

Stigma Indicators Monitoring Project People Living With HIV – New South Wales

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Background

Stigma and discrimination have major health implications for people living with or at risk of blood borne viruses (BBVs) and sexually transmissible infections (STIs). Australia has five national strategies addressing HIV, viral hepatitis, and STIs, each with a clear goal to eliminate the negative impact of stigma and discrimination on people's health (Australian Government Department of Health, 2018a,b,c,d,e).

Since 2015, the Australian Government Department of Health has provided funding to the Centre for Social Research in Health (CSRH, UNSW Sydney) to develop and implement an indicator of stigma amongst priority groups identified by the national strategies, namely: gay and other men who have sex with men, people who inject drugs, people living with HIV, people living with viral hepatitis, and people who engage in sex work. Information regarding the development of the indicator has been published elsewhere (Broady et al., 2018). A mirrored indicator was also developed to monitor the expression of stigma by populations such as health workers or the general public. Since 2016, the stigma indicator and mirrored indicator have been periodically used in surveys of the priority populations, health workers, and the general population.

This report outlines the results from a survey of people living with HIV conducted between 2021 and 2022. Results specific to participants living in NSW are provided, including comparisons with participants from the rest of Australia and with participants from NSW in a previous survey of people living with HIV (conducted between 2018 and 2019).

Method

The stigma indicator was included in *HIV Futures 10* – a national survey about the quality of life of people living with HIV, conducted by the Australian Research Centre in Sex, Health and Society (La Trobe University). *HIV Futures 10* was conducted online and via paper questionnaires between June 2021 and July 2022. Survey questions included demographic characteristics and a range of questions regarding experiences of stigma and discrimination over the past 12 months (see Norman, et al., 2022).

Comparisons were made between participants from NSW and those living elsewhere in Australia. Findings from participants residing in NSW were also compared with results from NSW participants in *HIV Futures 9* (conducted between November 2018 and May 2019). Comparisons between binary or categorical variables were conducted using chi-square tests, comparisons between continuous variables were conducted using independent samples t-tests, and comparisons between ordinal variables (e.g., the stigma indicator) were conducted using Mann-Whitney U tests.

Table 1 compares the demographic characteristics of the 2021/22 sample from NSW and the rest of Australia, and the characteristics of the 2018/19 sample from NSW.

Table 1. Demographic characteristics of participants

	NSW 2021/22 n (%)	Rest of Australia 2021/22 n (%)	Comparison with NSW 2021/22	NSW 2018/19 n (%)	Comparison with NSW 2021/22
Total sample	323	489		317	
Gender			$\chi^2=3.00, p=.39$		$\chi^2=3.31, p=.35$
Male	287 (90.5)	424 (87.4)		277 (89.1)	
Female	27 (8.5)	50 (10.3)		25 (8.0)	
Non-binary/Gender fluid	2 (0.6)	9 (1.9)		7 (2.3)	
Different term	1 (0.3)	2 (0.4)		2 (0.6)	
Sexuality			$\chi^2=8.16, p=.15$		$\chi^2=9.75, p=.08$
Lesbian/Gay/Homosexual	252 (78.8)	371 (76.3)		234 (77.7)	
Heterosexual/Straight	27 (8.4)	58 (11.9)		35 (11.6)	
Bisexual	20 (6.3)	28 (5.8)		15 (5.0)	
Pansexual	0	6 (1.2)		4 (1.3)	
Queer	15 (4.7)	14 (2.9)		12 (4.0)	
Different term	6 (1.9)	9 (1.9)		1 (0.3)	
Age (years): Mean (SD)	57.0 (12.7)	53.3 (11.5)	t=4.29, p<.001	52.9 (13.6)	t=3.88, p<.001
Aboriginal or Torres Strait Islander	9 (2.8)	13 (2.7)	$\chi^2=0.01, p=.93$	7 (2.2)	$\chi^2=0.25, p=.62$
Born overseas	115 (35.6)	127 (26.0)	$\chi^2=8.63, p<.01$	105 (34.8)	$\chi^2=0.05, p=.83$
Education			Z=1.29, p=.20		Z=0.36, p=.72
Up to Year 10	49 (15.2)	62 (12.7)		50 (16.1)	
Year 12	32 (9.9)	77 (15.8)		33 (10.6)	
Diploma / Certificate	94 (29.2)	154 (31.6)		89 (28.6)	
University	147 (45.7)	194 (39.8)		139 (44.7)	
Employed full-time	132 (41.4)	27 (46.9)	$\chi^2=2.37, p=.12$	122 (38.6)	$\chi^2=0.51, p=.48$
Region			$\chi^2=8.68, p=.03$		$\chi^2=2.76, p=.43$
Capital city	180 (56.3)	271 (56.0)		195 (61.5)	
Outer suburban	37 (11.6)	89 (18.4)		35 (11.0)	
Regional	66 (20.6)	79 (16.3)		61 (19.2)	
Rural	37 (11.6)	45 (9.3)		26 (8.2)	
Current antiretroviral treatment	295 (97.0)	443 (98.7)	$\chi^2=2.45, p=.12$	303 (99.3)	$\chi^2=4.56, p=.03$
Undetectable viral load¹	285 (96.6)	416 (93.9)	$\chi^2=2.72, p=.10$	263 (88.3)	$\chi^2=14.76, p<.001$

¹ Among participants currently receiving antiretroviral treatment

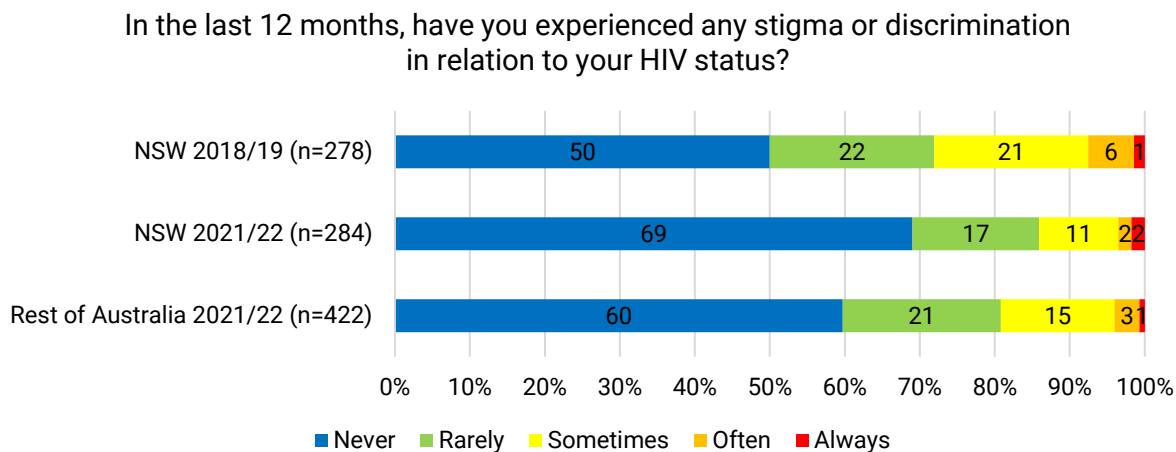
In 2021/22, the demographic profile of the NSW sample was largely similar to those from elsewhere in Australia. The only differences were in terms of age, country of birth, and residential region. Participants from NSW were older on average than those from elsewhere in Australia (57.0 years vs. 53.3 years) and were more likely to have been born overseas (35.6% vs. 26.0%). Compared to participants from elsewhere in Australia, those from NSW were more likely to live in regional or rural areas (20.6% vs. 16.3% and 11.6% vs. 9.3%, respectively) and less likely to live in outer suburban areas (11.6% vs. 18.4%).

Comparisons between NSW participants in 2018/19 and those in 2021/22 showed that participants were older on average in 2021/22 (57.0 years vs. 52.9 years). Almost all NSW participants in 2021/22 reported currently receiving antiretroviral treatment (97.0%), however, this was lower than in 2018/19 (99.3%). Among those who reported current antiretroviral treatment, 96.6% of NSW participants reported an undetectable viral load in 2021/22 – a larger proportion than in 2018/19 (88.3%).

Results

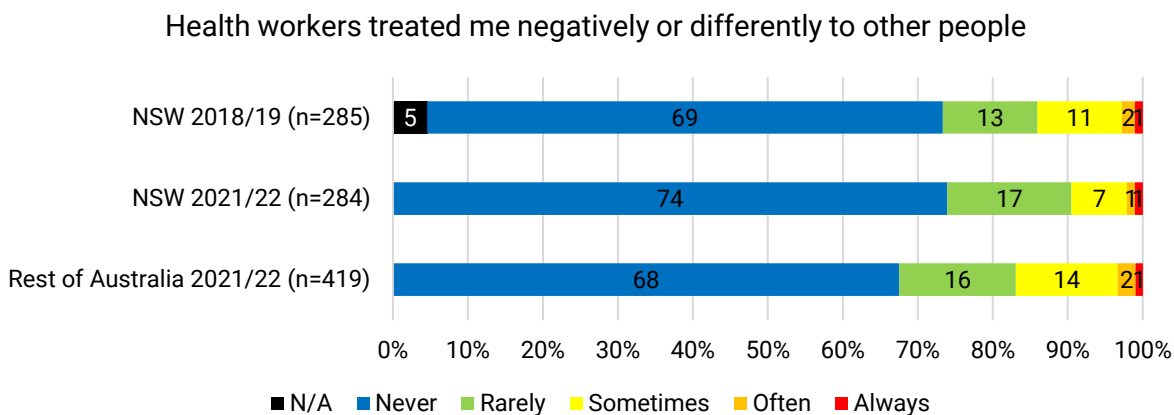
In 2021/22, 31% of NSW participants reported any experience of stigma or discrimination in relation to their HIV over the past 12 months, including 4% who indicated that this ‘often’ or ‘always’ occurred. This was a smaller proportion than the 50% of NSW participants who reported any stigma or discrimination in 2018/19 ($Z=4.81, p<.001$). In 2021/22, a smaller proportion of NSW participants reported any experience of HIV-related stigma compared to participants from elsewhere in Australia (31% vs. 40%, $Z=2.47, p=.01$).

Figure 1. Past 12-month stigma or discrimination in relation to HIV



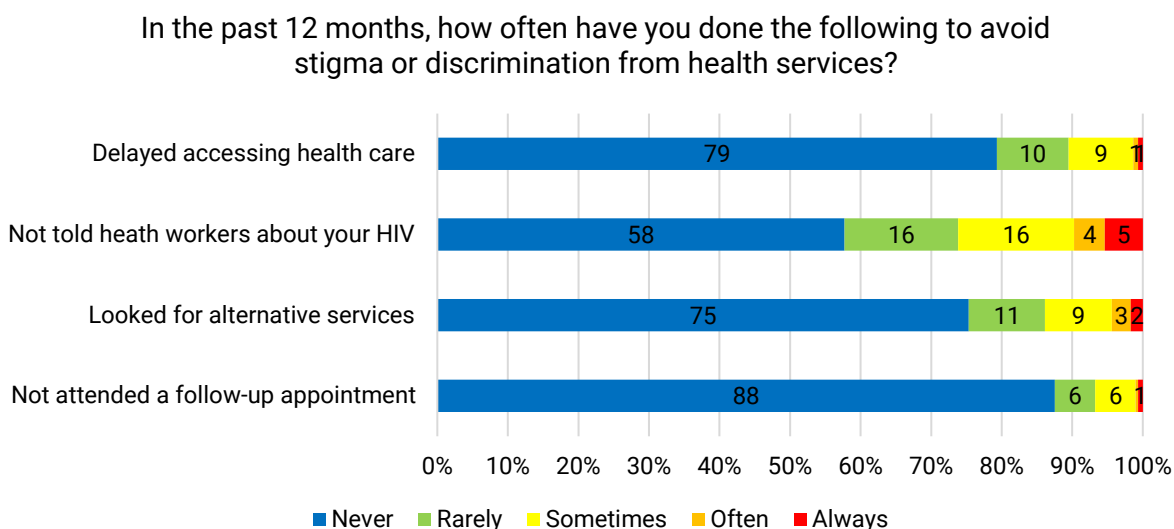
In 2021/22, 26% of NSW participants reported any negative treatment by health workers in the past 12 months. There was no difference in the frequency of reported negative treatment between NSW participants in 2021/22 and 2018/19 ($Z=0.79, p=.43$). In 2021/22, NSW participants reported less frequent experiences of negative treatment from health workers than those from elsewhere in Australia ($Z=2.14, p=.03$).

Figure 2. Past 12-month stigma or discrimination by health workers due to HIV



In *HIV Futures 10*, participants were asked about strategies they had utilised in order to avoid stigma and discrimination from health services. The most common strategy was not disclosing HIV status to health workers (reported by 42% of NSW participants), followed by looking for alternative services (25%), delaying health care access (21%), and not attending follow-up appointments (12%). Compared to participants from elsewhere in Australia, those from NSW less frequently delayed accessing health care ($Z=2.93, p<.01$), looked for alternative services ($Z=2.26, p=.02$), or did not attend a follow-up appointment ($Z=2.21, p=.03$).

Figure 3. Strategies utilised to avoid stigma or discrimination from health services, New South Wales participants 2021/22 (n=196)



Conclusion

Findings from *HIV Futures 10* indicate that stigma related to HIV continues to be commonly experienced in Australia. In NSW, the frequency of reported HIV-related stigma was lower in 2021/22 (31%) than in 2018/19 (50%). Reports of negative treatment by health workers, however, were similar across the two surveys. The continued experiences of stigma reported by people living with HIV in Australia therefore warrant ongoing attention.

The need to reduce stigma and discrimination towards HIV in health care settings is emphasised by findings related to strategies utilised by people living with HIV to avoid stigma. NSW participants were most likely to report not disclosing their HIV status to health workers in order to avoid stigma or discrimination. Detailed information regarding the circumstances surrounding this non-disclosure was not collected in the survey (e.g., which health care workers they did not disclose to, how relevant HIV status was to the health treatment being provided, etc.). Regardless of the circumstances under which participants avoided disclosing their HIV status, doing so to avoid stigma or discrimination suggests a perceived lack of acceptance which could contribute to people living with HIV not accessing the health care they need. The 21% of NSW participants who reported delaying accessing health care and the 25% who sought alternative services in order to avoid stigma or discrimination further highlight the significant barriers that stigma and discrimination create to appropriate health care among people living with HIV.

Ongoing monitoring of stigma and discrimination in relation to HIV is warranted to determine whether any meaningful changes occur over time. Given the impact of stigma among people living with HIV, particularly in relation to health care access, there is a clear need to invest in wide-reaching interventions to reduce stigmatising attitudes and behaviours towards people living with HIV and to sensitively respond to past negative experiences.

References

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