Hepatitis C data justice: The implications of data-driven approaches to the elimination of hepatitis C

Lenton E[1]., Seear K.[1], Kagan D.[1], valentine k.[2], Fraser S.[1,3], Farrugia A.[1,4] and Mulcahy S.[1]

[1]Australian Research Centre in Sex, Health and Society, La Trobe University, Melbourne, Australia; [2]Social Policy Research Centre, University of NSW; [3]Centre for Social Research in Health, University of New South Wales; [4]National Drug Research Institute, Curtin University.

Background

Globally, rates of hepatitis C treatment uptake have declined. Achieving elimination by 2030 is inspiring novel methods to find, diagnose and treat the 'missing millions' of people with hepatitis C. Public health approaches that use data-driven approaches including case finding, departmental notification and contact tracing are increasingly being developed and implemented to reach the elimination goal.

Method

Drawing from interviews with policymakers, lawyers, peers and others who work with people affected by hepatitis C (N=30), we explore they perceive the use of data-driven interventions to achieve elimination. Following Molldrem and Smith (2020), we interpret the interviews via the notion of hepatitis C 'data justice'.

Results

While there was some enthusiasm for data-driven interventions, several concerns were raised. Stakeholders were suspicious of the development of data collection processes and systems, or they believed that people with hepatitis C were. Some expressed concerns about the sharing of people's health data without their informed consent or prior knowledge, and worried that while systems offer putative protections for patient rights, they depended on a high level of legal health and data literacy. Concerns that data-driven approaches could perpetuate hepatitis C-related stigma and discrimination were also raised.

Conclusion

Hepatitis C elimination goals have created a strong mandate for the expansion of data-driven approaches. Given the marginalisation and stigmatisation of people affected by hepatitis C, the implementation of these interventions raised numerous ethical concerns among stakeholders. Following Molldrem and Smith's (2020) argument for HIV 'data justice' we interpret these concerns as a call for hepatitis C 'data justice'. This approach helps us account for complexities, risks and challenges, and critique what is at stake for those affected. In concluding, we argue that data-driven interventions must foreground social justice concerns and ensure the rights of people living with hepatitis C are preserved.

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