Privacy Unraveling Around Explicit HIV Status Disclosure Fields in the Online Geosocial Hookup App Grindr

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mHealth applications ("apps") must be searched for and downloaded prior to use, creating a potential barrier to uptake. Integrating health interventions into existing online social environments removes this barrier. However, little is known about the effects of linking sensitive health information to existing online identities. Our qualitative analysis of online comments (n=192) explores the user views of an HIV intervention integrated into the geosocial hookup app Grindr. We find that HIV positive users either keep their status private to reduce their stigma exposure or publicly disclose to avoid being stigmatised by others. Where users act to keep their status private, social assumptions can develop, creating a *privacy unraveling effect* which restricts disclosure choice. Using Peppet's four proposed limits to privacy unraveling, we develop a set of descriptive conceptual designs to explore the privacy respecting potential of these limits within this context and propose further research to address this privacy challenge.

CCS Concepts: • **Human-centered computing** → **Empirical studies in collaborative and social computing**; Social networks; • **Security and privacy** → *Social aspects of security and privacy*;

Additional Key Words and Phrases: Privacy Unraveling, Privacy, Self-disclosure, Identity, HIV Disclosure

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1 INTRODUCTION

Human Immunodeficiency Virus (HIV) interventions have been developed as stand-alone apps to increase awareness, reduce risk, and promote safer sex and regular testing [54]. Yet, they have attracted little user attention and few positive reviews [16, 42]. For health intervention apps to be effective, people must have intent to change by actively searching for and downloading the app, and then continue to engage with it. Reducing this barrier, a number of geosocial hookup apps have integrated HIV interventions into their platforms. These provide users with the option to publicly disclose their HIV status to other users. However, little is known about how introducing sensitive health data into these environments affects user privacy. This was evident when security

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researchers recently identified that Grindr was sharing its users' personally identifiable HIV status information with third-party companies [25].

In this paper, we explore whether these disclosure fields support marginalised groups who may feel unable to publicly disclose their status, especially in the early stages of accepting the diagnosis [7] where people require support and positive interactions [58]. Around half of MSM who live with HIV in the UK reported feeling of shame, guilt, and low self-esteem in relation to their HIV status in the 12 months post diagnosis [56]. Systems should be designed in such a way that neither disadvantages nor stigmatises any group of users [9]. Therefore, these marginalised users should be in control over when they choose to disclose potentially stigmatising personal health information. We report on a study in which we collected and analysed the online user views of introducing a structured field for publicly disclosing HIV status information in the popular geosocial hookup app Grindr, used by men who have sex with men (MSM).

Throughout this paper, we refer to the HIV disclosure option as an HIV intervention. The intended outcome of this intervention as reported by Grindr is to "create an open dialogue among our users about sexual health" [17]. Building Healthy Online Communities (BHOC)[1], who have advised Grindr on issues related to sexual health, stated that this intervention would also help create "a healthy online community through supporting HIV prevention and fighting stigma" [17]. This explicit disclosure field is part of a wider health intervention by Grindr, and since conducting this study, Grindr have also introduced testing reminders at certain intervals for users who choose to use this option [16].

With online geosocial dating apps expanding the means by which MSM are meeting, Grindr (released in 2009) has become the most popular of these apps within the MSM community. It has more than 3 million daily active users worldwide, who spend an average of 54 minutes interacting with the app each day [30]. App usage is primarily for finding hookups [57], but users also report usage for socialising, friendship, entertainment, dating, and gay community involvement [49, 60]. In contrast to interventions which focus on promoting awareness, Grindr proposed implementing an explicit field for publicly reporting HIV status on user profiles, and the ability to filter users based on their status. In 2016, Grindr conducted a survey related to these proposals. Whilst the results of the survey have not been published, it acted as a catalyst for online discussion. Several online websites attracted user comments related to the proposed disclosure of and filtering by HIV status.

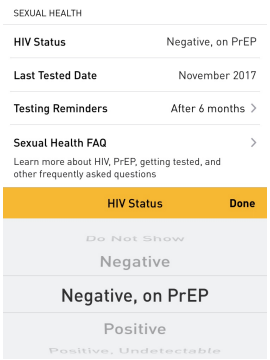

Fig. 1. Cropped screenshot of the explicit HIV status disclosure field in Grindr.

[1]BHOC are a consortium made up of public health leaders and key individuals from the gay dating industry who are working together support HIV and STI prevention online.

Grindr later modified its app to include an explicit field for reporting HIV status and last tested date information as shown in Figure 1. The implementation of this feature also attracted online comments and discussion. As HIV filtering was never implemented, our analysis and discussion is focused on the HIV status and last test date disclosure fields. Where we mention the public disclosure of HIV status, 'public' refers to a user's profile space within Grindr. Whilst not truly public as to view this information requires a Grindr account, we refer to it as being public within the Grindr environment. Our paper makes several contributions to the privacy and social computing literature.

- Our empirical analysis of online comments provides a first look at user perceptions of explicit HIV status disclosure field in an online hookup app used by MSM.
- We identify Peppet's privacy unraveling effect [46] occurring around these explicit disclosure fields. Whilst this effect has been observed in economic environments, to the best of our knowledge this is the first time it has been observed in an online social environment.
- Finally, we build on Peppet's work by developing a number of sub-categories and descriptive conceptual designs as a way of reducing the unraveling effect. These conceptual designs are developed to address the privacy concerns of marginalised groups who are most at risk of stigma as a consequence of this effect. In developing these designs, we provide a first look at how these limits could be applied in design, and extend the literature on privacy unraveling, identifying a new application domain within online social environments.

2 BACKGROUND AND RELATED WORK

This section provides an overview of the background and theories used to understand our empirical findings. We start by providing a brief overview of the HIV virus and treatments in the UK. We then discuss several social interaction theories in relation to HIV disclosure. As identity plays an important role in online social interaction, we present a brief overview of identity management and the role privacy plays in supporting both online social interactions and identity management. Finally, we explore privacy unraveling, providing a detailed definition and an overview of previous research which has explored its effects.

2.1 Human Immunodeficiency Virus (HIV)

In the UK, 54% of those newly diagnosed with HIV in 2016 identified as MSM, of which 32% were late diagnoses [13]. The majority of HIV transmissions in the UK are through sexual contact [23]. MSM living with HIV but unaware of their status was estimated to be 13% of the total number affected [13]. A high proportion of new infections amongst MSM are caused by HIV positive individuals unaware of their status [10, 31, 47]. People living with HIV in the UK who are treated with highly active antiretroviral therapy (HAART) often describe their status as being "undetectable". A term used to describe individuals who are HIV positive, but are responding well to treatment and have an undetectable level of the virus in their blood (and are therefore no longer at risk of forward transmission [50, 51]).

Serodiscordant is a term used to describe a sexual partnership where one individual has tested positive for HIV, and the other is HIV negative. Studies show HAART to be effective at minimising transmission between serodiscordant heterosexual couples [5, 21], as well as between serodiscordant MSM engaged in unprotected anal intercourse (UAI) [50, 51]. This has led to reduced transmission rates by those aware of their status and being treated, whilst those unaware continue to be a risk. In recent years, new HIV prevention drugs, pre-exposure prophylaxis (PrEP), have been made available to individuals at risk of HIV infection. These medical interventions have created an array of HIV status options that people may be identified as, or self-identify as, summarised in Figure 2.

Grindr provides users with five disclosure options: Do Not Show, Negative, Negative on PrEP, Positive, and Positive Undetectable. Below we briefly discuss what these options mean and who may self-identify with them.

If an individual has tested negative for HIV, they may identify as being negative; however, those untested may also identify as negative in the absence of a status unknown option. Of those who test negative, prevention drugs can be used to avoid HIV on exposure. These individuals may self-identify as being negative on PrEP and are typically required to test for HIV on a regular basis (6 months). There are two ways in which PrEP can be taken, daily (one tablet per day), or event based dosing (a number of tablets prior to and after sex), but the disclosure options in Grindr do not allow for this distinction. For those diagnosed as HIV positive, the effectiveness of modern treatments means that becoming undetectable and untransmittable is often achieved soon after diagnosis. If tests show an undetectable viral load for > 6 months, guidance within the UK states that they are then classed as being undetectable [44] and may then self-identify as being positive undetectable. If an individual responds badly to medication, or fails to adhere to medication, they may self-identify as positive. In both cases, in the UK, regular testing is recommended to monitor the status of the virus.

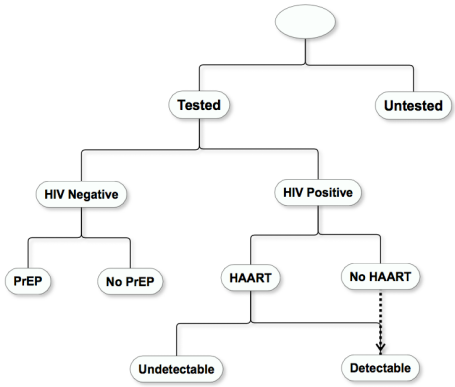

Fig. 2. Tree diagram showing a summary of HIV status conditions.

2.2 Self-Disclosure of HIV Status Information

On initial interaction, people have self-reported that to maximise their social desirability within their social environment, they self-disclose at a superficial level and gradually increase in intimacy and breadth as trust develops [61]. Whilst self-disclosure is important for relationship development, it can also increase a person's vulnerability to negative social consequences. In this paper we use the terms 'self-disclosure' to mean any form of intentional disclosure of HIV status [4], and 'serodiscussion' to refer more specifically to conversation based disclosures. Serodiscussion within couples can help individuals make more informed sexual risk decisions for themselves and their partners [63]. Serodiscussion not only informs, it also allows for the exchange of richer information that can educate. Educating others can act as an incentive for both men and women to disclose their HIV status [20], helping to change the out-of-date views and discourse that HIV still attracts [43].

Self-disclosing HIV status helps to create more openness, reducing stigma through the normalising of disclosure within society [15]. Paradoxically, however, for many MSM the attached stigma and subsequent fear of rejection creates a barrier to disclosure during sexual negotiations [19, 63]. Derlega et al.'s [20] study shows that fear of rejection, privacy, and self-blame can result in the non-disclosure of HIV status information within certain close interpersonal relationships. The factor of privacy is often linked with an individual's need to protect themselves from HIV related stigma [1, 29, 52]. MSM may avoid serodiscussion through fear of an exciting sexual experience becoming too serious, hampering the sexual mood of the interaction and being an unwanted reminder of their condition [14]. In a study of MSMs' online sexual negotiations, HIV negative men were found to be more likely to self-disclose their status than HIV positive men, with a large proportion of the latter reporting to have misreported their status [14]. Prior to Grindr implementing an explicit field for HIV disclosure, only a small number of users reported their HIV status on their Grindr profile using terms like "ddf" ("drug and disease free") [11].

2.3 HIV Threat to Identity

Users of social apps self-present by engaging in "profile work", exerting effort to maintain and manage their online personas [53]. Users may act to promote their profile, actively emphasising some aspects of their identity whilst concealing others with the goal of appearing desirable to their audience within a given social environment [41]. On being diagnosed with HIV, MSM may change their behaviour whilst going through identity transition, a term used to describe a multi-stage process of incorporating a new element into their identity [58]. They can find it difficult to integrate the illness as part of their self-construal, especially during early stages of this transition [24]. Identity transition can be aided through positive self-disclosures and interactions within social groups, helping individuals achieve a sense of belonging and maintain self-esteem [7, 58].

Being HIV positive is often seen as an undesirable attribute [58]. Those fearful or uncertain of how this new aspect of their identity will be perceived by others may act to more closely regulate self-disclosures and, thus, minimise the risk of a negative social response. Similarly, as the preventative drug PrEP becomes more widely used, research has found it attracting its own stigma, with impressions developing around PrEP users as being more promiscuous and into higher risk sex [28, 35]. It is therefore important to understand the effect of introducing HIV status information into an existing online identity, and to evaluate how disclosure is managed to ensure users maintain disclosure choice so they can effectively regulate self-disclosures in accordance with their needs.

2.4 Privacy in Social Interactions

Control of personal information, and how it is perceived by others, is an important aspect of identity management and often described when the concept of privacy is being explored [36, 38]. Understanding privacy as a user-centric, contextualised concept can help explain variations in privacy concerns. The Adams and Sasse privacy model [2] suggests people evaluate privacy using three interrelated factors. They judge the sensitivity of the information being disclosed, evaluate the trust in the information receiver and assess the cost/benefits of how the information is to be used. However, this model assumes that the initial disclosure is an explicit choice made by the user. In social interactions, people view information as having varying degrees of sensitivity and social value. In a dating environment, where an attribute - like an HIV negative status - increases attractiveness or desirability to others, it is then in the best interest for users with that attractive attribute to disclose. This can create a social privacy problem known as the privacy unraveling effect [46], limiting the effectiveness of control as a mechanism for respecting privacy. We use the term 'social privacy' as opposed to 'individual privacy' or just 'privacy' to recognise the effect the social environment has on the manifestation of this phenomenon.

2.5 Privacy Unraveling

Peppet [46] proposes unraveling as a privacy threat to a full disclosure future where personal information is more widely available and used to increase information symmetry in economic environments. For example, where a driver wants to signal their reduced risk to his insurer, they may allow a device to track their speed, cornering, and braking; where a life insurance customer wants to signal their healthy lifestyle, they may use a health tracker wearable to send daily step-counts, heart rate and sleep quality information. These full disclosures allow individuals to signal information to reduce information asymmetry between transaction parties. Information asymmetry otherwise increases uncertainty between the two parties, and where one side is unable to determine the reliability of the signals being given off by the other, the entire market value can reduce [3]. Privacy unraveling can occur within these environments where individuals choose not to disclose, leading to non-disclosures signalling an undesirable trait. This effect has been observed in an empirical study involving the disclosure of productivity costs within the labour market [8] and discussed in relation to the selling of cars on the online market place eBay [40]. Our search of the literature has only identified reports of this effect occurring within economic markets where goods and services are exchanged, but this effect may also exist in online social environments where individuals enact full disclosure to signal their social desirability to others.

To limit the effect of privacy unraveling, Peppet [46] suggest four mechanisms: transaction cost, unverifiability of ignorance, inability to accurately infer the negative, and norms. Negative assumptions may develop around non-disclosures when disclosing a desirable attribute is low-cost, as disclosure can be perceived as being an "obvious choice" for those with a desirable attribute. The first limitation suggests that if the cost of disclosing is increased, the "obvious choice" becomes less obvious, reducing stigmatising signals from non-disclosures. The second limitation proposed is unverifiability of ignorance. This limitation occurs when it is not possible to verify whether the disclosing party is aware of the state of the attribute not being disclosed. Peppet [46] uses the example of a transaction of a crate of oranges. Assuming the buyer is unable to verify that the seller knows how many oranges are inside the crate, if the seller does not disclose, the buyer is unable to draw negative inferences from non-disclosure due to the uncertainty over the seller's ignorance. The third limitation occurs when an inability exists that inhibits negative inferences being accurately inferred around non-disclosure. If the receiver of the signalled information is unable to comprehend that information, it will be difficult for them to develop assumptions from non-disclosures. Lastly, where norms develop around non-disclosure of information or actions, negative assumptions are much less likely to develop. An example of this can be seen in Germany, where it is much more common for home owners to request that their homes be blurred out on Google Street View to respect their privacy. In the UK, blurring of a home is seen as unusual, and may signal that they have something to hide, whilst in Germany, the norms around the use of this feature limit this privacy unraveling effect.

3 METHODOLOGY

The purpose of this study was to identify user views of introducing HIV status information into Grindr, the online geosocial hookup app used by MSM. We were interested in understanding the impact this may have on user privacy due to the sensitivities and stigma associated with HIV, and because this information would be associated with an existing online social identity. To study this, we examined the online views of users before and after Grindr implemented this feature into its app. User comments have previously been used to understand public health views [26, 37], and in HCI research to develop design recommendations [55]. The scope of this research was to understand

user views related to a specific interface change in Grindr and its impact on user privacy. This data collection method allowed us to ground our findings from a broad range of views.

3.1 Data Collection

When conducting our online searches we used an anonymous browser to reduce the risk of customised search results being returned. Searches to identify news articles and blog posts reporting on the Grindr survey or the introduction of HIV reporting within Grindr were conducted with Google Search and DuckDuckGo using multiple keywords [2]. We found 29 websites related to this interface change. As filtering by HIV status was never implemented, our research focused on the disclosure of HIV status within app. Therefore our criteria for inclusion were (1) the article or blog post was primarily about either the survey conducted by Grindr, or the later introduction of HIV status information in Grindr, and (2) at least one user comment had been posted. Using these criteria, 13 of the 29 websites found were selected. These websites containing a total of 149 comments which were added to a corpus of News Website (NW) comments. As a secondary source of data, we searched the UserVoice.com product feedback website to find user comments related to HIV disclosure within Grindr using the keyword "HIV". UserVoice.com is a managed customer feedback service used by Grindr to enable users to submit feedback and suggestions, and for other users to comment on that feedback. Our inclusion criteria for this source were (1) the user comment was primarily about HIV disclosure, and (2) the comment was related specifically to the Grindr application. This search identified a further 43 comments which were added to a corpus of Product Feedback (PF) comments. Figure 3 shows the word count size and distribution of comments collected, separated by source, and indicates a good distribution of comments across the 14 website sources that matched our inclusion criteria. The mean length of all the comments was 87 words. The largest comment consisted of 1134 words, and the shortest was 6 words.

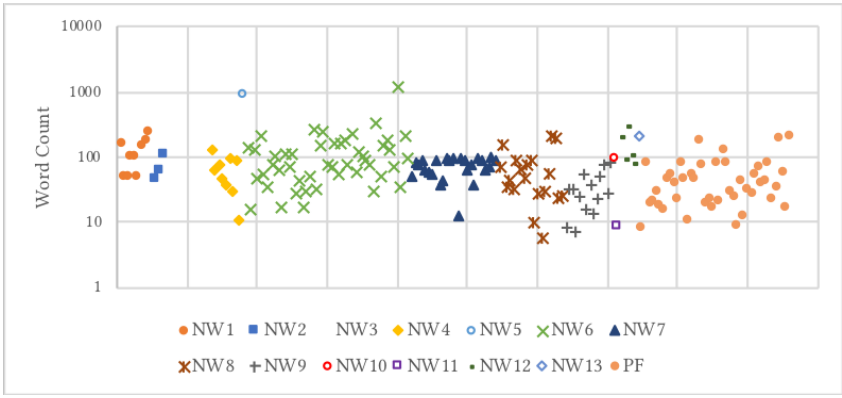

Fig. 3. Scatter plot of word count distribution (y-axis, log transformed) of all user comments (x-axis) separated by News Website (NW) and Product Feedback (PF) source websites.

3.2 Ethics of Using Online Data

This study has been approved by University College London ethics committee (ref: 11699/003). We requested that this study be reviewed for ethical approval due to the sensitive nature of some of the comments we were proposing to collect. During the process of the ethics review we consulted with

[2]HIV Disclosure Grindr, HIV Filter Grindr, HIV Filter Grindr survey

colleague to deliberate the ethical issues around the use of this data. Through these deliberations, the primary concern we identified was the anonymity of the original data subjects when reporting our findings due to the sensitivities around the information. This was also a concern as it was not possible to obtain informed consent from participants as users had posted anonymously or pseudonymously, or no realistic mechanism was available to make contact with them. Whilst the original data subjects posted in an online public space for the purpose of public consumption, an implied audience and purpose limitation existed that our research would otherwise extend. We became aware that, even if we were to publish direct quotes anonymously, these could be re-identified using an online search engine. As a result, where an original comment contained a user's real name or a username which could be easily re-identified, we either opted not to reproduce the comment in this paper or paraphrased the comment. In circumstances where paraphrasing is used, consensus on the wording was gained from at least three of the named authors to ensure accurate representation of the original content. We believe the steps we have taken mitigate any risk to the original data subjects whilst maintaining valuable insight into the views of an often hard to reach population.

3.3 Comment Analysis

Using a thematic analysis [12], the first author systematically reviewed each comment and coded them iteratively in NVivo 11. This allowed the analyst to become familiar with the data and to understand it within the context in which it had been written. On completion of the coding, the codes were grouped into themes and reviewed and revised by the second author.

Supplementary analysis was performed to identify whether particular views were more prominent for a particular HIV status group; we analysed the data for people explicitly disclosing their HIV status. We identified 39 (20.31%) comments which contained an explicit HIV disclosure. Of these, 32 (16.67%) reported a HIV positive status and 7 (3.65%) a HIV negative status, whilst 153 (79.69%) did not disclose. No comments were found containing explicit unknown status disclosures. Some of the comments in the corpus contained implied status disclosures; however, as they were not explicit and were subject to interpretation, they were grouped with non-disclosure for these statistics.

We also wanted to understand whether the sources (news articles/blog posts) and corpus of comments were biased towards people holding positive, negative or neutral views towards the intervention. To determine this, two of the authors conducted a manual sentiment analysis of both the sources and the comments. They independently labelled them as positive, negative, or neutral towards the intervention. Both raters met in person, discussed cases of disagreement between their ratings, and found additional cases of agreement, e.g. cases that were "borderline" or "on the fence" between neutral and positive or negative. The values reported below are the averages of the two raters. The Cohen's (unweighted) kappa κ was calculated across all source websites, and separately across the corpus of comments. Of the 13 source websites matching our inclusion criteria, 2.5 were positive, 6 were negative, and 4.5 were neutral (κ=0.87). Of the comments, 68.5 (35.68%) were marked positive, 61.5 (32.03%) negative, and 62 (32.29%) neutral (κ=0.85). This shows a good sentiment distribution of sources and comments, and a strong rate of agreement between raters. No additional quantitative analysis has been performed on this data, so these views are not necessarily generalisable to all app users. Quotes from the initial web searches are referenced using the abbreviation 'NW', followed by the website source number. Comments from the managed product feedback website are referenced using the abbreviation 'PF'.

4 FINDINGS

We identified a number of themes related to the attitudes and concerns of Grindr users around the use of their HIV status information. In this paper, we focus on the four most distinct themes: managing of sexual health, users desire to reduce their exposure to stigma, distrust of other users, and attitudes and concerns around disclosure choice.

4.1 Managing Sexual Health

The introduction of an explicit HIV status disclosure field in Grindr was intended to create a more open environment around sexual health information, allowing users to better manage their own sexual health [17]. Concerns around users' sexual health were a regular point of discussion in the analysed comments, with safe sex practices and education and awareness being of key concern. Yet, as people's opinions differed, a variety of sub-themes emerged. Raising awareness and educating people within Grindr was raised in a number of comments, and this appeared especially important to undetectable users. As the undetectable status option was relatively new in the context of HIV, a lot of educating within the community was still needed. Without this increased awareness and improved education, those with this status may find themselves having to regularly explain, and in some cases convince people of, the validity of their status and its sexual health consequences.

> *Appearing as undetectable will help the minds to understand better what it means. Removing the status option would send back hiv + guys to darkness. I appear on grindr as undetectable and I have discussion with others who are not aware about it so it helps to make minds improve* (PF)

Having a discussion about HIV status information to educate and raise awareness was often discussed in the comments, with some preferring to have a private discussion with other users rather than publicly disclosing their status on their profile.

> *People should always ask before having sex, it doesn't need to be posted for Everyone [sic] to see* (PF)

Whilst there were some users who felt that public disclosure could help stimulate discussion, others felt it would limit these discussions as the information was available on a user's profile, and therefore no longer needed to be discussed. With the introduction of the preventative drug PrEP and the increased awareness around the undetectable status, some felt that disclosure would be much less important in the future, as PrEP can prevent transmission, whilst effective HIV treatment can significantly reduce the risk of forward transmission. However, others were keen to point out that HIV was not the only STI of concern, with viruses like gonorrhea and hepatitis being a risk when engaging in unprotected anal intercourse.

> *I hope the guy with Hep B discloses! It's much more infectious than HIV, and can kill you just as dead. It'd be real ironic if for all his sanctimony about disclosure and victimhood, he was out there passing around his disease to unsuspecting victims* (NW1)

Whilst some felt HIV status information being made public could help them make better sexual risk decisions, others felt it could encourage people to have more unsafe sex. To counter this, some users suggested taking a default assumed state over other people's HIV status, assuming they were positive to reduce their risk of infection.

> *HIV status is completely stupid. You should always assume that a new partner might be positive and practice safe sex. Saying someone is negative just encourages unsafe sex practices* (PF)

Clearly sexual health is an important issue for some Grindr users, especially as the application is predominately used for finding sexual hookups [57]. However, there were conflicting views

around introducing HIV status information into Grindr, with some seeing it as a way of increasing awareness and reducing risk, whilst others held multiple contrasting views which we explore below.

4.2 Reduced Stigma Exposure

Stigma was a significant theme that emerged from our analysis. Previous research finds that stigma can create a significant barrier to disclosure during sexual negotiations due to concerns of social exclusion and loss of sexual opportunity [43]. Our study supports these findings, but in addition we also find stigma acting to motivate disclosure as it provides a way for users to reduce their stigma exposure. We found considerable concern related to the public disclosure of HIV status information on user profiles due to the stigma attached to HIV. There was concern that public disclosures would increase stigma rather than reduce it, and that it would disproportionally affect the subset of HIV positive users.

> *In my opinion it is awful to make people expose part of their medical record. This is sensiteve [sic], highly personal info. What is next? A full list of STDs check list? In many countries HIV comes with stigma so the only result of having this option on the app is to make most people lie about their status. It's dicsreminating [sic], racist even. I am not HIV+ but will soon delete Grindr if this goes as it is now.* (PF)

Supporting previous research, we found comments suggesting reduced sexual opportunity may be more likely if HIV status information was made public, with concerns that people would be stereotyped and rejected based on their perceived stereotype.

> *How does Grindr think that a system like this could possibly work? People are worried about being rejected and stereotyped. Do we really need to portray ourselves in that way?* (paraphrased: NW12)

However, not all users viewed this as a negative consequence of disclosure, with some identifying a stigma avoiding benefit. If they were to disclose their HIV positive status on their public profile, users who were uninterested in sexual contact with them could organically filter them out. The following comment from NW4 describes how the in-built block function is used to block users who are HIV positive. Whilst there was a general sense in the data that users are entitled to make their own private sexual risk decisions, comments like this were often stigmatising in nature.

> *Being HIV Negative is better. I would never ever have sex with someone HIV positive. I just block anyone who is + so I don't have to communicate to those people who made bad decisions* (NW4)

Public HIV status disclosure was also viewed as a way to provide HIV positive users with the information they need to make their own evaluations of users prior to engagement. Some users described being able to use this information to filter out HIV negative users, helping them avoid HIV based rejection.

> *I'm HIV+ and undetectable and I'd love to be able to have the option to look specifically for other HIV+ guys. I probably wouldn't use it all the time, but sometimes it's nice to look for someone knowing that you won't be rejected out of hand for having HIV* (NW1)

Finally, for some users, HIV disclosure acted as a tool for normalising HIV; a long-term stigma reduction strategy. Some users felt that openness about a HIV positive status would help raise awareness, educate others, and enable the familiarity of seeing HIV positive users to reduce feelings of exceptionalism around HIV.

> *I think it's a right step in the direction for better public health awareness. HIV has always been stigmatized, but diagnoses are becoming more accepted with medical advances. Being*

positive is becoming more streamlined, but that doesn't happen if people don't talk about it (NW4)

4.3 Distrust in Users

The third theme that emerged from the data relates to a distrust in HIV status information being disclosed by users of the app. This distrust seemed to develop for a number of different reasons, namely users being uninformed, unaware, or through a deliberate misreporting of information to avoid being stigmatised. Trust in information disclosed due to uninformed users seems to centre around the field that allows users to disclose the date of their last HIV test. Some users were concerned at the number of reported last test dates that were considered to be out of date. Our findings show that reporting an old last date test not only devalues the users reported HIV status, but can also send out negative, potentially stigmatising signals that the user is not looking after his own sexual health, thus reducing desirability.

*My other issue is the serious lack of information in the community. On a lot of profiles I see "tested negative *six months ago*" which seems to indicate these men think one test and they're good to go for long periods without retesting or don't care to* (NW1)

Men who are unaware of their HIV positive status was of particular concern to some. It was understood that by introducing HIV status information into Grindr, some men who were HIV positive but unaware might still be reporting to be HIV negative. One comment from NW8 expressed the view that this could *"lead to a false sense of security"* developing for people who overly rely on the information they see in Grindr and are less willing to discuss HIV in more intimate interactions. Some users suggested evaluating the last test date alongside a user's declared status to assess the validity of the information, with the validity reducing as the elapsed time since the last test date increases.

that's a completely different situation from a guy who tested negative 6 months ago, and is actually telling the truth about that… but in 6 months he's barebacked 25 times and got infected and has a viral load of 300 trillion or so. THAT'S the guy you really need to worry about! (NW6)

As our findings show, some HIV positive users felt stigmatised because of their status. These feelings of stigma could result in users misreporting their status as HIV negative, or as negative on PrEP to reduce their stigma exposure. In the longer term, this could have a negative impact on trust within the environment. Whilst Grindr provides users with a non-disclosure option, in the next section we present finding which suggests why some users may still act to misreport their status, rather using this option.

As long as society continues to put a stigma on HIV, People will continue to be less honest about [their status]. Why would someone tell you the truth, when you are going to be mistreated. Lying about [status] isn't right but people mistreating or ostracized someone because [of] it isn't right either (NW6)

4.4 Providing Disclosure Choice

Control over access and flow of personal information online is a well-established factor affecting privacy concerns when interacting online [34, 62]. For Grindr users, an important element of control is disclosure choice over when and to whom information is disclosed; especially when that information is sensitive and potentially stigmatising. As our previously reported findings indicate, the stigma around HIV can lead to users purposefully misreporting their HIV status to avoid exposure to stigma. This is reflected in our findings whereby users report that they want

choice over these disclosures, and if this choice is removed, there is potential for an increase in this type of purposeful misreporting.

> *When all said and done, it's forced disclosure that I dislike, or the fact that HIV+ users are expected to self-disclose their status straight away. Why should they?* (Paraphrased comment from NW8)

A number of comments identified the optional nature of the HIV disclosure field in Grindr, with a user from NW4 stating that: *"It's an optional field that isn't harming anyone"*. However, the privacy sensitivities around HIV status differ between user groups, with higher sensitivities and disclosure costs associated with users disclosing a HIV positive status. We identified evidence of this, with one person reflecting on the disclosure behaviours of Grindr users in his area. He describes people disclosing their HIV negative status and last test date as a means of showing off to other users, whilst other comments show HIV positive users fearing stigma.

> *In my area, there seems to be a rush to show (off) your hiv negative status with the date and everything and I just don't like it. It's like giving yourself a pat on the back for being lucky or "better" than other people* (NW4)

In an environment where users act to increase their own desirability, the potential for assumptions to develop around users who choose not to disclose was discussed. Identifying the unequal sensitivities around this information, several comments raised concern that stigmatising signals could develop around users not disclosing their status. It was felt by some that this could negatively impact on their right to choose, and their right to privacy.

> *Putting this option on a profile is prejudicial to those who are HIV positive but do not want to declare it publicly. By allowing users to state if they are negative or positive makes it seem that, if not completed, the user is actually positive. This option is, by default, against the private rights of those with HIV.* (PF)

However, these social assumptions were not universal, with some contrasting views also present. One comment from NW1 stated that enough *"alternative possibilities"* existed to stop people from drawing negative conclusions, whilst another user felt non-disclosure would simply indicate that the person had decided not to disclose.

> *I don't think that not posting one's status means he's positive. It just means the guy don't say nothing about his status.* (PF)

Privacy, and the right to choose is an important aspect of disclosure in any online environment. This is especially true within this context as it enabled people to manage their own concerns. For some, choosing not to disclose is a way of avoiding stigma, for others stigma is avoided through disclosure. Either way, if disclosure choice is removed, privacy of the user is impacted which could have a negative impact on levels of trust around HIV information online.

5 DISCUSSION

The goal of this study was to explore user views of an HIV intervention integrated into a geosocial hookup app, and its potential to impact on user privacy. In this section, we first discuss some of the contrasting views identified in our analysis. We then explore the social impact of introducing HIV status information into an online geosocial hookup environment which reveals why some users develop privacy concerns. In exploring social impact, we identify the presence of a social privacy problem which can result in assumptions developing around users who choose not to disclose. Finally, using four previously identified limits to privacy unraveling [46], we propose a number of descriptive conceptual designs to provide a first look at how these limits could be applied in design within this context.

5.1 Understanding the Users

Our analysis identified three main groups with varying views related to this HIV intervention: (1) The first group which we refer to here as the privacy group was concerned that the public disclosure of their HIV status information could lead to increased exposure to stigma, or that Grindr was an inappropriate environment to disclose such information. Our findings are consistent with previous studies which report fear of rejection [19, 63] and privacy concerns related to HIV stigma [1, 29, 52] as being reasons to withhold the disclosure of their HIV status information. We found this to be particularly pertinent in the case of disclosing publicly where much less control over the dissemination of the information is afforded to the individual. As such, this group preferred one-to-one HIV related discussions to increase disclosure control. (2) The second group consisted of HIV positive users who identified a benefit to publicly disclosing their HIV status to others as it provided them with a means of reducing their stigma exposure. When contacting and being contacted by other users, they expressed uncertainty over how their HIV status would be perceived. Supporting previous research [18], we found this group utilising public disclosure to reduce this uncertainty, allowing them to organically filter and be filtered out by individuals with whom they were at greater risk of HIV related stigma and rejection. We also found evidence to support previous research [20, 43] that some users within this group used public disclosure to help reduce HIV related stigma and normalise HIV through a more open disclosure approach. (3) Finally, for HIV negative users who were concerned about being infected with HIV, they viewed the publicly disclosed HIV status of others as a way of avoiding contact with HIV positive individuals, with the aim of lowering their risk of infection [63].

5.2 Limiting Social Interactions through Public Disclosures

Of the three main groups identified, two groups publicly disclosed their HIV status, either to reduce stigma exposure or to reduce perceived sexual risk. The privacy group preferred to restrict this information to one-to-one interactions. Whilst the focus on this study is on public HIV disclosure using this explicit HIV disclosure field, we are currently conducting a follow-up study to explore disclosure strategies which include these one-to-one interactions. In this section, we aim to understand the potential impact of failing to respect the views of this privacy group and explore the potential limitations they face when interacting in this environment if their privacy is violated.

When privacy is understood as a functional requirement for identity management, associating sensitive, potentially stigmatising information to an existing online identity can cause concerns that identity will become disrupted. When interacting in any online social environment, uncertainty exists over how information being disclosed about the self will be perceived by others and whether that information will be managed appropriately [45]. For example, in Emlet's [22] interview study with HIV positive individuals, they found 25% of their participants had the confidentiality of their HIV status violated by others at some point.

Uncertainty over the functionality of online social environments, the social norms present, and the users operating in these environments is likely to reduce through observational learning [6, 64]. These interactions can help users develop confidence in the environment prior to disclosure. However, when users publicly disclose information, they are no longer required to ask questions before learning new information about each other, reducing awareness of what people are interested in knowing. As an example, the immediacy with which someone requests personal information and the way they ask, is feedback which can help in forming opinions and trust. This is lost when individual disclosure choice is removed. This can be especially pertinent in the context of HIV, with our findings supporting previous research which shows users being concerned about the social stigma HIV creates, and the rejection it can cause [19, 63]. This can be especially pertinent for

those recently diagnosis, with MSM reporting high rates of mental illness in the 12 months post diagnosis [56]. As such, research has identified the need to support these individuals by fostering positive interactions during this period [58].

Respecting the privacy of this group can provide them with control and choice over when and who they disclose to. However, disclosure choice is not limited to when, who or even if information is revealed, but also how the information is relayed. Disclosing an HIV positive status - often perceived as a socially undesirable attribute – is not consistent with people's initial interaction goals of maximising social desirability [27]. Gradual, mutual self-disclosures can help develop trust between users, reducing uncertainty over how the other person may respond to new information. Self-disclosing within an emotionally constructed, contextualised narrative allows users to better manage the impressions they give-off. Public disclosures - often void of these narratives - may lead the information receiver to develop their own narrative and, where a person holds out-of-date or even stigmatising views of HIV, the narrative they develop is likely to align with those views, increasing the risk of rejection. Our findings show HIV positive respondents often mitigate this by disclosing later on in the interaction in more intimate one-to-one conversations (private chats). This increases disclosure control, allows them to shape their own narrative, and is an opportunity to educate those with less knowledge and awareness of HIV. However, if these users feel unable to keep this information private using the options currently available, this form of disclosure choice becomes limited.

When disclosure choice is limited, users may develop other strategies to keep their information private. As our findings and previous literature have shown [14], the fear of rejection individuals face as a result of HIV related stigma can lead users to misreport their HIV status. Whilst introducing this information into Grindr and similar environments could have a positive impact, it is important that information being disclosed is reliable. If users who feel unable to disclose are limited in their non-disclosure choice, this has the potential to increase HIV status misreporting. For this reason, we focus on non-disclosure choice and explore the potential impact privacy unraveling can have, and ways in which this effect can be reduced.

5.3 "Unraveling" HIV Non-Disclosures

The privacy group were concerned at the public nature in which their HIV status would be available. As discussed, publicly disclosing sensitive information can limit a person's ability to manage their identity and can inhibit aspects of social interaction. To avoid this, the privacy group have the option to select 'Do not show', allowing them to keep their HIV status private. However, consistent with previous findings [48], the unequal costs to disclosure between HIV positive and negative states can cause social assumptions to develop which can act as stigmatising signals. We identify this as the privacy unraveling effect [46] occurring in an online social environment where individuals are utilising signals (through disclosure) to maintain their social desirability. Recall the Universal Design principle of Equitable Use. This states that any system should be designed in such a way that it neither disadvantages nor stigmatises any group of users [9]. The unequal sensitivity of HIV status information across users mean that requesting users to publicly disclose using this current design would violate this principle and limit the reality of disclosure choice for users wishing to keep their status undisclosed.

The appropriateness of sharing sensitive and often stigmatising health data in an online environment like Grindr was questioned in some comments. Contextual inappropriateness, as well as stigma associated with HIV could affect HIV positive and negative users alike, both of whom may prefer not to disclose their status publicly. Our findings show users may feel increased pressure to disclose their status through fear of non-disclosure creating stigmatising signals. Unless positive users misreport their status as being either negative, or perhaps even negative on PrEP, the privacy

unraveling effect could result in stigma being attached similarly to both disclosed and non-disclosed states. Similarly with increased usage of PrEP and the stigma associated with the preventative drug [28, 35], users may feel pressured to disclose, with non-disclosure similarly attracting stigma. However, it is important to note that this unraveling effect may differ across cultures. As our data was collected from English language, western media outlets, it is likely to have a cultural bias. A future study exploring the cultural impact of these effects will be conducted.

5.4 Designing out Privacy Unraveling

In this section of the paper, we draw on Peppet's [46] four limits to privacy unraveling to propose a set of descriptive conceptual public HIV status disclosure designs. We use these conceptual designs to explore the potential benefits and restraints of using these unraveling limits in this context, to explore more detailed segregation of the limits, and to stimulate further research and discussion around privacy unraveling within the privacy and social computing communities. The conceptual design artefacts developed are not intended to change the outcome of the intervention, but to increase the privacy it affords users who prefer to keep their HIV status information undisclosed. As such, we focus the design of these artefacts on marginalised groups who experience higher risk of social stigma.

5.4.1 Transaction Cost. The first limit of privacy unraveling occurs when the cost of disclosing is increased, limiting the signal created through non-disclosure. In effect, increasing transactional cost for HIV negative users is intended to artificially re-balance the cost of HIV status disclosure. We propose a more detailed segregation of transaction cost than Peppet, proposing three sub-categories (financial, functional and time) to artificially inflate transaction cost. In making the disclosure of a desirable attribute more difficult or costly, it is more likely that other users would assume non-disclosure is a result of these associated disclosure costs, and less likely to infer an undesirable attribute.

To increase the financial cost of disclosing HIV status information, this design limits the disclosure of HIV status information to "premium" users who pay for using the app. Most dating applications, including Grindr, provide users with the ability to pay for membership to remove adverts and increase functionality. The aim of this design is to reduce the stigma signal associated with non-disclosure of HIV status by associating a financial cost with disclosing. However, restricting disclosure to paid users would also limit the numbers disclosing and engaging with the intervention which could reduce the intervention's overall effectiveness. Lastly, if a sufficient portion of users utilise the premium service to disclose a negative HIV status, this could stigmatise and, thus, disadvantage people who are unwilling or unable to pay for premium features.

Our second design concept increases transactional cost by limiting software functionality for users who choose to disclose their HIV negative status. For example, users who choose to disclose could be limited in their use of in-app features such as attribute filters e.g. filters for age and ethnicity. In this example, users who disclose their HIV negative status would then be limited to applying 1 filter, instead of the normal 2 and made aware of this cost prior to disclosing. Alternatively, people could be limited in the overall number of attributes available to disclose, including attributes such as age, weight, ethnicity, and HIV status. Knowledge of these costs would then propagate within the community, increasing known transactional cost around a negative HIV status disclosure. For the privacy group, this would help disguise their non-disclosure, whilst for the other groups, disclosure remains an available option.

A similar functionality cost existed prior to Grindr introducing the HIV intervention. Some users would disclose their HIV positive status in the free-text field on their profile [11]. This area has a character limit, and so disclosing would reduce the available characters, limiting space to present

themselves to others. Unlike the financial transactional cost, this transactional cost would allow all users to disclose their HIV status. However, it is questionable whether disadvantaging a certain demographic of users is an appropriate design choice and one that a commercial entity would be willing to implement.

Finally, we develop a time transactional cost approach by implementing a pre-disclosure process that requires the user's attention and interaction. This pre-disclosure process could include educational and awareness information related to HIV. For example, if a user decided to disclose their HIV status, they could be required to watch an educational video or to scroll through a series of educational screens or quizzes prior to disclosing. This would act as a transactional time cost that could both educate and limit the privacy unraveling effect. Unlike the financial solution, this does not limit the disclosure function to a sub-set of users, and does not remove any functionality, but instead serves as an educational and HIV awareness feature. For the two groups who choose to disclose, this design would not inhibit them in doing so except for the slight increase cost in time required.

It would be important to evaluate this solution for its long-term effectiveness to ascertain whether expectations develop around the engagement with these designs that could reduce perception of costs over time. It would also be important to understand potential unintended consequences of these designs. For example, increasing the transaction cost of disclosing in order to benefit HIV positive users might cause HIV negative users to question why they were being disadvantaged, which could increase stigma towards HIV positive users. One advantage of the last design is the nature in which it is disguised within a wider HIV awareness intervention, and may even help to reduce stigma around HIV and hence to reduce the social cost of disclosing an HIV positive status.

5.4.2 Unverifiability of Ignorance. Another method of limiting unraveling is to make it more difficult for the signal receiver to be able to verify that the concealing party (signal sender) is aware of the state of their own attribute, which in this case is their HIV status. For example, Alex would be unable to unravel Bob's HIV status if Alex was unable to verify that Bob knew his own status. One method of implementing this into design would be to introduce an explicit 'I don't know' HIV status option, designed to create uncertainty over the awareness the user has of their own status. There are however a number of problems with this approach. Firstly, if a user publicly states that they are unaware of their own HIV status, this could create an undesirable signal that they are not taking care of their sexual health. Secondly, if used by an HIV positive user, it would be an inaccurate statement which could raise concerns of legal ramifications.

An alternative approach again draws on time, but in this design it is used to artificially increase unverifiability of ignorance. This approach implements an idle period against a person's HIV negative status so a person's status would change independently to "undisclosed" after a certain amount of time, e.g. 6 months (in line with existing HIV testing guidance). This would allow users who do not want to disclose their status to disguise themselves as people who haven't spotted that their profile idled back to the undisclosed state. For HIV negative users, it would also promote a periodic sexual health check. For HIV positive users who choose to disclose, their status would not need to be reset and could remain static to avoid having to repeat this unnecessary disclosure step. Whilst this could lead to stigma for users who do not keep their profile up-to-date, this stigma would only be likely if the majority of other users frequently updated their profile information.

5.4.3 Inability to Accurately Infer the Negative. The third limitation occurs when it is not possible to accurately infer an undesirable attribute through non-disclosure. Previous attempts have been made to introduce ambiguity into the HIV disclosure process which could help reduce users' ability to infer undesirable attributes. One real-time MSM dating website requires all of their users to disclose their HIV status, but provides an optional "Ask Me" flag to limit disclosure to others [33].

This removes the non-disclosure state but replaces it with an "Ask Me" state. Whilst this does set itself apart from the more traditional approaches of providing a non-disclosure option, a state still exists around which undesirable assumptions can be inferred. Drawing on this approach, our design concept uses similar ambiguities, but includes data clustering to remove these single non-disclosure states. An example of this would be information grouping, allowing users to mark a group of fields as undisclosed rather than each individually. It is important to note here that HIV status information is not the only information type that is subject to social stigma within these environments. Age, weight, ethnicity, and other information types can be a cause of stigma [32], or even stigma upon stigma (e.g. an older HIV positive man may be stigmatised for his age as well as his HIV status). This design would create uncertainty over all the explicit fields the user is unwilling to disclose publicly, reducing the accuracy around inferences made, whilst at the same time allowing disclosure of information for those who choose to make it public.

5.4.4 Norms. The final limit of privacy unraveling can occur when norms develop around non-disclosures. Previous research identified disclosure norms which have developed around the exchange of pictures in MSM hookup apps, with some conversations being dependent on the exchange of personal pictures (e.g. "no pic no chat") and certain requirements being applied to these pictures (e.g. "no headless torsos") [59]. However, around HIV status information, apps like Grindr could encourage norms to develop within their environments by removing the option to disclose an HIV negative status, e.g. providing disclosure options for every status other than HIV negative and negative on PrEP, effectively allowing only positive users to disclose. The benefit of this approach would be a limitation of the unraveling effect, as stigmatising assumptions would be much less likely to develop around non-disclosure when not all disclosure options are available within the explicit field. However, removing the option for HIV negative users would limit engagement with the intervention, and may further isolate HIV positive users who would be singled out when disclosing their status. Alternative HIV reporting models have been introduced in other MSM dating environments that move away from explicit HIV negative status disclosure. The dating app Scruff for example does not provide users the option to disclose HIV status information, instead it asks users to disclose their safer sex practices i.e. Condoms, PrEP, Treatment as Prevention (TasP). Interestingly they also build ambiguity into their design by not explicitly stating whether these safer sex practices are ones the user is adhering to, or practices they are looking for in others. This approach however would disadvantage HIV positive users who disclose publicly to avoid HIV related rejection, as well as HIV negative users wanting to be open about their status and aware of the status of others.

5.4.5 Cultural Signals. Whilst not a limit of unraveling, designers could also consider ways to reduce the stigmatising costs of disclosing a HIV positive status within these types of geosocial hookup applications. Previous efforts have been made to attempt culture changes in MSM dating environments by asking users to pledge to live "stigma free lives" [39]. Whilst this would not limit the unraveling effect around non-disclosures, it might reduce the cost of unraveling if it occurred, through reduced social stigma associated to the undesirable attribute.

6 LIMITATIONS

The methods used in this research were limited in that we were unable to ascertain the demographic information of people who posted comments. As previous mentioned, the comments analysed were associated with English language news websites and blog posts, so our data is likely to be under-representative of certain demographics. We cannot exclude the possibility that people cross-posted across websites. Using this data collection method, we were unable to direct the conversation to

explore themes further. The sample size was pre-determined by the study design, although we have no indication that a larger sample would have been necessary.

7 FURTHER WORK

In conducting this research, we have identified several areas of further research which could help develop our understanding of privacy unraveling within the privacy and social computing fields. Firstly, we suggest the development of a quantitative measure for evaluating the level of privacy unraveling that exists around sensitive data in online social environments. This would allow future researchers to evaluate unraveling reducing designs such as those proposed in this paper. Using this measure, we recommend that HIV disclosure designs in existing MSM dating applications be evaluated alongside alternative prototype designs, allowing us to further investigate unraveling limitations. Finally, we are conducting an in-depth interview study with HIV positive and negative users to understand the implications of the unraveling effect in greater depth. This follow-up study will provide a better understanding of how users develop strategies around signals that develop within these online environments. Finally, we propose an observation study to explore the external validity of our findings which, currently rely on self-reported data.

8 CONCLUSIONS

In this paper, we present the findings from an online qualitative analysis of online comments about an HIV intervention that was integrated into the online geosocial hookup app Grindr. Our analysis identified privacy concerns when linking sensitive health information to an existing online identity due to the stigma that HIV attracts. We found this stigma can create a barrier to disclosure, with some users choosing to keep their HIV status information private to reduce their stigma exposure, which supports previous research. In addition to this, we also found that fear of being stigmatised caused some men to publicly disclose, as it allowed them to organically filter out, or be filtered out by users who they were at greater risk of HIV related stigma and rejection. Where users preferred to keep their HIV status information private, we identified a limit to the non-disclosure options that Grindr provides. We found that the HIV status of users who choose not to disclose can sometimes be inferred through their non-disclosure decision, an effect known as *privacy unraveling*. To address this, we reviewed four methods that can limit this effect [46], for which we developed a number of sub-categories and descriptive conceptual designs to explore the potential for these limits to be applied in design within this context. By doing so, we extend the literature on privacy unraveling and identify a new application domain within online social environments.

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