Do I Really Have To Publicly Disclose My HIV Status?

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Abstract

Many of the sexual health prevention interventions designed into today's gay and bisexual dating or "hook-up" applications ("apps") ask users to publicly disclose their Human Immunodeficiency Virus (HIV) status, with the intention of helping users make more informed sexual risk decisions. However, the privacy sensitivities around this information are unequal across user groups, with the stigma associated with HIV increasing the sensitivities of this information for HIV positive users. In this position paper, we discuss whether the privacy of this sub-set of users is appropriately respected, and whether providing these users with a non-disclosure option is a viable privacy respecting design strategy. We reflect on the preliminary findings from an interview study and briefly present a number of descriptive conceptual designs to increase privacy around HIV disclosure.

Author Keywords

Privacy, Unraveling Effect, Signaling, HIV Disclosure

ACM Classification Keywords

H.5.2. Information interfaces and presentation (e.g.,HCI): User Interfaces

Figure 1: Billboard advert associating sexual health with dating and "hook-up" apps Tinder and Grindr. Photo from newsweek.com

Introduction

Our research is focused on HIV status disclosure in online social environments, and how HIV positive users perceive their privacy in these environments. We have conducted a number of qualitative studies to better understand how HIV affects men who have sex with men (MSM), when interacting online. We focus on MSM as they are disproportionally affected by HIV in the UK, representing 54% of those diagnosed in 2016 [1]. Amongst this demographic, 32% were diagnosed late [1], increasing their risk of passing on the virus to sexual partners when engaged in unprotected anal intercourse (UAI). Based on our findings, we are developing design recommendations to help make online environments more supportive for this often vulnerable group. In this position paper, we reflect on the findings from an interview study which identify unequal privacy sensitivities around HIV status information, requiring the privacy of certain groups to be considered differently to those of the wider community.

In this paper, we take a more focused look at Grindr, a dating or "hook-up" app used by MSM, as it provides users with the option to publicly disclose their HIV status. Grindr is also one of the most popular apps in this market, with more than 3 million daily active users worldwide, spending an average of 54 minutes interacting with the app each day [4].

In 2015, Grindr was featured in a billboard campaign run by the AIDS Health Foundation in the US (See: Figure 1). The campaign was designed to raise awareness around regular testing for Sexually Transmitted Infections (STI), and drew a very public link between Grindr and STIs. Since then, Grindr have introduced several features to raise awareness around HIV to its users.

In 2016, Grindr updated its app to include an HIV prevention intervention which allows users to select an HIV status option (see: Table 1) and to set their last HIV test date. If set, this information appears publicly to other users of the app. Finally, Grindr provides users with a sexual health FAQs section where they state users can: *'Learn more about HIV, PrEP, getting tested, and other frequently asked questions'.*

Previous research exploring social networks as environments for HIV prevention and awareness identified the need to consider *privacy*, *stigma* and *social norms* of online social networks to reduce rates of HIV amongst MSM [7]*.* Whilst it is encouraging that awareness is being raised to reduce the spread of HIV, to educate, and to reduce stigma, we will discuss why the adoption of a "one-size fits all" approach fails to address the privacy needs of these users.

Preliminary Findings
In this position paper, we reflect on a privacy related finding from a recent interview study conducted with HIV positive and negative MSM participants (n=28) in the UK.

Do Not Show
Negative
Negative, on PrEP
Positive
Positive, Undetectable

Table 1: HIV status options available to Grindr users

Grindr provides users with a number of HIV disclosure options (see: Table 1), as well as a non-disclosure "Do Not Show" option. Whilst initially this option appears to provide non-disclosure choice, our preliminary findings suggest that assumptions develop around non-disclosures, causing them to signal an HIV positive status to some users. Peppet [6] describes these social assumptions as the product of an "unravelling effect". In an environment where users act to promote their own desirability to others, personal information disclosures act as promotional signals. When the cost (effort, stigma) to disclose is low, disclosure of positive attributes becomes expected. This can result in HIV negative users who may prefer not to disclose to feel pressured to, as not doing so may attract stigma and be personally disadvantageous. For HIV positive users, the stigma attached to the condition makes disclosure much more challenging. Previous research has identified stigma as a barrier to disclosure during sexual negotiation [3], with fears of social exclusion and loss of sexual opportunity [5]. For these users, their choice is limited to (1) not disclosing (2) misreporting their HIV status.

The Universal Design principle of Equitable Use requires that a system should neither disadvantage nor stigmatize any group of users [2]. Due to the unequal sensitivities that exist around HIV status information, requesting users to publicly disclose would violate this principle by stigmatising this group. Where HIV positive users choose not to disclose to protect their online identity from being stigmatised, the unravelling effect can disadvantage them, limiting the reality of their choice.

Drawing on previously suggested limits to privacy unravelling [6], we have developed a number of descriptive conceptual designs in the process of

exploring the use of these limits within this context. Here we focus on increasing the transactional cost of disclosing as a mechanism to reduce unraveling. We briefly present a financial, functional, and time transactional cost approach to reducing the effect.

Firstly, disclosure of HIV status could be limited to premium users who pay for the app, increasing the *financial* cost of disclosure. As not all users subscribe to the premium app, this could increase uncertainty over the reason for non-disclosure. Secondly, disclosure could result in a *functionality* cost, with users having to trade HIV status disclosure with another app function. Finally, a *time* cost could be introduced, requiring users to watch an HIV awareness video, or complete an awareness quiz prior to disclosure. These designs are all intended to increase the transactional cost of disclosure to create ambiguity over the reason a user has selected "Do Not Show".

Future Work
The goal of this workshop is to highlight approaches to privacy which 'fail to consider individual differences in concerns, preferences, and behaviors'. Our research provides an example of this 'one-size fits all' approach failing a sub-set of users. We believe this approach not only affects this sub-group, but the community as a whole. We plan to expand on the conceptual designs briefly presented here to develop a more privacy inclusive approach to managing HIV status information, whilst providing users with the information they need to make informed sexual risk decisions.

Acknowledgements

References
1.   Alison Brown, Peter Kirwan, Cuong Chau, Jameel Khawam, Noel Gill, and Valerie Delpech Contributors. 2017. Towards elimination of HIV transmission, AIDS and HIV-related deaths in the UK. *Public Health England, London*.

2.   Benyon; David. 2013. *Designing interactive systems : a comprehensive guide to HCI, UX and interaction design*.

3.   Valerian Derlega, Kathryn Green, Julianne Serovich, and William Elwood. 2002. Perceived HIV-related Stigma and HIV Disclosure to Relationship Partners after Finding Out about the Seropositive Diagnosis. *Journal of Health Psychology* 7, 4: 415–432.

4.   Grindr. 2017. Grindr Factsheet 2017. *Grindr.com*. Retrieved June 26, 2017 from https://www.grindr.com/press/

5.   P. J. Murphy, D. Hevey, S. O'Dea, N. Ni Rathaille, and F. Mulcahy. 2015. Serostatus Disclosure, Stigma Resistance, and Identity Management Among HIV-Positive Gay Men in Ireland. *Qualitative Health Research*: 1049732315606687. https://doi.org/10.1177/1049732315606687

6.   Scott R. SR Peppet. 2011. Unraveling privacy: The personal prospectus and the threat of a full-disclosure future. *Nw. UL Rev.* 105: 1153.

7.   Jorge Ramallo, Thomas Kidder, Tashuna Albritton, Gary Blick, John Pachankis, Valen Grandeleski, and Trace Kershaw. 2015. Exploring social networking technologies as tools for hiv prevention for men who have sex with men. *AIDS Education and Prevention* 27, 4: 298–311. https://doi.org/10.1521/aeap.2015.27.4.298