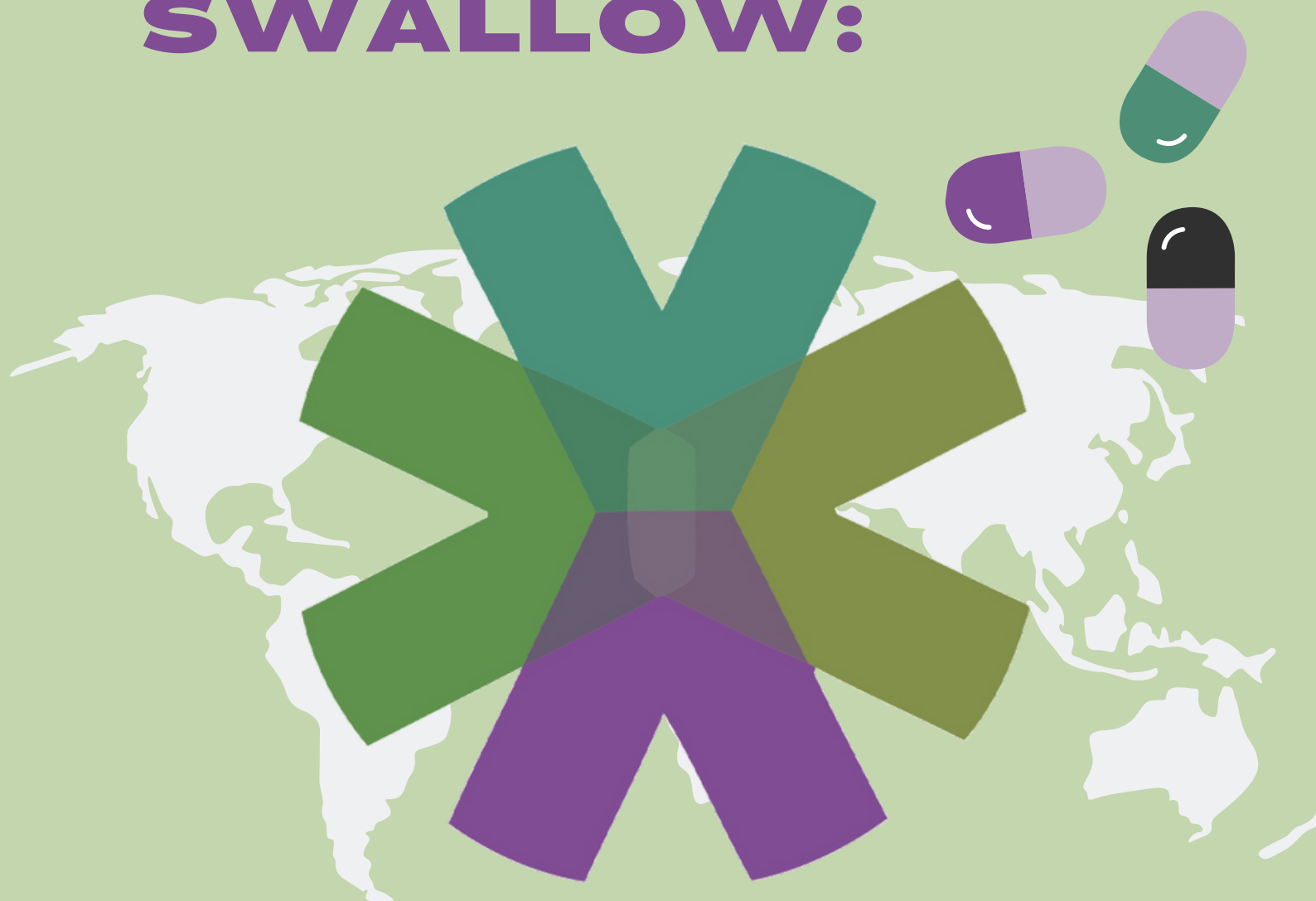


# A BITTER PILL TO SWALLOW:



## GAPS AND DISCRIMINATIONS IN HEALTHCARE FOR LESBIANS

FEBRUARY 2022



ELC

EUROCENTRALASIAN  
LESBIAN\* COMMUNITY

# A BITTER PILL TO SWALLOW: GAPS AND DISCRIMINATION IN HEALTHCARE FOR LESBIANS

EL\*C submission to the UN Independent Expert on Sexual Orientation and Gender Identity

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## ABOUT EL\*C

The EL\*C - EuroCentralAsian Lesbian\* Community is a non-governmental organisation, representing lesbian, queer, bi and trans women and non-binary people as well as lesbian organisations in Europe and Central Asia. The EL\*C uses the word lesbian as a broad inclusive term, including lesbians who identify as trans, non-binary, as well as intersex lesbians, and bisexual or queer women. For this reason, in this document, unless otherwise specified, the term “lesbian” includes all non-heterosexual LBTIQ women.

## INTRODUCTION

The present submission aims to provide a summary of the existing data and information concerning the health and wellbeing of lesbians. It focuses on research gaps, discrimination in accessing healthcare and on mental health, because the little data available points to worrisome situations, and on the impact of the COVID-19 pandemic, drawing in particular from the results of the EL\*C research **“Resistance as a way of living: lesbian lives through the COVID-19 pandemic”** [1].

The specific vulnerabilities that lesbians face depend on two intersecting factors: 1) the structural inequalities regarding women’s health in general and 2) the social stigma related to a non-heterosexual sexuality and to the heteronormative structures embedded in the healthcare systems. The first effect of this combination is wide-spread invisibility of lesbians, and their healthcare needs, in researches related to health and wellbeing. Conversely, lesbians are also vulnerable to discrimination when accessing healthcare, with relevant impacts on their physical and mental health.

The lack of data and the difficulties in accessing healthcare exemplify the complexity of appropriately including lesbians’ needs in processes related to Sustainable Development Goal (SDG) no. 3. Given lesbians’ intersectional position and the broader invisibility of their experiences, this is a concern that applies to the whole SDG process, for example the HLPF or the VNR presented by countries. In the case of health-related issues, involving lesbians in the SDG3 demands specific and targeted initiatives, which are currently lacking both in the actions of State actors as well as in those of other stakeholders, such as healthcare providers, funders, and researchers. As a result, the lesbian communities have often been obliged to take the lead in filling the gaps in knowledge and services.

EL\*C collaborates with many organisations and groups who provide information on sexual and reproductive health to the community [2] and who ensure that physical and mental health services are made accessible to lesbians, especially those in more vulnerable positions [3]. It is worth emphasizing that these projects have developed despite a chronic lack of funding for services targeting lesbians [4], often thanks to private donations by community members [5]. The situation has worsened with the COVID-19 pandemic [6]. Thus, without robust actions from State actors and other stakeholders, the difficulties in integrating lesbians in the fulfilment of the SDG3 can only be aggravated. For these reasons, a set of Recommendations detailing the actions needed in health-related research and policies is annexed to this document.

## THE INVISIBILITY OF LESBIANS IN HEALTH-RELATED RESEARCH

The underrepresentation of lesbians in research is not a recent phenomenon. Almost two decades ago, a review [7] on the inclusion of sexual and gender minority populations in public health research from 1980 to 1999 found that 28% of articles on sexual or gender minority health included data on lesbians and 9% include data on bisexual women, while the numbers were 80% and 39% for gay and bisexual men respectively. This “gender gap” seems to be driven mostly by the research focuses on sexually transmitted diseases of men who have sex with men, while not considering the sexuality of non-heterosexual women.

In 2017, the EL\*C released a **Brief Report on Lesbian Lives in Europe** focusing on the experience of discrimination and data on health for lesbians in Europe [8]. This study was based primarily on the largest EU-wide survey on discrimination and hate crime among LGBT populations at the time [9], as well as individual results from peer-reviewed journal articles and grey literature in European countries. It denounced a scarcity of research on lesbian and non-heterosexual women’s health. Most of the information available concerning mental, physical, and sexual health for this population was not sufficient to draw reliable conclusions.

Likewise, in the 2020 research on **The State of Lesbian Organising and the Lived Realities of Lesbians in the EU and the Accession Countries**, [10] EL\*C analysed the representation of lesbians in global health-related research on sexual minority populations. Considering data from health-related systematic reviews, we found that lesbians are underrepresented in research even within sexual minority populations: Out of the 230 health-related reviews eligible for inclusion, only 8% (19) focused on lesbian, bisexual and other non-heterosexual women specifically. Conversely, 51% (118) focused exclusively on gay, bisexual, and other non-heterosexual men and another 40% (93) focused on mixed populations.

In addition, we found that research on lesbian women is characterized by predominantly North American research, while studies from Europe and Central Asia are rare. On average, only 10% of studies included in a health-related systematic review stem from a European country and include data on lesbians. European research including data on lesbians is predominantly conducted in a handful of countries which are very progressive in terms of social acceptance and legal recognition of sexual and gender minorities. Finally, data is often lacking on part of the lesbian community affected by additional

stigma and subject to intersectional forms of discrimination, as is the case of migrant lesbians, lesbian with refugee status/asylum seekers and lesbians of colour, as well as of older lesbians [11].

### LACK OF RESEARCH DURING THE COVID PANDEMIC

The COVID-19 crisis has amplified existing inequalities in many areas, including healthcare. Furthermore, while the public debate in Europe and Central Asia increasingly focused on healthcare issues, lesbian activists could not fail to notice the underrepresentation, the invisibility and the discriminations faced by lesbians.

In 2021, when EL\*C decided to conduct a study on the impact of COVID on lesbian communities, there were already studies focusing on the disproportionate effects of the pandemic on women and the LGBTIQ community as a whole. Unfortunately, most of the studies that we came across did not consider thoroughly the combinations of factors such as gender and sexual orientation in the experiences linked with the pandemic.

The survey conducted by EL\*C is the largest study focusing specifically on lesbians' experiences during the pandemic, collecting the answers of 2113 individuals and 134 organisations and groups in Europe and Central Asia. The survey focused, among other things, on healthcare access and mental health.

## DISCRIMINATION IN THE ACCESS TO HEALTHCARE SERVICES

In the EU, one in six (16%) lesbian and bisexual women responding to the 2019 LGBTI Survey of the Fundamental Rights Agency of the European Union (FRA) reported episodes of discrimination when interacting with healthcare or social services staff [12]. The research available, albeit scarce, shows that the combination of misogyny and social stigma related to a non-heterosexual orientation can result in harmful or inadequate treatments by healthcare professionals, including inappropriate curiosity, lack of knowledge about specific healthcare needs, and assumed heterosexuality and heteronormativity by healthcare staff and in healthcare settings [13]. This can lead lesbians to not disclose their sexual orientation, even when this information would be instrumental for them receiving holistic healthcare. Ultimately, this situation can lead to avoidance or withdrawal from the healthcare system altogether [14].

Furthermore, the (rightful) distrust in healthcare systems is even higher for lesbians exposed to additional intersecting forms of discrimination. Lesbians of colour and migrant lesbians face unique but under-researched vulnerabilities [15]. For instance, lack of data makes invisible the specific health needs of lesbians (and transgender persons) living with Female Genital Mutilation (FGM) in Europe [16]. Moreover, transgender lesbians face unique experiences of discrimination, such as being misgendered or being confronted with practitioners who lack awareness regarding transgender health [17].

*Access to sexual and reproductive health*

The combination of gender-related inequalities endured by women (and people perceived as such) and discrimination based on sexual orientation is particularly relevant in health care settings where those personal characteristics are crucial in the access to appropriate treatments, such as in the case of sexual and reproductive health.

Participants in a qualitative study on lesbian and bisexual women's experiences conducted in **Finland** described healthcare as being heteronormative. Their own poor experiences and those of others had a negative impact on their utilisation of healthcare services. Participants had apprehensions about encountering stereotyping in healthcare and did not always disclose their sexual orientation [18].

Research from other European countries indicates that these concerns are likely not unfounded. In **Portugal**, for example, a survey of health practitioners identified heterosexist attitudes on issues such as same-sex marriage and reproduction, and a lack of professional knowledge in dealing with non-heterosexual women [19], emphasizing the need for training of healthcare professionals on the specific needs of lesbians. A **German** study revealed that only 40% of lesbian and other non-heterosexual women had revealed their sexual orientation to their doctor, while 11.9% had not done so even though they considered it important for examination or treatment. Furthermore, 12.4% had also experienced discrimination in the health care system, 3.8% were denied examination or treatment because of their sexual orientation, and 16.4% felt the need to talk about their sexual orientation and were not taken seriously by medical personnel [20].

Furthermore, when lesbians do reveal their sexual orientation, they may receive incomplete or incorrect medical information based on stereotypes or misconceptions. For example, while it is unclear from the state of the research whether lesbians are at an *increased* risk of developing any specific type of cancer, there is no doubt that cancer is a reality for lesbians just like any other population. This statement may seem trivial, but a prevailing myth among some healthcare professionals and in lesbian communities holds that women with exclusively female sexual contacts are not at risk of a Human Papillomavirus infection and thus of developing cervical cancer [21]. A study from **Sweden** showed that women who have sex with women had less experience of gynaecological examination and Papanicolaou smear screening. Yet, more than one-fifth of these women had at some time contracted a sexually transmitted infection and 12.6% reported a history of cervical anomalies [22]. Thus, empirical studies highlight the need for lesbians to engage in cervical cancer screening programmes [23].

#### *Role of partners and caregivers*

Patients themselves are not the only people affected by a heteronormative healthcare system. In the case of lesbians living with disabilities, chronic illness or other long-term diseases, the integration of caregivers and intimate partners is an important factor in the full enjoyment of highest attainable standard of physical and mental health. A recent systematic review on predominantly US-based studies identified partners of lesbians living with cancer as a crucial source of social support. Yet, the study showed that (female) partners of lesbians were confronted with discrimination in the healthcare system, experienced isolation, or alienation due to a lack of inclusive services and support groups for same-gender partners [24].

Again, these issues are exacerbated by systemic factors. In countries where lesbians do not have access to legal recognition of their relationships, same-gender partners might not be granted visitation rights or may not be treated as an intimate partner [25]. This is especially true if individual medical personnel and healthcare structures are unable or unwilling to acknowledge the role of a same-gender caretaker. Patients may be forced to choose between receiving the support they need by concealing their sexual orientation, or disclosing their sexual orientation in an unfriendly setting, thereby risking discrimination. Women with a same-gender partner are generally more economically vulnerable than men with a same-gender partner or women with a male partner [26]. Therefore, finding the financial means to fill the gaps in support and care in order to solve this conundrum, at least partially, can be more difficult or even impossible.

#### COVID IMPACT ON ACCESS TO HEALTHCARE

Access to healthcare proved to be problematic for lesbians during the COVID-19 pandemic. Almost one in three (29%) respondents to the EL\*C survey experienced difficulties in getting an appointment with a health care practitioner and almost one in four (23%) respondents experienced issues related to accessing special medical treatments (hormone treatments, fertility treatment, chemotherapy, psychotherapy). Sexual orientation appears to be a factor limiting access to healthcare. 22% of the lesbian organisations answering EL\*C's survey reported difficulties in accessing healthcare by their community members because of their sexual orientation

For respondents subject to further intersectional discrimination, access to healthcare was even more difficult. Trans respondents experienced difficulties in accessing general health care services in 35.5% of the cases (against 27% of cis respondents) and to specific treatments in 35% of the cases (against 19.6% of cis respondents). Having a disability was also a major factor limiting access to healthcare. The majority (55%) of lesbians with a disability experienced difficulties in accessing general healthcare (against 27% in cases of respondents without a disability), as well as in accessing special medical treatments (50% of respondents with a disability versus 21% of respondents without a disability).

## MENTAL HEALTH

The lack of data on the health of lesbians is particularly worrisome if we consider that the available studies show that lesbians face specific or higher risks of experiencing mental health problems, in comparison to heterosexual women [27].

In our own meta-analyses [28] using pooled data from studies conducted within European countries, we found that European lesbians display high risks related to suicide (41% with regard to lifetime suicidal ideation and 17% with regard to lifetime suicide attempts) compared to heterosexual women (17% with regard to lifetime suicidal ideation and 4% with regard to lifetime suicide attempts). These higher rates can (at least partially) be explained by the psychological consequences of systemic lesbophobia, such as experiences of discrimination, negative internalized thoughts about one's sexual orientation, or having to conceal one's sexual orientation [29]. Data shows that the lack of legal recognition for lesbian couples and families in many countries in the region has a negative impact on the mental health of lesbians [30] as well as their children [31]. For example, access to artificial

reproductive technologies (ARTs) for lesbians couples is a minefield of difficulties that are largely unknown to heterosexual couples, including conflicting legislations, prohibitions, expensive travels, and heteronormative and discriminatory attitudes by services providers [32].

#### **MENTAL HEALTH DURING THE COVID-19 PANDEMIC**

During the pandemic, 87% of the respondents of the EL\*C survey experienced feeling nervous or anxious, at least occasionally. 82% reported feeling depressed at least some of the time. 78% felt lonely and 75% felt hopeless. 60% reported having had physical reactions such as sweating, trouble breathing, nausea, insomnia, and/or a pounding head at least some of the time. 31.5% had physical reactions related to their menstrual cycles (e.g. deregulation of the menstrual cycle). Trans and non-binary participants were particularly likely to report feelings of loneliness and reduced access to LGBTIQ spaces during the pandemic (67% vs. 55%)



## ANNEX I - RECOMMENDATIONS FOR STATE ACTORS AND OTHER STAKEHOLDERS

1. Improve research and data collection on lesbians, particularly in studies on health of women and/or LGBTI people, by including tailored survey items and reporting disaggregated data for lesbians
2. Ensure that research and data collection efforts that focus specifically on lesbians are implemented and funded by national and international actors, and that such research specifically address barriers in lesbians' healthcare access as well as health disparities (e.g., sexual health needs, heightened mental health vulnerabilities)
3. Ensure the inclusion of lesbian-led organizations and community experts throughout the research cycle, in order to conduct research that is not only rigorous, but also inclusive, intersectional, and beneficial to the community
4. Put additional efforts into reaching and studying the situation of lesbians beyond the US and those European countries that are very progressive in terms of social acceptance and legal recognition of LGBTI people
5. Promote and support research projects specifically aimed at understanding the effects of intersectional discrimination on lesbian (e.g. older, lesbians, transgender lesbians, lesbians of colour, migrant lesbians and lesbians who are asylum seekers or have refugee status) and the impact of these multi-layered discrimination on access healthcare and specific health disparities
6. Ensure equal access to assisted insemination and IVF processes for lesbians (and transgender persons) as well as to preservation of eggs, in equal terms with heterosexual couples and single cis-hetero women
7. Design targeted campaigns and training for healthcare professionals with regard to the specific needs of lesbian health, with the direct involvement and leadership of lesbian civil society organisations, and include those campaigning and training in general health-related policies
8. Strengthen and increase visibility, participation, and representation of lesbian civil society organisations in policies and policy-making processes concerning public health and healthcare services
9. Finance community-based initiatives aimed at addressing existing gaps on access to healthcare for lesbians and specific health-related disparities for this population
10. Ensure that lesbians are explicitly recognised as a target group in funding priorities and that long-term operational and action funding is provided to lesbian organisations at every level



## ANNEX II – REFERENCES

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- [2] In Switzerland, the Klamydia, Association for the sexual health of women who love women, disseminates information on the health of lesbians (<https://www.klamydias.ch>). Similar projects exist in France, e.g. the project “Tomber la culotte” ([https://www.sida-info-service.org/?Tomber-la-culotte-Pour-s-informer&fbclid=IwAR2902Fvm6raGNjx-2OOyLtcuO4\\_JOqduYL1MoiU4NDwmYZFueO-w09F4](https://www.sida-info-service.org/?Tomber-la-culotte-Pour-s-informer&fbclid=IwAR2902Fvm6raGNjx-2OOyLtcuO4_JOqduYL1MoiU4NDwmYZFueO-w09F4)) and in Belgium where the GotoGyneco (<https://gotogyneco.be>) project puts lesbian, non-binary, bi and trans women in contact with doctors, especially gynaecologists, trained in providing inclusive care.
- [3] The project “Support for Lesbian, Bisexual and Queer Women in Russian-speaking Countries” (<https://europeanlesbianconference.org/locked-down-lesbians-listening-for-russian-speaking-lesbians-and-mental-health-issues/>) developed by a group Russian-speaking activists offered weekly online support groups with the presence of a trained psychologist, for lesbians living mainly in Russia and Ukraine. The Lesbian and Queer Counseling Center of Cologne (<https://www.cologne-counseling.com>) in Germany offers psychological support and therapy especially to lesbians and migrants in a very precarious and distressing situation.
- [4] Lesbians organisations and groups in Europe and Central Asia survive with median annual budget of less than 5.000 euro while only 8% of global funds related to LGBTIQ project are directed toward LBQ women. See for example the research report “Vibrant yet under-resourced: the State of LBQ Movement” ([https://www.mamacash.org/media/publications/astraea\\_mamacash\\_lbq\\_report\\_vdef.pdf](https://www.mamacash.org/media/publications/astraea_mamacash_lbq_report_vdef.pdf)) by the private foundation Astrea and Mamacash as well as the 2017-2018 report from the Global Philanthropy Project on Governmental and Philanthropic support for LGBTIQ Communities ([https://globalresourcesreport.org/wp-content/uploads/2020/05/GRR\\_2017-2018\\_Color.pdf](https://globalresourcesreport.org/wp-content/uploads/2020/05/GRR_2017-2018_Color.pdf))
- [5] A notable exception is the project “Salud integral de la mujeres diversas” (<https://fundacion26d.org/salud-integral-mujeres-diversas/>) of the Fundacion 26 Diciembre in Spain, focusing on health needs of women of the LGBTIQ community and funded by the Spanish government.
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- [8] EL\*C (2017), Brief Report on lesbian\* lives in (parts of) Europe. Focus topics discrimination and health <https://europeanlesbianconference.org/elc-brief-report/>
- [9] European Union Agency for Fundamental Rights (2014). European Union lesbian, gay, bisexual and transgender survey: Main results. Luxembourg: Publications Office of the European Union..
- [10] EL\*C (2020), The state of lesbian organizing and the lived realities of lesbians in the EU and the accession countries <https://europeanlesbianconference.org/the-state-of-lesbian-organising-a-groundbreaking-research/>
- [11] For example, in the EL\*C survey on the impact of COVID only 9% of the respondents were above the age of 55 and only 4% of the respondents identified as migrant, 3% as lesbian of colour and 1% as asylum seeker and refugees
- [12] FRA (2019), EU survey database available here: <https://fra.europa.eu/en/news/2020/fras-lgbti-survey-dataset-now-available>
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- [32] See for example the report published by Civio: <https://civio.es/medicamentalia/2021/11/02/ART-EU-access/>