# It Starts With Me: Privacy concerns and stigma in the evaluation of a Facebook health promotion intervention

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Sources of Support

This evaluation was commissioned by the Terrence Higgins Trust and Public Health England as part of the broader evaluation of the HIV Prevention England programme.

Word count: 3982

# Abstract

Background: As efforts continue to increase rates of HIV testing and condom use among at-risk communities in England, organisations have sought to use social media to promote interventions. .

Aim: As part of a wider evaluation of *It Starts With Me* (ISWM), a sexual health promotion intervention in England targeting gay and bisexual men and African people through Facebook, we sought to explore how the online environment shapes end user engagement with sexual health interventions. A primary objective was to explore how privacy concerns can act as a barrier to engagement for the audience of ISWM.

Methods: We recruited a purposive sample of 40 individuals targeted by the intervention for in-depth interviews. Data collection was in two phases. In the first phase individuals were sampled based on engagement with online health interventions in general, while in the second phase all were sampled on the basis of engagement with the intervention.

Results: Privacy concerns related to the ecology of social networking sites, issues with implied disclosure and discrimination as well as uncertainty over control of data. These concerns limited the organic reach of the intervention by confining the intervention to those who already held the norms diffused through it, and by discouraging participants from sharing and commenting on content.

Conclusions: Care should be taken to address concerns when designing interventions delivered through social media. Gated interventions may be more beneficial for marginalised communities, while large-scale interventions such as ISWM may provide a useful backdrop for face-to-face interventions.

Key Words: HIV testing; social media; Facebook; MSM; African communities; online interventions

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# Background

HIV in the United Kingdom predominantly affects black African communities and gay, bisexual and other men who have sex with men (MSM) [1]. In recognition of modelling that indicates the majority of new HIV infections are transmitted by those who are unaware of their infection [2], and that treating HIV positive individuals early drastically reduces onwards transmission [3], expanding HIV testing has become a major public health priority in the UK.

The advent of Web 2.0 has significantly increased online interactivity and has led to a huge rise in the use of blogs, social networking sites (SNSs), podcasts and online support groups [4]. Accompanying the increasingly widespread use of SNSs across the social spectrum, many health promotion organisations have been developing and delivering interventions in online spaces (see Gold *et al* 2011). However, a number of concerns relating to user privacy and safety exist when considering health related interventions in online social media settings [4, 5]. These concerns are especially pronounced in relation to *Facebook* where most SNS health promotion interventions to date have taken place [6], and where privacy settings change quite frequently. While users have a degree of control over their data, settings are often complicated and rarely intuitive [7].

While there are particular tensions inherent in delivering interventions about a highly personal topic such as sexual health or HIV within a semi or entirely public space such as a social media sites, the literature on privacy concerns in relation to these interventions is limited. What evidence does exist points to key privacy concerns which potentially limit the reach of these interventions: Firstly that SNSs are not appropriate for health interventions (including, but not limited to, those focusing on sexual health) because they are not seen to be a sufficiently private space [4, 8, 9]. This is largely because of the phenomenon of context collapse, whereby audience segmentation becomes more difficult because of the multiplicity of relationship types that individuals maintain in social media environments, which necessitates the need for strategies to manage diverse conversations and connections online [10]. Correspondingly, a high degree of control over personal information on SNSs is important for people accessing sexual health information through these platforms [11]. A further issue is that engaging with sexual health information is threatening to the establishment and maintenance of online identities, which is incongruent with widespread engagement, particularly around users liking and sharing content with their own followers [4, 9]. While this existing literature is illuminating in terms of the issues that may be considered by those engaging with online health interventions, studies to date have only explored the privacy concerns of those who had engaged with the interventions, rather than those who may have had exposure to them had but chosen not to engage because of concerns related to privacy.

This paper presents the findings of a qualitative, end-user evaluation of HIV Prevention England’s (HPE) health promotion programme *It Starts With Me* (ISWM). This programme of interventions began in April 2013, and involves several linked offline and online components aimed at African people living in England as well as gay and bisexual men with the aim of reducing HIV transmission by promoting HIV testing and more consistent condom use [12]. ISWM targets African people between the ages of 25 and 45 and gay and bisexual men under the age of 35 [12]. Interventions in the programme included mass media adverts, printed materials, face-to-face outreach and online interventions on *Facebook* and *Twitter*. The social media component of ISWM, which this paper examines, features two pages on *Facebook* divided by target demographic. Social media users are encouraged to engage with the content through ‘Likes’, comments, and occasional competitions, and this interaction is vital to increase the organic reach (and therefore the audience) of this intervention.

The overarching goal of our study was to evaluate ISWM social media goals in relation to why and how people engage with interventions in these environments. While other manuscripts relating to pathways to impact in social media spaces and reflections on the ISWM online performance are in preparation, this particular paper focuses on data that emerged relating to privacy concerns that users held, and how these influenced their engagement with the intervention. By examining ISWM in relation to privacy concerns we deepen our understanding of how privacy impacts the type of engagement that users have with interventions on SNSs, as well as the ways in which the organic reach of the intervention may have been limited by these concerns. Finally, we can compare and contrast concerns of different groupings within the target population and their strategies to engage with content without compromising their identities. For the purposes of this study we construct engagement as contribution to the intervention with ‘likes’ and comments, as this is the criteria through which similar evaluations measure success [4, 5].

# Methods

Data collection consisted of two phases carried out between September and December 2014. To be eligible criteria, participants had to be 18 years of age or older, live in England and identify as either gay or bisexual men, as Black African (or use a similar term to denote African ancestry), or as both.

As there was comparatively little literature surrounding the use of SNS for health promotion interventions with our target groups, we initially sought to understand the motivations and barriers to engagement with health interventions in online spaces generally. Therefore, in the first phase of interview we focused on how groups engaged with health information on social media generally, including: their use of social media platforms; their experience of engaging online with health related information or organisations (including their motivations for doing so); and the reasons why they chose not to engage with such information or organisations. Such foregrounding of issues that influence online engagement in a holistic sense was crucial before examining engagement with ISWM specifically. We conducted short semi-structured interviews (approximately 25 minutes in duration) with 20 users of SNSs. All were users of *Facebook*, often in addition to many other sites such as *Twitter* or *Tumblr*. Participants were recruited through the online social networks of prominent HIV and LGBT and African-focused voluntary sector organisations (VSOs) across England using tweets, posts and adverts which appeared on both Twitter and Facebook. Potential participants who clicked on the adverts were directed to an online survey which captured demographic and contact info. Participants were then selected from those who had responded and were invited to interviews. Social media users in this phase were not sampled based on their engagement with ISWM, although a few did mention the the intervention during the interview.

Following our examination of the barriers and motivators to engagement with health promotion interventions on SNSs generally, we sought to understand how individuals engaged with ISWM specifically. I In the second phase, a purposive sample of 20 individuals was recruited through the *Facebook* and *Twitter* pages associated with ISWM (i.e. they were all individuals who had engaged with the ISWM intervention on *Facebook* or *Twitter*). These interviews lasted approximately 45 minutes and began by covering the same topics as the short interviews but also explored: their assessment of the goals of ISWM; motivations for engaging with the interventions; and the ways in which and reasons why individuals shared particular content with other online contacts. In order to explore how individuals responded to interventions participants in this phase were shown ISWM alongside Change 4 Life, a healthy living intervention, while women were shown breast cancer UK’s site and men shown Movember’s UK page. Issues relating to privacy or confidentiality were not the subject of specific questions in either phase of interview but we were attentive to their mention by participants and followed with prompts or probes where relevant.

Understanding motivations and barriers to access and uptake of any intervention requires such dual insight. All interviews were conducted remotely via telephone or Skype, were audio recorded and transcribed verbatim. A thematic coding framework was produced through consensus with all researchers, piloted, refined, and applied to all data with the aid of QRS NVivo 10.

Approval for the study was granted by the Research Ethics Committee of the London School of Hygiene & Tropical Medicine.

# Results

In total, our sample from both phases consisted of 40 individuals drawn from groups targeted by the ISWM interventions and who were users of social media. Twenty-nine identified as MSM and 13 identified as being African. Two participants identified as being both MSM and African so have been included in the age calculations in both groups.

The majority (n=26) of respondents in the MSM stream described their sexual orientation as gay, while two described themselves as bisexual. The mean age of MSM in the sample was 33, (range 18-57).

All African participants identified as heterosexual except for two who identified as gay men. Four African participants were men and nine women. The mean age in this group was 39 (range 31-56).

While we did not explicitly asked for participants’ HIV status, four participants (3 gay men and 1 African heterosexual man) voluntarily disclosed during interviews that they were HIV positive.

Nearly all of our participants held concerns about privacy relating to their social media use and their engagement with sexual health interventions that arose organically within the course of the interview. Privacy concerns fell within three broad and often inter-related themes, which individuals often experienced in tandem. The first – ‘sexual health and context collapse’ - was that engaging with these interventions was not necessarily congruent with participant’s use of social media because of the type of online space *Facebook* was understood to be based on the integration of personal and professional relationships. The second, ‘safety concerns and implied disclosure’, builds on the first and explores how some participants were concerned about the potential for and experience of stigma based on their engagement with sexual health interventions (especially ISWM). The third theme – ‘data and control’ - related to mistrust of the social media platform or the organisations delivering interventions and concerns about the level of control that individuals had over their own information.

## Context collapse and sexual health interventions

ISWM was effective in speaking to deeply held norms surrounding responsibility, HIV and sexual health. While true for some African participants, this was particularly so for the MSM in our sample who saw engagement around HIV and HIV prevention as a moral imperative and a cultural norm. When asked about his motivation for following an HIV organisation on *Facebook* a participant responded:

*I share a lot of the Terrance Higgins* [Trust’s] *stories, because I have a lot of friends who are positive…* [and] *there’s also a lot of ignorant people out there. I’ve got people who I went to school with who will make a flippant statement about someone having AIDS or someone doing this and I’m just like, I kind of think it’s my duty to educate and make people more aware.* (33 year old gay man, data collection phase 2).

This perspective conflicted with other cultural norms producing tensions for many participants. Indeed, the primary theme in the analysis was that participants thought of SNSs as particular kinds of online spaces which were characterised by the relationships represented within them, and these spaces were often considered inappropriate for sexual health interventions because of a desire to maintain divides between sections of one’s social sphere. This phenomena has been described elsewhere as ‘context collapse’ [10].

Unsurprisingly, this issue of context collapse was most acute for those who were not open about their sexual orientation and therefore would have had multiplicity of identities potentially represented amongst their Facebook ‘friends’. It was, however, also present for African participants for whom open discussions surrounding sex were sometimes seen as taboo.

An African participant explained how she was able to engage with information on HIV medications by positioning herself as interested in medical advances. She didn’t feel comfortable engaging in other sexual health interventions however, due to the fact that they often had content of a sexual nature:

*It’s not that I don’t want people to know. Sometimes we tell people too much, they will change because if you tell people your sexuality you lose them as a friend that’s what I thought about HIV in the beginning but it’s not about me and HIV it’s about progress on medication.* (56-year old African woman, data collection phase 1).

Indeed, a common issue for our participants was that while they assumed others might find content useful, because the norms operationalised within ISWM clashed with norms relating to other facets of their identity, they felt unable to share and pass on the information from the intervention. This ultimately served to limit the organic reach of the intervention via typical online networking.

In order to manage collapsed contexts, while some participants carefully curated content, others opted to only share posts in a targeted manner to people who it was assumed would find the material useful. This allowed them to maintain divides between spheres of their lives online.

*Interviewer: OK, so you might directly share it with one person, straight onto their wall, or you might put it on your Facebook page?*

*Participant:* [Say] *…this report is about the Facebook campaign, it’s about HIV, and I know a few people who have got HIV. And instead of putting it out to the fourteen hundred, I would just put it on these people, on their walls. I’m not really out as bisexual or a gay person, I’m only out to certain people. And so out of these fourteen hundred people, most of them I wouldn’t want them to know.* (57 year old bisexual man, data collection phase 2).

Never-the-less, despite strategies being used to manage content curation, the high level of concern amongst our participants in relation to context collapse indicates that these issues may limited the organic reach of ISWM, particularly by confining it to those who hold the norms perpetuated by the intervention most deeply.

## Safety concerns & implied disclosure

A majority of participants were conscious or concerned as to how their engagement with health information or interventions on *Facebook* might be perceived by others. A common concern among African respondents was that proximity to the ISWM intervention could trigger homophobic reactions from their peers which limit engagement among participants.

*There’s still a lot of stigma around issues regarding HIV and also a lot of people know about people being gay. If I start liking things, gay and HIV, there’ll be a lot of questions being raised... .* (39 year old African MSM, data collection phase 1)

Concern regarding homophobia from within the African community was partially ameliorated by the fact that ISWM had been designed with separate sites for gay and bisexual men and African streams of the project (although accounting for the overlap in these populations was more problematic). While this was likely done to ensure that individuals from the groups received the content most appropriate for their cultural background and their specific needs, it was also effective in countering a potential privacy concern.

In relation to sexual health specifically, among both gay men and African participants, there were significant concerns that people would perceive them to be HIV positive if they engaged with ISWM, or material from the intervention.

Interviewer: *On Facebook, have you liked any charities or organisations related to HIV?* Respondent: *Yes. I’ve liked [VSO in Northern England]. I volunteered with them for Pride. And [VSO in Manchester]. I’ve liked those. But I don’t like too many of the organisations, because I don’t want too many people to know that I’ve got it. Obviously it’s not something that I go around telling people at all.* (37 year old gay man. Data collection phase 1).

The concerns about HIV related stigma which limited engagement were not without foundation, and two participants reported being on the receiving end of comments that they perceived to be stigmatising from others based on the content they shared.

*I remember that time I had shared a petition about better access to PrEP. Then I had a bunch of messages like asking me if I’m HIV* [positive]*. And I had to justify to quite a few people that I’m not, but I’m quite passionate that prevention should be there. But then I did feel a bit apprehensive about liking some stuff and being involved in some campaigns because it’s that sort of thing of people assuming your status by that.* (25 year old gay man, data collection phase 2).

While some felt uncomfortable engaging in any health interventions online, the vast majority of participants found interventions not to do with sexual health accessible and were not concerned about associated stigma. When showed the *Facebook* page for Movember, a participant said the following:

Participant: *I think I might actually be more inclined to share something off this page compared to the It Starts With Me one.*

Interviewer*: Why do you say that?*

Participant*: I think for some reason, I think people wouldn’t like judge me sort of thing if I shared something off here compared to off It Starts With Me. I think because of judging the status thing, even if people judged that I had prostate cancer of some sort, they don’t make some sort of assumption of it.* (25 year old gay man, data collection phase 2).

These concerns are particularly illuminating as to how individuals perceive sexual health interventions generally as the primary messages transmitted through the ISWM intervention were about increasing rates of HIV testing, rather than wellbeing of people who have HIV. The fact that individuals felt that being associated with an intervention aimed primarily at HIV negative individuals led to perceptions that they themselves have HIV indicates that either the messages weren’t sufficient clear, or, more likely, that for many of our participants proximity to the concept of HIV in social media spaces is in itself threatening.

## Data, uncertainty & control

Technological aspects of SNSs and the ambiguity surrounding competence of individuals who ran these interventions were frequently perceived as a risk. This usually related to concerns about the ambiguous nature of *Facebook* privacy settings and confusion over who could see what, but in a few cases also included concerns about the misuse of data by others.

*So I suppose it’s a very open space* [*Facebook*]*. Even though you can change your privacy settings, as soon as you tag someone in it, those who are friends with them get to see that as well… It’s not overly secure.* (20 year old MSM. Data collection phase 2).

There was a perception among some participants that despite using privacy settings to control the flow of information, there was opportunity for data to be found by other people through privacy loopholes.

Engaging with a health intervention on *Facebook* was also considered risky by some participants because of uncertainty surrounding the competence of the individuals working on the accounts of voluntary sector organisations carrying out interventions.

*Someone posted something to* [VSO] *Facebook wall as a question of something.* [VSO] *answered it, but they also shared it as a public post. That person flipped out, because they weren’t necessarily out to everyone.* (28 year old gay man, data collection phase 1).

# Conclusions

Our findings illustrate the extent to which individuals in the target demographic of the online *ISWM* HIV prevention intervention who had, and had not, engaged with the intervention were concerned about their privacy. Individuals expressed concern that *Facebook* was not an appropriate environment in which to engage with issues of a sexual nature, given the linkage with friendship, family and professional networks. Collapsing contexts meant that individuals were not necessarily comfortable having proximity to ISWM.. Given that the reflection of deeply held norms surrounding HIV prevention were a primary motivation for individuals to engage with ISWM, and that it was these norms which were perceived to be threatening to others, the reach of ISWM likely would have been confined to those who potentially had less utility for engagement with the intervention. This is largely congruent with findings of other studies in which *Facebook* was seen to be a potentially inappropriate space for sexual health interventions, and an inappropriate setting in which to communicate about personal ill-health [13, 14].

The most pressing privacy concern related to a fear that engaging with the intervention might mean assuming a stigmatised identity, either that as a gay man or someone living with HIV. Stigma represents the biggest barrier for both African people as well as gay and bisexual men in accessing testing services, in part because of the perceived reputational risks associated with these services [15, 16]. Based on our findings, issues relating to stigma should be understood to have limited engagement with ISWM. Troublingly the most marginalised of these groups (who could potentially have the greatest benefit from engaging with ISWN) are to have the most pressing concerns in relation to privacy, indicating that an overreliance on these approaches could lead to a worsening of health inequalities.

Concerns regarding control of data in online social media environments and the competence of those delivering interventions was also perceived as a major barrier for participants. Given the very high level of ambiguity surrounding privacy settings expressed by our participants, trying to raise literacy of privacy controls amongst this group is not necessarily the most appropriate way to try and boost engagement (nor is it particularly practical). Instead, moving towards a ‘gated’ social media intervention may be more appropriate for hard to reach individuals, which would provide a boundaried, moderated space. In such a space it is possible that a greater element of peer support may emerge with end users supporting each other. This approach has been seen to be appropriate for young black MSM and HIV positive MSM in the US [11, 17, 18].

Social media facilitated interventions are not without utility and our findings indicate that they are effective in perpetuating norms, however it is important that those producing these interventions understand their strengths and limitations and incorporate them into combination approaches which harness their benefits while addressing their shortcomings.

While significant recruitment efforts were made, the upper age range of our sample is slightly higher than the target demographic of ISWM. While it is possible that the magnitude of privacy concerns may be over-estimated given this older age range, the near universality of these concerns amongst our participants suggest this is unlikely. More realistically we likely would have significantly under sampled those with the greatest concerns around privacy in relation to health promotion and social media due to their reluctance to take part in interviews.

We also acknowledge the range of ways in which individuals engage with health promotion materials at times differs from our definition of engagement. In particular some individuals would have passively engaged with content drawing useful information from the interventions without ‘liking’ and commenting. Taking a broader view however, the success of interventions such as ISWM are predicated on active engagement to increase the number of individuals who are exposed to them through SNSs, particularly in penetrating networks of marginalised people.

As a qualitative, end-user evaluation, this study establishes some of the motivations and barriers to engagement with a *Facebook* based sexual health intervention as they relate to privacy and online safety. It does not speak to the broader impact of the intervention on the target population and, as a qualitative study, any such impact reported by our sample might be considered indicative rather than representative. However, findings indicate that privacy and online safety concerns may pose a significant barrier when seeking to engage members of minority, marginalised or otherwise ‘hard to reach’ communities for interventions on sensitive topics. The findings of this study suggest that caution is warranted not to exclude individuals from marginalised groups in such a way that might exacerbate existing health inequalities. Social media offers a range of ways in which target audiences can be engaged with (sexual) health interventions and the use of gated or closed social media groups might be considered, as well as traditional, physical and offline mass media interventions.

**Conflicts of interest**: none.

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