national strategic framework to address HIV stigma and build resilience capacity for people living with HIV

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CONTENTS

Acronyms

AFAO   Australian Federation of AIDS Organisations
ART   Antiretroviral therapy
CALD   Culturally and Linguistically Diverse
GIPA   Greater Involvement of Positive People
GP   general practitioner
HIV   Human Immunodeficiency Virus
MIPA   Meaningful Involvement of Positive People
MIWA   Meaningful Involvement of Women and Girls Living with HIV
NAPWHA   National Association of People with HIV Australia
PrEP   Pre-Exposure Prophylaxis
TASP   Treatment-as-Prevention

NAPWHA

NAPWHA is the national peak organisation representing people living with HIV in Australia. Through leadership in advocacy, policy, education and prevention, NAPWHA strives to minimise the adverse personal and social effects of HIV. By championing the participation of HIV-positive people at all levels of the national response we aim to build a positive future for all people living with HIV.

President's message

Recent and very welcome advances in treatment and prevention (including biomedical prevention) have delivered hugely significant improvements and possibilities in the daily life and wellbeing of people living with HIV. However, there is still much to be done to ensure that all people living with HIV are equally sharing in and flourishing through those health and wellbeing gains. The creation of enabling environments and safe, relevant, stigma-free spaces and services is essential if we are to reap the benefits of developments in clinical care and prevention, drive down new infections, and eliminate the burden of stigma.

The National Association of People Living with HIV Australia (NAPWHA) is thrilled to have had the opportunity to lead the creation and development of this first ever National Strategic Framework to Address HIV Stigma and Build the Resilience Capacity of People Living with HIV ('The HIV Resilience Framework'). The HIV Resilience Framework is the outcome of a substantive consultation process across the community of people living with and affected by HIV. The aim of the framework is to support the developments of policies, legislation, programs, interventions and services, and practices within the HIV sector and at all levels of government that will deliver on the vision of an Australia in which all people living with HIV are personally resilient, benefiting equally from advances in testing, care, prevention, treatment and support.

The HIV Resilience Framework will be of relevance to a wide range of people involved at all levels of the HIV response. We hope it provides encouragement for government decision makers and policy developers to pursue consistent and enabling policy and legislative environments and work cooperatively between jurisdictions and across departments to achieve best practice. Our consultation suggests that consistent legislation with the goal of supporting strong health outcomes, making disclosure safe, and eliminating stigmatising laws is crucial to creating environments in which people with HIV feel safe to access testing, treatment, and care. The HIV Resilience Framework also contains valuable insights for those who have responsibility for HIV health program management and service delivery, providing guidance to help ensure that programs,

services, interventions or strategies supporting people living with HIV are developed and delivered in a way that is mindful of the interlinked twin goals of building personal resilience and eliminating stigma and discrimination.

A substantive consultation process underpins the Framework. NAPWHA has consulted and engaged with sector leaders, service providers and peer leaders. Most importantly, we sought direction from people living with HIV who shared their stories about living with HIV, their experiences of stigma or discrimination in legal, social or health care settings, and their insights into and strategies around personal resilience. This wide-ranging consultation supplemented by the generous sharing of personal stories allowed us to identify with confidence some shared Strategic Objectives to help facilitate and build resilience. We have structured the HIV Resilience Framework around these goals, underpinned by recommended Strategic Priority Actions. Under each of these actions, we identify activities currently being undertaken that support each of those objectives and their Strategic Priority Actions, identify gaps and areas of unmet need, and discuss specific unresolved or emerging issues affecting people living with HIV from populations who may be more vulnerable to HIV risk, or to the effects of inequitable access to services, programs or supports. We then comment on and recommend potential strategies or steps to address those gaps and needs that can be taken at all levels: by government decision and policy-makers; by program or service designers; by people who deliver services; by HIV community and peer educators, and by individuals.

This document will be of value to a wide range of partners in the HIV response. It will allow policy-makers, service planners, program developers, peer workers and leaders and those providing clinical, psychosocial or other supports to:

- assess the relevance of programs and policies against the needs of people living with HIV
- support and strengthen the peer response
- understand the principles of building personal resilience and flourishing
- ensure services are equitable, accessible and stigma free and
- identify gaps or issues that need to be addressed when evaluating existing programs, services or interventions, or when considering priorities for the introduction of new services.

We encourage you to use this document in the spirit of a shared vision of an Australia in which people living with HIV are resilient, thriving, and living free from the burden of stigma. In particular, we encourage you to read and reflect on the stories of people living with HIV that have been shared.

We acknowledge, and are immensely grateful for, the work of Bill Paterson, who as Operations Manager of NAPWHA, ably led this project, and whose passion for building
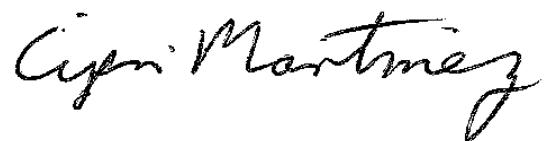
resilience was instrumental in guiding the consultation and its grassroots approach. We would also like to thank the lead consultants and principal writers, Brent Allan and Dr Kirsten Machon, for leading the consultation, undertaking research and interviews, and drafting this Framework.

We would very much like to thank the NAPWHA members, HIV community organisations, and sector and peer leaders, for their considered input, and for sharing the great resource that is available in their collective insight and wisdom.

Particular thanks are due to the individuals living with HIV whose personal stories, experiences, and collective intellectual and experiential insights helped to build the comprehensive framework and strategies outlined in Objective 3 of the Framework, addressing those specific and vulnerable populations for whom there are particular needs and considerations in building resilience strategies. Our gratitude is warmly extended to the following co-authors: 'Joe', Natasha Io (Positive Speakers' Bureau, Positive Life NSW), Melania Mugamu, Joël Murray, Katherine Leane, Michelle Tobin and Jason Turner.

Thanks are due to Craig Cooper, Richard Keane, Christabel Millar, Max Niggl, Carla Treloar, Ted Cook, Graham Brown, Anthony Lyons, Daniel Gallant, Kath Leane, Lisa Bastien, Sharna Quigley, Chris Howard, and Sarah Feagan for their advice on initial drafts. Lisa Tomney supported us by distributing information to her networks during the consultation process and reviewed the final draft. Lance Feeney, John Rule and Aaron Cogle all contributed informed and pertinent considerations and valuable feedback throughout the drafting. We would also like to acknowledge the collective wisdom shared by those who attended and contributed to a drafting workshop at the 2018 NAPWHA Special General Meeting in May 2018.

The National HIV Resilience Framework would not have been possible without their support for the concept, their time, their generous and thoughtful contribution to the drafting, and willingness to tell their stories.

Cipri Martinez
President, NAPWHA

Building resilience: what you can do

| Government and policy-makers | ■ Consistent cross-jurisdictional commitment to legislative reform to eliminate stigmatising or discriminatory laws that increase fear of disclosure and pursue personal criminalisation at the expense of health outcomes

■ Whole-of-government approach to addressing HIV-related stigma, including introduction of model policies in government agencies

■ Work with community-based organisations and people living with HIV to promote the message that an undetectable viral load means HIV cannot be transmitted through sexual contact and ensure this is understood in the wider Australian community

■ Continue to ensure that the perspective and experience of a diverse range people living with HIV is actively sought and reflected at all levels of the national and state policy response

■ Fund the response effectively by identifying and responding quickly to emerging needs, directed by evidence from surveillance data and other relevant information

■ Report on the progress of addressing reducing HIV-related stigma through national and state HIV strategies, using evidence from the national HIV stigma indicators and other available data

■ Direct resources specifically toward addressing the unmet needs of specific vulnerable populations of people living with HIV: indigenous people; people who inject drugs; mobile and migrant populations, including refugees and international students, and trans and gender diverse people. |

Community-based organisation program managers and decision-makers	■ Ensure programs and services are regularly evaluated and benchmarked against best practice, evidence-based approaches that include building resilience as an explicit outcome
	■ Share effective programs, strategies, interventions and approaches with other organisations
	■ Build programs responsive to community needs using relevant and current technologies
	■ Support peer leaders, including volunteers, with high quality training and support
	■ Audit peer and other support services to ensure they are safe, inclusive and stigma-free spaces for all people living with HIV
	■ Provide opportunities for specific communities to have their peer needs met by encouraging a diverse range of peer leaders, and commit to regular gap analysis to ensure funds are being directed towards areas of unmet need
	■ Have mechanisms in place for service users to safely provide regular feedback on safety and quality
	■ Encourage service users to share their experiences of stigma and discrimination and its effects, to drive improvements in services and contribute to a national picture and understanding
	■ Report on efforts to address stigma and discrimination, and their outcomes, in annual reports and other forums

Health and clinical services	■ Be aware of how the service environment affects people living with HIV ■ Collect relevant health information about individuals in a way that respects privacy and confidentiality and helps direct people to appropriate services ■ Be aware of the effects of stigma and discrimination and focus on stigma reduction and building resilience as a health outcome ■ Engage with community-based organisations to incorporate the lived experience of people living with HIV in the development of policies and procedures ■ Ensure that all staff are equipped with up-to-date information to facilitate referral to peer-based services ■ Offer a mechanism for health service users to report poor experiences, including stigmatising behaviours or discrimination, to drive improvements in services
Peer leaders	■ Undertake regular and ongoing training and skills building ■ Provide informed guidance ■ Model good behaviours, and share this knowledge and practice through example with other peer leaders ■ Celebrate successes and inspire others ■ Foster safe online and face-to-face peer environments that are mindful of the diverse peer experience, and are culturally safe and inclusive

Service users living with HIV	■ Provide feedback on quality of services to service providers, including positive or negative experiences ■ Respect individual difference within peer networks, be mindful of diversity, and share the responsibility for making peer services safe and inclusive for all
Research community	■ Implement and extend universal indicators for stigma and resilience ■ Prioritise research to provide insights into the specific needs of communities identified in this Framework ■ Continue to seek opportunities to ensure that clinical and social research is inclusive of women, heterosexual men, trans and gender diverse people, indigenous people, and people from culturally diverse, mobile or migrant backgrounds ■ Conduct research in partnership with affected communities ■ Engage in community-based peer-led research practices

PART A

Background, evidence and supporting discussion for the Framework

Australians living with HIV have a huge diversity of lived experience. There are many clinical, psychosocial and sociocultural factors that influence an individual's health, wellbeing, personal resilience and ability to flourish. Longevity of HIV diagnosis is, of course, one of these factors — albeit a very important one. Other social determinants of health include gender, geographical, physical or social isolation, security of housing and finances, employment and the ability to contribute meaningfully to the community, the effects of social marginalisation or discrimination, mental health, and health comorbidities. These factors can affect people in multiple ways, on top of the fact of a HIV diagnosis. They may influence whether a person receives a timely diagnosis and appropriate clinical care and treatment, whether a person is referred into services that meet and support their health needs and psychosocial wellbeing, and whether (or how) people create, develop and sustain supportive clinical, personal and social networks.

In the age of PrEP, treatment as prevention (TasP), and new options for clinical management, the effects of stigma and discrimination nonetheless remain a significant, decisive issue in the lives of many people living with HIV, as people negotiate the disclosure of HIV status to friends, families, intimate contacts or in the employment setting; commence or change treatment; or manage the effects of a longstanding diagnosis that has had continued impacts on daily life over many years.

There is a varied and inconsistent level of knowledge about HIV across the Australian community— including among health care workers. People living with HIV continue to report the occurrence of stigmatising behaviours or attitudes, which may be encountered as they negotiate their intimate lives, seek employment or housing, or access services.

There is now, more than ever, a need to work together in a coordinated effort at all levels of the HIV response to challenge myths and outdated information around transmission and prevention, stereotypes and negative assumptions, and correct outdated understandings about HIV treatment. Above all, we need to work together in a way that is mindful of the many cultural and social factors that can influence whether a person is able not just to live with HIV, but to live well and flourish.

The importance of partnership in building resilience and eliminating HIV stigma

Building resilience and addressing and challenging the personal and community burden of HIV related stigma and discrimination requires partnership within and between all levels of the response to HIV in Australia.

We can look to government decision makers and policy leaders to contribute to the critical task of creating an enabling legislative and policy environment and framework, including bipartisan approaches and cross-jurisdictional support for a legislative environment that:

- ensures laws and policies support the health and wellbeing of HIV through a consistent framework that minimises the impacts of stigma and discrimination

- ensures criminalisation of personal behaviours is not pursued at the expense of health outcomes, and

- champions best-practice health outcomes-focused policy initiatives that acknowledge the social and cultural determinants of health.

Throughout the consultation process that informed the creation of this Framework, people living with HIV, and stakeholders in the sector, identified a wide range of organisations, individuals, and social groupings with a potential role to play in building the skills building and providing ongoing support for people living with HIV to respond resiliently to HIV-related stigma or discrimination — from structured programs within community-based organisations, to informal friendship networks, or social media communities.

Not all people living with HIV have the same needs or experiences, and individuals will build their own resilience strategies from available support networks and opportunities.

A diverse mix of partners will be involved in helping any one person with HIV build resilience. Importantly, it is recognised throughout this Framework that the partners who may be called upon in any one instance because they may offer a unique service or program suitable for some people with HIV will not be the same everyone in every circumstance. What is critical is that all partners supporting people living with HIV — from health services through to informal social networks — understand that they have a role to play in the broader task of combatting HIV stigma and discrimination, and explicitly commit to doing so.

Resilience for any one individual person living with HIV may be facilitated by the following interactions and personal partnerships:

- **Clinical health services** (e.g., primary and GP care; specialist care; hospital care; psychological clinical services, allied health)

- **Community-based networks of social support** (e.g., organisations supporting members of the gay and lesbian community; community-based organisations for people who identify as trans or gender diverse; indigenous community organisations; social networks; sexual networks; faith-based organisations)

- **HIV peer networks, services and community organisations**

- **Community health services**

- **State, federal and local government leaders, decision-makers and policy-makers**.

Vision and values underpinning the Framework

In developing this Framework, people living with HIV and HIV service providers from across the country were asked to share their insights into the qualities and characteristics of resilient people living with HIV. Their responses highlighted the following personal qualities:

- confidence
- flexibility
- tenacity
- strength
- authenticity.

A significant challenge for all people living with HIV is dealing with the personal impacts of HIV-related stigma, whether in daily social interactions, intimate and sexual life, family life, at work, or in the health care setting.

Eliminating HIV-related stigma

The goal of building resilience is unavoidably connected to the goal of challenging and eliminating HIV-related stigma and discrimination. Stigma — that is, the practical outcome of negative or discriminatory judgements or views — is not just an abstract concept for people living with HIV, but rather, an actively experienced reality. The stigmatising of people with HIV is not just an attitude about people, it is both an action and a behaviour directed towards them, with direct and real consequences.

In 2016, an online survey of people living with HIV conducted to inform the Stigma Indicators Monitoring Project found that within the previous 12 months, 74% of respondents had experienced at least some form of stigma relating to their HIV status.[1]

Stigmatising behaviours include judging the behaviour or actions of people in a negative way based on the fact of their HIV diagnosis. This might take some of the following forms:

- Making assumptions about people or their behaviour because they are living with HIV (including judgments about their morals, ethics, personal values or practices, or social worth)

- Apportioning personal blame for a positive HIV diagnosis

- Shaming people directly or by implication

- Breaching peoples' privacy or confidentiality by, e.g., revealing their HIV status without permission

- Treating people differently when providing health care or other services

- Failing to take responsibility for having the correct knowledge about HIV when providing a health or social service, and/or

- Excluding or isolating people from services, employment, family networks, social opportunities, or intimate contact purely on the basis of their positive HIV status.

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1 Cama, E., Broady, T., Brener, L., Hopwood, M., de Wit, J., & Treloar, C. (2018). Stigma Indicators Monitoring Project: Summary Report. Sydney: Centre for Social Research in Health, UNSW Sydney. https://csrh.arts.unsw.edu.au/research/projects/stigma-indicators/

This Framework emphasises that addressing stigma will require multiple approaches that range from building individual resilience and promoting practical strategies for people who experience stigma, through to community-wide efforts to improve the understanding of what it means to live with HIV in Australia now, and to equip the community with up-to-date knowledge about HIV testing, treatment and prevention that will directly challenge stigmatising attitudes and outdated myths and stereotypes.

The consultation process emphasised the following factors as being crucially linked to the capacity for sustained resilience that enables personal flourishing:

- **A sense of connection**: People living with HIV feel connected to communities and have supportive social networks.

- **A feeling of personal empowerment**: People living with HIV are enabled and empowered to make decisions about their own life, health and circumstances.

- **Identification with peers**: People living with HIV feel their experiences and lives are validated and affirmed by strong, visible peer role models.

- **Eliminating the stigmatising treatment of people living with HIV**: through policy and legislative reform, community education, and service provision.

Framing principles

This document is underpinned by the following overarching principles.

Meaningful involvement of people living with HIV

- This Framework is both inspired by, and is an outcome of, the Greater Involvement of Positive People (GIPA), Meaningful Involvement of Positive People (MIPA) and Meaningful Involvement of Women and Girls Living with HIV (MIWA) principles. We also acknowledge the NAPWHA Declaration of the Rights of People Living with HIV/AIDS.

Social justice and Human Rights

- This Framework recognises the burden of social inequality on many people living with HIV in relation to gender, sexuality, country or culture of origin, and socio-economic status, and acknowledges that social inequalities intersect with and can magnify the effects and impacts of stigma and discrimination

- This Framework is founded on a human rights approach, with health, sexual and reproductive rights at its core.

- This Framework identifies the ways in which people living with HIV have been differentially affected by the history of the HIV epidemic and that appreciating the struggles and successes in the HIV response contributes to an informed and vibrant community.

Supporting innovative research and policy principles

- This Framework is only possible with sustained investment in interventions based on sound evidence and which are regularly reviewed, and their outcomes monitored.

- This Framework is premised upon the appropriate and ethical collection of data that strengthens understanding of the epidemic, facilitates identification of changes over time, including emerging priorities. This data should be collected a safe, respectful and secure way and directed toward improving individual health outcomes, and better understanding the challenges of living with HIV.

The aspirational qualities of resilience building strategies

In building this Framework, we consulted with people living with HIV and other stakeholders, and sought feedback about current programs, services, interventions, strategies and social network opportunities that contribute to the goals of challenging HIV-related stigma and discrimination and building resilience.

We asked people to consider and describe the ideal or aspirational qualities and best-practice principles common to those that were specifically effective.

From this feedback about specific programs, it was apparent that there are some general characteristics, qualities and practices common to effective programs, services, interventions or strategies. In the Framework, we have termed these aspirational qualities: i.e., the characteristics to which those designing, developing or evaluating services might usefully aspire or aim. These are the characteristics that those consulted felt were highly associated with effective interventions: they helped foster individual resilience, and make services safe and stigma free.

Further on in the document, we have listed some of those aspirational qualities for specific services or interventions that would meet the specific desired strategic outcomes identified in this Framework.

Here, we have pulled together a broad list of qualities that we recommend be kept in mind when establishing, monitoring and evaluating resilience building programs, services, supports and interventions for people living with HIV.

Interventions and strategies should aspire to:

■ recognise and affirm the value of diversity

■ place peer knowledge and experience at the centre of program, service or intervention

■ acknowledge the self-determination of people living with HIV as a clear goal

■ promote self-awareness and individual flourishing

■ have robust methods for ensuring the integrity and accountability of the service

■ be safe and accessible to people living with HIV

■ be culturally relevant, appropriate and meaningful

■ awareness of and sensitivity to the specific impacts of sexuality, gender, cultural or language background, and responsive to key populations as their needs change over time

■ ensure that people living with HIV are in and at the forefront of conversations about testing, treatment care and prevention of HIV.

General social considerations and contexts

Throughout this Framework, we emphasise the importance of fostering and strengthening peer-based and innovative approaches to support specific populations of people living with HIV. We have identified several significant, inter-related population considerations that can affect availability of and access to services, and we encourage policy-makers and those designing, delivering or evaluating programs and services to bear these in mind.

Geographical considerations

Rural and remote communities, in particular, may lack substantive local peer groups or networks that can support services sustainably, so service planning may need to utilise different approaches, including outreach and distance communication technologies, to build peer-based services

Cultural considerations

There is an ongoing need to strengthen and expand sustainable culturally-appropriate peer support opportunities for priority populations, including indigenous people, and people from culturally and linguistically diverse backgrounds. Research shows that people living with HIV from these particular populations may be more likely to fear or to experience stigma, and to lack peer contact.

In Strategic Objective 3, we discuss some specific marginalised and vulnerable groups within the population for whom developing culturally appropriate resilience responses requires particular considerations.

These are:

- Aboriginal and Torres Strait Islander people living with HIV
- people living with HIV who inject drugs
- people living with HIV from mobile or migrant populations, including refugees (inclusive of people with HIV of culturally or linguistically diverse experience)
- people living with HIV who identify as transgender or gender-diverse.

Legal considerations: the effect of the legislative environment

Several groups within the broad Australian population have increased risks or vulnerabilities associated with HIV that may be exacerbated by laws and policies that are directly stigmatising, or discriminatory, or which increase peoples' fear of diagnosis or disclosure. Among the groups most vulnerable to poor policies or laws, particularly laws that pursue the criminalisation of personal behaviours over health outcomes, are sex workers and people who inject drugs. Individuals who engage in sex work or inject drugs may avoid testing or treatment for fear of prosecution.

For those seeking asylum or going through the immigration process, fear of disclosure affecting legal outcomes may mean people choose not to be tested, disclose their status, or access treatment.

People who are incarcerated have specific needs in relation to HIV and health care that must be met within state-based policy frameworks.

We encourage a cross-jurisdictional commitment to adopting best practice legislation.

Women

We have not taken the approach of identifying women as a specific, vulnerable population within the goals of the Framework. Rather, we want to be explicit that each of our Strategic Objectives is directed equally to addressing the needs of women living with HIV, and was developed with an inclusive aim.

In Strategic Priority Action 3, we have included the specific stories of individual women, and we have commented extensively on the specific needs of women, and where the response falls short of meeting those needs.

Australian-born gay men remain the largest population group significantly affected by HIV. It is therefore crucial that in prioritising this group, we do not fail others, and there must be ongoing and explicit efforts to ensure women are visible in the strategic effort to build resilience, that services recognise and respond to women's health and social needs, and that we continue to specifically address the significant disadvantages at which women are often placed by variable or poor levels of knowledge about HIV across the community and within health services.

Women commonly report isolation and fear as a key experience of a new diagnosis. Women are more likely to be diagnosed in settings where there is less experience with the diagnosis and management of HIV, and there is often a corresponding a lack of information on the part of health practitioners as to where to refer women after diagnosis. Indicative of this, it has been reported that health professionals often test for HIV in female patients only after eliminating several other health conditions, suggesting that many doctors do not consider HIV to be a potential health issue for women in Australia.[2]

This heightens the risk of women living with HIV experiencing fear and isolation as part of a new diagnosis, being diagnosed at a later stage of infection and/or being at risk of lacking access to supportive and sustainable personal, social and clinical networks.

2 Moreira, C., Ryan, K., Higgins N., El-Hayek, C. (2016). Characterising HIV among women diagnosed in Victoria, Australia. mHIVE WORLD AIDS DAY Symposium.

Building resilience for women: key themes in the consultation

Families

There needs to be a consistent effort to ensure that services designed for women are safe spaces for women, their partners, and their children. Considerations in service design might include the physical location of services, the physical environment in which services are delivered, opening or running hours of services for women who work and have children, and an enabling environment (such as ensuring all staff have appropriate training, and appropriate or required checks if providing services involving children).

Importance of peer-led and peer-built programs, education and services

It is crucial that a peer-led approach is taken, and that we prioritise the development of sustainable networks of confident women living with HIV able to be peer leaders and role models, representing a diversity of experience, ages and backgrounds.

Financial, housing and social vulnerability

Women living with HIV often report significant levels of financial vulnerability. This may be associated with under-employment (or unemployment), family circumstances (such as raising children as a single parent or with a low income), and concerns such as affordable housing. Women juggling complex needs often report that they prioritise the support of children, families or domestic partners over strategies to support their own personal health and wellbeing. For some women, gender-mediated social issues, such as intimate partner violence, have an additional impact on social stability, health and wellbeing.

Effects of social stigma

Understanding of HIV and its implication may be lower or more varied across the general community than among gay men. This increases the risk of stigma and discrimination

being experienced by women in health services, or their daily lives in the community. There are persistent myths and social stereotypes about HIV to which women are vulnerable.

Disclosure, dating and intimate partnership

For many women with HIV, a particular concern is managing HIV disclosure to potentially intimate partners or when dating, as a consistent level of knowledge about HIV and its transmission cannot be relied upon across the general community. Supporting women to feel safe and confident to disclose HIV to family, friends and intimate partners is crucial to building resilience. This needs to be a peer-led and directed effort.

A key theme of this consultation is that consideration be given to a national effort to increase the level of knowledge of HIV across the general community, represent the diverse lived experiences of women with HIV to create visible role models, and to familiarise the Australian community with important messages around HIV treatment and prevention. This was seen by many people in the consultation as crucial to addressing HIV-related stigma, and especially for women.

Heterosexual men

Heterosexual men are a frequently marginalised and often invisible group of people living with HIV in Australia. As new diagnoses in gay men and men who have sex with men are falling, heterosexual transmissions are making up an increasing proportion of new diagnoses. An estimated one in five Australians living with HIV identify as heterosexual. There is significant cultural and social diversity among heterosexual men living with HIV. An Australian study, the Straighpoz Study[3], identified the following as significant issues which would be expected to affect the resilience of heterosexual men living with HIV:

- Disclosure, relationships, sex, reproduction and community have different priorities and subtexts in a heterosexual context;

- HIV is socially marginalised, frequently misunderstood and highly stigmatised in the heterosexual context;

- HIV is deeply coded by ideas of gender and sexuality, and frequently perceived as a 'gay men's' disease. Largely disengaged from the community of people living with HIV in many cases, heterosexual men often develop supportive strategies through small, sheltered communities of trusted individuals;

- Heterosexual men may more frequently live outside of inner cities, or rural or regional communities, where HIV-specific or experienced health services may be more difficult to reliably locate — HIV is often diagnosed by non S100 prescribers;

- For participants in the Straightpoz study, HIV was rarely their only, and often not their most significant, health concern.

There has been relatively little attention paid to the implications of recent developments in HIV transmission and prevention, including TasP and PreP, and their implications for HIV in terms of wellbeing, disclosure and negotiation of sex, and reproduction and families.

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3 Persson, A., Richards, W., Barton, D., & Reakes, K. (2009). Men and women living heterosexually with HIV: The Straightpoz study, Volume 2 (Monograph 1/2009). Sydney: National Centre in HIV Social Research, The University of New South Wales.

The challenge of stigma and its relationship to mental health and wellbeing

International research suggests as many as half of all people living with HIV report the experience of feeling stigmatised due to their HIV diagnosis. A systematic review of studies looking at the mental health and wellbeing of people with HIV reported in the international literature analysed how these issues related to the presence or experience of stigma.[4] The mean prevalence of reported depression in people living with HIV across the high-income countries in the study was 25.8%, and the one-to-four-week reported prevalence of depression was around 40%. Anxiety was reported to be higher for people living with HIV in the high-income countries in the review, which included Australia.

The reported experience of stigma in the studies reviewed was high — with a range of between 42% and 83% of people across the studies reporting the experience of some type of stigma associated with their HIV diagnosis — including 'internalised stigma', or a lowered sense of self-worth.

The impact of HIV-related stigma and discrimination has been widely recognised as one of the most pernicious and ubiquitous barriers to effective HIV awareness, prevention, testing, treatment, care and support. It manifests around the world in various guises and often exploits the weakest aspects of health and social policy, affecting populations that are often marginalised, and further exacerbating vulnerabilities by fuelling erroneous stereotypes and prejudices. The insidious nature of HIV stigma and discrimination often mean that it is obscured by moral panic and righteous indignation and can take shape in

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4 Lowther, K, Selman, L, Harding, R and Higginson, I. (2014) Experience of persistent psychological symptoms and perceived stigma among people with HIVHIV on antiretroviral therapy (ART): A systematic review. International Journal of Nursing Studies 51(8): 1171 1189 http://dx.doi.org/10.1016/j.ijnurstu.2014.01.015.

such enactments of overly broad criminalisation or passive acceptance of stigmatising language used across social media.

Tackling HIV stigma means nothing less than a long-term commitment to social change over time.

In the Australian context, the first report from the national HIV Stigma Indicators Monitoring Project found that 74% of people living with HIV who responded to the survey had at least some experience of stigma or discrimination associated with their HIV diagnosis in the 12 months prior to completion of the survey.[5]

5 Cama, E., Broady, T., Brener, L., Hopwood, M., de Wit, J., & Treloar, C. (2018). Stigma Indicators Monitoring Project: Summary Report. Sydney: Centre for Social Research in Health, UNSW Sydney. https://csrh.arts.unsw.edu.au/research/projects/stigma-indicators/

The importance and impact of building resilience

The NAPWHA report on HIV Stigma in Australia identified that social support and psychological resilience are two variables known to reduce the negative effects associated with a stigmatised illness.[6] They are also variables that are correlated and work together to buffer the individual from the negative effects of stigma. When looking at the factors associated with social support and resilience the authors found that both social support and resilience were positively correlated with a higher quality of life, greater levels of self-efficacy, higher self-esteem and greater engagement with an HIV community. On the other hand, lower levels of both were associated with a greater experience of HIV-related stigma as well as an increased risk of stress, depression and anxiety.

Building psychological resilience:

- enables people to develop mechanisms for protection against experiences which could be overwhelming,

- helps people to maintain balance in our lives during difficult or stressful periods of time; and

- can buffer people from developing mental illnesses such as depression, anxiety or post-traumatic stress disorders. It does so by helping offset certain risk factors that increase the likelihood of experiencing psychological distress.

The additional psychosocial factors (such as stress, depression, social isolation, hopelessness, and job control), combined with a marginalised identity, social status and co-morbidities, intersect with HIV stigma to further confound and exacerbate low levels of resilience and reinforce vulnerability. To build a sustained resilience capacity among

6 Slavin, S., Brener, L., Callander, D., and de Wit, J. (2011) 'The HIV Stigma Audit Community Report.' National Association of People Living with HIVHIV/AIDS. Website publication.

people living with HIV means that identifying and mitigating these additional factors should be seen as important as building the personal skills to challenge HIV stigma. Research indicates that among the personal psychosocial factors which can ameliorate the personal impacts of HIV are dispositional optimism, active coping, and having a personal belief system.

■ **A focus on building resilience among people with HIV** can increase personal agency and reduce the impacts of specific social vulnerabilities.

■ **A focus on developing enabling environments and approaches to service provision** can support the development of services that are accessible, equitable and stigma-free.

■ **An understanding of how to incorporate the principles of psychosocial resilience into services, programs, interventions and strategies** may improve the quality and relevance of services.

Flourishing

Flourishing is conceptualised as having two main components.[7] The first can be described as those experiences which elicit frequent positive emotions, such as happiness and optimism. The second is when a person has a sense of self-acceptance, a sense of meaning or purpose, and feels that much of their life is lived in accordance with their values.

In a national sample of Australian HIV-positive gay men, internalised HIV-related stigma was found to be a major barrier to flourishing. Higher levels of flourishing, however, were found among those who perceived a greater level of practical support in their lives, who had a sense of belonging or companionship, and who felt supported by family.[8]

These findings provide guidance for policymakers, health professionals, support workers, and anyone seeking to optimise support programs for people living with HIV. In particular, this study and its findings offer new information to help facilitate programs that are not only aimed at treating or preventing mental illness among people living with HIV, but also seek to foster higher levels of well-being or indeed flourishing.

7 http://www.jstor.org/stable/3090197?seq=1#page_scan_tab_contents

8 https://bmcpsychology.biomedcentral.com/articles/10.1186/s40359-016-0154-z

PART B

The National Strategic Framework to Build Resilience Capacity for People Living with HIV

Objectives and Strategic Priority Actions and Areas

An initial national consultation with people living with HIV, and HIV service providers, led to the identification of three objectives that provide the basis of the Framework.

The first two objectives focus upon actions being taken (or in some cases, additional actions to strengthen the current response) that provide the basis for building resilience among individual people living with HIV across all communities.

The third objective recognises the changing nature of the epidemic in Australia, and the effect that the introduction and access to biomedical prevention technologies (PEP, PrEP and TasP) is having upon the current nature of the epidemiology.

OBJECTIVE 1: Create environments that promote resilience from diagnosis and onwards

- Strategic Priority Action 1.1: Promote an expectation of wellbeing and address fear

- Strategic Priority Action 1.2: Build an adaptive capacity

- Strategic Priority Action 1.3: Support people with HIV to build strong, flexible social and personal networks

- Strategic Priority Action 1.4: Provide timely and appropriate information

OBJECTIVE 2: Provide efficient, effective and appropriate support to people living with HIV to optimise quality of life

- Strategic Priority Action 2.1: Respond to the HIV 'generations'

- Strategic Priority Action 2.2: Support quality peer-led responses

- Strategic Priority Action 2.3: Promote equity and accessibility

- Strategic Priority Action 2.4: Strengthen mechanisms and systems for sharing information across service provision boundaries

OBJECTIVE 3: Develop resilience responses for specific and vulnerable marginalised populations

- Strategic Priority Area 3.1: Aboriginal and Torres Strait Islander populations

- Strategic Priority Area 3.2: People who inject drugs

- Strategic Priority Area 3.3: Mobile and migrant populations; refugees (inclusive of people from culturally and linguistically diverse background)

- Strategic Priority Area 3.4: Trans and gender diverse populations

Whereas the previous two objectives listed actions to be initiated, maintained and/or expanded, this third objective lists four strategic priority areas where it is not only action that is required to build resilience and address HIV stigma, but there is an urgent need to address the systemic and structural issues that put these populations not only at a heightened risk of HIV infection, but at greater risk of poorer health outcomes and a diminished quality of life.

The description of these populations is deliberately general in nature, and it is recognised within the principles of the Framework that they are made up of many different sub-populations, genders, sexualities, ages, social statuses and cultures.

Identification of current activities, aspirational qualities of interventions, and gaps and issues within each of the Strategic Priority Action Areas

Under each of the identified Strategic Priority Action Areas, we have set out the Framework using the following four-part scheme.

- **Explanation and discussion**

    A short explanation is given as to why the strategic objective was identified, with a brief summary discussion of the relevant issues and considerations behind its inclusion in the Framework.

- **Examples of current activities being undertaken as part of the national and state HIV response that are relevant to that specific strategic goal**

- **Aspirational qualities of services**

    Drawing on feedback from the consultation, we describe and identify the aspirational characteristics or qualities of services, programs, interventions, or strategies that aim to meet that strategic priority or goal.

■ Gaps and issues identified, with recommendations for strengthening the response

Drawing on feedback from the consultation, and an analysis of the current environment, we identify specific gaps, issues and concerns, and list potential strategies that could be put in place to address those gaps, resolve any issues, and strengthen the response to better meet the specific strategic goal.

As part of Strategic Objective 3, we also provide additional insight through the inclusion of personal stories and experiences.

OBJECTIVE 1: Create environments that promote resilience from diagnosis onwards

Strategic Priority Action 1.1
Promote an expectation of wellbeing and address fear

The point of diagnosis is a critical time for people living with HIV, and it is important to direct resources to supporting people during this process.

After diagnosis, people can experience acute and ongoing anxiety and fear related to issues such as:

- ongoing health and wellbeing;

- treatment decisions;

- disclosure to friends and family; and

- sex and relationships.

Given the significance of developments in relation to biomedical prevention, it is even more important that people living with HIV are provided with consistent, clear and supportive information and a system for referral to psychosocial support at the point of

diagnosis.[9] The Standards for Psychological Support for Adults living with HIV developed by ASHM is an important resource to ensure that both clinical and non-clinical services are working together to support the mental health and wellbeing of people living with HIV.[10]

Approximately 70% of people living with HIV are offered psychological services or support at the point of diagnosis, indicating there are still a substantive number of individuals, perhaps as many as one-third, not receiving this critical support.[11] (Home testing may be one area where a specific strategy to link people to psychosocial support may be needed.)

Aspirational qualities of services, programs or interventions

■ Builds confidence and supports skills in disclosure in sexual negotiation, and in social contexts (family, friends, employment)

■ Opens avenues to connect with peers

■ Invites sharing of personal experiences safely and balances this with an appreciation of the experiences of others

Examples of current activities undertaken that are relevant to the strategic priority 'promote an expectation of wellbeing and address fear'

■ Formal and informal stigma-reduction efforts currently being undertaken through social media, community-driven activism and community-based organisations

■ Visible promotion of the 'Undetectable = Untransmittable' message among people living with HIV and in particular, gay men, through community and social networks

■ Structured, intensive workshop-style programs with an individualised focus targeted at people living with HIV with a new diagnosis

■ Peer navigation programs

■ One-on-one peer support or counselling

■ Structured programs to support newly-diagnosed individuals

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9 The Kirby Institute Annual Surveillance report 2017 states that about 6% of the estimated total number of gay and bisexual men in Australia, or some 7,266 gay or bisexual men, were enrolled in PrEP implementation projects across the nation's jurisdictions.
Source: Kirby Institute. HIV, viral hepatitis and sexually transmissible infections in Australia: annual surveillance report 2017. Sydney: Kirby Institute, UNSW Sydney; 2017.

10 https://www.ashm.org.au/products/product/9781920773717

11 http://www.latrobe.edu.au/__data/assets/pdf_file/0010/766900/HIVHIV-Futures-8-Broadsheet-3-on-HIVHIV-exposure-and-testing.pdf

Strengthening the response: issues, considerations and additional strategies

Identified need or issue	Potential strategy
■ The fear or experience of HIV-related stigma remains a significant barrier to testing and access to care. Specific populations, including women, people from culturally and linguistically diverse communities and indigenous people, are at increased risk of obtaining a HIV diagnosis later than desirable, and with a lower CD4 count than Australian-born gay men. There is a need to reduce the impact of stigma to facilitate equitable access to the health and prevention benefits of timely diagnosis and treatment.	■ Ongoing education programs targeting health care workers and doctors in general practice, and in health services regularly seeing individuals from vulnerable and marginalised communities, to build skills in HIV diagnosis and management ■ Funded strategies to facilitate and promote community-wide knowledge and improved understanding of the current experience of living with HIV, including changed expectations of health and treatment outcomes ■ Strategies, including specific visible, campaigns, to raise community-wide awareness that successful HIV treatment means that HIV cannot be transmitted ■ Specific, targeted interventions to reduce the impact of HIV related stigma in priority populations: see Section 3
■ An understanding of the expected health and prevention benefits of HIV treatment may not be evenly shared across the community, or by all health care providers. These benefits may not be flowing to equitably all people living with HIV.	■ Undertake activities to improve the visibility of people with HIV in the media (including through social media) and to promote a greater understanding of the present experiences of people living with HIV ■ Invest in research to understand the specific opportunities and relevance of PrEP for women living with HIV ■ Put in place strategies to ensure HIV peer workers are equipped with up-to-date and reliable knowledge about HIV treatment, and supported with the skills to communicate this

Identified need or issue	Potential strategy
■ There is a need to diversify population specific peer support opportunities	■ Detailed information about this can be found in Strategic Objective 3
■ There may be a lack of distance (i.e., technology-based) support services for rural and regional people living with HIV, particularly to support people in the early stages of diagnosis, in some jurisdictions	■ Organisations may wish to advocate at the local or jurisdictional level for greater availability of clinical support services, and improving the knowledge of existing services in referring, if this is identified as a deficit. ■ Learning modules, including flexible e-learning, for regional, rural and remote health care workers ■ Community development strategies to build peer skills in rural/remote settings
■ There is currently no consistent benchmark for assessing the quality and relevance of information provided at diagnosis and throughout peer contact	■ Consider developing a nationally agreed mechanism or standard to help organisations assess quality and currency of information provided in resources (e.g. a quality check or information endorsement program or resource, with approved training)
■ Quality services require a broad and integrated approach to health, with physical wellbeing and flourishing as a goal	■ Integrate opportunities for physical health activities into social and other activities, for people living with HIV to maximise health and mental health outcomes ■ A mechanism to identify safe services

Strategic Priority Action 1.2
Build an Adaptive Capacity

'Adaptive capacity' refers to an individual's capacity to cope and adapt to change including stressors that may negatively affect wellbeing and a quality of life. Adaptive capacity means:

- having the insight to identify and understand a stressful situation;

- having the skills to respond to stress and ideally prevent similar stressors having a recurrent negative effect; and

- fostering a positive attitude and outlook to minimise the impact of any stressors.

Aspirational qualities of services, programs or interventions

- People are provided with effective tools to talk about, name, and reduce the impacts of, stigma and discrimination

- Interventions recognise the need for an individualised approach—not all people living with HIV have the same experiences or support needs

- There are 'check-in' and 'follow-through' provisions, so that flexible but clear opportunities for ongoing contact and engagement with supports are provided for those who desire it

- A safe environment to invite the sharing of personal experiences is balanced with an expectation that the experiences of others are accepted and respected

- Service options are diverse, welcoming and recognise specific population needs

Examples of current activities undertaken that are relevant to the strategic priority 'build an adaptive capacity'

- Counselling services

- Mentoring programs

- Social media network models: independent and community-organised, and organisational

- Structured programs for developing and building life skills

Strengthening the response: issues, considerations and additional strategies

Identified need or issue	Potential strategy
■ Stigma and discrimination remains a key concern. Three quarters of those who completed the HIV Stigma Indicators survey instrument reported having at least some experience of stigma or discrimination in relation to their HIV status over the 12 months prior to completing the survey.	■ New data options such as the Stigma Indicators Monitoring Project[12] and the PozQual[13] tool provide the opportunity to track changes in the experience of stigma over time and improvements in HIV wellbeing over time, with the potential to include this information as a national measure of efforts to eliminate stigma and build resilience ■ Nationally and at the jurisdictional level, review programs and support services for people living with HIV with the explicit aim of ensuring they are building skills for people living with HIV to challenge stigma, and disclose their HIV status in social and intimate networks ■ Consider a national mechanism to give people living with HIV an opportunity to report experiences of stigma and discrimination

12 Cama, E., Broady, T., Brener, L., Hopwood, M., de Wit, J., & Treloar, C. (2018). Stigma Indicators Monitoring Project: Summary Report. Sydney: Centre for Social Research in Health, UNSW Sydney. https://csrh.arts.unsw.edu.au/research/projects/stigma-indicators/

13 Brown, G., Mikołajczak, G., Lyons, A., Power, J., Drummond, F., Cogle, A., ... O'Connor, S. (2018). Development and validation of PozQoL: a scale to assess quality of life of PLHIV. BMC Public Health, 18, 527. http://doi.org/10.1186/s12889-018-5433-6

Identified need or issue	Potential strategy
■ Many people living with HIV continue to face pressing practical problems that need to be addressed concomitant with interventions to build resilience. Housing vulnerability, injecting drug use, lack of secure income, mental health issues, family responsibilities, and intimate partner violence were all examples provided during the consultation.	■ Strengthen targeted activities through community-based organisations and other services aimed at reducing the impacts of these vulnerabilities. Identify specific gaps and provide fund interventions where appropriate at jurisdictional level. ■ Develop and strengthen partnerships with existing services within jurisdictions to improve support for the needs of people living with HIV in relation to housing needs and intimate partner violence ■ Ensure evidence-based interventions to reduce the health and social impacts of injecting drug use among people living with HIV are available in all jurisdictions and promote awareness of these options
■ There is a need to diversify options for support, which are population-specific and cater towards unique cultural or social situations.	■ Detailed information can be found in Strategic Objective 3. Examples of strategies might be to build/expand on peer and support opportunities in partnership with faith-based networks, and engage in capacity building with ACCHOs to develop peer opportunities through AMS services
■ There is a need to expand the availability of broad and accessible 'life-skills' courses and support opportunities that provide practical coping techniques or strategies to counter stressors unique to people living with HIV, in a safe and supportive environment	■ Regularly review programs at jurisdictional level to ensure they are reflecting currently important concerns for people living with HIV ■ Ensure that existing peer programs and counselling services are providing people with HIV with the personal tools to explicitly address and challenge stigma and discrimination when it occurs ■ Use opportunities to share 'what works' between agencies

Identified need or issue	Potential strategy
■ More people may benefit from 'peer-navigation' techniques than currently have access to them	■ Assess relevance and applicability of these programs in jurisdictions, utilising feedback and evaluation from existing peer navigator programs in Australia and in overseas
■ Increase access to diverse and visible peer role models	■ Investigate novel opportunities for peer to peer contact, such as the use of online peer mentoring, the use of technologies such as apps etc. ■ Diversify approaches through, e.g., video stories and social media campaigns to ensure diverse and accessible representation of the lived experience of people living with HIV
■ Mental health services may not be universally well equipped to cater for the mental health needs of people with HIV	■ Community-based organisations undertaking capacity building and partnership with relevant mental health services at jurisdictional level
Identified need or issue	Potential strategy

Strategic Priority Action 1.3 Support people with HIV to build strong, flexible and sustained social and personal networks

People living with HIV rely heavily upon a range of social networks (including family and friendship networks) as a mechanism of support, and this changes over time.[14] However, social networks and their use vary. They are not ubiquitous among people living with HIV (many people living with HIV remain socially isolated and do not have strong social networks). Some social networks are very robust and diverse, while others are intimate and confined. Most, importantly it must be understood that no social network is static over time, and people's degree of engagement can change too.

Increasingly, social networks include virtual and online networks, and drawing safely and productively upon these networks for support and information requires a different and specific set of skills.

Resilience is facilitated when a person is able to recognise who, within their available networks, is able and available to provide support needed in any given situation. This may well not be the same person or network in all circumstances.

Resilience in this context means having the necessary insight and sophistication to understand what networks are available to which a person may safely turn for support at any given time.

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14 http://www.latrobe.edu.au/__data/assets/pdf_file/0006/766896/HIVHIV-Futures-8-Broadsheet-1-on-Health-and-wellbeing.pdf

Aspirational qualities of services, programs or interventions

- Appreciate, are responsive to, and promote diversity

- Flexible and sustained networks create shared norms, understandings and expectations for engagement

- Flexible networks are responsive and pragmatic and will change over time

- Makes use of the best available technologies to sustain networks

- Networks are a safe space to share, and inclusive and appreciative of the diverse needs and experiences of all users

Examples of current activities undertaken that are relevant to the strategic priority 'build an adaptive capacity'

- Alumni programs building on contacts and communities of engagement from peer-based groups, workshops and leadership development programs

- National forums of HIV sector and community organisations

- Peer-specific group support targeting particular needs: age, gender, family, point of diagnosis, or cultural or linguistic background

- Personal friendship networks

- Opportunities for families and friends of people living with HIV to come together in supportive social settings

Strengthening the response: issues, considerations and additional strategies

Identified need or issue	Potential strategy
■ Strengthen and diversify interventions that are population-specific and cater towards unique cultural or social situations	■ Build capacity and competence within existing non-HIV related support networks within the community to provide safe and supportive environments for people living with HIV (e.g., within faith-based community organisations). This work should have a focus on reducing the impact of stigma and increasing the understanding of living with HIV in community and other services, through peer-led approaches.

Identified need or issue	Potential strategy
■ Support safe, competent use of social media and other networks	■ Support people living with HIV with skills and competence to develop and maintain online social networks safely and use productively, e.g., through courses, information, staff training, and peer social network leadership ■ Provide and promote to moderators involved in setting up peer online networks with resources such as model rules, codes of conduct for users, and information to support cultural competence and inclusiveness
■ Continuity of care needs to be balanced with flexibility of care	■ Ensure that services are designed so that people have the chance to dip in and leave services based on need, and follow-up is undertaken
■ Services need to be reputable, and of high quality	■ Consider a program/system to create and designate 'safe spaces' (including physical and online safe spaces) and guide mainstream services, to ensure that staff have undertaken specific training and so are appropriate for people with HIV. This may well be a task that can be undertaken by an existing leadership forum within the community HIV sector.
■ There may be poor GP knowledge of available programs, interventions and support opportunities outside high HIV caseload practices and services	■ Improve GP training so that GPs are aware of social network opportunities that exist, and are referring people to those services
■ Information needs to be shared effectively between providers, workers and individuals	■ Consider possibilities for centralised opportunity to share networks

Strategic Priority Action 1.4
Timely and appropriate provision of information

Resilience depends upon the ability of a person to respond in an immediate way to a source of anxiety or a physical or psychological stressor, e.g., a new diagnosis, commencing or changing treatments, a sexual rejection due to HIV, the need to disclose HIV in a particular context, a relationship breakup, or diagnosis with a comorbidity.

A resilient response means being able to access reliable, culturally appropriate and specific information quickly, and being or feeling in control of that information and situation.

Timely access to information does not always equate to more information. Under certain circumstances, individuals may struggle to take in and retain large amounts of complex information. The amount of information needs to be appropriate, and appropriately targeted, recognising that health literacy varies, and health literacy skills may take some time to develop. However, timely may mean 'urgent', so it is important that people living with HIV have the skills and develop supports to recognise when they need to immediately access information or services, and that information is available.

There has been an historical reliance on written materials which are expressed in a very general way but may not be suitable for all people living with HIV, due to differences in literacy, or because they lack cultural specificity. There has been a notably patchy uptake of new technologies as a means of providing information to people living with HIV, especially when compared with overseas settings and organisations.

The current bias towards text-based approaches also fails to capture the different styles in which people learn, such as visual, aural or kinetic learning.

Aspirational qualities of services, programs or interventions

- Receptive to innovation in information delivery systems

- Responsive to changes in knowledge

- Builds critical thinking and analysis skills for people living with HIV

- Sensitive to the individual's readiness or capacity to receive that information

Examples of current activities undertaken that are relevant to the strategic priority 'timely and appropriate provision of information'

- Longstanding, reliable printed HIV news resources with a trusted historical 'brand'

- Programs that support and further the skills of community workers delivering information through HIV services

- Websites of community-based organisations and health agencies

- Agencies and services able to assist in knowledge translation and interpretation, such as medical organisations

- Information services provided through community-based organisations, e.g., phone access, webinars

- Reliable and correct information is provided and disseminated through social media and online networks

Strengthening the response: issues, considerations and additional strategies

Identified need or issue	Potential strategy
■ Quality of information needs to be maintained over time	■ Establish and promote best practice principles for organisations to guide the auditing and updating of existing information resources and the development of new resources (i.e. the development of Australian peer information standards)
■ Individuals living with HIV may have a variety of learning styles and needs, while there may be an historical over-reliance on print materials	■ Resource organisations appropriately to develop key information in novel and varied formats (i.e., not just text-based)
■ There is a need to build and support health literacy using a range of approaches	■ Develop programs for people living with HIV to increase health literacy and information capacity; build this goal into existing programs where feasible
■ There are few specific resources available to the general community challenging the assumptions that can lead to HIV-related stigma	■ Consider funding the development of some specific information resources and messaging materials that can be used by health service providers, community organisations and other relevant agencies to tackle HIV-related stigma

OBJECTIVE 2: Provide efficient, effective and appropriate support to people living with HIV to optimise quality of life

Strategic Priority Action 2.1
Respond to the HIV 'generations'

Broadly speaking, the period during which an individual was diagnosed with HIV places that person in a cohort that we can describe as a HIV 'generation'.[15] The generations can be defined by characteristics including the likely life expectancy or mortality at the time of diagnosis, the availability of treatment options (what drugs are available), the prognosis and outlook following any treatment (e.g., effectiveness of therapy, resistance patterns or side effects) as well as social factors and the changing medical and epidemiological patterns of transmission.

Some programs and services may best be targeted towards a specific 'generation' while others are best implemented when the generations are mixed.

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15 See, for example, Newman, CE, Mao, L, Canavan, PG, Saltman, DC, Kidd, MR, Kippax, SC (2010) HIV generations? Generational discourse in interviews with Australian general practitioners and their HIV positive gay male patients. Social Science & Medicine, 70(11): 1721-1727. doi:10.1016/j.socscimed.2010.02.006

1. Pre-HAART generation (before 1996)

This generation can be typified as 'older and ageing'. Gay men are the largest population within this demographic. Many individuals were diagnosed with HIV at a time when it was expected to substantively reduce life expectancy, and where psychosocial impact such as stigma, fear and isolation were common place and wide spread. Typically, this group is highly treatment-experienced, and likely to have experienced treatment side effects from some treatment regimens over the years since diagnosis. Individuals in this cohort have survived through a period with great changes to health, and expectations of health and treatment outcome.

What we know about people living with HIV diagnosed prior to HAART

- Among this group, strategies for resilience may have been built over time, during which the nature of the challenges of living with HIV have changed substantially. There may be a need to undo unhelpful resilience strategies from the past, and encourage people to respond effectively to new and different challenges. For example, people diagnosed with HIV in the 1990s may have had to consider issues such as personal mortality, but are now dealing with issues such as dating, or the need to re-enter the workforce.

- They may have considerable accumulated grief, loss and trauma, including the loss of personal networks.

- They may have a high burden of disease and significant comorbidity.

- Often strong historical ideas about how services should be received.

- Possible instability of housing, e.g., associated with fluctuating socio-economic circumstances due to periods of ill health, accessing superannuation, or lengthy periods of unemployment.

2. HAART generation (1996–approx. 2008)

This group was diagnosed with HIV at a time when there was a diminishing sense of immediate mortality but considerable vulnerability to the uncertainty of long-term outcomes, often affecting ability of long-term life planning in employment, relationships, finances, housing, etc. Individuals in this cohort are likely to have experienced side effects to treatments including physical changes due to therapies, with an associated psychosocial impact and stigma, particularly those who started treatments on combination regiments often prescribed in the late 1990s that had significant toxicities, and to which the development of resistance was common. Stigma and discrimination associated with negotiating sex was still an issue similar to the pre-HAART generation.

What we know about people diagnosed in the early era of HAART

- Their varied experiences can be difficult to generalise.

- They have often experienced high levels of discrimination and stigma.

- There is a broad range of life circumstances impacted by HIV.

- They may have been markedly affected by the AIDS-related deaths of peers or mentors.

- They are likely to be coming into contact with an aged care sector naïve and unprepared for the issues.

3. Post HAART, pre-PrEP (2008–2014)

Individuals diagnosed in this generation typically have increased confidence in treatments and an expectation of a life-span near normal. Treatments have reduced side effects and improved tolerability, reduced pill burden, with less chance of resistance. Some in this group still report negative effects of HIV-related stigma and discrimination, including elements of self-stigma and blame/shame for having contracted HIV, as well as stigma associated with negotiating sexual relationships.

Some of the most important things to realise about this population when it comes to HIV stigma and building resilience building:

- They often have a strong health literacy to draw upon.

- Still have fears of expectations of wellness in to the future.

- This is a group often very willing to stand up and fight for their rights.

- They often report feeling judged by older people living with HIV.

- They are frequently tech-savvy and very able to create virtual networks of support.

4. People diagnosed in the era of PrEP and TaSP

Individuals diagnosed on this period are more confident of a normal life span, and of not developing AIDS. However, service providers in the consultation suggest that some may feel sense of regret or shame regarding a diagnosis in the PrEP era. They have strong levels of confidence in biomedical prevention, particularly given new developments, e.g., U=U.

Of significant concern is the changing epidemiology and this has a differential presentation of health and wellbeing outcomes from what we have seen from a largely gay epidemic. Heterosexual transmissions now account for 1 in 5 diagnoses, but nearly half of heterosexual people diagnosed with HIV are diagnosed late and likely to have acquired HIV four years or more before diagnosis. In indigenous communities, there is a greater proportion of diagnoses due to injecting drug use, which presents unique and specific challenges for people living with HIV and their resilience and psychosocial wellbeing.

Issues for people living with HIV diagnosed in the era of PrEP and TaSP

■ Who to trust, and how to maintain sexual and social relationships

■ How to maintain control of their own HIV disclosure

■ Dealing with negative judgments about receiving a HIV diagnosis

■ Late diagnosis may be a specific issues for some individuals

■ Knowing they have a future role in lessening the burden and transmission of HIV

Aspirational qualities of services, programs or interventions

■ Takes a strength-based approach: identifies and builds on individual strengths rather than beginning with negatives and deficits

■ Accessible: they don't make assumptions that all people living with HIV have the same experience

■ Triaging aspect: people living with HIV are referred to appropriate services from that starting point

■ Promote a social and supportive structure

■ Flexible and mobile

■ Encourages the sharing of experiences between different generations of people living with HIV

Examples of current activities undertaken that are relevant to the strategic priority 'respond to the HIV generations'

■ Outreach programs

■ Community social support events or centres

■ Regular social gatherings at pubs

■ Family camps

■ Positive Speakers' Bureaus

■ Initiatives to build skills and future positive leaders

■ Housing and employment support interventions

■ Interventions relating to supporting HIV and ageing

■ Social support and networks for young newly diagnosed gay men

■ Peer navigator projects

Strengthening the response: issues, considerations and additional strategies

Identified need or issue	Potential strategy
■ There is a need for the benefits of new developments in treatment and prevention to be shared equitably among the different HIV generations	■ Develop tools to give all people living with HIV the capacity to explain and utilise the U=U message in their personal and intimate social interactions: e.g., work, family, and sexual negotiation
■ There is a need to recognise the specific health and wellbeing needs of longer-term people living with HIV, in particular, those for whom obtaining a consistently undetectable viral load may be difficult	■ Develop a national strategic framework to highlight and respond to the needs of people living with HIV as they age ■ Provide information/resources recognising and supportive of people unable to maintain a consistently undetectable viral load as a response to treatment as part of the U = U message
■ There is a need to recognise how broader social contexts and practical challenges affect health and wellbeing outcomes, and that people living with HIV may be differentially affected by these	■ Partner within jurisdictions to strengthen responsiveness to housing vulnerability, financial stress, and unemployment or underemployment

Strategic Priority Action 2.2
Support quality peer-led responses

It is widely acknowledged that not only are peer-based and peer-led responses in the HIV response effective, they have the effect of building personal skills and positively impacting on notions of social responsibility and participation — both of which enable and encourage a capacity for resilience.

However, there are inherent limitations and challenges to peer-based responses, and it is important to understand what is feasible and reasonable to assume that peer programs are able to achieve.

At the heart of any peer-based response is ensuring that peer educators and personnel in programs and activities are enabled with knowledge, skills and attitudes to allow them to provide information effectively to those participating in programs and supports.

Responding effectively in this context mean strengthening the quality and consistency of peer-led approaches.

Aspirational qualities of services, programs or interventions

- Centralises and recognises the 'peerness' of the peer response: although you may be professional, you are still a peer
- Based on feedback loops: the individual peer educator learns over time with regular input, and constructive criticism and opportunities for debriefing
- Peers are equipped with the skills to be an active listener

Examples of current activities undertaken supporting quality, peer-led responses

- Positive Speakers' Bureaus
- Peer volunteer training and mentoring
- Peer navigation

Strengthening the response: issues, considerations and additional strategies

Identified need or issue	Potential strategy
■ There is a need to develop a strong, confident and visible network of peer educators able to effectively represent the experience of living with HIV in the media and other community forums, as an essential part of reducing the impacts of stigma	■ Develop and support a network of visible HIV positive leaders, and utilise their skills
■ Need for effective, consistent and accountable outcomes	■ To achieve effective and consistent outcomes, organisations need to treat volunteer peer educators and support workers as on par with those in paid employment. For example, peer workers should: 　■ be entitled to time off 　■ be provided with regular training and upskilling opportunities 　■ have access to all organisational support available to paid staff (e.g., grievance procedures, psychosocial support, debriefing opportunities) 　■ be equipped and encouraged to reflect on their practice 　■ be appointed by a transparent selection process, which takes account of their qualifications, experience and suitability to roles, and 　■ be valued for their insights. ■ There are a range of tools and guidelines that can provide general insight into evidence-based best practice in peer-led health interventions.

Strategic Priority Action 2.3
Promote equity and accessibility

There is evidence that particular groups are at increased risk of missing out on the benefits of advances in HIV treatment and prevention. This puts them at increased risk of:

- later diagnosis with a lower CD4 count,

- lower rates of uptake of antiviral therapy, and/or

- a greater risk of the impact of stigma and discrimination.

More detailed information relating to this can be found in our discussion of women and heterosexual men in the Introduction to the Framework, and in Strategic Objective 3.

The reasons behind inequitable access are many but the following are some with broad application:

- being diagnosed in a health care setting or by a health care practitioner that may be unfamiliar with HIV, the needs of people living with HIV, and the social and support services needed and available following diagnosis

- an outdated understanding of HIV, its transmission and its treatment in the general community, and in specific cultural communities isolated from information about HIV, or who may have particular religious or cultural attitudes to people living with HIV

- barriers to disclosure such as fear of discrimination or domestic violence.

Aspirational qualities of services, programs or interventions

■ Open, accessible and welcoming

■ Non-judgmental

■ Respectful of diversity

■ When a person leaves, the service is accountable, and there is follow-through

■ Respects anonymity and privacy

■ Establish expectations of conduct, which are communicated and shared

Examples of current activities undertaken supporting the straetegic aim 'promote equity and accessibility'

■ Group and individual skills-building programs

■ Anonymous service provision models: e.g., online or phone counselling that don't require disclosure of identity

■ Faith-based programs

■ Programs and activities supporting people who engage in specific practices, such as injecting drug use, or who identify with particular communities of sexual practice, such as sexually adventurous men

Strengthening the response: issues, considerations and additional strategies

Identified need or issue	Potential strategy
■ Inconsistent application of evidence-based best practice guidance for tackling stigma and discrimination and building resilience	■ An integrated, whole-of-government plan and approach for addressing HIV-related stigma ■ Ensure that currently available guidelines on best practice in testing, treatment, care and support are being consistently applied in practice within state and national health services
■ Inconsistent information or a lack of information for health and service providers working with people with HIV from vulnerable communities may increase risk of stigma	■ Equip and fund a suitable organisation to be an information hub for health and community service workers in specific communities ■ Develop resources to support communities with a very low HIV literacy level that are both easily accessible and function as baseline knowledge
■ There is a need to improve the quality of data collection and for access to disaggregated data sets to understand impacts of HIV on particular populations completed by continuous collation and drawing upon insights	■ Continue to support activities aimed at improving data completeness and collection in the primary care setting
■ Implement policies of the likelihood of capturing a HIV infection yet undiagnosed through sexual health screenings and other appropriate contact s within the health system	■ Commit to regular 'gap analysis' using available surveillance and other relevant data sets

Strategic Priority Action 2.4
Strengthen mechanisms and systems for sharing information across service provision boundaries

To tackle the experience of stigma and build resilience among people living with HIV, it must be recognised how health systems can be a barrier to effective information sharing.

If there is no collection of high quality data and evidence about stigma and its impacts on the quality of life of different people living with HIV, and no sharing of this information between service providers, then we reduce opportunities for effective collaboration and planning and to set realistic priorities for action.

Currently, health data collection is not consistent across jurisdictions and is often incomplete. These systemic issues affect our ability to identify vulnerable populations, and emerging vulnerabilities.

There is no regular or consistent effort to collect data on the experience of people living with HIV in terms of the experience of stigma and discrimination or changes in quality of life at key points of engagement with services. Thus, service providers and policy-makers often make assumptions or rely on anecdote or outdated or unsuitable information.

The opportunity for the application of a shared set of stigma and quality of life indicators across services providers will enable data sets (regardless of the service type or jurisdiction) to be comparable, and more reliable.

There is a need to establish policies, procedures and mechanisms for de-identifying personal and sensitive health data related to the experience of stigma so providers can be confident privacy and integrity of data is maintained when sharing this information.

Aspirational qualities of services, programs or interventions

■ There is clarity around and understanding of shared and separate roles and agendas

■ Develops and maintains networks

■ Inspires trust and a willingness to share

■ Uses shared terminology or lexicon

■ All those involved understand privacy laws

■ Seeks informed consent from those whose information may be shared

Examples of current activities undertaken supporting the strategic aim 'strengthens mechanisms and systems for sharing information across service provision boundaries'

■ Professional networks that share components of service provision experience or data (de-identified as appropriate) with other providers to share insights, e.g., case breakfasts, case stories discussed at counselling networks or meetings

■ Research into indicators for HIV stigma and quality of life measures

■ Conferences, and inter-agency meetings and round tables

■ Informal information sharing between sector workers and organisations

■ Funded and informal strategies to support/improve health data completeness and consistency

Strengthening the response: issues, considerations and additional strategies

Identified need or issue	Potential strategy
■ We do not have a complete picture of the experience of stigma and discrimination as a baseline for information about where to target efforts and how to monitor outcomes in tackling it	■ Prioritise the application of agreed national HIV stigma and quality of life indicators ■ Encourage and support agencies and service providers to actively collect data about the experience of stigma and discrimination ■ Consider establishing a national mechanism to allow people to report experiences of stigma or discrimination to a peer organisation

Identified need or issue	Potential strategy
■ Sensitive and personal health information needs to be collected and transmitted between agencies in accordance with privacy legislation and community expectation, including the expectations of people living with HIV	■ Identify and address technical barriers to the transmission of personal and sensitive health information between agencies ■ Adopt an intersectional approach to improving data collection and completeness that involves organisations representing and working with communities where health privacy may be a specific concern and a barrier to disclosure and to accessing services: e.g., Aboriginal Community Controlled Health Organisations, mental health services, injecting drug use services, and services providing health care and support for refugees and asylum seekers
■ Agencies don't routinely report on tackling stigma or building resilience as an outcome of activities	■ Consider opportunities for regular updates or agency roundtables to monitor HIV-related stigma and the effectiveness of efforts in tackling this. This need not be face to face meetings but could entail activities such as webinars. ■ Make a review of efforts to tackle stigma and discrimination part of the standing strategic plan of all agencies in the HIV sector, and evaluate and report against this goal at all AGMs ■ Improve mechanisms for the sharing and adoption of programs that work in relation to building resilience

OBJECTIVE 3: Develop resilience responses for specific vulnerable and marginalised populations

The previous two objectives contained general recommended actions and approaches to be initiated, maintained and/or expanded of support resilience for all people living with HIV.

Building resilience and addressing HIV-related stigma for people living with HIV from marginalised and vulnerable populations needs to be supported by efforts to address systemic issues and social determinants of health.

We engaged in some one-on-one discussions with people living with HIV from four specific groups. We sought to better understand the personal impact, to hear directly from people about strategies or interventions that had helped them build resilience, and to gain insight into the both the aspirational qualities of resilience-building interventions and approaches that could be prioritised to address identified gaps.

We heard consistently that building personal resilience is far more than just a matter of supporting individual psychological capacity. People identified clear practical barriers to resilience and flourishing that call for a focused effort to ensure that all people living with HIV are benefiting equally from advances including effective treatment and biomedical prevention and have access to social supports — including peer networks.

Partnership-based approaches

For important reasons identified in the following sections, it is especially important for strategies to support resilience to be grounded in and build on partnerships with the community-based organisations, health service organisations, and policy organisations working with and for these four identified populations.

Inter-relatedness of populations

Any one individual living with HIV may be part of one or more of these identified populations. This is reflected in the personal stories and experiences described. A holistic view, as well as a population-specific and targeted approach, is required to address these issues and build resilience for potentially marginalised or vulnerable people living with HIV in a coherent, integrated and sustainable way.

Impediments to flourishing among priority populations identified in the consultation

Social isolation
Not knowing other people living with HIV at the time of diagnosis was a common experience of people living with HIV who are a part of each of these populations. There may be few — or no — strong, visible peer role models.

Inconsistent knowledge and practice across health services
Health care workers providing testing, diagnosis, and clinical or psychosocial care in these populations may have a lack of information about HIV or may be inexperienced in managing HIV. Service providers may behave in what is experienced as a judgmental, stigmatising or discriminatory manner. Health service providers may not know where to refer people who are looking for support, and/or support that is culturally suitable and appropriate may not be available or accessible.

Cultural community isolation
HIV may be highly stigmatised, or simply invisible and unknown, within some communities and personal networks. This can be a significant source of shame, blame, discrimination, fear or invisibility. There may be a lack of knowledge, or poor knowledge, about HIV among community leaders, and within social networks.

Lack of access to appropriate services
For people living outside of central metropolitan areas, it is more difficult to access peer support, HIV-specific care, specialist care, and other support. While this is a problem generally acknowledged right across the health sector and affects people with a wide range of health conditions, it is a significant impediment to flourishing, especially for many rural and regional people living with HIV. Issues identified include time required to reach services, capabilities and capacities of services, cost, coordination and sharing of

information between services, and that services may be of a generalist nature, with less HIV-specific knowledge.

Access to treatment
Within each of these populations, there are some specific practical factors that may complicate access to HIV treatment. For example, section 100 prescribing capacity is far from universal among regional and rural health services, including Aboriginal medical and health services. Asylum seekers or refugees or those without Medicare cards may be unable to access treatments due to the cost or unwilling to access programs through fear that disclosure may compromise the outcomes of immigration assessments. Immediate practical concerns like homelessness or housing insecurity may make taking or prioritising treatment difficult. For people who inject drugs, there may be legal and social barriers to accessing treatment.

Family life
HIV may have specific impacts due to the demands of family life. Women with HIV in these populations identify circumstances in which they may place the needs or priorities of their children or domestic partners above their own personal health needs. Services may not be flexible in when or how they provide opportunities for peer engagement, which may limit the possibilities for parents, particularly parents who work.

Employment, financial and housing instability
People with HIV with whom we engaged through this part of the consultation noted frequently that building personal resilience was 'not a priority' for people experiencing financial, housing or employment instability: "You're just getting by," as one participant commented. Another participant said: "You don't 'live' on a pension, you barely survive." Organisations could consider looking further at how relevant overseas countries manage this issue.

A general lack of knowledge about what it is like to live with HIV among the general population
It was universally noted in discussions that there is often a low general knowledge about what it is like to live with HIV among the wider Australian community. An enormous opportunity to target stigma based on outdated knowledge, myths and fear is being missed. In Australia, there has not been a coordinated national effort to educate the general community about the experiences of people living with HIV since the mid 1990s. The negative aspects of the cultural legacy of the 1980s Grim Reaper advertisements lingers, however, education responses have been targeted to specific populations, such as gay men.

Addressing stigma

Participants in this consultation repeatedly referred to the fact that readily-addressed fears and myths about HIV were a barrier to testing, diagnosis and treatment, and personal flourishing. It was identified that the Australian community may have very outdated knowledge, or poor knowledge, about: improvements in treatment, prognosis after diagnosis, and the fact that an undetectable viral load means HIV cannot be transmitted. There are few role models for people living with HIV visible in the general community and relatively little attention has been paid by the mainstream media to important breakthroughs for people living with HIV about treatment and how it improves health, and biomedical prevention options.

It was repeatedly suggested by those we consulted with in developing this part of the Framework that a breakthrough in addressing stigma and discrimination and paving the way for personal flourishing would be a visible, national campaign focused on conveying what HIV is like now and highlighting the lived experiences of a broad range of people living with HIV. This could make use of social media, to increase its reach and diversity.

Importance of culturally-specific peer support

It was stressed that to be effective, any such visible campaign needs to be backed up by opportunities for culturally specific peer support to which people can be referred.

Strategic Priority Area 3.1
Aboriginal and Torres Strait Islander populations

Epidemiology[16]

In 2016, there were estimated to be 574 Aboriginal and Torres Strait Islander Australians living with HIV. Of these, 111 people living with HIV are estimated to be undiagnosed (a rate of 20%, compared to 7% for the Australian-born non-indigenous population).

In 2016, there were 46 new HIV diagnoses among Aboriginal and Torres Strait Islander people. The age-standardised rate of HIV notifications among Aboriginal and Torres Strait Islanders has increased since 2012, while declining in the Australian-born non-indigenous population.

Compared to the Australian-born non-indigenous population, Aboriginal and Torres Strait Islander people living with HIV are more likely to be heterosexual, more likely to be women, and more likely to have a history of injecting drugs. Over the years 2012–2016, a higher proportion of HIV notifications in the Aboriginal and Torres Strait Islander population were attributed to heterosexual sex (20%) and injecting drug use (14%) than in the Australian-born nonIndigenous population (15% and 3%, respectively).

Of particular relevance to stigma and discrimination, and to its potential to lead to inequitable health outcomes, one quarter of the new HIV diagnoses for Aboriginal and Torres Strait Islander people in 2016 were people diagnosed late, with a CD4 count of less than 350, suggesting HIV had been acquired at least four years prior to testing.

Less access to, and a lower uptake of, biomedical prevention strategies may be a relevant factor in HIV rates among Aboriginal and Torres Strait Islander people.

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16 Kirby Institute. Bloodborne viral and sexually transmissible infections in Aboriginal and Torres Strait Islander people: annual surveillance report 2017. Sydney: Kirby Institute, UNSW Sydney; 2017.

Issues identified in the consultation

We spoke to an indigenous gay man who did not wish his name to be used (here called Joe), and to Michelle, and indigenous woman, as part of this consultation.

Michelle's story

Michelle is a mother and grandmother. Michelle was diagnosed with HIV in 1990. At the time, she knew no other indigenous women with HIV, and points out that twenty-eight years on, there is still great need for indigenous HIV positive peer role models — a fact Michelle says demonstrates the continued deep stigmatisation of HIV in communities. As a result of her own HIV diagnosis, she lost supportive contact with important members of her family. This personal stigmatisation affected Michelle's resilience.

Periods of being unwell, the day-to-day impacts of HIV on family and personal relationships, the loss of her partner, and the responsibilities of being a young mother all affected Michelle's capacity to turn her attention to her own personal wellbeing and support resilience through the first decade of her diagnosis.

Michelle highlights that for many women living with HIV, the challenge of developing personal resilience is often inseparable from the challenge of supporting and strengthening families to be able to cope with HIV. The pressures of motherhood for women living with HIV, with few reliable social supports and often, considerable financial and life insecurity, mean that women prioritise the health and wellbeing of their families, and may not have the time to concentrate on their own needs.

Michelle points out that there is a chronic lack of support for women living with HIV dealing with the challenges of motherhood. There are few or no options in regional or rural areas. A network of volunteer carers available to support women and children no longer exists, in part due to the legislative requirements around child safety and working with children having been a barrier to volunteer participation.

After living with HIV for around 10 years, Michelle took the step of becoming involved with a community-based organisation, and has since become an involved role model for indigenous women living with HIV.

Michelle says the lack of visible voices and role models made her more determined in her activism on behalf of indigenous women living with HIV.

"There's so much stigma attached to a diagnosis in communities," she says.

This is still a major reason that women do not openly discuss having HIV. Michelle also has experience of Aboriginal health services being unwilling to openly talk about and

acknowledge HIV, and its risks and impacts on indigenous communities—at a time when as Michelle points out, the epidemiology in Aboriginal communities shows it is more important than ever to be talking about HIV.

Patterns of drug and alcohol use within communities are something that Michelle points out can increase the HIV risk and personal vulnerability of indigenous women. She believes addressing this requires a continued effort to provide young women in communities with the support and role models they need to develop healthy self-esteem and self-regard, and enjoy healthy personal and sexual relationships.

Michelle's perspective on what is needed to support resilience

- Support enabling opportunities for women indigenous peer leaders and other leaders among indigenous people living with from around the country HIV to regularly communicate, network, share ideas and meet, and build their capacity and confidence as educators

- A visible campaign using a variety of role models, including indigenous women, to promote a message about what it is like to live with HIV now and address fear about testing and treatment — many resources and messages are out of date

- Working with Aboriginal and Torres Strait Islander health and medical services to improve knowledge of, and understanding about, HIV and its transmission/ prevention, and referral opportunities that include indigenous peer support

- **For young women:** Utilising opportunities such as HIV Speakers Bureaus to encourage young women, and in particular, young indigenous women, to value themselves and gain confidence to negotiate their sexuality safely

- **For older women:** Information and support for women in their 40s coming out of relationships to negotiate sex safely and confidently through online dating, including HIV discussion/disclosure with potential partners

- **For women living longer-term with HIV:** Research into the effects of ageing on women with HIV, to support their health and esteem. Updating resources for women about managing issues such as menopause or long-term health impacts of HIV and its treatment, which can affect resilience

- **Sex and sexuality:** There is an urgent need to understand how PrEP fits into the lives of women, and to give women confidence to consider PrEP as an option in their intimate relationships

- Build opportunities and improve skills for peer educators

- Include opportunities for direct outreach to health services, rather than rely on technology

An indigenous gay man's perspective

Joe (who chose not to use his real name), a gay man, grew up in a regional community in a family with strong cultural connections to country. He was diagnosed with HIV five years ago. Since then, Joe has also experienced another major health concern, requiring significant medical intervention.

Joe has periodically been a methamphetamine user. His complex health concerns have been further complicated by financial insecurity — he has been unable to commit to working full-time — and consequent housing instability that has necessitated him frequently moving between rural and metropolitan locations, living at times with relatives, friends and acquaintances. This has made it difficult to reliably access long-term support and health care in a coordinated and continuous way.

Though individual episodes of care and engagement were often good, it has been almost impossible to maintain continuity.

Joe notes that one source of wariness for some indigenous people when accessing services is that they may be questioned about their indigenous status or eligibility based on assumptions about their appearance.

Joe's experience of accessing online support communities and face-to-face peer programs was not always good. He felt negatively judged by peers online. Some insensitive and personally intrusive behaviours made him wary of face-to-face peer programs. Joe suggests guidelines and clearly described expectations about behaviours may ensure peer leaders and participants in social networks and other peer contexts are sensitive to Aboriginal and Torres Strait Islander members, and to members with multiple health needs and the reasons they may be accessing support. It may be that where such guidelines exist, programs and services may want to draw attention to them and keep them in mind for all participants.

Joe's perspective on what is needed to support resilience

- Opportunities to upskill in a safe environment to support the goal of reintegration into the workforce

- Peer navigation and peer support flexible enough to support people who may use multiple services across more than one jurisdiction to coordinate care

- Improved training in rural and regional health services so that workers understand the issues facing people with HIV and improve their knowledge of referral opportunities

- Online and face-to-face peer communities need to be sensitive to cultural difference between people living with HIV, and understanding of the different health needs faced by individuals

Aspirational qualities of services, programs or interventions

■ Respects anonymity and privacy, and fosters an environment where it is safe to disclose legally and culturally

■ Programs and interventions specifically supporting Aboriginal and Torres Strait Islander people living with HIV are peer-designed, peer-determined and peer-delivered

■ Any information about Aboriginal and Torres Strait Islander identification for people accessing services is sought only when relevant, and is collected in a culturally appropriate and non-judgmental manner

■ Understands that literacy may be a concern: provides information in a variety of forms, including visual forms and personal stories

■ Uses non-stigmatising language

■ Understands the importance of being a safe place to share personal stories that respects trust and privacy. Guidelines and codes of conduct are in place for face-to-face and other services where personal stories might be shared, and people understand and accept those codes. Discriminatory language or behaviour is not tolerated.

■ Does not make assumptions about technology being available to deliver support: outreach and face-to-face contact for Aboriginal and Torres Strait Islander people living with HIV is supported and enabled through health services and other opportunities

■ There is an understanding of and connection to other health services that people living with HIV may need to access, e.g., medical; psychosocial; relevant peer-based information about harm reduction for people who inject drugs; housing or family support services

■ Is mindful that women and men have cultural needs to discuss issues in confidence: allows for separate opportunities for peer engagement and sharing for women and for men.

Examples of current activities supporting the strategic aim

■ Aboriginal peer collaboration, advocacy and policy network for Aboriginal and Torres Strait Islander people living with HIV

■ Counselling and psychological support services available through community-based HIV organisations

■ Psychosocial support and counselling available through Aboriginal and Torres Strait Islander health services

■ Aboriginal and Torres Strait Islander peer educators and Positive Speakers

■ Written resources and materials about HIV diagnosis and treatment

Strengthening the response: issues, considerations and additional strategies

Identified need or issue	Potential strategy
■ There is a need for health care workers, service providers and individuals to recognise the diversity of Aboriginal and Torres Strait Islander identity. It is often assumed that discrimination may be based on appearance, but indigenous people also report the experience of being questioned about the legitimacy of their indigenous status	■ HIV community and health service leaders partner with relevant Aboriginal health and cultural services to improve sensitivity in assessing people for services and collecting health information about Aboriginal or Torres Strait islander identity in a culturally competent and appropriate manner
■ Stigma, fear and silence about HIV in communities is a significant barrier to prevention, testing and disclosure	■ Foster and encourage visible peer role models and support opportunities within HIV community organisations for Aboriginal and Torres Strait Islander communities to gain confidence as peer educators ■ Support opportunities for indigenous peer leaders living with HIV to come together to share perspectives, experiences and strategies that can strengthen and deliver authenticity to resources, peer education and policy ■ Encourage schools and other community settings to make use of options such as Aboriginal and Torres Strait Islander people who are part of Positive Speakers' Bureaus

Identified need or issue	Potential strategy
■ Geographical mobility can be a barrier to coordinated care	■ This is a major issue requiring broader health system reform, but HIV organisations can and should continue to work on this and raise this issue in their jurisdictions ■ Addressing barriers to information sharing is an important part of this
■ Addressing the impact of health comorbidities, including mental health diagnoses	■ Workers in health and peer services providing services for Aboriginal and Torres Strait Islander people living with HIV are equipped with knowledge of appropriate services and referral networks for issues such as housing availability, services for people who inject drugs, family support services, and legal support
■ Address the impact of injecting drug use	■ Support opportunities to increase peer contact and outreach
■ Potential for discrimination against Aboriginal and Torres Strait Islander people within social networks and peer services for people living with HIV	■ Include cultural competency training as part of professional training for peer leaders in HIV organisations ■ Develop best-practice guidance and codes of conduct for leaders and moderators of online peer networks for people living with HIV
■ Vulnerability and isolation of women is increased where there is sexual discrimination, or intimate partner or family violence	■ Substantive issue requiring significant broad reform and partnership-building ■ Ensure women living with HIV who are peer workers are equipped and supported to be able to assist women safely where domestic violence is identified, including awareness of appropriate services

Identified need or issue	Potential strategy
■ A lack of visible, indigenous HIV positive role models	■ Consider partnerships to support discussion and facilitate understanding of HIV within family violence services ■ Provide opportunities for Aboriginal and Torres Strait Islander people living with HIV to gain peer education/support skills and share those skills with each other ■ Support opportunities for Aboriginal and Torres Strait Islander people living with HIV to come together regularly to share perspectives, stories and strategies for communicating their experiences

Strategic Priority Action 3.2
People who inject drugs

Epidemiology

In 2016, injecting drug use was the identified HIV risk exposure in the case of 14, or 1%, of new diagnoses. Male-to-male sex plus injecting drug use were identified in a further 51, or 5% of diagnoses, as the exposure risks.

In the five years between 2012 and 2016, a greater proportion of HIV cases among Aboriginal and Torres Strait Islander people were attributed to the identified risk of injecting drug use (14%) than compared to the Australian-born non-indigenous population (3%).

The Australian Needle and Syringe Program (NSP) Survey has been conducted since 1995. HIV prevalence in this survey sample has remained low (2.1%). Hepatitis C prevalence is high, however, at 50%.[17]

There have been significant changes in social patterns of drug use, with the number of people reporting methamphetamine as the drug last injected increasing between 2012 and 2016 from 33% to 46% of those surveyed through the NSP, and a decrease for heroin.

Rates of methamphetamine use are higher amongst gay men than in other parts of the Australian community. Among gay and bisexual men who reported recent methamphetamine use in 2014, HIV positive men were more likely than HIV negative men or men who had not been tested to report any injecting drug use.[18]

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17 Memedovic S, Iversen J, Geddes L, and Maher L. Australian Needle Syringe Program Survey National Data Report 2012-2016: Prevalence of HIV, HCV and injecting and sexual behaviour among NSP attendees. Sydney: Kirby Institute, UNSW Sydney; 2017.

18 Lea, T., Mao, L., Hopwood, M., Prestage, G., Zablotska, I., de Wit, J. & Holt, M. (2016). Methamphetamine use among gay and bisexual men in Australia: Trends in recent and regular use from the Gay Community Periodic Surveys. International Journal of Drug Policy, 29, 66-72. Cited in Mao, L., Adam, P., Treloar, C., & de Wit, J. (Eds.) (2016). HIV/AIDS, hepatitis and sexually transmissible infections in Australia: annual report of trends in behaviour 2016. Sydney: Centre for Social Research in Health, UNSW Australia. http://doi.org/10.4225/53/57C52B1A5C6F2, p.32.

Injecting identities and behaviours

The relationship between identity as a person who injects drugs, and the behaviour of injecting drugs, is difficult to quantify and not necessarily well-understood. This can make it more difficult to target or reach this group of people living with HIV, and to identify what messages or approaches might resonate with or be needed by any given individual to support wellbeing and build resilience.

Generalised approaches are less likely to be effective.

Many people with HIV may inject, sometimes occasionally and sometimes more regularly, but people may not necessarily identify as a person who injects drugs, or discuss or acknowledge this behaviour outside of specific contexts.

Among gay men, methamphetamine use is a frequent part of social and sexual practices and sexual identity, but regularity or frequency of use and patterns of use (such smoking versus injecting) may not be consistent. Harm reduction information or programs might tend to be biased toward smoking amphetamines.

The issues raised and reported by people living with HIV who reported injecting drugs, or having injected drugs at some point, are inter-connected with the other issues and concerns identified under each of the population headlines.

Themes raised in the consultation

'A double stigma'

The use of injecting drugs was noted by those who were interviewed as a behaviour that can lead to an experience of being 'doubly stigmatised'. We spoke to Kath, who contributed her story to the consultation. Kath is a peer educator who has been living with HIV since 1987 and is now a grandmother.

Kath's experience has that the discrimination and "user-phobia" she has encountered as an injecting drug user is often just as significant as that she has experienced as a woman living with HIV. Moreover, she points out that stigma towards injecting drug use occurs within the HIV community sector and health services.

"User-phobia is huge," commented Kath. "The stigma is far greater around injecting [of drugs]. Socially, it's still a hugely stigmatised behaviour."

Kath comments that it is very commonly assumed that injecting drugs is a purely negative form of behaviour that represents or is due to a personal or social problem or "deficit". People who inject drugs may be stereotyped as 'bad people', as antisocial or

criminal, or as taking drugs to deal with mental health concerns. It is rare, for example, to see representations of people talking about injecting drugs for pleasure or for enjoyment.

Attitudes to injecting among people living with HIV

- People living with HIV who inject drugs comment that the use of injecting drugs is often stigmatised, misunderstood and negatively judged by others with HIV.

- People who inject drugs may also perpetuate negative attitudes amongst each other. For example, people who use heroin may judge, stereotype or stigmatise those who use methamphetamine, or vice versa.

- Among gay men, there may be a stigma attached to injecting methamphetamine, which may be judged as a dysfunctional or extreme behaviour, compared to smoking, which may be considered more socially acceptable.

Attitudes to HIV among people who inject drugs

- Rates of hepatitis C infection are relatively high among people who inject drugs in Australia, whereas HIV rates are far lower. HIV is less visible and so potentially more marginalised within communities or groups of people who inject drugs, while hepatitis C may be better understood and more socially accepted. There are fewer visible HIV positive role models who openly discuss injecting than there are among people living with hepatitis C.

- Because of the many different contexts in which people use drugs, it may be that some harm reduction services or support opportunities are not suited to or accessible to particular individuals or groups of people who inject. For example, men who inject amphetamines as part of sexual cultures may perceive particular services as being directed to, e.g., heroin users, and/or as being culturally irrelevant or unwelcoming. Heterosexual men or women living with HIV who inject drugs may be reluctant to access peer services if they perceive them as being for, or dominated by, gay men.

Community and legal attitudes

- Injecting drugs is highly stigmatised in the community and in the media.

- Legal concerns are one obvious reason why this is a far more 'hidden' population.

- Some HIV positive people who inject drugs may avoid using or contacting services if they obtain income through dealing or sex work, due to fear of being identified and potentially prosecuted.

- E-health may be an issue in accessing services, and there may be some educational work to be done around letting people know their rights, particularly about involvement in or the information included in MyHealthRecord.

Women with children

Most needle and syringe exchange programs report far fewer women among those who use services. According to the 2016 data set from Australia's needle and syringe exchange programs, three in four, or 73% of, all attendees were male. This figure may reflect the strong social stigma relating to women who inject drugs, and who have children. Women may fear being morally judged on their parenting if they are seen using these services, because they are not perceived as health services.

For women who inject drugs and who have children, Kath commented that privacy in use is a "huge concern". She is aware of women who avoid using or accessing services where they may be seen or identified, due to significant anxiety that child welfare agencies may become aware of their drug use, and potentially intervene or even remove their children.

"I have so many women who ask me can I pick up clean injecting materials for them," she noted. "When I do talks [as a peer educator living with HIV], I still talk about the fear — when I first had my kids—that welfare workers might find out I injected."

There are negative stereotypes of people who access needle and syringe exchange programs, and these need to be challenged, and the social and community health benefits emphasised.

They are also a place for peer engagement with potential educators who may have skills they can share with others.

Stigma and the health and life impacts of injecting

Several people we interviewed commented that they had used drugs more frequently in the years following their diagnosis, in part to escape overwhelming emotional stresses. Joe commented that his methamphetamine use had increased following his HIV diagnosis, eventually contributing to a feedback loop of social isolation and discrimination, including from other gay men living with HIV, as well as financial and housing instability, and health and mental health impacts.

Potential mental health impacts of injecting drug use that may be a barrier to accessing services include depression, paranoia (such as that sometimes associated with methamphetamine use), and social isolation.

Not all injecting drug use affects people's daily activities.[19] However, injecting drug use that does significantly impact on daily activities can be a barrier to accessing HIV treatment and supportive services. Cost and physical access to services may be one aspect of that. Another may be that it's difficult to prioritise wellbeing or think about personal resilience if more fundamental problems such as housing instability, financial vulnerability, or intimate partner violence, which may be inter-related with injecting drug use for some people, are not able to be addressed.

Potential for stigma and discrimination within health services

The first report of the National Stigma Indicators Monitoring Project suggests that there is a significant potential for discriminatory behaviour or the stigmatisation of injecting drug use within health services. Some 35% of 353 health care providers who participated in an online survey reported that they believed they may have treated patients or clients differently on the basis of injecting drug use.

One person we interviewed described a health care worker referring casually to 'druggies'. She commented that she would have liked to have challenged this stigmatising language, however, did not want to disclose her injecting drug use in this personal health care context. As a patient in the hospital, she felt vulnerable to discrimination.

Indigenous communities

While injecting drug use is more commonly reported as the risk factor in new HIV diagnoses among Aboriginal and Torres Strait Islander people than in the Australian-born non-indigenous population, it is also a behaviour around which communities are often silent.

There may be specific vulnerabilities for gay indigenous men who also inject drugs and for indigenous women. Some people, for example, inject drugs as part of social networks which may also have a sexual element to them, including sex as a form of payment for drugs.

Transgender and gender-diverse communities and individuals

Sex work is frequently one form of income open to transgender people, who may be discriminated against in and effectively closed out of the employment market. That work may be highly associated with a culture in which drug use is common. A transgender

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19 Hammoud M, Jin F, Degenhardt L, Lea T, Grierson J, Mackie B, Pastorelli M, Batrouney C, Bath N, Bradley J, Prestage G. Flux: Following Lives Undergoing Change, Gay community life, drug use, and taking care of ourselves and each other, Report 2014-15. Monograph, The Kirby Institute, UNSW Australia, Sydney Australia, 2016

woman we engaged with as part of this project noted that sex work for trans women can be dangerous, with risk of predatory behaviours. Sexual assault is not uncommon, but it is rarely reported. Disclosing HIV and/or injecting drug use in this context is even more personally risky.

These factors can increase vulnerability and isolation from peers and services for transgender people living with HIV.

Service models and peer visibility

There are lost opportunities for peer contact and education due to changes in service provision models

Kath says that from her perspective, there have been some significant changes in policy and service provision over the last five years.

She describes these changes as a major lost opportunity to ensure the peer voice is heard and included in the design of services and support programs, and of policy relating to the use of injecting drugs.

In the state in which she works, a number of services and programs for people who inject drugs have been amalgamated or closed. The trend towards a user-pays system for clean injecting equipment, as well the introduction of needles dispensed through vending machines, has had the effect of decreasing the social interaction of people through service access and decreasing access to peer information. Kath sees this as a lost opportunity for peer engagement and harm reduction, with the risk of further isolating people within private spaces or small communities of people with whom they may inject.

She also believes there is a less open culture for issues to be discussed.

"It used to feel safe to publicly stand up and talk about injecting drugs," she commented, but she feels this has significantly changed.

Cultural sensitivity and awareness within HIV services and organisations

It was noted that health services and community-based organisations for people living with HIV may benefit from regular training and support to ensure peer workers are using appropriate language and are sensitive towards the issues, needs and potential health concerns of people living with HIV who inject drugs.

"We do this training for indigenous and CALD communities," commented Kath. "But user-phobia is like the silent cousin."

Aspirational qualities of services, programs or interventions

■ Respects anonymity and privacy, and fosters an environment where it is safe to disclose legally and culturally

■ Opens avenues to connect with and be supported by peers

■ Is sensitive to the difference between identity as a person who injects drugs, and injecting drug use as a behaviour. Understands that there are different patterns to injecting behaviour, and individuals may move between these

■ Understands that literacy may be a concern and provides information in a variety of forms

■ Uses non-stigmatising language

■ Respects different motivations for injecting — that these may be positive and/or negative

■ Does not make assumptions about how people feel about their own injecting, but provides opportunities for people to determine their own strategies for identifying and reducing harm

■ There is an understanding of and connection to appropriate health services — e.g., medical; psychosocial; peer-based information about harm reduction; and services for people who wish to reduce or stop their drug use

■ Is sensitive to and aware of legal issues relating to injecting drug use: does not require disclosure of identity or HIV status, protects and maintains confidentiality, and is mindful of sensitivities such as for women with children, or people whose income may be supported by dealing or sex work

■ Interactive: peers can contribute activities and are encouraged to see and share their own personal experiences as relevant expertise

Examples of current activities relevant to the strategic priority

■ Peer navigator programs

■ Programs for sexually adventurous men who have sex with men

■ Online and web-based information services aimed at gay men and men who have sex with men who use drugs

■ Confidential community health services that provide free health checks for people who use drugs such as stimulants

■ Counselling services

Strengthening the response: issues, considerations and additional strategies

Identified need or issue	Potential strategy
■ A need to improve understanding of social contexts, patterns and cultures of injecting drug use, and diversify representation of injecting experience, the cultures in which it occurs, and behaviour, within services for people living with HIV	■ Community-based organisations or people living with HIV and community-based and organisations for people who inject drugs working in partnership on program design, content and promotion of programs and services accessed by people who inject drugs ■ Opportunities for peer training led by people who inject drugs for workers in health services and community services, including community-based HIV organisations
■ Ensuring women with children are not missing out on peer engagement, health promotion information, and social opportunities due to concerns their disclosure of HIV may also disclose injecting drug use	■ Explore current legislative frameworks relevant to peer distribution of injecting equipment to see if there are further opportunities for peer education specifically targeting women through networks of people who inject ■ Expand training to ensure those collecting health information and sensitive health information and data do so in a way that gives confidence to the health service user that their privacy is protected ■ Expand phone-based anonymous support for women living with HIV, and outreach peer approaches through health services ■ Promote the social and community value and benefits of needle and syringe exchange programs and challenge stereotypes with positive stories ■ Provide family-friendly space or room with age-appropriate equipment for children at peer support activities and ensure spaces have materials which are family-appropriate and welcoming

Identified need or issue	Potential strategy
■ Need to ensure the experience of people who inject drugs and are living with HIV is fed into policy and program decisions	■ Organisations may want to look at the makeup of experience and engagement on board/staff to ensure that the experience of people who inject drugs is reflected and represented ■ Share relevant documents and consult with partner organisations in policy development
■ Services need to be clearly understood as safe places for HIV positive people to disclose/discuss injecting	■ Provide clear information about strategies and policies to protect privacy when people make contact with services ■ Provide clear guidelines for those using peer services to ensure they respect the privacy of other service providers ■ Enhance peer contact in NSP services in areas with higher rates of methamphetamine use, with the expanded use of peer-distributed equipment, and peer delivery of harm reduction and CBT interventions
■ Harm reduction is on a continuum—services need to be sensitive to a variety of experiences, motivations and desired outcomes of peer engagement	■ Review programs/services at jurisdictional level to ensure they meet a range of needs ■ Equip peer workers with a knowledge of existing health programs and services for people who inject drugs, including rehabilitation services or programs, harm reduction information, and programs/strategies to support health and wellbeing

Identified need or issue	Potential strategy
■ There is a significant potential for discriminatory behaviour or the stigmatisation of injecting drug use within health services. 35% of 353 health care providers who participated in an online survey as part of the Stigma Indicators Monitoring Project reported that they believed they may have discriminated against patients or clients on the basis of injecting drug use.	■ Address in partnership with key health practitioner groups ■ Track, monitor and report on progress in this area through the HIV stigma indicators
■ Ensure that health services for Aboriginal and Torres Strait Islander people who inject drugs are sensitive to the specific needs of people living with HIV	■ Strengthen peer education and outreach opportunities for indigenous people living with HIV to share their experience with workers in Aboriginal health services and make that support available to clients e.g. through phone support or counselling as well as direct community contact

Strategic Priority Action 3.3
Mobile and migrant populations; refugees (inclusive of people of culturally and lingustically diverse experience)

Epidemiology

Patterns of HIV among people in Australia among mobile and migrant populations, including refugees, are different to those in the Australian-born population. People living with HIV from these populations are more likely to be:

- heterosexual

- female

- diagnosed with a lower CD4 count — the proportion of people with late diagnoses in 2016 was highest in people born in south-east Asia and sub-Saharan Africa.

Of 209 HIV diagnoses in 2016 that were attributed to heterosexual sex, 17% were in people born in a high-prevalence country (recognised by UNAIDS as having 1% or higher adult national HIV prevalence).

Among men born overseas with male-to-male sex as their risk exposure, the proportion who were born in Asia (Southeast Asia, Northeast Asia, and Southern and Central Asia) has increased over the past 10 years from 30% in 2007 to 58% in 2016.[20]

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20 Kirby Institute. Bloodborne viral and sexually transmissible infections: annual surveillance report 2017. Sydney: Kirby Institute, UNSW Sydney; 2017.

Issues identified during the consultation

Access to services

Stigma, fear, language, and a perception that HIV community organisations are largely or mostly set up to accommodate the needs of gay men living with HIV have all been factors identified as reasons why many people living with HIV who have culturally or linguistically diverse backgrounds, including migrants and refugees, may not access support or services.[21]

Diversity

The diverse experiences and backgrounds of people living with HIV who were not born in Australia or who part of mobile populations means it is not appropriate to generalise or make assumptions about peoples' experiences. Among these populations are:

- people who were born overseas but have settled in Australia

- members of transnational workforces, including sex workers

- international students

- refugees now living in Australia

- asylum seekers

- temporary residents or those awaiting a legal decision about their residency status.

This represents a highly diverse individual lived experience of HIV—something which is often overlooked and made invisible when generalised terms such as 'CALD' are used.

To provide support in the case of any one specific individual, it is important for services and service providers, including peer workers, to make efforts to understand and respond to the individual subjective need of any particular person, and not to apply general assumptions about things such as:

- language spoken or English language skills/literacy

- culture, including assumptions based on a person's stated religious beliefs, or about attitudes to sexuality or gender

- capacity to understand medical and other information

- degree of connection to community in Australia or overseas

- a person's motivations or personal history, including the reasons why a person may be in Australia

- financial circumstance.

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21 Living Positive Victoria Needs Assessment, 2015

Building resilience: issues identified in the consultation

Cultural isolation

While it may not always be the case, there may be a general lack of knowledge about, or experience of, living with HIV within a person's specific community or social network. HIV may simply not be an issue that is openly discussed within some communities, while others may be more open to this.

A person may live, work or socialise in a community where leaders such as teachers, religious/spiritual leaders or health care workers have limited knowledge about, or experience of, issues affecting living with HIV. These leaders may not know where to refer people for further support or services, or what information or actions may be needed to support wellbeing or resilience.

There may be few, or no, visible cultural peers openly living with HIV.

Legal uncertainty

People with HIV from this population may be living with considerable legal uncertainty, such as uncertainty about residential status, refugee status or the recognition of their relationships. That uncertainty may affect peoples' willingness to disclose or openly discuss HIV, for fear it may prejudice outcomes. It also needs to be recognised that the legal process relating to immigration can present an extreme financial burden.

Treatment access

Although there are some programs and services in place to allow people who are not Australian residents to obtain HIV treatment, there remains a significant concern that people from these populations are at greater risk of not accessing treatment. This might include issues such as: not holding an Australian Medicare card, being unable to afford health service co-payment due to not having an income or being unable to work, or being unwilling to disclose HIV to health care workers.

Cultural experience, such as attitudes to treatments, or coming from a country where health outcomes or expectations for people living with HIV are often poorer, may also affect peoples' wellbeing.

Language

Information about HIV may not be available in a person's language. Health care workers may not be able to access interpreters. For example, the population of Western Australia is one of the most diverse in the country, including people from every country in the world, people who speak over 250 languages, and people who identify with over 100 faiths.

Cultural, including religious, background
People may be from a cultural background or faith that has particular attitudes or beliefs which affect that person's willingness or ability to discuss HIV, disclose, or seek support. Attitudes may relate to gender or gender identity (e.g. attitudes to the social status or role of women or men), sexuality, sexual identity or sexual practice (attitudes towards men who have sex with men, or women's sexual expression), or to specific practices (like injecting drugs).

That said, it is also important that assumptions are not made about cultural attitudes: within all faith groups and cultures there is considerable diversity of opinion about and experience with these issues.

Complexity and uniqueness of the Australian health care system
The Australian health care system is not straightforward and may be difficult to negotiate without assistance/support for those not familiar with it.

Laws relating to HIV
The legal context for HIV may be very different from that experienced in other countries, e.g., people may fear legal implications and avoid disclosure of HIV status to sexual partners, at work, or in particular social contexts, such as those relating to parenting, for fear of repercussion, based on experiences in countries which have a highly punitive approach to HIV.

DIFFERING PERSPECTIVES

Melania's story

Melania, with whom we engaged as part of this conversation, is a volunteer peer worker who was previously employed in Zimbabwe as an educator, counsellor, and peer worker supporting women living with HIV, as well as their husbands and partners, families and children. Melania has worked in not-for-profit organisations, and also provided outreach and clinic-based peer support through health clinics. She explains some of the cultural perspectives and differences that she has noticed since being in Australia.

Because gay men are the population most affected by HIV in Australia, and the responses to HIV and services have been informed by and often developed through, that community perspective, Melania believes there may still be a lack of awareness in some services as to how profound the impacts of stigma and discrimination may be on people living with HIV from some other communities and the particular way it may affect women.

For example, Melania says that she does not assume that faith or cultural leaders among the community she presently lives in in Australia know very much about HIV. This situation is quite different from being in Zimbabwe, where necessarily, the church has

had to play a significant support role for many people living with HIV and has in fact been a visible leader in challenging stigma and encouraging people to break their silence. A church-led campaign in Zimbabwe which used the slogan "The church has AIDS. Break the silence" was a crucial turning point for Melania's own disclosure, after nine years of living with HIV, and helped her overcome internalised stigma.

"Naming HIV is powerful," she comments. Until she was able to disclose, she felt "root bound", "couldn't learn", and avoided HIV treatment.

Paradoxically, Melania feels that the cultural isolation of many women living with HIV in Australia from diverse cultural backgrounds has a tendency to hide the experience in a way that it may not be hidden in countries where HIV prevalence is higher among heterosexual populations and women.

She believes HIV should be an "unremarkable fact", as with many health issues such as diabetes. For example, if women living with HIV are not having intimate relationships due to fear, shame or self-stigma, or because dating sites or apps are not safe places to disclose HIV, then "that is not flourishing, that is not thriving".

Melania's family currently lives in Australia, with her son, a professional worker, initially having arrived in 1996 and her daughter in 2007. She makes the point that the current immigration process is often blind to the contribution an individual's family may be making to the Australian community. She feels that historically, families were recognised as adding crucial cultural and economic value to the immigration process. For people living with HIV, in particular, the immigration process concentrates instead on the negative aspect of the potential 'cost' to the country of an individual person's medical care. This is a stigmatising and alienating attitude.

Melania notes that people living with HIV from overseas countries often bring highly relevant skills, experience and personal insights that can strengthen the peer HIV response in Australia, particularly where HIV affects people from mobile, migrant, and refugee communities.

Melania's perspective on what is needed to support resilience

- Develop strong, women-centred referral networks led by women of diverse experience and faith/cultural background
- Work specifically with faith-based leaders to understand and strengthen their knowledge about HIV, and the needs of people living with HIV in their communities
- Support people dealing with the burden of legal uncertainty in the immigration process — "the immigration process is [for people living with HIV] incredibly stigmatising: it's a mountain, a hump that you cannot surmount."

- Improve information about and pathways for people who are not permanent residents to access treatments safely and in a way that protects privacy and addresses fear that HIV treatment may prejudice legal outcomes

- Recognise, support and value disclosure as a powerful way for women and all people living with HIV to free themselves from stigma

- Understand that the perspectives for women living with HIV may be very different, including different understandings of what constitutes flourishing and freedom

- Value inclusion — we need to reach every population

- Recognise that addressing the broader issues of stigma and discrimination to build pathways to resilience is often a matter of persistence: "You've got to 'chip away' at it," she says.

- Valuing people's contributions and possibilities as being more than about being a potential 'cost' to the health system.

Aspirational qualities of services, programs or interventions

- Fosters environments where it is safe to disclose legally and culturally— understands the nature of the many reasons people may not disclose

- Opens avenues to connect with and be supported by peers

- Is grounded in community: improves HIV literacy and knowledge about the health and wellbeing needs of people living with HIV within local communities

- Understands that English language literacy may be a concern and provides information in a variety of forms and languages

- Uses language communities can relate to

- Is sensitive to diversity and plurality of faith and cultural belief

- Does not make assumptions about or judge attitudes to HIV treatment: takes a supportive rather than a judgmental approach to treatment decision-making

- Is well connected and able to refer to supportive health and legal services, e.g., treatment programs for people without Medicare cards, immigration services etc., peer services

- Supports and engages families

- Need for HIV services to be sensitive to issues of cultural and religious diversity

- Need for community services for migrants, refugees and asylum seekers to have a greater understanding of the needs of people living with HIV

- Recognises overseas experience and qualifications as relevant to Australia, to allow people to feel valued by the immigration process, and to have opportunities for financial stability

- Values and draw on overseas cultural community histories and connections, including insights into services, and how these might translate to Australian communities

Examples of current activities relevant to the strategic priority

- A comprehensive national mapping of HIV health promotion activities relevant to culturally and linguistically diverse communities, including those for people living with HIV, has been undertaken by the Australian Federation of AIDS Organisations (AFAO) in 2015.[22] Although the availability of services and programs varies, and not all approaches occur in all jurisdictions among the types of programs identified:

- State-based multicultural HIV and hepatitis information services

- Peer-led support groups for people living with HIV from diverse populations, including heterosexual people living with HIV, culturally-specific groups, and peer programs for men who have sex with men

- Treatment support information, including online support and support developed for people with low literacy

- Immigration legal support: services that link people living with HIV to legal support services and information

- Fact sheets and written information for people living with HIV available in community languages

- Programs working with community cultural leaders, including faith leaders, to address stigma, support testing, and encourage discussion about HIV within local communities

- Capacity-building programs to equip peers to lead on discussions about HIV within communities

- HIV community-based organisation counselling services with specific support available

- Programs supporting sex workers from diverse cultural backgrounds which are inclusive sex workers who are living with HIV

22 AFAO

Strategic Priority Action 3.4
Trans and gender-diverse populations

Trans and gender-diverse identities

Trans and gender-diverse is a term to describe people who identify that their gender is different from that which was designated or assigned at birth. People express that identification of difference in individual and personal ways. That may, or may not, involve medical steps such as hormones or surgery. It may also be expressed socially, through things like clothing, appearance or name. Some people have a strong identity as a trans man or a trans woman, while others identify as male or as female. Some people prefer not to define or state their gender in a fixed way, or as 'non-binary'.

Intersex refers to people born with variations in sex characteristics — e.g., in genitals, hormones or chromosomes, or secondary characteristics — which can mean they do not fit typical definitions of 'male' or 'female' bodies. People who are intersex may also consider themselves aligned to or a part of the trans, gender-diverse or non-binary community — although personal experiences, needs and issues for transgender and intersex people can be very different.

HIV and trans and gender-diverse people

Given the plurality of experience and sexual identity and practice among trans or gender diverse individuals, it is neither useful nor accurate to make blanket or generalised claims about HIV risk. In addition, surveillance data and health service use data almost certainly does not provide a clear picture of present or historical prevalence, because information about gender identity has historically not been sought in a way that reflects gender diversity, and transgender people may be invisible to data, subsumed within other surveillance categories such as gay men/men who have sex with men or heterosexual women, without acknowledgement that these categories may include, for example, transgender men who have sex with men, transgender women who have sex with men, or intersex people.

The World Health Organisation suggests that globally, transgender women—particularly those who have sex with men, and transgender women sex workers—bear a significant burden of HIV. One systematic review which looked at transgender women in 15 countries indicated a HIV prevalence of 19% among trans women, compared to 13% among men who have sex with men. There is a lack of reliable data about HIV among transgender men who have sex with men.

Transgender people also remain under-served in the global HIV response, with WHO reporting that only 39% of countries reporting in the National Commitment and Policy Instrument had HIV strategies that specifically address transgender people.[23]

Specific vulnerabilities for transgender women in relation to HIV may include the impacts of cultural or sexual violence, housing and financial vulnerability, sex work, the use of injecting drugs, and social and legal marginalisation and discrimination.

For transgender men, while data is more sparse, specific vulnerabilities or risks might include having sex with men, sex work, the use of injecting drugs, or social or legal marginalisation and discrimination.

Natasha's story

Natasha has been living with HIV since 2008, when she was diagnosed while living overseas. In Natasha's words, "I'm pos, and I'm trans and I have had to make that work for me" — but to have achieved the resilience to make that statement has been far from easy or straightforward.

At the time of her diagnosis, Natasha was not yet open about her gender identity. Diagnosed with a very low CD4 count, Natasha faced health difficulties including serious AIDS-defining illness.

Discrimination against transgender people in employment is very common. Transphobic attitudes shut Natasha out of further employment opportunities in her profession as a teacher. As a result, she experienced a period of uncertainty, transience, serious financial uncertainty and sexual assault, including living homeless in a freezing Melbourne winter. This is a common scenario for transgender women.

Many transgender women at times earn income through sex work. Natasha points out that cultural violence, sexism and misogyny—including misogynistic and transphobic portrayals in pornography and the media—is often expressed in an extreme fashion against transgender women generally, and those who are sex workers are particularly vulnerable to this. Sexual violence, including the sexual assault of transgender women in sex work, is common. Discussion or disclosure of HIV status is both legally and culturally very risky for transgender women who are sex workers, and this is a major disincentive to report violence or assault, and to talking openly about HIV.

"Men don't always realise how trans women are affected by their actions," Natasha comments, adding that many transgender women also experience demeaning and sexist

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23 World Health Organisation 2015. Policy Brief: Transgender people and HIV

attitudes and assumptions, including transphobia, some from men in the gay community.

For Natasha, life began to improve when she was able to secure stable housing, following a determined effort and an 18 month process involving persistence with several housing support agencies.

Natasha says it is frustrating that while for many people living with HIV, life is improving due to great improvements in treatments, care and prevention opportunities like PrEP, transgender women are among those most at risk of missing out on those advantages, because they may not be accessing and using health services.

Natasha emphasises that the under-representation of transgender experience and gender diversity in HIV data is an important problem. This, in turn, raises an important issue about data collection: whether the terminology used to describe gender at the point of diagnosis, or in health care or service use reflects peoples' identities, and whether people feel safe to discuss or disclose gender identity with health care and support service providers.

Natasha's views on what will help build resilience

For Natasha, the first key and step to building resilience for transgender women living with HIV is for organisations to develop strategies for peer-specific support.

Transgender women need to be put in contact with each other: "If you're trans and pos, you want something peer centred, but that doesn't exist. You really need to have that rapport and connectivity, where you're talking to someone who identifies the same way you do."

That peer centrality needs to recognise that transgender identity and experience is itself diverse.

For Natasha, being put in touch with another transgender woman living with HIV was an important turning point. This was informal contact facilitated through individual networks—but Natasha says more formal peer support structures need to be available through community-based HIV organisations and health services so that when transgender people living with HIV access services, and workers in those services know how to ensure people can access them.

"You have dots, you have islands, of trans people," she says. "The isolation is extreme. Throw HIV into the mix, and that's a whole new ball game."

While workers in community-based organisations provide excellent services, Natasha believes that the visibility of transgender experience is something that needs to be improved, not just through peer education and support opportunities, but through the

representation of transgender lives and voices among people living with HIV.

She believes this first step is necessary to encourage transgender women to be active and involved in health promotion messages and materials.

Jason's story

Jason was diagnosed with HIV in 2000, under complex and confronting personal and legal circumstances. Jason, who is intersex, now lives as male. At the time Jason learned he was HIV positive, he was just in the process of negotiating his own personal gender identity journey, and was faced with a complex range of legal and medical services that additionally had to be negotiated, including HIV clinical services, sexual assault support, and police and legal services.

Making contact with a supportive community-based service for young gay, lesbian and gender-diverse people in the city in which Jason then lived was a turning point. This contact allowed Jason to start to come to terms with his circumstances.

Jason highlights the fact that across Australia, there is diversity in not just the availability of, but also the style of delivery of, HIV clinical and support services. In the city Jason was living in at the time of diagnosis, HIV clinical services are very hospital-based, whereas in some other cities, clinical services are more devolved throughout the community and GPs.

Jason expresses great gratitude for the youth service that initially helped him find his feet after the trauma associated with his HIV diagnosis. From that service, he was referred to a psychosocial support service experienced in gender-related issues, but it was only after packing up and moving to another city that Jason found his feet, and began to develop peer network of people living with HIV to which he could form a connection. In a community-based HIV service in his new city, he made immediate contact with a peer worker who would go on to be a friend, mentor and source of ongoing support.

"I was not sure of where I was; I was scared and alone," he says of his first experience of attending the centre. But after the experience of meeting a confident peer worker, who was very aware of the services and options available, "I could breathe". They had common interests in music: "He focused on the fact that I was human", and not the fact of Jason's HIV status or gender. For Jason, this is an important aspect of peer-based support: seeing and interacting with others beyond the labels they may have for themselves.

"A lot of young people, when they become HIV positive, gain that label, and forget there is more to it . . . [this worker] identified that I was focusing on the label."

Jason has since himself become a peer worker.

Jason has been affected by a degree of disability that can often be associated with being intersex — given this, as well as the circumstances of his HIV diagnosis, it took "a long time for me to be resilient".

Jason is involved with community-based organisations in the trans and gender-diverse communities, and there has encountered many people who provide "a great sounding board".

However, he does not believe that there are any services that are truly for, or fully represent the particular needs, of intersex people, and identifies this a gap.

Jason believes that an assumption that HIV is now "over", and an associated a lack of clarity between service providers as to their roles and identities, has led to the erosion of HIV peer services.

Jason believes that many people with HIV do from time to time need, and seek, more intensive peer-based support: they may not always need 'hand-holding', but may want to dip in or out. While his doctors effectively support his mental wellbeing and health, Jason comments that there are times when he would benefit from re-engaging with a more extensive peer support network.

"Good mental health leads to good resilience."

Jason's perspective on what may help support resilience

- Good mental health is the first step to good resilience

- Among trans men, there may be a lack of engagement with HIV, beyond the use of PrEP—trans men need to be encouraged to talk to each other about HIV

- Within HIV organisations, while there is overall a good and growing understanding of issues affecting trans and gender diverse men, there are still opportunities to improve that understanding. Conversely, organisations supporting transgender and gender diverse people need to ensure they are making HIV visible and connecting is as an issue to their communities.

- Jason has some involvement with some longstanding community-based social organisations for gay men. He is concerned these organisations have begun to lose a once-strong connection to community-based HIV organisations and services.

- As a parent of children who are now adult, Jason notes that there remains a need to improve support for and to accommodate the needs of people living with HIV who have children.

Aspirational qualities of services, programs or interventions

■ Opens avenues to be connected to and supported by peers. Programs and interventions or services are designed and led by transgender or gender diverse peers.

■ Recognises and is sensitive to and respectful of the plurality and individuality of experience, sexual practice and gender identification among people living with HIV who identify as trans or gender diverse—does not make assumptions and judgments

■ Is linked to and connected with appropriate peer support pathways in community organisations for transgender and gender diverse communities

■ Information about current gender identity for service users is sought only if relevant to the service, and is collected in a sensitive manner that respects privacy

■ There are opportunities for one on one peer support for transgender or gender diverse people connecting with services

■ Is connected to and able to refer people to other relevant services to support physical and mental health and wellbeing needs, such as housing services, peer support organisations for sex workers, or psychological support services

■ There is appropriate support and training for peer leaders, both for volunteers and paid workers

■ There is clear guidance and codes for participants in peer programs, including online and face-to-face programs, to ensure that participants who identify as trans or gender diverse are respected and feel safe

■ There are opportunities for people to make contact and seek support anonymously, e.g. by phone, email or online. Confidentiality is respected.

Examples of current activities relevant to the strategic priority

■ Peer-led health promotion programs for trans and gender diverse people

■ Counselling services available through community-based HIV service organsations that have capacity to support people who are trans or gender diverse

■ Information and support available for community-based organisations representing or advocating on behalf of people who are trans, intersex or gender diverse

Strengthening the response: issues, considerations and additional strategies

Identified need or issue	Potential strategy
■ Health and surveillance data sets and service use data may not include or reflect data about HIV and its impacts for trans or gender diverse people	■ Improve skills and capacity for health services and HIV community organisation services to collect relevant information about current gender identity in a safe, consistent and culturally appropriate way
■ There is a need for expanded opportunities for peer contact for people with HIV who are trans or gender diverse when accessing HIV services, such as transgender peer workers or volunteers	■ Provide opportunities for transgender and gender diverse people living with HIV to gain peer education/support skills and share those skills with each other
■ There is a need to improve the diversity of representation of people living with HIV to increase the visibility of positive peer role models for people living with HIV who identify as trans or gender diverse	■ Consider opportunities to use social media, campaigns and other strategies to ensure the stories of people living with HIV who are trans or gender-diverse are represented in the community

Identified need or issue	Potential strategy
■ HIV community-based organisations need strong connections to community-based organisations and services for trans or gender diverse people. ■ Community-based organisations and health/wellbeing services for trans and gender diverse people need an understanding of how service users may be affected by HIV, and clear pathways for referral	■ Partnership-building ■ Consider MoUs between organisations ■ Consider opportunities for organisations to share resources, including staff and policy development resources ■ Cross-organisational training opportunities
■ There may be a specific gap in terms of services specifically addressing the needs of intersex people	
Identified need or issue	Potential strategy

national strategic framework to address HIV stigma and build resilience capacity for people living with HIV

napwha national association of people with HIV australia