

WORKING WITH PWID TO BUILD RELEVANT MODELS OF CARE

INHSU 2017

SIONE CRAWFORD; HEP VICTORIA

BACKGROUND



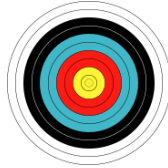
**14 years embedded in affected community work—
predominantly peer based organisations – personally
affected (since mid 90s)**

Community response impt in Australia re BBV

**BBV/HCV prevention/treatment; Health promotion;
community development; peer ed and peer support; policy
development; program and organisational management**

ELIMINATION

DAA = wonderful opportunity



2030?

Elimination not eradication

Those people who inject who are most marginalised and isolated from society and healthcare – *people not even considering Tx right now* - MUST be engaged if we are to achieve this

This will be who misses out on elimination if we do not focus on this population

A DIFFICULT HISTORY

HCV treatment access *has* improved for PWID – but this is recent and it isn't case for everyone

It is still a medical intervention delivered by a system perceived by users to have failed us time and time again

Primary care and PWID both locked out of treatment 20+ years – and many users have awful experiences of primary care as well

Poor treatment and discrimination still echoes through the using community

DAAS



PEER ED & SUPPORT

Works to improve outcomes but more evidence / research required

Growing body exists however

Generally peers provide an interface between a medical service or intervention and people who use / inject drugs but can do so much more

Of great benefit to service models that are not entirely fit to deliver HCV Tx people who use drugs or which have competing priorities

A FEW PEER MODELS

ETHOS – NSW Australia

Peg IFN/RBV days

- OST Settings
- 1 to 1 peer support / group support
- In some cases peer worker part of larger OST team
- Supported by Drug User Organisation and by clinicians

Community NSP model - NZ

- Peer based needle syringe program partner with community nurse to focus on most marginalised injectors

EC & Peer Networker project - VIC Australia

- peer educator referrals to treatment

PEER MODELS

Integrated Peer Educators

Peer groups and peer navigators incorporated into service models

Often an integrated service model incorporating psychosocial drug treatment along with HCV treatment (Sylvestre 2007)

Concurrent Group Treatment (Stein et al. 2012; Grebely et al 2010)

Integrated with OST – (Roose et al 2014)

A number of peer educators and navigators are here this week from Montefiore and more and can speak to their work

ONE STORY

Minh is in his early 30s

Currently homeless; estranged from family; injecting opioids daily; not on OST; had an HCV RNA test 3 weeks previous

Both he and partner have DVT. In his case this was his 3rd DVT and he had cellulitis also and a serious leg infection

Attended hospital but had negative experience and left.

NSP workers spent 3 days trying to get him to hospital

Agreed to alternative hospital – on other side of city

Workers went with to Emergency and waited to support thru intake – hours of waiting

Methadone and pain relief was arranged with hospital

CONT...

Surgery required followed by 6 weeks of IV antibiotics

2 days after surgery Minh left – had received no methadone or pain relief

The NSP workers had been providing blood thinners to his partner and are now giving antibiotics to him daily as well.

Unfortunately a lesion has opened up on his leg.

He's still homeless but is able to access pain relief and opioids – just not from a doctor

Meanwhile he still hasn't received his RNA result. But I don't think that's top of his mind

CASCADE OF CRACKS?

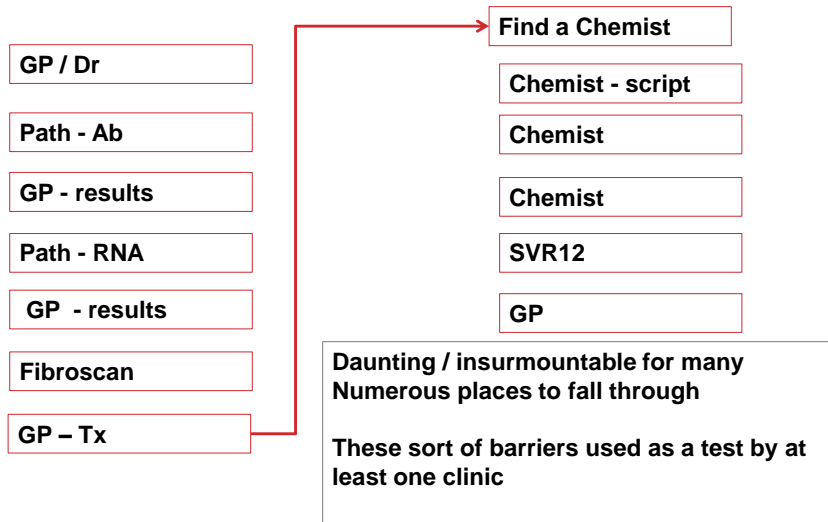
PWID often alienated from healthcare systems

Cascade of Care for HCV Tx is a Cascade of Cracks to fall through

Even with primary care engagement Tx journey is fraught:



BUMPY JOURNEY



7 LIVES; 7 DEATHS

Preventable deaths & preventable illness still takes an enormous toll

M – Bowel Cancer

C – Unconfirmed – heart failure?

J – Opioid OD

Cam - Opioid OD

Tom – Opioid OD

K – Unconfirmed Heart Failure

R – Liver Failure

Just one death related to HCV

All are reflection of a system that seems to fail us

PRIORITIES

Core activity is illegal



Criminalization drives cost higher ...
revenue raising takes time &/or risky



Avoiding sickness & juggling withdrawal symptoms; OST & life/work/family

Injection equipment; Venous access; Wounds & Abscess care;
Naloxone / OD reversal

Housing; family issues; other chronic illnesses

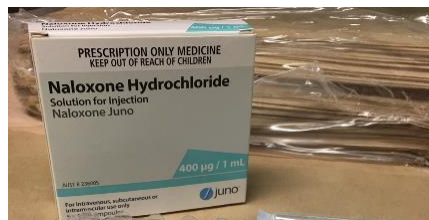
SERVICES FOR US

Treatment must be linked to immediate material change and benefit
- often this is harm reduction

Or must be linked to places we seek these things out –

Needle Syringe Programs; drop-in centres; charity; housing /
homelessness services and co-ops; User Organisations, community
organisations and so on

Services must recognise our priorities and must be open to working
around them and with them



ROLES FOR USERS

Systems Level

Contributing to government and other policy development – either as individuals or representatives

e.g. invited to regulatory committees for HCV DAA approvals

OR position statements / contributions to legislative committees etc

OR engaged on government drug / disease strategy development

Engagement in research planning and dissemination / translation

ROLES FOR USERS

Organisationally

As community statement mentioned we do have things to teach service providers.

Often service providers are great at helping others but not great at being helped by us

e.g. consumer committees; consumer reps on organisational committees and even employment panels; stigma and discrimination training for staff; policy review

Often Services happy to have a suggestion box but not happy to have a service user on an employee review panel....baby steps may be needed

ROLES FOR USERS

Directly

As advocates for local change

As educators and support workers; as trainers - for service providers not just other users/peers

We need to have spaces to say what we really want and need. It may not be hep c treatment right now

With support peers can close many of those cracks in the cascade discussed earlier

SUGGESTIONS

Build relationships with us to build trust – with individuals as service users; with organisations as advocates and partners –let us help you build effective models of care. Researchers also

Peers must be valued and understood as a core component of a service - paid, contracted and planned for long term

Sustainable, independent representative organisations - they can say the difficult things that a paid peer employee may not feel safe saying – these exist all over globe but need resources

SUGGESTIONS

As in the case of Minh – sometimes services need to go more than the extra mile for people. Usually peers are those who are most willing – but we all have to

More than “hand- holding” – need robust advocacy both by users and by service providers / clinicians - coordinated

Seriously consider embedding peers at every place along the cascade of cracks and at every level of service provision – including treatment delivery.

Be aware of why we might be using the language of recovery

CRITICAL PLACES

OK – so if you can’t have peers everywhere what are the key locations?

ASK your community first..

In the community referring to treatment. Also prison to Tx

- HRVic PNP project and Hep Vic prison with Burnet

-Blood collection and workup period (esp following Ab tests)

-Post Tx pre SVR 12 – massive chasm

- As research partners – yes on advisory groups but also planning priorities long term

FINALLY



We need you to recognise our priorities

We respond to our needs being fulfilled

We need material change and benefits from Tx engagement

We need treatment linked to places we can get what we most need – NSP; OST; housing; etc.

We need to improve User Health generally

Re-read the Community Statement for inspiration!

THANKS

Thanks especially to:

Annie Madden / Charles Henderson / Jenny Kelsall

**Sam from HRVic, amazing local community here in NJ/NY
and in Australia**