

# **Signalling and Unravelling: (Non)Disclosure of HIV Status Information in Sex-Social Apps Used by Men Who Have Sex With Men**

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I, Mark Warner, confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the work.

# Abstract

As people's offline and online social lives become increasingly entwined, the sensitivity of the information people disclose online increases. Personal information is often disclosed through structured disclosure fields (e.g. drop down selections). This thesis explores privacy and disclosure attitudes and behaviours around these types of fields within the context of HIV status disclosure in sex-social apps used by men who have sex with men (MSM).

Mixed methods were used to understand user attitudes towards, and privacy and disclosure behaviours around, these fields. These included an analysis of online comments related to Grindr's HIV status disclosure field, semi-structured interviews with people living with HIV and HIV negative app users, and an online study simulating a dating app environment to better understand how HIV status non-disclosures affect people's evaluation of online dating profiles.

Analysis of online comments suggests that these fields may be susceptible to a social effect known as *privacy unravelling*. This can result in those not disclosing being perceived as hiding some unfavourable information, limiting the voluntary nature of these fields. Analysis of the interview data using signalling theory found support for *privacy unravelling*, and identified a potential benefit of this effect which allows for indirect forms of disclosure. Analysis of the interview data using motivation theory to understand why users choose to disclose their HIV status within these sex-social environments highlights the failure of these fields to support narrative rich forms of disclosure. Measuring *privacy unravelling* in the final study found that its effect can be limited by reducing the visibility of undisclosed information fields, but that minority groups may continue to be affected by *privacy unravelling*,

irrespective of the visibility of the undisclosed information field.

This thesis highlights how the loss of a rich narrative around HIV disclosures can reduce motivation to disclose. It shows how *privacy unravelling* can limit the voluntary nature of structured disclosure fields, and how design can reduce this effect. Finally, it contributes new insights into how social technologies can be appropriated through the evolution of new meaning around digital artefacts to enable indirect forms of sensitive information disclosure.

# Impact Statement

This thesis investigates how designing sensitive information disclosures into online social environments using structured disclosure fields affects privacy and disclosure behaviours.

The findings from this research have an impact both within and outside of academia. Within academia, this research has extended our understanding of how people interact with structured disclosure fields. Firstly, it has shown how these fields can be susceptible to a social effect that disadvantages users who choose not to disclose. Secondly, this work shows how structured disclosure fields that appear fixed in their design, can be appropriated by users by cultivating new meaning around disclosure options. This finding, and the subsequent notion of signal appropriation that has been developed, can be used by future researchers when exploring behaviours around online social technologies. Finally, this research provides new insights into HIV disclosure behaviours in sex-social apps, advancing our understanding of both how and why MSM disclose their HIV status using structured disclosure fields within sex-social apps.

Outside of academia, this research is relevant to designers of online social platforms, as well as policy makers, sexual health professionals, and public health professionals. Whilst introducing sensitive information such as HIV status information can help tackle stigma around the virus, this research highlights a number of limitations of these fields. The findings from this study can impact on the future development of social technologies which include disclosures of sensitive information attributes, such as HIV. From a policy and public health perspective, this research highlights how public HIV health campaigns not only educate people, but are used

by MSM as conversation tools to help them talk about HIV. This knowledge could be used by sex-social app designers, allowing them to develop better educational and disclosure mechanisms that are supported by these social narratives. This knowledge could also be useful to sexual health professionals providing disclosure advice and guidance to recently diagnosed individuals.

During this research, the researcher was involved in delivering a workshop on conducting research with stigmatised populations. This workshop resulted in a large number of ideas being developed in this area, and discussions continue with people within and outside the workshop to progress research practices that promote sustainable research with stigmatised populations.

# Publications

The following publications have been incorporated into this thesis:

**Warner, M.**, Kitkowska, A., Gibbs, J., Maestre, J and Blandford, A. (2020) Evaluating ‘Prefer not to say’ Around Sensitive Disclosures. In *CHI Conference on Human Factors in Computing Systems Proceedings (CHI 2020), April 25 - 30, 2020, Honolulu, Hawaii, USA*. ACM, New York, NY, USA, 13 pages. <http://doi.org/10.1145/3313831.3376150>

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**Warner, M.**, Gutmann, A., Sasse, M.A., and Blandford, A. (2018) Privacy Unraveling Around Explicit HIV Status Disclosure Fields in the Online Geosocial Hookup App Grindr. In *Proceedings of the ACM on Human-Computer Interaction Vol. 2, CSCW (November 2018)*, 22 pages. <https://doi.org/10.1145/3274450>

**Warner, M.** and Blandford, A. (2018) Do I Really Have To Publicly Disclose My HIV Status? In *CHI Conference on Human Factors in Computing Systems Workshop Moving Beyond a ‘One-Size Fits All’ Approach: Exploring Individual Differences In Privacy*. (CHI 2018), April 21 – 26, 2018, Montreal, Canada. ACM, New York, USA.

The following publications are related to work presented in this thesis:

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Maestre, J., Eikey, E., **Warner, M.**, Pater, J., Jacobs, M., Yarosh, S., Marcu, G. & Shih, P. (2018). Conducting Research with Stigmatized Populations: Practices, Challenges, and Lessons Learned. In *Companion of the 2018 ACM Conference on Computer Supported Cooperative Work and Social Computing* (pp. 385 – 392). ACM. <https://doi.org/10.1145/3272973.3273003>



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# Contents

<b>1</b>	<b>Introduction</b>	<b>21</b>
1.1	Motivation and Research Objectives . . . . .	24
1.2	Overview of Chapters . . . . .	30
1.3	Contributions . . . . .	32
<b>2</b>	<b>Related Work</b>	<b>34</b>
2.1	Privacy and Disclosure Management Online . . . . .	35
2.2	Privacy Unravelling . . . . .	37
2.3	Case Study Related Literature . . . . .	39
2.3.1	Human Immunodeficiency Virus (HIV) . . . . .	39
2.3.2	HIV Related Stigma and Disclosure . . . . .	41
2.3.3	The Impact of Disclosing HIV Status Information . . . . .	44
2.3.4	HIV Threat to Identity . . . . .	45
2.3.5	Structured HIV Status Disclosure Fields . . . . .	46
2.4	Conclusions and Research Direction . . . . .	47
<b>3</b>	<b>User Attitudes Towards a Newly Introduced Structured HIV Status Disclosure Field in Grindr</b>	<b>48</b>
3.1	Introduction . . . . .	48
3.2	Background . . . . .	49
3.3	Method . . . . .	50
3.3.1	Use of Online Comments . . . . .	50
3.3.2	Data Collection . . . . .	51
3.3.3	Comment Analysis . . . . .	52

	<i>Contents</i>	13
3.3.4	Ethics of Using Online Data . . . . .	53
3.4	Findings . . . . .	54
3.4.1	Managing Sexual Health . . . . .	54
3.4.2	Managing Stigma . . . . .	56
3.4.3	User and Information Trust . . . . .	57
3.4.4	Providing Disclosure Choice . . . . .	59
3.5	Discussion . . . . .	60
3.5.1	Understanding the Users . . . . .	61
3.5.2	Limiting Social Interactions through Public Disclosures . . . . .	62
3.5.3	“Unravelling” HIV Non-Disclosures . . . . .	64
3.5.4	Implications . . . . .	65
3.5.5	Limitations . . . . .	65
3.6	Conclusions . . . . .	66
<b>4</b>	<b>Interview Study Methodology</b>	<b>67</b>
4.1	Introduction . . . . .	67
4.2	Participant Sampling and Recruitment . . . . .	68
4.2.1	Sampling Method . . . . .	69
4.2.2	Recruitment Strategy . . . . .	70
4.3	Data Collection . . . . .	71
4.4	Analysis Approach . . . . .	72
4.5	Ethics . . . . .	75
<b>5</b>	<b>Managing Privacy Through Signal Appropriations of Structured HIV Status Disclosure Fields</b>	<b>76</b>
5.1	Introduction . . . . .	76
5.2	Background and Related Work . . . . .	77
5.2.1	Signalling Theory . . . . .	77
5.2.2	Signals and Cues in HCI . . . . .	79
5.3	Analysis Method . . . . .	81
5.4	Findings . . . . .	82

5.4.1	Changing Cost Dynamics . . . . .	83
5.4.2	Non-Disclosure Cue . . . . .	84
5.4.3	Signal Reliability . . . . .	85
5.4.4	Signalling Strategies . . . . .	87
5.5	Discussion . . . . .	90
5.5.1	Cultivating Stigma Reduction . . . . .	90
5.5.2	Signal Appropriation . . . . .	91
5.5.3	Harmful Evolution of Signals . . . . .	94
5.5.4	Implications . . . . .	95
5.5.5	Limitations . . . . .	97
5.6	Conclusions . . . . .	97

**6 Exploring Motivation to Disclose HIV Status Using Structured Disclosure Fields in Sex-Social Apps 99**

6.1	Introduction . . . . .	99
6.2	Background and Related Work . . . . .	100
6.2.1	Motivation Theory . . . . .	100
6.2.2	Human Values . . . . .	103
6.3	Analysis Method . . . . .	104
6.4	Findings . . . . .	106
6.4.1	How Are People Disclosing HIV in Sex-Social Apps? . . . . .	106
6.4.2	Global Level . . . . .	107
6.4.3	Contextual Level . . . . .	112
6.4.4	Situational Level . . . . .	119
6.5	Discussion . . . . .	120
6.5.1	Stigma's Influence on Disclosure Motivation . . . . .	121
6.5.2	Taking Control Over the Narrative . . . . .	124
6.5.3	Disclosure as a Gateway to Support . . . . .	125
6.5.4	Reshaping Perceptions Around HIV . . . . .	126
6.5.5	Implications . . . . .	126
6.6	Conclusions . . . . .	127

<b>7</b>	<b>Measuring the Effect Non-Disclosure of HIV Status Has On Profile Desirability</b>	<b>129</b>
7.1	Introduction . . . . .	129
7.2	Background and Related Work . . . . .	131
7.2.1	Designing for Non-disclosure . . . . .	132
7.2.2	Social Norms Around Disclosure . . . . .	134
7.3	Method . . . . .	135
7.3.1	Study Variables . . . . .	135
7.3.2	Participant Recruitment . . . . .	138
7.3.3	Data Collection . . . . .	139
7.3.4	Experiment Overview . . . . .	139
7.3.5	Pilot Testing and Profile Design . . . . .	142
7.3.6	Consent and Ethics . . . . .	146
7.3.7	Analysis . . . . .	146
7.4	Results . . . . .	147
7.4.1	Interface Design . . . . .	149
7.4.2	Social Disclosure Norms . . . . .	151
7.4.3	Additional Analysis . . . . .	151
7.5	Discussion . . . . .	152
7.5.1	Is Privacy Unravelling Around These Structured Disclosure Fields? . . . . .	152
7.5.2	Social Disclosure Norms . . . . .	154
7.5.3	Impact of Other Profile Information . . . . .	155
7.5.4	Privacy Unravelling as an Indirect Disclosure . . . . .	156
7.5.5	Ambiguity Around Non-Disclosures . . . . .	156
7.5.6	Implications . . . . .	158
7.5.7	Limitations . . . . .	158
7.6	Conclusions . . . . .	159
<b>8</b>	<b>Discussion</b>	<b>160</b>
8.1	Summary of Research . . . . .	160

	<i>Contents</i>	16
8.2	Case Study Specific Discussion . . . . .	162
8.3	Loss of Narrative Rich Disclosure . . . . .	164
8.4	Signal Appropriation . . . . .	165
8.5	Privacy Unravelling Online . . . . .	167
8.5.1	Peppet's Unraveling Limits . . . . .	168
8.5.2	Privacy Unravelling as an Indirect Disclosure Mechanism . . . . .	170
8.5.3	Countersignaling . . . . .	171
8.5.4	Privacy Unravelling Tension . . . . .	171
8.5.5	Implications and Design Considerations . . . . .	172
8.6	Limitations . . . . .	174
8.6.1	Deductive Data Analysis . . . . .	174
8.6.2	Participant Sampling . . . . .	174
8.6.3	Use of Profile Pictures . . . . .	175
8.6.4	Longitudinal Effects . . . . .	175
8.7	Further Work . . . . .	176
8.7.1	Testing Peppet's Proposed Privacy Unravelling Limits . . . . .	176
8.7.2	Generalizability of Privacy Unravelling . . . . .	176
8.7.3	The Impact of Privacy Unravelling on Minority Groups . . . . .	176
8.7.4	Exploring Cultural Differences . . . . .	177
8.7.5	Additional Testing Variables . . . . .	177
8.7.6	Online Stigma Reduction Strategies . . . . .	178
<b>9</b>	<b>Conclusions</b>	<b>179</b>
	<b>Bibliography</b>	<b>182</b>
	<b>Appendices</b>	<b>207</b>
<b>A</b>	<b>Semi-Structured Interview Materials (Chapters 5, and 6)</b>	<b>207</b>
A.1	Participant Information Sheet . . . . .	207
A.2	Informed Consent Sheet . . . . .	211
A.3	Pre Interview Survey . . . . .	213



A.4 Interview Guide . . . . .	217
<b>B Quantitative Study (Chapter 7) Materials</b>	<b>221</b>
B.1 Participant Information Sheet . . . . .	221
B.2 Informed Consent Sheet . . . . .	224
B.3 Test Profile Data Set . . . . .	225

# List of Figures

2.1	Cropped screenshots of the HIV disclosure fields in Grindr (left), and Scruff (right). . . . .	47
3.1	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. . . . .	52
4.1	Bar chart showing age distribution of participants, separated by HIV status (n=27). . . . .	73
4.2	Bar chart showing years since diagnosis for all participants self-reporting to be living with HIV (n=13). . . . .	73
5.1	Cropped screenshots of the HIV disclosure fields in Grindr (left), and Scruff (right). . . . .	92
6.1	The Hierarchical Model of Intrinsic (IM) and Extrinsic (EM) Motivation Vallerand (1997, 2000) . . . . .	101
6.2	Bar charts showing participants (N=27) self-reported public HIV disclosures in sex-social apps, separated by HIV status. . . . .	107
7.1	Example of a profile pair (disclosed/undisclosed). The first profile shows ‘Mike’ who discloses his HIV status. The following three profiles show Mike’s profile repeated but with the name switched to Matt and with HIV status undisclosed. The three profiles show how undisclosed HIV status information appears in the three different design conditions: (a) visible, (b) hidden, and (c) ask me. . . . .	136

7.2	Overview of the different stages of the study method which is described in detail in the methods section. . . . .	139
7.3	Screenshots of the edit profile screens shown to participants before they start the profile rating task. These are designed to familiarise participants with the profiles before viewing and rating them. The left screen is shown to participants in the <i>Visible</i> condition, the middle shown in the <i>Hidden</i> condition, and the right screen shown to participants in the <i>Ask Me</i> condition. . . . .	140
7.4	The effect of HIV status information on profile ratings. Error bars: CI 95%. . . . .	149
7.5	This figure shows the estimated marginal mean rating of all test profiles. This includes rated profiles that disclosed HIV status information, as well rated profiles that did not disclose an HIV status (y-axis). The mean ratings are presented across the three interface design conditions (x-axis). Error bars: CI 95%. . . . .	150
7.6	This figure shows the estimated marginal mean rating of all test profiles. This includes rated profiles that disclosed HIV status information, as well as rated profiles that did not disclose an HIV status split into non-minority and minority ethnic profiles (y-axis). The mean ratings are presented across the three interface design conditions (x-axis). Error bars: CI 95%. . . . .	153
8.1	Pepe the frog is an example of new meaning developing around a digital artefact, with the frog being appropriated to become a symbol of the alt-right movement (Zannettou et al., 2018). . . . .	166
A.1	Semi-structured Interview Guide - Online Social Media Use . . . . .	218
A.1	Semi-structured Interview Guide - Online Social Media Use . . . . .	219
A.1	Semi-structured Interview Guide - Online Social Media Use . . . . .	220

# List of Tables

1.1	Summary of the different HIV status options . . . . .	28
5.1	Abbreviated HIV status symbols and number of participants were reported HIV status . . . . .	82
7.1	Distribution of profiles disclosing HIV status in each test set distributed to all participants across each condition. . . . .	138
7.2	Distribution of disclosed HIV status information in the set of profiles used to prime participants in the high and low social disclosure norm conditions. . . . .	141
7.3	Summary of demographic information of study sample ( $N = 183$ ). . . . .	143
7.4	Descriptive statistics for mixed design ANOVA model. . . . .	148
7.5	Pairwise comparison of estimated means between the designs conditions. . . . .	151
B.1	Profile Data Used In Test Profiles . . . . .	226

## Chapter 1

# Introduction

Online social and dating platforms such as Facebook, Twitter, Tinder and Grindr provide people with new ways of establishing and maintaining relationships and communities. This has resulted in people from across the world using a variety of online platforms to share information about their lives, from mundane everyday events to deeply personal and sensitive information. Self-disclosure helps people engage in what Goffman (1959) refers to as self-presentation. This behaviour allows people to accentuate or mask different aspects of their self within different contexts to help them achieve their goals. People use self-disclosure to engage in online self-presentation through the curation of online profiles (Silfverberg et al., 2010). This can help influence how others perceive them online. For instance, a person may accentuate an aspect of their self to appear more attractive in an online dating app (Ellison et al., 2006) whilst masking the same attribute on an employment-oriented website like LinkedIn to appear more professional. Yet, online social platforms often fail to support people in this form of self-presentation. Marwick and Boyd (2011) highlight how some of these technologies (e.g., Twitter) 'collapse' audiences from different contexts into one, making it much more difficult for people to engage in effective self-presentation on a single platform. Moreover, information disclosed on these platforms is very often indiscriminately viewed, making it difficult for users to manage their individual privacy. Online environments susceptible to this form of context collapse are referred to as context collapsed environments.

Most online social platforms are now accessible via location-aware smart-

phone apps, increasing their ubiquitous nature and further entwining people's online and offline lives (Blackwell et al., 2015). Online dating apps are a good example of this. Their location-aware nature can help people find nearby prospective partners, but can merge online dating with other offline contexts. For instance, people co-located in an office environment may discover each other in a dating app.

Other forms of social threat can lead to concerns over information being self-disclosed online (Krasnova et al., 2009). For instance, concerns of stalking, inappropriate messages, and violence can result in people restricting self-disclosures on dating profiles (Cobb and Kohno, 2017). Whilst privacy is often characterised as a form of information restriction (Nissenbaum, 2009), this is in tension with self-disclosure being a pre-requisite to online participation (Marwick and Boyd, 2014). To help resolve this tension, people may engage in more strategic forms of self-disclosure, especially around sensitive information.

Since starting this research, there has been a growing body of work exploring sensitive self-disclosure behaviours online. Haimson et al. (2018) explored how people disclose relationship breakups on Facebook, which highlights how subtle disclosures (e.g., changing relationship status), and selective disclosures (e.g., messaging Facebook friends individually) are used to manage privacy. Similar forms of subtle online disclosures have been identified around pregnancy loss, with women using hints and other forms of indirect disclosure to reveal their loss to people online (Andalibi et al., 2018a). Prior to this more recent research, Boyd and Marwick (2011) coined the term 'social steganography' to describe the concealing of a message within a message. This relies on the sender knowing that a sub-set of their audience will be able to interpret the hidden part of their message, enabling a form of selective self-disclosure in plain sight. These indirect disclosure strategies allow people to reveal sensitive aspects of their self within online social spaces to participate within these online communities, whilst limiting the social risks that open-disclosure can expose them to. They often require people to curate carefully constructed, personalised messages using ambiguity as a means of increasing the subtlety around information disclosed (e.g., Marwick and Boyd (2014);

Andalibi et al. (2018a); Haimson et al. (2018)). Yet, the design of online disclosure fields in some online social platforms can make this form of curation much more challenging.

Most widely-deployed form fields can be characterised as being either unstructured, semi-structured, or structured. An example of an unstructured field is the status update feature in Facebook which asks “What’s on your mind?” and allows users to input a personalised message that lacks any pre-defined categorisation of the information disclosed. Semi-structured fields ask users for a particular piece of information, but allow for a personalised response. For instance, within Facebook users can add the name of their employer in a text box and are not constrained in what they can disclose. Structured disclosure fields differ from both the aforementioned fields as they do not allow personalised user inputs, instead they constrain disclosures to a set of pre-defined options, such as the gender identity disclosure field in Facebook (Haimson et al., 2015b).

Haimson et al. (2015b) highlights how using structured disclosure fields for requesting gender information can limit individualised expressions of identity by constraining users to a fixed array of choices. These fields may also limit marginalised users in engaging in what Andalibi et al. (2018b) refer to as “indirect disclosure”. This enables a form of selective disclosure through the use of implicit cues embedded within messages. Structured disclosure fields commonly provide users with a non-disclosure option. However, this research suggest that this may be an ineffective means of providing users with disclosure control, as the act of non-disclosure may lead to information being inferred about an individual by other users: an effect known as “privacy unravelling” (Peppet, 2011).

Whilst prior work highlights disadvantages to using structured disclosure fields, especially around sensitive information attributes, these are in tension with some of their advantages. For instance, structured fields allow for classification of data within a system, which is more challenging around unstructured data (Bowker and Star, 2000). Their constrained design can also help formalise and de-stigmatised language around stigmatised identities (Levy and Barocas, 2017). For instance,

reducing the use of the word 'clean' in reference to someone who is HIV Negative. The use of this word is stigmatising as it suggests people living with HIV are somehow unclean or dirty.

## **1.1 Motivation and Research Objectives**

Whilst prior research has explored privacy and disclosure behaviours around unstructured and semi-structured fields that allow for personalised responses (e.g., Marwick and Boyd (2014); Andalibi et al. (2018a); Haimson et al. (2018)), less is known about how these behaviours develop around structured fields where this personalisation is not possible. It is not known whether these types of fields support users who prefer to keep certain information private, or whether they allow for indirect forms of disclosure to help people to manage their privacy in context collapsed online environments. Therefore, this thesis focuses on understanding privacy and disclosure attitudes and behaviours around these fields using the context of HIV status disclosure in sex-social apps used by men who have sex with men (MSM). This context is used as a case study as many of these sex-social apps have introduced the option for users to disclose their HIV status using structured disclosure fields. Research around these fields is particularly pertinent at a time of considerable scrutiny around the management of personal information in online social networks. This was made evident in 2018 when security researchers identified Grindr sharing its users' personally identifiable HIV status information with third-party companies resulting in a significant public response from users (Ghorayshi and Ray, 2018).

These structured HIV disclosure fields have been introduced into the majority of sex-social apps used by MSM, with little attention from researchers within Human-Computer Interaction (HCI) or other fields. One recently published U.S. based structured interview study was found which specifically investigates these fields (Medina et al., 2018). Whilst the focus of this study was on the impact of these fields on sexual risk, the study did explore the effect different HIV status options have on the likelihood of participants contacting users with the intention



of having sex with them. They found participants were more likely to contact a user who reported an HIV Negative status, or reported using Pre-Exposure Prophylaxis (PrEP); less likely to contact users who reported being HIV Positive or Undetectable; and no difference reported if HIV status information was not disclosed. Whilst this study provides valuable insights into how these disclosure fields influence user behaviour, the structured nature of the interview method used limits the depth of understanding around how and why MSM use these fields. The findings also rely on self-reported behaviours which may not translate to in-situ behaviours.

Prior studies have explored the design and development of mobile phone based interventions to help prevent HIV (e.g., Holloway et al. (2014, 2017); Goldenberg et al. (2014); Goedel et al. (2017)), improve antiretroviral medication adherence in patients (e.g., Salib et al. (2018); Marcu et al. (2016); Joshi et al. (2014); Ramanathan et al. (2013)), and to promote HIV self-management (e.g., Bussone et al. (2016); Ramanathan et al. (2013)). HIV prevention interventions have also been explored around social networking technologies (e.g., Ramallo et al. (2015); Huang et al. (2016); Rosengren et al. (2016)). Whilst none of these studies look specifically at disclosure through structured fields, they do explore disclosure more generally in relation to integrating HIV interventions into existing technologies. A common finding amongst many of these studies is the need to consider user privacy when communicating sensitive information such as HIV and other sexually transmitted infections (Aicken et al., 2016). Privacy considerations are especially pertinent around HIV status information, where being HIV positive still attracts considerable stigma (stigmaindexuk.org, 2015), and to a lesser extent, so too does the use of the HIV prevention drug PrEP (Golub, 2018; Jaspal and Daramilas, 2016).

**This thesis aims to understand how the structured nature of disclosure fields affects the way in which people manage the disclosure and privacy around sensitive information, using the case study of HIV status information in sex-social apps used by MSM.**

To address this aim, this thesis focuses on answering four main research questions which are addressed in four components of this thesis. The first component

takes a step back to look more broadly at how the community of users perceive the introduction of these HIV status disclosure fields. Understanding user attitudes towards the introduction of these fields is important, as these attitudes may influence the ways users behave and interact with these fields. As such, the first research question this thesis looks to address is:

**RQ1:** *What are the user attitudes towards structured HIV status disclosure fields being implemented into sex-social apps used by MSM?*

To address this first research question, the researcher focused on Grindr's implementation of this feature as it was implemented only a few months prior to the researcher starting this research. During Grindr's consultation and implementation of their HIV status disclosure field, a number of news outlets and online forums reported on the feature which attracted public posts and comments from users. This online public domain data was collected and analysed using qualitative methods. Through this analysis, a concern was found relating to how non-disclosing users could be assumed to be hiding some undesirable HIV status which could limit the effectiveness of any non-disclosure option within these structured HIV disclosure fields. This finding was linked to Peppet (2011)'s *privacy unravelling* effect, which has its roots in signalling theory, a communication theory from economics (Spence, 1978) and evolutionary biology (Zahavi, 1975).

Whilst this first study provides useful insights into user attitudes towards these fields, the data collection method has limitations, and did not allow the researcher to probe deeper into attitudes, perceptions, and behaviours of users around these fields. As such, this thesis asks a second question:

**RQ2:** *How do users interact with structured HIV disclosure fields to manage the disclosure and privacy of their HIV status?*

To address some of the limitations of the first study, semi-structured interviews were conducted with users of sex-social apps. Both MSM who were living with HIV, and those reporting to be HIV negative were interviewed. The second research question was addressed in the second component of this thesis by directly applying signalling theory to the analysis of the collected interview data. This theory was

used due to its links with *privacy unravelling* and its past application to similar areas of study (e.g., social networks Lampe et al. (2007)). The application of this theory to this area of research provides new insights into how users cultivate or “evolve” these seemingly rigid, structured disclosure fields to help them manage privacy around their HIV status information.

Through this analysis, further support was found which suggests that the social effect of *privacy unravelling* (Peppet, 2011) can limit the voluntary nature of these fields. Yet, this same social effect may also provide users with the means to indirectly disclose an HIV positive status. However, the social effect of *privacy unravelling* identified relies on the assumption that those holding the least desirable quality have no incentive to reveal, and this theoretical framework was unable to develop insights into disclosure motivations.

Prior research has explored why people choose to disclose or not disclose HIV status information (e.g., Emler (2008); Grov et al. (2013); Adam et al. (2011); Greene et al. (1993); Serovich and Mosack (2006); Chaudoir and Fisher (2010)), with Gillard and Roark (2013) drawing on a theory of motivation to understand the HIV disclosure behaviours of older adolescents. Yet, much of the previous research was conducted outside of the UK, and prior to HIV status disclosure fields being implemented into the most popular sex-social apps used by MSM. Alongside the changes in the way HIV status information is managed in sex-social apps, the landscape around HIV itself has changed in recent years. These changes include new and more effective treatments for HIV prevention and management, as well as an increase in public campaigns to raise HIV awareness. The availability and efficacy of highly active antiretroviral therapy (HAART) mean individuals diagnosed and commenced on effective treatment often become ‘undetectable’. This term is used to describe people living with HIV who have an undetectable level of the virus in their blood (undetectable viral load). Extensive studies now show that when a person living with HIV has a sustained, undetectable viral load they cannot transmit HIV to their sexual partners (Rodger et al., 2014, 2019).

To raise awareness of this, a number of national campaigns were launched

across the UK to promote the terms ‘Undetectable = Untransmittable’ (often shortened to ‘U=U’ or ‘UequalsU’), and ‘I can’t pass it on’. In a dual treatment and prevention approach, in late 2017, NHS England together with Public Health England started recruiting people at high risk of HIV into a trial of PrEP. Scotland and Wales made it available on the NHS, and Northern Ireland introduced a pilot which made PrEP available to those at high risk. PrEP is an HIV prevention drug, and when adhered to can protect those at risk of infection, preventing the virus from becoming established in the system of someone on exposure.

These changes in HIV treatment and prevention have resulted in a variety of HIV status options that MSM may identify with. These include being HIV positive and undetectable, and being HIV negative on PrEP (see: Table: 1.1). These additional statuses now appear as options in many of the HIV status disclosure fields found in sex-social apps.

**Table 1.1:** Summary of the different HIV status options

<b>HIV Status</b>	<b>Description</b>
HIV Negative	Tested negative; however, those who are untested may also identify with this status.
HIV Negative, on PrEP	Tested negative and taking PrEP.
HIV Positive	Someone who is diagnosed as HIV positive and has a detectable viral load. This means they are still at risk of onward transmission during condomless sex.
HIV Positive, Undetectable	Someone who is diagnosed as HIV positive, but has an undetectable level of HIV in their blood. This is likely to be because they are on effective treatment to manage their condition.
HIV Status Not Known	Someone who is either not recently tested, or who has never been tested for HIV.

To better understand the context used as a case study within this research, and to understand *why* MSM disclose or conceal their HIV status in sex-social apps, this thesis asks the following question:

**RQ3:** *How are structured HIV status disclosure fields affecting user motivation to disclose within sex-social apps?*

The third component of this thesis addresses this research question. It does

this through an analysis of the semi-structured interview data using an existing theoretical framework for understanding motivation (Vallerand, 2000, 1997). This allowed for greater insights into user behaviours around structured HIV disclosure fields in sex-social apps, as well as providing an in-depth understanding of why users choose to disclose or not to disclose within this research context.

Through the exploratory qualitative stages of this research, the social effect of *privacy unravelling* (Peppet, 2011) was identified. This could limit the optional nature of these fields whilst also providing users with a means of indirectly disclosing sensitive information. To understand how significant this effect is within these online environments, this thesis asks a final question:

**RQ4:** *Do structured HIV status disclosure fields provide users with an effective non-disclosure option?*

In the fourth component of this thesis, a quantitative study which simulated an online dating environment was developed to test people's responses to alternative ways of presenting (or hiding) HIV status information. This final study provides new insights into how the visual design of structured disclosure fields can help enhance privacy where information is undisclosed, but also limit people's ability to use these fields to engage in subtle forms of indirect disclosure.

The knowledge developed through this research around structured disclosure fields is important to ensure that these fields support users in managing their privacy in online social environments. This includes providing support for users who prefer not to disclose their status, as well as supporting more subtle forms of information disclosure for those straddling the line between full disclosure, and non-disclosure. For developers, understanding user attitudes and behaviours around these fields can provide important insights to support the future development of systems and interfaces that support users in managing the privacy and disclosure of their status.

## 1.2 Overview of Chapters

Below is a breakdown and summary of each chapter in this thesis. These chapters provide progressive insights into how structured disclosure fields affect privacy and disclosure behaviours around sensitive information online. This is explored around HIV status information in MSM sex-social apps, and so these chapters also provide insights that are specific to this research context.

- 2 - Related Work: This chapter provides a detailed review of relevant privacy research, including research on the privacy paradigms of 'control', privacy in online social interactions, and the *privacy unravelling* effect. As HIV disclosure is used as an exemplar for this research, this section also provides an overview of context relevant literature including an overview of the current state of HIV within the UK, as well as research on HIV related stigma and disclosure. Finally, it provides an overview of the different HIV disclosure designs introduced into many of the sex-social apps in use at the time this thesis was written.
- 3 - User Attitudes: This chapter uses online public domain data to explore user attitudes towards structured HIV status disclosure fields in sex-social apps used by MSM, showing how the structured nature of these fields could limit their voluntary nature through the social effect of *privacy unravelling* (Peppet, 2011).
- 4 - Interview Methodology: This chapter details the semi-structured interview methodology used. It details how participants were recruited and selected, how the interviews were developed and conducted, and the ethical considerations of this study. It also provides a broad overview of the analysis method used, and rationale for utilising two existing theories to perform multiple deductive analyses across the interview data.
- 5 - Signal Appropriation: This chapter reports on the analysis of the collected interview data using signalling theory. In applying this theory, further support is found for *privacy unravelling* presented in chapter 3. Yet, this chapter also

highlights how users can appropriate online social platforms to develop signals to counter the effect of *privacy unravelling* (countersignalling), as well as to exploit the effect of *privacy unravelling* to engage in subtle indirect forms of disclosure. This analysis formalises these behaviours into a notion referred to as 'signal appropriation' which describes the use of signals to appropriate online social technologies.

- 6 - Motivation to Disclose: This chapter reports on the analysis of the collected interview data, drawing on Vallerand (1997, 2000)'s hierarchical model of intrinsic motivation. It explores why users choose to reveal their status, and helps to better understand *privacy unravelling* within this context, as this effect relies on the assumption that those who hold the least desirable quality have no incentive to reveal. It highlights how disclosure of HIV status is complex, and that people are not always incentivised to disclose for personal gain, but may also disclose for the purpose of social good, such as educating others and to help reduce stigma.
- 7 - Measuring Privacy Unravelling: This chapter presents the final study in this research. It presents the method and findings from a study designed to measure the effect of *privacy unravelling* around structured HIV status disclosure fields. In doing so, it highlights how the visibility of undisclosed information fields can reduce the effect of *privacy unravelling*, but that minority groups may still be disadvantaged due to this effect, even when the visibility of undisclosed information fields is reduced.
- 8 - Discussion: In this chapter each study is discussed and reflected upon as a whole. A discussion is presented that relates specifically to the case study used within this thesis, yet the findings from this work extend more broadly. As such, the researcher draws from work outside of the context of HIV status disclosure and sex-social apps, reflecting on how the findings from this research relate more broadly to online communications and the appropriation of digital artefacts in online social spaces. This section presents a number

of implications from this research, suggesting ways in which designers could use these findings to address some of the negative effects around structured disclosure fields that have been highlighted in this thesis. Finally, this section reflects on some of the limitations of this research, self-critiquing the work and suggesting future work that could help to address some of these limitations, and in doing so further extend our knowledge and understand in this area.

- 9 - Conclusions: The final chapter outlines the main conclusions from the research, and highlights its substantive contribution to knowledge.

### 1.3 Contributions

The broad contribution of this thesis is a better understanding of how structured disclosure fields affect privacy and disclosure behaviours around sensitive information online, using the case study of HIV status information in sex-social apps. More specifically, this thesis provides insights into the effect of *privacy unravelling* around structured disclosure fields in online social environments. This effect can limit the voluntary nature of these fields, by causing undesirable inferences to develop around non-disclosures. In contrast to previous work which has explored this effect in economic contexts (e.g., Benndorf et al. (2015)), this thesis explores the effect around sensitive information within an online social context. As this effect relies on the assumption that those holding the least desirable quality have no incentive to disclose, this thesis also contributes by providing up-to-date understanding into why some MSM choose to disclose their HIV status information in sex-social apps. This study comes during a time of significant change around HIV with changes in HIV treatments and preventions and an increased social awareness around the 'undetectable' status. In addition to the above contributions, this thesis also provides new insights into how the effect of *privacy unravelling* could be used to support users in managing the privacy around their HIV status information, by allowing users to indirectly disclose their status through inferences developed through the act of not disclosing. This thesis encapsulates these subtle interaction behaviours as 'signal appropriation'. This described the appropriation of social



technologies through the cultivation of new meaning around digital artefacts. Finally, this thesis presents the first known quantitative study that measures the effect of *privacy unravelling* in an online social environment by testing the impact of HIV non-disclosures on how people evaluate online dating profiles.

## Chapter 2

# Related Work

*Parts of this chapter have been published across the following publications:*

**Warner, M.**, Kitkowska, A., Gibbs, J., Maestre, J and Blandford, A. (2020) Evaluating 'Prefer not to say' Around Sensitive Disclosures. In *CHI Conference on Human Factors in Computing Systems Proceedings (CHI 2020), April 25 - 30, 2020, Honolulu, Hawaii, USA*. ACM, New York, NY, USA, 13 pages. <http://doi.org/10.1145/3313831.3376150>

**Warner, M.**, Maestre, J., Gibbs, J., Chung, C. and Blandford, A. (2019) Signal Appropriation of Explicit HIV Status Disclosure Fields in Sex-Social Apps used by Gay and Bisexual Men In CHI Conference on Human Factors in Computing Systems Proceedings (CHI 2019), May 49, 2019, Glasgow, Scotland UK. ACM, New York, NY, USA, 15 pages. <https://doi.org/10.1145/3290605.3300922>

**Warner, M.**, Gutmann, A., Sasse, M.A. and Blandford, A. (2018) Privacy unravelling Around Explicit HIV Status Disclosure Fields in the Online Geosocial Hookup App Grindr. In *Proceedings of the ACM on Human-Computer Interaction Vol. 2, CSCW* (November 2018), 22 pages. <https://doi.org/10.1145/3274450>

This thesis explores the effect structured disclosure fields have on the way in which people manage their online privacy. Whilst a substantial body of research exists around the concept of online privacy, it has only been in more recent years

that researchers have started to develop an understanding of how people manage their own online privacy through strategic forms of disclosure. Therefore, this section starts by reviewing this recent literature on strategic forms of online disclosure, and in doing so explores the concept of information 'control' that is commonly discussed in relation to online data privacy. The next chapter of this thesis explores user attitudes towards the introduction of a structured HIV status disclosure field introduced into a sex-social app. It draws on a social effect known as *privacy unravelling* that may limit the voluntary nature of these types of fields. Prior literature on this effect is presented below which explores research into the effect of *privacy unravelling*. This research has primarily been conducted within economics contexts (e.g., labour markets). Finally, in order to investigate the effect structured disclosure fields have on privacy and disclosure behaviours in online environments, the case study of HIV status disclosure within sex-social apps is used. Therefore, this chapter provides context specific insights by reviewing work related to HIV disclosure and privacy, as well as providing an overview of the design of HIV status disclosure fields implemented into many of the sex-social apps used by MSM.

## 2.1 Privacy and Disclosure Management Online

Prior to the advent of online social networks, people's networks were much smaller, often limited to family, close friends and colleagues (Donath, 2014). Moreover, because networks were much smaller, with data flows easier to understand, it was easier for people to control privacy around their personal information. As such, much of the early work on understanding privacy was centred around the concept of *control* (e.g., Westin (1968); Fried (1968)). As technology developed to allow people to share information with large networks of connections around the world, questions of online privacy started to surface. Extensive research was conducted to understand how people perceived privacy and disclosure online, with much of this work drawing on the concept of control to understand people's privacy and disclosure behaviours (Acquisti and Gross, 2006; Hoadley et al., 2010; Xu, 2007; Krasnova et al., 2009). Yet, the nature of modern communication networks makes

absolute control an almost impossible task (Allen, 1999). People regularly share very personal information about themselves to large networks of connections, unable to control how this information may be copied and shared with others, whilst still expecting a level of privacy to exist around the data.

Online social networking platforms often merge or 'collapse' different contexts, making it difficult for people to maintain privacy between contextual boundaries (e.g., between family and work colleagues on Facebook) (Marwick and Boyd, 2011). However, for many these platforms play an integral role in supporting relationships and communities. Therefore, people must find ways to manage these issues of context collapse. Looking first at how people manage selective disclosures in offline environments, Clair et al. (2005) developed a model of invisible identity management in offline workplaces which includes a self-disclosure strategy referred to as 'signalling'. This strategy involves the dropping of hints to 'signal' an invisible aspect of identity. For example, a person may wear a religious cross necklace or carry prayer beads to signal their religious beliefs, or use verbal or symbolic hints such as leaving HIV awareness pamphlets on a coffee table to 'signal' their HIV status (Serovich et al., 2014, 2005). Often these cues are subtle and ambiguous in nature, limiting disclosure to those who are able to interpret these cues. Moving to online environments, Boyd and Marwick (2011) refer to this behaviour as 'social steganography', similarly describing the use of unstructured disclosure fields to conceal a hidden message within a message. In recent years, researchers have explored forms of indirect disclosure around sensitive information in various online contexts, from the use of unstructured disclosure fields to share poetry to signal a pregnancy loss (Andalibi et al., 2018b), to complex engagement with Facebook relationship settings to signal a relationship breakup (Haimson et al., 2018; Robards and Lincoln, 2016). These behaviours provide a means of managing privacy within these online environments where multiple contexts are collapsed into one space. These behaviours are not made with the intention of maintaining absolute control over sensitive information, but to maintain what Nissenbaum (2009) refers to as 'appropriate information flow'.

Nissenbaum (2009) suggests that instead of information flows being subject to rigid controls, they should adhere to a set of expectations and norms, or 'transmission principles'. Privacy is then considered to be violated if information flows in a way that is deemed inappropriate by the information sender. This is an important distinction, as it allows people to engage in online communities through the act of sharing, whilst maintaining their need for self-determination to shape and manage the narrative of their online identities (Buitelaar, 2014). If a person decides against disclosing some personal information about themselves online, contextual integrity theory (Nissenbaum, 2009) suggests the need for this choice to be respected. Yet, if the act of not disclosing results in information "leaking" through socially developed inferences around the decision not to disclose, this would violate a person's privacy.

## 2.2 Privacy Unravelling

Akerlof (1978)'s "Market for Lemons" work showed the importance of revealing honest information in economic markets as the value of an entire market can reduce where information asymmetry exists between buyers and sellers. Signalling, where one party reveals information to another, was proposed to reduce information asymmetry (Spence, 1973), with numerous researchers (e.g., Grossman (1981); Milgrom (1981)) showing that the absence of signalled information is presumed to be unfavourable when the cost of signalling is low and when others have incentive to reveal.

In Peppet (2011)'s work on *privacy unravelling*, he describes this game-theoretic effect and its potential impact on privacy in relation to unilateral voluntary disclosures. He proposes unravelling as a privacy threat in a "full disclosure future" where it becomes expected that personal information is "signalled" to others in order for them to be distinguishable from others. For example, where a driver wants to signal their reduced risk to their insurer, they may allow a device to track their speed, cornering, and braking (Quintero and Benenson, 2019); 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. Pri-

vacy may unravel around those who choose to withhold information, as others may assume them to be “hiding” undesirable information, and could lead to them being stigmatised or penalised as a consequence (Peppet, 2011).

Privacy unravelling threatens the voluntary aspect of disclosure in signalling environments as it can lead to all parties revealing to avoid being perceived to be withholding unfavourable information. This effect has been previously explored in a labour market where workers can optionally self-report their own productivity. Those with the highest productivity (high types) have an incentive to reveal, while workers with average productivity (medium types) may also reveal to differentiate themselves from workers with a lower than average productivity. This continues, unravelling down to the least productive workers (low types) who may be forced to reveal, or be assumed to be the least productive (Benndorf et al., 2015).

As well as this effect being explored in a market (Benndorf et al., 2015), empirical studies have also explored the effect in auctions (Forsythe et al., 1989; Lewis, 2011), including online auctions (Lewis, 2011) around the disclosure of information in relation to car sales. Much of this prior work focused on the disclosure side of unravelling, exploring how disclosure increases throughout the market to maintain individual desirability. *Privacy unravelling* can also be studied from a perceptions perspective to understand how people perceive undisclosed information. Jin et al. (2015) explored perceptions that develop around undisclosed information, finding that where feedback was received on previous transactions, the effect of privacy unravelling was reduced. Ma et al. (2017) explored the relationship between information disclosure of Airbnb hosts and perceived trustworthiness, finding a reduction in information disclosed correlated with reduced trustworthiness.

To limit the effect of *privacy unravelling*, Peppet (2011) suggests 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 (2011) 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 unravelling effect.

## **2.3 Case Study Related Literature**

This section provides an overview of HIV with a focus on the landscape around HIV within the UK, which is where this research has been conducted. As this research is looking specifically at structured HIV status disclosure fields within sex-social apps, it is important to understand HIV specific literature around disclosure. The literature reviewed below explores how stigma can affect disclosure, and how HIV disclosure impacts on people's lives and identity formation. Lastly, the different structured HIV status disclosure fields implemented into various sex-social apps are reviewed, as they are referred to throughout this thesis.

### **2.3.1 Human Immunodeficiency Virus (HIV)**

HIV disproportionately affects MSM in the UK, making up 54% of new diagnoses in 2016 (Brown et al., 2017a). From 2007 to 2015 there was a sustained increase in

rates of new HIV diagnoses. However, since 2016 there has been a continuing decline in newly reported cases amongst MSM (31% decline from 2015 to 2017 (Nash et al., 2018)). This decline occurred after a number of significant changes. A UK policy shift in 2015 means that those newly diagnosed are placed on treatment, often within weeks of diagnosis, irrespective of their CD4 count which is an indicator of immune system health (Waters et al., 2016). Once on effective treatment, the viral levels within a person's system should reduce to a point where the virus is no longer detectable, meaning they are no longer at risk of onward transmission (i.e., Treatment as Prevention (TasP)). This was shown in a series of studies known as the PARTNER studies where more than 76,000 condomless sexual acts were reported between serodifferent gay couples, with zero linked transmissions being detected (Rodger et al., 2014, 2019). Of the MSM who were diagnosed in 2017, 33% were deemed to have been diagnosed within the later stages of infection (Nash et al., 2018). As such, many new cases are caused by people who are undiagnosed HIV positive (Bezemer et al., 2008; Phillips et al., 2013; Hall et al., 2012). Together with treatment options, some antiretroviral drugs are being given to people at high risk of HIV, as a primary prevention method to prevent the virus from becoming established in a person's system in the event of exposure. Known as pre-exposure prophylaxis (PrEP), there is an increased prevalence in self-reported use of these drugs in the US and worldwide (Kamitani et al., 2018). A worldwide initiative known as 90:90:90 (UNAIDS, 2015) aims to ensure that 90% of people living with HIV know their status, that 90% of these are accessing treatment and 90% have a suppressed viral loads.

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 and are at ongoing high risk of exposure to HIV, prevention drugs can be used to prevent HIV transmission on exposure. These individuals may self-identify as being negative on PrEP and are typically required to test for HIV on a regular basis (every three months). There are three ways in which PrEP can be taken, daily (one tablet per day), intermittent (single dose of



PrEP on alternating days with at least four doses per week taken), or event based dosing (a number of tablets prior to and after sex) (Brady et al., 2019). However, the disclosure options in sex-social apps 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 more than 6 months, guidance within the UK states that they are then classed as being undetectable (NHS, 2018) and may then self-identify as being positive undetectable. If a particular antiretroviral medication combination fails to suppress an individual's viral load, or an individual fails to adhere to medication, and that individual has a detectable viral load, they may self-identify as positive. In both cases, in the UK, more frequent viral load testing is recommended to monitor the status of the virus until a sustained undetectable viral load is seen.

### **2.3.2 HIV Related Stigma and Disclosure**

Stigma is a social construct based on the existence of “marks” or “traits” among individuals that make them be perceived as ‘different’ or ‘not normal’ from a socially-conceived perspective. According to Goffman (1963), the bearers of such discrediting marks have ‘spoiled social identities’ that often lead to negative outcomes in social interactions such as rejection from others and self-isolation.

In the UK, around half of MSM who live with HIV reported feeling shame, guilt, and low self-esteem and/or self-blame in relation to their HIV status in the 12 months after diagnosis (stigmaindexuk.org, 2015). It is important to note, however, that HIV-related stigma exists as long as it is perceived by people living with HIV themselves, and the degree to which stigma affects these individuals is related to the valence and salience of such perceptions (Meisenbach, 2010). Consequently, much of the research on stigma from the social sciences has been focused on the identification of coping strategies that allow individuals to ameliorate the negative effects of stigma in their lives. Such strategies include accepting the stigmatising trait and showing it to others (e.g., a gay man showing his sexual interest for other men in public), hiding the stigmatising condition (i.e., passing as someone who

does not have the stigmatising trait), denying that the stigmatising condition applies to the individual, or denying that such stigma even exists (Meisenbach, 2010).

Stigma has been linked to negative outcomes such as discrimination, prejudice, identity devaluation and deterioration of physical and psychological health (Maestre et al., 2018; Herek, 2014; Bocking et al., 2013; Livingston et al., 2012). In the case of HIV, stigma has been associated with depression and anxiety, especially when people living with HIV have been the target of stigma in the form of discrimination or rejection (Herek, 2014; Nyblade et al., 2009). HIV stigma creates barriers to HIV testing (Dodds et al., 2018), with a broader range of testing options, including self-testing and self-sampling enabling people to maintain privacy around testing, helping to remove these barriers (Witzel et al., 2016). However, moving HIV testing into more private spaces, such as the home, reduces its visibility. This could perpetuate the stigma around HIV with testing seen as something that needs to be hidden away and performed in secret (Singh et al., 2019).

Stigma can also impact on access to and exchange of social support as people living with HIV find it difficult to disclose their status to others due to fears of rejection (Peterson, 2010; Williams and Mickelson, 2008; Jaspal and Williamson, 2017). Moreover, reduced HIV disclosure can risk increasing HIV transmission rates (Pinkerton and Galletly, 2007). Yet research with certain ethnic groups in the US shows people living with HIV are often not disclosing (Chiu and Young, 2015) or are misreporting (Carballo-Diéguez et al., 2006) their status to potential sexual partners met online, prior to meeting. While studies have shown that individuals are more comfortable discussing HIV status online, as opposed to offline (Carballo-Diéguez et al., 2006; Serovich et al., 2014), the desire for privacy can create barriers to disclosure.

Previous research finds people develop different disclosure strategies for managing tensions between privacy to shield them from stigma, and disclose to facilitate the revealing of their status to gain support (Smith et al., 2008). For instance, people living with HIV have been found to develop signalling strategies in interpersonal communications to reveal their status. These signalling strategies allow people to

“straddle the line” between being public and remaining private (Clair et al., 2005). As noted earlier, people may engage in verbal hinting, or use physical items as symbolic hints (e.g. HIV leaflets left on a coffee table) (Serovich et al., 2005). Research on revealing sensitive, potentially stigmatising information about the self in online social networks found similar strategies being adopted (e.g., sharing a blog post that someone else wrote on the sensitive topic) (Andalibi et al., 2018a).

Researchers have tried to identify ways to minimise stigma at the individual (i.e., the bearer of the stigmatising trait) and at the population level (i.e., society). At the individual level, it has been found that people living with HIV can alleviate the effects of HIV-related stigma by receiving peer support from “buddies” or “mentors” who are going through a similar experience (Veinot, 2010; Bockting et al., 2013). At the population level, misinformation regarding HIV transmission and negative attitudes toward same-sex relationships have been identified as significant factors that exacerbate HIV-related stigma (Veinot and Harris, 2011; Herek, 2014; Harris et al., 2008). Consequently, interventions have been designed to promote positive attitudes towards people living with HIV. Brown et al. (2003) completed a meta-analysis of 22 studies assessing interventions to reduce HIV-related stigma in the general public in the US and elsewhere. Results showed that providing information about HIV regarding transmission was not enough to minimise HIV-related stigma. Instead, there also had to be more direct contact and interaction with people living with HIV.

Previous research has explored HIV status disclosure through the theoretical lens of the motivation theory Self-Determination Theory (SDT) (Deci, 1971; Ryan and Deci, 2000) to better understand the types of disclosure motivations that develop amongst adolescents living with HIV. In Gillard and Roark (2013)’s interview study with nine youths aged 17-19, amotivations, extrinsic, and intrinsic motivations were all identified. Participants who were amotivated to disclose reported fear of being stigmatised or losing disclosure control. Extrinsic disclosure motivations primarily related to relationship development and social support goals. A small number of participants were intrinsically motivated to disclose as HIV had become part

of their lives, and they received satisfaction when their acts of disclosure resulted in greater awareness and education (Emlet, 2008; Gillard and Roark, 2013). Emlet (2008)'s interview study with older adults living with HIV found similar results to researchers investigating HIV disclosure amongst younger people. They found those who were motivated to disclose more widely did so to educate others, and to help support and guide the next generation of people living with HIV.

Supporting these findings, between 2010 and 2011, Grov et al. (2013) conducted an interview study with MSM who used craigslist.org to meet sexual partners. They found participants avoiding asking people about their HIV status through fear of violating the individual's privacy. The amotivational factor of privacy can often be linked with people's needs to protect themselves from the effects of HIV related stigma (Adam et al., 2011; Greene et al., 1993; Serovich and Mosack, 2006). A study found men to be amotivated to disclose to friends and intimate partners as a result of privacy concerns; however, their sense of loyalty increased motivation to disclose to family members, whilst honesty and concerns for health motivated disclosure to intimate partners (Derlega et al., 2004).

### **2.3.3 The Impact of Disclosing HIV Status Information**

The most significant impact on HIV disclosure reported in the literature relates to the effects of stigma. For example, in interviews conducted with men living with HIV in Scotland (n=14) between 2003 and 2005, participants reported HIV as a death sentence, and a life changing and shameful attribute resulting in internalised stigma and self-shame (Flowers et al., 2011). A similar study in Ireland (n=15) in 2013 reflected these findings, identifying participants rejecting their HIV positive status as being part of their identity (Murphy et al., 2016). A more recent report in 2015 found that around half of MSM living with HIV that were surveyed reported feelings of HIV related shame, guilt, and low self-esteem within the previous 12 months (stigmaindexuk.org, 2015).

HIV as a topic of discussion is often avoided by MSM when looking for prospective partners online due to the stigma that it attracts (Ramallo et al., 2015). In Grov et al. (2013)'s interview study, they found that those who did ask about a sexual

partner's status reported to wait until meeting face-to-face, and reported to only ask when sex was imminent. This behaviour indicates a desire to limit discussion to circumstances where it is felt necessary to disclose. Disclosing face-to-face and disclosing minimal information may help users reduce their exposure to risk. When participants were more open about their status online, they found disclosure occurring within free-text fields on profiles (e.g., "about me" section), often using derogatory terms like "clean" or "ddf" which is an acronym for 'drug and disease free' (Groves et al., 2013). However, they also found users living with HIV benefiting from the anonymous nature of the Internet, as it allowed them to disclose with reduced long-term consequences to their social identity. Interviews with MSM in London found people living with HIV could reduce HIV stigma related social rejection through disclosure (Davis et al., 2006).

In a recently published study, MSM participants self-reported to be far less likely to contact another dating website user if their profile reported an HIV Positive (80%) or Positive Undetectable (57%) status, indicating a significant loss in sexual opportunity when disclosing. Comparatively, participants were far more likely to contact a user who reported an HIV Negative status (52%), or a Negative on PrEP status (47%) (Medina et al., 2018).

#### **2.3.4 HIV Threat to Identity**

Users of social apps self-present by engaging in "profile work", exerting effort to maintain and manage their online persona's (Silfverberg et al., 2010). Users may act to promote their profile, actively emphasising some aspects of their identity whilst masking others with the goal of appearing desirable to their audience within a given social environment (McRoberts et al., 2017). 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 (Tsarenko and Polonsky, 2011). They can find it difficult to integrate the illness as part of their self-construal, especially during early stages of this transition (Flowers et al., 2011). Identity transition can be aided through positive self-disclosures and interactions within social groups, helping individuals achieve

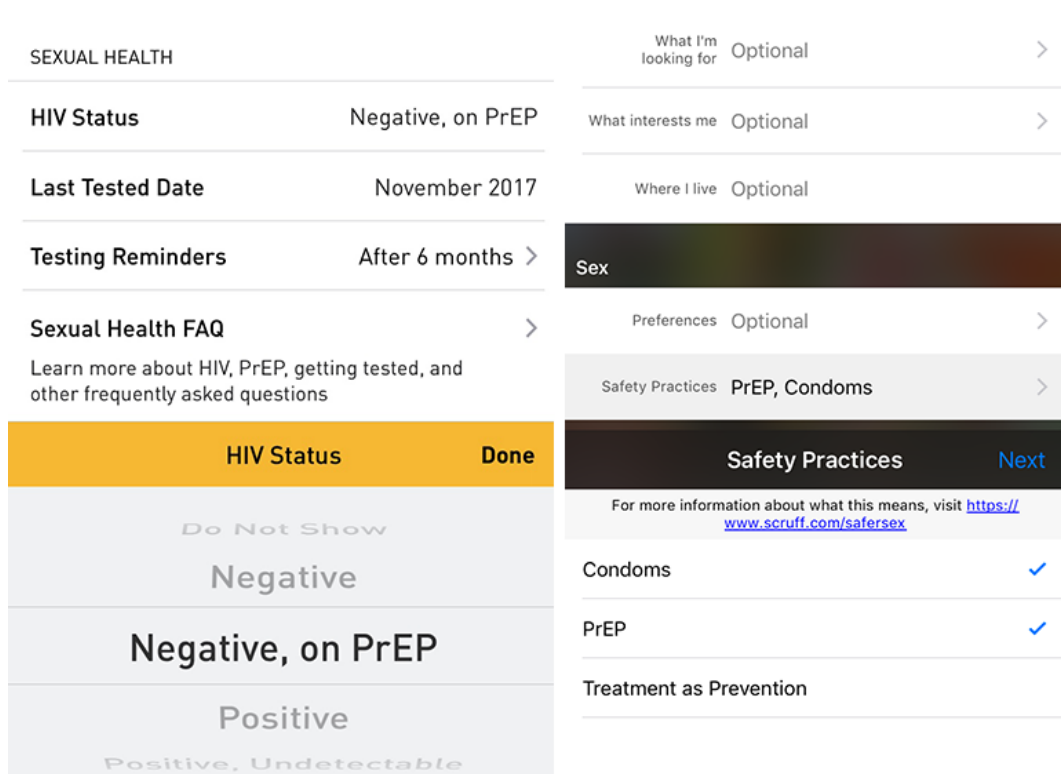
a sense of belonging and maintain self-esteem (Tsarenko and Polonsky, 2011; Baumgartner, 2007).

Being HIV positive is often seen as an undesirable attribute (Tsarenko and Polonsky, 2011). 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 an undesirable 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 (Golub, 2018; Jaspal and Daramilas, 2016). 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.

### **2.3.5 Structured HIV Status Disclosure Fields**

There are a large number of sex-social apps designed for MSM, and the way in which HIV status information is managed differs between apps. However, broadly two approaches are used. The first, and most common approach is an explicit option to disclose HIV status information. Users are presented with a structured disclosure field containing a selection of HIV status options, and a last test date input field (see example: Figure 2.1 left). The HIV status options can vary between apps; for example, some apps provide users with a “Not Sure” option, whilst others do not. The second approach used primarily in the app Scruff shown in Figure 2.1 (right) provides a safer sex practice structured disclosure field, allowing users to select from a range of safer sex practices (e.g., condoms, PrEP, Treatment as Prevention). This design allows users to select more than one option, and is ambiguous as to whether it is the safer sex practices of the individual disclosing, or what this individual is looking for in others, or both.

Some applications also provide users with the option to identify with the HIV positive community in other ways. For example, Grindr allows users to join ‘tribes’ which allow them to identify with a niche group. One of these groups is called “Poz”



**Figure 2.1:** Cropped screenshots of the HIV disclosure fields in Grindr (left), and Scruff (right).

for people to self-identify as being HIV positive, whilst Scruff allows users to state “I am Poz”.

## 2.4 Conclusions and Research Direction

After reviewing relevant literature on privacy and disclosure in online social platforms, and case study specific literature around disclosure of HIV status information, what is clear is the need to consider privacy around sensitive information online, extending beyond a platform’s privacy settings. Offline disclosure shows how people engage in indirect forms of disclosure. More recent research into online disclosure of sensitive information show a similar privacy and disclosure behaviour being adopted, using unstructured disclosure fields to engage in subtle hinting of an invisible aspect of identity. What is not known is how structured disclosure fields for disclosing sensitive information, such as HIV, will affect these privacy and disclosure behaviours.

## Chapter 3

# User Attitudes Towards a Newly Introduced Structured HIV Status Disclosure Field in Grindr

*The following publication is based on work featured in this chapter:*

**Warner, M.**, Gutmann, A., Sasse, M.A. and Blandford, A. (2018) Privacy unravelling Around Explicit HIV Status Disclosure Fields in the Online Geosocial Hookup App Grindr. In *Proceedings of the ACM on Human-Computer Interaction Vol. 2, CSCW* (November 2018), 22 pages. <https://doi.org/10.1145/3274450>

### 3.1 Introduction

This first study addresses the first component listed in chapter 1, and draws on the *privacy unravelling* literature described in chapter 2. It provides the foundations for the development of the studies presented in chapters 4 to 8, by exploring user attitudes towards structured HIV status disclosure fields in sex-social apps used by MSM to address the first research question of this thesis:

**RQ1:** *What are the user attitudes towards structured HIV status disclosure fields being implemented into sex-social apps used by MSM?*

This question is addressed by analysing the online user comments related to the introduction of these fields into the popular sex-social app Grindr. In exploring this question, this study looks at whether these fields are supportive of MSM who may feel unable to publicly disclose their status. This is especially pertinent for



people living with HIV in the early stages of accepting their diagnosis (Baumgartner, 2007) where people require support and positive interactions (Tsarenko and Polonsky, 2011). As discussed in chapter 2, stigma around people living with HIV is still significant, with those recently diagnosed being particularly affected. Systems should be designed in a way that neither disadvantages nor stigmatises any group of users (Benyon, 2014). Therefore, these marginalised users should be in control over when they choose to disclose potentially stigmatising personal health information.

## 3.2 Background

Online sex-social apps have expanded the means by which MSM are meeting. Grindr (released in 2009) has become one of the most popular of these apps within the MSM community with more than 3 million daily active users worldwide, who spend an average of 54 minutes interacting with the app each day (Grindr, 2017). App usage is primarily for finding hookups (Taylor et al., 2017), but users also report usage for socialising, friendship, entertainment, dating, and gay community involvement (Rice et al., 2012; Van De Wiele and Tong, 2014).

In contrast to HIV interventions which focus on promoting awareness, Grindr proposed implementing a structured field for publicly reporting HIV status on user profiles, and the ability to filter users based on their status. Grindr later modified its app to include an HIV disclosure field for reporting HIV status and last test date information as shown in Figure 2.1 (left). The intended outcome of introducing HIV status disclosure fields into the Grindr app, as reported by Grindr, was to “create an open dialogue among our users about sexual health” (Davids, 2016). Building Healthy Online Communities (BHOC)<sup>1</sup>, who have advised Grindr on issues related to sexual health, stated that the introduction of this disclosure field would help create “a healthy online community through supporting HIV prevention and fighting stigma” (Davids, 2016). This is part of a wider sexual health awareness initiative by Grindr, and since conducting this study, they have also introduced testing reminders

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<sup>1</sup>BHOC are a consortium made up of public health leaders and key individuals from the gay dating industry who work together to support HIV and STI prevention online.

at certain intervals for users who choose to use this option (Chow and Klausner, 2018).

### **3.3 Method**

In 2016, Grindr conducted a survey related to the introduction of a structured HIV status disclosure field, and the ability to filter users by HIV status. Whilst the results of the survey were never 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. As HIV filtering was never implemented, this study focused on understanding user attitudes around the HIV status disclosure field feature.

#### **3.3.1 Use of Online Comments**

Online comments have previously been used to understand public health views (Glenn et al., 2012; Laestadius and Caldwell, 2015), to study public discussion (Fiesler and Hallinan, 2018; Vines et al., 2013), and in HCI research to develop design recommendations (Stawarz et al., 2014). Conducting research with stigmatised populations that are often hard to reach has led researchers in the social sciences to utilise online platforms and other online digital resources (Maestre et al., 2018). These resources include user-generated comments in naturalistic settings such as forums and in the comments section on news websites. The user-driven nature of these comments may be well suited to revealing the issues that matter most to the individuals posting (Henrich and Holmes, 2013).

Using a secondary data source allowed the researcher to engage in data related to HIV disclosure early on in the research. This allowed him to become familiar with terminology and language used by this population and to become familiar with many of the issues around HIV, such as the stigma that circulates it. This was important to do prior to conducting any face-to-face studies as it provided the researcher with the knowledge to more effectively develop future face-to-face studies, and the confidence to engage with the population. However, the researcher also recognises that the use of online comments has ethical implications which are dis-

cussed below. Moreover, this method of data collection has limitations which are discussed in section 3.5.5.

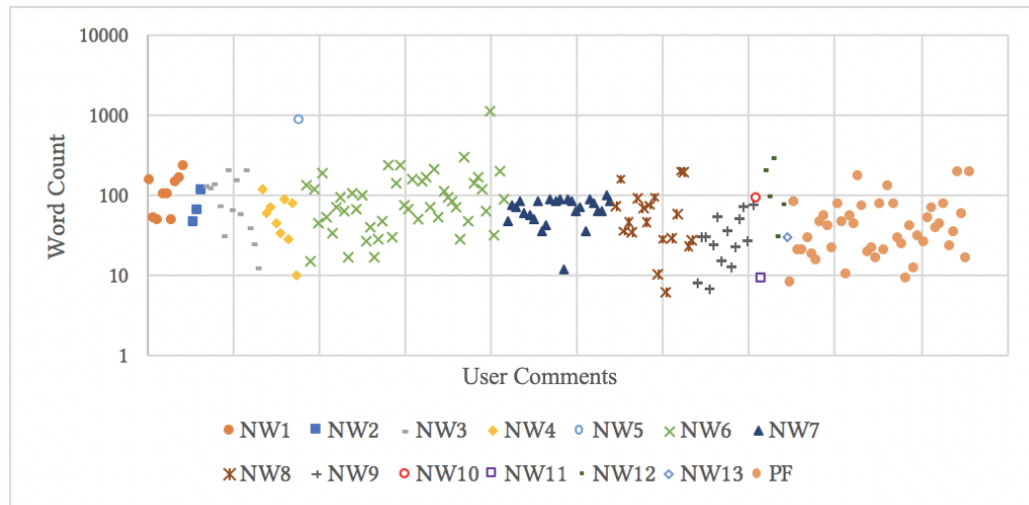
### 3.3.2 Data Collection

When conducting online searches for relevant posts, the researcher 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<sup>2</sup>. A total of 29 websites related to this interface change were identified. As filtering by HIV status was never implemented, this study focused on the disclosure of HIV status within the app. Therefore, the criteria for inclusion were (1) the article or blog post was primarily about either the survey conducted by Grindr, or the later introduction of structured HIV status disclosure fields in Grindr, and (2) at least one user comment had been posted. Using these criteria, 13 of the 29 websites met the eligibility criteria. These websites containing a total of 149 comments posted between July 2016 and August 2017. These were added to the first corpus of comments named 'News Website (NW)'. As a secondary source of data, the UserVoice.com product feedback website was searched 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. The inclusion criteria for this source were (1) the user comment was primarily about structured HIV disclosure fields, and (2) the comment was related specifically to the Grindr application. This search identified a further 43 comments posted between November 2016 and May 2017. These were added to the second corpus of comments named 'Product Feedback (PF)'. Figure 3.1 shows the word count and distribution of comments collected, separated by source, and indicates a good distribution of comments across the 14 website sources that matched this study's inclusion criteria. The mean length of all the comments was 87 words. The longest comment consisted of 1134 words, and the

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<sup>2</sup>HIV Disclosure Grindr, HIV Filter Grindr, HIV Filter Grindr survey

shortest was 6 words.



**Figure 3.1:** 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.

### 3.3.3 Comment Analysis

Using a thematic analysis (Braun and Clarke, 2006), the researcher systematically reviewed each comment and coded them iteratively in NVivo 11. This allowed the researcher 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 a second researcher.

Supplementary analysis was performed to identify whether certain attitudes were more prominent for a particular HIV status group; an analysis of the data for people explicitly disclosing their HIV status was performed. This 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.

To determine whether the sources (news articles/blog posts) and corpus of comments were biased towards people holding positive, negative or neutral at-

titudes towards these disclosure fields, the researcher and a second researcher conducted a manual sentiment analysis of both the sources and the comments. They independently labelled them as positive, negative, or neutral towards these disclosure fields. 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 (e.g., “average 2.5 were positive”). The Cohen’s (unweighted) kappa  $\kappa$  was calculated across all source websites, and separately across the corpus of comments. Of the 13 source websites matching the inclusion criteria, 2.5 were positive, 6 were negative, and 4.5 were neutral ( $\kappa=0.87$ ). Of the comments, 68.5 (35.68%) were marked positive, 61.5 (32.03%) negative, and 62 (32.29%) neutral ( $\kappa=0.85$ ). 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 findings 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’.

#### **3.3.4 Ethics of Using Online Data**

Due to the sensitive nature of some of the comments collected, a request was made for this study to be reviewed for ethical approval. During the process of the ethics review the researcher consulted with colleagues to deliberate the ethical issues around the use of this data. Through these deliberations, the primary concern identified was the anonymity of the original data subjects when reporting the 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 this research would extend. It became apparent that, even if direct

quotes were to be published anonymously, they could still be deanonymised using online search engines. As a result, where an original comment contained a user's real name or a username which could be easily re-identified, it was either not reproduced in any public facing document (e.g., this thesis, conference papers) or was paraphrased. In circumstances where paraphrasing was used, consensus on the wording was gained between the researcher and at least two other researchers. These steps help to mitigate any risk to the original data subjects whilst maintaining valuable insight into the attitudes of an often hard to reach population. This study was approved by University College London ethics committee (ref: 11699/003).

## **3.4 Findings**

A number of themes were identified which related to the attitudes and concerns of Grindr users around the use of structured HIV status disclosure fields. In this section, four themes were identified from the analysis and are presented, which are (1) managing of sexual health, (2) desire to reduce exposure to stigma, (3) trust of other users, and (4) attitudes and concerns around disclosure choice.

### **3.4.1 Managing Sexual Health**

The introduction of a structured 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 (Davids, 2016). 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. Increasing 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 education 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. A comment from PF stated: *"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”.*

Having discussions about HIV status information to educate and raise awareness was often mentioned in the comments, with some preferring to have a private discussion with other users rather than publicly disclosing their status on their profile, as described here in a comment from PF: *“People should always ask before having sex, it doesn’t need to be posted for Everyone [sic] to see”.*

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 remove the risk of forward transmission. However, as shown in this comment from NW1, others were keen to point out that HIV was not the only STI of concern, with infections like gonorrhoea 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”.*

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 described here in a comment from PF: *“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”.*

Clearly sexual health is an important issue for some Grindr users, especially

as the application is primarily used for finding sexual hookups (Taylor et al., 2017). However, there were conflicting attitudes 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 are explored below.

### 3.4.2 Managing Stigma

Stigma was a significant theme that was identified from the analysis. Previous research finds that stigma can create a barrier to disclosure during sexual negotiations due to concerns of social exclusion and loss of sexual opportunity (Murphy et al., 2016). This current study supports these findings, but in addition also finds comments suggesting stigma could act to motivate disclosure for some users, as it could provide a way for them to reduce their stigma exposure. Considerable concern related to the public disclosure of HIV status information on user profiles was identified, due to the stigma attached to HIV. There was concern that public disclosures would increase stigma rather than reduce it, and that it would disproportionately affect the subset of users living with HIV. An original comment from PF stated: *"In my opinion it is awful to make people expose part of their medical record. This is sensitive [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 discriminating [sic], racist even. I am not HIV+ but will soon delete Grindr if this goes as it is now."*

Supporting previous research, this current study 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, reflected here in a paraphrased comment from NW12: *"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?"*

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 he used the in-built block function to block users who are HIV positive, stating: *“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”*. 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.

Some comments also suggested that public HIV status disclosure could provide HIV positive users with the means to make their own evaluations of users prior to engaging with them. For instance, some described being able to use this information to filter out HIV negative users, helping them avoid HIV based rejection. This was described in a comment from NW1 who said: *“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”*.

Finally, some users described how public HIV disclosure could help them normalise HIV; a long-term stigma reduction strategy. Some users felt that openness about an 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. A comment from NW4 stated: *“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.”*

### **3.4.3 User and Information Trust**

The third theme that was identified relates to trust in HIV status information being disclosed. Some comments raised concerns over the reliability of reported HIV status information due to users being uninformed, unaware, or deliberately misreporting their status to avoid being stigmatised. Trust in information disclosed due to uninformed users seems to centre around the disclosure field that allows users to share the date of their last HIV test. Some users reported concern at the number of

reported last test dates they observed, which they considered to be out of date. The current study's findings suggest that reporting an out-of-date last date test could potentially devalue its corresponding HIV status, and result in undesirable signals that the user is not looking after their own sexual health. In these instances, out-of-date information appeared to act similarly to non-disclosures, causing privacy to unravel around both the last test date and reported HIV status, with stigmatising assumptions developing as a consequence of these out-of-date tests. As an example, this comment from NW1 stated: *"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".*

Men who were unaware of their HIV positive status were 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. As reported above, some 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. One comment from NW6 describes this behaviour, stating: *"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!"*.

As the current findings suggest, some users living with HIV felt stigmatised because of their status. These feelings of stigma could result in users misreporting their status as HIV negative, or negative on PrEP to avoid the stigma associated with a non-disclosure, as described here in a comment from NW6: *"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*". In the longer term, this could have a negative impact on trust within the environment. Whilst Grindr provides users with a non-disclosure option, the findings presented in the next section suggests why some users may still act to misreport their status, rather than using this non-disclosure option.

#### **3.4.4 Providing Disclosure Choice**

The final theme that was developed from the data relates to control over access and flow of personal information online. This is a well-established factor affecting privacy concerns when interacting online (Hoadley et al., 2010; Xu, 2007). 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 these findings suggest, the stigma around HIV could lead some users to purposefully misreport their HIV status to avoid exposure to stigma. This is reflected in the findings from this study, where users report their desire for HIV disclosure choice. In an environment where all users are expected to disclose, *privacy unravelling* around non-disclosures may limit this choice. A paraphrased comment from NW8 stated: *"When all is 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?"*.

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 an HIV positive status compared to those disclosing an HIV negative status. Support for this was found, with one comment from NW4 reflecting on the disclosure behaviours of Grindr users in his area. He described 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. He stated that (original comment): *"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".*

In an environment where users act to increase their own desirability, the potential for privacy to *unravel* 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 non-disclosing users. It was mentioned by some that this could negatively impact on their right to choose, and their right to privacy. For example, an original comment from PF suggested that *"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."*

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 undesirable conclusions, whilst another user felt non-disclosure would simply indicate that the person had decided not to disclose as was the case in this original comment from PF: *"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."*

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 enables people to manage their own concerns. For some, choosing not to disclose could be a way of avoiding stigma, while for others stigma could be 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.

### **3.5 Discussion**

The goal of this study was to explore user attitudes towards integrating HIV status information disclosures into sex-social app using structured disclosure fields. This discussion first explores some of the contrasting views identified in the analysis.

The potential impact of introducing HIV status information into these platforms is then explored, revealing why some users may develop privacy concerns around these structured disclosure fields. In exploring user attitudes around these fields, a potential social privacy problem known as *privacy unravelling* (Peppet, 2011) was identified which could lead to assumptions developing around users who choose not to disclose using these structured disclosure fields.

### 3.5.1 Understanding the Users

This analysis identified three main groups with varying views related to these structured HIV status disclosure fields: (1) The first group which is referred 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. These findings are consistent with previous studies which report fear of rejection (Derlega et al., 2002; Zea et al., 2003) and privacy concerns related to HIV stigma (Adam et al., 2011; Greene et al., 2003; Serovich and Mosack, 2006) as being reasons to withhold the disclosure of their HIV status information. This appeared to be particularly pertinent in the case of public disclosure where much less control over the dissemination of the information is afforded to the individual. As such, this group indicated a preference for one-to-one (or 'pairwise') HIV related discussions to increase disclosure control. (2) The second group consisted of users living with HIV who identified a potential 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 (Davis et al., 2006), this group was found to utilise proactive public disclosures 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. This study also found support for previous research (Derlega et al., 2004; Murphy et al., 2016) that some users within this group disclose publicly to help them reduce HIV related stigma and to normalise HIV through a proactive disclosure approach. (3) Finally, some HIV negative users

who were concerned about being infected with HIV 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 (Zea et al., 2003).

### **3.5.2 Limiting Social Interactions through Public Disclosures**

Of the three main groups identified, two groups suggested proactive public disclosure of their HIV status could reduce their stigma exposure or reduce their perceived sexual risk. The privacy group reported a preference for restricting this information to pairwise interactions. This section explores the potential impact of failing to respect the views of this privacy group and explores the potential limitations they face when interacting in this environment if their privacy is violated.

When privacy is understood as a functional requirement for self-presentation, associating sensitive, potentially stigmatising information to an existing online identity could 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 (Nissenbaum, 2009). For example, in Emlert (2008)'s interview study with people living with HIV, he found 25% of his participants reporting having 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 (Ashuri et al., 2018; Zytka et al., 2014). These interactions could help users develop confidence in their environment and interactions prior to disclosure. As an example, the immediacy with which someone requests personal information and the way they ask, is feedback which may help them in forming opinions and trust. This is reduced when individual disclosure choice is removed. This can be especially pertinent in the context of HIV, with the findings from this study supporting previous research which shows users being concerned about the social stigma HIV creates, and the rejection it can cause (Derlega et al., 2002; Zea et al., 2003). A study found recently diagnosed MSM experiencing higher rates of mental illness in the 12 months post diagnosis (stigmaindexuk.org, 2015).

As such, research has identified the need to support these individuals by fostering positive interactions during this period (Tsarenko and Polonsky, 2011).

Respecting the privacy of this group would provide them with greater 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 (Goffman, 1959). 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 through structured disclosure fields are void of these narratives which may cause the information receiver to develop their own. Where a person holds out-of-date or even stigmatising views of HIV, the narrative they develop may align with those views, and increase their risk of rejection. The findings from this study suggest people living with HIV could mitigate this by disclosing later on in the interaction in more intimate pairwise conversations (private chats). This could increase disclosure control, and allow them to shape their own narrative. This may also provide an opportunity to educate those with less knowledge and awareness of HIV. However, if these users feel unable to keep this information private around these structured disclosure fields, this form of disclosure choice becomes limited.

When disclosure choice is limited, users may develop other strategies to keep their information private. As findings from this study and previous literature have shown (e.g., (Carballo-Diéguez et al., 2006)), the fear of rejection individuals face as a result of HIV related stigma may lead users to misreport their HIV status; a behaviour Sannon et al. (2018) refer to as 'privacy lies'. 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, the focus in the remainder of this section

is on exploring non-disclosure choice around these structured disclosure fields.

### 3.5.3 “Unravelling” HIV Non-Disclosures

The privacy group reported being 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 could inhibit aspects of social interaction. To avoid this, the privacy group have the option to select ‘Do not show’ in the predefined list of options in the structured disclosure field, allowing them to keep their HIV status private. However, consistent with previous findings (Ramallo et al., 2015), the unequal costs to disclosure between HIV positive and negative states have the potential to cause social assumptions to develop, creating stigmatising signals. This study identifies this as an effect of *privacy unravelling* (Peppet, 2011) which may occur in an online social environment where individuals are utilising signals (through self-disclosure) to maintain their social desirability. The Universal Design principle of Equitable Use states that a system should be designed in such a way that it neither disadvantages nor stigmatises any group of users (Benyon, 2014). The unequal sensitivity of HIV status information across users mean that requesting users to publicly disclose using this current design could 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 people living with HIV and negative users alike, both of whom may prefer not to disclose their status publicly. The findings from this study suggest users may feel increased pressure to disclose their status through fear of non-disclosure creating stigmatising signals. Unless users living with HIV misreport their status as being either negative, or perhaps even negative on PrEP, the privacy unravelling 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 this preventative drug (Golub, 2018; Jaspal and Daramilas, 2016), users may feel pressured



to disclose where non-disclosure attracts stigma.

### 3.5.4 Implications

From a design perspective, a non-disclosure option appears like an obvious and effective way of providing users with disclosure choice, resulting in an increase in user agency. Yet, this initial study suggests that the structured nature of these fields may limit control around disclosure in a number of ways. Firstly, control over how the information is communicated and interpreted is reduced by the removal of any form of narrative when disclosing through these types of fields. Secondly, the non-disclosure option may be limited as it could infer an HIV positive status due to the social effect of *privacy unravelling*. A follow-up study presented in the next chapter uses a different method to explore privacy and disclosure behaviours in more depth, addressing some of the limitations of the method used in this study which are discussed below.

### 3.5.5 Limitations

The use of online comments has limitations. For instance, these findings are based on self-reported data which may not translate into actual in situ attitudes and behaviours. Using this data source removes the ability to direct the conversation, limiting the scope to the discussions raised by participants. Participants are also self-selecting, and could consist of a group who are more dominant in certain discussions, leaving the voices of the broader audience to remain comparatively quiet, homogenising the debate (Albrecht, 2006). The comments are also limited to details those commenting feel comfortable disclosing in an online public space which should be given special recognition when conducting research around sensitive topics. However, the anonymous nature of these online spaces may provide an environment where individuals feel more able to discuss certain topics, although this anonymity may also lower the quality of the discourse (Hargittai and Hinnant, 2008). As such, studies using online comments as a data source are not necessarily generalisable to the wider population, although they may generalise to a smaller segment of the population (Henrich and Holmes, 2013), and so to help support

these findings, where possible the researcher has evaluated them against previous research.

### **3.6 Conclusions**

This chapter presents the findings from a qualitative analysis of online comments related to the introduction of a structured HIV status disclosure field into a specific sex-social app. This analysis identified privacy concerns when linking sensitive health information to an existing online identity due to the stigma that HIV attracts. Where users preferred to keep their HIV status information private, a potential limit to the non-disclosure options within structured disclosure fields was identified. This chapter describes how the non-disclosure option within structured disclosure fields has the potential to infer a less than desirable quality, an effect known as *privacy unravelling*. Recognising the limitations of this initial study, the findings were used to develop the study presented across chapters 4, 5, and 6. The next study uses semi-structured interview method to address many of the limitations of this study. It will explore in more depth the privacy and disclosure behaviours of users around these structured disclosure fields. In the next chapter, the methodology used to conduct the semi-structures interviews is presented.

## Chapter 4

# Interview Study Methodology

*The following publication is based on work featured in this chapter:*

**Warner, M.**, Maestre, J., Gibbs, J., Chung, C. and Blandford, A. (2019) Signal Appropriation of Explicit HIV Status Disclosure Fields in Sex-Social Apps used by Gay and Bisexual Men In *CHI Conference on Human Factors in Computing Systems Proceedings* (CHI 2019), May 4 – 9, 2019, Glasgow, Scotland UK. ACM, New York, NY, USA, 15 pages. <https://doi.org/10.1145/3290605.3300922>

### 4.1 Introduction

This section presents the semi-structured interview method used to understand online privacy and disclosure behaviours of MSM app users around HIV status information. Initially, interviews were not focused on any particular form of disclosure (e.g. structured, unstructured). However, as a structured design is most commonly used around HIV status disclosure fields in sex-social apps used by MSM, an increased focus developed around this form type as data collection progressed. Where participants discussed disclosure in unstructured fields, this was also explored and discussed in later analysis. The researcher limited interviews to MSM app users, excluding app developers. This decision was made as prior to this study, the researcher had insufficient understanding of the behaviours of users of these apps to confidently approach app developers, and to structure and justify a study with them.

The semi-structured interview method allowed the researcher to address lim-

itations highlighted in the first study, as he could use it to probe into the user behaviours around these fields to gain richer insights and a deeper understanding of these privacy and disclosure behaviours. The data collected through these interviews was analysed using two existing theoretical frameworks. The deductive analysis method and findings from these analyses are presented in the following two chapters. Whilst theory was used to support data analysis, it did not influence data gathering. This chapter details how participants were recruited, the interview process, an overview of the analysis approach, and the ethical considerations of the study.

## **4.2 Participant Sampling and Recruitment**

The online comments used in the previous study provided a useful source of data to analyse user attitudes towards a specific HIV status disclosure field implementation. As discussed previously, using a secondary source provided the researcher with an easy to access data set that allowed him to engage with data from this population prior to conducting face-to-face studies. This helped the researcher build knowledge and confidence when engaging in follow-up user research studies with this population. However, this secondary dataset limited the researcher in the scope of questions that could be answered as the researcher was unable to influence the type of data that was being collected. To address this limitation, a semi-structured interview study was developed. Semi-structured interviews were chosen as they are well suited to understanding people's perceptions of, and experiences with, technologies (Blandford et al., 2016) and allowed the researcher to gain insights from both MSM living with and without HIV who use sex-social apps. Moreover, interviews can be more intimate than other data collection methods, and this intimacy is important when discussing sensitive topics such as the one addressed by this research.

Participants were asked to physically attend the University campus in London. As such, the majority of participants were living in the London area. However, one participant was interviewed over Skype as he was living elsewhere in the UK.

The initial inclusion criteria for participants were: (1) identify as male, (2) over the age of 18, (3) interested in having sex with men, and (4) active on at least one social networking website or sex-social app. As this thesis became focused on disclosure around structured HIV disclosure fields in sex-social apps, the inclusion criteria were adjusted, requiring participants to be active on at least one sex-social app irrespective of whether they used social networking websites. Moreover, in the early data gathering period, people living with HIV were underrepresented in the collected sample. Therefore, a further adjustment was made later on in the data gathering stage to exclude further recruitment of MSM who were self-reported to be HIV negative.

#### **4.2.1 Sampling Method**

Convenience sampling method was used in the process of recruiting participants to this study. Convenience sampling is a non-probability sampling method that was chosen as it was anticipated that recruiting participants living with HIV would be challenging. This sampling method reduces the practical restrictions on selection when compared to purposive sampling methods. For instance, participants that meet the inclusion criteria can be recruited based on their willingness to engage in the research, levels of accessibility and geographical distance from the researcher, and their availability at a particular time (Etikan et al., 2016). However, the researcher did evaluate a number of different criteria during and after data collection to ascertain how balanced the collected sample was in terms of time since diagnosis for those reporting to be living with HIV (see: Figure 4.2), and age (see: Figure 4.1). The aim of balance around these two factors was to ensure that views were not only being sought from individuals living with HIV prior to the introduction of social and dating technologies, but also from those diagnosed when these technologies were mediating many of their communications and activities. Moreover, as levels of stigma have changed over time, it was important to gain insights from men of different ages to understand how the effects of stigma impact on privacy and disclosure behaviours around HIV status information in online social environments.

Whilst a balanced sample in terms of age and time since diagnosis was

achieved (see section 4.2.2 for a more detailed breakdown), this sampling method is limited in that it does not allow for particular categories within a given sample to be selected, making broader empirical generalisations more difficult (Robinson, 2014). However, the use of existing theory in the analysis of this data allowed the researcher to understand how the behaviours identified within the sample may apply more broadly by abstracting these observations up to these extant theories to understand their theoretical generalisability (Lewis and Ritchie, 2003; Blandford et al., 2016). Moreover, selected observations from this qualitative study were tested in a quantitative study with a large sample size (see: chapter 8), adding support for the empirical generalisability of some of these qualitative findings.

An entwined data collection and analysis approach allowed the researcher to identify themes that were developing from the collected data. This allowed the research to adjust questions in future interviews to explore certain behaviours in more depth and across multiple participants. Data collection from participants continued until the point at which no new insights were being gained by the research and where no new adjustments to the interview structure were required to further investigate prior identified behaviours.

#### **4.2.2 Recruitment Strategy**

Study recruitment adverts were placed onto online social and sex-social networks and to a lesser extent in cafes in central London. The online recruitment strategy used was found to be effective, and whilst online recruitment can lead to sampling biases, this study's inclusion criteria included online sex-social usage. Therefore, the researcher did not anticipate this having a significant impact on the study findings.

The details of the study were published on a recruitment website<sup>1</sup> which people were directed to in all of the study advertisements. This allowed prospective participants to obtain details of the study without first revealing their identity. It also allowed them to privately reflect and consider the details of the study without external pressure from the research team.

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<sup>1</sup><https://talkabouthiv.wordpress.com/>

The recruitment campaign ran for approximately six months. A total of 44 men responded to the campaign, of which eight did not respond to follow-up emails, eight arranged interviews but cancelled, 28 were interviewed, and 27 were included in the final analysis as one participant reported no sex-social app usage. From these 27 participants, 13 self-reported to be living with HIV, 12 of whom self-reported as undetectable; and 14 as HIV negative, five of whom self-reported to be taking PrEP. Figure 4.1 shows the age distribution of participants, showing a broad range of ages, except for under-representation of participants between 18–24 and 65+. This can be partially explained by nearly 75% of new HIV diagnoses in the MSM population being aged between 25-49 years (Brown et al., 2017a), and Internet usage falling in people over the age of 60 (ONS, 2018). When participants were asked which sex-social apps they used, 82.1% reported to use Grindr, 64.2% Scruff, 28.5% Tinder, 21.4% Hornet, and 14.2% reported using BareBackRT ('BBRT').

### 4.3 Data Collection

Data collection was conducted by the researcher between October 2017 and March 2018 and each interview lasted between 41 and 88 mins (Median = 63). Each participant was asked to complete a pre-interview questionnaire (see: Appendix A.3) to collect basic demographic information, sexual health history, and an overview of their use of online social and sex-social apps.

Participants were then interviewed following an interview guide which was informed by both the previous study and prior literature (see: Appendix A). It was developed and conducted by drawing on a range of user interview methods and techniques (Blandford et al., 2016; Braun and Clarke, 2013; Portigal, 2013). The interview guide started with an "ice breaker" question to help relax participants by asking them to talk generally about their use of online social and sex-social platforms. This also helped to inform the researcher of the types of social and sex-social networking websites each participant used, and why and how often they used them. Participants were then asked about their HIV status disclosure behaviours

online. Whilst initially these questions were focused on HIV disclosure across both social networking and sex-social platforms, after initial interviews it became clear that the issue of HIV disclosure was most prevalent and consequential to participants within sex-social apps. Therefore, further questions were focused around sex-social apps, and the inclusion criteria for the study was revised. Drawing on the findings from the previous study, the guide was developed to explore insights around the impact of stigma on disclosure, as well as how participants were engaging with the privacy around their HIV status information. As a result of reviewing prior literature, the guide also included questions related to online social support to understand whether disclosure was being used as a means of gaining support from online peers within sex-social environments.

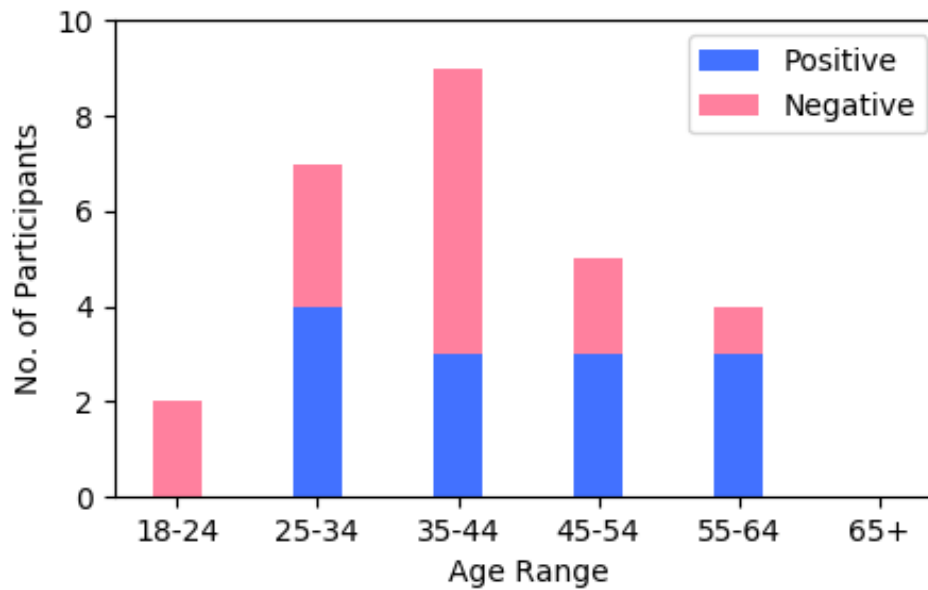
Questions to participants were open-ended to encourage them to speak freely about their experiences, feelings, and behaviours around different topics. Participants were encouraged to use relevant stories from their past to discuss different topics where they felt comfortable doing so. Where participants discussed something of interest, the interviewer used probing phrases to seek more detail and to encourage greater participant reflection (e.g., “could you elaborate a little on what you mean by that?”). Where a participant stated something that was unclear or used language unknown to the interviewer, the interviewer asked for clarification (e.g., “Could you explain that term?”).

## **4.4 Analysis Approach**

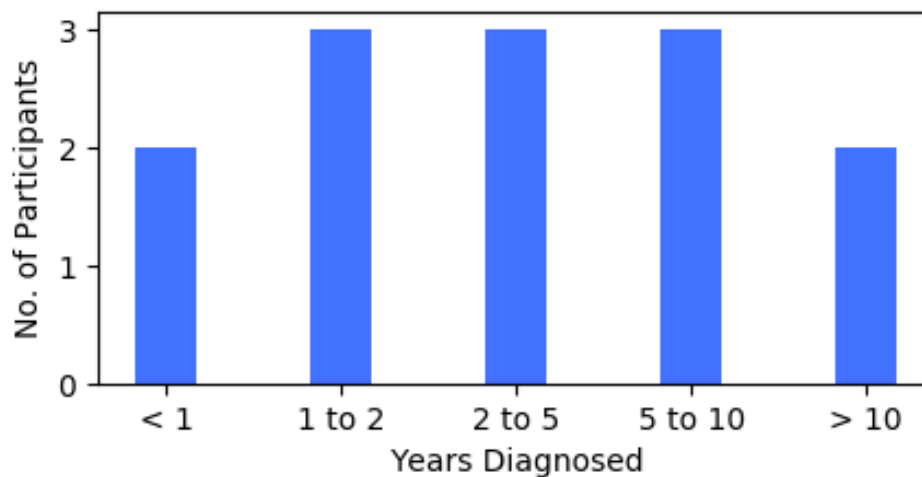
An initial inductive thematic analysis was used to analyse this data using the approach developed by Braun and Clarke (2006). Data collection was interleaved with the familiarisation and initial code development phases. This allowed the researcher to immerse himself in the data and reflect on the interviews, adapting subsequent interviews as knowledge and understanding of the topic developed.

Data familiarisation involved the researcher transcribing each of the interviews manually whilst writing notes on significant aspects of the data, such as disclosure behaviours, concerns around sharing of HIV status, and perceptions of HIV status





**Figure 4.1:** Bar chart showing age distribution of participants, separated by HIV status (n=27).



**Figure 4.2:** Bar chart showing years since diagnosis for all participants self-reporting to be living with HIV (n=13).

options. A second round of data familiarisation was performed which involved reading the transcripts whilst listening to the audio recorded interviews. Next, an initial round of code development was performed using Nvivo 11 software. Each transcript was individually coded with a latent descriptive code being applied to each section of each transcript. If no code was assigned to a section of the transcript it was labelled 'not coded' to be reviewed at a later stage of the analysis.

After data collection and the completion of an initial inductive thematic analysis, the researcher reflected on the interviews and the initial codes developed, yet was unable to make sense of how different aspects of the data fitted together, and how the data could be further analysed inductively to address the research questions posed (RQ2, RQ3). As such, the researcher explored existing theory to help make sense of the collected data and support in theoretical generalisability of the findings (Lewis and Ritchie, 2003). Applying theory provided the researcher with the critical tools to enable data analysis and sense making of the data to facilitate a more direct data analysis approach to address the research questions. As such, no further inductive analysis was conducted.

The second research question looked to understand how users interact with structured HIV disclosure fields to manage the disclosure and privacy of their HIV status. Drawing on the findings from the first study (Chapter 3), signalling theory was explored due to its links with the social privacy problem *privacy unravelling*. Signalling theory has also been previously applied to research to understand aspects of behaviour in online social networks (e.g., Lampe et al. (2007)), collaborative work system (e.g., Shami et al. (2009)), and online market places (e.g., Ma et al. (2017)). As such, the author chose signalling theory as a tool to analyse and interpret this interview data to help address RQ2.

A disadvantage of applying theory to data is the findings will be constrained by that theory. Whilst signalling theory may be well suited to understanding how users disclosed and interpreted disclosures of others, it was not well suited to addressing the third research question. As discussed in chapter 2.2, *privacy unravelling* relies on the assumption that people who hold the least desirable quality have no incentive to reveal. Within social environments, people's incentives to reveal may be much more complex than in economic environments. It is therefore important to understand the different incentives that MSM have to disclose in order to provide a more nuanced understanding of the *privacy unravelling* effect around these fields. As such, a theory of motivation was used to address the third research question which looked to understand *why* users choose to use these fields to disclose their

HIV status information.

Details of both deductive analyses, and the results of these analyses are presented in chapters 5, and 6.

## **4.5 Ethics**

Prior to each interview, participants were provided with an informed consent sheet detailing the study. This information was also on the study website which each participant was directed to prior to attending the interview. Each participant was then asked to complete an informed consent form. This informed consent process was conducted in accordance with the researcher's study design which was approved by the University College London Ethics Review Board, approval number: 11699/001.

## Chapter 5

# Managing Privacy Through Signal Appropriations of Structured HIV Status Disclosure Fields

*The following publication is based on work featured in this chapter:*

**Warner, M.**, Maestre, J., Gibbs, J., Chung, C. and Blandford, A. (2019) Signal Appropriation of Explicit HIV Status Disclosure Fields in Sex-Social Apps used by Gay and Bisexual Men In *CHI Conference on Human Factors in Computing Systems Proceedings* (CHI 2019), May 4 – 9, 2019, Glasgow, Scotland UK. ACM, New York, NY, USA, 15 pages. <https://doi.org/10.1145/3290605.3300922>

### 5.1 Introduction

The first study, presented in chapter 3, provides insights into user attitudes towards a structured HIV status disclosure field implemented into a specific sex-social app. In doing so, it highlights a concern with the structured nature of these fields, in that they may be susceptible to the *privacy unravelling* effect. The first study also identified a limitation to implementing HIV status disclosures into structured disclosure fields, in that they remove any form of narrative around the disclosed information. Whilst prior research suggests that people engage in novel ways of disclosing sensitive aspects of their identity such as indirect forms of disclosure (Clair et al., 2005; Andalibi et al., 2018b), the previous study was unable to gain insights into more subtle disclosure behaviours due to limitations around the data used in this analysis.

To build on the findings of the previous study and to deliver the second component listed in chapter 1, this chapter looks to address the second thesis research question:

**RQ2:** *How are users interacting with structured HIV disclosure fields to manage the disclosure and privacy of their HIV status?*

To investigate this research question, a deductive analysis was performed across the data collected from semi-structured interviews. This data was analysed using the conceptual framework of signalling theory, a communication theory developed in the areas of evolutionary biology (Zahavi, 1975) and economics (Spence, 1978). Chapter 3 highlights the potential for privacy to *unravel* around HIV, an effect that manifests itself in signalling environments like sex-social apps. These environments operate in a similar way to markets (Levy and Barocas, 2017; Ellison and Hancock, 2013; Heino et al., 2010), with a supply and a demand and the need for users to ‘signal’ otherwise private information to each other to promote their own desirability. In applying this theory to the data, this chapter provides new insights into how participants interact with these HIV “signalling systems” to manage the disclosure of their status.

## **5.2 Background and Related Work**

### **5.2.1 Signalling Theory**

Signalling theory has its roots in evolutionary biology and economics, with signalling proposed as a mechanism for dealing with information asymmetry, where one transaction party holds more or better information than another. In Akerlof (1978)’s “Market for Lemons” work, he relates uncertainty and quality to provide a structured understanding of how dishonesty can negatively impact an entire market. Using the second hand car market as an example, he describes how good cars and bad cars (lemons) must sell at a similar price, as the uncertainty and potential for dishonesty mean buyers are unable to differentiate between the two, making it a market for lemons. To mitigate this, Spence (1973) proposed signalling as a means for one party to reveal information to another to reduce information asym-

metry. These are often referred to as ‘signalling environments’ (Feltovich et al., 2002).

In environments where individuals act to maximise their own value, Frank and Parker (1991) described a phenomenon, the “full disclosure principle”, which is the opposite of the “Market for Lemons” principle in that all individuals disclose to distinguish themselves from others, causing non-disclosure to become unsustainable (Baird et al., 1998). Non-disclosure can then have what Peppet (2011) describes as a game-theoretic *privacy unravelling* effect where undesirable assumptions develop around non-disclosures, effectively removing the element of control from privacy decision-making. This effect has been explored in an experiment involving information disclosure in a labour market (Benndorf et al., 2015), in a study of eBay Motor listings (Lewis, 2011), and the qualitative analysis of online comments related to Grindr’s HIV status disclosure field presented in chapter 3.

Whilst signalling in economics is focused on reducing information asymmetry between transaction parties, in evolutionary biology the focus is on understanding how signals maintain reliability. This is especially important as signalling is thought to be a key mechanism in biological evolution, from mate selection (Zahavi, 1975), to predatory avoidance (Mallet, 1993). If signals are so critical to evolution, how do they stay reliable? One way is for signals to be costly to produce, and therefore costly to fake. If a signaller uses excessive amounts of a finite resource, the “wastage” of this resource can act as a signal. Those with less of this resource would be unable to waste it, making the signal more reliable. Zahavi (1975) coined this the “handicap principle” referring to golfer’s who “waste” their strokes to signal their ability.

Signals are also present in human communication (Pentland, 2008), developing through a much faster process of cultural evolution (Donath, 2006). Donath (2006) identifies three types of signals that can occur in human social interactions. The first two are categorised as assessment signals, as the quality being signalled is inherent within the signal itself. These are (1) honest signals (e.g., handicap principle), and (2) index signals, which require the individual to possess the quality

for the signal to be produced, e.g., golfers signal the strength in their arms by the quality of their swing. The final type is a (3) conventional signal which develops meaning through an established process of social convention. For example, the use of capitalised letters to signal SHOUTING!

This chapter uses Donath (2006)'s cues, signals, and evidence framework. She defines *cues* as anything used to infer some hidden quality or information. A cue becomes a *signal* where the sender has intention to convey the information, and *evidence* where the information is unintentionally conveyed. These communication mechanisms do not have to exist in isolation. For example, a person may signal some hidden quality, yet when the signal is received it may be evidence of a very different quality. As an example, a person may drive a large petrol sports car to signal their wealth, yet the signal receiver may use the car as *evidence* of the person's lack of concern for the environment.

### 5.2.2 Signals and Cues in HCI

Previous researchers have drawn on signalling theory to understand and explain a range of online social technologies and behaviours, from how people interact in online dating platforms, to visualising non-verbal cues in communication skills training software (Pereira et al., 2018). Often, when social researchers utilise signalling theory, they make reference to constructs from the market metaphor (e.g., costs). Although metaphors can help make sense of complex processes, they can also impact on the shaping of people's social constructions of reality (Baxter, 1992). This could have negative consequences when used in the context of online dating, such as the objectification of potential partners (Heino et al., 2010). However, this chapter focuses on understanding the management of HIV status information, rather than using signalling theory to understand relationship formations.

Although not explicitly applying signalling theory, previous HCI researchers have explored the use of digital artefacts to mediate signalling in various different forms. For example, a recent study found people repurposing emojis with different meanings to signal affection to specific groups or individuals (Wiseman and Gould, 2018). Cultural evolution of emojis has also occurred; for example, the peach fruit

emoji is now a common signal for buttocks rather than a type of fruit (Wiseman and Gould, 2018; Azhar, 2016).

In one study (Lee and Niederle, 2014), online daters were provided with a limited number of virtual roses that they could send to other users to signal their interest. Limiting the number of roses per user created an artificial cost, increasing the reliability of the sender's signal.

Signals have also been explored in an online job market which identified "costly to fake" automatically generated content about a user as being more influential in impression formation than self-reported content (Shami et al., 2009). However, self-reported data may not always be unreliable. The social aspect of online social networks can create a form of validation of claims (also known as warranting (Walther et al., 2009)), that individuals make about their identity, with incorrect information being "called out" by other users in their network (Lampe et al., 2007; Hong et al., 2012; Walther et al., 2009).

Online dating environments differ, usually consisting of pairwise interactions (Masden and Edwards, 2015), limiting this type of social information validation. This can be particularly challenging when users misreport or embellish aspects of themselves to increase their online attractiveness (Ellison et al., 2006). In the absence of reliable information, people may develop other techniques to evaluate identity claims. One study found people using subtle "costly to fake" signals like poor spelling and grammar to support claims related to education levels (Ellison et al., 2006). Another found linguistic cues on dating profiles correlated with profile deceptions (Toma and Hancock, 2010). The unintentional nature of these signals mean they are more costly to produce, and could act as honest signals.

Signals can also be used to help foster changes in perceptions in social environments. Levy and Barocas (2017) research on designing against discrimination identified a sex-social app using 'pledges' to help cultivate stigma reducing norms around HIV. The app asked users to pledge to "Live Stigma-Free". Once made, the pledge appeared on the user's profile which also acted as a signal to other users, allowing them to learn more about one another.



Where information could be used to stigmatise and discriminate, one approach could be to suppress it. However, unintended consequences of this approach may disadvantage a wider set of users, as was observed around an initiative to remove questions related to job applicants' criminal conviction histories from job application forms. Initially it was thought this could help those with criminal records find employment, yet researchers found the absence of this information caused other cues (e.g., age, ethnicity, socioeconomic status) to be used by some employers as *evidence* of a candidate's likelihood of past criminal behaviour (Doleac and Hansen, 2016). Another approach is to allow users individual choice to disclose, yet this too has limitations due to the *privacy unravelling* effect that was discussed in section 2.2. This effect could cause those not disclosing to be assumed by others to be hiding something undesirable (Peppet, 2011).

What all these signalling systems have in common is the need to be reliable. Systems that consistently support dishonest signalling lose reliability and break down. As Donath argues, signalling systems should develop to be beneficial for participants to produce reliable signals, yet costly to produce deceptive ones (Donath, nd).

### **5.3 Analysis Method**

This section presents the method used to conduct an analysis of the semi-structured interview data using signalling theory as a deductive framework. The interview method for the data analysed in this section is detailed in chapter 4.

The deductive analysis using signalling theory was performed across the data, with the previously developed codes collapsed into an initial set of themes using Nvivo 11. Additionally, as recommended by Braun and Clarke (2006), mind maps were used as a visual aid to help sort the different codes into themes. As this analysis was deductive, themes were developed based on their relationship to aspects of signalling theory (Spence, 1978; Zahavi, 1975). These included: signalling costs; signal reliability; signal honesty; countersignals. Donath (2006)'s cues, signal, and evidence constructs were separately coded. The themes were further

**Table 5.1:** Abbreviated HIV status symbols and number of participants were reported HIV status

Reported HIV Status	Abbreviated Symbol	<i>N</i> Participants
Negative	Neg	9
Negative on PrEP	PrEP	5
Positive	Pos	1
Undetectable Viral Load	UVL	12

reviewed, and sub-themes developed to ensure that the codes that were collapsed within each theme formed a coherent pattern. A further re-read of the transcripts was performed, revising themes to accurately reflected the data, and to code any aspects of the data that may have been missed in the previous rounds of coding. The final phase prior to data reporting is the naming of themes (Braun and Clarke, 2006). As signalling theory does not have a fixed model and has been developed across disciplines, the names developed for the themes were refined to better relate to the contextual findings of this analysis. These were: Changing Cost Dynamics, Non-Disclosure Cues, Signal Reliability, Signalling Strategies.

In reporting the findings from this analysis, each participant is identified by a participant number, followed by their self-reported HIV status as a superscript abbreviation (see: Table 5.1). To simplify reporting, when talking generally we refer to two groups, people living with HIV, and HIV negative participants.

## 5.4 Findings

This section presents the findings from the deductive analysis performed using the conceptual framework of signalling theory. The first part of the results explores the cost dynamics around HIV status disclosure fields and how these dynamics are changing. The next part looks more closely at the non-disclosure option, exploring it as a cue to understand meaning intention and formation developing around the non-disclosure option. As a signalling system, the next part looks at reliability around these fields, touching on factors such as trust, and deception. Finally, the last part explores signalling strategies used by participants to help them manage their HIV status within these sex-social environments.

### 5.4.1 Changing Cost Dynamics

As was discussed in chapter 2, the stigma that HIV attracts means that for many MSM living with HIV, disclosure of their status comes with a high social cost. This is especially significant in sex-social environments, as HIV historically led to fear, anxiety, and stigma around sex for MSM, and is often still perceived that way today.

Whilst being HIV negative remains low cost, the time elapsed since being tested often had a negative effect on disclosure cost. As P10<sup>PrEP</sup> described: *“I’m always a bit dubious when last time tested is like 2016, that’s always a bit “ok, you seem to think that it’s ok [to test] every year””*. An out-of-date test could be used as *evidence* that the signaller was not taking care of their sexual health. Some participants recognised this and instead removed the last test date from their profile to avoid this acting as an undesirable cue.

The increasing use of PrEP within this community has the potential to increase the cost of a negative status for those not on PrEP. The date of last test is perhaps less significant when the profile is disclosing PrEP use, as they are actively protecting themselves from HIV between tests even when engaging in condomless sex. Moreover, as part of the PrEP prescription, they are likely to be undergoing regular testing. For example, P8<sup>Neg</sup> stated: *“PrEP has kind of reduced my status, so before PrEP being negative was as good as you could get, but now with negative on PrEP that’s like an A\* so I’ve been demoted, irritating”*. However, not all participants perceived PrEP status as being a low cost signal. Some felt unintentional signals had developed around its use, with the status becoming *evidence* of an increased willingness to engage in condomless sex, a behaviour known as “barebacking”. P23<sup>U=U</sup> reported the reason his husband did not disclose being on PrEP: *“He said there’s a perception, and he’s right, in the gay community that if you’re on PrEP, then you are therefore automatically into bareback sex and he’s not, so he doesn’t want the solicitations from people who are going to assume that”*.

Along with increasing the cost of a negative status, increased usage of PrEP within the community, combined with the advent of U=U, appears to have reduced the cost associated with an HIV positive disclosure. The findings from this current

analysis suggest this has resulted for two reasons: Firstly, PrEP taken correctly prevents the acquisition of HIV which allows people to be in control of their own HIV risk, reducing fear. Secondly, in the process of learning about and being prescribed PrEP, many participants reported becoming much more aware and knowledgeable of wider HIV related issues. One participant even suggested that it had resulted in a cultural shift: *“I think because the culture has changed so much because of PrEP and the recent findings that if you’re undetectable then you just can’t pass it on that guys are a lot more relaxed about it”* (P25<sup>U<sup>V</sup>L</sup>).

#### 5.4.2 Non-Disclosure Cue

This section looks to understand the social impact non-disclosures have on both people living with HIV and HIV negative participants, and whether the *privacy unravelling* effect causes non-disclosures to act as cues. The analysis presented here identified a number of instances where people living with HIV were concerned that by leaving their HIV status undisclosed, this would act as a cue which could be used to infer their HIV status. As an example, P9<sup>U<sup>V</sup>L</sup> removed his status after he noticed a drop in responses: *“when I took it down I thought everyone’s going to think I’m positive. Maybe that’s one of those things where like, seeing it as a whole is different from what it personally means to you”*. Whilst this fear did not result in P9<sup>U<sup>V</sup>L</sup> disclosing, P6<sup>Neg</sup> did choose to disclose, in part, because of a fear of being perceived as being HIV positive: *“I put myself as negative also because I think there’s a growing stigma, it might be just in my head, but if you don’t put anything, it seems like you’re trying to hide something, maybe, but that may just be in my head but I thought, I am negative so I might as well say so”*.

Whilst some participants felt their own non-disclosure could act as *evidence* of an undesirable status, they did not always perceive this when viewing other profiles with undisclosed HIV statuses. For instance, P6<sup>Neg</sup> disclosed his status through fear of being stigmatised, but when asked how he perceived this in others he stated: *“I think if you don’t have anything, my initial reaction is, they just haven’t put it in, [...] I don’t think “oh they’re positive and they don’t want to say anything”*. Others felt non-disclosure was used by people who didn’t know their status (e.g., P3<sup>Neg</sup> said:

*“I’d assume you didn’t know actually.”*), or that some people did not disclose because they felt the information was irrelevant (e.g., P14<sup>Neg</sup> said: *“they might just not want to [disclose] and might just think it’s not relevant.”*) Some participants also felt non-disclosure assumptions were reduced where other profile fields (e.g., age, height) were incomplete: *“you get those people who don’t put anything on their profile, have nothing or just one line, so they don’t file their age their height anything like that, umm but I think for people that bother to fill in, you know a reasonable section of the profile information, they answer their HIV question”* (P8<sup>Neg</sup>).

### 5.4.3 Signal Reliability

When users publicly signal their HIV status information in sex-social apps, there is typically no form of verification that the status disclosed is accurate. This section explores the reliability of these signals by looking at what makes a signal reliable, and how participants act to increase their trust in the signals of others.

The most common statuses being signalled amongst participants were either HIV negative or HIV negative on PrEP. It was not uncommon for the reliability of these signals to be questioned due to the trust that is required in the signal sender: *“in a way [public disclosure] is bad because you’re relying on that person to be honest”* (P2<sup>Neg</sup>). The reliability of HIV negative signals was often questioned, especially when the time since last test had elapsed passed a certain point. The change in cost dynamics discussed in section 5.4.1 appeared to affect the reliability of HIV status information: *“I kind of think, if [...] it’s [last HIV test] a year or two ago well, it doesn’t mean anything really, you don’t know is what you’re saying”* (P8<sup>Neg</sup>).

The relatively low-cost associated with a negative on PrEP status means individuals who possess a high cost status may become incentivised to misreport their status to avoid being stigmatised. Whilst non-disclosure is an option, the *privacy unravelling* effect discussed in section 5.4.2 can also result in non-disclosures becoming stigmatised. A number of people living with HIV were found to have misreported or seen others misreporting their HIV status. For example, one person living with HIV who used Scruff stated: *“I’ve unticked the treatment one [Treatment as Prevention], because that’s implying that you’re on treatment [HIV positive], so I*

*didn't want to just broadcast that [...] I left PrEP on there because I'm in that same category"* (P27<sup>UVL</sup>). However, for a number of other participants the disclosure options provided by Scruff created uncertainty causing them to either abandon the feature, or tick all the options available: *"it isn't very clear whether it's what you engage in, or what you expect your partner to engage in, so I tick them all because I think if somebody who is on PrEP wants to approach me, then yes there would be a conversation"* (P28<sup>UVL</sup>). A number of other participants reported that they felt being negative on PrEP was very similar to being undetectable. Both are unable to pass on the virus, and both are taking very similar medication. This caused some undetectable participants to misreport or contemplate misreporting their status as negative on PrEP.

Typically, the most reliable signal that was reported was an HIV positive or undetectable status. As these signals come with high social costs, the perception was that a person would be unlikely to signal these statuses unless they were accurate. For men looking to engage in unprotected "bareback sex", the reliability of these signals was much more important than to those with a preference for condoms. For these individuals, signals with higher reliability were much more attractive: *"I think the one thing about the majority of the guys in my fraternity being HIV positive, we're getting regularly checked for other diseases, which in itself umm, negative guys have said "well, you can tell you're quite attractive to a negative guy because you're a pretty safe bet" do you know what I mean?"* (P16<sup>UVL</sup>).

Participants felt inhibited in their ability to build trust online as opposed to offline. Consequently, participants found it more difficult to evaluate the reliability of information more generally, and in particular the reliability of HIV status information: *"anyone online can say "yeah I'm on PrEP, I'm positive that I've got an undetectable viral load" but you don't know, but I think if you're meeting with someone and you're going out with them and you're dating them, you build that trust"* (P4<sup>Neg</sup>). Some participants reported evaluating other aspects of a user's profile, attempting to establish the reliability more generally: *"there's that element of trust that actually that picture of the 29 year old is actually, one, that they are actually 29, rather than*

45, positive, obese rather than, do you know what I mean? umm, which at some point you're gonna [sic] find out and in a way, if [...] that and that don't match up to reality then you might kind of think, well hang on a minute, does this [HIV status information]?" (P2<sup>Neg</sup>).

#### 5.4.4 Signalling Strategies

##### 5.4.4.1 Costly to produce

One strategy used by participants was the “costly to produce” strategy. As discussed in section 5.4.3, HIV statuses with high social cost are often deemed more reliable. Although being undetectable was not seen as the most costly, some felt the cost was high enough to be costly to produce: *“I just don't understand why you would lie to say you're undetectable when you could just lie to say you're negative, do you know what I mean?”* (P3<sup>PrEP</sup>). Yet, others felt a positive status was *“the only really believable claim”*, suggesting *“everything else should be taken with a pinch of salt”* (P8<sup>Neg</sup>).

This “costly to produce” signal strategy was particularly effective with HIV negative participants who engaged in regular unprotected “bareback sex”, as signal reliability for this group was much more important than for those using condoms. Yet, regular condom users also saw the benefit of an undetectable status and its reliability: *“I would feel safer sleeping with somebody that was HIV positive and told they were undetectable and I was on PrEP then I would if I wasn't and somebody was just randomly saying that they'd had a [HIV] test”* (P10<sup>Neg</sup>). P23<sup>UVL</sup> recognised the benefit his public status could afford others, and was very explicit in relaying this information: *“One of the things that I state on my profile [...] is: “do you know what? you're so much safer having sex with somebody who knows themselves to be positive and undetectable than having sex with somebody that tells you that they are negative””*.

##### 5.4.4.2 Countersignaling

As discussed in section 5.4.2, whilst many of the sex-social apps provide a non-disclosure HIV status option, where users choose to keep their status undisclosed,

stigmatising cues can develop. A number of people living with HIV who chose not to publicly disclose their status performed “countersignaling”. They acted to reduce the strength of these non-disclosure cues by limiting disclosure across other parts of their profile (e.g., weight, interests). This was explicitly described by P26<sup>UVL</sup> who stated: *“mine’s very limited in what I fill out anyway so I think it just says my height and my position and that’s it [...] so I guess if you answered all the other questions and excluded that one [HIV status] then maybe someone might ask questions”*, when asked whether he restricted disclosure of these other fields on purpose, he replied: *“yep, (laughter) [...] it’s that thing of I just don’t want everyone kind of knowing about everything I guess”*

Whilst P26<sup>UVL</sup> was explicit in his intention to countersignal the effects of unravelling, other participants who preferred to keep their HIV status undisclosed also described limiting disclosure across their profile: *“my profile is exceptionally thin on the ground, it’s basically got a picture of me where you can’t see all of my face, you can see my mouth, it’s just got my age, my background, my ethnicity, my height and that’s all”* (P24<sup>UVL</sup>).

People living with HIV who preferred to disclose their HIV status in more intimate pairwise interactions often reported developing educational strategies to counter the stigmatising effects of their HIV positive status. Participants reported various means of achieving this. P21<sup>UVL</sup> used a feature in Grindr called ‘saved messages’ to share HIV related information, and a link to an online video <sup>1</sup> related to undetectable: *“the first one is quite a short paragraph which is [...] do you know what undetectable means? Do you understand what that’s all about?, the second is more kind of detailed, a statistical kind of thing, and the third one is a link to a YouTube video”*. P27<sup>UVR</sup> used an image containing information related to evidence based research on undetectable transmission rates: *“I have a photo that I send them which is from a recent study which is basically a screenshot of text”*.

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<sup>1</sup>E.g., [https://youtu.be/-Vew9W\\_dbkg](https://youtu.be/-Vew9W_dbkg)



#### 5.4.4.3 Unravelling as an intentional signal

So far, the effects of *privacy unravelling* have been discussed in terms of its potential to disadvantage users and limit their disclosure choice. However, one participant reported exploiting the effect to his advantage. P27<sup>U<sup>V</sup>L</sup> wanted to disclose his status to others on Grindr to find other people living with HIV that he could relate to. This was challenging due to the location-aware nature of the app creating a context overlap, meaning information disclosed in his online sex-social life could leak across into his professional life. In contrast to participants who engaged in countersignaling to reduce the effect of unravelling, P27<sup>U<sup>V</sup>L</sup> exploited this effect, recognising that by leaving his HIV status undisclosed it would send a subtle signal of his HIV positive status to other people living with HIV, whilst limiting information leakage to his work colleagues: *“I don’t want to lie, and I also need to find a way to let other people know [of his HIV positive status] that are in the same scenario [...] it’s like finding common ground, but you can’t find common ground if you’re not going to share anything and then you don’t want some idiot at work, you know flying off the handle kind of thing, it’s a bit of a fine line [...] I think Grindr has got it the best because you can just put nothing, and everyone puts something, so it’s very subtle but you know, it’s actually not really subtle”* (P27<sup>U<sup>V</sup>L</sup>). Here, the unravelling effect is exploited as an intentional signal, allowing him to regain some control over the disclosure of his status. This strategy afforded him a new type of plausibly deniable HIV disclosure, allowing him to manage the ill effects of information leakage across contexts.

#### 5.4.4.4 Status Repurposing

The final strategy identified was the repurposing of signals. Whilst the HIV status disclosure options that many sex-social apps provide seem very explicit and rigid in their meaning, this analysis identified some users attempting to change their meaning. For example, a number of participants reported undetectable users disclosing as negative on PrEP to reduce disclosure cost and to signal a desire to engage in bareback sex. A number of participants perceived PrEP users as being more promiscuous and into higher risk sex than non PrEP users. This repurposing of

negative on PrEP status was explicitly described by P20<sup>UVL</sup>: *“I actually put negative on PrEP on my profile for a bit, [...] I think some positive people might use that as code [...] it’s not used by positive people as a way of slipping under the radar of bigots umm, it’s definitely used by people who want bareback sex, to advertise that, I think that’s something that people do”*. Supporting this, as discussed in section 5.4.3, a number of undetectable participants stated strong similarities between being undetectable, and negative on PrEP: *“I like kind of see them as, I kind of think that if you’re undetectable it’s kind of the same as being on PrEP, like you’re protecting other people and yourself”* (P26<sup>UVL</sup>). P16<sup>UVL</sup> reported seeing a number of undetectable users disclosing as negative on PrEP: *“I just sort of felt that, is it HIV guys actually saying they are negative to make themselves more attractive? They’re on PrEP so I’m looking after myself and all this stuff, and therefore can use that as a lever, I might be wrong”*.

## 5.5 Discussion

This chapter extends the analysis presented in chapter 3 by applying the theoretical framework of signalling theory to collected semi-structured interview data. Signalling theory is a communication theory developed in the fields of evolutionary biology (Zahavi, 1975) and economics (Spence, 1978). The application of this theory here is novel, and is applied to better understand how MSM interact with, and adapt, HIV status disclosure fields within sex-social apps to manage the disclosure and privacy around their HIV status information.

### 5.5.1 Cultivating Stigma Reduction

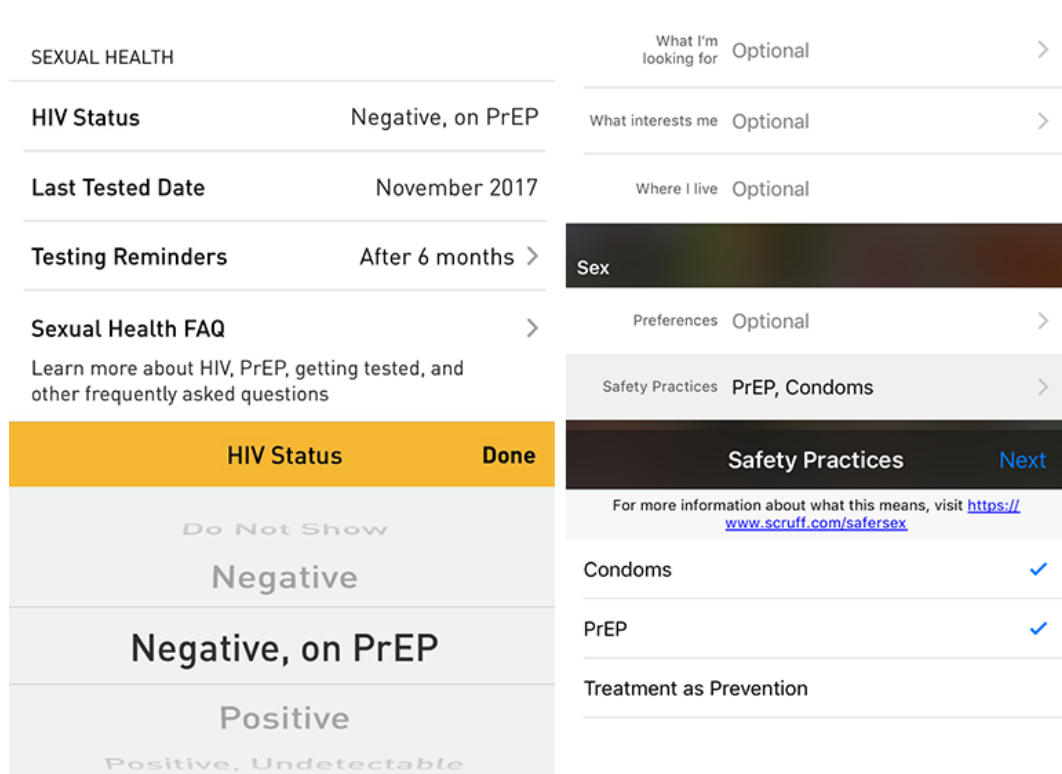
Online sex-social apps are often well subscribed, with large numbers of prospective partners available. Additionally, the effort required to reject users is low, often performed with a single on-screen finger gesture. As such, the social and physical costs needed to reject users are minimal. This can make public disclosure a difficult proposition for people living with HIV. As the findings show, the social cost of an HIV positive status is high due to its perception as a socially undesirable attribute. Public disclosure can become unaligned with people’s initial interaction goals of ap-

pearing desirable to others (Goffman, 1959). The findings in this chapter support this, with a number of people living with HIV preferring to disclose in more intimate pairwise interactions after rapport had developed, which can increase the social cost of rejection. As discussed in section 2.3.2 there are many health and social benefits to public HIV disclosure, and sex-social apps are well positioned to help reduce these costs through design. Previous attempts have been made to design out stigma with community ‘pledges’ (Levy and Barocas, 2017) which ask users to ‘pledge’ to live stigma free lives. These could benefit online environments like these in two ways: firstly by placing HIV stigma into the social consciousness of users, and secondly the ‘pledge’ could act as a *conventional signal* to others, which may help people living with HIV feel more confident in disclosing to users signalling this ‘pledge’.

Education as a means of updating out-of-date views around HIV is used to help reduce stigma (Klein et al., 2002; Wohlfeiler et al., 2013), lowering the cost of disclosing an HIV positive status. Some participants took on the role of educator, both in public disclosures (e.g., adding educational information on a profile), and in one-to-one interactions. Yet, frustrations developed with having this role, which lead to users developing strategies to speed up and regulate this process using existing app features. While some of the sex-social apps integrate educational information, it is often outside the daily user interactions, and is not easily accessible for sharing with others.

### 5.5.2 Signal Appropriation

Researchers have studied how users self-present in various online spaces, from social networking sites (Zhao et al., 2008; McRoberts et al., 2017; Hogan, 2010; Uski and Lampinen, 2016) to online dating environments (Ellison et al., 2006; Gibbs et al., 2006; Yurchisin et al., 2005; Zytka et al., 2014). They have also looked at how online users perceive the impressions of others (Fiore et al., 2008). However, it is only recently that researchers have started looking at how users navigate self-presentation in online environments that are not designed to support their needs, especially amongst stigmatised populations (Andalibi et al., 2018a). Structured



**Figure 5.1:** Cropped screenshots of the HIV disclosure fields in Grindr (left), and Scruff (right).

disclosure fields provide support for users wanting to disclose their status publicly, but for those that are not, these fields can limit their ability to keep this information private. As a consequence, users were found to be appropriating these fields using ‘signal appropriation’ strategies. This term is used to describe the use of signals as a mechanism for appropriating social technologies.

The structured HIV disclosure design shown in Figure 5.1 (left) provides users with a non-disclosure option, yet the findings from this analysis provide evidence to support the findings from chapter 3 that these fields do not provide sufficient disclosure choice. The low disclosure cost, and subsequent ease with which an HIV negative status is disclosed, can cause privacy to *unravel* around these fields when undisclosed, becoming *evidence* of a signaller’s undesirable HIV status. The ambiguity of the second design approach shown in Figure 5.1 (right) appears to limit this *unravelling* effect. The lack of definition can support users in developing their own interpretations and meanings around designs (Gaver et al., 2003; Handel

and Shklovski, 2012; Boehner and Hancock, 2006), and support users in less direct forms of disclosure to reveal stigmatised aspects of their identity (Clair et al., 2005; Edgar, 1994; Serovich et al., 2005; Andalibi et al., 2018a). Yet, if ambiguity is implemented through increasing complexity (e.g., providing many possible variations of disclosure), this may confuse users, as it becomes harder for signals and their meaning to cultivate and gain consensus within a given social environment.

In part, the lack of complexity around *privacy unravelling* contributes to its privacy invasive nature, yet this same simplicity allowed for this effect to be appropriated to reveal its affordance properties. The effect can provide people living with HIV with a means of indirectly disclosing their status, allowing them to connect with similar others for support. This can also contribute to developing feelings of relatedness and belonging - shown to help reduce stigma (Veinot, 2010; Bockting et al., 2013). This is especially pertinent for users who fear the social risk of post-disclosure rejection (Peterson, 2010; Williams and Mickelson, 2008). Haimson et al. (2015a) found anonymity being used to create a less socially risky environment for information seeking and support, which is reflected in findings in this chapter. But signalling can provide an alternative approach to disclosing sensitive information online within existing, identifiable social networks and is not isolated to the disclosure of HIV status. Andalibi et al. (2018a)'s research on communicating pregnancy loss found women using digital artefacts as *cues* to *signal* their loss to others. This too afforded them plausible deniability which allow users to be selective in who they would respond to if asked directly about their loss.

This has another potential benefit. As discussed in the introduction and related work section of this thesis, the location-aware nature of sex-social apps can lead to context collapse (Marwick and Boyd, 2011). For instance, work colleagues may view each others' profiles while co-located at work. Research found people living with HIV protect their workplace roles by having a preference for privacy (Fesko, 2001). The affordance properties of *privacy unravelling* could help protect this form of context overlap, while allowing people living with HIV to *signal* their status. Many of the current structured disclosure fields provide binary disclo-

sure states (Disclosed/Undisclosed). If subtle signalling systems were developed around HIV disclosures, this transition from one state to another could be made more fluid, providing a continuum of disclosure regulation through indirect, ambiguous disclosure behaviours, consistent with previously identified offline disclosure strategies (Serovich et al., 2005; Clair et al., 2005).

### 5.5.3 Harmful Evolution of Signals

A number of other signal appropriation behaviours occurring within these HIV signalling systems were identified in this analysis. Like the repurposing of emojis to signal affection (Wiseman and Gould, 2018), some participants repurposed both low-cost HIV statuses (e.g., “Negative, on PrEP”) and high-cost HIV statuses (e.g., “Undetectable status”) to signal sexual risk preferences (e.g., “bareback sex”). Where these signalling systems, which rely primarily on *conventional signals*, were unaligned with the user’s needs, attempts were identified to evolve new meaning around HIV status *cues* by changing social convention around them. Yet, this form of signal appropriation can have a detrimental effect on honest signallers. For example, those signalling PrEP use may be harmed by their status being interpreted as evidence of wanting “bareback sex”, leading to increased stigmatisation around its use (Golub, 2018; Jaspal and Daramilas, 2016). The effects of this could be MSM at risk of HIV not seeking PrEP as a result of this stigma (Calabrese and Underhill, 2015). Where dishonest signals develop, Donath (2006) suggests finding ways of making these signals more costly to produce. However, this can be challenging with *conventional signals*, and while other researchers have explored designing artificial costs into systems (e.g., Lee and Niederle (2014)), this may not always be possible or appropriate. An alternative approach would be to design in countersignals to support users to reduce these stigmatising signals, and help prevent “devolution” of these *conventional signals*. The second design shown in Figure 5.1 (right) allows for this type of countersignalling, providing users with the ability to disclose a preference for both PrEP and condoms.

Countersignals were also developed naturally by people living with HIV, helping them counter the undesirable effects of *privacy unravelling*. Some people living with

HIV who preferred to keep their HIV status undisclosed would limit the disclosure of other information on their profile to reduce the strength of the *privacy unravelling* signals. However, this meant limiting the non-HIV related information disclosed which could disadvantage them. Although past research has found disclosure of fixed fields in dating applications to be unrelated to perceived attractiveness (Fiore et al., 2008), many modern sex-social application allow users to filter on these fixed fields (e.g., age, height). If these fields are left undisclosed, the user may experience reduced visibility to others.

#### 5.5.4 Implications

The previous chapter highlighted two main issues around the structured nature of these fields. The first is the loss of narrative around information disclosed through these fields, and the second is the potential for non-disclosure to infer an HIV positive status due to the *privacy unravelling* effect. This chapter provides further support for the *privacy unravelling* effect occurring around these fields, yet also highlights how the effect could be used as a way for users to indirectly disclose their status to others. However, as discussed in chapter 2, the *privacy unravelling* effect relies on the assumption that those holding the least desirable quality have no incentive to reveal. The incentive to reveal sensitive information in a social environments may be much more complex than in the economic environments where *privacy unravelling* is more commonly explored. Therefore, the next chapter investigates these incentives around HIV disclosure by investigating what motivates users to disclose their HIV status using these fields.

This current chapter also extends the findings from the previous chapter by highlighting a broader user behaviour that encompasses *privacy unravelling*. It develops the notion of 'signal appropriation' which is the use of signals as a mechanism for appropriating social technologies by cultivating new meaning around digital artefacts. The *privacy unravelling* effect is a form of signal appropriation; so too is the cultivation of an alternative meaning around the Negative on PrEP status. Signal appropriations can be harmful and potentially stigmatising, so it is suggested that designers carefully monitor the way in which signalling systems are appro-

priated by users, and to develop purposeful countersignals to limit their negative impact. In the example of the Negative on PrEP status being appropriated to signal a desire for condomless sex, here the inclusion of an explicit field for signalling a preference for condoms could help counter this stigmatising signal appropriation.

Stigma around HIV is still very prevalent within these environments. Stigma is a complex social phenomenon that can cause people significant harm. In the case of stigma around HIV there is no single solution, yet signalling could help to reduce the stigma around the virus. Cultivating perception change around HIV should be a long-term goal within these environments, and designers could consider developing stigma reducing signalling systems, such as “living stigma-free” pledges (Levy and Barocas, 2017). However, whilst outside the scope of this thesis, it is important to point out that there has been very little research into the effectiveness of these forms of pledges, and whether over time they are effective at cultivating change in user perceptions.

What this current analysis shows is that the ambiguity that non-disclosure creates allows for indirect disclosures, helping those straddling the line between being open about their status and keeping it concealed. Yet at the same time, this same ambiguity around non-disclosure can limit the optional nature of these fields for users who do not want to reveal their status. Designers should therefore carefully consider the privacy implications of near-binary structured disclosure fields. Ambiguity could be used as a resource to limit the effect of unravelling, and promote a socially cultivated signalling system. These could be used to develop indirect forms of disclosure to support marginalised users in sharing sensitive aspects of their identity. Moreover, it could help these users connect with similarly positioned others for support, and to fulfil psychological needs of relatedness and belonging whilst respecting privacy. For instance, in the app Scruff (see Figure: 5.1 (right)), it is unclear whether the safer sex selections are ones that the user adheres to, or that the user is expecting of others. If a user was to select all three options, it is unclear whether they are on PrEP and happy to meet other users who are Undetectable, or whether they are Undetectable and happy to meet people who are on



PrEP. Increasing ambiguity in structured disclosure fields is explored in chapter 7 as a way of reducing the effect of *privacy unravelling* around non-disclosures.

### 5.5.5 Limitations

The focus of this analysis was to understand how users interact with HIV disclosure fields to manage the disclosure and privacy of their HIV status. Yet all participants were from the UK, and most were recruited from London which has a higher proportion of MSM, and higher rates of HIV. Therefore, participants may not be representative of the wider MSM population. Ethnicity was not controlled for in this study, and whilst this was only raised once during interviews, different signalling behaviours may cultivate differently within different ethnic groups, and in different cultural settings. Therefore, it is important to recognise that while the signal appropriation principle presented in this chapter is likely to generalise, the specific signalling system cultivated may not.

## 5.6 Conclusions

HIV disclosure in sex-social apps used by MSM is now commonplace, and most integrate disclosure using structured disclosure fields. However, tensions are created when using structured disclosure fields for this information. As discussed in chapter 3, the structured nature of these fields can provide benefits to stigmatised users by formalising and de-stigmatising the language used around HIV (Levy and Barocas, 2017). However, the studies conducted so far suggest that the structured nature of these fields can lead to privacy concerns, with non-disclosures suggesting an HIV positive status due to the effect of *privacy unravelling*. Designers therefore have the challenging task of building interfaces to both support those who do not yet feel able to disclose, whilst promoting disclosure for the benefits it can provide.

This chapter also highlights another tension around these fields. Whilst *privacy unravelling* can limit disclosure choice, it can also provide users the means to indirectly disclose an HIV positive status through the intentional use of this effect. This chapter develops the notion of ‘signal appropriation’, a user behaviour that encompasses *privacy unravelling* that refers to the appropriation of social technologies

by cultivating new meaning around digital artefacts. However, research into the effect of *privacy unravelling* has predominantly been conducted around financial markets (e.g., labour markets). These markets are focused on maximising profits, with incentive to reveal linked to this singular goal. Within social environments, the incentive to disclose personal information, such as HIV status information, is likely to be much more complex. Therefore, the next chapter of this thesis reports on an analysis that explores these incentives to disclose by applying a theory of motivation to the collected semi-structured interview data. This will provide richer insights into why users choose to disclose or not disclose their HIV status using these disclosure fields.

## Chapter 6

# Exploring Motivation to Disclose HIV Status Using Structured Disclosure Fields in Sex-Social Apps

### 6.1 Introduction

The first study, and the previous analysis of the collect interview data highlight how the effect of *privacy unravelling* may limit the voluntary nature of HIV disclosure within sex-social environments. The previous analysis also identified a potential for this effect to be exploited as a means for people living with HIV to indirectly disclose their HIV status. Yet, as discussed in the previous chapter, information disclosure within social environments differ from disclosures within economic markets. Whilst *privacy unravelling* may occur in economics markets where people are incentivised to reveal information to maximise profit, in social environments the incentives for revealing personal information are likely to be much more complex.

Past research contributes insights into decision-making around the disclosure of HIV status information in offline interpersonal relationships (Derlega et al., 2004). Drawing on a theory of motivation Gillard and Roark (2013)'s study provides a better understanding of young adults' motivations to disclose their HIV status. Online, Grov et al. (2013) explored disclosure around sexual negotiations to better understand sexual risk decision-making amongst MSM. Research has also looked at the potential for online social environments like these to be used as tools for

HIV prevention and interventions (Holloway et al., 2017). These studies, whilst not specifically exploring HIV disclosure through structured disclosure fields, do provide insights into how users manage the disclosure and privacy around HIV status information online. Since starting this research the landscape around the virus has changed quite significantly. Much of the prior work around HIV disclosure discussed in chapter 2 highlights the significance of stigma as a factor affecting disclosure. Changes in treatment and prevention and the increase in public health campaigns, as well as the introduction of structured HIV disclosure fields within many of the popular sex-social apps, may have changed the levels of stigma around the virus, affecting HIV disclosure behaviours. As such, this analysis delivers the third component listed in chapter 1 by addressing the following research question:

**RQ3:** *How are structured HIV status disclosure fields affecting user motivation to disclose within sex-social apps?*

This question is addressed through a deductive analysis of the semi-structured interview data using Vallerand (1997, 2000)'s hierarchical theory of motivation to understand how situational, contextual, and global factors influence disclosure motivation around structured HIV disclosure fields. The findings from this analysis are used to build on the broader implications of this research which are presented in the discussion section of this chapter.

## **6.2 Background and Related Work**

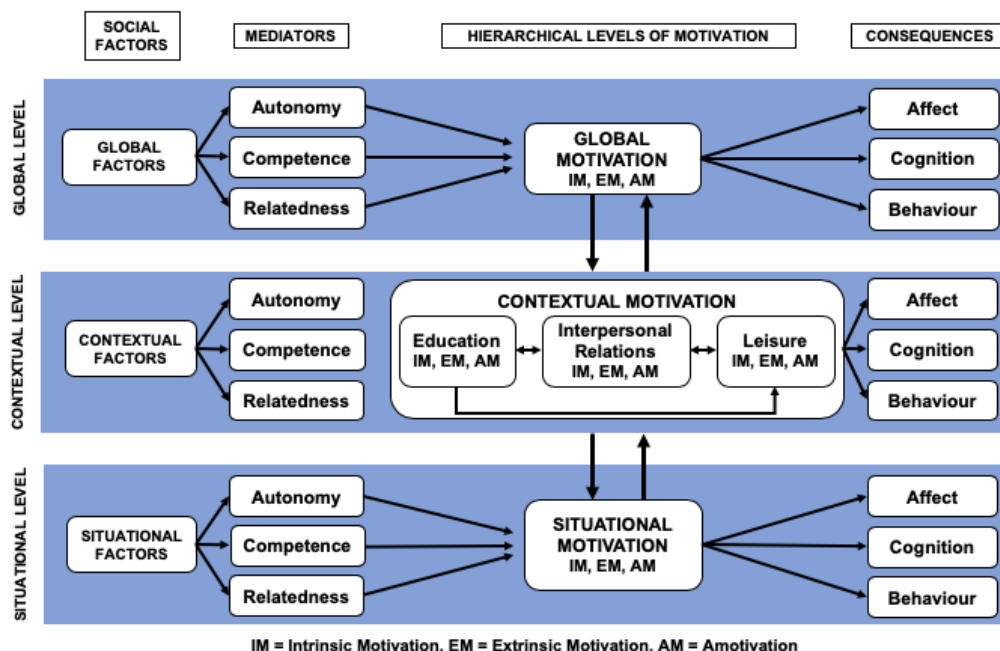
This section introduces and details the theoretical framework used in the analysis presented in this chapter. Before discussing this theory in more detail, a general overview of the concept of motivation is provided. Finally, this section presents prior work on understanding human values in order to situate findings in this chapter which highlight how values, in part, drive motivation around HIV status disclosure.

### **6.2.1 Motivation Theory**

Motivations are often theorised as reasons for people to think and act (Deci and Ryan, 2008). Disclosing personal information is an act which is motivated by a goal or set of goals; and as such, disclosure is often described as a goal-orientated

behaviour (Derlega and Grzelak, 1979; Omarzu, 2000). Motivations are typically categorised as being either intrinsic or extrinsic (Deci, 1971; Vallerand, 1997). Intrinsic motivations involve behaviours which are satisfying to the individual, and so the satisfaction from the behaviour is the source of motivation. For example, an individual enjoys disclosing a desirable aspect of their self to others because it makes them feel good. Contrary to this, extrinsic motivations do not lead directly to satisfying behaviours, but are created by an outcome which provides the satisfaction. For instance, an individual may not enjoy discussing an undesirable aspect of their self to others, but doing so provides them with emotional support. This dichotomous view of motivation is somewhat problematic however. Whilst an individual may be intrinsically motivated towards a certain behaviour, it may still depend on an external element that contributes to making the behaviour satisfying.

Ryan and Deci (2000)'s Self-Determination Theory (SDT) recognised this, and moved the thinking away from this dichotomous view. They instead suggest that motivation exists along a continuum of regulation, from non-regulation where an individual is amotivated, to intrinsic regulation where an individual acts autonomously,



**Figure 6.1:** The Hierarchical Model of Intrinsic (IM) and Extrinsic (EM) Motivation Vallerand (1997, 2000)

and is self-motivated. Whilst motivation may initially be extrinsic, the reduced self-determination from extrinsic motivations can result in individuals becoming inclined to move regulation internally. This provides the individual with autonomy and greater self-determination through reduced reliance on external factors. Many content theories of motivation focus on human needs. For example, Maslow (1943) proposed a hierarchy of needs that range from essential physiological (e.g. food, water) to psychological needs (e.g. belonging). SDT proposes three psychological needs that motivate the self towards certain behaviours, namely: autonomy, competence and relatedness.

Vallerand (1997, 2000) proposes that motivation is regulated across three hierarchical levels of varying generality, with motivation developing within a specific event (*situational*), in a certain life domain (*context*), and within a person's wider life (*global*). This frames motivation not just as an intrapersonal phenomenon, but also as a social one. As such, this model suggests social factors at each hierarchical level that influence motivation, mediated by perceptions of *autonomy* (feeling able to control our own actions), *competence* (being able to effectively interact within a given environment), and *relatedness* (feeling connected to significant others). The model proposes a top-down influence effect, with motivation at the higher level influencing motivation in the lower levels. For instance, a person's values (*global*) may influence motivation within different *contexts*, and within a given situation. A recursive relationship is also suggested between motivation at the different hierarchical levels, so for example regular *situational* motivation can over time influence motivation at the *contextual* level. Motivation also has consequences, which can be *cognitive*, *affective* and *behavioural*, with more positive consequences being expected from intrinsic motivated behaviour, as opposed to extrinsic behaviour, or behaviour that a person has become amotivated to perform. Consequences exist across each level of the hierarchy. For example, situationally motivated behaviour will have situational consequences. Enjoyment experience from an extrinsically motivated task at the situation level may over time lead to intrinsic motivation, and could influence motivation at the contextual level. Our research draws on Vallerand's hierarchical

model to both structure and interpret our findings.

The analysis presented in this chapter uses Vallerand (1997, 2000)'s theory of motivation which was developed from SDT. However, it provides a framework for exploring motivation across different levels of granularity, from understanding how a person's values affect their motivation, to how aspects of a particular situation may affect a person's behaviour towards action. Using this theory allowed for a more granular understanding of behaviours which affect disclosure motivation.

### 6.2.2 Human Values

The *global* level of the above motivation model suggests that certain individual characteristics remain consistent across contexts and situations. At this level, Vallerand (1997, 2000) suggests a person's values influence motivation. Value theory highlights how values can act as both constraints and stimuli towards action (Rescher, 1969). For instance, a person who values conservation and the environment may be stimulated towards recycling, whilst being constrained to travelling by rail as opposed to by air. Whilst people often intuitively know what their own values are, theorists have struggled to develop a definition for the conception of basic human values. Yet, theories do exist that allow us to better understand values and their effect on individual and social behaviour and decision-making.

Schwartz (2012)'s value theory incorporates six main features that have been implicitly incorporated into prior theories on human values. Firstly, it states that values are beliefs and are infused with emotion and feeling. Secondly, values refer to desirable goals and as suggested by Rescher (1969) can lead to constraints and stimuli towards certain actions. Thirdly, values transcend specific actions and situations meaning values are distinct and of a higher order when compared with social phenomenon such as societal norms which is why they are positioned at the *global* level of Vallerand's hierarchy. The fourth feature of values is that they serve as standards or criteria, they guide people's decisions and serve an important role when people evaluate the implications of their own and other people's actions. The fifth feature states that values are relative to one another, and are ordered by their importance. People prioritise some values over others and this

helps to distinguish values over attitudes and societal norms. Associated to this is the final feature which states that the relative importance of a set of values helps to guide a person's actions. The importance and order of values helps to drive a person's behaviour and influences their actions especially when a particular value is of a higher relevance within a specific context. Having multiple values that are ordered by relative importance can result in value conflicts (Fleischmann, 2013) whereby a person finds a particular decision is being influenced and challenged by differing values. For instance, a person may want to be *honest* with their friend, but honesty may result in that friend becoming needlessly upset. When these types of conflicts exist, people negotiate them according to their own goals and priorities within specific contexts or situations which results in varying value trade-off's (Friedman and Kahn Jr, 2002).

More recent work on the impact and role of technology on human-values shows how technology is value-laden and as a result, the way technologies are designed can shape and drive the actions and behaviours of its users (Friedman et al., 2013). In a world of mass communication, this is likely to have significant consequences for society.

### **6.3 Analysis Method**

This section presents the method used to conduct an analysis of the semi-structured interview data using motivation theory as a deductive framework. The interview method for the data analysed in this section is detailed in chapter 4.

In the process of analysing the interview data to understand how users disclose and perceive other people's HIV disclosures (presented in chapter 5), further evidence of the *privacy unravelling* effect was found. However, during the initial inductive analysis of this data, the reasons participants mentioned for disclosing their status were often complex and varied. As *privacy unravelling* within economic environments assumes that those with the least desirable quality will have no incentive to reveal (Peppet, 2011), it is important to better understand people's incentives within this social context, as these incentives may be more complex than what has



been seen within economic settings. As such, a deductive analysis was performed across this data to understand what motivates users to disclose their HIV status.

In developing this analysis, the researcher explored a range of motivation theories. Self-Determination Theory (SDT) was explored due to its popularity, and the empirical support that has developed around it. It is also a theory that is becoming commonly used within the field of HCI, with researchers utilising this theory to better understand user motivation in gaming (e.g., Birk and Mandryk (2013); Johnson et al. (2015)), interactive systems (e.g., Brühlmann et al. (2018)) and online social networking and online social health technologies (e.g., Wohn (2012); Lerch et al. (2018)). More specifically, prior work draws on SDT to understand offline HIV disclosure (Gillard and Roark, 2013). Whilst the underlying constructs of SDT are powerful tools that can be used to help us understand why users act the way they do when interacting with different technologies, disclosure is a complex social behaviour. To understand why a user discloses sensitive information within a social platform like Grindr requires us to explore this social behaviour at varying levels of generality. For instance, one user may always choose to disclose their status, whilst prior work indicates that for many, disclosure of sensitive information happens in a more selective fashion (e.g., Andalibi et al. (2018b); Marwick and Boyd (2014); Haimson et al. (2018)). As such, the researcher explored the use of Vallerand (1997, 2000)'s hierarchical model of intrinsic motivation. This model was selected as it is based on the central constructs of Deci and Ryan (2008)'s SDT whilst also accounting for factors influencing motivation at various levels of generality. These range from factors within a specific situation, within a given context, as well as factors at a global level (e.g., a person's values).

A second deductive analysis was performed across the data using this theoretical model, with the initial set of codes developed during the inductive analysis collapsed into an initial set of themes using Nvivo 11. Like the previous analysis performed, this analysis was deductive; it used the constructs from Vallerand (1997, 2000)'s model to guide and support theme development. Initially, this involved identifying disclosure behaviours that were situated within one of the three levels of the

model's hierarchy (*situational, contextual, or global*). After this, data at each level was further analysed to identify sub-themes. These were, for example, related to user goals, their values, or social norms.

The themes were further reviewed to ensure that the codes that were collapsed within each theme formed a coherent pattern. A further review of the transcripts was performed to ensure that the themes accurately reflected the data, and to code any aspects of the data that may have been missed in the previous rounds of coding. The final phase prior to data reporting is the naming of themes (Braun and Clarke, 2006). As the analysis conducted here was deductive using an existing model, the naming of the top level themes related to the names of constructs within the model. Sub-themes were developed to most accurately represent the behaviour identified.

As in the previous chapter, when reporting the findings of the analysis in this chapter, each participant number is followed by an abbreviation of the participant's self-reported HIV status (see: Table 5.1). In abbreviating people living with HIV, the term 'Pos' is used to refer to those who did not report being undetectable, and 'UVL' to refer to those who did report being undetectable. When discussing participants more generally, to reduce complexity, they are referred to as being either people living with HIV (i.e., HIV positive/undetectable) or HIV negative. Where a construct from Vallerand (1997, 2000)'s hierarchical model is used, it is written in *italics*.

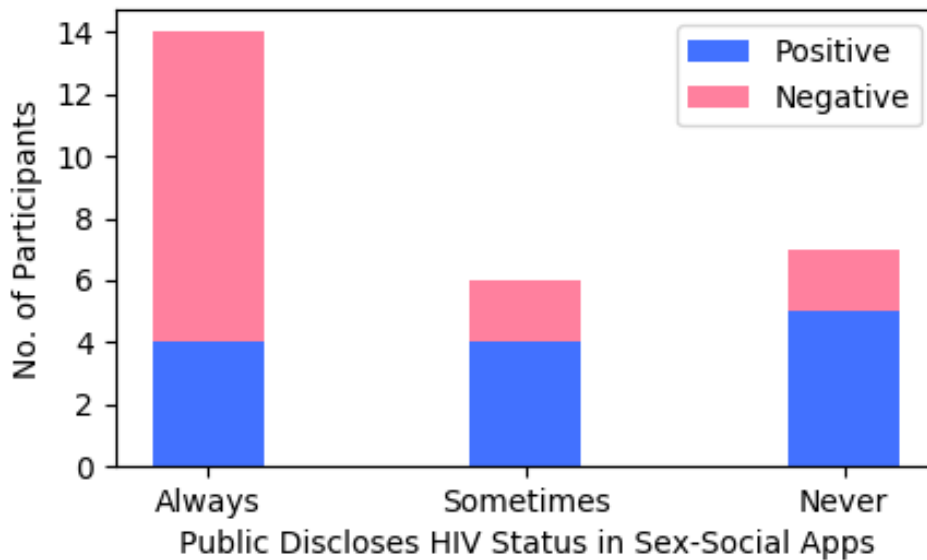
## **6.4 Findings**

This section provides an overview of how participants disclosed their HIV status across different sex-social apps. It then presents findings related to identified factors that affect an individual's motivation to disclose. These are situated within three levels of generality using Vallerand (2000, 1997)'s hierarchical mode.

### **6.4.1 How Are People Disclosing HIV in Sex-Social Apps?**

#### **6.4.1.1 Disclosing publicly to other users.**

Whilst the majority of HIV negative participants (N=10) chose to always publicly disclose their HIV status, this type of disclosure was much less frequent amongst peo-



**Figure 6.2:** Bar charts showing participants (N=27) self-reported public HIV disclosures in sex-social apps, separated by HIV status.

ple living with HIV, with only four choosing to disclose in all instances. Of the people living with HIV, four described how they would only sometimes disclose (intermittent disclosure), whilst five never disclosed (non-disclosure). Both intermittent disclosure and non-disclosure were less common amongst HIV negative participants, with only one reporting intermittent disclosure, and three reporting non-disclosure.

#### 6.4.1.2 Disclosing in private direct messages.

Of the subset of people living with HIV who reported to never publicly disclose their HIV status in any of their sex-social apps, three said they would always disclose when direct messaging another user, one said they would only sometimes disclose when direct messaging, and one reported never disclosing. The two HIV negative participants who reported never publicly disclosing their HIV status reported only sometimes asking about HIV status in private direct messages with other users.

### 6.4.2 Global Level

This section presents factors at the top of Vallerand's hierarchical model, the *global level*, that were found to influence HIV disclosure motivation. These consist of values (e.g. honesty), aspects of self-identity (e.g. identifying as a person living with HIV), and knowledge (e.g. awareness around PrEP).

#### 6.4.2.1 Personal Values

A number of values that influenced HIV disclosure motivation were identified and positioned at the *global level* of the hierarchy, yet these values were often in tension due to factors at other levels of the model. Most participants reflected a broad desire to be open and honest with other users, and expected the same in return. However, a number of people living with HIV described tensions between these values of openness and honesty, and concerns for their personal well-being if they were to disclose their status publicly. These concerns were situated around the stigma that is still present and felt by many within these online environments. For example, as previously quoted, P27<sup>UVL</sup> said “*you have to be honest, well [...] for me anyway I need to be honest*”, whilst later expressing concern at being recognised by work colleagues and a desire to keep this information separate from his work life: “*I don’t want to lie, and I also need to find a way to let other people know that are in the same scenario [...] it’s like finding common ground, but you can’t find common ground if you’re not going to share anything and then you don’t want some idiot at work, you know flying off the handle kind of thing, it’s a bit of a fine line*”. For some participants, the stigma felt caused them to compartmentalise the knowledge of their HIV status, restricting this aspect of their self from becoming fully integrated into their identity and being a regular source of tension.

Honesty was also a commonly discussed value amongst HIV negative participants who described public disclosure as a way of being more transparent with others. Like P27<sup>UVL</sup>, P13<sup>PrEP</sup> described honesty as acting to motivate him to disclose when a structured disclosure field was introduced. Prior to its implementation, non-disclosure may not have felt like a deceitful act, partly due to the lack of social expectation to disclose. The reshaping of the norms and expectations around disclosure at the *contextual level* as a consequence of this field appears to have made non-disclosure feel like a deceitful act, conflicting with global values around honesty at the *global level*. He said: “*I think it’s because it makes everyone’s life easier, and it’s to be honest with everyone. That’s one value, one quality I value a lot is honesty*”.

In contrast, individuals with an increased concern for privacy found disclosure of personal information a more challenging prospect across *contexts*. This appeared heightened for people living with HIV who viewed their status as being especially sensitive, but was also reported by HIV negative participants who had a general preference for reducing levels of disclosure online. For example on Grindr, P11<sup>PrEP</sup> reported keeping his HIV status and many other details about himself private, preferring instead to disclose in direct messages. This allowed him to regulate disclosure based on the level of intimacy established with prospective partners. P5<sup>Neg</sup> reported a similar behaviour in the app Scruff, describing his concern at the immediacy with which his information would be available to others if disclosing publicly. P25<sup>UVL</sup> described: *“this friend who is also HIV positive was saying that he doesn’t [...] like to disclose [his HIV status], he’s very private about it so, even with sexual partners, he tends to keep it a secret, he tends to keep it to himself”*.

#### 6.4.2.2 Identity integration

For those who had integrated their HIV status into their broader social identity, the tension between their values and dealing with the negative effects of disclosure appeared reduced, with an increased level of disclosure autonomy described by participants. Those wanting to be open and honest were more likely to disclose, whilst those who had a preference for privacy would be less likely. The analysis highlighted a distinction between a person’s broad identity, and their sexual identity. Those who had accepted and integrated their status into their broad identity had not always accepted it as part of their sexual identity. For some, being a person living with HIV was no longer sexually relevant due to the the improvements in treatments and the increased evidence and publicity that people who are undetectable are at zero risk of onward transmission.

Importantly, having integrated and accepted their status into their broader social identity, their disclosure choices became driven by their internal value systems rather than by external social influences such as stigma. For example, whilst in the period post-diagnosis P19<sup>UVL</sup> struggled with accepting his status, at the time of interview he described being very open about his status in most aspects of his

life, even publicly posting about it on social media. Yet, he preferred not to disclose his status publicly on his sex-social app profile as he did not see it being a relevant part of his sexual identity. He said: *“your HIV status is [...] medical, it’s part of who you are yes, but it’s not you, it doesn’t describe me, it doesn’t describe who I am or what I’m like”*.

Factors at the *contextual level* related to stigma were significant in reducing disclosure motivation for those who had yet to integrate HIV as part of their identity. For many years after he was diagnosed, P24<sup>UVL</sup> found it difficult to discuss or disclose his status with others due to the stigma that he felt. Yet, he described being ready to disclose publicly through an increased confidence in himself as a person living with the condition, saying: *“now I feel confident and better in myself to say this is who I am”*.

#### 6.4.2.3 Knowledge and information seeking

A recurring theme across many of the interviews was HIV related information seeking. For individuals who were diagnosed, this was more prominent in the post-diagnosis period, equipping them with the information needed to discuss their status with others, and to understand it themselves. This appears to be a critical part of identity integration and is supported by sense-making research in other health domains (e.g., Genuis and Bronstein (2017); Patel et al. (2019)). Our analysis identified younger participants understanding, accepting, and integrating their HIV status into their lives more effectively than older participants. A number of reasons may exist for this. Firstly, information resources for HIV are much richer than they have been in the past, with electronic peer-support, online forums, and online information resources readily available. The public health campaigns have also started to shift thinking and perceptions away from HIV being a highly contagious and deadly virus, towards it being a manageable health condition. The increased access to information and the changing perceptions around the condition appear to be helping with identity integration for younger, recently diagnosed men.

Knowledge as a factor in helping identity integration was also identified around PrEP use which has a developing stigma attached to it. A perceived lack of knowl-

edge that P10<sup>PrEP</sup> felt he had about the drug PrEP had a direct negative impact on his motivation to disclose as a PrEP user. However, after increasing his awareness and knowledge around PrEP, he gained confidence to disclose to others. In this case, it appeared that his previous lack of knowledge and understanding led to uncertainty, making it difficult for him to fully integrate this aspect of his life into his identity, and to challenge stigmatising comments received from others at a *situational level*. He said: “I changed it to on PrEP after [...] I understood more about, and I knew I could talk about it better. Up until then I just knew that it was a drug that you could take that you know, you couldn’t get HIV”. Other participants referred to knowledge about what it means to be undetectable as “the science”, using this knowledge during sexual negotiations. For instance, P20<sup>UVL</sup> said: “one guy was about to come over and have sex with us, and then just like, didn’t, and we had a conversation about it, and I eventually convinced him with the science”.

In first exploring motivation at the *global level*, we learn how factors at this level influence and are influenced by factors at the *contextual level*. For instance, an individual’s values can permeate into the *contextual level*, allowing identity integration and values around openness and honesty to reduce the effects of *contextual level* stigma that can otherwise reduce disclosure motivation. This will be discussed more in the next section.

We also learn how the integration of HIV status into the identity of an individual can result in increased autonomy by removing barriers to disclosure for those wanting to be open and honest about their status. Yet this increase in autonomy does not necessarily translate to an increase in disclosure, with a desire to compartmentalise aspects of an individual’s broader identity and their sexual identity, as well as values around privacy limiting public disclosure of status within these environments. Identity integration appears linked with knowledge and information seeking as it allows individual’s to better understanding their own self and to communicate this aspect of their self with others.

### 6.4.3 Contextual Level

Whilst it can be challenging to define exactly what is meant by 'context' (Dourish, 2004), in Vallerand's motivational hierarchy (Vallerand, 1997, 2000) he uses a broad definition of 'life domain' to define context (e.g., education, leisure). Using this broad definition, in this research the context is the online sex-social environment in which our participants are engaged. Factors at this level differ to those at the *global level*, as these factors are contextually dependent. For instance, stigma which is discussed below may be more prevalent within these sex-social environments than in other online environments, yet values are less contextually dependent and are commonly held by individuals across multiple different contexts.

Motivation is not just an intrapersonal phenomenon, but a social phenomenon, with other people and aspects of our surroundings having an influence on our motivations. This is especially relevant around social behaviours such as disclosure. The way people interact and engage with others in their broader lives, and within these sex-social apps can influence them at the *global level*. Stigma or low levels of understanding around their condition can limit the process of integrating HIV as part of their identity which can negatively impact on their disclosure decision-making autonomy. In this section, the *contextual level* factors that can influence individuals and their disclosure decision are presented. Firstly, the structure of these sex-social apps were found to influence disclosure, as well as the stigma that is still present in many of these environments. Secondly, contextual norms that develop within these environments are highlighted, as well as levels of user anonymity and population density.

#### 6.4.3.1 Online network structure.

Interactions in online social networks are shaped by their community structures (Donath, 2014). The structure of an online network can influence its effective use. Structures that reduce perceived user *competency* (i.e., reducing a user's ability to effectively interact within an environment), and *autonomy* (i.e., reducing user choice over certain actions like disclosure), can in turn limit their ability to interact with others and reduce perception of *relatedness* within their online environment. Social



networks such as Facebook and Twitter provide users with the ability to broadcast narrative rich messages to an entire network of pre-established connections, whilst sex-social apps limit disclosure to previously unestablished connections who happen to be in close proximity at a given point in time. This was described by P20<sup>UVL</sup> who said: *“One of the nice things about doing it on social media is it’s, you do it once and it’s public for all to see, so you might have a thread discussion afterwards [..], but you know you’re reaching everyone who’s seeing that, whereas on Grindr it’s just one on one and so [..] I imagine quite easily how I’ll get to a point where I’m just bored of having that conversation”*. Moreover, this information typically consists of replies to pre-defined questions (e.g., relationship status) which are void of a narrative. Whilst narrative rich disclosures do occur, they are often limited to pairwise interactions within private chats.

The different community structures of online social networks were reflected in the ways in which participants approached the disclosure of their HIV status. Some people living with HIV were *amotivated* to disclose in sex-social apps, whilst reporting to be very open about their status in online social networks such as Facebook. Participants were able to use social networks with a high degree of *competence* and *autonomy* to shape and control the narrative around their HIV status with a limited amount of effort. However, in sex-social apps, participants found this much more challenging. The dynamic nature of the connections within a sex-social network and the inability to broadcast messages resulted in participants having to use pairwise interactions such as private chats in order to gain control over the narrative around their HIV status. Yet, some found the process of disclosing in private interactions frustrating as it moved the focus of their interaction away from the goal of seeking sexual excitement and towards being an educator. For example, P24<sup>UVL</sup> removed his status from his profile to avoid regular discussions about his status, saying: *“I can’t be bothered with all the, having to explain, having to explain, having to explain. So I just took it off”*.

### 6.4.3.2 Social stigma.

When people living with HIV discussed the disclosure of their status, stigma and its effects were often at the centre of their decision-making, resulting in the restriction of status disclosure to less public forms. Although there were concerns that non-disclosure would create assumptions that the user was HIV positive, thereby reducing feelings of control around the disclosure of their status, it was still seen as the less stigmatising option. Social stigma was commonly felt through a reduction in perceived *relatedness* due to a lack of response from other users and subsequent lack of sexual opportunity. Some also experienced this in the form of direct messages containing abusive language. This type of social response at the *situational level* often led to a less enjoyable online experience and reduced *contextual* motivation, with participants often becoming amotivated to disclose their status. P20<sup>UVL</sup> describes his experience of this after he disclosed being undetectable: *“I remember it because I put positive undetectable on my profile, and then quite quickly took it off again because I noticed a decline in responses, like quite a significant decline umm, like yeah nothing else about my profile changed”*.

To a lesser extent, HIV negative participants experienced social stigma that centred around the use of PrEP. A number of participants discussed their apprehension at disclosing their PrEP use through fear of being viewed as sexually promiscuous. P10<sup>PrEP</sup> described this concern and how it caused him to “pause” for some time before he felt comfortable enough to disclose publicly, he said: *“I think there’s a negative stigma that’s attached to the PrEP drug umm, and I think that was the only time I thought, should I put it on there, because everybody’s going to think that I’m off to chemsex<sup>1</sup> parties all of a sudden”*.

Stigma was also at the centre of many of the disclosure decisions for people living with HIV. As well as acting to *amotivate* disclosure, it was also found to be acting to *extrinsically* motivate some users. When contacting or being contacted, uncertainty exists over how users will react to an HIV positive status, with fears of rejection and abuse. To mitigate this, some people living with HIV used public

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<sup>1</sup>chemsex refers to the consumption of drugs to facilitate sexual activity

disclosure to create a manual filter. For example, P1<sup>Pos</sup> was interested in finding a long-term relationship but was fearful at the prospect of disclosing his status after becoming emotionally invested. Similarly, P16<sup>UVL</sup> avoided last minute rejection by disclosing publicly and in direct messages prior to physical meetings. Whilst the type of relationship these two participants were seeking differed, both used disclosure to avoid feelings of rejection and reduced levels of perceived *relatedness*. In a similar strategy, P24<sup>UVL</sup> said: *“I’m at that stage now where I will probably update my profile and put it in there because it will just sift out a lot of people who are just going to be ugly, and if people see it and they don’t like it, they can just block or they can simply just choose not to respond”*. Here, P24<sup>UVL</sup> can be seen becoming motivated to publicly disclose to reduce his risk of being contacted by abusive, stigmatising users.

This type of manual filtering relies on other users reading profiles, which did not always happen. A number of participants reported frustration at being asked questions relating to information they had already disclosed on their public profiles. Manual filters also rely on stigmatising users ignoring people living with HIV, which again was not always the case. People living with HIV reported receiving stigmatising messages from both solicited and unsolicited approaches. P3<sup>Neg</sup> described the experiences of his friend living with HIV: *“most of the time it would be if [he says] “Hey how are you?”, and then they would reply and be like: something horrible. But every now and again [...] he will get [...] a random [person], saying [...] something horrible”*.

In an environment where stigma is still prevalent, a number of participants were reflective of their own ability to reduce stigma by taking a more open approach to HIV disclosure. While this *global* level motivation affected motivation to disclose at the *contextual level* for some, for others it was a source of internal conflict and guilt. For instance, P7<sup>UVL</sup> said: *“I’m also partly aware that in me not being as open about it as I am about so many other things that I’m actually not helping, and I’m actually almost perpetuating that [stigma], which is something that I keep thinking that I need to address”*.

For those who disclose publicly, the normalising of HIV acted as a source of *extrinsic* motivation, with users disclosing with the intention of increasing people's exposure to people living with HIV. As an example, P23<sup>UVL</sup> said: "*it's about normalising things, it's about, when something becomes usual people stop having an issue with it, people stop noticing it*". There is an imbalance in the sensitivities and social costs associated with being HIV positive which is reflected in the levels of HIV status disclosure amongst participants (see: Figure 6.2) which can make disclosure for people living with HIV more difficult. People living with HIV are in a minority, and with far fewer disclosing, the relative underexposure of HIV positive profiles can then increase *amotivation* of other people living with HIV to disclose through fear of "standing out" as undesirable. Whilst normalising and raising awareness *extrinsically* motivates some participants to disclose, the *extrinsic* nature of this motivation does not always translate into a long-term intrinsic disclosure motivation. For example, P9<sup>UVL</sup> described his desire to publicly disclose to normalise and raise awareness, and whilst this initially acted to motivate him, he became *amotivated* when experiencing behaviours at the *situational level* related to loss of sexual opportunity through reduced responses and approaches.

#### 6.4.3.3 Contextual norms.

Explicit HIV status disclosure fields (see: Figure 2.1 (left)) were found to motivate previously *amotivated* users to disclose. This was most prevalent amongst HIV negative users, leading to HIV disclosure even where the user felt the information was irrelevant within sex-social environments. For example, P14<sup>Neg</sup> viewed HIV information as irrelevant due to his safer sex practices. Yet, when asked whether he disclosed his HIV last test date, he replied: "*if they ask, I will put it in*" suggesting he viewed this field as a question which needed answering, as opposed to an optional disclosure field.

The inclusion of these types of fields can significantly shift disclosure motivation and in turn shape disclosure norms. As highlighted in chapter 3, where the disclosure of information can result in social stigma, an increase in disclosure norms could affect the optional nature of disclosure fields, with users becoming

*extrinsically* motivated to disclose to avoid stigma that can come from remaining silent (Peppet, 2011). This concerned both people living with HIV and HIV negative participants, though few participants articulated this concern as explicitly as P6<sup>Neg</sup> who felt non-disclosure would result in people assuming he was “*trying to hide something*”.

The relevance of information within a particular context was found to change depending on the safer sex practices of the app’s population. BareBack RT (BBRT) is an app targeted at MSM interested in condomless anal intercourse. Social norms related to HIV disclosure were markedly different in this app when compared to more mainstream apps like Grindr and Scruff, and facilitated users to becoming *intrinsically* motivated to disclose. For instance, P26<sup>U<sup>V</sup>L</sup> said: “*it’s on my profile, so it says undetectable but I think that’s a bit different because I think most of the guys I chat to on there are positive or on PrEP, so yeah I think that’s different. I kind of judge someone on there if someone was negative and they weren’t on PrEP on there because I think people should prevent trying to get infected*”. This shift in desirability away from HIV negative profiles that P26<sup>U<sup>V</sup>L</sup> describes appears to manifest within higher sexual risk environments as a consequence of the increased knowledge of U=U and bio-medical interventions for HIV prevention (e.g., PrEP).

Being either undetectable or on PrEP can act as a more reliable indicator of status than an HIV negative status (see: Chapter 5), leading those who are HIV negative and not on PrEP being judged by others. This allows those disclosing PrEP use or an undetectable status to interact more effectively within the environment (*competence*), without significantly affecting perceptions of *relatedness*. Individuals reporting to be HIV negative may have been exposed to the virus since their last test, or had the virus at their last test but had tested too early (i.e. within the window period) for the virus to be detected by the test (Bezemer et al., 2008; Phillips et al., 2013; Hall et al., 2012). Therefore, users reporting to be HIV negative, having condomless sex and not being on PrEP, may be perceived as increasing overall viral transmission rates and lacking awareness and care for their own sexual health. Whilst there was a clear demarcation of disclosure norms between higher

sexual risk environments like BBRT, and the more mainstream apps like Grindr, there were less distinct divisions within apps. For instance, P8<sup>Neg</sup> suggests that on Grindr, *“the world is divided very clearly into those that have safe sex and those that don’t, and the two don’t really mix”*.

#### 6.4.3.4 Anonymity and population density.

The stigma attached to HIV meant that some people living with HIV felt unable to disclose their status to offline friends and family. This had an effect on disclosure motivation within sex-social apps through fear of their HIV status information leaking from one online context to another, and was more common amongst those who were more recently diagnosed. As an example, P26<sup>UVL</sup> who was recently diagnosed (<1 year) reported disclosing to his close circle of friends, but feared his wider friendship circle becoming aware of his status if disclosing publicly in sex-social apps. As a consequence, he chose to regulate HIV disclosures in private direct messages.

Concerns over a person’s HIV status crossing between life contexts (e.g., sex life crossing with work life) were sometimes mitigated by using more anonymous apps or accounts. BBRT is a less “mainstream” app that permits anonymous profiles with no face pictures or real names, reducing the risk of offline recognition. Participants described anonymity as a fluid rather than a binary state that reduced certain social barriers to disclosure that exist in non-anonymous interactions (e.g., face-to-face). Users were often not completely anonymous, but as restrictions to personal information increased, their perceived accountability was reduced. For instance, aspects of anonymity also appeared related to offline population density, with disclosure being regulated according to the user’s physical location. The location-aware nature of sex-social apps supports users in searching for men close-by. As such, the location of the user can affect the norms of the online space and their ability to “get lost in the crowd”. As the offline population density increases, so too does the density of active and available users within the app. Where a user moves outside of a densely populated urban area into a more rural location, profiles disclosing an HIV positive status will reduce, making profiles that do disclose much

more evident, making it more difficult to effectively interact within the environment (*competence*). This was described by P22<sup>UVL</sup> who would regulate his status when changing locations: *“for example if you go to Devon, I mean you won’t find many people putting pos [HIV Positive] on their page or, [...] it’s a small community [...] and if I use Scruff it’s often the same people”*.

The location-aware nature of the app resulted in a dynamic online context which required some users to regulate disclosure according to their physical location. When concerns exist around the social desirability of an HIV positive status, even when undetectable, being more conspicuous within a smaller group can create feelings of vulnerability. Within smaller cities and towns where HIV rates are lower than in London, attitudes and beliefs can also differ, creating additional barriers to disclosure leading to increased amotivation. P18<sup>Neg</sup> recognised this, saying: *“in other cities away from London and Brighton and other places there are almost a few more social hurdles to clear before you can actually talk about certain things”*.

Some people living with HIV described feeling fearful of how people’s perceptions of them would change, and the social isolation this may cause, reducing perceived *relatedness*. The anonymity these apps can afford users provides an environment in which some participants were more comfortable seeking out support and “testing the waters”, helping them to find similarly positioned users to feel less isolated. For example, P19<sup>UVL</sup> stated: *“I think in the early days, within the first 6 months I was doing that whole anonymous talking to people, so I’d taken my pictures so you couldn’t see my face etc, and then I remember messaging people and talking generally about sex and talking about relationships and talking about HIV”*.

#### **6.4.4 Situational Level**

Data coded at the situational level related to specific interactions or incidents that occur at a particular point in time. Often these incidents shaped how individuals perceived the context of their online environments.

At the *situational level* some participants reported using language cues when engaging with others, in order to evaluate potential partners and the likelihood of being stigmatised by them. For instance, P9<sup>UVL</sup> said: *“if generally people are like,*

*“are you clean” or like not even necessarily HIV, [...] but just in general, they are the types of people that like, I don’t particularly have too much time for”.* Those who restricted disclosure to pairwise interactions were afforded greater *autonomy* over the disclosure of their HIV status, allowing them to restrict disclosure to situations where it was necessary and the personal risk of disclosing was perceived to be low.

As well as language cues, some participants used implicit or explicit sexual risk cues on the profiles of prospective partners to evaluate sexual risk appetite, and regulate disclosure accordingly. For instance, P26<sup>U<sup>V</sup>L</sup> described how he perceived users of PrEP or condoms as having a lower sexual risk appetite and would be more likely to disclose his HIV positive status to them, allowing them to make their own evaluation of the risk as his status may reside above their risk threshold. At the other end of the spectrum, his motivation to disclose would reduce when engaging with those with a higher sexual risk appetite, perceiving his status to reside below their risk threshold. He said: *“if someone doesn’t want to use condoms and they were on PrEP, maybe [I would disclose] because I feel like they would be kind of like more worried [...] some people’s profiles seem to be like, they are only like into like having bareback sex and I kind of feel if that’s what you’re advertising on your profile, maybe I feel less inclined to tell them”.*

Most people living with HIV described disclosing publicly, or in pairwise interactions prior to physical meetings. However, one participant reported never disclosing as he felt his undetectable status which provides protection from onward transmission made it unnecessary. Asked whether at any point prior to meeting he would disclose, P20<sup>U<sup>V</sup>L</sup> responded: *“No, I don’t think so [...] because as I said, the medication just means that there’s no difference in terms of sexual health or transmission”.* This was not an isolated view with a number of other participants suggesting a reduced need to disclose when undetectable.

## **6.5 Discussion**

Chapter 3 provided an overview of people’s attitudes towards the introduction of a structured HIV status disclosure field within a specific sex-social apps. One of the



concerns identified relates to the non-disclosure option, and how privacy may *unravel* around this option. Chapter 5, the analysis of the interview data using signalling theory, provides further support for this effect, but also highlights how the effect can be used to enable indirect disclosures of an HIV positive status. Yet, this effect has mostly been studied in economic market environments where incentives to reveal are linked to economic gain. This analysis aimed to understand why users become motivated to disclose their HIV status information within sex-social environments, and how these structured disclosure fields may affect these motivations.

More broadly, prior work discussed in chapter 2 shows how challenging it can be for people living with HIV to navigate HIV disclosure during online sexual negotiations. As sexual encounters are increasingly facilitated online, understanding how structured disclosure fields shape HIV disclosure can provide insights for designers on how to improve these structured disclosure fields. This is especially pertinent within the changing landscape around treatment and prevention options for people living with HIV and HIV negative men respectively discussed in chapter 2. This chapter explores the dynamic nature of HIV disclosure motivation using Vallerand (1997, 2000)'s hierarchical model of intrinsic and extrinsic motivation as a theoretical framework.

The findings from this analysis show that social factors such as stigma and anonymity affect motivation within the sex-social *context*, and are often in tension with certain *global* level factors such as a personal values. Vallerand's model was used to organise the interview data to understand the recursive relationship between motivation at different levels of generality (*global, contextual, situational*), and how factors at each level of the hierarchy are mediated by perceptions of *autonomy, competence, and relatedness*.

### **6.5.1 Stigma's Influence on Disclosure Motivation**

Progress has been made in reducing stigma around HIV since the height of the HIV/AIDS pandemic in the 1980s yet, as was found in the first study (Chapter 3), it is still prevalent within many sex-social apps used by MSM. In this analysis it was found to be affecting disclosure motivations of people living with HIV across

the continuum of motivation regulation from amotivation to intrinsic motivation, and at each level of the hierarchical model. This section discusses stigma's influence on disclosure motivation and how the findings from this analysis relate to previous research in this area.

Stigma can take the form of both internalised self-stigma and externalised social stigma (Deacon, 2006). In its social form it has been described as active verbal abuse or passive avoidance. The subsequent reduction in sexual opportunity meant for many, non-disclosure in sex-social apps was a preferred option, even for those who were open about their status in other spheres of their lives. Yet, there were some concerns that non-disclosure could lead others to assume they were positive, an effect previously attributed to *privacy unravelling* in chapters 3 and 5. This effect may be a result of an increase in disclosure frequency norms as a consequence of the introduction of these fields, with those HIV negative participants who previously did not disclose now disclosing in order to be open and honest, or to avoid being perceived negatively by others.

Finding that people living with HIV are amotivated to disclose as a direct consequence of HIV related stigma is consistent with previous work in this area (Carballo-Diéguez et al., 2006; Gillard and Roark, 2013; Adam et al., 2011; Derlega et al., 2004; Greene et al., 2003; Serovich and Mosack, 2006). This analysis found that amotivation was more common amongst those recently diagnosed, a group that suffer from high rates of low self-esteem and negative self-image (stigmaindex.org, 2015) and often experience life disruption as they work to understand, accept, and integrate HIV as part of their identity (Murphy et al., 2016; Jaspal and Williamson, 2017).

In contrast to previous findings, yet in support of the findings in chapter 3, this analysis found stigma acting to extrinsically motivate some people living with HIV to disclose their status as it provided them with a way to filter out users from whom they were at greater risk of HIV related rejection. Whilst their sexual opportunity was reduced, they connected with more compatible users, and perceived their risk of HIV related rejection to be less. However, this behaviour was much less common

in participants who were recently diagnosed (<2 years) which supports previous research showing individuals going through a process of accepting HIV as part of their self and social identity (Flowers et al., 2011; Jaspal and Williamson, 2017), limiting disclosure before this integration has occurred.

As this chapter's findings show, most participants found it challenging to accept their diagnosis in the early stage post-diagnosis, however younger participants appeared to suffer from less internalised self-stigma than many of the older participants. This form of stigma can lead to feelings of forced ownership of an unwanted and undesired possession (Baumgartner, 2007; Tsarenko and Polonsky, 2011) that risks "spoiling" ones sexual identity if it were to become known (Goffman, 1963). The public health campaigns around undetectable status have reduced the fear associated with HIV. Participants often identified as having a manageable chronic condition, rejecting the death sentence narrative that public health campaigns pushed in the early years of the HIV/AIDS crisis. Younger men benefit from not having lived through this period, and from being exposed to more up-to-date public health campaigns such as "can't pass it on" and "undetectable = untransmittable". These campaigns have developed new social narratives around HIV and have helped increase awareness of the untransmittable nature of undetectable status to reduce fear from sexual contact with people living with HIV, something which has been a source of stigma (Emlet, 2006).

Consistent with previous research (Golub, 2018; Jaspal and Daramilas, 2016), stigma was also reported around PrEP, with its use being associated with promiscuity and the chemsex scene. Yet, PrEP stigma was preponderantly external, with internal self-stigma limited due to its optional nature. Although some participants reported being amotivated to disclose PrEP use, an increase in knowledge and awareness around the drug appeared to increase disclosure motivation. Knowledge provided users with the tools and confidence to discuss the drug, and to challenge socially stigmatising attitudes. In some online environments that attracted higher sexual risk behaviours, being HIV negative and not on PrEP was stigmatised. Those engaging within these environments may perceive HIV negative users

to be of higher risk than those on PrEP, or those living with HIV who report an undetectable status.

### **6.5.2 Taking Control Over the Narrative**

This analysis identified social network structures and the structured nature of HIV status disclosure fields influencing HIV disclosure motivation. The stigma and anachronistic discourse that still exists around HIV meant people living with HIV who chose to disclose would typically do so within a carefully constructed narrative. This helped them reduce the negative effects of stigma by embedding educational and informative details about HIV into their narrative. This was often helped with the use of pre-constructed social narratives such as those developed from the “can’t pass it on” and “U=U” campaigns. Their use also provides internal and external consistency to the message being relayed to other users. Yet, as was found in the first study, the almost dichotomous design of structured HIV disclosure fields in many sex-social apps fails to support narrative forms of disclosure. Moreover, the location based nature of many of these apps means the audience is in a constant state of flux as the physical location of users is changing. This means that, unlike most social networks which allow users to broadcast messages to a predefined network of contacts, dating networks rely on pairwise interactions for narrative forms of disclosure. Although users could disclose within the unstructured free text field on their profile, these fields are often limited in character count, reducing the space a user has to present other aspects of their self and giving the information an often undesired centre stage and importance. Moreover, when broadcasting messages on social networking platforms it is often possible to manage the flow of the message (e.g., to friend only on Facebook). This is much more difficult on location-based sex-social apps where user profiles are viewed as a consequence of location, making it harder for users to control, or even be aware of who has viewed this information.

### 6.5.3 Disclosure as a Gateway to Support

Seeking support from those with shared experiences of being diagnosed with HIV can help alleviate feelings of internalised stigma (Veinot, 2010; Bockting et al., 2013). Users became extrinsically motivated to disclose to seek this form of support as it could help satisfy certain psychological needs such as relatedness and belonging (Ryan and Deci, 2000). Similar behaviours have been identified around other health conditions, such as infertility (e.g., Malik and Coulson (2008); Patel et al. (2019)) and cancer diagnosis (e.g., (Klemm et al., 2003)). Genuis and Bronstein (2017) describe this type of online support seeking as a sense making activity, with people exploiting certain affordance properties of online spaces such as anonymity, to explore new aspects of their self with the aim of understanding their “new normal”. The findings in this chapter reflect this, with participants discussing their use of anonymity when seeking support from others, especially people living with HIV in the period soon after diagnosis. Anonymity was often sought through repurposing, or creating new profiles void of any personally identifiable attributes that may risk “spoiling” their offline identity.

Use of anonymous profiles appeared to be temporary in most instances as they only fulfilled the individual’s psychological needs within the anonymous environment itself. These environments were often separate from other sex-social networks and from the participant’s offline self. This limited their ability to integrate their HIV status into their identifiable social self, reducing continuity across these online spaces. Maintaining continuity between the past, present, and future can help motivate a person to integrate new information into their identity (Jaspal and Breakwell, 2014). Whilst one participant (P16<sup>UVL</sup>) changed his lifestyle significantly after diagnosis, for most this need for continuity acted to motivate them to at least partially integrate aspects of their HIV status into their existing social identity. To help with this process, individuals discussed longer-term goals of reducing stigma within their sex-social networks through a process of normalising HIV.

In addition to anonymity being used to seek support with reduced social risk, other strategies were used in non-anonymous environments. For example, those

who feared the social stigma of HIV would often still disclose, but in more discreet pairwise interactions (i.e., direct messages). This meant people living with HIV could regulate disclosures at a situational level, allowing them to evaluate each user prior to disclosing, with cues related to language and sexual risk used to inform disclosure decisions. This type of behaviour is not dissimilar to more general online dating behaviours where users evaluate one another using certain linguistic cues prior to meeting (Ellison et al., 2006).

#### **6.5.4 Reshaping Perceptions Around HIV**

Supporting Emlet (2008)'s work on HIV disclosure in older adults, this analysis found participants who openly discussed their HIV status in sex-social apps typically did so to educate others and to help de-stigmatise HIV by attempting to normalise it to help others. This is an approach to revealing a stigmatised identity to others in a way that establishes and promotes it as being minor and normal (Clair et al., 2005). Whilst the effects of social stigma were still prevalent in sex-social apps, those that had accepted HIV as part of their identity experienced reduced internalised stigma which acted to weaken the effects of experienced social stigma. The act of raising awareness and educating others became a source of intrinsic motivation, and provided some with a sense of purpose and meaning around their diagnosis. Yet, for others the perception that openness could help reduce HIV related stigma became a source of guilt. Although they shared the same values of openness and honesty, the stigma that they experienced amotivated them to disclose their HIV status.

#### **6.5.5 Implications**

This work highlights the complex and multifaceted nature of HIV disclosure within sex-social apps. Whilst *privacy unravelling* may occur around these structured HIV disclosure fields, HIV disclosure behaviour is complex, and so the effect may not be as significant within online social environments.

Chapter 3 showed how the structured nature of these disclosure fields limits the formation of narratives around HIV status information. This current analysis

finds further support for the structured nature of these fields limiting narrative forms of disclosure. Yet, this analysis finds that social narratives that have developed through public health campaigns provide users with a conversational tool to help them discuss their condition with others, raising awareness of HIV and the undetectable status to reduce the fear and stigma associated with it. Designers could therefore consider integrating region specific sexual health information into their apps to support the narratives developed from these public health campaigns. Furthermore, to reduce the effort required for users to explain “the science” related to new treatment and prevention options in these location-based environment, designers could develop features to allow users to share relevant information to other users during pairwise interactions. For example, sex-social apps could detect when certain words or phrases are used (e.g., ‘PrEP’, ‘undetectable’, ‘can’t pass it on’) and prompt the sender to add a dynamic link to relevant educational health information. This would bring the information into the everyday use areas of the application, as opposed to being embedded in a settings menu, making information accessible when contextually relevant to increase its usability.

Finally, with concerns of stigma developing around PrEP use, similar public health campaigns which develop social narratives around its use could help provide these users with similar conversational tools when discussing their use of the preventative drug online.

## **6.6 Conclusions**

During a period of significant change within the landscape of HIV, this analysis provides timely insights into the HIV disclosure motivations of MSM in sex-social applications. This analysis used Vallerand (2000, 1997)’s hierarchical model of motivation to interpret and make sense of the data. In doing so, factors were identified at each level of the hierarchy that affected disclosure motivation. Stigma permeated each level, with people using socially constructed narratives from public health campaigns as conversational tools to support them in disclosing to gain access to support, educating, and reshaping perceptions around HIV and PrEP. Yet, this re-

search highlights how the structure of sex-social app networks, and the structured nature of HIV disclosure fields can frustrate narrative forms of disclosure which can reduce motivation to disclose.

The complex nature of disclosure of HIV status information highlighted by this analysis may reduce the effect of *privacy unravelling*, as people who choose not to disclose their status may do so for a variety of reasons. For instance, they may choose not to disclose their status due to privacy concerns, or because they deem sex-social environments to be an inappropriate place to disclose such information. The next chapter looks to measure the effect of *privacy unravelling* using a quantitative online user study that simulates an online dating environment. This next study is designed to understand whether *privacy unravelling* is occurring around these fields, and if so how significant the effect is. It will explore whether disclosure norms or the visual design of the undisclosed information attribute (i.e., HIV status) impact on *privacy unravelling*.



## Chapter 7

# Measuring the Effect Non-Disclosure of HIV Status Has On Profile Desirability

*The following publication is based on work featured in this chapter:*

**Warner, M.**, Kitkowska, A., Gibbs, J., Maestre, J and Blandford, A. (2020) Evaluating ‘Prefer not to say’ Around Sensitive Disclosures. In *CHI Conference on Human Factors in Computing Systems Proceedings (CHI 2020), April 25 - 30, 2020, Honolulu, Hawaii, USA*. ACM, New York, NY, USA, 13 pages. <http://doi.org/10.1145/3313831.3376150>

### 7.1 Introduction

The first study conducted in this research, presented in chapter 3, highlighted a concern that the structured nature of HIV status disclosure fields may limit control around disclosure. This concern developed for two reasons. Firstly, these fields do not allow users to disclose their HIV status within any form of personalised narrative. As such, those viewing this information would sometimes develop their own interpretive narrative. This raised the question of whether structured disclosure fields support narrative forms of disclosure. Secondly, a concern was present that an HIV Positive status could be inferred through the act of non-disclosure; an effect linked to *privacy unravelling* (Peppet, 2011). This raised the question as to whether structured HIV status disclosure fields provide users with an effective non-disclosure option.

In the first analysis of the semi-structured interview data, presented in chap-

ter 5, further support was found for *privacy unravelling* occurring around these structured disclosure fields. Yet, this analysis also highlighted how this effect could be used intentionally by users to indirectly disclose an HIV Positive status. This raised the question: Do structured HIV status disclosure fields support indirect forms of disclosure? This analysis also highlighted how users appropriate these disclosure fields by instilling new meaning into disclosure options. For instance, appropriating the 'signal' given off by the Negative on PrEP status so it becomes 'evidence' of a person's willingness to engage in condomless sex. Countersignalling behaviours were also identified, with some participants reducing the amount of information disclosed on their profile, to help reduce the effect of *privacy unravelling*. This raised the question of whether the completeness of a profile affects the level of *privacy unravelling* around undisclosed HIV status information.

The second analysis of the semi-structured interview data, which was presented in chapter 6, provides an up-to-date understanding of MSM's motivation to disclose their HIV status information within sex-social apps, using these disclosure fields. In doing so, it found some users being amotivated to disclose due to the lack of narrative that is communicated. Moreover, it found that social narratives developed through public health campaigns were being used as conversational tools to help support users in disclosing and discussing their status with others. This raised the question of whether more explicit links between disclosure fields and these social narratives could support users in disclosing and discussing their status, and whether this would help in better educating others. In addition, it found users regulating the disclosure of their status depending on the population density of the area they were in, and the disclosure norms of that area. This raised the question: do social disclosure norms influence the levels of *privacy unravelling*.

The third study, which is presented in this chapter, addresses the question:

**RQ4:** *Do structured HIV status disclosure fields provide users with an effective non-disclosure option?*

It does this by measuring the effect of *privacy unravelling* in a simulated MSM oriented sex-social environment. In doing so, it also addressed the question of

whether this effect could support users in indirectly disclosing an HIV positive status using these fields, whether ambiguity around these fields may help to reduce the effect of *privacy unravelling*, and how social disclosure norms impact on *privacy unravelling*. The researcher focused on these questions as they were the most interesting to the researcher, and could be addressed through an online quantitative user study. Moreover, this provided the researcher with an opportunity to gain additional skills in developing, deploying, and analysing data from a quantitative study. Finally, this study was feasible within the time available to the researcher during his PhD.

To address this research question, the researcher developed an online mobile phone based user study. The study tested different designs for displaying (or not displaying) information fields that have been left undisclosed, and tested the effect social disclosure norms have on *privacy unravelling*.

This chapter presents the first known quantitative study exploring the impact of non-disclosures around structured disclosure fields, using the case study of HIV status disclosure in sex-social apps. Moreover, it shows how the design of the interface can affect *privacy unravelling*. It doing so, it provides supporting evidence that structured disclosure fields used in many of the existing sex-social apps used by MSM to disclose HIV status information, are effective at reducing privacy unravelling, and thus provide effective disclosure control. However, minority users may still be disadvantaged by this effect.

## 7.2 Background and Related Work

This study aimed to investigate the privacy implications of implementing a non-disclosure option into structured disclosure fields used to disclose sensitive HIV status information. It explored whether the design of these fields, and disclosure norms within a given online environment, affects the level of *privacy unravelling*. Therefore this section, firstly, reviews work related to how current systems design for non-disclosures. Secondly, it presents prior work that has explored the influence disclosure norms have on disclosure behaviours and discusses how these norms

may influence levels of *privacy unravelling*. To address the final thesis research question (RQ4), four additional research questions are posed, detailed below.

Chapters 3, 5, and 6 in this thesis found concerns developing around HIV status information in sex-social apps used by MSM. Yet, an affordance in this effect was also found. If unravelling occurs around non-disclosures, it could provide HIV positive users with a subtle means to disclose, allowing them to communicate their status to others, whilst maintaining a form of plausible deniability. However, the findings from these previous studies on HIV disclosure were based on exploratory, qualitative research, and whilst they identified concerns that undesirable assumptions were developing around undisclosed HIV information, these concerns have yet to be tested quantitatively. In this final study, the researcher built upon the work presented in chapters 3, 5, and 6. As such, this study investigated the first additional research question:

**RQ4a:** *Do undisclosed HIV status fields affect the desirability of profiles?*

### 7.2.1 Designing for Non-disclosure

Thinking and research around designing for non-disclosure is only just starting to emerge. Peppet (2011) identified a number of ways in which the effects of *privacy unravelling* could be limited. Chapter 3 conceptualised these limits in various different designs around HIV disclosure in a dating context. Governments have also started engaging with this issue, with the UK government considering and evaluating different non-disclosure design options around sensitive information such as gender, for the 2021 housing and population census (U.K.Government, 2018). In the US, many states have adopted “ban the box” policies which prevent employers from asking about criminal records on job application forms. Whilst this was intended to help those with convictions secure work, it had an undesired and unintended effect of causing minority groups to be further disadvantaged. The absence of the criminal record information caused other information (e.g., age, ethnicity) to be used to help infer a candidate’s past criminal behaviour (Doleac and Hansen, 2016).

Where information could be used to stigmatise and discriminate, one approach could be to suppress it. However, unintended consequences of this approach may disadvantage a wider set of users, as was observed in the “ban the box” example above. Another approach is to allow users individual choice to disclose, yet this too has limitations due to the *privacy unravelling* effect. This effect could cause those not disclosing to be assumed by others to be hiding something undesirable (Peppet, 2011).

When thinking about non-disclosure in the context of online social platforms, the visibility of undisclosed information fields should be considered. In today’s sex-social apps used by MSM, information fields that have not been disclosed are mostly hidden from a user’s profile, meaning when a user decides not to disclose information (e.g., HIV status), the field is no longer visible on their profile. Yet, other social networks maintain the visibility of this information.

Therefore, the research presented in this chapter explored how the visibility of undisclosed information fields affected the way people evaluated dating profiles by asking the following question:

***RQ4b:*** *Does the visibility of undisclosed information fields affect the desirability of profiles?*

The concept of ambiguity is often discussed in relation to privacy and disclosure. Prior work that explored indirect forms of disclosure shows the importance of ambiguity in allowing these forms of communications to develop (Andalibi et al., 2018b; Marwick and Boyd, 2014; Haimson et al., 2018). Therefore, ambiguity can be a resource when self-disclosing, which provides a level of “soft” boundary control (Petronio, 2010). Ambiguity is a concept used in face-to-face communication which can help harmonise interactions where social difficulties occur, such as unexplained unresponsiveness (Aoki and Woodruff, 2005). For instance, Alex may miss and not return Billy’s call. The ambiguity around why Alex did not return the call allows Alex to develop a story (an excuse) to tell Billy when they meet, with this same ambiguity allowing Billy to accept Alex’s story. If Billy was to have perfect

information about Alex (i.e. know everything about them), the harmony within the interaction may break down. However, less information does not necessarily mean more ambiguity; instead it reduces the constraints around which a story can be shaped (Boehner and Hancock, 2006).

Designers have developed ambiguity into HIV disclosure fields using an “Ask Me” placeholder for information fields that have not been disclosed by users. Past research has explored this “Ask Me” non-disclosure design, finding that the increased ambiguity that these fields create reduces the amount of engagement a profile receives (Handel and Shklovski, 2012). This research explored the impact an ambiguous response had on the way profiles were rated by asking the following additional research question:

***RQ4c:** Do ambiguous undisclosed information fields affect the desirability of profiles?*

### **7.2.2 Social Norms Around Disclosure**

Well established interpersonal theories such as social penetration theory (Altman and Taylor, 1987), and uncertainty reduction theory (Berger and Calabrese, 1974) suggest that self-disclosures occur as a way for individuals to make themselves known to each other. According to these theories, people engage in reciprocal pairwise interpersonal interactions to increase the breadth and depth of information known about one another, reducing uncertainty between conversation partners. Yet, Andalibi and Forte (2018)’s theory of *network-level reciprocal disclosure* suggests reciprocity extends beyond pairwise interactions, with observations of other people’s disclosures of stigmatised information within a network acting to motivate further self-disclosures. Moreover, learning the norms around disclosure within an online environment may also encourage disclosure (Spottswood and Hancock, 2017). As discussed in chapter 2, Peppet (2011) suggests that norms may limit the effect of unravelling, with those not disclosing in high frequency disclosure environments more likely to be assumed to be hiding some unfavourable information. Therefore, this study investigated the final additional research question:

**RQ4d:** *Do social disclosure norms within an online environment affect the desirability of profiles?*

## 7.3 Method

Drawing on the findings from chapters 3, 5, and 6, this section details the method developed to investigate the *privacy unravelling* effect around undisclosed HIV status disclosure fields. This study explored how users perceive non-disclosures, rather than their actual disclosure behaviours. Findings from the prior qualitative work suggest that undesirable perceptions and concerns can form around users who choose not to disclose, and impact on the desirability of their online profile. However, it was unclear whether or not these concerns are as a result of actual negative inferences that users develop when viewing profiles that do not disclose HIV status information.

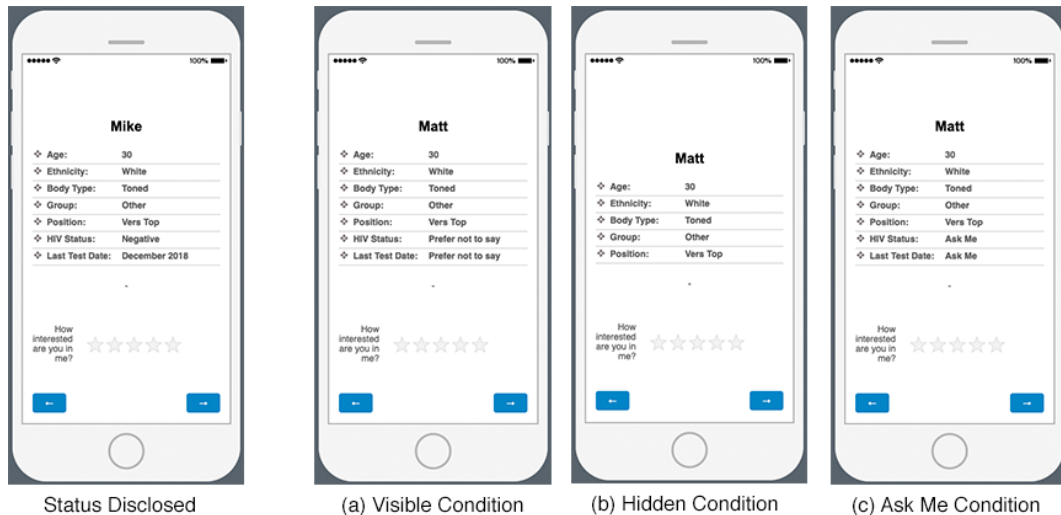
The method developed consisted of a mobile phone-based, online dating app style survey. Participants were asked to rate a number of profiles. Rated profiles that formed part of the analysis were developed as pairs. Only one profile in each pair disclosed HIV status information, whilst the other remained undisclosed. The way in which the undisclosed information was presented to participants differed depending on which *Interface Design* test condition they were randomly assigned to. Using paired profiles allowed the researcher to control for desirability and variance of other profile information (e.g. body type, position).

A 3 x 2 x 4 mixed factorial design was used to determine the effects of the between-subject variables *Interface Design* (Visible vs. Hidden vs. Ask Me) and *Social Disclosure Norms* (High Social Disclosure Norms vs. Low Social Disclosure Norms); and within-subject variables *HIV Status* displayed on the profiles (Negative vs. Negative on PrEP vs. Positive, Undetectable vs. Undisclosed).

### 7.3.1 Study Variables

#### 7.3.1.1 Dependent variable

The central construct of privacy unravelling was indirectly tested by asking participants to rate profiles on a 5-star rating scale in response to the following question:



**Figure 7.1:** Example of a profile pair (disclosed/undisclosed). The first profile shows ‘Mike’ who discloses his HIV status. The following three profiles show Mike’s profile repeated but with the name switched to Matt and with HIV status undisclosed. The three profiles show how undisclosed HIV status information appears in the three different design conditions: (a) visible, (b) hidden, and (c) ask me.

“How interested are you in me?” (see Figure 7.1). Each participant was asked to rate a number of profile pairs. These are profiles that are identical in all respects other than whether or not HIV status is disclosed. An indirect testing method to test the privacy unravelling construct was used to avoid directly asking participants what they perceived the HIV status of a profile to be. This was done for a number of reasons. Firstly, this avoided the question itself acting as a cue, which would have made it difficult to understand the impact of hiding undisclosed information fields. Secondly, this helped in understanding not only the conscious choices of participants, but also the unconscious choices which may be subject to implicit bias (Levy and Barocas, 2017). Lastly, in the ethical deliberation of this study, it was felt unethical to ask participants to infer the HIV status of a non-disclosure profile, as it was felt that this could change the way they evaluated these types of profiles when engaging in future sex-social apps.

When soliciting people’s preferences, two methods are commonly used. Absolute preferences provide the rater with an absolute scale (e.g., 5 star rating), whilst relative systems ask raters to choose between items (e.g., which of the two profiles do you prefer?). Using a relative preference system was considered, but dismissed



as it would have reduced the ecological validity of our study design. Dating apps typically do not provide users with two profiles side by side and ask them to choose between them and do not typically restrict users in who they can contact.

Whilst most dating apps do not provide users with an absolute preference system either (i.e., they do not ask users to rate profiles), a form of cognitive rating is likely to occur in the decision-making and selection process. However, absolute preferences are not without limitations. For instance, it can be difficult to calibrate between and within participants (Hacker and Ahn, 2009). As an example, one person may score higher on average than another or may be inconsistent in their judgement, rating items differently as their knowledge of the entire set grows. Our study compensated for calibration limitations by asking participants to rate an initial set of profiles before rating the two test profile sets.

#### 7.3.1.2 Independent (between-subject) variables

This study tested the effect undisclosed HIV status information had on profile ratings under three interface design conditions. The *Visible* design explicitly informed participants when HIV status information was undisclosed (see: Figure 7.1a), the *Hidden* design condition removed the HIV status field from the profile when undisclosed (see: Figure 7.1b), and the *Ask Me* condition prompted participants that the undisclosed HIV status information was only available on request (see: Figure 7.1c).

This study also tested the effect undisclosed HIV status information had on profile ratings under two social disclosure norm conditions. The *High Social Disclosure Norms* condition exposed participants to profiles that disclosed HIV status information ~65% of the time. The *Low Social Disclosure Norms* condition exposed participants to profiles that disclosed HIV status information ~40% of the time. Disclosure norms were manipulated by priming participants with an initial set of profiles (see Section: 7.3.4.2).

#### 7.3.1.3 Independent (within-subject) variables

The independent within-subject variables computed were: HIV Negative, HIV Negative on PrEP, HIV Positive Undetectable, and HIV Status Undisclosed. The overview

of variables is presented in Table 7.4. To compute the rating of the profiles reporting different HIV statuses, the means of ratings across the two sets of test profiles were used (see: Table 7.1). Two sets of profiles were used to control for other profile information (e.g., age, ethnicity) (see: Section 7.3.4.3). Effective treatment, together with the worldwide 90:90:90 initiative, are now making it a much less common for someone living with HIV to be detectable. As such, we did not include HIV positive (detectable) as a variable in our study.

**Table 7.1:** Distribution of profiles disclosing HIV status in each test set distributed to all participants across each condition.

	Test Set A	Test Set B
	Profiles	Profiles
Total profiles	12	12
HIV Negative	2	2
HIV Negative, on PrEP	2	2
HIV Positive, Undetectable	2	2
HIV Undisclosed	6	6

### 7.3.2 Participant Recruitment

An a priori power analysis was performed to estimate sample size. This resulted in a recommended sample size of 171 for within-between subjects interaction effect (when  $\alpha = 0.05$ ,  $1 - \beta = 0.8$ ,  $f = 0.1$ ). Participants were recruited via the academic participant recruitment platform Prolific<sup>1</sup>. Recruiting via this platform allowed the researcher to compensate participants for their time (UK living wage of £8.21 per hour). It also limited the amount of personal information collected from participants whilst providing an easier to reach pool of participants. Finally, it allowed for the screening of participants who met our inclusion criteria. All participants had to meet the inclusion criteria of: (1) being male, (2) being over the age of 18, (3) being interested in having sex with men (4) and having used a sex-social app. The researcher targeted men who had used a sex-social app as they would have had experience of these apps, and would have been in a dating mindset. Participants were mostly young (under 24 (28.9%), 24-34 (50.3%)), mostly White (77.5%) and from Europe

<sup>1</sup><https://www.prolific.ac>



**Figure 7.2:** Overview of the different stages of the study method which is described in detail in the methods section.

(62.3%) or North America (30.6%). Reflective of our population (e.g., in UK, 7.7% of MSM aged 15 to 59 living with HIV Brown et al. (2017b)) most reported being HIV Negative (86.1%), see detailed breakdown of participant demographics in Table 7.3.

### 7.3.3 Data Collection

The study was conducted online over four days from 8 March to 11 March 2019. Participants took from 3.25 to 24.36 minutes to complete the study ( $M=7.83$ ,  $SD=3.00$ ). In total, 235 responses were received. Of these, 43 failed study attention checks and were removed from the sample, five were removed due to being incomplete and a further four outliers were removed (see: section 7.3.7). Table 7.3 provides an overview of the sample ( $N = 183$ ). It shows a skew towards younger participants, with 28.9% aged under 24, and 50.3% aged between 24-34. Over three quarters of the participants were white, and over 90% reported being HIV Negative, or Negative on PrEP.

### 7.3.4 Experiment Overview

This section provides an overview of the four steps of the online study (see: Figure 7.2). The first step familiarised participants with the disclosure options, the second exposed participants to a social disclosure norm prime, the third involved participants rating one set of paired test profiles that displayed different HIV statuses (HIV Positive Undetectable, HIV Negative, HIV Negative on PrEP) with each profile paired with an HIV status Undisclosed profile. Ratings of all paired test profiles were used in the analysis (see: section 7.4). Finally, the fourth step involved prime manipulation checks and an exit demographics survey.

The figure shows three side-by-side screenshots of a mobile application's 'Edit Profile (Demo)' screen. Each screen has a 'Name' field and a 'Last Test Date' dropdown menu. Below these are seven rows of profile attributes, each with a selection button:

- Visible Condition (Left):** Name (empty), Age (Prefer not to say), Ethnicity (Prefer not to say), Body Type (Prefer not to say), Group (Prefer not to say), Position (Prefer not to say), HIV Status (Prefer not to say).
- Hidden Condition (Middle):** Name (empty), Age (Do not show), Ethnicity (Do not show), Body Type (Do not show), Group (Do not show), Position (Do not show), HIV Status (Do not show).
- Ask Me Condition (Right):** Name (empty), Age (Ask Me), Ethnicity (Ask Me), Body Type (Ask Me), Group (Ask Me), Position (Ask Me), HIV Status (Ask Me).

At the bottom of each screen is a 'Done' button and a list of HIV status options: Prefer not to say, Negative, Negative+PrEP, Positive, and Undetectable. The 'Prefer not to say' option is highlighted in the Visible condition, 'Do not show' in the Hidden condition, and 'Ask Me' in the Ask Me condition.

**Figure 7.3:** Screenshots of the edit profile screens shown to participants before they start the profile rating task. These are designed to familiarise participants with the profiles before viewing and rating them. The left screen is shown to participants in the *Visible* condition, the middle shown in the *Hidden* condition, and the right screen shown to participants in the *Ask Me* condition.

#### 7.3.4.1 Step 1. Environment Familiarisation

Research shows that the format of a question within online forms is important, and that responses to opt-in questions are not equal to opt-out questions (Johnson et al., 2002). The difference being that opt-in is an ‘active’ response, and opt-out a ‘passive’ response. Research has shown that the different framing of questions has an effect on disclosure decision-making (Joinson et al., 2008). Fields that are designed with a default non-disclosure option are referred to as passive non-disclosures as users are not required to act in order to keep their information undisclosed. In contrast, active non-disclosures require users to explicitly select a non-disclosure option (e.g., ‘Prefer not to say’).

To keep the study aligned to the design of existing HIV status disclosure fields in current sex-social apps, this study employed a passive non-disclosure design. All users were primed on the default nature of the non-disclosure by providing them with a demo *edit profile* screen (see: Figure 7.3) to interact with before rating any profiles.

#### 7.3.4.2 Step 2. Rating of Social Disclosure Norm Priming Set

Before being presented with the test profiles, participants were randomly assigned to either the *High or Low Social Disclosure Norm* condition. Participants were primed by asking them to rate an initial set of 15 randomly ordered priming profiles. The distribution of these two priming sets are detailed in Table 7.2.

#### 7.3.4.3 Step 3. Rating of Paired Profile Test Set

Participants were randomly assigned to one of the three interface design conditions (*Visible vs. Hidden vs. Ask Me*) and asked to rate 12 randomly ordered paired profiles. To control for other profile information (e.g., age, ethnicity), all information within each profile pair remained the same except for the profile name (e.g., Mike becomes Matt). This was to help each profile appear unique to the participants. Significantly, the only other change between each profile pairing was HIV disclosure status, with one profile in each pair disclosing an HIV status (either HIV Positive Undetectable, HIV Negative on PrEP, or HIV Negative), and the other not disclosing an HIV status information undisclosed. Figure 7.1 is an example of a profile set, and Table 7.1 shows the distribution of disclosed/undisclosed profiles in each set. Each participant in each group rated 4 HIV Negative profiles, 4 HIV Negative on PrEP profiles, 4 HIV Positive Undetectable profiles, and 12 profiles with HIV status information undisclosed.

#### 7.3.4.4 Step 4. Manipulation check and survey

Two types of checks at the end of the study were integrated. The first was a simple attention check question which asked participants: *“How often do you think the*

**Table 7.2:** Distribution of disclosed HIV status information in the set of profiles used to prime participants in the high and low social disclosure norm conditions.

	High Norm	Low Norm
	Profiles	Profiles
Total profiles	15	15
Negative	6	2
Negative, on PrEP	6	1
Positive, Undetectable	1	1
Undisclosed	2	11

*profiles you just rated disclosed ethnicity information?*". As each of the 39 profiles rated disclosed ethnicity information, those selecting either "Sometimes", or "Never" were removed from the analysis. The second asked participants to respond to the following 5-point likert scale question: "*How often do you think the profiles you just rated disclosed HIV status information?*". Responses to this question were analysed to ascertain the effectiveness of the social disclosure norm manipulation prime. The manipulation check was placed at the end of the study to check whether the prime was effective after all profiles had been rated. The responses ranged from 1 (Never), 2 (Sometimes), 3 (About half the time), 4 (Most of the time), and 5 (Always). An independent samples t-Test was applied to identify whether the manipulation was effective. The results showed a significant difference in responses between the respondents from *High* ( $M = 3.59, SD = .683$ ) and *Low* ( $M = 2.39, SD = .513$ ) social disclosure norm groups,  $t(181) = -13.478, p < .001$ . Participants exposed to the *Low* disclosure norm manipulation group scored minimum of 1 and maximum 3. Respondents from the *High* disclosure norm group scored minimum 3 and maximum 5. Therefore, it was determined that the manipulation was effective, and so the priming variable was included in further statistical analysis.

Participants were then asked how important HIV status information was to them in an online dating context using a 5-point likert scale question: "*How important is knowing someone's HIV status to you when using hook-up apps?*".

Of the sample ( $N = 183$ ), 179 responded to the question, with responses loaded towards the higher end of the 5-point scale, with a mean response of 3.39 ( $SD=1.12$ ) suggesting that HIV status was important to know when engaging with dating/hook-up apps.

Finally, participants were asked a series of demographic questions, a summary of which is shown in Table 7.3.

### **7.3.5 Pilot Testing and Profile Design**

In the process of developing this study the researcher was faced with a number of decisions in relation to the design of the test profiles. This section first presents

**Table 7.3:** Summary of demographic information of study sample ( $N = 183$ ).

		<b>N</b>	<b>(%)</b>
<b>Age</b>	Less than 24 years old	54	28.9
	24 - 34	94	50.3
	35 - 44	29	15.5
	45 - 54	9	4.8
	55 - 64	1	0.5
<b>Ethnicity</b>	White	145	77.5
	Black	5	2.7
	Asian	14	7.5
	Hispanic/Latino	9	4.8
	Arab	1	0.5
	Mixed	11	5.9
	Other	1	0.5
	Prefer not to say	1	0.5
<b>Continent</b>	Africa	1	0.5
	Asia	7	3.8
	Europe	114	62.3
	North America	56	30.6
	South America	2	1.1
	Australia/Oceania	3	1.6
<b>Education</b>	Less than high school	3	1.6
	High school education	51	27.9
	Undergraduate	83	45.4
	Postgraduate	44	24
	Prefer not to say	2	1.1
<b>Sexuality</b>	Homosexual	106	56.7
	Bisexual	70	37.4
	Heterosexual	2	1.1
	Other	8	4.3
	Prefer not to say	1	0.5
<b>HIV Status</b>	Negative	161	86.1
	Negative, on PrEP	7	3.7
	Positive	3	1.6
	Positive, Undetectable	5	2.7
	Not sure	11	5.9

an overview of the pilot studies conducted, and then discusses the different design elements considered, and the rationale for the decisions made.

#### 7.3.5.1 Pilot Studies

A series of pilot studies were conducted during the development of this study; these included (1) paper based, (2) and lab-based pilots. After each pilot, issues identified that would be likely to affect the study were corrected, and the corrected design tested in further pilots.

An initial lab-based paper pilot study was conducted with MSM who used sex-social apps ( $N = 3$ ). Participants were shown a series of mock dating profiles, sample questions (e.g., “Would you be interested in me?”), and different scale response designs (e.g., 5-star rating, slider style rating). This stage of the pilot study was designed to elicit feedback on the visual designs of the mock profiles, the information attributes included in the profiles (e.g., age, ethnicity), the interpretation of different questions to gauge profile rating, and the design of the rating system.

The second stage involved lab-based pilots with both MSM who used sex-social apps, as well as non-MSM ( $N = 7$ ). The non-MSM participants were provided personas to help them through the study. Participants were asked to work through the study tasks on their own or a lab mobile phone. Participants were asked to comment on what they were looking at, doing, and feeling in relation to each stage of the study. Participants were instructed that, during the rating of the test profiles, unless there was something specific they felt they needed to mention, they should not think aloud during the rating of the profiles, but provide feedback after. This allowed the researcher to observe and understand how participants perceived this stage of the study uninterrupted. This was important to gauge, for example, whether attention dropped after a certain period, whether profiles were analysed differently over time due to the somewhat monotonous nature of the study, and whether the social disclosure norm priming manipulation was effective.

#### 7.3.5.2 Exclusion of Profile Pictures

Previous studies have found profile images having a significant impact on the way people develop judgements of others, and typically outweigh other visual cues such



as text in a biography (Olivola and Todorov, 2010). Men appear to be more susceptible to influence than women, with one study finding that even when men are informed that images being viewed on dating profiles were fake and not representative of the profile owner, the profile pictures still had a significant impact on judgement formation (Bak, 2010).

To control for profile pictures, the same picture would need to have been used across each profile pair. This would have increased the risk of participants becoming aware that they were rating paired profiles, which may have influenced the result. It was therefore decided to exclude profile pictures from the profiles in our study. However, during piloting participants highlighted the lack of profile pictures. Participants were therefore explicitly informed that, for the purposes of this study, the profiles they would be asked to rate would not contain profile pictures.

#### 7.3.5.3 Profile Layout

This study explored the effect non-disclosure interface design factors have on profile ratings. The first of these designs is a visible non-disclosure cue where the signal sender explicitly informs the signal receiver that they have chosen not to disclose (see: Figure 7.1a). The second design removes undisclosed fields from view (see: Figure 7.1b). When the field is removed it leaves an empty space which may act as a non-disclosure cue. Therefore, two different layouts were tested, moving the white space to (1) the top of the profile, and (2) the bottom of the profile. Whilst the non-disclosure cue could not be completely eliminated, placing the white space at the top of the profile (see: Figure 7.1c) reduced the effect of white space as a cue. It was therefore decided to develop the hidden cue design with spacing placed at the top of the profile.

#### 7.3.5.4 Profile Information

To select the type of information being presented on each profile, three popular dating apps used by MSM (i.e., Grindr, Scruff, Hornet) were reviewed. Information attributes (e.g., ethnicity, position) that were present across all three were selected. These information fields were also tested in pilots to ensure enough information was available to participants for them to be able to rate their preference. Pro-

file names were selected from a number of most popular US/UK/Worldwide name lists <sup>2</sup>. Finally, the researcher, and one other researcher familiar with these dating apps collaboratively populated a data set of test profiles. In pilot tests, participants were asked questions about the profile information to assess its credibility. Iterative adjustments were made based on this feedback.

### 7.3.6 Consent and Ethics

People were asked to participate in this online study (see: Figure 7.2) using their mobile phone's internet browser to simulate the experience of using a mobile phone based app. At the start of the online study, participants were presented with an on-screen information sheet and consent form which provided details of the study and asked for their consent before proceeding. They were informed that the research was being conducted by a team of UCL researchers conducting a study into the usability of online dating apps, and provided a brief overview of the study. At the end of the survey, participants were asked for optional anonymous demographic information (e.g., age, gender, ethnicity), as well as their HIV status (i.e., Positive, Undetectable, Negative, Negative on PrEP) and regularity of testing.

This study followed GDPR data minimisation principles <sup>3</sup> ensuring no data was being collected unnecessarily, and where possible the data was collected anonymously. As the research is interested in how people develop perceptions around undisclosed information, informing them of the true purpose of the study may have introduced certain biases (e.g., social desirability/confirmation bias). Therefore, mild deception was used within the study. The researcher's ethical considerations and those of the institutional ethical review board found it unlikely that this would result in any harm or distress to participants. The study protocol was approved by the University College London ethical review board, reference: 11699/004.

### 7.3.7 Analysis

A mixed design repeated measures ANOVA was used to analyse the data. Mixed design is a method that incorporates two or more predictor variables of which at

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<sup>2</sup>e.g., <https://www.babycenter.com>

<sup>3</sup>Article 5(1)(c) of the General Data Protection Regulation (GDPR)

least one has been manipulated using different participants, and one or more has been manipulated using the same participants (Field, 2013).

In order to use the mixed design, the collected study data was first screened and the test's assumptions checked. The data screening process resulted in the identification of four significant outliers: one univariate and three multivariate outliers (identified with Mahalanobis distance). After removing outliers, the remaining assumptions were checked. The data was approximately normally distributed, with slight violations to normality. However, mixed ANOVA is robust against violation of normality so analysis proceeded (Field, 2013). The Box's test for equality of covariance matrices was not significant ( $p > .05$ ) confirming that the covariance matrices of the dependent variables are equal across groups. Lastly, sphericity was checked (assumption that the variances of the differences between different treatments are equal). Mauchly's test was used, which was significant for HIV status (4 levels) with Greenhouse-Geisser  $\epsilon > .75$ , violating the assumption. Hence, Huynh-Feldt is reported for corrected degrees of freedom of the  $F$  ratio (Field, 2013).

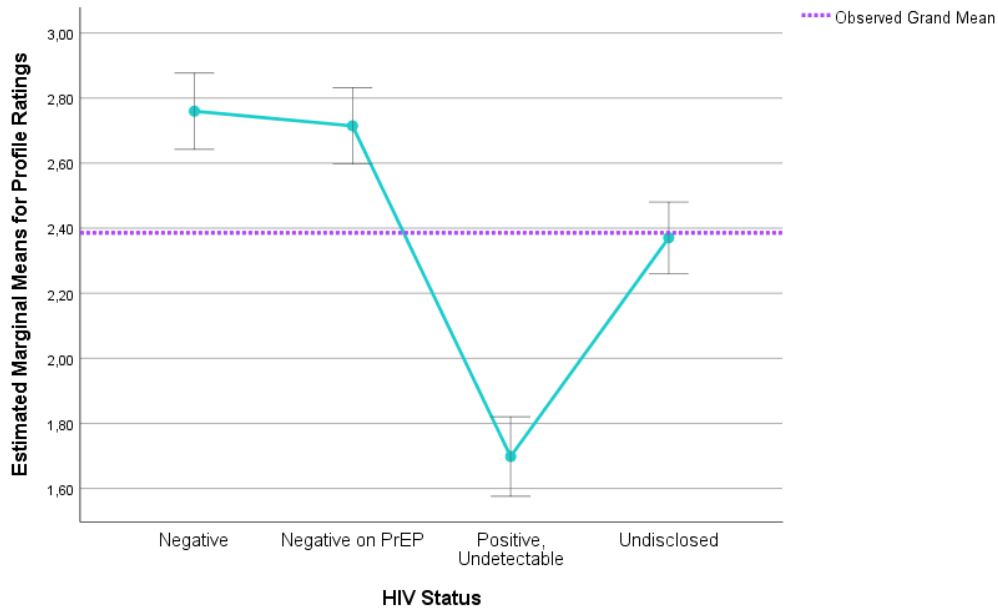
## 7.4 Results

To address the research questions, a statistical analysis using a mixed design repeated measures ANOVA was used. There were two between subject factors: interface design condition (*Visible*  $N = 61$ , *Hidden*  $N = 61$  and *Ask Me*  $N = 61$ ) and social disclosure norm condition (*Low Social Disclosure Norms*  $N = 92$ , *High Social Disclosure Norms*  $N = 91$ ). The descriptive overview of the variables from the model is presented in Table 7.4.

The within-subject Huynh-Feldt corrected test result was used to answer RQ4a. This showed a significant overall effect of HIV status on profile ratings,  $F(2.461, 435.544) = 132.426$ ,  $p < .001$ ,  $\eta^2 = .428$ . HIV Positive, Undetectable profiles were rated lower than other profiles. HIV Undisclosed profiles were rated closely to the grand mean and higher than HIV Positive, Undetectable profiles (see Figure: 7.4).

**Table 7.4:** Descriptive statistics for mixed design ANOVA model.

Variable name	Design Condition	Priming Condition	<i>M</i>	<i>SD</i>	<i>N</i>
<i>Negative</i>	Visible	Low Disclosure	2.856	.765	33
		High Disclosure	2.928	.920	28
		Total	2.889	.833	61
	Hidden	Low Disclosure	2.679	.796	32
		High Disclosure	2.663	.669	29
		Total	2.672	.732	61
	Ask Me	Low Disclosure	2.814	.892	27
		High Disclosure	2.639	.798	34
		Total	2.717	.838	61
	Total	Low Disclosure	2.782	.809	92
		High Disclosure	2.736	.802	91
		Total	2.759	.804	183
<i>Negative on PrEP</i>	Visible	Low Disclosure	2.871	.780	33
		High Disclosure	2.714	.753	28
		Total	2.799	.766	61
	Hidden	Low Disclosure	2.703	.741	32
		High Disclosure	2.767	.844	29
		Total	2.733	.786	61
	Ask Me	Low Disclosure	2.546	1.004	27
		High Disclosure	2.661	.727	34
		Total	2.610	.855	61
	Total	Low Disclosure	2.717	.841	92
		High Disclosure	2.711	.767	91
		Total	2.714	.803	183
<i>Positive, Undetectable</i>	Visible	Low Disclosure	1.697	.686	33
		High Disclosure	1.848	.941	28
		Total	1.766	.809	61
	Hidden	Low Disclosure	1.710	.764	32
		High Disclosure	1.379	.680	29
		Total	1.553	.738	61
	Ask Me	Low Disclosure	1.907	1.133	27
		High Disclosure	1.669	.772	34
		Total	1.774	.948	61
	Total	Low Disclosure	1.763	.860	92
		High Disclosure	1.631	.815	91
		Total	1.698	.838	183
<i>Undisclosed</i>	Visible	Low Disclosure	2.376	.690	33
		High Disclosure	2.202	.846	28
		Total	2.296	.764	61
	Hidden	Low Disclosure	2.593	.699	32
		High Disclosure	2.402	.807	29
		Total	2.502	.752	61
	Ask Me	Low Disclosure	2.429	.861	27
		High Disclosure	2.220	.619	34
		Total	2.312	.737	61
	Total	Low Disclosure	2.467	.745	92
		High Disclosure	2.272	.752	91
		Total	2.370	.753	183



**Figure 7.4:** The effect of HIV status information on profile ratings. Error bars: CI 95%.

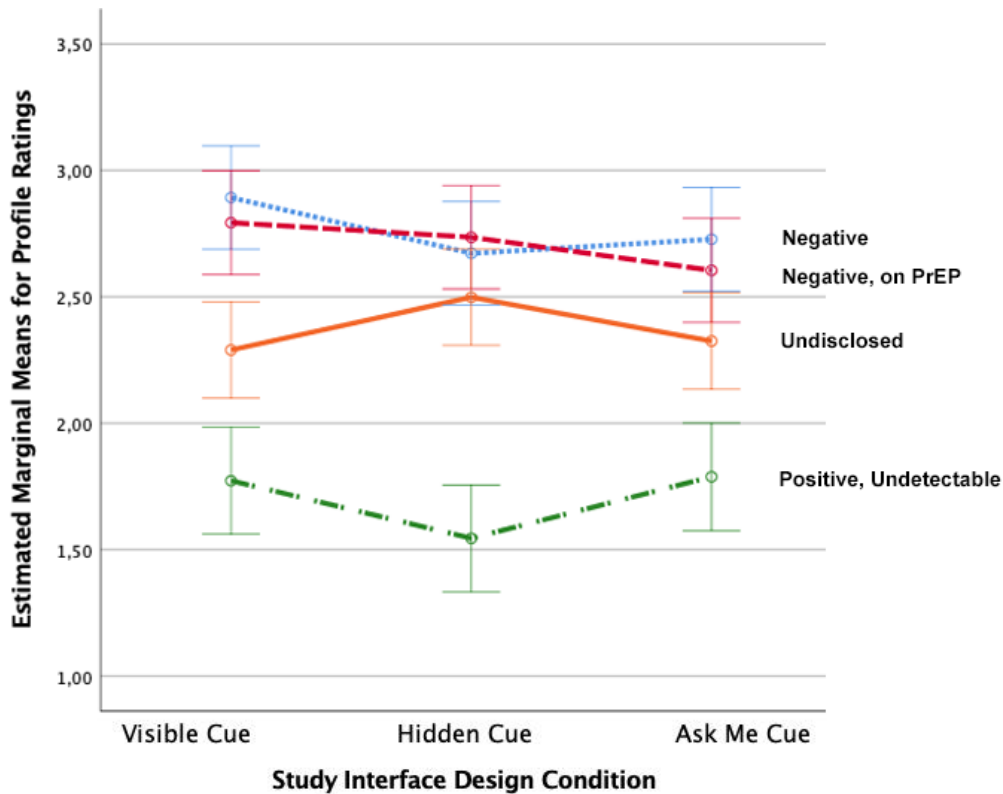
#### 7.4.1 Interface Design

The within-subject results for the three interface design conditions were used to answer RQ4b and RQ4c. The findings show a significant interaction effect between HIV status disclosure and the interface design conditions,  $F(4.921, 435.544) = 2.841$ ,  $p = .016$ ,  $\eta^2 = .031$ . The results of the interaction effect are presented in Figure 7.5 which show the estimated marginal mean rating of profiles disclosing HIV status information, as well their paired profiles that did not disclose HIV status but were still rated.

To identify which within-subject ratings significantly differed, simple effects were investigated. Specifically, pairwise comparisons with Bonferroni correction were applied to control for familywise error rate. The overall results of simple effects are presented in Table 7.5.

##### Visibility of Undisclosed Information Fields (RQ4b)

In the *Visible* condition there was a significant difference between means of HIV Undisclosed ratings against HIV Negative ( $p < .001$ ), HIV Negative, on PrEP ( $p < .001$ ), and HIV Positive, Undetectable ( $p < .001$ ) ratings. The means of HIV Positive, Undetectable ratings also differed significantly from the means of HIV Negative



**Figure 7.5:** This figure shows the estimated marginal mean rating of all test profiles. This includes rated profiles that disclosed HIV status information, as well rated profiles that did not disclose an HIV status (y-axis). The mean ratings are presented across the three interface design conditions (x-axis). Error bars: CI 95%.

( $p < .001$ ), and HIV Negative, on PrEP ( $p < .001$ ) ratings. However, there was no significant difference between HIV Negative and HIV Negative on PrEP means.

Similar to the above findings, in the *Hidden* condition there was a significant difference between the means of HIV Positive, Undetectable ratings against HIV Negative ( $p < .001$ ), HIV Negative on PrEP ( $p < .001$ ) and HIV Undisclosed ( $p < .001$ ) ratings. However, the means of HIV Undisclosed ratings were not statistically significantly different from the means of HIV Negative and HIV Negative on PrEP ( $p > .05$ ).

#### Ambiguous Information Fields (RQ4c)

In the ambiguous *Ask Me* condition there was a significant difference between means of HIV Undisclosed ratings against HIV Negative ( $p < .001$ ), HIV Negative, on PrEP ( $p = .022$ ), and HIV Positive, Undetectable ( $p < .001$ ) ratings. The means

**Table 7.5:** Pairwise comparison of estimated means between the designs conditions.

Design Condition	HIV status	Mean difference
Visible	HIV Negative vs. HIV Negative on PrEP	.100
	HIV Negative vs. HIV Positive, Undetectable	1.120**
	HIV Negative vs. HIV Undisclosed	.603**
	HIV Negative on PrEP vs. HIV Positive, Undetectable	1.020**
	HIV Negative on PrEP vs. HIV Undisclosed	.503**
	HIV Undisclosed vs. HIV Positive, Undetectable	.517**
Hidden	HIV Negative vs. HIV Negative on PrEP	-.063
	HIV Negative vs. HIV Positive, Undetectable	1.127**
	HIV Negative vs. HIV Undisclosed	.174
	HIV Negative on PrEP vs. HIV Positive, Undetectable	1.190**
	HIV Negative on PrEP vs. HIV Undisclosed	.237
	HIV Undisclosed vs. HIV Positive, Undetectable	.953**
Ask Me	HIV Negative vs. HIV Negative on PrEP	.123
	HIV Negative vs. HIV Positive, Undetectable	.939**
	HIV Negative vs. HIV Undisclosed	.402**
	HIV Negative on PrEP vs. HIV Positive, Undetectable	.816**
	HIV Negative on PrEP vs. HIV Undisclosed	.279*
	HIV Undisclosed vs. HIV Positive, Undetectable	.537**

\* significant at  $p < .05$ ; \*\* significant at  $p < .001$ .

of HIV Positive, Undetectable ratings also differed significantly from the means of HIV Negative ( $p < .001$ ), and HIV Negative, on PrEP ( $p < .001$ ) ratings.

However, there was no significant difference between the means of HIV Negative and HIV Negative, on PrEP ratings.

#### 7.4.2 Social Disclosure Norms

Finally, the researcher investigated whether social disclosure norms affect perceptions of HIV status non-disclosures (RQ4d), finding no significant interactions between the social disclosure norm conditions ( $p > .05$ ). Moreover, the statistical analysis did not identify significant between subject effects for different design conditions and social disclosure norm conditions ( $p > .05$ ).

#### 7.4.3 Additional Analysis

Additional analysis was conducted to understand whether the ethnicity reported on the dating profiles had an effect on how the undisclosed profiles were rated. The repeated measures ANOVA was re-run, splitting the HIV Undisclosed variable into two (non-minority, minority). Over 77% of the participants of this study reported

an ethnicity of 'White', making this the majority ethnicity. We used this figure to define our two variables of non-minority and minority. To compute them, the mean rating was calculated for undisclosed profiles that reported their ethnicity as 'White' to create the Undisclosed (non-minority) variable and the mean rating of all other undisclosed profiles to create the Undisclosed (minority) variable.

In doing so, profile desirability was found to increase across all design conditions for profiles reporting a non-minority ethnicity. In the *Ask Me* condition, desirability of undisclosed minority profiles was reduced, with no significant difference in means found between Undisclosed (non-minority) and Negative, on PrEP profiles ( $p > .05$ ,  $\alpha = 0.05$ ). Significantly, unlike non-minority profiles, minority profiles continue to be affected by reduced desirability even when the undisclosed information field was removed from view, with the means of Undisclosed (minority) ratings being significantly different from the means of Negative ( $p < .05$ ), Negative, on PrEP ( $p < .05$ ) in the *Hidden* condition (see: Figure 7.6).

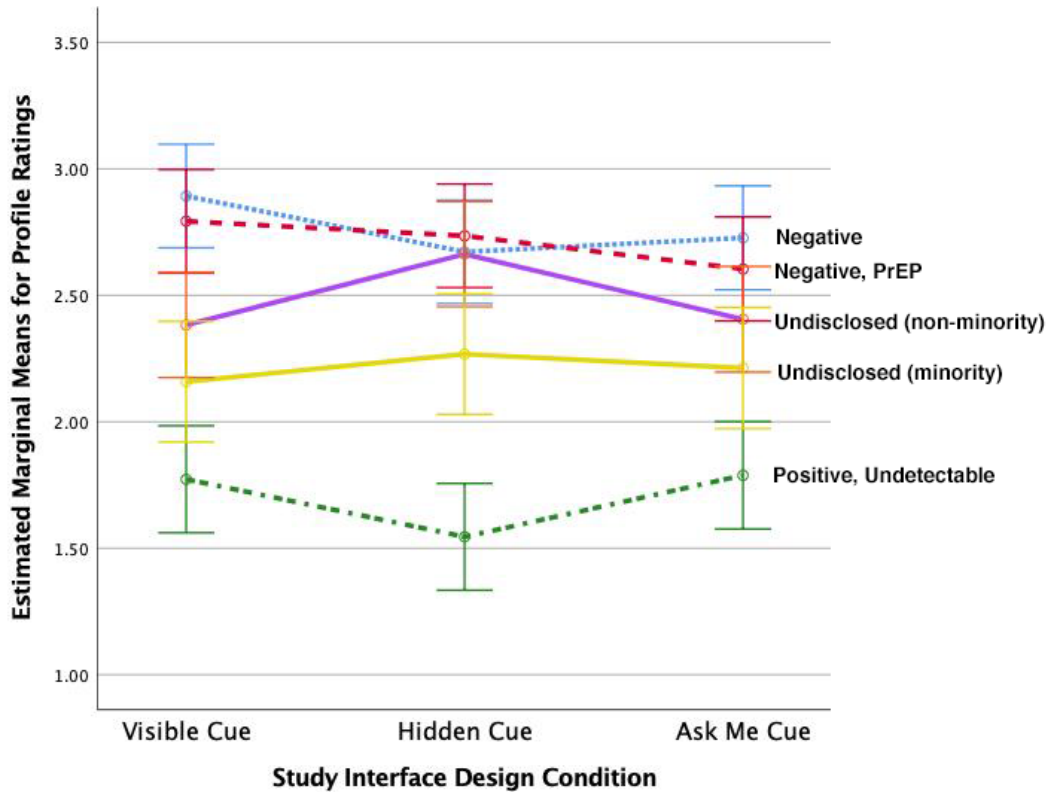
## 7.5 Discussion

In summary, participants rated HIV Undisclosed profiles lower than both HIV Negative and HIV Negative on PrEP profiles in both the *Visible* and *Ask Me* interface design conditions, but not in the *Hidden* condition. In all three interface design conditions, a significant difference in rating between HIV Undisclosed profiles and profiles disclosing an HIV Positive Undetectable status was found. However, no significant effect on the rating of profiles under different social disclosure norm conditions was found, irrespective of HIV status.

### 7.5.1 Is Privacy Unravelling Around These Structured Disclosure Fields?

The findings from this study suggest that privacy is unravelling around these structured disclosure fields. However, as an indirect measure for testing the construct of *privacy unravelling* was used, it is important to explore an alternative interpretation of this data. Profiles that are not disclosing HIV status information provide less information to participants when making their evaluations. This increase in informa-





**Figure 7.6:** This figure shows the estimated marginal mean rating of all test profiles. This includes rated profiles that disclosed HIV status information, as well as rated profiles that did not disclose an HIV status split into non-minority and minority ethnic profiles (y-axis). The mean ratings are presented across the three interface design conditions (x-axis). Error bars: CI 95%.

tion asymmetry and uncertainty may explain why the mean rating of Undisclosed profiles is significantly lower than HIV Negative and HIV Negative on PrEP profiles. However, both the *Visible* and *Ask Me* conditions contained the same information as the *Hidden* condition, yet no significant drop in profile rating in the *Hidden* condition was found (see: Figure 7.5). This suggests that, whilst the increase in uncertainty may reduce profile ratings, this was not the only reason for this reduction.

In the previous empirical work on *privacy unravelling* within economic contexts (e.g., labour market Benndorf et al. (2015); Jin et al. (2015)), most studies found partial unravelling occurring. This means that undisclosed information is neither perceived as the most desirable, nor least desirable, but sits somewhere between these two states (Benndorf et al., 2015; Jin et al., 2015). A similar pattern was found in this study in both the *Visible* and *Ask Me* design conditions.

In all design conditions, the mean rating of HIV Undisclosed profiles was significantly higher than HIV Positive Undetectable profiles. Therefore, HIV Positive Undetectable users benefit from the non-disclosure option. However, these Undisclosed profiles experienced a significantly lower mean rating than HIV Negative, and HIV Negative on PrEP profiles in the *Visible* and *Ask Me* conditions, whilst no significant difference was found in the *Hidden* condition. As such, users who are HIV Negative, or HIV Negative on PrEP are significantly disadvantaged through non-disclosure in both the *Visible* and *Ask Me* design conditions, but are not disadvantaged in the *Hidden* condition. Whilst non-disclosure benefits HIV Positive Undetectable users, non-disclosure places them at a disadvantage when compared to users disclosing either a HIV Negative, or HIV Negative on PrEP status. Yet, this study shows that when hiding the Undisclosed HIV status field from view, this disadvantage is reduced to a statistically insignificant difference.

### 7.5.2 Social Disclosure Norms

Past research suggests that levels of disclosure can be affected by social disclosure norms (Spottswood and Hancock, 2017) and through observing of other people's disclosure behaviours in online networks (Andalibi and Forte, 2018). This study hypothesised that, if disclosure norms were high, non-disclosure would appear more prominent and lead to higher levels of *privacy unravelling*. Yet, this was not found in this study. However, norms typically develop gradually, with people taking time to learn what behaviours are required for a particular group to function (Feldman, 1984; Bettenhausen and Murnighan, 1985). Participants may have been primed through prior, longer-term interactions with dating apps. Moreover, only the disclosure of the HIV status was changed, no other profile information was undisclosed which may influence the development of disclosure norms. As such, the researcher is cautious in rejecting this hypothesis, and instead suggests further work discussed at the end of the next chapter (chapter 8.)

### 7.5.3 Impact of Other Profile Information

Past research on designing for non-disclosure suggests that removing one piece of information can cause other information to be used to help other people infer the information that is missing (Doleac and Hansen, 2016). In online dating environments, Ellison et al. (2006)'s highlight how the mediated nature of these environments cause fewer *cues* to be available for users to make their evaluations of others. As such, they highlight how the few *cues* that remain gain an amplified importance. For instance, one of their interview participants reported using the "last activity date" information to infer whether someone had started dating, or had some sort of problem in their lives. Another participant used a person's physical body position to infer weight, avoiding users who were sitting down as this acted as a *cue* that they were hiding an overweight body.

Doleac and Hansen (2016) highlight how the removal of criminal record history information disadvantaged minority groups applying for jobs. Similarly to daters using small cues to infer missing information, job candidates' ethnicity information was used to infer likely criminal past. In the additional analysis that was performed, the HIV Undisclosed variable was split into HIV Undisclosed (minority) and HIV Undisclosed (non-minority). When this variable was split, the *privacy unravelling* around HIV Undisclosed (minority) profiles increased, whilst the level around HIV Undisclosed (non-minority) profiles reduced. Where previously the *privacy unravelling* effect was insignificant in the *Hidden* condition, the additional analysis shows minority profiles are still susceptible to *privacy unravelling* even when the undisclosed information field is removed from view. This finding supports prior work (Doleac and Hansen, 2016), which suggests the need to consider and evaluate the unintended consequence of removing information in situations where people are performing evaluation or assessment tasks.

In addition to the effects of other profile information, the study presented in this chapter was intentionally designed without profile pictures, as discussed in section 7.3. Similar to the effect ethnicity has on the mean rating of undisclosed profiles, profile pictures may also be used to infer undisclosed information. For ex-

ample, profile pictures provide visual *cues* to a person's ethnicity and age. If this information is not disclosed, it may be inferred through these visual cues. Moreover, prior work suggests men are significantly influenced by profile pictures on dating profiles (Olivola and Todorov, 2010; Bak, 2010) which could influence the impact *privacy unravelling* has on undisclosed information.

#### **7.5.4 Privacy Unravelling as an Indirect Disclosure**

Chapter 5 shows how the effect of *privacy unravelling* can facilitate a form of indirect disclosure, which would allow users living with HIV to indirectly disclose their status by purposefully concealing their status through non-disclosures. Yet, this study's initial findings show that privacy does not unravel around undisclosed statuses when the undisclosed information field is hidden from view. As most of the sex-social apps hide undisclosed information fields, this initially appears to be an ineffective indirect disclosure strategy. However, as prior researchers have shown, indirect disclosures often rely on a sub-group being able to interpret the hidden message within a message (Marwick and Boyd, 2014; Andalibi et al., 2018b). Participants in this study were mostly HIV Negative (89.8%), with only 4.3% reporting to be HIV positive. If HIV positive users interpret non-disclosures as being HIV positive, the small size of this population within the study sample would not show this effect.

#### **7.5.5 Ambiguity Around Non-Disclosures**

Chapters 3 and 5 show how the structured nature of disclosure fields can limit a user's ability to disclose their status within a personalised narrative. The ambiguity that this lack of narrative creates can result in the receiver developing their own interpretation around information disclosed, as well as an act of non-disclosure. Chapter 5 highlights how people develop different narratives to explain undisclosed HIV status information. For instance, if a profile does not disclose an HIV status but most other fields have been disclosed, a 'something to hide' interpretative narrative sometimes developed. This can increase the risk of undisclosed profiles being assumed to be HIV positive. Alternatively, if other fields have not been disclosed,

narratives around ‘lack of effort’, or the user being more ‘privacy aware’ can develop, reducing the risk of these undesirable assumptions developing. Whilst the structured nature of these fields limits the personalised narrative that the sender can communicate around their status, less information disclosed does not necessarily lead to an increase in ambiguity, additional information just provides a more constrained environment around which interpretations can develop (Boehner and Hancock, 2006).

The ambiguity that non-disclosure creates may result in people focusing on other profile information in order to create these inferences around the missing information, drawing on social assumptions around these other pieces of information in an effort to make more accurate inferences. To understand whether increased ambiguity affects *privacy unravelling*, this study implemented an *Ask Me* design. In doing so, this study provides some support for prior work (Handel and Shklovski, 2012) which suggests that undisclosed information fields marked with an ambiguous label (i.e., “Ask Me”) do have a negative impact on the way profiles are evaluated by users. However, no significant difference was found between the *Ask Me* and *Visible* design conditions. This suggests that the *Ask Me* design used in some MSM oriented online dating websites provides no more ambiguity than that of the more traditional “Prefer not to say” design.

However, the analysis presented in this chapter shows that the negative impact of this “Ask Me” label may be more significant for minority users. Ambiguity in interactions is relied upon for indirect disclosures, used to selectively disclose sensitive information. This has been shown in both offline (Clair et al., 2005) and online interactions (Andalibi and Forte, 2018; Andalibi et al., 2018b; Haimson et al., 2018; Marwick and Boyd, 2014). Chapter 5 suggests non-disclosure around structured disclosure fields may provide the ambiguity needed to support indirect disclosures; as discussed above, further work is needed to understand the conditions under which this may occur.

### 7.5.6 Implications

This study provides a more focused look at the effect of *privacy unravelling* around structured HIV status disclosure fields by developing a method to measure it. The initial analysis conducted in this study suggests that the current design in most sex-social apps (*Hidden* condition) reduces the *privacy unravelling* effect to an insignificant level, providing a usable non-disclosure option for users. However, the additional analysis that looked at the impact of ethnicity on *privacy unravelling* suggest a more complex situation. Limiting the visibility of fields may help to increase the effectiveness of the non-disclosure options, but this may not be effective for minority groups. Designers need to consider how different information types on a profile may act as *cues* used by users to infer non-disclosed sensitive information.

This study highlights the complexities around structured disclosure fields. Whilst on the surface they appear to be simple disclosure fields, when people start to interact with them, their complexities start to emerge. This research highlights how non-disclosure options used within the design of structured disclosure fields may not always be an effective means of providing users with disclosure choice.

### 7.5.7 Limitations

This study was conducted with a skewed sample of predominately younger, white, European/North American participants. As discussed previously, these structured disclosure fields are fragile to social change, therefore the findings from this study may differ between cultures. Within the context of HIV status disclosure, behaviours are likely to differ depending on the level of stigma within a society. Stigma is often developed through fear and so countries with access to universal health care and to HIV treatments may experience less fear, and reduced stigma. Whilst highly active anti-retroviral treatments are commonly prescribed to people living with HIV within the UK, in other countries without access to universal health care, this number may be much lower. To simplify the study and to ensure participants were not having to rate a large number of profiles that could result in attention reduction of participants, this study did not include HIV Positive as an independent (within-subject) variable. As such, it is not possible, from the results of this study, to understand how profiles

with an HIV positive status would be rated when compared to profiles with other HIV status options displayed. The results from the additional analysis, whilst useful in providing insights into how other profile information may be used in the absence of HIV status information, should be interpreted with care. As this analysis was not originally designed to test this, future research should intentionally explore the effects different types of information have on people's inferences around undisclosed information.

## 7.6 Conclusions

This final study suggests that structured HIV disclosure fields are susceptible to the social effect of *privacy unravelling* (Peppet, 2011), but do not fully unravel in any of the design conditions tested. This research highlights how the design of the interface around undisclosed information can limit the *privacy unravelling* effect which creates a tension for designers. Whilst *privacy unravelling* can limit the voluntary nature of these fields, it can also help users straddling the line between open disclosure and remaining private about the hidden aspects of their identity. It is important to provide users with control over self-disclosures to allow for them to engage in effective self-presentation behaviours (Buitelaar, 2014).

In the next chapter, each of the studies presented will be discussed to explore the broader implications of structured disclosure fields on privacy and disclosure behaviour and the tension that exists around *privacy unravelling*. Limitations of the research conducted will be discussed, and further work suggested that could build on the findings from this thesis.

## Chapter 8

# Discussion

This chapter presents an overall discussion of the empirical work, and the chosen methods used as part of this research. It first summarises the research conducted and reviews the methods used. It explores some of the important concepts identified throughout this research, discussing tensions between or within these concepts, and suggests implications for design. Finally, it highlights some of the research limitations and provides an overview of potential future work that could develop from this research.

### 8.1 Summary of Research

The empirical mixed methods approach used in this research has been presented and discussed across four chapters. The first three chapters presented a series of qualitative studies exploring privacy and disclosure attitudes and behaviours around structured disclosure fields, using the case study of HIV status disclosure in sex-social apps used by MSM. The final chapter presented findings from a quantitative online user study designed to further investigate selected findings from the qualitative studies. The first study presented in chapter 3 highlighted the potential privacy implications of developing sensitive online disclosures around structured disclosure fields, due to the social effect of *privacy unravelling* (Peppet, 2011). This effect can cause undesirable assumptions to develop around users who choose not to disclose. To explore these fields and this effect further, semi-structured interviews were conducted with sex-social app users with differing HIV statuses. These interviews were analysed using two distinct theoretical frameworks, the analysis of



which was presented in chapters 5 and 6.

The analysis, presented in chapter 5, applied a communication theory from economics and evolutionary biology which found users were able to appropriate these structured disclosure fields to help them achieve their goals. One form of appropriation related to the *privacy unravelling* effect which enables a form of indirect disclosure. The analysis, presented in chapter 6, explored the motivations of users to disclose their HIV status within these online environments. To achieve this, Vallerand (1997, 2000)'s hierarchical model of motivation which extends Ryan and Deci (2000)'s Self-Determination Theory was used. This established the significance stigma has on a user's decision to disclose, and the failure of structured disclosure fields to support narrative forms of disclosure. In chapter 7, the final study is presented which tests the effects of *privacy unravelling* using an online user study. This study found further support for *privacy unravelling* around these structured fields and highlighted design factors that can reduce (or increase) its effect.

This research applied a mixed methods approach, widely used in HCI (van Turnhout et al., 2014). To address four main research questions, it combined both qualitative and quantitative methods as described above. All research methods have their strengths and weaknesses (Blandford et al., 2016) and these have been highlighted throughout these four study chapters. The benefit of using different research methods is that certain weaknesses in one method can be addressed with the strength in others (Denscombe, 2014). For instance, the first study used online public domain data for an exploratory analysis of user attitudes towards structured HIV disclosure fields. This data source is ideal for a first study, especially around sensitive topics, as it allowed the researcher to become familiar with the sensitive topic area, and helped them gain an understanding of language and terminology used around the topic prior to conducting face-to-face studies. It is also a much easier data set to obtain when compared to other methods (e.g., focus groups, interviews). However, using existing data sources for analysis has limitations. For instance, there is no means of directing the conversation or probing deeper into

particular areas of discussion. Moreover, there is often no demographic information available and, as discussed in chapter 3, there are unique ethical factors that need careful consideration. The strengths of semi-structured interviews as a data gathering method can address some of these limitations. For instance, semi-structured interviews allow researchers to direct the conversation and probe areas of interest to gain deeper insights. Yet, this method also has its limitations. It is reliant on people's ability to accurately self-report facts, which can be limited (Blandford et al., 2016). People may simply not think something is important enough to mention, or fail to remember something accurately (Braun and Clarke, 2013). The final quantitative study addresses some of these limitations by not relying on self-reported information; rather it uses a variable (5 star rating of profile desirability) to indirectly test selected findings from the qualitative research.

## **8.2 Case Study Specific Discussion**

Whilst this research was primarily interested in understanding the implications of designing sensitive information disclosures into structured fields, in using the case study of HIV disclosure in MSM oriented sex-social environments, insights were gained that relate specifically to this context.

In conducting this research it was evident how much stigma still exists around HIV within MSM oriented sex-social environments. Supporting prior studies, this research finds stigma creating barriers to people disclosing which can limit access to social support within these apps (Peterson, 2010; Williams and Mickelson, 2008; Jaspal and Williamson, 2017). This research finds that the inclusion of HIV status disclosure fields may cause an increase in disclosure rates amongst HIV negative users, as they do not want to be perceived as hiding an undesirable status. This has the potential to further perpetuate stigma around HIV, with increased levels of disclosure making people who are living with HIV feel as though they too need to disclose. Previous research suggests that increased HIV disclosure rates can help promote sexual risk decision-making and that these disclosure options should be promoted further amongst MSM meeting partners online (Medina et al.,

2018). However, the implications of these fields on marginalised users should not be ignored. Guidelines around legal aspects of HIV disclosure within the UK now suggest that people living with HIV who have an undetectable viral load, or those engaging in sex with a condom, are under no legal obligation to disclose to sexual partners (Phillips et al., 2014). This raises the question as to whether these fields are necessary within these online environments. However, these apps are used worldwide, and so legal aspects around HIV disclosure within the UK are unlikely to be mirrored in each area of the world these apps are used. Moreover, as Singh et al. (2019) found in their recent study on HIV home self-testing, making HIV less visible could make HIV appear as something that needs to be hidden away and kept secretive, perpetuating stigma around HIV. Moreover, Brown et al. (2003)'s research suggests that encouraging more direct contact and interaction with people living with HIV could help to reduce stigma around the condition by normalising HIV. This desire to normalise HIV by people living with the condition was highlighted in this current research, with some MSM reporting to become motivated to disclose their status on these platforms in order to normalise and educate others.

Lastly, prior work has highlighted a stigma developing around the use of PrEP by MSM. Whilst this research also found support for a stigma around PrEP, it was not as individually harmful or prominent when compared to that which is experienced by people living with HIV. In this research, PrEP was found to act as *evidence* by some that an individual is more willing to engage in condomless sex, or to engage in chemsex practices (Golub, 2018; Jaspal and Daramilas, 2016). Moreover, this research also found that in some MSM oriented sex-social environments, people who disclosed to be HIV negative and not on PrEP were subject to stigma. This appeared in environments intended to facilitate condomless sex between users. Within these environments, users who are HIV negative and not on PrEP are seen as being higher risk than people living with HIV who are undetectable, or people who are HIV negative and reporting PrEP use.

In the next section of this chapter, the main concepts that have developed from this research are discussed, with design implications providing some broad guid-

ance on helping to address some of the issues identified. Firstly, the role structured disclosure fields play in reducing narrative forms of disclosure are discussed. The concept of signal appropriation is then discussed and characterised by drawing on the empirical work undertaken as part of this research, and prior work discussed in chapters 2, and 5.

### **8.3 Loss of Narrative Rich Disclosure**

This research draws on concepts of identity and self-presentation to explore privacy and disclosure behaviours around structured fields for disclosing sensitive information online. In doing so, it recognises that privacy is an essential resource which allows users to manage what information about themselves is known by others (Buitelaar, 2012), helping them shape how they are perceived by the world around them. Whilst information control is not always possible (e.g., people still expect privacy around photos they share on Facebook), an expectation exists around how information will “flow” to others, with inappropriate flow of information being considered a violation of that privacy (Nissenbaum, 2009). Yet, much less focus has been placed on how meaning forms around information and how this impacts on people’s privacy. For instance, a photo may “flow” appropriately through a social network, but the meaning or narrative that forms around that photo may differ across audiences and be unaligned with the expected narrative of the original sender. The narrative that forms around, or that is distilled into, information that is disclosed online often gives it its meaning, its value.

In the case of HIV disclosure within sex-social apps, moving from structured to unstructured disclosure fields may help users in communicating a narrative around their HIV status to others, but this is in tension with some of the potential benefits of structured disclosure fields. Grov et al. (2013) shows how stigmatised language, such as “clean” or “drug and disease free (DDF)” is used by MSM when communicating HIV status in free text fields. Levy and Barocas (2017) point out how structuring responses can help reduce the stigmatised nature of language used by restricting the interface. This research shows how social narratives developed as

part of public health campaigns can provide users with a conversational tool to help them discuss their condition and could be integrated into these structured disclosure fields to help address the lack of narrative around these fields. Connecting these disclosure fields with social narratives to educate and raise awareness may also help to shift attitudes and avoid misinformation spreading around HIV transmission, which has otherwise been shown to exacerbate stigma (Veinot and Harris, 2011; Herek, 2014; Harris et al., 2008).

## **8.4 Signal Appropriation**

Since this research started, there has been an increased interest in behaviours similar to those referred to in this thesis as ‘signal appropriation’; a term used to describe the use of signals as a mechanism for appropriating social technologies. Wiseman and Gould (2018) explored the repurposing of emojis and discovered that the meaning (or “signal”) of these digital artefacts is socially cultivated across cultures, and within smaller groups. Research into meaning formation around instant messenger “stickers” highlight evolution of meaning, as well as ambiguity in meaning resulting in confusion and misinterpretation (Cha et al., 2018). Zannettou et al. (2018) highlights how the meaning of internet ‘memes’ is cultivated over time. Signal appropriation of these memes is often harmless, but some (like Pepe the frog meme shown in figure 8.1 which has been appropriated as a symbol of the alt-right movement) are driven by hate groups who intentionally cultivate hateful, racist, and aggressive meaning around these online digital artefacts.

Whether signal appropriation occurs for fun, or for more sinister reasons, its intent is to reshape or ‘evolve’ online communications and interactions by instilling new meaning into digital artefacts. Whilst on the surface, structured disclosure fields appear very fixed in their design, this research shows how their fixed nature can be made more malleable through signal appropriations.

Unlike unstructured and semi-structured disclosure fields, structured fields do not provide users with flexibility in the language used to communicate. Yet, as

humans, we evolve language (Lightfoot, 2006). Structured disclosure fields may limit this evolution by constraining language use through predefined disclosure options. Whilst this may limit the stigmatised language that can otherwise develop in unstructured responses, signal appropriation may be a societal response to this constraint, allowing people to ‘evolve’ constrained systems, reshaping them to their needs.

Dourish (2003) explored similar forms of appropriation around electronic document management systems. Commenting on prior empirical work, he highlights how users develop various appropriation strategies to overcome constraints designed into systems. All systems are designed with constraints, either purposefully or otherwise. For example, Twitter limits the number of characters a user can send in a single tweet, yet people have developed techniques to extend character count by joining multiple tweets together. As highlighted in chapter 6, the structure of a social network can also place constraints into a system, and play a role in the way people interact and communicate. As people move their communications and interactions evermore into these online digital spaces, they may explore ways to enhance their communication and interaction by using various forms of appropriation.



**Figure 8.1:** Pepe the frog is an example of new meaning developing around a digital artefact, with the frog being appropriated to become a symbol of the alt-right movement (Zannettou et al., 2018).

## 8.5 Privacy Unravelling Online

*Privacy unravelling* is a signalling process and a form of signal appropriation. Peppet (2011) describes how those with a desirable quality are incentivised to disclose in order to increase their social value. Moreover, those with a less than desirable quality may still be incentivised to disclose in order to differentiate themselves from those with an even less desirable quality. Peppet (2011) describes how this behaviour continues to unravel down to those who hold the least desirable quality, who then have no incentive to reveal. This may lead those not revealing to be assumed by others to be withholding a least socially desirable quality.

*Privacy unravelling* not only affects those who hold the least desirable quality, but all users who wish to exercise their right not to disclose personal information. As this research has highlighted, HIV negative individuals as well as people living with HIV who prefer not to disclose, do so to avoid potential stigma from remaining silent, further perpetuating the effects of *privacy unraveling*. Under certain design conditions, for these individuals their decision not to disclose disadvantages them by limiting the desirability of their online profile.

Prior research into *privacy unravelling* has primarily focused on economic contexts (e.g., Benndorf et al. (2015); Lewis (2011)). As was described by Peppet (2011), its potential impact on industries like insurance are significant if these industries move away from sorting economic models, to signalling models. Most insurance companies have historically used comparatively basic information about customers to sort them into risk categories (Quintero and Benenson, 2019). An adolescent male would be placed into a higher risk category than a middle-aged female on the basis of historic motor insurance claims. When this model shifts from sorting to signalling, people are evaluated on a more individual basis using information voluntarily signalled to the insurer (e.g., driving style, location, time of day) (Quintero and Benenson, 2019). *Privacy unravelling* suggest that under this model, those who fail to disclose may be perceived by the signal receiver to be withholding the least desirable quality (Peppet, 2011). In an insurance context this may mean higher financial costs; in an online social environment it could affect people

socially.

Online dating is a good example of an online social platform shifting from a *sorting* to a *signalling* model. Traditional dating systems rely on sorting algorithms (Hitsch et al., 2010) whilst newer platforms are moving towards preference ‘signalling’ (Coles et al., 2013). Within this type of online social environment, structured disclosure fields may exacerbate the effect of *privacy unravelling* by limiting the possible responses users are able to select from. Yet, whilst this research identified significant concerns around this effect, like other research on *privacy unravelling* in economic contexts (e.g., Benndorf et al. (2015); Lewis (2011); Mathios (2000)), the full effects of *unravelling* were not identified. Instead, partial unravelling was found under certain design conditions, and reduced when the information field was hidden where undisclosed. As has been shown in chapter 6, incentives to reveal or conceal HIV status information are complex. As such, people may choose non-disclosure for a variety of reasons, with “alternative possibilities” allowing for alternative narratives to develop to explain a person’s reason for not disclosing. Moreover, in the absence of a “Not Known” status disclosure field, people who are unaware of their HIV status (i.e., someone who has not been recently tested) may use non-disclosure rather than disclosing to be HIV Negative. Therefore, the non-disclosure option could signal different things to different people.

### 8.5.1 Peppet’s Unraveling Limits

As discussed in chapter 2, Peppet (2011) suggests four means by which the *privacy unravelling* effect could be limited. In the research conducted as part of this thesis, the removal of an explicit visual *cue* linked to the undisclosed information has been shown to help limit the effect of *privacy unravelling*. This section discusses Peppet (2011)’s proposed limits, and explores where the findings from this research fit within these limits.

The first two limits discussed relate to transaction (or disclosure) cost, and the recipient’s inability to verify the ‘ignorance’ of the sender. Firstly, reducing visibility of an undisclosed information field does not increase the transaction cost to the sender. Equally, the visibility of undisclosed information does not enhance or inhibit



a receiver's ability to verify whether or not the sender is aware of their own HIV status. Verification of status is not something that is required within sex-social apps, and is inherently difficult to do.

The next two limits discussed relate to privacy norms, and the receiver's inability to accurately infer a negative quality from the non-disclosure. Firstly, if a non-disclosure norm exists around certain information, this can limit *privacy unravelling* as non-disclosure is no longer assumed to be an act to hide an undesirable quality, but an act that conforms to the norms within a given environment. Whilst this research tested the effect norms have on *privacy unravelling*, no effect was found. Yet, as discussed in the previous chapter, further work is needed before this hypothesis can be rejected. In relation to the visibility of undisclosed information fields, their visibility is not likely to affect disclosure norms, and so this limitation does not fit within the description of the privacy norms limit proposed by Peppet (2011).

The next limit is the inability of the receiver to accurately infer a negative quality from the non-disclosure. In the case presented in this research, when the undisclosed HIV status field was hidden, the receiver was still able to infer a negative from the lack of information present. However, the accuracy of these inferences is low due to HIV status information being unverifiable within these sex-social apps.

In the final study, presented in chapter 7, the removal of the non-disclosure *cue* (i.e., the undisclosed information field) and the subsequent effect this had on the level of *privacy unravelling* suggest that hiding undisclosed information fields can reduce the negative inferences that develop around non-disclosures. When exploring the effect of ethnicity, this reduction was no longer present for minority groups. This suggests that hiding the undisclosed information field does not cause users to stop evaluating the information, but does reduce the significance of it. Therefore it does not completely remove a user's ability to accurately infer a negative, but it does reduce their ability to perform inferences around undisclosed information fields. As such, the limit identified as part of this research does fit within Peppet (2011)'s previously proposed set of limits.

### 8.5.2 Privacy Unravelling as an Indirect Disclosure Mechanism

The same effect that can limit a user's disclosure choice, can also provide users with the ability to perform indirect disclosures. This research supports previous findings that show people's desire to protect themselves from the stigma around HIV can result in reduced motivation to disclose (Adam et al., 2011; Greene et al., 1993; Serovich and Mosack, 2006). Yet, the findings from this research also show how disclosure can have a positive impact on people's lives, allowing them to connect with similar others for support and to help them feel a sense of "normal". Indirect disclosures can provide users with a middle ground between open disclosure, and complete concealment of their status.

As discussed in chapter 2, since starting this research an increasing number of researchers have explored indirect forms of disclosure around more sensitive information shared online (e.g., Andalibi et al. (2018a); Haimson et al. (2018)). Prior research has also explored indirect means of online communication (e.g., Marwick and Boyd (2014)) and offline communication (e.g., Clair et al. (2005); Serovich et al. (2014, 2005)). What these previous studies show is the need to provide people with the means to perform selective forms of disclosure to help them manage their privacy. In online environments this can be especially challenging, as many of the online platforms in use today collapse audiences into a single online space (Marwick and Boyd, 2011). As both Andalibi et al. (2018a) and Marwick and Boyd (2011) highlight in their research, unstructured self-disclosure fields allow for a level of ambiguity within communications. This can help users carefully curate self-disclosures to subtly signal or hide messages within messages that relate to sensitive aspects of their lives or identity. For instance, Marwick and Boyd (2011) highlight an example whereby a parent follows her daughter in an online social network. Her daughter wants to communicate sadness to her friends over her relationship breakup without alarming her mother. Rather than being explicit about her feelings, she uses song lyrics that signal her sadness to her friends who were able to interpret her hidden message, whilst her mum remained oblivious.

Structured disclosure fields do not allow for this flexibility which reduces am-

biguity around these fields. The array of responses available to users when interacting with HIV status disclosure fields is fixed, making them less open to forms of appropriation. Whilst Dix (2007) suggests artefacts with fixed meaning make appropriation more difficult, the findings from this research show how, despite their fixed nature, these types of fields can still be appropriated. This was identified around the 'Negative on PrEP' status option being used as *evidence* of a person's willingness to engage in condomless sex. Moreover, the ambiguity which develops around inaction (i.e., non-disclosure) can further open these structured fields to forms of signal appropriation. Ambiguity develops around uncertainty which can be used as a resource in design (Gaver et al., 2003). In this case study, this ambiguity enables a form of indirect disclosure, exploiting the effects of *privacy unravelling* by changing the intentionality around the effect. It is no longer *evidence* of a person's HIV status, but an *intentional signal* of their status.

### 8.5.3 Countersignaling

The work presented here highlights how design can play a role in reducing or increasing the effect of *privacy unravelling*. Yet, as has been identified across this research, if an element of an online social platform fails to meet the needs of a certain group of users, those users may attempt to cultivate change around that interface element. This research highlights a behaviour used by people who were concerned that their non-disclosure may stigmatise them. As discussed in the findings section of chapter 5, some users developed a signal appropriation strategy to reduce this effect, by limiting the information they were disclosing across their entire profile. This type of behaviour is described here as countersignaling, as it is an intentional behaviour designed to counter the effects of an unwanted signal.

### 8.5.4 Privacy Unravelling Tension

The findings from this research highlight a tension around *privacy unravelling*. The effect can both limit disclosure choice and offer the means to indirectly disclose to help users manage online privacy around sensitive information disclosures. Ambiguity has previous been explored around HIV status information. Handel and

Shklovski (2012) explored a social networking platform that was oriented towards MSM, highlighting the use of the “Ask Me” disclosure option, which was tested in our final study. Due to the nature of asking people to disclose sensitive information in an online social environment, they argue that even the smallest of design decisions around these options require careful consideration, with small changes having a potentially significant impact on user interaction. The findings from our research support this hypothesis and result in the researcher being purposefully mindful in the level of detail developed into the design implications presented in this chapter. The research here has shown how, when exploring these fields as signalling systems, subtle changes in the way a system is designed can lead to significant shifts in the way users interact with each other through these mediated online environments.

Whilst the ambiguity created around non-disclosure can increase the risk of signal appropriation through the effects of *privacy unravelling*, ambiguity could also be explored as a design resource (Gaver et al., 2003) to limit the effect of unravelling, and help promote a socially cultivated signalling system. Ambiguity in this instance could be used to increase the uncertainty of *why* a person has chosen to keep this information private. Yet, as our findings and the findings of Handel and Shklovski (2012) show, any such design choices would have to be carefully integrated, evaluating the impact of the design on user interaction.

### **8.5.5 Implications and Design Considerations**

One of the main implications of this research centres around the effectiveness of structured disclosure fields to provide users with adequate control around the disclosure of their personal information. When designing sensitive information disclosures into online social systems, designers need to carefully consider the implications and unintended consequences of the effect of *privacy unravelling* and how it may, for example, disadvantage different groups of users. In the section below, a number of design implications are presented which could be considered by designers when integrating sensitive disclosures into online social technologies.

### 8.5.5.1 Design Implications

Four main design implications are presented below. However, it is important to recognise that the research conducted centres around often very subtle interactions. As Handel and Shklovski (2012) point out, even slight changes to the design of a system can result in significant changes to the way users interact. It would therefore be important, as highlighted in design implication 4, that designers carefully monitor 'signalling systems' to understand how they are being used, and in some cases appropriated and then misused by users.

1. **Engaging with Social Narratives:** Designers could consider ways to embed socially developed narratives within, or around, structured disclosure fields to help mitigate the tension described above. For instance in the case of HIV disclosure, the term "Positive, Undetectable" could be replaced with "Undetectable = Untransmittable" within the structured disclosure fields. Within pairwise interactions, certain words or phrases (e.g., 'PrEP', 'undetectable', 'can't pass it on') could trigger prompts for the message sender to add a dynamic link to relevant educational health information. This would have the added benefit of bringing this educational information into the everyday use areas of these apps, as opposed to being embedded in a settings menu, making information accessible when contextually relevant to increase its usability.
2. **Visibility of Undisclosed Attributes:** To limit the effect of *privacy unravelling* which can reduce disclosure control, designers should consider the visual design of fields where information is undisclosed. Reducing visibility can help to minimise the effect of *privacy unravelling*. However, designers must also consider how other information may impact on levels of *privacy unravelling* around non-disclosures. Further work outlined at the end of this chapter is suggested to better understand how the visualisation of information may impact on *privacy unravelling* around undisclosed information fields.
3. **Designing for Indirect Disclosures:** Online platforms often 'collapse' multiple contexts (or audiences) into one. People utilise ambiguity to indirectly com-

municate sensitive information, whilst hiding it from others. When designing sensitive disclosure fields, designers should consider how users could appropriate disclosure fields to support indirect forms of disclosures, helping those straddling the line between being open and closed about sensitive aspects of their lives.

4. Purposeful Countersignals: Recognising the way signal appropriation can be used to increase the malleable nature of structured disclosure fields, designers could monitor online environments to identify inappropriate or stigmatising appropriations, purposefully designing in countersignals to mitigate these types of signal appropriations (e.g., allowing PrEP users to signal a preference for condoms).

## **8.6 Limitations**

As with all research, this research and the methods used have limitations. Due to the time constraints of this research, it was not possible to conduct additional studies to address many of these limitations and so further work has been outlined in the next section.

### **8.6.1 Deductive Data Analysis**

The most substantive part of this research is the semi-structure interview study, and the two deductive analyses that were performed across this data. Whilst performing deductive rather than inductive analysis in qualitative research can help in addressing more specific research questions, this form of analysis provides a less rich description of the data overall (Braun and Clarke, 2006). However, this was somewhat mitigated by performing two deductive analysis across the data using very distinct theoretical models to explore and understand multiple behaviours.

### **8.6.2 Participant Sampling**

The qualitative work presented in chapters 3, 5, and 6 did not control for ethnicity. The case study used as part of this research explored a stigmatised population, yet Schlesinger et al. (2017) highlight how identity is a construction of overlapping

attributes, of which multiple could be subject to stigma. Moreover, the interview data from which many of the findings from this study were derived was limited to UK participants, most of whom were living in London. Whilst the final study presented in chapter 7 explored selected findings from the qualitative work with a broader demographic which included ethnicity information, the study was conducted with a skewed sample of younger, white, European/North American participants. This thesis explores behaviours that are subtle in nature, and develop through a process of cultural evolution. Therefore, whilst the underlying concepts may generalise, the way in which they form within different cultures or amongst people experiencing multiple stigmatisations may vary.

### 8.6.3 Use of Profile Pictures

Another consideration when interpreting the findings from this research is the lack of profile pictures on the dating profiles used as part of the final study presented in chapter 7. Olivola and Todorov (2010) found profile pictures have a significant impact on judgement formation and can outweigh other visual cues (e.g., structured disclosure fields). Profile pictures were excluded to avoid participant bias and to help in observing any effects around undisclosed sensitive information. However, this same bias may impact on levels of *privacy unravelling* around undisclosed information, potentially reducing or increasing its effect.

### 8.6.4 Longitudinal Effects

The interviews conducted were retrospective in nature, asking participants to recall their experiences from the past. Whilst this was valuable in understanding how their behaviours and decisions developed over time, this method relies on self-reports which are susceptible to error (Blandford et al., 2016; Braun and Clarke, 2013). The final study presented in chapter 7 did not rely on self-reported data as it measured the effect of *privacy unravelling* in a simulated online dating environment. However, it was limited in that it did not provide any longitudinal insights into the effect. The final study, contrary to predictions, found no significant effect from disclosure norms on levels of *privacy unravelling*. However, these norms may have been previously

established in participants through their prior use of sex-social apps.

## **8.7 Further Work**

In reflecting on prior literature together with the studies conducted as part of this research, it is clear that there is a lot of work yet to be completed in this area; far too much in fact, for any one PhD. However, it is hoped that this research can act as a springboard for others to address some of the unanswered questions. This section outlines some of the areas which would benefit from further work.

### **8.7.1 Testing Peppet's Proposed Privacy Unravelling Limits**

As discussed in chapter 2 and in this current chapter, Peppet (2011) proposed four limits to *privacy unravelling*. Thus far, only very limited evaluation of these have been conducted, with no evaluation of these limits being applied around information within an online social context. Further work could be conducted that applies these limits across different online social contexts to understand how they could be practically and effectively applied in order to reduce this effect.

### **8.7.2 Generalizability of Privacy Unravelling**

This research has highlighted how privacy can unravel around HIV status information when these disclosures are designed using structured information disclosure fields. HIV status information is used as a case study in this thesis as it is a highly stigmatised condition, as well as being information that has been recently introduced into dating applications used by MSM. What is not known is how generalised the findings related to *privacy unravelling* are to other sensitive information types. For instance, would a similar effect exist around ethnicity information in dating applications? The research method developed and used within this thesis could be used to explore this effect across other information types in different contexts to understand the generalisability of the findings of this research.

### **8.7.3 The Impact of Privacy Unravelling on Minority Groups**

The additional analysis that was conducted in chapter 7 suggests that the effect of *privacy unravelling* may be greater amongst minority groups. Further research is recommended to explore how different minority groups are affected by unraveling.



Moreover, this further work could explore how different information visualisations impact on *privacy unravelling*. For instance, whether the order in which information is presented has an impact on the effect. Moreover, the studies conducted as part of this research were unable to show whether the effect of *privacy unravelling* increased amongst people living with HIV. This is important to understand, as if levels of *privacy unravelling* are higher amongst people living with HIV, this could allow for indirect, selective disclosures of HIV positive status information amongst people living with HIV, in what Marwick and Boyd (2014) refer to as ‘social steganography’.

#### **8.7.4 Exploring Cultural Differences**

Whilst the concepts discussed and developed as part of this research are likely to generalise across most cultural contexts, the concepts themselves rely on evolution of meaning which is likely to be affected by culture. How one culture uses signal appropriation to shape meaning around a digital artefact may differ to another. Therefore, further work should explore how signal appropriation differs across cultures, and whether culture affects levels of *privacy unravelling* in different online social contexts. Such a cross cultural exploration may also help identify factors that could be used to reduce its effect.

#### **8.7.5 Additional Testing Variables**

As discussed in the methods section of the final study presented in chapter 7, profile pictures were not included in the study design to avoid participant bias. Further work could be conducted to develop a method that includes profile pictures, to understand how they impact on levels of *privacy unravelling*.

The findings in chapter 5 suggest that the completeness of a profile may influence levels of *privacy unravelling* around sensitive information with some users purposefully reducing the amount of information disclosed in order to counter the effect of *privacy unravelling*. For instance, a profile disclosing high amounts of information that does not disclose HIV status may experience higher levels of *privacy unravelling* when compared with a profile disclosing low amounts of information. Further research is needed to understand whether this countersignaling strategy is

an effective one.

Moreover, prior research on *privacy unravelling* has explored feedback, and how additional feedback may impact on the effects of unraveling (Benndorf et al., 2015; Jin et al., 2015). For instance, if users receive feedback on actual HIV status, does this affect levels of *privacy unraveling* over time? Whilst prior work shows mixed results on the impact of feedback (Benndorf et al., 2015; Jin et al., 2015), no prior research has explored the feedback variable either longitudinally, or within a social context.

### **8.7.6 Online Stigma Reduction Strategies**

Throughout this research, stigma has been highlighted as having an undesirable impact on people's online interactions. Chapters 3 and 5 both draw on prior research (Levy and Barocas, 2017) in discussing community 'pledges' as a potential means of reducing stigma within online social platforms over time. Longitudinal research could be conducted to understand the long-term efficacy of community pledges as a stigma reducing mechanism. Moreover, the design implications on social narratives developed in this chapter could also be evaluated for their short and long term effectiveness.

## Chapter 9

# Conclusions

Structured disclosure fields are commonly used across online social networking websites. They make it easier for users to disclose personal information and provides structure to that information which allows for easier sorting and filtering. They constrain users to a set of pre-defined responses which can help de-stigmatise language around information attributes such as HIV status (Levy and Barocas, 2017). However, the structured nature of these disclosure fields was found to limit people's ability to disclose their status within a rich narrative, limiting information control. This loss of control is not around how information is "flowing" within a system or between people (Nissenbaum, 2009), but how information is interpreted by others. This research highlights the potential for social narratives, developed through public health campaigns, to help alleviate this loss of narrative. Embedding educational information into the everyday use areas of sex-social applications may help to reduce stigma around HIV.

Structured disclosure fields often provide users with a non-disclosure option, and on the surface this seems like an effective way to provide users with disclosure choice. However, this research shows how concerns develop around these non-disclosure option, as users fear that non-disclosure may signal to other users that they are hiding an undesirable quality; an effect known as *privacy unravelling*. It also shows how people develop their own countersignalling strategies to limit the effect of *privacy unravelling*, like reducing information disclosed on a profile to signal alternative narratives such as being more privacy aware, or having exerted a low

amount of effort when setting up the profile.

Privacy was not found to fully *unravel* around HIV status disclosure fields, but partial *unravelling* was found when undisclosed information fields were visible on user profiles. Using Vallerand (1997, 2000)'s hierarchical model of motivation to analyse the semi-structured interview data, a complex disclosure landscape was found. Incentive to disclose went beyond a desire to increase an individual's social value, with people being motivated to disclose for social good. This helps to explain why only partial *unravelling* is occurring around these fields. Yet partial *unravelling* can still disadvantage certain user groups, with minority groups being more susceptible to this effect which can further marginalise them. However, whilst concerns exist of *privacy unravelling* occurring around structured HIV status disclosure fields in MSM oriented sex-social apps, this research shows that the way most current apps are designed significantly limits the effect of *privacy unravelling* for most users. This is because most of these apps hide undisclosed HIV status fields on user profiles, which this research shows to be an effective means of reducing this effect.

Unlike unstructured and semi-structured disclosure fields, structured fields fix the available responses users are able to make. This too, on the surface, appears to place constraints that limit people's ability to engage in more subtle forms of disclosure (e.g. indirect disclosures (Andalibi et al., 2018a) and social steganography (Boyd and Marwick, 2011)). Drawing on signalling theory, this research shows how people can overcome system constraints by appropriating digital artefacts through cultivating new meaning into their design. This form of technology appropriation is referred to in this thesis as 'signal appropriation'. This research highlights how people engage in various forms of 'signalling' to manage the privacy around their HIV status, such as appropriating the effect of *privacy unravelling* to indirectly disclose an HIV Positive status. However as previously stated, the level of *privacy unravelling* around HIV status fields in sex-social apps is likely to be low due to the way they are designed, suggesting that this is an ineffective indirect disclosure strategy.

Whilst there are many advantages to designing sensitive disclosures into structured disclosure fields, there are disadvantages too. Whilst the effect of *privacy unravelling* was found to be low for most users, marginalised users may still be affected even when the undisclosed field is hidden from the user's profile. It is also important to consider the visibility of undisclosed information fields, as increasing visibility is likely to increase the effect of *privacy unravelling*. Finally, even if *privacy unravelling* is limited around HIV status disclosure fields in MSM oriented sex-social apps, the concerns of users need to be addressed. This research can contribute to addressing these concerns.

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## **Appendix A**

# **Semi-Structured Interview Materials (Chapters 5, and 6)**

## **A.1 Participant Information Sheet**

### **1. Invitation**

You have been asked to participate in a PhD research study exploring the online HIV disclosure behaviours of men who have sex with men (MSM). To participate in this study, you must be male, 18 years or older, identify as interested in having sex with men, and regularly use at least one online social network or dating application. Before you decide whether to take part in this study, we would like to provide you with some background to our research, the consent process, and details of how we will keep your data secure and confidential.

### **2. What is the projects purpose?**

The purpose of this study is to better understand the behaviours of men who have sex with men (MSM) in online social environments when diagnosed with HIV or when interacting with others who may have been diagnosed as HIV positive. We are also interested in the online behaviour of HIV negative men, or those who are unaware of their HIV status. The aim of this study is to inform designers of online social technologies, to enable them to develop technologies that are supportive of those at risk of, or diagnosed with HIV.

### **3. Why have I been chosen?**

To take part of this study, you must be male, and identify as interested in having sex with other men. You must be over the age of 18, and use at least 1 online social media application (app) or online dating app.

#### **4. Do I have to take part?**

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep (and be asked to sign a consent form). You can withdraw at any time without giving a reason and without it affecting any benefits that you are entitled to. If you decide to withdraw you will be asked what you wish to happen to the data you have provided up that point.

#### **5. What will happen to me if I take part?**

We will start by asking you some questions in a questionnaire. These questions relate to HIV testing and status information, as well as questions related to your online social network activity. Whilst we encourage you to answer these questions, we understand that the information is sensitive and encourage you to check Prefer not to say if answering makes you feel uncomfortable.

Once you have completed the questionnaire, we will start an audio recorded interview. During the interview, you will be asked questions related to your use of different online social networks. We would like to understand how you decide when to discuss your HIV status online and learn about your experiences talking about HIV online with others. We may ask questions related to your online privacy, your experiences around online stigma and how you deal with these issues, as well as questions related to the way you manage your identity online.

Completion of the survey and interview should take no longer than 60 minutes. Once the interview is over, within 1-2 months, we will transcribe the audio recording and anonymised the data so you can no longer be identified. Within 6-12 months of the interview, or earlier, the personally identifiable audio recordings will be securely deleted. Prior to this, the audio recordings will be stored securely on an encrypted storage device and physically locked inside a filing cabinet within a locked room at UCL.



**6. Will I be recorded and how will the recorded media be used?**

The audio recordings of your activities made during this research will be used only for analysis. No other use will be made of them without your written permission, and no one outside the project will be allowed access to the original recordings.

**7. What are the possible disadvantages and risks of taking part?**

You may feel some discomfort discussing some of the issues related to HIV and your online behaviours. If at any time this becomes too much, you can ask for the study to be paused, or to stop completely without giving a reason and without it affecting any benefits that you are entitled to.

**8. What are the possible benefits of taking part?**

Whilst there are no immediate benefits for those participating in the project, (except for the Amazon voucher) it is hoped that longer term, your involvement will help inform the design of online social technologies, to better support those with HIV. HIV positive participants, those subsequently diagnosed with HIV or those that know someone who is HIV positive, may benefit from these technological improvements in the future.

**9. What if something goes wrong?**

Should you wish to raise a complaint as a result of any part of your treatment during this research project, in the first instance please contact Prof Ann Blandford (Telephone, E-Mail)

If for any reason, you are unsatisfied with the way your complaint has been handled, please contact the Head of Department at the UCL Interaction Centre, HoD, (Telephone, E-Mail), or Chair of the UCL Research Ethics Committee [ethics@ucl.ac.uk](mailto:ethics@ucl.ac.uk)

**10. Will my taking part in this project be kept confidential?**

All information gathered during the research will remain confidential and handled in accordance with the provisions of the Data Protection Act 1998. Any work which is published which uses data we have collected about you will be anonymised. Personally identifiable information collected will be stored on encrypted storage and locked in a secure physical storage cabinet. Whilst the data is being analysed,

it will be stored on an encrypted laptop. No personally identifiable data will be taken out of the UK. The original, personally identifiable data (audio recordings) will be deleted within 12 months of collection, or earlier if its determined to be no longer required.

**11. Limits to confidentiality**

Please note that assurances on confidentiality will be strictly adhered to unless evidence of wrongdoing or potential harm is uncovered. In such cases the University may be obliged to contact relevant statutory bodies/agencies.

**12. What will happen to the results of the research project?**

The results of this research project will be published either in academic conference proceedings or within academic journals. The results will also contribute to a PhD thesis. Any work which is published which uses data we have collected about you will be anonymised.

**13. Data Protection Privacy Notice****Notice:**

The data controller for this project will be University College London (UCL). The UCL Data Protection Office provides oversight of UCL activities involving the processing of personal data, and can be contacted at [data-protection@ucl.ac.uk](mailto:data-protection@ucl.ac.uk)

Your personal data will be processed for the purposes outlined in this notice. The legal basis that would be used to process your personal data will be the provision of your consent. You can provide your consent for the use of your personal data in this project by completing the consent form that has been provided to you.

Your personal data will be processed so long as it is required for the research project. We will anonymize the personal data you provide, and will endeavor to minimise the processing of personal data wherever possible.

UK data protection law is regulated by the Information Commissioners Office (ICO). If you are concerned about how your personal data is being processed you may wish to submit a complaint to them. Contact details, and details of data subject

rights are available on the ICO website at: <https://ico.org.uk/for-organisations/data-protection-reform/overview-of-the-gdpr/individuals-rights/>

#### **14. Who is organizing and funding the research?**

This research is being undertaken at the University College London, but is funded by EU Horizon 2020 research and innovation program under the Marie Sklodowska-Curie grant agreement No 675730

**Thank you for reading this information sheet and for considering to take part in this research study.**

## **A.2 Informed Consent Sheet**

Thank you for considering taking part in this research. The person organising the research must explain the project to you before you agree to take part. If you have any questions arising from the Information Sheet or explanation already given to you, please ask the researcher before you decide whether to join in. You will be given a copy of this Consent Form to keep and refer to at any time.

I confirm that I understand that by ticking each box below I am consenting to this element of the study. I understand that it will be assumed that unticked boxes means that I DO NOT consent to that part of the study. I understand that by not giving consent for any one element that I may be deemed ineligible for the study.

- 1 - I confirm that I have read and understood the Information Sheet for the above study. I have had an opportunity to consider the information and what will be expected of me. I have also had the opportunity to ask questions which have been answered to my satisfaction and would like to take part in an individual interview.
- 2 - I understand that I will be able to withdraw my data up to 4 weeks after interview
- 3 - I consent to the processing of my personal information (information discussed or recorded during the interview) for the purposes explained to me. I under-

stand that such information will be handled in accordance with the UK Data Protection Act 1998.

- 4 - I understand that all personal information will remain confidential and that all efforts will be made to ensure I cannot be identified. I also understand that my data gathered in this study will be stored anonymously and securely. It will not be possible to identify me in any publications.
- 5 - I understand that my information may be subject to review by responsible individuals from the University (to include EU Horizon2020 project) for monitoring and audit purposes.
- 6 - I understand that my participation is voluntary and that I am free to withdraw at any time without giving a reason. I also understand that if I decide to withdraw, any personal data I have provided up to that point will be deleted unless I agree otherwise.
- 7 - I understand the potential risks of participating and the support that will be available to me should I become distressed during the course of the research.
- 8 - I understand the direct/indirect benefits of participating.
- 9 - I understand that the data will not be made available to any commercial organisations but is solely the responsibility of the researcher(s) undertaking this study.
- 10 - I understand that I will not benefit financially from this study (except from an Amazon voucher) or from any possible outcome it may result in in the future.
- 11 - I understand that I will be compensated with an Amazon voucher for the time spent in the study.
- 12 - I agree that my de-identified research data may be used by others for future research. No one will be able to identify you when this data is shared.
- 13 - I understand that the information I have submitted will be published as a report and I wish to receive a copy of it. Yes/No

- 14 - I consent to my interview being audio recorded and understand that the recordings will be destroyed within 6-12 months after the data has been collected or following transcription.
- 15 - I understand that I must not take part if I do not fall under the inclusion criteria as detailed in the Information Sheet and explained to me by the researcher.
- 16 - I am aware of who I should contact if I wish to lodge a complaint.
- 17 - I voluntarily agree to take part in this study.

### **A.3 Pre Interview Survey**

The below survey was used prior to each semi-structured interview that was conducted, the results of which are presented across chapters 5, and 6.

#### **1. In what age group are you?**

- 18 - 24
- 25 - 34
- 35 - 44
- 45 - 54
- 55 - 64
- 65 or over

#### **2. Which sexual orientation do you most identify as?**

- Straight
- Bisexual
- Gay
- I identify as:
- Prefer not to say

**3. Do you regularly test for HIV?**

Yes

No

N/A

Prefer not to say

**4. When did you last have an HIV test?**

Less than a month

Between 1 and 3 months

Between 3 and 6 months

Between 6 and 12 months

More than a year ago

N/A

Prefer not to say

**5. How would you describe your current HIV status?**

Negative

Negative, on PrEP

Positive

Undetectable

Other:

Prefer not to say

**6. When did your HIV status last change?**

Never

- Less than a month
- Between 1 and 12 months
- Between 1 and 2 years
- More than 2 years
- More than 5 years
- Prefer not to say

**7. When were you diagnosed HIV positive?**

- I haven't been diagnosed as HIV positive
- Less than a month
- Between 3 and 6 months
- Between 6 and 12 months
- Between 1 and 2 years
- Between 2 and 5 years
- More than 5 years
- More than 10 years
- Prefer not to say

**8. Which online social/dating networks do you use?**

- Facebook
- Instagram
- Twitter
- Snapchat
- LinkedIn

- Tumblr
- Grindr
- Hornet
- Jackd
- Scruff
- OkCupid
- Tindr
- Others:
- Prefer not to say

**9. How active are you in online social networks?**

- Not at all active
- Rarely active
- Somewhat active
- Often active
- Always active
- Prefer not to say

**10. How active are you in online dating networks?**

- Not at all active
- Rarely active
- Somewhat active
- Often active
- Always active

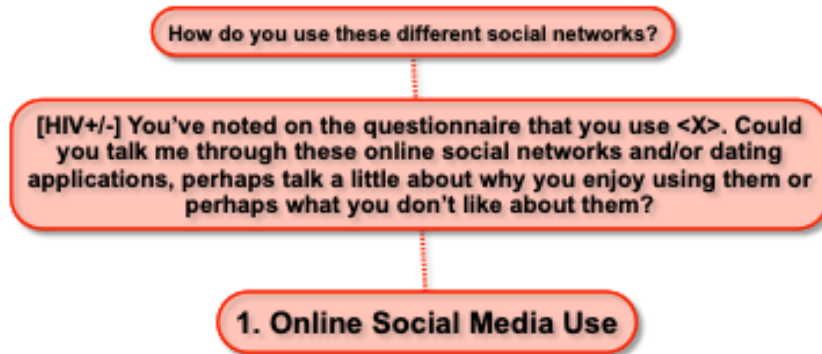


[ ] Prefer not to say

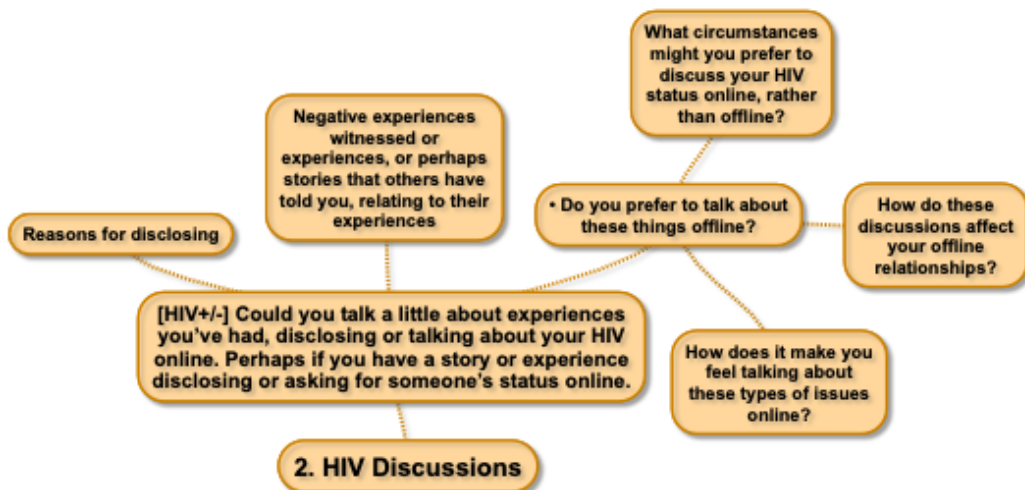
**End of Survey**

## **A.4 Interview Guide**

Each interview of the interview conducted was semi-structured, and the researcher guided the interviews using a developed interview guide based around six themes. The interview guide is presented in Figure A.1. The findings from these semi-structured interviews are presented across chapters 5, and 6.

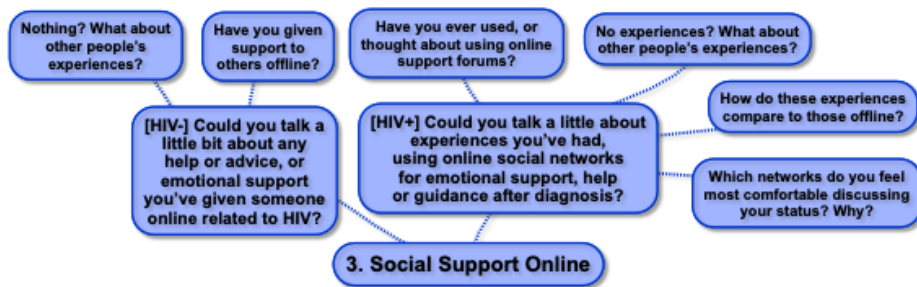


(a) Online Social Media Use

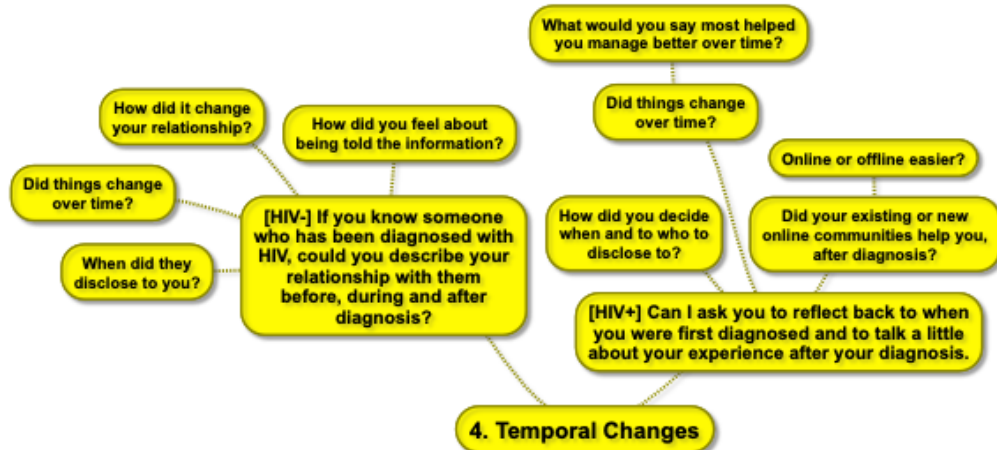


(b) HIV Discussions

Figure A.1: Semi-structured Interview Guide - Online Social Media Use

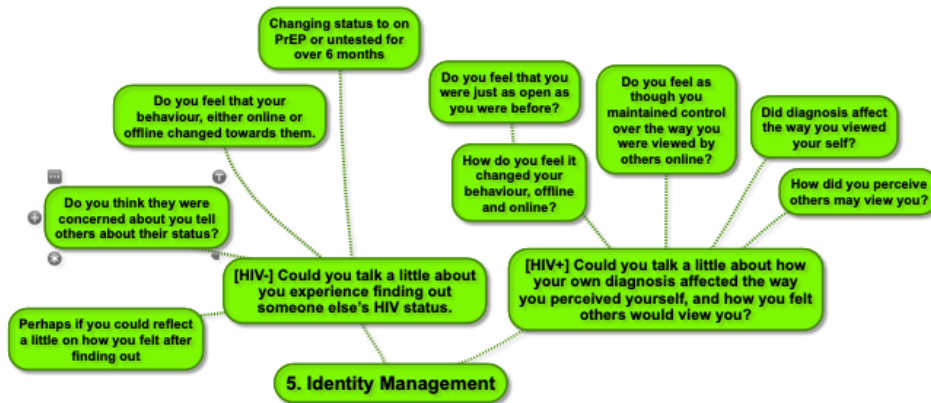


(c) Social Support Online



(d) Temporal Changes

Figure A.1: Semi-structured Interview Guide - Online Social Media Use



(e) Identity Management



(f) Disclosure Decision-Making

Figure A.1: Semi-structured Interview Guide - Online Social Media Use

## **Appendix B**

# **Quantitative Study (Chapter 7) Materials**

## **B.1 Participant Information Sheet**

### **1. Invitation Paragraph**

You are being invited to take part in a research project. Before you decide whether or not to take part, it is important that you understand why the research is being conducted and what your participation would involve. Please take the time to read the following information carefully and discuss it with others if you wish. If there is anything you are unsure about, feel free to send us an email for more information.

### **2. What is the projects purpose?**

The purpose of this project is to understand how gay and bisexual men use online dating applications, what information is or is not important, and how people evaluate certain information in dating applications.

### **3. Why have I been chosen?**

You have been chosen to participate in this study as you meet the studies inclusion criteria. This criteria states that you must be: (1) male (2) over the age of 18, (3) interested in having sex with men (4) used a dating application within the last 12 months.

### **4. Do I have to take part?**

Participation in this study is entirely voluntary. If you decide to take part, you will be shown this information sheet which you can save or print out.

If you decide you no longer want to be involved, you may withdraw without having to

give a reason or being disadvantaged in any way. Before submitting the survey you may close the browser page which will withdraw you from the study and delete your data. Once you have submitted the survey, we will not be able to delete your data as it will be stored anonymously.

**5. What will happen to me if I take part?**

The study consists of a survey within which you will be shown a series of dating profiles and asked to rate each profile. To complete this survey you must provide a rating for each profile that you are shown. The study will last no longer than 10-15 minutes. After rating the profiles, you will be asked some demographic questions. Some of these questions may appear sensitive and so your disclosures are anonymous and optional. The only demographic information we require relates to your general location i.e. which continent you live, and whether you live in a town or city.

**6. What are the possible disadvantages and risks of taking part?**

You may feel some discomfort answering some of the demographic questions at the end of the study. Answering these demographic questions is mostly optional, and ALL information is kept completely anonymous.

**7. What are the possible benefits of taking part?**

Apart from the Prolific payment that you will receive, there are no immediate benefits to participating in the project, however longer term it is hoped that this work will help improve the design of dating applications used by gay and bisexual men.

**8. What if something goes wrong?**

If something happens that you are unhappy with while participating in this study, and you would like to discuss it or raise a complaint, please get in contact with the principal researcher Prof. Ann Blandford (email). If you feel that your complaint has not been handled to your satisfaction by the principle researcher, you can contact the Chair of the UCL Research Ethics Committee ([ethics@ucl.ac.uk](mailto:ethics@ucl.ac.uk)).

**9. Will my taking part in this project be kept confidential?**

All the information that we collect about you during this research will be kept strictly confidential subject to legal constraints and professional guidelines. You will not be

identifiable in any ensuing reports or publications.

#### **10. Use of Deception**

Research designs often require that the full intent of the study not be explained prior to participation to avoid results being biased. However, we have described the general nature of the tasks that you will be asked to perform.

#### **11. What will happen to the results of the research project?**

The data collected as part of this study will be published in a PhD thesis which will be available through the UCL Discovery portal (<http://discovery.ucl.ac.uk/>). The data may also be used in published journal article(s) or conference paper(s) which will also be made available on the following website: <https://ucl.ac.uk/people/ann-blandford>. Alternatively, you may contact the principal researcher ([a.blandford@ucl.ac.uk](mailto:a.blandford@ucl.ac.uk)) to request a copy of any published documents using data collected as part of this study.

#### **12. Data Protection Privacy Notice**

##### **Notice:**

The controller for this project will be University College London (UCL). The UCL Data Protection Officer provides oversight of UCL activities involving the processing of personal data, and can be contacted at [data-protection@ucl.ac.uk](mailto:data-protection@ucl.ac.uk)

This local privacy notice sets out the information that applies to this particular study. Further information on how UCL uses participant information can be found in our general privacy notice:

For participants in research studies, click <https://www.ucl.ac.uk/legal-services/privacy/ucl-general-research-participant-privacy-notice>

The information that is required to be provided to participants under data protection legislation (GDPR and DPA 2018) is provided across both the local and general privacy notices.

The categories of personal data used will be as follows:

- Prolific ID.

The lawful basis that would be used to process your personal data will be performance of a task in the public interest.

Your personal data will be processed so long as it is required for the research project. If we are able to anonymise or pseudonymise the personal data you provide we will undertake this, and will endeavour to minimise the processing of personal data wherever possible.

If you are concerned about how your personal data is being processed, please contact UCL in the first instance at [data-protection@ucl.ac.uk](mailto:data-protection@ucl.ac.uk). If you remain unsatisfied, you may wish to contact the Information Commissioners Office (ICO). Contact details, and details of data subject rights, are available on the ICO website at: <https://ico.org.uk/for-organisations/data-protection-reform/overview-of-the-gdpr/individuals-rights/>

Who is organising and funding the research? This research is funded by EU Horizon 2020 and sponsored by UCL.

**Thank you for reading this information sheet and for considering to take part in this research study.**

## **B.2 Informed Consent Sheet**

In selecting each box below I am consenting to this element of the study. I understand that it will be assumed that unselected boxes mean that I DO NOT consent to that part of the study. I understand that by not giving consent for any one element that I may be deemed ineligible for the study.

I confirm that I have read and understood the information for this study. I have had an opportunity to consider the information and what will be expected of me. I have also had the opportunity to ask questions via e-mail, which have been answered to my satisfaction, and would like to take part in this survey study.

I understand that I am able to withdraw from the study at any point without penalty or being disadvantaged in any way, and that if I decide to withdraw



from the study after submitting the survey, it will not be possible for my data to be delete as it will be stored anonymously.

I consent to participate in this study. I understand that my personal information will be anonymised and used for the purposes explained to me. I understand that according to data protection legislation, “public task” will be the lawful basis for processing.

I understand that all personal information (i.e., your Prolific ID) will remain confidential and that all efforts will be made to ensure I cannot be identified and it will not be possible to identify me in any publications.

I understand the potential risks of participating and that I can contact the research team for support should I become distressed during the study.

I understand that the data will not be made available to any commercial organisations but is solely the responsibility of the researcher(s) undertaking this study.

I understand that I will not benefit financially (except for any incentive offered) from this study or from any possible future outcome it may result in.

### **B.3 Test Profile Data Set**

Table B.1 contains the data used to populate the test profiles used in the quantitative study presented in chapter 7.

Table B.1: Profile Data Used in Test Profiles

Set	Name	Age	Ethnicity	Body Type	Group	Position	HIV Status	Last Test Date
A	Mike	30	White	Toned	None	Vers Top	Negative	December 2018
A	Josh	29	White	Average	None	Vers Bottom	Negative+PrEP	November 2018
A	James	19	Black	Average	Discreet	Versatile	Negative	Prefer not to say
A	Sebastian	32	Latino	Muscular	None	Vers Bottom	Negative+PrEP	Prefer not to say
A	Harry	18	Mixed	Slim	Clean-cut	Bottom	Undetectable	Prefer not to say
A	Ben	20	White	Slim	None	Vers Top	Undetectable	Prefer not to say
A	Jake	28	White	Toned	None	Versatile	Undisclosed	Prefer not to say
A	Andy	24	White	Toned	Bear	Top	Undisclosed	Prefer not to say
A	Justin	23	Asian	Slim	Discreet	Vers Bottom	Undisclosed	Prefer not to say
A	Callum	19	White	Muscular	None	Vers Top	Undisclosed	Prefer not to say
A	Malcolm	31	White	Toned	Daddy	Top	Undisclosed	Prefer not to say
A	Zach	20	Asian	Slim	Clean-cut	Bottom	Undisclosed	Prefer not to say
B	Matt	30	White	Toned	None	Vers Top	Undisclosed	Prefer not to say
B	Joseph	29	White	Average	None	Vers Bottom	Undisclosed	Prefer not to say
B	Jason	19	Black	Average	Discreet	Versatile	Undisclosed	Prefer not to say
B	Sam	32	Latino	Muscular	None	Vers Bottom	Undisclosed	Prefer not to say
B	George	18	Mixed	Slim	Clean-cut	Bottom	Undisclosed	Prefer not to say
B	Brandon	20	White	Slim	None	Vers Top	Undisclosed	Prefer not to say
B	John	28	White	Toned	None	Versatile	Negative	December 2018
B	Anthony	24	White	Toned	Bear	Top	Negative+PrEP	November 2018
B	Jason	23	Asian	Slim	Discreet	Vers Bottom	Negative	Prefer not to say
B	Connor	19	White	Muscular	None	Vers Top	Negative+PrEP	Prefer not to say
B	Mark	31	White	Toned	Daddy	Top	Undetectable	Prefer not to say
B	Kyle	20	Asian	Slim	Clean-cut	Bottom	Undetectable	Prefer not to say

Group refers to a label that someone can self-identify with.