Lessons From the Front Lines

Research Impact Analysis

amfAR, The Foundation for AIDS Research
In addition to amfAR, major support for the GMT Initiative is provided by:

Cover photos (top to bottom right): Grantee partner colleagues from Health Options for Young Men on HIV, AIDS and STIs (HOYMAS) in Nairobi, Kenya; Collaborative Network of Persons Living with AIDS/Belize (CNET+) in Belize City, Belize; United Belize Advocacy Movement (UNIBAM) in Belize City, Belize; Club Life+ in Odessa, Ukraine; and the Penitentiary Initiative in Nikolaev, Ukraine.
The world is increasingly aware of the scale, scope, and severity of the global HIV epidemic among gay men, other men who have sex with men (MSM) and trans individuals (collectively referred to as “GMT”). However, current interventions for preventing HIV infection, improving access to treatment, and addressing a range of other HIV- and STI-related issues among GMT are inadequate, and those that are supported by evidence of efficacy have not been taken to scale for GMT in much of the world. As a result, HIV rates among GMT continue to rise.

An ambitious research agenda is urgently required to develop effective combination prevention interventions, markedly improve access to antiretroviral therapy (ART), address structures that inhibit access to health services, and investigate the role of treatment as a prevention tool for GMT individuals. This is a moment of unprecedented scientific opportunity.

Yet enormous challenges face all who are engaged in this effort or seeking to become involved. In much of the world, GMT and other sexual and gender minorities still face discrimination of various kinds, including discrimination in healthcare, denial of their existence in some countries, and criminal sanctions and social exclusion in others. It remains challenging to undertake research with GMT populations in many places, and in some settings, the safety of study participants and research and clinical staff can be a very real concern. Yet this important work must be done, and done well.

History has indicated that effectively engaging men who have sex with men and the lesbian, gay, bisexual, and trans communities (MSM/LGBT) is crucial for the development and implementation of comprehensive and effective HIV/AIDS responses. Meaningfully engaging those most at risk of HIV significantly improves the quality of research because it creates a sense of trust and ownership among the community research participants. It also maximizes efforts to protect the participants and improves research uptake and implementation by ensuring the sustainability of the programs after the research concludes.

Additionally, in more repressive environments, governments and healthcare providers are often unwilling to provide services to GMT individuals and other sexual and gender minority populations, making GMT community engagement in research, service provision, and advocacy critical. In these environments, working without GMT community organizations is simply not feasible. Adequate input from the MSM/LGBT community legitimizes the research aims and improves measures of appropriateness, transparency, and social equity across the study spectrum.

Too often the engagement of community organizations in research is limited to using them to recruit potential community study participants. To counteract this, it is crucial that the participation of communities is not limited to any one stage of the design, implementation, analysis, or presentation of research studies. Rather, participation should be a consistent component throughout the research process. Research that includes long-term, committed engagement of communities can result in these community organizations building the capacity to solve their own problems, including reducing the spread and impact of HIV, while continually decreasing external involvement and support.

Since its inception in 2007, the GMT Initiative (run by amfAR, with generous support from the Elton John AIDS Foundation, ViiV Healthcare Positive Action, AIDS Fonds of the Netherlands, the Levi Strauss Foundation, and the Ford Foundation) has supported GMT-led community organizations in conducting their own community research. With an investment of US$15,000–$20,000 in each grantee organization, amfAR has funded this research to develop a base of information about GMT that is lacking in many countries in the world. The dedication and success of these grassroots MSM/LGBT organizations has often resulted in governments or bilateral donors providing funding to scale up their community-led research and to implement programs based on the results.

To date, amfAR has invested nearly half a million dollars in small grants to community-led organizations working to gather information on HIV prevalence and vulnerabilities to infection and to increase knowledge about effective programming for GMT individuals. In total, 20 studies have been supported across five regions—Africa, Asia-Pacific, the Caribbean, Eastern Europe and Central Asia, and Latin America. This report highlights some of these community-led research studies and the impact they have had.

Additionally, amfAR—in collaboration with the Johns Hopkins University School of Public Health, the United Nations Development Program, and the International AIDS Vaccine Initiative—released a research guidance document that offers guidelines for safe and effective GMT community engagement in HIV-related research, and guidance to help communities recognize the inherent worth of such collaboration.
Community-Led Research

*For the purposes of this report, grantees conducting needs assessments for direct programmatic use were not included. The GMT Initiative has supported numerous needs assessments to better inform the work grantees are implementing.

Latin America

Silueta X, Guayaquil, Ecuador

Silueta X is a trans organization in Guayaquil, Ecuador, that is working to improve the lives of trans individuals through policy, advocacy, and research. In 2012, the GMT Initiative funded the first trans-specific health and human rights study in Ecuador. The objective of the study was to analyze factors that may influence HIV transmission among trans women in Guayaquil and the greater coastal cities around Guayaquil using a series of focus group discussions, personal interviews, and surveys of 767 trans women.

A Silueta X staff meeting.

Key Findings:

- 35 percent of respondents did not know their HIV status, making it difficult to know actual HIV prevalence among trans individuals in Ecuador.
- 55 percent of respondents reported that frequent discrimination by health workers makes health centers inaccessible.
- 90 percent of respondents reported at least one experience of discrimination on the basis of gender identity.
- Health centers’ data on trans patients is incomplete or inaccurate and data systems vary across centers.
- Despite the fact that Ecuador’s inclusive do not criminalize same-sex sexual behavior nor discriminate based on gender identity, discrimination is still a major impediment in the daily lives of trans individuals.
- 34 percent of respondents reported engaging in sex work due to lack of job opportunities and to limited education caused by intense discrimination in schools.

Key Recommendations:

- Continue working with Ecuadorian society to bring truthful information about trans individuals to demystify the population and reduce stigma and discrimination.
- Increase government and regional stakeholders’ financial support of trans-specific HIV prevention, treatment, and care.

Following Silueta X’s study, the Ecuadorian government reviewed the results and agreed to finance the same study on a national level and expand it to address the broader LGBT population. Silueta X led the design and implementation of the national study, which surveyed 2,805 members of the LGBT community on topics including healthcare access, discrimination, and education. Additionally, based on the results of the initial survey, Silueta X received funding from the Dutch-based Mama Cash to implement a national media campaign to combat stigma and discrimination against LGBT in education, health, and employment, and another grant from HIVOS for lesbian and trans health consultation. The GMT Initiative is also supporting Silueta X for another year to address stigma and discrimination against trans individuals in Ecuador within the government and broader society.

Additional GMT Initiative Research Grants in Latin America

VIVO POSITIVO – Santiago, Chile (2011)
Homophobia, Quality of Life, and Vulnerability to HIV/AIDS in Homosexuals
The quantitative research project examined homophobic attitudes among both heterosexual and homosexual men, and the relation of those attitudes to HIV vulnerability among MSM. In addition, the study examined real and perceived discrimination among gay men and how this discrimination affects their quality of life. It also examined protective factors that lead to the reduction of the spread and impact of HIV/AIDS.

Instituto de Estudios en Salud, Sexualidad y Desarrollo Humano – Lima, Perú (2011)
Contextual Issues of the Transgender Experience and Their Relation to Vulnerability
The qualitative research study informed interventions focused on reducing the spread and impact of HIV among trans women in Peru. The study examined gender identity, sex work, gender enhancement techniques, and substance use in relation to HIV vulnerabilities.

Asociación Civil De Desarrollo Social Y Promoción Cultural Adesproc Libertad LGBT – La Paz, Bolivia (2010)
Adesproc Libertad LGBT
The project analyzed the relationship between access to HIV/AIDS services and homophobic/transphobic attitudes and behaviors at government-run health centers in the cities of Santa Cruz, Trinidad, Tarija, Oruro, Potosí, and La Paz. Both health workers and potential clients were interviewed and the results and policy recommendations were disseminated to key stakeholders in the LGBT community and the public health system.

Name withheld * – Recife, Brazil (2010)
Merchants of Illusions
The project supported outreach to engage sex workers (both male and trans female) at saunas, cinemas, and other venues by offering them condoms, lubricant, and peer counseling information sessions. Once trust was gained, the project team administered a semi-structured interview process to map socioeconomic profiles of sex workers. In addition, project staff engaged police and public health practitioners in recognizing the needs of sex workers and sponsored forums for sex workers to exchange information and disseminate health information.
The Caribbean

Jóvenes de la Vida Real, Santo Domingo – Dominican Republic

Jóvenes de la Vida Real is an LGBT-led community organization working to improve the HIV-related welfare of marginalized youth. Jóvenes de la Vida Real worked closely with Centro de Orientación e Investigación Integral (COIN), a major research organization in the Dominican Republic, on the 2012 study Male Sex Workers and Their Clients in the Dominican Republic: Exploring the Dynamics of Sex Work and Other Health Variables Related to the Prevention and Intervention of HIV and other STIs. This qualitative study looked at two distinct populations—245 male sex workers (MSW) and 49 of their clients—to improve understanding of the sexual dynamics between MSW and their clients in the Dominican Republic in order to improve health interventions for both populations. Jóvenes de la Vida Real used questionnaires approved by each target population and more in-depth focus groups from both populations.

Key Findings:

Male Sex Workers

- Nearly 100 percent of rural or peri-urban MSW reported not wanting to seek treatment for STIs due to stigma, compared to 13 percent of urban MSW.
- 25 percent of MSW had never been tested for HIV.
- Of the respondents who had been tested for HIV at least once, 20 percent had not been tested in the past year.
- 56 percent of MSW reported having unprotected anal intercourse (UAI) in the past seven days.
- 42 percent reported regular alcohol and drug consumption.
- 44 percent reported stigma and discrimination from family, friends, police, and/or health professionals.

Male Sex Workers’ Clients:

- 90 percent of clients reported getting tested for HIV in their lifetime and 27 percent in the last six months.
- 87 percent reported no experience of stigma when going for STI treatment in clinics.
- 42 percent usually used condoms with MSW (no mention of lubricant use).
- 54 percent reported regular alcohol and drug use.

Key Recommendations:

- Develop a system to refer MSW and their clients to health centers that are free from stigma and discrimination to increase access to HIV/STI testing, treatment, and care.
- Promote and advocate for affordable HIV testing campaigns throughout the year for MSW and their clients.
- Create and implement harm reduction programs to address the HIV/STI risks among MSW and their clients related to frequent alcohol and drug consumption.
- Create a document that will record and report cases of discrimination against MSW and their clients by police, government officials, and healthcare providers to create awareness and reduce discrimination.

Following this study, Jóvenes de la Vida Real signed official agreements with the National Ministry of Health in the Dominican Republic to provide certain public health centers and their staff with the necessary training to reduce stigma surrounding MSW and their clients. Jóvenes de la Vida Real also shared study results with local police to promote the safety and health of MSW. This study made it apparent that there was little or no formal organization representing MSW, the majority of whom do not identify as gay or homosexual. As a result, groups of MSW are holding meetings to discuss their needs and developing a strategy to become a legal entity.

The Health Policy Project (with funding from USAID) has invited Jóvenes de la Vida Real, in collaboration with COIN and other local organizations, to submit a proposal to strengthen targeted organizations’ institutional and individual capacity to effectively prevent gender-based violence against sex workers of all genders and sexual orientations. The proposal will also aim to strengthen partnerships between government and civil society at the national and local levels to address violence and discrimination.
Asia and the Pacific
STDs/HIV/AIDS Prevention Center (SHAPC) – Hanoi, Vietnam

SHAPC is an organization in Hanoi, Vietnam, working to reduce HIV transmission among vulnerable populations and stigma and discrimination among people living with HIV. In 2010, SHAPC implemented a research study among MSW titled MSM Sex Workers in Hanoi – High Risks and Barriers to HIV Prevention. This quantitative and qualitative research study examined high-risk behaviors among MSM sex workers in Hanoi and the factors that inhibit them from using sexual health services, in an effort to improve HIV prevention programming for the population. Due to the stigma surrounding this population, SHAPC recruited MSW for the study using the snowball method—in which participants recruit additional participants through acquaintances and social networks—and used personal interviews and questionnaires to obtain more in-depth information.

Key Findings:
- A majority of respondents had limited understanding about the modes of transmission and prevention of HIV/STIs.
- Many respondents felt discriminated against by healthcare providers when they were open about being MSM or MSW.
- A majority of respondents had a high number of clients and sex partners.
- A majority of respondents had experienced at least one violent or coerced interaction with a client or clients.
- 67 percent reported having felt pressured or coerced into not using condoms.
- 24 percent reported regular drug use.

Key Recommendations:
- Improve and increase HIV knowledge among MSW.
- Advocate for brothel owners to implement interventions that improve awareness about HIV risk among MSW, and promote the use of condoms and lubricants in their brothels.
- Promote workshops for medical providers to improve their sensitivity about the issues MSM and MSW face and the care they offer them.
- Scale up research about MSM and MSW in Vietnam and across Southeast Asia to improve understanding of their specific health needs related to HIV/STI prevention, treatment, and care.

Following this study, SHAPC held a study dissemination meeting for regional stakeholders. The findings were used by USAID and other partner organizations to develop stronger HIV programs targeting MSM in Vietnam.

Additional GMT Initiative Research Grants in Asia and the Pacific

PT Foundation – Kuala Lumpur, Malaysia (2012)
MSM and Transgender (TG) Sexual Health Profile Study in Kuala Lumpur
This community-led research project aimed to estimate the seroprevalence of HIV, syphilis, and hepatitis B in the high-risk segment of the MSM population of Kuala Lumpur. Utilizing a clinic-based sample, the project also provided free treatment or vaccinations when appropriate.

Chengdu Gay Care – Chengdu, China (2012)
PCA, Empowerment, Advocacy: Improve the Living Status of TG in Chengdu, China
This research, direct service, and advocacy project implemented a participatory community assessment of the trans community in Chengdu and worked to establish the first formalized trans community-based organization in China. The project also promoted the inclusion of trans individuals in local and national HIV/AIDS prevention strategies.

Sangama (in partnership with Aneka) – Bangalore, India (2011)
Community-Centered HIV Prevention Intervention Models Among Transgender
The research study used qualitative methods to analyze existing HIV prevention program models among trans communities. It also developed guidelines to increase the involvement of trans individuals in future programs and recommendations to achieve universal access to HIV services.

Name withheld * – Secunderabad, Andhra Pradesh, India (2010)
Field Based Oral HIV Testing and Linkage to Government Care in a High HIV Prevalent Region of India
The project evaluated the use of peer outreach workers for field-based oral HIV testing that included linkage to confirmatory testing and care. The peer educators showed a digitally recorded pre-test counseling session on laptop computers to attract clients for testing and risk reduction counseling. Post-test results were given by a professional counselor in a health center and “health navigators” were engaged to assist MSM who tested positive for HIV in accessing quality care services.
**Eastern Europe and Central Asia**  
**Safe Pulse of Youth (SPY) – Belgrade, Serbia**

SPY is a grassroots organization in Serbia that works to protect the human rights and health of LGBT people. SPY conducted a qualitative research analysis of HIV/AIDS-related services for GMT within the public healthcare system and the private non-governmental system. The project assessed GMT clients’ perceptions of and satisfaction with services. It was designed to provide recommendations to improve existing services at the Drop-in Center, a SPY-supported health center catering to GMT, and recommendations to improve public-sector services.

SPY undertook this effort as part of an economic analysis of the cost effectiveness of its Drop-in Center in Belgrade, with the ultimate goal of producing projections for the fiscal sustainability of the center over a five-year period. SPY also undertook a legal analysis of Serbian laws that affect clients at its Drop-in Center, with the intention of using the information to develop an advocacy agenda to promote sound public health policies that increase GMT individuals’ access to quality health services.

After completion of the study, SPY organized a high-level meeting with prominent government and national stakeholders to discuss the outcomes. They viewed the study results as important and as the first of their kind in Serbia. The National Office for HIV/AIDS promised to rapidly adopt the research findings and to incorporate them into the five-year National HIV Strategic Plan. The government also recognized that civil society organizations have significant expertise in working with at-risk populations and promised to lend these organizations further support.

Given that the Global Fund to Fight AIDS, Tuberculosis and Malaria will not be funding Serbia in 2014, the government, SPY, and other stakeholders collaborated in drafting a seven-step action plan that effectively ensures a sustainable and local approach for continued work with GMT in Serbia. The plan includes sustained efforts to work with healthcare providers to offer stigma-free services for LGBT people. In addition, SPY created an advocacy toolkit to be used in all drop-in health centers to ensure that GMT receive systematic, quality care. SPY will also receive a three-year grant from the GMT Initiative to ensure sustainability and continue their important work in Serbia.

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**Key Findings:**

- GMT individuals lacked knowledge of where to find GMT-friendly testing and counseling services.
- Healthcare systems were missing a standard of care for HIV counseling and testing and a process to monitor the quality of care.
- Public health centers lacked confidentiality.

**Key Recommendations:**

- Create an action plan to implement the recommendations of the economic and legal analyses to ensure the financial sustainability of the Drop-in Center.
- Create a strategic plan that includes activities for the next five years based on the economic and legal analyses.
- Develop a plan to redistribute funds in accordance with the strategic plan and that prioritizes the Drop-in Center services that have the most value.
- Obtain accreditation and certification of the Drop-in Center’s services to help ensure service quality is based on relevant international and European standards.
- Prioritize fundraising to ensure long-term sustainability of the Drop-in Center, including by targeting funding requests to both national and international donors.

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**Additional GMT Initiative Research Grants in Eastern Europe and Central Asia**

**NGO Insight – Kiev, Ukraine (2011)**

*T – Time*

This research and advocacy project conducted a qualitative study of trans needs and opportunities. Various issues were studied, including access to hormones and other medical services, sexual behaviors and awareness of safer-sex practices, and strategies for effective HIV/STI prevention among trans individuals. The project also held trainings and skills-building workshops for trans women on human rights, healthcare access, and HIV prevention, and distributed condoms and lubricant. Insight is also working to challenge Ukrainian laws related to gender reassignment surgery.

**Republican Youth Public Association “Meeting” – Minsk, Belarus (2009)**

*Factors Promoting Risky Behavior in MSM*

This project helped researchers design and implement a study focused on sociological factors of self-identity, social networks, behaviors, exposure, risks, and vulnerability among a sample of at least 500 MSM in Minsk, and the collected data was used to inform the development of national HIV prevention efforts.

**The Donbas-SocProject (DSP) – Donetsk, Ukraine (2009)**

*Self-Identity, Social and Sexual Networks, and HIV Infection Risk for MSM*

This project designed and implemented a research study on sociological factors of self-identity, social and sexual networks, sexual behaviors, and potential HIV exposures among MSM in the cities of Mariupol, Gorlovka, Kramatorsk, and Torez. It generated data and findings that informed the development of HIV prevention efforts and were compiled and presented to regional and national HIV and LGBT networks and submitted for publication in academic peer-reviewed journals.
Condom use was markedly inconsistent due to lack of availability and lack of negotiation with sexual partners. Knowledge of sexual health was very poor, underlining the serious issues regarding the inaccessibility and inequality of health services in South Africa. Many respondents had experienced discrimination from healthcare workers.

Key Findings:

- Public health services for trans women and men were generally unsatisfactory. Many respondents preferred paying higher costs (when they could afford it) at private centers for better care. Many respondents had experienced discrimination from healthcare workers.
- In instances where trans women were perceived to be biologically female, the quality of services was better.
- In facilities where services were more inclusive of GMT, they were typically aimed only at gay men or other MSM, and trans-specific health services continued to be poor in quality.
- Many respondents reported a negative experience when getting tested for HIV, citing degrading or moralistic remarks. This experience was also a reason for many not to get tested for HIV.
- Knowledge of sexual health was very poor, underlining serious issues regarding the inaccessibility and inequality of health services in South Africa.
- Condom use was markedly inconsistent due to lack of availability and lack of negotiation with sexual partners.

Key Recommendations:

- Address abuse, discrimination, and unprofessional behavior by healthcare workers on a national level to ensure that all individuals, regardless of sexual orientation or gender identity, can access health services.
- Increase training for healthcare workers on providing quality, professional care for all individuals.
- Address other structural issues, such as the lack of educational and professional opportunities for LGBT, specifically trans, individuals.
- Scale up programs addressing substance use and condom use and negotiation for trans individuals to help prevent HIV transmission.
- Distinguish between male health (heterosexual and homosexual) and trans health to provide the services necessary for each particular population.

Following this pioneering study on trans issues in Africa, Gender DynamiX worked with an independent doctor who wrote two sets of targeted guidelines. The first, which targets trans individuals, is called Sexual Health for Transgender & Gender Non-Conforming People, and the second targets service providers. The guidelines have been distributed widely at national and international conferences and with key health staff and government members in South Africa. Gender DynamiX is currently searching for funding to have the guidelines translated into several local languages.

Additional GMT Initiative Research Grants in Africa

WhyCan'tWeGetMarried.com (WCWGMC) – Freetown, Sierra Leone (2012)

Breaking Down Taboos and Raising HIV/AIDS Awareness Among MSM

The project worked with MSM and trans populations to strengthen HIV/AIDS knowledge, distribute condoms and lubricant, and promote HIV testing using street theater techniques. To inform these outreach efforts, the organization implemented a knowledge, attitude, and practice (KAP) study to gauge the level of knowledge among these populations. The results of this study were used to advocate for improved support for MSM- and trans-specific health services in Sierra Leone.

Gays and Lesbians of Zimbabwe (GALZ) – Harare, Zimbabwe (2011)

HIV Prevention Project for MSM by MSM in Zimbabwe

The project aimed to reduce HIV/STI transmission among MSM within GALZ and throughout Zimbabwe by improving outreach and discussion groups and distributing condoms and lubricant. Additionally, GALZ designed and implemented an HIV seroprevalence study among MSM and worked to strengthen relationships with government agencies and other major stakeholders to improve community visibility and advocacy efforts.

Friends of RAINKA (FoR) – Lusaka, Zambia (2010)

Seroprevalence Study for Zambian MSM

This community-based, respondent-driven sampling research study assessed HIV-related risk behaviors and described the epidemiology of HIV infection among MSM in three urban sites and one rural site in four provinces of Zambia. Findings were disseminated to myriad stakeholders and used to advocate for greater commitments to HIV programming for MSM in Zambia.

Concern For Humanity (CFH), Inc. – Monrovia, Liberia (2009)

Qualitative Assessment of HIV Risk Behaviors Among MSM in Liberia

CFH conducted in-depth, qualitative interviews with at least 25 young MSM in Monrovia to document HIV-related risks, risk factors, and program needs. The findings were used to develop program recommendations for future interventions.
Conclusion

Despite growing awareness about the importance of HIV research that includes GMT, there remain significant gaps in epidemiologic data and funding for GMT research and evidence-based programming. Directly involving GMT in the design, implementation, and validation of research about their community is vital to its success. Community involvement also ensures greater visibility of GMT organizations and understanding of the issues GMT face, and it helps increase the organizations’ capacity to perform ongoing, independent research and to advocate for the health and human rights of GMT.

The community-led research highlighted in this report outlines several effective strategies to better engage GMT populations in HIV and other health services. These include:

- Training medical professionals to provide GMT with health services that are free of stigma and discrimination.
- Developing a system to refer GMT to health centers where the staff has received this training.
- Scaling up research about GMT to better understand the community’s specific health needs.
- Improving prevention programs that address substance use, sexual health, and condom use and negotiation.
- Advocating for GMT human rights, including educational and employment opportunities, to address the structural issues that can increase a population’s vulnerability to HIV.

Additionally, the highlighted organizations’ success demonstrates that community-led research about the HIV-related needs of GMT and the best strategies for meeting them can cause national governments and other stakeholders to improve their GMT programming by adopting these recommendations and funding the community organizations to implement them. The studies also generate data about GMT and HIV where this data was not previously collected, providing the community with an invaluable advocacy tool to show that they do exist and are in need of healthcare funding and legal protection from discrimination.

amfAR remains committed to addressing these research gaps by continuing to promote GMT involvement and leadership in research and evidence-based programming. amfAR’s model shows that a small investment can have a tangible impact.
Cover photos: Grantee partner colleagues working with (top left to bottom right) Collaborative Network of Persons Living with AIDS/Belize (CNET+) in Belize City, Belize; United Belize Advocacy Movement (UNIBAM) in Belize City, Belize; Club Life+ in Odessa, Ukraine; and the Penitentiary Initiative in Nikolaev, Ukraine.