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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)

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# 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)

Darrin Adams, Kent Klindera, Christopher S Walsh and R. Cameron Wolf

## Abstract

*This Special Issue of Digital Culture & Education (DCE) provides innovative programmatic approaches to HIV prevention and care services for gay men, other men that have sex with men (MSM) and transgender persons using information and communication technology (ICT) at a time when these same populations are experiencing an alarming upward trend of new HIV infections. During a successful participatory consultation in Washington D.C. in May 2013 hosted by the U.S. Agency for International Development (USAID) and co-supported by the U.S. President's Emergency Plan for AIDS Relief (PEPFAR), amfAR, the Foundation for AIDS Research, and the National Institutes of Mental Health (NIMH), representatives from Africa, Asia, the Caribbean, Latin America, Europe, Australia and the United States shared innovative uses of communication technology across HIV research, programs, outreach, advocacy and public-private partnerships. Believing it crucial to share their innovations more widely—through open-access channels—led us to working in partnership with these frontline workers, activists, researchers and educators to further document and share their technological innovations in different global contexts. Importantly, we prioritised working with frontline workers and activists by providing cyclical and targeted writing mentoring to assist them in writing about their successful digital interventions. Disseminating this timely work through open-access channels, like Digital Culture & Education (DCE) means that researchers in less resourced institutions, practitioners and activists in the field and the general public can better understand how ICT, particularly mobile technologies, provides unprecedented opportunities to more effectively reach and engage gay men, other MSM and transgender populations across the HIV prevention, testing, treatment and care cascade.*

**Keywords:** HIV, gay men, men that have sex with men (MSM), transgender, Information and communication technology (ICT), HIV prevention, HIV treatment, Internet, communication, mHealth

## Introduction

This Special Issue of *Digital Culture & Education (DCE)* celebrates and shares the timely and crucial work of frontline workers, activists, researchers and educators working in the field of HIV prevention, testing, treatment and care. It builds on, and extends, the work included in an earlier collection of related open-access articles published in this journal entitled, 'Building the HIVE' (Singh and Walsh, 2012). This Special Issue acknowledges that combination HIV prevention, that draws on "evidence-informed strategic, simultaneous use of complementary behavioural, biomedical and structural

prevention strategies” (UNAIDS, 2010, p.5) can effectively and successfully work to address the contextual and diverse needs of gay, other MSM and transgender populations. The articles presented in this Special Issue emerge 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. The consultation and the articles presented here recognise the strong synergy between biomedical and social science approaches to HIV that work by:

- Understanding emerging trends in gay men, other MSM and TG populations’ use of ICT;
- Identifying innovative programmatic approaches and lessons learned for reaching gay men, other MSM and TG populations using technology;
- Informing strategies for future gay men, other MSM and TG populations’ programming and research; and
- Working to engage the private sector and public health partners in the use of ICT to better reach gay men, other MSM and transgender populations with HIV prevention and care messages and linkage/referrals to social and health services.

As a result of the technical consultation, nine important recommendations<sup>1</sup> emerged from discussions among diverse frontline workers, activists, researchers and educators (Alexanderson, Chintalova-Dallas and Cornman, 2013):

1. Develop targeted content that specifically addresses TG populations’ 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 this Special Issue of *DCE* take up, exemplify, illustrate and provide timely guidance on current innovations and lessons learned across diverse cultural contexts. The Special Issue contributes, collectively, to make the above recommendations a reality in order to stem the tide of new HIV infections among gay men, other MSM and transgender populations.

### **Leveraging ICT 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

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

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 worldwide.

Currently, HIV prevention, treatment, and care programs still remain largely unreachable and often unavailable for many gay men, other MSM and transgender persons. 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 ICT 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; Chaiyajit 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 Special Issue take a step forward in further addressing these issues and reporting on successful and innovative programmatic approaches.

## **Networking to build the HIVe**

This Special Issue of *Digital Culture & Education (DCE)* showcases the diverse ways gay men, other men who have sex with men (MSM) and transgender persons engage and use ICT for HIV research, prevention, treatment, care, support services and programming. The purpose of this Special Issue is to share and learn from non-governmental and community-based organisations’ innovative practices using digital technologies to scale up HIV-related services and support for sexual minority communities worldwide and to continue and improve the ‘Building the HIVe’ work begun in 2012 (Singh and Walsh, 2012).

Forty-four prominent HIV activists, scientists, researchers, entrepreneurs and public health leaders 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 persons. 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. in May 2013, all participants were invited to submit manuscripts for the Special Issue. The call for manuscripts was broadened to include other community-based organisations and partnerships innovating by leveraging ICT productively in the fight against new HIV infections.

This Special Issue of *DCE* complements 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’. We 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. We undertook multiple rounds of editing and peer reviewing and provided 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 Special Issue is to publish successful interventions through open-access channels in their entirety, not just the abstracts.

This Special Issue showcases a rich and representative sample of innovative programming, findings and recommendations from different contexts. Guest Editors and authors from the Special Issue attending the *2014 International AIDS Conference* in Melbourne Australia highlighted 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 Special Issue will also be added to [The HIVe](#), an open-access networked ecology of HIV activists, practitioners, researchers and scholars. Following this, an edited and expanded book will be published under a Creative Commons (CC) license, including articles from this and the previous Special Issue. This forthcoming edited book will be completely open-access and shared widely through our collective networks.

*DCE* continues the journey to build *The HIVe* by developing, exploring, and substantiating the creative and effective merging of HIV and ‘e’ around sexual-social practices and networks, which can shape and influence the future of interdisciplinary and interconnected public health, human rights and education programs and policies (Singh and Walsh, 2012). *The HIVe* is a constantly evolving alternative resource for frontline and community-based workers to access social science and biomedical research and prevention practices that are normally inaccessible because this research is not commonly published in open-access journals.

## **Diverse voices, unprecedented innovation**

With ten contributions from diverse settings working across HIV research, prevention, treatment, care and support we have organised the Special Issue into 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 four community-led interventions in Sweden, Thailand, Tanzania and Ecuador. Then section four provides a new perspective on the potential application of public-private partnerships in the use of ICT, particularly geo-social apps, in reaching gay men and other MSM with important HIV health related information in Australia and the US.

#### *Scaling up HIV services for MSM and transgender communities*

In their article “[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 YBMSM/TW.

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.

#### *Working in collaboration with community-based partners*

In their article, “[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 article, '[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.

### *Community-led interventions*

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

In '[TLBz Sexperts! Using Information Technology to Get to Zero HIV Infections among Thai Transgender People](#)', Nada Chaiyakit argues that because access to sexual health information that serves the needs of transgender individuals is non-existent or severely limited, "Getting to Zero"—the official UNAIDS campaign to achieve zero new HIV infections, zero discrimination and zero AIDS-related deaths—is impossible. Chaiyakit's article identifies gaps and challenges in HIV services for transgender individuals living in Thailand. By recognising the need for the 'de-coupling' of transgender services from those serving gay men and other MSM, she describes an innovative ICT project, the *Thailadyboyz (TLBz) Sexperts!* The program is a low-cost, transgender-led, community project offering accurate online transgender-specific sexual health information, social support and legal advice.

Collins M. Kahema, John Kashiha, David Kuria Mbote and Michael R. Mhando's article 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 article, '[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 article, [‘Silueta Z: Lobbying to establish a specialised LGBTI counseling and medical center in Ecuador’](#) 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.

#### *Forging public-private partnerships*

Yves Calmette describes how ‘Ending HIV’, an interactive social marketing campaign based on peer-education principles that incorporates communication, campaign and community mobilisation initiatives, is working to ‘end’ HIV in New South Wales Australia by 2020. His article, [‘Ending HIV: an innovative community engagement platform for a new era of HIV prevention’](#), argues ending HIV is possible. ACON’s Ending HIV campaign was launched at the start of the 35th annual Sydney Mardi Gras festival. This multiplatform campaign is targeted at gay men to educate them about the real possibility that HIV transmission in New South Wales (NSW) Australia could be virtually eliminated by 2020.

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 ICT**

The editors anticipate this Special Issue will motivate implementing partners and other community-based actors to continue to be creative and innovative in their endeavors to further the use of ICT for HIV services. Individually—and collectively—the articles illustrate the potential impact of innovative programmatic approaches to HIV prevention and care services for gay men, other MSM and transgender persons using ICT at a time when these same populations are experiencing an alarming upward trend of new HIV infections. The articles in this Special Issue present creative, promising,



emergent and evolving programmatic approaches to be shared widely through open-access channels.

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 Special Issue. We also acknowledge, congratulate and celebrate the innovative work and dedication of frontline workers in community-based and led organisations, that despite forecasted shortfalls in funding, continue to be innovative programmatically through ICT. We believe the profound changes brought about by ICT on sexual practices can increase the effectiveness of social and biomedical HIV and AIDS research, prevention and care. Lets 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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## Biographical Statements

**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.

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**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.

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**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](#).

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**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.

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