



Beyond the 'empty warehouse': exploring barriers and facilitators for reaching those 'next in line' for the new HCV treatments

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Acknowledgements



- ▶ Traditional owners of the land
- ▶ Collaborative effort of the AIVL staff team on the projects presented today
- ▶ The courage and determination of my peers across the world who persist despite often life threatening circumstances

Who is AIVL?



- ▶ The Australian Injecting & Illicit Drug Users League (AIVL) is the national organisation representing people who use/have used illicit drugs and is the peak body for the state and territory peer-based drug user organisations.
- ▶ AIVL operates on a **peer-based, user-centred** philosophy, which means the organisation is run *by* and *for* people who use/have used illicit drugs

HCV – what are PWID telling us about their experiences?



- ▶ **Drawing upon several AIVL projects and initiatives:**
- ▶ Hepatitis Awareness Project (commenced in 2015 and concludes beginning of 2017)
- ▶ Hepatitis Connection (website launched on World Hepatitis Day 2016)
- ▶ Stigma and Discrimination Survey Report – “We live with it almost everyday of our lives” (2015)
- ▶ Re-use of injecting equipment report – “No one likes using the dirties (2015)”

Barriers



- ▶ Lack of knowledge of what type of test had been performed (antibody, PCR, RNA)
- ▶ Informed consent
- ▶ Where and when to access information re HCV

Barriers cont....



- ▶ Legacy of previous treatment regimens
 - ▶ – biopsy
 - ▶ – severe ‘side effects’
 - ▶ – low success rate
 - ▶ – exclusions based on current injecting

- ▶ Fear of ‘letting the new treatments down’
 - ▶ – these new ‘miracle’ drugs are really expensive, what if they don’t work on me?

Barriers cont...



- ▶ AIVL's survey on stigma and discrimination found that the two most common places PWID experience stigma and discrimination is while **seeing a doctor or prescriber** or at a **hospital**. This is followed closely by the **pharmacy**.
- ▶ This has serious implications for both testing and treatment with the new HCV medications

Stigma and Discrimination – where does it come from and what does it look like?



- ▶ Impact of Criminalisation:
- ▶ Marginalises drug user and drives them ‘underground’ making them hard for mainstream services to reach
- ▶ Isolates – drives drug users away from services and the support of family and friends
- ▶ Reduces options – leads people to take risks and do things they may not ordinarily do (like commit crime).
- ▶ Compromises Health and Wellbeing – put up with chronic, painful, frightening and even life threatening conditions due to fear of accessing services
- ▶ Stigmatises – by devaluing drug users as people and as members of the community – stigma dehumanizes people
- ▶ Shames – makes them too guilty and ashamed to come forward for assistance, treatment and support...

Stigma and discrimination



- ▶ – PWID become accustomed to being denied basic health services and as a result may not advocate for their own health needs
- ▶ – Women describe being fearful of having children removed from their custody and therefore often avoid health providers
- ▶ – Aboriginal people describe feeling ‘surveyed’, ‘monitored’ or ‘harassed’ when accessing basic health services such as those provided by NSPs and will therefore try to avoid contact with such services

Stigma and discrimination



- ▶ Getting ‘the look’ when disclosing current or previous drug use or HCV status
- ▶ Perpetuated by stereotypes of PWID – untrustworthy, unclean, violent..

What can be done about stigma and discrimination?



- ▶ Can be addressed by targeted training and education of health providers around stigma and discrimination and the poor health outcomes associated with this – e.g HETI training based on AIVL training module
- ▶ Drug law reform advocacy
- ▶ Peer support and resourcing of peer based organisations

What works? How to work with and speak to PWID



- ▶ Peer education and support – Hepatitis Connection
- ▶ Hepatitisconnection.com.au

AIVL HCV Campaign

**FIX
HEP C
IN 3**

1 Antibody Test
test for exposure
to the virus.

Negative*
not exposed.

Positive*
exposed to
Hep C virus.

2 Virus Test (PCR RNA)
test for ongoing
Hep C infection.

Negative*
no Hep C infection.

Positive*
ongoing Hep C infection.

3 Treatment
a cure is available now.
talk to your doctor about it.

AIVL
Australian Injecting & Illicit Drug Users League
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*practise safer injecting, whatever your Hep C status.

Dr Angella Duvnjak Viral Hepatitis
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What works?



- ▶ Meaningful engagement and participation of the PWID community in education and communication forums
- ▶ Collaborate and support DUO in our work
- ▶ Challenging systemic and ingrained stigma and discrimination wherever you find it

What works?



- ▶ Above all PWID need to be viewed as part of the solution not as ‘vectors’, ‘transmission networks’, ‘non compliant’, ‘at risk’ or any number of other ‘catch all’ terms.
- ▶ We are as diverse as any other population and we are as invested in our well being and health as anyone else.



- ▶ Thank you.
- ▶ Copies of reports mentioned today can be found on our website at:
- ▶ aivl.org.au