Medical records and stigma production: Insights from a national research project to reduce stigma in healthcare

Authors:

Lenton E¹, Seear K¹, Cama E², Lemoh, C³ and Treloar C²

¹Australian Research Centre in Sex, Health and Society, La Trobe University, ² Centre for Social Research in Health, University of New South Wales, ³ Western Health.

Background: There are growing calls to address blood borne virus-related stigma including through systemic and structural reforms. This paper explores the links between health information technologies including electronic medical records, case notes and clinic narrative profiles, and stigma and considers whether these systems and practices might require reform as part of a wider stigma reduction initiative.

Methods: Fifty interviews were conducted with key stakeholders with extensive experience in the BBV health sector (n=20), and clinical and non-clinical healthcare workers (n=30) as part of a larger project trialling a 'universal precautions' approach to stigma reduction. Participants were asked to identify institutional and organisational level practices and policies that produce or have the capacity to reform stigma.

Results: Interview participants expressed numerous concerns and tensions about the practices of medical record keeping and stigma for people living with (histories of) BBVs/STIs. Our analysis is set out in two themes, informed by literature that recognises stigma is a social and political construct and inheres in institutions. First, we identify the ways participants reported medical records are technologies that (re)produce stigma. Second, we examine how access to health records and the use of alerts across and between healthcare services are rarely bounded by privacy and confidentiality requirements, and the problems associated with this visibility to medical information and clinic profiles.

Conclusion: We conclude by highlighting how electronic medical management systems are adapting and evolving, and the opportunities to intervene in the re/production of stigma afforded by these universal forms of communication. Further education and training on language and stigma-sensitive communication to inform the content of these communications is required. However, importantly, careful consideration is required in the development of these systems, ensuring the flow of health information does not breach privacy laws and regulations and produce stigma in future health encounters.

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