

EXPLORING THE POTENTIAL USE OF NOTIFICATION DATA TO INCREASE HEPATITIS C TREATMENT UPTAKE

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Background: In Australia, the unrestricted and subsidised availability of direct-acting antivirals has made hepatitis C elimination possible. Recent declines in treatment uptake, however, suggest achieving this goal less likely. Notifying hepatitis C diagnoses to jurisdiction health departments is mandatory in Australia and there is growing interest in the potential use of these data to link people diagnosed with hepatitis C to treatment services. However, little evidence exists on the acceptability and feasibility of this approach. Our study aimed to address this gap and guide future strategies to improve hepatitis C treatment uptake.

Methods: Twenty-seven people with lived experience of injecting drug use and/or hepatitis C participated in two focus groups to explore their views on using notification data to locate people diagnosed with hepatitis C and seek to engage them in care. Individual interviews were also conducted with 20 government, clinical, research and community sector key informants to further examine ethical, logistical, and regulatory implications of implementation. Data was analysed thematically and presented using participant narratives.

Results: There was overall consensus that the potential benefits of using notification data to increase engagement in hepatitis C care outweigh potential harms. There were, however, a range of ethical and logistical concerns that such an approach could exacerbate stigma and discrimination for an already marginalised group. In the context of these concerns, conflicting views were expressed regarding the best potential method of contact (including in particular by whom) and if record linkage should or could feasibly be used to enhance follow-up.

Conclusion: Results demonstrate the potentially significant benefits that could be gained by using notifications data to increase access to hepatitis C treatment. Novel approaches to better and cautiously utilise notifications to guide care pathways could improve hepatitis C elimination efforts and prevent hepatitis C-related morbidity and mortality.

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