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# Aotearoa New Zealand People Living with HIV Stigma Index

2020 Report



**“HIV Stigma is a huge problem in Aotearoa New Zealand. To face this problem it is imperative that we have the voices of people living with HIV speaking out and sharing their experiences.”**

– Anonymous research participant

The Aotearoa New Zealand People Living with HIV Stigma Index  
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# Foreword

This is the first time the People living with HIV Stigma Index has been conducted in Aotearoa New Zealand. It is a unique survey in nature, as it is run by, for and alongside people living with HIV.



The meaningful involvement of people living with HIV, known as the MIPA principle, is at the heart of the Stigma Index. From inception and through development, implementation, monitoring and evaluation of HIV research, policies and programmes, the motto “nothing about us without us” has been amplified. In this context, from the outset the project has sought to be inclusive through representation by a range of organisations with the common goal of ending HIV stigma and discrimination as a result.

Further to this, and unique to Aotearoa New Zealand, is a heartfelt attempt to acknowledge and implement Te Tiriti o Waitangi throughout the research process. Māori are the ‘tangata whenua’ (people of the land). From the late 1700s a political agenda of colonisation resulted in the widespread alienation of Māori lands and resources, the suppression of Māori language, cultural practices and ultimately a dismantling of Māori social structures. In 2020, Te Tiriti o Waitangi provides a mechanism for challenging and addressing the injustices of the past, the inequities of the present, and as an assertion of Tino Rangatiratanga, or self-determination in relation to colonising governmental processes. In Aotearoa, this most certainly includes the right to good health and wellbeing.

The Stigma Index is an internationally validated questionnaire. Attempts to customise the questionnaire to capture Māori realities and perspectives has been a challenge. Māori interviewers were employed to assist participants, interpreting the questions in ways that were

more relatable for Māori. To aid in this the Stigma Index Working Group was joined by Te Whāriki Takapou, a Māori sexual and reproductive health organisation. Concerns remained, however, that Māori perspectives could be lost within the overall report. With expertise in Kaupapa Māori approaches to health promotion, research, policy and advocacy, it was agreed that Te Whāriki Takapou would write an independent report which would better reflect perspectives of Māori people living with HIV, to stimulate discussion and enable Māori approaches to reducing HIV-related stigma. While this decision was unanimously supported, especially as it aligned with the principles of both Te Tiriti o Waitangi and MIPA, the process was not without its misunderstandings and tensions. In rising to the challenge, the learning and insight gained has been valuable for all Working Group members, enabling pathways to becoming supportive Te Tiriti o Waitangi partners, in partnership with tangata whenua.

The outcome has been the writing and creation of two Stigma Index reports for Aotearoa New Zealand: a Māori Participants report and an All Participants report. It is imperative that both reports be read in conjunction to gain an understanding of the overall context of HIV-related stigma and discrimination in Aotearoa New Zealand.

These reports are a baseline. Further analyses will be undertaken, and reports produced to look in more depth at the experiences of sub-groups such as women and gay and bisexual men, and to explore the free-text comments of participants.

**The meaningful involvement of people living with HIV, known as the MIPA principle, is at the heart of the Stigma Index.**

# Table of contents

Foreword	4
List of figures	8
Acknowledgments	10
Acronyms	11
Definitions	11
Executive summary	12
Summary of recommendations	14
Introduction	16
MIPA principle	17
Te Tiriti o Waitangi	17
HIV in Aotearoa New Zealand	18
The research context: HIV stigma and discrimination in Aotearoa New Zealand	19
The policy context: Legislation on stigma and discrimination in Aotearoa New Zealand	20
Study objectives	22
Methodology	23
Study design	23
Stigma Index Working Group	23
Recruitment and training of interviewers	23
Eligibility criteria of study participants	23
Study population, sample size and participant selection	24
Study procedure and data collection	24
Data analysis	24
Confidentiality	25
Ethical approval	25
COVID-19 pandemic	25
Limitations	25

1. Who took part?	26
2. HIV testing, diagnosis and treatment	28
2.1 Testing and diagnosis	28
2.2 Treatment	29
3. HIV disclosure	32
3.1 Partners	33
3.2 Family and friends	34
3.3 Workplace	35
4. Experiences of stigma and discrimination	38
4.1 HIV-related stigma	38
4.2 Non-HIV related stigma	40
5. Internalised stigma	42
6. Mental health and wellbeing	46
7. Healthcare	48
8. Human rights	52
9. Support, advocacy and effecting change	54
10. Interviewer empowerment	58
Conclusion	60
References	62

# List of figures

<b>Figure 1</b>	Area of residence in Aotearoa New Zealand	26
<b>Figure 2</b>	Age, gender, and ethnicity of participants	26
<b>Figure 3</b>	Education, employment, and ability to meet basic needs	27
<b>Figure 4</b>	Country of birth and length of time living in Aotearoa New Zealand	27
<b>Figure 5</b>	Sexual identity of participants	27
<b>Figure 6</b>	Time and place of HIV diagnosis	28
<b>Figure 7</b>	Decision to test for HIV among participants diagnosed in Aotearoa New Zealand in the last 10 years	28
<b>Figure 8</b>	Length of time to start treatment for those diagnosed in Aotearoa New Zealand in the last 10 years	29
<b>Figure 9</b>	Reasons for delay or hesitation in getting care or treatment for HIV for participants diagnosed in Aotearoa New Zealand in the last 10 years	29
<b>Figure 10</b>	Disclosure of HIV	32
<b>Figure 11</b>	Experience of participants who had disclosed their HIV to family or friends	34

<b>Figure 12</b>	Experience of stigma and discrimination in the last 12 months due to HIV	38
<b>Figure 13</b>	Feelings expressed by participants	42
<b>Figure 14</b>	Internalised stigma within the last 12 months	42
<b>Figure 15</b>	Proportion of participants negatively affected within the last 12 months according to their time of HIV diagnosis and whether or not they were in a current intimate relationship	43
<b>Figure 16</b>	Internalised stigma within the last 12 months	44
<b>Figure 17</b>	Internalised stigma within the last 12 months according to whether or not a participant was in a current intimate relationship	44
<b>Figure 18</b>	Bother within the two weeks prior to interview	46
<b>Figure 19</b>	Quality of life (PozQoL) score	47
<b>Figure 20</b>	Experiences in the last 12 months with: a) HIV-related healthcare, and b) non-HIV related healthcare	48
<b>Figure 21</b>	Abuse of rights experienced	52
<b>Figure 22</b>	Effecting change and advocacy within the last 12 months	54

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# Acronyms

<b>AIDS</b>	Acquired Immunodeficiency Syndrome
<b>CDC</b>	Centers for Disease Control and Prevention
<b>GBM</b>	Gay, Bisexual and other Men who have sex with men
<b>GIPA</b>	Greater Involvement of People living with HIV and AIDS
<b>HIV</b>	Human Immunodeficiency Virus
<b>MELA</b>	Middle Eastern and Latin American
<b>MIPA</b>	Meaningful Involvement of People living with HIV and AIDS
<b>MSM</b>	Men who have Sex with Men
<b>NZ</b>	New Zealand
<b>NZAF</b>	New Zealand AIDS Foundation
<b>PHARMAC</b>	The Pharmaceutical Management Agency
<b>U=U</b>	Undetectable equals Untransmittable
<b>UNAIDS</b>	The Joint United Nations Programme on HIV and AIDS
<b>UVL</b>	Undetectable Viral Load

# Definitions

**HIV-related stigma** is commonly understood as irrational or negative attitudes, behaviours and judgments towards people living with or at risk of HIV. Often stigma is directed at a group of people, or an individual who are perceived to be of lesser importance, and it is used to discriminate against them and treat them unfairly (CDC, 2019).

Self-stigma or **internalised stigma** relates to the way a person thinks about themselves and refers to when a person has negative feelings or thoughts about themselves due to their HIV status. It can lead to depression, isolation, or feelings of shame (CDC, 2019).

Stigma experienced and internalised stigma can impact on a person's ability to lead a fulfilling life, seek healthcare, know their status, or adhere to medication.

# Executive summary

The People Living with HIV Stigma Index was carried out in Aotearoa New Zealand between July 2019 and September 2020.

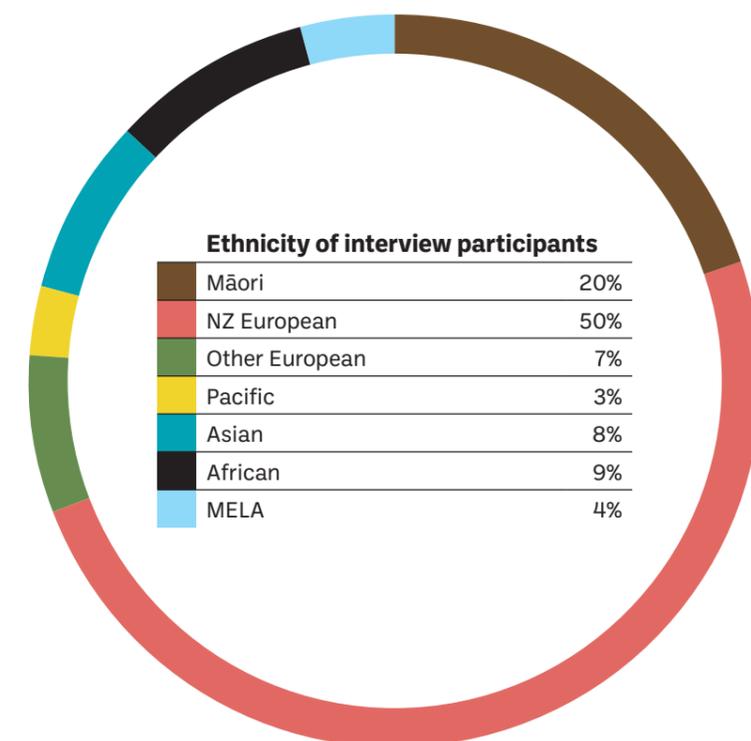
**Twelve interviewers living with HIV interviewed 188 participants from across the country, ranging in age from 20 to 75 years. Just over half of the participants were European (56%), 20% Māori, 9% African, 8% Asian, 3% Pasifika, and 4% Middle Eastern and Latin American. Most participants had been living with HIV longer than 10 years.**

- In 2020, people living with HIV in Aotearoa New Zealand continue to face HIV-related stigma and discrimination.
- Nearly a quarter of participants diagnosed in Aotearoa New Zealand in the last 10 years reported it was not their decision to test for HIV, with it either being done without their knowledge, without consent, or under pressure.
- While all participants were on antiretroviral treatment, some reported delays or hesitation in starting their treatment due to fear of stigma or worries about people finding out their HIV status.
- For a significant number of people living with HIV, stigma remains an obstacle which affects how, when and to what extent disclosure occurs. Nearly three-quarters of participants found it difficult to tell people about their HIV, with some hiding their diagnosis. Whilst most participants had shared their HIV status with partners, friends and family, only half agreed that disclosing to people not close to them had been a positive experience, and many have had their status disclosed without their consent.
- Disclosure within the workplace was low, and HIV had broader effects on people's ability to work with one-fifth of participants reporting they did not apply for a job because of their HIV.
- Healthcare workers living with HIV reported high levels of non-disclosure, due to anticipating stigma and negative reactions from their colleagues.
- Over a third of participants reported experiencing HIV-related stigma in the last 12 months, with this being higher among participants outside the main cities. This most often occurred through discriminatory remarks, gossiping, or verbal harassment.
- HIV-related stigma was often compounding on stigma related to a person's gender, sexual orientation, drug use or sex work. There were high levels of drug use within the community, either in the past or currently, and high levels of casual sex work, particularly among GBM.
- One-third of participants reported feelings of being ashamed, guilty, worthless, and dirty, and therefore high levels of internalised stigma, which had affected their quality of life.
- Internalised stigma was higher among those newly diagnosed, and those not in a relationship.
- Almost half of participants said they had decided not to have sex in the last 12 months, with this higher among GBM and those newly diagnosed.

**Over a third of participants reported experiencing HIV-related stigma in the last 12 months**

- Nearly half of participants reported having a mental health condition such as depression, anxiety, or insomnia in the past 12 months.
- Experiences of stigma within healthcare were common. More participants reported experiencing stigma from their non-HIV related care, with avoidance of physical contact most reported. Nearly one-third of participants reported they do not disclose their HIV for non-HIV related healthcare, with stigma and discrimination previously experienced reinforcing this desire not to disclose.
- Over half of the participants were not aware or confident that their medical records were confidential. Furthermore, people had concerns about who within healthcare could access their records and whether non-clinical staff were held to the same professional privacy standards.
- Over one-third of participants did not know there are laws in Aotearoa New Zealand to protect people living with HIV from discrimination.
- Many participants reported experiencing human rights abuses. The most frequently reported were having to disclose or get tested to obtain medical insurance (discrimination that is currently allowed by law) and being refused employment or losing a source of income. People also reported having to disclose or get tested for immigration purposes as a human rights abuse.
- The participants were motivated, engaged, and keen to support their community, with almost three-quarters being members of a support network, and high numbers reporting having taken action or offered support in effecting change.

**Twelve interviewers living with HIV interviewed 188 participants from across the country, ranging in age from 20 to 75 years.**



# Summary of recommendations

The following are recommendations stemming from the research results for the Aotearoa New Zealand People Living with HIV Stigma Index.

People living with HIV need to be at the forefront of the response and visible across the sector in each of the recommendation areas – in research, advocacy, outreach and support, and campaigns. We invite government agencies, health providers, community groups, researchers, and funders to collaborate with people living with HIV to action the findings and recommendations of this report.

## Education about HIV and AIDS:

- Improved workforce education to address stigma and discrimination within healthcare, including education campaigns on the safety of healthcare workers living with HIV. Additional training and mentoring, and a renewed emphasis on the use of universal precautions, is necessary to ensure a safe and inclusive working environment.
- Increased education within healthcare on how to talk about HIV. Many participants reported receiving questions relating to how they contracted HIV making them feel uncomfortable or stigmatised.
- Training for healthcare providers on HIV and privacy must include non-clinical staff (managers, human resources, and front-line administrative and reception staff).
- Increased education on the importance of informed consent for testing is needed.
- More education is needed for people living with HIV to know their rights to privacy and confidentiality under The Privacy Act (1993) and Human Rights Act (1993), providing greater clarity on when disclosure is required, how medical records are stored, and how protection against discrimination is afforded to them.
- Campaigns targeting the general population with information about HIV transmission with a focus on U=U are needed. These need to explain the differences between HIV and AIDS, and reinforce that people living with HIV can lead long and productive lives.
- Anti-stigma campaigns must also be targeted to population groups outside of the main city centres, to address the higher stigma reported and a sense of disconnection by people living with HIV in the regions.
- Campaigns to address stigma must be targeted to and address the unique needs and compounded stigma related to being a migrant, sexual orientation, using drugs, or sex work.

## Programmes and funding:

- More funding for HIV community support organisations to administer programming as indicated in these recommendations and to provide increased strengths-based support focussed on empowerment, self-determination and wellbeing for people living with HIV.
- Expand campaigns on Undetectable equals Untransmissible (U=U) to all relevant communities.
- Resources for and from HIV community organisations to support the empowerment of people living with HIV to know their rights and legal responsibilities.
- Scale up community-based testing and campaigns to normalise regular HIV testing and promote the range of testing options available (including self-testing).
- Modernise and widen the range of funded treatment options offered to people living with HIV to ensure optimal treatment outcomes and adherence. This is especially timely as we now have an ageing population living with HIV who may be experiencing the growing burden of medication toxicity.
- Improved resources are needed for when disclosure occurs in the workplace to ensure colleagues are educated about HIV and supportive of the person living with HIV. These resources to also address the importance of the Human Rights Act (1993) and non-discrimination in the workplace – as well as the ramifications of breaches of these. Respondents reported losing jobs, career opportunities and experiencing workplace discrimination due to their HIV – which is illegal.
- More culturally appropriate programming and resources to support people living with HIV to know their rights and feel confident in their decision to disclose or not as there are higher levels of non-disclosure in African, Asian, Pasifika and MELA communities.
- Increased programming, support, and resources to meet the needs of GBM who use drugs.
- Targeted sexual health campaigns on casual sex work among GBM.

## Policy and practices:

- A review of standard operating procedures for HIV testing across clinical sites must occur as findings indicated nearly a quarter of participants (23%) were tested without their knowledge, without consent or under pressure.
- Healthcare to develop, implement and reinforce workplace policies that are non-discriminatory and supportive to reduce HIV-related stigma.
- Attempts to recriminalise sex work through council bylaws restricting solicitation and street-based work must cease. Such initiatives only serve to further stigmatise vulnerable populations and create barriers to accessing healthcare.
- Consistent training and monitoring of employee behaviour within healthcare must occur to reinforce obligations under The Privacy Act (1993). Greater protection of medical records and personal health data by healthcare professionals and social services would contribute to this, with confidence at times being undermined by lapses within the system.
- Remove HIV from the Immigration New Zealand list of conditions (A4.10.1) automatically considered a burden to the health system. The automatic exclusion of people living with HIV does not reflect the current health status and life expectancy of people living with HIV nor does it take into account rapidly declining treatment costs.
- The time period for which a health condition is assessed by Immigration New Zealand needs to be reduced to being over ten years, and the cost threshold increased. This would be following in the footsteps of Australia, where in 2019 the cost threshold was increased to \$49,000, and the time period over which a health condition is formally costed reduced to being just ten years rather than a lifetime. The health condition cost threshold has not been reviewed since 2012 and is widely agreed to be an arbitrary and outdated figure.
- Insurance providers must review their policies to enable health, life and travel insurance for people living with HIV, without surcharge.
- HIV transmission must be managed within the public health system. End the use of the criminal justice system to address cases of HIV non-disclosure, exposure, or transmission.
- The HIV Action Plan (2003) is outdated. A renewed and ambitious HIV Action plan is needed to guide the sector.

## Care and support of people living with HIV:

- Newly diagnosed people living with HIV must have a clear and formalised referral pathway to ensure rapid linkage to care and treatment and easy access to support services and counselling.
- With low levels of disclosure to family and friends among people diagnosed within the past five years, it is important people are linked to counselling and peer networks and are supported in their decision on when to disclose.
- Counselling services for people living with HIV must be resourced sustainably with services to be scaled up to be more accessible and timelier.
- Programmes that focus on the broader wellbeing of people living with HIV to be scaled up, including initiatives on building self-confidence, mindfulness, nutritional advice, and peer support.
- Greater access to support services and safe networking places for people living with HIV outside of the main centres.

## Further research is needed:

- on people living with HIV who are not members of a support organisation, as it is possible their diagnosis and linkage to care experience is different to those who took part in this study.
- to explore stigma among the newly diagnosed, who only made up a small number of our participants yet reported higher levels of internalised stigma.
- to explore the ageing population of people living with HIV, including programmes for integrated care and support across health and social services with the needs of older LGBT people to be considered. This will present several challenges which may affect their experience of ageing and maintaining good mental and physical health.
- to be person-centred with people living with HIV involved as implementers, to increase the cultural relevance and applicability of the research and programming.
- to shift the perspective of HIV programming and research whereby people living with HIV are recognised for their agency rather than assumed passive beneficiaries or research participants. This approach taps into the resourcefulness, resilience and knowledge of the person and their communities, to strengthen research and programmes, making them more relevant, appropriate, and effective.

**We invite government agencies, health providers, community groups, researchers, and funders to collaborate with people living with HIV to action the findings and recommendations of this report.**

# Introduction

Central to the Aotearoa New Zealand Health Strategy 2016-2026 is that “All New Zealanders live well, stay well, get well” (Minister of Health, 2016, p. 2). Achieving this requires a society and a health system that protects and supports the rights of all people.

**The landscape of HIV is dramatically different to how it was ten or twenty years ago, with advances in treatment meaning people living with HIV can lead long and productive lives. Being on treatment and having an undetectable viral load (UVL) also reduces the risk of HIV transmission. Despite these advances, many New Zealanders still hold stigmatising attitudes towards people living with HIV, limiting their ability to live well, stay well and get well.**

People living with HIV often face stigma and discrimination which can have a profound impact on their emotional, mental, social, and physical wellbeing. HIV-related stigma also impacts on the uptake of HIV testing, disclosure, engagement in care, and uptake of and adherence to HIV treatment, thereby fuelling the ongoing transmission of HIV (Grossman & Stangl, 2013; Mahajan, et al., 2008; UNAIDS, 2005). As stated by UNAIDS (2005, p. 4), “Not only is HIV-related discrimination a human rights violation, it is also necessary to address such discrimination and stigma in order to achieve public health goals and overcome the epidemic.”

In Aotearoa New Zealand, the number of people living with HIV has steadily increased over the years. However, despite HIV now mostly being a manageable chronic illness, stigma remains. In conducting a review of services for people living with HIV in Aotearoa New Zealand, Miller (2010, p. vii) called stigma “the elephant in the waiting room of the HIV response – often invoked as the cause of sub-optimal population responses to prevention and support activities, yet hard to quantify or isolate by region or population.” A national conversation on HIV stigma is therefore needed to enable a broad understanding of what it is, how it works and how it can be addressed. Strategies to reduce stigma and discrimination are vital. Not only

to ensure the rights of people living with HIV are protected, but also because reducing HIV-related stigma and discrimination is critical to the overall reduction of new HIV transmissions.

This study sought to identify the stigma and discrimination experienced by people living with HIV in Aotearoa New Zealand, using “The People Living with HIV Stigma Index” (GNP+, 2020). The Stigma Index is a standardised tool to be used by people living with HIV, and was created to reflect and support principles for the greater and meaningful involvement of people living with HIV and AIDS (MIPA), where people living with HIV are empowered to lead the implementation of the study. Since its launch in 2008, the Stigma Index has been implemented in more than 100 countries with over 100,000 people living with HIV participating in the process. This is the first time the Stigma Index has been run in Aotearoa New Zealand. It is a unique survey in nature, as it is run by, for and with people living with HIV. This approach enhanced openness and built confidence to allow the sharing of experiences during interviews without fear or prejudice, thereby incorporating the MIPA principle. Undertaking this survey in Aotearoa New Zealand presented a unique challenge and opportunity of not only working within the MIPA principle but also acknowledgement of Te Tiriti o Waitangi to ensure and affirm the inclusion of Māori voices.

## MIPA principle

MIPA is a strengths-based principle that amplifies the motto, “nothing about us without us”. MIPA calls for the active, full, and meaningful involvement of people living with HIV in the inception, development, implementation, monitoring and evaluation of HIV research, policies and programmes. It states that when informed by people living with HIV, the HIV response is better able to respond to the needs and priorities of the community, increase access to programmes, challenge negative attitudes, and build capacity of services. It promotes the personal development of people living with HIV, respecting their knowledge and abilities while promoting confidence, upskilling, and creating support networks.

Since the beginning of the response to the HIV epidemic, people living with HIV have been at the centre propelling action. First articulated in the Denver Principles in 1983, these principles were formalised in the 1994 Paris Declaration, and have been endorsed by UNAIDS, the body that coordinates global action on the HIV epidemic. It is considered good practice to apply these principles when working in the field of HIV, acknowledging the universal rights of people living with HIV to self-determination and participation in decisions that affect their lives.

The Aotearoa New Zealand People Living with HIV Stigma Index translated the MIPA principle into practise by holding people living with HIV at the centre of the research process as implementers, interviewers, researchers, writers and participants, with each of these driving how the information was collected, analysed and used. The research was not intended to be an abstract academic exercise done “to” the community, rather it was intended to embrace a participatory spirit for all involved, and empowering people living with HIV in the process.

**MIPA is a strengths-based principle that amplifies the motto, “nothing about us without us”.**

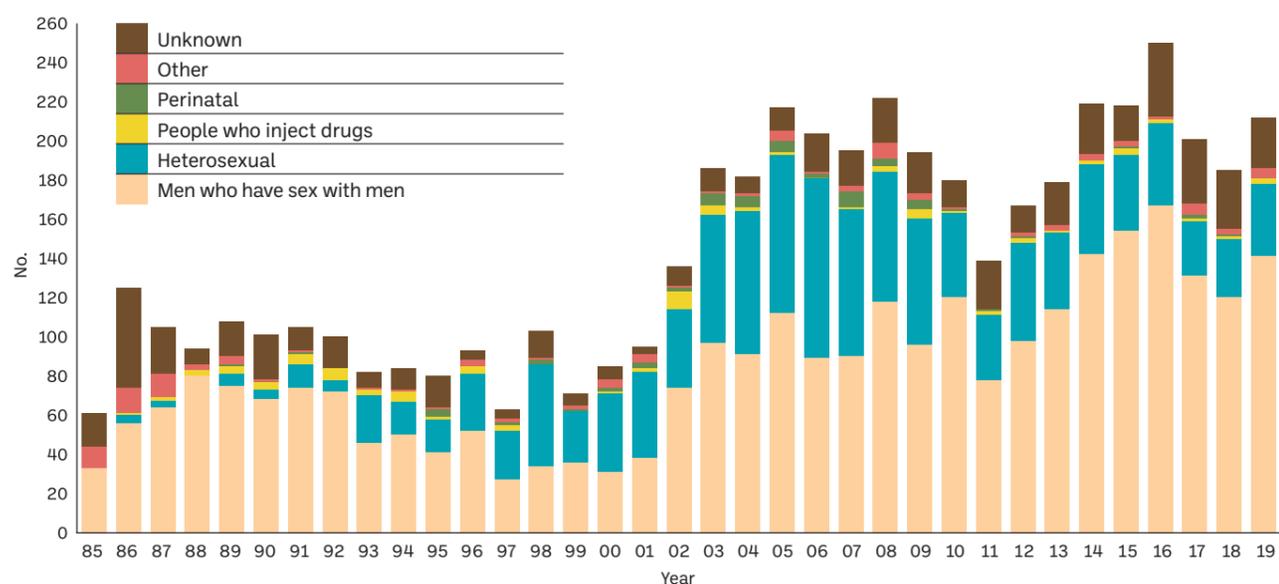
## Te Tiriti o Waitangi

One key area of work for the HIV sector in Aotearoa New Zealand, as well as in other colonised contexts, is to increase indigenous voices and thus the capacity for MIPA to effect transformative change. In the unique context of the Aotearoa New Zealand People Living with HIV Stigma Index, an acknowledgement of Te Tiriti o Waitangi in the design and processes of the Stigma Index has been crucial to affirm the inclusion of Māori people living with HIV.

Te Tiriti o Waitangi is an expression of Māori aspirations for autonomy and self-determined futures (Walker, 1990; Durie, 2003). In the Te Tiriti relationship between tangata whenua (people of the land, or Māori) and the Crown, Māori have the right to good sexual health and wellbeing; the Crown and its agencies have an obligation to protect and promote the sexual health and wellbeing of Māori, including Māori people living with HIV, responding to their health aspirations and meeting their health needs (Ministry of Health, 2019). The recently revised Te Tiriti o Waitangi principles - Tino Rangatiratanga, Partnership, Active Protection, Equity and Options (Waitangi Tribunal, 2019) - were developed to guide the health and disability system to achieve equity and healthy futures for Māori (Pae Ora) (Ministry of Health, 2020).

The organisations represented on the Working Group have expressed a commitment to uphold the principles of Te Tiriti o Waitangi and the aims and objectives of He Korowai Oranga (the Māori health strategy) (Ministry of Health, 2014/2020), even though at times this has proved challenging. The project has provided the opportunity for the organisations to build their capacity in working in partnership with Māori and develop their understanding of how to apply the revised principles of Te Tiriti o Waitangi in their work.

## HIV in Aotearoa New Zealand



Number of people diagnosed with HIV in New Zealand through Western Blot antibody test and, since 2002, through viral load testing (AIDS Epidemiology Group, 2020)

In 2019, the number of people living with HIV in Aotearoa New Zealand on antiretroviral treatment was approximately 3000 (AIDS Epidemiology Group, 2020). The HIV epidemic is mostly concentrated in sub-populations of men who have sex with men (MSM), and heterosexual people from sub-Saharan Africa and Southeast Asia (Dickson, Lee, Foster, & Saxton, 2015). By the end of 2019, just over half of those diagnosed with HIV were MSM (57%), followed by heterosexual men and women (12%). Half of those diagnosed are of a European ethnicity (50%) and 8% are Māori. Other main ethnic groups include Asian (15%), African (14%), and Pasifika (4%) (AIDS Epidemiology Group, 2020).

HIV diagnoses among MSM are mostly European men reported to have been infected in Aotearoa New Zealand. This has changed slightly in the last couple of years with an increase in men of other ethnicities who had previously been diagnosed with HIV overseas.

HIV diagnoses among heterosexual people infected overseas increased sharply from 2002 to 2006. This corresponded to an increase in migrants and refugees from countries with a high HIV prevalence when HIV screening was not a compulsory part of the immigration process. Heterosexual diagnoses began to decline from 2007, coinciding with immigration

policy changes in late 2005 when mandatory HIV testing for residency applicants and people applying for visas for longer than 12 months was introduced. This policy is still in effect today and shapes the ethnic make-up of the community, as many people living with HIV still face challenges obtaining visas when attempting to immigrate to Aotearoa New Zealand.

Low numbers of people who inject drugs (PWID) and the successful operation of an effective national Needle Exchange Programme since 1988 has meant that injecting drug use as a route of transmission accounts for very few HIV infections in Aotearoa New Zealand (2%) (AIDS Epidemiology Group, 2020; Saxton, McAllister, Noller, Newcombe, & Leafe, 2020).

Similarly, there has been a low rate of HIV transmission in the Aotearoa New Zealand sex industry. This is due to organisations like the New Zealand Prostitutes Collective who advocate for the rights, safety, health, and wellbeing of all sex workers, and a culture of condom use among sex workers (NZPC, 2020).

There are low numbers of transgender women diagnosed with HIV (0.5% of all diagnoses at the end of 2019), which may be partly due to the reporting process which has been adapted over time to better capture this information.

Widespread antenatal screening and effective treatment for pregnant women means that the transmission of HIV from mothers to babies is very low (1%), with no children with perinatally-acquired transmission born in Aotearoa New Zealand since 2007 (AIDS Epidemiology Group, 2020).

All these results are considered highly successful worldwide.

### The research context: HIV stigma and discrimination in Aotearoa New Zealand

Research on the experiences of stigma and discrimination among people living with HIV in Aotearoa New Zealand is currently limited. Most studies were conducted in the earlier stages of the epidemic, or with small, localised populations.

Some research has been conducted specifically on stigma experienced within healthcare settings. Mundt and Briggs (2016) surveyed 213 people living with HIV at the Auckland City Hospital HIV clinic. They found that 47% reported experiencing stigma and discrimination due to their HIV, with many of these experiences occurring within the past five years. Settings with the most complaints were encounters with general practitioners (GPs), dentists, and non-infectious diseases hospital wards and outpatient clinics. Several study participants indicated that they constantly worry about disclosing to healthcare providers in case discrimination occurs, with participants more cautious and vigilant about disclosing in their future encounters with healthcare providers. A few participants admitted they had not disclosed their HIV in order to avoid (perceived) discrimination, which could have negative consequences for their health (Mundt & Briggs, 2016).

Brinsdon, Abel and Desrosiers (2017) interviewed 14 people living with HIV in Christchurch, of whom nearly all had faced stigma during their healthcare interactions. Most of these stigma experiences were a result of healthcare workers perpetuating exaggerated fears of transmission or not maintaining confidentiality. Several participants also experienced layered stigma due to ageing, sexual orientation, or low socio-economic status. The main way that participants managed

this stigma was through seeking control in their interactions, which again led to some participants choosing not to disclose (Brinsdon, Abel, & Desrosiers, 2017). Fisher and Henrickson (2019) further argued that these experiences of stigma and discrimination extended to healthcare workers living with HIV, who experienced a toll on their health and wellbeing in the workplace.

Research has also been conducted on the experiences of stigma for women living with HIV. It is argued that women are often invisible actors in a disease discourse constructed by men for men. Bennett (2007) argued that women often have a more tarnished image due to societal attitudes surrounding women's sexuality and double-standards around promiscuity. In her interviews with women, some indicated that by revealing their status they often felt stigmatised, dirty, contaminated and judged for practising "so-called" deviant behaviour, and that it was stressful both to conceal and reveal their HIV status. There was also extra stigma experienced due to concerns their children may also be stigmatised (Bennett, 2007). Bruning (2009) also found a deep irrational fear experienced by female participants around possible accidental transmission through casual contact, and an inability to disassociate themselves from the virus such as, "I am HIV positive so I am the virus" (rather than I have a virus).

Much research has also focussed on the layered stigma experienced by African migrant and refugee populations living with HIV in Aotearoa New Zealand. Fouché et al. (2011) found that despite participants feeling more secure in their physical and political environment, they experienced marginalisation and discrimination for being Black and migrants as well. Henrickson et al. (2015) also found that stigma about HIV remained high within African communities, thus many Africans avoided testing and prevention information (or condoms) publicly, because these activities imply that they are engaging in risk behaviours. Approaching gay organisations for information amplifies the already considerable levels of stigma towards HIV in African communities, though this has largely been addressed with the Pamoja HIV programme for African people. Poindexter et al.'s (2013) study of African women's experiences within

medical settings again found inappropriate use of universal precautions, violations of confidentiality rights, discriminatory comments about Africans or people living with HIV, and misinformation about HIV transmission.

There has been limited research on the experiences of stigma within the context of Undetectable equals Untransmittable (U=U, or when people living with HIV are on treatment with an undetectable viral load (UVL) and cannot pass on HIV). A survey of 1002 New Zealanders in 2018 reported three-quarters of participants could accurately define how HIV was transmitted, and most participants reported they would be comfortable being friends with someone living with HIV (84%). However, 88% said they would be “uncomfortable” or “very uncomfortable” having a sexual relationship with someone living with HIV. Only 7% were aware that having a UVL means that HIV cannot be passed on during sex (Consumer Link, 2018).



## The policy context: Legislation on stigma and discrimination in Aotearoa New Zealand

There are no HIV-specific laws in Aotearoa New Zealand, however people living with HIV are protected by and part of many other general Acts, Strategies and Plans, such as:

### A. HIV Action Plan (2003)

Provides the overall principles, obligations, strategic context and direction for achieving the vision of good sexual and reproductive health for all New Zealanders.

### B. New Zealand Health Strategy (2016-2026)

This Strategy outlines the high-level direction for Aotearoa New Zealand’s health system from 2016 to 2026. It lays out some of the challenges and opportunities the system faces, and describes the future people want, including the culture and values that will underpin this.

### C. The Human Rights Act (1993)

Under the Human Rights Act, people living with HIV are categorised as people living with a disability due to “the presence in the body of organisms capable of causing illness”. Subsequently people living with HIV are protected from HIV-related discrimination in employment, housing, medical or dental services under (Section 21(h)(vii)). The right to non-discrimination for HIV extends to partners, family, friends, and colleagues of people living with HIV.

The exception is insurance, as the Act still allows for discrimination based on HIV status and requires HIV disclosure in this instance. Most insurance providers currently exclude coverage of any costs relating to HIV for health insurance, and exclude people living with HIV from life insurance products. Acknowledging the advances in HIV medications, some insurance companies will now offer life insurance to people living with HIV. However, these policies often have limited terms (5-7 years) and higher premiums. This discrimination is also

allowed for under the Fair Trading Act (1986) provision of ‘unfair contract terms’.

Disclosure of HIV status is not required for employment or education. Employers have a responsibility to protect people from workplace harassment on the basis they have HIV.

People who experience discrimination can make a complaint to the Human Rights Commission, which offers free advice and mediation to assist with unlawful discrimination.

### D. The Crimes Act (1961)

Under this Law, everyone has a legal duty not to endanger the life, health, or safety of others. For people living with HIV, this means they must take reasonable precautions to avoid transmitting HIV to partners by either participating in low risk activities or using condoms for vaginal or anal sex.

Disclosure with sexual partners is not required if condoms are used as this is recognised as “taking reasonable precautions.” Sexual activity without disclosure and condom use, with or without transmission, can lead to prosecutions and convictions under the Crimes Act. Case law has not been tested in Aotearoa New Zealand in the context of people living with HIV having a UVL, as UVL prevents onward sexual transmission of HIV even without condoms, which is supported by the U=U Consensus statement (Prevention Access Campaign, 2016).

### E. The Privacy Act (1993)

This Act regulates the collection, storage, use and disclosure of personal information. It prohibits disclosure of medical information without signed consent, and therefore protects the privacy of people living with HIV regarding their HIV status.

### F. The Health Act (1956)

This Act regulates many areas relating to the management of infectious diseases, including sexually transmitted infections. AIDS has been listed as a notifiable disease since the outset of the HIV epidemic, and HIV became notifiable in 2017 due to

an amendment to the Act. Therefore, new diagnoses of both HIV and AIDS are reported anonymously to the Medical Officer of Health for surveillance.

All people who have, or are suspected of having, an infectious disease as defined in one of the schedules of the Health Act are automatically eligible to receive publicly funded treatment for their condition under Section B23 of the Health and Disability Services Eligibility Direction 2011. Subsequently, all people living with HIV within Aotearoa New Zealand, regardless of residency status and visa type, are eligible for publicly funded treatment. Antiretroviral treatment for HIV is publicly funded by PHARMAC, the national pharmaceutical purchaser. The CD4 threshold for accessing treatment was removed in July 2017, enabling rapid linkage to care and treatment.

All pregnant women are offered HIV antenatal screening at the time of their first antenatal blood test. While women can opt-out, testing has generally become standard practise.

### G. Homosexual Law Reform Act (1986)

This law legalised consensual sex between men aged 16 and older. It removed the provisions of the Crimes Act (1961) which had previously criminalised sex between men.

### H. Prostitution Reform Act (2003)

Sex work was decriminalised in Aotearoa New Zealand in 2003. This Act replaced laws criminalising sex workers and third parties, creating a safeguard for the human rights of sex workers and to provide protection from discrimination.



Gay Liberation Movement demonstrating, Parliament grounds, Wellington, New Zealand. Dominion post (Newspaper); Photographic negatives and prints of the Evening Post and Dominion newspapers. Ref: EP-Ethics-Demonstrations-Homosexual Law Reform-01. Alexander Turnbull Library, Wellington, New Zealand.

## I. Health (Needles and Syringes) Regulations (1998)

Harm reduction has informed a public health approach for injecting drug use with the establishment of the Needle Exchange Programme. It is funded by the Ministry of Health and was developed on the principles of the Ottawa Charter (World Health Organization, 1986) which is also used as a framework for planning public health in Aotearoa New Zealand.

## J. Immigration Act (2009)

HIV is a listed health condition automatically considered to be a burden on the health system in Aotearoa New Zealand under A4.10.1 of the Immigration New Zealand Operation Manual. This means people living with HIV wishing to immigrate to Aotearoa New Zealand will most often be denied. People can apply for a visa waiver which will be considered on a case by case basis depending on the circumstance of the application. People living with HIV are also assessed as to whether they have an acceptable standard of health and are subject to the health requirements for all residence visas. This requires an assessment of whether HIV is a high-cost condition (costing \$41,000 over a lifetime) at A4.10.2 of the Operation Manual, which further restricts the ability for many to receive a visa.

In 2011 regulations were relaxed for partner reunification if the immigrating person is living with HIV. Tourists and people on work visas staying for less than one year are not required to test for HIV. International students are not required to test for HIV and can stay as long as their student visa allows.

## K. International Policy

Aotearoa New Zealand is a valued partner of UNAIDS and commits to the following:

- Producing an HIV Country Progress report every two years to monitor progress on the UNAIDS goals.

- The UNAIDS Fast-Track Targets as outlined in the 2016 Political Declaration on Ending AIDS. To help achieve this, UNAIDS set up a Global HIV Prevention Coalition, of which Aotearoa New Zealand was appointed Chair. This coalition seeks to ensure accountability for delivering prevention services to achieve the targets, including a 75% reduction in HIV infections by 2020 and to ending the AIDS epidemic by 2030.
- Working towards achieving the 90–90–90 treatment targets set out by UNAIDS.
- Working towards the 2030 Agenda for Sustainable Development.
- The Implementation of the MIPA principle at all levels of the HIV response.

## Study objectives

The overall goal of this study was to identify the stigma and discrimination experienced by people living with HIV in Aotearoa New Zealand.

### Specific objectives were to:

- a) Enable the meaningful involvement of people living with HIV in all aspects of the project.
- b) Incorporate the principles of Te Tiriti o Waitangi.
- c) Inform an evidence baseline relating to stigma and discrimination that can be monitored over time.
- d) Contribute to policy and programmes in Aotearoa New Zealand.

## Methodology

### Study design

The study comprised a cross-sectional quantitative survey of stigma and discrimination among people living with HIV in Aotearoa New Zealand using the internationally developed and validated People Living with HIV Stigma Index Version 2.0, and quality of life using the PozQoL Scale.

## Stigma Index Working Group

In keeping with the MIPA Principle, people living with HIV in Aotearoa New Zealand were the implementors of and involved in all aspects of the study. A Working Group was established with diverse representation of people living with HIV from the New Zealand AIDS Foundation (NZAF), Positive Women Inc., Te Whāriki Takapou, Pamoja and the Needle Exchange Programme, alongside allies and people affected by HIV within Body Positive, the New Zealand Prostitutes Collective and the University of Otago. This enabled active and meaningful participation of people living with HIV in the decision-making process for implementing the study and analysing the data.

## Recruitment and training of interviewers

Twelve interviewers living with HIV of different ethnicities, gender, and from across Aotearoa New Zealand were recruited through peer network organisations. Reaffirming a strengths-based approach, all interviewers were paid for their time, upholding the MIPA principle by truly acknowledging their value to the project. The effect of this was more opportunity to connect and increase a sense of community. Peer



researchers were central to this community-based research since they contributed unique perspectives from their lived experience to the entire research process. Given the nature of one-to-one interviewing, their presence has been crucial to recruitment and the support provided to participants for successful implementation of the study. For a closer analysis on the impact that interviewing and participating in the HIV Stigma Index had on our interviewers, please refer to Section 10 of the report.

All interviewers participated in a two-day training on data collection techniques, and taught research ethics of informed consent and confidentiality. Training also focused on maintaining interviewer boundaries and staying safe and well when interviewing. Interviewers were provided a study manual with instructions and guidelines.

## Eligibility criteria of study participants

People living with HIV with the following criteria were eligible to participate:

- 16 years of age or older
- Able to provide informed consent



**Twelve interviewers living with HIV of different ethnicities, gender, and from across Aotearoa New Zealand were recruited through peer network organisations.**

## Study population, sample size and participant selection

We initially aimed to recruit 100 people and to have similar numbers of men and women from each main ethnic group affected in Aotearoa New Zealand (Māori, African, Asian and European/Other). This target was not based on statistical considerations but rather as a response to the limited funding available. As such we considered that this approach would provide an adequate number of diverse participants to gain insight into their experiences. Excitingly, funding was increased during the study and we were able to increase the sample size to 200.

The study population is therefore not representative of all people living with HIV in Aotearoa New Zealand, nor is it a random sample. Recruitment of participants was first through:

- a) Community organisations for people living with HIV (websites, email, and newsletters),
- b) Notices placed in HIV clinics attended by people living with HIV throughout the country,
- c) Pharmacies commonly used by people living with HIV to collect their medication, and
- d) Participants contacting and informing other people living with HIV.

After some months of recruitment, the specified target of European participants was met, and further recruitment ceased for this demographic. At that stage, to increase the number of Māori participants, a Māori recruiter was employed to implement a focussed recruitment drive for Māori living with HIV. Māori interviewers were also encouraged to contact other Māori living with HIV, and targeted marketing was undertaken through radio and television interviews, and te reo Māori videos posted on social media.

## Study procedure and data collection

A study website was developed for people to find information and sign up (stigmaindex.nz). The Study Coordinator contacted interested participants to establish their location and whether they had

any preference for an interviewer. Their name and contact details were then provided to the interviewer to contact and interview.

Interviews were arranged in a location agreed upon by the participant and interviewer where privacy was ensured. All participants went through an informed consent process before participating and were only interviewed if they were happy to provide written consent.

The side-by-side interviewing technique was used whereby the participant and interviewer were sitting next to each other and able to see each question and answer. Answers to all questions were written onto a paper copy of the Stigma Index, and sent to the Study Coordinator, who then entered the information into the REDCap 10.1.2© secure database.

## Data analysis

Results are presented as numbers and proportions.

For comparison between groups, gender identity was categorised to women (including trans women and whakawahine), men (including trans men), and non-binary.

Ethnicity was categorised to Māori, European (including Aotearoa New Zealand and other European), and other ethnicities (African, Asian, Pasifika, Middle Eastern, Latin American) are combined due to their small numbers. These terms are used to refer to these study populations throughout the report.

Area of residence was categorised to urban (cities of more than 100,000 population: Auckland, Wellington, Hamilton, Tauranga, Christchurch, Dunedin) and rural.

The section asking about “stigma and discrimination you may have experienced because you have HIV” comprised of 11 questions in areas of stigma such as being excluded from social or other gatherings, verbal or physical harassment, and employment issues. Answers to each of the 11 questions were analysed separately. The answers were also combined to a single variable incorporating participants who answered ‘yes’

to any one of the 11 questions (categorised as ‘stigma ever’) and another variable of participants who answered ‘yes’ to any one of the 11 questions reporting that the stigma or discrimination had occurred in the last 12 months (categorised as ‘stigma in the last 12 months’).

The Quality of Life “PozQoL Scale” asked questions relating to the psychological, social, functional and health concerns of people living with HIV. Participants could indicate their response to the 13 questions on a scale from one “Not at all” to five “Extremely” and these were coded according to the PozQoL Scale Implementation Kit (Brown, et al., 2018).

Free text responses from the participants to any questions were noted at the end of the questionnaire. A thematic analysis occurred of these comments, and quotes from these have been provided throughout the report.

## Confidentiality

To ensure confidentiality, each participant was given a unique study identification number that was used on study documentation and in the confidential database. The names and contact details of participants were known only to the Study Coordinator and the assigned interviewer. These details were kept separate to other study documentation.

## Ethical approval

The study obtained ethical approval from the University of Otago Human Ethics Committee (Health) (H18/135).

## COVID-19 pandemic

On 25 March 2020, Aotearoa New Zealand commenced a nationwide lockdown in response to the increasing number of COVID-19 cases. This lockdown lasted until 14 May when restrictions were eased. In-person interviews were suspended during the lockdown and interviewers were advised they could do interviews online via Zoom or Skype, if both the participant and interviewer were comfortable with this medium and felt able to interview. Most interviewers preferred to wait until lockdown restrictions were eased.

The main impact of this lockdown was increased project costs, delayed recruitment, and increased levels of anxiety amongst participants and interviewers, with the Stigma Index Working Group reluctant to contribute further to anxiety by continuing interviews. However, the medium of online interviewing remained an option after restrictions eased and was preferred by some participants. Of all study participants, 70% had completed their interview before the COVID-19 lockdown.

## Limitations

This study provides an overview of stigma and discrimination experienced by people living with HIV in Aotearoa New Zealand but still has limitations.

First, the small number of participants meant we were unable to explore meaningful differences between groups – particularly ethnic groups. Any future study on stigma and discrimination would require considerably more funding that allowed for a much larger sample of participants to be recruited across the range of ethnic groups, and gender and sexual identities to better represent people living with HIV within Aotearoa New Zealand.

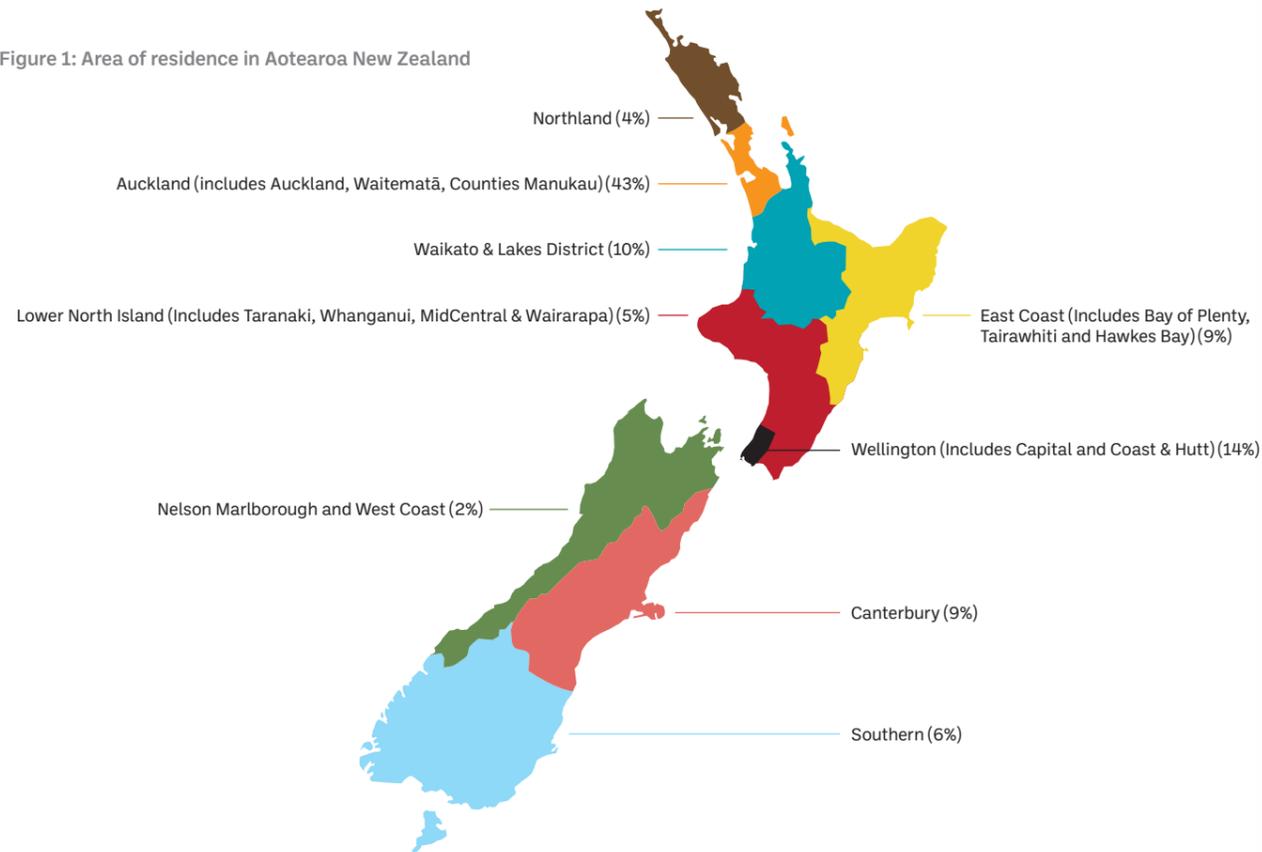
Second, participant recruitment was mostly through the networks of people living with HIV, specialist clinicians and pharmacies rather than a random selection. This is therefore potentially a biased sample of people who are engaged in care and support. Further research would require finding ways to reach people living with HIV outside of these groups to truly understand the stigma and discrimination experienced.

Third, the International Stigma Index questionnaire is primarily quantitative, using generic questions able to be used across many settings and countries. While this is useful in having a baseline of validated questions that allow us to compare stigma and discrimination between countries, it does not allow for local context. Moreover, interviewers in their feedback reported that behind each question were many stories, and it was not possible to effectively capture these within the index framework. Any future research needs to allow for a qualitative component to record these stories in greater depth.

# 1. Who took part?

A total of 188 people living with HIV from around Aotearoa New Zealand were interviewed between July 2019 and September 2020, as can be seen in Figure 1.

Figure 1: Area of residence in Aotearoa New Zealand



Participants broadly represented the current demography, characteristics and diversity of people living with HIV in Aotearoa New Zealand in geography, age, gender, and ethnicity (Figure 2).

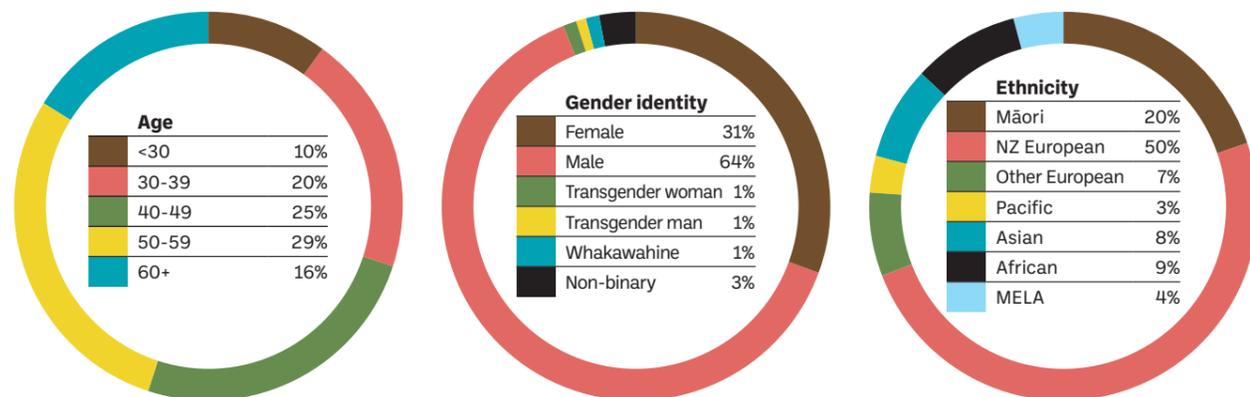


Figure 2: Age, gender, and ethnicity of participants

Most participants had completed tertiary level education and were currently in paid employment, either full or part-time, which reflected that participants were well-educated and mostly able to meet their basic needs (Figure 3).

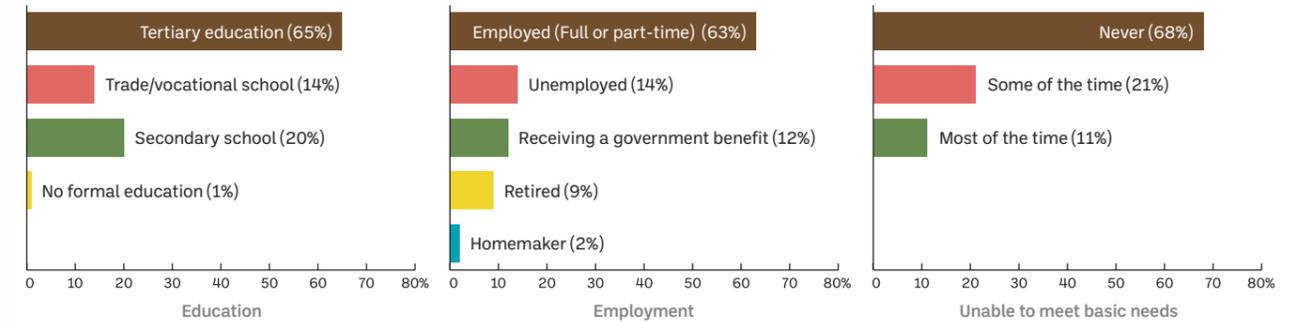


Figure 3: Education, employment, and ability to meet basic needs of participants

Sixty percent of participants had been born in Aotearoa New Zealand. Of those born overseas, the majority had been living in Aotearoa New Zealand for more than five years (Figure 4).

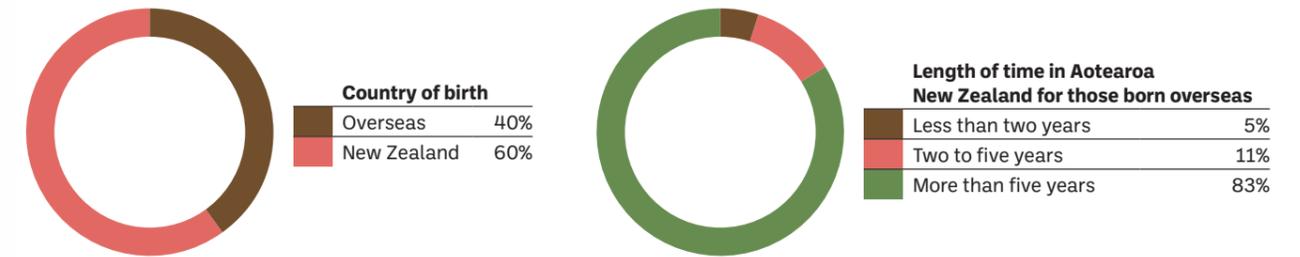


Figure 4: Country of birth and length of time living in Aotearoa New Zealand

Over half of the participants identified as a gay, bisexual, or a man who has sex with men (GBM), and 35% of participants (12 men, 55 women) were heterosexual (Figure 5).

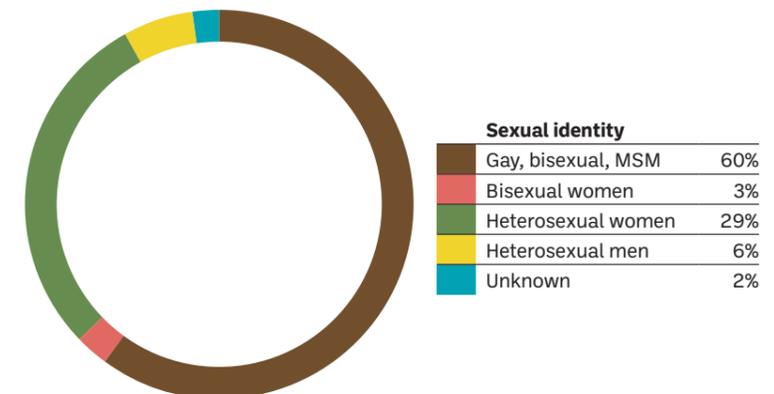


Figure 5: Sexual identity of participants

Sixty-nine (37%) participants said they had ever injected or habitually used drugs such as heroin, cocaine, or methamphetamines. Of these, 59 (6 women; 53 men) identified as a person who uses (or used) drugs.

Sixty-two (33%) participants said they had ever had sex in exchange for money or goods but only four people identified as a sex worker.

# 2. HIV testing, diagnosis and treatment

## 2.1 Testing and diagnosis

Most participants were first diagnosed with HIV in Aotearoa New Zealand and most (61%) were diagnosed more than 10 years ago. Only 10 participants were diagnosed in the last two years (Figure 6). Most participants had therefore been living with HIV for some time and were members of support networks or organisations (71%). This also suggested they were more likely and able to engage with this research.

Of those diagnosed in Aotearoa New Zealand in the last 10 years, nearly a quarter reported that testing was either without their knowledge, without consent, or under pressure; the remainder reported it was their own choice to be tested (Figure 7).

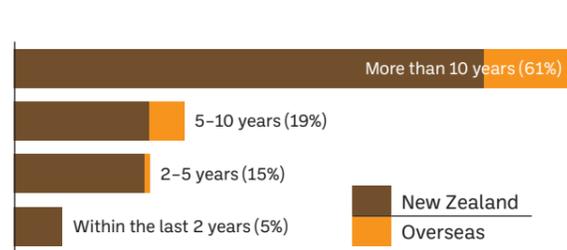


Figure 6: Time and place of HIV diagnosis (n=188)

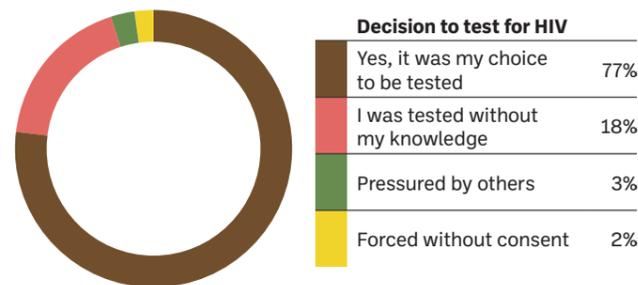


Figure 7: Decision to test for HIV among participants diagnosed in Aotearoa New Zealand in the last 10 years (n=65)

*The worst experience I have ever had with a healthcare worker was on the day I was diagnosed. After the test result came back positive and I was in shock they said to me "Didn't you know there was a drug you could have taken soon after to prevent this." This was six years ago, and I am still fuming at the stupidity of the question.*

NZ European, heterosexual, female, 29

*I got a cancer diagnosis and as part of general screening got tested for HIV. I'd had it for seven to ten years. I'd had general STI screening in that time and never had been made aware that HIV was a separate test.*

NZ European, heterosexual, male, 40

**Most participants were first diagnosed with HIV in Aotearoa New Zealand and most (61%) were diagnosed more than 10 years ago.**

## 2.2 Treatment

All participants were currently on antiretroviral treatment. Most participants who were diagnosed in Aotearoa New Zealand within the last 10 years started treatment within six months of their diagnosis (Figure 8).



Figure 8: Length of time to start treatment for those diagnosed in Aotearoa New Zealand in the last 10 years (n=65)

Of the 16 people who started treatment later than six months after their diagnosis, nine said they chose to start as soon as it was offered. Prior to July 2017, treatment was not available to those with a CD4 count over 500 which may have contributed to delays. Seven said they made the decision to wait and start treatment later. A variety of reasons for hesitating or delaying getting care or treatment were reported by all participants diagnosed in the last 10 years, as indicated in Figure 9.

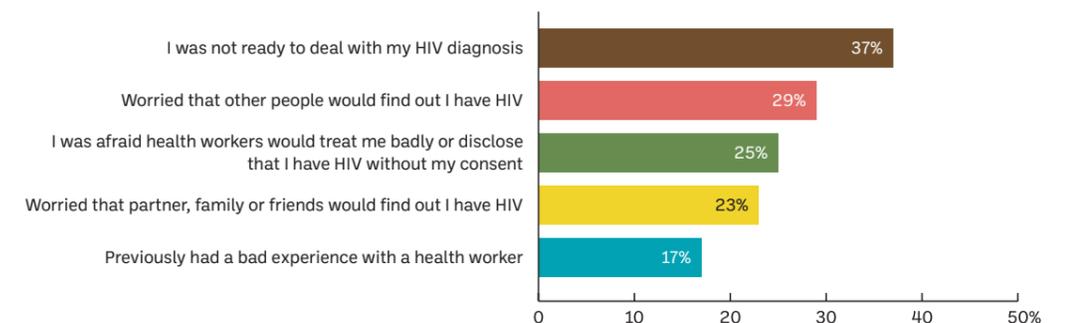


Figure 9: Reasons for delay or hesitation in getting care or treatment for HIV for participants diagnosed in Aotearoa New Zealand in the last 10 years (n=65)

Ninety-five percent of participants reported their viral load was undetectable, which was higher than the 82% reported in a recent study in Aotearoa New Zealand (McAllister, et al., 2020), reflecting that the study participants were a highly engaged population.

*Middle aged undiagnosed women are at the greatest risk of dying in NZ because the NZ medical professionals never consider their constant illnesses could be HIV related.*

NZ European, heterosexual, female, 57

*The pharmacy used to resist getting in meds because they were expensive, and they weren't sure I'd come to collect them. I ended up changing pharmacies.*

NZ European, heterosexual, female, 35

# Recommendations

- Further research is needed on people living with HIV who are not members of a support organisation, as it is possible their diagnosis and linkage to care experience is different.
- With nearly a quarter of participants (23%) tested without their knowledge, without consent or under pressure – a review of standard operating procedures for HIV testing must occur across clinical sites. Further education is required on the importance of informed consent for testing.
- Community-based testing and campaigns to normalise regular HIV testing and promote the range of testing options available (including self-testing) need to be scaled up.
- PHARMAC must modernise and widen the range of funded treatment options offered to people living with HIV to ensure optimal treatment outcomes and adherence. This is especially timely as we now have an ageing population living with HIV who may be experiencing the growing burden of medication toxicity.

# 3. HIV disclosure

Almost three-quarters (70%) of participants said it is difficult telling people about their HIV. A similar proportion said they often hide that they have HIV from others (69%), and this was reported more in the combined group of Asian, African, Pasifika or MELA participants (84%).

When disclosing to people they did not know very well, only half agreed it had been a positive experience. Similarly, only half agreed that people they did not know very well were supportive when they first learned the participant had HIV.

Participants were most likely to tell their spouse or partner (83%), family (67%), or friends (63%) about their HIV, and were less likely to disclose to classmates, colleagues, and employers (Figure 10).

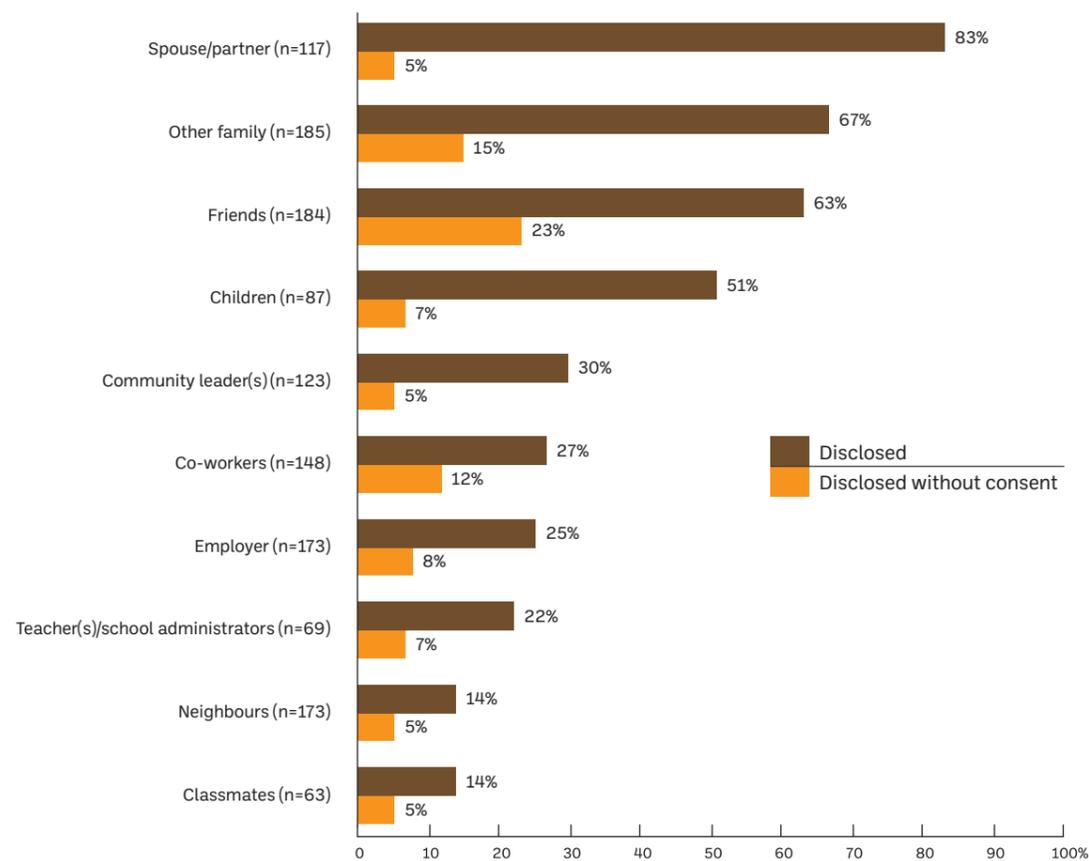


Figure 10: Disclosure of HIV

*I have heard health professionals discussing my health in the corridor of a busy practice with others without any concern of my right to privacy and confidentiality... Secrets around my HIV status are part of my daily living now. I have grown accustomed to hiding a part of myself because of fear for my family and self.*

Asian, heterosexual, female, 44

## 3.1 Partners

Eighty-one (43%) participants were currently in an intimate sexual relationship. For the majority (93%), their spouse or partner knew about their HIV, although four people said their HIV had been disclosed without their consent. Seven participants (9%) reported spouses or partners had experienced discrimination within the last 12 months because of their HIV.

*I am open about my HIV status and I can disclose about it to anyone easily, but I find it so hard to do it when it comes to or involves intimacy.*

African, heterosexual, female, 47

*I am fearful of disclosing to a potential partner not knowing where that info will go. I'm more worried about how it would affect my whānau.*

Māori, gay, male, 54

*I have not had much stigma if any. It has helped me having full support of my family which has helped me be more comfortable with having HIV and it is getting to a point where I am strong enough to not care what people think. I had a partner at the time who tested negative however he stayed with me and was happy and supportive. I didn't feel comfortable as I felt like I was going to hurt him by giving him the virus. Little by little receiving love and hugs it gave me hope and made it easier for me to accept love in the future.*

Māori, gay, male, 40



### 3.2 Family and friends

While most participants had told their family (67%) or friends (63%) about their HIV, this disclosure was without consent for 15%, and 23%, respectively (Figure 10).

The family of all Māori participants knew about their HIV compared to 83% of Europeans and only 64% of participants in the combined group of Asian, African, Pasifika and MELA. Similarly, the friends of 92% of Māori and 93% of European participants knew about their HIV compared to only 64% of participants in the combined group of Asian, African, Pasifika and MELA.

Fewer of the participants diagnosed in the previous five years had disclosed to their family (68%), suggesting there were barriers to disclose for newly diagnosed people living with HIV.

Amongst those whose family or friends knew, the majority agreed this has been a positive experience and that people close to them were supportive when they first learned of their HIV (Figure 11).

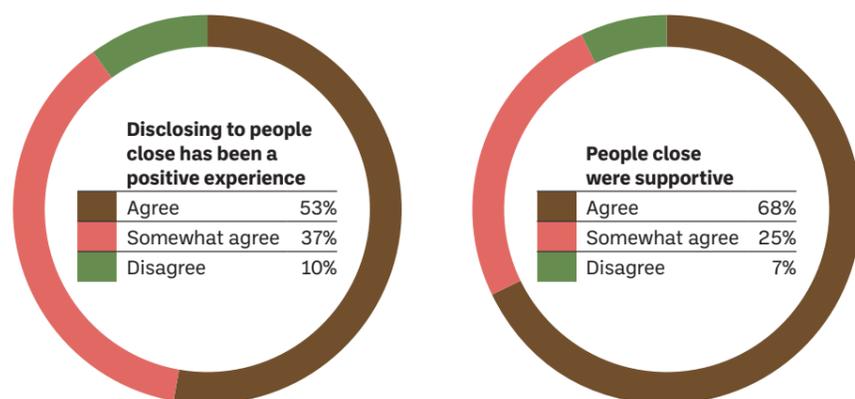


Figure 11: Experience of participants who had disclosed their HIV to family or friends

*I've never had a bad reaction to telling people so far – My family don't know because I don't want them to worry or look at me differently. I know they would be 100% supportive and would rapidly become clued up on the situation and likely become activists.*

NZ European, gay, male, 38

*My personal lived experience of growing up as young Māori male in his early 20's took a great toll on me. There were many times I felt ashamed or unsure how I would tell friends and family. It was an exhausting secret kept to myself... However, one day after seeing my GP I had had enough, and I decided to reach out those who were living what I was going through. and it gave me hope.*

Māori, gay, male, 27

**Fewer of the participants diagnosed in the previous five years had disclosed to their family (68%), suggesting there were barriers to disclose for newly diagnosed people living with HIV.**

### 3.3 Workplace

Disclosure within the workplace was low. Of the participants currently working, 32% reported their employer was aware of their HIV status, and 28% said their colleagues were aware. Although for 4% and 8%, respectively, their HIV had been disclosed without their consent.

HIV was also having broader effects on people's ability to work. In the last year, 20% of all participants had decided not to apply for a job, 4% had been refused employment or lost a source of income, and 5% said their work had changed – all due to their HIV.

*The issue of disclosing to an employer is awkward and fraught with fear. I often haven't told an employer but, in some situations have, for example, when needing to disclose the reason for going to specialist medical appointments regularly. The potential impact of disclosing has to be weighed up and can cause an internal struggle.*

NZ European, gay, male, 58

*I feel that I haven't experienced stigma but that is most likely because I have not disclosed to many people. So that is a form of stigma because I feel there would be a negative response to my disclosure. I work as a teacher... The way I feel most secure at school is to tell no one at school that I have HIV.*

Māori, heterosexual, female, 59

Through the free text comments, a number of participants reported they were healthcare workers and expressed difficulty disclosing their HIV in the workplace, anticipating negative reactions and stigma from their colleagues. This supports the earlier research done by Fisher and Henrickson (2019), which found that despite legal protections from workplace discrimination for people living with HIV, stigma and discrimination within the medical workplace remains a significant issue for healthcare workers living with HIV.

*I won't go to the hospital I work in to get bloods done as I want to protect my identity... I am hesitant when needing healthcare as it's difficult to remain anonymous. I get meds delivered to another hospital to keep private.*

NZ European, heterosexual, female, 58

*As a health worker, I get in contact with so many naive people about HIV. As a result, I am extremely protective of my status – as it may affect the patients and people I give service to at my work.*

African, heterosexual, female, 48

*I work as a healthcare professional and I have witnessed other colleagues expressing badly about HIV+ patients. I need to get a surgical procedure, but I feel uncomfortable disclosing my status as I work in health environment.*

Asian, heterosexual, female, 37

It is clear therefore that for a significant number of people living well with HIV, stigma remains a significant obstacle which affects how, when and to what extent disclosure occurs.

**Of the 119 participants currently in full or part-time employment:**

**32%**

**38 PARTICIPANTS** said their employer knows about their HIV and 5 (4%) said their HIV had been disclosed to their employer without their consent.

**28%**

**33 PARTICIPANTS** said their co-workers know about their HIV and 10 (8%) said their HIV had been disclosed to their co-worker/s without their consent.

**Of all participants (n=188):**

**18%**

**33 PARTICIPANTS** had been refused employment or lost a source of income or job because of HIV and 8 (4%) within the last 12 months.

**13%**

**24 PARTICIPANTS** had their job description or nature of their job changed, or were denied a promotion because of their HIV, and 9 (5%) within the last 12 months.

**4%**

**7 PARTICIPANTS** said they were forced to get tested for HIV or disclose their HIV in order to apply for a job or get a pension plan, and 6 (3%) within the last 12 months.

# Recommendations

- Greater education is needed for people living with HIV to know their rights to privacy under The Privacy Act (1993) and Human Rights Act (1993), providing greater clarity on when disclosure is required.
- Resources for and from HIV community organisations need to be created to support the empowerment of people living with HIV to know their rights and legal responsibilities. Improved workplace resources are needed for when disclosure occurs, so colleagues are educated about HIV and supportive of the person. These resources will also need to address the importance of the Human Rights Act (1993) and non-discrimination in the workplace – as well as the ramifications of breaches of these. Respondents reported losing jobs, career opportunities and experiencing workplace discrimination due to their HIV – which is illegal.
- With low levels of disclosure to family and friends among people diagnosed within the past five years, it is important people are linked to counselling and peer networks and are supported in their decision on when to disclose.
- High levels of HIV stigma exist among healthcare professionals. Greater workforce education is needed to address stigma and discrimination within healthcare, including education campaigns on the safety of healthcare workers living with HIV. Additional training and mentoring, as well as a renewed emphasis on the use of universal precautions, is necessary to ensure a safe and inclusive working environment.
- Healthcare must develop, implement, and reinforce workplace policies that are non-discriminatory and supportive to reduce HIV-related stigma.
- More culturally appropriate programming and resources to support people living with HIV to know their rights and feel confident in their decision to disclose or not as there are higher levels of non-disclosure in African, Asian, Pasifika and MELA communities.

# 4. Experiences of stigma and discrimination

## 4.1 HIV-related stigma

Seventy-five percent of participants reported they had experienced stigma or discrimination related to their HIV and 35% said this had been experienced within the last 12 months. Stigma in the last 12 months was reported more by people living in rural areas (47%) compared to those living in the main cities (Auckland, Hamilton, Tauranga, Wellington, Christchurch, Dunedin) (31%).

Stigma or discrimination within the last 12 months was also reported less by people in the combined group of Asian, African, Pasifika or MELA (20%) compared to Māori (43%) and Europeans (39%). It is unclear, however, if this was partly due to people of these other ethnicities not disclosing their HIV as much. Such findings are supported by the earlier research done exploring the cultural reluctance to disclose among African migrant and refugee communities, and the desire to avoid layering more stigma on top of existing stigma related to being Black and migrants (Henrickson, Dickson, Mhlanga, & Ludlam, 2015).

The main types of stigma experienced were discriminatory remarks, gossiping, or verbal harassment (Figure 12).

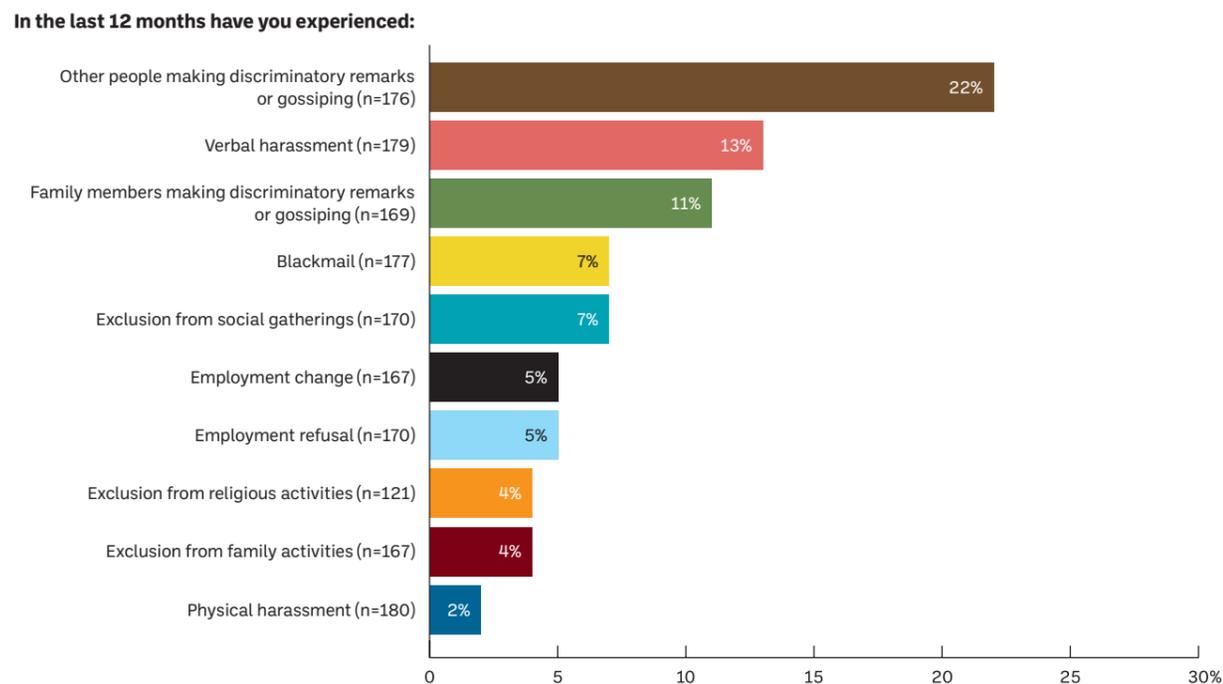


Figure 12: Experience of stigma and discrimination in the last 12 months due to HIV

*I was born with HIV. I was seven years old and my best friend invited me to a sleepover and when I took my ARVs [antiretroviral treatment], his father (a doctor) looked at them and he kicked me out, changing his son to another class in the school. I was in year 11 when I wanted to join high school, but I was rejected; my social worker managed to get me into the school, but I was bullied and harassed. In year 12 I dropped high school because of peer pressure and bullying.*

NZ European, heterosexual, male, 25

*We were staying in a flat six years ago. The head tenant was asking repeatedly why my partner was not working so he disclosed he had HIV, as I have as well. We were given notice to leave the flat. Three weeks' notice to move out was given. We had a roommate who was sharing a house with us and he even went to take a test cuz he shared shower and spaces with us, and he didn't want AIDS. So, we decided to go and look for another place. When we saw a place, someone (a friend of our ex-flatmate) somehow contacted our new landlord to tell him we are HIV+. The landlords didn't want to have us as tenants anymore. We decided to go the Housing/Tenancy Tribunal to denounce that, but it was hard to prove he was told we were living with HIV. We were homeless because of this horrible experience.*

NZ European, heterosexual, female, 24

*...in our culture homosexuality is viewed as a sin, living with HIV a death sentence. When my parents discovered I had HIV they were actively wanting me to use separate dishes, to use 'tongs' when I handle food in the kitchen. It made me feel really dirty, and very low. The people in my life who are meant to love me and take care of me, think I am some infectious leper.*

Asian, gay, non-binary, 27

Based on participants comments throughout the interviews, it is clear this discrimination and harassment occurs not only in person, but increasingly through social media and dating apps.

*The main areas I have felt stigmatised or discriminated against has been when I have disclosed my positive HIV status to guys I have dated. I would either never hear from them again or they would block me from social media apps.*

NZ European, gay, male, 45

*Prior to diagnosis it was easier to get sex. As soon as I disclosed my status on dating apps, there was a decline in the amount of people having a conversation.*

NZ European, gay, male, 23

*On Grindr, when disclosing my status, I was told "fuck off, you're dirty."*

Māori, gay, male, 50

**“When my parents discovered I had HIV they were actively wanting me to use separate dishes, to use ‘tongs’ when I handle food in the kitchen. It made me feel really dirty, and very low.”**

## 4.2 Non-HIV related stigma

Stigma is affected by many factors, and many people living with HIV may also live with other intersecting factors they are also stigmatised for, such as their gender, sexual orientation, and ethnicity. Each of these can be stigmatising on their own, yet they can also layer and compound upon HIV-related stigma.

Of the 112 men who identified as GBM, 77% reported experiencing stigma or discrimination relating to their sexual orientation, with 29% experiencing this in the last 12 months. Most of this was in the form of verbal harassment or family making discriminatory remarks, with these experiences likely resulting in a layering of stigma on top of HIV-related stigma. There were no differences for GBM of different ethnic groups relating to stigma because of their sexual orientation.

Sixty-nine participants reported having used drugs such as heroin, cocaine, or methamphetamines. Of these, 59 said they identified as a person who uses or used drugs. Of those who identified as a person who uses or used drugs, 61% reported experiencing stigma or discrimination because of their drug use and 25% of those experienced this within the last 12 months.

Of the 112 GBM in the study, 49 (44%) identified as a person who uses or used drugs. Stigma experienced in the last 12 months was higher among GBM who use drugs (49%) compared to GBM who do not use drugs (22%), again showing the potential impact of layered stigma. It is not clear at this stage whether the use of drugs could be driven by a desire for community connection and a sense of belonging, as a coping mechanism, or by feelings of marginalisation, isolation, or stigma, with further research needed.

Of the 62 participants (33%) who said they had ever had sex in exchange for money or goods (54 of whom were GBM), 18% had experienced stigma or discrimination because of this. For only 2%, the stigma or discrimination was within the last 12 months, although it is not clear whether this was due to them not having engaged in sex work in the last 12 months. Interestingly, only four participants identified as a sex worker, reflecting either a reluctance to identify as a sex worker and stigma related to the profession, or the casual nature of much sex work between GBM.

All non-binary and trans participants reported to have experienced stigma due to their gender identity, both within the past 12 months and before.

*When married (to a woman), my wife was sick. She wanted to stop treatment for her cancer. The GP then made a comment “no wonder why she doesn’t want to continue treatment” given context of me being gay and HIV+. People often ask if my wife died of AIDS.*

New Zealand European, gay, male, 50

**Stigma is affected by many factors, and many people living with HIV may also live with other intersecting factors they are also stigmatised for, such as their gender, sexual orientation, and ethnicity.**

## 4. Experiences of stigma and discrimination

# Recommendations

- Campaigns targeting the general population with information about HIV transmission with a focus on U=U are needed. These need to explain the differences between HIV and AIDS, and reinforce that people living with HIV can lead long and productive lives.
- HIV stigma is often compounded upon by other stigmas related to being a migrant, sexual orientation, using drugs, or sex work. Campaigns to address stigma therefore also need to be targeted to and address the unique needs of these communities.
- Increased programming, support, and resources to meet the needs of GBM who use drugs.
- Targeted sexual health campaigns are needed on casual sex work among GBM.
- Attempts to recriminalise sex work through council bylaws restricting solicitation and street-based work must cease. Such initiatives only serve to further stigmatise vulnerable populations and create barriers to accessing healthcare.

# 5. Internalised stigma

Feelings of being ashamed, guilty, worthless, and dirty were reported by about one-third of participants (Figure 13). Feeling guilty (58%) and dirty (50%) were reported more by participants who had been diagnosed with HIV within the last five years, compared to those living with HIV longer. This may be an indication of the length of time it takes to reach a level of acceptance about having HIV and may also be a reason for the smaller proportion of newly diagnosed participants recruited in the study.

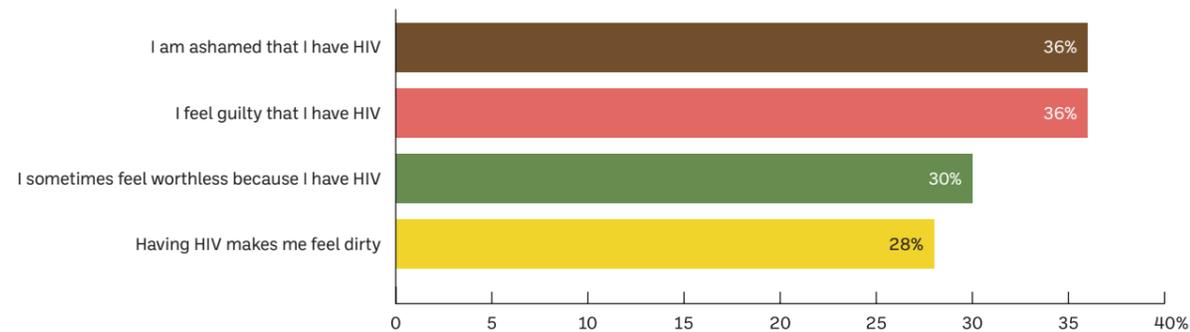


Figure 13: Feelings expressed by participants

Quality of life, as measured by the PozQoL, was lower for participants who expressed each of the feelings outlined in figure 13, which reflects the impact such views have on the ability of people living with HIV to lead full and productive lives.

When asked about the way they felt about themselves over the last 12 months, participants mostly reported being negatively affected in their ability to find love, close and secure relationships, and in their self-confidence (Figure 14). For the first two of these factors, this was reported more in participants diagnosed with HIV within the last five years and in people not currently in an intimate relationship (Figure 15).

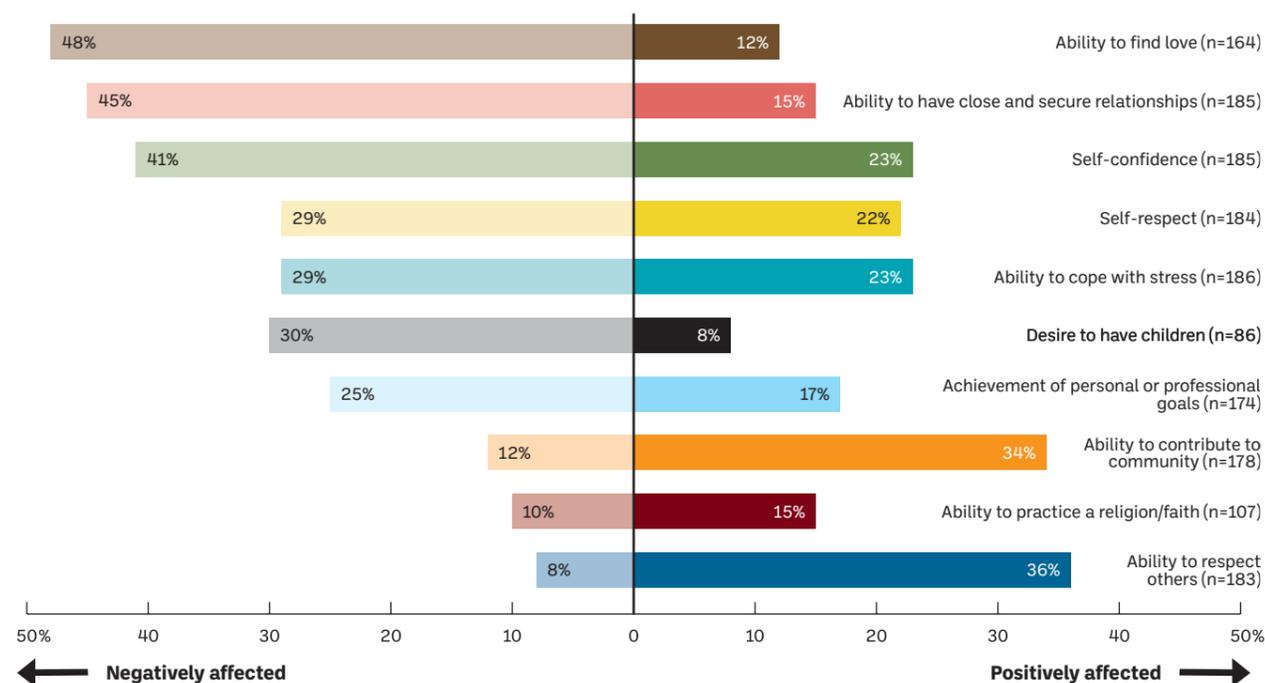


Figure 14: Internalised stigma within the last 12 months

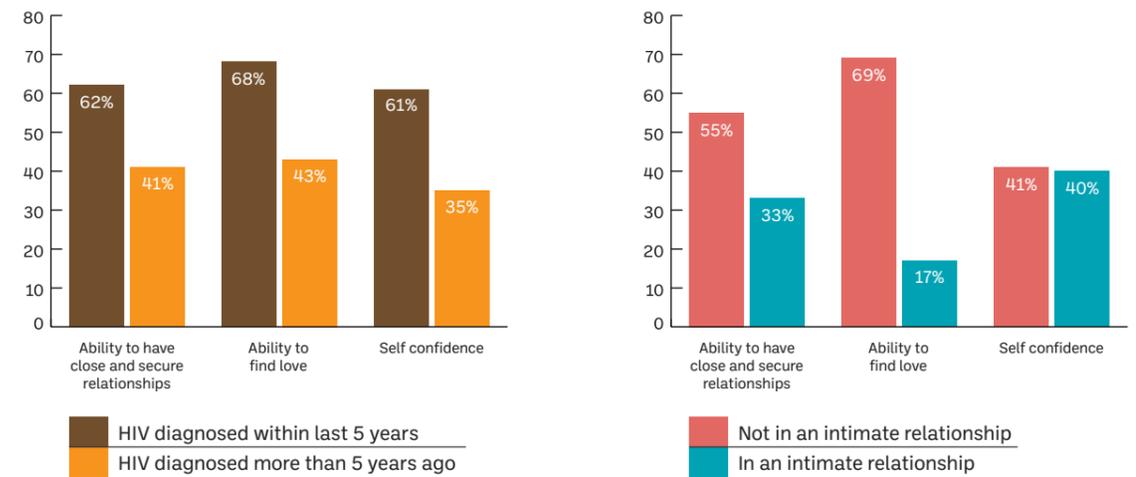


Figure 15: Proportion of participants negatively affected within the last 12 months according to their time of HIV diagnosis and whether or not they were in a current intimate relationship

*Being diagnosed with HIV has changed my life bigtime. The pressure isn't only affecting me but also to the few people who I have disclosed my condition to. I haven't experienced being a victim of stigma from other people even those who knew I have HIV. The stigma I am experiencing is within me. It's internalised. There's a voice saying to me I am outcast, and it is hard not to feel this way. I am trying hard to accept because there's no other options. And I know one day I will succeed.*

Asian, heterosexual, female, 58

*I'd rather be dead than living with this. I HATE THIS! ...Everyone thinks I've got AIDS and I feel deadly.*

NZ European, bisexual, male, 37

*Self-stigma has been huge for me! I have 'beaten' myself up, felt not worthy enough. Betrayed my life values and acted out in very negative ways. I've made two attempts to end my life. I had thought by having HIV my life had ended. I felt guilty that I live and there is now medication I can take to prevent symptoms and allow me to live. I have lost numerous friends to HIV/AIDS they have died - young. I now feel joyful I live and grateful for science and the people that fought to implement change with stigma, medication and human rights. I now am able to assist with combating stigma and discrimination.*

NZ European, gay, male 65

**When asked about the way they felt about themselves over the last 12 months, participants mostly reported being negatively affected in their ability to find love, close and secure relationships, and in their self-confidence.**

Almost half of participants said they had decided not to have sex in the last 12 months (Figure 16). This decision was higher for European men (51%) compared to Māori men (27%) and participants in the combined group of Asian, African, Pasifika or MELA (27%). Thirty-five percent of women said they had decided not to have sex in the last 12 months.

Of the 72 participants who decided not to have sex, 64% were GBM. Fifty-five percent had their HIV diagnosed within last five years compared to 37% who had been living with HIV for longer, again signalling greater self-stigma among those newly diagnosed.

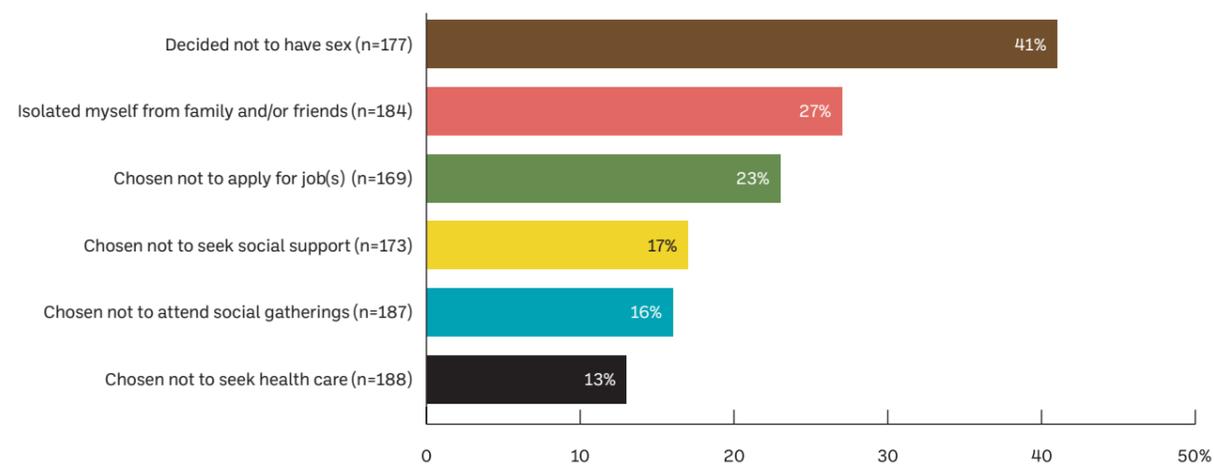


Figure 16: Internalised stigma within the last 12 months

Participants not in a relationship reported higher levels of internalised stigma, perceiving it to have had a strong effect on their ability to find love and to have close relationships (Figure 15). They were also more likely to not attend social gatherings, isolate from friends and family, and decide not to have sex (Figure 17). Their quality of life score was lower (46.0 compared to 48.7) although this difference was not significant.

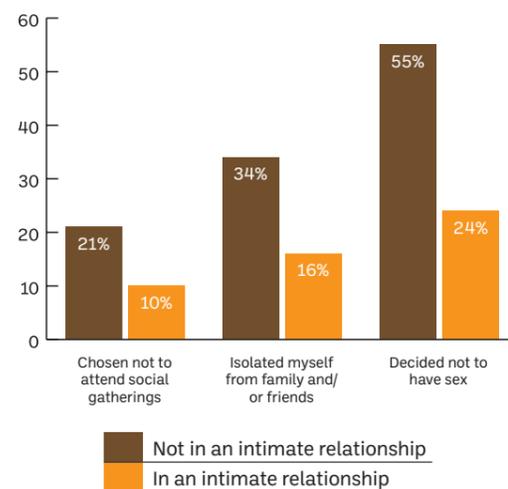


Figure 17: Internalised stigma within the last 12 months according to whether or not a participant was in a current intimate relationship

## 5. Internalised stigma

# Recommendations

- More funding for HIV community support organisations to provide increased strengths-based support focussed on empowerment, self-determination and wellbeing for people living with HIV.
- Further research is needed to explore stigma among the newly diagnosed, who only made up a small number of our participants yet reported higher levels of internalised stigma.
- Newly diagnosed people living with HIV must have a clear and formalised referral pathway to ensure rapid linkage to care and treatment and easy access to support services and counselling.
- Campaigns on Undetectable equals Untransmittable (U=U) need to be expanded to all relevant communities.

**Participants not in a relationship reported higher levels of internalised stigma...**

# 6. Mental health and wellbeing

Nearly half of participants (43%) reported having a mental health condition such as anxiety, depression, or insomnia in the past 12 months, showing significant burden. Most of these participants reported being on treatment or receiving support. This would appear to be higher than the one in five New Zealanders reported to be living with mental distress and or addiction in a given year (Health and Disability Commissioner, 2019)

Furthermore, about a third of participants reported feeling various types of worry or bother over the past two weeks (Figure 18). When comparing the data from participants who completed their interview before the national lockdown due to COVID-19 with those who completed their interview afterwards, there was no evidence that this affected the results or that participants were more worried.

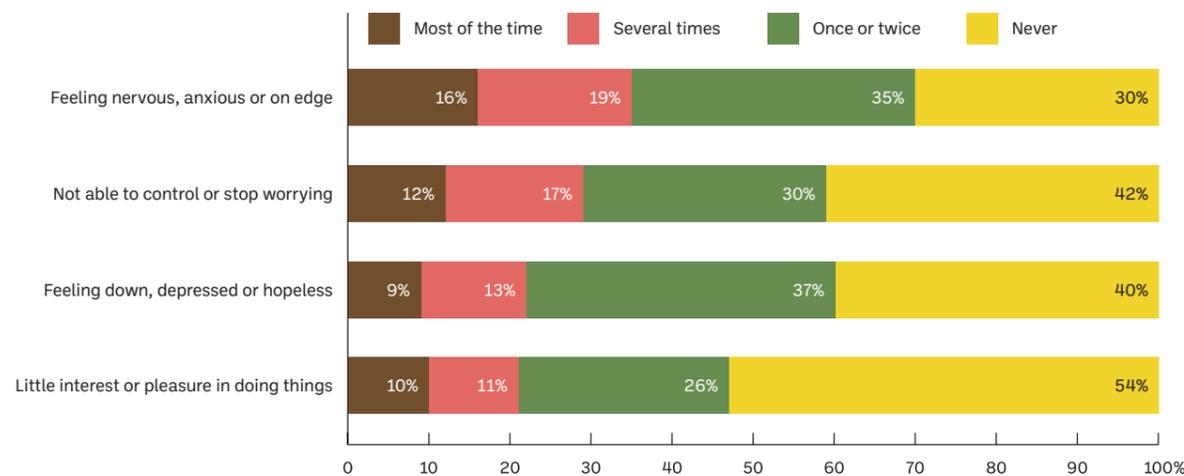


Figure 18: Bother within the two weeks prior to interview

*After working hard to come to terms with my status and improving my personal health (e.g. get off drugs) I have now found myself in a position where I feel extremely lonely. I don't know how or where to meet genuine people or to get involved with others in my same position. I feel very lost and feel that my HIV status holds me back because of my lack of confidence.*

NZ European, gay, male, 41

*I feel I handle my HIV very well and a lot of my issues relate to being a gay man – getting older, ageing, etc... being alone as I get older. When first diagnosed I was very open about my status, at the time I worked in hospitality, and when trying to get back into the workforce, I got a lot of “Don't call us, we will call you”. So, it was difficult to get back into the workforce. And this was not good for one's self esteem.*

NZ European, gay, male, 60

1: PozQoL is a scale which measures a person's psychological and social wellbeing, as well as functional abilities and views on their health. Each participant was given a score on the PozQoL scale with the possible range being 13-65. Participants with scores under 36 are considered to have a low quality of life, with moderate being between 37 and 45, high between 46 and 53, and very high above 54.

These results are further supported by the quality of life PozQoL score, which showed that for 39% of participants, their quality of life was considered low or moderate (Figure 19).<sup>1</sup> The PozQoL score was lower for people who had ever reported any type of stigma or discrimination, and for those who had reported stigma or discrimination in the last 12 months. There was no difference in quality of life scores according to length of time since HIV diagnosis.

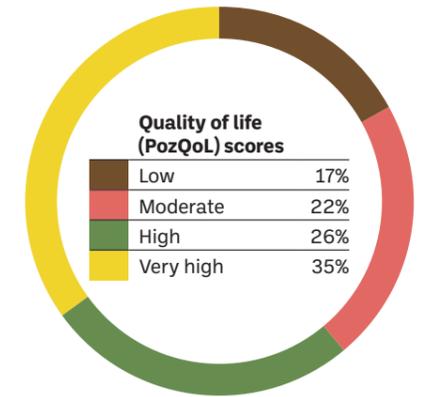


Figure 19: Quality of life (PozQoL) score <sup>1</sup>

*Most of these situations I have been in, I have claimed it and owned it. Having HIV has made me a better person. It has made me more compassionate, empathetic and aware what true suffering is really about.*

NZ European, gay, male, 48

*I've had employment loss and a myriad of other negative experiences from many directions but I do feel the way to change this is to continue to face the hurdles and own the journey until it changes and society accepts HIV for the manageable health concern it is rather than the “big bad”.*

Other European, heterosexual, female, 53

## Recommendations

- Counselling services for people living with HIV must be resourced sustainably with services to be scaled up to be more accessible and timelier.
- Newly diagnosed people living with HIV must have a clear and formalised referral pathway to ensure rapid linkage to care and treatment and easy access to support services and counselling.
- Programmes that focus on the broader wellbeing of people living with HIV to be scaled up, including initiatives on building self-confidence, mindfulness, nutritional advice, and peer support.

# 7. Healthcare

Twenty three percent of participants described their health as only fair or poor.

Many participants reported experiencing stigma or discrimination from interactions with healthcare. The main types are shown in Figure 20, with avoidance of physical contact being the most frequently reported.

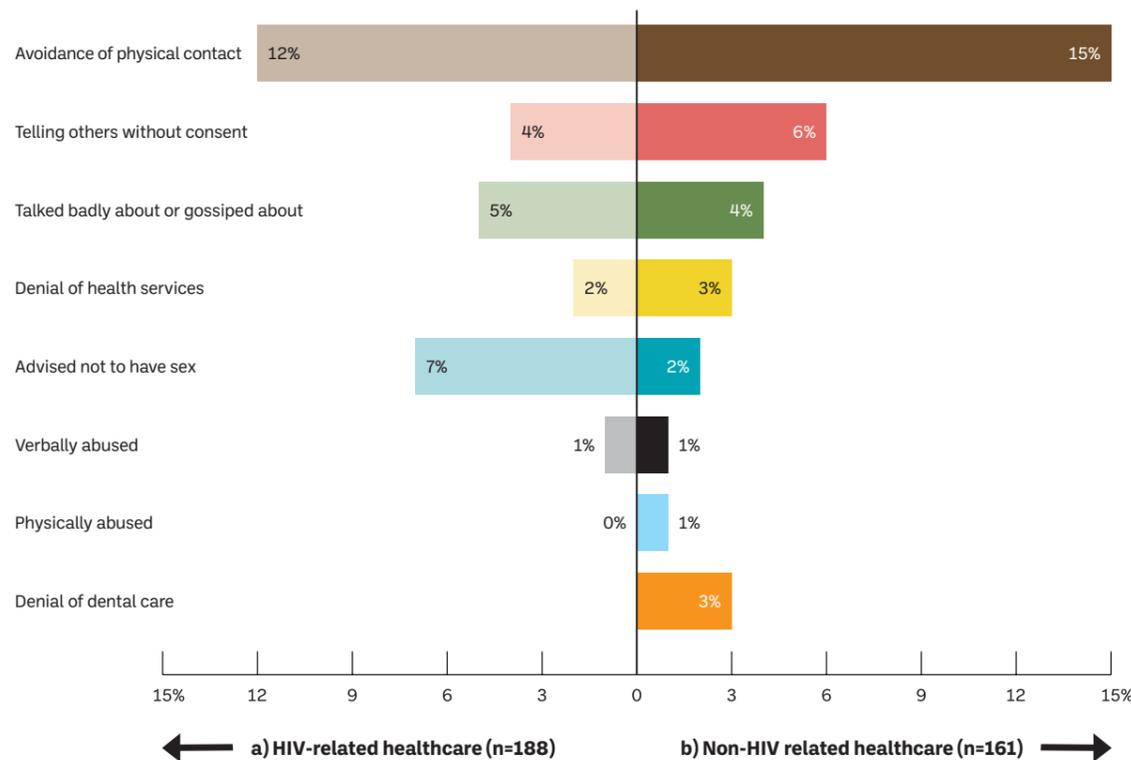


Figure 20: Experiences in the last 12 months with: a) HIV-related healthcare (n=188), and b) non-HIV related healthcare (n=161)

The minimal difference in stigma and discrimination between HIV and non-HIV related healthcare may partly be explained by participants not disclosing their HIV. Thirty-one percent of all participants reported they do not usually disclose that they are living with HIV when they go outside the HIV clinic for general non-HIV related healthcare. It was not clear whether it was fear of stigma driving non-disclosure, or whether participants considered disclosure unnecessary in the context of U=U. Nevertheless, such low levels of disclosure suggest these practitioners may not be getting a holistic understanding of the person's health.

**Many participants reported experiencing stigma or discrimination from interactions with healthcare.**

Thirteen percent of participants believed their medical records were not being kept confidentially and 40% did not know about the confidential status of their medical records. Furthermore, people had concerns about who within healthcare could access their records and whether non-clinical staff were held to the same professional standards.

*I am not too sure if the receptionists abide by privacy laws as healthcare professional are, therefore disclosing your status to someone who is not a healthcare professional can make people not want to disclose.*

African, heterosexual, male, 63

*Abortion – told to have a termination because of HIV diagnosis. Caesarean – was told would have to have caesarean because I'd refused to have termination. Bottle fed/breastfed – couldn't breastfeed due to HIV diagnosis.*

Māori, heterosexual, female, 50

*Was taken to the emergency department at the hospital. At handover, a nurse said to another nurse "you need to double glove, he's got it" (HIV status wasn't disclosed to staff at ED).*

NZ European, gay, male, 54

*Recently I went to my GP to get smoking cessation advice. Every time I go in, the first thing he asks about is my HIV. I explained to him that I didn't want to talk about my HIV, so he refused to give me the prescription for smoking cessation.*

Māori, heterosexual, female, 47

*A few months ago a doctor from the sexual health clinic asked me if I was gay, when I replied that I have a wife and she is my only partner, he asked me "so how did you get HIV then?" and this was an awkward situation.*

Latino, bisexual, male, 36

*When first diagnosed I was worried about the implications to me and my family. Almost immediately the ID staff were supportive, knowledgeable, dispelled myths etc.*

NZ European, bisexual, male, 67

A higher proportion of females (21%) had chosen not to seek healthcare in the last 12 months because they had HIV, compared to males (9%), reflecting greater impact of internalised stigma upon health-seeking practices.

*Stigma and discrimination: sometimes it can be hard to know if you have been denied an opportunity or been abused because of HIV. Because someone will never admit that I can't get this job or enter the uni programme because of my HIV. Even if I feel positively living with HIV, I always have that HIV status playing on my mind. Which I guess it makes me feel different compared to someone who is HIV negative.*

African, heterosexual, female, 47

**...people had concerns about who within healthcare could access their records and whether non-clinical staff were held to the same professional standards.**

# Recommendations

- Increased education within healthcare on how to talk about HIV. Many participants reported receiving questions relating to how they contracted HIV making them feel uncomfortable or stigmatised.
- Consistent training and monitoring of employee behaviour within healthcare must occur to reinforce obligations under The Privacy Act (1993). Greater protection of medical records and personal health data by healthcare professionals and social services would contribute to this, with confidence at times being undermined by lapses within the system.
- Training for healthcare providers on HIV and privacy must include non-clinical staff (managers, human resources, and front-line administrative and reception staff).
- More education is needed for people living with HIV to know their rights to privacy and confidentiality under The Privacy Act (1993) and Human Rights Act (1993), providing greater clarity on when disclosure is required, how medical records are stored, and how protection against discrimination is afforded to them.
- Aotearoa New Zealand's population of people living with HIV are an ageing population, and there are several challenges that may affect their experience of ageing and maintaining good mental and physical health. Further research is needed to explore the ageing population of people living with HIV, including programmes for integrated care and support across health and social services with the needs of older LGBT people to be considered.

# 8. Human rights

Sixty-eight participants (36%) did not know there are laws in Aotearoa New Zealand to protect people living with HIV from discrimination.

The different types of rights abuses reported are shown in Figure 21. The main abuses reported were having to disclose or get tested for HIV to obtain medical insurance or being refused employment or losing a source of income. Insurance companies are still allowed to discriminate against people living with HIV and deny coverage. While this is not a breach of the Human Rights Act, this is a clear area of concern for the participants and the community of people living with HIV. The number who reported having to disclose or get tested for immigration was very small, however, from free text comments it is clear this is still an issue of concern for participants migrating to Aotearoa New Zealand.

Of the 37 participants who reported human rights abuses within the last 12 months, 16 people (43%) said they had challenged the abuse and tried to do something about it.

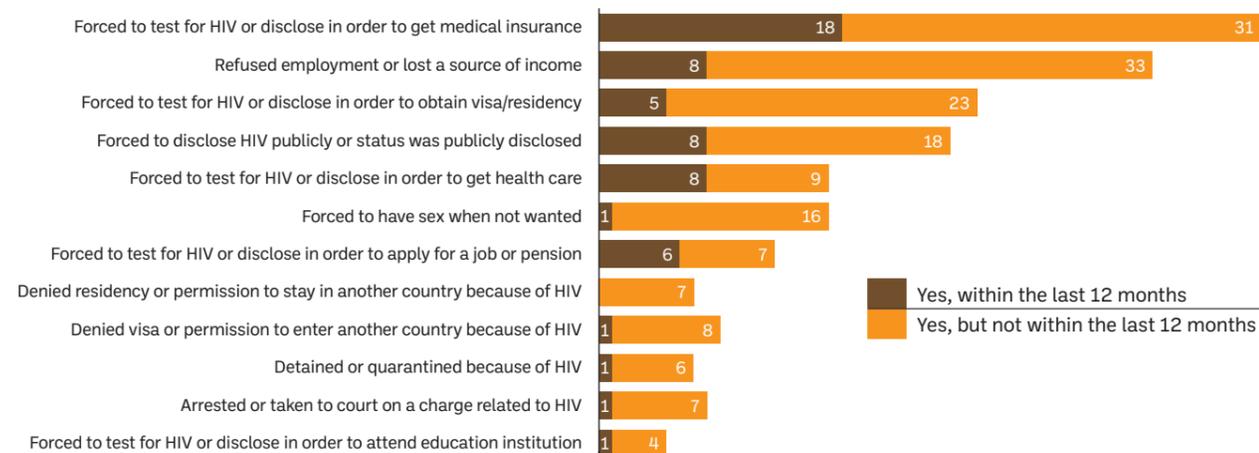


Figure 21: Abuse of rights experienced

*As a person living with HIV it is not clear what my rights are under the human rights act and what constitutes a breach. I am also unaware of laws protecting people living with HIV from discrimination.*

NZ European, MSM, male, 36

*The whole immigration process cost me thousands of dollars and years of instability and insecurity. I feel the experience of being discriminated against by the immigration process was more stressful than the diagnosis of HIV.*

Other European, gay, male, 43

*I was arrested & detained and had to beg on day two to be taken home to pick up my meds, and in the process police broke confidentiality and disclosed my status to flatmates.*

NZ European, bisexual, male, 37

*The laws that are supposed to protect us from discrimination, when considered and lodged as I have done in 2018, are a complete bullshit due to the time lapse of complaints being actioned. This is the same with the Privacy Commission. When I had this experience, which shattered my career I was traumatised and devastated and simply did not have the inner strength to fight.*

NZ European, heterosexual, female, 57

# Recommendations

- HIV must be removed from the Immigration New Zealand list of conditions (A4.10.1) automatically considered a burden to the health system. The automatic exclusion of people living with HIV does not reflect the current health status and life expectancy of people living with HIV nor does it take into account rapidly declining treatment costs.
- The health condition cost threshold used by Immigration New Zealand has not been reviewed since 2012 and is widely agreed to be an arbitrary and outdated figure. The time period for which a health condition is assessed needs to be reduced to being over 10 years, and the cost threshold increased. This would be following in the footsteps of Australia, who in 2019 increased their cost threshold to \$49,000, and the time period over which a health condition is formally costed reduced to being just 10 years rather than a lifetime.
- Insurance providers must review their policies to enable health, life and travel insurance for people living with HIV, without surcharge.
- Greater education is needed to people living with HIV on the protections from discrimination afforded to them by the Human Rights Act (1993).
- HIV transmission must be managed within the public health system. End the use of the criminal justice system to address cases of HIV non-disclosure, exposure, or transmission.

# 9. Support, advocacy and effecting change

Almost three-quarters (71%) of participants belonged to a network or support group of people living with HIV. This was much higher for women (89%), though this may reflect a bias due to Positive Women's key role in recruitment, and that many participants were contacted through their support networks. Fewer men who identified as GBM belonged to a support group (61%). For those who were not a member of a network or support group of people living with HIV, 53% said their support was from their HIV specialist or nurse.

There was no difference in the proportion of participants belonging to a support group according to whether they lived in one of the main urban centres (Auckland, Hamilton, Tauranga, Wellington, Christchurch, Dunedin) compared to other smaller towns or cities in Aotearoa New Zealand. However, a sense of isolation and disconnection among rural participants was reflected within free-text comments and the feedback from interviewers. Moreover, a greater proportion of participants in rural communities had experienced stigma and discrimination. It may be the stigma and the sense of isolation in more rural communities that reinforces the need to belong to a support group, but this would require further investigation.

Overall, participants appeared motivated, engaged, and keen to support their community, as evidenced by the high proportion who took action or offered support in effecting change (Figure 22), embodying and enabling the MIPA principle.

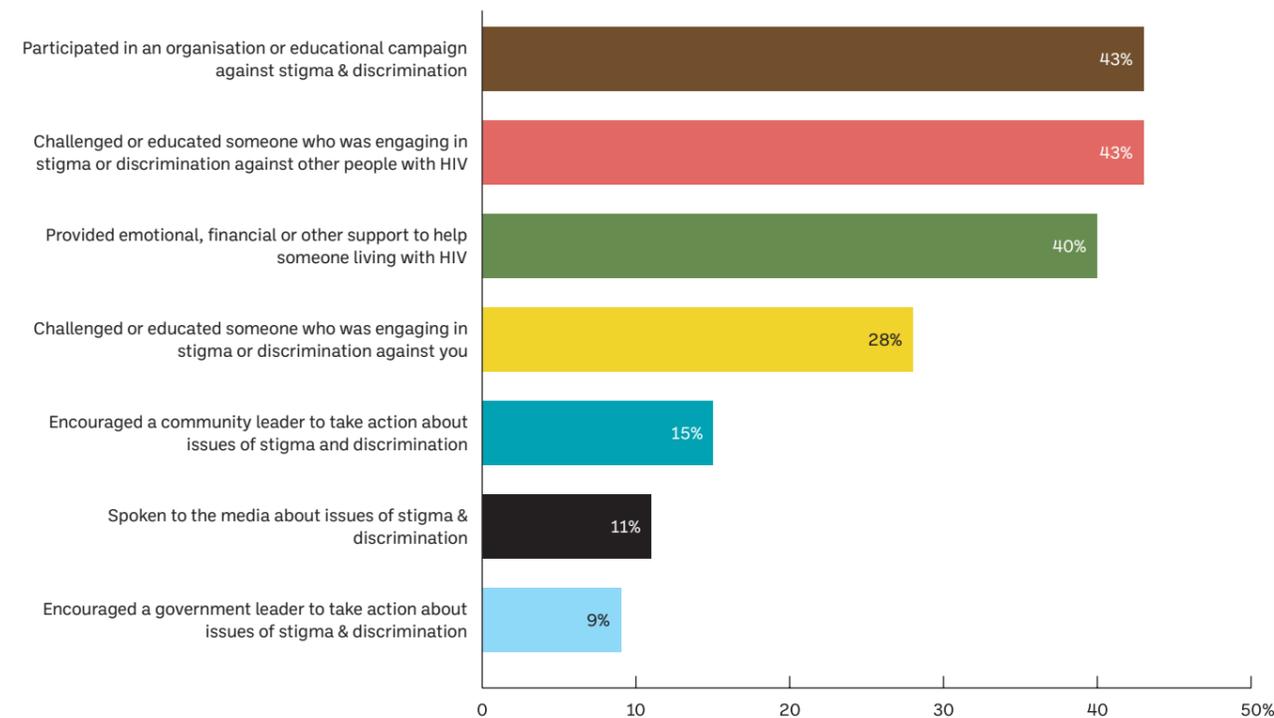


Figure 22: Effecting change and advocacy within the last 12 months (n=188)

## ...a greater proportion of participants in rural communities had experienced stigma and discrimination.

*Self-empowerment starts with yourself. I've also learned a lot of horrible stuff about the world. I've become more aware which has made me more empowered. I'm wiser now and aware. I am now in a better position to call out HIV stigma/discrimination when I see it. Living in the regions (out of the main cities) has been a challenge due to the lack of support and awareness in the regions. I feel it is worse than the bigger centres. I think it is important to have positive voices speak up to make it more normal and to help reduce stigma.*

Māori, gay, male, 35

*I was pretty sure from the get-go, HIV was going to be positive in my life. I was scared. I asked myself - Do you want to die? I thought - Nah I want to live. I really want to do things with my life. Making that decision as a young person has helped keep me youthful, young and happy. It was also about being Māori growing up in the 70s and 80s - my attitude was nah "fuck you", I'm not going to roll over and die and be another Māori stat. I'm not going to be a victim of colonisation. Those kinds of thoughts were very present in my head when I contracted HIV.*

Māori, whakawahine, 44



# Recommendations

- People living with HIV must be empowered to be at the forefront of the response and visible across the sector, in research, advocacy, outreach and support, and marketing.
- The HIV Action Plan (2003) is outdated, and a renewed and ambitious plan is needed to guide the sector.
- People living with HIV outside of the main centres need more access to support services and safe networking places.
- More anti-stigma campaigns need to be targeted to population groups outside of the main centres, to address the higher stigma reported and sense of disconnection.
- More funding for HIV community support organisations to administer programming as indicated in these recommendations and to provide increased strengths-based support focussed on empowerment, self-determination and wellbeing for people living with HIV.
- Further research conducted must continue to be person-centred with people living with HIV involved as implementers, to increase the cultural relevance and applicability of the research and programming.
- Research and programmes must continue to shift the perspective of HIV programming and research whereby people living with HIV are recognised for their agency rather than assumed passive beneficiaries or research participants. This approach taps into the resourcefulness, resilience and knowledge of the person and their communities, to strengthen research and programmes, making them more relevant, appropriate, and effective.

# 10. Interviewer empowerment

To evaluate the impact of peer researchers, we also sought to review how interviewing affected the roles and lives of interviewers. A debrief meeting was held on 12 September 2020 to mark the close of the interviewing period, discuss initial results, and reflect on the interviewing process. From these discussions it became clear that interviewing had a strong impact upon the interviewers. With the principle of MIPA at the centre of this project, we consider these experiences and this impact to also be a result of the study, and of equal importance as the data.

The interviewers shared that, for many interviews, it took hours to go through the questionnaire. Not only to allow time to relax with each other and become comfortable discussing subjects that are often personal and difficult, but also because behind every box ticked within the questionnaire there was a story to tell. While the questionnaire was largely quantitative and based around closed questions, this did create a limitation in translating these stories to the results, with the participants voices limited to the final free-text question. However, the nature of the interview was often casual and relaxed, like two friends chatting, with the discussions and interview happening over meals together or helping with household chores. Yet the interviewers also faced challenges, not wanting to be a burden on the participant's time.

Information gathered during the debriefing session has identified significant stressors related to the project. By taking on a professional role in which the interviewers were interacting with others who shared their lived experiences, this increased their exposure to challenging stories, with the possibility of being reminded of triggering situations from their own past. A prolonged engagement with peers in an interview capacity can impact a person's sense of wellbeing. Furthermore, when research is not progressing as anticipated, interviewers can feel accountable which has the potential to negatively impact their morale. Many found it challenging to balance their role as interviewer, a person living with HIV, and a support person with a clear line needing to be drawn when people needed greater support. Such findings will require greater examination.

However, many interviewers also expressed how much of a privilege it was to sit with people and listen, and to hear their stories. This was described as humbling and heartening, as participants discussed things that some had never had a chance to do before. The interviewers felt they carried these stories with them now, with each story enriching their own lives. It brought up deeply sad and personal moments, as well as funny, relatable ones. It was of interest to the interviewers that some participants expressed they never thought about HIV and that it is just in the background as a part of their lives. Yet for others it was something they had never been able to talk about, and the interview was their first opportunity to do so. One gay male interviewer shared that listening to the women's stories had been enlightening for him, as he had not thought about the experience for women.

**...many interviewers also expressed how much of a privilege it was to sit with people and listen, and to hear their stories.**

**The interviewing process had a strong impact upon the interviewers and how they thought about their own lives and HIV. For some, it has highlighted things they did not realise about themselves.**

As COVID-19 interrupted the study, this not only put a pause on interviewing, but changed the medium and nature of interviews for some. Interviewers expressed difficulty with the online interview format, with the screens sometimes representing a barrier in their ability to connect and talk freely, and it raised concerns about privacy with the possibility of being overheard.

The process of reaching out also reinforced the importance of the work and connecting the community for many interviewers, raising questions for them on what they could do to further support and contribute. Appreciation was given to the NZAF counsellors who gave time and space for these interviewers to reflect on the interview process, and the impact it was having on them. One interviewer shared that by connecting with these services and other positive people, it had made life easier and helped them to feel more connected and confident. The interviewers also discussed the importance of participants who did not go through with their interview for some reason, whether because they expressed they were not ready, pulled out, or did not turn up. While these voices may be missing from this report, the interviewers still built a degree of rapport with them and were often a source of support. Their stories will also be carried by the interviewers.

The interviewing process had a strong impact upon the interviewers and how they thought about their own lives and HIV. For some, it has highlighted things they did not realise about themselves. One interviewer shared that the more interviews he did, the more he realised he had in common with other people and how each had dealt with their own diagnosis, increasing his sense of connection to the community. His diagnosis had been a "nuclear explosion" in his own life but hearing other stories brought things into perspective for him. This showed him the resilience of the community. Some interviewers found it uncomfortable to read out statements in the questionnaire such as, "Having HIV makes me feel guilty", which forced them to reflect on how they felt about their HIV. Others felt that they had not had time to process what they had been through yet, noting that the project had been strenuous and emotional work. Nevertheless, the process helped to understand what stigma and discrimination looked like for many. They also felt they were contributing to its end through having these discussions, which resulted in many beginning to strategise on what to do next. They hoped that this report was just the starting point, and a launchpad for beginning to change the landscape for HIV stigma in Aotearoa New Zealand.



Photo 1: Interviewers, published with consent

# Conclusion

This is the first time the People Living with HIV Stigma Index has been run in Aotearoa New Zealand. The key strength of the study was that it was led by people living with HIV. This presented unique challenges and opportunities for all who were involved to work in a way that was inclusive, empowering and truly upholding the MIPA principle.

Interviewers, themselves being people living with HIV, gave their time, energy and skills to embrace the study that went far beyond the collection of information, hearing the stories that lay behind each question. This report, sitting alongside the companion Māori Report, provides enlightening descriptions of stigma and discrimination experienced by people living with HIV in Aotearoa New Zealand.

Funding was limited and the study population small, nevertheless participants were incredibly generous in sharing their experiences and it is vital their voices are heard. The information presented in this report requires meaningful consideration of policymakers and programme coordinators to incorporate the findings so that all New Zealanders can live well, stay well, and get well.



# References

- Abel, G., & Thompson, L. (2017). "I don't want to look like an AIDS victim": A New Zealand case study of facial lipoatrophy. *Health & Social Care in the Community*, 26(1).
- AIDS Epidemiology Group. (2020). *AIDS - New Zealand*. Retrieved from AIDS Epidemiology Group: <https://www.otago.ac.nz/aidsepigroup/otago737423.pdf>
- Bennett, J. (2007). New Zealand women living with HIV/AIDS: a feminist perspective. *Nurs Prax N Z*, 23(1), 4-16.
- Brinson, A., Abel, G., & Desrosiers, J. (2017). "I'm taking control": how people living with HIV/AIDS manage stigma in health interactions. *AIDS Care*, 29(2), 185-188.
- 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(1), 527-.
- Bruning, J. (2009). Stigma and Women Living with HIV: A Cooperative Inquiry. *Thesis submitted in fulfillment of a Master of Social Practice*. Auckland: UNITEC.
- CDC. (2019, September 27). *HIV Stigma*. Retrieved from Centers for Disease Control and Prevention: <https://www.cdc.gov/hiv/basics/hiv-stigma/index.html#:~:text=HIV%20stigma%20is%20negative%20attitudes,believed%20to%20be%20socially%20unacceptable.>
- Consumer Link. (2018). *New Zealanders' Attitudes and Perceptions of HIV*. Auckland: Colmar Brunton.
- Dickson, N., Lee, B., Foster, T., & Saxton, P. J. (2015). The first 30 years of HIV in New Zealand: Review of the epidemiology. *New Zealand Medical Journal*, 31-48.
- Durie, M. (2003). *Ngā Kāhui Pou: Launch Māori Future*. Wellington: Huia Publishers.
- Fisher, M., & Henrickson, M. (2019). Are statutory protections sufficient to protect people living with HIV who are employed in the medical workplace? *International Journal of Healthcare Management*, 12(1), 75-80.
- Fouché, C., Henrickson, M., Poindexter, C., Scott, K., Brown, D., & Horsford, C. (2011). 'Standing in the Fire': Experiences of HIV positive Black African migrants in New Zealand. Retrieved from University of Auckland: <https://researchspace.auckland.ac.nz/handle/2292/7362>
- GNP+. (2020, October 31). Retrieved from PLHIV Stigma Index: [stigmaindex.org](http://stigmaindex.org)
- Grossman, C., & Stangl, A. L. (2013). Global action to reduce HIV stigma and discrimination. *Journal of the International AIDS Society*, 16(3 Suppl 2), 18881.
- Health and Disability Commissioner. (2019). *New Zealand's Mental Health and Addition Services: Monitoring indicator update 2017 & 2017/28*. Wellington, New Zealand.
- Henrickson, M., Dickson, N., Mhlanga, F., & Ludlam, A. (2015). Stigma, lack of knowledge and prevalence maintain HIV risk among Black Africans in New Zealand. *Australian and New Zealand Journal of Public Health*, 39(1), 32-37.
- Henrickson, M., Fisher, M., & Ludlam, A. M. (2016). What do African new settlers in New Zealand know about HIV? *New Zealand Medical Journal*, 129(1434).
- Mahajan, A. P., Sayles, J. N., Patel, V. A., Remien, R. H., Sawires, S. R., Ortiz, D. J., . . . Coates, T. J. (2008). Stigma in the HIV/AIDS epidemic: a review of the literature and recommendations for the way forward. *AIDS*, 22 (Suppl 2), S67-79.
- McAllister, S., van Asten, H., Anglemeyer, A., Crengle, S., Zeng, J., Raymond, N., . . . Priest, P. (2020). Cascade of care of people diagnosed with HIV in New Zealand between 2006 and 2017. *HIV Medicine*, DOI: 10.1111/hiv.12983.
- Miller, D. (2010). *Review of services for people living with HIV in New Zealand*. Retrieved from Ministry of Health: <https://www.health.govt.nz/publication/review-services-people-living-hiv-new-zealand>
- Minister of Health. (2016). *New Zealand Health Strategy 2016: Future direction*. Retrieved from Ministry of Health: <https://www.health.govt.nz/publication/new-zealand-health-strategy-2016>
- Ministry of Health. (2014/2020). *He Korowai Oranga*. Retrieved from Ministry of Health: <https://www.health.govt.nz/our-work/populations/maori-health/he-korowai-oranga>

- Ministry of Health. (2019). *Achieving Equity in Health Outcomes – Summary of a discovery process*. Retrieved from Ministry of Health: <https://www.health.govt.nz/publication/achieving-equity-health-outcomes-summary-discovery-process>
- Ministry of Health. (2020). *Te Tiriti o Waitangi framework*. Retrieved from Ministry of Health: <https://www.health.govt.nz/our-work/populations/maori-health/te-tiriti-o-waitangi>
- Mundt, S., & Briggs, S. (2016). HIV-related stigma and discrimination in the New Zealand healthcare setting: a mixed-methods study. *Sex Health*, 13(6), 582-588.
- NZPC. (2020). *Information for Sex Workers in New Zealand Aotearoa*. Retrieved from NZPC: <https://www.nzpc.org.nz/Information-for-sex-workers-in-New-Zealand-Aotearoa>
- Poindexter, C. C., Henrickson, M., Fouché, C., Brown, D., & Scott, K. (2013). "They don't even greet you": HIV Stigma and Diagnosis Disclosure Experienced by HIV-Positive African Immigrants and Refugees in New Zealand. *Journal of HIV/AIDS & Social Services*, 12(1), 99-120.
- Prevention Access Campaign. (2016). *Consensus Statement: Risk of sexual transmission of HIV from a person living with HIV who has an undetectable viral load*. Retrieved from Prevention Access Campaign: <https://www.preventionaccess.org/consensus>
- Saxton, P., McAllister, S., Noller, G., Newcombe, D., & Leafe, K. A. (2020). Injecting drug use among gay and bisexual men in New Zealand: Findings from national human immunodeficiency virus epidemiological and behavioural surveillance. *Drug and Alcohol Review*, DOI: 10.1111/dar.13046.
- UNAIDS. (2005). *HIV-related Stigma, Discrimination and Human Rights Violations*. Retrieved from UNAIDS: [https://www.unaids.org/en/resources/documents/2005/20051005\\_jc999-humrightsviol\\_en.pdf](https://www.unaids.org/en/resources/documents/2005/20051005_jc999-humrightsviol_en.pdf)
- Waitangi Tribunal. (2019). *Hauora: Report on stage one of Health Services and Outcomes Kaupapa Inquiry (WAI 2575)*. Retrieved from Waitangi Tribunal: <https://waitangitribunal.govt.nz/news/report-on-stage-one-of-health-services-and-outcomes-released/>
- Walker, R. (1990). *Ka whawhai tonu matou: Struggle without end*. Auckland: Penguin Books NZ.
- World Health Organization. (1986, October 30). Retrieved from <https://www.who.int/healthpromotion/conferences/previous/ottawa/en/>



**THE PEOPLE  
LIVING  
WITH HIV  
STIGMA  
INDEX**

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