

Stigma Indicators Monitoring Project Summary Report

Introduction

Stigma has a major impact on health outcomes for people living with blood borne viruses (BBVs) and sexually transmitted infections (STIs). Stigma is associated with mental health issues and social isolation, and can prevent people from using health care. This in turn can create difficulties for public health initiatives targeting the prevention and management of these infections.

Australia currently has five national strategies addressing HIV, viral hepatitis, and STIs. Each strategy has a clear goal to eliminate the negative impact of stigma and discrimination on people's health. Despite this, there is currently no system in place to monitor experiences of stigma among people with BBVs or STIs.

In 2015, the Australian Government Department of Health provided funding to the Centre for Social Research in Health (CSRH) to develop an indicator of stigma among the priority groups identified by the national strategies.

This report summarises key findings from phase one of the Stigma Indicators Monitoring project.



Development of the Stigma Indicator

In the first phase of the Stigma Indicators Monitoring Project, the team at CSRH selected a single question to be used as an indicator of stigma across the priority groups. An additional item about negative treatment in health care settings was also included, as was an item about intimate and sexual relationships.

The indicator is shown below:

In the last 12 months, to what extent have you experienced any stigma or discrimination (e.g. avoidance, pity, blame, shame, rejection, verbal abuse, bullying) in relation to your:						
	Never	Rarely	Sometimes	Often	Always	Not applicable
Sexual orientation	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>	9 <input type="checkbox"/>
Use of drugs for injecting	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>	9 <input type="checkbox"/>
HIV status	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>	9 <input type="checkbox"/>
Hepatitis B status	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>	9 <input type="checkbox"/>
Hepatitis C status	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>	9 <input type="checkbox"/>
Sex work	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>	9 <input type="checkbox"/>
Other (please specify)	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>	9 <input type="checkbox"/>

In the last 12 months, to what extent do you agree that the following occurred?						
	Never	Rarely	Sometimes	Often	Always	Not applicable
Health workers treated me negatively or different to other people	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>	9 <input type="checkbox"/>
People didn't want to have sex or an intimate relationship with me	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>	9 <input type="checkbox"/>

A mirrored version of the indicator was also developed to measure the expression of stigma by health care professionals. Due to some initial misinterpretation of the question, the mirrored indicator was revised – the original and revised versions are shown below:

Original mirror indicator

We may judge or regard people negatively at times because of differing cultural background, lifestyle or health issues. The following question asks about whether you have done this to others, and we understand that it may be difficult for you to answer. Please be honest in your responses, they will be kept anonymous and confidential.

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

	Never	Rarely	Sometimes	Often	Always	Not applicable
Sexual orientation	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>	9 <input type="checkbox"/>
Use of drugs for injecting	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>	9 <input type="checkbox"/>
HIV status	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>	9 <input type="checkbox"/>
Hepatitis B status	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>	9 <input type="checkbox"/>
Hepatitis C status	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>	9 <input type="checkbox"/>
Sex work	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>	9 <input type="checkbox"/>
Other (please specify)	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>	9 <input type="checkbox"/>

Revised mirror indicator

We may judge or regard people negatively at times because of differing cultural background, lifestyle or health issues. The following question asks about whether you have done this to others, and we understand that it may be difficult for you to answer. Please be honest in your responses, they will be kept anonymous and confidential.

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

	Never	Rarely	Sometimes	Often	Always	Not applicable
Sexual orientation	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>	9 <input type="checkbox"/>
Use of drugs for injecting	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>	9 <input type="checkbox"/>
HIV status	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>	9 <input type="checkbox"/>
Hepatitis B status	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>	9 <input type="checkbox"/>
Hepatitis C status	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>	9 <input type="checkbox"/>
Sex work	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>	9 <input type="checkbox"/>
Other (please specify)	1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>	9 <input type="checkbox"/>

Data collection

The indicator was tested across the following groups:

- People living with HIV
- Gay and other men who have sex with men
- People living with hepatitis C, and
- People who inject drugs.

The mirrored indicator was tested among health care professionals who have contact with:

- People living with HIV
- People living with hepatitis C, and
- People living with hepatitis B.

Samples

To collect data for each group, the indicator was either included in existing surveys, or in surveys specifically developed for this project, as outlined below:

Target group	Data collection system	Data custodian
People living with HIV	New online survey	CSRH, UNSW Sydney
People who inject drugs	Australian Needle and Syringe Program Survey (ANSPS)	Kirby Institute, UNSW Sydney
Men who have sex with men	Telling	Kirby Institute, UNSW Sydney
People living with hepatitis C / People who inject drugs	New online survey	CSRH, UNSW Sydney
Health workers	New online survey	CSRH, UNSW Sydney

Results

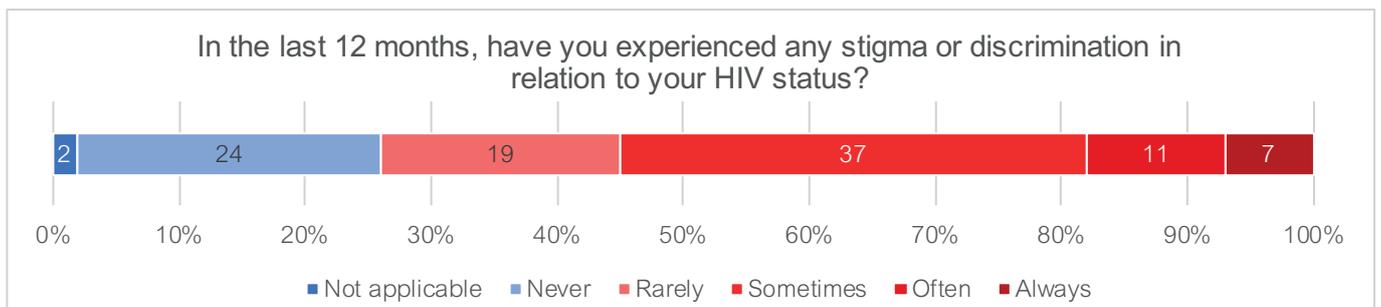
People living with HIV

The online survey sample consisted of 181 people living with HIV, with an average age of 50 years. Most participants were male (88%) and reported being gay (71%). They were mostly born in Australia (72%), and were recruited from each state and territory, with the most common being New South Wales (39%), Victoria (18%), and Queensland (16%). Only 1% identified as Aboriginal. Most were employed either full-time (44%) or part-time/casually (16%), and had completed university education (53%). As well as living with HIV, 30% reported some other STI diagnosis in their lifetime, and 61% had experienced mental health issues at some point.

Participants had been living with HIV for an average of 16 years, and sex with a man was the most common route of transmission (86%). Only one participant was not currently receiving antiretroviral therapy, and 94% reported an undetectable viral load. More than half (57%) had missed a dose of medication within the previous three months, and more than a quarter (27%) reported noticeable symptoms resulting from their HIV or treatment.

The findings from the stigma indicator among people living with HIV are presented below:

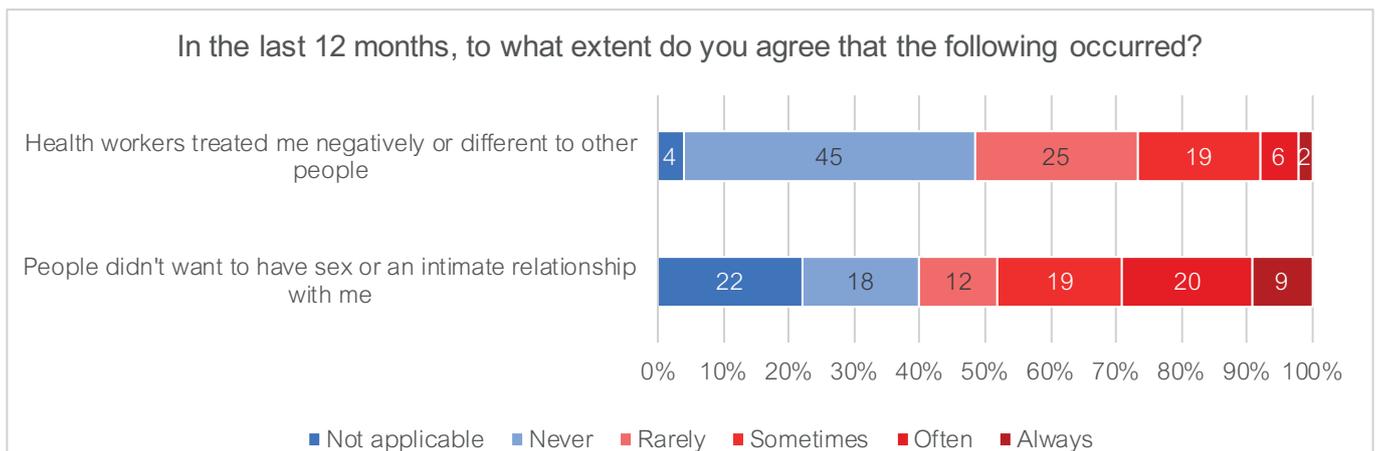
Figure 1. Stigma indicator data among people living with HIV (n=181)



In 2016, 74% of people living with HIV reported any stigma related to their HIV status. Stigma did not occur regularly, however, with participants more likely to report experiencing it 'rarely' or 'sometimes' (56%).

More than half of respondents to the online survey of people living with HIV reported experiencing negative or different treatment by health workers (52%). Most indicated that this occurred 'rarely' or 'sometimes' (44%), possibly reflecting infrequent contact with health professionals. Three out of five participants reported that people did not want to have sex or an intimate relationship with them, with 29% stating this had 'often' or 'always' occurred.

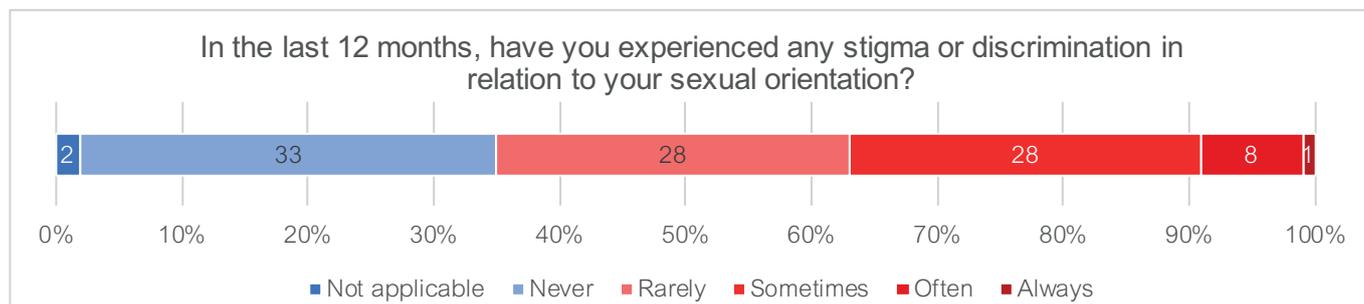
Figure 2. Additional indicator items among people living with HIV (n=181)



Men who have sex with men

A total of 339 participants from the *Telling* survey answered the stigma indicator in relation to their sexual orientation, 81% of whom identified as gay/homosexual and 17% identified as bisexual. Their average age was 39 years, 72% were of Anglo-Celtic background, and 2% identified as Aboriginal or Torres Strait Islander. Participants were recruited from each state and territory, with the most common being New South Wales (36%), Victoria (28%) and Queensland (17%). Over half (58%) had completed university education, and most were employed either full-time (59%) or part-time (14%). Around one in five were HIV positive (19%) and 21% had ever been paid for sex. The findings from the sexual orientation stigma indicator among this group are shown below:

Figure 3. Stigma indicator data among men who have sex with men (n=339)



Stigma related to sexual orientation was clearly a relevant issue for this group, with 65% of men indicating any stigma in the last 12 months. Stigma related to sexual orientation was generally experienced 'rarely' or 'sometimes' (56%).

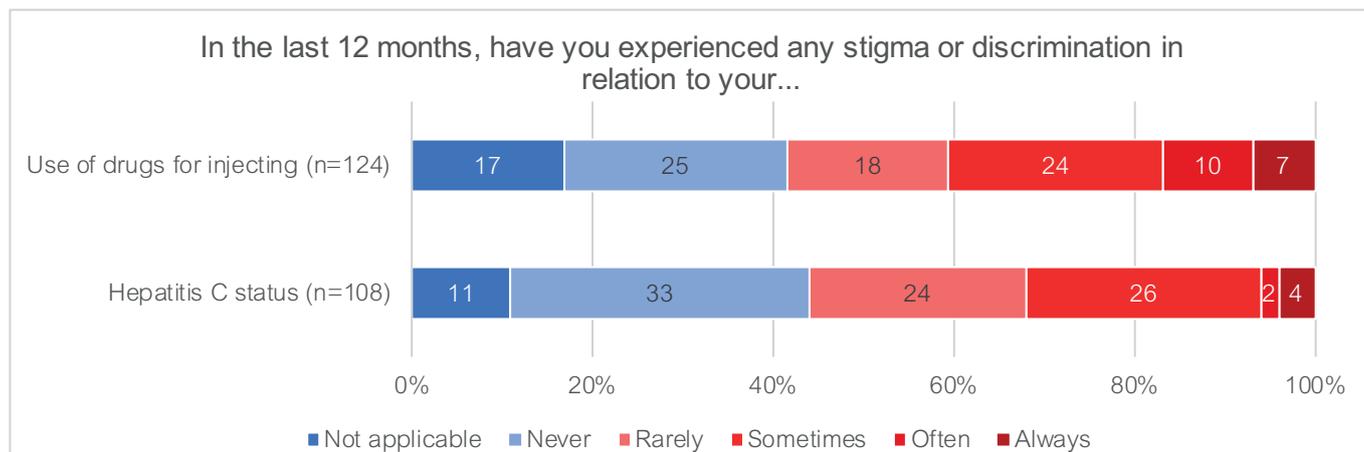
People living with hepatitis C and people who inject drugs

The online survey sample consisted of 165 people, with an average age of 48 years and 62% of whom were female. Most were born in Australia (84%), and 4% identified as Aboriginal or Torres Strait Islander. Participants were recruited from each state and territory, with the most common being Victoria (27%), New South Wales (26%), and Queensland (16%). One-third were employed full-time, and one-third were employed part-time, with 39% having completed a university degree. A majority of participants identified as straight/heterosexual (72%), and 63% reported experiencing mental health issues at some point in their lives. This profile is different to samples usually recruited (e.g. more females, higher rates of employment and university education), which may be due to the online recruitment approach.

Of the 123 participants who had ever had hepatitis C, 72% acquired it through using non-sterile equipment for injecting drugs, and 27% were on HCV treatment at the time of the survey. Every participant was aware of the new treatments for hepatitis C, which were released in March 2016 (the same year as the survey). Despite this, 36% of participants who had never received treatment had no intention of ever receiving it and 15% were undecided.

The findings from the stigma indicator among people who had ever lived with hepatitis C and/or injected drugs is shown below:

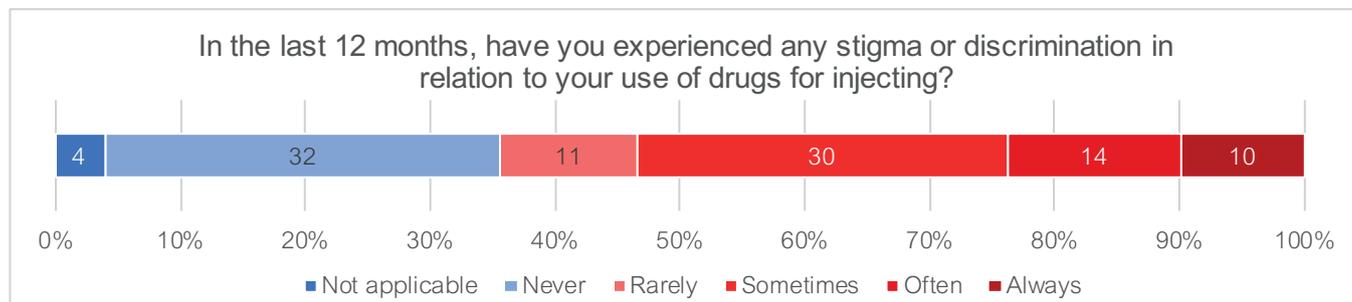
Figure 4. Stigma indicator data among people who had ever lived with hepatitis C and/or injected drugs



More than half of participants reported experiencing stigma within the last 12 months related to their injecting drug use (59%) or hepatitis C status (56%). These experiences were more frequent in relation to injecting drug use, with 17% reporting that they 'often' or 'always' experienced stigma or discrimination compared to 6% in relation to hepatitis C status.

The stigma indicator was also included in the 2016 Australian Needle and Syringe Program Survey (ANSPS), with the results shown below:

Figure 5. Stigma indicator data among Australian Needle and Syringe Program Survey participants (n=2060)

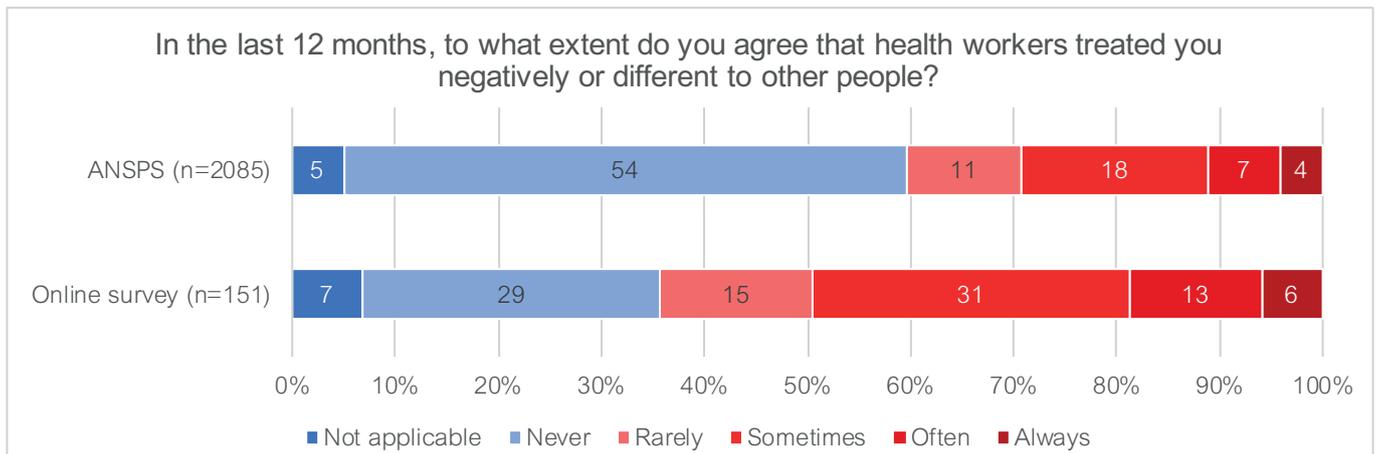


N.B. 'Not applicable' responses could represent participants who do not have the attribute being referred to, therefore results should be interpreted cautiously.

Compared to the online survey, a slightly larger percentage of ANSPS participants reported any injecting-related stigma in the last 12 months (65% vs. 59%). This could be due to the different recruitment methods of the surveys, and the ANSPS sample having a larger proportion of participants who currently injected drugs.

In relation to the question of stigma in health care, more than half of the online sample reported that it had occurred (57%), compared to 40% of the ANSPS sample.

Figure 6. Additional indicator items among people who had ever had hepatitis C and/or injected drugs



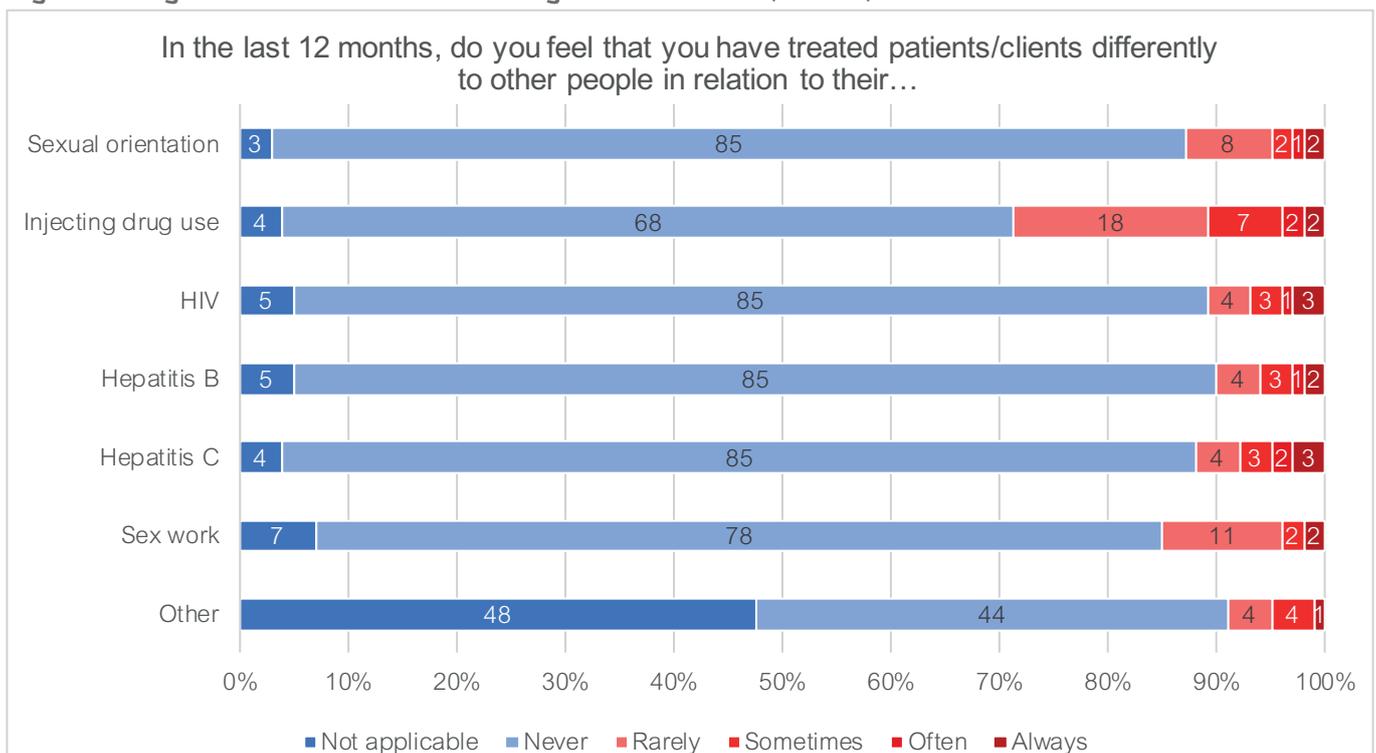
Health workers

The sample consisted of 353 health workers, with an average age of 48 years and who were mostly female (72%). Most were born in Australia or New Zealand (69%), and were recruited from each state and territory, with the most common being New South Wales (43%), Victoria (19%), and Queensland (18%). Around three-quarters (74%) indicated that they were straight/heterosexual.

Participants were mostly in full-time employment (63%), with 41% working in a nursing role and 30% in a medical role. Most had been working in their field for over 10 years (78%), and 90% had professional contact with people who inject drugs and people living with hepatitis C, 86% had contact with people living with hepatitis B, and 84% had contact with people living with HIV. Less than 5% of participants reported that none of their clients lived with hepatitis B, hepatitis C, HIV, or had ever injected drugs.

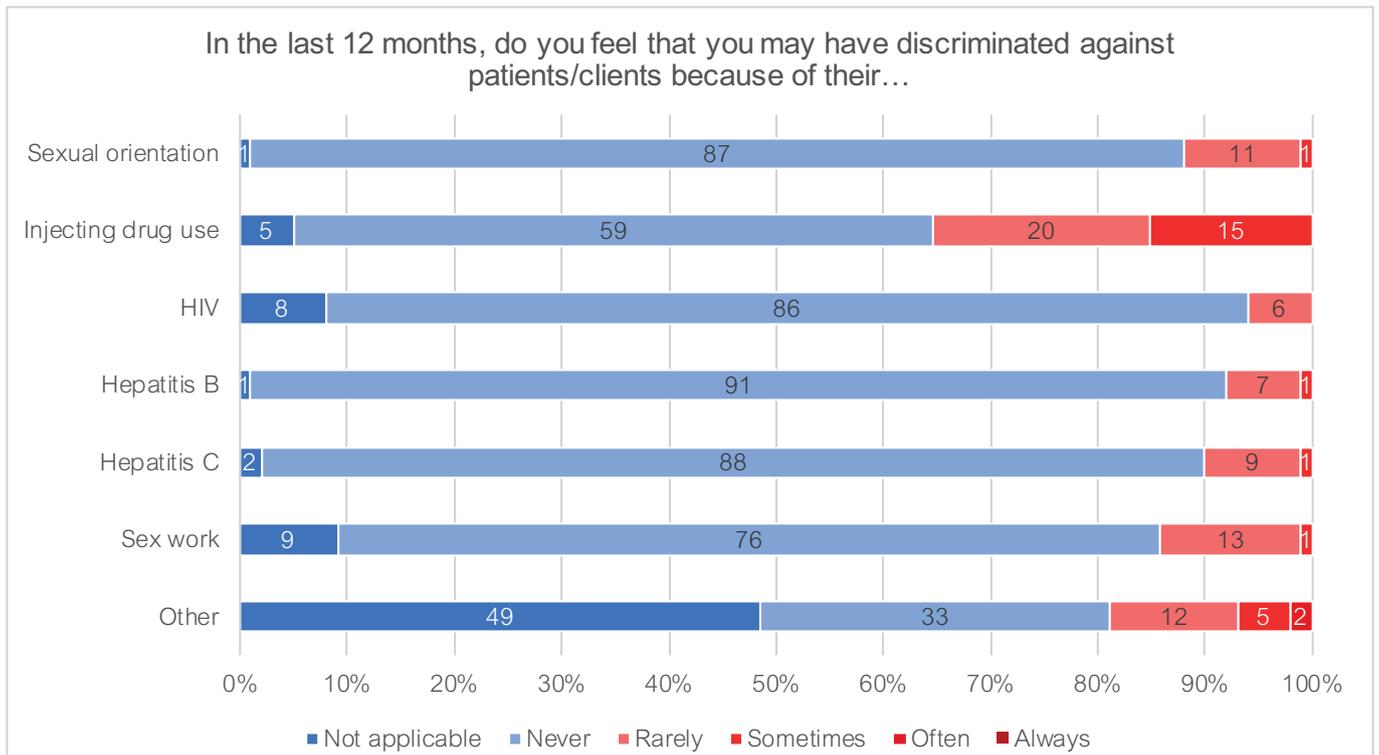
Findings from the original and revised indicators are shown below:

Figure 7. Original mirrored indicator among health workers (n=255)



N.B. "Other" category included: Aboriginality, gender diversity, cultural diversity, cultural beliefs, homelessness, aggressive behaviour, intoxication, criminal background, sexual assault, and family violence.

Figure 8. Revised mirrored indicator among health workers (n=98)

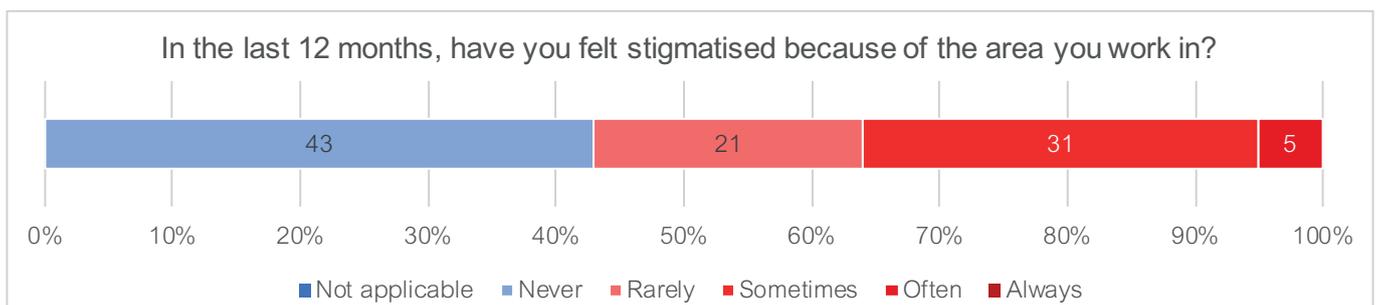


N.B. “Other” category included: gender diversity, refugee status, cultural diversity, unsafe sex practices, mental health, family and sexual violence perpetration, aggressive or threatening behaviour, and people who make “negative choices”.

While participants reported infrequent instances of discrimination against people with any of the attributes listed, discrimination against people who inject drugs was more common than any other group (29% in the original indicator, 35% in the revised indicator).

Health workers were asked the extent to which they had felt stigmatised because of the area in which they were employed. More than 43% of participants did not feel this was ever the case, though 36% reported ‘sometimes’ or ‘often’ feeling stigmatised.

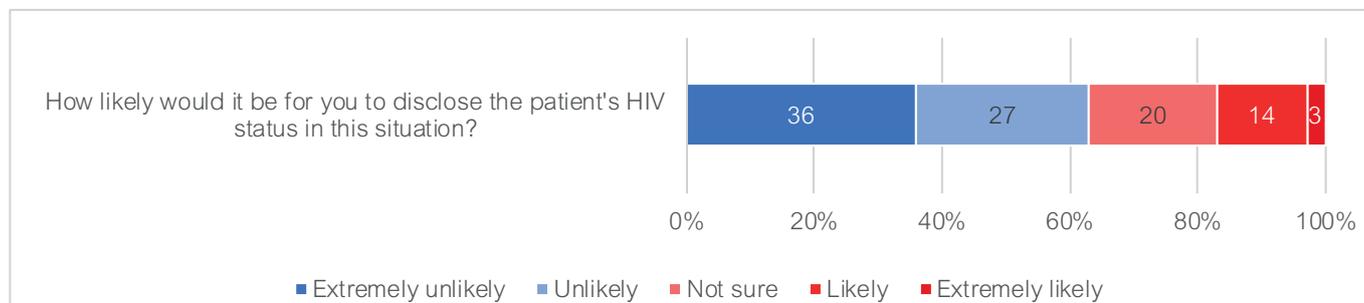
Figure 9. Health workers’ feelings of stigma due to employment (n=353)



Health workers were also asked to respond to a series of scenarios that examined the likelihood of responding to a patient in a discriminatory way. Some examples of these scenarios are shown below:

Figure 10. Health care workers responses to HIV-related scenario (n=353)

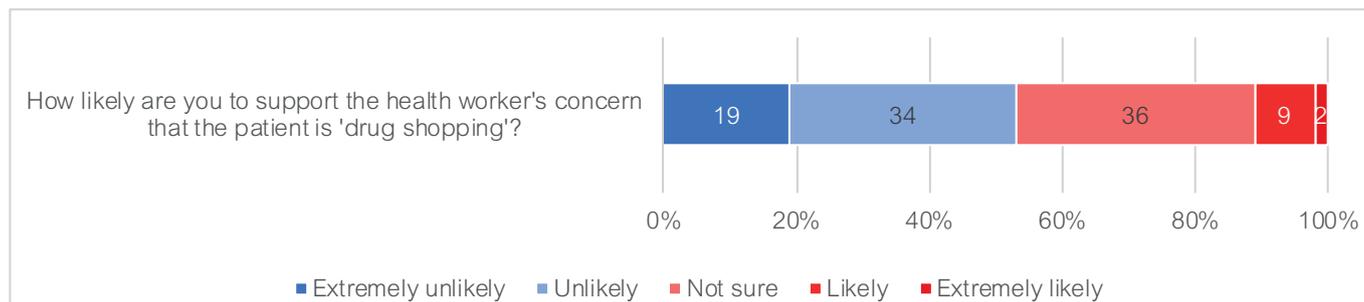
Scenario: A patient with HIV attends a GP to have a routine blood test. The patient is unable to obtain an appointment with their usual doctor, and is assigned to a different doctor. The usual doctor hears that the patient has made an appointment and decides to inform the new doctor that the patient has HIV.



A majority of participants indicated it was unlikely that they would disclose a patient's HIV status (63%), though one in five were unsure whether or not they would disclose this information.

Figure 11. Health care workers' responses to injecting drug use related scenario (n=353)

Scenario: A health worker is treating a patient who injects drugs and also suffers a painful medical condition. The patient insists on pain relief but the health worker worries that the patient does not actually have bad pain but is 'drug shopping'.



Approximately half of participants reported being unlikely to believe that this hypothetical patient was 'drug shopping' (53%), and only 11% indicated they would support this view. More than one in three (36%) were unsure, highlighting the potential complexity of these situations.

Health workers mostly reported that they were unlikely to discriminate against patients belonging to any of the groups of interest, however, a minority suggested that they would discriminate and many were unsure of how they would respond. This trend was common across scenarios related to HIV, injecting drug use, hepatitis C, and hepatitis B. It is possible, however, that many participants were not willing to openly admit to any discriminatory behaviour. Health workers may not consciously hold discriminatory attitudes towards these groups, but negative attitudes can still manifest in ways that result in discrimination within their health care practice.

Conclusion

Development of a stigma indicator is important to monitor progress against the government's strategic objective to eliminate the negative impacts of stigma and discrimination on people's health.

This report has outlined the development of the stigma indicator and the results of its first implementation. The next phase of this project will expand the focus of the stigma indicator to include additional groups identified by the national strategies for BBVs and STIs. Being able to quantify the experience of stigma among these groups is an important first step towards introducing evidence-based strategies to eliminate its negative effects.

If the results presented in this report have upset you in any way, we encourage you to seek support from any of the following: QLife (1800 184 527); National Association of People with HIV Australia (1800 259 666); National Hepatitis Infoline (1800 437 222); Lifeline (13 11 44).

Acknowledgements

We would like to acknowledge the valuable contribution of the project advisory committee. We are especially grateful to those organisations who assisted with recruitment, and to the Kirby Institute for including the stigma indicator in their existing surveys.

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Organisations who provided recruitment assistance

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