

AIVL

RESEARCH & POLICY

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Welcome to the Australian Injecting and Illicit Drug Users League (AIVL) Research & Policy Update – a regular electronic publication designed to support AIVL staff, staff and members of the AIVL member organisations, peer educators, peer support workers and other key stakeholders to stay up-to-date on the latest research evidence and policies in the areas of blood borne viruses (BBVs), injecting drug use, opioid pharmacotherapies and drug treatment, harm reduction, legal issues and human rights.

The 12th issue of AIVLs Research and Policy Update predominantly features the results from AIVLs 'Online Discrimination Survey'



which has been running for just over six months. The survey is part of a larger National Anti-Discrimination Project that AIVL are running where the overall aim is to reduce stigma and discrimination, improve access to services – particularly health-related services – and reduce social exclusion among people who inject drugs (PWID) and those on pharmacotherapy programs. This will be achieved by raising awareness, increasing the knowledge of drug users about discrimination what it means and how it manifests, and also reducing fears and addressing myths and misinformation among the general public and the media about PWID.

The survey is targeted at people who inject drugs (PWID), people on pharmacotherapies, and/or those living with hepatitis C. These people very often manage complex situations in relation to poor treatment and discriminatory practices. It can frequently be difficult to separate the reason for the poor treatment; injecting drug use, being on a pharmacotherapy, hepatitis C infection or a combination of these issues. So far there have been an overwhelming amount of responses to the survey, which highlights the need for action, education and change in regards to discrimination and stigma that people are currently experiencing and reporting. This paper reports on the results of 110 completed surveys. The survey is still running and can be accessed here: aivl.org.au/discriminationsurvey.

AIVL would like to give their thanks and appreciation to everyone who contributed to this issue. We welcome any feedback, information, or relevant publications that readers would like to contribute, likewise, if you have research or policy news to share with us please contact Laura at: laural@aivl.org.au

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AIVL National Anti-Discrimination Project: Online Discrimination Survey Results

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Introduction and background

The AIVL 'Online Discrimination Survey' is part of the larger National Anti-Discrimination Project that AIVL have been working on for the last three years. The overall aim of the National Anti-Discrimination Project is to reduce stigma and discrimination, improve access to services – particularly health-related services – and reduce social exclusion among people who inject drugs and those on pharmacotherapy programs. This will be achieved by raising awareness, increasing the knowledge of drug users about discrimination what it means and how it manifests, and also reducing fears and addressing myths and misinformation among the general public and the media about PWID.

The Online Discrimination Survey presented here is targeted at people who inject drugs (PWID), people on pharmacotherapies, and/or those living with hepatitis C. These people very often manage complex situations in relation to poor treatment and discriminatory practices. It can frequently be difficult to separate the reason for the poor treatment; injecting drug use, being on a pharmacotherapy, hepatitis C infection or a combination of these issues. This means the information needs of PWID and those on pharmacotherapy are not the same as other groups in relation to reporting discrimination and the making of, and proceeding with complaints. People on pharmacotherapy

are also physically dependent on their medications and therefore have more complex issues to manage when dealing with, and contemplating the reporting of discriminatory practices. In short, they simply cannot risk being removed from their pharmacotherapy treatment service due to making a complaint or lodging a negative report.

The survey commenced several months ago and has had over 110 responses.

When reading the report please note:

- *For ethical/privacy reasons, any material within the survey containing potentially identifying information has been removed and recorded as 'XXXX'. Types of services; for example "hospitals" and "pharmacies" have been left as we believe this information is integral to the purpose of the survey.*
- *Spelling and grammar have been edited in the qualitative responses, however intent has been maintained. Where this is not possible the qualitative response has not been edited.*
- *In some instances data was removed (as comments), as it was mistakenly entered as numerals.*

Demographics

To date, the majority of responses have been from the age range of 36-45 yr. olds (36%), 26-35 yr. olds were the second highest age group (33%) to respond to the survey. Victoria had the highest percentage of respondents (25%), with New South Wales second at 24% (this may be due to concentrated effort(s) by these state's drug user organisations to promote the survey to clients). A majority (70%) of respondents classified themselves as living in the metropolitan area of their state or territory. When asked what gender respondents identified with 54% stated female, and 43% male. 1% did not wish to specify their gender, and 1% identified as transgender.

“My family no longer trusts me even though I'm seeking help. I've lost close friends who no longer trust me even though I'm on methadone maintenance.”

Where the discrimination took place

Respondents to this question could select multiple options in answering, therefore figures do not total to 100%. When asked 'where the discrimination took place?' the main services indicated by respondents were 'hospitals' at 54%, this was followed closely by 'doctors/prescribers' (52%), and then 'pharmacies' (41%) and 'police' (33%). 'Health services' (e.g. mental, youth, or community health centres) and 'drug and alcohol services' were reported to a lesser degree of 19% equally. Following this, respondents reported 'dentists' (16%), 'government services' such as housing or Centrelink at

15%, and 'prisons' at 8%. Finally, 'Needle and Syringe Programs' (NSPs) were identified by 7% of respondents.

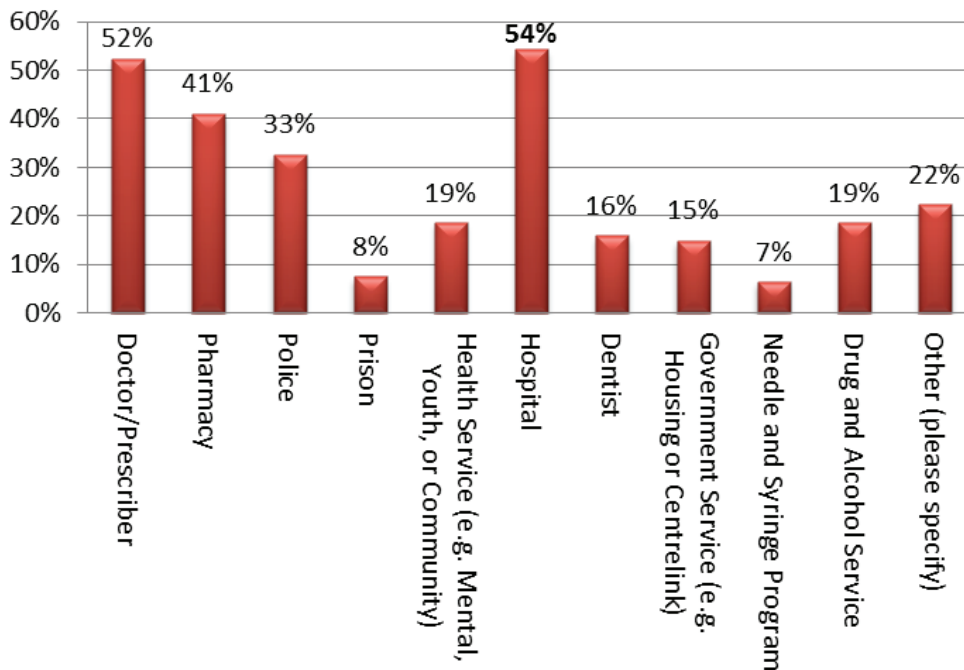
Twenty-two (22%) of respondents also stated 'Other' as a response to where the discrimination took place. In this case, all but 1 respondent continued to comment on where they believed they were discriminated against (see below dot points).

Examples of 'Other' responses for the question: "Where did the discrimination take place?"

- "Workplace" x6
- "Pain clinic" x2

- "By a surgeon who is also a psychiatrist"
- "All aspects of my life, outside my immediate, trust worthy networks"
- "Drug user group"
- "Child services & day-care provider"
- "Insurance company"
- "Friend"
- "Other people who are judgemental"
- "Friends' and loved ones"
- "Family no longer trusts me even though I'm seeking help. I've lost close friends who no longer trust me even though I'm on methadone maintenance."

Where did the discrimination take place?



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Why people were discriminated against

Respondents to this question could select multiple options in answering, therefore figures do not total to 100%. When asked 'why people thought they were discriminated against?' The majority of respondents (79%) believed it was because of their injecting drug use status (others thinking they were current injecting drug users), 47% of people believed it was because they were on opioid replacement pharmacotherapies (ORP) such as Methadone, or Suboxone, and 27% of responses were due to respondents believing that their hepatitis C status was one of the reasons they were discriminated against. Twenty four percent (24%) of responses were indicated for reasons other than those listed in the survey (as listed below). Some of the reasons given for the 'other' category were; because respondents were sex workers and mental health issues. Pain management (or lack thereof), refusal of medical treatment, and inadequate treatment within hospitals also emerged as a common theme.

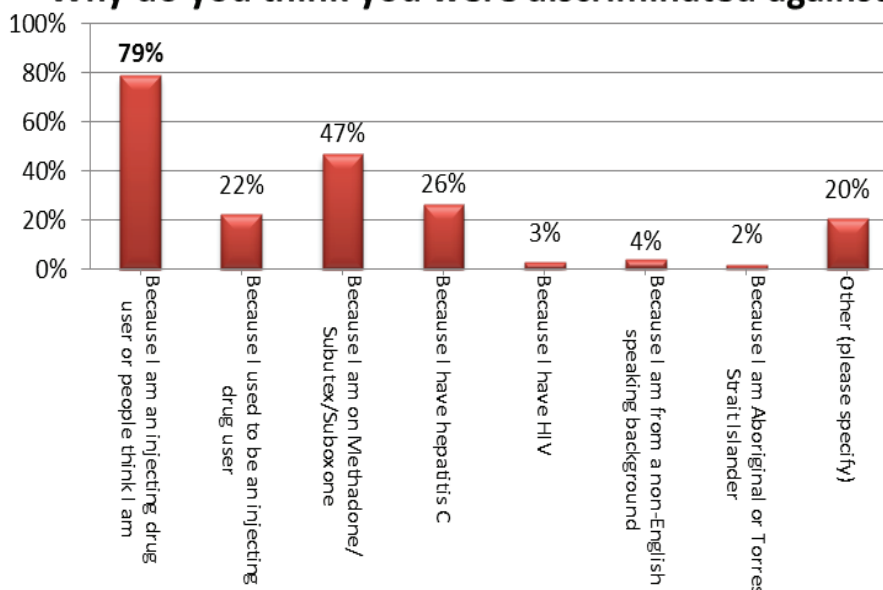
Examples of 'Other' responses for the question: "Why do you think you were discriminated against?"

- Sex workers x2
- Workplace x6
- "People think I have BBV Et am a criminal who cannot be trusted
- Pain management issues and problems with hospitals and Doctors (examples below);
- "I was on Hep C treatment when I was being admitted for another procedure. The doctor who did my intake informed me they would have to double glove around me and I would be the last procedure of the day. This shocked me as it was my belief that XXXX health followed universal BBV and infection protection procedures i.e. treat everyone as if they have a BBV. I was also in the police cells at one time when a female officer refused to enter my cell because she was scared she would "catch something" and pass it to her baby, I had 4 children of my own at the time, the

police force has a disgusting, misinformed and ultimately dangerous attitude, to PWID"

- "After my partner died I wasn't coping and went to a local GP and asked for some valium to help me get through the week and the funeral his family coming over, my kids etc. I had no support and a lot to do and I didn't want to use drugs as I had not used for 18 months. But the Doc refused and said I should try an alternative like yoga, that he wasn't comfortable prescribing me medication. I ended up cutting off all my hair one night and going out and using heroin the very next day and then spent the next 2 years struggling with addiction again."
- "Denied pain relief for back problem at XXXX Hospital. The Doctor had written a prescription but on further reading of my file and seeing I had been on Methadone 3 years previously, she tore the prescription up and told me to "go home and have a panadol".

Why do you think you were discriminated against?



How the discrimination made people feel

When asked 'how the discrimination made people feel?' the majority of respondents (71%) stated it made them 'angry'. 'Stressed', 'depressed', 'sad', and 'isolated' were other emotions felt, at 52%, 55%, 45%, and 46% respectively. Three respondents (3%) reported that discrimination had 'no effect' on them. 'Other' was reported by 31% of people and a wide variety of emotions were commented on, alarmingly feeling "suicidal" was reported by two respondents.

What happened to people as a result of the discrimination experienced

When asked 'what happened as a result of the discrimination?' responses were varied; 49% of respondents stated they were "outed as drug users", and 45% believed they were refused service as a result of perceived discrimination.

Forty six percent (46%) of respondents stated 'other' consequences (as opposed to the answer options given in the survey); these

ranged from 'problems with employment', people choosing to leave their jobs, or experiencing problems at work which consequently made things very difficult for people. Other reasons given were primarily to do with health service provision of some kind; not being able to get certain prescriptions or suitable medication for pain, poor service in hospitals, and violations of confidentiality.

Answer Options	Response Percent	Response Count
Angry	71.4%	75
Stressed	52.4%	55
Depressed	55.2%	58
Sad	44.8%	47
Isolated	45.7%	48
No effect	2.9%	3
Other (please specify)	31.4%	33
<i>answered question</i>		105
<i>skipped question</i>		5

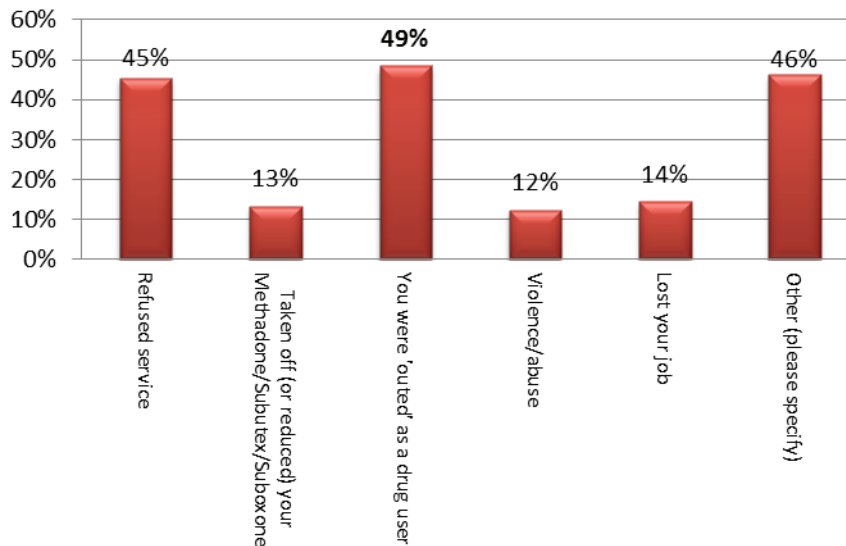
Examples of 'Other' responses for the question: "How did the discrimination make you feel?"

- Disappointed x3
- Ashamed x3
- Frustrated x4
- Suicidal x2
- "Actually resulted in me getting sick"
- "Like a 'nothing'. Disenfranchised"
- "I felt powerless and as though I deserved to be in pain"
- "Worried for my health options"
- "In pain"

I was denied pain relief for a back problem at XXXX Hospital. The Doctor had written a prescription but on further reading of my file and seeing I had been on Methadone 3 years previously, she tore the prescription up and told me to "go home and have a panadol".

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Did anything happen as a result of this discrimination?



Did people make complaints to resolve the discrimination?

When asked 'if people had tried to make complaints to resolve discriminatory acts?' 61% of respondents answered 'no' and 39% 'yes'. Further to replying 'yes'; respondents were asked how satisfied they were with the outcome/s they received; 9% indicated they were 'very satisfied' or 'satisfied', and the majority (91%) remained either 'unsatisfied' or 'very unsatisfied' with outcomes.

Those who responded 'no' (that they had not tried to resolve the complaint or discrimination) were also asked why they choose not to do so. Fifty one percent (51%) of respondents answered that they 'thought it would make things worse for them' if they complained, and 47% 'didn't think anyone would listen'. Twenty seven percent (27%) of respondents stated it was 'too much effort to make a complaint', thirty three percent (33%) either 'didn't know how' or 'didn't know

where' to make a complaint.

Twenty four percent (24%) of respondents specified 'other' reasons for not making complaints. Some examples of these are listed below:

- "Make it worse for the children"
- "I was too unwell and my lifestyle would have been exposed within the smaller community in which I lived at the time"
- "Reinforces stereotypes"
- "Made to feel ashamed and didn't want to 'out' myself"
- "How do you complain when something is illegal"
- "Physical set up of pharmacy pharmacotherapy collection area makes it difficult to implement changes to avoid periods of waiting longer than other "non-collecting" customers. You raise the longer waiting periods

with pharmacist who apologises, but it doesn't change the issue."

- "Every time I complain XXXX threatens me to be locked up. Whenever I start to cry or get upset they say 'Stop that XXXX or do you need to have a little "holiday" I know what they are saying because they've done it before. I keep quiet."
- "If they had the attitude they had, then NO complaint procedure would change the way they feel about me although they had known me my whole life, until I told them I was on a methadone program and getting my life on track, my family doctor said that once a junky always a junky and relapse would certainly happen and that he did not want to see me in his surgery again. And that was seeing him since a baby, my whole family seeing him, and prior to this event me having a great relationship with him; it cut me to the core."

Had the discrimination happened before?

When asked 'how often the discrimination had happened to them?' 61% of respondents answered that they had been discriminated against on more than one occasion, 29% said that the discrimination had happened before but at another service (or for a different reason). Nine percent (9%) stated that it had happened only on the one occasion.



Other comments section

Following is a small sample of comments (we received a total of 51 entries) that respondents added in the final part of the survey in response to: 'Do you have any other comments or anything else you like to add?'

- "I have been discriminated against multiple times by multiple different people in multiple different situations. Pharmacy staff treating me like (expletive), making me wait more than half an hour - then told to come back in an hour for my dose - when I was obviously in the agony of withdrawal as I had just begun the program. They asked me to come after 9, so I waited until 5 past 9 before I drove to town, got there at 9:15am and then this happened on my first day of the program."
- "Getting a blood test the nurse treated me with contempt after she saw needle marks."
- "I've lost friends because they don't understand drug use, nor want to. They only know what lies and propaganda the media/government have told them and lump me with the stereotypical "junky" even though I am so far away from that stereotype it's not funny."
- "Providers of AOD services need to be trained better and this training to include attitudes and discrimination. Lots of times when I have experienced discrimination I pretty sure the people didn't even know they were doing it or didn't think it was important. Better promotion of drug users i.e. normal people that don't all fit the stereotype of being bad people who rob and steal etc. Slowly changing attitudes through media and staff training and promotion of the positives contributions drug user make."
- "General practices are difficult to complain to, or about due to their threat and ability to refuse to service you and their knowledge of the difficulty in finding another practice willing to take methadone patients. This means that I feel I can't complain about clinical issues or even disputes about fees, etc."
- "I will never divulge my status again, in detriment to my health, in fact I rarely ever go to a doctor unless in critical circumstances."
- "I was spotted going into methadone clinic and i was outed at work - asked the service if there was any recourse. The answer I got was some mistakes you pay for over a lifetime."
- "For almost 20 years I have struggled to exercise my right to access health services at the same level, and quality as the general population. I am fortunate to be literate, somewhat articulate and I have always ensured that I am as well informed as possible about any issues, information and new policies/legislation etc. that relate to my wellbeing and health (physical, emotional and mental) as a drug user, sex worker, human being and

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a mother. I have always been as assertive and pro-active as possible about accessing relevant services and have found, on many, many occasions that I have to all but demand to be treated with dignity, equality and sometimes any treatment at all. I recently was diagnosed with breast cancer and subsequently underwent a mastectomy, oophorectomy (removal of the ovaries) and an intensive series of chemotherapy treatments. Perversely, as a cancer patient, I was granted treatment at a level and quality which had heretofore eluded me when I was just a second class cancer free, mentally ill addict. As a patient of Dr XXXX, I was absolutely astounded by the quality of the plethora of services which 'miraculously' became available to the newly cancerous me. Suddenly, I had access to an army of health professionals encompassing a vast range of disciplines and specialties; e.g. dental, psychiatric, physiotherapy, social workers, oncologists, acupuncture, infectious disease specialists, pharmacists, to name but a few. I was also offered a gamut of completely cost free logistical support- including transport (to and from home, hospital and other clinics), financial assistance, access to a number of support networks, home help with cleaning etc, exercise programmes, workshops aimed at improving self-esteem through 'improving' ones appearance by learning how to wear make-up and wigs including free cosmetic gift packages, free wigs etc. I was offered massage therapy, manicures, pedicures etc. all of this because I was now a member of the Cancer club. What I found most amazing was not so much the cancer specific treatments which I was now entitled to, but the access to top quality

treatment for my pre-existing conditions, namely opiate dependency, Hepatitis C and bipolar disorder. Why did cancer turn me into someone that mattered? A previously second class someone who had been screaming for decades for her right to be heard, treated with dignity and receive health care of the quality I always knew existed, but was precluded from due to the unsavoury, and decidedly 'un-sexy' nature of my pre-existing illness/es. Ironically, the cancer caused me very little discomfort in comparison with the years of agony, despair, self-loathing and pain I had suffered as a result of my addiction and bipolar condition. Once I was diagnosed with cancer, everyone treated me differently. My G.P, Pharmacist, Psychologist and Psychiatrist afforded me instant credibility and displayed compassion which I had actually needed for years yet despaired of ever receiving. I could go on and on, but I'm sure you get the picture. This is some seriously fucked up shit! I'm still the same person I ever was but now I don't have to wait in the back of the chemist for my dose, I actually get to see my doctors within the actual hour of my appointment. Suddenly I have credibility because some doctor decided I had cancer and chose to cut some bits from me. I never noticed being unwell from this so called cancer(until they chopped me up and pumped me full of toxic chemicals) but I sure as hell suffered for years in the dark, waiting to be 'thrown a bone' or be granted some relief from the omnipotent Doctors in their unreachable ivory towers. They who saw me as an undeserving burden on the system, unworthy of care and/or compassion due to my diagnosis as a head fucked

junkie. Yet now, apparently I have become worthy; I receive respect, compassion, understanding and care from those same health professionals, and many others, the only difference is now I have had cancer. If I had to choose between cancer and addiction/mental illness, I'd choose cancer in a heartbeat."

- "I told a staff member I had HIV/HEP C and it was confidential. She told the boss without my ok. (I worked in child care) and was thinking of going on treatment for HEP so needed support. I got called into the office & although they knew legally couldn't sack me I knew it would not be comfortable. I decided to leave rather than be stressed at work..."
- "This is routine in almost every hospital I have visited through-out Australia. Once you say you are prescribed methadone, everything changes. You are faced with the choice of disclosing that you are on methadone and facing discrimination and poor service/inadequate access to pain killers etc. or not disclosing and....getting inadequate help with your pain because of your tolerance..."
- "...Over the 10 years I have been on OST- I have given my chemist over \$10,000! How can that be justified?"