

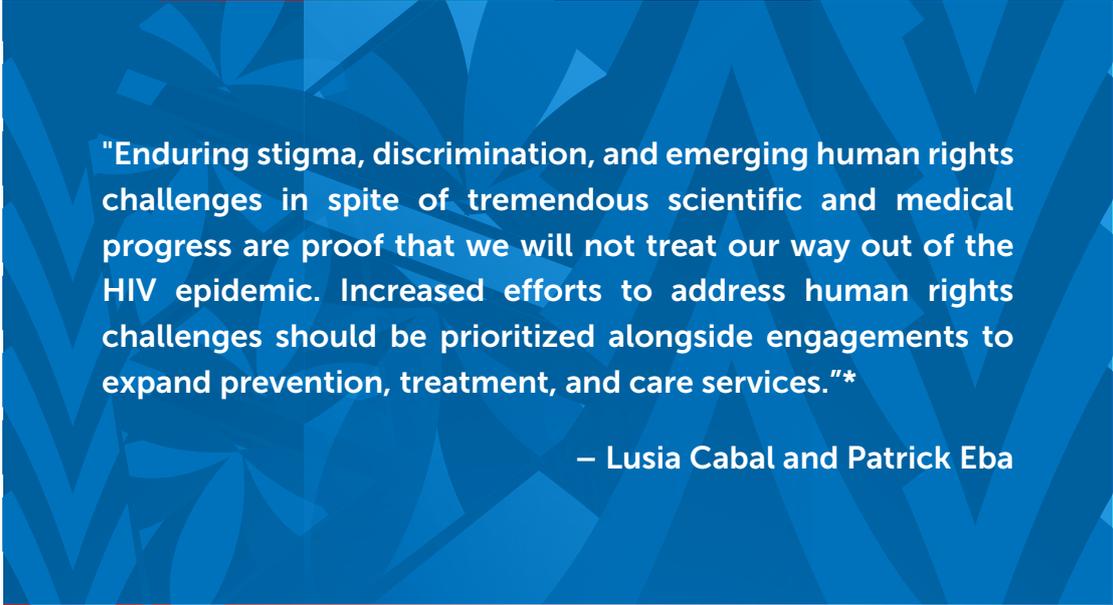


**THE PEOPLE
LIVING
WITH HIV
STIGMA
INDEX**

Overview Report

of the People Living with HIV Stigma Index
Study in Seven Countries in the Pacific





"Enduring stigma, discrimination, and emerging human rights challenges in spite of tremendous scientific and medical progress are proof that we will not treat our way out of the HIV epidemic. Increased efforts to address human rights challenges should be prioritized alongside engagements to expand prevention, treatment, and care services."*

– Lusia Cabal and Patrick Eba

* Lusia Cabal is chief of human rights and law at UNAIDS, the Joint United Nations Programme on HIV/AIDS. And Patrick Eba is senior human rights and law adviser at UNAIDS, the Joint United Nations Programme on HIV/AIDS. Quote from the Editorial in Health and Human Rights Journal special edition: HIV and Human Rights Volume 9 Number 2 December 2017.

ACKNOWLEDGEMENTS

The People Living with HIV Stigma Index study was carried out in seven countries in the Pacific region: Federated States of Micronesia (FSM), The Republic of the Marshall Islands (RMI), Samoa, Palau, Kiribati, Tonga and Vanuatu, under the leadership of the Fiji Network for People Living with HIV (FJN+). FJN+ is grateful to the United Nations Development Programme (UNDP) Pacific Office in Fiji for the technical and administrative support provided during this study. FJN+ is also grateful to the participants - people living with HIV in all countries who contributed to this study as interviewees by sharing their personal experiences and perceptions on the stigma that is attached to HIV in their country.

FJN+ extends its gratitude to the hard working team for consolidating stigma index data from seven countries. It is hoped that this report will inform change and innovation in the Pacific region.

We trust that these findings will contribute to improving the health and quality of the lives of people with HIV, as well as those most affected by the epidemic.

We also would like to sincerely acknowledge the work of the Research Assistants, Emosi Ratini Vukialau, Tavaita Senikaucaava, Apolosi Lasei, Margaret Seduadua, Christopher Benjamin and Rebecca Kubunavanua, for their perseverance and hard work which has made this project a success.

ACRONYMS

ARV	Antiretroviral	ICW	International Community of Women Living with HIV/AIDS
ART	Antiretroviral treatment	MIPA	Meaningful Involvement of People Living with HIV and AIDS
CCM	Country Coordinating Mechanism (for delivery of Global Fund interventions)	MSM	Men Who Have Sex with Men
CSO	Civil Society Organisation	NGO	Non-Governmental Organisation
FBO	Faith-based Organisation	PLHIV	People Living with HIV
FJN+	Fiji Network of People Living with HIV	PMTCT	Prevention of Mother-To-Child Transmission
FSM	Federated States of Micronesia	PPTCT	Prevention of Parent-To-Child Transmission
GARP	Global AIDS Response Progress Reports	RMI	Republic of the Marshall Islands
GIPA	Greater Involvement of People Living with HIV and AIDS	SRHR	Sexual Reproductive Health Rights
GNP+	Global Network of People Living with HIV	STI	Sexually Transmitted Infections
HCWs	Health Care Workers	UNAIDS	Joint United Nations Programme on HIV/AIDS
IDU	Injecting Drug User (also PUDs people Who Use Drugs)		

Table of Contents

Acknowledgements	2
Acronyms	3
Table of contents	4
1. Aim of this report	5
Background data on the region	5
2. Project approach	5
3. The findings	7
Testing and diagnosis	14
Rights	15
Effecting change	15
Disclosure and confidentiality	16
Treatment	17
Having children	18
4. Conclusion	19
5. Recommendations	20
6. Lessons learnt: the implementation of the regional PLHIV Stigma Index study	24
7. Afterword	25
8. References/recommended further reading	26



1. AIM OF THIS REPORT

This report highlights the findings from a seven-country study of stigma and discrimination in the Pacific region funded by the Global Fund through the UNDP Pacific Office in Fiji. The report will also give recommendations for how stigma and discrimination can be reduced and ultimately eliminated in the region in line with UNAIDS' global treatment targets such as 90-90-90.

"By 2020, 90% of all people living with HIV will know their HIV status. By 2020, 90% of all people with diagnosed HIV infection will receive sustained antiretroviral therapy. By 2020, 90% of all people receiving antiretroviral therapy will have viral suppression."¹

For more detailed analysis individual country reports should be referred to – these reports can be found at www.stigmaindex.org while the People Living with HIV Stigma Index report for Fiji (two studies conducted in 2010 and 2016) can be found here. Data from the Fiji report has not been recorded here since the research was conducted more than 12 months apart.

UNAIDS warns that HIV-related stigma and discrimination is preventing people from accessing HIV services.

Background data on the region

The following data was extracted from a review of the Global AIDS Response Progress Reports produced by UNAIDS:

- > A total of 181 cases have been reported in 11 countries in the region
- > Currently, 69 PLHIV are living in the region (11 countries)
- > In 2014, 13 new cases were diagnosed
- > From the reported ever diagnosed total, 91 (61%) were men and 57 (39%) were women²
- > The HIV prevalence rate is generally low
- > Efforts are currently focussed on prevention (e.g. PMTCT)
- > The HIV response is part of a larger STI response
- > STI levels are high and in some cases increasing
- > While HIV rates are still very low, high STI rates reveal a high level of risk behaviours and vulnerability to HIV.

1 <http://www.unaids.org/en/resources/documents/2017/90-90-90>

3 Data not available for all countries.

2. Project approach

The project follows the recommendations laid down by the International Partnership of the PLHIV Stigma Index in the 'PLHIV Stigma Index User's Guide'. The regional project was designed to involve a 2-phase approach in each country: a country visit by the project coordinator and project researcher to meet the Ministry of Health counterparts, which would then facilitate the second phase visit by the survey team to conduct the interviews. Given the distances and costs involved in getting from Fiji to some of the countries, the phases were merged to allow the visit with country officials to take place in the first few days, immediately after which, the survey team then conducted the peer interviews.

The regional project was managed and conducted by the Fiji Network for People Living with HIV (FJN+) based in Suva, Fiji. The questionnaire and methodology used are the official PLHIV Stigma Index questionnaire (English version) and PLHIV Stigma Index User Guide endorsed by the global partnership of UNAIDS, GNP+ and ICW published in 2008.

Scope of the project

The project included the Republic of the Marshall Islands, Federated States of Micronesia, Kiribati, Palau,

Samoa, Tonga and Vanuatu. Tuvalu was initially part of this study, however certain challenges ruled out the possibility of conducting the study there.

In total, 32 people completed the questionnaire from a total of seven countries. The break down of respondents per country can be found in the following table along with the numbers where additional qualitative data was collected in follow up interviews:

Country	Number of people reported to be living with HIV per country ³	Number who participated in this study	Case studies/ follow up interviews
Republic of Marshall Islands	8	5	1
Federated States of Micronesia	9	6	3
Kiribati	28	4	3
Vanuatu	6	5	4
Tonga	4	3	3
Samoa	11	7	3
Palau	5	2	0

References to specific data have not been attributed to countries in this report in the interest of maintaining confidentiality. In almost all cases actual numbers, rather than percentages have been referred to. Where a percentage is mentioned, the number follows in brackets (N=).

³ Based on UNAIDS GARPR data from 2016.

3. THE FINDINGS

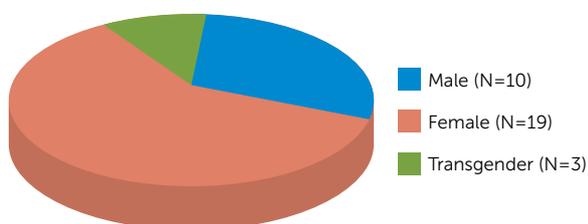
A. Personal information about the participants

The following gives some basic information about participants and the diversity of profiles of people living with HIV in the Pacific.

1. Sex of participants

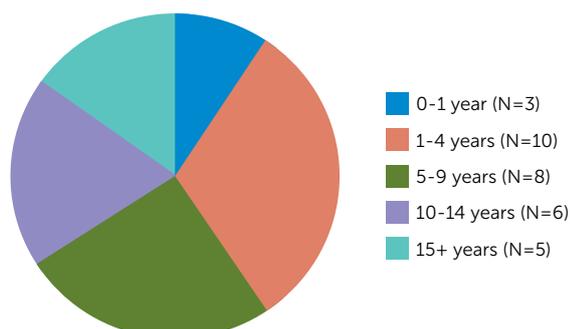
Sex	Number (N=)	Percentage
Male	10	31%
Female	19	59%
Transgender	3	10%
TOTAL	32	100%

A high number of females took part in the study. This could be in part because they were more willing to come forward, however it does remind us that the epidemic has a heterosexual face.



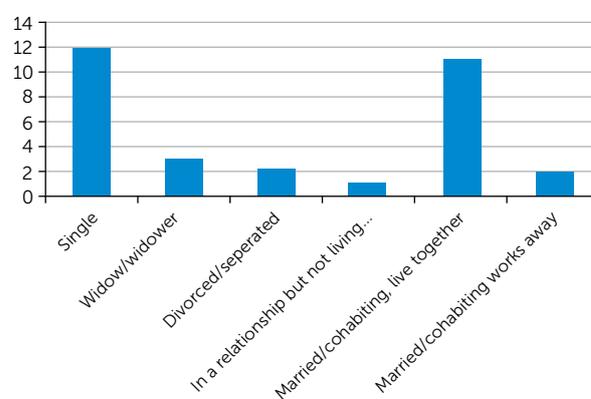
2. Length of time living with HIV

A large number of people who were diagnosed in the last 4 years were willing to come forward and talk about their experiences. Further research could be conducted on how experiences of testing and counselling have changed over time.



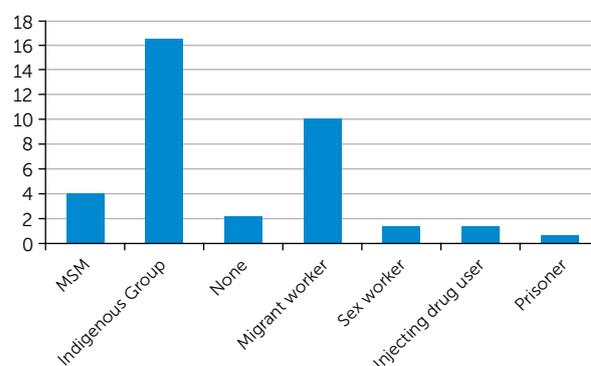
3. Marital status

Over half of the respondents are not in a relationship, with 12 out of 32 being single. Seven of those in a relationship have been in the relationship for 10 years or more.

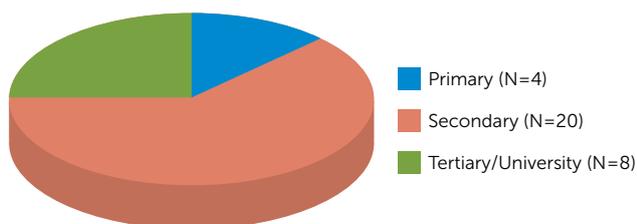


4. Participants were asked to indicate from a list if they had ever belonged to a key population (multiple answers permitted).

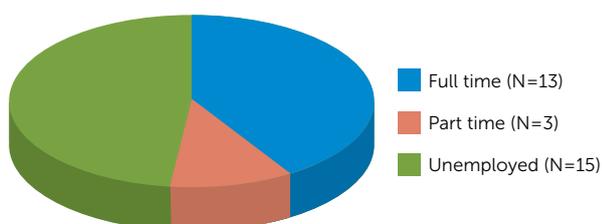
The category of seafarer was not included in the list, which could have been relevant in the context of the Pacific, and many identified as being indigenous (N=18), however this would not be a minority group in the context of the Pacific islands. Eleven out of 32 people (34%) said they had never belonged to any of the groups listed.



5. Level of education



6. Level of employment



Education levels are high with 63% completing secondary level education this is in keeping with national statistics. Employment rates are low.

7. Household income

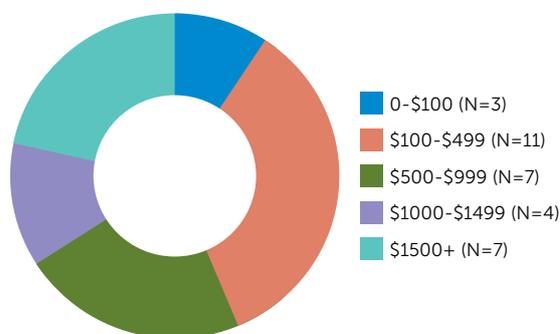
Fifteen (out of 31) respondents reported going some days in the last month with a member of their household not having enough to eat. This varied from 20 days to 1 day. Nine people reported 1-4 days, two people reported 5-10 days and four reported 11-20 days. The number of days of food shortage may be linked to economic hardship experienced by some families in this study. Furthermore, food insecurity established for the PLHIV household in this study could also have adverse effects for PLHIV with regards to their HIV management, ARV treatment, and especially adherence for this group.

The chart below shows monthly income levels in US dollars. Out of 32 respondents, 14 (44%) of households with PLHIV are surviving on less than \$500 USD per month. Household sizes ranged between 2 and 20 people of all ages with the average being 8 people per household. Further analysis of

the data revealed only 12 households (38%) had an income of more than \$100 per month per person, and only 8 (25%) had an income of over \$250 USD per person per month.⁴ This indicates that there are many households surviving on very little and the costs required to, for example, go monthly and collect ARV medication must represent a significant burden to the household.

“It’s expensive now to come and get my treatment, almost \$6 USD. I am hungry most of the time.”

“Financial support to pick up ARVs is a struggle as I either ask my sister or weave mats in our women’s group to be able to get financial assistance to pick up treatment. I also get [\$59 USD] from a leprosy NGO for hardship support.”



Seven out of 32 people had been forced to change their residence in the last 12 months and three of them said it was because of HIV. Four people had lost work in the last 12 months, all stating HIV as the reason for the loss – two because of discrimination from a boss or co worker and two due to ill health or a combination of poor health and discrimination. In the last 12 months, three people had been refused employment or a work opportunity because of their HIV status due to either poor health or discrimination. Five people had been denied health services (including dental care) in the last 12 months because of their HIV status.

⁴ To give some benchmarking data a yearly minimum wage according to <https://www.minimum-wage.org> for Palau and Vanuatu is \$5,200.00 USD, Samoa \$2828.00 USD, FSM \$2600 USD.

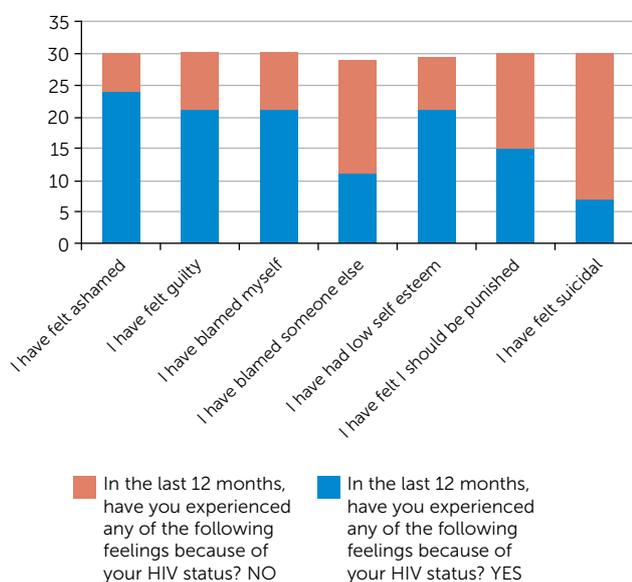
B. Self-Stigma

Participants were asked if they had experienced shame, guilt, blame, punishment, and suicidal thoughts in the past 12 months. Over 70% (N=16 or more) of respondents had felt ashamed, guilty, blamed themselves or had low self-esteem in the last 12 months and seven individuals (22%) had felt suicidal.

“When I knew I was HIV positive I thought about suicide because I was so ashamed of it. I grew up knowing that HIV is one of those diseases that nobody should sit close to you, it’s really discriminated against and learning that I has HIV I told my husband that that’s it for me, I am going to take my own life. I was so ashamed and then my husband told me not to do it, we should pray and I should think about the kids.”

Levels of self-stigma across the region were fairly high, this included emotions relating to self stigma but also actions they had taken to self exclude themselves socially, from health services and from education or employment.

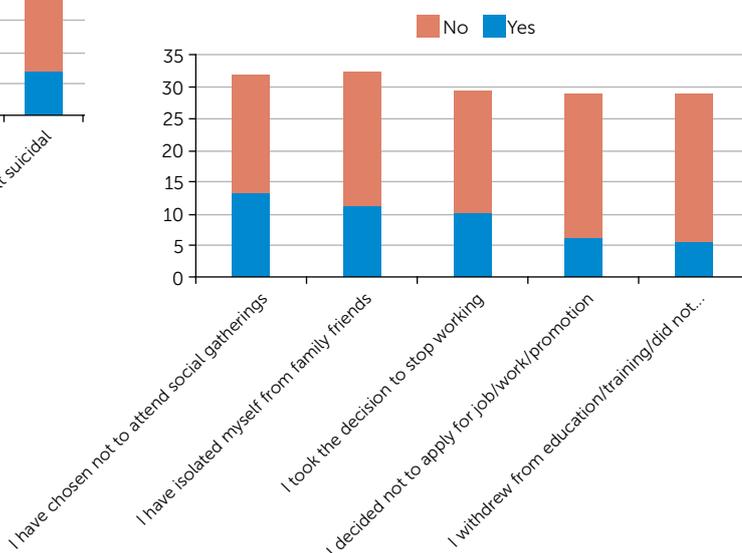
8. Emotions relating to self stigma



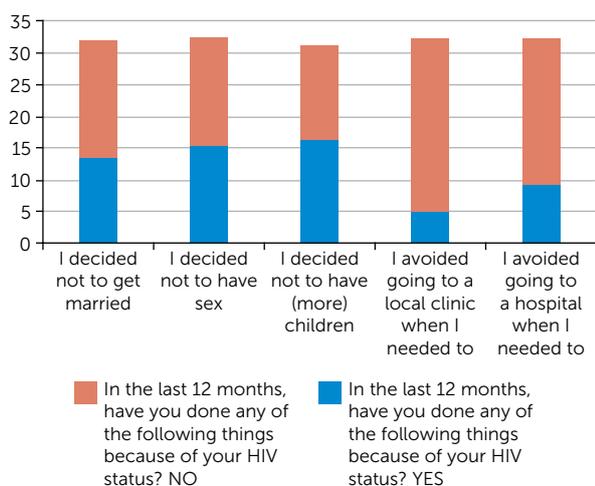
The table below shows the disproportionate number of men who had experienced self stigma feelings in the last 12 months.

	YES			NO			TOTAL
	Male	Female	Trans gender	Male	Female	Trans gender	
I have felt ashamed	N=10	N=13	N=3	N=0	N=6	N=0	32
I have felt guilty	N=10	N=11	N=1	N=0	N=8	N=2	32
I have blamed myself	N=9	N=11	N=3	N=1	N=8	N=0	32
I have blamed someone else	N=4	N=7	N=0	N=6	N=11	N=3	31
I have had low self-esteem	N=7	N=13	N=0	N=3	N=5	N=3	31
I have felt I should be punished	N=6	N=9	N=1	N=3	N=9	N=2	32
I have felt suicidal	N=4	N=3	N=0	N=6	N=16	N=3	32

9. Social, employment and education self exclusion emotions relating to self stigma

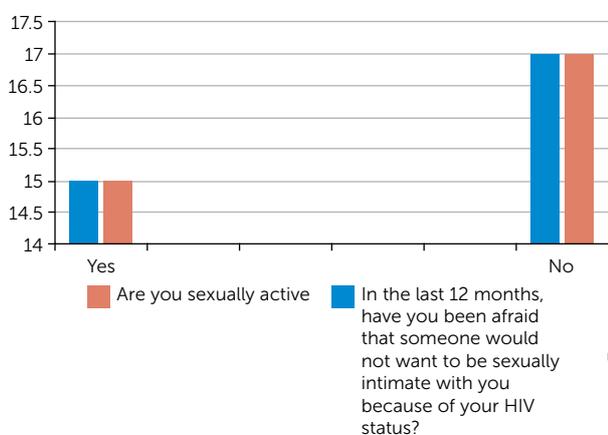


10. Intimate relationship and health care self exclusion



With nearly 41% deciding not to get married (N=13 out of 31), 47% not to have sex (N=15 out of 32) and 50% not to have (more) children (N=16), it seems that the important messages about treatment (e.g. having an undetectable viral load means it is not possible to transmit the virus) are not getting through.

11. Sexual relations



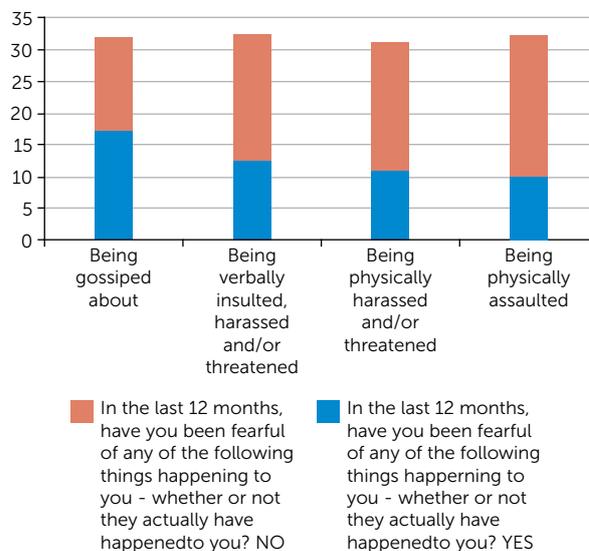
12. Actual experience of violence

Six people said they had experienced verbal insults, harassment and/or threats in the past 12 months and of those, 4 attributed it to their HIV status. Five

people had been physically assaulted in the last 12 months and three attributed this to their HIV status. Two people reported having been subjected to psychological pressure or manipulation by their husband/wife or partner in which their HIV-positive status was used against them. Only one person reported sexual rejection as a result of HIV status, which given the context is probably to do with low levels of disclosure to sexual partners.

Five people reported that their family members had experienced discrimination as a result of their HIV-positive status.

13. Fear of victimization



Gossip

In addition to the question above, respondents were asked if they were aware of being gossiped about in the last 12 months, 18 respondents said they had been aware of it happening usually more than once (N=17), and 16 identified HIV as the reason for that gossip.

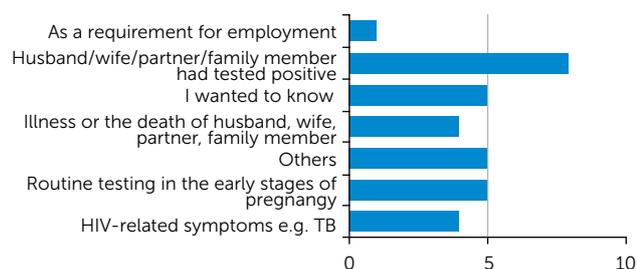
“People always talk about me because of my many (sexual) partners, and until now I don’t know who I got infected from.”

"I did not tell my family, only my partner knew my situation but sometimes my brothers they call me and ask if I am HIV positive but I don't reply. I don't know where the gossip is coming from."

"... when we got discharged from the hospital [my brother in law] stopped coming to [visit] us and people started looking at us differently and treating us differently just when we got out of the hospital."

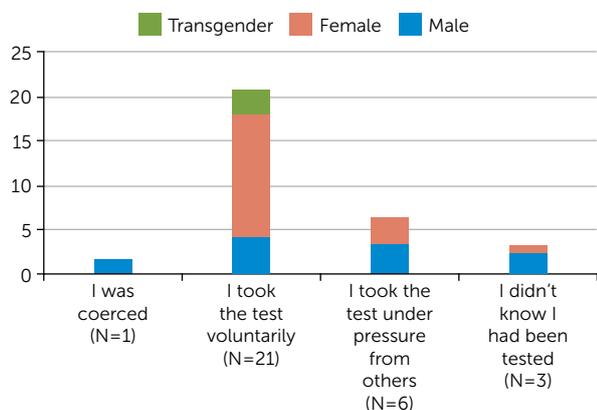
Testing and diagnosis

14. Reasons for getting tested



Reasons given in the 'Others' category included as membership of a sports team, for permanent immigration purposes and as part of a blood donation screening.

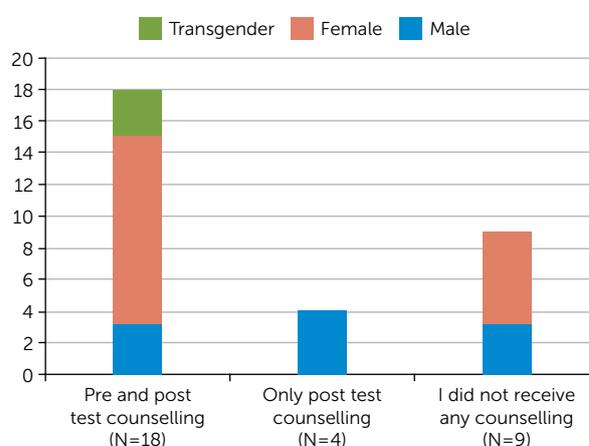
15. Whose decision was it to test you for HIV



Twenty-one respondents reported that they had taken the test voluntarily, three people were tested

without their knowledge, one was coerced and six were made to take the test under pressure from others.

16. Counselling



As can be seen here, men are particularly poorly served when it comes to counselling.

"I think that testing is private and I don't see any problems, and I think I get good support upon my diagnosis."

"They have a lot of problems. Although they have put in place a lot of testing sites but people don't go and get tested. People don't trust the health care workers to keep their results confidential."

When people were asked why they thought they had experienced stigma and discrimination in the last 12 months, 13 people responded "People are afraid of getting infected with HIV from me"; 7 said "People think that having HIV is shameful and they should not be associated with me"; 4 believed it was "Religious beliefs or moral judgements" and 11 were uncertain of the reasons.

Rights

Non-disclosure can often be a reason for a person not to be on the receiving end of stigma and discrimination and therefore not needing to seek redress.

Only five respondents knew about national laws, policies or guidelines which protect the rights of people living with HIV.

“There is no legislation to protect PLHIV in this country and we need laws and guidelines to protect PLHIV.”

One person had been ‘detained, quarantined, isolated or segregated’ and two were ‘forced to submit to a medical or health procedure’, however nine people were unsure if their rights as a person living with HIV had been abused and only one person was seeking legal redress for which the outcomes was not yet known. Reasons given for not seeking redress included feeling intimidated or scared to take action (N=1), and no/little confidence that the outcome would be successful (N=1).

“The biggest challenge is my capacity and ability to be a potential advocate. I fear I might say something wrong. I am worried about my elder children and how this can have an impact on their lives.”

Effecting change

Six respondents reported having confronted, challenged or educated someone who was stigmatizing and/or discriminating against them in the last 12 months. The organisations or groups respondents knew about to go to for help if they experienced stigma or discrimination were: local NGO (N=5); faith based organisation (N=4); human rights organisation (N=1); legal practice (N=1); national NGO (N=2); National AIDS Council or Committee (N=2); international NGO (N=2); and ‘other’ (N=8), which included hospitals and STI clinics. No one identified a PLHIV support group (N=0). Five respondents have sought help from one of the above organisations.

“As PLHIV, I will come to the STI clinic and I don’t know any other organisation or person”.

Eleven respondents had supported other people living with HIV in the last 12 months both emotionally (N=9), physically (e.g. money or food, doing an errand for them) (N=7) and giving a referral to another service (N=2).

Only two (both female) people reported being a member of a people living with HIV support group and/or network. Three people (all from Samoa) have been involved, either as a volunteer or as an employee, in any programme or project (either government or non-governmental) that provides assistance to people living with HIV.

Disclosure and confidentiality

Non disclosure is very high across the region and many people have not told hardly anyone, choosing to keep the information to themselves largely due to fear of gossip, discrimination and losing face.

“I am not ready to share my status or disclose myself to public, I am afraid of being isolated, stigmatized, and discriminated against. For me its good for me to only know my status rather than disclose it to other people.”

Twelve people self identified as single, and of the remaining 20 only 9 had informed their spouse or partner themselves about their HIV status. Two had someone else tell them on their behalf, two people had someone else tell them without their permission, and two people had not told their spouse or partners. Seven did not answer.

“I don’t have any problems for testing, however even though I am married to a PLHIV, when I first knew that I am infected only I knew my status. The challenge is that her partner did not tell her that he is HIV+.”

“My husband was tested back in Fiji so my husband had to hide it from me until my sister saw the brown envelope with my husbands result HIV+. It was very hard for me

to accept it, but after counselling then she understood what being HIV positive meant.”

“I felt very scared because my wife might leave me and I will be alone.”

Non-consensual disclosure to other adult family members was high at 5 out of 32, and a further 9 had not disclosed to another adult family member. Out of the 23 whose family knew about their status, 17 had got a supportive or very supportive response and 5 had got a discriminatory response.

“ (I am) scared of being disowned”

Only 2 people had disclosed their status to their children and 25 had not disclosed to children in their family.

“My only problem at the moment is how will I disclose my status to my children and how they will cope once they know I am HIV positive.”

“I didn’t know anything, my mother disclosed my status [to me] when I grew up then I knew I am HIV+.”

Twenty out of 32 people had not chosen to tell their friends or neighbours about living with HIV, with non-consensual disclosure happening for 4 respondents. Only 7 respondents had disclosed to another person living with HIV and 16 said no other PLHIV knows their status. Of the 12 whose friends or neighbours knew about their HIV, 5 reported receiving a discriminatory response.

“People are ashamed to disclose because of the stigma from community and confidentiality. Some people will keep my status private and some will spread it.”

Six respondents had willingly disclosed to their religious leaders with a further 23 choosing not to disclose at all, and 4 reporting that someone else had told them without their consent. One person said the response was discriminatory.

Eight respondents had willingly disclosed to health care workers with a further 6 choosing not to disclose at all and 7 reporting that someone else had told them without their consent and 7 reporting that someone else had told them with their consent. Five people said this was not applicable to them.

“I don’t know but I don’t like the hospital staff sometimes because I think they spread the news about my status and sometimes I don’t want to get my medicine because of the hospital staff.”

“When my son gets admitted he is always isolated and branded [labelled] that he has a communicable disease. The ward assistant labels my sons utensils to ensure that he does not share them.”

When asked if disclosure was an empowering experience 20 said yes, 6 said no and 5 said this was not applicable to them.

Nineteen people felt that their medical records had been kept confidential, 9 were not sure and 4 knew that their records were not kept confidential.

Treatment

Twenty-eight out of 32 respondents were taking treatment at the time they were interviewed and three of those that were not were all from the same country, where at least two have defaulted on treatment largely due to a lack of information.

“The reason why I am not on treatment is that my partner is not on treatment, so what is the use of me taking the treatment when we are having marriage intercourse and we don’t use prevention. We don’t use any prevention so I don’t see why should I take treatment when he is not on it”

“I think the main problem is we still have not admitted [to ourselves that] we are living with HIV.”

Others reported treatment interruptions due to problems with the supply chain management.

"The greatest challenge for me is the financial part of getting a monitoring test and collecting treatment, so I feel that we should have them to come to us and promote testing."

"Sometimes I run out of medicine for 2 days before the health care workers bring my supply."

"Coming to 'Island A' from 'Island B'*. The boat fare and then the taxi fare plus the distance is far."

"The challenge is picking up my drugs as I sometimes wait for my husband to get paid [to be able] to come. So I am asking for a ration of 2 months instead of 1 month."

"Accessibility of ARV in my island is a big problem because sometimes it is delayed and it will force me to stop [taking medicine] and wait for the next plane to get my ARV."

"In my case, access to ARV is a problem because I live in the outer island and the boat only comes every 3 weeks. I am not working but I will find ways to come to the mainland for my ARV."

"Lack of expertise in administering treatment, not enough information on ARV is my biggest problem."

Four respondents reported not having had a constructive discussion with a health care worker about their treatment options in the last 12 months. Twenty reported having had a constructive discussion with a health care professional on other subjects such as sexual and reproductive health, sexual relationships, emotional well-being, drug use, etc. in the last 12 months. From the qualitative data, respondents raised the following problems and challenges:

"I think my medicine is not working because I am very sick."

"The side effect of ARV was a problem for me and I need to know my treatment well. I take a medicine, I don't even know if it's working or not."

"The ARV is okay but I think our drugs need to be kept in the fridge so my medicines are kept at my neighbours house."

"There is no problem with the medicine except sometimes my doctor is not at the hospital, I can't get my medicine."

"The problems were of transport, food, no proper medication and only one doctor looking after every patient and her."

"The pill burden for my son is a challenge, I have to come up with a strategy for him to like his ARV treatment. Otherwise he wants to vomit. My son has been a peer support for both our medication and he reminds me to take my medication. Dealing with my son's other infections/poor health is a challenge"

Having children

There was a lot of misinformation relating to having children that are free from HIV and some did not know this was possible. From the qualitative responses, respondents raised the following problems and challenges:

"I have heard that if a pregnant women is HIV positive then the mother or baby can die during birth."

"I don't want to have children, it's a barrier for me to look after children because I am HIV positive."

"I am worried that the baby is going to be HIV positive"

"I was confused and I didn't know how to feel if my baby was positive. I had a c-section and unfortunately my baby died."

"If the baby is negative I won't have any problems. But if the baby is positive you can't count the problems. What if the child gets older and does not accept their status, what if the child choose to stop taking ARV..."

"I'm afraid the child might get infected. Also I don't know much about PPTCT and I think I need to learn more about it."

Nineteen of the respondents (59%) have children, five of whom have positive children.

Eighteen respondents had received counselling about their reproductive options since being diagnosed. Seven out of 28 (25%) had been advised by a health professional not to have children after their HIV diagnosis,

"I think that health staff should be more encouraging to have children and live a normal life. I want to have children."

"I was told I shouldn't have more children because they will suffer because I have HIV. I wasn't told about PPTCT."

Four people reported being coerced into sterilization by a health professional after their HIV positive diagnosis, one had been coerced into the method of giving birth and one had been coerced on infant feeding practices. Three people reported that their ability to obtain antiretroviral treatment is conditional on the use of certain forms of contraception.

"I find it hard to have children at the moment but if my health gets better I will have a wife and I need to have a child."

"I feel that little attention is provided for positive mothers and positive children. Right now there is no support for them. I feel they need peer support and financial support to be able to cope well with treatment and living with HIV."

Five women had been given antiretroviral treatment to prevent mother-to-child transmission of HIV during pregnancy (PMTCT). One woman reported that she did not have access to such treatment.



4. CONCLUSION

Although small in scope, the evidence gathered presents a unique insight into the situation facing people living with HIV in the Pacific region, one that has been so rarely seen before. The evidence provides a framework for action to improve the isolation, stigma and discrimination faced by the participants and to reduce stigma and discrimination for the good of everyone.



5. RECOMMENDATIONS

- A. The PLHIV Stigma Index research was undertaken and led by PLHIV, in this case from Fiji, however this should be an example to decision makers and those working in the health movement of what capacity, willingness and lived experiences PLHIV have to offer. The meaningful involvement of people living with HIV in the design, development and implementation of decisions, policies or programmes relating to them is not only empowering but will also lead to more effective programming. Currently the levels of involvement and opportunities to take part in the HIV response, either through government or NGO run programmes as paid staff or as volunteers is zero in all countries except Samoa (N=3).
- i. Establish HIV platforms with the inclusion of PLHIV as representatives of their communities.
 - ii. Facilitate peer support groups and cover the costs to run them.
 - iii. Support leadership development from the PLHIV community.
 - iv. Design and/or strengthen specific HIV policies and laws that safeguard the privacy, health and general wellness of PLHIV.
 - v. Adopt national HIV champions (preferably people living with HIV), who are influential and widely respected by all stakeholders, to advocate HIV prevention messages as well as address health, wellness, stigma and discrimination issues for PLHIV.
 - vi. Establish PLHIV peer support groups at the communal, national and regional levels to reflect and safeguard our interests including providing information, support and advocacy.
- B. Work in partnership with relevant government, civil society and faith-based organisations to raise awareness of HIV with the public, in communities and the family with a view to supporting and understanding PLHIV and their human rights. In the case of religious leaders, encourage the use of religious scriptures to support their positive interventions. Use existing tools, e.g. the Framework for Dialogue <http://www.frameworkfordialogue.net>, to bring together PLHIV and religious leaders, community leaders and health care workers to discuss face to face the findings of this study.
- C. Develop and implement culturally sensitive, gender sensitive, effective and sustainable programmes involving people living with HIV that address:
- Rights of PLHIV and seeking redress for the abuse of those rights.
 - Stigma and discrimination coping strategies.
 - Identify communities that are more vulnerable to HIV (key populations) and address their needs.
 - Bridge information gaps and support gaps for the families of PLHIV.
 - Ensure confidentiality is understood and maintained and support disclosure.
 - Educate on having children and looking after children living with HIV.
 - ARV treatment literacy, management and adherence.
 - Overcoming internal fears.
 - Prevention, including prevention of onward transmission for PLHIV.
 - Strengthen the resilience of PLHIV and their family members and support networks.
 - Economic hardship/income generation.
 - Food security and nutrition.
- D. We now have the evidence and can see where the problems areas are, where PLHIV are experiencing stigma, and this allows governments and NGOs to make targeted interventions to address underlying prejudices.
- Health care**
- i. Provide cost-effective, responsive and sustainable HIV and AIDS continuum of care to a widely dispersed spread of islands.
 - ii. Assess confidentiality of current HIV and STI testing sites and feasibility of relocating sites to more discrete locations.

- iii. Develop and conduct an 'Effective and safe disclosure procedures and programmes' training with health care workers (which protect and enhance the well-being of PLHIV), including mental health components, in line with HIV and STI treatment guidelines and protocols.
 - iv. Review existing protocols and Standard Operating Procedures (SOP) for all HIV-related issues to ensure they are in line with new global guidelines, e.g. WHO's June 2017 Consolidated guidelines on person-centred HIV patient monitoring and case surveillance (<http://www.who.int/entity/hiv/pub/guidelines/person-centred-hiv-monitoring-guidelines/en/index.html>).
 - v. Review and strengthen protocols and guidelines to address breach of confidentiality concerning PLHIV information amongst health care workers.
 - vi. Ensure that minimum standards for quality of care are established and maintained to effect healthy life choices and the well-being of PLHIV.
 - vii. Strengthen the testing process to ensure HIV testing is part of the earliest tests for all pregnant mothers to facilitate prevention of mother-to-child transmission.
 - viii. Make hospitals, clinics, dental clinics, etc. stigma free zones.
 - ix. Provide a system for complaints and redress in the cases where rights have been abused.
 - x. Empower PLHIV to disclose to health care workers where it may have a bearing on their own health or where they are uncertain.
- E. Increase the agency of PLHIV. PLHIV do not have information about treatment options and largely do not understand what the cascade of treatment, care and support should look like for them. Giving them the opportunity to take control of their health and understand what is happening will lead to far better health outcomes. Treatment literacy will inform and empower people living with HIV in the Pacific region. Information is power and, without access to the information, isolation and ill informed decisions are being made by people living with HIV.
- i. Giving training to PLHIV (male, female and transgender) to be counsellors would be a way of skilling up PLHIV, providing them with an income, and ensuring networks and connections are made to help overcome isolation.
 - ii. Build their capacities to better understand their health condition and to become agents of change.
 - iii. A regional 'buddy' system should also be considered to link people together (via social media) to share experiences and support one another. This could be done regionally.
- F. Increasing public awareness of HIV and STIs and using up to date information will help drive down stigma and discrimination. As one interviewee said, "we are still in the dark ages as regards HIV." Stigma and discrimination is profound and it seems largely based on out dated information about HIV. Public awareness campaigns will open up the opportunity for discussions around HIV, this will help shift the taboo that exists around discussing issues relating to sex. Lifting this taboo will enable people to be in a stronger position to negotiate safe sex. In the quantitative responses, there were still many, many references to separation of cooking utensils indicating a general ignorance about modes of transmission of HIV.
- i. Review and strengthen existing campaigns.
 - ii. Implement new innovative public campaigns using gender and culturally sensitive language that talk openly about HIV and STIs, and include myth-busting.
 - iii. Incorporate storylines into existing popular tv / radio dramas which sensitively address some of the issues.
 - iv. Use social media.
 - v. Ask popular local celebrities to talk about these issues in public.
 - vi. Share such campaigns across the region.

vii. Work with community and religious leaders to educate them and encourage them to give well-informed and positive messages to their communities.

G. Review existing IEC material and improve it by providing more targeted information for women, men and transgender people living with HIV on their reproductive health, sexual health and family planning, including provision of training on coping mechanisms for PLHIV parents, as well as PPTCT and PMTCT, nutrition, mental health and general well-being.

H. Levels of self stigma, disclosure and social self exclusion were high, and many were meeting another person living with HIV for the first time. Such levels of isolation are of great concern and in an era of global communication this should not be the case. More information should be available to PLHIV for how they can seek peer support. Part of the solution is a sub regional network of people living with HIV which would help reduce the feelings of isolation. Though there has been in the past, there is no longer such an organization. The Asia Pacific Network for PLHIV has supported the work of Fiji in the past, however it covers a huge number of countries and is overstretched.

The 1983 Denver Principles advised that people living with HIV must form caucuses to choose their own representatives, to deal with the media, to choose their own agenda and to plan their own strategies.

The communications strategy for such a network will be vitally important and time and investment should be given to ensure it is sustainable and takes advantages of improvements in technologies as well as identifying their shortcomings. For example: Use of moderated and closed group discussions on social media as a way of sharing experiences, asking questions and informing people living with HIV across the region.

i. Governments can support individual's self-determination through participation in such networks and regional (Asia Pacific) and global events. This will give important connections to global advances in HIV treatment and care that may improve their quality of life.

ii. Promote and establish on-going wellness and psychosocial support to PLHIV and their affected spouses, partners, families and children including peer, financial and other support for PLHIV mothers and their HIV positive children.

iii. Improved counselling over time can help overcome feelings of self stigma and low self esteem especially in the early stages. In the context of HIV there may be a need for counselling at different points in a persons life so the counselling should be made available at anytime, especially in the context of geographic and psychological isolation. Men diagnosed with HIV are not being included in counselling and this must be improved on.

iv. Promote and provide wellness and psychosocial support to PLHIV and their affected spouses, partners, families and children through the establishment of special interest groups or organisations in partnership.

I. Addressing issues of poverty, many of the PLHIV included in the survey had very low incomes, lived in households with many others and were reporting significant days without adequate food for members of their households. Adherence and efficacy of antiretroviral treatment could be greatly affected by poverty and inadequate food. Taking medicine on an empty stomach is largely not recommended and some ARVs have very strict instructions about taking with food. Furthermore, poverty will affect a persons ability to access the centre to collect their medication, which most are still being asked to do on a monthly basis in spite of the high cost of transport. Health Ministries should consider:

i. Providing ARVs for longer than 1 month at a time to everyone.

ii. Ensuring people only need to travel once (i.e., to complete monitoring blood tests – CD4 and Viral Load – and to collect their next prescription).

iii. Consider subsidizing transport costs to PLHIV.

iv. Develop and implement sustainable food security policies and programmes for PLHIV,

their families and communities to support ARV treatment, management and adherence.

J. Further research and more in-depth analysis of the quantitative and qualitative data collected by this study, including cross analysis to understand how change has occurred over time, e.g. pre and post test counselling according to time since diagnosis will reveal if the situation has improved for people who were diagnosed 1-4 years ago.

- i. Additional research to support the development of supportive laws, policies and programmes which provide support for PLHIV to live full and rewarding lives free from discrimination.
- ii. An analysis of coping strategies of PLHIV in relation to stigma and discrimination; issues such as disclosure, non-consensual disclosure, internalised stigma and fears, self-imposed isolation and others.



6. LESSONS LEARNT: THE IMPLEMENTATION OF THE REGIONAL PLHIV STIGMA INDEX STUDY

The following represents some of the successes and challenges faced by FJN+ implementing the multi country study.

Successes

1. Data was collected from 7 countries and the reports for each have been finalized.
2. The data will be included in global data (by UNAIDS) which is used to inform high level decisions about stigma and discrimination,
3. The Stigma Index has provided a channel for the voices of PLHIV to be heard by their own governments and beyond in a way that has never happened before.
4. This is the first time that stigma and discrimination has been researched in such depth in the Pacific region in a process driven by PLHIV.
5. Connecting FJN+ with people living with HIV and doctors and nurses working closely with PLHIV across the region.
6. Peer to peer support has been a key to PLHIV participation. Once the potential interviewees know that the interviewers are also living with HIV they are willing to talk to us.

"At first I was skeptical about coming here when I was first asked to come for the interview, but since you mentioned that you were also HIV positive I immediately felt more comfortable and able to speak [openly] with you. Thank you."

7. For many it was the first time they had ever met another person living with HIV.

"Now you are the very first one [PLHIV] I ever met. Since I have been on the medication I never met anyone, you know, like a counselor or peer advocate but you are the first one and I am glad you are from an island too."

8. Interviewees were asked about their willingness to be more public about their status and after meeting the interviewers many were willing to be part of the response and being more open about living with HIV.
9. Some of the interviewees had poor adherence and some had even given up (defaulted) with ARVs. Through this process we were able to encourage

them to return to the medication by explaining the benefits (e.g., FSM, Kiribati, RMI),

10. Kiribati had their first ever PLHIV meeting straight after the SI interview.

Challenges:

1. Sampling was difficult since the stigma is high and the numbers of PLHIV in each country very low, however there were additional difficulties as the health care workers were often very enthusiastic gatekeepers to participants. Since there are no support groups or platforms where PLHIV are meaningfully involved, the only people who could reach PLHIV were the medical staff.
2. It took a long time to obtain ethical approval for the studies in each country which meant the project experienced delays.
3. Data collection in the seven sites occurred over a period of 12 months (December 2016 – November 2017).
4. Shifting timelines made it hard to ensure the commitment of freelance human resources to support the technical aspects of the project.
5. Not enough funds to cover human resources to manage the project and provide financial management for the project. This has hampered the continuity of the work. For future work of this caliber, hiring a qualified finance person would be crucial.
6. The concept held by many health care workers that meaningful involvement of PLHIV can only be implemented when PLHIV are out in the open, needs to be undone. PLHIV still can be involved in decisions affecting their lives and maintain the confidentiality of their status.
7. At the report writing stage, the small numbers of people in each place meant maintaining confidentiality of responses has been more complex (it is for this reason quotes have not been attributed, not even to the country they originated in).
8. In some cases getting the governments on side with the study took longer than anticipated, largely due itself to stigma and a belief there is no HIV (e.g. Tuvulu) or that they did not want to draw attention to the subject.



7. AFTERWORD

It is with great sadness that we learnt of the death of one of the participants since the interview took place. Let this record that includes her responses be a memorial of her life, at least that part of it that involved HIV.



8. REFERENCES/RECOMMENDED FURTHER READING

UNAIDS 2017: 'Confronting discrimination: Overcoming HIV-related stigma and discrimination in health care settings and beyond.' (http://www.unaids.org/sites/default/files/media_asset/confronting-discrimination_en.pdf)

HIV, human rights and gender equality. Technical brief. Geneva: The Global Fund to Fight AIDS, Tuberculosis and Malaria; 2017.

Political Declaration on HIV and AIDS: On the Fast-Track to Accelerate the Fight against HIV and to End the AIDS Epidemic by 2030.. New York: United Nations General Assembly. 2016.

UNAIDS special analysis, 2017 (methods described in Ending AIDS: progress towards the 90–90–90 targets. Geneva: UNAIDS; 2017).

Demanding access to justice: UNAIDS spearheads establishment of the Coalition of Lawyers for Human Rights. Geneva: UNAIDS; 2016 (<https://results.unaids.org/sites/default/files/documents/Nigeria%20Case%20Study.pdf>).

United Nations Development Programme, UNAIDS, United Nations Economic and Social Commission for Asia and the Pacific. Review of country progress in addressing legal and policy barriers to universal access to HIV services in Asia and the Pacific. Bangkok: United Nations Development Programme; 2016 (<http://www.aidsdatahub.org/sites/default/files/publication/rbap-hhd-2016-review-of-country-progress.pdf>).

HIV and adolescents: guidance for HIV testing and counselling and care for adolescents living with HIV. Geneva: World Health Organization; 2013.

Strengthening the capacity of community health workers to deliver care for sexual, reproductive, maternal, newborn, child and adolescent health. Technical brief by the H4+ (UNAIDS, UNFPA, UNICEF, UN Women, WHO and the World Bank). Geneva: World Health Organization; 2015.

Greater involvement of people living with HIV (GIPA). Good practice guide. International HIV/AIDS Alliance, Global Network of People Living with HIV; 2010 ([http://www.aidsalliance.org/assets/000/000/411/464-Good-practice-guide-Greater-involvement-of-people-living-with-HIV-\(GIPA\)_original.pdf?1405586730](http://www.aidsalliance.org/assets/000/000/411/464-Good-practice-guide-Greater-involvement-of-people-living-with-HIV-(GIPA)_original.pdf?1405586730)).

Ten reasons why criminalization of HIV transmission harms women. Athena Network [website] (<http://www.athenanetwork.org/our-work/promoting-sexual-and-reproductive-health-and-rights/10-reasons-why-criminalizationharms-women>)







**THE PEOPLE
LIVING
WITH HIV
STIGMA
INDEX**

