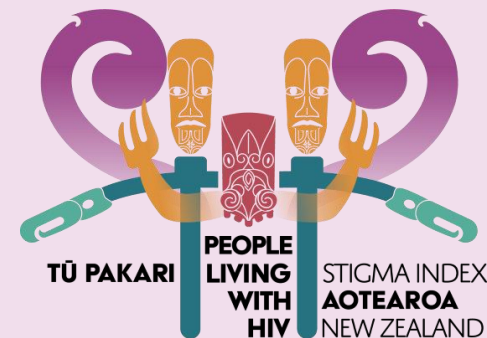


The Aotearoa People Living with HIV Stigma Index Round Two

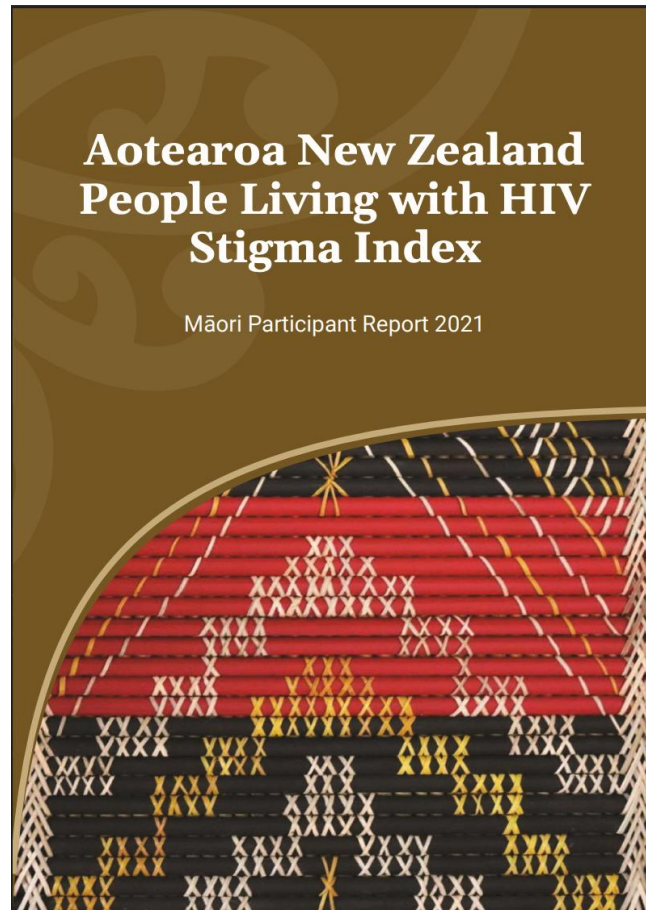


What is the Stigma Index?

Research by and for people living with HIV

- An international research programme led by and for people living with HIV
- Documents experiences of HIV-related stigma and discrimination
- Looks across healthcare, relationships, work, community and everyday life
- Centres the voices and experiences of people living with HIV
- Repeated over time to understand what is changing and what still needs attention







THE PEOPLE LIVING WITH HIV STIGMA INDEX

AOTEAROA NEW ZEALAND

Positive Women



NZAF
Te Tūāwhiri Māori
Aotearoa o Aotearoa



BODY POSITIVE
NEW ZEALAND
Te Tūāwhiri Māori
Aotearoa o Aotearoa



Te Whāriki Takapou



New Zealand
Prostitutes
Collective



New Zealand
Needle Exchange
Programme



MSD
INVENTING FOR LIFE



AIR NEW ZEALAND



Lottery Grants Board
Te Puna Takeke
LOTTO FUNDS FOR YOUR COMMUNITY



FOUNDATION
NORTH
Te Kaitiaki Takeke o
Tāmaki o Tūi Takeke

The first Aotearoa Stigma Index

Our first round: 2019–2021

188

people living with HIV
participated

2019-20

data collection

Peer-led

people living with HIV at the
centre

2 reports

national + dedicated Māori
report

First international Stigma Index to separately examine Indigenous findings

Findings were published and used in advocacy and policy, including the HIV Action Plan.

What did we learn?

Stigma was still shaping people's lives

35%

experienced stigma or
discrimination in the
previous 12 months

~1 in 3

experienced internalised
stigma

~3 in 4

found disclosure difficult

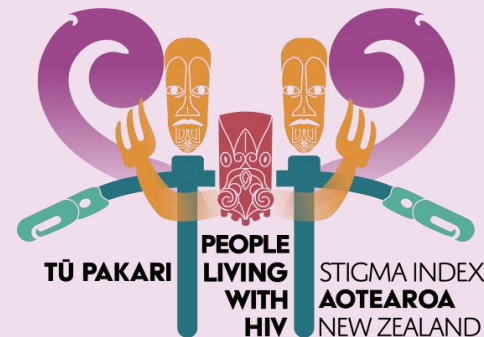
~1 in 2

reported a mental health
condition

Stigma was not experienced equally. Looking at Māori findings separately helped reveal experiences and inequities that can be hidden within national averages.

HIV disclosure

- **70%** difficult to tell people about their HIV
- **69%** hid that they have HIV
- **83%** disclosure was mostly to a partner
 - **67%** family
 - **63%** friends
 - however, many reported that disclosure of their HIV had occurred without their consent
- Only **32%** of people in current employment said their employer knows about their HIV



Photos from first launch





From evidence to action

Policy

Stigma Index findings cited and used in the National HIV Action Plan

Monitoring

Established a benchmark for tracking stigma and discrimination over time

Research

Dataset used for further peer-reviewed research, including quality of life among people living with HIV, Ageing with HIV, and on experiences of criminalisation.

Why do it again?

Has HIV stigma changed in Aotearoa?

Has it become easier to tell people you have HIV?

To find love and intimacy?

To access healthcare?

To feel accepted?

To simply be yourself?

Six years later, we need to find out.

Round 2: what stays the same?

Building on what came before

- The international Stigma Index questionnaire remains at the core
- Research remains centred on people living with HIV
- Peer interviewers are themselves living with HIV
- National recruitment across Aotearoa
- Key findings can be compared with 2020 and internationally
- Evidence is designed to support community action, services and policy

Our p

Stigma Index Meeting

14:16

Chat People Raise Hand Reactions View Controls Notes Rooms Apps More Camera Mic Share Leave

Marie Brunning

Milly Stewart

Rodrigo Clén Gormán (he/him)

Carl Greenwood

Jonathan Bateman

Mark Fisher

Sue McAllister

Brooke Marie Hollingshead

catherine healy

Type here to search

26°C 1:05 pm 8/12/2025

Health New Zealand

What is different this time?

Round 2 builds on what we learned

More ways to participate

Complete the questionnaire with a peer interviewer, in person or online, or self-complete online.

Embedded Māori leadership from the start

Greater Māori involvement in governance, questionnaire development, interpretation, data considerations and reporting.

Kairangahau Māori / Tangata Whenua rōpū

Stronger equity focus

More intentional outreach and planned recruitment across communities, identities, ages and regions.

Accessibility – Geography – Outreach – Connection - Community

A stronger model of practice

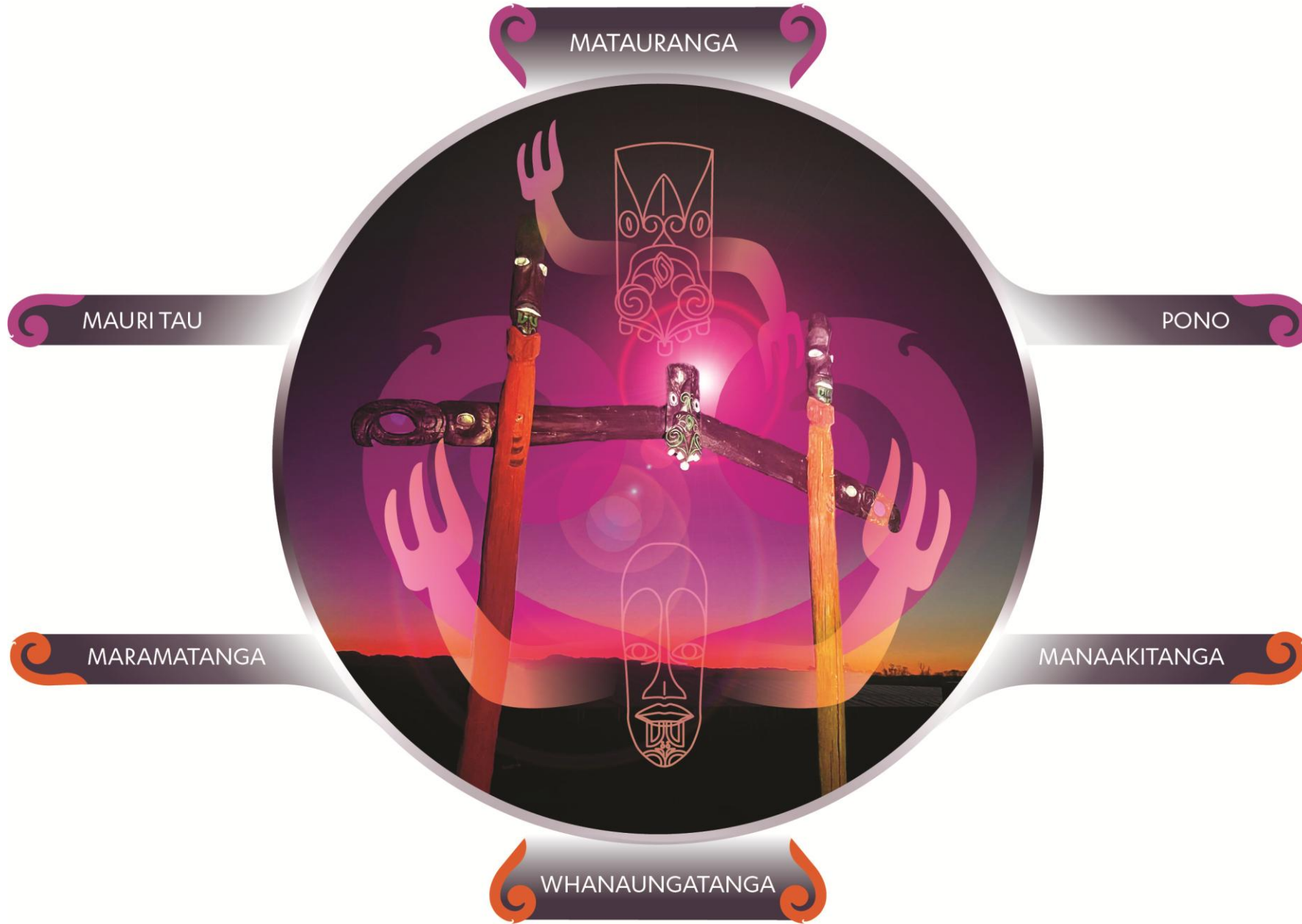
Tū Pakari shapes how the research is done, not simply what questions are asked.

More interviewer peer support

Designated peer support leads for manaakitanga, space for whanaungatanga, and stronger referral pathways

Tū Pakari

A model of
practice for
how we
work
together
and how
participants
experience
the
research





TŪ PAKARI

**PEOPLE
LIVING
WITH
HIV**

**STIGMA INDEX
AOTEAROA
NEW ZEALAND**

Tū Pakari in practice

Visible across the whole research journey

Governance

Leadership by
people living
with HIV

Recruitment

choice +
accessibility

Online self-
complete
Face-to-face
Zoom

Participation

peer-led +
culturally safe

Data care

privacy + mana

Interpretation

community + Māori
leadership

Reporting

evidence for
change

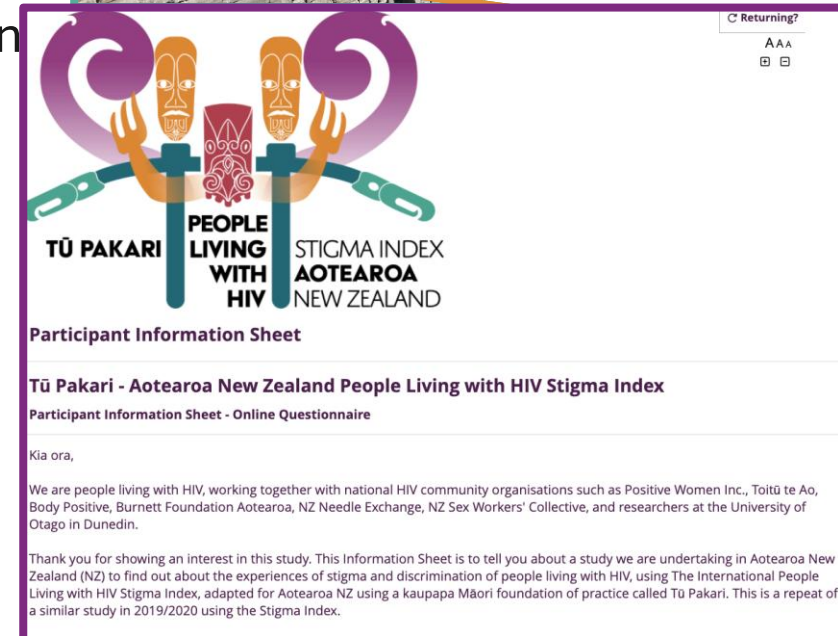
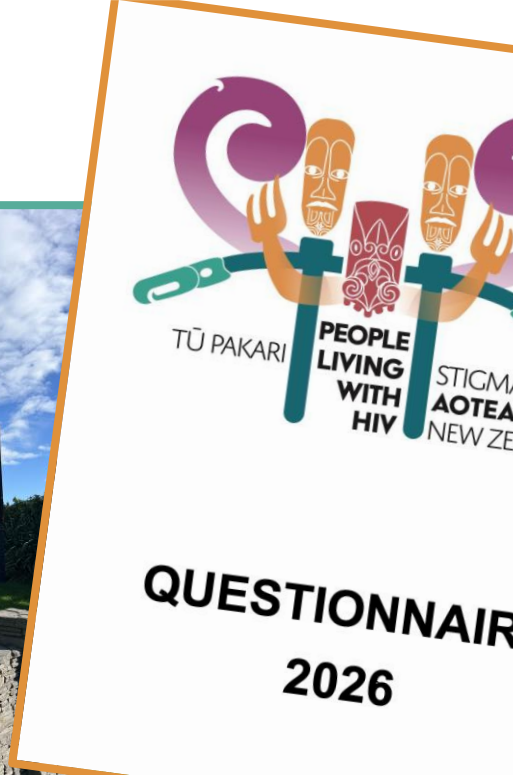
Where are we now?

- Questionnaire and study materials substantially developed
- Research and community governance established

Partnership Rōpū, Research Rōpū, Tangata Whenua hui, Peer Interviewers

- Ethics process underway
- Strong peer interviewer team: 20 interviewers (Kaitaia to Dunedin)
- Further work underway with Tāngata Whenua Rōpū to strengthen the approach for Māori
- Recruitment will begin once the protocol and ethics processes are complete

We had hoped to launch around now. We are allowing the time needed to get the approach right before recruitment opens.



STAND
STRONG

www.stigmaindex.nz



www.stigmaindex.nz

TELL YOUR
STORY



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TŪ PAKARI



**SHAPE
CHANGE**



www.stigmaindex.nz

The Aotearoa New Zealand
People Living with HIV
Stigma Index is coming back,
with a new name, a refreshed look,
and a renewed opportunity for
people living with HIV to
shape change...

TŪ PAKARI
www.stigmaindex.nz



Launching soon!



**Stand strong.
Tell your story.
Shape change.**

Tū Pakari recruitment coming soon