# Quality Improvement Stories

Improving the Referral System for HIV clients in the Livingstone and Kazungula Districts of Zambia

# Corridors of Hope HIV/AIDS Prevention Initiative

# October 2012

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The Corridors of Hope HIV/AIDS Prevention Initiative (COH III) forms part of the USAID-supported regional ROADS Project through PEPFAR. Running from October 2009 to September 2014, COH III is implemented by FHI 360 in partnership with Afya Mzuri, Zambian Health Education and Communication Trust (ZHECT), and the Zambia Interfaith Networking Group on HIV and AIDS (ZINGO). A community-driven and community-based project, COH III aims to decrease HIV transmission, morbidity and mortality in border and transit districts. One of the main strategies is to provide comprehensive HIV-prevention services and behavior and social change interventions. A second strategy is to strengthen referral networks and linkages with organizations that provide HIV care and treatment, as well as those offering legal protection and economic support for women who are at high-risk of contracting HIV and are affected by HIV and AIDS.

Through facilities and mobile sites, COH III supports HIV counseling and testing, screening and treatment for sexually transmitted infections, as well as family planning services. Counseling and testing is also offered by health care providers and lay counselors who go door-to-door within communities. This service, which incorporates information about sexually transmitted infections, reproductive health, nutrition and other health areas, is of particular value to disabled people and other marginalized groups.

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# Acronym List

ART	Antiretroviral treatment
Chreso	Greek word for "need"
СВО	Community-based organization
СНЖ	Community health worker
СОН	Corridors of Hope
CSO	Central Statistics Office
DHO	District Health Office
DMO	District Medical Officer
FBO	Faith-based organization
FGD	Focus group discussion
FP	Family planning
FPP	Focal point person
НС	Health center
НСР	Health care provider
нтс	HIV testing and counseling
LTFU	Lost-to-follow-up

MARP	Most-at-risk population
МОН	Ministry of Health
NGO	Nongovernmental organization
NZP+	Network of Zambian People Living with HIV
PEPFAR	President's Emergency Plan for AIDS Relief
PLHIV	People living with HIV
PSC	Prevention Services Coordinator
PSO	Prevention Services Officer
QA	Quality assurance
QC	Quality control
QI	Quality improvement
SMEO	Site Monitoring and Evaluation Officer
STI	Sexually transmitted infection
тв	Tuberculosis
USAID	United States Agency for International Development
ZHECT	Zambia Health Education and Communication Trust
ZINGO	Zambia Interfaith Networking Group On HIV/AIDS

#### **Executive Summary**

The Corridors of Hope HIV/AIDS Prevention Initiative (COH III) is a five-year, USAID/ PEPFAR-funded project. The two main objectives of the project are (1) to provide comprehensive HIV and AIDS prevention services, which include HIV testing and counseling (HTC), and (2) to strengthen the continuum of care, including antiretroviral treatment (ART) services, through referral. COH III primarily provides services via Wellness Centers and outreach activities, through which health care providers/counselors provide HTC, screening and treatment for sexually transmitted infections (STIs), and family planning (FP) counseling. Referrals for HIV-positive clients include an assessment of their immediate needs for HIV care and supportive services and the provision of information on where and how to access HIV services from health facilities that offer the continuum of care.

COH III staff determined that although all HIV-positive clients are referred by Wellness Centers, less than a quarter of them reach the referral sites. In order to increase the proportion of completed referrals, COH III launched a quality improvement (QI) project in December 2009 in two districts, Livingstone and Kazungula. A QI team was formed to ensure that at least 50 percent of clients who tested HIV positive at COH Wellness Centers and who were referred for HIV care reach the referral ART facility within two months.

Through gap analysis, the QI team identified issues that contribute to a poor continuum of care, and then generated ideas of changes that might lead to improvement which began to be introduced in December 2009. These changes were studied in May 2011, by reviewing run charts of completed referral rates from January 2010 to March 2011. Run chart analysis demonstrated that although both Wellness Centers reached the 50 percent target occasionally, neither reached the target of 50 percent of referred clients completing their referral visit on a consistent basis, and both showed wide variation in their results from one month to another.

To better understand these differences, COH III staff conducted telephone interviews and focus group discussions (FGDs) with clients that did not reach the referral site and with PLHIV to identify the reasons for the low referral rate. Telephone interviews with 30 clients who did not complete their referral revealed the following reasons for not visiting a referral site 1) they were not interested in pursuing treatment (which could have been due to stigma or inaccurate beliefs about ART), 2) they were busy with work, and 3) they were out of town. Three FGDs were held which centered on why people might not go to the referral site after being given a referral. FGD participants identified issues surrounding stigma as key factors in not seeking out HIV clinical care services. According to participants, stigma leads to the preference for attending nongovernment or nonpublic service sites where clients have more anonymity. Furthermore, participants identified fear of spousal rejection or loss of their marriage if they revealed their HIV status. The issue of drug toxicity and fear of drug reactions was also identified as a barrier. Lastly, FGD participants provided a host of recommendations to address the challenges they identified. Key suggestions included providing ART at Wellness Centers, collecting specimens for CD4 count enumeration among HIV-positive clients at Wellness Centers, and making ART referrals only to clients with CD4 test results.

In September 2011, COH III then staff organized a meeting to discuss the findings of the run chart analysis, telephone interviews and FGDs. The QI team also reviewed how the QI monitoring system was being implemented. During this meeting, the team prioritized a set of additional changes to introduce, which were discussed with the district health teams. This second set of changes was then implemented.

In order to study the effects of the second set of changes, a wide stakeholder meeting took place in June 2012. During this meeting, COH staff together with health providers and district health officials conducted a review of the performance. The analysis confirmed that there was an improvement in the referral rate after the second cycle of changes in both sites, though considerable issues remained. Based on the run chart analysis, the QI teams sustained and modified the changes identified through Cycle 2.

In addition to challenges related to access, lack of client understanding of HIV and stigma, this QI project highlighted broader health system barriers. Issues that were beyond control of the Wellness Centers include long waiting times, limited laboratory services, lack of integrated HIV services, and lack of client follow-up at the ART centers and the government-run facilities; these contributed to less than optimal uptake of referrals for HIV care. Additionally, sites did not provide couples counseling and, in most cases, spouses came separately. Some areas are far away and in need of mobile outreach, but the district has been slow to facilitate this process.

Overall, the most important lesson learned was that it is difficult to achieve significant improvement in the quality of care if access to services is not addressed. Both teams applied QI methodology rigorously and were able to achieve some improvement. Many issues remained that go beyond the control of COH Wellness Centers. Moreover, a health system is limited in what it can do to retain clients in the system when there are two steps in the process of care that are not provided in the same location.

The introduction and maintenance of QI activities was possible due to stakeholder buyin, involvement and ownership. Regular QI meetings provided a platform for COH III staff to share the challenges they faced and ART center staff offer potential solutions. Regarding monitoring and documenting, we learned that while improving the reliability of measures during the improvement cycle helps make better decisions, changing improvement measures and the way indicators are collected might limit the interpretation of the run charts. Some issues and processes are selected over others for identifying changes, and it is not always clear how and why they were prioritized.

In summary, the consistent efforts and rigorous application of a QI model provided an opportunity for learning important lessons about reaching hard-to-reach populations in the health care system in Zambia. The QI project contributed to a slight improvement in the referral system that should be confirmed over a longer time period. An in-depth discussion should be held with USAID, Ministry of Health and COH III about the value of integrating two parallel systems of government-supported ART clinics and COHsupported Wellness Centers. Expansion of the services by the COH Wellness Center to include TB screening, FP counseling, CD4 testing and dispensing of ART can be part of a broader solution to reduce the number of missed referrals and lost clients and to improve the population's access to care. Additionally, the District Health Office should be engaged to address the issue of long queues at referral sites, including streamlining the appointment system. Clients should be given an option to choose where they want to receive ART. Lastly, expansion in services needs to be well thought out in terms of sustainability and therefore requires the strong support and involvement of the government and other stakeholders. It is important, in regard to ART, that there is an exit strategy for the project that would enable clients to continue receiving services without disruption or reduction in quality of care.

#### Introduction

The Corridors of Hope HIV/AIDS Prevention Initiative (COH III) is a five-year, USAID/ PEPFAR-funded project issued as an Associate Cooperative Agreement under the Regional Health and HIV/AIDS Office of USAID East Africa. The leader for this Associate award is the Roads to a Healthy Future (ROADS II) project, headquartered in Nairobi and implemented by COH III/FHI 360 in Zambia. Working in 10 districts of Zambia, COH III intends to reduce the spread of HIV in high prevalence border and transportation corridor communities by targeting traditional high risk groups, bridge populations and others whose behaviors put them at risk for HIV transmission. The two main objectives of the project are (1) to provide comprehensive HIV and AIDS prevention services, which include HIV testing and counseling (HTC), and (2) to strengthen the continuum of care, including antiretroviral treatment (ART) services, through referral to public health facilities.

The COH III project began October 1, 2009, and will end September 30, 2014. It is implemented by FHI 360 in partnership with three local nongovernmental organizations (NGOs): Afya Mzuri, Zambia Health Education and Communication Trust (ZHECT) and the Zambia Interfaith Networking Group on HIV and AIDS (ZINGO). Afya Mzuri is responsible for the behavior-change components of the project. ZHECT is the manager of the COH sites and provides monitoring activities, HTC and other reproductive health services. Working through a network of community- and faith-based organizations, ZINGO targets in-school and out-of-school youth, adults and families in churches, mosques and schools to deliver abstinence and be-faithful messages to appropriate target groups.

COH III primarily provides services though Wellness Centers, which are the COH office centers in each of the 10 district sites. Each center has a site manager; two health care providers/counselors; a behavior change and social mobilization officer; an M&E officer; an advocacy and livelihood officer; community mobilization officers; and groups of volunteers (lay community-based counselors, peer educators and adult youth mentors). Through services in the Wellness Center and outreach activities, health care providers/ counselors provide HTC, screening and treatment for sexually transmitted infections (STIs), and family planning (FP) counseling. They offer FP methods and provide referrals for (1) HIV-positive clients for HIV care, (2) TB suspects for TB screening and (3) malaria suspects for malaria screening and treatment. In addition, the Wellness Centers provide behavior change counseling, social and economic support and some outreach services. Through the District Health Office (DHO), the government provides HIV and syphilis testing reagents, drugs for managing STIs and FP methods to the Wellness centers. Referrals for HIV-positive clients include an assessment of their immediate needs for HIV care and supportive services and the provision of information on where and how to access HIV services from health facilities that offer the continuum of care. Referrals also include reasonable follow-up efforts to facilitate contact between service providers and to solicit clients' level of satisfaction with the services.

One of the COH project goals is to refer 100 percent of clients who test positive for HIV in COH III Wellness Centers or through mobile outreach programs to ART facilities for further testing and/or care or treatment services, with 50 percent of them reaching ART services for HIV care and treatment. In reality, although all HIV-positive clients are referred by Wellness Centers, less than a quarter of COH clients reach the referral sites. Delays in registering for HIV-treatment clinic services following an HIV diagnosis can lead to the late initiation of ART or prophylactic treatment against opportunistic infections, which could result in poorer prognoses for clients and an additional clinical burden on overstretched health services. In order to increase the proportion of completed referrals and thereby increase access to treatment, COH III launched a quality improvement (QI) project in December 2009 in two districts, Livingstone and Kazungula, in Zambia's Southern province. These sites were chosen to pilot a QI project because (1) they were the first to train community-based lay counselors to support health care providers (HCPs) in HTC and referrals, (2) they represent an urban setting and a semirural town, (3) they share borders and (4) directors of both districts expressed interest in the QI project.

The district of Kazungula is sparsely populated and very rural. In 2010, it had a population of 98,292 and covered 15,873 km<sup>2</sup>. It has no hospital, but does have 20 rural health facilities and provides mobile ART services in the health centers every two weeks. The district lies within the Southern province and is a significant trucking stop en route to South Africa through Botswana.

The district of Livingstone is bordered on the east, north and west by the district of Kazungula and on the south by the Zambezi River, which forms the international border with Zimbabwe. In 2010, the district had a population of 142,034 and an area of 1,427 km<sup>2</sup>. Until 2011, the town of Livingston was the provincial capital of Southern Province.

In contrast to the town of Kazungula, Livingstone is a more developed city with ART clinics and health facilities that provide ART services. In addition, Chreso Ministries, a church organization, is well established in Livingstone and provides baseline laboratory tests for people living with HIV (PLHIV) and ART. The Livingstone Wellness Center tests

an average of 313 new clients per month, 20 percent of whom test positive and are referred to ART clinics. The Kazungula Wellness Center tests an average of 378 new clients per month, of which 8 percent test positive for HIV and are referred to ART clinics.

In addition to the Wellness Centers in Kazungula and Livingstone, the QI pilot included six ART facilities in Livingstone, six mobile ART facilities in Kazungula, and one NGO within each district.<sup>1</sup> The health services provided by NGOs complement the efforts of the government in the provision of health services, including ART. This is the system of care that COH is trying to improve at the district level with the involvement of key stakeholders.

### FHI 360's Model for Quality Improvement

FHI 360 used the quality improvement model<sup>2</sup> represented in Figure 1. This model guides a team of service providers to test system changes through the use of the Plan/ Do/Study/Act (PDSA) tool.<sup>3</sup> The model has four main steps:

- I. *Identify the explicit improvement aim and objectives* that express in measurable terms a benefit for the beneficiaries/population.
- II. *Develop the improvement measurement system* in which the improvement team collects a few indicators, frequently on a small sample of sites or beneficiaries, and plots the results on run charts.
- III. *Generate ideas for changes*, using brainstorming, benchmarking, gap analysis and a list of known change concepts.

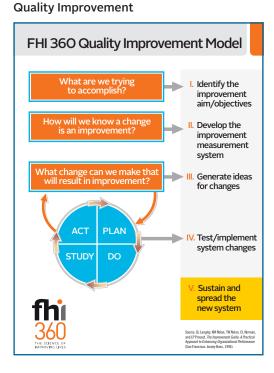


Figure 1: FHI 360's Model for

<sup>1</sup>The six ART sites in Livingstone are part of five government health centers — Maramba, Zambia Police, Mahatma Ghandi, Mosio-O-Tunya and Batoka Health Center — and one NGO — the CHRESO ministries clinic. In Kazungula, six government health centers — Mukuni, Mabova, Kazungula, Makunka, Sikaunzwe and Ngezi — and one NGO — Sons of Thunder — were included.

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<sup>&</sup>lt;sup>2</sup> Langley GL, Nolan KM, Nolan TW, Norman CL, Provost LP. The Improvement Guide: A Practical Approach to Enhancing Organizational Performance. 2009, 2nd edition.

<sup>&</sup>lt;sup>3</sup> Plan-Do-Study-Act: A tool for introducing a change and testing its effect on an improvement objective.

IV. *Test/Implement system changes (with PDSA cycle)*. Changes are introduced on a small scale (a few units), either one by one or as a package of changes, and their effect on the improvement aim/objectives is assessed through the monitoring system established in Step II. If a specific change yields improvement, it is sustained and replicated in the rest of the system. If the change does not yield the expected improvement, it is then abandoned and another change is tested.

# Application of the QI Model by COH III in Zambia

#### *Step I. Identify the explicit improvement aim and objectives.*

Efforts to launch the QI pilot began with a QI capacity building training in December 2009, which was led by a QI expert from FHI 360. The meeting was attended by all COH III site managers as well as representatives from Livingstone and Kazungula DHOs with quality assurance and quality control (QA/QC) responsibilities.

The capacity building training used a logical process where the teams followed the steps of the QI Model that led to identifying areas for improvement, developing specific indicators and an improvement measurement system and determining systems changes to be applied on a small scale.

Through discussion, the participants recognized that almost 100 percent of clients who tested positive for HIV at COH Wellness Centers received referrals to ART facilities, but less than 25 percent reached the facilities. The participants agreed that the problem of poor follow-through of referrals was the key barrier to an effective continuum of care for HIV.

Based on this analysis, participants developed the QI pilot's improvement aim and objective:

- Overall aim: Improve the continuum of care through a stronger referral system for HIV-positive clients.
- Objective: Ensure that at least 50 percent of clients who tested HIV positive at COH Wellness Centers and who were referred for HIV care actually reached the referral ART facility within two months.

The end point of a successful referral is when a client is seen by a clinician and the referral slip is deposited in the referral box of the ART center.

#### Step II. Develop the improvement measurement system.

The following indicator was proposed to track the improvement objective: the proportion of clients who tested HIV positive that reached the referral site within a two month period. Initially the indicator included a one month time period for clients to complete their referral to an ART center. However in December 2011, the time period was extended to two months in order to capture clients that received referrals towards the end of one month and visited an ART center the next month. This indicator matches the objectives of COH III, on which the project is required to routinely report. A monitoring system was established to track the indicator. (See Table 1.)

Improvement Objective	Operational Definition of Indicator	Definition of Indicator	Data Source and Collection Method	Frequency of Data Collection	Person Responsible
Ensure that at least 50% of clients who tested HIV positive at COH Wellness Centers in Livingstone and Kazungula and were referred for HIV care reached the referral ART facility within two months.	The proportion (%) of clients who tested HIV positive that reached the referral site within two months	<b>Denominator</b> (D): the number of clients who tested HIV positive and were referred within the month, two months before the monitoring date*	Count the number of clients who tested positive and referred within the full month, two months before the monitoring date. <b>Source:</b> code/names of the clients from the clinical form. *[For example; if you are collecting data in October, the period of time for the denominator would be the full month of August]	Monthly	Staff at COH Wellness Center in Livingstone and Kazungula
		Numerator (N): the number of clients who referred two months ago and reached the referral point within two months after referral	Count referral slips collected from ART sites for the last two months matching the code/ names of the clients from the clinical form. <b>Source:</b> referral slips of those clients with code/names matching the clients from the clinical form.		

#### Table 1: Quality Improvement Monitoring System

#### Step III. Generate ideas for change.

Through gap analysis, the participants identified the following issues that contribute to a poor continuum of care:

- The Wellness Center and ART facilities worked in a fragmented way and lacked coordination to ensure a smooth continuum for HIV-positive clients.
- HIV-positive clients felt there is a stigma in attending an ART center that is part of a primary health clinic.
- The ART center is too far, particularly in Kazungula.

These gaps helped participants generate a set of changes that would lead to improvement. This set of changes is called "the referral bundle" and is described in Table 2.

#### Table 2: Referral Bundle

	Changes
1	Send a copy of the list of referred clients to the ART centers.
2	Appoint a focal point person (FPP) for referral at the ART centers.
3	Use referral forms for all further management and not specifically for ART.
4	Conduct regular follow-up meetings to share experiences and emerging issues in the referral system.
5	Distribute standardized lockable referral boxes to all ART centers.
6	Display the referral system flow chart on the walls of COH Wellness Center and ART centers as a reminder of the referral process.
7	Contact by phone the clients whose referral slips were not found in the referral boxes.
8	Involve PLHIV to promote ART services.
9	Introduce the new referral system guidelines in the district health management system.
10	Conduct door-to-door follow-up of clients.
11	Health providers from counseling and testing sites and ART centers coordinate referrals from counseling and testing to ART for HIV-positive clients.

### **First PSDA Cycle**

#### Plan

To plan the testing of the set of changes, the capacity building training was followed by an onsite mentoring workshop, also led by the FHI 360 QI expert, to support the formation of QI teams in Livingstone and Kazungula. The workshop was held over three days. Twenty-one participants attended, including the District Medical Officer (DMO) for Kazungula.

The objectives of onsite mentoring included an explanation of the QI model, a discussion of the project developed by the team who attended the capacity building training in Lusaka, the prioritization of the "changes" that were likely to lead to an improvement with regard to the referral system and the development of an implementation plan for each proposed "change" within the referral system. (See Table 2.)

#### Do

Immediately following the capacity building workshop in December 2009, both sites gradually introduced the changes described above as a referral bundle.<sup>6</sup> (See Table 3.) One of the first changes supported by Wellness Centers was the provision of the referral boxes in ART centers in Livingstone and Kazungula. The referral boxes provided a means to measure the effectiveness of referrals by matching the referral slips that were deposited in the boxes with the list of referred clients, which in turn helped to identify the missed referrals for initiating a rapid-tracking response. Not all changes were implemented at the same time nor were they all completed by the same date.

<sup>6</sup> According to IHI, a bundle is a straightforward set of evidence-based practices that have been proven to improve patient outcomes when performed collectively and reliably.

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#### Table 3: Referral Bundle of Proposed Changes

	Proposed Change	Status of Implementation
1	Send a copy of the list of referred clients to the ART centers.	Implemented in December 2009
2	Appoint a FPP at the ART centers.	Implemented in January 2010
3	Use referral forms for referrals made for further management.	Implemented in January 2010
4	Conduct regular follow-up meetings to share experiences and emerging issues in the referral system.	Implemented in April 2010; meetings held every quarter
5	Distribute standardized, lockable referral boxes.	Implemented in April 2010
6	Display the referral system flow chart on the walls of COH Wellness Centers and ART centers as a reminder of the referral process.	Implemented in April 2010
7	Contact by phone the clients whose referral slips were not found in the referral boxes.	Implemented in April and May 2010
8	Involve PLHIV to promote ART services through counseling to newly diagnosed HIV clients.	Implemented on an ongoing basis
9	Introduce the new referral system guidelines in the district.	Has not been implemented
10	Conduct door-to-door follow-up of clients.	Has not been implemented
11	Health providers from counseling and testing sites and ART centers coordinate referrals from counseling and testing to ART for HIV-positive clients.	Has not been implemented

Referral letters were provided to all clients who were referred to HIV care. When clients attended the ART center, the referral slip was deposited in a designated box. Every month the referral slips at the referral sites were collected by one of the two HCPs, counted, and referenced against the record of the clients who received referral slips the previous month. Following the review, all the clients whose referral slips were not found in boxes were contacted by phone using phone numbers provided on the client form. HCPs and lay counselors collect referral feedback slips from ART centers on the last working day



Photo 1: Nurses at Batoka Hospital Checking the Referral Box

of the month. After collection, HCPs together with the Site Monitoring and Evaluation Officer (SMEO) count and document the number of clients proven to have accessed ART services within two months.

As noted in Table 3, a number of proposed changes were not implemented. For example, the new referral system guidelines were not widely introduced in the district because local health providers preferred to continue using their existing referral forms until a district referral slip under DHO was developed or adopted. There was concern that the new referral forms were not as relevant to their work and would not adequately capture information vital to their work. Additionally, while door-to-door follow-up of clients has not been introduced, HIV clients referred to ART centers were followed with appointment reminders through telephone calls, but some did not have phones or they gave phone numbers that could not be reached or numbers that were not theirs. Lastly, the coordination of the HCPs' referrals for counseling and testing and ART for HIV-positive clients was not carried out. The change involves having a book in each ART clinic where all HIV-positive clients enlisted for ART are recorded for all interest groups to check new clients that reached and received service.

#### Study

#### Data Review and run chart interpretation

In May 2011, the data for the period of January 2010 to March 2011 was analyzed and presented to key stakeholders at the results dissemination meeting. In total, Kazungula

provided HTC to 2,677 clients, while Livingstone provided HTC to 2,018 clients. (See Appendix 1 for a breakdown.) The proportion of positive results for Livingstone and Kazungula were 17 percent (n = 363) and 10 percent (n = 237), respectively, and all were referred to a center providing ART.

To interpret the data, we first calculated a median<sup>7</sup> from a prior dataset to use as a baseline in the run chart (light green lower dashed line). Then we indicated



Photo 2: QI Team Members Analyzing the Referral System at the Police Health Center

a target (orange dashed line). After plotting the new data for each month on a run chart, we compared these indicators before and after the introduction of changes, the timing of which is indicated.

The results for the Kazungula Wellness Center showed two peaks at 100%: one in January 2010 when implementation of changes first began and one in May 2010 after the introduction of all changes. (see Figure 2.) One explanation for these peaks is that initially the team was counting all the referral slips regardless of how long it took for clients to reach the referral site. According to the operational definition, only those clients who completed the referral within two months should have been considered as completing their referral.

<sup>7</sup> The median of a data set is the numerical value separating the higher half of a sample population from the lower half.

IMPROVING THE REFERRAL SYSTEM FOR HIV CLIENTS IN THE LIVINGSTONE AND KAZUNGULA DISTRICTS OF ZAMBIA For the other months, the run charts demonstrated a wide variation in the referral system performance. A relatively small sample size (average 31 cases per month are referred) caused many swings around the median (18 percent). According to the COH Wellness Center site manager, the main challenge to the referral process in Kazungula is the population's limited geographical access to ART services.

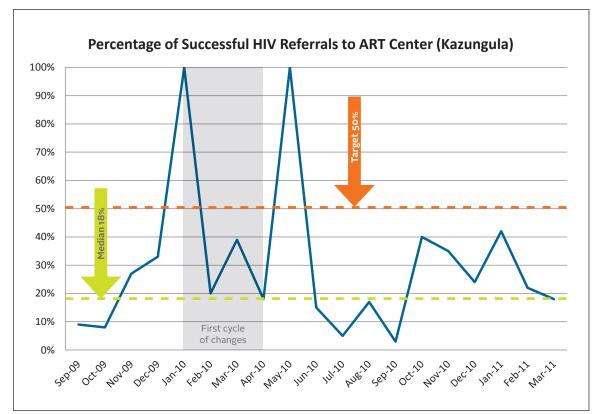


Figure 2

Data from the Livingstone Wellness Center indicated a median of 38.5 percent before the QI intervention. (See Figure 3.) Given that clients accessing services in Livingstone have better geographic access to ART clinics compared to clients in Kazungula, it is reasonable to observe a higher median in Livingstone. However, the run chart analysis of the Livingstone data did not indicate a significant improvement following the introduction of changes. Similar to the Kazungula run chart, Livingstone data shows a wide variation in the referral system's performance.

Two potential causes for underestimation of the referral rate included (1) challenges with the data monitoring system and (2) tendency of foreigners to access HIV testing at Wellness Centers. Regarding the data monitoring system, repeat testers distorted the calculation of the number of clients who accessed continuum of care services. It was not uncommon for HIV-positive clients on ART to access HIV testing at Wellness Centers. Limited knowledge and lack of understanding of HIV and ART led some clients to seek multiple HIV tests even though they were already on ART. Another cause for underestimating the proportion of clients completing referrals is due to a number of foreigners that were tested in Wellness Centers but who would access continuum of care services outside of Zambia.

The team concluded that changes in the supply side of service delivery did not produce the expected improvement and needed to be supplemented by additional changes in both the supply side and the demand side of services.

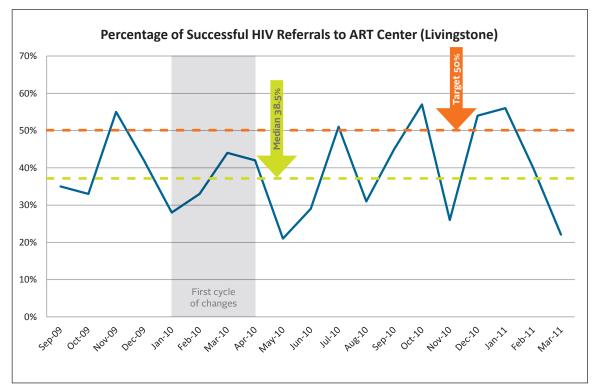


Figure 3

IMPROVING THE REFERRAL SYSTEM FOR HIV CLIENTS IN THE LIVINGSTONE AND KAZUNGULA DISTRICTS OF ZAMBIA

#### Act

Given the low referral-completion rates observed through the data review, COH III staff recognized that further investigation was necessary to determine the reasons why clients who tested HIV positive did not reach ART referral sites. In May 2011, COH III conducted a cross-sectional analysis of clients from the Livingstone area who did not complete their referral for the last six-month period of October 2010 to March 2011. Referral slips were collected at the sites and matched to clients who were provided referrals from Wellness Centers. The findings were presented to QI teams and other stakeholders from both Kazungula and Livingstone at a meeting held in September 2011 in Livingstone and it was decided to conduct telephone interviews and focus group discussions (FGDs).

#### Telephone Interviews

The contact numbers of suspected defaulters, who had no referral slips in the box, were obtained from records in the Wellness Center. Those who had not provided contact numbers were excluded from follow-up. Repeat telephone calls were made to those not reached during the first attempt. Clients who were identified as having not completed their referral to the ART center were contacted by telephone and asked whether they did or did not attend a referral site. Those who confirmed that they did not attend a referral site were asked their reasons for not doing so.

Out of the 221 clients considered lost-to-follow-up (LTFU) from the Livingstone Wellness Center, 49 (22 percent) were successfully contacted by telephone. The remaining clients could not be reached due to missing phone numbers on referral slips and other reasons.

Telephone interviews were conducted after oral consent with the 49 clients who answered the phone calls. Nineteen (39 percent) of them said they did actually go, but that they were not asked to hand in the referral slip by the health care provider. Out of these clients, some said they had started ART; others were waiting to do their CD4 test (at the time of their visit to the referral site, the CD4 count machine was not functioning); several clients were given an appointment to return after three weeks; one went to a different clinic where she was not known; and another went to the referral, but no doctor was present.

When asked about the quality of counseling, all 49 clients contacted said they were adequately counseled and understood the purpose and importance of going for further care. They also felt that confidentiality was maintained. Some clients felt that self- denial and not accepting the results was a problem. The remaining 30 (61 percent) clients who answered calls confirmed that they did not go to the referred site, citing a variety of reasons (see Table 4). Nearly a quarter said that they were not interested in pursuing treatment, which could have been due to stigma or inaccurate beliefs about ART. Approximately 25 percent also cited that they were too busy with work. The next most common reason given for failure to reach the referral site was being out of town.

Table 4: Client's Reasons for Not Receiving Referral Site Services

Reason given	Number (%)
Not interested/not necessary	7 (23%)
Busy with work	7 (23%)
Out of town	6 (20%)
Reached the site and found the clinic closed	3 (10%)
Went for prayers and got healed	2 (7%)
Already knew their HIV status, they wanted to confirm it	2 (7%)
Went to another ART center where they were not known	3 (10%)
Total	30 (100%)

Clients who participated in the telephone interviews also provided recommendations on how to improve the referral rate. Key suggestions included:

- Help make appointments for clients at referral sites and escort those who may not feel comfortable dealing with new people.
- Use text messages to remind or follow up with referred clients and find out whether they reached the referral site.
- Improve the attitude and practice of service providers at the referral sites.
- Conduct follow-up visits to clients of the Wellness Center to identify any issues.
- Involve PLHIV in counseling clients.
- Provide ART at Wellness Centers, rather than referring clients to other sites.

#### Focus Group Discussions

To increase the validity of the data and get more in-depth information from the PLHIVs' perspective, the phone interviews were followed by three FGDs with PLHIV in Livingstone and Kazungula. Two FGDs were conducted in Livingstone, one with 10 males and another with 10 females. A third FGD with 17 participants (eight males and nine females) was held in Kazungula. Participants were invited to join FGDs through the Livingstone and Kazungula chapters of the network of people living with HIV and AIDS (NZP+).

**Quality Improvement Stories** 

In Livingstone, the average age of participants in the male group was 43 years while the average age in the female group was 41 years. The male group was slightly more educated with an average of 11 years of school while the female group had an average of 10 years. Half (n = 5) of the males and four of the females were currently on ART.

The discussion held in Kazungula, FGD#3, was comprised of both men and women. The average age of participants was 42 years, and the average educational level was 8 years, and 44 percent were on ART.

Focus group discussions centered on why people might not go to the referral site after being given a referral. Participants highlighted a variety of reasons why they did not visit a referral site (see Table 5), discussed their perceptions of the quality of counseling they received at the Wellness Centers, and provided suggestions for improvements in the referral process and at ART sites. Appendix 3 organizes the reasons under a cause-effect relationship, using a fishbone diagram.

FGD #1 (Men only) in Livingstone
Long distance and cost of transportation
Lack of information on the benefits of ART
Fear, stigmatization and denial
Feeling fine, energetic, do not feel a need to be on treatment
Multiple referral sites: HTC, CD4 and ART services not integrated
Lack of choice as to where they could go for ART
Fear of drug reactions and toxicity, such as liver damage
Self-medicating
Lack of privacy
Already knew their HIV status and simply went for re-test

Table 5: Reasons Cited by FGD Participants for Not Completing Referrals to ART Site

FGD #2 (Women only) in Livingstone	
Self-stigma	
Lack of choice as to where they could go for ART	
Belief that HIV is only for the poor	
Long queues at ART and CD4 count centers	
Multiple referral sites: HTC, CD4 and ART services not integrated	
Lack of confidentiality of HCPs at referral clinics	
Fear of rejection by husbands if they learn of wife's status	
FGD #3 (Men and Women) in Kazungula	
Self-stigma and stigma from community	
Suspicion of satanism when blood is collected or repeat blood tests are conducted	
Fear of drug toxicity and taking medicines for life	
Fear of losing marriages	
Lack of understanding importance of ART or why they were referred	
Misplacing referral letters	
Lack of privacy in the clinic	
Myths, beliefs in faith healing	

Table 5: Reasons Cited by FGD Participants for Not Completing Referrals to ART Site (continued)

In all three groups, participants identified issues surrounding self-stigma and stigma in the community as key factors in not seeking out HIV clinical care services. According to participants, stigma leads to the preference for attending nongovernment or nonpublic service sites such as COH or NZP+ where clients have more anonymity. They are afraid of meeting members of their community who may know them if they go to an ART center near where they live. In FGD #3 in Kazungula, for example, participants mentioned that on Thursday, the day when ART drugs are collected, it is not uncommon for clients to go to a general outpatient department instead of the ART clinic for fear of being seen collecting drugs. Moreover, in FGD #2, the women-only FGD, some participants discussed the perception that HIV is an infection of the poor. They said that because wealthy people think that HIV is for poor people, they are hesitant to disclose their HIV status and shy away from ART clinics. Related to stigma and privacy, participants of both genders identified fear of spousal rejection or loss of their marriage if they revealed their HIV status, and this became a barrier to completing referrals.

In FGD #1 and FGD #3, the issue of drug toxicity and fear of drug reactions was identified as another factor that hinders people from attending the ART clinic. It was mentioned that there are people in the community who discourage others from starting ART treatment by suggesting that ARV destroys the liver. This leads to fear that one's economic activities would be negatively affected as a result of ART side effects.

Participants in both FGDs held in Livingstone mentioned the lack of CD4 count machines as a factor contributing to people failing to visit referral sites. In Livingstone, only two health facilities (at one health center and hospital) have CD4 cell machines. They mentioned appointment times and specific days that have been given to collecting specimens for CD4 cell tests. This is a challenge because it involves repeat visits to the facility, which add to transportation costs, delays in starting ART, and long waiting times at congested facilities.

It is also important that PLHIV are involved in counseling especially around adherence counseling. Integrating related services (HTC, ART, FP) and providing adequate information, including the benefits of ARTs, might also be helpful in motivating clients to use the referral centers.

Lastly, participants in the FGDs provided a host of recommendations to address the challenges they identified. Key suggestions included providing ART at Wellness Centers, collecting specimens for CD4 count enumeration among HIV-positive clients at Wellness Centers, and making ART referrals only to clients with CD4 test results. (See Table 6.) Another important change recommended by all participants is the establishment of a client empowerment system, which would focus on improving post-test counseling, and linking newly diagnosed HIV clients with PLHIV support groups.

#### Table 6: Recommendations Provided by FGD Participants

Involve PLHIV as counselors for new clients.

Work with NZP+ to provide more counseling surrounding stigma to increase involvement at referral sites

Provide integrated HTC and ART in one location to reduce referrals and delays at referral sites.

Refer clients to sites where they feel most comfortable to attend. (Ask clients where they prefer to receive services.)

Provide adequate information and counseling.

Equip support groups with tools and information on ART to pass on to newly diagnosed HIV clients.

Encourage disclosure of previous tests so that individuals who already know their test results and have been referred previously are not recorded as first-time referrals.

Expand the scope of COH III to include conducting CD4 tests and providing ART services.

Provide adherence counseling.

Provide counselor support meetings.

In September 2011, COH III staff organized a meeting to discuss the findings of the run chart analysis, telephone interviews and FDGs. The QI team also reviewed how the QI monitoring system was being implemented. The meeting was attended by the Livingstone DMO, the clinical care specialist, the QA/QI specialist in the District Health Office, the provincial AIDS coordinating advisor and the chairman of the Livingstone District AIDS Task Force. This meeting led to the continuation of the QI effort through a second PDSA cycle.

## Second PSDA Cycle

#### Plan

During the quarterly review meeting in September 2011, the QI team divided into three groups to first conduct a gap analysis and then brainstorm on how to best address the barriers to effective referrals, taking into account the results from the patients' interviews and FGDs. The gap analysis revealed the following issues:

- In Kazungula, the mobile ART clinic conducts outreach every two weeks.
- Clients often have to wait to get CD4 count done and the lab works limited hours.
- HIV testing, CD4 testing and ART treatment services are not integrated at one location, which forces a client to go through several facilities to get HIV care.
- Mobile outreach services for some designated areas are still not available.

The team then provided a list of change ideas targeting health providers, clients and the health system to improve referral systems. (See Table 7.), including the suggestions made by the PLHIV during FGDs.

#### Table 7: Summary of Changes Identified by the QI Team to Improve the Referral System

Improve the quality of post-test counseling and peer counseling to encourage HIV-positive clients to reach referral sites.

Establish information desks at referral health facilities managed by volunteers.

Conduct a consultative meeting with partners on a regular basis.

Sign a Memorandum of Understanding with the DMO and adopt the SMART care system<sup>8</sup> of tracking clients in as many health facilities as possible.

Integrate PLHIV in service provision at the community level.

Develop approaches to reduce different types of stigma (self, community and health facility)

Intensify follow-up visits during the visits of the lay counselors.

Involve the community to strengthen referrals.

Standardize referral monitoring tools and the referral flowchart.

Increase the number of staff trained in ART.

Strengthen the referral network and its coordination.

Strengthen the referral network and its coordination through regular communication between Wellness Centers and ART centers.

<sup>8</sup>SMART is an electronic database patient information system that was adopted and piloted by the Ministry of Health in some of the health facilities providing ART services.

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Table 7: Summary of Changes Identified by the QI Team to Improve the Referral System (continued)

Expand the service for HIV-positive clients at the COH Wellness Center by collecting specimens for CD4 tests.

Improve the management and logistics of reagents for CD4.

Address long waiting times in ART clinics.

Introduce an appointment system for HIV-positive clients.

Decentralize ART sites to make care more accessible for distant areas (outreach mobile ART services).

Develop a client empowerment system to support clients after testing positive (post-test counseling).

Strengthen supportive supervision at the district level.

After brainstorming these ideas, the group had discussions with the district health team to identify the changes that were the most feasible to implement quickly. Five such changes were prioritized and represent the "second referral bundle":

- Have lay counselors make appointments for clients and escort them to ART centers.
- Collect the blood specimens for CD4 tests at the Livingston Wellness Center and take them to the ART center.
- Conduct joint mobile outreach visits with rural health center staff where registration for ART and CD4 baseline investigation could be done immediately when a client tests positive for HIV.
- Improve reliability of the indicator by removing the clients referred outside of the district from the denominator.
- Conduct joint visits with an HTC government clinic in Livingstone, Sepo, to the ART centers to build the clinic's capacity in the referral process.

#### Do

In September 2011, the five prioritized changes listed above were refined and implemened and, during the course of implementation, the team identified additional changes. The final bundle of changes was the following:

- The Livingstone site introduced a system of volunteer lay counselors to escort HIV-positive clients to referral sites for appointments to reduce defaulters.
- Collection of blood specimens for CD4 tests was not implemented because of the breakdown of the CD4 machine at the government health facility, and the nongovernment ART center allowed them to refer clients on daily basis. In Kazungula, where all ART clinics are mobile, the Wellness Center joined local service providers in mobile outreach to conduct HTC for new clients that can be immediately enrolled for CD4 testing.

- The time period for determining whether a referral was completed was extended. Initially a client had one month to visit the referral site, after which the client was considered LTFU. The time period was extended to two months because some clients were still waiting for CD4 results and other baseline test results. The process used to verify the numerator was clarified. In addition to conducting a check of the pre-ART register and incoming register, follow-up through telephone calls was added to determine if clients visited the referral site, but were not properly captured or had used a different name. Additionally, to determine the denominator, only those clients that were referred to sites within districts that had referral boxes were counted. Clients who were outside the referral slips and those already on ART were excluded from both denominator and numerator.
- Joint visits to ART centers to collect referral feedback slips by COH III staff and government run HTC Sepo Center staff in Livingston were initiated to build the capacity of the Sepo center staff on implementing and improving the referral system.
- Livingstone started providing HTC door-to-door in Simoonga village. The village was selected due to the large number of HIV-positive clients in need of ARVs and its distance to an ART center. The door-to-door program is jointly implemented by COH III and ART staff from Mahatma Ghandhi clinic, which is a Ministry of Health clinic.
- The volunteers started providing information on behavior change messages and the benefits of HIV testing to all those who visited the COH III Wellness Center.
- Health care providers/counselors were trained in motivational interviewing<sup>9</sup> to improve the quality of post-test counseling and to train volunteer lay counselors to improve adherence to referral through gentle guidance in resolving clients' ambivalence and motivating them to take action.

<sup>9</sup>Motivational Interviewing is a collaborative conversation to strengthen a person's own motivation for and commitment to change.

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#### Study

A wide stakeholder meeting took place in June 2012, during which the COH staff together with health providers and district health officials conducted a review of the performance using run charts and a problem analysis using flowcharts and root cause analysis. The analysis confirmed that there was an improvement after the introduction of the second cycle of changes (see Figures 4 & 5), but issues remain that will require continuous commitment to this initiative.

The run chart of the referral process for Kazungula Wellness Center shows a shift<sup>10</sup> above the median that appears to have begun in June 2011, which indicates that the changes implemented resulted in an improvement.

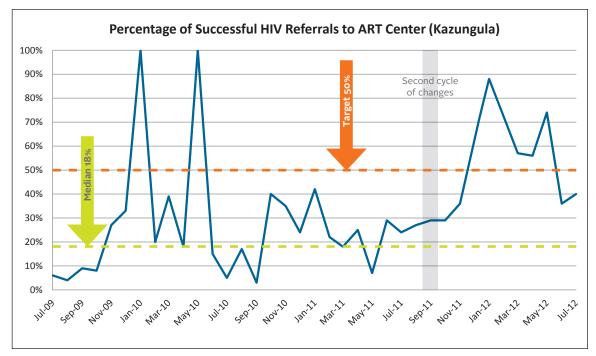


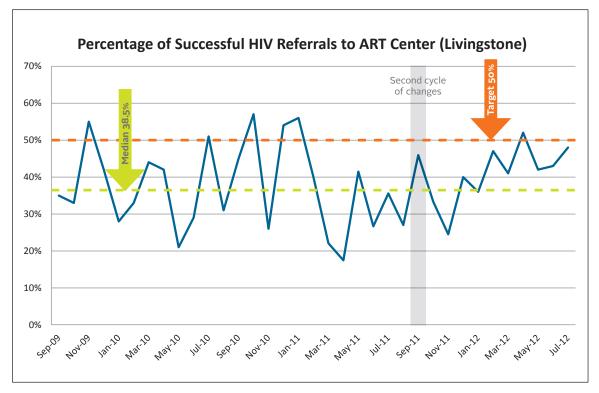
Figure 4

<sup>10</sup> A shift is six or more consecutive points, either all above or all below the median.

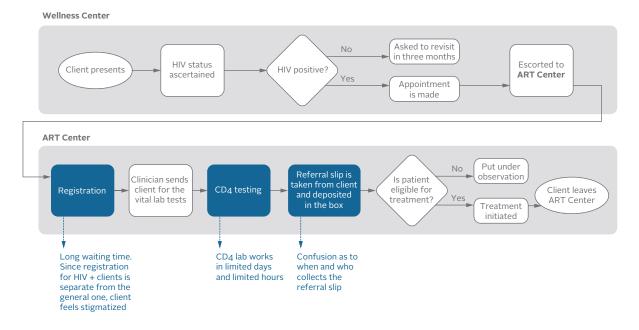
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The run chart of the referral process for the Livingstone Wellness Center shows a shift with six points above the median after September 2011, when the second bundle was introduced (See figure 5), indicating an improved performance.





During the meeting, the stakeholders also depicted the current referral process between the Wellness Center and ART Center in Livingstone using a flow chart. This tool helped highlight that despite the changes they have introduced (escorting the clients and blocking appointment) there are still issues remaining (highlighted in the flow chart in blue) that should be addressed in collaboration with the ART Centers. The issues are described in detail with root causes in the fishbone analysis in Appendix 3.



#### Figure 6: Flowchart of the referral between Wellness Center and ART centers in Livingstone

#### Act

As a result of continuous study, QI teams sustained and modified the changes identified through the second PDSA cycle. The below changes are currently sustained in both sites:

- Joint mobile and door-to-door provision of HTC and ART services are offered by COH III and some ART centers to the population that resides in distant areas.
- Prior booking for baseline investigations with laboratory staff at the ART centers is available.
- Lay counselors or health providers accompany clients who are willing to be escorted.
- Clients who were referred outside of the district are removed from the denominator to reflect the referral process accurately. (This limitation should be taken into account during the analysis after September 2011, since it introduces some bias in comparing before/after.)
- The list of clients referred to the ART clinics is provided by COH for easy follow-up.

The joint visits helped government Sepo Health Center to identify health facilities that do not offer ART services. Using this information, the center came up with a correct list of health facilities to which to refer clients for ART services. This is expected to reduce the number of lost referrals as clients will now be referred to the correct ART centers, where there will also be referral feedback boxes to help track feedback details for their clients.

**Quality Improvement Stories** 

#### **Lessons Learned**

#### Challenges experienced by patients

As described above, the findings from both telephone interviews and focus group discussions highlighted challenges for patients that centered on access, of client understanding of specialized HIV care, stigma, and health system issues.

*Access:* The distance between ART centers and residential areas was prohibitive for some clients, mainly due to the cost of transportation. Clients without money to pay for transportation to the ART center were not able to access services.

*Client understanding of HIV care:* Counseling for clients recently diagnosed with HIV did not adequately address issues such as the benefits of taking ART and risks of drug toxicity. Nor did they correct the inaccurate beliefs and myths that spread in the communities regarding HIV treatment.

*Stigma:* Stigma and discrimination against PLHIV by family and friends remains a problem in many communities. As a result, some clients would not provide contact information (or provide incorrect information), would deny the results of a positive HIV test, or would be reluctant to attend an ART center in their community for fear of being seen there. Some people would not disclose their HIV status to their family or partner out of fear, which contributed to their reluctance to visit ART centers.

*Health system barriers:* Issues that were beyond the control of the Wellness Centers include long waiting times, limited laboratory services, lack of integrated HIV services, and lack of client follow-up at the ART centers; these contributed to less than optimal uptake of referrals for HIV care. Additionally, ART sites did not provide couples counseling and, in most cases, spouses came separately. Some areas are far away and in need of mobile outreach, but the district is slow in addressing this issue.

#### What worked well with the QI process

The introduction and maintenance of QI activities was possible due to stakeholder buy-in, involvement and ownership, which was maintained through QI quarterly meetings and feedback. These regular meetings provided a platform at which COH III staff shared the challenges they faced, and ART center staff offered potential solutions. Sharing feedback during quarterly meetings encouraged ART center staff to overcome challenges and stimulated a sense of competition among them, as each one wanted to see their center report a high completion rate of referrals from the Wellness centers.

Furthermore, continuous mentorship of the team proved to be vital as changes take place, especially among trained government staff, some of whom are periodically transferred or leave for better conditions of service. This experience also highlighted the added value of technical assistance for QI teams from a QI expert. An FHI 360 QI expert from headquarters provided continuous support in monitoring and analysis of the improvement process.

#### What were the main issues with the QI process

In terms of monitoring and documenting QI efforts, we learned that while improving the reliability of measures during the improvement cycle helps make better decisions, it could limit the interpretation of the run charts. Some issues and processes are selected over others for identifying changes, and it is not always clear how and why because a decision-making process that involves many stakeholders over many meetings is difficult to document

Overall, the most important lesson learned was that despite rigorous monitoring and implementation of the QI model, it is difficult to achieve significant improvement in the continuity of care if the issue of access to services is not addressed and if fragmented services are delivered in different locations with limited interactions between the facilities and the service providers. Many issues are beyond the control of COH Wellness Centers, especially once the patient leaves the centers. Moreover, a health system is limited in what it can do to retain clients in the system when there are multiple steps in the process of care that are not provided in the same location.

**Quality Improvement Stories** 

#### **Next Steps**

In summary, the consistent efforts and rigorous application of a QI model provided an opportunity for learning important lessons about the way the current health system in Zambia is delivering services to hard-to-reach populations. The QI project contributed to a slight improvement in the referral system that should be confirmed over a longer period of observation and continuous improvement cycles.

An in-depth discussion should be held with USAID, the Ministry of Health (central level and districts) and COH III about the value of integrating two parallel systems of government-supported ART clinics and COH- supported Wellness Centers. Expansion of the services by the COH Wellness Centers to include TB screening, FP counseling, CD4 testing and dispensing of ART might be part of a broader solution to reduce the number of missed referrals and lost clients and to improve the population's access to care. Another option is to integrate the services delivered by the Wellness Centers into the public health facilities. Additionally, the District Health Offices should be engaged to address the issue of long queues at referral sites, including streamlining the appointment system. A more client-centered healthcare delivery system should allow patients to choose where they want to receive ART and the tracking/referral system should be designed accordingly.

Finally, the sustainability of the currently fragmented healthcare delivery system must be studied and addressed before the end of the COH III project.

## Appendix 1: Breakdown of Referral Service Statistics

After the first bundle of changes was introduced, a review of service statistics was conducted. Between October to March 2011, a total of 2082 people were tested and counseled for HIV and 17% of them turned out HIV positive. All the 363 (100%) who tested positive were referred with letters to referral sites for continuum of care.

Number of people tested for HIV and number positive tests in Livingstone COH III project: October–March 2011

Activity	Oct 10	Nov 10	Dec 10	Jan 11	Feb 11	Mar 11	Total
Number provided TC	237	318	256	305	410	556	2082
Number positive	53	62	37	50	75	86	363
Proportion HIV positive	22%	19%	14%	16%	18%	15%	17%

Number of people tested for HIV and number positive tests in Kazungula COH III project: October–March 2011

Activity	Oct 10	Nov 10	Dec 10	Jan 11	Feb 11	Mar 11	Total
Number provided TC	644	362	230	525	466	450	2677
Number positive	45	34	30	30	44	54	237
Proportion HIV positive	7%	9%	13%	6%	9%	12%	9%

### Appendix 2: Examples of Detailed Responses to FGD Questions

# *Q1: Do you feel that you were adequately counseled and understood the importance of referral for further management?*

- Most of the participants thought that they were given adequate information at referral sites, but complained about long waiting times for CD4 testing and broken CD4 machines.
- Counselors used some terms (such as CD4 cells) that they did not understand and the counselors could not explain them well. Now they understand because of their involvement as members of NZP+.
- One man in Livingstone talked of an incident when he was referred and a health care provider sarcastically said, "Naimwe nama tenda yanu mutivutisa ni ma tenda yo chekela ku corridors." (The literal translation is "You also you are troubling us with a disease you contracted from the corridors/risk places.")

# *Q2: Did you ever go to the ART center or to other facilities after your referral? Why did you not go?*

- A number of them said they did not go for the first time because they did not believe the results: "I hope for change of results."
- Many participants said they took up to three HIV tests before they were convinced that they had HIV, because they felt fine.
- Some went to centers other than the ones to which they were referred. They did not want to go where they might be known.
- Others went to the referral clinic only when they started feeling sick.
- Others feared to start ART because if they got out of stock they might die.
- Others said they were scared of starting treatment because ART makes you become sicker.

#### *Q3: Do you feel that the services in ART facilities can be improved?*

All of the FGD participants thought the service could be improved in several ways:

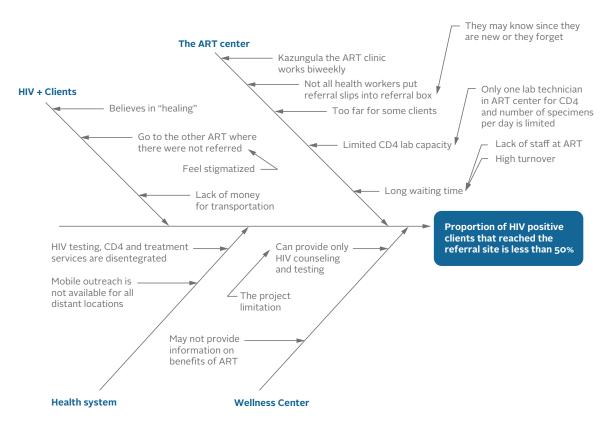
- Improve privacy and issues of confidentiality.
- Reduce processes and factors causing delays.
- Organize the ART clinic days by separating service days, those attending for first time (not yet on ART), those coming for re-supplies, etc. Schedule on different days.
- Increase the number of centers providing ART.
- Counselors should avail their phone numbers or business cards to their clients and ask clients to call them once they have been seen.
- Have social workers and treatment that will promote adherence.

Q4: How would you suggest we better track the referrals or people referred?

- Follow up in homes using residential addresses.
- Track through phone calls and messaging.
- Use support groups and community volunteers and encourage clients to join support groups.
- Have community agents do follow-ups.
- Remind clients to bring back referral slips.

Q5: Do you prefer someone to escort you? If yes who should be escorted?

• In all the FGDs, some participants felt this was not a good idea, and a few said that it would increase stigma.



# Appendix 3: Root Cause Analysis of Issues Relevant to the Referral Process

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