

The application of the HIV stigma index in the Western Highlands and Chimbu provinces of Papua New Guinea

A SUMMARY REPORT

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The main report provides acknowledgement of partner organisations and their role in supporting the research and producing the reports.

... the narrative — the as yet far from complete narrative — of HIV/AIDS brings to light human rights issues at every turn. To name just the most obvious, these include: discrimination against ‘outsider’ groups; the need to confront taboo subjects . . .

Jonathan Wolff *The Human Right to Health*

SUMMARY

Research was conducted on HIV stigma and discrimination using the Stigma Index (see stigmaindex.org) in the Papua New Guinea (PNG) provinces of Western Highlands and Chimbu*. The research was funded by a grant from PNG's National AIDS Council (NACS). When Igat Hope, the national representative organisation of people living with HIV in PNG, began the project the aim was to conduct interviews in all regions of PNG. However, due to funding constraints and organisational capacities, the Stigma Index has only been applied in one region, that is, the Highlands Region.

The data, the analysis and the recommendations are important and should be taken into account by all involved in the response to the HIV epidemic in PNG. The catch-cry in PNG is that ‘HIV is everybody’s business’ so finding solutions to the problems identified in this report is indeed everybody’s business.

The research conducted thus far, and the results contained in this report should be considered as the first steps in an ongoing project aiming to cover all regions in PNG. Igat Hope will need the assistance of numerous partners to continue with this work and there may be other research models, such as action research approaches, that could enhance the information being gathered through the implementation of the Stigma Index in PNG. The Stigma Index is an important international initiative and now, through the completion of at least a small part of the project, PNG finally has some data to provide to this important international work.

The full report titled *HIV-related stigma and discrimination and human rights in Papua New Guinea* is available online in flipbook format at https://issuu.com/napwa/docs/png_stigma_report_2016_flipbook.

*Chimbu is the province’s official name; it is also known as Simbu.

The aim

The research aimed to provide data on how stigma and discrimination create barriers to accessing services and how they impede the scaling-up of delivery of antiretroviral therapy (ART) in PNG. Another aim was to detail the levels of stigma and discrimination faced by people living with HIV (PLHIV) in the different provinces and regions.

There are differing experiences of PLHIV based on gender, sexuality or gender identity. The research aimed to determine and understand the contributing factors to stigma and discrimination faced by PLHIV through a research project that valued differences across gender and sexuality and generated information about those different experiences.

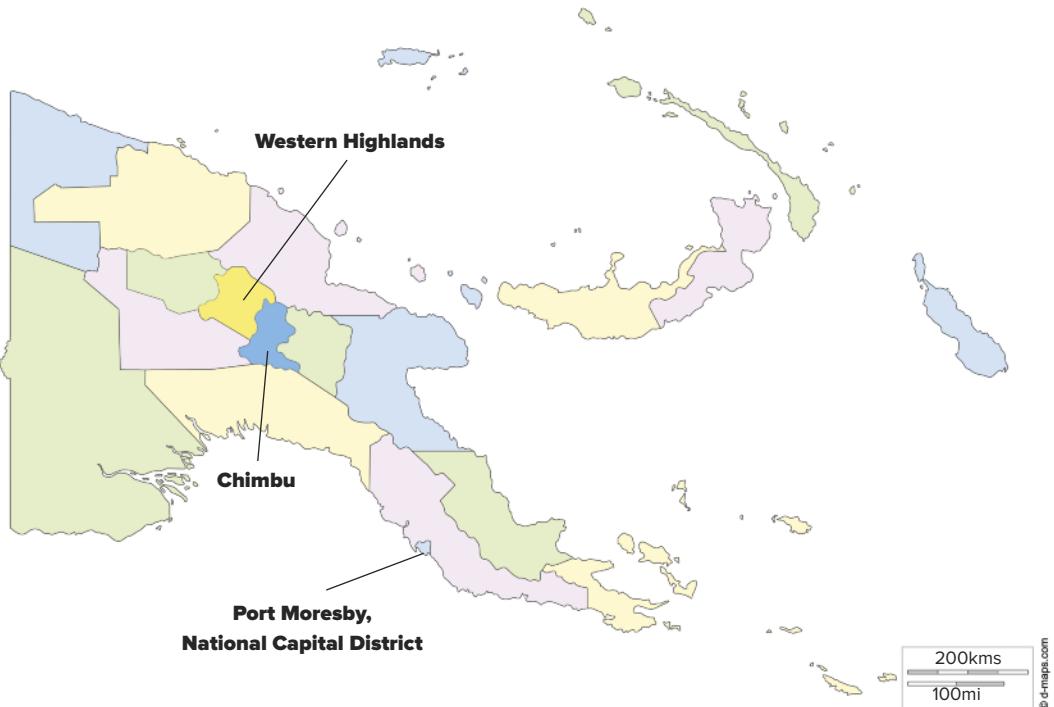
The international Stigma Index was the tool used to identify those situations that created heightened risks for PLHIV. Previous studies in PNG have pointed towards some of the experiences of stigma and discrimination and living with HIV but this research, using the Stigma Index, is the first of its kind in PNG to address the issue directly and is unique because the research is conducted by PLHIV. Because the project was initiated by PLHIV, and the results interpreted by PLHIV, PLHIV were not positioned as objects but were actively engaged in research about their own experiences and needs; in this way the problem of PLHIV being ‘spoken about’ or being the ‘objects of research’ was resolved.

In 2013, a seven-country consultation in the Pacific — sponsored by the Joint United Nations program on HIV/AIDS (UNAIDS) — identified national laws and policies that needed review and/or reform to support PLHIV. PNG was one of the countries where it was recognised that good practice in human rights-based responses to HIV was needed. The findings from the Stigma Index can contribute to these policy discussions and reform processes.

The research process

Research ethics approval was granted in 2010 (NACS RES 10 014) but funding for the implementation in the provinces of Western Highlands and Chimbu was not secured through the National PNG HIV Research Grants process until late 2011. Logistics were quickly put in place by Igat Hope and the research team was immediately prepared for implementation and data collection.

The Stigma Index tool, which was a structured interview, was translated into Tok Pisin, the most widely-used language in PNG. A research team of PLHIV was selected and trained in basic research methods. A total of 80 interviews were conducted, 40 in each of the two provinces of Western Highlands and Chimbu.



Map of Papua New Guinea

The sample was selected so as to gain insights into the experiences of diverse PLHIV in relation to stigma and discrimination. It is not a representative sample of all PLHIV in PNG, nor is it a random sample. The sample was selected on the basis of convenience. All hospitals, clinics, aid posts, antenatal clinics and drop-in centres were identified in the provinces and from this list, key care and treatment sites as identified by PLHIV networks in each province were selected. The convenience method was used, whereby key site managers advertised that interviewers would be available for those wanting to participate in the research. More details on data management and analytic methods are provided in the full report found at https://issuu.com/napwa/docs/png_stigma_report_2016_flipbook

The role of the research team in interpreting data and undertaking a thematic analysis of the information was a key part of the process. This involved the team engaging in regular discussion before, during and after the interviews were conducted and discussing the nuances of translating words and concepts from Tok Pisin into English. This research actively engaged PLHIV in the design, application and analysis of the research data, and in this way, positioned PLHIV centrally in research about living with HIV in PNG. It is not only the first of its kind in PNG to address the issue directly, but the first to

have PLHIV conduct the research, consider how to best articulate the results, then to decide and act on it. It is unique in the PNG context and a very important model for future work.

The Highlands Region

Estimates and surveillance data available at the time the project commenced showed that the Highlands Region had the highest HIV prevalence rate in PNG (see NDoH and NACS 2006 in the main report) and therefore was targeted as the first and most important place to implement the project. While there has been a significant investment in services and health infrastructure in response to HIV in Western Highlands, Chimbu does not have such infrastructure development, despite the fact that many people come to Chimbu from all over the Highlands Region. It was thought this would also enable some comparison of how HIV service response and infrastructure may affect experiences of stigma and discrimination.

Another important factor was the preparedness of local PLHIV organisations to engage in the partnership research. In PNG there has been a long tradition of active PLHIV representation in the Highlands Region and this is also why Western Highlands and Chimbu were chosen for the first implementation of Stigma Index. It was in these places that the local PLHIV groups were most ready to engage with health service partners and to produce information that might be of benefit to all partners.

Western Highlands covers an area of 4300 square kilometres and has 254,227 inhabitants, making it the most densely populated province; its provincial capital is Mount Hagen. Chimbu covers 6100 square kilometres, with a population of 259,703; its capital is Kundiawa.

The findings

Most respondents were between the ages of 25 and 39 and the majority had been living with HIV for five to nine years. Some important findings include

- Nearly all respondents indicated they were sexually active, although fewer than a quarter said they were married or co-habiting with a partner. This has important implications for HIV prevention messages, especially because the interview information showed that not all people were taking ART.
- More than 10 percent identified as belonging to the category of sex worker. A small percentage said they belonged to the group men who

have sex with men (MSM) or gay. This also has important implications for any future interventions as it suggests there are more people who describe themselves as sex workers than was thought before project began.

- Almost 70 percent said they had been physically assaulted in the previous twelve months and that it was because of their HIV status. This demonstrates that living with HIV in PNG carries significant personal risks and more support is needed to ensure the safety of PLHIV. The reality is that some interviewed do not feel safe in their own communities and this is because of their HIV status.
- More than half said they had not attended social gatherings because of their HIV status. Being gossiped about was identified as the major problem and nearly half of the respondents said they felt ashamed, guilty or blamed themselves for their HIV status. This implies there is much work needed to support PLHIV to understand that HIV is not their fault and that they need to be supported to be resilient in the face of gossip and fear of how they will be treated.
- More than a third of those interviewed identified that in the past twelve months they had been excluded from religious activities in their communities because of their HIV status.
- The majority of respondents said they had felt isolated from family and friends in the previous twelve months because of their HIV status and nearly half said they had, at one time in the last twelve months, felt suicidal.
- There were other decisions that some respondents had taken because of their HIV status, including deciding not to marry (n=11); not to have children (n=21); to stop work or find they could not continue to work (n=36); avoiding a hospital or clinic for treatment when they needed to (n=17); withdrawing from training or education (n=9). That significant numbers reported negative experiences relating to their HIV status presents many challenges in overcoming stigma and discrimination in work, health and education and demonstrates that the direct experience of discrimination is probably far more pervasive than previously thought.
- While the majority of respondents knew there were particular support groups, networks, non-government organisations (NGOs) and faith-based organisations (FBOs) that may be able to offer assistance, just over one-quarter (n=27) had sought help to resolve an issue of stigma and

discrimination. This is a very small number compared to the number of incidences of stigma and discrimination experienced.

- When it came to testing and diagnosis, at least 14 respondents said they had been tested without their knowledge. While the majority did receive pre- and post-test counselling, some said they did not receive any counselling when they had the test (n=7).
- In comparing and contrasting the data from the two provinces, what is most obvious is the common and shared experience of PLHIV across the two provinces. These include
 - 1** that the experience of gossip related to HIV status was almost universal;
 - 2** a majority of respondents reported being verbally insulted, harassed and/or threatened;
 - 3** two-thirds reported some experience of physical harassment/threat or actual physical assault and;
 - 4** most respondents reported a similar array of perceived reasons why stigma and discrimination occur.

Further information is detailed in Part 5 of the full report.

Based on some of the information above, and through thematic analysis, the research team identified that there were a number of settings in which stigma and discrimination were found and these included

- family and clan
- community and peer networks
- workplaces and health care settings.

From data, which is provided in full detail in Part 5 of the main report, PLHIV reported that they

- avoided being identified as HIV-positive
- experienced feelings of hurt and abandonment
- felt that they were treated like rubbish

- were physically assaulted and/or threatened with assault
- were excluded by the family and clan
- had been gossiped about
- did not have fair access to work, health services and education
- often felt betrayed
- felt their sexuality was despised by others.

Recommendations

A summary of the areas identified where action can be taken is provided below and expanded in Part 6 of the main report.

PLHIV networks and community relationships

Strategies could include communities being educated about PLHIV and provided with HIV information; more awareness of and sensitisation about PLHIV in their communities is crucial for healthier understanding; PLHIV need to take the lead in information dissemination, even if they are not open about their HIV status; PLHIV need to talk about stigma within the communities even if they haven't disclosed their HIV status; and PLHIV need to help each other and be empowered to be part of the HIV response.

PLHIV network building and peer interaction

PLHIV networks and support groups need to build their capacities in the knowledge of human rights and the use of conflict resolution to better uphold the work to reduce the incidence of stigma at the provincial level. Networks can also help develop skills and build resilience for members so they are able to respond when acts of stigma and discrimination are encountered.

Capacity-building in health care settings

Health care workers (HCWs) need more capacity-building in care, support and treatment to better serve PLHIV. Services provided by the HCWs should and must respect individual rights; all clients should have their confidentiality protected; and HCWs also need to be sensitive in all areas of HIV, especially those engaged in antenatal clinics, STI (sexually transmitted infection) clinics and the general outpatient departments of hospitals.

Further engagement with the legal and para-legal practitioners

While it is up to PLHIV to learn about their rights, it is also recognised that

legal personnel must take the initiative and make it their responsibility to start working with stakeholders and help PLHIV to take any action to redress discrimination. Legal personnel should also be able to assist in disseminating information about human rights through the PLHIV networks.

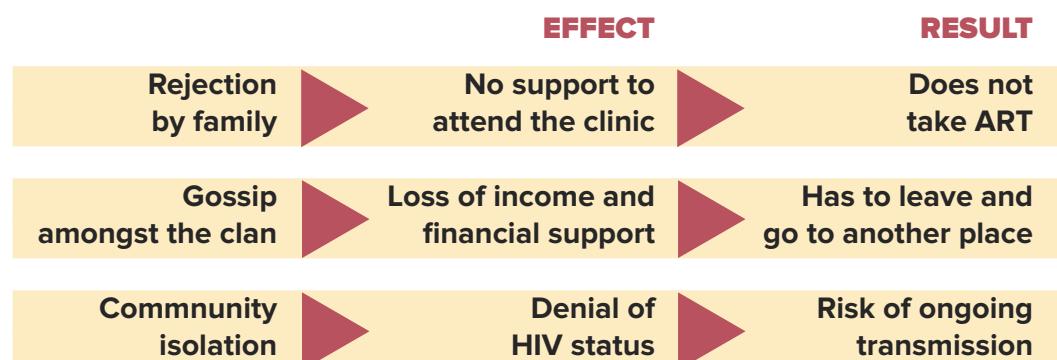
Improving stakeholder relationships with the positive communities

Stakeholders should be more sensitive about PLHIV and their experiences, systematically including PLHIV in planning and designing projects and activities, especially at the provincial level. Stakeholders need to build relationships with legal entities within their provinces to help PLHIV; and all stakeholders need to properly document HIV-related stigma and human rights abuses.

Analysis

Thematic analysis by the research team was an iterative and reflexive process that took place throughout the research activity. Thematic analysis identified that PLHIV in PNG

- avoided being identified as HIV-positive
- experienced feelings of hurt and abandonment
- felt that they were treated like rubbish
- were physically assaulted and/or threatened with assault
- were excluded by the family and clan

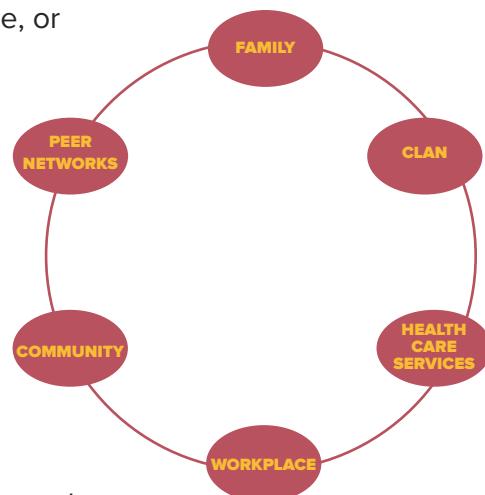


The effects and impacts of stigmatisation

- had been gossiped about
- did not have fair access to work, health service and education
- often felt betrayed
- felt their sexuality was despised by others.

Stigma and discrimination occur

- when family and community members gossip, verbally harass, reject, express through tone of voice, or verbally and physically assault PLHIV
- in institutions such as health care services when health care workers act very unprofessionally by not attending to PLHIV or their family members when they are sick; other breaches of confidentiality occur when, without their approval, PLHIV have had their status disclosed to other relatives or community members
- in hospital settings through professional negligence and the attitudes of health personnel
- when there is a delay in providing ART, even when it should be immediately accessible
- in interactions with the police force and churches
- when the children of PLHIV are harassed
- when in some parts of the country, PLHIV are not allowed to participate in cultural activities, for example, initiation ceremonies for boys moving from young teen to manhood
- when community members are scared to come closer to PLHIV and sit next to them and share food, bedding and eating utensils.



The research team also developed a model (above) for understanding the settings in which stigma and discrimination occurred.

Experience of stigma and discrimination in Western Highlands

figure numbers refer to the main report

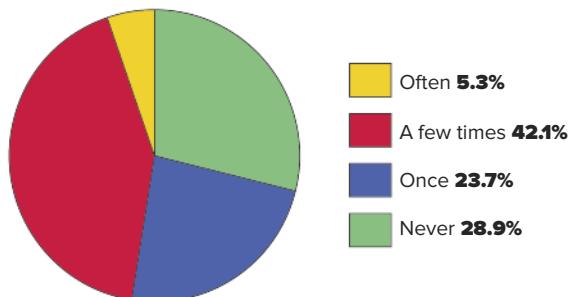


Figure 11 Exclusion from social gatherings/activities

This figure demonstrates that nearly two-thirds of the participants reported that they had been excluded from social gatherings and activities once, often or a few times.

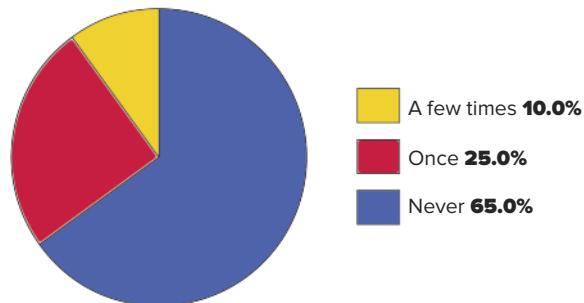


Figure 12 Exclusion from religious activities

This figure shows that more than one-third of respondents reported having been excluded from religious activities in the past twelve months.

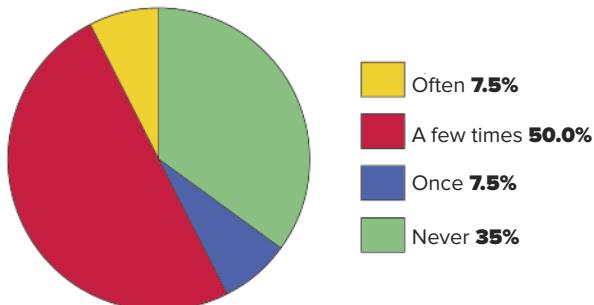


Figure 13 Exclusion from family gatherings

This figure shows that over half the respondents had been excluded from family gatherings often or a few times; although this was self-reported, respondents thought this exclusion was because of their HIV status.

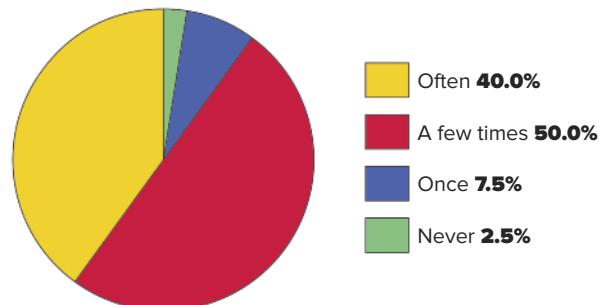


Figure 14 Experience of gossip

This figure shows that nearly all those interviewed said that they had been gossiped about because of their HIV status. The experience of gossip related to HIV status was common amongst respondents.

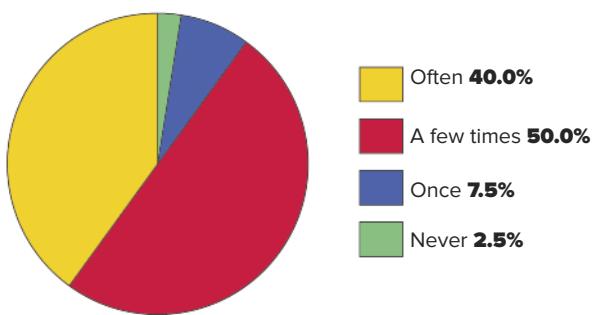


Figure 15 Experience of verbal insult, harassment or being threatened

This figure shows only one person reported that they *had not* been verbally insulted, harassed and/or threatened because of their HIV status. A high percentage of respondents (90 percent) indicated they had been verbally insulted, harassed and/or threatened often or a few times.

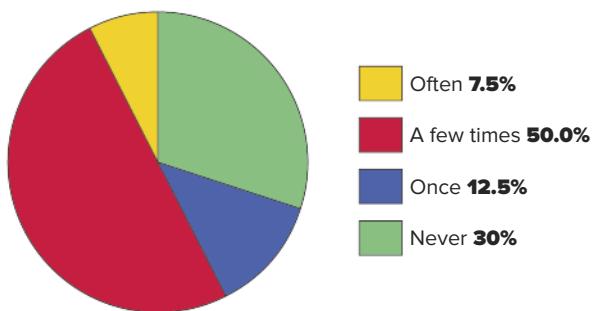


Figure 16 Experience of physical harassment or threat

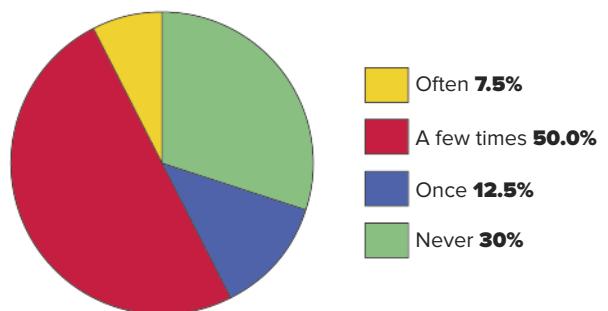


Figure 17 Experience of physical assault

Figures 16 and 17 show that physical harassment, threats or assault were less common than verbal. But still 70 percent reported experiencing physical harassment or threats because of their HIV status.

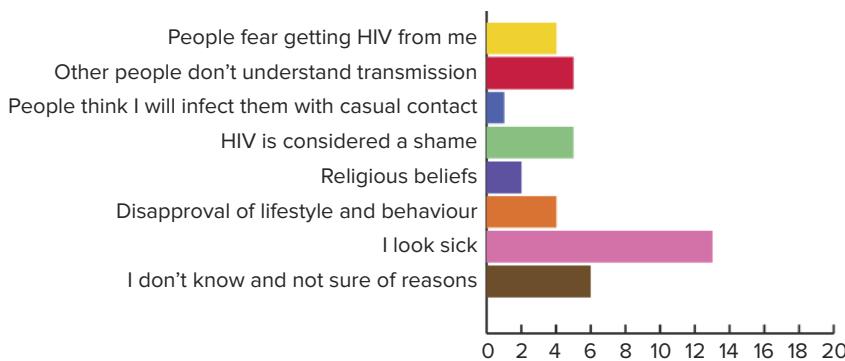


Figure 18 Reasons for occurrence of stigma and discrimination

Respondents were given a range of options to identify the reason for the instances of stigma and discrimination.

Figure 18 shows that while a small number (4) said they did not know or were not sure of the reason for

the discrimination, most were able to identify what they thought was the cause. Five people thought it was due to religious beliefs, but most identified fear and shame, or lack of knowledge about HIV transmission.

Experience of stigma and discrimination in Chimbu

figure numbers refer to the main report

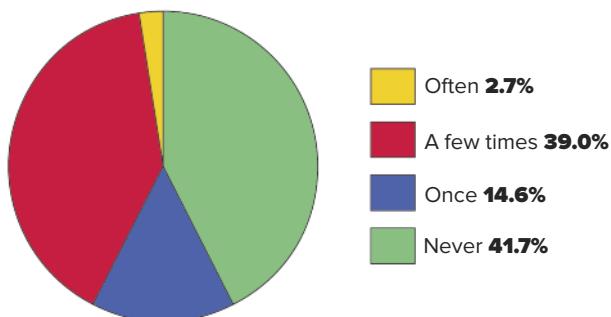


Figure 28 Exclusion from social gatherings/activities

This figure demonstrates that more than half of the participants reported they had been excluded from social gatherings and activities once, a few times or often.

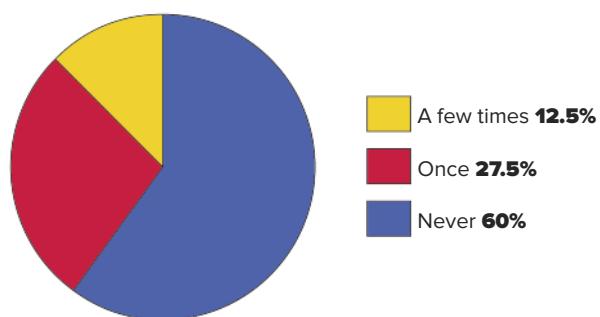


Figure 29 Exclusion from religious activities

This figure shows that 40 percent of respondents reported having been excluded from religious activities once or a few times in the past twelve months.

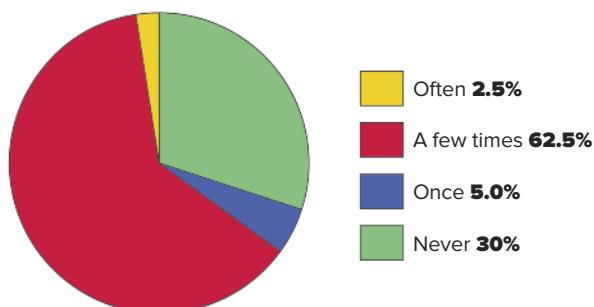


Figure 30 Exclusion from family gatherings

This figure shows that more than two-thirds of the respondents had been excluded from a family gathering or event once, a few times or often. All thought this exclusion was because of their HIV status.

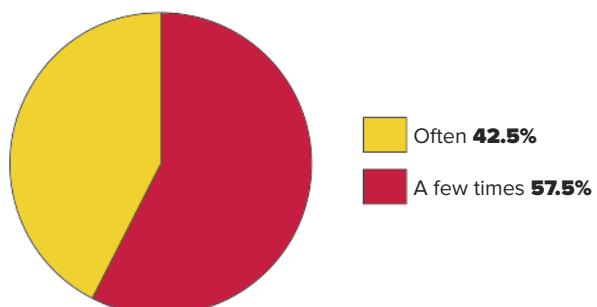


Figure 31 Experience of gossip

This figure shows that the experience of being the subject of gossip (reported as relating to HIV status) was reported by all respondents, that is why the words 'tok baksait' seem to be so important in the actual impact on PLHIV. The experience of feeling gossiped about, or indeed being gossiped about, is reported as a very negative experience and is a key feature of what it means to experience stigma and discrimination in PNG.

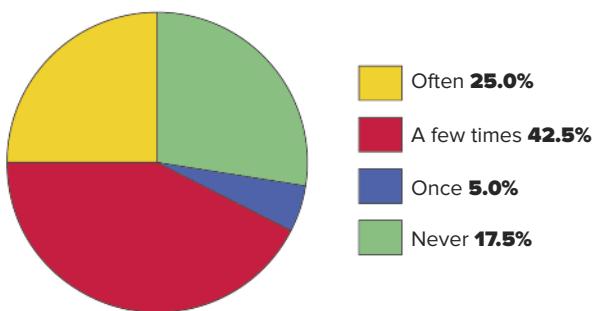


Figure 32 Experience of verbal insult, harassment or being threatened

This figure shows, more than two-thirds of respondents reported that they had once, a few times or often been verbally insulted, harassed and/or threatened because of their HIV status in the previous twelve months.

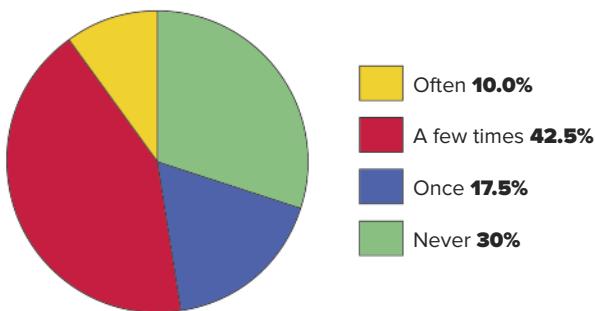


Figure 33 Experience of physical harassment or threat

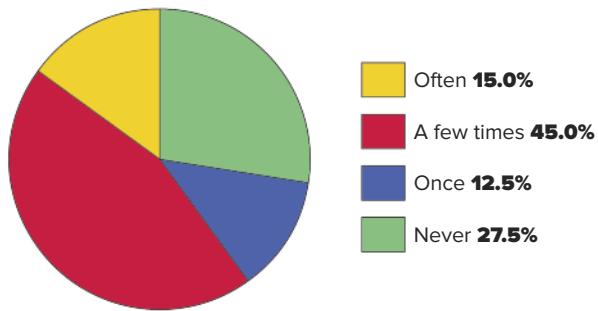


Figure 34 Experience of physical assault

Figures 33 and 34 show that physical harassment, threats or assault because of HIV status were common. Almost two-thirds of respondents have been physically harassed, threatened or assaulted because of their HIV status. The question of physical harassment, threats or assaults generally – due to community life or gender violence, for example – were not specifically explored in the survey, although information was provided on these matters in some of the interview data.

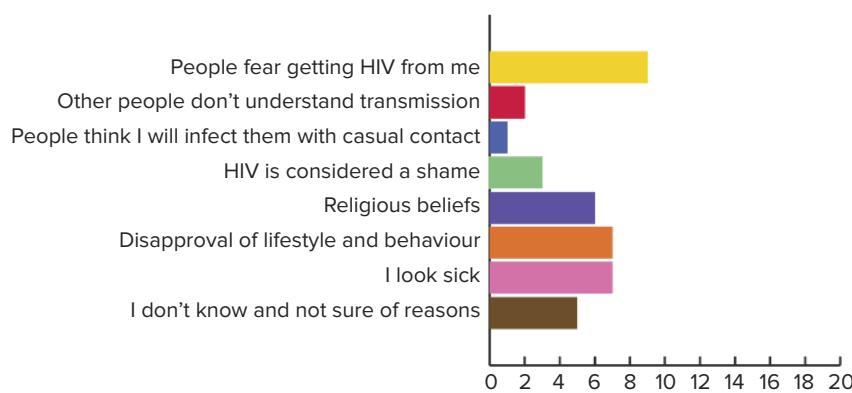


Figure 35 Reasons for occurrence of stigma and discrimination

Respondents were given a range of options to choose as to the reason for instances of stigma and discrimination.

Figure 35 shows fear of people with HIV and misunderstandings to do with HIV transmission were the main reasons PLHIV thought others stigmatise and discriminate against them.

Papua New Guinea is a nation based on relationships; we have large networks of extended families and clans as well as our friendship networks and thus it is inevitable that we will have friends or family members who are living with HIV. Unfortunately, when the early diagnoses of HIV were being made in the 1980s and 1990s, HIV/AIDS was labelled 'gorere dikana'/'siknogut' ('bad sick') rather than another STI. Very quickly, fear, shame, blame and all the social processes that contribute to stigma and discrimination created difficulties in responding to a complex but manageable disease.

It is so important to reach the relationship networks throughout Papua New Guinea so it is understood that HIV does not kill people but stigma can kill and knowledge and compassion can prevent many unnecessary deaths. This report captures just some of the wisdom, knowledge and experience of a small sample of PLHIV and their health providers and caregivers in just two provinces of our diverse nation. I trust that serious note will be taken of this report and its recommendations and that it will be the beginning of more studies to build a repository of knowledge and technical expertise that will bring positive changes and reduce to zero our tolerance of stigma and discrimination in our HIV response realities. The strategies and legislation exist already; it is now time for a concerted effort to fully understand and change the realities. I encourage government, NGOs, the private sector and our development partners to help extend this stigma index research to help change the reality of stigma that still exists for PLHIV in Papua New Guinea.

I congratulate all organisations and individuals who contributed to making this initial PNG Stigma Index Research a reality.

Carol Kidu DBE
Founder, PNG Parliamentary Committee on HIV
Member, Global Commission on HIV and the Law