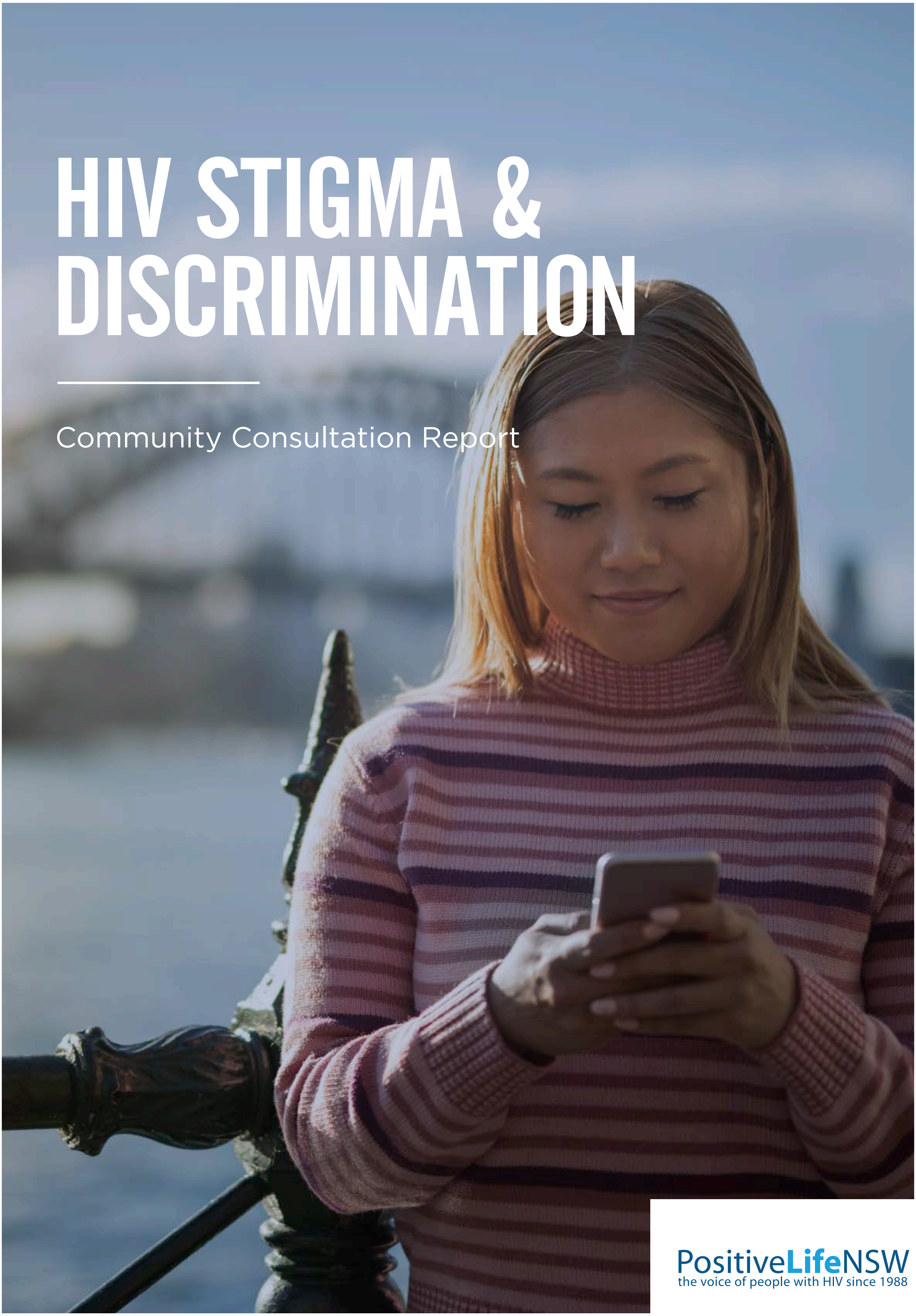


HIV STIGMA & DISCRIMINATION

Community Consultation Report

PositiveLifeNSW
the voice of people with HIV since 1988

Executive Summary

The community consultation highlighted and confirmed that HIV stigma and discrimination is a daily reality for people living with HIV (PLHIV). These included the impact of repeated trauma, shame and 'othering' causing extra burden for PLHIV from clinicians and systemically.

Trauma of repeated HIV stigma and discrimination

Many participants living with HIV talked about the traumatic experience of repeated HIV stigma and discrimination which forms a barrier to our ability to engage with, access and navigate health services. Clinicians shared how colleagues can unwittingly perpetuate stigma with their patients prolonging shame and trauma. Participants from a culturally and linguistically diverse (CALD) backgrounds shared how language barriers further confounds experiences of stigma and blocks PLHIV from receiving appropriate health care.

The burden of stigma and discrimination

A transgender woman spoke about the burden of shame and the risk of isolation for people when they internalise negative feelings arising from stigma and discrimination. All participants mentioned the 'education burden' they feel as they're constantly having to educate others and challenge HIV stigma and discrimination, among personal within health care settings. A clinician shared how her colleagues unwittingly impose extra burdens of secrecy and shame on patients.

Othering and second-class citizens

A Japanese gay man living with HIV shared how stigma and discrimination gave him feelings of being a 'second class citizen'. This 'othering' negatively affected his self-esteem and reduced his access to clinical services.

Strategies of response

Participants were agreed around the importance of PLHIV confronting stigma and developing our own strategies for managing stigma and discrimination. Participants discussed the role of developing relationships with our clinicians to mitigate stigma and discrimination in clinical settings.

The community consultation highlighted and confirmed that HIV stigma and discrimination is a daily reality for people living with HIV

On Saturday 29 September 2018, Positive Life NSW (PLNSW) engaged and consulted with people living with HIV (PLHIV), HIV service providers and other sector representatives about the impacts of stigma and discrimination on PLHIV. In particular, how HIV stigma and discrimination impact on our ability to remain engaged with and navigate our own health needs in the health system.

Approx. 35-40 people attended the forum made up of PLHIV community members, the HARP Unit and service industry personnel. The room was laid out with chairs surrounding large circular tables with the aim of encouraging inclusion, discussion and contributing to the free-flowing dynamic among all participants. The forum was held at the Adina Hotel at Railway Square, so people could easily attend the forum and access the venue via public transport (buses, trains, light rail, Uber, taxi etc.).

PLNSW CEO, Craig Cooper introduced the Terms of Reference of the community consultation for attendees, outlining the objectives of the day, including safeguards for individuals and group agreements regarding confidentiality, avoidance of ‘victim-blaming’, internalised stigma, and strategies to mitigate secondary trauma and maintaining a ‘safe space’ for disclosure. Craig offered a brief outline of the interaction between stigma, discrimination and the potential impacts of navigating the health system. He highlighted this Community Consultation Forum planned by the PLNSW Board was due in part to the recent development of the NSW Health Joint Stigma and Discrimination Work Plan. Craig invited attendees to share their thoughts, experiences and impressions through a variety of methods anonymously, including a mobile number to text questions through to a staff member, and the use of Mentimeter (www.mentimeter.com).

PLNSW Program Administrator, Neil Fraser introduced the function of Mentimeter and posed the first question of the forum: *What word/s would you use to describe stigma and discrimination*? Participants were invited to offer as many words, as many times without restriction throughout the first half of the forum to populate a Word Cloud. 91 responses were received in total which is an average of 2.6 entries per person.

What word/s would you use to describe stigma and discrimination

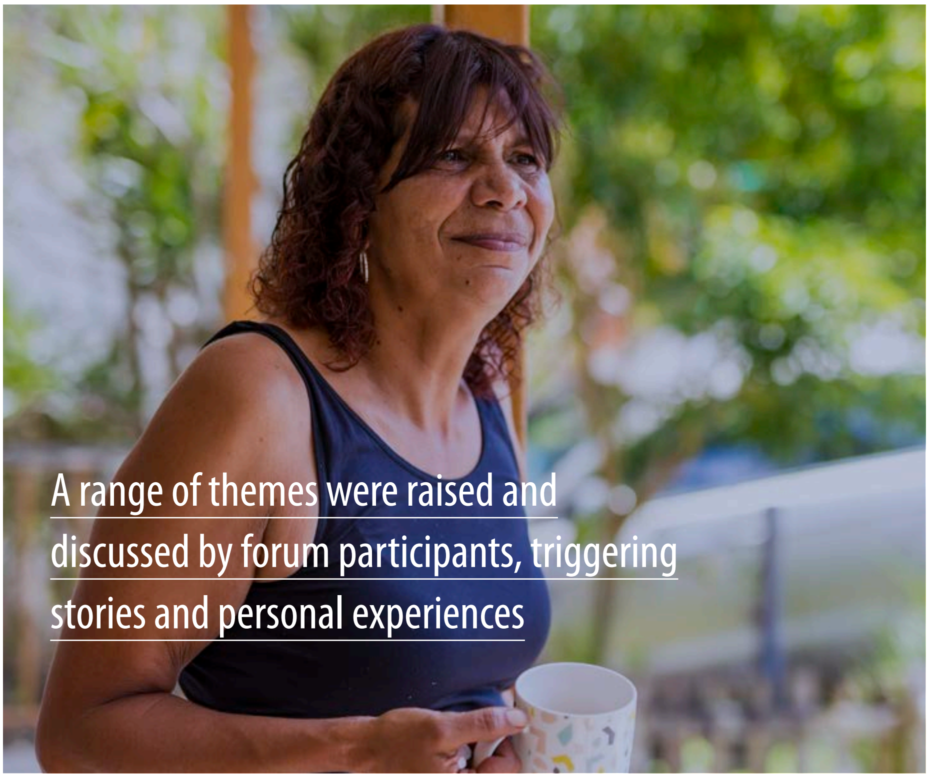
Four ‘rapid-fire’ participants shared their experiences and thoughts over the next twenty minutes. The ordering of speakers was to highlight firstly the primacy of the voice of people living with HIV and the diverging nature of the lived experience of HIV. These first two short presentations were from Dai, a Japanese Gay Man living with HIV and Natasha, a transgender woman living with HIV. The third rapid-fire was represented by Paul Caleo, PLNSW Board member with the final presenter from Jade, a Western Sydney HIV Social Worker with the South West Sydney Local Health District (SWSLHD) HIV Outreach team.

Dai spoke of the intersection of cultural differences and impacts of stigma and discrimination as well as issues of ‘othering’ from the perspective of a PLHIV from a culturally and linguistically diverse (CALD) community. He described this in terms of feeling like a ‘*second class citizen*’, which affected his self-esteem and access to clinical services. He discussed the difficulty of locating services and clinicians who are culturally accommodating and understanding of language and cultural barriers. Dai highlighted how impatience blocks PLHIV from receiving appropriate health care service especially when there are language barriers which often further stigmatises PLHIV from CALD backgrounds. He concluded with the statement that “*while HIV doesn’t kill us today, stigma does*.”

Natasha addressed the intersecting elements of stigma as a transgender woman living with HIV and shared how she has developed different strategies for managing stigma and discrimination. She acknowledged she uses self-deprecating humour to manage and deflect stigmatising behaviour from others. She also mentioned the burden of shame and the risk of isolation for people when they internalise negative feelings arising from stigma and discrimination. Natasha described her nonaggressive response to combat stigma and discriminatory attitudes coupled with offering education with humour. She highlighted that while her style of managing stigma and discrimination tends to lead to positive outcomes for herself this might not suit everyone and not everyone is positioned to use this strategy.

Participants were agreed around the importance of PLHIV developing our own strategies for managing stigma and discrimination

Paul Caleo spoke to the impacts and issues of stigma and discrimination from the perspective of a Gay Man living with HIV and PLNSW Board member and stressed that HIV stigma and discrimination is unacceptable. He acknowledged HIV stigma and repeated stigma and discrimination forms a barrier to our ability to engage with, access and navigate health services. These traumatic experiences of HIV stigma and discrimination can severely impede us and can have considerable adverse effects on our health and interactions with the health system. Paul suggested some strategies for combatting the effects of HIV stigma and discrimination in clinical, healthcare settings or systemic structures. These included confronting stigma when it occurs, and if appropriate escalate the incident through the complaints process and seek change through education. Paul highlighted the benefit of building and maintaining our relationships with key people involved in our health care, especially the GP as allies to assist and support during the navigation and advocacy process. He affirmed the importance of self-care


A range of themes were raised and discussed by forum participants, triggering stories and personal experiences

and nurture of ourselves for our own resilience and that of our peers. Lastly Paul suggested PLHIV might consider ways we can influence system change through a range of options, such as being part of focus groups, committees or working groups involved in health system improvement, joining advocacy bodies such as Positive Life or Health Consumers NSW and taking roles as patient or consumer advocates to advise and support system co-design.

Lastly, Jade, a HIV Social Worker from SWSLHD shared her insights based on her interactions with PLHIV. She was emphatic that clinicians unknowingly perpetuate internalised stigma, by telling clients they don't need to tell anyone about their HIV diagnosis. She raised concerns that this has the potential to cause shame and trauma to the PLHIV and impose a burden on individuals when they leave the safe harbour of the clinical space. Jade highlighted the need for PLHIV to build resilience within situations outside their control and went on to articulate the need to change the current system. The change needs to occur from a perspective of not punishing clinicians but rather educating fellow colleagues, who find it confronting to unpack their own practice and their role in perpetuating stigmatising interactions. She encouraged PLHIV to develop resilience and strength within themselves, surrounded by supportive friends and family and acknowledged the difficultly in confronting a challenging situation.

All rapid-fire presenters and numerous participants mentioned the 'education burden' they feel as they're constantly having to educate others and challenge HIV stigma and discrimination, among personal within health care settings.

The PLNSW Board used an external facilitator to equalise the power dynamic among PLHIV (peers) and to ensure the Board members and staff, including the CEO, were free to participate in the conversation alongside the rest of the attendees. Megan Brooks, SWSLHD HARP Manager who is well known to the agency and community (HIV positive peoples) and understands the role and benefits of peers living with HIV, initiated the facilitated discussion with attendees. This discussion covered a range of domains of PLHIV's experience, understanding and impact of HIV stigma and discrimination, in terms of health, relationally, socially, psychologically, culturally, spiritually etc. (Appendix A). She also explored the different strategies people used to maintain and enhance self-determination and self-esteem in the face of HIV stigma and discrimination and ways they cope with and respond to HIV stigma and discrimination.

A range of themes were raised and discussed by forum participants, triggering stories and personal experiences flowing from issues raised by the rapid-fire presenters. Some of the themes and stories were; experiences of internalised and perceived stigma from PLHIV themselves; discrimination within clinical settings and poor treatment and care; and direct experiences of stigma and discrimination from clinicians.

An example of living with HIV-Associated Neurocognitive Disorder (HAND) or being a woman living with HIV was shared. Forum attendees discussed different methods for dealing with stigma and discrimination such as: confrontation; removing themselves from situations; avoidance; educating; not returning to services; humour; disclosing HIV as a tool to establish if a service will provide quality care; and when you find a quality health service provider that doesn't discriminate, you stay with them because they're hard to find.

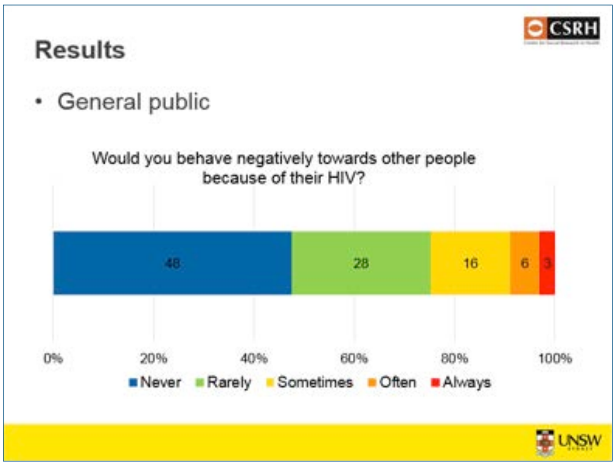
As the group broke for morning tea, the Mentimeter word cloud remained visible. During the break, conversations continue to flow which was seen as a safe forum dynamic promoting an open and thought-provoking space for discussion.

Immediately following morning tea Neil posed a second interactive Menti Meter question: *What word/s would describe how you manage stigma and discrimination*? Again, participants were invited to anonymously submit, without restriction, as many times as they like into the word cloud. 82 responses were received in all, which was an average of 2.3 entries per person.

What word/s would describe how you manage stigma and discrimination?

Professor Carla Treloar, the Director of the Centre for Social Research at UNSW, presented data from The National Stigma Indicator Project in her presentation titled *HIV Stigma and Discrimination Impacts on Navigating Health*.

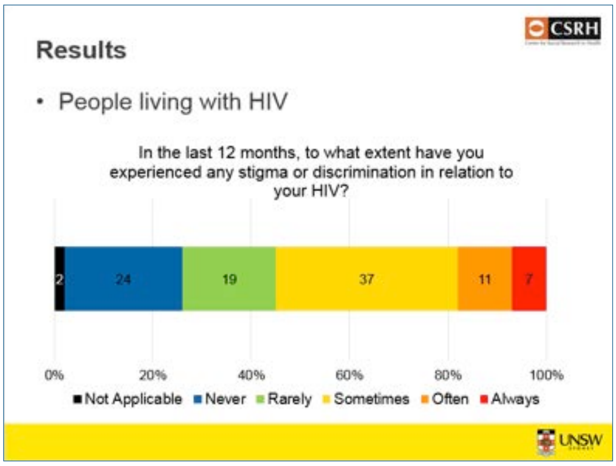
She highlighted that 25% of the general public indicated they would behave negatively towards PLHIV at least 'sometimes', and more than half of PLHIV reported discrimination at least 'sometimes'.



Results

- General public

Would you behave negatively towards other people because of their HIV?

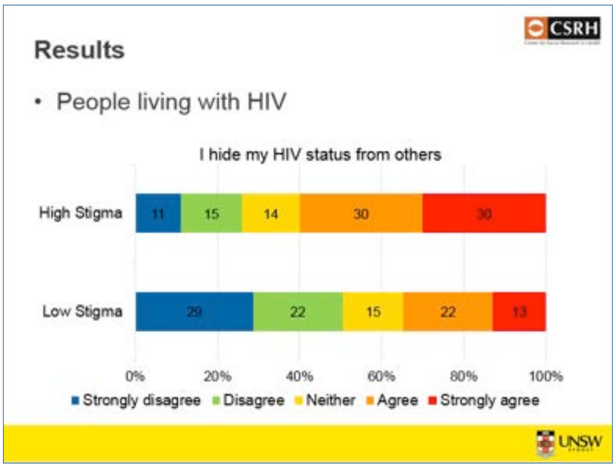


Results

- People living with HIV

In the last 12 months, to what extent have you experienced any stigma or discrimination in relation to your HIV?

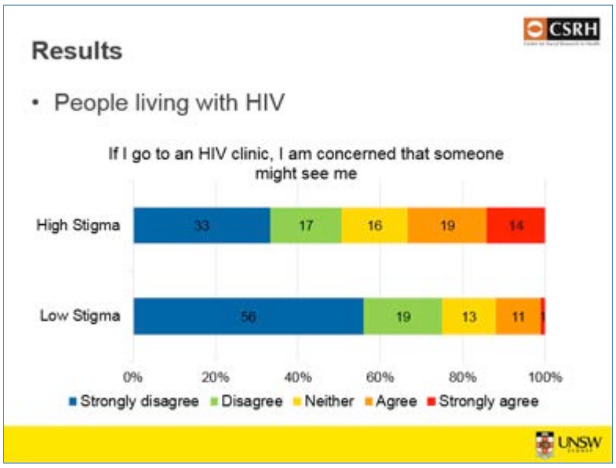
PLHIV who experience more stigma are more likely to hide their HIV status from others. People not 'out' about their HIV status also held concerns about being seen to engage with HIV health services which also impacts their engagement with health services (e.g. collecting medication from pharmacy, taking medication in public).



Results

- People living with HIV

I hide my HIV status from others

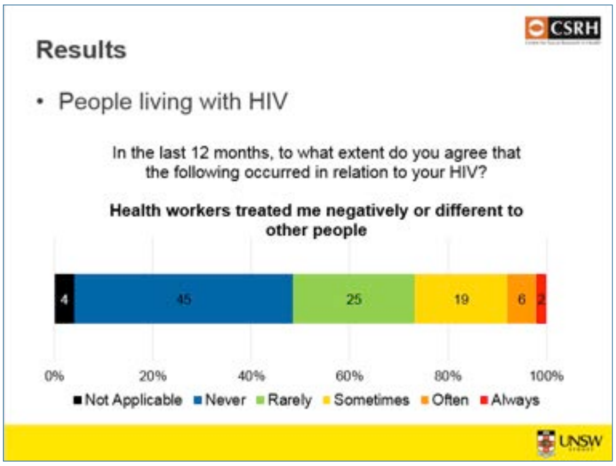


Results

- People living with HIV

If I go to an HIV clinic, I am concerned that someone might see me

The study found at least 27% of PLHIV reported that 'health workers treated me negatively or different to other people. This was in contrast 92% of health care workers who believe they rarely or never discriminate against people because of their HIV.



Results

- People living with HIV

In the last 12 months, to what extent do you agree that the following occurred in relation to your HIV?

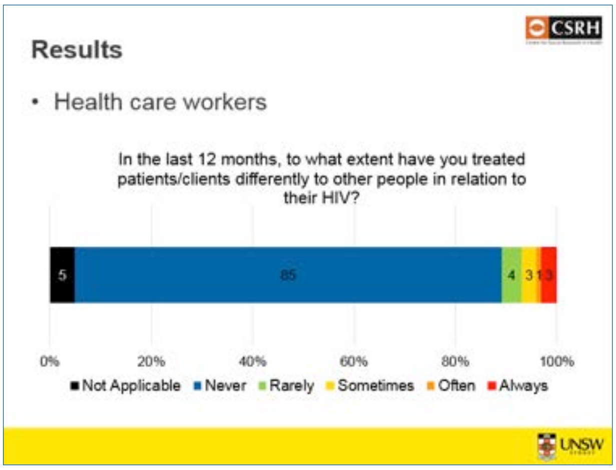
Health workers treated me negatively or different to other people

Results

- Health care workers

In the last 12 months, do you feel that you may have discriminated against patients/clients because of their HIV?

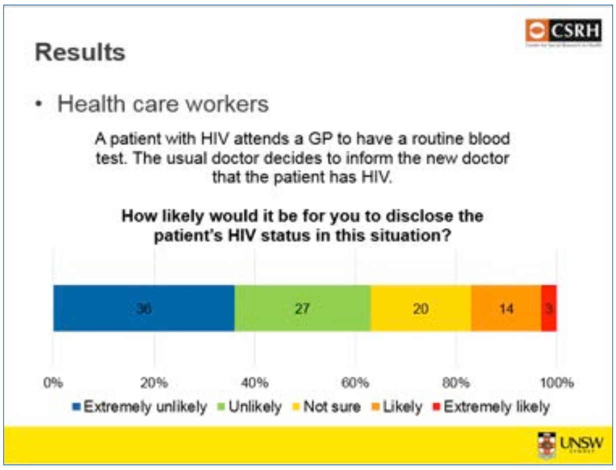
Carla also shared while very few health professionals reported discriminating against their patients living with HIV, over 25% were likely to disclose the individual's HIV status to a new doctor. It is noteworthy, in light of the very small numbers reporting any stigma or discrimination towards patients with HIV, there are some health care workers who don't consider this example to be discriminatory.



Results

- Health care workers

In the last 12 months, to what extent have you treated patients/clients differently to other people in relation to their HIV?



Results

- Health care workers

A patient with HIV attends a GP to have a routine blood test. The usual doctor decides to inform the new doctor that the patient has HIV.

How likely would it be for you to disclose the patient's HIV status in this situation?

PLHIV who experience more stigma are more likely to hide their HIV status from others.

After Carla's presentation, Megan continued to facilitate the discussion with a focus around people's experiences with stigma and discrimination in relation to accessing, navigating and remaining engaged in HIV treatment and care. A participant highlighted the impact of stigma and discrimination in relation to the My Health Record (MyHR) as a decision was made by directors of his local health clinic not to upload his information to the MyHR without consulting him or other health consumers accessing their clinic. He felt this unilateral decision made on his behalf restricted his control of his health information and limited his options to received quality healthcare from other healthcare providers. Another participant highlighted he chose to opt-out of the MyHR to avoid any unintended stigma and discrimination by healthcare providers, entirely due to his past history with drug injecting use, which doesn't reflect his current experience and health needs.

Participants agreed that stigma and discrimination made it harder to access, navigate and remain engaged in the HIV treatment and care continuum. Many of the attendees spoke about their extra vigilance around HIV stigma and discrimination, whether that was actual, perceived, or internalised.

A participant living with HIV employed in healthcare settings shared his experience of developing a respiratory tropical illness while on holiday. While he experienced a high level of healthcare without stigma or discrimination, when an unobtrusive warning notice appeared above his bed, he assumed this was due to his HIV status. It was only after a colleague clarified for him the notice was regarding the respiratory tropical illness diagnosis, that he realised the impact of internalised stigma from years earlier when he was diagnosed with HIV during the paranoia and fear of the early years of the epidemic.


Participants agreed that stigma and discrimination made it harder to access, navigate and remain engaged in the HIV treatment and care continuum

Another participant who is a woman living with HIV shared her experience of clinical discrimination and education fatigue when she was seeking treatment for a knee injury. When her treating specialist was informed of her HIV status he then persisted and pressured her to disclose how she acquired HIV, despite it was not relevant to the physical pain she was experiencing in her knee. At first, she challenged the doctor that it was irrelevant how she acquired the virus, in the face of excruciating pain she did not feel in a position to educate the clinician on HIV stigma and discrimination. She felt forced to disclose how she acquired HIV in order to receive the medical attention she needed. 'Education burden' and fatigue was acknowledged by many PLHIV within the room as an exasperating reality especially within clinical settings.

Another participant shared his experience of discrimination and breach of privacy in relation to continued health system access and navigation, when his GP who had treated him for many years shared his Hepatitis C diagnosis at a private function. While this participant is well resourced and skilled to make a complaint, he had little faith that his complaint would achieve the desired outcome. Rather than disengage in his healthcare, he felt his only recourse and priority was to find another GP.

Participants were mixed around their various decisions and strategies using feedback and complaints mechanisms when discriminated against. Various elements impacting these decisions included: the overt or covert nature of the stigma and discrimination; the bureaucracy and timeliness of the complaint process; as well as the personal stamina and resilience the individual felt at the time and needs to confront and manage the stigma.

The following questions were asked: how has making a complaint about your experience of HIV stigma and discrimination made a difference? If you decide to not make a complaint, please tell us your reasons for not doing so? If you have made a complaint, what was that like for you? People considered that immediate complaints processes, were the best fall-back position, but acknowledged this wasn't always practical. A suggestion was made by a forum participant for PLNSW to take on a role in the community to document PLHIV experiences of HIV stigma and discrimination and to feed back this to health service providers, in stories and during training. Additionally, patient advocacy and peer support on a one-on-one basis was provided as an option for managing and combating HIV stigma and discrimination.

In conclusion, the forum was an opportunity for PLNSW staff and board to engage and consult with PLHIV and our partners on HIV stigma and discrimination. As PLHIV we knew that HIV stigma and discrimination, along with racism, sexism and other forms of prejudice, remains a constant companion in our journeys. The forum created a safe space and moment for us to confer and validate the HIV stigma and discrimination experiences of our peers. HIV stigma and discrimination remains a reality for many PLHIV and was confirmed as something that has to be negotiated and confronted on a daily basis. We have many capabilities and ways of coping with, managing and combating internalised and external HIV fear, shame, phobia, stigma and discrimination.

PLNSW is thankful for the people that made the forum a reality, in particular our brave peers who shared their stories and demonstrate skilled resilience and strength in our battle with HIV stigma and discrimination. The forum participation and conversation provide testimony and evidence of our strength, while we remain strong and alive despite people being paid with public money to provide us with prejudiced sub-standard healthcare. Furthermore, we thank all doctors, nurses, social workers and other staff in the health workforce that do not treat us any differently because we're living with an infectious disease and provide us with quality health care. As PLHIV, the forum confirmed we're a resilient bunch, warriors in the battle against HIV stigma and discrimination, remaining engaged in health and alive.

Appendix A

Mentimeter questions:

1. What word/s would you use to describe stigma and discrimination?
2. What word/s would describe how you manage stigma and discrimination?
3. If you personally experience stigma or discrimination, how do you respond?
4. If you observe stigma or discrimination towards someone else, how do you respond?

Forum prompts or questions:

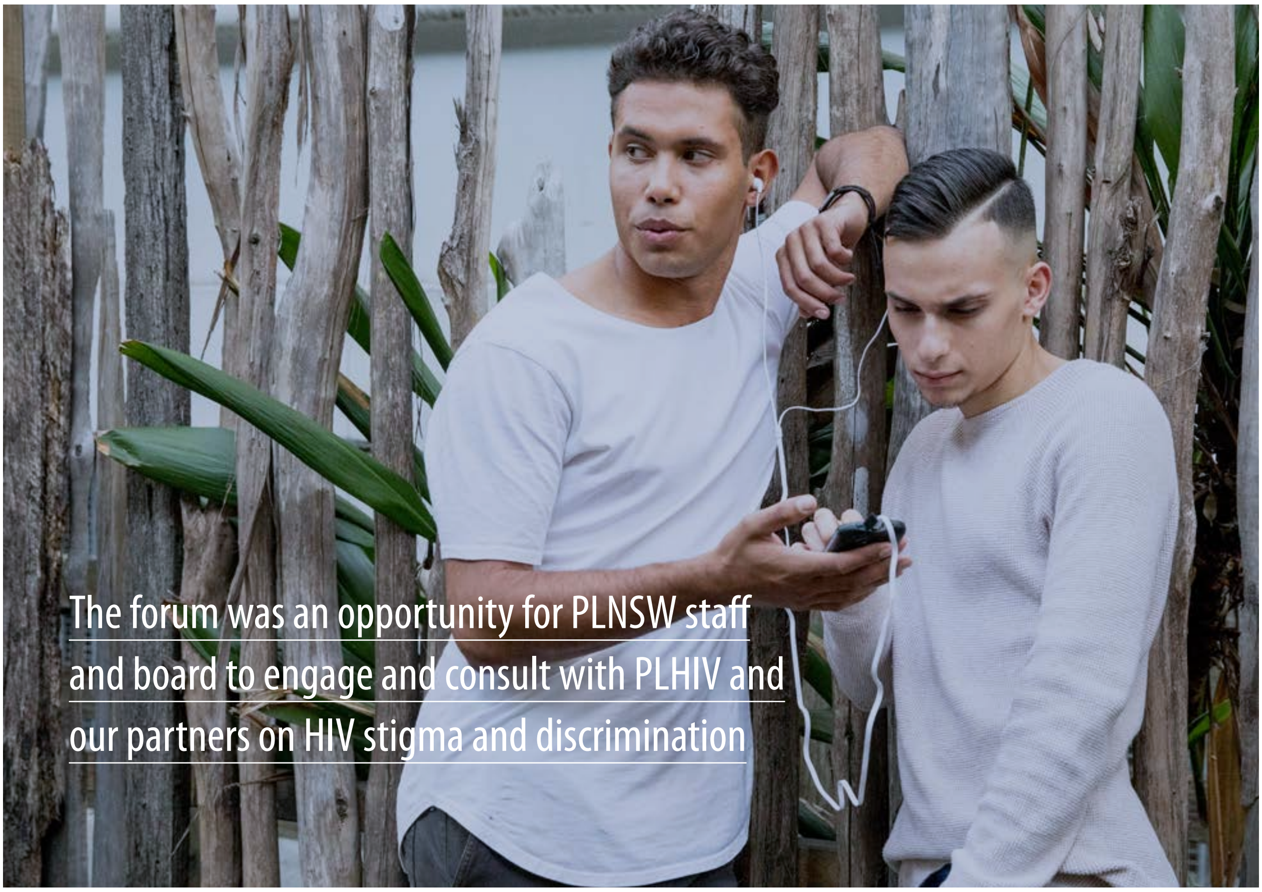
Individual experience and feedback

1. What is your experience and understanding of HIV stigma and discrimination?
2. How does stigma and discrimination impact on you? Health, relationally, socially, psychologically, culturally, spiritually etc.
3. How do you maintain your self-determination and self-esteem in the face of HIV stigma and discrimination?
4. How do you cope with and respond to HIV stigma and discrimination?

For exploration after the morning tea break

Health system and contextual

5. Does stigma and discrimination make it harder to access, navigate and remain engaged in the HIV treatment and care? Please tell us about your story or experience? What has been your experience?
6. What is the impact of HIV stigma on your engagement in their health? Are there implications as a result of HIV stigma and discrimination for continued health system access and navigation?
7. Do you use feedback and complaints processes when discriminated against? If not, why not? How has making a complaint about your experience of HIV stigma and discrimination made a difference? If you decide to not make a complaint, please tell us your reasons for not doing so? If you have made a complaint, what was that like for you?



The forum was an opportunity for PLNSW staff and board to engage and consult with PLHIV and our partners on HIV stigma and discrimination

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