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ICT & HIV prevention: Experiences from a biomedical HIV prevention trial among men who have sex with men (MSM) in Cape Town, South Africa

Andrew Scheibe, Ben Brown and Linda-Gail Bekker

Abstract

HIV prevalence among men who have sex with men (MSM) in South Africa has been shown to be disproportionately higher than among the general population. Increased vulnerability to HIV among MSM has been associated with structural, social and individual factors. While information and communication technologies (ICT) now commonly mediate the sexual practices of many MSM, little research exists on how to design and deliver effective biomedical and combination HIV prevention interventions targeting MSM that consider the role of ICT in this context. In this paper, we describe the use and impact of ICT for a biomedical HIV prevention trial in South Africa as part of the larger Global iPrEX trial. We outline the research rationale, design and results and examine how SMS, email, social networking sites, and the Internet were used to target MSM. Drawing on our experience, we argue that the low cost and wide usage of various components of ICT among MSM offer significant potential for future targeted HIV prevention efforts.

Keywords: HIV prevention, information, communication, technology, ICT, MSM, South Africa

HIV prevention among MSM in South Africa

The goal of implementing effective HIV prevention strategies among vulnerable populations, especially among gay men and other men who have sex with men (MSM), is likely to require a combination of biomedical and behavioural approaches (Beyrer et al., 2011). Additionally, an enabling environment to achieve health and protect the human rights of all citizens is required (Campbell & Cornish, 2010), particularly in South Africa. Traditional HIV prevention efforts do not appear to be reaching MSM in the South African context. As a result, high HIV prevalence among MSM in several South African locations has been documented (Burrell, Mark, Grant, Wood, & Bekker, 2010; Lane et al., 2009; Rispel & Metcalf, 2009a).

In the United States and Western Europe, a resurgence of new HIV infections among young gay men and MSM has encouraged prevention specialists to develop approaches which are relevant to this new generation (Sullivan et al., 2009). Emphasis on the potential role ICT plays in gay men and MSM's social and sexual practices have been made by several organisations, including the United States National Institutes of Health, in an attempt to improve HIV prevention efforts among MSM (National Institutes of Health, 2010).

Strategies which employ ICT—either through the use of mobile phones, the Internet or other digital platforms—can be used to provide instant health related information,

link individuals to relevant services and facilitate knowledge dissemination. ICT can also be used in all stages of HIV prevention research. ICT has the potential to revolutionise the HIV response and to expedite the development and implementation of effective HIV prevention solutions (Lim, Hocking, Hellard, & Aitken, 2008; Noar, Black, & Pierce, 2009; Ybarra & Bull, 2007). Tailoring these interventions with ICT to specifically address the needs of gay men and other MSM could partially adress the disproportionate vulnerability to HIV faced by many MSM (National Institutes of Health, 2010).

MSM in South Africa, especially those from lower socio-economic backgrounds, continue to be affected by structural and social factors which increase their vulnerability to HIV infection. Structural factors and social factors which have been associated with increased vulnerability of MSM to HIV in South Africa include limited government support for HIV prevention programming targeting MSM, and high levels of unemployment and poverty as well as limited economic opportunities (Burrell et al., 2010; Lane et al., 2009; Rispel & Metcalf, 2009b).

In South Africa, the coverage of existing MSM focused services is limited to major urban centres that are often inaccessible to MSM living beyond these areas (Metcalf, de Swardt, Tallis, & Jobson, 2009). Homophobia, discrimination and stigma are common social drivers of risk that affect the nature of service provision and serve as barriers to accessing sexual health services and care (Cloete, Simbayi, Kalichman, Strebel, & Henda, 2008; Vu, Tun, Sheehy, & Nel, 2011). Few HIV prevention services successfully reach non-gay identified MSM. Ogoing human rights abuses and the insensitivity of health care professionals to gay-identified MSM continue to act as barriers to accessing health care (Desmond Tutu HIV Foundation & Johns Hopkins University, 2011; Metcalf et al., 2009).

The lack of social science based interventions specifically tailored to suit the needs of MSM in contemporary South Africa has limited the effectiveness of prevention efforts. The need to address the biological, psychological and social factors which increase the vulnerability of MSM to HIV infection has been highlighted as a priority for effective programming (American Foundation For AIDS Research, 2008). Addressing factors which contribute to biological vulnerability, such as the presence of an ulcerative sexually transmitted disease; psychological vulnerability that may be associated with depression or substance use; and social vulnerability—particulalty stigma and discrimination—with holistic HIV prevention programming could decrease HIV incidence among MSM (Beyrer et al., 2011). Developing evidence-informed holistic HIV prevention programmes now requires serious consideration of the ways in which ICT mediate the lives of MSM in South Africa.

ICT in South Africa

Mobile phones, including smart phones with Internet connectivity are widely accessible in South Africa. Approximately 20.5 million adults (41%) have access to a mobile phone, and 10 million (20%) have one (Market Tree Consultancy, 2011). As a result mobile phones are one of the most accessible ways to access the Internet in a country with unreliable access to wired connectivity and economic inequality. Additionally, it was estimated that in 2010 approximately 6.2 million South Africans had access to the Internet (The World Bank, 2011). Corporate firms, small enterprises, government departments and individuals utilise online facilities to market goods, conduct sales and provide information online. Many South Africans use social media networks for communication, entertainment and to establish personal relationships. A plethora of online dating sites, catering for all sexual preferences, exist. In terms of social media

there were over 2.4 million registered Facebook users in South Africa in 2009 (Burcher, 2010) and there were over 55,000 active South African Twitter users. Cape Town had the largest number of Twitter users, but few tweets were health related (Fuseware, 2010).

Mobile phones have the potential to facilitate the social, behavioural and political changes required for HIV prevention interventions to have an impact on the HIV epidemic in the South African context. To date, the use of digital technologies to facilitate knowledge sharing, improve access to services, link to care and support treatment adherence in South Africa has been limited. Initial pilot projects have been initiated but support by government and the roll-out of such programmes have yet to be realised. This may be partly due to limited data on the cost-effectiveness or impact of ICT in health programming in the South African context. Yet their growing role in mediating sexual practices of MSM, as indicated by the large number of online dating and sex sites in South Africa, challenges the effectiveness of traditional biomedical and behavioural HIV prevention approaches.

To confront this changed reality, approaches like the one we present below are needed to consider the potential of ICT in designing more effective models of HIV prevention. We describe our participation in a biomedical HIV prevention project, the Global iPrEX trial. We then illustrate our experiences of using SMS messaging, email, online social media and websites. In conclusion we reflect on the challenges and consider lessons from our efforts to engage, mobilise, recruit and retain participants in Africa's first biomedical HIV prevention trial among MSM.

A case study of the role of ICT in an HIV biomedical prevention trial among MSM in South Africa

Organisation

The Desmond Tutu HIV Foundation (DTHF) is a non-governmental organisation whose mission is the pursuit of excellence in research, treatment, prevention and training around HIV and infectious diseases in Southern Africa. The DTHF has been working with the Cape Town MSM community since 2007. Our current repertoire of projects includes HIV related research, community engagement, training, advocacy and HIV prevention activities.

Context

In 2008, the DTHF was selected as the only African site to participate in an international pre-exposure prophylaxis trial for the prevention of HIV among MSM and transgender women, known as the Global iPrEX trial. Pre-exposure prophylaxis (PrEP) involves the use of medications in people who do not have an infection to prevent such an infection from occurring. For example, the use of anti-malarial drugs to prevent malaria infection among individuals who are visiting a malaria endemic area. The opportunity to participate in this internationally significant project signalled the beginning of an explorative journey in the use of novel ICT strategies to mobilise, engage and educate MSM around HIV prevention in Cape Town.

Research

The Global iPrEX trial was a double blind, randomised, placebo-control trial to assess the safety and efficacy of once daily oral combined emtricitabine and tenofovir disoproxil fumarate (Truvada) for the prevention of HIV among MSM and transgender women. This trial was the first biomedical HIV prevention trial to be conducted among MSM in Africa. Funding was provided by the United States National Institutes of

Health as well as the Bill and Melinda Gates Foundation. Truvada, the study drug, was provided by the pharmaceutical company Gilead Sciences. Individuals aged 18 years and older, who were born male, had sex with men and who were assessed as being at high risk for acquiring HIV, and who tested HIV negative, were eligible for enrollment in this trial. Figure 1 is an example of a recruitment flyer used for this trial. The flyer details the eligibility criteria and provides details on how potential participants could contact the researchers.



Figure 1. Recruitment flyer for the PrEP Trial.

Approximately 2500 MSM and transgender women were enrolled from sites in the United States, Peru, Ecuador, Brazil, South Africa and Thailand. Recruitment at the Cape Town site started in September 2009 and ended in mid 2010. Overall, the Cape Town site screened 119 participants, 88 of which were enrolled. Participants were followed up monthly to assess HIV seroconversion. In addition to safety monitoring, participants were provided with monthly HIV testing, condoms and lubrication, risk reduction counselling as well as sexually transmitted infections (STIs) and hepatitis B screening, vaccination and treatment as appropriate.

The results of this trial showed that daily tenofovir-emtricitabine was safe and was 44% (95% confidence interval 15% – 63%) efficacious for the prevention of HIV among participants receiving study medication. There were no major safety concerns and the apparent protective effect of PrEP increased with increasing compliance (Grant et al., 2010). Details of the trial, trial results and the open label extension phase can be accessed at www.globaliprex.com and www.iprexole.com.

Use of ICT

The iPrEX trial was the DTHF's first attempt to combine digital based recruitment and retention activities with standard field worker based strategies. The novel recruitment strategies that we employed included: a SMS based system to collect contact details of interested individuals; online recruitment through a Facebook group; and the use of

online dating and general advertising sites. Retention efforts included the use of reminder SMS messaging, emailing and messaging on a social networking platform, Facebook. Computer assisted self-administered questionnaires were administered at several study visits in line with the study protocol.

Reflections on the the role of ICT in an HIV biomedical prevention trial among MSM in South Africa

After the successful implementation of the first phase of the iPrEX trial, we have been able to reflect on the experience. Below we highlight the challenges and possible solutions for the use and role of ICT for biomedical HIV prevention trials among MSM in South Africa.

SMS services for study recruitment

Our initial attempts to mobilise and inform the Cape Town MSM community about HIV prevention research and the concept of PrEP through a mobile phone SMS message campaign were disappointing. The initial SMS campaign lasted for the first 6 months of the recruitment period. Details of the free SMS service and on how to find out more information about the study were placed on a poster and on printed advertisements, including details on the aims of the study, as well as the target group (Figure 2). Advertisements were published in gay newspapers (Pink Tongue and EXIT) and OUT Africa magazine. Posters were placed in gay venues throughout Cape Town.

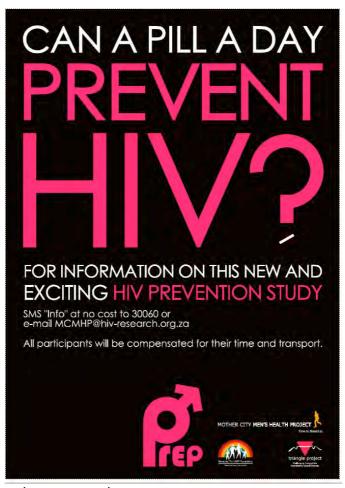


Figure 2. SMS recruitment campaign poster

A Microsoft Excel spreadsheet was developed to capture the details of interested individuals in order for a representative from the DTHF to contact them and conduct a rapid, anonymous telephone-based screening. Interested and potentially eligible participants were then given an appointment to undergo a formal screening visit.

Despite wide dissemination of posters and printed advertisements, and the free nature of the service, this method proved to be fairly inefficient in its ability to attract eligible participants. Of the 195 individuals who replied, only 13 were potentially eligible and only three were eventually enrolled.

Although the posters clearly stated that the project was aimed at exploring new HIV prevention methodologies among men, they did not specify MSM. This was because the posters were only placed in venues frequented by members of the Lesbian, Gay, Bisexual, Transgender, and Intersex (LGBTI) communities.

As a result, a large number of women, non-MSM, and other community members outside our targeted audience sent in their contact details to the SMS service. Ultimately, this increased costs and required significant human resources to identify potential participants. We were not aware of this potential problem before initiating the trial. To the knowledge of the authors, no data on the use of SMS technology for recruitment of MSM for a biomedical HIV prevention trial in SouthAfrican had been published.

Mobile phones

The iPrEX trial continued for over 2 years, and required monthly site visits. Study retention efforts would have failed if it had not been for mobile phones. Few participants had fixed telephones and mobile phones provided a means for contacting MSM enrolled in this study verbally as well as through SMS messaging. Even in the context of an African country with a liberal constitution, MSM face high levels of stigma (Baral et al., 2011). The use of mobile phones as a primary medium for contacting participants was thus essential for preventing unintentional disclosure as MSM during the study. SMS messaging was an effective means for communicating reminders and arranging appointments which needed to occur on monthly occasions. However, our reliance on contacting MSM through mobile phones had its draw-backs. In particular, we found it challenging to contact MSM using mobile phones in areas with high crime rates and relatively expensive mobile provision.

Online platforms – websites, social networks and advertisements

Our experience of online services included the use of websites (the DTHF website and Gumtree), a social networking site (Facebook), an online dating site (Gaydar) and an online advertising service. A section of the existing DTHF website was used to include details of the iPrEX study in Cape Town. However, neither our budget nor our capacity allowed for substantial investments to be made in ensuring appropriate development, marketing and promotion of the study specific pages, or of the DTHF website. As a result the number of hits for the study related webpages and the resulting benefit of this approach was limited.

Gumtree is a website that offers the sale of services and products online. This service is free for non-commercial use, and requires payment for regular or prominent positions on the site. Options to meet sexual partners are available on this service and it is open to people from all sexual orientations and gender identities. We placed an advert for participation in the iPrEX trial on the Gumtree site. A brief description of the trial and a link to the DTHF website were included. The study recruitment officer's email address was included in order for interested people to contact the DTHF and learn more about the study and to consider participation. However, daily posting of the advertisement

without payment was not allowed, and ultimately only one participant was recruited through this mechanism.

Facebook is a well known social media site where we developed a DTHF iPrEX group. This group was initially set up as a recruitment tool. This group did not gain popularity and did not prove to be a feasible avenue to recruit new participants. It was disbanded a year after its launch. Failure of the iPrEX Cape Town Facebook group to attract potential participants may have been due to an ineffective marketing strategy and the relatively small number of iPrEX participants who reported to be Facebook users at the time of study recruitment. For example, by the end of 2011, almost all participants were active Facebook users. Further efforts to launch a Facebook group were not attempted, but our researchers attempted to "friend" participants on an individual basis once they reported having a Facebook account. To ensure confidentiality, researchers contacted participants only through private messaging services rather than through the 'wall' function, and only after asking permission from each participant to do so.

The possibility of advertising on online gay dating and sex sites was also explored. Many online sex sites had stringent requirements that restricted the advertisement of health related services or research, which limited their potential use. Other sites, like Gaydar, were willing to advertise the trial, but charged expensive rates beyond the project's budget.

Computer assisted interviews (CASI)

As researchers in search of the highest possible data quality, we were committed to exploring new ways of minimising reporting bias and maximising participants' trust. To do this, computer assisted self-administered interviews (CASI) were implemented as part of our study protocol. The participants' experience of CASI still needs to be formally evaluated and will be done as part of the overall iPrEX trial in the future. Anecdotally, few of our participants appear to have been hindered by issues related to computer illiteracy. Interestingly, our data also allows us to hypothesise that many may have reported unbiased accounts of their sexual behaviour and practices through the use of computer based questionnaires as compared to speaking to an interviewer.

Despite high speed ADSL connections however, IT problems and tardiness of skip patterns caused frustrations to staff and participants with using computer assited interviews. The relatively high frequency of this issue affected our ability to provide an efficient service.

Implications for maximising the potential of ICTs and for evaluating impact

By reflecting on our experience we have been able to identify several lessons we have learnt relating to the effective use of ICT within the context of HIV prevention research among MSM in South Africa. We believe that many of the lessons and recommendations may be applicable to HIV prevention interventions in Africa and beyond.

The effective use of SMS services

The flexibility of SMS-based activities is well suited to respond to the changing needs of MSM, as well as future HIV prevention interventions in South Africa and further afield. For instance, SMS services could be used to provide details on where to access free and confidential HIV testing and sexual health services for MSM. SMS messaging in African contexts, may be particularly useful in contexts where MSM sexual behaviour frequently occurs "underground" and where identity protection is a priority. The impact of SMS

services could be increased through targeted promotion of these services. Initial market research and piloting of SMS based services, incuding posters, may also improve effectiveness of promotional material and uptake of HIV SMS prevention services. Additionally, future posters and materials promoting HIV SMS prevention services should clearly state the target population. In order to prevent inadvertent disclosure of MSM identity, staff working on such projects must be trained to recruit MSM sensitively. For example preapproved scripts could be developed. Also, messages should be designed as so as not to compromise the confidentiality of the SMS recipient. In order to be cost effective, SMS services should be delieverd at minimal cost and be automated as far as possible. This might require working with a mobile phone operator.

The effective use of online social networks and websites

Our initial forays into online social networks and websites for a biomedical HIV prevention trial suggest that the effective design and delivery of online recruitment, follow up and retention tools for MSM is complicated. It requires the significant investment of resources to be fully effective. In addition, a clear understanding of the behaviours of users of social networks is required to adapt tactics and messages in ways that support active participation. In order to attract cyber traffic to sites promoting MSM health issues, they need to be well designed, cutting edge and interesting, as well as informative. Additionally, a clear marketing analysis is needed before web-based MSM social marketing strategies are implemented. Ongoing, dedicated resources are required to ensure all online services, including marketing, site maintenance and hosting are kept current and well maintained.

Making use of social media like Facebook can play an important role in communicating and networking with HIV prevention study participants. ICT allows for confidential communication and can be used for scheduling appointments, reminding participants about visits, sharing new information and maintaining contact between different phases of a project. Online social media sites can be especially useful in optimising study retention and for communicating with participants who do not wish to be contacted by telephone.

We argue that for greater impact, understanding how and why to develop groups on social networking platforms for HIV prevention that will stimulate the interest of the greater MSM community is crucial. Some key issues to consider that emerge from our experience include:

- How social networking platforms could be designed to provide safe spaces for engagement and dialogue around HIV prevention with MSM;
- How social networks could be facilitated to address the social constructs which influence vulnerability and risk to HIV; and
- How social media communication could improve access to health services, address community stigma, develop MSM self-esteem, increase capacity for employment and involvement in larger community structures.

Conclusion

In this article, we have described how and why the DTHF used ICT to facilitate the implementation of a complex HIV prevention biomedical trial in South Africa. Despite the mixed picture of success that emerged, our experiences provide an argument for the role of such tools in designing engaging, targeted and appropriate HIV prevention interventions, including biomedical approaches. To date limited literature exits on the role of ICT within HIV prevention biomedical studies. We believe that our particular

approach stands out in the way that we added novel activities to established study methodological practices. The flexibility in our use of novel activities has provided key insights necessary to inform future interventions.

We suggest the need to rethink existing biomedical HIV prevention trial designs to relate to the changed behaviours of MSM with ICT today (Walsh & Singh, 2012). In particular, opportunities exist for the design of specific tools and approaches for HIV prevention geared towards MSM who access the Internet through mobile devices. We would recommend SMS related activities that are targeted in ways that prevent inadvertent breaches of confidentiality.

Looking to the future, we have embarked on a research agenda to formally assess the acceptability, feasibility, and impact of using ICT as part of combination HIV prevention efforts among MSM in South Africa, and we will use our experience to inform our future use of ICT.

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