

The role of enhanced health and hepatitis C literacy

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*European Conference on Hepatitis C and Drug Use
23-24 October 2014, Berlin.*

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The state of play

- **Prevalence**

~15 million people living with HCV in WHO European Region.
PWID from 21% (Finland) to >90% (Estonia)

- **Prevention**

90% new cases due to use of unsterile injecting equipment

- **Testing**

Only 10-40% of people diagnosed

- **Treatment**

From 16% (France) to <1% (Romania, Poland, Greece, Russia).

Few treated are current PWID.

Where HCV tx free & PWID eligible, PWID often denied access



What is the role of hep C literacy?

- For prevention

- Enhance safe practices

- For testing

- Reduce rates of undiagnosed

- For treatment

- Increase access to & uptake of HCV treatment

- For health

- Enable engagement in health care & HCV self management

- For empowerment

- Enhance needed advocacy & activism



Prevention

- Confusion still abounds
- NSP based on a HIV prevention model
- Missed opportunities for hep C information provision

Through them years, I have used a spoon that maybe someone else has used, but I've never used dirty works. You know, nothing dirty. (Max)

You should always have your own works. I didn't really pay too much attention to spoons. (Bruce)

"I shared with him because he was never unfaithful to me", Helene



Testing / diagnosis

- UK: 36% of PWID attending drug services have never received a HCV test
- Widespread drug worker & GP ignorance reported

I've had boosters for hep C. I'm not due anymore boosters now. (Colin)

I was only diagnosed last June, but I had been backwards and forwards to the GP for many years just unwell and they did loads of tests, even gave me a hysterectomy, full hysterectomy, had the lot out ... so I don't know if that was necessary or not. (Jane)

- The value of peers

"I've never had a test. I don't want a test..."

"I don't feel I'd be strong enough in my mind if I did have it to handle it."

"As long as I know it's curable then I can face it." (Max – over 3 interviews)



Treatment

- Little knowledge among PWID about eligibility for treatment
- Little knowledge about new treatments on horizon
- Few referrals & treatment assessments despite eligibility

With the treatment, you can't use or drink alcohol or anything on top (Ivana)

I think their exact words were 'it's an expensive drug, you're using on top and we're not treating people who are using, because you could get re-infected couldn't you?'. (Shane)



Health

- Desire for knowledge about cirrhosis, natural progression of HCV, injecting related issues (venous access, wound care etc)

I just want to know what's going on with me, these pains, what do the pains mean? Can you tell, what is my [life] expectancy? ... It's scary because you haven't got a clue what's going on. (Frieda)

Sometimes I just can't get [the femoral vein] look, I got two fingers here, can you tell me where the best place is to go? (Helene)

I've never felt comfortable with any GP because, in the past, when you've gone to a GP, you say "I wonder if you can help me, I take heroin..." "(exclamation of horror) sorry, I don't deal with that here." (Fred)



Empowerment!

- Information → advocacy → action
- Peers should be central to any information interventions
- HCV & PWID health literacy inadequate among healthcare workers
- Moralism / discrimination & treatment denial common
- Need to move from a responsabilising to rights-based approach

From info resource under development (UK):

*All people with hep C are **entitled** to assessment and, unless there are medical reasons not to such as pregnancy, are also **entitled** to treatment.*

*HCV treatment **must be considered for PWIDs**, provided they wish to receive treatment. (EASL, hepatitis C treatment guidelines 2014)*



The proposal

“We strongly recommend the development and implementation of standardized training for healthcare workers and for people who use drugs on HCV prevention, treatment updates and drug use issues”.

Actions:

- Develop & implement EU and nationally supported training programs
- PWUD and their organisations must be at the centre of health and HCV literacy measures.
- Dedicate funding for healthcare worker training & interventions
- Fund PWUD peer-based organisations to produce and provide education and training, addressing gaps in knowledge among healthcare workers and peers in regard to cultural and specific needs of PWUD

Acknowledgements

- Data is drawn from three LSHTM HCV qualitative research studies:
 - The HCV Treatment Journey
 - HCV treatment access for PWID barriers & facilitators
 - Staying Safe
- The LSHTM HCV study participants
- The LSHTM HCV study partners and study sites
- The LSHTM HCV study funders
- The Correlation Network
- Magdalena Harris is funded by a National Institute of Health Research Postdoctoral fellowship: NIHR-PDF-2011-04-031

