UNSW SYDNEY | CSRH Centre for Social Research in Health

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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Acknowledgement of Country

We acknowledge traditional custodians; this presentation was recorded on Bedegal Country. We pay our respects to Elders, both past and present, and to emerging leaders in the Aboriginal community.

We recognise and support the calls in the Uluru Statement from the Heart for a First Nations voice to Parliament, and a Makarrata Commission to oversee a process of agreement-making with governments and truth-telling about the historic and continuing impacts of colonisation on Aboriginal people across Australia.

Investments in Digital Health

- Digital health = electronic health records, mobile apps, wearables, social media and online forums, virtual health consultations
- Optimism that investments in digital technologies are effective for supporting or promoting health **(Australian Digital Health Agency, 2017)**
- BUT ’technoutopian portrayals’ of digital health potentially gloss over unintended and potential risks for new technologies to ‘entrench existing sociocultural disadvantage or social marginalisation.’ **(Lupton 2018, p. 3)**
- My Health Record → transition from opt-in to opt-out
- Concerns from organisations representing sex workers and people living with HIV **(Duxfield, 2018)** → ‘if in doubt, opt out’

Australian Digital Health Agency (ADHA). (2017). Safe seamless and secure: evolving health and care to meet the needs of modern Australia, Australia’s National Digital Health Strategy

Lupton, D. (2018). Digital health: critical and cross-disciplinary perspectives. Routledge.

Duxfield, F. (2018, Jul, 19). Concerns My Health Record could expose sex workers, people living with HIV to prosecution. *ABC News.*

Trust in (Digital) Health?

- Dimensions of (dis)trust important to understand – people need to be able to trust that systems work, and that personal data will be managed sensitively
- OED: ‘firm belief [or confidence or faith] in the reliability, truth, or ability of someone or something’
- Declining trust in institutions – trust ‘can no longer be assumed, it is conditional and has to be earned’ **(Calnan & Rowe, 2008, p. 101)**
- Populations affected by BBVs and STIs continue to experience stigma in health care settings and broader community **(Broady et al., 2020)**
- Limited social research on the perspectives of populations affected by BBVs and STIs regarding trust in digital health systems → ‘Trust in Digital Health’ study

Calnan & Rowe. (2008). Trust matters in healthcare. Open University Press.
Broady et al. (2020). Stigma Indicators Monitoring Project: Summary Report. Phase Two. CSRH Report.

Methods

- Partnership with community organisations representing four priority populations in BBV/STI strategies: people with HIV, trans and gender diverse people, sex workers, and gay and bisexual men
- Semi-structured interviews with key informants (*n*=16) representing priority populations
- Interviews conducted by Christy Newman in March-June 2020 via phone/Zoom
- Reflexive thematic analysis **(Braun & Clarke, 2019)**
- This analysis focuses on factors shaping (dis)trust for priority populations

Braun & Clarke. (2019). Reflecting on reflexive thematic analysis. *Qualitative Research in Sport, Exercise and Health*

Inadvertent or unwanted disclosure

- Health records open up potential for inadvertent or unwanted disclosure
- ‘Trans broken arm syndrome’:

> If you do pursue a physical transition, you can still have health records that are in your old gender, that are floating around. [It] becomes really problematic if, for example, you’re admitted into emergency and you’re unconscious, and somebody pulls up your Medicare for whatever reasons. And then everybody gets really confused and starts focusing on that as opposed to anything else **[P10]**

- Similar experiences for others, especially people who inject drugs

Stigma, discrimination, and trust

> I don’t think there’s any such thing as full trust between patients and doctors. There are functional levels of trust.
>
> […]
>
> I cannot think of any circumstance in my life [or in] the lives of anyone I know that I’ve talked to about this, where being 100 per cent honest about my drug use, my current drug use, [with a] healthcare provider [where that] has been a positive thing. [So] you almost inevitably need to lie about exactly what you do, because it’s not worth the negative [impacts] **[P09]**

- If trust is interpersonally negotiated, potentially incompatible with whole system

Criminalisation

- Practices related to HIV, sex work, and drug use continue to be criminalised, and therefore unsafe information to be stored as data:

> If you’re disclosing something that relates to criminal or otherwise stigmatised activity and you have children, people are genuinely worried about that being reported to child services, and maybe being reported to law enforcement. Like it happens now because health professionals do make such referrals. **[P07]**

- Interrelated identities and practices:

> Especially if you have intersections like HIV status and sex work. And, you know, the crime of being Black, Indigenous **[P16]**

Trusting the system

- Political (and legal) system underpins digital health systems:

  > I think we come back to this lack of faith. Lack of trust. Unless [the Government] improve their track record and give us some reason to trust them on these matters, we're, like a large proportion of people are not going to download an app [COVIDSafe] or opt into My Health Record. **[P14]**

- Cynicism about trusting some institutions with data: 'I'm not sure if we're ever gonna be in a political system that people will trust' **[P10]**

Sharing/accessing data without consent

- Concerns about data leakage, hacking, access of data by other departments (e.g. health insurance, employers, law enforcement)

> If health data can be accessed by the police or by a licencing authority, then obviously we have a problem with that. And that’s a short-term and a long-term question because maybe at the moment it’s about criminalisation [of sex work] but maybe in 15 years it’ll be about custody [of children]. **[P16]**

- What are the future (re/mis)uses of data?

Increasing Trust in (Digital) Health?

- Increased privacy and protections
- Consent is specific, dynamic, and informed
- Control over types of data accessible to others
- Decriminalisation of practices related to HIV, sex work, and drug use
- Inclusive system design (accessibility + inclusive of diverse gender)
- Improved government track record regarding priority populations
- Meaningful consumer engagement to ensure systems are developed and implemented appropriately

Conclusions

- Key Informants offered the following factors for why priority populations may be reluctant to trust and engage with digital health:
  - Discrimination and stigma
  - Criminalisation
  - Exclusionary system design
  - Lack of confidence in political system
  - Concerns over data being shared, leaked, or hacked
- Decriminalisation and efforts to reduce discrimination and stigma could increase trust in digital health for priority populations
- Investments in meaningful consultation, privacy and other data protections, and consent mechanisms are necessary for innovations in digital health

Report Available

www.trustindigitalhealth.org.au

Future publications in progress

Newman, C., MacGibbon, J., Smith, A. K J., Broady, T., Lupton, D., Davis, M., Bear, B., Bath, N., Comensoli, D., Cook, T., Duck-Chong, E., Ellard, J., Kim, J., Rule, J., & Holt, M. (2020). Understanding trust in digital health among communities affected by BBVs and STIs in Australia. Centre for Social Research in Health, UNSW Sydney. https://doi.org/10.26190/5F6D72F17D2B5

Understanding trust in digital health among communities affected by BBVs and STIs in Australia

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