



# PEPFAR South Africa Care and Support Review

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## I. Executive Summary

South Africa, with a population of 49 million people, is home to 20 percent of all HIV/AIDS cases in the world with an estimated 5.7 million infected persons; the number of those eligible for ART is estimated at 2 million. The joint efforts of the South African Government (SAG) and USG have contributed significantly to reaching ambitious goals set forth to scale up provision of ART to one million people. Despite these outstanding achievements, there are still an estimated one million in need of ART and an additional three million who are in need of care and support. The aim is to provide care and support services to all HIV positive individuals to delay the need for ART in those not yet eligible and to maximize quality of life, while reducing the risk of transmission of HIV to others.

To develop recommendations for a way forward to provide better care and support for all PLHIV, the South Africa PEPFAR Program in conjunction with the OGAC Care and Support Technical Working Group conducted an in-country review of PEPFAR-supported HIV Care and Support programs in South Africa. The purpose was to: 1) highlight successes, best practices, and lessons learned; 2) identify challenges and gaps to implementation; 3) set priorities and formulate a strategic focus for the next few years; and 4) recommend ways to meet HIV Care and Support goals, including scale-up of care services at home, community and facility levels.

Over the course of two weeks, the review team met with SAG Department of Health officials, representatives from other international agencies, including the WHO and UNICEF, and PEPFAR Care and Support Partners in Gauteng, Free State, Kwazulu-Natal, Western Cape and Eastern Cape provinces. This report constitutes the final report of the PEPFAR South Africa Care and Support Review and includes the observations of the review team and recommendations for the PEPFAR/South Africa Program. These recommendations are focused on improving PEPFAR supported care and support programs at both the facility level and the community level, with particular attention to persons not yet eligible for ART. Additional recommendations to strengthen monitoring and evaluation and sustainability of care and support programs are also included.

**The most important recommendations are included here; additional recommendations may be found in the text that follows.**

- ❑ **Enroll individuals into pre-ART registry for care and support at point of diagnosis.** Individuals should be considered enrolled into care and support at the time of HIV diagnosis, on the basis of the services expected to be provided at that time, which include: CD4 blood draw and counseling to return for results, screening for symptoms of active TB, and referral for ongoing care and support through local support groups. All clients enrolled into care and support should be entered in the pre-ART register, which should be available at all facilities at which HIV care is offered. Individuals who test positive at mobile sites should be referred to facilities for

enrollment into care and/or treatment and entered into pre-ART registers at those facilities.

- ❑ **Ensure a standard of care and support services at the facility level and assist in the revision of PEPFAR South Africa Treatment Technical Guidance to include pre-ART care services.** Standard care and support services to be provided at the facility level should include screening and treatment for active TB, STIs, and other opportunistic infections, cotrimoxazole prophylaxis, (pre-ART patients are eligible for CTX if they have clinical stage II disease), IPT for patients without active TB, nutritional assessment and support, pain assessment and management, and linkage to support groups and to other community services. These services should be provided to both ART and pre-ART clients. Essential pre-ART services should also include psychological and social support, CD4 count monitoring to determine eligibility for ART, and referral to ART programs when eligible. SAG and PEPFAR in collaboration with other stakeholders should standardize these pre-ART and ART care and support services.
- ❑ **Strengthen the supply chain system for OI medications.** Specifically, prevent shortages of cotrimoxazole and isoniazid through provision of technical assistance for the supply chain management system at the provincial, district, and site levels.
- ❑ **Support implementation of the Basic Care Package.** The BCP and its resultant support groups were noted as cutting edge innovations towards empowerment of PLHIV. The BCP and support groups should be rolled out to all provinces.
- ❑ **Strengthen linkages between pre-ART care in communities and facilities through support of facility-based referral coordinators.** This will enhance pre-ART follow-up and timely ART initiation.
- ❑ **Support the CCW regulatory policy framework and related activities through support of the policy implementation framework and assessment of the cost of the implementation of the framework.** The framework should include a career path (ladder) for the community care worker cadre to increase retention of these skilled practitioners into the health care professional system. A clear plan for PEPFAR's support of the Community Care Worker Policy should be included in the Partnership Framework with a detailed plan of action and related costs included into the Partnership Framework Implementation Plan.
- ❑ **Define a minimum set of services for HBCWs to include in guidance to CBOs.** In the interim before the CCW Framework is implemented, this scope of work should reflect a transition of the role of HBCW from general household and physical care to tracing ART and pre-ART defaulters, encouragement of patients to remain in care, referral to community services, and psychological counseling.

- ❑ **Review balance of service provision at the community level.** Include greater emphasis on pre-ART care and support services along with developing a minimum standard of community care services for both pre-ART and ART patients. Re-focus partner service provision to pre-ART care for WHO clinical stage 1 and 2 patients with all PEPFAR partners, in particular, those who currently limit their services to strictly end-of-life care.
- ❑ **Strengthen PLHIV organizations at the community level by providing appropriate advocacy and capacity building skills for cohorts of PLHIV.** Ideal conduits for growing PLHIV organizations are through home-based care programs and support groups, through BCP cohorts and through community based income-generating activities for PLHIV.
- ❑ **Implement Caregiver Support Programs.** In concert with the DOH, investigate existing curriculum, adapt existing methods, and support care for caregivers programs for all HIV health service providers with a particular emphasis on HBCWs. Minimum standards for caregiver support would include weekly support group discussions, availability of referral to a trained mental health provider for serious issues, staff retreats and respite as needed. Consider rotation amongst facility-based HBCW coordinators and HBCW staff.
- ❑ **Adopt and utilize new (national) PEPFAR indicator of percent of persons initiating ART who have CD4 count <100 cells/uL as an indicator of how early HIV positive persons are accessing care.**
- ❑ **Support the SAG's efforts to develop indicators for care and support, to utilize data to drive programmatic decisions and to merge with other data management systems.** Consider additional programmatic indicators to capture what is happening in pre-ART care (e.g., percent of persons newly-diagnosed with HIV who return for their CD4 count result, percent of pre-ART patients who return for repeat count at 6 months, percents of patients who are assessed for pain, who receive PwP services, and who receive nutritional assessment and support). Consider additional data collection tools and programmatic indicators to capture referrals and uptake of community services. (e.g., number that complete BCP).
- ❑ **Support National HMIS efforts to create national systems of health information that can track HIV and TB clients beyond the district and provincial level, especially in order to track migrant populations.**
- ❑ **Encourage partners to actively engage with and encourage leadership from the district health forums to advocate for strengthened care and support service and policy issues.**



## **II. Introduction**

South Africa with a population of 49 million people is home to 20 percent of all HIV/AIDS cases in the world with an estimated 5.7 million infected; the number of those eligible for ART is estimated at 2 million. The Government of South Africa (SAG) has made tremendous progress in fighting the HIV battle over the last six years by expanding the number of South Africans receiving ART from less than 50,000 in 2004 to over one million by March 2010.

The President's Emergency Plan for AIDS Relief (PEPFAR) South Africa supports care and treatment policies and services aligned with the South African National Strategic Plan (NSP) for HIV & AIDS and STI, 2007-2011. The joint efforts of the SAG and PEPFAR have contributed significantly to reaching the ambitious goal of provision of ART to one million people. PEPFAR has made a significant contribution to reaching and initiating ART for these one million South Africans.

Despite these outstanding achievements, there are still an estimated one million in need of ART and an additional 3.7 million who are in need of HIV care and support. The aim is to provide care and support services to all HIV positive individuals to delay the need for ART in those not yet eligible while maximizing the quality of life and reducing the risk of transmission of HIV to others.

To develop recommendations for a way forward to provide better care and support services to all individuals living with HIV, the South Africa PEPFAR Program in conjunction with the OGAC Care and Support Technical Working Group conducted an in-country review of PEPFAR-sponsored HIV Care and Support programs in South Africa. The purpose of the review was to 1) highlight successes, best practices and lessons learned; 2) identify challenges and gaps to implementation; 3) set priorities and formulate a strategic focus for the next few years; and 4) recommend ways to meet HIV Care and Support goals, including scale-up of care services at home, community and facility levels. The full scope of work for this review is found in Appendix A.

## **III. Methodology**

The South Africa HIV Care and Support TWG engaged an interagency team comprised of two technical advisors from headquarters and two technical advisors from the field, from Uganda and Nigeria, respectively, to join the South Africa in-country team to carry out the HIV Care and Support Review. The review team included Dan Wamanya (USAID/Uganda), Kate Anteyi (CDC/Nigeria), Jon Kaplan (CDC/Atlanta) and Karen Stewart (USAID/GH Tech/Washington), Peter Vranken (CDC/SA) and Thobekile Finger (USAID/SA). Over the course of two weeks, the review team reviewed relevant reports and program documents, met with SAG

Department of Health officials, representatives from other international agencies, including the WHO and UNICEF, and PEPFAR Care and Support Partners in five provinces including Gauteng, Free State, Kwazulu-Natal, Western Cape and Eastern Cape. Persons met and observations made during these visits are included in Appendices B and C. The review team met with the in-country PEPFAR interagency senior management team (including management from USAID, CDC, and the PEPFAR Coordinator Office) at the beginning and conclusion of the two week review. During the outbrief meeting with PEPFAR management, the review team presented and discussed initial findings from the meetings and site visits. This report is the final report of the PEPFAR South Africa Care and Support Review and includes the observations of the review team and recommendations for the PEPFAR/South Africa Program.

## **IV. Key Observations**

### **A. “Pre-ART Care”**

Within the South African HIV/AIDS response, the concept and understanding of “pre-ART care” varies. In some contexts “pre-ART care” refers to services offered to individuals who have been diagnosed with HIV and are confirmed eligible to initiate treatment but for a variety of reasons have not yet accessed it. In other contexts, “pre-ART care” refers to services offered to individuals who have been diagnosed HIV positive and evaluated and are not yet eligible for treatment. Regardless of how “pre-ART care” is defined, it was widely acknowledged that significant losses to follow-up occur between the time of HIV diagnosis and return for the CD4 count result and between receipt of the CD4 test result and return for repeat CD4 testing if the patient is not yet eligible for ART. The result is that many patients do not return until they have advanced HIV disease; the average CD4 count at initiation of ART in South Africa is less than 100 cells/uL resulting in significant (6-10%), preventable mortality within the first year of ART. Thus the importance of pre-ART care, especially in persons not yet eligible for ART, was widely acknowledged within the South Africa PEPFAR team, by partners and by health officials across all the provinces.

### **B. Pre-ART Registry at Facility Level**

The SAG and Provincial health departments have recently introduced Pre-ART registers to be used at all HIV treatment facilities. However the review team found use of these registers to be sporadic. The practices for entry of HIV-infected individuals into these registries also varied across sites and across partners, with some registering all individuals with an HIV-positive result, and others entering only those who have received their CD4 test result. There was also varied expertise in inputting clients’ data into the register and limited use of information in the pre-ART register to inform programmatic decisions. These variations in enrollment practices

make it difficult for the SAG and PEPFAR to have an accurate understanding of the challenges encountered in caring for persons not yet on ART, including those not yet eligible for ART.

### **C. Facility-based Care and Support**

The SAG is in the process of decentralizing ART services to over 4,000 health facilities in the country, such that no patient will be more than five kilometers walking distance from the nearest HIV care facility. In general, the facilities visited during the review, which included district hospitals, community health centers and primary health centers, articulated elements of a package of care provided to ART patients that includes cotrimoxazole prophylaxis (for clinical Stage II and above, or CD4 count <200 cells/uL); TB symptoms screening, treatment of active TB, and in some cases isoniazid preventive therapy (IPT) for those without active TB. Supportive services such as nutrition assessment and support; behavioral counseling and encouragement of partner testing; STI screening; and linkage to support groups were found but were not standard across facilities. Some larger sites reported family planning services and Pap smear testing; the SAG has recently rolled out a Pap smear screening campaign in the Western Cape. Some sites reported distribution of multivitamins, including Vitamin B and nutritional supplementation drinks. In general, the standard of care in South Africa appears to exceed that observed for these services in other sub-Saharan African countries.

Services for pre-ART patients (referring to those not yet eligible for ART), were found to be more limited, since facility care has focused predominantly on ART patients. Across the entire spectrum of stakeholders (NDOH, PEPFAR, INGOs, civil society), it was acknowledged that pre-ART care (in this context, those with a positive diagnosis yet not eligible for ART) has been given low priority within the overall national HIV/AIDS response. There appears to be a disproportionate emphasis on treatment, which focuses on provision of ART and strategies for adherence; the bulk of the services listed above are generally not provided to those not yet eligible for ART. From this review, the lack of a clearly defined set of pre-ART services attests to this low prioritization of care and support for these patients.

A very positive finding was that individuals who test HIV-positive generally have a specimen sent for CD4 testing the same day, a practice that has the potential to enhance early identification of those in need of treatment. However as many as 50% of these individuals do not return to receive their CD4 test result. With the advent of the national roll-out of HIV Counseling and Testing (HCT), people are getting tested sooner and many may be identified with high CD4 counts. However, those whose CD4 counts are >200 cells/uL (unless pregnant or with a diagnosis of TB) are not eligible for treatment and do not generally receive follow up services such as on-going psychosocial care, cotrimoxazole prophylaxis, IPT, nutritional assessment, or preventive care that are needed to enhance their quality of life and delay their need for ART. These PLHIV are generally instructed only to return for repeat CD4 testing in six months and upwards of 90% of these patients do not return for the six month follow-up. Many of these individuals may disappear until they present with advanced HIV disease, thus compromising

their quality of life and survival and negating the beneficial effects of more timely initiation of ART.

To understand the reasons behind the high rates of client attrition, the team sought to know the most important determinants of retention in care from the perspective of providers. It was overwhelmingly reported that PLHIV need facilitation to have adequate knowledge on HIV/AIDS, on the services needed to manage HIV infection and how to be empowered to advocate for their care. It is also commonly known that patients do not want to go to clinic when they feel well. They may also not want to go unless some commodity (like food) will be provided to them. Many factors appear to influence poor retention in care, including long waiting lines at the ART clinic, time away from their jobs and funding for transport to and from the clinic.

Accordingly, the SAG is supporting the roll-out of the “basic care package” (BCP), a six session support group program that includes information about HIV and its management to enable HIV-positive individuals to better understand the dynamics of HIV infection, to understand the services being offered to them and to advocate for their care. Currently, the BCP is being rolled out mainly in the Eastern Cape and in the Free State and is heralded as a best practice. The BCP is also a forum for organizing PLHIV more formally and introducing income-generating activities to a cohort of people going through the training. The aim is that all newly diagnosed PLHIV go through the BCP program and sustain themselves as a continuous support group following graduation from the program. The BCP and support groups are potentially excellent mechanisms to engender PLHIV empowerment and could be in themselves motivators or incentives for PLHIV to remain in care. While these initiatives are touted, they are also in initial stages of implementation and have yet to be rolled out to all communities and provinces.

A gap in the facility-based programs in South Africa is lack of psychosocial and emotional care. Available psychosocial services were limited to pre and post-test counseling and this was noted to be inadequate. Knowledge of HIV/AIDS is still low in many of the households and communities in rural South Africa, with associated stigma and discrimination. The ongoing stigma and discrimination create enormous challenges for those tested HIV positive to live comfortable lives within their communities. In such contexts, psychosocial care is of paramount importance. Poor access to psychosocial care is taking its toll on individuals and families affected by HIV. Anecdotal reports from partners indicated a rising prevalence of mental health needs, in particular depression and substance abuse among the affected individuals and families. These growing needs combined with a dearth of social workers, psychologists and psychiatrists and a growing epidemic create a dire outlook for the mental health needs of PLHIV.

There were frequent stock-outs of essential HIV/AIDS care commodities, particularly cotrimoxazole and INH. In fact, there was very little INH available in all provinces visited. The procurement of these commodities is decentralized to provinces and districts. A pull system of procurement is used, through which districts and facilities draw from stocks at provincial

warehouses. There were challenges with forecasting and timely ordering and other supply chain logistics both at the site level and the provincial level.

Other gaps are the lack of pain assessment and management, a structured Prevention with Positives (PwP) package, and roll-out of IPT. Although patients are typically asked about chief complaints, in general, there is no systematic assessment of pain and other symptoms. A more complete package of PwP services including family planning, assessment of alcohol use, and couple counseling and testing, was found to be lacking. IPT is just rolling out in all places visited; barriers have been inconsistency in recommendations (formerly for just pre-ART patients, but now for all patients), whether tuberculin skin testing is required to determine eligibility for IPT; lack of buy-in from providers who are concerned about the presence of active TB, and drug stock outs.

Care and support for HIV positive children was noted to be another significant challenge within the overall South African HIV/AIDS response. The country is implementing an impressive PMTCT program through which many children have been saved from HIV infection. However, post PMTCT care services are inadequate. Also, pediatric ART service provision is available only at the hospital level, although adult ART is being decentralized to the primary health care sites, thus increasing the time a parent on ART spends in waiting lines (and out of work) for both themselves and their children. The biggest challenges were noted to exist in regard to care for mother to child infected HIV-positive adolescents, many of whose parents have not disclosed their HIV status to them. There is no defined age for disclosure of status for pediatric PLHIV. Besides their curiosity to know why they are in care and treatment programs and their growing mental health needs, many of these children are maturing and are becoming sexually active even before they know their status. There are no appropriate care and support interventions for adolescents in general. With lack of appropriate care for these patients and a weak mental health system and support interventions, these children may manifest behaviors that endanger themselves and others when they learn of their status.

Finally, caregiver support for health care professionals was completely lacking. Some group sessions for home-based care workers were held, depending on the site visited, but these sessions were usually managed by an auxiliary nurse rather than a trained counselor. There was no discussion or acknowledgement of the needs of higher level health professional support and no discussion of whether or not working in HIV/AIDS care led to higher rates of burn-out or turn over other than within the HBCWs cadre.

#### **D. Community-Based Care and Support**

Strong community advocacy and mobilization was not observed. There is still a large degree of stigma and discrimination surrounding HIV and AIDS, which impedes uptake of community-based care services. In many smaller communities, CBO headquarters where Home-Based Care Workers (HBCWs) are based, are known as “the place where you go if you have HIV”.

Despite this, in some communities, we found true champions of care, those who had taken it upon themselves to bring PLHIV together to do community gardens and begin support groups. Additionally, some CBOs highlighted their work with engaging traditional leaders and traditional community structures as a conduit for building community-based service provision. Little to no income-generating activities were observed for PLHIV although abuse of SAG HIV social grants was noted and the poverty status of PLHIV was re-emphasized by the consistent request for food for many of the support group related activities. Overall, the review team's findings are that community-led advocacy and outreach is in its infancy in South Africa and the voice of PLHIV is not heard at the community level.

There are varying degrees of home-based care and community-based care workers' training, with no career path for even the accredited programs. Applicants who meet the criteria go through the 59 day accredited HBCW training, and upon graduation, earn between 1,000 to 1,500 Rand per month. When the SAG pays 1,000 Rand per month, some CBOs and NGOs supplement these stipends to anywhere between 1,200 and 1,500 Rand per month. There is a high rate of attrition among this cadre of staff due to an ill-defined career path and poor remuneration among other factors.

There are varying degrees of quality of care service standards provided by HBCWs. Typical home-based care services include turning bed-ridden patients, bathing, doing light household work, basic HIV education and ART adherence education. Many HBCWs are viewed as leaders in their community and are asked to help with other social needs like government grants applications and other health related inquiries. However, they are inadequately engaged in identification and tracking of pre-ART clients, which from the public health standpoint, would likely be a better use of their time. There is also varying nomenclature for this cadre of community-based workers including home-based care worker (HBCW), lay health counselor, tracer and community care worker.

Coordination, nursing supervision and mentorship of CCW is inconsistent. In some programs, there was no supervisor for the HBCWs and they met only with the nursing supervisor on a monthly basis. Other programs had a nursing supervisor based at the facility who managed the HBCWs and provided a strong linkage between the community and the facility by triaging and providing appropriate referral of patient needs identified by HBCWs.

The SAG is leading an effort to standardize and accredit an existing cadre of health care workers called "community care workers". The policy is stalled in the SAG and there is dissent among non-governmental partners because the policy as it is currently written will add a significant cost burden to the NGOs and CBOs to assume benefits and other personnel costs for this cadre. The strength of this movement by the SAG is that it will establish an accredited cadre of health professionals with standardized training and a standardized skill set which will legitimize this community-based cadre amongst the broader health care professional community.

Care for caregivers is not well-defined. There are variable scenarios for how often and with whom, a HBCW can share their thoughts and emotions about taking care of high need patients in their own community. Some projects provided a semi-annual retreat for HBCWs, which is commendable, but more structured psychological support of caregivers, especially HBCWs, is needed to retain workers and allow a forum to discuss the challenges of their work.

## **E. Referral and Linkages**

Throughout the review team's meetings and discussions, the need for referral, linkages and networks was emphasized as a great need. It is commonly agreed that an overwhelming number of patients are lost to follow-up due to weak referral systems. In particular, the referrals between HCT sites and community-based programs to HIV care facilities, and vice-versa, are fragile and need strengthening. During the site visits, few referral systems with feedback loops were observed. It is clear that referral must be addressed at many levels including from the HCT site to the facility, amongst services in the facility, and facility to community. Therefore, there is great opportunity to increase referral and decrease patients lost to the system.

The strongest programs of referral from facility to community included a type of coordinator or lay health counselor based at the facility whose responsibility was to oversee and coordinate the work of community-based "tracers" or workers to follow-up clients who had dropped out of care. This was done primarily for ART patients and TB patients, but not for pre-ART patients. In most settings, however, there was no referral coordinator at the facilities tasked with linking patients to community-based services. Additionally, lists or referral directories of available community services were not evident at the facility level.

Some models utilized paper referral systems from HCT sites to facilities to ensure that newly diagnosed patients accessed care at the facility. These paper systems were tracked by community-based organizations through monthly pick up of referral forms. In most places, there were no feedback mechanisms in place. As pre-ART and ART registers are developed along with provincial and national health information systems, referral and tracking patients for follow-up could be enhanced, especially for tracking migratory patients.

One significant systems barrier to referral was revealed by many of the community-based organizations. They expressed frustration with the delay in getting MOUs signed with facilities. There was no clear guidance on the MOU process between CBOs and facilities. This lag time of MOU development is an impediment to the referral and linkage systems. Additionally, retaining migrant patients in care proves to be very difficult since currently there is no portable or interconnected system of patient records across the provinces.

Another way to strengthen referral was structured, periodic meetings amongst providers and CBOs through community health councils and other organized structures at the district and

community levels. When utilized, this system appears to enhance referrals and linkages within the community.

## **F. Monitoring and Evaluation, Care and Support**

PEPFAR South Africa utilizes the required New Generation Indicators (NGI) for Care and Support; these include the “umbrella” care and support indicator, which includes infected and affected persons and OVC; the HIV clinical care indicator; and the cotrimoxazole indicator. PEPFAR SA adopted additional national indicators, although in addition to several TB/HIV indicators, the only other indicator pertinent to care and support is the percent of ART initiators with CD4 <100 cells/uL which will help inform how early people are accessing care. The PEPFAR HIV clinical care indicator is defined by receiving at least one clinical and at least one service in another category and is provided by facility partners who report numbers of persons in care in two categories, both ART and pre-ART. The other two NGI indicators are more problematic: the “umbrella” indicator is reported as the sum of reports from facility and community partners (plus OVC) without effort to de-duplicate; the cotrimoxazole indicator is complicated by discontinuation of cotrimoxazole in persons on ART with CD4 >200 and the fact that information is not disaggregated by ART versus non-ART patients.

There are limited care and support indicators at the national level. PEPFAR has identified one PEPFAR partner per district to work with local government on development of indicators, harmonization with existing data collection systems and use of data to drive programmatic decisions.

At the facility level, there is some additional information available from ART and pre-ART registers, such as prescription of cotrimoxazole and refills, TB screening and IPT. Since the pre-ART registry is in its infancy, PEPFAR is working with the SAG to make this data more accessible at the national level. Partners have additional data collection systems, which may include some data pertinent to care and support.

Usefulness of the “umbrella” and Cotrimoxazole NGI indicators will be limited due to the reasons listed above and the lack of national indicators on care and support limits both the impetus to collect information from service providers and to use any such data for decision-making. Although PEPFAR does not want to increase the number of indicators, there is clearly the potential to develop additional ones, such as percent of newly-diagnosed persons who return for their CD4 count, the percent of pre-ART patients who return for their six-month, repeat CD4 count, and the percent of patients assessed for pain.

Operational research on care and support is essentially lacking; opportunities would include evaluation of the BCP to determine its effect on patient outcomes; and assessment of retention in care, as measured by the percent of persons who return for their CD4 count result and who return for repeat CD4 testing at 6 months.

## **G. Sustainability of Care and Support Programs**

Due to the urgency of the epidemic, PEPFAR was rolled out in an emergency fashion, with an eye towards immediate access to ARVs for PLHIV. With such a rushed approach to the initiative, many of the necessary structures for sustaining this level of service provision were not factored into the policies and funding governing the initiative. However, the SAG has thoughtfully addressed the need to balance urgency with sustainability. Now, five years into the initiative, after many successes have been achieved, the SAG and PEPFAR are embarking on a Partnership Framework to formalize their combined vision of providing HIV/AIDS treatment, care and prevention programming over the next five years.

Throughout the last few years, the NDOH and PEPFAR have experienced a strong partnership in responding to the HIV/AIDS pandemic in South Africa. The NDOH ensured strong involvement of health departments at all levels. Recently, PEPFAR placed PEPFAR liaisons at the provincial level as a collaboration model to work with provincial and district health departments and PEPFAR partners in those districts. In South Africa, many PEPFAR implementing partners work in integrated structures with the NDOH facilities avoiding building parallel structures of service delivery; however, this has resulted in a heavy reliance on PEPFAR supported human resources and staff supplementation in DOH facilities.

A successful transition of PEPFAR ART “Track 1.0” partners is underway with ICAP and EGPAF and this transition of Track 1.0 partners can serve as a model for eventually shifting personnel at government facilities and NGOs back to the SAG coffers.

The CCW Framework described in the Community-based Care section (IV. D) above represents an effort by the SAG to institutionalize a cadre of salaried community health workers. The details of this program are being worked out, but this group of CCWs will clearly be in a position to provide a minimal set of key HIV services at the community level; these services might include tracking of pre-ART patients who do not return for care.

For the HIV/AIDS response, there has been a heavy reliance of the SAG on PEPFAR funds for human resources for service delivery. There is a limited level of coordination from district health departments to CBOs within health districts, which will require leadership from the DOH to guide them on what they are to do in the districts and the catchment areas in which they work. Additionally stock outs of commodities, described above, will need to be addressed.

The SAG has shown strong leadership in the decentralization of ART treatment to the clinic level. At the same time, there is a lack of decentralization and access to pre-ART care and support services and the capacity at the community level has not been addressed through this decentralization process. Pre-ART services are not being decentralized or receiving focus. Additionally, pediatric ART service delivery is not decentralized causing added waiting time,

transportation costs and time away from work for those families with parents and children on ART. Even in the era of treatment, it should be recognized that treatment is not just providing medications; it is about systems, about human resources and supportive care. An immediate question for the health care delivery system is what structures are needed for those newly diagnosed PLHIV from the HCT roll-out campaign who are not eligible for ART.

Finally, the mental health system is lacking for HIV/AIDS care and support in South Africa. In order to build a strong system of care and support, both the NDOH, Department of Social Development and PEPFAR will need to work together to come up with solutions for adequate provision of mental health services to PLHIV, including HIV-infected adolescents.

## **V. Recommendations for Care and Support at the Facility Level**

**1. Enroll individuals into pre-ART registry for care and support at point of diagnosis.** Individuals should be considered enrolled into care and support at the time of HIV diagnosis, on the basis of the services expected to be provided at that time, which include CD4 blood draw and counseling to return for results, screening for symptoms of active TB, and referral for ongoing care and support through local support groups. All enrolled clients should be entered in the pre-ART register, which should be available at all facilities at which HIV care is offered. Individuals who test positive at mobile sites should be referred to facilities for enrollment into care and/or treatment and entered into pre-ART registers at those facilities.

**2. Modify pre-ART registers to include information on whether/when the patient has returned for the CD4 test result, CD4 count, WHO clinical stage, referral to ART (if eligible), prescription of cotrimoxazole, return for CTX refills, return for repeat CD4 count at 6 months, TB screening, IPT, and initiation of TB treatment.**

**3. Efforts should be made to pursue point of care CD4 testing. Such products are in development and may be commercially available soon.**

**4. Ensure a standard of care and support services at the facility level and assist with the revision of PEPFAR South Africa Treatment Technical Guidance to include pre-ART care services.** Standard care and support services to be provided at the facility level should include screening and treatment for active TB, STIs, and other opportunistic infections, cotrimoxazole prophylaxis, (pre-ART patients are eligible for CTX if they have clinical stage II disease), IPT for patients without active TB, nutritional assessment and support, pain assessment and management, and linkage to support groups and to other community services. These services should be provided to both ART and pre-ART clients. Essential pre-ART services should also include psychological and social support, CD4 count monitoring to determine eligibility for ART, and referral to ART programs when eligible. SAG and PEPFAR in

collaboration with other stakeholders should standardize these pre-ART and ART care and support services.

**5. Strengthen the supply chain system for OI medications.** Specifically, prevent shortages of cotrimoxazole and isoniazid through provision of technical assistance for the supply chain management system at the provincial, district, and site levels.

**6. Strengthen the quality of life of PLHIV at the facility level.** Consider additional services to roll out at the facility level including a systematic assessment of pain and other symptoms (vs. simply eliciting a chief complaint from patients), psychological health support, and a more complete package of PwP services.

**7. Support implementation of the Basic Care Package.** The BCP and its resultant support groups were noted as cutting edge innovations towards empowerment of PLHIV. The BCP and support groups should be rolled out to all the provinces.

**8. Strengthen linkages between pre-ART care in communities and facilities through support of facility-based referral coordinators.** This will enhance pre-ART follow-up and timely ART initiation.

**9. Review what PEPFAR treatment partners are doing with care and support funding, to ensure that funds are utilized to provide the care and support services listed in Recommendation 4 (above).** Include pre-ART care service description with PEPFAR treatment guidance to partners and focus partner service provision more on pre-ART care for WHO clinical stage 1 and 2 patients.

## **VI. Recommendations for Care and Support at the Community Level**

**1. Strengthen PLHIV organizations at the community level by providing appropriate advocacy and capacity building skills for cohorts of PLHIV.** Ideal conduits for growing PLHIV organizations are through home-based care programs and support groups, through BCP cohorts and through community based income-generating activities for PLHIV.

**2. Support development of the Basic Care Package program in all provinces.**

**3. Support the CCW regulatory policy framework and related activities through support of the policy implementation framework and assessment of the cost of the implementation of the framework.** The framework should include a career path (ladder) for the community care worker cadre to increase retention of these skilled practitioners into the health care professional system. A clear plan for PEPFAR's support of the Community Care Worker Policy should be included in the Partnership Framework with a detailed plan of action and related costs in the Partnership Framework Implementation Plan.

**4. Define a minimum set of services for HBCWs to include in guidance to CBOs.** In the interim before the CCW Framework is implemented, this scope of work should reflect a transition of the role of HBCW from general household and physical care to tracing ART and pre-ART defaulters, encouragement of patients to remain in care, referral to community services, and psychological counseling.

**5. Review balance of service provision at the community level.** Include greater emphasis on pre-ART care and support services along with developing a minimum standard of community care services for both pre-ART and ART patients. Re-focus partner service provision to pre-ART care for WHO clinical stage 1 and 2 patients with all PEPFAR partners, in particular, those who currently limit their services to strictly end-of-life care.

**6. Implement Caregiver Support Programs.** In concert with the NDOH, investigate existing curriculum, adapt existing methods, and support care for caregivers programs for all HIV health service providers with a particular emphasis on HBCWs. Minimum standards for caregiver support would include weekly support group discussions, availability of referral to a trained mental health provider for serious issues, staff retreats and respite as needed. Consider rotation amongst facility-based HBCW coordinators and HBCW staff.

## **VII. Recommendations for linkages between facility- and community-based care and support programs**

- 1. Strengthen linkages between facility- and community-based care through support of facility-based case managers/referral coordinators.** This will enhance pre-ART follow-up and timely ART initiation in these patients.
- 2. Collaborate with NDOH to develop guidance for development of MOUs between facilities and community-based partners.**
- 3. Consider other means of optimizing facility-community linkages, such as periodic meetings and reverse site visits between facility- and community-based partners.**
- 4. Support and strengthen district and sub-district health teams and clinic committees to strengthen referral systems.**

## **VIII. Recommendations for Monitoring and Evaluation of Care and Support Programs**

- 1. Work with Strategic Information Advisors to define newly-diagnosed HIV positive patients as being “in care,” for purposes of counting persons receiving HIV clinical care, provided they receive at least one clinical service (e.g, obtaining sample for CD4 testing, screening for active TB).**
- 2. Adopt and utilize new (national) PEPFAR indicator of percent of persons initiating ART who have CD4 count <100 cells/uL as an indicator of how early HIV positive persons are accessing care.**
- 3. Support the SAG’s efforts to develop indicators for care and support, to utilize data to drive programmatic decisions, and to merge with other data management systems.** Consider additional programmatic indicators to capture what is happening in pre-ART care (e.g., percent of persons newly-diagnosed with HIV who return for their CD4 count result, percent of pre-ART patients who return for repeat count at 6 months, percents of patients who are assessed for pain, who receive PwP services, and who receive nutritional assessment and support). Consider additional data collection tools and programmatic indicators to capture referrals and uptake of community services. (e.g., number that complete BCP).
- 4. Conduct periodic PEPFAR Care and Support partner meetings as forums for sharing of best practices, tools, and data regarding care and support services**

**5. Support National HMIS efforts to create national systems of health information that can track HIV and TB clients beyond the district and provincial level, especially in order to track migrant populations.**

**6. Encourage operations research in the area of HIV care (e.g. evaluation of the BCP), evaluate of interventions to improve pre-ART linkage and retention and utilize APCA quality of life scale to improve patient outcomes.**

## **IX. Recommendations for Sustainability and Health System Strengthening**

**1. Once the Community Care Worker Framework is finalized and implemented, align PEPFAR partners with the framework (and away from parallel structures of home-based care).**

**2. Include detailed activities to support the Community Care Worker Framework in the PEPFAR/South Africa Partnership Framework and subsequent Partnership Framework Implementation Plan with a clear five year plan for gradual uptake by of NDOH responsibility for CBO based and other PEPFAR supported Community Care Workers.**

**3. Recruit PEPFAR Provincial Liaisons to assist with supply chain of care and support commodities, to advocate for strengthening care and support services, to assist with MOU development between facilities and CBOs, and to encourage NDOH leadership in care and support. This should include defining CBO catchment areas and strengthening linkages between facility- and community-based programs.**

**4. Encourage partners to actively engage with and encourage leadership from the district health forums to advocate for strengthened care and support service and policy issues.**

**5. Provide technical assistance and capacity building skills to community-based PLHIV organizations to become self-sufficient and self-sustaining.**

**6. Support leadership, mentorship and skill building training for health professionals at the facility and the community level to strengthen health systems and retain professionals in the system. This is especially important for the new cadre of Community Care Workers.**

## **X. Conclusions**

A tremendous amount of systems strengthening to deliver treatment and supportive care services to the people of South Africa has been realized over the past six years. This review intends to acknowledge these successes while providing helpful recommendations to enhance these systems of care, especially for pre-ART clients. Expansion of community health services along with incorporation of private health care facilities is necessary in order to reach the 3.7 million PLHIV in need of pre-ART services. Further discussion on how the private health system and community health services can compliment the national health system are warranted as the numbers of people living with HIV and AIDS grows and encumbers the already over-burdened national health care system. Recommendations within this report are meant to provide some direction to the South Africa PEPFAR team, specifically technical advisors who are focused on treatment provision and care and support services.

## **XI. Acknowledgements**

The Care and Support Review Team would like to thank the PEPFAR South Africa team, specifically Thobekile Finger, Peter Vranken and Mary Fanning for the outstanding preparation that went into the review and for their support during the visit. The review team feels this was an outstanding interagency effort in all aspects. Additionally, the composition of the review team (including two technical advisors from headquarters and two from the field) constitutes a best practice for providing TA and reviewing interagency programs under PEPFAR. The participation of field staff from other PEPFAR country programs is an excellent example of South-to-South collaboration. The idea for this model came from the PEPFAR SA team and should be commended.



# **Appendices**

## **Appendix A – Scope of Work**

### **SOW for HIV Care & Support Consultation in South Africa, July/August 2010**

The President's Emergency Plan for AIDS Relief (PEPFAR) is making significant progress towards its target of providing care for 10 million people worldwide. A significant contribution to this achievement is made in South Africa. At this phase of implementation, the HIV Care & Support team in South Africa, in conjunction with the HIV Care & Support Technical Working Group (TWG) of the US Office of the Global AIDS Coordinator, is recommending performing an in-country review of all PEPFAR-sponsored HIV Care & Support programs. The purpose is to: 1) highlight successes, best practices, and lessons learned; 2) identify challenges and gaps to implementation; 3) set priorities and formulate a strategic focus for the next few years; 4) recommend ways to meet HIV Care & Support goals, including scale-up of care services at home, community and facility levels.

The HIV Care & Support TWG will send an interagency team comprised of 4 consultants (both OGAC-based and field based) to join the South Africa in-country team to carry out the HIV Care & Support Consultation. This team will:

1. Consult widely with Department of Health officials and other key stakeholders
2. Review the report of the PEPFAR partners meeting on HIV Care & Support (Feb 2010)
3. Participate in targeted meetings with PEPFAR implementing partners
4. Perform site visits to cover a broad sample of PEPFAR program implementation sites
5. Produce a review report with strategic recommendations prior to departure
6. Provide an out-brief to the in-country PEPFAR team, key stakeholders and the NDOH

Main areas for review will include:

1. Is the PEPFAR Care & Support program moving in the right direction?
  - a. Is the program in line with PEPFAR priorities and guidelines?
  - b. Is the program designed to achieve the strategic objectives of the South African Government?
  - c. Is the program aligned with the national HIV Care and Support program?
  - d. Is the program integrated with HCT, ART, TB, OVC, PMTCT, and HIV preventions activities?
  - e. Does the program have adequate focus on early enrollment into care and pre-ART?
  - f. Is the program designed to evolve towards a chronic care model for better outcomes for chronic conditions?
2. Identify gaps in the Care and Support program with reference to:
  - a. Geographic coverage

- b. Retention into care
  - c. Quality of care
  - d. Linkages between the community and health care services
  - e. Balance between clinical and supportive care
  - f. Appropriateness of service delivered at each level of care
  - g. Examine areas of care and support services ( M & E)
3. Sustainability
- a. Is the program designed to support the national plan?
  - b. What plans are being implemented to phase out partner TA?

## Appendix B – List of Organizations and Meeting Participants

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## **Appendix C – Summaries of Meetings and Site Visits**

### **UNICEF Meeting**

**Date:** July 26, 2010

**Who we met with:** Joan N. Matji, Nutrition and Child Survival, Stephen Blight, Child Protection, Heidi Loening-Voysey

#### **Summary:**

1. Majority of their work is with the Ministry of Social Development. They have several ongoing projects including work with community care workers to identify vulnerable children and provide psychosocial support to these children, they have child protection activities and education programs for adolescents. UNICEF operates on a five year program cycle.
2. Adolescent HIV care requires specialized programs specific to adolescent issues and needs. Psychological support is needed for both positive adolescents and their parents who may not disclose the child's positive status until their adolescent years, a very sensitive and critical time in their development.
3. UNICEF focuses on early infant diagnosis, working with the ECHO program to develop Standard Operating Procedures. Trying to answer the question – how do you normalize early infant diagnosis?
4. UNICEF is considering re-engaging in PMTCT activities, specifically through the community care workers initiative. Currently assessing PMTCT guidelines to identify what the role of the community care workers could be.
5. Need to integrate PMTCT into primary MCH
6. Child Care Act – children 12 years of age and older can consent to medical procedures, including HIV testing. If positive, what are the supports in place in schools for children who never knew they were HIV positive? We are facing a whole new generation of the epidemic. UNICEF would like to embark on a query of children to determine who they would like to counsel them if given a positive HIV result.
7. Most of the time you find that a community based care worker knows little about what is going on in a child's home. The CBHW may give the child food, follow up on their homework, but they do not usually ask about their family or know whether the parents are living or whether it is a child-headed household.
8. Child Care Forums – first safety network for (vulnerable) children in South Africa, these forums are supported by the government
9. Home and community based organizations have to provide four of ten services to be considered?

#### **Findings:**

1. Joan noted a report by Helen Schneider on how to incorporate other areas of service into PMTCT Community Care Workers
2. Icbindi Model – training children and youth care workers (is this a best practice?)

**Recommendations:**

1. Work with UNICEF to develop a specific campaign to scale up service provision for HIV positive adolescents nearing sexual debut.
2. Reschedule meeting with the UNICEF person we were originally supposed to meet with.

## WHO Meeting

**Date:** July 28, 2010

**Who we met with:** Patrick Abok (WHO, SA) and Morkor Newman (AFRO)

**Purpose of the Site Visit:** to learn about the HIV care and support programs and activities at the World Health Organization (WHO) in South Africa.

### Summary:

1. Government is proactive in providing quality of care; Current expansion of MOH is to focus on quality of care and looking at improving quality clinical outcomes; with a focus on quality of life, CARE is the logical area to strengthen to improve quality
2. Innovations – NSP is cornerstone of HIV programs and managed by SANC
  - a. Main need is to improve access to care
  - b. Charge to move from numbers to quality care
  - c. Lots of progress with M&E
  - d. Provinces take a lot of autonomy
  - e. Need for health sector review to look at community structures and bolster leadership
  - f. SA has 4000 health care facilities and only 500 are accredited to provide ART, there is a long way to go
3. High mortality among women and pregnant women cited in recent Morbidity and Mortality report (July 2009)
4. Need to continue to strengthen M&E systems
5. Community level strengthening –
  - a. Need to strengthen referral systems
  - b. Need standards, training, M&E, financial services, leadership and mentorship
  - c. Need to strengthen leadership and management structures
6. Human capacity and Task Sharing is happening and is also a way for health systems strengthening in the future; Community care workers – possible services for task-sharing include adherence counseling and follow-up support; assessing patients; psychosocial needs (currently being addressed by traditional leaders); referrals and TB care
7. Nurse initiated support goes beyond the health facility
8. Pre-ART, people are not interested in pre-ART data tools under universal access there is little on CARE, universal access only focuses on treatment
9. Accountability is a big issue; partners are only accountable through their own channels and the NDOH does not have that information
10. WHO priorities: much of work is at strategic planning level – HIV prevention, provide TA to country and ART care; WHO is working to push prevention and strategic information
11. HTC campaign, trying to test 50,000 people; HTC is seen as Prevention and Care (addressing wellness, blood sugar and TB screening): entry point for care; started with 500 sites and adding 500 each quarter; referral is critical here; need resources and facility resources

**Findings:**

1. Lesotho, community health workers can do finger sticks
2. SAG is coming up with a new National Plan on Prevention
3. KZN – using cell phone technology; adapting IMAI module (including lab, doctors, patient advocates); highest percentage of HIV in SA; next province to adapt IMAI might be Eastern Cape; IMAI has evaluation built into training

**Recommendations:**

1. Follow-up with Progressive Primary Health Care (PPHC) partner about how to place Community Care Workers utilizing a military approach
2. Care and Support initiatives should collaborate closely with the HTC campaign as the entry point for care and the critical juncture for retention in care via a strong referral system
3. Leadership for new systems/programs is really needed – the problem now is implementation because the SAG outsources primary functions (i.e. practitioners in clinics); There is need for strengthening leadership and governance support at district and clinic level

## **HPCA Sungardens Hospice Meeting**

**Date:** July 27, 2010

**Who we met with:** Ilze Kruger, Esme Potgeiler, Elue v. Niekerk, Juanita Kruger, Wendy Uys, Jolie Nkusi, Mizziam Mabiletsa, Andre Berrange, Lynette Martin, Sandi de Villiers

**Purpose of the site visit:** to learn about the HIV care and support program at Sungardens Hospice and Mamelodi Hospice

### **Summary:**

1. "Quality of life" is their mission. "Reverse the reversible" is how they approach symptomatic care.
2. Founded 25 years ago, includes an in-patient care unit for predominantly cancer and HIV/AIDS patients; has a large charitable arm of the program consisting of fundraising and a second-hand items store and café that bring in the majority of revenues for the program.
3. Member of Hospice and Palliative Care Association of South Africa (HPCA) and maintains a five-star the Council for Health Service Accreditation of South Africa (COHSASA) rating (COHSASA is similar to JCAHO accreditation of health facilities in the States).
4. SGH serves as a center of excellence for training or "exemplar center". SGH provides an 8-month certificate course in palliative medicine for nurses, a management development program on governance, leadership, change management and budgeting, TB training, bereavement training, in-service training, a one week intro to pediatric palliative care and workshops for the community among other curriculae.
5. Staffed with a part time palliative care doctor and volunteer doctors, eight registered nurses, four social workers, an executive director, cooks and housekeepers and 16 health care workers.
6. Mamelodi Hospice has two professional nurses. They get referrals from the primary health care center; they go to the home to assess the client, then they categorize the client. Nurses liaise with the palliative care doctor daily.
7. Patients are 80% cancer/20% HIV at Sungardens Hospice and 20% cancer/80% HIV in Mamelodi Hospice.
8. Trying to get patients into care before terminal phase, category 1 patients versus category 3 patients. They are seeing fewer category 3 patients and are focusing their efforts on identifying category 1 and 2 patients. Also starting to see AIDS related cancers.
9. SGH follows-up with Category 3 clients 2-3 times per week.
10. M&E for loss to follow-up clients -- Hospice Doctor Management System (HDMS), an electronic tracking system for clients. If client hasn't been seen in 33 days, the computer system alerts the user.

## Findings:

1. To provide high quality care and monitor patients closely, programs must be staffed adequately.
2. Support of a client's mental health is essential to quality outcomes of client care.
3. The Integrated Community Home Based Care Model is a best practice – it is the model adopted by the NDOH, piloted by HPCA (I believe Suncoast Hospice in KZN, Kath dePhillipi developed this model)
4. The Mamelodi district has over 300 service providers and there are issues of donors and CBOs who are fighting over patients and neighborhoods. Essentially, there are too many CBOs with the same mission in that district.
5. Case managers are absent from primary health care centers.
6. Counseling and family support set palliative care apart from mainstream primary care. We need more active interventions to improve quality of life, more acute care of PLHIV, especially for Category I clients, increase adherence and psychological support are needed.
7. The main needs of clients on ARVs are symptom control and treatment compliance.

## Recommendations:

1. Consider the center of excellence or “exemplar center” as a distance-learning program for health care practitioners to increase skills of quality of care; in particular this center of excellence could be most appropriate for lay health counselors and health care managers. This training site is low-overhead with great resources that could benefit more than just people training in palliative medicine.
2. Hospice Doctor Management System (HDMS) health information system is a replicable data system for both facility and community-based programs – the system has specific interventions coded with particular emphasis on home-based care interventions.
3. Integrate basic mental health counseling/psychosocial support into a basic level of service for pre-ART and ART clients.
4. Work with government of South Africa to develop a cadre of mid to low level mental health counselors, possibly as a specialist through the CCW.
5. Review Integrated Community Home Based Care Model as a best practice for expansion through CBOs funded by PEPFAR

## **Department of Health, District Health Systems Cluster/NGO Coordination Cluster Meeting**

**July 26, 2010**

**Officials met:** Mr. R. Morewane, Chief Director Primary Health care, District and Development

**Purpose of the meeting:** The meeting was purposed to clarify the linkages between community and health facility services, particularly vision of the Department of Health regarding the role of community care givers.

### **Findings:**

1. The Department of Health feels that traditionally, HIV/AIDS services have been vertically managed at the central government level with minimal decentralization to the provinces.
2. Services that exist at district level are not integrated, which undermines the confidence and willingness of patients to demand them, hence low utilization. For instance, a mother coming for ANC should be able to get an HIV test, be screened for TB, have a test for random blood sugar and also be counseled on family planning without need for making separate appointments which attract significant financial and opportunity costs.
3. The community is recognized as the ultimate sanctuary for patients, highlighting the need and importance of strengthening community based services. Individuals who exit the services delivered in health centres ideally require on-going support and follow up, which communities are best placed to provide.
4. Community care givers (or community health workers) were acknowledged as a critical resource in bridging services between health facilities and communities.
5. Community care givers have been vertically trained, each focusing on a unique area, which has resulted in duplication of services, multiple and sometimes overlapping visits to clients and ultimately irrational use of resources. The need for multi-skilling of community care givers to enable them address multiple needs of individuals and families was highlighted. Two polarized descriptions of community care givers have emerged, namely the specialist and the generalist. While the latter is preferred there is apprehension as to whether there is sufficient dexterity within the cadres of community caregivers to assume multiple care roles and be able to maintain quality and effectiveness of services.
6. The revitalization of the primary health care is a high strategic priority within the government of South Africa. In order to effectively revamp PHC, the community health worker concept needs to be repositioned within the overall health care landscape, with clear definition of roles for CHW, relationship with health facilities, qualifications, supervision, remuneration and career trajectories.

7. A framework for CHW is in advanced stages of development and is a key priority of the Department of Health. The technical officers have up to end of August 2010 to finalise and ratify the framework. Although developed under the auspices of the DOH, the framework can be adapted by other departments such as Social Welfare, Local Government and Agriculture.
8. The technical staff of the DOH are very keen to see this initiative off the ground as it is seen as the most viable mechanism for identifying patients, linking them to health facilities and retaining them in care. Without such a mechanism, it is recognized that existing referral networks are not linked and patients exist the health care system at the top, with no backward linkages/referrals.

**Recommendations:**

1. PEPFAR was requested to support the on going move to revitalize PHC and in particular to support the strengthening of health care systems in areas of supervision, record management, pharmaceutical logistics management and health worker motivation.
2. Finalization and ratification of the community caregiver framework is of utmost importance as it will go a long way in streamlining the roles and expectations of caregivers.
3. The caregiver concept, though mooted in the Department of Health, is a good framework for community extension services, making it relevant to several other government departments. Therefore, the engagement of more stakeholders than DOH is necessary and this would assist in ameliorating the burden of supporting this initiative as currently perceived by the DOH.

## **USG Care Partners, The Basic Care Package Focus Group Discussion**

**Date:** July, 2010

**Who we met with:** M. Matsene, Mosilo Marumo, R. Mlangeni, Neo Mohajane, Maxwell Modi, Emmanuel Modikwane, Damakatso Khiba

**Purpose:** The purpose of the discussion was to get insights into the understanding and application of the concept of the Basic Care Package from the perspective of the South African HIV/AIDS partners.

### **Findings:**

1. The basic care package is a new but popular activity to support people living with HIV/AIDS in South Africa. The components of the package have been agreed upon in light of the needs of PLHA in South Africa, hence making it uniquely different from how it is defined in other countries. The South African basic care package includes:
2. Essentially, the package is aimed to facilitate PLHA, their immediate families and communities to better understand the realities of HIV/AIDS, enhance positive living, reduce stigma, improve health care seeking behavior and ultimately improve quality of life for those infected and affected. The BCP is also a critical piece of HIV prevention.
3. The package is disseminated to PLHA through a six month training, usually conducted in phased approach. Perhaps due to the prevalent stigma associated with HIV/AIDS, training is conducted through two different sessions, a closed one discretely targeted at PLHA and another open one for PLHA and any other people.
4. PLHA who graduate from this training serve as facilitators to in turn train groups of PLHA in their respective communities.
5. The basic care package, especially when applied in the context of the support groups is of significant importance in supporting HIV positive individuals that are not yet enrolled in treatment programs and also serves as a potential community based mechanism for improving greater engagement of PLHA in care and treatment programs.

### **Recommendations:**

1. Roll out the basic care package to reach more regions and districts. Support group facilitators that have had BCP training are an important link to facility based care. Their presence at health facilities would ease and smooth the entry of PLHA into services at these facilities. Therefore, as much as possible, while recruiting and training lay counselors, consideration should be made to include eligible expert PLHA to serve as buddies and build confidence of other PLHA in the health system.

## **National Department of Health HIV/AIDS Cluster**

**Date:** July 26, 2010

**Who we met with:** Mokgadi Phokojoe and Vuyelwa Nqapayi

### **Findings:**

PEPFAR Care and Support program review team highlighted priority areas in care as:

- Early identification, referral to care services and retention in care
- Reduction in HIV morbidity and mortality through interventions like Basic Care Package
- Improve linkages between Facility-care and Community-care
- Prevention with Positives

NDOH Care priorities:

- Positive living for PLHIV
- Support group
- Prevention
- Community based care services

Challenges:

- Issues with enrollment and retention to care
- Poor understanding of PwP interventions and it not been in cooperated into care and support package
- Couples' counseling - barrier
- Community care services: recruitment, standardization of training documents and remuneration. NDOH NGO-funding directorate pays stipend (R500) to CCG.

Barriers to pre-ART retention in Care:

- Linkages to care and support after counseling and testing
- Referral and feedback between facility and community programs
- Inadequate patient tracking systems
- Poor enrollment of pre-ART clients into care.
- Inconsistent distribution of NGOs

NDOH standardized pre-ART program will include strong linkage between counseling and testing and initiation/enrollment into care at facility-care or Community Home based-care.

NDOH operational plan for task sharing:

- Nurse initiation of ART(NIART)
- HIV Counseling and testing ( C&T) to be done by lay counselors
- Community Care Workers ( CCW) to do household C&T

The training curriculum and service package of CCW s are been reviewed. Inputs are been received from all stakeholders.

## **USG Care Partners Community Care Workers (CCW) Framework Policy Working Group Meeting**

**DATE:** July 27, 2010

**Who we met with:** Implementing Partners (see Appendix B)

### **Summary:**

- CCW framework developed Nov 2009. Addresses issues concerning CCW definition, ownership, training, remuneration, career path and best model for SA.
- Key points of the CCW framework:
  - CCW provide essential services that should be provided by SA government.
  - CCW work fragmented presently with different cadres with varied trainings.
  - SAG need to engage all CCW, integrate and standardize training and remunerations.
- Proposed model: integrated community care and service delivery by health and social development teams.

### **Findings:**

- CCW curriculum should be comprehensive but focus.
- Ensure standards and quality of care provided by CCW.
- Harness efforts of donors for CCW, with the district DOH as regulatory agency.
- Develop clearly defined CCW job description.
- Coordination, supervision and mentorship of CCW critical.
- Develop transition plan to move CCW from NGOs to SAG.
- Monitoring and evaluation of CCW programs.
- Conduct impact evaluation and link quality of life gains to CCW services.
- CCWs' CME possibly through FET-Further Education Training board, for career development.
- Develop multi-sectorial integrated CCW model

### **Recommendations:**

- Support the development of CCW norms, policy, SOP, guideline.
- Provide TA to develop implementation plan for the CCW framework and transition plan.
- HSS: training of CCW and consider funding community need assessment survey.
- Highlight CCW framework in Partnership framework.
- Support costing CCW program.
- Support harmonization of existing M&E tools.

### **Next Steps:**

- Incorporate inputs from all stakeholders.
- Leverage GFATM Round 10 funds for PHC HSS – HR and infrastructural renovation

## **CARE South Africa Site Visits, Petsana Child Care Forum/Thabo Mofutsanyane District and Lechabile AIDS Awareness Center**

**Date:** July 29, 2010

**Who we met with:** Petsana: Mamosela Matsembe, Liphapaney Mogilieini, Neo Mohajane, Tlalery Tshabalala, Rebecca Mhangeni, Nicosana Mkrosi, Selina Modise, Masilo Marumo, Emmanuel Modikwane; Lechabile: Mamosela Matsembe, Mosilo Marumo, Rebecca Mhangeni, Neo Mohajane, Maxwell Modiri, Emmanuel Modikwane, Dimakatso Khiba

**Purpose of the site visit:** To learn about the HIV care and support program at Petsana Child Care Forum and Lechabile AIDS Awareness Centre

### **Findings from Petsana Child Care Forum:**

1. Program has expanded from an OVC program to HBC program. Program has a nurse, project manager, coordinator, finance staff, M&E and 20 carers.
2. Demographics – 25,000 people in catchment area (from 2000/2001 Census); have approximately 366 patients. They cover 4 wards and utilize community meetings to tell about their services.
3. Referral – clinic gives them a list of people who have defaulted on HIV or TB meds and Petsana acts as tracers in the community. Patients also come to their site. Clinic sisters work closely with them. There is one clinic for entire township. Patients are tested on a daily basis and referred for counseling if positive.
4. Services – program provides awareness campaigns, support groups (working on lifestyle change), preventative and psychosocial services; another organization helps with transportation and this has really helped a lot with access to care. Also linking with clinic to help with TB. Patients are compliant on CTX (200 CD4 and below). District hospital screens all patients for TB and utilizes tracers to find + clients.
5. Linkages -- Working with MOH clinic to get an MOU. There is a mobile unit that comes from district hospital and goes to farms once a month. District hospital asks Petsana Child Care Forum to trace patients and district hospital does refer pre-ART clients to Petsana.
6. Home-based Care – used to feed, wash the patient and they work with families to create memory boxes. They refer “less sick” patients to support groups. 20 CBHWs go before breakfast to help TB clients take their medication.
7. Support Groups – talk about stigma, adherence, education on importance of ARVs, provide spiritual care and education on creating wills.
8. pre-ART patients – it is difficult to get to them. Petsana has two members going to BCP training. Pre-ART clients do not get CTX.
9. Stigma – is STILL an issue, clients prefer closed peer support groups.
10. Pediatrics – HIV+ children get antibiotics at 6 weeks, positives are enrolled in ART, they test all children at 18 months.
11. Adolescents – services for adolescents ARE needed.
12. Commodities – supply of ART is good.
13. Nutrition – government supplies porridge but sometimes they run out – they would like to initiate gardens

14. Pain assessment is being done. (not sure where)

### **Findings from Lechabile AIDS Awareness Center:**

1. Serve an area of 29,000 people. They have 259 clients with a census of +/-300. Popular NPO, they take care of all patients; work with TB and “chronics” including diabetes, hypertension and cancer patients.
2. They want to reach out to the people working on the farms but they do not have a car for the program.
3. They work in conjunction with the clinics and municipalities, however they do not have an MOU at the present time.
4. IECC department conducts a lot of community outreach via carers, fliers, radio stations and community hall forums – this helps bring clients into their program – also the Love Life program in schools refers a lot of adolescents to their program.
5. Home-based care program – provides training for families at home, for bed-ridden patients, the carers wash the patient, they do light house cleaning and show patient how to take medication; they have a consent form regarding confidentiality in the home; also have confidentiality forms signed by all their staff.
6. Referrals – they receive referrals from the Child Care Forum; they also have referral forms for HBC program and the carers. Clinics refer to this center and center refers back to clinic to get a family member to bring them in
7. Services provided – in addition to HBC and IECC, the program provides 1) counseling, 2) spiritual care either via a pastor or traditional healer, 3) work with patient to disclose status, 4) psychosocial support 5) adherence support. Support Groups -- They do not have open support groups however they have closed support group for all HIV + PLHIV – these cover treatment adherence, disclosure, and nutrition. Pain assessment and management is happening.
8. Stigma – A lot of stigma still exists in the community
9. Poverty – most patients have no jobs, no disability grants and the ART clinic is in the next town, Marquat. There is no public transport.
10. No public doctor stationed in Senekal.
11. Lechabile patients have to travel many kilometers to the closest ART site in the next major town (Marquat). When possible the Lechabile Center staff pays for taxis (out of their own pockets) to take patients to the ART site. There is a need for transportation vouchers for CBOs where ART sites are not in walking distance for patients.
12. CCW Framework discludes CBHW from any benefits due to accidental death such as a car accident. If carers are transporting clients by car, this is a real liability for both carers and CBOs.
13. Gaps – the relationship between the NGO and the government is not well utilized. They get funds from district (for HBCWs?) however they don’t seem to capitalize on relationship. (I believe they were talking about strengthening linkages between CBOs and district hospital here).
14. Gaps – pre-ART is a huge gap because patients do not present at their 6 month follow up. Instead they present on a stretcher when they are very ill.
15. Gap – CTX is not used prophylactically.
16. Gap – PWP, how do we do it when we are letting people slip out of care.

17. Gap – support for children between 5-10 years old.
18. Gap – food, gardens are not adequate and this is the only option available. There are some therapeutic foods but not adequate.

**Recommendations:**

1. Encourage/require nursing supervisor for community caregivers as an essential component to a community-based outreach organization to ensure oversight of the carers and to bolster the referral system.
2. Consider supporting transportation vouchers via the CBO supported programs as a band-aid until the ART sites are rolled out to the community level. For pediatric ART clients, the need for transportation will continue beyond the ART roll-out since pediatric care is still cordoned to the hospital.
3. Stigma reduction is a great need. Interventions to decrease stigma at the community level should be addressed by the Care and Support funding of USG.
4. Need to build linkage between support group and clinic where testing occurs. Need to make sure there is adequate support in these groups.
5. Need trained psychological counselors as part of referral from testing to support groups.
6. Provide guidance to CBOs on engaging with community care forums to let community government know about their services.
7. Work with NDOH to revitalize community care forums.

## **NASTAD Meeting**

**Date:** July 30, 2010

**Met with:** NASTAD, Free State

**Purpose of the site visit:** To learn about the HIV care and support programs, particularly the BCP roll-out through NASTAD partners

### **Summary:**

1. BCP – 6 sessions for closed groups of HIV+ individuals. Try to keep the cohort together for all six sessions. No more than 25 people per cohort. Pilot was directed to NGOs that already have a relationship with the facility. Free State has trained 23 facilitators already.
2. Piloting BCP in Free State, first piloting in Motheo then Xhariep
3. Motheo District include partners from CARE
4. NGOs are very supportive of BCP. NAPWA stated they “support BCP 100%”
5. NASTAD is filtering NGO capacity needs (to implement BCP) back to MOH
6. Building sustainability at the Regional Training Center for BCP
7. Itjareng – need PLHIV to get training as carers. Church involvement is very helpful to de-stigmatize HIV and increase awareness in the community
8. Mozamaria – testing 1400 people a month, provide OVC support through food preparation, prepare trench beds for vegetable gardens and provide treatment literacy for PLHIV.
9. Basheuelo (sp) – challenges with BCP are with lay counselors who protect their territory. Need for books, pens, notebooks for training. Need for refreshments. A certificate after BCP training is helpful and encouraging. Some stipends aren’t making it to facilitators. Facilitators don’t have a great deal of facilitation skills.

### **Findings:**

1. No real cooperation between NDOH and Dept of Social Development
2. Need assistance with MOH to move MOUs forward
3. Need stipends to do the BCP facilitation. Facilitators go to different areas to train at their own expense and supplies such as notepads, pens, etc are needed.
4. NAPWA wants validation by NASTAD to mentor other PLWHA organizations
5. NAPWA stated they need additional funds to make the BCP work regarding funds for refreshments or food parcels. Although this is a really an issue for the Department of Social Development, it continues to affect the success of BCP and/or other support groups for PLHIV. Need incentives or food parcels for BCP.
6. “After diagnosis, you feel alone. Support groups make you feel better.” If PLHIV are in denial, they don’t like support groups
7. “Others come for strength and courage before they go to test”/
8. “Negative attitudes of professionals (are a barrier). (PLHIV) are not respected within the medical community.”
9. “(PLHIV) default intentionally because they are dependent on the government grants.”

10. Need for community sensitization of BCP. Stigma still exists.
11. Difficult to do training at clinics because they close and lock their doors at 4:00 pm.
12. Need BCP Pediatric Adaption.

**Recommendations:**

1. Develop strategy to work with Department of Social Development to grant food parcels to BCP support groups.
2. Work with NDOH to expedite MOU development. (This is a role for PEPFAR Liaisons at Provincial and District levels)
3. Work with NDOH to incorporate BCP into primary health care wellness programs.

**ICAP Columbia, Amathola District, Eastern Cape Province Site Visit; Am district office, Nkqubela TB Hospital, NU 8 primary health center, Duncan Village Day Center (Community Health Center)**

**Date:** August 4, 2010

**Who we met with:** Ralph Ntomy (Technical Director, ICAP, SA); Xoleda Somahela (Director, East London Region, ICAP), Nokuthula Futwa, Scott Worley (Care and Support, ICAP, East London Region); Selly Mabandla (Buffalo City Sub District Health Office); Coceka Noguduka (PEPFAR liason to Eastern Cape Region); Sister T Tiso (Nkqubela TB Hospital); Sister Ngemntu (NU 8 Health Center); Mrs. N.L. Mani (Duncan Village Day Center)

**Findings:**

1. ICAP works in 3 Districts in Eastern Cape Province, as well as in several other provinces in SA. They are an ART Track 1.0 partner. They work in 9 facilities (ranging from referral hospitals to primary health centers) in Amathola District. 7 of these are ART initiating sites; all the rest are down-referral sites. (In fact, the District Health Office is planning for a total of 112 treatment sites—including initiating and down-referral) in the District, such that no patient will be more than 5km from a treatment site.
2. Care and Support services for ART patients include CTX, screening for TB/IPT, nutritional assessment and support, PwP (meaning behavioral counseling, encouragement of partner testing, occasionally as couples), Fx planning, referral to support groups.
3. Support groups are at both facility and community, but not as strong as the SA partners BCP package, which is rolling out slowly in Amathola District
4. Occasional drug shortages of CTX and especially INH (IPT is in fact slow to roll out, in part because of drug shortages, provider reluctance, and confusion regarding policy of having to do TB skin (Mantoux) tests.
5. All sites have pre-ART registers. In general, patients not entered into this register until CD4 result is returned to the patient (and patient therefore “in care”). However, practice seems to be variable; personnel at Duncan CHS indicated patients entered when the CD4 specimen is drawn (before result is obtained). They think high percentage of patients return for result; don’t have figures about % that return for repeat CD4 in 6 months, although they believe this might be high as well.
6. Services provided to pre-ART patients are CTX (for patients with WHO stage II, TB screening, nutritional assessment, PwP, referral to support groups.
7. Of the various services provided by CCWs, they seem occupied by ART defaulter tracing and DOTS defaulters. Agree that pre-ART patients important, but lower priority. A good practice is keeping a log of ALL patients that require defaulter tracing, whether ART, pre-ART, or DOTS
8. They think that most important factor associated with pre-ART retention will be patient knowledge.
9. They work closely with District Health Office and feel that they are really providing TA; the implementer is the District Health Office.

**SA Partners: Eastern Cape Province Site Visit; HQ at Ibhaye Living Center in Port Elizabeth, and 2 partner sites—Silvertown Clinic in Uitenhage, and Masizakhe Community Project in Kwiwe.**

**Date:** August 2, 2010

**Who we met with:** Tony Diesel (Project Director); Thembi Zungu, Nomfundo Zotyeni, Casino Agalini; Agnes Thys, Ayanda Williams, Linda Mkolo (trained Basic Care Package support group facilitators); Denver N Mientjes (Silvertown Clinic supervisor); Beatrice Meat, Babanna Stamper (Masizakhe Community Project).

**Findings:**

1. General information about the Basic Care Package—its history and implementation--per meeting with BCP partners in Johannesburg, July 27, 2010. The Ibhaye Living Center may be considered the birthplace of the BCP, since project started in Eastern Cape Province. Approximately 48 (from NGOs) plus 148 (lay counselors in DOH facilities) have been trained as Support Group Facilitators (SGFs) in Eastern Cape; about 24 are actively leading SGs at this time. We met 3 of them during this visit.
2. Silvertown Clinic is a small clinic in Uitenhage. Will become a “down referral” ART site later this month, but in fact they are already following about 50 HIV+ patients currently. 2 trained SGFs are jointly leading an SG with 16 persons, which is in its 3<sup>rd</sup> week. Thus far, response very positive.
3. Other observations at Silvertown Clinic: clinic offers monthly visits for ART patients (many will be officially “down-referred” within next month); current services include referral to this BCP SG, CTX, nutrition assessment, TB screening. When it becomes a “download” site, will also refill ARVs at this site.
4. Starting using pre-ART register about 2 months ago. Services offered are same as above. Some confusion about eligibility criteria for CTX (whether includes WHO stage II, but in fact pre-ART register shows that some stage II patients have been given CTX). Some patients have not received CTX--apparently due to drug stockouts, which appears to be multifactorial—problems at both the site and at the Provincial level. IPT has not been started because of lack of drug.
5. Clinic supervisor thinks that about 80% of new patients with CD4 >200 return for their CD4 count result. They have community workers that can trace the others. He also believes that about 60-70% of these patients return for repeat CD4 count at 6 months (cannot verify).
6. Personnel feel that most important factor associated with retention in care will be knowledge about HIV and its treatment, which will hopefully be facilitated by the BCPs.
7. Masizakhe Community Project has one trained SGL; she is currently conducting 3 SGs— one with PLWHAs, one with grandparents of HIV-infected children, and one with infected and affected children. She seems very knowledgeable about the basic services required for ART and pre-ART patients. Also feels that knowledge most important factor for retention in care.
8. Masizakhe project also has several HBC volunteers, who see very ill patients on referral from local health facilities. Apparently, this service not supported by PEPFAR, which supports the BCP work only.

## **Africare SA (CDC) Site Visit, Eastern Cape; Injongo Yethu Project and Nonzamo Clinic, East London, Eastern Cape**

**Date:** Aug 3rd, 2010

**Who we met with:** Dr Gregory Jagwer, Sr Jordan, Mrs Soduku

### **Findings from Injongo Yethu Project:**

1. Goal of comprehensive support: expanded use of quality, comprehensive HIV/AIDS services in at least 3 sub-districts in the Eastern Cape.
2. Eastern Cape province HIV prevalence: 27.6%
3. Strategies: safe and rapid enrolment and maintenance in care and treatment, close collaboration with Eastern Cape Department of health (DOH).
4. Quality of care emphasized. Continuum of care model in place. Mode of care assessment done at the inception of program and standard of care instituted where applicable.
5. Collaboration with SA Partners to implement Basic Care Package curriculum.
6. Africare support EC district DOH with technical assistance in human resources, development of policy documents, guidelines, work plan and SOP.
7. Pre-ART registers recently introduced in all Africare sites.
8. Strong community engagement
9. Main challenges are stock out of CTX and INH, and lost to follow up.

### **Findings from Nonzamo Clinic (PHC):**

1. Site providing ART re-fill and routine care. Soon to commence nurse initiated ART.
2. Pre-ART registers are used to register all PLHIV. Tracking done for clients with low CD4.
3. Decision to initiate ART will be based on multi-disciplinary team (MDT).
4. CTX coverage poor: 15%

### **Findings from Sinthemba Community Based Organization (CBO) & Community care Workers (CCW):**

1. CBO did a situation analysis of PLHIV and OVC in the community. Results showed poor support services available for these groups.
2. Target population is PLHIV, OVC, and TB/HIV. CCW conduct door to door visits and provide psychosocial support, trace defaulters, social grant access, and linkage to support groups.
3. Denial and Stigma still a big challenge in the community and these explain clients presentation to health facility very late, with an average CD4 count of less than 100cells/mm<sup>3</sup>
4. Couple disclosure also a big challenge.
5. Experience from home visits show that there are fewer advanced, bed ridden patients at home, with the advent of ARVs.
6. The CBO management committee decides on whom to visit at home, based on report from previous home visit and referral from the facilities.

## **TB HIV Care Association, Jolivet and Hlokozi clinics, Sisonge District, KZN Province; and Sisonke District Health Office – Site Visit**

**Date:** July 29, 2010

**Who we met with:** Harry Houser, Dir, TB HIV Care Assoc; JL McLaughlin, TB HIV Care Jolivet site manager; TG Dlamino, Jolivet Clinic OPM; N Gasa, Hlokozi Clinic OPM; SA Cirkinnoan, CFK Hospital CEO; Zanele Maseko, Care and Support lead, KZN DOH; Chalone Savant, PEPFAR KZN provincial liaison; Gcina Radebe, Sisonke District Manager

### **Findings:**

1. These 2 clinics among 7 (?) in Sisonke District served by TB HIV Care Assoc, in collaboration with the Sisonke District Health Office
2. Both clinics operate as “down-referral” sites for ART patients initiated on treatment at Christ the King Hospital, the local District Hospital
3. Number of patients currently on ART/pre-ART in these two clinics: 195/546, and 263/963, respectively
4. ART patients are seen monthly for drug refills
5. Care services provided to these patients include baseline nutritional assessment (and intervention to those with BMI <18.5), CTX prophylaxis (all patients), IPT (recently started, but not yet widely implemented because of lack of drug—see below), screening for active TB, behavioral counseling and support group access
6. All patients linked to a community care worker via a community care facilitator. Main purpose of home visits is to support adherence (to both ART and CTX) and to provide preventive counseling. Patients must sign a consent form to allow home visits; some patients do not sign.
7. Pre-ART patients are entered into a pre-ART register at the site. These patients are also linked to community care; main purpose is to ensure f/u visit for CD4 count at 6 months. Random look at a page from Jan 2010 at Hlokozi: 11 of 20 patients had CD4 >200 (pre-ART); only 1 of these 11 has returned for repeat CD4 in July 2010.
8. Delivery of CTX and IPT has been hampered by occasional stock outs for CTX and very limited supply of isoniazid. Clinics operate on a “pull” system, and problem appears to be at the Provincial level in terms of filling orders in a complete and/or timely manner.
9. Otherwise, care services for ART patients appears comprehensive, although little mention of IGA activities. Also, PwP limited to behavioral counseling, provision of condoms, and encouragement of partner HIV testing; couple counseling/testing not mentioned
10. Pre-ART services are more limited; hampered by lack of ability to offer IPT. Since CD4 <200 used as criteria for CTX prophylaxis, pre-ART patients not eligible, although should be noted that recent NDOH guidelines suggest CTX also for persons with WHO stage II disease, which would include many of these patients. Also TB screening not recorded in pre-ART register for many of these patients.
11. In general, pre-ART care probably way above average for ART programs in SA. Availability of pre-ART register, referral to community care workers, and recording of who has returned for repeat CD4 at 6 months are positive findings. One thing that could be improved: confirmation that those with CD4 >200 are in fact aware of their

CD4 count (that is, did they keep f/u appt to get result?). If not, can they be considered “in care”?

12. Excellent relationship with District Health Office (per debrief with District Manager later in the day)

## **HPCA St. Luke's Hospice, Western Cape Site Visit**

**Date:** August 3, 2010

**Who we met with:** Priscilla Nelson (Director), Kathy Hanning (HPCA/Cape Town), Mervyn J. Kanjure, Margot van der Wielen, Valene Reman, Muriel Stevens, Sharon Sutherland, Jessica Rebert

**Purpose:** to learn about the HIV care and support program at St. Luke's Hospice

### **Summary:**

1. St. Luke's is a 30 year old organization in Western Cape. Census is approximately 60% cancer patients and 30% HIV patients with 10% chronic illness. Employs 4 registered nurses, 16 carers, one supervisor and kitchen and janitorial staff. Have a number of volunteers. Patients – Site A 179 patients/50 which are category I; Site B – 49 patients, 8 of which are category I; One HBC site has 103 patients; 820 patients in community. Category I patients receive ART adherence, TB dots, seen once or twice a month through home-based care.
2. Home-based care program in Kayelisha (sp) and Klipfontain (dictated by NDOH) DOH subsidizes ward (hospice) and home-based care, although not adequately. They are constantly training HBCWs because there are high rates of attrition after the four year program. DOH supplies relief carers with other are in school.
3. HBCW stipends – relief carers get 850R, permanent carers get 970R (from NDOH) and St. Luke's adds 500R to give them a total of 1365R per month. St. Luke's Hospice continues to top off the HBHW stipend. Six of its HBCWs have completed their EPW4 training. HBCWs get an additional stipend from St. Luke's when going to school. St. Luke's pays air time (cell phone), transport and additional stipend top-off for HBCWs. They also provide training, retraining.
4. HBCW services -- see mostly Category 3 patients with chronic disease care and palliative care needs. Category I patients receive ART adherence, TB dots, seen once or twice a month through home-based care. HBCWs provide IMCI, PMTCT, palliative care. DOH has high expectations for HBCWs – expecting them to be auxiliary nurses with not enough adequate training. DOH prescribes that HBCWs training in PMTCT, IMCI, etc. Auxiliary nurses are about 12,000R and require math, English, biology. The South Africa Nursing Council does not recognize the auxiliary nurses
5. HIV Clients -- Even before ART, the care from St. Luke's would have a discharge of 50% for HIV patients because they provided strong symptom control and were able to rejuvenate the patient. HIV patients still present very late with CD4 counts below 50. 60% of inpatients are discharged.
6. Social issues – drug abuse in community, poverty, malnourishment, migrant workers, wasting away, need longer hospitalization. Food is still a huge issue. Hospice receives these patients from entire metropol area from hospitals, clinics, etc. These are bed-bound clients, they come in to start ART, stabilize them, etc. policies discharge the patients too soon and then they end up back at the facility, The district hospital has 20 beds, 85% occupancy and most have TB, most are HIV+

7. TB Care -- taking care of TB is expensive to protect the health care professionals (i.e. masks, ventilator systems, etc)
8. Prevention with positives -- “Condomize” is their response to PWP; also working with AIDS legal network to strengthen the rights of PLHIV; also facilitate disclosure with patients. Discordance – males wait longer to access care and this works against counseling for discordance
9. Stigma related to carers coming to home is an issue, especially if they are a Category I client.
10. Leadership and governance is needed to decrease stigma. Need a multi-sectoral response. HIV is being normalized
11. Even in the era of ARV, there are still 1000 deaths a day. Those are reported deaths due to HIV. Many people ask for a different diagnosis on the death certificate so many HIV related deaths are going under-reported.
12. Very excited about BCP, prevention messages and decreasing stigma. HPCA and BCP – category I clients, HPCA is well-positioned to do training and do psychosocial support. BCP will alleviate the load on hospice – primary patient of BCP is to get people into care as soon as possible following diagnosis. St. Luke’s has 14 satellite sites throughout the Western Cape ranging from primary care facilities and other hospices to day care sites to support group sites.
13. Care for caregivers – spiritual leaders who are psychologists, etc; 2 sessions; support groups with community staff via a social worker; provide sources in counseling; debriefing amongst staff in ward daily

### **Findings:**

1. Increasing HBCW hours from 4.5 hours a day to 8 hours a day would help with retaining these trained workers in the health profession.
2. St. Luke’s provides the 59 days standard training which is now a 3-month training course. HPCA is helping to standardize this carer training to build a career path to auxiliary nurse. HPCA sees this as a way to help over-burdened nurses. (This is a best practice) HPCA identifies carers with potential and provides a bursary or scholarship which leads to a one-year commitment for the student to work for the hospice.
3. HPCA is well-positioned to do training and do psychosocial support. St. Luke’s Hospice alone has 14 satellite sites in the Western Cape where the BCP could be rolled-out.

### **Recommendations:**

1. Adapt the HDMS system for facility and home-based care program monitoring for USG care and support projects to include both ART and pre-ART patients and family members.
2. Utilize the HPCA “exemplar centers” as training sites for expansion of 3-month HBCW training and with an eye towards the roll-out of CCW curriculum for generalists and specialist once the CCW Framework is implemented.
3. Consult with HPCA regarding retention scheme ideas to maintain the current cohort of trained and skilled HBCWs.

4. In conjunction with NDOH, consult with HPCA on how to structure career ladders for CCWs to move up the health professional ladder to auxiliary nurse.
5. Stigma – make HIV a notifiable disease; make testing compulsory. Death certificates – people don't want to have HIV/retroviral disease on their death certificate. The present way that HIV is managed perpetuates stigma. It is more acceptable for patients to have cancer than HIV.
6. Conduct a review and focus groups to determine the best way to institutionalize care for the caregivers. Consider developing an extension of the BCP to families and carers with particular focus on caregiver support.

**Kheth'Impilo Care and Treatment Program (USAID) Site Visit; Sundumbili community Health Center (SCHC), Mandeni sub district, Illembe district, Kwa-Zulu, Natal**

**Date:** July 30<sup>th</sup>, 2010

**Who we met with:** Anita Jason and Mokgadi Malahlela

**Findings at clinic visit:**

1. SCHC –mid level health center, supported by Kheth'Impilo Care and Treatment program
2. PEPFAR program commenced at SCHC in 2005. SCHC catchment population is 75,091.
3. Stanger hospital is 'Hub' to SCHC and CD4 test result turnaround time is 3 – 10 days.
4. HIV prevalence: Sundumbili - 32.4%. Illembe district - 40%.
5. Services available in SCHC: HIV Care and Treatment, PMTCT, TB screening and treatment, general disease management.
6. Care and support services available at SCHC are focused on ART patients and include: cotrimoxazole ( CTX) prophylaxis– criteria for initiation: CD4<200cells/mm3), IPT – recently introduced in SCHC, TB screening, diagnosis and treatment, OI management, partner's screening, support group
7. SCHC have no pre-ART register, no intervention focused on pre-ART clients.
8. For community care services; Kheth'Impilo (KI) engages, train and stipend Patient Advocates(PA), whose roles are focused on ART patients to provide home visits, adherence counseling, psychosocial and disclosure support, support group facilitation, and referral to social development and home affairs department for social support. One PA is attached to about 60 patients. PA with minimal supervision and mentorship.
9. KI- NGO not working with DOH community care workers
10. Major challenges at the SCHC are drugs (CTX, INH) stock out, few numbers of PA and issues with stigma and discrimination.
11. Service gaps: non availability of pre-ART care, PwP package, nutrition assessment and interventions and enrollment into care.
12. Patients presented late for ART initiation.
13. Poor 6 months follow up rate.
14. Inadequate interventions for defaulters' tracking
15. CD4 test results not know to patients until they return for follow-up visit.

**Findings from home visit:**

1. Team visited index case that lives with her aunt, who cares for a family of 13 people. All live in a three bedroom bungalow.
2. Index case is a 26 –year single mother with a five old daughter. Both on ARVs, CTX and are stable.
3. Other family members have not done HCT despite counseling by the PA.
4. Main issues are challenges with drug adherence, disclosure and support group participation.



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