



Hepatitis C: (1) stigma indicators (2) patient reported outcome measures for DAA treatment

Never Stand Still

Arts & Social Sciences

Centre for Social Research in Health



Stigma indicators: Acknowledgements

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

Brief indicator of experienced stigma in 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;

Mirrored indicator for health care professionals and the general population – expressed stigma

Stigma is a complex construct – anticipation, perception, experience, internalised, vicarious, range of settings and relationships, institutional, power relations, multiple/layered





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 - HCW

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

- New and existing surveys:
 - People living with HIV – new, online survey
 - Men who have sex with men (Telling) – online survey via Kirby Institute
 - People living with hepatitis C and people who inject drugs – new, online survey
 - People who inject drugs – via ANSPS, Kirby Institute
 - Health workers – new, ASHM contact list
- New surveys:
 - examine covariates, including disclosure, treatment, substance use, social support and mental health (psychological distress).
 - additional stigma measures, such as internalised and vicarious stigma.





(New) – ppl living with hep C, ppl who inject

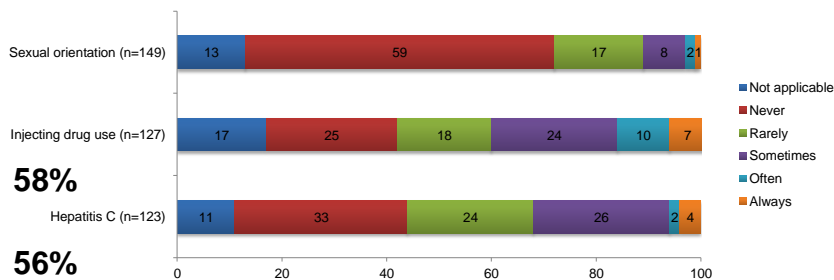
Online survey

- 165 people
- Mean age = 50 years
- All states and territories: NSW 26%, Vic 27%, Qld 16%
- Male = 35%
- Born in Aus = 84%
- Education > high school = 73%
- Govt benefits, unemployed = 24%
- Lifetime mental health = 63%
- Lifetime injecting drug use = 83%; Past month = 35%
- Aware of DAA treatments = 100%
- No current/previous hep C treatment = 27%
- Among not treated, no plans to do treatment = 36%, undecided = 15%



Indicator – ppl living with hep C, ppl who inject

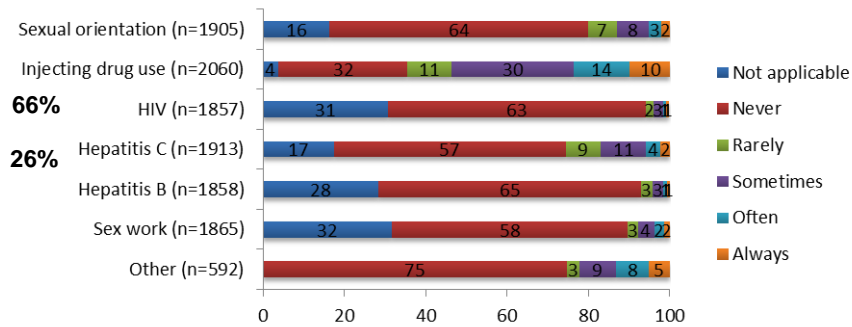
In the last 12 months, have you experienced any stigma or discrimination (e.g. avoidance, pity, blame, shame, rejection, verbal abuse, bullying) in relation to your... (%)





Indicator – ANSPS sample

In the last 12 months, have you experienced any stigma or discrimination (e.g. avoidance, pity, blame, shame, rejection, verbal abuse, bullying) in relation to your... (%)



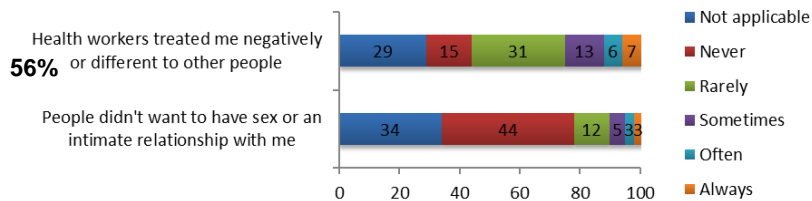
66%

26%



Additional Indicator – ppl living with hep C

In the last 12 months, to what extent to you agree that the following occurred? (%)

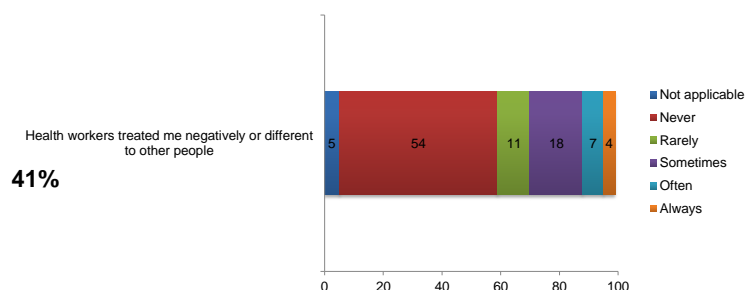


56%





Additional indicator - ANSPS sample



(new sample) Indicator and other measures

- Indicator re hep C status – significantly correlated with:
 - HCV-related discrimination
 - HCV-related vicarious stigma
 - Injecting-related vicarious stigma
 - Indicator – injecting drug use

- Indicator re injecting drug use – significantly correlated with:
 - Injecting-related discrimination
 - Injecting-related vicarious stigma
 - Psychological distress
 - Personal wellbeing





Conclusion

- Complexities of sample and measures
 - Develop data management pathways, reduce data “messiness”
 - Ask if person lives with each attribute, then ask indicator (remove N/A)
- Stigma 2:
 - People living with hepatitis B – qualitative work
 - General public – representative sample
 - Extend sex worker research, following qual research via Scarlet Alliance
 - ? STIs – expressed stigma in general population
 - Work to extend hep C, injecting drug use samples
- Ntl strategies aim to eliminate stigma
 - measure and monitor experiences of stigma is required



PROMS: Acknowledgements

Team:

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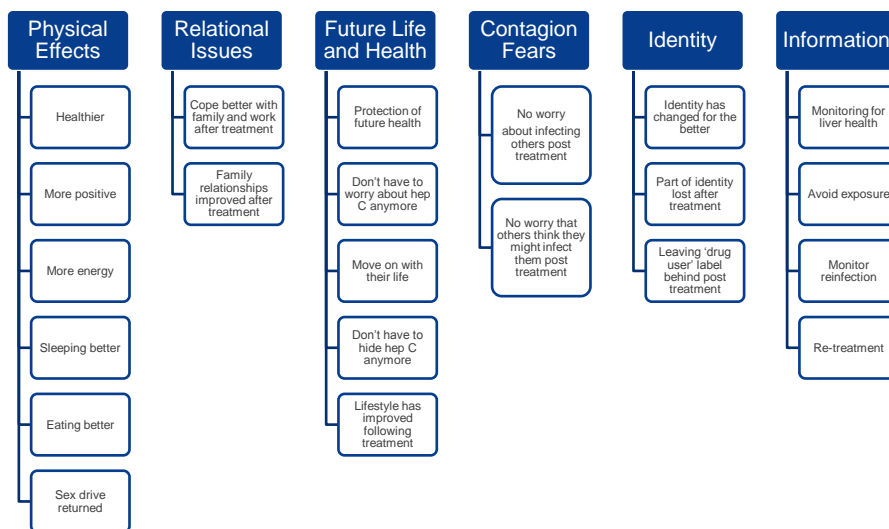


What is beyond the cure?

- Current study – groups of people who inject:
 - No engagement with treatment
 - Some engagement
 - Currently on treatment
 - Completed treatment
- New measures – Patient Reported Outcome Measures (PROMs)
- Needs beyond the clinical/public health goals in a high “promise” environment



What is beyond the cure?





Patient Reported Experience Measure (PREM)

Please think about your last hep C treatment episode and then tick 'agree' or 'disagree' with the following statements...

Access/Models of Care		Agree	Disagree
<i>"Based on my last hep C treatment experience I now feel that..."</i>			
1.	I could access treatment when I wanted it	<input type="checkbox"/>	<input type="checkbox"/>
2.	The clinic was easy for me to get to	<input type="checkbox"/>	<input type="checkbox"/>
3.	I liked the way that treatment was provided	<input type="checkbox"/>	<input type="checkbox"/>
Treatment Preparation		Agree	Disagree
<i>"Based on my last hep C treatment experience I now feel that..."</i>			
4.	I was well prepared to start treatment	<input type="checkbox"/>	<input type="checkbox"/>
5.	I had enough information prior to treatment	<input type="checkbox"/>	<input type="checkbox"/>
6.	There were no delays in starting treatment	<input type="checkbox"/>	<input type="checkbox"/>
7.	I had enough support with ordering medications through the pharmacy	<input type="checkbox"/>	<input type="checkbox"/>
8.	I was encouraged by my doctor/GP to do treatment	<input type="checkbox"/>	<input type="checkbox"/>
9.	I was asked if I had hep B before starting treatment	<input type="checkbox"/>	<input type="checkbox"/>



Patient Reported Outcome Measure (PROM)

Please think about your last hep C treatment episode and then tick 'agree' or 'disagree' with the following statements...

Cure/Clearance/Sustained Virological Response (SVR):		Agree	Disagree
<i>"As a result of my last hep C treatment episode I..."</i>			
1.	Have cleared hep C	<input type="checkbox"/>	<input type="checkbox"/>
2.	Have been given good information about clearing the virus	<input type="checkbox"/>	<input type="checkbox"/>
3.	Feel my treatment has been a success	<input type="checkbox"/>	<input type="checkbox"/>
4.	Feel confident I will remain hep C free	<input type="checkbox"/>	<input type="checkbox"/>
5.	Feel like I will have a longer life because of clearing the virus	<input type="checkbox"/>	<input type="checkbox"/>
Being Healthier (Physical & Mental)		Agree	Disagree
<i>"As a result of my last hep C treatment episode I..."</i>			
6.	Have more energy	<input type="checkbox"/>	<input type="checkbox"/>
7.	Feel physically different	<input type="checkbox"/>	<input type="checkbox"/>
8.	Feel healthier	<input type="checkbox"/>	<input type="checkbox"/>
9.	Am more active	<input type="checkbox"/>	<input type="checkbox"/>
10.	Am sleeping better	<input type="checkbox"/>	<input type="checkbox"/>



Preliminary feedback – focus groups

- Participants really engaged with the draft measures
- Overwhelming feedback – questions ‘really resonated’ and focused on issues ‘no-one else had asked them’.
- Participants thought measures useful as a ‘conversation starter’ with SPs for complex/difficult issues partic with marginalised & stigmatised communities.
- Help SPs to better understand the patient perspective and what matters most to patients – what *they* are seeking from HCV treatment – beyond SVR/clinical expectations.



Preliminary feedback – focus groups

- Not feeling validated/believed:
 - Experience of treatment side-effects were dismissed or not taken seriously
 - Clinical trials – ‘there are no side-effects – you can’t have them!’
 - ‘Not as bad as the previous treatments’
 - Lack of information/understanding on basic consumer health issues – medications, how to prepare, existing liver disease, potential for liver repair & ongoing infectiousness, etc.
- This could impact on HCV treatment uptake due to negative experiences and outcomes being communicated to others – 1 bad story travels a long way
- HCV PREM & PROM focus on ‘quality of care’ vs ‘continuity of care’ (treatment cascade)



Thank You



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