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# Experiences of discrimination drive distrust in digital health

**Communities affected by blood-borne viruses and STIs are more likely to opt out of digital health services, says a new national study.**

People who have experienced stigma and discrimination in health care settings are more likely to distrust digital health services, a new UNSW study says.

The study, [Understanding trust in digital health among communities affected by BBVs and STIs in Australia](http://unsworks.unsw.edu.au/fapi/datastream/unsworks:72141/binecb2e57e-5d67-4639-8b9f-3370b0c619fd?view=true&xy=01), is the first national survey into perspectives on the digital health of populations affected by blood-borne viruses (BBVs) and sexually transmissible infections (STIs).

The report, from [UNSW’s Centre for Social Research in Health](https://www.arts.unsw.edu.au/csrh) (CSRH), surveyed more than 2000 people across Australia from April – June 2020, including 600 people classified as members of one or more populations affected by BBVs and STIs.

People with HIV, trans and gender diverse people, sex workers, and gay and bisexual men reported the lowest levels of trust in digital health care services, such as My Health Record, and the most frequent experiences of stigma.

While these groups reported better knowledge of My Health Record than the general population, they were much more likely to report opting out.

“These communities are highly engaged, well informed and notably reluctant to put their trust in some aspects of digital health,” says [Associate Professor Christy Newman](https://research.unsw.edu.au/people/associate-professor-christy-e-newman), one of the lead investigators from CSRH.

“This suggests that an understanding of the potential benefits of digital systems like My Health Record did not overcome the doubts that these communities considered when opting out.

“More meaningful consultation with affected communities and the peer-based organisations that have their trust is required to ensure that communities affected by stigma and discrimination are not left behind when it comes to digital health.”

### **Criminalisation of stigmatised practices damaged trust**

Those participants who expressed distrust in digital health also reported having fears relating to the criminalisation of some behaviours related to HIV, sex work and drug use.

These groups reported concerns that personal data and health information related to stigmatised identities or practices could be shared without their consent, placing them at risk.

“I don’t have faith in the federal government creating IT infrastructure with the necessary privacy constraints or kinks worked out just yet,” one survey respondent said.

“If there was some type of alert that I could set up that could allow me to consent or withdraw consent for my data being used for something I’d be fine with that but not people just using my data without my knowledge,” another respondent said.

[James MacGibbon](https://www.arts.unsw.edu.au/our-people/james-macgibbon), a chief investigator of the project from CSRH, says: “These communities typically fear that their personal information is more easily shared through digital means without the consent of the affected person, with a range of potential social, legal and economic consequences.

“They do not opt out of digital health initiatives because they don’t understand the promise offered by more integrated and effective data management systems. Nor because they do not have need of these improvements.

“They opt out because they are not convinced the potential benefits outweigh the risk to their personal privacy and security, at least in the form in which they have been designed and promoted.”

### **Stigmatised groups more likely to access digital health care during COVID-19**

Affected groups were also least likely to share personal information with health authorities during the pandemic, but more likely to have made use of digital services to access essential health care.

Affected populations reported higher recent use of online consultations and online pharmacies than the general population respondents. They were also more likely to report stockpiling essential medications and organising online health consultations in the early weeks of the COVID-19 pandemic.

There were particular fears reported regarding the impacts of the COVID-safe app and contact tracing on communities at risk of criminalisation and discrimination.

“I understand the public health importance of this kind of tracing but I think for historically targeted communities it makes sense to opt out,” one survey respondent said. “As a migrant sex worker, I wouldn’t risk it, no matter how well they think they’re doing with digital security.”

“I simply don’t disclose that I am a sex worker, or trans, or queer/asexual unless it absolutely needed because I have had horrific experiences when doing so previously,” another survey respondent said.

“Queer health in many aspects is incredibly moralised and pathologised in contemporary Australia – I don't want my data to be collected by any centralised database for whatever use.”

### **Community groups express concern over consequences of digital health**

Key informants working in advocacy, policy, health promotion and research with expertise in helping communities affected by BBVs/STIs, stigma and marginalisation were also interviewed between March – June 2020.

“While they acknowledged the promise of digital health, these experts were also concerned about the consequences for communities affected by BBVs/STIs in engaging with these systems,” A/Prof. Newman says.

“Rather than viewing this as issues with digital literacy, we can see through our research that it is the relational and structural factors that underpin institutional trust in health care that drive distrust in digital services.”

In tandem with extensive government investment to expand digital health, more effort should be given to addressing the social, cultural, and political issues that continue to marginalise some communities from participating in digital health systems, the study found.

“To address these concerns, we recommend finding new and more effective ways to ensure that consent is secured to collect, store and share health data, and that consent is specific, dynamic, and informed,” A/Prof. Newman says.

“More resources should be directed towards remediating the legal and policy conditions that continue to discourage some communities from participating in digital health, and in supporting meaningful consultation with peer-based organisations who have the trust of communities affected by BBVs and STIs.”

Read the [full report](http://unsworks.unsw.edu.au/fapi/datastream/unsworks:72141/binecb2e57e-5d67-4639-8b9f-3370b0c619fd?view=true&xy=01).

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