

Why trust digital health? Key informant perspectives on the promise and risks of digital health for priority populations in the Australian HIV and STI response

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Background:

Despite extensive government investment in expanding digital health systems, minimal research has documented community views on these systems in Australia. And there has been almost no research on the perspectives of populations affected by blood-borne viruses (BBVs) and sexually transmissible infections (STIs). The Trust in Digital Health study was conducted by CSRH in collaboration with community organisations representing four of the priority populations in the current national BBV/STI strategies: people with HIV, trans and gender diverse people, sex workers, and gay and bisexual men.

Methods:

We conducted qualitative phone/computer interviews with 16 key informants holding expertise in policy, advocacy, education, research and health promotion across one or more of the priority populations and/or in relation to digital health. The purpose of the interviews was to identify key issues in engaging these communities with digital health systems, and a thematic analysis was conducted of deidentified transcripts.

Results:

In addition to specific issues for priority populations, participants commonly argued that trust in digital health was affected by the (1) the pervasive and persistent stigma and discrimination experienced in health care settings, (2) the criminalisation of particular behaviours related to HIV, sex work, and drug use, (3) and the potential for personal information, particularly about stigmatised or pathologised identities or practices, to be shared without the knowledge or consent of the affected person. Meaningful consultation, law reform, inclusive system design, and mechanisms for community members to control data access were proposed as essential for increasing trust.

Conclusion:

Community stakeholders offered many reasons that populations affected by BBV and STIs may be reluctant to engage with, and therefore realise the promise of, digital health. In addition to driving new technological innovations, resources must be directed towards remediating the social, cultural, and political issues that continue to marginalise some communities from participating in digital health systems.

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