



Stigma Indicators Monitoring Project

Project Summary Phase 2

Introduction

Project Background

In Australia, five national strategies address HIV, viral hepatitis, and sexually transmissible infections (Australian Government Department of Health, 2018a, 2018b, 2018c, 2018d, 2018e). Each strategy contains a clear objective to eliminate the negative impact of stigma, discrimination, and legal and human rights issues on people's health. In 2015, the Australian Government Department of Health provided funding to the Centre for Social Research in Health at UNSW Sydney to develop an indicator of stigma among the priority groups identified by the national strategies in order to monitor progress against the strategies' objectives.

Phase One

The Stigma Indicators Monitoring Project commenced in 2015 and developed a brief indicator of stigma to be used across the following priority groups:

- Gay and other men who have sex with men (MSM)
- People who inject drugs (PWID)
- People living with HIV (PLHIV)
- People living with viral hepatitis (B and C)
- People who are employed in sex work.

A single question was selected to be applicable across all the priority groups. An additional item addressing negative treatment in health care settings was also included. Detail regarding the development of the indicator has been published elsewhere (Broady et al., 2018).

In 2016, Stigma Indicator data were collected in surveys of people living with HIV, people who inject drugs, men who have sex with men, people living with hepatitis C, and health care workers. The indicator was also included in the 2016 Australian Needle and Syringe Program Survey (ANSPS: Memedovic, Iversen, Geddes, & Maher, 2017) and the *Telling* survey of men who have sex with men (both conducted by The Kirby Institute, UNSW Sydney). A summary report of results from Phase One has been previously published (Cama et al., 2018).

Phase Two

The second phase of the project aimed to repeat Stigma Indicator data collection among priority groups and to improve sampling and data collection procedures. In Phase Two, data were also collected from the general public, and data regarding the experience and expression of stigma towards sexually transmissible infections (STIs) were collected for the first time. In addition, the health care worker survey was expanded to include health care and medical students.

In Phase Two, a qualitative study targeting the Chinese community was conducted to investigate experiences of stigma and discrimination related to hepatitis B. This study aimed to scope key issues relevant to this group in relation to stigma and discrimination, and to determine the feasibility of conducting future surveys including the Stigma Indicator. A summary of findings from this study has been published elsewhere (Hopwood et al., 2019).

Also in Phase 2, a qualitative study was conducted in collaboration with Scarlet Alliance. Focus groups and interviews were conducted with sex workers who had worked in all Australian states and territories. The findings were used to develop a survey that will be implemented in later phases of the Stigma Indicators Monitoring Project.

Method

Changes to Stigma Indicator

In Phase Two, the 'not applicable' response option was removed from the Stigma Indicator. Instead, each survey first asked if participants had an attribute prior to asking if they had experienced any stigma in relation to that attribute (see Broady et al., 2018).

Data collection

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

Target group	Data collection system	Data custodian
General public	Australian Survey of Social Attitudes	Australian Consortium for Social and Political Research Incorporated
Health care workers and students	New online survey	CSRH, UNSW Sydney
People with sexually transmissible infections ¹	<i>Debrief</i> survey	CSRH, UNSW Sydney
People who inject drugs	New paper-based survey	CSRH, UNSW Sydney
Men who have sex with men	New online survey	CSRH, UNSW Sydney
People living with HIV	<i>HIV Futures 9</i>	Australian Research Centre in Sex, Health and Society (ARCSHS; La Trobe University)
People living with hepatitis C	New online survey	CSRH, UNSW Sydney

¹ Rather than specifically targeting people with STIs, the Stigma Indicator was included in a survey of young people about their sexual health (including STIs).

Data analysis

Due to some changes in the Stigma Indicator between Phase One and Phase Two (i.e. removal of 'not applicable', revised wording of the mirrored Indicator, different recruitment procedures), direct comparisons cannot be made between results from each phase. Results from both phases are presented in this report, however, caution should be used when comparing these findings.

Results

General public

The general public sample consisted of 1,001 Australian adults, with an average age of 54 years. Just over half were female (57%), most were born in Australia (76%) and 2% identified as Aboriginal or Torres Strait Islander. Participants were recruited from each state and territory, most commonly New South Wales (32%), Victoria (27%), and Queensland (17%). Approximately one-third (34%) had completed university, 37% were in full time employment and 20% were in part time employment.

One in ten participants (10%) indicated that they knew someone who injects drugs, and 10% knew someone living with hepatitis C. A smaller proportion knew someone living with HIV (6%), and 18% knew someone who has had a sexually transmissible infection.

The findings from the mirrored Stigma Indicator measuring the expression of stigma among the general public towards priority populations are shown in Figure 1.

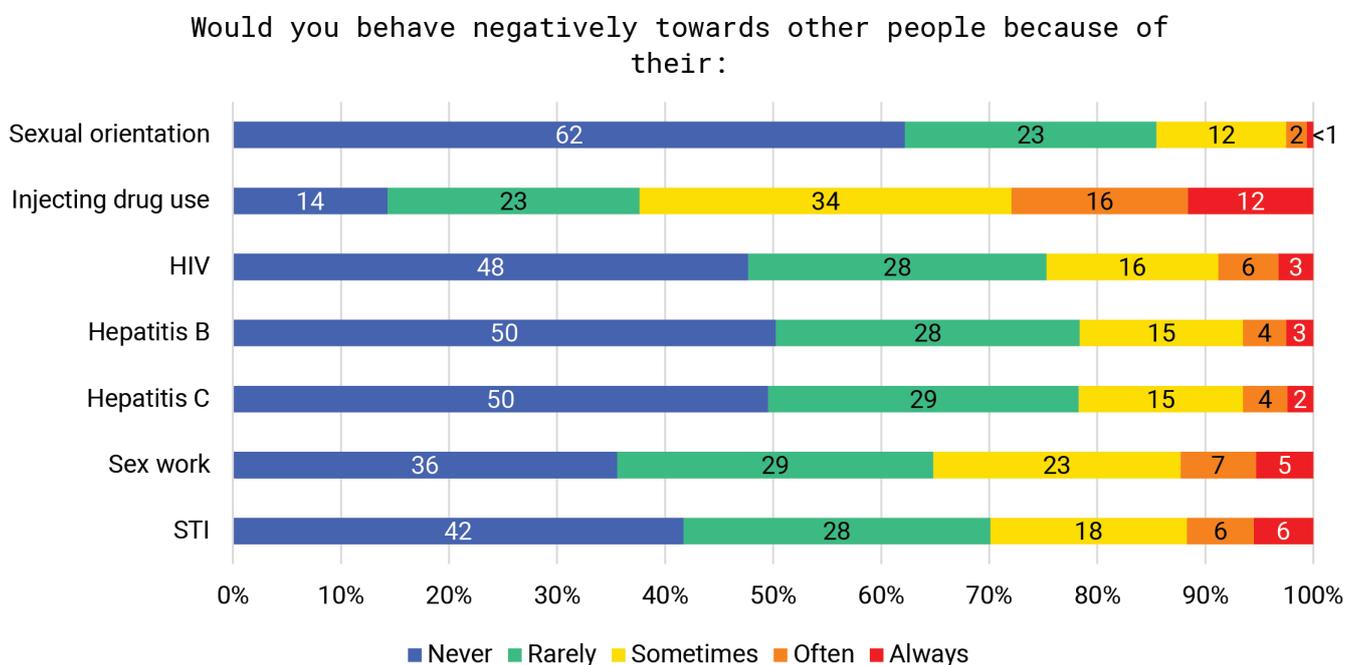


Figure 1. Mirrored Stigma Indicator - General public (n=960)

Injecting drug use was the attribute that members of the general public were most likely to report that they would behave negatively towards, with 86% reporting they would do so to some extent. More than one-quarter of participants (28%) indicated that they would ‘often’ or ‘always’ behave negatively to others because of their injecting drug use. Sexual orientation was the attribute least likely to attract negative behaviour (38%). Responses towards HIV, hepatitis B, and hepatitis C were similar, with roughly half of participants reporting that they would behave negatively towards someone with those attributes. Likely negative behaviour towards sex workers was reported by 64% of participants and 58% indicated that they would behave negatively towards people with STIs.

Health care workers and students

The online survey was completed by 750 participants – 551 health care workers and 199 health/medical students. On average, health care workers were 42 years old and most were female (94%). The majority were born in Australia or New Zealand (84%) and 4% identified as Aboriginal or Torres Strait Islander. Health care workers were recruited from each state and territory, most commonly New South Wales (29%), Queensland (24%), and Victoria (21%). One quarter of health care workers reported knowing someone living with hepatitis B (25%), with larger proportions knowing someone living with HIV (32%), hepatitis C (42%), someone who injects drugs (45%), or someone who has had an STI (69%). Health care workers were most commonly employed full time (54%) and in nursing roles (59%).

On average, students were 27 years old and most were female (87%). The majority were born in Australia or New Zealand (84%) and 3% identified as Aboriginal or Torres Strait Islander. Students were recruited from each state and territory, most commonly New South Wales (37%), Queensland (24%), and Victoria (14%). One in ten students reported knowing someone living with hepatitis B (10%), with larger proportions knowing someone living with HIV (19%), hepatitis C (20%), someone who injects drugs (35%), or someone who has had an STI (62%). Most students were studying undergraduate degrees (80%).

The findings from the mirrored Stigma Indicator among health care workers and students are shown in Figure 2 and Figure 3.

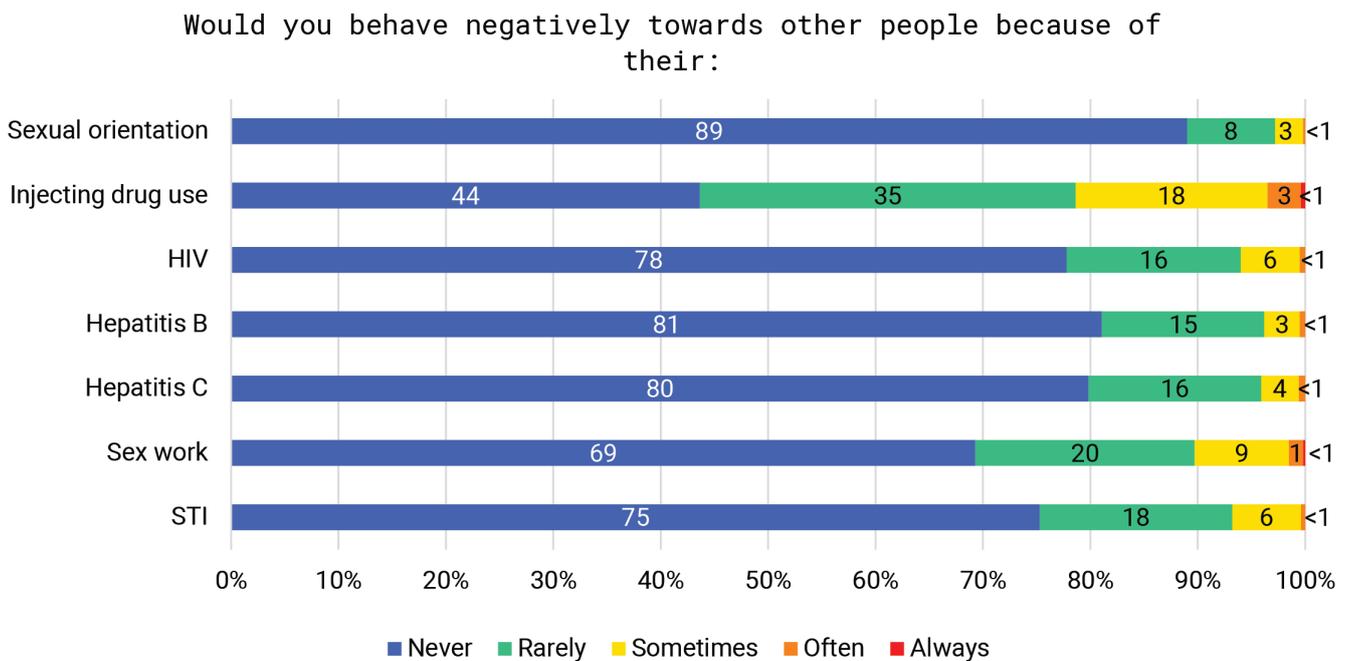


Figure 2. Mirrored Stigma Indicator - Health care workers (n=550)

Would you behave negatively towards other people because of their:

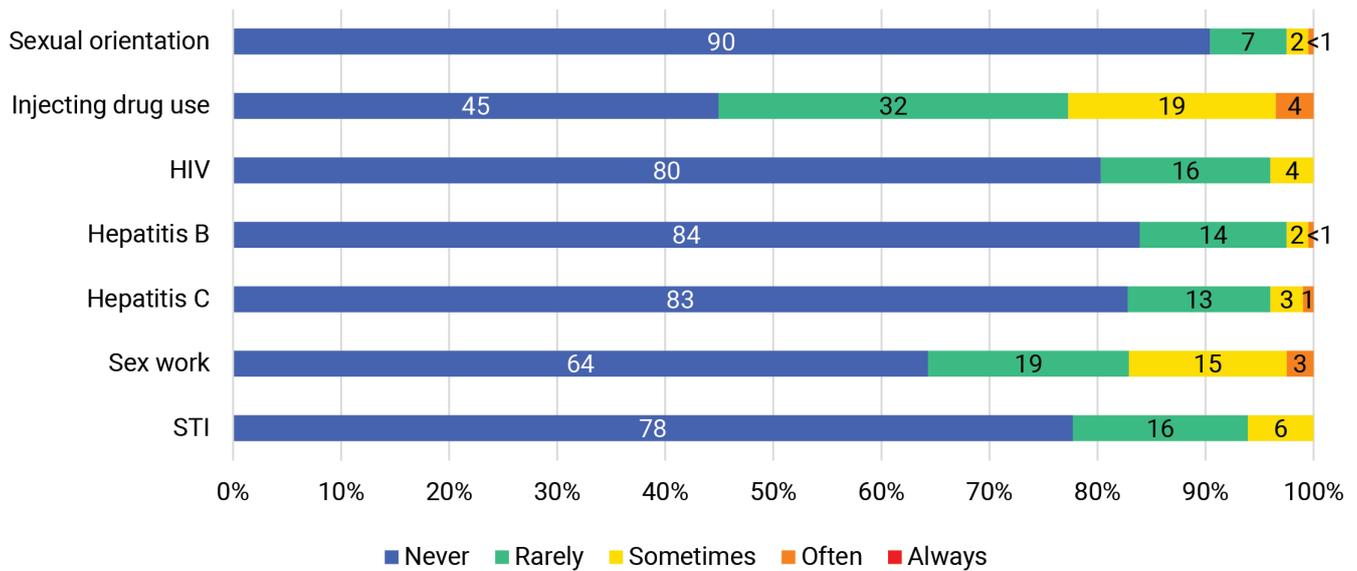


Figure 3. Mirrored Stigma Indicator - Health care/medical students (n=199)

Responses to the mirrored Stigma Indicator were similar for health care workers and students. Both groups were most likely to report that they would behave negatively towards people who inject drugs (56% of health care workers, 55% of students) and least likely to report that they would behave negatively towards others because of their sexual orientation (11% of health care workers, 10% of students). Responses to HIV, hepatitis B, hepatitis C, and STIs all showed similar trends, with 19%–25% of health workers and 16%–22% of students indicating that they would behave negatively towards people with those attributes. Sex workers were the only group that appeared more likely to be treated negatively by students (36%) than by health care workers (31%), though this difference was not statistically significant.

An additional question was included to measure the extent to which health care workers and students had witnessed other health workers behaving negatively towards each of the priority groups (Figure 4 and Figure 5).

In the last 12 months, have you witnessed any health workers behaving negatively towards patients/clients because of their:

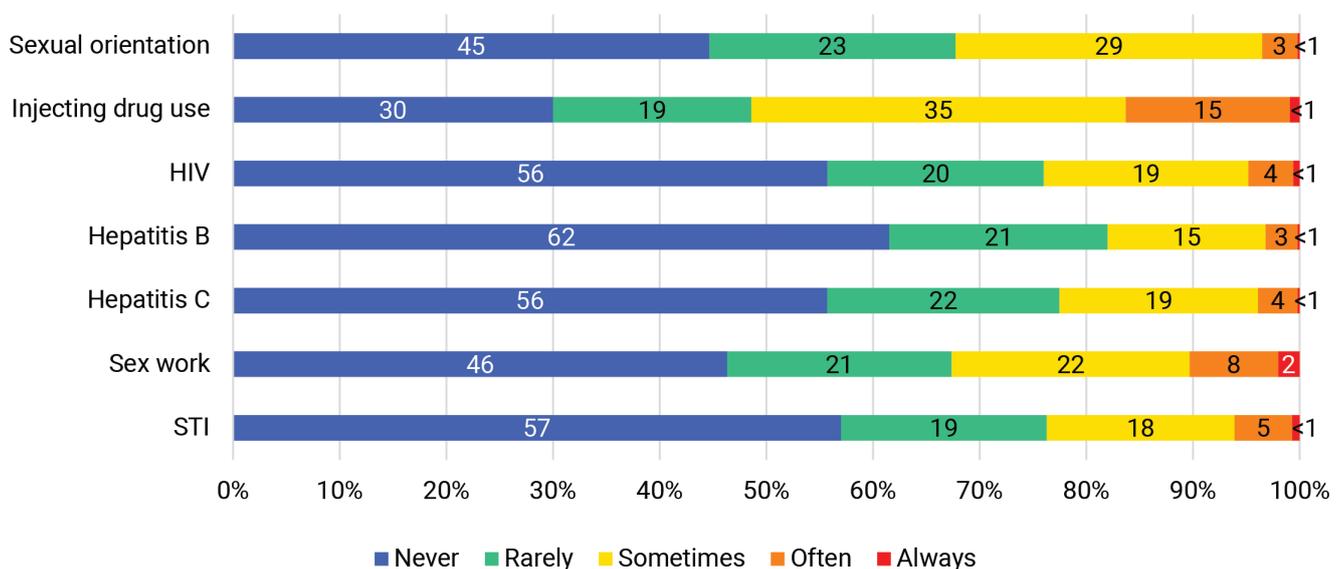


Figure 4. Witnessing stigma from other health workers - Health care workers (n=550)

In the last 12 months, have you witnessed any health workers behaving negatively towards patients/clients because of their:

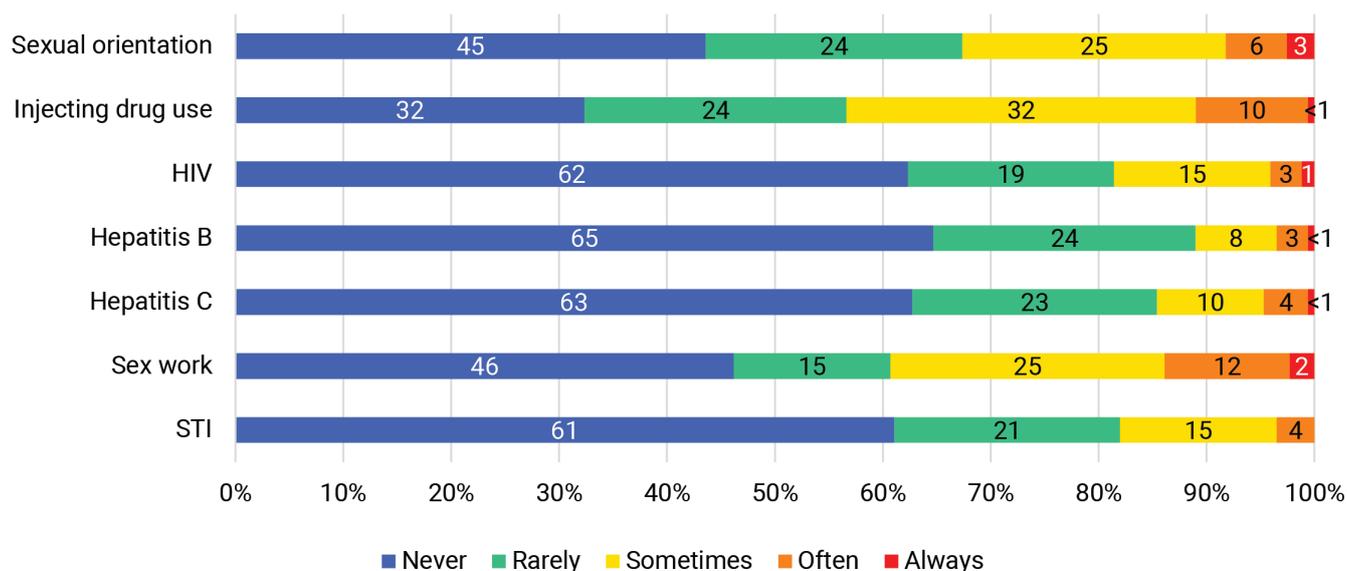


Figure 5. Witnessing stigma from other health workers – Health care/medical students (n=199)

Health care workers and students were more likely to report witnessing other health workers behaving negatively towards each of the listed groups of patients/clients than they were to indicate that they themselves would behave negatively. As with self-reports on the mirrored Indicator, injecting drug use was the attribute most likely to have received negative treatment (witnessed by 70% of health care workers and 68% of students). The largest discrepancy related to sexual orientation. While 11% of health care workers and 10% of students indicated that they would behave negatively towards other people because of their sexual orientation, 55% of health care workers and 56% of students reported witnessing other health workers behaving negatively towards patients/clients on the basis of their sexual orientation. Hepatitis B was the attribute reported to receive the least negative treatment from other health workers (witnessed by 38% of health care workers and 35% of students).

People who inject drugs

The paper-based survey was completed by 603 people who inject drugs (PWID). The average age was 43 years and more than half of participants were male (60%). Participants were recruited from all states and territories, most commonly Western Australia (27%), Queensland (17%), and Northern Territory (16%). Most participants were born in Australia or New Zealand (89%) and 21% identified as Aboriginal or Torres Strait Islander. One in ten had completed university (10%) and 22% were employed. Most participants had injected drugs within the last month (91%), with 44% injecting at least daily.

The results from the injecting drug use Stigma Indicator are shown in Figure 6, along with results from the 2016 online survey of PWID and 2016 Australian Needle and Syringe Program Survey (ANSPS) data (Memedovic et al., 2017).

In the last 12 months, have you experienced any stigma or discrimination in relation to your injecting drug use?

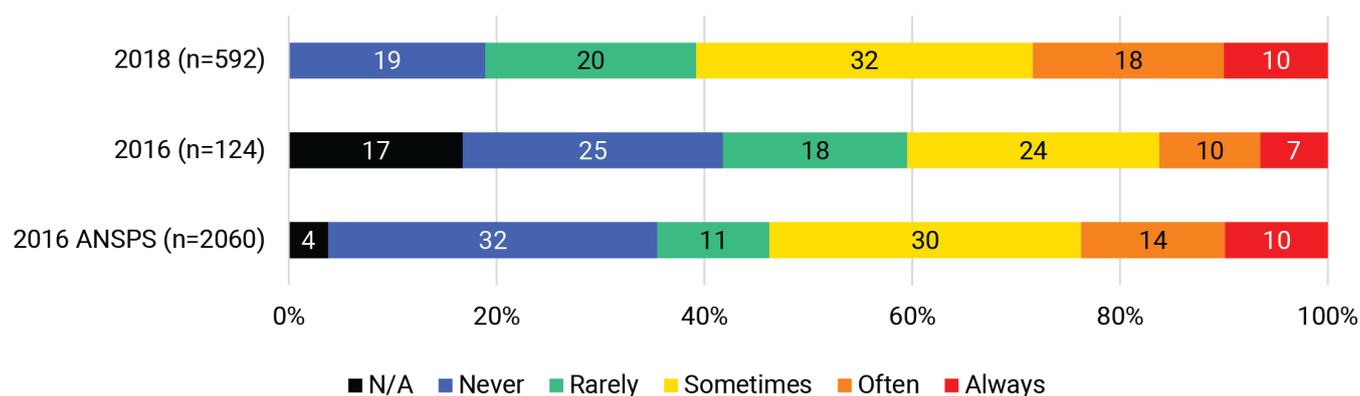


Figure 6. Stigma Indicator - People who inject drugs

In 2018, 81% of participants reported experiencing any stigma or discrimination in relation to their injecting drug use. More than one-quarter (28%) indicated that they ‘often’ or ‘always’ experienced stigma or discrimination. These proportions are higher than those reported in 2016.

Health workers treated me negatively or differently to other people

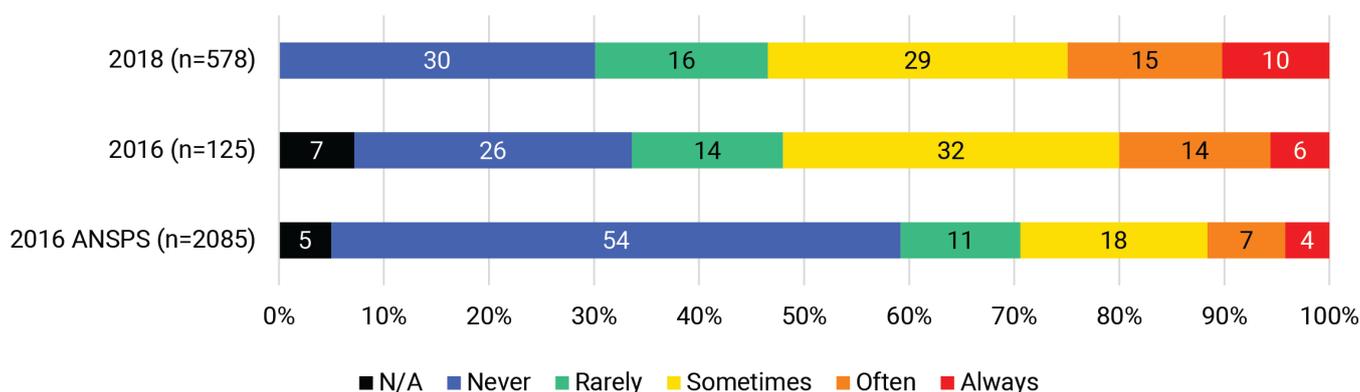


Figure 7. Additional stigma item - People who inject drugs

As with the 2016 online survey, more than two-thirds of participants in 2018 (70%) felt that health workers had treated them negatively or differently to other people. One in four participants (25%) indicated that this was ‘often’ or ‘always’ the case. Participants in these surveys reported more negative treatment than 2016 ANSPS participants, which may be reflective of the different sampling methods utilised in each survey.

These findings are in line with reports from members of the general public, health care workers and students, who were all more likely to report that they would behave negatively towards PWID than any other group. Results from Phase One and Phase Two of this project clearly demonstrate that PWID are particularly at risk of experiencing stigma and discrimination from members of the public and in health care settings. While results from the two phases cannot be directly compared, the comparatively high levels of stigma expressed towards and experienced by PWID suggest that there has been little change in the stigmatisation of PWID over the last few years.

Men who have sex with men

The online survey was completed by 1,280 participants, with an average age of 32 years. Most identified as gay (82%), while 14% identified as bisexual. Participants were recruited from all states and territories, most commonly New South Wales (31%), Victoria (28%), and Queensland (22%). Most participants were born in Australia or New Zealand (79%) and 4% identified as Aboriginal or Torres Strait Islander. Nearly half of the sample had completed university (45%) and 50% were in full time employment.

The results from the 2018 online survey of men who have sex with men (MSM) are shown in Figure 8, along with results from the 2016 *Telling* survey of MSM. It is worth noting that while both surveys were completed by MSM, they used different recruitment methods.

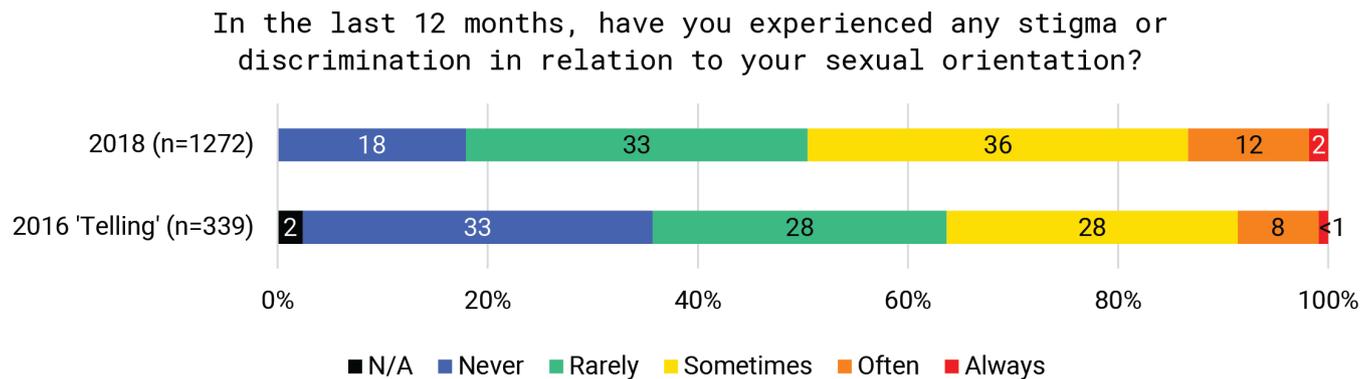


Figure 8. Stigma Indicator - Men who have sex with men

In 2018, a majority of participants (82%) reported that they had experienced any stigma or discrimination in relation to their sexual orientation over the previous 12 months, with 13% indicating this 'often' or 'always' occurred. This is a larger proportion than reported any stigma or discrimination in the 2016 *Telling* survey (64%). For context, it is worth noting that the 2018 survey was conducted within 12 months of the conclusion of the Australia Marriage Law Postal Survey. The impact of the postal survey on experiences of stigma within the LGBTIQ community at structural and personal levels have been documented, as have the consequent negative implications for their mental health and wellbeing (Perales & Todd, 2018; Verrelli, White, Harvey, & Pulciani, 2019).

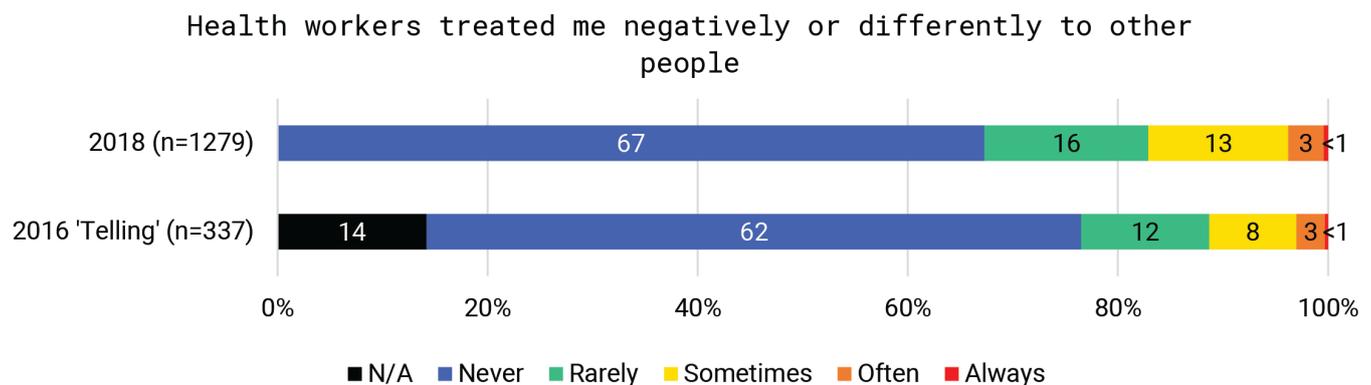


Figure 9. Additional stigma item - Men who have sex with men

While most participants reported some degree of stigma or discrimination, significantly fewer (33%) indicated that health workers had treated them negatively or differently to other people (Figure 9).

People living with HIV

The *HIV Futures 9* survey was completed by 847 people living with HIV (PLHIV), with an average age of 50 years. Most participants were male (88%) and identified as gay or homosexual (74%). Participants were recruited from all states and territories, most commonly New South Wales (38%), Victoria (27%), and Queensland (16%). Most were born in Australia (71%) and 2% identified as Aboriginal or Torres Strait Islander. Nearly half of participants had completed university (46%) and 42% were in full time employment (Power et al., 2019).

The Stigma Indicator results from *HIV Futures 9* are shown in Figure 10, along with results from the 2016 online survey of PLHIV. It is worth noting that while both surveys were completed by PLHIV, they used different recruitment methods.

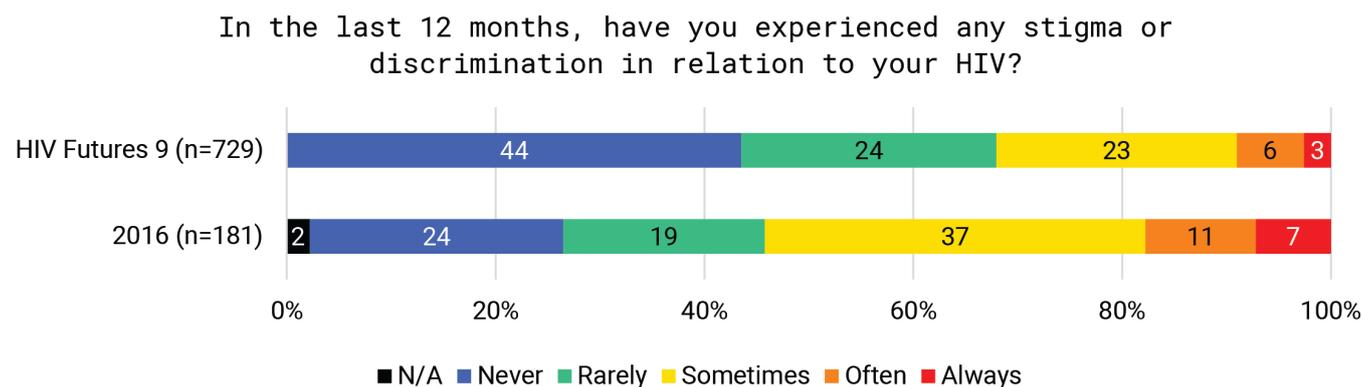


Figure 10. Stigma Indicator - People living with HIV

More than half of participants (56%) reported that they experienced any stigma or discrimination in relation to their HIV in the last 12 months, with 9% indicating that this 'often' or 'always' occurred. The proportion reporting experiencing any HIV-related stigma was smaller in 2018 (56%) than in 2016 (74%).

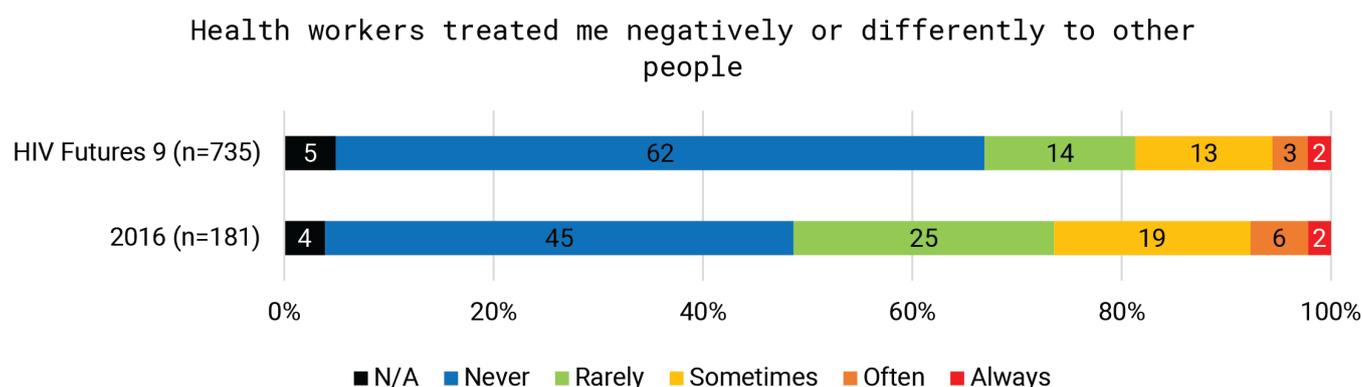


Figure 11. Additional stigma item - People living with HIV

Similarly, the proportion of PLHIV who reported being treated negatively by health workers was smaller in 2018 (38%) than in 2016 (51%; Figure 11).

While noting that results from the two phases are not directly comparable (particularly due to methodological differences between the 2016 online survey and *HIV Futures 9*), these findings are an indication that stigma towards PLHIV may have reduced in health care settings and the wider community. Regular monitoring of stigma within this population is required to allow meaningful comparisons over time.

Supplementary data

The HIV stigma indicator was also included in the 2018 survey of MSM (for participants who reported being HIV-positive; Figure 12).

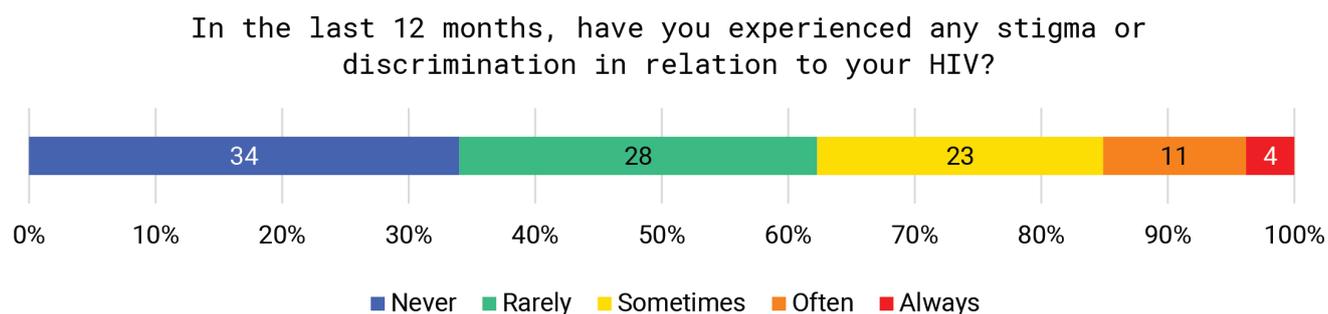


Figure 12. HIV Stigma Indicator - Subsample of men who have sex with men (n=53)

Nearly two-thirds of HIV-positive MSM (66%) reported any experiences of HIV-related stigma or discrimination in the last 12 months – more than the 56% of *HIV Futures 9* participants reporting HIV-related stigma.

Young people and sexually transmissible infections

The *Debrief* survey was completed by 2,303 young people (aged 15–29 years) living in Australia, with an average age of 22 years. Just over half were female (54%) and most identified as heterosexual (70%). Participants were recruited from all states and territories, most commonly New South Wales (30%), Victoria (27%), and Queensland (19%). Most participants were born in Australia (85%) and 3% identified as Aboriginal or Torres Strait Islander (Adam, de Wit, Ketsuwan, & Treloar, 2019).

Among participants who had ever had sex, 58% reported having ever tested for STIs and/or HIV, including 36% who had tested within the previous 12 months. The majority of participants who had ever tested for STIs and/or HIV indicated that they had not been diagnosed with an STI or HIV (88%), while 7% had received an STI diagnosis.

Findings from the Stigma Indicator among young people with STIs (n=30) are shown in Figure 13.

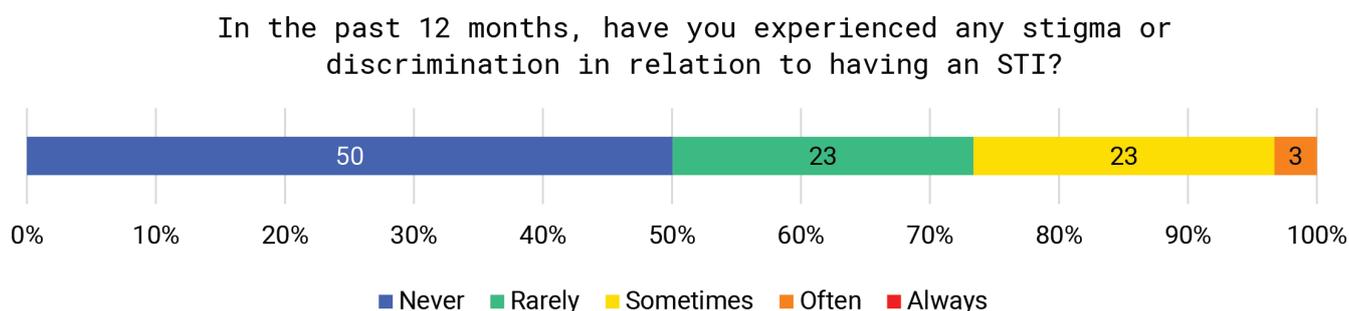


Figure 13. Stigma Indicator - Young people with STIs (n=30)

Half of the participants who had been diagnosed with an STI in the last 12 months reported experiences of stigma and/or discrimination in relation to that STI. Due to the small number of participants diagnosed with an STI in the last 12 months (n=30), these results should be interpreted cautiously.

The mirrored Stigma Indicator was also included to explore the extent to which all *Debrief* participants would express stigma towards other people diagnosed with STIs (Figure 14).

Would you behave negatively towards other people because they have (or have had) an STI?

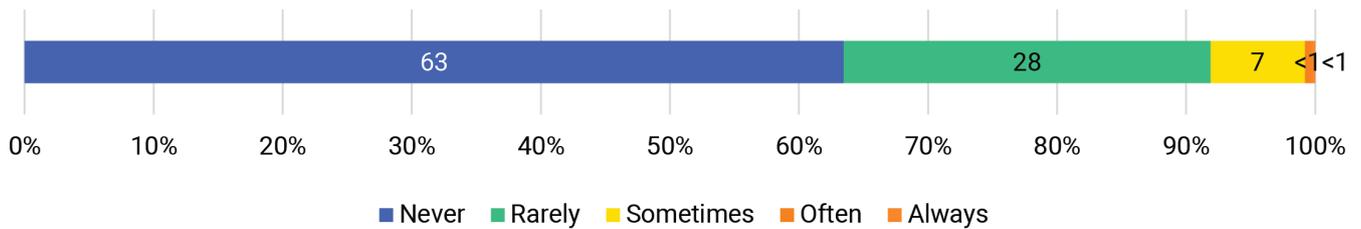


Figure 14. Mirrored STI Stigma Indicator – Young people (n=1,526)

Nearly two-thirds of participants (63%) indicated that they would never behave negatively towards other people due to having an STI, and only 1% indicated that they would ‘often’ or ‘always’ do so.

To supplement the STI Stigma Indicator and mirrored Indicator, a hypothetical Stigma Indicator question was included to measure the extent to which participants believed they would experience stigma or discrimination if they ever did have an STI (Figure 15).

If you ever had an STI, do you think you would experience any stigma or discrimination in relation to this STI?

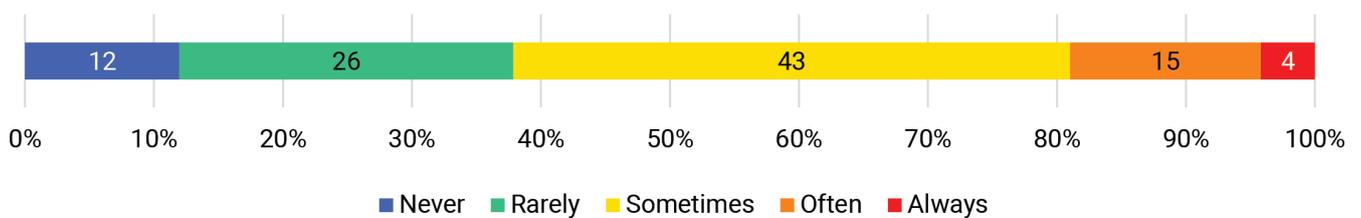


Figure 15. Hypothetical STI Stigma Indicator – Young people (n=669)

A majority of participants (88%) expected that they would experience stigma or discrimination if they ever had an STI – a significantly larger proportion than reported that they would behave negatively towards other people with an STI. Nearly one in five (19%) believed that they would ‘often’ or ‘always’ experience stigma or discrimination in relation to having an STI.

These findings highlight the potential for discrepant accounts of stigma from various sources. The proportion of people diagnosed with STIs who reported experiencing any stigma was larger than the proportion of people who indicated that they would behave negatively towards other people because of an STI. Further, the proportion of people who had not been diagnosed with an STI but expected they would experience stigma if they ever were diagnosed was significantly larger than the proportion who had experienced stigma in relation to an STI. It is therefore important to continue collecting data directly from the priority groups as well as from sources such as the general public and health care workers in order to monitor various perspectives on the anticipation, expression, and experience of stigma and discrimination.

Supplementary data

The STI stigma indicator was also included in the 2018 survey of MSM (for participants who reported an STI diagnosis in the previous 12 months; Figure 16).

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

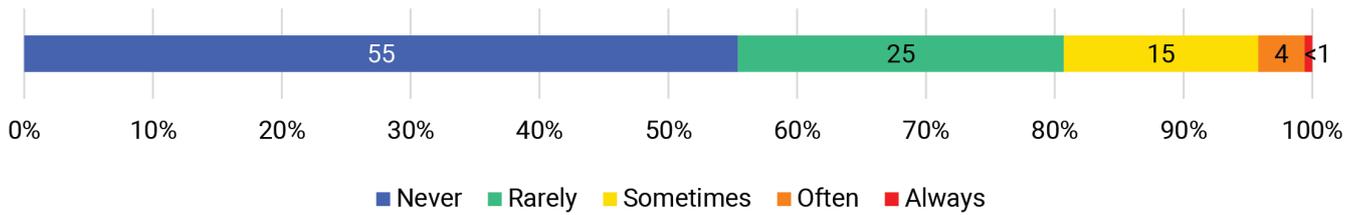


Figure 16. STI Stigma Indicator - Subsample of men who have sex with men (n=166)

These supplementary findings are similar to the results from the *Debrief* survey, with 45% of participants reporting experiences of stigma or discrimination in relation to their STI diagnoses.

People living with hepatitis C

The online survey was completed by 68 people living with hepatitis C, with an average age of 51 years. Most participants were female (76%), and they mostly lived in New South Wales (43%), Victoria (22%), and Queensland (21%). The majority were born in Australia or New Zealand (88%) and 6% identified as Aboriginal or Torres Strait Islander. Just over one-third had completed university (36%) and 66% were employed. Two-thirds of participants (66%) had cleared the virus through treatment, while 18% had cleared it spontaneously and 16% reported that they currently had hepatitis C.

The results from the 2018 survey of people living with hepatitis C are shown in Figure 17, along with results from the 2016 online survey of people living with hepatitis C.

In the last 12 months, have you experienced any stigma or discrimination in relation to your hepatitis C?

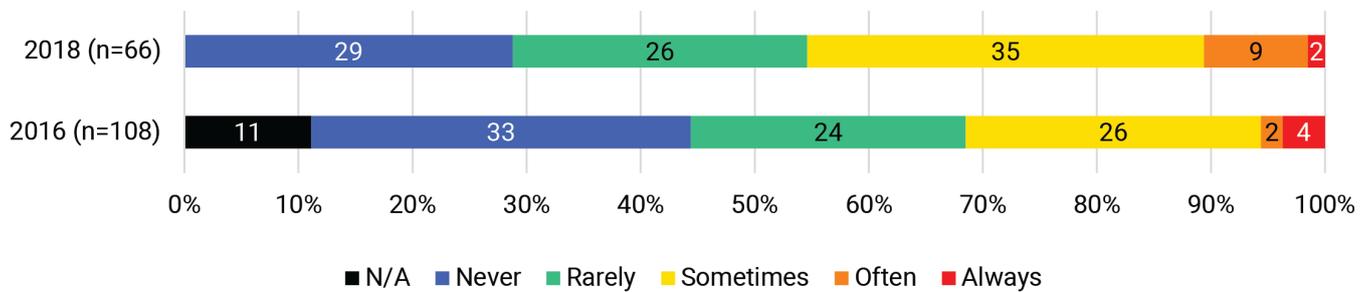


Figure 17. Stigma Indicator - People ever diagnosed with hepatitis C

In 2018, stigma or discrimination in relation to hepatitis C was experienced by 71% of participants, with approximately one in 10 (11%) reporting that this occurred 'often' or 'always'. This represents a slightly higher proportion of people ever diagnosed with hepatitis C reporting stigma than in the 2016 survey.

Health workers treated me negatively or differently to other people

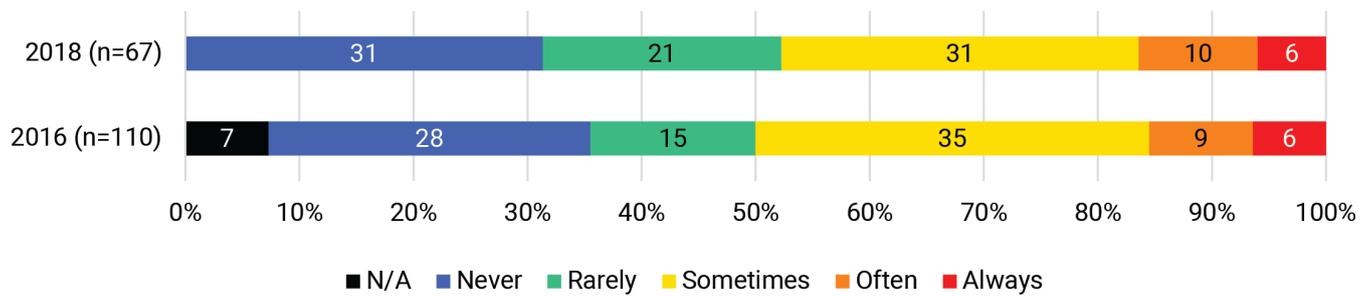


Figure 18. Additional stigma item – People ever diagnosed with hepatitis C

The results of the additional stigma item reflect the Stigma Indicator, with more than two-thirds of participants in 2018 (69%) reporting that health workers treated them negatively or differently to other people, including 16% who indicated that this was ‘often’ or ‘always’ the case. These findings are similar to those from the 2016 survey.

Collecting data in relation to hepatitis C proved to be more difficult than other priority groups. Despite repeated promotional efforts, response rates remained low, similar to recruitment challenges experienced in Phase One. Part of the difficulty in recruiting people who have ever lived with hepatitis C may be due to the effectiveness of new hepatitis C treatments, meaning that once people have cleared the virus, they no longer engage with hepatitis organisations or view hepatitis as being relevant to their lives. It may therefore be difficult to conduct time-specific surveys of people living with hepatitis C in order to quantitatively monitor stigma and discrimination in relation to hepatitis C. Alternative methods of collecting Stigma Indicator data should be considered, such as partnering with health care providers to administer the indicator at the time of treatment.

Supplementary data

The hepatitis C Stigma Indicator was also included in the survey of PWID (for those who reported ever being diagnosed with hepatitis C; Figure 19).

In the last 12 months, have you experienced any stigma or discrimination in relation to your hepatitis C?

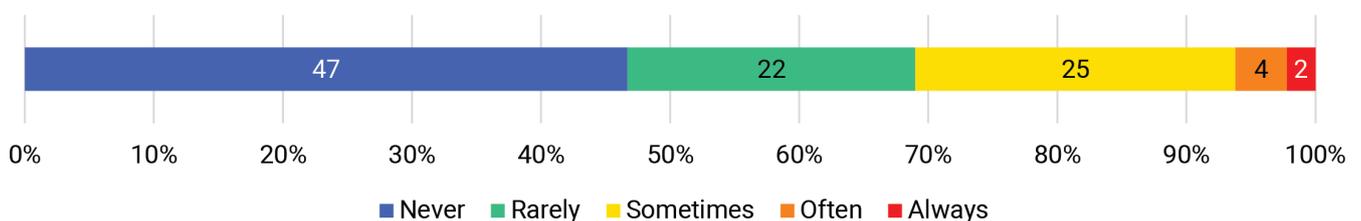


Figure 19. Hepatitis C Stigma Indicator – Subsample of people who inject drugs (n=274)

Compared to online hepatitis C survey participants, PWID who had been diagnosed with hepatitis C were less likely to report experiences of stigma or discrimination (53%). It is worth noting, however, that PWID were more likely to report stigma or discrimination in relation to their injecting drug use, which may have been a more salient experience than stigma related to their hepatitis C.

Future directions

Future phases of the Stigma Indicators Monitoring Project will continue to collect data across the priority groups. This will include implementation of a survey of sex workers, including the Stigma Indicator, for the first time. The sampling procedures used to recruit health care workers and students, people who inject drugs, men who have sex with men, and people living with HIV were successful in Phase Two and warrant future replication.

In order to monitor progress against the national strategies' objectives, broad scale interventions should be implemented to address stigma and discrimination that has been identified across priority groups in this project. Following consultation with key members of the project advisory committee, a brief stigma intervention project has been developed, which is currently being piloted with a sample of the Australian general public. Results regarding the effectiveness of this intervention, including options for upscaling its reach will be published later in 2020.

Conclusions

The results in Phase Two of the Stigma Indicators Monitoring Project demonstrate that stigma and discrimination continue to be significant issues experienced by people within the priority groups identified by the national strategies addressing blood borne viruses and STIs. This report expands on Phase One of the project, by including data on experiences of stigma among new priority populations, as well as the expression of stigma from health care workers, health care/medical students, and the general population.

There are simultaneously similarities and differences evident across the Stigma Indicator data for each of the priority groups and across the datasets collected at two different timepoints, underscoring the importance of collecting relevant data from health care workers, members of the general public, and the priority groups themselves. Ongoing monitoring is necessary to continue tracking progress against the national strategies' objectives to eliminate the negative effects of stigma and discrimination in people's lives. Future phases of Stigma Indicator data will enable more meaningful comparisons of data over time, particularly as broad level intervention efforts are implemented to address stigma and discrimination at structural, community, and individual levels.

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Publications from the Stigma Indicators Monitoring Project

Journal articles

- Broady, T.R., Brener, L., Cama, E., Hopwood, M., & Treloar, C. (2020). Stigmatising attitudes towards injecting drug use, blood borne viruses, and sexually transmissible infections in a representative sample of the Australian public. *PLOS ONE*, 15(4), e0232218. <https://doi.org/10.1371/journal.pone.0232218>
- Brener, L., Broady, T., Cama, E., Hopwood, M., de Wit, J.B.F., & Treloar, C. (2019). The role of social support in moderating the relationship between HIV centrality, internalised stigma and psychological distress for people living with HIV. *AIDS Care*. <https://doi.org/10.1080/09540121.2019.1659914>
- Brener, L., Cama, E., Broady, T.R., Hopwood, M., de Wit, J., & Treloar, C. (2019). Predictors of health care workers' support for discriminatory treatment and care of people who inject drugs. *Psychology, Health & Medicine*, 24(4), 439-445. <https://doi.org/10.1080/13548506.2018.1546018>
- Broady, T. R., Cama, E., Brener, L., Hopwood, M., de Wit, J., & Treloar, C. (2018). Responding to a national policy need: Development of a stigma indicator for bloodborne viruses and sexually transmissible infections. *Australian and New Zealand Journal of Public Health*, 42(6), 513-515. <https://doi.org/10.1111/1753-6405.12809>

Project reports

Hopwood, M., Cui, J., Chen, C., Brener, L., Broady, T., Cama, E., & Treloar, C. (2019). *Hepatitis B-related stigma among Chinese Australians living in Sydney (Summary report)*. Sydney: Centre for Social Research in Health, UNSW Sydney. <http://doi.org/10.26190/5cfeeed12fb4e>

Cama, E., Broady, T., Brener, L., Hopwood, M., de Wit, J., & Treloar, C. (2018). *Stigma Indicators Monitoring Project: Summary report*. Sydney: Centre for Social Research in Health, UNSW Sydney. bit.ly/stigma-indicators

One page summaries of completed surveys are also available on the project website: bit.ly/stigma-indicators

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