HIV IN GREATER WESTERN SYDNEY

TAILORING A CULTURALLY SPECIFIC, COMMUNITY-INFORMED RESPONSE

ACON POLICY PAPER 2024

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HERE FOR HEALTH

CONTENTS

1

EXECUTIVE SUMMARY

Australia has achieved great success in bringing HIV notification rates down since the early outbreak of the epidemic. This is evidence of the ongoing success of the partnership approach to HIV, initiated in Australia and praised globally, which enables and encourages governments, clinicians, epidemiologists, social researchers, and community organisations to work together to understand and respond to HIV comprehensively, emphasising innovation and agility through collaboration with affected communities.[1,2,3]

In NSW, this coordinated, collaborative response has resulted in dramatic declines in notifications in urban, inner Sydney areas with the highest populations of gay, bisexual and other men who have sex with men (GBMSM). However, these efforts haven't had the same impact in certain regional areas, and, in particular, in Greater Western Sydney (GWS), where numbers of new HIV notifications in key Local Health Districts (LHDs) haven't enjoyed the same downward trends over time.[4] The 2023 Annual NSW HIV Surveillance Data Report shows that, of the 168 MSM diagnosed with HIV in 2023, 53 (31.5%) are from the GWS region.[5]

While raw numbers of notifications aren't necessarily increasing in GWS, because they are decreasing elsewhere, especially in Sydney's gay postcodes, the overall proportion of notifications coming from GWS has increased (from 14.9% in 2013 to 31.5% in 2023) and has become the subject of substantial discussion across the sector. There is a need for a shift toward more targeted responses across the sector that can bring down numbers of new HIV notifications in this region.[6]

This paper discusses key issues affecting access to sexual healthcare for LGBTQ+ communities in GWS and sector-wide strategies for a renewed focus on HIV in this region that includes culturally tailored, community-informed responses. Highlighting the importance of accommodating the rich cultural diversity of LGBTQ+ communities in GWS, we identify persistent factors that inhibit access to prevention, testing, and treatment interventions, and we suggest targeted interventions to remove these barriers.

We also present two examples of culturally tailored, community-informed pilot initiatives, driven by a co-design approach that includes participation at all levels from LGBTQ+ people living in GWS, aimed at engaging the unique LGBTQ+ communities of this region with their sexual health. These examples demonstrate that meaningful consideration of the complex role of culture in the formation of community, as well as the inclusion of community consultation and co-design, are key factors driving more successful uptake of health messaging, and engagement with sexual health services – factors that are crucial in achieving better outcomes for priority populations affected by HIV in GWS.

2

INTRODUCTION

To date, the coordinated response to HIV in NSW has had high levels of success in engaging GBMSM with prevention, testing, and treatment programs in inner Sydney areas that are home to large, established and highly visible LGBTQ+ populations. These efforts have resulted in significant and sustained declines (88% since 2010) in notification rates in inner Sydney postcodes estimated to have more than 20% of male residents identifying as gay to the point that these areas are on the cusp of virtual elimination of HIV.[7] This remarkable success, due in large part to the benefit of strong, collaborative partnerships between government, clinicians, researchers and community organizations, has greatly benefited GBMSM and PLHIV living in inner Sydney.

However, reaching GBMSM in the migrant and multicultural communities of GWS has been less successful by comparison. Here LGBTQ+ people have been less engaged with the kinds of messaging and imagery that have been prominent in mainstream LGBTQ+ health campaigns and community engagement strategies since the beginning of the HIV epidemic.[8]

Typically, LGBTQ+ people living in the multicultural communities of the GWS region have been described as "hard to reach".[9] However, in consultation with LGBTQ+ people from this region, it is argued that these communities are in fact not hard to reach, but that services are not designed with their needs in mind and are consequently hard for them to navigate.[10]

INTRODUCTION CONTINUED

With the increasing popularity of events like West Ball and Sissy Ball, and the rise of social media groups for queer people of specific cultural and ethnic backgrounds, LGBTQ+ people living in GWS are coming together and connecting with each other more frequently. Reaching them with prevention, testing and treatment interventions more effectively, however, will require nuanced approaches that demonstrate meaningful understanding of the complex cultural influences that affect how they form their social networks and how they navigate their familial relationships.

In particular, young LGBTQ+ communities in GWS are forming complex and diverse networks in very different ways to that of established GBMSM communities living in inner Sydney. They are identifying with more fluid interpretations of gender and sexuality, and coming together around events that amplify their own unique sense of fashion, style, art, and culture rather than events focussed on their sexuality alone.[11]

To be effective in engaging LGBTQ+ communities in GWS, the HIV sector will need to be more attuned to these emerging trends. A standard "one size fits all" approach to prevention, testing and treatment interventions across NSW is likely to be less successful than a tailored, community-informed approach. Peer-led programs and community engagement initiatives must be co-designed in partnership with local community organisations and run by the communities they are intended to serve, to ensure they are culturally appropriate, and meeting the people of GWS where they're at.

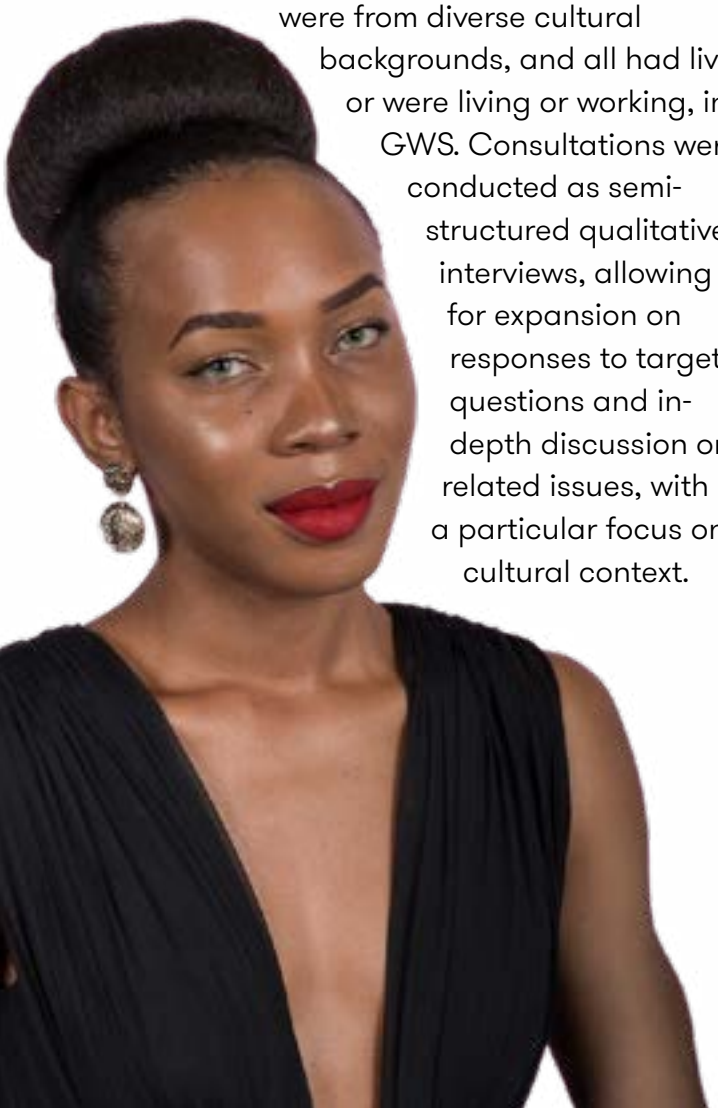
Community leadership will be essential in fostering the kind of trust that drives connection and engagement with sexual health messaging. But, to achieve sustainable, long-term reductions in HIV notification rates in GWS, we also need community-informed innovation, and expansion of service delivery. Further, this innovation and expansion cannot be at the expense of the achievements made in transmission reductions for LGBTQ+ communities in inner-Sydney, where established programs and services are achieving their objectives and sustaining steady reductions year on year.

We must ensure that the work we do to reduce notification rates in GWS does not result in a corresponding uptick for the other areas as a result of redirecting resources. Funding must be allocated in a way that results in sustainable reductions in notification rates across the state.

3 METHODOLOGY

This policy paper was developed through an extensive review of both grey and academic literature on the impacts of HIV on culturally and linguistically diverse (CALD) communities, drawing from peer-reviewed articles, governmental and non-governmental reports, policy documents, and other relevant, evidence-based sources to contextualise the socio-economic, cultural, and health-related challenges these communities face in relation to HIV.

Internal and external consultations were conducted with sector professionals working with LGBTQ+ communities in GWS, including peer support workers, community outreach teams, and clinical staff with high caseloads of patients living with HIV. The majority were from diverse cultural backgrounds, and all had lived, or were living or working, in GWS. Consultations were conducted as semi-structured qualitative interviews, allowing for expansion on responses to targeted questions and in-depth discussion on related issues, with a particular focus on cultural context.



Additionally, in 2023, we participated in symposiums and partnership meetings focused on HIV in GWS, hosted by both the Prevention Research Implementation Science and Monitoring (PRISM) Partnership, and the Culturally and Linguistically Diverse Sexual Health Action Group (CALDSHAG). We refer to evidence provided by researchers, clinicians, and community organisations at these events and meetings, and we have sought approval from those whose work we have referred to directly.

It should be noted that there is a significant general lack of research on access to HIV and sexual health services for multicultural and migrant populations living in Western democratic nations, although this is beginning to improve with recent studies currently underway.[12] This is particularly true for GWS, where very few studies have to date focused specifically on HIV in a cultural context. Körner's important 2007 papers are two of the only peer reviewed social research studies focused specifically on HIV in culturally and linguistically diverse (CALD) communities in Sydney, and the role of community and culture as factors that both enable and constrain engagement with health and well-being.[13,14]

Our review of the literature has informed the direction of this paper and evidence provided in these symposiums, meetings, and consultations have informed our policy recommendations and supported our ability to identify key barriers and effective strategies for improving HIV responses in this region.

METHODOLOGY CONTINUED

NOTE ON THE TARGET POPULATION OF THIS PAPER

While ACON acknowledges GWS is home to communities with Western European and Anglo-Celtic heritage, this paper will focus primarily on LGBTQ+ people from culturally, ethnically, and linguistically diverse migrant and refugee backgrounds and, in particular, on LGBTQ+ people of colour. The aim is to address the specific needs of those who are from non-Western backgrounds.

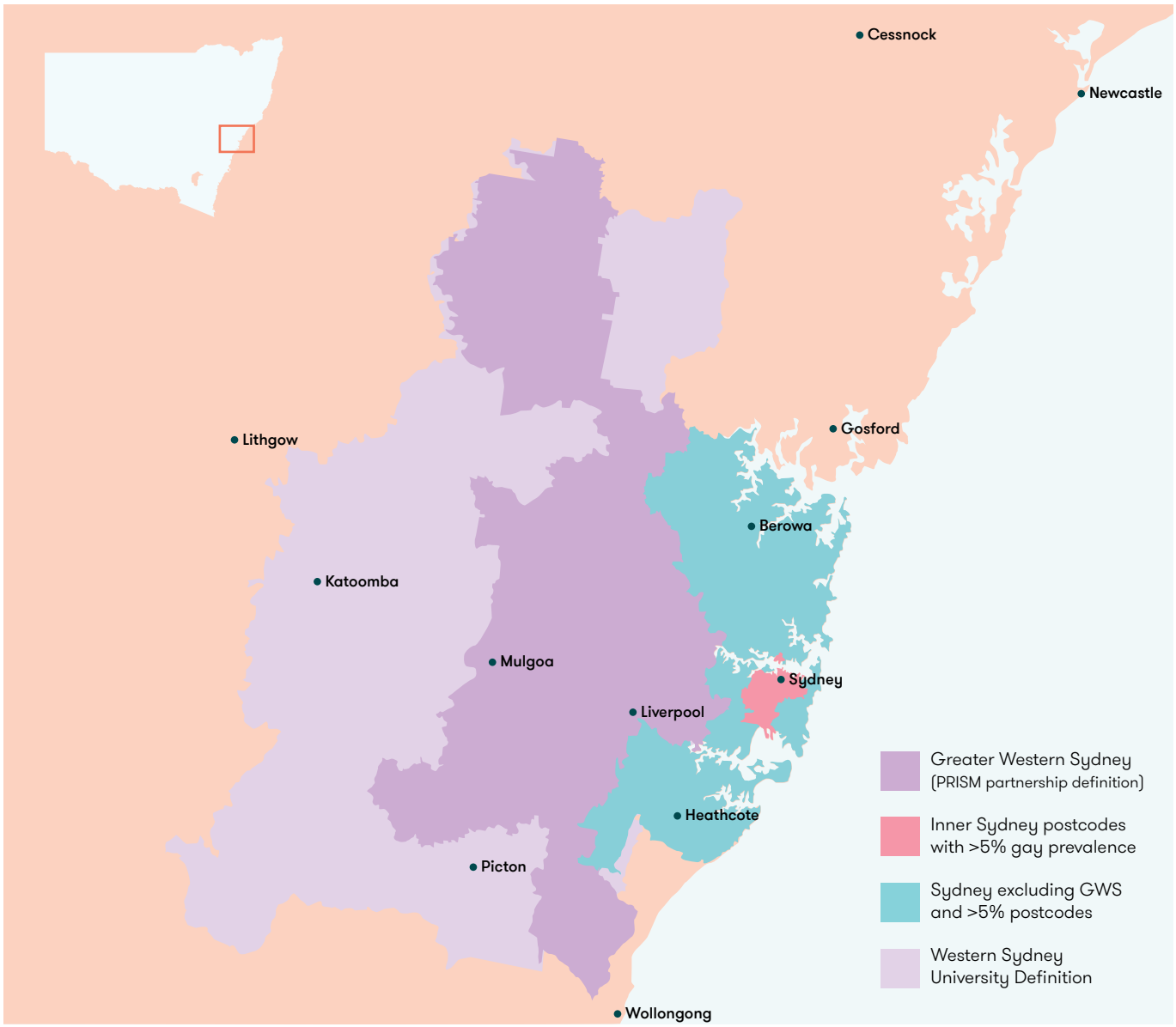
We acknowledge that GWS is home to the largest urban population of Aboriginal and Torres Strait Islander people in Australia. However, First Nations people require HIV responses that address their needs separately to that of migrant communities, as they are distinct from that of other communities in GWS. While this paper does not address these specificities, ACON has written about HIV in the NSW Aboriginal and Torres Strait Islander population here. Addressing HIV interventions for Aboriginal and Torres Strait Islander people will be the subject of ongoing future interrogations as part of ACON's policy work.

Further, we are aware that HIV affects people in GWS who are not sexuality or gender diverse. As ACON's work has a particular focus on people who are part of sexuality and gender diverse communities, this paper cannot address the specificities of what a community-led approach would look like for heterosexual groups.

METHODOLOGY CONTINUED

BOUNDARIES OF GREATER WESTERN SYDNEY

When referring to the Greater Western Sydney Region, this paper follows the definition produced by the Prevention Research, Implementation Science and Monitoring (PRISM) Partnership, of which ACON is a collaborating partner. It defines GWS according to 87 postcodes, which have been used to create the following map:



These boundaries were produced according to both the boundaries used by the University of Western Sydney, and in consultation with people who live and/or work in, or recently grew up in, GWS. There is no general consensus on the boundaries of GWS however, as of 2023, this was the definition used by the Ministry of Health in their Annual HIV data reporting.

4

BACKGROUND

NSW POLICY CONTEXT

The Australian Federal and State Government's strategic response to the HIV epidemic has evolved over time. The Federal Government released its first National HIV/AIDS Strategy in 1989, and the NSW Government have subsequently released a series of NSW focused HIV strategies alongside them.[15,16]

These strategies have maintained a consistent focus on prevention, testing, and treatment alongside stigma reduction and recognition of the importance of partnering with community-based organisations to drive engagement in sexual health messaging and health promotion initiatives.[17]

The community-informed approach led to what has been globally recognised as a highly effective HIV response, both in NSW and across Australia.[18,19] And, since the organisation was formed in 1985, ACON has worked in partnership with the government, clinicians, and researchers, playing a pivotal role in advocating for the importance of community voices in the HIV response.

Over time, community based, peer-led interventions have become a cornerstone of National and State led HIV Strategies, including the latest NSW HIV Strategy 2021–2025.[20] This most recent HIV strategy lists GBMSM who are from culturally and linguistically diverse backgrounds, and people from, or who travel to, countries of high prevalence and/or who are living with HIV as priority populations for prevention, testing, treatment, and stigma reduction interventions in NSW.

In addition, the NSW LGBTIQ+ Health Strategy 2022–2027 marks GBMSM and people from culturally and linguistically diverse backgrounds as priority sub-groups, listing GBMSM as at greater risk of HIV, and cultural stigma, shame, and increased discrimination as barriers to service access for culturally and linguistically diverse communities.

Further to this, the NSW Plan for Healthy Culturally and Linguistically Diverse Communities 2019–2023 describes cultural stigma and shame around HIV, as well as trauma, negative past experience with state health systems, English proficiency and access to professional interpreters, and isolation as priority areas within the goal of improving access to health services for these communities.[21]

BACKGROUND CONTINUED

HISTORICAL AND CULTURAL CONTEXT

GWS is home to vibrant and thriving migrant communities from Southeast, East and South Asia, the Middle East, and the Pacific Islands and there are distinct and explicitly visible differences between the cultural enclaves of each area of GWS, which is indicative of a highly culturally diverse region.[23]

Those who have settled in this region may experience complex and intersecting dimensions of marginalisation, including racism. They may have come from countries affected by conflict and war, had traumatic experiences with authoritarian regimes in their home countries, or had complex or problematic experiences with health care services before arriving in Australia. They may speak multiple languages, speak little to no English, or have parents born overseas, but only speak English themselves.[24]

Socio-economic factors are known to impact mental health and limit an individual's ability to prioritise their general health.[25,26] In GWS, average annual incomes measure lower when compared to the national average, and the region also experiences higher than average unemployment.[27] For someone living in GWS on a limited income, this can mean that regular GP visits, prescriptions, and visits to sexual health clinics may be perceived as unaffordable, even if they are currently accessible free of charge in specific locations.

LGBTQ+ people living in GWS may also have varying degrees of interdependence within their cultural communities, but many describe in particular the importance of family as uniquely integral to their cultural identity, which has significant impacts on the ways in which LGBTQ+ communities come together and how they respond to HIV health messaging.[28,29,30,31]

Sexuality and gender diverse populations in GWS also receive health messaging and service delivery differently to those living in the well-established LGBTQ+ communities of inner Sydney. Traditional campaigns and services that heavily utilise LGBTQ+ symbolism, like the rainbow flag and/or openly sexualised messaging and imagery, are meaningful, appropriate, and effective for inner Sydney audiences. However, to better reach the LGBTQ+ community in GWS, adoption of more tailored and culturally specific campaign imagery and symbolism may be necessary, and ACON recently piloted two new initiatives that have utilised this approach, with success (see initiatives listed in Section 6. "Looking Ahead").[32,33]

5

THE DATA

WHAT THE NSW SURVEILLANCE DATA IS TELLING US

New HIV diagnoses are not declining in GWS and have risen among overseas-born MSM since borders reopened following COVID-19

While numbers of new diagnoses among MSM in inner Sydney have dropped dramatically over the past decade, in GWS they have remained relatively unchanged. Across NSW, notifications among overseas-born MSM declined significantly during the period of COVID-19 related border closures (2020–2022).

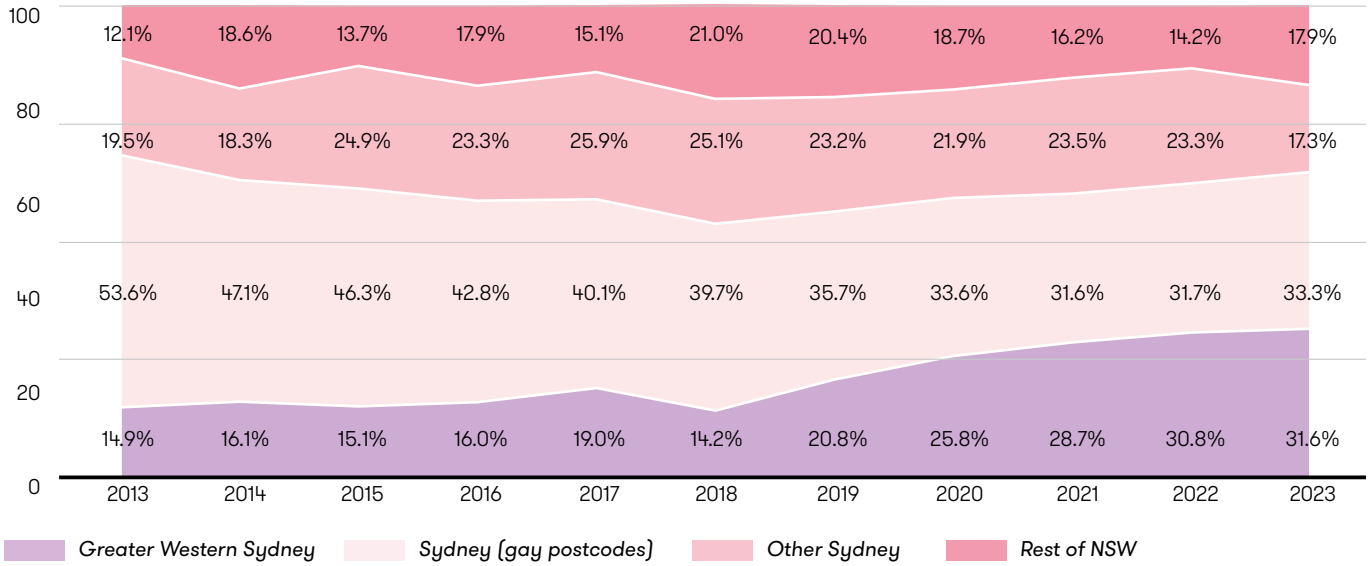
However, while the 2023 data indicates an increase in notifications among overseas-born MSM in Sydney's "gay postcodes" since 2022, these figures are still lower than notifications each year prior to the beginning of the pandemic in 2020. By comparison, notifications among overseas-born MSM in GWS in 2023 are not only higher than they were prior to the beginning of the pandemic, they are the highest they've been in the ten year period between 2013 and 2023.

Figure 6: New HIV diagnoses in MSM by area of residence and place of birth, 2013 to 2023

From NSW Annual HIV Data Report 2023 (Source: NCIMS, Health Protection NSW, 27 February 2024)

Additionally, although total numbers of new notifications in GWS have not necessarily been steadily rising over time, the overall proportion of notifications from GWS has risen (from 14.9% in 2013 to 31.6% in 2023) because there have been significant and sustained decreases elsewhere, particularly in Sydney's gay postcodes. This indicates that while prevention, testing and treatment interventions are working, the GWS region is not enjoying the same declines as other areas of Sydney.

New HIV diagnoses in MSM by area of residence



Source: NSW Annual HIV Data Report 2023

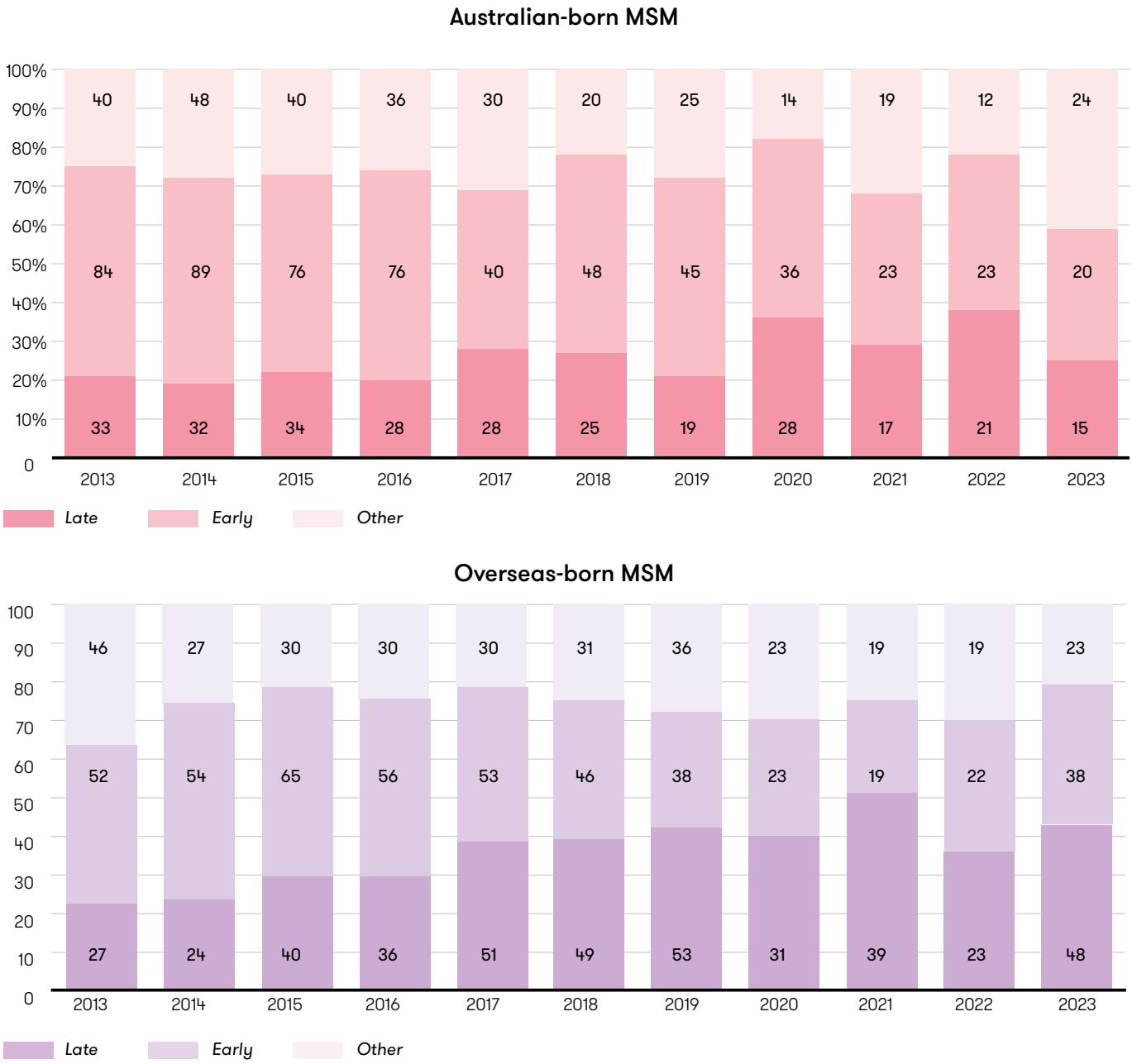
Higher rates of late diagnoses

Because of the risk of compromising a person's identity, data that breaks down numbers of late diagnoses by postcode are, understandably, not made publicly available.

However, we do know that, across Australia in the period from 2009 to 2018, late diagnoses decreased by 28% among Australian-born MSM alongside a notable increase of 47% among overseas-born MSM during the same period. Across Australia, 2018 marked the first year that late diagnosis for overseas-born MSM (55%) were higher than that for MSM born in Australia (43%). Among overseas-born MSM diagnosed late, it was also more likely that they acquired HIV before coming to Australia.[37,38]

For NSW, the proportion of late diagnoses among overseas-born MSM has remained higher than that of Australian-born MSM since 2015, with the exception of some fluctuation around COVID-19 border closures.[39]

New HIV diagnoses in MSM by place of birth and stage of infection



Source: NSW Annual HIV Data Report 2023

It is not known to what extent these numbers of late diagnoses will increase but it is reasonable to expect that, in the future, a high proportion of overseas-born MSM arriving in NSW will settle within the migrant communities of GWS with whom they may have cultural or familial connections.

No one should be diagnosed with late-stage HIV, as this has severe impacts on their health. While numbers of new notifications may include people who have arrived in NSW already living with a late-stage infection, these figures demonstrate the importance of linking our migrant populations, in GWS and across NSW, to care as soon as possible.

THE DATA CONTINUED

Additionally, as the HIV crisis was brought largely under control in Australia, numbers of deaths caused by AIDS-defining illnesses stopped being formally reported to NSW Health. However, at a key sector wide symposium hosted by community organisations, researchers, and clinicians it was reported that, unfortunately, multiple people in SWSLHD had died with an AIDS-defining illness in 2023. Of these, around half were patients from culturally, ethnically, and linguistically diverse backgrounds. Considering effective prevention, testing, and treatment interventions have been available throughout Australia for some time, this is of serious concern.

GBMSM from GWS more likely to travel to inner Sydney for testing and prescriptions

Currently, around half of GBMSM living in GWS travel outside of their location of residence to obtain PrEP prescriptions.[34] Significant proportions also travel outside of GWS for STI testing. ACON's 2015-2019 evaluation of community-based a[TEST] HIV and STI testing services, all of which are located in inner Sydney, reported that those who live in <5% gay postcodes accounted for 40.3% of all unique a[TEST] clients. While numbers outside <5% gay postcodes include a broader area than just GWS, this does indicate that a[TEST] services have significant reach to those living outside of inner Sydney suburbs.

Importantly, data from a recent and as yet unpublished qualitative study on HIV stigma in GWS showed that participants living in GWS who visited a GP in their local area also reported experiencing discrimination towards their sexuality and HIV status, inadequate sexual health screening, and an attitude that sexual health was not their role as a GP, and not part of their training. Some were also denied a PrEP prescription.[35] Ongoing records related to levels of stigma experienced by PLHIV also report similar findings.[36]

We must respond to instances of discrimination and address prejudiced and stigmatising views from health care providers if we are to achieve sustained and significant reductions in notification rates in GWS.

THE DATA CONTINUED

WHAT THE SURVEILLANCE DATA ISN'T TELLING US

Cultural, ethnic, and linguistic diversity/ sexuality and gender

NSW has one of the best surveillance systems in the world. However, there is additional demographic information that is not currently collected - and perhaps not possible to collect within this system - that would enable us to better understand some of the barriers to HIV interventions experienced by particular populations.

At the time of diagnosis in NSW, clinicians only collect information on a patient's country of birth. This means we have limited understanding of the cultural, ethnic, and linguistic backgrounds of the Australian-born and overseas-born groups.

This is significant for those in GWS who may have been born in Australia but who, for example, may speak a language other than English at home, and/or belong to a culturally or ethnically diverse community, and who may experience barriers to care, such as racism.

When information about ethnicity and race is not collected in notification data, we end up with an incomplete understanding of cultural, ethnic, and linguistic diversity among those diagnosed with HIV in the GWS region.[40]

Additionally, HIV notification data collection procedures have only recently begun to include information about a person's sexuality and does not yet report this data. At the time of diagnosis, exposure is recorded as either "men who have sex with men (MSM)" or "heterosexual (HET)" depending on likely HIV exposure history, and based on a person's sex recorded at birth, rather than their gender. This does not necessarily capture the sexuality or gender diversity of the individual.

For example, HIV transmission between a bisexual cisgender woman and bisexual cisgender man, and between a cisgender gay man and a transgender gay man, would both be classified as "HET". These classifications erase the diversity of our communities and limit our understanding of HIV transmission routes.

Furthermore, because of the size of the datasets, surveillance reports do not distinguish exposure history geographically, leaving us with little information about exposure history, or gender and sexuality within certain regions.

While it may not be appropriate in public health surveillance data, understanding cultural, ethnic, and linguistic diversity among those who are diagnosed with HIV would help community organisations like ACON to better understand the impact of stigma, prejudice, and racial discrimination on access to equitable sexual health care in GWS – factors that heavily influence targeted HIV health promotion strategies.

6

BARRIERS

Migrant communities experience intersecting dimensions of marginalisation based on multiple factors.[41,42,43] They may have past experience with complex and/or intergenerational trauma related to racial violence, war, negative experiences with government institutions in their home countries, or they may have already had problematic interactions within the Australian immigration or health care systems.

These experiences of marginalisation can be further compounded by sexuality and gender-based prejudice, discrimination and violence, and HIV related stigma that exists within their cultural communities.[44,45] They may have come from countries where homosexuality is heavily policed and HIV is criminalised, with little or no privacy around HIV status, and strong negative community perceptions of PLHIV.

These factors can explain elevated levels of fear and distrust towards government institutions, including state-based health systems and sexual health services. Consequently, for those who experience intersecting dimensions of marginalisation, choices about sexual health may not necessarily be driven by knowledge of sexual health risk factors alone.[46]

Decision-making processes around health may be complicated by concern for more immediate legal or socio-economic pressures, or other more serious threats to personal safety. However, while the barriers we address here are known to obstruct access to prevention, testing, and treatment interventions for people at risk of, or living with, HIV in GWS we also know that attitudes are changing in some communities.[47, 48, 49]

Over time, in some regions of the world, progress has been made in the struggle to protect the rights of LGBTQ+ people. As social movements seeking to further these protections continue, this can be seen in an increase of positive visibility of LGBTQ+ people in some communities.[50]

While this is true of some regions, in others LGBTQ+ people continue to face oppression, ostracism, imprisonment, and even the threat of death. As the global political landscape changes, there are also often setbacks alongside progress.

Understanding the complexity and interconnectedness of barriers at a systemic, societal, and individual level will be crucial in developing strategies that better serve the sexuality and gender diverse populations of this culturally diverse region.[51, 52]

BARRIERS CONTINUED

SYSTEMIC

Visa eligibility and immigration requirements
Permanent residency (PR) is the only class of visa in Australia that requires the applicant to also submit an HIV test, and a positive result will affect an applicant's eligibility.

In Australia, visa applicants are subject to an assessment of their potential cost to the health care system over the term of their stay. HIV is currently ascribed a cost of between $12,000 and $16,000 per year to the Australian health care system, with a cost threshold currently set at $51,000 over the term of the visa.[53] This means that, unless the applicant is able to engage legal representation to argue for an exemption, applications for permanent residency will likely be denied to PLHIV. The effect this has on the perception of HIV in GWS cannot be overstated.

According to the *Global Database on HIV-specific travel and residence restrictions*, Australia is the only remaining Western developed nation that continues to impose restrictions on long term visas based on the applicant's HIV status.[54] Given this policy promotes experiences of stigma and discrimination, it is likely those experiences of stigma and discrimination would be minimized if Australia were to change this policy, as other Western democratic nations have done.[55]

While understanding of HIV varies among different groups in multicultural communities, in general, health literacy around HIV in GWS is low.[56, 57] The fact that discussions about the visa implications of HIV may be the only information many in the community have make these restrictions significant primary drivers of stigma and prejudice around HIV in general among these communities.

The visa implications of HIV status are reported to be a constant source of uncertainty and anxiety for PLHIV among migrant communities.[58, 59] Fear and hesitancy to engage with sexual health services also exists for those on temporary visas who intend to pursue longer term visas at a later stage, regardless of their current HIV status – a situation applicable to many international students.[60]

Evidence indicates that international students have lower health literacy around sexual health in general, when compared to domestic students.[61] The combination of anxiety, hesitancy, low HIV literacy and fear can result in testing avoidance for those concerned that a positive result may impact visa status, either in the immediate or in the longer term, regardless of whether this is a legal reality.

Currently, applicants for temporary visas are not required to undergo HIV testing, and HIV services, as well as access to subsidised HIV treatment, is available regardless of Medicare status. However, access to biomedical prevention, such as PrEP, is not subsidised for those who are ineligible for Medicare (but is still available at low cost), and confusion around issues related to access and cost remain persistent within migrant communities.

The Australian Government Department of Health and Aged Care's 2023 HIV Taskforce Report explicitly states that immigration requirements should not discourage access to HIV testing and treatment.[62]

Efforts to dispel prominent myths related to visas and migration pathways would allay fears and improve understanding within the GWS community and increase confidence in accessing testing and treatment. Any immigration requirements that exclude visa applicants based on their HIV status should be removed.

BARRIERS CONTINUED

Prejudice, discrimination, and stigma from GPs, HCPs, pharmacists, translators and interpreters

Prejudicial and stigmatising attitudes and discrimination from health care workers regarding sexuality and HIV status is a known barrier to accessing HIV prevention, testing, and treatment interventions.[63, 34, 65, 66, 67]

Unlike inner Sydney, GWS does not have a well-established network of general practitioners with understanding of LGBTQ+ communities and expertise in HIV care that could share the increasing caseload and serve to buffer the impact on currently strained resources in hospital settings.

Numerous case studies from symposiums on HIV in GWS in 2023 and from those working in the HIV sector in GWS reported accounts of prejudiced and stigmatising responses from health care providers and health service professionals, including from GPs, pharmacists, and medical administrators. These have included demeaning remarks, judgemental lines of questioning, missed opportunistic testing, and explicit denial of services.[68, 69]

Despite the NSW HIV Strategy 2021-2025 naming stigma and discrimination as key barriers to virtually eliminating HIV transmission, examples of GPs in GWS (and elsewhere in NSW, especially in regional and rural areas) refusing to prescribe PrEP and pharmacists refusing to stock or sell HIV medication continues to be reported.

We must respond to examples of discrimination and stigma if we are to achieve our goals of reducing HIV notifications in GWS. Additional funding is needed to upskill GWS doctors on HIV and LGBTQ+ communities. This would increase the capacity to provide care to people at risk of or living with HIV, improve clients' mental health and quality of life, and reduce loss to follow up. Routine and uniform collection of data on client satisfaction can help health services better understand their clients' experiences and to make adjustments that encourage trust from clients and confidence in service delivery.

As an organisation, ACON routinely and uniformly collects data on client satisfaction, the results of which inform our service delivery design. ACON's client satisfaction data indicates that confidentiality, accessibility, peer-engagement, and freedom from judgemental and stigmatising views from health care workers are important in achieving high levels of client satisfaction. This feedback has helped ACON adjust our service provision, communication, and marketing strategies over time. It has helped us to promote accountability and to improve trust between our clients and our services. This data can also help services identify and address examples of discrimination.

When health services do not routinely and uniformly collect data around client satisfaction, they are missing a valuable opportunity to gain insights that have been key to the success of ACON's a[TEST] services. Efforts to redesign services in alignment with this data can help address client concerns, identify existing barriers, and help to achieve sustained reductions in notifications in GWS.

BARRIERS CONTINUED

Medicare eligibility, treatment, and safe, accessible testing locations

Across Australia, as of July 2022, HIV treatment is free, regardless of Medicare eligibility, when accessed through a government-funded public hospital.[70] However, many continue to be unaware of this change. In addition, while PrEP is expensive for those who are Medicare ineligible, there are ways to access more affordable options, although overseas-born MSM continue to experience internalised stigma around accessing biomedical interventions.[71, 72]

Many are also unaware that testing can be accessed at a free and confidential service. Some may also face logistical barriers to accessing free testing services, and some may choose only to travel to specific locations in suburbs where they feel confident they will not be recognised by people they may know.

Including the clinic at the Blue Mountains District Hospital in Katoomba, there are only five publicly funded sexual health clinics (PFSHCs) located in the GWS region, compared to inner Sydney, which has more than double this number distributed over a much smaller geographic area.

Significant numbers of people from GWS travel to locations in the inner suburbs to access testing and treatment, indicating a lack of access to, or knowledge of, local and culturally safe prevention, testing, and treatment service providers in the GWS region. It may also be logistically easier to access services located on a direct train line, even when they are located in the inner city, rather than a local service in a location that requires multiple train and/or bus transfers.

Expanding the number of PFSHCs in GWS would improve access, resulting in increased rates of testing. These services must also consider location, public transport accessibility, discretion, and cultural sensitivity to be effective.[73]

While discretion is essential, this must also be balanced alongside efforts to ensure the relevant communities know these services exist and know where they are located. Increasing access to, and knowledge of, self-testing options will also increase overall rates of testing within these communities.

BARRIERS CONTINUED

SOCIETAL

Perceptions of stigma, prejudice, and discrimination

The outcome of the 2017 Marriage Equality Postal Survey indicated a widespread lack of support for equal marriage rights across all electorates of GWS, which is often interpreted as a broader lack of support for the rights of sexuality and gender diverse communities in general, in this region.[74]

However, many non-Western, non-Judeo-Christian communities feel that their cultural histories, religious traditions, and familial and social structures are frequently misinterpreted and devalued, particularly when framed as inherently opposed to perceived Western ideals of individual freedom, democracy, and social progressiveness.[75, 76]

In a 2011 study on Arab communities in GWS, one respondent explicitly noted their frustration around the racist framing of their communities and families as somehow inherently more conservative, prejudiced, and homophobic than that of the wider Australian population.[77]

In contrast to this position, and as the report from the Special Commission of Inquiry into LGBTIQ hate crimes revealed, a long-standing culture of violence and homophobia has existed within the wider Australian society, and systemically embedded in state run institutions, for a long time. Parts of NSW, especially regional NSW, are also experiencing a rise in anti-LGBTQ+ sentiment from far-right white supremacist groups.

Regardless of the postal survey outcome, like LGBTQ+ people globally, LGBTQ+ people from GWS experience a range of both positive and negative responses to coming out as sexuality and/or gender diverse to friends and family.[78, 79, 80, 81]

Working together with cultural and faith-based community leaders and organisations based in GWS, as well as with families and allies of the LGBTQ+ community, will be key to addressing this issue. This will require long-term partnerships, and relationships built on respectful and culturally informed approaches that avoid racist and reductive stereotypes.

As an organisation with decades of experience working across the sector with and for PLHIV, we understand the importance of culturally aligned peers, non-judgemental attitudes among staff and healthcare workers, and a culture of taking action to address judgemental attitudes when they are identified, in mitigating the debilitating impacts of societal stigma. This, along with specific attention to maintaining accessible hours, providing language appropriate resources, offering reassurance around confidentiality, and providing a friendly, open, non-clinical feel to our sexual health services are all factors ACON knows to be effective in removing barriers to access for LGBTQ+ people.

Over time, it will be necessary to do further work within the multicultural communities of GWS, to better understand their experiences of prejudice and discrimination, and to explore additional options that will support the ongoing engagement of multicultural LGBTQ+ communities in GWS with sexual health messaging and service delivery.[82]

BARRIERS CONTINUED

Cultural safety the importance of family

Seeking out sexual health services or disclosing sexuality, gender diversity, or HIV status can be extremely complex if the wider cultural community hold the prejudiced view that these issues bring a sense of shame to the family.[83, 84, 85] In consultation with peer-workers and community leaders, many also commented on a tendency towards gossip and rumour among their cultural communities around issues related to sexuality and gender diversity.

Research conducted with Arab communities in GWS reported a deeply ingrained belief that "family is everything", and this was further supported by comments from LGBTQ+ community members in later consultations.[86]

Unfortunately, these factors can result in anxiety and fear that rumours about sexuality, gender diversity and/or HIV status may circulate within the community and get back to family members. This fear can make it difficult, or even impossible, to risk being seen seeking out sexual health care services that are explicitly advertised as LGBTQ+ oriented.[87]

Research shows that these factors can also create a tension in which a person is torn between expressing or disclosing their sexuality, gender diversity or HIV status, and a sense that disclosure will threaten the cohesion of their family.[88]

A person may go to great lengths to maintain harmonious family relations as their highest priority, and this may result in a division in which they are living two separate lives. In consultation, many commented by saying "We just don't talk about it" and that their partner would often be referred to as a "friend" or that the nature of their relationship with their partner was never spoken about.

To support those in GWS who do face prejudice, stigma, and discrimination from their families and cultural communities, it is important to show understanding for these complex weightings of cost and benefit in either "coming out" or "staying in", and the constant struggle of feeling pulled in both directions.[89, 90]

Those living in GWS also describe alternative approaches towards disclosure, including one known in contrast as "coming in", where the person maintains control over which specific people in their familial and social networks are granted the privilege of knowing about their sexuality and/or gender diversity or their HIV status. In these instances, maybe an aunt or a sibling, or a select few trusted friends will know, but the wider familial and social group will not.

It is important that respect and understanding is shown for a person's right to make their own decision about whether to prioritise harmonious relationships with family and community over their desire to disclose information about their sexuality, gender, and/or HIV status.[91, 92]

Cultural knowledge, respect, and understanding that establishes ongoing connection and long-term trust will be key in reaching sexuality and gender diverse communities living in GWS with appropriate sexual health messaging and services. Campaigns and interventions must be designed with an informed appreciation of cultural complexity at their core. Doing so will make LGBTQ+ people living in GWS feel a stronger sense of safety and security when accessing programs or services, and disclosing their sexuality, gender identity, and/or HIV status.

BARRIERS CONTINUED

INDIVIDUAL

Language barriers and access to safe translators and interpreters

Around half of GWS residents speak a language other than English at home.[93] For these communities, complex technical medical information about sexual health and HIV can be extremely difficult to understand if the information is not provided in a comprehensible language.

Clinicians working in hospital settings make every effort to provide translation and interpretation services, but it can take time to access interpreters and translators who speak the right language, particularly if the person is from a small linguistic community. Access to translation and interpretation is also not necessarily available across the whole sector.

In addition, in consultation with peer-support workers, clinicians, and community leaders serving the GWS community, it has been repeatedly noted that finding safe translators and interpreters for people of diverse sexualities and genders or PLHIV in GWS can be challenging.

If a translator or interpreter harbours, or is perceived to harbour, prejudiced or stigmatising views they may be seen as unsafe, and as a potential threat of disclosure to family or to cultural community, particularly if their linguistic community is small, and gossip is prevalent.

This poses an extremely complex challenge to the health care system, as culturally appropriate translators and interpreters are imperative in the process of communicating sensitive or complex sexual health information accurately.

HIV knowledge, internalised shame, and fear of stigma

In consultation with community leaders working with PLHIV in GWS, low understanding of HIV has been identified as a significant factor contributing to entrenched stigmatising views held by the community. Reluctance to discuss sexuality openly leads to low levels of understanding about sexual health in general, as well as internalised shame around sexual practices.

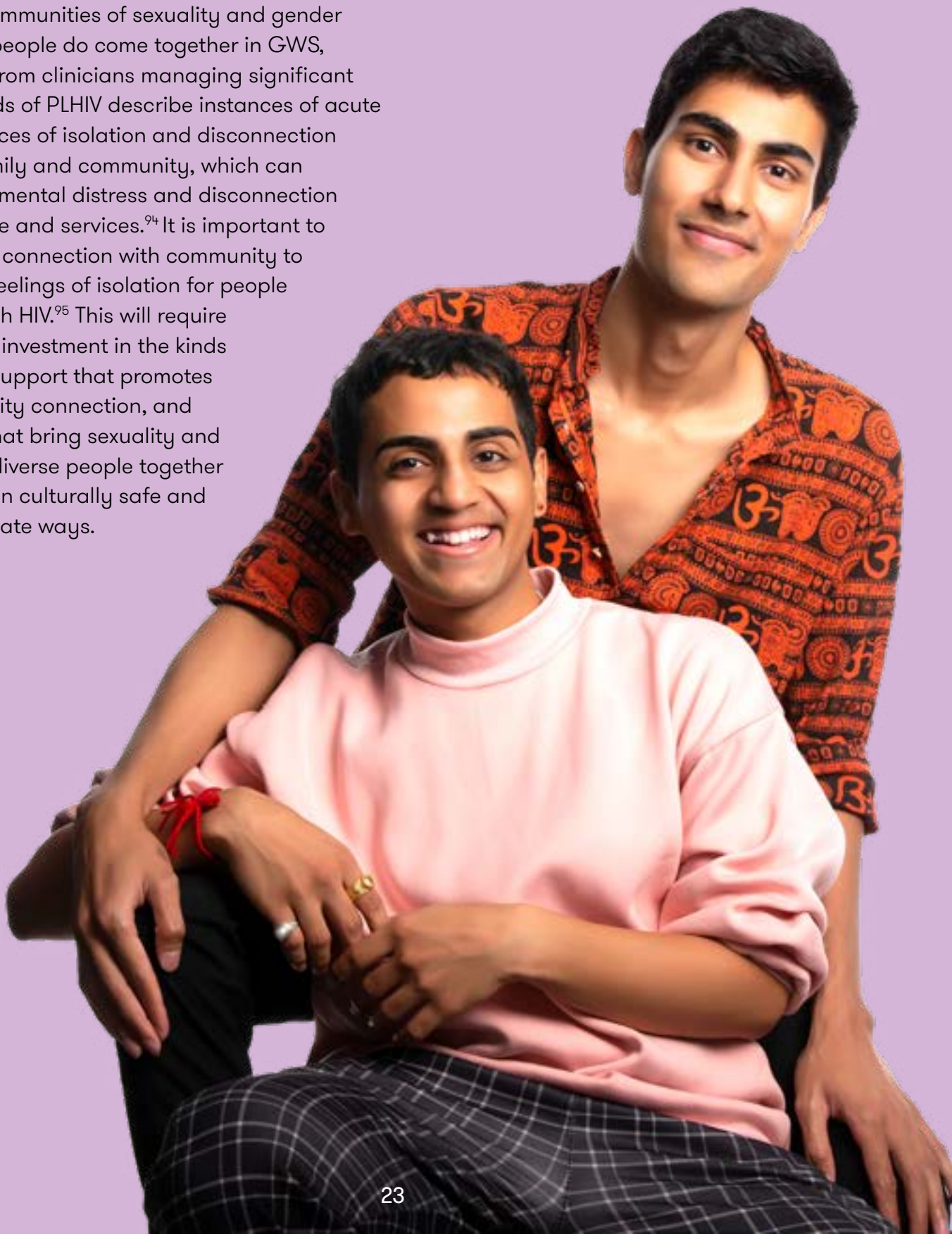
Roundtable discussions held by The Multicultural HIV and Hepatitis Service (MHAHS) have revealed that communities may also be reluctant to discuss HIV as a standalone health issue because of these factors.

It may be beneficial for the sector to consider bundling sexual health messaging in a way that can reach GBMSM whilst allowing them to remain anonymous as a target audience, and to consider routinised HIV testing (opt-out testing), or routine sexual health testing that includes HIV testing as only one part, allowing the patient to keep their sexuality confidential.

BARRIERS CONTINUED

Isolation and a lack of connection to sexuality and gender diverse communities

While communities of sexuality and gender diverse people do come together in GWS, reports from clinicians managing significant caseloads of PLHIV describe instances of acute experiences of isolation and disconnection from family and community, which can result in mental distress and disconnection from care and services.[94] It is important to promote connection with community to reduce feelings of isolation for people living with HIV.[95] This will require ongoing investment in the kinds of peer-support that promotes community connection, and events that bring sexuality and gender diverse people together in GWS in culturally safe and appropriate ways.



BARRIERS CONTINUED

TESTING AVOIDANCE AND LATE DIAGNOSES

Ultimately, the barriers outlined in this section lead to testing avoidance, and people becoming lost to care.[96, 97, 98] While a proportion of those receiving a late-stage diagnosis may have acquired the virus outside of NSW, if a person in NSW dies with an AIDS-defining illness, it means at some stage they have not been connected to care or treatment.

It is crucial that we are able to empower all people living with or at risk of HIV to take control of their health, and to reduce the barriers obstructing their access to critical care.

If we can reduce these barriers, we will be better positioned to encourage prevention, reduce testing avoidance and loss to care, bring numbers of new diagnoses down, and ensure GWS is included in the fight to end HIV for all.

7

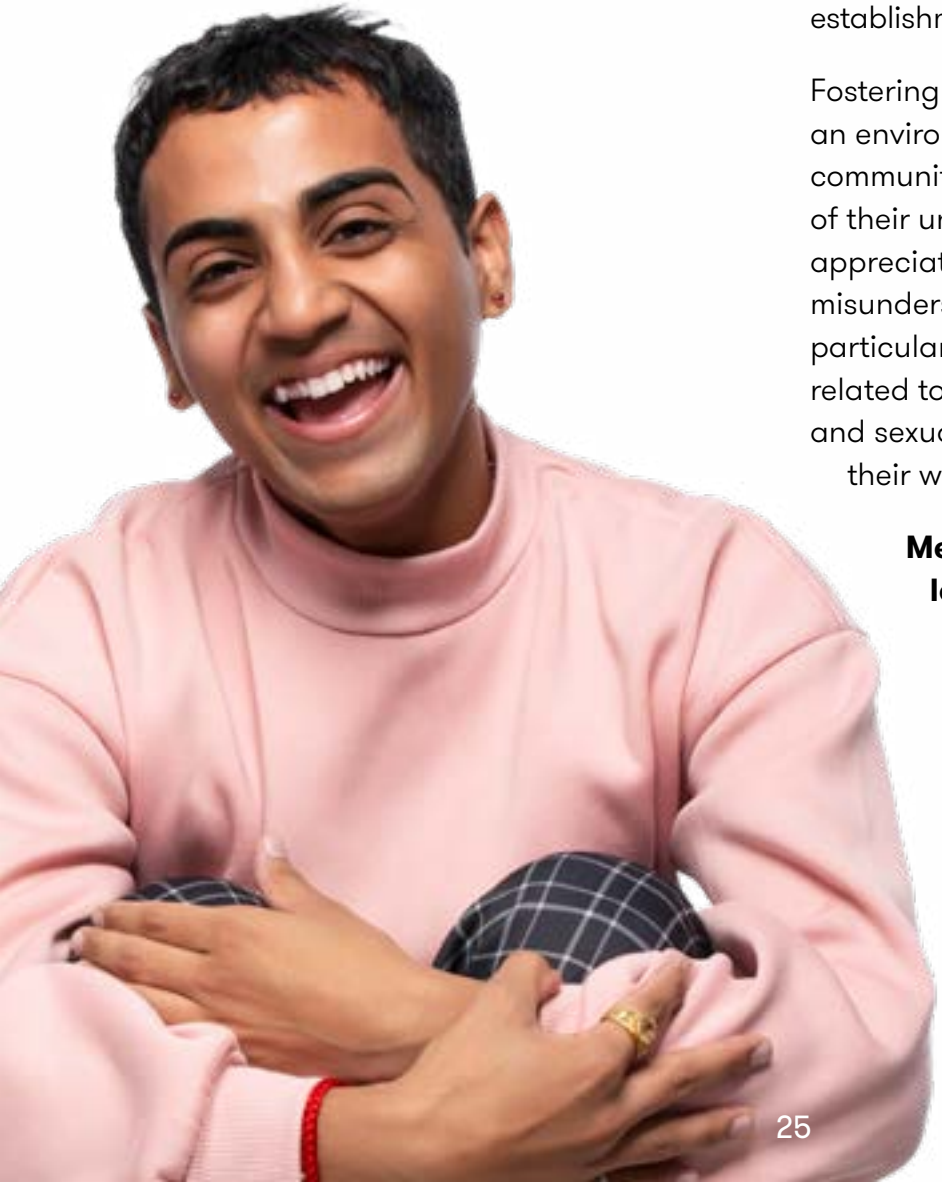
LOOKING AHEAD

UNDERSTANDING CULTURAL APPROPRIATENESS AND CULTURAL SAFETY

Recognising intersectionality

LGBTQ+ people from culturally, ethnically, and linguistically diverse migrant and refugee backgrounds and LGBTQ+ people of colour experience prejudice, discrimination and stigma because of their gender and sexuality as well as their race and ethnicity, and they often experience these simultaneously.[99]

Interventions must recognise that the intersecting dimensions of the oppression they experience are compounded when experienced together, and this should inform the process of consultation and the co-design of programs and campaigns.



Consultation and co-design

Tailoring programs to be culturally appropriate requires a commitment to the process of community consultation and co-design in a way that will ensure interventions are responsive to the needs of the communities they are designed to serve. It also requires the inclusion of people with lived experience at every stage of development, including their involvement in decision making processes at high levels.

Partnering with community groups with strong cultural connection to the people they represent encourages the development of meaningful networks and community relationships, and the establishment of mutual trust.

Fostering a sense of trust and respect supports an environment in which diverse cultural communities feel safe to expect that aspects of their unique cultural experience will be appreciated and supported, rather than misunderstood, dismissed, or ignored. This is particularly important when it comes to issues related to disclosure of HIV status or gender and sexuality to their family members, or to their wider cultural community.

Meaningful and appropriate language

Consultation and co-design should also involve specific attention to inclusive, meaningful, and appropriate language. It is important to acknowledge that the terms used to describe diverse cultural identity and heritage depend on the context in which they are being used, and the person using them.

LOOKING AHEAD CONTINUED

RENEWED STRATEGIC FOCUS & INVESTMENT

The importance of long-term investment in the development of meaningful relationships and strong community partnerships in GWS are highlighted in various parts of this paper. However, there is also an urgent need to address existing issues within the healthcare system. This will be crucial in achieving sustained and significant reductions in notifications over time, for culturally and linguistically diverse populations living in GWS.

Greater engagement with health promotion will be difficult to sustain without service redesign and a change in approach. Without these improvements, increased efforts to engage the LGBTQ+ communities of GWS in sexual health services may not result in reduced HIV notifications in this region.

While we recognise the impact that COVID-19, the mpox response, and the health messaging required for Sydney World Pride had a significant impact on our HIV resources in NSW, we cannot allow this to prevent us from reaching our targets of virtual elimination of HIV in NSW.

Meaningful efforts to re-design and expand existing services are recommended. The development of innovative new services, such as increased access to self-testing options, alongside enhancements to existing services including peer-led clinics with flexible opening hours, and increasing cultural diversity among staff, will be required to achieve change.

From a policy perspective, the NSW Government must apply substantial resources to the engagement of multicultural communities across a range of priority areas. We suggest an approach that is developed in partnership, in consultation with community organisations, to help drive new investment in sexual healthcare in GWS.

LOOKING AHEAD CONTINUED

ACON'S PAST WORK

For almost 40 years, in addition to maintaining its focus on the inner Sydney areas with the highest recorded prevalence of HIV, ACON has consistently demonstrated a commitment to education, prevention, and support for LGBTQ+ communities in GWS. This work has included community outreach programs, peer-led workshops, HIV prevention education, and support for people living with HIV. Over the years, ACON has also broadened its focus to include many more areas of LGBTQ+ health.

This work has involved collaboration with various health services and community groups in GWS, and while ACON has continuously adapted its approach to better serve the diverse needs of LGBTQ+ communities in this region, a new strategic focus on culturally tailored, peer-led interventions is underway to better reach communities in GWS.

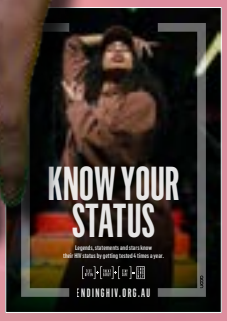
Building on a strong history of community engagement, and research conducted with Western Sydney University, ACON launched two exemplary new pilot projects that signified a shift in strategy towards culturally tailored initiatives targeted specifically to GWS communities, and represent possible options for future community-informed responses.

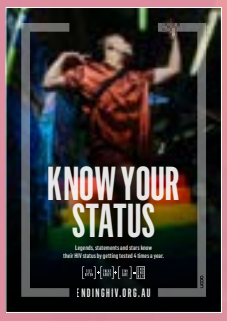
They were:

LOOKING AHEAD CONTINUED

West Ball Campaign (2022-2023)

ACON launched its West Ball Campaign at GWS's annual West Ball – a ballroom event celebrating queer and trans people of colour from GWS through fashion, dance, and music. Co-designed by ACON and participants from West Ball, and with a focus on HIV prevention, testing, treatment, and stigma, the campaign centred images of the unique style, fashion, and culture of GWS's LGBTQ+ community members and participants in the ballroom event.





In 2022, in partnership with Liverpool Sexual Health Clinic, the campaign was accompanied by a pop-up HIV testing booth, and in 2023 ACON handed out 300 sexual health packs that included Atomo HIV self-testing kits. This campaign has received overwhelming levels of engagement online.

Stories Out West (2022-2023)

In partnership with Sweatshop, ACON launched a writing project, collating essays from LGBTQ+ writers from multicultural backgrounds living in GWS. The book launched at an event during Sydney World Pride to resounding praise.

These two new projects exemplify an innovative and inclusive approach to bringing LGBTQ+ communities together in a cohesive group that has allowed ACON to better reach them with health messaging tailored to their needs.

This work combines community based, peer-led partnerships with culturally informed creative expression, centring the strengths and aspirations of these unique and diverse LGBTQ+ communities.

With the primary focus of supporting and amplifying community connection, this work represents the re-establishment of trust and brand recognition that will help facilitate more effective delivery of HIV prevention, testing, and treatment interventions for the culturally, ethnically, and linguistically diverse communities of the GWS region.

8

CONCLUSION

The continuation of existing efforts across the sector will be crucial in ensuring the significant and substantial reductions in HIV notifications across NSW continue, but also, critically, that notifications do not rise again in areas of inner Sydney with the highest populations of GBMSM. Currently, there is no vaccine or cure for HIV. This means that sustained efforts to maintain low notification rates are fundamentally important to ensuring the epidemic remains under control. Strong HIV programming and investment is still required, even as we achieve strong results, to ensure NSW achieves and maintains its goal of virtual elimination of HIV across the state.

While the achievements made in the reduction of new HIV notifications in inner Sydney have been widely celebrated, it is critical that we also recognise the importance of the unique LGBTQ+ communities of GWS as part of the rich and diverse cultural fabric of NSW. These communities participate in, and contribute substantially to, LGBTQ+ culture across the state. Addressing HIV in GWS requires a tailored, culturally appropriate, community-led approach that recognises their unique diversity and the role of culture in the uptake of sexual health messaging and engagement in prevention, testing and treatment interventions.

It is unacceptable that people are dying with AIDS-defining illnesses in this region and that HIV notifications have been stagnant alongside such substantial declines in inner Sydney suburbs. The death of any person who has an AIDS-defining illness is deeply concerning, and re-introducing a system for quantifying these, not only in GWS, but across Australia, would help us better understand the demographic and social circumstances of those affected.

CONCLUSION CONTINUED

LGBTQ+ communities in GWS are thriving, and achieving a comparable decline in HIV notifications in this region will require a departure from previous approaches targeted towards inner Sydney GBMSM. Acknowledging the role of culture and improving our understanding of the complexity of the intersecting dimensions of marginalisation experienced by LGBTQ+ people living in this region will ensure new approaches to prevention, testing and treatment interventions are more effective in engaging the unique LGBTQ+ communities of GWS.

Ensuring those with lived experience are engaged in a co-design process at all stages of development and delivery of campaigns, programs, and sexual health services designed to reach them will be crucial in improving sexual health practices among these priority populations. Amplifying opportunities for these communities to come together and support each other will help end the kinds of isolation that result in low health literacy, poor mental health outcomes, and loss to care for PLHIV in GWS.

New interventions must be developed alongside meaningful partnerships with influential community leaders, as well as strategies that include family networks and LGBTQ+ community allies. In addition, more culturally sensitive approaches must be deployed that are respectful of the unique ways in which sexuality and gender diverse people living in GWS negotiate their relationships with their families and their cultural communities.

Alongside dedicated commitment from stakeholders across the sector and guided by existing policy frameworks and the *National HIV Taskforce Report*, this renewed strategic focus, of ACON and across the sector, will mark a pivotal shift toward a future where GWS stands alongside the rest of NSW in the collective effort to achieve the virtual elimination of HIV in Australia.

9

RECOMMENDATIONS

ACON makes the following recommendations for addressing HIV to improve HIV-related health outcomes for LGBTQ+ communities in GWS:

Peer-led, community-based initiatives

1. Fund the expansion of partnerships between existing community organisations to strengthen networks, and support events that bring sexuality and gender diverse communities together in GWS.
2. Resource existing community-based organisations to develop initiatives and interventions for LGBTQ+ communities in GWS with a co-design approach that includes community consultation.
3. Ensure participation of LGBTQ+ people from GWS at all levels of leadership in the development of the programs and initiatives designed to serve them.
4. Include cultural and faith-based leaders, as well as families and allies, in the consultation process, to understand the key drivers of social prejudice and discrimination and how best to address them.
5. Ensure all interventions are built on respectful and culturally informed approaches that avoid reductive stereotypes.

Sexual Health Service redesign

6. Resource the addition of HIV and sexual health services in GWS that are easily accessible by public transport.
7. Expand access to interpreters and translators with specific knowledge of and experience with LGBTQ+ communities as well as an understanding and appreciation for the privacy of their clients.
8. Expand HIV notification data collection to include cultural background and ethnicity more accurately.
9. Ensure routine and uniform collection of data on client satisfaction in all publicly funded sexual health services across NSW and report on examples of discrimination, including prejudicial and stigmatising views from health care workers.
10. Increase access to, and knowledge of, POCT and other self-testing options in GWS.
11. Introduce a trial of Opt-Out HIV testing to emergency departments in GWS to monitor whether this form of routinised testing can help reconnect those who may have been lost to care, bring down rates of late diagnosis, and prevent further HIV related deaths in this region.
12. Introduce a new system for recording and reporting AIDS-related deaths in clinical data reporting.

RECOMMENDATIONS CONTINUED

Migration reform

13. Work with federal partners to advocate for the removal of migration health requirements for applicants to submit an HIV test to the Australian department of home affairs and review the "significant cost threshold" to reduce immigration barriers for PLHIV.

14. Increase efforts to dispel prominent myths related to the impact of HIV status on temporary and short-term visa applications.

Medicare reform

15. Promote awareness of recent changes in eligibility rules allowing all PLHIV to access free HIV treatment, regardless of Medicare status.

16. Work with federal partners to advocate for subsidised access to biomedical prevention, such as PrEP and PEP, for all GBMSM in NSW, regardless of Medicare status.

Education, training, and health literacy

17. Resource comprehensive cultural and LGBTQ+ training for GPs, pharmacists, and health care workers across NSW, empowering them to discuss sexual health without prejudice, and to understand HIV risk factors as well as prevention, testing, and treatment options.

18. Increase awareness of HIV risk factors alongside information about modern medical interventions including how and where to access them and dispel outdated ideas about HIV and AIDS to increase understanding of HIV within the community in GWS.

19. Work with tertiary institutions to ensure LGBTQ+ and cultural competency training is included in coursework as a prerequisite for attaining qualification and accreditation.

10

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OUR COVER ART

In 2022 and 2023, ACON partnered with West Ball to run a sexual health campaign that included an online visual campaign featuring event participants, as well as a pop-up HIV testing service that distributed 300 safe sex packs.