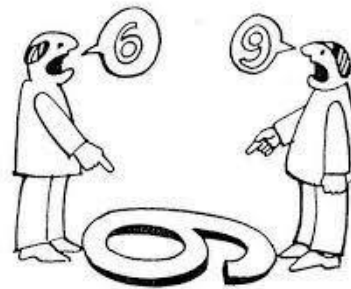


Maximising DAA uptake: Tensions between 'lay' and 'expert' knowledges

'Lay' and 'expert' knowledges

- knowledge is specific to and produced in particular social, political and economic conditions.
- Multiple and diverse knowledges
- Some knowledge esteemed and valued to the exclusion of others





The social research



Bryant J, Rance J, Hull P, Mao L, Treloar C (2019). Making sense of 'side effects': Counterpublic health in the era of direct-acting antivirals, *IJDP*, early online.

Harris M, Rhodes T (2018). Caring and curing: Considering the effects of hepatitis C pharmaceuticalisation in relation to non-clinical treatment outcomes. *Int Journal of Drug Policy*, 60: 24-32.

Harris, M. (2017). Managing expense and expectation in a treatment revolution: Problematizing prioritisation through an exploration of hepatitis C treatment 'benefit'. *Int Journal of Drug Policy*, 47: 161-168.

Henderson C, Madden A, Kelsall J (2017). 'Beyond the willing and waiting' – the role of peer-based approaches in hepatitis C diagnosis and treatment. *Int J of Drug Policy*, 50: 11-115.

Madden A, Hopwood M, Neale J, Treloar C (2018a). Beyond cure: patient reported outcomes of hepatitis C treatment among people who inject drugs in Australia. *Harm Reduction Journal*, 15: 42. DOI 10.1186/s12954-018-0248-4

Madden A, Hopwood M, Neale J, Treloar C (2018b). Beyond interferon side effects: What residual barriers exist to DAA hepatitis C treatment for people who inject drugs? *Plos One* <https://doi.org/10.1371/journal.pone.0207226>

Richmond JA, Ellard J, Wallace J, Thorpe R, Higgs P 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 antivirals in Australia. *Hepatology, medicine and policy*, 3: 8.

Wright C, Cogger S, Hsieh K, Goutzamanis S, Hellard M, Higgs P (2018). I'm obviously not dying so its not something I need to sort out today': Considering hepatitis C treatment in the era of direct acting antivirals. *Infection, Disease & Health*, <https://doi.org/10.1016/j.idh.2018.10.006>



Enthusiasm

- Staggering uptake of DAA treatments!
- Enthusiastic, grateful, disbelieving

"I hear a lot of people talking about it and a lot of them are amazed. And I see the smile on their face when they come back and go 'I've got rid of my Hepatitis; my Hep C is gone' you know? And people with smile on their faces. And I'm like, good on you, keep it up." (Steve, 50 years)

Bryant J, Rance J, Hull P, Mao L, Treloar C (2019). Making sense of 'side effects': Counterpublic health in the era of direct-acting antivirals, *IJDP*, early online.





Meanings of 'cure'

- Social reconnection, return to 'normality'
- 'relief about no longer living with the burden of an uncertain future'
- 'breaking a connection with the past, if injecting is part of their past.'

Harris, M. (2017). Managing expense and expectation in a treatment revolution: Problematizing prioritisation through an exploration of hepatitis C treatment 'benefit'. *Int Journal of Drug Policy*, 47: 161-168.

Madden A, Hopwood M, Neale J, Treloar C (2018a). Beyond cure: patient reported outcomes of hepatitis C treatment among people who inject drugs in Australia. *Harm Reduction Journal*, 15: 42. DOI 10.1186/s12954-018-0248-4

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Doubt, distrust, suspicion

- 37% of those not treated worried 'a lot' about 'side effects'
- 'side effects' of DAAs understood to be fatigue, irritability, headache, loss of appetite

"sometimes I think that I am a **guinea pig**, do you know what I mean? Do they really have something that's really going to work? Because I don't know, it just seems to me that, well, ok you've got drug addicts, they are already down. They virtually do whatever you want for \$50. They would sell their soul to the devil if they could."

(Steve, 50)

Bryant J, Rance J, Hull P, Mao L, Treloar C (2019). Making sense of 'side effects': Counterpublic health in the era of direct-acting antivirals. *IJDP*, early online.





Tensions between 'lay' and 'expert' knowledges

Differences in understandings of...

- How DAAs act on bodies
- The opportunities afforded by cure
- Others?

What impact does this have on our efforts to promote DAA uptake?



Tensions between 'lay' and 'expert' knowledges

1. Dismissing 'lay' understandings as erroneous and wrong is risky...
 - Reconstitutes people as deficient and lacking 'appropriate' knowledge
 - Stigmatising
 - Reinforces suspicion and mistrust





Tensions between 'lay' and 'expert' knowledges

2. We should not assume that all people have faith in scientific and biomedical claims about DAA treatment

'Side effect free'

'Only 8-24 weeks'

'Over 90% success'

'Cure with minimal side effects'



Tensions between 'lay' and 'expert' knowledges

3. Calls for us to question who needs to be educated and corrected?

- People with hepatitis C or 'experts'?
- Can we better educate professionals and clinicians?





What sort of approaches/messages are needed?

Biomedical-based messages? Yes!

'Side effect free'

'Only 8-24 weeks'

'Over 90% success'

'cure with minimal side effects'

Broader appeals to living well and 'renewal'? Yes!

'live free from the worry of hep C'

'can help you feel better about yourself'



The delivery is crucial...

- Peer networks provide a unique and trustworthy entry point (Henderson, Madden, Kelsall, 2017)
- Community and culturally relevant – story-telling

Postcards



[Ad 1 \(High Res PDF\)](#) (.pdf | 966kb)

[Ad 1 \(High Res JPG\)](#) (.jpg | 4.47mb)

[Ad 1 \(Low Res JPG\)](#) (.jpg | 80kb)

[Ad 2 \(High Res PDF\)](#) (.pdf | 966kb)

[Ad 2 \(High Res JPG\)](#) (.jpg | 4.47mb)

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[Ad 3 \(High Res PDF\)](#) (.pdf | 966kb)

[Ad 3 \(High Res JPG\)](#) (.jpg | 4.47mb)

[Ad 3 \(Low Res JPG\)](#) (.jpg | 80kb)

Stories

[Cathy's story](#)

[Kerr's story](#)

[Toby's story](#)





Thank you.

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