Stigma indicators: Acknowledgements

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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:

<table>
<thead>
<tr>
<th></th>
<th>Never</th>
<th>Rarely</th>
<th>Sometimes</th>
<th>Often</th>
<th>Always</th>
<th>Not applicable</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sexual orientation</td>
<td>☐</td>
<td>☐</td>
<td>☐</td>
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<td>Use of drugs for injecting</td>
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<td>HIV status</td>
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<td>Hepatitis B status</td>
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<td>Sex work</td>
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<td>Other (please specify):</td>
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</tbody>
</table>

Additional items

In the last 12 months, to what extent do you agree that the following occurred?

<table>
<thead>
<tr>
<th></th>
<th>Never</th>
<th>Rarely</th>
<th>Sometimes</th>
<th>Often</th>
<th>Always</th>
<th>Not applicable</th>
</tr>
</thead>
<tbody>
<tr>
<td>Health workers treated me negatively or differently to other people</td>
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<tr>
<td>People didn’t want to have sex or an intimate relationship with me</td>
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</table>
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:

- Sexual orientation
- Use of drugs for injecting
- HIV status
- Hepatitis B status
- Hepatitis C status
- Sex work
- Other (please specify):

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<tr>
<th></th>
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<th>Often</th>
<th>Always</th>
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<td>Sex work</td>
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<tr>
<td>Other (please specify)</td>
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</table>

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

<table>
<thead>
<tr>
<th>Never</th>
<th>Rarely</th>
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<th>Always</th>
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</table>

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... (%)

- Sexual orientation (n=1905)
  - 16: Not applicable
  - 64: Never
  - 7: Rarely
  - 8: Sometimes
  - 32: Often
  - 8: Always

- Injecting drug use (n=2060)
  - 10: Not applicable
  - 32: Never
  - 11: Rarely
  - 30: Sometimes
  - 14: Often
  - 10: Always

- HIV (n=1857)
  - 31: Not applicable
  - 31: Never
  - 53: Rarely
  - 2: Sometimes
  - 14: Often
  - 10: Always

- Hepatitis C (n=1913)
  - 17: Not applicable
  - 27: Never
  - 57: Rarely
  - 9: Sometimes
  - 11: Often
  - 4: Always

- Hepatitis B (n=1858)
  - 25: Not applicable
  - 28: Never
  - 65: Rarely
  - 3: Sometimes
  - 11: Often
  - 4: Always

- Sex work (n=1865)
  - 32: Not applicable
  - 75: Never
  - 7: Rarely
  - 8: Sometimes
  - 9: Often
  - 5: Always

- Other (n=592)
  - 16: Not applicable
  - 64: Never
  - 7: Rarely
  - 8: Sometimes
  - 32: Often
  - 8: Always

Additional Indicator – ppl living with hep C

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

- Health workers treated me negatively or different to other people
  - 29: Not applicable
  - 15: Never
  - 31: Rarely
  - 13: Sometimes
  - 6: Often
  - 7: Always

- People didn't want to have sex or an intimate relationship with me
  - 34: Not applicable
  - 34: Never
  - 44: Rarely
  - 12: Sometimes
  - 5: Often
  - 3: Always
Additional indicator - ANSPS sample

Health workers treated me negatively or different to other people

41%

(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:

Carla Treloar, Annie Madden, Max Hopwood, CSRH
Professor Jo Neale; Service Users Research Group, National Addiction Centre, Kings College London

Funding:

PLuS Alliance Seed Grant; Australian Government Dept of Health
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?

**Physical Effects**
- Healthier
- More positive
- More energy
- Sleeping better
- Easing better
- Sex drive returned

**Relational Issues**
- Coping better with family and work after treatment
- Family relationships improved after treatment

**Future Life and Health**
- Protection of future health
- Don’t have to worry about having hep C anymore
- Move on with their life
- Don’t have to hide hep C anymore
- Lifestyle has improved following treatment

**Contagion Fears**
- No worry about infecting others post treatment
- No worry that others think they might infect them post treatment

**Identity**
- Identity has changed for the better
- Part of identity lost after treatment
- Leaving ‘drug user’ label behind post treatment

**Information**
- Monitoring for liver health
- Avoid exposure
- Avoid re-treatment
- Re-treatment
## Patient Reported Experience Measure (PREM)

Please think about your last Hep C treatment episode and then tick ‘agree’ or ‘disagree’ with the following statements:

<table>
<thead>
<tr>
<th>Access/Models of Care</th>
<th>Agree</th>
<th>Disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. I could access treatment when I wanted it</td>
<td>☐</td>
<td>☑</td>
</tr>
<tr>
<td>2. The clinic was easy for me to get to</td>
<td>☐</td>
<td>☑</td>
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<tr>
<td>3. I liked the way that treatment was provided</td>
<td>☐</td>
<td>☑</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Treatment Preparation</th>
<th>Agree</th>
<th>Disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>4. I was well prepared to start treatment</td>
<td>☐</td>
<td>☑</td>
</tr>
<tr>
<td>5. I had enough information prior to treatment</td>
<td>☐</td>
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<tr>
<td>6. There were no delays in starting treatment</td>
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<tr>
<td>7. I had enough support with ordering medications through the pharmacy</td>
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<td>☑</td>
</tr>
<tr>
<td>8. I was encouraged by my doctor/GP to start treatment</td>
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<tr>
<td>9. I was asked if I had Hep B before starting treatment</td>
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</tbody>
</table>

## Patient Reported Outcome Measure (PROM)

Please think about your last Hep C treatment episode and then tick ‘agree’ or ‘disagree’ with the following statements:

<table>
<thead>
<tr>
<th>Cure/Clearance/Sustained Virological Response (SVR): “As a result of my last Hep C treatment episode I…”</th>
<th>Agree</th>
<th>Disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Have cleared Hep C</td>
<td>☐</td>
<td>☑</td>
</tr>
<tr>
<td>2. Have been given good information about clearing the virus</td>
<td>☐</td>
<td>☑</td>
</tr>
<tr>
<td>3. Feel my treatment has been a success</td>
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</tr>
<tr>
<td>4. Feel confident I will remain Hep C free</td>
<td>☐</td>
<td>☑</td>
</tr>
<tr>
<td>5. Feel like I will have a longer life because of clearing the virus</td>
<td>☐</td>
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</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Being Healthier (Physical &amp; Mental): “As a result of my last Hep C treatment episode I…”</th>
<th>Agree</th>
<th>Disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>6. Have more energy</td>
<td>☐</td>
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<tr>
<td>7. Feel physically different</td>
<td>☐</td>
<td>☑</td>
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<tr>
<td>8. Feel healthier</td>
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<td>☑</td>
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<tr>
<td>9. Am more active</td>
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<td>☑</td>
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<tr>
<td>10. Am sleeping better</td>
<td>☐</td>
<td>☑</td>
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</tbody>
</table>
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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