

**‘Pipel I stap wantaim HIV Stigma Index’**

# **HIV-related Stigma and Discrimination and Human Rights in Papua New Guinea**

**A REPORT ON THE APPLICATION OF  
THE HIV STIGMA INDEX IN THE WESTERN  
HIGHLANDS AND CHIMBU PROVINCES**

**Dr John Rule and Don Liriope**

**JUNE 2016**

**IGAT HOPE INC.** 

## **DEDICATION**

This report is dedicated to the memory of Don Liriope, a passionate advocate for the rights of people living with HIV/AIDS in Papua New Guinea. Don wanted to see an end to the stigma and discrimination against people like himself in PNG and he worked hard to achieve this aim during his life.

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## ABOUT THE AUTHORS

**Dr John Rule** has a background in building community organisations and community education. He has experience in consultation and program development across a wide variety of health and social programs in Australia and the Asia-Pacific region. His recent publications have been in the area of human resources for health. John has degrees in economics and education and completed a PhD through the University of Technology, Sydney in 2006. He currently holds an Associate Lecturer (Conjoint) position with the School of Public Health and Community Medicine, Faculty of Medicine at the University of New South Wales. He was formerly International Programs Manager and Deputy Director of the National Association of People living with HIV Australia.

**Don Liriope** was the Stigma and Discrimination Officer at Igat Hope, the national organisation representing PLHIV in Papua New Guinea. As part of that role, he represented the interests of PLHIV in some regional forums, including presenting a preliminary report on the stigma research at a workshop conducted at the Australian National University titled Sexualities, Sexual Rights, and HIV in Papua New Guinea and the Pacific held in July 2012. He represented PLHIV on the National AIDS Council Research Advisory Committee until the time of his death. Don was also a founding member of the Kapul Champions in Papua New Guinea and held the position of vice-president in the organisation's first constituted board.

## **What is stigma?**

‘bagarapim ol narapela manmeri’

‘pasin blo rabisim ol narapela manmeri’

‘tok basait long ol narapela manmeri’

## **What is discrimination?**

‘wokim pasin nogut long ol narapela manmeri’

‘mekim nogut long manmeri’

**Trying to understand other people means destroying the stereotype without denying or ignoring the otherness.** (Eco 2013 p18)

**When people refuse to accept stigma and mobilise to ameliorate suffering, real-world differences within and across cultures will become increasingly important; here lies the future.** (Herdt 2001 p148)

**. . . 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 . . .** (Wolff 2013 p39)

## ACRONYMS AND ABBREVIATIONS

|           |  |
|-----------|--|
| ADB       | Asian Development Bank                                   |
| AIDS      | Acquired Immunodeficiency Syndrome                       |
| ART       | antiretroviral therapy                                   |
| ARV       | antiretroviral   |
| AusAID    | Australian Aid and Development Agency                    |
| CBO       | community-based organisation                             |
| FBO       | faith-based organisation                                 |
| GIPA      | Greater Involvement of People living with HIV/AIDS       |
| GNP+      | Global Network of Positive People                        |
| HAMP Act  | HIV and AIDS Management and Prevention Act               |
| HCWs      | health care workers                                      |
| HIV       | human immunodeficiency virus                             |
| HIV+      | HIV-positive   |
| Igat Hope | translation: 'I have/we have/there is' hope              |
| IHI       | Igat Hope Incorporated                                   |
| MSM       | men who have sex with men                                |
| NACS      | National AIDS Council Secretariat (PNG)                  |
| NAPWHA    | National Association of People Living with HIV Australia |
| NCD       | National Capital District (PNG)                          |
| NDoH      | National Department of Health (PNG)                      |
| NGO       | non-government organisation                              |
| PAC       | Provincial AIDS Council                                  |
| PLHIV     | people living with HIV                                   |
| PMTCT     | prevention of mother-to-child transmission               |
| PNG       | Papua New Guinea   |
| SOPs      | standard operating procedures                            |
| STIs      | sexually transmitted infections                          |
| UNGASS    | United Nations General Assembly Special Session          |
| UNAIDS    | Joint United Nations Programme on HIV/AIDS               |
| UNDP      | United Nations Development Programme                     |
| VCT       | voluntary counselling and testing                        |



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## FOREWORD

I feel privileged to have been asked to comment on the HIV-related Stigma and Discrimination and Human Rights in Papua New Guinea research study. I congratulate and highly commend our dedicated and passionate advocates for the rights of people living with HIV/AIDS in Papua New Guinea, the late Helen Samilo and the late Don Liriope for their roles in bringing this important study to fruition. They wanted to see an end to the stigma and discrimination against people like themselves in PNG. I also highly commend Dr John Rule for bringing together the results of this research into a very readable and useful research report.

This report is an extremely important document for providing an evidence base for our nation's response to HIV and I hope it marks the beginning of a very necessary ongoing process to extend the research to all provinces in Papua New Guinea. It would be inappropriate to extrapolate the findings of this research to the total nation because of its limitations in terms of geographical location and in terms of total number of interviewees. However, I encourage you to read the report in detail – the background information; the research methodology and findings. The five main recommendations are important and do not miss the Appendix, which I personally found very interesting and indicated other areas of needed research to inform a comprehensive response to HIV in Papua New Guinea.

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 PLHIV. 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*

## EXECUTIVE SUMMARY

This report covers research conducted on HIV stigma and discrimination using the Stigma Index in the Papua New Guinea provinces of Western Highlands and Chimbu\*. The research was funded by a grant from the National AIDS Council. When Igat Hope 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. In future, the hope is to gather comparable data from other regions in PNG. Despite the fact that the overall project aims have not yet been achieved, the data contained in this report provides useful information that can be considered as work continues in PNG on HIV-related stigma and discrimination and human rights.

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 information will not only help Igat Hope develop programs, it will be useful to other agencies and organisations, including health care providers developing their own responses to the vexed problems of stigma and discrimination experienced by people living with HIV 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.

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

## **What was our aim?**

We wanted to provide data on how stigma and discrimination create barriers to accessing services and how they impede the scaling-up of delivery of ART in PNG. We also wanted to detail the levels of stigma and discrimination faced by PLHIV in the different provinces and regions.

There are differing experiences of PLHIV based on gender, sexuality or gender identity. We 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.

We thought the Stigma Index would be a useful tool to identify those situations that created heightened risks for PLHIV and, if possible, develop policy and programs to reduce this risk. We know stigma and discrimination prevent people from testing and accessing treatments, so we aimed to gather information about the ways in which the persistence of stigma and discrimination inhibits and undermines effective prevention strategies. Our aim is to provide an evidence base for program planning and interventions in response to HIV-related stigma and discrimination in PNG

## **How did we set about finding out?**

We took the view that this was Phase 1 of a larger project. The Stigma Index tool, which was a structured interview, was translated into *Tok Pisin*. A research team of PLHIV was selected and trained in basic research methods. A convenience sample was set up by inviting PLHIV to take part in interviews through various health service and community sites. A total of 80 interviews were conducted, 40 in each of the two provinces of Western Highlands and Chimbu. Interview data was re-checked in Port Moresby by the interview team, under the supervision of a co-principal investigator as part of quality assessment.

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.

## What did we find out?

Descriptive demographic data has been collated. 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 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.
- A high percentage 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 that were



negative 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, NGOs and 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 are reported in detail in Part 5 and 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.

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 the data, which is detailed more fully in Part 5, 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.

## **What does this mean and where to from here?**

This research project is significant because it was managed by Igat Hope and by people living with HIV. It is building community knowledge and engagement of PLHIV as it proceeds, directing attention to the ways in which stigma is being experienced by PLHIV in a range of contexts.

Recommendations provided in this report are tentative, being based on findings in two provinces only. A summary of the areas identified where action can be taken is provided below and expanded in Part 6.

### **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 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.

# PART 1

## Introduction

### **The Stigma Index used in international contexts**

The People Living with HIV Stigma Index was initiated in 2005 (GNP 2008 p5) in recognition of the fact that HIV-related stigma and discrimination is an international problem that inhibits effective HIV prevention and treatment programs. The index is a tool used by, as well as for, people living with HIV and their networks. The GIPA Principle (Greater Involvement of People living with HIV and AIDS) has also been applied in the use of the index. The index's survey tool has been designed and developed by the Global Network of People Living with HIV/AIDS (GNP+), the International Community of Women Living with HIV/AIDS (ICW), the International Planned Parenthood Federation (IPPF), and the Joint United Nations Programme on HIV/AIDS (UNAIDS). UNAIDS has also supported the development of the index and assisted its roll out in many countries. Groups can then use it to understand experiences of stigma and discrimination in their localities. GPN+ argues the use of index over time will be instrumental in increasing the collective understanding of stigma and discrimination and detecting changes and trends in HIV-related stigma and discrimination.

The aim of the initiative is to:

- document various experiences of PLHIV within a particular community or country with regard to HIV-related stigma and discrimination
- compare situations of PLHIV in one country or across different countries with respect to a particular issue
- measure changes over a period of time to ascertain if conditions for PLHIV have improved or worsened with regard to stigma and discrimination
- provide an evidence base for policy change and programmatic interventions, and
- use the data generated as a local, national and global advocacy tool to fight for improved rights for PLHIV.

The benefits of the index for those using it go beyond collecting much-needed evidence; it is intended to be a catalyst for creating and fostering change in the communities in which it is used, empowering PLHIV, their networks and communities in the process.

In each country the implementation of the research project would be different but consistent with the principles and general aims of the Stigma Index. The number of people interviewed would vary, according to what was possible within each country. As well, the outreach and composition of responses from different groups (such as men who have sex with men, sex workers, injecting drug users and other vulnerable groups) would vary according to the circumstances of each country.

Worldwide by September 2013, more than 1300 PLHIV had been trained as interviewers and a further 45,000 PLHIV in 50 countries had been interviewed. The index questionnaire has been translated into 54 languages. For more information on the Stigma Index, click [here](#).

## **The Stigma Index adapted for use in PNG**

It is widely acknowledged that HIV-related stigma and discrimination remain barriers or hurdles to effective prevention, treatment, care and support programs in PNG. There is ample anecdotal evidence and some research suggesting that the experience of stigma and discrimination discourages people from presenting for testing, or, upon diagnosis, not returning for follow-up; in short, stigma and discrimination create barriers to accessing health services (Kelly et al 2009, Gibbs and Mondu 2010).

Reference to stigma and discrimination has been made in successive PNG national strategies and has been prioritised for attention in a range of consultations and reports. In PNG, the response to HIV has been conceptualised as 'everybody's business' and so the problems created by HIV-related stigma and discrimination should be considered 'everybody's business'. At a program delivery level, and as outlined in national plans, Igat Hope, the organisation representing PLHIV throughout PNG, has been tasked with furthering an understanding of the impacts of stigma and discrimination. Igat Hope has been identified as the organisation for developing and advising on a range of strategies and interventions that would assist in resolving problems of stigma and discrimination at both the local level and nationally.

In hearing stories of stigma experienced by HIV-positive people, the PNG Independent Review Group on HIV/AIDS (Aggleton 2011), clearly noted that

stigma continues to be a real barrier to HIV prevention. Its report determined that the index needed to be finalised and implemented with speed so that findings could be incorporated into program responses.

The potential use of the Stigma Index tool was discussed at the first national conference for PLHIV in PNG in 2009. Helen Samilo, a staff member of Igat Hope, attended a meeting in Bangkok on international efforts to implement the Stigma Index. The Igat Hope board supported the creation of a special position within the National Secretariat specifically to implement the Stigma Index in PNG and Don Liriope was employed in this role. The second national conference for PLHIV in PNG in 2010 endorsed efforts to implement the index in PNG.

The index was seen as a useful instrument to try to apply in the PNG context, although it had always been the view of Igat Hope that the index would need to be adapted and amended for PNG. This adaptation was not just a matter of translation into the relevant languages, but would also take into consideration the preparedness of local communities of PLHIV to work with the survey instrument. The implementation of the index applies a rigorous methodology and is also a way of enabling PLHIV to take a more active role in responding to the HIV epidemic in PNG by managing a significant national research project.

Igat Hope was determined at the outset to ensure the index's implementation would be owned by all partners in the HIV response. While some countries completed nationwide surveys within one year, it was not possible in PNG, partly due to funding constraints but also because the methodology was always intended to be continuously subject to change as the situation demanded.

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 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.

## **Implementation in the Highlands Region**

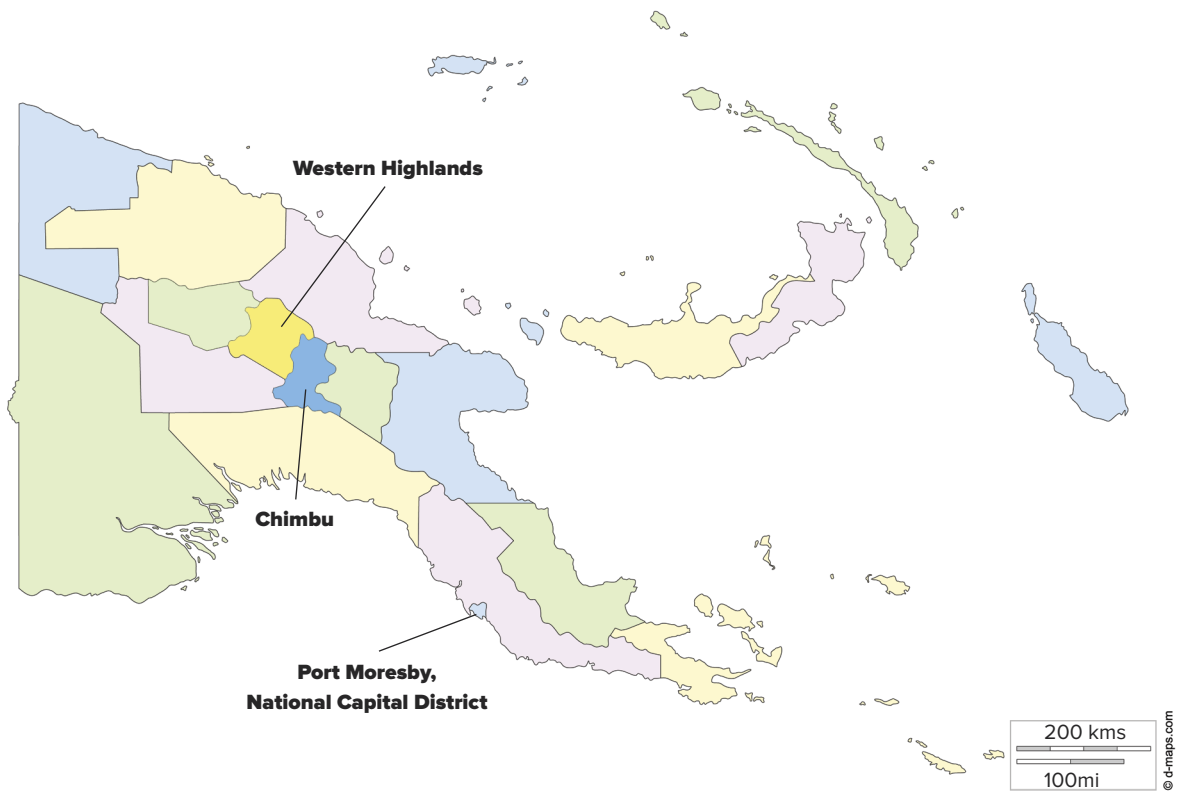
Estimates and surveillance data available at the time the project commenced showed that the Highlands Region had the highest HIV prevalence rate in PNG (NDoH and NACS 2006) and therefore was targeted as the first and most important place to implement the project. Within this region, the Western

Highlands province had the highest prevalence rate for HIV infection in PNG and Chimbu had the lowest (NDoH and NACS 2007). The pilot project would therefore target an important point of intervention and include a low-prevalence and a high-prevalence province within the same region.

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.

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.



Map 1 **Map of Papua New Guinea**



## PART 2

# Background

### **Stigma and discrimination: the PNG research**

The Systematic Literature Review of HIV and AIDS Research in PNG (King and Lupiwa 2007-2008) noted there were few studies focused solely on people living with HIV (p34). This is despite significant reporting of the ways in which people living with HIV have been violently mistreated and shamed (Hammer 2008, Eves and Butt 2008, Hayley 2010). The Systematic Literature Review identified that of those studies that did report on stigma and discrimination, the perspectives reported were those of health care workers (HCW) or study respondents' attitudes towards people living with HIV, not from the perspective of PLHIV themselves.

One study on the experiences of PLHIV showed there was limited support for those experiencing stigma and discrimination to pursue their legal rights and that, although there have been some changes in community attitudes, there are still many PLHIV (especially women) reporting verbal and physical abuse (Kelly et al. 2009). This study identified research in other countries in the region, in relation to stigma and the challenges PLHIV face, but noted that the data available in PNG needs to be further developed; and that further research needs to be carried out from the perspective and experiences of PLHIV.

Any study of stigma and discrimination must take into account the context of high levels of gender violence in PNG (Lepani 2008, Jolly 2012, Stewart 2012). In trying to understand the level of violence directed towards PLHIV it is necessary to recognise a gender system in PNG that imposes violence on women generally and especially women involved in sex work (Kelly et al 2011). Jolly has noted that “. . . gender violence is often seen as a customary, collective practice in PNG – em pasin blo ol – (TP: that's their way) and as normal – em nomol ya – (TP: that's normal)” (2012. p3). Macintyre (2012) has argued that men are seen as 'entitled', and assume the right to be violent towards women, in any number of social contexts.

Gibbs (2009, 2012) and Gibbs and Mondu (2010) have reported on the Chimbu area, noting that in some awareness programs and interventions — initiated through church networks — have had a positive impact and

potentially limited overt discrimination in community settings. However, they also noted that stigma remains pervasive and has dire consequences in some community settings. Gibbs describes how illness is often linked with practices of sorcery and witchcraft; and how violence and deep misunderstandings continue to occur in relation to HIV, especially fear of sickness, with HIV often at the centre of these misunderstandings.

Reid has reported on “. . . stories of goodness, of good practice” (2010a, 2010b) in relation to the epidemic in PNG but also notes the horrific stories of stigma and discrimination experienced by women, by children whose parents have died from HIV, already marginalised groups of men who have sex with men, transgendered people and sex workers, all of whom have very little support in their own community contexts. Hammer (2008, 2010) has written of the problems created by religious officials and ill-fitting ‘western practices of public health and epidemiology’; stigmatisation and the violence done to PLHIV feature in much of his writings. MacPherson and Rule (2010) have reported on the Inaugural PNG National People living with HIV Conference where many participants spoke personally about their direct experiences of stigma and discrimination, asking for support to redress their losses and problems.

Various PNG UNGASS progress reports, successive National HIV Strategies and the Report of the Commission on AIDS in the Pacific 2009 have all noted that stigma and discrimination limit the effectiveness of controlling the spread of HIV. As the PNG national HIV research agenda continues to develop, understanding the direct and lived experience of PLHIV and the impact of stigma and discrimination on accessing care and treatment and halting the spread of HIV is an area of priority.

Previous studies in PNG, as noted above, 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 themselves. This research attempts to resolve the problem of PLHIV being ‘spoken about’ or being the ‘objects of research’. Because the project was initiated by PLHIV, and because the results are interpreted by PLHIV, PLHIV are not positioned as objects but are actively engaged in research about their own conditions and needs.

This research model actively engages PLHIV in the design, application and analysis of the research, and in this way, positions 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.

## **Stigma and discrimination: the international literature**

Brown, Macintyre and Trujillo (2003) reviewed 22 interventions explicitly designed to reduce HIV stigma in fifteen developed and seven developing nation settings. The majority of interventions reviewed included messages that PLHIV were not to be blamed for their infection and should be accepted into the community. Review results suggested some stigma-reduction interventions appeared to work, at least on a small scale and in the short-term, but many gaps remained. For example, the long-term impacts of interventions need to be understood and specific intervention strategies to support HIV positive women, MSM and sex workers need to be implemented and monitored.

A UNAIDS Report (2005) documented some examples of successful case studies and programs addressing HIV-related stigma. However, the authors noted that the root causes of AIDS-related stigma also need to be dealt with and these included, social inequality, gender inequality, inequalities of sexuality and inequalities of wealth. It was concluded that stigma-reduction approaches at the community level were important but that it was essential they be accompanied by specific anti-discrimination measures, the promotion of human rights, and the development of legal mechanisms for individuals to seek redress for HIV-related discrimination. Kippax and Holt (2009) noted that most published research focused on the social and political drivers of the epidemic, or, were an assessment of biomedical and behavioural interventions and responses. Overall, there is still very little published literature on the stigmatisation of HIV.

## **Stigma and discrimination as social processes**

Scambler (2009) notes that many current interventions to reduce stigma remain individualistic, and do not concentrate on the wider social processes that set up the conditions for discrimination to be enacted. So in our analysis we draw on the conceptual work of Link and Phelan (2001) who describe stigma and discrimination as social processes. Parker and Aggleton (2003) have sought to distinguish and emphasise the role and purpose of stigma in sustaining and reinforcing the social order, in particular, marginalisation and oppression. They argue that stigma can only be understood in relation to broader notions of power and dominance, causing some groups to feel

devalued and others to feel superior, reproducing social inequality and exclusion.

Therefore, we are interested in understanding exactly how exclusion occurs in the PNG context. We want to know

- why PLHIV are devalued and excluded
- how PLHIV are devalued and excluded
- why PLHIV are dehumanised.

We want to know so change can be made in the social processes that continue to stigmatise and devalue the lives of PLHIV. PLHIV will have to be part of that change but others will also have to change. Attitudes, structures and social organisation will have to change. Culture cannot be static in the social change process, conceptions of culture will necessarily be challenged — a claim that was clearly articulated by Herdt (2001) and supported by the recent writings and useful contemporary theorisations about ‘otherness’, see, for example, Eco (2013).

The question of how to understand stigma remains problematic and, as noted by Herdt (2001), part of the difficulty is that outsiders may see stigma operating differently or in a different dimension to those who are inside the situation. Through implementing the Stigma Index in PNG and by engaging local PLHIV in this work we hope to work ‘within’ the situation rather than to impose outsider understandings of social arrangements. We agree with Herdt that studying how stigma operates is essential, that this work will necessarily be cross-cultural, and in the long-term we expect this work to enhance prevention efforts and to find ways to respond to what he describes as “. . . the insidious nature of stigma and social exclusion”.

## **Why a human rights approach is important in PNG**

In 2008, the first national conference of PLHIV from across PNG was held over four days with nearly 100 PLHIV attending the first day. Nominated PLHIV representatives came from each of the 19 provinces. The first day included a session with a brief presentation from each of the regions. We attended the summit and were very surprised by the number of representatives who were using the concept and the language of human rights in their presentations. Some PLHIV in PNG are quite articulate about a human rights approach.

We have observed what Jolly (2012) observed during a rally against gender violence in Port Moresby in March 2006, namely that ‘the global vocabulary of human rights’ has been taken up by those seeking change in PNG. We also observed along with Stewart (2012) and Jolly (2012), that often the discourse of human rights is dismissed as a set of foreign values and that the achievement of human rights remains fragile. We take the position argued by Wolff (2013) that the progressive realisation of health and human rights should not be an excuse by governments to do nothing. The right to human health is well established in international law and is the correct target to aim for.

We support the arguments made by Farmer (2004) that it is necessary to

- track human rights violations and monitor the efficacy of interventions
- seek health improvement and better services and equity for those who are suffering
- carefully document and research problems and interventions.

Through the application of the HIV-related Stigma Index and stigma audit in PNG, non-government organisations and civil society actors — such as Igat Hope and PLHIV in PNG — have an important and central role to play working with a human rights approach. The rights of PLHIV are inextricably linked to human rights and the human right for health.

The UNAIDS-sponsored seven-country consultation in the Pacific identified national laws and policies that need review and/or reform, including in PNG (Mesurier 2013). PNG is one of the countries where it is recognised that good practice relating to human rights and rights-based HIV responses are needed. The findings from the Stigma Index can contribute to these policy discussions and reform processes.

## **The relevance of the HAMP Act in PNG**

Papua New Guinea’s HIV Management and Prevention Act (HAMP Act) was certified in 2003 and came into effect in October 2004. The act makes it illegal “to deny a person access, without reasonable excuse, to a means of protection from infection of himself or another by HIV,” including information about the disease, condoms, and other items. The act also makes it illegal to discriminate against anyone because he or she is “infected or affected by HIV/AIDS,” unless “the discrimination is no more detrimental than discrimination on the ground of having another life-threatening medical

condition.” For more information on the HAMP Act, click [here](#).

But how does the HAMP Act protect those infected or affected by HIV or AIDS? The act makes it unlawful to discriminate against anyone on the grounds that he or she is infected or affected by HIV or AIDS. The discrimination must be to the detriment of that person. The HAMP Act also sets out a number of areas in which discrimination might be found, including employment and contract work; partnerships; industrial and professional organisations and clubs; education and training; persons in custody; the provision of accommodation; surveillance and access to goods, services and public facilities. The act makes it unlawful to stigmatise anyone on the grounds that he or she is infected or affected by HIV/AIDS. The term ‘stigmatise’ is defined and includes “to vilify or incite hatred, ridicule or contempt against a person or group on the grounds of an attribute”. Means of stigmatisation include publication and communication, which extends to gestures and actions.

At the second national summit for PLHIV in PNG in 2011 there was a theme session covering the HAMP Act. Delegates were presented with information from UNAIDS and legal representatives, however, it was agreed that while the act was an important tool for PLHIV in PNG, to date it has not been well used. There were statements of frustration made by participants that the act had not been used to protect people with HIV from discrimination; instead, it was only being used against PLHIV. Participants asked, “What is the point of having this act if we are never able to use it to help us?” To overcome this problem, delegates thought more people should be made aware of the act and that PLHIV needed to be assisted to use it. It would also be important to find qualified people to provide legal representation for PLHIV wanting to use the HAMP Act.

## PART 3

# Methodology and data management

### The Stigma Index and the research team

As noted in Part 1, the PLHIV Stigma Index was to be used as an investigation tool into part of the social reality of PLHIV in PNG, that part represented by 'stigma' and 'discrimination'. We say that stigma and discrimination are relational words, and that they do not refer to a persistent and immutable reality but are words that make reference to how people relate to each other. We emphasise the possibility that people may learn to relate differently to each other, in other words, stigma and discrimination need not persist.

The Stigma Index uses a structured interview. The first section of the interview asked demographic questions, such as age and gender identification. Each of the subsequent sections of the interview asked questions about different hypothesised dimensions of the social experience of stigma and discrimination. Within each section the questions recorded one or more of the indicators of that dimension. Those dimensions were:

- experience of stigma and discrimination from other people (Section 2A of the interview schedule);
- access to work and health and education services (Section 2B);
- internal stigma (the way people feel about themselves) and fears (Section 2C);
- rights, laws and policies (Section 2D);
- effecting change (Section 2E);
- testing/diagnosis (Section 3A);
- disclosure and confidentiality (Section 3B);
- treatment (Section 3C);

- having children (Section 3D);
- problems and challenges (Section 3E).

The index, as used in PNG, was translated into *Tok Pisin*. An adaptation was made to include an open-ended question asking respondents to describe in their own words their experiences of living with HIV in the last 12 months. Another question was added, allowing respondents to nominate whether they wanted to be involved in another in-depth follow-up interview with the research team. This additional information was recorded as Tables 1 and 2 in the next part of the report.

The team piloted the Stigma Index questionnaire in Port Moresby in September 2011, and agreed to use the translated document without significant changes. One problem encountered was that the survey only asked for experiences in the last 12 months and this was felt to be a limitation. The research team agreed that if there were lessons learned from the implementation of Phase 1 in the Highlands Region, then changes could be incorporated as the index is implemented in other regions.

The selection criteria for being a member of the research team and the details of the selection were managed by the co-principal investigator and Igat Hope's Executive Director. Those criteria included

- being a person living with HIV
- the person had to be recommended by a local PLHIV network and endorsed by the provincial AIDS Council
- the person needed to be schooled to year 10 with work experience or to year 12 and to be able to communicate in tok-pisin, English and some other *Tok Ples*
- the selection criteria also included recruiting individuals who identified as MSM, sex workers or transgender so that the team would include the diversity of key affected populations.

Igat Hope identified 13 PLHIV representing the four different regions of PNG meeting these criteria. The research team was gender-balanced and represented the diversity of the PNG PLHIV population, including people who identified as sex workers, MSM and transgender.



The team members attended sessions on basic research approaches and were provided with an explanation of quantitative and qualitative research. Sampling, data collection, analysis and report writing were covered in the training, as were consent and confidentiality. Training also included discussions of the different methodologies, and noted that the project would be using a convenient sampling method, which enabled the research team to have easy access to interviewees at interview sites such as clinics and hospitals. The training provided an avenue for individuals to share the type of stigma and discrimination they had personally experienced, enabling the team to broadly understand where the stigma may be coming from. Concepts of self or external stigma were discussed and the team was introduced to the Stigma Index survey. Standard operating procedures specific to the PNG context were discussed and the research team finalised questionnaires (both in English and *Tok Pisin*). The initial trainings were conducted by Dr Holly Buchanan-Aruwafa from the National Research Institute in PNG and supported by Maria Nepal from UNAIDS.

Research team members listed their expectations from training as follows.

- To learn more about stigma and discrimination and also how to do research
- To be a role model to the PLHIV and assist in stopping stigma and discrimination
- To learn and know about stigma index and to learn the interviewing process and to be fully equipped with skills and knowledge
- To learn as much as I can and better my knowledge and understanding on what the research is all about, and how to use the research materials
- To learn more to upgrade my knowledge and apply skills
- To develop my capacity in administering the Stigma Index and in interviewing
- To have the knowledge of a researcher and to assist in changing stigma
- To be able to identify the different forms of stigma and discrimination and to know how to handle them. Firstly, because it is in line with my work and, secondly, I am a positive woman and I need to build my capacity to help my peers.

- To learn new things and see other places, stand up to fight stigma and discrimination, to help others to avoid termination of their lives.
- To be able to know proper ways of approaching and communicating with other people, proper ways of using questioning skills during and after an interview; to evaluate what is said from various settings or communities interviewed; and to be certain about the various age groups affected by HIV and related issues.

Training included topics such as basic information on HIV and AIDS, HAMP ACT 2003, gender based violence and HIV, PMTCT, STIs, an introduction to the principles of GIPA and Universal Access to care, treatment and support. Equipped with this kind of knowledge, the interview team would also be able to engage with their peers in an information sharing role, where appropriate, as well as being able to professionally and competently conduct and record the interviews.

After the training the team members reported they had

- consolidated their understanding of the key concepts associated with HIV-related stigma and discrimination
- the skills to implement the questionnaire, and complete the associated forms and agreements that are part of the interview process
- knowledge of how to conduct and record interviews with PLHIV in their community using appropriate methods
- the knowledge and confidence to be able to access the necessary support from the team leader as required.

## **Sampling**

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.

Entry to all research sites was negotiated by the principal investigators through discussions with key personnel. Appropriate authorities and documentation were exchanged for access to the sites. It was agreed that interviewers would be onsite for at least one day and that interviews would take place in locations that protected the confidentiality and privacy of participants.

There was no coercion involved and interviewees were provided with clear information on the nature and scope of the interview, and verbal and written consent was sought and confirmed before interviews began. At the end of each interview, the interviewee established whether the interviewer might need referral information and, if so, they were provided with a copy of the list of local organisations compiled by the research team to assist PLHIV.

Because the interviewers represented a diversity of the PLHIV population — MSM, sex work, transgender and gender balance — the interviewees were matched with the interviewer with whom they felt most comfortable. The co-principal investigator was onsite to manage all logistics and respond to problems that may have arisen.

## **Data management**

Data was managed according to the Standard Operating Procedures (SOP) for the project. A copy of the SOP was lodged with the Ethics Application and approved by the National AIDS Council Research Advisory Committee.

Each interviewee was assigned a unique identifying code. Completed questionnaires were returned to the co-principal investigator onsite for quality review. The investigator ensured that all consent forms and lists containing the names, contact details and unique identifying codes of all interviewees were kept in a safe place arranged for those documents. The co-principal investigator also ensured that all completed questionnaires were kept in a separate safe place for transfer to the database.

A debriefing session was held each day onsite to discuss interviewer experiences. Information from all debriefing sessions was maintained and was used to contribute to the qualitative data analysis.

The SOP included ethical principles for the research team; a code of conduct; a step-by-step interview process; and a detailed description of the roles and responsibilities of research team members.

Data management procedures noted that

- 1** The interviewer will give the completed interview questionnaire, including the consent form to the principal investigator and the co-principal investigator.
- 2** Either or both the principal investigator and the co-principal investigator will then check the data (quality check).
- 3** The data will be given to the data entry operator to enter and then be stored safely.
- 4** It is also the sole responsibility of the principal investigator or the co-principal investigator to
  - 4.1** supervise data collection
  - 4.2** monitor the data on-field and off-field
  - 4.3** ensure storage of the data in the safe place
  - 4.4** maintain security of the data
  - 4.5** manage the data
- 5** After completion of field trips, the data will be transferred to the office safe in the presence of the Igat Hope Secretariat Coordinator or the Finance Officer.
- 6** If and when the data entry operator is ready to enter the data, the principal investigator, co-principal investigator will open the locked safe in the presence of the Igat Hope Secretariat Coordinator or the Finance Officer to release the data for entering.
- 7** Before the data entry operator enters the data, the data entry operator will sign a confidentiality agreement.
- 8** After the data operator has entered the data, the finished questionnaire will be given to the principal investigator or the co-principal investigator to be locked away in a safe place.
- 9** After all data has been entered, the data analyst will analyse the data and write a report of the findings.
- 10** After the report has been finalised, the data will be disseminated to all Igat Hope partners and will be presented in seminars, conferences, workshops and meetings.

## Thematic analysis

Thematic analysis was chosen because it focuses on describing research participants' concepts and beliefs by means of categories that 'emerge from data' (Ezzy 2002 p83). Our data also includes information generated through debriefings with the survey team. The diagrams in Part 5 are an attempt to represent some of the major themes that had emerged. The process of thematic analysis, adapted from Aronson (1994) and Braun and Clarke (2006) was used in this research as follows:

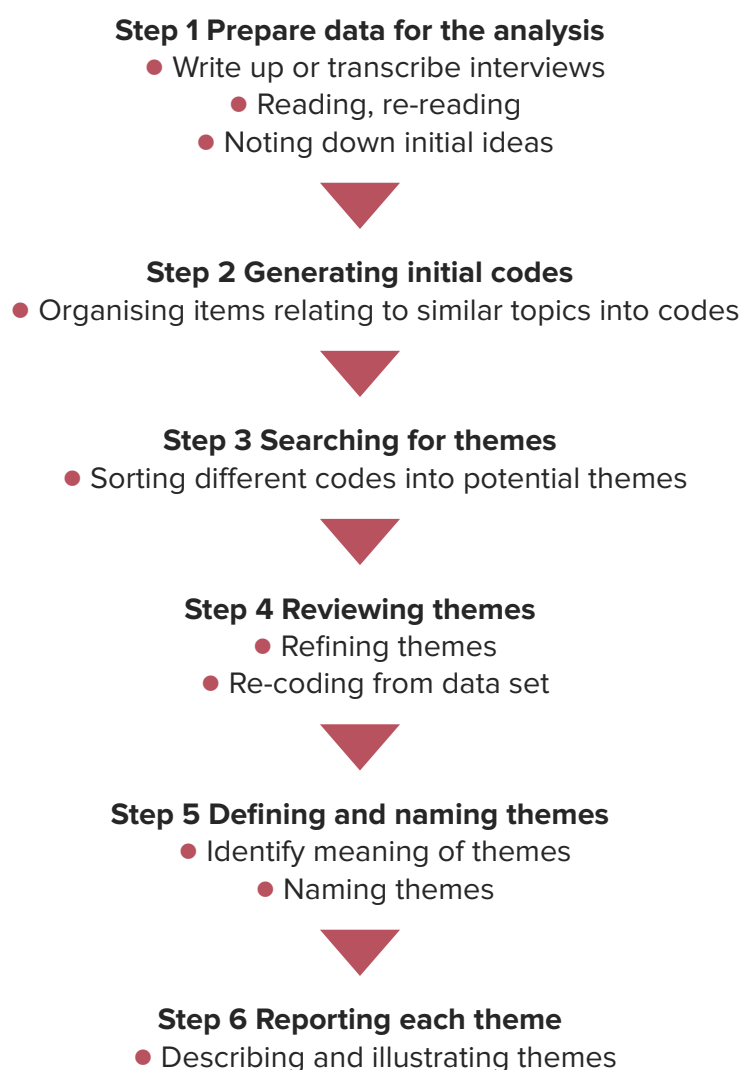


Figure 1 **Process for identifying themes in the research**

## PART 4

# Results

This part includes basic demographic and interview response data. The results are the basis for the thematic analysis about HIV-related stigma and discrimination in PNG. For this report, we have chosen to separate the summaries from Western Highlands and Chimbu as requested by PACS and other agencies originally consulted. The data tabled is presented in the same order as questions used in the survey, which cover the following aspects of PLHIV experience:

- stigma and discrimination from other people (Section 2A of the interview schedule);
- access to work and health and education services (Section 2B);
- internal stigma (the way people feel about themselves) and fears (Section 2C);
- rights, laws and policies (Section 2D);
- effecting change (Section 2E);
- testing/diagnosis (Section 3A);
- disclosure and confidentiality (Section 3B);
- treatment (Section 3C);
- having children (Section 3D);
- problems and challenges (Section 3E).

## Data Summary

# Western Highlands

**Figure 2** shows that 17 males and 16 females were interviewed. A small number who identified as transgender agreed to be interviewed.

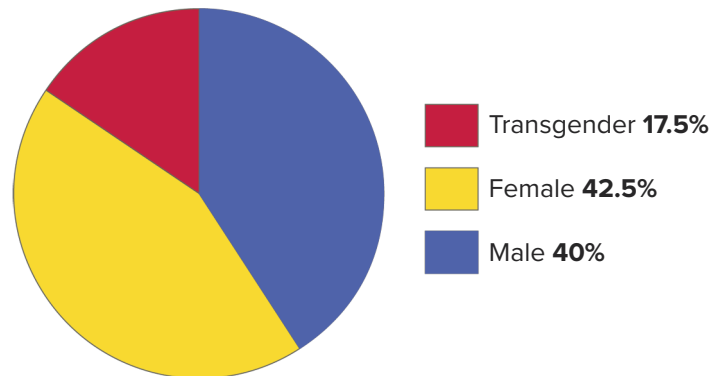


Figure 2 **Gender**

**Figure 3** shows that 18 respondents were aged between 15 and 29 years, 22 were over the age of 30 and none were more than 50 years of age.

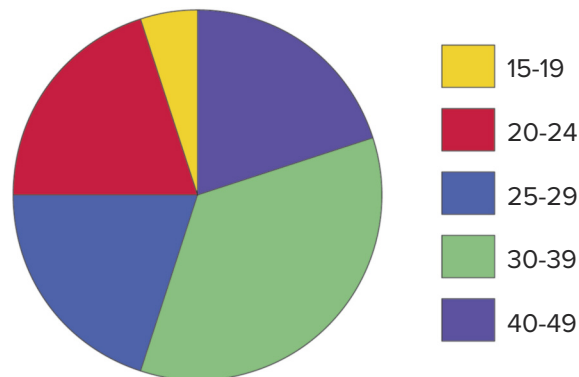


Figure 3 **Age**

**Figure 4** shows that more than 20 people had lived with HIV for at least five years. Thus, the sample represented a range of PLHIV, including those with a recent diagnosis and those who had been living longer with HIV.

When future phases of the research are conducted in other regions and a statistical analysis of the data can be carried out, then it might be possible to explore whether the experiences of stigma and discrimination differ between those recently diagnosed and those who have been living with HIV longer term.

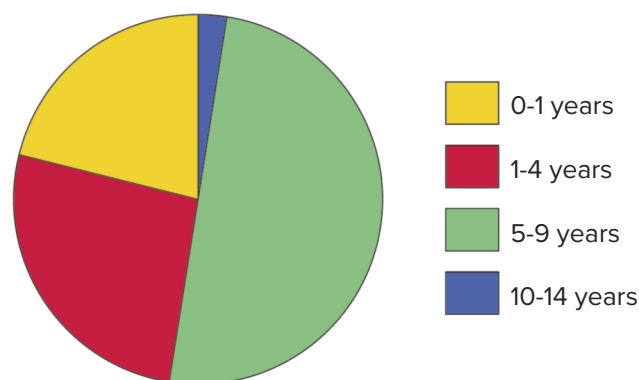


Figure 4 **Recency of diagnosis**

**Figures 5 and 6** give some indication of the length of and relationship status of the respondents. While these are only self-reported, there is no way of triangulating the data for proof of, for example, years spent in a relationship. However, this basic data is initially interesting as it demonstrates, for example, that just over one-quarter participants are in an arrangement of co-habitation or living together. Put another way, nearly three-quarters of respondents live outside a permanent relationship situation. It could be conjectured that this may be because of their HIV status, but further quantitative analysis would be required to make those connections.

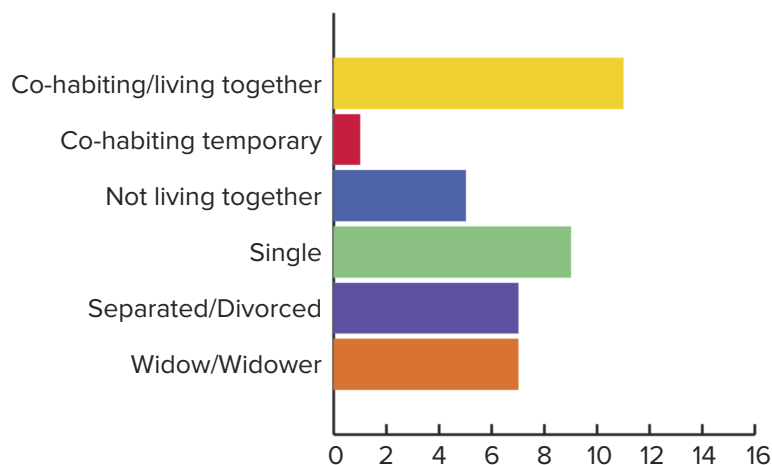


Figure 5 **Relationship status**



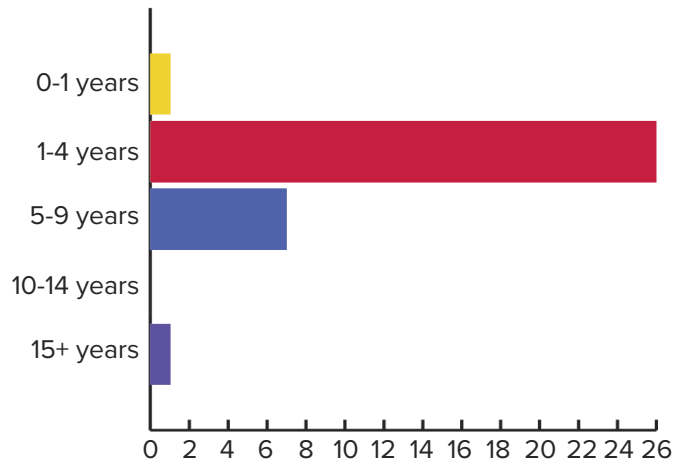


Figure 6 **Years in a relationship**

**Figure 7** shows that nearly all respondents were sexually active. This does have some implications for providing support for PLHIV to disclose their status to sexual partners.

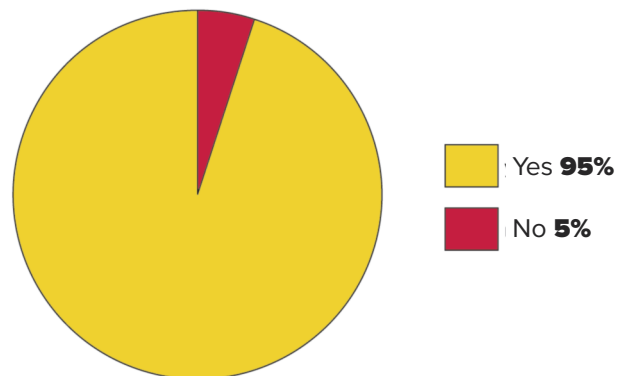


Figure 7 **Level of sexual activity**

**Figure 8** shows that 14 participants identified with the sex worker group and a similar number identified as belonging to no grouping (general population).



Figure 8 **Identification with a group**

Figures 9 and 10 show that one-third of participants had achieved primary school education, a significant number (13) had no formal education and one-third of the participants were in casual employment or part-time employment only.

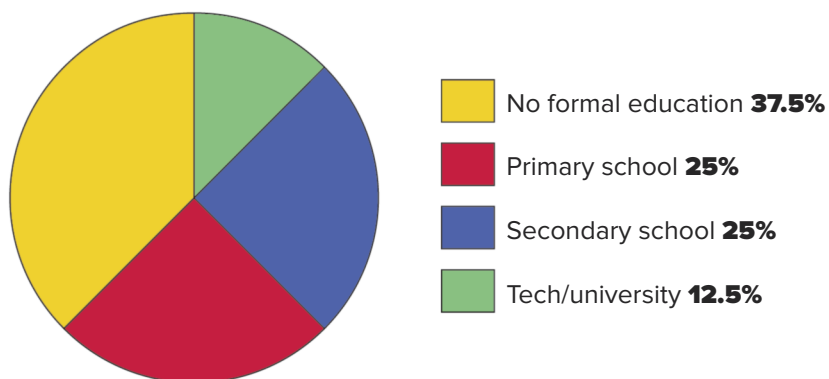


Figure 9 **Education level achieved**

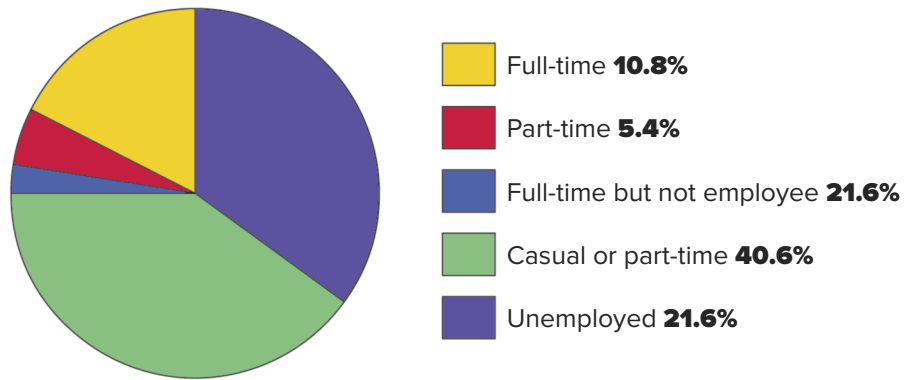


Figure 10 **Employment status**

## EXPERIENCE OF STIGMA AND DISCRIMINATION

**Figure 11** 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.

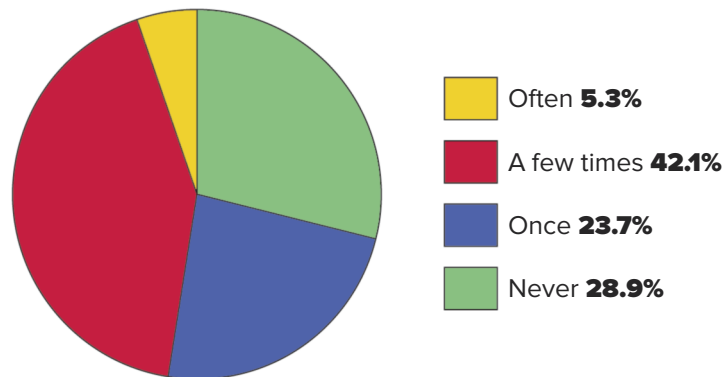


Figure 11 **Exclusion from social gatherings/activities**

**Figure 12** shows that more than two-thirds of respondents reported having been excluded from religious activities in the past twelve months.

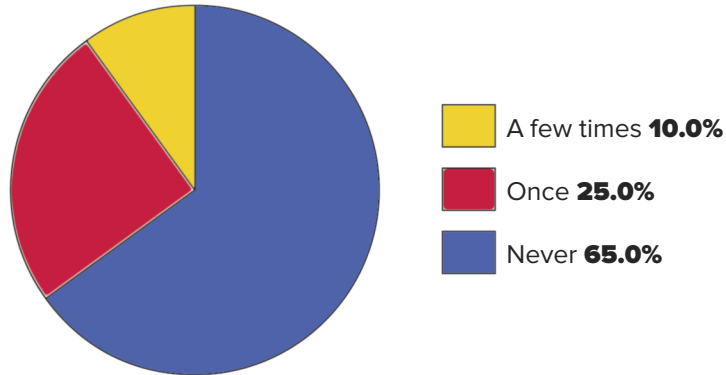


Figure 12 **Exclusion from religious activities**

**Figure 13** 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.

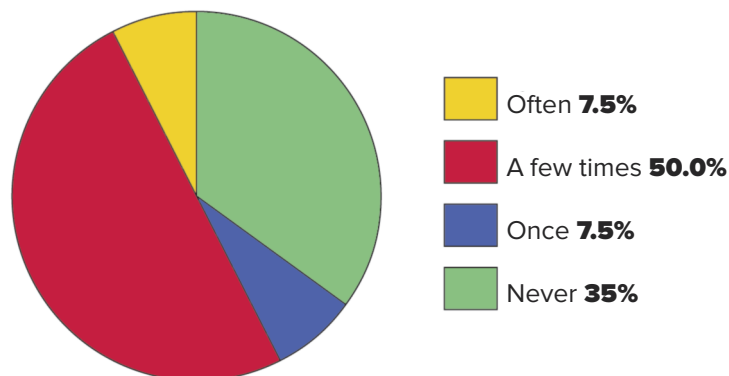


Figure 13 **Exclusion from family gatherings**

**Figure 14** 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.

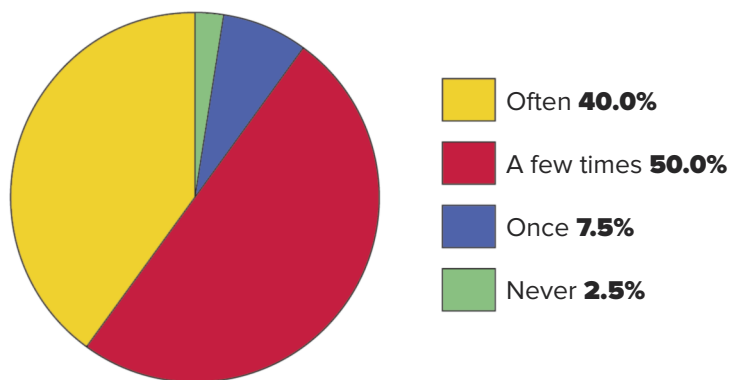


Figure 14 **Experience of gossip**

As shown in **Figure 15**, 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.

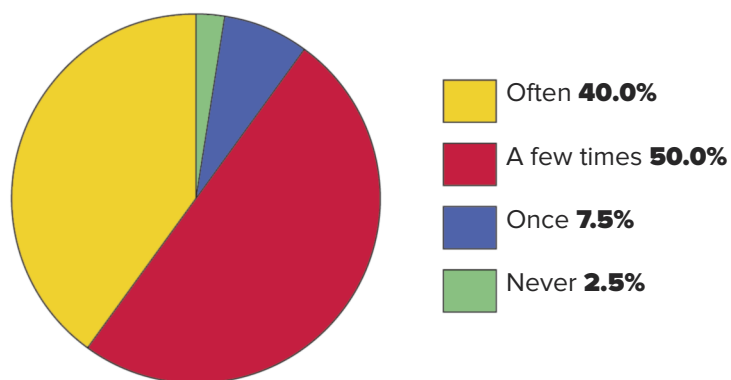


Figure 15 **Experience of verbal insult, harassment or being threatened**

**Figures 16** and **17** show that physical harassment, threats or assault were less common than verbal. But still more than 50 percent reported experiencing physical harassment or threats because of their HIV status.

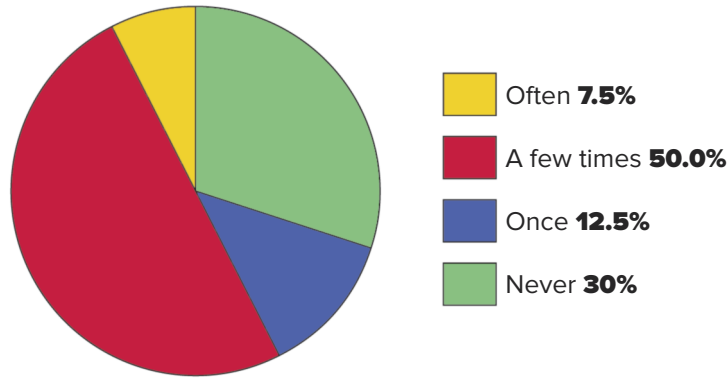


Figure 16 **Experience of physical harassment or threat**

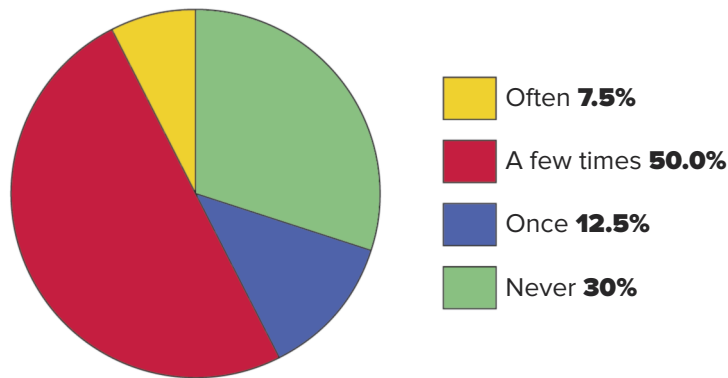


Figure 17 **Experience of physical assault**

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

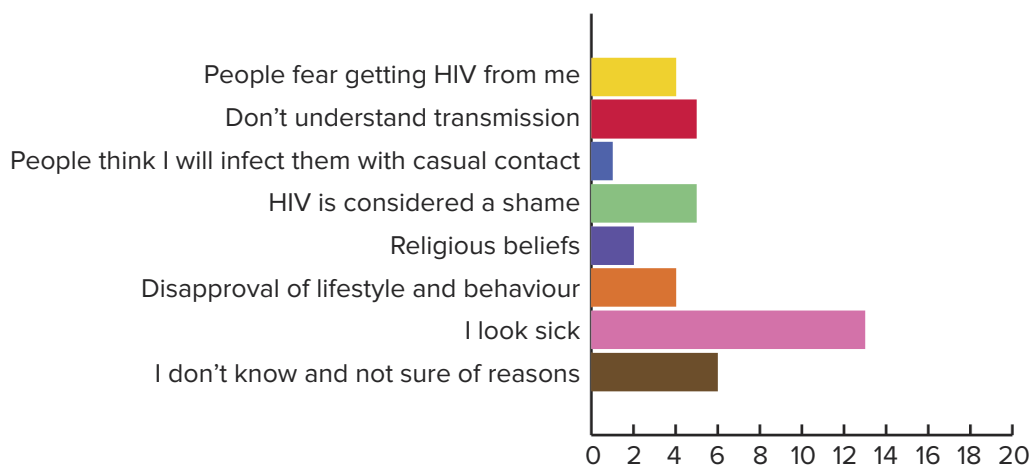


Figure 18 **Reasons for occurrence of stigma and discrimination**

## WORK, HEALTH AND EDUCATION SERVICES

**Have you been refused employment or work opportunity because of your HIV status?**

Yes 13 No 27

**Have you been denied health services, including dental care, because of your HIV status?**

Never 14  
 Once 13  
 A few times 4  
 Often 1  
 Not applicable 8

**Have you been denied family planning services because of your HIV status?**

Never 8  
 Once 8  
 Not applicable 24

**Have you been denied sexual and reproductive health services because of your HIV status?**

Yes 13

Table 1 **Experience of being denied various services**

**INTERNAL STIGMA**

**Table 2** shows responses from interviewees when asked whether they had experienced any of the following feelings as a result of their HIV status.

| Type of Feeling      | Yes | No |
|----------------------|-----|----|
| Feel ashamed         | 29  | 11 |
| Feel guilty          | 27  | 13 |
| Blame myself         | 28  | 12 |
| Blames others        | 12  | 28 |
| Have low self-esteem | 18  | 22 |
| Should be punished   | 11  | 29 |
| Feel suicidal        | 18  | 22 |

Table 2 **Feelings of internal stigma due to HIV status**

**Table 3** shows responses from interviewees when asked whether they had experienced any of a list of situations because of their HIV status or had been fearful that any of these situations might happen because of their HIV status. The situations included their social life, sexual life and interactions with health services.

| Situation   | Yes | No |
|---|-----|----|
| Did not attend social gatherings                  | 22  | 18 |
| Were isolated from family and friends             | 23  | 17 |
| Decided to stop work                              | 16  | 24 |
| Told not to apply for a job/work or for promotion | 6   | 34 |
| Withdrew from training or education               | 3   | 37 |
| Decided not to get married                        | 4   | 36 |
| Decided not to have sex                           | 6   | 34 |
| Decided not to have child/children                | 8   | 32 |
| Avoided going to local clinic when necessary      | 3   | 37 |
| Avoided going to a hospital when necessary        | 5   | 35 |



| Particulars about which people felt fear                                  | Yes | No |
|---|-----|----|
| Being gossiped about  | 25  | 15 |
| Verbally insulted, harassed or threatened                                 | 27  | 13 |
| Physically harassed, and/or threatened                                    | 28  | 12 |
| Physically assaulted  | 18  | 22 |
| That someone would not want to be sexually intimate because of HIV status | 32  | 2  |

Table 3 **Experience of actual events or fears of events occurring**

## RIGHTS, LAWS AND POLICIES

**Have any of the following things happened to you because of your HIV status?**

|  |   |
|--|---|
| Forced to submit health procedure including HIV test | 5 |
| Denied health or life insurance                      | 1 |
| Appeared in court on charge related to HIV           | 1 |

**Have any of your rights as a PLHIV been abused?**

|                |    |
|----------------|----|
| Yes            | 31 |
| No             | 5  |
| Not applicable | 4  |

**Have you tried to get redress for any of your rights as a PLHIV?**

|                |    |
|----------------|----|
| Yes            | 3  |
| No             | 27 |
| Not applicable | 10 |

**What was the reason for not trying to get legal redress?**

|  |    |
|--|----|
| Had insufficient financial resources to take action              | 10 |
| Said process of addressing the problem appeared too bureaucratic | 1  |
| Felt too intimidated or scared to take action                    | 6  |
| Were advised against taking action by someone else               | 4  |
| Felt that little confidence on the outcome would be successful   | 5  |
| None of the above  | 1  |

**Have you tried to get a local or national politician to take action against an abuse of your rights as PLHIV?**

Yes 2 No 38

**What was the result?**

The matter has been dealt with now 1  
Nothing happened and the matter was not dealt with 1

Table 4 **Impact on rights**

## **EFFECTING CHANGE**

**Do you know of any group or organisation you can go to if you need assistance?**

Yes 32 No 8

**If yes, what kinds of groups or organisation do you know about?**  
*(Respondents were able to select more than one group or organisation.)*

|                                   |    |
|-----------------------------------|----|
| PLHIV support groups              | 30 |
| PLHIV networks                    | 30 |
| Local NGO                         | 16 |
| FBO                               | 11 |
| Legal practice                    | 10 |
| Human rights organisation         | 6  |
| National NGO                      | 6  |
| National AIDS Council Secretariat | 23 |
| International NGO                 | 2  |

**Have you sought assistance from the organisations listed above to resolve an issue of stigma and discrimination?**

Yes 20 No 20

Of those who said 'no', most said they had not done so for fear of gossiping.

### Have you supported other people living with HIV?

Yes 33 No 7

### Are you currently a member of a PLHIV network or support group?

Yes 32 No 8

There are number of organisations of people living with HIV working on stigma and discrimination. If one of them asked you, “what is the most important thing we should be doing as an organisation to address stigma and discrimination?” what would you recommend? *(Respondents were able to select more than one priority.)*

|  |    |
|--|----|
| Advocating for the rights of all people living with HIV  | 23 |
| Providing emotional support, physical and referral support for PLHIV   | 8  |
| Advocating specifically for the rights of/or providing support to particularly marginalised groups such as MSM, IDU or sex workers | 7  |
| Educating PLHIV including treatment literacy   | 2  |
| Raising awareness and knowledge to the public about HIV  | 10 |

Table 5 **Impact on effecting change**

## TESTING AND DIAGNOSIS

### Why were you tested for HIV?

|  |    |
|--|----|
| Employment   | 1  |
| Pregnancy  | 3  |
| Referred to by other clinic for transmitted infections | 15 |
| Referred to for other HIV-related symptoms             | 9  |
| Illness or death of a husband/wife or partner          | 2  |
| Only wanted to know                                    | 2  |
| Other reasons  | 8  |

### Was the decision to test for HIV up to you?

|  |    |
|--|----|
| Took the decision to be tested themselves      | 28 |
| Took the test because they were under pressure | 8  |
| Made to take a HIV test                        | 1  |
| Tested without his/her knowledge               | 3  |

## Did you receive counselling when you were tested for HIV?

|   |    |
|---|----|
| Received both pre and post-test counselling | 33 |
| Received only post-test counselling         | 4  |
| Did not receive any counselling when tested | 3  |

Table 6 **Testing and diagnosis**

## EXAMPLE STATEMENTS FROM INTERVIEWS

Key Meri: woman TG: transgender

|               | Testing and diagnosis  | Disclosure and confidentiality                       | Antiretroviral treatment  | Having children   | Extra comments  |
|---------------|--|--|---|---|---|
| <b>1</b> Meri | Some HCW, a man, verbally abuses me and does not assist                    | Self-stigma is a problem                             | It costs more money for bus fare  |   | We are sinners  |
| <b>2</b> Meri | Fear, shame and thinking too much on what your result would turn out to be | Fear of stigma and discrimination to disclose status | Distance and bus fare are a problem to get to the clinic. I have some side effects. | Not sure whether or not to have a child while in this situation                         | Go to PLHIV network/support group for help and advice |
| <b>3</b> Man  | Not many testing sites and no proper follow-up for positive clients        | Fear and shame. Stigma and discrimination.           | Logistic support to receive ART at treatment sites (especially bus fare)            | Create more burden and pain, especially when child is HIV-positive, therefore we should |   |

|               | Testing and diagnosis   | Disclosure and confidentiality    | Antiretroviral treatment   | Having children  | Extra comments   |
|---------------|---|-----------------------------------|--|--|--|
|               |   |                                   |  | enforce PPTCT program in all provinces.  |  |
| <b>4</b> Man  | Confidentiality not guaranteed  | Shame                             | Due to geographical locations and distance to nearest ART clinics, difficult to obtain ART | Insecure feeling about children's security and future  | I was rejected and verbally abused. Took it to village court but the case was overlooked. Nobody to help me so the matter was dropped. |
| <b>5</b> Meri | When you are very sick, you don't have any choice, you just have to agree to have a test. It's better to go for a test while you are well and healthy but then a lot of people are afraid and ashamed to do so. | Fear of stigma and discrimination | Few side effects. Quite a distance to access ART treatment at the clinic.                  | For me personally, I feel that it's very challenging and a difficult situation to have children when you are HIV-positive. |  |

|               | <b>Testing and diagnosis</b>                            | <b>Disclosure and confidentiality</b>  | <b>Antiretroviral treatment</b> | <b>Having children</b>   | <b>Extra comments</b>  |
|---------------|---|--|---------------------------------|--|--|
| <b>6</b> Meri | Fear, in doubt, worried what the result would be like.  | The first time, it's a difficult situation and it takes time and boldness for a person to be open about status.  | Side effects                    | Sometimes couples cannot afford to get milk and bottles to bottle-feed their babies. It's quite an expensive exercise. | Had family dispute (with small sister)<br><br>Take it as a challenge and live on with life |
| <b>7</b> Man  | I think of my children                                  | I came out <i>but</i> it's difficult   | It's okay no problem            | I want children but I am waiting for the doctor's response   | Removed me from the people   |
| <b>8</b> Man  | Lots of men and women feel fear and shame to go for VCT | Fear of stigma and discrimination and also for the sake of the children, many don't feel comfortable to disclose | Causing a lot of side effects   | Quite difficult and seems to be very big burden and challenge to many positive couples                                 |  |
| <b>9</b> TG   | Very challenging. I had fear of death in me.            | Big problems, sometimes there is no trust among TGs  | Am not ready to take it         |  |  |

|                   | <b>Testing and diagnosis</b>   | <b>Disclosure and confidentiality</b>  | <b>Antiretroviral treatment</b>   | <b>Having children</b>  | <b>Extra comments</b>   |
|-------------------|--|--|---|---|---|
| <b>10</b><br>Man  | You have to be strong and accept your HIV status and don't think too much as your thinking will kill you | With other PLHIV it's okay, and the immediate family but for other people it's hard because of fear of stigma and discrimination | ART is a lifetime treatment and it's important and you have to go to the clinics for your review date |   |   |
| <b>11</b><br>Man  | I think a lot about my family  | I need to do ground work first   | Okay, no problem  | Take answer from the doctor   | My family telling me in public that I brought HIV to the family |
| <b>12</b><br>Meri | I found it very hard to tell my friends I went for a VCT test  | Fear and shame due to stigma and discrimination  | It's okay to access treatment, but I need to have enough money for transportation or bus fare         | Now I live with HIV virus and I don't want any children because it's another burden |   |
| <b>13</b><br>Man  | Fear and shame to tell my partner and wife to go for test  |  |   |   |   |

|                | <b>Testing and diagnosis</b>   | <b>Disclosure and confidentiality</b>                            | <b>Antiretroviral treatment</b> | <b>Having children</b>                                | <b>Extra comments</b>  |
|----------------|--|--|---------------------------------|---|--|
| <b>14</b> TG   | I fear rejection   | Being TG and positive at the same time, am not ready to disclose | Okay                            |   | My client had sex with me then wouldn't pay me because someone told him I was HIV-positive |
| <b>15</b> Meri | My big problem is I think of my son, I thought the test result was negative but it turned out positive | I don't come out   | Side effects                    | Yes, I will seek advice from doctor                   | My sister's child called my son AIDS carrier   |
| <b>16</b> Meri | I am a sex worker and man and woman stare at me.   | Not ready to come out  | Okay                            | I want a child but I need to wait for doctor's answer |  |



|                   | <b>Testing and diagnosis</b>   | <b>Disclosure and confidentiality</b>               | <b>Antiretroviral treatment</b>   | <b>Having children</b>  | <b>Extra comments</b>  |
|-------------------|--|---|---|---|--|
| <b>17</b><br>Meri | No form of consent from a client before HIV test is done. Also no proper counselling | Fear of stigma and discrimination                   | Remote places don't have ART drugs available in the clinics, makes it difficult for PLHIV to find means and ways to access these services | Being positive with a positive child is really a burden and the most difficult part of life | I felt weak and down and worried about being killed. I live in remote place and ART is not available as yet. |
| <b>18</b><br>Meri | People know I am a sex worker and if I walk into the VCT centre they gossip          | A very big problem, am not ready to come out public | No problems   | Doctors did not give me good advice   |  |
| <b>19</b> TG      |  |   |   |   | My friends (TG) helped me.   |
| <b>20</b><br>Man  | The big problem was I didn't want to know my status                                  | I am public advocator so no problems                | Side effects are killing me   | I don't want babies now because I am living with HIV  | They want to remove me from the clan   |

Table 7 **Statements from respondents to various interview questions**

## Data Summary

# Chimbu

**Figure 19** shows that 17 males and 20 females were interviewed in Chimbu. A small number who identified as transgender had agreed to be interviewed and while this was a smaller number than in Western Highlands, it still provides a good sample to gain some information on the experiences of PLHIV who identify as transgender — whether the identification was transgendered male-to-female or female-to-male was not explored.

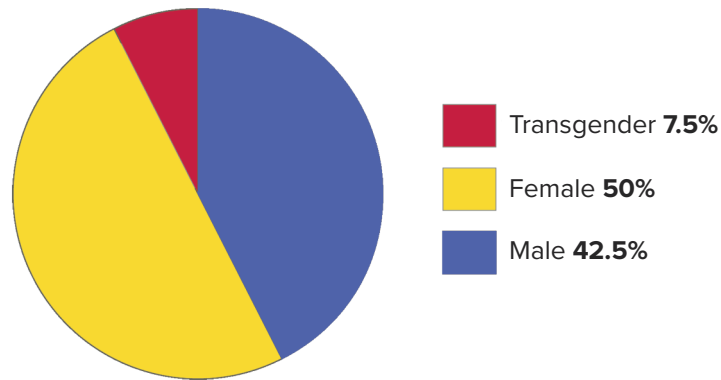


Figure 19 **Gender**

**Figure 20** shows that 19 of the respondents were aged between 15 and 29 years, 20 were over the age of 30 years and one respondent was more than 50 years of age.

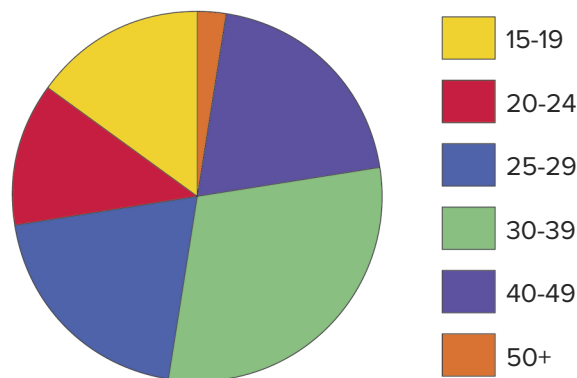


Figure 20 **Age**

**Figure 21** shows that more than half of those interviewed had lived with HIV for less than five years. This included those with recent diagnosis and those who had been living longer with HIV.

There were fewer people living longer with HIV interviewed in Chimbu than in Western Highlands. Whether that indicates there were more people being recently diagnosed in Chimbu than Western Highlands, or whether, because of the services available to PLHIV, they were living longer in Western Highlands would require triangulation of data that is not possible within this study. For the purposes of this study though, it shows that people interviewed covered a range, from recently diagnosed to those living longer with HIV.

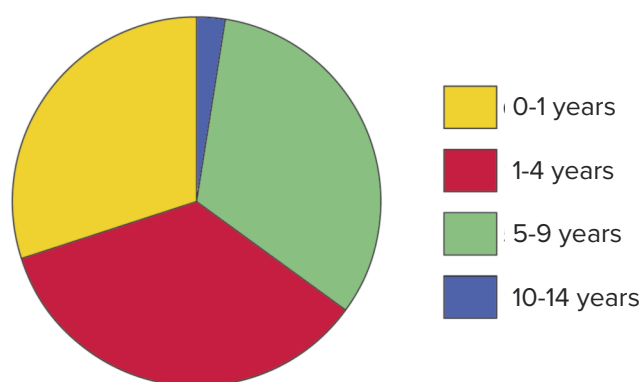


Figure 21 **Recency of diagnosis**

**Figures 22** and **23** give some indication of the length of and relationship status of respondents. As these are self-reported, there is no way of triangulating the data for proof of, for example, years spent in a relationship.

It should be recalled that respondents were asked for their experiences over the previous twelve months, which could explain why a number spoke of being in relationships for longer periods of time; they may have been referring to previous relationships.

However, this basic data is initially interesting as it demonstrates, for example, that only a very small number of respondents (6) were co-habiting or living together in the previous twelve months. In other words, the majority of the respondents are outside of a permanent relationship situation. It could be conjectured that this may be because of their HIV status but further quantitative analysis would be required to make those connections.

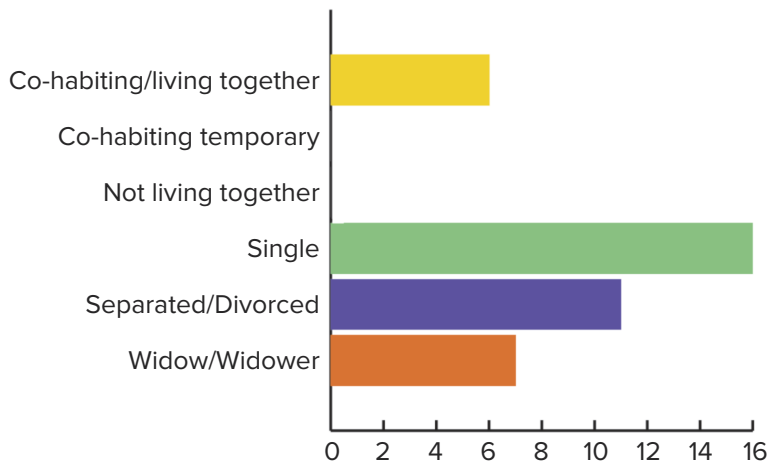


Figure 22 **Relationship status**

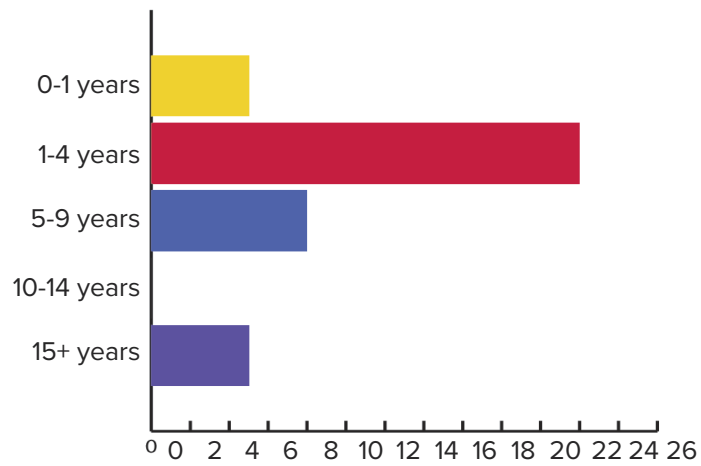


Figure 23 **Years in a relationship**

As with the data from Western Highlands, most respondents identified they were sexually active.

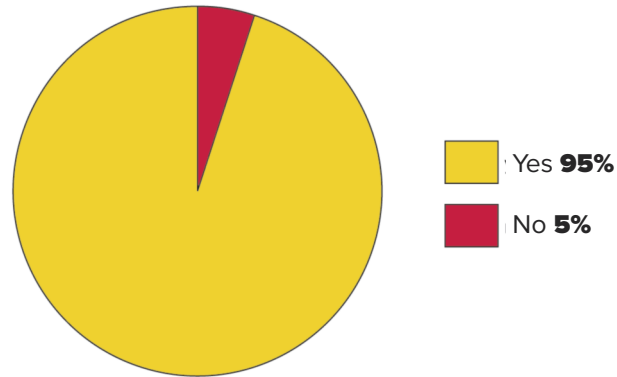


Figure 24 **Level of sexual activity**

**Figure 25** shows that 15 participants identified with the sex worker group and half the respondents identified as belonging to no grouping (general population).



Figure 25 **Identification with a group**

**Figures 26 and 27** show that a significant number (15) had no formal education and most had casual or part-time employment only or no employment.

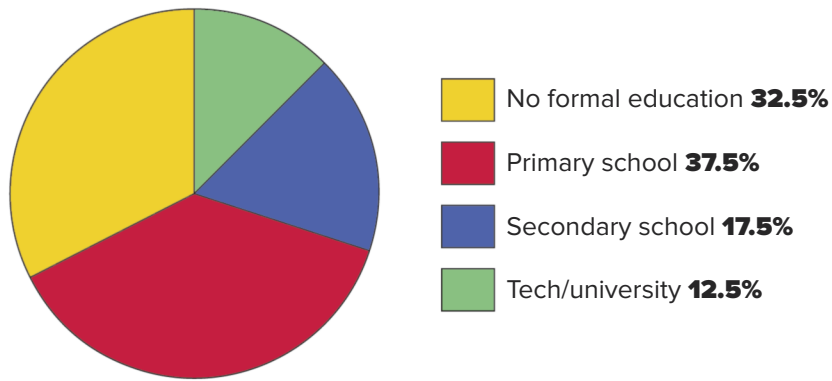


Figure 26 **Education level achieved**

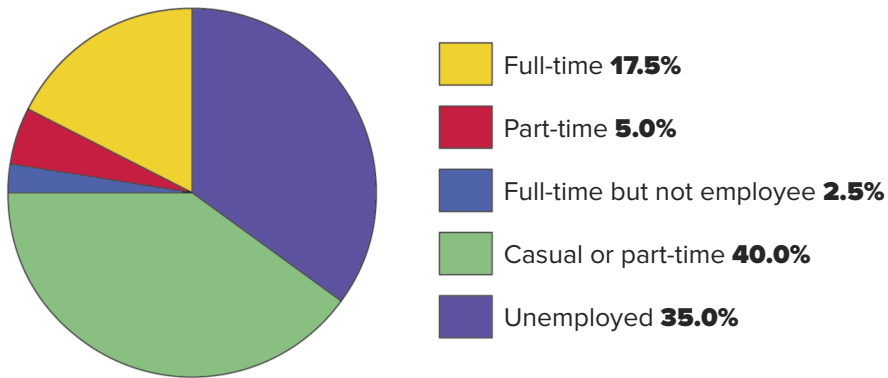


Figure 27 **Employment status**

## **EXPERIENCE OF STIGMA AND DISCRIMINATION**

**Figure 28** demonstrates that more than half of the participants reported they had been excluded from social gatherings and activities once, a few times or often.

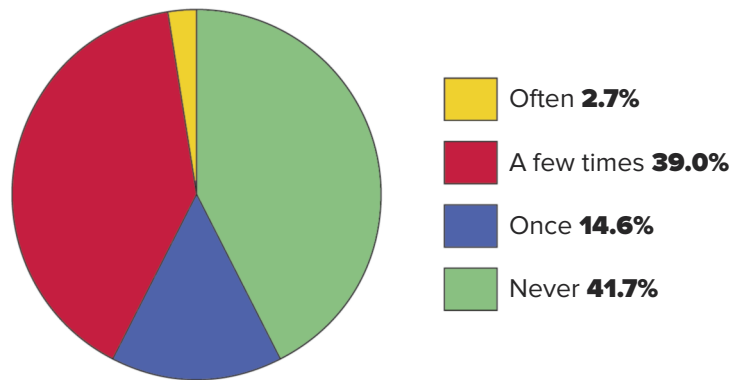


Figure 28 **Exclusion from social gatherings/activities**

**Figure 29** shows that 40 percent of respondents reported having been excluded from religious activities once or a few times in the past twelve months.

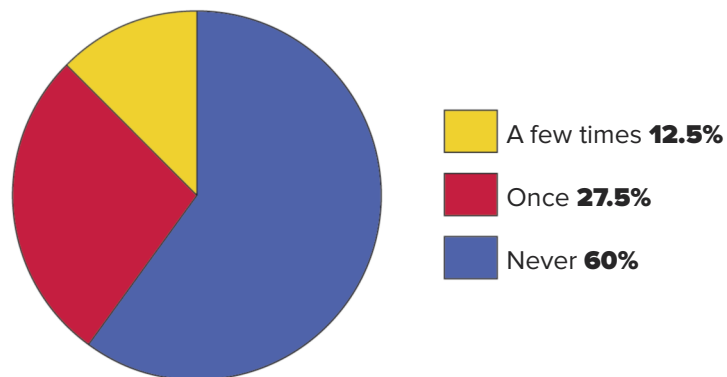


Figure 29 **Exclusion from religious activities**

**Figure 30** 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.

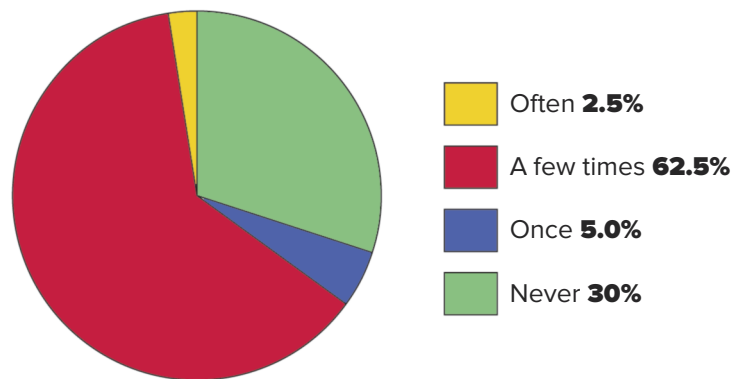


Figure 30 **Exclusion from family gatherings**

**Figure 31** 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.

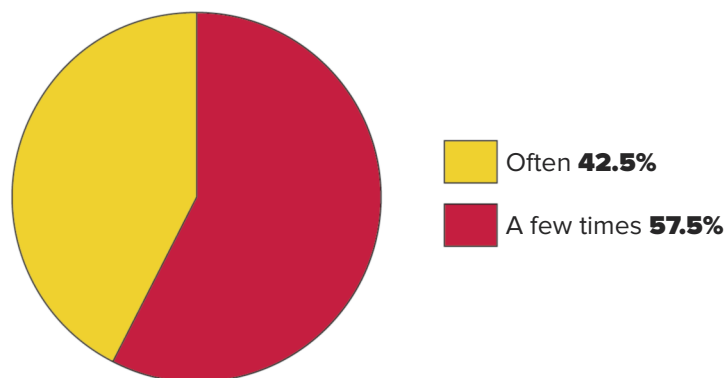


Figure 31 **Experience of gossip**

As **Figure 32** 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.



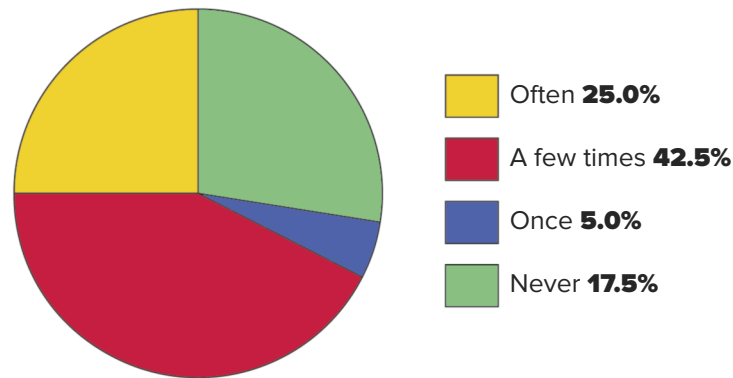


Figure 32 **Experience of verbal insult, harassment or being threatened**

Figures 33 and 34 show that physical harassment, threats or assault because of HIV status were common. More than 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.

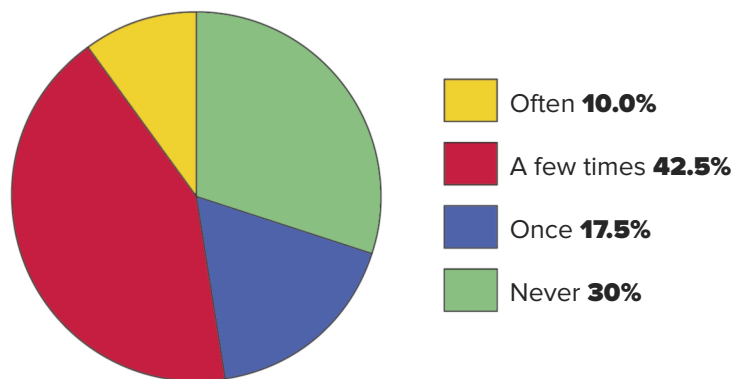


Figure 33 **Experience of physical harassment or threat**

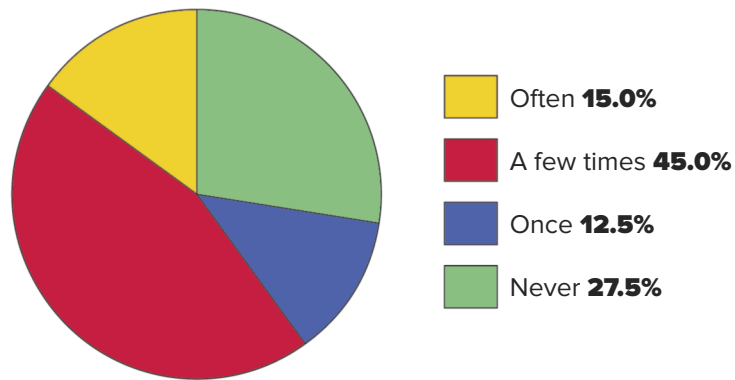


Figure 34 **Experience of physical assault**

Respondents were given a range of options to choose as to the reason for the instances of stigma and discrimination. Fear of people with HIV and misunderstandings to do with HIV transmission were the main reasons why PLHIV thought others stigmatise and discriminate against them.

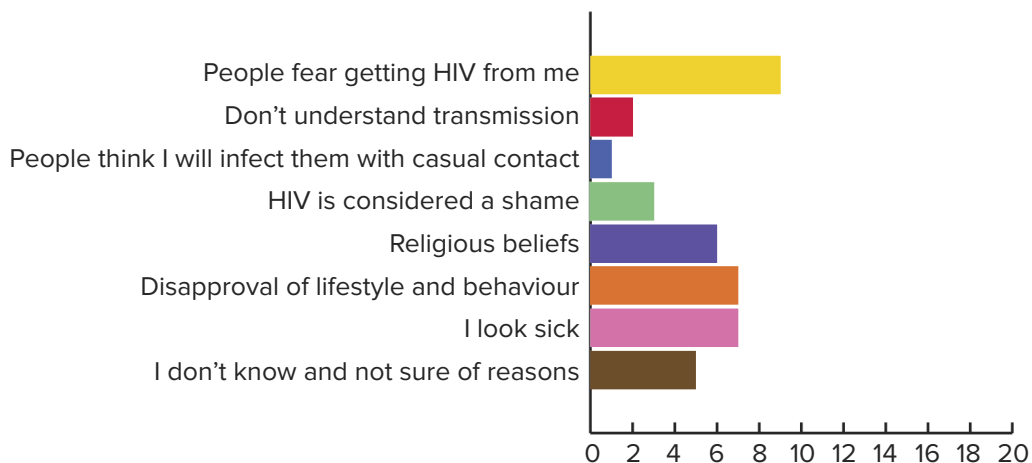


Figure 35 **Reasons for occurrence of stigma and discrimination**

## **WORK, HEALTH AND EDUCATION SERVICES**

**Have you been refused employment or a work opportunity because of your HIV status?**

Yes 10      No 30

**Have you been denied health services, including dental care, because of your HIV status?**

Never 18  
Once 12  
A few times 3  
Often 0  
Not applicable 7

**Have you been denied family planning services because of your HIV status?**

Never 12  
Once 8  
Not applicable 20

**Have you been denied sexual and reproductive health services because of your HIV status?**

Yes 13      No 27

Table 8 **Experience of being denied various services**

## INTERNAL STIGMA

Have you experienced any of the following feelings to do with your HIV status?

| Type of Feeling      | Yes | No |
|----------------------|-----|----|
| Feel ashamed         | 37  | 3  |
| Feel guilty          | 36  | 4  |
| Blame myself         | 33  | 7  |
| Blames others        | 11  | 29 |
| Have low self-esteem | 29  | 11 |
| Should be punished   | 22  | 18 |
| Feel suicidal        | 28  | 12 |

Table 9 **Feelings of internal stigma due to HIV status**

Have you done any of the following things because of your HIV status?

| Situation   | Yes        | No        |
|---|------------|-----------|
| Did not attend social gatherings  | 28         | 12        |
| Were isolated from family and friends                                     | 27         | 13        |
| Decided to stop work  | 20         | 20        |
| Told not to apply for a job/work or for promotion                         | 7          | 33        |
| Withdrew from training or education                                       | 6          | 34        |
| Decided not to get married  | 7          | 33        |
| Decided not to have sex   | 8          | 32        |
| Decided not to have child/children  | 13         | 27        |
| Avoided going to local clinic when necessary                              | 5          | 35        |
| Avoided going to a hospital when necessary                                | 4          | 36        |
| <b>Particulars about which people felt fear</b>                           | <b>Yes</b> | <b>No</b> |
| Being gossiped about  | 33         | 7         |
| Verbally insulted, harassed or threatened                                 | 32         | 8         |
| Physically harassed, and/or threatened                                    | 26         | 14        |
| Physically assaulted  | 33         | 7         |
| That someone would not want to be sexually intimate because of HIV status | 37         | 3         |

Table 10 **Experience of actual events or fears of events occurring**

## RIGHTS, LAWS AND POLICIES

Have any of the following things happened to you because of your HIV status?

|  |    |
|--|----|
| Forced to submit health procedure including HIV test | 2  |
| Denied health or life insurance                      | 1  |
| Appeared in court on charge related to HIV           | 1  |
| None of the above                                    | 36 |

Have any of your rights as a person living with HIV been abused?

|                |    |
|----------------|----|
| Yes            | 23 |
| No             | 2  |
| Not applicable | 15 |

Have you tried to get redress for any of your rights as a PLHIV being abused?

|                |    |
|----------------|----|
| Yes            | 1  |
| No             | 22 |
| Not applicable | 27 |

What was the reason for not trying to get legal redress?

|  |   |
|--|---|
| Had insufficient financial resources to take action              | 5 |
| Said process of addressing the problem appeared too bureaucratic | 3 |
| Felt too intimidated or scared to take action                    | 8 |
| Were advised against taking action by someone else               | 4 |
| Felt that little confidence on the outcome would be successful   | 2 |

Table 11 **Impact on rights**

## **EFFECTING CHANGE**

**Have you confronted, challenged or educated someone who was stigmatising and discriminating against you?**

Yes 19      No 21

**Do you know of any group or organisation you can go to if you need assistance?**

Yes 23      No 17

**If yes, what kinds of groups or organisations you know about?**

|                                   |    |
|-----------------------------------|----|
| PLHIV support groups              | 11 |
| PLHIV networks                    | 11 |
| Local NGO                         | 10 |
| FBO                               | 2  |
| Legal practice                    | 5  |
| Human rights organisation         | 4  |
| National NGO                      | 3  |
| National AIDS Council Secretariat | 8  |
| International NGO                 | 1  |

**Have you sought assistance from the organisations listed above to resolve issues of stigma and discrimination?**

Yes 7      No 33

Most said they had not for fear of gossiping.

**Have you supported other people living with HIV?**

Yes 28      No 12

**Are you currently a member of a PLHIV network or support group?**

Yes 28      No 12

**There are number of organisations of people living with HIV working on stigma and discrimination. If one of them asked you, “what is the most important thing we should be doing as an organisation to address stigma and discrimination?” what would you recommend? (Respondents were able to select more than one priority.)**

|   |    |
|---|----|
| Advocating for the rights of all people living with HIV   | 28 |
| Providing emotional support, physical and referral support for PLHIV  | 11 |
| Advocating specifically for the rights of/ or providing support to particularly marginalised groups such as MSM, IDU or sex workers | 26 |
| Educating PLHIV including treatment literacy  | 28 |
| Raising awareness and knowledge to the public about HIV   | 27 |

Table 12 **Impact on effecting change**

## **TESTING AND DIAGNOSING**

### **Why were you tested for HIV?**

|  |    |
|--|----|
| Pregnancy  | 2  |
| Referred to by other clinic for transmitted infections | 9  |
| Referred to for other HIV-related symptoms             | 6  |
| Illness or death of a husband/wife or partner          | 4  |
| Only wanted to know                                    | 1  |
| Other reasons  | 18 |

### **Was the decision to test for HIV up to you?**

|  |    |
|--|----|
| Took the decision to be tested themselves      | 17 |
| Took the test because they were under pressure | 3  |
| Tested without his/her knowledge               | 11 |

### **Did you receive counselling when you were tested for HIV/AIDS?**

|   |    |
|---|----|
| Received both pre and post-test counselling | 21 |
| Recieved only pre-test counselling          | 10 |
| Received only post-test counselling         | 2  |
| Did not receive any counselling when tested | 7  |

Table 13 **Testing and diagnosis**

## EXAMPLE STATEMENTS FROM INTERVIEWS

Key Meri: woman TG: transgender

|               | Testing and diagnosis                | Disclosure and confidentiality  | Antiretroviral treatment  | Having children  | Extra comments   |
|---------------|--------------------------------------|---|---|--|--|
| <b>1</b> Man  | Not many follow-up and testing sites |   | Adherence problems due to low diet/protein uptake daily                 |  |  |
| <b>2</b> Man  | Environment not user-friendly        | Gossiping   | Having the bus fare   |  |  |
| <b>3</b> Man  | Shame and self-stigma                | Fear of rejection and isolation from immediate family members, claiming the family name will be tarnished | Service providers at the treatment site (environment) not user-friendly | Burden and loads of problems   |  |
| <b>4</b> Meri | People will look down on me          | Am not ready to come out public people are not open-minded  | Have side effects   | Am not free to have a baby now I think when I get my health back, yes I will have baby | My brother told me to leave the house because I was HIV-positive |
| <b>5</b> Man  | I feared receiving my test result    | Very big challenge for me.  | No problems   | I don't want to, I could destroy the   |  |



|               | Testing and diagnosis   | Disclosure and confidentiality                           | Antiretroviral treatment                                   | Having children                                      | Extra comments   |
|---------------|---|--|--|--|--|
|               |   |  |  | child and this is my biggest challenge               |  |
| <b>6</b> Man  | Care and support on treatment patients (Lack of follow-up)      | Fear/shame/ stigma                                       | Not easily accessible by rural people. Adherence problems. | Nil service on PPTCT program                         | The problem of my child custody was not fixed/ resolved by Save the Children and welfare office                                      |
| <b>7</b> Meri | I was thinking am gonna die next year                           | Am thinking of my child. Not ready to come out publicly. | Side effects   | Am infected and I don't want my child to be infected |  |
| <b>8</b> Meri | Only problem is my client seeing me walking into the VCT centre | The people in my province are not open-minded people     | No problem   | If I die nobody to take care of my children          | I was denied sexual and reproductive health services because I was a sex worker. A client brought me to the room and there were four |

|                | Testing and diagnosis                          | Disclosure and confidentiality                                    | Antiretroviral treatment    | Having children                            | Extra comments  |
|----------------|--|---|-----------------------------|--|---|
|                |  |   |                             |  | men in the room too, I was raped that time.   |
| <b>9</b> TG    | I was afraid of the result                     | Not confident to come out publicly                                | No problems, just okay      | I don't want                               | HAMP protects PLHIVs but not TGs. I have experienced sexual abuses.   |
| <b>10</b> Man  | I was scared to hear or receive my test result | I am not strong enough to disclose or be open about my HIV status | Yes, there are side effects | I don't want children                      | My former wife called me gay ass fucker and AIDS carrier in public.   |
| <b>11</b> Meri | If I know my status I will be worried          | Fear to come out public   | No problem                  | Big challenge, I don't want to have babies | I was very sick and my family didn't want me to stay in the house. Peer friends helped. Went to my family and we talk about my illness, so they got me back to stay in the house. |

|                   | <b>Testing and diagnosis</b>  | <b>Disclosure and confidentiality</b>   | <b>Antiretroviral treatment</b>                          | <b>Having children</b>   | <b>Extra comments</b>                                  |
|-------------------|---|---|--|--|--|
| <b>12</b><br>Man  | Stigma and discrimination at the testing sites/clinics by health care workers                     | Fear and shame  | Not enough money to go to the clinic to access treatment | I don't know   |  |
| <b>13</b><br>Man  | I don't feel scared   | I don't feel all right to see or my friends   | I feel scared  | The child will get sick too and that will be another big problem                         |  |
| <b>14</b><br>Meri | I was in fear because I was so young to get HIV   | Is a challenge. I need more training and capacity-building for me to disclose my status | If am on the drugs I think there won't be a problem      | No, I don't want to have baby, am HIV positive, I might pass it on to the innocent child |  |
| <b>15</b><br>Meri | I fear because I am a sex worker and now that I am infected, I won't be able to make enough money |   | No problem with this                                     | My big problem is I want to conceive a child but I must wait for the right timing        | General public should not discriminate or spoil people |
| <b>16</b><br>Man  | Problems with the follow-up of clients who tested positive  |   | ART is sometimes not available when need                 |  |  |

|                   | Testing and diagnosis  | Disclosure and confidentiality                       | Antiretroviral treatment   | Having children   | Extra comments  |
|-------------------|--|--|--|---|---|
| <b>17</b><br>Man  |  | Shame and fear of rejection                          | Accessibility to ART at clinic (logistic problems)                                 | Creating more feelings of insecurity                            | My children were rejected from enrolment due to my HIV status, so I had to see the headmaster to resolve the matter   |
| <b>18</b><br>Meri | Health care workers must give health education before they can be able to perform tests on their clients | Fear of stigma and discrimination to disclose status | I must have enough bus fare to travel all the way to town to get my ART medication | Not sure  | No man wants to marry me.<br><br>Was a sex worker before when I was in town but when I was diagnosed HIV-positive I was sent home and now I only stay in the village. |
| <b>19</b><br>Man  | I was scared to do my testing. Maybe I could be infected with HIV virus.                                 | I find it very hard to disclose my status            | Can the clinics give education on ART and food (nutrition)                         | Forget about children, it will take up my time to care for them |   |

|                   | <b>Testing and diagnosis</b>  | <b>Disclosure and confidentiality</b>               | <b>Antiretroviral treatment</b>   | <b>Having children</b>   | <b>Extra comments</b> |
|-------------------|---|---|---|--|-----------------------|
| <b>20</b><br>Meri | When it's time for testing the HCW must give information to the clients and explain the importance of the treatment. And any other information for that matter. | In most health settings there is no confidentiality | No good information on treatment for HIV and on how to protect other people | I feel that it is priority to care for myself and care for my children later |                       |

Table 14 **Statements from respondents to various interview questions**

## PART 5

# Analysis and discussion of results

### Comparison and contrast of data from Western Highlands and Chimbu

This report is not a quantitative analysis so no statistical analysis has yet been applied to the results. Quantitative analysis was not within the NACS funding agreement but the data is there for future work. In Part 5, we are not trying to analyse statistically significant similarities or differences. We are making general observations about these two sets of data and then provide information from thematic and qualitative analyses. Overall, we can say there is considerable similarity in the reported experiences of PLHIV in both provinces, specifically

- the majority of respondents identified as currently sexually active
- the majority of respondents had either no formal education or only primary school education
- the majority of respondents were either unemployed or in casual/part-time employment
- more than two-thirds of the respondents reported being excluded from social gatherings and activities
- more than a third of respondents reported being excluded from religious activities
- half the respondents reported being excluded from family gatherings
- the experience of gossip related to HIV status was almost universal
- a majority of respondents reported being verbally insulted, harassed and/or threatened, although this experience seems higher in the Western Highlands
- two-thirds reported some experience of physical harassment/threat or actual physical assault

- respondents reported a similar array of perceived reasons why stigma and discrimination occur.

## **Stigma and discrimination in the PNG context**

In *Tok Pisin*, the words for ‘stigma’ vary but the research team made this translation ‘bagarapim ol narapela manmeri’; likewise, the words for ‘discrimination’ might also vary but the research team selected this translation ‘wokim pasin nogut long ol narapela manmeri’. Some of those other words are shown in the title of the report. The discussion of language is important in understanding stigma and discrimination in the PNG context. The words ‘stigma’ and ‘discrimination’ are now widely used and most PLHIV in PNG, through networks and contacts, would have heard these words and acknowledge what they are. Most health and care service providers would also use these words and have their own understanding of what the words mean.

Rather than attempting to gain conformity of meaning amongst different ways of speaking about stigma and discrimination, this research has sought to understand the diversity and complexity of the experiences of PLHIV in response to what is called stigma and discrimination. The research has also sought to explore what Parker and Aggleton (2003) refer to as the cultural processes that lead to stigma and discrimination and also the social and structural effects of stigma and discrimination in PNG.

Using the translations made by the research team, a few straightforward points can be made to understand what stigma and discrimination mean in the PNG context. What can get lost or not heard when we categorise various experiences as stigma and discrimination are those many experiences and words comprising stigma and discrimination. This is why the research team paid particular attention to words that emerged during the research.

**‘narapela’** is a word that refers to ‘the others’. It is a word in translation that also refers to ‘another’; so already in the language there is a distancing of PLHIV from others. In other words, PLHIV are already placed in a position of ‘otherness’, of ‘being someone else’ and ‘not being me’.

**‘bagarapim’** is a word that refers to attitudes and behaviours. It is a word that is more about the feelings and behaviours of the person who is being affected, but it speaks powerfully about the feelings of that person. What it says is that through your actions (or words) you have created a spoilt me, you have spoiled me, you have destroyed my trust in you and you have destroyed my character. The language shows very clearly the effects of stigma and

discrimination. In PNG, *Tok Pisin* words show that the identity of PLHIV is spoiled and that trust and character have been destroyed.

**‘pasin rabisim’** – ‘pasin’ is an attitude or behaviour, which may be expressed in action, but might also be expressed in words. Actions might be undertaken or attitudes might be held that treat other people as rubbish, or ‘rabisim’. They are actions, attitudes or words that might ‘rubbish’ another person – hence, ‘pasin rabisim’. People might be created or treated as rubbish. Sometimes PLHIV are seen or treated as rubbish in PNG and quite often the means of creating PLHIV as rubbish are done verbally.

**‘baksait’** refers to something happening ‘around the back’ or ‘behind’ or in a place that ‘cannot be seen or identified’. Quite often the actions that indicate stigma and discrimination cannot be seen and heard, those who do the stigmatising or those who discriminate are often hidden, and sometimes cannot be seen or heard by the person suffering the stigma and discrimination.

Link and Phelan (2001) have a number of ways of describing stigma and discrimination, including the fact that it consists of distinguishing and labelling differences; negative stereotyping; and creating a separation of ‘us’ and ‘them’ within a context of domination and power. We have attempted to explore the impact of stigma and discrimination in context and we have identified the many ways in which it has been manifest in a range of settings. What is reported here are the ways in which stigma and discrimination are understood in the PNG context. We have seen that the differences attributed to PLHIV are invested with societal disapproval, even with contempt. Moreover, these attributed differences form the core identity PLHIV have of themselves.

The knowledge of PLHIV of stigma and discrimination in relation to HIV emerges from the results; we speak of this knowledge as themes. Themes may be thought of as recurring; observable — through all or any of our senses — patterns of behaviours; or as codes, aspects of the main story. Some themes come directly from the reported experiences of PLHIV. Others come from the knowledge of the researchers — who are also PLHIV — as they listen to and try to make sense of the various experiences being reported. Some themes likely to provoke argument are those that are expressive of feelings. Our research regards feelings as legitimate data, not to be ignored. It is necessary that we keep in mind this research is about the experiences of PLHIV. Hence, the themes emerging from the experiences of PLHIV are not necessarily the same as the themes that may emerge from a study of health care workers or health administrators working in the field of HIV.



Themes are not the same as the hypothesised dimensions of the concepts of stigma and discrimination. The hypothesised dimensions informed the development of the survey, but themes that emerge from the application of the survey in PNG are quite another matter and are the result of the iterative work of the research team.

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
- 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.

After the interviews were conducted and information collated, the research team met to discuss the information. In this iterative and reflexive process, the research team identified many areas of concern but nominated three summary statements concerning HIV stigma and discrimination in PNG.

- 1** It is a set of attitudes and behaviours.
- 2** It is about not treating someone with respect.
- 3** It has the effect of moving the stigmatised person, the PLHIV, away from the group, whatever that particular group may be.

The research team also developed a model (see Diagram 1) for understanding the settings in which stigma and discrimination occurred.

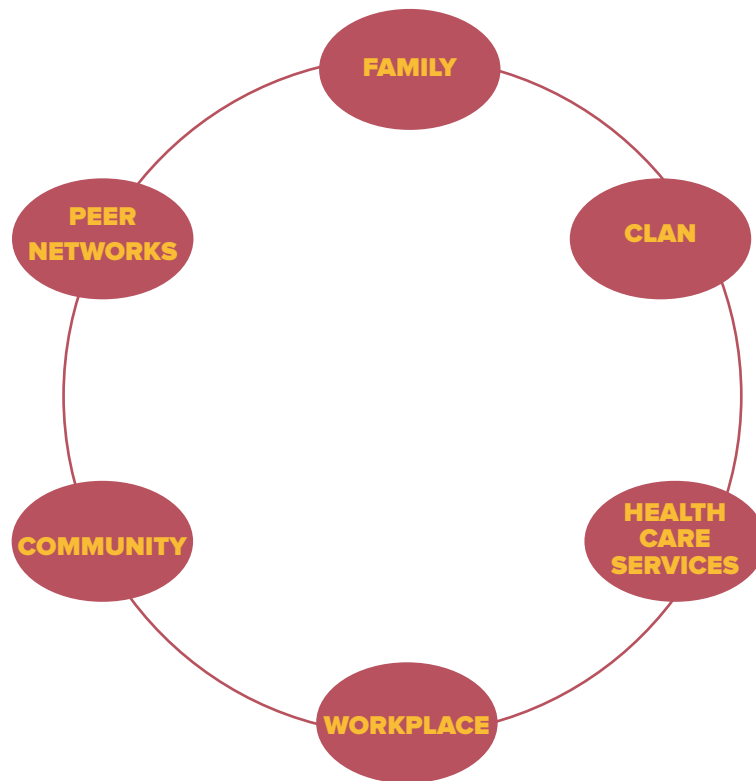


Diagram 1 **Settings in which stigmatisation occurs**

Before conducting the research, the team discussed their knowledge of stigma and discrimination and this included their own experiences and the experiences of peers and networks. These discussions were recorded as part of the research project because they demonstrate an evolving knowledge of the ways in which stigma and discrimination are understood in PNG.

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.

### **What we mean by self-stigma**

The situations above also create a condition of self-stigma for PLHIV. They can feel worthless, fear death, isolation and neglect. Self-stigmatisation occurs when people living with HIV begin to feel a sense of shame about being HIV-positive, leading to low self-esteem and a sense of worthlessness and depression. They are scared to disclose their status because of fear of being ignored, not wanted or not loved. Some say they have had feelings of being incapable of performing activities that were done before being diagnosed. PLHIV are fearful of disclosure, believing that if they do, their family members will be unsympathetic and give them less hope for survival. The whole situation leads to PLHIV thinking or believing that people are gossiping about their HIV status.

There is considerable international literature on stigma. Scambler (2009) makes an important distinction between the thoughts and feelings about oneself and the experience of stigmatising acts. He calls this “felt stigma” and “enacted stigma”. It is important to recognise the difference, but it is also important to recognise that both felt stigma (or self-stigma) and enacted stigma (acts that stigmatise others) adversely affect the individual.

## The effects and impacts of stigmatisation

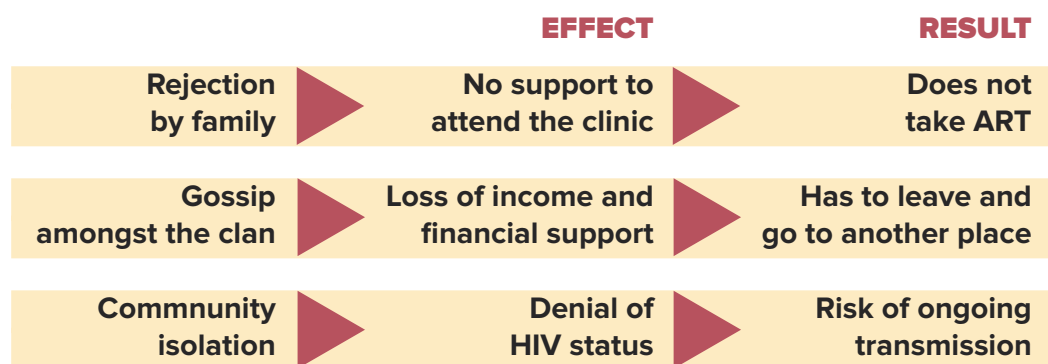


Diagram 2 **The effects and impacts of stigmatisation**

## PART 6

# Recommendations

As the survey has only been conducted in two provinces, with 80 interviews completed, the survey instrument should be applied in the other three regions of PNG as intended, and that at least 450 interviews be conducted. This will ensure that baseline data is established so that strategic national interventions can be considered and change from those interventions can be monitored over time.

Responding at a program or policy level to the types of stigma and discrimination that have been found in the first round of data collection will not be a simple matter. As we have pointed out earlier in the report, stigmatisation occurs due to complex social and cultural arrangements, and especially the ways in which some forms of violence are manifested in community life in PNG. These will not be easily displaced or challenged. In considering programs or interventions that have already been attempted, we could consider as examples to draw upon the kinds of dedicated small group work that Eves (2006) has suggested. Other methods of awareness-raising and empowerment aimed at social and behavioural change through ‘community conversations’ and small interventions attached to progressive church-based groups, for example, have been tried and documented by Reid (2010b) and Gibbs and Mondu (2010).

In the context of gender violence in Melanesia, Macintyre (2012) describes the ‘innumerable implementation problems’ of campaigns that are meant to address violence and provide empowerment for those who are experiencing violence; this includes the many practical difficulties in implementing programs at a community policing level or in seeking redistributive or restorative justice.

The recommendations we suggest here, based on what we see as some of the problems identified in the research, may seem somewhat hopeful given the context. However, they are proposed as a starting point and a talking point for the consideration of all partners in the PNG HIV response; a response where HIV should be considered ‘everybody’s business’. The recommendations have been discussed by the research team and checked with other stakeholders as achievable and realistic directions. They are grouped under the following headings:

- 1 PLHIV networks and community relationships
- 2 PLHIV network-building and peer interaction
- 3 Capacity-building in health care settings
- 4 Further engagement with the legal and paralegal practitioners
- 5 Improving stakeholder relationships with the positive communities.

## Recommendations 1

### PLHIV networks and community relationships

- Communities need to be educated about PLHIV and provided with HIV information.
- More awareness of and sensitisation for PLHIV in 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 their communities even if they have not disclosed their HIV status.
- PLHIV need to assist each other and be empowered to be part of the HIV response.
- Community leaders should be involved in community HIV work or HIV-related activities.
- Different groups, such as youth groups, women's groups, out-of-school youth groups and men's groups should be included in community HIV responses.
- PLHIV networks and support groups should be including institutions such as schools and aid posts with the communities in the HIV interventions.

- PLHIV networks and support groups should include women and girls in their programs; gender balance should be considered.
- Networks and support groups should develop tools to better monitor issues of stigma, discrimination and human rights abuses.

## **Recommendations 2**

### **PLHIV network-building and peer interaction**

- Networks and support groups need their capacities built on human rights and conflict resolution to better uphold the work of reducing stigma at the provincial level.
- Networks and support groups need to assist PLHIV peers to lessen the burden added to service providers.
- Networks and support groups need to collaborate and work together with stakeholders.
- There should be peer counselling programs to assist other positive people and those affected by HIV.

## **Recommendations 3**

### **Capacity-building in health care settings**

- Health Care Workers (HCWs) need more capacity-building in the area of maintaining care, support and treatment to better serve the positive community.
- Services provided by HCWs should and must respect individual rights and all clients should have their confidentiality protected.
- HCWs need to be sensitised in all areas of HIV and especially those engaged in antenatal clinics, STI clinics and the general outpatient departments of hospitals.
- Health services should engage positive women in antenatal clinics to assist in counselling and adherence, including sharing of experiences for women living with HIV.

- Health care settings should meaningfully involve women and girls living with HIV in the development, design and delivery of HIV programs and services.
- Staff in health care settings should be trained or have their capacity built in regard to palliative care and quality care for PLHIV.

## **Recommendations 4**

### **Further engagement with legal and paralegal practitioners**

- The legal fraternity needs to be educated about HIV and the HAMP Act.
- Legal personnel should be included in trainings and seminars on information on HIV and in other HIV-related information-sharing workshops.
- Legal personnel should inform or educate people on the processes, protocols and the mechanisms of the court system.
- Legal personnel must take the initiative and make it their responsibility to start working with stakeholders and assist PLHIV.
- Legal personnel should be able to help disseminate information about human rights through the networks.

## **Recommendations 5**

### **Improving stakeholder relationships with the positive communities**

- Stakeholders must have their capacity built to assist and empower the positive community.
- Stakeholders talk about human rights but understanding the theory and practical aspects of achieving human rights needs to be further improved.
- Stakeholders should be more sensitised about PLHIV and their experiences.



- Stakeholders should involve PLHIV in the planning and design of projects and activities, especially at the provincial level.
- Stakeholders need to build relationships with legal entities within the provinces.
- Stakeholders need to properly document HIV-related stigma and human rights issues.
- Stakeholders need to share information and challenges that they might have at the provincial level on stigma, discrimination and human rights.
- Stakeholders need to implement the Greater Involvement of People Living with HIV (GIPA) Principles in their response to HIV.
- Stakeholders should meaningfully involve women and girls living with HIV in the development, design and delivery of HIV programs and services.
- Stakeholders need their capacity built on human rights and conflict resolution to better assist work to reduce the incidence of stigma at the provincial level.
- Stakeholders need to support PLHIV in program areas of importance such as stigma, discrimination and human rights in their activities or projects.

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## APPENDIX

### Notes from site visits

#### Western Highlands Provincial AIDS Council

##### Joshua Meninga, Provincial HIV Response Coordinator

- There is not a lot of stigma and discrimination in the Western Highlands province because there are quite a number of people who have come forward about their status. Tru Warriors is an example of a group that has been public and this has helped reduce the stigma and encouraged people to come forward for testing and eventually treatment.
- It would be good to have more information about PLHIV experiences because interventions and programs need to be based on evidence.
- PACS has provided what support it can for the positive groups, such as provision of an office and basic equipment at the PACS office, but funding support is needed for the group so it can be better organised and communicate to others.
- The PACS office has approached both AusAID and NACS for support for the group but these applications have not been successful in the past.
- Perhaps the findings of the Stigma Index will provide evidence for submissions into the future and to support planning.

#### Mt Hagen Provincial Hospital, Tininga (Our) Clinic

##### Dr Petronia Kaima, Regional ART Coordinator

- It will be important to get a broad profile of those who are diagnosed. Unfortunately, professional people such as teachers and lawyers who are diagnosed have stayed in denial and do not want to be public about their status. It would be important to interview all groups and understand their problems.
- The Tininga Clinic is overwhelmed by numbers. The clinic is a referral point for nearby VCT sites and there are conditions that can be managed in other health care settings but patients keep coming back to this clinic.

- There have been a number of research studies at the site, including clinical studies, and it is important to get consent and maintain confidentiality during the work.
- Currently there are three ART-dispensing sites in the area: Tininga, the government-run facility; Kudjib, run by the Nazarene Mission; and Rabiamul, run by the Catholic Health Services. There are two new ART sites that are being developed and perhaps this can relieve some of the pressure currently being faced in the Tininga Clinic.
- It is important to understand what stigma patients are facing because we need to know why some are lost to follow-up and may not return for treatment.
- In the clinic it has been noted that a successful way of managing patients is to include counselling and support of other positive people who are on ART. This is especially the case for mothers and children. The HIV-positive counsellor is then able to spend time with patients who the doctor and clinic staff cannot see because they are too busy. Also, patients are more likely to tell another HIV-positive person their problems because they are too embarrassed to tell the doctor. There have been some observable benefits from this system.

**Togoba, VCT Clinic, Seventh Day Adventist Mission  
Director and health care workers (HCW)**

- There is discrimination, some say in the family setting and some say the discrimination comes from the clan.
- As HCWs, we don't know exactly what is happening for individual patients.
- At our clinic they are referred on, but we get no information about what happens to patients when they are referred; we do not know of their progress.
- Funding is a problem because transport to the ART clinic is expensive.
- Funding is also needed so our workers can go with patients when they go back to their homes and family. They are protected in the clinic but they also need protection when they leave the clinic.

- There needs to be greater coordination between the PACS office, VCT services and the ART sites.
- No one should be forced to participate and consent must be properly obtained.

**Nazarene Hospital, VCT Clinic, Kudjib  
Clinic Director and Health Care Workers**

- The clinic in its practice tries to reduce the possibility of stigma occurring by having all different kinds of patients attending the clinic, not just HIV but STI, antenatal care and cervical cancer screening.
- There are probably examples of stigma occurring but HCWs report that most people are willing to take an HIV test and they encourage all patients attending the clinic to do this.
- A major problem for those who need access to treatments is the cost of transport and another problem is that patients often cannot attend the clinic to collect their ART because tribal fighting impedes movement in the area.
- Dispensing of ART happens only on a Wednesday. Staff say there is a need to have dispensing sites outside Mt Hagen expanded.

**Shalom Centre, VCT Site, Banz  
Sr Regina and Volunteer Counsellors**

- The site has sleep-in arrangements for those PLHIV needing support; they arrive on a Monday and stay until Friday when there is a celebration ceremony.
- The place operates as an ART-dispensing site only on Wednesdays.
- Positive people are volunteers at the centre and work to produce some clothing for the promotion of the centre.



**Chimbu Provincial AIDS Council**  
**Nick Apa, HIV Response Coordinator**

- The registration of the PLHIV organisation for the area will allow funds to be received and managed by the group. This will help in efforts to reduce stigma.

**Kundiawa General Hospital**  
**Officer-in-Charge of STI Clinic**

- Patients feel comfortable in the clinic. But the front door of the clinic is actually visible from the front gate of the hospital and quite open to public view. So those who use the facility prefer to come around the back of the building and use that entrance so they cannot be observed by others.
- The hospital is rated as a three-star facility. With recent support from Japan, hospital facilities have had a major upgrade and the hospital is apparently well-equipped for a range of surgery and tertiary health services not available in nearby provinces.

**Mingendi Catholic Health Services**  
**Sr Rose Abba, Officer-in-Charge ARV Dispensing**  
**Maria Mondu, Caritas Research Officer**

- It seems many people prefer to travel to Mingendi, even from Mt Hagen and Kundiawa. It would be interesting to know why this is the case and the stigma research might uncover some clues about this.
- There has been some other research at the centre on discrimination and it would be useful to bring this information together as there still seems to be a lot of loss to follow-up.
- Many people do not return to the clinic after diagnosis: why is this so?

**Rabiamul Catholic Mission**  
**Sr Davida, Officer in Charge ART Dispensing**

- More than 1900 people have registered for ART, although there have been 300 lost to follow-up. Recommendations are to treat all who are testing positive but supplies are continually interrupted and this makes it not possible to meet the recommendations.
- Even though orders are placed one month ahead, sometimes only half of what is ordered arrives.
- These circumstances mean that it is only safe to supply one week at a time to patients and this creates many difficulties for patients to return to the clinic and adhere to their treatments.
- It is very confusing as to why such delays are occurring. Are the management orders in Port Moresby being received and processed properly? Are the TNT contractors being paid properly and are deliveries occurring on time? The site spends a lot of time ringing DoH and faxing through to ensure that supplies are kept up and timely but often no result.



# **HIV-related Stigma and Discrimination and Human Rights in Papua New Guinea**

**A REPORT ON THE APPLICATION OF  
THE HIV STIGMA INDEX IN THE WESTERN  
HIGHLANDS AND CHIMBU PROVINCES**

**IGAT HOPE INC.** 