

# Stigma and discrimination experienced by people living with HIV in Aotearoa 2020 Report

## A Woman's perspective



**THE PEOPLE  
LIVING  
WITH HIV  
STIGMA  
INDEX**

**AOTEAROA NEW ZEALAND**



# International Study

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- 100 Countries
- 100,000 people living with HIV interviewed
- Side-by-side interview technique with peers
- Based on GIPA and MIPA principles





**THE PEOPLE  
LIVING  
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STIGMA  
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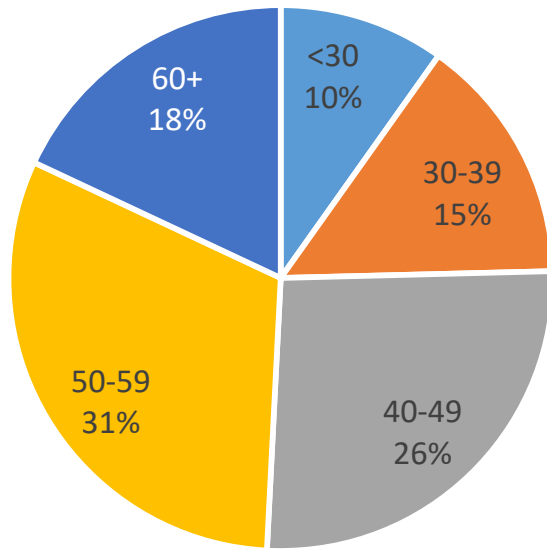
**AOTEAROA NEW ZEALAND**

Thank you very much to the following organisations for their contributions to the Stigma Index  
A special thank you to all of the interviewers and participants

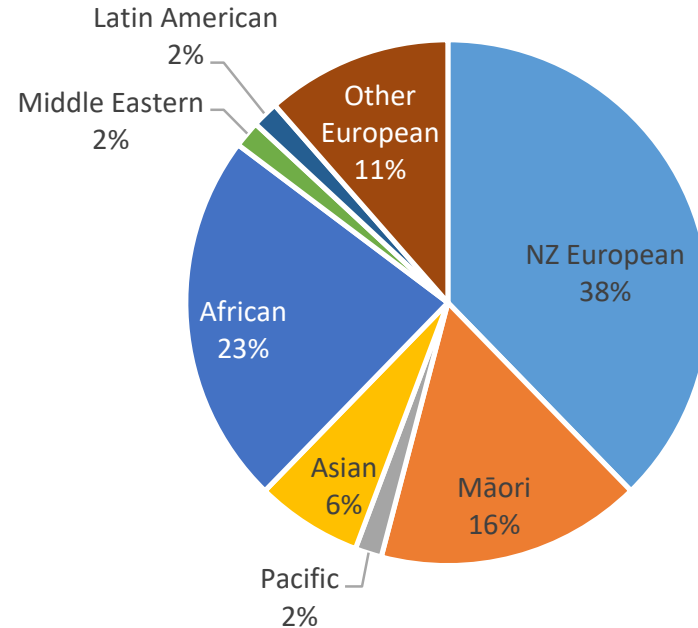


# Who took part?

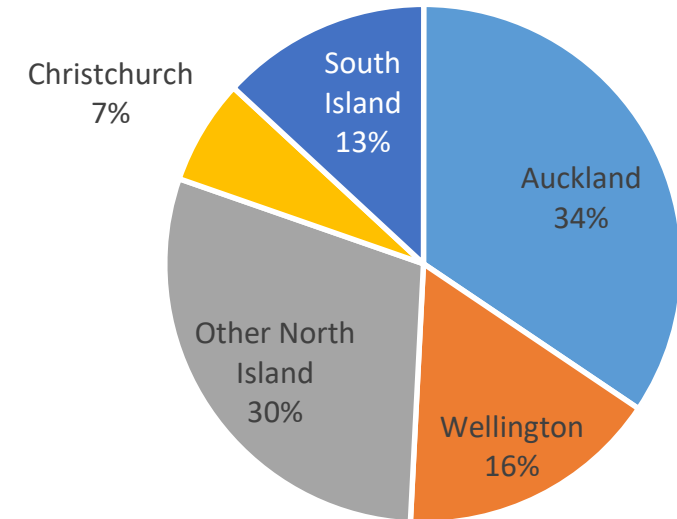
Age



Ethnicity



Residence

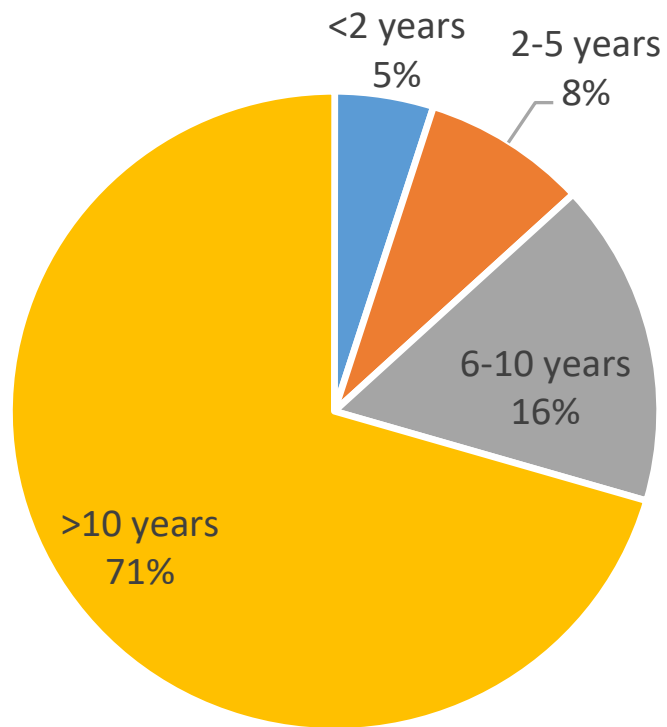


61 Women which includes transwomen and Whakawhahine

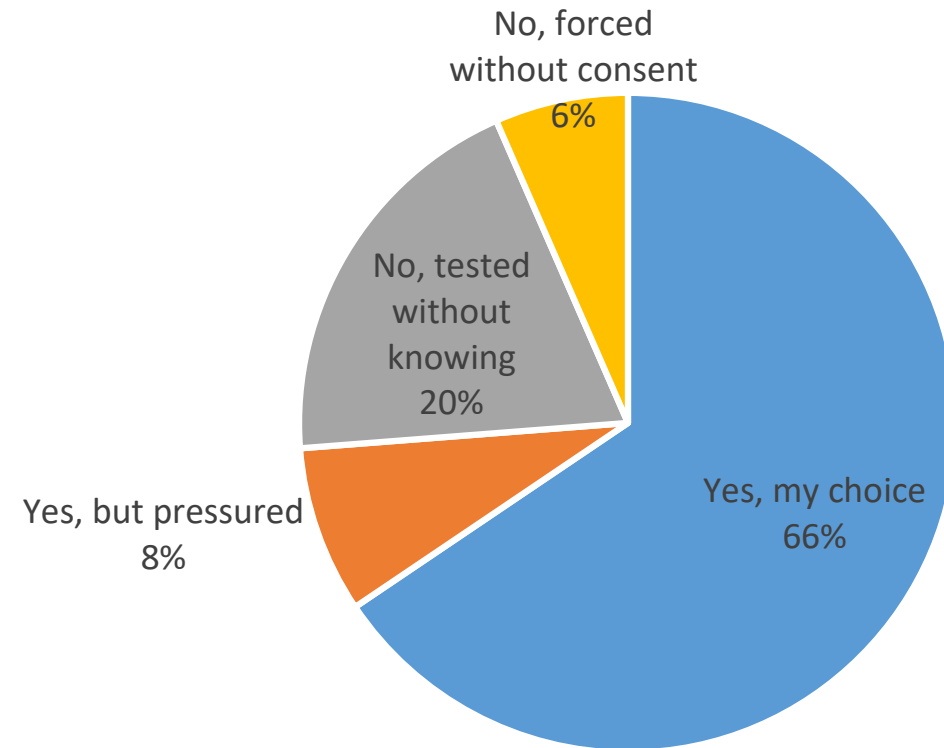
# HIV testing, diagnosis and treatment

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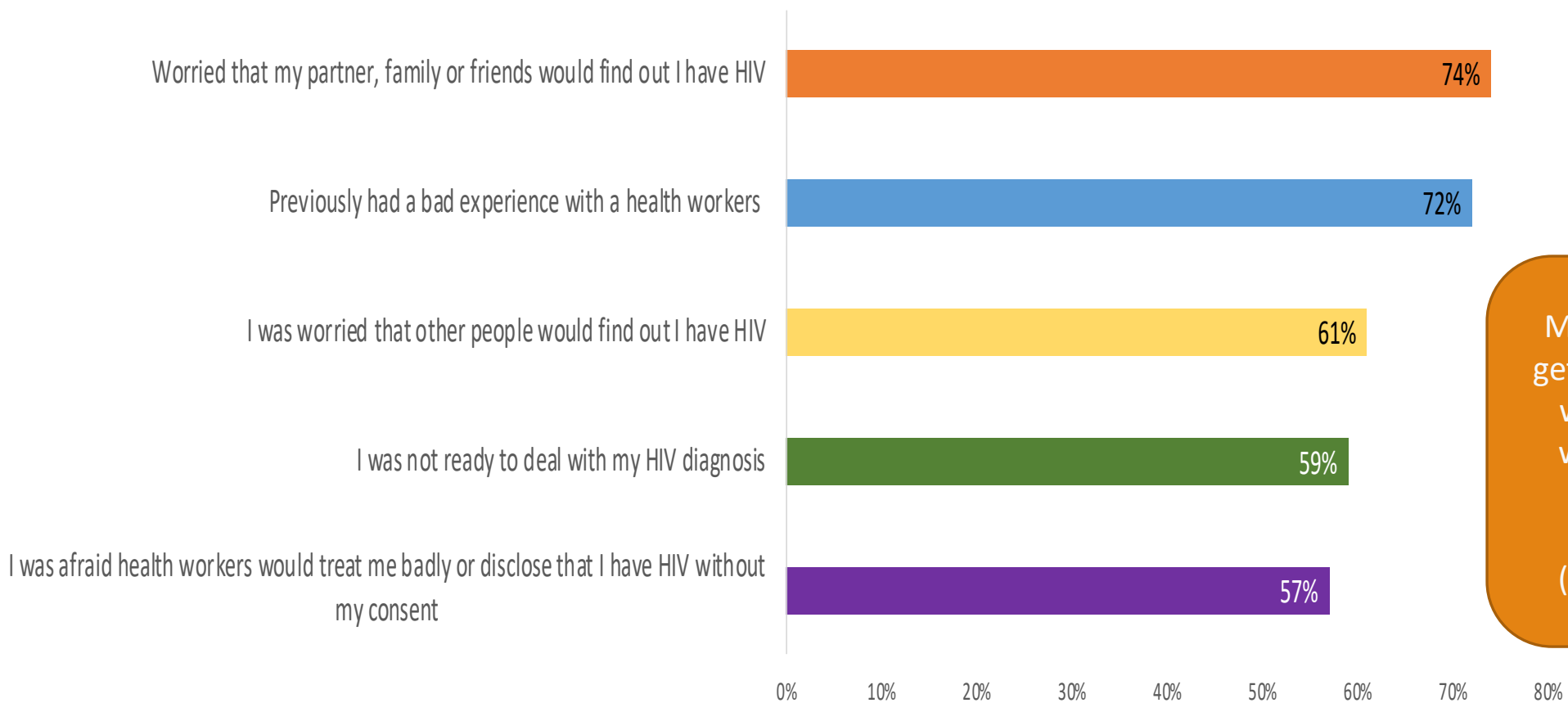
Time since HIV diagnosis



Decision to test for HIV



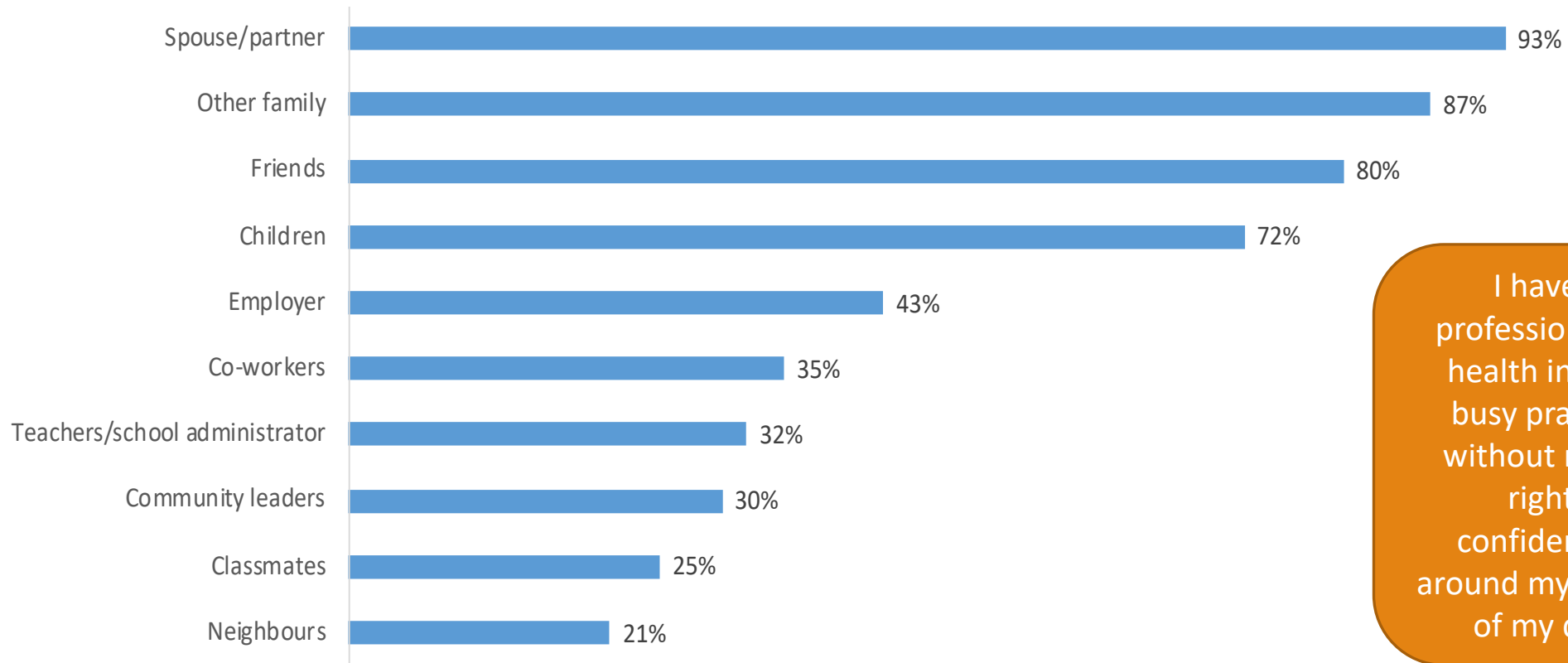
# Reasons for delay in care or treatment



My pharmacy used to resist getting in meds because they were expensive, and they were not sure I'd come to collect them. I ended up changing pharmacies.  
(NZ European woman, 35)

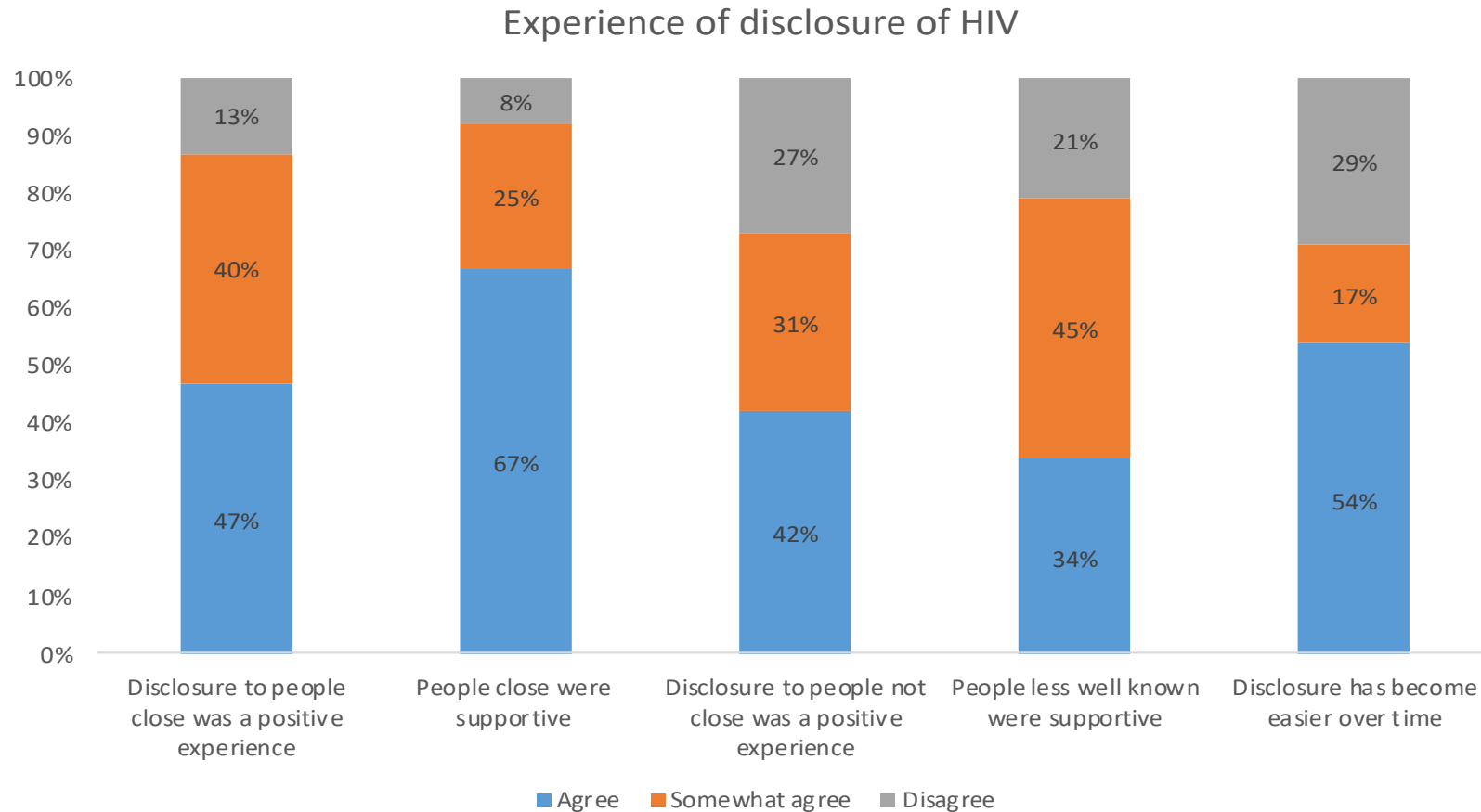
# HIV Disclosure

Disclosure of HIV



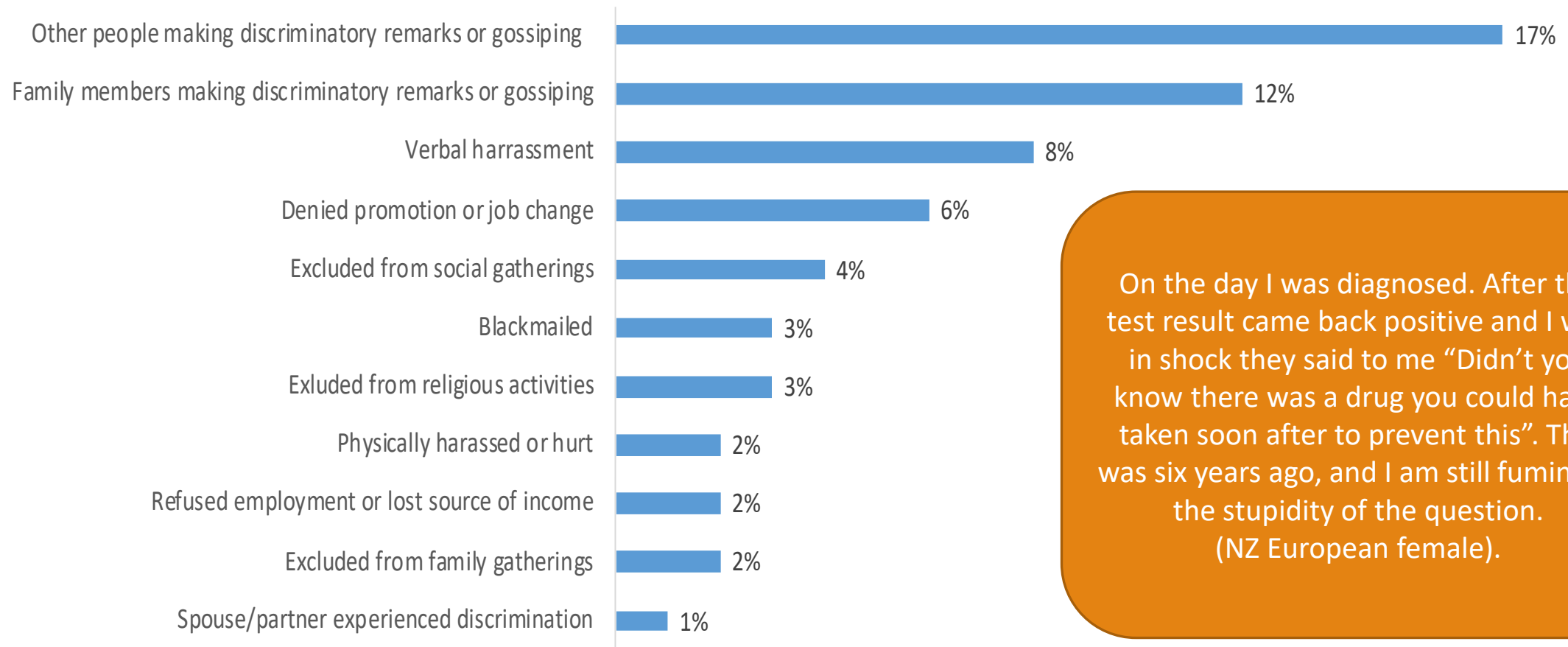
I have heard health professionals discussing my health in the corridor of a busy practice with others without my concern of my right to privacy & confidentiality.....secrets around my HIV status are part of my daily living now.

# Experience of disclosure of HIV status



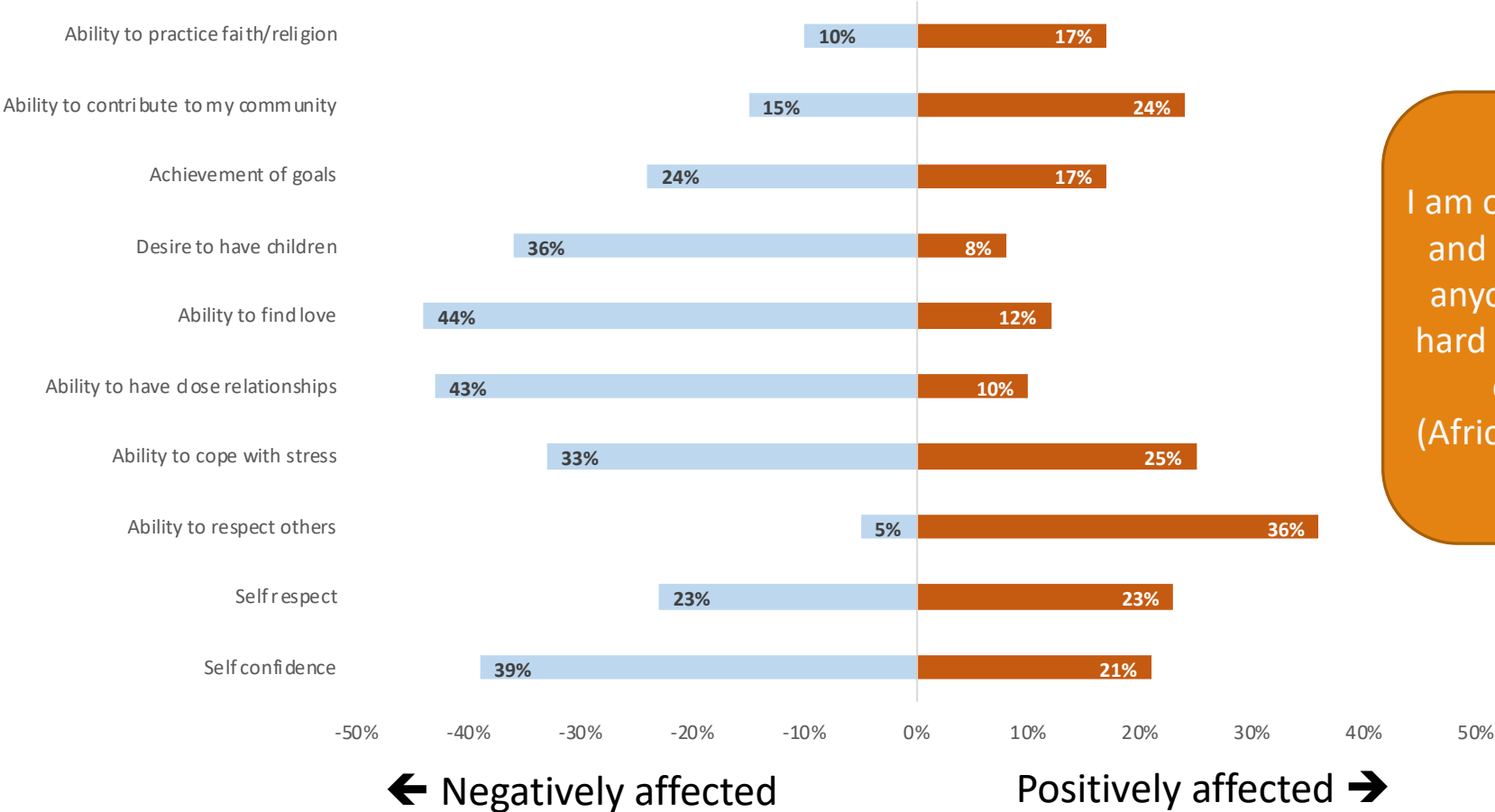


# Experiences of stigma and discrimination in the last 12 months due to HIV



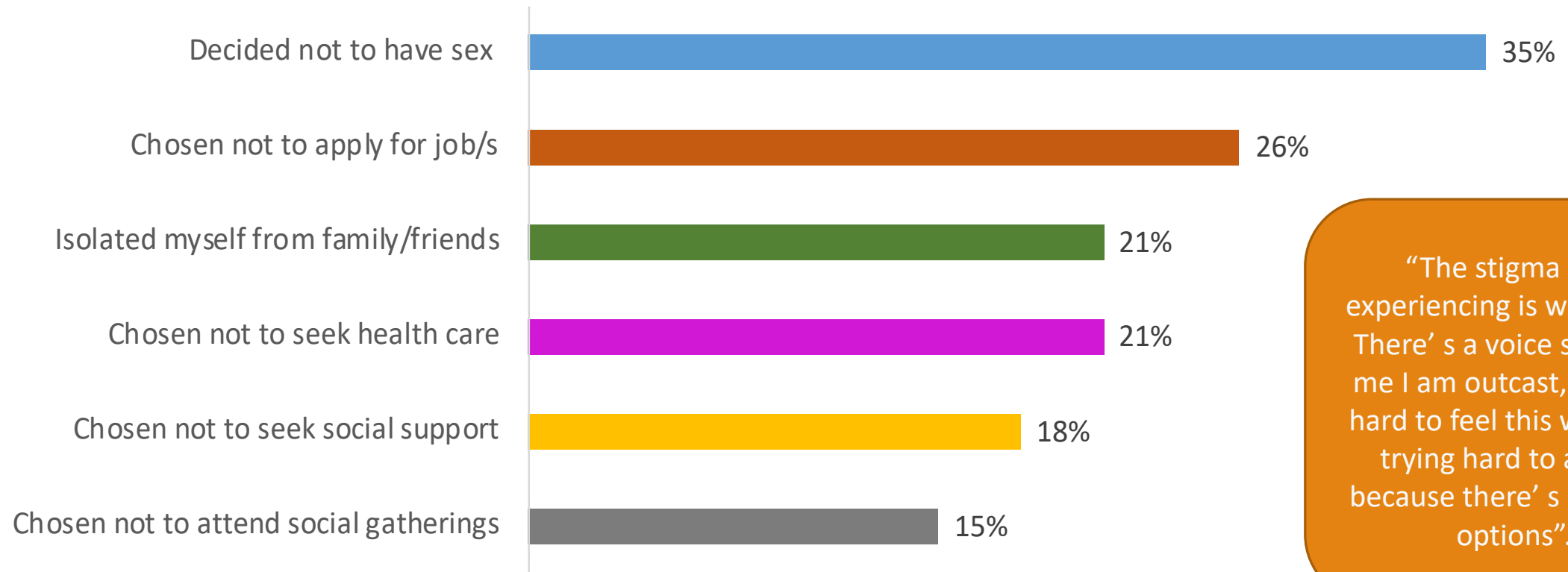
On the day I was diagnosed. After the test result came back positive and I was in shock they said to me “Didn’t you know there was a drug you could have taken soon after to prevent this”. This was six years ago, and I am still fuming at the stupidity of the question.  
(NZ European female).

# Internalized stigma within the last 12 months



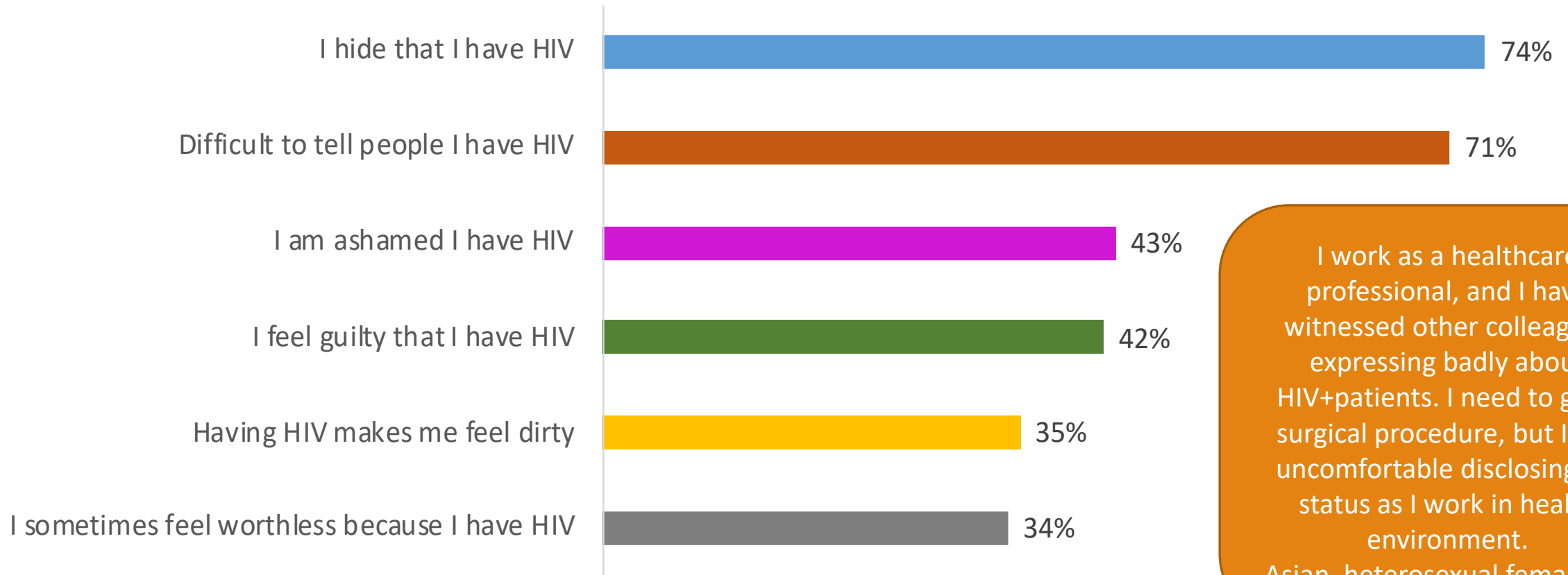
I am open about my HIV status, and I can disclose about it to anyone easily, but I find it so hard to do it when it comes to or involves intimacy. (African, heterosexual female)

# Internalized stigma within the last 12 months



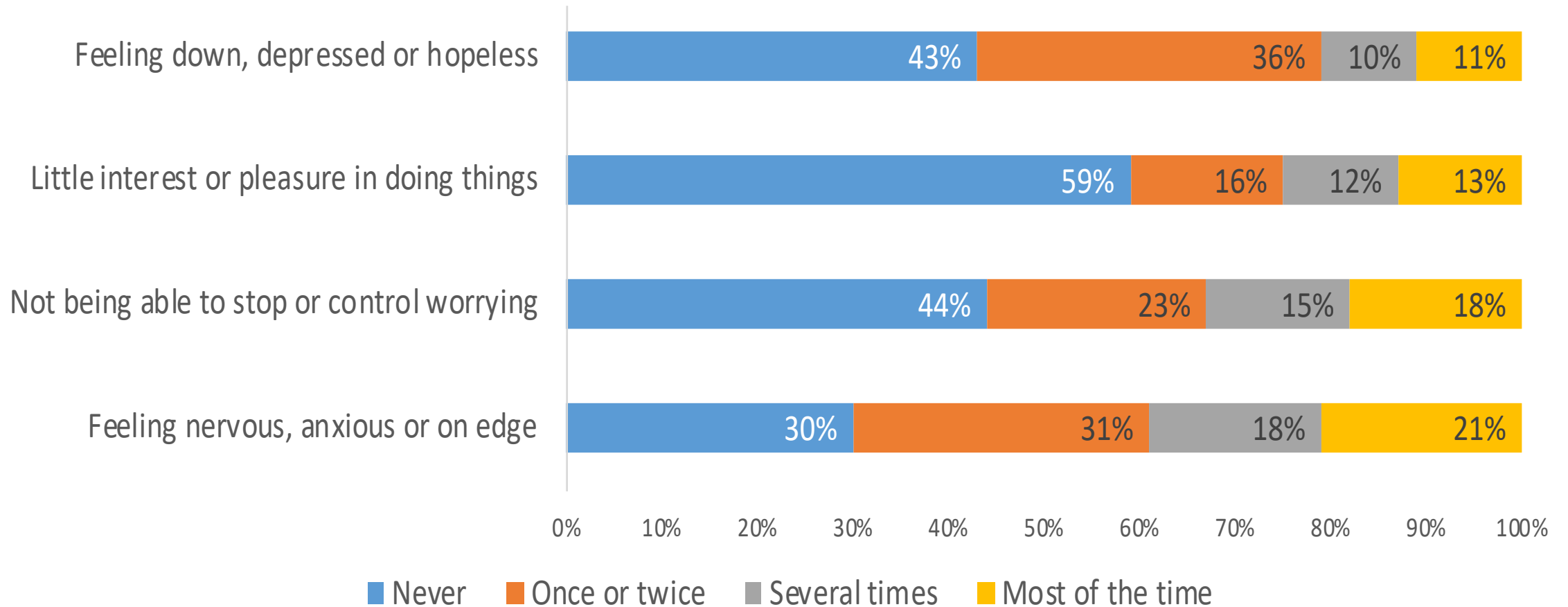
“The stigma I am experiencing is within me. There’s a voice saying to me I am outcast, and it is hard to feel this way. I am trying hard to accept because there’s no other options”.

# Feelings expressed by women



I work as a healthcare professional, and I have witnessed other colleagues expressing badly about HIV+patients. I need to get a surgical procedure, but I feel uncomfortable disclosing my status as I work in health environment.  
Asian, heterosexual female, 37

# Mental health and wellbeing



# Healthcare

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## HIV specific health care in the last 12 months

- Denial of health services – 1
- Advised not to have sex – 2
- Talked about or gossiped about because of HIV – 3
- Avoidance of physical contact/taking extra precautions – 11
- Telling others without consent – 1

## Non-HIV related health needs in the last 12 months

- Denial of health services – 1
- Talked about or gossiped about because of HIV – 2
- Avoidance of physical contact/taking extra precautions – 6
- Telling others without consent – 6

Do you think your medical records relating to your HIV are kept Confidential?

- Yes 23 (38%)
- No, not confidential 8 (13%)
- Don't know 30 (49%)

# Reproductive health

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## **In the last 12 months....**

- Pressured to get sterilized – 1
- Advised to terminate a pregnancy – 1
- Pressured to use a specific type of contraception – 2
- Pressured to use a particular method of giving birth – 2
- Pressured to use a specific infant feeding method – 2
- Pressured to take ART during pregnancy – 2

# Human rights

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Forced to get tested or disclose that I have HIV within the past 12 months in order to:

- obtain a visa – 1
- apply for a job/pension – 2
- get health care – 3
- get medical insurance – 4

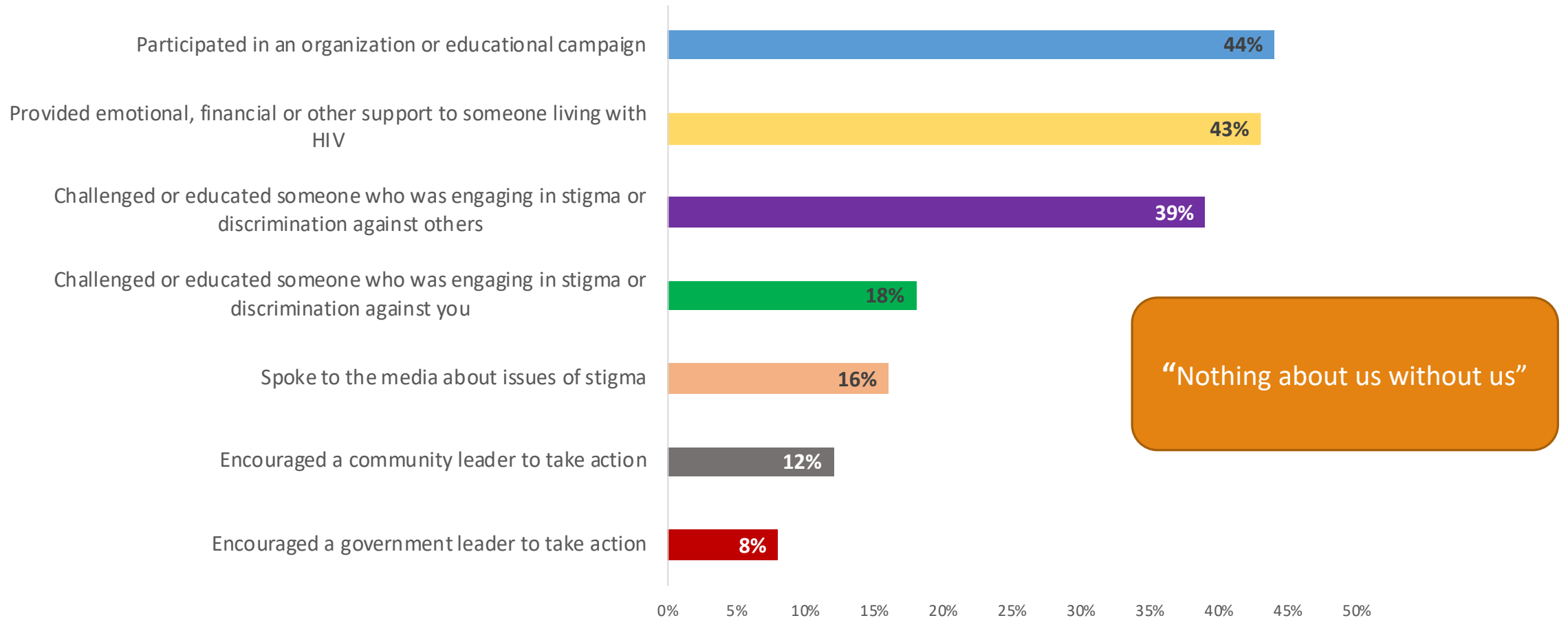
Forced to disclose my HIV publicly or my status was publicly disclosed without my consent – 1

Do you know if there are laws in NZ to protect people living with HIV from discrimination?

- Yes, there are laws 37 (61%)
- No, there are no laws 4 (7%)
- Don't know 20 (33%)



# Effecting change and advocacy within the last 12 months



*“We are a strong and determined community that will achieve all the goals it has set out to do. Because of this I am very positive about the end of HIV and hopefully, one day the stigma that has accompanied it.”*



*“I'm not a victim. I'm not a hero.  
I'm ordinary and grateful.”*

# Summary of Recommendations

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- ❖ Education about HIV and AIDS
- ❖ Programmes and funding
- ❖ Policies and procedures
- ❖ Care and support of people living with HIV
- ❖ Research

# Education

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- For healthcare workers on how to talk about HIV and how to maintain privacy and confidentiality:
  - Consent and testing
  - Stigma and discrimination
  - Renewed emphasis on the use of universal precautions.
- Safety of healthcare workers living with HIV.
- For people living with HIV about their rights to privacy and confidentiality.
- **Anti-stigma campaigns addressing:**
  - Isolation in regions across Aotearoa New Zealand
  - Unique needs and compounded stigma.

# Programmes and funding

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- Funding for HIV community organisations.
- Programming to focus on empowerment, self determination and wellbeing for people living with HIV.
- Expand campaigns on Undetectable=Untransmittable.
- Modernise and widen the range of funded treatment for people living with HIV.
- Improved resources to support people living with HIV when facing stigma and discrimination in the workplace and violation of their human rights.
- Culturally appropriate programming and resources.

# Policy and procedures

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- Review of Standard Operational Procedures for HIV testing across clinical sites.
- Healthcare to develop, implement and reinforce workplaces policies.
- Consistent training and monitoring of healthcare staff to reinforce obligations under the Privacy Act (1993).
- Remove HIV from the Immigration New Zealand list of conditions (A4.10.1) deemed to impose a burden.
- Review of policies to enable health, life and travel insurance for people living with HIV.
- End the use of the criminal justice system to address cases of HIV non-disclosure, exposure or transmission.
- A renewed and ambitious HIV Action Plan.

# Care and support of people living with HIV

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- Increased funding for people living with HIV peer organisations.
- Wider availability of counselling and peer support networks.
- Ensure rapid linkage to care and treatment and easy access to support and counselling services.
- Programmes focusing on broader wellbeing for people living with HIV that includes building self-confidence, mindfulness, nutritional advice and peer support.
- Greater access to support services for people with HIV outside of main urban centres.

# Further Research is needed

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- To explore stigma among newly diagnosed
- To explore the ageing population of people living with HIV, including programmes for integrated care and support across health and social services, with the needs of older LGBT people to be considered.
- To be person-centred with people living with HIV involved as implementers, to increase the cultural relevance and applicability of the research and the programming.
- To shift the perspective of HIV programming and research whereby people living with HIV are recognised for their agency rather than assumed passive beneficiaries or research participants



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Full report available at:

[WWW.stigmaindex.nz/resources](http://WWW.stigmaindex.nz/resources)

Thank you

