

Hepatitis C

testing & treatment:

A personal & research perspective

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THE CENTRE
FOR RESEARCH ON DRUGS
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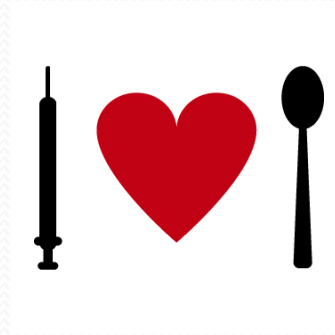
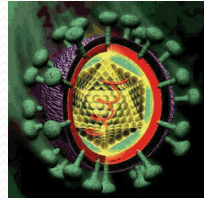


Overview

- A personal introduction
- The research
- Hep C: State of play in the UK (some facts & figures)
- Testing: barriers & benefits
- Treatment: decisions, provision – what works, benefits
- Gratitude or entitlement: time to mobilise!
- Conclusions & recommendations

A personal introduction....

- Heroin
- Hep C – diagnosis
- Heroinalcoholbenzosspeedpotheoin...
- Prison / rehab
- Hep C dilemmas / research
- Hep C treatment
- UK!





The research

- *Staying Safe (2009 – 2012)*

Q: What helps long term injectors stay hep C free?

Sites: Brixton and Islington, London

Interviews: 38 PWID (2 interviews & life timeline)

- *Hepatitis C treatment study (2011 – 2012)*

Q: How well is hep C treatment provided in D&A settings?

Sites: 2 partnerships between D&A and hospital services

Interviews: 36 service users & 13 service providers



State of play in the UK

- 216,000 people with chronic hep C (Globally 170 mill)
- 90% of new transmissions related to drug injecting
- 49% injectors hep C positive (65% London & Nth West)
- Interferon & ribavirin treatment successful for 50-85%
- Only 3% of all diagnosed treated each year
- NICE 2004: current injectors eligible for treatment



Testing: barriers

“The NTA guidelines are about offering [testing]. They're not about delivering. And those two words are extremely different” (Hepatologist 1)

“I kept on saying to [nurse], ‘Look, you know, my veins are a nightmare, you know, let me do it’. [She said] ‘Oh you people, you think you know about your veins and all that, when you know nothing’. (Dillon, SU, HCVtx)



And benefits ...

“When I was in prison I was paranoid in my head. I am, I am, I am HIV. I was sure in my head ... When they said, yeah you are negative, I was what? Even hepatitis C? Yes. That is not possible.” (Marco, SU, SS)

“As long as I know it’s curable then I can face it”.
(Max, SU, SS)

“As soon as I found out I wanted to know how to get this out of the way. What treatment could I do to get rid of it? ... So I knew. Not knowing where you stand is worse than knowing, I think.” (Jeff, SU, HCVtx)



Treatment decisions

“[My key worker] just died recently from hep C ... I know stuff has been going on in my liver the last couple of years. I can feel it, I’m just constantly tired ... I went to the key worker’s funeral and there was quite a few people that I knew there and I knew they were hep C and we were all thinking the same thing, ‘Shit, we need to get this sorted’.” (Dillon, SU, HCVtx)

“I feel that I’ve got a disease and it’s not nice ...It's in the back of your mind all the time.” (Marty, SU, HCVtx)

“I didn’t realise that you could be on treatment if you’re using occasionally. When I heard that, I told them, ‘Well in that case, I want to start the treatment straightaway’.” (Ben, SU, HCVtx)



Treatment in D&A settings

“I wouldn’t have gone to hospital [for hep C treatment]... I was really badly treated and I know loads of people that have been treated abysmally down there, really blatant discrimination.” (Len, SU, SS).

“We’re going to a place that’s convenient for patients, it’s a place they know, it’s a place they feel comfortable, it’s a place where their key worker can come to the consultation too, if they want. They can coincide it with any appointments they’ve got there. It’s good for us for learning, for seeing what the drug and alcohol setting is like, what issues they face.” (Viral Hepatitis Nurse, Hospital)

Flexibility

- Appointment times

“We’re quite flexible about seeing patients, we don’t necessarily have an appointment system .” (BBV nurse 1, D&A)

- Phlebotomy

“I’ve had clients that say “you’re not testing me because nobody can get blood off me” ... [I] listen to them because very often, they do know where the vein is because they use their veins to inject so they know which veins.” (BBV nurse 2, D&A)

- OST provision

“Knowing that I’ve got it [methadone] there, to wake up to in the morning. I haven’t got to rush out to get it at the chemist ... I get it weekly, I’ve been trusted for a long time” (Matt, SU, HCVtx)



Service user involvement

“I said to [hospital] it’s a good time for peer supporters to be involved [in hep C treatment], **but we want something in return.** So they’ve offered us any training that we want, anything to do with blood, which is cool” (Len, SU, SS)

“When we started treatment, [hepatologist] went and saw 3 or 4 patients. He [asked] ‘**what do you think of the service, what could we do better**’ and they really appreciated that, because it’s valuing their opinion and their input because they’re the ones who are using the service.” (Viral Hepatitis Nurse, Hospital)



Treatment: benefits

“For once I'm actually sticking to something and doing something. Because usually I fuck things up, so **I feel really proud of myself for sticking through it** [treatment] ... to get this far that's even an achievement for me.” (Alec, SU, HCVtx)

“**I don't think I'll be going back to injecting drugs...**The treatment's really handy in the sense that I'm going to jeopardise so much if I use.”
(Sam, SU, HCVtx)



'Gratitude' or entitlement?

I like the drug user clinic, it's a lot of fun and you get a lot more bang for your buck **because they're so grateful** that someone's bothered to turn up and see them. **They have such low self esteem, they won't make a fuss, and they really don't jump up and down.** The idea that tranches of people with haemophilia could not be offered hepatitis C treatment because it was inconvenient or something, it's just an extraordinary concept and they would make a huge fuss, but the drug users just accept that **they're not worth it and they won't go there.** I see that as one of the hidden benefits, that actually we're raising people's self esteem, giving people a leg up. (Hepatologist 2)



Together we stand?

I felt like the attitude [in hospitals] is like we're busy enough as it is ... **They're [service users] not high on the political agenda, you know, they're not, generally speaking, they're not tax payers, they're not voters, they don't vote really. They might have the right to vote but they won't vote, you know, they're not high on the political agenda for whoever. (BBV nurse 1, D&A)**

Frankly, until patients or until clients take a grip and **start to advocate for their own health needs in a much more focused and proactive way, then they're going to be seen as silent populations that aren't that important (Hepatologist 1)**



Conclusions

- Service users experience a number of barriers to testing & treatment – especially in hospital settings
- Treatment & testing in D&A services – increased flexibility
- Fostering an environment of trust & respect
- HCV testing & treatment: many benefits
- Time to ‘make a fuss’! Service user deservedness & demand for exemplary services



Recommendations

- Taking testing and treatment to service users (outreach, D&A services)
- Service user involvement
- Tailored phlebotomy services
- Flexible OST provision
- Flexible appointment policies
- Enhanced HCV information provision
- Training : Service users and service providers
- Service user activism & advocacy!



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