

Healthcare experiences at the intersection of LGBTQ+ identity and chronic illness

An interdisciplinary understanding

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Background

- Evidence that LGBTQ+ people experience health inequalities both internationally (Jennings et al, 2019; Zeeman et al, 2019) and in the UK (Elliot et al, 2015; Booker et al, 2017; Cross et al, 2023; Kneale et al, 2020).
- LGBTQ+ people may have poorer overall health and have worse healthcare experiences than their heterosexual, cisgender peers (Meads et al, 2019; Elliot et al, 2015; Saunders et al, 2023)
- Evidence suggests LGBTQ+ people experience higher rates of some long term conditions, and increased multimorbidity (Saunders et al, 2021; Saunders et al, 2023; Han et al, 2020)
- Health inequalities contributed to by complex interaction of factors (Zeeman et al, 2019)

- People living with chronic illness (PwCI) have also been shown to experience barriers to accessing healthcare (Schulman-Green et al., 2016; McManimen et al., 2019).
- Differences in healthcare systems can make generalising research difficult, particularly between US healthcare and UK healthcare (Schneider et al, 2021).
- Exists an association between deprivation and chronic illness (Raymond et al, 2024). For LGBTQ+ people the picture is more mixed (Askoy et al, 2017; McKechnie, 2023) In particular, LGBT people in the US more likely to experience poverty (Badgett et al, 2019).
- In US, cost of access to healthcare is a prominent barrier (Dahlhamer et al, 2016) . This does not translate to UK context.

How can we improve access to healthcare for people who are LGBTQ+ and living with chronic illness in England?

Phase 1 Scoping review

What is known from the literature?

Phase 2 Qualitative creative methods

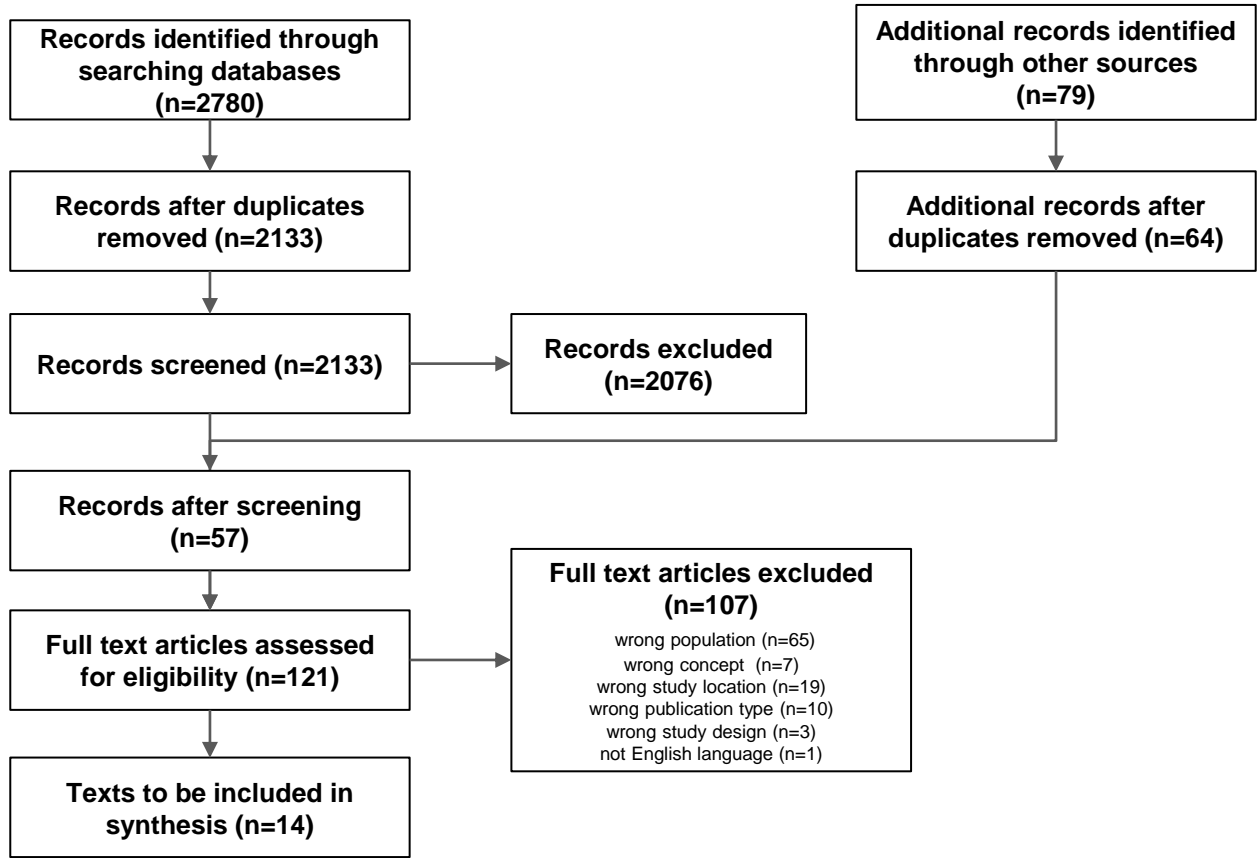
What do LGBTQ+ PwCI know about navigating healthcare?

Phase 3 Online focus group

What might improve access for LGBTQ+ PwCI?

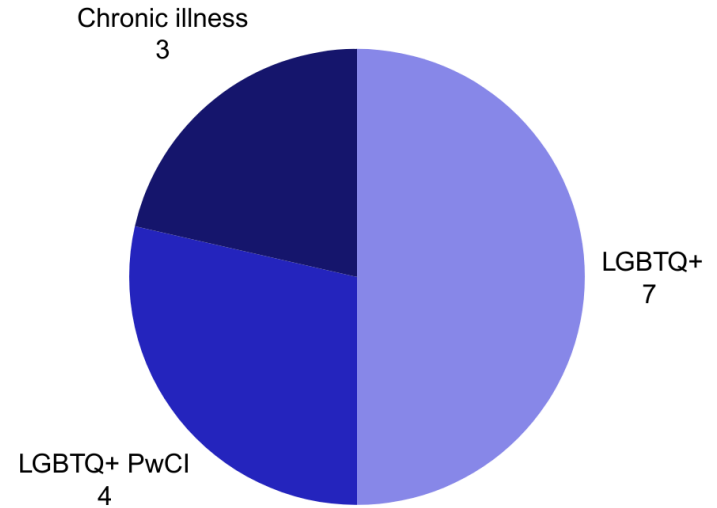
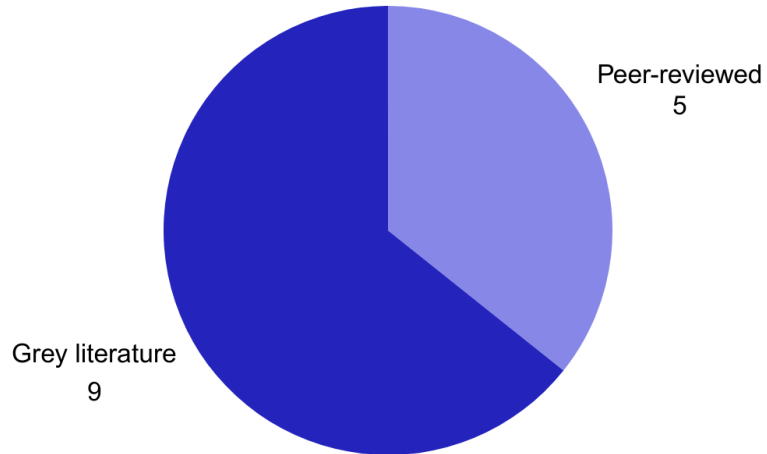
Methods

- **Aim:** To understand what is known from the existing literature about healthcare for LGBTQ+ people living with chronic illness in the United Kingdom
- **Method:** Scoping review (Arksey and O'Malley, 2005)
- **Population:** LGBTQ+ people living with chronic illness; **Concept:** healthcare; **Context:** UK, all healthcare settings including community
- Systematically searched PubMed, Scopus, Academic Search Complete, ScienceDirect, and JSTOR
- Grey literature search covered 2 grey lit databases, nhs.uk domains, 53 organisational websites
- Excluded studies relating to cancer and HIV/AIDS only



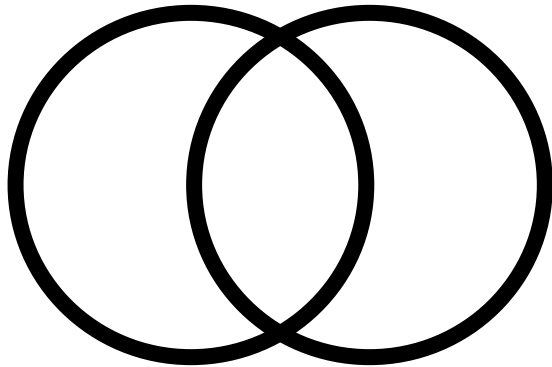
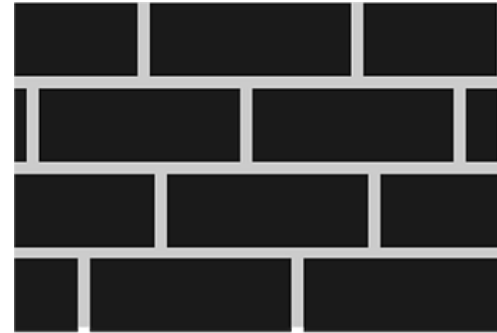
Results

14 publications included



Shared barriers

Consistent with wider LGBTQ+/chronic illness literature (Heteronormativity: Meads et al, 2019; language: Brooks et al, 2018; disbelief: McMannion et al, 2019)

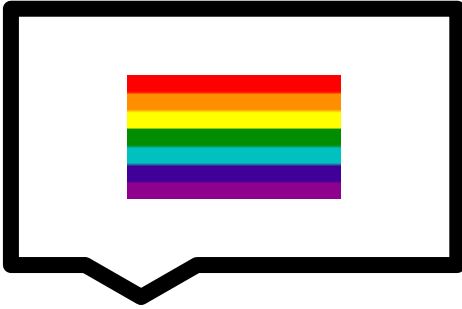


Intersectional discrimination

Ableism in trans health care (Pepe, 2021; Evans et al, 2023)

Homophobia/transphobia in secondary health care (Hord and Metcalf, 2021; Pepe, 2021)

Intersectional? (Evans et al, 2023; Lampe and Nowakowski, 2020)



Disclosure and disbelief

Conditions affect likelihood of disclosing sexual orientation/gender identity (Evans et al, 2023; Healthwatch North Yorkshire, 2020; Healthwatch Luton, 2023)

Training

8 studies recommended more training for healthcare professionals (Kokay et al, 2023; Hord and Metcalf, 2021; Tollemache et al, 2021; Healthwatch Merton, 2015; Varney and Newton, 2018; Evans et al, 2023; Healthwatch North Yorkshire, 2020; Healthwatch Luton, 2023)



Transition-related care

Long waits lengthened (Hord and Medcalf, 2021; Healthwatch North Yorkshire, 2020)

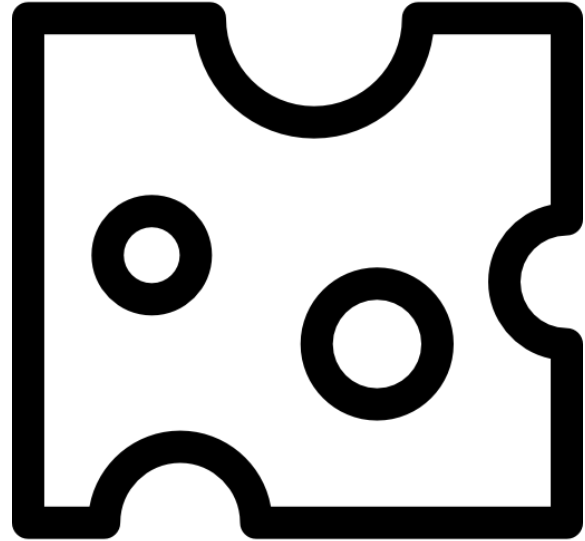


Data systems

Current NHS system recording sex/gender challenging (Braybrook et al, 2023; Evans et al, 2023; Hord and Medcalf, 2021)

Current gaps in the literature

- Exploration of intersectional nature of experiences
- Accounts of navigating care
- Evaluating effectiveness of recommendations
- Accounts in particular settings



Next steps

Phase 2 **Qualitative creative methods**

What do LGBTQ+
PwCI know about
navigating healthcare?



References (1)

Note: Reference in bold have been included in the review

- Aksoy, C.G., Carpenter, C.S. and Frank, J., (2018) Sexual Orientation and Earnings: New Evidence from the United Kingdom. *ILR Review*, [online] 711, pp.242–272. Available at: <https://doi.org/10.1177/0019793916687759> [Accessed 12 May 2024].
- Arksey, H. and O'Malley, L., (2005) Scoping studies: towards a methodological framework. *International Journal of Social Research Methodology*, [online] 81, pp.19–32. Available at: <https://doi.org/10.1080/1364557032000119616> [Accessed 2 May 2023].
- Badgett, M.V.L., Choi, S.K. and Wilson, B.D.M., (2019) *LGBT poverty in the United States*. [online] Los Angeles: The Williams Institute and American Foundation for Suicide. Available at: <https://epgn.com/wp-content/uploads/2019/11/National-LGBT-Poverty-Oct-2019.pdf> [Accessed 11 May 2024].
- Booker, C.L., Rieger, G. and Unger, J.B., (2017) Sexual orientation health inequality: Evidence from Understanding Society, the UK Longitudinal Household Study. *Preventive Medicine*, [online] 101, pp.126–132. Available at: <https://www.sciencedirect.com/science/article/pii/S0091743517302141> [Accessed 10 Apr. 2023].
- Braybrook, D., Bristowe, K., Timmins, L., Roach, A., Day, E., Clift, P., Rose, R., Marshall, S., Johnson, K., Sleeman, K.E. and Harding, R., (2023) Communication about sexual orientation and gender between clinicians, LGBT+ people facing serious illness and their significant others: a qualitative interview study of experiences, preferences and recommendations. *BMJ Quality & Safety*, [online] 322, pp.109–120. Available at: <https://qualitysafety.bmj.com/content/32/2/109> [Accessed 1 Jan. 2AD].**
- Brooks, H., Llewellyn, C.D., Nadarzynski, T., Pelloso, F.C., Guilherme, F.D.S., Pollard, A. and Jones, C.J., (2018) Sexual orientation disclosure in health care: a systematic review. *British Journal of General Practice*, [online] 68668, pp.e187–e196. Available at: <https://bjgp.org/content/68/668/e187> [Accessed 13 May 2024].
- Cross, H., Bremner, S., Meads, C., Pollard, A. and Llewellyn, C., (2023) Bisexual People Experience Worse Health Outcomes in England: Evidence from a Cross-Sectional Survey in Primary Care. *The Journal of Sex Research*, [online] 00, pp.1–9. Available at: <https://doi.org/10.1080/00224499.2023.2220680> [Accessed 10 May 2024].
- Dahlhamer, J.M., Galinsky, A.M., Joestl, S.S. and Ward, B.W., (2016) Barriers to Health Care Among Adults Identifying as Sexual Minorities: A US National Study. *American Journal of Public Health*, [online] 1066, pp.1116–1122. Available at: <https://ajph.aphapublications.org/doi/abs/10.2105/AJPH.2016.303049> [Accessed 12 May 2024].
- Dibley, L., Norton, C., Schaub, J. and Bassett, P., (2014) Experiences of gay and lesbian patients with inflammatory bowel disease: A mixed methods study. *Gastrointestinal Nursing*, [online] 126, pp.19–30. Available at: <https://www.scopus.com/inward/record.uri?eid=2-s2.0-84907506410&doi=10.12968%2fgasn.2014.12.6.19&partnerID=40&md5=f2579bae110eb51e50952e19dfbd02d1>.**
- Elliott, M.N., Kanouse, D.E., Burkhart, Q., Abel, G.A., Lyratzopoulos, G., Beckett, M.K., Schuster, M.A. and Roland, M., (2015) Sexual Minorities in England Have Poorer Health and Worse Health Care Experiences: A National Survey. *Journal of General Internal Medicine*, [online] 301, pp.9–16. Available at: <https://doi.org/10.1007/s11606-014-2905-y> [Accessed 9 Jun. 2023].

References (2)

- Evans, B., Allam, A., Hale, C., Pereira, A.B., Rose, M. and Ruddock, A., (2023) *Gendered experiences of healthcare for people with energy limiting conditions*. [online] Liverpool: Disbelief and Disregard. Available at: <https://disbeliefdisregard.uk/wp-content/uploads/2023/09/1-Background-executive-summary.pdf> [Accessed 25 Sep. 2023].
- Han, B., Duncan, D., Arcila-Mesa, M. and Palamar, J.J., (2020) Co-occurring mental illness, drug use, and medical multimorbidity among lesbian, gay, and bisexual middle-aged and older adults in the United States: a nationally representative study. *BMC Public Health*, [online] 201, p.1123. Available at: <https://doi.org/10.1186/s12889-020-09210-6> [Accessed 9 Jun. 2023].
- Healthwatch Luton, (2023) *Voice of LGBTQIA+ Luton residents: Denny Engagement Report*. [online] Luton: Healthwatch Luton. Available at: https://nds.healthwatch.co.uk/sites/default/files/reports_library/20231020_Luton_Voice%20of%20LGBTQIA%2B%20Luton%20residents.pdf.
- Healthwatch Merton, (2015) *Merton LGBT workshop report*. [online] Mitcham: Healthwatch Merton. Available at: https://nds.healthwatch.co.uk/sites/default/files/reports_library/20151127_Merton-%2520LGBT%2520report.pdf.
- Healthwatch North Yorkshire, (2020) *LGBTQ+ people's experience of using health and social care services in North Yorkshire*. [online] York: Healthwatch North Yorkshire. Available at: https://nds.healthwatch.co.uk/sites/default/files/reports_library/20230329_Waltham_Forest_long-term-conditions.pdf.
- Hord, L. and Medcalf, K., (2021) *Trans people's experiences of healthcare in England*. [online] London: TRANSforming Futures project. Available at: https://www.transformingfuturespartnership.co.uk/files/ugd/76972e_ce8838ff555049b993397610e44e7135.pdf.
- Jennings, L., Barcelos, C., McWilliams, C. and Malecki, K., (2019) Inequalities in lesbian, gay, bisexual, and transgender (LGBT) health and health care access and utilization in Wisconsin. *Preventive Medicine Reports*, [online] 14, p.100864. Available at: <https://www.sciencedirect.com/science/article/pii/S221133551930049X> [Accessed 9 Jun. 2023].
- Kneale, D., Thomas, J. and French, R., (2020) Inequalities in Health and Care Among Lesbian, Gay, and Bisexual People Aged 50 and Older in the United Kingdom: A Systematic Review and Meta-analysis of Sources of Individual Participant Data. *The Journals of Gerontology. Series B, Psychological Sciences and Social Sciences*, 758, pp.1758–1771.
- Kokay, W., Power, E. and McGrath, M., (2023) Mixed Study Systematic Review and Meta-analysis of Sexuality and Sexual Rehabilitation in LGBTQI+ Adults Living With Chronic Disease. *Archives of Physical Medicine and Rehabilitation*, [online] 1041, pp.108–118. Available at: <https://www.sciencedirect.com/science/article/pii/S0003999322005779> [Accessed 12 Dec. 2023].
- Lampe, N.M. and Nowakowski, A.C.H., (2020) New horizons in trans and non-binary health care: Bridging identity affirmation with chronicity management in sexual and reproductive services. *International Journal of Transgender Health*, [online] 221, pp.141–153. Available at: <https://www.scopus.com/inward/record.uri?eid=2-s2.0-85094923703&doi=10.1080%2f26895269.2020.1829244&partnerID=40&md5=7dbb0ebddffc8634949c4e6afa144355>.

References (3)

- McKechnie, D.G.J., O’Nions, E., Bailey, J., Hobbs, L., Gillespie, F. and Petersen, I., (2023) Transgender identity in young people and adults recorded in UK primary care electronic patient records: retrospective, dynamic, cohort study. *BMJ Medicine*, [online] 21. Available at: <https://bmjmedicine.bmj.com/content/2/1/e000499> [Accessed 12 May 2024].
- McManimen, S., McClellan, D., Stoothoff, J., Gleason, K. and Jason, L.A., (2019) Dismissing chronic illness: A qualitative analysis of negative health care experiences. *Health Care for Women International*, [online] 403, pp.241–258. Available at: <https://doi.org/10.1080/07399332.2018.1521811> [Accessed 9 Jun. 2023].
- Meads, C., Hunt, R., Martin, A. and Varney, J., (2019) A Systematic Review of Sexual Minority Women’s Experiences of Health Care in the UK. *International Journal of Environmental Research and Public Health*, [online] 1617, p.3032. Available at: <https://www.mdpi.com/1660-4601/16/17/3032> [Accessed 9 Jun. 2023].
- National Institute for Health and Care Excellence, (2018) *Endometriosis: Quality standards*. [online] London: National Institute for Health and Care Evidence. Available at: <https://www.nice.org.uk/guidance/qs172> [Accessed 1 Jan. 2024].**
- NHS North East London Integrated Care Board, (2023) *Long term conditions*. [online] London: NHS North East London Integrated Care Board. Available at: https://nds.healthwatch.co.uk/sites/default/files/reports_library/20230329_Waltham_Forest_long-term-conditions.pdf.**
- Pepe, M., (2021) *Nobody Teaches You How To Be a Patient: The lived experiences of neurodivergent, disabled and chronically ill trans people*. [online] TransActual. Available at: <https://transactual.org.uk/wp-content/uploads/Nobodyteachesyouhowtobeapatient.pdf> [Accessed 13 Dec. 2023].**
- Raymond, A., Watt, T., Douglas, H.R., Head, A., Kypridemos, C. and Ratchet-Jacquet, L., (2024) *Health inequalities in 2040 - The Health Foundation*. [online] London: The Health Foundation. Available at: <https://doi.org/10.37829/HF-2024-RC01> [Accessed 13 May 2024].
- Saunders, C.L., Berner, A., Lund, J., Mason, A.M., Oakes-Monger, T., Roberts, M., Smith, J. and Duschinsky, R., (2023) Demographic characteristics, long-term health conditions and healthcare experiences of 6333 trans and non-binary adults in England: nationally representative evidence from the 2021 GP Patient Survey. *BMJ Open*, [online] 132, p.e068099. Available at: <https://bmjopen.bmj.com/content/13/2/e068099> [Accessed 10 Jun. 2023].
- Saunders, C.L., MacCarthy, S., Meads, C., Massou, E., Mant, J., Saunders, A.M. and Elliott, M.N., (2021) Long-term conditions among sexual minority adults in England: evidence from a cross-sectional analysis of responses to the English GP Patient Survey. *BJGP Open*, [online] 55. Available at: <https://bjgpopen.org/content/5/5/BJGPO.2021.0067> [Accessed 9 Jun. 2023].
- Schneider, E., Shah, A., Doty, M., Tikkanen, R., Fields, K. and Williams, R., (2021) *Reflecting Poorly: Health Care in the U.S. Compared to Other High-Income Countries*. Mirror, Mirror. [online] New York: The Commonwealth Fund. Available at: https://www.commonwealthfund.org/sites/default/files/2021-08/Schneider_Mirror_Mirror_2021.pdf [Accessed 18 May 2023].

References (4)

Schulman-Green, D., Jaser, S.S., Park, C. and Whittemore, R., (2016) A metasynthesis of factors affecting self-management of chronic illness. *Journal of Advanced Nursing*, [online] 727, pp.1469–1489. Available at: <https://onlinelibrary.wiley.com/doi/abs/10.1111/jan.12902> [Accessed 9 Jun. 2023].

Tollemache, N., Shrewsbury, D. and Llewellyn, C., (2021) Que(e) rying undergraduate medical curricula: a cross-sectional online survey of lesbian, gay, bisexual, transgender, and queer content inclusion in UK undergraduate medical education. *BMC Medical Education*, [online] 211. Available at: <https://www.scopus.com/inward/record.uri?eid=2-s2.0-85100867591&doi=10.1186%2fs12909-021-02532-y&partnerID=40&md5=3e458bbd210ad1c06031790e5914ff04>.

Varney, J. and Newton, E., (2018) *Improving the health and wellbeing of lesbian and bisexual women*. [online] London: Public Health England. Available at: https://allcatsrgrey.org.uk/wp/download/public_health/inequalities_in_health/Improving_health_and_wellbeing_LBWSW.pdf.

Zeeman, L., Sherriff, N., Browne, K., McGlynn, N., Mirandola, M., Gios, L., Davis, R., Sanchez-Lambert, J., Aujean, S., Pinto, N., Farinella, F., Donisi, V., Niedźwiedzka-Stadnik, M., Rosińska, M., Pierson, A., Amadeo, F., and Health4LGBTI Network, (2019) A review of lesbian, gay, bisexual, trans and intersex (LGBTI) health and healthcare inequalities. *European Journal of Public Health*, [online] 295, pp.974–980. Available at: <https://doi.org/10.1093/eurpub/cky226> [Accessed 9 Jun. 2023].