



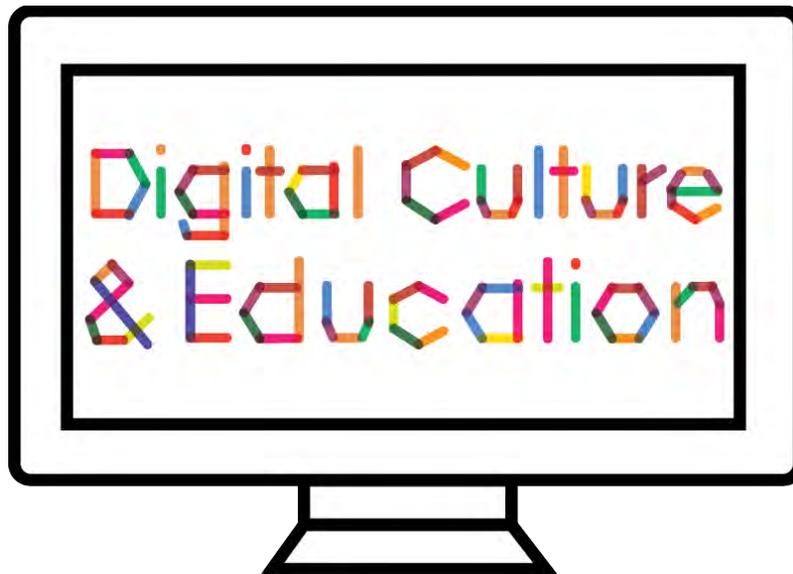
TRANSFORMING HIV PREVENTION & CARE FOR MARGINALISED POPULATIONS

USING INFORMATION AND COMMUNICATION TECHNOLOGIES IN COMMUNITY-BASED AND LED APPROACHES

EDITED BY CHRISTOPHER S WALSH

**TRANSFORMING
HIV PREVENTION & CARE
FOR MARGINALISED POPULATIONS**
Using information & communication technologies
(ICTs) in community-based & led approaches

Edited by Christopher S Walsh



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Preface

Introducing Transforming HIV prevention & care for marginalised populations: Using information & communication technologies (ICTs) in community-based & led approaches

The very notion of the ‘end of AIDS’ is an ideal that many people—communities, researchers, policymakers and programmers—have tirelessly strived for over many years. Turning this into a living reality is predicated on applying lessons creatively with ‘out of the box’ thinking and ensuring that communities at the forefront of the epidemic are a key part of the response. This is especially true with rapidly evolving online environments where populations most affected by HIV and AIDS now frequently connect and communicate, from reaching key populations who meet partners and clients online to ensuring that prevention and care messages and services meet the demands of today’s online reality.

We are only 20 years into the digital revolution, but now is the time to "upload" our HIV research, service delivery, and programming approaches to this virtual environment. This open-access and online book edited by Christopher S Walsh is highly welcomed and timely. Its contributors address in succinct and practical ways, the challenges and opportunities of using information communication technologies (ICTs) to improve HIV outcomes among especially marginalised communities. Any researcher, programmer or practitioner working towards an “AIDS-free generation” should read this agenda-setting book, for in equal measure this resource enlightens and educates. It also instigates and inspires.

Kevin Osborne

Project Director
LINKAGES FHI360

Forward

Powerful tools to reach and engage marginalized individuals in HIV prevention and care

Information and communication technologies (ICTs) offer powerful tools to reach and engage marginalised individuals in HIV prevention and care. This book provides a compilation of strategies for how best to reach and engage gay, bisexual and other men who have sex with men (MSM) and transgender persons around the world, people who have historically been excluded from many of these efforts.

It has been almost 20 years since I started work as a clinical psychologist with children and families affected by HIV and AIDS. It was a different time in the HIV epidemic. The early and mid-1990s had brought a number of strides in HIV prevention and treatment that were literally life-saving, for example the discovery of the ability of antiretrovirals (ARV) to prevent mother to child transmission (PMTCT; Connor, Sperling, Gelber et al., 1994) and the advent of triple ARV drug therapy to effectively treat individuals living with HIV (Hammer, Squires, Hughes, et al., 1997; Gulick, Mellors, Havlir et al., 1996). Individuals living with HIV now had access to treatments that worked, at least in the United States, and HIV began to shift from a lethal disease to a chronic illness. This new era, however, brought new challenges. While we knew how to treat HIV and prevent MTCT, we struggled with determining when individuals should start treatment, how to help them stay on therapy and we still had only a limited number of strategies to prevent new HIV infections. We had few tools at our disposal to address these challenges, but we used what we had. I handed out numerous pillboxes, saw families for therapy to address the challenges in their lives that hampered medication adherence, purchased and programmed countless watches with alarms, and printed charts that I handed out with stickers. I even had a colleague who called a family every day to make sure that they had given their son his medication. Not only were there limited tools at our disposal but also limited ways in which we could reach and work with families. Appointments took place at the clinic or hospital, requiring families to come to us during clinic hours outreach services were available but the demand far exceeded the supply forcing outreach workers to focus on families in crisis, not those struggling with maintaining adherence.

The last few years have brought yet another set of life-saving advances in both HIV treatment and prevention. We now have confirmation that HIV treatment should start immediately after diagnosis (The INSIGHT START Study Group, 2015) and we know about the power of ARVs to prevent the onward transmission of HIV among those living with HIV (Cohen, Chen, McCauley et al., 2011) and prevent acquisition among those who are HIV- but exposed (pre-exposure prophylaxis or PrEP; Grant et al., 2010). In addition to all of this new knowledge, we have more tools at our disposal to reach those not traditionally engaged in HIV prevention and care.

Mobile technologies are growing exponentially all over the world helping to overcome barriers due to weak infrastructure. In 2013 there were 778 million mobile subscriptions in Africa and that number is projected to reach 1 billion during 2015 (Informa Telecoms & Media, 2013). Technology breaks down boundaries that distance imposes and increases our ability to reach and connect with people. This growth in information and communication technologies over the past decade has produced a wealth of new tools for working with MSM and transgender persons.

This book, *Transforming HIV Prevention and Care for Marginalized Populations: Using Information and Communication Technologies in Community-Based and Led Approaches* brings together researchers, practitioners and activists to describe how to harness ICT to reach and engage MSM and transgender persons. The programs described in this book cover the globe with chapters focusing on HIV prevention and care programs in over 20 countries; some of them reaching into multiple countries to engage those in need. A wide range of technologies are described including internet outreach and chatrooms in Cameroon (Chapter 3), cyber educators in Central America (Chapter 14), YouTube (Chapter 10), social networking sites (Chapters 4, 5, and 9), instant messaging (Chapter 8), open distance flexible learning (Chapter 6) and online mobile platforms specifically designed for MSM and transgender persons (Chapter 12), just to name a few. Many of the authors—frontline workers themselves—discuss the ability of these tools to not only address knowledge and skills but also address social and structural barriers to HIV prevention and care.

We are at a point in the epidemic when goals to end AIDS and curtail new HIV infections are within reach. However, these goals will only be achieved by using the powerful digital tools that are available to us. This book includes information on how to engage and build capacity among communities to ensure that everyone has the information and services they need. ICTs can be used to close the gap between the science and service of HIV treatment and prevention. Ensuring MSM and transgender persons stay healthy, whether they are living with HIV or not, requires strong community-led initiatives as well as strong collaborations between practitioners, researchers, activists and MSM and transgender persons like the ones described in these pages. As more efforts continue to move forward, the focus should continue to be on active engagement, ensuring that efforts are collaborative, working with MSM and transgender persons to match the services to their needs. The time is now to close the gap for MSM and transgender persons and move us closer to an AIDS free world.

Susannah Allison, PhD

Scientific Program Officer

Infant, Child, & Adolescent Research Programs

National Institute of Mental Health (NIMH) Division of AIDS Research

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Introduction: Transforming community-based and community-led HIV prevention and care through ICTs

Christopher S Walsh
Darrin Adams
Kent Klindera
R. Cameron Wolf

Introduction

Information and communication technology (ICT) is transforming community-based and community-led HIV prevention and care services for gay men, other men who have sex with men (MSM) and transgender people. This book celebrates and shares crucial work of frontline HIV workers, activists, researchers and educators whom are using innovative ICT. The book builds on, and extends the work included in two earlier issues of *Digital Culture & Education (DCE)*, entitled '[Prevention is a solution: Building the Hive](#)' (Singh and Walsh, 2012) and '[Innovative programmatic approaches to HIV prevention and care services for gay men, other men who have sex with men \(MSM\) and transgender persons using information and communication technology \(ICT\)](#)' (Adams, Klindera, Walsh and Wolf, 2014). It also includes three additional articles published by the journal.

Over 60 prominent HIV activists, scientists, researchers, entrepreneurs and public health leaders have contributed as authors within *Using information and communication technologies (ICTs) to transform community based and led HIV prevention and care for marginalised populations*. This book was published under a [Creative Commons Attribution-NoDerivatives 4.0 International License](#) to complement academic and biomedical publishing through introducing a dynamic writing mentorship process with academics, researchers and activists to assist frontline and community-based organisations publish their innovations, results and 'lessons learned'. The editor drew on a cadre of experienced professionals who provided pro-bono writing mentorships for those individuals with less experiencing writing up their successful programmatic approaches into journal articles. Multiple rounds of editing and peer reviewing were conducted, as well as access to critical resources often unavailable to individuals working in community-based and led organisations. Recognising the diversity of authors across professional, academic, and English language proficiencies, this Special Issue highlights community-led efforts through this unique publishing opportunity. An important goal of this book is to publish successful interventions through an open-access channel in their entirety, not just the abstracts. This book showcases a rich and representative sample of innovative programming, findings and recommendations from different global contexts.

The concepts and programs described in this book acknowledge that

evidence-informed combination HIV prevention strategies (e.g., the simultaneous use of complementary behavioural, biomedical and structural strategies) can effectively address the contextual and diverse needs of gay, other MSM and transgender populations (UNAIDS, 2010). The recent global commitment from UNAIDS, PEPFAR 3.0 and The Global Fund to achieve the following 90-90-90 goals now aim to:

- ensure at least 90% of those who are HIV-positive know their status;
- promptly enrol at least 90% of those diagnosed HIV-positive in antiretroviral therapy; and
- ensure at least 90% of those enrolled in treatment are retained, so that they are virally suppressed.

As a result, it is now understood that the days of HIV prevention programs standing alone are over. In order to ‘turn the tide on HIV’, we must ensure a linked continuum of prevention, care and treatment services, also known as “the cascade”. ICTs therefore, have only just begun to be applied and the future will bring countless new possibilities to expand access across the prevention, care and treatment cascade.

Part 1 of this book began in 2010 when Christopher S Walsh and Gurmit Singh first organised the seminar entitled, ‘Hear Us’ at the *Global Forum on MSM and HIV’s (MSMGF) Preconference at the 2010 XVIII AIDS Conference* in Vienna. The forum shared innovative digital HIV prevention, education and care interventions from and with frontline workers, activists, researchers and educators working with, and in, communities of gay men, other MSM and transgender persons. Drawing on the robust conversation at the seminar, Walsh and Singh invited presenters to share their community-based and led interventions and practices using the Internet and other digital media for HIV prevention, care and support. Within this framework and process, Walsh and Singh facilitated two years of rigorous online and face-to-face mentoring, multiple rounds of editing and peer reviewing and providing access to critical resources not often available to individuals working in community-based and led organisations. Then in 2012, *DCE* published the Special Edition with an introduction by Judith D Auerbach, eight global case studies, a public ‘health perspective’ piece by Professor Jonathan Elford and ‘funder’s perspective’ by Kent Klindera.

A year later, Part 2 of this book emerged from a successful technical consultation entitled ‘Innovative Use of Communication Technology for HIV Programming for MSM and TG Populations’ held in Washington DC in May 2013. Hosted by the U.S. Agency for International Development (USAID) through the President's Emergency Plan for AIDS Relief (PEPFAR) and co-sponsored by amfAR, The Foundation for AIDS Research and the National Institute of Mental Health (NIMH). Forty-four participants shared and debated how the internet, social media, and other forms of ICT are improving—or have the potential to improve—the impact of HIV programs for gay men, other MSM and transgender people. Meeting participants

included representatives from Africa, Latin America, the Caribbean, Asia, Europe, Australia and the US. The goal of the meeting was to provide a forum for key stakeholders in HIV research, programming, implementation and evaluation to take stock of important developments in the field and develop key recommendations to enhance the use of ICT in the delivery of HIV prevention and care for gay men, other MSM and transgender persons (Allison et al., 2014). Following the consultation in Washington D.C., all participants were invited to submit manuscripts for a second Special Issue of *DCE*. The call for manuscripts was broadened to include other community-based organisations and partnerships leveraging ICT productively in the fight against new HIV infections. The consultation and the articles presented in Part 2 recognise the strong synergy between biomedical and social science approaches to HIV for gay men, other MSM and transgender people that work by:

- understanding emerging trends in ICT use;
- identifying innovative programmatic approaches and lessons learned for using technology for outreach;
- informing strategies for future programming and research; and
- working to engage the private sector and public health partners in the use of ICT to better reach for HIV prevention and care messages and linkage/referrals to social and health services.

As a result of the technical consultation, nine important recommendations¹ emerged from discussions among diverse frontline workers, activists, researchers and educators (Alexanderson, Chintalova-Dallas and Cornman, 2013):

1. Develop targeted content that specifically addresses transgender people's needs
2. Foster intersectoral collaboration
3. Understand the strengths and limitations of virtual and physical spaces and identify opportunities to incorporate both into HIV programs
4. Present the human face of HIV
5. Think of health providers as users too
6. Improve monitoring and evaluation for ICT programs
7. Know the audience
8. Respect and protect
9. The time to prioritise ICT is now

The articles presented in Part 2 take up, exemplify, illustrate and provide timely

¹ For more information see: [*Innovative Uses of Communication Technology for HIV Programming for MSM & TG Populations: May 2-3, 2013, Washington, DC. Meeting Report*](#)

guidance on current innovations and lessons learned across diverse cultural contexts. They focus on the above recommendations in order to stem the tide of new HIV infections among gay men, other MSM and transgender people.

Leveraging ICTs to transform current HIV research, prevention, treatment, care, support services and programing

Transgender persons and men who have sex with men (MSM), including gay-identifying men, face an alarmingly high burden of HIV globally. This is confirmed by high HIV prevalence and where available, incidence rates (Beyrer et al., 2012; Sullivan et al., 2009; Baral et al., 2013). In available global HIV incidence rates among MSM, HIV infection is significantly higher for MSM than in the general population over a one-year period. For example, in Kenya, Malawi, and Thailand, HIV incidence over a one-year period among MSM is reported to be 5.8 percent, 7.1 percent, and 5.9 percent, respectively (Baral IAS 2013; Sanders et al., 2012; Van Griensven et al., 2013). HIV prevalence among MSM in high-income settings surprisingly mirrors their low- and middle-income country counterparts. Overall new infections are on the rise in the United States, particularly among young black MSM (Sullivan et al., 2009; CDC 2012; Maulsby et al., 2013; Sullivan et al., 2014). The UK, Western Europe, and Australia have also experienced recent increased HIV incidence increases among MSM (Phillips et al., 2013; Sullivan et al., 2009; Murray et al., 2011).

Insufficient data on HIV prevalence or incidence exists for transgender persons worldwide. A recent global systematic review (Baral et al., 2013) reports transgender women are nearly 50 times more likely to be living with HIV, than adults in the general population and their pooled HIV prevalence was reported at 19.1 % for the countries where data was available. These data indicate a high burden of HIV in transgender women globally.

Currently, HIV prevention, treatment, and care programs still remain largely unreachable and often unavailable for many gay men, other MSM and transgender persons (Wheeler et al., 2015). Online sampling of over 3700 MSM in 140 countries reports only 35% had access to HIV testing, 43% to treatment, 35% to condoms and less than 25% to condom-compatible lubricants (Ayala et al., 2013). A global review reports that MSM are recipients of a small proportion of total HIV prevention interventions (Sullivan et al., 2012). Little is known on the use of and accessibility to HIV services among transgender persons globally, as scarce data exists evaluating evidence-based HIV interventions among this population (De Santis et al., 2010; Garofalo et al., 2012).

HIV research, services and programs for gay men, other MSM and transgender persons are often lumped together under the umbrella term 'MSM', yet these populations' sexual behaviours, practices and HIV risk behaviours differ considerably. Gender identity, gender expression, sexual behavior and sexual orientation are factors that need to be considered separately (Wolf et al, 2013). These categories and their local understanding shift—in scope and perspective—at the global, regional, country, and even municipal levels. The ubiquity of ICTs and new and emerging applications—

including geo-social apps (Grindr, Jack'd, Hornet, MISTER, etc.)—provide unprecedented opportunities to complement, even transform, current HIV research, prevention, treatment, care and support services and programming to fill the data and service provisions' gaps for these key populations. Gay men, other MSM and transgender persons use apps on smartphones and websites to find romantic and sexual partners (Allman et al., 2012; Beck et al., 2012; Chaiyakit and Walsh, 2012; Dasgupta, 2012; Henry et al., 2012; Scheibe, Brown and Bekker, 2012; Singh and Walsh, 2012; Shenck and Singh, 2012; Allison et al, 2014). The articles in this book take a step forward in further addressing these issues and reporting on successful and innovative programmatic approaches.

Guest Editors and authors who contributed to Part 2 attended the *2014 International AIDS Conference* in Melbourne Australia and shared their work at the 2014 MSM Global Forum Pre-Conference: 'Setting the Pace: Gay Men, MSM, and Transgender People in the Global AIDS Response'. All of the articles from this book have also been added to [The Hive](#), an open-access networked ecology of HIV activists, practitioners, researchers and scholars.

This book further develops, explores and substantiates the creative and effective merging of HIV and 'e' around socio-sexual practices, networks and service delivery systems, which can shape and influence the future of interdisciplinary and interconnected public health, human rights and education programs and policies (Singh and Walsh, 2012).

Diverse voices, unprecedented innovation

With 20 contributions from diverse settings working across HIV research, prevention, treatment, care and support the book is organised into two parts. The first part, 'Building the HIVE' presents articles from the 2012 Special edition as a whole. Part 2, 'Networking to build the HIVE' has four sections. Section one presents formal research from Asia and the US with HIV positive MSM which has implications for scale up of HIV services for MSM and transgender persons. The next section highlights the successful work of international NGOs working in collaboration with community-based organisational partners in Central America, Ghana and China. The third section showcases three community-led interventions in Sweden, Tanzania and Ecuador. Section four provides a new perspective on the potential application of public-private partnerships in the use of ICTs, particularly geo-social apps, in reaching gay men and other MSM with important HIV health related information in the US.

Part 1: Building the HIVE

The chapter by Jack Beck, Lily Catanes, Pato Hebert and George Ayala, "[Local languages, global exchange: Digital networking, communication and collaboration for the health and human rights of men who have sex with men](#)", reports on a global effort by a key civil society non-state actor to build the digital platform, www.MSMGF.org. This unique user network

strengthens the capacities of front-line civil society organisations around the world. Using data from user feedback, they argue for the need to move beyond expanding access to resources to enabling grassroots actors to deploy these digital resources effectively in their work to impact on the health outcomes of minority MSM populations.

Emilie Henry, Yves Yomb, Lionel Fugon and Bruno Spire critically take up the issue of risk and sexual practices in Cameroon, Africa in "[The use of the Internet in male sexual encounters by men who have sex with men in Cameroon](#)". Their study draws on data from a survey on MSM sexual practices and from a pilot online HIV outreach and prevention programme run by a community-based organisation in a very harsh legal environment where MSM face extreme violence. Their work points to the urgent need to confront the wider contextual factors that affect HIV risk and the potential of digital approaches to be expanded for this goal, particularly in contexts where MSM face disempowering legal and socio-cultural contexts that pathologise their right to be who they are.

Working within a larger global biomedical HIV prevention trial, the study by Andrew Scheibe, Ben Brown and Linda-Gail Bekker from the *Desmond Tutu HIV Foundation* in South Africa explores their use of information and communication technologies (ICTs) to mobilise participation from the MSM community. In "[ICT & HIV prevention: Experiences from a biomedical HIV prevention trial among men who have sex with men \(MSM\) in Cape Town, South Africa](#)" they argue that the rise of digitally mediated sexual practices of MSM in Africa needs to be better understood and used to address the structural barriers to HIV prevention.

Rohit Dasgupta employs a postcolonial queer lens to describe his experience working with an HIV prevention charity, *Solidarity and Action Against the HIV Infection in India (SAATHI)* in "[Digital media and the Internet for HIV prevention, capacity building and advocacy among gay, other men who have sex with men \(MSM\), and transgender \(TG\): Perspectives from Kolkata, India](#)". He describes SAATHI's use of ICTs for HIV advocacy and capacity building across the country, with a focus on Kolkata. Dasgupta points out how what could on the surface be perceived as an ordinary capacity building initiative supplemented by a web presence, can be re-theorised through the lived experience of not only the colonising structures of MSM and transgender people, but through '*kothi*' and '*hijra*'. His work provides important implications for the practical use and design of digital technologies for HIV prevention and education in ways that valorise the subjectivity of the multiplicities of gay men, other MSM and transgender people that are present in the global South.

Val Sowell, Juliet Fink and Jane Shull from *Philadelphia FIGHT* present evidence and insights on designing a successful open distance flexible learning (ODFL) programme called Frontline TEACH. Their chapter, "[Innovative digital HIV and AIDS education and prevention for marginalised communities: Philadelphia's Frontline TEACH](#)" highlights how traditional AIDS Service Organisations can use open access digital technologies to design digital HIV education that serves the needs of marginalised communities from lower socioeconomic backgrounds. Frontline TEACH has

significant implications for the theory and practice of using open-access community-based digital HIV education and prevention programmes because it not only widens access, but also improves health and literacy outcomes.

Dan Allman, Ted Myers, Kunyong Xu and Sarah Jane Steele interpret gay men and other MSM's social media usage in Canada drawing on socio-technographics and Web 2.0 theoretical frameworks in their chapter, "[The social technographics of gay men and other men who have sex with men \(MSM\) in Canada: Implications for HIV research, outreach and prevention.](#)" Their work foregrounds the issue of age and other demographics in structuring the digital behaviours of gay men. Their analysis clearly shows that something more than spreading safe sex messages online and on mobile phones needs to be done to work creatively with gay men's socio-technographics. This chapter poses the question, "what kinds of specific digital individual and community support systems would gay men and MSM value that could increase their capacity for agency to make changes to their sexual practices?"

Nada Chaiyakit and Christopher S. Walsh present their work on designing, implementing and analysing two Sexperts! Programs with community-based groups in Thailand. Their chapter, "[Sexperts! Disrupting injustice with digital community-led HIV prevention and legal rights education in Thailand](#)" documents how social networking and instant messaging were used to provide HIV prevention and education to communities of gay men, other MSM and transgender people. These unique digital interventions explicitly focus on sexual pleasure and health, legal rights, and where to go to access justice when individual rights are violated. Through contextualised online and mobile platforms, both programmes refreshingly highlight digital interventions that aim to reduce stigma and discrimination around gender identity, sexuality, sex work and gender reassignment.

The article "[YouTube viral videos and HIV prevention among African-Americans: Implications for HIV prevention](#)" by Jocelyn Patterson and Khiya Marshall focuses on the potential use of viral videos for HIV/AIDS prevention activism and education. Patterson and Marshall present a content analysis of YouTube member responses to viral videos featuring African Americans that had a theme of HIV/AIDS prevention. This detailed analysis of user comments suggests that the motivation to share and view such videos includes a spectrum of emotional responses, ranging from anger and frustration, to heartfelt encouragement and support.

"[Variations in recruitment yield, costs, speed and participant diversity across Internet platforms in a global study examining the efficacy of an HIV/AIDS and HIV testing animated and live-action video among English- or Spanish-speaking Internet or social media users](#)" by Winnie Shao, Wentao Guan, Melissa A. Clark, Tao Liu, Claudia C. Santelices, Dharma E. Cortés and Roland C. Merchant presents a world-wide, Internet-based study on HIV/AIDS and HIV testing knowledge that compared the yields, speed and costs of recruitment and participant diversity across free postings on 13 Internet or social media platforms, paid advertising or postings on 3 platforms, and separate free postings and paid advertisements on

Facebook. Platforms were compared by study completions (yield), time to completion, The study results highlight the need for researchers to strongly consider choice of Internet or social media platforms when conducting Internet-based research.

Benjamin Eveslage's chapter, "When in Ghana, do as sexual minorities do: using Facebook to connect gay men and other men who have sex with men to HIV services", chapter highlights how social stigma and discrimination, compounded by the criminalization of homosexuality, influence gay men and other MSM to avoid in-person peer-networks and settings where HIV prevention and care services are available. He argues that Facebook is uniquely well suited for connecting these at-risk populations to sexual health interventions and services. Drawing on findings from an ethnographic study, Eveslage outlines how CBOs and NGOs delivering sexual health services could possibly improve HIV prevention and care outreach within these subpopulations of gay men and MSM by mimicking how they use social media. He also outlines a number of logistical considerations and specific methods sexual health CBOs and NGOs could implement using social media for HIV prevention and care, arguing they have the potential to improve outreach to underserved subpopulations of gay men and other MSM in contexts where discrimination, fear and stigma prevent them from accessing these vital resources.

Part 2: Networking to Build the HIVe

Section 1: Scaling up HIV services for MSM and transgender communities

In their chapter "[Achieving HIV risk reduction through HealthMpowerment.org \(HMP\) a user-driven eHealth intervention for young Black men who have sex with men and transgender women who have sex with men](#)", Kathryn E. Muessig, Nina B. Baltierra, Emily C. Pike, Sara LeGrand and Lisa B. Hightow-Weidman succinctly illustrate how young, Black men who have sex with men and transgender women who have sex with men (YBMSM/TW) who are disproportionately at risk for HIV and other sexually transmitted infections (HIV/STI) can be reached through an online mobile platform. HMP's platform is an innovative mobile phone optimised online intervention that utilises behaviour change and gaming theories to reduce risky sexual behaviours and build community among HIV-positive and negative young black men who have sex with men and transgender women who have sex with men.

Benjamin Hanckel, Laurindo Garcia, Glenn-Milo Santos and Eric Julian Manalastas present work that confronts the sexual stigma, HIV-related stigma and isolation HIV-positive gay men and other men who have sex with men (MSM) experience when accessing information related to HIV. Their study, "[Assessing needs and capabilities: Towards an ICT resource to support HIV-positive gay men and other MSM in Southeast Asia](#)" presents the human face of HIV by exploring the technology use of HIV-positive MSM. Their research was part of a formative assessment undertaken at the initial stage of the development an information and communications technology (ICT) resource and peer-support web-app for HIV-positive MSM

in Southeast Asia. Hanckel, et al.'s work tentatively illustrate how the capability deprivations experienced by HIV-positive men can be overcome by mobilising Amartya Sen's capability approach to developing an ICT resource that addresses the deprivations and information deficiencies of HIV-positive MSM by enhancing peer support and increasing access to HIV-related information and resources.

Section 2: Working in collaboration with community-based partners

In their chapter, "[Hidden on the social media": HIV Education on MSM through Cyber-educators in Central America](#)", Jorge Rivas, Jennifer Wheeler, Marcos Rodas and Susan Lungo present how they worked with The Pan-American Social Marketing Organization (PASMO) to develop a combination prevention intervention in Central America that delivers HIV prevention behavior change communication (BCC) messages, products, services, and referrals to promote improved condom and condom-compatible lubricant use, HIV testing, violence reporting and the use of complementary services. This innovative online "cyber-educator" intervention for MSM provides virtual one-on-one BCC and HIV counseling and testing referrals launched.

Kimberley Green, Phillip Girault, Samuel Wambugu, Nana Fosua Clement and Bashiru Adams describe the '[Strengthening HIV/AIDS Response Partnerships with Evidence-Based Results \(SHARPER\)](#)' intervention which reached 92% of the estimated number of MSM in Ghana with HIV prevention interventions. Achieving this significant reach at scale was the result of changing their earlier approach using face-to-face traditional outreach activities which only reached and estimated half of MSM in Ghana. By being innovative, resourceful and collaborative with MSM affiliated with CBOs, they began using social media to reach an additional 15,440 unique MSM in addition to the 12,804 MSM they reached through traditional outreach activities involving peer educators.

In China gay men and other MSM who use ICT to meet up are less likely to visit 'traditional' venues where they can receive interpersonal HIV prevention interventions. In their chapter, '[Two internet-based approaches to promoting HIV counselling and testing for MSM in China](#)', Matt Avery, Gang Meng & Stephen Mills present how FHI 360 and Guangzhou Tongzhi (GZTZ) piloted separate, but complementary, approaches to using ICT to promote uptake of HIV counselling and testing (HCT) among gay men and other MSM in three Chinese provinces: Yunnan, Guangxi and Guangzhou. Both interventions included dedicated websites featuring online risk assessment and appointment making, crowd-sourced service promotion messages and dissemination via participants' microblog accounts and social media profiles.

Section 3: Community-led interventions

Nicklas Dennermalm introduces how the Swedish Federation for Lesbian, Gay, Bisexual, Transgender and Queer Rights (RFSL Stockholm) designed the [Röda Paraplyet](#) webpage in collaboration with male sex workers and Rose Alliance, a leading sex worker organisation in Sweden. His chapter,

[‘Resistance to the Swedish model through LGBTQ and sex work community collaboration and online intervention’](#) stresses the need for targeted community-based sexual health services in Sweden because sex workers are often viewed as ‘victims in denial’ by public health authorities. Dennermalm critiques the ways Swedish sexual health interventions traditionally focus on women and utilise face-to-face interventions and exit strategies over interventions targeting male and/or transgender sex workers that utilise harm reduction approaches or low threshold on-line interventions. His work with *Röda Paraplyet* illustrates how a broad coalition between organised and non-organised sex workers, LGBTQ organisations, academics and the health care system can create a sustainable platform of multi-disciplinary knowledge to improve the sexual health and legal rights of sex workers in Sweden and globally.

Collins M. Kahema, John Kashiha, David Kuria Mbote and Michael R. Mhando’s chapter describes how Tanzania Sisi Kwa Sisi Foundation (TSSF) used online HIV peer education and outreach methods, particularly with Facebook, to increase HIV prevention knowledge and encourage the use of health services, condoms and lubrication among MSM in Tanzania. Their chapter, [“Bambucha Media: Using social media to build social capital and health seeking behaviour among key populations”](#) describes how TSSF launched educational campaigns using various social media that pre-existing members reported using for social and sexual networking, or “hooking up”. As a community-based organisation with limited resources, TSSF’s Bambucha Media (in Swahili ‘bambucha’ means cool) is innovative in the way it has designed a non-traditional avenue to provide HIV and AIDS information and referral. In a country where sexuality remains a major taboo subject, providing health messaging and forum discussions to educate about HIV, alert users when safe sex supplies are in stock or not, facilitate online discussions and sharing and provide direct peer counselling via private messages when needed and requested not only allows them to open up communication lines with gay men, other MSM, transgender persons and sex workers in the first place, but also enables TSSF to provide needed follow-up on specific and targeted HIV services.

Diane Marie Zambrano Rodríguez’s chapter, [‘Silueta X: Lobbying to establish a specialised LGBTI counseling and medical center in Ecuador’](#) presents Asociación Silueta X which is working to create accessible living conditions for lesbian, gay, bisexual, transgender and intersex (LGBTI) individuals with an emphasis on the transgender and intersex population in Ecuador. Silueta X engages social media via social networking sites and apps—especially Facebook—to provide its LGBTI members with updates about its organisational and advocacy activities. Silueta X leverages the powerful role of social media and has created specific sites and accounts for different activities.

Section 4: Forging public-private partnerships

Carl Sandler, a gay social networking entrepreneur and the developer of the geo-social networking app for gay men, [MISTER](#), discusses the enormous reach and untapped potential of private sector geo-social networking. He

makes the case for better coordination and flexible funding between the public health sector and the private sector for nimble, timely responses to public health crises while building a sense of community among users of the MISTER app. He argues the public health sector can work effectively with app developers because apps can reach thousands of users a day.

Thinking differently about the future of HIV prevention and care with ICTs

We anticipate *Using information and communication technologies (ICTs) to transform community based and led HIV prevention and care for marginalised populations* will motivate and inspire diverse community-based actors, researchers, educators, scientists and frontline workers to continue to be creative and innovative in their endeavors to further the use of ICTs for HIV services. Individually—and collectively—the chapters illustrate the potential impact of using information and communication technologies (ICTs) for HIV prevention and care services for gay men, other MSM and transgender persons at a time when these same populations are experiencing an alarming upward trend of new HIV infections.

With the urgent HIV public health crisis growing amongst gay men, other MSM and transgender people, these innovative programmatic approaches offer models to be further tested and shared for ‘scale-up’. We hope funders can work collaboratively and creatively to fill the anticipated resource gap for HIV funding for 2015 (UNAIDS, 2013), so that populations disproportionately at risk of HIV can continue to benefit from programmatic approaches similar to those presented in this book. We also acknowledge, congratulate and celebrate the innovative work and dedication of frontline workers in community-based organisations, who, despite forecasted shortfalls in funding, continue to be innovative programmatically through ICT. We believe the profound changes brought about by ICTs on sexual practices can increase the effectiveness of social and biomedical HIV and AIDS research, prevention and care. Let us not forget, ‘the time is now’ to continue improving access to health and human rights for marginalised gay men, other MSM and transgender populations.

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Part 1

Chapter 1

The HIVE: Harnessing digital technologies to challenge the dominant HIV and AIDS paradigm

Judith Auerbach

In this chapter, Judith Auerbach highlights how the chapters in this book are co-authored by researchers, activists, and practitioners who understand the central role of communities. The importance of this is in understanding that communities are not tokens in, consultants to, or passive recipients of interventions imposed from the outside. Rather they are social entities and structures that make or break the AIDS response, including the outcomes of clinical trials and the scale-up of promising strategies. This chapter, and book, she argues, makes it clear that it is only by engaging and building critical capacity among communities—including those emerging in and from our ubiquitous digital universe—that we will see the true effectiveness of HIV and AIDS prevention and treatment globally in the decades to come.

Introduction

In the fourth decade of the global AIDS epidemic, the digital universe has solidified itself as a new setting for HIV and AIDS risk, prevention, and community response. This is particularly true among gay and other men who have sex with men and transgenders (G/MSM/TG). As the papers in this special issue detail, networked and digital technologies are used in multiple ways in the global fight against HIV and AIDS. These include education, the design and conduct of research and prevention programmes, and fomenting community mobilisation.

Networked and digital technologies have been vital to expanding access to information about HIV and AIDS and its attendant health and social issues to anyone with access to and basic competency in using a computer or smart phone. One can easily find an array of brochures, educational videos, fact sheets, blogs, news feeds, and other resources that provide updates on research and policy developments, and that air controversies in the field—including those that relate to the interpretation of research findings and the conduct of research itself. The information sharing made possible by the Internet also has produced opportunities for creating new online networks to build communities not bound by geographical proximity. This has been essential to building advocacy and strengthening civil society responses among G/MSM/TG people and their allies around the world, as evidenced in the work of the Global Forum on MSM and HIV (MSMGF). Producing new knowledge and buffeting civil society organisations among those most vulnerable to HIV are essential ingredients in combating the pandemic for the long term.

At the same time, the Internet and other social networking and digital technologies have changed interpersonal interactions, including enhancing the ease of opportunities for seeking and selecting partners for sexual encounters. This has particular relevance to HIV transmission and prevention in G/MSM/TG communities. The vast array of websites and smart phone applications for finding sex partners selected for specific sets of characteristics—body type, HIV-serostatus, age, race/ethnicity/cultural group, gender preferences, geographic proximity, etc.—afford users a level of frequency, agency, and control not previously available. The relative privacy of online interactions also allows for those who do not wish to publicly acknowledge their sexual preferences (for personal, legal, or safety issues) to meet others with desirable characteristics without “outing” themselves to the broader world. This then enables individuals to control—to a great extent—the performance of their gender and sexual identities.

By promoting and facilitating sexual encounters that are often fleeting, based on desire, focused on pleasure, and conducive to individual agency, networking sites run counter to traditional HIV risk reduction approaches. These emphasise the sublimation of individuals’ desire, pleasure and agency in service to the greater public health goal of disease prevention. In this way, the growing information-sharing, network-creating, community-building, and sexual encounter-facilitating usages of social media and other digital technologies complicate and challenge mainstream, hegemonic public health and biomedical science-based approaches to HIV prevention.

The HIVE is conceptualised to embrace this challenge for the long-term. Its mandate is to enhance understanding of the impact of current—and future—networked and digital technologies on HIV transmission. This includes the meanings people imbue to it. The HIVE aims to harness the potential of such technologies for new dynamic models of HIV prevention and care that are relevant to and sustained by G/MSM/TG communities. The HIVE explores how networking and digital technologies have, and can be used, to build AIDS-resilient communities (Campbell and Cornish 2010) and effective AIDS response coalitions (Grebe 2009) among G/MSM/TG groups. In so doing, the HIVE is poised to flip the traditional, pathology-based frame that has dominated HIV prevention discourse for decades to an assets-based frame.

This contribution is particularly important in the context of two paradigms currently dominating the mainstream AIDS response: “treatment as prevention” and “combination prevention.”

Advances in new HIV prevention techniques using anti-retroviral drugs have shown that treating HIV-infected individuals earlier in their disease can suppress the virus sufficiently to reduce transmission to partners by as much as 96 percent (Cohen, Chen, McCauley et al., 2011). This has spawned an almost dogmatic belief among leaders in the global HIV and AIDS response that treatment *is* prevention. In this view, the core to stemming the epidemic is to identify everyone with HIV infection through more routinised testing and to get them on drugs as early as possible. This is the so-called “test and treat” or “seek, test, and treat” approach. Much less is said about what to do with people found to be HIV-negative or people

who decline treatment. The belief is that, not only will widespread use of anti-retroviral medication improve the health and well-being of HIV-positive individuals, it also will reduce the amount of virus circulating in a community, known as ‘community viral load’. This thereby reduces the likelihood of new HIV transmissions across a whole population (Das et al., 2010; Johnston et al., 2010).

While some in the HIV and AIDS field are zealous about this singular approach, others advocate a broader, comprehensive strategy that includes biomedical, behavioural and social/structural interventions, community mobilisation, and social change, under the rubric of “combination prevention” (Hankins and de Zalduondo 2010; Coates, et al., 2008; Padian, et al., 2011). In this view, it is necessary to not only develop effective tools, including but not limited to antiretroviral drugs for prevention, but also to assure access to them and to create an enabling environment in which they can be used with maximum effect by both HIV-positive and HIV-negative persons as appropriate (see Auerbach, et al., 2011).

But, how best to design, implement, and evaluate “test and treat” and “combination prevention” approaches remains a practical and methodological challenge. The core issue is how to move from the efficacy of different strategies demonstrated in the rarified context of clinical trials to effectiveness at the population level in “real-world” contexts. This move requires more than reliance on the somewhat ill-defined fields of “implementation science” and “operations research” which focus on health systems, supply chains and other infrastructure necessary for scaling-up proven interventions. And it requires more than adding “one from column A and one from column B” of efficacious interventions to create an effective, packaged response that can be tested in clinical trials. Rather, it requires understanding and addressing the ways in which people—as individuals and members of communities—comprehend and interact with HIV prevention and treatment tools and incorporate them into their everyday lives (or not) in a reflexive way. This is the purview of historically marginalised critical social science (see, for example Mykhalovskiy and Rosengarten 2009) and collaborative community research of the sort being operationalised by The HIVE.

The HIVE, through its global examples, incorporates an important critique of hegemonic public health science and its valorisation of controlled clinical trials as the gold standard of real “evidence” of what works. It applies a broad range of “ways of knowing” derived from social and political science and the lived experience of communities. These ways acknowledge the contextual, relational and reflexive nature of individuals’ participation in HIV transmission and prevention, including through their use of networking and digital technologies. The papers in this volume are co-authored by researchers, activists, and practitioners who understand the central role of communities. Communities are not tokens in, consultants to, or passive recipients of interventions imposed from the outside. Rather they are social entities and structures that make or break the AIDS response, including the outcomes of clinical trials and the scale-up of promising strategies. This Special Issue makes it clear that it is only by engaging and building critical

capacity among communities—including those created in the digital universe—that we will see the true effectiveness of HIV and AIDS prevention and treatment globally in the decades to come.

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Chapter 2

Local languages, global exchange: Digital networking, communication and collaboration for the health and human rights of men who have sex with men

Jack Beck
Lily May Catanes
Pato Hebert
Goldie Negelev
George Ayala

This chapter reports on a global effort by a key civil society non-state actor to build the digital platform, www.MSMGF.org. This unique user network strengthens the capacities of front-line civil society organisations around the world. Using data from user feedback, they argue for the need to move beyond expanding access to resources to enabling grassroots actors to deploy these digital resources effectively in their work to impact on the health outcomes of minority MSM populations

The HIV epidemic among MSM and the role of civil society

Since the beginning of the HIV epidemic, gay men and other men who have sex with men (MSM) have been among the most affected populations worldwide. A recent collection of data on HIV epidemics among MSM around the world reveals a striking global trend:

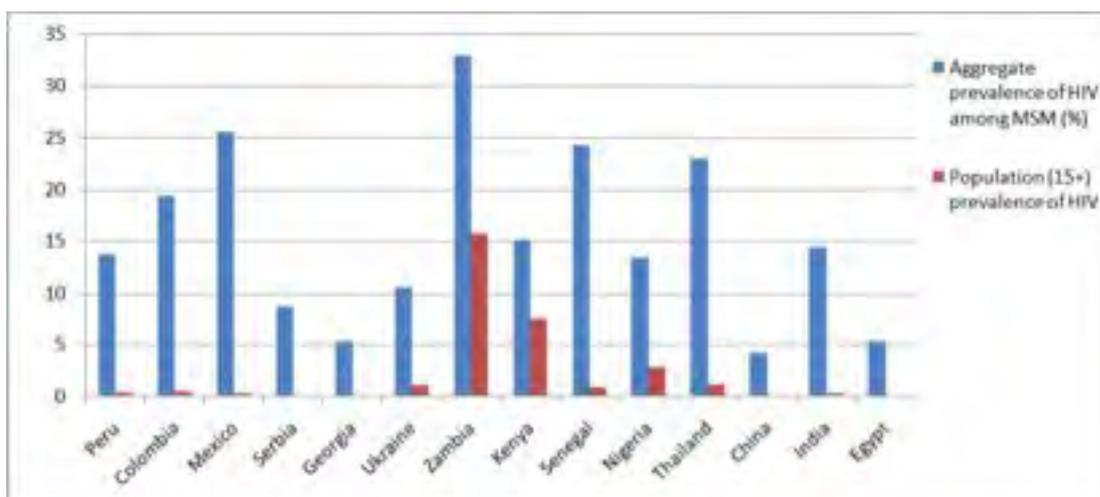


Figure 1: HIV Prevalence rates for MSM and general population, selected countries (World Bank, 2011).

Despite the clear need for resources to address HIV among MSM,

investment is severely lacking. A 2008 analysis of self-reported financing data from UN member nations showed that only 1.2% of all HIV prevention funding was targeted toward MSM (Saavedra, 2008). The dearth of financial support is compounded by a widespread lack of political will to address the epidemic among MSM. According to a report released by the International HIV/AIDS Alliance in mid-2011, only one fourth of the 132 government-generated country reports reviewed by the Alliance contained recent data related to HIV among MSM (International HIV/AIDS Alliance, 2011).

Beyond ignoring MSM, many governments actively persecute them. Nearly 80 countries around the world have laws that criminalise same-sex sexual acts between consenting adults (Bruce-Jones & Itaborahy, 2011). Laws against homosexuality drive MSM underground, making it difficult for service providers to reach them with HIV prevention, treatment and care (Ayala, 2010). Even in countries where homosexuality is not explicitly criminalised, pervasive discrimination, stigma and violence continue to have a devastating impact on the ability of MSM to access life-saving services (Arreola, 2010).

All of these factors have helped to complicate the landscape of HIV prevention, treatment and care for MSM around the world today. It is estimated that HIV prevention services reach only 9% of MSM globally (Global HIV Prevention Working Group, 2007).

In the vacuum created by government indifference and hostility, community members have stepped forward and taken matters into their own hands. In many countries, the local response to HIV among MSM is driven by non-government organisations (NGOs) and community-based organisations (CBOs). Often staffed by MSM themselves, these organisations are leading efforts to make a difference within their own communities (Cáceres, 2002; Radix, 2006; USAID, 2008; Xinhua, 2010).

NGOs and CBOs are often well-positioned to provide a number of health system functions, including service provision, capacity building, information exchange, representation of community interests in policy, and enforcement of transparency and public accountability (World Health Organization, 2001; amfAR, 2010). Health services provided by MSM-led NGOs and CBOs can be especially valuable in environments with high levels of homophobia, as many MSM will refuse to seek HIV testing and medical care in clinical settings due to past experiences of stigma and discrimination from healthcare providers (Peryshkina, 2010; Arreola, 2010).

Despite their strengths, NGOs and CBOs providing HIV-related services to MSM in low- and middle-income countries face a critical lack of published research and financial support to develop and implement interventions for MSM. A 2008 review of the literature on behavioural interventions for MSM showed that all but two of the 58 interventions included were conducted in the United States, United Kingdom, Australia, New Zealand and Canada (Beyrer, 2010). In a recent overview of effective community-led responses to HIV among MSM in the global south, amfAR noted that a lack of adequate resources was a common experience across all organisations featured in the report (amfAR, 2010). Finally, organisers of key national, regional and global meetings often fail to engage civil society

appropriately, effectively sidelining these organisations from decision-making processes that determine research agendas, funding levels, programme coverage and the details of policy.

An innovative response: MSMGF.org

To support the work of NGOs and CBOs addressing HIV among MSM, the Global Forum on MSM & HIV (MSMGF) created MSMGF.org: a multilingual online platform designed to overcome the unique obstacles that undermine the community response to HIV among MSM.

MSMGF.org does this by:

- Providing a suite of innovative web-based tools for information exchange and networking
- Offering full open access in seven major world languages
- Seeking regular feedback from grassroots advocates and organisations around the world

By using a digital platform for information exchange and networking, the MSMGF has been able to reach the advocates and organisations leading the response to HIV among MSM in communities around the world with the information and resources they need.

MSMGF.org supports NGOs and CBOs in their efforts to:

- Advocate for increased funding to address HIV among MSM
- Advocate for more and better research on HIV among MSM
- Advocate for a government response to HIV among MSM
- Advocate for decriminalisation of homosexuality
- Access information to develop and implement effective interventions for MSM
- Access key high-level processes that impact the health and human rights of MSM
- Access partners and funders for MSM initiatives

Background

The MSMGF is an expanding network of MSM advocates and organisations working to ensure appropriate coverage of and equitable access to effective HIV prevention, care, treatment, and support services tailored to the needs of gay men and other MSM. The MSMGF is led by a 20-member Steering Committee representing 19 countries across all major world regions and supported by a small Secretariat based in the United States.

When the MSMGF began work on MSMGF.org in 2007, there was no comprehensive global source of information on the health and human rights of MSM. A number of niche news sites would occasionally carry articles

that contained information useful to MSM advocates, but this material was often buried among other stories on less-relevant topics and very difficult to browse. Regional email-based listservs that focused on MSM and HIV provided a more targeted resource, circulating useful articles from news websites as well as reports from meetings and other valuable grey literature. However, most of these listservs were only focused on a single region, precluding interregional exchange. Listservs also lacked archives of past posts organised in a way that would facilitate browsing by topics like “Young MSM” or “Behavioural Interventions.” In addition, when opportunities for advocacy and involvement in high-level processes arose, they were often advertised only for a short period of time, with a narrow distribution and details only available in one or two languages.

Despite barriers to knowledge production like stigma, criminalisation and lack of funding, new and important material valuable to MSM advocates and service providers is released every day. It comes from a wide range of sources across the Internet that must be identified and searched daily. In cases where written information does not yet exist on a specific topic, a global network of advocates and experts would allow individuals to communicate directly to share knowledge and collaborate. To the knowledge of the MSMGF staff, there was no online resource designed by, with and for MSM advocates and service providers to share information and opportunities to enhance the efficacy and reach of their work.

MSMGF.org represents the MSMGF’s effort to use networking and digital tools to fill this gap.

The development of MSMGF.org

In 2008, the MSMGF launched the first iteration of MSMGF.org – a simple English-language website organised into eight regional sections for easy browsing. The platform was updated daily by MSMGF staff with materials that could be used by grassroots organisations to promote MSM health and human rights.

A list of the new materials uploaded to the platform was sent out in a weekly email newsletter – the MSMGF Eblast – to users who signed up for the MSMGF email list. Subscribers to the Eblast formed the first ranks of what is now a growing group of advocates and organisations that are members of the MSMGF.

In 2010, the MSMGF updated the platform with new tools for information exchange and networking. Most notably, the 2010 update included the addition of six new languages: Arabic, Chinese, French, Portuguese, Russian and Spanish.

Throughout the development and implementation of MSMGF.org, the MSMGF Secretariat has continuously sought the guidance of grassroots advocates and organisations working with MSM around the world. Input has been gathered in a number of ways, including user surveys in 2009 and 2012, key informant interviews with MSM leaders from around the world in 2009 and 2012, and the archiving of all emails sent to the Secretariat regarding the website. This ongoing feedback is our primary reference point

for improving the design and utility of MSMGF.org, resulting in the current iteration of the website, as shown in Figure 2 below.



Figure 2: A screenshot of the homepage of MSMGF.org as it exists today, captured on March 15, 2012 (Global Forum on MSM & HIV, 2010).

MSMGF.org today

MSMGF.org today is an improvement on the first iteration in many respects. It has incorporated a number of new features requested by users to make the site more accessible, user-friendly and effective. The site also features new research and networking tools to enhance support for the development of MSM initiatives.

As of March 15, 2012, the site had 3,182 subscribers from 147 countries. The database has over 4,000 articles on the health and human rights of MSM around the world. Since the new website launched two years ago, new Eblasts have gone out every business day, each one tailored to the unique settings of each user. The new MSMGF social network has been active, with numerous user-initiated communications passing back and forth through the online discussion forums and private messaging systems available on the MSMGF.org platform.

Finding Material: What is useful and where can it be found?

The criteria we use to determine whether or not an article is appropriate for posting are:

1. whether an item sheds light on the current status of health and human rights of MSM, and
2. whether an item discusses and explains factors that play a role in affecting the health and human rights of MSM.

To collect this information, MSMGF staff analyses hundreds of sources every day. These include regional and global niche news websites and blogs, regional and global listservs, relevant Facebook pages and Twitter accounts, and keyword alert systems like Google Alerts programmed with relevant search terms. This wide net brings in a broad range of useful resources, from journal articles and newspaper stories to capacity building toolkits and meeting reports from grassroots organisations.

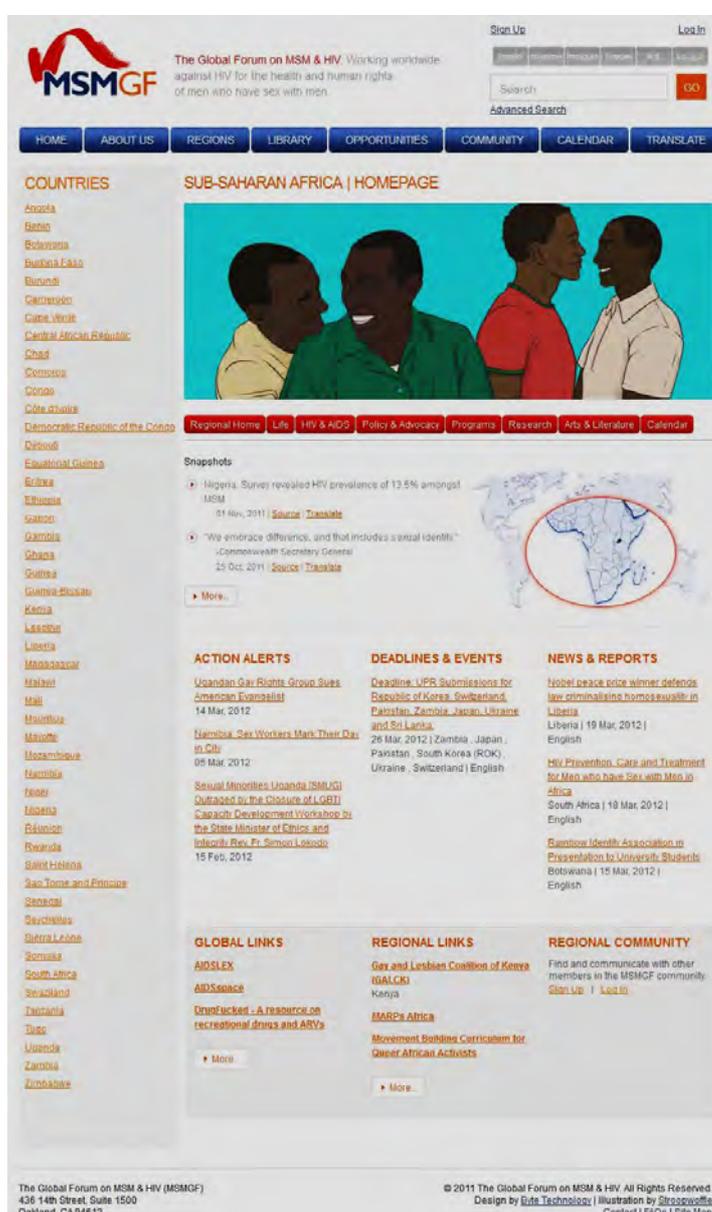


Figure 3: A screenshot of the homepage of the Sub-Saharan Africa regional section, captured March 19, 2012 (Global Forum on MSM & HIV, 2010).

When a relevant item is found, it is posted on MSMGF.org, with tags added to identify country, type of information, MSM sub-population, and cross-cutting themes. The tags send the item to the appropriate pages on MSMGF.org. For example, articles concerning Cambodia appear on the Cambodia page. Users are able to cross-reference tags using an advanced search tool to find specific information. If a user is looking for articles on the impact of stigma on access to HIV services in Latin America, the tags “stigma,” “access to services” and “Latin America” can be cross-referenced. In addition, MSMGF.org automatically compiles a unique Eblast for each member that includes links to all newly uploaded articles with tags that match their interest areas.

Structure of MSMGF.org

The site is primarily organised into nine regional sections: Asia, Caribbean, Central Europe, Eastern Europe & Central Asia, Latin America, Middle East & North Africa, Oceania, Sub-Saharan Africa, and finally Western Europe, Northern Europe & North America. Each regional section includes profile pages for each country in that region, as well as a secondary navigation bar to browse regional information by topic (See Figure 3).

The screenshot shows the MSMGF.org website interface. At the top, there is a logo for MSMGF and a tagline: "The Global Forum on MSM & HIV. Working worldwide against HIV for the health and human rights of men who have sex with men." Below the logo is a search bar and a navigation menu with buttons for HOME, ABOUT US, REGIONS, LIBRARY, OPPORTUNITIES, COMMUNITY, CALENDAR, and TRANSLATE.

The main content area is titled "ASIA | INDONESIA". On the left, there is a list of countries under the heading "COUNTRIES". The central part of the page features "Statistics" with three bullet points:

- According to a 2007 IBBS study of high-risk groups there are around 35,000 waria in Indonesia. (29 Dec, 2010 | Source | TRANSLATE)
- HIV prevalence rate among waria sex workers had reached 34% in Jakarta, 28% in Surabaya and 16% in Bandung. Less than 50% were using condoms. (29 Dec, 2010 | Source | TRANSLATE)
- MSM contribute 3.1% of HIV transmission (Indonesia) (29 Dec, 2010 | Source | TRANSLATE)

Below the statistics is a table titled "UNGASS Indicators for MSM":

Indicator	Data Reported	Year of Report
Percentage of MSM that have received an HIV test in the last 12 months and who know the results.	33.7%	2009
Percentage of MSM reached with HIV prevention program	43.99%	2009
Percentage of MSM who both correctly identify ways of preventing the sexual transmission of HIV and who reject major misconceptions about HIV transmission	40.33%	2009
Percentage of men reporting the use of a condom the last time they had anal sex with a male partner	58.22%	2009
Percentage of MSM who are HIV infected	5.23%	2009

On the right side of the page, there is a "News & Reports" section with three items:

- Sex workers educated through training (01 Mar, 2012 | English)
- Indonesia Labels LGBT Rights Advocacy Site Pornographic (08 Feb, 2012 | English)
- As HIV Rises, Balikpapan to Shut Down Red Light Area (06 Feb, 2012 | English)

At the bottom right, there is a section titled "International Agreements, Commitments, and Progress Reports" with links to various international treaties and declarations.

Figure 4: A screenshot of the Indonesia country page, captured March 19, 2012 (Global Forum on MSM & HIV, 2010).

Country profile pages feature all information available on MSMGF.org concerning a particular country. All individuals and organisations based in that country that are members of MSMGF.org are also listed on country

profile pages (See Figure 4).

Information Exchange

In addition to a structure designed to facilitate easy browsing, MSMGF.org has several additional tools for information exchange built in. A selected list of the tools is presented below:

TOOL	DESCRIPTION	BENEFIT	RECENT EXAMPLES
Statistics Archive	A searchable archive of statistics, each one with tags indicating country and subject matter.	Allows users to find hard data on specific topics quickly, aiding the development of policy documents and grant proposals. Users can search for data on specific topics like “HIV Risk” or “Sex Work,” quickly review a list of available statistics, and be linked back to the original source of the information.	<i>Lesotho</i> : Only 3.7% of MSM surveyed knew water-based lubricants are most appropriate to use with condoms <i>Hong Kong</i> : 49.5% of male sex workers had unprotected anal intercourse with clients in the last six months
Opportunities Board	A list of current opportunities for jobs and funding, as well as other opportunities like survey consultations for United Nations agencies. Organised by region and deadline.	Facilitates access to available funding and opportunities for MSM programmes, as well as involvement in high-level decision-making processes, by listing them in all one place and regularly circulating announcements through the Eblast.	Deadline: Request for Proposals, amfAR MSM Initiative Community Awards: Eastern Europe and Central Asia Deadline: UPR submissions for Czech Republic, Argentina, Gabon, Ghana, Peru, Guatemala and Benin
Calendar	A listing of events and opportunities pertaining to the health and human rights of MSM.	Keeps users informed of upcoming dates and deadlines, helping to increase involvement in activities that can support MSM health and human rights.	March 15: Rectal Microbicide Research Update Teleconference March 19: HIV in Europe Copenhagen 2012 Conference

Eblast

An email newsletter featuring all new materials, events and deadlines uploaded to MSMGF.org, tailored to each user's desired frequency and focus topics.

Helps ensure users are aware of the latest information and opportunities to enhance their work with MSM.

An example of the Daily Eblast from February 28, 2012 is presented in Figure 5.

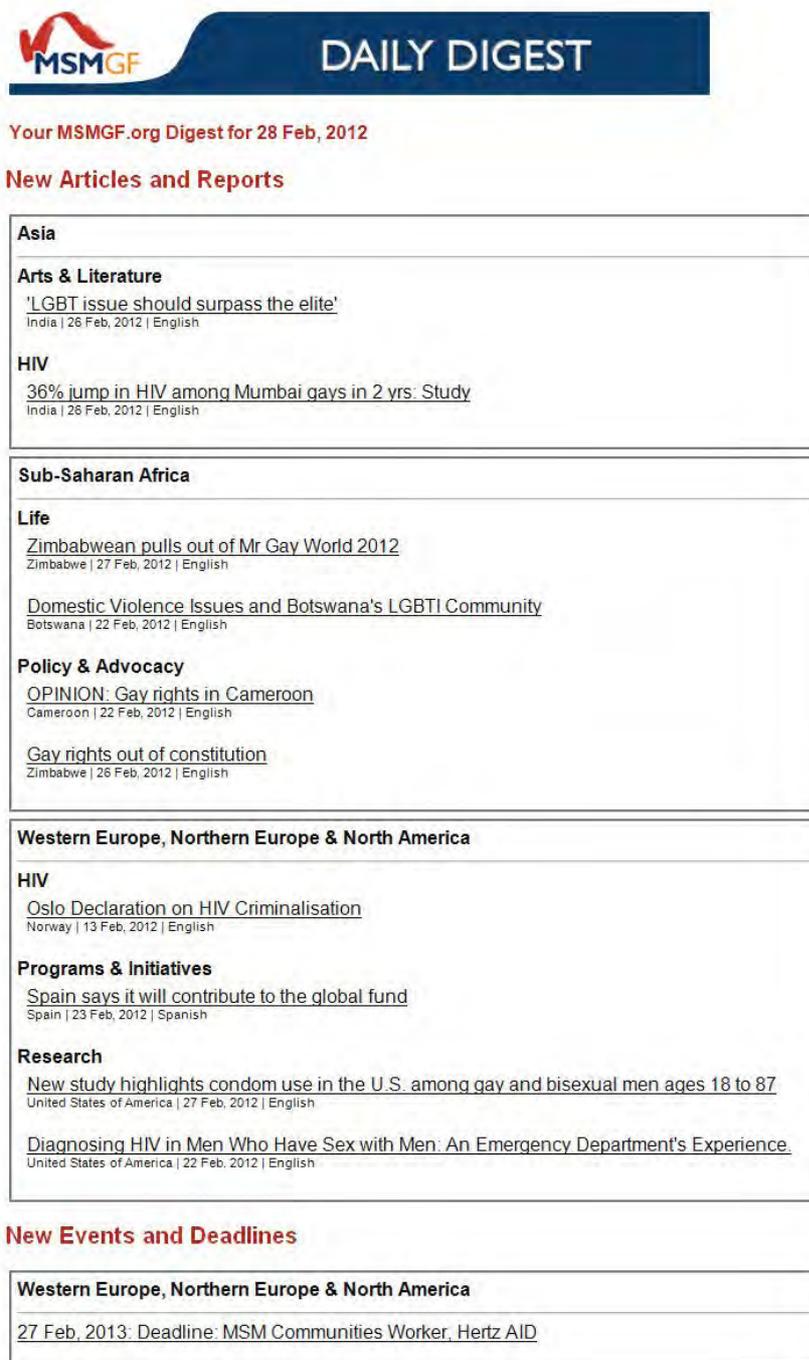


Figure 5: Screenshot of an MSMGF Eblast, sent to a member via email on February 28, 2012 (email communication, February 28, 2012).

Global Network Development

In addition to circulating information, MSMGF.org also serves as the connective tissue for the evolving global community of advocates and service providers working for the health and human rights of MSM. The platform features a number of tools to facilitate networking and communication between members around the world. These tools help members to find and connect with potential partners and funders for collaboration and information exchange. A selected list of these tools is presented below:

TOOL	DESCRIPTION	BENEFIT	RECENT EXAMPLES
Social Network	Features searchable profiles of all MSMGF members that choose to be visible. Profiles include a brief biography, as well as details that can be cross-referenced in a search, including location, focus population and expertise.	Helps members find potential consultants, partners and funders to support their work for the health and human rights of MSM. As of March 15, 2012, 291 messages had been sent through the Social Network.	Helped an international advocacy organisation find community consultants in Eastern Europe for a policy document on HIV among MSM in the region (February 2012) Helped a U.S. attorney find human rights consultants for an asylum case regarding a
Global Directory	Features searchable profiles of organisations that work for the health and human rights of MSM around the world. Organisation profiles include descriptions of the organisation's work and contact information.	Helps members find organisations that can partner on projects or provide necessary services. Profiles can be browsed by region or type of organisation (NGO, multilateral, clinical care provider, or funder).	Helped US-based volunteers skilled in HIV services find MSM organisations in Cambodia for volunteer work (March 2012) Helped an international implementer find organisations in West Africa for capacity building on MSM issues and outreach (February 2012)
Discussion Forums	Email-based listservs available in each of the MSMGF's target languages. Available to members only, and archived in a password protected section of MSMGF.org.	Allows MSMGF members to communicate with each other directly, sharing information and inquiries with the broader community. Includes translation to allow members from one language group to keep up with dialogues in others.	"Dominican GLBT Collective Discomfort with the Dominican Republic First Lady" (Spanish, February 2012) "Carving our own path: the pursuit of LGBT rights in the Middle East" (English, October 2011)

Survey Panel	A group of MSMGF members that has expressed interest in being involved with research activities, including qualitative assessments and quantitative studies. As of March 15, 2012, the survey panel had 191 members from 62 countries.	Helps increase available knowledge on the health and human rights of MSM, providing a platform for the voices of advocates and community members to reach high-level decision makers, influencing policy and funding priorities.	Members of the Survey Panel participated in a study commissioned by the World Health Organization on the prevention and treatment of HIV among MSM and transgender people; survey panel members from 27 different countries provided 39 in-depth interviews (July 2011).
Volunteer Teams	A group of MSMGF members that have expressed interest in volunteering on MSMGF projects and the projects of MSMGF partners. As of March 15, 2012, the MSMGF Volunteer teams had 214 members from 63 countries.	Volunteers provide a wide variety of services, including consulting on documents, survey implementation and volunteer translation.	As of March 15, 2012, MSMGF volunteers had provided 44 translations of articles on MSMGF.org

Bridging the Lingual Divide

Language barriers pose a major obstacle to the work of MSM advocates and organisations. There is already a dearth of information on HIV among MSM in most countries, and the vast majority of existing information is written in English and rarely translated. Many of our constituents have expressed a desire for the MSMGF.org platform to be available in as many languages as possible.

In order to bridge this gap, we identified seven languages to target for information exchange: Arabic, Chinese, English, French, Portuguese, Russian and Spanish. These languages were selected based on the number of people who speak them worldwide and their spread across different countries. In order to ensure the translation budget was used as optimally as possible, the Secretariat chose to translate the full skeleton of the website and translate only the titles of each new item uploaded. This way, speakers of all seven languages can browse the website entirely in their preferred language. Figure 6 offers an example, showing the English and Chinese versions of the Latin America: Programs & Initiatives page. Note the original language of each of the items listed on this page (indicated beneath each title); this example shows how MSMGF.org can allow English and Chinese speakers to find and access relevant materials that were originally written in French, Portuguese and Spanish.

Although site navigation can be conducted entirely in a user's chosen language, funding restrictions prevent full-text translation of every article posted. Users can click a button to the right of each article to view an

automatic Google-translation instantly. If the Google-translation is inadequate or unclear, users can vote for an MSMGF volunteer or staff member to translate the full article. Translation is quickly assigned to a translator and is usually completed within a week. This approach ensures that translation resources are devoted to materials that members have already identified as useful. As of March 15, 2012, MSMGF volunteers and staff had translated 247 articles that received votes from users.

In order to carry out daily translation needs, the MSMGF has contracted translation services from MSM-focused community-based organisations in Lebanon, China, Cameroon, Brazil, Russia and Peru. Organisations were selected based on a reputation for high-quality work with MSM, registration status (an organisation must have a formal bank account to receive funds), and size and stability. We also believe that supporting community-based organisations that are carrying out important work with MSM in their region is preferable to contracting a large commercial translation agency, providing an additional avenue to support grassroots work for MSM health and human rights.



Figure 6: Screenshots of the Programs & Initiatives page in the Latin America section, English version at left and Chinese version at right (Global Forum on MSM & HIV, 2010).

Impact

The MSMGF has collected a significant amount of data on the use and effectiveness of MSMGF.org since the platform was first launched in 2008.

MSMGF.org: 2008 - 2010

Data concerning the first iteration of the platform, from July 2008 through August 2010, is limited to statistics on members who signed up for the MSMGF Eblast and information collected from those members via online surveys. The number of subscribers to the MSMGF Eblast during

this period is broken down by region in the following table:

MSMGF Subscribers by Region: Iteration 1	
Western Europe, Northern Europe & North America	846
Asia	228
Sub-Saharan Africa	168
Latin America	87
Eastern Europe & Central Asia	64
Caribbean	46
Middle East & North Africa	11
Central Europe	N/A

Table 1. MSMGF Subscribers by Region, Iteration 1 (Global Forum on MSM & HIV, 2008).

In mid-2009, the MSMGF surveyed these members to learn more about who they were and how they used MSMGF.org. Thirty-two users responded to the online survey. The majority of respondents were service providers, activists and researchers, with most respondents working in the NGO/CBO sector. The most common reasons for using the website included reading recent research, learning about social issues facing MSM in a certain region, and finding opportunities for jobs, scholarships, and grants.

In response to the open-ended question, “Which features do you find most useful?”, key findings included:

It improves my work in prevention among MSM and provides more scientific info

-Czech Republic (December 15, 2009)

We circulate information to inform our health system

-Belize (November 18, 2009)

Knowing about latest publications and opportunities in grants

-Paraguay (November 19, 2009)

The eblast's deadlines, focus is very relevant to my work. Easy to read/navigate, gives a great overview! My favorite newsletter

-United States (November 18, 2009)

The website is the best collection of MSM-related data and news of recent developments

-Australia (November 18, 2009)

Many users also provided useful suggestions for improvement:

Perhaps arranging resources, contact organizations, etc, by topic? Or developing a search tool to give the option to search for resources by topic (e.g. harm reduction, migration, etc)

-Netherlands (November 19, 2009)

Having a social networking component would be useful to link with other researchers in area of interest, for example

-United States (November 19, 2009)

MSMGF.org: 2010 – Present

When the second iteration of MSMGF.org was launched on August 4, 2010, the MSMGF invested in Google Analytics to help track website use and activity. The reports from Google Analytics, as well as membership records from our current and previous website and an online survey conducted in early 2012, represent the bulk of the data we have on the platform in its current form. We present key findings below.

Usage

From August 4, 2010 to March 15, 2012, a period of eighteen months, MSMGF.org received 106,286 visits from 68,974 unique visitors. During this period, the site received a total of 405,278 page views. Looking the rate of visits in the latest month available (February 15 - March 15, 2012), the average number of visits per weekday was 341.6, with an average of 5:23 minutes spent on site.

The regional breakdown of all visits received from August 2010 to March 2012 is shown below:

Visits by Region: Iteration 2	
Western Europe, Northern Europe & North America	48,371
Asia	17,726
Sub-Saharan Africa	11,364
Latin America	10,915
Eastern Europe & Central Asia	5,566
Middle East & North Africa	5,531
Oceania	2,959
Not set	2,689
Caribbean	1,525

Table 2. Total number of visits to MSMGF.org from August 4, 2010 to March 15, 2012, by region (Global Forum on MSM & HIV, 2010).

Examining the breakdown by language, 66% of visits were made in English. Of the MSMGF's six non-English target languages, most visits were in Spanish, followed by Chinese and French.

Members

While one does not have to be a member to browse the resources available on MSMGF.org, membership allows registrants to customise the information they receive in Eblasts and the opportunity to join the MSMGF Social Network. As of March 15, 2012, MSMGF.org had 3,182 members from 147 countries. This number includes those who subscribed before the new website was launched (1,450 members) and those who subscribed since (1,732 new members). Of members from the old website, only the ones that re-subscribed to the new site (222

members) receive customised Eblasts and access to the social network.

While the older website only allowed subscriptions in English, the new site allows subscriptions in the MSMGF's six additional target languages. Of the 1,954 members who subscribed on the new platform, 1,505 (77%) have signed up for services in English and 449 (22%) have signed up for services in languages other than English: Spanish (132), French (116), Arabic (70), Chinese (49), Russian (41), and Portuguese (36). An additional 5 members signed up in languages that are not included in the MSMGF's seven target languages.

MSMGF.org 2012: Member Experience and Perceptions

In early 2012, the MSMGF Secretariat conducted an online survey to learn more about members' use and experience of MSMGF.org. The survey was open from January 4, 2012 – March 15, 2012, and offered in Chinese, English, French, Portuguese, Russian and Spanish.

A total of 224 members responded across all languages. Table 3 below shows a breakdown of survey participants by region and language:

	by Language		
Sub-Saharan Africa	51	English	143
Western Europe, Northern Europe & North America	43	Spanish	32
Asia	31	French	19
Latin America	30	Russian	20
Eastern Europe & Central Asia	22	Portuguese	2

Table 3. MSMGF 2012 Member Survey respondents by region and language (Global Forum on MSM & HIV, 2012).

The vast majority of survey respondents worked in the CBO/NGO Sector (82%; N=184), followed by less than 1% in other sectors (Research Institutions N=17, Government N=11, Multilaterals N=5, and Foundations N=4). In terms of their work with MSM, most survey respondents identified their primary role as Activist (N=140), followed by Service Provider (N=81), Researcher (N=54), Funder (N=11) and Other (N=11).

When asked, "Where do you get most of your information on MSM health and human rights?", more than 83% (N=188) indicated "Websites via computer," followed by "Email listservs" at 50% (N=113), and "Local grassroots organizations" at 39% (N=89).

Respondents were asked if and how they used different resources on MSMGF.org in their work with MSM. The survey indicated that 71% of respondents use MSMGF.org to advance their in-country advocacy, 72% of respondents use MSMGF.org to advance their international advocacy, 78% of respondents use MSMGF.org to find information on the design and implementation of MSM programmes, and 82% of respondents use MSMGF.org to research issues related to MSM health and human rights.

In order to better understand how non-English speakers were using the

platform, a secondary analysis was run that excluded responses from the English-language survey. A total of 81 respondents took the survey in Chinese, French, Portuguese, Russian and Spanish.

Of all non-English respondents, 74% use MSMGF.org to advance their in-country advocacy, 75% use MSMGF.org to advance their international advocacy, 77% use MSMGF.org to access information on MSM that is not available in their language, 82% use MSMGF.org to find information to inform the design and implementation of MSM programmes, and 86% use MSMGF.org to research issues related to MSM health and human rights.

In regard to the various tools available on MSMGF.org, a majority of all respondents indicated that the Eblast was most useful to their work with MSM (65%, N=146), followed by the Opportunities Board (58%, N=130), and the Regional Pages (35%, N=79). The lowest rated items were the Library (17%, N=40), Translation Services (14%, N=32), and the Directory (13%, N=29). It should be noted that when the English-speaking participants were removed, 34% of non-English speaking participants indicated that Translation Services were most useful.

More than 50% of respondents indicated they used MSMGF.org “Frequently” (28%, N=63) or “Often” (27%, N=61) in their work with MSM. Twenty-four percent of respondents indicated they “Sometimes” used MSMGF.org in their work with MSM (N=54), and 4% indicated they “Never” did (N=10).

The survey also offered participants an open text box to write what they found particularly useful about the platform. The most frequent themes found in user responses were: A) an appreciation for the reliability, timeliness and comprehensiveness of the information available on MSMGF.org, and B) an appreciation for the ability to learn about MSM initiatives in other regions to help inform the respondent’s local work. A representative sample of comments is listed below:

I often visit the regional pages that are specific to Africa to look for advertisements of upcoming conferences, meetings and also for funding deadlines. This is my surest source of information on funding calls.

- Uganda (February 22, 2012)

I admire the stuff of the MSMGF its gives me inspiration for an advocacy strategy in my country Cameroon where the laws are yet to permits us to advocate for our rights.

- Cameroon (February 23, 2012)

The services are useful in supporting my work on MSM research. Email updates and sessions presentation are indeed vital in facilitating deeper contextual issues on MSM research agenda in Africa.

- Kenya (February 8, 2012)

New ideas and experiences of other organizations to develop and implement programs for MSM in Estonia.

- Estonia (February 29, 2012)

Continue the good work. It is the need of the hour and many organisation looking for these kind of support. I always use this forum to get information.
India (February 7, 2012)

Respondents were also asked for suggestions on how to improve MSMGF.org and its services. Most respondents requested: A) improved networking, B) increased promotion of the site and its resources, and C) the addition of more languages. A representative sample of comments is listed below:

Connect to all MSM Network around the world and build a platform for communication.
-Cambodia (February 21, 2012)

Would like to see greater collaboration. Promote and support for regional and national MSM networks and organisations.
- Vietnam (February 7, 2012)

I did not know they had such information; these should be promoted more.
Peru (February 16, 2012)

Local languages such as Hausa/Fulani should be included in the translation languages due to the high number MSMs of these ethnic groups in need of information on sexual health.
- Nigeria (February 21, 2012)

Direct emails from constituents and key informant interviews conducted with prominent MSM leaders and heads of regional MSM networks also reflected the same set of themes. The most prominent theme to emerge from key informant interviews was a strong desire for enhanced networking capacity.

Connecting and collaborating with digital networking

Men who have sex with men are a marginalised population at risk for HIV and human rights violations in most parts of the world. In many countries, there are only a handful of advocates and service providers actively working with MSM. With MSM advocates and service providers so geographically dispersed – and sometimes isolated to a particular language group – many local actors are disconnected from vital information, resources, opportunities and support. A networked and digital response presents a viable option for connecting people working on similar issues in different parts of the world for information sharing and collaboration, allowing actors in one region to benefit from advances in another. With limited funding, opportunities, and research available for those working with MSM, efforts must be made to ensure this kind of information is easily accessible to MSM advocates working in all countries. This is especially important because many of these

opportunities and resources originate in a very small number of countries and languages.

As a networked and digital intervention, MSMGF.org is designed to connect the individuals and organisations that comprise the vast majority of the HIV response for MSM with the opportunities and resources they need to work most effectively. The MSMGF's 2012 survey of MSMGF.org members suggests that most of these individuals and organisations get their information on MSM health and human rights from web-based sources, primarily websites and email listservs. By offering a platform that combines both website and listserv formats, MSMGF.org utilises the channels that appear to be used most frequently by the advocates and organisations at the forefront of addressing the HIV epidemic among MSM.

Evaluation indicates that user experience with the platform is positive. More than 70% of survey respondents indicated that they used MSMGF.org to advance their advocacy work, design and implement MSM programmes, and research issues related to MSM health and human rights; more than 50% indicated that they use it frequently or often in their work with MSM. With the Eblast, Opportunities Board, and Regional Pages at the top of the list of "Most Useful" features, services focused on information exchange appear to be the most effective tools on the site.

Data indicates that non-English subscribers are using the site to support their work with MSM as well. More than 75% of non-English subscribers indicated that they use the platform to access information that would be otherwise unavailable in their own language, and more than 70% are using the platform to advance in-country and international advocacy, design and implement programmes, and research issues on MSM health and human rights. However, many members have commented that they would like more translations than are currently available on the site at present. This indicates a need for resources to ramp up translation work on the site, helping to bridge the pervasive language barrier.

The 2012 survey also clearly indicates a number of additional areas for improvement. Above all, it appears that users would like more and better opportunities for facilitated networking. With the Directory near the bottom of the list of "Most Useful" features, there is no question that a need exists for effective networking mechanisms. In response to this feedback, the MSMGF is currently retooling the Directory and Social Network sections of the web platform in order to make it easier for users to find potential partners and funders for their work with MSM. Completion of these updates is expected by mid-2012.

Like many interventions, the MSMGF.org web platform requires staff to maintain it. Collecting the information for site updates requires the employment of one part-time employee for 20 hours a week. Making the material available in non-English languages also requires contracting external translators, which constitutes an additional cost. However, the MSMGF feels that the benefits of the intervention are worth these modest

costs, considering the reach and impact of the service worldwide.

Conclusion

This chapter has reported on the rationale, design, implementation, and formative evaluation of MSMGF.org, an innovative response to the lack of access to knowledge, resources and collaboration among practitioners working on issues concerning MSM. Evaluation of this approach shows that a digital and networked intervention is a valuable tool for supporting the health and human rights work of grassroots organisations. This is especially true for those working with MSM in low- and middle- income countries, where HIV is taking a heavy toll on MSM and infection rates are continuing to climb. Investments in new research, new funding initiatives, and new programme designs for these populations will have limited impact if the organisations working with MSM in these countries cannot gain access to them. Bridging this access gap is how MSMGF.org makes a difference.

The participatory development of a single comprehensive hub of information, resources and partners has proven to be a useful practise for MSM advocates and implementers around the world. Overall the site has shown strong uptake by users, as evidenced by page visits, the expanding number of registered members, and the ways that members use the site. The platform appears to be effective at helping grassroots organisations in low- and middle-income countries overcome many of the obstacles that undermine their work for the health and human rights of MSM. This approach could be effective in work with other marginalised minority populations that are scattered in small groups across distant geographies, including other populations at risk for HIV like sex workers, people who use drugs, and transgender people.

Moving forward, the challenge and the opportunity is to further refine our “virtual village.” We aim to go beyond information sharing to create meaningful and relevant opportunities for individuals across a range of identities to interact and collaborate to address HIV, health and human rights among MSM (Walsh & Singh, 2012). Through ongoing research and evaluation with our stakeholders, we will build on MSMGF.org’s current contributions to develop critical networking and partnership tools toward improving the health outcomes of MSM.

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Chapter 3

The use of the Internet in male sexual encounters by men who have sex with men in Cameroon

Emilie Henry
Yves Yomb
Lionel Fugon
Bruno Spire

In this chapter, Emilie Henry, Yves Yomb, Lionel Fugon and Bruno Spire critically take up the issue of risk and sexual practices in Cameroon, Africa. Their study draws on data from a survey on MSM sexual practices and from a pilot online HIV outreach and prevention programme run by a community-based organisation in a very harsh legal environment where MSM face extreme violence. Their work points to the urgent need to confront the wider contextual factors that affect HIV risk and the potential of digital approaches to be expanded for this goal, particularly in contexts where MSM face disempowering legal and socio-cultural contexts that pathologise their right to be who they are.

Introduction

Several studies have highlighted both the heightened risks faced by men who have sex with men (MSM) in Sub-Saharan Africa in terms of their exposure to HIV and AIDS (Niang et al., 2003; Parker, Khan, & Aggleton, 1998) and the higher HIV prevalence among MSM when compared with other populations living with HIV and AIDS (Baral, Sifakis, Cleghorn, & Beyrer, 2007; Van Griensven, 2007; A. Wade et al., 2005). However, the growing visibility of these previously 'invisible' or unrecognised concentrated epidemics has not been accompanied by any real change in terms of targeted government responses to the HIV and AIDS epidemic among gay men, other MSM and transgenders (Henry et al., 2010; McIntyre, 2010).

To date in most Sub-Saharan countries, national strategies to fight the HIV and AIDS epidemic and HIV sexual prevention messages are primarily directed only toward heterosexual populations (Henry et al., 2010). Prevention messages and interventions targeting MSM are often left to the goodwill of local community organisations (CBOs) working in a complex and hostile social, political and sometimes legal environment. This situation makes it difficult for CBOs and non-governmental organisations (NGOs) to mobilise and address the increasing HIV prevalence among MSM in Cameroon and other Sub Saharan countries. Moreover, during the last two years, while international organisations have mobilised in the fight against HIV and AIDS, notably UNAIDS and the Global Fund making the question of the respect of

human rights and sexual minorities a priority (The Global Fund, 2009, UNAIDS, 2009), many African countries have seen their legislation and/or its application evolve towards further penalisation of homosexual practices¹.

These examples of restrictive legislation effectively banish gay men and other MSM underground, in turn depriving them of access to HIV and AIDS prevention and care (Henry et al., 2010). While data and observations from the field (*Alternatives- Cameroun*, 2011) suggest the Internet is a medium wherein disclosure, communication and sexual encounters between gay men and other MSM are made possible, few studies have examined this in an online context in Sub-Saharan countries. This gap consequently deprives frontline workers of potentially important knowledge in terms of adapting, proposing and enacting new HIV prevention strategies and interventions.

In Cameroon, the prevalence of HIV and AIDS in the general population is 5.3%. But this general data masks very large disparities. Although prevalence data for MSM are not locally available, several research studies (Gueboguo, 2006; Henry et al., 2010) and data collected in centres for HIV and AIDS prevention and care show that MSM are confronted with an increased risk of HIV infection. Indeed, the Cameroonian context is stigmatised by an intense social and political rejection and repression of homosexuality² that makes access to HIV and AIDS prevention and care very difficult.

A localised community-based and led response

In response to the difficult context described above in Cameroon, *Alternatives- Cameroun*—a non-profit CBO for the defense of sexual minorities—was launched in 2006. Initially investing its efforts in the defense of human rights, the organisation has progressively become involved in on-the-ground work, tackling the lack of HIV and AIDS and STIs prevention and care for gay men and other MSM. Today, its activities include prevention campaigns, promoting voluntary confidential counseling and testing (VCCT), distributing condoms and lubricating gel as well as the organisation of focus groups around sexuality and sexual risk reduction. *Alternatives-Cameroun* is funded by [Sidaction](#), [amfAR](#), [Solidarité Sida](#), and [Fondation de France](#). 30 volunteers, 10 full-time and 23 part-time employees work for the organisation. In 2007, *Alternatives-Cameroun* launched an online HIV and AIDS outreach and prevention intervention that we describe below.

Using data from both a survey on 168 MSM in Douala, the economic capital of Cameroon, and from *Alternatives-Cameroun's* online HIV outreach and prevention pilot study, we present preliminary findings on the use of the Internet by gay men and other MSM for meeting male sexual partners in Douala. The objective of our pilot study was to define the proportion and profile of persons who access online encounters in order to implement targeted prevention messages to this population of gay men and other MSM.

Methodology

Definition of the term MSM

The term MSM is widely used in the literature and denotes men who have sex with men. These men do not necessarily describe themselves as gay or homosexual (Young & Meyer, 2005). In our study, we decided to use this term to denote these populations' sexual practices rather than sexual identity. Even though this choice fails to capture the specificities of men of different sexualities identities (Pathela, Blank, Sell, & Schillinger, 2006), a focus on MSM sexual practices is effective for designing HIV prevention interventions by promoting agency and changes in sexual behaviour (Kippax et al., 2007).

Study Design

The study draws on data from a quantitative survey and from qualitative data gathered through an online HIV outreach and prevention pilot study.

ESANHOD Survey (étude sur la santé des hommes à Douala)

Excerpts of the data presented in the results section are taken from the ESANHOD survey on the sexual activity and practices of MSM, carried out by *Alternatives-Cameroun* with the support of the French association [AIDES](#) between May and June 2008 in Douala. A convenience sample of 168 MSM was used. The criteria for inclusion in the study were as follows: being a man aged at least 18 years; resident in Douala for at least six months; and having had at least one sexual encounter with another man during the course of his life.

Moving about in a hostile environment, the MSM population is often described as being difficult to reach in Cameroon. The recruitment of survey participants was facilitated by the integration of members from *Alternatives-Cameroun* into MSM networks. Five members of *Alternatives-Cameroun* recruited participants from their social networks and in places where MSM regularly meet in Douala (nightclubs, snack bars, mixed or gay bars in Douala and its suburbs as well as via the Internet). This 'snowball' sampling method facilitated the extension of recruitment to persons having less contact with *Alternatives-Cameroun*. Using an 85-item questionnaire, the various ways sexual partners met were investigated. Qualitative data was also collected from 25 respondents in order to specify the responses to the questionnaire itself.

Variables derived from the face-to-face questionnaire items were first tested using univariate logistic regression (see Table 1 below). Those which achieved a liberal significance level of ≤ 0.20 in the univariate analyses were included in the multivariate model. For the multivariate analysis, a backward elimination approach to logistic regression was used and variables with a p value of ≤ 0.05 were considered to be significantly associated with the outcome. A good means for assessing a binary logistic regression model's ability to accurately classify observations is to construct a receiver operating characteristic (ROC) curve and evaluate its associated area. A model with a high area under

the ROC curve suggests that the model is able to accurately predict the value of an observation's response (Hosmer & Lemeshow, 2000).

Alternatives-Cameroun Online HIV outreach and prevention pilot study

The study also collected qualitative data on accessing the Internet for MSM sexual encounters from the online outreach and prevention pilot study carried out by *Alternatives-Cameroun*. Since 2007, following an exchange of experience with [Association de lutte contre le sida \(ALCS\)](#) a Moroccan association which was experimenting with a similar type of intervention, *Alternatives-Cameroun* has extended its work on Internet-based prevention actions. The intervention was enhanced in 2009 from the results of the ESANHOD study and is ongoing in Douala today.

Alternatives-Cameroun's online HIV outreach and prevention pilot study was implemented by first identifying the websites used most for gay and mixed sexual encounters in Cameroon. [GayRomeo](#) and [123LOVE](#) appeared to be the most popular websites. Not having any agreement with the webmasters of these Internet sites, the association created "gay" nicknames or profiles (e.g. "gay prevention"), accompanied by slogans which enabled it to become rapidly visible and identifiable by online users. On these websites, chats are organised on a nationwide basis, allowing *Alternatives-Cameroun* direct contact with MSM participants connecting online from different cities throughout Cameroon. Figure 1 below shows an example of a typical chatroom from the 123 love website:

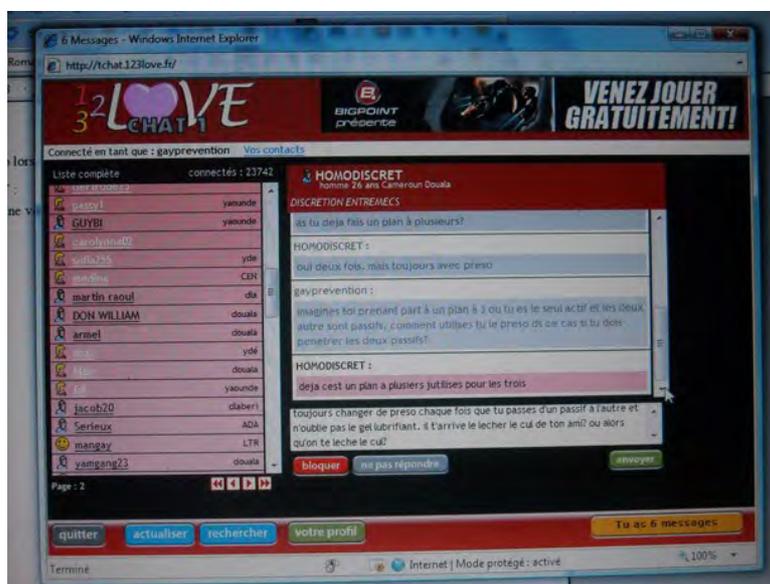


Figure 1. Chatroom on the commercial cruising website [123 LOVE](#) used for the pilot study

Several trained HIV and AIDS prevention counselors, who have good knowledge of these sites, direct online chats with individual MSM several times a week. In addition, the visibility of the nickname, suggesting prevention and gay sexuality, prompted online users to directly contact the counselors.

The dialogues facilitated in the chatrooms draw on health

psychology and health promotion theories such as client-centered therapy (Rogers, 1957) and motivational interviewing (Miller & Rollnick, 2002). Counselors have been trained to adapt their discourse to the needs of MSM they meet online, to develop their personal skills, and to give people greater control over their health and the environments in which they live. Thus, online counselors ask open-ended questions like: “What do you think of HIV and AIDS?” or “Do you use condoms and lubricating gel during sexual encounters?” The aim is to enable free and non-judgmental discussions, to establish contact with Internet users, to provide MSM with the opportunity to express themselves about their sexuality, and to discuss personal problems or questions they may have about sex and/or HIV and AIDS prevention. Counselors then provide MSM sexual risks reduction information. Online users with whom contact is established are then directed towards a private MSN Messenger chat hosted by the association, so as to maintain regular contact with the MSM met online.

For the needs of the pilot study, thematic qualitative analysis was carried out on the activity reports (*Alternatives-Cameroun, 2011*) and on interviews with members of Alternatives-Cameroun working on Internet-based prevention. This was only a pilot study with a limited evaluation, and it was not possible to systematically analyse the chat contents. Under these constraints, a thematic approach enabled a first cut in-depth analysis of the data collected.

Results

Among the 168 MSM taking part in the ESANHOD survey, we restricted the analysis to the 153 who replied to the question regarding meeting places. Among the 15 persons who did not respond to the question, 14 had not had sexual partners during the six previous months and 1 refused to answer.

Thirty-four percent of respondents (52) indicated having met their partners over the Internet. This was the second most frequent means of meeting partners after meeting through friends (42.5%).

In the univariate analysis, the following factors were associated with meeting one’s partners on the Internet ($p \leq 0.20$): having a university educational level, not having a lucrative activity, being single, not having any children, not having paid for sexual relations during the previous six months and having had a greater number of partners during the previous six months.

Variables	N (%) or Median / [IQR]	OR [95%CI]	Pvalue	aOR [95%CI]	Pvalue
Having being exposed to HIV prevention interventions	88 (58%)	0.80 [0.41 - 1.56]	0.51		

The use of internet in male sexual encounters

Having a university educational level	43 (28%)	2.51 [1.21 - 5.22]	0.01	3.01 [1.36 - 6.64]	0.006
Having had one or more unprotected anal penetrations with one or several male partners in the previous six months	79 (52%)	1.15 [0.57 - 2.33]	0.69		
No stable male partner during one's lifetime	11 (7%)	0.41 [0.08 - 1.97]	0.26		
Sexual orientation disclosed to at least one relative or friend	69 (45%)	0.95 [0.48 - 1.86]	0.88		
Having a lucrative activity	82 (54%)	0.50 [0.25 - 0.99]	0.05	0.37 [0.17 - 0.81]	0.01
Being single	130 (85%)	6.56 [1.48 - 29.19]	0.01		
Having at least one child	45 (29%)	0.45 [0.20 - 1]	0.05		
Not having been in Douala for at least four weeks during the previous year	44 (29%)	1.53 [0.74 - 3.15]	0.25		
Having already paid for sexual relations during the previous six months	23 (15%)	0.36 [0.11 - 1.11]	0.07		
Knowing someone with Age-Year	72 (47%)	1.20 [0.61 - 2.34]	0.6		
	25 [23 - 30]	0.96 [0.91 - 1.03]	0.26		
Age at time of first sexual relation with a man - year	19 [17 - 22]	1.04 [0.95 - 1.13]	0.43		
Number of male sexual partners during the previous six months	2 [1 - 4]	1.26 [1.08 - 1.46]	0.003	1.32 [1.12 - 1.55]	0.001

Having met 52 (34%)
sexual partners
over the Internet

Table 1: Results from univariate and multivariate analyses for the logistic regression of factors associated with the use of the Internet in order to meet sexual partners (N=153)

In the multivariate analysis, having a university educational level, not having a lucrative activity and having had a larger number of partners during the course of the previous six months were independent correlates of having met sexual partners on the Internet (Table 1). The area under the ROC curve is 0.75 [0.66 – 0.83] which is an acceptable discrimination (Hosmer & Lemeshow, 2000).

During 2010, data from the online HIV outreach and prevention intervention have shown that the sites most visited by MSM in Cameroon were [GayRomeo](#) and [123LOVE](#), which is a mixed site. Thirty-seven Internet chats were hosted over the course of the year. Three hundred and seven contacts were made during these interventions. Amongst these, 104 persons were directed to the association's center (Centre Access) and 75 to Alternatives-Cameroon MSN chat rooms for further personalised follow-up.

Qualitative data from the pilot study reveal that the perception of risk of exposure to and infection with HIV and AIDS was not widespread among MSM encountered in the chat rooms. Their knowledge about modes of transmission and sexual risks reduction was limited and many had erroneous ideas on personal risk to HIV infection. Some of the Internet-users thought for example they were protected from HIV and AIDS when having anal sex. Others explained they used various products like skin conditioner or vaseline as lubricants. This was much more frequently the case for those MSM who were "underground". The term "underground" is used by *Alternatives-Cameroun* to describe individuals who hide their sexuality with men and who are not in contact with the MSM or gay networks in Douala. This reality has been widely described with the term "hidden MSM" in the international research literature (Geibel, Tun, Tapsoba, & Kellerman, 2010; Walsh, Lasky and Morrish, 2011).

Complementing the pilot study, the interviews carried out within the ESANHOD Survey study participants, revealed numerous cases of blackmail and violence encountered by participants who had physically met with sexual partners contacted through the Internet. For many, these encounters effectively turned into traps where they were blackmailed using disclosure of sexual orientation as a threat, robbed and/or beaten. The fear of being exposed to different forms of violence as a result of frequenting the Internet and sharing their identity, orientation, and/or sexual practices with unknown others was consequently a recurrent subject for discussion with counselors in the online chats.

Consequently the association met with great difficulty when trying to follow-up these Internet-based prevention chats. Most of Internet users were cautious and distrustful when the contacts started to become

closer. With the majority of them, it was difficult to continue the counseling beyond a chat or an interpersonal exchange (i.e a direct contact via email or phone). Few participants took advantage of referrals to the association's centre. "Underground" participants were the most reticent about going to the association's center when referred there.

Discussion

This pilot study's results are among the first to focus on the Internet as a meeting place for MSM and on the possibilities of implementing Internet-based HIV prevention interventions in Cameroon. They show that more than a third of those interviewed (52 out of 153) used the Internet to meet sexual partners. These findings are consistent with a meta-analysis of 22 studies in English-language publications (Liau, Millett, & Marks, 2006). This analysis showed that in studies recruiting MSM not through the Internet, 40% reported using the medium to meet sexual partners. In the United States, studies have also shown that the Internet plays an important role in the constitution and functioning of social and sexual networks (Chiasson, Hirshfield, & Rietmeijer, 2010). In contexts where same sex sexuality is punishable by law, as in Cameroon, meeting places are limited and our results suggest that the Internet constitutes a favoured meeting place that requires further critical analysis. Yet, few studies have investigated and tried to address this issue to improve the design of online HIV prevention interventions.

In our study, meeting sexual partners over the Internet was associated with having a university educational level, with not having a lucrative activity and having had a greater number of partners during the previous six months (Table 1). One inference is that MSM in Douala with a university educational level have greater capacities in the use of computers through their studies and therefore are more inclined to use the Internet for seeking sex. University education level may also be correlated with higher social class and better Internet access. According to the results of several studies, one's educational level is a developmental factor in the use of new technologies at country level (Billon, Marco, & Lera-Lopez, 2009; Mocnik, 2010). In contrast, not having a lucrative activity is undoubtedly associated with more free time coupled with an increase in social isolation. Using the Internet might enable individuals without a lucrative activity to overcome their isolation. These results provided us important information to tailor HIV prevention messages and interventions.

Unlike the results from the meta-analysis done by Liau (Liau et al., 2006), our study did not highlight any association between meeting one's partners on the Internet and having a greater number of unprotected sexual relations. Nevertheless, the results suggest a non-negligible risk of HIV and AIDS exposure. Indeed, our study points out that there were a greater number of MSM using the Internet in Cameroon as a means to meet sexual partners. A similar association was highlighted in a community research study carried out in British Columbia (Ogilvie et

al., 2008). Studies have also highlighted the greater number of sexual partners in the MSM population as a factor associated with a greater risk of HIV and AIDS exposure (Xu, Sternberg, & Markowitz, 2010). These results emphasise the need for continuous HIV and AIDS prevention interventions in this population. Internet-based outreach should be developed to complement classical prevention approaches such as peer education and community mobilisation.

This study's qualitative data underline the fact that Internet prevention actions enable contact with MSM who do not usually frequent places where traditional prevention actions are undertaken, for example pick-up joints. The particular profile of the respondents and their weak perception of HIV and AIDS risk call for the implementation of targeted interventions (Bauermeister, Giguere, Carballo-Diéguez, Ventuneac, & Eisenberg, 2010). Better knowledge of Internet users' risks profiles should particularly be used to better equip counselors to adapt discussion and risk reduction strategies. While there have been encouraging experiments in the United States and in the Western European countries (Bowen, Horvath, & Williams, 2007; Kok, Harterink, Vriens, De Zwart, & Hospers, 2006; Rosser et al., 2009; Davidovich, De Wit, & Stroebe, 2004), these approaches cannot simply be translated to the Cameroonian context, where homosexuality is criminalised and access to Internet is limited. Instead Internet-based HIV outreach and prevention needed in such disabling environments require an alternative framing that places greater attention on fighting stigma and discrimination online.

The cases of violence, extortion and blackmail within the MSM population in the Cameroonian context have already been well documented in a 2008 [ILGA](#) survey (Gueboguo, 2008). However violence has also been described within contexts that are *a priori* less hostile. A recent study carried out in the United States has shown that young gays who meet their sexual partners on the Internet are at greater risk of violence (Bauermeister et al., 2010). As in our study, for younger people, the perception of the risk of violence is much greater than that of exposure to HIV and AIDS. Online interventions need to be tailored taking these risks in consideration and could focus on the development of more secure spaces for discussion between MSM. These interventions could also be extended to broader anti- stigma and discrimination campaigns for a wider public, especially on the websites used most for gay and mixed sexual encounters in Cameroon. Finally hotline development should be considered to maintain contact with "hidden" MSM who do not want to be in contact with gay networks in Douala and who are reticent about going to the association's center when referred there.

Limitations

Our results have limitations. Firstly, although convenience sampling was the only way of assuring the safety of the participants, the snowball technique may have introduced selection bias (Evans, Wiggins, Mercer,

Bolding, & Elford, 2007). The qualitative data from the interviews suggest that the study sample might have led to an overrepresentation of young MSM with a high educational level. An [RDS](#) (respondent-driven sampling) method could perhaps have helped to better avoid any selection bias. Nevertheless, the qualitative data suggest that the use of the snowball technique was useful in mobilising participants.

Our study was partly carried out in a limited urban zone, that of Douala. An economic center of Douala's size probably offers a greater degree of sexual liberty and greater opportunities to meet male sexual partners. Furthermore, access to and use of the Internet (Billon et al., 2009) is much greater than in other regions and cities in Cameroon. With its two million inhabitants, this port city is the most cosmopolitan of the country, both in terms of ethnic and regional origins of the population and its socioeconomic stratification (Eboko, 2000).

The study was carried out on a limited number of participants. Despite the hostile context, it nevertheless showed the feasibility of carrying out surveys in the MSM population in Cameroon with the help of networks of associations acting as on-the-ground intermediaries.

Practical steps to improve online community-based and led responses

Despite its limitations, our study clearly shows the need to implement Internet-based prevention interventions while developing parallel complementary research of social and political contexts in order to better understand the use of the Internet by MSM, both in Cameroon and in other countries where a hostile environment compels a large number of MSM to go underground.

Even though research in the field of online HIV preventions is booming in Western countries, very few studies have looked at the question in Sub-Saharan African countries where the need for Internet-based HIV and AIDS outreach and prevention is just as great. From the point of view of social, economic, political and legal realities, all HIV prevention intervention strategies need to be contextualised. Expertise of new researchers of Internet and social networking technologies and practices is necessary (Walsh & Singh, 2012).

Our study analysed data collected in 2010. In the meanwhile Internet-based interventions have been developed in many countries in Sub-Saharan Africa and pilot projects have been extended and strengthened. Nevertheless a regional strategy is still lacking compared to other contexts such as Latin America or Asia. Challenges are also specific to the social and political context. A mapping of online community-based and led interventions could help to identify available expertise, best practices and to define guidelines for existing and upcoming interventions. To improve the quality of interventions and their impact, the design and implementation of Internet-based interventions for gay and other MSM communities should include precise evaluation systems in order to rapidly make good practices available to

researchers, practitioners and activists engaged in HIV prevention.

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¹ Including Burundi 2009 and Uganda in 2010. Rwanda and the DRC recently discussed the framework for a law criminalizing sexual relationships between same sex people. A declaration by the Kenyan Prime Minister in November 2010 asked for that country's existing but unenforced law to be rigorously applied, and MSM arrests to be made.

² Penal Code (Law No. 65-LF-24 12th November 1965 and Law No. 67-LF-1 12th June 1967) Homosexuality : « Any person who has sexual relations with a person of the same sex is punishable with imprisonment from six months to five years and a fine of 20,000 to 200,000 Francs (*between 30 and 305 Euros*)

Chapter 4

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
Linda-Gail Bekker

Working within a larger global biomedical HIV prevention trial, this chapter illustrates how Andrew Scheibe, Ben Brown and Linda-Gail Bekker from the *Desmond Tutu HIV Foundation* in South Africa explore their use of information and communication technologies (ICTs) to mobilise participation from the MSM community. They argue that the rise of digitally mediated sexual practices of MSM in Africa needs to be better understood and used to address the structural barriers to HIV prevention.

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 address 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. Ongoing 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—particularly 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.

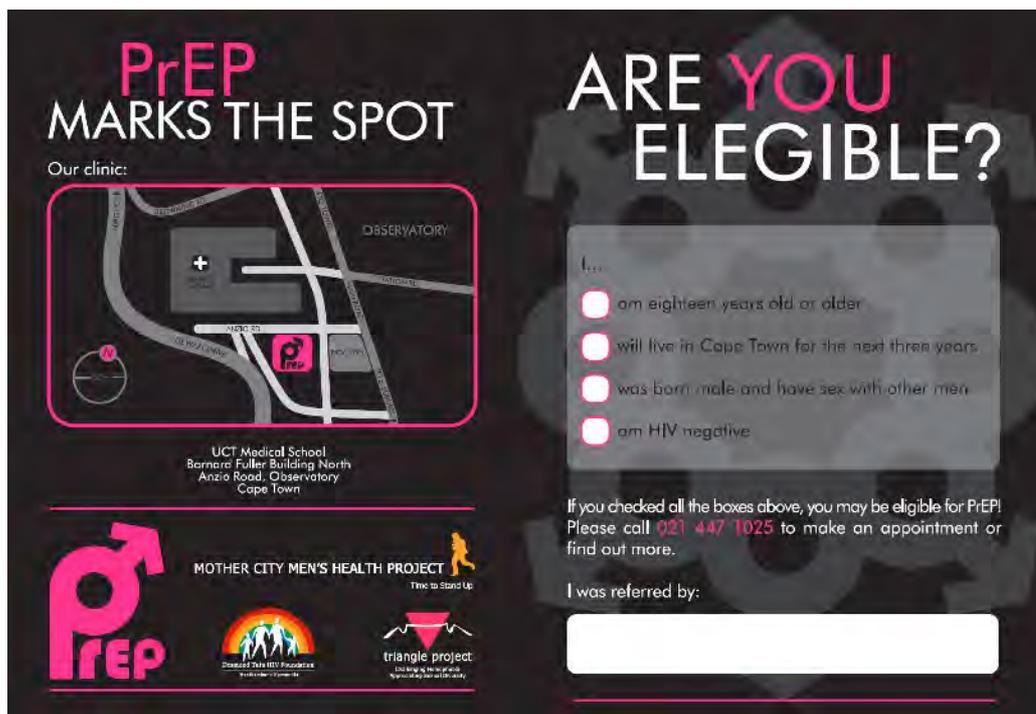


Figure 1. Recruitment flyer for the PrEP Trial.

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.

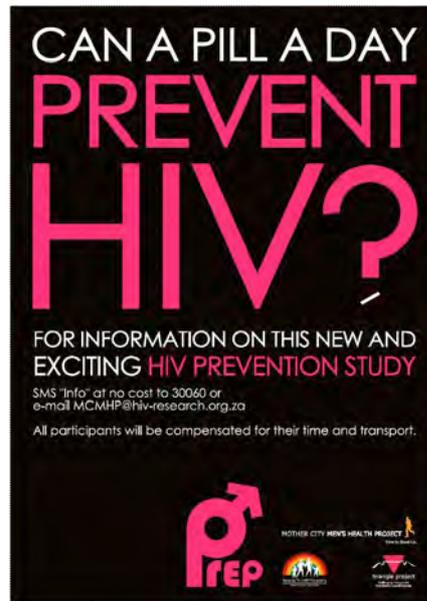


Figure 2. SMS recruitment campaign poster

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.

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 South African 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 drawbacks. 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 assisted 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, including 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 delivered 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 exists 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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Chapter 5

Digital media & the Internet for HIV prevention, capacity building & advocacy among gay, other men who have sex with men (MSM) & transgenders: Perspectives from Kolkata, India

Rohit K. Dasgupta

This chapter focuses on how Rohit Dasgupta employs a postcolonial queer lens to describe his experience working with an HIV prevention charity, *Solidarity and Action Against the HIV Infection in India (SAATHI)*. He describes SAATHI's use of ICTs for HIV advocacy and capacity building across the country, with a focus on Kolkata. Dasgupta points out how what could on the surface be perceived as an ordinary capacity building initiative supplemented by a web presence, can be re-theorised through the lived experience of not only the colonising structures of MSM and transgender people, but through 'kothi' and 'hijra'.

Introduction

Gay men, other men who have sex with men (MSM) and transgender individuals in India are at higher risk of new HIV infections than other men (NACO, 2008). Due to the broader disempowering national social and legal frameworks that criminalise and 'regulate' their behaviours, they face robust hostility from mainstream health providers (Khan, 2004; World Bank, 2009). The availability of Voluntary Confidential Counselling and Testing (VCCT) services does not appear to have alleviated apprehension among gay men, other MSM and transgender communities in accessing health services. Despite the decriminalisation of same-sex relationships with the reading down of India's Section 377 in 2009 (Misra, 2009), the biggest challenge for HIV prevention and capacity building approaches is the lack of tailored healthcare provision specifically designed to meet their needs. This situation is made worse due to the structural violence experienced by gay men, MSM and transgenders, and the lack of understanding of the complexities of their sexual practices among healthcare providers (Chakrapani, Newman and Shunmugam, 2008). Solidarity and Action Against the HIV Infection in India (SAATHI) is at the forefront of challenging and tackling social stigma, discrimination and violence towards gay men, other MSM and transgenders in India through its innovative use of digital media and the Internet. This paper reports on lessons learned from the experiences of SAATHI's use of digital media and the Internet to address issues around stigma and discrimination, support expanded access to HIV and

AIDS services among gay men, other MSM and transgender communities in Kolkata, India.

HIV stigma and discrimination in India

Despite the decline in adult HIV prevalence in India, new HIV infections among MSM and transgender populations continue to rise (NACO 2009, 2010). National surveillance data (see Figure 1) provides evidence that the MSM populations in West Bengal accounts for 5.61% of the HIV prevalence in India, followed by Orissa (7.37%), Maharashtra (11.80%), Delhi (11.73%), Manipur (16.40%) and Andhra Pradesh (17.04%).

Globally, it has been reported that despite the scale up of targeted HIV prevention to gay men, other MSM and transgenders, entrenched stigma and discrimination impede prevention efforts, resulting in proportionately higher HIV incidence among these vulnerable groups. Although 5-10% of HIV infection worldwide is attributed to MSMs, only 1.2% of the entire funding for HIV prevention is geared towards this group (MSMGF, 2010), making it one of the most underfunded groups among populations at risk.

territory	prevalence 2007 (%)	prevalence 2007 (%)	2007 (%)	2007 (%)	prevalence 2007 (%)
Maharashtra	0.50	11.62	24.40	11.80	17.91
Manipur	0.75	4.08	17.90	16.40	13.07
Meghalaya	0.00	2.21	4.17
Mizoram	0.75	7.13	7.53	...	7.20
Nagaland	0.60	3.42	1.91	...	8.91
Orissa	0.00	1.60	7.33	7.37	0.80
Pondicherry	0.00	3.22	...	2.00	1.30
Punjab	0.00	1.60	13.79	1.22	0.65
Rajasthan	0.13	2.00	4.16
Sikkim	0.09	0.00	0.47	...	0.00
Tamil Nadu	0.25	8.00	16.80	6.60	4.68
Tripura	0.25	0.40	0.00
Uttar Pradesh	0.00	0.48	1.29	0.40	0.78
Uttaranchal	0.00	0.00
West Bengal	0.00	0.80	7.76	5.61	5.92

Figure 1. HIV prevalence within MSM and transgender communities in India, (NACO, 2010)

Violence, stigma and discrimination make it difficult not only to estimate HIV seroprevalence accurately, but also create challenges for effective HIV education and prevention among gay men, other MSM and transgenders in India (Chakrapani, Newman and Shunmugam, 2008). Internationally, evidence of human rights violations against sexual minorities and HIV and AIDS peer outreach workers in community and healthcare contexts continues to exist (Gutierrez et al., 2010). Research further suggests that despite the continued mobilisation of marginalised communities to challenge stigma and discrimination, changing the wider social context requires building more effective and targeted structural

change approaches to reduce HIV infections among MSM and transgender communities (Campbell and Cornish, 2010; MSMGF, 2010).

Gay men and other MSM and transgender who do not necessarily identify as 'gay' or 'MSM' remain hidden to HIV prevention and outreach programmes (Boyce, 2007; Dutta, 2009; Deb et al, 2009). This includes *panthis*, who are the masculine partners of the *kothis* (Dutta, 2009). *Kothis* is a term generally used to describe transgenders in India (Cohen, 2005; Khanna, 2007). Married men who have sex with men also remain 'hidden', often not receiving sexual health and HIV prevention information. This also applies specifically to *kothis*. These groups frequently remain outside targeted HIV prevention because it is hard to identify and reach them (Ramakrishnan, 2007). Despite the targeted interventions provided for visible gay men, other MSM and transgender communities (NACO, 2007) certain groups, due their invisibility, remain at higher risk for HIV infection.

It is also important to note that I view the continued use of the normative categories of 'MSM' and 'transgender' as problematic when the individuals being referred to can find these terms demeaning and irrelevant. While I use them in this paper, my experience suggests it is hard to believe in a singular 'MSM' or 'transgender' with a homogenized experience. Thus, I use these terms only because they are the dominant tropes, recognising they are specific subjectivities indexed by the fields of power of HIV and international development research and policy (Gosine, 2009). In this paper, I draw on the contextual backdrop presented above to consider how the use of digital media and the Internet can reach out to multiple audiences and particular groups of gay men, MSM and transgenders who remain 'hidden' or invisible.

HIV prevention, digital media and the Internet in India

A key challenge to the impact of existing HIV prevention approaches has been the widespread impact of the Internet on gay men, other MSM and transgender communities. This is especially true in Kolkata India. This is due to the ubiquitous access to the Internet at home and in public Internet cafes. Many MSM in Kolkata and across India access the Internet as a major resource in helping them acknowledge and 'gather more information about their sexuality' (Sahani, 2008, p. 85). Popular websites such as PlanetRomeo and Guys4Men work to shape sexual expectations, norms and practices of gay men, other MSM and transgenders (Silveira, 2010). These popular sites are used for socialising and 'hooking up' and provide anonymity for users who do not want to disclose their sexuality.

Shaw (1997) points out that whilst heterosexual people have access to participate in conversations outside the chatroom, for example the bar or a store to find a potential sex partner, not as many opportunities and options exist for homosexual or queer people. I prefer to use the identity marker queer for the purposes of this paper. The chatroom, and by extension the Internet, provides the means for queer people to meet and

socialise instantaneously. Shaw (1997) puts it this way:

In the gay world, a gay itch is satisfied by going out to a club or a party which requires a certain time commitment, while IRC is literally at my fingertips (at work and home). (p. 138)

Following Shaw's line of enquiry Mowlabocus (2010) points out that this relationship between the online world created by new media technologies and the offline world of an existing gay male sub culture complicates the questions concerning the character of online communities and identities. He says that 'the digital is not separate from other spheres of gay life, but in fact grows out of while remaining rooted in, local, national and international gay male subculture' (p.7).

Mowlabocus's statement about the digital being rooted in the local gay male subculture is important in understanding queer cyberspace. I shall argue whilst anti discrimination laws exist on a national level in the United Kingdom and some countries in Europe and parts of the United States of America, sodomy laws still exist in most parts of the world and until as recently as 2009, homosexuality was criminalised in India. It is within this hostile atmosphere that I situate queer men using the Internet.

Prior research in India has shown how digital spaces have evolved and changed perceptions of cruising, anonymity and safe sex (Seabrook, 1999). Ten years on, Internet social networking and dating sites have begun to take sexual health information and awareness seriously (Mowlabocus, 2010; Clift, 2010). As Figure 2 below shows, PlanetRomeo regularly hosts discussions on sexual health issues including HIV prevention. Both PlanetRomeo and Gaydar have started making sexual health information prominently available on their website. PlanetRomeo announced in 2009 that they would only offer porn films for download which depict safe sex and have explicitly stated they will not endorse or host bareback porn films for their users.

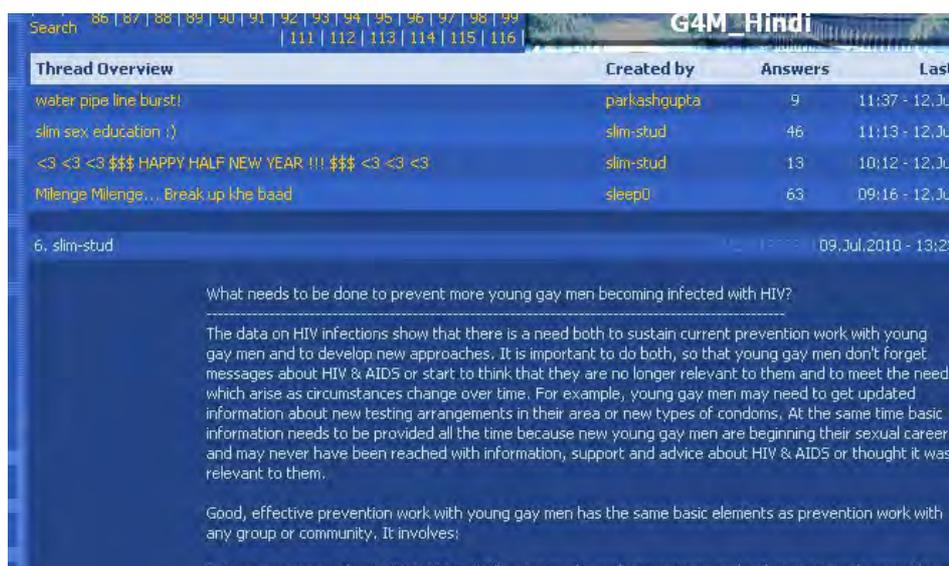


Figure 2. PlanetRomeo (India) discussion forum

Little critical analysis exists in the research literature to develop the evidence on the use and impact of these informal digital HIV prevention approaches or the extent to which they prevent/do not prevent new infections. To date, there has not been a serious effort to link these types of intervention with large scale public health and face- to-face community mobilisation efforts in India. Furthermore, these commercial websites lack a sustainable commitment to fighting stigma and discrimination and do not make available critical online educational opportunities. This suggests a need for context-specific community-based and led HIV prevention and education approaches (within the context specifically of India) using digital media and the Internet to develop theoretically-informed structural change approaches for community strengthening towards HIV prevention (Walsh & Singh, 2012).

Leveraging social networking sites for HIV prevention and education

In addition to the rise in cybercruising by gay men, other MSM and transgenders in India, exile is a very common motif among these communities (Rani, 2005). In addition, another significant aspect of queer lives in India is their stratified existence based on class dynamics. Gupta (2005) explains the frustration faced by kothis in mainstream society, where money and the ability to speak English dictate social boundaries. This makes it difficult for gay men, other MSM and transgenders who cannot speak English to interact with others.

This is where I believe digital media and the Internet can meet the challenges of HIV prevention for these invisible populations. I believe there is a critical need to address the intersection of HIV prevention with the lived experiences of violence, stigma and discrimination against visible and invisible gay men, other MSM and transgender communities. This is particularly paramount in light of increasing Internet ubiquity across the country. In what follows, I present SAATHII—a pioneer in using digital media and the Internet—to improve access to HIV prevention and capacity building approaches in Kolkata. My intention is to highlight SAATHII's innovative use of technologies in the hopes that other community based and led organisations can design similar HIV and AIDS education and prevention programmes and contextualise them for the diverse needs of gay men, other MSM and transgender communities they serve.

SAATHII as a response

Queer Kolkata

SAATHII's work with the existing gay, MSM and transgender communities draws on a thriving and existing queer scene in Kolkata. Unlike other cities in India, the queer scene in Kolkata, as well as Bombay, was visible by the 1990s. One of the earliest queer initiatives in Kolkata was the Fun Club (Dhall, 2005). The Counsel Club followed this in 1993,

which advocated slightly more political and social aims. At the same time, there was a noticeable growth of political and sexual health activism in Kolkata. For example *Pravartak* was a popular newsletter that was typewritten, photocopied and distributed discreetly amongst gay men, other MSM and transgender communities.

With the arrival of the Internet in India in 1995, several gay men in India began to subscribe to an email listserv called [Khush](#), which established one of the first online discussion spaces for lesbian, gay, bisexual and transgender (LGBT) identified South Asians (Sahani, 2008). However sexual health issues, at a time when HIV infections were spreading among gay men, other MSM and transgender communities in India, were largely absent from the early issues of the listserv. In an AIDS seminar in 1991, the key speakers insisted 'that India's culture would prevent AIDS from spreading much' (Dhall, 2005, p. 117). Given the need to interrupt this rather naïve and idealized heteronormative perception of what was happening, SAATHII emerged.

SAATHII

Solidarity and Action Against the HIV Infection in India (SAATHII) was founded in 2000 at the Retrovirus Conference in San Francisco, USA.. A registered charity in India and the USA, SAATHII addresses the sexual health needs of gay men, other MSM and transgender communities in India. SAATHII envisions a concerted response to the HIV/AIDS epidemic in India and strengthening the capacity of organizations working against the HIV/AIDS epidemic in India. SAATHII is currently funded by various national and international funding organisations which include The Elton John Aids Foundation, World Health Organisation (WHO), National AIDS Control Organisation, DFID - Civil Society Challenge Fund, Global Fund to Fight AIDS, Tuberculosis and Malaria, Elizabeth Glaser Pediatric AIDS Foundation, American Jewish World Service and Oxfam Trust. SAATHII currently operates from its main office in Chennai with regional offices in West Bengal (Kolkata), Andhra Pradesh, Rajasthan, Orissa, Manipur and Maharashtra. It has 60 staff in India and operates through a volunteer model in USA.

SAATHII in Kolkata

The Kolkata Branch Office of SAATHII was started in May 2002 and initially functioned from the home of the director Pawan Dhall. Programmes in the Kolkata office focus on information dissemination, research, networking, advocacy and training on interlinked issues of gender, sexuality, human rights, sexual and reproductive health, and HIV/AIDS prevention, care, support and treatment. Most of the Kolkata programmes involve partnerships with voluntary and government agencies working with sexual minorities, people living with HIV, women, youth and other vulnerable populations in eastern and north-eastern India. Programmes with a national coverage in partnership with civil society, government and multilateral agencies are also undertaken by this office.

SAATHII and the use of digital media and the Internet in HIV and AIDS interventions

SAATHII was among the first non-profit organisations based in India to use digital media and the Internet in HIV and AIDS interventions (Ramakrishnan, n.d). They have been working to bridge information, networking and other capacity gaps through various digital channels including: a website, listserv, a virtual mobile library, an interactive online interface and through films and music videos.

To address the problems of HIV prevention, capacity building and advocacy specifically targeted towards hidden gay, other MSM, and transgender communities, SAATHII strongly believed that it needed to leverage popular digital media and the Internet to be as effective as possible. This was both because of the extent of the penetration of the Internet into the lives of its service users, the numerous difficulties they faced in meeting publicly and their reluctance to meet up physically for fear of disclosure and stigma. Moreover, SAATHII also realised that this work needed to stretch beyond the Eastern region of India, and decided that widening access with digital media and the Internet would allow for national and global knowledge sharing and collaborative learning on the ongoing problems of HIV prevention among diverse MSM and transgender communities across the country.

www.SAATHII.org

SAATHII has its own website: www.SAATHII.org (Figure 3). The website serves as an online repository of its reports, research and educational resources for vulnerable populations. It contains an event list which notifies the general public about events related to HIV and sexual health, educational programs, and training workshops. The website also works as a human resources facility advertising latest job postings, conferences and funding initiatives from around the world.



Figure 3. [SAATHII Online Resource Centre](http://www.SAATHII.org)

The website boasts a comprehensive directory with information about drop in centres, testing and counselling services within different

regions of the country. The directory maintains a constantly updated report on those areas of the sector where urgent intervention is required. Thus it acts as a global communicating tool in getting together various funding and social policy bodies with service providers. The directory also has a print version used by almost 1200 organisations including NGOs, government agencies, hospitals, and educational institutions.

Many SAATHII staff members who are involved in the design and implementation of these initiatives and collating the information together identify as MSM or transgender, thus bringing to the work a reflexive awareness of their own lived realities and social positions. Some of the NGOs and organisations participating include National AIDS Control Organisation (NACO), WHO (India), UNAIDS, UNDP, John Lloyd Foundation, American Jewish World Service, as well as individual hospitals, colleges and businesses such as Hotel Arthi (Pune), Kumarasamy Engineering College, and HDFC bank.

SAATHII Listserv

SAATHII makes use of the yahoo listserv saathii@yahoogroups.com to keep members up to date with information related to news about HIV treatments, funding initiatives and training programs (Figure 4). Staff constantly post news on current research activities on HIV and sexual health initiatives around the world. This listserv provides MSM and transgender activists and educators access to advocacy and research initiatives. It also enables community-based organisations to join in various discussions and network, and acts as a site for e-conferencing between various stakeholders. Some of the recent discussions on the listserv have been about funding and consultancy invitations, and scientific and social updates on HIV relevant to MSM and transgender communities.

SAATHII mobile and virtual library

A physical mobile library was started in November 2007 as SAATHII expanded projects to cover more states within the Eastern region (See Figure 5). The project, called “Building the Capacity of People Living with HIV and Sexual Minorities in Orissa and West Bengal to Advance their Health and Rights”, is a five-year initiative and started in July 2008. It is supported by the UK Department for International Development – Civil Society Challenge Fund, Glasgow and an international NGO, Interact Worldwide, London.

The mobile library works as a reference collection of books, magazines, journals, newsletters, films and magazines along with a range of educational resources. Because of its ‘mobile’ nature, the library travels to rural and suburban regions of eastern India where people might not have access to these materials. The mobile library visits strategic public venues in Bhubaneswar, which is one of the larger cities outside Kolkata in the Eastern region, and other cities or towns where distribution and display of library material can take place along with interactive activities such as film screenings.

Perspectives from Kolkata, India

Messages: Simplify Expand (Group by Topic)	Author	Sort by Date
4602 HIV News from India (February 23 - March 08, 2011) ===== SAATHII Electronic Newsletter HIV NEWS FROM INDIA Source: Deccan Herald, Sify.com, The Times...	SAATHII News saathii news@...	Mar 8, 2011 10:37 am
4603 GLOBAL FUND OBSERVER (GFO) - Issue 141: 7 March 2011 GLOBAL FUND OBSERVER (GFO), an independent newsletter about the Global Fund provided by Aidspace to over 8,000 subscribers in 170 countries. Issue 141: 7 March...	EMPOWER INDIA ttn_empower@...	Mar 9, 2011 11:03 am
4604 Inauguration of web portal : stop trafficking Inauguration of web portal www.stoptrafficking.in To combat human trafficking and for better service delivery in India NGO, Arz (Anyay Rahit Zindagi) in...	Mariette Correa mariettecorrea	Mar 9, 2011 11:04 am
4605 Swasthya India and Jodhpur School of Public Health Congratulate Dr J Swasthya India and Jodhpur School Public Health (JSPH) congratulate Dr Joe Thomas on his appointment as Director of Technical Support Facility (TSF) South...	Ishdeep Kohli ikohli@...	Mar 16, 2011 10:46 am
4606 UNICEF invitation for consultancy: (HIV/AIDS, decentralization, Sout	L Ramakrishnan l_ramakrishnan	Mar 21, 2011 2:05 am
4607 HIV News from India (March 08 - 18, 2011) ===== SAATHII Electronic Newsletter HIV NEWS FROM INDIA Source: Express Buzz, The Times of India,...	SAATHII News saathii news@...	Mar 23, 2011 7:25 am
4608 GLOBAL FUND OBSERVER (GFO) - Issue 142: 17 March 2011 GLOBAL FUND OBSERVER (GFO), an independent newsletter about the Global Fund provided by Aidspace to over 8,000 subscribers in 170 countries. Issue 142: 17 March...	EMPOWER INDIA ttn_empower@...	Mar 23, 2011 7:25 am
4609 Re: PMTCT_Cases Dear Sowmya. Greetings from Prayas! Thanks for your answers. However as regards case 1, as far as I know the evidence presented was a comparison was between...	Dr. Vinay Kulkarni prayashealth@...	Mar 23, 2011 4:48 pm
4610 Scientific Updates On HIV/AIDS À SAATHII Electronic Newsletter HIV/AIDS Updates À À SOURCE: Web:À Medscape_HIV@... Medscape HIV/AIDS à€" March 23, ÀÀÀ 2011À Blackwell...	saathii	Mar 26, 2011 9:21 am

Figure 4: SAATHII Yahoo listserv (India) discussion forum

SATHII's virtual library (Figure 5), which is integrated into the main SAATHII website offers users opportunity to browse through recent research and case studies on HIV and related topics. The library also includes resources for funding initiatives.

The screenshot displays a list of five documents available for download in the SATHII E-Library. Each entry includes a PDF icon, a title, and a 'hot!' status indicator. Below each title are three buttons: 'Download', 'View', and 'Details'.

- WHO - Priority HIV and interventions MSM May10** hot!
- UNGASS - India Progress Report 2010** hot!
- Population council - Translating medical evidence into practice: Working with communities and provid** hot!
- Population council - The PLHA-friendly Achievement Checklist** hot!
- Population council - Sexual harassment in the workplace: Experiences of women in the health sector** hot!

Figure 5: SATHII's E-Library

Mobile counselling

SAATHII, in addition to physical counselling services, also provides counselling services through telephone and email. SAATHII set up a mobile HIV counselling and testing unit, certified by NACO, to provide flexible access with hours that are convenient to clients in hard-to-reach areas. Telephone and email counselling is useful as it provides a preliminary introduction between the service user and the organisation. Counsellors also help to determine what the needs are of the user and advise them, building a level of confidence amongst the service users before they decide to go for a session in person.

E-conferencing and forums

SAATHII is in the process of creating an Eastern India coalition with other groups and organisations working in the HIV and AIDS sector. Apart from regular face-to-face meetings, the coalition also exchanges news and ideas through e-conferencing and forums. An example of the impact of the coalition's use of e-conferencing includes restoring the property ownership of a woman living with HIV in Asansol, Burdwan district of West Bengal. In partnership with the Burdwan Society of People Living with HIV AND AIDS, the legal Unit of SAATHII facilitated the participation of its coalition partner in a unique Christian theological roundtable on human sexuality and the Delhi High Court ruling on Section 377 of the Indian Penal Code. This was a programme jointly organized by the National Council of Churches in India, Sceptre (an extension programme of the Senate of Serampore College located in the Hooghly district of West Bengal), Christian Institute for Study of Religion and Society, and the Student Christian Movement of India.

Music and videos

The initial lack of public discussion around HIV and sexual health, along with the overtly medical language used in health and community settings, has been a deterrent in connecting the public with HIV prevention and care. SAATHII finds music videos and films beneficial tools to spread HIV prevention messages quickly in a medium that is both appealing and easy to understand. Music and video for HIV awareness raising campaigns have also begun to appear on the national level. The success of films such as *Phir Milenge* and *My Brother Nikhil* and Shubha Mudgal's popular *Mati* song (AIDS- INDIA listserv, n.d) in sensitising the public about HIV and AIDS cannot be overstated. Recent approaches using films and music videos have led to widespread public attention and interest on HIV and AIDS and managed to reach out to a wider range of people.

One of SAATHII's partners in the West Bengal state wide sexuality NGO coalition is [Elaan](#). It is a youth group that works with schools and government agencies to develop counselling and sensitisation to sexual health issues for teenagers and urban youth. SAATHII and Elaan collaborated with consultants, and MSM and transgender identified individuals to design and implement a HIV awareness raising campaign using music and videos. This campaign also involved partnering with

several music bands, and holding an annual rock concert – White Noise on World AIDS Day.



Figure 6. Elaan White Noise Poster, 2006



A visual journey into the lives of lesbian, gay, bisexual and transgender people in West Bengal and Orissa: An advocacy initiative of SAATHII, Calcutta Office and Calcutta-based independent photographer Kallol Nath to "demystify" queer lives

Reproduction of photographs requires permission from SAATHII (saathii@yahoo.com).
Credit: Kallol Nath

Individuals interested in being on either side of the camera are welcome to get in touch to add to this initiative!

Courtesy Elton John AIDS Foundation, London, May 2008

Figure 7. Photo Feature from SAATHII [Facebook](#) Page

Using Facebook to demystify queer lives in India

SAATHII uses Facebook to keep in touch with all their service users and the larger gay, other MSM and transgender community in India.

Through the innovative Santi Seva Development Project, SAATHII worked with the transgender population in Bhadrak, Orissa to document their histories, share their struggles, write their own stories and share them on Facebook. This empowerment project culminated in a visual collection documenting their lives, which was showcased as a poster in the 2008 International AIDS conference. For the first time, this transgender community decided to leverage the power of the Internet to share their stories. SAATHI supported them by setting up an online exhibition on their Facebook group (Figure 7). By using Facebook, the impact and visibility of the project was further expanded. Such capacity building activities have been effective in raising awareness, increasing solidarity, mobilizing social capital and strengthening clout in a stigmatising context to reduce vulnerability to HIV and AIDS.

Queer Film Festival

India has always had a very 'filmic culture' and is hugely influenced by films. Gokulsing (2004) has argued that "Cinema in India makes available a semioticised space for the articulation of the imaginary and its formation within the phenomenology of the local." (2004, p. 78) Films in India allow imaginations and fantasies to be played out, within appealing specific local contexts. Understanding the potential impact and outreach of films, SAATHII established the [Siddhartha Gautam Film Festival](#) in Kolkata in 2003. This festival showcases films on queer sexuality, HIV and AIDS issues, and provides a lively space for discussion and debate. Because of its' popularity, the film festival has now been made a mobile travelling festival.

SAATHI engaged a popular Bengali band Cactus to produce a music video, Pokkhiraj (Figure 8). This approach involved adapting a popular cultural product to craft a story and script lyrics for a powerful song. This music video had the intention to change mindsets and express solidarity with lesbian, gay, bisexual and transgendered (LGBT) people. It also urges and empowers people to break the entrenched barriers of prejudice. This music video reached millions of homes within West Bengal and received very favourable feedback.

SAATHII has also produced three films on transgender issues and the impact of HIV and AIDS on the community (See Figure 9). Funded by the United Nations Development Programme (UNDP), Thoughtshop Foundation and SAATHII, three movies were produced: Amitava Sarkar's [Rupantar](#) (Transformation) (2008) and *From the Third Eye* (2009), a film that documents the achievements of several "transgender heroes", and Debashis Ray's *Shuru* (Beginnings) (2008). The films build on real life situations from West Bengal and elsewhere to stress the point that HIV prevention, care, support and treatment are not only possible in transgender communities, but a strong antidote to stigma and discrimination surrounding HIV in general. The films also touch on issues of HIV caregivers, sexual and reproductive health, and emphasise the importance of gender empowerment in tackling the HIV epidemic.



Figure 8. Pokkhiraj Music Video

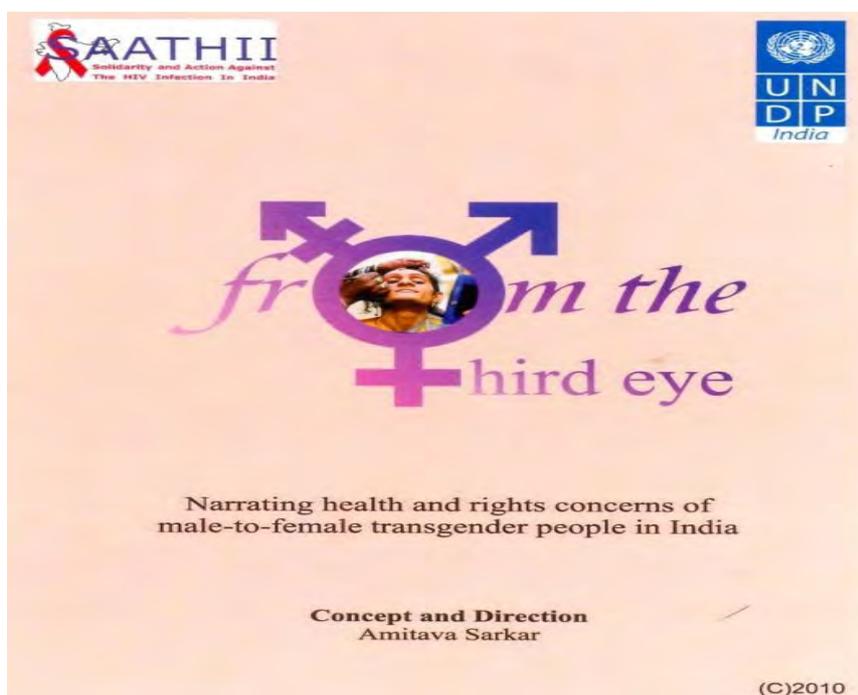


Figure 9. From the Third Eye film poster

SAATHII has also supported two major Bollywood productions which deal with issues related to sexuality and HIV and AIDS: [My Brother Nikhil](#) (Onir, 2005) and [I Am](#) (Onir, 2011). These films are revolutionary for India because they take the issues of HIV and AIDS out into mainstream Indian Cinema. By collaborating with mainstream celebrities like Onir to produce films on issues of gay men, other MSM, transgenders and HIV, SAATHI has deployed the existing cultural resources of vulnerable communities to educate a broad and diverse audience all over India and abroad.

Lessons learnt

As SAATHII begins to think about how to move forward from their initial efforts, a few lessons have emerged to ensure the use of digital media and the Internet create sustained connections between gay men, other MSM and transgender communities with valuable knowledge and practices to fight violence, stigma and discrimination.

Language barriers

One of the main limitations of using digital media and the Internet in HIV and AIDS projects has been the language barrier. Because most existing resources available online are in English, significant numbers of gay, other MSM and transgender communities still do not have access to these resources. In contrast, Sappho for Equality, a lesbian support group in Kolkata, produces a bilingual newsletter entitled Swakanthey (Figure 10). This approach has helped them to reach out to individuals in the community who do not speak English.. SAATHII too has begun to translate, publish and disseminate information online in regional languages in addition to English. In fact multilingual skills has become essential for SAATHII in their recruitment. Still more work needs to be done to better understand how to sustain the impact of online HIV prevention, advocacy and capacity building by addressing language barriers.

Addressing privacy and ethics issues

Another emerging problem is the issue of privacy and ethics. Although projects are visually documented for impact analysis and dissemination, many of the MSM and transgender participants I spoke to have felt that visibility threatens both their status and their sexual orientation. Whilst the efficacy of the Internet for communication and outreach is unparalleled, there is a particular need for vigilance around the protection of sensitive personal information stored online (Times of India, 2006; Boyce & Hajra, 2011). To address this issue, SAATHII makes sure that any visual material that is recorded during an event is only used for official purposes and is only available to the public with the consent of the individual who has been photographed or recorded. There is always a need to be careful about representing people in a MSM or transgender context. Boyce and Hajra, who worked on a photographic project with the MSM and transgender community in West Bengal articulate their concern, “We were concerned that people may not wish to be portrayed in a photographic project as a man who has sex with men or as a person of transgender.” (2011, p.8)

Building digital literacies and capacities

While SATHII's initial efforts have allowed MSM and transgender communities to increase their access to information, future work needs to build their digital literacies and skills to transition from content consumers to meaningful participants. It is still true that much of India is

untouched by the digital revolution and Internet has only reached

a select few in the urban cities and fringes. Even in cases where the Internet has reached rural areas, people may not know how to use a computer. Thus there is an immediate need to implement complementary programs towards reducing this digital divide.

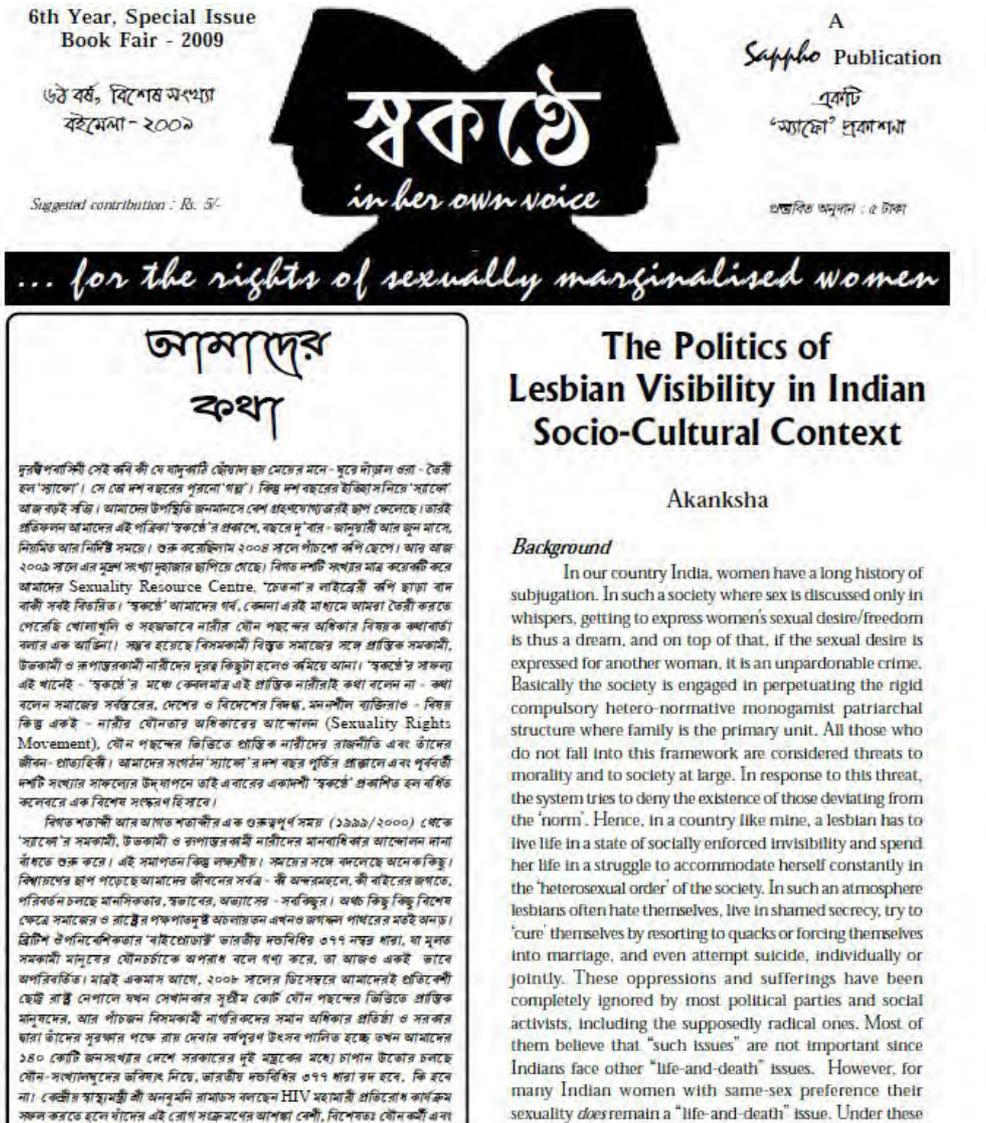


Figure 10: Swakanthey newsletter

Limited Internet access

The limited access to the Internet by gay men, other MSM and transgenders in rural or semi urban areas where there is little or no access to computers can mean that many potential service users do not benefit from perceived benefits in widening access via these digital means. In such cases, print dissemination is the only way. However of late, mobile phones have made an incursion into rural India for e-health and e-learning use, and opportunities exist for SAATHII to leverage these developments in line with its current suite of programmes.

Strategic networks

Sustaining strategic networks through e-forums moderated by facilitators for sharing knowledge and for advocacy has allowed SAATHI to leverage their limited resources to benefit large sections of the MSM and transgender communities across India. Through the sharing of experiences in online spaces, a culture of collaborative learning has emerged that overcomes historical regional separations.

As a result, new and better practices have been identified, collaboratively developed and implemented. The enhanced strategic support from mentors and experts in the e- forums for testing and trying out new ideas has increased the confidence of HIV prevention educators and activists. This approach also implies an opportunity to rethink prevention, advocacy and capacity building to focus on the added value of strategic networking to tackle specific problems in practice, rather than locating such efforts in reified static notions of ‘communities’ that NGOs can ‘intervene’ into.

The role of key individuals

What we have also observed in this project is the important role of key individuals in building and sustaining a network with digital media and Internet. The tools and resources we created and implemented were not simply ‘put out there’ but needed to become naturalised as part of service users’ daily practices if they were to have any impact. Over time, these key individuals instigated crucial processes to ensure the success of our project. They created a ‘one-stop’ legitimate portal for gathering and disseminating valued information on sexual health, prevention, treatment, care and support to disrupt the negative and incorrect information on a variety of websites. They provided opinions and advice to make sharing tacit knowledge in online spaces a valued resource for service users in remote areas lacking information. As these key individuals built trust and resilience, over time, the network began to transition from merely downloading to uploading and exchanging resources with one another. These experiences challenge the traditional ‘training-of-trainer’ approaches that dominate HIV prevention today. Instead, it suggests a need to understand and design more effective digitally mediated educational approaches to mobilise HIV prevention activists and educators in ways that facilitate their capacities as boundary crossers, knowledge mediators, and network sherpas with digital media and the Internet among gay, other MSM and transgender communities.

Summary of lessons learnt

Overall, SAATHI has produced new ways of communicating with its stakeholders, through the use of websites, online discussion forums, listervs and counselling services. Gradually, a new framework for HIV prevention, capacity building and advocacy has emerged that leverages digital media and the Internet productively. Within this framework, gay, other MSM and transgenders can become collaborators in shaping digital

interventions. We have found that these new identities sustain connections over time and distance, shape discourses to challenge persistent stigma and discrimination, and connect advocacy and capacity building with the enactment of positive queer identities.

Such work is open-ended and flexible, rather than a one-off use of technologies. It requires practitioners to rethink positivist notions of 'interventions' reflexively by first having clear understandings of the critical needs of MSM and transgender communities. It can work when digital media and Internet use align with the strategic deployment of advocacy and capacity building resources. It can also become more productive when integrated with organizational and national HIV policies and programmes, donor and stakeholder coordination, and continued deliberation on the lessons from the experiences of users. For instance, as a result of the ongoing nature of its work, SAATHII has learnt that it made strategic sense to integrate e-learning courses into its overall project design (Figure 11). Through the widespread use of courses such as grant proposal writing and impact evaluation by staff from community-based organisations, the Internet has proven beneficial in dealing with issues of scaling-up capacity building in practical ways. These digital approaches supplemented outreach activities and did not take activists and practitioners away from their communities.



Figure 11: [E-learning courses](#) at SAATHII

Conclusion

In this paper I have described SAATHII and shown how its use of digital media and the Internet can make a positive contribution to HIV prevention, advocacy and capacity building approaches among gay, other MSM and transgender communities. I have argued why it is important for community-based and led organisations like SAATHII to leverage multiple platforms to redesign conventional and dominant approaches to HIV prevention in a digital world. To conclude I now

briefly reflect on SAATHII's work with digital media and the Internet from a postcolonial and queer perspective. I provide my reflections as an emerging South Asian queer scholar based on my experiences in Kolkata India.

Virtual spaces have the potential for greater deterritorialisation and the performance of productive identities (Wakeford, 1997; Campbell, 2004; Mowlabocus, 2008, 2010). Wakeford (1997) citing Kira Hall and Judith Butler sees identity as fluid and performative and the cyberspace as a place "where you can be whoever you want to be" (Ibid, p. 25). Butler (1999), writing about this performativity says, "practices in both homosexual and heterosexual contexts...open surfaces and orifices to erotic signification or close down others [and] effectively reinscribe the boundaries of the body along new cultural lines" (1999, p.169).

In addition, Mclelland (2002) and Mowlabocus (2010) argue that virtual spaces can break down social and cultural boundaries. As such, virtual spaces can provide a safe space for performance of identities to make new practical knowledge and sensitivity about HIV risk. These approaches have been tried with MSM and transgenders in Thailand (Walsh, 2008; Walsh, Lasky and Morrish, 2011; Chaiyajit and Walsh, 2012). This prior research has potential for use in India, as it implies that digital HIV prevention and education can affect and respect agency, while situated in the sexual and social practices of gay men, other MSM and transgenders, in ways that traditional decontextualised approaches such as workshops may not.

Unlocking the performance of productive gay, other MSM and transgender identities for HIV prevention is critical when seen against the historical shifts in sexual health policies and practices in India from colonial to contemporary times. Ballhatchet's (1980) pioneering work looked at colonial interventions during eighteenth and nineteenth century India through the building of 'lock hospitals'. These were one of the first specialist hospitals created to treat soldiers and prostitutes suffering from sexual infections. Since these early interventions, India is a country where tradition and modernity in gender, sexuality and sexual health have continued to play against each other (Vanita and Kidwai, 2000; Vanita, 2002). Whilst 'Western' education, knowledge and skills are being encouraged and supported through state mechanisms under the guise of economic progress (Shrivastava, 2005; Vanita, 2002), the state and the international development sectors also check these influences through managing the sexual respectability and impulses of the Indian man (Shrivastava, 2005).

Masculinity has largely been conceptualised as a homogenous and monolithic construct, often identified by what is not feminine, thus creating narratives of a singular way of being masculine, and ultimately creating a hegemonic masculinity (Connell and Messerschmidt, 2005). Against this, Mowlabocus explores the idea of the sociality of the online queer space, arguing "websites such as [Gaydar](#) have provided important resources to combat the isolation and marginalisation that growing up gay in a straight world often engenders" (2010, p. 87). The queer space

offered by the Internet, and in this example SAATHI, thus affirms gay life by emphasising and centralising participants' sexuality and gender identity. However Alexander (2002) is quick to point out that such affirmation comes with a cost:

Imposition of boundaries, including some unfortunate bigotries within the gay community itself... "No fats, femmes, fish or trolls please!" – a biting reminder that in-group membership status within the gay male community often comes at a certain price, extracted on the body of those seeking inclusion. (p. 90)

This makes me question, what sorts of Indian masculinities are valorised as objects of desire formation and what remains trapped in a victimised femininity. Cyberspace despite disembodiment of the physical body, identifies the preoccupation of the queer individual with the 'real' body. Mowlabocus citing Campbell's work says, "Gay men... are not only regulated by such systems, they are also rendered visible via such processes" (2010:78).

Against these changing perceptions of hegemonic Indian masculinities, queer sexuality is still seen as a 'western import' by mainstream institutional, ideological and cultural discourses (Bhan and Narrain, 2005; Bose and Bhattacharya, 2007). Despite the repeal of Section 377, homosexuality remains a hot political issue in India. An example comes from recent comments made by an Indian minister at the Supreme Court hearing on Section 377, where he maintained homosexuality was illegal and not healthy for the cultural fabric of India (Times of India, 2012).

The emergence and significance of a digital queer sexuality in India, despite the rise of gay prides, online spaces, and LGBT associations, thus becomes even more critical in confronting such a constrained approach to rationally managing masculinity, sexual health and HIV risk in an increasingly digital world. Yet, frontline workers, educators and HIV prevention activists who teach about sexual health and human rights face tensions and dilemmas in handling controversial topics about culture and sexuality. Messages in curriculum and media that emphasise family values and heavily check sexuality through stigma and 'hetero-nationalist' rhetoric (Gosine, 2009) condemn and reframe sexual behaviour and practices in the name of rational behaviour change. Such denial of desire, pleasure and intimacy are unhelpful for young people and marginalised communities struggling with sexuality and gender identity issues. To date, the potential the emerging Indian digital queer culture in disrupting regulatory habits and choices to improve the impact of normative HIV prevention and education has not yet been explored.

Against these changes and complexities, the call now is to build AIDS-resilient and AIDS-competent communities to fight HIV and reduce vulnerability. This has led to researchers calling for structural interventions that consider the cultural, legal and economic aspects of health and human rights (Auerbach et al., 2010), and the critical use of networking and digital technologies for community-based and led HIV prevention and

education (Walsh and Singh, 2012).

I suggest that how Indian gay, other MSM, and transgender communities can adequately meet this challenge and address these recommendations is by an analysis of the ways in which the complexities of masculinity and sexuality are being performed by Indian gay, other MSM and transgenders in digital spaces. The potential for true growth lies in navigating and confronting the many difficult tensions of sex and sexuality head-on, whether in digital spaces or in society. Benchmarking the best sexual health and community development practices of international donors and NGOs working in HIV prevention interventions will involve bringing in postcolonial and multicultural forms of inquiry that disrupt technical-rational thinking and programming about norms of targets, indicators and outcomes, and idealised abstractions of behaviour change, solidarity and 'empowerment' for those labelled as 'vulnerable communities'. These approaches will open up practices and spaces to widen creativity and imagination in the negotiation of non-colonising sexual identities to align with the spirit of 'redesigning the AIDS response' (Larson et al., 2011; Gosine, 2009)

It appears that international agencies, national actors, and civil society organisations are serious about fighting HIV in gay, other MSM and transgender communities in India. To move forward, we will now have to decide which taboos on gender, sexuality and masculinity have to be rearticulated with the dynamic use of digital media and the Internet for diffusing power and contesting heteronormativity in policy and programming practices targeted at gay, other MSM and transgender communities in order to recraft the as yet unrealised nirvana of Universal Access to health and human rights.

I conclude that if HIV and AIDS stakeholders want to work critically with gay men, other MSM and transgender communities in social and legal environments that continue to deny human rights and equitable access to healthcare, it is time to deal with the changed sexual behaviours of gay men, other MSM and transgenders precipitated by the use of digital media and the Internet. The kind of interventions SAATHI has kicked-off in India, based on working with communities to leverage digital media and the Internet in ways that are useful and valuable in expanding access and fighting stigma and discrimination, are productive in rethinking existing HIV prevention, advocacy and capacity building approaches. Ultimately, solving the problems of community-based and led HIV prevention with digital media and the Internet by working with the lived realities and multiple identities of gay men, other MSM and transgender is more empowering than idealised abstractions of solidarity and 'empowerment'.

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Chapter 6

Innovative digital HIV and AIDS education and prevention for marginalised communities: Philadelphia's Frontline TEACH

Val Sowell
Juliet Fink
Jane Shull

In this chapter, Val Sowell, Juliet Fink and Jane Shull from *Philadelphia FIGHT* present evidence and insights on designing a successful open distance flexible learning (ODFL) programme called Frontline TEACH. Their chapter highlights how traditional AIDS Service Organisations can use open access digital technologies to design digital HIV education that serves the needs of marginalised communities from lower socioeconomic backgrounds. Frontline TEACH has significant implications for the theory and practice of using open-access community-based digital HIV education and prevention programmes because it not only widens access, but also improves health and literacy outcomes.

Introduction

Three decades into the HIV epidemic, American mass media struggles to convey effective messages about HIV and AIDS regarding the complexity of prevention, care and support. Herek, Capitanio and Widaman (2002) conducted national telephone surveys examining the prevalence of AIDS stigma and misinformation in 1997 and 1999. When they compared their results to a similar survey from 1991, they found that while overt expressions of stigma around HIV and AIDS had declined by 1999, “inaccurate beliefs about the risks posed by casual social contact increased, as did the belief that people with AIDS (PWAs) deserve their illness” (p. 371). Similar findings were uncovered in a later study (Herek, Widaman and Capitanio, 2005) that observed areas of significant HIV misinformation among 1,283 American heterosexuals. For example, “nearly one fourth of male respondents and more than one third of female respondents believed that a single act of unprotected intercourse between an uninfected man and woman can cause one of the partners to develop AIDS” (p. 30). Their study also noted that “accurate beliefs [about HIV transmission] were more common among respondents with higher socioeconomic status” (p. 31).

We have found that for adults from low socioeconomic backgrounds, whether they are living with HIV or at risk of infection, accessing reliable information about the virus online is often difficult, even impossible. Searching for health information effectively online requires high levels of computer and digital literacy. Many individuals from marginalised communities may not have regular access the Internet at home and may

face restrictions accessing the Internet in public spaces. Additionally, the Internet may be too expensive to access from their mobile phones.

Decreased attention to HIV in American mass media since combination therapy became widely available is simultaneous with the growth of the Internet as a source of health information. One recent survey found that of the 74% of 3,001 respondents who reported using the Internet at least occasionally, 80% have looked online for health topics (Fox, 2011). However, the remaining 26% of those who did not use the Internet may represent the populations most at risk for HIV infection. When Benotsch, Kalichman, and Weinhardt (2004) surveyed 324 adults living with HIV in America concerning their Internet use for health information, they observed that “[w]omen, ethnic minorities, and persons living in poverty represent the populations most likely to be cut-off from information technology, and the same demographic characteristics represent the fastest growing populations of people living with HIV and AIDS” (p. 1004).

Kalichman et al.’s (2006) research presented similar results showing that “assigning higher credibility to unfounded Internet information was predicted by lower incomes, less education and avoidant coping styles” (p. 205). In their discussion, the investigators made the following recommendation:

People living with HIV infection, as well as other life-threatening illnesses, who use the Internet for health information should be informed about the potential for misinformation and unfounded claims online ... AIDS service organizations, residential centers, and clinics that have Internet access for people living with HIV/AIDS can offer skills-based educational programs for people living with HIV infection to improve their critical thinking skills and train individuals in systems and strategies for evaluation of health-related Web sites (p. 210).

The challenges of digital health information and education

In contrast to static information-disseminating approaches to online HIV education and prevention resources, there have also been public health Internet-based HIV prevention education attempts to change behaviour. Bowen et al. (2008) found that “the Internet appears to be an effective method of delivering HIV prevention” (p. 463) for rural men that have sex with men (MSM) in America. Another brief online video intervention to promote HIV prevention among MSM in New York City resulted in significant, self-reported increases in HIV disclosure and decreases in risk behaviour three months after MSM viewed the video (Chiasson, Shaw, Humberstone, Hirshfield, and Hartel, 2009).

The increasing usage of social networking technologies such as Facebook, mobile phones and MP3 players offer innovative possibilities for further enhancing the prospects for digital HIV prevention and education (Walsh, 2011; Schenk and Singh, this issue). Social media for peer-led HIV prevention through Facebook and MSN messenger have proven effective among marginalised communities such as transgenders in Thailand (Chaiyajit and Walsh, this issue) and African American and Latino Men in California (Jaganath et. al. 2011; Henry et al., this issue). The success of

these peer-based approaches indicates the importance of locating HIV prevention and education in digitally mediated social-sexual practices of marginalised communities (Walsh and Singh 2012).

Another recent development is the rapid acceptance of Open Distance Learning (ODL) as an effective educational approach in health care (US DOE, 2010; Bradley and Yates, 2000; Lewis 1999). ODL is an umbrella term for teaching and learning that mobilises different course design and technological facilities to deliver targeted educational programmes and support mechanisms for a variety of populations facing barriers to learning (Rocha Trinidade, et.al., 2000). Among students from low socio-economic backgrounds and those with no or little prior experience with computers, effective ODL approaches in health care combine targeted support for individuals to access health information and resources with flexible learning opportunities (UNESCO, 2012).

Overcoming capability constraints (Birochi and Pozzebon, 2011) with an understanding of the wider social contexts that influence the decisions and designs of digitally mediated education for adults from low socio-economic backgrounds is critical (Aderinoye and Ojokheta, 2004; Rocha Trindade, et. al., 2000). In the context of HIV education and prevention, Pridmore and Yates (2005) argue that ODFL (open distance and *flexible* learning) design frameworks are more effective because they “overcome the various forms of distance and separation...” (p.5) and “social inequality, social exclusion, sexism, racism, and homophobia.” (p.23). ODFL approaches work to provide learning opportunities where attempts are made to intentionally reduce the barriers that can inhibit learning with the goal of enhancing access. Hodgson (1993) identifies these barriers as the possible physical separation of learners from teachers, or even the inability of learners and teachers to meet at mutually convenient times.

ODFL interventions in Mozambique and South Africa have been shown to “mitigate the impact of HIV and AIDS on affected young people by providing materials that give practical advice and emotional support for their everyday lives” (Pridmore and Yates 2005, p. 22). A core recommendation from this work is that educators working with highly disadvantaged populations at risk of HIV should “meet their needs for basic education and livelihood programmes so that they can tackle structural barriers and have real choices in their lives. ODFL could do much to overcome these barriers, and offer many wider, life-giving choices” (p. 23). They make a strong argument that ODFL “must build empowerment and motivation, strengthen supportive social networks, and increase access to services and links to outside agencies” (p. 22).

There is a growing availability and use of online HIV and AIDS resources (Table 1). But, these remain inaccessible to people from lower socioeconomic backgrounds and those who lack of high levels of literacy, including computer and digital literacy. Additionally, marginalised communities disproportionately at risk of HIV infection lack opportunities to engage in structured and easily accessible ODFL approaches, particularly in an enabling context that builds learning capacity and provides access to resources. Addressing these challenges in our context of inner-city

Philadelphia, we have adapted a successful face-to-face HIV education intervention for people living with HIV and AIDS—Project TEACH—to serve HIV-negative people through an ODFL format. In what follows we describe these innovative programmes within the context of Philadelphia.

Organization	Type of Online Resource	Drawbacks
Project Inform	Fact sheets and articles regarding living with HIV	Non-interactive web resource
AIDS Info Net	Low-literacy fact sheets on many aspects of HIV disease	Non-interactive web resource
The Body	News, fact sheets, question and answer forums, and articles regarding living with HIV	Various reading levels available; static question and answer forums
The Body Pro	News, fact sheets, question and answer forums, and articles regarding living with HIV	Sophisticated information for medical providers and AIDS service professionals; static question and answer forums
PubMed	Journal articles from multiple disciplines and reference materials	Highly sophisticated medical vocabulary; non-interactive web resource; corporate ownership/authors
MedLine Plus	Fact sheets and articles on many health conditions, including HIV and AIDS	Non-interactive web resource with the exception of one interactive tutorial
HealthHIV	Educational webinars and technical assistance	Intended for AIDS service professionals
HELP	HIV education videos for people living with HIV	Provides widget to make embedding their videos on your website easy; however, only two videos are available

Table 1. Organisations providing online HIV educational resource and their drawbacks.

HIV and AIDS in Philadelphia

Cumulatively in Philadelphia, 28, 274 people have tested positive for HIV from 1980-June 2010, (Shpaner, Brady and Eberhart, 2009) with 19, 237 people known to be living with HIV at the end of 2009. In 2006, Centers for Disease Control (CDC) data indicated that “Philadelphians are being infected at a rate more than 50 percent higher than residents of New York City and five times the national average” (Sapatkin, 2008). Fortunately, Philadelphia also has a vibrant community of people who are active in the fight against HIV, including one of the largest remaining chapters of ACT UP, the AIDS Coalition to Unleash Power, which has been meeting weekly since 1988. [ACT UP Philadelphia](#) has been a central force in the fight against AIDS in Philadelphia. Over the years it has been formative in creating, and in resisting the closure of, many community prevention and treatment interventions in the city. One prominent and sustainable intervention, Project TEACH, is administered by Philadelphia FIGHT.

Philadelphia FIGHT(ing) back

[Philadelphia FIGHT](#) is an HIV and AIDS service organisation (ASO) that originated as a clinical research organisation in 1990. It has expanded to include:

- An HIV specialist clinic ([Lax Center](#));

- Mental health and recovery treatment ([Diana Baldwin Clinic](#));
- The [AIDS Library](#), Internet and computer access and digital literacy courses ([Critical Path Project](#));
- A youth prevention and drop-in programmes ([Youth Health Empowerment Project](#));
- Drop-in services for people recently released from jail or prison ([Institute for Community Justice](#));
- Ongoing support groups for people living with HIV and AIDS (PLWHA); and
- An innovative treatment education course for PLWHA, [Project TEACH](#).



Figure 1: Philadelphia FIGHT's website, featuring the staff profile of one of the authors.

Project TEACH is open to anyone with HIV. Class students represent an unusually vulnerable and disenfranchised population: 72% are formerly incarcerated; around 80% have a history of substance abuse of which 25% are intravenous drug users; and about 10% are sex workers. Furthermore, 24% are gay men and other men who have sex with men (MSM) and 73% are African-American. 71% percent of our students live at or below US federal poverty levels. Many struggle with HIV-related dysfunctional beliefs and suffer a history of repeated sexual and physical trauma (Philadelphia FIGHT, 2011). Additionally, Philadelphia is a poor city with a 27% poverty rate (Lubrano, 2011). 11% of adults reported skipping or reducing the size of a meal because they could not afford enough food (Public Health Management Corporation's Community Health Data Base, 2010).

Project TEACH is a flexible, non-judgmental, theoretically informed educational approach that enhances students' skills and confidence in

changing health behaviours (Prochaska and DiClemente, 1982). Project TEACH draws on evidence of the effectiveness of this approach in HIV prevention programmes for high risk individuals who engage in high risk behaviours, including gay men and other men who have sex with men (MSM), (Parsons, et al., 2005) sex workers (Rekart, 2005), and heterosexuals (Zambrana, Cornelius, Boykin, and Salas Lopez, 2004).

Project TEACH Ch-ch-ch-changes

While the course structure has remained relatively stable since 1996, the content covered in Project TEACH has changed to keep up to date with the latest evidence-based HIV treatment and prevention information. Staff has remained engaged in reviewing and updating the curriculum to reflect current understandings of HIV treatment and prevention research. This is the same adaptive spirit that has allowed staff to bring the benefits of Project TEACH to the broader community in Philadelphia. Currently, Project TEACH is offered four times a year, alongside three ongoing “spin off” or sibling classes: TEACH Outside, Latino TEACH, and Frontline TEACH. TEACH Outside is for PLWHA who have a history of incarceration and emphasises connecting to resources and surviving life ‘on the outside’ of prison or jail. Latino TEACH is a class for Spanish-speaking PLWHA, collaboratively adapted by Philadelphia FIGHT and [Prevention Point Philadelphia](#), the city’s only syringe exchange programme. Having set the context for our intervention, in what follows we present our ODFL approach, Frontline TEACH.

Frontline TEACH

Frontline TEACH was originally developed by Philadelphia FIGHT in 1999 as a face-to-face course for HIV-negative individuals from HIV-affected communities. Although Project TEACH had addressed the needs of PLWHA, many graduates had sexual partners, family members, loved ones or other HIV-affected community members who expressed a need for education and support in the same topics. These individuals, affected by and potentially at risk for HIV, include injecting drug users, gay men or other men who have sex with men, sex workers, and heterosexuals who engage in unsafe sex. From 1999 to 2007, Frontline TEACH was delivered at least once a year as a 5-week face-to-face course. Frontline TEACH had no financial backing or grants during this period. The objectives of Frontline TEACH are:

- To provide accurate information about HIV and AIDS, including:
 - Relative risks of HIV transmission through sexual behaviors, shared needles, and perinatal transmission, and the accompanying prevention techniques
 - Debunking myths regarding HIV transmission through casual contact
 - Knowledge about HIV treatment options, goals, and guidelines
- To support individuals in recognising and combating HIV stigma in community settings

- To connect participants to resources, including health care, harm reduction, and AIDS activist organizations.

Frontline TEACH recruited course students through the approaches shown in Table 2 below:

Target Population	Recruitment Strategies
Sexual partners and families of PLWHA	Referrals from Project TEACH graduates; word of mouth; Frontline TEACH applications at health fairs
People at risk from HIV infection (gay/MSM, IDU, sex workers)	Identified by FIGHT staff, Project TEACH or Frontline TEACH graduates, staff of ASOs or allied organisations
Staff of ASOs or allied organisations, or aspiring job seekers	Referrals from Philadelphia FIGHT community members; self-directed web research

Table 2. Target populations and recruitment strategies for Frontline TEACH.

The different constituencies of Frontline TEACH have distinctive education needs, but share a need for comprehensive knowledge of HIV and AIDS prevention education. Frontline TEACH provides individuals with accurate and supportive information about preventing HIV transmission. The course also provides opportunities for understanding personal risk to HIV alongside a framework for making changes in sexual behaviours and addressing stigma.

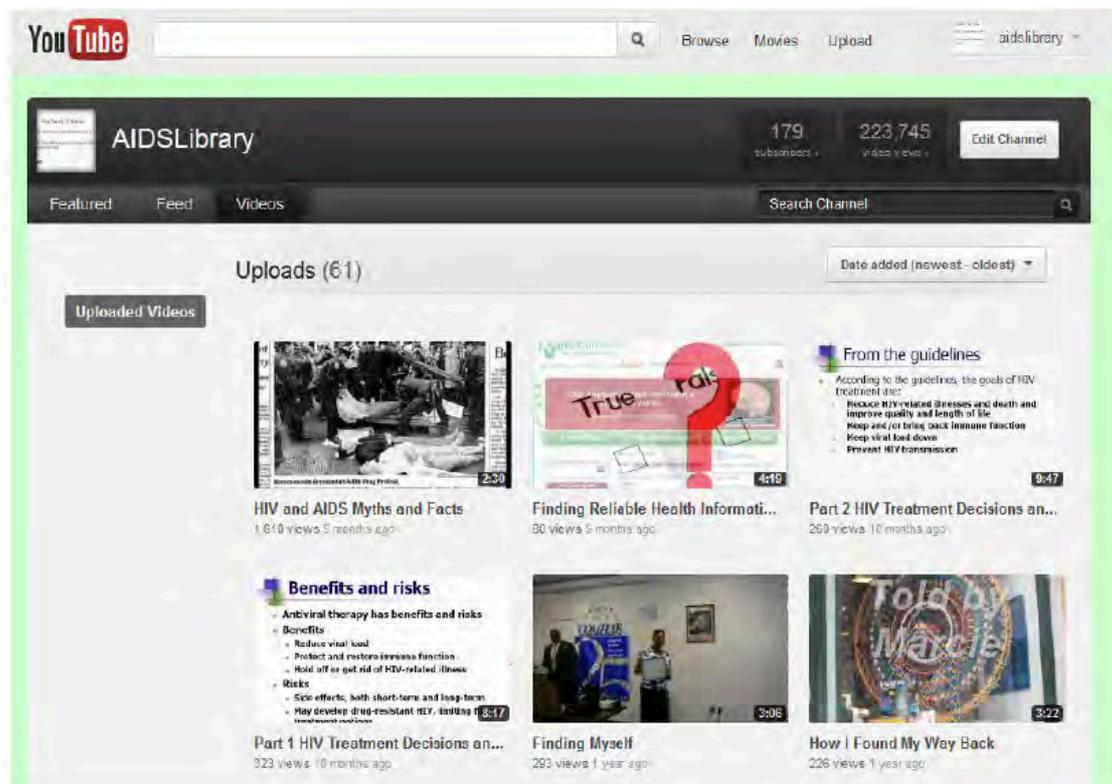


Figure 2: The AIDS Library of Philadelphia YouTube user channel.

Frontline TEACH goes digital

In an increasingly digitally mediated society, those who lack access to the

Internet risk missing key information about HIV prevention, care and support as well as breaking developments in the field. An expressed need for community-based ODFL for service providers in housing, recovery or mental health fields seeking flexible and accessible community-based HIV education became evident. To meet the needs of these HIV-negative populations, Philadelphia FIGHT decided to adapt the face-to-face course into an ODFL course. We received a grant to design, deliver and evaluate an ODFL approach using [Moodle](#), an open source learning management system. The Frontline TEACH population was a good fit for piloting an ODFL platform, because three-quarters of the applicants had already demonstrated a measure of digital literacy by providing an email address on their Frontline TEACH application. For the remaining quarter of Frontline TEACH students, we provided additional computer and digital literacy support. This included additional computer and Internet access, help gaining necessary basic computer skills, including an overview of hardware and software, keyboard and mouse use, Internet browsing, and email tutorials.

Components of Frontline TEACH

Since 2009, Frontline TEACH has been offered as an ODFL course. Many steps were involved in adapting the face-to-face Frontline TEACH course. A lead instructor was identified within Philadelphia FIGHT, and classroom space was booked for the face-to-face sessions. Staff learned how to operate and adapt Moodle and developed a course outline arranged through Moodle's "topics" format. This allowed multiple activities and resources to fit within each topic. Twenty-nine topics were developed for the ODFL course (see Appendix 1 for the course outline). There were already slideshows for all course content, which the instructor developed into videos and narrated with screen capture software. The videos were posted on YouTube, featured on the [AIDS Library's YouTube channel](#) (Figure 2) and then embedded in web pages created within Moodle.

Pre-existing activity guides were used to inform the creation of new questions for Moodle's activities, including "Choice," "Journals," "Forums" and "Quizzes." Each topic was developed to include at least one video, one activity and background readings (see Figure 3). The background readings were carefully chosen to demonstrate reputable sources of online information. Pre-existing pre-post test questionnaires were turned into anonymous pre-post online questionnaires. Other face-to-face components of Frontline TEACH include:

- The application process and enrolment interviews;
- Four class sessions including Orientation and Graduation;
- Accompanying meals (and cake at Graduation);
- Retention calls;
- Supportive lab time;
- Individualized tutorials; and
- Assistance with email set-up for those learners enrolling without email addresses.

Moodle contains a suite of activities to support learning in different ways and with varying levels of sophistication. As indicated in Table 3, the most common Moodle activity in Frontline TEACH is the “Choice” activity, which is a single-question, anonymous poll of the class. The Journal activities allow for private writing, while the Forums encourage group discussion. Finally, Quizzes and Questionnaires allow for a variety of assessment tools.

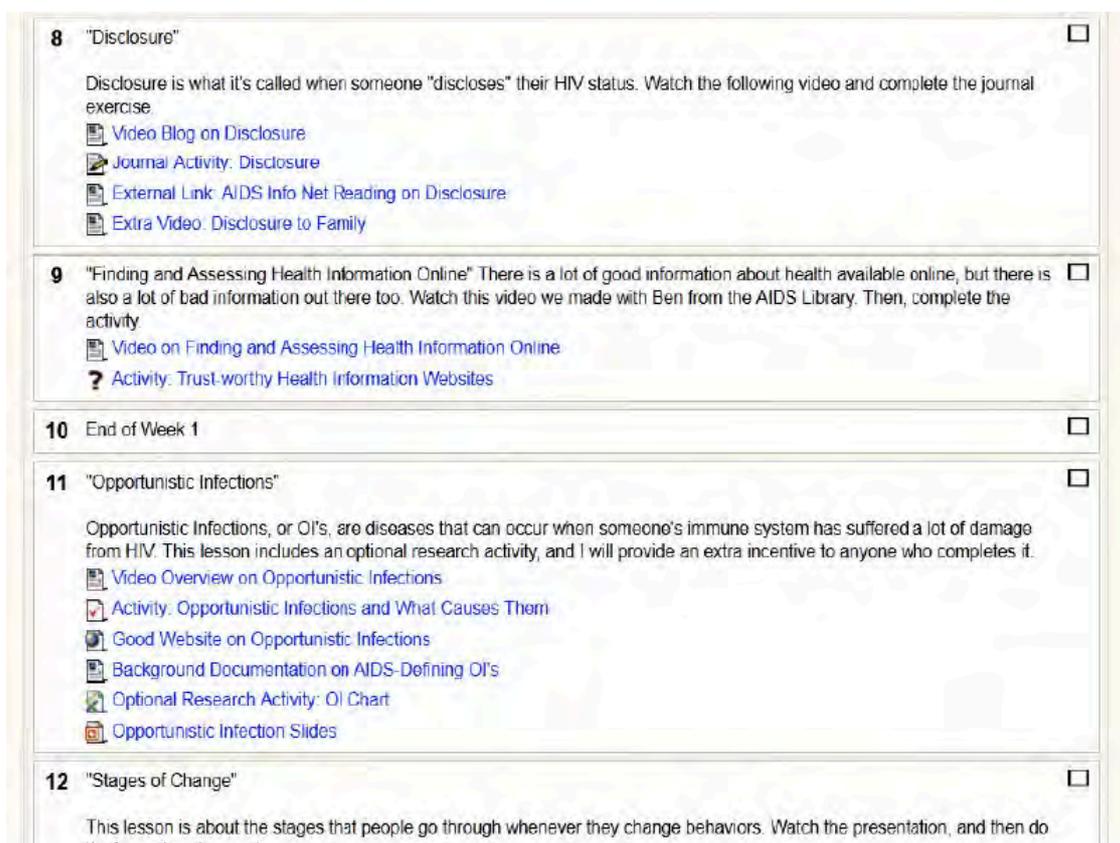


Figure 3: An illustration of the topic format in Moodle.

Moodle activities	Reason for use	Number of topics using this activity
Choice	Single-question polls are very easy for learners with very basic computer skills; conducted anonymously, making them useful for opinion polling of contentious issues	10 topics
Journals	Poses questions allowing private responses; encourages critical engagement with complicated or contentious issues	7 topics
Forums	Poses public questions for critical engagement and skills building topics, like communication style, stress relief, and debunking HIV myths	6 topics
Quizzes: True/False, Multiple Choice, Short Answer, Matching Questions	True/False and Multiple Choice questions assess very basic information, similar to the Pre and Post Questionnaire; Short Answer and Matching questions are more complicated and assess retention of information and understanding of chronological or causative processes	6 topics
Questionnaire	Highly customizable document allowing different	2 topics (used for

types of questions within the same assignment: pre and post Test)
Likert Scale, Multiple Choice, and True False

Table 3. Moodle activities, reasons for use, and distribution of use.

For our students who have strong computer skills, the online components take about 3 to 4 hours per week. For students with intermediate computer skills, it takes 5 to 7 hours, and for beginners 8 to 10 hours. As students' computer skills and digital literacy improve over the course, each course component takes less time to complete. In order to graduate, students must attend all of the face-to-face components or attend make-up sessions. Additionally they are required to watch all of the videos and attempt all of the course activities in Moodle.

Evaluating the outcomes of Frontline TEACH

Quantitative results

Frontline TEACH is an ongoing programme that seeks to increase HIV, health and digital literacy that students can use to improve their lives and their communities. The scope of the class is broad, but there are a few concrete measures through which we could assess the effectiveness of Frontline TEACH from 2009 to 2011. In order to get a broad perspective on the impact of Frontline TEACH using the ODFL approach, four types of data were collected using a variety of methods as shown in Table 4 below:

Source	Method	Data Collected
Attendance Charts	Enrolment, attendance and graduation numbers	Retention and graduation rates; email uptake; use of supportive computer lab access
Participants	Pre and Post Questionnaire with Scale and Multiple Choice questions	HIV transmission and treatment info; self-assessment of risky behaviours including unprotected sex and needle sharing
Graduates	Final Class Evaluation	General course satisfaction, most and least useful topics, ideas for course improvements, attitudes towards PLWHA
YouTube Channel	Total views	Most viewed videos

Table 4. Data and methods for evaluating Frontline TEACH

Indicators	2009	2010	2011
No. of courses	1	1	4
Number of students enrolled	16	24	98
Number of students graduated	7	11	52
Number of students who did not have email on enrolment who graduated	1 out of 8	3 out of 9	8 out of 25
Number of students who had email on enrolment who graduated	7 out of 16	11 out of 24	52 out of 98
Number of YouTube channel visits (including people not on the course)	26,000	65,940	105,636
Number of students who took the pre-course questionnaire over 3 years	10 out of 16	14 out of 24	77 out of 98

Number of students who took the post-course questionnaire over 3 years	7 out of 7	11 out of 11	51 out of 52
% of respondents to pre-test and post-test question “what body fluids transmit HIV”	100%	100%	100%
% of pre-test respondents correctly indicating that blood, semen, vaginal fluids and breast milk can transmit HIV	40% (4 out of 10)	71.43% (10 out of 14)	66.23% (51 out of 77)
% of post-test respondents correctly indicating that blood, semen, vaginal fluids and breast milk can transmit HIV	85.71% (6 out of 7)	90.9% (10 out of 11)	94.12% (48 out of 51)
% of pre-test respondents incorrectly indicating that snot, saliva, urine, ear wax, or belly button lint can transmit HIV	30% (3 out of 10)	78.57% (11 out of 14)	23.38% (18 out of 77)
% of post-test respondents incorrectly indicating that snot, saliva, urine, ear wax, or belly button lint can transmit HIV	0% (0 out of 7)	0% (0 out of 11)	1.96% (1 out of 51)

Table 5. Frontline TEACH Indicators and Outcomes from 2009 to 2011.

Data from Table 5 indicates that the ODFL approach provided an advantage over non-interactive web resources in helping its course students from marginalised communities to understand HIV prevention and HIV treatment information. Over the three years, graduation rates increased from 44% in 2009 to 46% in 2010 and to 53% in 2011. In 2011 we ran the course 4 times, where as in the past we had only run the course once a year. One core observation of the class evaluation was that those students enrolling without an email address had a much lower graduation rate than students who had an email at enrolment across the three years. Efforts were made to increase the amount of individual support and computer access to these students, with varying results.

These 36 Frontline TEACH students over the three years who were provided with email addresses at the time of enrolment struggled to complete the classes. Only one-third of the class members enrolled who were provided with email addresses and individual tutorials on using email went on to graduate the class (17%). However, the 12 individuals represented who did graduate Frontline TEACH without having had an email address before the class gained more than just an email address. By the end of the course, they demonstrated proficiency in many basic computer skills. This included use of the mouse and keyboard, Internet browsing for health information, exposure to online resources, participation in online discussion forums and other activities. This suggests that in order to scale up ODFL approaches like Frontline TEACH sustainably, it is important to provide students—particularly those from marginalised communities—with computer digital literacy skills before and during the programme. As an indicator of the programme’s potential to affect participants’ behaviours, the most viewed Frontline TEACH video on the YouTube video channel hosted by the AIDS Library was the “[Stages of Behavior Change](#)” viewed over 50,000 times. These YouTube videos have a life beyond the confines of the Frontline TEACH course on Moodle, but a closer examination of their use and impact is beyond the scope of this paper. However, it is exciting and

worthy of note that this core online component of Frontline TEACH can reach an audience beyond those in our local context of Philadelphia, and the significant potential of YouTube prompts reflection on broadening and deepening the reach of ODFL approaches like Frontline TEACH.

Rethinking Frontline TEACH based on lessons learned

Our goals were to provide accurate information about HIV and AIDS, including transmission information, myths, and the impact of stigma on PLWHA for HIV negative students who needed this knowledge for a variety of reasons. Importantly, our goal of providing information and battling misinformation about HIV transmission was fulfilled through a flexible ODFL format. As the pre and post test data indicate, students reported significantly greater awareness of which body fluids transmit HIV and which ones do not.

Although the concept of behaviour change is central to the philosophy of Frontline TEACH, there was no discernible difference between the pre and post test questions about self-reported risky behaviours such as using condoms for vaginal, anal and oral sex as well as sharing needles. This unexpected result is prompting Frontline TEACH to rethink our course implementation into the daily lives of participants to better promote, encourage, and track behavioural changes. We are also analysing the qualitative data that we gather to consider how to investigate the social drivers of participants' behaviours. We will use these findings to redesign our course and revise the pre and post tests to ask questions about risk behaviours and change over time. We are now considering asking students to set a behaviour change goal for themselves over the course of the semester. We are also considering how to use ODFL to improve the choices and opportunities of participants from marginalised communities so that they can more effectively tackle structural barriers around HIV risks (Pridmore and Yates, 2005).

We believe that there is potential for collaborating with other CBOs to share and develop digital resources and learn from one another how to leverage them to design more effective ODFL formats for marginalised communities. Our experience shows that open source software such as [Moodle](#) provide flexible low-cost platforms for community groups and ASOs who lack the funding to purchase expensive off-the-self commercial software. Moodle is easy to learn and use. Its 'building block' approach is well suited for frontline workers who wish to experiment with ODL or ODFL that includes and possibly enhances face-to-face HIV education and prevention.

However, it is clear that Frontline TEACH has not yet maximized the use of Moodle. Many of the activity components offer potential benefits particularly for marginalised learners. For example, our experience shows that it is likely that students with fewer computer skills, but more spare time, could benefit from the intensive "lesson" activity in Moodle. Educators could develop didactic and responsive elements into the same activity where a lesson might contain a few facts, and a question related to the content

delivered. A correct response moves the participant to the next point, while an incorrect response takes the participant to a new page with an alternate way of expressing the same content. Alternately, course students with strong computer skills who live far away could benefit from social collaborative learning activities using the “chat” activity in Moodle.

Overall, Frontline TEACH’s ODFL approach has been recognised as having enormous potential. We are continuing to develop our understanding and approach to ODFL so as to reach many of our key constituencies outside Philadelphia, and those who are currently under-served by existing digital HIV education and prevention. It is our hope that Frontline TEACH—or something similar—could be offered to suburban or rural communities and promoted online via social networking. However, adapting Frontline TEACH to a larger audience requires careful examination of the course components and resources available for students from diverse communities and socioeconomic backgrounds.

Furthermore, Philadelphia FIGHT is committed to investing in material and capital resources in Frontline TEACH so that learners can overcome the economic constraints they face. The provision of food and subway tokens at every session is a crucial element in retaining learners who live in resource-poor Philadelphia. The \$20 gift card incentive upon graduation is a small but concrete way that Frontline TEACH hopes to encourage participants to meet the graduation requirements. Because Philadelphia FIGHT has computer labs across multiple AIDS service sites, Frontline TEACH been better able to overcome access constraints for students. Graduates are encouraged to leverage their completion of Frontline TEACH for their economic betterment by putting it on their resumes. Programme staff alert students that they can provide letters of support, instructor and character references for job-seekers who successfully graduate the course. Since 2011, Frontline TEACH has begun to offer the class sessions at different times, including evening classes. The December 2011 course was the first evening class since Frontline TEACH was offered as an ODFL course.

Unfortunately, those who lack basic computer and digital literacy skills remain at a disadvantage in graduating from Frontline TEACH. Some members of this population may opt out of participating in classes before they even fill out the application, due to feeling intimidated or unsure about their ability to fulfil the course requirements. It remains a challenge to determine how to reach this segment of the population better. One opportunity that has arisen at Philadelphia FIGHT since Frontline TEACH was developed into an ODFL course is an increase in computer training through Philadelphia FIGHT’s [Critical Path](#) department. Along with many community partners, the Critical Path team won a 2010 federal stimulus grant in the [Broadband Technology Opportunities Programmes](#). This grant affords the opportunity for many more learners to take computer classes and build their digital literacy skills. Before the next course, Frontline TEACH will invite Critical Path digital literacy trainers to conduct additional email and Internet workshops. Hopefully, these initiatives will improve the success of Frontline TEACH into the future.

Conclusion

Frontline TEACH's ODFL is an effective and adaptable approach for developing community-based and led innovative digital HIV and AIDS education and prevention for marginalised communities that have a modicum of computer literacy. Few models like Frontline TEACH exist for designing ODFL that suits the needs and builds the capacities of marginalised communities at risk of HIV and AIDS. Yet more and more health information, education and prevention is moving online in today's digital age, putting these groups at the additional risk of exclusion caused by the digital divide. While tackling these issues in Frontline TEACH, we learnt the following lessons which are relevant to HIV educators seeking to improve the use of networking and digital technologies for HIV prevention and education programmes with marginalised communities:

- Open distance flexible learning (ODFL) can be a useful community-based and led approach to design, deliver, and evaluate programmes to meet the needs of marginalised communities at risk of HIV and for those who lack the capacity to engage meaningfully with mainstream web-based programmes;
- Careful implementation of ODFL formats should happen in discussion and collaboration with stakeholders to ensure buy-in and ownership, and reflect on the course's relevance over time;
- Build a committed project team who are connected with the community, and speak its language;
- Implement the course as a continuous improvement and revise in phases, to learn and apply lessons and solve problems as they emerge;
- Take account of contextual factors and analyze the capacity of the target communities, attempting to bridge capability constraints where possible;
- Devise course activities that convey core content at the same time that they build computer and digital literacy skills;
- Tailor and adapt the content, processes and assessment to appropriately to serve a variety of communities with high HIV risk;
- Promote safe online non-judgmental spaces for negotiation and dialogue on sensitive issues with trusted peers and mentors; and
- Evaluate to measure learning outcomes. This can be extended to measure other outcomes that concern communities in the future as they become more comfortable with the technologies to contribute to social change.

We have presented a small-scale innovation in one community-based organisation. We are still learning from our experiences and do not presume to generalise what works. However, we have shown how the benefits of ODFL can be made to work when power is placed in the hands of a community-based organisation to collaborate with their service recipients and walk the digital journey together. We acknowledge the over-easy refrain

that marginalised communities do not have computer and digital literacy skills or broadband access. But, we reject this deficit thinking as a false barrier that needs to be smashed to refresh our programmes. We work with the capacities we and our students have, and then bring technologies in to enable and improve our HIV education and prevention practices and goals. We believe policymakers and funders looking to invest in cost-effective approaches to online and digital HIV education and prevention need to strengthen the capacities of educators to participate and develop ODFL approaches for marginalised communities. This becomes crucial in today's financially challenging funding climate and the increasing saturation of the Internet into our daily lives. While Project TEACH affirms a participant's position in the pilot's seat of her own life, our digital Frontline TEACH produces knowledgeable and reliable, rather than marginal and excluded, navigators of HIV risk in a Web 2.0 world.

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Chapter 7

The social technographics of gay men and other men who have sex with men (MSM) in Canada: Implications for HIV research, outreach and prevention

Dan Allman
Ted Myers
Kunyong Xu
Sarah Jane Steele

In this chapter, Dan Allman, Ted Myers, Kunyong Xu and Sarah Jane Steele interpret gay men and other MSM's social media usage in Canada drawing on socio-technographics and Web 2.0 theoretical frameworks. Their work foregrounds the issue of age and other demographics in structuring the digital behaviours of gay men. Their analysis clearly shows that something more than spreading safe sex messages online and on mobile phones needs to be done to work creatively with gay men's socio-technographics. This chapter poses the question, "what kinds of specific digital individual and community support systems would gay men and MSM value that could increase their capacity for agency to make changes to their sexual practices?"

Introduction

This paper demonstrates how men of different ages and characteristics in Canada use the Internet. It explores how they engage with the Internet, how they inhabit social spaces created or facilitated by the Internet, and how these technologies, networks and spaces are utilised for seeking and meeting sexual partners. It explores the datasets of four distinct studies to understand what social or structural factors may enable such activities. It engages with theoretical perspectives to help contextualise such activities, and it reflects on the implications such work has for HIV research, prevention and outreach targeting gay men and other men who have sex with men (MSM).

Here we focus on "Web 2.0 sociable technologies" (Boulos & Wheeler, 2007) and how they enable men's interactions and communications. These sociable technologies include:

social networking services, collaborative filtering, social bookmarking, folksonomies, social search engines, file sharing and tagging, mashups,

instant messaging, and online multi-player games...wikis, blogs and podcasts...[that] quite revolutionary way of managing and repurposing/remixing online information and knowledge repositories. (Boulos & Wheeler, p. 2)

We argue that researchers need to “ ‘catch up’ and exploit these same media for health promotion purposes” (Freeman & Chapman, 2008, p.781). Additionally, we argue that an understanding of “Web Science”, its architectures and its future trajectory requires “a research agenda that targets the Web as a primary focus of attention” (Hall, de Roure & Shadbolt, 2009, p. 992).

Social Technographics

Descriptions of social technographics and their implications for understanding consumer behaviour originate within the commercial marketing literature (Li et al., 2007; Li & Bernoff, 2008, 2009). As described by this literature, a social technographic approach to understanding classifies consumers into overlapping levels of social technology participation. This paper applies these technographic concepts in the analysis of multiple datasets from Canada in order to better understand the utility of a social technographic framework for HIV research, prevention and outreach for gay men and other men who have sex with men (MSM) in Canada. Based on these analyses, the paper uncovers how social participation varies among gay men and other MSM in Canada and uses the data to consider how HIV research, prevention and outreach can incorporate this information into targeted strategies. We employ technographics to get a high-level snapshot of the social technology behaviors of gay men and other MSM because it reflects the interactive elements of Web 2.0 technologies. For the purposes of this paper, social technographics refers to men’s use of which communication mediums, for what purpose, with what investment, and to what end. Applied to social computing, social technographics extends the “analysis of consumers’ approach to technology – to the Social Computing world” (Li et al., 2007, p. 4).

Derived from psychographics, or the grouping of individuals based on psychological profiles, social technographics can be understood to exist on two main axes (Eaton, 1997, p. 8). The first axis is an individual’s degree of involvement with technology; the second is the type of technology used. A third axis, and one which is important to this paper, would be the kind of demographic profile that may be associated, both with particular mediums, and with degree of involvement (Figure 1). These technographic considerations are valuable for HIV research, prevention and outreach among populations of gay men and other MSM because they consider how vested individuals are in their online worlds, and the technologies individuals use to enter and exit their online worlds. Additionally technographics is useful for HIV work because it signals whether there are particular types of individuals who may be more or less likely to use particular types of social

computing technologies and as such display differing paths of participation that may then be targeted (Li et al., 2007).

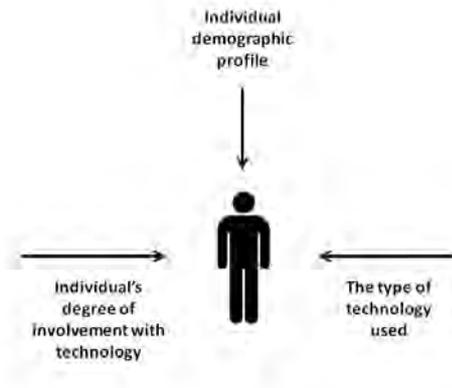


Figure 1: Technographic influences to consider for HIV research, outreach and prevention with gay men and other MSM.

The Technographic Groundswell

Social technographics classify people according to how they use Web 2.0 social content technologies. Relative to one-dimensional Internet use patterns, multidimensional technographic patterns can be envisioned as a continuum or a ladder, as shown in Figure 2 below.

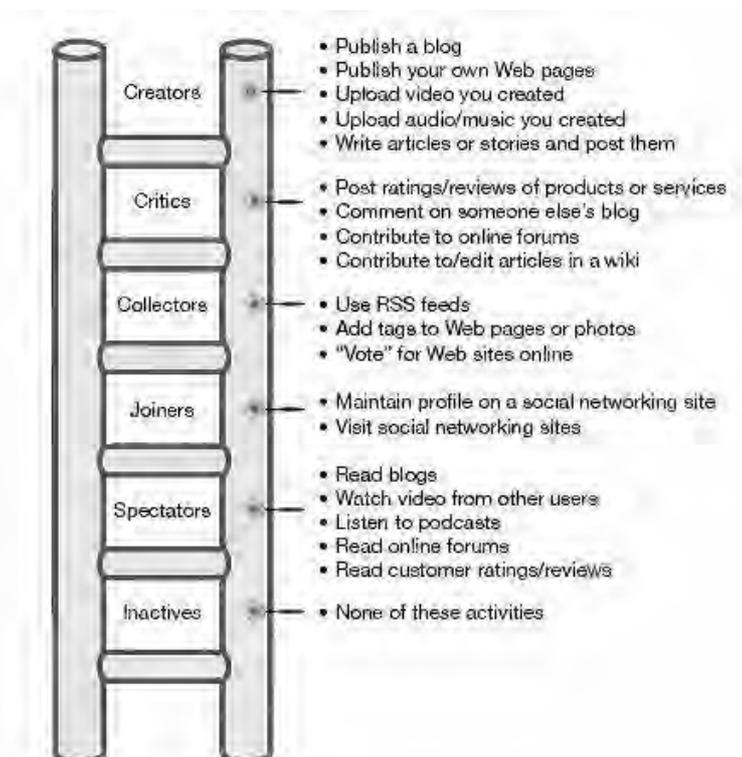


Figure 2: A ladder of social technographics1.

In such a depiction, Creators make social content. They write blogs or create and upload video, music, or text. Creators drive Web 2.0 social content. Critics respond to content from others. They post reviews,

comment on blogs, participate in forums, and edit wiki articles. Critics respond to social content from others. Collectors organise content for themselves or others using RSS feeds, tags, and voting sites. Joiners connect in social networks like Google+, Facebook, Twitter and MySpace. Spectators consume social content including blogs, online video, podcasts, forums, and reviews. Unlike other types, Inactives create or consume social content much less, preferring more traditional outlets for news, information, content, and presumably sex and sex seeking behaviours. The ladder can be applied to existing datasets in order to understand how gay men and other MSM are stratified by Web 2.0 social technologies, as well as potential and useful avenues for HIV research, prevention and outreach that these different layers of stratification might offer.

Gay men, other men who have sex with men and the Internet

In this paper we use technographic analysis to illustrate ways that gay men and other MSM report using the social web to communicate and interact. We contribute to an emerging discourse that seeks to understand how evolutions in communication and intimacy as reflected in men's use of these technologies mirror and reify their lives (Adam, Murphy & de Wit, 2011). It has been suggested that the Internet is an arena in which individuals can explore and express aspects of sexuality without fear of the same kind of repercussions that they might experience elsewhere (McKenna & Bargh, 1998; McKenna, Green & Smith, 2001). Given that people who use the Internet to search for sexual partners have been shown to also use the Internet as a starting place for offline relationships, the Internet can be a potentially notable high risk environment for Sexually Transmitted Infections (STIs) and Diseases (STDs) (Carvalho & Gomes, 2003). This is further corroborated by authors who suggest that people with the motivation and initiative for making new sexual connections through anonymous or semi-anonymous virtual means are risk takers, or sexual adventurers (Toomey & Rothenberg, 2000; McFarlane, Bull & Reitmeijer, 2000; Tashima et al., 2003; Tewksbury, 2003). This is also supported by the idea that risk taking in virtual social lives may be accompanied by risk taking in actual sexual lives (Adam et al., 2011). However, while the Internet has become an efficient facilitator of a range of risky behaviours and practices implicated in epidemics like HIV, it is important to not lose sight that the Internet is a vehicle or a path for behaviours at risk for HIV infection and transmission, rather than an HIV risk behaviour itself.

In much of the pre-Web 2.0 literature from the 1990s and early 2000s, gay men and other MSM who reported using the Internet to seek sexual partners were believed to be less open and public with regard to their sexual preferences, and presumably less comfortable using or being associated with gay-identified venues or services (Ogilvie, 2008; Döring, 2009). Gay men and other MSM who reported meeting sexual partners online have been shown to be younger and more likely to report recent sex with casual partners as well as recent sex with HIV-positive partners, compared with men who did not use the Internet to seek sexual partners (Kim et al., 2001).

Men meeting partners via the Internet have also been shown to report higher rates of sexual risk behaviours including unprotected intercourse. (Benotsch, Kalichman & Cage, 2002),

As use of the Internet increases, the proportion of men using other venues to seek sex (pubs, bars, saunas, washrooms and other public sex environments) has decreased (Weatherburn, Hickson & Reid, 2003; Weatherburn et al., 2005). Mirroring trends identified in North America, in the United Kingdom, the Internet has been found to be among the most popular setting for meeting sexual partners, after pubs and clubs. Further, among men recruited for study from virtual sources, the Internet was the most commonly reported venue for meeting new sexual partners (Weatherburn et al, 2003). From the perspective of research, men recruited for study from the Internet have been shown to have less contact with gay organisations, yet greater contact with public sex environments such as saunas, video clubs, and erotic movie houses (Ross et al., 2000; Daneback et al., 2011).

Since its popularisation in the mid-1990s, men have been the dominant users of the Internet, and the dominant users of the Internet for online sexual activity (Cooper et al., 2002; Daneback et al., 2011). Research suggests that individuals who use the Internet to search for sex, have been more likely to be male and homosexual; to report higher rates of previous STIs; greater number of sexual partners, higher rates of anal sex, and more sexual interaction with partners known to be HIV positive (Toomey & Rothenberg, 2000; McFarlane, Bull & Reitmeijer, 2000; and Tashima et al., 2003). With the advent of Web 2.0 technologies, HIV research, outreach and prevention have to reconsider how the relative anonymity of contemporary web communication and interaction contributes to less individual inhibition, in part because the contexts of these communications can create powerful, even accelerated senses of trust and intimacy (Adam et al., 2011).

Methods

To illustrate how a social technographic approach for gay men and other MSM can inform HIV research, outreach and prevention, we explore analyses from Forrester's North American Technographics® Benchmark Survey (2008), the Canadian Internet Use Survey (2007), the M-Track Ontario [Lambda] Survey (2007), and the Ontario Men's Survey (2002). Together these datasets allow us to reflect on the ways in which men in North America and Canada apply themselves to the Internet and to the social web. The data sets were explored for associations between age and men's greater and lesser Internet use; as well as how gay men and other MSM are using the Internet for *technosexual motives*. That is, how men are using these technologies to seek partners, gather and disseminate information on sex and activities, avail themselves to education and prevention information, and participate in research.

North American Technographics® Benchmark Survey

The first of the four datasets derives from Forrester's 2008 North American Technographics® Benchmark Survey. Forrester Research is a publicly

traded technology and market research company that provides pragmatic advice to global leaders in business and technology. Using a mail survey, it polls its North American Technographics Benchmark Panel quarterly. This paper relies on analysis of Forrester's 1st quarter Technographics Benchmark survey of individuals ages 18 and older from 5,314 US and Canadian households. The dataset as provided by Forrester weighs individual respondent data by age, gender, household income, household size and composition, education level, employment status, region, and market size (combined statistical area). The survey sample size, when weighted, was 5,310 North American respondents at the individual level. The sample was drawn from members of an existing panel, and respondents were motivated by a sweepstakes drawing.

Canadian Internet Use Survey

The second data set was the Canadian Internet Use Survey, a telephone survey produced by Statistics Canada and administered in October and November 2007 to a subsample of the dwellings recruited for the Labour Force Survey. The sample was drawn from the civilian, non-institutionalised population 15 years of age or older in Canada's 10 provinces. Specifically excluded from the survey's coverage are residents of the Yukon, Northwest Territories and Nunavut, persons living on Indian Reserves, full-time members of the Canadian Armed Forces and people who reside in institutions. The survey was administered to one randomly selected individual per household. The random selection was carried out at the time of the interview. In total, 35,023 persons were eligible for the survey and the interview was completed for 26,588 of these persons for a response rate of 75.9%.

M-Track Ontario [Lambda] Survey

The third data set was from the Ontario component of M-Track, an ongoing second generation surveillance system conducted at sentinel sites across Canada. The Ontario component of M-Track, known as The Lambda study recruited 2,536 men (2,020 in Toronto and 516 in Ottawa). It was a venue-based cross-sectional survey that consisted of a questionnaire and collection of biologic samples (dried blood spots) to measure HIV, HCV and syphilis prevalence. It recruited men who have sex with men between March and August 2007. Men aged 16 years or older were recruited in bars, bathhouses, community organisations and social events. A standardised self-administered questionnaire was used to collect the data, which included demographic information and frequency of use of the Internet to seek sexual partners. Lambda also sought to collect information about risk behaviours associated with HIV/STI infection and general issues relevant to sexual health and sexual behaviour among gay men and other MSM (Myers et al., 2010).

Ontario Men's Survey

The fourth dataset draws on a sample of 5,080 men from the 2002 Ontario Men's Survey. This was an anonymous, cross-sectional, venue-based study

of socio- behavioural issues and sexual health in a community sample of self-identified gay and bisexual men. Men over age 15 were recruited through gay bars, bathhouses, and community groups from 13 cities or regions in the province of Ontario, Canada. A purposive sampling strategy was utilised to ensure the diversity of gay and bisexual men in the sample. As with the Lambda study, this study consisted of a questionnaire and collection of biologic samples (in this instance, saliva) to measure HIV, HCV and syphilis prevalence. Among its questions were those that looked at men's use of the Internet to look for sex (Allman et al., 2009, Myers et al., 2009).

For the present paper, all data analyses are descriptive. Standardised age categories are used to explore simple across-group trends in patterns of Internet use. Owing to the different sources of the data sets, different software packages were used to conduct the analyses. Forrester's data were analysed through an in-house analytic tool available through the company's website. Statistics Canada data were analysed through an in-house analytic tool accessed through the University of Toronto Data Library. SPSSSTM was used to analyse the M-Track and the Ontario Men's Survey data (Table 1). Across all four datasets differences in the use of the Internet for sexual and non-sexual purposes were investigated by age, standardised across ten-year age groups.

Data set	Analytic tool
North AmericanTechnographics® Benchmark Survey (2008)	In-house analytic tool available through Forrester's research
Canadian Internet Use Survey (2007)	In-house analytic tool accessed through the University of Toronto Data Library
M-Track Ontario [Lambda] Survey (2007)	SPSSSTM
Ontario Men's Survey (2002)	SPSSSTM

Table 1. Data sets and analytic tools used to analyse them.

Results

Men in the Canadian Internet Use Survey of 2007 reflect a pattern repeated elsewhere in these analyses. The older the respondent, the less technographically-inclined he appears. As an example, examining the responses of males to the Internet Use Survey reflects a clear trend for younger men to report using the Internet more often (Figure 3). This trend is also evident in the reported number of hours spent on the Internet from home (Figure 4).

The social technographics of gay men and other MSM

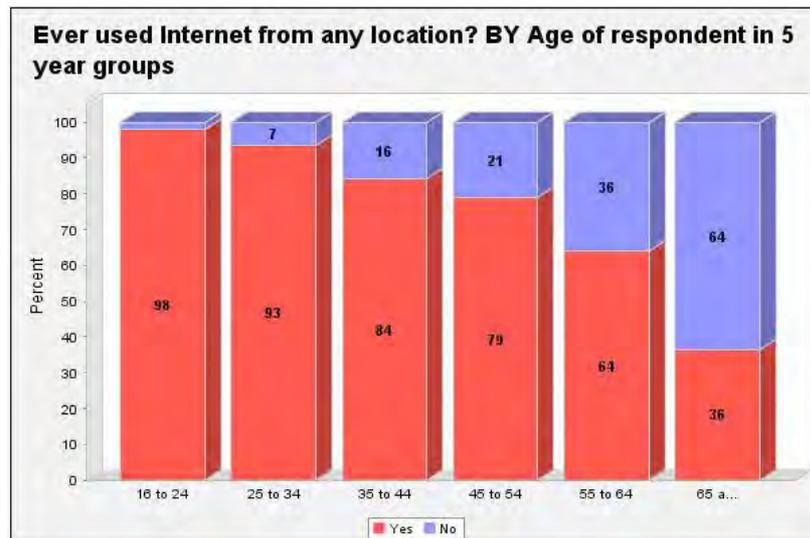


Figure 3: Men in Canada's Internet use, ever, by age2.

Further, in this national Canadian sample, younger men reported that they were more likely to chat or blog on the Internet (Figure 5) and instant message (Figure 6) than older men. Conversely, the older the respondent, the less likely he was to use the Internet, spend hours on the Internet from home, or use the Internet to chat, blog or instant message.

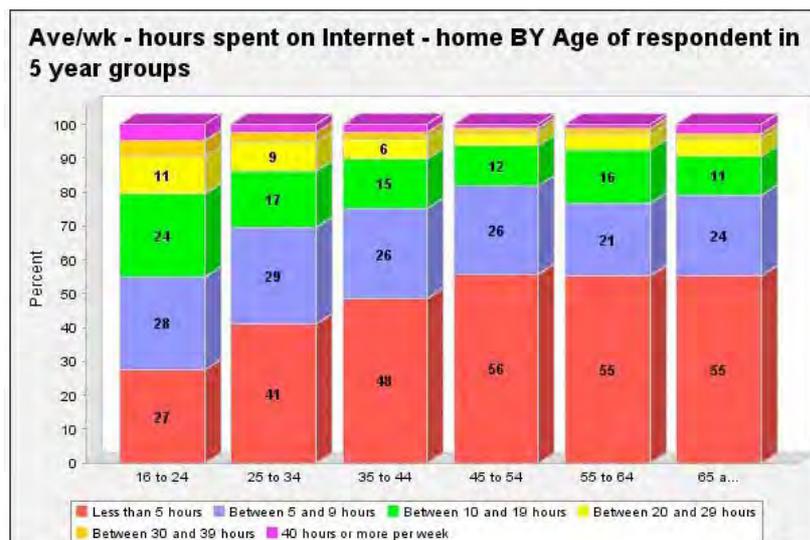


Figure 4: Men in Canada's home Internet usage, by age3.

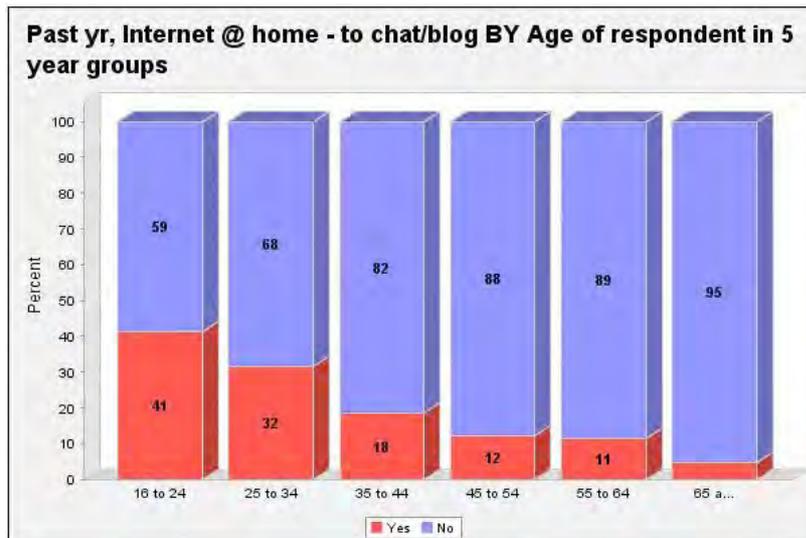


Figure 5: Men in Canada’s home use of Internet to chat/blog, by age4.

Similar national data are not available specifically for gay men and other MSM in Canada, however, data to reflect trends among gay men and other MSM in Ontario were available. In 2002, the Ontario Men’s Survey recruited 5,080 men from 13 communities. Among the questions posed was whether men had used the Internet to seek sex in the previous six months. Descriptive analysis suggests that there is a clear stepwise trend by age (Figure 7) with younger men more likely to report Internet use to seek sexual partners than older men.

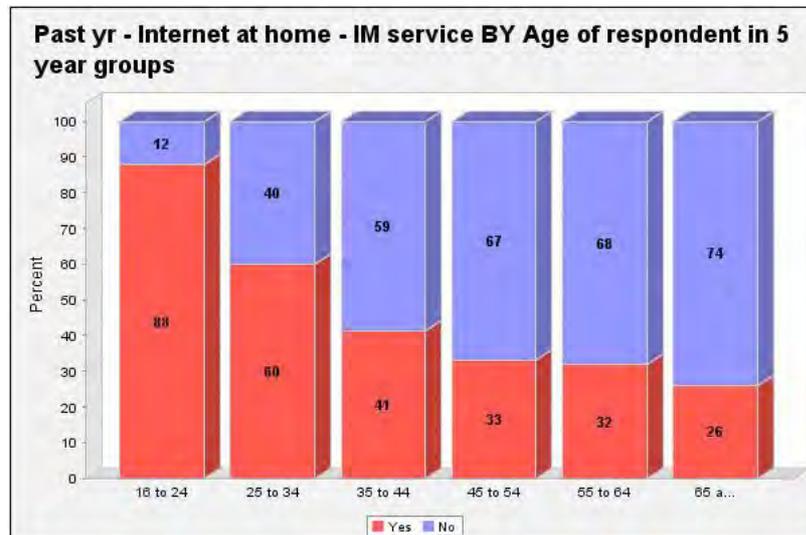


Figure 6: Men’s home use of instant messaging, by age5.

The social technographics of gay men and other MSM

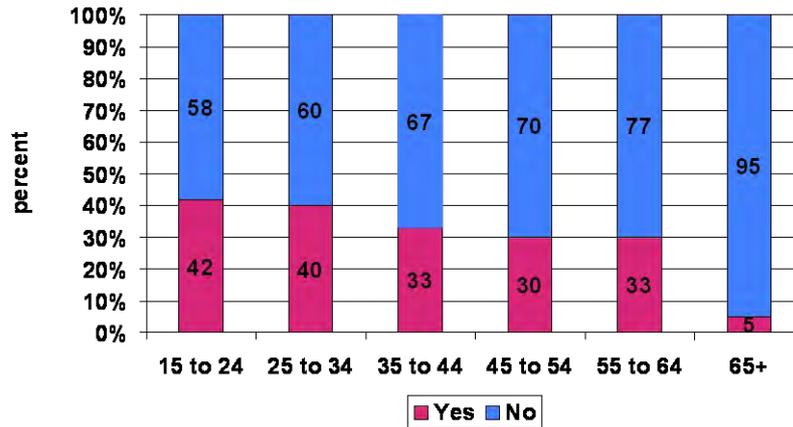


Figure 7: Proportion of men in 13 Ontario communities who looked for sex with men on the Internet in the past 6 months, by age 6.

Five years later, a similar question was asked of the M-Track Ontario [Lambda] sample of self-identified men who have sex with men from the province of Ontario. This study used similar recruitment methods as the Ontario Men's Survey. In the 2007 Lambda study, younger men were also more likely than older men to report using the Internet to look for sex (Figure 8). Interestingly, as illustrated in Figure 9, there was a near-consistent trend for more men in all age groups to report using the Internet to seek sex in 2007 than in 2002.

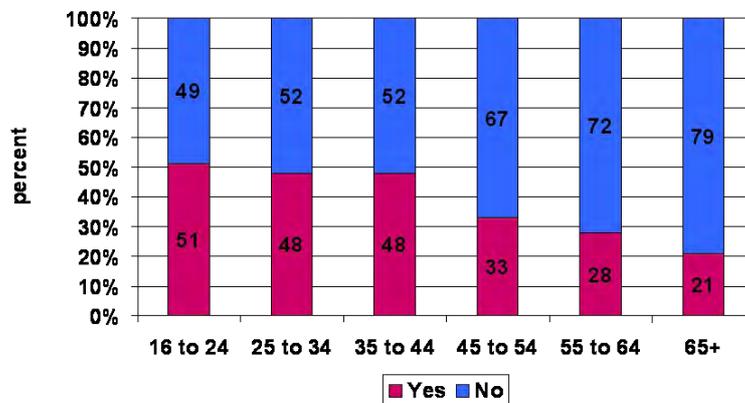
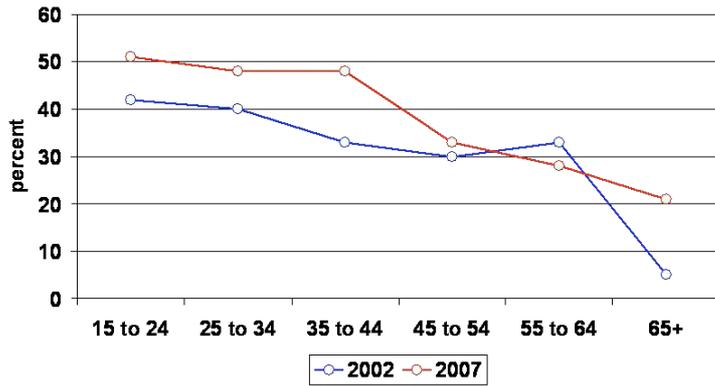
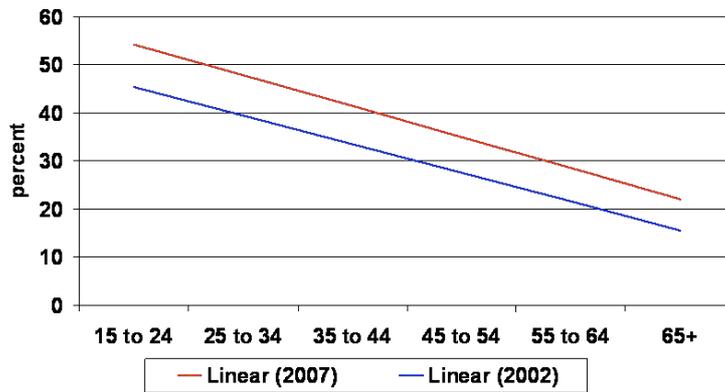


Figure 8: Proportion of men who looked for sex with men on the Internet, past 12 months, by age7.



COMPARISON



TREND

Figure 9: Comparison and trend lines for men in Ontario’s reported use of the Internet to look for sex in 2002 and 2007, by age 8.

The analyses of the first three data sets support our argument about how in Canada, men of varying age groups, including gay men and other MSM, use the Internet in different ways. Analysis of Forrester’s 2008 North American Technographics Benchmark Survey build on this by illustrating that in a sample of North American men, associations between age and Internet use can be similarly sorted along the rungs of the ladder of social technographics (Figure 10).

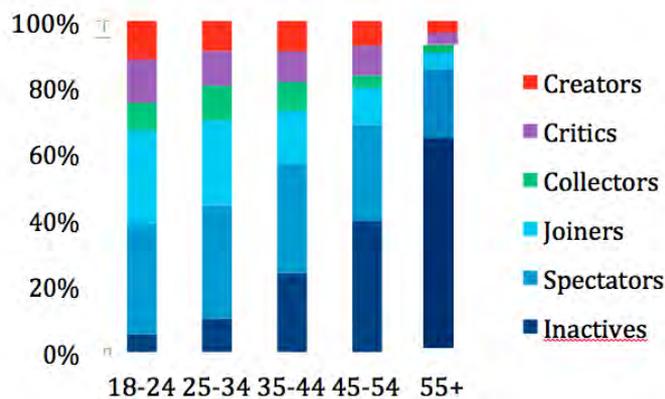


Figure 10: The social technographics of men in Canada and the United States.

As the figure shows, the trend was for younger men to report more participatory social web activity and greater content creation. For example, 11.6% of respondents 18 to 24 years of age and 9% of those 25 to 34 years of age were able to be classified as Creators while only 7.5% of those 45 to 54 years of age and 3.5% of those 55 years of age or older were similarly classified. In contrast, 84.2 % of those 55 years of age or older were able to be classified as Spectators or Inactives, and 68.7% of those 45 to 54 years of age compared to 44.5% of those 25 to 34 years of age and 38.6% of those respondents 24 years of age or younger.

Discussion

This paper has conducted a series of trend analyses to illustrate generational differences among men in different parts of Canada, and their use of the Internet and the social web. It has focused on gay men and other MSM and their reported use of the Internet to seek sex. While the datasets are marked by differences, including variation in study objectives, populations, recruitment strategies and final samples, together their analyses inform a narrative of the socially technographic male. The data examined suggest that the technographics of men in Canada including gay men and other MSM are structured by age. Concurrently, analysis has shown that the younger the man, the more likely he is to be a Creator and Critic, in addition to being a consumer of social content; whereas, the older the man, the more likely he will be either a Spectator or Inactive as a consumer of social content.

As a story about how different kinds of men use the social web, the results from these analyses reflect on the degree of men's "Web 2.0-ness" (Chiang, Huang & Huang, 2009). That is, that younger men have more Web 2.0-ness, or are more *Web 2.0 inclined*— both in their increased likelihood of using the web to engage with and create social content, and in their likelihood to use the web to seek sex.

Yet, this study has not considered an array of other demographics, including gender, geography, education and socioeconomic status. Following Kippax (S. Kippax, personal communication, June 12, 2011) and Mahajan et al., 2008, we argue that these determinants or structural drivers act as additional social *(re)producers* that mitigate how individuals access the Internet. In particular, both geographical and socioeconomic differences can play a role in structuring men's ability to interact with the Internet, and the degree of participation with which they interact.

Implications for HIV Research, Prevention and Outreach

A social technographic approach holds that contemporary marketing and consumer engagement perspectives require consideration of how a target audience will come to be engaged, what will be offered to engage them, and specific to the web, the ways that different kinds of content, features, activities and interfaces can create paths for participation (Li et al., 2007). Incorporating a social technographics perspective into HIV research,

outreach and prevention activities would begin by understanding the social technographic profiles of the target audience(s) and to develop understandings of the social computing technologies these audiences both favour and tend to use. It would also do this to develop and make available different opportunities for participation that match or are attractive to the distinct ways these technographic groupings tend to approach and utilise the social web. This could include simple, non-threatening ways for first-time Creators to contribute, as well as prevention and outreach activities sufficiently flexible to be able to adapt to changes in utilisation, for those contexts where people's technographics evolve across the life course (Boehmer et al, 2012). An example is when those active as Spectators evolve to become Collectors, or when Collectors advance to become Creators (Li et al., 2007) as in Figure 11 below.

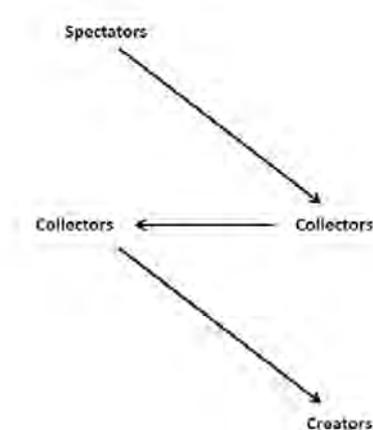


Figure 11: Potential technographic evolution across the life course.

At the same time, a technographically-informed approach would have us remain attentive to the ways that developments within the social web can occur at a rate that may challenge research and outreach. Thus, efforts may be required to rapidly develop equally as responsive strategies to implement contact, outreach and recruitment while preventing attrition (Bennet & Glasgow, 2008). For researchers, the preponderance of Web 2.0 applications may speak to Bauman's (2007) and Beer's (2008) descriptions of "confessional society". That is the kind of society where people purposefully and actively participate in publicly revealing many different kinds of information about themselves. Certainly the utility of user-generated confessions as a data source for the content analysis of social artefacts are numerous (Brown & Bobkowski, 2011; Hum et al., 2011; Small, 2011; Denecke & Nejdli, 2009; Hinduja & Patchin, 2008), as are the opportunities to reach a broad, diverse base. At the same time however, the research enterprise needs to contend with the fact that it and the researchers:

...are not the intended audience towards which these confessionals are aimed. Web 2.0 users are not generating and organising the content of Web 2.0 with us in mind or with the intention of helping us to find answers

to our research questions. Their agenda, in this case the user of Web 2.0, is somewhat different to our agenda as researchers. (Beer, 2008, p. 627-28)

We argue that HIV research, outreach and prevention can better learn from the wired confessions of gay men and other MSM, by attending to the sociotechnographic profiles of the men in question. In reflecting on the divergent datasets explored here, on the overlapping trends identified, and on reflections in the literature that validate these findings, we argue that research, education and outreach across these wired venues will need to consider how to modify or complement existing approaches that utilise the social web. This is because while research and other activities that incorporate social content may be well-suited to being observed, responded to, organised and disseminated to others by younger men, similar activities aimed at older men in Canada also should consider concurrently tailoring more traditional forms of outreach and interaction.

Conclusion

To consider the social technographics of gay men and other MSM in Canada, we used trend analysis to highlight technographic patterns between subgroups. We argue that the Internet alone is not sufficient to reflect and shape social and sexual lives. Rather, consideration of the power of the Internet to modify social and sexual lives needs to account for how social producers such as age, geography and accessibility act to moderate lived experience. As Wellman and Hogan (2004) explain:

The Internet plugs in to existing social structures: reproducing class, race, and gender inequalities; bringing new cultural forms; and intersecting with everyday life in both unconventional and conventional ways. (p. 390)

We agree that the early Internet was an arena in which individuals could explore and express aspects of sexuality free of the kinds of fear-based structures experienced elsewhere. However, we would add that understandings of the ways people interact with virtual environments as Web 1.0 users, as described by Hall et al. (2009), may benefit from new thinking. This is because what differentiates the use of Web 1.0 from the more social practices of Web 2.0 is that some of the social producers influencing the content consumption of Web 1.0 will likely differ from the participatory practices of 2.0's social web. An example of this would be older, more technologically-inactive men who may not find it quite so easy to fluidly incorporate new forms of social structures into their social lives. It might be also that the divide between life lived on and off the Internet, may be reflective of forms of risk and harm minimisation compartmentalised not only by risk environment, demographic or determinant, but by technographic as well.

This paper has not considered risk relative to social technographics. It has considered the seeking of sexual partners via the Internet and its

relationship with age, yet not whether seeking sex in itself is inherently risky. While some have suggested that those who use the Internet to seek sexual partners may be greater risk takers, this paper cannot contribute to this debate other than to inform a nascent body of literature which reflects on the technographics of those that use the social web. At the same time, the web and patterns of web use, in a country like Canada, have proved far from static. Because of this,

...the story would not stop here. Just as Web 1.0 resulted from how we used the read-only Web (eCommerce, search engines, etc.), and Web 2.0 has resulted from the applications that have been built based on the interactive Web (blogs, wikis, social networks, etc.), so Web 3.0 will be the result of applications that are built based on the Semantic Web and a Web of linked data. (Hall, de Roure & Shadbolt, 2009, p. 1000)

Technology and the kind of technological determinism suggested by Ellul (1964) and others is not the sole source of gratification driving Internet use, regardless of how the technographic trends for that use might be stratified. For those who do use the social web to create or access opportunities for sex, gratification can appear in multiple forms. Some of these forms may be purely voyeuristic, while others intimately interpersonal. Forms of collaboration, content sharing and culture construction may be shared with other, more proximally-intimate activities to become “remixed, redistributed and reconsumed” (Harrison & Barthel, 2009, p. 157), and in doing so may gratify users by providing them a continuum of active, generative roles.

How then, in an evolving era of transformative virtual intimacies, might HIV work itself evolve in response? One approach in an age when many of the socio-cultural traditions and interpretations we seek to understand are being abandoned or reconfigured (Barraket & Henry-Waring, 2008), would be to seek to interpret the social world through lenses that lend themselves to the kinds of theoretical frameworks that allow our understandings of intimacies in the global era to be detached from traditional interpretations. For example, to subscribe, as Gross (2005) has suggested, to Bauman’s (2003) argument that virtually-contingent intimacies reflect a “liquid love” which itself is built upon a kind of undulating “liquid modernity”, where virtuality acts to privilege desire over any intimacy sought. Utilising the social web for sexual purposes does allow “participants with the opportunity to collect new sexual experiences and engage in sexual activities with a diverse range of partners in a relatively safe and playful setting” as well as to contribute to forms of sexual empowerment (Whitty, 2008 cited in Döring, 2009, p. 1095). Perhaps Web 2.0 allows those who access it even more sexual empowerment through its liquefaction of both desire *and* intimacy, all from the relatively removed position of a confessional interweb.

Successfully interacting within the Internet’s confessional society requires an element of willingness on the part of the actor to cooperate with the norms and rules governing our increasingly public demonstrations of what have traditionally been private worlds. For to be unable or unwilling “to fulfil this obligation to confess” is to be “left behind, excluded, derided, pushed

into a variegated and heterogeneous ‘underclass’ of ‘failed consumers’” (Beer, 2008, p. 624 referencing Bauman, 2007). The lessons such considerations offer to those who are seeking to capitalise on the social web for purposes related to HIV research, prevention and outreach are multiple.

One lesson for interventions that intend to harness the utility of the Internet would be to consider how the liquidity of the virtual environment varies by type of user, and how this may be patterned by the array of determining factors suggested by Wellman and colleagues (Wellman & Haythornthwaite, 2002; Wellman & Hogan, 2004). As we have argued here, the role of age relative to Internet use would be one of the factors to consider.

Another lesson for HIV research, prevention and outreach would be to recognise that even when considered through the lens of socially producing or structuring categories, users may not necessarily be homogeneous. Further, that it is almost certain that use and investment in the Internet will ebb and flow across the course of any given man’s life course, as he ages, as technology evolves, as his use evolves with it, and as mechanisms come into play that both facilitate but potentially also obstruct an individual’s degree of Web *.*-ness—where the MS-DOS-like wildcard *.* represents 1.0, 2.0, 3.0 or beyond.

We would argue that an additional point of consideration and of caution would be for HIV research, prevention and outreach practitioners and the policies that guide and inform them to guard against tendencies to focus work only on the seemingly ever-expanding frontier that is the World Wide Web. We argue that to place all efforts completely in virtual environments,

or even in computer technology-based environments (Noar, 2011; Noar, Black, & Pierce, 2009; 2010) risks negating that while the Internet may play a facilitative role in HIV infection, HIV cannot be transmitted via the electronic currents that drive these virtual environments. Rather HIV is transmitted by human physical relations. As such our attentions to the porousness of the Hive should be complemented also by our attention to the harder and fleshier physical world. Throughout this paper we have argued that HIV research, prevention and outreach that employ social media have a better likelihood of successful impact when targeted to younger age categories of men in Canada. Additionally we argue research, prevention and outreach activities aimed at older age categories of men will have a greater likelihood of impact when utilising more traditional forms of communication. This is not to imply that older men should be excluded from HIV work that seeks to engage them with social media, but rather, that our findings suggest that many older men are less engaged with social media because they tend to direct their energies towards more traditional forms of social interaction. We would contend that these differential forms of engagement result in part from kinship practices, as well as the habits and identities employed by older men as they navigate spaces where men meet or interact with other men for sex.

Our argument has built on analyses that highlight the ways that the patterns of gay men and other MSM use of new mediums for social and sexual purposes may continue to evolve as different and more varied social

media communication applications become available. Also, and importantly, how, as a result, HIV research, prevention and outreach interventions will need to continue to monitor these developments in order that they may shift accordingly. Such activities would be encouraged to consider stratifying research recruitment, information delivery and outreach educational activities based on the kinds of social technographics reflected in this paper, so as not discriminate or otherwise negate late or non-adopters of the kinds of liquidities promoted by the social web. This is a profound challenge for public health and for community development to improve the impact of liquid HIV prevention in a Web *.* world.

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Chapter 8

Sexperts! Disrupting injustice with digital community-led HIV prevention and legal rights education in Thailand

Nada Chaiyajit
Christopher S Walsh

Nada Chaiyajit and Christopher S. Walsh present their work on designing, implementing and analysing two Sexperts! programs with community-based groups in Thailand. Their chapter documents how social networking and instant messaging were used to provide HIV prevention and education to communities of gay men, other MSM and transgender people. These unique digital interventions explicitly focus on sexual pleasure and health, legal rights, and where to go to access justice when individual rights are violated. Through contextualised online and mobile platforms, both programmes refreshingly highlight digital interventions that aim to reduce stigma and discrimination around gender identity, sexuality, sex work and gender reassignment.

The need to disrupt denial of access to justice

Local responses to the global HIV and AIDS epidemic cannot be effective unless the human and legal rights of those infected and affected by HIV are clearly and undeniably addressed (amfAR, 2008). Globally, four decades into the HIV and AIDS epidemic, many countries, including Thailand, have adverse or unfriendly legal environments that potentially undermine the impact of HIV and AIDS outreach and prevention programmes. Thailand has been experiencing an on-going and often violent political struggle between the People's Alliance for Democracy ('Yellow Shirts') and the People's Power Party ('Red Shirts') since 2005. This social upheaval—alongside existing entrenched stigma and discrimination towards gay men, other MSM and transgender communities—is precipitating negative discourses that produce increased risk of HIV infection among gay men, other MSM and transgenders.

As a transgender activist, researcher, peer educator and sexual health counsellor (Chaiyajit) and an openly queer academic and activist (Walsh), we understand all too well that violence, stigma and discrimination are drivers of HIV vulnerability and deny access to prevention, education and care. In our collaborative work around face-to-face and online HIV education and prevention, we are constantly reminded of how gay men, other MSM and transgender individuals struggle against unrelenting social exclusion caused by stigma, discrimination, violence, poverty, lack of access to housing, violations of human and legal rights, homophobia, transphobia and heterosexism. In Thailand specifically, as well as our work in

neighbouring Viet Nam, pervasive negative attitudes and violence toward gay men, other MSM, and transgenders are commonly condoned not only by some local police, but also by the state and society in general.

This situation makes it difficult, even impossible, for openly lesbian, gay, bisexual and transgender (LGBT) individuals to find sustainable employment, housing and healthcare outside major cities such as Bangkok, Chiang Mai, Pattaya and Phuket. The situation is particularly dire for transsexuals because they are unable to legally change their gender on state identification cards, even when they have undergone gender reassignment surgery and live as women. This fact alone ‘outs’ them as transgender when they seek employment and housing, something gay men and other MSM do not necessarily have to deal with. Thai media is rife with negative representations of LGBT individuals, with the exception of a few films. Thai cinema and public television often use humour to maintain and reinforce deeply embedded and taken for granted negative stereotypes (Barea, 2012; Jackson and Sullivan, 1999). These media distortions make it difficult for openly gay and bisexual men, other MSM and especially transgenders to identify themselves openly. As a result, a fear of identity disclosure or ‘coming out’ makes it exceedingly difficult to provide LGBT and other MSM with practical HIV education and prevention resources they need on how to access justice when their human or legal rights are violated.

This article describes our work in designing the Mplus Sexpert and the TLBz Sexperts!—two online peer outreach and prevention programmes (OPOP)—that tackle this problem. Putting social justice at the forefront of our work, we examine how two small community-based and led organisations worked in collaboration with strategic partners to integrate contextualised HIV education and prevention alongside access to free university-based clinical legal education (CLE). First we outline the often-unrecognised situation in Thailand in regards to stigma and discrimination faced by gay men, other MSM, transgenders and sex workers. We then provide background information on HIV prevalence and inconsistent condom use among these communities that was the catalyst for our design of both programmes. We next illustrate how the Mplus Foundation and ThaiLadyBoys.net redesigned peer-based community-led HIV education and prevention using social networking and instant messaging software online and on mobile phones. We highlight how each programme focused explicitly on sexual pleasure as well as health and legal rights. We discuss the key features of both programmes and elucidate implications for quality community-based and led digital interventions. We argue that disrupting denial of access to justice by leveraging digital technologies requires building trust, and continuous stakeholder involvement, to challenge the status quo while reworking and rethinking static biomedical notions of HIV prevention and education.

The land of smiles?

Often referred to ‘as the land of smiles’, Thailand is generally viewed as a tolerant country in regards to its lesbian, gay, bisexual and transgender

(LGBT) communities. It is also a popular travel destination for LGBT travellers who experience an open and 'gay-friendly' environment that appears absent of stigma and discrimination. Unlike LGBT tourists however, Thai gay men, other MSM and transgenders face extreme stigma and discrimination (Breton, 2009; Brenton and Gonzalez-Figueroa, 2009; UNESCO, 2011; WHO, 2011). This is particularly true for transgender individuals (Nakpor, 2011; UNESCO, 2011). They are also victims of gender-based violence (Egremy, Betron, Eckman, 2009). The authorities often ignore violence against transgenders because they represent a direct challenge to traditional gender norms and roles (Gilles, 2011). The people and government of Thailand *tolerate* these groups but many certainly do not accept them. In fact, many Thai policymakers and officials believe homosexuality is inappropriate or misdirected (UNGASS, 2010; UNAIDS, 2010).



Figure 1: Parade participants' non-violent response to the Chiang Mai Rak 51's 'gay parade get out' public rally to cancel the 2009 Chiang Mai Gay Pride Parade

Stigma and discrimination towards Thai LGBT and other MSM

An overt example of stigma and discrimination against the LGBT community in Thailand was the cancellation of the 2nd Annual Gay Pride Parade on January 21, 2009 (Fridae, 2009; Saunders, 2009). Just before the parade started, organisers and parade participants were locked in a compound and subjected to public harassment and prejudice by the Rak Chiang Mai 51 political group, or 'Red Shirts'. Parade participants suffered overt discrimination, some were injured, and all were prevented from leaving or entering the compound for over 4 hours while 150 police officers observed (The Nation, 2009). The parade organisers, participants and supporters responded non-violently by sitting in prayer (Figure 1). The Rak Chiang Mai 51 believes that LGBT individuals and parade participants were destroying traditional Thai Lanna culture by having a Gay Pride parade. They broadcasted this notion via local radio stations calling on Chiang Mai residents to come and block the parade. This overt violence publicly sanctioned and increased homophobia, transphobia, stigma and discrimination towards gay men, other MSM and transgenders. Seen in the light of the wider on-going political struggle in Thailand, this event highlighted for us that effective HIV prevention and education could only be achieved in a favourable environment where LGBT and other MSM's rights are fully respected. The harm caused by this experience brought us together to mobilise the community, conceive of, seek funding for, design and launch

peer-based online and mobile HIV prevention and education that explicitly integrated access to legal rights.

Standing in solidarity with marginalised groups

Unlike some Thai officials and policymakers, we believe the trite notion of ‘tolerance’ is not helpful for gay men, other MSM, sex workers and transgender individuals who need to understand and navigate personal risk to HIV. Instead it is likely to increase their vulnerability to the virus. Vulnerability to the virus prior to the moment of exposure takes the form of stigma and discrimination directed at these groups. These discourses in society can lead to feelings of low self-esteem. These internalised feelings are often symptomatic of other high-risk behaviours, such as substance abuse, transactional sex, or engaging in unsafe sexual practices. As educators and activists, we strongly believed that we needed to transcend the weak and pathetic belief in tolerance that does little to challenge the overt stigma, discrimination and violence faced by gay men, other MSM, sex workers and transgenders in Thailand. This prompted us to rethink and redesign our approach to HIV education and prevention to critically and practically focus on empowering LGBT and other MSM to understand their rights under Thai law and to access justice when they find their rights violated.

“Tolerance” is a word commonly used when speaking about appropriate responses to difference. In fact, practicing “tolerance” is what many educators see as the best indication of a civil and respectful society. (Nieto, 2009, p. 247). It is important to note that the LGBT community in Chiang Mai did not tolerate the vicious attack on their rights. The cancellation of the parade galvanised local, national and even international community based groups (CBOs) and non-governmental organisations (NGOs). After two years of constant struggle and persistence, the LGBT community collaborated with other CBOs and NGOs in Chiang Mai to successfully organise a “Peace Walk” in 2011. They were unable to call it a Gay Pride Parade because they were subject to the same kind of public opposition and discrimination they faced in 2009. A successful peace walk does not mean that LGBT and other MSM do not still face considerable discrimination as well as a forfeiture of their legal and human rights at the hands of police, health care professionals and Thai citizens. Aung Myo Min (2011), the director of the Human Rights Education Institute of Burma(HREIB) and a gay member of the Chiang Mai LGBT community said, in relation to the 2011 Peace Walk:

We are struggling and we still have to try much harder to obtain equality for LGBT people. We can say that it is a struggle within a struggle. It means that the LGBT rights activists are struggling even in the communities which promote democracy and human rights. (Irrawaddy, 2011, ¶ 10)

HIV prevalence among Thai gay men, other MSM and transgenders

Current research clearly indicates that MSM—the term used in the research literature to refer to a wide spectrum of individuals, regardless of stated sexuality or even gender identity—are at a higher risk of contracting HIV in concentrated urban areas such as Bangkok, Chiang Mai and Phuket as well as rural provinces (Avert, n.d.). A 2008 demographic survey found that HIV incidence among MSM in Bangkok increased from 17% in 2003 to 28% in 2005 and 31% in 2007. The rate of new HIV cases in Chiang Mai rose from 15.3% in 2005 to 16.9% in 2007, while rates in Phuket increased from 5.5% to 20% in the same time period (Wimonsate, et al., 2008). The survey also found that half of MSM do not use condoms and that male commercial sex workers (MSW) are at high risk of contracting HIV because they engage in unsafe sexual behaviour. Yet, some progress has been made in terms of reducing new infections:

HIV infection among men who have sex with men (MSM) remains higher and does not show any indication of declining. HIV among MSM is higher in large urban centers and important tourist locations. Nevertheless, the intensified prevention activities among this population over the past two years, especially in Bangkok, are starting to show results in terms of reduced HIV prevalence, from 30.7% in 2007 to 24.7% in 2009. (UNAIDS, 2010, p.3)

Despite the welcome decrease in HIV prevalence, UNAIDS (2010) forecasts a different scenario. Drawing on epidemiological data merged with data from ad hoc serosurveys, this report indicates an overall trend toward a continued spread of HIV. It also indicates the almost certain possibility of a return to an increasing trend among high-risk groups such as gay men, other MSM, male sex workers and transgenders. This trend is consistent with a significant 2010 study of young MSM in Bangkok, Chiang Mai and Phuket. This study found high levels of inconsistent condom use among sexually active young MSM (15-24 years). Of the 837 participants, 33.1% were regular MSM, 37.7% were MSW, and 29.1% were transgenders. 46.7% of MSM, 34.9% of MSW and 52.3% of transgenders reported recent inconsistent condom use (Chemnasiri et al., 2010).

A particular concern we faced alongside the high levels of inconsistent condom use was the increasing use of social networking technologies and mobile phones to potentially access more sexual partners and clients by gay men, MSM, transgenders and sex workers in Thailand. This trend mirrors trends noticed globally in these populations (Liau et al., 2006). There has also been an increasing focus among public health researchers on using online approaches for designing HIV prevention and education among gay men and MSM (Ybarra & Bull, 2007; Rosser et al., 2010). Against these trends however, we were troubled by the lack of attention to the continuing problem of unequal access to justice in community-based and HIV prevention and education. Despite the global push for human rights, gay

men, other MSM and transgenders in Thailand are still more likely than heterosexuals to suffer injustice.

Justice, justice, justice

Against a disenabling social and cultural environment and concerns with rising HIV infection, we felt it important to look wider than ‘evidence-based’ biomedical and public health perspectives on online HIV prevention and education (see Rosser et al., 2010). Often, these approaches ignore the need to address human rights and focus on rational behaviour change. They assume gay men, MSM and transgenders exposed to explicit sexual materials, vignettes, reflective journeys, videos, cartoons, and “ ‘hot sex’ calculators” (Rosser et al., 2010, p. 2100) through e-Learning curricula will simply reproduce the tips and tricks they are given by virtual peer educators in forums and chat rooms. However, these ‘safe sex’ messages focus on psychosocial aspects of sexuality and do not teach gay men, MSM and transgenders how to challenge harmful thinking in public spaces in ways that did not put them at harm. They also do not consider the significance of educating gay men, MSM and transgenders about the importance of knowing and accessing their basic human rights as citizens.

Consequently, we grounded our thinking in how to design and deliver effective HIV education and prevention in affirmation, solidarity and critique (Nieto, 1994) with gay men, other MSM, sex workers and Transgenders. We designed both programmes “on the understanding that culture is not a fixed or unchangeable artefact, and it is therefore subject to critique. Passively accepting the status quo of any culture is thus inconsistent with this level of...education” (Nieto, 1994, pp. 5-6). Thus we focused our programmes on educating LGBT, other MSM, sex workers and transgenders about the law and human rights, drawing on the United Nation’s Universal Declaration of Human Rights, as well as their rights under the Thai constitution. We view the generative production of human rights as a necessary element of any HIV prevention and education response to the HIV pandemic in Thailand. As we discuss in the two case studies below, the Sexpert programmes are community-based and led. They are *intentional* public health and legal rights strategies that deliberately stand in solidarity with LGBT, other MSM and sex workers to reduce stigma and discrimination through digital HIV prevention and legal rights education. This novel, yet significant, approach is paramount and timely to tactically disrupt injustice in light of increasing HIV infection rates among these groups.

Both programmes we discuss below are examples of critical work aimed at strengthening the rule of law through clinical legal education (CLE) and outreach directed at gay men, other MSM, sex workers and transgenders. This is pedagogic action that transcends the notion of tolerance. This is also what led us to work closely with Bridges Across Borders South East Asia Community Legal Education Initiative (BABSEA CLE). Their goal is to provide legal knowledge and legal services to poor, vulnerable and marginalised communities. By collaborating directly with them, we were able to improve access to justice to Mplus and

ThaiLadyBoyz's target populations by providing resources to peer educators that made the system and rules of law in Thailand more transparent. Thus they can simultaneously provide rights-based education alongside HIV prevention and outreach. The right-based education is provided through free clinics housed at universities, as well as through multi-platform online and mobile CLE training materials to raise awareness of rights to Mplus and ThaiLadyBoyz community members and stakeholders.

Sexperts!

A 'Sexpert!' is essentially an expert about sex. They specialise in making peers feel comfortable talking about their sexual practices. They provide HIV, sexual health and legal rights education in non-threatening and anonymous virtual environments. A priority for Sexperts is to openly acknowledge the pleasure in having sex while discussing sex with peers online. A Sexpert understands that making a person feel guilty about their sexual practices will sacrifice any viable opportunity to discuss safe sex and personal risk to HIV. Unlike doctors, social workers or therapists, Sexperts are peers recruited from stakeholder communities who receive specialised training, practice and supervision.

The programmes we implemented and currently run were collaboratively designed with the LGBT and sex worker communities in Chiang Mai. This was essential to properly contextualise peer-based HIV prevention and education. These programmes also focus the attention of these communities on understanding the laws and rights that are in the Thai constitution, particularly around access to healthcare, employment and housing. The first case study we describe details our work with the Mplus Foundation from 2010 to 2011. The second study presents our current work with ThaiLadyBoyz.net. Both organisations are community-based and led. They are dedicated to reducing new HIV infections and battling stigma and discrimination.

Mplus is centrally located in Chiang Mai with a physical drop in centre. It works in and around the city with 12 fulltime staff. It is a recognised community-based organisation (CBO). It is primarily funded by USAID through PACT Thailand. It receives additional funding from the Global Fund to Fight AIDS distributed through Rainbow Sky Association Thailand (RSAT).

ThailadyBoyz.net is entirely Internet based. It runs without any external funding. It serves the transgender community across Thailand. Transgender volunteers staff it. The TLBz Sexperts! programme is currently funded through Bridges Across Borders South East Asia Community Legal Education Initiative (BABSEA CLE) an international non-governmental organisation, that focuses on ethically oriented legal capacity development and community empowerment to enhance access to justice in marginalized communities[i].

The Mplus Sexpert! and TLBz Sexpert! programmes were designed with funding from amfAR's MSM Initiative received in 2009. The Swedish Federation for Lesbian Gay, Bisexual and Transgender Rights (RFSL) provided initial training and support to adapt and localise their successful

“We are the Sexperts!” programme (Dennermain and Herder, 2009). BABSEA CLE provided capacity building for collaborative research. It also assisted with continuous community stakeholder involvement in the project.

These efforts produced a 72 pages manual entitled *Sexual, human and legal rights for Chiang Mai’s men that have sex with men (MSM), male sex workers (MSW) and transgender (TG) communities*[*ii*] (Figure 1). The manual is an invaluable resource for peer educators and counsellors. It provides them a structured approach to support gay men, other MSM, male sex workers (MSW), transgenders and transgender sex workers understand HIV prevention and their human, legal and sexual rights under Thai law. Twelve peer educators were trained to use this manual for both face-to-face and online support in both programmes. The manual provides a comprehensive listing of references to access local rights and referrals to health services, including free voluntary confidential counselling and testing (VCCT) and university-based clinical legal education (CLE). Both programmes also make use of a number of educational digital animations to help young gay men, male sex workers, transgenders and ‘hidden’ MSM understand personal risk to HIV and how to access justice when an individual finds their rights violated. These animations were designed through behavioural research done by and with these populations. (Walsh, 2011; Walsh, Laskey and Morrish, 2011; Walsh, Chaiyajit, and Thepsai, 2010).



Figure 2: Sexual, human and legal rights manual produced by BABSEA CLE, Mplus and The Open University

Mplus Sexpert!

Objectives

Mplus implemented the Mplus Sexpert! an online outreach and prevention program (OPOP) from 2010 to 2011 in Chiang Mai (Figure 2). The objective of OPOP is to equip gay men, other MSM, sexworkers and transgenders

with the knowledge and skills to tackle the social factors that influence their vulnerability to HIV. OPOP aimed to reduce stigma and discrimination around sexuality, sex work, sexual orientation, gender identity, and legal and human rights. In launching the project, Mplus' overall goal was to improve and expand its HIV education, prevention and outreach coverage (direct services) with the goal of facilitating the achievement of universal access to appropriate HIV prevention. This commitment was grounded in an ethos to simultaneously promote human and legal rights.

Target Audience

The primary groups targeted by the Mplus Sexpert! programme were:

- Young MSM who may identify as gay or bisexual and generally tend to be under 25. They missed out on the successful HIV campaigns of the 1990s and often have low perceptions about personal HIV risk. Reports suggest around 85% of Thai youth do not see HIV as something that they should be concerned about, even though 70% of all STI cases in Thailand occur among this group (IRIN, 2006).
- Transgenders are a diverse group in Chiang Mai. This makes them hard to access for HIV prevention and education. Many are university students, some are everyday workers and others are sex workers. Although HIV prevalence in this group decreased from 17.6% on 2005 to 16.8% in 2007[iii], it is still high. Like many young gay men, transgenders missed out on the successful HIV campaigns of the 1990s and often have low perceptions about personal HIV risk. They also suffer stigma and discrimination.
- Thai MSM and MSW who work across a variety of venues including bars, saunas, massage parlours, karaoke lounges, and brothels. Additionally, many work independently on the streets, in parks or cinemas, as well as online. Because of the many different kinds of MSW that work across these establishments for different reasons, most work in isolation and many do not fully identify themselves as sex workers. As a result, they have little access to specific sexual health education or services or community legal rights education and are most often underrepresented in current programming and advocacy (UNAIDS, 2007). Data also suggests that the majority of Thai MSM and MSW have sex with men and women, making them a potential "bridge population" as well as an important target for HIV prevention and education (Beyrer, et al., 1998)
- Hidden MSM, a 'hidden' subgroup of MSM most likely due to overt stigma who do not identify themselves as gay or bisexual and who are difficult to target HIV prevention outreach towards. It is believed these men meet secretly online, in parks, restrooms, or other public places with the intention of having sex elsewhere or at the public location. Frequently, the male-to-male sex between these often masculine-identified MSM happens quickly and furtively due to the location and the possibility of discovery by police. This lack of time often leads to unsafe sex (MAP, 2005).

Outreach

Mplus was strategic in advertising its services. Sexperts leveraged social networking sites that Chiang Mai's gay men, other MSM, sex workers and transgender use to socialise, meet, or engage in sex work. The most common sites they used to let the intended service users know about the

service were Pirch, GayRomeo, Post Jung and MissLadyBoys. An example of an Mplus Sexpert! online advert that was designed and deployed for the project is shown in Figure 3 below:



Figure 3: Mplus Sexpert! Advert

The approach

The Mplus Sexpert programme, implemented in September 2010, introduced a ‘safe space’ online. This safe space was provided through MSM messenger or the chat function on Pirch, GayRomeo, Post Jung and MissLadyBoys. This gave peers the opportunity to remain anonymous. If using MSN messenger; they could also become return clients to seek additional information.

In this safe space, Chiang Mai’s gay men, other MSM, sex workers and transgender communities could meet, talk openly and receive sexual health and HIV education and prevention. For the first time, this also included information about their rights under Thai law and how to access justice at no cost through clinical legal education at a local university-based clinic. Mplus understood gay men, other MSM, sex workers and transgenders have specific STI-related needs but often feel uncomfortable going to conventional public sector health services. The launch of the Mplus Sexpert! programme thus provided a new viable online option to reach these communities.

From September 2010 until January 2011, Mplus Sexperts conducted more than 1200 peer-education conversations using MSM Messenger and Facebook chat via the Internet and individuals’ mobile phones. In December 2010 and January 2011, Sexperts logged more than 200 conversations each month. This rapid success increased targeted HIV prevention and education situated in the social and sexual practices of MSM. This responsive approach also proved very useful for generating local community-based knowledge to continually refine and tailor the Mplus’ Sexpert! programme.

One project manager and Mplus’ outreach and prevention staff supervised the OPOP. To preserve confidentiality, each conversation was saved and the peer’s screen name was deleted. The conversations were systematically reviewed to ensure that the peer educators were providing correct information in regards to sexual health and legal rights. Additionally, the number and kinds of referrals to services in the community was documented. Referrals were often also directly provided to Mplus’ outreach team so that individuals could call a number to discuss issues they faced, and receive information about VCCT services in Chiang Mai.

In the next section, we discuss and analyse the chats. We show how Sexperts worked with peers from their stakeholder communities to challenge stigma and change their thinking in small shifts. For us, these shifts represent the increasing ‘sexpertise’ of these marginalised populations. Sexpertise is empowerment that reconnects at-risk gay men, other MSM, sex workers and transgenders with prevention and education grounded in justice, helping them produce new identities as a result of their increased understanding of their legal rights under Thai law.

Online chats on HIV prevention and accessing justice

A qualitative review of the 1200 chats indicates that service users asked Sexperts a diversity of questions. These ranged from questions about how to deal with one’s own sexuality to the availability of antiretroviral (ARV) drugs. The most common topics discussed in the online chats among Mplus Sexperts and peers included:

1. Risk of sexual behaviour in relation HIV and other sexually transmitted infections (STI);
2. Penis size, enlargement and appearance;
3. Love, relationships, loneliness and broken hearts;
4. Dealing with stigma, discrimination and violence;
5. Coming out to family and/or gender identity confusion;
6. Sexual pleasure, premature ejaculation and improved orgasms;
7. Effects of drugs during sex;
8. How to access free and confidential counselling and VCCT;
9. Hormone usage and sex reassignment questions and referrals to transgender friendly doctors;
10. How to properly use a condom with lubricant; and
11. People living with HIV (PLHIV) related issues including accessing Antiretroviral (ARV) drugs.

Negotiating risks

Below is a translated sample conversation between an Mplus Sexpert and a peer from the MSM community:

Mplus Sexpert: If you have sex, it is better to have safe sex.
A1: Yes I use a condom.
Mplus Sexpert: You should use a condom each time you have sex
A1: Of course, I don’t bareback.
Mplus Sexpert: Good that is practicing safe sex.
A1: So if we have group sex, is it risky behaviour?
Mplus Sexpert: It can be high risk if you don’t practice safe sex and use condoms.
A1: But if everyone uses a condom, it is ok?
Mplus Sexpert: Yes, but you must change the condom every time you have sex with a different person.
A1: If someone puts his cock into another guy and then he puts it in me...I should ask him to change to a new condom?
Mplus Sexpert: Yes, exactly
A1: Thanks so much for the good information!

The preceding online chat is a telling example of the kinds of situations Sexperts encountered. Sexperts are connecting with the peers' lived experience without judgement. Here, a peer understands the need to use a condom and not to engage in unprotected sex ('barebacking'). But, he also does *not* understand how to properly use condoms to reduce the risk of possible HIV infection and STIs (i.e., changing condoms when changing partners). The ability to ask a Sexpert for clarification about a risky sexual practice ('group sex') provided this peer the strategic support needed to shift his frame of reference very quickly.

Access to legal advice

In another chat we analysed, a young gay man confided in the Mplus Sexpert that he had been drugged and raped by multiple men. When Sexperts encounter such a violation, they refer the victim to a free CLE clinic run by the Faculty of Law at Chiang Mai University. They also give the number of someone at Mplus who can talk to them on the phone if they choose. The intention is to help the peer access additional help and resources, particularly post exposure prophylaxis (PEP). At the Chiang Mai University (CMU) Legal Clinic gay men, other MSM, sex workers and transgenders (or anyone else) can get free advice and help. Staff at the legal clinic can also accompany individuals to the police to help them report crimes and provide them with free legal advice. The following translated chat between an Mplus Sexpert and a transgender peer illustrates this point:

Mplus Sexpert:
TG317: Hello welcome to Mplus Sexpert. Anything I can help you today?
I am studying at Chiang Mai University (CMU) and have problem with a professor who has a problem with me wearing a female uniform. I fell so discouraged from going to class. I need some help will dealing with some senior students and the professor who is against me wearing a female uniform.

Mplus Sexpert:
TG317: Firstly I have to say that the situation you are facing is not easy and it is challenging to deal with. But you are not alone because you have an Mplus Sexpert beside you who will be available online to discuss this issue with you. But there is another place that you may try to get some help dealing with this professor and the other students at CMU.
Where?

Mplus Sexpert:
TG317: The Chiang Mai Legal Clinic at the Faculty of Law. Have you ever heard about this clinic?
Oh yes, I have walked past the office. It located close to Faculty of Social Science.

Mplus Sexpert:
TG317: Exactly.
But they are willing to help transgender like me? They are Faculty of Law...sound conservative and not welcome to transgender.

Mplus Sexpert:
TG317: Actually they are very friendly towards transgenders and they provide advice on access to justice and will even go with you to report any injustices you may face that are illegal under Thai Law. There is an animation

you can watch on YouTube that explains how they work and some of the issues they help transgenders with. Here is the link. Watch and then we can talk some more.

<http://www.youtube.com/watch?v=LQ4rBIZo1qk>

Ok...Oh Is there this kind of service like this for transgender? Legal clinic friendly with Transgender, Unbelievable!

Mplus Sexpert:
TG317:

Yes but you can truly believe what you just saw. Mplus Sexpert works closely with the CMU Legal clinic and BABSEA CLE and the CLE Thailand Foundation. For more information you can visit www.babseacle.org I feel really better now. Do you have other clips?

Mplus Sexpert:
TG317:

Yes we have a number of animations, please wait a moment. Here is the link to a story about practicing safe sex, This video has been viewed nearly 100,000 times. It is also about supporting transgenders to live with dignity and take responsibility to practice safe and healthy sexual lives.

<http://www.youtube.com/watch?v=2aYGbzt6VeA>

Haha, I'm shy. I don't have boyfriend yet.

Mplus Sexpert:
TG317:
Mplus Sexpert:

That's ok, even if you don't have boyfriend HIV prevention knowledge is necessary! That way you be ready to practice safe sex when the time comes or you can share the animation with your friends.

Hopefully I will talk with you again and thanks so much. You are always welcome to chat with us and you can drop in anytime and say hi.

In 2009, BABSEA CLE worked with Chiang Mai University's (CMU) Clinical Legal Education Clinic, the Open University and Mplus to produce the animations discussed above. These animations teach transgenders and anyone else who has experienced sexual violence how to access the CMU Legal Clinic. It also explains individuals' legal rights under the Thai constitution, the importance of reporting crimes to the police, and the availability of free PEP treatment to prevent HIV infection after a sexual assault. Sexperts smartly infused these animations into their online chats with peers. They were widely used in a very short period of time during the OPOP programme. This targeted integration of digital resources and information about access to justice into online chats situated in stakeholders' lived experience is an indicator of the success of the Sexperts approach. It increased 'sexpertise' and enabled the transgender to overcome her anxiety in accessing her rights, built up over years of stigma and discrimination in a harsh climate. We next consider how we strove to widen the impact of Sexperts through another innovative online programme focused on transgenders, the TLBz Sexperts!

TLBz Sexperts!

The amfAR funding ran out for the Mplus Sexpert programme in 2011. Even though it was extremely successful, it was not continued. The reasons for this are complex and discouraging, considering its impact and the number of successful chats over six months. Not wanting to lose the momentum in

the Sexperts approach among the community, we lobbied a number of other Thai organisations committed to fighting HIV to see if they would be willing to launch a similar programme. ThaiLadyBoyz, or www.TLBZ.me an online community-based and led Internet community for transgenders agreed. The OPOP received funding through the BABSEA CLE and the Thai CLE foundation to continue a form of the Mplus Sexpert programme hosted on their website. The primary difference was that it was marketed and adapted to meet the needs of male to female (M2F) transgenders across Thailand. This OPOP was named TLBz Sexperts! (Figure 4). The funding is used to pay peer TLBz Sexperts! to run an online peer-counselling service for three hours a day, five days a week.



Figure 4: TLBz Sexpert! Advert

The TLBz Sexpert! launched in September 2011 and is on-going. Unlike Mplus with over 1400 registered members and an active and public campaign programme, TLBz.me is relatively small and entirely Internet based. To attract transgenders peers, the TLBz Sexperts! programme advertises its peer-counselling programme on three prominent sites: its webpage, Facebook’s open and ‘closed’ Thai transgender groups (450 members across three groups), and the LGBTI Human Rights Thailand Group (1,861 members). The following diagram outlines how the service was designed and delivered to peers:

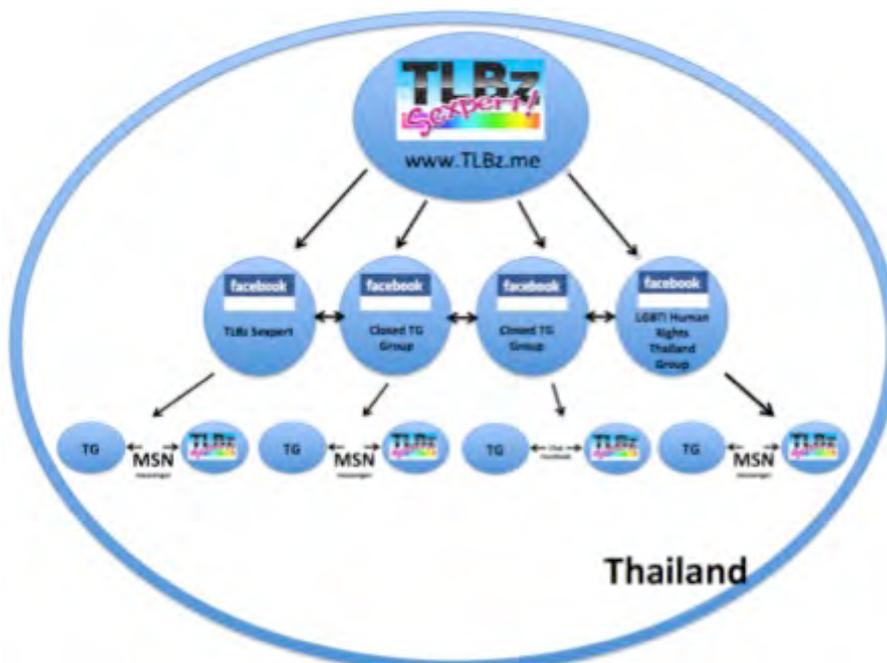


Figure 5: TLBz Sexpert! OPOP design and delivery

Regular advertisements allow members of the 4 Facebook groups know that a TLBz peer counsellor is online and can chat via MSN messenger or Facebook's chat function on any issue a transgender finds relevant.

A goal of the programme is to use the conversations as a platform for providing information on HIV prevention, sexual health and legal rights. In the next section, we highlight two examples from the online chats that show how TLBz Sexperts! positively shaped the thinking of transgenders on sex and body issues as they came to understand and educate transgenders.

Coping with a sex change operation

TG1-01-02-2012: Hello TLBz, are you free to chat?
 TLBz Sexpert!: Hello, TLBz Sexpert! always ready to chat?
 TG1-01-02-2012: Any topics I can ask?
 TLBz Sexpert!: Our service provides the sexual health information for transgenders such as hormone use, surgery, general sexual health and safe sex methods. We also provide human and legal rights info and referrals to free Legal Clinics that close to where you are living.

TG1-01-02-2012: So I had a sex change operation about 3 months ago.
 TLBz Sexpert!: Congratulations! I hope your recovery is going very well.

TG1-01-02-2012: Yes but it is still swelling and I'm not confident with it because of the smell.
 TLBz Sexpert!: About smell you can handle it. After dilation you have to clean inside with soap free shower gel and rinse with lot of water. During the day you may have to use tampons to absorb the cleaned water that still inside your in neo-vagina.

TG1-01-02-2012: I am so worried every time that I have to use public toilet. Any suggestion for me?
 TLBz Sexpert!: To use public toilet in a theater or shopping mall, it is a good idea to carry a small sized bottle that is approx. 300-500 cc in your bag soap free shower gel. Wash your hand before and after you urinate. Because we then have to use our hands to widen the labia to clean the neo-vagina with the water in the bottle. It is important to clean each time after you urinate because if you don't it will cause it to smell. After you clean with the water, then absorb with tissue until dry.

TG1-01-02-2012: I never thought that post operation life would be difficult like this.
 TLBz Sexpert!: Stay strong!. Please don't get too discouraged because it's worth, isn't it?

TG1-01-02-2012: Yes I'm so happy to have a pussy.
 TLBz Sexpert!: Any more questions to ask? We are open to talk about anything

TG1-01-02-2012: Yes I have, but shy to say ha ha ha.
 TLBz Sexpert!: Is it about sex? You can ask, our service is confidential.

TG1-01-02-2012: I want to know the difference between anal sex and neo-vagina? Any suggestion? I used to have anal sex only.

- TG1-01-02-2012:
TLBz Sexpert!: Before I give the answer can you tell me whether you had skin graft or sigmoid colon technic?
Just skin graft.
- TG1-01-02-2012:
TLBz Sexpert!: Basically skin graft technic reverses the penile skin to create the vagina wall. So human skin can't produce lubricant, thus when having sex you need to use condom together with water based lubricant. Think about when you have to do dilation, having sex is nearly the same, you just replace from the dilator a human one!
- TG1-01-02-2012:
TLBz Sexpert!: Ha ha so shy.
Of course first time should be exciting! You may have to talk with your partner, persuade him to trying to touch your vagina through foreplay. He needs to know that your pussy is not 100% similar to a genetic female. This will help both of you feel relaxed and ready to move on! So having sex with neo-vagina is different from anal because of different feel between skin graft and rectum tissue and you don't have to worry too much about the depth when having anal sex :D
[...]
- TG1-01-02-2012:
TLBz Sexpert!: If I really want to try barebacking. I want to feel like real woman!
To feel like woman in term of having sex is about imagination. We don't know how a woman feels because we were not born female born. Even genetic female, they also have to use condom for safe sex. Thus with or with out condom is not the sign of femininity. But...finally you still really want BB, then take him to have HIV screening with you. Right now there are MSM and transgender sexual health clinic, safe and confidential.
- TG1-01-02-2012:
TLBz Sexpert!: Hmm I'm not ready for screening. So I will invite him to practice safe sex.
That's fine indeed because screening needs to be voluntary, no one can force us to get tested for HIV. But in the future if you want to go, just get back to us and we will refer you to get free testing services.
- TG1-01-02-2012:
TLBz Sexpert!: Thanks so much. It's fun chatting but I gain knowledge at the same time.
Your welcome! If you like us please tell your friends or if they use Facebook, please ask them to click "like" to our page TLBz Sexperts! And they will get updates to all kinds of information about transgender life.

In the online chat above, we see the concerns of a transgender struggling with coping with changes to her body as a result of surgery. This significant change in her life provided a basis for the Sexpert to consider how she might use the peer's lived experience to stimulate a wider discussion about sexual practices. In this online chat, we see how the Sexpert empathises with the peer's situation without judgement. As the Sexpert became aware of the peer's specific psychological issues, she went on to suggest a number of practical actions that the peer could take (use tampons, carry a

small bottle). In response, the peer begins to feel comfortable enough to ask more questions about having sex. The Sexpert encourages the peer to discuss and negotiate sex with her partner and allays her fears about feeling 'like a woman'. Instead of teasing and scorn about a sex change operation, the Sexpert speaks of 'imagination' and how the 'first time should be exciting!' Here, the transgenders' sexual pleasure and intimacy is valorised and supported by the Sexpert mediating her sexual practice to shift the peer's frame of references about what is possible with her new body. Finally, the Sexpert draws the peer into HIV prevention; by assuring the peer that free 'safe and confidential' HIV testing is available. We thus see how the infusion of a simple online chat using low-cost MSN messenger enabled a Sexpert to share resources, information, and advice to support the transgender maximise the enjoyment of her new body. Importantly, the contact made also provided an opportunity to encourage the peer to engage her friends to access TLBz Sexperts! and build their 'sexpertise' through Facebook.

This approach makes sense because it focuses the online chats around issues important to transgenders. As compared to traditional peer support workshops and online peer education, this approach allows for greater customisation and tailoring of the messages to the specific needs of community stakeholders. As we see below, the increased confidence of the Sexperts allowed them to take responsibility for transgenders' HIV education and prevention.

TLBz Sexpert!: Hello welcome to TLBz Sexpert! services.
 TG1-18-01-2012: I want to know about KY, What is the best lubricant between KY, Vasline and body lotion?

TLBz Sexpert!: That's really good question :)
 TG1-18-01-2012: I have a new boyfriend. I used to try Vaseline or body lotion sometimes because it's easy but have heard KY is better for having sex.

TLBz Sexpert!: Exactly water-based lubricant is designed for sexual activities. With water based, there is less irritation. Vasline or moisture lotion contains oil that cause condom to break.
 [...]

TLBz Sexpert!: Let's back to the safe sex issue. From your question about KY, Vaseline and body lotion, do you use with condom?
 TG1-18-01-2012: With the first period of love I use, but with long-term partner I rarely use it.

TLBz Sexpert!: Let me start with KY and condoms, they are the perfect match! They are like soul mates, always orgasm together! But if we separate condom by using it with Vaseline then...it can be a tragedy because condom will die because of breakage! ...
 TG1-18-01-2012: I never realized before, I just know that KY is smoother, non greasy and non irritation. Not much about condom using...
 If I don't want to use condom...

TLBz Sexpert!: If you are sure that your partner is completely monogamous with to you and he never has sex with anyone accept you! Are you sure? Even yourself, can

you have sex with only one guy until the rest of life?
Of course not ha ha ha, so what I should do?

TLBz Sexpert!: Do you want to get condoms and water-based lubricant
TG1-18-01-2012: for free?
Yes I do! where I can get it?

TLBz Sexpert!: Where to do you live?
TG1-18-01-2012: Bangkok, water gate area.
TLBz Sexpert!: You can get it at Rainbow Sky Association of Thailand.
[...]

TLBz Sexpert!: Are you interested in blood testing? We can refer you to
TG1-18-01-2012: free services. There are MSM and TG clinic in BKK. All
free and confidential...You can go with your partner.
Just tell him that you want to get a health check up for
free. I suggest Silom Community Clinic

TG1-18-01-2012: So can I get contact number?
TLBz Sexpert!: With pleasure! Silom Community Clinic is located at 3rd
floor Bangkok Christian Hospital. Very private and
peaceful. Open Tuesday-Saturday 16.00-22.00 You can
call to check basic info at or 634 2917 or 02 634 2945
Mobile phone: 085 123 8738 email:
silom@silomclinic.in.th

TG1-18-01-2012: Thanks again for suggestion.
TLBz Sexpert!: Bye! Feel free to get back to us

The preceding chat shows a common misconception encountered by many peer counsellors among transgenders. They often do not know that a water based lubricant is best for use with condoms to avoid breakage. Furthermore, it is important to stress that in Thailand, like many countries in South East Asia, condoms and lubricant remain expensive for many individuals. Providing knowledge of where to go to get free condoms and VCCT is important. The TLBz Sexperts have information on all of the transgender friendly free clinics and CBOs across Thailand to provide referrals to transgenders near to where they live.

In contrast to static repositories of health promotion information written by health experts, or amateur feedback in online support groups for transgenders, the chat above shows how the social interaction with a legitimate Sexpert provided knowledge infused with fun and excitement. This is evident in the use of terms like 'perfect match', 'like soul mates together', which resonate with the kinds of vocabulary used by Thai transgenders in their life. This form of pleasurable engagement between Sexperts and peers is fundamental to our redesigned approach. These are crucial entry points to bring in more sober discussions about HIV testing within the broader framing of access to health and human rights.

Like the Mplus Sexpert chats, all chats are saved, anonymised and reviewed to make sure the peers give correct and accurate information. At the time of writing this article, the TLBz Sexperts! Programme has conducted 155 individual counselling sessions on MSN messenger or Facebook chat. They have made 30 referrals to CBOs and NGOs for VCCT as well as free condoms and lubricant. As the project gained traction, the TLBz Sexpert! team also collaboratively designed a sexual health online library and hosted 7 topical Q&A forums on www.TLBZ.me.

Conclusion

In this paper, we have presented how two small community-based and led organisations in Thailand strategically deployed digital technologies to disrupt injustice that increased the vulnerability of gay men, other MSM and transgenders to HIV. Our approach has significant implications for CBOs and NGOs who wish to use low-cost technologies in contexts where social stigma and violence prevent MSM and TGs from accessing their rights.

Firstly, the Mplus and TLBz Sexperts programmes we analysed are unique because they show how CBOs can build bridges between disparate HIV and AIDS education, prevention and outreach, legal rights and access to justice. Both programmes demonstrate the added-value of continuous stakeholder involvement. A collaboration among frontline workers, lawyers, researchers, peer educators, and leaders from an affected community resulted in a greater understanding about each other's lifeworlds. This reflexive awareness overcame the common negative perceptions of these populations by public health researchers that do not adequately valorise the knowledge of these populations when trying to change their behaviours but ignore understanding the wider social practices which mediate behaviours.

Secondly, our approach shows that it is important for CBOs not to be seduced by the novelty of social media. CBOs need to think critically about how low-cost digital technology available—in this case MSN Messenger, and a variety of social networking sites—can be used to target peer education and counselling, optimise the use of digital resources, and provide access to rights that marginalised people may not know about. In this case, we needed to retaliate against the political and cultural persecution faced by gay men, other MSM and transgenders (and to some extent sex workers) in Thailand. We have found that the use of clinical legal education (CLE) can make a significant contribution to address the specific localised needs of a community around accessing justice under Thai law. We recommend this approach to other organisations who are keen on incorporating a rights based approach into online HIV education and prevention programmes.

Thirdly, our approach shows that modelling non-colonising culturally appropriate educational practices is vital to sustaining meaningful and relevant connections with individuals at risk. Unlike dominant public health approaches to online HIV prevention and education with marginalised communities such as MSM (Rosser et al., 2009), our approach framed the problem of HIV around the broader issue of access to justice. This framing is important for community organisations. This is because the scientific interests and motives of public health researchers and practitioners often do not cater for pleasure, intimacy, sexual and legal rights as important signifiers of perceptions of access to justice among individuals such as gay men, other MSM and transgenders. We thus argue that public health researchers would do well to serve the cause of access to justice so as to enable marginalised communities to move outside deficit assumptions about 'vulnerability' and innovate broader interventions that make a difference not only to traditional behaviour change outcomes (although

these in themselves are important), but also to the quality of justice experienced by stakeholders.

The Sexpert! programmes developed, implemented and piloted online and mobile resources that offer new avenues to protect public health and promote human rights. However, as the loss of funding from amfAR revealed, it remains a challenge to launch a sustainable and reinventing community-owned response with stigmatised populations disproportionately at risk of HIV infection: gay men, other men that have sex with men (MSM), male sex workers (MSW) and transgenders and transgender sex workers. The success of such innovations is not guaranteed, given the relentless push to 'biomedicalise' the AIDS response (Auerbach, this issue). The projects, while small in scale, can have a larger impact only if the connections built through digital technologies continue to engage communities in addressing social, legal and educational barriers through each and every affected individual, without forcing them into workshops or support groups. The chats we have analysed in this paper show how this is possible with trained online peer educators, but we know that these individuals will continue to face stigma and discrimination relating to housing, employment, religion, and accessing justice.

Moving forward, we argue that involving CBOs and individuals in designing online safe spaces for inquiry and sharing offers funders, researchers and practitioners unique opportunities to address important questions of health and well being to reduce HIV risk at low-cost. Although the Sexperts online approach is distinctive and has wider applicability across contexts to circumvent barriers to learning in countries which exclude gay men, other MSM and transgenders, the approach also has raised new questions and unexpected insights for us. Justice is now more than ever at the forefront of our design when we work with the daily experiences of ordinary gay men, other MSM and transgenders in their digital lives, rather than dominant calls for 'treatment as prevention' or 'structural interventions'.

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Endnotes

[i] To read more about the work BABSEA CLE does with LGBT and other MSM see this article: Walsh, C.S., Lasky, B., and Morrish, W. (2011). Building Local Capacity to Protect Public Health and Promote Social Justice Through Online Peer Education. *IADIS e-Democracy, Equity and Social Justice Conference 2011*. Rome, Italy. Available at: http://open.academia.edu/ChristopherWalsh/Papers/803084/BUILDING_LOCAL_CAPACITY_TO_PROTECT_PUBLIC_HEALTH_AND_PROMOTE_SOCIAL_JUSTICE_THROUGH_ONLINE_PEER_EDUCATION

[ii] To view in English

[http://babseacle.org/sites/default/files/Sexual,%20Human%20and%20Legal%20Rights%20for%20Chiang%20Mai%27s%20MSM,%20MSW%20and%20TG%20\(English\).pdf](http://babseacle.org/sites/default/files/Sexual,%20Human%20and%20Legal%20Rights%20for%20Chiang%20Mai%27s%20MSM,%20MSW%20and%20TG%20(English).pdf)

[iii] Information comes from research conducted by the US-CDC-TUC (2005) and the Thailand Ministry of Public BoE (2007).

Chapter 9

When in Ghana, do as sexual minorities do: using Facebook to connect gay men and other men who have sex with men to hiv services

Benjamin Eveslage

Benjamin Eveslage's chapter, highlights how social stigma and discrimination, compounded by the criminalization of homosexuality, influence gay men and other MSM to avoid in-person peer-networks and settings where HIV prevention and care services are available. He argues that Facebook is uniquely well suited for connecting these at-risk populations to sexual health interventions and services. Drawing on findings from an ethnographic study, Eveslage outlines how CBOs and NGOs delivering sexual health services could possibly improve HIV prevention and care outreach within these subpopulations of gay men and MSM by mimicking how they use social media.

Sexual health organisations, sexual minorities and social media

At the 2014 International AIDS Conference in Melbourne, it was made clear that those who provide sexual health services to gay men and other MSM need to rethink the intersection between sexual health organisations, sexual minorities and social media in “stepping up the pace” to address HIV. It is critical to better understand how sexual minorities' use of social media can inform sexual health interventions targeting these populations. Gay men, other MSM and transgender women are sexual minorities targeted by sexual health organisations because they are at a disproportional risk for contracting and transmitting HIV and other STIs (UNAIDS, 2014; Wilson et al., 2013, Baral et al., 2013). These sexual minorities, as well as people involved in sex work and people who inject drugs comprise the “key populations” framework for targeted HIV/AIDS interventions by USAID (2014).

In this chapter, I argue nongovernmental organisations (NGOs) and community-based organisations (CBOs) who focus on sexual health could broaden their reach within and to subpopulations of gay men and other MSM by mimicking how these populations use social media. Such an approach entails more ambitious and undercover methods for leveraging these populations' use of social media networks, like Facebook, to better connect them to localised HIV prevention and care services. In what follows I review a number of successful HIV programs to highlight successful examples of NGOs and CBOs using social media to provide HIV services to gay men, other MSM and transgender people to underscore the potential benefit of integrating similar approaches to strengthen HIV efforts into the

future. Then, drawing on an ethnographic study with sexual minorities in Ghana, I describe specific methods and logistical considerations used to successfully reach underserved populations using Facebook. Drawing on data sets across participants from urban areas in six regions in Ghana, I illustrate how many gay men and other MSM in Ghana reported having little or no knowledge of local sexual health services. Findings highlight the need to expand the reach of sexual health interventions on offer in Ghana targeting gay men and other MSM. This led me to explore the potential benefits of using Facebook to broaden and diversify the reach of HIV services to gay men and other MSM, as well as other sexual minorities disproportionately at risk to HIV. However, new ethical dilemmas arose as a result of my "when in Rome, do as Romans do" approach of mimicking how sexual minorities' use social media. I conclude by examining these ethical dilemmas and then outline how they influenced my recommendations for approaches sexual health NGOs and CBOs can implement. I argue these methods have the potential to better reach underserved subpopulations of gay men and other MSM in Ghana and more globally to provide contextualised HIV prevention and care.

Outreach to sexual minorities through social media

The increasing ubiquity of online social media corresponds with a surge in numbers of sexual minorities engaging these platforms (Jones & Fox, 2009; Martinez et al., 2014; Oosterhoff, 2014). Furthermore, the recent and dramatic politicisation of homosexuality and high levels of stigma and discrimination in many Sub-Saharan African countries not only influence some sexual minorities to avoid public interaction, but also negatively affects the provision of HIV care and prevention services (Corey-Boulet, 2012, Currier, 2014, Epstein et al., 2004; IRIN, 2006; Walsh, Laskey, Chiayajit and Morrish, 2010). Over the past decade, Ghana has witnessed not only a proliferation of more affordable information communication technologies (ICTs) (Frempong, 2012; infoDev 2014), but also the politicisation of homosexuality and increased instances of human rights abuses directed at sexual minorities (Eveslage, 2015; Essien & Aderinto, 2009; PANA, 2011; Citi FM Online, 2010; Daily Guide, 2010; Mac-Darling Cobbinah, 2015). In this context, online social media networking becomes increasingly attractive for sexual minorities seeking sexual partners. It also provides unexplored platforms to maintain anonymity and discretion in accessing health services and information. Importantly, this also potentially opens up new avenues of exploitation (O'Mara, 2013) and violence (Wood, 2014; Avari 2014).

HIV prevention and care interventions in various regions – from North and Central America (Allman et al., 2012; Rivas et al., 2014) to Africa (Henry et al., 2012; Scheibe et al., 2012) and Asia (Avery et al., 2014; Chiayajit & Walsh, 2012; Dasgupta 2012) – have highlighted the ways sexual minorities use social media to better inform the practice of HIV prevention and care (also see Kahema et al., 2014; Beck et al., 2012; Young & Jaganath 2013). These research studies highlight the importance of understanding how and

why sexual minorities use social media in order to improve outreach into the virtual locations where they connect and communicate (Hanckel et al., 2014, p. 183-185). The available ICT resources range in their ability to directly reach gay men and other MSM. For example, designing a new website for sexual health education as Muessig et al. (2014) describes may allow for more tailored messages and service delivery, but will likely be encumbered with getting their target population engaged on their platform. Instead, Rivas et al. (2014) and Chaiyajit and Walsh (2012) document projects that more directly reached sexual minorities through chat rooms and social media websites already in use by sexual minorities. Specifically, the Sexperts! project, developed by RFSL (2009) in Stockholm and deployed by Mplus+ Thailand and TLBz Sexperts!, included two CBOs in Thailand that engaged on social media to reach populations of MSM and transgender women (Walsh, 2008; 2011; Walsh, Chaiyajit & Thepsai, 2010). In Thailand, the TLBz Sexperts! Program is “a low-cost, transgender-led, community project offering accurate online transgender-specific sexual health information, social support and legal advice” (Chaiyajit, 2014). With 10 years of experience, the Sexperts! projects serves as example of directly reaching key populations to connect them to HIV and broader STI education.

In Ghana, Green et al. (2014) detailed the experience of USAID-funded HIV prevention and care efforts for key populations under the SHARPER project. In 2012 they reached less than 50% of the estimated number of MSM in Ghana when using traditional means of reaching MSM through “peer educators” (p. 210; Aberle-Grasse et al., 2013). However, peer educators within their project “were aware of other MSM networks – particularly those that were older or discreet about their sexuality, and who were not interested in being directly contacted by a peer educator” (p. 210). To incorporate these un-reached populations SHARPER invested in new efforts to reach MSM through social media (including Facebook and dating websites), increasing their coverage to 92% of the estimated population of MSM in Ghana (ibid.).

These studies evidence that sexual health CBOs and NGOs are capitalising on expanding ICT resources and social media used by sexual minorities. However, there remain large populations out of the reach of current HIV programming for various reasons. For one, many of the population size estimates of gay men and other MSM – which are used to measure the success of HIV reach, prevention, care and treatment services – are typically based on biased starting points such as respondent driven sampling or a “wisdom of the crowds” approach (Paz-Bailey et al., 2011; Quaye et al., 2015). While there are methods that attempt to control for this bias (Lane, 2009, p. 73), they tend to overlook subpopulations not connected to peer-networks whatsoever. Furthermore, there remain issues of how researchers and demographers understand sexual identities and how they conceptualise the impact of these identities on sexual behaviours (as discussed in Lane, 2009, p. 71; Sandfort & Dodge, 2009, p. 55; Nel, 2009).

The current approaches harnessing social media and ICTs to reach subpopulations of gay men, other MSM and transgender women to connect them to HIV services have room for growth. The goal of my research,

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reported below, is to add to and augment these methods by describing a study that could also be used to connect an at-risk population in Ghana to sexual health interventions and services. In what follows, I describe an independent field study conducted in Ghana that leverages subpopulations of gay men and MSM's use of Facebook—by mimicking how they use social media—to:

- broaden the reach of sexual health CBOs and NGOs to currently un-reached sub populations of gay men and other MSM on Facebook in Ghana;
- to bridge the gap from online to in-person CBO and NGO contact with gay men and other MSM (e.g. to connect them to research studies or HIV prevention, care and treatment); and
- to successfully navigate and address ethical dilemmas that arise when using such an innovative approach in a context where social stigma and discrimination towards gay men and other men MSM is severe.

Detailing my field study experience in Ghana will provide a deeper context for how sexual minorities use social media in Ghana and how sexual health CBOs and NGOs can learn from and mimic sexual minorities' use of social media to develop methods to reach largely hidden subpopulations of gay men and other MSM who have little to no knowledge of sexual health services available to them.

Using Facebook to reach gay men and other MSM

Background and review of the study

To provide a background to my research, my use of the phrase “when in Ghana, do as sexual minorities do” is a reflection of my own experience as a sexual minority, and within broader sexual minority populations in Ghana. Over a 10-month period between 2009 and 2010 I became acquainted with sexual minority populations in Ghana as well as a number of sexual health NGOs targeting key populations at disproportionate risk to HIV. Unquestionably, I operated from a position of privilege being a white, male foreigner while in Ghana. However, my methods of making contacts and developing friendships within these populations were similarly shaped by the apparent risks that sexual minorities experience when connecting with others and disclosing sensitive information about sexuality. I also learned about methods of networking within sexual minority populations by interacting within sexual minority communities, taking their advice, and learning from their strategies. The experience integrally shaped my understanding of how sexual minorities interacted, connected and socialised on Facebook in the context of heightened stigma and discrimination.

My field research in Ghana was conducted in 2014 for my Masters degree at the School of Oriental and African Studies, University of London. The field study was designed to gather a broad range of data to address the research

question: “How have the politicisation of homosexuality and the transcultural production of sexual orientation and gender identity impacted people with non-normative sexual orientations and gender identities in Ghana?” Preparation for the field study began in January 2014 including obtaining ethical clearance and designing field research methods. Beginning in March, and spanning till the end of the field study in August, I reached out to 400 gay men and other MSM on Facebook to recruit research participants (Facebook recruitment methods are described in the following section). From mid-June to mid-August I was located in Ghana to collect data from participants recruited from Facebook, as well as through respondent driven sampling (i.e. snowballing) and gatekeeper referrals that brought in some lesbian women participants.

Participants predominantly included sexual minorities, including 113 gay men and other MSM and five lesbian women. A small number of participants recruited described themselves as heterosexual during interviews (N=9). Additional interviews included staff of human rights and sexual health NGOs and other business, civil society and community leaders that impact sexual minorities (N=9). While my field study sought to speak with a diversity of sexual minorities, this chapter specifically focuses on how I identified and recruited gay men and other MSM using Facebook. Data collection with the larger group of gay men and other MSM included in-depth interviews (N=70), focus group discussions (N=36) and participant observation (N=7). Gay men and other MSM recruited using Facebook only participated in-depth interviews, while some recruited through snowballing, gatekeepers and sexual health NGOs participated in focus groups. Of the 113 gay men and other MSM who participated in the study, Facebook recruitment methods recruited 64 participants, while 49 other participants had been identified through traditional strategies. In-depth interviews lasted between 30 minutes to three hours, with an average of about 90 minutes. An interview discussion guide was used in all interviews and focus groups, which included a list of standard open-ended questions (see Appendix 1), divided between these eight sections:

- 1) Social-demographic profile (age, religious/ethnic background and family details);
- 2) Economic profile (means of livelihood, education and future plans);
- 3) Sexuality profile (description of sexuality, sexual behaviours/dating life, and any economic factors related to sexual relationships);
- 4) Globalisation and perception of sexuality (Connectedness to ICT resources and friends located globally, means of learning about sexuality, perceived marginalisation/agency that comes with their sexuality);
- 5) Politicisation of homosexuality (Understanding of the politicisation of homosexuality in Ghana and how this has impacted their life);

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- 6) Societal norms (perception for how societal norms and others' expectations impact their gender performativity and their relationships including marriage and having children);
- 7) Religious/spirituality profile (Role/impact of religion in life, marginalisation experienced and agency demonstrated through participation in religious activities/organisations or spirituality); and
- 8) Sexual health knowledge (knowledge of sexual health services/NGOs, health seeking behaviour, and suggestions for organisations working with sexual minorities in Ghana).

Analysing this data took the form of transcribing interviews, where I categorised responses into themes that I then codified and tallied. However, the data collection was not administered uniformly across participants. Some concepts and questions were added to interviews after participants identified them as important. At times, participants commanded the direction of the interview, addressing many of the questions on their own, while at other times, I led the conversation and adapted the wording and order of questions to maximise continuity and depth of conversation. At the conclusion of interviews, I typically sought to clarify any unclear responses or address skipped questions. Yet, in some instances not all sections or questions were answered, resulting in a number of incomplete interviews.

Methods for identifying gay men and other MSM on Facebook as potential research participants

Three methods were used to identify gay men and other MSM on Facebook as potential participants for my research project. Some of these methods are distinguished from others employed by other NGOs because they reached populations whose status as gay or MSM was not assured before contacting them, leading to both an imperfect but also widely cast sample. These methods included:

1. **Adding friends-of-friends:** I reached out to my previous contacts and friends in Ghana who I knew as gay men or other MSM by requesting their "friendship" on their Facebook profile. From this initially small group of Facebook contacts, I requested friendship with their friends, and friends of their friends (and so on).
2. **Joining Facebook groups for gay men and other MSM:** I searched for and joined Facebook discussion groups for gay men and other MSM. To connect with the members of these groups, I posted a short research description in the discussion board indicating that interested members could reach out to me directly to participate and I directly contacted and requested friendship with some members.
3. **Searching for "men interested in men":** I used Facebook's search box to find "men interested in men". Using this last method, I searched for "men who are interested in men from [name of city]".

Entering these search criteria returned profiles on the basis of the details that Facebook users entered on their profiles, such as their gender, who they are “interested in” (which can include “men, women, or both”), and their current location and hometown.

Each method had unique strengths and weaknesses for identifying gay men and other MSM as potential participants. For instance, those I identified using methods two and three created additional entry-points for the first method to be used again to deepen and broaden to friends-of-friends. However, the first method’s accurate identification of gay men and other MSM was predicated on the assumption that my initial contacts (and their friends) used their Facebook profile primarily to connect with similar men. This appeared especially true for those who used an anonymous Facebook profile (i.e. containing no personally identifiable information or photos), which allowed them to connect with other gay men and MSM and openly discuss matters related to sexuality and sexual interests while avoiding exposure. However, some individuals reached using this method did not only use Facebook for these reasons, some had friends who were heterosexual or others were pretending to be gay or MSM in order to exploit/blackmail or direct violence towards these groups. Others used their real name and photo to connect with gay men and other MSM among a range of other people including friends and family.

Many Facebook groups for gay men and other MSM are openly accessible, which allowed me to view the list of group members and communicate with members directly. The openness of these groups also indicated they were particularly high risk, as they were open to any Facebook user including people interested in finding other gay men for financial gain (e.g. commercial sex work, blackmail or and theft/violence). Accurately identifying potential participants by searching for “men interested in men” on Facebook was predicated on the assumption that “interested in” meant a sexual interest. Many people I identified using this method appeared to use Facebook profiles that were not anonymous, meaning that some gay men and other MSM used the “interested in” section of their profile to discreetly communicate sexual interests to other gay men and MSM who could interpret this. For example, some participants I identified using this method, and later interviewed, described that their Facebook friends who are neither gay nor MSM would understand “interested in men” on their profile to mean an interest in friendship with other men. Using this method allowed me to identify potential participants located in regions where I had little success with other methods. However, this method also identified a number of “straight” or heterosexual Facebook users (as was revealed during interviews).

In each of these methods, I targeted Facebook profiles that I judged as being more likely to be owned by gay men or other MSM, such as profiles with a high number of mutual friends with me or those who used their Facebook to discuss topics about gay men or other MSM.

Interview recruitment strategies

Knowing how gay men and other MSM use social media not only guided my

methods for identifying potential participants on Facebook, but also my strategies to recruit these contacts into in-person interviews. I focused the use of these recruitment strategies on contacts with interest to participate in the research. Conducting my research in Ghana as an independent researcher required that I build my credibility as a legitimate researcher to those I reached on social media. For instance, because Facebook is commonly used as a dating website among gay men and other MSM in Ghana, it was important that I first clarified the goals of my study to those I reached using plain language and inviting a wide range of participants to join the study. In order to protect the privacy and non-disclosed sexuality of possible participants recruited using Facebook, my project description was authored in such a way that it avoided narrowly targeting sexual identities with admittedly quite vague wording. An example of the standard messages sent to those identified on Facebook as possible research participants are included in the graphic below. (The image was edited to blur the profile photo and the named was changed).



Figure 1: Screenshot of Standard Recruitment Messages on Facebook

Being an independent researcher allowed me to travel alone and remotely in order to meet with participants in a variety of locations and settings comfortable to them. Being a gay man who also used social media to connect with other gay men and MSM, meant I assumed additional risks when meeting with participants for interviews. I believe this context offset the typical unequal power relationship between researcher and participant, providing for a friendlier two-way discussion by showing that (in some ways)

we had our queer sexuality in common.

For many potential participants identified on Facebook, my positionality facilitated the process of building trust and setting up interviews. Most notably, I am referring to being an “out”, gay, white male researcher who is not from Ghana. Many participants indicated they would not have met with me had I been Ghanaian, or even black. Being seen as an outsider (and my whiteness being evidence of that) but also an insider as a sexual minority, meant many of the contacts I made on Facebook felt more comfortable meeting with me to discuss issues related to their sexuality.

Obtaining informed consent and addressing other ethical considerations

My methods and strategies of reaching gay men and other MSM on Facebook led to unique ethical dilemmas. Here, I account for how participants’ informed consent was obtained, anonymity ensured, confidentiality of personally identifying information secured and the chance for undue harm reduced.

Obtaining participants’ informed consent

To obtain participants’ informed consent, I sent those I reached on Facebook who were interested to participate in the research a “participant consent form” (see Appendix 2 & 3), which detailed the purpose of the study, procedures, ethical considerations, benefits, duration and a statement of confidentiality. I asked each participant to review the participant consent form through Facebook (where possible) before deciding to meet for an interview. Further, I reviewed the participant consent form fully with all individuals who met me for an interview by asking them to read it or, where that was difficult, I read it to participants. Before moving into an interview, I addressed any remaining questions and confirmed their voluntary participation with a verbal consent (to avoid any names being written on paper for anonymity purposes). All of those who met with me consented to participation in the research, while a few opted for informal discussion instead of a formal interview.

Ensuring anonymity and confidentiality of personally identifying information

At the point when my contacts on Facebook indicated an interest to participate, I noted their details into a password protected key file, which included their Facebook name, a link to their Facebook profile and additional contact information provided (e.g. email and phone numbers). I commonly made note of their city or neighbourhood location to schedule interviews by geographic location. I never asked for real names, but rather asked for a name they preferred to use. During audio-recorded interviews the participant and I used a completely new pseudonym that no one knew the participant by. All notes and files associated with participants’ interview responses were linked to their pseudonym and a 4-digit code and only linked to their other names and identifying information in the key file. All field study data, including the key was encrypted before backing up to Google Drive.

Interviews were held in various public and private locations, but never in designated, interview sites or rooms where former participants could find me interviewing later participants.

Reducing chance of undue harm

Even before a participant agreed to participate, those I reached on Facebook could be adversely impacted. For instance, there remained chances that my Facebook ‘friends’ could see whom I was connected to on my Facebook and might suspect these contacts as sexual minorities. For these reasons, I hid my list of friends from others and was sure to invite a wide range of participants (and not narrowly target sexual minorities) so others could not assume that I only connected with sexual minorities on my Facebook account. Further, I depended on those I reached and recruited to recognise and mitigate their own risk when using Facebook, such as using privacy settings, or preventing others from viewing their communication with me on their phone, laptop or public computer.

Minimising risks to participants also resulted from me acknowledging participants’ level and manner of communication and matching this, commonly using less than straightforward language that preserved discretion and plausible deniability for their participation in my research or any basis for them to receive undue harm.

Data and results

Knowledge of sexual health services

Of the 64 interviews with gay men and other MSM recruited through social media, 55 completed the interview discussion guide section on sexual health services. Data from these interviews revealed a very low level of knowledge about sexual health services. Of these 55 men, 24 (44%) had no knowledge of sexual health services for gay men or other MSM in Ghana, while 14 people (25%) merely knew of their existence, but could not name the organisation or what their activities were. A remaining 17 people (31%) were familiar with these organisations and their services (see Figure 2 below).

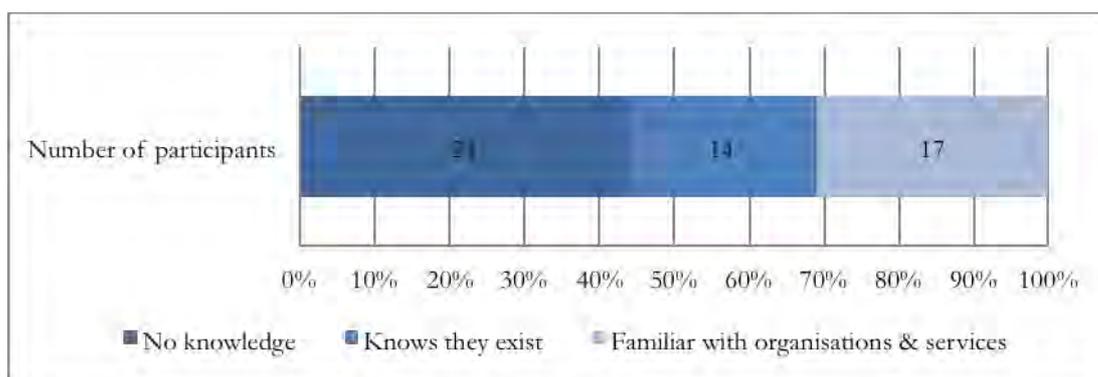


Figure 2: Knowledge of Sexual Health NGOs/Services for Gay Men & MSM in Ghana

Another series of questions asked participants about their knowledge of, connection to, and interest in “peer educators” and their services. 40% of participants recruited through social media (N=23) had no knowledge about peer educators. The remainder knew about peer educators (25%), had peer educators as friends (24%) or was either a peer educator himself or had been previously (4%). Slightly more participants were aware of the kinds of

services that peer educators provide (N28), while 26 participants (44%) had no knowledge about their services (see Figure 3 below)/

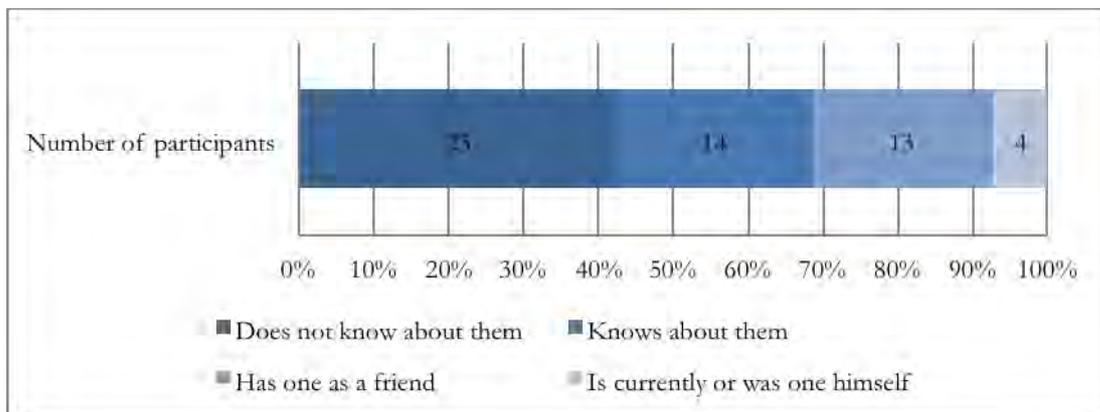


Figure 3: Knowledge of Peer Educators for Gay Men & MSM in Ghana

After confirming that participants were familiar with peer educators (or after I told them about the kinds of services they provide), 34 participants indicated that at some point they would have wanted to speak with a peer educator about issues they were facing. These participants demonstrated unmet needs for peer educators' services because 15 people indicated both that they did not know about peer educators, but would have liked to speak with one had they known. However, 10 participants who were aware of peer educators did not want to speak to one. An additional 8 participants similarly felt no need to speak to a peer educator even after learning about their services (see Figure 4 below).

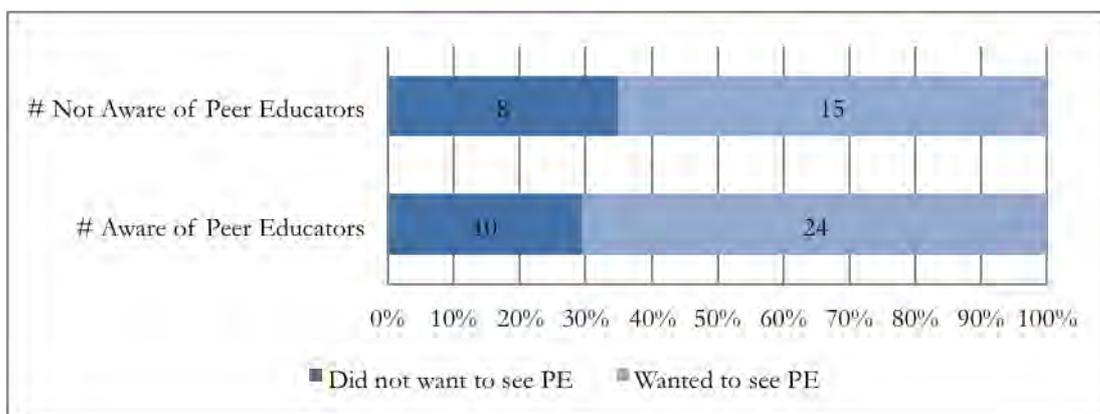


Figure 4: Demand for Peer Education Services

A number of these individuals explained that they felt no need to speak with a peer educator because they already received education on sexual health or felt more confident using the Internet or books to find reliable sexual health information. Some of these respondents did not face many barriers to accessing commodities provided by peer educators (i.e. condoms and lubricant). However, a few indicated that they actively disassociated themselves from sexual health services for gay men and other MSM (e.g. peer educators). For instance, a participant called "Michael" indicated awareness that peer educators provided services to gay men and other

MSM in Ghana. “So I know these things are there,” Michael said. “I think I have made a conscious effort not to be a part of them”. Like Michael, there were other participants who shared his sentiments, indicating a self-distancing from sexual health organisations and services targeting sexual minorities – not due to their lacking awareness, but because they wanted to avoid compromising the confidentiality of their sexuality by affiliating with such organisations.

Limitations

Despite successfully gathering a broad range of participants both demographically and geographically (see Appendix 4-6), my methods proved unsuccessful or insufficient for including some groups of gay men and other MSM (e.g. those older than 45 years old, those located in rural areas or outside the six regions where I conducted fieldwork). Furthermore, my positionality as a white, gay researcher likely complicated the participation of gay men/MSM who engage in blackmail against others because it would be financially non-remunerative (I offered no incentive for participation) or they could feel morally vexed by being interviewed by a queer researcher and may be afraid to discuss how they exploit other gay men/MSM for financial gain. My use of social media also did not help me to reach those *not* using social media (or those not using it for same-sex sexual interests) and those who cannot speak or read English (due to my own language limitations). For a number of these gay men and other MSM who remain unreached, they likely face added factors making them vulnerable to sexual health concerns (e.g. economic vulnerability) and are distanced from the NGOs who provide sexual health prevention and care services. These sub-populations are a new frontier for future research and service delivery methods in the field of sexual health.

Discussion and conclusion

My field study in Ghana is relevant to sexual health organisations because its methods facilitated outreach and recruitment of gay men and other MSM who are not being reached by the sexual health services targeted for them. I argue this offers a new and innovative approach that sexual health CBOs and NGOs, who are possibly struggling to reach gay men and other MSM, could leverage to provide their services. Furthermore, my participants’ knowledge of, and attitudes towards, available local HIV services can also usefully inform programmatic options to address the sexual health needs of more diverse groups of gay men and other MSM.

Improving sexual health CBOs and NGOs’ outreach to gay men and other MSM

I argue my approach of mimicking how sexual minorities use social media—specifically Facebook—is a timely approach that sexual health CBOs and NGOs could possibly implement to improve outreach to subpopulations of gay men and other MSM in Ghana and elsewhere where homosexuality is criminalised (or where gay men, other MSM and transgender person face extreme stigma and discrimination). CBOs and NGOs could also possibly

appoint a social media peer “champion” from the community tasked with mimicking how sexual minorities use social media to improve and augment their outreach programs. Such a peer champion could connect with other gay men/MSM by accumulating contacts and by snowballing through his contacts’ Facebook “friends”, by joining and contacting members of Facebook discussion groups for gay men and other MSM, and by directly searching for “men interested in men” on Facebook.

By using these methods, along with traditional recruitment methods, my research project included the experiences and opinions of 121 sexual minorities; 113 of whom identified as gay men or other MSM. With nearly 70% of participants recruited on social media having little to no knowledge of sexual health services for MSM, it struck me that not only were existing CBOs and NGOs still struggling to connect to sexual health services to these populations in Ghana, but also that outreach strategies, similar to those outlined in this study, could help address this issue. Furthermore, outreach in this manner could connect individuals to sexual health services that they want but don’t know exist (27% of social media-recruited participants indicated this). While some participants did not want to be associated with these sexual health organisations and services, the larger number who did gives cause for sexual health services to continue rethinking how they provide outreach to gay men and other MSM.

Ethically integrating methods into sexual health CBOs and NGOs

While my methods for reaching gay men and other MSM and strategies to recruit participants worked well for my study, they may not be entirely suitable or appropriate for implementation by CBOs and NGOs. Mimicking gay men’s and other MSM’s use of Facebook is a complicated task for sexual health organisations, namely in how they integrate the methods that I was able to employ as an independent researcher into their organisational structure given the many ethical and political dilemmas that may arise.

The specific strategies I chose for identifying participants on Facebook were relatively simple and could be adopted by sexual health CBOs and NGOs. If sexual health CBOs and NGOs do not need to recruit sexual minority participants for studies or have them meet with their staff in-person, these social media recruitment strategies could be implemented quite easily. For instance, the peer educators of some sexual health CBOs and NGOs already use social media to increase their outreach to broader sexual minorities populations, as noted by the SHARPER project in Ghana (Green et al. 2014). However, more ambitious methods could seek those left unreached by other methods by extending beyond the networks of gay men and other MSM on social media that peer educators are already in contact with. They could diversify the entry points into these virtual networks by incorporating contacts well beyond their circle of friends, by adding friends of friends, including 3rd, 4th, and 5th degree connections. They could also join social media groups meant for sexual minorities or simply search for “men interested in men”.

Because these strategies cast a wider net, and are based on assumptions about how gay men and other MSM use social media, it means many “straight” or heterosexual people may be included in those who are

contacted. This sort of recruitment and outreach by sexual health CBOs and NGOs should be encouraged while also tailoring the language of sexual health messages for relevance to both broader audiences as well as to sexual minorities. Broadening the language of sexual health services to avoid messages targeting only gay men and other MSM would help prevent ostracising some audiences who would not want to be associated (on social media or otherwise) to organisations or people known to have this focus. This is particularly important for social media outreach to gay men and other MSM who are using a Facebook with personally identifying information.

However, peer educators and sexual health CBOs and NGOs using these approaches may be placed at increased risk, because they will likely reach audiences that are beyond the safety and trust that is developed within in-person peer-networks. Peer educators may not be open about their sexuality beyond small groups of friends or the sexual health CBO or NGO may be discreet about their outreach efforts. Maintaining a balance between methods that seek to reach people who are more likely to be gay men or MSM, while at the same time mainstreaming the communication and messages for general audiences may help to reduce these risks. Additionally, it may help for peer educators to conduct outreach in cities, regions or even countries different than their own and where they feel comfortable with the risks. Alternatively, peer educators could also use anonymous Facebook profiles to conduct outreach if it is not important for sexual health organisations to recruit the gay men and other MSM for in-person meetings.

When sexual health CBOs and NGOs seek to recruit sexual minority populations into physical meetings for research or to deliver sexual health services, there are more pronounced ethical and logistical considerations. Many sexual health NGOs are not well suited to employ the tactics I used to successfully bridge the gap between social media outreach and recruitment for in-person interviews. I was successful in this regard due to the manner of my fieldwork and my own positionality. For the most part, my fieldwork was conducted in isolation from sexual health CBOs and NGOs and as an independent researcher. I chose this manner of fieldwork to distance myself from the stigma that many participants feared when associating with groups who target gay men and other MSM. Operating independently in the field also allowed me to be more vulnerable and accessible to potential participants, meeting them in contexts and in manners convenient to them. This helped reduce the inhibitions of some participants to meet me. Furthermore, my positionality as a white, gay, foreigner who was not working for sexual health CBOs or NGOs was especially important for securing in-person interviews.

My experience demonstrates a case for sexual health CBOs and NGOs to consider employing independent consultants or even including foreigners into social media outreach in addition to their domestic peer educators and researchers. Many of my research participants only met with me because I was a foreigner. However, when dealing with sexual minority populations and marginalised populations generally, there are heightened concerns for sexual health CBOs and NGOs who may want to employ independent

researchers. The lacking ability for these CBOs or NGOs to oversee these researchers' operations is one concern, as well as reconciling their specific policies and ethics procedures that detail how to engage with marginalised populations. This is not to mention the prohibitively high cost of hiring foreign staff by these CBOs and NGOs. Striking a balance between researchers whose positionality and experience will grant them preferential access to sexual minority communities is integrally important. My positionality and experience was helpful for my participants to feel comfortable to talk with me on social media as well as in-person during interviews. However, it is unlikely that any single researcher will be capable of adequately accessing all sub-populations. Even with my preferential access, I was also disadvantaged in accessing other subpopulations.

Targeting gay men and other MSM for HIV prevention and care

My research sought to improve outreach of HIV prevention and care to gay men and other MSM, however it also brings into question the logic of targeting these groups in the first place. While 44% of those I recruited through social media had no knowledge of sexual health services in Ghana for gay men and other MSM, this should not be construed as an overwhelming desire for such services among these participants. For participants recruited through social media, 18% (N10) were aware of peer educators and the sexual health services for gay men and other MSM, but were not interested in their services. Another 15% (N8) were not aware of these services, and even after being informed about peer educators and their services, were not interested. Some of these participants indicated that they did not experience any barriers to accessing sexual health services, but others avoided sexual health services targeting gay men and other MSM specifically because they targeted gay men and other MSM.

My research found that some gay men and other MSM feared the stigma of being associated with these organisations. Recognising this, I argue that complementary efforts should be employed by sexual health CBOs and NGOs to better reach those who actively avoid them. This is important because these populations are still at a high risk to HIV, yet social circumstances and personal preferences place them at odds with accessing the currently available services directed to them. These additional efforts should include stigma reduction through nurses and doctor trainings within the public health services and offering more affordable private health services that can meet the health needs of gay men and other MSM. Human rights organisations may be well suited for this mandate, including the broader work of educating the public about sexual minorities and addressing misconceptions and stigma that exacerbate health outcomes for these populations. While the targeting of HIV care and treatment to key populations is certainly a frontier worth furthering, especially for the sake of populations who are denied health services on the basis of sexual orientation or gender identity, other methods will be necessary for those who would avoid these organisations' targeted services.

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Appendixes

Appendix 1: Interview Discussion Guide

Pre-Interview

- Take note of participant’s pseudonym, participant code and the location/date/time of interview.
- Participant should read the “Participant Consent Form”, which includes an introduction of the researcher and overview of the research topic.
- Does the participant have any questions or confusion? If so, the participant and researcher should address these before moving forward.
- Review ground rules for the interview (e.g. timing, confirm audio recording or other means of recording responses).
- Request participant for their consent to partake in the research

Interview Discussion Topics

1. Demographic Profile

- a. Sex

- b. Age
- c. Current location of residence
- d. Previous locations
- e. Family members
- f. Nationality
- g. Ethnic group(s)/Tribe
- h. What is your relationship with your family like?
- i. Parent relationships, who was caretaker?

2. Socio-Economic Profile

- a. Education completed
- b. Future education plans
- c. What is your living arrangement? Where do you sleep/live?
- d. How do you take care of your daily financial needs and long-term career goals?
- e. Who are the people in your life that help you out from time to time?
- f. When facing financial difficulties, how do you make ends meet?
- g. What are your career goals, how they plan to get there?

3. Sexuality Profile

- a. Terms and Descriptions
- b. What terms do you prefer to use to describe your own sexuality?
- c. What do you think of your sexuality?
- d. What are the pros or cons when using English terms to describe your sexuality, such as gay, lesbian, bisexual, or homosexual?
- e. If you prefer to use different local terms at times or with your friends, which terms do you use, and why do you use them?
- f. Sexuality and Dating Life
 - i. When did you realise your sexuality?
 - ii. What were the thoughts that went through your head when you realised this about yourself?
 - iii. Describe your dating-life (or sex-life), from your first experiences to present day. What has it been like? Have there been any problems?
 - iv. What kinds of assistance or support do you share with the people you date or have sexual relations with?

4. Globalisation and Perception of Sexuality

- a. General Learning and Interests
 - i. How do you normally learn about things happening outside Ghana, such as news and events?
 - ii. Do you have any family, close friends, or pen pals abroad that you regularly speak with? If yes...
 - iii. Where are they?
 - iv. What kinds of things do you discuss with them?
 - v. What have you learned from your pen pals and what do you enjoy about your connection with them?
 - vi. Generally, when you go online, what kinds of things do you do? What type of information do you search for? What websites do you most commonly visit?
- b. Learning About Sexuality
 - i. Over the years, how have you learned about sexuality and sex? (For instance did you learn about these things from family, reading books, school, other people/friends, your church, etc?)
 - ii. When did you first learn about homosexuality and what did you learn about it?
- c. Experiences of Marginalisation
 - i. Is there anything negative about having your sexuality?
 - ii. Do people ever give you problems or worry you much on the topic of your sexuality? If yes...
 - iii. When does this happen to you most commonly and what people do this to you?
 - iv. Has the state of Ghana (i.e. government or police) oppressed sexual minorities in Ghana or promoted homophobia. How so? Has this ever effected you or any of your friends?
 - v. Have you ever felt that you would be stigmatised if you were to report a case to the police or seek health assistance because of your sexuality?
- d. Demonstrating Agency
 - i. How do you avoid feeling stigmatised by them?
 - ii. What is positive about your sexuality? Have there been any beneficial outcomes from being the way you are?

5. Politicisation of Homosexuality

- a. General Process of Politicisation
 - i. From your perspective, how has homosexuality become a political debate in Ghana recently? (You can think about the following questions when responding.)
 - ii. Has homosexuality always been discussed in Ghana, or is it more

commonly discussed nowadays?

- iii. From your memory, do you remember any events or causes for the times where homosexuality had become heavily discussed?
- iv. Who speaks about this topic in society the most, what kinds of things do they say?

b. Gov't - Process of Politicisation

- i. How do you think Ghana's national leaders and politicians have treated the topic of homosexuality?
- ii. What do you think when politicians or other leaders in Africa say homosexuality is not African or is not of Ghanaian culture?
- iii. Do you think Ghana is becoming more independent or more dependent on other countries?
- iv. How do you think Ghana's dependence on outside countries influences the decisions of Ghana's leaders and politicians on LGBT rights?
- v. Effects of Politicization (in Society)
- vi. How has this heated political debate over homosexuality affected society's opinion on homosexuality? (Think about the following questions for your response).
- vii. Since this topic has been discussed, have opinions on the topic changed?

c. Effects of Politicization (Personal Experiences)

- i. How did you feel when this topic had been heavily discussed in Ghana?
- ii. Have you become more cautious in recent years?
- iii. Have you changed your behaviour or movements because of the way homosexuality was discussed in society? If so, how did you change?

6. Societal Norms

a. Relationships

- i. What does your family expect of you in the future? (In terms of relationships).
- ii. Are there any conflicts between the family expectations and your own sexuality and what you want to do? If yes...
- iii. Can you explain these conflict and how do you plan to resolve them
- iv. Who pressures you the most to conform to these expectations?

b. Gender

- i. What does it mean to be a man (or woman)? Or, what do you have

to do to show you are a man (or woman)?

- ii. In what ways do you experience problems or feel marginalised if you don't live up to standards of being a man (or woman)
- iii. Is it difficult to live up to the standards of being a man/woman in Ghana, explain your answer?
- iv. Do you feel that you do not always want to live up to these standards?

7. Religious/Spirituality Profile

- a. What church or religious community do you belong to?
- b. Did your religious affiliation ever change? If yes, what influenced the decision?
- c. What kinds of religious activities do you normally partake in during the week?
- d. How important is religion and spirituality in your life?
- e. What do you enjoy about religious life and activities?
- f. Do you sometimes disagree with some things your church teaches? Which things/why?
- g. What does your church say about homosexuality? What do you think about how your church says about homosexuality?
- h. How do you engage in the religious community in ways that avoid feeling marginalised or stigmatised?

8. Knowledge LGBT, Human Rights Organisations and Sexual Health

- a. Feedback on Organisations Generally
 - i. Do you know about any organisations working with people in Ghana for LGBT rights, human rights, or rights for sexual minorities? What is your knowledge/opinion on them?
 - ii. Are there things these organisations could do better to address the needs of lesbians or gays? Is there anything they could do for you?
- b. Do you use condoms?
- c. Why do you use condoms? Why do you not use condoms?
- d. For the selling of condoms and lubricant, does the price need to be lowered, is that really a barrier to use?
- e. Do you remember a time you didn't use a condom, why?
- f. Do you know about peer educators or LGBT allies in your community?
- g. If yes or no, have you ever felt a need to talk to such a person?
- h. If no, but you wanted to talk to such a person, would you know where to find them?

- i. Do you know what kind of services a peer educator provides?

Appendix 2: Research Info Sheet/Consent Form (page 1 of 2)

Postgraduate Dissertation

SOAS, University of London

Participant Consent Form for Postgraduate Dissertation Research Study

Benjamin Eveslage

Postgraduate Dissertation
SOAS, University of London
Department of Development Studies
London, England

Title of Project: 'Trans-Cultural Production of Values' Influencing Recent Politicization of Homosexuality in Sub-Saharan Africa (SSA)

Purpose of the Study

This study analyses why and how homosexuality has recently become a heated political topic in many African countries and the outcomes this has had on sexual minorities. The research includes the study of global factors in this process and compares these findings with a case study of domestic processes and local experiences in Ghana, West Africa. Specifically, fieldwork in Ghana aims to understand the connections between this recent political debate, its effects on marginalisation and the response from sexual minorities.

The findings will be used to form part of my dissertation and will be used to feedback to Ghanaian human rights organisations. Additionally, the findings may be published in an academic journal.

Procedures to be Followed

To assist my research I am asking you to agree to a personal interview, partake in an informal focus group discussion, and/or allow my presence and participation in your social settings for immersive and informal data collection. We can arrange a time and date which is convenient to you once you have confirmed your consent

Discomforts and Risks

I do not envisage a significant likelihood of risk in the study if you choose to participate. Given the social stigma and politicised nature of topics of homosexuality in Ghana, I have taken special care to identify and employ methods of 1) conducting the interview and communicating in safe methods and settings; 2) handling your interview data securely; and 3) making anonymous any of your identifying information. I would like to work with you to identify the best ways to minimise any discomforts and risks as a result of this research. In case some questions make you uncomfortable, you may refuse to answer them or may stop the interview at any time.

You may also withdraw your permission for your interview data to be used at any time up to 1st September in which case transcriptions and recordings of your interview will be destroyed.

Benefits

The information gained by this research could help to create a better understanding of how sexual minorities in Ghana experience and deal with marginalisation in a changing global environment. Additionally, the research will support Ghanaian NGOs and human rights organisations to improve their efforts to assist sexual minorities in Ghana.

Duration

If I interview you, it should take no longer than 1 hour to complete. Alternatively I may like to spend additional time together for informal individual or group discussions.

Appendix 3: Research Info Sheet/Consent Form (page 2 of 2)

Postgraduate Dissertation

SOAS, University of London

Statement of Confidentiality

Your personal identity will be kept confidential unless you specifically request to have your real name associated with your responses.

If you wish to receive a copy of the final dissertation once completed in mid-September then I will be happy to provide you with an electronic copy.

Right to Ask Questions

Please feel welcome to ask questions about this research by contacting me using the following contact details:

Ghana cell phone number: 055 411 3124

Email: 605539@soas.ac.uk

Alternatively, you may wish to contact my supervisor, Dr Colette Harris at: +44 20 7898 4488 or colette.harris@soas.ac.uk. Or the Centre for Popular Education and Human Rights, Ghana (CEPEHRG) at cepehrg@gmail.com or 028 910 8829.

Voluntary Participation

Your decision to be in this research is voluntary. Please be aware that you can stop at any time and that you do not have to answer any questions you do not want to.

If you agree to take part in this research study and the information outlined above, please sign your name and indicate the date below.

Confirmation and Consent

I confirm that I have freely agreed to participate in the research project of Benjamin Eveslage. I have been briefed on what this involves and I agree to the use of the findings as described above. I agree/disagree to the recording of the interview, which will be used only to ensure the correct transcription of the interview and will be heard by me alone.

Participant signature: _____

Name: _____

Date: _____

I confirm that I agree to keep the undertakings in this contract.

Researcher signature: _____

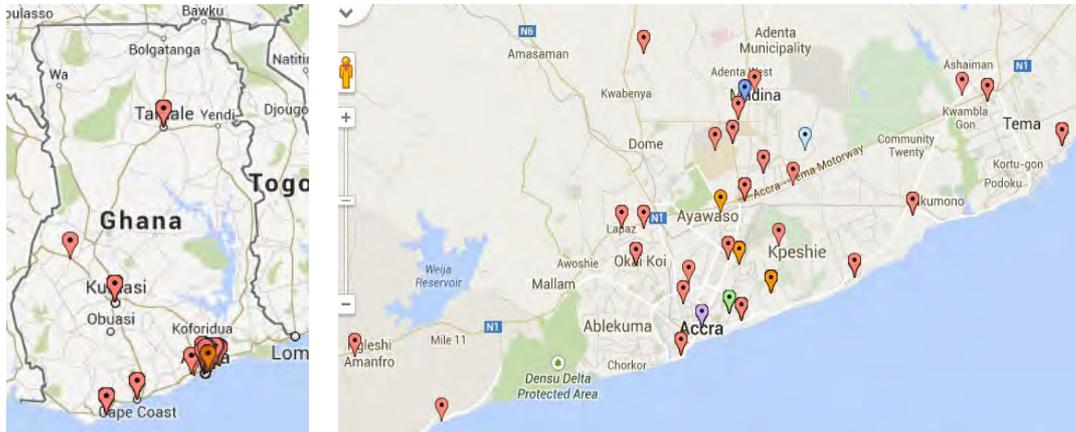
Name: _____

Date: _____

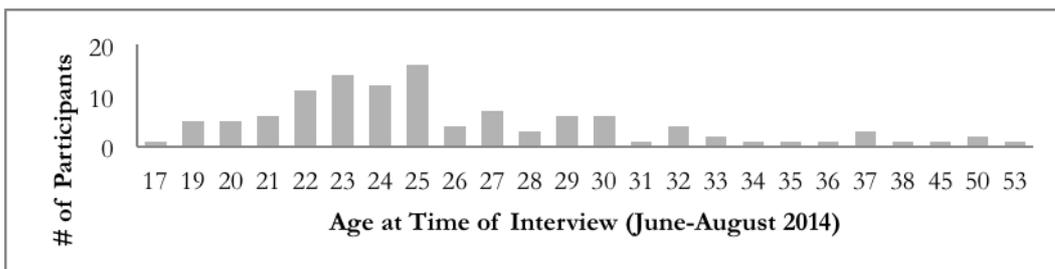
Please keep this form for future reference.

When in Ghana, do as sexual minorities do

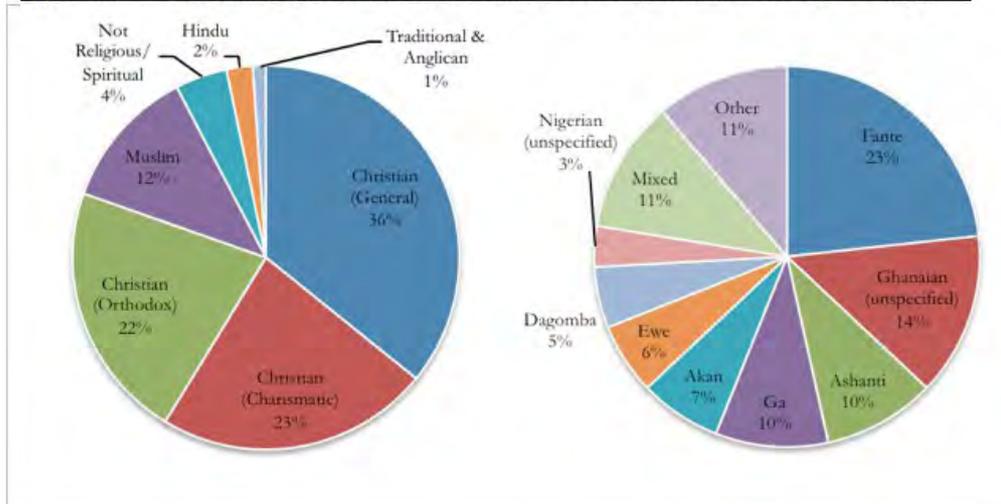
Appendix 4: Location of Interviews with Sexual Minority Participants in Ghana (Left) and in Greater Accra Region (right)



Appendix 5: Ages of Sexual Minority Participants



Appendix 6: Religious (left)/Ethnic (right) Backgrounds of Sexual Minority Participants



Chapter 10

YouTube viral videos and HIV prevention among African-Americans: Implications for HIV prevention

Jocelyn D. Patterson
Khiya J. Marshall

Jocelyn Patterson and Khiya Marshall's chapter focuses on the potential use of viral videos for HIV/AIDS prevention activism and education. Patterson and Marshall present a content analysis of YouTube member responses to viral videos featuring African Americans that had a theme of HIV/AIDS prevention. This detailed analysis of user comments suggests that the motivation to share and view such videos includes a spectrum of emotional responses, ranging from anger and frustration, to heartfelt encouragement and support.

Introduction

YouTube (www.youtube.com) is a free Internet-based video sharing and storage website launched in February 2005. The website is designed to publicly store short video clips which visitors can view and share with others. The website's users have the ability to connect and communicate with other users by posting responses and written comments. Videos uploaded to YouTube can be accessed across the Internet through the YouTube website, links embedded in other websites, mobile devices (e.g., Smartphones), email, or social networking sites, making it easy for video clips to be shared and quickly circulated around the world. According to YouTube statistics, every minute 48 hours of video are uploaded to the website. With an audience of over 800 million unique visitors per month (YouTube, 2012), YouTube should be considered an important resource for gauging health information available to the public. However, despite the extensive viewing audience and potential reach of YouTube video clips, the public health impact of viral videos has yet to be measured (Freeman & Chapman, 2008).

Among the millions of videos housed on the YouTube site, there are certain videos that "go viral." Viral videos are video clips that are widely disseminated and become popular due to large scale social transmission in the form of email, embedding in webpages, and sharing on social network sites. Viral videos are unique phenomena that offer a special opportunity to communicate a discrete message with thousands, perhaps even millions, of people. These videos have the potential to capture the attention of mainstream culture without large financial investments in video development and distribution. Yet, little is known about what motivates online video consumers to disseminate videos to others. In light of the scalability and low cost of viral videos, it is important to learn more about how to maximize this resource.

Previous research exploring video health messages posted on YouTube has included issues related to prostate cancer (Steinberg et al., 2010), tanning beds (Hossler & Conroy, 2008), tobacco (Freeman & Chapman, 2007), and immunizations (Keelan et al., 2007; Ache & Wallace, 2008). Internet-based video sharing sites like YouTube are a new platform for healthcare providers and public health officials to consider when conveying health messages. However, few studies have examined how YouTube can be used to disseminate and promote HIV prevention. In order for public health officials to maximise this medium for video-based HIV prevention messaging, research needs to be conducted on existing HIV-related videos to explore the content driving their popularity.

The incidence of HIV among African Americans is nearly eight times that of their white counterparts (HIV Incidence Surveillance Group, 2011). African Americans comprise 14% of the United States population, but represent 44% of new HIV infections (HIV Incidence Surveillance Group, 2011). The disproportionate impact of HIV among African Americans sheds light on the need to identify innovative prevention efforts targeting this population. Previous research suggests that video-based HIV/STD interventions are a promising tool for HIV prevention among African Americans (Calderon et al., 2011; Downs et al., 2004; Heaton & Messeri, 1993; Kalichman et al., 1999; O'Donnell et al., 1998). The success of existing video-based HIV prevention interventions implies that videos will continue to be useful in future prevention efforts. A better understanding of Internet video-based sharing communities, like YouTube, may be a key step in maximising the creation and dissemination of effective HIV prevention initiatives for African Americans.

African Americans are central consumers of Internet-based mobile technology. An estimated 71% of African Americans use the Internet, which can be accessed through various mediums such as personal computers and cell phones (Radio One, 2008). Visiting YouTube and other video-sharing websites is among the most common online entertainment activities for African Americans (Radio One, 2008). In fact, African Americans are 51% more likely to use YouTube than the general online Internet-using population as a whole (Quantcast, 2012). Because of its widespread use and accessibility, YouTube may be an important venue for reaching African Americans at high risk of acquiring or transmitting HIV.

This chapter describes the results of a content analysis that was conducted to identify and describe the most popular videos posted on YouTube related to HIV/AIDS and African Americans/Blacks. We further examined the content and comments posted in response to the viral videos identified in our search to explore what made people share those particular videos.

Methods

The YouTube community consists of video viewers and website subscribers. YouTube requires video owners to subscribe to a free membership in order to post and comment on videos. However, subscriptions are not required to

view videos. When posting, video owners enter keywords called “tags” to help users find certain videos or search for particular types of videos. YouTube operates in real time and therefore the content is constantly changing with videos being added and removed. Search strategies were implemented at two different time points to observe changes over time.

Video clips were determined to be eligible if: content focused on HIV/AIDS and video included images or discussion with African Americans or Blacks. Videos were excluded if there was indication that the video clip was filmed outside of the United States or focused on the HIV/AIDS epidemic outside of the United States.

On June 1, 2009 (T1), search strategies were entered into YouTube’s (www.youtube.com) search engine to capture videos tagged as African American/Black. The two search terms were limited to the English language. The first search used the keywords *African American and (HIV or AIDS)* and the second search used *Black and (HIV or AIDS)*. The results of each search were sorted by the number of times the videos were viewed. The top 50 viewed videos in search one and the top 50 in search two were entered into an Excel spread sheet.

YouTube displays each video’s popularity as measured by the number of times the video link has been accessed, commonly referred to as number of “hits”. The number of hits was used as a representation for number of times the video has been viewed as well as an implication for the number of times the video was shared with others. Two researchers independently reviewed all videos for eligibility and coded content of the video according to the following variables: category (YouTube’s pre-defined topic areas), date posted, tags (keywords video posters used to identify their video), duration of video (in minutes), popularity (number of times viewed), rating (based on a five-point scale [five being the best and one being the worst] by video viewers), number of comments, and identified common themes in video content.

Discrepancies were reconciled through discussion. The preceding search strategy and data collection procedures were repeated again five months later on November 16, 2009 (T2). For the purposes of this study, viral videos were defined as videos that had been viewed over 100,000 times. In order to identify the characteristics of viral videos; additional content analyses were conducted on viewer comments posted for the viral videos identified in our sample. Again, two researchers independently reviewed the original comments on the videos for common themes and discrepancies were reconciled through discussion.

Results

After combining the top 50 videos for African American/Black and HIV/AIDS there were 35 unique and eligible videos identified at T1 and then 35 again at T2. Only the videos that overlapped at T1 and T2 were included, leaving a total of 28 eligible videos (Table 1). Videos covered a broad range of topics and specific target populations. These 28 videos in the sample were posted between June 24, 2006 and March 16, 2009. The range for the number of

views per video was broad (T1 range: 1,061 to 181,299, M=16,288; T2 range: 1,382 to 202,199, M=17,524).

YouTube gives video owners the option of selecting one of 15 pre-established categories to group their video. The videos in our sample represented nine of those categories: Entertainment (N=6), People/Blog (N=5), Education (N= 4), Film & Animation (N=3), News& Politics (N=3), Non-profit (N=3), Music (N=2), Science & Technology (N=1), and Comedy (N= 1). The top two categories that video owners chose for their videos pertaining to HIV/AIDS were Entertainment and People/Blogs. Our analysis of video content identified the following themes: HIV testing (N=10), HIV transmission and exposure (N=8), HIV treatment and living with HIV(N= 7), compassion and advocacy (N=6), HIV education and awareness (N=6), safe sex and using condoms (N=4), youth (N= 4), gay men (N=2), men (N=3), women (N= 2), and HIV/AIDS conspiracy (N=2).

The top two most frequently viewed videos identified at both T1 and T2 were *Trashman gives 15000 women/Girls hiv aids virus* and *Know Your Status*, each with over 100,000 views. Details on the content and data abstracted for these videos are reported in Table 1. Further examination of these videos shed light on characteristics and possible reasons for their rise in number of hits. Review of the number of views over time reveals that there was an initial explosion of number of hits on both videos that later levelled off. However, the number of views for both videos remained consistent at T1 and T2. Furthermore, other videos identified in our search, although posted prior to the top two videos, never reached their level of popularity. Therefore, the length of time a video is posted did not appear to directly impact the number of views or its popularity.

Table 1. YouTube Videos that Overlap at Time 1 and Time 2 (n=28) (See PDF for full chart)

T1 Rank	T2 Rank	Title of Video	Description of Video Content	Original Date Posted on YouTube	Duration (minutes)	No. of views	No. of comments
1	1	Trashman gives 15000 women/Girls hiv aids virus.	Masked African American man who calls himself Trashman, lists some of the 15000 of the women, by name, who he claims to have knowingly infected with HIV.	April 23, 2008	6:43	T1: 181,299 T2: 202,199	T1: 837 T2: 917
2	2	Know Your Status	A former African American adult film actress makes a video documentary of getting tested for HIV.	February 4, 2008	10:03	T1: 152,426 T2: 154,709	T1:459 T2: 467
3	3	GurTalkkTV-The Game of Death -- 1500 Infected	Response to Trashman video-confessions of a black man explaining how he does not respect women but women should respect and protect themselves from black men like him.	January 31, 2008	9:00	T1: 48,469 T2: 51,308	T1: 215 T2: 215
4	4	Loony-T - She Got It Remix (Parody)	Music lyrics about a man who thinks his girlfriend has an STD/HIV and now he thinks he is infected.	May 15, 2008	3:41	T1: 18,614 T2: 21,428	T1:59 T2: 67
5	5	Vivica Fox & Bill Duke Interview	Vivica Foxx and Bill Dukess promote a new independent film Cover about men on the down low (DL), which was inspired by the prevalence of HIV/AIDS in the black community.	March 4, 2008	8:21	T1: 13,803 T2: 16,112	T1:28 T2: 28
6	6	Mr. Del (Rain Cry) Music	A music video with an African American rapper in the rain showing images of woman dancing in rain, washing away	November 29, 2007	3:10	T1: 12,798 T2: 15,486	T1: 82 T2: 82

		Video -From EGM.tv WEEKLY page	all infirmities and God giving new life.				
7	7	All of Us - Trailer	A Trailer of the documentary ALL OF US where a young doctor in the South Bronx embarks on a research project to find out why black women are becoming infected with HIV at alarming rates.	January 3, 2008	2:26	T1: 11,376 T2: 13,265	T1: T2: 8
8	9	ChingoBling: Keep Your Torta Clean	Rap artists encouraging safe sex in a pre performance interview.	July 26, 2006	2:07	T1: 11,291 T2: 12,109	T1: 4 T2: 4
10	8	The Present	An African American woman returning from trip tells her girlfriend about wonderful guy she just met. During the trip he gives her a present to open when she gets home. The present is a box with "welcome to the world of HIV" written inside.	October 11, 2006	3:43	T1: 10,837 T2: 12,522	T1: 27 T2: 27
11	12	Joe Biden Discusses AIDS, Al Sharpton gives the evil eye	Joe Biden discusses HIV prevention during a debate of the 2008 Presidential Election. He mentions working to reduce HIV in black neighbourhoods by holding rallies and telling black men to wear condoms.	June 30, 2007	1:03	T1: 8,467 T2: 8,795	T1: 40 T2: 40
12	10	Fake AIDS / HIV Diagnosis For Black People pt1	The accuracy of HIV tests is discussed.	April 13, 2008	10:00	T1: 8,118 T2: 10,864	T1: 314 T2: 479
14	11	Skorpion Interviews BET's Baldwin Hills Cast Member Etienne Maurice	Etienne, from the television show <i>Baldwin Hills</i> talks about a range of topics, including HIV/AIDS.	March 16, 2009	17:27	T1: 7,097 T2: 8,862	T1: 155 T2: 162
16	18	Sen. Obama on Homophobia and Stigma	A 2008 Presidential debate in which, Senator Obama discusses CDC's report regarding young African-Americans and HIV/AIDS.	July 6, 2007	1:43	T1: 5,914 T2: 6,263	T1: 11 T2: 12
17	14	SistahGirl: Black Women & HIV/AIDS. Documentary First Look	A documentary project that profiles the lives and experiences of HIV-positive black women from the United States who will journey to sub-Saharan Africa to meet other HIV-positive women activists.	November 29, 2007	5:49	T1: 5,686 T2: 7,219	T1: 9 T2: 14
18	13	I just got a phone call from a young lady... You have to watch this video!!	A young African American male decides to get tested for HIV/AIDS after learning that a previous sexual partner's HIV/AIDS test results came back UNDETERMINED. He explains the difficulty he had finding a testing location. He tested negative.	September 8, 2008	9:37	T1: 5,354 T2: 7,229	T1: 36 T2: 38
19	16	Justin's HIV Journal First Entry	Justin B Smith chronicles his experience being HIV-positive to help educate everyone, young, old, black, white, red, yellow, straight and gay.	May 27, 2008	2:41	T1: 5,190 T2: 6,413	T1: 37 T2: 44
21	20	HIV/AIDS Documentary Trailer	A documentary showing the effects that HIV/AIDS has on the African American community. It provides statistical information as well commentary from various movie, television and radio personalities, sports figures.	May 30, 2007	2:16	T1: 3,993 T2: 4,553	T1: 17 T2: 17

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22	21	AIDS	60 Minute report focusing on an African American woman who is HIV-positive.	January 28, 2007	2:36	T1: 3,932 T2: 4,505	T1: 4 T2: 4
23	17	HIV Research: Beyond the Vaccine - KQED QUEST	Chronicles HIV/AIDS in the United States over the past 15 years since the peak of the HIV/AIDS epidemic. It closely examines HIV/AIDS among the African American community and possible reasons for the high prevalence in certain communities. Also discusses the history of HIV/AIDS.	October 16, 2008	11:07	T1: 3,703 T2: 6,270	T1: 1 T2: 2
24	22	Living with HIV	African-Americans discuss living with HIV.	July 31, 2007	7:59	T1: 3,194 T2: 3,642	T1: 0 T2: 0
25	26	Who Can I Talk To, Who Can I Tell - WombWork Productions	Performance of "Who Can I Talk To, Who Can I Tell" by the Nu World Art Ensemble. Based in Baltimore, Maryland, the Nu World Art Ensemble shows through dance and lyrics, the experience of a woman who was told that she was HIV positive.	July 25, 2006	2:57	T1: 2,526 T2: 2,687	T1: 2 T2: 2
26	34	A Need to Know	CDC TV - <i>Health Matters</i> discusses how young, old, men, women, gay, and straight can be at risk for HIV/AIDS. HIV/AIDS poses a great risk for African American community men who have sex with men. Promotes getting tested for HIV.	March 16, 2009	3:24	T1: 2,250 T2: 2,448	T1: 0 T2: 0
27	28	fearful TRUTH	Discusses HIV/AIDS in the African American community of Oakland, California.	June 24, 2006	1:05	T1: 2,202 T2: 2,405	T1: 1 T2: 1
28	24	Deeply Rooted Dance Theater - Jagged Ledges	A lyrical dance performance depicting the plight of people living with HIV/AIDS.	April 15, 2008	4:27	T1: 2,166 T2: 2,885	T1: 7 T2: 7
29	25	The Barbershop	A PSA with two African American men who discuss HIV prevention in a barbershop.	March 16, 2008	0:32	T1: 1,497 T2: 2,814	T1: 2 T2: 2
30	31	The Closing Argument (a video book)	The first 10 minutes of a 150-minute video book of an African American man accused of spreading AIDS in Connecticut.	March 26, 2007	10:00	T1: 1,47 T2: 1,634	T1: 0 T2: 0
31	32	Stomp	A PSA by the AIDS Community Resources. African American adolescent girls stomp about being knowledgeable, getting tested, and assertive regarding HIV/AIDS.	January 3, 2007	0:30	T1: 1,454 T2: 1,608	T1: 0 T2: 0
35	33	Standing-n-Truth	This video discusses sex, sexuality, and HIV/AIDS in the African American community.	June 10, 2008	8:53	T1: 1,061 T2: 1,531	T1: 1 T2: 0 ^a

At the time of analysis, the most viewed video, *Trashman gives 15000 women/Girls hiv aids virus* had an identical video entitled, *Aids man 'trash Man' fitting Name*, which was not yielded in our search, this video was posted on YouTube by another host. At time two, this duplicate posting had over 1.5 million hits and over 3,000 comments. The content of both the number 2 (*Know Your Status*) and number 3 (*GurlTalkkTV-The Game of Death -1500 infected*) ranked videos made direct references to the *Trashman* video posting. This suggests that the popularity of one video may influence the number of hits on other related videos. As a result, one video's popularity may not be independent of another.

Community reaction to the top two videos was assessed using a content analysis of comments posted by viewers (Table 2). The *Trashman* video yielded written comments (N=837) under three major themes: angry threats and insults toward the maker of the video, questions about the authenticity of the video maker’s claims, and positive comments supporting the statements made in the video. A number of respondents questioned the authenticity of the video and found it mathematically unlikely for Trashman to have had sex with thousands of women. In contrast, a smaller portion of respondents (approximately 10%) had positive reactions to the video. Some felt the video was an effective tool for educating African American and Latina women about the dangers of unprotected sex. Others supported Trashman’s video because they felt the women mentioned in the video were guilty of being promiscuous and not using condoms.

There were 474 comments posted for the *Know Your Status* video (Table 2). Miss Jia, a YouTube blogger and former African American adult film actress, takes viewers with her as she is tested for HIV. Most of the comments posted by viewers were positive. Some shared that they were motivated to be tested for HIV or actually received an HIV test after viewing the video. Several of the viewers asked questions related to HIV.

Table 2. Major themes and examples of relevant quotes for of *Trashmangives 15,000 women/girls HIV AIDS virus* and *Know Your Status* comments section

Trashman	Quotes N=966
<p>Anger and negative threats</p> <p>N=498 (63%)</p>	<p>I am Pissed somebody lock this dumb JERK up what the heck I wannaloose all my Christianity and KILLLLLLL HIM!!! (kingdomchild22, 11/2009)</p> <p>This is one sick f[---] he needs to be put somewhere and tortured until he dies I mean slow torture who could so that he has to be a sick sick person and needs to be put under the jail (sweetthang9488, 2009).</p> <p>Wow this dude needs to be castrated. Pathetic. It’s people like him that makes us have an imperfect society (saiyyru14, 2009)</p>
<p>Disbelief</p> <p>N=158 (21%)</p>	<p>This is fake cause how is he going to remember all of the firsts and lasts names of all those girls. He is sick cause he made this video. Hopefully this is not true (SHAR383, 11/2009)</p> <p>This man is fake I don’t believe this (NyFin3st11, 2009)</p> <p>This had to be a joke cuz if he had sex with a girl everyday it would take him 41 yrs to reach 15,000 girls (TheCharleycat, 2009)</p> <p>I look betta than this [n word] and I drive a jaguar and I don’t get that much ass so I know he lyin’ (Keezy59, 11/2009)</p>
<p>Support for Trashman</p>	<p>I don’t feel sorry for any of these women because they put themselves in this position, with the aids rate steady increasing why would anyone sleep with anyone unprotected they don’t know from Adam?!? they are getting exactly what they deserve</p>

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<p>N=83 (11%)</p>	<p>(MissOakCliffUSA, 3/2009)</p> <p>That's bad but that will teach them sluts to have unprotected sex with random guys (Straightgenius, 3/2009)</p> <p>Man has a point, women need to learn how to respect themselves and close their damn legs. Not saying I agree with his methodology (stracinsrt4, 2009).</p> <p>"Most people here can't read between the lines to see that you were just giving advice to young women. I understand clearly, it also reminds me that I need to talk to my daughter even more about not having unprotected sex. Thanks. (justin5551212, 2009)</p>
<p>Know your Status</p>	<p>N=474</p>
<p>Appreciation/thanks</p> <p>N=294(77%)</p>	<p>Kudos to you and Nicole...it takes guts to show something this personal (sprat10, 2008)</p> <p>Thanks for the video jia, people need to know (enjoi3s, 2008)</p> <p>God Bless, you could have saved lives (reese3005, 2008)</p> <p>Jia I'm so proud of you for steppin up and makin this video. You attract a large audience, and you used that for a good cause. Yay, you!! (homemadegravy17, 2008)</p>
<p>Motivation to get tested</p> <p>N=28 (9%)</p>	<p>wow this has inspired me to get test. I just searched a local testing clinic in the area. Thanks a lot ;) (emjayoath, 2009)</p> <p>I honestly just left a testing site about 2.5 hours ago. This video along with advertisements motivated me to get test.</p> <p>Knowing your status is the business...and I'm glad I am sure of mine now. Also, being negative is the business!!!! J Take care. (reneikad, 2008)</p> <p>Forgot to tell you...I went the week I say this...I'm negative!! (Ceci247, 2009)</p> <p>Thank you for making this video. I watched it so many times. This vid[eo] along with my best friend's encouragement I did it. I'm 38 and go my first test today (negative). WHOO HOOO! (nunya33763, 2009)</p>
<p>Questions about HIV and testing</p> <p>N=15 (4%)</p>	<p>negative means you don't have HIV and positive means you do right? (sacabuchi, 2008)</p> <p>Quick question. How much did it cost you to get tested (racso329, 2008)</p> <p>Do you have to be 18+ to get tested (iTRUTHperiod, 2009)</p> <p>isn't he suppose to tell u that u need to come back in 6mo after the last time u had sex to kno[w] if one is truly negative? (bow2jade, 2009)</p> <p>do condoms help prevent HIV? (bow2jade, 2009)</p>

Discussion

The purpose of this study was to identify and describe viral YouTube videos addressing HIV/AIDS and African Americans/Blacks in order to learn more about the characteristics of and community response to the most popular videos. Our primary findings were related to the content of the videos found, the characteristics of the most popular or viral videos, and lessons learned in searching YouTube to find videos related to HIV/AIDS and African Americans/Blacks.

There were several themes that emerged from the video content. The major themes included the continuum of prevention, from HIV testing, to HIV transmission and exposure, and finally HIV treatment. The videos focused less on specific target groups (youth, gay men, heterosexual men and women) or HIV/AIDS conspiracy theories. The most frequently viewed videos, *Trashman* and *Know your Status*, included negative and positive feedback. *Trashman* had threats, insults, and questions regarding the authenticity of his claims, while *Jia* had positive feedback and support in the *Know your Status* video.

There were several important lessons learned about searching YouTube. Because the assignment of tags is left to the discretion of the video publisher, videos may be labelled with irrelevant tags or missing key words. There is limited direction and no systematic oversight in the assignment of tags. Additionally, flexibility and search controls are limited in YouTube videos when compared to science-related search engines. As a result, we conducted two separate searches to meet our study objectives (African American and HIV/AIDS; Black and HIV/AIDS).

The comments section was a key mechanism for identifying community responses to the video. The viral videos generated the most viewer comments and the amount and content of comments posted on these videos may be a reflection of the emotion generated by the video. Having a strong reaction to the video content may have inspired viewers to pass the video along to others or motivated them to post comments. For the two viral videos identified in our study, the most common sentiments generated in video comments were anger towards *Trashman* and positive support for *Know your Status*. Previous research suggests that situations, news, or information (both positive and negative) which heightens arousal boosts social transmission (Berger, 2011). Eckler and Bolls (2009) found that college students reported having the strongest intent to forward viral video ads with pleasant emotional tone. In another recent study by Berger and Milkman (2011) examining how content characteristics impacted the “most emailed” New York Times articles, researchers found that content evoking high positive arousal (awe) or negative arousal (anger or anxiety) were more likely to go viral. These findings suggest that HIV-related videos that elicit anger and frustration or those that inspire encouragement and support may motivate people to share the videos.

One feature that makes online video viewing sites unique and novel is the reliance on user-generated content. As a result of online video sharing sites like YouTube, anyone has access to a worldwide audience. In the past,

health-related videos could only be circulated and disseminated by organisations and agencies. This user-generated online video market has reshaped possible forums for delivering health messages. Perhaps the popularity of top videos measured in terms of numbers of views and viewer comments can be attributed to a video blogger featured in the video. It is possible that video bloggers like Trashman and adult film actors like Ms.Jia draw or capture the attention of a broad audience. Internet video bloggers may be an untapped resource for accessing high-risk target populations.

Our study has the following limitations. This research was conducted in 2009 amidst the initial surge in social networking sites like Facebook and Twitter. The introduction of these mediums vastly increased the ability to share the video beyond the traditional YouTube community members, forwarded emails, and blogging sites. The growth in these social networking sites created new and different pathways for going viral. It is important to also note that the definition of viral video in this study is specific to the videos identified in our sample. Within the larger sample of all YouTube videos the most popular viral videos have hits/views in the millions.

Conclusion

YouTube provides a new opportunity, resource, and venue for the widespread dissemination of public health messages. The site continues to introduce new features to enhance interactive capabilities and descriptive information collected about the video viewers. This information could be used to learn more about the demographics of a population (age, location, gender) who watch a particular video, and the types of videos that appeal to specific audiences.

New forms of media and technology, like the Internet-based social networking sites that are accessible via smartphones (e.g., Facebook and Twitter), have introduced a different landscape for communicating and connecting with people. The potential impact of these media for HIV prevention messaging has yet to be fully understood. In light of the disproportionate impact of HIV on subgroups in the US population, such as African Americans, it is imperative that we consider new and innovative HIV prevention approaches for this population. Moreover, given the current economic climate of sparse resources, free and accessible resources like YouTube should be considered for public health initiatives. Future research that focuses on developing video-based health messages that evoke strong emotions may be useful in creating HIV prevention videos that the public is motivated to share. There is still more to learn about how web-based resources like YouTube can reach persons at the highest risk of acquiring and transmitting HIV/AIDS.

Disclaimer

The findings and conclusions in this report are those of the authors and do not necessarily represent the views of the Centers for Disease Control and Prevention.

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YouTube viral videos and HIV prevention among African-Americans

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Chapter 11

Variations in recruitment yield, costs, speed and participant diversity across internet platforms in a global study examining the efficacy of an HIV/AIDS and HIV testing animated and live-action video among english- or spanish-speaking internet or social media users

Winnie Shao
Wentao Guan
Melissa A. Clark
Tao Liu
Claudia Santelices
Dharma E. Cortes
Roland C. Merchant, MD

The chapter by Winnie Shao, Wentao Guan, Melissa A. Clark, Tao Liu, Claudia C. Santelices, Dharma E. Cortés and Roland C. Merchant presents a world-wide, Internet-based study on HIV/AIDS and HIV testing knowledge that compared the yields, speed and costs of recruitment and participant diversity across free postings on 13 Internet or social media platforms, paid advertising or postings on 3 platforms, and separate free postings and paid advertisements on Facebook. Platforms were compared by study completions (yield), time to completion, The study results highlight the need for researchers to strongly consider choice of Internet or social media platforms when conducting Internet-based research.

Introduction

By the end of 2014, there were approximately three billion Internet users worldwide, and 44% of all households worldwide had Internet access (International Telecommunication Union, 2014). Of all Internet users in 2014, two-thirds were from developing countries, whose population of Internet users has doubled since 2009. It is no surprise that with this massive user population that the Internet is considered a valuable tool for both health information dissemination and for researchers seeking to recruit a global sample of participants.

The advantages of Internet or social media-based research include low research costs for gathering data, short turnaround time for study completion, the ability to reach people in geographically remote areas and the opportunity to include individuals who may be hard to access through other recruitment methods (Wright, 2005). Potential disadvantages of using the Internet for study recruitment include difficulty reaching populations appropriate to the goals of the study and lack of representativeness among the accessed population, which can affect the external validity of the study findings (Heiervang & Goodman, 2011). The Internet has an overwhelming number of platforms through which people can be recruited. Few

studies have sought to compare yield of participants, cost of advertising, speed of solicitation, and demographic characteristics of those recruited using different Internet recruiting strategies. Understanding these aspects is vital for Internet-based research since, depending on the effectiveness of recruitment, results of the research study can be adversely impacted by even well-intentioned strategies. Therefore, there exists a need for researchers to know how to identify the websites and methods that can reach the greatest number of people appropriate to the goals of the study, are the most cost effective, and produce an appropriate sample for the research in question.

The Internet and social media appear to be enticing means of widely disseminating information about HIV/AIDS and HIV testing, perhaps particularly for those who use these media as their primary resource for information, are geographically isolated, or are hesitant to seek sensitive information in person or from other traditional sources. Accurate and engaging HIV/AIDS and HIV testing information presented through free, easy-to-access digital technologies offer new and broader ways to access communities who would benefit from this information (Singh & Walsh, 2012). Opening this avenues permits empowerment through knowledge whether for prevention, self-understanding of risk and behavior, encouragement of testing, or with hope, reduction of HIV/AIDS stigma without compromising anonymity. One such Internet-based open distance and flexible learning program is Frontline TEACH (Treatment Education Activists Combatting HIV), an adaptation of Project TEACH in Philadelphia (Sowell, Fink, & Shull, 2012). This interactive website has been offered HIV information and education since 2009, although as its authors note, its full impact has not yet been fully measured.

We recently studied the efficacy of an informational HIV/AIDS and HIV testing animated and live-action video (the “parent study”, (Shao et al., 2014)), available at <http://biomed.brown.edu/hiv-testing-video/>, among a global English- and Spanish-speaking Internet audience. We found that the video was able to improve knowledge about HIV/AIDS and HIV testing information among this worldwide Internet and social media-using population. While conducting this study, we utilized a myriad of Internet and social media platforms to recruit participants and through the study disseminate HIV/AIDS and HIV testing information. However, we observed that there were few prior studies that examined best practices on recruiting participants through Internet and social media platforms. Thus, we wanted to analyze our results from the parent study to show which platforms and recruitment strategies can be most effective in yielding better participation rates, yet are not cost prohibitive and yield participant samples appropriate to the goals of the study.

Our primary objective in this current investigation was to determine for a global sample of English- or Spanish- speakers which Internet or social media platforms and recruitment strategies yielded the most study completions within the shortest time, highest level of completions to enrollments (total completions/clicks or completion to enrollment ratios [CERs]), and lowest costs/completion for a study examining the efficacy of an informational HIV/AIDS and HIV testing animated and live-action video. Our secondary objective was to assess the extent to which participant demographic characteristics, HIV testing history, and health literacy varied among the samples recruited across these different Internet or social media platforms and strategies.

Methods

Design and purpose of the current investigation

This investigation examined the yield and speed of recruitment (the number of completed responses solicited from each Internet or social media platform), estimated the costs of advertising, and compared participant characteristic differences from a worldwide Internet-based study on HIV/AIDS and HIV testing knowledge. The study was approved by the investigators' Institutional Review Board.

Parent study on which the current investigation is based

The parent study was a pre- vs. post-video knowledge improvement investigation among a global sample of English- or Spanish-speaking Internet and social media users of any age. The objectives were to determine if a fifteen-minute, live-action and animated video "What do you know about HIV/AIDS and HIV testing?" (English-language version)/"¿Qué sabes sobre el VIH y sobre las Pruebas del VIH?" (Spanish-language version) (Merchant, Clark, Santelices, Liu, & Cortes, 2015) improved HIV/AIDS and HIV testing knowledge (Shao et al., 2014). The video used in this study were developed by members of the research team and described in detail previously. (Merchant et al., 2015) In brief, the fifteen-minute animated and live-action video contains United States Centers for Disease Control and Prevention (CDC)-recommended elements of HIV/AIDS and HIV testing information (Centers for Disease & Prevention, 2001), as well as information about acute HIV infection and current methods of HIV testing. The narrated video follows two characters, racially and ethnically ambiguous male and female protagonists, as they receive information about HIV/AIDS and HIV testing and proceed through the HIV testing process. The characters are not named so to appeal to a wider audience and avoid social labels. Throughout the video, animation, graphics, images, still shots, text, and live-action segments are used to emphasize the topics presented. The English- and Spanish-language versions of the video contain equivalent content.

For the parent study, we created a study website which hosted English and Spanish versions of the study consent form; demographic characteristics, HIV testing history and health literacy questionnaires; identical pre- and post-video versions of a 25-item questionnaire that measured improvement in HIV/AIDS and HIV testing knowledge after watching the video (the "HIV/AIDS and HIV testing knowledge questionnaire"); and the video. English-language versions of the study questionnaires are provided in Appendix 1. The "HIV/AIDS and HIV testing knowledge questionnaire" contains five domains that examine understanding of and parallel the video's content: the definition, nature, and distinction between HIV/AIDS; HIV transmission; HIV prevention; HIV testing methods; and the interpretation and meaning of HIV test results. The questionnaire's development and evaluation have been described previously. (Merchant et al., 2015) The testing knowledge questionnaire was used as an objective assessment of improvement in knowledge before vs. after watching the video.

English or Spanish-speaking Internet users were solicited online to participate in the study across seventeen paid and free Internet or social media platforms. English- or Spanish-speaking Internet or social media users of any age who accessed the website were study eligible if they were not known to be HIV infected

(by self-report), could complete the study via separate but linked English or Spanish language portals, and consented to participate. Participants were asked to give their consent on the first page of the website. Next they answered questions about their demographic characteristics, HIV testing history, the health literacy questions, a self-perceived knowledge question (which assessed subjective improvement in knowledge) and then the “HIV/AIDS and HIV testing knowledge questionnaire.” Next, they watched the video. The study website did not allow participants to fast-forward through the video to the post-video questionnaire and did not allow them to watch the video again. Afterwards they answered the self-perceived knowledge question and the “HIV/AIDS and HIV testing knowledge questionnaire” again. After completing the study, all participants were offered the chance to enter a lottery for one of four \$50 Amazon.com gift cards.

Recruitment strategies

Seventeen Internet or social media platforms were used to solicit participants (Table 1) with either free postings or paid advertising. A mix of the top social networking websites by user traffic (eBiz, 2014), commerce websites, blogs, bookmarking, research solicitation websites and a general search engine were used. Platforms were selected based on their user penetration and recognition (i.e., the top sites used most frequently globally). Social bookmarking sites were selected based on number of users and ease of access (Alexa, 2014). We created a different Uniform Resource Locator (URL) for each Internet or social media platform, which allowed us to identify which platform participants used to reach the study and to track the number of times people clicked on each platform’s post. English and Spanish versions of each post were created for every platform.

Free and paid platforms

We first posted a short explanation of our study and a link to the study website on platforms that did not require posting costs or paid advertising (i.e., “free” platforms). Next, we paid for advertisements on four Internet or social media platforms: Facebook, Amazon Mechanical Turk, Google, and FindParticipants (Table 2). Google and Facebook were selected due to their status as the most used websites in the world (Facebook, 2013; NationMaster, 2014). FindParticipants and Amazon Mechanical Turk are websites specifically designed to locate participants for research studies. According to previous studies, participant recruitment on Amazon Mechanical Turk was found to be at least as reliable as traditional study recruitment methods (Berinsky, Huber, & Lenz, 2012; Buhrmester, Kwang, & Gosling, 2011).

For Facebook, we made our paid advertisements visible to the top 20 English-speaking and Spanish-speaking countries by population (NationMaster, 2014). No other characteristics were targeted or specified in the Facebook advertising campaign (i.e., no specific interests, age groups, gender or other attributes were selected to narrow the scope of those who could see the advertisements). Separate advertisement campaigns were created for the English and Spanish languages. For each language, we created two advertisements on Facebook. One advertisement linked directly to the study website, and the other linked to our Facebook page (which also hosted a link to the study website). Participants could access the study on Facebook either directly through an advertisement, through our Facebook page

(which they also could access through an advertisement), or by seeing the Facebook page through a friend's activity (a "like" of our page).

For Amazon Mechanical Turk, we posted a link to the study on that website and advertised payment offers for every completed response. Payment offers are bids that are advertised to viewers on the website which pay participants to complete a task, such as our study. We made separate posts in English and Spanish, which constituted different participant pools. Based on previous research, a \$0.50 payment offer on Amazon Mechanical Turk could solicit participants from the United States (Berinsky et al., 2012). We experimented with increasing payment offers during the study to examine their effects on the speed and yield of recruitment (Table 2). For Google Adwords, we launched two advertising campaigns (in English and in Spanish) which linked to our study website. For FindParticipants, we paid a fixed subscription cost for the ability to solicit participants via this platform and direct them to complete the study on our study website.

Data analysis

Completions, completions/day, CERs, and cost/completions were measured by language (English or Spanish). We recorded the number of times people clicked on our posts (if these data were available), the number of people who began the study, and the number of people who completed the study, as stratified by Internet or social media platforms. For each platform, we also calculated the average number of completed surveys per day (averaged throughout the duration of the post) to determine the speed of successful recruitment for each platform. For the paid platforms, we estimated the average cost of each completed survey by platform.

We compared the distributions of demographic characteristics, HIV testing history, and health literacy levels of the participants recruited across platforms by language. For English speakers, we compared these aspects among Facebook, Amazon Mechanical Turk, versus all other platforms combined. For Spanish speakers, we compared these aspects between Facebook and Amazon Mechanical Turk due to the small number of participants recruited on other platforms. Outcomes were reported as median and interquartile ranges (IQRs) for continuous variables and percentages for categorical variables. ANOVA testing was used for comparing continuous variables among multiple groups and the Kruskal-Wallis test for categorical variables.

Results

Yield and cost of recruitment across Internet or social media platforms

English speakers. Amazon Mechanical Turk had the highest yield for recruiting English-speaking participants (Figure 1, Table 3a). It had the highest CER, no refusals, and the fewest incomplete responses. Mechanical Turk recruited participants at the fastest rate and was the most cost effective (measured in average cost/completion) platform (Table 4). Paid Facebook advertising had the greatest visibility in that more Internet users saw the advertisement on this venue as compared to the other platforms. A large number of people also accessed our study through a newsfeed or ticker update because their friends "liked" our Facebook page after the launch of the advertisement campaign. Paid Facebook advertising was the second most effective for English speakers in terms of aggregate number of those recruited. Paid Facebook advertising also yielded the most refusals and ineligible participants, the CER was much lower than the other platforms, and cost/completion was significantly higher than that of Mechanical Turk (but lower than the other two paid platforms).

Google was the least effective of our paid platforms for English-speaking participants,

Variations in recruitment yield, costs, speed & participant diversity across internet platforms

having generated no completions. It also solicited a significant number of ineligible participants. Of the free platforms (Table 3a), Facebook (the page and shares before the launch of the advertisement campaign) and Reddit had the most number of completions among English speakers. Few of the free platforms had more than 20 clicks on the posts about the study.

Spanish speakers. Facebook yielded the most completed responses for the Spanish-speaking participants (Figure 2, Table 3b) and the fewest ineligible responses across all recruitment platforms.

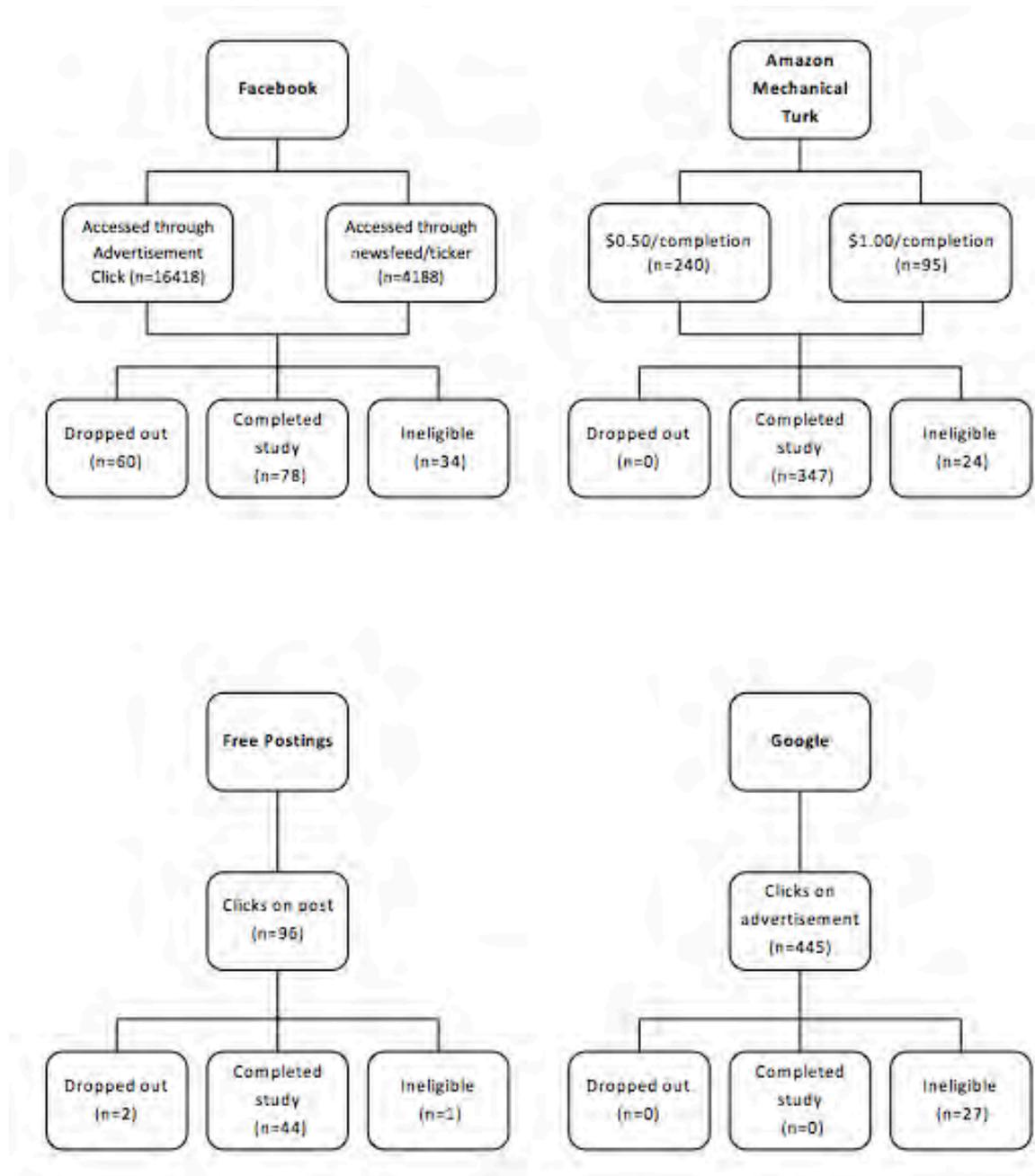


Figure 1: Summary of English-speaking participant recruitment enrolment

Facebook solicitation was faster for Spanish than for English-speakers, and was the fastest method of solicitation across all platforms for Spanish-speaking participants

(Table 4). Mechanical Turk had the second most completed responses and was the most cost effective for Spanish speakers. Solicitation, however, was not successful until we offered \$2.00 per completion. CER was higher for Mechanical Turk than other platforms. Google solicited four completed responses from Spanish-speakers, the second lowest of the paid platforms (FindParticipants had zero). It also solicited the most number of ineligible responses. Free advertising was ineffective for Spanish-speaker recruitment, having only solicited three clicks and two completed responses.

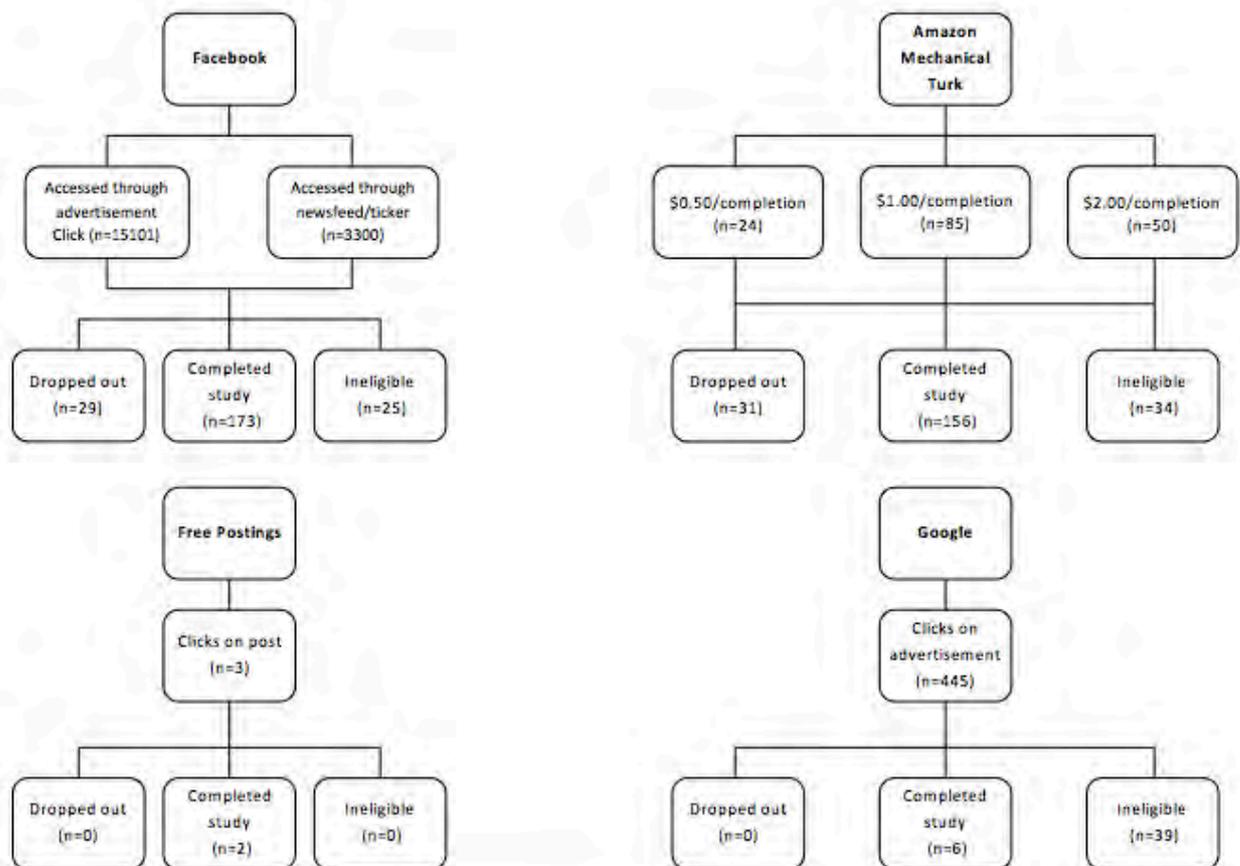


Figure 2: Spanish-speaking participant recruitment enrollment summary

Participant differences across Internet or social media platforms

English speakers. Across platforms, approximately half of English-speaking participants were in their mid-twenties in age, most had received formal education after high school, and most self-described themselves as having strong English-language skills (Table 5a). There were notable differences in participants across platforms. As compared to the other platforms, English-speaking participants from Amazon Mechanical Turk were slightly older, had more years of formal education and had higher health literacy skills. Participants from Facebook were more likely to be male, had lower self-described English language skills, were less likely to have ever been tested for HIV (but more likely to have been tested recently), and had lower health literacy skills. Participants from all other sites were more likely to be female, have fewer years of education (high school or less), have stronger self-described English-

language skills, and have been tested previously for HIV.

Spanish speakers. Across platforms, Spanish-speaking participants were in the latter twenties in age, mostly male, and most had received formal education after high school, yet many indicated that they had lower health literacy skills. Compared to those recruited through Facebook, Spanish-speaking participants from Mechanical Turk were slightly older, more likely to be male, and were more likely to have college degrees. Participants from Facebook indicated better Spanish-language proficiency than those recruited from the other platforms. There were no differences between the platforms in participants' HIV testing history and for two of the health literacy measures (Table 5b).

Geographic diversity

Among English speakers who completed the study, a majority came from Asia, primarily from India (Table 6). North America was the second most represented region. Of the Spanish-speaking participants, a majority was recruited from South America, with Venezuela, Colombia, and Ecuador being the most represented countries. Of those who came from Mechanical Turk, an overwhelming majority resided in India, with some from the Philippines or Pakistan. Facebook recruits were from a much more diverse geographic region, spanning an even distribution over several Latin American countries among Spanish-speaking recruits.

Discussion

This investigation provides important insight into differences in recruitment across Internet or social media platforms in terms of their yield, cost, and participant characteristics for a global study of English- or Spanish-speakers about increasing HIV/AIDS and HIV testing knowledge. Each platform used in this study exhibited advantages and disadvantages in regards to recruitment and participant diversity, which have implications for future research when using the Internet or social media for studies such as these.

Amazon Mechanical Turk and Facebook exhibited the greatest overall recruitment results. Amazon Mechanical Turk was the most effective in recruiting English-speakers in terms of cost effectiveness, CER, and total yield. This was likely due to participants being guaranteed a payment for each complete response. However, one might be concerned that participants from this platform are trained in completing online questionnaires for payment. As such, this group of participants might be less interested in learning about the topic, as compared to those who might seek information about HIV/AIDS and HIV testing for their own knowledge empowerment. We cannot gauge, however, motivation to complete the study, as that was not measured outcome. Researchers should be mindful that although websites such as Amazon Mechanical Turk might be very useful in finding participants, the applicability of the research findings to other populations might be questioned. This caution might particularly be relevant for investigations that measure the impact of educational or informational media, such as examined in the parent

study on the utility of the HIV/AIDS and HIV testing video. In this study, Amazon Mechanical Turk participants could have been less engaged in the topic, which could have reduced the measured utility of the video. However, as noted, the video was shown to improve knowledge among participants (Shao et al., 2014). Future researchers examining other digital educational interventions might not be as fortunate.

Paid Facebook advertising was not as cost effective, but reached a more diverse sample geographically and demographically. Paid Facebook advertising was also more effective at reaching a Spanish-speaking audience. Another advantage in using Facebook was in the organic capabilities of content sharing. Many participants engaged in our Facebook page left comments and further questions, indicating interest in the subject beyond the scope of the parent study. In addition, participants or visitors to our page also “Liked” and “Shared” our page throughout the duration of the study, and activity on the page continued even after the advertisement campaigns ceased. These activities led to increasing the spread of the study which led to further recruitment possibilities. Further, “liking” and “sharing” led to further dissemination of the video, which is a highly useful aspect of social media networking and commensurate with the underlying goal of improving HIV/AIDS and HIV testing knowledge.

Amazon Mechanical Turk and Facebook, however, had other significant limitations despite their greater total yield and cost effectiveness. Amazon Mechanical Turk included primarily well-educated participants from South and Southeast Asia, and future researchers should expect this trend as well. There were also not as many Spanish-speakers with access to Amazon Mechanical Turk, so those wishing to recruit Spanish-speakers should investigate Facebook as an option instead. Yet, Facebook had a much lower completion rate in relation to the amount of people who accessed the study. If researchers are purely looking for quick survey completions without regards to specific demographic representation concerns, Amazon Turk would be preferable. However, this choice comes with costs and the aforementioned concerns regarding internal and external validity of the study findings.

For researchers who plan to use the Internet or social media to recruit participants, it is important to anticipate challenges during the study planning stages and consider how certain platforms might be better suited for one’s budget, demographic targets, and research goals. As demonstrated in this investigation, the reach of the study (i.e., who will see it) and conversion of views to completions differs among the platforms and can vary significantly depending on the amount of money spent for advertising and offered compensation. If a researcher is unable to spend money on recruiting, free platforms can be used, but as shown by this study’s results these platforms might be less effective at recruiting participants and time elapsed to completing recruitment goals might be longer.

The online platforms chosen for participant solicitation for studies can have significant implications on a researcher’s findings. There is a potential to reach a large, global audience, yet there also is the possibility of obtaining inappropriate or non-representative samples. Researchers should be explicit in their participant demographic characteristic needs and plan Internet-based

recruitment strategies carefully, so not to discover after recruitment that the sample collected is not representative of the targeted population. Researchers also need to keep in mind that some platforms may not be fully globally accessible. Both Google and Facebook, for instance, are currently blocked in China, providing limited access to that population (Frizell, 2014). Facebook also has experienced censorship in Cuba, North Korea, and Syria. Google and YouTube have faced restrictions in China, Iran, and Pakistan (Google, 2015). Facebook and Google also are not the most used social media and search engines in all countries. There also exist popular social media websites in Latin America that are not readily used in the United States. Researchers may be interested in expanding availability of content to these other large platforms, particularly in areas experiencing censorship. Based on our experience with this study, we recommend that whenever possible researchers should examine Internet or social media platforms on their projected recruitment yields, cost of advertising and characteristics of the platform's users. We also recommend that studies provide explicit details on their recruitment yields and participant characteristics when using multiple Internet or social media platforms to help inform future researchers on best pathways to achieve their goals.

Limitations

Given the study topic and the platforms chosen for recruitment, the findings from this study may not apply to other types of research that targets specific groups, solicits participants with other demographic characteristics or spoken languages, addresses different topics, uses other study formats or involve other Internet or social media platforms. Also, because our aim was to recruit as many participants as possible, this was an observational study, and so the platforms were not randomly chosen; the study findings (e.g., yield, costs of recruitment, recruitment diversity) were undoubtedly influenced by these factors. However, we believe that the observations were valid for the platforms chosen and study design employed.

Conclusion

In conclusion, we observed significant variations in study completions, time to study completions, level of completions to enrollments and costs/completion across Internet and social media platforms in this global study of increasing HIV/AIDS and HIV testing knowledge through an animated and live-action video. In addition, we observed that participant demographic characteristics, HIV testing history, and health literacy varied among the samples recruited across Internet or social media platforms. Some platforms led to quick recruitment, yet had costs and potential concerns about internal and external validity of the study findings. Other platforms provided slower recruitment, but enabled opportunities to spread knowledge opportunities through social networking. As shown by the results of this study, there is an inherent trade-off between the rate of data collection and the diversity of participants recruited for Internet-based research. Depending on research needs in terms of speed, completions, and participant language, the choice of recruiting strategies

through social media and the Internet can have very different yields, costs, and resultant participant characteristics. Researchers choosing Internet-based recruitment for studies should consider these aspects and invest their resources wisely in light of their study goals. Public health workers and advocates outside of academia concerned with information dissemination and survey work should also consider appropriate Internet and social media platforms commensurate with their objectives.

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Tables

Table 1: Description of recruitment Internet or social media platforms utilized in the study

Platforms	Type	Description	Number of Users
FREE PLATFORMS			
Tumblr	Blog	Enables sharing and reposting of content	110M
Craigslist	Commercial	Displays classified advertisements	50M
Facebook**	Social Media	Enables sharing of photos, videos, pages, and apps	1.3 Bn
LinkedIn	Social Media	Networking business and professional	200M
MySpace	Social Media	Enables sharing of photos, videos, pages, and apps	30M
Twitter	Social Media	Enables Micro-blogging, RSS*, updates, following organizations and individuals	600M
4Chan	Social Bookmarking	Enables rapid sharing of content and images	N/A
Blinklist	Social Bookmarking	Enables tracking, saving, and sharing of website links	N/A
Chime.in	Social Bookmarking	Aggregates news and links	N/A
De.li.cious	Social Bookmarking	Enables storing, sharing, and discovering web bookmarks	5.3M
Digg	Social Bookmarking	Aggregates news	N/A
Pinterest	Social Bookmarking	Enables sharing of images, website, content	48.7M
Reddit	Social Bookmarking	Enables sharing of images and website and aggregating news	N/A
Stumbleupon	Social Bookmarking	Enables storing, sharing, and discovering web bookmarks	N/A
PAID PLATFORMS			
Google	General	Enables content searching	1Bn+
Findparticipants	Research Specific	Enables connecting academic researchers with research participants worldwide	N/A
Facebook**	Social Media	Enables sharing of photos, videos, pages, and apps	1.3 Bn
Amazon Mechanical Turk	Commercial	Enables crowdsourcing of Internet marketplace and completion of tasks for a small fee	100K

*Bn=Billion, M=Million, K=Thousand, N/A=not applicable, RSS=Rich Site Summary **Facebook was used as both a free and paid platform

Variations in recruitment yield, costs, speed & participant diversity across internet platforms

Table 2: Paid platform descriptions, costs, and recruitment duration

Platforms	Population to whom advertisement was visible	Budget (per language)	Cost method	Cost details	Duration of recruitment	Details
Facebook	Top 20 English- and top 20 Spanish-speaking countries by population	\$50/day	Cost per click	\$.50/click	11 days	Separate English- and Spanish-language campaigns, each with two advertisements: one linking to Facebook page, one linking to study website directly. Users could share the Facebook page to invite others to the study.
Google	All website users	\$56.63/day	Bid per click	<\$.2/click	4 days	Advertisements appear as people searched for relevant topics. Link also provided to study's Google+ page.
Amazon Mechanical Turk	All website users	See cost details	Payment per completion	<p>1) 240 participants solicited per language at \$0.50/completion;</p> <p>(2) 95 participants solicited per language at \$1.00/completion; and (3) 50 Spanish-speaking participants solicited at \$2.00/completion</p>	14 days	Posted "task" (completion of study) in English and Spanish languages.
FindParticipants	All registered participants	\$20 total	Lump-sum subscription	Lump-sum subscription	30 days	English version of a recruitment email sent to 1000 participants. Spanish version sent to 53 participants.

Table 3a: English-speaking participant recruitment by platform

Advertising route	Duration of recruitment (days)	Dollars (USD) spent	Number of clicks	Cost/click	Completed responses	Incomplete responses	Refusals	Ineligibles	Cost/attempt	Cost/Completion
Free advertising										
Delicious	42	0	>96	0	44	56	2	1		
Reddit	42	0	>50	0	>10					
Twitter	42	0	>34	0						
Tumblr	42	0	0	0						
Blinklist	42	0	0	0						
Classified Ad	42	0	1	0						
Chime.in	42	0	1	0						
Digg	42	0	2	0						
craigslist	42	0	1	0						
LinkedIn	42	0	0	0						
4chan	42	0	2	0						
Pinterest	42	0	1	0						
Unadvertised Facebook Page (friend invitation)	42	0	>14	0	14					
Myspace	42	0	2	0						
Paid advertising										
Findparticipants.com	30	20	N/A	0	13	19	2	0	N/A	N/A
Facebook Advertising	11	550	16148	0.034	78	728	60	34	0.61	6.9
Google Advertising	4	226.5	445	0.508	0	0	7	27	6.66	N/A
Amazon Mechanical Turk	14	247.5	N/A	N/A	347	78	0	24	0.55	0.7
TOTAL		1044			482	908	71	59		

*USD=United States dollars, N/A=not applicable

Variations in recruitment yield, costs, speed & participant diversity across internet platforms

Table 3b: Spanish-speaking participant recruitment by platform

Advertising route	Duration of recruitment (days)	Dollars (USD) spent	Number of clicks	Cost/click	Completed	Incomplete responses	Refusals	Ineligibles	Cost/attempt	Cost/ Completions
Free advertising	42	0	>25	0	2	1	0	0		
Delicious	42	0	1	0						
Reddit	42	0	10	0						
Twitter	42	0	7	0						
Tumblr	42	0	3	0						
Blinklist	42	0	1	0						
Classified Ad	42	0	1	0						
Chime.in	42	0	1	0						
Diigo	42	0	0	0						
craigslist	42	0	1	0						
LinkedIn	42	0	1	0						
4chan	42	0	0	0						
Pinterest	42	0	0	0						
Unadvertised Facebook Page (friend invitation)	42	0	0	0						
Myspace	42	0	0	0						
Paid advertising										
Findparticipants.com	30	20	0	0	0	0	0	0	20	20
Facebook	11	550	2424	0.036	173	501	29	25	0.753	3.14
Google	4	226.5	492	0.46	4	0	0	39	5.033	37.75
Amazon Mechanical Turk	14	209.5	N/A	N/A	156	50	2	9	0.95	1.31
TOTAL		1006			335	591	31	34		

Table 4: English- and Spanish-speaking participant paid Internet or social media platform recruitment summary

English

Platform	Completion/Day	Cost/Completion	Clicks	CER
Facebook				
Paid Advertising	7.1	\$6.90	16148	0.09
Free Advertising	0.33	\$0.00	18	0.09
Amazon Mechanical Turk				
\$0.50/completion	120	N/A	N/A	0.78
\$1.00/completion	107	\$0.50	331	0.73
Google	0	\$1.00	123	0.87
Free Resources	1.05	N/A	445	0.0
			50	0.39

Spanish

Platform	Completion/Day	Cost/Completion	Clicks	CER
Facebook				
Paid Advertising	15.9	\$3.14	15101	0.24
Free Advertising	0.02	0		0.24
Amazon Mechanical Turk				
\$0.50/completion	N/A	N/A	N/A	0.72
\$1.00/completion	2.14	\$0.50	25	0.6
\$2.00/completion	10.57	\$1.00	96	0.77
Google	50	\$2.00	99	0.51
Free Resources	1.5	\$37.75	445	0.13
	0	N/A	3	0.0

*CER=Total Completion/Clicks, N/A=not applicable

Table 5a: English-speaking participants demographic characteristics comparison

	Facebook	Amazon Mechanical Turk	Others	p-value
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Variations in recruitment yield, costs, speed & participant diversity across internet platforms

	n=78	n=347	n=57	p<
Age (years; median, IQR)	25.5 (20.0, 36)	28.0 (25.0, 37.0)	25.0 (20.0, 33.0)	0.00
	%	%	%	
Gender (female)	29.5	44.1	57.9	0.00
Education				0.43
No school	0.0	0.0	0.0	
Elementary	1.3	0.3	1.8	
High school	3.8	2.4	3.5	
General equivalency diploma	6.4	8.9	14.1	
College	20.5	26.5	33.3	
Bachelor degree	48.7	45.5	31.6	
Graduate school or higher	9.2	16.4	15.8	
Language skills				0.00
Very well	59.0	82.4	93.0	
Well	34.6	17.6	7.1	
Somewhat	3.9	0.0	0.9	
Not well	2.6	0.0	0.0	
Self-reported HIV test				
Have ever tested for HIV	21.8	38.6	45.6	
Last HIV test				0.02
Less than 6 months ago	52.9	17.2	23.1	
Less than 1 year ago	5.9	16.4	15.4	
Less than 2 years ago	29.4	18.4	26.9	
Less than 5 years ago	0.0	20.9	26.9	
More than 5 years ago	11.8	26.1	7.7	
Health literacy				
Confidence with completing forms				0.00

Not at all	12.8	0.9	1.8	
A little bit	12.8	6.6	5.3	
Somewhat	14.1	17.3	21.1	
Quite a bit	28.2	32.0	43.9	
Extremely	32.0	43.2	28.1	
Difficulty reading/understanding forms				0.02
Most of the time	2.6	3.8	7.0	
Some of the time	15.4	21.0	7.0	
A little of the time	39.7	32.3	22.8	
None of the time	42.3	43.0	63.2	
Needing help with forms				0.00
Most of the time	7.7	5.8	5.3	
Some of the time	20.5	17.9	3.5	
A little of the time	29.5	32.9	21.1	
None of the time	43.5	70.2	70.10	

*IQR=interquartile range

<i>Table 5b: Spanish-speaking participants demographic characteristics comparison</i>				
	Facebook	Amazon Mechanical Turk		p-value

Variations in recruitment yield, costs, speed & participant diversity across internet platforms

	n=173	n=156	p<
Age (years; median and IQR)	27.0 (21.0, 38)	29.5 (25.0, 36.0)	0.02
Gender (female)	% 49.7	% 47.4	0.00
Education			0.00
No school	0.0	0.0	
Elementary	1.2	0.0	
High school	9.8	1.3	
General equivalency diploma	16.2	8.3	
College	37.0	28.2	
Bachelor degree	27.8	49.4	
Graduate school or higher	8.1	12.8	
Language skills %			0.00
Very well	91.3	78.2	
Well	8.7	18.0	
Somewhat	0.0	1.9	
Not well	0.0	1.9	
Self-reported HIV test			
Have ever tested for HIV	55.0	52.0	
Last HIV test			0.60
Less than 6 months ago	24.2	22.2	
Less than 1 year ago	19.0	24.7	
Less than 2 years ago	14.7	19.8	
Less than 5 years ago	28.4	19.8	
More than 5 years ago	13.7	13.6	
Health literacy			
Confidence with completing forms			0.00
Not at all	14.5	18.0	
A little bit	20.3	7.7	
Somewhat	30.1	23.7	
Quite a bit	27.8	32.7	
Extremely	7.5	18.0	
Difficulty reading/understanding forms			0.20

Most of the time	2.9	2.6	
Some of the time	19.1	14.1	
A little of the time	31.2	42.3	
None of the time	46.8	41.0	
Needing help with forms			0.06
Most of the time	4.6	0.0	
Some of the time	15.6	17.3	
A little of the time	25.4	26.9	
None of the time	54.3	55.8	

Table 6: Recruitment by region and country

Regions	Accessed in	English	Spanish

Variations in recruitment yield, costs, speed & participant diversity across internet platforms

	English and Spanish (Total)	Accessed study (total)	Refused	Ineligible	Incomplete	Complete	Accessed study (total)	Refused	Ineligible	Incomplete	Complete
North America	285	182	0	2	73	182	103	1	1	46	103
Canada	4	4	0	0	7	4	0	0	0	1	0
Cuba	0	0	0	0	0	0	0	0	0	1	0
United States	267	178	0	2	66	178	89	1	1	34	89
Mexico	14	0	0	0	0	0	14	0	0	10	14
Central America	32	1	0	0	2	1	31	0	5	50	31
Anguilla	0	0	0	0	0	0	0	0	1	0	0
Antigua and Barbuda	1	1	0	0	0	1	0	0	1	0	0
Aruba	0	0	0	0	0	0	0	0	0	1	0
Bahamas	0	0	0	0	2	0	0	0	0	0	0
Belize	0	0	0	0	0	0	0	0	0	0	0
Costa Rica	3	0	0	0	0	0	3	0	0	2	3
Dominican Republic	17	0	0	0	0	0	17	0	3	20	17
El Salvador	5	0	0	0	0	0	5	0	0	9	5
Guatemala	0	0	0	0	0	0	0	0	0	3	0
Honduras	1	0	0	0	0	0	1	0	0	3	1
Nicaragua	5	0	0	0	0	0	5	0	0	12	5
South America	151	1	0	0	1	1	150	2	18	237	150
Argentina	8	0	0	0	1	0	8	0	1	10	8
Brazil	1	0	0	0	0	0	1	0	0	0	1
Bolivia	14	0	0	0	0	0	14	0	1	27	14
Chile	6	0	0	0	0	0	6	0	1	19	6
Colombia	32	0	0	0	0	0	32	0	2	47	32
Ecuador	28	0	0	0	0	0	28	0	1	34	28

Variations in recruitment yield, costs, speed & participant diversity across internet platforms

India	236	202	0	22	74	202	34	0	3	7	34
Indonesia	0	0	0	0	1	0	0	0	0	0	0
Iran	0	0	0	0	1	0	0	0	0	0	0
Israel	2	2	0	0	1	2	0	0	0	0	0
Japan	1	0	0	0	0	0	1	0	0	0	1
Malaysia	2	2	0	0	0	2	0	0	0	0	0
Myanmar	0	0	0	0	1	0	0	0	0	0	0
Oman	0	0	0	0	1	0	0	0	0	0	0
Pakistan	19	19	0	9	115	19	0	0	0	0	0
Philippines	38	36	0	4	80	36	2	0	1	0	2
Qatar	0	0	0	0	2	0	0	0	0	0	0
Saudi Arabia	1	1	0	0	2	1	0	0	0	0	0
UAE	3	3	0	0	1	3	0	0	0	0	0
Vietnam	1	0	0	0	0	0	1	0	0	0	1
Greater Australia	1	1	0	0	8	1	0	0	0	3	0
Papua New Guinea	0	0	0	0	1	0	0	0	0	0	0
Australia	1	1	0	0	7	1	0	0	0	0	0
Africa	17	16	0	2	28	16	1	1	0	1	1
Algeria	0	0	0	0	0	0	0	0	0	1	0
Botswana	0	0	0	0	0	0	0	1	0	0	0
Egypt	14	13	0	1	21	13	1	0	0	1	1
Kenya	0	0	0	1	1	0	0	0	0	0	0
Morocco	1	1	0	0	0	1	0	0	0	0	0
Nigeria	0	0	0	0	3	0	0	0	0	0	0
South Africa	2	2	0	0	2	2	0	0	0	0	0
Zambia	0	0	0	0	1	0	0	0	0	0	0
Pacific	3	0	0	0	0	0	3	0	0	0	3

French Polynesian Islands	1	0	0	0	0	0	0	0	0	1	0	0	0	0	1
Other	1	0	0	0	0	0	0	0	0	1	0	0	0	1	
Antarctica	1	0	0	0	0	0	0	0	0	1	0	0	0	1	

Part 2

Chapter 12

Achieving HIV risk reduction through healthmpowerment.org, a user-driven ehealth intervention for young black men who have sex with men and transgender women who have sex with men

Kathryn E. Muessig
Nina B. Baltierra
Emily C. Pike
Sara LeGrand,
Lisa B. Hightow-Weidman

In their chapter Kathryn E. Muessig, Nina B. Baltierra, Emily C. Pike, Sara LeGrand and Lisa B. Hightow-Weidman succinctly illustrate how young, Black men who have sex with men and transgender women who have sex with men (YBMSM/TW) who are disproportionately at risk for HIV and other sexually transmitted infections (HIV/STI) can be reached through an online mobile platform. HMP's platform is an innovative mobile phone optimised online intervention that utilises behaviour change and gaming theories to reduce risky sexual behaviours and build community among HIV-positive and negative young black men who have sex with men and transgender women who have sex with men.

Introduction

Within the United States (US), young, Black men who have sex with men (YBMSM) and transgender women (TW) who have sex with men face a disproportionate burden of HIV infection (Baral et al., 2013; Herbst et al., 2008; Johnson et al., 2013; Oster et al., 2013; Wejnert et al., 2013). Compared to older and non-Black MSM, YBMSM are less likely to know their HIV status and receive optimal HIV care [ENREF 18](#) (Millett et al., 2012; Oster et al., 2011; US Centers for Disease Control, 2010). Structural-level interventions are needed alongside supported individual behaviour-change to reduce transmission and improve care for HIV and STI among YBMSM/TW. A few individual-level interventions for Black MSM have demonstrated reductions in unprotected anal intercourse (UAI) and increased HIV/STI testing (Maulsby et al., 2013). However, in-person delivery and sustained behaviour change demand significant resources, limiting intervention scalability and impact.

High ownership of computers and mobile devices among YBMSM provides a cost-effective, familiar platform to deliver tailored internet- and mobile web-based (electronic health, or eHealth) interventions to improve HIV prevention and care (Community Marketing Inc., 2012). YBMSM's widespread use of

online social and sexual networking tools (Duggan & Smith, 2014) suggests that eHealth interventions that utilise social networking and other engaging strategies such as gamification have a greater chance of adoption and sustainability (Gay, Pollak, Adams, & Leonard, 2011; Gustafson et al., 1999). Virtual communities can act platforms through which to implement eHealth interventions by connecting like-peers who can share their experiences, exchange information, and provide mutual counselling, support, and encouragement (Meier, Lyons, Frydman, Forlenza, & Rimer, 2007; J. J. Prochaska, Pechmann, Kim, & Leonhardt, 2012).

Past internet-based interventions for MSM have shown preliminary success in increasing condom use (Carpenter, Stoner, Mikko, Dhanak, & Parsons, 2010; Chiasson, Shaw, Humberston, Hirshfield, & Hartel, 2009; Ko et al., 2013; Miranda, 2013; Rosser et al., 2010) and HIV testing (Ko et al., 2013; Rhodes et al., 2011; Blass et al., 2010; Chiasson et al., 2009). Numerous eHealth intervention components can support sustained engagement and behavior change including: tailoring and user-focus (Lustria, Cortese, Noar, & Glueckauf, 2009; Lustria et al, 2013), user engagement features such as gamification (Baranowski, Buday, Thompson, & Baranowski, 2008; Brox, Fernandez-Luque, & Tollefsen, 2011; Enah, Moneyham, Vance, & Childs, 2013; Primack, 2012), social networking and support (Gay et al., 2011; Gustafson et al., 1999), and access via mobile devices (Gay et al., 2011; Gabarron, Serrano, Wynn, & Armayones, 2012). Our goal was to incorporate all of these promising features in an HIV/STI eHealth intervention explicitly tailored for YBMSM/TW.

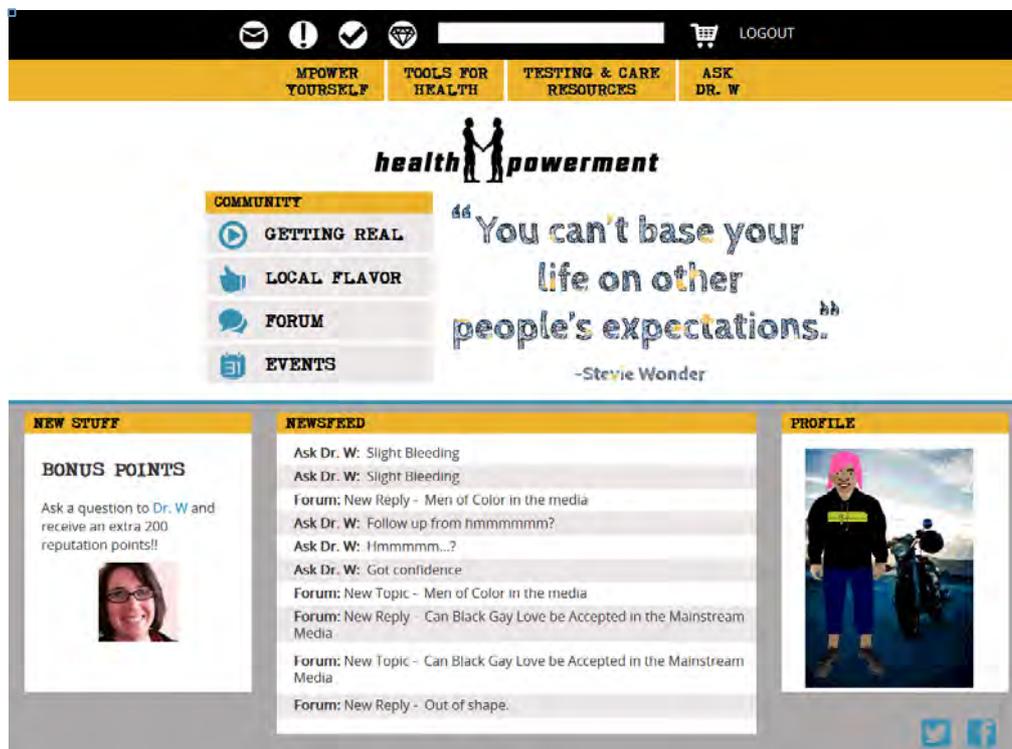


Figure 1. Screen shot of the HMP.org intervention home screen

HealthMpowerment.org intervention

HealthMpowerment.org (HMP) (Figure 1) is a multi-feature eHealth intervention to reduce risky sexual behaviours, promote health and wellness, and support

community-building among YBMSM/TW (Hightow-Weidman et al., 2012; LeGrand, Muessig, Pike, Baltierra, & Hightow-Weidman, 2014; Muessig et al., 2013). We developed HMP through consecutive rounds of evaluation among 130 YBMSM/TW. The website is user-driven and employs responsive web design to optimise computer and smartphone access.

Through HMP's user-driven design, participants choose when and how to engage with the intervention. Each user creates a profile and an avatar to allow personalisation with anonymity. Information on HMP covers a range of health and lifestyle topics (Table 1) to support users' diverse backgrounds and varying need over time. For example, HMP includes resources and support forums for those: never tested for HIV (Figure 2), recently diagnosed HIV-positive, starting antiretroviral medications (ART), and already on ART for a number of years. Health and HIV/STI information is provided through multiple site features including: Quizzes, Know Your Risk (behavioural risk assessments), Ask Dr. W (Figure 3), The Scene (choose-your-own adventure decisional balance game) and the House of Mpowerment (library of brief educational articles and videos) (Table 1). Participants can explore areas of interest and then use the forums, Ask Dr. W, and external resource links to gather additional information and feedback from other users.

Table 1. Components of the healthMpowerment intervention website

Site section	Intervention user activities	Intended outcomes
House of Mpowerment	Read articles (HIV/STI, health)	- Gain new knowledge
Ask Dr. W (Figure 3)	Post anonymous health questions for HMP doctor who responds	- Gain new knowledge - Dispel inaccurate knowledge - Decrease sexual health stigma - Decrease risk behaviours
Judge Your Skills	Complete health knowledge quizzes	- Gain new knowledge - Dispel inaccurate knowledge
Know Your Risk	Complete HIV/STI risk assessment profiles	- Increase risk awareness (e.g. sexual behaviours, alcohol/drug use) - Gain new knowledge
My Life, My Goals	Set steps to achieve health goals and receive links to support resources (e.g. tobacco quit lines)	- Increase healthy behaviours (e.g. quit smoking, increase exercise, increase condom use)
The Scene	Make behaviour decisions to navigate a choose-your-own adventure game for real-life scenarios.	- Increase risk awareness - Explore potential health outcomes of decision pathways (e.g. forgoing condom use with a new partner leads to an STD)
Journal	Complete entries in private journal sections (medical history, sexual partners, free text)	- Increase risk awareness - Increase self-monitoring and assessment
Get Tested	Use GPS locator for HIV/STI testing and care resources	- Increase awareness of testing, counselling & care resources - Increase self-reported HIV/STI testing
HMP Store (Figure 2)	Earn points by using HMP to "purchase" prizes (e.g. condom wallet, HMP tshirt), order free	- Sustained intervention use - Provide free self-testing resources

	HIV/STD test kits	- Increase HMP social network
Local Flavour	Read and post reviews of local businesses and health services	- Build community among YBMSM by increasing social options, shared interests and raising awareness of gay-friendly venues and providers.
Events	Read and post events to the community calendar application	- Build community among YBMSM by increasing social connections/ options, shared interests and raising awareness of LGBTQ events.
Getting Real	View, create and share multi-media submissions (e.g. poetry, videos, photos) on relevant health and life issues	- Build community - Decrease HIV, race-ethnic minority and MSM-related stigma - Establish positive social norms
Forum	Post and comment to message boards for health and life topics and advice	- Build community - Establish positive social norms - Gain new knowledge

To encourage continued use, participants earn points for completing actions on HMP (e.g. submitting an event to the activities calendar, 5 points; achieving perfect scores on all the health quizzes, 100 points). Points “level-up” users’ status within the site (“new face”, “statement”, “star” and “legend”) and earn prizes from the HMP store (e.g. water bottle, messenger bag, hoodie sweatshirt, condom wallet, Figure 2).

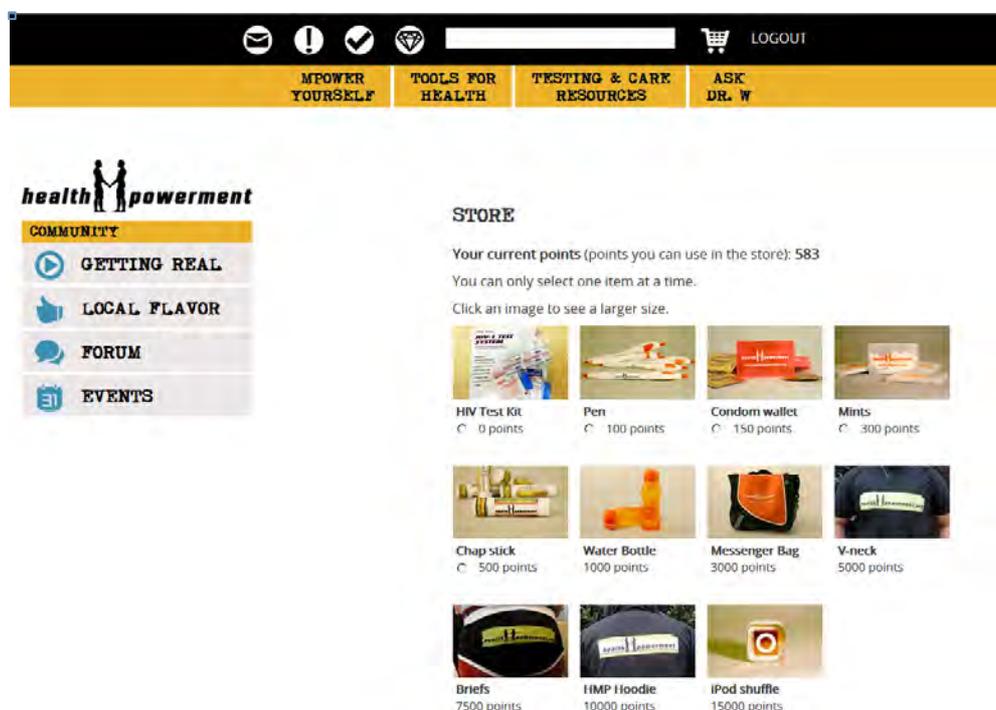


Figure 2. Screen shot of the HMP.org “Store” and available prizes

Prior to HMP’s full randomised controlled trial, we conducted a four-week pilot trial. In this manuscript we demonstrate how HMP components led to changes

during the pilot trial in participants' health behaviour intentions and actions across the spectrum of the Stages of Change (J. O. Prochaska & DiClemente, 1992; J. O. Prochaska, Redding, Harlow, Rossi, & Velicer, 1994). We describe features of HMP that provided actionable health information for participants and facilitated sustained intervention engagement.

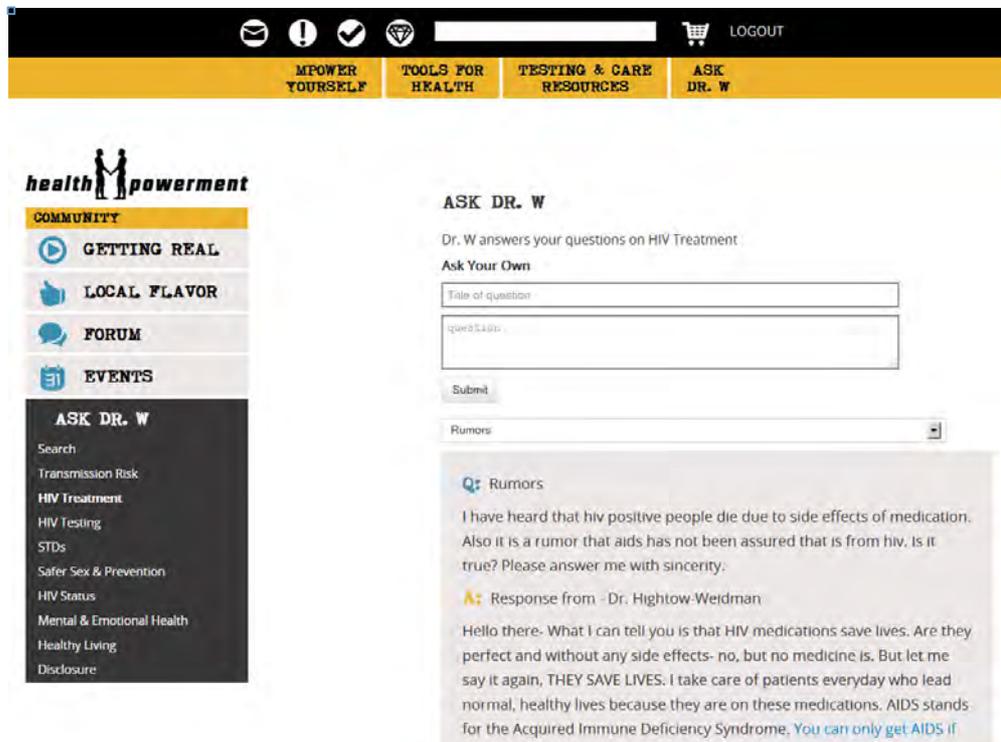


Figure 3. Screen shot of the HMP.org intervention “Ask Dr. W” health care provider forum

Methods

Participants

Study methods and quantitative survey outcomes are reported elsewhere (Hightow-Weidman et al., under review). In brief, study announcements were posted in diverse settings in the North Carolina Research Triangle area and online. Inclusion criteria were: born biologically male, age 18 to 30, self-identify as Black or African American, report ever having sex with another man, and reside in North Carolina.

Procedures

At the baseline office visit, participants completed a computer-assisted, multi-domain survey (sexual behaviours, condom attitudes, HIV/STI test history, depression/anxiety, stigma experiences) and a hands-on, guided HMP.org tutorial during which they created a user log-on name and password. Participants were instructed to use the HMP site for at least one hour per week for four weeks. As there are currently no best practice guidelines for type or length of dose for internet-based interventions (Donkin et al., 2013; Lustria et al., 2009; Lustria et al., 2013) one hour per week was selected as a minimum desired dose to be comparable in length to a weekly in-person one-on-one or group counselling session. The user-driven design of HMP.org allows

participants to selectively use site features most relevant and timely to them without regard for the length of time it takes to complete a particular activity. For example the length of time required to locate an HIV test clinic, complete a risk assessment, and contribute to a discussion forum might vary, but these activities could all be of equal importance in the behaviour change process of different (or the same) users. Text message reminders were sent to participants who did not log-on to the site at least once per week.

At the end of the four week trial, a second in-person follow-up visit included a repeat of the baseline survey with added website usability questions and a semi-structured qualitative interview exploring users' evaluation of HMP. During the exit interview study staff loaded HMP.org on a computer. Participants navigated through the site while commenting on each section including their use (or non-use) during the field trial, impressions, and assessments. All participants were asked to discuss how their use of the site changed over the four weeks and whether anything in their life changed as a result of using the site. Qualitative interviews lasted between 30 and 70 minutes and were recorded with participants' consent. The analysis in this manuscript focuses on this qualitative interview data.

Theoretical framework

This analysis applies the Stages of Change behavioural theory as a conceptual framework and organisational tool to accommodate the diversity in HMP's intervention components and to identify pathways and mechanisms through which HMP may affect participants' behaviour change processes. In the Stages of Change theory, also referred to as the transtheoretical model, an individual moves through five stages of behavioural change (precontemplation, contemplation, preparation, action, and maintenance, Table 2) from being unaware and having no intention to change, to ultimately maintaining long-term change in a desired behaviour (J. O. Prochaska & DiClemente, 1992). At each stage there are hypothesised mechanisms, processes, and cues to action that encourage movement toward the subsequent stage (J. O. Prochaska et al., 1994). This theory has been applied extensively to study condom use behaviours (Ferrer et al., 2009; Grossman et al., 2008; Gullette & Turner, 2004; Noar, Crosby, Benac, Snow, & Troutman, 2011; Prat, Planes, Gras, & Sullman, 2012; Tung, Lu, & Cook, 2010) and, less so, HIV medication adherence behaviours (Genberg, Lee, Rogers, Willey, & Wilson, 2013; Willey et al., 2000). While the Stages of Change theory is often portrayed linearly, individuals may cycle through stages multiple times during the behaviour change process (Chang et al., 2006).

Analysis

Interview recordings were professionally transcribed (© 2014 Verbal Ink) and entered into *ATLAS.ti* for analysis (qualitative data analysis software, Version 7, Berlin 2011). Three study team members reviewed all transcripts and developed a coding scheme. The code book was designed to capture all examples of health behaviours/actions and behavioural intentions that a participant related to their use of HMP during the four-week pilot trial, components of HMP mentioned, and the participant's reflections on the

outcomes of their actions. Codes were inclusive of all health areas discussed (e.g. diet, exercise, smoking, sexual health). Each coded behaviour/intention was assigned one or more stage(s) of change as summarised in Table 2 and informed by the context of the participant’s interview. For example, for the health behaviour change outcome of “establishing regular HIV testing”, an instance of *talking about wanting* to get a HIV test based on an article read on HMP was categorised as “Contemplation”, while an instance of *describing an actual plan* for getting an HIV test (e.g. clinic identified, appointment scheduled) was categorised as “Preparation”. Coders referenced participants’ quantitative survey data for additional information about behaviours reported during the interview.

Table 2. Stages of Change addressed by healthMpowerment components

Stage	Definition	HMP components	Example user statements
Precontemplation	Does not perform behaviour. No intention to change	House of Mpowerment; Know Your Risk; Forum	I didn’t really know what I was looking for until I happened to stumble upon it ¹
Contemplation	Thinking about adopting the behaviour	House of Mpowerment; Know Your Risk; Forums; Judge Your Skills; Ask Dr. W	That’s what I would go on a website for, see what people are talking about...if I could benefit from anything. Made me want to post... questions ²
Preparation	Plans to perform the behaviour, may try out the behaviour but does not do it consistently	House of Mpowerment; Ask Dr. W; Forum; My Life, My Goals; The Scene; Journal	[The site] has gotten me to...go outside of my comfort zone. This gave me a stepping stone...I’m able to socialise a little bit more! ³
Action	Consistently performing the behaviour (<6 months)	Ask Dr. W; Journal; My Life, My Goals; Get Tested; Forums; Point system	My whole attitude about condom use changed... [condoms are] one of the big things I’m working on now ⁴
Maintenance	Persisted in performing the behaviour consistently (> 6 months)	Journal; Get Tested; Point system; Forum; Local Flavor; Events	[The Forum] related to me...to see people reaching out for help...I’ve been through it too, and that’s where I will give advice. ⁵

¹ HMP13, HIV-positive, age 29; ² HMP06, HIV-positive, age 23, TW; ³ HMP08, HIV-positive, age 27; ⁴ HMP04, HIV-negative, age 29; ⁵ HMP07, HIV-negative, age 23.

Two team members independently coded all interview transcripts within *ATLAS.ti*. Discrepancies were reviewed by a third team member and resolved by group consensus. Coded text and participants’ demographic information (e.g. age, education, HIV status) were used to generate matrices in Microsoft Excel to facilitate grouping and comparing behaviours, participants, HMP intervention usage, and stages of behavioural change.

Detailed analysis of the intervention site usage measurement and patterns is reported elsewhere (Baltierra et al., 2014). In brief, participant activity on the website was tracked through a secure administrative portal. Built-in site tracking included time stamps for each user's activity on the site and automated log-out which occurred after 10 minutes of inactivity. Usage data was validated against aggregate statistics from Google Analytics reports and each participant was assigned a usage category based on total time spent on the site during the trial (low=less than one hour; medium=one to five hours; high=more than five hours). Participants' usage categories were also checked against their total points earned on HMP. As expected, these measures were correlated: those who were high users had the highest total points, while low users had the lowest total points. The usage categories were applied in this qualitative analysis to explore patterns between intervention usage and stages of behavioural change.

Results

Sociodemographic characteristics

Table 3 presents the sample's sociodemographic characteristics. Participants ranged in age from 20 to 30 years old. Six participants were HIV-negative and nine were HIV-positive. Participants were asked their: biological sex at birth (required "male" for study inclusion), current gender identity, and current sexual identity (Table 3). While these categories include some overlap (e.g. a transgender person may also identify as gay or bisexual), participants were asked to select the category that "best" describes them and allowed unlimited space for write-in options if they preferred to state their gender or sexual identity in their own words. Six men described their sexual identity as gay, four as bisexual, one as transgender, and four wrote-in a description (queer, same sex loving, MSM, agnostic). Six out of 15 men earned under \$11,000 annually and 12 had greater than high school education.

HMP usage

Our field trial had 100% four-week retention: all 15 participants completed baseline and follow-up surveys and qualitative interviews. Two of the 15 participants did not log on to the site during the four-week trial. Among the remaining 13 active HMP users, average total time spent on the site was five hours and three minutes (range: 0.5 – 13.3 hours). Among the two participants who did not use the site during the trial, the first reported difficulty logging in and the second explained that they were too busy. However, both participants completed the guided tours of the site at baseline and four-week exit interview (described above). Thus, all 15 participants were exposed to HMP enough to comment on its design, desirability, and usefulness.

Analysis of participants' usage of HMP and stages of change revealed specific patterns (Table 4). First, participants who were categorised as "high" users were more likely to describe behaviours across all the stages of behavioural change. Second, across all stages, low users were most proportionally represented in the Contemplation stage, while medium users were most proportionally represented in the Preparation stage and high users

were most proportionally represented in the Action stage. Third, the Action and Maintenance stages were the least commonly represented overall, while the Contemplation stage was the most commonly represented.

Table 3. Sociodemographic characteristics of 15 HMP.org field trial participants

Continuous Variables	Mean	[SD]
Age in years	26.1	[3.3]
Categorical Variables	N	(%)
Education		
High school or GED	3	(20.0)
Professional, technical or trade school	1	(6.7)
Some college	8	(53.3)
College degree	2	(13.3)
More than a college degree	1	(6.7)
Currently employed	9	(60.0)
Income last year		
Less than \$10,999	6	(40.0)
11,000-20,999	7	(46.7)
21,000-30,999	2	(13.3)
What gender currently best describes you? ¹		
Man	10	(66.7)
Woman	0	(0.00)
Transitioning	1	(6.7)
Undecided	1	(6.7)
Not reported	3	(20.0)
How do you best describe your sexual identity? ¹		
Gay	4	(26.7)
Bisexual	1	(6.7)
Transgender	4	(26.7)
Write-ins: queer, same gender loving, MSM, agnostic		
HIV Status		
Positive	9	(60.0)
Negative	6	(40.0)

¹ Gender identity and sexual identity questions were asked separately with the categorical choices listed above and a write-in option. No participant wrote-in an option for the gender identity question, while four participants wrote-in an option for the sexual identity question.

Behaviour change

Based on participants' feedback, the user-driven structure, interactive components, and point reward system of HMP allowed participants to explore information of greatest interest to them, compete against themselves, and engage with other users and study staff around a number of HIV-related topics such as coping with diagnosis, dealing with discrimination and stigma, managing medications, and navigating sexual relationships. This engagement with the intervention components took various forms including receiving and providing advice, debating user-generated topics (e.g. disclosing HIV status to

a new partner), providing affirmation, and sharing experiences.

As described in the exit interviews, participants connected their online engagement with HMP features to real-world actions and behaviour changes completed during the four-week trial. Some of the actions we describe in this manuscript are primary intervention target outcomes (e.g. reducing unprotected anal intercourse) while other actions are secondary outcomes (e.g. increasing HIV/STI testing) or intermediate changes in behaviour (e.g. increasing awareness about triggers of risk behaviours) along the pathway to the primary behaviour change outcome.

Table 4. healthMpowerment intervention usage and Stages of Change

User ID	Usage category	Stage of change				
		Precontemplation	Contemplation	Preparation	Action	Maintenance
1	Low	√	√			√
5	Low		√		√	√
9	Low	√	√	√		
10	Low		√			
2	Medium	√	√	√		√
3	Medium	√	√	√	√	√
6	Medium	√	√	√		√
13	Medium	√	√	√	√	
14	Medium	√	√			
15	Medium			√		√
4	High	√	√	√	√	√
7	High	√	√	√	√	√
8	High	√	√	√	√	√
11	High	√	√	√	√	√
12	High	√	√	√	√	√
	Overall % (n)	80% (12/15)	93% (14/15)	73% (11/15)	53% (8/15)	67% (10/15)
	Low	17% (2/12)	29% (4/14)	9% (1/11)	13% (1/8)	20% (2/10)
	Medium	42% (5/12)	36% (5/14)	45% (5/11)	25% (2/8)	40% (4/10)
	High	42% (5/12)	36% (5/14)	45% (5/11)	63% (5/8)	40% (4/10)

The intentions/actions/behaviours described by participants ranged across all phases of the Stages of Change (precontemplation, contemplation, preparation, action, maintenance) including, for example: changing attitudes about HIV testing, increasing awareness about triggers of risk behaviours (e.g. drugs, alcohol, depression, lack of social outlets), asking partner(s) about their sexual history/HIV status, reducing number of sexual encounters, getting HIV tested, and telling others to get HIV/STI tested. In addition to HIV-related health behaviours, other health-positive behaviour changes that participants attributed to their use of HMP included: going to the gym, losing/gaining weight, quitting/reducing smoking and alcohol use, saving money, and attending community-based social events.

Precontemplation

In our analysis, sections of interview discussions that were characterised in the precontemplation phase of behaviour change commonly included participants' references to the social support features of HMP. Among men whose HMP-

affected behaviours could be classified in the precontemplation stage, the most commonly reported barriers to behaviour change included lack of awareness, fear, and lack of social support. As described by participants, HMP provided information, examples, and activities in an engaging manner, raising awareness and facilitating further consideration of specific health topics and risk behaviours. As one participant explained about health and sexuality information he read on HMP, “I didn’t really know what I was looking for until I happened to stumble upon it” (HMP13, HIV-positive, age 29).

Men reported feeling a sense of connection to others through HMP and the responses they received from Ask Dr. W and other participants. As one man explained, “It’s all about information, learning together, helping each other” (HMP07, HIV-negative, age 23). Some participants reported not feeling comfortable enough to participate in certain sections of HMP (e.g. photo and video posts of the Getting Real section) due to their shyness or fear of being recognised. The user-driven design of these sections facilitated engagement for these individuals at the precontemplation stage. As one YBMSM noted, when he watched others’ videos, “It was something I could relate to because it was a similar situation for me” (HMP14, HIV-positive, age 30). Although this participant did not contribute actively to the Getting Real section, he read and watched other peoples’ contributions.

Participants also described examples of how HMP provided experience-based information that helped to dispel fears and instil hope. In reading about other YBMSM/TW’s experiences, one man explained, “I connected a lot, and when I did feel connected, I would share my information with them” (HMP07, HIV-negative, age 23). This participant went on to describe how HMP could help users extend empathy toward each other. YBMSM/TW could also learn coping strategies from each other. In describing healthcare management, one participant described how HMP connected HIV-infected men at different stages post-diagnosis:

I can truly help you because I understand where you’re at in life...because I’ve been dealing with it [HIV] for 10-plus years and I have the same bills you have, I have the same concept of being a grown-up that you do, so I can help you get through it easier than somebody who is not dealing with it [or] nowhere near your age group. (HMP15, HIV-positive, age 25)

These social interactions on HMP provided motivation: “What really caused me to get on [HMP] was hearing how other people were dealing with things” (HMP01, HIV-positive, age 29). Participants especially liked the videos and postings in the Getting Real section of HMP. Similarly, another participant explained, “I would come on to the site if I needed to talk with someone, maybe I’m going through the same depression that someone else is” (HMP09, HIV-positive, age 30, TW). Another participant echoed this sentiment stating, “It was good to see that I’m not the only one going through certain things in life and that we’re all human...that just changed my perspective a little bit about my outlook on life...a little more hope” (HMP06, HIV-positive, age 23, TW).

Contemplation

In our analysis of HMP-affected behaviours that were categorised in the contemplation stage of behaviour change, participants' discussions included how HMP provided additional information, social support, and goal-setting features. As described by a number of participants, these features mutually reinforced learning. For example, participants would take a quiz, then read articles and retake the quiz to increase their score. One user explained, "The whole point to be on [HMP] was to gain information and knowledge" (HMP01, HIV-positive, age 29); another user stated: "The educational part for me was most interesting...[I] started off with the Forum and then really started getting into the information and tests sections – wanted to learn, wanted to win" (HMP03, HIV-negative, age 30). This user highlighted the importance of the games, challenges, and built-in reward features of HMP which positively reinforced continued intervention engagement.

Importantly, users described how the interactive knowledge-based components of HMP provided new information: "I didn't know too much before, especially [about] STD and sexual health" (HMP14, HIV-positive, age 30). Participants strongly endorsed the HMP feature of being able to talk to a doctor anonymously (Ask Dr. W) and described feeling comfortable asking personal questions. A number of users reported being drawn to this section of the website when they noticed that they had similar questions as others: "Somebody may have the same question but they may be scared to ask, while somebody else may be bold to ask" (HMP05, HIV-negative, age 23).

A number of participants described being inspired by other users to ask a question. As one man stated, "We can ask [Dr. W] anything...after reading how she responded to other people" (HMP10, HIV-negative, age 22). All participants reported high ratings for the HMP Forums: "That's what I would go to on a website for, to see what people are talking about and see what they think....see if I could benefit from anything. It made me want to post some questions of my own" (HMP06, HIV-positive, age 23, TW).

Preparation

Participants described examples of how information and virtual interactions on HMP helped them take steps toward healthy behaviours. A number of participants credited HMP with facilitating in-person health-related conversations with their friends and partners. For example, two participants noted that HMP prompted them to begin asking their partners about their sexual history, HIV status, and drug-use (HMP04, HIV-negative, age 29; HMP02, HIV-negative, age 20). For other men, interactions on the site moved them closer to health care services including HIV/STI testing, general health, and mental health: "When I asked the question [on the Forum]...people replied to me in the post, I ended up calling to a couple places...and set up [counselling] appointments in the realisation that I could possibly benefit" (HMP06, HIV-positive, age 23).

Some participants noted that they could share HMP's resources with others. As one man stated, "If I knew someone who did have questions, it'd be an easy place to say 'oh you should check this out.'" (HMP13, HIV-positive, age 29). Another man explained, "I learned a lot...and then, say if you had a friend

that is going through a dilemma...you can say....hey I found this, maybe we can go [get tested] together” (HMP07, HIV-negative, age 23). Importantly, participants recognised HMP as a tool they could apply in their daily lives: “I think the really cool thing about the site that I want it to facilitate is these kind of real-world spaces” (HMP13, HIV-positive, age 29).

YBMSM/TW also described the role of HMP as: “Empowering yourself physically, ethically, psychologically” (HMP09, HIV-positive, age 30, TW). As one user described,

A: [The site] has gotten me to...go outside of my comfort zone...gave me a stepping stone, and I actually found that I'm able to socialise a little bit more, and I was surprised when that happened!

Q: How did that happen?

A: Opening up and seeing other people open up. (HMP08, HIV-positive, age 27)

This passage is typical of how HMP facilitated movement from the preparation to action stage for many participants through modelling behaviour and providing social support.

All participants responded positively to HMP prizes describing how this feature motivated them increase their site use. One man also described how the HMP logo on the prize items (see HMP Store screenshot, Figure 2) provided opportunities to tell others about HMP and initiate sexual health conversations with friends and partners (HMP15, HIV-positive, age 25).

Action

Some participants reported changes in their behaviour during the pilot trial based on their interaction with the HMP intervention. This included reductions in sexual-risk behaviours, but also extended to other health areas including nutrition and fitness, substance use, and mental health.

One participant was motivated to reduce unprotected sex after reading the response to the question he posted on Ask Dr. W about his genital herpes infection:

One thing I didn't know that genital herpes, you carry it after you get it...and you can have outbreaks...and [are] more susceptible to transmitting HIV...I have a boyfriend...he's HIV negative and we're in an open relationship. We have unprotected sex...so now we're not having unprotected sex. (HMP12, HIV-positive, age 26)

Of note, this man previously talked with his partner about condoms but had not made the decision to use condoms until after his involvement with HMP.

The goal setting feature of HMP—My Life, My Goals—was also popular among participants for facilitating behavior change related to exercise and nutrition. For example, one participant credited this feature and suggestions from the Forum with his return to the gym and losing 10 pounds (HMP03, HIV-negative, age 30). Another participant used resources from HMP to start a food journal and was able to begin losing weight toward his fitness goals (HMP13,

HIV-positive, age 29).

One man described how the educational articles and the Ask Dr. W forum inspired him to try switching from traditional cigarettes to electronic cigarettes (HMP11, HIV-positive, age 26). Similarly, a number of participants described how information and quizzes on HMP helped them identify the roles that drugs and alcohol played for them in doing unsafe things and two men used resources on HMP to find local assistance programs for substance use (HMP04, HIV-negative, age 29; HMP05, HIV-negative, age 23).

A key feature of the Stages of Change model is “cues to action”. The House of Mpowerment articles, Know Your Risk screeners, and My Life, My Goals applications all provide suggested action steps toward changing a specific behaviour and recommended resources to execute each action. Some participants described how user reviews and suggestions in the Local Scene provided trusted, useful information that helped them make decisions about where to go for testing or finding a gay-friendly venue to socialise. Our analysis showed that HMP participants also became cues to action for each other through sharing experiences in the Forum and Getting Real, and to their peers outside of HMP. As one participant explained: “I ask my friends now, ‘do y’all use condoms?’” (HMP05, HIV-negative, age 23). We found that HMP also provided positive reinforcement which can operate as a cue to future action; one participant described a sense of pride at having his videos online: “I look so good!” (HMP03, HIV-negative, age 30). HMP’s text and email message reminders also served as cues to action. These messages encouraged logging on, highlighted site sections and new material, or wished users a fun and safe weekend.

Maintenance

Our analysis found that HMP supported users who were maintaining positive behaviour changes by providing continued social support, advanced information and resources, and strategies for reinforcing healthy behaviours. In the Forum, some participants were motivated to respond to other users’ comments: “I was shocked! Somebody actually feels that way? I can answer that question from experience. It wasn’t just me taking from the site, but I was also giving to the site as well” (HMP01, HIV-positive, age 29). Forum discussions helped empower users who had more experience dealing with an issue – such as sexuality or HIV – to support those who were less experienced. By sharing in this way, participants also reminded themselves of their own progress and reinforced their positive behaviours: “[The Forum] related to me...to see these people reaching out for help and being able to talk about it...it reminded me, I’ve been through it too, and that’s where I will give advice in the Forums: It all gets better” (HMP07, HIV-negative, age 23). Another participant echoed this sentiment as he explained, “Reading about what others posted about being newly diagnosed brought me back to that place, ok, I already got over that, I already dealt with that” (HMP15, HIV-positive, age 25). Participants who were already practicing positive sexual health behaviours described how information on HMP provided a new perspective and offered new resources to support continued positive behaviours. One man who regularly gets HIV tests explained that using HMP helped him change his

attitude about testing from viewing it as a hassle to a regular part of care (HMP03, HIV-negative, age 30).

The majority of users stated that the HMP points and rewards system was highly engaging. As one participant explained, “it made time on the site more personal, made you feel like you were doing something” (HMP06, HIV-positive, age 23, TW). Another participant described the points system as: “A visual representation of your progress on the site” (HMP04, HIV-negative, age 29). The point system motivated participants to use the site via competition: “You’re gonna be on there nonstop because that’s what you’re focused on...I gotta do everything to get these points!” (HMP05, HIV-negative, age 23). Similarly, another man said, “It’s an incentive if they tell me I’m gonna get something for it [points], I’m gonna be on there every single day” (HMP14, HIV-positive, age 30).

Discussion

HMP optimises the benefits of eHealth through its user-driven structure, provision of anonymity and confidentiality, and accessibility anytime, anywhere. HMP provides a framework and mechanisms for participants to encourage each other across the stages of health behaviour change and numerous features contribute to the intervention’s sustainability which is required to support the transition through—and long-term maintenance of—behaviour change. The HMP administrative team and user-driven web structure facilitate and reinforce participants’ movement across stages of behaviour change for their own specific target behaviours at their own pace and comfort level. Participants attributed their behaviour changes to various site features, further emphasising the critical role of user-driven design for facilitating the specific behaviour change that a participant is most ready to embrace.

HMP’s experience sharing and community building features (LeGrand et al., 2014) alongside the gamification features (e.g. reputation points, HMP Store rewards, quizzes) all act as motivators and cues to action (Baltierra et al., 2014; Pike et al., 2014). Furthermore, the self-efficacy fostered by HMP helped instill confidence—a key Stages of Change mechanism (J. O. Prochaska & DiClemente, 1992)—as users tried out new behaviours.

There must be perceived community or social network for positive peer pressure and social norms to operate. Many YBMSM report high levels of stigma and social isolation (Ayala, Bingham, Kim, Wheeler, & Millett, 2012; Bogart, Landrine, Galvan, Wagner & Klein, 2013), which limits opportunities to use social support networks to facilitate healthy behaviours. An interactive, engaging eHealth intervention such as HMP has great potential for addressing this need while also maintaining a comfortable level of privacy and anonymity for YBMSM/TW.

The components of the HMP intervention can be aligned with one or more stages of behavioural change. One strength of the intervention is the plasticity allowed within these sections such that the same activity can address different stages of change for different participants. For example, The Forum could be a first exposure for one man about new ways to communicate HIV status to

one's partners, while for another man it serves as reinforcement of a behaviour already in place. Similarly, the prize items users earn through their virtual interactions that feature the HMP logo (e.g. water bottles, messenger bag, sweatshirt hoodie) could serve as a visual cue to action for a participant who is initiating a new health behaviour, while for another participant in the maintenance phase, the logo serves as a reminder and an opportunity to initiate in-person sexual health conversations. Our analysis lays theoretical groundwork for future quantitative testing of these behaviour change processes through the HMP RCT and other similar projects under development such as the CDC-funded "Project Power" for Black bisexually active men (Maulsby et al., 2013) and Project HOPE for African American and Latino MSM (Jaganath, Gill, Cohen, & Young, 2012).

Conclusion

eHealth interventions for YBMSM/TW have the potential to reach marginalised, at-risk individuals in a novel, more engaging way. For YBMSM/TW in this pilot trial, HMP was a frequently used, highly acceptable means for HIV/STI as well as whole health intervention. HMP showed promise for being able to deliver a sufficient intervention dose and maintain exposure/engagement over time in order to achieve behaviour change, and in this qualitative assessment of 15 participants we found a pattern between the amount of intervention site use and stages of behaviour change. Our findings emphasise the importance of user generated feedback in the design and evaluation of tailored web and mobile phone based interventions. The Stages of Change theory integrated with theories of social support may offer a useful framework for assessing the mechanisms through which web and mobile phone based interventions can achieve and sustain real-world behaviour change. Furthermore, measuring outcomes along multiple stages of behavioural change may help to demonstrate that these interventions have positive impacts on critical earlier stages of behaviour change as well as main study outcomes.

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Chapter 13

Assessing needs and capabilities: Towards an ICT resource to support hiv-positive gay men and other msm in Southeast Asia

Benjamin Hanckel
Laurindo Garcia
Glenn-Milo Santos
Eric Julian Manalastas

In this chapter, Benjamin Hanckel, Laurindo Garcia, Glenn-Milo Santos and Eric Julian Manalastas present work that confronts the sexual stigma, HIV-related stigma and isolation HIV-positive gay men and other men who have sex with men (MSM) experience when accessing information related to HIV. Their study presents the human face of HIV by exploring the technology use of HIV-positive MSM. Their research was part of a formative assessment undertaken at the initial stage of the development an information and communications technology (ICT) resource and peer-support web-app for HIV-positive MSM in Southeast Asia. Hanckel, et al.'s work tentatively illustrate how the capability deprivations experienced by HIV-positive men can be overcome by mobilising Amartya Sen's capability approach to developing an ICT resource that addresses the deprivations and information deficiencies of HIV-positive MSM by enhancing peer support and increasing access to HIV-related information and resources.

Introduction

Gay men and other men who have sex with men (MSM) globally face institutions, policies, and discourses that continue to position their same-sex attraction and intimate relationships as negative (Hammack, Thompson, & Pilecki, 2009; Herek, 2007). This homonegativity works to marginalise MSM and in many contexts lays the grounds for legislation that criminalises their sexual activities (Csete & Dube, 2010) and expression. At least 76 countries worldwide, and at least 5 countries within Southeast (SE) Asia, continue to criminalise same-sex sexual behaviour among consenting adults, with punishments ranging from fines, to imprisonment, or even death sentences (Itaborahy and Zhu, 2013).

This marginalisation is particularly concerning for HIV-positive gay men and other MSM who face stigma associated with their sexual activity and expression, their gender identity and expression, as well as their HIV status. For HIV-positive MSM the perceived stigma can result in a feeling of guilt or shame and if their status becomes known they could experience discrimination and verbal abuse (United Nations, 2011), including from other MSM (Smit et al., 2012). This paper takes the starting point that information and communication technology can support and empower such populations. At present no

transnational ICT resource for HIV-positive MSM exists within SE Asia to address this regional HIV epidemic. B-Change Foundation, a non-profit civil society organisation based in the Philippines identified this gap and is developing an ICT resource called PLUS to connect HIV-positive MSM to resources and support to enhance their lives. The development of this resource began with a formative assessment that included a survey to further understand the needs of HIV-positive MSM in SE Asia. The paper reports on the findings from this assessment.

Background

The Affordances of Network Technologies

Through providing people with opportunities to come together, the Internet has ‘...afforded greater involvement in communities of shared interests’ (Wellman, 2001, p. 247). These communities are not constrained by propinquity and can be conceptualized as ‘cyberplaces’ (Wellman, 2001) or ‘networked publics’ that provide distinct affordances for people to gather and connect with similar others (Boyd, 2011).

These spaces afford particular opportunities for those who have been marginalized by ‘mainstream society’. Research has shown that same-sex attracted and gender-diverse young people (Hanckel & Morris, 2014; Paradis, in press), BDSM community participants (Rambukkana, 2007) and crossdressers (Ferreday & Lock, 2007; Hegland & Nelson, 2002) engage in online spaces for social connection, resources, and identity formation. These spaces afford people living with marginalised identities the opportunity to find similar others in anonymous spaces that are not restricted by temporal and geographic boundaries.

Similarly, research with HIV-positive individuals has found that online spaces provide them with opportunities to be exposed to information and resources about HIV, as well as to connect with other HIV-positive people (Bar-Lev, 2008; Courtenay-Quirk et al., 2010; Drushel, 2013). In doing so these spaces act as supportive environments, which Chenard (2007) argues are crucial for people living with HIV because they function as supportive spaces that protect individuals from stigma and allow them to feel and act ‘normal’. These spaces afford opportunities for brokering new forms of social capital between participants (Drushel, 2013). Social capital occurs here in the form of specific ties that are created between these HIV-positive MSM. In this sense, social capital refers to the resources and benefits that are derived from a network of connections with peers (Bourdieu, 1986; Beaudoin & Thorson, 2004). These connections can lead to support and positive outcomes for people living with varied health concerns (Beaudoin & Tao; 2007; Chung, 2014). Specifically, for HIV-positive MSM, online spaces have been shown to not only reduce feelings of isolation, but they also provide opportunities for individuals to give and receive support and derive positive meanings about living with HIV (Mo & Coulson, 2010; Mo & Coulson, 2013).

There is also evidence to suggest that these online spaces lead to positive coping benefits and increased self-care self-efficacy for HIV positive people who use them (Mo & Coulson, 2010, 2012). Engagement in these spaces can

increase participants' adherence to ART (Samal et al., 2011) as well as provide individuals with the tools and efficacy to address their lived experiences of marginalisation and engage in varied forms of activism (Reeves, 2001). These forms of online engagement have the potential to lead to an increased quality of life for HIV-positive MSM; however more research is required to understand how well these findings hold true for MSM in low to middle income countries (Scanlon & Vreeman, 2013).

This sharing of information and resources between participants can be conceptualised as 'subcultural knowledge.' Recent research (Hanckel & Morris, 2014; Munt, Bassett, & O'Riordan, 2002) has shown how online spaces can play a peer-based mentoring function whereby more self-aware or experienced participants provide advice and support and pass on forms of 'subcultural knowledge' to others in the community. In this way these online spaces operate as a '... forum for the transfer of (sub)cultural capital' (Munt et al., 2002, p. 130). In a similar way, HIV-related online spaces afford individuals living with HIV the opportunity to acquire new forms of knowledge about HIV and come together to debate and discuss moral dilemmas of living with HIV/AIDS (Bar-Lev, 2008; Mo & Coulson, 2013; Rier, 2007). However these online spaces may be more likely to transmit dominant discourses about life with HIV to the exclusion of alternative discourses and narratives (Bar-Lev, 2008; Sandaunet, 2008). In Rier's (2007) work on discussions of HIV disclosure online, he shows how the participants "...police online discourse to mark and attack positions they deem immoral and dangerous" (p. 1053). This hierarchy of subcultural capital (Jensen, 2006) presents limitations and constraints to the possibilities of users on these sites. As Rier (2007) suggests, discourses online are likely to reinforce offline behaviours, and likely to impact people's values as well. This point presents an interesting challenge for online programs that aim to assist HIV-positive MSM in navigating their lives living with HIV.

Furthermore challenges in access to, and use of, these websites and web-based applications -- also known as 'web-apps' -- persist. One major challenge facing ICT projects continues to be the access individuals have to engage with online-based projects (Kalichman et al., 2002). In addition, several other challenges exist for HIV-positive people. One of these is the prevalence of HIV-related Internet sites that provide false and misleading information. Benotsch, Kalichman, & Weinhardt (2004) in their study, that explored how HIV-positive individuals obtain health information online, found that those from lower socio-economic backgrounds and with minimal formal education are more likely to trust misleading information and be less able to critically evaluate it.

Another challenge HIV-positive people face is finding ICT resources that provide them with the particular information they need. As Horvath et al (2010) suggest, many HIV websites might be overwhelming for newly diagnosed people, which is a particular concern as these individuals are also likely to be one of the primary users of online support groups (Mo & Coulson, 2010). Furthermore different groups have different needs, such as women (Walsh, Horvath, Fisher, & Courtenay-Quirk, 2012), trans* people (Herbst et al., 2008), and, for the purposes of the current paper, gay men and other MSM. As Horvath et al (2010) suggest, the information provided on websites needs to

reflect differing demographics and situational diagnoses, which may help HIV-positive people manage their disease more effectively. These challenges have design implications that impact on the functionality of ICT resources (Courtenay-Quirk et al., 2010).

Enhancing the Capabilities of HIV-positive Gay Men and Other MSM in SE-Asia
As recent authors (Courtenay-Quirk et al., 2010; Horvath, Wilkerson, McFarlane, & Courtenay-Quirk, 2012; Scanlon & Vreeman, 2013) have advocated, including HIV-people in the design and development of community development interventions is crucial. This work is based around the guiding principle 'Greater involvement of people living with HIV/AIDS' (GIPA) which aims to ensure that HIV-positive people are recognised for their expertise of living with HIV and are consulted at every stage of the process of developing the ICT resource (International HIV/AIDS Alliance & Global Network of People Living with HIV, 2011).

To develop an ICT resource that will enhance the quality of life for HIV-positive gay men and other MSM, B-Change Foundation sought to initially assess the needs of this population. Understanding the needs of individuals, and how it will enhance their quality of life is crucial to doing development (Sen, 1999). We draw on the Capability Approach which is focused on expanding individuals' substantive freedoms, that is, their capabilities, and removing the "various types of unfreedoms that leave people with little choice and little opportunity of exercising their reasoned agency" (Sen, 1999, p. xii). If individuals have enhanced capabilities they are able to exercise a greater amount of choice than those with diminished capabilities. For example, the capabilities of a person who has had access to sexual health literacy programs will be far greater than a person who has had no access to such information.

ICTs, we argue, present an opportunity to enhance an individual's capabilities while circumventing or at least buffering existing multiple stigmas and legislative barriers. Thus ICTs can be used to enhance the opportunities that individuals have available to them, which can result in individuals leading lives they have reason to value. The formative assessment undertaken at the beginning of the development of PLUS sought to understand the daily experiences of these MSM and what they need from an ICT resource to improve their capabilities and thereby improve their quality of life.

Method

An online survey was undertaken at the initial stages of the development of PLUS, from December 2012 to March 2013. The survey sought to understand the experiences of HIV-positive MSM in SE Asia, and the needs they felt could be addressed through an ICT resource. It also sought to understand how they use ICTs within their everyday lives. An online survey was determined to be the best data collection method to ensure diversity and allow access to participants across SE Asia. As has been found previously, web-based self-report questionnaires provide accessibility to a wide and broad audience (Gosling, Vazire, Srivastava, & John, 2004; Ayala et al., 2013). Using an online survey gave us access to a diverse number of participants across Asia at a low

cost, which was important as the ICT resource is transnational in scope. The survey could be accessed on a computer, or through a mobile or tablet device. The use of online surveys also has the benefit of allowing volunteers to participate anonymously, ensuring their privacy.

A targeted sampling procedure was devised to reach HIV-positive MSM in SE Asia who have had a diversity of experiences living with HIV, including both those who have had contact with support and services, and those who have not. Participants were recruited through social media channels, including Facebook and Twitter. They were also recruited via email networks and contact with staff who work with HIV-positive MSM in the region who were asked to forward on the anonymous survey to their clients. As part of the recruitment strategy a poster (see Figure 1) was developed which included a blurb about the questionnaire, as well as a call to action that encouraged potential participants to either click on a hyperlink, or scan a quick response (QR) code to access the survey. The recruitment material was produced in all the languages of the survey - English, Bahasa Melayu, Bahasa Indonesian and Chinese (both simplified and traditional scripts).

Community-based organisations that support MSM living with HIV in PLUS Phase I coverage sites (Kuala Lumpur, Jakarta, Manila and Singapore) assisted with translating the 25 closed questions in the survey. Draft translations were subsequently peer reviewed by independent third-parties from within the community prior to publication online.

Participants were eligible to participate in this program formative assessment if they self-reported as an HIV-positive male who has sex with other men. Informed consent was collected and participation in the survey was voluntary and anonymous. Participants were given the option of getting more information about the launch of PLUS by providing an email address. Email addresses were stored securely and were not linked to their survey data.



Figure 1. Survey recruitment poster

Measures

The instrument collected data on demographic, social and clinical characteristics. Questions about sexual attraction and behaviour offered

The instrument collected data on demographic, social and clinical characteristics. Questions about sexual attraction and behaviour offered participants the option to provide more than one response to these questions. Information was collected about needs from an ICT-based resource by asking participants to rank 11 functions (i.e., potential uses) of an ICT peer-support service. These functions were under the following broad themes: opportunities for social and sexual relationships; access to HIV-related information and resources; information about legal and health services; and opportunities to engage in advocacy (the individual functions are listed in Table 2). Data were also sought on participants' current use of ICTs, including information about hardware and software that they use to access the Internet, and how they engage with new ICT resources.

Sample and Analysis

During the research period, 344 people started the survey. Once the data were cleaned and 'non-completes' removed, there were 302 cases in total. Of these 302 there were 119 MSM who identified as being HIV-positive. This paper focuses on the experiences and needs of these HIV-positive MSM. The survey data were coded and analysed using SPSS. Summary statistics were calculated for data among HIV-positive MSM and stratified by different covariates of interest. Between-group differences among HIV-positive MSM were assessed using Wilcoxon rank-sum test for means and Fisher's exact test for proportions; statistical significance was evaluated using a p-value cut-off of 0.05.

Results

Participants

Of the participants 117 were male and 1 identified as a female to male (FTM) transgender person. Participants ranged in age from 21 years to 68 years in age (M = 35). The majority of participants identified as Asian (n=89; 75%); few identified as Caucasian (n = 21; 18%), 'mixed' (n = 4; 3%), African (n =3; 3%) or Latino (n=1; 1%). Twenty-nine (24%) participants came from Malaysia, 17 (14%) came from the Philippines, 13 (11%) came from Singapore and 11 (9%) came from Taiwan. Ten (8%) came from the United States, 8 (7%) came from Indonesia and 6 (5%) were from Canada. Five or less participants (in descending order) came from Thailand, UK, HK, China, Australia, Russian Federation, Netherlands, Sri Lanka, Cambodia, Japan, India and Andorra. Almost all participants reported being attracted to other men (99%).

Table 1. Profile of survey respondents

	Number	%
Age		
<30	38	32%
>30	77	65%
Gender		
Male	117	98%
FTM	1	1%
Race		
Asian	89	75%
Caucasian	21	18%
'Mixed Race'	4	3%
African	3	3%
Latino	1	1%
Country of residence[†]		
Malaysia	29	24%
Philippines	17	14%
Singapore	13	11%
Taiwan	11	9%
US	10	8%
Indonesia	8	7%
Canada	6	5%

[†]Includes >6 participants

Note: Numbers may not add to 119 and percentages may not add up to 100 for questions with missing data due to participant non-response.

Participants Experiences with HIV

On average, it has been 6.5 years since the participants were diagnosed with HIV. A significantly greater proportion of young MSM (<30), were diagnosed with HIV within the last year compared to those aged over 30 years of age (53% vs. 17%). Participants last HIV test took place within the last 3 years ($M = 2.18$) and their most recent consultation with a health care specialist was on average 5.36 months ago.

Eighty-seven (81%) participants indicated that they had started antiretroviral treatment (ART), while 21 (19%) participants indicated they were not on ART. Of those who had started ART, the average time since treatment initiation reported was four to five years ago ($M = 4.61$). Of those who were diagnosed with HIV within the last year, a significantly greater proportion had not yet started ART compared to those diagnosed over a year ago (39% vs. 12%; $p = .003$). A significantly greater proportion of these participants were MSM under 30 who had not started ART compared to those above 30 (33% vs. 12%; $p = .02$).

Following their diagnosis, many respondents reported that they experienced negative changes in the areas of sex (52%), relationships (47%) and their expectations for the future (44%). These experiences highlight domains where ICT resources can be targeted to better address the quality of life of newly diagnosed MSM. Some participants indicated a negative change in employment (31%), education (25%), friends (22%), family (17%) and religion

(10%). A number of participants reported a positive change with regard to friendships (31%) and family (32%) relationships.

Accessing HIV-related Information and Support

Information related to HIV was obtained from a variety of sources. Participants indicated that they accessed HIV information from the [Internet](#) (71%), doctors (62%), support groups (48%), and friends (30%). In addition, 93% of participants reported other sources for HIV information including health professionals other than doctors, such as counsellors and nurses. They also indicated obtaining information from print media, through books, brochures and magazines, and through HIV-campaign related resources.

As previous studies (Chenard, 2007) have indicated, being able to draw on the support of friends and others living with HIV is important for social connections, belonging and resource sharing. However for the MSM in this assessment, a significantly greater proportion of those diagnosed with HIV within the past year reported not having any friends who were HIV-positive compared to those diagnosed over a year ago (16% vs. 3%; $p = .023$). This is also particularly true for MSM under 30, of whom a significantly greater proportion reported not having any HIV-positive friends, compared to older MSM (14% vs. 3%; $p = .04$).

HIV-Positive MSM's Technology Use

Respondent's use of technologies to access the [Internet](#) for private use were varied. They were more likely to use laptops (61%) and smartphones (49%), rather than desktop computers (33%) for accessing the [Internet](#). The respondents were most likely to use computers with Windows-based operating systems (OS) (65%) followed by a Mac-based OS (31%), Google OS (13%) or Linux OS (1%). Respondents who use smartphones were most likely to use either an iPhone or Android-based phone (45% vs. 31%). Fewer participants use a Blackberry (RIM) (13%), Nokia (7%) or Windows mobile phone (2%). Four percent were unsure of the smartphone OS they use and 2% indicated 'other.'

More than half of the participants (58%) indicated that they are likely to wait to hear about new technologies prior to incorporating them into their everyday lives. Of these respondents 23% waited for advice from those close to them prior to adopting new ICTs. In contrast 38% of the sample indicated that they actively sought out new ICTs while 4% of the respondents indicated a frustration with using technology.

Preferred functions of a Peer-Support ICT Resource

For HIV-positive MSM the most important aspect of an HIV peer support website or app are opportunities to connect with similar others to share their experiences of living with HIV. Among the participants, 43% ranked this item as number 1 and 79% highly-ranked (ranked it in the top 5) this feature.

Table 2. Preferred functions of an ICT resource for HIV-positive gay men and other MSM by rank

	% who highly ranked the functionality (top 5)	% that ranked this functionality as number 1
Sharing experiences with other HIV-positive MSM	79%	43%
Opportunity to find health services in local areas	78%	9%
Ask questions about medication	75%	8%
Learn about how others deal with emotional issues	69%	7%
Opportunity to find Legal/Human Rights services in local areas	66%	10%
Meet others for friendships	34%	6%
Ask questions about sex	29%	4%
Opportunity to feedback about Health services in local areas	22%	2%
Documenting examples of discrimination	18%	5%
Meet others for relationships	18%	5%
Meet others for sex	13%	3%

Note: The percentages are rounded to whole numbers

The participants indicated that they wanted to connect with other HIV-positive MSM to share information about medication (75% highly ranked this function) and share strategies to deal with the emotional issues of living with HIV (69% highly ranked this feature). Furthermore, being able to share strategies related to emotional issues was important for a significantly greater proportion of MSM who were diagnosed with HIV within the past year, compared to those diagnosed over a year ago (84% vs. 62%, respectively).

Though the opportunity to share their experiences of living with HIV is important, of less interest to participants was having an online space to meet others for sexual encounters or for relationships (only 13% and 18% highly-ranked these features, respectively).

The HIV-positive MSM in this assessment also indicated that having access to information about local resources was important. They indicated that being connected to local health resources (78%) and legal and human rights services (66%) are important functions of an ICT resource. Few participants though saw a need for using the space as a feedback mechanism where they could rate these local health and legal services (22% highly-ranked this function). Noteworthy also is that few participants considered being able to report cases

of discrimination and stigma as important; only 18% of respondents highly ranked this function.

Discussion

Taken together this formative assessment indicates that HIV-positive MSM in SE Asia seek opportunities to connect with similar peers for emotional support and belonging, and to discuss their experiences of living with HIV. Those who had been diagnosed within the last year were more likely to want to be able to share strategies related to the emotional issues of living with HIV. This finding corresponds to previous research (Horvath et al., 2012; Walsh et al., 2012) that found that socialisation and emotional support are important for people living with HIV, particularly for those individuals in their first year of diagnosis as they transition into a life living with HIV. This assessment also indicates that HIV-positive MSM under 30 and those diagnosed within the first year were least likely to know others who are living with HIV. This has implications for the types of support and (sub)cultural knowledge they have access to. Moreover, our data suggest that HIV-positive MSM under 30 and MSM recently diagnosed with HIV may be more isolated, and thus might benefit more greatly from ICTs that can mitigate their isolation.

HIV-positive MSM utilise both the Internet and offline resources to enhance their knowledge of HIV. There is an indication that what is missing from these resources are opportunities to connect with similar others whom they can share coping strategies and knowledge to increase their own HIV-related expertise. These men specifically seek information related to medication and the opportunity to share strategies for handling emotional issues related to living with HIV. In doing so they seek opportunities to enhance their own expertise of HIV, and subsequently improve their quality of life. This sharing of resources and information with similar others is sharing of subcultural knowledge; that is, these MSM seek opportunities to further enhance their knowledge and access to information about living with HIV from their peers, i.e., gay men and other MSM living with HIV.

This peer-to-peer engagement lies at the heart of enhancing social capital. The access to networks of HIV-positive MSM that online spaces afford, and the resulting subcultural knowledge is important for these men. Interestingly these HIV-positive gay men and other MSM reported less interest in an ICT-resource that connects them to opportunities for romantic relationships or sexual encounters. One possible explanation for this is that providing a space to share their emotional experiences and share resources is a more pressing priority. In addition, online spaces, such as Grindr, Jack'd, PlanetRomeo and Manhunt exist elsewhere that may fulfill the sexual and intimacy needs of these men. Our findings are similar to Courtenay-Quirk et al's (2010) study with persons recently diagnosed with HIV in the US, where participants rated meeting others for dates or sex partners as less important than being able to socially connect with others for support.

HIV-positive gay men and other MSM are also interested in knowing more about local health care, as well as legal and human rights services. This information is crucial as many SE Asian MSM reside in areas of stigmatisation

and legislation marginalisation (Csete & Dube, 2010). The discrimination encountered can result in delayed access to services (Kinsler et al., 2007). Knowing about accessible services that meet their needs are important for these MSM. Furthermore, the prospect of having a directory of safe(r) services allows for HIV-positive MSM to handle concerns about disclosure and potentially stigmatising reactions from homonegative professionals.

While identifying these services is important for these MSM, less important is being able to assess and report on their experiences of using these services. We believe that the importance of being able to assess and report on these services may change over time once these men have actually used these services and had varying experiences with them. A greater understanding of minimum standards of HIV care and support is also likely to trigger a greater interest in assessing and providing feedback on these services.

New ICTs provide opportunities for forms of advocacy and mobilization, and opportunities to document cases of discrimination. Interestingly, however, few of the men in our survey reported an interest in ICT resources that allow them to report cases of discrimination and stigma. It may be that participants believed that HIV-related discrimination was not a reportable offence or a human rights violation. Question wording may have also shaped responses. The item asked participants if they thought it was important to be able to 'document examples of discrimination and stigma.' Participants may have reservations about whether documenting this information actually works or if it puts them at risk for further stigma and discrimination. How these MSM might be empowered through ICT resources to document and report lived experiences of stigma, a critical practice in HIV and LGBT advocacy, remains an area for future investigation.

Taken together these needs represent capabilities that participants do not have access to, or do not believe current services adequately fulfill. A peer-support website or app has the potential to fulfill these capability deprivations. By being able to provide HIV-related information and connection to similar others, an ICT resource can address the information deficiencies that these men experience because of the multiple stigma they face as gay men and MSM living with HIV. In doing so, ICTs can help improve their quality of life by breaking down barriers due to stigma and connecting them with resources and information important to their needs.

Limitations

Like all formative studies, the current assessment has several limitations. One is that the conclusions drawn here are from a small non-representative sample of predominantly HIV-positive MSM from SE Asia. Secondly, though we presented data on technology use, these behaviours are likely to change over time as new hardware and software emerge. In addition, our data are based solely on self-reports, rather than direct observations of technology use. Finally, even though we sought to get a diverse sample of participants and translated the survey into several languages, the survey could not reach HIV-positive gay men with literacy constraints, who do not readily use or access ICTs, and those with technological limitations during the time of data

collection.

Conclusion

There is a need in SE Asia to connect HIV-positive MSM to safe, supportive settings where they can accrue the (sub)cultural capital and knowledge they need to be able to enhance their capabilities and thereby improve their quality of life. This is particularly the case for MSM under 30 and those who have been recently diagnosed with HIV who may not have the connections with others living with HIV.

HIV-positive MSM are actively engaged in using new technologies. The particularly large number of mobile phone users is unsurprising given the increasing uptake of mobile phones in Asia (International Telecommunications Union, 2013). This development provides increasing opportunities for the deployment of ICT resources that engage HIV-positive MSM in SE Asia. Through a greater understanding about how HIV-positive MSM adopt and use new technologies, as well as the needs that ICTs might be able to fulfill, we can ensure that the limited resources available are used effectively for developing and designing effective ICT resources for their needs.

This assessment has been an important initial stage in engaging HIV-positive MSM in the design of PLUS, an ICT resource being developed by B-Change Foundation. These findings and the ongoing testing of the service with HIV-positive MSM will inform the creation of a resource that is responsive to the needs and capability deficits experienced by these MSM in SE Asia, which has the potential to be scaled up across other geographic regions.

Our formative assessment indicates that HIV-positive MSM are looking for information, emotional support, and resources from similar others to learn more about living with HIV. These needs, or capability deficits, can be addressed and enhanced through strategically designed ICT resources that can circumvent marginalising stigmas. In doing so ICT resources afford the opportunity for enhancing the participants' lives and overall quality of life.

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Section 2: Working in collaboration with community-based partners

Chapter 14

“Hidden on the social media”: HIV Education on MSM through Cyber-educators in Central America

Jorge Rivas
Jennifer Wheeler
Marcos Rodas
Susana Lungo

In their chapter, Jorge Rivas, Jennifer Wheeler, Marcos Rodas and Susan Lungo present how they worked with The Pan-American Social Marketing Organization (PASMO) to develop a combination prevention intervention in Central America that delivers HIV prevention behavior change communication (BCC) messages, products, services, and referrals to promote improved condom and condom-compatible lubricant use, HIV testing, violence reporting and the use of complementary services. This innovative online “cyber-educator” intervention for MSM provides virtual one-on-one BCC and HIV counseling and testing referrals launched.

Introduction: HIV in Central America

The Central American region includes Belize, Guatemala, El Salvador, Honduras, Nicaragua, Costa Rica and Panamá. Approximately 380,000 people live with HIV in Central America, most of whom reside in El Salvador, Honduras, and Guatemala. Epidemiologic surveillance in the region suggests a concentrated epidemic in large urban areas, with prevalence among the general population ranging from 0.2% to 0.9%, with the exception of Belize, where HIV prevalence is 2.3% (UNAIDS, 2009). HIV prevalence is much higher among MSM (7.5% to 13% across the region) and TW 24% in Guatemala (Soto, R. et al, 2007) and 26% in El Salvador (Hernandez, F. Guardado, M. Paz-Bailey, G. 2010)— The only two countries that have collected prevalence data in this group.

Stigma and discrimination against sexual minorities is high in Central America. According to the public opinion study conducted by USAID/PASCA in El Salvador in 2011, 50% of the general population reported discriminatory attitudes towards high-risk groups, including MSM; 85.1% of respondents agreed that "people have the right to assault trans/transvestites for being who they are" and 72.4% disagreed that “transgender/transvestites have the right to have legal documents that identify them as women.” HIV/AIDS-related stigma is also high, and there is widespread belief that people who are infected deserved their illness because of a wrongdoing usually linked to sex or illegal

or socially disapproved behaviors. The same USAID/PASCA study cited above found 38.1% of respondents believed "female sex workers with HIV or AIDS deserve it for their bad behavior." Another study conducted in El Salvador about Internalized Homonegativity (IH) in 2012 reveals that higher levels of IH shown to be a factor for higher risk behaviours and postponement of health care treatment and adherence (Andrinopoulos K, Hembling J. 2014).

A recent study conducted with 3,748 MSM globally found that perceptions of homophobia within the respondent's country functioned as a consistent barrier to accessing HIV products and services. Higher levels of homophobia were significantly associated with lower odds of access to condoms, lubricants, HIV testing, and HIV treatment. Similarly, MSM who reported that they would feel comfortable discussing HIV with a health provider were significantly more likely to report access and use of products and services (Ayala G. et al, 2013). Discrimination and stigma towards MSM by health care providers may also result in reluctance to access care, reluctance to disclose sexual behaviour or clinical symptoms of STI, negligence or substandard care on the part of the provider, or even refusal of service. (Chakrapani V. et al, 2007)

Homophobia and HIV stigma in Central America result in challenges reaching MSM with HIV prevention, treatment, and care, particularly those who are most socially vulnerable and thus most at risk. HIV prevention, treatment and care programs in the region must confront two key challenges: reaching a population that does not want to be identified and the overly close identification of HIV with sexual minorities, which may trigger further stigmatisation, as well as rejection by lesbian, gay, bisexual, transgender groups and communities who strive to downplay the role of HIV in sexual minority politics (Dibble, S. Roberts, S. Nussey, B. 2004). According to the UNAIDS 2013 Global report, the percentage of MSM reached by HIV prevention programs in Latin America remained unchanged, at 51%, between 2009 and 2012. The median condom use at last anal sex in 43 countries also remained unchanged at 57% over the same time period. This stagnation may be due in part to the social inequalities and traditional norms that reinforce stigma towards high-risk groups and in turn interfere with the effectiveness of HIV prevention programs (De Boni, R., Veloso, V., & Grinsztejn, B. 2014).

There is a need to identify better strategies to serve hard-to-reach MSM, including those who are isolated, who do not identify as gay, and who are married, with adequate, sensitive HIV prevention, treatment, and care programs. A new and promising mechanism for reaching these groups is offered by the Internet. This technology is both already used by men who seek sex with other men in many countries in the world, and is also already being adopted as a space where health-related information and referral services can be offered confidentially and securely (Caceres, C. Aggleton, P. & Galea J. 2008).

The PASMO program

The Pan-American Social Marketing Organization (PASMO), with regional headquarters in Guatemala, has the mission of improving the availability,

access and use of information, products and key health services, through its social marketing techniques, aiming to significantly contribute to the development of an enabling environment that facilitates good health and a better quality of life for vulnerable people in Central America. PASMO, an affiliate of Population Services International (PSI), began operating in 1997 and has expanded its presence to all countries in Central America, with a local infrastructure in each of the seven countries. In 2010, PASMO and its partners began implementing the USAID-funded Combination Prevention for HIV in Central America and Mexico, with the objective of helping individuals make positive behavior changes and access HIV prevention products and health services by providing a minimum package consisting of behaviour change communication (BCC) activities, biomedical interventions, and structural approaches.

The BCC activities are aimed to promote healthy behaviours and must involve a sequence based on the monitoring of prevention work. Traditionally these activities have included a series of methodologies that allow the target populations to interact with the educator and make the intervention more appealing and different. This component would not be complete if you do not have accessibility and availability of products to promote behaviour in this case condoms and water based lubricants. All educators must verify the availability of these products on site and/or nearby places so as to ensure that people can find them when needed.

The core component of combination prevention, named the biomedical, comprises all those actions of a medical nature - supporting clinical prevention efforts on HIV, such as STI screening, treatment, testing, detection of viral load, etc. This component must ensure that each share of combination prevention, people: a) constantly have access to sexual health checks (prophylaxis). B) In case of infections, carry out the treatment prescribed in doses and timing, following the doctor's instructions. C) When taking a voluntary HIV test, provide the pre and post counseling. All referrals for this component are made through numbered vouchers that allow the program to count these types of interventions.

The complementary or structural component are the services and/or products that complement the actions called "Combination Prevention", this is a series of products and/or services based on the specific needs of each population, actions to be considered at this level are: a) referral to support groups (stigma and discrimination, legal support, violence, etc., self-acceptance, nutrition programs (PVS) virtual etc.) b) Reference to Care centers for decreasing behavior related to alcohol/drugs.

Closing the Combination Prevention Cycle

By PASMO's definition, closing the combination prevention cycle includes ensuring that individuals are exposed to three BCC interventions, one services intervention (either HIV counseling and testing or STI screening and treatment) and one complimentary service referral.

A new intervention

Given the high levels of stigma, discrimination and violence in Central America,

new technologies, such as computer-delivered interventions, could be an important means for reaching subgroups of MSM, such as those who are non-gay identified, or who may not feel safe through face-to-face interactions from gay or bisexual peers (Sullivan, P. et al. 2012). Some examples of interventions including educational websites and other more interactive theory-based interventions are shown by Rietmeijer & McFarlane 2009, which translate traditional behavioral interventions to an online format, such as computer-based counseling models or chat-room interventions. These recent advances in interactive and participatory Internet technologies (termed Web 2.0) have transformed the pattern of communication, including health-related communications (Eysenbach, G. 2008). Health communications programs have put forth efforts into identifying new opportunities for using social media to impact population health (Thackeray et al. 2008; CDC, 2014; Norman, McIntosh & Eysenbach, 2008; Vance, Howe, & Dellavalle, 2009). While the implementation benefits of these online interventions, including the ability to target multiple sites from a central operating location and the ability to use real-time data to target the busiest sites for improved reach are clear, (Caceres, C. Aggleton, P. & Galea J.) evidence about the effectiveness of these new interventions in achieving behavior change is emerging. Some studies have shown that well-conceived, theory-based interventions can achieve short-term changes in proximal determinants of behaviour change (such as knowledge, self-efficacy, and motivation) and also on some key sexual risk behaviours, such as condom use during anal sex (Bowen et al. 2008; Carpenter et al., 2010).

As shown by Jones & Fox 2009, the use of social media has grown significantly in Central America over the past decade. Participation in social networking sites more than quadrupled between 2005 & 2009. In order to reach MSM, particularly hidden or non-disclosed MSM, in 2011 PASMO launched and currently implements an online outreach “cyber-educator” initiative that adapts face-to-face outreach to online and social media channels as part of the USAID Combination Prevention Program. The intervention is specifically designed to target young MSM, bisexual men and MSM who do not self-identify as “gay” in all program countries—those who were not being served by other outreach activities that are traditionally implemented in high-risk zones and other physical spaces.

The intervention consists of peer cyber-educators using chat functions to engage MSM in conversations about HIV prevention and initiate BCC activities. Framed in the stages of change model (Figure 1), cyber-educators use information divulged during the conversation to identify where in the behavior change process a user could be with regards to a specific and desired HIV prevention behaviour. The BCC engagement is intended to motivate the user to advance to a stage closer to the desired healthy behaviour.

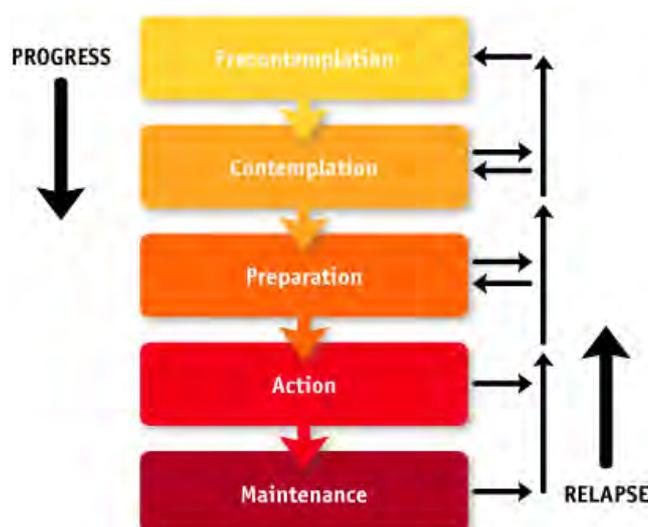


Figure 1: The Stages of Change Continuum (DiClemente and Prochaska, 1998)

When MSM disclose HIV risk behaviour, cyber-educators also provide online referral vouchers for HIV testing and counseling services in clinics where staff are trained and sensitized to provide services to the MSM/TW population. The online voucher system allows users to download vouchers that can be redeemed at partner institutions for biomedical services that are free of charge or provided at discounted prices. An emergent window also offers the user a list of all clinics available in each city. To download the voucher, a link prompts the user to enter data to create a unique identifier code (UIC) and print the online voucher. The UIC is used to track individuals throughout all the program's intervention components and allows the program to identify individuals reached with each type of intervention (behavioral, biomedical or structural).

Table 1. PASMO's informational websites

Name	Target audience	Reach	Purpose
The "Generación Cero" initiative's Facebook fan page	MSM, FSW, Transgender	14,059 fans on Facebook in 2013	Inspired by the UNAIDS initiative to achieve zero discrimination, zero new infections and zero deaths related to HIV, PASMO launched this regional program to promote a respectful dialogue on issues of stigma, marginalisation, and discrimination. The initiative emerged as a result of a PASMO regional study conducted to understand the dynamics of discrimination and stigma related to HIV and vulnerable populations in the region from the perspective of those who discriminate. The values and principles on which this movement is based are respect, acceptance, and equity. A new Facebook fan page was created and is used as a complementary tool to share messages, experiences and legal claims.

“Hidden on the social media”

Y ahora qué? website	PLHA	7570 visitors in the webpage and 4395 fans by 2013 on Facebook	A web site portal to provide information and support for people living with HIV, their families and friends, specific to Central America. The portal contains information about experiences from users, HIV-related news, reference and contact information for services and organisations, chat portals, quizzes and virtual self-support groups. www.yahoraque.info
Mi zona H website	Heterosexual men and MSM	7626 visitors in the webpage and 30,720 fans by 2013 on Facebook	Campaign and associated website about masculinity called “Hombres de Verdad.” Formative research was used to develop archetypes that define different types of machismo a masculinities, which are presented in the campaign and website www.mizonah.com

Peer outreach workers were recruited and trained as “cyber-educators” to deliver the intervention. The outreach workers were trained in the use and management of online tools and social media for the purposes of behaviour change communication. In each country, local teams conducted a formative assessment to identify the most popular websites, chat rooms and social networking sites used by the target population and their patterns of use, including the times of day or night when they were most frequently online. In all countries, the most popular mechanism through which to conduct the online outreach is Facebook. Other country-specific sites like gayguatemala.com are also used.

Given the vast amount of information available on the Internet, cyber-educators must be well versed and prepared to discuss subject matter that is of educational importance and interest to MSM and TW. In addition to the online outreach activities, PASMO developed informational websites that are tailored to the program’s target groups and cover specific topics, such as stigma and discrimination, HIV information, and masculinity (Table 1). The online outreach activities and websites are integrated in that the websites serve as a resource for cyber-educators and as a place to refer users to further HIV prevention information. Constant communication between the cyber-educators and the Webmaster at the regional PASMO office keeps the material on the websites current and responsive to input from the online outreach activities.

Description of the websites created by PASMO

Monitoring activities is keen when tracking the success of the Combination Prevention Program. A series of procedures and tools are constantly implemented to track the reach of all activities across the region:

a. SAM

SAM is the Activities Monitoring System, which allows the program to enter, store, analyse and generate reports related to all Combination Prevention

components; Interpersonal Communication Activities (IPC), Biomedical and Structural. Each site in the region enters their activities, biomedical vouchers and trainings. Monthly, information is exported and sent to the Regional Office, where is consolidated into a central database. In addition, adjustments to overall system configuration, including settings in the various lists interface databases are established and managed from the Regional Office.

b. The Cyber educators portal (www.cibereducadores.com)

Recently launched, this website was created as a complement to the monitoring system and a resource for the difficult labour of tracking online interventions. The website has three main functions: a) Serve as a data-entry source for cyber-educators. b) Transfer information of all online outreach activities to the MIS (SAM). c) Generate unique links to be sent to the users which allow to track the interaction of the user with the link sent and determine if the person opened the link, accessed the website, the frequency of access, and if they downloaded the biomedical voucher for the test or not.

Findings

The cyber-education intervention results

The online outreach activities are now implemented as a mechanism for delivery of BCC through the Combination Prevention Program in all of the Program countries. Using UIC, individuals were tracked through the program interventions and across the services offered by implementing partners. Based on the MIS records (Table 2), during 2013, PASMO was able to reach 7,219 individuals through online peer education activities across Central America. The Program in Nicaragua not only reached, but also doubled its initial target of 1,300, providing online outreach interventions to 2,647 individuals. A total of 2,515 referrals for HIV testing services were provided in 2013 (both online and through face to face interventions) and 145 individuals reached with online activities were counseled and tested for HIV at partner clinics that were trained by PASMO to provide services to MSM.

During the same calendar year, 836 individuals completed a minimum of one BCC intervention, one biomedical intervention and one complementary referral, and 126 (15%) of those 836 closing the cycle did so by participating in at least one online outreach activity (table 1).

The online format of the cyber-educator intervention facilitates the collection of monitoring data that includes: unique identifier code (UIC), type of message delivered, population; and can be used to provide rapid feedback to the program, making the program flexible and responsive. New monitoring data fields can be tracked to assess the implementation of activities. For example, in Costa Rica an increase in duration of online activities from 10 to 20 minutes (on average) demonstrates greater engagement and exposure to the BCC intervention.

“Hidden on the social media”

Table 2. MIS Records: Regional PASMO Combination Prevention interventions January to December 2013

	El Salvador	Panamá	Nicaragua	Costa Rica	Guatemala	Belize ¹	Regional
Face-to-Face BCC interventions	5220	5395	338	902	4217	493	16565
Online BCC interventions	382	1188	2647	839	2155	8	7219
Biomedical interventions	540	366	273	202	995	139	2515
At least one BCC intervention, one biomedical service and one complementary referral	146	52	N/A	78	399	35	710
At least one online BCC intervention, one biomedical service and one complementary	13	34	12	10	57	0	126

The quality and consistency of implementation, however, is difficult to monitor and requires extensive support and supervision. PASMO uses three mechanisms for quality control: 1) reviewing past chat conversations to ensure quality of the intervention; 2) supervising the delivery of the intervention during implementation, and 3) reviewing activity reports provided by the cyber-educators.

The interactive nature of social media also allows users to provide instantaneous feedback and facilitates follow up, both on the cyber-educator and on the user side. Throughout the course of implementation, many users have returned to the webpages to share their HIV test results after having received a referral and to obtain follow-up and support. In Panama, in-person follow-up was provided by cyber-educators to users initially reached online. This follow up consisted of accompanying users to receive counseling and testing, facilitating the use of the referral voucher, and ensuring that they felt safe and confident during the HIV testing process.

No quantifiable information exists about the impact of the cyber-educators component in the change of HIV risky behaviours of the MSM in the region. As part of the evaluation of the Combination Prevention program, PASMO will conduct a quantitative study in 2015 to gather information from a representative sample of the target population. The data collected from this study will allow the program to measure health behaviours, and knowledge and use of health products in the target population over time. From this study programmers will be able to measure effectiveness of the different components of the program including the exposure to the cyber-educators component.

¹ Belize program was starting the online interventions program in 2013.

² Numbers reflect the quantity of individuals that received this type of intervention, based on the UIC.

The websites interaction

Traffic on the program websites is high and the number of hits and likes for the webpages has grown significantly:

- The "Generación Cero" Facebook fan page (focused on reducing stigma and discrimination) grew from 530 fans (persons who liked the fan-page) in 2012 to 14,059 in 2013, an increase of 13,529 new fans during the last year. By the end of 2013, the fan page had 177 twitter followers and 60 tweets.
- The "Y ahora que?" webpage had a total of 7,570 visitors by September 2013—60% of whom were new visitors. This web site also has a fan page on Facebook, which earned a total of 3,457 likes in 2012 and 4,395 in 2013. In 2013 it had 938 new fans, 285 posts and 338 twitter followers.
- "Mi zona H" webpage had a total of 7,626 visitors in 2013, 74% of whom were new visitors. The success of this web page on the Facebook fan page in the last year is tangible, increasing from 7,667 fans in 2012 to 30,720 in 2013, which indicates in the most recent year, the webpage earned 23,053 new fans—and increase of over 300 percent. Mi zona H had also 80 twitter followers and 172 posts.

Discussion

Reaching hidden populations with HIV programs has been challenging due to various social and political barriers in Central America. HIV programs in the region have worked hard to overcome these barriers. This article describes a pilot program that explored whether advances in social media could be used as an alternative or a complement to traditional health communication channels in Central America. PASMO has found that using virtual chat and web-based approaches for HIV BCC interventions successfully reached a different cohort of MSM population, as evidenced by UIC emerging from the online program that are not previously registered through other interventions (Table 3). Some of those reached online also went on to receive other program interventions, including counseling and testing services.

Table 3. Age ranges of MSM exposed to online activities in 2013, by country.

Age range	Country					Total
	Guatemala	Costa Rica	El Salvador	Nicaragua	Panama	
20 years old or younger	18.1%	14.4%	26.7%	21.7%	26.7%	20.9%
21 - 24	29.0%	26.0%	31.9%	28.4%	27.0%	28.2%
25 - 30	29.4%	26.1%	23.8%	33.0%	24.3%	29.2%
31 - 35	14.4%	13.2%	11.5%	9.9%	10.0%	11.7%
36 - 40	5.2%	9.6%	3.1%	4.0%	7.1%	5.4%
41 years old or older	4.0%	10.7%	2.9%	3.0%	4.9%	4.5%

From 2011 to 2013 more than 10,000 individual MSM were reached through online activities, which represents nearly one-third (31%) of the total population of MSM and TW reached by PASMO with prevention services in Central America. Using the Facebook interactive platform as a resource has made possible to have more than 30,000 persons aware of at least one of the resources available online, according to the fans reported. The use of online activities for the Combination Prevention Program is growing—in Nicaragua, PASMO is no longer implementing BCC activities directly, and now exclusively implements interventions through training and supervision of subcontracted NGOs, making the implementation of online approaches a key component of the overall intervention in that country.

Traffic on the various program websites has also grown significantly; in some cases even more than 10 times from one year to the next. Having thousands of new visitors and “fans” represents an important opportunity to continue delivering messages to a growing audience and maximizing the instant access to information that the internet provides. As an educational program, being present in the popular sites and resources, not only gives the program more exposure but also relevance and credibility, since most of internet users are constantly looking for trends and popularity.

Online interventions have the potential to greatly contribute to HIV prevention programs in the region because they can reach a different demographic within the target group, or serve as an entry point to other interventions, such as counseling and testing. Several projects in Central America deliver HIV prevention activities through face-to-face approaches or interpersonal educational interventions. Online interventions are a new tool and, if expanded, properly implemented, and integrated into a program that allows for follow up support and services, can improve access, coverage and plausibly improve the effectiveness of combination prevention programs for HIV prevention, treatment and care. The online approaches used by the Combination Prevention Program in Central America are designed so that any organisation inside or outside the region can use the materials and tools as references.

The cyber educators program has been able to reach a different cohort of MSM from those reached with face to face interventions; however it is important to understand that other populations in the region have high HIV prevalence. There is no substantial evidence that this program can be replicated with transgender women or female sex workers, and if that were necessary, it represents another series of limitations and challenges that need to be addressed.

Conclusion

As technology and social media continue to develop, new communication technologies represent an opportunity that cannot be ignored. PASMO’s experience with cyber-educators in Central America has been successful in targeting and reaching MSM with key HIV BCC and referral services. Although a new intervention, web-based communication now makes up a third of PASMO’s BCC interventions through the Combination Prevention program,

with traffic on websites including more than 12,000 new visitors only in 2013.

Because the Internet is a global tool with increasing coverage, it ensures that this strategy can be replicated in almost any country where the Internet is accessible to a large segment of the population. Using this strategy also becomes important when target populations are difficult to reach through traditional methods, such as interpersonal communication programs. The use of online media provides the opportunity to instantly link the individuals to different sources of information which are not easily replicated in person.

After three years of implementation, some important lessons and limitations in the implementation of web-based communication programs are:

- Some other populations with high HIV prevalence in the region, such as Female Sex Workers and Transgender women, represent a challenge for this approach. The cyber-education approach is primarily designed from the MSM perspective, which may be irrelevant to these groups.
- Both FSW and TGW have lower SES and educational attainment than MSM, two factors that are significantly associated with internet access within the region, thus limiting the effectiveness of cyber-educators as a viable intervention.
- Tracking the virtual vouchers is a challenge in some clinics, particularly when they have not been trained properly. In some clinics biomedical interventions were recorded with no differentiation between personal and virtual referrals because of lack of training.
- There is no scientific evidence about the impact of this program on changing HIV risk behaviours, however, a new study will be conducted in 2015 aiming to respond to these premise.
- Cyber-educators need to be trained intensively on the communication process and be mentored for a substantial period after that. Online conversations can be difficult to redirect and manage and the skills necessary to ensure proper implementation of the intervention are not easily learned. Refresher trainings are important to keep cyber-educators updated on health information and new approaches.
- Continuously monitoring the program is crucial in order to keep content updated and relevant. Monitoring popular trends among the target group allows the program staff to make adjustments immediately, before losing users' interest.
- Online approaches have the potential to grow rapidly. It is challenging to adequately and continuously monitor the quality of the educational interventions and ensure rapid and efficient responses when required.
- More evaluation activities are needed to determine the effectiveness of these approaches and their impact on motivating users to seek HIV counseling and testing and other services.

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Chapter 15

Reaching men who have sex with men in Ghana through social media: A pilot intervention

Kimberly Green
Philippe Girault
Samuel Wambugu
Nana Fosua Clement
Bashiru Adams

In their chapter, Kimberley Green, Phillip Girault, Samuel Wambugu, Nana Fosua Clement and Bashiru Adams describe the ‘Strengthening HIV/AIDS Response Partnerships with Evidence-Based Results (SHARPER)’ intervention which reached 92% of the estimated number of MSM in Ghana with HIV prevention interventions. Achieving this significant reach at scale was the result of changing their earlier approach using face-to-face traditional outreach activities which only reached and estimated half of MSM in Ghana. By being innovative, resourceful and collaborative with MSM affiliated with CBOs, they began using social media to reach an additional 15,440 unique MSM in addition to the 12,804 MSM they reached through traditional outreach activities involving peer educators.

Background

Deeply rooted social stigma towards men who have sex with men (MSM) in Ghana affects their ability to access critical information and services for the care and prevention of HIV. In 2011, the Ghana Men’s Study revealed a high prevalence of HIV (17.5%) among MSM at five sites in Ghana, with the highest rates in Greater Accra (34.4%) and the Ashanti region (13.6%) (Aberle-Grasse et al., 2013). The majority of study participants (>70%) were between the ages of 18-24, living at home and reported having no or low income. That study found that the prevalence of HIV was higher among older MSM (>35 years) and those with higher levels of income. The same study found that less than half (44.8%) of the surveyed MSM population had accessed HIV-prevention services in the previous year, and that 37% in Greater Accra and 23% in Kumasi had been reached by a peer educator. They also estimated a population of 30,579 MSM in Ghana.

Before 2012, the USAID/Ghana SHARPER Project employed conventional HIV-prevention outreach activities through MSM peer educators who were associated with community-based organization (CBO) implementing partners in Ghana. The peer-education program was branded by MSM (as part of SHARP, the precursor to SHARPER) with a rainbow symbol and the tagline “It’s my turn” — to indicate that it was their right to be acknowledged, respected, and to have access to the same information and services as anyone else. Peer educators were selected by the CBOs for their leadership and communication skills, interest in HIV prevention and in supporting peers living

with HIV, and their ability to complete short reports on completed work.

All peer educators were trained over a five-day period using a standard curriculum that focuses on communication skills, the role of the peer educator, HIV risk-reduction counseling, use of condoms and lubricant, management of sexually transmitted infections (STIs), HIV testing and counseling (HTC), illicit drug and alcohol use, mental health and self-esteem, gender-based violence, familiarity with key services, and learning to facilitate referrals. After training, peer educators are equipped with a toolkit to guide peer interactions between individuals and within groups. In light of the repressive environment, most interactions with peer educators are one-on-one. Outreach events are organized in a safe, discreet location, where from 20 to 50 MSM can take part in role-playing games and on-site HTC and STI services. These are known as “Love n’ Trust” events, which focus on the promotion of safer sex, routine HTC and STI screening, and partner HIV-status communication.

In addition, 11 MSM drop-in-centers (DICs) staffed by MSM leaders and part-time Ghana Health Service (GHS) nurses, offer HTC, STI screening and other health services. The SHARPER project also trained GHS nurses that were located in health facilities near “hot-spots” in key population-friendly service delivery to facilitate greater MSM access to public health care services. MSM can also use “Text Me, Flash Me, Call Me HelpLine” to speak anonymously (and free of charge) with a trained GHS nurse about their health, psychosocial concerns or gender-based violence. After providing counseling, the nurses make referrals to peer educators, DICs or GHS services based on the client’s wishes, and provide follow-up counseling where needed.

Peer educators and DIC staff assigned unique identifier codes to all MSM they reached (for the protection of their clients). National standardized monitoring forms are used to record key information about the clients and the counseling and services that were provided. Peer educators are supervised by peer leaders and CBO field supervisors. Peer educators meet once a week to plan their schedule; and they participate in monthly meetings to review challenges and successes, and to learn new or reinforce previously acquired skills.

Despite attempts by the CBOs to recruit peer educators that represented different MSM sub-groups, the majority were less than 25 years old. In 2012, peer educators reached more than 12,000 MSM, most between the ages of 15 and 24 years old (FHI 360, 2012). This amounted to less than 50% of the estimated number of MSM in Ghana (Aberle-Grasse et al., 2013). Peer educators and CBO staff members indicated that they were aware of other MSM networks — particularly those that were older or discreet about their sexuality, and who were not interested in being directly contacted by a peer educator.

Through discussions with MSM affiliated with the CBOs, SHARPER learned that social media were increasingly popular among MSM, and might be a new way to reach older or more discreet MSM who were not currently interacting with peer educators. The majority (88%) of the Ghanaian population uses mobile phones; 76% own their own mobile phone (CDD, 2012). There has also been a rapid expansion of social-media use in Ghana, especially Facebook, which is the most frequently used platform. In the United States, Europe, Latin

American and Asia, social media have been increasingly used for communicating HIV-prevention information, promoting the use of HIV testing and counseling with MSM, and for recruiting and to a lesser extent retaining MSM in research studies (Ko et al., 2013; Sullivan et al., 2013; Young et al., 2013; and Young and Jaganath, 2013). Therefore, the SHARPER project piloted social media outreach among MSM with the aim of reaching sub-networks of MSM that were not being reached by peer educators. This case study describes this pilot and examines the resulting level of coverage of traditional peer education and social media outreach.

Program Description

In early 2012, SHARPER canvassed its partner CBOs for recommendations of MSM leaders who might be at the center of MSM networks that included subgroup populations, such as older MSM, those who were more discreet about their sexuality, and others who might not be reached by peer educators. Three men who fit this profile were identified, one each in Accra, Kumasi and Tamale. These MSM were hired as community liaison officers (CLOs) to initiate social-media outreach activities in their respective communities. The CLOs recommended Facebook as the primary vehicle for reaching new networks of MSM, followed by Badoo, Whats App and Gay Romeo. The CLOs were supplied with a smart phone and a laptop computer and trained over the course of five days on HIV information and services – based on the same curriculum used to train peer educators. The CLOs were also trained how to count the MSM they reached and how to record monthly outputs.

The CLOs established new social media accounts and began to invite friends and contacts, while they conducted daily discussions on sex that interwove messages about HIV prevention, the use of condoms and lubricants, and routine HIV testing and STI screening. In addition, the CLOs operate a number of closed groups that discuss HIV, safer sex, sexuality, gender-based violence and psychosocial support needs. These groups are segmented by age and interests. The CLOs would also conduct private on-line and telephone conversations with MSM who requested more information or who were seeking referrals. In some cases, the CLOs physically accompanied their social-media contacts to the recommended services.

The CLOs also conducted outreach in bars, parties and other venues where their network congregated. In this way, they were able to increase their social-media contacts and to reach peers with information and referrals as needed. Peer educators rarely appeared at these venues, which typically attracted wealthier people.

The CLOs were recruited over different time periods; the one in Accra was hired first to test the original concept, learn from it, and then apply it to social-media outreach efforts in other locations. The CLO in Accra mentored and supported the CLOs in Kumasi and Tamale, explaining their roles and how to complete their monthly reports.

Project staff met with the CLOs every two weeks to review their progress, and once a month to discuss the CLOs' monthly outreach reports. The CLOs tracked the number of unique MSM that were reached. For the SHARPER

project, an MSM is defined as “reached” if he received all of the following: a risk assessment, information on HIV prevention and a referral to HTC (or another HIV service). Each MSM was assigned a unique identifier code to facilitate the counting of reached individuals. We assessed for client overlap between peer education and social media outreach and found that 18% of MSM in Accra and 27% in Kumasi were also contacted by a peer educator in the past twelve months. We adjusted the number of MSM reached through social media by these proportions.

Results from the pilot

2013, 15,440 unique MSM were reached through social media by three CLOs compared to 12,804 contacted by 110 peer educators. This amounted to 28,244 individual MSM reached which represented 92% of the estimated number of MSM in Ghana (FHI 360 2013). The majority of MSM reached through social media or by peer education were contacted two or more times during the reporting period.

Reporting data suggest that HTC service utilization may have increased as a result of social media outreach. In Accra, more than 99% of MSM reached through social media reported having accessed HTC in the past year. While only 64% of MSM reached by peer educators in the same period reported having been tested for HIV.

CLOs reported of high level of acceptability among MSM in their extended network of their on-line outreach. MSM found it to be a convenient and safe way of communicating about their sexual health needs and how to locate MSM-friendly services.

In addition, the CLOs report being sought by staff from MSM CBOs and others working with MSM in Ghana to advise them on their outreach strategies, and how to better utilize social media and tap into new networks of MSM needing access to HIV prevention and care information and services.

Discussion

This pilot study underscores the value of social media in reaching new networks of MSM in Ghana, and using a more diverse approach to reach MSM with HIV-prevention interventions. Studies in the United States, Europe, and Asia that compared internet-based and face-to-face approaches to recruit MSM for HIV-prevention interventions, research, or surveillance concluded that internet-based approaches not only tended to reach new networks of MSM, they also reach higher risk sub-populations (Evans, Wiggins, Mercer, Bolding, & Elford, 2007; Fernández et al., 2004; Tsui & Lau, 2010; Guo et al., 2011; Khosropour et al 2014; Sanchez, Smith, Denson, Dinunno, & Lansky, 2012).

There were a few important challenges experienced during implementation of the pilot. The first was managing accurate enumeration of MSM reached through social media. During the first several months of the pilot, the CLOs and SHARPER team tested a number of different approaches to accurately measure unique contacts until a method was devised that was both sound and acceptable to the CLOs (as described in the program description). The second

challenge involved the difficulty of verifying service utilization among MSM contacted by the CLOs. Peer educators use carbon copy referral slips that are collected by implementing partners at service delivery sites once a month. With social media outreach, it was not possible for CLOs to provide MSM with referral slips, or to verify from the service provider that the service was accessed given the long list of public and private providers utilized by MSM across the three pilot cities. We were only able to collect self-reports as part of this pilot.

A number of questions need to be answered about the use of social media to reach MSM in Ghana. Formative research among MSM has touched on social media but more is needed to explore for which MSM sub-populations social media is most appropriate, types of information preferred and in what format, and frequency of use of different social media platforms (Sabin et al., 2013a; Sabin et al., 2013b).

We need to learn more about the risk behaviors of MSM contacted through the social media intervention, and whether they are at greater risk of HIV than MSM who are typically reached through peer education. We also need to determine the relative effects of social-media outreach and peer-education efforts on changes in HIV-prevention behavior and knowledge, including the use of condoms and lubricants, and the use of HTC and STI screening. In the United States, social-media outreach among MSM was associated with reductions in reported sexual risk-taking and an increased uptake of HIV testing (Ko et al., 2013; Young et al., 2013; Young and Jaganath, 2013).

Also, there may be ways to enhance the depth and quality of the social-media outreach experience. For example, more structured on-line HIV prevention “events” such as brief stories or case studies, video shorts or games could focus on generating discussion that may be more engaging to social media contacts (Jaganath et al 2012). MSM social media contacts could also interact with scenario-based applications where as avatars they navigate real-life challenges to HIV prevention (Christensen et al., 2013).

Facebook offers an opportunity to post advertisements for HTC. In the US, the Centers for Disease Control and Prevention (CDC) “Testing Makes us Stronger Campaign” is an excellent example of using social media to promote HTC uptake among MSM (CDC *ND*). We also need to identify ways to track referrals made through social media to HTC including the use of e-vouchers.

Conclusion

Social media is a very important avenue for reaching MSM not traditionally accessed by peer educators in Ghana and should be adopted as an integral outreach approach for HIV prevention interventions moving forward.

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Chapter 16

Two internet-based approaches to promoting HIV counselling and testing for MSM in China

Matt Avery
Gang Meng
Stephen Mills

In China gay men and other MSM who use ICT to meet up are less likely to visit 'traditional' venues where they can receive interpersonal HIV prevention interventions. In their chapter, Matt Avery, Gang Meng & Stephen Mills present how FHI 360 and Guangzhou Tongzhi (GZTZ) piloted separate, but complementary, approaches to using ICT to promote uptake of HIV counselling and testing (HCT) among gay men and other MSM in three Chinese provinces: Yunnan, Guangxi and Guangzhou. Both interventions included dedicated websites featuring online risk assessment and appointment making, crowd-sourced service promotion messages and dissemination via participants' microblog accounts and social media profiles.

Background

A 2008-2009 survey of 61 Chinese cities indicated a nationwide HIV prevalence of 5% among men who have sex with men (MSM), though specific provinces reported notably higher prevalence, including Yunnan province at 10.9% (Wu, et al., 2013). Since that study was conducted, the China Ministry of Health in 2011 estimated prevalence among this population to be 6.3%, suggesting the epidemic continues to expand (China Ministry of Health, 2012). HIV testing and counselling (HTC) is a key entry point into the cascade of prevention, treatment, care and support for people living with HIV (Hull, Wu, & Montaner, 2012; Kilmarx & Mutasa-Apollo, 2013; Sullivan, et al., 2012); however, increasing HIV prevalence in the MSM population has not resulted in sufficiently increased rates of HIV testing among Chinese MSM. Despite HIV counselling and testing (HCT) services being provided free of charge by the Chinese government, as of 2011 half of Chinese MSM had not received an HIV test within the previous 12 months (China Ministry of Health, 2012). Specific barriers to increasing HTC uptake among Chinese MSM include perceptions that available services are low-quality and discriminatory (USAID/Health Policy Initiative, 2009; Yu, An, & Tong, 2009). Testing behaviour among MSM is also influenced by community norms – a 2010 behavioural survey among MSM indicated that individuals were more likely to get tested themselves if they perceived testing as a norm among their peers (Population Services International (China), 2010).

Information and communications technology (ICT) platforms including websites, social media and microblogs, are one channel for promoting HTC services since the Internet has become an increasingly popular means of

finding sexual partners for MSM in China as well as globally (Lim, Guadamuz, Wei, Chan, & Koe, 2012; Zhang, et al., 2007). Reaching these men with HIV prevention services may be particularly important as studies conducted in China and elsewhere have suggested that MSM who seek sexual partners online may be at higher risk for HIV infection due to a greater likelihood of engaging in unprotected anal sex (Berg, Tikkanen, & Ross, 2013; Grov, 2012; Parsons, Vial, Starks, & Golub, 2013; White, Mimiaga, Reisner, & Mayer, 2013; Zhang, et al., 2007), higher rates of sexually transmitted infections (Lau, Kim, Lau, & Tsui, 2003), or a greater likelihood of having multiple and concurrent sexual partners (Chew Ng, et al., 2013; Li, et al., 2012; Rosser, Miner, et al., 2009; Rosser, Oakes, et al., 2009; Young, Szekeres, & Coates, 2013; Zhang, et al., 2007). While the 61-city survey in China did not find a specific link between Internet use and HIV prevalence, that study did indicate that MSM who interact primarily online are likely to be younger and better-educated than other MSM – the authors suggested that the young age of Internet users could mask undetected, acute infections (Wu, et al., 2013). Further, many MSM who use the Internet to “cruise” for partners never visit or seek sexual partners in traditional gay venues (Saxton, Dickson, & Hughes, 2013). The Internet may thus provide a medium to gain access to a subpopulation of MSM who are at especially high risk, do not necessarily have strong social networks with the local gay community, and are thus not reached by traditional, venue-based peer outreach activities.

Aim

Several organisations working in China have piloted what is referred to as an “online-to-offline (O2O)” model where populations of MSM are targeted over web-based platforms where they interact, with the goal of initially engaging these men online in order to foster eventual in-person interaction, including uptake of HIV counselling and testing and sexual health services. In this paper, we present and compare two specific approaches to social media strategies, their evaluation designs and metrics on reach and effectiveness, and options for the future.

Social and Antisocial Media: Two ICT approaches

Yunnan and Guangxi provinces (pop. 46.31 million and 46.45 million, respectively), in southwest China, are among the highest HIV prevalence provinces in the country, with a number of community-based organisations conducting HIV prevention education, HTC referral and community-based testing in both provinces. The six-month “Xiu Boy” campaign was launched by the USAID-funded Spring Rain and Green City Rainbow MSM community-based organisations in the provincial capitals of Kunming and Nanning, respectively, in order to increase MSM dialogue around and uptake of HTC services. The centrepiece of Xiu Boy was a microsite which hosted HTC information; an online, anonymous HIV risk calculator; and a “digital video” competition wherein participants shared videos of themselves talking about testing across their social media networks (SinaWeibo, RenRen.com, and 56.com among others) and encouraged their friends to vote for their favourite video. The campaign was additionally integrated into traditional outreach

programming, with trained peer educators promoting the Xiu Boy microsite at MSM “hot spots” including bars, bathhouses and public parks and organizing special campaign events including a launch party and “Show Your Best Self” underwear show.

Guangzhou (pop. 12.78 million), the capital of Guangdong Province in southern China, is roughly twice the size of Kunming or Nanning, with a larger and more cosmopolitan MSM community. Guangzhou Tongzhi (GZTZ) has operated an LGBT-themed website since 1998, and has partnered with the Guangzhou CDC to offer community-based HTC since 2008. In contrast to the Xiu Boy campaign, which integrated in-person interaction and encouraged open experience sharing via social media, GZTZ built an ICT platform which consciously limits the human interaction necessary to promote HIV testing: online games encourage self-efficacy and responsibility, a self-risk evaluation targets awareness of personal-risk and decision-making, online ads publicise services and user-friendly tools facilitate appointment making and deliver testing reminders.

While these interventions took different approaches to harnessing web-based platforms for HCT promotion, they also shared several points in common. Both combined innovative web-based approaches with more traditional service promotion activities; both tied service promotion to service delivery through specific partner agencies, and both partnered with local government (municipal centre for disease control and prevention) to deliver these services.

Evaluation designs and metrics

The two social media projects utilised a variety of designs and metrics to measure their penetration into MSM networks and to estimate their impact on service utilisation. Both used Google Analytics to track data on website usage (site visits, site visitors, % new visits, page views and bounce rate).

Users were directed to the Xiu Boy online risk calculator either via the website home page or else via paid banner ads, displayed on a number of for-profit gay Chinese websites, which linked directly to the calculator. The calculator collected data on website users’ self-identified gender, partners’ gender, number of sexual partners within the last six months, and specific risk behaviours (sex with strangers; commercial sex; sex while under the influence of drugs or alcohol; injection drug use; unprotected oral, anal and vaginal sex) and health-seeking behaviours (STI screening and HIV testing). Frequencies were calculated for these measures using SPSS (Version 11.0), in order to build a risk profile of website users who completed the risk calculator.

Levels of risk as reported by the risk calculator were based on a simple calculation of the number of risk or health-seeking behaviours in which an individual reported engaging. Each individual behaviour (male-to-male sex, multiple sexual partners, sex with unknown partners, commercial sex, STI check-up, sex under the influence of drugs or alcohol, needle sharing, HIV testing, unprotected anal or vaginal sex) was assigned a point value (0-15 points) with particularly risky behaviours (commercial sex, needle-sharing, unprotected vaginal/anal sex) automatically assigned higher values. Final

summative scores of 0-2 points were considered minimal risk, 3-4 were considered somewhat risky, 5-14 were considered of moderate risk, and scores of 15 or above were considered high risk. This methodology was adapted from similar risk calculators used in other HIV interventions; however, it was primarily intended to generate increased risk perception among campaign participants and not intended to accurately reflect statistical levels of HIV risk.

Use of the risk calculator was tracked via I.P. address. In order to avoid double-counting of respondents, the database was screened for multiple instance of the same I.P. address. In all cases of multiple entries from the same I.P. address, the entry with the earliest time stamp was retained and all others were removed from the data set. This was based on the assumption that a website user was most likely to respond to risk calculator questions accurately on their first completion of the survey, and then experiment on subsequent attempts with changing their responses to see how it affected the results of their risk calculation.

The digital video competition was evaluated according to the number of videos posted by website users and the number of “Likes” recorded by the website for each video, as tracked via unique I.P. address. Only the first instance of a unique I.P. address was recorded for the purpose of calculating total number of Likes.

The number of individual MSM reached by the Xiu Boy campaign with campaign messages via face-to-face interaction with a project-trained peer educator was tracked using standardised monitoring and evaluation data collection forms. In order to avoid double counting of project clients reached by multiple peer educators, or by the same peer educator multiple times, these data distinguish between “new” and “follow-up” contacts using the recall method so that the total number of persons “reached” is specific to the individual service rendered and does not mix new and repeat clients. GZTZ did not conduct traditional, face-to-face “outreach” activities.

For both interventions, the number of MSM who accessed HIV testing services at an affiliated testing site and received their test result, and the number of MSM tested positive through campaign-affiliated testing sites was recorded through standardised data collection forms. GZTZ was also able to collect data on the number of individuals confirmed positive through Western Blot confirmatory testing, and the number of positive individuals successfully referred to follow-up care, through their partnership with the Guangzhou Municipal CDC. However, antiretroviral treatment (ART) in China is managed through a separate (non-CDC) hospital system; thus, data on ART initiation and maintenance are not reported for clients referred for treatment through these interventions.

Results

Using the above-described metrics, we present the most recently available data and indicators of both the Xui Boy and GZTZ websites and approaches in Table 1 (below).

Table 1. Usage statistics for Xiu Boy and GZTZ websites.

Intervention	Site Visits	Unique Site Visitors	Page Views	Bounce Rate
Xiu Boy (April-Sept. 2011)	9,461	7,082	40,566	53.45%
GZTZ (Jan.-Dec. 2012)	6,679,707	2,298,808	48,899,134	33.67%

For the purposes of these interventions, “site visits” refers to the total number of visits to the specified website, and “page views” refers to the total number of times individual pages within the website were visited. “Unique site visitors” refers to the number of unique individuals who spent time on any page of the website, whether they did so once or multiple times, though this information is subject to data collection errors. The number of unique site visitors is tracked by Google Analytics using “cookies” – small pieces of information installed on a computer when it visits a website, allowing the website to recognise that computer on subsequent visits. If a returning website visitor deletes the cookies stored on their computer, or uses a different machine or Internet browser to visit the site, they may be misclassified as a new unique visitor; thus, Google Analytics tends to place more importance on total site visits.

“Bounce rate”, finally, represents the number of visits when users leave your site after just one page, regardless of how they got to your site or how long they stayed on that page. There are a number of potential explanations for a high bounce rate, including that visitors received the information they needed after visiting only one page, that they visited the site in error or were not interested in the website content, or that they experienced design or usability issues with the website.

XIU BOY campaign

The Xiu Boy campaign ran for six months (April through September 2011) and the social media digital video competition was conducted for the 2nd half of the campaign. During the campaign period there were a total of 9, 461 site visits, with 7,082 unique site visitors and 40,566 page views. The most popular pages by page views, outside of the main landing page, were Information for HIV-positive Individuals, Online Risk Calculator, and Information on Finding a Testing Centre. These figures do not include visitors to the separate web page that hosted the digital video competition.

74.47% of visits to the Xiu Boy website were new visits, and the average user visited roughly 4 pages per visit. The bounce rate (percentage of visitors who enter the site and “bounce” - leave the site - rather than continue viewing other pages within the same site) was 53.45%.

99% of site visitors were from China. Of those visitors, 57% were from the targeted campaign cities, and 70% came from the target provinces. Traffic from outside of the target cities is also significant as MSM from the countryside commonly travel to the provincial capital to access healthcare and other services.

During the campaign period, trained peer educators additionally reached 1,799 MSM through either one-on-one outreach, small group activities, or large-scale community events. While outreach activities were not all specifically related to the Xiu Boy campaign, peer educators were trained to provide campaign messages and promote the website through all outreach encounters. It was not possible to estimate what percentage of individuals reached with one-on-one outreach were also reached via the campaign website.

Online Risk Calculator. 961 site visitors accessed the online risk calculator and 904 (94%) completed all items. Of those who completed the calculator, based on their answers to the survey items, 88.9% were at medium or high risk for HIV infection.

Table 2. Xiu Boy Campaign: Characteristics of website visitors who used the anonymous risk calculator (n=961)

	n (%)
Gender (n=961)	
Male	948 (98.6%)
Female	6 (0.6%)
Transgender	7 (0.7%)
Partners' gender (n=912)	
Male	703 (77.1%)
Female	48 (5.3%)
Both	161 (17.7%)
No. Sex Partners Last 6 Months (n=876)	
0	108 (12.3%)
1	235 (26.8%)
2-4	376 (42.9%)
5-10	102 (11.6%)
>10	55 (6.3%)
Sex with a Partner You Do Not Know (n=862)	
No	221 (25.6%)
Yes	641 (74.4%)
Engaged in Commercial Sex (n=848)	
No	666 (78.5%)
Yes	182 (21.5%)
Sex under the Influence of Drugs or Alcohol (n=831)	
No	712 (85.7%)
Yes	119 (14.3%)
Shared Injecting Equipment to Use Drugs (n=824)	
No	818 (99.3%)
Yes	6 (0.7%)
Tested for STIs (n=841)	
Yes (w/in last 6 months)	145 (17.2%)
Yes (not w/in last 6 months)	185 (22%)
Never Tested	511 (60.8%)
Tested for HIV (n=812)	
Yes (w/in last 6 months)	133 (16.4%)
Yes (not w/in last 6 months)	179 (22%)
Never Tested	500 (61.6%)
Sexual behaviour	
Oral Sex	
Performed Oral Sex on Partners	650 (67.6%)

Consistently Used Condoms when Performing Oral Sex	32 (4.9%)
Received Oral Sex from Partners	657 (68.4%)
Consistently Used Condoms when Receiving Oral Sex	26 (4%)
Anal Sex	
Penetrated Partner Anally	499 (51.9%)
Consistently Used Condoms when Penetrating Partner Anally	177 (35.5%)
Penetrated Anally by Partner	474 (49.3%)
Consistently Used Condoms when Being Penetrated Anally	168 (35.4%)
Vaginal Sex	
Penetrated Partner Vaginally	115 (12%)
Consistently Used Condoms when Penetrating Partner Vaginally	30 (26.1%)
Risk Profile (n=904)	
Minimal Risk	54 (6%)
Some Risk	47 (5.2%)
Medium Risk	317 (35.1%)
High Risk	486 (53.8%)

The majority of risk calculator users self-reported as males (98.6%, n=948) who only had sex with other men (77.1%, n=703). Among those website users who reported engaging in anal sex, 35.5% (n=177) reported consistent condom use as the penetrating partner and 35.4% (n=168) reported consistent condom use as the penetrated partner. A significant minority of users (17.7%, n=161) reported sex with male and female partners, and among those who reported penetrating their partner vaginally only 26.1% reported using condoms consistently.

The majority of users (54.5%, n=478) reported between 2-10 sexual partners within the last six months, and 74.4% (n=641) reported having sex with partners they did not know.

Despite high levels of reported sexual activity and relatively low levels of consistent condom use, 60.8% (n=511) of risk calculator users reported having never been screened for sexually transmitted infections, and 500 (61.6%) had never been tested for HIV (22% had been tested, but not within the last year).

Digital Video Competition

In total, 48 videos were uploaded for the digital video competition and 6,673 total votes were cast – voting was only permitted during the final month of the campaign to avoid privileging videos which were posted earlier. The winning video collected 1,745 votes while the first runner-up received 1,347 votes.

Due to a technical error, page views attributed to the digital video competition were not included in the total views or visitor counts for the Xiu Boy website, which might otherwise have contributed significantly to increasing those numbers as social media viewers could link directly from a video to the competition page. However, the video competition still drove increased traffic to other content on the main Xiu Boy site - during the competition the site recorded just over 6,000 visits (4,466 unique visitors) an increase of 128% over the three-month period preceding the competition.

HIV Counseling and Testing

During the Xiu Boy campaign period, HCT uptake by MSM for the three

affiliated clinical sites increased by 26% (from 896 to 1135) and the number of positive cases identified increased by 22% (from 57 to 70) when compared to the previous six-month period. As can be seen in Chart 1 (below), most of the increase in HCT uptake is attributable to the Guangxi campaign site (Site 3), which accounted for 82% of all testing conducted during the campaign period, a 33% increase over the previous six-month period as compared to the 3% increase in testing uptake in Yunnan (sites 1 and 2, combined).

Table 3. HIV testing uptake during the Xiu Boy campaign.

	FY11 Q1-Q2	FY11 Q3-Q4
	Tested/Tested +	Tested/Tested+
Site One	64/13	58/8
Site Two	136/6	148/9
Site Three	696/38	929/53
Total	896/57	1,135/70

□

Chart 1. HIV Testing Uptake During the Xiuboy Campaign



GZTZ

An O2O procedure has been developed by GZTZ since 2008 to support MSM in accepting HIV tests and relevant services. Its main components include:

- An online service module aimed at encouraging, reinforcing and validating safer sex behaviours and awareness of HIV testing by providing information on HIV prevalence and service promotion, offering a self-service risk evaluation tool, and conducting embedded vignette-based interventions;
- A link between online and offline services (testing and results delivery), to mitigate clients' unwillingness to receive an HIV test and to advocate for testing among sex partners of newly diagnosed HIV-positive clients by maintaining an online appointment and notification system, self-service results query, and anonymous partner notification;

- An offline services module to boost clients' confidence regarding service quality through provision of CBO-based pre- and post-test counseling, rapid testing, and supportive services for HIV-positive individuals.

During calendar year 2012, the GZTZ website received a total of 6,679,707 visits, made by 298,808 unique visitors, who made 48,899,134 page views. Not only did the site (which was more established than the Xiu Boy site) generate significantly more traffic, the bounce rate of 33.67% was noticeably lower, indicating that a higher percentage of those visiting the site actually intended to do so.

Over the course of 2012, GZTZ conducted 5,389 HIV screening tests for MSM, an increase of 130.5% since 2010. Of those MSM tested, 8.57% (n=462) were screened positive, which reflects a 33.76% increase in the 2010 case finding rate (5.1%, n=119). The Guangzhou CDC testing algorithm for members of high-risk populations is a single, rapid HIV screening test followed by Western Blot confirmatory testing which is processed off-site by the CDC. Of those individuals screened positive through the GZTZ service, 90% (n=416) agreed to receive an HIV confirmatory test, and 75% (n=312) were notified of a confirmed positive result. Of the 25% of clients screened positive who did not receive a confirmatory test result:

- 5.5% (n=23) were found through ID tracking to have already been confirmed positive and thus not re-tested,
- 2.4% (n=10) received a confirmatory test but were later determined to have been previously confirmed HIV-positive and, thus, not recounted as "new cases"
- .48% (n=2) were found to be false positives,
- 16.6% (n=69) did not receive their confirmatory test results within the reporting period, though they may have been informed of their test results at a later date.

CD4 testing is also provided by the CDC (and ART treatment centre) for all confirmed HIV-positive individuals, regardless of where they received their HIV test. Among those GZTZ clients who did receive their confirmatory test result, 12.5% were reported by the Chinese government not to have received a follow-up CD4 test.

Table 3. HIV testing and referral to care and treatment by GZTZ

	2012	2011	2010
Received HIV screening (3 affiliated sites)	5,389	3,247	2,338
Screened positive	462	275	119
Agreed to receive confirmatory tests	416	N/A	N/A
Non-duplicate clients who received confirmatory test	383	179	73
Confirmed to be	312	166	59

newly found HIV+			
HIV+ & received CD4 count tests	273	N/A	N/A

Additionally, while there are a number of different community-based organisations that partner with the Guangzhou CDC to offer HIV counselling and testing for MSM (see Figure 1, below), in calendar year 2012 GZTZ was responsible for roughly 83% of all clients screened for HIV within Guangzhou City who identified themselves as MSM.

□

6526 MSM Screened

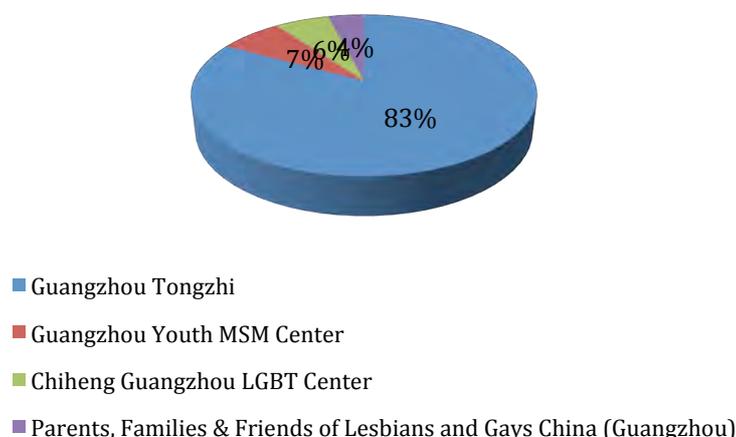


Figure 1. MSM screened for HIV in Guangzhou City, 2012

Discussion

Findings and results from both social media approaches support the hypothesis that web-based platforms can be an effective channel for the promotion of HTC services for MSM in China. Internet-based approaches in China have typically recreated traditional, venue-based outreach practices – the development and distribution of promotional materials, peer education etc. – and recreated these approaches while treating websites and chat rooms as a kind of “virtual venue.” While this approach has its advantages in that it is possible to apply existing tools and manpower with limited need for adaptation or training, the Internet can be a more efficient tool when interventions make use of the unique advantages of this medium. Both approaches described in this paper took different approaches which limit the need for a trained cadre of semi-professional peer staff. GZTZ sought to automate intervention services in order to minimise or completely remove the need for direct human involvement – for instance, a telephone hotline was originally established to help online staff interact with clients; however, calls to the hotline decreased dramatically once dedicated software was put into place allowing users to make appointments and receive transportation directions and service reminders.

In contrast, the Xiu Boy campaign sought to supplement the provision of

information about HIV transmission and prevention delivered by trained and employed peer educators with positive normative statements about the desirability of knowing one's HIV status, which were disseminated by regular service clients and propagated virally through their online social networks. The Xiu Boy microsite additionally allowed potential (but hesitant) clients to view photographs and digitally-recorded introductions of clinic staff, facilities and procedures as well as client testimonials about participating HCT service centres without the need to actually visit a clinic, thus reducing what are sometimes termed the "entry costs" for counselling and testing – fear, discomfort, embarrassment – without the need for direct human intervention. Critically, information collected through the Xiu Boy risk assessment tool indicates that testing information delivered via the website reached a population of men who have never (or not recently) received an HIV test despite engaging in unprotected anal sex either as the penetrating or penetrative partner.

These interventions also demonstrate that evaluation is essential to the success of any public health intervention, and freely available tools like Google Analytics can greatly simplify the process of collecting and analysing monitoring data for web-based intervention activities. However, the greatest obstacle to effective monitoring and evaluation isn't collecting extensive user engagement data such as the number of "Likes" or the website bounce rates; the key obstacle is a failure to determine what return on investment the online strategy is intended to generate in the first place. It may be tempting to envision web-based metrics as an end unto themselves, but this approach fails to acknowledge the reach and impact of broader communications activities (Gordon, 2013). Rather than thinking in terms of internet metrics versus traditional public health indicators, monitoring and evaluation systems should focus holistically on the overall goal (in this case, HCT uptake) and then identify the best indicators to determine whether intervention strategies are working.

A key barrier to integrating Internet metrics more holistically into monitoring and evaluation frameworks, however, is the difficulty in tracking unique contacts across virtual and physical engagements, and the primacy in many monitoring and evaluation frameworks (for instance, the UNGASS and PEPFAR indicators) for real-life contact. More research is needed to determine how "virtual" contacts and measures of engagement can best be integrated into these frameworks so as to highlight the increasing relevance and importance of digital interactions.

Coordination between community-based organisations and the municipal government was critical to the success of the GZTZ and Xiu Boy interventions. Across the Asia-Pacific region it is estimated that as many as half of all members of key affected populations are unaware of their HIV status (UNAIDS, 2012), and while community-based HTC is recommended by the WHO (WHO, 2012) and has been demonstrated to be highly acceptable to testing clients (Suthar, et al., 2013), there are numerous policy barriers to adopting this strategy across the region, including in China. The interventions reviewed here contributed to increased service uptake without significant loss to follow-up, false positivity or reported adverse events (breaches of confidentiality, etc.) and

thus further demonstrate the potential key role CBOs can play as partners to the China CDC in increasing the number of MSM who know their status and access care and treatment in line with the national strategy.

Two key links in the cascade of HIV prevention to care and treatment which did exhibit worrying loss to follow-up were in the gaps between clients screening positive for HIV infection, receiving a confirmed positive result, and receiving a CD4 test for assessing ART readiness. The current Chinese testing algorithm calls for expensive and technically demanding Western Blot confirmatory testing which typically delays provision of results by one to two weeks, but in some cases more than a month, delaying access to pre-ART staging and treatment initiation and potentially contributing to loss to follow-up. Delays in administering CD4 tests may be an additional barrier to treatment initiation. It is necessary to advocate for the adoption of newer confirmation strategies which would reduce or eliminate wait times for test results (Styer, Sullivan, & Parker, 2011) such as scaling up the use of point-of-care CD4 tests in selected community-based testing centre settings (Jani, et al., 2011; Mtapuri-Zinyowera, et al., 2010), which would help to move clients more efficiently through the HIV care continuum.

Finally, the interventions reviewed here also demonstrate that many people underestimate the human resources and skills needed to develop and sustain a technology-driven intervention. It is worth noting that, of the two intervention sites participating in the Xiu Boy campaign, the Guangxi site far outperformed the Yunnan site terms of testing uptake. This disparity is unlikely the result of differences in service delivery model (both sites offered community-based rapid testing, while only Yunnan additionally offered clinic-based testing) or HIV risk (reported HIV prevalence is in fact significantly higher in Yunnan than Guangxi). However, the implementing team in Guangxi was younger and more social media savvy, as evidenced by team members having their own, pre-existing social media accounts and having significantly more success attracting social media followers and soliciting submissions for the digital video competition. Guangxi additionally accounted for 45.12% of all visits to the Xiu Boy website during the campaign period, as compared to 23.8% from Yunnan.

As the experience of these two programs shows, launching and supporting an Internet-based intervention requires a Web- and social media-savvy communications team who are comfortable working within the platforms the intervention will target, project managers who understand the possibilities and limitations of these technologies, community experts who are in tune with community needs and preferences, administrators who can maintain strong control over the workflow, and a well-trained team of service providers. The unique skill sets needed to design, manage and monitor Web-based and social media activities may not always be available within one organisations but will require several who bring distinct expertise to a well-planned consortium.

Limitations

There are a number of limitations which should be taken into account when interpreting the above results: most notably that, as neither intervention used a rigorous evaluation design, the influence of confounding variables cannot be discounted when considering the demonstrated increase in HIV testing rates.

Potential confounders may include other HIV prevention and test promotion activities (peer education, media coverage etc.) taking place concurrent with the GZTZ and Xiu Boy activities, or the influence of major seasonal events in the Chinese calendar, such as Spring Festival.

Data reported on the risk and health-seeking behaviours of visitors to the Xiu Boy website must also take into account that, since these data come from a convenience sample, they are not representative either of the wider population of MSM or of all MSM who visited the website. It is also possible that website visitors who declined to complete the risk assessment tool systematically differed from those who completed the assessment in key variables. It should also be noted that this data represents self-reported behavioural data; MSM who completed the assessment may have been motivated by reason of social desirability bias to report safer levels of behaviour than they actually practice. However, participant self-report is a widely used methodology in behavioural research, and studies have suggested that instruments such as Internet-based surveys which do not feature face-to-face interaction may reduce the influence of social desirability bias (Kreuter, Presser, & Tourangeau, 2008). Further, self-reported levels of sexual risk behaviour were broadly similar to behaviours reported in Zhang (2011) and Zu (2013) with the exception that a much higher proportion of Xiu Boy visitors reported having engaged in commercial sex (21.5% versus 5.8% and 5.7%, respectively).

Conclusion

Despite content restrictions and the limited reach of some key global services (i.e. Facebook, YouTube and Twitter) inside of China, information and communication technology platforms, including microsites, online games, digital videos and social media represent an important channel for reaching Chinese MSM and can contribute to increased HTC service uptake and case finding. Indeed, ICT strategies which generate service demand and facilitate service delivery are likely to grow in importance as target audiences increasingly shift to online interactions and funding for resource intensive, venue-based strategies becomes limited. Successful online intervention models hold the promise not only of increased coverage, but also of relatively simple scale-up. It is, however, important not to underestimate the level of resources and technical skill required to implement and sustain these interventions and the importance of partnership and collaboration with governments and service providers if promotion is to translate into service uptake. Finally, it is critical that these interventions be planned with robust monitoring and evaluation measures in place, and that existing monitoring and evaluation systems evolve in order to capture the added value of online intervention activities along with more traditional models such as venue-based peer outreach, in order to further develop an evidence base in support of ICT intervention models.

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Chapter 17

Resistance to the Swedish Model through LGBTQ and sex work community collaboration and online intervention

Nicklas Dennermalm

In his chapter, Nicklas Dennermalm introduces how the Swedish Federation for Lesbian, Gay, Bisexual, Transgender and Queer Rights (RFSL Stockholm) designed the [Röda Paraplyet](#) webpage in collaboration with male sex workers and Rose Alliance, a leading sex worker organisation in Sweden. His chapter stresses the need for targeted community-based sexual health services in Sweden because sex workers are often viewed as 'victims in denial' by public health authorities. Dennermalm critiques the ways Swedish sexual health interventions traditionally focus on women and utilise face-to-face interventions and exit strategies over interventions targeting male and/or transgender sex workers that utilise harm reduction approaches or low threshold on-line interventions. His work with *Röda Paraplyet* illustrates how a broad coalition between organised and non-organised sex workers, LGBTQ organisations, academics and the health care system can create a sustainable platform of multi-disciplinary knowledge to improve the sexual health and legal rights of sex workers in Sweden and globally.

Recognising the lived experiences of Swedish male and transgender sex workers

This article describes the process of the Stockholm branch of *The Swedish Federation For Lesbian, Gay, Bisexual, Transgender and Queer Rights* (RFSL Stockholm) work to design an HIV prevention intervention based on the voices of male and transgender sex workers, two groups generally absent in the Swedish discourse around sex work. Sex work is not even a word used in the Swedish discourse, which favours 'prostitution' or 'sex trade'. In Swedish the definition of 'prostitution', by default, signifies a degrading act of violence that does not only affect the individual woman (e.g. a 'prostitute'), but all women. The negative aspect of the terms 'prostitution' or 'sex trade' in Swedish discourse are the result of the structural violence of men, rather than an effect of stigma from society at large.

In the *Order of The Discourse* (1993), Foucault illustrates three main procedures of exclusion: the forbidden speech; the division of madness; and the will to truth (p. 7ff). Within this emerges the concept of the prohibition, regulating, among other things, who is allowed to speak and about what. The tradition of these procedures has a long history in Sweden, not only in the case of sex work but other marginalised social phenomena including homosexuality,

ethnic minorities, transgender communities, people with mental illness and others. The story of 'prostitution' is being filtered through the institutions of the police, social services and government, and reproduced over and over again, creating 'knowledge' by an 'author', not in the sense of an author of fiction, but an author and co-creator of the discourse. The knowledge produced is that of the Swedish Welfare State and of the 'supreme' morals of Sweden. Critically, it is not reflective of the lived experiences of Swedish male and transgender sex workers.

The official Swedish opinion is that sex work is harmful to both the individual and society; therefore efforts should focus on exit, rather than health improvement or harm reduction through information and other interventions. The general Swedish approach is a zero tolerance one firmly against sex work with the main focus on exit, not harm reduction, the latter of which is an approach common in other countries (SOU 2010:49, p 95). Sweden's zero tolerance approach stands in stark conflict with the more empowering harm reduction approach. The Swedish government's high priority of providing support for exiting might be the explanation for the lack of social interventions aiming to increase sexual and emotional health among sex workers in a context outside the prostitution units and similar interventions. The dichotomy between zero tolerance and harm reduction has been challenged by The National Board of Welfare and Health (2010, p.3).

RFSL Stockholm believes everyone has the right to define who they are and what they do. There is no one term available to describe people who work in the Swedish sex industry. Most terms in use connote different paradigms or beliefs. 'prostitute' and 'exploited in prostitution' are examples of terms used in Sweden reflective of an oppressive paradigm. RFSL prefers the terms: 'sex worker' or 'person selling sex'; because these are reflective of an empowerment paradigm. RFSL has a rights based perspective deeply rooted in the empowerment paradigm on our successful work with the lesbian, gay, bisexual, transgender and queer (LGBTQ) community as well as HIV prevention targeting the MSM and the transgender communities. Because the intervention discussed in this paper is an HIV prevention project, we have chosen to use the term 'sex worker' as it is used by UNAIDS.



Figure 1: The safer sex website <http://rodapaplyet.org>

This chapter describes the work conducted by RFSL Stockholm in collaboration with sex workers and Rose Alliance—an organisation operated by and for current and former sex and erotic workers in Sweden—to design the safer sex website <http://rodaparaplyet.org>³. Figure 1 shows the poster marketing the website. The process was a semi-structured process with no ambitions to present the work in an academic setting. The overall design of the intervention reflects and draws on RFSL Stockholm's experience working productively and successfully with MSM and transgender communities through online interventions via The Sexperts Program⁴ (Dennermalm & Herder, 2009).

RFSL Stockholm

RFSL was founded in 1950 and the Stockholm branch was established in 1972. RFSL Stockholm is one of 33 local branches and represents approximately 1900 out of RFSL's 6700 members. RFSL aims to provide social platforms for its members, address political issues and act as a community-based service provider on health and HIV. RFSL Stockholm was officially an organisation for lesbian, gay and bisexuals. Importantly the transgender community has been a part of the organisation for a long time, but was not recognised as an equal part until 2002. People with a queer identity or queer gender expression were officially added equally recognised members in 2014.

RFSL Stockholm conducts an annual two-day method lab in order to be at the forefront of Swedish HIV prevention efforts with reports written after the lab to document the lectures, talks and workshops. For the 2009 method lab we invited male sex workers, colleagues, clinicians and researchers from Malmö University and Gothenburg University together to set the direction of RFSL Stockholm's future health interventions (Jonsson & Söderström, 2009). The sex workers did not represent any sex workers organisation but were free agents. To our knowledge, this was the first time sex workers were invited to co-design an intervention in Sweden, which was acknowledged by Niklas Eriksson, one of the researchers invited. The method lab process defined eight key areas from which RFSL and/or other actors could draw inspiration for future work. The ideas varied from research ideas, political statements and health-based interventions.

These eight areas were:

1. Empowerment;
2. Create platforms;
3. Knowledge and openness;
4. Complete a review on the legal situation, including the criminalisation of procuring;
5. Highlight nuanced and experience-based images of men who sell sex;
6. RFSL's counsellors need tools to meet minors who sell sex;
7. Identify how to work with the target group from an 'arena' perspective and initiate dialogue with the target group with focus on need assessments; and

³ An English version of the website can be accessed here: <http://rodaparaplyet.org/en>.

⁴ See <http://the-sexperts.org>

8. Identify strategies on safety and safer sex.

Drawing on the experience of RFSL's HIV prevention work and the method lab, RFSL Stockholm formulated key principles on communication and collaboration with targeted stakeholders:

- a. HIV prevention is not only a question of promoting correct condom usage; it is a collection of tools that can be used as part of a comprehensive holistic health approach.
- b. The intervention should be conducted within the empowerment paradigm, similar to the rest of RFSL Stockholm's HIV prevention work.
- c. Sex workers are the experts on what it means to be a sex worker, and their voices and multi-faceted experiences are key to making the intervention relevant and accepted by their community.
- d. Sex workers should be included in all key steps of the intervention design.
- e. Key stakeholders must be involved in the work, including local and national sex workers' organisations, health providers, researchers and other relevant NGO's. Sex workers and other experts should review all text before being published.

The need to confront the Swedish Model

The Swedish Model

Sweden was the first country in the world to introduce legislation that criminalised the purchase of sexual services rather than selling them. It has become known as The Swedish Model, but is sometimes also referred to as the "Nordic Model" since similar legislations were introduced in Norway and Iceland in 2009. The Swedish Model is being internationally promoted by the Swedish Government due to its self-claimed success of decreasing the amount of sex workers in the three largest cities by an average of 50 % between 1999 and 2008, based on the official evaluation report *Criminalisation of Purchase of Sexual Service – An Evaluation 1999-2008* (SOU 2010:49). Both the legislation and its evaluation has been the subject of heavy critique from the several Swedish GOs, NGOs, academia as well as international actors. The legislation stands in stark contrast to health recommendations from UNAIDS and Network of Sex Work Projects (NSWP), among others.

Most Swedish research and reports on sex work have been written within the context of the oppression paradigm. Most of its data were derived from sex workers from a street work setting (Hulusjö, 2013, p.33) (SOU 1995:15, p. 11). The majority of Swedish research on sex work has been focusing on street based women. Women working in other settings, MSM and TG sex workers have been largely neglected, which has created a void in the research. The void further fuels the image of sex work as being an experience, which puts limitation on both the individuals and the Swedish health care system. A health care system designed for perceived needs of street based female sex workers within an oppression paradigm will be single minded and not appeal to sex workers with different needs.

Sex workers as a risk group within Swedish HIV prevention efforts

Within the context of the Swedish HIV prevention guidelines, sex workers of all genders are seen as one of the key target groups. There are no data on HIV prevalence among male sex workers in Sweden, but data from North America, South Africa, El Salvador and other settings state that HIV prevalence among male sex workers is as high or higher than MSM not engaged in sex work, but there are other data from Australia and China suggesting that HIV prevalence among male sex workers being lower than MSM not engaged in sex work (Baral et al, 2014, p. 75ff). Nor are there data on HIV prevalence within the transgender community, engaged or not engaged in sex work, but data from The Centre of Disease control from The United States of America tells us that that trans women in the USA are subject to a high prevalence of HIV, and the group trans men is understudied within the field of HIV (CDC, 2014).

In *Consolidated Guidelines On HIV Prevention, Diagnosis, Treatment And Care For Key Populations* from WHO (2014) it is stated that key populations with overlapping vulnerabilities (e.g. MSM who sell sex or inject drugs) are likely to have a higher HIV prevalence than key populations with no overlapping vulnerabilities. Sub-groups within key populations are also likely to have a higher prevalence of HIV, for instance MSM with a migrant background. (WHO, 2014, p.6.) In light of this, being 'the other' becomes even more serious within the context of HIV prevention and other health contexts. Special focus should be placed on two or more overlapping vulnerabilities and/or belonging to sub-groups of the MSM and transgender communities.

Stockholm-based Spiralprojektet were the only programme in 2012 that had HIV prevention for sex workers as an objective. It is a clinic offering HIV/STI testing for all genders as well as Pap smear, routine check-ups and counselling on abortion and birth control. To our knowledge, there were no sexual health webpages targeting the needs of sex workers of any gender in Sweden before the Röda Paraplyet webpage. The websites on sex work were either political or had the purpose of informing sex workers about the existence of services within the prostitution units of the social service in Sweden.

Collaborating with male sex workers to design an online HIV intervention

The importance of working online, where sex workers recruit potential clients, and providing them with HIV prevention information is a reoccurring theme in the literature on sex work (Björndal, 2010, p. 53) (Eriksson & Knutagård 2005, p 77) (Johansson & Turesson, 2006, p. 39). MSM in general are in favour of online interventions in the context of HIV prevention (Tikkanen, 2010, p. 85). Other needs described in the literature are counselling, strategies for exit, safe spaces, tools to handle clients, legal assistance etc.

Rose Alliance is the only Swedish sex workers' NGO with a clear empowerment perspective, and therefore RFSL approached them to assist in designing a bespoke Swedish HIV prevention web-based intervention as critical stakeholders. Besides establishing a collaboration, RFSL Stockholm

wanted to make sure that the two organisations did not compete regarding funding or initiated overlapping programmes.

After dialogue with Rose Alliance, RFSL Stockholm submitted an application to the Stockholm County, which is in charge of the health care system as well as distribution of national HIV funding for a three-year project which included research, design, launch and marketing of a safer sex website, a series of empowering short films inspired by Dr Joyce Hunter's *Working It Out* program, integration with The Sexperts Program for low-threshold safer sex information, an expert network with broad competence and representation, an easy to use safer sex conversation methodology that could be adapted to fit a clinical setting, as well as a peer education setting, and safer sex kits for distribution free of charge.

RFSL did not incorporate all eight aspects from the Method Lab into one project but it did an overview on what was 1) the most effective interventions within realistic budget, 2) possible within the Swedish discourse of 'prostitution', since our intervention conflicted with it, 3) which interventions can be sustained in the case funding was cut short and 4) what can be done *with* sex workers rather than *by* sex workers.

RFSL Stockholm were given 38, 000 USD, less than what was asked for, so we focused on three areas: A) setting up an expert network including sex workers, using a model developed by LAFA (Knöfel Magnusson, 2009, p. 11) and inspired by the mixture of expertise from the 2009 method lab. B) Setting up a health website aimed for male and transgender sex workers later named Röda Paraplyet, which is Swedish for The Red Umbrella, the symbol of sex workers rights. C) Explore how we could use mobile phone technology and commercial mobile phone apps as platforms for health interventions.

This paper describes mainly area B and C but will briefly mention the concept of the expert network, area A. The expert network was a network active during the first 18 months of the intervention, the aim was two-fold, first; to collectively raise the awareness and competence about sex work among the participants of the network. Second, to provide feedback on the design of the webpage. We invited Rose Alliance to represent sex workers, staff from key HIV/STI clinics, researchers, other relevant NGO's and staff from The Stockholm Prostitution Unit.

RFSL began with literature studies and researching existing resources from sex worker initiatives from Sweden and the English speaking world, as part of the formative process resulting in an interview guide (hips.org, hook-online.com, rosealliance.org, Akers & Evans 2010). The expert network provided input on several stages, both in the formative process as well as feedback during the production of the webpage.

The interview guide included personal information such as age, sexual identity, if the person was currently selling sex, et cetera. It also included reasons for selling sex, positive and negative aspects of selling sex, need of knowledge and support, safer sex strategies, strategies concerning personal safety, personal relations in the light of selling sex and strategies for setting boundaries. The aim of the interviews was to gain pragmatic strategies to make a useful and realistic website rather than to generate new knowledge about the target group as a whole.

The strategy to recruit participants included the network of Rose Alliance, the project manager's personal network as well as an editorial article on qx.se, the main Swedish LGBTQ on-line community. From the thirteen people who RFSL Stockholm got into contact with (twelve MSM and one transgender woman) RFSL Stockholm was able to initiate seven interviews (all MSM) creating a convenience sample. The participants were informed about the purpose of the interviews, they were given the option of not answering specific questions and also to withdraw their participation. RFSL Stockholm viewed the people being interviewed as consultants, rather than participants of research. Therefore we offered a 500 SEK (less than 80 USD) as compensation for their time.

The interviews were conducted in a multitude of ways; in-real life interviews, telephone and via Skype depending on the wishes of the informant. For some of the Skype interviews RFSL Stockholm used the chat interface and for other we used the videophone option, with or without their face showing. The interviewer's face was always visible to the informant. RFSL Stockholm decided not to record the interviews but to do a word by word typing simultaneously as the interviews were conducted to minimise the risk of the informants becoming uncomfortable. RFSL's impression is that the organisation gained a high degree of trust with the informants, if this was the result of above-mentioned strategy or something else is unclear. Additional interviews will be conducted during 2014 to include a transgender perspective since we were not able to conduct any interviews with transgender sex workers. These interviews will be based on an updated interview guide and be recorded and transcribed according to academic standards for further research in the field.

The interviews did not provide practical health information on sex as a strategy of self-harm, apart from one informant who stated that he had sold sex as a way of self-harm after being raped as a child. The text on how to balance the private sex with the commercial sex was withdrawn since Rose Alliance was not satisfied with the quality of the text. A new text on that topic as well as more in-depth texts on some key areas will be published later 2014.

As the legal owner of the website RFSL Stockholm were the one choosing which feedback to heed and which to discard. RFSL Stockholm did not look for consensus in the larger expert group but our main principle was that the reviewers from Rose Alliance and medical staff from The Gay Clinic would find consensus. No texts that they did not agree on made it into the published site.

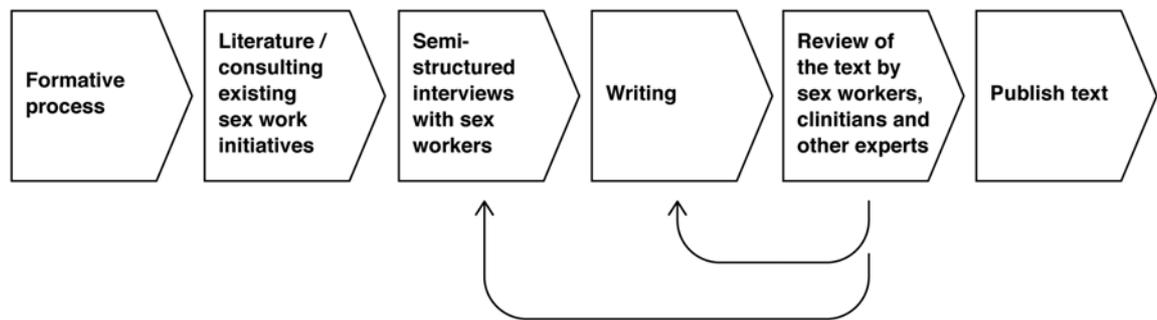


Figure 2: RFSL's Formative Process

The content

The content can be divided into eight categories; these categories do not match the layout of the webpage. Most articles begin with putting the theme into a sex work context to make the information more relevant to the reader and to avoid a sense of us merely providing generic HIV prevention to them.

Condom and lubricant

The page provides basic information on condoms and lubricant with focus on condom size to minimise risk for breakage. There are also texts on condom negotiation and how to make sure that the condom is on throughout the sexual intercourse.

Sexual practices

In this section we provide information on sexual technics from the aspect of control, safety and ergonomy. There are texts on oral, vaginal and anal sex, plus BDS. Vaginal sex is written from both cis and trans perspective.

Facts on HIV/STI and legislation

The fact sheets on HIV and STI are up to date basic facts on routes of transmission and treatment. The texts on legislation are written from a pragmatic point of view, they are not political statements but more on what to consider as a sex worker.

Where and how to get tested

Getting tested on a regular basis is important for all MSM/TG; we included general information on how HIV/STI tests are conducted, addresses and what to keep in mind beforehand. We altered the recommendation for regularity from every six or twelve months to every three months. Partner tracing is standard procedure if one is testing positive for HIV or an STI and in the context of the Swedish Model this is problematic since the people the sex worker might name are, from a legal point of view, criminals. Our recommendation is to name them as casual sex partners rather than sex buyers, and to contact them themselves, rather than having the clinic contact them. There is also a free of charge test reminder service via SMS, more about

this below.

Setting boundaries

Setting one's own boundaries and being empowered to uphold these were key findings during the interviews, so this is an important message that was weaved into several articles on the page.

Personal safety

This section is based on recommendations from Rose Alliance used by kind permission rather than the interviews since they did not provide enough recommendations. We also included a piece on where to seek help if you are subjected to sexual violence.

Alcohol and drugs

We have included basic harm reduction information on alcohol and the most commonly used drugs in Sweden with a referral to the LGBT addiction centre.

Support

The project does not provide support but the website do have a referral service via e-mail.

Using mobile phone technology and commercial Apps

Mobile phones are widely used in Sweden, and a useful tool for sex workers in a variety of ways. Dating apps like Grindr, Scruff and Growlr are being used for pleasure and finding buyers or sellers of sexual services. Within the limited budget we received, we identified three activities: 1) Design a mobile phone adaption of the webpage for increased accessibility, 2) Creating a short message HIV testing reminder service and 3) Looking into the possibility of starting an on-line hotline on the main commercial app. Each is described below

Mobile phone version of rodaparaplyet.org

When looking into Google Analytics connected to our web pages, we noticed a high level of users using their smart phone to look for information about safer sex, a majority of them using Apple iPhones rather than other devices. In order to make all of our safer sex web pages more accessible and user friendly, we invested in an adaptation of the web pages to fit smart phones and other mobile devices better (Figure 3).

Creating a short message HIV testing reminder service for sex workers

RFSL Stockholm provides a short message HIV testing reminder service targeting MSM and TG with reminders every six or twelve month according to our recommendations for the general MSM/TG population. This intervention was inspired by an intervention described and evaluated by Bourne et al (2011). In the original design, the clinic connected the medical record of their consenting HIV negative patients to a short message system sending out text messages reminding them to get tested for HIV in order to facilitate re-testing.

This resulted in this group being 4.4 times more likely to get re-tested (95% CI 3.5 to 5.5) compared to the control group of the study. After consultation with The Gay Men's Clinic on the medical record system of the hospital, we decided not to connect the short message reminder service to any medical records but to use a default mobile phone subscription sending out the reminding texts. The reason for the decision was the lack of clear regulations at the time regarding confidentiality in the context of digital security and mobile phone technology within the Swedish health services. Also, we identified an advantage in opening up for collaboration with several clinics rather than one. This created a minor change in the method.



Figure 3: Rodaparaplyet.org phone APP

When launching a version aimed for sex workers marketed via rodaparaplyet.org and leaflets, we created a three-month interval option according to recommendations from the Expert Network. We also added a feature promoting the option to order free condoms and lube. For discretion, the text reminders come from our general MSM/TG sexual health site <http://www.sexperterna.org> rather than the sex worker specific <http://www.rodaparaplyet.org>. One negative aspect of this is that we are not able to identify how many of the users of the intervention are sex workers or how many condom kits are being sent out, since there may be sex workers subscribing to the six or twelve month interval as well as non-sex workers subscribing to the three month interval.

Communicating with sex workers on commercial apps

There is no up-to-date Swedish data on the usage of mobile technology for sex workers but through our contacts with male sex workers we know that it is widely used by sex workers and sex buyers to initiate contact. RFSL Stockholm has been working with peer education chats on commercial LGBTQ on-line communities since 2005 using multi-lingual profiles on-line where MSM

and transgender can ask questions, get referrals and order free condoms and lubricant (Dennermalm & Herder, 2009). One of the key aspects of the intervention was that it was set within a context of an existing and, among MSM/transgender, popular platform, thereby being as close to the sexual encounter possible digitally as well as being part of the culture of the community. During 2012 we looked into complementing the Röda Paraplyet webpage and adjust the method to fit into the context of commercial MSM dating apps like Grindr. The adjusted method would be the base of an application for new funding for sex workers within the framework of our intervention.

When one log on to the app, the free app uses location technology to display the closest 100 profiles/users in a grid. Each profile can contain one photo and various kinds of data; distance, age, body type, “tribe” and free text. It can also contain direct links into a variety of social media like Facebook and Instagram. By paying a fee, one can subscribe to Grindr Xtra for additional functions and the ability to watch the nearest 300 profiles. When logged on, there is a green dot visible on the users profile. This green dot will disappear after not being active for 15 minutes the profile remains in the grid. After being un-active for another 45 minutes, the profiles disappear as you become off-line. When off-line, one can only be texted by profiles who previously marked your as a “Favourite” or already texted you. There is no search functionality in the app in order to display non-active users.

The design provided new challenges for us:

- First, one smartphone based at our central office in Stockholm would provide the service to users in downtown residents or workers while multiple phones strategically located over the region would require a higher level of logistic work and less cost effectiveness.
- Second, the lack of search functionality would require us to have constant on-going chats with the target group or manually stay active to remain visible in the grid. And last, since we would not been able to digitally “visit” the profiles, we had to re-think our main marketing strategy.
- Purchasing advertisement space on the apps would be a secondary strategy for two reasons. First, the online hotline would not be in the frame of the app they were using but on our external webpage e-mail questionnaire which does not operate in real time. Our fear was that this might create impatience within the target groups since they had to swap between the app and the phones browser. Second, people purchasing the Grindr Xtra feature also pay not see advertisement, which means that they would not be able to identify and use the intervention.

Ideally, this problem could be solved by a special status of the profile showing endorsement and collaboration with the owners according to our previous work and emphasized by Mowlabocus et al (2014). This special status could also provide a key to the issue of the users only seeing the 100 or 300 closest profiles that had been on-line the past hour, if Grindr could make our profile by

default the nearest profile. This would require a deeper collaboration with Grindr benefiting HIV prevention globally. Unfortunately, Grindr were not interested in a collaboration and we were not given permission to pilot an intervention. This setback led to the decision to start buying traditional banners in 2014 to market the Röda Paraplyet webpage.

Conclusion and lessons learned

The Röda Paraplyet webpage was developed on national HIV funding, yet the website turned out to be controversial. The funders did not express concerns with the design or content. Several actors within the field of HIV/STI, as well as the sex workers who participated in the interviews, expressed positive feedback to the page. We did, however, receive unofficial criticism, most of which reached us through third parties. The criticism came from a coalition of social workers, health care professionals and representatives from feminist NGOs. The webpage was accused of encouraging people to sell sex, to 'normalising' sex work, and of not representing the experience and needs of the average 'prostitute'. To boot our illustrations were said to have nothing to do with what 'prostitutes' actually look like. The webpage did not correlate with the Swedish discourse of 'prostitution': exiting was not the paramount objective of the program. Instead of recognising that the experience of sex work is multi-faceted and therefore needs multi-faceted health interventions, the reactions were hostile.

The concept of a broad coalition has been part of RFSL Stockholm's work for decades in the fight against HIV and AIDS where we have engaged the target groups, commercial actors, the academia, key clinics and other NGO's in our work and participated in other's efforts and as a collective stated: We stand united. As we have described in this paper, this effort has continued within the Röda Paraplyet project and even though the expert network does not exist anymore, the broad coalition of sex workers, clinics, NGO's, the academia and other key actors still does as we are about wrap up the project's third and final year in which we are trying out a pilot training on sex worker's health for Venhälsan, the Gay Men's Clinic together with Rose Alliance as well as launching a safety guide written by a former male sex worker.

The authors of the policy document *Implementing Comprehensive HIV/STI Programmes with Sex Workers* compare two different programme approaches from a community empowerment perspective, interventions "done for sex workers" and "done with/led by sex workers". Our programme qualifies into the second category, but not the highest standard of it since RFSL is a LGBTQ organisation; it is not an organisation run for and by sex workers, although some of our members are or have been sex workers. During the editing of this paper, *The Lancet* released an issue on sex work in which they highlighted that sex worker led health interventions as the most effective.

Inviting sex workers and sex worker's organisations into one small NGO run project is not enough. More is needed to ensure that the voices of sex workers are heard. First, sex workers organisations must be funded in order to create more professional organisations, which is crucial for a sustainable dialogue. Second, sex workers must be invited to participate, respected and listen to

when key political decisions are being made, when official governmental reports are written and within the overall discussion on sex worker's health.

Health is always politics, and this seems truer than ever in the context of sex work in Sweden. The Swedish Model and the Swedish discourse of 'prostitution' stand in stark conflict with international guidelines, recommendations and evidence-based interventions. Röda Paraplyet is forced to exist in the intersection of the two paradigms, a pragmatic health programme confronting and resisting the Swedish discourse of 'prostitution'. Sweden must realise that its 'supreme morals' preclude the health and well-being sex workers, of those they purport to protect.

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On-line resources

www.cdc.gov/hiv/risk/transgender
www.enannanhorisont.org
www.hips.org
www.hookonline.org
www.rfslstockholm.se
www.rosealliance.se

Chapter 18

Bambucha Media: Using social media to build social capital and health seeking behaviour among key populations

Collins M. Kahema
John Kashiha
David Kuria Mbote
Michael R. Mhando

Collins M. Kahema, John Kashiha, David Kuria Mbote and Michael R. Mhando's chapter describes how Tanzania Sisi Kwa Sisi Foundation (TSSF) used online HIV peer education and outreach methods, particularly with Facebook, to increase HIV prevention knowledge and encourage the use of health services, condoms and lubrication among MSM in Tanzania. Their chapter describes how TSSF launched educational campaigns using various social media that pre-existing members reported using for social and sexual networking, or "hooking up". As a community-based organisation with limited resources, TSSF's Bambucha Media (in Swahili 'bambucha' means cool) is innovative in the way it has designed a non-traditional avenue to provide HIV and AIDS information and referral. In a country where sexuality remains a major taboo subject, providing health messaging and forum discussions to educate about HIV, alert users when safe sex supplies are in stock or not, facilitates online discussions and sharing and provide direct peer counselling via private messages when needed and requested not only allows them to open up communication lines with gay men, other MSM, transgender persons and sex workers in the first place, but also enables TSSF to provide needed follow-up on specific and targeted HIV services.

Background

Vulnerability to HIV infection among the MSM, TG and SWs is associated with lack of access to correct and comprehensive HIV prevention information and services. These populations face discrimination in every facet of life, including in healthcare settings and in access to essential services (Beyrer, 2014). In Tanzania these populations are at greater risk of acquiring HIV than the general population. Recent surveillance has consistently shown HIV prevalence among MSM, TG and SWs to be well above general population estimates. The Tanzania AIDS Commission reports show of the MSM tested 41% were HIV positive, 43.2% had not used any condom with their last casual sexual partner and only 49.1% used condoms with their regular sexual partners. (TACAIDS, 2013, p. 20). To further compound the issue, HIV and sexual health information in Swahili, the official and widely spoken language of Tanzania, is limited, let alone information and education materials for targeted materials for the MSM, TG and the SWs. Criminalization, stigma, and discrimination also play a part in putting barriers to HIV and health service access. Information communication technologies (ICTs) offer distinct advantages to conventional methods in

delivering HIV prevention education and legal counsel. Tanzania Sisi Kwa Sisi Foundation (TSSF) uses social media to reach MSM, sex workers (SWs) and trans persons across Tanzania.

Introduction

The Tanzania Sisi Kwa Sisi Foundation is a registered youth voluntary, non-partisan, non-governmental organization (NGO) led by members of Tanzania's lesbian, gay, bisexual, transgender (LGBT) community, men who have sex with men, and sex workers. It operates as a national organization, with projects that span the geographic scope of the Tanzania Mainland. TSSF's goal is to promote the dignity, safety, human rights and fundamental freedom for all persons, without regard to gender, ideological, political and sexual orientations. The organization is guided by the mission to pioneer new standards of hope, equity and involvement of their beneficiary populations. The vision is to have a society free of discrimination, preventable diseases, and where all economic, social, civil and, political rights are enjoyed by everyone.

In order to realize this vision TSSF has the following objectives:

- Create awareness on issues of human rights for young LGBT and their networks
- Fight the spread of HIV/AIDS, malaria, tuberculosis, cancer and other chronic and deadly diseases through Information Education, and Communication (IEC).
- Promote, lobby and advocate improving the status and conditions of the young LGBT persons in Tanzania.
- To create, raise and promote community awareness on issues on human rights, good governance, stigma and discrimination and their causes and effects within the context of sexual orientation and gender diversity.

TSSF's experience is validated by growing body of knowledge that identify benefits social media brings on board for HIV prevention, treatment and care for the MSM.

"...the growing popularity, decreasing digital divide, and multi-functionality of social networking sites, such as Facebook, make this an ideal time to develop innovative ways to use online social networking sites to scale HIV prevention interventions among high-risk groups (Jaganath, 2012)."

One study found that "Facebook could provide a simple, easy to implement and adopt approach to prevent condom use decline for the short-term and that clinics providing sexual health services to youth might benefit from having a presence on Facebook (Bull, 2012)." Yet while "social networking for HIV prevention is an exciting area that combines HIV prevention/public health, engineering/technology (Young, 2012)" only about 12% of the population have access to the Internet with slightly under a million registered Facebook users by the end of 2012 (Internet World Stats, 2012). In recent years however,

Internet enabled mobile phones have been on a rapid increase in Africa, including in Tanzania. According to Ihub – a technology company in East Africa, 79.39% of those who had access to Internet in Tanzania, in 2012, did so through their mobile phones (Mutuku, 2012).

Recognizing the limits on face-to-face HIV and health outreach and awareness among MSM and transgender persons, TSSF undertook an Internet outreach program to reach those who may be unreachable due to stigma, discrimination, homophobia, and/or geography. Calling the program Bambucha Media, “Bambucha” in Swahili is similar to American English language slang for “cool”, TSSF launched educational campaigns using the various sites that pre-existing members reported using for social and sexual networking, or “hooking up”. As a community-based organization with limited resources, TSSF’s Bambucha Media includes health messaging and forum discussions to educate about HIV, alert users when lubrication stock replenished (or stocked out), facilitate online discussions and sharing (or to watch and learn passively), and provide direct peer counselling in private messages when needed and requested.

By providing networking opportunity for the MSM in Tanzania, TSSF has in the process created a non-traditional avenue to provide HIV/AIDS information and referral. In a country where sexuality remains a major taboo subject, TSSF uses social media tools, to communicate in general terms, about health services as opposed to writing directly about HIV services at the first instance. Yet once communication lines have been opened, follow-up on specific and targeted HIV services are then provided.

Road blocks to care

In the few places where LGBTI-friendly health services are available, criminalization and stigma and discrimination maintain low levels of service uptake. As the Tanzania Commission for AIDS in its 2013 strategy, titled Tanzania Third National Multi-sectoral Strategic Framework For HIV and AIDS (2013/14 – 2017/18) notes:

Stigma and discrimination against MSM remains high, posing a significant challenge to outreach and delivery of [LGBT] friendly health services. Given the criminalization of consensual adult homosexual intercourse, the multi-sectoral national response requires significant cooperation from all key stakeholders to ensure that MSM are reached with HIV and AIDS services. (TACAIDS, 2013)

The Tanzanian penal code criminalizes “canal knowledge against the order of nature.” Indeed the Sexual offenses special provisions of 1998 (Tanzania: Act No. 4 of 1998, 1998), reviewed the penal code and added stiffer penalties for attempt and commission of these offenses. The penalties for these offenses now range from 10 years to life imprisonment

The presence of criminalization, fuels social stigma, and crimes against LGBT persons in Tanzania by creating a hostile environment that is characterised by verbal and physical violence, torture and rape, assault, arbitrary arrest, and extortion (Human Rights Watch, 2013). This environment

discourages LGBT persons from self-identifying when they seek health services or even avoid seeking these services all together. By going underground, sexual and gender minorities are deprived of critical health and legal information and the Tanzanian health system is kept unaware of their specific health service needs. It is in this environment that TSSF have brought on innovative tools for outreach, such as those offered by ICT.

Bambucha Media

Social media offers a unique opportunity for HIV/AIDS organizations and other health institutions to disseminate health information and even legal counsel quickly, easily, and anonymously. Recognizing the advantages social media brings in reaching stigmatized individuals, TSSF's approach is to integrate with social media and dating services popular with LGBT people in Tanzania such as *Twitter, Whatsapp, Facebook, Instagram, Marafiki, Manjam, and adam4adam*. For those who may lack the means and access for social media and the Internet, TSSF sends bulk messages to mobile phones with health information.

Membership

TSSF is acutely aware how the need to hide for fear of violence and criminalization not only drives the MSM underground where they cannot access services, but it also isolates them from meeting their peers. This not only limits their ability to form social capital, but denies them opportunity to know where to access services or even whether services targeting their sexual practice are available. The Social media strategy is focused on addressing this need for providing information on the available services as well as providing linkages to these services.

The outreach is however challenged by the need to navigate a social and political environment that may perceive growing organizational membership negatively as “recruiting people into homosexuality” rather than enabling personal freedom and protection from S&D. An opposition MP in the Tanzanian Parliament even feels that the existing laws need to be made more stringent so that they can punish those who “*induce others to become gays or those who promote the behavior* (Muga, 2014)” Under the circumstances, TSSF has to craftily use the social media networking tools judiciously both to provide the much needed information, but also to avoid the much feared characterisation as an organization that “recruits” people into homosexuality.

Confidentiality

To accommodate for different confidentiality needs, TSSF also displays its mobile phone numbers and email addresses on the social networking websites so that the MSM can send messages through the short message services (SMS) or emails. Through this channel, people who do not wish to participate openly on social media platforms can still receive information and make inquiries. This mixed approach has allowed TSSF to reach many different members using the form of communication that works for them (Table 1; Figure 1; Figure 2).

Table 1. Social media tools and registered members reached

Social Media tool	Registered members	Means of Engagement and tracking participation
SMS	2000	SMS exchanges with a database of 2000 numbers
Facebook	500	Membership likes, comments and shares
Instagram	120	Likes and comments
Adam4Adam	80	Profile views and messages exchanged
Marafiki.com	50	Profile views and messages exchanged
Twitter	40	Re-tweets and favourites
Whatsapp	20	Message exchanges



Figure 1: Screenshot of the total number of TSSF online outreach page unique 'likes' between October and December 2013



Figure 2: Screenshot of total number of people who viewed group posts in the TSSF online outreach page from October 2013 to December 2013

Managing online content

TSSF has volunteer Information and Communications Officer who handles communications needs, including updating the various online and offline communications channels. TSSF's Director and other staff members are also tasked with capturing new information or events that require immediate response; and in doing so, initiate and sometimes participate in online discussions.

Topic Generation

Discussion topics are determined by monitoring important changes in the political, legal and social environment or gauging popular interests through paying close attention to our member's inquiries. Large-scale social events that concern the scope of TSSF's work (e.g., World AIDS Day, International Day Against Homophobia and Transphobia (IDAHOT), Transgender Day of Remembrance, Human Rights Day) might also prompt a discussion. Other times, it is a unique encounter with public officials, health officials and religious or cultural leaders that will encourage us to engage with our online and offline members. This way of engagement accomplishes many objectives by informing our members of current events and information, getting their feedback, and creating a place where they can talk freely about the topic and with each other. Recurring topics of conversation posted by our members include LGBT health, human rights, sexual health and reproductive rights, referral services, employment opportunities, security alerts, and social events.

Effectiveness & Sustainability

Social Media tools have proved to be very effective in disseminating information on health services in Tanzania as the Internet increasingly becomes accessible through mobile devices (Pfeiffer, 2014). Targeted social media websites such as *Marafiki*, *Manjam*, and *adam4adam* bring people with similar interests such as sexual orientation or gender identity. This makes it possible to provide outreach and referral information to MSM, TG & SWs. TSSF's experience has demonstrated that social media tools, serve to reach even the most isolated individuals, if they have access to the Internet because, people with similar interests tend to "flock" together (Jernigan, 2009). TSSF also engages in weekly analysis of their reach, tracking the performance of their outreach messages, to find out why some messages outperform others in terms of views, feedback or onward sharing.

In a highly dynamic social media environment, sustainability for TSSF's approach requires ability to constantly adjust health information to this changing environment. The growing fusion between Internet and mobile phone technology has significantly scaled back barriers associated with running social media advocacy strategies. To ensure sustainability of this social media project, TSSF allocates associated costs across all the other projects under implementation. The justification for this cost allocation is that all projects have a communications component, which is effected through online and offline media. TSSF has also been pursuing a "co-branding" strategy, in partnership with mainstream human rights and donor organizations keen on

communicating directly with the MSM, TG and SWs in Tanzania. The co-branding approach provides some income that goes into the Social media communications kitty, with the clear desire to making it sustainable in the long run.

Challenges

Given the precarious state of LGBT rights in Tanzania, TSSF is often faced with scepticism about its ability to exist while maintaining its mission and objectives. It becomes important to answer such questions, typically asked by potential members, institutional partners, or government, comprehensively to preserve confidence in its work.

The second challenge has to do with resources; particularly as it relates to attracting and retaining staff members. Managing the numerous social media interactions especially when members increasingly require prompt responses required a fulltime staff member. This has not been possible due to limited resources to hire persons with relevant communication skills.

Another challenge has to do with the language barrier. Since most people understand Swahili, it becomes necessary to translate most of the documents and discussion topics to Kiswahili. Yet it is not always possible to translate scientific and technical terms (e.g., anal warts, transgender) leading to some people who have yet to encounter these realities to be left out of the discussion forums or even at times to assume things not under discussion.

Another recent challenge has been the withdrawal of TSSF's registration due to the organization's presence in online and social media. On the 4th of April 2014, TSSF's registration was withdrawn by the government and the reason given was that their social media program was perceived as advocating for homosexuality (Mpekuzi, 2014). This follows a Facebook post that TSSF had posted online as follows:

“je wewe in mwanaume anayejihushisha katika mapenzi ya jinsia moja? TSSF inakualika katika semina fupi, itakayofanyika kesho Ijumaamaada zitakazoongelewa ni: Magonjwa ya ngono yanayowaathiri kuchu; Namna ya kujilinda na magonjwa hayo, kujiepusha na magonjwa hayo na tiba ...(Are you an MSM? TSSF would like to invite you for a short seminar tomorrow on Friday,the agenda will be about Sexually transmitted diseases, and how you can prevent or treat them...)”

The ensuing National debate however proved quite productive for even greater reach for TSSF's message. Because the news was broadcast over a prolonged period of time, through mainstream media, even those living deep into the country where the organization would never have had resources to provide outreach heard of TSSF's work. As a result, many people have been writing to TSSF seeking linkages to HIV and other health services.

Examples of ICT use by TSSF

The following snapshots of online discussions, in Swahili with English translations, demonstrate how communications with the MSM can be initiated in a conservative cultural context. The first presents information on an MSM friendly health clinic. At this clinic the MSM are advised to seek services regardless of their sexual practice because the clinicians are competent and friendly enough to engage with them. Just like the other cases below it, HIV/AIDS conversations are not discussed directly since such upfront engagement would be considered culturally unacceptable. However, such information is progressively introduced in the comments sections or at the point of health service uptake. It is noteworthy that even this rather laid back approach to outreach has been criticised as being too upfront for the Tanzanian audience (Muga, 2014).

Discussion 1: Facebook Outreach for Health Services

CLINIC CLINIC CLINIC CLINIC CLINIC

Hivi Unatambua kwamba Clinic yako ya Afya Bora Inafunguliwa hadi Juma Mosi na pia haiangalii wewe ni Bottom, Top, Versetile au Bisexual na pia unatambua kwamba unaweza hata kuja na mwenza wako kwaajili ya uchunguzi wa Kiafya zaidi??

Bado hujachelewa fanya hima uje uonane na wataalamu mahiri ambao wataweza kujibu maswali yako yote yanayohusiana na Ujinsi na Ujinsia wako au Afya ya Mkunduni. Pia unaweza kuwasiliana moja kwa moja wa wataalamu wetu kwa njia ya simu ya mkononi.

[Contact phone numbers removed]

Waweza ongea nao na kupanga mikakati ya kukutana.

Tafadhali tambua Afya Bora ndio Msingi Bora penda maisha jali Afya yako.

Translation

CLINIC CLINIC CLINIC CLINIC CLINIC

Do you realize that clinic for your health and wellbeing is always opened even on Saturdays and it does not discriminate whether you are Bottom, Top, Versetile or bisexual? And also do you realize that you can come even come with your partner for screening in order to remain Healthy??

But you are not yet late; make effort to come and meet vibrant professionals who will answer all your questions about sex and sexuality related to your health. You all contact us our experts through mobile phone numbers.

[Contact phone numbers removed]

you can talk to them and schedule when to meet with them. Please note that good health is the good foundation [for life]; love life, care about your health.

*Discussion 2: Facebook Discussion the Experience of LGBT High School Students
(120 views)*

KUCHU/GAYS: Jamani hili swala mashule kuwa na sheria ya kuwafukuza shule wale wanaogundulika kuwa ni gays limeota mizizi sasa.

Jana mtoto wa jirani yangu alirudishwa nyumbani kutoka boarding school kwa kuwa alihisiwa anavitendo vya kishoga. kwavile baba wa mtoto yupo safarini mama wa mtoto aliniomba nimsindikize mpaka shuleni tukasikilize hayo mashtaka. tulipofika tuliambia kuwa yule mtoto alikuwa akihisiwa anavitendo vya ushoga na kinyume ya taratibu za shule ile.

Tulipopata maelezo ya awali toka kwa mwalimu nilimhoji Mwalimu Mkuu na Patron wa wanafunzi kwa kumuuliza ya kwamba waliwezaje kutambua kuwa huyo mtoto ni shoga, Patron wa shule alijibu kwa kuanza kusema ya kwamba wanafunzi wenzake ndio waliomripoti kuwa ni shoga/Kuchu.

Nikawauliza tena "Je wao kama watoa maamuzi waliwahi kumkuta akifanya vitendo hivyo walivyo muadhibu navyo?" walinijibu Hapana ila waliegamia kwenye kauli za wanafunzi.

Swali la mwisho nikawauliza "Je walimpa Mtuhumiwa fursa ya kumsikiliza ama kumkanya?"....

Tafadhali unaweza kututumia kupitia email yetu ya Tanzania Sisi Kwa Sisi Foundation tanzaniasisikwasisi@yahoo.com

Translation

NI KUCHU / GAYS : Friends this question of expelling students found to be gay has taken root in our schools

Yesterday my neighbor's son was sent home from boarding School after being suspected of homosexual acts. As the father of the child had been traveling the mother asked me escort the student back to school to be told of the charges. When we arrived we were told that the child had been suspected of homosexual acts and is contrary to the school rules.

Initial details from the head teacher I interviewed and the school patron of how they recognized the student was gay, the school Patron responded by starting to say that it was his fellow students who reported him of being gay/kuchu.

I asked them again, "since they are the decision makers had found the student doing the acts for which they were punishing him? " No they said, but they were relying on information from the other students.

The last question I asked is "whether they had given the student an opportunity to defend himself or even admonish him? "(read more)

Please send us your observations through our Tanzania Sisi Kwa Sisi Foundation email

tanzaniasisikwasisi@yahoo.com

Discussion 3: Questions & Answers (Q & A) session on Facebook peer education (503 views)

JE! UNA MASWALI YENYE UTATA KATIKA MAISHA YAKO YANAYOHUSU HALI YAKO YA KUWA GAY, LESBIAN, BISEXUAL, TRANSGENDER & INTERSEX??

Tafadhali tunaomba mtuandikie Maswali yanayowatatiza katika Maisha juu ya hali yako ya kuwa Gay, Transgender, Bisexual, Lesbian and Intersex tutakujibu na kukupa maelezo kwa Kina.

Translation

DO YOU HAVE ANY CONTENTIOUS QUESTIONS REGARDING YOUR BEING GAY, LESBIAN, BISEXUAL, OR TRANSGENDER AND INTERSEX??

Please we are requesting you to write to us any question that you may have regarding your being Gay, Transgender, Bisexual, Lesbian or intersex and we shall give you detailed responses.

Discussion 4: Call to Report Human Rights abuses & Outreach (629 views)

UDHALILISHAJI UDHALILISHAJI UDHALILISHAJI

Ndugu jamaa na marafiki na wapenzi wetu wote tukiwa kama wadau wa kusimamia haki za kila mwanadamu Tumehudhunishwa na Wimbo wa mpendwa wetu na Rafiki yetu MATONYA alioutoa hivi karibuni unaojulikana kwa jina la "Agwelina" unaopinga Usagaji .

Tunatambua kweli haya ni maisha ya ndani ya kila mtu ambayo kwa namna moja ama nyingine ndivyo anavyofurahia maisha. Tumesikitishwa na ujumbe kwenye wimbo huu kwani umezungumzia upande mmoja wa shilingi tu yaani mabaya ya wasagaji. Kwani hawa hawana mazuri yanayofaa kuimbwa??

Tafadhali ukiwa kama mdau, mshirika, rafiki ndugu pinga udhalilishaji huu kwa kuunga hii kapmeni na kutonunua wala kusikiliza nyimbo wala cd za matonya.

Na hii iwefundisho kwa watu wengine na wenye tabia za kuzungumza mabaya na kupotosha ukweli kuhusu homosexuality tunatambua kila mtu anahaki ya kuishi vile anavyotaka na anavyojisikia imefika mwisho sasa kudharaulika na kunyanyasika kwa vile tu ya jinsi na ujinsia wetu

Tafadhali tunaomba usambaze ujumbe huu kwa wadau wote na members wote na wa like the post.

Translation

ABUSE ABUSE ABUSE

Brothers, family and friends and all of our partners; As stakeholders in the Human rights fraternity, we have been saddened by the song sung by our beloved friend Tonya known by the name of " Agwelina " which seeks to fight homosexuality.

We know that this is about the private life of an individual. We are saddened because this song only talks about one side of the coin – the bad about gays. Is it that gays have nothing good that can be sung about? ?

Please if you are a stakeholder, partner, friend, or brother protest this and join the campaign of not listening to this song or buying any music CDs by matonya.

Please help to spread this message and also 'like' the post.

Discussion 5: Peer Education through a Posting on Facebook (501 likes)

SHUHUDA USHUHUDA USHUHUDA USHUHUDA

Du jamani hivi vilainishi kumbe vinasaidia hata kuondoa mapele sehemu zangu za siri,tazama nilikuwa na rashezi katika sehemu ya mkundu nilijaribu kutumia dawa mbalimbali mara nilipoanza kutumia nimeshangaa vimeisha na ngozi ya mkunduni imekuwa nyororo hatari. Nadhani sasa tumepata mkombozi kwani sasa ufumbuzi umepatikana.

Jamani huo ulikuwa ushuhuda wa mdau wetu aliyekuwa Mkoani Morogoro aliyetumia Vilainishi na vikamsaidia.

Wewe unasubiri nini???? Kamata Kilainishi Twenzetu!!!

Translation

TESTIMONY TESTIMONY TESTIMONY TESTIMONY

Du! So lubricants can help to remove rashes in my private parts, I had rashes and I tried using various medications I was surprised when I started using lubricants the rashes in the anus region are over and it has been very smooth. I think now we've found the solution for this.

That was the testimony from one of our member from the Morogoro region, for whom lubricants changed his life

Advocacy Tagline: What you waiting for???? Grab your lubricants my friends!!

Social media/capital

From the foregoing, there are a number of lessons TSSF have learnt over time and can share with our partners in the region. One is that social media is an effective social capital building tool and critical in addressing health service and human rights needs of the LGBT community in the region. Social capital

here refers to the building of “*networks with shared norms, values and understandings that facilitate co-operation within or among groups* (World Bank, 2011).” Given the high social stigma, risk of violence and even rejection by family, most LGBT persons strive to reach out to each other anonymously. Increasingly, social media addresses this need, not just because people can join through the forums, using aliases or hidden identities, but also because of its ability to aggregate many more people together like them. This is especially important in increasing snowballing effect of health services linkages, increasing social capital among the MSM networks and increasing personal efficacy in their HIV prevention, treatment and care needs.

Furthermore, social media tools provide an opportunity to create a system of referrals to MSM-friendly and LGBT knowledgeable HIV service providers. The scarcity of such service providers is most notable in rural areas where essential services are geographically far, even for the general population. An online referral system is thus cost effective and an important way to ensure that LGBT persons who invest in traveling to these locations receive access to qualified services. To date social media has enabled TSSF to refer about 50 people from different parts of the country to HTC services, psycho-social support and supportive medical consultations.

The online forum provides people with space to be and affirm themselves. As one member described it, “It is our home.” As such, it becomes a space for individual and collective empowerment, where members do not have to pretend to be anyone other than themselves. Often, the online social forum becomes a stepping stone for LGBT members to gain the self-confidence and self-acceptance that then lead them to “come out” in real life.

Secondly, social media can provide a broader outreach opportunity for programs working with MSM. HIV and health programs that use “traditional” peer support programs could see a benefit in complementing with online peer outreach and support. Historically, peer support has included a person or persons meeting face-to-face in spaces where LGBT people meet and as referrals through LGBT social network gatekeepers. This method is still valid and should be used in addition to, and as a complement of, online outreach programs. The difference between the two methods, however, is timing.

The online program can respond and dispatch with instant information, collective and dynamic social support that responds to their particular needs, and references and referrals to where users can find in-stock HIV prevention supplies like condoms and lubricants. This instantaneous information exchange can happen anywhere the user normally access the Internet. Physical space peer support, as compared to the virtual/online space, requires planned meeting times or spaces, and appointments can be missed or spaces rendered unsafe.

Though the physical space peer educator can directly address the concerns and questions of a person they are with, the online space gives users the freedom to search for and ask questions and address concerns. This freedom of information has proven beneficial for TSSF member retention and maintaining levels of interest in the Bambucha Media program. Furthermore, the anonymity of social media enables a more accurate estimation of the magnitude a particular problem. It becomes possible to triangulate health

problems that people typically keep secret and then reach out to them with information and even encouragement.

In the last few months Nigeria and Uganda have adopted extremely regressive anti-LGBTI rights legislations that further criminalize homosexual conduct and for the first time criminalizing promotion and the organizing of LGBTI rights groups. These regional policies are having an impact in Tanzania. There is a debate now in the Tanzanian parliament on further criminalizing “induce others to become gays or those who promote the behavior (Muga, 2014).” Our response to this issue is still the same as when there is a hotly debated subject in public domain particularly the press.

TSSF experience has been that, pulling out from commenting on this or any other contentious issues generally lead to the debate dying down – in other words we do not “add fuel to the fire.” During situations such as these we would often pull out the social media campaigns, as well as boycott and urge our partners, friends and stakeholders in the Human rights fraternity to boycott News outlets that advance contentious issues – especially if they do so to increase hostility against the LGBT people.

Conclusion

TSSF’s experience shows that it is possible to engage a considerable number of target audiences through social media and other ICT tools. When working with criminalized and often socially stigmatized populations innovative outreach services can determine success or failure of a particular service or program. TSSF has been able to create, raise and promote community awareness on issues on HIV and other health services, human rights, good governance, stigma and discrimination, even in the context of a socially conservative culture.

Even when the social media engagement led to national debate and eventual withdrawal of TSSF’s registration certificate, their presence in social media still continued to serve its purpose of providing information and linkage to services. Indeed the very discussion online scaled up the reach of these tools since people who had not heard about TSSF and services, began to actively search for TSSF on the Internet.

Programs looking forward to working with the LGBT community under similar social context, particularly in many African countries can find in this approach an effect tool for outreach, peer education and community mobilization.

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Chapter 19

Silueta X: Lobbying to establish a specialised lgbti counseling and medical center in ecuador

Diane Marie Zambrano Rodríguez

In her chapter, Diane Marie Zambrano Rodríguez's presents Asociación Silueta X which is working to creating accessible living conditions for lesbian, gay, bisexual, transgender and intersex (LGBTI) individuals with an emphasis on the transgender and intersex population In Ecuador. Silueta X engages social media via social networking sites and apps—especially Facebook—to provide its LGBTI members with updates about its organisational and advocacy activities. Silueta X leverages the powerful role of social media and has created specific sites and accounts for different activities.

Asociación Silueta X

I established Asociación Silueta X when I was 28 years old. It is a grassroots organisation that was created on May 12, 2008 and legally established on May 5, 2010 by Presidential Decree MIES # 9989 of Ecuador. It is a nonprofit association whose mission is to fight for lesbian, gay bisexual, transgender, and intersex (LGBTI) rights in Ecuador. Asociación Silueta X specifically works to create accessible living conditions for LGBTI individuals with an emphasis on the transgender and intersex population. These conditions encompass health, education, employment, and social justice programs for sexual diversity. After nearly four years of working for the LGBTI people of Ecuador, Asociación Silueta X has transformed from a small grassroots organisation reaching people through face-to-face interactions into a highly visible grassroots association with a virtual presence that has helped the LGBTI population experience unprecedented visibility and access to information important to its diverse communities. This critical step not only highlights Silueta X's innovative methodological process to successfully execute our advocacy plans, projects, and campaigns and celebrate the impact achieved nationwide, but also reflects Silueta X's innovative and successful use of information communication technologies (ICTs). Asociación Silueta X runs numerous campaigns that focuses on holistic health and sexual and reproductive rights for LGBTI individuals, including:

- Capacitaciones a Voluntarios (Training Volunteers)
- Capacitaciones a Instituciones Públicas (Training for Public Institutions)
- Salud Integral (Integral Health)
- Juventud GLBTI (LGBTI Youth)
- Incidencia Política (Political Advocacy)
- Arte y Cultura (Arts and Culture)
- Derechos Humanos (Human Rights)
- Comunicaciones (Communications)

Importantly, as an LGBTI organisation, we are able to use ICTs to communicate widely and effectively with all of our members across Ecuador.



Figure 1: Facebook of Asociación Silueta X

From its founding until the present day, Silueta X has experienced a dramatic increase in coverage by the mass media coverage, which now covers more of its activities than those of LGBTI organisations in Ecuador that were founded earlier. Silueta X leverages the power of social media via social networking sites and apps, especially Facebook (with more the 5,800 members), using it to provide updates about its organisational and advocacy activities (Figure 1). Asociación Silueta X clearly understands the powerful role of social media and has created multiple sites that cover specific activities. In part, Silueta X measures its impact by the tremendous amount of mass media coverage that grows out of social media strategies.

To date, ICTs have allowed Silueta X (Figure 2) to reach a diverse population of LGBTI individuals, especially those who are targeted through distinct approaches, such as the trans or intersex populations. The use of technology has not only brought the trans and intersex populations closer to organisational activities, but has also allowed the organisation to save time. Previously, as a grassroots organisation, we working primarily thorough field work, which of course is still carried out, but has been made easier thanks to ICTs.

Technology has also been involved in legal matters, such as the recognition of name changes on ID cards (Campana Mi Genero en Mi Cedula/My Gender Identity in My ID Card), collecting data for trans-focused studies, and addressing proposed laws that include sexual diversity. Primarily though using ICTs, Silueta X has created paradigm shifts regarding the safety of trans sex workers; has engaged and trained national police officers (Capacitaciones a Instituciones Públicas/Training for Public Institutions); and has created several promotional and preventative programs with emphasis on the trans population regarding STDs and HIV using videos on YouTube as part of the Tiempo de Igualdad (Time for Equality) campaign, among other activities.



Figure 2. Silueta X's website

We also have the three virtual campaigns we are very proud of:

- BESOS LGBTI (Kisses LGBTI);
- Tiempo de Igualdad (Time for Equality); and
- Campana Mi Genero en Mi Cedula (My Gender Identity in My ID Card)

BESOS LGBTI (Kisses LGBTI)

Beso Gay Les Bi Trans is Asociación Silueta X's campaign that confronts homophobia. It uses Facebook and YouTube videos. It promotes a public kiss between the participating LGBTI partners. Besos LGBTI has had three massive public "kiss ins" in Guayaquil, Ecuador that have been replicated across Latin America.



Figure 3. Asociación Silueta X's BESOS LGBTI campaign

Tiempo de Igualdad (Time for Equality)

Asociación Silueta X's campaign Tiempo de Igualdad (Time for Equality) is focused on the structural and paradigmatic changes for LGBTI populations

that resulted from the conservative and fundamentalist mentality in Ecuador that often denies LGBTI individuals their human and sexual rights. The campaign has five poignant videos that address the following topics:

1. Centros de Tortura/Torture Centers
2. Acceso a Salud/Access to Health
3. Acceso a Empleo/Access to Employment
4. Acoso/Bullying
5. Educación Laica/Secular Education

Silueta X is using these videos, which are posted on YouTube, to promote structural changes through advocacy and agreements with various state institutions. By collaborating with a number of LGBTI organisations, the films explore various topics from issues of sexuality to fighting for justice and rights. This national campaign would not have been possible without the support of Silueta X's sponsors, including Mama Cash, amfAR, and Hivos.



Figure 4. Tiempo de Igualdad's (Time for Equality) video, 'Discriminación a transexuales en centros de Salud' (Discrimination of transsexuals in medical centers)

Campana Mi Genero en Mi Cedula (My Gender Identity in My ID Card)

On June 6, 2012, the Ecuadorian Confederation of Trans and Intersex Communities (CONFETRANS), which is part of Asociación Silueta X's Transgender Project "Building Equality," presented a draft amendment to the Civil Registration Act of Ecuador that would remove the gender/sex on the Ecuadorian citizenship identity card. The campaign My Gender Identity in My ID Card accompanied the amendment and was presented to the Rule Governments and Decentralization Commission of the National Assembly of Ecuador on July 23, 2012. The campaign includes a YouTube video (Figure 5.)



Figure 5. Asociación Silueta X's *Campana Mi Genero en Mi Cedula (My Gender Identity in My ID Card)* YouTube video

Background

Social inclusion for lesbian, gay, bisexual, transgender, and intersex (LGBTI) persons regarding public health policies in Ecuador is still challenged, despite the fact that sexual orientation and gender identity are included in the constitution of the Republic of Ecuador ([Constitution of the Republic of Ecuador](#), 2008). In fact, this recognition of gender identity and/or expression is one the first trans-inclusive constitutional provisions in the world (Martínez Dalmau, 2008). However, the enforcement of and/or adherence to this 'said' recognition is complex in a conservative and exclusionary culture, such as the one in Ecuador.

In addition, in 2012 Ecuador's Secretary of Health, Carina Vance Mafla, was the first openly lesbian secretary to be appointed in Ecuador (Garcia, 2012). The inclusion of a lesbian Secretary would make most people believe that Ecuador is progressing on social acceptance of LGBTI human rights, even with regards to gender identity in the public or government sphere. Nevertheless, accessing the right to gender identity or expression in public services is still complicated. To address this glaring issue, as part of its social responsibility, Asociación Silueta X has requested countless dialogues with the authorities in order to be able to come to an adequate agreement.

Using ICTs to support advocacy

Depathologization of Transsexuality

Starting in 2012, Silueta X successfully engaged in dialogue with academia and the Department of Health to incentivise those who would appear before the WHO to advocate for the Depathologization of trans sexuality in a forum entitled "Psychology and the Department of Health on the Depathologization of Transsexuality." This advocacy resulted in success. Gabriela Rivadeneira from the Department of Health's Division of Standardization and Silueta X drafted a statement and appeared at a hearing on the subject. All of the planning and

community mobilisation activities for this event were done through contact via ICTs, including Silueta X's website, Facebook, and Twitter. This allowed Silueta X to elicit constant feedback from members that was used to develop the document that was presented to the Department of Health. With this statement Secretary Rivadeneira was prepared to appear before the WHO in

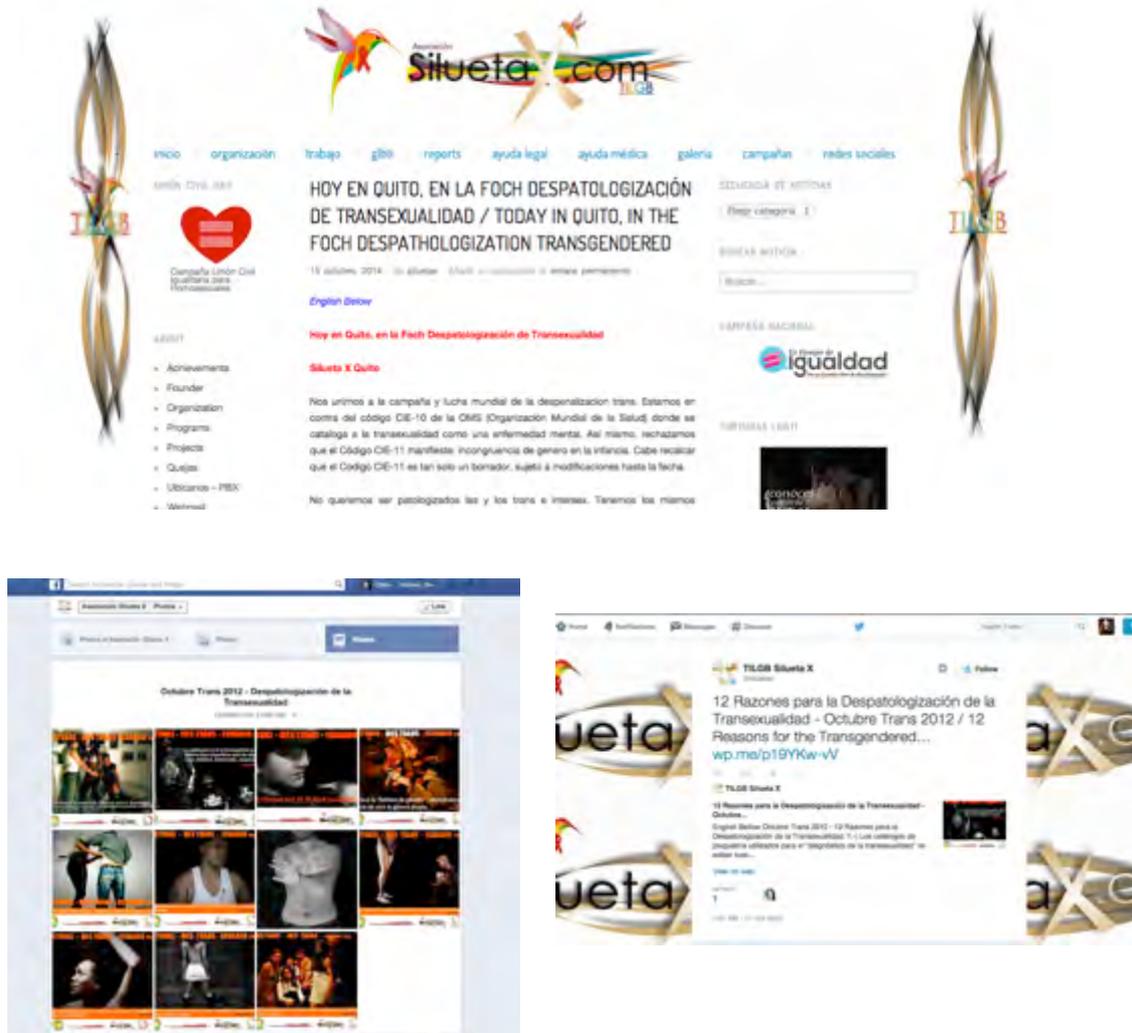


Figure 6. Silueta X's social networking mobilisation activities for the *Depathologization of Transsexuality*

December and advocate for the depathologization of transsexuality publicly in March of 2013. An official Letter was sent to the WHO from the Department of Health on the depathologization of transsexuality thanks to Silueta X's work engaging in dialogue with the Department of Health. This is not only important because of Silueta X's commitment, but also because Silueta X's activities successfully influenced the political sphere to support the transsexual population, in this case by advocating for depathologization. Moreover, it is vitally important to emphasise that the organisation's success lies in the use of information technology to mobilise LGBTI individuals and the general public.

Silueta X lobbying to establish the first trans friendly medical office

Asociación Silueta X has also sought to work more effectively with the Secretary of Health and educate the entire ministry about transsexuals and hormone therapy. This led to Asociación Silueta X successfully hosting a formal meeting to inform the Secretary about the difficulties that transsexual and intersex populations face regarding gender identity. Silueta X also asked for support to establish the first LGBTI counseling and medical center in Ecuador. After the meeting, the Department of Health verbally agreed to take on this task. Division 7 from the Department of Health was present to support the the LGBTI medical center, along with state authorities such as the Secretary’s Advisor Patricio Aguirre and representatives from multilateral organisations such as UNAIDS, among other high ranking key players (Salazar, 2013).

This medical center was specifically created due to statistical data recognising the low level of access to healthcare services among Ecuadorian trans individuals (Figure 7). A bio-behavioral survey of the HIV epidemic carried out in 2012 by the Department of Health of Ecuador shows that the trans population has an HIV incidence of 31.9%, followed by 11% among men who have sex with men (MSM) (Pan American Health Organization, 2012). These results truly show that the trans population is the most exposed to HIV. To compliment this study, Silueta X conducted another study in 2012 (in partnership with the University of Guayaquil and financially supported by amfAR) that indicated that 55% of female trans have been discriminated against while seeking public healthcare services (Asociación Silutea X, 2012). Close to one hundred surveys from this study were collected online through Facebook.



Figure 7. The inauguration of the first LGBTI health center (El Telegrafo, 2014)

Silueta X also used its online community to help recruit clients for a study called “Report on LGBTI Access to Justice and Human Rights 2010 to 2013.”

In the study, Silueta X gathered concrete data proving that the trans population is exposed to violence on multiple levels. For example, data indicated of 20 murders where victims were from the LGBTI community, two were gay men, three lesbian women, and 15 trans individuals (Asociación Silueta X, 2013). The report also made recommendations for Ecuadorian public policies paying greater attention to the needs and rights of trans individuals, including a call for research to estimate the size of the trans population, a call for gender-affirming healthcare, and a call for programs addressing simple quality of life issues that are free from stigma and discrimination based on gender identity and expression. The key goal of the study was to obtain a realistic picture of the lived realities of trans individuals and inform policies to match those needs, thus having greater impact on the health and rights of this population.

This study added to data from a study conducted by the National Institute of Statistics and Censuses, which used a sample of almost 1000 trans individuals. This study also showed major deficits in social services—58% of trans participants did not have access to basic services including, social health insurance (INEC, 2013).

A private medical consult for trans individuals typically costs USD \$35 to \$50, without the cost of medication, which is often quite expensive. Additionally, the hormone therapy needed by the trans and intersex populations is not often covered by social insurance and has exorbitant costs. In fact, Ecuador does not regularly stock specific varieties of masculine and feminine hormones. With the new Comprehensive Organic Penal Code, access to a medical consult for hormone therapy is almost impossible to obtain, due to the fact that there is no protocol for such services in Ecuador, and the Department of Health is not aware of established international norms, such as the guidelines developed by the Center of Excellence for Transgender Health in San Francisco.

In addition to collecting this data and supporting these meetings held with the Department of Health, Silueta X has continued operating its own counseling and medical center, while dealing with countless difficulties—namely lack of financial resources. Silueta X also held the first meeting between several governmental and mainstream non-governmental sexual diversity organisations to offer greater support for and achieve a greater impact on the trans population by discussing the common needs felt by all of the groups of Ecuador. In other words, Silueta X wanted to stop creating methodological processes that intend to solve social issues without having the key affected populations present during the design. Thus, the first meeting was held during which sexual diversity groups talked about health, education, employment, and justice for the LGBTI population. It was entitled, “Four Oversight Committees Will be Created for the LGBTI Community in Ecuador” (2013).

The group proposed establishing a department of health oversight and a pilot program focusing on the topic of health. The results of the oversight only reaffirm the study done by Asociación Silueta X in 2012 (supported by amfAR) and the survey data from the Department of Health’s study done by the National Institute of Statistics and Censuses, which for the 4th time has reaffirmed the need for separate health processes for LGBTI populations.

Although Asociación Silueta X carried out this study as a relatively small

community-based organisation, the impact of the study has had a very significant effect. Asociación Silueta X worked with the National Institute of Statistics and Census to incorporate their methodology to implement a national study. Due simply to the complexity of the trans population, the study was based on the popular “snowball” sampling methodology, which seeks additional participants for the study through interviewees’ friends and acquaintances.

Silueta X’s “Descriptive Study of the Influential Factors of HIV Rates and Discrimination of Female Trans on the Coast of Ecuador in 2012” surveyed 767 transsexuals on the coast of Ecuador. In order to carry out the survey and administer the questionnaires, Asociación Silueta X hired Ramón Aranguren, a Spanish Neuropsychologist specialising in scientific research who traveled from his home country of Spain to make a commitment to work with the organisation. An agreement was also reached with the State University of Guayaquil department of Psychology and its scientific ethics committee to constantly monitor the development of the proposed methodology.

In order to collect both the physical and digital data for the study, a questionnaire was developed that included questions focuseing on lived realities, such as socio-economic status, legal issues regarding gender identification, and sexual and reproductive health issues specific to trans individuals. The questionnaire was created by the research team and was reviewed and approved by the Scientific Ethics Committee of the Department of Psychology of the University of Guayaquil. The questionnaire was distributed in person to a sample of 621 transsexuals and transgendered people. An additional 146 trans people were reached online. Awealth of information was obtained regarding the transsexual community in Ecuador, because a trans-led organisation—Silueta X—was the implementer.

The study confirmed that trans individuals have needs and demands that are not met by the department of health, such as hormone therapy and the use of aesthetic surgeries without risk of silicone use, to name a few. All in all, Silueta X recognises that a process that provides healthcare under a gender affirming doctor in order to achieve an adequate transition without much risk to one’s health is vital for transgender individuals.

The Asociación Silueta X study also revealed that 55% of the trans population does not have access to healthcare in Ecuador. This is a very troubling figure if we review the needs of the trans population that have not been adequately met due to the lack of access to healthcare in the country. Moreover, 47% reported to be engaging in risky sexual behaviours, such as not using a condom on one or two occasions over several encounters. Condom use must be consistent, and this results in a greater risk of exposure to HIV for the transsexual population, according to the data reported by Silueta X’s study.

Another health issue is that there is high mortality among trans individuals improperly using silicone (Salazar, 2013). Silueta X, troubled by this issue, worked to create a protocol for better “gender affirming” services to meet the needs of the transgender population, given that the Department of Health, in spite of these deaths, has not paid much enough attention to this issue (“Death: The price to pay for beauty,” 2011).

Another issue specific to HIV and trans individuals is the lack of care being taken with regards to condom use, based on certain prejudices and religious beliefs. Rejection by medical personnel due to the anatomy of trans populations does not allow service providers to adequately serve different gender identities and offer them all the necessary information in order to use adequate prevention regarding condom care and use. These factors therefore become complimentary factors to the lack of adequate health services.

The first LGBTI-specific counseling and medical center in Ecuador

Recognising these challenges, Silueta X developed a sexual health strategy that includes a medical center and a gender-affirming sexual health handbook. “Incentive to Make Your Femininity a Reality” is now available at the first LGBTI Counseling/Medical Center in Ecuador that opened its doors in May of 2013 (Figure 8). In launching the medical center, Silueta X engaged numerous media outlets, announcing the launch using technology and social networks.

Supported by amfAR, Asociación Silueta X responded to the the trans population’s need for a place where they can have access to healthcare without being mistreated by healthcare personnel or even other patients. These findings were based on the qualitative study mentioned above, in which 20 focus groups were held throughout the country. Each discussion resoundingly suggested a specific healthcare space for the trans population was vital.

The medical center was launched as a clinic for all LGBTI individuals to be as inclusive as possible; however, the clinic primarily services trans individuals, simply due to the turnout of the organisation’s community members and social networks.



Figure 8. Facebook page of the first LGBTI-specific counseling and medical center in Ecuador

Therefore, in spite of its name, the clinic specialises in trans health. To date, the clinic has been successful in serving trans clients because of the focus on the health issues that matter to the population, including supporting positive body images for trans people and helping them claim their sexual lives. By addressing structural issues, Silueta X is more likely to see greater enrollment in such health services.

It is undeniable that identifying these challenges and finding solutions for them has not been easy. Nevertheless, Silueta X recognises the power of social networks and communication technology to increase the organisation's reach and effectiveness. In addition, Silueta X has been able to offer comprehensive services, including both physical and mental health, and to collect patients' medical data. HIV testing is required for individuals before they receive hormone therapy. Thus, the number of community members seen at the clinic is growing due to the trans-specific healthcare that is provided. Silueta X provides effective and healthy hormone therapy provided by specialised doctors, and promotes this service to draw clients in on both a fieldwork level and through technologies such as social networks, e-mails, and even phone apps like Whatsapp. During hormone therapy, the staff speaks to patients about the importance of caring for their sexual health by using support from the Department of Public Health. At the same time and as part of the process (with their consent), Silueta X asks them to undergo HIV testing.

It is worth mentioning that coming up with this process has not been easy. In 2013, Silueta X did empirical work in implementing proposals for hormone therapy follow-ups. Afterwards, staff was offered financial resources to develop a formal protocol for appropriate use of hormone therapy as administered by a doctor.

It should be noted that the process of hormone therapy is important in identifying people who are living with HIV. In fact, we have considered all necessary factors in order to protect the confidentiality of those who have been tested. This has given the population confidence in us, and caused them to promote the services that we offer.

Of the nearly 271 female trans individuals who have a chart at our medical center, 135 have been tested. Twenty-eight of these trans individuals have tested positive for HIV. It should be pointed out that the center uses rapid tests and therefore these data should be verified at public medical centers that administer micro-ELISA and western blot tests. In this aspect we are still working out an agreement with the Department of Health so that we can access data that we have sent regarding these 28 individuals who tested HIV positive.

The first signs of satisfaction have been seen in our very own members. In spite of not having yet been formally documented, they have made their satisfaction publicly known. Below is a local news piece on the care provided at our medical center and a statement by one of our trans members:



Figure 9: Local news piece on the care provided at the LGBTI medical center at <https://www.youtube.com/watch?v=YsQm8Mq0Wh4>

The whole program has been based on the experience and goodwill of the doctor and psychologist currently working at our medical center. Due to the fact that the classification and behaviour of the trans population does not vary for the most part, our model that is under development could be implemented in other places in Ecuador and across Central and South America

Conclusion

In our experience, we estimate that Silueta X's innovative 'gender affirming' sexual healthcare and HIV prevention methodology, complimented by both advocacy and demand creation activities through the use of communication technology, has affected the trans population in positive ways. Even with the lack of support received by the Department of Health, which has only passed legislation but not acted to implement it. Based on several meetings, including one held at the university hospital during which we thoroughly discussed the issue of hormone therapy, we recognised that other centers could not meet the demand for hormone therapy at this time. Thus, we created our own center as a pilot project to entice the government to implement their legislation. Additionally, through our program, Silueta X is able to collect and store medical outcomes of trans clients, which could benefit researchers, advocates, and government. We even hope to increase the capacity of our services to expand on a national level since there are many trans individuals who want to have access to our services, but unfortunately are from other provinces where access is difficult. Our pilot project is becoming a comprehensive HIV care model for the trans population, and we have decided that it is useful to share

our experience so that it can possibly be replicated in other contexts.

ICTs have been the cornerstone of our successful efforts to advocate for and serve trans individuals. With our daily e-blasts, Silueta X is recognised as a regional leader on trans rights and GLBTI health. We consistently are looking for new technologies that would further our cause. Clearly, in this day and age, these technologies make it easier to help trans individuals and allies get involved in demanding their rights.

Our next challenge is signing a formal agreement with the Department of Health, so that we can link our medical database to the national one (especially in cases of HIV diagnosis). Unfortunately, this issue is a major challenge due to the fact that the new Comprehensive Organic Penal Code penalises the divulging of medical data. The Department of Health will not come to an agreement on the confidentiality of the data of people who have had a seropositive test result since there is a new penal law, and many public healthcare officials do not want to provide public information on statistical data regarding HIV prevalence unless they divulge it themselves whenever they see fit. So the information becomes monopolised using the new law as justification when the statistical data do not have anything at all to do with the new law.

Of our 28 trans members living with HIV, close to 13 have come back to our offices and continued therapy with the psychologist. Nevertheless, we have 12 that are not participating, and we can identify those who have quit. Our goal is not only to identify HIV prevalence, but also to give follow-up to trans individuals living with HIV. Above all, we understand that individuals living with HIV are still discriminated against in Ecuador, and it is necessary to consider that an HIV-positive trans individual is dually discriminated against.

We will continue researching how ICTs can help Silueta X attract and educate the LGBTI population, provide outreach, and pressure state institutions to take action. While we have been taking full advantage of ICTs, we believe that perhaps there are means that we have not identified to improve the productivity of our outreach.

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Interview with Carl Sandler, CEO of FMISTER®



Introduction

Carl Sandler started as the founder of DaddyHunt.com, a website geared towards older men and people who like older men. DaddyHunt.com was founded in 2005 and quickly grew into the largest online community for men over 40 and their admirers. Sandler found that what the community of DaddyHunt users wanted was validation that they were still ‘hot’ and desirable even as they grew older. The interview below is a conversation between Sandler and Diego Solares on behalf of *Digital Culture & Education (DCE)* on the role of Apps and HIV in the modern age.

DCE: *Tell us about the origins of the MISTER App*

Sandler: DaddyHunt.com was the immediate predecessor to MISTER. During a time when mobile Apps were becoming more popular, I saw an opportunity to build a community around the same principles as DaddyHunt, but in a mobile format. The challenge was finding a way to become more than a utility for hooking up within the constraints of the mobile format. To create a sense of community on MISTER we start by asking users to opt into a “MISTER code” when they join the App. The MISTER code of conduct encourages members to protect their health and the health of their partners and to treat others with respect, among other things. It’s very basic and simple and yet, remarkably uncommon for an App or website. In fact the only thing similar I am aware of is the Cockyboys Manifesto on <http://cockyboys.com>.

DCE: *Are users forced to accept the code of ethics in order to use the App?*

Sandler: We have considered doing this but no, we don't make it a requirement. We simply ask users to opt in when they join. Users also have an opportunity to opt-in to the code in the future. Users who choose to opt-in get a MISTER CODE badge on their profile and this helps foster a nicer and less judgmental environment for men to meet men.

DCE: What else does MISTER do with respect to HIV?

Sandler: The MISTER Manifesto encourages members to live HIV Neutral. We ask users if they are open to dating someone of any (HIV) status. We did this because our research found that users are not very willing to self-report status on an App or website. We took a novel approach and instead ask users to state if they are open to dating and loving someone of any status. Users who select this option get a badge on their profiles that state they LIVE STIGMA FREE next to an icon from *MR. FRIENDLY*. *MR. FRIENDLY* is a non-profit that works tirelessly to reduce HIV stigma and we partnered with them to do this initiative. We think this is the right approach towards expanding the conversation around HIV within the context of an App. It's extraordinary but there is still a tremendous amount of misinformation, fear and stigma within the gay online and mobile communities. Unfortunately, there is little support from the public health sector for Apps and websites that wish to work to influence behavior and educate users.

DCE: *What is MISTER's reach?*

Sandler: MISTER has had over a million downloads and continues to get thousands of downloads per day. We know that people meet in the real world after using the App but we don't know how frequently it happens. MISTER collects data on usage and messages sent but most of our queries are done via third party tools like Flurry and Google Analytics. We have yet to work with a non-profit or HIV organisation to look at the data and ways to design and test interventions.

DCE: *How did you become interested in public health as a mobile App developer?*

Sandler: I have always been interested in providing support to the gay community, including those who live and love with HIV every day. In 1994, I produced a safe sex gay porn film called *Leg Licking* that won first place at the International Gay and Lesbian Film Festival in San Francisco. *Leg Lickin'* sought to eroticise condom use in porn at a time when it was still a relatively new concept. It was sponsored by Falcon Studios and the San Francisco AIDS Foundation. I also worked on the San Francisco AIDS Foundation hotline in 1993 while I was at Stanford University. I personally feel an obligation to try and do my part to encourage gay men using MISTER to stay safe. I also write a column on sex and ethics for Huffington Post (www.huffingtonpost.com/carl-sandler) where I've tackled issues around Truvada/PrEP, HIV stigma and important health-related issues. You can also find me on the Morning Jolt on

Sirius/XM Radio talking about sex, health, dating and relationships.

DCE: *What changes have you noticed in the HIV response among gay men and the proliferation of Apps and social media?*

Sandler: Before online/App culture, health organisations went into bathhouses to reach gay and bisexual men at risk for transmission of HIV to perform local interventions. That was bold. Unfortunately, public health organisations haven't taken as bold an approach with mobile Apps, despite their proliferation in the past 5 years as the principal gay meet-up environment for many millions of sexually active gay, bi and trans men. It's very disappointing to be honest and quite short-sighted to see public health so slow to recognise the power of Apps and the potential opportunities to working with Apps—particularly those like MISTER—to design and test interventions.

The concept of 'gay' isn't the same as it was before. Mobile Apps has increased reach. There are many men whose 'gay' lives are lived online through Apps and whose first experience with the gay community (including safer sex messages) is through an App. Many men live their entire gay lives online, through porn, websites and Apps. Public health needs to learn how to reach these populations where they live, just like the brave people who went to bathhouses back in the 70s and 80s to do outreach.

DCE: *What challenges have you experienced in working with the public sector?*

Sandler: I am sorry to say that our experience with the public sector has been disappointing at best. The Public Health Sector has not figured out how to efficiently work with Apps and websites to test, create and measure successful HIV interventions. Or if they are doing it, it's not something I am aware of.

Additionally, it seems public health providers are ill prepared to leverage social media to reach key populations at risk of HIV and other sexually transmitted infections. When the Meningitis Outbreak hit New York City a few years ago, it took many months for the City's Department of Public Health to coordinate any sort of Facebook based approach because all messaging required layers of approval. Presently, public health departments at all levels seem ill-prepared for the rapid response and agile advertising and marketing environment that is crucial to designing successful campaigns. Even the payment of invoices in public health takes many, many months. Many website owners I know won't accept those kind of payment terms. Public Health Sectors globally, need to evolve to be able to leverage both Apps and social media when responding to an epidemic to reach key populations.

Additionally, the public sector needs to develop an return-on-investment approach to public health marketing. Period. They also need to attract and hire people to manage their media who are savvy and understand how to influence target populations and partner with the Apps who already have scale and have developed vibrant, active online and mobile platforms.

DCE: *Have there been other instances of public health departments running ads through MISTER?*

Sandler: A few, but to our knowledge, they don't necessarily have good methods of testing whether the ads were effective or viewed widely. It doesn't appear that public health providers are doing much more than running banner ads with limited and un-engaging ads.

It is remarkably inefficient for each state or county in the United States to be managing their own health promotion program within their small catchment area without collaborating or coordinating at a national level. Everyone seems to be managing small piles of money and marketing departments are looking at how to spend this money locally. However, this isn't how the world works anymore. Geosocial Apps and online websites used by men, to meet men, have national and global reach. Ad buys need to be coordinated where campaigns are tested, optimised and then launched nationally so that effectiveness and the return on investment can be quantified. This is how savvy for-profit companies operate. The Public Health Sector can learn much from the private sector.

The real value in Facebook (or any mobile App) is not simply to expose people to an ad, but to take a specific kind of action or to share a piece of content. We live in a time when people are willing to consume media and share powerful messages. Some key questions to ask when designing online interventions are: How can public health learn from mainstream viral sensations? Where are these powerful pieces of content? Who is managing these kinds of efforts on a national or global level?

DCE: *What can be done to promote collaboration between public sector health agencies and Apps like MISTER?*

Sandler: I've heard many people in public health complain that Apps and websites are not willing to partner but I can tell you that MISTER has been open to collaborating with public health for years, and no one has approached us with a single innovative project for collaboration. No one in the public sector has taken us up on our offers to collaborate.

In fact, the most significant contact we've had with the public sector has been vis-à-vis Positive Impact of Atlanta who sued us in the United States District Court for the Northern District of Georgia over trademark issues. If HIV organisations like Positive Impact have enough time and resources to spend their government and state funding fighting Trademark lawsuits then surely there must be resources available to collaborate with Apps to drive increased testing, reduce HIV stigma and educate the community about PrEP, PEP and other STIs.

Public health departments think they have reach because they may serve a few

thousand people a year. Consider that the top 10 mobile Apps reach tens of millions of members DAILY. Imagine what kind of reach they could have if they spend time and energy developing successful partnerships?

DCE: *Are there any changes that you believe should happen within the community of App developers?*

Sandler: There's a lot that can be done with the design of the App itself. But to make that happen we need input from the public sector. We recently added the option for users to say they are open to dating someone of any status. Why would the public health community leave it up to a web developer to make these kind of critical, important changes that effect millions of users in a complete vacuum? The public sector needs to lead here. We just don't have the expertise. What we know how to do is to build sustainable communities.

DCE: *What can be done to motivate mobile App developers to be involved in this work?*

Sandler: The Public Health Sector needs to put *real* resources behind working with Apps; not just buying banner ads but really working in concert with Apps. I don't think the Public Health Sector has effectively worked with the websites that preceded Apps but there is a new generation of App owners, like myself. Then there needs to be serious resources allocated to supporting and working with Apps because this is not our focus. This includes financial resources but also expertise and time because anything we do involves a large investment and risk.

DCE: *How can we foster more collaboration among App developers in HIV programming?*

Sandler: Appoint an App Czar for the gay community. Someone whose job is to sit down with each of the Apps and websites and identify top priorities in terms of public health goals. This person can act as the liaison to the Byzantine world of public health to see how changes can be implemented on each App, tested, refined and supported over time.

DCE: *Do you have any suggestions for improving Apps for HIV messaging?*

Sandler: In general, Apps are designed to work in the same way in every country (with the exception of language). However, there is a need to communicate with members from different countries in different ways due to cultural differences and levels of education required. The health needs of a developing nation can be very different from those of a country like the U.S. Apps need different levels of partnership for each country and perhaps, a unique set of tools for messaging. These are complex issues that need to be studied and evaluated.

DCE: *How much communication happens currently among App developers?*

Sandler: I think that in general we don't talk to one another since we are competitors. This is why it's more important that The Public Health Sector drive individual conversations with App developers, rather than trying to work with the App developers as a group.

DCE: *What challenges remain for those seeking to make public health-focused Apps?*

Sandler: The Public Health Sector doesn't have the resources or the expertise to support and build active and growing communities online. They should instead focus on partnering with existing Apps and websites that already have the audience if at all possible.

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Biographical Statements

Bashiru Adams is a research, monitoring and evaluation (RME) professional with over 5 years of experience in health, social research, monitoring and evaluation of programs. Currently, he is the Monitoring and Evaluation Specialist with GRM International/Futures Group Europe where he oversees the implementation of the overall M&E plan for an Adolescent Reproductive Health Programme, coordinating with government at the national, regional and district levels as well as partner NGOs among other stakeholders on the programme.

Darrin Adams, MSPH has led research, programming, strategic information, advocacy, capacity development, and empowerment and engagement initiatives among key populations globally for nearly a decade. He is a Senior Technical Advisor for HIV at the Health Policy Project in Washington, D.C. where he oversees and manages a key populations portfolio. Some activities include development of an Asia Pacific Trans health blueprint, regional MSM policy and advocacy interventions in sub-Saharan Africa, development of global programming guidance for MSM programs, and supporting governance strengthening for African regional MSM and sex worker organizations. Previously as a consultant, Darrin advised a country on how to scale up key population services, enhanced capacity of governments and community-based MSM organizations to conduct HIV surveillance, and has published and presented articles and reports that demonstrate a need for integrated, responsible engagement of key populations in all aspects of HIV service design, delivery, and management. Darrin holds a Masters of Science in Public Health from the Johns Hopkins Bloomberg School of Public Health.

Contact: dadams@futuresgroup.com

Dan Allman, PhD, is a Senior Scientist at the HIV Social, Behavioural and Epidemiological Studies Unit, Dalla Lana School of Public Health, University of Toronto and a member of the CIHR Centre in HIV Prevention Social Research (SRC). He read Sociology at the University of Edinburgh where his thesis work considered the concept of social inclusion. His research and writing focus on the social production of well-being, particularly for those considered marginal, vulnerable or peripheral to a society's core. He has written academically for an array of audiences. He is a member of the Editorial Advisory Board of the journal *Culture, Health & Sexuality* published by Routledge.

Email: dan.allman@utoronto.ca

Judith Auerbach is a public sociologist currently working as an independent science and policy consultant in San Francisco, California, USA. She has held high-level positions in a number of organisations, including the San Francisco AIDS Foundation, amfAR (The Foundation for AIDS Research), the Office of AIDS Research at the U.S. National Institutes of Health (NIH), the White House Office of Science and Technology Policy, and the Institute of Medicine. Dr. Auerbach received her Ph.D. in sociology from the University of California, Berkeley, and has taught, presented, and published in the areas of HIV/AIDS, social science and public policy, and sex and gender, with articles appearing in such journals as *Global Public Health*, *American Journal of Public Health*, *Science*, *Health Affairs*, and the *Journal of Health and Social Behavior*. She serves on a number of commissions, editorial, and advisory boards, and has received a number of awards, including the 2008 Career Award from the Sociologists AIDS

Network.

Email: judithd.auerbach@gmail.com

Matt Avery is a Regional Technical Advisor on Strategic Behavioural Communications with the FHI 360 Asia-Pacific Regional Office in Bangkok, Thailand. He has been working in HIV prevention with MSM and other key affected populations for more than 10 years.

Contact: MAvery@fhi360.org

George Ayala serves as Executive Director of the MSMGF. Dr. Ayala has worked in the nonprofit HIV/AIDS sector managing social service programmes for nearly thirty years. He is the former Director of Education at AIDS Project Los Angeles (APLA), where he oversaw HIV prevention; capacity building assistance; community-based research; print, video, and web-based media programmes for six years. A clinical psychologist by training, Dr. Ayala has also conducted social science and community-based intervention research since 1996. Dr. Ayala worked as a researcher at RTI International and the University of California, in Los Angeles and San Francisco. His research has mainly focused on understanding the mechanisms through which social discrimination impacts health among gay men and other men who have sex with men.

Jack Beck serves as Communications Associate at the MSMGF, where his work is dedicated to promoting meaningful global communication and collaboration on issues concerning MSM and HIV. Toward these goals, Mr. Beck has led the development of MSMGF.org since its inception and continues to oversee the platform's ongoing evolution. Mr. Beck also leads the MSMGF's global communications, as well as the continued growth of the MSMGF's international network of advocates and service providers.

Contact: jbeck@msmgf.org

Lily May Catanes serves as Operations Associate at the MSMGF. With foundations in international business, leadership and marketing, and a background in instructional design and development for online education and training, she supports the MSMGF in an administrative and logistical capacity for all of its operations, which include project implementation, office management, travel and meeting planning/coordination.

Nina Baltierra is a Research Assistant in the Institute for Global Health and Infectious Diseases at the University of North Carolina - Chapel Hill. She is currently pursuing a Master's of Public Health and has been working in sexual and reproductive health for seven years.

Nada Chaiyajit is a founding member of the 'Thai Transgender Alliance', a fellowship network that promotes understanding and equality for transgender people in Thai society. The Thai Transgender Alliance is using the Internet to compile a database of human and sexual rights violations against transgender people to prove to the authorities that this gender-based violence (GBV) is a violation of their human rights and a major public health issue. Nada has lobbied individually and collectively to modernize the Thai criminal law on rape, advocating for a specific equality provision for both men and women. Drawing on funded research and her experiences as advocate for human rights, Nada has worked collaboratively with marginalised and stigmatised populations in initiatives to promote democracy, social justice and equity

by strengthening their capabilities and promoting their involvement in online communities of practice.

Email: nada.chaiyajit@gmail.com

Melissa A. Clark is Professor of Epidemiology of the Brown University School of Public Health and Professor of Obstetrics and Gynecology of the Alpert Medical School of Brown University.

Nana Fosua Clement is a social development management professional with 16 years' experience in HIV programming for Key Populations, strategic behavior change communication, project implementation/management and research. She is currently the Associate Director, Technical of SHARPER Project in Ghana, a USAID funded HIV prevention project implemented by FHI360 with working experience in 8 African countries.

Dharma E. Cortés is Adjunct Assistant Professor of the Northeastern University Institute on Urban Health Research and Practice.

Nicklas Dennermalm has a Bachelor's Degree in Peace and Conflict Studies from Uppsala University. Since 2004, he is the Head of HIV/STI programmes at RFSL Stockholm where he has co-developed the Sexpert intervention on sexual health for MSM and TG. He has also participated in several international collaborations, including the TLBz Sexpert intervention in Thailand and the pan-European Correlation Network's Internet Expert Group. He is currently working on new media communication strategies and safer sex for the BDSM and sex work communities.

Contact: nicklas@rfslstockholm.se

Benjamin Eveslage is a consultant to FHI 360 on the LINKAGES project. He holds an MSc in Research for International Development from the School of Oriental and African Studies, University of London. His research focuses on analysing the experience of marginalised populations within processes of transcultural change and international development practice. He has taken on a number of capacities during his 15 months in Ghana from 2008 to 2014, including fieldwork with sexual minorities, key populations and sexual health organisations. From these experiences and research endeavours he hopes to highlight the tensions and prospects for joint health and human rights approaches in international development.

Contact: ben.eveslage@gmail.com

Kimberly Green is Chief of Party, [Strengthening HIV/AIDS Response Partnership with Evidenced-Based Results \(SHARPER\)](#), FHI 360 Ghana, has more than twenty years of experience in public health management, policy development and research. She specializes in HIV prevention and care systems and policy development, working with key populations, mHealth/ICT, ART adherence and retention in care, palliative care, and health intervention implementation and evaluation. She is the author of several technical reports, articles, training curricula and presentations and has provided technical assistance in more than 15 countries in Asia and Africa.

Contact: KGreen@fhi360.org

Philippe Girault is an epidemiologist and public health expert working on key populations, particularly MSM, programming and research. Over the past 24 years, he has provided technical assistance to MSM programs in more than 12 countries in Asia and two countries in Africa. He has also conducted biological and behavioral surveys and research studies and published in peer-reviewed journals.

Wentao Guan is a biostatistics graduate student at the Brown University School of Public Health. He was supported by a graduate assistantship from the Brown University Department of Emergency Medicine.

Pato Hebert serves as Senior Education Associate at the MSMGF. Mr. Hebert has been working in HIV prevention since 1994. His focus has been cultural production, programming and information messaging. He leads the HIV prevention foci of the MSMGF while also helping to develop identity and cohesion across our coordinated programmatic and material efforts.

Dr Hightow-Weidman, MD/MPH, is Clinical Associate Professor in the Division of Infectious Diseases, Department of Medicine, at the University of North Carolina School of Medicine, has been engaged in clinical and behavioral research focusing on HIV among Black MSM in the southeastern U.S. for more than a decade. She has expertise in mobile technologies and the design of primary and secondary HIV prevention interventions for young MSM.

Collins M. Kahema is the Information and Communication officer at Tanzania Sisi Kwa Sisi Foundation. He is an actor and is in the main cast of DW Swahili's radio series called Noa Bongo for the past three seasons. Collins dreams of better world of young lesbian, gay, bisexual, transgender, and sex workers are well informed and educated of various issues pertaining to their life through ICT.

John Kashiha is the Program Director of the Tanzania Sisi Kwa Sisi Foundation, a lesbian, gay, bisexual, transgender, intersex (LGBTI) and sex worker organization, based in Dar es Salaam. Kashiha is a young researcher, social worker, programmer, activist and human rights defender. His research and advocacy over the last six years has enabled him to gain experiences in LGBTI sexuality, human rights and health and HIV/AIDS programming. A graduate of Cooperative and Finance Management, Kashiha received a M.A. in Community Development in 2012.

Kent Klindera, MPH, has 25 years of experience working on health and human rights programming, with emphasis on HIV-related key affected populations, youth, gender, and behavior change communication. Currently based in New York City, he serves as the Director of the GMT Initiative at amfAR, the Foundation for AIDS Research, managing a portfolio of implementation science grants for HIV service delivery among gay men, other men who have sex with men and transgender individuals (Collectively GMT). The initiative also supports GMT community led advocacy and service delivery projects, as well as strategies for greater community engagement in research. Previous to amfAR, Kent served as Chief of Party on a USAID-funded male gender norms initiative in South Africa impacting the dual epidemics of gender-based violence and HIV. He also had a ten-year tenure at Advocates for Youth, directing various initiatives focused on HIV among most at risk youth in the US, the Caribbean and Sub-Saharan Africa. Kent holds a Masters in Public Health degree from the University of Minnesota and a Bachelor of Science in Political Science from the University of Iowa.

Contact: kent.klindera@amfar.org

Sara LeGrand, PhD, is an Assistant Research Professor at the Duke Global Health Institute and Center for Health Policy and Inequalities Research with a doctoral degree in Health Services Research. Dr. LeGrand has extensive experience conducting qualitative and quantitative research related to HIV prevention and care with findings published in peer-reviewed journals. She is currently serves as principal investigator, investigator and evaluator for numerous federally and foundation-funded HIV prevention and care grants. Dr. LeGrand is particularly interested in the design and evaluation of technology-based interventions that address disparities in HIV prevention and care.

Tao Liu is Assistant Professor of Biostatistics of the Brown University School of Public Health.

Susana Lungo is the PASMO deputy Director and COP of the USAID Combination Prevention Program. She has specialized expertise in brand management, new product positioning and communication, consumer research and evaluation. Ms. Lungo has also extensive experience in Social Marketing, Behavior Change Communication and knowledge in HIV/ AIDS and STI prevention methods.

Khiya J. Marshall received her DrPH in Social and Behavioural Sciences and MPH in Community Health from the University of North Texas Health Science Center- School of Public Health. She is currently a behavioural scientist within Centers for Disease Control's Division of Violence Prevention. Her research has included HIV/AIDS, focusing on HIV prevention for populations disproportionately impacted by HIV (African American women, African American heterosexual men, and HIV-positive men who have sex with men (MSM) in the United States), medication adherence interventions, and new media and technology related to HIV prevention.

David K. Mbote works with Futures Group; USAID funded Health Policy Project as policy and advocacy Advisor in Nairobi Kenya. He has over 10 years working in the field of HIV & Human rights advocacy in Africa. He holds an MBA from University of Nairobi and MSc in commerce (finance), from the KCA University.

Gang (Roger) Meng is a head of a Lingnan Huoban a CBO working with MSM and the LGBT community in China. By implementing Internet-based strategies, Lingnan Huoban provided 21,038 HIV tests to MSM during 2008-2013 in Guangdong Province. The CBO was awarded an "Advanced Group" by the Ministry of Health of China in 2013, which is the only grassroots organisations among all of the 156 award-winners.

Roland C. Merchant is an emergency medicine physician and researcher in the Department of Emergency Medicine of Rhode Island Hospital, and Associate Professor of Emergency Medicine, Alpert Medical School of Brown University, and Epidemiology, Brown University School of Public Health.

Contact: Roland C. Merchant, MD, MPH, ScD, Rhode Island Hospital, Department of Emergency Medicine, 593 Eddy Street, Claverick Building, Providence, Rhode Island, USA 02903. rmerchant@lifespan.org

Michael R. Mhando is a Capacity Building Officer at Tanzania Sisi Kwa Sisi Foundation. He is a Teacher and Accountants. He has been working on the Key Population Issues over three years here in Tanzania, He is the one who Initiate the

program called Create a space for Young LGBT where by the learn and overcome the stigma and Discrimination through their talents and He is also initiated the program called Peer to Peer Support Group through the Social Media space. He has earned his BAC in 2010 at Tanzania Institute of Accountancy and has been a Secondary School Teacher for 4 years.

Stephen Mills, PhD, MPH is Technical Director, Health, Population, and Nutrition, with the FHI 360 Asia-Pacific Regional Office in Bangkok, Thailand. He has been working in HIV programming, capacity building and surveillance for over 20 years.

Kathryn Muessig, PhD, is an Assistant Professor in the Department of Health Behavior at the Gillings School of Global Public Health at the University of North Carolina at Chapel Hill (UNC). Her research is primarily focused on intervention development to improve the prevention and treatment of HIV and other sexually transmitted diseases in particular among at-risk and underserved populations. Dr. Muessig's work is divided between North Carolina and China and she is affiliated with UNC's Institute for Global Health and Infectious Diseases and Project UNC in Guangzhou South China.

Contact: kate_muessig@med.unc.edu

Ted Myers is a Professor in the Dalla Lana School of Public Health, University of Toronto, Head of the Division of Social and Behavioural Health Sciences, and Director of the HIV Social, Behavioural and Epidemiological Studies Unit. His work has centered on a variety of community-based research and evaluation projects in the field of HIV. These have involved gay and bisexual men and other men who have sex with men, First Nations Peoples, ethno-cultural minorities, injecting drug users and incarcerated populations. Much of his research has taken a national perspective. He has published numerous articles and presented papers related to sexual behaviour, sexuality, and recreational drug use.

Goldie Negelev serves as Communications Assistant at the MSMGF. Ms. Negelev is responsible for the production of the MSMGF Eblast, as well as maintaining the MSMGF's online database of articles and reports on the health and human rights of MSM around the world.

Jocelyn D. Patterson is a behavioural scientist with the Centers for Disease Control and Prevention in the Division of HIV/AIDS. She has a Master of Public Health degree from Emory University and a Master of Professional Counselling degree from Georgia State University. Her previous research includes waiting room videos for STD clinic patients and HIV behavioural interventions for African American men who have sex with men. Her most recent work focuses on HIV prevention and medication adherence using New Media and technology.

Email: jpatterson@cdc.gov

Emily Pike is a Project Coordinator in the Institute of Global Health & Infectious Diseases at the University of North Carolina at Chapel Hill. Emily's research focuses on the social, structural, and behavioral factors that drive HIV and other sexually transmitted infections among at-risk population, especially racial and ethnic minority men and transgender women who have sex with men (MSM/TW), and utilising technology to address disparities in care and education. She is trained in qualitative methods for public health research and intervention design and evaluation.

Jorge Rivas is the Senior Quantitative Researcher for the Pan American Social Marketing Organization. With a marketing degree, he provides technical support and builds research capacity in study design, analysis and interpretation of results for new strategies.

Contact: jrivas@pasmo-ca.org

Marcos Rodas is the Social Media Specialist for the PASMO regional office. He is responsible for the Cyber-educators program, social networks and websites of the projects, developing communication strategies for behavior change communication and strategies to generate traffic on the websites.

Diane Marie Zambrano Rodríguez was born on March 16, 1982 in Guayaquil – Ecuador. She is a male to female transgender activist working for human rights and LGBT issues. Diane is currently the president of Silueta X, a trans specific health and advocacy organisation as well as the representative of the "LGBTI Observatory of Ecuador". In 2009 she successfully advocated for the Ecuadorian government to legally allow transgender people to change their names. During the elections of February 2013, Diane became the first openly transgender candidate to run for public office in Ecuador. Through Diane's intense advocacy, she was able to obtain funding from multiple donors for a trans-specific health care center in Guayaquil that specialises in hormone replacement therapy.

Carl Sandler is the CEO of Daddyhunt.com and the MISTER APP on iOS/Android. He writes about dating, HIV and health in his columns on Huffington Post (<http://www.huffingtonpost.com/carl-sandler>) and can also be found talking about relationships on The Morning Jolt on Sirius/XM Radio. He has a degree in Economics from Stanford University and lives in New York City.

Contact: carl@daddyhunt.com

Claudia C. Santelices is Associate Research Scientist of the Northeastern University Institute on Urban Health Research and Practice.

Winnie Shao is an undergraduate student at Brown University. She completed this study as part of an independent study project. She was supported by a summer undergraduate research opportunity from the Lifespan/Tufts/Brown Center for AIDS Research (P30AI042853), which is supported by a grant from the National Institute of Allergy And Infectious Diseases.

Sarah Jane Steele (nee Taleski) is a PhD Candidate in Epidemiology and a student in the Collaborative Program in Global Health (CPGH) at the University of Toronto's Dalla Lana School of Public. Her dissertation work explores the contextual-, individual-, partnership-, and network- factors that contribute to sexual behaviour among gay men and other men who have sex with men in Shanghai, China. In addition, she has worked in Canada, The Gambia, Zambia,

Christopher S Walsh is an Associate Professor of Education and the Director of Education Programs at Torrens University Australia. He specialises in digital technologies, literacy, multimodality, international development and HIV education and prevention. Walsh was central researcher on number of highly competitive grants awarded by The Spencer Foundation, The American Foundation for AIDS Research (amfAR), the Australian Research Council (ARC) and the Australian Federation of AIDS Organisations (AFAO) and the European Commission. Currently, he also works as a Senior Research Analyst and Policy Advisor for the Bridges Across Borders South

East Asia Community Legal Education Initiative ([BABSEA CLE](#)). He is also the co-founder and co-facilitator of [The Hive](#).

Contact: christopher.walsh@tua.edu.au c.s.walsh@babseacle.org

Samuel Wambugu has 14 years of experience in project management, monitoring and evaluation, surveillance and research of public health programs in Africa. He is currently the Deputy Chief of Party of SHARPER project in Ghana, a USAID funded HIV prevention project implemented, with special interest in the use of technology to improve access and utilization of health services among underserved populations. by FHI360. He has worked in several projects across Africa

Jennifer Wheeler is PSI's Regional Researcher for Latin America/Caribbean. She manages and provides technical assistance to the region's research portfolio, including formative and evaluation studies in the areas of HIV/AIDS, FP, and gender violence. Dr. Wheeler has a PhD and MPH in International Health and Development from Tulane University.

Cameron Wolf, PhD, has worked in AIDS-related public health since 1988. Cameron studied Sociology at the University of Maryland and holds a Master of Science degree from Harvard University and PhD from Johns Hopkins University. He taught at the University of Maryland and also designed and ran an HIV prevention program for men who have sex with men with AIDS Action Baltimore. Dr. Wolf began his government service at the HIV/AIDS Bureau in the Health Resources and Services Administration (HRSA) in 2001. He began work at the USAID Office of HIV/AIDS in Washington, DC in 2003 as Senior Technical Advisor for M&E and later as Senior Regional HIV/AIDS Technical Advisor for USAID's Regional Development Mission Asia (RDMA) based in Bangkok in 2007. He served as Acting HIV Team Leader for RDMA from 2010 until his return to the USAID/DC Office of HIV/AIDS where he currently serves as Senior Key Populations Advisor. He has authored numerous publications, reports, journal articles and book chapters on HIV/AIDS.

Contact: cwolf@usaid.gov

Kunyong Xu is a 3rd year medical student at the Michael G. DeGroot School of Medicine at McMaster University, Canada. His HIV research concentrates on social, behavioural, epidemiological, and clinical issues among marginalised populations, such as gay men and other men who have sex with men and people living with HIV.

Cover Art

Liam Kenny is a design student from Adelaide, Australia. He studies a Bachelor of Media Design at Torrens University, focusing on graphic, motion and interactive design.

Contact: liam.kenny@student.tua.edu.au

TRANSFORMING HIV PREVENTION & CARE FOR MARGINALISED POPULATIONS

Using information and communication technologies (ICTs) in community-based and led approaches

Edited by Christopher S Walsh

“This publication fills the gap between traditional theory driven research and practical HIV prevention and care achieved by highly qualified and committed community-based and led implementers. During my masters studies in Public Health these articles, some previously published in Digital Culture & Education (DCE), proved to be an important supplement to the assigned course literature. This timely work provided my colleagues and me valuable insight and understanding into how ICTs are used across a wide variety of settings to reach key populations disproportionately at risk of HIV who not always covered in public health programs. I believe that anyone within the field of Public Health and HIV, regardless of whether they are a student, an academic, frontline health worker or working with community-based organisations, can benefit from the valuable experiences and inspiring programs and interventions the authors describe in this book.”

Tobias Herder, MPH - HIV Prevention Officer, Sweden

