Challenges Analysis

—The wicked problem of HIV Prevention, Sexual Education and PrEP Rollout, for DDES9905

Intro:

All problems have their own aspects of complexity, but not all complexity is equal. Some complexity exists within the scale of the problem. The problem of how to cross rivers has been solved in many different ways over thousands of years. One way is to build a bridge, and yet the complexity of building a bridge still exists today. We have gained a large amount of experience, but the scale of the task enables its complexity. However, that is not entirely true. Building bridges is well-understood. It is applying that knowledge to a specific location and set of needs in that context that creates complexity. A bridge that functions well in the heartland of America would be a rusted hulk in a year on the coast of Queensland or shattered by the first earthquake it experienced in Japan. We already know the shape of the solution, but the hard part or complexity of it comes from working out how to generalise that solution to a specific location.

But how do we know we need a bridge in the first place? What if we went back further and looked at the problem we are trying to solve? For anything to be called a solution, a person needs to be able to cross a river. We already know the shape that the solution will take. That basic foundation makes this problem exponentially simpler because of it. Our solution is partially solved already. Anything that doesn't have a person cross the river automatically falls out of the solution space. But what if we have a problem that we can confidently say we have no idea what actions or interventions, or even the solution, will entail? Bringing it back to the bridges, what if we looked at why people needed to cross that specific river? What societal, political, or economic pressure drives people to need to cross? Can we solve them better without a large piece of expensive infrastructure? Would building the bridge solve the problem at heart, or are we solving a symptom of a longer-held systemic problem that would be better addressed directly? If people need to cross the river to make enough money to support their families, why can't they live on the other side of the river? Why can't we promote more jobs closer to them? Or if they need to get medical attention on the other side of the river, why can't we build a hospital or medical centre closer to them? If we look further out from solutions, we gain a better view of complexity and interdependencies and get a sense of the workings that happen unseen underneath human life. Which then allows us to move back closer into the problem space to then find the right problems to solve for.

Encouraging PrEP Uptake in Australia:

Pre-Exposure Prophylaxis, abbreviated as PrEP, is a drug that, when taken daily, reduces a person's chance of contracting the Human Immunodeficiency Virus (HIV) when exposed by 99% (CDC 2022). If we could maximise the uptake of PrEP to help prevent HIV infections, we would save the commonwealth the cost of treatment and care, which is $1 million over a person's lifetime (AFAO 2021).

Yet, not nearly enough people have access to this medicine. There are still problems with affordability, education, access, and adherence, which means that people are contracting HIV who don't have to. As we further explore this problem, we'll come to understand how politics, education, religion, economics, and history come to create the complexity found within this wicked problem.

Why is it so complicated?

HIV cannot be seen as a neutral topic. With the history of the AIDS epidemic starting in the Eighties, the politics of HIV treatment and prevention is inextricably associated with gay men and the wider LGBTQ community. Yet, 27% of HIV notifications came from heterosexual sex in 2021 (AFAO 2023), which is an increase of 3% from 2020 (AFAO 2022). If these communities continue to believe that HIV is a virus that doesn't affect them, then infections will continue to rise, and lives that could have gone unaffected by HIV will unnecessarily negatively affect people's lives.

It is hard for the general population and key decision-makers to understand that HIV is a risk to everyone, not just men who have sex with men (MSM). A lot of this resistance stems back to the start of the AIDS epidemic and the moralistic sentiments and homophobia that slowed the initial response to the virus (Halkitis 2012). Within the general population, these sentiments have largely lost favor, and yet, in many ways, there isn't a political will to engage with such a potentially charged political area. Consider the recent religious discrimination bill and the continuing dragging of trans kids into the political spotlight for short-term political gain. There is a risk that larger sweeping changes in policies around funding, education, and prevention could garner the same kind of vitriolic attacks from conservative communities.

Interacting with the historical and cultural baggage of HIV is the lack of effective and consistent education in schools about HIV prevention and sex education in general. With little certainty that material, even when mandated, is taught properly or

beyond an abstinence-only biased model (Jones, Mitchell 2014). Which means the responsibility for people to find out information and make informed decisions around sex and safer sex is up to the person themselves. In Australia and NSW, partially advertising rates up a large part of this role of patching up the holes in how we educate young people around HIV, partially led by the AIDS Council of NSW (ACON) called Ending HIV. Which continues to bring basic information about HIV, Regular Testing, Undetectable viral loads, Monkeypox vaccines, and PrEP out into communities and places that would not have had ready-made access to this information otherwise. Yet, even though ACON and organizations like it do incredible work, there is a limit to the effectiveness that these second party sources to information and education can have, and really pose a stop gap to reduce the harm that ineffective policy around sexual education has. Especially when considering particular culturally and religiously diverse communities which pose harm to the free and open discourse on queer education in amount their communities.

Another significant limitation to the effectiveness of PrEP is economic access. Through the introduction of PrEP into the Pharmaceutical Benefits Scheme (PBS), the cost of PrEP was lowered to $42 for general patients and $6.60 for those receiving government support payments, and just over the past year, the cost of PrEP for general patients was lowered to $29 for a one-month supply. This is undoubtedly a move in the right direction, but it still falls short of what is needed for fair and equal access to PrEP. In the inner city of Sydney. That might just seem like the choice between one brunch a month and having 99.9% protection against HIV, but that is because I am writing this, and most likely you are reading this are almost some of the most privileged percentage in this city and probably the country as well. If you look out towards regional areas and lower socioeconomic areas, Let's say you are currently out of work and on Jobseeker as of March 2023. That works out to be $1,386.2 a month, which means that PrEP at $29 a month works out to 2.1% of their monthly budget, which is actually a really considerable percentage. Within this context, you can really see how people can very logically choose to budget differently and take on more risk in the hopes that they won't be unfortunate enough to become infected.

PrEP's effectiveness as a pharmaceutical against HIV infection is 99%. Yet, for it to achieve that level of effectiveness, a user needs:

To have received sexual education or marketing to know what PrEP is.

To perceive a need to actually take PrEP.

To be able to have access to a PrEP general practitioner to get a prescription.

To be able to afford that PrEP prescription.

To then take PrEP as prescribed.

Just in this simplified list of the steps needed to have PrEP be effective, we can see how interdependent it is on educational, political, economic, and cultural factors. Rigorous sexual education depends on which school a child attends or has access to, whether they are based within a cultural or faith-based group that promotes or allows adequate sexual education, and whether they perceive the need to actually take PrEP based on their own risk factors. Do they have access to a GP and feel comfortable enough to talk to them about getting a PrEP prescription? Can they afford a visit to the GP or the cost of PrEP? Do they know how to take PrEP effectively and consistently? Each one of these factors or steps along a person's journey with PrEP could be the site for a specific intervention.

Stakeholders that need to be considered in any solution are:

Medical Professionals: General Practitioners, Pharmacists, and Testing Clinics.
Educators: Teachers, Lecturers, and Community Organisations.
Cultural: Queer Venues, Pride Events, Faith-based Groups, Cultural Institutions, and Leaders.
Political: Local, State, and Federal Governments.
And persons with HIV.

Using Design Research methods to find a particaular solution:

So, a logical question to ask is how we can use design to increase the uptake of PrEP and help eliminate the spread of HIV in Australia. How can we use design research methods to understand the problem space and uncover a path to a functional and viable solution?
Working in a field like HIV requires acknowledging decades of research and effort that has gone into achieving the current level of knowledge and education around PrEP. Australia has been rather privileged in its proactive approach to HIV

in recent years, and there is already a lot of high-quality data and information available. However, understanding the current state of the community's understanding of HIV and PrEP is important as a foundation for further work. It is also essential to understand the wider general public's awareness of HIV and PrEP.

We can gather information by collecting mass quantitative data, including online surveys. However, we also need to access a large and diverse dataset from urban and regional areas by going out to community venues.

Then, performing interviews with specific people in and around particular groups of interest, such as Aboriginal and Torres Strait Islanders, people born overseas, members in and around fundamentalist religious groups, patrons of queer spaces such as gay bars and sex clubs. Each of these groups contains members who are particularly susceptible to HIV and the complexities around prevention. As an example, for Aboriginal and Torres Strait Islanders, AFAO found that diagnosis of HIV among these communities is around 1.3 to 1.9 times higher than Australian-born non-Indigenous people. This seems to be in part due to the neglect of adequate medical care for regional areas, access to education, and more.

Alongside gathering this community knowledge around PrEP and HIV, we need to consult with experts in the field and gain an understanding of where we'd like our community's understanding to be. Once we have these sets of data, we can see how each community's understanding matches up with our expert's understanding. From that, we can see where in the problem space there is the greatest opportunity for harm reduction and target our response accordingly. We'll also be creating different ways of approaching the problem for each community; what will work for one won't necessarily work for the other.

Immersive technology has less of a role in intervening in the problem itself but more in how we work to communicate future solutions. Immersive tech isn't going to make PrEP cheaper and more affordable, but it could help in how we tell the story of how cheaper PrEP and better education could change how we approach sexual health. If we could design a narrative around sexual health that was generative rather than prescriptive, we could maybe all be a lot happier. There is lots of room to discuss and talk about the risks involved with casual sex, monogamous partnerships, and open relationships that don't pit them against each other but as choices that can be made by reasonably informed adults. A discussion that involves harm reduction rather than harm

elimination through celibacy.

How we talk about sex education is so interconnected to how we talk about treating HIV. If we could shift the approach towards HIV to something that considers the wider space of STIs, then we can really build something. Immersive tech is really good at moving people into different contexts and telling compelling stories. If we could leverage that to start systematic change among policymakers, community leaders, and educators, then we could build a really cool and embedded solution to this wicked problem.

Bias:

Coming from a user experience design background, I think that with good data and some Post-it notes, I can build anything. But medicine and healthcare are deeply complicated, expensive, and political fields to work within. It is straightforward to say that we need to talk to stakeholders like policy makers at the local, state, and federal levels, but what that means is bringing in massive amounts of conflicting perspectives and needs and justification needed as to why we are spending our time and our attention on this particular space of governance. Not that HIV isn't important and something that shouldn't be worked on eradicating from our communities, but as a queer person and because of its history and effect on our community, it has a far higher sense of urgency and need for action for me personally then that of the general population.

A particular difficulty in sexual education as a whole is working within cultural and religious diverse communities. Not to say that they are all equally difficult to work within, but the prevalence of abstinence until marriage or at least the appearance of it is seen as the only appropriate cultural narrative in a lot of these communities, and that isn't necessarily a bad thing. The problem is when those narratives are enforced through a lack of knowledge and education and basic informed choice. Teaching someone how to have safe sex isn't the same thing as telling someone to go out and have sex, and yet to a lot of people, they are seen as the same thing. That will be really hard to come across and constructively dialogue with. And yet we need those communities on board to provide effective education for all of our students, not just those in the public system.

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