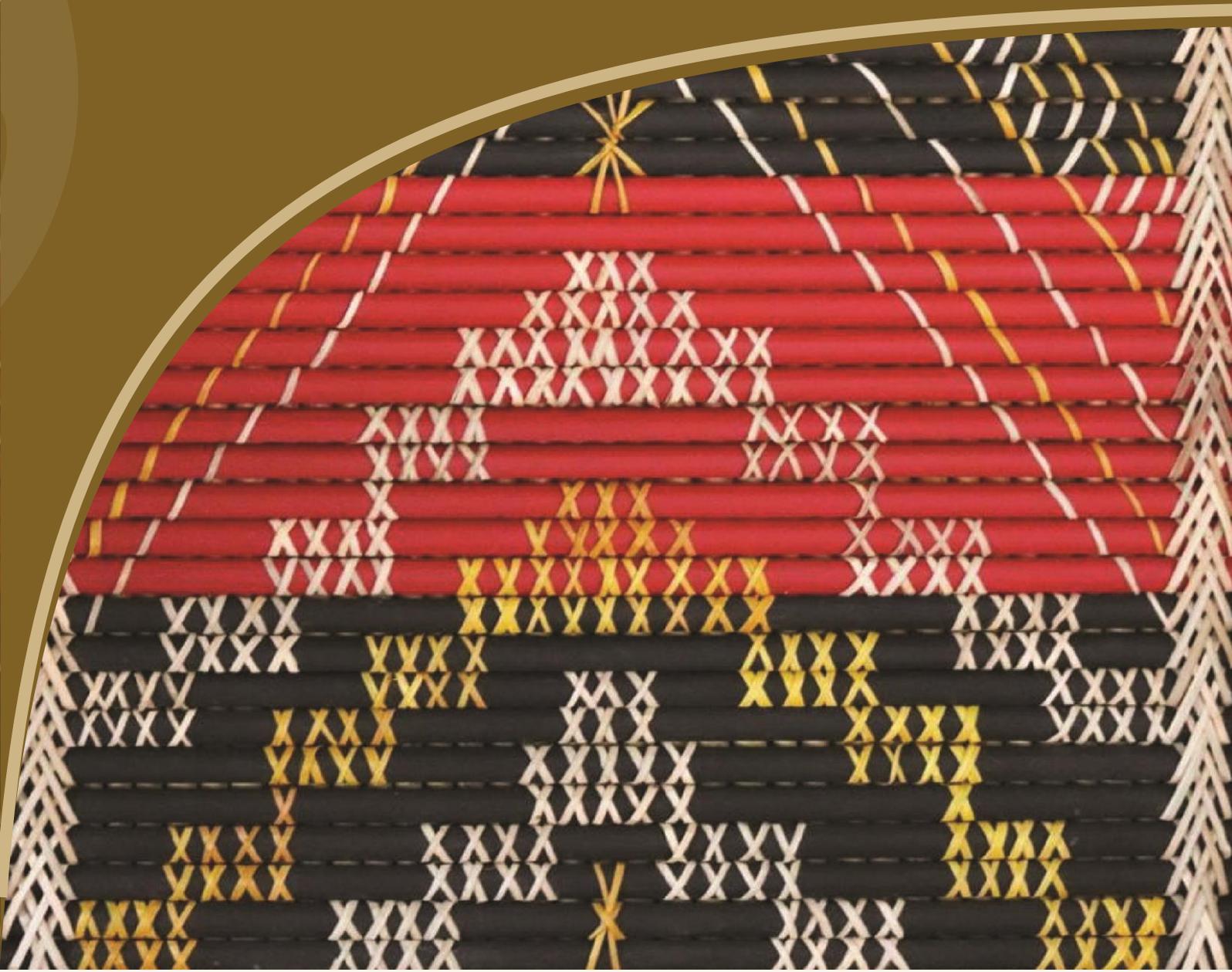


# Aotearoa New Zealand People Living with HIV Stigma Index

Māori Participant Report 2021





Te Whāriki Takapou

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## Artwork:

‘Te Ao Marautanga’ (tukutuku panel) by Kahutoi Te Kanawa.

We asked the Māori interviewers what sort of image or theme they envisioned for the cover of the report and the concept of the ‘poutama’ resonated for them. The poutama represented the gratitude, humility, persistence, resilience and strength they had experienced, from the participants they interviewed and also within themselves, in the shared journey of contributing the experiences of living with HIV to the Stigma Index survey. The poutama also symbolised the interviewers’ aspirations for all Māori people living with HIV to flourish.

For the cover image, with the artist’s permission, we have featured a poutama design from the lower section of a larger tukutuku panel, named ‘Te Ao Marautanga’. The artist, Kahutoi Te Kanawa gives the following explanation of the various symbols in the chosen section:

- The white star pattern is the knowledge being passed on to the next generation; knowledge that is taught by the extended whānau;
- The yellow steps are the poutama, and the white are the pouhine; together these provide the aroha and protection for the child;
- The bottom line represents the foundation, and growth of the child;
- The brown and black backgrounds represent Rangi and Papa.

The tukutuku design that runs from top to bottom on both sides of the cover image is called Whakaiwituna. Te Kanawa explains Whakaiwituna as ‘the binding together of people, the backbone of the iwi, when mātauranga is adhered to through tikanga.’

## Design concept and graphics:

Jacki Coffey and Danielle Kane at Gravitas Media, Hamilton

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# Acronyms

HIV	Human Immunodeficiency Virus
AIDS	Acquired Immunodeficiency Syndrome
PLHIV	people living with HIV
Māori PLHIV	Māori people living with HIV
PLWHA	people living with HIV or AIDS
MSM	men who have sex with men
MSMW	men who have sex with men and women
IDU	injecting drug user <sup>1</sup>
GNP+	Global Network of People Living with HIV
ICW	International Community of Women living with HIV
UNAIDS	The Joint United Nations Programme on HIV and AIDS
STI	sexually transmitted infection
NZHS	New Zealand Health Survey
NZ	New Zealand
PozQoL	a scale to assess Quality of Life of PLHIV

<sup>1</sup> 'IDU' was the terminology used in the Ministry of Health's 'HIV/AIDS Action Plan' (2003) and that is the reason it is included in the list of acronyms. However, IDU is now regarded by many in the HIV+ community as further stigmatising people living with HIV who inject drugs. The term preferred by the New Zealand Needle Exchange Programme is PWID (people who inject drugs).

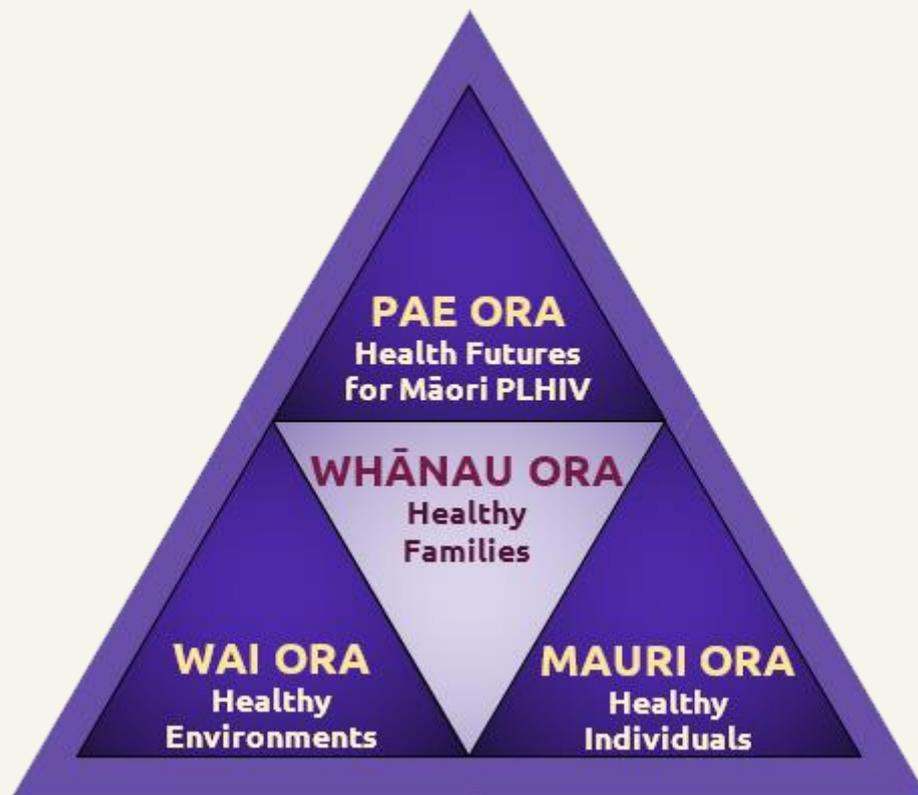
# Glossary of Māori terms

hapū	kinship group, tribe or sub-tribe
iwi	extended kinship group, tribe, nation
mātauranga	knowledge, wisdom, understanding
pouhine	a weaving pattern (see 'poutama'). For some, poutama and pouhine symbolise a vertical and horizontal integration of knowledge, understanding and perspective
poutama	a stepped pattern in tukutuku panels and woven mats, symbolising genealogies and also the various levels of learning and intellectual achievement
Papa; Papatūānuku	a female deity, the personification of Earth
Rangi; Ranginui	a male deity, personification of the Sky and heavens. Rangi and Papa are the primordial deities from whom all living things originate
pūrākau	powerful stories or narratives that enable us to better understand the experiences of our lives as Māori
Takatāpui	Historically, Takatāpui referred to an 'intimate companion of the same sex'. Reclaimed in the 1980s, the term was used by Māori people who identify as gay, lesbian, bisexual, transgender, intersex or part of the 'rainbow community'. Use of Takatāpui as an identity is a response to western binary ideas of sex, sexuality and gender, and emphasises ones identity as Māori as inextricably linked to their gender identity or sexuality
tikanga	the customary system of Māori values and practices that have evolved over time and are deeply embedded in the social context
tukutuku (panels)	ornamental lattice work on panels, typically hung between carvings around the walls of a meeting house
whānau	extended family or family group; the primary unit of traditional Māori society
whakapapa whānau	extended family who are linked by common genealogical/ kinship ties or 'whakapapa'
kaupapa whānau	In a modern context, whānau is sometimes used to include friends who may not have any kinship ties to other members; or to a group that is united around a common cause or purpose (kaupapa)
whakawahine	to become a woman; trans woman
whāngai	a customary Māori practice where a child is brought up by someone other than their birth parents – usually another relative

# Executive summary

For Māori people living with HIV, achieving healthy futures (Pae Ora) will require a sustained national approach to eliminating HIV-related stigma and discrimination. Eliminating HIV-related stigma and discrimination means that Māori PLHIV can strengthen their own health as individuals (Mauri Ora), their whānau will be well informed about HIV (Whānau Ora), and they will have access to resources and live in environments that support and sustain a healthy life (Wai Ora).

This report adopted the vision of Pae Ora or Healthy Futures which, in the context of this study, means good health and wellbeing for all Māori PLHIV. The vision of Pae Ora is adapted from He Korowai Oranga: Māori Health Strategy (Ministry of Health, 2001).



Three interconnected elements of Pae Ora - Wai Ora, Whānau Ora, and Mauri Ora - were used to understand the impact of HIV-related stigma and discrimination on the health and wellbeing of Māori PLHIV who took part in the HIV Stigma Index survey. This approach departs from conventional Western approaches that focus strongly on the health of individuals - often to the exclusion of whānau, friends and communities, and wider environments.

Our approach - a Kaupapa Māori approach - analysed the data with regard to the health and wellbeing of Māori PLHIV as individuals, Māori PLHIV as members of whānau, and the extent to which Māori PLHIV are supported and resourced to live healthy lives and achieve their potential as Māori.

In many ways, participants conveyed the sense that to be Māori and living with HIV in New Zealand today requires tremendous courage, fortitude and a belief in oneself. What was also required was a belief that, all together with other PLHIV and allies, HIV-related stigma and discrimination could be eliminated.

Māori PLHIV who participated in the survey wrote *'The stigma won't change unless we band together'*, and *'I am now in a better position to call out HIV stigma and discrimination when I see it'* and *'I loathe stigma with every fibre of my being. It's so un-evolved, it's a caveman's reality...we don't roll like that'*.

Despite courage and fortitude in what appeared to be bucket loads, the challenges Māori PLHIV reported in the survey were significant. Compared to the health and wellbeing of the general Māori population, Māori PLHIV who participated in the survey were on par in terms of how they rated their own health, but two to three times more likely to be struggling with their mental health. And compared to non-Māori survey participants, Māori survey participants were more likely to struggle to meet their basic living needs - despite having a high level of education. Māori participants were also more likely to report being bothered by an undiagnosed mental health condition, for which they were less likely to be receiving support.

## Mauri Ora - Individual health and wellbeing

- Despite many participants reporting they had lived with HIV for two to three decades, what they told us strongly suggests that HIV-related stigma and discrimination in Aotearoa New Zealand has not reduced since the first Māori reproductive health and HIV/AIDS<sup>2</sup> national hui was held in Auckland in 1995;
- Around a quarter of participants reported they were forced to disclose their HIV-status or experienced rights abuses when using healthcare, justice and employment services, and in the workplace;
- HIV-related stigma and discrimination seriously affected participants' ability to earn an income that met their needs, as well as affecting their close relationships, self-confidence, and ability to find love;

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<sup>2</sup> In 1995, the acronym HIV/AIDS was in common usage internationally and in Aotearoa New Zealand. Since 2007, the UNAIDS guidelines advise that the preferred terminology is 'HIV', unless specifically referring to AIDS, or to both, i.e., 'HIV and AIDS'.  
[https://www.iasociety.org/Web/WebContent/File/un aids\\_terminology\\_guide\\_en.pdf](https://www.iasociety.org/Web/WebContent/File/un aids_terminology_guide_en.pdf)

- Most participants reported they were very concerned about a declining quality of life as they aged;
- Almost a third of participants reported isolating themselves from whānau and friends;
- Three quarters of participants reported that stigma and discrimination made it hard for them to tell people about their HIV status, causing many to hide their HIV status;
- More than half the participants reported they struggled with anxiety and feeling 'down', but only a third received support;
- A very small number of Māori PLHIV reported having attempted to do something about forced disclosure and rights abuses. Reasons for not addressing these matters included participants reporting the complaints process was complicated, they feared retaliation, and they had low confidence in the process to bring about real change.

## **Whānau Ora - Whānau health and wellbeing**

- Most participants agreed that disclosing their HIV status to partners, whānau and close friends had been a positive experience. In general, whānau and friends were supportive;
- While most participants' whānau knew about their HIV status, more than a quarter had had their status disclosed to whānau without consent;
- Three-quarters of participants and a small number of their partners had experienced HIV-related stigma and discrimination from whānau or other people.

## **Wai Ora - Environmental health and wellbeing**

- While most participants said their friends knew about their HIV status, almost a quarter of them had had their status disclosed to friends without their consent;
- Smaller numbers of participants had their HIV status disclosed without their consent at work, at school, or in the community;
- Less than half of participants agreed that disclosing their status to people they didn't know very well had been a positive experience and that people they didn't know very well were supportive;
- More than a third disagreed that disclosure of HIV status had gotten easier over time;

- Three quarters of participants had experienced some form of stigma or discrimination because of their HIV status: just under half had been verbally harassed by members of the public, a quarter had been refused employment, and a small number had experienced verbal abuse when accessing HIV-specific healthcare;
- Three quarters of participants said it was their choice to be tested for HIV; however, others were pressured into being tested or were tested without their knowledge;
- Almost a third of participants had been diagnosed within the last 12 months with a sexually transmitted infection (STI), and a similar number had been diagnosed with mental health conditions;
- Almost a quarter of participants had been the recipient of discriminatory behaviour or attitudes from healthcare staff when seeking care for non-HIV related care;
- A small number of Māori women living with HIV who participated in the study had been pressured, incentivised or advised by healthcare professionals to get sterilised, terminate a pregnancy, use particular infant feeding practices; and take ART during pregnancy to reduce the chance of HIV transmission;
- Almost a third of participants reported they don't disclose their HIV status when using non-HIV related health care services as they fear discrimination;
- Almost a quarter of participants reported they thought their medical records were not kept confidential.

## **Pae Ora - Vision for the future**

- Responses from participants indicate that despite Te Tiriti o Waitangi and international human rights agreements, the right of Māori PLHIV to freedom from HIV-related stigma and discrimination is poorly understood by health and social services and the Aotearoa New Zealand public. As a consequence, these rights are rarely enacted;
- Over half of participants reported that living with HIV over a long period of time did not make it easier to disclose their HIV status;
- Most participants reported the passage of time did not improve their ability to increase their income, achieve life goals, manage stress or contribute to their communities.

# Recommendations

- Eliminating HIV-related stigma and discrimination as experienced by Māori PLHIV is a requirement of Te Tiriti o Waitangi, New Zealand's international human rights framework, and local legislation. An advocacy and public health education policy and implementation plan is urgently required to ensure eliminating HIV-related stigma and discrimination for all PLHIV is a priority, including for Aotearoa New Zealand's 2024 Universal Periodic Review.<sup>3</sup>
- A national HIV and AIDS policy, action plan and associated implementation plan is urgently required, a component of which is the elimination of HIV-related stigma and discrimination.
- A Whānau Ora component is required for the advocacy and public health education implementation plan that is developed by and for Māori PLHIV - with input from whānau representatives. This is essential in order to strengthen and support healthy whānau relationships.
- A nationwide public health education campaign - similar to the 'Give Nothing To Racism' campaign is required to provide evidence-based information and counter misinformation about Māori and other New Zealanders living with HIV.
- A component of the campaign is access to online and face-to-face sexual and reproductive health information and services, including access to modern contraception, reproductive health services, and medical and surgical abortion services.
- Sexual and reproductive health services for Māori women and all women living with HIV In New Zealand must be grounded in principles of gender equality and rights-based approaches in order to achieve long-term improved health status and equity<sup>4</sup>
- A well promoted easy-to-use online HIV stigma and discrimination complaints process designed with and for Māori and other New Zealanders living with HIV is urgently required.

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<sup>3</sup> The Universal Periodic Review (UPR) is a unique mechanism of the Human Rights Council (HRC) aimed at improving the human rights situation on the ground of each of the 193 United Nations (UN) members. The UPR is a five-yearly review of our domestic human rights record, at which UN member states have an opportunity to make recommendations on our progress on human rights. New Zealand's third UPR was in January/February 2019 (New Zealand Foreign Affairs and Trade, 2019).

<sup>4</sup> World Health Organisation 2015, p. 1

- Free advocacy, counselling, support and referral services are urgently required for Māori and other PLHIV - either face-to-face or via an online platform - to address low self-esteem, anxiety, depression and other issues associated with HIV-related stigma and discrimination.
- Health service contracts to DHBs and the Ministry of Health must require clinical and non-clinical staff in HIV-specific and general health services to undergo online or face-to-face professional development courses in order to promote rights-based services, including rights-based disclosure and confidential patient records management, whilst actively eliminating HIV-related stigma and discrimination.
- Resourced positions are required - either within existing nationwide HIV peer support organisations or within a new purpose-built Māori PLHIV-run organisation, to ensure that the issues concerning Māori PLHIV are appropriately represented and addressed. Māori PLHIV advocacy and support networks are urgently required in the North and South Island.
- Resourcing is required to support a Māori PLHIV-led project to customise the People living with HIV Stigma Index survey so that it better represents the aspirations of Māori PLHIV, their whānau, and communities.
- The relationship between Māori PLHIV and the International Indigenous Working Group on HIV & AIDS<sup>5</sup> must be strengthened in order to share successful strategies and build partnerships with governments, Indigenous leaders, research bodies and HIV and AIDS organisations on issues of common interest.

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<sup>5</sup> See <https://www.iiwgha.org/about/#:~:text=IIWGHA%20is,AIDS%20organizations>

# Introduction

## Why a Māori Participant Report?

Te Whāriki Takapou, with the support of the Stigma Index Working Group, produced this independent report that focuses solely on Māori people living with HIV (Māori PLHIV) who took part in the People Living with HIV Stigma Index survey. The aim of the report was to provide Māori participants with a sense of their health and wellbeing compared to the general Māori population, and compared to the non-Māori study participants living with HIV.

Until the end of 2019, there had been 317 Māori people ever diagnosed with HIV in Aotearoa New Zealand (NZ) (AIDS Epidemiology Group, 2020). This is likely to be an underestimate, as the recorded numbers of Māori PLHIV is influenced by factors including 'late presentation' for HIV testing, marginalisation, and stigma and discrimination. Late presentation and presentation with 'advanced HIV' are more common among older men who have sex with men (MSM), with Māori MSM about twice as likely to present with 'advanced HIV' after adjustment for age (Dickson et al., 2011). Marginalised communities are also less likely to be counted because of geographical isolation from health services, while stigma and discrimination act as barriers to disclosing HIV status (Miller, 2010).

HIV-related stigma and discrimination in Aotearoa NZ is widespread, including among Māori and minority populations (Miller, 2010; Te Puni Kōkiri, 1995) and is a significant concern. The first ever national hui on Māori and 'HIV/AIDS' was held at Papakura Marae, South Auckland, in 1995. Sir Paul Reeves, patron of Te Rōpū Tautoko Trust, spoke at the opening of the hui and noted that discrimination, inequity and injustice fuelled preventable illnesses such as HIV and AIDS (Te Puni Kōkiri, 1995).

Over a quarter of a century later and the responses of many Māori PLHIV who completed the HIV Stigma Index survey indicate that stigma and discrimination, inequity and injustice are as present today as in 1995 and are amongst the worst barriers facing Māori PLHIV.

The effects of HIV-related stigma and discrimination have a major impact on people's engagement with HIV-related healthcare and services (Miller, 2010), as well as their self-esteem and relationships; no less so for Māori. A small New Zealand survey of 213 HIV-positive participants (Mundt & Briggs, 2016) found that 47% had experienced HIV-related stigma and discrimination by a healthcare provider. That

report was the first to document a small sample of Māori PLHIV (23 participants) and their experiences of HIV-related stigma and discrimination.

Looking ahead, there is an urgent need for HIV-related data to inform the refinement of national surveys, research, health policy and development of services for PLHIV (Miller, 2010), including data on the socio-economic circumstances of Māori PLHIV.

## HIV policy to address stigma and discrimination

Currently, no up-to-date policy exists to address stigma and discrimination experienced by PLHIV in Aotearoa NZ, including policy for Māori PLHIV. The Sexual and Reproductive Health Strategy: Phase One provides an account of HIV and AIDS in Aotearoa NZ, and notes at risk populations, surveillance and the impact of advances in HIV medication (Ministry of Health, 2001), but the policy has not been updated since. In 2003, the 'HIV/AIDS Action Plan' was developed by the Ministry of Health. The Plan takes a priority population approach (PLWHA, MSM, MSMW, refugee and migrant people from high prevalence counties, IDUs and sex workers)<sup>6</sup> to HIV prevention and draws upon the study by Grierson et al (2002), but the Tiriti o Waitangi rights-based approach is overshadowed by this approach.

The study by Grierson et al (2002) highlights the destructive impact of HIV-related stigma and discrimination experienced by PLWHA. The Plan notes,

'The majority of PLWHA considered their HIV status an important part of their identity. Nearly half (47%) of the respondents were on a pension or benefit.... Paying for food and medical services was very difficult for 14% and 32% of respondents' (Ministry of Health, 2003, p. 11).

The Plan describes Objective 2 of Goal 1 as 'Decrease stigma and discrimination surrounding HIV/AIDS' and promotes de-stigmatisation programmes and national campaigns for priority populations and the general population. In 2010 the Ministry of Health commissioned a review (the Miller Report) of services available to PLWHA. The review identified a number of strengths in the HIV service sector; however, gaps were identified, including the need for a national conversation on HIV and AIDS-related stigma in terms of what it is, how it works, how it can be addressed, and an updated action plan (Miller, 2010).

## The People Living with HIV Stigma Index

This report presents a Kaupapa Māori approach to the Māori participant data from The Aotearoa New Zealand People Living with HIV Stigma Index survey (2020). The

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<sup>6</sup> PLWHA (people living with HIV/AIDS) and IDUs (injecting drug users) were the terms in common usage in 2003, however the preferred terms are PLHIV (People living with HIV) (UNAIDS, 2015) and PWID (people who inject drugs) (World Health Organisation, 2021).

Aotearoa New Zealand Stigma Index was adapted by the Working Group from the international People Living with HIV Stigma Index (GNP+, 2020), a standardised questionnaire 'tool' designed to gather evidence on how stigma and discrimination impacts the lives of PLHIV in countries across the globe. Future surveys using the Index will require stronger local customisation in order to collect data based upon Māori models of health as determined by Māori PLHIV in Aotearoa NZ.

Meantime, the Stigma Index model is unique in that it has the UNAIDS Meaningful Involvement of People Living with HIV (MIPA) principle at its core. This approach positions PLHIV at the centre of the research process, as drivers of what and how data are gathered, analysed and used, and as interviewers and interviewees. Since it was first launched in 2008, the PLHIV Stigma Index has been implemented in more than 100 countries, with over 100,000 PLHIV participating in the process (GNP+, 2020). To our knowledge, Aotearoa New Zealand is the first country in the world to produce a report by and for the country's Indigenous population; that is, Māori PLHIV.

The PLHIV Stigma Index Aotearoa NZ study was undertaken by a collective of People living with HIV network groups, a Working Group made up of members from organisations that are part of the HIV National Forum,<sup>7</sup> representing key affected populations living with HIV in Aotearoa New Zealand, and included an experienced researcher from the AIDS Epidemiology Group at the University of Otago.<sup>8</sup> The purpose of the study was to address the urgent need for data on the extent and impact of stigma and discrimination experienced by PLHIV in Aotearoa NZ. While the primary goal was to assess the stigma and discrimination experienced by PLHIV in Aotearoa NZ, the study also had the following objectives: 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; and d) Contribute to policy and programmes in Aotearoa NZ. Results from the study will also be used to provide a benchmark on how Aotearoa NZ is progressing toward its commitment to eliminate HIV-related stigma and discrimination (UNAIDS, 2020), and empower people, networks and communities (Aotearoa New Zealand People Living with HIV Stigma Index, 2020).

The initial phase of the study aimed to recruit 100 participants, comprising similar numbers of men and women from each of the main ethnic groups affected in Aotearoa NZ: (Māori, African, Asian and European/ Other). A response to limited funding available for the project rather than statistical considerations, the Working

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<sup>7</sup> Positive Women Inc., Body Positive, NZ AIDS Foundation, NZ Prostitutes Collective, NZ Needle Exchange Program, Pamoja (NZAF prevention programme for African peoples), and Te Whāriki Takapou.

<sup>8</sup> Dr Sue McAllister.

Group considered that this approach would provide an adequate number of diverse participants to gain insight into their experiences. An increase in funding during the study then allowed the sample size to be increased to 200 (Aotearoa New Zealand People Living with HIV Stigma Index, 2020). However, recruitment of Māori participants was slow. While the actual number recruited for the study was 188 participants overall, unfortunately only 20 percent (37) of the participants identified as Māori. Also unfortunate, just under half of all Māori participants were interviewed by a Pākehā PLHIV, a decision which likely affected the quality of the data.

## Methodology - What guided us

The analysis of Māori participant data collected as part of the PLHIV Stigma Index Aotearoa NZ is underpinned by a Kaupapa Māori methodological approach. Kaupapa Māori is indigenous to Aotearoa NZ and evolved from Māori struggles for tino rangatiratanga (self-determination) and mana motuhake (Māori autonomy). Grounded in Māori lived experiences, aspirations, values and understandings of the world, Kaupapa Māori provides an appropriate framework and tools to understand, explain and respond to issues that impact Māori (Pihama, 2010).

In the context of Māori PLHIV, a Kaupapa Māori approach aims to increase Māori PLHIV control of their health; validate the importance of Māori knowledge, language and culture; and transform the structures in the health system that act as a barrier to the health and wellbeing of Māori (Green, Tipene & Davis, 2016), including HIV-related stigma and discrimination.

These objectives reflect the Kaupapa Māori principles of He Korowai Oranga: Māori Health Strategy (Ministry of Health, 2001) that was the outcome of extensive Māori-led consultation with hapū, iwi and Māori communities across Aotearoa NZ. Implicit in all Kaupapa Māori principles is the principle of Whānau which speaks to collectivity and relationships that are central to the Māori worldview, and to Māori ways of being and doing.

Te Tiriti o Waitangi is an expression of Māori tino rangatiratanga and autonomy. Under Te Tiriti, Māori PLHIV have the right to good health and wellbeing, while the Crown has an obligation to protect and promote their health aspirations and deliver equitable health outcomes (Ministry of Health, 2020). Accordingly, Te Whāriki Takapou adopted the recently updated principles of Te Tiriti o Waitangi recommended by the Waitangi Tribunal (2019). In the context of analysing and reporting on data pertaining to Māori PLHIV's experiences of stigma and discrimination, we were guided by the Ministry of Health's Te Tiriti Framework principles of Tino rangatiratanga, Equity, Active protection, Partnership and Options as these apply to achieving Māori aspirations for Pae Ora (Healthy futures for Māori) (Ministry of Health, 2020).

The principle of MIPA (Meaningful involvement of people living with HIV) is foundational to the empowerment of PLHIV and is woven into the fabric of the PLHIV Stigma Index tool. The four principles represented by the MIPA acronym – Meaningful involvement, Inclusion, Participation and Access – aim to resist perceptions of PLHIV as ‘passive’, ‘helpless’ or ‘victims’, and position them as self-determining experts of their lived experiences. MIPA affirms that the active participation and inclusion of PLHIV in the development and implementation of services and policy-making for PLHIV is likely to result in more relevant, acceptable and effective services and programmes. In the context of the PLHIV Stigma Index Aotearoa NZ, the aim of involving Māori PLHIV as peer interviewers, interviewees, community researchers and members of the Stigma Index Working Group was to empower, build capacity, improve self-esteem, boost morale, decrease isolation and improve health through access to better information (UNAIDS, 2007).

## Māori understandings of stigma and discrimination

The online Māori Dictionary, Te Aka, provides Māori language definitions for the terms ‘stigma’ (poapoataunu) and ‘discrimination’ (toihara). It is interesting to note, however, that neither of these Māori terms is listed in the Māori Language Commission’s Māori-only wordlist, He Pātaka Kupu.<sup>9</sup> ‘Poapoataunu’, defined as ‘stigma, shame’, appears to be a compound word made up of ‘poapoa’ (stain, discolouration) and ‘taunu’ (to jeer, scoff at, ridicule, mock, criticise). In particular, the reference to ‘stain’ as a definition for ‘poapoa’ carries a distinctly Christian connotation, reflecting its use in 16th century English in the sense of ‘defilement, disgrace’. Taken together, these characteristics indicate the term ‘poapoataunu’ is likely a modern Māori translation of a term or concept (‘stigma’) that has no grounding in Māori ideas, thoughts and perceptions (Mika, forthcoming, cited in Pihama, Green, Mika et al., 2020). Similarly, the term ‘discrimination’ originates from late 16th century Latin and is defined as “the making of distinctions; [the] act of observing or marking a difference” (Online Etymology Dictionary, 2020 ). Both terms are grounded in the fundamental beliefs and understandings of a worldview that seeks to separate or ‘other’ that which is different, in order to ‘know’ it; a worldview that privileges the individual over the collective. Mika argues that this phenomenon is directly opposed to Māori understandings of all things being in relationship to each other (Pihama, Green, Mika et al., 2020, p. 15). In producing this report, we are mindful of the colonial origins of the terms ‘stigma’ and ‘discrimination’, their potential to undermine fundamental Māori concepts such as whānau, whakapapa

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<sup>9</sup> He Pātaka Kupu: Kai a te Rangatira’ is a comprehensive and authoritative dictionary of the Māori language, drawn from a wide corpus of written material in te reo. For each entry, an ‘atua category’, parts of speech, definitions, examples of the word used in context, and an etymology of the word are given.

and community, and the threat that Western terms pose to the ability of Māori to “represent things in accordance with our own tikanga” (p. 15).

## How we did it

A framework for analysis of the Māori Participant data was developed using the elements of He Korowai Oranga, the Māori Health Strategy (Ministry of Health, 2020a). The vision is centred on the overall aim of Pae Ora - Healthy Futures for Māori, and is strengthened by three interconnected elements: Mauri Ora - Healthy Individuals; Whānau Ora - Healthy Whānau, and Wai Ora - Healthy Environments.

Selected questions from all but one of the eight main sections of the Stigma Index questionnaire (see below) were grouped thematically among the three elements and overall aim of He Korowai Oranga. The sections of the questionnaire we used were:

- A: About You
- B: Disclosure
- C: Your Experience of Stigma & Discrimination
- D: Internalised Stigma and Resilience
- E: Interactions with Healthcare Services
- F: Human Rights and Effecting Change; and
- H: PozQoL or Quality of Life Scale

The section that was not addressed in the analysis, due to only very small numbers represented in the Māori data, was Section G: Stigma & Discrimination for Other Reasons.

Criteria for the selection of questions were based on their correspondence with

- (a) the Kaupapa Māori principles - in particular, the Te Tiriti principle of Equity, and MIPA; and
- (b) what the Māori interviewers who took part in the data collection told us were important for them and the Māori PLHIV they interviewed.

Where the participants’ brief qualitative responses in Section J: Personal Experience of Stigma/ Discrimination provide lived experience of the issues highlighted in the quantitative data, selected quotes have been included throughout the report.

There were limitations to the data used in this study. Considering the number of Māori who have ever been diagnosed with HIV in Aotearoa NZ (317) (AIDS Epidemiology Group, 2019), our small sample of thirty-seven Māori participants, at only 11.7% of that number, meant that the findings should not be taken as

representative of the experiences of all Māori PLHIV. Nonetheless, the sample is the largest to date concerning Māori experiencing HIV-related stigma and discrimination and as such it would be unjust to marginalise their realities (Reid, 2006).

## Comparative approach

Our response to the data limitations was to use the comparative method to compare and contrast findings reported by Māori participants to relevant findings from other surveys such as Te Kupenga, the Honour Project Aotearoa, the New Zealand Health Survey, and the New Zealand General Social Survey. This approach facilitated the aim of the Māori Participant report to reflect the experiences of HIV-related stigma and discrimination as experienced by Māori PLHIV; compare the health and wellbeing of Māori PLHIV relative to the position of other Māori in New Zealand; increase Māori community knowledge and awareness of the stigma and discrimination experienced by Māori PLHIV; stimulate Māori community discussion and Māori approaches to eliminating HIV-related stigma and discrimination in Māori communities; and inform national policy and planning in relation to Māori PLHIV.

The Working Group undertook a review of the Stigma Index with a view to customising the questionnaire for the Aotearoa New Zealand context. To this end, some additional questions were added, such as the Quality of Life scale (PozQoL)<sup>10</sup> (Section H), while other questions were modified. However, there was a missed opportunity to tailor questions to reflect the complexities facing Māori PLHIV, their whānau relationships, cultural contexts, the determinants of health, and intersections between HIV-related stigma and discrimination, racism, homophobia, transphobia, misogyny and other forms of discrimination. To pilot such an approach would be of value to other English-speaking settler nations - Australia, Canada and the United States - with Indigenous populations living with HIV.

## The methods we used

### Survey

The People Living with HIV Stigma Index utilises an assisted survey technique involving, in this case, community-based PLHIV being present with and assisting PLHIV to complete a survey questionnaire about their experiences of HIV-related stigma and discrimination. In the majority of cases (21 of the 37), Māori PLHIV were peer-interviewed by Māori PLHIV but not in all cases. The 'side-by-side' approach to the interview process is designed to strengthen networks between PLHIV, as well as minimising power imbalances often experienced in 'face-to-face' interviews

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<sup>10</sup> Based on an acknowledgement that HIV prevention policy needs a stronger focus on quality of life (QoL), the PozQoL was developed as a 'valid, short and practical' tool to evaluate the quality of life of PLHIV (Brown et al., 2018).

(International Planned Parenthood Federation UK, 2008). Given the sensitive nature of the topic and questions covered in the questionnaire, a more desirable outcome would have been for all 37 Māori participants to be peer-interviewed by Māori PLHIV of the same self-identified gender. This approach would have recognised a Māori rights-based approach and allowed for tikanga Māori in order to mitigate any risk to Māori participants' comfort and cultural safety in the interview process. This further highlights the need for customisation of the Stigma Index questionnaire and its implementation in the Aotearoa New Zealand context so that it better represents the aspirations of Māori PLHIV and their whānau. Predominantly quantitative, the survey questionnaire was designed to take approximately sixty minutes to complete; however, the Māori interviewers told us that some interviews took up to 4-5 hours.

## Peer interviewers

The importance of peer interviewers in the implementation of the Stigma Index cannot be overstated. As discussed above, it was critical to have Māori interviewers who are openly living with HIV (i.e. are comfortable disclosing their status to others) engaging with the Māori PLHIV who were participants in the study, providing a supportive environment and encouraging the interviewees to talk about their experiences of living with HIV (GNP+, 2020). Three Māori PLHIV, identified through members of the positive people's network, were recruited to take up positions as peer interviewers in the HIV Stigma Index study. Between them they completed 21 of the 37 interviews with Māori, with the remaining 16 participants interviewed by non-Māori PLHIV. All peer interviewers completed a two-day training workshop on interviewing and data collection techniques, informed consent and confidentiality, maintaining boundaries, and keeping themselves safe while conducting the interviews.

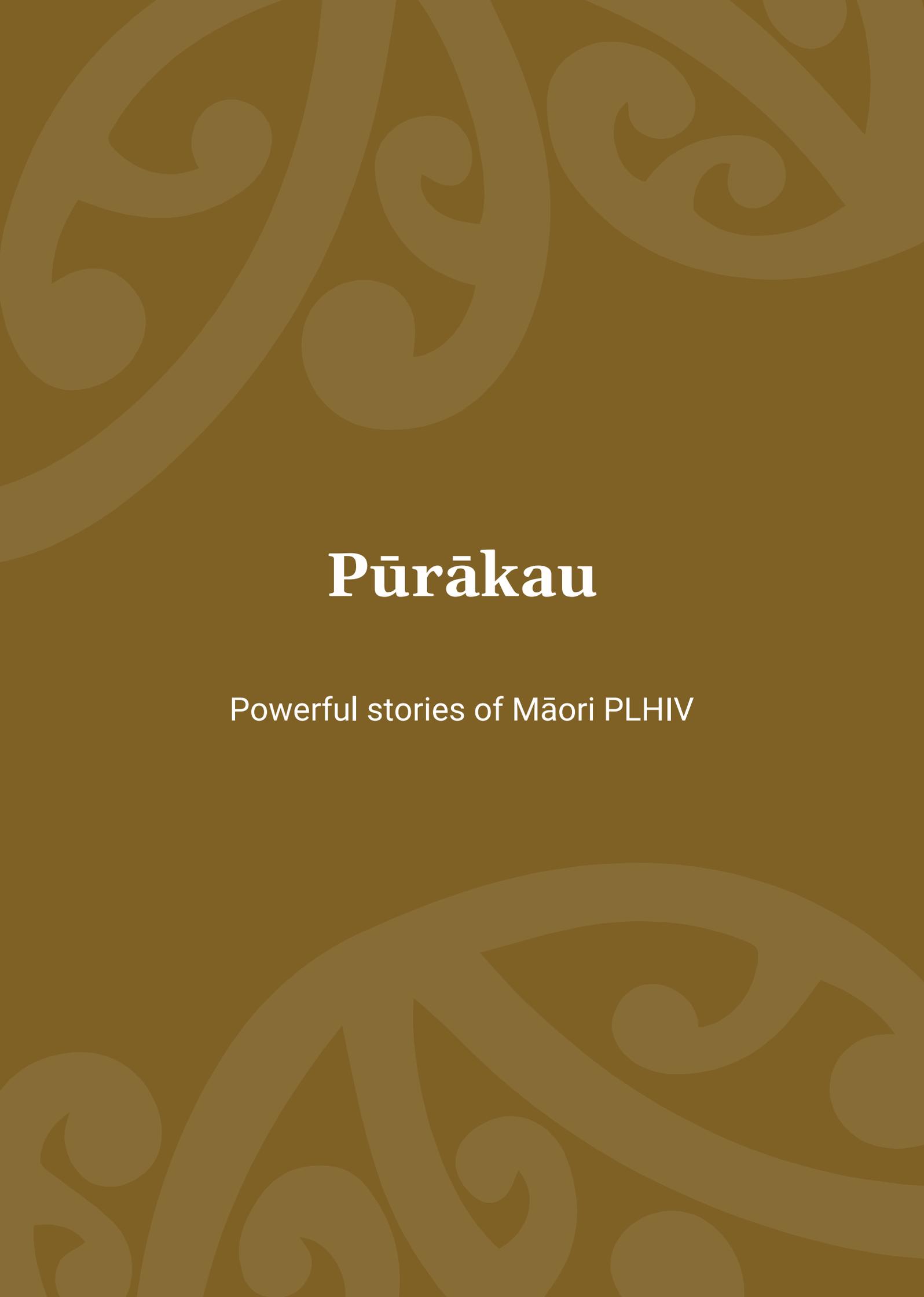
## Who took part

Thirty-seven Māori PLHIV were recruited over a 12-month period for the HIV Stigma Index Study. Of these, 16 lived in cities - Auckland, Wellington and Christchurch - and 21 lived in provincial cities, towns and rural centres. Almost a quarter of participants self-identified as female and whakawahine, and nearly three quarters self-identified as male, with a small number self-identifying as non-binary. Just under half of the participants were aged under 50 years. The youngest Māori participant living with HIV was 27 years, and the oldest was 64 years. Māori PLHIV recruited to interview other Māori PLHIV shared that some Māori PLHIV they contacted were not interested to take part in the survey because they were not confident that their input would produce change.

## COVID-19 and the HIV Stigma Index Study

The recruitment of Māori PLHIV for this study was affected by the Covid-19 epidemic and the New Zealand government's response to eliminating Covid-19. The epidemic slowed down recruitment and affected where and how interviews took place.

Although the downstream effects of the pandemic are still being assessed, it is likely that poverty, powerlessness and intolerance – key determinants of poor sexual and reproductive health and stigma and discrimination – will have been amplified by the pandemic (Hussein, 2020).

The background of the entire page is a solid olive-green color. Overlaid on this background are large, faint, stylized Maori decorative motifs. These motifs consist of thick, flowing lines that curve and swirl, creating a sense of movement and depth. The patterns are reminiscent of traditional Maori art, such as the intricate designs found on a haka or on a korowai. The motifs are positioned in the upper and lower corners, framing the central text.

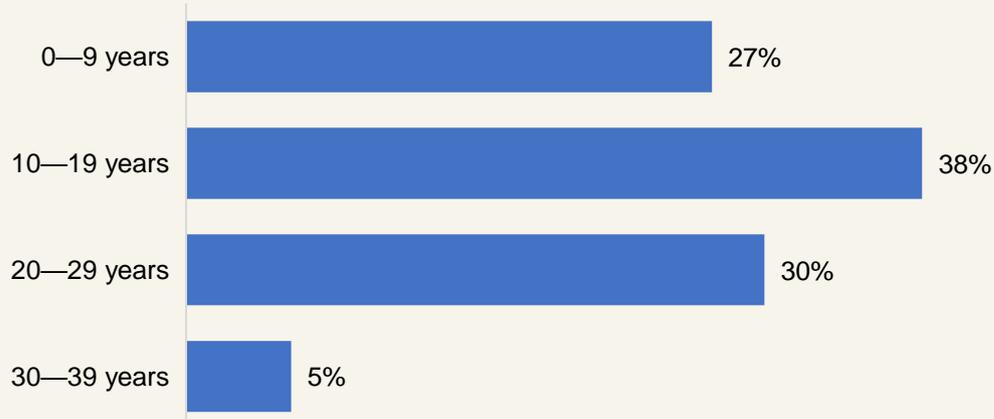
# Pūrākau

Powerful stories of Māori PLHIV

# 1. Mauri Ora – Healthy individuals

Most Māori PLHIV who participated in the survey reported they had known their HIV positive status for 10 or more years, and a smaller number had known they were HIV positive for less than 5 years (see Figure 1, below). The longest a participant had known they had HIV was 34 years.

Figure 1: How long have you known you have HIV?



*I chose to volunteer for this study because I was a child during the 80s. At that time HIV was all over the media as a bad thing. I heard many, MANY, adults talk about it and show loathing towards anyone who had the disease as well as any homosexual regardless of whether they had it or not . . . As an adult I see that most of my generation feel an almost ingrained feeling and response that people with HIV are to be disliked and that it is their own fault so they shouldn't be given any support or care.*

## Household

Participants were asked about the number of children living in their household. A quarter of participants had children living in their households that they took care of. In connection with this, Te Kupenga 2018 (Stats NZ, 2020a) reported that 40% of Māori 'Looked after their own or someone else's child under 14 years of age living in the same household' as an expression of Manaakitanga, which is a measure of Oranga or wellbeing. Statistics on the determinants of life satisfaction for Māori

(Statistics New Zealand, 2015) found that living with children has a small positive association with life satisfaction, and therefore with wellbeing.

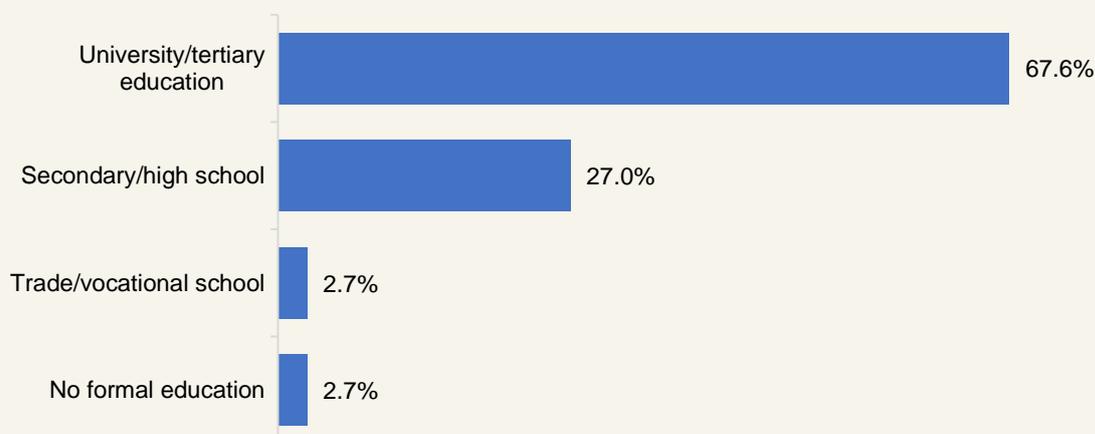
## Education, study and work

Eleven percent of study participants indicated that they were currently studying, either full-time (20 hours or more a week) or part-time (less than 20 hours a week).

With regard to the highest level of education attained: a little more than two-thirds of participants had attended university or other tertiary education; more than a quarter had attended secondary/ high school; and small numbers had completed trade/ vocational school, or had had no formal education. The high proportion of study participants who attended university or tertiary education was particularly notable in such a small sample.

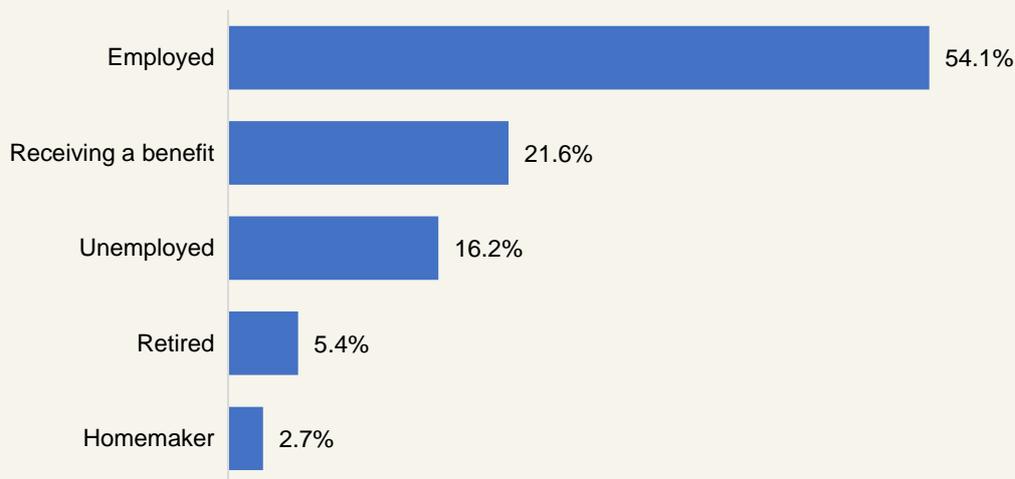
The recent Honour Project Aotearoa study (Pihama, Green, Mika, et al., 2020), an investigation of health and wellbeing in Takatāpui and Māori LGBTQI+ communities, had similar findings: 42% of the study participants were more likely than the general Māori population to have a tertiary qualification, while 36% were involved in some form of study. Latest statistics from Education Counts (2020) show that, for Māori, participation rates in bachelors or higher qualifications has increased from 2007 to 2017 by 0.6 of a percentage point to 4.9 percent.

Figure 2: Highest level of formal education?



When asked about their current work status, over half the participants indicated they were employed, either in full-time or part-time work as an employee; or casual or part-time work (either self-employed or paid work for others); while a small number were working full-time, either self-employed or a business owner. Just under a quarter of participants were receiving a benefit and a smaller number were unemployed.

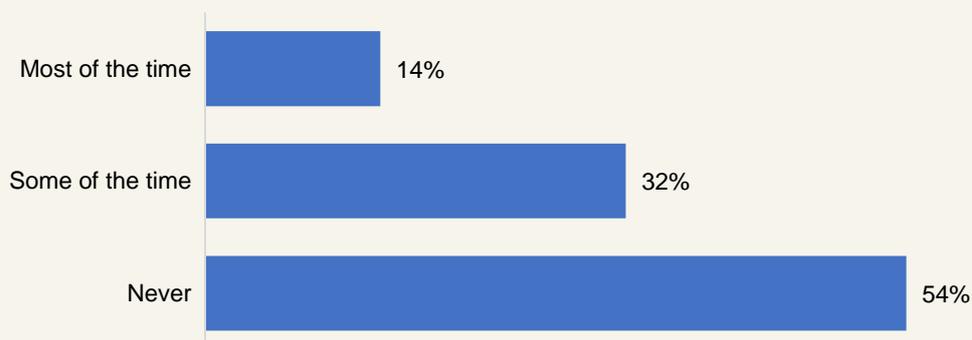
Figure 3: Current work status?



## Unable to meet basic living needs

Asked whether, in the last 12 months, they had ever been unable to meet their basic needs (i.e. food, shelter, clothing), almost half of the Māori participants living with HIV responded 'Some of the time' or 'Most of the time'. Likewise, the Honour Project Aotearoa study (Pihama, Green, Mika et al., 2020) found that over half of Takatāpui and Māori LGBTQI-plus participants reported their income was not enough or only just enough to meet their basic needs. By comparison, in the Te Kupenga 2018 'Oranga measures' data, just over a third (35%) of the general adult Māori population reported their household had not enough, or only just enough income to meet their everyday needs (Stats NZ, 2020); and of the general New Zealand population who participated in the 2018 New Zealand General Social Survey, just under 10% reported that they (and their partner if relevant) did not have enough income to meet their everyday needs (Stats NZ, 2019).

Figure 4: Unable to meet basic needs?



In connection with this, our participants' higher levels of education, as identified in Figure 2 (p. 23) should correlate to sufficient levels of income, however, for a significant number of Māori participants living with HIV in this study, and Takatāpui/ Māori LGBTQI+ participants in the Honour Project Aotearoa study, that was not

necessarily the case. This suggests that factors such as HIV-related stigma and discrimination, including racism, homophobia and transphobia, may act to prevent Māori PLHIV with strong education backgrounds from securing incomes that meet their everyday needs (Pihama, Green, Mika et al., 2020).

*I would appreciate a segment around appropriate social housing/ cost/ matching to be mandatory in the next questionnaire. e.g. How are people living? What are they living in? How are they managing their stigmatisation? . . . Could we please focus more on housing as that is a basic need that requires more support and attention in these types of questionnaires.*

## Connected to network/ support group

While more than two-thirds of participants identified themselves as members of an HIV community network or support group; more than a quarter said they were not a member of a network or support group. All 10 participants who were not a member of a PLHIV network or support group identified as male.

A review of services for people living with HIV in New Zealand (Miller, 2010) found that geographical location can impact access to services, including support groups and networks. However in the same review,, participants in a focus group discussion about the prevalence of HIV-related stigma identified the lack of integration of gay Māori within traditional gay networks, and the pressure of social frameworks in small towns, as obstacles to overcoming stigma.

*Living in the regions (out of the main cities) has been a challenge due to the lack of support + 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.*

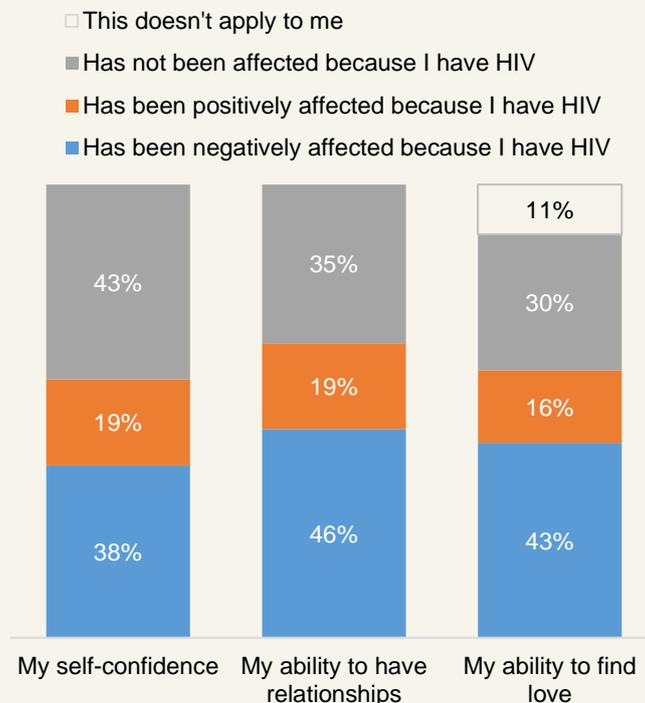
*Before I was living in the city where there was more LGBTQ, moving to the regions/ provincial has its own challenges. Especially with being HIV+.*

## Personal relationships affected by HIV

Māori participants in the PLHIV Stigma Index study were asked whether, over the past 12 months, their ability to meet their needs (i.e. personal, relationship and lifestyle needs) had been positively affected, not affected, or negatively affected by having HIV. Almost half of the participants said that, over the last 12 months, their ability to have close and secure relationships with others was negatively affected by having HIV, and a similar number reported that their ability to find love was negatively affected. More than a third reported their self-confidence was negatively affected by having HIV.

Conversely, more than a third of participants said their ability to respect others was positively affected in the last 12 months by having HIV, and just under a third said their ability to contribute to their community was positively affected.

Figure 5: Ability to meet needs affected by having HIV?

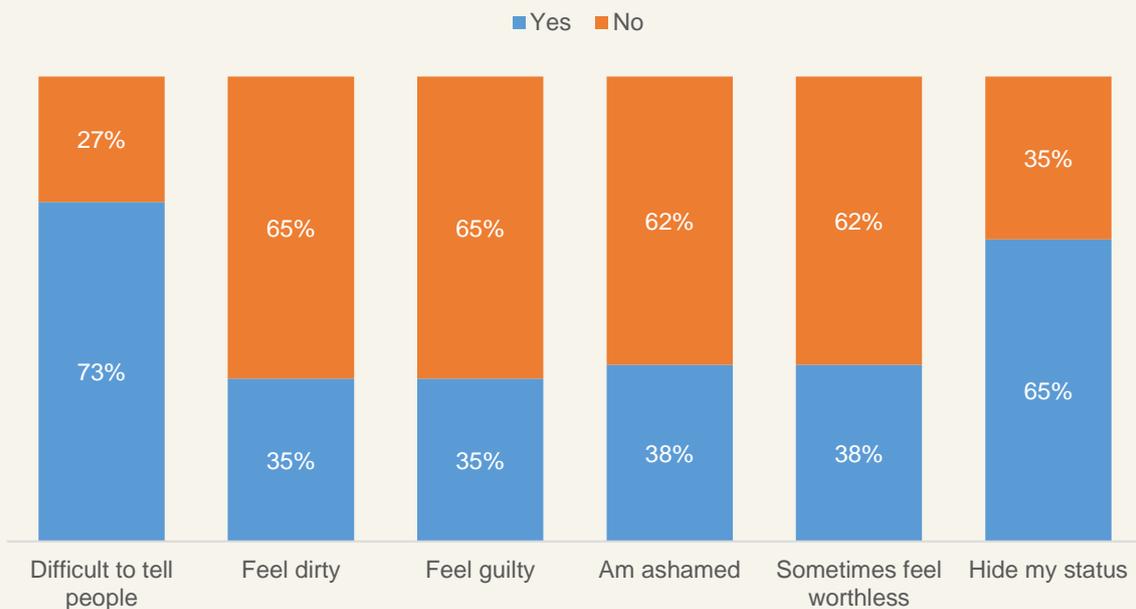


Participants were also asked whether they had chosen to not do certain things in the last 12 months, because of having HIV, such as not attend social gatherings, not seek healthcare, or not apply for a job. The two most significant responses were that almost a third (32%) decided not to have sex in the last 12 months; and slightly fewer (30%) isolated themselves from family and friends.

## Internalised stigma

In response to whether, in general, they agreed or disagreed with statements about living with HIV, such as 'Being HIV positive makes me feel dirty', 'I feel guilty' / 'I am ashamed that I am HIV positive', or 'I sometimes feel worthless because I am HIV positive', about a third of participants agreed that having HIV made them feel dirty, guilty, ashamed or worthless. Three-quarters of participants agreed it was difficult to tell people about having HIV; and just under two-thirds agreed that they hide their HIV status from others.

Figure 6: About living with HIV?



*My personal lived experience of growing up as a young Maori male in his early 20s took a great toll on me. There were many times I felt ashamed or unsure how I would tell friends & family. It was an exhausting secret kept to myself.*

*I'm probably more introverted now than I used to be as a result of my status. Deciding who to trust, etc.*

## Receiving HIV treatment

All of the Māori participants in the study were currently taking HIV treatment (ART), as were all the non-Māori participants. It should be noted that Māori PLHIV who knew about the survey and participated may be more likely to know about HIV antiretroviral medication and where to access it than Māori PLHIV who didn't participate in the study. This suggests that the study participants may not be representative of PLHIV who are harder to reach.

Participants were also asked if they had been told they had an undetectable viral load. Ninety-two percent of Māori participants responded yes, compared to 95% of non-Māori participants.

In connection with this, a recent article by McAllister and colleagues (2020) noted that Aotearoa New Zealand's progress towards the UNAIDS target to end HIV, referred to as '90-90-90',<sup>11</sup> is challenging to measure accurately. This is due to a lack

<sup>11</sup> '90-90-90' - 90% of people LHIV are diagnosed; 90% of those diagnosed receive ART; and 90% of people on ART have a suppressed viral load (UNAIDS, 2021).

of national data on the proportion of PLHIV who are undiagnosed, and the lack of a central laboratory depository from which to obtain confirmed information on the current viral loads of PLHIV. The study found that improved data linkage through the National Health Index (NHI), combined with ongoing annual collection of up-to-date data would enable a better understanding of Aotearoa New Zealand's progress towards the goal of ending HIV.

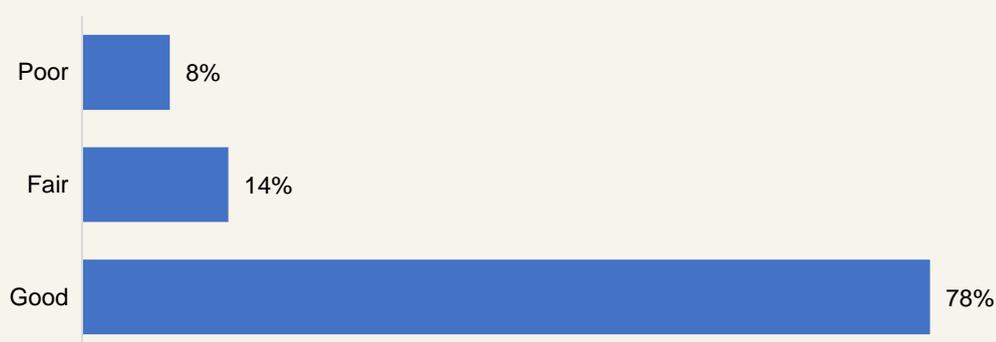
## Current self-rated health

Participants were asked to describe their current health, rating it as 'Good', 'Fair' or 'Poor.' More than three-quarters of participants self-rated their general health as 'Good'.

As a comparison, the most recent New Zealand Health Survey (Ministry of Health, 2020c) showed that 87% of the general adult population self-rated their health as 'good' (including 'very good' or 'excellent'), compared with 77% of the general Māori population surveyed. According to the previous year's survey (Ministry of Health, 2019b), Māori adults were less likely to report their health as good (or very good, or excellent) than non-Māori adults; and people living in the most deprived areas were less likely to self-rate their health as good (or very good or excellent), compared to those living in the least deprived areas.

A report by Kukutai, Sporle and Roskrug (2017), Subjective Whānau Wellbeing in Te Kupenga, found that for Māori in most age groups (but not those aged 55 years or older), self-rated health has a relatively strong association with perceived whānau wellbeing. Their findings align with work by Durie and others (Durie 1985, 1997, 2006; Panelli & Tipa 2007, cited in Kukutai et al, 2017) that emphasises the holistic nature of wellbeing and the interconnections between the wellbeing of the individual and of the whānau.

Figure 7: Describe your health at the moment?



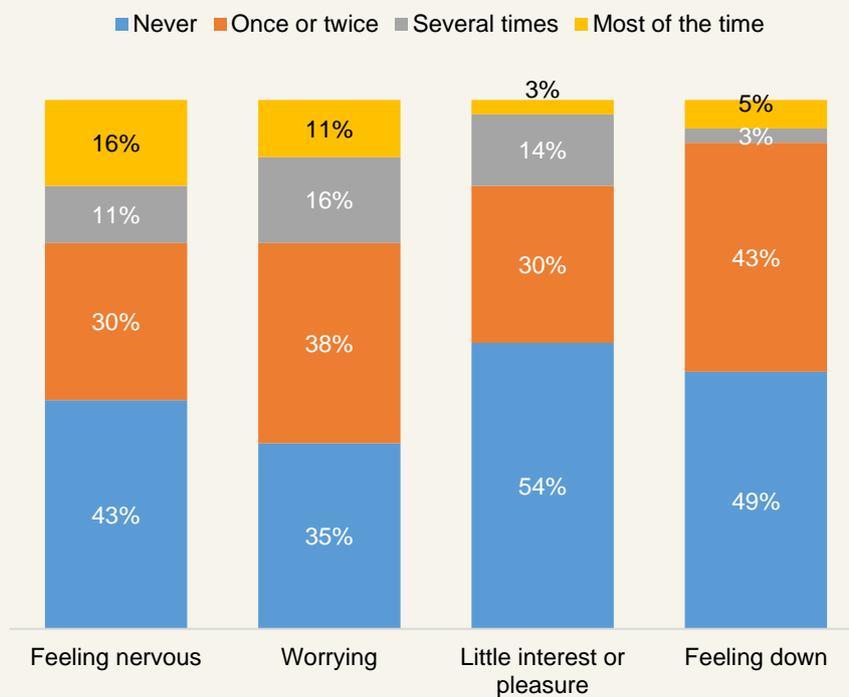
*Living with HIV has been overall a positive thing. I've realised a lot about myself and I've changed as a person. My outlook on life has changed. I know myself more . . . I've also learned a lot of horrible stuff about the world. I've become*

*more aware which has made me more empowered . . . I am now in a better position to call out HIV stigma/ discrimination when I see it.*

## Psychological stress and worry

When asked how often they had been bothered in the last two weeks by anxiety, worry, lack of interest in doing things or feeling down and depressed ('most of the time', 'several times', 'once or twice' or 'never'), more than half of the participants said they had felt nervous, anxious or on edge over the last two weeks; well over half reported not being able to stop or control worrying; almost half said they had little interest or pleasure in doing things over the last two weeks; and just over half had felt down, depressed or hopeless in the last two weeks.

Figure 8: Bothered by anxiety, worry, feeling down?



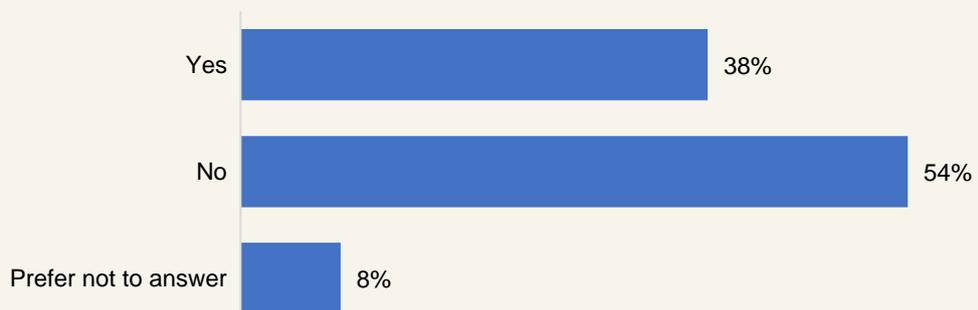
By comparison, data from the NZHS (Ministry of Health, 2020d) show that, of the general New Zealand population surveyed in 2019-20, 7% were affected by psychological distress; 20% by a mood or anxiety disorder; and 16% by depression. Māori data from the same survey showed that, in the four weeks prior to taking part in the survey 14% of the general Māori population were affected by psychological distress; 22% by a mood or anxiety disorder; and 19% by depression. Māori adults were 1.9 times as likely to have experienced psychological distress as non-Māori adults (after adjusting for age and gender) (Ministry of Health, 2020d).

*I'm No Shrink, maybe that's why I've lived with the stigma for so long, 25+ yrs?  
Mental health is a Serious and a big issue here in New Zealand amongst Men  
regardless of status - or +.*

## Receiving support

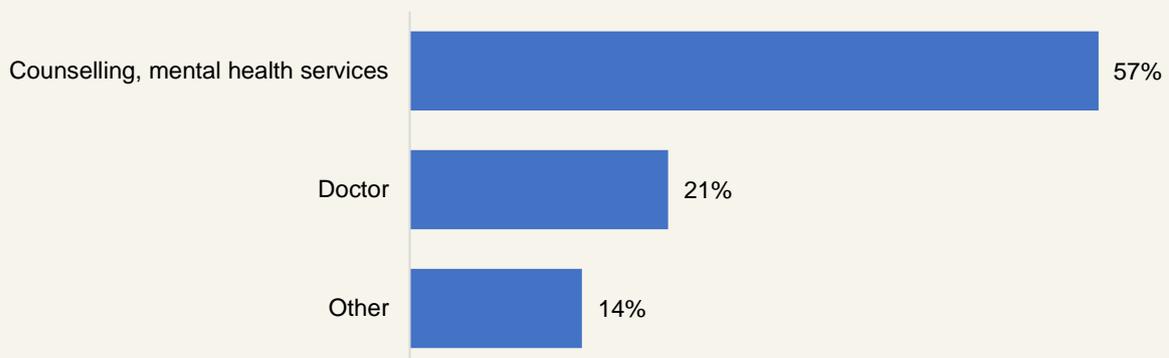
In response to whether they had received any type of counselling or other type of support in the last 12 months for the mental health issues identified in the previous question (Figure 8), over a third of participants said they had, while over half said they had not.

Figure 9: If so, received support in last 12 months?



The types of support received by participants included: hospice, peer or family support, counselling, psychiatrist, general practitioner, and mental health services. Counselling was by far the most commonly received type of support.

Figure 10: Types of support received



## Individual rights

Māori PLHIV have inherent rights, rights derived from Te Tiriti o Waitangi, and human rights established in law to protect them from a range of abuses arising as a consequence of their HIV status. While the human rights of Māori PLHIV are enshrined in the 1948 Universal Declaration of Human Rights, their collective rights are recognised by the Declaration on the Rights of Indigenous Peoples (UNDRIP) which New Zealand adopted in 2010. However, it is in the coming together of

individual and collective rights that He Korowai Oranga proposes is most likely to achieve health and wellbeing for Māori (Ministry of Health, 2020a), including Māori PLHIV.

In the context of HIV prevention, treatment and elimination of HIV-related stigma and discrimination, approximately a quarter or less of Māori PLHIV reported ever being forced to disclose their HIV status. Furthermore, their rights were abused when accessing healthcare, when engaging with the justice system, obtaining medical insurance, interacting with national and international border control services, and with regard to employment and the workplace. A small number of Māori participants reported their rights were abused when they were forced to disclose their HIV status. A small number also reported having been forced to have sex.

In Aotearoa New Zealand, the Crimes Act 1961 requires an adult to disclose their HIV status when engaged in consensual sex without using a condom. Where there is no disclosure, using a condom and or maintaining an undetectable viral load may be sufficient to discharge the Act's duty of care.<sup>12</sup> However, government investment in public education of individuals' inherent rights, rights arising from Te Tiriti o Waitangi, UNDRIP, and other national and international rights related to HIV and stigma and discrimination, has been minimal.

This was confirmed by the small numbers of Māori and non-Māori PLHIV who attempted to try and do anything about individual rights abuses. When asked whether they attempted to do anything about such abuses in the last 12 months, only a small number of Māori PLHIV said they had done so, due to complicated response processes, fear of retaliation, and low confidence that the outcome would be successful. Likewise, the number of Non-Māori PLHIV who attempted to do something about the abuse of rights they experienced was also small. They too cited complicated processes, feeling intimidated, and low confidence of a successful outcome as reasons for not trying to address rights abuses.

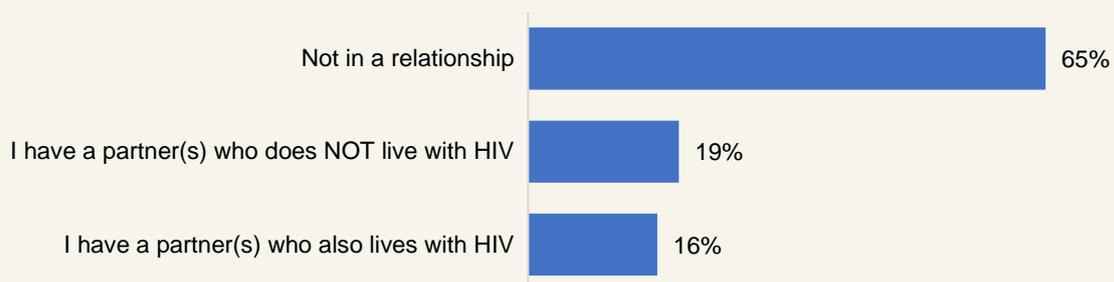
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<sup>12</sup> [https://www.bodypositive.org.nz/resources/PDFs/HIV\\_And\\_Law\\_Legal\\_Opinion\\_2011.pdf](https://www.bodypositive.org.nz/resources/PDFs/HIV_And_Law_Legal_Opinion_2011.pdf)

## 2. Whānau Ora - Healthy Whānau/families

Māori PLHIV who participated in the survey were asked a series of questions about their current living situation: whether they were in an intimate/ sexual relationship, and if they were, whether or not their partner(s) were also living with HIV. More than a third of participants said they were currently in an intimate/ sexual relationship, some with a partner(s) who did not have HIV, and some with a partner(s) who was also living with HIV. Almost two-thirds of participants indicated they were not currently living in an intimate/ sexual relationship.

Figure 11: In a relationship? Partner(s) living with HIV?



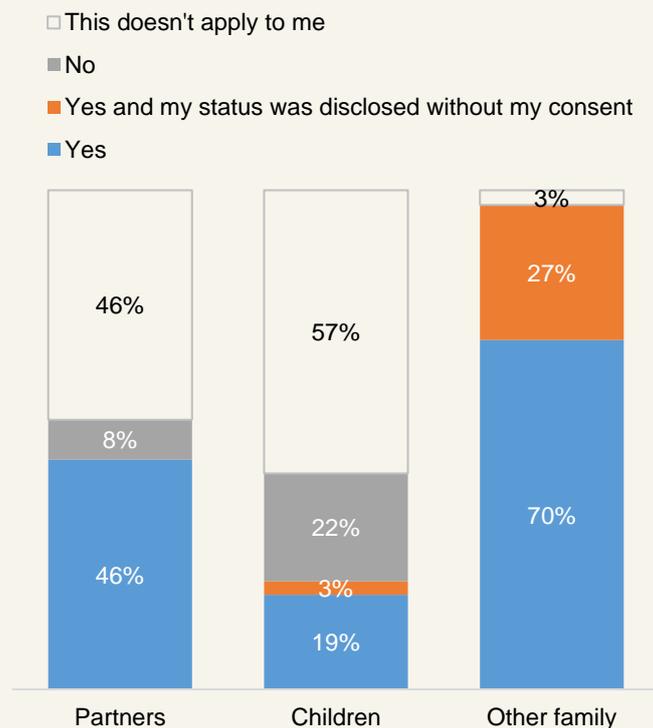
In connection with this, responses from a section of the questionnaire that asked about internalised stigma, highlighted that 46% of Māori participants found their 'ability to form close, secure relationships', and 43% found their 'ability to find love' were negatively affected by having HIV. According to a report on the determinants of life satisfaction for Māori (Statistics New Zealand, 2015), Māori who were partnered gave higher ratings for life satisfaction than those who were not partnered, indicating that living in a stable relationship is positively associated with life satisfaction.

*I had a partner at the time who tested negative however stayed with me & was happy & 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 loves & hugs it gave me hope & made it easier for me to accept love in the future.*

## Disclosure to people close to you

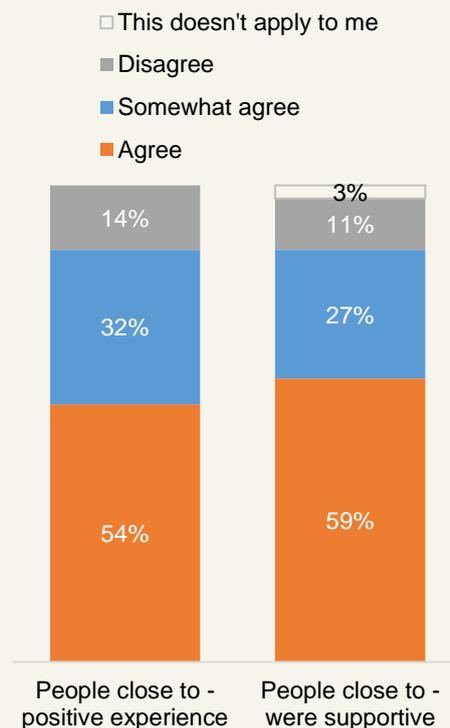
Participants were asked about the people or groups of people who know about their HIV, and whether their HIV had ever been disclosed to that person or group without consent. Almost half responded that their husband, wife, partner(s) knew. While less than a quarter said their children knew about their HIV, a small number of them had their status disclosed to their children without their consent. Likewise, while more than two-thirds of participants' other family members knew about their HIV, more than a quarter of participants had their status disclosed without their consent.

Figure 12: People/groups close to you know you live with HIV?



Most Māori participants agreed or somewhat agreed that, in general, disclosing their HIV status to people they are close to (such as partner, family, close friends) was a positive experience; and most agreed or somewhat agreed that the people they are close to were supportive when they first learned of the participant's status.

Figure 13: Disclosing to people close to you is positive?



*HIV now is manageable and you can live with it. There is still stigma out there. 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 whanau.*

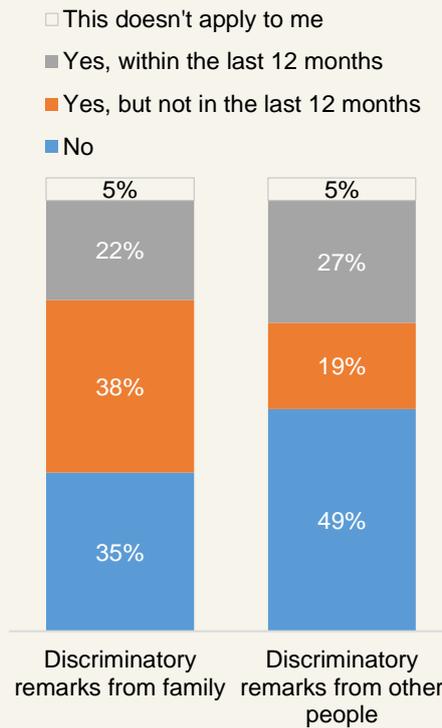
*It has helped me having full support of my family which has helped me be more comfortable with having HIV & is getting to a point where I am strong enough to not care what people think.*

## Stigma and discrimination - whānau and community

Participants were asked a series of questions about stigma and discrimination they may have experienced, both within the last 12 months and not in the last 12 months, because of having HIV. These included having been: excluded from social gatherings, religious activities or family gatherings; affected by discriminatory remarks or gossip, within their family or from other people.

Overall, three quarters of participants responded that they had experienced some form of stigma and discrimination: more than half had experienced discriminatory remarks or gossip within their family; just under half had experienced discriminatory remarks or gossip from other people; under a quarter had been excluded from family activities; and a smaller number had had a partner or partners experience discrimination because of their HIV status.

Figure 14: Stigma and discrimination (family/others) because of HIV?



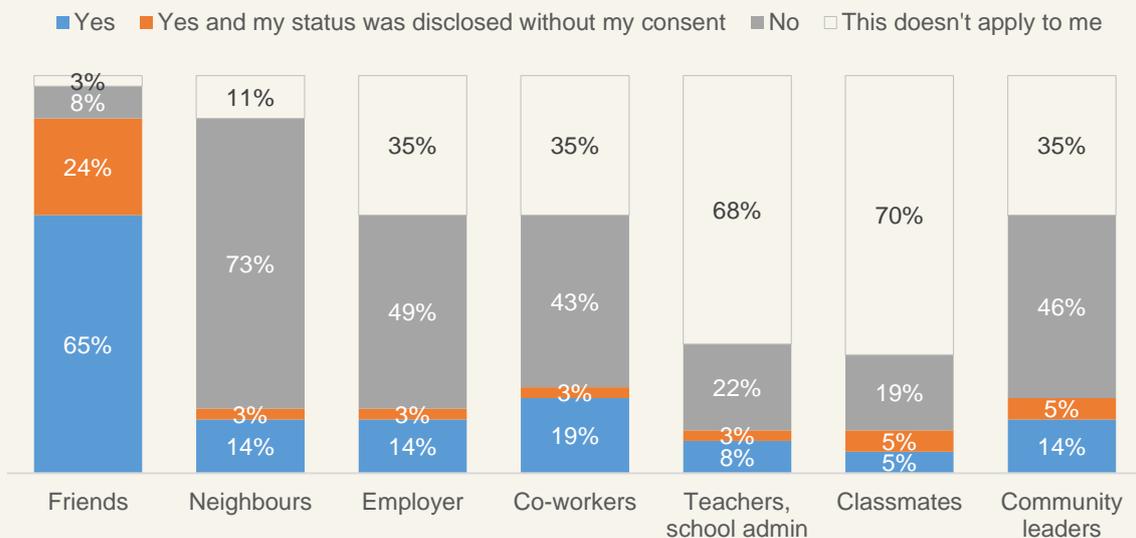
*Most of these situations I have been in. I have claimed it and owned it. Having HIV has made me a better person. It's made me more compassionate, empathetic + aware what true suffering is really about. I loathe stigma with every fibre of my being. It's so unevolved, it's a caveman's mentality. You just go on with this hateful outlook. We don't roll like that.*

*I invited a friend to come stay with me in my house. He wasn't comfortable with me eating from / using different plates. He was asking me to eat from one plate. That hurt me because he was my friend . . . A mate did ask me after we shared a smoke from a pipe if he could catch AIDS.*

# 3. Wai Ora - Healthy Environments

When asked about the people or groups outside of their family who knew about their HIV, and whether their HIV had ever been disclosed to the person or group without consent, most participants responded that friends knew about their HIV, however almost a quarter said their HIV had been disclosed to friends without their consent. To a lesser degree, participants' co-workers, employers, community leaders, teacher-school admin, and classmates knew about their HIV. Within each of these smaller groups, however, there were small numbers of participants whose status had been disclosed without their consent.

Figure 15: People/groups outside family know you live with HIV?



*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.*

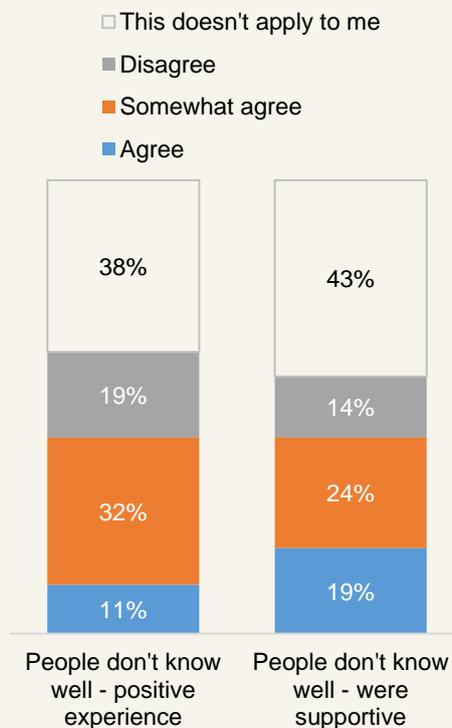
*During my counselling training my classmate was working on a project on HIV. I told her I could help as I'd done some volunteering work. During the course of helping her I disclosed to her. During her presentation she outed me to the*

*whole class and told my story to everyone. My final year was horrible & I eventually became very isolated. I almost gave in and withdrew but I stayed at it. This experience stayed with me & groups of people make me feel anxious. It kicked the shit out of my self-esteem.*

## Disclosure to people not close to you

In contrast to the experiences of disclosing their status to people they were close to, when it came to participants disclosing to people they didn't know very well, less than half agreed or somewhat agreed it had been a positive experience, or that those people had been supportive. In connection with this, while over half the participants agreed or somewhat agreed that disclosure had gotten easier over time, more than a third of participants disagreed with the statement.

Figure 16: Disclosing to people you don't know well is positive?

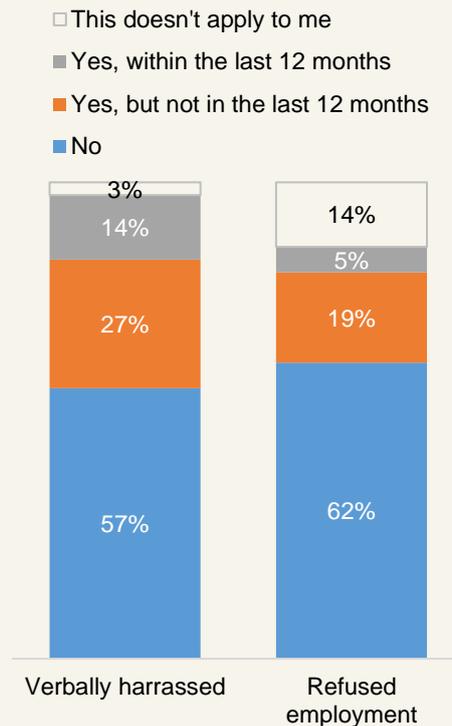


*I work as a teacher and there are way too many people I have contact with who may or may not respond negatively. Basically only one person at school knows my diagnosis but that is because I have known her a long time and she knew before she started working at school with me. The way I feel most secure at school is to tell no one at school that I have HIV.*

## Stigma and Discrimination - society

Participants were asked about stigma and discrimination they may have experienced, 'within the last 12 months' and 'not in the last 12 months', because of having HIV. Overall, three quarters of participants responded that they had experienced some form of stigma and discrimination. In particular, well over a third had been verbally harassed; and just under a quarter had been refused employment.

Figure 17: Stigma and discrimination (society) because of HIV?



An article by Grierson and colleagues (2004, cited in Pihama, Green, Mika et al., 2020) and a second by Sheaf, Aspin, Dickson, & Penehira (2011, cited in Pihama, Green, Mika et al., 2020) have reported that, as a result of stigma and discrimination, Māori PLHIV experience less favourable treatment at medical centres, less favourable treatment regarding their employment, and confidentiality problems regarding their HIV status.

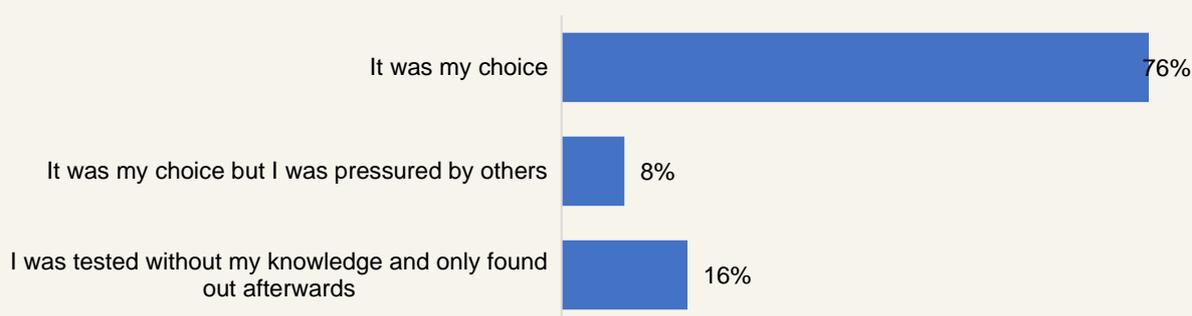
The Te Kupenga 2018 supplementary tables (Stats NZ, 2020b) provide data on the general Māori adult population (15 years and over) in relation to selected trust and discrimination measures. The data show that in 2018, 29% of Māori experienced discrimination in the last 12 months; and 66% had ever experienced discrimination, with the three highest incidences taking place at school (43%), at work (25%), and on the street or in a public place (22%). The most commonly perceived reason for discrimination, at any time, was 'my race or ethnic group' (56%).

*I have been living with HIV for nearly 30 years and during that time have experienced many different discriminatory (and stigma) situations, especially in the health system and employment field.*

## Being tested for HIV

Asked whether it was their choice to be tested for HIV, most of the respondents said it had been their choice. However, a few responded that they were pressured by others to test; while some said that they were tested without their knowledge and only found out after the test had been done.

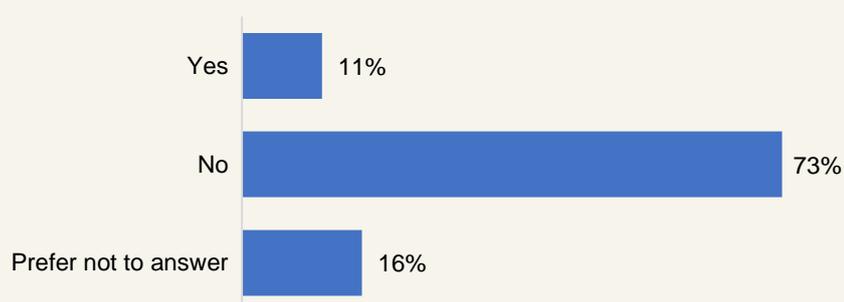
Figure 18: Your choice to be tested for HIV?



*I was tested against my will when I was working in a hotel, health insurance was going to be given. HIV was one of the tests performed.*

Participants were asked whether they had ever hesitated to get tested for HIV, due to fears about how other people, e.g. friends, family, employers and community, might respond if they tested positive. While most said no, a small number said yes.

Figure 19: Fear of others' responses make you hesitate to get tested?



## STIs and mental health conditions

In response to whether they had been diagnosed in the last 12 months with an STI or mental health condition, almost a third (30%) of participants said they had been diagnosed with an STI; and slightly more (32%) had been diagnosed with a mental health condition or conditions.

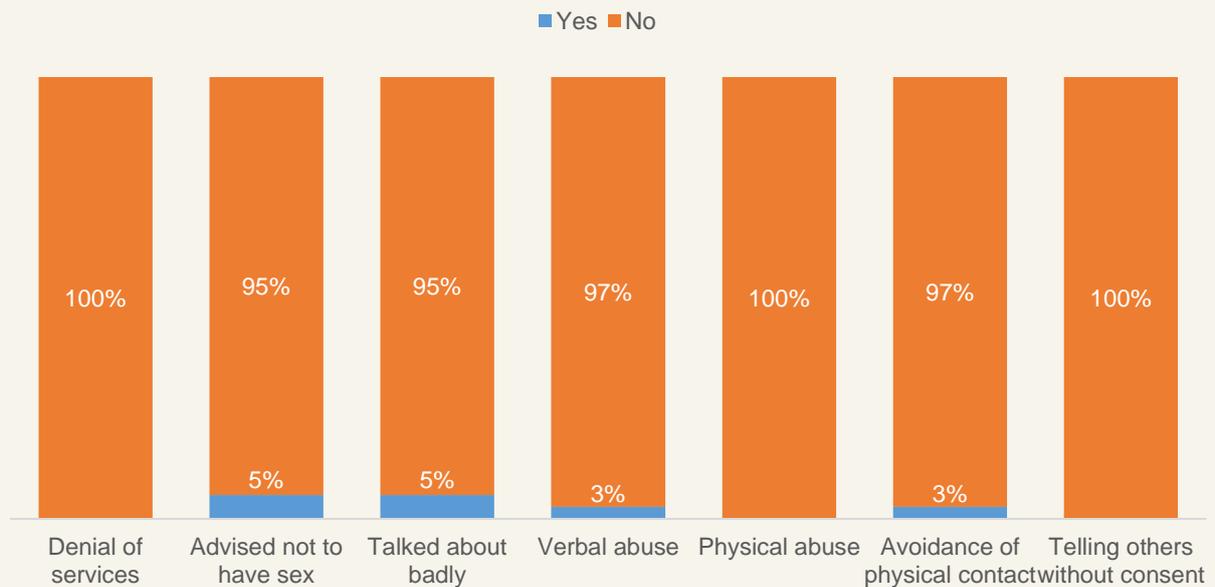
One of the key findings regarding STIs from the NZHS 2014-15 (Ministry of Health, 2019c) was that more Māori men and women had ever been diagnosed with an STI than non-Māori men and women. Sexual and reproductive health data from the NZHS 2014/15 showed that STI infection diagnosed in a lifetime (among adults who had ever had sex) was 1.72 times higher for Māori than for non-Māori; and STI infection diagnosed in the past 5 years (among adults who had ever had sex) was 2.22 times higher for Māori than for non-Māori (Ministry of Health, 2019d).

In terms of where participants usually receive their regular HIV care and treatment, most (86%) said 'a public clinic or facility', while a smaller number (13.5%) said 'a private clinic/ hospital or doctor'. As a comparison, almost all (95%) the non-Māori participants received their HIV care and treatment in a public clinic or facility, with very few (3.3%) getting care and treatment from a private clinic, hospital or doctor.

## **Stigma and discrimination in health care**

Participants were asked whether they had experienced discriminatory behaviour from health care staff in the places where they receive HIV care, because of their HIV status. For example, denial of health services; being advised not to have sex; being talked badly about or gossiped about; verbal abuse; physical abuse; avoidance of physical contact or taking extra precautions, such as wearing double gloves; and other people being told about their status without their consent. Although most responded 'no' to the questions, a few participants responded 'yes' to having been advised not to have sex; being talked badly about or gossiped about; being verbally abused; or health care staff avoiding physical contact with them, in the last 12 months, because of their HIV status.

Figure 20: Discrimination when seeking HIV-specific health care?



*I also had a pharmacist telling his colleagues about my medication, what it is and the price of it. This is whilst collecting my antiretroviral meds. It was a lot to deal with at the time however I confronted him the next day to say how inappropriate & I didn't appreciate that as it made me feel stigmatised.*

Most participants (84%) said they had sought healthcare for non-HIV related health needs, such as flu, dental services, vaccinations or injury, in the last 12 months. Participants were also asked whether, in the past 12 months, they had experienced discriminatory treatment by health facility staff, such as denial of services, including dental care; being advised not to have sex; being talked badly or gossiped about; being verbally or physically abused; having staff avoid physical contact with them; or their HIV status being told to others without their consent. Almost 20% of participants had been the recipient of discriminatory behaviour by health facility staff, with the highest incidence being staff avoiding physical contact with them.

*I showed up to A&E because of my asthma and was told it was because of my HIV. The doctor said to me "I hope you're practicing safe sex with your clients." It was shocking and upsetting.*

*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.*

*I visited a GP recently for a skin problem, & a prescription repeat, this was not my usual GP. He was hard to communicate with. During the consultation he got up to wash his hands several times. He had asked about other conditions & when it came to my HIV he said am I having safe sex. I was not happy with that question & told him to finish up the consultation. He printed out the XR and one of my meds were not repeated and I asked him to change this. He did but he threw the XR at me and left the room.*

When seeking general, non-HIV related healthcare services, almost a third (32%) of participants reported they do not usually disclose that they are living with HIV.

*Healthcare - I go up to support HIV patients in the hospital - they tell me health workers ask them how they got HIV. I tell them to make a complaint because that info is private, or tell them not to answer. They feel their level of care drops when staff find out they have HIV. So I see and talk with their doctor.*

Asked whether they thought that medical records relating to their HIV status were kept confidential, 40% of participants responded 'I don't know', while 22% said it was clear to them their records were NOT being kept confidential.

## **Sexual and reproductive health services**

The questions in the survey related to sexual and reproductive health services asked participants about their interactions with healthcare professionals in the last 12 months: specifically, whether they had been pressured or advised to undertake certain actions or procedures, or been denied sexual and reproductive health services based solely on their HIV status. Of the ten questions in this section of the Stigma Index survey, five were directed specifically at women. Our rationale for highlighting the 'Women only' section in this analysis is based on equity. Because men who have sex with men (MSM) are disproportionately affected by HIV, accounting for over 80% of all locally acquired HIV diagnoses in 2019 (New Zealand AIDS Foundation, 2021), research, resources and services often centre on MSM as a key population. In 2019, Māori males comprised 89% of all Māori diagnosed with HIV, while Māori females diagnosed with HIV made up just 11% (AIDS Epidemiology Group, 2020). If the experience of being a woman living with HIV in Aotearoa New Zealand has been described as feeling like 'a minority in a country of low prevalence' of HIV (Miller, 2010, p. 29), Māori women living with HIV could well be conceived as

being “a minority within a minority” (Pihama, Green, Mika et al., 2020, p. 17). In terms of HIV-related stigma and discrimination, Māori women are just as susceptible as Māori men (Miller, 2010) and, in the context of seeking reproductive health care, are likely to be more so.

*I have historic trauma & HIV on top of this & being Maori & being a woman can be an ongoing challenge . . . In saying that, I don't know if I'd be as I am had I not had HIV.*

## Stigma and discrimination in reproductive health care

A small number of Māori women participants gave affirmative responses to the questions about being pressured, incentivised or advised by a healthcare professional in the last 12 months: to get sterilised; to terminate a pregnancy; to use a particular method of giving birth or delivery option; to use a particular infant feeding practice; and to take ART during pregnancy to reduce the chance of HIV transmission, rather than being counselled about ART as an option.

Although the number of Māori participants who experienced these discriminatory scenarios were few, the fact that they happened at all reflects an urgent need for all healthcare professionals to be educated in the current guidelines for treatment and management of HIV, to ensure that the Wai Ora of Māori women living with HIV is sustained and supported, and that their Te Tiriti rights, human rights and Indigenous rights to good sexual and reproductive health are upheld.

*Most of my discrimination has been from health/ reproductive staff. When I was pregnant I was given 24 hrs to decide and was repeatedly told I had to make the decision based around my HIV. I felt really pressured & decided to go ahead with the termination.*

*Abortion - told to have a termination because of HIV diagnosis, 2003 + 2010.  
Caesarean - was told would have to have caesarean because I'd refused to have termination.*

## Collective Rights

With regards to knowing about and then enacting their collective rights as Māori PLHIV to address HIV-related stigma and discrimination, the survey only focused on participants' individual rights and did not ask about collective rights. As a mechanism to respond to HIV-related stigma and discrimination there has been no national advocacy or promotion developed with Māori PLHIV collectives or with Māori communities whose support of Māori PLHIV whānau members is so critical. Two examples of the collective rights of Māori PLHIV are recognised by the United

Nations Declaration on the Rights of Indigenous Peoples (2007). The right to freedom from any kind of discrimination is addressed in Article 1, and the right to redress associated with the subjugation of mātauranga Māori with regard to gender and sexual identity and HIV are covered by Articles 13 & 15. To our knowledge, no collective of Māori PLHIV has filed an HIV-related stigma and discrimination claim against the government to the United Nations or to the Waitangi Tribunal concerning government policies that failed to protect Māori from HIV or from stigma and discrimination arising from their HIV status.

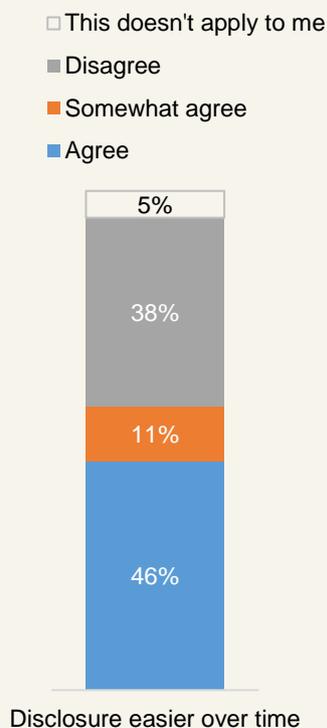
# 4. Pae Ora - Healthy Futures for Māori

Pae Ora is the Government’s vision for Māori health. Comprising Mauri Ora, Whānau Ora and Wai Ora, Pae Ora provides a platform for Māori to live with good health and wellbeing in an environment that supports a good quality of life. The concept of Pae ora encourages everyone in the health and disability sector to work collaboratively, to think beyond narrow definitions of health, and to provide high-quality and effective services (Ministry of Health, 2020a).

## Looking to the horizon

Looking ahead, nearly half of the participants reported they’d found it easier over time to tell others of their HIV status, and just over half somewhat agreed or disagreed that telling people they were HIV positive got easier with time.

Figure 21: Disclosure easier over time?



Likewise, time did not seem to determine whether Māori PLHIV felt better or worse about themselves. When asked whether the effect of their HIV status on their self-confidence, ability to cope with stress, achieve goals and contribute to their communities had improved with time, most reported their situation was the same or worse, with only a small number reporting improvement.

For reasons that were not explored in the survey, only a small number of Māori PLHIV reported healthcare professionals had influenced their reproductive decision-making as a consequence of their HIV status. Barriers and opportunities to parenting their own or whāngai children or the removal of children from their care as a consequence of their HIV status were also not covered by the survey. Nor did the survey ask Māori PLHIV about their whānau and hapū-related goals and aspirations for the future, in terms of whakapapa and succession of their interests in collectively owned Māori lands.

## Quality of life

In the final section of the survey, participants were asked to rate the extent to which they were enjoying life, felt in control of their lives, and were optimistic about their future. More than half of the Māori participants living with HIV reported they were enjoying their lives and felt optimistic about the future; however fewer participants reported they felt totally in control of their lives. For Māori, tino rangatiratanga or the ability to control one’s individual and collective destiny is a key component of individual and collective wellbeing (SUPERU, 2016).

Figure 22: Quality of life sub-scales (PozQoL)

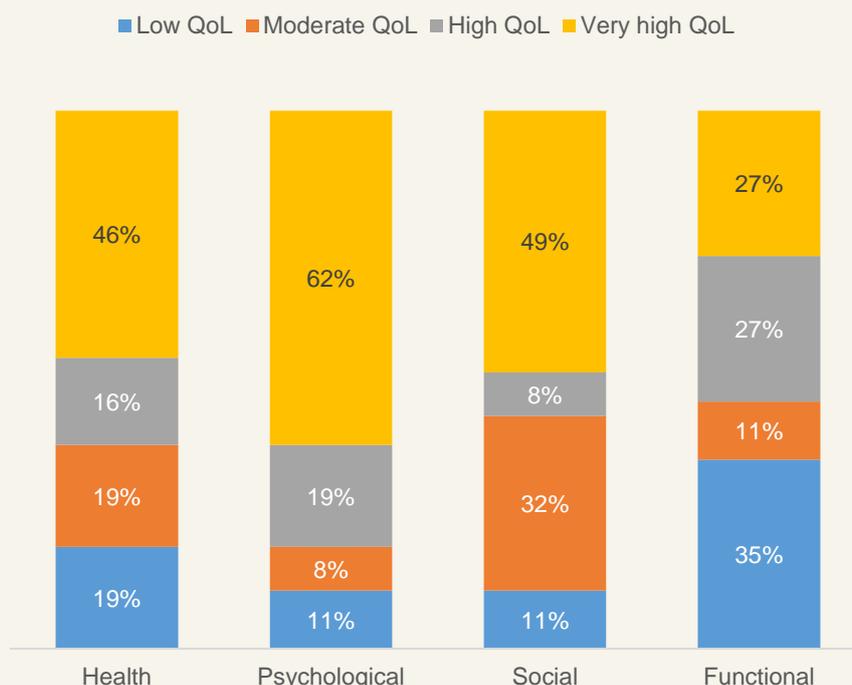
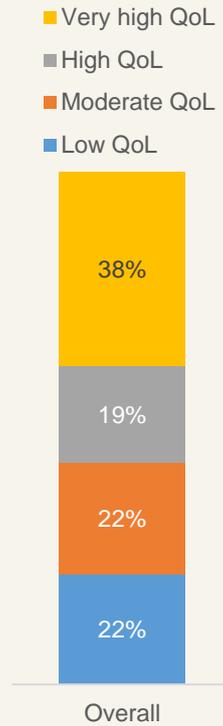


Figure 23: Quality of life combined total scale



*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 Maori growing up in the 70s + 80s - my attitude was nah, fuck you, I'm not going to roll over and die and be another Maori stat . . . a victim of colonisation. Those kinds of thoughts were very present in my head when I contracted HIV.*

*I have been positive 25 yrs +. Stigma has changed. I've learnt to manoeuvre myself around this change. We need more accessibility to these projects (HIV Stigma Index). The stigma won't change unless we band together . . . Big ups to our younger generation.*

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Te Whāriki Takapou