sampling for a study. Moreover, researchers use different ways to cluster people from the LGBTIQ community, making it difficult to compare data. Another main problem is the lumping together of different identities under an umbrella definition, not accounting for their differences. This makes it impossible to stratify the data and retrieve information on specific groups (e.g. putting together 'LGBTIQ community', without specifying data for trans people, intersex people, gay people and so on, making it difficult to see which community relates to the specific data). The problem in collecting data representative of SOGIESC (Sexual Orientation, Gender Identity, Gender Expression and Sex Characteristics) communities, was reported as well by the civil society organisations who participated in the meeting, highlighting the lack of inclusiveness during the data collection phase.

Problems with healthcare

People from the LGBTIQ community face discrimination at different stages of the cancer pathway. As shown by data presented during the working group meeting by **Stewart O'Callaghan from OUTpatients**, which demonstrated that people from the community tend to be more exposed to risk factors, such as being a current or former smoker, alcohol consumption, and higher burden of HIV and hepatitis[4, 5]. However, in healthcare, the sources targeted at LGBTIQ people to raise awareness around these prevalent risk factors are insufficient.

Additionally, people from the LGBTIQ community might perceive healthcare as a potential source of discrimination, rather than a safe space. This is true for gay people who have been historically discriminated against in healthcare, particularly in the aftermath of the HIV epidemic. This is also the case for the transgender community, because of the current rise in the anti-trans movement that seriously impacts transgender healthcare. For intersex people healthcare is a source of

discrimination and stigmatisation since birth, for example when invasive, non-consensual surgical interventions are forced onto intersex children. With the growth of the intersex human rights movement over the last decade, more data about intersex persons' experience with cancer is emerging. Data from the oncology field shared by OUTpatients showed that problems arise when interacting with the oncology workforce. LGBTIQ people are less likely to be able to discuss concerns prior to treatment, to feel informed about different forms of therapies, to have the right amount of support for their health, and to receive emotional support after treatment. This information draws a picture of institutional stigma singling out individuals from the community, further marginalising them from the very start of the cancer path, the moment LGBTIQ patients face healthcare practitioners. These issues might contribute to making LGBTIQ people less prone to seek the help of the healthcare system, potentially leading to later diagnosis and worse prognosis.

Workforce issues

Workforce awareness of LGBTIQ specific needs is very limited, as these topics are rarely discussed during the educational path of healthcare practitioners. Additionally, attitudes towards the community might be imbued with ignorance towards realities affecting LGBTIQ people, but also with negative beliefs, both of which contribute to creating an unfavourable environment for queer people. During the meeting, data presented by Dr. Alberto Leone from AIOM that was collected in Italy, showed that only 19% of the Italian healthcare practitioners interviewed in the research felt competent in providing assistance to transgender patients, whereas 72% deemed receiving training on trans health needs as necessary, and 89% believed trans people are at risk of discrimination in healthcare. The research also highlights that 32% of the transgender respondents reported having experienced one or more acts of discrimination by healthcare providers[6,7]. The ASCO Sexual and Gender Minority task force points out that making patients feel comfortable in healthcare involves going beyond asking SOGIESC-specific questions, and includes:

- Training of workforce to sensitise them of the use of appropriate terminology and pronouns, in order to avoid minority stress and or microaggressions
- Being able to earn trust, through understanding and valorisation of the experiences of these patients
- Creating an inclusive atmosphere in the facility, in its public image, and when interacting with patients

Lack of resources

The topic of workforce relates also to the lack of resources that are specifically targeted to the queer community. Despite the community showing higher rates for certain risk factors, there is a substantial shortfall of resources developed to raise awareness towards cancer-specific risks related to those risk factors. Lack of resources include a lack of campaign and educational material, networks where LGBTIQ patients can receive peer support, a lack of publications and a lack of efforts in including topics related to systemic marginalisation when talking about inequities in oncology. To overcome this issue, campaigns like 'Remove the Doubt' from OUTpatients to raise awareness towards cervical smear test can contribute to increasing engagement within the community. However, work must also be done within the European cancer workforce.

Lack of policy

The lack of comprehensive cancer policy specifically addressing the LGBTIQ community results in significant healthcare disparities. At the EU level, the specific needs of queer people are not addressed, and documents dealing with cancer care may mention a general intention to tackle inequalities but fail to specify these intentions and align with the needs of the actual communities who experience this marginalisation. This, for example is evident from the over genderisation of screening programmes, which often leads to the exclusion of transgender people from screening programmes after aligning their documents with their gender, changing them from the one assigned at birth, and therefore losing healthcare coverage for screening procedures related to their sex characteristics. The absence of targeted policies contributes to the exacerbation of the issues faced by LGBTIQ people in oncology, leading to delayed diagnoses and poorer health outcomes. Developing inclusive cancer care policies that recognise and address these unique needs is essential for improving cancer prevention, early detection, and treatment among LGBTIQ individuals.

3. Recommendations for improving oncology for LGBTIQ people

Recommendations from North America, shared by ASCO, include creating and enforcing policies ensuring access to culturally competent care, ensuring adequate insurance coverage, and developing and enforcing policies prohibiting discrimination.

To align with international standards and enhance equity in cancer care across Europe, the recommendations and guidelines derived from the workstream meeting — endorsed by the European Cancer Organisation — should be included in future policy and advocacy development within the oncology community. These are as follows:

- **Screening**: screening programmes and policies should account for the realities of trans and LGBTIQ people; in order to ease access and improve the adherence rate to screening programmes, which would lead to earlier diagnosis and start of treatment, and consequently, better outcomes. This involves developing screening programmes based on body parts and/or sex characteristics of the individuals rather than on the gender markers on their identity documents.
- **Treatment**: clinical guidelines should be revised and should be updated to depathologise LGBTIQ identities, through decoupling them from psychiatric care and promoting a holistic approach to health based on physical needs. Additionally, advocacy programmes for personalised medicine plans should be supported, which could account for the identities of LGBTIQ people.
- **Education and training**: there should be an effort to raise awareness about risk factors related to cancer that are specific to the queer community, both within the community and workforce. Educational and training materials should be developed, and shared with clinics, information points, community centres, and other hot spots for the oncology community and the queer community. Finally, advocacy for training programmes should be increased to enhance healthcare professionals' cultural competence and understanding of LGBTIQ health needs.
- **Social and healthcare interventions**: campaigns should be developed that are targeted towards LGBTIQ people, for example HPV Vaccination campaigns or sensibilisation towards risk of substance abuse related to cancer (e.g. tobacco, alcohol). Similar efforts should aim to raise community engagement, e.g. queer people with first-hand experience of cancer. Healthcare environments should strive to develop an inclusive and open communication more welcoming towards LGBTIQ community.
- **Policy change**: policies should be developed in collaboration with representatives of the LGBTIQ community, in order to effectively address their specific issues. Additionally, policies should be evidence-based, basing their developments on the available intelligence. Strategies for healthcare providers to create more inclusive and affirming care environments for LGBTIQ patients might include:

    a. Education and Training: Advocate for training programmes to enhance healthcare professionals' cultural competence and understanding of LGBTIQ health needs.

    b. Policy Recommendations: Propose policy changes at institutional, regional, or national levels to promote equity in cancer care for the LGBTIQ community.

    c. Community Engagement: Emphasise the importance of involving LGBTIQ advocacy groups and community members in the development and implementation of initiatives.

4. Conclusions

The workshop organised by the Inequalities Network of the European Cancer Organisation underscored the significant disparities faced by the LGBTIQ community in oncology care. Participants highlighted systemic barriers such as discrimination, lack of culturally competent care, and limited access to healthcare services, which contribute to delayed diagnoses and suboptimal treatment outcomes. The evidence presented revealed that LGBTIQ individuals are less likely to participate in cancer screenings and more likely to encounter negative experiences within the healthcare system, exacerbating health disparities.

Furthermore, research on LGBTIQ cancer care in Europe is markedly insufficient, with most data originating from North America and often not addressing the specific psychosocial impacts or responses to diagnosis within this community.

The workshop's findings emphasise the need for inclusive and intersectional research methodologies that reflect the diverse identities within the LGBTIQ community. There is a clear call for improved training for healthcare professionals to enhance cultural competence and reduce discrimination, alongside developing targeted resources and campaigns to raise awareness about cancer risks specific to LGBTIQ individuals.

Additionally, the creation of comprehensive cancer policies that address the unique needs of LGBTIQ people is essential. These policies should include depathologising LGBTIQ identities, personalising medicine plans, and ensuring that screening programmes are inclusive. Implementing these recommendations is crucial to achieving equitable cancer care and improving health outcomes for the LGBTIQ community in Europe.

GLOSSARY

Gender assigned at birth: Gender that was given at ones' birth based on sex characteristics at birth, which can differ to the actual gender of a person.

Gender Expression: The external presentation of gender, which can include clothing, hairstyle, behaviour, and voice, and which may or may not conform to societal expectations of masculinity or femininity.

Gender Identity: A person's deeply-felt internal experience of gender, which may or may not align with the sex they were assigned at birth. It is fluid and there is room for variation in the course of a person's life. As a rule: always trust the person when they tell you their gender identity, even when it seems odd to you. The person knows better.

Inequalities/Equality vs Inequities/Equity: Inequalities refer to measurable differences or disparities between individuals or groups in various domains such as income, education, and health, without necessarily implying unfairness. Inequities, on the other hand, denote those inequalities that are considered unjust, unfair, and avoidable, often arising from systemic discrimination and social, economic, or political disadvantage. In essence, equality strives to give everyone the same tools, whereas equity strives to take into account the different conditions and give tools based on those conditions to reach an equitable life.

Intersectionality: A framework for understanding how various social identities such as race, gender, sexuality, and class intersect and create overlapping systems of discrimination or disadvantage. It highlights that individuals can experience multiple, interconnected forms of oppression simultaneously.

Intersex: An umbrella term used to describe the spectrum of variations of sex characteristics (primary or secondary) that naturally occur within the human species. Sex characteristics are set out from birth, the fact that someone has an intersex body can become apparent at different times in their life: at birth, during childhood, in puberty or even in adulthood. Intersex people can have any gender identity or sexual orientation.

LGBTIQ Community: An acronym that stands for "Lesbian, Gay, Bisexual, Transgender, Intersex, Queer". Note that the acronym can vary e.g. LGBT, LGBTI, LGBTIQA, with or without a "+", and others.

Minority Stress: The stress that affects people that are part of a stigmatised marginalised community due to being part of that community - it arises from forms of discrimination and factors of stress (micro and macro) arising from discrimination in different contexts of society (healthcare, institutions, law, daily life etc). It can arise from different factors including blatant hate, poor social support, low socioeconomic status, prejudice and others.

Non-binary: Refers to gender identities other than male or female.

Pronouns: Words used to refer to someone in place of their name. Common pronouns include the masculine 'he/him', the feminine 'she/her', and the neutral 'they/them'. It is important to correctly use pronouns that align with the gender identity of the person you are referring to, and to avoid misgendering them.

Queer: An umbrella term to define people who are not cisgender, nor heterosexual and differ on SOGIESC characteristics, and are part of the LGBTIQ community. It is a word reclaimed by the LGBTIQ community which was previously used as a slur to define them in the twentieth century.

Sexual Orientation: A person's emotional, romantic, or sexual attraction to others. This does not depend on gender identity. This is fluid and can vary during ones' life.

SGM: Sexual and Gender Minority is another acronym used for the queer community. Health research often

uses 'sexual and gender minority (SGM)' as a broader term for LGBTIQ populations. SGM includes people with same-sex or same-gender attractions or behaviours, differences in sex development, and non-binary sexual orientation, gender, and/or sex constructs.

SOGIESC: Sexual Orientation, Gender Identity, Gender Expression and Sex Characteristics is another acronym used for the queer community, which rather than enlisting the different names of the groups pertaining the community, indicates the characteristics on which these communities 'varies' and can be the source of their marginalisation.

Transgender/Trans people: Umbrella term that indicates an individual who has a gender identity that is different from the sex/gender assigned at birth.

Trans-specific Healthcare: Refers to medical care and services specific to the unique needs of transgender and gender non-conforming individuals. This type of healthcare aims to support the physical, mental, and emotional well-being of trans people, acknowledging and addressing the specific challenges they may face.

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Information on the organisations contributing in the meeting

ASCO: The American Society of Clinical Oncology is a professional organisation for physicians and oncology professionals involved in the study and treatment of cancer. Founded in 1964, ASCO's mission is to fight cancer through research, education, and promotion of the highest quality patient care. The society provides educational resources, professional development opportunities, and clinical guidelines for oncology practitioners, and it also advocates for policies that improve cancer care, including policies to improve the experience of marginalised communities in oncology, and address inequities.

Website: https://www.asco.org/

AIOM: The Associazione Italiana di Oncologia Medica (Association of Medical Oncology) is a professional organisation based in Italy dedicated to the field of medical oncology. AIOM aims to promote scientific research, education, and clinical practice in the prevention, diagnosis, and treatment of cancer. The association provides support to oncologists through training programs, conferences, and publications, and it also advocates for policies that improve cancer care and patient outcomes in Italy.

Website: https://www.aiom.it/

ILGA-Europe: The European region of the International Lesbian, Gay, Bisexual, Trans and Intersex Association (ILGA), is a worldwide federation dedicated to advocating for the rights of LGBTIQ people. Founded in 1996, ILGA-Europe works to achieve legal, political, and social equality for LGBTIQ individuals across Europe and Central Asia. The organisation engages in advocacy, research, and capacity-building activities, providing support to local and national LGBTIQ organisations, and working with European institutions for inclusive policies and legislation. ILGA-Europe also produces the annual Rainbow Map, an index which ranks European countries based on their legal and policy practices impacting LGBTIQ rights.

Website: https://www.ilga-europe.org/

Rainbow Map: https://rainbowmap.ilga-europe.org/

OII Europe: The Organisation Intersex International Europe, is a European umbrella organisation of intersex-led human rights organisations, dedicated to advocating for the rights of intersex people. Founded in 2012, OII Europe works to raise awareness about intersex issues, promote human rights, and combat discrimination faced by intersex individuals. The organisation engages in advocacy, education, and policy development, striving to ensure that intersex people have the same rights and opportunities as others. OII Europe collaborates with European institutions and governments to adopt inclusive and protective measures for intersex people. OII Europe publishes their annual Good Practice Map, which identifies and showcases best practices in supporting intersex individuals' rights and well-being in Europe, Central Asia and the Maghreb region.

Website: https://www.oiieurope.org/

Good Practice Map: https://www.oiieurope.org/good-practice-map-2023/

OUTpatients: OUTpatients is a UK-based organization focused on addressing and improving cancer care for LGBTIQ individuals. The organisation works to ensure that LGBTIQ people receive equitable and inclusive healthcare services by raising awareness about the specific health needs and disparities faced by the community. OUTpatients provides resources, training, and support to healthcare professionals to help them offer culturally competent care. Additionally, the organisation engages in advocacy to influence cancer care policies and practices, aiming to reduce discrimination and improve health outcomes for LGBTIQ patients. Their initiatives often include educational campaigns, research, and collaboration with other organisations to promote health equity.

Website: https://outpatients.org.uk/

University of Amsterdam (UvA): is a leading research university located in Amsterdam, Netherlands. Established in 1632, it is one of the largest and most prestigious universities in Europe. Prof. Henny Bos is a distinguished academic in the field of psychology and sexuality studies. Prof. Bos has made significant contributions to research, teaching, and advocacy related to sexual health, gender identity, and LGBTIQ issues. Her work may encompass areas such as sexual minority mental health, family dynamics, and the well-being of LGBTIQ youth and families.

Website: https://www.uva.nl/profiel/b/o/h.m.w.bos/h.m.w.bos.html

Utrecht University: research university located in Utrecht, Netherlands. Established in 1636, it is one of the oldest universities in the Netherlands and is known for its high academic standards and diverse range of programs across various disciplines. Prof. John de Wit is a prominent figure in the field of psychology and public health, particularly known for his work in sexual health research and in the field of LGBTIQ health. Prof. de Wit's research often focuses on HIV/AIDS prevention, sexual behaviour, and health psychology, contributing significantly to academic literature and public health policies in these areas.

Website: https://www.uu.nl/staff/jdewit

TGEU: Transgender Europe, is a European organisation dedicated to advocating for the rights and well-being of transgender people. Founded in 2005, TGEU works to improve the lives of trans people through advocacy, education, research, and capacity building. The organisation aims to combat discrimination, violence, and inequality faced by trans individuals across Europe and Asia. TGEU engages with policymakers, conducts research to inform policy and public opinion, and provides resources and support to trans communities and organisations. Their efforts focus on a range of issues, including legal gender recognition, healthcare access, and protection from violence and discrimination. Each year TGEU publishes the Trans Rights Index, a comprehensive visualisation tool that evaluates and compares the legal and policy landscape for transgender rights across different European countries.

Website: https://tgeu.org/

Trans Rights Index: https://tgeu.org/tgeus-trans-rights-index-map-2024-reveals-polarisation-in-trans-rights-in-europe-and-central-asia/

As the not-for-profit federation of member organisations working in cancer at a European level, the European Cancer Organisation convenes oncology professionals and patients to agree policy, advocate for positive change and speak up for the European cancer community.

Publication: June 2024

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