2030

IMAGINING HIV IN 2030

DISCUSSION PAPER

[TEST OFTEN] + [TREAT EARLY] + [STAY SAFE] = [ENDING HIV]

acon HERE FOR HEALTH

ABOUT ACON

ACON is New South Wales' leading health promotion organisation specialising in HIV prevention, HIV support and lesbian, gay, bisexual, transgender and queer (LGBTQ) health.

Established in 1985, our mission is to enhance the health and wellbeing of our communities by ending HIV transmission among gay and homosexually active men, and promoting the lifelong health of LGBTQ people and people with HIV.

ACKNOWLEDGEMENTS

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We acknowledge and pay respects to the traditional custodians of all the lands on which we work.

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ACRONYMS

ART	Antiretroviral therapy
ARV	Antiretroviral
BBV	Blood-borne virus
DBS	Dried blood spot
FDA	(United States) Food and Drug Administration
GIPA	Greater involvement of people living with HIV/AIDS
HAND	HIV-associated neurocognitive disorder
HIV	Human immunodeficiency virus
HPV	Human papilloma virus
LGBTQ	Lesbian, gay, bisexual, trans and queer
LHD	Local health district
MIPA	Meaningful involvement of people living with HIV
MSM	Men who have sex with men
NCI	Neurocognitive impairment
NSP	Needle and syringe program
NSW	New South Wales
PBS	Pharmaceutical Benefits Scheme
PEP	Post-exposure prophylaxis
PLHIV	People living with HIV
PrEP	Pre-exposure prophylaxis
PWID	People who inject drugs
SIV	Simian immunodeficiency virus
TB	Tuberculosis
TasP	Treatment as prevention
TGA	Therapeutic Goods Administration
UNAIDS	Joint United Nations Programme on HIV/AIDS
WHO	World Health Organization

CONTENTS

INTRODUCTION

In 2012/13, the New South Wales Government developed one of the most ambitious HIV strategies in the world.

The Strategy visioned a virtual end of new HIV transmissions, and backed in this bold public health goal through enlivening partnership, investing in technologies and staying the course.

In 2018, NSW recorded the lowest rate of new HIV notifications since 1985. This important milestone invites us to celebrate the successes of Australia's world-leading HIV responses, reflect on how far we have come and acknowledge the contributions of so many in our communities who have fought so hard to achieve these results.

From a time in the 1980's and early 1990's, when little was known about a new disease that would take the lives of thousands, to the current era of highly effective treatment and prevention methods, our communities have been at the forefront of HIV responses, caring for each other and shaping public policies.

Because of that inspired collective audacity, we are now able to cast our eyes to 2030.

This paper is an invitation to be part of a conversation about the kind of future we want for our communities, and how to make it happen.

There are numerous considerations and questions that are helpful in guiding our collective reflection, two of which are pressing.

Firstly, how do we accompany our communities to thrive into old age?

Advances in treatment and lower notification rates mean that the HIV positive population is getting older. How do we make sure the best treatment, care and support are provided at home, in the community and in aged care settings? Section two of this paper addresses these questions, imagines three possible scenarios and advocates for the meaningful involvement of people living with HIV/AIDS (MIPA) in HIV responses.

Another critically important consideration is how we will make sure that no one gets left behind.

It is clear from HIV notification data that not everyone in our communities is benefiting from prevention and treatment advances to the same extent.

The majority of new HIV notifications among gay and bisexual men are now from people who were not born in Australia. While there is no doubt that more technological and biomedical advances lie ahead, we need to think of ways that these can be accessed by all, without discrimination or unnecessary barriers. Section three unpacks these recent trends and imagines three possible scenarios.

1. CONTEXT

> There is light in the gloom of this epidemic. We will ultimately defeat HIV, but in doing so we will have achieved even more. We will have wrought fundamental changes in health care, in reducing discrimination and prejudice, and in enhancing social justice. The changes we make in the cause of defeating HIV will make this country a better place for all Australians.
>
> *Bill Whittaker (1988)*
>
> *ACON CEO 1986 – 1990*

1. CONTEXT

Before casting our eyes to 2030, this section provides an overview of the context in which HIV responses are currently situated.

HISTORICAL CONTEXT

At the beginning of the epidemic in the early to mid 1980's, little was known about a new disease often referred to as 'the Gay Plague' in the media and diagnosed by doctors as the 'Gay-related immune deficiency' (GRID).

With no understanding of how the virus was transmitted, no treatment and the criminalisation of populations who were most at risk - gay men, injecting drug users and sex workers - HIV spread rapidly.

The first recorded case of AIDS in Sydney was recorded in October 1982, and the epidemic reached a peak of 1,636 new HIV notifications in NSW in 1987.

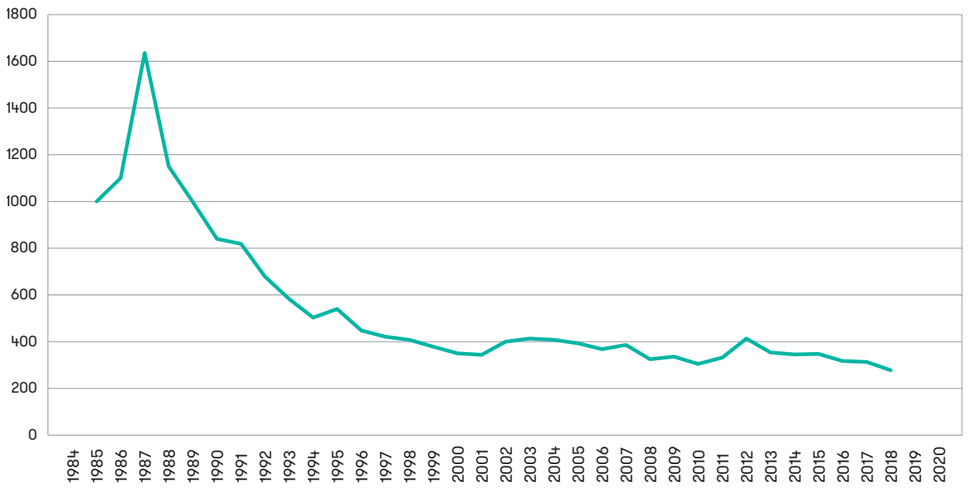
At the time, the public discourse around HIV/AIDS was characterised by fear - fear of death for those affected and also a public health fear that this virus would spread across the population. In this context, fear led to some rapid responses.

The HIV/AIDS epidemic was quickly met by strong and multi-faceted responses, including care and support for those who were dying and their loved ones and relatives, community education, advocacy and activism. In *Through Our Eyes*, NAPWHA presents the rich and complex history of HIV responses through the voices of PLHIV who have been involved in the making of Australia's effective HIV response.[2]

Together with significant advances in treatment that dramatically improved health outcomes for PLHIV, law reforms and investments in targeted HIV responses led to significant reductions in HIV transmissions in the 1990's (see figure 1).

Figure 1

Number of new HIV notifications in NSW



Source: Adapted from NSW Government, Epidemiology of HIV in NSW residents newly diagnosed with HIV infection up to 31 December 2013 and NSW Government, NSW HIV Strategy 2016 – 2020 Quarter 4 & Annual 2018 Data Report.

POLITICAL CONTEXT

The early days of HIV/AIDS demanded a swift, evidence-based, bold response. Effective, pragmatic and commendable actions were taken across the political divide to protect lives.

These evidence-based population health approaches continue to provide the foundation of the contemporary response to HIV in Australia.

This long-standing, bipartisan approach to delivering evidence-based, adequately funded HIV responses is reflected in the Commonwealth[3] and NSW Government's HIV strategies.[4] The core pillars of the HIV response include:

- **PARTNERSHIP** between communities, governments, the clinical/health and research sectors. This includes ongoing relationships between organisations representing people living with or at risk of HIV who are the centre of HIV responses, and the NSW and Commonwealth Governments.
- **ACCESS TO TREATMENT & CARE.** Access to more effective, affordable medication and primary as well as HIV-specific care underpinned by Medicare and the Pharmaceutical Benefits Scheme (PBS), is central to both HIV prevention and care.

  Investments in the development of new technologies (testing, treatment, biomedical prevention), as well as the surveillance system, are also key.
- **TESTING OFTEN** is critically important to detect new HIV cases rapidly, link newly diagnosed people to treatment and care, and prevent transmission clusters.
- **COMBINATION PREVENTION** is the recognition that no single HIV prevention approach alone can stop the epidemic. Meeting ambitious HIV transmission reduction targets requires a mix of evidence-based HIV prevention interventions, including condom provision, biomedical prevention (treatment as prevention, PrEP, PEP), and risk reduction and harm minimisation for people who inject drugs (e.g. needle and syringe programme).
- **ACCESS TO STERILE INJECTING EQUIPMENT** to prevent blood-borne virus transmissions and injecting-related harm.
- **DECRIMINALISED SEX WORK**, which is essential to ensuring that sex workers can safely access testing and health care services.

ACON acknowledges that much has been written about the historical and political context of HIV/AIDS in Australia. As the focus of this document is forward-looking, this section is necessarily brief and summarily natured.

COMMUNITY CONTEXT

Our response to HIV started with the community, and it continues to rely on communities engagement, mobilisation, health behaviours and essentially a belief that we can "beat" HIV.

The socio-demographic profile of the HIV positive population is changing. There were 10,110 PLHIV in NSW in 2016.[5] Mirroring trends in the NSW population, the HIV positive population is ageing (see section 2.2) and increasingly diverse.

Gay and homosexually active men remain the most at-risk population. The reported transmission routes for the 278 people who were newly diagnosed with HIV in NSW in 2018 were: sex between men (71.2%), sex between men and injecting drugs (6.5%), heterosexual sex (18.7%), injecting drugs (1.8%) and another or unknown transmission route (1.8%).

Despite a lack of data on the holistic health of gay and homosexually active men, we know that the ways in which gay men connect with each other, socially and sexually, as well as a range of behavioural factors relevant to HIV prevention and support, are evolving.

The Sydney Gay Community Periodic Survey[6] found that the proportion of men reporting condomless anal sex with casual partners is increasing, with PrEP becoming the most commonly used HIV prevention strategy by men who report condomless anal sex. Safe sex cultures have changed but are continuing.

A range of impediments, however, restrict overseas-born gay and homosexually active men's access to prevention strategies. While the number of new diagnoses among Australian-born gay and homosexually active men in 2018 was 33% less than the average of the previous five years, the number of new diagnoses among overseas-born gay and homosexually active men was just 3% less than the corresponding period.[1]

Much remains to be done for the meaningful inclusion and visibility of trans and gender diverse communities in HIV responses, including future policy responses.[7] In 2018, three transgender people were reported to have been newly diagnosed with HIV in NSW.

Aboriginal and Torres Strait Islander people face compounded disadvantage, structural barriers and discrimination in accessing health services. In 2018, eleven Aboriginal people were reported to have been newly diagnosed with HIV in NSW.

Finally, it is important to stress that the identities, paths and experiences of people in our communities are intersectional and shaped by a multitude of factors, including their socio-economic background and cultural identities.

TECHNOLOGICAL CONTEXT

The ability to collect, store and share more patient data offers both opportunities and challenges for HIV responses. The availability of more detailed patient data may assist in establishing individual health diagnostics, managing polypharmacy, creating continuity of care and tailoring prevention and healthcare to meet the needs of individual patients.

A well-balanced approach is required to ensure that individuals benefit from and maintain their rights over their own data, including the right to confidentiality.

Confidentiality is critical, as HIV is still one of the most stigmatised diagnoses a person can receive.

Controversies surrounding the introduction of My Health Record, an individualised medical record automatically created for all Australians, have highlighted difficulties in making sure that these records remain consistent with the primary purpose of improving health outcomes for patients.

Health promotion is constantly evolving to adapt to changes in social media and smart phone usage, which has dramatically changed the way our communities engage with each other and with their own health.

Digital transformations are also rapidly changing the ways in which members of our communities connect. In the 2018 Sydney Gay Community Periodic Survey, 51% of respondents said they had found their male sex partners through mobile apps.[6] The online space is fast-changing and increasingly able to cater for the specific interests within the gay community. This allows for greater targeting of key populations, but presents challenges as advertising costs have risen in an increasingly monetised social media landscape.

While technologies have evolved, it is important to maintain investment in community programs that allow for face-to-face peer connection and support to occur. This is beneficial for people who do not engage online, as well as for the digitally connected. Peer-based face to face interactions are invaluable in improving health literacy, nurturing wellbeing, building resilience and improving health outcomes.

NATIONAL, REGIONAL AND GLOBAL CONTEXT

Targeting key populations in urban areas while also servicing regional and rural NSW has been a challenge for HIV responses.

It is estimated that 65% of the NSW population lives in Greater Sydney.[8] The city is home to a large gay population[9] and the majority of PLHIV also reside in Sydney – about three-quarters of the ART dispensed in NSW was to patients residing in the following five local health districts (LHD): South Eastern Sydney, Sydney, South Western Sydney, Northern Sydney and Western Sydney.[10]

National HIV responses are also crucial to ending HIV in oNSW. Nationally, there were 963 new HIV diagnoses in 2017, the lowest number of diagnoses since 2010, and HIV prevalence (the proportion of all people in Australia who are living with HIV) is low compared to other high-income countries in the Asia-Pacific.[11]

In a globalised world where populations are more mobile, the international context also has implications for NSW.

It is estimated that the majority of new HIV acquisitions among overseas-born people in NSW occur in Australia, not in their home country. This highlights the importance of HIV education for people who are unaware of HIV risks in Australia, and whose perceptions of HIV may be grounded in experiences from their home countries where HIV may not be talked about, stigmatised and/or criminalised.

Australians traveling to countries with a high HIV prevalence may also be unaware of their exposure to risks overseas.

2. LIVING WITH HIV IN 2030

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After more than 35 years of the HIV epidemic in NSW, the centrality of people with HIV and their meaningful involvement in driving the response remain as important as ever. The leadership and contribution of people living with HIV in the Australian response is public health at its best.

How we move forward to address stigma, discrimination, social isolation, ageing, and build the strength and resilience of HIV positive people with their continued involvement, will not only shape our future success, but will continue to set a high benchmark for the provision of good healthcare more broadly.

Steven Berveling

ACON Board Member, HIV+ since 1996

2. LIVING WITH HIV IN 2030

Experiences of living with HIV are shaped by a multitude of individual, social and structural factors. This section explores how a greater range of treatment options, changes to address the needs of an ageing population and a range of other social determinants will impact the lives of PLHIV in the future.

HIV TREATMENT

Antiretroviral medications have dramatically changed since combination therapy first became available in the mid 1990's. Antiretroviral therapy (ART or ARVs) is now more effective at controlling the replication of the virus in the body, less likely to cause side-effects and easier to take.

With foreseeable biomedical advances, the future of HIV will be shaped by our collective ability to ensure everyone has access to the treatment options that best suit their needs.

TREATING EARLIER

In NSW, the time from diagnosis to treatment initiation is now shorter and retention in care is high. The proportion of people diagnosed with HIV in January to June 2018 who commenced treatment within six weeks of diagnosis was 83%. The median number of days to ART uptake among those diagnosed during that period was 21 days, a significant decline from the median of 45 days in 2013.[1]

There is evidence to support accelerated ART initiation, including starting ART on the same day as HIV diagnosis.[31] Starting treatment on the day of diagnosis can lead to improved clinical outcomes, including in regards to virological suppression[32] and in lowering viral reservoirs within the central nervous system.[33] It is worth noting, however, that same-day initiation is particularly effective at addressing attrition during the period from HIV testing to ART initiation in settings where retention in care is low,[34] which is not the case in NSW.

The World Health Organization (WHO) now "strongly recommends ART initiation on the same day as HIV diagnosis *based on the person's willingness and readiness* to start ART immediately, *unless there are clinical reasons to delay treatment*".[35] In the US and Australia, guidelines indicate that on a case-by-case basis, ART may be deferred because of clinical and/or psychosocial factors.[36] Clinical reasons for not starting ART immediately include whether a patient has tuberculosis (TB), which should be treated first.

There are indications of community support for starting treatment at the same time as a HIV diagnosis. In a survey conducted by Positive Life NSW, 84.9% of respondents indicated they would support starting treatment at the same time as a HIV diagnosis. Of those who identified as HIV positive, 79.8% supported starting treatment same day as diagnosis compared with 90.5% among those who identified as HIV negative or unknown status.[37]

NEW TREATMENTS ON THE HORIZON

Safer drugs, fewer pills, still undetectable

As has been the case for the last 30 years, it is highly likely that treatment regimens will continue to improve. Despite advances, current treatments have a number of limitations for individuals and the health system, including toxicities associated with lifelong care, the need for daily pill-taking and associated psychological burden and costs. Although modern regimens are forgiving of missed doses, adherence to prescribed regimens remains paramount.

Two-drug regimens[16] (i.e. two drugs contained in a single pill), may partially address toxicities associated with lifelong antiretroviral therapy. A review of the literature on evidence documenting toxicities associated with long-term ART, particularly among ageing PLHIV, found that newer treatment regimens with fewer drugs may mitigate some of the cumulative toxicity burden of long-term ART[17], while having a similar efficacy to a three-drug regimen.[18]

Technological advances may also make it easier for a person to maintain an undetectable viral load (UVL) in ways that are similar to the management of other chronic conditions like diabetes. This includes maintaining a UVL with fewer pills thanks to **longer-acting** or **extended-release antiretrovirals**, which could take the form of:

- injections administered on a monthly or less frequent basis;
- a slow-release capsule able to deliver a week's worth of HIV drugs in a single dose; and
- implants that are similar to diabetes-control mini-pumps or implanted contraceptive devices.

Longer-acting antiretrovirals may facilitate adherence to treatment for both therapeutic and prophlactic purposes. Some may find these innovative forms of treatment more convenient, especially for people who have to travel long distances to see their prescriber.

PLHIV might someday be able to maintain a UVL with biannual infusions of **anti-HIV antibodies**. Small studies involving a handful of patients have shown that broadly neutralizing antibodies had some potential.[21] A new clinical trial will evaluate whether periodic infusions delivered together every two to four weeks are safe and effective at suppressing HIV following discontinuation of ART.[22] Results are expected by mid-2022.

Because they are able to target HIV-infected cells, broadly neutralizing antibodies are also examined for their potential to be a part of a cure strategy.

In addition to a greater range of treatment options, technological advances may improve one's ability to monitor their own viral load and adjust treatments accordingly. This may become possible though smarter devices that would enable a person to gain greater control over their HIV monitoring.

PLHIV may soon be able to check their viral load from home, in a way that would resemble blood glucose monitors for the management of diabetes.

Prospects for greater autonomy raise important questions about ways to take advantage of self-monitoring devices while also maintaining engagement in care and support.

Finding a cure

In the context of HIV, the term 'cure' has been used to mean different things. A **sterilising HIV cure** generally means the complete eradication within an individual of all HIV-infected cells, while a **functional HIV cure** is generally understood as achieving long-term remission (i.e. the absence of viral rebound after ART cessation for at least several years). In other words, with a functional cure, even after stopping ART, HIV would not reactivate in a person's body and they would be able to maintain viral control.

While it is hard to predict the future of cure research, significant developments should be noted.

In 2009, much hope was raised by the case of Timothy Brown, also known as the "Berlin patient", the first person to have been cured of HIV after undergoing stem cell transplantation.[23] Timothy Brown has not experienced viral rebound since ceasing ART after his procedure.[24]

Ten years later, a second case of long-term HIV remission also drew attention worldwide[25] - a London man has had no remaining detectable HIV since undergoing a bone marrow stem cell transplant to treat lymphoma. According to findings presented at the Conference on Retroviruses and Opportunistic Infections (CROI 2019), "it is premature to conclude that this [London] patient has been cured."[26]

Significant progress has been made in understanding the latent HIV reservoir and how much virus persists after ART is ceased.[27]

Several individuals are known to have maintained UVL for months or years after stopping ART[28 29] and a number of trials in simian immunodeficiency virus-infected (SIV) macaque monkeys have led to sustained viral remission.[27] Research on vaccines is also considered in section 3.

Considerations should also be given to ensuring that any advances in treatment are accessible to all NSW residents as soon as they become available.

ACCESS TO TREATMENT

As better drug regimens become available, it will be essential to ensure that everyone is able to access the treatment that best suits their needs.

NSW has already met UNAIDS' treatment target[5] as per the global *2016-2021 Strategy - On the Fast-Track to end AIDS*, and is getting closer to meeting the ambitious targets set by the NSW and Commonwealth Governments (see figure 1).

It was estimated[5] that:

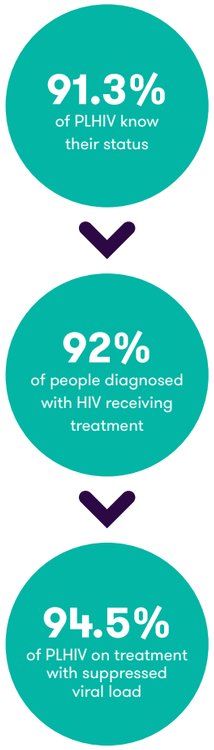
- 10,110 PLHIV resided in NSW in 2016, among whom 9230 (91.3%) were diagnosed. This is just over the target set by UNAIDS. That 90% of PLHIV know their status.
- In 2016, 8490 (92.0% of those diagnosed) were receiving ART. This is over the 90% target set by UNAIDS but under the NSW Government's target of 95%.
- Among PLHIV receiving ART in NSW, 8020 (94.5%) had suppressed their viral load (<200 HIV-1 RNA copies/mL). This is over the 90% target set by UNAIDS. Overall, 79.3% of all PLHIV (including those who know their HIV status and those who do not) had HIV virological suppression in NSW.

ESTIMATING HOW MANY PEOPLE DO NOT KNOW THEY HAVE HIV

Estimating the number of undiagnosed HIV cases, (i.e. the number of people who have HIV but don't know it) can be done via three main methods: biological assays, mathematical modelling, and a statistical approach called back-projection.[38]

In Australia, the COUNT study is a key reference that estimates the number of undiagnosed HIV using biological assays. Participants of the Sydney Gay Community Periodic Survey were asked to provide oral fluid specimens for HIV testing to estimate the level of undiagnosed HIV among gay and bisexual men in New South Wales.[39]

Figure 1: HIV Treatment Targets - How is NSW Tracking?



Source: adapted from Keen, P., et al., 2018. Based on 2016 data.

Barriers will need to be addressed to ensure that all people access the same standard of treatment, care and choice.

Current restrictions to Medicare eligibility have created dual health systems. According to Positive Life NSW, as at October 2018 an estimated 281 people living with HIV were accessing HIV medicines via pharmaceutical companies' compassionate access schemes and sexual health clinics or other public health services in NSW. There are concerns that *ad hoc* solutions – applying for compassionate care from pharmaceutical companies, or seeking specific doctors – are inconsistently applied and not sustainable. A system or systems that enable newly diagnosed people to get access to ARVs quickly and sustainably are required.

Barriers also need to be addressed to ensure that people living in non-metropolitan areas are able to access HIV medication more easily.

EVOLVING CARE NEEDS

Beyond maintaining an undetectable viral load, a range of factors impact the health outcomes and quality of life of people living with HIV as they age. Addressing these factors will be essential to reach the 2018 - 2022 National HIV strategy target of 75% of people with HIV reporting good quality of life by 2022, and a greater proportion by 2030.

HEALTH RISK FACTORS

PLHIV have an increased risk of serious non-communicable diseases, including cardiovascular, liver and kidney disease, malignancies and bone disorders compared with the general population.[40,41] Human papilloma virus (HPV) related anal cancer incidence is significantly elevated among PLHIV, especially in gay and homosexually active men.[42]

In addition to advances in treatments for co-morbidities, modifying lifestyle behaviours can substantially improve health outcomes for PLHIV. Ceasing smoking[44], reducing alcohol consumption and addressing harmful substance use[45], access to a healthy diet[46], and exercising[47] contribute to greater health outcomes by preventing or reducing the impacts of comorbidities.

Smoking in particular is one of the most important modifiable traditional risk factors for non-communicable diseases. It is estimated that daily smoking rates amongst PLHIV are three times higher than in the general population.[48]

AGEING AND DISABILITY

Addressing ageing needs will be key to meeting the *2018 - 2022 National HIV Strategy* target of 75% of PLHIV reporting good quality of life by 2022, and greater percentages by 2030.

Extended life expectancy due to better treatment, combined with the overall ageing Australian population, means that the average age of the HIV positive population will continue to rise. In 2017, 46% of PLHIV in Australia were over fifty.[49] Life expectancy, quality of life and personal experiences will vary between individuals within our communities, notably depending on when they initiated ART.

New health challenges and care needs will emerge for a number of PLHIV as they age, including the management of several medications, frailty[50] (i.e. deficits in functional capacity and ability to perform activities of daily living), and various forms of mild to major neurocognitive impairment (NCI).

The exact role played by HIV in neurocognitive disorders and the extent to which these affect PLHIV is disputed. PLHIV may undergo accelerated cognitive ageing[51], with some estimating that HIV-associated neurocognitive disorder (HAND) may already affect more than 20% of PLHIV.[52]

A recent survey found that HIV-associated neurocognitive disorder (HAND) was a concern among PLHIV in Australia.[53] However, another study of UK HIV-positive and HIV-negative men who have sex with men suggests that neurocognitive impairments may be overestimated in HIV-positive gay and homosexually active men and may not be attributed to HIV, calling into question the use of the term HAND.[54]

Much remains to be done to support PLHIV to age in their own homes, address gaps in aged care packages and better address complex needs.[55] This includes the need to manage the potential for polypharmacy, which can be complex for anyone living with any chronic condition.

Due to histories of stigma and discrimination, our communities often fear disclosing that they are LGBTQ or HIV positive, which may lead to some of their needs being unaddressed. Experiences of discrimination and poor treatment within aged care programs mean that many fear the consequences of being 'out' in older age.

It should also be noted that, currently, aged care packages are reserved for people over the age of 65, leaving gaps in the management of complex and advanced ageing needs for some PLHIV.

Systems interactions, eligibility criteria and the quality of packages under the National Disability Insurance Scheme will also play a significant role in achieving greater quality of life for people who concomitantly live with HIV and a disability.

ADDRESSING SOCIAL DETERMINANTS

What it means to live with HIV will also depend on our collective ability to address social determinants of health, including by strengthening resilience, connection and social protection.

STIGMA AND DISCRIMINATION

The literature on stigma and health in general, and on HIV-related stigma in particular, has highlighted the impacts of discrimination (i.e., enacted stigma) on health outcomes. A review of 134 psychological studies found that perceived discrimination sets into motion a process of physiological responses (e.g., elevated blood pressure, heart rate, cortisol secretions) which can have downstream negative effects on health (e.g. cardiovascular disease risk).[56]

Stigma is associated with depressive symptoms among PLHIV and can be a barrier to both HIV prevention and engagement in HIV treatment and care. It contributes to treatment adherence difficulties and may prevent people from using health care.[57]

Our greater understanding of the considerable impacts of stigma highlights the need for renewed efforts to reach national stigma reduction targets. The 8th National HIV Strategy aims to reduce by 75% the reported experience of stigma among people with HIV, and expression of stigma, in relation to HIV status by 2022 and UNAIDS' has a target of 90% of people living with, at risk of and affected by HIV reporting no discrimination, especially in health, education and workplace settings.

In 2018, HIV-related discrimination remained high in NSW. While the Disability Discrimination Act makes it unlawful to discriminate against people because of their HIV status, according to an online survey conducted in 2016 as part of the Stigma Indicators Monitoring Project, 74% of PLHIV reported any stigma related to their HIV status.[58]

Over half reported negative experiences or different treatment by health workers.

Discrimination on the basis of HIV status also continues to occur within the gay community, including in the context of hook-ups where HIV-negative men choose not to have sex with HIV positive partners, even if they are undetectable.[6] Additional layers of stigma and discrimination are often experienced by PLHIV who are discriminated against because they are gay or have sex with men, inject drugs and/or engage in sex work.[59]

HIV-related stigma, gender discrimination and racial discrimination are significantly correlated with one another.[60]

There has been considerable progress to identify effective interventions to reduce stigma and its impacts.[61] This includes interventions aimed at improving a better understanding of HIV in society or among specific groups who may be perpetrating discrimination, as well as approaches that focus on building resilience – i.e. the ability to function adaptively following an HIV diagnosis.

Social support and community engagement are positively associated with resilience, which in turn is associated with psychological health-related quality of life among older HIV-positive gay and bisexual men.[62]

ISOLATION

Loneliness and isolation are commonly reported as a major issue by PLHIV in major cities around the globe. A study in the city of San Francisco found that 58% of HIV-positive adults over the age of fifty who participated in the research reported any forms of loneliness symptoms.[63] Positive Voices, a large survey of 4,415 HIV clinic patients in the UK found that help with dealing with loneliness and isolation was their greatest unmet need.[64]

Considering the significant health impacts of chronic social isolation – with one British study finding it had implications for heart disease and stroke that are comparable to smoking 15 cigarettes a day[65] - strengthening community connection will become increasingly essential.

It has been shown that HIV-positive gay men are more likely to flourish when they have a greater level of practical support in their lives, a sense of belonging or companionship, and feel supported by family.[66]

SOCIAL PROTECTION

Based on an increasing volume of research that suggests that social factors are the cause of many health inequalities[67], UNAIDS' global plan to end AIDS aims for 75% of people living with, at risk of and affected by HIV, who are in need, benefit from HIV-sensitive social protection.

Progress towards this indicator is not systematically monitored in Australia but a number of indicators point to socio-economic disadvantage among PLHIV. Of the PLHIV who completed the *Futures 8* survey, half were living on household incomes substantially lower than the average Australian income and close to one in four had experienced significant financial stress in the past two years.

Those who had experienced financial stress had poorer health, more experiences of HIV-related stigma and lower levels of resilience, although causality could not be established by this study.[68]

In addition to income inequalities, action will be required in the areas of education, employment, housing and social support, and other social determinants of health.[69] A number of service gaps in these areas should be addressed, including the lack of safe, affordable and secure housing. People over 55 are over-represented among those living in temporary and insecure housing, and are at greater risk of homelessness, due to a chronic shortage of age-appropriate and affordable housing.[70]

Political decisions and structural changes that relate to working for welfare payments, changes to the retirement age and access to the aged care pension will impact PLHIV.

FUTURE SCENARIOS FOR 2030 - LIVING WITH HIV

Based on the foreseeable trends examined in previous sections, the way the future looks for PLHIV could vary substantially. In this section, we present three possible trajectories for the NSW HIV response, and their potential impacts on PLHIV. All three scenarios assume that some advances in biomedical prevention will occur but that no cure or vaccine will be available in the next decade.

CHARACTERISTICS OF NSW HIV RESPONSES

SCENARIO 1: HEALTHY, CONNECTED AND THRIVING

Policy responses are developed with the greater and meaningful involvement of people living with HIV (GIPA/MIPA)

The current pillars of, and investment in, NSW's world leading HIV responses are maintained, including:

- political bipartisanship
- partnership
- a focus on testing to reduce the number of undiagnosed HIV cases, early treatment initiation and viral suppression
- peer support

Investments are made to ensure everyone can access biomedical advances by removing barriers, including restrictions to accessing Medicare and the PBS.

The needs of an ageing HIV positive population are better understood and addressed holistically, including through investments in research and programs that address comorbidities for people living longer with HIV.

Deliberate action is taken to reduce stigma and discrimination and their impacts, including large-scale HIV information campaigns and targeted resilience-building programs.

SCENARIO 2: STATUS QUO

The key pillars of NSW's HIV responses are maintained; however, gaps remain unaddressed.

Significant biomedical advances are available, but not to everyone. People who are not eligible for Medicare rely on compassionate access schemes, the future of which is uncertain.

Beyond HIV treatment, the broader range of factors affecting the health and quality of life of PLHIV, particularly as they age, remains unaddressed.

The specific needs of PLHIV in aged care remain poorly understood.

Gaps remain in coordination and systems integration, including between health, digital health, disability and social services, remain.

The lack of funding for targeted approaches for PLHIV who are Aboriginal and those from a CALD background remains.

No further action is taken to tackle stigma and discrimination.

SCENARIO 3: INEQUALITIES

In this scenario, we see a retreat of investments in evidence-based and community-informed policies.

HIV becomes a battlefield in a political climate that no longer puts affected populations at the centre of the response.

In an increasingly Government-controlled response where the GIPA/MIPA is not prioritised, punitive measures are adopted to force testing and treatment adherence. A 2018 Police Association proposal to require the mandatory testing of people whose bodily fluids come into contact with police is adopted, against scientific evidence and community advice.

Other criminalising and stigmatising law reforms are mooted and gain popularity. Risk-reduction programs are withdrawn or operate with reduced funding.

Further restrictions for overseas-born NSW residents to access Medicare and social services are adopted.

Insufficient public investments are put in the healthcare system.

The position of NSW as a leader in the HIV response globally slides, and our response is less evidence-based and less well-resourced.

POSSIBLE IMPACTS

SCENARIO 1: HEALTHY, CONNECTED AND THRIVING

HIV becomes a case study of one of the best-managed chronic conditions due to NSW's world-leading response.

The number of people who are not aware they have HIV drops to extremely low levels, people who are newly diagnosed get access to treatment earlier on, and the vast majority of those on treatment achieve viral suppression.

All people with HIV benefit from pharmaceutical advances and have access to the treatment that best suits their individual needs. Most only have to take pills or receive injections a few times a year.

It is a more equitable future in which all PLHIV have equal access to high quality care and can age well.

PLHIV are connected to their community and can thrive, free of stigma and discrimination.

Partnerships are sustained and multi-party support for sustaining near zero HIV transmissions in NSW strengthens.

SCENARIO 2: STATUS QUO

The key pillars of HIV responses, combined with biomedical advances, lead to positive health outcomes, especially for non-Indigenous Australian-born Medicare-eligible PLHIV.

With unequal access to biomedical advances and care, however, PLHIV who are not eligible for Medicare, are Aboriginal or from a CALD background have poorer health outcomes.

Not living well with HIV increasingly becomes the experience of people who live in poverty or are socially disenfranchised.

Beyond treatment, gaps in service coordination and a lack of holistic responses mean that some of the challenges associated with ageing are not managed adequately.

Stigma and discrimination continue to negatively impact health outcomes for PLHIV, and are a disincentive for everyone to have a HIV test.

SCENARIO 3: INEQUALITIES

The healthcare system is increasingly unequal and expensive, leading to poorer health outcomes for those who cannot access it or afford out-of-pocket expenses.

Restrictions to accessing the public health system lead to poor health outcomes for overseas-born NSW residents, which in turn lead to poorer public health outcomes for the entire population.

Punitive approaches erode trust in public health institutions, leading to service avoidance. In this context, outcomes in relation to treatment targets deteriorate.

Punitive approaches also lead to heightened fears of HIV, stigma and discrimination, which in turn result in poorer public health outcomes.

Increases in HIV transmission in this context can easily be envisaged.

3. ENDING HIV TRANSMISSIONS

> While the number of transmissions is declining overall, the HIV epidemic is increasingly driven by new, or at least newly visible, forms of marginalisation.

3. ENDING HIV TRANSMISSIONS

While our efforts have led to a formidable decline in new HIV notifications, the end of HIV transmissions may not occur as early as we had hoped. Harnessing technological advances and adapting HIV response systems will be critical to reaching and maintaininig virtual elimination by 2030.

ARE WE ON TRACK TO END HIV TRANSMISSIONS?

The NSW Government has set the ambitious goal of virtually eliminating new HIV transmissions. The NSW 2016-2020 HIV Strategy aims to virtually eliminate HIV transmissions among gay and homosexually active men, which is the focus of ACON's '*Ending HIV*' campaign[71], and to sustain the virtual elimination of HIV transmission in people who inject drugs, sex workers and from mother to child.

The term 'virtual elimination' is commonly understood as a reduction of HIV transmissions to extremely low levels.

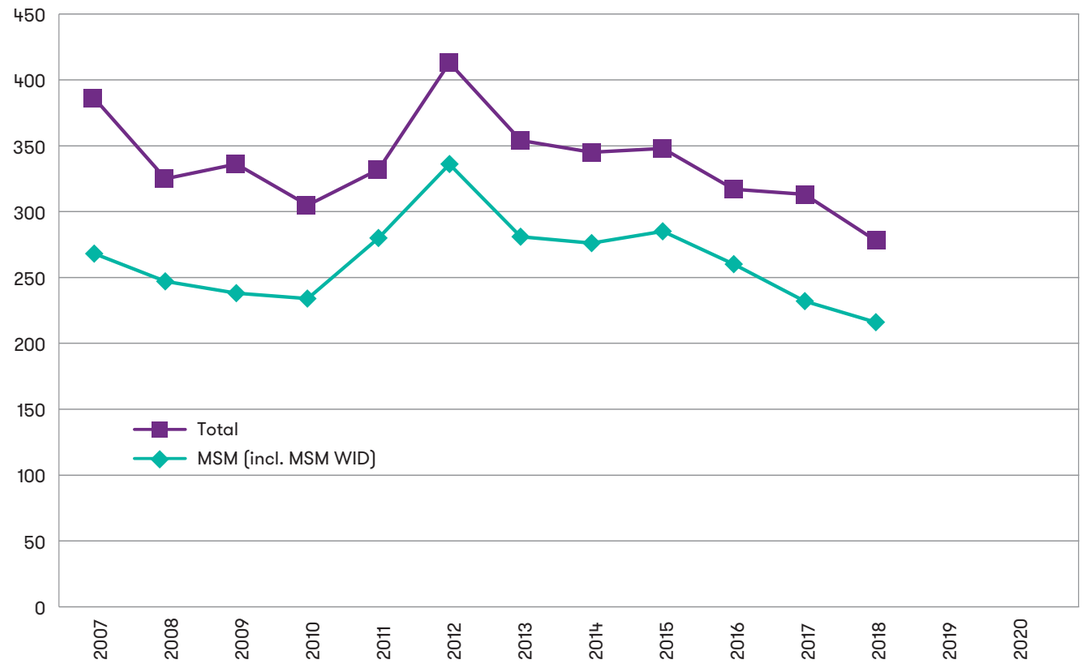
What we do know is that NSW recorded the lowest number of HIV notifications on record in 2018. This provides evidence that the key elements of our collective response are delivering results:

- **STAYING SAFE**. Refers to sustaining a safe sex culture over time. In addition to condoms, there are now a variety of biomedical options available to practice safe sex, including treatment as prevention, PEP and PrEP. Over 9,415 individuals were enrolled in the EPIC-NSW trial. Evidence shows that PrEP implementation was associated with a rapid decline in HIV diagnoses in NSW.[72] Initially distributed through the EPIC-NSW trial, PrEP is now available in pharmacies across the country and subsidised by the Australian Government. Between the PBS listing of PrEP in April 2018 and 30 September 2018, 4,771 NSW residents accessed HIV pre-exposure prophylaxis (PrEP) through the PBS.[1]
- **TESTING OFTEN**. The number of tests and frequency of testing have significantly increased since 2012.[1] Testing is now available in a variety of settings, including community rapid testing centres which have proven to be an effective testing model for engaging gay and bisexual men.
- **TREATING EARLY**. The proportion of people diagnosed with HIV in January to June 2018 who commenced treatment within six weeks of diagnosis was 83%. The median number of days to ART uptake among those diagnosed during that period was 21 days, a significant decline from the median of 45 days in 2013.[1] This contributes to reducing time to achieving undetectable=untransmissible viral loads, and therefore the number of HIV transmissions.
- **ACCESS TO STERILE INJECTING EQUIPMENT**. The number of units of injecting equipment distributed in NSW continues to increase. In 2017/2018, 14,130,769 units of injecting equipment were distributed in NSW.[73] There are extremely low transmission rates among PWID in NSW. The NSW HIV Strategy has a goal to continue the virtuial elimination of HIV among PWID.
- **DECRIMINALISED SEX WORK**, which is essential to ensuring that sex workers can safely access testing and health care services. Given the extremely low transmission rates for sex workers, the NSW Strategy speaks to a continuation of the virtual elimination of HIV among sex workers.
- **UNIVERSAL HEALTHCARE**. Access and linkage to quality care, underpinned by Medicare, is the foundation upon which all other aspects of HIV responses rely.

However, while excellent progress has been made, the 'virtual elimination' of new HIV transmissions may not occur as early as we had hoped (see Figure 2). A significant challenge will be to maintain our effective prevention work with the communities we already have excellent engagement with, while also responding to a diversified epidemic (see section 3.3).

Figure 2

Number of new HIV notifications, 2007-2018



Source: adapted from NSW HIV Strategy 2012 – 2015 2013 Annual Data Report and NSW HIV Strategy 2016 – 2020 Quarter 4 & Annual 2018 Data Report.

WHAT BIOMEDICAL AND TECHNOLOGICAL ADVANCES ARE ON THE HORIZON?

The research and development programs of pharmaceutical companies are not known - however, longer acting preparations, different delivery technologies, and a range of other reforms are forseeable in the next decade.

Technological advances will make it easier to test for HIV from virtually anywhere and to access various prevention methods. Making sure community members understand and have access to them will be critically important to reduce transmissions.

TESTING

Technological advances will reduce some of the barriers to getting tested for HIV and reach populations who are at a greater risk of acquiring the virus, including overseas-born gay and homosexually active men.

DRIED BLOOD SPOT

Dried Blood Spot (DBS) is a testing method that allows testing to occur from someone's home, or any other location a person chooses. Testing kits can be ordered online and allow a person to collect a finger prick sample of blood at home. The sample is then posted to a laboratory for analysis and results and follow up care is coordinated through the NSW Sexual Health Infolink.

DBS testing is available in NSW via a pilot program[74] which has demonstrated it is an effective approach for populations who may not get tested in traditional settings. Between November 2016 and 30 June 2018, 1,082 DBS kits were ordered and 672 DBS tests completed in NSW (return rate of 62%). Over 40% of the people who registered for a DBS kit had never tested for HIV before or had their last test over two years ago, 0.7% of tests (n=5/672) were reactive.[1]

DBS (and self-testing) may be one of the responses to the increasing dispersion of gay and bisexual men outside the inner city suburbs of Sydney.

SELF-TESTING

HIV self-tests use similar technology to rapid HIV tests but they are operated directly by the person wishing to take the test, from wherever they want. Contrary to DBS, self-testing kits provide a result within about 30 minutes without requiring posting to a laboratory. In the event of a reactive result, confirmatory laboratory testing is required.

HIV self-testing could significantly increase status awareness among key populations. A randomised controlled trial among HIV-negative high-risk gay and bisexual men in Australia, found that HIV self-testing resulted in a two times increase in frequency of testing, and a nearly four times increase in non-recent testers, compared with standard care.[75] By providing near immediate results, self-testing would be well-suited for over a quarter of those who order a DBS test but never send it back to get the results.

In November 2018, the Therapeutic Goods Administration (TGA) approved the Atomo self-test as the first rapid test for the detection of HIV antibodies for home use in Australia. As per the TGA's decision, the test can be purchased online, subject to consumers viewing an instructional video; and through clinics or health organisations with trained staff. The device has now become available at a cost of approximately AUD$25.

As HIV self-tests become available across NSW, it will be important to support its informed and effective use, including by encouraging people to test at frequencies which are most appropriate for their risk behaviours, and ensure that people who return a reactive self-test are linked to and remain in care as soon as possible (should laboratory testing confirm a positive diagnosis).

Self-testing kits may be particularly appropriate for people who do not feel comfortable in traditional testing facilities or may have little awareness of their exposure to risk.

In the longer term, subject to changes in TGA approval conditions, kits could be distributed in a wider range of settings including in pharmacies, universities, public toilets, beats and sex-on-premises venues.

GENERAL HEALTH CHECK-UPS

Opportunities to increase HIV and STI testing may also include GPs offering testing as part of a general health check-up.[76] This may be particularly relevant to people who have a limited understanding of HIV risks, including newly-arrived migrants. A recent study on barriers to testing among Australian residents born in South East Asia and sub-Saharan Africa found that offering HIV as part of a general health check-up and making HIV 'an issue for everyone' may be an effective strategy to address fears of disclosure and stigma.[76]

PREVENTION

Biomedical options are rapidly becoming gay men's prevention method of choice. In 2018, over half of men reporting condomless anal sex with casual partners in the Sydney Gay Community Periodic Survey were either HIV-positive men with an UVL or HIV-negative men using PrEP.[6]

As the reach and range of biomedical options available for HIV prevention are expected to keep expanding, the challenge will be to make sure they are accessible to everyone who needs them.

CONDOMS

In recent years, consistent condom use has decreased among gay and homosexually active men. Since 2014, a larger number of gay and bisexual men have been reporting condomless anal sex with casual partners (57% in 2018), while the proportion reporting consistent condom use has dramatically fallen from 47.3% in 2014 to 26.4% in 2018. This is largely due to a growing number of men using PrEP as their preferred HIV prevention method. Similar trends are observed in the context of relationships, most notably in serodiscordant couples[6]

Decreased condom use raises challenges for the prevention of other sexually transmissible infections. Since the early 2010's, there has been an increase in the number of syphilis, chlamydia and gonorrhoea notifications in NSW. The latter is raising growing concerns both nationally[77] and internationally[78] due to possible drug resistance.[79]

Over the past five years, the number of gonorrhoea notifications in NSW has been increasing each year. While some of this increase may be attributed to increased testing, changes in the notification-to-test ratio suggests there has been an increase in gonorrhoea transmission in NSW as well.[80]

PEP

PEP is an effective method to prevent HIV transmission in emergency situations shortly after a high risk exposure. Currently, PEP medication must be started at most 72 hours after a possible risk exposure, and should be continued for 28 days to be effective.

As HIV treatment research progresses, PEP may also evolve and become available in new forms such as injections, with reduced side effects.

PREP

PrEP is a highly effective HIV prevention strategy at both individual and population level[72] and has become the most commonly reported risk reduction strategy by HIV-negative men who have condomless anal sex with casual partners.[6]

New and more affordable PrEP drugs, as well as tailoring dosing to people's lifestyles and risk profiles, could significantly increase HIV protection coverage and application.

Reducing side effects

The small number of people experiencing side effects from current PrEP drugs (e.g. issues related to kidney health and bone mineral density) could soon have access to new effective drug options with fewer or less serious side effects.

PrEP dosing options

Different dosing options have the potential to significantly increase coverage among at-risk populations but will require clarifying clinical guidelines and community education messages.

- **Daily PrEP**

  PrEP has commonly been prescribed in NSW as a one-pill-a-day prevention method since the beginning of the PrEP research trials*. The rapid decline of HIV transmissions in NSW is associated with daily PrEP use.[72]

  The current clinical guidelines issued by the Australasian Society for HIV, Viral Hepatitis and Sexual Health Medicine (ASHM) recommend daily PrEP to be used as a key HIV-prevention option for gay and homosexually active men, transgender people, heterosexual men and women, and people who inject drugs at substantial risk of HIV acquisition.[81]

  Daily PrEP can be used continuously or for shorter periods of time also known as "seasons of risk" such as a holiday.

- **On-demand PrEP**

  On-demand PrEP means using PrEP around episodes of risk, rather than taking a pill a day over a long period. There is a demand for non-daily PrEP.[82]

  According to the ASHM guidelines, "on-demand PrEP should be considered an alternative regimen for gay and homosexually active men and transgender women and offered where appropriate". Yet, the guidelines lack precision, particularly in regards to how long before and after risk exposure a person should take their on-demand PrEP. The guidelines note that "on-demand PrEP should not be used in cis-gender women and heterosexual men as there is currently no evidence of effectiveness in these populations."[81]

  On-demand PrEP is routinely prescribed in some countries such as France where its efficacy has been studied in a randomised, placebo-controlled trial which concluded that the "use of TDF-FTC before and after sexual activity provided protection against HIV-1 infection in men who have sex with men".[83] An extension study also found that on-demand PrEP remained highly effective in high-risk gay and homosexually active men as long as it was taken.[84]

  Research is also under way for new drugs that concentrate better in vaginal tissue and thus give people having vaginal sex more flexibility with dosing.

- **Long-acting PrEP**

  Improvements to ARV treatments (see section 2) could also be used to make PrEP more convenient to take. This includes longer-acting or extended-release PrEP in the form of a slow-release capsule able to deliver a week's worth of PrEP in a single dose; injections administered on a monthly or less frequent basis; and PrEP-delivering implants.

  Cabotegravir (integrase inhibitor) is being studied in both an oral tablet form and a long-acting injectable form which could work over a long period of time, making treatment or prevention regimens simpler to take.[85]

  Two studies testing whether an investigational antibody can prevent HIV infections are also underway. The Antibody Mediated Prevention (AMP) studies seek to establish if giving people an antibody called VRC01 intravenously will protect them from getting infected with HIV.[86] One study is looking at the effects on men and transgender persons who have sex with men[87] and the other is looking at the effects on women[88]. Results from both studies are expected in 2020.

A better understanding of rare transmission cases

While PrEP is a highly effective prevention method, there have been extremely rare instances of HIV transmission in PrEP adherent patients. It is hoped that progress in research will bring a better understanding of the factors that have contributed to six rare cases of HIV transmission in PrEP adherent people worldwide, including the role of other STIs.[89]

VACCINES

Since the late 1980's, the history of HIV vaccine development has often raised hopes and created disappointments. While it is not possible to predict when we will have a vaccine with sufficient efficacy, recent developments offer interesting insights for the future of research into HIV vaccines that would protect HIV-negative people from acquiring the virus. Scientists have attempted a number of approaches for the development of a vaccine.[90]

So far, the RV144 trial is the first and only trial of a vaccine against HIV-1 to show a degree of efficacy. The ALVAC vaccine and AIDSVAX booster vaccine regimen was tested among 16,402 healthy Thai men and women at heterosexual risk of HIV infection. Research published in 2009 showed that the vaccine had a 31.2% efficacy and did not affect the CD4+ T-cell count in subjects who were later diagnosed with HIV-1 infection.[91]

The APPROACH phase 1/2a trial also offers cautious optimism.[92] The mosaic Ad26/Ad26 plus gp140 HIV-1 vaccine induced robust immune responses in healthy adults. The term mosaic is used because this vaccine regimen aims to elicit an immune response against an array of HIV subtypes. The regimen also protected monkeys against infection from the Simian human immunodeficiency virus (SHIV). This vaccine has now advanced to the next phase of the pre-approval trial process (phase 2b clinical efficacy study) and will be tested in sub-Saharan Africa.[93]

* From 2016 to April 2018, PrEP was predominately accessed by the 9,415 individual EPIC-NSW Study participants and prescribed as a one-pill-a-day regimen.

TREATMENT AS PREVENTION – UNDETECTABLE=UNTRANSMISSIBLE

Treatment as Prevention (TasP) is the use of antiretroviral medication by PLHIV to prevent the transmission of HIV. Treatments suppress the HIV viral load in a person's bodily fluids to undetectable levels, meaning that the virus cannot get passed on to another person during sex. As indicated in section 2, treatment coverage is high in NSW. It was estimated that in 2016 91.3% PLHIV knew their status, 92% of whom were receiving ART, 94.5% of whom had suppressed viral load.[5]

Numerous trials have confirmed that there is no risk of HIV transmission from someone who is on HIV treatment with an undetectable viral load. The HPTN 052 study of 1,763 HIV sero-discordant couples in nine countries, concluded that HIV transmission from HIV positive study participants to their partners was not observed when viral replication in the treated individual was stably suppressed by ART.[94] PARTNER, an observational study in HIV-serodiscordant heterosexual and gay couples having ongoing condomless sex over 1,238 couple-years of follow-up, did not record any cases of within-couple HIV transmission.[95]

The Opposites Attract study of male homosexual serodiscordant couples conducted in Australia, Brazil and Thailand found that no HIV-negative partner contracted HIV from his HIV-positive study partner, despite nearly 17,000 reported acts of condomless anal sex within couples.[96]

Community perceptions of HIV treatment have shifted in recent years in NSW. Online surveys conducted since the start of the "Ending HIV" campaign show significant shifts in the percentage of respondents who agree that "HIV treatments significantly reduce the risk of passing on HIV" over time, from only 33% in February 2013 prior to the launch of "Ending HIV" to 84% in March 2018.[1]

Continued community education on the effectiveness of treatment as prevention will play a role in making sure that this method of prevention is understood.

COMMUNITY MOBILISATION AND ENGAGEMENT

In a prevention landscape that is increasingly centred on individualised biomedical interventions, the role of community health organisations is evolving.

Beyond promoting access to a range of prevention methods, community organisations have a key role to play in bringing peers together and developping holistic approaches to improve the health and quality of life of our communities beyong taking pills. This includes building community connection and resilience to address stigma and discrimination.

Health promotion is constantly evolving to be in the physical and digital places where people at risk of getting HIV connect with each other and seek information about their own health. In the 2018 Sydney Gay Community Periodic Survey, 51% of respondents said they had found their male sex partners through mobile apps[6], a trend that we expect to continue.

Increasingly sophisticated digital technologies are expanding the reach of health promotion messages in a cost-effective manner. They also allow the delivery of more sophisticated messages tailored to individuals, and can facilitate the conversion from knowledge into service access (e.g. immediate booking for HIV testing apppointment or ordering a self-testing kit).

ENDING HIV TRANSMISSIONS FOR ALL

While the number of transmissions is declining overall, the HIV epidemic is increasingly driven by new, or at least newly visible, forms of marginalisation. Ending HIV transmissions will require maintaining our efforts with populations we have already reached, while also understanding and addressing the barriers that prevent some from testing and staying safe.

The response to the HIV epidemic in NSW has traditionally been centred on reducing transmissions among people who identify as gay, are well connected to their community and predominantly live in a restricted geographical area in the inner city suburbs of Sydney. While highly effective at reaching this population, HIV statistics raise concerns that some have been left behind.[1]

GAY AND HOMOSEXUALLY ACTIVE MEN

In 2018, over three quarters of HIV transmissions occurred among gay and homosexually active men, a majority of whom were born overseas. While the number of new diagnoses among Australian-born gay and homosexually active men in 2018 was 33% less than the average of the previous five years, the number of new diagnoses among overseas-born gay and homosexually active men was just 3% less than the average of the previous five years.[1]

To understand the factors behind these disparities, it is necessary to take into account the heterogeneity of the overseas-born population.

Of 216 MSM newly diagnosed with HIV in NSW during 2018, 44% were born in Australia, 19% in South-East Asia, 11% in Southern & Central America, 7% each in North-East Asia and North-West Europe, and less than 5% in each of North Africa & Middle East, Oceania, Southern & Central Asia, Southern & Eastern Europe and Sub-Saharan Africa.

Furthermore, overseas-born gay and homosexually active men include men who have arrived in Australia at various stages of their lives.

Some may have arrived recently, such as international students on temporary visas who may not have access to Medicare, nor be familiar with the Australian health system.

Others may have arrived in Australia when they were young, hold Australian citizenship, speak English natively and have access to Medicare.

Several factors have been put forward to explain the disparities between Australian-born and overseas-born gay and homosexually active men, including linguistic and cultural factors, and structural barriers.

Some research points to health literacy, language and cultural factors that may contribute to people in this group not getting tested or accessing prevention or treatment.

For instance, a recent study on barriers to testing for HIV for people born in South East Asia and sub-Saharan Africa found that participants' understanding of HIV and readiness to get tested were influenced by experiences in their country of birth, low visibility of HIV in Australia, perceptions of 'safety' in Australia and low levels of perception of individual risk for HIV.[76]

Others have highlighted the role of structural barriers and systemic failures that restrict people's ability to access healthcare in general, and HIV prevention and treatment in particular. This includes the dual standard of care that exists in Australia – Australians, permanent residents and temporary migrants from the UK, NZ and a number of European countries have access to Medicare and the PBS, while newly-arrived migrants from Asia, Africa and the Americas remain locked out of Medicare and the PBS.

Other structural factors include a lack of services in areas with large overseas-born populations. Equitable access to and coordination of care is a priority action area under the National HIV Strategy.

Increasing testing should be a priority among overseas-born gay and bisexual men. There are high levels of estimated undiagnosed HIV among overseas-born gay and homosexually active men. It is estimated that people born in Southeast Asia have the highest proportion of undiagnosed HIV (27%).[11]

In terms of prevention methods, there are indications of PrEP and condom use among overseas-born gay and bisexual men at levels that are comparable with those

of Australian-born gay and bisexual men:

- **PrEP** – of the 9,281 participants enrolled in EPIC-NSW between 1 March 2016 and 30 April 2018, over 40% were born overseas.[1] This is quite high considering that 34.5% of people living in NSW were born overseas.[97] The listing of PrEP on the PBS makes it difficult to evaluate how many overseas-born gay and homosexually active men are accessing PrEP.
- **Condoms** - In the 2018 Sydney Gay Community Periodic Survey 2018, overseas-born men were more likely to report consistent condom use (29%), and less likely to report receptive condomless anal sex with casual partners (16%).[6] Asian-born men were more likely to report no anal sex (28%), more likely to report condom use (21%), and less likely to report condomless sex (51%) with their regular male partners.[6]

Data from the NSW Ministry of Health suggests there are small differences in time to treatment initiation between overseas-born and Australian-born MSM. Where follow up data is available (i.e. for people who remained residents of NSW and were eligible for follow up), 92% of overseas-born MSM were on ART 6 months after diagnosis, compared with 94% of Australian-born MSM.[98]

HETEROSEXUAL PEOPLE

In 2018, 52 people acquired HIV via heterosexual sex, accounting for 19% of all new HIV notifications in NSW. This represents a small reduction compared with the new diagnosis averages of 2013-2017.

PEOPLE WHO USE DRUGS

In 2018, five people who inject drugs were diagnosed with HIV. In addition, 18 gay and homosexually active men who inject drugs were diagnosed with HIV.

The number of new diagnoses from injecting drugs is low and is expected to remain so as long as the fundamental pillars of the response to HIV are maintained, including the Needle and Syringe Program (NSP). Despite its effectiveness, the NSW's prisoner population is still denied access to a similar program.

TRANS AND GENDER DIVERSE PEOPLE

In 2018, three people who identified as transgender were notified that they had HIV.

A recent discussion paper published by ACON, PASH. TM and The Gender Centre highlighted failures of surveillance systems to capture data on the experiences and needs of trans and non-binary people in relation to HIV, and identified specific and unique HIV risks, including the physical effects of hormones on their susceptibility to HIV, risk of sexual assault, criminalisation, and transphobia.[7]

The report called for amendments to the HIV surveillance system and to reform the legal, social and funding environments that affect access to HIV prevention, treatment and care.

It further recommended that trans and gender diverse people be recognised as a high risk population with unique needs in the NSW HIV Strategy and Australia's National HIV Strategy.

The recent inclusion of trans and gender diverse people as a priority population under the 8th National HIV Strategy 2018-2022 is a hopeful first step towards their meaningful inclusion in HIV responses.

ABORIGINAL AND TORRES STRAIT ISLANDER PEOPLE

In NSW, the number of HIV notifications in the Aboriginal and Torres Strait Islander population has been relatively stable since the beginning of this decade but increased from an average of 8 new notifications per year in the 2013-2017 period to 11 new notifications in 2018.

At a national level, the HIV epidemic is growing in the Aboriginal and Torres Strait Islander population. The number of HIV notifications in the Aboriginal and Torres Strait Islander population increased from 24 in 2011 to 31 in 2017 in Australia. Over the years 2015–2017, a higher proportion of HIV notifications in the Aboriginal and Torres Strait Islander population were attributed to heterosexual sex (21%) and injecting drug use (18%) than in the Australian-born non-indigenous population (18% and 3%, respectively).[11]

Aboriginal and Torres Strait Islander people in Australia face structural barriers and compounded disadvantage, which are reflected in a range of health indicators. For the Aboriginal and Torres Strait Islander population born in 2010–2012, life expectancy was estimated to be 10.6 years lower than that of the non-Indigenous population for males (69.1 years compared with 79.7) and 9.5 years for females (73.7years compared with 83.1).[99]

ACON is currently developing a discussion paper on HIV among Aboriginal and Torres Strait Islander people in NSW.

PEOPLE IN CUSTODIAL SETTINGS

Ensuring that people have access to HIV prevention and care no matter where they are, including in prison, is essential to ending HIV transmissions. People in prison are excluded from Medicare coverage, with prison health care provided by states and territories.

It is hard to estimate the number of PLHIV in prison, including those who acquired HIV while incarcerated. Since 1999, all people in prison are offered screening for BBVs and STIs on a voluntary basis upon entry; however no testing is available on exit.

Despite the ongoing effectiveness of NSW's community-based needle and syringe program, people who are in NSW prisons are still denied access to a similar program.

FUTURE SCENARIOS FOR 2030 - HIV TRANSMISSIONS

In this section, we present three simplified scenarios for the NSW HIV response and their potential impacts on HIV transmissions in the State. All three scenarios assume that some advances in biomedical prevention will occur but that no cure or vaccine will be available in the next decade.

CHARACTERISTICS OF NSW HIV RESPONSES

SCENARIO 1: THE END OF HIV TRANSMISSIONS FOR ALL

The current pillars of the NSW HIV response and investments are maintained (see page 18) and, in addition:

- New programs and campaigns targeting overseas-born and CALD gay and homosexually active men are funded, rolled out and evaluated;
- Structural barriers to accessing prevention and healthcare are addressed. This includes extending Medicare and PBS to all residents;
- Funding for Aboriginal sexual health services is restored, and enhanced, and specific support is available State-wide;
- New strategies and investments are made to increase testing rates in Western Sydney and regional NSW, including through home and community-based testing services;
- A campaign targeting Australians travelling to countries of high HIV prevalence is rolled out.
- Adequate surveillance systems and rapid outbreak response planning are designed to sustain the virtual elimination of HIV transmissions.

SCENARIO 2: STATUS QUO

Current NSW HIV responses are maintained without additional investment, innovation or targeted responses.

The key elements of HIV responses in NSW include:

STAYING SAFE
TESTING OFTEN
TREATING EARLY
ACCESS TO STERILE INJECTING EQUIPMENT
DECRIMINALISED SEX WORK

SCENARIO 3: GOING BACKWARDS

Funding for testing, prevention and care services reduce due to lower rates of transmission and an assumption that 'the job is done'. HIV notifications are considered 'low enough' and disinvestment is considered appropriate in this context.

In an increasingly acrimonious political context, the fundamentals of the NSW HIV response are eroded.

The politicisation of drug use, sex work and other policies lead to a shift towards increasing criminalisation.

No change occurs in trying to reach CALD populations, Aboriginal communities and people who are not eligible for Medicare.

POSSIBLE IMPACTS

SCENARIO 1: THE END OF HIV TRANSMISSIONS FOR ALL

NSW becomes the first jurisdiction in the world to reach the virtual elimination of HIV transmissions.

No one gets left behind. Rates of HIV notifications drop significantly among all populations. Notification gaps between non-Indigenous Australian-born gay men and their Aboriginal and overseas-born peers close.

The virtual elimination is sustained throughout the entire decade.

Health literacy and service access is improved for CALD populations at risk of HIV transmission.

Access to HIV prevention and treatment is not subject to the Medicare eligibility barrier.

The HIV response in NSW is multi-faceted, diverse and world leading.

SCENARIO 2: STATUS QUO

The number of new HIV transmissions in NSW continues to decrease, although at a rate that is too slow to realise the goal of virtual elimination of HIV transmissions.

HIV responses continue to reduce transmissions among Australian-born gay and bisexual men who live in Sydney's gay suburbs and for whom frequent testing and PrEP have become a norm.

However, notifications among other gay and bisexual men plateau or rise – overseas-born gay men, international students, people who are not eligible for Medicare or familiar with the health system, and those who live outside gay suburbs.

The notification rate gap between non-Indigenous and Aboriginal and Torres Strait Islander people remains.

The NSW HIV epidemic is characterised by inequality, disadvantage and marginalisation. Some populations are left behind.

HIV responses continue to prove highly effective at maintaining the virtual elimination of HIV transmissions in people who inject drugs, sex workers and from mother to child.

SCENARIO 3: GOING BACKWARDS

Similar to what has occurred in jurisdictions that have adopted punitive responses or withdrawn funding from HIV services, the number of new HIV transmissions in NSW increases again.

The impacts of these policies are particularly severe for populations who are most stigmatised, marginalised or otherwise isolated.

4. REFFERENCES

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