

# Integrating treatment

Key findings from a qualitative evaluation of the Enhancing Treatment of Hepatitis C in Opiate Substitution Settings (ETHOS) study

Jake Rance and Carla Treloar



## Introduction

Worldwide there is a growing interest in the provision of care and treatment for hepatitis C virus (HCV) infection within opiate substitution treatment (OST) programs. In Australia, national health policy currently targets a doubling of HCV treatment uptake to ameliorate the looming healthcare burden of end-stage liver disease and transplantation. Of the over 46,000 people currently receiving OST Australia-wide, it is estimated that over 21,000 live with chronic HCV infection (Day & Haber, 2009), yet less than 5% have commenced treatment (Dore & Jauncey, 2009). This needs to be considered against the high rates of willingness to undertake treatment reported among people who inject drugs (PWID), many of whom would also be receiving OST (Doab, Treloar, & Dore, 2005; Grebely et al., 2008); and further, that outcomes of treatment (adherence and sustained virological response)

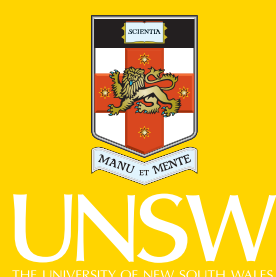
among service users concurrently receiving methadone maintenance have been demonstrated as acceptable and equivalent to those in other populations (Hellard, Sacks-Davis, & Gold, 2009).

The ETHOS study was established with two aims: firstly, to develop a collaborative network of OST clinics and community health centres piloting the introduction of hepatitis C care and treatment in NSW, Australia; and secondly, to facilitate an evaluation of the implementation process, the uptake of care, and the outcomes of treatment, among the OST service-user population. Nine clinics across NSW are involved in the ETHOS study, with each site integrating hepatitis C care and treatment according to the particularities of their location and the resources available. While some sites have HCV specialist nurses routinely in situ to

engage and assess service users, organise (or conduct) blood pathology work and so forth, service users are nonetheless required to visit a gastroenterologist offsite before commencing treatment; at other sites, HCV prescribers are available on-site. Peer support programs are currently running at two sites with peer workers—employed and supported by the NSW Users and AIDS Association (NUAA)—available to complement and extend the services offered by the clinical care team. The model of peer support also differs across sites.

This study employed qualitative methods to explore OST service-user and health-professional reports concerning the barriers and facilitators affecting the delivery and uptake of HCV care and treatment within OST clinics, including those in which peer support was offered.

*continued ...*



## Key findings

Never Stand Still

Faculty of Arts and Social Sciences

National Centre in HIV Social Research



Qualitative methods are particularly helpful when applied to new and under-developed areas of research (such as HCV treatment and care in OST). Qualitative methods enable researchers to understand the ways individuals perceive and/or experience the impact of phenomena, which then assists in the

## Method

### Recruitment and study sites

Our qualitative study recruited a specific sub-sample of people enrolled in or eligible for the larger ETHOS project: individuals attending selected OST clinics who reported living with

---

"I wouldn't have been able to do [HCV treatment] if it wasn't accessible through this clinic here and now ... and it's great. It's great. I'm probably one of the people that need it the most".

---

identification of key issues—in this case the barriers and incentives to HCV care, treatment delivery and uptake within OST clinics (Patton, 2002).

Our previous work raised a number of critical concerns regarding the proposed introduction of HCV care and treatment within the OST setting (Rance, Newland, Hopwood, & Treloar, 2012). We examined the experiences of service users and staff in the context of the potential complexities and contradictions when two distinct health systems are merged into one delivery site. The aims of this qualitative component of the ETHOS study were to evaluate:

- service-user and provider attitudes towards the provision of services for the assessment and treatment of HCV infection in OST
- peer-based support as a strategy for enhancing knowledge and uptake of treatment for HCV infection in the OST setting

These aims were investigated via in-depth interviews with OST service users, staff and peer-support workers. Specifically these interviews were guided by the following questions:

- What influenced the decisions of OST service users to engage in assessment, care and treatment for HCV?
- What staffing, policy and environmental factors affected the delivery of assessment, care and treatment of HCV infection?
- What impact did the presence and conduct of a peer support program have on decisions and experiences regarding the assessment, care, treatment and operation of HCV treatment in OST?

a chronic HCV infection. We were interested in the attitudes, experiences and motivations of these service users; both those who were assessed for HCV treatment and those who were not. Even if participants did not move onto HCV treatment their engagement with the assessment process was significant in terms of opportunities it afforded for care and support. In understanding the patient journey, three groups of service-user participants were recruited: firstly, those who declined any engagement with HCV assessment as their stories were equally important in attempting to understand the barriers to providing HCV care within OST settings; secondly, those who attended for initial HCV assessment but did not progress further with HCV care or treatment; and finally, those who had moved towards or were undertaking HCV treatment. For the purpose of this report, these three categories will be referred to as 'declined assessment', 'initial assessment only' and 'awaiting or initiated treatment' respectively.

Interviews were also conducted with a range of clinic staff and peer-support workers involved in the ETHOS project to ascertain their views on the response of service users to the initiative, the barriers and incentives to HCV treatment reported by service users, the general effect of the initiative on the clinic, and any organisational factors affecting the delivery of services (clinical and peer).

Recruitment and interviewing took place across four ETHOS pilot sites in NSW: three within OST clinics (inner city private clinic, outer metropolitan public clinic, regional city public clinic) and one within a NSW community health centre (large rural town) operating a public OST clinic. Sites were selected to include two which were currently providing peer-support programs (inner city and regional city) and two which were not (outer metropolitan and large rural town).

### Interview schedules

In-depth interviews were conducted across the four study sites. Semi-structured interviews were constructed around a set of core issues. OST service-user interviews included: a brief demographic and clinical overview, including drug treatment history; recollections of initial HCV diagnosis and subsequent management; attitudes towards and/or experiences of HCV treatment (including motivations, barriers and reasons for deferment or non-engagement); general thoughts regarding the co-location of HCV treatment within OST; understanding of, attitude towards, and engagement with peer support. The core set of issues raised with staff participants included: their initial expectations of the ETHOS initiative; service-user responses; barriers to service-user engagement with HCV treatment (including stability on OST, fear of side-effects, absence of family support etc.); organisational issues; and attitude towards peer support. Interviews with peer-support workers explored: motivations for undertaking the role; thoughts on the ETHOS initiative including service-user reactions; barriers to service-user engagement with HCV treatment; staff reactions to peer support role; organisational issues; and the general impact of the peer-support program on the clinic.

### Data management and analysis

Digitally recorded interviews were transcribed verbatim. The transcripts were then *cleaned* to remove any identifying details and ensure participant anonymity. Each transcript was given an identifying clinic number, a pseudonym, and a code designating *service user*, *staff* or *peer support worker*. Transcripts were then entered into a qualitative software program (NVivo 8) to assist in identifying and organising participants' interview responses.

The study was approved by the Human Research Ethics Committees of The University of New South Wales and NSW Health. Informed consent, either written or audio recorded, was obtained from all participants. In total, only three telephone interviews were conducted, involving staff from one site. In accordance with convention, service-user participants were reimbursed \$20 for their time and expertise.

## Acknowledgments

The authors would like to extend their thanks to all those involved in the study.

### Funding

The ETHOS study was supported by a National Health and Medical Research Council Partnership Grant and the NSW Ministry of Health. The National Centre in HIV Social Research and The Kirby Institute are supported by the Australian Government Department of Health and Ageing.

### ETHOS

Chief investigators: Greg Dore, Paul Haber, Jason Grebely, Carolyn Day, Carla Treloar, Lisa Ryan and Rosie Thein

Project Steering Committee: Paul Haber (Chair), Nicky Bath, Bob Batey, Sione Crawford, Carolyn Day, Greg Dore, Jason Grebely, Claire Honey, Murray Krahn, Stuart Loveday, Michelle Micallef, Jake Rance, Lisa Ryan, Rosie Thein, Carla Treloar and Cate Wallace

### Participants

The 76 service users, staff and peer-support workers who generously gave of their time to participate in interviews.

### Interviewer

Jake Rance (National Centre in HIV Social Research)

## Findings and discussion

### Sample

A total of 76 in-depth interviews were completed. Face-to-face interviews were conducted with 57 service users, ranging in age from 29 to 58 years. Of the service-user sample, 17 were 'declined assessment', 21 were 'initial assessment only' and 19 were 'awaiting or initiated treatment'; about half were men ( $n=32$ ), nearly all were social security recipients ( $n=52$ ), with seven in either full-time or part-time employment (two participants reported being both employed and receiving social security), and one-third identified as Aboriginal and Torres Strait Islander ( $n=19$ ).

Of the 16 staff participants, nine were nurses, four were clinical managers, two were administrators and one was a medical practitioner. Each of the three peer-support workers were either current or past service users of the OST clinics that now employed them; each was remunerated via ETHOS funding, with initial and ongoing training plus supervision provided by NUAA.

### The integrated treatment model

#### Service-user responses

Across the four pilot sites participants consistently lauded the logical and appropriate co-location of HCV care and treatment within settings where its high prevalence is common knowledge. The introduction of HCV care was valued as a practical, clinical intervention that intimated a more comprehensive, holistic form of service-user care. Its *one-stop shop* convenience coupled with its *in your face* visibility received critical approval among many interviewees, from those contemplating treatment to those who had successfully cleared the virus:

It's in your face so it's available to you ... We come here anyway. We feel safe coming here. So why wouldn't you feel safe to go and talk about [HCV] as well? (Ruby, 41, initial assessment only)

I wouldn't have been able to do [HCV treatment] if it wasn't accessible through this clinic here and now ... and it's great. It's great. I'm probably one of the people that need it the most. (Paul, 43, initial assessment only)

I'm so bloody thankful they're there ... 'Cause I probably wouldn't have walked into the opportunity [undertaking HCV treatment]. (Mick, 47, awaiting or initiated treatment)

Concerns among service users regarding the integrated treatment model were largely restricted to issues of privacy and confidentiality and, more abstractly, to questions of treatment identity. A number of participants expressed concern that the social and physical structure of their OST clinic meant it would be difficult for them to access HCV care without drawing unwanted attention regarding their HCV status from fellow service users. The issue of treatment identity is a complex one and deserves more attention than can be afforded here. Put simply, it speaks to feelings of being trapped in a model of treatment that attracts an undesirable and stigmatised identity, of being or having been a *drug user*. As these two participants explain:

I mean if I had my way, I'd pick up six take-aways and not come here at all. I like to pick mine up, my 'done up, and then pretend I'm just a normal person in my head ... but ... it's very hard to get away from the scene when every time you come in here you're at that scene. (Sarah, 45, initial assessment only)

I just find it really depressing this place. It just really gets me down ... you just wanna get on with the future ... you don't wanna be in that box [as *drug user*] ... I mean I haven't used drugs for 20-something years. (Maryla, 51, declined assessment)

For these participants the invitation to take up additional treatment (HCV) alongside their existing OST was a complicated and confronting one.

#### Staff responses

Responses to the ETHOS initiative among staff were overwhelmingly positive. Staff shared with service users a sense that integrating HCV and OST treatments was a laudable and logical move:



## References

Day, C., & Haber, P. (2009). Managing drug dependence in people with hepatitis C. In G. J. Dore, & M. Jauncey (Eds.), *Hepatitis C clinical management in opiate pharmacotherapy settings* (pp. 35–42). Sydney: Australasian Society for HIV Medicine. [http://www.ashm.org.au/images/publications/monographs/aod\\_mono/aod\\_mono\\_3-12-09\\_online.pdf](http://www.ashm.org.au/images/publications/monographs/aod_mono/aod_mono_3-12-09_online.pdf)

Doab, A., Treloar, C., & Dore, G. J. (2005). Knowledge and attitudes about treatment for hepatitis C virus infection and barriers to treatment among current injection drug users in Australia. *Clinical Infectious Diseases*, 40(S5), S313–S320. doi:10.1086/427446

Dore, G., & Jauncey, M. (2009). An overview of hepatitis C clinical management in opiate pharmacotherapy settings. In G. J. Dore, & M. Jauncey (Eds.), *Hepatitis C clinical management in opiate pharmacotherapy settings* (pp. 7–14). Sydney: Australasian Society for HIV Medicine. [http://www.ashm.org.au/images/publications/monographs/aod\\_mono/aod\\_mono\\_3-12-09\\_online.pdf](http://www.ashm.org.au/images/publications/monographs/aod_mono/aod_mono_3-12-09_online.pdf)

Grebel, J., Genoway, K., Raffa, J., Dhadwal, G., Rajan, T., Showler, G., ... Fischer, B. (2008). Barriers associated with the treatment of hepatitis C virus infection among illicit drug users. *Drug and Alcohol Dependence*, 93(1), 141–147. doi:10.1016/j.drugalcdep.2007.09.008

Hellard, M., Sacks-Davis, R., & Gold, J. (2009). Hepatitis C treatment for injecting drug users: a review of the available evidence. *Clinical Infectious Diseases*, 49, 561–573. doi:10.1086/600304

Patton, M. (2002). *Qualitative research and evaluation methods*. (3rd ed.). Thousand Oaks, CA: Sage.

Rance, J., Newland, J., Hopwood, M., & Treloar, C. (2012). The politics of place(ment): providing hepatitis C treatment within opiate substitution. *Social Science & Medicine*, 74(2), 245–253. doi: 10.1016/j.socscimed.2011.10.003

Under the one umbrella, the one-stop shopping option is always gonna work with our patients ... And I think we've demonstrated that with ETHOS. (Lenny)

Absolutely pro. I felt that, I felt that that's where [HCV care] fits, you know. Hep C is primarily an injecting drug condition so I felt that this is where you'd find predominantly the amount of people that needed access to treatment. (Anthea)

Here too, comments regarding the success of high visibility—*in your face*—care were common:

Now if someone's in [the service user's] face addressing it, then they will respond to it, and that is what's happened. (Jane)

Historically, a lack of resources in the OST sector had left staff with little or no time to deal appropriately with HCV. With ETHOS the opportunity for staff to actively and effectively promote the care and treatment of HCV clearly resonated with their professional duty of care. As this staff member explains:

And while [HCV care] was really, really important, one of the most important things we do, we couldn't kind of do it good because of the manpower and the hours we just didn't have. (Lenny)

Bearing witness to the positive transformation in the lives of those who successfully engaged in treatment was, of course, a particular highlight:

I think [treating HCV in OST] a great idea. And you just have to see, you know, the people that we've actually treated and have cleared the virus, the change in their life. (Angela)

### Engaging with HCV assessment and treatment: facilitators

Participants reported multivarious motivations for engaging with HCV assessment and treatment, ranging from the liver-related death of a close friend to an impending sense of age-related mortality to a new found sense of responsibility with the birth of a child or the custody of a grandchild. What our interview data highlights is the imperative of having a treatment pathway and associated support structures readily available, both to facilitate the decision-making process (if needed) and to act expeditiously when the decision is made. Damon's story is emblematic of many. Damon had lived with HCV for many years, explaining that, "while it's bothered me a great deal ... in the way that it can kill ya", it was also quite possible to co-exist with that concern, "cos over time you seem to forget about how important it is" (45, awaiting or initiated treatment). It was only after hearing about the new HCV clinician that Damon was prompted to take action:

Wow! She got the ball rollin' for me straight away mate. I mean straight away ... Like had everything done real quick. (45, awaiting or initiated treatment)

The facilitating role a trusted clinician can play was emphasised throughout the service-user interviews and was reiterated by staff. HCV clinicians emphasised the role of proactive engagement and rapport building among OST attendees, particularly during the initial months of their recruitment to the clinic. For a number of service users it was a conversation with a key clinician that ultimately prompted their engagement with the treatment process. As Mick and Tracy explain:

[The ETHOS clinician] started chatting and we'd talk and ... then she put forward the idea: asked me if I'd ever, ever considered [HCV treatment] ... I thought it'd be great to have the opportunity. I thought, "This is not gonna come around again," you know, so ... (Mick, 47, awaiting or initiated treatment)

[The OST manager] had positive words about it ... And for a person to take the time out and actually talk to me about it, I trusted her and I thought, you know, "Well maybe I should give it a go." (Tracy, 33, awaiting or initiated treatment)

Under the traditional, tertiary hospital model of care the referral process—from OST to hospital based liver clinic—had proved notoriously problematic. The ETHOS initiative has eliminated this step. As this OST staff member explains:

it's been fabulous ... cos we like to offer other options to the service users ... rather than pointing towards the hospital and saying, "Go up to the liver clinic, just up there," we can just say, "Have you got five minutes?" You can call [the HCV RN] and she'll come over. I just think that that's been a really good thing. (Bev)

Clinicians not only emphasised their relief at no longer having to refer service users offsite for HCV care—an unsatisfactory and unsuccessful process for many—but spoke of the appreciation people clearly felt upon being offered immediate and tangible onsite care. As staff member Teresa elaborates:

To be able to assist them with [HCV] ... when they hear that and they hear that there's, there's a helping role, they actually open up a lot more and they start to become more comfortable ... Just basically you being proactive towards them. You're actually taking concern in their welfare ... it develops a trust and that ... there's support there, and there's help ... So it all rolls into one.

It is not only the ease and availability of onsite care that facilitates a greater likelihood of engagement but the obvious advantages afforded once treatment has commenced. As Will explains:

It's very helpful. It's better. Like I find it easy 'cause like I can go and get my methadone and if I've got any problems I wanna talk about, well bang! I can just walk down here and come straight in [to the HCV clinician]. (40, awaiting or initiated treatment)

Finally, what cannot be underestimated when considering facilitating factors associated with an integrated treatment model – where frequent and routine contact among OST recipients is inevitable – is the positive effect of witnessing a growing number of fellow service users engaging in (and successfully completing) treatment. As Raquel explains, that was the key factor in her decision to embark on treatment:

Oh just hearin' other people in the clinic here talkin' about it, yeah. And then seeing good results that have come out of me mates that have survived it. (44, initial assessment only)

### Engaging with HCV assessment and treatment: barriers

Despite the apparent advantages of an onsite treatment model a number of barriers persist. The fear of side effects continues to saturate discussions of HCV treatment. As peer support worker Hannah explains, "Myths, all the myths ... They're not all myths. Some are real, real side-effects". Hannah's somewhat ambiguous comment is revealing here precisely because people's fears cannot be freighted away just to myth and

misinformation. HCV treatment remains arduous and exacting, with a very real possibility of serious and unpleasant side-effects. For some this fear is genuinely debilitating, despite their professed desire to commence treatment:

I think I'd probably almost need to be dragged along to something like that [HCV treatment]. But, at the same time, I have to do it. I really wanna do it. I don't know why I'm being so chicken about these bloody side-effects. I'm so worried about. (Stuart, 36, awaiting or initiated treatment)

While for others, especially those living with HCV who remain asymptomatic, the possibility of their health actually deteriorating (if only temporarily) during treatment remains a real and clear deterrent:

I just don't get it. I don't understand. You know, if you're not sick why would you step-up to that plate? ... [I]t's a year and that's a long time to be, you know, fucked-up, when it's brought on, you know, by yourself like, you know, by [your] decision. (Lilly, 48, declined assessment)

Family responsibilities, unstable housing, and a generalised sense of it just not being a priority at this point in their life, particularly for those currently asymptomatic, were commonly cited explanations for those living with HCV who remain reluctant or disinterested in pursuing treatment. Income, employment and legal issues were also commonly cited barriers to treatment. These included the negotiation of existing arrangements for participants reliant upon claiming both Centrelink benefits and working *cash-in-hand*. How would they cope on reduced incomes if treatment side-effects forced them to forgo their casual work? Those in fulltime employment explained their reticence to negotiate extended sick leave with their employers, fearing a negative response to honest disclosure about their HCV. Staff cited pending court cases as an organisational barrier to inducting service users onto HCV treatment, particularly if incarceration was a likely outcome.

One barrier that deserves mention concerns a potential conflict of interest between the administration of the two co-located treatment modalities and their respective responsibilities of care. The administration of HCV treatment can include an expectation of honest disclosure from service users regarding ongoing illicit drug use; this

is couched as principally a therapeutic or treatment matter. The protocols that govern OST are somewhat tighter due to the risks associated with schedule 8 drugs of dependence, such as methadone. A number of participants raised the concern that the sharing of information regarding the use of illicit drugs with their HCV treatment team could potentially jeopardise their OST if subsequently disclosed to pharmacotherapy staff. In services where the same staff member worked across both HCV and OST treatment teams this was a particularly troubling feature of the integrated treatment model. As Hannah, one of the peer support workers explained:

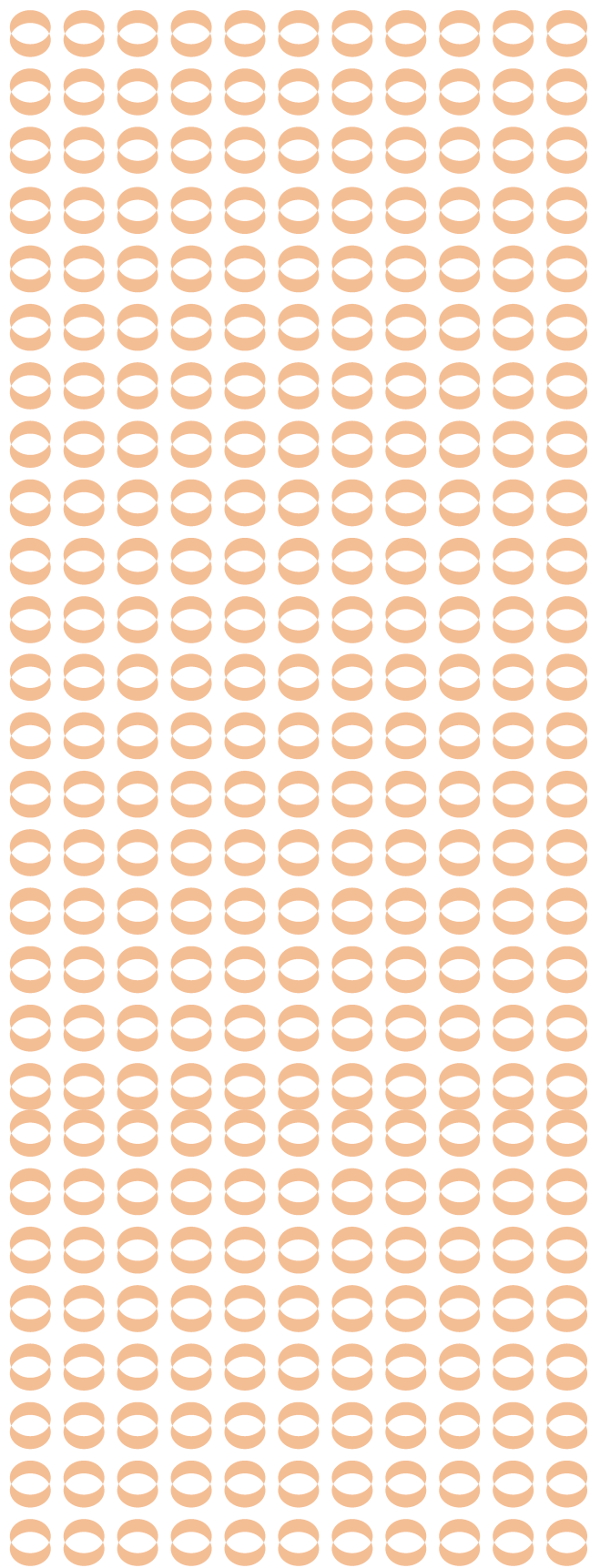
When I started here, I made it clear to [staff] that ETHOS is a separate part of the clinic ... that whatever ETHOS does, [this does] not go over to the [OST] part. It wouldn't work. As soon as [OST] confidentiality in there and ETHOS is broken, no-one's gonna trust, trust it to be the way it should be.

While this potential conflict of interest was flagged by both staff and service-user interviewees there were no reports of instances where this concern had been borne out in practice.

### Organisational and clinical issues and changes

The introduction of the ETHOS initiative across three of the four pilot sites was largely accommodated without significant administrative, organisational or clinical restructure; the degree of re-organisation depending primarily upon the breadth of existing clinical and administrative infrastructure. The rural site, however, was forced to build its HCV service from scratch, becoming the first HCV treatment service in town for several years. Nonetheless, even then the integration of ETHOS into the existing community health centre was achieved relatively seamlessly; the bulk of the work involving promotion within the regional medical community (notification in the newsletter of the Division of General Practitioners, letters to local GPs and specialists, and so forth).

While each service noted the need for idiosyncratic modifications or adaptations to be introduced alongside the ETHOS initiative, negotiating pathology, specialist gastroenterology appointments, fibroscanning, and the availability of S100 medications were issues common to all pilot sites. While existing legislation requires that S100



medications be distributed via hospital-based pharmacies only, several sites managed to negotiate bulk storage in their own onsite refrigeration, allowing for more convenient pick-up by service users undergoing treatment. While onsite pathology was available at some clinics, others continued to refer service users to local offsite laboratories. Similarly, appointments with specialists and the availability of fibroscans were a matter for each clinic to negotiate with the resources and options available and with as minimum disruption for service users as possible. Nonetheless, as one HCV clinician noted, the onsite availability of all these elements of HCV treatment remains the ultimate goal:

Potentially we could see the gastro, have the pathology and the medication, and ... the fibroscan and everything else for simple, uncomplicated hep C treatment. (Anthea)

Some of the more remarkable data emerging from the ETHOS initiative concerns reports of transformation among both individual participants and clinics. Here some systemic contextualisation is required. While the public health system has regularly proven unsatisfactory for people who inject drugs—references to sub-standard hospital care were commonplace throughout both service-user and staff interviews—OST clinics have been equally implicated in the perpetuation of systemic discrimination and disadvantage as well as the provision of sub-standard care. This clinician explains her perception of both the hospital system and the under-resourced drug and alcohol sector:

When it comes to methadone service users they're the end of the food chain as such. There's no money in drug and alcohol ... They go out to the hospital here and, as soon as it's, "Oh, you're on methadone," their problems are disregarded. They're not seen as important ... If it was cardiac thoracics, they'd have a million dollars thrown at them every year ... We [in OST] do not offer the greatest service ... It's just, you know, dosing people, dosing people and getting them out ... (Remi)

Against this background, it is perhaps not surprising that the enhanced opportunities afforded by the ETHOS initiative have been embraced by both

staff and service users. Here Tracy describes her experience of ETHOS:

It was nice to know that somebody actually, you know, looked out for Tracy, not just 'Methadone Tracy' kind of thing ... they took the time out to realise that there was something more than me just coming to get methadone. I had other issues. And it was something I didn't wanna address. And she helped me address it ... (33, awaiting or initiated treatment)

What is perhaps most remarkable in this instance is that while Tracy's HCV treatment was ultimately not successful her appreciation of the care involved remains undiminished. Perhaps this clinician provides a partial explanation:

I think it is, a lot of it is just being treated as a ... normal person. Just the way you're talking to them ... there isn't the judgment and they ... pick that up pretty early ... They almost wait for the judgement when you're talking about, you know, "Have you ever used?" And ... taking a care in the whole of their body, you know. It's like what else is going on in life ... [I]t all comes down a lot to that stigma and judgment stuff but it's a shame because yeah, you just know that a few simple things can often transform a person's sense of themselves ... (Bea).

---

One initial and encouraging finding from the study suggests the potential for integrating OST settings and treatment into OST settings to address problematic aspects of

---

Alongside reports of individual transformation were those describing the change in atmosphere or *feel* of the clinics. Interestingly, but perhaps not surprisingly, this change was most commonly noted in those two clinics where peer support programs operated. As these two peer support workers both independently noted of their OST clinic:

The culture of the clinic itself is, is different ... the atmosphere, in general, is, has changed enormously. (Simon)

I think this place has improved out of sight as far as the, the feeling, the vibe of the place. (Jacky)

These two observations are confirmed by a staff member from the same clinic:

It's just, it's just a feeling ... friendliness or something. (Jane)

This same staff member goes on to provide one possible clue to this change in atmosphere:

I think ... some of the service users respect us a bit more 'cause they see us actually being interested in their overall health and welfare; we're not just there to dose them ... I think that change a lot of perceptions of us as these strange, cold people that sit behind the counter and dole out methadone ... They actually see us now as involved in their health. (Jane)

What starts to emerge here appears to be a collective manifestation of the themes of individual transformation discussed above. While the clinician quoted earlier suggested that a few simple things can often transform a person's sense of themselves, the same it appears can be said of places, including OST clinics. As one service user remarked of the regular weekday when the peer-support program operated, "even a small thing, like a bowl of fruit, you know, it does wonders". (Tim, 58, awaiting or initiated treatment)

Finally, a note of caution. While encouraging, these data are not

has been recognised and promoted in all three of the National Hepatitis C Strategies. Peer education harnesses the organic exchange of information that inevitably takes place between members of a common social network. As an alternative or adjunct to traditional, institution-based education and the culture of the 'expert' (professional), it prioritises the participatory and self-determination principles of adult learning. As Rachel, a service user of one of the clinics piloting an ETHOS peer support program, explains:

I like that we have our own peers who are in the same predicament as we are. Encouraging and helping others in the same predicament. For someone like me ... instead of having a text book person there, I listen more to [peer support workers] Simon and Jacky because they've been there, they've done that. They've come through the other side but yet they're still on the 'done [methadone] ... And, you know, some people are not, might not be interested in it but it slowly sinks in ... It slowly, it slowly resounds to people that, "Hey, we're here. We're your peers. We're trying to help you out. If you need anything, come and ask." And I just think that's a top idea as opposed to the people who are dosing us doing it. (34, initial assessment only)

While only two of the four pilot sites included a peer support program all participants were questioned about the initiative. The positive responses from Mick, a service user, and Bev, a clinician, are representative:

I think the perception of a user, especially somebody who's, who's been around ... they're traits that come with ... they're life, they're life skills (47, awaiting or initiated treatment)

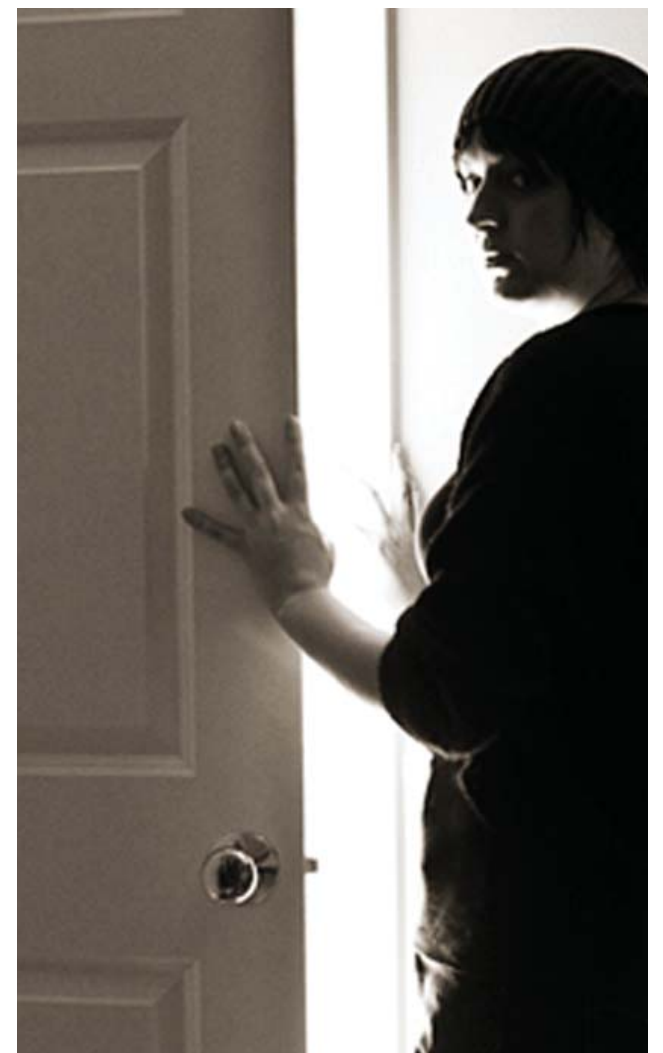
I like the idea of, of a service user being the expert and ... helping other service users. I think that's a good way to go ... There are just things that don't need to be spoken but they're already understood. (Bev)

To appreciate its near universal appeal requires – once again – recognising the degree of social stigma that surrounds hepatitis C and its corollary in the popular imagination: injecting drug use. As Sally explains:

That's why a lot of people won't say, "Yeah, I've got [HCV]", because there's a stigma to it and, and you're instantly, like instantly treated different ... I've been [at a public hospital] all day and been treated lovely, and like everyone else, but the moment they see that [points to track marks] it changes. (54, awaiting or initiated treatment)

The peer workers themselves were acutely aware of their unique role and the myriad opportunities it created. As Simon puts it:

Even though everybody who's a user or, or whatever, don't have exactly the same stories, but there's that camaraderie, and just that *no judgment*. Nobody feels like they're being judged by the person they're talking to. They've been through the same sort of stuff ... I think for drug and alcohol the last thing somebody wants is someone preaching to 'em. And coming from someone who's been there ... there's that openness and that trust, you know ... if you get it right it's a powerful tool. A very powerful tool.



As with the ETHOS initiative generally, the introduction of peer support programs generated a number of unanticipated yet welcome effects. As noted above, participants commented on the positive change in atmosphere on the days when peer support workers were present in the clinic. As Jane, a clinician, explains:

---

## ... emerging from the ETHOS ... the introduction of HCV care ... to challenge, and even change, ... OST culture and care.

---

evidence of systemic change across the four clinics or of universal, individual transformation among the service using population. However, nor are they merely isolated reports; the persistence with which they occurred warrants the space this report has accorded them.

### Peer support: attitudes and experiences

Peer education has been a central plank in the Australian response against the spread of blood-borne virus infections, such as human immunodeficiency virus (HIV) and hepatitis C, among people who inject drugs (PWID). Its utility

Like on the days when they do bring food and fruit, and stuff, I said to one guy, "You better take a piece of fruit." And he said, "I haven't had a piece of fruit in over 10 years." And he took it ... It's a much friendlier atmosphere when there's, you know, a piece of fruit or a packet of sultanas, or something for nothing. The atmosphere changes. And everyone's in a good mood.

Other participants commented on the mediating role peer support workers had sometimes played; their unique position of trust enabling them to intervene at critical moments when *misunderstandings* between service users and staff were threatening to escalate. As Hannah, one of the peer support workers, puts it:

It's changing people so that they know how to work the system a bit too. Because if you don't work the system, you'll never get out of here [OST clinic]

National Centre in HIV Social Research  
Level 3, John Goodsell Building,  
University of New South Wales  
Sydney NSW 2052 Australia  
Telephone: +61 2 9385 6776  
Fax: +61 2 9385 6455  
Email: [nchsr@unsw.edu.au](mailto:nchsr@unsw.edu.au)  
Website: <http://nchsr.arts.unsw.edu.au>

Monograph 3/2012

© National Centre in HIV Social Research 2012  
ISBN 978-1-921493-45-4 (print)  
ISBN 978-1-921493-46-1 (online)

### Suggested citation

Rance, J., & Treloar, C. (2012). *Integrating treatment: key findings from a qualitative evaluation of the Enhancing Treatment of Hepatitis C in Opiate Substitution Settings (ETHOS) study* (Monograph 3/2012). Sydney: National Centre in HIV Social Research, The University of New South Wales.

## Conclusion

Interviews with both staff and service users revealed typically positive experiences of HCV care and treatment within OST settings as part of the ETHOS study. Participants endorsed the notion of co-located services and the opportunity to offer (or access) immediate and available HCV care. For many, the provision of HCV treatment within OST clinics was perceived as a means to avoid the judgemental or discriminatory attitudes routinely encountered in other settings. However, there were service users who expressed reservations about the integration of HCV treatment within OST settings. For some, their reservations concerned a perceived lack of privacy and confidentiality, while for others it was associated with a desire to move on from the drug using identity they felt was reinforced by association with their OST clinic.

A number of valuable observations emerged from interviews with service users and clinicians of the pilot sites. Service users reported feeling encouraged by witnessing their peers undertake and complete HCV treatment, while staff similarly spoke of witnessing the positive transformation of service users who engaged with HCV care, even among those who did not necessarily take up treatment itself but nonetheless benefitted from additional, targeted care. Here service users noted appreciatively the benefits a more-person centred and holistic form of care than the tired routine of OST dosing that offers little opportunity for ancillary assistance. The provision of peer support in two sites was also reported favourably by both staff and service

users. Alongside the support afforded individual service users, the presence of peer workers was credited with improving the atmosphere or culture of the clinic.

There remains a prevalence of treatment exclusion that is unique to OST when considered within the broad domain of clinical treatment provision, let alone the principals of harm reduction. Systemic shortcomings such as this hold critical implications for the successful introduction of HCV care and treatment into Australian OST settings. While the initial qualitative data emerging from ETHOS pilot sites suggest cause for cautious optimism they do not negate the need for sustained attention to be paid to the stigmatisation embedded in the everyday institutional practices and culture of OST. We also note the influence of self-selection: clinics volunteered to participate in the ETHOS trial and as such were willing to accommodate such organisational and cultural changes as documented here. It is important to emphasise that our intention here is not to undermine the value of Australia's OST program nor to negate the differences that exist across OST services and between the philosophical approaches of individual workers but to focus specifically on some of the shared, troubling aspects of its culture and practice, with particular reference to the potential implications they hold for the introduction of HCV care and treatment. One initial and encouraging finding emerging from the ETHOS study suggests the potential for the introduction of HCV care and treatment into OST settings to challenge, and even change, problematic aspects of OST culture and care.

Photographic credits: cover © Suzanne Fraser, page 3 © iStockphoto/bikeitup, page 6 © iStockphoto/stockcam, page 7 © Flickr/Ivory Illusion

