NGĀ TAIPAKEKE O TE URUTĀ HIV

AGEING WITH HIV IN AOTEAROA NEW ZEALAND

Report
2023

> "We are amongst the first to become older and living with HIV. So, we don't know what we don't know yet because nobody has ever been here before."
>
> Research participant 2023

Positive Women
Wāhine Kaha

Ngā Taipakeke o te Urutā HIV | Ageing with HIV in Aotearoa New Zealand Report 2023

The study obtained ethical approval from the Otago Polytechnic Research Ethics Committee (981).

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E kore mātou, e kore tātou.
Ka tū kahikatea i te uru.

Nothing about us, without us.
With unity comes strength.

A Māori world-view | Introducing Hauora, Mauri and Wairua

To better understand the context of this report, it is important to know this was a qualitative research project led by people living with HIV and developed in partnership with Māori. From a Māori worldview, life's essence is based on three fundamental concepts: Hauora, Mauri, and Wairua. These concepts can be complex for non-Māori to understand so we have used the Kahikatea tree as a metaphor to help explain them.

The roots, branches, and leaves of the Kahikatea are each interconnected and rely on the other, while also standing alone, just as Hauora, Mauri and Wairua cannot function without the other and are essential for total wellbeing. Neglecting one aspect can impact on the others.

The essence of Mauri flows through this report, encompassing all who were involved from the Kaipupuri (Positive Women Inc.), the Kaiārahi (Leaders), the Kairuku (Interviewers), and the Roopu Tautoko (community organisations support network. The Mauri continues through the voices of the research participants, to the research findings and the recommendations.

By reading this report your Mauri is also included. By uniting our collective mahi, we can create a place where people ageing with HIV can holistically thrive, where their voices are heard, and their Wairua is honoured.

Tihei Mauri ora

Kaua e takahia kei runga i te mana o tētahi atu.

Do not trample on the mana of another.

The Kahikatea

Wairua
The Leaves

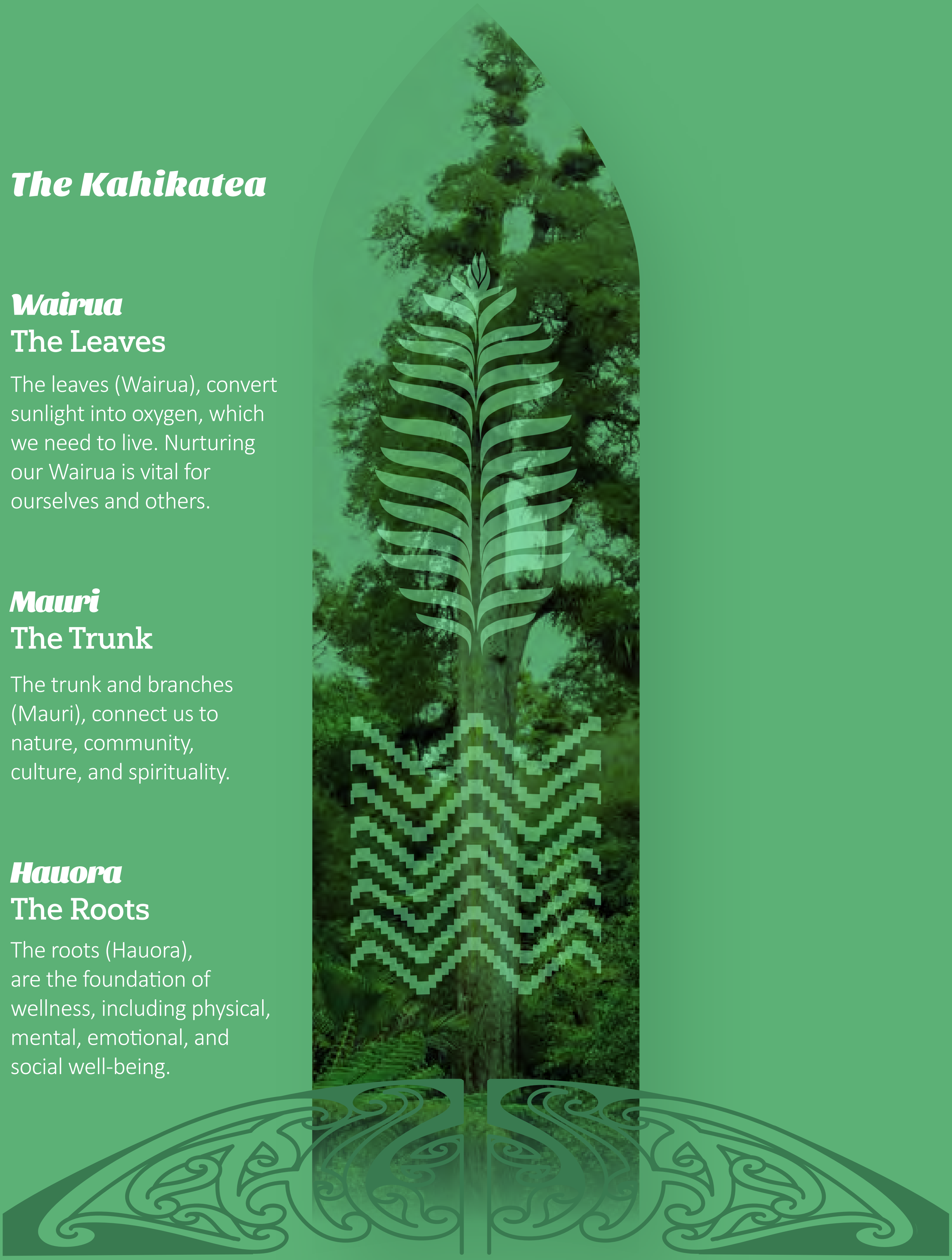
The leaves (Wairua), convert sunlight into oxygen, which we need to live. Nurturing our Wairua is vital for ourselves and others.

Mauri
The Trunk

The trunk and branches (Mauri), connect us to nature, community, culture, and spirituality.

Hauora
The Roots

The roots (Hauora), are the foundation of wellness, including physical, mental, emotional, and social well-being.



Contents

Ngā mihi | Acknowledgements

We wish to thank and acknowledge the study participants who gave their time and trust to share their personal experiences of ageing with HIV with us, and the following people for their contribution.

Kaipupuri Mauri: Jane Bruning (Positive Women Inc.) | **Kaiārahi:** Milly Stewart and Abby Leota | **Kairuku:** Milly Stewart, Abby Leota, Geoff Rua'ine, Rodrigo Olin, Peter Ford, Lianne | **Roopu Tautoko Contributors:** Judith Mukakayange (Positive Women Inc.), Milly Stewart (Toitū Te Ao), Ben Black (Toitū Te Ao), Alex Anderson (Burnett Foundation Aotearoa), Rodrigo Olin (Burnett Foundation Aotearoa), Thom McDonald (Body Positive Inc.), Carl Greenwood (New Zealand Needle Exchange Programme), Jerram Bateman (AIDS Epidemiology Group, University of Otago), Patricia Morgan (New Zealand Prostitutes Collective).

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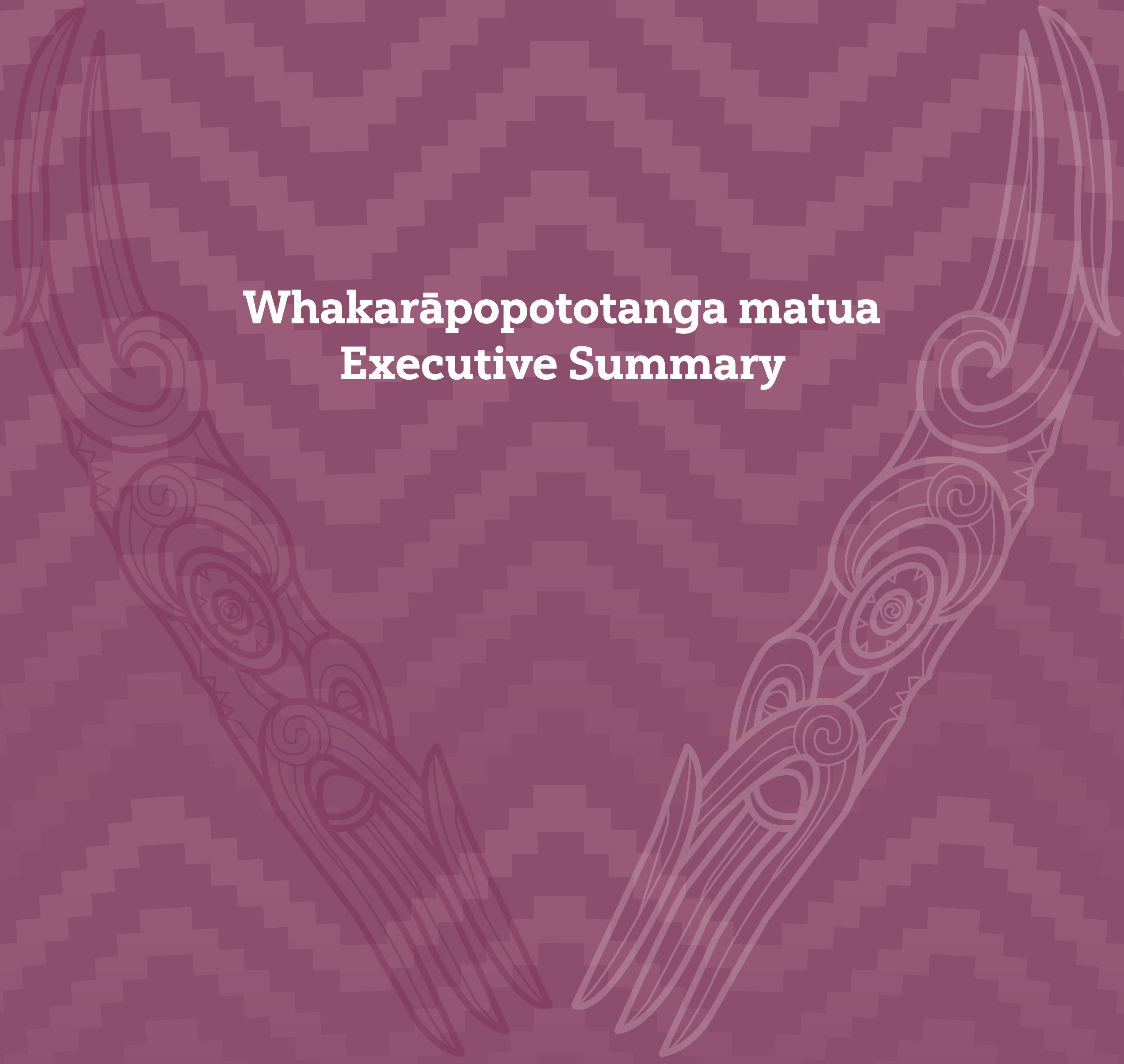

Whakarāpopototanga matua
Executive Summary

This report details the key findings and recommendations from a community-led qualitative research project which focusses on the experiences of people ageing with HIV in Aotearoa New Zealand. A first of its kind for HIV qualitative research, the project goes beyond the biomedical management of HIV and traditional academic research and places the expertise of lived experience at the forefront.

The project has three key objectives:

1. Identifying the needs of people ageing with HIV through qualitative research.
2. Formulating actionable recommendations for addressing these needs.
3. Reporting the findings and sharing recommendations for further action.

A vital aspect of this project is the collaboration and partnership between Māori and non-Māori living with HIV. This collaboration ensures this report is deeply rooted in the essence of Te Ao Māori (the Māori worldview). The collaborative process involved building trust and a new understanding of tikanga. The project's Model of Practice provides a framework of principles about how to work in this space. Principles like whanaungatanga, manaakitanga and kaitiakitanga guided us on how to carry out the mahi.

One of the key project objectives was to identify the needs of people ageing with HIV through qualitative research. From this research, four key themes were identified:

Ko Wai Au | Identity & Belonging
Poapoataunutanga | Impact of Stigma & Discrimination
Rangirua | Uncertainty
Tino Rangatiratanga | Self-empowerment

Ko Wai Au | Identity & Belonging highlights the importance of connection to community and whānau, sexuality identity, and gender identity, as well as cultural identity for people ageing with HIV.

The research found that the level of connection participants experienced had a direct impact on their sense of self and overall identity. Those who reported stronger connections to their communities, whānau, and cultural backgrounds expressed a greater sense of self and exhibited a stronger sense of identity and belonging.

Poapoataunutanga | Impact of Stigma & Discrimination highlights the challenges faced by people ageing with HIV due to unresolved trauma and the extent of self-stigma and layered stigma.

The impact of stigma & discrimination, and the fear of recurrence, continue as emotional and mental barriers for people living with HIV, regardless of their age.

Rangirua | Uncertainty was a prevalent theme. While uncertainty is not uncommon to ageing, ageing with HIV introduces unique and often complex challenges.

A large proportion of participant's uncertainty was due to the unknowns of long-term HIV, treatment side-effects and toxicity, comorbidities, socioeconomic challenges, and fear of the readiness of the aged care sector. This could suggest that when coupled with disconnection from identity and belonging and the impact of stigma and discrimination, the uncertainty surrounding ageing with HIV becomes even more significant.

Tino Rangatiratanga | Self-empowerment underscores the vital importance of education and knowledge, along with the principles of MIPA (Meaningful Involvement of People Living with HIV or AIDS) and GIPA (Greater Involvement of People Living with HIV or AIDS), in nurturing participants self-reliance and freedom as they age with HIV.

In particular, increasing stigma awareness in the healthcare sector, and empowering people ageing with HIV with knowledge and education on HIV and its treatments, may help reduce uncertainty. The research found a growing power imbalance between participants and medical professionals, highlighting the need for a change in the dynamics of the healthcare system. Involving people ageing with HIV in decision-making processes and ensuring their active participation in their health choices, can help facilitate inclusion and self-worth.

While each research theme stands independently, they are also interconnected, and participants often experience them as cause and effect. For example, participants who faced unresolved trauma were more likely to feel loneliness and/or disconnection. These feelings, in turn, affected their sense of self-empowerment and led to increased uncertainty and anxiety about ageing with HIV. Conversely, those with a strong sense of self-empowerment exhibited less uncertainty regarding the challenges of ageing with HIV.

This research serves as a starting point for future work in this field. The recommendations provided in the report are intended to offer practical actions, that promote the well-being and quality of life for people ageing with HIV in Aotearoa New Zealand.

Adopting a broader perspective on HIV management can enable people ageing with HIV not just to survive HIV, but to thrive with HIV.

Ngā Tūmanako | Summary of Recommendations

The following statements are a summary of the detailed recommendations found under each of the research themes within this report. The recommendations are based on the identified needs of people ageing with HIV who participated in the research study, developed by the Kairuku, then refined and prioritised by the Roopu Tautoko. They serve as a starting point for change. Further research and work will be required as the population of people ageing with HIV in Aotearoa grows. The meaningful inclusion of people ageing with HIV (GIPA/MIPA) in every aspect of this response is central to achieving successful outcomes.

The summary statements are presented under the following focus areas:

Supporting people ageing with HIV

Priority #1

Provide culturally appropriate and easily accessible up-to-date information, skills, and knowledge on ageing with HIV. This encompasses a wide range of topics, including but not limited to associated comorbidities and risks, polypharmacy (taking multiple medications) and toxicity, understanding one's rights, end-of-life planning, and the practice of self-care. These resources aim to strengthen the ability and confidence of people ageing with HIV, to advocate for themselves, better navigate health care services and thrive.

Services and organisations supporting people ageing with HIV

Priority #2

Strengthen and diversify the range of accessible and inclusive services to address the well-being of all people ageing with HIV in Aotearoa. This includes mental, emotional, and spiritual support, incorporating peer and home-based programmes and events for increased opportunities for people to connect with whānau, friends and like-minded communities, broadening mental health services including access to psychologists and psychotherapists who specialise in trauma, and offering therapeutic and complementary therapies including traditional therapies such as mirimiri and rongoā to help with possible side-effects of HIV medication.

Priority #3

Increase and expand healthcare workforce education and awareness programmes to include services and other organisations which people ageing with HIV and their whānau may interface with. This may include but is not limited to topics around the mental, physical, and emotional impact of HIV, HIV stigma and discrimination, high risk comorbidities, drug interactions and polypharmacy.

Priority #4

The development of guidelines and/or wrap-around rapid response services for people ageing with HIV and their whānau, who need immediate support navigating aged care facilities and/or services.

Priority #5

Continue to advocate and work collaboratively to implement the recommendations included in the Aotearoa New Zealand People Living with HIV Stigma Index reports which specifically address stigma and discrimination of people ageing with HIV.

Research and monitoring

Priority #6

More targeted research and monitoring which is informed by the needs and experiences of people ageing with HIV in Aotearoa. This includes but is not limited to stigma and discrimination, readiness of aged care services/facilities, quality of life, polypharmacy and toxicity, HIV and trauma, and the viability for the provision of LBGTQI+ aged care friendly facilities & services.

Policies, advocacy, and funding that enables organisations to provide services

Priority #7

Establish a working group of allied organisations to collaborate and resource common actions and goals. This may include but is not limited to the investigation and development of strategies for Aotearoa on preparing for an ageing population with diverse physical, emotional, spiritual, and cultural needs, the investigation, and development of strategies for Aotearoa on new models of care (not just the biomedical), and advocacy for patient-centred approaches (not policy-led) which gives people ageing with HIV the autonomy over the management of their condition/s.

Priority #8

A public health-led campaign targeting the general population of Aotearoa to address HIV misinformation & stigma.

Priority #9

Dedicated funding and resources specifically for initiatives and programmes which support people ageing with HIV.

The overarching aim of all of the recommendations is to enhance the quality of life and well-being of people ageing with HIV and the continued efforts to strengthening rangatiratanga and agency for people living with HIV in Aotearoa.

Ngā Tīmatatanga | Introduction

This community-led qualitative research project focusses on the unique experiences of people ageing with HIV and is a direct response to one of the recommendations outlined in the Aotearoa New Zealand Stigma Index Report.

What sets this project apart is the involvement of people living with HIV and the true partnership with Māori. From its inception to analysis, Māori and people living with HIV have played a central role in all aspects of the project. Through this inclusion and by amplifying these voices and perspectives, this research seeks to gain a comprehensive understanding of the challenges, needs, and aspirations of people ageing with HIV in Aotearoa New Zealand.

The Structure of this Report

This report begins by providing a brief background on what is known about ageing with HIV in Aotearoa New Zealand. It details the project's objectives and methods, including how the research was conducted using the Te Hā- Model of Practice. The research findings are presented by exploring the main themes and topics from the participant's interviews, along with insights from the Kaiārahi. The report concludes with each of the Kairuku sharing their experience of being an integral part of this project.

Te Reo Māori

Te Reo Māori has its own mana. It holds a depth of meaning which cannot always be directly translated into English. At the end of the report, there is a Ngā Taka o te Kupu providing context-specific translations, which may vary to official dictionaries but is how it has been applied to this report.

Intended Audience

The report has been written with inclusivity in mind, aiming to make the research findings easily understood for a diverse audience. Research, particularly qualitative HIV research, needs to be accessible to all, irrespective of whether readers are policy makers, healthcare professionals, researchers/academics, or people living with HIV who are interested and wanting to be informed.

Partnership & Collaboration

This project is an example of genuine and meaningful partnership with Māori and non-Māori . As a result, the report has a strong Te Ao Māori essence. Not only because we honour our obligations to the principles of Te Tiriti o Waitangi, but because we strongly believe this is how it must be.

This collaboration involved the building of trust, and an understanding built on a foundation of tikanga. This meant recognising and applying mana enhancing principles such as Tino Rangatiratanga, mana motuhake, and sharing all decision-making processes at every point. The Te Hā model of practice was developed for this project and provided a platform to hold these values and principles, and guided us on how to meaningfully work together.

What we know about Ageing and HIV in Aotearoa New Zealand

More than two decades since HIV treatment was developed, HIV has evolved from a fatal disease to a manageable chronic illness where people living with HIV can expect to live as long as someone who does not have HIV. Consequently, over 61%[1] of people living with HIV in Aotearoa are now over the age of 50. Future projections estimate that by 2030 this will rise to 72%[2]. Despite this, there has been no research on ageing and HIV conducted in Aotearoa New Zealand until now.

International research shows people in their fifties who live with HIV are considered 'older' adults because at this age, the immune system is lower and slower than in younger people. This means that despite leading long healthy lives, people living with HIV often age faster, and places people living with HIV over 50 at increased risk of developing age-related comorbidities (Brañas et. al., 2022).

Evidence in existing reports such as the Aotearoa New Zealand People Living with HIV Stigma Index (2020), NZ Aged Care Association (2022), and the Office of the Auditor-General (2014), indicate there are insufficient support services and workforce to care for people ageing with HIV, whether that be provided by aged residential care (ARC) workers, by whānau, or by home-based care and support workers. The Government's strategy for Aotearoa's ageing population is called Better Later Life – He Oranga Kaumātua 2019 to 2034. Despite one of the guiding principles of the strategy being ***Recognising diversity and that everyone is unique***, there is currently no surveillance, rangahau or specific workforce training to ensure the growing population of people ageing with HIV, and their unique needs, will be met.

Project Purpose

The project concept was to produce a training resource for the aged care sector. To do this, we first needed to consult with the community to find out 'What do people ageing with HIV in Aotearoa, need?'. Subsequently, to do this well, it was decided to break the project into two (2) phases: Phase one would be the qualitative research, and the evidence gathered from this research would guide us more accurately into phase two.

The objective of Phase one was to identify the needs of people ageing with HIV in Aotearoa New Zealand.

The project had three key objectives:

1. **Identifying the needs of people ageing with HIV through qualitative research.**
2. **Formulating actionable recommendations for addressing these needs.**
3. **Reporting the findings and sharing recommendations for further action.**

Using the outputs of phase one, phase two will focus on developing community-led resources on ageing with HIV. The design and delivery of phase two is planned for later in 2023/2024.

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[1] *Of those notified with HIV up to the end of 2021 and thought to be alive in NZ, 61%* were estimated to be aged 50+ at the end of 2021. (AIDS Epidemiology Group, University of Otago). *This percentage is likely to be an overestimate due to the true number of people who have died or gone overseas being unknown.*

[2] *By the end of 2030, the proportion of people with HIV estimated to be aged 50+ is approximately 72%** (AIDS Epidemiology Group, University of Otago). **This percentage is likely to be an overestimate due to the true number of people who have died or gone overseas being unknown.*

Te Hā – Model of Practice

Te Hā (pictured on the right) has many significances and meanings. The tohu is of two Manaia, one green, one white. Manaia are ancient traditional art forms that are used as kaitiaki (guardians) in whakairo and taonga. The green Manaia represents Papatūānuku - our earthmother, carer, and supporter. She keeps us grounded and stable. She denotes all that we know. Our known knowns.

The second manaia sits without colour. It needs and looks for colour. To manaaki this Manaia that sits without colour we look to our sky father - Ranginui to guide and protect. The two Manaia come together to share their Hā (breath). This forms one heartbeat where all life begins, and where we all come from - the one space.

Each eye of the manaia looks and draws from each other's strengths. The eye of the Manaia also looks beyond the inner strengths forming Te Kitenga - seeing, observing, perceiving.

In whakairo (traditional carving), Manaia takes on the resemblance of arms and hands, which enables us to reach and lean on each other for support in our work (Te Mahi). Mahi is the practise of the work that needs to be done. When the work is done, we arrive at Te Tau. Tau is a place of being settled, a place of wellbeing, connected to all things.

The light behind Te Hā is where we draw our passion from. The triangular shaped background is two-fold. The Poutama shows our life's journey – the stairway to heaven, encompassing the highs and lows as we learn from both adversity and triumph. The Kaokao, is the stance we have when our hands rest upon our hips, representing our strength and determination.

At the base is the koru pattern – symbolising the continuation of life. Where it ends, it also begins. This is where our model of practice sits and forms the foundation to remind us that we can never stay (or want to stay) dormant, we must always go back to Te Hā, the breath, where life begins.

Whāia te iti kahurangi ki te tūohu koe me he maunga teitei

Seek the treasure you value most dearly.
If you bow your head, let it be to a lofty mountain.

Te Hā

The Breath

Tino Rangatiratanga

Mauri Ora

Te Kitenga

See, observe, perceive

Whanaungatanga
Manaakitanga
Kaitiakitanga
Wairua
Aroha
Pono

Te Mahi

Practice/work

Te Kitenga

See, observe, perceive

Whanaungatanga
Manaakitanga
Kaitiakitanga
Wairua
Aroha
Pono

Te Mahi

Practice/work

Te Tau

Settle

Tikanga Whakahaere | Methodology

Research Approach

The methodology of this research deliberately positions people living with HIV at the centre of the report. The project was designed and delivered by people living with HIV, with support from allied organisations made up of representatives who are people living with HIV, and those working in the HIV sector.

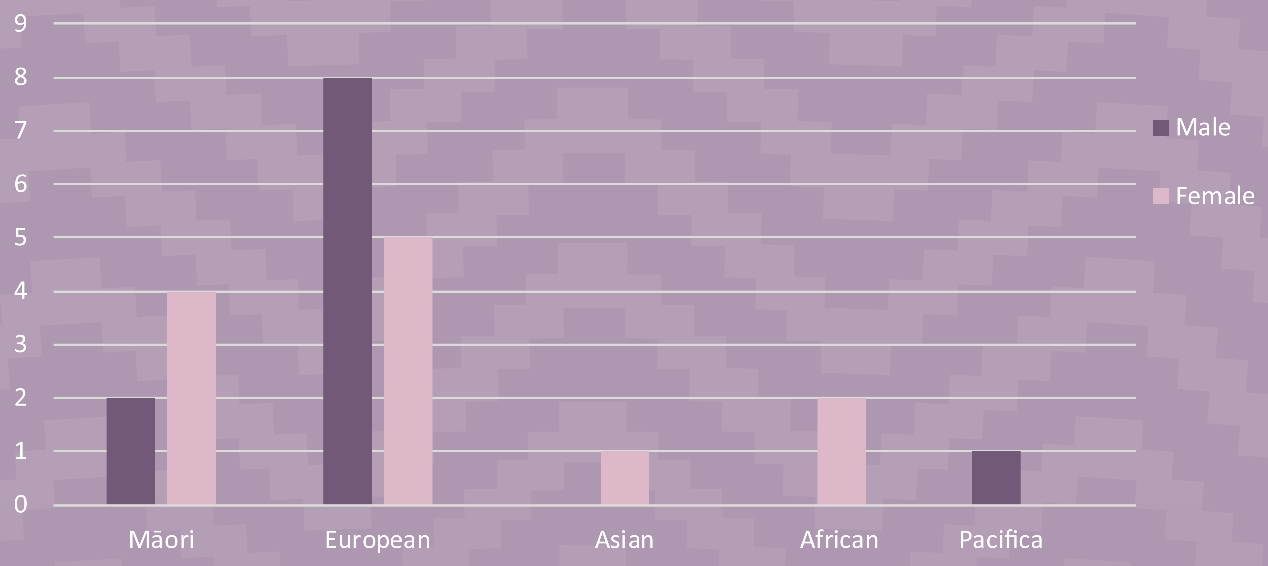
Positive Women Inc. held the role of Kaipupuri Mauri, being responsible for the overall project, funding and outcomes. Milly Stewart and Abby Leota were the Kaiārahi responsible for leading and guiding the project. The Roopu Tautoko consisted of seven organisations working in the HIV sector (Positive Women Inc., Toitū Te Ao, Burnett Foundation Aotearoa, Body Positive Inc., New Zealand Needle Exchange Programme, New Zealand Prostitutes Collective, and the AIDS Epidemiology Group at the University of Otago). This Roopu worked collaboratively throughout the project to help refine the objectives, offer advice, and support the kaupapa. The Kairuku (Interviewers) were all people living with HIV.

The Aim of the Research

There has been some quantitative research conducted globally on ageing with HIV that looks at specific health-related issues such as comorbidities and drug interactions. However, there has not been any qualitative research conducted that looks to identify the needs as seen by the people ageing with HIV in Aotearoa New Zealand. The research aim was to understand these experiences, and the key question was:

What are the needs of people ageing with HIV in Aotearoa New Zealand?

Figure 1. Study Participants



Participants Recruitment

The project aimed to recruit participants representative of the ethnically diverse HIV community, who were aged over 50 years or older, and living with HIV. The Roopu Tautoko agreed that the mode of transmission (how someone acquired HIV) was not relevant to this study. Participants were recruited through the existing peer network of the Roopu Tautoko. Information was made available to potential participants via a comprehensive webpage, where people were invited to register their interest.

Twenty-two (22) people in total were interviewed as seen in Figure 1. Whilst we were unable to recruit the ethnic diversity we had aimed for, we were pleased to have a high representation of Māori and female participants who are often underrepresented in research.

Population groups such as men who have sex with men (MSM), people who inject drugs, and sex workers, were not specifically recruited on this basis. However, some participants may also identify with these demographics. Recommendations by peer-led support organisations within the Roopu Tautoko which support these population groups, have been included in this report.

Interview Questions

The approach to interviewing was centred around whakawhanaungatanga (building rapport) and establishing a relationship with each participant. This was essential to foster a safe foundation of trust where natural kōrero could happen.

Understanding the needs of people ageing with HIV in Aotearoa New Zealand required a broad set of interview questions. The Kairuku collaborated to identify what questions would be asked. This helped ensure participant questions were not influenced by the Kairuku lived experiences.

Semi-structured questions were incorporated into each interview to prompt conversation, as follows:

1. **Can you tell me why you wanted to be involved in the ageing with HIV study?**
2. **What is important to you as you age with HIV?**
3. **Can you describe what total-wellness (hauora) might look like for you as you age?**
4. **What worries/concerns you the most about ageing with HIV?**
5. **Is there anything else you want to say that we haven't covered?**

The Kairuku also used probing and clarifying questioning techniques to gain a deeper understanding of participants responses. Interviews were conducted over five (5) weeks with the majority done face-to-face; a few were conducted online.

Confidentiality

To ensure confidentiality in the research study, each participant was assigned a unique identification number, which was used on all study documentation. Participants' details were only known to the lead researcher and the assigned Kairuku. This approach protected participants' privacy by anonymising their data and securing their personal information.

Data Gathering and Analysis

Participant interviews were recorded and transcribed using Otter.ai, an online transcription and recording software. Following each interview, the Kairuku reviewed the recordings and corrected any transcribing spelling errors. The Kairuku documented their own reflections and what they observed in each interview. The lead researcher then listened and read the transcript and documented their observation. Each participant was sent an electronic copy of the transcript for reviewing and final approval. Once approved, both the lead researcher and Kairuku met to discuss each other's reflections and agreed to the emerging topics which were then populated in a comprehensive spreadsheet and grouped around commonality. Using thematic analysis with an inductive approach, preliminary themes and sub-themes were drafted and then finalised collectively.

Some of the findings in this report have been presented as percentages and in graphs. While this deviates from traditional qualitative research reporting, there was so much valuable information, we wanted to ensure the voices of the participants are heard and accessible to readers and felt this was best presented in graphs. The percentages were arrived at by identifying the number of times the same topics were mentioned by participants.

Māori Perspective

A dedicated chapter providing a discussion of te ao Māori understanding and perspectives, Te Hā- Model of Practice, and themes impacting Māori ageing with HIV has been included in the report to ensure the unique needs and voices of Māori are not overlooked.

Kairuku | Interviewers

All six (6) Kairuku are living with HIV, of Māori and non-Māori ethnicities who have experience in providing peer support and/or interviewing for research. The research process involved ongoing consultation and engagement with Kairuku at all stages, including the development of questions, interpretation of analysis, and the development of draft recommendations. The richness of the Kairuku lived experiences served as a source of strength, albeit accompanied by its own set of challenges. This was managed through the application of ethical principles and maintaining integrity throughout the interviewing and analysis process. The Kairuku share their experiences of interviewing and participating in this project on pages 80-81 of the report.

Kairuku Training and Support

The Kairuku were given training which included qualitative research considerations by an experienced academic researcher. The administration of the process was supported by a Hoa Haere (checklist), and the Kairuku had access to professional counselling services if and when needed.

Ethics Approval

The study obtained ethics approval from the Otago Polytechnic Research Ethics Committee (981).

The Limitations of the Research

It is important to highlight in the context of this research 'Ageing' with HIV is considered to apply to a person living with HIV who is over the age of 50 years old, regardless of when they were diagnosed. We recognise there are other people living with HIV in Aotearoa who consider themselves as people 'ageing with HIV', including people who acquired HIV as babies or those who were diagnosed in early adulthood who are not yet 50 years old, but may also be impacted by long-term HIV and HIV treatments.

We were not successful in recruiting transgender people, Latin American, Middle Eastern or a wide demographic of Asian ethnicities of people ageing with HIV, and subsequently the research is limited in its representation. Any future research on ageing with HIV would want to ensure wider participation but would require significantly more fundings to do so.

As this is a small qualitative study, the research is not representative of the experiences of all people ageing with HIV. Any future study on ageing would require considerably more funding to allow for a much larger sample of participants to be recruited to better represent all people living with HIV within Aotearoa New Zealand.

Our interview approach was participant-led. This meant the Kairuku questions were semi-structured, conversational, and open-ended, guided by the comfortability of the participant and not conducted as a rigid set of questions to work through. This did not always allow for in-depth dialogue of some topics. If more research was to be conducted on ageing with HIV, specific topic questions or a survey may need to be considered.

For ethical reasons, we did not interview participants who were currently in aged residential care.

Recommendations - what's next?

The recommendations included in this report were drafted by the project Kaiārahi and Kairuku based on the findings of the research, and the needs identified by the participants. The Summary of Recommendations (page 13) include priority statements. A list of the recommendations will be found at the conclusion of each theme.

Te Rangahau | The Research Findings:

What do people ageing with HIV in Aotearoa need?

Four significant themes and thirteen (13) sub-themes emerged from the research findings. These have been highlighted in Image 2 on the following page.

The themes and sub-themes have been presented within the form of the koru. The Koru symbolises the never-ending cycle of life, representing growth, renewal, nurturing and balance which intertwines with the constant movement of people's Hauora, Mauri, and Wairua.

No theme has greater value than the other. Each theme stands strongly on its own, yet also overlaps with each other. For many participants, the themes which emerged were the cause and effect of each other. For example, we saw that participants who had experienced unresolved trauma were more likely to experience loneliness or disconnection. Participants who spoke of these feelings also demonstrated a low degree of Tino Rangatiratanga and in turn, had more uncertainty and anxiety about ageing with HIV. Similarly, those who felt a strong sense of Tino Rangatiratanga, showed less Rangirua (uncertainty) for the unknowns of ageing with HIV.

Image 2:
Research Themes & Sub-themes

How the findings are presented

This section begins with a recorded kōrero between Milly Stewart and Kevin Haunui discussing the model of practice - Te Hā and the themes of the research in relation to Māori. This is followed by sharing a te ao Māori perspective on the research findings and participant experiences. It includes recommendations for improved well-being for Māori ageing with HIV.

Identifying and introducing oneself - "Ko Wai Au" (Who am I?) is how Māori begin kōrero. Therefore, the findings are led by the Ko Wai Au theme, followed by Poapoataunutanga, Rangirua and Tino Rangatiratanga. Each theme concludes with a list of recommendations for action, drafted by the Kairuku in response to what participants shared. A summary list of priority recommendations can be accessed on page 13.

This section concludes with Discussion Points, offering lived experience perspectives and observations from Kaiārahi and Kaipupuri Mauri.

Whakaaro Tuku Iho | Thoughts of Māori

Milly and Kevin speak openly about their understanding and knowing of who they are as Māori, Te Hā - Model of Practice, and the themes that emerged from the findings. We invite you to view the short 12 minute video either by clicking or scanning the QR code.

Kevin Haunui

Kevin Haunui is Māori and takatāpui (Māori LGBTQIA+). His iwi are Ngāti Tūwharetoa, Āti Hau, Ngāti Rangi, Ngāti Ūenuku, Whānau a Apanui, Ngāti Kahungunu, Ngāi Tūhoe.

His work and academic studies reflect a strong sense of social justice, manaakitanga and aroha for the communities and movements with whom he identifies and supports; Māori, whānau, takatāpui, and the general well-being of the community.

Kevin's current work projects include international and domestic research and community facilitation in the Sexual and Reproductive Health and Human Rights sector, and the intersectionality with HIV, Māori, and Takatāpui. Kevin is a Trustee for Tīwhanawhana Trust, a Wellington-based national organisation serving the takatāpui community. He has represented Tīwhanawhana on international LGBTQIA+ organisations as an advocate for takatāpui and indigenous cultural views that are inclusive of people of diverse sexual orientation, gender identity and expression and sex characteristics.

Milly Stewart

Milly Stewart is Māori and lives with HIV. Her iwi are Rongowhakaata, Ngāi Tūhoe.

Pou Tahuhu and Founder of Toitū te Ao – a charity providing support and advocacy for Māori living with HIV in Aotearoa. Her background in social work, professional supervision and teaching provides a solid foundation of knowledge and knowing. Raised in Te Tairāwhiti, Milly was emersed in her elder's wisdom and teachings of what it means to be Māori. Fluent in reo, she wears her moko kauae with mana.

Milly within her Māori worldview unapologetically holds others accountable for the principles of Te Tiriti o Waitangi, she actively works towards rectifying historical injustices and promoting equity and tino rangatiratanga for Māori living with HIV.

Ngā Kōrero a Waha o ngā Tāngata Māori | Māori Voices

Kia hiwa rā, kia hiwa rā	Listen and be alert
Kia hiwa rā ki tēnei tuku	Listen and do not faulter
Kia hiwa rā ki tēnā tuku	Listen to what has been released
Kia tū	Stand up
Kia oho	And be awaken
Kia mataara	Be vigilant
Tihei mauri ora	We have the right to speak.

The themes and sub-themes identified in the research are applicable for both Māori and non-Māori participants. Upholding our obligations and responsibilities to Te Tiriti o Waitangi this chapter ensures Māori perspectives on the research are not lost. Recommendations for action that aim to strengthen the over-all wellbeing of Māori ageing with HIV have also been included in this chapter.

The following perspective needs to be read alongside the report findings to provide more context.

Ko Wai Au

Mai i a ranginui nui kia Papatūānuku- from our sky father to our earth mother we draw on our knowing of who we are and where we are from. Ko wai au gives us belonging, a place of ownership, connection to self, whānau and whenua, our identity.

Without this there is no direction, no purpose, no stories. Disconnection from oneself, whānau, hapu and iwi is evident. A loss of culture, a loss of language is a loss of identity.

Hauora, Wairua, and Mauri needs nurturing, caring for to ensure a total well-being.

Poapoataunutanga

Whakamutua atu – end the stigma. Being subjected to stigma and discrimination is something Māori has always experienced, layer after layer. When these messages are continuously repeated, one's truth becomes invaded by these messages, and overtakes our self-knowing of acceptance, resulting in self-stigma.

From first sight, disadvantaged from the onset for reasons associated with a person's identity. Stereotyping, homophobia, and racism were specifically raised as being experienced along with the associated stigma of living with HIV. There is subtle discrimination not spoken but implied by action. This has a direct impact on our Hauora, a wairua, a hinengaro, a tinana in achieving total well-being.

Rangirua

Disconnect is twofold ‘a tinana’ body ‘a wairua’ spirit. If there is not a balance between the two something suffers. When there is a disconnect to culture, to identity, reoccurring stigma and discrimination, and unresolved trauma there is an imbalance which enforces the uncertainty. With a positive diagnosis coupled with ageing, the long-term effects of HIV treatment can cause a high proportion of uncertainty. You don’t know what you don’t know, until you know.

Tino Rangatiratanga

Tino Rangatiratanga a term used too lightly but means so much. To have tino rangatiratanga is to have total autonomy and control over oneself, one’s health and wealth. The question is do we? The short answer is, no we don’t. To achieve tino rangatiratanga is to have understanding by Māori and non-Māori in the same space, talking a language that supports and respects the person culturally and holistically, without fear of our voices and concerns being minimised.

Standing in our knowing of ‘Ko wai au’ is the beginning of how Māori can obtain tino rangatiratanga, standing strong, standing proud, knowing your whakapapa knowing who you are, your purpose. It gives confidence to call out inequities and discrimination experienced. It allows us to stand in our power paving the way for our rangatahi, and all those who follow while navigating through poapoataunutanga and rangirua. Tino Rangatiratanga is every Māori’s birth right.

E kore mātou, e kore tātou.

Recommendations for action

From a Māori worldview, well-being is based on the balance of three fundamental concepts: Hauora, Mauri, and Wairua. Each element is individually significant but can also influence each other. It is very important these are taken into consideration when implementing the following recommendations.

1. **Provide holistic services and support to address the mental, emotional, and spiritual well-being of Māori ageing with HIV including but not limited to, traditional Māori therapies such as mirimiri, and rongoā to help with possible side-effects of HIV and treatment.**
2. **Ensure the voices and unique needs of Māori ageing with HIV are included in workforce education and wider education programmes.**
3. **The development of culturally appropriate support for Māori ageing with HIV and their whānau, who need immediate guidance and support.**
4. **Ensure the voices and experiences of Māori ageing with HIV are used to informed research, and the mana of those who participate, is upheld.**
5. **A public health-led education campaign to address microaggressions and inequity for Māori ageing with HIV in healthcare.**
6. **Ensure all engagements for Māori ageing with HIV, involves meaningful partnerships and collaboration with appropriate Māori-led organisations.**
7. **Dedicated funding and resources specifically for initiatives and programmes which support Māori ageing with HIV.**

Theme

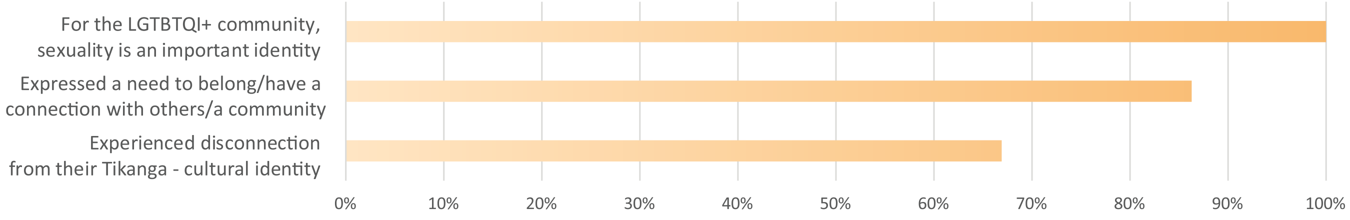
Ko Wai Au (Who Am I?) | Identity & Belonging

Connection With Community & Whānau + Sexuality & Gender + Cultural Identity

The key findings of this research theme show the importance of connection to community and whānau. It also highlights the importance of sexuality, gender and cultural identity for people ageing with HIV (Figure 2). Many participants expressed their loneliness and spoke of feeling disconnected. The more connected participants were, the greater their sense of self, and in turn, they expressed a stronger sense of identity and belonging.

Connection with Community & Whānau, Sexuality & Gender and Cultural Identity are all subthemes in their own right but are also interconnected. One of the key findings of this research was how important people's identity and sense of belonging is in order to experience connection. Participants who shared their positive experiences of connection to their culture or identity were likely to be more resilient, and able to experience Tino Rangatiratanga and less likely to be impacted by stigma and concerned about their future as they age with HIV. The impact of stigma and the importance of Tino Rangatiratanga are overlapping themes of this research to be shared in the following chapters .

Figure 2. Key Finding - Ko Wai Au | Identity & Belonging



Subtheme:

Connection with Community & Whānau

86% of participants expressed their desire to feel they belong/are connected to others/a community. (Figure 2). A paper commissioned by the Ministry of Social Development speaks of the impact social connections have in aspects of people's lives, from getting advice on important decisions, to receiving support during difficult times, to having someone to enjoy life with (Frieling, Krassoi Peach, & Cording, 2018).

One participant shared their positive experience of connection:

> "Connecting is so important because if you live in a bubble, and you don't let people in, well, everything is gonna go down the drain."
>
> (Research participant)

It is interesting to note this participant also expressed less concern about experiencing stigma, or less concern about their future as they age with HIV. This suggests if someone ageing with HIV has good social connections, they may be less likely to feel as concerned or fearful about other aspects of ageing with HIV.

Figure 3. Isolation and Loneliness

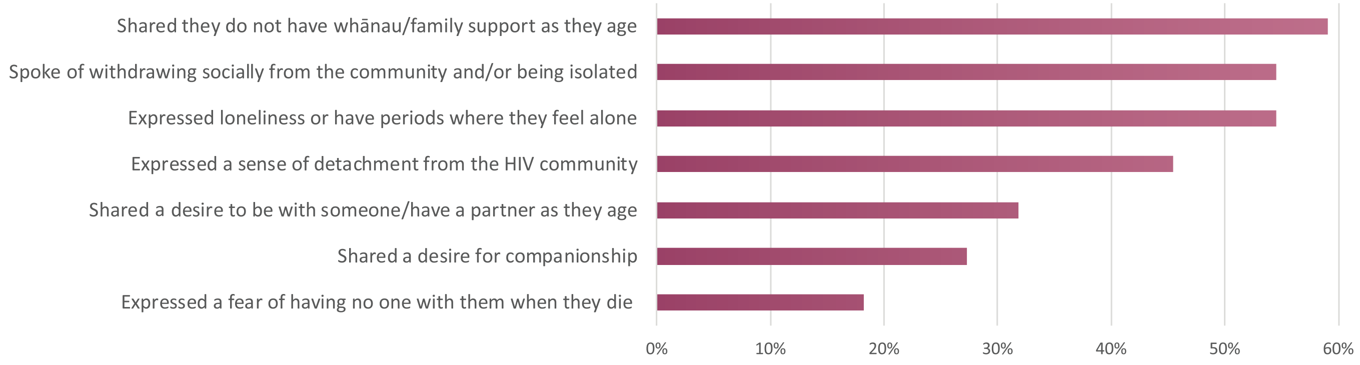


Figure 3 highlights some of the participants' experiences of isolation and loneliness which appears to be significantly higher than research undertaken with general ageing populations. According to the National Academies of Sciences, Engineering, and Medicine (2020) more than one-third of the general population of adults aged 45 and older, feel lonely and nearly one-fourth of adults aged 65 and older are considered to be socially isolated. Whereas at least half of all participants shared their experiences or feelings of loneliness and or isolation.

Living with HIV can often lead to feelings of isolation because of the stigma associated with HIV. This suggests that stigma could be a likely and significant contributing factor to why a greater percentage of participants are experiencing loneliness and social disconnection.

> "...I need to connect more. With people like me. That's a bit that's missing in my life. I don't know what I need from that. But I do know there is a need".
>
> (Research participant)

> "...when I go on a retreat, and reconnect with everyone, I've never ever felt that level of acceptance anywhere in my life".
>
> (Research participant)

These participant's experiences expressed the specific need to, or value of, connecting with other people who also live with HIV. A sentiment echoed by many participants. In particular, this participant valued a retreat organised by a community organisation for people living with HIV, which enabled them to access peer support.

HIV peer support is provided by people who are also living with HIV. It involves the exchange of knowledge, experiences, and emotional support between people who understand the unique challenges and issues associated with living with HIV. The benefit of peer-support is further validated in research undertaken in Australia which reports HIV peer support programmes assist people living with HIV in navigating the clinical, emotional, and social aspects of living with HIV (Wells et. al., 2022).

In this study, 59% of the participants shared they do not have any whānau support and 32% expressed their desire to be with someone/have a partner as they age (Figure 3). This could suggest these participants do not have family members to rely on for emotional, financial, practical assistance or support. According to the Ministry of Social Development, at least one in ten New Zealanders provide care for a friend, loved one or whānau member needing everyday assistance (Ministry of Social Development, n.d.). Whānau also play a significant role in fostering social connection for people as they age by helping to facilitate social interactions, organise gatherings or visits, and providing opportunities to engage with their extended whānau and community. Furthermore, family often serve as a health advocate and are able to recognise when more support might be needed and arrange for this to happen.

> “I haven't got any family anymore. There’s only my sister and we’re not very close. My Dad died not long after I got HIV. My Mum died last year. I didn't want her to know. There was no possible benefit in her knowing. To me, or her.”
>
> (Research participant)

This participant’s quote shares their experience of having both parents pass away and a distant relationship with their sibling. It suggests it was intentional not to share their status with their whānau which highlights the complexity often surrounding the reason people ageing with HIV experience disconnection from family.

This subtheme demonstrates the significant importance of maintaining connections with the community and whānau. While this study was limited to a small number of participants, the findings suggest that people ageing with HIV experience greater feelings of isolation and loneliness compared to the general ageing population, in part due to the stigma associated with HIV. Participants specifically highlighted the need for connecting with other people living with HIV, emphasising the value of peer-support programmes in fostering those connections, especially as people age with HIV. The lack of connection with whānau means many participants do not have access to the emotional, financial, and practical assistance which whānau can provide.

Disclosure and fear of potential negative consequences were some of the reasons participants intentionally kept their HIV status hidden from their families. Overall, the importance of social connections for people ageing with HIV cannot be overstated. Being strong in one's identity and experiencing a sense of connection and belonging are considered essential to Hauora, Mauri, and Wairua.

Subtheme:
Sexuality & Gender Identity

Almost half of the study participants identified as being part of the LGBTQI+ community. All LGBTQI+ participants emphasised the importance of their sexuality in relation to their identity as they age with HIV in some way (Figure 2). Sexual identity and gender identity are integral components of a person's individuality, influencing self-perception, relationships, and communities. It further shapes how these aspects of identity are essential to not only people's identity of self, but people's connection and sense of belonging.

According to Barrett et. al. (2015), the experience of coming out or disclosing sexual orientation impacts people's sense of self, relationships, and social connections. Many older, gay men, transgender people, and lesbians have lived through a time when their only protection against violence and discrimination was to make themselves invisible, and to publicly deny their sexual orientation. This intersects with another theme of this research report related to layered stigma and trauma.

While sexual identity and gender identity can be sources of strength and connection, it can also expose people to unique challenges, particularly around accessing aged care services in the community. Half of the participants expressed their desire for LGBTQI+-friendly aged care facilities.

> “...in the last few years, I've talked to other gay, male friends of mine about, what if we could all pull our resources and buy a big house somewhere and have a housekeeper and a cook and the nurse, and we can sit around and talk about all the naughty things we got up to as gay men. Because that would actually make me want to live longer”.
>
> (Research participant)

The quote above suggests the idea of creating a shared living arrangement, where people can reminisce about their shared experiences and enjoy companionship, further illustrates the importance of being connected with a community of people with similar sexualities and understanding. It was noted that these participants had given a lot of consideration to how they may be able to continue experiencing being part of the LBGTQI+ community as they age with HIV. Most participants shared that they had extended these conversations to other friends and loved ones too.


AUDREY HEPBURN
BREAKFAST AT TIFFANY'S
HERGÉ
LES AVENTURES DE TINTIN
LE LOTUS BLEU

> “When you’re a gay man, and you're in a “normal” sort of retirement village or whatever, it doesn't...it doesn’t feel right. I would be out of place.”

(Research participant)

This participant shares how they do not feel the traditional retirement village lifestyle fits for them. This is further supported by recent research (Henrickson, Cook, & Schouten, 2022) which emphasises the importance of creating inclusive environments that understand, accept, and support diverse sexual and gender identities within residential aged care settings. The readiness for aged care and services overlaps with findings in the theme of Rangirua | Uncertainty.

This subtheme demonstrates that sexual identity and gender identity are fundamental aspects of a person’s individuality, shaping self-perception, relationships, and communities. The specific desire of participants for LGBTQI+-friendly aged care indicates the need for inclusive environments that understand, accept, and support diverse sexual and gender identities. Recognising the unique needs of LGBTQI+ who are also ageing with HIV, can ensure people have a better sense of belonging and overall better quality of life.

Subtheme:

Cultural Identity

Cultural identity is at the heart of knowing who we are and how we relate to others. Within a Māori worldview, the concept of "Ko Wai Au"- Who Am I, forms the foundation for understanding identity, connection, and purpose. Ko Wai Au fosters a profound sense of belonging and can impact where Māori place themselves within whānau, hapū, iwi, but also within the wider community of people living with HIV in Aotearoa.

> "I really like learning about other people and their cultures and their stories and stuff. It's just that there's a real affinity when it's your 'own', you know, whether that's Māori, Pasifika, or Rainbow, you know - you just click straight away. Whereas with straight people, you can take time to get to know people. I guess I don't feel that instant connection".

(Research participant)

This quote emphasises the affinity which exists when a participant engages with people from a culture which they identify with, whether that relates to ethnicity, religious beliefs, sexuality, or gender. This participant speaks about the immediate connection and understanding they felt when amongst their known community in contrast with the challenges with building relationships with people from different backgrounds, such as those who identify as straight. This quote highlights the deep sense of safety and connection that cultural identity can provide for people as they age with HIV and how central culture identity is to Ko Wai Au.

Of note, within this study two thirds of participants who identified as Māori shared their disconnection to their tikanga (Figure 2). This suggests that some Māori ageing with HIV in Aotearoa may not be able to experience a sense of belonging or understanding of their cultural values.

> “I've never really had support from my family about learning my whakapapa or making connections to my people.... I have an understanding of tikanga and kawa but I'm still very much learning and that's gonna be a lifelong journey. And I can sometimes feel a little bit whakamā about not knowing”.
>
> (Research participant)

This quote expresses the participant’s experience of being unable to learn their whakapapa and make connections to their cultural heritage. The mention of feeling "whakamā" suggests that this participant feels embarrassed by this, making it more difficult to associate with where they come from and connect with their cultural identity. Studies have consistently found robust correlations between positive affiliation and engagement with people’s culture (Wexler, 2009). This signifies the important role culture plays not only in identity, but also with how people can experience connection.

> “...it wasn't till after I became an adult, and started hanging out with Takatāpui people, and doing kapa haka, and hanging out with some of my other gay friends that I got the real learning about karakia.”
>
> (Research participant)

This participant gained a deeper understanding of tikanga and cultural practices through their interactions with Takatāpui and engaging in other cultural activities such as kapa haka. This highlights the role of community and cultural events in learning and connecting with one's cultural practices and values. These findings underscore the importance of cultural identity and connection for people’s experience of belonging and connection. The subtheme of Cultural Identity highlights how important, Ko Wai Au (who am I?) is for people ageing with HIV and the benefits of being with other people who they feel safe and connected with.

Ko Wai Au (Who Am I?) | Identity & Belonging

In summary,

the research theme Ko Wai Au (Who Am I?) | Identity & Belonging discovered a shared need among participants ageing with HIV. It emphasises the significance of social connections in building resilience and helping reduce stigma's impact. It highlights the important role of whānau play in providing the additional support often needed as people age. The theme also highlights the need for inclusive care spaces for LGBTQI+ communities in aged care service and how central cultural identity is, especially for Māori, in fostering a connection to self and the context of who you are. Ultimately, the research underscores that having friends, whānau, and a strong sense of self greatly influences the well-being of people ageing with HIV.

1.1 Develop peer support programmes for people ageing with HIV.

1.2 Education/Training for aged-care/home-support workers to include diversity, stigma, discrimination, care of People living with HIV, HIV treatments

1.3 Establish a mobile team and/or guidelines for supporting People living with HIV into aged care facilities/services

1.4 Establish peer support home-visit programmes

1.5 Identify community events for people ageing with HIV

1.6 Practise of GIPA/MIPA - inclusion of people ageing with HIV

1.7 Provision for more culturally appropriate therapies i.e. mirimiri & rongoā and complimentary therapies i.e. Massage/Yoga

1.8 Investigate new models of care for people ageing with HIV (beyond the biomedical)

1.9 Better support (& inclusion) for the whānau of people ageing with HIV

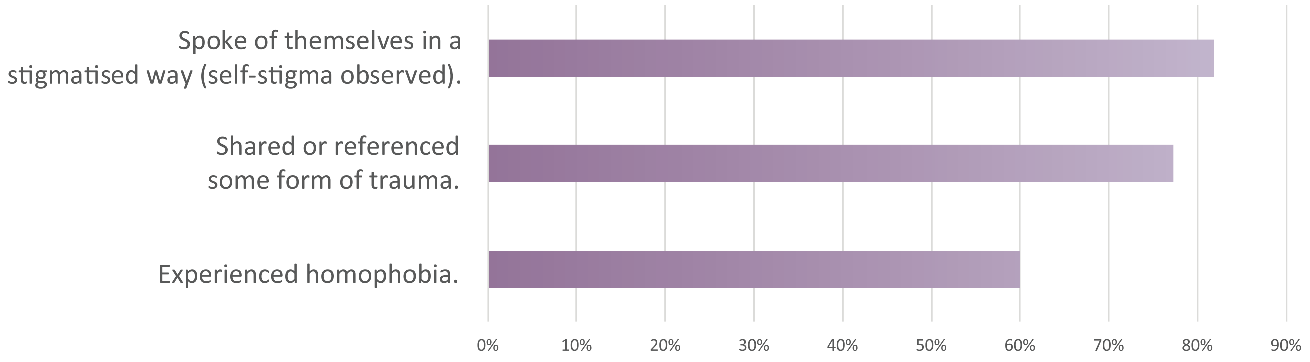
Theme

Poapoataunutanga | Impact of Stigma & Discrimination

Trauma + Self-Stigma + Layered Stigma

The research findings under this theme show the lasting impact of stigma and discrimination on the lives of people living with HIV. It was evident that the effects of and/or fear of future stigma or discrimination was so profound, participants shared their experiences unprompted. Figure 4 below highlights the effects of prolonged HIV stigma and suggests participants have internalised it (self-stigma), affecting how they perceive themselves and how others perceive them. Many participants share their unresolved past trauma and how it continues to perpetuate in their lives today. Sadly, many of the participants spoke of living with multi-layered stigma and prejudices like homophobia.

Figure 4. Key Findings - Poapoataunutanga | Impact of Stigma & Discrimination



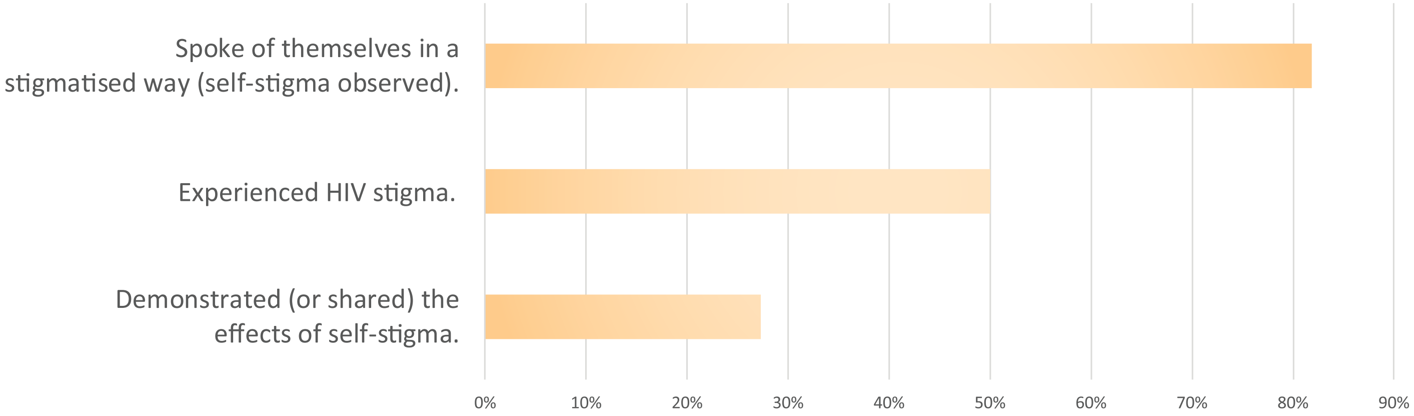
HIV-related stigma and discrimination continues to be one of the greatest barriers to health and well-being of people living with HIV (Emlet, 2017). Stigma is negative attitudes, beliefs, and stereotypes held by society towards people living with HIV. Discrimination involves unfair treatment or exclusion based on a person's HIV status. Typically, HIV stigma manifests and impacts people living with HIV in three ways: perceived, experienced/enacted, and internalised (Nyblade, 2007) .

Subtheme

Self-Stigma (Internalised Stigma)

The Centres for Disease Control and Prevention (2021) defines self-stigma or internalised stigma as something ‘that happens when a person takes in the negative ideas and stereotypes about people living with HIV and starts to apply them to themselves’. HIV internalised stigma can lead to feelings of shame, fear of disclosure, isolation, and despair. In the findings seen in Figure 5, over 80% of all participants spoke of themselves in a stigmatised way. The reason participants experienced self-stigma appeared to be a result of traumatic experiences or fear associated with disclosure, rejection and past stigma and discrimination.

Figure 5. Self-stigma (Internalised Stigma)



> “I never expected to get back into a relationship at my age and was blown over when you know, I did. I just didn’t expect… just never thought that… anyone would have me.”
>
> (Research participant)

This quote shows how the participant’s experience of stigma from others had been internalised, and they did not believe anyone would want to have a relationship with them after they were diagnosed with HIV. This participant was very emotional in their interview, particularly at the beginning when the Kairuku asked them how they were. The participant said that no one had really ever asked them that before.

The Kairuku observed participants using self-stigmatising language in many participant interviews which the participants appeared unaware of. This may suggest internalised stigma affects people’s sub-conscious more than they realise and further supports the dissociation findings indicated in Figure 5.

> “The sense of being dirty and infectious was so, so deep. But now I look at people and think NO ...I’m happy on my own. There’s no way I want to go there again.”

(Research participant)

This participant’s quote exemplifies the deep internalisation of stigma and as a result, how reluctant they are to have another relationship and how they want to avoid ever experiencing the trauma again. This is particularly relevant to people ageing with HIV who have been diagnosed for 15 years or more, and those who identify with the rainbow community and are likely to have experienced prolonged, layered stigma and discrimination.

> “I haven’t really revealed to many people that I know that I’m HIV positive. And I suppose now is the kind of time where I’m like, am I ever going to? Or is this just something that I’m going to keep with myself forever?”

(Research participant)

In this quote, the participant reveals a hesitancy and uncertainty about disclosing their HIV status to others. They express they have not revealed this information to many people they know, suggesting a reluctance to share their diagnosis. This hesitation may stem from their fear of potential judgment, rejection, and discrimination from disclosing their HIV status. The quote also highlights the potential long-term impact of self-stigma on their wellbeing. Audet et. al. (2013) found a significant relationship between HIV stigma and self-isolation which suggests that this participant may also experience greater isolation, and increased anxiety or worry about disclosure.

> “I’ve reached the stage where I don’t give a fuck what other people think about me. It’s none of my business what they think. What I’m more concerned about is the internal stigma because that’s far more damaging”.
>
> (Research participant)

This participant, who has lived with HIV for a long time recognised the destructiveness of their self-stigma. It suggests that while they no longer care what others believe, the damage from the stigma they have perceived has now manifested within their own beliefs.

In summary, the finding of this sub-theme suggests that despite the efforts being made to educate people about HIV stigma, the general population of Aotearoa New Zealand remains ignorant and mis-informed. The effect of ongoing societal stigma has internalised, and for many participants self-stigma is impacting their quality of life as they age with HIV, their sense of self, how, and who they interact with- particularly for participants from marginalised groups and cultures like the LBGTQI+ community and Māori.

Image 3:
The Cyclical Nature of
Stigma & Discrimination

Subtheme:
Layered Stigma

Layered stigma is when a person experiences more than one kind of discrimination or unfair treatment at the same time and this subsequently means they are dealing with a number of other forms of stigma and discrimination on top of having HIV. According to Reidpath and Chan (2005), in their quantitative analysis of the layering of HIV-related stigma, they found that in addition to an HIV diagnosis, there were additional stigmas associated with the routes of transmission (e.g., sex work and injecting drug use) and personal characteristics (e.g., race, religion, ethnicity and gender).

Just under half of all participants identify as being part of a LBGTQI+ community and 60% of these participants shared their experiences of homophobia and HIV stigma.

> **“...I don't know whether a facility would meet my needs as well as you know, being a gay man. Me actually living in some facility would probably open up a few questions. I worry being HIV positive, would people know how to treat me?”.**
>
> (Research participant)

This participant expresses uncertainty about whether an aged care facility would be able to address their needs as a gay person living with HIV. The concern the facility may not fully understand or cater to their specific needs, taking into account their health condition and their sexual orientation, suggests that they fear being stigmatised as a gay man and for having HIV. Layered stigma faced by people ageing with HIV is a complex issue because they could be influenced by various aspects of their lives, such as their personal backgrounds, other health conditions, ethnicity, social relationships, and the discrimination they encounter.

30% of all Māori participants spoke about their experience of racism in healthcare settings. The impact of racism on health and its role in creating health disparities has been firmly established, both in Aotearoa New Zealand and on a global scale (Talammaivao et. Al., 2020).

These multiple experiences of stigma (whether it be perceived or experienced) can compound and elevate the perceived stigma and discrimination people ageing with HIV experience now, and fear in the future. Research shows the numerous factors, including socio-demographic characteristics, health-related aspects, social connectedness, and experiences of stigma and discrimination, contribute to a lower quality of life for people living with HIV (McAllister et. al., 2022).

People ageing with HIV may face multiple forms of discrimination and exclusion. This is because they are not only dealing with the challenges of ageing but also the stigma associated with having HIV and belonging to marginalised communities. Layered stigma can further marginalise and isolate people ageing with HIV, and create barriers to accessing healthcare, and other necessary support.

Subtheme:
Trauma

Trauma refers to experiences that are emotionally distressing and overwhelming, often leaving lasting psychological and emotional scars. An HIV diagnosis can itself be a traumatising event and when combined with the challenges of living with HIV, the effects of trauma on people ageing can be multifaceted and often interconnected. There has been increasing global recognition of how trauma can impact on both the treatment and prevention of HIV (Sales, Swartzendruber, & Phillips, 2016), including poor treatment adherence.

Trauma can intensify mental health challenges like depression and anxiety, reinforce HIV-related stigma and shame, and trigger unhealthy coping mechanisms, potentially leading to substance abuse. Unresolved trauma can affect people ageing with HIV in their relationships, which could result in social withdrawal and even exacerbate age-related health issues. For some, overcoming trauma has built resilience and established positive coping strategies.

Three quarters of all participants shared their experience of some form of trauma (Figure 4), whether that be caused through a traumatic event, prejudice, abuse, or HIV-related stigma and discrimination. According to López et. al. (2020), people living with HIV have higher rates of exposure to traumatic events and Post Traumatic Stress Disorder (PTSD) than the general public. This further supports the findings in this research of the high numbers of participants who shared traumatic experiences .

What was not said directly by participants but identified by the Kairuku, was that some of the participants displayed some form of dissociation with the emotional and mental impact of their HIV. According to the International Society for the Study of Trauma and Dissociation (2023), dissociation is a process in which a person disconnects from their thoughts, feelings, memories, behaviours, physical sensations, or sense of identity, in order to distance themselves from the trauma.

> “When I had my very first and only HIV test, it was positive. So that was quite a sobering moment for me. A rather traumatic beginning because I was losing my partner, my house and my health. You might say, all in one.”
>
> (Research participant)

In this quote, the participant who is gay, expresses that from the beginning of their diagnosis, it was traumatic due to simultaneously losing a loved one, their housing security, and receiving a potentially fatal diagnosis since this occurred in the early 90’s before effective HIV treatments were available. In this case, the participant initially expressed a sense of detachment from the effects of HIV by stating "HIV doesn't really affect me." However, through further conversation, they later revealed their experiences of HIV self-stigma and struggles with poor health, indicating a potential dissociation between their initial statement and their actual lived experiences.

> "I suppose HIV was just another step in my sexual journey, because I'd been raped four times... I had actually forgotten how bad it was, or how good it was. I'd forgotten about it and even forgotten the person's name [that raped me] and everything. I had forgotten it happened at all. It wasn't until a friend sent me a news feed about him being charged... I didn't want to believe it happened, but he did it. To a whole lot of other kids too. I'm one of the survivors".

(Research participant)

This quote shares the participant's past sexual trauma. This 'forgetting' suggests a dissociation from the traumatic event. The participant disconnected from the memories and emotional impact until an external trigger (a friend talking about it) brought the memories and awareness back.

A high percentage of participants spoke of their potentially addictive behaviours and patterns. In particular their daily consumption of alcohol, cigarettes/vape, recreational drug use and overeating. Some participants shared this information casually as the following quote demonstrates:

> "I mean, I know what I should be doing, you know, in order to increase my life span, stop smoking, stop drinking wine. But I don't think I ever will."

(Research participant)

It is possible that these patterns of behaviours may be used by participants as coping mechanisms or as a means to help disassociate from their past trauma. While there is not sufficient evidence to support this theory in these findings, there is other research to support that people living with HIV often have complicated histories, even before they are diagnosed, including traumatic events like sexual abuse, violence, and discrimination which can be linked to PTSD, mental illness, and addiction (Whetten et. Al., 2008). More broadly, addiction can also be influenced by mental un-wellbeing, environmental factors, and genetics.

This subtheme demonstrates the impact of unresolved trauma. Some participants disconnect from their emotions and use unhealthy coping mechanism to manage the emotions of their trauma which creates the potential for other mental and physical health issues. Past experience of discrimination in healthcare settings can make people ageing with HIV fearful and provoke a sense of mistrust towards healthcare providers and systems with the risk of withdrawing completely from accessing the care they need. Trauma can impact outlook, decision-making for their future, and prevent people living with HIV from seeking the care or support that they need as they age.

Alarmingly, nearly half of all participants shared their experience of discrimination, particularly from oral health professionals. Medical professionals are expected to adhere to principles of non-discrimination and provide care to all people regardless of their HIV status or any other health condition, which makes these findings very concerning

The following participant expressed a sense of mistrust of all dentists and had concerns about their future care, particularly around aged care services and residential facilities.

> "When I was in a rest home getting some respite care, I had to visit a dentist and he found out just by my medication I was on, that I had HIV. He refused to treat me."
>
> (Research participant)

The following quote illustrates the impact of discrimination while receiving respite care in a residential aged care facility. In the interview it was evident the person was understandably traumatised by this experience:

> "I don't know why they [dentists] are too scared. All the other health services are okay, except them. And I have heard other people with HIV mention that as well. I don't like the way we are treated, but I'm just prepared for a big fight the next time I go to the dentist".
>
> (Research participant)

This participant was mentally preparing to fight against discriminatory treatment at their next dental appointment which could suggest that there is a heightened level of anxiety involved with accessing oral care and service. The participants mentioned hearing similar experiences from other people they knew who were living with HIV, indicating that the discriminatory treatment is not isolated but part of a larger systemic issue. Participants appeared to 'normalise' this behaviour to the point that they expected it. This is further supported in The Aotearoa New Zealand Stigma Index (2020) report, which found experiences of discrimination can result in people not accessing the necessary care and treatment that they need.

When people living with HIV have unresolved traumatic experiences, they may internalise their negative emotions, beliefs, perceptions or even judgment from others (especially from healthcare professionals). The findings of this research supports that the impact of trauma has the potential to endure and can continue to affect people living with HIV in their later years.

Poapoataunutanga | Impact of Stigma & Discrimination

In conclusion,

participants who shared their poapoataunutanga in this research also expressed greater levels of anxiety, more accounts of isolation leading to the feeling of loneliness, which in turn can result in disconnection, inducing more uncertainty and fear. This highlights the profound impact and the continuous and cyclical nature of stigma and discrimination (see Image 3, page 48).

Unfortunately, this cycle has continued for participants on their journey of living and ageing with HIV and may keep them in this cycle of survival and hinder their ability to be able to thrive as they age with HIV.

Currently the only form of therapeutic support available to people ageing with HIV consists of counselling services. While some counselling services are available for free or partially subsidised, face-to-face sessions are restricted to major centres such as Auckland, Wellington, and Christchurch, and access is subject to specific set criteria.

Notably absent is access to psychologists and psychiatrists (regarded as experts in addressing complex psychological and emotional needs), other complementary therapies, or any traditional Māori therapies like mirimiri or rongoā which look to support people holistically.

2.1 **Broadening of therapeutic therapies i.e. psychologists and psychotherapists to reduce impact of trauma and self-stigma**

2.2 **Deliver an HIV public awareness campaign to reduce stigma**

2.3 **Education/Awareness workshops for people ageing with HIV**

2.4 **Increase & expand stigma & discrimination education in healthcare settings, including aged care**

2.5 **Research focussed on the impact of self-stigma/layered stigma, particularly for Māori living with HIV**

2.6 **Research on linkages with HIV and past trauma/layered stigma**

2.7 **Research to understand aged care facilities current staff training/policies to support people living with HIV.**

2.8 **Viability study on a LGBTQI+ aged care service**

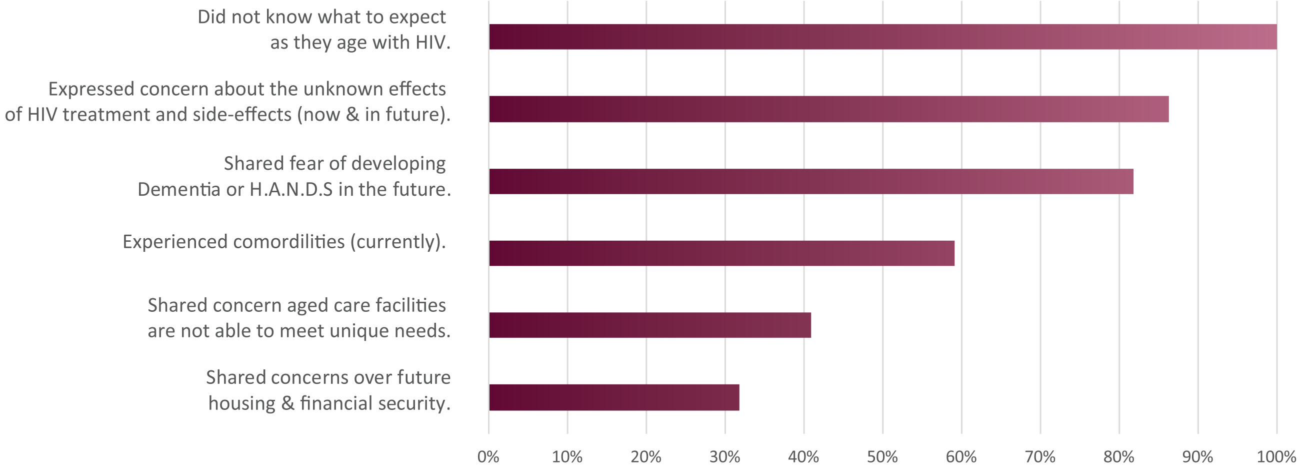
Theme

Rangirua| Uncertainty

Long Term HIV & Treatment + Comorbidities & Neurological Issues + Financial & Housing Security + Aged Care Sector

Rangirua (uncertainty) was the most common theme and significant concern for participants from the findings of this research.

Figure 6. Key Finding - Rangirua | Uncertainty



Uncertainty is not unusual for people as they age – but ageing with HIV presents its own unique challenges. Living with HIV involves managing a chronic illness and treatment side-effects, increased risk of comorbidities, dealing with potential stigma, stereotyping and discrimination, and navigating the complexities of disclosure and privacy. The findings from this research suggests that coupled with disconnection and the impacts of unresolved trauma from stigma and discrimination, this may make the uncertainty about ageing with HIV even more significant.

Uncertainty can lead to anxiety, stress, and emotional distress (Solomon et. al., 2013). Concerns about the progression of HIV, the development of comorbidities, and the effectiveness of treatment options can create a constant state of worry and fear about the future for people ageing with HIV (Figure 6). This emotional burden can negatively impact the mental wellbeing and therefore the Hauora, Mauri and Wairua of people ageing with HIV. The Kairuku noted during the interviews that worry and fear were of significant concern for participants when they spoke about their future as they age with HIV.

Subtheme:

Long-term HIV and HIV Treatments

The first cases of AIDS in Aotearoa New Zealand were notified in 1984. The early cases were people who became infected overseas and returned home already ill. Transmission of HIV in New Zealand was not recognised until about a year later (National Council on AIDS, 1989). Relative to other viruses it is considered a fairly new virus with evidence continuing to emerge. This makes it difficult to predict the long-term effects of HIV because there are many different factors that can affect how people's bodies react to the virus. Treatment regimens are also evolving rapidly as biomedical advances are applied and new medications emerge. Evidence of long-standing side effects created by people on earlier drug regimes, in comparison to new medications is still emerging. These concerns are expressed well in the following participant’s quote:

> **“I don't suppose anyone really knows because we are amongst the first to become older and living with HIV. So, we don't know, what we don't know yet because nobody's ever been here before”.**
>
> (Research participant)

In contrast, 82% of participants (Figure 6), expressed their deep gratitude for having access to HIV treatments, which has extended their lives. This sentiment was particularly evident among the 81% of participants who have lived with HIV for more than 15 years and have witnessed the devastating impact of HIV prior to effective HIV treatment.

Research shows that older adults’ ability to metabolise HIV treatments lessens over time which may result in increased toxicity (Burgess, Zeuli, & Kasten, 2015), and some people who continue to experience side effects from early medications that are associated with increased toxicity. Furthermore, studies have shown that liver and cardiovascular disease, both associated with long-term use of HIV treatment, are leading causes of mortality among older people living with HIV (Cahill & Valadéz, 2013).

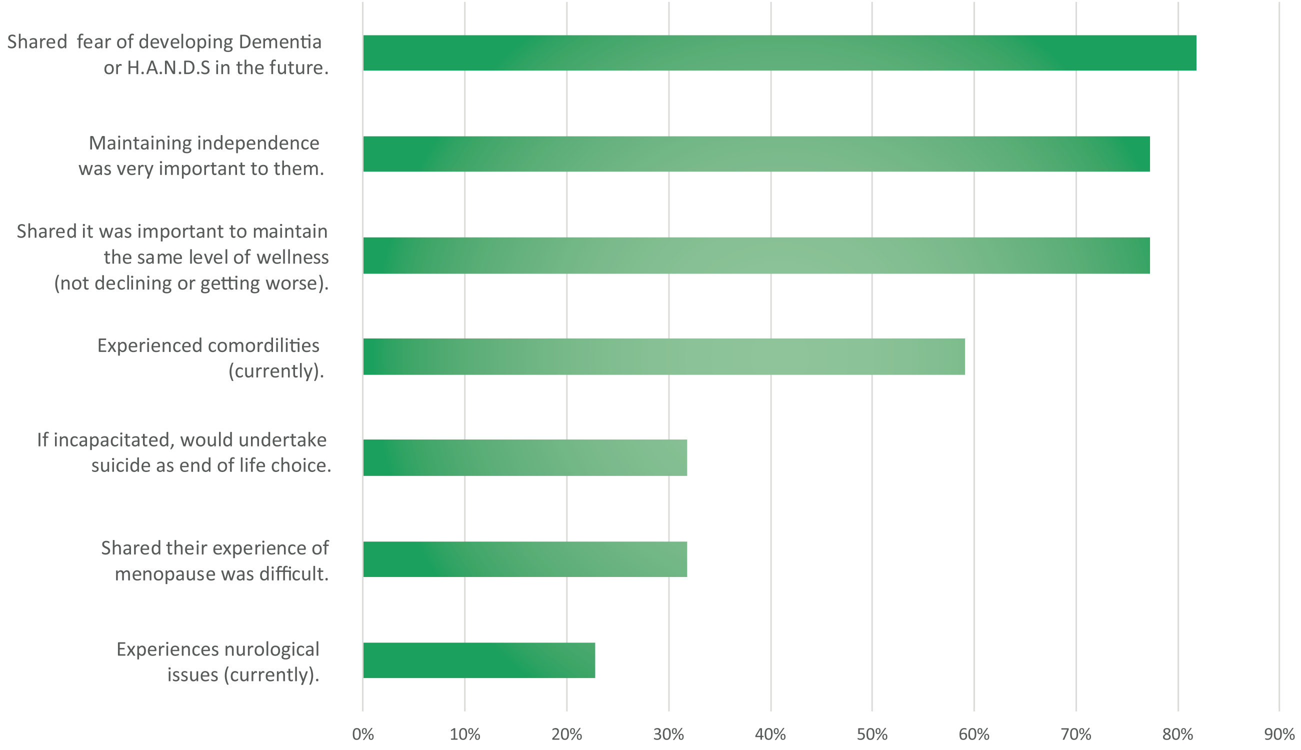
When participants were asked about what concerns them the most about ageing with HIV, most had a similar response to this quote:

> **“I guess just the effects that the medication has on your body and as much as it keeps you well, it's probably doing other things. So that's really my main issue.”**
>
> (Research participant)

There was an overarching concern expressed by participants about the impact of ongoing treatment and for those who only had access to earlier treatments, ongoing side effects and/or toxicity. One participant was interviewed while in hospital recovering from multiple organ failure, which they shared was a result of HIV treatment toxicity.

Importantly, due to the limited number of HIV treatments funded through Pharmac and available in Aotearoa New Zealand, one of the study participants can only take one type of treatment due to the development of treatment resistance. There are no other options currently available to them after this.

Figure 7 Uncertainty: Comorbidities & HIV-related Neurological Disorders



Subtheme:
Comorbidities & HIV-related Neurological Disorders

Comorbidities were also a significant cause of fear, concern and/or anxiety for many participants, at some level (Figure 7). It was noted that many of these concerns arose from the participants genuine desire to maintain their independence, wellness and quality of life while managing their HIV.

> **“...I'm not scared of death...I want to live for years but I mean, I may, I may not. I just want to keep as healthy and lively as much as I can”.**
>
> (Research participant)

In addition to being more susceptible to comorbidities, older adults with HIV or AIDS are at greater risk of developing cancer compared with the general population (Solomon et. al., 2013). People living with HIV experience greater incidence of cancers, including Hodgkin’s lymphoma, leukaemia, melanoma, and colorectal, renal, anal, vaginal, liver, lung, mouth, and throat cancers (Solomon et. al., 2013).

HIV can cause premature ageing of the cells (Rodés et. al., 2022) and therefore there is an increased risk of age-related conditions such as dementia or HIV-Associated Neurocognitive Disorders (H.A.N.D.S1). This research found that over 80% (Figure 7) of all participants referenced this as a concern.

32% of participants expressed that they planned to end their life prematurely if they were to lose their mental faculties or were incapacitated (Figure 7). This stemmed from a variety of reasons including the deterioration of their mental capacity, loss of autonomy over their bodies, personal cares and/or becoming a burden on whānau. It is worth noting here that currently the End-of-Life Act 2019 (NZ Parliament, 2019) does not have any provision for these scenarios .

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1 H.A.N.D.S stands for HIV-Associated Neurocognitive Disorders. It refers to a spectrum of neurocognitive impairments that can occur in people living with HIV. As people age with HIV, they may face an increased risk of developing these cognitive problems (Rodés et. al., 2022)

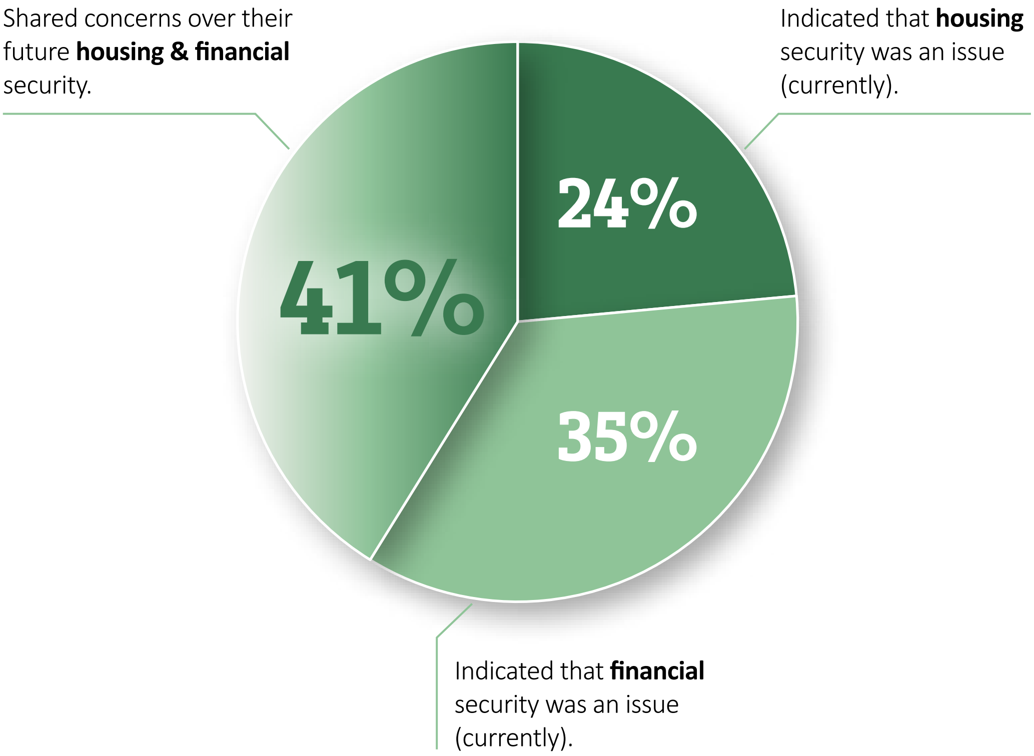
Subtheme:
Financial and Housing Security

Financial hardship and housing insecurity was also a common concern among participants (Figure 8). For those participants who currently experience hardship, there was a genuine concern for their future and how they will manage. These concerns reflect the broader social and economic challenges faced by many people as they age in Aotearoa New Zealand.

> **"... Stuck in a room with a bed - that's my biggest fear of ageing – it's not actually having a place. I don't care if I don't own it. But somewhere I know that is secure. Living in rentals, you're always worry "Am I going to have to pack and move"? When I do move and get settled, then will I have to move again? That's my biggest concern."**
>
> (Research participant)

These findings were mirrored in a Canadian study on healthy housing for people living with HIV, which identified housing as a fundamental unmet need for people living with HIV (Chambers et. al., 2014); yet there has been little qualitative evidence exploring housing and HIV, particularly from an Aotearoa New Zealand context.

Figure 8. Uncertainty: Financial & Housing Security



Subtheme:
Aged Care Services

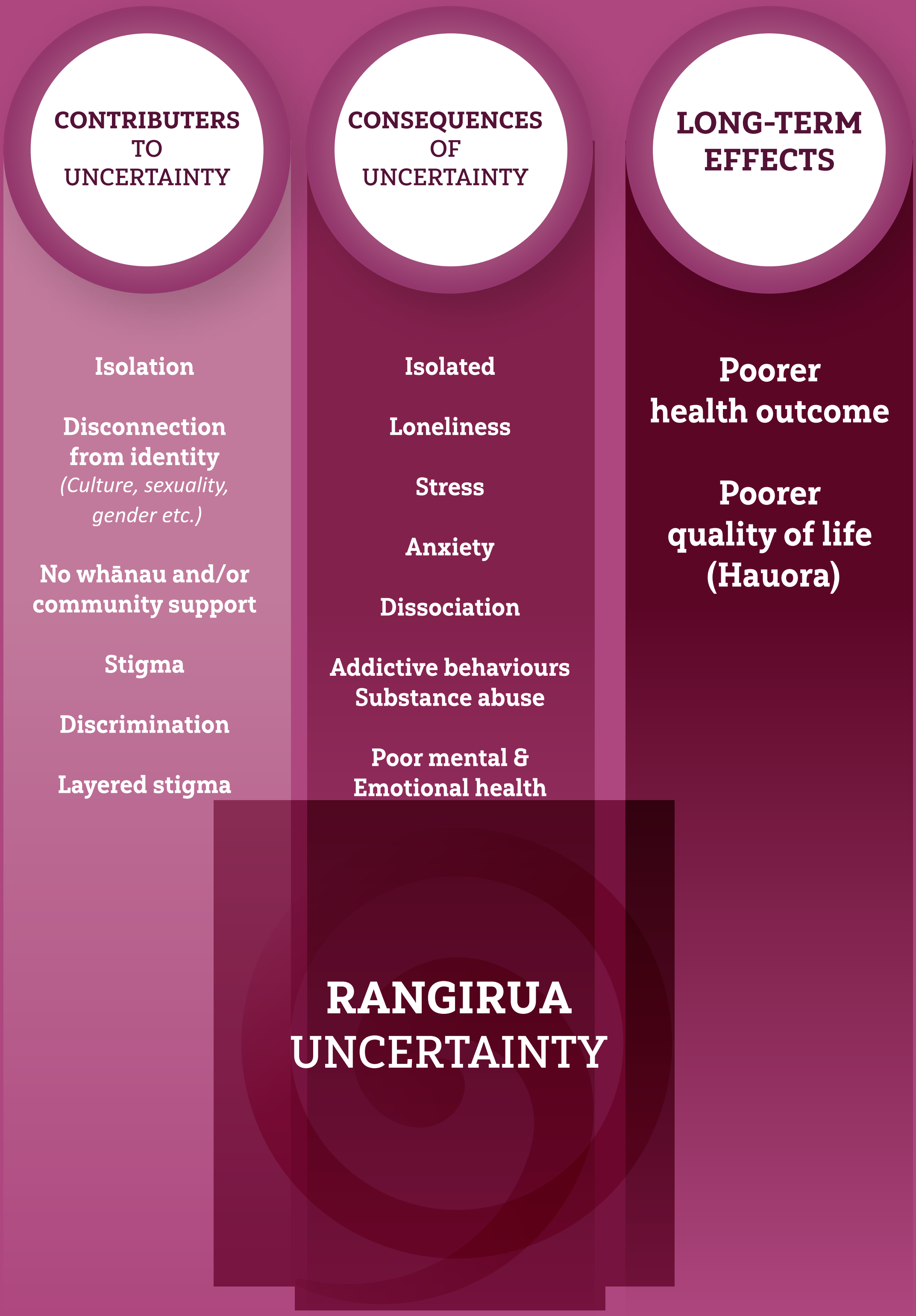
With a high number of participants who reported not having any whānau support, and an unmet housing need for people living with HIV, it may be that accessing either government subsidised aged residential care or home-based care services may be inevitable for many people ageing with HIV in Aotearoa. It was perhaps not surprising to see in these finding a concern by participants related to accessing care and support or entering into aged residential care facilities. Participants expressed fear of potential HIV stigma and discrimination from aged care workers. In particular, participants spoke about their HIV disclosure and fearing homophobia, and therefore aspects of layered stigma again. A concerning increase in reports of homophobic behaviours in aged care facilities are starting to surface in global news (Banfield-Nwachi, 2023).

> **“I visit rest homes weekly. And I wonder where am I going to fit because of my HIV status? I have got no dependents so nobody would look after me, so I have to consider rest home care as a possibility - there won't be any other backup plan. And then it just makes you think, how would the aged care [staff] respect my issues and how would they cope with my HIV, and the normal ageing process? It's a wonder that I have no answer for”.**
>
> (Research participant)

In this quote, the participant expressed acceptance that they will need care as they become older, but that they are unsure how they will be respected. Many of the participants doubt if aged care facilities and home-based services were equipped with the necessary skills and knowledge to care for them, particularly those ageing with HIV who also come from diverse communities.

Long-term HIV and treatment, present challenges due to the complex interaction of the virus and people’s different responses to medication and with toxicity increasing over time. There was fear and justified worry about people’s increased risk of comorbidities and HIV-related neurological disorders and financial and housing insecurity concerns reflect the broader socioeconomic challenges faced by many people living in New Zealand. Finally, the preparedness of the aged care sector to address stigma, discrimination, and provide inclusive care for people ageing with HIV raises significant concerns.

Image 4: The Significance of Uncertainty



CONTRIBUTERS TO UNCERTAINTY

- Isolation
- Disconnection from identity *(Culture, sexuality, gender etc.)*
- No whānau and/or community support
- Stigma
- Discrimination
- Layered stigma

CONSEQUENCES OF UNCERTAINTY

- Isolated
- Loneliness
- Stress
- Anxiety
- Dissociation
- Addictive behaviours Substance abuse
- Poor mental & Emotional health

LONG-TERM EFFECTS

- Poorer health outcome
- Poorer quality of life (Hauora)

RANGIRUA UNCERTAINTY

Rangirua | Uncertainty

In conclusion,

Rangirua (uncertainty) was a significant theme in this research. There are a number of contributors to uncertainty which have consequences and have the potential to have long-term effects (**see Image 4**). As indicated by the participants in this study, people ageing with HIV want to maintain their independence and quality of life. However, HIV brings unique challenges to ageing and coupled with disconnection and the impact of stigma and discrimination, presented in other themes, these uncertainties are compounded.

3.1 **Build resources/relationships with pharmacist to educate on polypharmacy/toxicity**

3.2 **Development of resources for aged-care workforce on the unique needs of people ageing with HIV**

3.3 **Develop safe places for people ageing with HIV to ask questions**

3.4 **Dedicated funding and resources specifically for ageing with HIV**

3.5 **Monitoring of high risk comorbidities i.e.. HAND, heart disease, kidney failure, bone degeneration etc.**

3.6 **Monitoring of HIV treatment side-effects**

3.7 **Research (broader & ongoing) on ageing with HIV**

3.8 **Research on the 'readiness' of aged care services (residential and home-based)**

3.9 **Training for aged-care workers on stigma and caring for people with Blood Born Viruses**

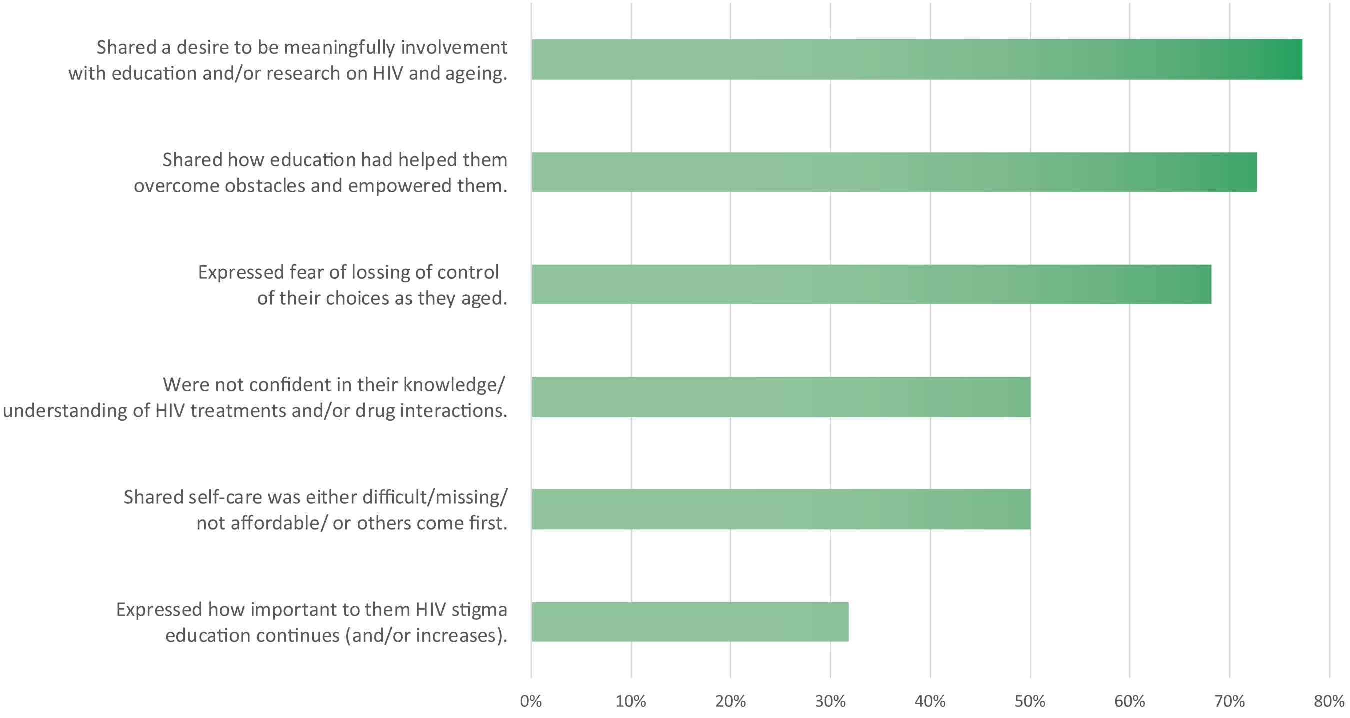
Theme

Tino Rangatiratanga| Self-Determination

Education | Knowledge + Power Imbalance + MIPA/GIPA Principles

The findings under this theme and its subthemes, emphasises the importance of Tino Rangatiratanga (self-determination) for people ageing with HIV. The pivotal roles of education, knowledge, and the principles of MIPA and GIPA, foster autonomy and independence for people ageing with HIV. For Māori, Tino Rangatiratanga reflects the aspirations of Māori for returned control, authority, and decision-making power. The research also revealed a growing perception of power imbalance between participants and medical professionals and highlights what people ageing with HIV need from their health practitioners.

Figure 9. Key Finding: Tino Rangatiratanga | Self-determination



Subtheme:

Power Imbalance

Perhaps some of the most unexpected findings of this research was the imbalance of power perceived by a significant number of the participants about their relationship with their health care provider. Whether that was about not being heard or in relation to how the health professional responded, over half of the participants expressed feeling that their concerns were not taken seriously or minimised by healthcare providers (Figure 10). It is possible that healthcare professionals like HIV specialists, are eager to reassure their patients, but in doing so may overlook real concerns that are impacting people ageing with HIV.

Figure 10: Power Imbalance

> “I had a late [HIV] diagnosis so I've got a lot more health issues that are, you know, that need to be dealt with…I’d gone through some of my old medical notes and all my health was on point a few years ago. Then I was diagnosed with HIV and started medication in 2019. By 2022/23 everything is so out of control. It's not funny. So, I don't know why the doctors are saying there is no connection but then they can’t explain why its suddenly changed.”
>
> (Research participant)

In this quote, the participant highlights their late HIV diagnosis and subsequent health issues that have arisen. They express frustration with the fact that their health seemed to be under control before their HIV diagnosis, but afterward, their health deteriorated rapidly. The participant feels that the doctors are not acknowledging the potential connection between their late HIV diagnosis and the subsequent changes in their health.

This sentiment was reflective throughout the participant interviews and may possibly be an emerging challenge for healthcare professionals as they navigate new and uncharted territory of treating people ageing with HIV, treating older people who have been diagnosed late, or treating people with significant comorbidities and polypharmacy[2] (Grosso et. al., 2023). It is possible that healthcare professionals may focus more on managing the immediate impact of HIV, such as viral load suppression and managing HIV treatment side-effects, without giving the required attention to the potential long-term effects or comorbidities associated with ageing. This can lead to a perception from people ageing with HIV that concerns related to their changing health are being overlooked or minimised.

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[2] *Polypharmacy is the term used to describe taking a large number of medicines (usually more than five). Some people may need to take a large number of medicines, but there are times where the use of some medicines may be unnecessary (Health Navigator, 2023).*

> “When I approached my doctor to say, “Is this related to HIV?” They'll always say oh, no, no, no, no. But I just wonder whether it is, I don't know. You know, I have quite a few things that are wrong with me. Has HIV exacerbated it or not? Who knows - it's fairly unresearched.”.
>
> (Research participant)

The participant describes how when they approach their doctor with concerns related to their health, the immediate response is often to dismiss any connection to HIV. This may lead to uncertainty and doubt. The participant also mentions that research on the relationship between HIV and their specific health issues is limited, and this could further exacerbate the uncertainty and lack of clarity surrounding their health conditions and the relationship to their HIV.

People ageing with HIV have the right to actively participate in their own healthcare instead of just receiving care. Yet, 68% (Figure 10) of participants expressed concerns about the potential loss of control and choices as they age with HIV. The lack of clarity and control expressed by participants suggests there may be a power imbalance, and this can have significant implications on Hauora. It can lead to feelings of mistrust, frustration, helplessness, and disempowerment, as well as a reluctance to seek out healthcare services and support when they are needed. It can also lead to poorer health outcomes (Nimmon & Stenfors-Hayes, 2016), as people may not receive the care and support needed to manage their HIV and other comorbidities.

> "I would like to say to him [my doctor], and other specialists that they haven't learned to explain things. It's probably the most difficult thing that a specialist has to do - is to be able to explain it with words of one syllable. You know what I mean? Yeah, I think it's really important to inform us, whatever the situation is, and quite often I end up asking questions because they don't think to tell you. But you've actually got to be confident to ask and know how to ask the questions".

(Research participant)

This participant expresses the desire for healthcare professionals to be able to simplify complex concepts and use layman's terms to ensure effective communication and that they are being understood. They suggest that medical professionals need be able to explain medical information in a clear and concise way.

> "Māori and Pasifika like to be led and shown what to do. And once they're shown, then they take it on board themselves. Because we learn by seeing, and by hearing. Not by sitting in a doctor's office and getting dictated to. I hate sitting in a doctor's office and listening to everything. Can't they see it isn't the medication that I need? I've got it. I need to know how, and need to know when, and need to know why, and I need to know what. Because if you don't give me that, I'm not going to take it."

(Research participant)

This participant's quote shows the significance of Tino Rangatiratanga, emphasising the importance of self-determination and autonomy in healthcare for Māori ageing with HIV. The statement highlights a preference for being shown and led in understanding health information, as well as frustration with the power dynamics between them and their healthcare provider. It emphasises how important knowledge, active participation, and cultural understanding is to treatment adherence. Aligning with Tino Rangatiratanga promotes the empowerment of people ageing with HIV to develop a stronger sense of agency[3], especially for Māori and Pasifika people ageing with HIV.

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[3] *Agency refers to a person's ability to make choices, take actions, and exert control over their own life within the context of their social, cultural environment and lived experiences. It emphasises the capacity of the individual to act with intention, make decisions, and influence their own lives and the world around them. (Wikipedia, 2023).*

Another concern related to self-determination was the self-care practiced by participants. Many of the participants said they struggle with self-care because it can be expensive but also because they deprioritise themselves. International research shows the benefits of self-care for the management of anxiety and fear associated with HIV (Kemppainen et. al., 2003).

> “Yes, self-care. I'm not very good at it. I am good at guiding others to look after themselves. But not necessarily for myself. And I think as we get older, it's a key part to health and well-being.”
>
> (Research participant)

The statement reflects a commonality experienced by many of the research participants when it comes to prioritising their own self-care. It suggests a tendency to place the needs of others above their own, neglecting their own well-being in the process. This could be because of various factors, including unresolved trauma, self-stigma, or layered stigma where people are left wondering “are they deserving enough?”.

The findings of this subtheme suggest there is a perceived power imbalance between healthcare providers and people ageing with HIV in Aotearoa. An imbalance of power can result in feelings of mistrust, disempowerment, and a reluctance among people ageing with HIV to seek necessary healthcare services or adhere to HIV treatments. Effective communication, including the use of simplified language, is crucial. Encouraging self-care may help people ageing with HIV manage some of the uncertainty that has been raised in other research themes. Recognising and addressing any possible power imbalance can strengthen Tino Rangatiratanga and contribute to improved healthcare experiences and better health outcomes for people ageing with HIV in Aotearoa.

Subtheme:

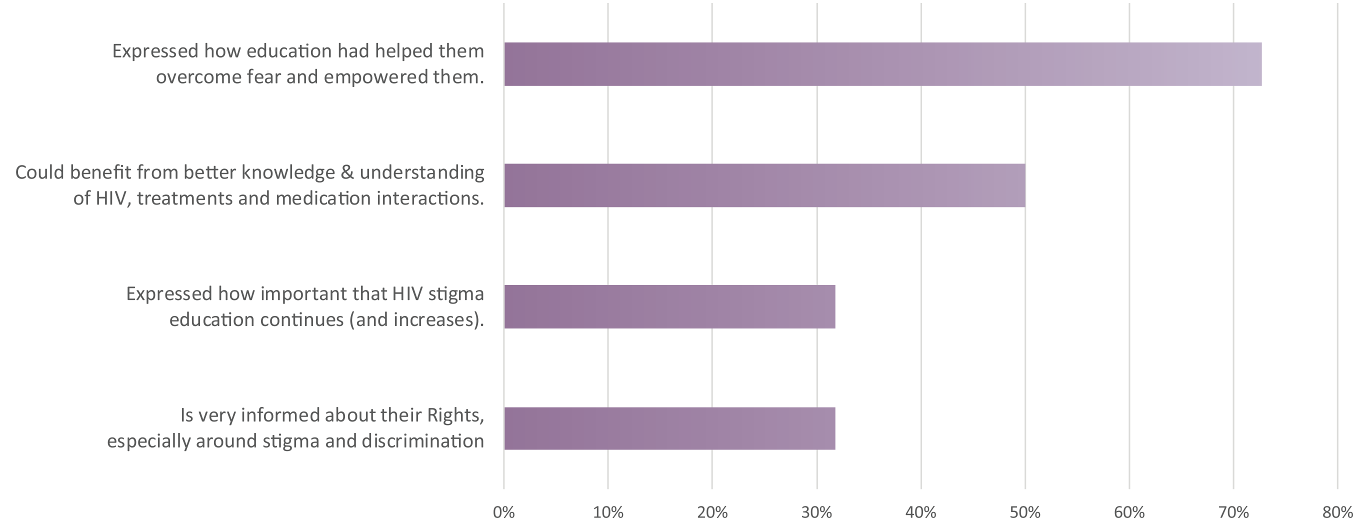
Education and Knowledge

> "...as I get older, I do get more worried about things...I guess if there was maybe more information out there about ageing, that would be good."

(Research participant)

This quote is supported by the 77% (Figure 10) of participants who spoke about the need for more information on ageing with HIV. Education plays a vital role in building self-determination by providing knowledge, skills, and opportunities for personal growth and empowerment. It equips people ageing with HIV to make informed decisions and assert their needs, enabling people to take control of their own lives. This is further supported in Emlet et. al. (2011), who argues **that people living with HIV who are well informed and have a good understanding of HIV are more resilient, self-accepting, optimistic, and independent.**

Figure 11. Education & Knowledge



One significant aspect highlighted by the research findings is the need for increased HIV stigma education (Figure 11).

> "So, I think some of the education around HIV has dropped, and no one's doing anything about it."

(Research participant)

Findings show participants see a need for increased HIV stigma education and a better understanding of HIV in general, HIV treatments, and medication interactions not only for themselves, but also in particular for the health sector.

> "HIV doesn't care about your sexual orientation, your gender, your colour, your religion - it doesn't! But straight people have this thing in their head, that HIV doesn't affect them... and some doctors out there still think that too, so they do not diagnose people until it's way too late. And they finally get diagnosed when they have AIDS and a few weeks later, they die. This is happening in New Zealand! So, we are still losing people to misinformation. We need to do more education."

(Research participant)

This gay participant was passionate about destigmatising HIV to ensure that heterosexual people who perhaps do not fit a high-risk category[4] or stereotypes of HIV, are also being tested for HIV, but also health professionals are not stereotyping and misdiagnosing those from key populations.

Overall, education and knowledge are vital to supporting people aging with HIV in Aotearoa to experience Tino Rangatiratanga. By giving agency to people ageing with HIV, education and knowledge can help with informed decisions on treatment and general healthcare, empowerment to advocate, and make better choices for wellness and wellbeing.

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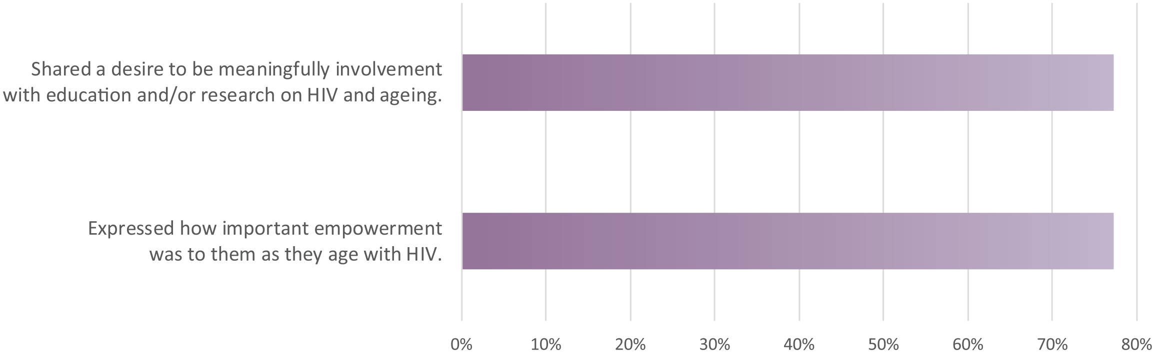
[4] *Anyone can contract HIV, and while people who inject drugs (PWID) are at great risk because of practices related to their drug use, anyone who engages in unsafe sex (e.g., unprotected sex with an infected partner) could be exposed to HIV infection. However, while all groups are affected by HIV, some are more vulnerable than others, who UNAIDS refer to as key populations and include: gay men and other men who have sex with men, people who inject drugs, transgender people, and sex workers and their clients (UNAIDS, 2022, p. 3).*

Subtheme:

Greater and Meaningful Involvement of People Living with HIV (GIPA/MIPA)

Figure 12 shows that 77% of participants indicated how important it was for them, as people ageing with HIV, to be involved in the development of resources and education related to HIV. The UNAIDS GIPA and MIPA principles recognise the rights of people living with HIV to actively participate in decisions and policies that affect their lives. GIPA and MIPA principles support the rights of people ageing with HIV to have a say in matters that affect their health, well-being, and rights (Hawa & Gillis, 2021). MIPA and GIPA go on to further support the concept of Tino Rangatiratanga.

Figure 11. Education & Knowledge



> "I want HIV education to continue. I just want to get rid of the stigma and discrimination. And I know the best way to do that is for people living with the virus to be part of that".
>
> (Research participant)

This quote highlights the participant's desire to be actively involved in shaping HIV education that can help eliminate stigma and discrimination. By involving those with lived experience, it may also help address some of the isolation issues and disconnect addressed in earlier themes.

> "...it's important to me to participate. The information might not necessarily help me but in the future, you know, it might help someone else."
>
> (Research participant)

For Māori living with HIV, the GIPA and MIPA principles are even more significant, as it is the enactment of Tino Rangatiratanga. By enabling Māori living with HIV to have an active role in shaping policies, programmes and services that are culturally appropriate, these will then be responsive, and respectful of their needs. It also recognises the unique challenges and experiences of Māori living with HIV and ensures Māori voices are heard and valued in decision-making spaces. The Crown has obligations to uphold the principles of partnership, participation, and protection. This includes recognising and respecting Māori Tino Rangatiratanga.

It was noted by the Kairuku that participants who experienced self-determination were more actively involved in the advocacy for people living with HIV and were regarded as leaders and/or educators in their communities. This is particularly evident in peer-led organisations and programmes such as the Positive Speakers' Bureau which gives people living with HIV, the training and support to have a voice.

> "When I reflect on where I was when I first was diagnosed or my life beforehand, and how it's changed and then where I am now, and I've come such a long way and in quality of life and the ability to speak up. I wouldn't have spoken up nearly as much about anything to anybody if it wasn't for HIV. But now I found my voice and here I am".
>
> (Research participant)

> "I am openly HIV positive. My friends know about it. My family knows about it. We have conversations about it - none of these things could have happened 20 years ago, without fear of incredible discrimination or repercussions or being thrown out of somebody's life, you know? It's a very different time. It's a very different conversation and it's an exciting conversation to be included in".
>
> (Research participant)

Both these participant quotes demonstrate the positive impact of self-determination. They highlight the power of finding one's voice, advocating for others, and engaging in open conversations about HIV. These participants narratives reflect a shift towards greater acceptance, reduced stigma, and increased opportunities for people ageing with HIV to actively participate in the HIV response at every level.

Tino Rangatiratanga| Self-Determination

In summary,

Tino Rangatiratanga can empower people ageing with HIV to have autonomy, make informed decisions, and advocate for their needs and rights. Education for HIV stigma reduction, HIV and HIV treatments, and self-care, will improve knowledge and awareness and help reduce uncertainty. Involving people ageing with HIV will help those ageing with HIV to feel more included and valued

4.1 Address the power imbalance in healthcare settings

4.2 Advocacy for patient-centred approaches (not policy led)

4.3 Build allies in health, ministry, ageing, social work, community support

4.4 Develop strategy for preparing for ageing population of people living with HIV

4.5 Establish a dedicated social worker for ageing with HIV to help navigate social support services & health care

4.6 Establish a multi-org working group on Ageing with Blood Born Viruses (facilities, government funding, aged concern etc.)

4.7 Increase health literacy amongst people living with HIV

4.8 Promote importance of Tino Rangatiratanga and self-care.

4.9 Workshops/Education: for people living with HIV on knowing & understanding their rights to health & ageing well with HIV

4.10 Workshops/Education for people living with HIV on end of life care/funerals & power of attorney etc.

4.11 More accessible up-to-date HIV information

Whākawhitiwhiti Kōrero | Discussion Points

One of the known challenges of this community-led research was that Kairuku brought their own lived experience of HIV and deep understanding of the topics. While this bias may concern some academic researchers, it is also a strength that challenges traditional research paradigms, providing unique insights and a deeper understanding that would have otherwise been missed.

The discussion points of this report are centred on discussions between the Kaiārahi and Kaipupuri Mauri, noticed and observed, not what was said by the participants. The following insights emerged from a place of deep knowing through our lived experiences, and in response to what we felt after discussing all of the interviews and transcript analysis.

HIV Stigma Persists

While there has been progress in HIV stigma and discrimination education in healthcare setting, there have not been any significant public awareness campaigns, so the general population of Aotearoa remains ignorant and unaware, and so HIV stigma, persists. Many of those ageing with HIV still live in fear of, and/or carry trauma of discrimination and stigma, leading to self-stigma, low self-esteem, and a reluctance to form relationships in fear of disclosing one's HIV status. This internalised stigma has detrimental and long-lasting effects. The public policies underpinning the management of HIV continues to be solely biomedical, ignoring the psychological implications of an HIV diagnosis, and in doing so, keeps many people locked in a cycle of trauma, hindering their right to age, free of the emotional burdens of HIV.

Gratitude vs Quality of Life

There appeared to be a distinct polarity regarding HIV treatment and the quality-of-life participants were prepared to accept. There was very obvious tension between participants feeling immense gratitude for being alive and living longer due to having access to HIV treatments but at the same time, downplayed the immense challenges they face and sacrifices in their quality of living.

We Don't Know What We Don't Know

This research aimed to understand the needs of people ageing with HIV in Aotearoa. Perhaps not surprisingly, almost all participants struggled to articulate what they needed despite knowing the purpose of the research.

For many people living with HIV, being asked '***what do you need?***' may be somewhat of an anomaly. Within the healthcare system, people living with HIV are often told what they need, or don't need. Most people comply with what they are told in fear of ill-health or passing HIV on. Rarely are people asked about their mental, emotional, or spiritual wellbeing. Over time, this normalised approach to HIV management can diminish peoples intuitive understanding of what they need, and sadly may be forgotten altogether.

An unspoken and undocumented psychological side effect of HIV diagnosis is the loss of the ability to imagine or plan, a future. Now participants are facing ageing as a part of their HIV experience, many realising that they hadn't considered ageing with HIV because they never expected to reach this stage.

In conclusion,

despite knowing people living with HIV can live as long as someone who does not have HIV, the deep psychological impact of an HIV diagnosis, and the emotional and mental response to it, can deeply impact the well-being of a person as they age with HIV. The continuous need for medical care, the uncertainty of long-term health outcomes, can collectively contribute to a perpetual state of feeling impermanent in the world.

Therefore, it is then understandable why many participants were uncertain of what was needed as they age with HIV. Instead, shared what they knew 'known knowns'. To answer the question "what do people ageing with HIV need", some participants had to confront complex emotions and worries, and try to envision what a meaningful and fulfilling future looked like, despite all the 'unknown knowns' of ageing with HIV.

It is hoped these discussion points provide further insight and context to the findings of this research, and invoke further conversations and action on ageing with HIV in Aotearoa New Zealand.

Ngā Whakaaro o ngā Kairuku | Kairuku Viewpoint

Geoff Rua'ine

Being a Kairuku in the Ageing with HIV project was a deeply rewarding experience that allowed me to support the kaupapa and connect with my community. In my role as a Kairuku, I captured stories reflecting the kaupapa and provided moral support to the participants, acting as a kaitautoko. This peer Kairuku role contributed to my personal and professional growth, giving me a sense of contribution to the wider kaupapa, and reenergising my connection with the world of HIV. One particularly memorable experience was interviewing a participant who recently passed away. It was an honour and a humbling experience to capture their stories, and their memory will always hold a special place in my heart. Moe mai rā e te rangatira. May their soul rest in peace.

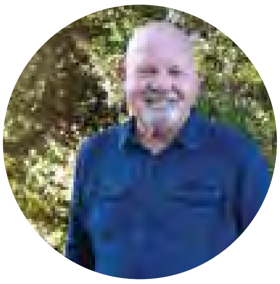
Rodrigo Olin

It was an honour and a pleasure to be considered and act as Kairuku for the Ageing with HIV Project. I loved having these very real and important conversations with other people living with HIV about what it means to grow older with this virus. Connecting to other people and hearing their stories on how they are living with HIV is always such an interesting and powerful experience. We all live and experience HIV in different ways. Projects like this facilitate people living with HIV to become part of the processes, empowering ourselves at the same time as contributing to the HIV response, actively embracing the Greater and Meaningful Involvement of People living with HIV.

Lianne

Being a peer Kairuku allowed me to connect with interviewees on a personal level, fostering a comfortable and safe environment for them to share their experiences. This resulted in discussions about sensitive topics, and I hope, brought a sense of self-acceptance to the participants. Observing others facing similar challenges provided valuable insights for my own reflections. However, the emotional toll of the interviews was significant, as some stories triggered distressing memories and anxieties from my own life. Despite the challenges, I felt privileged to receive these narratives and developed immense respect for the women who had survived and thrived through challenging circumstances. The project was a collaborative effort, supported by a framework of safety and guided by Te Hā, our model of practice. Overall, being a peer Kairuku for this study has been a unique and rewarding experience that emerged from my HIV diagnosis, offering personal growth and the opportunity to co-create something valuable.

Peter Ford



Ageing with HIV is a new thing and it's great to see a project asking us people living with HIV how we feel. So, living with HIV myself and being 60 I certainly felt personally connected to the stories of the people I interviewed. It was a roller coaster as we went on highs and lows together as the story unfolded. Some of these people lived in a time when there was no hope, never thinking of planning for old age, let alone being interviewed about it. I enjoyed the project and working with the team to uncover and discover the common themes of the people we interviewed. I truly hope this work doesn't sit in a draw but becomes a working document to make a difference for us ageing with HIV in Aotearoa.

Abby Leota

My experience as Kaiārahi and one of the Kairuku on this project has been a journey of personal growth and professional development. I had the privilege of listening and analysing each interview. This was very humbling. The stories shared were a testament to the diverse challenges and triumphs faced by people living and ageing with HIV. I felt an immense responsibility to ensure we represent people's experiences and ensure participant voices were respected and honoured.

Perhaps what I did not anticipate was how much the process made me reflect my own experience of ageing and HIV. It stirred an anger in me I have not expressed before now. This anger comes from my own experiences of not being heard. This project has awoken something within me, for me, that I can no longer ignore. I realise now, I owe that to myself.

The challenges encountered in writing the report were also great and very new to me. It was important that this document balanced accessibility with academic rigor but more importantly, that my own perspectives stayed neutral to the findings. At times, this was very hard to keep in check.

I am immensely proud that this is a community-led project and so grateful for the collaborative efforts of the Roopu Tautoko, and my fellow Kairuku. An extra special thank you to Milly and Jane, who have supported me every step of the way. Thank you both for your guidance and unwavering belief in me. He aha te mea nui o te ao? He tangata he tangata he tangata! What is the most important thing in the world? It is people it is people it is people!

Milly Stewart – Kaiārahi and Kairuku

"E kore matou – E kore tatou" Nothing about us without us. This has been a long time coming. This project was led by those living with HIV for those living with HIV, from the beginning to the end. This made the whole project enjoyable and mana enhancing. To be a part of something that will go down in history for those living with HIV, personally, it gave me a better insight into other perspectives, and we are not alone in this space. Lifelong relationships were formed, and meaningful engagements were had. There was no disconnect which is what research can sometimes do. Enthralled with the fact that the voices of not only Māori but of those living with HIV are not tarnished and finally reported with dignity and respect. Humbled that all our participants allowed for their stories to be told and then retold in their words. Heoi anō ki tātou, ahakoa te aha, ahakoa pēhea kia tū rangatira ai tātou.

Grateful is an understatement, humbled is a restraint, however noble, illustrious, dignified, resilient, rewarding, valiant all comes to mind. Thank you, Jane, for holding the mauri in this space as a true mana wāhine. To you Abby Leota, words cannot express the gratitude, your willingness to understand the unknown, to the manaakitanga you gave to all the Kairuku. I am honoured and proud to stand by your side as you anchor your stand in this space. Mana tū, Mana ora, Mana Motuhake, Tihei Mauri ora.

Toitū te Tangata,
Toitū te Whenua,
Toitū te Ao.

We stand undisturbed as people,
we stand undisturbed on our foundations,
we stand undisturbed in the world.

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Ngā taka o te Kupu | Glossary

Ahakoa	Although, notwithstanding, despite, even though, whatever, no matter, in spite of, nevertheless
Ai	Always, regularly, usually- shows habitual action
Ao	World, globe, global
Aroha	Compassion, empathy, love
E kore matou - E kore tatou	Nothing about us, without us
Hauora	Which represents all things that make up wellness, including mental, emotional, spiritual, and social wellness.
Heoi anō	So much for that, there is no more, there is none other, and so, well! so so, but, however, that's all
Hoa Haere	Checklist
Kaiārahi	To guide/oversee (the mahi), Project Leader(s) (the person), mentor, to show the way
Kaipupuri Mauri	Holder of the vision and aspirations of the essence of the mahi
Kairuku	The Interviewer (person doing the mahi), who dives deep and ask questions
Kaitautoko	Supporter, sponsor, backer, advocate
Kaitiaki/Kaitiakitanga	To oversee, look out for others. To protect
Kaokao	Side (mountain) – a strong triangle shape
Karakia	A set form of words to state or make effective a ritual activity, ritual chant, prayer
Kaupapa	Your work/project’s purpose and/or approach/ topic
Kete	Basket or kit
Ko wai au?	Who am I?
Kōrero	Conversation / to talk
Koru	Spiral motif (in kōwhaiwhai patterns and carving)
Mana	Prestige, authority, control, power, influence, status, spiritual power, charisma
Manaaki/Manaakitanga	Respectful, kindness, generosity, care for others
Manaia	Spiritual guardian often presented as part seahorse and horse.
Mauri	Life principle, life force, vital essence, energy, a material symbol of a life principle, source of emotions- the essential quality and vitality of a being or entity.
Mauri ora	Self well-being
Motuhake	To separate, set aside, position independently, be stand-alone
Ngā mihi nui	Thank you very much
Ora	Life, health, vitality
Pēhea	How
Poapoataunutanga	Stigma, shame (impact of)
Pono	Be truthful with integrity

Poutama	Stepped pattern of tukutuku panels and woven mats- symbolising genealogies and also the various levels of learnings up and downs
Rangahau	The process for meaningful engagement or research
Rangatiratanga	Leadership, the right to exercise authority, ownership, self-empowered
Rongoā	Traditional healing
Roopu tautoko	A group/network of organisational supporters
Taonga	Treasure, anything prized, culturally valuable objects, resources, techniques.
Taipakeke	People who are middle aged, mature
Takatāpui	Someone who may identify as being: whakawāhine, tangata ire tāne, gay, lesbian, bisexual, trans, intersex, or queer
Tangata	To be a person, man, human being, individual
Tāngata	People, men, persons, human beings
Tātou	We, us, you (two or more)
Te Ao Māori	Used in reference to 'common' Māori cultural philosophy, theory, living and practice
Te Hā	The Breath
Te Kitenga	To see, the observation of, to perceive
Te Mahi	The practice of/work
Te Reo	Language
Te Tau	To settle, arriving at a place of wellbeing and connectedness
Tihei Mauri ora	The first take of life, claim the right to speak
Tino Rangatiratanga	Self-determination, sovereignty, autonomy
Tohu	Design, sign
Toitū	to be undisturbed, untouched, permanent, entire
Urutā	Disease
Wāhine	Female
Wairua	Spirituality / energy, the spiritual dimension of a person's being
Whakairo	Traditional carvings
Whakapapa	Where you are from, genealogy, lineage, descent
Whakawhanaungatanga/ Whanaungatanga	Make connections, build relationships, work together
Whenua	Land, the earth, ground

Positive Women
Wāhine Kaha

NGĀ TAIPAKEKE O TE URUTĀ HIV
AGEING WITH HIV IN AOTEAROA NEW ZEALAND

Report
2023