



REDUCING STIGMA AND DISCRIMINATION

**in Access to HIV Health Care for Gay
and Bisexual Men and Transgender
Women Using Mystery Patients in
Cameroon and Zimbabwe**

A CASE STUDY



Summary. This case study highlights two examples of a community-led monitoring approach using mystery patients to document stigma and discrimination in the provision of health care. The process and outcomes of using these strategies in Cameroon and Zimbabwe are described. In each country, over a period of 10-12 months, gay and bisexual men and transgender women documented their experiences at select health care facilities using standardized tools. In Cameroon, findings from 162 covert observations were used to create a sensitization training for health care workers. During trainings of 120 health care officials and workers from three health districts, quantitative findings and mystery patient testimonials were shared. Trainings led to the development and implementation of corrective action plans in districts' facilities. In Zimbabwe, patient reports were fed back to health care facilities on a quarterly basis. Changes in response to feedback from the 456 mystery patients included establishing new training policies, hanging affirming signage, and advocacy led by nurses for sensitization to be included in their degree programs' curriculum. Continuous improvements led to increased use of facilities by gay and bisexual men. In both countries, the use of mystery patients had a community mobilizing effect. The projects also brought gay and bisexual men, transgender women, and local health care facilities together to work collaboratively on eliminating barriers to access to care.

Advocacy and other Community Tactics

(Project ACT) was a 2-year demonstration project to reduce stigma and discrimination and eliminate violence impeding access to HIV health care for gay and bisexual men and transgender women. Funded by the Elton John AIDS Foundation through its LGBT Fund and led by MPact Global Action for Gay Men's Health and Rights, based in Oakland, California, USA, the project pilot-tested community-led advocacy initiatives in seven African and Caribbean countries: Burundi, Cameroon, Cote d'Ivoire, Dominican Republic, Ghana, Jamaica, and Zimbabwe.

MPact sponsored a prospective longitudinal evaluation of Project ACT to help identify the challenges of implementing advocacy approaches successfully and to document the setbacks and achievements to which the advocacy efforts contributed in each country. The evaluation relied on close on-site monitoring of four of the projects (Cameroon, Cote d'Ivoire, Jamaica, Zimbabwe) during and after project implementation. Evaluation site visits incorporated observations, interviews, and focus groups, in addition to collection

and review of documents. A post-project peer-to-peer reflection and learning workshop brought together all Project ACT partners as the projects neared their conclusions. Drawing on these informational sources, in this case study we describe the results of two of the pilot efforts that used mystery patient methodology and the lessons learned through their implementation experiences.¹

From June 2018 through February 2020, Project ACT supported pilot tests of community-led monitoring



Project ACT partners identify lessons learned at a post-project reflection workshop in Rwanda, December 2019.



A mystery patient shares her experiences of stigma seeking healthcare with Cameroonian health care workers and officials in Douala.

of health care provision using mystery patients in Cameroon and Zimbabwe². In Cameroon, the project was led by Affirmative Action and operated in three health districts in the capital city of Yaoundé. In Zimbabwe, the Sexual Rights Centre led the mystery patient monitoring effort in one private clinic, one government hospital, and the citywide system of local clinics serving the Bulawayo metropolitan area. In each country, monitoring using mystery patients was coupled with training to sensitize health care workers on bias reduction and to improve their understanding of the unique health care needs and concerns of gay and bisexual men and transgender women.

CAMEROON: MY PROVIDER, MY HEALTH

Background. Cameroon's population comprises roughly 24,767,836 people. About 37.5% of Cameroon's adults live below the national poverty line. A country with weak healthcare infrastructure, Cameroon has an average life expectancy of only 54 years. As of 2018, HIV prevalence among Cameroonian adults aged 15-49 years was 3.6%. The annual incidence rate among people

aged 15-49 stood at 1.6%. However, estimated HIV prevalence among gay and bisexual men in Cameroon is 20.7%. Reliable prevalence estimates for transgender populations are unavailable.

Cameroon criminalizes same-sex sexual relations with a maximum of 5 years imprisonment and is considered among the most inhospitable countries in the world for lesbian, gay, bisexual, transgender, queer, and intersex (LGBTQI) people. According to the Williams Institute, in 2017 Cameroon ranked 145th out of 174 countries on an index of social acceptance of LGBTQI people. Human rights advocates writing for the blog *76 Crimes* report Cameroon's LGBTQI community suffered over 1,700 incidents of homophobic and transphobic violence in 2018 alone. Unsurprisingly in consideration of its deeply entrenched stigma of homosexuality, Cameroon scores low on a 2019 index of indicators reflecting how well countries meet gay and bisexual men's HIV prevention needs. The 2018 World Health Organization's analysis of Africa's National AIDS Strategic plans observed Cameroon's plan was silent on addressing the unique needs of transgender populations; it laid out minimal plans for targeting gay and bisexual men.

According to local activists and health care workers, the health care needs of gay and bisexual men and transgender women are made acute by widespread societal and familial rejection. Activists report it is a common practice for families to eject children who are suspected of being LGBTQI from the household and to withhold from them financial resources. Withdrawal of



The street view of CAMNAFAW Medical Centre, Yaoundé, Cameroon.

family resources and supports prevents young LGBTQI people from completing an education and may force them to survive day to day on the streets. Landlords are said to be reluctant to rent to people known or suspected of being a member of the LGBTQI community. Stories of being evicted are commonplace. Activists report community members may be evicted without first being accorded the opportunity to retrieve any of their personal possessions from their homes. Community members remain ever vigilant to threats of violence from landlords, family members, neighbors, co-workers, fellow students, and strangers. These conditions challenge community members to prioritize and address health concerns.

Evaluation Data Collected in Cameroon. In Cameroon, the evaluator visited the project in February of 2019 during the early stages of project implementation, in August of 2019 after mystery patient implementation had been ongoing for 6 months, and in March of 2020, after 10 months of mystery patient activity and the training of health care workers had been completed. Each visit lasted 5 to 6 days. Across visits, interviews and focus groups were completed with 6 staff and volunteers of Affirmative Action, 3 government officials, 7 staff from collaborating organizations, 9 mystery patients, 3 health district heads, and 7 health care workers from two of the targeted facilities. Eleven of these individuals were interviewed on more than one occasion. Facility tours, observations, and document reviews were also completed as part of each visit.

Designing and Implementing Mystery Patient Monitoring. Although Affirmative Action operates on a national scale, it chose to implement its mystery patient efforts in Yaoundé where it is headquartered. Yaoundé, Cameroon's capital and second largest city, is in the south-central region of the country. A Francophone city of roughly 3.2 million people, the city is divided into six health districts, each of which contain four to 12 health areas. Affirmative Action chose to target facilities in Biyem-assi, Nkoldongo³, and Cité Verte districts for mystery patient monitoring. In Nkoldongo, a private clinic that is a member of the International Planned Parenthood Federation and which has historically



Data from 162 mystery patient visits are shared with health care providers, administrators, and government officials in Douala.

enjoyed a reputation as welcoming to the gay community was selected for monitoring. In Cité Verte, the largest public hospital in Cameroon was chosen; its day hospital provides outpatient HIV care to more than 10,000 people living with HIV. In Biyem-assi, the most populous of the three districts, the district hospital was selected. Officials at the facilities in Nkoldongo and Cité Verte were aware of the project and knew that their facilities would be monitored. Biyem-assi officials were not told of the project's activities in advance.

To implement mystery patient monitoring, Affirmative Action chose to partner with a seasoned, non-governmental human rights watchdogging agency, Positive Generation. Positive Generation specializes in covert monitoring of health care service provision to root out corruption, identify supply chain and other systemic failures, and document human rights violations. For Affirmative Action, partnering with a mainstream group such as Positive Generation represented an organizational first. The project provided an important test of whether a mainstream organization focused on the general population and an organization focused on LGBTQI people could collaborate as trusted partners. Nine additional organizations, primarily fledgling organizations representing the diversity of Yaoundé's LGBTQI community and of its LGBTQI people living with HIV, collaborated in the effort by serving as sources of mystery patients and assisting in the development of monitoring indicators. Each of these nine organizations identified two individuals for project participation.

Mystery patients were all volunteers. Organizations' initial pool of volunteers comprised of gay and bisexual men and transgender women. As the project evolved, volunteers came to include lesbians who presented themselves as men when collecting data.

Positive Generation employs a standardized approach to mystery patient monitoring honed over years. To prepare mystery patients to document their experiences of seeking health care in targeted facilities, the mystery patients attended a 2-day training; the training was condensed from the 5-day training Positive Generation ordinarily requires of prospective mystery patients due to budgetary constraints. Mystery patients were instructed in their country's laws and policies regarding health care access, as well as in their constitutional rights to health care as Cameroonians. A key element of the training addressed the various stages through which patients might progress during a visit to a health care facility from the point of entry to exit. Patients were trained on what to expect in waiting rooms, patient registration procedures, pharmacy access, and physician consultations, among other details. They were counseled on what fees to expect at each of the various stages in the process. In Cameroon, patients must pay a consultation fee to progress to see a health care provider. The mystery patients were instructed not to pay any fees but were asked to attend closely to what amounts they were told they must pay. They were taught how to gain access to areas of the facility without having to pay for a booklet. The training emphasized how mystery patients should behave while making visits. The training stressed the importance of avoiding calling undue attention to themselves. Training also covered how data were to be recorded and transmitted to Positive Generation and the schedule for data submissions. Mystery patients role-played aspects of data collection. They also completed a pilot data collection visit, after which they received corrective feedback. Once deployed to the field, Positive Generation staff remained available to mystery patients by phone and text message to address problems encountered in the field.

Mystery patients were provided a standardized tool with which to rate the quality of their experiences. The tool

was organized to record information on the quality of treatment by all facility personnel encountered at each phase of a visit. The tool was developed in collaboration with the identity organizations so that the indicators reflected the most common experiences reported to them informally by constituents. The indicators included exposure to inappropriate, judgmental, and naïve questions; verbal violence (e.g., insults, taunting, mocking, belittling); disparaging gestures and facial expressions; and, failures to protect privacy and confidentiality. For each indicator, patients wrote a brief statement describing why they provided the quantitative rating they chose. In addition to reporting using the standardized tool, mystery patients were instructed to write a brief narrative account of their experience at each facility.

Mystery patients were initially deployed in January of 2019. They were instructed to visit each of the three chosen facilities once during the initial 3-month period. In the first quarter of their deployment, 12% of 54 observations were provided by transgender mystery patients and 88% were provided by gay and bisexual men. The data from these early visits indicated that stigmatizing treatment commonly occurred, especially for transgender mystery patients. Use of dismissive and derogatory gestures, derisive mimicry, pejorative terms, mocking, and comments on personal appearance were recorded in over 40% of patients' first-quarter reports. Many of these experiences occurred on the way to or in the waiting room. They were also reported in the pharmacy and during the initial process of registration, orientation, and consultation. Nurses, pharmacists, and doctors were cited as the common perpetrators of stigmatizing behaviors, yet all personnel were implicated down to the security guards. Other patients were also implicated. Comparing gay men and transgender experiences, gay men reported the bulk of the discrimination they experienced during patient orientation and when accessing the pharmacy came in the form of gestures and providers' expressed attitudes. Transgender patients, by contrast, were considerably more likely to experience judgements made on their appearance, reproachful attitudes, and verbal violence from nearly everyone they encountered.

Although these data were compelling, Positive Generation staff expressed dissatisfaction with aspects of their quality and the timeliness of their transmission for analysis. Missing data resulted in 8 of 54 observations being discarded and replaced with observations from non-community members. One cause of missing data in the initial month was mystery patients walking out of facilities before completing the entire circuit of stations selected for observation due to the ill treatment they encountered. One mystery patient reported becoming so livid at her treatment, she provoked an altercation with a security guard. Others reported they simply walked out after being mocked and treated rudely during their initial welcome. Mystery patients underwent booster training before being deployed to collect another set of observations. The booster training stressed the importance of completing each visit and behaving in a non-provocative manner in order to document the stigma and discrimination the community endured with systematically collected evidence. Even with this booster, some mystery patients reported that they were still not well prepared to handle the unpleasantness of their healthcare-seeking experiences.

The next quarter of data produced more complete observations. Observations by transgender mystery patients comprised 40% of the total. Yet, challenges collecting data persisted. Mystery patients believed that repeatedly returning to the same three facilities without ever seeking actual care limited the data they might collect by, for example, excluding information on seeking anal health care. They wanted support to pay the booklet fee that would allow them to gain access to an initial medical consultation or a service such as an HIV test. Simply having money to pay their transportation seemed too little, given the goal of documenting what a person from the community might experience in an actual health care interaction.

Mystery patients recognized the risks they took in visiting facilities - risks that were especially great for the transgender mystery patients. The mystery patients believed that having so few people making repeated appearances to the same places made them vulnerable to discovery. The mystery patients described instances in

The figures I saw for my district made me ashamed because as a health care provider, I ought to provide care to all patients regardless of their sexual orientation.

— District Health Director

which it seemed more than likely they had aroused a staff person's suspicions. The mystery patients felt they would be better protected by seeking actual services and doing so as part of a larger cadre of mystery patients. The more mystery patients making repeated visits for legitimate needs, the less likely any single patient might prompt distrust of the stated reason for their visits to facilities.

Four of the nine collaborating identity organizations operate under a culture of restitution practices. Restitution practices require those who have the privilege of attending off-site trainings share their newly acquired knowledge and skills with those members of their organizations who did not have the privilege to attend. Through these restitution practices, more mystery patients were available than were being deployed. Positive Generation staff agreed it was desirable to increase the number and the diversity of the observers. Positive Generation staff believed that the more mystery patients each organization deployed, the greater their organization's ownership of and commitment to the task of holding facilities to account for providing non-stigmatizing treatment. In their view, the accountability effort should belong to the community.

Reflections on the experiences over the initial 2 quarters of mystery patient data collection prompted modifications to the data collection approach. First, the project re-budgeted to provide mystery patients with



Cameroon's Secretary General of the National Commission for Human Rights and Freedoms presents the senior staff of an identity organization with a certificate of excellence for their supervision and support of mystery patients.

the funds to pay fees necessary to access simple services, namely HIV testing or an initial consultation. Second, the project allowed mystery patients trained through the identity organizations' restitution processes to contribute to the collection of data. Those organizations that had trained additional people could now rotate data collection visits among a larger cadre of individuals, 28 in total, reducing the possibility of their discovery and the stresses of making repeated visits. These 28 individuals participated in additional training on how to collect data. Finally, the project implemented a series of supervision and support meetings for pairs of participating identity organizations in order to obtain their feedback and insights, increase the speed with which Affirmative Action and Positive Generation could respond to issues and challenges occurring in the field, provide support for managing the stresses of the work, and offer tailored corrective feedback on data quality. For many of the mystery patients who were interviewed, these supervisions and the retraining efforts were crucial to understanding the high stakes associated with the project and how the project served their constituents' interests. The supervisions drove home that their communities were relying on them and these data to leverage improvements in access to health care. Mystery patients said that the supervision meetings helped them to perceive they had the support that they wanted and required to do the work. The supervisions marked a major turning point. The mystery patients now saw they had

a voice in the project. Rather than conduct the project on the community's behalf, the project was now being conducted with the community.

During the final phase of data collection, mystery patients from each identity organization coordinated between them as a team to create a schedule for the month's visits. They developed their own plan to each visit a facility on separate occasions or at different times, if each were visiting a chosen facility on the same day. The schedule they created was reviewed and approved by both Affirmative Action and Positive Generation. The schedule was later checked against the reports and expense receipts submitted by each mystery patient as an accountability mechanism.

Using the Mystery Patient Data. The findings obtained from the mystery patients' observations were used by Affirmative Action to create a sensitization training tailored to address the commonly identified sources of stigma and bias reported by the mystery patients. The quantitative and qualitative findings across 10 months of observation detailing 162 covert visits were presented to health care workers at four training sessions. The first training lasted 5 days. It was held in Douala, Cameroon's largest city and economic capital, and was attended by officials and workers from the targeted facilities, the health district heads of Biyem-assi, Nkoldongo, and Cité Verte, and other top government officials. Three 1-day restitution trainings were subsequently held in the districts for health care workers from the facilities that served the greatest numbers of patients living with HIV infection. Workers came to these restitutions at the invitation of the health district directors. In Nkoldongo, the workers invited included the heads of health care services from two of Yaoundé's three prisons. Workers from the district who had participated in the 5-day Douala training co-led their district's training. Across the four trainings, about 120 people were trained.

Mystery patients were present in each of the trainings to provide testimonial accounts of their experiences at the facilities. One discussed her experiences as a transgender mystery patient and the other discussed his experiences

The methodology of Affirmative Action directly talks to people's conscience. It forces us to become close and puts us in proximity. It helps us see these people are not wicked. We see the cultural, religious, and legal context molds us to see them that way.

— Physician

and those of the five other mystery patients from his organization. When asked what they remembered from the training, these testimonials were universally mentioned by health care workers and the others who had been in attendance. The testimonials humanized the quantitative ratings in ways that trainees reported stuck with them, calling their attention to how unpleasant and demeaning an experience it was for gay and bisexual men and transgender people to come to their facilities. They made trainees “*feel how to be in the flesh*” of the community.

The results of the mystery patient data prompted the heads of the health care districts and the staff of targeted facilities to come together to address stigma and discrimination and take the problems identified in the data seriously. Facilities and districts developed preliminary corrective action plans in the trainings and began to enact them afterward. Among the changes facilities committed to enact included all-staff internal trainings, revised waiting room orientations for all patients that emphasized the facility was a stigma-free zone and welcome to all, a WhatsApp group for health

district directors to stay abreast of issues pertinent to stigma-free care provision, and the establishment of limited off-site health care provided at one of the larger identity organization's headquarters. The prison health officials also requested that their entire health care staff receive training. A gala ceremony of appreciation for the mystery patients, their identity organizations, and the targeted facilities was held. Each received a certificate of accomplishment signed by Cameroon's UNAIDS country director, its Secretary General of the National Commission for Human Rights and Freedoms, Affirmative Action's Executive Director, and the Permanent Secretary of the National AIDS Control Program.

Mystery patients' reflections on their participation. For mystery patients, the experience of visiting facilities that they would never otherwise choose to access until they were on their deathbed reduced their reluctance to make use of and refer others to these facilities. Even though encounters with stigma were common, visiting and gaining firsthand knowledge of the health care facilities challenged their preconceptions, both good and bad. Mystery patients said they now felt more confident in navigating health care facilities. As a result of their training and experience, they perceived themselves as positioned to coach others on how to engage health care systems successfully. Several said they are better equipped to push past stigma to get the health care they came to a facility to receive rather than allow stigma to discourage them. They are willing to demand that their rights are fulfilled. “*If I go there and I leave with the health care I need,*” one mystery patient said, “*then I am the one who wins.*”

Lessons learned in Cameroon about implementing the mystery patient method included:

1. Mystery patients require substantial training and ongoing support to collect accurate and complete data. Mystery patients should understand why they are collecting data and how those data will be used as one aspect of ensuring data quality.

2. In a context like Cameroon, mystery patients are placing themselves in positions of vulnerability. They take psychological, emotional, and physical risks to collect data, especially for transgender and gender non-conforming people. Project plans must consider how to maximize the safety and security of mystery patients via the training that they receive, the adequacy of financial supports offered to them for safe transportation to and from facilities, the number of patients and their rotation as data collectors, and systems of check-in and monitoring surrounding their visits. Training must anticipate the diverse situations that patients will encounter and provide ample opportunities to practice how to manage those situations. Mystery patients noted training in diffusing conflict to be particularly useful.
3. Mechanisms for meaningful engagement of community members in project planning and implementation are essential to fine-tune and make mid-course corrections, secure community buy-in and build community members' capacity. Mystery patients can develop ownership of the projects' activities through their inclusion. Ongoing methods for input and community engagement can also help project managers keep their eyes on the intended beneficiaries of the work rather than solely on implementing the activities and tabulating the outputs promised in the project's workplan.

"We won't win with our fists," one advocate said as he reflected on Affirmative Action's mystery patient approach and temperate advocacy strategy, *"but by showing how vulnerable the community is."* By showing this vulnerability through its quantitative and qualitative mystery patient data, Affirmative Action laid the foundation for partnership between the community of identity organizations with which it collaborated and the three health districts and facilities to continue to address obstacles to access to health care for gay and bisexual men and transgender women.

ZIMBABWE: DELAYED DIGNITY IS A RIGHT DENIED (3D)

Background. Zimbabwe's population is currently estimated at 14,816,574 people. The country is crippled by a protracted financial crisis marked by unchecked hyperinflation, extreme economic contraction, and severe shortages in basic resources such as food and power. According to the World Bank, 70% of Zimbabweans lived below its national poverty line in 2017. The country is amidst a severe drought that threatens nearly half the country's population with starvation. Approximately 51.3% of the population is already malnourished.

Life expectancy in Zimbabwe currently stands at 62.2 years, having risen sharply since 2002 when its life expectancy was a mere 42 years. The rise in life expectancy is largely attributable to Zimbabwe's improved response to its HIV epidemic, which, despite a strengthened HIV response, remains among the worst in the world. According to the most recent estimates, HIV prevalence among people aged 15-49 in Zimbabwe is 14%. The general population prevalence in Bulawayo, the country's second largest city, stands at 17.9%. Annual HIV incidence among persons aged 15-49 is 4.86%. The estimated HIV prevalence among gay and bisexual men is 31%. Reliable prevalence estimates for transgender populations are not available.

Zimbabwe criminalizes same-sex sexual behavior between men punishable up to 1 year in prison. On the Williams Institute's Global Acceptance Index, Zimbabwe ranks 110th out of 174 countries in its social acceptance of LGBTQI people. Its recently deposed longtime leader, Robert Mugabe, famously referred to homosexuals as *"worse than dogs and pigs"* on national radio, reinforcing entrenched stigma and discrimination of sexual minority people as the country norm. Zimbabwe's legal and political context, coupled with its economic

deterioration and chronic instability, contribute to its limited effort to address the unique needs of gay, bisexual, and transgender populations at risk of or living with HIV. According to an analysis by the World Health Organization, Zimbabwe's National AIDS Strategic Plan fails to address the needs of transgender people entirely and only minimally addresses the impediments to HIV prevention, testing and treatment faced by gay and bisexual men.

Evaluation Data Collected in Zimbabwe. The evaluator visited Zimbabwe in early February of 2019 and in July of 2020. Each visit included 5 days of data collection. A planned final visit in March of 2020 was cancelled due to the SARS-CoV-2 pandemic. Across the two site visits, interviews and focus groups were conducted with 5 staff, 9 peer educators, 15 beneficiaries, and 6 health care workers from the local government hospital and the private clinic targeted for mystery patient visits. In addition, the evaluator toured each of these facilities and spoke to 6 health care workers on site, observed a health care worker sensitization training, conducted a document review, and observed a 3-day strategic planning retreat in which 21 Sexual Rights Centre staff and leaders from its six identity-based collectives⁴ participated. Other data obtained included a virtual interview conducted with the MPact country lead and 1 staff person in place of the cancelled post-project site visit.

Designing and Implementing Mystery Patient Monitoring. The Sexual Rights Centre (the Centre) headquarters



Participants in Zimbabwe's Looking In, Looking Out self-stigma reduction training.

itself in Bulawayo, Zimbabwe's second largest city. Located in the southwestern region of the country, Bulawayo Province has a population of roughly 638,000 people. A majority in Bulawayo are from the Ndebele tribe, with Shona among the larger tribal minority groups in the region. Bulawayo is the country's industrial capital and the hub of its railways. Many of its factories are shuttered and in disrepair, devastating the local economy.

Private health care is unaffordable for a vast majority of the Zimbabwean people. Government-provided and not-for-profit clinics are what most people can afford to access. Bulawayo contains a network of small private hospitals, a government hospital, non-profit clinics, and a citywide public clinic system to serve its central and outlying districts. Advocates report the LGBTQI community relies heavily on two central facilities for care if they pursue Western-styled medical care at all. The Sexual Rights Centre chose to target these two facilities – the Mpilo Central Hospital and Population Services International's (PSI) Bambanani New Start Centre⁵ – for its deployment of mystery patients. These two facilities were also selected because it would allow the Centre to compare whether stigma and discrimination was greater in a public versus private facility.

The government hospital in Bulawayo, Mpilo Central Hospital, is the second largest hospital in the country. The hospital runs a large nursing school and school of midwifery, in addition to providing medical services. Mpilo serves three provinces, Matabeleland North, Matabeleland South, and Midlands, in addition to Bulawayo. Added together, the hospital's catchment area contains over 6.6 million people. The 1,000-bed facility, once considered among the best hospitals in sub-Saharan Africa, struggles to maintain an adequate staff of physicians because of the country's economic precarity. The overcrowded campus has seen only one new building since its original construction in the 1950s, a neonatal intensive care unit. The former tuberculosis clinic now serves as the HIV outpatient treatment facility. Bambanani New Start Centre is a sexual and reproductive health day clinic run by PSI. PSI is a global not-for-profit health organization focused on



Zimbabwe's peer mobilizers preparing to help patients document experiences of stigma and discrimination on the patient checklist.

care experience. To develop a checklist against which patients could report on the quality of their health care experiences, the Centre held a 2-day workshop with 20 gay and bisexual men. The workshop resulted in a preliminary checklist of indicators to monitor stigma and discrimination. The Centre recruited 10 young men to pilot-test the tool. Five young men were deployed to Mpilo and five to Bambanani over a 2-week period. At Bambanani, the mystery patients sought HIV testing or STI screening. At Mpilo, they sought a range of health services or pursued health information. A meeting was convened with the pilot mystery patients to review the data they had collected to assess the adequacy of the preliminary tool. The final tool contained 14 items each of which was rated using a simple rubric. The Centre used the revised final checklist in three ways: as a mystery patient monitoring tool, as a Patients' Rights charter for the community, and as an educational checklist for health care workers on the elements of a non-stigmatizing health care interaction. The Centre printed copies of the checklist and distributed them to the facilities prior to the monitoring effort so that health care workers were aware of the quality of treatment the community expected and what aspects mystery patients were attending to on their health care visits.

The final preparatory activity was to identify 10 individuals within the targeted health care facilities who could champion the project internally. These individuals played diverse roles within their facilities and included

physicians, nurses, and payment clerks. The champions were tasked with ensuring mystery patients' feedback was used. They also served as thought-leaders within their facilities and internal advocates for change. To assist them in fulfilling their roles, they received training in advocacy from MPact staff.

Once the checklist was ready to use, the peer mobilizers began to work with gay and bisexual men in the community, encouraging them to seek health care at Mpilo or Bambanani. Community members who had health care needs were introduced to the tool by a peer mobilizer and requested to complete it immediately post-visit. The peer mobilizers went to the health care settings with the patients to collect the completed forms after their visits and to assist them in the completion of forms, if needed. Over the course of 12 months, 26 patient reports were made on services at Mpilo and 430 on services at Bambanani.

Using the mystery patient data. On a quarterly basis, peer mobilizers, Centre staff, champions, and a health care worker representative from each facility met as a team to review the completed forms. In these meetings, the discussions focused on the individual forms that raised the most serious concerns regarding incidents of stigma and discrimination. Possible courses of action were brainstormed. Champions and the health care worker representative brought the incidents of concern back to their facilities and worked with their colleagues to develop corrective action plans, such as crafting or modifying internal policies and altering approaches to staff supervision.

Although in Zimbabwe it is not possible to separate neatly the impact of mystery patient monitoring from other activities, the project resulted in a dramatic increase in patients using the facilities; Bambanani witnessed an increase in visits from gay and bisexual men of roughly 355% in the first quarter of monitoring alone. For gay and bisexual men, the fact that providers demonstrated that they were listening, responding to community feedback, and open to learning, encouraged their greater use of these facilities.



A peer mobilizer and SRC manager present their poster on Project ACT at the International Conference on AIDS and STDs in Africa.

The facilities made observable changes resulting from the feedback they received and the knowledge they were gaining on what an affirming health care interaction entailed. The changes put into place included sensitivity training policies for new employees, posting welcoming signage that openly affirms LGBTQI people and their right to be in the setting, offering a weekly clinic held in the Sexual Rights Centre compound, and the crafting of an internal advocacy campaign by champions that Mpilo's nursing program systematically cover material on affirming and non-stigmatizing care. The effort also led the citywide system of 29 neighborhood public health clinics in Bulawayo to request to join the project. A Memorandum of Understanding with the city public health clinics was established in summer of 2019.

Lessons learned in Zimbabwe about implementing the mystery patient method included:

Using actual patients as data collectors had multiple advantages, not least of which was its community mobilizing effect. Use of real patients ensured that the data captured the experiences of a highly diverse set of people pursuing a wide range of health needs. However, real patients may not be expert at data collection and training all of them to become expert may be infeasible. The system developed by the Sexual Rights Centre in which a cadre of trusted peer mobilizers assisted in data collection provided a solution to this challenge. Peers used in this way proved a cost-efficient means to obtaining complete data. Additionally, this approach allowed low-literate patients' input to be recorded. Patients also gained a trained advocate to accompany them to a facility. A side benefit of the peer-based approach included developing these young men's skills and offering them meaningful opportunities in a fiscal environment where these have become rare.

The downsides of relying on real patients were also realized in the project. Real patients pursued the facilities they preferred or that were best suited to their needs and transportation budgets, producing far less data on Mpilo than Bambanani over the course of a year. The flow of patients in and out of facilities was not steady, producing fewer data points in some months than in others.

The use of real patients who are not trained experts in recording stigma and discrimination in health care interactions required the Centre use a very simple general tool, one that did not capture nuance but was of minimal burden to complete. A community-designed monitoring tool provides an opportunity to capture what is important to the community. However, indicators must meet additional standards of quality to be interpretable, accurate, and useful. Among the standards of quality measurement for indicators are unambiguous clarity of focus and meaning in how indicators are operationally defined and phrased, that indicators reflect a singular focus, and that indicators are readily and reliably observable across persons and

settings. Rubrics must be similarly well designed. Even communities with basic research and evaluation capacity may require training in sound measurement to assist them in developing tools that meet these basic standards to inspire confidence in the accuracy and validity of community-led findings.

The partnership model employed in Zimbabwe leveraged health professionals' fundamental commitment to care for all Zimbabweans, creating collaborative synergy between health care facilities and representatives of the gay and bisexual men's community. The benefits of routine feedback and solution development realized through the quarterly meetings between the health care workers and community representatives included rapid corrective responses, assisting facilities to earn the community's trust. Trust coupled with improving experiences of care, in turn, furthered use of services. For health care workers who took on the role of ensuring their facilities responded to the mystery patient data, the partnership model embedded them in a system of support to cope with the inevitable stigma they faced from colleagues for championing the needs of gay and bisexual men. For the community, the partnership model opened an unprecedented line of direct communication with actors in the health care system. The model allowed the Centre to enlist the health care workers as allies in the community's efforts to put pressure on the system to eliminate stigma and discrimination as obstacles to health care.

FINAL THOUGHTS

Although this effort focused on opening access to affirming HIV-focused care for transgender women and gay and bisexual men because they bear a disproportionate burden of people living with HIV, the LGBTQI-focused organizations that engaged in using mystery patient methods tailored the approach to stay true to their missions, engaging the diversity of their LGBTQI communities in the project. The symbolic and practical importance of embracing the entire community emerged in very different ways in each case. Yet, the value attached to the community-building role

of this method and the urgency of not leaving anyone in the community behind was emphasized by people in each setting and demonstrated in how each project proceeded. Further, adopting an inclusive approach to project implementation proved essential to the ultimate success of each project. Although Affirmative Action and the Sexual Rights Centre took distinct approaches to involving local LGBTQI communities in their projects' conceptualization and implementation, grounding the work in and co-owning it with the community lent the projects credibility in the eyes of local health care workers, other duty bearers, and the community itself. Inclusion established collective stewardship of the effort to hold the health care system to account to just treatment of LGBTQI people and laid the foundation for a sustained effort to continue to break down the barriers to care.

RECOMMENDED CITATION

Miller, R. L. (2020). *Reducing stigma and discrimination in access to HIV health care for gay and bisexual men and transgender women using mystery patients in Cameroon and Zimbabwe*. East Lansing, MI: Michigan State University.

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ENDNOTES

- 1 Other common terms for mystery patients include mystery shoppers, mystery clients, and patient witnesses.
- 2 Ghana also implemented mystery patient methodologies and its work was to be included in this case study. However, measures to prevent the spread of SARS-CoV-2 required postponement of data collection in Ghana.
- 3 According to its health district head, Nkoldongo has the highest HIV prevalence rate in Yaoundé at 5% of the general population. Only 50% of those who are HIV infected in Nkoldongo are estimated to know their HIV status; just under 25% of the approximately 25,000 people living with HIV in the district are estimated to be on antiretroviral therapy.
- 4 In addition to its core staff, the Sexual Rights Centre provides capacity building, office space, and other organizational development support for six identity-based collectives, two of which focus on sex workers, one focused on lesbian and bisexual women, one focused on transgender people, and two focused on gay and bisexual men.
- 5 After the project was well underway, the citywide clinic system requested to join the project. The request came in anticipation of a national strategic effort to provide antiretroviral treatments and other HIV-related care through local and neighborhood government-sponsored clinics.
- 6 The health care workers interviewed for the evaluation in both Cameroon and Zimbabwe characterize anal condyloma as epidemic among the men they treat. In Zimbabwe, the SRC peer mobilizers reported they often encounter young men with condyloma or newly diagnosed HIV infection who were unaware anal intercourse poses a risk of STI and HIV transmission.