ACON SUBMISSION TO

The Australian Cancer Plan 2023-2033

March 2022

About ACON

ACON is Australia's largest health organisation specialising in community health, inclusion, and responses for people of diverse sexualities and genders. We are a fiercely proud community organisation, unique in our connection to our community and in our role as an authentic and respected voice.

Established in 1985, our early years were defined by community coming together to repose to the HIV/AIDS epidemic in NSW. As we have grown, ACON's work has expanded to create opportunities for people in our communities to live their healthiest lives. We have offices in Sydney and regional centres across NSW and provide services and programs locally, state-wide and nationally.

Members of Australia's sexuality and gender diverse communities experience health disparities when compared to health and wellbeing outcomes experienced by the total population. They may also face significant barriers to accessing traditional healthcare pathways. These health disparities are often the result of stigma and discrimination, and as a result, we are committed to protecting everyone from discrimination, equally.

We recognise that members of our communities share their sexual and gender identity with other identities and experiences and work to ensure that these are reflected in our work. These can include people who are Aboriginal and Torres Strait Islander; people from culturally, linguistically and ethnically diverse, and migrant and refugee backgrounds; people who use drugs; mature aged people; young adults; and people with disability.

ACON acknowledges that people with intersex variations experience health inequities and barriers to health services and should be considered in the development of the Australian Cancer Plan. People with intersex variations are sometimes included in evidence referenced in our submission. However, ACON does not represent the intersex community and recommend that consultation with Intersex Human Rights Australia to better understand the issues and needs of the intersex community.

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ACON acknowledges the Traditional Owners of the lands on which we work. We pay respect to Aboriginal Elders past, present and emerging.

Executive Summary

Australia has made significant progress in the prevention, early detection and treatment of cancer.[1] However these gains are not shared equally across the cancer control continuum.

LGBTQ (lesbian, gay, bisexual, transgender, and queer) communities are at greater risk of cancer than the general population due to higher rates of smoking and alcohol consumption[2], and lower engagement in cancer screening programs.[3] [4] Screening services, as well as cancer treatment and support services that are not visibly inclusive and knowledgeable of our health needs result in poor or low engagement and contribute to significant ongoing health disparities. Sexual orientation and gender also intersect with issues of race, ethnicity, disability, and rurality in the context of cancer risk, access to care and treatment. Healthcare disparities are especially compounded for members of our communities in these areas who are trans, including Brotherboys and Sistergirls, Aboriginal and Torres Strait Islander LGBTQ people, LGBTQ people from culturally, linguistically, and ethnically diverse or migrant or refugee backgrounds, and those living with a disability or chronic condition, including HIV. Many members of the LGBTQ community have multiple identities that intersect to create unique healthcare experiences which also need to be acknowledged and addressed.[5]

The integration of research into the delivery of community cancer programs is essential to ensure caner control is underpinned by evidence. However, LGBTQ people remain largely absent from cancer risk and outcomes research.[6] A lack of sexuality and gender inclusive data in Australia has long been a barrier to understanding and addressing cancer screening needs and lifestyle behaviours. To inform the delivery of targeted cancer programs, improvements need to be made to the measurement of cancer risk factors, cancer incidence, and cancer experiences among LGBTQ people. This submission provides more detail on the health disparities experienced by our communities, the role that community health organisations play in improving cancer outcomes for target populations, and opportunities for change.

[1] Australian Institute of Health and Welfare. (2020). *Cancer data in Australia*. Cat. no. CAN 122. Canberra: AIHW. Retrieved from https://www.aihw.gov.au/reports/cancer/cancer-data-in-australia/

[2] Australian Institute of Health and Welfare (2020). *Alcohol, tobacco & other drugs in Australia*. Cat. no. PHE 221. Canberra: AIHW. Retrieved from https://www.aihw.gov.au/reports/alcohol/alcohol-tobacco-other-drugs-australia

[3] Polek, C., & Hardie, T. (2020). Cancer Screening and Prevention in Lesbian, Gay, Bisexual, and Transgendered Community and Asian Lesbian, Gay, Bisexual, and Transgendered Members. *Asia-Pacific Journal Of Oncology Nursing*, 7(1), 6-11. doi: 10.4103/apjon.apjon_46_19

[4] Tracy, J., Schluterman, N., & Greenberg, D. (2013). Understanding cervical cancer screening among lesbians: a national survey. *BMC Public Health*, 13(1). doi: 10.1186/1471-2458-13-442

[5] Damaskos, P., Amaya, B., Gordon, R., & Walters, C. (2018). Intersectionality and the LGBT Cancer Patient. *Seminars In Oncology Nursing*, 34(1), 30-36. doi: 10.1016/j.soncn.2017.11.004

[6] Quinn, G., Sanchez, J., Sutton, S., Vadaparampil, S., Nguyen, G., & Green, B. et al. (2015). Cancer and lesbian, gay, bisexual, transgender/transsexual, and queer/questioning (LGBTQ) populations. *CA: A Cancer Journal For Clinicians*, 65(5), 384-400. doi: 10.3322/caac.21288

Recommendations

ACON makes the following recommendations for the Australian Cancer Plan 2023 - 2033 to improve cancer prevention, care and outcomes for sexuality and gender diverse communities in Australia.

- Collect gender and sexuality data in surveys, registries and patient records to improve the measurement of cancer risk factors, cancer incidence, and cancer experiences among LGBTQ people
- Fund research to better understand cancer risks and experiences of LGBTQ people
- Implement LGBTQ inclusion and diversity training among health professionals to reduce barriers and discrimination in cancer screening and cancer care
- Fund community-led partnerships to address inequities in cancer risk factors, access to screening and cancer support.

Introduction

ACON welcomes the opportunity to inform The Australian Cancer Plan 2023 – 2033. We make this submission particularly as it relates to the LGBTQ communities we serve.

There is a dearth of Australian evidence about sexuality and gender diverse people and cancer. This is a systemic issue caused by sexuality and gender data not collected and reported consistently and appropriately across population health surveys, screening participation data, cancer registries and cancer research. Lack of data limits the ability to accurately measure the extent and specifics of the situation. Quantifying the size of the LGBTQ communities is complex because the Census does not include LGBTQ people and other estimates vary widely from less than 3 percent to more than 20 percent, depending on the sample. [7] [8] Based on these estimates ACON assumes 5 percent of the Australian population describe themselves as LGBTQ. This would translate to approximately 23,000 LGBTQ cancer survivors in Australia, with over 7,500 new cancer diagnoses expected in 2021.[1] Some cancers, such as anal, cervical, bowel, endometrial, breast, lung and prostate may be more prevalent or

[7] Australian Bureau of Statistics. (2021). *General Social Survey: Summary Results*, Australia, 2020. Retrieved 3 March 2022, from https://www.abs.gov.au/statistics/people/people-and-communities/general-social-survey-summary-results-australia/2020

[8] Fisher, C., Waling, A., Kerr, L., Bellamy, R., Ezer, P., & Mikolajczak, G. et al. (2019). *6th National Survey of Australian Secondary Students and Sexual Health 2018*. Bundoora: Australian Research Centre in Sex, Health & Society, La Trobe University.

at least equal to the general adult population in some LGBTQ communities. [9] [10] [11] [12] [13] [14] [15] [16] Cancer is also a frequent comorbidity for people living with HIV (PLHIV) which impacts members of the LGBTQ community who experience higher prevalence of HIV transmission including men who have sex with men (MSM).[17] For example, PLHIV have a 20 to 100 fold increased risk of anal cancer than then general population.[18]

LGBTQ communities experience disproportionately worse physical and psychological health outcomes compared to the general population in Australia[19] [20] [21] due to a number of systemic and societal factors. These disparities are, in many cases, a result of stigmatisation, discrimination and a fundamental lack of understanding about the lives and bodies of people of diverse sexualities and genders. These factors impact our communities across the cancer continuum, resulting in greater cancer risk, as well as inequitable access to care, outcomes, and treatment quality.

Research indicates that LGBTQ people engage in higher rates of modifiable lifestyle factors that increase cancer risk, including tobacco and alcohol consumption, compared to the general population. The 2019 National Drug Strategy Household Survey found people who identified as gay, lesbian, or bisexual aged 14 years or older were more likely to smoke cigarettes daily (16 percent) compared with heterosexual people (10.7 percent). Within our communities, a higher proportion of cisgender men were daily

[9] Boehmer, U., Miao, X., & Ozonoff, A. (2011). Cancer survivorship and sexual orientation. *Cancer*, 117(16), 3796-3804. doi: 10.1002/cncr.25950

[10] Boehmer, U., Ozonoff, A., & Miao, X. (2012). An ecological approach to examine lung cancer disparities due to sexual orientation. *Public Health*, 126(7), 605-612. doi: 10.1016/j.puhe.2012.04.004

[11] Boehmer, U., Ozonoff, A., & Miao, X. (2011). An ecological analysis of colorectal cancer incidence and mortality: Differences by sexual orientation. *BMC Cancer*, 11(1), 400. doi: 10.1186/1471-2407-11-400

[12] Chin-Hong, P. V., Vittinghoff, E., Cranston, R. D., Browne, L., Buchbinder, S., Colfax, G., Da Costa, M., Darragh, T., Benet, D. J., Judson, F., Koblin, B., Mayer, K. H., & Palefsky, J. M. (2005). Age-related prevalence of anal cancer precursors in homosexual men: The EXPLORE study. *Journal of the National Cancer Institute*, 97(12), 896–905. doi: 10.1093/jnci/dji163

[13] Meads, C., & Moore, D. (2013). Breast cancer in lesbians and bisexual women: Systematic review of incidence, prevalence And risk studies. *BMC Public Health*, 13(1), 1127. doi: 10.1186/1471-2458-13-1127

[14] Quinn, G. P., Sanchez, J. A., Sutton, S. K., Vadaparampil, S. T., Nguyen, G. T., Green, B. L., Kanetsky, P. A., & Schabath, M. B. (2015). Cancer and lesbian, gay, bisexual, transgender/transsexual, and queer/questioning (LGBTQ) populations. *CA: A Cancer Journal for Clinicians*, 65(5), 384–400. doi: 10.3322/caac.21288

[15] Rosario, M., Corliss, H. L., Everett, B. G., Reisner, S. L., Austin, S. B., Buchting, F. O., & Birkett, M. (2014). Sexual orientation disparities in cancer-related risk behaviors of tobacco, alcohol, sexual behaviors, and diet and physical activity: Pooled youth risk behavior surveys. *American Journal of Public Health*, 104(2), 245–254. doi: 10.2105/AJPH.2013.301506

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[17] Park, L. S., Hernández-Ramírez, R. U., Silverberg, M. J., Crothers, K., & Dubrow, R. (2016). Prevalence of non-HIV cancer risk factors in persons living with HIV/AIDS: A meta-analysis. *AIDS*, 30(2), 273. doi: 10.1097/QAD.0000000000000922

[18] Clifford, G., Georges, D., Shiels, M., Engels, E., Albuquerque, A., & Poynten, I. et al. (2020). A meta-analysis of anal cancer incidence by risk group: Toward a unified anal cancer risk scale. *International Journal Of Cancer*, 148(1), 38-47. doi: 10.1002/ijc.33185

[19] Australian Institute of Health and Welfare. (2022). Lesbian, gay, bisexual, transgender and intersex people. In *Australia's Health 2018*. Canberra: Australian Institute of Health and Welfare. Retrieved from https://www.aihw.gov.au/getmedia/61521da0-9892-44a5-85af-857b3eef25c1/aihw-aus-221-chapter-5-5.pdf.aspx

[20] Ussher, J., Perz, J., Kellett, A., Chambers, S., Latini, D., & Davis, I. et al. (2016). Health-Related Quality of Life, Psychological Distress, and Sexual Changes Following Prostate Cancer: A Comparison of Gay and Bisexual Men With Heterosexual Men. *The Journal Of Sexual Medicine*, 13(3), 425-434. doi: 10.1016/j.jsxm.2015.12.026

[21] Ussher, J. M., Allison, K., Perz, J., Power, R., & The Out with Cancer Study Team. (2022). LGBTQI Cancer Patients' Quality of Life and Distress: A Comparison by Gender, Sexuality, Age and Cancer Type *Frontiers in Oncology*, forthcoming.

smokers (14.2 percent), compared with cisgender women (7.7 percent), non-binary participants (7.9 percent), trans men (9.3 percent) and trans women (9.5 percent). [22] Only 57 percent had never smoked, compared with 63 percent among heterosexual people. In regard to alcohol consumption, gay, lesbian, and bisexual respondents were more likely to consume more than 2 standard drinks per day (22 percent) compared with heterosexual people (17.6 percent).[23] The Private Lives 3 study found there are different rates within our communities, for example 38 percent of cisgender men and 32 percent of trans women report exceeding two drinks on a typical day.[11] Higher rates of smoking and alcohol consumption are due to various factors including smoking and drinking as coping mechanisms for stress and anxiety (including minority stress), LGBTQ communities being targeted and marketed by tobacco and alcohol industries, the fact that smoking and drinking are engrained in the culture and social lives of many LGBTQ people, as well as the extremely high proportional representation of smoking in LGBTQ media such as films and television.[24] [25] [26] [27]

National and international studies also show that sexuality and gender diverse people have lower screening rates for cancer.[28] [29] For example, one study on LBQ (lesbian, bisexual and queer) women living in NSW found 37 percent were overdue for a cervical screen, 31 percent of 50 to 69 year olds were due for a mammogram and 41 percent of 50 to 74 year olds were overdue for a bowel screen.[30] This may be due to several factors including lack of affirming health services and fear of discrimination. There are also factors unique to certain cancer types. This includes misinformation being given to patients about the lack of need for cervical screening for parts of the LGBTQ community, in particular, transgender men and same-sex attracted women.[31] This may contribute to differences between LBQ women, for example those who report they had never had sex with a man (cisgender or transgender)

[22] Hill, A., Bourne, A., McNair, R., Carman, M., & Lyons, A. (2021). *Private Lives 3: The health and wellbeing of LGBTIQ people in Australia*. Melbourne: Australian Research Centre in Sex, Health and Society, La Trobe University. Retrieved from https://www.latrobe.edu.au/__data/assets/pdf_file/0009/1185885/Private-Lives-3.pdf

[23] Australian Institute of Health and Welfare. (2020). *National Drug Strategy Household Survey 2019*. Canberra: AIHW. Retrieved from https://www.aihw.gov.au/reports/illicit-use-of-drugs/national-drug-strategy-household-survey-2019

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[25] Truth Initiative. (2021). *Tobacco Use in LGBT Communities*. Retrieved 6 January 2022, from https://truthinitiative.org/sites/default/files/media/files/2021/06/Truth_LGBT%20FactSheet2021_FINAL_062221.pdf

[26] Spivey, J., Lee, J., & Smallwood, S. (2018). Tobacco Policies and Alcohol Sponsorship at Lesbian, Gay, Bisexual, and Transgender Pride Festivals: Time for Intervention. *American Journal Of Public Health*, 108(2), 187-188. doi: 10.2105/ajph.2017.304205

[27] Lee, J., Agnew-Brune, C., Clapp, J., & Blosnich, J. (2013). Out smoking on the big screen: tobacco use in LGBT movies, 2000–2011: Table 1. *Tobacco Control*, 23(e2), e156-e158. doi: 10.1136/tobaccocontrol-2013-051288

[28] Polek, C., & Hardie, T. (2020). Cancer Screening and Prevention in Lesbian, Gay, Bisexual, and Transgendered Community and Asian Lesbian, Gay, Bisexual, and Transgendered Members. *Asia-Pacific Journal Of Oncology Nursing*, 7(1), 6-11. doi: 10.4103/apjon.apjon_46_19

[29] Tracy, J., Schluterman, N., & Greenberg, D. (2013). Understanding cervical cancer screening among lesbians: a national survey. *BMC Public Health*, 13(1). doi: 10.1186/1471-2458-13-442

[30] Mooney-Somers, J., Deacon, R., Anderst, A., Rybak, L., Akbany, A., & Philios, L. et al. (2020). *Women in contact with the Sydney LGBTIQ communities: Report of the SWASH Lesbian, Bisexual and Queer Women's Health Survey 2016, 2018, 2020*. Sydney: Sydney Health Ethics, University of Sydney. Retrieved from https://www.acon.org.au/wp-content/uploads/2020/10/SWASH-Report-2020_Final.pdf

[31] Stardust, Z., Wee, A., McGregor, V., Cook, T., & Gray, J. (2017). *Discussion Paper. At Your Cervix: Screening for Cervical Cancer Among LGBTIQ People in NSW*. Sydney: ACON.

were more likely to have never screened for cervical cancer (34 percent) compared to those who had reported sex with a man (19 percent).[16]

LGBTQ people also face many unique barriers once they receive a diagnosis, engage in cancer treatment, and navigate life after treatment. While there is limited research on LGBTQ cancer care experiences in Australia, the Out with Cancer study at Western Sydney University, funded by the Australian Research Council (ARC), has recently investigated discrimination in cancer care. Their research has found that a third of 430 LGBTQI+ study participants reported experiencing discrimination as part of their cancer care because of being LGBTQI, with transgender and people with intersex variations experiencing highest levels at 52.4% and 50.0% respectively. Forty-one percent of study participants report high or very high distress levels, 3-6 times higher than non-LGBTQI cancer populations.[32] International studies also report on issues of disclosure of sexual orientation and gender identity, perceived and experienced homophobia and transphobia, suboptimal healthcare professional behaviour, heteronormative language, systems, and care, as well as discomfort in predominantly heterosexual support groups and lack of LGBTQ support groups. Many LGBTQ cancer patients report unmet needs including lack of follow-up care, need for discussion of sexual matters and lack of information, and a greater need for patient-centred care.[33] For example, changes in sexual functioning significantly impact cisgender gay men and other members of our communities with a prostate.[34] [35] [36] However few health care providers ask about their patients' sexual practices, understand the impact of prostate cancer on LGBTQ people's sexuality or are aware of culturally component referral pathways.[37] [38] The Out with Cancer study has also audited 69 Australian cancer organisation websites and 255 patient information resources (i.e. booklets, factsheets). The audits found a minority of organisation websites mentioned same-sex attracted people (14 percent), trans or gender diverse people (14 percent), or people with intersex variations (6 percent). Of the 255 information resources, only 13 mentioned same-sex attracted people, 6 mentioned people who are trans or gender diverse and 4 mentioned people with intersex variations.

The Out with Cancer study recently published data which showed that only 56 percent of health care professionals surveyed were confident in their knowledge of the health needs of sexuality diverse patients, 33 percent were confident in their knowledge of the health needs of trans and gender diverse

[32] Ussher, J. M., Allison, K., Perz, J., Power, R., & The Out with Cancer Study Team. (2022). LGBTQI Cancer Patients' Quality of Life and Distress: A Comparison by Gender, Sexuality, Age and Cancer Type *Frontiers in Oncology*, forthcoming.
[33] Lisy, K., Peters, M., Schofield, P., & Jefford, M. (2018). Experiences and unmet needs of lesbian, gay, and bisexual people with cancer care: A systematic review and meta-synthesis. *Psycho-Oncology*, 27(6), 1480-1489. doi: 10.1002/pon.4674
[34] Hart, T., Coon, D., Kowalkowski, M., Zhang, K., Hersom, J., & Goltz, H. et al. (2014). Changes in Sexual Roles and Quality of Life for Gay Men after Prostate Cancer: Challenges for Sexual Health Providers. *The Journal Of Sexual Medicine*, 11(9), 2308-2317. doi: 10.1111/jsm.12598
[35] Amarasekera, C., Wong, V., Jackson, K., Yura, E., Patel, M., Manjunath, A., & Kundu, S. (2020). A Pilot Study Assessing Aspects of Sexual Function Predicted to Be Important After Treatment for Prostate Cancer in Gay Men: An Underserved Domain Highlighted. *LGBT Health*, 7(5), 271-276. doi: 10.1089/lgbt.2018.0245
[36] Ussher, J., Rose, D., & Perz, J. (2016). Mastery, Isolation, or Acceptance: Gay and Bisexual Men's Construction of Aging in the Context of Sexual Embodiment After Prostate Cancer. *The Journal Of Sex Research*, 54(6), 802-812. doi: 10.1080/00224499.2016.1211600
[37] Rose, D., Ussher, J., & Perz, J. (2016). Let's talk about gay sex: gay and bisexual men's sexual communication with healthcare professionals after prostate cancer. *European Journal Of Cancer Care*, 26(1), e12469. doi: 10.1111/ecc.12469
[38] Ussher, J. M., Power, R., Perz, J., Hawkey, A. J., Allison, K., & The Out with Cancer Study Team. (2022). LGBTQI inclusive cancer care: A discourse analytic study of health care professional, patient and carer perspectives. *Frontiers in Oncology*, in press.

patients, and only 20 percent confident in their knowledge of the health needs of patients with intersex variations. The same study found that less than 5 percent of doctors stated they were uncomfortable treating sexuality diverse patients, 4 percent uncomfortable treating trans and gender diverse patients, and 8 percent uncomfortable treating patients with intersex variations. Most health care professionals were interested in education and training about the health needs of LGBTQI people, with nurses and allied health professionals having higher levels of interest compared to medical and leadership professions.[39]

Education and training on LGBTQ-inclusive practice for healthcare providers across the cancer care spectrum is vital for increasing knowledge and confidence. This is turn will reduce barriers to attending health services, enable healthcare professionals to provide person-centred care, give providers the courage to challenge discriminatory behaviour, and enable them to create safe and inclusive spaces. These factors are all important for improving outcomes and equity of care for gender and sexuality diverse people.[40] The Out with Cancer study identified several negative consequences of non-inclusive care for LGBTQI patients and their carers. This included fear of disclosure of sexuality and gender identity, fear of discrimination or inadequate healthcare following disclosure, and avoidance of cancer screening or follow-up treatment because of hostile interactions with cancer health care professionals.[41]

> *Being part of a marginalized community brings additional pressures and stresses, and the anticipation of potential discrimination, or everyday misunderstanding, is always there. This creates additional burdens which impact on health and wellbeing. This awareness needs to be out there* LGBTQI+ cancer patient
>
> *Due to my gender presentation, I often felt mainstream services did not willingly engage with me or provide me with the support I needed* LGBTQI+ cancer patient
>
> *I've had some that I've said I'm gay and they've just sort of shut down after* LGBTQI+ cancer patient

Primary care play an important role in the health care of LGBTQ people. Despite LGBTQ people being more likely to visit a general practitioner than their heterosexual counterparts, LGBTQ people are often less satisfied with their care. [42] [43] [44] Dissatisfaction may be due to assumptions of heterosexuality, inappropriate language, or assumptions that the primary health concern is sexual health. Cancer

[39] Ussher, J., Perz, J., Allison, K., Power, R., Hawkey, A., & Dowsett, G. et al. (2021). Attitudes, knowledge and practice behaviours of oncology health care professionals towards lesbian, gay, bisexual, transgender, queer and intersex (LGBTQI) patients and their carers: A mixed-methods study. *Patient Education And Counselling*. doi: 10.1016/j.pec.2021.12.008

[40] Wakefield, D. (2021). Cancer care disparities in the LGBT community. Current Opinion In Supportive & Palliative Care, 15(3), 174-179. doi: 10.1097/spc.0000000000000557

[41] Ussher, J. M., Power, R., Perz, J., Hawkey, A. J., Allison, K., & The Out with Cancer Study Team. (2022). LGBTQI inclusive cancer care: A discourse analytic study of health care professional, patient and carer perspectives. *Frontiers in Oncology*, *in press*.

[42] McNair, R., Szalacha, L., & Hughes, T. (2011). Health Status, Health Service Use, and Satisfaction According to Sexual Identity of Young Australian Women. *Women's Health Issues*, 21(1), 40-47. doi: 10.1016/j.whi.2010.08.002

[43] Neville, S., & Henrickson, M. (2006). Perceptions of lesbian, gay and bisexual people of primary healthcare services. *Journal Of Advanced Nursing*, 55(4), 407-415. doi: 10.1111/j.1365-2648.2006.03944.x

[44] Allen, O. (2008). *Lesbian, gay and bisexual patients: the issues for General Practice*. Dublin: Irish College of General Practitioners.

prevention and screening are key opportunities for primary care to influence behaviours of LGBTQ patients, as well as through cancer treatment and secondary prevention.

Given that many gender and sexuality diverse people have had negative experiences in health settings, there is growing recognition that LGBTQ communities may be reluctant to engage with mainstream health promotion efforts or health care environments. From conversations with our communities, we know that a lack of targeted, inclusive, and representational messaging contributes to lower screening rates in our communities. This includes mainstream prostate cancer messaging being targeted towards men and not including transgender women, and cervical and breast screening message being targeted solely towards cisgender women. There is evidence that targeted interventions are more acceptable to these communities and may be more feasible in some contexts.[45] Interventions delivered by competent practitioners in safe settings include creating spaces for other LGBTQ people to connect, shifting peer norms around alcohol or tobacco use, experiencing inclusive healthcare, and connecting to LGBTQ-friendly health service providers. These experiences confirm and communicate to LGBTQ people that their health needs are important and that their gender and/or sexuality is recognised as relevant to and implicated within their health and wellbeing. Social marketing campaigns that are representative of LGBTQ people are also a powerful way to reach the community, shift attitudes and encourage health-seeking behaviours.

The Out with Cancer study has also researched what LGBTQI+ patients want. Their findings are that LGBTQI+ patients want an intersectional approach to addressing the support and information needs for them and their carers. These needs have been grouped into four facets. First, they want gender and sexuality responsive cancer care from health professionals including not assuming heterosexuality or cis-gender, acknowledging and involving partners and carers in care, and using appropriate language and pronoun, guided by the patient.[46]

> *"I would love for forms to give you the option of choosing your pronoun. Even though medical forms have to represent gender for tests and screenings, knowing a desired pronoun would make me feel much more comfortable."*
>
> – LGBTQI+ cancer patient

> *"It needs to be part of everyday thinking for all staff that not everyone is straight or male or female, so questions need to reflect this as well as support options."*
>
> – LGBTQI+ cancer patient

[45] Drysdale, K., Cama, E., Botfield, J., Bear, B., Cerio, R., & Newman, C. (2020). Targeting cancer prevention and screening interventions to LGBTQ communities: A scoping review. *Health & Social Care In The Community*, 29(5), 1233-1248. doi: 10.1111/hsc.13257

[46] Ussher, J. M., Power, R., Perz, J., Hawkey, A. J., Allison, K., & The Out with Cancer Study Team. (2022). LGBTQI inclusive cancer care: A discourse analytic study of health care professional, patient and carer perspectives. *Frontiers in Oncology*, in press.

The second facet was a non-discriminatory and visibly supportive healthcare environment including services where diversity is welcome, inclusive intake forms and keeping sexuality on record. A third facet was access to meaningful avenues for support including practical support, tailored support groups, support from the LGBTQI+ community, and support for cancer. The final facet was culturally safe information that addresses needs of LGBTQI+ people and carers, such as non-heteronormative or cis-gender focused information, information and support pioneered by LGBTQI+ communities, and information that is gender and sexuality sensitive particularly on sex, fertility, physical changes and intimate relationships.

Community partnerships are instrumental in coordinating targeted cancer awareness and prevention efforts for LGBTQ communities. Since 2017, ACON has worked with Cancer Institute NSW to engage LGBTQ communities with cancer screening and healthy lifestyle messaging, as well as providing a community-led approach to improving workforce education, inclusion and programming for better cancer health service access and outcomes for LGBTQ communities in NSW. This body of work has included a website with cancer information specifically for gender and sexuality diverse people, targeted social marketing campaigns for breast, bowel, and cervical cancer screening and smoking cessation, support for a community-led sexual health and cervical screening clinic for LGBTQ people known as Check OUT and an online learning module on LGBTQ inclusion for healthcare professionals working in cancer available to Cancer Institute NSW staff. Funding for this community partnership has also created opportunities for advocacy and education with other stakeholders in the cancer, LGBTQ health and health research sectors.

The development of ACON's Cancer Program was founded on evidence that discrepancies exist between LGBTQ communities and heterosexual populations regarding cancer risk factors, participation in cancer screening, and poor experiences of healthcare. However, there is still insufficient knowledge about how LGBTQ communities experience cancer prevention, care, and treatment. This is often because of poor data collection and sampling in research that does not include the broad spectrum of diverse genders and sexualities, as well as insufficient funding opportunities for research. Developing effective programs and messaging to close the cancer gap between LGBTQ communities and heterosexual people requires a greater understanding of participation in screening, cancer prevalence, health care needs, outcomes, lived experiences, as well as what interventions are most effective.

Conclusion

While Australian data on cancer and LGBTQ communities is limited, there is sufficient evidence that LGBTQ communities have higher incidence of cancer risk factors and face barriers and discrimination in cancer screening and cancer care. The Australian Cancer Plan should to an equity approach to reducing the impact of cancer in Australia and that approach must include LGBTQ communities as a priority population. This approach should be underpinned by improving data and investing in targeted research to measure the extent of the inequities and to inform investments in community-led solutions to reduce cancer inequities for LGBTQ populations.

What would you like to see the Australian Cancer Plan achieve?

Think ahead to the next 10 years. What do you want the Australian Cancer Plan to achieve? Think big – what transformational change(s) should we be aiming to influence?

The Australian Cancer Plan should broadly seek to improve cancer outcomes for all Australians, including LGBTQ communities. ACON also advocates for:

- Improved measurement of cancer risk factors, cancer incidence, and cancer experiences among LGBTQ people and the general population
- Improved understanding of cancer risks and experiences of LGBTQ people through funded research
- Reduced inequities of cancer risk factors, cancer screening, cancer incidence and cancer survival between LGBTQ people and the general population
- Increased confidence and comfort among health professionals in providing inclusive cancer care for LGBTQ people through education and training
- Improved availability of easy-to-understand and relevant cancer information for LGBTQ people including targeted resources and inclusion in mainstream cancer websites and resources
- Funded community partnerships to reduce inequities in cancer risk factors and screening

What are the opportunities with the greatest potential to realise your vision?

Think about what you would like the Australian Cancer Plan to achieve. What priorities need national action? In what areas could national action drive or accelerate progress?

To meet the needs of LGBTQ populations in Australia, the Australian Cancer Plan should prioritise the following action items:

- Research
    - Investing in research with LGBTQ communities on cancer risks and outcomes, particularly to address gaps in different subgroups and in cancers other than prostate and breast cancer
    - Advocating for adequate sampling of LGBTQ people for subpopulation analysis
    - Creating dedicated funding streams for research with priority populations, including LGBTQ people, in cancer
    - Including LGBTQ consumers in research review processes
    - Enhancing access to and participation in cancer clinical trials for LGBTQ communities
    - Providing easy to understand information to LGBTQ people experiencing cancer that supports their involvement in cancer research
- Workforce
    - Improving experiences with primary care and cancer service providers through regular, effective LGBTQ diversity and inclusion training for staff

    - Building leadership and supportive workplace cultures that champion safe and inclusive care for LGBTQ people
- Innovation
    - Co-designing with LGBTQ consumers new models of prevention, diagnosis, cancer care treatment, support, and follow-up
- Collaboration
    - Establishing a national tender process for community organisations to partner with Government to develop communication strategies for targeting specific vulnerable populations, including LGBTQ communities
    - Funding LGBTQ community-led programs and campaigns to raise awareness and deliver services and support for cancer prevention, screening, diagnosis, and treatment
- Person-centred care
    - Supporting best practice cancer care for LGBTQ communities
    - Ensuring LGBTQ people who experience cancer and their partners and families, are linked to culturally appropriate care and services, such as psychosocial care, allied health care and financial planning advice
- Governance
    - Ensuring that LGBTQ community organisations are represented on relevant Government committees
    - Advocating for executive-level positions that focus on equity and equality

What examples and learnings can we build on as we develop the Australian Cancer Plan?

Think about great examples of work within or outside the cancer sector in Australia and internationally. How can we learn from these examples and build on them to improve cancer outcomes and experience for all Australians?

To ensure the Australian Cancer Plan is developed for all Australians, community engagement should be a core objective when addressing priority populations. Peer-led and community-based programs aim to strengthen the capacity of communities to identify and respond to health issues[47] and have been a powerful health promotion and risk reduction tool for priority populations across a range of health issues.[48] Peer support as a health promotion tool is about sharing lived experiences to educate and support one another[49], whether it relates to age, ethnicity, sexuality, or gender.[50] Peer work embodies

[47] McLeroy, K., Norton, B., Kegler, M., Burdine, J., & Sumaya, C. (2003). Community-Based Interventions. *American Journal Of Public Health*, 93(4), 529-533. doi: 10.2105/ajph.93.4.529

[48] Nickel, S., & von dem Knesebeck, O. (2019). Effectiveness of Community-Based Health Promotion Interventions in Urban Areas: A Systematic Review. Journal Of Community Health, 45(2), 419-434. doi: 10.1007/s10900-019-00733-7

[49] Svenson, G. (1998). European Guidelines for Youth AIDS Peer Education. Malmö, Sweden: Department of Community Medicine, Lund University. Retrieved from https://healtheducationresources.unesco.org/sites/default/files/resources/HIV%20AIDS%20102e.pdf

[50] Parkin, S., & McKeganey, N. (2000). The Rise and Rise of Peer Education Approaches. *Drugs: Education, Prevention And Policy*, 7(3), 293-310. doi: 10.1080/09687630050109961

the notion of people and communities working together to address their own health behaviours, concerns and issues.[51]

LGBTQ communities in Australia have been remarkably successful in dealing with a range of health issues, most notably HIV, through the establishment of community-based and peer-led organisations and groups. The importance of these groups and initiatives for addressing the prevalence of HIV in LGBTQ communities have been recognised as evidenced by the emphasis of the importance of peers in guiding federal and state Government HIV Strategies.[52] [53]

ACON has over 35 years of experience targeting sexuality and gender diverse people with health messaging on a range of issues, including HIV prevention and support, sexual health, mental health, alcohol and drugs, domestic and family violence, ageing and cancer. Because sexuality and gender diverse people may experience decreased trust in the health sector and related health promotion from mainstream services, it is important that messaging, engagement, and recruitment is community based and builds on the experiences and knowledge of peers. Peer education and community based social marketing has been shown to be a very effective way of engaging LGBTQ communities.

The Inner Circle

The Inner Circle was ACON's ground-breaking cervical cancer screening awareness campaign for all LGBTQ people with a cervix. Responding to our communities' questions about cervical screening, the relationship between HPV and cervical cancer, as well as the complicated medical rationale behind the change from the Pap Smear to the new Cervical Screening Test, The Inner Circle Phase 2 campaign produced a series of 10 new videos. Using diverse community talent, the video series LGBTIQ&A: Your Questions, Answered by The Inner Circle, were clear, concise, and accessible answers to FAQs. The videos garnered over 180,000 views across social media and drove over 3,000 visitors to The Inner Circle website. An overwhelming majority of people surveyed after the campaign thought the videos were informative, high quality and encouraged them to get tested.

Check OUT: LGBTIQ+ Sexual Health Clinic

Check OUT is a community led sexual health clinic run by ACON in partnership with Family Planning NSW. The clinic is staffed by expert sexual health nurses and trained LGBTIQ+ peer workers. Check OUT is open to anyone who identifies as LGBTIQ+, and sex workers are always welcome. In 2018-19, the clinic saw 285 clients for HIV and STI testing, and/or cervical screening. While the majority of our clients were queer-identified cis women, 25% were trans and gender diverse, 1.75 % had an intersex variation, 2.5% identified as Aboriginal and/or Torres Strait Islander, and 32% were born outside of Australia. Almost 20% identified as living with a disability. We hired and trained five new LGBTIQ+ peer workers, and over the 2018-19 period, 99% of clients were satisfied by our service and 99% would use the service again.

[51] Molyneux, A., Delhomme, F., & Mackie, B. (2021). *It's Who We Are: Exploring the Role, Impact and Value of Peers*. Sydney: ACON. Retrieved from https://www.acon.org.au/wp-content/uploads/2021/10/Its-Who-We-Are-Exploring-the-Role-Impact-and-Value-of-Peers-1.pdf

[52] Australian Government Department of Health. (2018). *Eighth National HIV Strategy 2018-2022*. Canberra: Australian Government Department of Health. Retrieved from https://www1.health.gov.au/internet/main/publishing.nsf/Content/ohp-bbvs-1/$File/HIV-Eight-Nat-Strategy-2018-22.pdf

[53] NSW Ministry of Health. (2020). *NSW HIV Strategy 2021 – 2025*. Sydney: NSW Ministry of Health. Retrieved from https://www.health.nsw.gov.au/endinghiv/Publications/nsw-hiv-strategy-2021-2025.pdf

The Check OUT clinic is temporarily closed due to COVID-19 but we look forward to reopening again soon.

Our United Front

Our United Front is an inclusive campaign to promote the importance of regular breast screening among LGBTQ people in NSW. The campaign was developed in partnership with BreastScreen NSW and supported by Cancer Institute NSW. Over the two year funding period, Our United Front produced 11 community engagement events across NSW including events that brought the BreastScreen NSW mobile screening van directly to LGBTQ communities. The campaign also collaborated with ACON's Aboriginal Project, Aboriginal Medical Services Redfern and BreastScreen NSW to promote regular breast screening among Aboriginal communities, which tend to have lower screening rates. The campaign launched with a video which had over 82,000 views and over 8,000 engagements across social media during the nine week digital campaign. The campaign concluded with an exhibition featuring the photography of ACON's Photographer in Residence Nicola Bailey who engaged with a diverse range of LGBTQ community groups and individuals across urban and regional NSW, exploring the importance of community in regard to LGBTQ health and wellbeing, particularly around breast cancer. The campaign was successful in reaching the target audience, reported a substantial level of recall, and received many positive comments about its inclusive and representative approach.

Get Your Kit Together

The Get Your Kit Together campaign promoted participation in the National Bowel Cancer Screening Program (NBCSP) for lesbian, gay, bisexual, transgender, and queer (LGBTQ) people aged 50-74 years old in NSW in June – August 2021. The campaign was implemented by ACON as part of a three-year funding agreement with the Cancer Institute NSW. A targeted media approach was used to promote the campaign through out-of-home media, print media and online channels. Overall the campaign was successful in communicating its key messages, had strong recall amongst the target audience and received positive feedback from community.

Can We

Can We is ACON's single brand platform for every cancer. Every cancer campaign, communication, conversation, and piece of information from previous and future campaigns sit 'under this umbrella'. The strategic purpose of the Can We brand is to raise awareness within community on the research findings that we're considered more at risk from cancer. We then build actions from this awareness, through empathetic engagement and the promotion of staying healthy. We achieve this through sharing real stories of success, actively promoting achievable ideas, and introducing community-centric health initiatives.

Emen8

Now in its fourth year, Emen8 is ACON's national health promotion initiative produced in partnership with Thorne Harbour Health and funded by the Australian Government. The project provides key information for good sexual health behaviours – including information and resources on HIV prevention and risk – among same-sex attracted men (cisgender and trans), online and on social media.

ACON's Pride Inclusion Programs

ACON's Pride Inclusion Programs comprise a suite of national support programs specifically designed to assist Australian employers, sporting organisations and service providers with all aspects of LGBTQ inclusion. These programs provide year-round support along with access to training, expert advice, resources, and tools that allow members to not only benchmark but accelerate their LGBTQ inclusion work. The three national programs collectively have a membership of over 430 organisations with staff situated in New South Wales, Western Australia, Victoria, and Queensland.

Pride in Health + Wellbeing

The Pride in Health + Wellbeing program specifically provides customised support to health and wellbeing organisations to assist them become more inclusive of LGBTQ people and improve the health and wellbeing of LGBTQ communities. The program currently has 47 members, including Camp Quality, NSW Agency for Clinical Innovation, Rural and Remote Medical Services (RARMS), Lifeline Australia and Australian Red Cross Lifeblood.

Say it Out Loud

Launched in November 2020, Say it Out Loud is ACON's national digital resource focusing on LGBTQ relationships with support and resources on domestic and family violence (DFV). The website is also a hub of information for professionals who work with LGBTQ people experiencing DFV. The website features content from every state and territory, along with a service directory, a healthy relationships quiz, a safety planning tool, and stories from community members. Since its launch, the website has been visited by over 13,000 unique users. As part of this project, ACON partnered with various mainstream DFV services across the country to develop awareness training and conduct policy reviews which complemented and strengthened the services' capacity to work with, and be inclusive of, LGBTQ communities.

ACON is also collaborating with the Out with Cancer study team to translate research findings into practical resources and actions to begin to address some of the gaps and needs identified. This will include the production of resources for LGBTQI patients and carers, and practice recommendations for health care professionals.

The National LGBT Cancer Network in the USA is also a good example of an organisation that provides information to the LGBT community, training to health care providers and advocacy for LGBT cancer survivors. This type of network could be developed and supported in Australia to build capacity among LGBTQ organisations and facilitate collaborations between the LGBTQ community with research institutions and cancer organisations.

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