Acceptability of a community-controlled complaints portal for HIV stigma: consultations with people living with HIV and community-based advocates

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AC sits on HALC Board

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Acting on stigma is essential... (1)

...for meeting national and global commitments to end HIV transmission by 2030
- For quality of life targets
- For dignity and respect
- For better health outcomes beyond HIV
- For better health services overall

The imperative for innovative solutions and action is more important than ever

Lived experience is hugely valuable – we ignore that at our peril – so need a way to capture – inform our services and make them better

1. Nyblade, L., Mingkwan, P., & Stockton, M. A. (2021). Stigma reduction: an essential ingredient to ending AIDS by 2030. *The Lancet HIV, 8(2), e106-e113.*
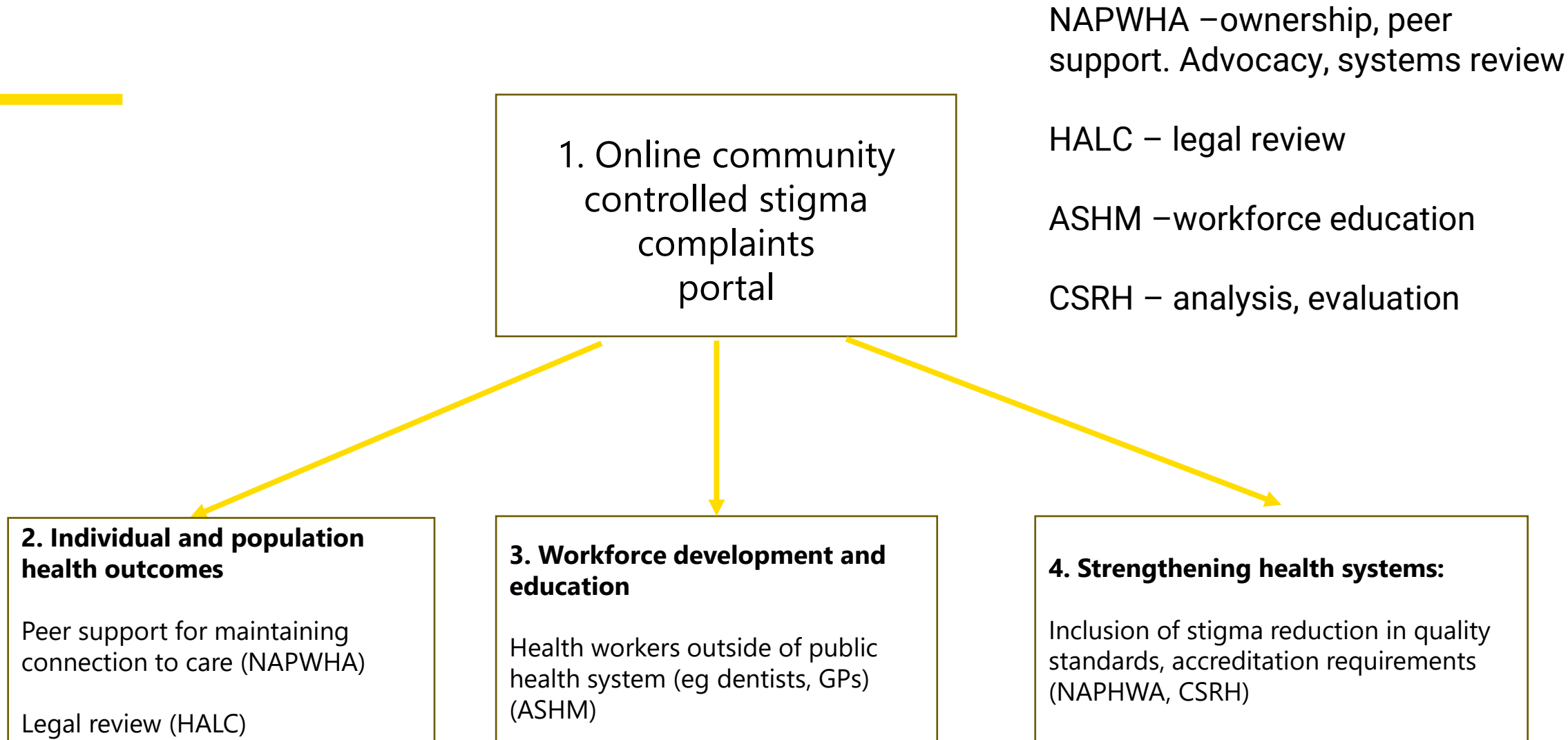
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SYDNEY

But action on stigma is atomised

Individual client/consumer complaints

- Key means by which incidents of stigma become known to health systems
- Can be onerous, further harm if dependent on a service for care
- Complaints often fail to generate change in practice, policies or systems
- Power is with the health service (1)

Questions:

- What would it look like if community took control of stigma complaints?
- Would a community-controlled portal be acceptable to HIV community and advocates?

1. Ahmed, S. M. (2021). *Complaint! Duke University Press.*

Schematic of community-controlled complaints portal

Consultation method

12 people working in HIV organizations
- Victoria (n=3), NSW (n=2), Northern Territory (n=2), Australian Capital Territory (n=2), and one each in Western Australia, Queensland and South Australia

24 people living with HIV - 23/24 provided demographic information
- Average age was 41 (24-67 years)
- 3 identified as women, all of these as heterosexual
- 18 identified as men - 15 identifying as gay, 2 bisexual, 1heterosexual
- 1 identified as non-binary and queer
- 1 identified as transgender and gay
- Living with HIV: 1-40 years
- Victoria (n=10), NSW (n=6), Queensland (n=3), Western Australian (n=2) and Tasmania (n=2)
- 2 lived in regional or rural areas, remainder in metropolitan areas
- 11 Australian/Anglo, 6 Asia, 5 Latin America, 1 identified as Aboriginal or Torres Strait Islander

Acceptability (1)

ethicality *whether the intervention is "morally good or correct"*

- permeated all aspects of the proposed portal design and operations

ethical aspects of this proposal were inextricably tied to perceptions of

- effectiveness, burden, attitude, self-efficacy and coherence.

1. Sekhon et al. (2017). Acceptability of healthcare interventions: an overview of reviews and development of a theoretical framework. *BMC Health Services Research, 17(1), 88.*

Acceptability

Establishing a portal - How stigma is understood or identified

sometimes we <u>normalize</u> some behaviours, and you <u>don't even identify them</u> as a stigma anymore. Because you think that this is <u>just the way that things are</u> (P20, people with HIV)

stigma <u>doesn't translate in my language</u>. Need to be clear about what is being asked about (P10, people with HIV)

Acceptability

Promoting the portal
- who "owns" the portal was key to its perceived trustworthiness
- partnership between NAPWHA and UNSW adds to "credibility"
- to convince people of the value of their "asset" (their stigma experience) for a collective enterprise (P23 people with HIV)

Collecting data in the portal

Something might have happened 10 years ago. But it's <u>still impacting a person today</u>. It's the option to once again connect that person with the supports (P3 HIV organization)

needs to be super easy, person's voice needs to be heard otherwise <u>it becomes responsibility of person who has experienced trauma</u> to report it, vicarious, trauma compounding (P12 HIV org)

Acceptability

Using data from the portal
- Organisations: "help us with advocacy", "lightens our load", current clients "represent the tip of the iceberg" (P6 HIV org)

- reporting upwards to systems with the capacity to make change

- reporting to community to change norms of the inevitability of HIV-related stigma.

I think there's sometimes an <u>expectation</u> from positive people that <u>stigma is part of the journey</u>, and so I think sometimes we absorb a whole range of stuff that other people wouldn't. I also think that reminding people that. you know <u>stigma is really shit</u>, and the more we know about it, the <u>more opportunity that we've got to address</u> some of these kind of underlying themes (P2 HIV org)

Acceptability

Overall value proposition of portal – responsibility for action on background of trauma

I think one of the biggest things that I find you know, being HIV positive is that it frustrates the hell out of me that <u>I can't talk about it</u>. I can't. And I and I think we need to be given <u>somewhere where we can do it out in public</u> rather than behind closed doors ... I want it to be opened up in such a way that it's talked about in general and so that it's not a forbidden topic. And I think when you start to do that, that <u>actually opens up solutions</u> (P22 people with HIV)

because sometimes, for example, I've felt that every institution in place is like "we're here to help you. We're here to hear you out", and it's just <u>retraumatizing to tell the story over</u> and over again, and <u>no one does anything to fix anything</u>, and nothing surmounts to anything. So it. It's just about like, oh, another place to dump everything that I've suffered yet again, without anything gonna happen ever into the future. So it just it feels that it could be that. (P7 people with HIV)

What does this mean for a portal?

Ethical design in new technologies

- technology as "material expressions of human knowledge" - have capacity to build-in the contexts and prejudices that shape knowledge (1)

Making change

- People with HIV in this study focused on individual case, less discussion of the potential for system-wide improvement

  - goes to need for careful explanation of individual benefit <u>as well as</u> system wide improvements

1. Vandemeulebroucke et al. (2022). Which Framework to Use? A Systematic Review of Ethical Frameworks for the Screening or Evaluation of Health Technology Innovations. *Science and Engineering Ethics, 28(3), 26*

What does this mean for a portal?

Portal - issues of stigma, power, new collectives and complaints processes

- Responds to call for "novel policy strategies that enable a distinct improvement pathway to address systemic and system-wide issues reported in complaints" (1)

- Not about calling out specific services/workers – aim is to provide constructive ways for health services/systems to adapt to the contemporary realities of stigma

- For positive people – a positive way to talk about their problems with services

Funding proposal with DOH for consideration

1. van Dael et al (2020). Learning from complaints in healthcare: a realist review of academic literature, policy evidence and front-line insights. BMJ Quality & Safety, 29(8), 684.

- Tackling Stigma Network

- Short course

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