



Stigma among people living with hepatitis C and people who inject drugs in Australia

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Never Stand Still

Arts & Social Sciences

Centre for Social Research in Health

Acknowledgements

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Background

- Stigma originally conceptualised as “*an attribute that is deeply discrediting*” (Goffman, 1963).
- Moving towards an understanding of stigma as a social process of exclusion of an individual, who may possess an attribute devalued by the broader social group.
- Stigma is associated with social isolation, psychological distress, poor quality of life and poor physical outcomes.
- Communicable diseases (e.g. HIV, hepatitis C) have been a particular target of stigma due to possibility of transmission to others and negative attitudes towards transmission pathways (e.g. unsafe sex, injecting practices).
- People may experience double stigma or layered stigma if they possess multiple, co-occurring stigmatised attributes e.g. stigma related to infectiousness of hepatitis C, plus the perceived mode of transmission.

“stigma remains the single most important barrier to public action”

United Nations General Secretary

17th International AIDS Conference in Mexico City in August 2008

- There are five national strategies that address HIV, viral hepatitis and sexually transmissible infections.
- The strategies represent a coordinated national response to reduce the transmission, morbidity and mortality associated with these infections.
- Each contain a set of objectives and targets, with progress measured using a set of indicators via which progress is monitored.

Example:

Objective	Indicator
Reduce the incidence of hepatitis C	Annual incidence of hepatitis C in people who inject drugs

- Each strategy contains a clear objective to “eliminate the negative impact of stigma, discrimination, and legal and human rights issues on people’s health”.

<p>FOURTH</p> <p>National Hepatitis C Strategy</p>	Objective		Indicator	
	Eliminate the negative impact of stigma, discrimination, and legal and human rights issues on people's health			
<p>SECOND</p> <p>National Hepatitis B Strategy</p>	Objective		Indicator	
	Eliminate the negative impact of stigma, discrimination, and legal and human rights issues on people's health			
<p>SEVENTH</p> <p>National HIV Strategy</p>	Objective		Indicator	
	Eliminate the negative impact of stigma, discrimination, and legal and human rights issues on people's health			
<p>THIRD</p> <p>National Sexually Transmissible Infections Strategy</p>	Objective		Indicator	
	Eliminate the negative impact of stigma, discrimination, and legal and human rights issues on people's health			
<p>FOURTH</p> <p>National Aboriginal and Torres Strait Islander Blood-borne Viruses and Sexually Transmissible Infections Strategy</p>	Objective	Sub-objective	Indicator	
	Eliminate the negative impact of stigma, discrimination and human rights issues on Aboriginal and Torres Strait Islander health	Actively engage with the Aboriginal and Torres Strait Islander community		

The Stigma Indicators Project

In 2015 the Australian Government Department of Health provided funding to the Centre for Social Research in Health at the University of New South Wales to develop an indicator of stigma among the priority groups identified by the national strategies.

The primary aim of this project is to develop a brief indicator of stigma to be used across the following priority groups:

- Gay and other men who have sex with men;
- People who inject drugs;
- People living with HIV;
- People living with viral hepatitis (B and C); and
- People who engage in sex work;

This project also aims to develop a related indicator that can be used among health care professionals and the general population. This indicator would be used to measure the expression of stigma, such as discriminatory or negative treatment of patients or clients by health care professionals.

Considerations

- Stigma is a complex construct, which can include anticipation, perception and actual experience of being treated differently to others.
- It occurs in a range of relationships and settings: interpersonal (family, friends, sexual partners), health care (e.g. GP, dentist), criminal justice, housing, etc.
- Social and political institutions can serve to legitimise exclusion e.g. negative portrayal by the media.
- Enacted stigma (i.e. discrimination) includes a variety of behaviours from avoidance, excessive pity, blame, shame, verbal abuse, physical abuse, social exclusion, sexual exclusion, among others.
- For people living with blood borne viruses and sexually transmitted infections, there are multiple layers of stigma.

The indicator

In the last 12 months, to what extent have you experienced stigma or discrimination (e.g. avoidance, pity, blame, shame, rejection, verbal abuse or 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"/>

Additional items

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 differently 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"/>

Mirrored 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 ever 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"/>

In the last 12 months, have you felt stigmatised because of the area you work in?

Never	Rarely	Sometimes	Often	Always
1 <input type="checkbox"/>	2 <input type="checkbox"/>	3 <input type="checkbox"/>	4 <input type="checkbox"/>	5 <input type="checkbox"/>

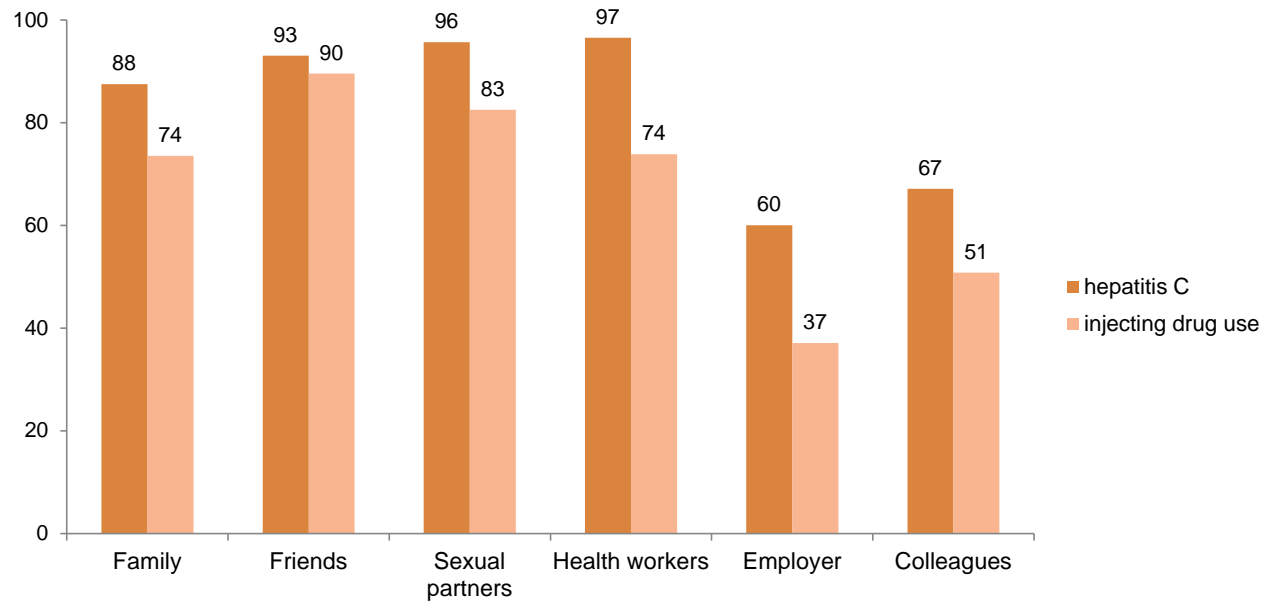
Methods

- Stigma indicator to be included in existing, routine surveys of people who inject drugs and gay and other man who have sex with men (October – December 2016).
- CSRH initiated three new surveys in June 2016:
 - People living with HIV;
 - People living with hepatitis C and people who inject drugs;
 - Health workers.
- New surveys to examine covariates, including disclosure, treatment, substance use, social support and mental health (psychological distress).
- New surveys include additional stigma measures, such as internalised and vicarious stigma.

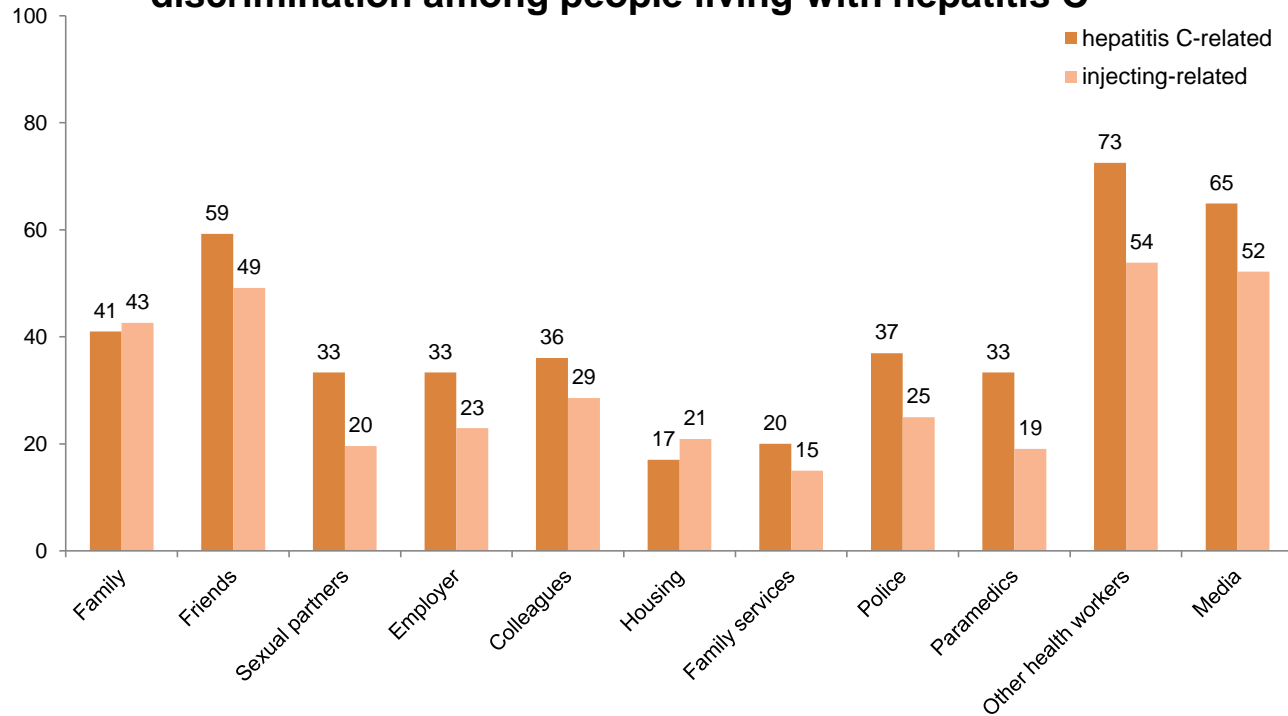
Preliminary results

N=89	N (%)
Age Mean (SD)	51.42 (8.64)
Female gender	61 (69)
Heterosexual sexual orientation	71 (80)
ATSI	3 (3)
Diagnosed mental illness	57 (64)
HCV status	
Has hepatitis C	20 (23)
Currently on treatment, unaware of outcome	44 (49)
Cleared spontaneously/through treatment	25 (28)
HCV route	
Using non-sterile equipment to inject drugs	66 (74)
Blood transfusion blood products	5 (6)
Vaccination or other health/dental procedure overseas	3 (3)
Other / Don't know	15 (17)
Waiting list for new HCV treatments	13 (15)
HCV treatment	
Never received	20 (23)
Previously received	41 (46)
Currently receiving	28 (32)
Ever injected drugs	75 (84)
Past month injecting drug use	23 (31)

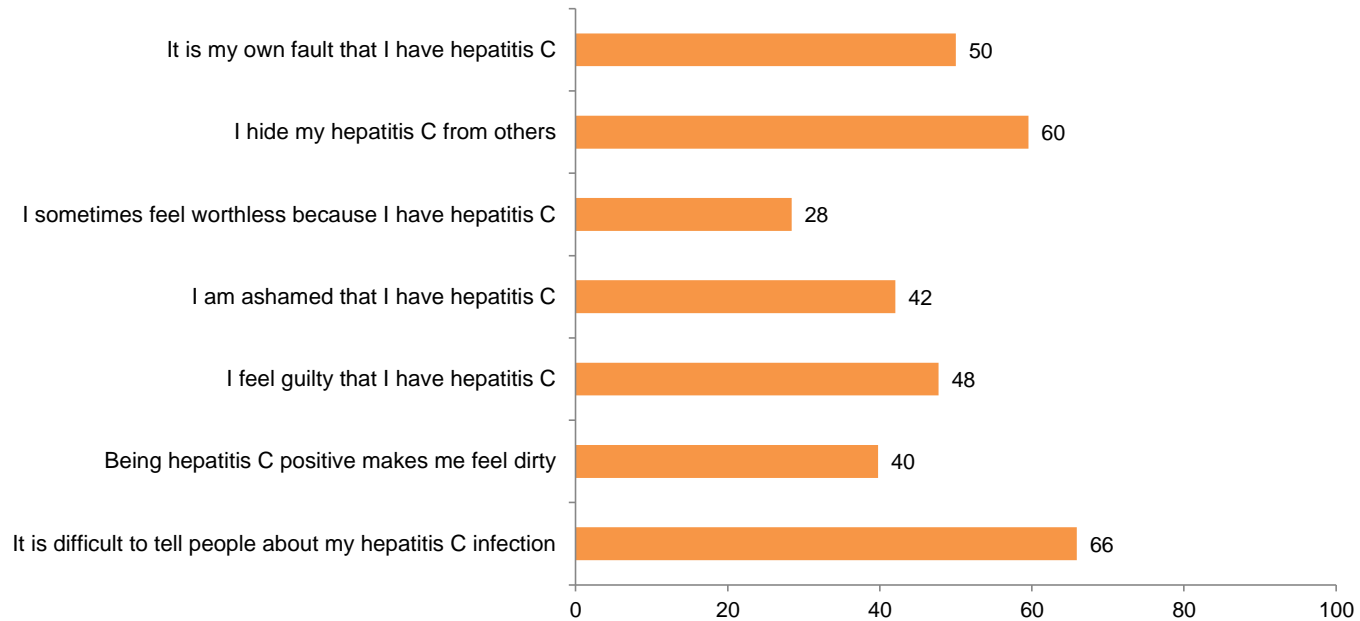
% Lifetime disclosure among people living with hepatitis C



% Past 12 month experiences of stigma and discrimination among people living with hepatitis C

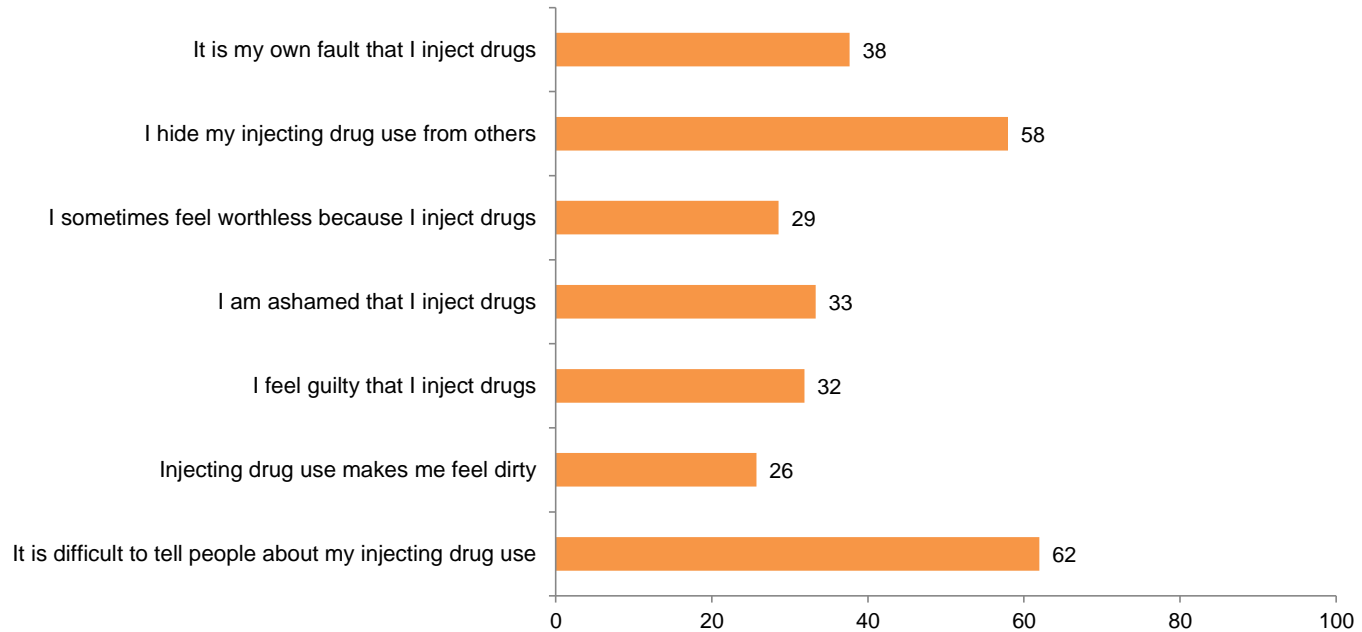


% Hepatitis C-related internalised stigma



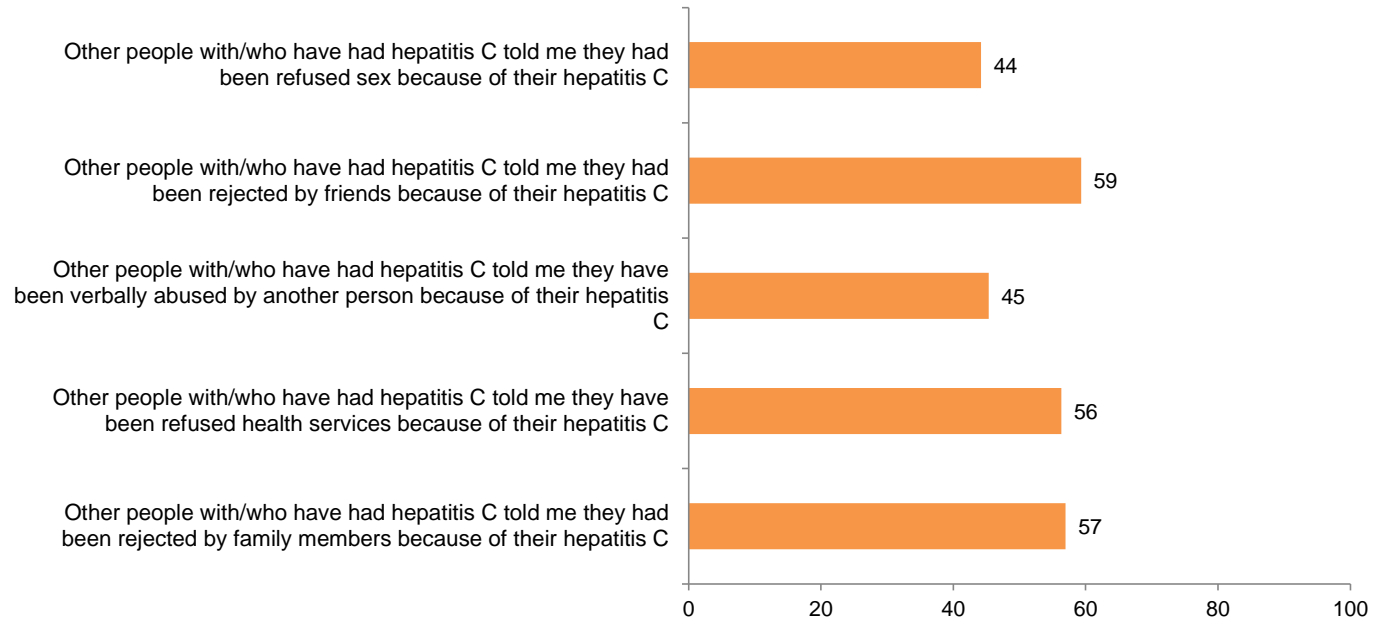
Mean 22, SD 8, Range 1-35

% Injecting-related internalised stigma



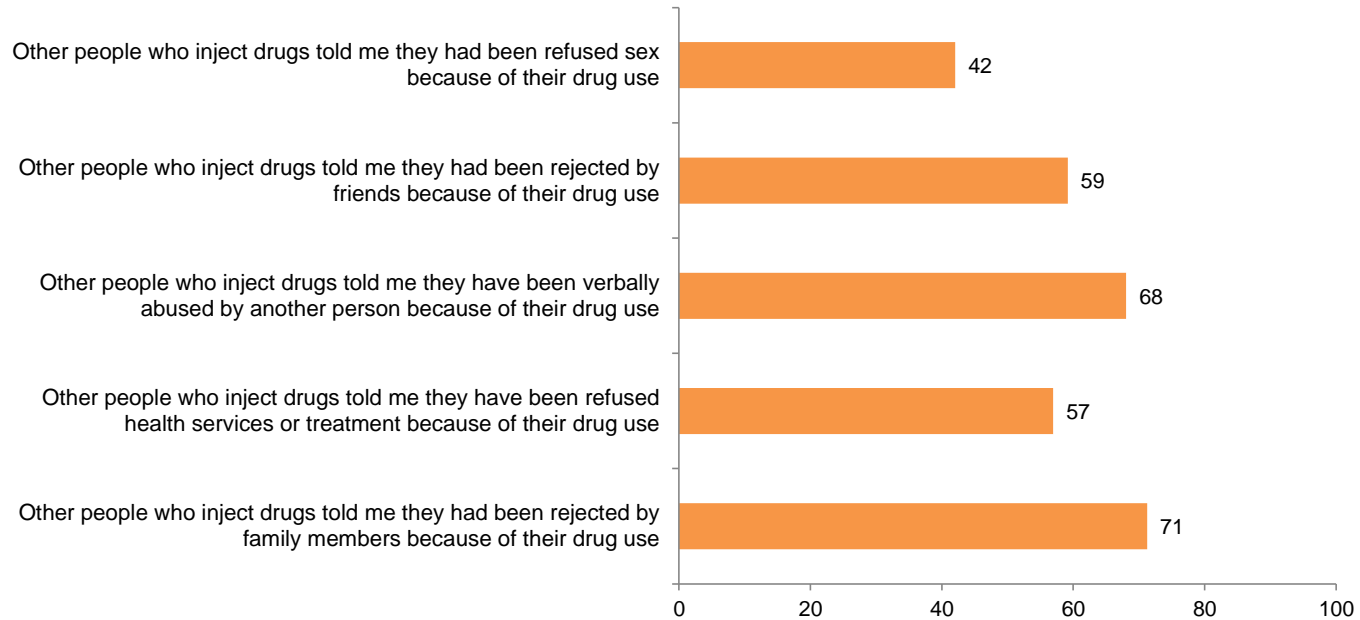
Mean 21, SD 7, Range 4-35

% Past 12 month hepatitis-related vicarious stigma



Mean 8, SD 3, Range 2-20

% Past 12 month injecting-related vicarious stigma



Mean 9, SD 4, Range 3-20

Conclusion

- Our preliminary findings show that experiences of stigma and discrimination are common, particularly in health care settings and by the media.
- We will be able to assess and monitor changes in stigma among people living with blood borne viruses and sexually transmitted infections over time.
- Once data collection is completed, we will be able to look at the relationship between stigma and covariates of interest e.g. mental health.
- We are developing qualitative work among sex workers in partnership with the Scarlet Alliance.
- We aim for future work to include a survey of people living with hepatitis B.
- This is an exciting project and the findings will feed back into the national strategies on HIV, viral hepatitis and sexually transmissible infections.
- Keeping in mind that the national strategies aim to eliminate stigma – being able to objectively measure and monitor experiences of stigma at the national level is the first step towards introducing strategies to reduce it.

The Centre for Social Research in Health at UNSW Australia is seeking people who have had or are currently living with hepatitis C AND/OR people who have ever injected drugs to take part in a 15 minute online survey about experiences of hepatitis C and/or injecting drug use, including treatment, sources of social support, your use of substances like alcohol, mental health and wellbeing and your experiences of stigma and discrimination.

This study is part of a broader project funded by the Australian Government Department of Health to examine stigma and discrimination among people living with blood borne viruses and sexually transmitted infections.



Have your say on stigma and discrimination

To complete the survey
or find out more, visit:
bit.ly/hepcstigmasurey
or contact Elena at
e.cama@unsw.edu.au

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