

From lived experience to cure: Activating hepatitis C notifications

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Background

Despite improvements in hepatitis C (HCV) testing and diagnosis in Australia, many people do not proceed to treatment. Notification systems present an important yet underutilised opportunity to bridge the gap between diagnosis and care. Bridging surveillance data and timely care requires meaningful engagement with people with lived experience and healthcare providers. Connect C aims to explore community-informed changes to surveillance, follow-up, and care pathways to strengthen treatment linkage and engagement.

Methods

From 2024 and 2026, Connect C convened co-design workshops in the Northern Territory and Queensland, engaging people with lived experience, health providers, policymakers and community organisations. Participants explored how notification systems could facilitate linkage between diagnosis and treatment, mapped care pathways, and identified barriers, including legislative and data handling requirements.

Results

Communities and stakeholders in both jurisdictions strongly endorsed the model. There was agreement that with community partnership, barriers to using notifications data more effectively to link people into care can be overcome. Participants valued contributing to solutions and provided clear guidance on the supports needed to enhance engagement in follow-up and treatment. Co-designed solutions clarified roles, streamlined referral pathways and embedded peer-supported approaches. Key insights were consolidated into consensus statements guiding regulatory and data recording reforms, enabling systematic follow-up and improved linkage to care.

Conclusion

Centring community voices and lived experience enables meaningful reform of notifications and care systems. Integrating community health services and peer support into the active use of notifications data shifts health systems from passive reporting to actively supporting people into care, and for HCV, towards cure. The Connect C model demonstrates how co-designed, consensus driven approaches have the potential to overcome barriers to notification data use, strengthen treatment linkage, and provide a transferable framework for HCV elimination and other communicable diseases in Australia.

Disclosure of Interest Statement:

The Burnet Institute recognise the significant intellectual contribution that our partners, namely state and territory' Departments of Health, make to Connect C's research activities. Furthermore, we recognise the need for transparency of disclosure of potential conflicts of interest through acknowledging these when sharing publicly the work of Connect C.