Breaking through the “Cascade of Scare”

Peer-led community hepatitis C testing and treatment navigation through HepLink DBS

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Why peer-led testing matters

People from priority populations living with hepatitis C often face stigma, fear of diagnosis, past negative healthcare experiences, unstable housing, mental health concerns, incarceration, limited contact options and low connection to mainstream health services. These barriers can create a “cascade of scare”, where people disengage after testing or diagnosis even though highly effective treatment is available.

Reducing the ‘Cascade of Scare’

HepLink DBS, a Hepatitis NSW program funded via Hepatitis Australia†, uses peer-led Dried Blood Spot testing in community settings where people already access non-clinical support, including food kitchens, shelters, opioid agonist therapy services, Needle Syringe Programs, community events and at a weekly pop-up clinic delivered via the ACON NSP. Peer workers provide a trusted, non-clinical entry point, explain testing, address treatment myths, obtain consent for follow-up and connect participants with clinical partners for confirmatory testing and treatment.

30 outreach events	40 pop-up clinics	605 DBS samples collected	334 people tested through outreach
16 partner sites engaged	1,251 contact attempts	69%* successful follow-up contacts	64%** HCV RNA+ participants supported onto treatment

Challenges and changes

Peer-led DBS testing reached people who may rarely test through mainstream services. Follow-up remained challenging, but persistent outreach and service partnerships enabled seven of 11 people diagnosed as HCV RNA positive to commence treatment, exceeding the program target of 50%. One participant has confirmed SVR-4 and SVR-12, with further treatment completion outcomes pending through clinical partners.

What we learned

HepLink DBS highlights the effectiveness of peer-led outreach and Dried Blood SPot testing for engaging priority populations who may otherwise not access hepatitis C testing and care. Peer workers were critical to building trust, increasing participation, and supporting people through treatment pathways. Strong partnerships with community services and Local Health Districts also improved access and follow-up outcomes.

Key challenges included difficulties contacting participants due to unstable housing, incarceration, lost phones, and other social factors, resulting in significant effort being required to achieve follow-up contact. Delays in receiving positive test notifications and the requirement for a confirmatory venous blood test also created barriers to treatment initiation.

Ultimately, strengthening peer-led models; collecting multiple contact methods and utilising partner services to support follow-up; maintaining formal data-sharing and notification pathways with clinical providers; expanding flexible treatment options, including remote prescribing can reduce the Cascade of Scare for priority populations.

SNAPSHOT 1: NO PHONE, NO EMAIL

A participant could not be contacted directly. Peer follow-up through the testing-site support worker and a medically supervised injecting centre enabled result confirmation and treatment commencement.

SNAPSHOT 2: RESULTS TO CURE

A participant attended the Hepatitis NSW office after site-based follow-up, received results through SHIL, was referred to Kirkton Road Centre, commenced treatment and later achieved SVR-4 and SVR-12.

SNAPSHOT 3: FROM AMBIVALENCE TO ACTION

One participant initially said he did not care whether he had HCV. Peer discussion about lived experience, simple treatment and cure helped re-engage him; he was referred to Storr Liver Clinic and commenced treatment.

SNAPSHOT 4: CONTINUITY THROUGH CUSTODY

A participant commenced treatment shortly before entering custody. Liaison with clinical partners and community corrections enabled treatment to recommence, demonstrating the value of flexible cross-service coordination.

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† **Disclosure of Interest Statements** HepLink DBS is supported by HepLink which is administered by Hepatitis Australia and funded by the Australian Centre for Disease Control.

Phillip Read has received honoraria for speaking from Gilead Science and AbbVie.