

USING HISTORIC NOTIFICATION DATA TO INCREASE ACCESS TO THE HEPATITIS C CURE: KEY STAKEHOLDER PERSPECTIVES

Authors: Latham NH¹, Wallace J¹, Walker S^{1,2}, Higgs P^{1,3}, Pedrana A^{1,4}, Doyle JS^{1,4,5}, Hellard ME^{1,4,5,6,7}, Stoové M^{1,4}

¹ Disease Elimination Program, Burnet Institute, Melbourne, Australia

² National Drug Research Institute, Faculty of Health Sciences, Curtin University, Bentley, Australia

³ School of Psychology and Public Health, La Trobe University, Bundoora, Australia

⁴ School of Public Health and Preventive Medicine, Monash University, Melbourne, Australia

⁵ Department of Infectious Diseases, The Alfred Hospital and Monash University, Melbourne, Australia

⁶ Peter Doherty Institute for Infection and Immunity, Melbourne, Australia

⁷ School of Population and Global Health, University of Melbourne, Parkville, Australia

Background: Government notification systems in Australian jurisdictions record information about individuals who test positive for hepatitis C. While these large datasets present opportunities to improve case finding, linkage to care, and treatment, such processes also raise practical and ethical issues, particularly relating to privacy. We aimed to characterise these issues and explore the acceptability of using historic notification data for linkage to care in Australia.

Methods: Twenty representatives from community organisations, jurisdictional health departments and academic institutions participated in semi-structured interviews. As well, 27 people with lived experience of hepatitis C and/or injecting drugs participated in focus groups convened by community organisations. Transcripts were thematically analysed.

Results: Interviewees broadly supported using historic notification data for linkage to care. However, views diverged on operational issues: method of contacting cases (e.g., mail, telephone, SMS), who should make contact (e.g., diagnosing or current clinician, health departments, peers) and the acceptability of using data linkage to obtain current contact details. Some jurisdictions felt that using historic notification data for case finding was within the scope of existing legislation; others felt amendments were required. Most focus group participants were unaware that hepatitis C is a notifiable disease and expressed concern about inadvertent privacy breaches in light of the stigma associated with hepatitis C. Within the focus groups there were divergent views on the practicalities of contacting people without breaching privacy: how contact is made, who makes contact (e.g., a doctor who knows the case, health departments, peers). Nonetheless, participants expressed in-principle support for using historic notification data to improve access to treatment.

Conclusion: There was overall support for using historic notification data to improve linkage to care. Diverse views regarding how this can practicably be done highlight the importance of co-design initiatives if widespread use of notification data for linkage to care is pursued.

Disclosure of Interest Statement: The Burnet Institute acknowledges funding received from the Paul Ramsay Foundation.