



Developing patient reported outcome measures for HCV DAA treatment among people who inject drugs: what else besides “cure”?

Thank You



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Co-investigators:

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

email c.treloar@unsw.edu.au, twitter [@carlatreloar](https://twitter.com/carlatreloar)



What is beyond the cure as DAA outcome?

- New measures – Patient Reported Outcome Measures (PROMs)
 - Beyond clinical measures
 - Existing measures: Self-report, QoL
 - New measures: Derived from “patient” experience
- For HCV DAA: Needs beyond the clinical/public health goals in a high “promise” environment



Current study

- Interviews – groups of people who inject:
 1. No engagement with treatment
 2. Some engagement
 3. Currently on treatment
 4. Completed treatment
- Development of a draft PROM (and PREM) from qual data
- Testing of PROM in 4 focus groups with people who inject
- Further refinement, psychometric testing



Experiences of treatments

I: So then you mentioned just then that your thinking has shifted around hep C treatment, so you're not on treatment yet, but you are thinking about possibly?

R: I am and I actually went to have a real good go at it and they couldn't get blood out of me ... I mean [the health professionals] are cool, they say they get it, they understand it, but ... I don't feel they really do understand it, because you know they just say, "well you whack up don't you?" Like you know, "you don't understand the difficulty I have whacking up" ... it's like every now and then you hear of "oh there's good nurses at so and so, let's go there and get her to have a go", but you know I just don't want to sit there and be pin cushioned by people, so yeah ... [re overcoming this key barrier] I've read about perhaps dry blood spot PCR's in the future, however, you know there's still going to be other stuff that needs to be done. I don't think it's going to be as easy as, "oh we're 12 months down the track, now we can just do a PCR". I'm not saying you won't be able to do a PCR, but just all the other stuff that's needed. I don't ... yeah. (participant 1.2)



Experiences of treatment

- '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.' (Participant 2.6)



Experiences of treatment

- As other barriers (efficacy, side effects) fall away
 - Stigma may become more important

Brener et al., (2015)

'My mum treats me like I've got AIDS ... like the other day, she bought a juice and I wanted to have a taste of it, she said, "no because I might catch your Hep C" and she's even gone and got herself immunized against it so she doesn't get it from me. She's so paranoid.'

(participant 2.3)

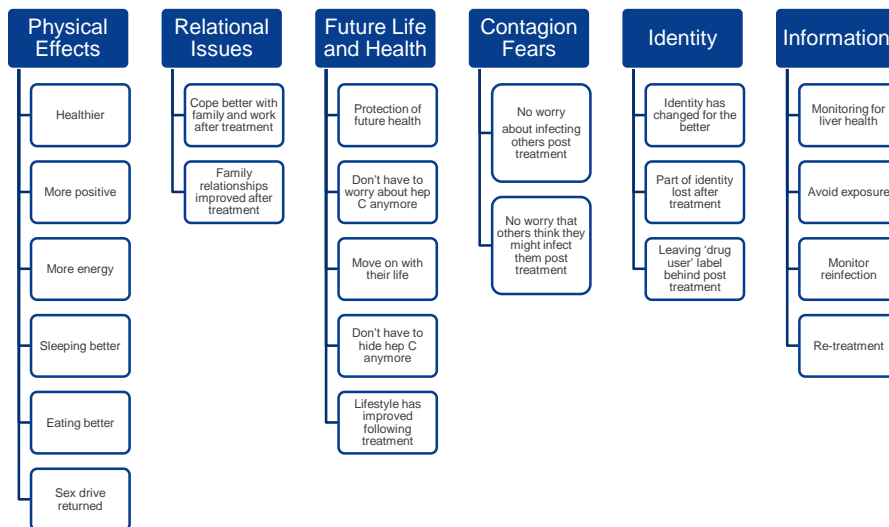
'I still don't tell anyone, I don't disclose, never disclose. Even at the dentist I leave it blank. ... Discrimination. Not for me, for my kids. You know it's for them, I don't want them being judged because of my mistakes.'

(participant 2.6)

CSRH Prom project, (forthcoming)



What else besides 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

<i>"Based on my last hep C treatment experience I now feel that..."</i>	Agree	Disagree
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

<i>"Based on my last hep C treatment experience I now feel that..."</i>	Agree	Disagree
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):

<i>"As a result of my last hep C treatment episode I..."</i>	Agree	Disagree
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)

<i>"As a result of my last hep C treatment episode I..."</i>	Agree	Disagree
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

- Overwhelming feedback – questions ‘really resonated’ and focused on issues ‘no-one else had asked them’
- 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



Preliminary feedback

- Participants felt draft measures could be useful but ‘how’ they are used is really important due to the extent of stigma & criminalisation for PWID.
- For ppl to answer honestly would need to be anonymous (fearful of punitive responses)
- 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



Conclusions

- Tensions between ‘**HCV elimination goals/outcomes @ population level**’ and ‘**individual patient goals/outcomes**’
- What outcome is being sort and by whom?
- Goals: significantly affect how services are designed and delivered.
- HCV elimination – focus on treating as many people as possible, as quickly as possible & achieving viral clearance.
- But do such MoC (and the measures used to evaluate these) adequately account for ppl’s individual & social circumstances
 - ***their*** ‘experience’ of treatment & ‘outcomes’ ***they*** are seeking from it?



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