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From personal survival to public health: community leadership by men who have sex with men in the response to HIV

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This is the fourth in a *Series* of six papers about HIV in men who have sex with men

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Community leadership and participation by gay men and men who have sex with men (MSM) have been central to the response to HIV since the beginning of the epidemic. Through a wide array of actions, engagement of MSM has been important in the protection of communities. The connection between personal and community health as drivers of health advocacy continue to be a powerful element. The passion and urgency brought by MSM communities have led to the targeting and expansion of HIV and AIDS research and programming, and have improved the synergy of health and human rights, sustainability, accountability, and health outcomes for all people affected by HIV. MSM are, however, frequently excluded from the evidence-based services that they helped to develop, despite them generally being the most effective actors in challenging environments. Without MSM community involvement, government-run health programmes might have little chance of effectively reaching communities or scaling up interventions to lessen, and ultimately end, the HIV pandemic.

Introduction

For the past three decades, HIV has severely affected gay men and other men who have sex with men (MSM).¹ This heavy burden is seen in every country affected by HIV, including those where MSM have been excluded from surveillance studies.² Gay men and other MSM community groups have been central to the response to HIV in every setting where it has been safe for them to do so, and in many places where it has not.³

Lesbian, gay, bisexual, and transgender (LGBT) and MSM communities have achieved important successes in the response to the AIDS epidemic, and an international community of MSM is developing, facilitated by the internet and other new media. Emerging and increasingly networked communities are demanding recognition and rights, challenging discrimination and social exclusion, and sharing ideas, experiences, and skills. Vibrant communities are emerging across many low-income and middle-income countries in the midst of widespread HIV epidemics, in which MSM are disproportionately affected.

MSM communities frequently face inherent challenges to their effectiveness. The members of these communities and the social and political spheres in which they operate are strikingly diverse, and attitudes towards them range from celebration to tolerance, to indifference, to aggressive hostility, and many MSM struggle for dignity and human rights. Funding for AIDS dwarfs that available to support LGBT rights and, therefore, HIV-related services potentially divert time and energy away from activities related to LGBT rights.⁴ Many MSM groups are nascent and are not led by experienced advocates, and there are few resources to promote their professional development. Despite campaigns to increase awareness of the effect of HIV on

Search strategy and selection criteria

We held in-country consultations in eight countries (China, Ethiopia, Guyana, India, Mozambique, Nigeria, Ukraine, and Vietnam) selected to represent ranges of HIV prevalence data, HIV burden, legal environments for LGBT groups, and multilateral funding levels for HIV. In each country we spoke with ten to 12 government officials, people involved in implementation of international and country-based programmes, country-based donor staff, civil-society representatives, and networks of people living with HIV or AIDS. Discussions were implemented by domestic partners with expertise and current roles in the MSM-community response to HIV. Discussions pertained to knowledge of MSM-specific research and programming rather than to personal experiences. The information was synthesised by community leaders with technical support from the authors. We also contacted thought leaders to ask about the role of communities in the HIV response, including involvement in research and programming, and further input was provided by representatives in low-income and middle-income countries in Asia, Africa, eastern Europe and the former Soviet Union, and the Americas. Finally, we searched the PubMed, Embase, Global Health, SCOPUS, PsycINFO, Sociological Abstracts, CINAHL, Web of Science, and POPLINE databases with the subject headings “community networks” and “homosexuality” for peer-reviewed reports related to the role of gay and MSM organisations in the HIV response, published between Jan 1, 2007, and Jan 8, 2012. We also searched earlier peer-reviewed reports on the early period of gay men’s involvement in the HIV/AIDS epidemic (from 1981 onwards) that described the roles of community engagement and social norms in the HIV response.

MSM worldwide over the past three decades, which have raised compassion and expanded resources, that same awareness is also unfortunately being used to support homophobic policies, to create cultures of blame, stigma, violence, and the deepening of associations of homosexuality with disease,⁵ and to exclude MSM from the very services they helped to develop. This conundrum continues to challenge MSM community groups.

As described in other papers in this HIV in MSM Series,⁶⁻⁸ improvements in funding and strategy are needed for the response to HIV by MSM all around the world. Acceptance is growing among donors and multilateral institutions about the need to better address HIV in MSM, and many organisations have emphasised the fundamental importance to success of engaging the MSM community. WHO guidelines on HIV and MSM, issued in June, 2011, state that, “Health services should be made inclusive of MSM and transgender people, based on the principles of medical ethics and the right to health”.⁹ The World Bank noted at the same time that “Community participation is crucial in every step of HIV program development and implementation related to MSM”.³ Guidance from the US President’s Emergency Plan for AIDS Relief (PEPFAR) notes the importance of using members of the MSM community to connect with their peers and to engage and retain them in health interventions.¹⁰ A panel of experts has proposed an updated global HIV investment framework and recommends that core investment should include “building of social solidarity and networks of support through community organisations, community-based peer support for health, community-based coalitions for health-care access, human rights, and access to justice”.¹¹

How to reduce the infection rate in MSM and treat men already living with HIV continues to be debated. In this HIV in MSM Series paper, we suggest that community-centred approaches for MSM programmes are essential, and should be supported by the best available evidence and by human rights frameworks of inclusion, non-discrimination, and the recognition of the inherent dignity of all people. We put forward defining concepts and provide a historical perspective of the long-standing record of MSM community leadership and participation in the HIV response and review opportunities and recommendations for enhanced leadership and participation aimed at improving outcomes for MSM in the HIV epidemic. Definitions and concepts used to frame this analysis are included in panel 1.

History of gay and MSM participation

The earliest community responses to AIDS by gay men arose from an awareness of personal danger and government neglect. In the USA, for example, many men recognised that having sex with other men put their lives at immediate risk, but that their government was failing to respond to the then-called gay-related

Key messages

- HIV has disproportionately affected gay men and other MSM since the beginning of the pandemic, and in response they have made major contributions to the fight against AIDS
- Gay men and MSM have led and participated through advocacy, education, research, and design and delivery of prevention, treatment, and care programmes that have benefited all affected by HIV
- In stigmatising environments, MSM and LGBT community groups are often the only groups willing to advocate for recognition and rights or to provide HIV-related services to gay men and other MSM
- Gay and MSM advocates have achieved important successes in the response to HIV, but they have faced challenges, including pervasive stigma and threats of violence, limited funding, and the need to represent highly diverse populations
- The recognition that protecting personal health requires community-level action has been catalytic in the response to AIDS worldwide, and will continue to be essential
- To take maximum advantage of new HIV technologies and growing recognition of the MSM epidemic, communities will require increased resources, support to develop capacity, and expanded opportunities to serve and lead

MSM=men who have sex with men. LGBT=lesbian, gay, bisexual, and transgender.

immune deficiency.¹² They realised that to maintain personal health, collective mobilisation and action were required. For many men, this understanding provided impetus to belong to a community that was struggling against marginalisation. In the early 1980s, gay community actions included the first peer-support programmes (so-called buddy programmes) to care for people dying from AIDS and publication of the first educational guides about safe sex and HIV-related risk reduction in sexual practices.¹³⁻¹⁶ Gay men were also central to the earliest rights-based framing of the HIV response. In 1983, the Denver principles were drafted in condemnation of attempts to label people living with AIDS as victims, to recognise the central role of people living with AIDS in the response to the epidemic (now commonly known as the principle of greater involvement of people living with HIV/AIDS), and to embrace prevention and treatment through a human rights approach.¹⁷ By the middle of the 1980s, gay men had also created or were deeply involved in non-governmental community-based AIDS organisations that were providing various services and advocacy in high-income and middle-income countries (eg, Group of Support and AIDS Prevention and Grupo Pela Vidda in Brazil, and the Gay Association of South Africa in South Africa).¹⁸

From 1986, owing to increasing frustration about inaction by governments, gay men and others in North America, Latin America, western Europe, South Africa, and Australia forged a new style of AIDS activism that was overtly political, confrontational, and visible (figure 1). A notable example was the AIDS Coalition to Unleash Power (ACT UP), which explicitly stated the connection between government neglect and homophobia.

Panel 1: Definitions and concepts for community participation among MSM**Community**

- The term community refers to any group of people with shared perspectives, interests, or identities, including invisible, fragmented, or poorly defined groups. For MSM the settings, contexts, and motivations for engaging in sex, self-identified sexualities, and gender identities vary widely. Men who self-identify as gay or MSM¹ might identify with other labels and affiliations, including relationships to family, clan, religion, politics, cultural, and national identities, or geographic location.
- MSM communities are frequently linked through social and sexual networks, shared cultural and political affinities, and groups seeking rights and health or fighting discrimination, such as coalitions of LGBT or people living with HIV.

Leadership and participation

- This term refers to the effort of MSM to mobilise networks to improve the response to HIV and AIDS. These group members might not effectively represent all MSM in a society. Rather they serve various roles on the basis of perceived needs and opportunities. Activities include engagement with networks of MSM, creation and use of space for communication, and organisation across social, sexual, and professional networks to build literacy, capacity, and cohesion for action against HIV. Factors and dynamics are well defined and include social capital, empowerment, and community development.¹⁻⁵ Many effective community responses have evolved from personal or shared experiences, or direct or indirect mentorship from other advocacy entities, or both.

HIV advocacy

- HIV advocacy is the promotion of the rights and health of people at risk of and affected by HIV and AIDS, to improve control of and ultimately end the HIV epidemic. Rather than dealing with individual issues, advocacy contributes to the broader goals of health and human rights to develop combined interventions and programmes to curtail the spread of HIV and build capacity for health.¹

Community engagement (experience from Lima, Peru)

- Mapping of social venues involves the discovery, recording, and updating of MSM-related venues in cities where HIV

- prevention interventions are being planned, and provides an inventory of sites for recruitment and sometimes intervention. Venues are classified into types on the basis of risk of exposure to HIV and sexually transmitted infections: type 1, bathhouses, adult-movie theatres, adult-video arcades, and sex-work venues (eg, streets, parks, and avenues); type 2, discotheques, nightclubs, and bars; type 3, venues associated with social activities after work, such as beauty parlours and transgender houses; and type 4, athletic facilities and places where people go to relax, such as the beach.
- Implementation of the peer educators system, since 1998, has enabled the MSM community to disseminate preventive messages to peers that do not adhere to the traditional clinical perspective. Trust is built between MSM and health facilities.
- Gay-friendly clinics with advocates for male patients who have sex with men who are trained in good clinical practice and can act as guides maintain the confidence generated by peer educators. Clinic staff are trained to respond to MSM needs and receive monthly feedback from advocates.
- Local regional community organisations promote safe sex and HIV prevention, promote and support medical interventions, and provide training on leadership, self-esteem, self-promotion, and development of management strategies for other MSM groups. They also advocate for increased rights for gay people.
- MSM community groups disseminate information related to sexual health and help to develop educational materials customised to their community to increase uptake.
- Community advisory boards include popular opinion leaders who volunteer to represent subcultures, which empowers MSM leaders to strengthen their communities for sexual health and advocacy.
- Community consultation forums include members of the MSM community and non-governmental and community-based organisations with the aim of discussing and gaining insight on specific topics. The forums facilitate consultation with academic leaders, scientific bodies, and decision makers.

MSM=men who have sex with men. LGBT=lesbian, gay, bisexual, and transgender.

In some cities, early HIV activist coalitions evolved into highly specialised advocacy groups with focused goals and targets, including drug research and development, drug pricing, vaccine research, and sexual and reproductive rights. The combination of this radicalised advocacy with large-scale mobilisation of people and media generated some important successes in the 1990s, particularly in the USA, where regulatory approval of products for expanded clinical research was accelerated, the prices of licensed HIV medicines were lowered, and national legislation was created in relation

to funding of HIV programmes and services.^{19,20} Indeed, as is discussed elsewhere in this Series, development of and access to highly active antiretroviral therapy might not have arisen at all, or at least it would have been much slower and many millions more people would have died, without the advocacy of huge numbers of gay men in the USA and Europe.²¹

In all settings, including in low-income and middle-income countries, MSM community responses to HIV evolved from local contexts, histories, norms about gender and male sexuality, political and human rights



Figure 1: 1986 poster adopted by the AIDS Coalition to Unleash Power
The text at the bottom reads "Why is Reagan silent about AIDS? What is really going on at the CDC, the FDA, and the Vatican? Gays and lesbians are not expendable... Use your power... Vote... Boycott... Defend yourselves... Turn anger, fear, grief into action".⁶ Image provided by Avram Finkelstein and reproduced by permission of the Silence=Death Project. CDC=Centers for Disease Control and Prevention. FDA=Food and Drug Administration.

environments, and the ways that gay men and other MSM connected and were affiliated through social and sexual networks. HIV advocacy agendas for MSM have also always been informed and influenced by other social movements, such as independence from colonial rule or from dictatorship, equal rights, and anti-apartheid struggles (figure 2). For instance, early gay leadership was seen in São Paulo and Rio de Janeiro, Brazil, where activism related to HIV arose in the early 1980s out of broader civil society mobilisation for the restoration of democracy and human rights and against military rule.²² In Johannesburg and Cape Town, South Africa, the first responses to HIV among gay men around the same time were based on previously established gay social support and clinical services for sexually transmitted infections.^{23–25} In Shanghai and Beijing, China, early community responses to HIV-related illness and deaths were seen as part of wider social liberalisation trends.²⁶ In Bangkok, Thailand, the MSM community response to its earliest cases of HIV

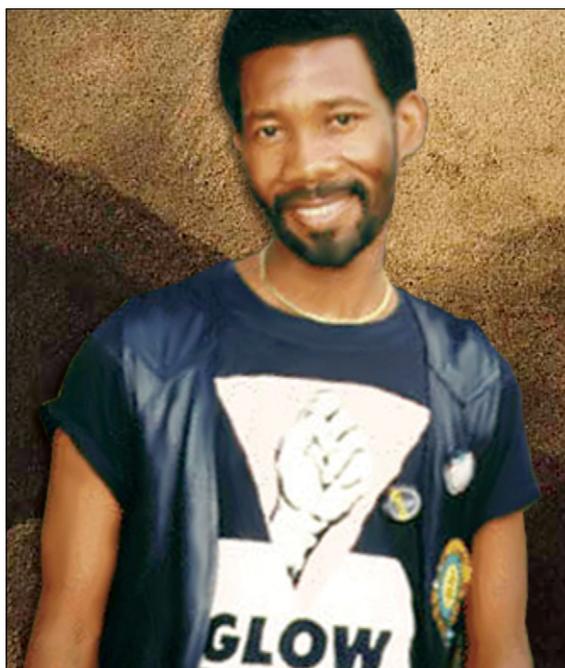


Figure 2: South African activist, Simon Tseko Nkoli
Simon Tseko Nkoli typified the social movement that fought to end apartheid in South Africa and to increase the rights and recognition of gay men and other MSM in South Africa. As one of the first openly HIV-positive African gay men, he supported the decriminalisation of same-sex practices in South Africa and the creation of targeted HIV services for MSM.⁷ Reproduced by permission of Braxton University, Pretoria, South Africa. MSM=men who have sex with men.

evolved from gay networks in Si Lom. Irrespective of the origin, however, a shared theme that has transcended continents and economics has been advocacy for a comprehensive response to a health emergency through application of rights-affirming programmes.

As early as the 1990s, the internet began to facilitate the networking of gay men and other MSM who were working for health and rights. Lessons could be learned in real time across countries, languages, and economic levels. Although programmes need to be locally relevant and appropriate, MSM groups have become increasingly aware of each other's work around the world, which has led to continuous scaling up of HIV advocacy and service provision.

HIV advocacy emerged most readily where LGBT rights movements were well developed. In the past decade a new trend of advocacy among MSM has been seen, in the context of the wider HIV response. Many of the newly formed MSM groups and organisations advocate for rights, such as inclusion in programming and access to MSM-friendly clinic services. This approach has strengthened the response where HIV resources are abundant but where LGBT rights resources are non-existent or extremely limited. In Malawi, for example, MSM community groups have completed assessments of HIV prevalence that have resulted in MSM being added as a vulnerable population

Panel 2: Just following my heart: experience of a gay man in China

As a middle-aged gay man living in mainland China, I have witnessed and experienced so many changes in the gay or MSM communities in my country over the past 30 years. When I was in my 20s, during the 1980s, we had nowhere to go for gay knowledge or for friends. Many of us gathered around public toilets, in parks, and in nearby streets, where we were often attacked by police and local security-team members. Like many of us, I was beaten and detained for what was called loitering. Other gay friends were put in prison, where they suffered even more severe physical punishments and penalties. We lived in fear. Then, in the 1990s, we started to have HIV/AIDS in our community. Some of my very closest friends died of AIDS. This was a cause of great sadness. In the late 1990s, we started to organise ourselves. Gay bars began to appear, and later HIV newsletters, and even later HIV awareness groups and more open prevention activities. I volunteered for the first gay hotline in China. I felt more fulfilled in this period of my life because of this work, but still sad, since more and more gay and MSM friends were becoming infected with HIV. Since 2002, more and more HIV activities have been organised among MSM in China. I attended most of them and made friends with gay HIV activists across our country. Due to my English capacity, some international organisations also approached me to organise meetings and consultations. I gradually got to know more international gay HIV activists. Influenced by them, and together with group leaders for MSM and HIV in China, we formed the China Male Tongzhi Health Forum, the first MSM and HIV alliance in China, in 2008.

Until 2010, I worked as a government official, as a businessman, and as an international organisation programme officer. My work in HIV and with MSM had always been as a volunteer. In 2010, when I looked back on my life, in the middle of my life's course, I found that what has always attracted me is the work for MSM and HIV. I realised then that only gay men's issues could constantly keep my attention and that this was where I could be most smart. So from then on I have worked as a full-time activist for MSM and HIV. Only in this way can I be myself and sleep well.

MSM=men who have sex with men.

to the HIV/AIDS National Strategic Plan and to applications to the Global Fund to Fight AIDS, Tuberculosis, and Malaria.²⁷ More importantly, the work of domestic MSM community groups has contributed to the announcement by the new president of Malawi that a process to decriminalise same-sex practices would begin in May, 2012.²⁸

The availability of HIV-related resources has presented challenges, because although participation in the HIV response legitimises MSM community groups in stigmatising contexts, it can adversely affect the broader LGBT and human rights agenda, which might ultimately affect access to health services. Communities have struggled with this balance, and with the challenge of whether to advocate from the street, or the conference or boardroom. An important strategy of HIV activism in the USA was to have gay men in both places.²⁹ In many other settings, however, counter-attacks to MSM advocacy have been brutal, enforced by state powers, and many have been supported by popular opinion that strongly disfavors LGBT rights and freedoms.^{30–32} One man's account of how HIV activism and advocacy have changed over time in China is presented in panel 2.

New opportunities for HIV leadership and participation**HIV programming***Community empowerment for health*

Substantial evidence suggests that health outcomes are improved when individuals are engaged in advancing their own health and working with peers and partners in health promotion and services.³³ The provision to gay men and other MSM of the opportunity to express their health needs and collectively organise to negotiate solutions improves knowledge, awareness, motivation, skills, and efficacy for health at the individual level.^{34–37} MSM are frequently the best people to describe the sexual practices and dynamics of the social and sexual networks in their own community that drive incident HIV infections.³⁸ The Mpowerment project in the USA is an evidence-based HIV intervention that shows the effectiveness of engaging MSM community members in the design and diffusion of HIV prevention in the reduction of HIV risk.³⁵ This project proved to be cost effective, with net social savings in the communities assessed reported to be US\$700 000–900 000 over 5 years of implementation.³⁹ Packaged interventions such as the Mpowerment project should be implemented only after being deemed locally appropriate through critical analysis of context, local innovations, and community perceptions.⁴⁰ When these considerations are taken into account, rigorous evidence-based interventions and approaches can be shared, adapted, and scaled up. For instance, Mpowerment has been implemented for MSM in Mexico and is being assessed in South Africa.⁴¹

Community leadership and governance in government programmes

Community leadership and participation in health programmes can ensure appropriate design, reach, and quality of services through education of providers about how to create safe environments for testing and care. Additionally, help can be provided to health services to plan, design, implement, monitor, and assess that programming is appropriate, trusted, targeted, and, ultimately, usable by and scalable for MSM populations.^{42–45} The Global Fund to Fight AIDS, Tuberculosis and Malaria requires that key populations are asked to participate in HIV governance entities, such as country coordinating mechanisms, which are charged with the development of national proposals for the Fund.⁴⁶ MSM communities continue to try to use these mechanisms to ensure that HIV programmes address their needs, although they are frequently faced with challenges to being effective. In various countries, as wide-ranging as India, Jamaica, Macedonia, Nepal, the Philippines, and Senegal, MSM and other key populations already participate in some country coordinating mechanism groups and other national governance bodies.⁴⁶

In Senegal, MSM involved in the country coordinating mechanism are well placed to advocate for evidence-based

and rights-affirming HIV-prevention measures for their communities and other stigmatised communities. The Global Fund to Fight AIDS, Tuberculosis and Malaria has, therefore, been able to support more than a dozen MSM community groups by actively providing a range of services. With increased visibility, however, the risk of reprisal is also increased for stigmatised groups. In 2008, in Senegal, the principal recipient of aid from the National AIDS Commission and the Global Fund to Fight AIDS, Tuberculosis and Malaria had developed strong partnerships with MSM community groups. However, the leaders of these community groups were arrested on the basis of HIV educational material being evidence of homosexuality. After much subsequent negative media attention, the availability and use of HIV prevention, treatment, and care services decreased substantially and had not reached pre-arrest levels more than 3 years later.⁴⁷

Community-led services

HIV organisations led and staffed by MSM can better respond to community needs than those not based in the community, because they are able to tackle controversial issues and remain credible with targeted recipients.^{48–50} Investment in community leadership and capacity has proved to be an essential element of successful and sustainable services and advocacy for MSM.^{51,52} Promotion of the capacity and opportunity of MSM to express their own needs and advance decisions and actions in their own interests is good public health practice and is a fundamental principle of autonomy, ethics, and human rights. It also has the potential to provide the largest benefits through consistency in development, implementation, and evaluation of health policy and programmes.^{29,35,36,53,54} Additionally, engagement of leaders across populations has long been recognised as being of great importance in international health and human rights treaties and discourses.^{55,56}

Powerful examples of the potential for engagement and leadership of gay men and other MSM come from programmes in south Asia, where they are led by and staffed by MSM and transgender people. Support is provided by the Global Fund to Fight AIDS, Tuberculosis and Malaria in Afghanistan, Bangladesh, Bhutan, India, Nepal, Pakistan, and Sri Lanka. In India, a new programme, called Pehchan, which works closely with national and state governments, is developing 200 community-based organisations to provide HIV prevention and related services to more than 453 000 MSM and transgender people in 17 states. The priorities of the Pehchan programme are to strengthen community systems for MSM, transgender, and hijra populations to improve the effectiveness and sustainability of government prevention interventions.⁵⁷

HIV research

Since the earliest attempts to investigate AIDS in the early 1980s, gay men worldwide have been at the

forefront of HIV research. They have served as researchers, study subjects, community participants, and fundraisers, and have advocated for flexible, rapid, and inclusive study designs and regulatory approaches.^{58–62} Likewise, MSM have had similar crucial roles in studies, such as Project Explore, vaccine trials, rectal microbial research, and many other studies.^{63–68} In Peru, which is a site for many of these biomedical studies, MSM have been successfully recruited and retained in observational cohorts and clinical trials that have involved community partnership. Such an approach has been implemented since 1998, by researchers at IMPACTA, which is a non-governmental research organisation that facilitates the enrolment of MSM in numerous research studies (panel 1, appendix). The approach to community engagement has resulted in more MSM being recruited for biomedical trials in Peru than in any other low-income or middle-income country.

For MSM in many settings, engagement in research has been complicated by a history of neglect and mistreatment by researchers, health-care systems, and governments.^{69–71} Mistrust must be minimised and one way to do so is to involve MSM as co-investigators through community-based participation.⁷² By the application of the view of a community as a social entity that actively contributes to the intellectual development of research rather than merely serving in an advisory capacity, community-based participation in research enables communities to examine their own unique circumstances and to identify, test, and adapt best practices.^{73–77} When done correctly, research creates bridges between policy makers, scientists, and communities, facilitates reciprocal learning, assists in the development of culturally appropriate measurements and interventions (which improves the effectiveness and efficiency of projects), and establishes a level of trust that improves the quantity and the quality of data collected and, ultimately, the programmes delivered.^{78–80} The benefits of this approach could in turn encourage the adoption, sustainability, and dissemination of evidence-based interventions.⁸¹

Data from the iPrEX and HPTN 052 studies^{64,82} herald a new era of HIV prevention that places increased emphasis on HIV testing and linkage to chemoprophylaxis or treatment, in combination with structural approaches, such as community engagement. The success of these approaches for MSM will rely on men at high risk of HIV infection or transmission having opportunities to access risk reduction counselling, HIV testing and treatment, and support to enable care and adherence to treatment in safe settings. Guidelines for research that involve MSM in rights-constrained environments highlight that without the active engagement of MSM communities to address these structural barriers, they are unlikely to benefit from the prevention and treatment research, despite having played such pivotal roles in the human testing of these interventions.⁸³

See Online for appendix

	Country	Same-sex practices criminalised	PEPFAR focus	Global health initiative	Epidemic scenario ^a
1	Ethiopia	Yes	Yes	Yes	Widespread heterosexual epidemic
2	India	No	No	No	Equal contribution
3	Rwanda	No	Yes	Yes	Widespread heterosexual epidemic
4	Tanzania	Yes	Yes	No	Widespread heterosexual epidemic
5	Zambia	Yes	Yes	No	Widespread heterosexual epidemic
6	Malawi	Yes	No	Yes	Widespread heterosexual epidemic
7	China	No	No	No	Equal contribution
8	Nigeria	Yes	Yes	No	Widespread heterosexual epidemic
9	Russia	No	No	No	IDU-driven epidemic
10	Mozambique	Yes	Yes	No	Widespread heterosexual epidemic
11	South Africa	No	Yes	No	Widespread heterosexual epidemic
12	Democratic Republic of the Congo	No	No	No	Widespread heterosexual epidemic
13	Cambodia	No	No	No	Equal contribution
14	Uganda	Yes	Yes	No	Widespread heterosexual epidemic
15	Ghana	Yes	No	No	MSM predominant exposure mode
16	Sudan	Yes	No	No	Widespread heterosexual epidemic
17	Zimbabwe	Yes	No	No	No data available
18	Indonesia	No	No	No	Equal contribution
19	Côte d'Ivoire	No	Yes	No	No data available
20	Kenya	Yes	Yes	Yes	Widespread heterosexual epidemic
NR	Haiti	No	Yes	No	No data available
NR	Namibia	Yes	Yes	No	Widespread heterosexual epidemic
NR	Vietnam	No	Yes	No	Equal contribution
NR	Guyana	Yes	Yes	No	No data available
NR	Botswana	Yes	Yes	No	Widespread heterosexual epidemic

PEPFAR=President's Emergency Plan for AIDS Relief. IDU=injection drug use. NR=not ranked. ^aFrom Global Fund to Fight AIDS, Tuberculosis and Malaria and UNAIDS.

Table: Ranking of top HIV investment* countries by criminalisation and PEPFAR focus status and epidemic scenario

HIV advocacy

Advocates for MSM are core participants in the development of strategies, resource allocations, policy development, and decision making at an international level (panel 1). The Global Fund to Fight AIDS, Tuberculosis and Malaria, PEPFAR, WHO, other UNAIDS co-sponsors, and other major international health and human rights initiatives, such as the processes of the UN Commission on Human Rights and the Global Commission on HIV and the Law, take advocacy into account in their assessments.^{84–86} Despite this success, however, health and human rights reports suggest that the worldwide effects are limited and that MSM remain excluded from official processes in most places where same-sex practices are criminalised or heavily stigmatised (table).⁸⁷ Criminalisation and stigma manifest partly through differential reporting of MSM-related indicators to the UN General Assembly Special Session on the basis of stigmatising contexts represented by criminalisation of same-sex practices.⁸⁷ For example, in four countries where same-sex practices are criminalised—Ethiopia,

Mozambique, and Nigeria—only four MSM-related indicators of a potential 20 were reported. By contrast, in China, India, Ukraine, and Vietnam, where no such laws are in place, all 20 indicators were reported in 2010.⁸⁷

Through the global, regional, and national processes described above, MSM community leaders have articulated clear advocacy recommendations to improve the HIV response, including changes to government health and human rights policies and improvements in the quality, effectiveness, scalability, and reach of HIV programmes and services.^{49,51,88,89} Important advocacy themes that have emerged as priorities have included calls for increased governmental accountability and transparency, increased funding for HIV research and programmes for MSM, decriminalisation of same-sex practices, and other national efforts to address stigma and discrimination in health care, law enforcement, and other sectors.^{4,51} MSM community groups and other civil-society partners based in rights-constrained environments are well situated to hold partners accountable in view of their access to MSM communities, knowledge of funding streams, and HIV implementation partners and other service providers.^{87,90,91} Community responses to HIV are an essential component of a comprehensive and effective response to the epidemic.⁹²

Many organisations have had advocacy successes with regard to the HIV response among MSM. For instance, the TLF Sexuality, Health and Rights Educators Collective in the Philippines successfully advocated with local policy makers to extend the reach of MSM and HIV services.⁴⁹ The Blue Diamond Society in Nepal advocated the lifting of legal restrictions and the opposing of discrimination against sexual minorities.⁴⁹ In the Dominican Republic, Centro de Orientación e Investigación Integral successfully worked with law enforcement to combat harassment of MSM and transgender individuals as a way to improve access to medical services (figure 3).⁴⁹ HIV advocacy by MSM community groups and strategic partners has driven inclusion of these communities in national HIV strategies, and into programming by the Global Fund to Fight AIDS, Tuberculosis and Malaria and UNAIDS, even where same-sex practices are criminalised, heavily stigmatised, or both, such as Nigeria, Mozambique, Senegal, and Malawi. At a global level, outcomes of collective action have included multilateral funding mechanisms, which have led to increased commitment to support HIV prevention and treatment services for MSM in low-income and middle-income countries and publication of the sexual orientation and gender identities strategy from the Global Fund to Fight AIDS, Tuberculosis and Malaria in 2009,⁹³ and guidance from PEPFAR in 2011.¹⁰ Dividends of these funding initiatives have been seen with increased reporting of programmes to the UN General Assembly Special Session and more targeted programmes for MSM that include their communities.^{87,94,95}

These advocacy efforts have resulted in a notable backlash, and activists and advocates alike have been

beaten, arrested, and killed.³⁰ For every arrest and murder that is public, there could be many more unknown or untold. Arrests of MSM in Senegal, Malawi, The Gambia, and Uganda, and the deaths of Alim Mongoche in Cameroon, Steve Harvey in Jamaica, and David Kato in Uganda highlight that this struggle is far from won and that comprehensive HIV prevention, treatment, and care cannot yet be achieved in some places (figure 4, appendix).

In most countries, networks of MSM advocating about HIV are small and underfunded. The capacity of advocacy organisations is embedded in the experience and knowledge of a limited set of individuals who, in most places, do not have the time and resources to systematically train people to sustain this capacity. A major effort is needed to strengthen community systems to build capacity, particularly since most donors prefer to fund service provision and research over development of capacity during times of financial austerity. Additionally, as some international donors shift a part of their resources to a country-ownership model, in which decisions on policy and funding are made at a country level, the help of MSM to set priorities is crucial.^{51,96} In the context of criminalisation and intense stigma, mechanisms must also be put in place to facilitate community involvement. Responses based in civil society and the MSM community are important components of a comprehensive HIV response,⁹² and are strongest when community members are involved at all stages of programme development and implementation, rather than merely at the service provision stage.⁵⁴ For instance, in the 1980s, the multicentre AIDS cohort study suggested that the best predictor of reductions in high-risk sexual practices among MSM in the USA was when social norms changed in response to community-led initiatives.^{97,98}

HIV led to turmoil in the worldwide gay community in the 1980s,⁹⁹ yet it was also a time in which gay communities responded forcefully to advocate for their needs and provide services when no one else would. This situation is now paralleled by that for emerging MSM communities in low-income and middle-income countries.¹⁰⁰

Conclusions

Gay and MSM leadership in the response to AIDS has taken many forms and confronted many different challenges. Yet these diverse responses have shared a catalytic sense of urgency to protect personal health and the recognition that doing so requires community-level action to address stigma, discrimination, violence, outright neglect, and hostility from government and society. Seven of the ten countries receiving the greatest support from the Global Fund to Fight AIDS, Tuberculosis and Malaria, and more than half of the 88 countries supported through PEPFAR criminalise consensual same-sex practices (appendix). Enforcement of these laws has limited provision of care of peers by the MSM community through the placement of restrictions on funding and

service provision and uptake.^{47,101} To work with nascent MSM community groups can be challenging, since they are frequently expected to represent the needs of all MSM, irrespective of cultural identity, sexual orientation, and sociodemographic characteristics, such as marital status and age. Moreover, these groups are frequently expected to provide services with the same level of monitoring and evaluation expected of transnational HIV implementing entities but with negligible funding.⁴ Therefore, different MSM groups often remain on the margins of the response and are forced to compete with one another rather than collaborate. Despite these issues, there is cause for tremendous optimism. Just a decade ago, public health officials confidently asserted that there were no gay men in Africa or China, and that the very notion of emerging LGBT communities was foreign, western, or otherwise irrelevant (appendix). We have found quite the opposite: indigenous MSM groups are continuing to emerge worldwide and are communicating with their communities



Figure 3: Centro de Orientación e Investigación Integral workers with transgender individuals in the Dominican Republic

As a provider of HIV services, Centro de Orientación e Investigación Integral provides HIV prevention, care, and testing services to transgender individuals through a mobile clinic. Reproduced by permission of ProActividad/amFAR, The Foundation for AIDS Research.

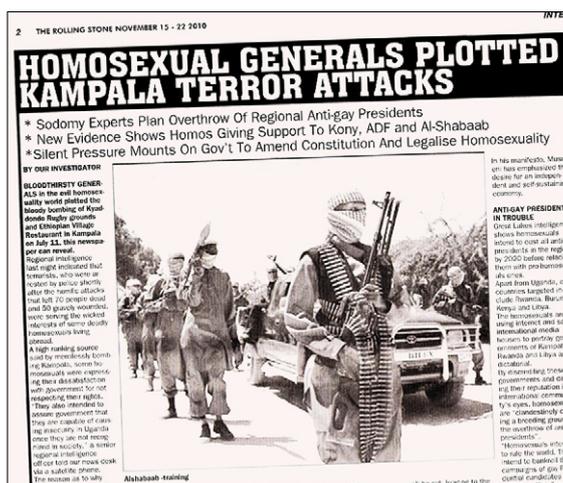


Figure 4: Increased awareness of gay and MSM groups can raise the risk of reprisal

Image shows an article from a short-lived Ugandan tabloid newspaper of Nov 15, 2010.

and with each other through regional bodies and virtual networks, such as the Global Forum on MSM and HIV, and are actively engaged in dialogue on HIV prevention, treatment, and care on a worldwide scale.

Where legal systems and social norms are highly prohibitive to same-sex activities, leaders of HIV programmes are becoming increasingly visible and vocal champions for human rights, gender equality, diversity, and pluralism. They will also have to address human rights violations and support legal protection to enable MSM communities to engage in health promotion, services, and planning. Ultimately, improvements in health and realisation of human rights are twin goals of MSM community leadership and participation, whether through advocacy, participation in research, service provision, or personal benefit attained through engagement in advancing the health of one's community.

MSM community groups have supported the collection of data that challenge the assumption that gay men and other MSM do not play substantial parts in the HIV epidemic in low-income and middle-income countries.⁸ These data suggest a renewed approach to HIV surveillance is needed that includes all at risk of HIV infection rather than merely those most visible in responses. International HIV funders, with the support of MSM community groups, will need to hold governments accountable for allocating HIV funding to MSM-focused programming proportionate to the HIV burden faced by the populations in question. Looking forward, MSM community advocacy and engagement will remain essential to ensure appropriate use of new technologies and benefit from scientific knowledge, to advocate for resources and their strategic and equitable use, to provide targeted services, and to address stigma and other issues related to health.

Gay men and other MSM in many contexts have been leaders in the response to HIV since the beginning of the epidemic, and their efforts have helped all affected by HIV to live and improve their quality of life. In the fourth decade of HIV, the paradoxical exclusion of MSM from the services they helped to develop must end if we are to achieve an AIDS-free generation.

Contributors

All authors provided input and guidance on the concept and outline of the manuscript. Each author then wrote different sections of the manuscript with guidance from GT and SB. SA, CC, CB, and SB edited the various sections into the final manuscript.

Conflicts of interest

We declare that we have no conflicts of interest.

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