

UNSW
SYDNEY

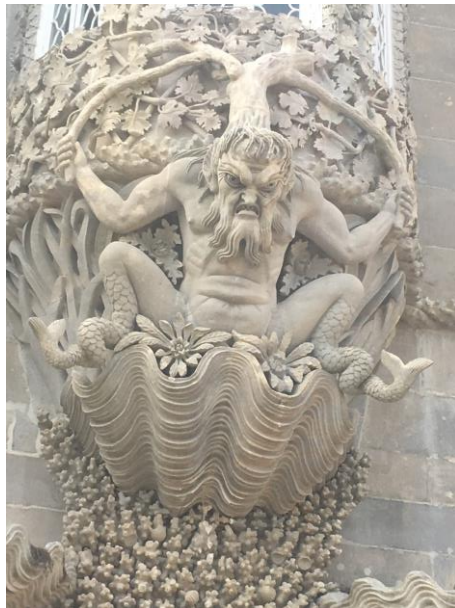
Australia's
Global
University

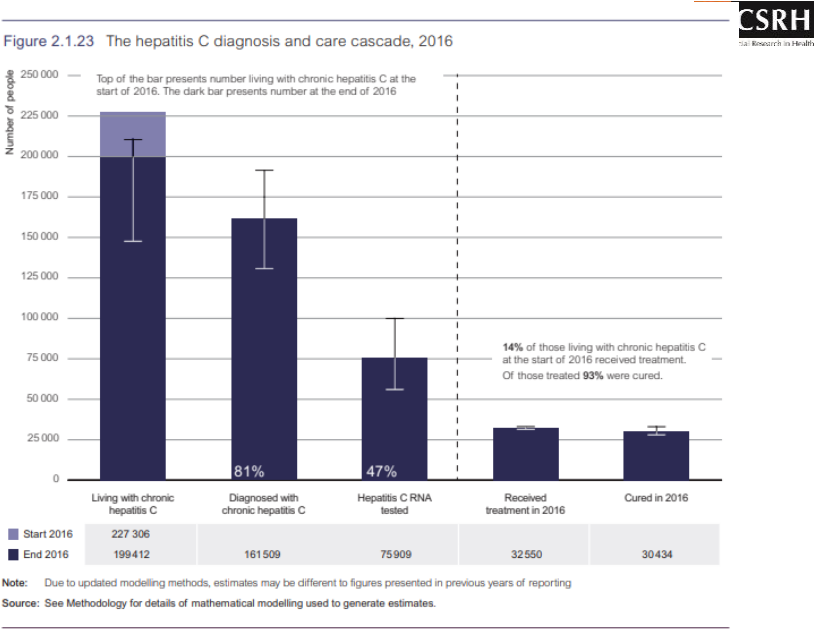
Arts & Social Sciences
Centre for Social Research in Health

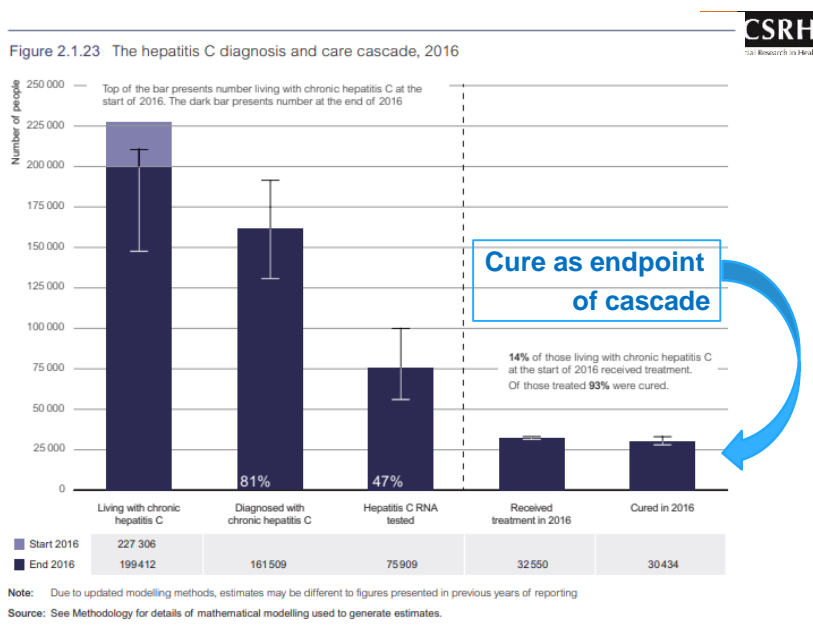
Life Beyond SVR

It is Not Just About SVR: The Social Benefits of Successful DAA Therapy Beyond Cure

Carla Treloar







Kirby Institute 2017



What do we know about life after SVR?



- SVR has implications beyond those of clearing viral infection
 - improved long-term clinical outcomes
 - economic benefits
 - improved health-related quality of life. ¹
- Ppl on OST report increased QoL during and after DAA treatment ²

¹ Smith-Palmer et al, BMC Infectious Diseases, 2015; ² Stepanova et al., J Infect Dis 2018



What do we know about life after SVR?



- SVR has implications beyond those of clearing viral infection
 - improved long-term clinical outcomes
 - economic benefits
 - improved health-related quality of life. ¹
- Ppl on OST report increased QoL during and after DAA treatment ²
- What does QoL look like for ppl who inject drugs?

1 Smith-Palmer et al, BMC Infectious Diseases, 2015; 2 Stepanova et al., J Infect Dis 2018



What is QoL for ppl who inject drugs?



- Widely documented - differences between patient and provider views of treatment outcomes
- QoL measure typically designed by clinicians/researchers with little exploration/inclusion of other perspectives
- Patient reported measures (PRM)^{1,2,3}
 - mechanism for patients to provide feedback about the issues that matter to them as patients
 - Understand how patients experience health services with an aim of informing improvements to the way services are provided

1 Basch Ann Rev Med 2014; 2 Boyce BMJ Quality and Safety 2014 3 Black BMJ 2013





Why a PRM for DAA for ppl who inject?

- Why important to develop a PRM for people who inject drugs undertaking DAAs?
 - PRM might be even more important for patient groups that typically experience marginalisation and lesser standing in society
 - when agenda is dominated by a race to elimination
 - tensions between the goals of the individual and outcomes at a population level
- previous literature - people who inject drugs
 - resigned to being silent and passive recipients of care for fear of jeopardising access
 - without voice
 - low expectations of quality care¹

¹ Madden et al., Drug Alc Review 2008



PROM – Domains¹

• F	Patient reported outcome measure
	1 <u>Cure</u> e.g. perceptions of treatment success
	2 <u>Health effects</u> e.g. physical and mental health
	3 <u>Liver health</u> e.g. treatment provider has provided a plan for ongoing care
	4 <u>Understanding results</u> e.g. confidence in understanding test results
	5 <u>New infections</u> e.g. discussed issue of new infections with treatment provider
	6 <u>Outlook on life</u> e.g. more positive about life
	7 <u>Daily life</u> e.g. cope better with responsibilities
	8 <u>Identity</u> e.g. changes in the way I think about myself

¹ Madden et al Harm Reduct Journal 2018





Health and psychological effects

- It's not so much about becoming healthier, it's about trying to prevent... it's more of a preventative measure for me than becoming healthier. I'm hoping that by doing treatment and taking the sort of tax off my liver, that will enhance my health in the future, as opposed to making me healthier now. (female, group 3, 58 years). ¹
- It hasn't changed my life that much because I never really had any symptoms... The biggest change is just...emotionally...you go from being someone with a chronic disease that has the potential to cut your life short to being free (Participant 18, female). ²

¹ Madden et al Harm Reduct Journal 2018; ² Richmond et al., Hepatology, Medicine and Policy, 2018



Understanding results, liver health plan

- I reckon I need to clarify that because, I think you still have got a low level, haven't you, of something in your system? (female, group 4, 63 years; participant emphasis added)
- No, they haven't asked. Nobody's really... yeah I don't think at the time there's any call for monitoring beyond SVR12. (male, group 4, 56 years) ¹

¹ Madden et al Harm Reduct Journal 2018





New identity

- I won't feel like I'm diseased. Like I'm carrying around something that is dirty to the world... I won't be scared about meeting people anymore and talking to them because I have nothing to hide. At the moment I am hiding two things and living a lie and I don't want to do that anymore. Once I'm hep C free I can move on. (female, group 2, 41 years) ¹

¹ Madden et al Harm Reduct Journal 2018



Acceptability of PROM

- *What do people who inject drugs think of this new approach to measuring DAA treatment outcomes?*

¹ Madden et al in press





Acceptability of PROM

- ...nobody else has asked these questions. The doctor hasn't asked it. The pharmacist hasn't asked it. The specialist at the hospital didn't ask it. And I was quite surprised with the hospital because I thought, with them being a hospital they may have done some sort of research afterwards... I wasn't asked anything really... (female, group 1, 55 years)¹
- The things that are important to us as patients aren't necessarily what's important to the system. More often than not you just feel like you're a stat in the health system. Doing this [completing the draft measures] made me think about a whole lot of things that I hadn't even thought about before. It's good... (male, group 1, 41 years)¹

¹ Madden et al in press



What else beyond SVR?

- Evidence of:
 - What may change
 - What may remain
 - What may emerge





What can change – complex lives

Treatment success - permitted a future¹; generated new positive feelings of confidence and an enhanced ability to navigate life's complexities.²

- None of this would have happened if I hadn't done the treatment, I wouldn't have got fixed, I wouldn't have sorted me drinking out and I wouldn't have had any future . . . I've got a future now .¹
- I can throw more energy and effort into more positive things ... Like I went through the shelter process, right now we are in transition for housing, I'm about... three months away from being independent completely," (Participant 20).³
- [Clearing hepatitis C] will help in defeating the bigger problems, because it's like trying to get up when you've got 100 bricks on ya. But then if I took half the bricks off from the Hep C, then now I've got a bit more movement and I can start taking the bricks off. (P14, high-level fibrosis)²

¹ Harris, IJDP 2017; ² Goutzamanis et al., BMC Inf Dis, 2018; ³ Batchelder et al., Drug Alc Dep, 2015



What remains – complex lives

Hepatitis C - relatively minor concern in the face of other medical issues, unemployment, financial difficulties, mental illnesses, drug use and dependence, and strained personal relationships.¹

- For example, last year when I had my family service worker, that's the reason I didn't get the treatment done, because I was like being sick from my methadone, so I couldn't travel so far unless I really took a lot of medications and I didn't want to get up to the hospital like that.... They might have refused to dose me or something and so I needed to get there and they wouldn't do it. They refused to do it ... their job was to get me to appointments, because I had panic attacks around a lot of people, in queues, what does my psychologist call it, 'social anxiety' and so I did need help and so I got the scans and everything done ready to go start my treatment and no one would bring me. I was sick as hell and so three times I rescheduled the appointment and I thought, 'oh my god, this is just hopeless' and so unless I could find someone who is going to help me and get me to where I've got to go, there's no point, so just wait. And so I thought, I'm going to find a GP in the northern suburbs that I can get to and not rely on anybody else. (female, group 2, 41 years)²

¹ Goutzamanis et al., BMC Inf Dis, 2018; ² Madden et al., under review





What remains - stigma

Stickiness of HCV stigma, residual underbelly of shame²

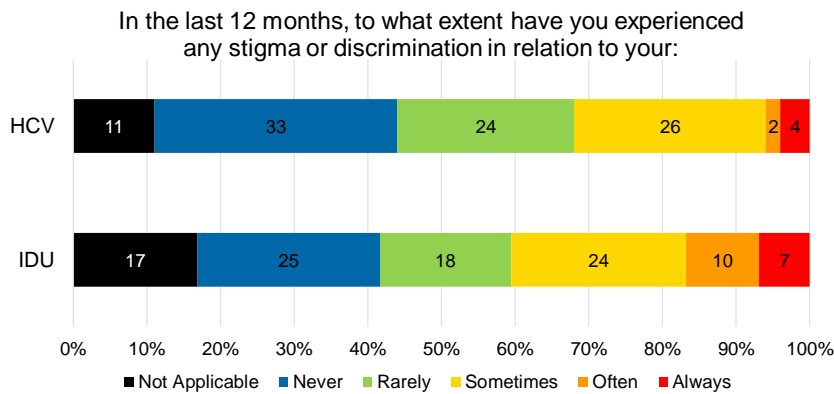
- I still hide it, no matter what... I just won't do it...um, and yeah that's from fear of judgment I'd say but I don't think it would have really mattered. It's more from me... it's the stigma within as much as the stigma without. (male, group 4, 56 years) ¹
- When asked if there was “any spark of light” in having cleared HCV, participant replied:
 - No, because the scarring's already there. Mental scarring . . . things that she said to me that, even though I've cleared the virus, still hurt, mentally . . . It doesn't just go away. ²

¹ Madden et al under review; ² Harris, IJDP 2017



Australian stigma indicator¹

- People living with hepatitis C and people who inject drugs

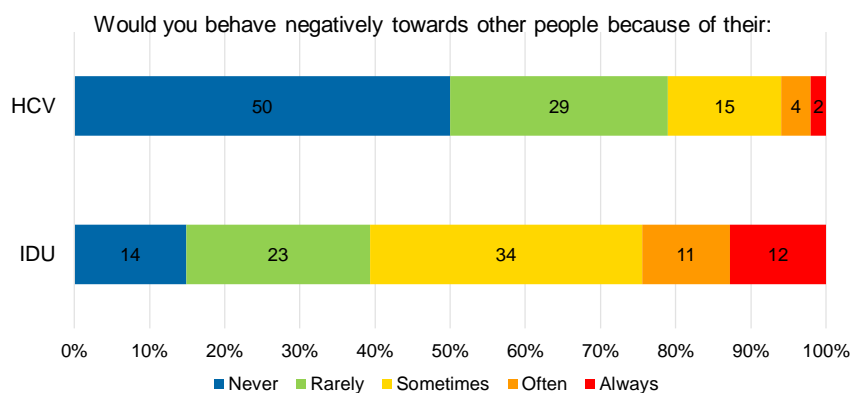


¹ Broady et al., 2018



Australian stigma indicator¹

- General public



What may emerge?

re-infection as a new source of stigma:

- I think that there's also something to be said about the stigma and the guilt that goes along with re-infection. That's a whole new monster that we're going to have to deal with soon (Participant 19, female).¹

¹ Richmond et al., Hepatology, Medicine and Policy, 2018



What remains - structural inequality

- Structural inequality¹
 - Socioeconomic and other markers of difference
 - Fewer resources to challenge inequality
 - Stigma
- How do health systems deal with structural inequality?
 - Not working for those with least resources
- Structural competency
 - Emerging framework to train health workers to identify and respond to structural inequalities

¹ Bourgois et al., Acad Med, 2017



Structural competency¹

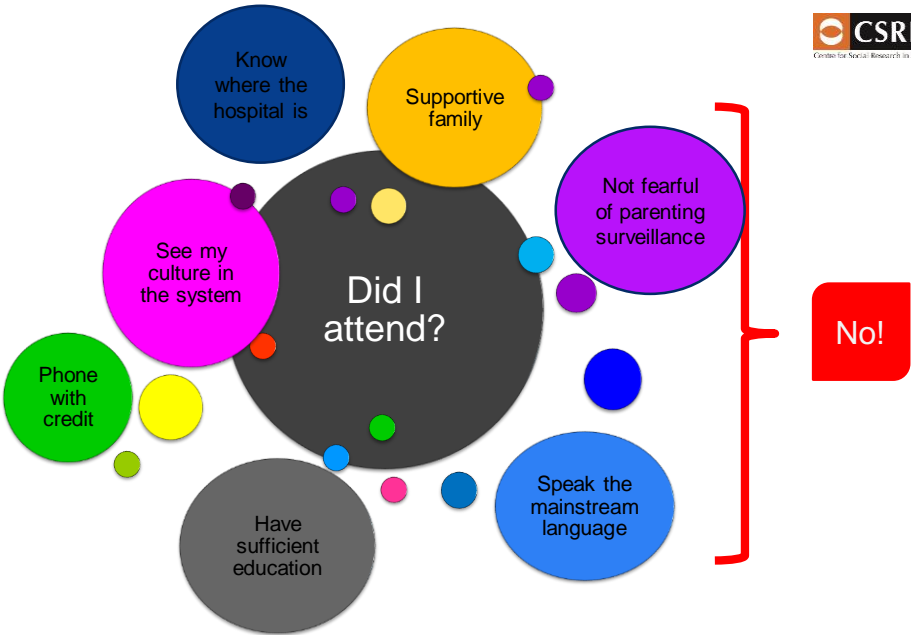
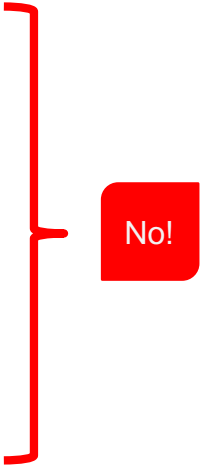
- Previously training: listen and respond to patient's individual stories
 - This makes influence of structural factors on health and illness invisible
- Structural competency
 - look beyond patient, identify the causes of disease related to socioeconomic status, race, sexuality and other markers of difference
 - How actions and policies of the health system produce and sustain inequalities that marginalise and stigmatise patients
 - Generate structurally-informed responses to better meet patients' needs, promote better health outcomes

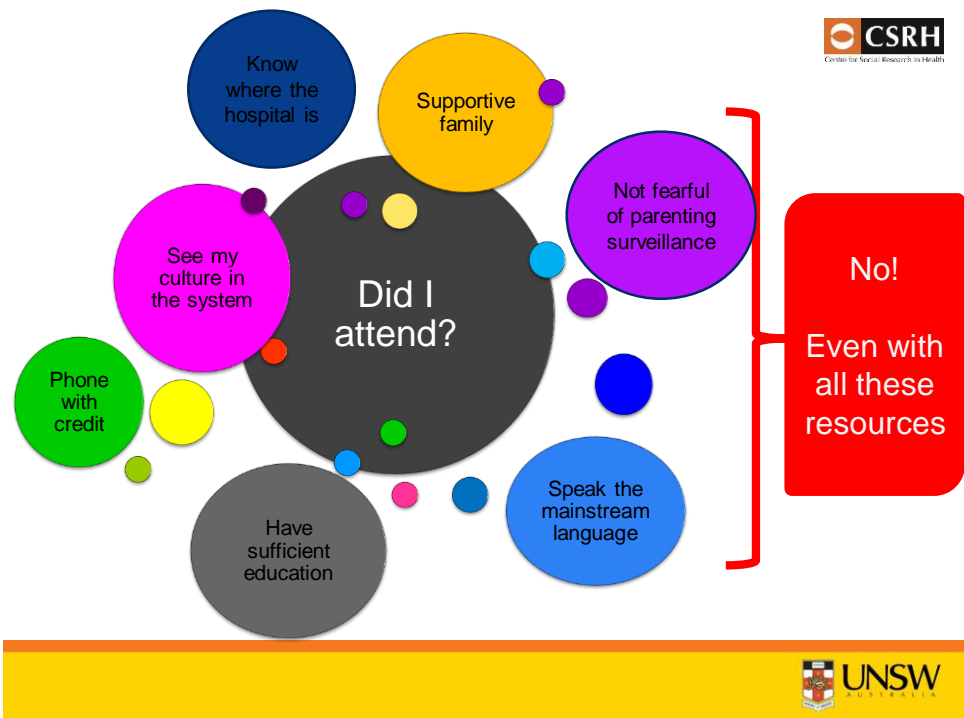
¹ Metzl & Hansen, Soc Sci Med, 2014



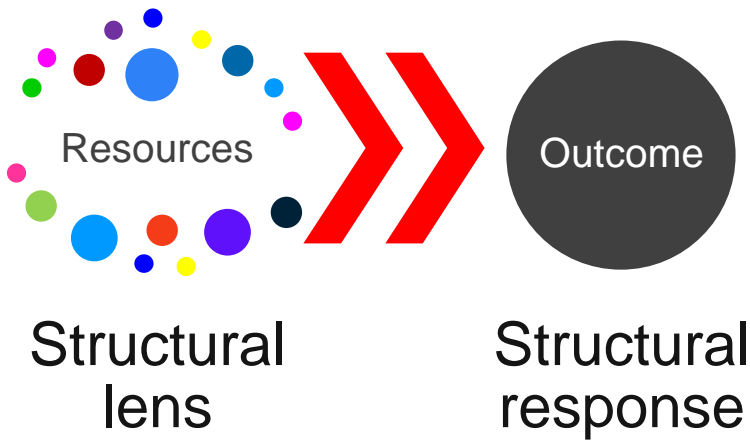
An example...



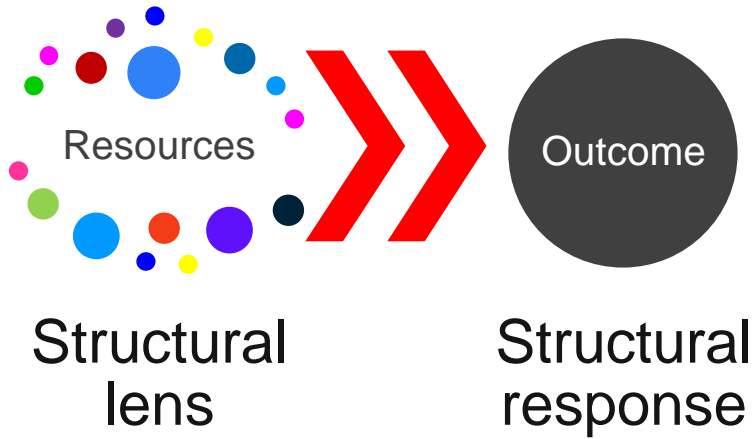




Structural competency to address inequalities



What structures can you influence?



What else beyond SVR?

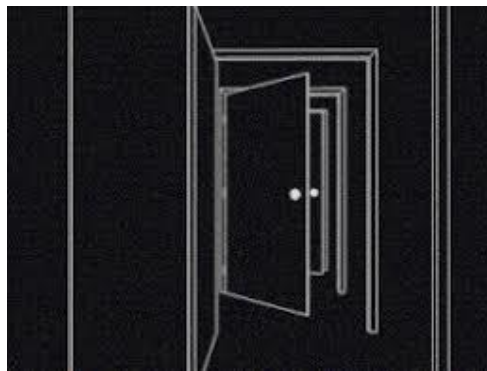
- Evidence of:
 - What may change
 - Complex lives
 - What may remain
 - Complex lives
 - Stigma
 - Structural inequalities
 - What may emerge
 - Stigma associated with reinfection

What else beyond SVR?

- Evidence of:
 - What may change
 - Complex lives
 - What may remain
 - Complex lives
 - Stigma
 - Structural inequalities
 - What may emerge
 - Stigma associated with reinfection

Stigma + complexity + structural inequality

- Use HCV as a resource to assist those with barriers to services related to stigma, complex lives and structural barriers to broaden benefit





HCV Rx as in-reach site?

- Practices of care 'beyond the virus'¹
 - HCV Rx as a core infrastructure for other health initiatives
 - Possible clinical/service re-design
- Resources
 - An existing service that clients know
 - Client trust;
 - Connection with clients - high unmet needs, low service access
 - Inter-personal impact with other clinicians (peer education)

1 Rhodes, et al., BioSocieties 2018



HCV Rx as in-reach site?

- Challenging policy and practice environment
 - ? Silo-ed focus on HCV vs broader focus
- Opportunities
 - Tobacco control; Closing the Gap (Indigenous); cancer prevention; heart foundation
 - Diversifying into other liver care¹ – including alcohol²
 - Validate health protection motivations and actions of patients, acknowledge their patient citizenship^{3,4}
- Care is required
 - Need for careful engagement with vulnerable clients; choice/logic of care must be determined by client

1 Harris & Rhodes, IJDP 2018; 2 Marshall et al., IJDP 2017;
3 Rhodes et al., Soc Hlth Illness, 2013; 4 Fraser & Seear 2010.





What else beyond SVR?

- Define QOL from “patient” experience
- What may change
 - Complex lives
- What may remain
 - Complex lives
 - Stigma
 - Structural inequalities
- What may emerge
 - Stigma associated with reinfection



Acknowledgements

- Time and expertise of participants in all studies
 - People who inject drugs; people living with HCV
- Co-authors
 - Annie Madden, Max Hopwood, Jo Neale, Elena Cama, Loren Brener, Tim Broady, John de Wit
- Advisory Committee for Stigma Indicator Project
 - Brent Allan, Jude Byrne, Aaron Cogle, Louise Geddes, Jules Kim, Jayne Lucke, Anthony Lyons, Annie Madden, Lisa Maher, Kevin Marriott, Rebecca Newton, Garrett Prestage, John Rule, Christine Selvey, Helen Tyrrell, Melanie Walker, Ben Wilcock
- Funding
 - Australian Government Department of Health
 - PLuS Alliance





Search '[UNSW SpeakEasy](#)' and subscribe to our podcast on iTunes



References



- Batchelder, A. W. et al (2015). "Hepatitis C treatment turned me around:" Psychological and behavioral transformation related to hepatitis C treatment. *Drug and Alcohol Dependence*, 153, 66-71.
- Basch E. New frontiers in patient-reported outcomes. *Annu Rev Med*. 2014;65:307-17.
- Black N. Patient reported outcome measures could help transform healthcare. *BMJ* 2013;346: f167
- Boyce MB, Browne JP, Greenhalgh J. The experiences of professionals with using information from patient-reported outcome measures to improve the quality of healthcare. *BMJ Quality and Safety*. 2014; 23(6):508-518.
- Bourgois, P et al (2017). Structural Vulnerability: Operationalizing the Concept to Address Health Disparities in Clinical Care. *Academic Medicine*, 92(3), 299-307.
- Fraser, S., & Seear, K. (2011). *Making Disease, Making Citizens: The Politics of Hepatitis C*. Farnham, Surrey: Ashgate.
- Goutzamanis, S. et al (2018). Experiences of liver health related uncertainty and self-reported stress among people who inject drugs living with hepatitis C virus: a qualitative study. *BMC Infectious Diseases*, 18(1), 151.
- Harris, M. (2017). Managing expense and expectation in a treatment revolution: Problematising prioritisation through an exploration of hepatitis C treatment 'benefit'. *International Journal of Drug Policy*, 47, 161-168.
- Harris, M., & Rhodes, T. (2018). Caring and curing: Considering the effects of hepatitis C pharmaceuticalisation in relation to non-clinical treatment outcomes. *International Journal of Drug Policy*, 60, 24-32.
- The Kirby Institute. (2017). *HIV, viral hepatitis and sexually transmissible infections in Australia Annual Surveillance Report 2017*. Retrieved from Sydney:
- Madden, A., Hopwood, M., Neale, J., & Treloar, C. (2018). Beyond cure: patient reported outcomes of hepatitis C treatment among people who inject drugs in Australia. *Harm Reduct J*, 15(1), 42.
- Madden, A., Hopwood, M., Neale, J., & Treloar, C. Acceptability of patient reported outcome and experience measures for hepatitis C treatment among people who use drugs. In press.
- Madden, A., Hopwood, M., Neale, J., & Treloar, C. Beyond interferon side effects: What residual barriers exist to DAA hepatitis C treatment for people who inject drugs? Under review
- Marshall, A. D et al (2017). 'I didn't want to let it go too far.' The decisions and experiences of people who inject drugs who received a liver disease assessment as part of a liver health promotion campaign: The LiveRLife study. *International Journal of Drug Policy*, 47, 153-160.
- Metzl, J., & Hansen, H. (2014). Structural competency: Theorizing a new medical engagement with stigma and inequality. *Social Science and Medicine*, 103, 126-133.
- Rhodes, T., et al (2018). The social life of HIV care: On the making of 'care beyond the virus'. *BioSocieties*.
- Richmond, J. A et al (2018). Achieving a hepatitis C cure: a qualitative exploration of the experiences and meanings of achieving a hepatitis C cure using the direct acting antivirals in Australia. *Hepatology, Medicine and Policy*, 3(1), 8.
- Smith-Palmer, J., Cerri, K., & Valentine, W. (2015). Achieving sustained virologic response in hepatitis C: a systematic review of the clinical, economic and quality of life benefits. *BMC Infectious Diseases*, 15(1), 19.
- Stepanova, M. et al (2018). Hepatitis C Virus-Infected Patients Receiving Opioid Substitution Therapy Experience Improvement in Patient-Reported Outcomes Following Treatment With Interferon-Free Regimens. *The Journal of Infectious Diseases*, 217(7), 1033-1043.

