Review of the HIV testing, CD4 testing and TB screening and diagnosis: The referrals systems within the selected CARE Partners in Free State, Mpumalanga and Limpopo

Analysis of routinely collected programmatic data by selected care supported cbos

care SA Review report

care SA Review report

HOPE AND LIFE

“I have been a client with this organization for 18 months. If it was not for the role they play in our community, I would have died of HIV and TB of the spine. I am now on ARVs and my TB treatment. Although I still cannot walk, am hopeful and feel better than I was a year ago”

+Ms M (a patient in FS)

**Authors:**

**Ms Nonkosi Khumalo – Senior Researcher**

**Dr Mahlane Phalane – MD. Senior Researcher**

**Ms Lillian Mwangulu – Research Assistant**

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**Executive Summary:**

**Background to the Review**

PEPFAR has been supporting CARE South Africa for the past 5 years. This support related to the provision of support services to CARE partners to deliver HIV/AIDS palliative care services, TB and HIV integrated services, HIV counselling and testing and linkages to the Integrated Access to Care and Treatment (I-ACT) program.

CARE commissioned a review/assessment of its 14 partners’ ability in the following:

1. Community-based HCT services.
2. The quality and successes of referrals of newly diagnosed HIV infected individuals for facility-based CD4 testing.
3. The subsequent enrolment of those individuals in care, treatment and support services,
4. Community based TB screening services.
5. The quality and success of referrals of newly identified TB suspects for facility based TB investigation, diagnosis and management.

This review/assessment examines the data and systems for the period covering September 2011 – August 2012 by looking at the following indicators:

1. Proportion of individuals counselled, tested and tested positive for HIV.
2. Proportion of HIV-infected referred by CBO to health facility.
3. Proportion of referred who presented at health care facility.
4. Proportion of referred who had blood drawn for CD4.
5. Proportion of referred HIV-infected for whom CD4 test results were available.
6. Proportion of referred HIV-infected patients whose results were communicated to them.
7. Average interval between referral and first presentation at health care facility.
8. Average interval between referral and blood draw for CD4 testing.
9. Average interval between referral and clinical staging.
10. Average turn-around time for availability of CD4 test results at health care facility.
11. Average turn-around time for disclosure of CD4 tests results to patients.
12. Average interval between referral and disclosure of CD4 results.
13. Proportion of patients registered on ART.
14. Proportion of patients registered on Pre-ART.
15. Average interval between date referred for CD4 testing and ART enrolment date.
16. Proportion of TB screened who become TB suspect.
17. Proportion of TB suspects referred by CBO to health facility.
18. Proportion of referred TB suspects who presented at health facility.
19. Proportion of referred TB suspects who had at least one sputum collected for TB diagnosis.
20. Proportion of referred TB suspects who were tested for whom sputum test result was available.
21. Proportion of referred TB suspects who were tested and disclosed a sputum test result.
22. Average interval between referral and first presentation at health facility.
23. Average interval between referral and sputum collection for TB diagnosis.
24. Average turn-around-time for availability of sputum test result (between date sputum collection and date result available at health facility).
25. Average turn-around-time for disclosure of sputum test result (between date sputum collection and date result disclosed to patient).
26. Average interval between referral and disclosure of sputum test result.
27. Proportion of diagnosed TB patients started on TB treatment).
28. Average interval between date referred and date initiated on TB treatment.

**Partners that were assessed for this review are as follows:**

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| **Free State** | **Mpumalanga** | **Limpopo** |
| * Lechabile, * Marqaud Moemaneng, * Khauhelo * Phela O Pheditse (Live and Let Live) * YOFCA   **Not assessed**   * Petsana * Beacon of Hope * Bophelong | * Thembalethu * Thembelihle * Masoyi   **Not assessed**   * Phaphamani * Thandanani | * Mohlanatsi, * Balantwa * Nhlayiso * Bophelo * Ramotshinyadi |

1. **HCT and CD4 Referral Systems**

For the period under review, CARE partners in the 3 provinces counselled 12,997 clients of whom 11,930 (91.8%) were tested for HIV. Of 11,930 that were counselled and tested for HIV, 1,845 (14.2%) tested HIV positive. Of those that tested positive for HIV, 1,703 (13.1%) were then referred to primary health care facilities for CD4 testing and 672 (5.2%) received their results back. According to the Ante-natal Survey 2011/2012, national prevalence of HIV amongst pregnant women was at 29.5% and this is the measure used to estimate prevalence of HIV amongst the population. As it noted with the ante-natal survey itself, although prevalence of HIV amongst women that attend ante-natal clinic gives an indication of what the prevalence would be, limitation to that is that it only focuses on a particular proportion of the population that in most instances would present to a health care facility and leaves out other proportions on population that attend health care facilities and test for HIV, but are not included in the ante-natal data collation for the mere fact that it is only ante-natal. In this report it was noted, as indicated from the graph below, that the prevalence was at 14%. There are a number of reasons that could be attributed to this. One of those is:

* Individuals who will test more than once, even though they already knew their HIV status as negative or positive for HIV. Partners noted this in instances when they conduct community based HCT campaigns where individuals will re-test because there are incentives offered for testing, e.g, giving t-shirts to people who test.

A public health approach to accessing HIV related services is through HCT. HCT is an entry point to a range of services for people living with HIV/TB, who might be in need of such.

All of the partners assessed provide both HIV and TB services and use the following strategies to find, counsel, test and screen as many people as possible:

* Community- based HCT campaigns – these campaigns are done in cooperation with health care facilities that CARE supported partners work with in their communities. The health facilities normally would provide extra resources such as health care workers that would assist with testing, provide testing kits and assist with the referrals.
* Home based care testing and screening – in these instances, community care workers would counsel and test clients in their own homes and refer to nearest health care facilities where there is a need for a referral.

Both these methods are very effective in ensuring that people test and know their status, more so with the convenience of not having to present to a health care facility for such service to be provided. It gives an opportunity as well for those people who would not ordinarily attend health care facilities, services are brought to them, even in the comfort of their own homes.

The processes followed from counselling, CD4 referral and presentation to PHCF are:

* Every person who is counselled during the campaign or at home is recorded on the green HCT book (provided by the DOH). In this HCT book information, information captured include residential address, age, gender, results of an HIV test, if the client was referred for CD4 count, whether an individual was screened for TB and referred for TB diagnosis.
* Care givers then fill out a referral form which is given to the client to take to the health care facility being referred to. The referral form specifies what each client is being referred for.
* The client is then encouraged to present to the health care facility.
* In cases where clients are very sick, are not comfortable to attend the health care facility alone or are not keen to attend, care givers would accompany them to the PHCF.
* If and when the client presents at the health care facility they are then attended and provided with services they are referred for, and where possible such information is then communicated back to the partner organisation that would have referred. There are challenges though where once clients have presented to health care facilities, they are mostly not referred back to referring organisations. This issue will be addressed further under the health systems section of this report in terms of how it impacts on further support and care services to the clients.

**Common challenges:**

* Records that show the numbers of clients that get initiated on ART treatment were not available to the team to assess as this information was not routinely collected / recorded for the period under review.
* Partners were mostly able to account for the number of clients that were referred by health care facilities back to them once they have initiated them on treatment. These clients would not be the same clients that the partners would have referred to the health care facilities but those that health care facilities would deem in need of home based palliative care. Hence discrepancies on who they refer to clinics and who the clinics refer back. They end up losing quite large numbers of clients that they refer and are not referred back.
* Some of the problems highlighted with not being able to follow up with clients that they would have counselled and tested for HIV, especially during community based HCT campaigns, is that some clients give wrong addresses.
* Although there is a “general” understanding that CARE referral form is the principal form for referrals, there were instances where partners were filling up to three different referral forms, e.g, CARE, DOH green HCT-CD4 testing form and DOH red TB screening form.
* There is a lack of record keeping and filing of CD4 results of clients referred, hence difficulty in accounting for “their own” clients and whether they have really been initiated onto treatment where clinically and medically indicated.
* One of the gaps that was identified in this area of work was that, although partners would also record testing children under that age of 5, it was not explained which kind of tests were used to conduct such. Common practise is that PCR test is used for testing children and results are available immediately as it the case with ELISA testing used in adults. This impacts on how quickly children are initiated on treatment.
* The team also noted below satisfactory levels on the understanding of the science of HIV/TB, including treatment literacy levels amongst health care workers. This was of serious concern considering that part of their responsibilities include providing palliative care to very sick patients who might be taking ART and/or TB treatment and to follow up on defaulters. If a care giver does not understand the different drug combinations and how they work, what the side effects are and how they are managed; it makes it difficult for them to then support those that need to be supported.
* General record keeping and filing (both manually and electronically) is not easy to work through and needs improvement.

**Innovative initiatives from partners:**

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| *There are organisations that have found innovative ways of navigating this challenge and a good example is Lechabile HBC where, under the leadership of Mr Phoofolo and the HBC coordinator, and Marquard Moemaneng under the leadership of Mr Rasekhobo and the HBC Coordinator, they have started developing new systems of capturing their clients data, which amongst others indicators, will include dates clients were referred to PHCF, dates clients were referred back to their respective organisations, to when they are initiated on ART and/or TB treatment. Lechabile is going an extra mile by designing this on an electronic form as well. Although their systems are not comprehensive enough yet, it demonstrated that they were able to pick up the gaps and derived better methods that will allow them to better account for the numbers that they reach.* |

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| Another great innovative method that the team found in terms of expanding the levels of treatment literacy levels for both HIV/TB was at Thembelihle HBC in Mpumalanga. At this organisation, all three care givers that the team had discussions with were excellent in their grasp, understanding and knowledge of HIV/TB. They were up to date with what the science and new drugs are that patients are being initiated on, could name some side effects. They indicated that their level of treatment literacy is excellent because the health care facility that they work with organises treatment literacy every Thursday for two hours and these are facilitated by health care workers that are leading each of the programmes in the clinic, e.g, TB, HIV, Ante-natal, STI’s, Malaria, etc.  Care givers at Masoyi on the other hand, use their meetings days at the office as information sharing opportunity. Each one of the caregivers will bring something new that they have learnt about HIV during the week and they have a discussion about it, and in doing that they would identify colleagues who are struggling with grasping concepts and names of drugs and assist them to understand better. So care givers took it upon themselves to capacitate themselves. |

1. **TB screening and Referral Systems**

For the period under review, a total of 12,195 were screened for TB, with 1,135 (9.3%) having signs and symptoms of TB and referred. Of those referred, 461 (3.8%) received their results and 121 (1%) of the total screened were then initiated on TB treatment.

A total of 1779 HIV+ and screened for TB (9.7%).

For all those who get counselled, tested and test positive, CARE partners in provinces would also screen for TB. The discrepancy between 12,997 counselled and 12,195 screened for TB could be explained through the following assumptions:

* Clients who go through HCT and already know their TB status hence don’t get recorded as such when CARE partners account for numbers reached,
* Children are also not recorded and accounted for.

The method used for screening for TB was by following the questionnaire tool developed by the Department of Health and a “Yes” answer to three or more of those questions indicate suspect of TB-infection. Those found to be TB suspect were then also referred to primary health care facilities for further care. Further care in this regard was understood by partners to mean diagnosis through sputum collection, which is standard for most cases of TB. What this method of collection and recording of data missed was that there were cases that required X-rays, blood cultures and/or skin tuberculin (Mantoux) tests. The records available are mainly on pulmonary TB and do not provide information on other types of TB such as, TB of the spine, TB of the bones or TB meningitis, thus explaining the turnaround time for test results availability and treatment lengths.

It must be noted that most of the partners are actually doing quite well with screening for TB in their communities. According to National Minister of Health Dr Motsoaledi, with the screening of TB that is now taking place in communities and includes and involves family members, the number of new diagnosis in the country has increased to 3,000 a month in 2013 from approximately 1,250 in 2009. These are efforts that should definitely be credited to the community health care givers who do this on a daily basis.

There is a certain level of comfortability even amongst the care givers in explaining processes and caring programmes for people with TB or those that show signs and symptoms of TB.

**Common challenges:**

* A concern picked up in this regard though was that they do not necessarily encourage those they screen and find to have signs and symptoms of TB to also get tested for HIV, which is what they would generally do for those that test positive for HIV. This is mostly the case with clients that they find when doing door to door / home visits. This is another missed opportunity of finding TB patients who might also be infected with HIV.
* Record keeping on those referred and initiated on TB treatment and continued to be under their care is not properly kept in the office, but mostly as notes on the care givers notebooks. A major concern in this is that in instances where the care giver leaves the organisation, such information is lost. Electronic recording of the information becomes vital in such instances.

**Innovative initiative from partners**

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| *Verification and recording of information for M&E purposes was best captured by Limpopo’s Mr Itumeleng Masia, where he made detailed notes on TB patients referred and received results back and where results were not received, he provided notes on why the results were not received. For an example, there will be notes on delayed results availability from the laboratory, patients having not presented at the health care facility to collect their result, etc. This was very helpful in identifying where the challenges could have been within the health and community systems.* |

1. **Health Systems and Linkages**

From the assessment it was noted that there are gaps in terms of how the referral systems function between the referring partners and the health care facilities. In almost all of the partners that were assessed, the referring organizations put in a lot effort in recording and referring most clients they assist to get into the system through HCT and home based palliative care. This effort is not necessarily met with the same enthusiasm from the health care facilities that also benefit greatly from the work done by the CBOs. The diagram below demonstrates how the relationship should be ideally, but in most instances than not, it breaks after the organization has referred to the health care facility.

The cycle breaks at the point when the organization has referred to health care facilities and only mostly connects again when clinics need to refer clients from the clinic to the CBO. Clients referred by health care facilities are mostly clients that are either defaulting or have not been presenting for follow up appointments at their health care facilities. These relationships need to be improved greatly for the benefit of the clients being serviced as they depend on both these relationships working seamlessly together.

There are quite a number of reasons that have been provided in terms of why the facilities do not refer back. Some of the reasons highlighted were the following:

* Health facilities not being aware of the referral tool being used.
* Health care workers overwhelmed and not being able to fill in the form all the time.
* Information required to be filled in by the health care workers being confidential and cannot be communicated to a third person.
* Not having a formal working relationship with the CBO.

These challenges are not insurmountable though, and there was evidence in some instances that where the management of the CBO is strong, these challenges can be overcome and common ground found for the benefit of the clients.

**Innovative initiative from partners**

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| *Such success stories in this regard include Thembalethu HBC in Mpumalanga. This project is under the leadership on Mr Cleopus and his management team includes Ms Zanele (VCT Coordinator) and Ms Jabulisile (HBC Coordinator). During the assessment this was the only organisation that was identified where there were down referral forms from the Block B clinic which they work with very closely. In their file records for an example of HCT for each month, they would file each client’s consent form, copy of the referral form to the clinic for each client referred and down referral for each client referred where such a form was referred back. The team could easily verify and read that information for each client because the consent form, up referral form and down referral form were stapled together for each client and for each month. Over and above that, they go an extra mile to recording CD4 results of clients referred back, and they do this by constantly following up with each client until results are communicated back and they are initiated on treatment. Although the recording of the CD4 results was not done properly (it was hand noted on the down referral form), it was easy to find and account for that information nonetheless.* |

1. **Averages from referral to ART and/or TB treatment**

The review also looked at the averages of periods taken for processes such as presenting to the health care facility after diagnosis and screening, to bloods drawn and CD4 results communicated back to clients, TB sputum collected to results communicated back to clients. This information was not readily available for verification from the partners as this was routinely collected and recorded as part of the monitoring and evaluation of the project. The team largely depended on care givers and health care workers recollection of what the averages were, especially in comparison to how long it takes now for those processes to unfold.

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| Average time between referral and PHCF presentation (HCT and CD4 testing) | 2 days |
| Average time between referral and CD4 testing  Average time | 2 days (CD4 blood is drawn on the same day the patient would have presented after being referred) |
| Average time between referral and clinical staging | 2 days (clinical staging is done on the day the patient present at the health care facility for CD4 testing) |
| Average time between PHCF presentation and CD4 results availability | 7 days |
| Average time between results availability to results disclosed to the patient | 7 days |
| Average time from referral to initiation on ART | 30 – 40 days (this period is this long because patients have to attend and finish treatment readiness and adherence classes) |
| Average time between referral and TB sputum collection for testing | 2 days |
| Average time between referral to PHCF presentation for TB diagnosis | 1-2 days |
| Average time between referral to sputum collection for TB diagnosis | 1-2 days |
| Average time between sputum collection and TB results disclosure | 3-4 days |
| Average time between referral and TB treatment initiation | 7-14 days |

These averages are only applicable post the period under review (2011/2012), as it was not possible to verify this data from any record from the partners. It was not part of the indicators of the data that was to be routinely collected, neither is it collected as a standard requirement for all partners, except for the few partners that were mentioned already above in this report. This is one area where there needs to be improvements with regards to data recording. This will also allow partners to pick up challenges where it is taking longer than acceptable period of time for clients to receive results and be initiated on treatment.

It was quite interesting to note, especially in the Free State, that there are health centres now where there are CD4 testing machines at the point of care, thus reducing waiting times for results from 7 days on average to 1 day. Also with the introduction of the GeneXpert machines, waiting periods have been reduced from an average of 22 days to 24 hours. There are also health care facilities that have laboratory results scanners which allows the PHCF to track, trace and receive results as soon as they have logged as available by the processing laboratory. From the discussions with the health care workers, it became evident that these developments are actually minimising instances of loss to follow up of patients as when results are available within a short space of time, patients are more likely to come back to the facility for get their results and receive the necessary medical care and treatment. This was compared to when it took more that 2-3 weeks for CD4 results to be communicated back to patients and patients deciding not to present back to the facility because of that.

Recommendation from the team in this regard is that this should form part of the routinely collected data each month so that where it takes too long for clients to receive results and access care, it can be followed up urgently. This would also be made easy by the manner in which data is recorded and kept by the partners. During this assessment it was noted that there is no one defined method of collecting, recording and filing data, so each partner employs a different method and a method that they think better serves their purpose. It is recommended that there is a standard data collection, record and filing of information.

The assessment team also recommends that there are standardized tools and systems of collecting, recording, filing as storing of data, both in terms of paper trail but electronically as well.

**Common challenges:**

* Data on the averages was not routinely collected for the period under review and post, except for a few organisations that have already been highlighted in this report.

1. **Limitations to the assessment**

There were limitations in the assessment itself. Some of the limitations were as follows:

* This assessment took place two years later from the period reviewed. There has been some improvements in the areas that are being assessed (referrals systems), and collection of data although there are still gaps that could be improved upon,
* Some of the partners that were to be assessed were not available for such. Reasons for such included the fact they are not funded by CARE anymore or have closed down the offices,
* HIV testing is mainly done by needle pricks for rapid test and Eliza, there was no mention of use PCR for infants and adults where such is applicable and the effect it obviously has on how soon they can be referred for further services at health care facilities,
* There was no permission to access patients records to verify the date the results were printed at the laboratory, and there is no information as to when the results were delivered at the clinic and communicated to the patients,
* There were no meetings with district and provincial officials as there review period time was limited,
* Assessment team could not access clinic records as special request must be well in advance to access these and permission must be given by the provincial DOH. Because of time constraints of the assessment itself, such permission could not be given with weeks during the assessment period.

1. **RECOMMENDATIONS**

* Revise the Monitoring and Evaluation Data Collection Form (National, Provinces and partners) so that it captures most of the indicators that the team was asked to assess. Indicators must include
  + Record type of HIV test provided, e.g. ELIZA and/or PCR as this has implications on the turnaround times for results.
  + Records of number of people initiated on ART treatment.
  + Records of number of people initiated on TB treatment.
  + Average times from referrals to initiation on treatment for both HIV and TB.
  + Records of treatment regimens clients are put on for both TB and HIV.
  + Type of TB diagnosis results, e.g Pulmonary TB, Extra-pulmonary TB.
  + Records of number of clients with TB, MDR TB, XDR TB (especially now that there is a growing and general use of GeneXpert machine that picks up resistance to some TB drugs).
  + Record numbers of clients referred by PHCF to partners that are not necessarily those that are referred by the partners to the clinics. This will assist partners in understanding, for their own benefit, the load of clients that gets referred to them by clinics,
  + Define means of verification of the above mentioned indicators.
* General records keeping and filing (of partners) can be improved greatly as well. For an example,
  + There are improvements that can be made to improve the information recorded over time for the patients and it all starts with the kind of data that is initially recorded on the green HCT book. Not only should they be recording that they have tested, screened and referred the clients on that book, they should also include date referred, date results received, date initiated on treatment. The HCT green book is not enough for this purpose, so maybe partners can design these themselves with guidance from CARE or these are designed by CARE and shared with the partners.
  + They should ensure that for every person they have tested, in a file for that particular month and file for that particular client, they keep the consent form, attach the referral form, and the down referral form if they get those back from the health facilities, record of CD4 results and or TB results and treatment initiated on.
  + There must be a spreadsheet document that records all this info and it is then filed in paper form and electronically. They should be able to trace progress of each patient at different intervals, e.g, 3, 6, 9,12,18,24 months after initiation on treatment.
  + Partners need to really intensify their electronic record keeping, inclusive of notes on the care givers notebooks. This will act as back up for their paper filing in cases of theft or fire as it happened in Marquard Moemaneng for an example.
* Encourage care givers to, at all times, offer an HIV test for every client they identify as having signs and symptoms of TB, which is the case with all those being tested for HIV who get screened for TB as well, considering the high rates of HIV/TB co-infection in this country.
* Patient categorisation system was interesting to learn about during this assessment and care givers were able to explain in clear terms what each category means in terms of home based palliative care. The team noted though in their records of clients they are providing care to, they fail to “let go” of category 1 patients, so they will have in their book, clients who have been category 1 for years but they still provide services to the, Where clients have recovered to category 1 phase, they need to make a conscious decision to discharge them and move on.
* Care givers fill in the patients’ registration form each time they visit their clients and record that state they found the client in and what they offered. Recommendation is a patient is registered once and there are patients’ evaluation forms that they keep each month to record progress of the patient. During the assessment and reading though the patients’ registration forms was that the data being filled in was not necessarily tracking health condition progress but more what services the care giver provided, e.g cleaned the house, cooked, bathed the client and gave out condoms. What is recorded is important as it must tell total health and social well-being of the client.
* Find creative ways of improving the partners’ levels of knowledge and capacity of the basic science of HIV/TB through focused treatment literacy programmes. One of those is to just design and execute solid training and re-training programmes that will entail refresher courses at least annually. In this report we have highlighted some of the innovative ways used by some partners. This could be used by other partners, e.g
  + Health care facilities / DOH taking over the responsibility of training and mentoring care givers.
  + Identifying master trainers amongst the partners themselves whose level of knowledge of HIV is excellent and they assist in developing same level amongst their peers.
  + Partner with other non-governmental organisations who can offer the training services for free or at a minimal cost.
  + Find HIV/TB materials that are easy to read but detailed enough and distribute those to partners. A good example of this is the recently published, up to date HIV in Our Lives Series from the Treatment Action Campaign.
* Find agreements on which referral form is going to be used by all partners and acceptable to the health care facilities that partners work with. This is meant to assist in clarifying which form, out the three used for referrals, must be used.
* The referral form that CARE partners uses was apparently agreed to by the DOH hence the assumption would be that health facilities know about it and would use it for referrals with the CBOs. However, as highlighted above, this is not the case in many CBOs. In this instance it is recommended that:
  + CARE Provincial Offices raise this issue with the DOH officials so that a directive is given from that level.
  + That CARE partners set up status meetings with the health care facilities they refer to and they are assisted in these meetings by CARE Provincial managers / Programme Officers so that they are also taken seriously on the work they do and services they provide.
  + The referral form be adjusted so that the information required to be filled in by the health care workers for down referrals is not laborious to a point where health care workers choose not to fill at all. It must request that information relating to the referral be filled in and nothing more or less from that. This could also be assisted by the consent and confidentiality form that patients fill in for testing and counselling to also include consent for limited information, relating to care services to be provided, to be filled in by the health care workers. This will assist as well with the shared confidentiality concerns that are raised by health care workers.
  + Partners must be encouraged establish formal working relationships with the health care facilities they work with. One of the outcomes of those relationships should be agreement to set up monthly status meetings with the clinics they refer to so that they can constantly update each other on the progress and challenges they are facing as they implement health services jointly to the benefit of the patients.

In conclusion, the above highlighted efforts are by no means a small contribution to a national goal of ensuring that people get tested and are enrolled into care as early as possible. The National Strategic Plan 2012 – 2016 envisages that by 2016, South Africa would have reduced new infections by 50%, enrolled 80% of people medically and clinically indicated onto treatment programmes. It also envisages to screen, trace, treat and retain onto care 50% of all cases of TB. UNAIDS rallying call is to ensure that there are *Zero new infection, Zero AIDS related deaths, Zero Stigma and Discrimination* and this is strategy that has been adopted by the South African government. It is in this context that the role played by these partners must be acknowledged as contributing greatly to the attainment of these goals and to the well-being of the communities they operate in and work with.

**INTRODUCTION:**

2012 marked 30 years since the first case of HIV was reported, 15 years since treatment became a reality, 10 years since the United Nations General Assembly Special Session on HIV/AIDS and five years since South Africa’s commitment to achieving universal access to HIV prevention, treatment, care and support.

South Africa has been more affected by the HIV/AIDS epidemic than any country in the world. AIDS has stolen the lives of thousands of children, brothers and sisters and has left many orphaned and vulnerable children and even some child headed households. According to the Ante-natal survey of 2011/2012, the country’s HIV prevalence was at 29.5%.

Early in 2010, the National Minister of Health, Dr. Aaron Motsoaledi announced a new effort by the South African government of escalating the number of people reached and tested for HIV. Part of this effort was to encourage South Africans to test early, know their HIV status, and where medically and clinically indicated, those that need access to ART will be initiated on time. This initiative was to be coupled with intensive campaign on escalated effort to trace and treat members in communities who are infected with TB. Combined efforts in such regard would mean that even those with HIV/TB co-infection are identified early and are put within a health care system that will be responsive to their health needs.

This initiative has actually yielded quite encouraging results for the country’s response to HIV/AIDS and TB epidemic. According to the National Department of Health reports, within the first year of the launch of HCT campaign, approximately 15 million people had actually tested and by 2012, there were approximately 1.4 million people accessing ART through the public health care system. This number has nearly doubled to date with approximately 2.4 million accessing ART treatment.

Although this can be hailed as the most progressive state in the country’s history’s response to HIV/AIDS, there are a whole of challenges that are associated with accessing care (from counselling and testing) to retention to care after being initiated on treatment. Detailed data on the country’s performance are hard to find, and evaluations on the quality of the existing data even harder.

While TB rates are decreasing worldwide, including in Africa, the World Health Organization’s *Global* Tuberculosis *Report 2013* notes that the estimated TB incidence in South Africa – already unacceptably high for many years – has continued to increase. TB incidence in South Africa is now estimated to be more than 1,000 cases per 100,000 people while in countries like USA, Japan, Australia and many countries in Europe it is less than 10 per 100, 000. In addition, South Africa is one of three countries (together with India and Ukraine) with the largest increases in multidrug-resistant tuberculosis (MDR-TB) between 2011 and 2012.

The percentage of cases on TB treatment in South Africa has been estimated to be [as low as] 22%. This is because many people who have TB symptoms do not access healthcare services, and many of those who *do* access the healthcare system with symptoms of TB are not tested. It is estimated that in South Africa, a quarter of people who are diagnosed with TB are never started on treatment. The gap in treatment coverage for detected cases of MDR-TB is also continuing to widen. The inability of health services to provide adequate follow-up and treatment is both cost inefficient and a poor use of health service resources.

Of course there are challenges that are associated with access to health care services and the demand for such services also increases within the health care system itself. With an increasing number of people that are going through the HCT campaign, so are the demands for services in health care facilities, and these are mostly not met because of the shortages of health care workers within the public health sector, an ever increasing number of reports of continuous drug stock outs and health system that is buckling under pressure. Over and above this, the public health system itself is struggling with its own monitoring and evaluation of how well the country is keeping track of people from the time they test for HIV, to when they are initiated on treatment, to when they are stable but remain within the system, In most instances the system cannot account for people loss to follow in the system, be it on the HCT programmes or the HIV/TB treatment programmes. This is attributed to the inadequate systems of tracking patients at the primary health care level all the way to the national level. The system still remain largely paper based and prone to a lot of mistakes and loss of information.

According to Dr Leigh Johnson of the University of Cape Town, the country’s population is largely migratory, and people move across towns, provinces and health centres, and health system is poorly integrated, keeping track of people who have tested but never return for further services and follow up is almost impossible.

On the very same token, Professor François Venter of the Wits University’s Reproductive Health and HIV Institute, estimates that at every stage of HIV Care, from the initial HIV test, to receiving CD4 test results, to being initiated on treatment, approximately 50% of patients are lost. Trends are all the same for TB as well. Long waiting times at health care facilities, poor attitudes from health care workers who work under difficult conditions, financial implications in terms of transport to get to the health care facilities, and work pressures are some of the contributing factors to loss to follow up in the system.

This brings to point the role that Home Based Care organizations play or can play in mitigating the impact of follow up of individuals already in the care from testing services that would have already been rendered, in terms of follow up with regards to presentation to health care facilities, ensuring that they get their CD4 tests done, TB diagnostics performed, results collected once available at the health centre, where clinically and medically indicated, that they are initiated to treatment and they adhere to their medicines. This is in recognition of the fact that, the on-site bound health care workers do not have the time nor the resources in most instance to follow up on such. But systems must be developed to support the work done by the community health organizations and workers so that they assist the system to serve the clients better.

**PROVINCIAL ASSESSMENTS**

**A: FREE STATE**

1. **Lechabile**

For the period under review, Lechabile HBC counselled a total number of 1,077 clients. These numbers were reached through a combination of interventions. Those interventions included community HCT campaigns, home visits/home based testing and office drop ins.

Of the total number of 1,077 that were counselled, 1,019 consented to being tested for HIV (94.6%). 117 of 1,019 tested HIV+ (10.9%). This data was verified through information recorded on the HCT book and consent forms records kept in the office.

From the records that the team were able to verify, only 7 (0.6%) were referred for CD testing, and all 7 received their results back (0.6%). There were no records indicating the results of the CD4 counts available at the office. This would have assisted in determining the number which ultimately was enrolled onto ART treatment. It is highly possible though that actually all of the 117 that tested positive were referred to the primary health care facilities, but lack of documented evidence made it difficult for such to be verified. Challenges around referrals to health care facilities are dealt with at the section below that looks and the practices of referrals by the organization to the health care facilities.

A total number of 1,019 clients were also screened for TB. The practice in this organization is that for every person counselled and tested for HIV, they get screened for TB as well. The practice is not always same for every person screened for TB and found to have signs and symptoms, that they would equally be offered an HIV test. This is a missed opportunity in finding people who might have TB to be also tested for HIV as chances are high that they might actually be infected with HIV.

Of the 1,019 that were screened for TB, 48 (4.7%) were found to have signs and symptoms of TB, and all 48 (4.7%) were referred to PHCF for further diagnosis. 21 (2.1%) of the 48 received their results back. For the period under review, the record keeping for such processes was not adequate. Documentation that the team was available to verify in this regard, were the home patient visit files and carers notes.

It was not possible to verify the total number that were then initiated on ART and TB treatment as this data was not routinely collected and recorded at the time. The record keeping process in this regard has since improved though from 2013 onwards although there are improvements that could still be made to better track the processes and the well-being of the clients. It was the same case with keeping data on when clients would ordinarily receive their results back so that there can be analysis of the averages it takes for results to be communicated back. Data on averages in this instance were only based on the discussions with health care workers at the health facilities and patients’ experiences. This information is attached on the excel workbooks that are part of this report.

**Assessment, Review and Observations on the CD4 and TB referral systems**

* Three care givers interviewed at this CBO have worked for the project for more than 10 years (so were already there for the period under review). They indicated that they have only been trained on Home Based Care twice in the 10 years they have been there and only once on basic science of HIV and TB. Home Based Care training was provided by the Department of Health and Basic science of HIV and TB training provided by CARE SA in 2013.
* That they will usually have massive HCT campaigns, from between one to three per quarter, and that those that test HIV positive from such campaigns will be referred to the health care facilities closer to them.
* They also do home based testing for HIV and screening for TB for family members, and those found HIV (+) and/or have signs and symptoms also get referred to their nearest health care facility.
* That they use the “green” HCT book to record details of those counselled, tested and tested positive, and those with signs and symptoms of TB, who then get referred after such campaigns. The statistics in this book is used to also submit data to the DOH in the district. Indeed the assessment team went through the 2011/2012 green book to confirm the data.
* They further indicated that they use a referral form that was designed by CARE for such referrals, and went through how they fill in that referral form.
* They also indicated that they (care givers) are not the ones who fill in the referral forms but the registered nurse. Care givers collect the filled in forms from the office and give them back to the clients they need to refer. The registered nurse also calls the clinics to make appointments for the clients that they refer.
* Once referred, they will go back to the client or health care facility to check if they have gone to the clinic for services indicated on the referral forms. Care givers indicated that there is no formal feedback from clinics in terms of the referral form being filled in and sent back to the referring partner. This only commenced in 2013, which is post the year under review.
* Their office now keeps photocopied copies of the referrals, and use those for follow ups and keeping records of who they have referred and who they will be supporting with home based care and psycho-social support through their I-ACT programme.
* For the period under review though, there was really not much evidence on follow-up of patients referred because records for such were not readily available, either in the form of notes from care givers or from HBC coordinators records. There are records though of clients referred by the clinics, who are not necessarily the same as the one they referred by the CBO to health care facilities.
* From the assessment, it became evident that referrals from the partner to PHCF were a one way process, as they were not getting down referrals of the patients they would have referred to the clinic. What would happen in most cases is that the clinic will down refer a new set of patients, who are TB defaulters, ART defaulters and patients referred to as Category 3 patients.
* During the assessment at one referring clinic (Mantwabe Clinic), it was quite evident that there was no understanding from the clinic officials of the referral form used by the partner and so no such record were kept by the clinic of the clients referred, but they were open to discussing ways of dealing with this issue. The clinic acknowledged the good job that Lechabile is doing in following up mostly TB patients that they refer to them.
* A meeting was held with the clinic officials to discuss the referrals between the parties and the last one was on the 18th February 2014, and at that meeting both parties agreed to utilize the CARE referral form going forward.
* The level of understanding of the basic science and treatment literacy of HIV and TB was low. The carers couldn’t explain what the guidelines are for HIV/AIDS Care and Treatment, could only name Nevaripine and Stavudine as HIV drugs, but never really sure when a person gets prescribed these or how they are supposed to take them. This raised alarms on how then are they supporting clients who are on ART and literally depend on them to take medicines.
* They knew their TB drugs and how they are administered through DOTS and after the intensive phase, and this was encouraging. Their level of understanding of MDR and XDR TB was worryingly low, considering that there is a growing number of MDR TB cases.

**Visitations to the clients:**

5 patients were visited with the assistance of the care givers. The aim of the visits was to get an idea of how accessing health care services with CBOs being their initial point of call to services at clinics and whether this method was helping them as general members of the community. The sense the team got here was that the care givers play the most vital role in terms of bringing the services to them and to continue to support them even after they have presented to health care centres. Of note from the clients visited was one client, \*Ms M, who has TB of the spine and is HIV (+). She was discovered by one of the carers last year around July, bedridden and lost a lot of weight. The care giver referred her to clinic, further referred to hospital, and was finally diagnosed with TB of the spine and HIV +. She was put on treatment for both HIV/TB. She has recovered a bit although she still can’t walk. She sang praises about how supportive the care givers have been, by collecting her medicines at the clinic every month, daily visits that include cleaning and cooking for her and assistance with taking her medicines on time.

**Recommendations:**

* That care givers are taken through a series of HIV/TB TL trainings, at the level they will understand but intensive enough for them to grasp as much as needed to allow them to carry out their tasks with diligence and provide best support to their clients.
* These trainings must also offer an element of follow-up support, so that it is not the once-off trainings with no proper support afterwards.
* That caregivers are trained on how to fill in the referral forms as they could clearly understand what is it that needs to be filled in and how to fill it in. Although there is clear motive for centralising the filling of the referral forms, which is that the office is able to make copies of the referrals and keep that as a record in the office. Care givers can be asked to fill in two forms so that one of those is taken to the office for such record keeping as needed by the office. That data must actually be fed back to the care givers so that they can also learn about how the program is progressing on a regular basis.
* Record keeping of clients referred by the partner to the health facility and follow up needs to be improved greatly, as the challenge here is that they refer quite a lot of patients to the health facilities but can’t really account for them post referral
* Develop a record keeping method that enters data of each patient reached, referred, CD4 done date, results of CD4, if indicated for ART when they commenced and trace progress in 3 months, 6months, 12months, until 24monts and discharge if prognosis is good at that time. Same for TB referred, date tested and results, if indicated for TB treatment record start date and end date and results for TB (-) confirmation after and discharge.

\*\*Star Carer for this project was Ausi Mookgo

1. **Marquard Moemenang**

During 2011/2012 Marquard Moemaneng reached 392 clients through counselling services. Of those, 391(99.7%) consented to being tested for HIV. These numbers were reached through a combination of activities, those being community based HCT campaigns and home based counselling, screening and testing services. 65 (16.6%) of 391 tested positive for HIV.

From the records that were presented to the team, it was not easy to verify the number that was referred for CD4 testing after testing HIV+, but from understanding of the processes that the organization follows, it can be assumed that all 65 were referred. The team could only verify that two were referred and received their results back. This can be attributed to the fact the programme was still new during the review period, but the mechanisms of record keeping and verifying those referred for CD4 testing have improved in the years following after the review period. So from what was verified, only 2 (0.5%) were referred and received results back

From the data presented, a total number of 391 people were screened for TB. Of those, 25 (36.4%) had signs and symptoms of TB. All 25 (6.4%) were referred to the PHCF for further diagnostics care and only 4 (1%) of those received their results and 4 (1%) were TB positive.

For the period under review, there were no records available in the office in terms with indications of a total number registered on ART as it was not routinely recorded at the time. This has improved though for the following years.

**Assessment, Review and Observations on the CD4 and TB referral systems**

* Three cares interviewed have worked for the project for between 8-12 years (so were already there for the period under review), and indicated that they have only been trained on Home Based Care once in the 10+ years they have been with Marquard Moemaneng, and only once on HIV and TB. Home Based Care training was provided by the Department of Health and Basic science of HIV and TB training provided by CARE SA in 2013. All of the care givers interviewed only provide home based care, they do not conduct counselling and testing as they have not been trained on HIV counselling but there are care givers within the organisation that are lay counsellors and can test clients.
* Only those that are trained as lay counsellors are able to do pre-testing counselling, the actual testing and post-testing counselling and make referrals for people diagnosed with HIV. The care givers that were interviewed for this review indicated an interest in being trained as lay counsellors as well, and that they feel they have missed opportunities when they visit families and such services are required and they can’t provide them. That becomes a missed opportunity to act there and there.
* Those that are not trained as lay counsellors only assess and refer clients found to have signs and symptoms of TB. They felt that there are missed opportunities for those that are not trained as counsellors, to reach even more people.
* Once people have been counselled and tested for HIV, they would be referred to their nearest clinic.
* Same for TB clients, those that were found to have signs and symptoms, they would be referred to the nearest health care facility.
* As is the case with most partners, up referral from partners to health facilities is done consistently but down referral of the same clients from the health care facilities back to the referring partner was and still not reciprocated.
* For the period under review it was impossible to locate the records of the referred clients, except for the records of the numbers counselled, tested and referred. On what happened to the clients at the other end of the system was hard to establish.
* All of the interviewed clients concurred on the use of the “green” HCT book to account for numbers reached during the HCT campaigns and home visits.
* Again all of then confirmed the use of the CARE referral form, and all of them fill in the form, unlike, for an example in Lechabile where only the project registered nurse fills in the forms. This allows the caregivers to refer on the point of contact instead of walking back to office where referrals are “centrally” written out and managed.
* The clinics also refer their “own” patients to the CBO, especially defaulters, so that the CBO can follow up and give feedback to the health facility on each client referred to them. There is no standard method of how the health facilities themselves will refer clients to the CBO. They either call in the office and provide names of patients to be followed up or fax through a notebook page with names and addresses of patients to be followed up,
* Moemaneng’s record keeping has improved drastically post the period under review. They have actually designed a method of keeping proper record of all clients they refer, when they referred them for CD4 counts testing, when CD4 results are communicated back to clients, TB diagnosis, what the CD4 results were and if 350 and below, when they are initiated on treatment. In cases of TB positives, they capture when they are initiated on treatment and end date of their TB treatment. They are the only CBO in the province who actually have this system in place. This showed forward thinking and applying themselves on how they can better account for the good work that they do,
* It was noted that Mamello clinic is one clinic they refer to that has a CD4 testing machine on site, and this has drastically reduced the time patients have to wait for their CD4 results to an hour on average on the same day. It would be interesting to note going forward how this impact on clients presenting back to health care facilities for their results when they do not have to wait for, on average, 7 days for results to be released.
* Kokelong is one of the three clinics that MM HBC refers their patients to. In a meeting with the clinic manager of this clinic, the following was highlighted,
  + The clinic does not have a CD4 testing machine and so they refer patients to Mamello clinic for a CD4 test and then come back to them for further assistance if needed. This leads to high levels of loss to follow up just for CD4 testing cases as patients become impatient of the long process due to this back and forth referrals amongst clinics, and for others it is an expensive exercise in terms of transport to and from the clinic.
  + The clinic also does not have a GeneXpert machine or a scanner at the moment. They therefore wait for the laboratory which is in Bloemfontein (>200km) to fetch their sputum samples and bring the results back and this lengthens the TB test results waiting period thereby delaying the patients on starting treatment, and actually loosing patients completely from the system.
* When the CBO refers clients who are TB suspects to the clinics, those clients are not referred back to the CBO that referred them but will be allocated a DOTS supporter at the clinic, who then follows up with the client. This is the same case even with existing clients who are on ART but develop TB, the clinic will not refer them to the CBO after initiation on TB treatment but will assign them to their own clinic DOTS supporter. This is creating a lot of tensions between Moemaneng care givers and the clinic’s DOTS supporters. There must be a strategy to deal with this from both sides as it really is to the disadvantage of the clients. DOTS supporters are only there for the first two months of treatment and that is far as they go with treatment monitoring and supporting.
* The level of understanding of the basic science and treatment literacy of HIV and TB was low. The carers couldn’t explain what the guidelines are for HIV/AIDS Care and Treatment, could only name Nevirapine and Stavudine as HIV drugs, but never really sure when a person gets prescribed this or how they are supposed to take them. This raised alarms on how then are they supporting clients who are on ART and literally depend on them to take medicines,
* They knew their TB drugs and how they are administered through DOTS and after the intensive phase, and this was encouraging. Their level of understanding of MDR and XDR TB was worryingly low, considering that there is a growing number of MDR TB patients,
* For the period under review, there was really no proper recording of follow up processes of the clients reached though HCT campaign and TB screening programmes. This has improved greatly from 2013.

**Recommendations:**

* That care givers are taken through a series of HIV/TB TL trainings, at the level they will understand but intensive enough for them to grasp as much as needed to allow them to carry out their tasks with confidence and provide best support to their clients,
* These trainings must also offer an element of follow-up support, so that it is not the once-off training with no proper support afterwards,
* That caregivers who have been in the project for more than 5 years at least, are given more responsibility and skills training so that they can feel valued and grow within the project. This is in relation, in this case, to two carers who have been with the project for between 10 – 12 years but all they have ever been in the project, is being home based carers, and have not been trained as lay counsellors.
* The areas that can be improved here is the tracking of the patients progress throughout the time they are either category 2 or 3 clients to when they have fully recovered and are discharged from care-giving programme and to community based adherence clubs. This will allow the partner to see realistically what progress they are making and claim their “brownie” points on the good work they are doing.

\*\*Star care giver – Ausi Tsi

1. **Khauhelo**

For the period under review, Khauhelo counselled a total of 569 clients. Of those 461 (81%) gave consent to HIV testing, and 83 tested HIV+ (14.6%). 75 (30.8%) of the 83 were referred for CD4 count testing and all 75 (30.8%) received their results. 461 were screened for TB, 16 (3.5%) of those found to have signs and symptoms. All 16 (3.5%) were referred and 12 (2.6%) of those received their results.

Record keeping at this CBO was below satisfactory. The information that the team was looking at was recorded in A5 note books that were not even filed properly. In this way it is very easy for such important data to be lost.

Only one person knew and understood how data is filed in the office. This poses a risk of non-availability of information in cases where such person is not available in the office, as was the case during this assessment. The team had to re-visit the organization as data could not be verified on the scheduled day.

**Assessment, Review and Observations on the CD4 and TB referral systems -**

* Care givers interviewed have been with the organization for more than 5 years, and were with the organization already during the period under review.
* They reach clients through community based HCT campaign and home visits.
* They also provide home based testing and screening for TB, then refer to nearest PHCF.
* As with many other organizations, they do not get referrals back from the clinics that they work with.
* Care givers level of knowledge of ART and TB treatment was below average.
* CBO has not developed the referral communication system and working relationships with the clinic, which has then made the clinic unable to keep a record of the patients referred from the CBO.
* The clinical manager stated that most of the referral forms end up at reception and not into the right hands which should be the attending nurse and requested that the referring care givers ask the referred patients to make sure the referral forms get to the nurses who attends them.
* The clinic manager at Mphohadi clinic spoke enthusiastically about the importance of a working referral system between the two as she acknowledged the role that the care givers are playing, especially helping the clinic a lot with TB patients who have defaulted, to get back on track.
* The clinical manager stated that there is no functioning referral system between the clinic and the CBO and had no records kept of patients referred from as such.
* She also spoke of the importance of the tool used in the referring process and how it should be encouraged and be used in the process and also acknowledged the role CBOs are playing in helping them reach patients they as a clinic cannot reach on their own.
* There is a CD4 testing machine testing machine at Mphohadi clinic which has made CD4 results to be available to patients within same day, compared to previously when it took a week or more to get the results back and communicate them to patient.
* There is also a scanner at the clinic now, which has made specimen tracing and getting results quicker than before.

**Recommendations:**

* There needs to be complete review of data capturing, recording and filing at this organization. M&E needs a lot of support in keeping and organizing files for easy access and availability to all if need be in her absence.
* Take leadership on establishing working relationships with health care facilities that they work with, who seemed very enthusiastic about the work done by CBOs but concerned about lack of communication with the management of Khauhelo.
* Intense trainings on HIV/TB for all staff, including management. An observation during a visit to one patient was concerning to the team where a care giver could not understand the ARTs taken by the client and how many times and what dosed are to be taken.
* Develop a record keeping method that enters data of each patient reached, referred, CD4 done date, results of CD4, if indicated for ART when they commenced and trace progress in 3 months, 6months, 12months, until 24monts and discharge if prognosis is good at that time. Same for TB referred, date tested and results, if indicated for TB treatment record start date and end date and results for TB (-) confirmation after and discharge.
* Record keeping of clients referred by the partner to the health facility and follow up needs to be improved greatly, as the challenge here is that they refer quite a lot of patients to the health facilities but can’t really account for them post referral

1. **Phela O Pheditse**

For the period under review Phela O Pheditse counselled a total of 433 clients. 430 (99.3%) of those gave consent for HIV testing and 51 (11.8%) tested HIV+. All the 51 (11.8%) that tested positive for HIV were referred for D4 testing and 8 (1.8%) received their results back.

An equal number of those tested for HIV were also screened for TB, which was a total of 430. 21 (4.9%) of the 430 were found to have signs and symptoms of TB and were all referred for diagnosis. There was no record of the total number that received their results back.

**Assessment, Review and Observations on the CD4 and TB referral systems**

* Two of the carers interviewed have only been trained on home based care, and those two are the ones who have been in the organization longer have but have had no further training beyond home based care,
* During HCT and home based visits, carers counsel, test for HIV and screen for TB,
* All those found to be HIV positive and / or have signs and symptoms of TB get referred to their nearest health care facility,
* Green HCT book is utilized to keep details of those that they have tested and screened for TB, and use this data for M&E purposes,
* They use three different types of referral forms, i.e., DOH “Green” HIV referral form, DOH “Red” TB screening tool and the CARE designed Referral form,
* CARE referral form in this instance was/is only used only on home visits screenings and testing,
* Although they put effort in filling all three referral forms, the facilities that they refer to do not refer back the clients that the CBO would have referred up. Instead they refer clients that would have been seen by the facility but not necessarily through the CBO. Although there is nothing wrong per se with clients being referred by the health facility to the CBO for further home based care, it creates problems for the CBO with getting up to date information about the clients that they have reached through the campaigns and home visits that they conduct,
* Some methods they use to track the clients that they have referred is by visiting them at their homes, or requesting access to their files from the health facilities. The latter method does not always work because client information at that level is classified as confidential and health officials are very reluctant to allow them to access this information, understandably so,
* There were no visible records where they trace and record CD4 results of clients referred, (they only depend on patient records of the daily visits, even those will not necessarily all the time match those that would be on the HCT register for each month), so highly possible as well that it would be clients referred by the health facility, or clients that they would have met as they do home visits, and not the continuation of the ones the CBO would have referred,
* In most instances it will be same with the referrals for TB suspects. Although they refer to the health facility, the facility will not refer back or communicate the findings with the partner. The carers have to then follow up with the clients at their homes,
* The disadvantage of not receiving any information back from the health facility is that clients sometimes report that they have gone to the clinic, when they actually have not gone, and this leads to missed opportunities for proper health care intervention for clients referred,
* From the meeting held with the clinic manager it became evident that there isn’t necessarily any established referral system communication with the CBO. Moreover the clinic keeps no records of clients referred to them by POP because there was not established agreement to do so from both parties,
* The clinical manager spoke with enthusiasm about developing and establishing the referral system relationship with POP as the CBO is doing a lot that helps them as a health centre to reach the people that the clinic would not normally reach as they are centre bound. The clinical manager further emphasized that communication between them has to be up to date at all times to maximize efficiencies,
* She also commented on the improvements in the turnaround time for CD4 and TB results since they got the scanner at the clinic, which allows them to track and receive results as soon as they have been logged in by the laboratory,
* There is a gap in the understanding of treatment literacy amongst carers, both new and old. They indicated that they have been trained only once in basic science of HIV/TB and in this and would appreciate constant trainings so that they feel confident tackling challenges they come across when caring for clients,

**Recommendations:**

* As with most other partners, there are problem with down referrals once POP has refereed clients to health care facilities for CD4 testing and/or TB diagnosis, and this requires urgent attention as it minimizes the value of the work done by the organization, and makes it a bit difficult for them to keep proper records of what had happened to the client once referred,
* As there was enthusiasm shown by the clinical manager and health facility manager on the work done by POP, they can use this as means of negotiating better ways of managing and referring the clients back to the referring organization,
* They develop a recording method, an improvement from the HCT green book, that picks up on each clients’ progression from time referred all the way to when they are initiated on treatment, (ART/TB or both) and progress of each client after certain periods on treatment until discharged,
* That care givers are taken through a series of HIV/TB TL trainings, at the level they will understand but intensive enough for them to grasp as much as needed to allow them to carry out their tasks with confidence and provide best support to their clients,
* These trainings must also offer an element of follow-up support, so that it is not the once-off training with no proper support afterwards,
* That care givers are taken through a series of HIV/TB TL trainings, at the level they will understand but intensive enough for them to grasp as much as needed to allow them to carry out their tasks with confidence and provide best support to their clients,
* These trainings must also offer an element of follow-up support, so that it is not the once-off training with no proper support afterwards,

1. **YOFCA**

During 2011/2012 YOFCA counselled and tested 788 (100%) clients. Of those 55 (7%) tested HIV+. All 55 were referred for CD4 testing and 0 had their results communicated back to them. A total of 788 were screened for TB, with 178 (22.6%) showing signs and symptoms of TB. All 178 were referred and 17 (2.2%) received their results back and 10 (1.3%) were initiated on treatment.

**Assessment, Review and Observations on the CD4 and TB referral systems -**

* Three carers were interviewed for this assessment. Two of the three have been with YOFCA for more than 13 years.
* Only two of the three have been trained on both HBC and lay counselling, but both of them have not been conducting any testing as they have not done practicals for testing.
* During HCT and home testing, carers counsel and test for HIV. They also screen for TB. For those found to be HIV positive or TB suspects or both, they refer them to the nearest health care facility.
* They use the CARE referral form to refer clients counselled, screened and tested at their homes, but when they have HCT campaigns they use DOH HIV-HCT and TB screening tools for referrals. It is near impossible to trace back clients with those DOH forms as they have no section that asks of the health facility to refer back to the CBO.
* They indicated though that even with the CARE designed referral form, their referring clinics do not fill the form and refer the clients back, and hence it becomes a one way process.
* Except for the HCT green book, patients records and carers notes, there is no system in the office, electronically or paper filing, that keeps track of referrals up and down, records of CD4 results communicated back to clients and patients initiated on treatment, or TB results communicated back and TB treatment initiated.
* They indicated though that the time intervals for both CD4 and TB results have improved drastically in the past two years, with TB results faster than CD4 results. This is largely due to the use of the GeneXpert machines at the laboratories and in some clinics where there are scanners that track the results faster back from the laboratories.
* The level of HIV treatment literacy was very low amongst the carers assessed, and they attributed this to them being more focused on TB than HIV generally.
* They are very good on their knowledge on TB and TB treatment.
* The clinical manager indicated that they have not kept any records of the referrals as no request was made to that effect.
* That she was quite impressed with the work done by the organization though as they reach people and places that they as the health facility would not ordinarily reach.
* She also commended the good working relationship the clinic has with YOFCA and how they have been of great assistance with TB patients.
* Tebang clinic is the only clinic that showed us their TB registers, that tracks when sputum are collected, results received, results communicated to patients and when each client is initiated on treatment and discharged.

**Recommendations:**

* There are too may referrals forms filled by the CBO. At times it gave an impression that the carers themselves were overwhelmed by this. After discussions with them and the project manager, it was evident that the CARE referral form is actually what can work best, but because of the reporting requirements by the DOH, they are obliged to fill in the other forms. Recommendation is that they utilize only one form, and that must be agreements on which it will be although suggestion would be that the CARE referral form is the one to be used, and that this must be agreed upon with the health care facilities that they work with. This could also be facilitated by the provincial office in terms of agreements with provincial and district health offices,
* That there is a discussion with the health care facilities on how they will account for the statistics other than filling all those forms,
* Records on follow up for clients referred and initiated on treatment were not available (copies of the referral forms or notes on outcomes of referred clients). Of course the cares keep note books where they record details of the clients they are looking after, they do not contain much detail on the information required in terms of this review or better accounting processes going forward. The carers notes are very useful though for the carers in understanding the needs of the clients they are looking after, but still those could be organized in a way that makes it easier for them to follow health progress of each of their clients,
* Office keeps evidence of clients referred and document outcomes of such and these be kept in files per each month so that data of clients reached and refereed will be matched by evidence of follow up processes from these. These should be the same with how carers organize their own notes in their notebooks so that any person can read those notes and follow what is happening each month, with each patient referred and followed up, and cared for if there is such an indication/need to do so.
* There doesn’t seem to be the same level of understanding on the importance of down referrals across all health care facilities they work with,
* CARE provincial to assist with meeting with the district health officials to once more find common ground on the referrals done by the partner and how this is assisting them at the department as well and it is not seen as another added burden to the health care workers,
* YOFCA project coordinator and HB’s coordinator set up meetings with health care facilities they refer to and explain once more why cooperation in this regard is important for both parties, but more for the clients they are all providing services to,
* That care givers are taken through a series of HIV/TB TL trainings, at the level they will understand but intensive enough for them to grasp as much as needed to allow them to carry out their tasks with confidence and provide best support to their clients,
* These trainings must also offer an element of follow-up support, so that it is not the once-off training with no proper support afterwards,

**B: MPUMALANGA**

1. **Thembalethu**

Thembalethu HBC counselled a total of 945 clients for the period under review. 943 (99.8%) of those gave consent for HIV testing. Of the 943, 225 (23.8%) tested positive for HIV. 182 (19.3%) of the 225 were referred for CD4 testing, with 96 (10.2%) results released by the PHCF. 93 (9.8%) of those results were communicated back to clients. The anomaly here was accounted for as accumulated numbers from previous months when such results were not communicated back to the clients by the clinics.

943 clients were screened for TB, with 68 (7.2%) showing signs and symptoms of TB. 68 (7.2%) were referred and 65 (6.9%) received their results back. 17 (1.8%) tested TB positive.

**Assessment, Review and Observations on the CD4 and TB Referral System**

* Team was informed that interviews with the carers was not going to be possible because of the weather conditions, bridges and roads were flooded. The team then had discussions with the HBC Coordinator, Project Manager, M&E officer and the HCT Coordinator, on the referrals methods they use between the project and the health care facilities they refer to**.** This included assessing the files for further evidence and data verification.
* The HBC Coordinator and VCT Coordinator have been with Thembalethu for more than 10 years, which means they were with the project already during the period under review.
* HCT programmes are mainly conducted via community based HCT campaigns, home based testing and screening and also on site (CBO offices).
* TB screening is done at counselling stage to avoid missing opportunities to screen those whose status is unknown but would be possible TB suspects.
* Once a client is tested and tests positive, they refer them to clinics that are close to them that work closely with the CBO. Preference however is to refer the clients to clinics that fill in and return the down referrals forms so that they are able to follow up with the clients in terms of further care and support.
* There is a nurse employed by the CBO, who assists with the referrals, pricking and testing for carers who are not yet trained to prick and test, but also assists with down referrals processes from the health care facilities.
* They use the CARE designed referral tool in all their referrals, i.e. home, community based HCT and on site.
* There are instances where caregivers accompany clients to the clinic, and that is in instances where clients are too sick, bedridden or are reluctant to go the clinic for their CD4 or TB tests.
* The referral system is functional in two of the five clinics they refer to, and those are Block B and C clinics.
* Thembalethu is the only CBO where the team found a lot of records that we never found in most CBOs ,e.g records of people who tested positive for both HIV and TB, records of results of CD4 counts although they were not recording when results were communicated back to clients.
* One of the weakness with their record keeping was that they were not organized or recorded in a way that would make it easy for them as well to follow through and constantly read and understand their own data. It would have been easier if their data was organized in a spreadsheet or record book so that one only pulls those out rather than going through a number of files and counting each and every form there.
* In the absence of the caregivers for the assessment, the team assessed the HBC Coordinator, Project Manager and the VCT Coordinator level and understanding of treatment literacy and it was noted that the levels were unsatisfactory, and by inference in this particular case, the same will be the case for the carers,
* From the discussions with the management of Block C clinic, which is one of the clinics that Thembalethu refers to, the team was made aware that they do not have GeneXpert, CD4 machine or scanner on site, which makes the turnaround time for results long.
* The clinic appreciated the working relationship they have with the CBO and also the work the HBC is doing in providing support and care to the patients in the community.
* Interestingly, when asked what motivates them (clinic staff) to fill in the down referral from the CBO, the clinic indicated that it is from “the love and commitment to their patients and their job”, and that “it is only fair to give feedback to an organization that helps reach the people that we can’t reach under most circumstances”,

**Recommendations:**

* That care givers are taken through a series of HIV/TB TL trainings, at the level they will understand but intensive enough for them to grasp as much as needed to allow them to carry out their tasks with confidence and provide best support to their clients,
* These trainings must also offer an element of follow-up support, so that it is not the once-off training with no proper support afterwards,
* The area that can be improved here is the tracking of the patients’ progress throughout the time they are either category 2 or 3 clients to when they have fully recovered and are discharged from care-giving programme and to community based adherence clubs. This will allow the partner to see realistically what progress they are making and claim their “victory” points on the good work they are doing.

\*\* Star care giver – Zanele

1. **Thembelihle**

Thembelihle counselled 637 clients during the period under review. Of the 637, 563 (88.4%) gave consent for HIV testing. 132 (20.7%) of those tested positive for HIV. Of the 132 that tested positive, 107 (16.8%) were referred for CD4 counts testing, with 13 (2.2%) receiving their results.

A total of 563 were screened for TB and 100 (17.8%) of those showing signs and symptoms of TB. All 100 (17.8%) were referred for TB sputum diagnosis, with 41 (7.3%) getting back their results.

**Assessment, Review and Observations on the CD4 & TB Referral Systems**

* Of the three carers interviewed, two have been with Thembelihle for more than 12 years and the third one has been with the CBO for 4 years. This means they were all around during the period under review.
* They all have been formally trained as counsellors and caregivers, two of them by CARE SA and the third one by the DOH.
* The two counsellors who have been with the CBO for over 12 years indicated that in the period they have been with Thembelihle, there has only been 3 refresher trainings on the basic science of HIV and TB and these were in the years of 2005, 2008 and 2010 which they both attended and the third care worker attended two of these because she was not around when the first one was carried out. All these trainings were provided by CARE SA. And all three agreed that there has not been another refresher course since 2013.
* Thembelihle only refers their patients to one clinic which is the only one in their catchment area.
* They record names and referrals of each month on the green HCT book.
* They then keep patient record file each month of the clients they are caring for and what services they provide to each client.
* In most instances than not, the names in the patients records will not reflect the same names on the HCT green book. And this can mean two things:

a) That because of the lack of down referral from the health care facility, what ends up happening is that the cares books will reflect clients referred by the clinic, which is not the same as ones referred by the carers, or,

b) As they do home visits for each month, those that they find in their homes already requiring palliative care, are on treatment and become “their clients”,

* When clients test HIV positive and/ or have signs any symptoms of TB, the care workers refer them to the clinic for CD4 testing and or TB diagnostics. In cases where the client is very sick or reluctant, the care worker accompanies him/her to the clinic if they give consent for such to be done.
* There is a box at the clinic which the project coordinator asked the clinical manager at Mangwane clinic to have the attending nurses keep down referrals to Thembelihle HBC in. This however is not being done as evidenced by the lack of records at the CBO which the team was informed was due to the fact that the referrals are not always being filled or even dropped in the suggested box.
* The carers do follow up visits with referred clients to find out if they presented at the clinic for their CD4 or TB tests. The means used to verify if the client presented is either a verbal report and in some instances, a clinic card with medication provided at the clinic.
* In the office there was no recorded evidence of follow up data on the clients referred for CD4 counts and actually received their CD4 results, so that it also reflects the number with low CD4 counts and those still healthy enough not to be initiated on ART. It was the same for TB.
* It was indicated though that as of 2013, there is some record keeping on the CD4 results of clients referred and that these records are kept by the nurse at the CBO offices. Upon requesting to see how these are now documented, the team was shown a template designed by the project, but there lots of gaps where results were meant to be filled in.
* To try and address the challenges of clients not being referred down after being referred to the health care facility, the HBC coordinator took an initiative to speak to the clinical manager on numerous occasions and in all those meetings the clinic’s response has been that, it is difficult to always have the forms filled in because not all nurses are allowed to fill in the forms. But in this instance, even those that can fill in the forms do not fill them and refer back to the CBO.
* The carers indicated that they attend classes at the clinic every Thursday where ARV and TB treatment lessons are provided by the clinic health professionals.
* This was evident through their excellent knowledge of both HIV/TB literacy. They were all able to state the names of ARVs on the first line regimen, how and when they are taken and some of their side effects. It was equally the same with TB treatment, both first time TB treatment and MDR TB.
* A visit to the clinic confirmed what the carers indicated about the clinic’s lack of cooperation in down referring as the clinic nurse kept emphasizing the difficulty in them filling the referral form as not all nurses are allowed/qualified to.

**Recommendations:**

* The areas that can be improved here is the tracking of the patients progress throughout the time they are either category 2 or 3 clients to when they have fully recovered and are discharged from care-giving programme and to community based adherence clubs. This will allow the partner to see realistically what progress they are making and claim their “victory” points on the good work they are doing.
* Records on follow up for clients referred and initiated on treatment were not available (copies of the referral forms or notes on outcomes of referred clients). Of course the care givers keep note books where they record details of the clients they are looking after, but they did not contain much detail on the information required in terms of this review or better accounting processes going forward. The care givers notes were very useful though for the carers in understanding the needs of the clients they are looking after, but still those could be organized in a way that makes it easier for them to follow health progress of each of their clients.
* They develop a recording method, an improvement from the HCT green book, that picks up on each clients’ progression from time referred all the way to when they are initiated on treatment, (ART/TB or both) and progress of each client after certain periods on treatment until discharged.
* Develop a record keeping method that enters data of each patient reached, referred, CD4 done date, results of CD4, if indicated for ART when they commenced and trace progress in 3 months, 6months, 12months, until 24monts and discharge if prognosis is good at that time,
* Same for TB referred, date tested and results, if indicated for TB treatment record start date and end date and results for TB (-) confirmation after and discharge.

\*\*Star Care givers – Elsie Msana, Elsie Mdaka and Lindiwe Mahlalela

1. **Masoyi**

During September 2011 – August 2012 Masoyi counselled 1,263 clients. Of those, 1227 (97.1%) gave consent to getting tested for HIV. 184 (14.6%) tested positive for HIV, and 169 (13.4%) of those were referred for their CD4 testing. Only 21 (1.7%) got their results back.

A total number of 1,227 were screened for TB, with 68 (5.6%) of those showing signs and symptoms. All 68 (5.6%) were referred and 13 (1.1%) of those received their results back.

**Assessment, Review and Observations on the CD4 and TB Referral Systems**

* Three care workers were interviewed for this assessment. All three care givers have worked at Masoyi HBC for more than 5 years, meaning they were already with the CBO during the period under review. They have all been trained as counsellors and caregivers, and again once more in 2013 on the basic science of HIV and TB provided by CARE SA.
* They conduct their HCT campaigns in 2 ways. Through having big community HCT campaigns, and by conducting home based care testing and screening.
* When they have big HCT campaigns, they invite local leaders to lead the process and encourage community members to test and highlight benefits of knowing one’s status. They also make use of an I-ACT member who is living positively and openly with HIV as an ambassador for healthy lifestyles and living. The care givers indicated that in many instances, a huge number of people will turn up for testing and screening as there are incentives provided for people who test and screen. Otherwise with no incentives, numbers are usually low. The incentives are usually in the forms of t-shirts.
* The people who test positive or become TB suspects are then referred to their nearest clinic for CD4 tests and subsequent facility based diagnostics.
* Down referrals are still problematic in most of the 5 clinics they refer to in their catchment area. This is because most of them do not fill the down referral forms and in some instances others even throw the referral forms in dust bins.
* Some clinics however have their own referral tool which they use when referring their patients to the CBO. They (clinics) fill in their own down referral form religiously and expect the CBO to fill them in and send them back to the clinics at all times.
* The care givers accompany clients who are very sick to have their CD4 tests done. They mostly follow up with clients in their homes to check if they got their results back.
* They use two different types of referral forms, i.e. the CARE referral tool for all their referrals plus the other one given by the clinic, which has been designed by Mpumalanga DOH.
* The team observed during the interviews with the care givers that they were very well versed with the HIV and TB treatment literacy. They were all able to name the drugs on the ART regimens as well as how they are taken and some of the drugs side effects. Asked on how they are getting it right when others are struggling, their response was that they help each other to learn and memorize the treatments for both HIV and TB. This was very impressive and encouraging.
* Jerusalem clinic was visited for this assessment, and it is one of the five that Masoyi refers to. At this clinic the team was shown a file where the health facility keeps referrals from this CBO and another where they keep the down referrals (from clinic which are not the same as ones referred by the CBO, but walk ins at the clinic) to be collected by the care givers.
* The team also learnt that the clinic has no functional telephone line, and that this has been the case for the past 6 years. So health care workers are forced to use their own personal cell phones to communicate with clients. This of course greatly affects the time it takes for the clinic to disclose test results to patients. They indicated that they, in most times, prioritize TB patients because of the nature of TB and how fast it spreads, and want to prioritize putting them on treatment first.
* The clinic sister also raised her concerns with the CARE SA referral form, mentioning that they sometimes feel uncomfortable writing the patients’ confidential details on the form when they need to refer back to the CBO.
* This is one of the clinics that do their best to help the care givers by down referring, even though they sometimes just stamp the down referral because of their sensitivity to writing patient details. They commended the working relationship that Jerusalem clinic has with Masoyi HBC which spans more than 14 years.
* Masoyi management also raised concerns around the unhealthy competition between volunteers and CARE supported care workers on stipend.

**Recommendations:**

* As with most other partners, there are problem with down referrals once Masoyi has referred clients to health care facilities for CD4 testing and/or TB diagnosis and they are not referred back. This requires urgent attention as it minimizes the value of the work done by the organization, and makes it a bit difficult for them to keep proper records of what had happened to the client once referred. Meetings should be set up with health care facilities they refer to so that there can be agreements on how they will be assisting each other and clients in accessing HIV/TB services and care beyond the clinic facilities,
* Records on follow up for clients referred and initiated on treatment were not available (copies of the referral forms or notes on outcomes of referred clients). Of course the care givers keep note books where they record details of the clients they are looking after, but they do not contain much detail on the information required in terms of this review or better accounting processes going forward. The care givers notes are very useful though for the carers themselves in understanding the needs of the clients they are looking after, but still those could be organized in a way that makes it easier for them to follow health progress of each of their clients.
* They develop a recording method, an improvement from the HCT green book, that picks up on each clients’ progression from time referred all the way to when they are initiated on treatment, (ART/TB or both) and progress of each client after certain periods on treatment until discharged.
* Develop a record keeping method that enters data of each patient reached, referred, CD4 done date, results of CD4, if indicated for ART when they commenced and trace progress in 3 months, 6months, 12months, until 24monts and discharge if prognosis is good at that time.
* Same for TB referred, date tested and results, if indicated for TB treatment record start date and end date and results for TB (-) confirmation after and discharge.

**C: LIMPOPO**

1. **Mohlanatsi**

For period under review, Mohlanatsi counselled 2339 individuals, tested 2045 (87.4%) and 267 (11.4%) of those tested positive for HIV. Of the 267 that tested HIV+, 230 (9.8%) were referred for CD4 testing, with 122 (5.2%) receiving their results. A total of 2255 were screened for TB, with 156 (6.9%) of those having signs and symptoms of TB. 156 (6.9%) were referred for sputum diagnosis and 155 (6.9%) of those received their results back. 7 (0.3%) tested positive for TB.

**Assessment, Review and Observations on the CD4 and TB Referral Systems**

* All the care givers interviewed have been working for the CBO for more than five years, and they have all been trained as both HIV counsellors and caregiver.
* They conduct their HCT campaigns in 2 ways, through having big community HCT campaigns, and by conducting home based care testing and screening.
* There is a good working relationship between CBO and PHCF although there is a minimal involvement of CBO in the patients’ management after the patients have been referred to the PHCF. It is only after the patient is referred back from PHCF to CBO that the care givers continue with their work.
* There is generally a good cooperation between patients and CBO and their role in healthcare service delivery, however community members expect caregivers to also address their socio-economic conditions such as provision of food parcels.
* There is about 5km radius within which CBO refers patients to PHCF, this distance allows patients to present within one day to PHCF after referral from CBO.
* The turnaround time for laboratory results is affected by factors such as the time of the day the specimens are taken, the availability of transport to collect the specimens and the delivery of the results back at the PHCF from a laboratory.
* There are unnecessary and avoidable delays in sputum collection for TB testing because CBO workers often don’t have the sputum bottles to do home sputum collection.
* There is a lack of standardized patient information recording tool.
* The caregivers possess an average level of knowledge about HIV guidelines, some have not been trained on the new guidelines.
* The care givers possess a high level of knowledge and understanding of TB guidelines.
* The TB screening tool limits care givers to only suspect pulmonary TB.
* There are various tools used for the same purpose, e.g there are three different referral forms, i.e. DoH, CARE and the new form recently introduced in the primary health care re-engineering programme.
* There are no standardized record keeping method or tools, each care giver uses a note book and record what is deemed to be important.
* The common challenge with patients is the cultural barriers and high levels of secrecy. This has been considerably broken down over the years through the CARE I–ACT programme, but stigma still remains a huge challenge.

**Recommendations:**

* There should be an integrated and seamless working relationship between CBO and PHCF; introduce a continuity of care by involving care givers in the entire process from identifying suspects, counselling, testing, adherence, initiation on treatment and treatment support.
* Agreeing on standardized data recording and patient record tools for CBO workers and referral forms that are functional for all parties involved in patient care.
* Develop a continuous professional development programme that will involve frequent trainings, workshops, and facility based education and training program.
* Improve on referral system to include not just a date of referral but also the time to avoid patients making a trip twice because samples can’t be collected in the afternoon after the specimen collecting vehicle has already been to PHCF. This causes serious inconvenience and negatively affect the patients who become reluctant to present to the health facility every day.
* Improve on both paper and electronic recording and filing of information.

1. **Balantwa**

In 2011/2012 Balantwa counselled and tested 603 (100%) clients. Of the 603, 209 (34.7%) tested positive for HIV. 172 (28.5%) were then referred for CD4 testing and 136 (22.6%) had their results communicated back to them. 582 were screened for TB with 99 (17%) of those found to have signs and symptoms of TB. 62 (10.7%) of the 99 were then referred for further diagnosis and only 5 (0.9%) had their results communicated back to them.

It must be noted that Balantwa is not being supported by CARE anymore.

**Assessment, Review and Observations on the CD4 and TB Referral Systems**

* The CBO has experienced funding problems over the years as a result they have lost about twelve staff members and their office space. Despite this challenge though, there is a high quality level of services rendered.
* All the CBO workers interviewed for the purposes of this review have more than 5 years working with Balantwa.
* There is lack of cordial working relationship between the CBO and another CBO in the same premises and PHCF and this hampers their collective efficiencies.
* There are various tools used for the same purpose such as different referral forms.
* There are variations in screening tools and record keeping methods.
* There are no standardized record keeping methods or tools, each care giver uses a note book and record what is deemed to be important.
* There is a challenge of shared confidentiality on clients HIV information and this impairs on feedback from PHCF to CBO on HIV care outcomes.
* The caregivers have a good level of knowledge about HIV guidelines, although some have not been trained on the new guidelines. Their level of understanding of TB and TB guidelines was of high level.
* There is a problem in tracing patients, especially HIV+ patients who provide incorrect addresses.
* The CBO and PHCF management have a poor working relationship.
* There is no funding available to conduct trainings and workshops.

**Recommendations:**

* Initiate mediation processes between Balantwa, PHCF and the other CBO based at the same PHCF.
* Establish agreements with the PHCF on the up and down referrals for better continuation of care for patients, considering the shared confidentiality as was highlighted by the health care workers.
* Funding and support be provided for Balantwa to be able to perform its functions.
* Education and training to be provided on a regular basis with regular support.
* Develop and or agree on standardized tools for screening, patient records, CBO home visits and organization of care givers notes.

1. **Nhlayiso**

For the period under review Nhlayiso counselled 1516, with 1291 (85.2%) giving consent for HIV testing. Of the 1291 that gave consent, 142 (9.4%) tested positive for HIV. 118 (7.8%) of those were the referred for CD4 testing, with 66 (4.4%) receiving their results back. A total of 1290 were screened for TB, with 265 (20.5%) showing signs and symptoms of TB. 205 (15.9%) of the 265 were referred, with 18 (1.4%) receiving their results back, and 18 (1.4%) being TB positive.

**Assessment, Review and Observations on the CD4 and TB Referral Systems**

* All care givers interviewed for this review have been with the CBO for more than 2 years and were part of the organization in 2011/2012.
* There are various tools used for the same purpose such as three different referral forms; they are from DoH, CARE and the new form introduced in with the PHC re-engineering programme.
* There is no standardized record keeping method or tools, each care giver uses a note book and record what is deemed to be important.
* There is generally a good working relationship between CBO and PHCF, although there were concerns raised about working relationships with some health care workers in the health care facilities.
* Feedback is not always given back to CBO workers on patients referred to the PHCF.
* There is a challenge of shared confidentiality with HIV and this impairs feedback from PHCF to CBO on HIV care outcomes for patients.
* The caregivers have an average level about HIV guidelines. Some have not been trained on the new guidelines. They have high levels of knowledge and understanding of TB guidelines. There is a need to improve HIV knowledge beyond screening for the care givers, there is no adequate knowledge of the drugs, side effects and the new combination pill (FDC).
* There is a problem with illegal immigrants without identity documents in terms of assisting them access basic health services.
* There is about 5km radius within which CBO refers patients to various PHCFs, this distance allows patients to present within one day to PHCF after referral from CBO.
* The weakness in the system is that after referring the suspects for TB and/or HIV to the PHCF, CBO plays no role during various steps such as adherence counselling and initiation into TB treatment or ART.
* The turnaround time for laboratory results is too long and steps need to be taken to shorten this.
* There are unnecessary and avoidable delays in sputum collection for TB testing because CBO workers often don’t have the sputum bottles to do home sputum collection.
* There is a lack of standardized patient information recording system, it is filled differently by different care workers, in some instances with very little details.
* The TB screening tool limits care givers to only suspect pulmonary TB by focusing only on the four symptoms, need to broaden to other forms of TB screening that will include signs and symptoms of extra-pulmonary TB.
* The use of personal note books to record patients’ information poses a risk of information being lost when CBO workers quit their jobs.

**Recommendations:**

* Provide regular training on HIV and TB guidelines on regular basis.
* Establish facility or CBO continuous professional development programme.
* Establish standardized tools for reporting and referring patients.
* Establish a working platform on feedback mechanism between CBO and PHCF on clients referred up and down between the parties.
* Establish working relationships with other organizations that work with undocumented migrants to ensure that they are adequately represented and supported for services such as access to health care services.

1. **Bophelo**

Bophelo counselled a total of 676 people during 2011/2012. Of those 432 (63.9%) gave consent to HIV testing and 66 (9.8%) tested positive for HIV. All 66 (9.8%) were referred for CD4 testing with 51(7.5%) receiving their results back. A total of 631 were screened for TB, with 36 (5.7%) showing signs and symptoms of TB. All 36 (5.7%) were referred for TB diagnosis, 8 (1.3%) received their results back and 6 (1%) tested positive for TB.

It must be noted that Bophelo is no longer supported by CARE.

**Assessment, Review and Observations on the CD4 and TB Referral Systems**

* All care givers interviewed for the purposes of this review have more than five years working experience. They have all been trained as HIV counsellors and home base care givers.
* There is a good working relationship between the CBO, community and PHCF.
* There are various tools used for the same purpose such as different referral forms, i.e. CARE, DOH and newly introduced PHC re-engineering programme.
* There are no standardized record keeping methods or tools, each care giver uses a note book and record what they deemed to be important but miss out a lot of other information on progress on each patient they have in their care.
* There is a challenge of shared confidentiality on HIV care information of patients and this impacts feedback from PHCF to CBO on HIV care outcomes.
* The caregivers have an average level of knowledge about HIV guidelines. Some have not been trained on the new guidelines. There is a need to improve HIV knowledge beyond screening for the care givers, there is no adequate knowledge of the drugs, side effects and the new combination pill (FDC).
* They all have high level of knowledge and understanding of TB guidelines and treatment.
* There is about 5km radius within which CBO refers patients to PHCF, this distance allows patients to present within one day to PHCF after referral from CBO.
* The weakness in the system is that after referring the suspects for TB and/or HIV to the PHCF, CBO plays no role during various steps such as adherence counselling and initiation into TB treatment or ART.
* There is a good turnaround for referrals and laboratory results.
* There are unnecessary and avoidable delays in sputum collection for TB testing because CBO workers often don’t have the sputum bottles to do home sputum collection.
* The TB screening tool limits care givers to only suspect pulmonary TB, basic information on TB of the bones or TB meningitis is lacking.

**Recommendations**

* Replace the note books and loose patient information sheets with a standardized solid tool.
* Establish regular workshops and training on HIV especially.
* Provide CBO workers with sputum bottles to improve access and speed of services.
* Establish a formal and regular feedback platform between PHCF and CBO.

1. **Ramontshinyadi**

Ramontshinyadi counselled 1,759 people during the period under review. Of the 1,759, 1737 (98.7%) gave consent for HIV testing and 248 (14.1%) of those tested positive for HIV. Only 172 (9.8%) were referred for CD4 testing, with 164 (9.3%) receiving their results back. A total of 1,615 people were screened for TB, with 68 (4.2%) found to have signs and symptoms of TB. 50 (3.1%) of those were referred for further diagnosis and 44 (2.7%) got their results back. 20 (1.3%) tested positive. There were no records of the number that tested positive for TB and initiated on treatment.

**Assessment, Review and Observations on the CD4 and TB Referral Systems**

* All the care givers interviewed have been with the organization for more than five years and were part of the team for the period under review.
* Care givers level of information and understanding of TB was very high.
* The CBO has very motivated staff members and have a good working relationship between the CBO, PHCF and the community. Community members themselves even refer their friends and relatives to the CBO for care and support services.
* The care givers record the patients’ information in their note books, with various elements being entered and some important data being missed in most instances, especially information that is required for this review.
* There are various tools used for the same purpose such as different referral forms.
* There is no standardized record keeping method or tools, each care giver uses a note book and record what they deem to be important.
* Care givers indicated that they do not conduct home based testing.
* There is a challenge of shared confidentiality on HIV and this sometimes impact on the kind of feedback from PHCF to CBO on HIV care outcomes.

**Recommendations**

* Encourage home based sputum collection.
* Develop and or agree on standardized tools for screening, referrals, reporting, data capturing and filing.
* Encourage the care givers to bring back their notes to the office once not book is full to avoid instances where when the care giver leaves the employ of the CBO, s/he leaves with all the vital information.
* Improve the referral system to include also the time of presentation to avoid delays in specimen being drawn and collected from PHCF to a testing laboratory.

{END}

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