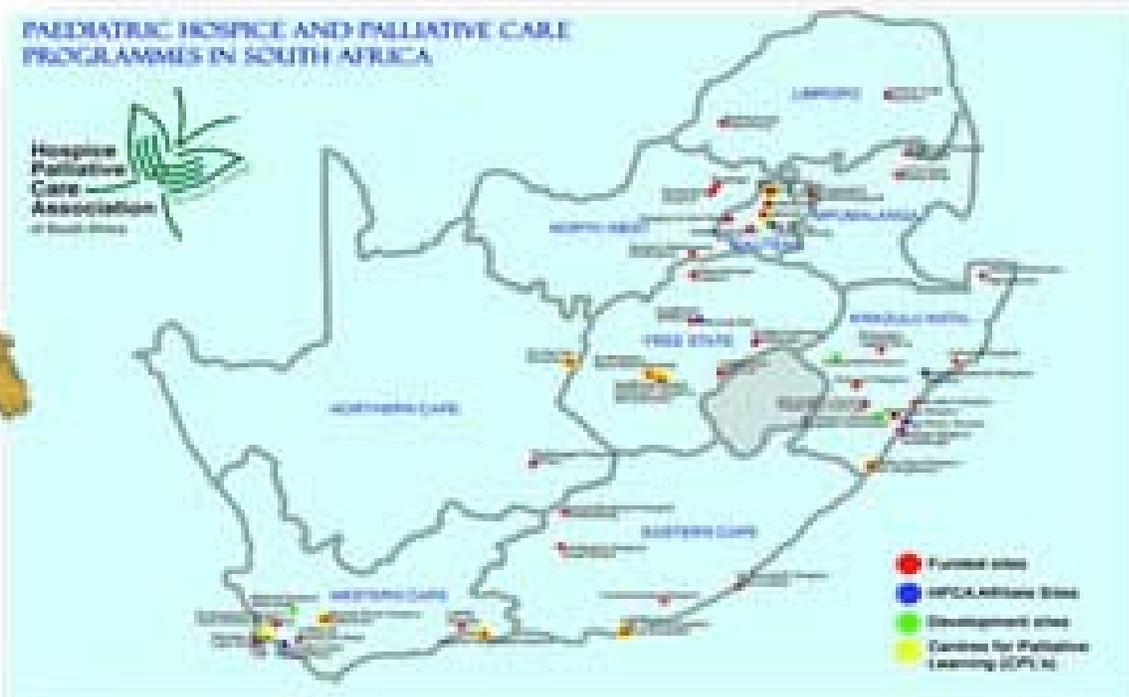




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## EVALUATION

# PERFORMANCE EVALUATION OF USAID SUPPORT TO PALLIATIVE CARE IN SOUTH AFRICA.

**[December 2012]**

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# **A PROCESS AND OUTCOME OF EVALUATION OF PALLIATIVE CARE IN SOUTH AFRICA: THE EVOLUTION OF HOSPICE CARE**

**1 December 2012**

**Cooperative Agreement No. 674-A-00-10-00023-00**

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### **DISCLAIMER**

The author's views expressed in this publication do not necessarily reflect the views of the United States Agency for International Development or the United States Government.

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# Acronyms

ABC	Abstinence, Be Faithful, Condoms
ACSM	Advocacy, Communications, and Social Mobilization
ARV/ART	Anti-Retroviral Therapy
BCC	Behaviour Change Communication
CBOs	Community Based Organizations
CHWs	Community Health Workers
DCS	Department of Correctional Services
DOE	Department of Education
DOD	Department of Defence
DSD	Department of Social Development
FBO	Faith-based Organization
GDP	Gross Domestic Product
HCT	HIV Counselling and Testing
HIV	Human Immunodeficiency Virus
HPCA	Hospice Palliative Care Association of South Africa
IEC	Information, Education, and Communication
M&E	Monitoring and Evaluation
MER	Monitoring, Evaluation, and Research
MIS	Management Information System
NACP	National AIDS Control Program
NDOH	National Department of Health
NGO	Non-Government Organizations
NSP	National Strategic Plan on HIV, AIDS, and STIs
OGAC	Office of the Global AIDS Coordinator
OVC	Orphans and Vulnerable Children
PAC	Provincial AIDS Council
PDOH	Provincial Department of Health
PEPFAR	President's Emergency Plan for AIDS Relief
PMP	Performance Monitoring Plan
QA	Quality Assurance

SADC	Southern African Development Community
SAG	South African Government
SANAC	South African National AIDS Council
STTA	Short-Term Technical Assistance
STI	Sexually Transmitted Infections
TB	Tuberculosis
UNAIDS	The Joint United Nations Programme on HIV/AIDS
UNGASS	The United Nations General Assembly Special Session
URC	University Research Co., LLC
URSA	University Research South Africa
USAID	United States Agency for International Development
USG	United States Government
WHO	World Health Organization

# Executive Summary

An evaluation of the Hospice Palliative Care Association (HPCA) project was conducted in South Africa between September 7<sup>th</sup> and October 26<sup>th</sup> to document the degree to which the USAID-funded palliative care interventions were successful, identify best practices, suggest improvements, and provide recommendations for follow-on interventions.

## BACKGROUND

In South Africa, HIV infection rates have increased from an average of less than one percent among pregnant women in antenatal clinics in 1990 to 29% in 2006 and 30.2% in 2011. According to the Joint United Nations Programme on HIV/AIDS (UNAIDS), about 5.7 million or 17% of all South Africans are now HIV-infected. The Government of South Africa (SAG) responded to the HIV epidemic by developing a National Strategic Plan 2007-2011 (NSP). One of the two primary aims of this NSP was to “reduce the impact of HIV and AIDS on individuals, families, communities, and society by expanding access to an appropriate package of treatment, care, and support to 80% of all people diagnosed with HIV.” USAID/South Africa provided support to the NSP 2007–2011 with the overall objective of increasing the use of HIV/AIDS and other primary health services in South Africa. The major focus of PEPFAR funding was to provide direct palliative care related services to patients and their families, through strengthening the capacity of palliative care hospices and other governmental and non-governmental organizations who provided quality services to HIV-infected persons and their families. The PEPFAR palliative care strategy was closely aligned to NSP Priority Area 2: Treatment, Care, and Support for HIV infected individuals. The overall strategy emphasized increased health systems strengthening and monitoring and evaluation activities in all nine provinces in South Africa.

USAID awarded the HPCA a Cooperative Agreement, No. 674-A-00-10-00023-00, on December 15, 2009 to be completed by December 30, 2012. PEPFAR, through USAID, provided funds to strengthen the capacity of member hospices and other governmental and non-governmental organizations to provide quality services to HIV-infected persons and their families. The total funding was \$32,730,174.00.

## THE SPECIFIC PROGRAM OBJECTIVES WERE:

- To strengthen and maintain the organizational capacity of the HPCA to manage the PEPFAR project
- To build the capacity of member hospices to provide quality palliative care
- To develop and promote palliative care education and training
- To strengthen provincial Palliative Care structures & develop new Palliative Care sites
- To promote public awareness and policy development in terms of palliative care
- To build the capacity of hospices to care for OVCs and Children requiring Paediatric Care

- To build a responsive M&E system

As an association, HPCA made sub-awards to member hospices, each an independent legal entity. In 2011, there were more than 176 sub-awards in place for health service delivery with more than 200 palliative care delivery sites. The focus of HPCA activities for the Palliative Care Program was aligned with NSP Priority Area 2: Treatment, Care, and Support, Goals 6 and 8.

## **METHODOLOGY**

URSA, with funding from USAID, mobilized three evaluation teams to conduct this evaluation. The approach was a performance evaluation with qualitative data collection using structured interview guides and focus group discussions augmented by quantitative data collection from HPCAs Data management system.

Individuals met included USAID/South Africa activity managers and other staff members, NDOH staff, Department of Correctional Services (DCS), HPCA National staff (CEO, COO, CFO, M&E, Advocacy head and Regional Managers), Hospice Chief Executive, Selected Community Health Workers and Beneficiaries (See Annex C). The data collection tools and interview and focus group guides can be found in Annex D.

## **EVALUATION FINDINGS**

The findings are regrouped under each of the evaluation objectives.

### **1) The Degree to Which USAID-Funded Palliative Care Had An Impact**

Overall the evaluation noted that the HPCA USAID funded palliative care program had made a significant impact on the provision of care in South Africa. A total of 333,027 adults received services from HPCA supported hospices between 2009 and 2012. The number of children receiving care increased from 2,927 to 7,241 in 2012 with hospice assisted OVCs increasing from 5,465 in 2009 to 23,727 in 2011. In addition 3,981 people have been screened for TB and 28,757 counselled and tested for HIV over the same three year period.

To support service delivery HPCA has directly been involved in the training of 46,499 professionals and non-professionals in various courses in palliative care, with 920 of these being government health care workers.

HPCA-supported hospices have grown from 70 in 2008 to over 176 in 2012 under the USAID program.

At the national and provincial levels HPCA and its member hospices have vibrant working relationships with the Department of Health (DOH), Department of Correctional Services (DCS), Department of Education (DOE) and Department of Social Welfare (DOSW). HPCA has also established the National Alliance for Palliative care with members from National Department of Health senior staff.

The evaluation noted an unmet need for paediatric palliative care as not all hospices were funded for paediatric care or OVC. Of patients served in 2012, 93% were adult and 7% were

paediatric patients. Given the relatively large number of households reached, approximately 90,000, and that in South Africa approximately 33% of the population is aged 0 to 14 years (Stats SA, 2012), more can be done to reach children.

The TB portfolio also has room for significant scale up, with the relatively high TB HIV coinfection rates of up to 65% ( Karim et al, 2009), the number reached is relatively low compared to the total (333,027) reached with palliative care.

## 2) Best Practices, Lessons Learned, and Areas Of Improvement

The HPCA/COHSASA standards process is credited with improving both the quality of management and service delivery by hospice management. The star and accreditation system through regular audits is a best practice, which has already been identified and adopted by the government as it seeks to implement the National Health Insurance Scheme.

The HPCA support to member hospices through the mentorship model is a best practice that can be adapted by other implementing partners to strengthen health service delivery. The use of decentralized Centres for Palliative Learning (CPL) and training sites is a novel way to cut down training costs. The number has increased from 10 in 2009 to 19 in 2012.

The Hospice Data Management System (HDMS) is an innovative monitoring and evaluation approach that provides for real-time uploading and analysis of data. The uptake, however, has been patchy with only half of hospices adopting the system. There is need to simplify the system.

Although HPCA started the process of developing a national strategy for palliative care, this activity appears to have stalled and needs to be resuscitated. This strategy will ensure palliative care is not forgotten, as new demands will be created with the rise in HIV associated cancers, adherence challenges, and with increasing life expectancy, the rise of non-communicable diseases like stroke and diabetes, which will create new and different demands on palliative care.

## 3) Recommendations and Future Directions

The most important recommendation is the need for USAID to assist HPCA diversify its funding sources, as it will be in significant danger when PEPFAR support ends. Linkages should be strengthened with the Government of South Africa to take on funding responsibilities for HPCA and member hospices.

The follow on project needs to have clear targets set for the key areas of trainings and service delivery. Specific targets based on evidence, geographical needs, burdens of disease, and service coverage need to be linked to objectives and activities. Quarterly and annual reports should focus on reporting against targets achieved and should have a narrative component to describe bottle necks and best practices. A mid-term evaluation needs to be built into the follow on project to allow for mid-course corrections if needed.

The paediatric and OVC portfolio needs to be prioritized going forward. Stronger linkages between HPCA and Child Health at the NDOH will enable paediatric care to receive focused attention. HPCA should dedicate more resources to training government health care providers

at all levels on palliative care, which will entrench this approach and improve knowledge in the public domain. USAID needs to determine the demand for paediatric and OVC care within target communities to cover unmet needs in the home. Palliative care is home-based and family-centred; going forward, the separation of care into adult and paediatric/OVC care is creating a split and gap in service delivery.

At the developmental level HPCA should devote more resources to its development work with affiliate members and Star 1 and 2 members. This will create a larger impact as a majority of supported hospices are at this level.

# EVALUATION PURPOSE & EVALUATION QUESTIONS

## EVALUATION PURPOSE

- Use evidence to document the degree to which USAID-funded palliative care interventions through HPCA worked or didn't work
- Identify best practices, lessons learned, and areas of improvement
- Provide recommendations to inform USAID's follow-on interventions in palliative care
- The overall evaluation objectives were guided by key questions that examined the development hypothesis of the program, program achievement, health system strengthening activities, lessons learned, key successes and failures, and long lasting benefits to palliative care in South Africa ( See annex for detailed evaluation questions in task order).

## EVALUATION QUESTIONS

- Did the development hypothesis of the HPCA program relate to the achievement of expected results as articulated in the original scope of work? If not, why not?
- What key interventions enhanced or weakened health service delivery efforts? Were there unanticipated results (positive or negative)?
- What were the key results, strengths, weaknesses, and unanticipated results of the Health Service Delivery processes implemented by HPCA under the Palliative Care Program?
- To what extent has the HPCA program informed and influenced the public sector provision of comprehensive palliative care services? Has the HPCA program strengthened health systems in South Africa?
- What key health systems strengthening interventions have been most effective? Least effective? What key lessons learned should be drawn from the success or failure of the HPCA program to inform future USAID program design?
- Are there examples of long lasting, sustainable benefits related to the delivery of palliative care services by the GoSA or other institutions in South Africa that the HPCA program has influenced?

# PROJECT BACKGROUND

USAID awarded the HPCA a Cooperative Agreement, No. 674-A-00-10-00023-00, on December 15, 2009 to be completed by December 30, 2012. PEPFAR, through USAID, provided funds to strengthen the capacity of member hospices and other governmental and non-governmental organizations to provide quality services to HIV-infected persons and their families.

HPCA provided support and coordination to strengthen palliative care programs within member hospices, the formal public and private health care sectors, and non-government organizations (NGOs) at national, provincial, and district levels, in all nine provinces. As an association, HPCA made sub-awards to member hospices, each an independent legal entity. In 2011, there were more than 176 sub-awards in place for health service delivery with more than 200 palliative care delivery sites. The focus of HPCA activities for Palliative Care Program was aligned with NSP Priority Area 2: Treatment, Care, and Support, Goals 6 and 8.

From the outset, the HPCA program had two major components: 1) Health Service Delivery and 2) Health Systems Strengthening. Health Service Delivery primarily included adult and paediatric palliative care, antiretroviral therapy, TB services, OVC services, and HIV Counselling and Testing services. Health Systems Strengthening included development of health coordination networks in the provinces, development of new palliative care sites, human capacity development, advocacy and liaison, and accreditation and quality improvement. Monitoring and evaluation activities were an integral part of all planned interventions.

## PROGRAM BENEFICIARIES

The program has multiple levels of beneficiaries including HIV infected and affected population, local program implementing organizations, and District, Provincial, and National government agencies.

## USAID PROGRAM STRATEGY AND ACTIVITIES

HPCA personnel were funded to expand access to services by strengthening existing systems within member hospices to promote accessibility and availability of palliative care in South Africa at national, provincial and district levels.

One of the two primary aims of the South Africa NSP 2007-2011 is "to reduce the impact of HIV and AIDS on individuals, families, communities and society by expanding access to an appropriate package of treatment, care and support to 80% of all people diagnosed with HIV". The focus of HPCA activities for this Program aligns with NSP Priority Area 2: Treatment, Care and Support, Goals 6 and 8. The support from PEPFAR contributed directly to the provision of services.

The major focus of PEPFAR funding was to provide direct palliative care related services to patients and their families, including TB, OVC, home based care, access to ARVS, HIV prevention and counselling and testing, increase health systems strengthening and monitoring and evaluation activities in all nine provinces in South Africa.

## **BRIEF DESCRIPTION OF IMPLEMENTING PARTNERS**

In 1987 South African hospices decided to form a national association, the Hospice Palliative Care Association, to share best practices amongst hospices. With a vision of “Quality Palliative Care for All.”

The WHO defines palliative care as an approach that improves quality of life of patients and their families facing problems associated with life threatening illness through the prevention and relief of suffering, and the early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual (WHO;2012).

HPCA supports 176 member hospices to provide quality care to adults and children, seeks to build and enhance good governance allied to organizational development, provides training and education in palliative care, promotes awareness on palliative care, and supports good financial practices by conducting financial reviews. In addition HPCA works with the Council of Health Services Accreditation for Southern Africa (COHSASA) to meet quality of care standards for services delivered.

# EVALUATION METHODS & LIMITATIONS

The evaluation approach was a performance evaluation combined with a process evaluation. It was a descriptive assessment with qualitative and quantitative data collection using structured interview guides and data questionnaires.

## DOCUMENTATION OF PROGRAM ACTIVITIES

Prior to qualitative data collection, the evaluation team collected key resource documents from USAID SA and HPCA.

The collection and compilation of documents was done in close collaboration with both USAID SA and HPCA. Available records were categorized, reviewed, and summarized by the evaluation team.

## SELECTION CRITERIA FOR PROVINCES AND SITES:

The total number of eligible hospices for evaluation was 176 hospices in 9 provinces. The distribution of hospices was based on the HPCA star rating system with affiliate members comprising 17%, 1 star grade 26%, 2 star grade 9%, 3 star grade 13%, 4 star grade 5% and 5 star grade 17%.

After discussion with USAID, considerations of timelines and budgets, a total of 34 hospices were selected representing approximately 20% of all member hospices. Random stratified sampling was used in 5 provinces: Western Cape, Northern Cape, Mpumalanga, Eastern and Gauteng. 24% of selected sites were affiliate members, 26% star 1, 12% star 2, 12% star 3, 6% star 4 and 21% star 5. Gauteng has 7 selected sites, Northern Cape 6, Eastern Cape 7, and Kwazulu Natal 8, Western Cape 6 and 1 sites in Free State.

A total of 48 individual interviews were carried, 5 focus groups discussion with a total of 80 community health workers, and interviews with 15 palliative care service beneficiaries.

## QUALITATIVE DATA COLLECTION – IN DEPTH AND FOCUS

### GROUP INTERVIEWS

The evaluation used structured in-depth and focus group interviews [one in each province] with key informants from NDOH, HPCA, and program beneficiaries [See Annex D]

## **TIMELINE**

The evaluation was done over a three week period.

## **DATA COLLECTION AND ANALYSIS**

Three teams carried out interviews and data collection in 4 provinces in the first week. Western Cape, where HPCA headquarters is located, was covered in the second week, and NDOH and DCS officials were interviewed in the third week. All individual organizational documents were collected during the interviews.

Frame work analysis was used for the qualitative data. Answers were coded under broad evaluation themes and entered into a data code book [see Annex E for evaluation matrix]. Emerging themes were noted, based on star rating and geographical differences. Quantitative data was extracted from HPCA's HDMS system, data was tabulated, and illustrative graphs were generated and compared against themes from qualitative interviews

## **CONSTRAINTS AND GAPS**

The purposive sampling approach is open to selection bias. Only 5 of the 9 provinces were evaluated and possible aspects missed out. The short time period limited the scope of the evaluation. The fact that actual service delivery was not observed could also be considered a gap. Data collected was based on interviewee responses with possible recall biases. During the evaluation 4 of the sites were replaced after HPCA advised the evaluation team and this might have introduced some element of selection bias.

The evaluation team addressed these gaps by selecting a mix of urban and rural facilities from the northern, eastern, western, and southern regions of South Africa. To prevent recall bias as far as possible, the evaluation team requested back up documentation.

The findings presented are representative and give a good picture of the reach and impact of the project.

# FINDINGS, CONCLUSIONS & RECOMMENDATIONS

The findings are grouped into the key objective areas as defined by USAID's Scope of Work for HPCA under its Cooperative Agreement . Each finding covers key results, what worked well, and lessons learned, and provides recommendations for future programming in keeping with evaluation objectives and questions.

## **FINDING I: Capacity building, organizational development, national and regional structures**

### ***Governance and capacity building***

This section of the findings seeks to identify HPCA's role in organizational development and capacity building of member hospices..

HPCA is the national coordination body for independent member hospices. Each province has provincial hospice associations including Western Cape, Northern Cape, Kwa-Zulu Natal, Gauteng, Eastern Cape, Mpumalanga, Free State, Limpopo and North West.

HPCA currently strengthens existing services and, through PEPFAR support, provides direct funding to 176 members hospices. PEPFAR is HPCA's largest single donor, providing approximately 90% of organizational funding with a three year budget that began in 2009 amounting to USD \$32,730,173.76. These funds not only support the HPCA national office but also enable HPCA to provide 6 major sub grants as well as 140 contracts and 450 small subcontracts to member hospices. HPCA has put in place financial management systems and tools to facilitate effective grants. These are supplemented by regular field visit audits. The 5 star and 4 star rated hospices receive between 0.5 to 2 percent of overall funds from HPCA. The affiliate to Star 3 hospices receive between 20 to 70 percent of funds from HPCA. HPCA is a registered section 21 organization in South Africa with a staff complement of 72 , up from 42 in 2009. A board of governors composed of a Chairperson, Provincial and co-opted directors, the CEO, COO, CS, and CFO oversee the work of the Chief Executive officers and her Management Committee (MANCO).

There are three key committees comprising Human Resources, Audit, and Ethics Committee which serve a critical oversight and leadership role. The committees report directly to the HPCA board.

The MANCO, in addition to the CEO, COO (who serves as the PEPFAR principle investigator and primary business official), CS, and CFO, also includes 4 Regional managers and a Monitoring and Evaluation manager. The regional managers oversee provincial core teams that comprise palliative care development officers, M&E officers who work with the provincial hospice associations, and partner organizations.

Organizational development, advocacy, education, finance, paediatric and palliative care, and monitoring and evaluation committees report directly to the CEO. Each of these technical committees is headed by a technical officer with supporting administrative and program staff.

The MANCO provides overall strategic guidance to HPCA, sets performance standards, and acts as the principle liaison with government and other partnerships both within and outside South Africa. MANCO quarterly meetings provide a forum to discuss issues emerging from the fortnightly technical review meetings.

HPCA has clear policies and guidelines for human resources management including job profiles and descriptions, and regular performance management is undertaken through appraisals and feedback to all staff. HPCA has strong governance guidelines with quarterly board meetings, and fortnightly technical and administrative management meetings.

Grants management activities extend from pre-award assessments, to contract approvals, monitoring of sub grantee expenditure through monthly reports as well as regular in-field audits and financial reviews to ensure compliance with US Government funding regulations.

The HPCA supports member hospices, through direct funding and mentorship, to provide palliative care to families within community settings. Each member hospice receives dedicated support to improve governance, leadership and management and is assisted to expand service delivery through training, education, workshops, mentorship, provision of guidelines, and supervisory support. At the national level, HPCA has taken the lead in enhancing the profile of palliative care in South Africa. The number of hospices has grown from 70 in 2008 to over 176 in 2012, as a direct result of this support.

Each individual member hospice is an independent Section 21 company that signs an MOU with HPCA, which clearly defines roles, responsibilities, and deliverables related to funding, capacity building, service delivery, risk management, and monitoring and evaluation.

All the evaluated hospices have an overall board that draws volunteer membership from the surrounding communities. The boards all have strong human resource, fundraising, networking and financial management committees. The hospices also have management committees composed of finance, administrative, and technical staff. Strong emphasis is placed on fundraising and networking. The majority of the hospices are led by non-medical staff with a long history of association with palliative care work, many coming through the ranks from the volunteer level. The decision to have a non-medical person in these positions is informed by the need to use any technical staff in service delivery. Clear administrative and financial policies were in place for all hospices ranging from organograms with clear lines of authority and reporting, updated job descriptions with job responsibilities, staffing plans, and disciplinary measures and personnel files. These clear systems that are consistent across all evaluated hospices are a direct result of HPCA support through PEPFAR.

The hospices all have large volunteer pools ranging from 12 to 127. Each volunteer undergoes rigorous assessment, with planned orientation and development plans, and they all sign a memorandum of agreement and yearly job descriptions. The role of volunteer is a historical and strong feature of hospice works in South Africa since 1980 when the initial hospices were established.

There is a clear link between rating levels as determined by the Council of Health Services Accreditation for Southern Africa (COHSASA) standards and the quality of management and administrative systems. This link is explained in the section on accreditation. HPCA's overriding mission is to constantly improve these systems and by extension improve service delivery by member hospices.

Clear financial management systems were in place including designated financial managers, budgeting processes, and regular audits by both HPCA and external auditors. Most hospices had fundraising as a major component with a Hospice Shop and designated fundraising committees in the larger hospices, though in many cases the chief executive played the role of fundraiser as well. Evaluated hospices noted that their financial health is directly attributable to HPCA support.

### ***Standards and Guidelines***

HPCA has developed national standards for governance, management and palliative care and conducts surveys to assess compliance with these standards. Hospices are mentored towards receiving accreditation from COHSASA and to maintain this accreditation.

By setting standards, HPCA has played a critical role in professionalizing palliative care in South Africa.

Guidelines for patients' right, gender, tuberculosis management, paediatric care and sustainability have also been developed by HPCA.

Most of the guidelines are currently in their second editions, indicating regular review and updating by HPCA.

### ***National and Regional Structures***

At the national level, HPCA has been supporting the National and Provincial Departments of Health (DOH) to implement palliative care in South Africa by working on a draft national strategy for palliative care, as well as constantly advocating for palliative care in existing HIV and other Health service delivery policies and plans. HPCA has also supported the national strategic plan for HIV & AIDS, TB, STIs, and a number of HPCA staff has served on SANAC technical task teams. The Government has called in HPCA to ensure palliative care is incorporated in the process of re-engineering Primary Health Care in South Africa.

The provincial palliative care structures set up by HPCA play the main role in providing capacity building support to member hospices. The provincial core team comprising the HPCA regional manager, Provincial mentors, Palliative care coordinators, Palliative care development officers and M&E officers work with member hospices to develop and maintain standards of care. These standards are contained in the HPCA/COHSASA hospice palliative care standards document. Provincial associations tap this structure to access training for their organization as well as ongoing mentorship support.

Regional hospice associations at the provincial level, which include the HPCA provincial staff, operate as semi- autonomous bodies that oversee and fulfil training requests, coordinate quarterly educational forums, work with the provincial department of health, and hold coordination and networking conferences. Requests for training and support emanates from

grassroots member hospices and is passed onto regional HPCA staff. The provincial associations also coordinate the selection of potential member hospices and then recommend them to HPCA for a pre-support and qualification survey before they are bestowed with affiliate status and begin the internal process of star ratings and surveys, which culminates in the external COHSASA accreditation.

HPCA holds yearly national conferences, inviting member hospices to a forum that serves as an avenue to disseminate the latest updates on palliative care. This forum also serves as an avenue for networking, something the hospices really appreciated. Some hospices felt that at times these conferences were too academic and did not focus on the day to day challenges of palliative care in South Africa.

There was a noted difference between the provincial structure as articulated in HPCA strategy document and existing structures in the field. In particular the Palliative Care Development Team was a term that was unfamiliar to almost all the evaluated hospices with most only aware of the provincial mentors and coordinators.

Member hospices spoke highly of the mentorship model and standards rating system. The HPCA staff at the regional and national levels were characterized as being extremely motivated, always available to help, and providing support that was unobtrusive and invaluable to maintaining organizational and service standards.

It was noted that high staff turnover in HPCA was a concern with some of the provinces being particularly affected. The majority of the mentors were non-clinical staff and hospices felt this was a gap as service delivery staff did not regularly benefit as much from mentorship.

### **Conclusion**

- The number of hospices has grown from 70 in 2008 to over 176 in 2012, as a direct result of PEPFAR funding to HPCA.
- HPCA has played a critical role in professionalizing palliative care services in South Africa. Its mentor model, supported by its HPCA/COHSASA standards rating system, has demonstrably improved organizational capacity and is a best practice.
- HPCA is the principal funder for most of the lower rated hospices and while efforts have been made to improve their fundraising abilities, most depend on PEPFAR support for sustenance. This is an unintended consequence of the support, which may have created dependency.
- The organizational strengths that are a result of the mentorship system appear long lasting as there is tremendous buy-in.
- HPCA is the leading organization in the Southern Africa region in the development of organizational and clinical practice guidelines for palliative care.
- The key weakness is an inadequate mix of clinical and non-clinical staff amongst the provincial mentors. This has potential to weaken the quality of clinical services offered by hospices.

### **Recommendations**

- Key Recommendation 1: The HPCA programme mentor model is a best practice that needs to be adapted by other implementing partners to strengthen the health system.

- Key Recommendation 2: USAID needs to support HPCA to diversify its funding sources, as it is in significant danger should PEPFAR funding stop. Linkages should be strengthened with the Government of South Africa to take on more of the funding responsibilities. This support should also extend to member hospices that depend on majority funding from HPCA.
- HPCA should have a mix of clinical and non-clinical staff as provincial mentors.

## **FINDING 2: System Strengthening: Government Collaboration, Advocacy, Liaison and Public Awareness**

### ***Government Collaboration***

This section explores HPCA's role in strengthening the health systems, its work with government of South Africa, and its advocacy role in raising awareness of palliative care.

The evaluation noted that the National Department of Health and the HPCA have a very close working relationship both at the national and regional levels. HPCA contributes to several SANAC technical task teams. The government has enrolled HPCA as a key partner to support the re-engineering of primary health care. HPCA has been tasked by the NDOH to lead the task team that is developing standards for non-communicable diseases on the basis of HIV being considered now a "chronic manageable illness." Unfortunately for our assessment the knowledge and awareness of the place and role of palliative care at the NDOH is still low due to frequent turnover of staff, as the predominant view is that it is care for the bed ridden or dying. Though the NDOH is a member of the Alliance for Access to Palliative Care, this forum is perceived as HPCA owned and attendance by government staff is patchy at best. Going forward, it appears that the government's re-engineering of PHC will depend heavily on the role of community health workers, the majority of whom are trained and supported by HPCA. This re-engineering has potential to overwhelm existing capacity.

In January 2009, HPCA began a pilot project with the Department of Correctional Services (DCS) in Kwa Zulu Natal. The focus of this project was to equip health staff within the DCS with skills to provide palliative care to offenders. HPCA worked with DCS to provide training, mentorship, and referral linkages, as well as advice on medical paroles for offenders. The MOU that was signed between HPCA and National DCS initially targeted four professional nurses and twenty inmates for training in palliative care from Westville prison and New Prison in Pietermaritzburg in KZN. Currently DCS staff is represented at Hospice association meetings at the regional level and their doctors are mentored on working with inter-disciplinary teams to provide palliative care. Hospice doctors also provide direct mentorship support to Westville prison twice a month. HPCA has also ensured drugs for palliative care are available at the prison health facilities. The project has been rolled out to Western Cape, Eastern Cape, and Gauteng with plans to roll out to other provinces.

The Hospice and Palliative Care Association (HPCA) and the Department of Defense (DOD) have also signed an MOU to implement a palliative care programme at St Luke's Hospice in Kenilworth in the Western Cape.

Under the PEPFAR Grant, HPCA was to coordinate the development of a national palliative care strategy. The draft document was developed in late 2010 but has still not yet been finalized. The reason given is that government is busy with the policy on re-engineering primary

health care. Provincial Departments of Health in tandem also started the process of developing provincial palliative care strategies and HPCA, sensing more progress at this level, have now switched focus to support the provincial processes. While this approach allows for the advancement of care at the regional level and enables HPCA to use its considerable regional knowledge base, the lack of an overall guiding document for palliative care in South Africa remains a major gap, and renewed efforts should be made to restart the process of finalizing the strategy.

At the regional level, HPCA has individual MOUs with provincial departments of health to assist in training community health workers and health care providers, and in service delivery improvement for HIV and TB. Through this support HPCA has trained close to 920 government health care providers in palliative care and TB support, thus contributing directly to strengthening the health system. These providers have been trained using HPCA funds upon direct requests made by NDOH and provincial DOHs. This is a good start, but given the large number of public sector health care providers is still a relatively low number.

Provincial DOH work directly funds member hospices to provide home based care, in the majority of cases contributing between 40% and 80% of the budget directly utilized for HIV and TB related home-based care for most of the evaluated hospices. This support helps hospices to recruit and pay community health workers. A significant number of Community Health Workers are able to provide services because of this government funding. In addition, hospices access treatment for Tuberculosis and pain management and refer clients for antiretroviral therapy to government clinics. Hospices have individual MOUs with NDOH to provide this support, often receiving up to ZAR 300 per patient supported.

Member hospices reported easy access to medication for patients. Hospice doctors write out prescriptions that are honoured at all government pharmacies. Patients are also referred to government clinics to access antiretroviral therapy, TB medications, and treatment for opportunistic and common infections. Additionally, hospices have been able to access health accessories including gloves, gauze, and other materials to undertake home based care. Patients are referred to government hospitals and clinics for further specialized care and others are referred to hospices for palliative care. There is no formal referral system in place in terms of referral letters or feedback forms. Also it might be useful for many of the hospices if some of these critical medications like antiretrovirals, TB medications, and essential drugs were available on site to minimize travel for patients.

In terms of national, reporting all the hospices report monthly to the NDOH using nationally-approved reporting templates and actively participate in national events and health campaigns, like the HIV testing campaign, national immunizations, child welfare, and World AIDS and TB days.

A unique feature of government collaboration was the fact that the government provides space free or at subsidized rents to many hospices. In some provinces hospices are located within government hospitals and most have direct service delivery relationships.

The majority of hospices have good working relationships with regional NDOH. In some hospices DOH staffs serve as board members and also contribute expertise, knowledge and

services when called upon. In addition hospices have close collaboration with other departments including the police, Department of Education, and Department of Social Welfare.

### **System Strengthening**

System strengthening undertaken by HPCA seeks to support the NDOH to strengthen the health system at district and sub-district levels with a focus on the WHO framework of service delivery, leadership, governance, strategic partnerships and strengthening health information systems. HPCA was mandated by USAID SA to establish health and welfare networking forums to strengthen care and support to community members. This support was necessitated by the need to prevent duplication of services, as several partners were working within the same communities. “A community health worker would leave a house only for another one from another organization to enter the same house to provide similar services.”

The initiative was piloted in 10 hospices in 2009 with the development of a Health Systems Strengthening Programme manual. Ten member hospices were initially funded by HPCA to coordinate the development of the network forums to improve coordination and raise awareness not only of palliative care but also primary health care and government health initiatives within 10 sub districts. The systems strengthening has, however, been faced with challenges as it appears most hospices started the process, which they bought into fully and enthusiastically, but then stopped implementation as funding for this activity was discontinued. Implementing hospices spoke very highly of the crucial role this networking forum was playing in mapping key partners, ensuring coordination, and assisting monitoring of health services. Unfortunately this program is driven exclusively by HPCA, and NDOH staff consider the network to be “Hospice affairs.” Overall, the DOH has not been receptive to the Health Systems Strengthening (HSS) forums established by hospices despite there being no other effective forums in many of the health sub districts.

### **Public Awareness**

HPCA has held and continues to hold national campaigns using celebrities to promote palliative care. The organization plays a critical role in articulating that palliative care is not just “dying care.” HPCA also has working relationships and MOUs with Networking AIDS Community of South Africa (NACOSA), and the Cancer Society of South Africa (CANSA). HPCA is partnering with Big Shoes and formed the South African Children’s palliative care network, which provides support to improve paediatric clinical care. HPCA also has an initiative to train traditional healers in palliative care.

At the regional level hospices are heavily involved in community outreach. Most have strong working relationships with the local media, getting radio spots and receiving strong support during fund raising and promotional drives. Hospices hold public demonstrations, creation-awareness days like “Hoot if you care” and candle light awareness campaigns. These campaigns have had a strong impact in raising the profile of palliative care.

Many hospices have vibrant volunteer bases and strong links within the community including business and opinion leaders, who serve in hospice boards and dedicate time to fundraising.

Individual and regional hospices have working relationships with organizations like St John’s Ambulance, Rotary club, Guild and Women’s forums, Universities like Free State, KZN, Cape Town, Churches, and other non-governmental institutions.

## **Conclusion**

- HPCA at the national and regional level has a vibrant working relationship not only with National and Provincial DOHs but also DCS, DOD, DOE and DOSW. The NDOH is a member of the Alliance for Access to Palliative Care, though knowledge about palliative care is still poor at the NDOH due to frequent turnover of staff.
- The government re-engineering of PHC will depend heavily on the role of community health workers, the majority of whom are trained and supported by HPCA. This re-engineering has potential to overwhelm existing capacity.
- HPCA has contributed directly to strengthening palliative care service provision within the government by working with DCS to implement palliative care in prisons. In addition HPCA has trained over 920 government health care providers in palliative care. This number is relatively low given the large number of public sector health care providers in South Africa.
- The Government also contributes directly to palliative care provided by member hospices, signing individual MOUs with many of them to provide TB/HIV services and home-based care through community health workers, often contributing between 40% to 80% of staff salary budgets. In addition, it provides drugs and other medications, space, and technical expertise of its staff members, who sometime sit on hospice boards.
- The health systems strengthening activity supported by HPCA to improve district level partner coordination had a promising start but has stalled due to poor government buy-in and funding delays.
- HPCA and its member hospices carry out regular advocacy and promotion campaigns that continue to raise the profile of palliative care.

## **Recommendations**

- Key Recommendation: HPCA needs to rededicate its efforts to ensuring the draft palliative care strategy is completed and implemented. This document will provide strategic guidance to ensure palliative care is not forgotten, with the increase in life expectancy of patients on ARVs, HIV associated cancers, ARV adherence challenges and non-communicable illnesses like stroke and diabetes will become increasingly important.
- The recent move by NDOH to relocate HPCA's work to non-communicable disease needs to be carefully monitored to ensure HPCA does not step outside its core mandate of palliative care.
- The support provided to DCS is worthy of replication to other prisons in South Africa, but clear roles need to be defined for both parties, and emphasis needs to be placed on ensuring quality of services, as this component appears to be missing.
- Member hospices should have critical medications like antiretrovirals, TB medications, and essential drugs on site to minimize travel for patients.
- The health systems strengthening activity needs to be redesigned and NDOH should be the lead with hospice only playing the role of catalyst.

## **FINDING 3: Education and Training**

### **HPCA Role**

This section examines the role of HPCA in strengthening palliative care training in South Africa. The evaluation established that HPCA is a premier organization in the provision of palliative

care training in South Africa. HPCA has helped establish 9 centres for palliative care learning (CPL) and 13 training sites in all 9 provinces in South Africa. These centres and training sites are run by member hospices and provide HPCA-accredited trainings to other hospices, interested organizations, and individuals at a fixed fee. Training sites are in place to supplement the CPLs should the demand in the area exceed the capacity of the CPL.

The first formal course developed was a 6 month short course in palliative nursing for professional nurses in 1994. Since then HPCA has developed over 14 Health and Welfare Seta (HWSETA), quality assured short courses for multi-professional and non-professional health care practitioners.

The organization also has provincial education forums with a selection of qualified professional nurses, social workers, and doctors with experience in training that provide support to the CPLs. HPCA has trained 46,599 professionals and non-professionals since 2009, with the majority of providers trained in 2010 (Graph 1 below)

As an accredited service provider, HPCA offers ancillary Health Care NQF level 1 and 2 Community Health Work training. These are targeted at community-based and home based caregivers and provide an opportunity for a career path in the health care field.

There are also provincial education forums that supplement the work of the CPLs and training sites.

In terms of training targets the USAID/HPCA time-phased work plan has a target of 10,000 learners trained per year, but this is not broken down into specific cadres and training courses.

At the national level, HPCA have supported the integration of palliative care training at the tertiary level resulting in a post graduate diploma and MPhil in Palliative Medicine being offered through the University Of Cape Town (UCT). The Chief executive of HPCA is also a senior lecturer at UCT. HPCA also has a leadership development programme developed for the purpose of providing management training to personnel in non-profit, community-based organizations and health and welfare sectors. So far this programme has helped train 123 leaders from provincial governments and other partners, and is a significant contribution to strengthening health leadership in South Africa.

Regional associations assess training needs yearly and develop training plans which HPCA assists to implement through the CPLs and training sites for member hospices. All training requests emanate from the member hospices. The majority of the hospices were happy with the current arrangement, although some complained about the distance to CPLs for some trainees and the added expense of daily travel since the trainings are usually non-residential. The CPL system is reactive to these needs. This makes it difficult to determine what capacity CPLs can handle.

### Courses offered by HPCA

- Introduction to Palliative Care
- Home Based Care
- Bereavement Support Care
- Short Course in Palliative Nursing Care
- Teacher's Bereavement Course
- Psychosocial Palliative Care
- Leadership Development Programme
- Train the Trainer
- Introduction to Paediatric Palliative Care
- Home Based Paediatric Palliative Care

From the evaluation it was clear that palliative care training is currently not aligned to government training plans or needs. Training activities are almost purely targeted at member hospices (with the exception of 920 government providers trained). This means little contribution is being made directly towards building public sector capacity.

A specific complaint was received about the Palliative Care Level 3 training which is aimed at non-professionals but is too technical, “using words like maleficence and beneficence....terms that are difficult to understand for a layperson.” Almost all the CHW have only elementary levels of knowledge, the training is in English. “What is palliative care in Sesotho?” “The training is very theoretical; we need more visual aids,” noted another CHW.

Evaluated hospices noted the need to strengthen the post training mentorship support, which was assessed as weak. “In particular the community health workers who undergo just a few weeks of training need to be closely followed up and supported as they start with very low skill levels and need significant support to develop and maintain competency.”

Hospices noted that there is often a long delay between training and post training follow up support, and trainings were usually done with very short notices.

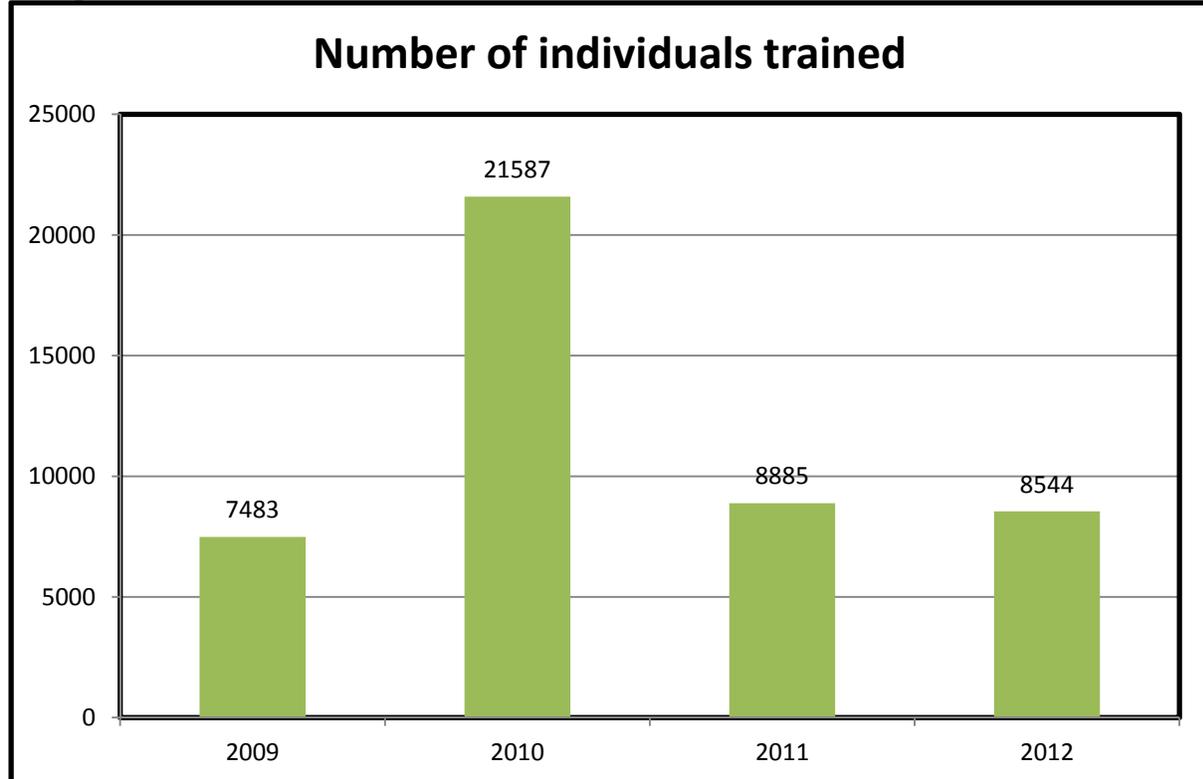
The CPL training mode is non-residential and decentralized, and this is a good model for reducing the cost of traditional training courses; however, several hospices noted that associated costs like daily travel to CPL and accommodation costs can be prohibitive.

The training courses provided at the CPL and training sites requires all participants to make upfront payments.

In terms of training innovation, HPCA is piloting two initiatives. The first is legal training. The aim of this training is to integrate legal information for patients. This was necessitated by a needs assessment in 2007 that showed legal, social, and practical problems were impacting negatively on the quality of life of patients. This led to the standards document developed by HPCA entitled the “Legal Aspects of Palliative Care,” published in 2009. The training seeks to capacitate staff on recognizing and respecting the rights of patients, and assist patients to exercise these rights up to and including end-of-life concerns. This is a first of its kinds training in the country.

The second initiative is capacity building on gender. This support is not directly funded by PEPFAR but was included for assessment as gender related issues are an integral part of the HIV responses, given the effects of HIV and AIDS on Women in South Africa (Shisana et al: 2010). HPCA has developed gender guidelines with support from CIDA. The guidelines are intended to address an imbalance rather than shift focus away from boys and men. The guidelines seek to promote gender sensitivity at the hospice level. These include addressing gender-based violence, supporting the girl child, and supporting single parents, including single fathers.

Graph I: Number of individuals trained in HPCA courses since 2009 [Source: HDMS, HPCA, 2012]



### **Conclusion**

- HPCA is the central organization in the provision of palliative care training for professionals and non-professionals in South Africa, with a total of 46,499 professionals and non-professionals trained in palliative care. The disaggregation for the figures in terms of provinces and cadre numbers trained was not available.
- The use of decentralized centres for palliative learning (CPL) and training sites is a novel way to cut down training costs.
- Training is done based on requests from the field and not necessarily on assessed needs and requirements. This is a potential weakness. The HPCA MER plan does not have specific targets aligned to training, and data collected is not disaggregated by cadre. It makes it difficult to determine the capacity of CPLs and training sites
- HPCA has only trained 920 health care providers from government institutions.

### **Recommendations**

- Key Recommendation: HPCA needs to have specific targets for training based on assessed needs for each province. Training numbers need to be better captured.
- The bottom up training approach, where each hospice determines its needs, means HPCA has no way to determine beforehand regional imbalances in training need. Thus training gaps are not determined and filled; this should be

changed and training gaps mapped beforehand, with training targeted towards regions and hospices that most need the support. This should be based on service demand and health worker capacity.

- Training data needs to be disaggregated based on course and professional targets to better determine impact. This is impossible to do with current information.
- Training content needs to be tailored to meet needs of trainees, including translating into vernacular and providing more visual aids and hands-on practicals.
- HPCA needs to be aligned and include government training needs and priorities to ensure capacity building of the public health system. Building public sector capacity should be prioritized.

#### **FINDING 4: Service Delivery**

The section on service delivery describes the contribution of PEPFAR funding towards service delivery in palliative care. The evaluation noted that, in general, approximately 97% of palliative care is provided by HPCA member hospices within the home setting, with the remaining 3% provided as in-patient care.

Historically palliative care in South Africa has been centred on care for chronic but terminal non-communicable diseases, like cancer, stroke and other debilitating illnesses. This was the role and traditional mandate for all the hospices established before 1990.

The need to respond to South Africa's twin HIV and TB epidemics has had a profound effect on the functioning of hospices in South Africa. The service delivery mix, and this applies to the older 4 and 5 star hospices, has changed to 40% care for the chronic non-communicable illness and 60% care for HIV and TB. The more recently established hospices, and these include the affiliate members and 1 to 3 star hospices, have a service mix of between 70% and 100% HIV and TB care.

HPCA at the national level has played a critical role in transforming its home care model, which depended exclusively on professional nurses, to adapt the huge service demands necessitated by HIV and TB. The roots of this transformation can be found in the model developed and piloted by the South Coast hospice in rural Kwa-Zulu Natal in 1996. This model christened the integrated community-based home based care (ICHC), uses trained lay- community caregivers, supervised by professional nurses, to provide home based palliative care to patients and families and includes basic clinical care, HIV prevention and education, psychosocial, spiritual and social service support. The programme is backed by the local PHC clinic and government hospital that supply medication and back up emergency interventions or admission as required.

PEPFAR support has allowed palliative care provided at the community level to evolve and to focus on specific groups or settings including adult palliative care, paediatric palliative care, OVCs, TB and Support Services.

#### ***Quotes from Beneficiaries on Care***

“Without this care...I would be dead...they came to my home and brought me here..I was crippled. Could not eat...now it is like I am reborn”

“The people at the hospice really care for us...they wash us clean...teach us to hope and want to live again”

## **Adult Palliative Care**

Adult palliative care is holistic care that includes home based and day care, outpatient services, and provision of psychological services including counselling and bereavement support. It also includes spiritual care. Clinical services provided include bed births, symptom and pain management (most hospices have opioids but need to refer patients out for other medications).

As mentioned, the majority of the care is provided at home. Inpatient care is extended to families that need temporary respite from caring for a chronically ill family member. Inpatient care according to HPCA guidelines is only recommended for two weeks and is done to allow for management of chronic disease complications including pain control, nutritional support, and decompression of lesions that cause pressure symptoms. Our assessment found that many hospices, particularly the star 1 and affiliate members, admit patients for periods of a year or more.

The evaluation noted that Community Health Workers are allocated specific geographical locations to visit and according to government guidelines should work for 5 hours a day and provide services to approximately 120 patients a week. The current monthly pay is pegged at ZAR 400 (USD 50), with almost all hospices supplementing this pay to ensure CHW stay motivated. Each CHW is required to clearly document each patient served. Patients are categorized into 3 groups, with Category 1 patients being ambulatory, 2 semi-ambulatory and 3 bed-ridden. There are clear guidelines on type and level of services offered to each category of patient.

### **Quotes from Community Health Workers**

"We teach families how to support patients... we provide emotional and psychological support."

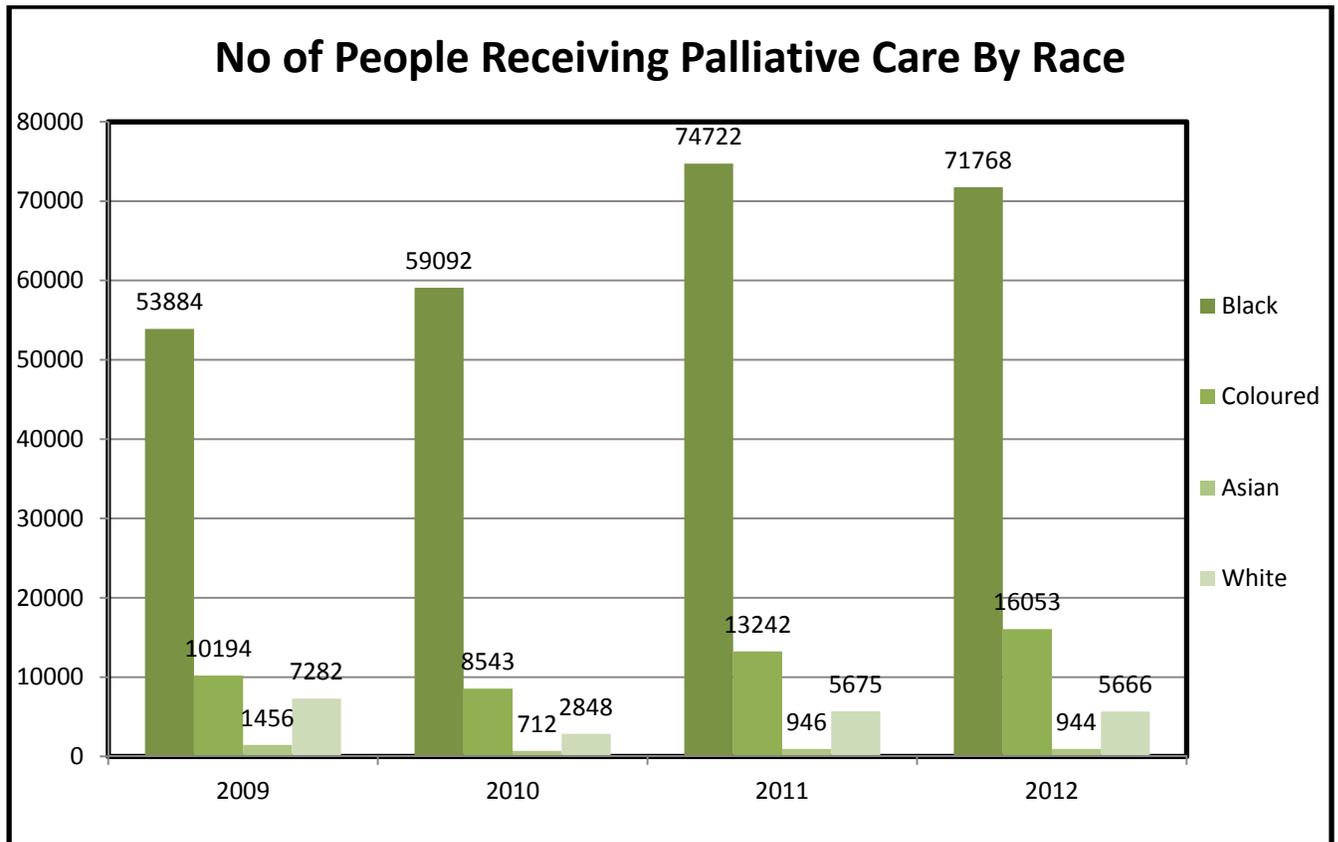
"Every morning we meet and discuss patient conditions... we are supported by the nurse."

"Sometimes we go there and cook, bath them, make sure they eat are comfortable and clean...it is hard work and we face hardships."

Home based care is difficult work and often the providers, who come from the communities they serve, are also HIV+ themselves and need support for their own emotional needs. The nurse plays an important role in ensuring CHWs receive ongoing training. The CHWs appreciate the support they receive and speak highly of their sense of pride in being able to offer care within the community.

Many feel more confident and though the pay is little, it provides some lessening of financial burdens. Many also complain that not having a specific uniform means they lack recognition. In those hospices where providers had uniforms, they noted with pride the sense of belonging they felt. In the past, uniforms were considered to stigmatizing for families and were abolished.

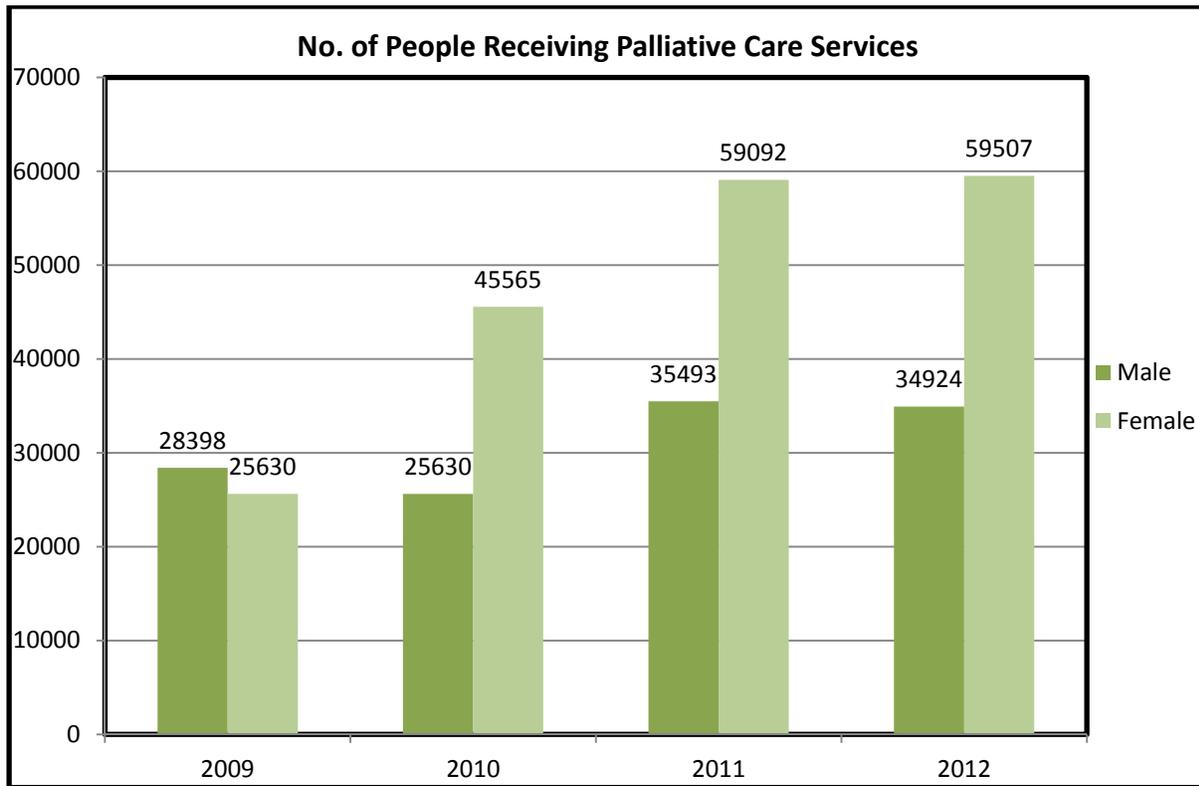
Graph 2: No .of People Receiving Palliative Care By Race 2009-2012 [Source HDMS, HPCA, 2012]



As seen from Graph 2 above there has been as steady increase in people receiving palliative care each year since PEPFAR support started in 2009. A total of 333,027 adults have received palliative care services with numbers increasing from 72,816 in 2009 when HPCA started receiving direct PEPFAR support to 94,431 in 2012. Disaggregated data shows that 77.9% were black, 14.4% were coloured, 1.2% Asian, and 6.4% White. The increase in number of blacks receiving palliative care could be due to HPCA support to newer hospices located in regions with predominantly black populations.

The PEPFAR time-phased work plan did not have specific targets for adult palliative care, making it difficult to determine progress and achievements.

Graph 3: No. of People Receiving Palliative Care By Gender 2009-2012 [Source HDMS, HPCA, 2012]



Graph 3 above shows the gender balance of services provided. Note the increase in services provided to women with slight decrease and then slow increase for men. This could be explained by the disproportionate number of women affected by HIV, and the poor health seeking behaviour of men, who often only seek testing and care when acutely symptomatic [WHO;2002b]. Another possible reason is that majority of CHWs are female, many reported that men often do not want to receive services in their homes from female CHWs. These gender differences are worthy of further exploration.

It was not clear from the guidelines what the optimal mix of professional nurse to CHW was; we found ranges from 1 to 3 all the way to 1 to 20. Considering nurses need to provide hands-on support, mentor, and supervise, guidelines are needed.

### **Paediatric Palliative Care**

HPCA has a paediatric care advisor who works closely with member hospices to improve services to children. The evaluation team noted that not all hospices provide paediatric palliative care. This appears to be a worrying gap since the essence of palliative care should be family centred care. Paediatric care is provided as a package for children aged less than 14 years. It includes outreach to children in the home and involves assessment for clinical conditions, nutritional assessment, screening and management of symptoms, and referrals. Screening extends to TB, as well as vulnerability assessment using the HPCA score card. Health education is provided to family. Social support is a major component of paediatric care including referral to Welfare to process grants, obtain clothing, access to nutrition food packages for children not on social grants.

The PEPFAR time-phased work plan set a target of 15,000 children to be reached by the end of 2009. The remaining two years had no specific target.

HPCA, working with Big Shoes Foundation, has developed clinical guidelines for paediatric care and these are used by hospices. Paediatric patients are also referred for HIV testing and counselling to PHC clinics and government hospitals.

During focus group discussion, many CHWs indicated that care for children was complex. Many felt inadequately trained to handle the needs of children. They mention that poverty is a challenge and lack of clinical personnel to handle children's issues is a significant barrier to service provision. Mismanagement of social grants, alcoholism, and breakdowns in social structure placed an extra burden on children.

The reason given for not providing paediatric services for was "we are not funded for paediatric services." Many mention that at almost all households they went to, they found children who could and might benefit from services. There is a large unmet need for paediatric services. In graph 4 below, it is noted that HPCA has been able to more than double support from approximately 2,927 children reached in 2010 to over 7,241 in 2012. This is for a total of 13,237 served .

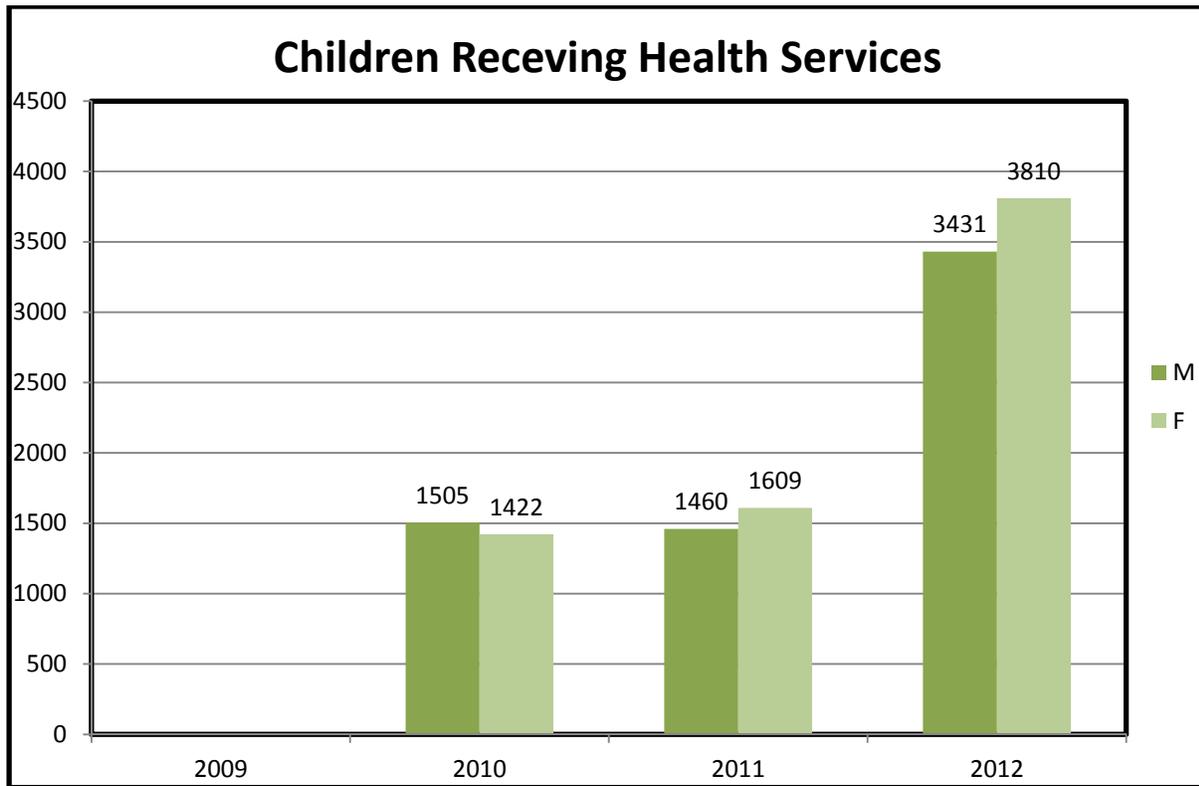
As can be noted from Graphs 4 and 5 below there is a large, unmet need for paediatric care. Of patients provided palliative care so far in 2012, 93% are adult and only 7% are paediatric. Statistics South Africa indicates that for mid-year 2011, approximately 33% of the population is aged 0-14 with a HIV prevalence of 3% ( StatsSA, 2012; UNGASS, 2012). The actual gap needs to be determined based on geographical prevalence, population, and service delivery needs.

#### **QUOTES ON PAEDIATRIC CARE- HOSPICE STAFF**

"We are not reaching all the children we can reach...look at the number of households we serve and the number of children we currently provide for...we are not getting enough funds....and the human resources are not sufficient."

"Children's needs are complex... you need confidence and training to deal with them."

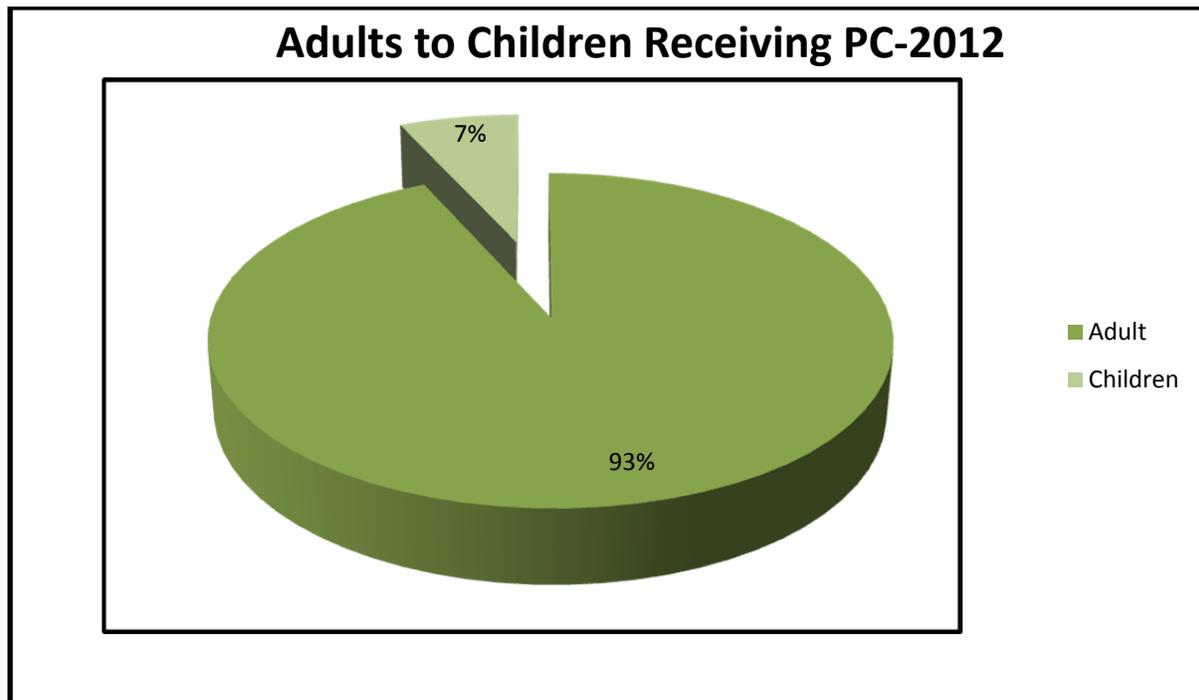
Graph 4: Children Receiving Health Services by Gender 2009-2012 [Source: HDMS,HPCA 2012]



The Paediatric palliative care portfolio manager, together with Big shoes Foundation and UKZN, has drawn up a proposal to pilot the integration of Paediatric palliative care into the health services in KZN. The proposal has been accepted and HPCA is still waiting for a response from DOH.

From our assessment the NDOH does not consider paediatric palliative care as a special sub component of overall palliative care. HPCA is working to meet with the head of paediatrics from NDOH to establish a partnership for integration of paediatric palliative care in the home based care setting together with Primary Health Care teams.

Graph 5: Proportion of Adults to Children Receiving PC-2012 [Source: HDMS,HPCA 2012]



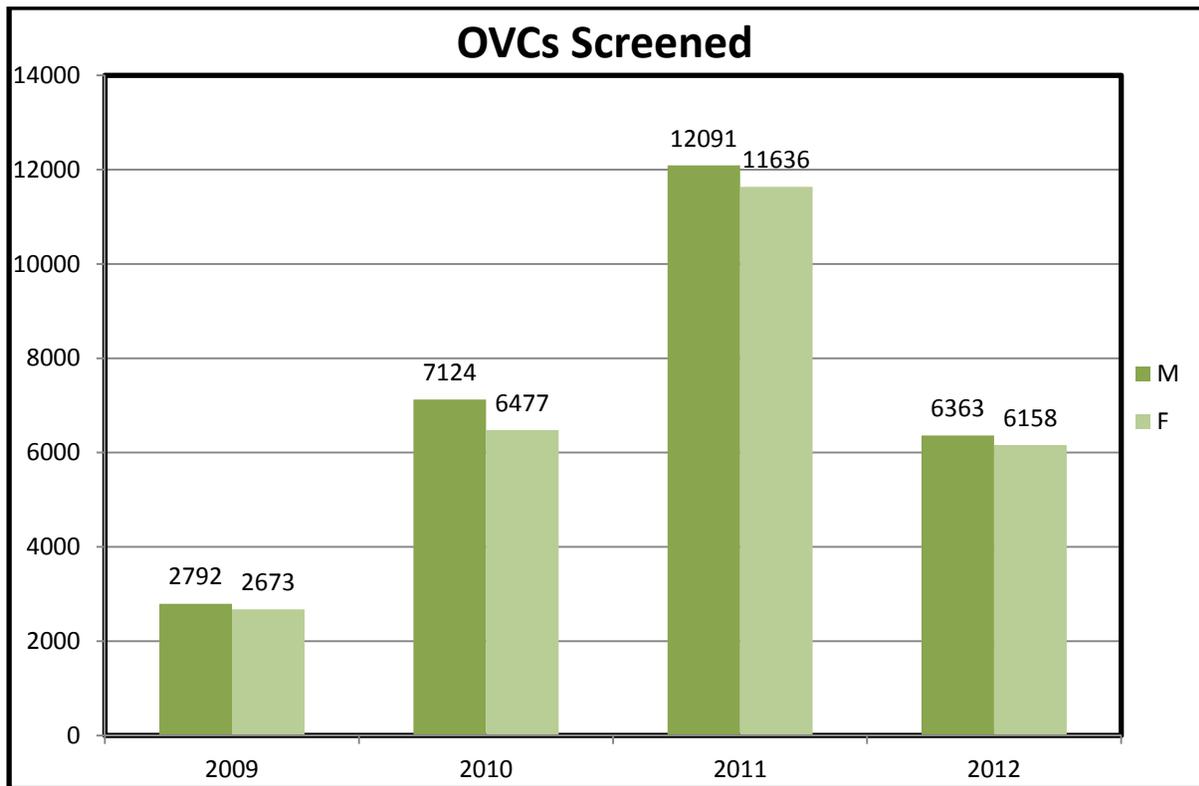
### OVCs

Much like paediatric care, OVC support is provided by only a select number of hospices. The main organization funded to support OVC work is St Nicholas Bana Pele in Free State. This support includes assessments using HPCA's vulnerability score card, linkages and referrals to child welfare services, social grants, Department of Home Affairs for birth registration, access to education, and nutrition. The OVC support is provided by social workers who evaluate children and provide counselling, memory training, and bereavement and spiritual care and counselling.

Several hospices also have linkages to legal and protection services to cater for abused children and provide safe havens for abandoned ones. Hospices also assist with emergency support for uniforms, food, and transport as and when the need arises.

Data from graph 6 below indicates that support from HPCA has dramatically increased screening for vulnerable and orphaned children from approximately 5,465 in 2009 to over 23,727 in 2011, a fourfold increase. The numbers have dropped off in 2012 due to reduced funding for the OVC portfolio. Please note the figures do not indicate a unique child served and includes an element of double counting as one child may get more than one OVC service in a year. The HDMS system is being adapted to capture just unique numbers.

Graph 6: OVC Screened-2009 to 2012 [Source HDMS, HPCA2012)



## TB

All hospices provide Tuberculosis support services. Many work directly with provincial DOH and have signed MOUs to take care of a specific number of patients; in return they are funded to cover CHW salaries. Most of the TB work consists of supporting the national DOTS programme ensuring patients take their TB medications in the community. CHWs also track down defaulters and refer them to restart treatment. CHWs also screen all household contacts of TB patients and refer them to hospitals for TB tests.

The collaboration with government appears to be working well and the supervision and support by technical officers including reporting is extensive.

The hospices report intensive door to door campaigns with DOH staff to screen for TB. HPCA has developed a screening tool based on national guidelines. Patients obtain their medication from government clinics and hospitals. CHWs also do infection control, which is mainly teaching cough etiquette to patients.

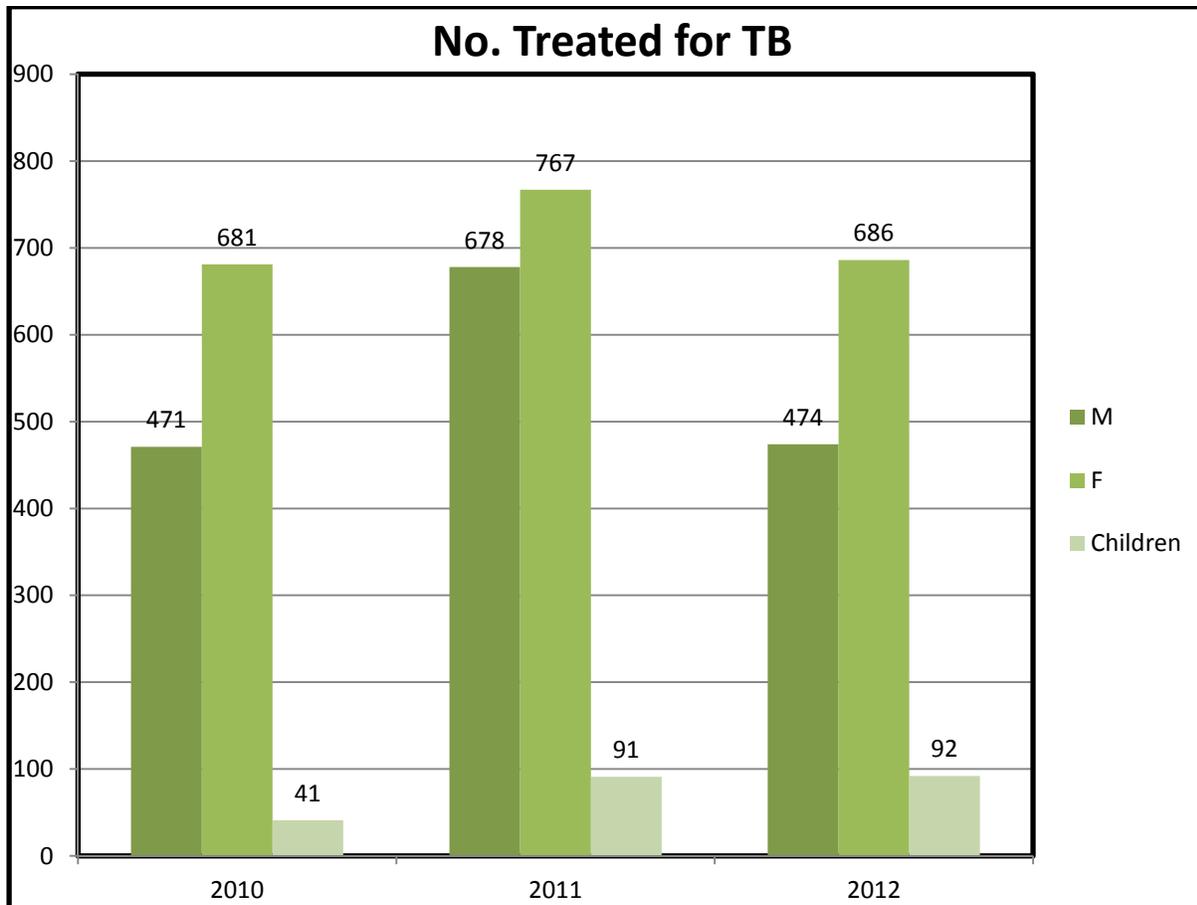
### QUOTE FROM CHWs ON TB SERVICES

“We visited a household screened for TB; of the 21 members screened 8 had TB.”

“We found 5 MDR TB patients in one area because of screening.”

It was noted that there was little in terms of protection for CHWs during their screening visits to the home.

Graph : No Treated for TB after Screening and Referral 2009-2012 [HPCA, HDMS 2012)



Through HPCA supported hospices 3,981 patients (Children 5.6% and Adults 94.4%) have been screened and found to have TB. With the relatively high TB co-infection rate of up to 65% [Karim et al, 2009], the number reached is relatively low compared to the number of people receiving palliative care [333,027]; the number of possible TB cases could be approximately 100,000 if a low estimate is taken.

#### HIV Testing

HPCA started collecting data on HIV testing in 2010, when 5,463 people were tested with no data disaggregated by age. The number tested increased to 10,908 in 2011 and 12,386 in 2012, with 96% tested in 2011 being above 15 years and 4% below 15 years and 95% in 2012 adults and 5% children below 15 years. [Refer to table I below]

No actual testing is done within the home setting, but referrals are done to the hospices where professional nurses provide testing. As part of support to HIV testing, HPCA was to train professional nurses in HIV testing the actual number of nurses trained could not be ascertained.

With the number of homes covered by hospices, there is still room to significantly expand access to HIV testing for family members.

	2009	2010	2011	2012
<b>M</b>	0	2,769	4,634	5,632
<b>F</b>	0	2,694	6,274	6,754
<b>HIV+</b>	0	876	2,313	1,806
<b>HIV+ %</b>	0	16%	21%	15%
<b>HIV+ Male</b>	0	42%	38%	42%
<b>HIV+ Female</b>	0	58%	62%	58%
<b>% &lt;15 yrs Tested</b>	0	-	96%	95%
<b>% &gt;15 yrs Tested</b>	0	-	4%	5%

Table I : Number of People Counselling and Tested for HIV

Of all the people tested 16%, 21%, and 15% were HIV positive in 2010, 2011 and 2012 respectively.

The HIV testing portfolio has significant room for improvement. The home setting is a natural constituent to expand access to testing as part of HIV education and prevention.

### Conclusion

- Community health workers and professional nurses working for hospices supported by HPCA have provided palliative care services to a total of 333,027 adults.
- The PEPFAR time-phased work plan did not have specific targets for adult palliative care, making it difficult to determine progress and achievements.
- The number of children receiving paediatric palliative care in 2010 was 2,927 and increased to 7,241 in 2012. There is still a large unmet need for paediatric palliative care. Of patients provided palliative care so far in 2012, 93% are adult and only 7% are paediatric. Statistics South Africa indicates that for mid-year 2011 approximately 33% of the population is aged 0-14 with a HIV prevalence of 3% ( Stats SA, 2012; UNGASS, 2012).
- The PEPFAR time-phased work plan had a target of 15,000 children in the first year; the overall total for 3 years ending 2012 was 13,237.
- Screening for vulnerable and orphaned children rose from 5,465 in 2009 to over 23,727 in 2011, a fourfold increase. But given the large number of households there is still a large unmet need.
- Through HPCA supported hospices 3,981 patients (Children 5.6% and Adults 94.4%) have been screened and found to have TB. With the relatively high TB co-infection rate of up to 65% [Karim et al, 2009], the number reached is relatively low compared to the number of people receiving palliative care [333,027].
- A total of 28,757 people were counselled and tested for HIV between 2009 and 2012 by hospices supported by HPCA. 95% were adults and 5% were children.

- There is close collaboration between government clinics and hospices with government provide medication and specialized services and hospices providing palliative care within the community setting.

### **Recommendations**

- Key Recommendation 1: HPCA should provide hospices with clearer guidelines on supporting community health workers including optimal number of patients to be seen per day, number effectively supervised by professional nurses and also strategies to help them cope with burn out. Especially as the Government of South Africa will place a greater burden on them with the re-engineering of PHC.
- Key Recommendation 2: Specific targets need to be set by province based on assessed needs this will serve as a guide to HPCA and improve targeting of service delivery.
- Key Recommendation 3: Stronger linkages between HPCA and Child health at the NDOH need to be established, this will allow paediatric palliative care to be prioritized within the PHC setting.
- Key Recommendation 4: Palliative care is holistic in nature (WHO;2012) and should be provided to all members in the household, specific targets should be set to increase HIV testing rates, paediatric clients reached and OVCs screened. This should be done within the context of redesigning how the project is funded and monitored.
- Key Recommendation 5: USAID need to determine the demand for paediatric care services and OVC within the community based on HIV prevalence and population and assists HPCA to better target and reach the unmet needs of children. Ideally all households supported should be supported for paediatric care this might involve more focused training for providers in paediatric palliative care. The one year target in the time-phased work plan of 15,000 against the actual number reached of 13,237 indicates a need to improve target setting.
- The HIV testing portfolio needs to be redesigned all hospices should incorporate on site HIV testing and all households members should be encouraged to test for HIV.

## **FINDING 5: Accreditation and Quality Improvement**

This section examines the role played by HPCA in improving the quality of palliative care service delivery in South Africa. The quality improvement initiatives were developed by HPCA as a response to the need to standardize and ensure the quality of palliative care provided by member hospices. As most hospices were outside the formal public sector health system, concerns were raised about ensuring patient safety and quality of care. The first HPCA standards booklet entitled Standards for the Provision of Palliative Clinical Care in Hospices was distributed to member hospices by the national patient care committee in 1998.

In 2004 HPCA introduced the provincial palliative care development team under the leadership of an employed coordinator. At the time the focus was on clinical care with an added focus on organizational development. As peer review took place to assess compliance with standards it became increasingly clear that good clinical care was dependent upon good management.

With funding from PEPFAR, HPCA started active collaboration with the Council for Health Services Accreditation of Southern Africa (COHSASA). This resulted in the development of the first edition of the comprehensive Hospice Palliative Care Standards circulated to hospices in 2005, with a second edition completed in 2009.

There are 12 service elements that make up the standards including 1) Governance and Leadership 2) Human Resource Management 3) Administrative Support Services 4) Risk Management 5) Quality Management and Improvement 6) Access to care and patients' rights 7) Interdisciplinary team 8) Holistic patient care 9) Medication management 10) Support services 11) Education and Research and 12) Fundraising.

Full accreditation requires a score of at least 80% for each relevant service element. To assist member hospices to meet these standards, HPCA has put in place a structured mentorship programme to create a culture of quality within each palliative care programme.

### **Star Rating**

Since embarking on the accreditation system it became apparent that the newer affiliate HPCA members were unlikely to ever achieve full accreditation. It was realized that once an organization met the requirement to move from being an affiliate member to a full HPCA member and to enter the accreditation programme, the requirements were overwhelming and almost unachievable. This led HPCA towards the decision to develop a staggered recognition system with ratings from 1 star to 5 star (full accreditation).

Once the 5 step process was introduced the phase 1 and 2 assessments became known as the 1 star and 2 star survey tools. An organization joins HPCA as an affiliate member in the development programme. A palliative care development officer conducts a 1 star assessment and identifies development needs. A development plan is put in place with the organization's management and includes details of activities required to meet standards criteria. After 6 months a progress survey is undertaken and repeated again until 80% is achieved in all service elements and a 1 star certificate is awarded. This process takes between 12 and 24 months.

In addition HPCA has a stream of funding called Development Funding for emerging hospices with potential and who passed the HPCA Base Line assessment, which is the admission criteria used before HPCA engages with a site.

This was considered to be "seed" funding and went together with intense capacity building and a development plan to enable to the hospice to reach a star rated status.

From our analysis it appears the Star 3, Star 4, and Star 5 criteria are much more rigorous and resource and time intensive, and these assessments are usually conducted by more experienced HPCA provincial coordinators. All Star 5 hospices are part of a maintaining accreditation program (MAP) developed by HPCA to ensure standards are maintained. Funding is currently staggered based on star rating, but also patient loads and performance.

Star Rating	Number	Proportion
5	28	16%
4	9	5%
3	20	11%
2	24	14%
I	37	21%
A	58	33%
<b>Total</b>	<b>176</b>	<b>100%</b>

Table 2: Star Rating and Accreditation of Hospices Supported by HPCA [Source, HPCA 2012]

As noted from the table above over 50% of the supported hospices are either affiliate or Star I rated. Most mentorship and direct support is devoted to Star rated hospices.

All assessed 5 star accredited hospices in the 5 provinces spoke of the enhanced recognition they received as a result of their rating. Increased funding, higher profiles, enlarged volunteer pools and media prominence were all attributed to the COHSASA rating. Each prominently displayed the 5 star certificates. Interestingly, all spoke about their initial reluctance to undertake the arduous accreditation process. The majority still note that the process is extremely intensive and highly bureaucratic at times. “The accreditation period is a real time of dread here; we need several months to mentally and physically prepare,” noted one hospice. “At the end though we heave a sigh of relief...since once you get your first 5 star grading you do not have to undergo the process for another two years,” another hospice commented.

The HPCA standards process reveals three distinct organizations. In the first category we have 4 and 5 star graded hospices. We noted that almost all the 5 star hospices had initial ratings of either 3 or 4 star and were able with one or two surveys to make the jump to 5 star grading (one went from 2 star to 5 star rating). The second category consists of the 3 Star graded hospice, with a few able to make the jump to 4 star, but the majority remaining at this level. The third category is the 1 and 2 star graded hospices, all of them former affiliate members.

The star 1, 2, and 3 hospices all appreciated the standards process and noted the increasing quality of care they were able to provide because of this system. Particular mention was made of the organizational development component including stronger financial reporting, with most getting clean financial audits every year. This was a real source of pride. “Donors pay particular attention to the strength of financial systems; this gives us an advantage.” The affiliate members are outside the HPCA standards process.

The star rating and accreditation process was described by one hospice as being “bureaucratic and paper-based... to assess patient service quality they look at patient files... not at actual patient care.” Another hospice made the comment “less paper more practice.”

### **Conclusion**

- The HPCA standards process is an innovative best practice that is credited with improving quality of both management and service delivery by hospice management.
- The fund raising component is important to ensure future sustainability of the supported organizations.

- Accreditation for the majority of hospices supported by HPCA is not possible with the current standards, which tend to favour older and more established hospices. This leaves out hospices in historically disadvantaged communities. This will have a direct impact if and when government adopts the national health insurance scheme.
- The standard process is time consuming and requires and presupposes prior availability of resources to achieve specific levels of star rating.
- The standards do not measure actual processes of care and there is no component to measure client feedback and satisfaction.
- Most affiliate members take between 12 months to 24 months to achieve 1 star rating. Direct mentorship is devoted to Star rated hospices.

### **Recommendations**

- Key Recommendation 1:The standards and accreditation system is a best practice that can be adopted by government and other partners, but it needs to be simplified to reflect the reality of service delivery in a resource limited setting
- Key Recommendation 2:The standards document should include a component for assessing actual process of provision of care and should also include client feedback.
- Key Recommendation 3: Going forward, HPCA should consider devoting more resources to the development fund for affiliate members and increase their engagement at this level; this will have a larger impact as the majority of rated hospices are affiliate members.
- Adapting the standards while maintaining the quality will allow HPCA to reach more organizations. HPCA should work with COHSASA to optimize the minimum package collapsing the administrative section, expanding the service delivery aspects and elaborate fundraising to include proposal writing and marketing. This will allow lower rated hospices to achieve accreditation and benefit when and if the national insurance scheme is implemented.

## **FINDING 6 : Monitoring and Evaluation**

This section of the findings assesses the Monitoring and Evaluation practice under the PEPFAR-funded programme.

All of the assessed hospices have work plans that outline monitoring and evaluation activities. Associated tools were also a key component of each plan, and are used to track programme activities and services. All hospices analyzed and used data for decision making.

The MER system at HPCA is built around the Hospice Data Management System (HDMS), developed in January 2007. The HDMS automatically synchronizes data to a central server to provide up-to-date information on patient and family care. The system has different levels of access to users to prevent accidental editing of data. There are built-in security checks to ensure accurate and uniform data capture of all mandatory information, enforcing standardized data capture. According to HPCA standards, data quality training is conducted at quarterly intervals and addressed through regular in-service MER training. The provision of MER support and mentorship is discussed at risk and quality improvement meetings. Using these platforms, all

persons involved in data management are educated on policies, procedures, and tools as well as shown how to address data threats.

The HDMS was developed for use by member hospices and was officially launched in 2009 with an initial pilot phase and ended in April 2011. The accelerated roll out phase was from May 2012 onwards and involved 10 hospices being added, with each signing agreements that committed them to have a dedicated data capturer and space for an HPCA donated computer, and to train each provider to use a HDMS data capture form.

The HDMS system is able to capture patient-specific data in terms of key demographics including age, race, and sex as well as diagnosis, treatment, service interventions and visits, services accessed, and provider information. The system does not have a narrative component. The real time features enables HPCA to access data immediately, analyze it, and provide immediate feedback.

Implementation of HDMS at the hospice level has been mixed. Half the assessed 5 star rated hospices have been able to successfully implement HDMS. The system seems to have been better resourced and supported at higher rated hospices, mostly Star 4 and 5. The reason becomes clear as the system is intensive to implement, the data capture form is detailed with community health workers sampled noting that it took an average of 30 minutes to fill in for each patient. Each hospice has developed its own system for uploading forms onto the HDMS web-server. Some do it daily, others do it once a week, or every fortnight. According to table 3 below HPCA was successful in rolling out HDMS first to 9 hospices in 2009, increasing to 39 in 2010, 58 in 2011 and 67 in 2012. This is less than half of all supported hospices.

Each CHW is expected to fill in a unique patient data capture form. Some noted it was difficult to understand the indicators; others mentioned that the form presumes a certain level of literacy amongst CHWs and this is not the case in practice.

In terms of data quality assurance practices, many hospices reported that the availability of accurate information “has been wonderfully beneficial.” “The information we can give to funders is of a high quality and demonstrates intensity of care, and we are able to make better operational decisions.” The monitoring data is being checked or verified frequently for missing and invalid values weekly by supervisors at all level of the organogram expect the affiliated hospices.

Generally professional nurses or social workers analyze data weekly in an attempt to identify gaps for corrections. It has been indicated that in most hospices with in-house developed databases, specific data quality checks have been incorporated during the design to minimize errors during capturing. The data quality checks are also conducted at the HPCA level using the built-in features of HDMS. The most identified weakness includes unavailability of mechanisms for regular data triangulation. None of the hospices carried out in-field data quality validity on submitted forms.

Other hospices reported that the system was cumbersome to implement and the need to have a full time data capturer was difficult to sustain. “The form can be confusing to the community

health workers.” “The system places extra burden on the supervising professional nurse, who must confirm the accuracy of each form with each community worker.” The pattern that comes out is that the HDMS is resource-intensive and often requires that hospices have dedicated staff to input forms and check accuracy.

Two assessed hospices reported differences in data reported by HPCA from HDMS and the data at hospice level.

It was noted that several hospices were currently running parallel systems of data capture. The reason given was that the previous excel based system developed by HPCA as well as other in-house developed systems were better able to provide data for reporting to different donors (e.g. NDOH) and programme management practices. Hospice thus had two systems. “One to report to HPCA and another to report to respective funders such as NDOH.” The NDOH reporting also included a significant reporting burden from the Global Fund, with data collection spanning 3 yearly cycles.

An analysis of reporting requirements from the HPCA and NDOH including Global Fund revealed the need to standardize the reporting platforms to reduce the burden of work.

The HPCA MER plan was detailed-oriented and clear. It provides clear guidance on rationale, reporting, data flow, data collection, data quality audits, and roles and responsibilities of staff. The HDMS system is well aligned to this plan. The specific implementation plan is only detailed for M&E functions. The programmatic indicators and targets deviate from the standard USAID format of anticipated outcome and intermediate results. The goals, strategic objectives, intermediate results, sub-results, and activities are not linked in one results framework. Specific targets are mentioned but no actual result numbers are mentioned, this could be an omission and HPCA and USAID may have the actual results framework with targets for each objective and activity.

In terms of reports submission, all hospices produce monthly, quarterly, or annual basis reports on their activities and send them to HPCA, DOH, DSD, and other specific donors. Quarterly reporting is the most common reporting interval mentioned. The majority of the reports produced consist of monthly/quarterly statistics in addition to the annual narratives.

AREA	2009	2010	2011	2012
Number of MER operational procedures developed	3	16	8	3
Number of HPCA members where MER guidelines were implemented				
Number of Data Quality Assessments conducted	0	10	50	0
Number of presentations conducted to promote a favourable environment for MER	1	12	27	14
Number of site visits conducted to HPCA members	91	65	17	61
Number of HPCA members where the HDMS was rolled out	9	39	58	67
Number of data captureurs trained on HDMS data capture and utilization	9	60	58	75

Table 3: M&E Activities undertaken by HPCA

### Conclusions

- The HDMS is the system that is currently in use for reporting program level activity data for the PEPFAR support program
- HPCA was successful in rolling out HDMS first to 9 hospices in 2009, increasing to 39 in 2010, 58 in 2011, and 67 in 2012. This is less than half of all supported hospices.
- The MER plan developed by HPCA clearly articulates monitoring and evaluation policies and practices at HPCA.
- The implementation of the HDMS has been easier for hospices with adequate staff and space. For the rest there have been challenges of space, dedicated staff for data entry, and lengthiness of data capture and entry.
- The data capture form is lengthy and difficult to fill in for many CHWs. Each form must be verified by the professional nurses before submission to the data clerk.

### Recommendations

- Key Recommendation 1: The data collected should be utilized at hospice, HPCA, regional and national level to enhance decision making.
- Key Recommendation 2: There is a need for reviewing HMIS or development of a management information system that would be able to integrate all data elements specific for different (donors') reporting requirements as well as programme management practices.
- There was also a strong need for specific resources (Personnel, computers, training and technical support) to be made available to M&E, including budgeting planning support - (star 1, 2, 3, and affiliated hospice).
- There is also a need to develop much stronger field support and technical assistance in M&E from HPCA, specifically targeting lower rated hospices (star 1 and affiliate).

## ISSUES: KEY TECHNICAL AND ADMINISTRATIVE

### USAID

- The performance monitoring plan and results framework as provided and developed was not complete.
- Emphasis should be placed on ensuring the yearly work plan developed by HPCA and submitted to USAID has specific programme targets for each activity area.
- HPCA reports should provide short narrative guidance on progress towards targets during each quarterly report submission and flag up any areas of concern.
- Programme targets should cascade to member hospices and their formats should be consistent and aligned to HPCA/USAID PMP.
- Mid-Term Review should be built into future programmes.

### HPCA

- The Monitoring and Evaluation plan is not supported by focused data collection, a lot of indicators and activities mentioned in the plan are not collected.
- Focus should be shifted towards development hospices ( affiliate, Star 1 and 2) to assist in rapid achievement of standards

## FUTURE DIRECTION

The future direction for the support to HPCA by USAID is informed by the changing patterns of the HIV epidemic, the need to have policy guidance, and the importance of generating and using evidence through monitoring and research.

In South Africa, strengthening the health system through re-engineering Primary Health Care and building on the six pillars of the health system (Figure 1 below) is the priority of the Government. The sustainability of any future program for palliative care will have to make a significant contribution to strengthening the health system (NDOH:2011).

The re-engineering process is envisaged to transform health care from donor funding towards government contracting with providers including NGOs like HPCA. Service delivery will move from disease diagnosis to functional outcomes. Hospice and hospital care will be transformed into community-based care. Instead of focusing on referral the new model will place emphasis on proactive screening. With HIV the new model should focus on managing chronic illness and less death and dying (though this role is still critical) ( NDOH:2011). Prioritization of child health is a key focus of the new approach, as childhood morbidity and mortality can be managed with evidence-based intervention including poverty eradication, school feeding, immunizations, and nutritional and social support. Working across departments and functions will be a skill that must be built into future programming.

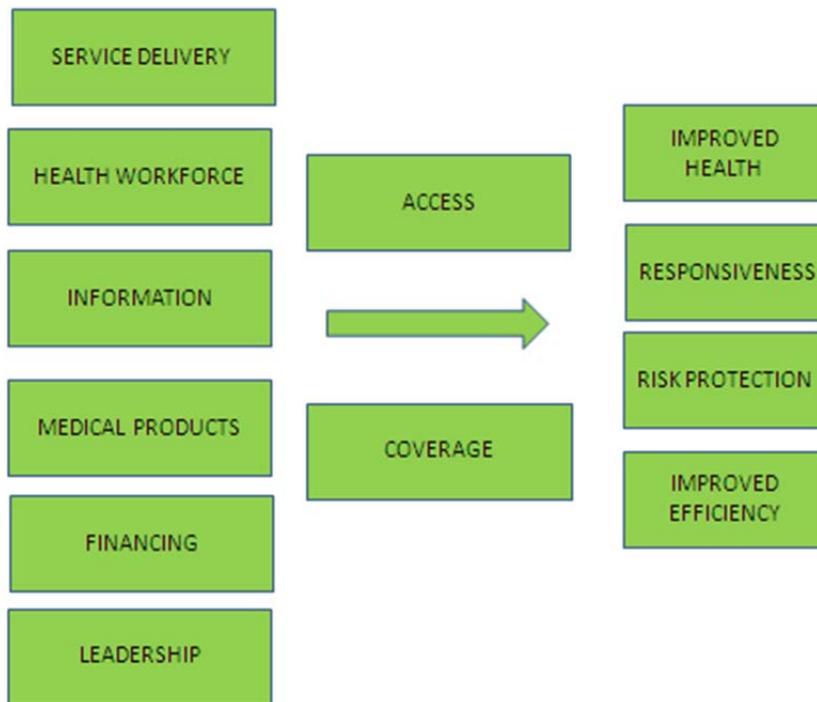


FIGURE 1: HEALTH SYSTEM BUILDING BLOCK (Adapted from WHO: Health System Strengthening, 2012)

## SERVICE DELIVERY

While HAART has significantly altered the trajectory of HIV and reduced deaths, the disease remains the top killer in South Africa because of co-morbidities like tuberculosis and poor support systems. With increasing lifespans from HAART, incidences of associated cancers are also on the increase ( Mantina, et al:2012). In future, the care of these "chronically ill" patients will become a pressing need.

Children remain a critical constituency for palliative care and their needs should be prioritized; forty percent of admissions into hospice care are children (Amery et al, 2009). There is a need to improve assessment of children in families in need of palliative care and to train providers to gain confidence and competence in handling children ( Amery et al, 2009).

## HEALTH WORK FORCE

Developing practice guidelines and career and training paths for CHWs should be a priority for future programming. Guidance is also needed for professional nurses tasked with supporting CHWs. Risk protection through care for care givers program as part of occupational health and safety must be incorporated into future programming. This can include supportive supervision and peer to peer support network.

Priority should be placed on integrating future HPCA training into government training plans at the district level as part of district plans.

Retention of the work force through monetary and non-monetary incentive will be crucial. The current low pay of CHWs will have long term implications for community-based care.

## INFORMATION

Collection of accurate programme monitoring data will allow for generation of evidence for effectiveness. Currently the absence of specific indicators that can track households reached and psychosocial, spiritual, and bereavement components of palliative care is a weakness. Going forward, USAID should consider developing more directed indicators that are easy to collect to allow monitoring of these components of the programme.

Further research is needed to determine the actual burden of palliative care needs in South Africa by province, as well as studies to examine current gaps in service provision.

## MEDICAL PRODUCTS

Access to medical products including essential medication, morphine (and other analgesics), HAART, gloves, and other allied health products is the aspect of the health system that is most difficult to influence as this remains the purview of government. Emphasis should be placed on strengthening supply chain systems to prevent wastage and on proper feedback and reporting.

## FINANCING

Palliative care is cost effective. A step down costing study done in South Africa showed outreach based care cost USD35 per month per patient compared to USD 80 for hospital visits per month per patient. (Hongoro & Dinat: 2011).

HPCA should position hospices through its standards program to achieve accreditation to qualify for government contracts. The overall financing will be equivalent to 8.2% of Gross Domestic Product or about ZAR 145 Billion at current rates and only accredited organizations will access these funds (NDOH: 2011b)

In the interim, specific budget support is still required from PEPFAR to maintain and build on gains made in the last 8 years of overall support.

## LEADERSHIP

South Africa has no national strategy on palliative care; this needs to be prioritized and integrated into the process of re-engineering palliative care.

Government ownership of palliative care should be emphasized in future programming. This should include working specifically with NDOH and other Departments to implement the palliative care strategy to build capacity at the local and national levels through training and get specific budgetary allocation towards palliative care through advocacy work.

OGAC recommends the provision of a package of care for HIV infected individuals adapted to fit into the country context. At a minimum the clinical services under palliative care should cover clinical monitoring, assistance in HAART initiation, adherence support and control of

symptoms of which pain is the most important. Psychological and spiritual care to support disclosure, mental counselling, bereavement, life review and social care which includes stigma reduction, access to grants, legal protection and HIV prevention within the family setting (2006). Specific indicators should be developed to flesh out the OGAC guidance. This package should include specific guidance on services to children and OVCs.

## **SUMMARY**

The project has had an appreciable impact. Future programming should target building the capacity of government at the national and regional level as well as training public sector health care workers. Capacity building at hospice level should target newer less developed hospice in historically underserved areas with continued emphasis on building organizational and management capacity. Diversifying funding, with increasing government support, should be a priority. Evidence based targeting setting in service delivery will ensure the most vulnerable in particular children are better served. Reporting should reflect this emphasis.

# ANNEXES

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## ANNEXES

### ANNEX A USAID TASK ORDER

#### SECTION B – SUPPLIES OR SERVICES AND PRICE

##### B.1 PURPOSE

To provide support to the United States Agency for International Development’s Mission in Southern Africa (USAID/Southern Africa) to assess the performance of the Hospice Palliative Care Association Project managed by Hospice Palliative Care Association of South Africa (HPCA) and its contribution to the USAID/Southern Africa’s objectives.

##### B.2 CONTRACT TYPE

This is a Firm, Fixed-Price Task Order. For the consideration set forth in the contract, the Contractor shall provide the deliverables or outputs described in Section F and comply with all contract requirements.

##### B.3 FIRM FIXED PRICE

The firm, fixed-price is \$210, 113. The contractor will not be paid any sum in excess of this firm, fixed price.

##### B.4 PAYMENT

The paying office is set forth in section G.4.

##### B.5 PAYMENT SCHEDULE

Payment of the fixed price shall be made on the schedule specified below:

Deliverable	(Percent (%) of Firm Fixed Price)
Initial briefing with USAID (this will be held in person with all evaluation team members)	25%
A draft evaluation report	25%
Final Evaluation Report	50%
<b>TOTAL</b>	<b>100%</b>

Payment of the amounts specified above are subject to approval by the COR and acceptance of the milestone event or deliverable by the COR. The paying office is USAID/SA as indicated in section G.3; payment processing shall be in accordance with the payment schedule in section G.4 of this RFTOP.

END OF SECTION B

## SECTION C – DESCRIPTION/SPECIFICATIONS/STATEMENT OF WORK

### I. Objective

The aim of the evaluation is to assess the performance of the Hospice Palliative Care Association Project managed by Hospice Palliative Care Association of South Africa (HPCA) and its contribution to the USAID/Southern Africa's objectives.

### 2. Background

USAID/Southern Africa's Health and HIV/AIDS strategy responds to the overwhelming challenges posed by the AIDS epidemic for individuals, families, communities and society in South Africa. The dramatic rise in HIV infections during the past decade is threatening to undermine many of the advances made in the sector since the first democratic election in 1994. HIV infection rates have increased from an average of less than one percent among pregnant women in antenatal clinics in 1990 to 29 percent in 2006. According to UNAIDS, about 5.3 million or one in ten South Africans are now HIV-infected.

In addition to the rising HIV/AIDS rates, active tuberculosis (TB) incidence rates are rising throughout South Africa, reaching 608 per 100,000 per annum. HIV-infected patients are at significant risk for developing TB, and 58% of patients attending TB clinics have been identified as HIV-infected. Of primary importance is the identification of TB in HIV infected individuals, with over 60 percent of co-infected patients being sputum negative. Improved and early diagnosis of TB in HIV-infected individuals improves outcomes of morbidity and mortality. Co-infected individuals need to be initiated on antiretroviral therapy, according to standard treatment guidelines, to ensure improvement in mortality, morbidity and TB cure rates.

Hospice Palliative Care Association of South Africa (HPCA) was founded in 1988 as a non-governmental organization (NGO) based in South Africa. The vision for HPCA is "Quality Palliative Care for all", building human resources capacity within a context of improved standards to provide care and support including palliative care. The Mission of HPCA is to provide and enhance the provision of sustainable, accessible, quality palliative care. HPCA strengthens existing services within member hospices and develops new integrated services through direct funding to member hospices to promote accessibility and availability of palliative care in South Africa. HPCA personnel at national, provincial and district levels continue to provide the infrastructure and coordination to develop and strengthen palliative care programs

within member hospices, the formal public and private health care sectors and NGOs. Improved collaboration between HPCA and the National Department of Health (NDOH) is a key objective, aimed at optimum utilization of scarce palliative care technical resource. The primary aim is to reduce the impact of HIV/AIDS on individuals, families, communities and society by expanding access to quality palliative care. HPCA has recognized the need for rapidly increasing palliative care services in a sustainable manner; in doing so it is developing and formalizing a partnership with the Government of South Africa (GoSA) at National and Provincial levels and acting as a technical resources responding to various requests. HPCA is working in all the nine Provinces in South Africa, within districts and sub districts. Their efforts will also be geared towards focusing on the 18 priority districts identified by the NDOH.

HPCA originally was managed as a sub-grantee under USAID's umbrella grant management organization. Based on past performance, size and scope of the programs, a determination was made to "graduate" HPCA to begin to receive direct funding award from USAID rather than continuing under an umbrella grant management organization. The current project started on December 15, 2009 and is scheduled to end on December 20, 2012. The total value of the USAID agreement is \$32,730,174 over these three years.

### 3. Purpose

The final evaluation report produced by the Contractor shall: 1) use evidence to document the degree to which USAID-funded palliative care interventions through HPCA worked or didn't work; 2) identify best practices, lessons learned, and areas of improvement; and 3) provide recommendations to inform USAID's follow-on interventions in palliative care. The final evaluation report should answer the following questions related to the development hypothesis, health service delivery, health systems strengthening, and local capacity development (both governmental and non-governmental).

- Does the development hypothesis of the HPCA program relate to the achievement of expected results as articulated in the original scope of work? If not, why not?
- What key interventions enhanced or weakened health service delivery efforts? Were there unanticipated results (positive or negative)?
- What were the key results, strengths, weaknesses, and unanticipated results of the Health Service Delivery processes implemented by HPCA under the Palliative Care Program?
- To what extent has the HPCA program informed and influenced the public sector provision of comprehensive palliative care services?
- Has the HPCA program strengthened health systems in South Africa?
- What key health systems strengthening interventions have been most effective? Least effective?
- What key lessons learned should be drawn from the success or failure of the HPCA program to inform future USAID program design?
- Are there examples of long lasting, sustainable benefits related to the delivery of palliative care services by the GoSA or other institutions in South Africa that the HPCA program has influenced?

#### 4. Implementation Schedule

The table below indicates activities to be performed under the task order. The contractor will follow the implementation/work plan it detailed in its proposal (See Attachment I for Contractor proposed Implementation Plan).

Activity	Timeline	Milestone
<b>Preparatory activities: In-briefing with USAID/SA, Team planning meeting, Evaluation Schedule, Tools development and debriefing</b>	Week 1	Brief meeting held with USAID/SA
<b>Review Documents, reports and existing materials; completed protocol, pretest and finalize questionnaires</b>	Week 2	Evaluation protocol and questionnaires complete
<b>Field Work/Data Collection</b>	Weeks 3-4	Data collection complete by end of week 4
<b>Analysis of findings and preparation of Draft Report</b>	Weeks 5-6	Draft report shared with USAID/SA, end of week 6
<b>Additional data collection/clarification of findings (as needed)</b>	Week 7	Feedback received from USAID
<b>Revision and Oral Presentation of the Final Evaluation Report</b>	End of week 8	Evaluation report presented to USAID/SA
<b>Evaluation Report Finalized</b>	Week 9	Final Report Submitted to USAID/SA

#### 5. Deliverables

The Contractor is required to deliver the following in the performance of the evaluation program:

- a) A **presentation** of the draft evaluation findings to USAID.
- b) A **draft evaluation report** to the Task Order Contracting Officers Representative (TO COR). One hard copy and one electronic copy will be provided to USAID. The report (not including attachments) will be no longer than 35 pages with an Executive Summary, Introduction, Methodology, Findings, Lessons Learned, Conclusion and listing of prioritized recommendations for future USAID palliative care development interventions (if recommended).
- c) **Final Evaluation Report:** USAID has 14 working days to review the draft report and provide written comments to the Contractor on the draft report. The Contractor will have 14 working days to incorporate these comments into a final report.

Contractor must provide both an electronic version and 5 hard copies of the final report to USAID. The report format should be restricted to Microsoft products and 12-point type font should be used throughout the body of the report, with page margins 1 inch top/bottom and left/right. The report should not exceed 35 pages, excluding references and annexes. The report will be released as a public document on the USAID Development Experience Clearinghouse (DEC) (<http://dec.usaid.gov>) after the TO COR provides formal written approval.

## 6. Reporting Format

- Executive Summary: summarizes project purpose and background, key evaluation questions, methods, findings, and recommendations. (3-5 pgs.);
- Table of Contents (1 pg.);
- Introduction and Background: purpose, audience, and synopsis of task, brief overview of HSPA project in South Africa, USAID program strategy and activities implemented in response to the problem, brief description of implementing partners (1-2 pages);
- Methodology: describes evaluation methods, including constraints and gaps (1-2 pg.);
- Findings/Conclusions/Recommendations—for each objective area; and also include data quality and reporting system that should present verification of spot checks, issues, and outcome (17–20 pgs.);
- Issues: provide a list of key technical and/or administrative, if any (1–2 pgs.);
- Future Directions: to inform the design of an additional palliative care development intervention (if necessary or not) (2-3 pgs.);
- References (including bibliographical documentation, meetings, interviews and focus group discussions);
- Annexes: annexes that document the evaluation tools, schedules, interview lists, tables, all sources of information, the Offeror’s final evaluation statement of work, statements of differences—should be succinct, pertinent and readable.

## 7. Final Report Criteria

- The evaluation report should represent a thoughtful, well-researched, and well-organized effort to objectively evaluate what worked in the project, what did not, and why.
- Evaluation reports shall address all evaluation questions included in this Scope of Work.
- The evaluation report should include Offeror’s final evaluation scope of work as an annex. No changes to the evaluation scope of work, whether in technical requirements, evaluation questions, evaluation team composition, methodology, or timeline shall be made to the final evaluation scope of work without a written modification to the task order. Only the Task Order Contracting Officer (TO CO) is authorized to make changes to the final scope of work.
- Evaluation methodology shall be explained in detail and all tools used in conducting the evaluation such as questionnaires, checklists, and discussion guides will be included in an Annex in the final report.

- Evaluation findings will assess outcomes and impacts on males and females.
- Limitations to the evaluation shall be disclosed in the report, with particular attention to the limitations associated with the evaluation methodology (selection bias, recall bias, unobservable differences between comparator groups, etc.).
- Evaluation findings should be presented as analyzed facts, evidence, and data and not based on anecdotes, hearsay, or the compilation of people’s opinions, Findings should be specific, concise, and supported by strong quantitative or qualitative evidence.
- Sources of information need to be properly identified and listed in an annex.
- Recommendations should be action-oriented, practical, and specific, with defined responsibility for the action.

## 8. Relationships and responsibilities

The Contracting Officer has appointed a TO COR. An alternate TO COR may be named upon award of the task order and the Contractor will be informed if this is the case. The Contracting Officer and the TO COR are the only official representatives of USAID for this contract and are the only ones authorized to provide technical direction to the Contractor throughout the evaluation. The Contractor is expected to work together with the TO COR to implement the scope of work.

## 9. Logistics

A six-day work week is authorized if not in conflict with your organization’s policies regarding work week. Local holidays are not authorized. The evaluation team will be responsible for all off-shore and in-country logistical support. This includes international and in-country travel (including vehicle rentals), hotel bookings, working/office space, computers, printing and photocopying. The evaluation team, in collaboration with USAID/Southern Africa, will arrange all meetings, interviews, site visits, in-briefing and out-briefing. In all other respects, the evaluation team should be self-sufficient.

[End of Section C - Statement of Work]

## SECTION D – PACKAGING AND MARKING

### D.I TASK ORDER PACKAGING AND MARKING

Task order packaging and marking shall be performed in accordance with the Evaluation Services IQC, Section D.

END OF SECTION D

## SECTION E - INSPECTION AND ACCEPTANCE

## E.1 TASK ORDER INSPECTION AND ACCEPTANCE

Task order inspection and acceptance shall be performed in accordance with the Evaluation Services IQC, Section E.

END OF SECTION E

## SECTION F – DELIVERIES OR PERFORMANCE

### F.1 PERIOD OF PERFORMANCE

This project is expected to begin on or about September 10, 2012, and be completed no later than 9 weeks after the start date. This would include preparation days, in-country work, and report writing and finalization of all deliverables.

### F.2. DELIVERABLES

The Contractor shall deliver:

- a) A **presentation** of the draft evaluation findings to USAID.
- b) A **draft evaluation report** to the Task Order Contracting Officers Representative (TO COR). One hard copy and one electronic copy will be provided to USAID. The report (not including attachments) will be no longer than 35 pages with an Executive Summary, Introduction, Methodology, Findings, Lessons Learned, Conclusion and listing of prioritized recommendations for future USAID palliative care development interventions (if recommended).
- c) **Final Evaluation Report:** The USAID has 14 working days to review the draft report and provide written comments to the Contractor on the draft report. The Contractor will have 14 working days to incorporate these comments into a final report. Contractor must provide both an electronic version and 5 hard copies of the final report to USAID. The report format should be restricted to Microsoft products and 12-point type font should be used throughout the body of the report, with page margins 1 inch top/bottom and left/right. The report should not exceed 35 pages, excluding references and annexes. The report will be released as a public document on the USAID Development Experience Clearinghouse (DEC) (<http://dec.usaid.gov>) after the TO COR provides formal written approval.

#### Reporting Format

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- Methodology: describes evaluation methods, including constraints and gaps (1-2 pg.);
- Findings/Conclusions/Recommendations—for each objective area; and also include data quality and reporting system that should present verification of spot checks, issues, and outcome (17–20 pgs.);
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- Annexes: annexes that document the evaluation tools, schedules, interview lists, tables, all sources of information, the evaluation statement of work, statements of differences—should be succinct, pertinent and readable.

#### Final Report Criteria

- The final evaluation report should represent a thoughtful, well-researched, and well-organized effort to objectively evaluate what worked in the project, what did not, and why.
- The final evaluation report shall address all evaluation questions included in the Scope of Work.
- The final evaluation report should include Offeror’s final evaluation scope of work (which will become part of any resulting task order) as an annex. No changes to the evaluation scope of work, whether in technical requirements, evaluation questions, evaluation team composition, methodology, or timeline shall be made to the final scope of work without a written modification to the task order. Only the Task Order Contracting Officer (TO CO) is authorized to make changes to the final evaluation scope of work.
- Evaluation methodology shall be explained in detail and all tools used in conducting the evaluation such as questionnaires, checklists, and discussion guides will be included in an Annex in the final report.
- Evaluation findings will assess outcomes and impacts on males and females.
- Limitations to the evaluation shall be disclosed in the report, with particular attention to the limitations associated with the evaluation methodology (selection bias, recall bias, unobservable differences between comparator groups, etc.).
- Evaluation findings should be presented as analyzed facts, evidence, and data and not based on anecdotes, hearsay, or the compilation of people’s opinions, Findings should be specific, concise, and supported by strong quantitative or qualitative evidence.
- Sources of information need to be properly identified and listed in an annex.
- Recommendations should be action-oriented, practical, and specific, with defined responsibility for the action.

#### F.3 TECHNICAL DIRECTION AND DESIGNATION OF RESPONSIBLE USAID OFFICIALS

##### **TASK ORDER CONTRACTING OFFICER:**

Eric Strong  
Task Order Contracting Officer

U.S. Agency for International Development  
100 Totius Ave  
Groenkloof 0027  
Pretoria, South Africa  
Telephone: +27 12-452-2166 / Fax: +27 12-460-3177  
Email: dmiller@usaid.gov

**The Task Order Contracting Officer Representative (TO COR):**

Charles Mandivenyi  
Task Order Contracting Representative (TO COR)  
U.S. Agency for International Development  
100 Totius Ave  
Groenkloof 0027  
Pretoria, South Africa  
Telephone: +27 12-452-2268 / Email: epacific@usaid.gov  
F.4 PLACE OF PERFORMANCE

The place of performance under this Task Order is South Africa, as specified in the Scope of Work.

**F.5 REPORTS AND DELIVERABLES OR OUTPUTS**

In addition to the requirements set forth for submission of reports in Section I, and in accordance with AIDAR clause 752.242-70, Periodic Progress Reports, the Contractor shall submit reports, deliverables or outputs to the TO COR. All reports and other deliverables shall be in the English language, unless otherwise specified by the TO COR.

END OF SECTION F

**SECTION G – TASK ORDER ADMINISTRATION DATA**

**G.I CONTRACTING OFFICE**

The Contracting Officer with authority to administer the order is Eric Strong at:

USAID/Southern Africa  
100 Totius Street  
P. O. Box 43  
Groenkloof 0027  
Pretoria  
South Africa

The Contracting Officer is the only person authorized to make or approve any changes in the requirements of this task order and notwithstanding any provisions contained elsewhere in this task order, the said authority remains solely in the Contracting Officer. In the event the Contractor makes any changes at the direction of any person other than the Contracting

Officer, the change shall be considered to have been made without authority and no adjustment shall be made in the contract terms and conditions, including price.

## G.2 TECHNICAL DIRECTION

USAID/Southern Africa shall provide technical oversight to the Contractor through the designated TO COR as described in Section F.3.

## G.3 ACCEPTANCE AND APPROVAL

In order to receive payment, all deliverables must be accepted and approved by the TO COR.

## G.4 INVOICES

One original of each invoice shall be submitted on an SF-1034 "Public Voucher for Purchases and Services Other Than Personal" to the Financial Management Office at USAID/Southern Africa. One copy of the voucher and the invoice shall also be submitted TO COR.

Electronic submission of invoices is encouraged. The SF-1034 must be signed, and it must be submitted along with the invoice and any other documentation in Adobe PDF to the Regional Financial Management Office to this address: [invoice@usaid.gov](mailto:invoice@usaid.gov)

Paper invoices shall be sent to the following address:

USAID/Southern Africa,  
P.O. Box 43, Groenkloof,  
Pretoria 0027  
/ or via courier to 100 Totius Street, Groenkloof, Pretoria

If submitting invoices electronically, do not send a paper copy.

## G.5 ACCOUNTING AND APPROPRIATION DATA

(To be completed with included with the final task order):

Budget Fiscal:

Operating Unit:

Strategic Objective:

Team/Division:

Benefiting Geo Area:

Object Class:

Amount Obligated: \$

END OF SECTION G

## SECTION H – SPECIAL TASK ORDER REQUIREMENTS

### H.1 AUTHORIZED GEOGRAPHIC CODE

The authorized geographic code for the purchase of goods and services under this task order is 937.

### H.2 LANGUAGE REQUIREMENTS

All deliverables shall be produced in English.

### H.3 GOVERNMENT FURNISHED FACILITIES OR PROPERTY

The Contractor and any employee or consultant of the Contractor is prohibited from using U.S. Government facilities (such as office space or equipment) or U.S. Government clerical or technical personnel in the performance of the services specified in the Task Order unless the use of Government facilities or personnel is specifically authorized in the Task Order or is authorized in advance, in writing, by the TO COR.

### H.4 CONFIDENTIALITY AND OWNERSHIP OF INTELLECTUAL PROPERTY

All reports generated and data collected during this project shall be considered the property of USAID and shall not be reproduced, disseminated or discussed in open forum, other than for the purposes of completing the tasks described in this document, without the express written approval of a duly-authorized representative of USAID. All findings, conclusions and recommendations shall be considered confidential and proprietary.

### H.5 CONTRACTOR'S STAFF SUPPORT, AND ADMINISTRATIVE AND LOGISTICS ARRANGEMENTS

The Contractor shall be responsible for all administrative support and logistics required to fulfill the requirements of this task order. These shall include all travel arrangements, appointment scheduling, secretarial services, report preparations services, printing, and duplicating.

### H.6 ENVIRONMENTAL COMPLIANCE

The Foreign Assistance Act of 1961, as amended, Section 117 requires that the impact of USAID's activities on the environment be considered and that USAID include environmental sustainability as a central consideration in designing and carrying out its development programs. This mandate is codified in Federal Regulations (22 CFR 216) and in USAID's Automated Directives System (ADS) Parts 201.5.10g and 204 (<http://www.usaid.gov/policy/ads/200/>), which, in part, require that the potential environmental impacts of USAID-financed activities are identified prior to a final decision to proceed and that appropriate environmental safeguards are adopted for all activities. Contractor environmental compliance obligations under these regulations and procedures are specified in the following paragraphs of this Task Order.

In addition, the Contractor must comply with host country environmental regulations unless otherwise directed in writing by USAID. In case of conflict between host country and USAID regulations, the latter shall govern.

No activity funded under this task order will be implemented unless an environmental threshold determination, as defined by 22 CFR 216, has been reached for that activity, as documented in a Request for Categorical Exclusion (RCE), Initial Environmental Examination (IEE), or Environmental Assessment (EA) duly signed by the Bureau Environmental Officer (BEO). (Hereinafter, such documents are described as “approved Regulation 216 environmental documentation.”)

An Initial Environmental Examination has been approved for projects funding this Task Order. The IEE covers activities expected to be implemented under this Contract. USAID has determined that a Categorical Exclusion applies to the proposed activities. This indicates that if these activities are implemented subject to the specified conditions, they are expected to have no significant adverse effect on the environment.

As part of its initial Work Plan, and all Annual Work Plans thereafter, the Contractor, in collaboration with the USAID COR and Mission Environmental Officer or Bureau Environmental Officer, as appropriate, shall review all ongoing and planned activities under this contract to determine if they are within the scope of the approved Regulation 216 environmental documentation.

If the Contractor plans any new activities outside the scope of the approved Regulation 216 environmental documentation, it shall prepare an amendment to the documentation for USAID review and approval. No such new activities shall be undertaken prior to receiving written USAID approval of environmental documentation amendments.

END OF SECTION H

## SECTION I – CONTRACT CLAUSES

**I.1** All applicable clauses as outlined in the basic Evaluation Services Indefinite Quantity Contract (IQC) and its subsequent amendments (if any) are incorporated by reference.

END OF SECTION I

## ANNEX B HPCA MEMBER ORGANIZATION [ATTACHED]

### ANNEX C WORK PLAN INTERVIEW LIST

PROVINCE	DATE S	SITES	TIME	KEY RESPONDENTS	FOCUS GROUP DISCUSSIONS (Y/N)
<b>GAUTENG</b>	5 October 2012	Centurion Hospice	2-4.30 PM	'Marie Backeberg	Y
	4 October 2012	Hospice Association of Witwatersrand	8-12AM	Nigel Unwin	
	5 October 2012	Kings Hope Development Foundation	8-12AM	Magdel Williams	
	3 October 2012	MES Impilo Hope for Life (Zaziwe hope for life)	'2-4:30AM	Francois Pienaar	
		Tshwaranang Hospice	8-12AM	Reuben Mohulatsi	
		Sparrow Ministries	2-4:30AM	Ms. Rose .R. Letwaba	
<b>KwaZulu Natal</b>	5 October 2012	Chatsworth Hospice	'2-4:30AM	Keith Moonsamy	
	4 October 2012	Highway Hospice	8-12AM	Lesley Van Zyl	
	5 October 2012	Maskey Health Services	8-12AM	'Doris Cele	
	2 October 2012	Saint Mary's Mission Hospital Trust, Mariannahill	12-4.30AM	Dr D P Ross	Y
	3 October 2012	Verulam Regional Hospice Association	'2-4:30AM	'Mr G Naidoo	

	5 October 2012	Vulamehlo Hospice	'2-4:30AM	Them bani Elizabeth Kumalo	
	3 October 2012	Zululand Hospice	'2-4:30AM	Lynn Rubly	
	5 October 2012	Thokomala Hospice	'2-4:30AM	V. Mdluli	
<b>Northern Cape</b>	4 October 2012	ICWIMP (Inter Church Women's "icose" Multi Purpose Project)	8-12PM	'Ebuang Rebecca Tshose	
	3 October 2012	Nightingale Hospice	'10-1PM	'Theresa Thompson	
	5 October 2012	Hospice Moeder Theresa	2-4:30PM	'Yvonne Roux	
	4 October 2012	Saint Teresa's Hospice	'2-4:30PM	'Marilyn Burrow	
	4 October 2012	Melomen (Kareeberg)	'10-2 PM	Theresa Thompson	Y
	5 October 2012	Renosterberg	'10-1PM	Theresa Thompson	
<b>Western Cape</b>	9 October 2012	Baphumelele Respite Care Centre	8-12PM	Marion Gready	
	10 October 2012	Saint Lukes Hospice, Kenilworth	8-12PM	'Priscilla Nelson	
	11 October 2012	Stellenbosch Hospice	8-12PM	Geraldine Nicol	Y
	10 October 2012	Themba Care- Athlone	2-4:30 PM	'Nomakula Mrubata	
	12	Tygerberg	8-12PM	Maureen Vente	

	October 2012	Hospice			
	8 October 2012	Abundant Life - Victoria Hospital	2-4:30 PM	'Clint Cupido	
<b>Eastern Cape</b>	4 October 2012	Blue Crane Hospice	8-12PM	'Jean Underwood	
	4 October 2012	'Camdeboo Hospice	8-12PM	Susan Van Der Linde	
	4 October 2012	Cradock Hospice	8-12PM	'Mrs. Cheryl C. Ferreira	
	3 October 2012	'Grahamstown Hospice	8-12PM	'Site manager	
	3 October 2012	'Saint Bernard's Hospice	'8-4:30 PM	David Barker	Y
	4 October 2012	Samaritan Care Centre	2-4:30PM	Michael Du Plessis	
<b>Free State</b>	9 October 2012	St Nicholas	As Available	'Site manager	
<b>NDOH</b>	8 October 2012	NDOH Lead	As Available	Mokgadi Phokojoe	
<b>DCS</b>	8 October 2012	Department of Correctional Services	As Available		
<b>HPCA</b>	9 October	CEO	2 pm-6.00 pm	Liz Gwyther	
		COO	2 pm-6.00 pm	Kathy Henning	
		SA	2 pm-6.00 pm	Jo Lazarus	
		M&E	2 pm-6.00 pm	Mervyan Kionjore	
		CFO	2 pm-6.00 pm	Callen Hodgkiss	

	Advocacy	2 pm-6.00 pm	Zodwa Sithole
	Regional Manager	2 pm-6.00 pm	Andre Wagner
	Regional Manager	2 pm-6.00 pm	Sue Cameron
	Regional Manager	2 pm-6.00 pm	Nkosozana Ngidi
<b>USAID</b>	I	Thobekile	
	October	Finger	
	2012	Charles	
		Mandivenyi	
		i	

## ANNEX D INTERVIEW GUIDES

### INTERVIEW GUIDE FOR HPCA NATIONAL OFFICE

#### IN CHARGE MEMBER HOSPICES

Name: \_\_\_\_\_ Date: \_\_\_\_\_

Time: \_\_\_\_\_

Position: \_\_\_\_\_

Interviewer:\_\_\_

The focus of this evaluation assessment is to assess the USAID funded palliative care program implemented by the HPCA.

My purpose in talking with you today is to learn more about your thoughts, feelings, and experiences with the program.

Anything you tell me will not be personally attributed to you in any reports that result from this evaluation. All of the reports will be written in a manner that no individual comment can be attributed to a particular person.

The interview will take about 120 minutes

Your participation in this interview is completely voluntary. Are you willing to be interviewed?

Do you have any questions before we begin?

ACTIVITY A: Capacity building-Organizational structure

- Could you describe the staffing structure at this facility?
- How is the facility managed? Who is in charge and what are the various responsibilities
- Could you please describe the roles and responsibilities of staff?
  - Admin
  - Clinical
  - Support
  - Community Based
  - Volunteers
- Could you briefly describe the work of your organizations/facility, what services do you provide, and who do you serve?
- Please describe specifically the support provided by HPCA to this facility/hospice?
- Finance
- Mentoring management
- Mentoring and building staff
- Support to service delivery
- Training
- Could you explain how your facility benefits from the mentorship programme coordinated and implemented by HPCA? [note question 4 answer]
- What are the benefits of your involvement with HPCA ?
- Please describe the activities undertaken by HPCA to build your ability to member to provide palliative care services
- What has been your experience with these activities
- Successes
- Challenges
- How can they be improved
- Do you have anything you would like to add?

**ACTIVITY B: Government collaboration, Gender, Advocacy and Liaison**

- Describe the relationship your facility has with National and or Provincial Department of health?
- Service delivery
- Essential drugs
- National programmes
- Reporting
- What role do you play in working with other palliative care organizations in the district, province and nationally? How does HPCA support this work?
- Please describe your collaboration with other partners besides government
- Can you briefly describe the work you do related to gender [Probe about implementing the HPCA gender guidelines of 2008-Training, promoting gender sensitivity and awareness]

**ACTIVITY C: Training/Human Capacity Development**

- Describe how you understand the work of the following HPCA staff and support structures
- Provincial mentor
- Accredited mentor hospices [Are you accredited]
- Provincial palliative care development coordinator
- Palliative care development team
- Describe the role of provincial palliative care education forums
- Explain how you benefit from the centres for palliative learning (CPL)
- Can you describe some of the training programs provided by HPCA to this facility/hospice?
- How many of your staff members have been trained in the following programs and who carried out these trainings? [Note concurrence with Question 4]
- Adult and paediatric palliative care
- Home based care,
- TB
- HIV counselling and testing/VCT
- OVC
- HIV care and treatment
- Others [Please specify]
- What has been your experience in implementing these trainings? [Success and Challenges]
- What recommendation do you have to improve the trainings?

#### ACTIVITY D: Accreditation and Quality Improvement

- Please describe HPCA's accreditation and quality improvement system implemented with COHSASA for member hospices?
- Star rating
- Surveys
- Kindly describe how the initial and follow up surveys were conducted?
- What do you believe were and are the benefits of the accreditation process?
- What do you believe is the strongest aspects of this accreditation process?
- What has been your experience in implementing quality monitoring and improvement?
- How has HPCA assisted in maintaining quality improvement?
- What have been some of the successes and challenges of implementing accreditation and quality improvement
- What recommendation would you make to improve the process?

#### ACTIVITY E: Adult palliative care services

- Please describe the services you provide through HPCA support by under adult palliative care services including program targets, populations served,
- How does HPCA support directly and indirectly?
- Home based care
- Day care

- Outpatient care
- In patient care
- Provision of psychological services
- Clinical services: provision of opportunistic infection prevention and treatment including TB, HIV and AIDS related complications including malaria and diarrhoea
- Pain and symptom management
- Nutrition support: Assessments and therapeutic feeding
- Preventive care package\*
- Social support
- HIV testing/VCT
- Screening for ARV
- Screening for TB and referral for treatment
- TB treatment : DOTS/Lab monitoring
- Infection control for TB
- Community based services
- Please describe significant successes in providing adult palliative care through member hospices?
- Please explain any significant challenges in achieving your targets in providing adult palliative care through member hospices?
- In what way could this support have been improved?

#### ACTIVITY F: Paediatric palliative care services

- Please describe services provided through HPCA support by member hospices under paediatric palliative care services including program targets, populations served, and
- How does HPCA support directly and indirectly?
- Home based care
- Day care
- Early infant diagnosis
- In patient care
- Provision of psychological and spiritual services
- Clinical services: provision of opportunistic infection prevention and treatment including TB, HIV and AIDS related complications including malaria and diarrhoea
- Preventive care package\*
- Social support
- HIV testing/VCT
- Screening for ARV
- Screening for TB
- Infection control for TB
- TB treatment
- Community based services
- Social support
- Protection and legal aid
- Early childhood development programs

- Identification of OVCs\* [Using vulnerability index]
- Assisting with access to education
- Liaison with department of social development and department of education
- Economic support
- Nutrition support: Assessments and therapeutic feeding
- Bereavement support, memory training, resilience
- HIV prevention education and counseling
- Please describe significant successes in providing paediatric palliative care through member hospices?
- Please explain any significant challenges in achieving your targets in providing paediatric palliative care through member hospices?
- In what way could this support have been approved?

#### ACTIVITY E2 and F2 COMMUNITY SERVICES

- Please describe services you provide within the community?
- How are these services linked with services at the facility?
- How do you get the community involved in your services?
- How do you target and increase or improve community participation
- What are some of the main challenges in providing community services?
- What recommendation can you make to improve community services?

#### ACTIVITY G: Public policy and awareness

- Describe your role in promoting public awareness about palliative care?
- What successes and challenges have you noted in these roles?
- What recommendation would you make to strengthen these roles?

#### ACTIVITY H: Monitoring and Evaluation

- Briefly describe how you monitor programs implemented in the region? Do you use the Health Data management system (HDMS)?
- What reports do you submit?, How often ?
- Who do you send reports to?
- How do you ensure data quality [Audits, checks, mentorship]
- What challenges have you noted in monitoring the programs
- What suggestions would you make to improve data collection and reporting if any?

#### ACTIVITY I: Program Design

- What in your opinion do you consider has had the biggest impact in the support you received from HPCA?
- How could this support have been improved?
- What services or program do you currently implement do you believe will continue with or without support from HPCA? Why?

### INTERVIEW GUIDE FOR HPCA NATIONAL OFFICE

CEO

Name: \_\_\_\_\_ Date: \_\_\_\_\_

Time: \_\_\_\_\_

Position: \_\_\_\_\_

Interviewer:\_\_\_

The focus of this evaluation assessment is to assess the USAID funded palliative care program implemented by the HPCA.

My purpose in talking with you today is to learn more about your thoughts, feelings, and experiences with the program.

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Your participation in this interview is completely voluntary. Are you willing to be interviewed?

Do you have any questions before we begin?

#### ACTIVITY A : Capacity building-Organizational structure

- Briefly describe the national palliative care strategy and how HPCA contributes to this strategy?
- Could you briefly describe HPCA's organizational structure at the national and regional level?
- What are the roles of various committees [National sub-committee, Provincial and Regional committees]
- Please describe activities undertaken by HPCA to sustain and develop the Management committee (MANCO)?
- How is the USAID program managed and coordinated? [ Who is in directly in charge, reporting lines, coordination, operations, finance, grants making, reporting]
- How would you describe the functioning of your grants to member hospices, any challenges and successes ?
- Briefly describe the relationship between HPCA and member hospices under this program
- Please describe your capacity building activities under the USAID programme in South Africa?
- How many member hospices are supported under this program? [palliative care service delivery sites]
- Could you explain how the HPCA mentorship programme functions
- Describe the current functioning of the palliative care resource centres?

- How do you select organizations for capacity building support?
- Describe the training you undertake for capacity building within HPCA?
- Describe the training undertaken for capacity building for member hospices?
- What role does the NDOH and Regional Department of Health play in your capacity building activities?
- What activities do you undertake to build the capacity of the NDOH and Regional Department of Health?
- What have been some of your successes?
- What have been some of the challenges?
- What recommendations would you make to improve capacity building activities?

#### ACTIVITY B: Provincial palliative care structure

- Please describe how provincial palliative care structures are set up ?
- Describe the role of provincial palliative care structures in supporting member hospices?
- How does HPCA facilitate the development and implementation of development plans and palliative care strategic plans, at new palliative care sites [ Might be covered under question I, if so only add extra information if needed]
- Please describe the contribution of provincial palliative care structures to public sector services
- Describe the key roles of HPCA staff at the provincial palliative care level
- Describe the support provided by the National office to the provincial structures?
- What have been the successes in the work of the provincial structures
- What have been some of the challenges
- What recommendation would you make to improve the functioning of the provincial structures
- Describe the process for setting up new palliative care sites provincially?

#### ACTIVITY C: Government collaboration, Gender, Advocacy and Liaison

- Please describe HPCA's work with Government of South Africa?
- What specific technical assistance requests have been made by Government of South Africa to HPCA? [policies, guidelines, training, M&E]
- Which committees at the national and regional level does HPCA attend and contribute to?
- Describe the role of the advocacy subcommittee to this program
- What research has HPCA undertaken as part of its collaboration with government
- Please describe HPCA collaboration with other partners besides government in South Africa [Probe about the work with palliative care society of South Africa]
- Elaborate on the development of the reference guide for patient rights and legal services for palliative care that HPCA has been working on
- Can you briefly describe the work you do related to gender [Probe about implementing the HPCA gender guidelines of 2008-Task-Training, promoting gender sensitivity and awareness amongst members, ]

- How best do you think your gender work can be fully incorporated into this program going forward?

#### ACTIVITY D: Training/Human Capacity Development

- Describe the role and functioning of the following structures
- Provincial mentor
- Accredited mentor hospices
- Provincial palliative care development coordinator
- Palliative care development team
- Describe the role of provincial palliative care education forums
- Explain the functioning of centres for palliative learning (CPL)
- Describe the range of training programs and courses supported by HPCA under this program? [Probe about support to tertiary education]
- Describe your involvement in palliative care education nationally and regionally [targets and achievements]
- Adult and paediatric palliative care
- Home based care,
- TB
- HIV counselling and testing/VCT
- OVC
- HIV care and treatment
- What have been some of the successes with your support to palliative care education?
- What have been some of the challenges with your support to palliative care education?
- What recommendation do you have to improve your support for palliative care education?

#### ACTIVITY E: Strategic partnerships /Member Hospices

- Please describe HPCA's support to member hospices?
- What are the benefits that HPCA provides to member hospices?
- How do you identify new palliative care sites for development
- How do you develop new palliative care sites
- Please describe the strategy for sub-district expansion of palliative care \* [Duplicate question]
- Describe activities undertaken by HPCA to build member hospices capacity to provide palliative care services
- How do you facilitate the development of palliative care partnerships between member hospices and other organizations?
- What have been some of the successes in these efforts to build capacity?
- What have been some of the challenges in these efforts to build capacity?
- What recommendation would you make to improve your capacity building efforts?

#### ACTIVITY F: Accreditation and Quality Improvement

- Please describe HPCA's accreditation and quality improvement system?
- What has been your experience in implementing quality monitoring and improvement?
- What has been HPCA's role in setting Standards for Palliative care in South Africa?
- What are the key components of the Standards for Palliative care in South Africa
- How has HPCA assisted in the expansion of accreditation and quality improvement of member hospices?
- What have been some of the successes and challenges of implementing accreditation and quality improvement
- What recommendation would you make to improve the process?

**ACTIVITY G: Adult palliative care services**

- Please describe services provided through HPCA support by member hospices & the Bana Pele Project under adult palliative care services including program targets, populations served, and districts targeted [Probe which specific officer is in charge at HPCA of these portfolio]
- Home based care
- Day care
- In patient care
- Provision of psychological services
- Clinical services: provision of opportunistic infection prevention and treatment including TB, HIV and AIDS related complications including malaria and diarrhoea
- Pain and symptom management
- Nutrition support: Assessments and therapeutic feeding
- Preventive care package\*
- Social support
- HIV testing/VCT
- Screening for ARV
- Screening for TB
- TB treatment
- Infection control for TB
- Community based services
- Please describe significant successes in providing adult palliative care through member hospices?
- Please explain any significant challenges in achieving your targets in providing adult palliative care through member hospices?
- In what way could this support have been improved?

**ACTIVITY H: Paediatric palliative care services**

- Please describe services provided through HPCA support by member hospices & the Bana Pele Project under paediatric palliative care services including program targets, populations served, and districts targeted [Probe which specific officer is in charge at HPCA of these portfolio]
- Home based care

- Day care
- Early infant diagnosis
- In patient care
- Provision of psychological and spiritual services
- Clinical services: provision of opportunistic infection prevention and treatment including TB, HIV and AIDS related complications including malaria and diarrhoea
- Preventive care package\*
- Social support
- HIV testing/VCT
- Screening for ARV
- Screening for TB
- Infection control for TB
- TB treatment
- Community based services
- Social support
- Protection and legal aid
- Early child hood development programs
- Identification of OVCs\* [Using vulnerability index]
- Assisting with access to education
- Liaison with department of social development and department of education
- Economic support
- Nutrition support: Assessments and therapeutic feeding
- Bereavement support, memory training, resilience
- HIV prevention education and counseling
- Please describe significant successes in providing paediatric palliative care through member hospices?
- Please explain any significant challenges in achieving your targets in providing paediatric palliative care through member hospices?
- In what way could this support have been approved?

#### ACTIVITY I: Public policy and awareness

- Describe HPCA role in promoting public awareness about palliative care in South Africa
- Describe HPCA role in policy development for palliative care in South Africa
- What successes and challenges have you noted in these roles?
- What recommendation would you make to strengthen these roles?

#### ACTIVITY J: Monitoring and Evaluation

- Briefly describe how you monitor programs implemented in the region using the Health Data management system (HDMS)?
- How do you support new and member hospices to roll out HDMS?
- What reports do you submit?
- Who do you send reports to?
- How do you ensure data quality? [Probe: Audits, timeliness, survey]

- What challenges have you noted in monitoring the programs
- What suggestions would you make to improve data collection and reporting if any ?

#### ACTIVITY K: Program design/Grants Management

- Can you briefly describe the key components of your USAID funded palliative care program
- Describe how HPCA manages sub awards to member hospices?
- What are the components of this program that you believe will enhance its sustainability?
- What have been some of the key lessons in terms of successes of this program
- What have been some of the key challenges
- Did the program achieve its aims? Describe how [Briefly]
- What recommendation would you make to USAID to improve the implementation of this program going forward

#### INTERVIEW GUIDE FOR NDOH

Name: \_\_\_\_\_ Date: \_\_\_\_\_

Time: \_\_\_\_\_

Position: \_\_\_\_\_

Interviewer:\_\_\_

The focus of this evaluation assessment is to assess the USAID funded palliative care program implemented by the HPCA.

My purpose in talking with you today is to learn more about your thoughts, feelings, and experiences with the program.

Anything you tell me will not be personally attributed to you in any reports that result from this evaluation. All of the reports will be written in a manner that no individual comment can be attributed to a particular person.

The interview will take about 70 to 90 minutes

Your participation in this interview is completely voluntary. Are you willing to be interviewed?

Do you have any questions before we begin?

#### Program implementation and design

- Briefly describe your role in palliative health care [Nationally and Regionally]

- Could you describe the work and contribution of HPCA in palliative health care in RSA Nationally and Regionally [Probe on knowledge about National, Regional and District structures, member hospices]
- Describe your experience working with HPCA nationally and regionally?
- What would you consider to be the significant successes of the HPCA programme?
- What have been some of the challenges?
- What recommendations would you make to improve program implementation and activities?

#### Service Delivery

- How would you describe HPCA contribution to service delivery for palliative care nationally and regionally?
- Reach : no of sites, region
- Recipients of services
- Equity in delivery
- What in your mind have been the key components that you believe created value?
- How has HPCA involved the government in ensuring quality of service delivery in the palliative care program they support
- What has been the contribution of HPCA member hospices in palliative care service delivery?
- What recommendations would you make to the program to improve service delivery?

#### Palliative care education and training

- How would you describe HPCA contribution to palliative care education and training for palliative care nationally and regionally?
- Briefly describe some specific HPCA education and training program you are aware of ?
- How does HPCA involve the government in their education and training activities?

#### Health System strengthening

- How has the HPCA contributed to health system strengthening [ Probe on the following-WHO Key component of a well-functioning health system]
- Leadership and Governance policy,
- Human Resources,
- Health Information systems,
- Finance
- Access to medical products

#### Government collaboration, Policy and public awareness

- How would you describe your collaboration with HPCA in general?
- What has been HPCA contribution to policy and public awareness in palliative care?
- What have been the significant successes in your collaboration
- How can the collaboration be improved?

Lessons learned

- What lessons are there for similar program implemented by other partners in South Africa
- How can this lessons be replicated and what do you see as your role as government?

Sustainability

- What are your thoughts on the sustainability of the initiatives implemented under the HPCA palliative care program
- What are some of the benefits of this program that you believe will be long lasting?
- Which components of this program do you believe still need to be supported? And Why?

FOCUS GROUP DISCUSSION GUIDE

COMMUNITY WORKERS

Name: \_\_\_\_\_ Date: \_\_\_\_\_

Time: \_\_\_\_\_

Position: \_\_\_\_\_

Interviewer:\_\_\_

The focus of this evaluation assessment is to assess the USAID funded palliative care program implemented by the HPCA.

My purpose in talking with you today is to learn more about your thoughts, feelings, and experiences with the program.

Anything you tell me will not be personally attributed to you in any reports that result from this evaluation. All of the reports will be written in a manner that no individual comment can be attributed to a particular person.

The DISCUSSION will take about 180 minutes

Your participation in this interview is completely voluntary. Are you willing to be interviewed?

Do you have any questions before we begin? Please feel free to participate fully as your responses will really help us in improving services

#### ACTIVITY A : Service Delivery

- Could you briefly describe your role with palliative care in the Community?
- How were you selected?
- Are you clear about your roles and responsibilities?
- Do you receive regular support ? From whom ? How would you describe this support? How can it be improved ?
- Could you also describe which palliative care centre you work with or under ? [How do they support you ? What services do you provide to the centre?]
- What has been your experience with Implementing community based services
- Successes
- Challenges
- How can they be improved
- Do you anything you would like to add?

#### ACTIVITY B: Training/Human Capacity Development

- What training have you been provided with to enable you carry out your duties?
- Who carried out the training? [HPCA, Hospices, NDOH, others]
- How would you describe the training? What is useful how did it help you undertake your duties? How can they be improved?
- What support were you/are you provided with after trainings?
- How else are you supported to carry out our responsibilities in the community?

#### ACTIVITY C : Adult palliative care services

- Please describe the services you provide
- How does HPCA support directly and indirectly?
- Home based care
- Provision of psychological services
- Preventive care package\* [HIV prevention]
- Social support
- HIV testing referral for family members
- Screening for TB and referral for treatment
- Please describe significant successes in these services you provide?
- Please explain any significant challenges?
- How do you ensure community participation
- In what way could this support have been improved?

#### ACTIVITY D: Paediatric palliative care services

- Please describe services provided
- Home based care
- Early infant diagnosis referral

- Provision of psychological and spiritual services
- Social support
- HIV testing/VCT referral
- Screening for TB and referral for treatment
- Infection control for TB
- Protection and legal aid
- Identification of OVCs\* [Using vulnerability index]
- Assisting with access to education
- Liaison with department of social development and department of education
- Economic support
- Nutrition support: Assessments and therapeutic feeding
- Bereavement support, memory training, resilience
- HIV prevention education and counseling
- Please describe significant successes ?
- Please explain any significant challenges?
- In what way could this support have been approved?

#### ACTIVITY E : Monitoring and Evaluation

- Briefly describe how the work you do is monitored?
- How do you report the activities you undertake in the community?
- Who do you report these activities to? Do you find this useful? Why or why not?
- How do you think the work you do can be improved ? [Could be repeat of 6 A]

### INTERVIEW GUIDE FOR HPCA NATIONAL OFFICE

#### REGIONAL MANAGER

Name: \_\_\_\_\_ Date: \_\_\_\_\_

Time: \_\_\_\_\_

Position: \_\_\_\_\_

Interviewer: \_\_

The focus of this evaluation assessment is to assess the USAID funded palliative care program implemented by the HPCA.

My purpose in talking with you today is to learn more about your thoughts, feelings, and experiences with the program.

Anything you tell me will not be personally attributed to you in any reports that result from this evaluation. All of the reports will be written in a manner that no individual comment can be attributed to a particular person.

The interview will take about 120 minutes

Your participation in this interview is completely voluntary. Are you willing to be interviewed?

Do you have any questions before we begin?

#### ACTIVITY A: Capacity building-Organizational structure

- Could you briefly describe HPCA's organizational structure at the regional level?
- Briefly describe the relationship between HPCA and member hospices under this program
- Please describe your capacity building activities under the USAID programme in South Africa?
- How many member hospices are supported under this program in your region? [palliative care service delivery sites, how do you manage and coordinate the program at provincial level]
- Could you explain how the HPCA mentorship programme functions
- How do you select organizations for capacity building support?
- What role does the NDOH and Regional Department of Health play in your capacity building activities?
- What activities do you undertake to build the capacity of the NDOH and Provincial Department of Health?
- What have been some of your successes?
- What have been some of the challenges?
- What recommendations would you make to improve capacity building activities?

#### ACTIVITY B: Provincial palliative care structure

- Please describe how provincial palliative care structures are set up [Palliative care development teams, how palliative care strategies are developed and implemented]?
- Describe the role of provincial palliative care structures in supporting member hospices?
- Please describe the contribution of provincial palliative care structures to public sector services
- Describe the key roles of HPCA staff at the regional and provincial palliative care levels
- Describe the support provided by the National office to the provincial structures?
- What have been the successes in the work of the provincial structures
- What have been some of the challenges
- What recommendation would you make to improve the functioning of the provincial structures
- Describe the process for setting up new palliative care sites regionally?

#### ACTIVITY C: Government collaboration, Gender, Advocacy and Liaison

- Please describe HPCA's work with Provincial Departments?
- What specific technical assistance requests have been made by Provincial Departments to HPCA? [policies, guidelines, training, M&E]

- Which committees at the Provincial level does HPCA attend and contribute to?
- Please describe HPCA collaboration with other partners besides government
- Describe activity carried out to promote gender sensitivity and awareness as part of implementing HPCA gender guidelines of 2008

#### ACTIVITY D: Training/Human Capacity Development

- Describe the role and functioning of the following structures
- Regional Manager
- Provincial mentor
- Accredited mentor hospices
- Provincial palliative care development coordinator
- Palliative care development team
- Describe the role of provincial palliative care education forums
- Explain the functioning of centres for palliative learning (CPL)
- Describe your involvement in palliative care education regionally [ targets and achievements]
- Adult and paediatric palliative care
- Home based care,
- TB
- HIV counselling and testing/VCT
- OVC
- HIV care and treatment
- What have been some of the successes with your support to palliative care education?
- What have been some of the challenges with your support to palliative care education?
- What recommendation do you have to improve your support for palliative care education?

#### ACTIVITY E: Strategic partnerships /Member Hospices

- Please describe HPCA's support to member hospices?
- What are the benefits that HPCA provides to member hospices?
- Describe activities undertaken by HPCA to build member hospices capacity to provide palliative care services
- How do you facilitate the development of palliative care partnerships between member hospices and other organizations?
- What have been some of the successes in these efforts to build capacity?
- What have been some of the challenges in these efforts to build capacity?
- What recommendation would you make to improve your capacity building efforts?

#### ACTIVITY F: Accreditation and Quality Improvement

- Please describe HPCA's accreditation and quality improvement system implemented with COHSASA for member hospices?

- Kindly describe how you conduct initial and follow up surveys at member hospices?
- How do you appoint, support and monitor accredited mentor hospices?
- What has been your experience in implementing quality monitoring and improvement?
- How has HPCA assisted in the expansion of accreditation and quality improvement of member hospices?
- What have been some of the successes and challenges of implementing accreditation and quality improvement
- What recommendation would you make to improve the process?

#### ACTIVITY G: Adult palliative care services

- Please describe services provided through HPCA support by member hospices under adult palliative care services including program targets, populations served, and districts targeted, how do you support the provision of these services directly and indirectly?
- Home based care
- Day care
- Outpatient care
- In patient car
- Provision of psychological services
- Clinical services: provision of opportunistic infection prevention and treatment including TB, HIV and AIDS related complications including malaria and diarrhoea
- Pain and symptom management
- Nutrition support: Assessments and therapeutic feeding
- Preventive care package\*
- Social support
- HIV testing/VCT
- Screening for ARV
- Screening for TB and referral for treatment
- TB treatment : DOTS/Lab monitoring
- Infection control for TB
- Community based services
- Please describe significant successes in providing adult palliative care through member hospices?
- Please explain any significant challenges in achieving your targets in providing adult palliative care through member hospices?
- In what way could this support have been improved?

#### ACTIVITY H: Paediatric palliative care services

- Please describe services provided through HPCA support by member hospices under paediatric palliative care services including program targets, populations served, and districts targeted how do you support the provision of these services directly and indirectly?
- Home based care

- Day care
- Early infant diagnosis
- In patient care
- Provision of psychological and spiritual services
- Clinical services: provision of opportunistic infection prevention and treatment including TB, HIV and AIDS related complications including malaria and diarrhoea
- Preventive care package\*
- Social support
- HIV testing/VCT
- Screening for ARV
- Screening for TB
- Infection control for TB
- TB treatment
- Community based services
- Social support
- Protection and legal aid
- Early child hood development programs
- Identification of OVCs\* [Using vulnerability index]
- Assisting with access to education
- Liaison with department of social development and department of education
- Economic support
- Nutrition support: Assessments and therapeutic feeding
- Bereavement support, memory training, resilience
- HIV prevention education and counseling
- Please describe significant successes in providing paediatric palliative care through member hospices?
- Please explain any significant challenges in achieving your targets in providing paediatric palliative care through member hospices?
- In what way could this support have been approved?

#### ACTIVITY I: Public policy and awareness

- Describe HPCA role in promoting public awareness about palliative care ?
- What successes and challenges have you noted in these roles?
- What recommendation would you make to strengthen these roles?

#### ACTIVITY J: Monitoring and Evaluation

- Briefly describe how you monitor programs implemented in the region using the Health Data management system (HDMS)?
- How do you support member hospices to roll out HDMS?
- What reports do you submit?
- Who do you send reports to?
- How do you ensure data quality [Audits, checks, mentorship]
- What challenges have you noted in monitoring the programs

- What suggestions would you make to improve data collection and reporting if any?

## INTERVIEW GUIDE FOR USAID

Name: \_\_\_\_\_ Date: \_\_\_\_\_

Time: \_\_\_\_\_

Position: \_\_\_\_\_

Interviewer:\_\_\_

The focus of this evaluation assessment is to assess the USAID funded palliative care program implemented by the HPCA.

My purpose in talking with you today is to learn more about your thoughts, feelings, and experiences with the program.

Anything you tell me will not be personally attributed to you in any reports that result from this evaluation. All of the reports will be written in a manner that no individual comment can be attributed to a particular person.

The interview will take about.....minutes

Your participation in this interview is completely voluntary. Are you willing to be interviewed?

Do you have any questions before we begin?

### ACTIVITY A : Capacity building-Organizational structure

- Briefly describe the national palliative care strategy and how HPCA contributes to this strategy?
- Could you briefly describe HPCA's organizational structure at the national and regional level?
- How is the USAID program managed and coordinated? [ Who is in directly in charge, reporting lines, coordination, operations, finance, grants making, reporting]
- Briefly describe the relationship between HPCA and member hospices under this program
- How many member hospices are supported under this program? [palliative care service delivery sites]
- What are some of the significant successes of HPCA palliative care program
- Training
- Selection of palliative care sites
- Service delivery
- Contribution to the National HIV response
- Work with NDOH nationally and regionally
- Describe the support provided by USAID technical officers to the HPCA National office?

- Can you describe the relationship between HPCA and the NDOH and Provincial Departments of Health ?
- What recommendations would you make to improve the program going forward?

#### ACTIVITY B: Provincial palliative care structure

- Please describe how provincial palliative care structures are set up ?
- Describe the role of provincial palliative care structures in supporting member hospices?
- Please describe the contribution of provincial palliative care structures to public sector services
- What have been the successes in the work of the provincial structures
- What have been some of the challenges
- What recommendation would you make to improve the functioning of the provincial structures

#### ACTIVITY C: Government collaboration, Advocacy and Liaison

- Please describe HPCA's work with Government of South Africa?
- What specific technical assistance requests have been made by Government of South Africa to HPCA? [policies, guidelines, training, M&E]
- Which committees at the national and regional level does HPCA attend and contribute to?
- What research has HPCA undertaken as part of its collaboration with government
- Please describe HPCA collaboration with other partners besides government in South Africa [Probe about the work with palliative care society of South Africa]
- Elaborate on the development of the reference guide for patient rights and legal services for palliative care that HPCA has been working on

#### ACTIVITY D: Training/Human Capacity Development

- Describe the role and functioning of the following structures
- Provincial mentor
- Accredited mentor hospices
- Provincial palliative care development coordinator
- Palliative care development team
- Describe the role of provincial palliative care education forums
- Describe the range of training programs and courses supported by HPCA under this program? [Probe about support to tertiary education]
- Adult and paediatric palliative care
- Home based care,
- TB
- HIV counselling and testing/VCT
- OVC
- HIV care and treatment

- What have been some of the successes with HPCA support to palliative care education?
- What have been some of the challenges with HPCA support to palliative care education?
- What recommendation do you have to improve your support for palliative care education?

#### ACTIVITY E: Strategic partnerships /Member Hospices

- Please describe HPCA's support to member hospices?
- What are the benefits that HPCA provides to member hospices?
- What have been some of the successes in these efforts to build capacity?
- What have been some of the challenges in these efforts to build capacity?
- What recommendation would you make to improve your capacity building efforts?

#### ACTIVITY F: Accreditation and Quality Improvement

- Please describe HPCA's accreditation and quality improvement system?
- What has been your experience with the implementation of quality monitoring and improvement by HPCA?
- What has been HPCA's role in setting Standards for Palliative care in South Africa?
- What have been some of the successes and challenges of implementing accreditation and quality improvement ?
- What recommendation would you make to improve accreditation and quality improvement?

#### ACTIVITY G: Adult palliative care services

- Please describe services provided through HPCA support by member hospices & the Bana Pele Project under adult palliative care services including program targets, populations served, and districts targeted
- Home based care
- Day care
- In patient care
- Provision of psychological services
- Clinical services: provision of opportunistic infection prevention and treatment including TB, HIV and AIDS related complications including malaria and diarrhoea
- Pain and symptom management
- Nutrition support: Assessments and therapeutic feeding
- Preventive care package\*
- Social support
- HIV testing/VCT
- Screening for ARV
- Screening for TB
- TB treatment
- Infection control for TB

- Community based services
- Please describe significant successes in providing adult palliative care ?
- Please explain any significant challenges in achieving your targets in providing adult palliative care ?
- In what way could this support have been improved?

#### ACTIVITY H: Paediatric palliative care services

- Please describe services provided through HPCA support by member hospices & the Bana Pele Project under paediatric palliative care services including program targets, populations served, and districts targeted
- Home based care
- Day care
- Early infant diagnosis
- In patient care
- Provision of psychological and spiritual services
- Clinical services: provision of opportunistic infection prevention and treatment including TB, HIV and AIDS related complications including malaria and diarrhoea
- Preventive care package\*
- Social support
- HIV testing/VCT
- Screening for ARV
- Screening for TB
- Infection control for TB
- TB treatment
- Community based services
- Social support
- Protection and legal aid
- Early child hood development programs
- Identification of OVCs\* [Using vulnerability index]
- Assisting with access to education
- Liaison with department of social development and department of education
- Economic support
- Nutrition support: Assessments and therapeutic feeding
- Bereavement support, memory training, resilience
- HIV prevention education and counseling
- Please describe significant successes in providing paediatric palliative care through the HPCA palliative program?
- Please explain any significant challenges in achieving your targets in providing paediatric palliative care ?
- In what way could this support have been approved?

#### ACTIVITY I: Public policy and awareness

- Describe HPCA role in promoting public awareness about palliative care in South Africa

- Describe HPCA role in policy development for palliative care in South Africa
- What successes and challenges have you noted in these roles?
- What recommendation would you make to strengthen these roles?

ACTIVITY J: Monitoring and Evaluation

- Briefly describe how HPCA monitors programs implemented using the Health Data management system (HDMS)?
- What challenges have you noted in monitoring the programs
- What suggestions would you make to improve program monitoring?

ACTIVITY K: Program design/Grants Management

- What have been some of the key lessons in terms of successes of this program
- What have been some of the key challenges
- Did the program achieve its aims? Describe how [Briefly]
- What recommendation would you make to USAID to improve the implementation of this program going forward

## ANNEX E: HPCA PROGRAM DATA

### DATA QUESTIONNAIRE HPCA ASSESSMENT EVALUATION RSA

#### Organizational Capacity

AREA	2009	2010	2011	2012
<b>Organizational staffing</b>	46	47	63	67
<b>Organizational strategic plan available</b>	Yes	Yes	Yes	Yes
<b>No of board meetings held</b>	4	4	4	3 & 1 to come
<b>Number of strategic planning meetings held</b>	1	1	1	1
<b>Number of portfolio meetings held Organisational Dev. OD</b>	11	8	0 See Core meetings	0 See Core meetings
<b>Number of portfolio meetings held Advocacy</b>	4	4	11	9
<b>Number of portfolio meetings held Patient Care</b>	0	4	0 See Core meetings	0 See Core meetings
<b>Number of portfolio meetings held M &amp; E</b>	12	12	0 See Core meetings	0 See Core meetings
<b>Number of portfolio meetings held Finance &amp; Resource Development</b>	4	3	1	0
<b>Number of Core Meetings (replaces portfolio meetings) NATIONALLY</b>	0	0	37	43
<b>Number of organizational management meetings held</b>	12	12	12	11 & 1 to come
<b>% of management meetings with minutes available</b>	100%	100%	100%	100%
<b>Finance* (US funded project) in SA Rands</b>	44,927,195	76,533,335	84,323,711	90,979,313
<b>No of regional committee meetings held (Total NATIONAL)</b>	27	27	27	23 & 7 to come
<b>No of resource centres established</b>	10	16	20	24
<b>Job description available and updated for key position HPCA Nationally, Regionally and Provincially</b>	Yes	Yes	Yes	Yes
<b>Record of communication of regional meetings and minutes recorded</b>	Yes	Yes	Yes	Yes

Capacity building/Quality Assurance-HPCA

AREA	2009	2010	2011	2012
<b>Document of hospice standards</b>	Yes	Yes	Yes	Yes
<b>Number of service outlets providing care and support</b>	211	191	178	176
<b>Number of old regional centers for palliative learning/training supported</b>	11	11	11	10
<b>Number of new regional centers for palliative learning training</b>	0	0	8	8
<b>Number of Provincial Palliative Care Development Teams in place</b>	5	5	7	8

Training in Palliative care [ Needs to be disaggregated by gender, sex and race]

AREA	2009	2010	2011	2012
<b>Percentage of provinces with an annual training plan</b>				
<b>Number of individuals trained</b>	7483	21587	8885	8544

Provincial palliative care structures

AREA	2009	2010	2011	2012
<b>Number of exemplar hospices identified in each province (mentor Hospices)</b>	11	18	97	105
<b>Number of palliative care task teams in each province (Nationally)</b>	16	19	27	35
<b>Number of new palliative care initiatives in each province* (Emerging Sites)</b>	48	53	77	71
<b>Number of regional committee meetings held*evidence</b>	Yes	Yes	Yes	Yes

District palliative care structures

AREA	2009	2010	2011	2012
<b>Number of exemplar hospices identified in each district(Districts with Mentor hospices)</b>	9	12	40	48
<b>Number of palliative care task teams in each province (NATIONALLY)</b>	16	19	27	35
<b>Number of palliative care resource centers</b>	10	14	18	22

Sub-District palliative care structures

AREA	2009	2010	2011	2012
<b>Number of sub-health districts supported</b>	115	119	113	99
<b>Number of organizations in sub health districts supported</b>	202	198	189	187

Counselling and Testing

AREA	2009	2010	2011	2012
<b>Number of providers trained in HIV testing and counselling and completed training according to national/international standards</b>	n/a	7	10	11
<b>Number of people counseled and tested and receiving their results</b>	n/a	Gender: Males = 2769 Females = 2694 Age: Above 15 = 5191 Below 15 = 272	Gender: Males = 4634 Females = 6274 Age: 0-14 yrs = 312 15-24 yrs = 3332 25+ yrs = 7264	Gender: Males = 5632 Females = 6754 Age: 0-14 yrs = 889 15-24 yrs = 3766 25+ yrs = 7731
<b>Number of people HIV positive disaggregated by age and gender</b>	n/a	Gender: Males = 371 Females = 505 Age: Above 15 = 828 Below 15 = 48	Gender: Males = 886 Females = 1427 Age: 0-14 yrs = 52 15-24 yrs = 610 25+ yrs = 1651	Gender: Males = 757 Females = 1049 Age: 0-14 yrs = 90 15-24 yrs = 378 25+ yrs = 1338
<b>Number of people HIV positive disaggregated by age and symptom screened for TB</b>	n/a	Gender: Males = 371 Females = 505 Age: Above 15 = 828 Below 15 = 48	Gender: Males = 589 Females = 886 Age: 0-14 yrs = 25 15-24 yrs = 294 25+ yrs = 1156	Gender: Males = 598 Females = 977 Age: 0-14 yrs = 91 15-24 yrs = 318 25+ yrs = 1166
<b>Test kits stocks</b>	n/a	n/a	n/a	n/a

status\*

Adult Palliative care

AREA	2009	2010	2011	2012
<b>Number of people receiving at least one palliative care service disaggregated by race and gender</b>	Gender: Males = 28398 Females = 44418 Race: Black = 53884 Coloured = 10194 Asian = 1456 White = 7282	Gender: Males = 25630 Females = 45565 Race: Black = 59092 Coloured = 8543 Asian = 712 White = 2848	Gender: Males = 35493 Females = 59092 Race: Black = 74722 Coloured = 13242 Asian = 946 White = 5675	Gender: Males = 34924 Females = 59507 Race: Black = 71768 Coloured = 16053 Asian = 944 White = 5666
<b>Number of people receiving in patient palliative care services</b>		712	3783	2833
<b>Number of people receiving home based care</b>		70483	90802	91598
<b>Number of patients undergoing assessment*</b>	72816	71195	94585	94431
<b>Number of family members receiving behavioural counselling (add testing to the testing section) Statistics on interventions are not available currently as all HPCA members are not yet on the HDMS</b>	Not collected/not captured	Not collected/not captured	Not collected/not captured	Not collected/not captured

Tuberculosis/TB-HIV

AREA	2009	2010 (Oct – Dec 2010)	2011 (April – June 2011)	2012 (Jan – Mar 2012)
<b>Number of people screened for TB disaggregated*</b>		Patients: Males = 2562 Females = 4557 Children = 295 Family: Males = 843 Females = 1161 Children = 284 Staff/Volunteers: Males = 75 Females = 798	Patients: Males = 3300 Females = 5849 Children = 323 Family: Males = 2925 Females = 4825 Children = 578 Staff/Volunteers: Males = 81 Females = 428	Patients: Males = 4766 Females = 6015 Children = 673 Family: Males = 1206 Females = 1671 Children = 247 Community: Males = 955 Females = 1177 Children = 0 Staff/Volunteers: Males = 86 Females = 659
<b>Number of people receiving TB services as part of home based care</b>		10575	18309	17455
<b>Number of people screened and referred for further TB investigation disaggregated*</b>		Patients: Males = 471 Females = 681 Children = 41 Family: Males = 172 Females = 317 Children = 29 Staff/Volunteers: Males = 12 Females = 112	Patients: Males = 678 Females = 767 Children = 91 Family: Males = 527 Females = 819 Children = 128 Staff/Volunteers: Males = 8 Females = 59	Patients: Males = 474 Females = 686 Children = 92 Family: Males = 383 Females = 470 Children = 135 Community: Males = 166 Females = 6 Children = 0 Staff/Volunteers: Males = 60 Females = 88
<b>Number of people on TB DOTS treatment including clinical and</b>				

<b>laboratory monitoring</b> <b>This is not an indicator which we collect data on currently</b>			
<b>Number of people started on TB treatment*</b>	Patients & Family: Males = 763 Females = 914 Children = 63 Staff/Volunteers: Males = 13 Females = 21	Patients & Family: Males = 650 Females = 842 Children = 124 Staff/Volunteers: Males = 3 Females = 8	Patients & Family: Males = 804 Females = 912 Children = 199 Staff/Volunteers: Males = 14 Females = 16
<b>Number of infection control risk assessment done</b>			
<b>Availability of infection control plans</b>			

OVC & Pediatric Children (\*in 2009 & 2010 The HPCA MER system could identify the unique number of children who received services but not identify how many each child received. The HPCA thus tracked the number of interventions children received)

AREA	2009		2010		2011		2012	
	M	F	M	F	M	F	M	F
<b>Number screened for vulnerability using the HPCA Vulnerability Score*</b>	2792	2673	7124	6477	12091	11636	6363	6158
<b>Number of recipients of children support services*</b>	2792	2673	7124	6477	12091	11636	6363	6158
<b>Number of children receiving basic education support</b>	21201		15317	13490	328	370	1283	1289
<b>Number of children receiving health care services (including HIV care and treatment)</b>	22849		15035	14422	1460	1609	3431	3810
<b>Number of OVCs receiving protection and legal aid</b>	6668		13660	13673	1030	1197	2705	2905
<b>Number of OVCs receiving economic support</b>	7848		4830	4613	311	350	900	981
<b>Number of</b>	Included under the number of children who received health care services							

<b>OVCs receiving health care services (including HIV care and treatment)</b>								
<b>Number of OVCs psychosocial and counselling support</b>	22849		12209	10971	308	333	974	1139
<b>Number of OVCs receiving HIV testing and counselling services</b>	Not measured with the Children's database							
<b>Number of youth/child headed households assisted</b>	Statistics on this intervention is collected via the HDMS but not currently extracted into a report							
<b>Number of OVCs referred for HIV treatment</b>	Not measured with the Children's database							

AREA	2009		2010		2011		2012	
	M	F	M	F	M	F	M	F
<b>Number of infants reached with early infant diagnosis</b>	Not measured with the Children's database							
<b>Number of children reached by day care centre</b>								
<b>Number of children</b>	2792	2673	7124	6477	12091	11636	6363	6158

<b>undergoing assessment to receive OVC care*</b>								
<b>Number of children receiving nutritional assessment and support</b>	22213	4870	4665	156	201	568	692	
<b>Number of children receiving psychological and spiritual support assessment and support</b>	22849	12209	10971	308	333	974	1139	

#### Monitoring and Evaluation Systems

<b>AREA</b>	<b>2009</b>	<b>2010</b>	<b>2011</b>	<b>2012</b>
<b>Number of MER operational procedures developed</b>	3	16	8	3
<b>Number of HPCA members where MER guidelines were implemented</b>	n/a	10	50	
<b>Number of Data Quality Assessments conducted</b>	1	12	27	14
<b>Number of presentations conducted to promote a favourable environment for MER</b>	91	65	17	61
<b>Number of site visits conducted to HPCA members</b>	n/a	n/a	99	50
<b>Number of HPCA members where the HDMS was rolled out</b>	9	39	58	67
<b>Number of data capturers trained on HDMS data capture and utilization</b>	9	60	58	75

Public awareness and policy development : Data not collected

AREA	2009	2010	2011	2012
<b>Number of advocacy referrals to HPCA portfolios</b>				
<b>Number of advocacy requests received from HPCA portfolios</b>				
<b>Number of advocacy activities executed with civil society at sub-district, district, provincial and national levels</b>				
<b>Number of individuals reached through advocacy-related community events</b>				

## ANNEX F: FRAMEWORK ANALYSIS MATRIX [RAW DATA]

THEMATIC AREA	KZN	EC	WC	NC	GAUTENG
<b>ACTIVITY A: Capacity building, organizational development, national and regional structures</b>	<p>Hospice programs are on the same standards with other hospices, e.g. infection control.</p> <p>The hospice is updated on new policies and guidelines.</p> <p>Networking partners – HPCA has signed MOU with departments such as Correctional Services, Defense and as a result of these partnerships Hospice is able to receive medical/clinical support to help low end affiliates.</p> <p>Increased awareness of palliative care, especially in view of the fact that the DOH has low</p>	<p>Improved the quality of services provided.</p> <p>Confidence of the staff providing the services.</p> <p>Able to maintain the standards– accreditation (maintaining 5 star rating).</p> <p>Well informed and updated about the palliative care services.</p> <p>Good relationship and trust from the community.</p> <p>Majority of hospice (4) indicated that CPL provided them with educational materials and training opportunities, which are needed to</p>	<p>Funding for TB.</p> <p>Funding for OVC care</p> <p>Support for attending conferences.</p> <p>Organizational development, quality improvement, networking, sustainability tools.</p> <p>Quarterly Regional meetings, organizational development programme.</p> <p>Palliative care, Leadership development.</p> <p>Regional / international exposure – Conferences &amp; HPCA quarterly meetings.</p>	<p>Training of Board on governance and leadership.</p> <p>Supported establishment of District Aids Council.</p> <p>Non-graded hospices do not receive direct mentoring apart from telephonic support.</p> <p>Salary for staff and funds for patient care.</p> <p>Hospices have a board which includes community members.</p> <p>All hospices have a hospital manager, however they often have other responsibilities than</p>	<p>To broaden the spectrum on palliative care to start at diagnosis, not deal with pain only.</p> <p>Assist HBC to move to nursing to upgrade the level of CHW to be professional.</p> <p>Increased knowledge on Pediatric Palliative Care, M&amp;E development.</p> <p>Accessible if stuck by telephone for guidance.</p> <p>4 Staff members received bursaries for social auxiliary nurse.</p> <p>Supported PN for one- year PC</p>

	<p>understanding of palliative care in the province.</p> <p>First contact with HPCA is through a Patient Development Officer (PCDO) who provides assistance to a Social worker and a professional nurse; she helps prepare for accreditation.</p> <p>HPCA provides monthly financial support to the Hospice for direct services, patient care, and OVC work.</p> <p>HPCA facilitated the formation of the KZN Provincial Hospice Association through which hospices in the province network with one another. It is through this that</p>	<p>deliver effective palliative care service on a number of palliative care topics and practical.</p> <p>The training programme provided by HPCA to the hospice include the following: Palliative care (adult &amp; pediatric), TB, Data Management, leadership and governance, home base care, and OVC care.</p> <p>Most hospices indicated that a considerable number of their staff under patient care services have received training on the following programme: Adults/pediatric palliative care, home based care, TB, HCT, OVC, Child</p>		<p>management such as training, managing HR &amp; Finances.</p> <p>All hospices have professional nurses that supervise the Care workers.</p> <p>All hospices have CHW, which include Social development workers, HBC providers and some have counselors and RPHC workers.</p> <p>Graded hospices have limited support staff and non-graded hospices do not have support staff.</p> <p>Administrative duties are mostly shared between hospice managers and other staff.</p> <p>Some hospices have data capturers</p>	<p>course.</p> <p>Infection control</p> <p>N95 Masks for TB patients.</p> <p>OVC (R8,983), direct patient care(R8,530), TB (R300 per month)and Palliative care.</p> <p>Only funds some clinical services.</p> <p>Payment for direct patient care towards professional nurses' salary.</p> <p>Also funds TB services. Financial systems linked to MES Mentoring limited – nikiwe available telephonically who provided psychological support.</p>
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	<p>mentoring was offered to smaller hospices and also received mentoring and support from Pinetown Highway Hospice</p> <p>“When we started, we never had patient files;” we did not know about standards but now the facility has policies for admitting patients."</p> <p>The hospice is a credible facility as a result of the mentoring.</p> <p>The mentors channel the hospices' dissatisfactions and suggestions directly to HPCA.</p> <p>The mentorship helped the hospice to draft guidelines and the work plans.</p>	<p>care, First Aids, Cancer medication, Data management and recording, stress and trauma</p> <p>The precise number of people trained can also be obtained from the HPCA records as the number given by the hospice during the interview is unconfirmed.</p> <p>Majority of the training indicated above were carried out by HPCA and to some extent the DOH and other organizations.</p>		<p>Quarterly Regional meetings where all meet and discuss common interests.</p> <p>Education forum Advocacy Forum, HPCA workshops. No direct support – telephonic support. Quarterly news letter</p> <p>Grant for direct patient care and OVC care.</p> <p>Organizational development, governance and leadership, Provincial Development officers provide support.</p> <p>Funding, Health system strengthening programme.</p> <p>Through mentorship from Nightingale</p>	<p>Training and mentoring Palliative care for caregivers and professional nurses</p> <p>Regional / international exposure Affiliation with regional / international palliative care associations.</p> <p>Opportunities for further study.</p> <p>Conferences.</p> <p>Turnover of HPCA mentors affects continuity. MES has had 8 mentors in 5 years.</p> <p>Attendance of meetings and training difficult due to few staff</p> <p>Sue Cameron, who comes in as</p>
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	<p>HPCA provides the hospices with an amount of R10 000 per month and additional R300 for every new TB patient screened.</p> <p>Home based care Manager: a Professional Nurse Manages the outpatient care activities; manages and supervises caregivers.</p> <p>Home Care Nursing Manager is a Team leader of community caregivers: works closely with the Purchaser, HR manager, Education HOD, and quality assurance manager. He also is a liaison and manages relationships of the hospice with churches, NGOs, NPOs, ward</p>			<p>Hospice: Organizational Development Board is functioning effectively; quality of service has improved.</p> <p>High staff turnover – they get better opportunities – have to constantly train new people; insufficient training.</p>	<p>necessary "She's the mama and founder." Training and mentoring mentors Wits Hospice. Initially relationship was good and valuable in absence of HPCA, particularly in provision of policies and guidelines, but there was overlap of services in Nikiwe. Assists in getting all the standards in place. Helps to move from one star to another and acts as liaison between MES and Sue.</p> <p>Not aware of this team.</p>
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	<p>counselors and committees.</p> <p>Direct financial support from HPCA  – R 8365 per month for stipends; R 300 per month for each TB patient identified; financial management training</p> <p>Provincial Mentorship</p> <p>We did not know much about the spiritual traditional healers' messages to patients.</p> <p>Receive HPCA guidance on strategic planning, conducting SWOT Analysis, Risk assessment.</p> <p>HPCA supports us with what we need for service delivery – e.g. masks, gloves.</p>				
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	<p>All training is provided by HPCA.</p> <p>All Caregivers have received training in home based care.</p> <p>We did not know how to help children.</p> <p>HPCA mentoring programme has helped us a lot: to draw contracts and be clear about roles and responsibilities of staff and volunteers. It has helped us with all aspects of service delivery; we got the star grading we have because of them, as we did not know anything about standards.</p> <p>The skills we have learned have helped us to be independent.</p>				
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<p><b>ACTIVITY B: System Strengthening: Government Collaboration, Advocacy, Liaison, and Public Awareness</b></p>	<p>The District template for hospices to report their work and stats to the district information system.</p> <p>District has not been obtaining inputs from NGOs and hospices and some advocacy on this took place.</p> <p>MOU with other organizations e.g. Private clinics, cancer organizations, NGO's and OVC Hospice sits in the Ethekwini Aids District Council representing 3 hospices under Ethekwini North District.</p> <p>The value of this initiative is that it promotes uniform understanding of palliative care,</p>	<p>Provide small talks in some events (churches, school, etc.) including local radio stations.</p> <p>Compile and distribute pamphlets to local newspaper as well in some gatherings.</p> <p>Increased referrals from health facilities &amp; other NGOs including self-referred from the community. Increased invitations from various communities.</p> <p>Good feedback from the communities.</p> <p>Increased teenage pregnancy rate Limited funding do restrict them to some of the activities to attend.</p> <p>Time consuming to</p>	<p>No relationship.</p> <p>Work closely with DOH, DOE, DOSW and police.</p> <p>60% of funding ( 2 star rating).</p> <p>Training for PN and carers.</p> <p>Monthly reporting to Social services and Department of health. Monthly and quarterly reports to HPCA.</p> <p>Initiated a support network for WC Pediatric palliative care through HSS programme of HPCA (children's homes, clinics, doctors, cancer association.</p>	<p>Work closely with DOH, DOE, DOSW and police.</p> <p>Work together on campaigns.</p> <p>Work closely with DOH, DOE, DOSW and schools.</p> <p>Work together on campaigns.</p> <p>Medication is provided directly to patients from DOH.</p> <p>Monthly reporting to Social services and Department of health. Monthly and quarterly reports to HPCA through Nightingale Hospice.</p>	<p>Premises rented from DoH.</p> <p>Provides stipends for staff. Has relationships with local clinics.</p> <p>Patients bring own medication.</p> <p>Monthly reports to Hillbrow Community center.</p> <p>Sponsorship of 5 inpatient beds.</p> <p>Salary for 5 caregivers.</p> <p>Supplies OTC medication through relationship with pharmaceutical company.</p> <p>New policies.</p> <p>Difficult due to poor communication.</p> <p>Monthly reports and</p>
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	<p>platform for joint planning and sharing of resources.</p> <p>The hospice works with Ethekwini North District, patients are referred between the clinics and the hospice.</p> <p>HPCA helps the hospice and other department like the prison health signing of the MOU.</p> <p>The hospice usually does demonstration on public roads and displays the banners on public parks (e.g. Hoot if you care” campaigns), Candle lighting awareness events, advertisements, etc.</p> <p>The hospice has a good working relationship with the local newspaper</p>	<p>publish article in a newspaper.</p> <p>Communities too big to be covered by the current staff.</p> <p>People no longer listen or attend bigger meetings especially if no food is provided.</p> <p>I. <u>How do involve the community in your services</u></p> <p>Campaigns (school, churches, soccer clubs and household visits).</p> <p>Through coordinated referral systems, and most of the services are provided at home.</p> <p>Use of caregivers from the local community.</p> <p>Involve teacher s</p>			<p>statistics and quarterly reports.</p> <p>Site visits from DoH less annual.</p> <p>Policies and guidelines are lacking.</p> <p>There are good relations with PHC clinics and 3 referral hospitals.</p> <p>Provides brochures to PHC due to staff turnover.</p>
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	<p>where they write about palliative care; the newspaper is issued every week fund raising events advertised in the newspaper.</p> <p>Community members are encouraged to volunteer.</p> <p>Use local media, centre page spread on local newspapers profiling the work of the Hospice.</p> <p>Good relations with Chatsworth Rotary, South Coast Doctors Guild and Women's Forums.</p> <p>Hospice observes all relevant national programmes.</p> <p>Re-engineering program: the program is coordinated by the</p>	<p>and ward Counselors in planning.</p> <p>Use of pamphlets, local radios, and newspaper</p> <p>Though community outreach forums campaign and talks Use of pamphlets, local radios and news paper.</p> <p>Targeting bigger gatherings and support other NGOs.</p> <p>Use of caregivers from the local community and sharing IEC material during home visits.</p> <p>All hospices indicated having a relationship with NDOH/PDOH through: Services Delivery: All hospices are</p>			
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	<p>Provincial government,</p> <p>The MOU with KZNHA (Kwa Zulu Natal hospice Association)</p> <p>We are battling to get more volunteers.</p>	<p>linked to PHC/hospitals through the establishment of referral systems at both levels.</p> <p>In some hospices (n= 2) serves as board member to the hospital and some DOH serves as board members to the hospices.</p> <p>Essential drugs: The entire hospice indicated that they don't dispense medicine except for morphine (n=1).</p> <p>However they do support compliance/ adherence for some medications (HIV, TB, etc.), including the collection from the pharmacy.</p> <p>Otherwise majority of hospice do refer their patients.</p>			
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		<p>National Programme  – Some hospices (n= 4) are also invited to participate in national programme campaigns (TB World Day, Cancer, HCT and other health awareness wherein they did some door to door campaigns in some of them).</p> <p>Reporting – expected to report to the DOH as part of accountability and reporting requirements</p> <p>Sharing ideas, strategies, and information about palliative care.</p> <p>Capacitating (advising, mentoring, providing TA, training) for the small hospice (5*)</p>			
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		<p>Working partnership with other hospices to expand coverage.</p> <p>One hospice indicated having a ward in the hospital for palliative care.</p> <p>All these activities are being monitored/ managed through monthly/quarterly meetings. By supporting and promoting the importance of networking and information sharing.</p> <p>Strengthening the partnership through quarterly meetings and do share some information and advice where needed.</p> <p>All hospices do collaborate with other partners other</p>			
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		<p>than government through the establishment of well-coordinated referral systems and maintaining good partnerships.</p> <p>Partners include Child Welfares, Churches, Mental Health Organizations, Lifeline, Sisonke, AIDS Council, Palliative Care forum and NACOSSA.</p>			
<b>ACTIVITY C: Education and Training</b>	<p>Language barriers</p> <p>Increase of visual materials for better understanding.</p> <p>Use of vernacular, i.e. Isizulu in the materials issued.</p> <p>The HPCA must provide the hospices with new resources that will</p>	<p>The hospices do understand the work of the HPCA staff and support structures in the following manner:</p> <ul style="list-style-type: none"> <li>• Visit them constantly and provide them with relevant updated information</li> <li>• Involve with training needs assessment</li> </ul>	<p>Need more clinical mentoring.</p> <p>Paediatric Palliative care, nursing care plans &amp; TB.</p> <p>Mentoring and support with policies, facilitate trainings, support as required.</p> <p>Training, networking</p>	<p>Very few – big need expressed-HIV care and treatment.</p> <p>More frequent training.</p> <p>Record of trained staff.</p> <p>Develop a “career path” for CHW.</p> <p>Shorter trainings</p>	<p>Training – gained knowledge.</p> <p>To Integrate patient with family.</p> <p>Being able to implement the program.</p> <p>Team multidisciplinary approach.</p>

	<p>accommodate the changes to the guidelines.</p> <p>Training on the following programs: TB, paediatrics, cancer, and palliative care. All training costs are covered by HPCA, the trainings are not fully accredited, trainees only receive attendance certificates.</p> <p>HPCA provide training on TB, peditrics, cancer and palliative care according to the needs of the hospice. HPCA also mentor the hospice in service trainings.</p> <p>HPCA runs Training of Trainers to sustain capacity building efforts.</p> <p>More training is</p>	<ul style="list-style-type: none"> <li>• Assisted the with implementation of some policies and procedures</li> <li>• Assisted with preparation and guidance on accreditation process, i.e. assist with relevant forms, policies and guidelines.</li> <li>• Supported with maintaining the required standards ratings.</li> </ul> <p>Only about two hospices have been accredited, hence no responses.</p> <p>Supported and assisted with the assessment of work plan and training needs.</p> <p>Assisted with the development of strategic plan, recording, and reporting the data.</p>	<p>Final year medical students from UCT do case studies.</p> <p>Paediatric palliative care</p> <p>TB and Infection Control.</p> <p>Risk assessment.</p> <p>Leadership training.</p>	<p>Bring training closer</p> <p>Funding for attending training.</p> <p>The proportion of staff trained is less than 50% for adult palliative care and very few are trained in paediatric palliative care.</p> <p>Limited staff CHW not well trained Staff work only 5 hours – not sufficient to meet need.</p> <p>Not all staff are adequately trained.</p>	<p>Paeds Palliative Care, TB, Infection Control, Strategic Planning, Policies, Data Capturing, M&amp;E, Leadership and Development program, Social Auxillary training, Advocacy, I Act (Support Group.)</p> <p>Provide monitoring of implementation. Better coordination of training courses to enable planning.</p> <p>Training is not free so has to be budgeted for.</p> <p>Adult and Paediatric palliative care. Home based care.</p> <p>TB care.</p> <p>Training gives a good understanding of palliative care definitions.</p>
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	<p>needed on OVC work</p> <p>Additional Palliative Care Training was offered by the Foundation for Professional Development (FPD) and this was made possible by HPCA, HDMS, TB.</p> <p>They train professional nurses to obtain a postgraduate course in palliative care.</p> <p>HPCA sponsors all the training activities of the CPL.</p> <p>Training is also offered to social workers based on the HPCA developed course.</p> <p>There is also a standardized home based carers course as well as specific</p>	<p>One hospice indicated that they were supported with fundraising.</p> <p>Assisted with training on Palliative care by sending advert as well as contacting other hospices (5 star).</p> <p>Assisted with capacity building (supervision, mentoring, sharing guidelines) of the hospice.</p> <p>The team usually uses a checklist to see if prior recommendations were implemented.</p> <p>Identify training needs, venues and opportunities.</p> <p>Develop training plan Involved with</p>			<p>Promotes holistic care approach.</p> <p>Caregivers better placed to fulfill roles.</p>
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	<p>courses on TB.</p> <p>Highway is the Centre for Palliative Care Learning for the province. They run short courses on palliative care for nurses. The courses are certificated and registered with the Nursing Council. They come for lectures once a week and get practical exposure.</p> <p>HPCA has 2 provincial development officers who help the Hospice with all matters pertaining to the accreditation. The mentor guides and informs the hospice about new standards.</p> <p>HPCA Officer also informs Highway if there is a new hospice service in</p>	<p>capacity building activities (mentoring, TA, job aids etc.).</p> <p>One hospice never heard of that forum.</p> <p>Majority of hospice (4) indicated that CPL provided them with educational materials and training opportunities, which are needed to deliver effective palliative care service on a number of palliative care topics and practical.</p>			
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	<p>the province – for mentorship purposes.</p> <p>HPCA helps a new hospice and also looks around for help from other hospices around to develop them more.</p> <p>Highway hospice received Train the Trainer courses from HPCA which enables them to train developing hospices in the province.</p> <p>Palliative Care Training; TB training, Home-based Care Training</p>				
<b>ACTIVITY D: Service Delivery</b>	<p>Weekly visits by professional and enrolled nurse to high care.</p> <p>Doctors and volunteers provide checks, refer to hospitals, volunteers</p>	<p>All hospices provide comprehensive adult palliative care service packages in similar fashion as outlined by their strategic/work plans.</p> <p>However majority</p>	<p>Health education to patient &amp; family, psychosocial and spiritual support.</p>	<p>Health education, screening and clinic referrals.</p>	<p>Home based care, day care, outpatient care, inpatient care.</p> <p>Provision of psychological services.</p> <p>Support patients</p>

	<p>provide spiritual counselling. There is general screening and support from a social worker.</p> <p>The hospice is an out-patient care facility; they have employed 3 care givers who visit the patients in their homes and provide the consulting rooms for the patients.</p> <p>The Hospice has a capacity of 8 beds and 3 patients are currently admitted.</p> <p>Respite care programme is offered to families.</p> <p>HPCA supports the hospice with the material such as the gloves and masks for infection control, and information brochures, which</p>	<p>of hospices (n= 4) do not provide the following services: day care, outpatient care, inpatient care, to some extent (n =3), HCT and pre-ART care.</p> <p>Improvements in adults' patient care.</p> <p>Staff is confident with the service provided.</p> <p>Patients and the community appreciated and are satisfied with the services provided by the hospices.</p> <p>Inability to reach everybody in need of the services due to high level of poverty in the community, shortage of personnel as well as early discharge from the hospitals.</p>			<p>through education.</p> <p>Assess pain - apply corrective measures.</p> <p>Clients encouraged to work in groups.</p> <p>Provision of hamper for support groups. Condom distribution, PLHIV (PnP), HCT Though Social Auxiliaries, refer to Social Worker, Home visits.</p> <p>Pain and symptom management.</p>
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	helps improve service delivery.	Very difficult to access all of the community due to distance, lack of transport for caregivers, staff safety, and crime.			
<b>ADULT</b>	<p>Pain management depends on nature of the condition, mostly on palliative care for cancer patients.</p> <p>Pain and symptom management charts are used on cancer patients.</p> <p>Patients are also referred to clinics and hospitals for screening for opportunistic infections.</p> <p>Patients suffering from cancer are screened on pain and symptoms. Pain management is</p>				<p>Home based care, day care, outpatient care, inpatient care.</p> <p>Provision of psychological services.</p> <p>Clinical services: provision of opportunistic infection prevention and treatment including TB, HIV and AIDS related complications, including malaria and diarrhoea.</p>

	<p>offered, especially for cancer patients</p> <p>The HBC manager works closely with the 3 caregivers who ensure treatment compliance for the patients, screening and referral of patients and patients' contacts; provide moral support and counselling to both infected and affected patients.</p> <p>Infected adults come to the Hospice every Wednesday for health education, meals, and donated clothing; Support groups are held for patients on this day.</p> <p>Visiting patients , bathing them, cooking nutritious food for them,</p>				
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	<p>basically delivering patient care in the home with the involvement of family members.</p> <p>Patients come to the centre and receive food. We also offer counselling and group support when they come.</p> <p>We follow up patients who have been discharged and help them in their homes.</p> <p>Counselling and group support to patients.</p> <p>We do not offer direct clinical services as we refer to local clinics and hospitals.</p> <p>Circumcision, in partnership with Clinic; referral to Family Planning.</p>				
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	Referral to testing sites and follow-up support.				
<b>PAEDS</b>	<p>Social worker works closely with the affected and infected children with regard to social grants and birth certificates.</p> <p>Bereavement support, memory training, resilience.</p> <p>The hospice currently supports 24 infected and 29 affected children.</p> <p>Infected children are monitored on treatment and caregivers provide the parents of the affected children with health education on how to prevent further spread of the</p>	<p>All hospices provide comprehensive paediatric palliative care services packages in similar fashion as outlined by their strategic/work plans.</p> <p>However majority of hospices (n= 4) do not provide the following services: day care, outpatient care, inpatient care, to some extent (n =3), HCT and pre-ART care.</p> <p>Only one hospice does not provide pediatric care services.</p> <p>Improvements in paediatric patient</p>	<p>OT Programmes, music therapy, play therapy, mental stimulation.</p> <p>Only outreach to children from facility that are placed back in community.</p> <p>No Paeds.</p> <p>Outsource age appropriate learning.</p> <p>Screen and treat.</p> <p>Total pediatric palliative care.</p> <p>Screening, management and referral.</p> <p>Nutritional plan &amp; monitoring.</p>	<p>Assess condition of children, screening, health education to family/care givers, referral to clinics, Welfare as required.</p> <p>Screen for TB and malnutrition and refer to clinic.</p> <p>Evaluated and refer to Social worker.</p> <p>Help with giving medication as prescribed and provided by clinic/hospital.</p> <p>We measure upper arm circumference and refer to clinic and welfare, do BMI.</p> <p>Provide food at after</p>	<p>Social support HIV testing/VCT Pre-ART care.</p> <p>Screening for TB and referral for TB treatment.</p>

	<p>disease to the children.</p> <p>Counselling and bereavement support</p> <p>Support with daily feeding and food parcels Improved health and normalization of children, recovery, adherence to medication, school attendance and improved/stable academic performance.</p> <p>We still need more training on Paediatric Palliative Care.</p> <p>Screen and refer the affected and infected children for TB, HIV and social services</p> <p>Category 3 children are admitted to the hospice</p>	<p>care.</p> <p>Staff is confident with the service provided.</p> <p>Patients and the community appreciated and satisfied with the services provided by the hospices. Inability to reach everybody in need of the services due to high level of poverty in the community, shortage of personnel as well as early discharge from the hospitals.</p> <p>Very difficult to access all of the community due to distance, lack of transport for caregivers, staff safety &amp; crime.</p> <p>Defaulters due to irresponsible</p>	<p>Work with Welfare to get grants, clothing, bus fares, accommodation, food counselling and testing.</p>	<p>school programme at day care centre.</p> <p>In patient care provides food.</p> <p>Health education, screening and referral, education on infection control.</p> <p>Pediatric in patient facility screen, test, treat and do infection control.</p> <p>Work with Welfare to get grants.</p> <p>Pediatric in patient facility send children to school.</p> <p>Tracing for PCR</p> <p>In patient facility: Counsel and test only paediatrics in patient facility.</p>	
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	<p>Children are screened and referred for TB especially the infected and affected</p> <p>Children who are not on social grants receive nutritional supplement</p>	<p>guardians and mobility.</p> <p>Lack of family planning.</p> <p>Insufficient and mismanagement of social grants.</p> <p>Provide enough resources (HR, IEC materials, training &amp; finance) to promote and educate the community about palliative care.</p> <p>Review of social grants, including foster care.</p>			
<b>OVCs</b>	<p>Both infected and affected children are provided with nutrition supplements.</p> <p>The social worker implements the OVC programs, refers to Child Welfare, DSD,</p>		<p>No OVCs</p> <p>Send children to school.</p> <p>Help with access the Child Support Grant Food, bus fees, clothes.</p> <p>Had a 8 year old</p>	<p>DSD – we have caregivers of Department of Social Development – Social workers services Education – through school principals for children who did not attend school.</p>	

	<p>SASSA and Dept of Home Affairs.</p> <p>Most affected children are at school and can only be reached after school. Long distances prevent them from attending day care services. Only school holiday programmes are held.</p> <p>Psychological evaluation and OVC work by the social worker. Assist access to social services, memory work is done.</p> <p>With the help of social worker (HIV Coordinator); help children enroll in schools.</p> <p>OVC work is generally weak, need more training and program design.</p>		<p>child with no home to go back to – found him a home, he is a happy child, in school and on ART. Doctors were sure that he was going to die.</p> <p>Former patients/ mothers of patients are now care workers at the facility.</p>	<p>Paediatric inpatient facility sends children to school.</p> <p>OVCs come and do homework at the facility.</p> <p>Help so that children access the Child Support Grant.</p> <p>In emergencies provide clothes and food.</p> <p>Provide meals at Day care centre – after school programme.</p>	
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	<p>Children who are not at school are referred to the social worker by the caregivers.</p> <p>Hospice refers children and caregivers to Child Welfare OVC programs, helps the children with access to social grants.</p>				
<b>TB</b>	<p>Monitoring of treatment adherence.</p> <p>Children who are diagnosed and born with TB are monitored on TB treatment.</p> <p>Children who live with TB infected patients are screened and referred to hospitals for TB test, TB treatment, or INH.</p> <p>The caregivers</p>		No TB.	<p>Use HPCA TB screening tool.</p> <p>Door to door – Intensive Case Finding with DOH.</p> <p>We offer DOT support in the community and trace defaulters.</p> <p>Motivate for open windows and cough etiquette.</p> <p>Identified a family where 5 members had MDR TB.</p>	<p>Seeing patient recovering.</p> <p>Improved cure rate to 80% from 56%.</p> <p>No Screening for TB and referral for treatment.</p> <p>No TB treatment : DOTS/Lab monitoring.</p> <p>No Infection control for TB.</p>

	<p>educate the TB infected patients about how to prevent the further spread of TB to others.</p> <p>A policy of infection control is also running at the hospice.</p> <p>Caregivers use the TB screening tool to screen patients and their families.</p> <p>Referrals to local hospitals if there is a need.</p> <p>The DOTS supporters refer the treatment defaulters to the IDT (Inter-disciplinary Team).</p> <p>TB affected children are on INH and the parents are advised on how to prevent further infections to the children.</p>			<p>Provided DOTS – all complied with treatment and cured.</p> <p>Quality of service has improved significantly.</p>	<p>Staff turnover – low salaries, lack of professional nurses to assist, traditional and culture beliefs – drug interaction.</p>
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	<p>TB infected patients are counselled on how to prevent further spread of the disease e.g. teaching the patient on how to cough; distribution of masks</p> <p>Compliance with TB treatment is ensured by the caregivers, but no formal DOTS support is offered so as not to interfere with the work of hospital; however additional support in the form of checking medications and compliance thereto is done.</p> <p>Referral, helping adhere to medications, promote knowledge of treatment and benefits thereof Tb screening and referral is done on TB contacts.</p>				
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	Infection control for TB – teaching people how to cough, using masks to prevent spread of infection.				
<b>HIV TESTING</b>	VCT is done at clinics and hospital.  Only post- test counselling is done on patients who have been diagnosed with HIV.				
<b>SOCIAL SUPPORT SERVICES</b>	Social worker identifies patients requiring nutritional support.  Donors have generally dwindled.  Hospice supplies patients with Movite and future lite.  Patients on medication, those with difficulties in ingesting food, and cancer patients are			Carers refer to SASSA for Grants and social worker.	

	<p>always prioritized.</p> <p>Food hampers are also sourced from local child welfare organization.</p> <p>Social worker works closely with child welfare and refers most children there for services.</p> <p>Referrals to educational services, support with school uniforms, referral to social workers and other social services; social work services</p> <p>A social worker volunteers in the hospice for assessment and referral of patients who need social grants and identity documents.</p>				
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<p><b>Challenges</b></p>	<p>Shortage of resources such as gloves, masks, due to financial constraints.</p> <p>Lost to follow up of category 3 patients because when patients recover they also move from urban area to their ancestral rural areas.</p> <p>Cultural beliefs: patients default their medication and consult traditional health practitioners, stop western medication as a result.</p> <p>They return to the hospice when it is too late and they are terminally ill.</p> <p>General stigma still exists, despite all the information and knowledge of HIV and AIDS.</p>	<p>It is very difficult to release staff for training to avoid interrupting the services.</p> <p>Short training notice from HPCA.</p> <p>Limited funding as some courses require the hospice to fund for transport/ accommodation costs.</p> <p>Policies and standards are high and too demanding to maintain.</p> <p>Improvement:</p> <p>HPCA needs to be advised on the implication of short training notices (annual training plan is necessary) and financial implications on training conducted far from</p>		<p>Children are not aware why they are on ARVs - difficult to deal with status when informed.</p> <p>Need more training on Paediatric Palliative Care.</p> <p>Neglected children.</p>	<p>Working with parents – do not allow care for their children as a result of denial.</p> <p>Children not aware of status and diseases.</p> <p>Removal of children to safe place.</p> <p>Training on PPC, OVC.</p> <p>Demarcation of geographical allocation can be confusing.</p> <p>Community still ignorant, uninformed.</p> <p>Lack of resources.</p> <p>Sustainability of NGOs.</p>
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	<p>Minimal support to palliative care. Limited resources.</p> <p>High incidence of social problems and needs (poverty &amp; hunger).</p> <p>Shortage of staff to deal specifically with children.</p> <p>No comprehensive OVC programme due to lack of capacity and funding.</p> <p>Existing hospice staff are not trained on children's services like OVC; even tracking Road to Health Card is something that caregivers are not equipped to do.</p> <p>Lack of support from government departments such as SAPS.</p>	<p>the hospice.</p> <p>More resources (HR &amp; finance) are made available as the need for palliative care turns to expand considerably as well as transport cost.</p>			
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	<p>TB re-infections are rife and there is no response and support from the municipality. More patients are discovered and there is a shortage of staff to attend to these patients and their needs on a daily basis.</p> <p>Some of the patients are re-infected after completing the treatment while the stigma around the notifiable diseases is still high.</p> <p>Patients tend to hide medication, go back to their ancestral rural homes, abscond from hospitals that stigmatize them.</p> <p>Though this is slowly improving, the stigma is still a</p>				
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	<p>challenge.</p> <p>The hospice participation in decision making by HPCA is limited.</p> <p>The government has stopped the supply of the gloves and masks, the hospices have to purchase these materials which are expensive.</p> <p>The social worker works on a part-time basis and the hospice does not have enough time and capacity to cater all children who need social support.</p> <p>The hospice uses agovernment ambulance, which takes about 3 to 4 hours to respond on emergency cases.</p> <p>There is no infrastructure in</p>				
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	informal areas and access to patients needing help the most is sometimes difficult, especially when the weather is bad.				
<b>SUGGESTIONS FOR IMPROVEMENT</b>	<p>HPCA must work with the government to implement national policy on palliative care services.</p> <p>Funding from HPCA goes towards salaries and little goes towards service delivery – this should improve.</p> <p>The manner in which HPCA works does not promote self - sufficiency for hospices, i.e. no capacity is built to help hospices be self- reliant.</p> <p>When HPCA withdraws or cuts its funding, hospices</p>	<p>Majority of the trainings indicated above were carried out by HPCA and to some extent the DOH and other organizations.</p> <p>Improved the quality of services provided.</p> <p>Increase capacity and confidence of the staff providing the services.</p> <p>Well informed and updated about the palliative care services.</p> <p>Able to develop proposals.</p>	<p>PCDOs are not clinically trained, they are social workers.</p> <p>Policy formulation, guidelines</p> <p>Quality has improved</p> <p>Expansion of service</p> <p>Training</p> <p>Baby born with HIV is now nine years old and is a motivational speaker at events related to HIV/AIDS.</p> <p>Had an 8 month old baby that did not thrive. We referred her for HIV testing.</p>	<p>Previous patients are now carers.</p> <p>Service expanded significantly to 4 times as many patients in the last two years.</p> <p>Quality of service has improved significantly.</p> <p>We visited a household, screened for TB and found some TB patients. We did contact tracing for all 21 members of the extended family (even went to their workplaces to find them). We found 8 of the family members to have</p>	

	<p>are left with no options.</p> <p>HPCA must remember that it came into existence because of the hospices and they should spend more money on improving service delivery than on attending international conferences (due regard is given to HPCA for the support they have given but more needs to be done).</p> <p>HPCA must increase its advocacy and sell the concept of palliative care to government, influence palliative care policy of government.</p> <p>HPCA must provide transport to the caregivers to allow them to attend to</p>		<p>She was found to be HIV positive and had TB as well. She is now on TB treatment and ART.</p> <p>Good relations with guardians and caregivers.</p> <p>We manage to get more children back to school.</p> <p>Children that were admitted as grade three improved to grade one clients.</p>	<p>TB. We provided treatment support and support for the prophylactic TB treatment for the contacts.</p> <p>We have a HIV/TB patient that is now cured from TB and on ART.</p> <p>We had a grade three client that is now a grade 1 and able to walk.</p> <p>We have a patient that had two bedsores. The bedsores are now healed and the family was taught how to prevent bedsores.</p> <p>HIV positive children that improved from grade 3 to 1. One now an exchange student in Canada another one now in</p>	
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	<p>more patients per day.</p> <p>HPCA must increase funding to the hospice to allow the hospice to employ more caregivers.</p> <p>Improved training for care givers on OVC services.</p> <p>HPCA must include the hospice staff on their brainstorming sessions and decision making.</p> <p>HPCA must conduct training for Hospice staff on children's Palliative care and OVC programming.</p>			<p>matric and has been approved for studies at University.</p> <p>Defaulters /interrupters start again on treatment.</p> <p>All hospices reported organizational development and expansion of service.</p> <p>Boards are functioning effectively.</p> <p>Knowledge and skills have developed to such an extent that they write their own proposals for funding.</p> <p>Quality of services has improved.</p> <p>Collaboration with government departments and other organizations has improved.</p>	
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<p><b>ACTIVITY E: Accreditation and Quality Improvement</b></p>	<p>HPCA must conduct training to staff members immediately after they have changed the guidelines and policies.</p> <p>The hospice must have their own risk assessment work plan and quality improvement plan.</p> <p>Funding of HPCA is different across all star ratings.</p> <p>Training on the new policies was not conducted to our staff which makes it hard for them to understand the new policies.</p> <p>HPCA conducts clinical audits, patient file audits, check if standards are maintained.</p> <p>HPCA also reviews</p>	<p>Majority of hospices (n=5) have been accredited by COHSASA with 2 hospices graded five stars.</p> <p>In general the process has involved a number of visits by COHSASA and HPCA at agreed intervals to assess the hospice on quality and provide assistance in understanding, implementing, and monitoring compliance with the standards set.</p> <p>At some stage some hospices indicated that they were requested to conduct a self-assessment of compliance with standards and they came back to validate the information.</p>	<p>Hard work and time consuming</p> <p>Help to obtain funding Credibility Image in community improved Quality of service improved</p> <p>Two stars. Promotes team work, development of policies: what to do and how A team from HPCA &amp; COHSASA did baseline assessment against HPCA standards using a COHSASA tool, performance scored – survey on areas not compliant and advice on how to set it up</p> <p>Helped establish required systems Patient care improvement</p>	<p>More guidance to not accredited facilities on how to prepare for accreditation: a written plan on working towards accreditation and provision of guideline on accreditation process Direct capacity building and mentorship by HPCA to not accredited facilities</p> <p>Approximately 2/3 of hospices accredited. Range from 1 star to 5 stars QI: Patient care and risk assessment</p>	<p>To break it down in steps as it is overwhelming to a 27 page document with difficult concepts Need more help from HPCA – not to just to give a sample document because situations are different</p> <p>Availability of standards Implementation of policies not just paper Knowledge and guidance on how to do things – clear direction and processes Getting buy in from all team members Improved quality of service</p> <p>Regular visits Training in Policy</p>
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	<p>policies like the admission and discharge policy of category 1,2,3 patients</p> <p>PCDOs (from HPCA) do an assessment at the hospice, check if we are still maintaining the standards; they check patient files to see if protocols are adhered to. If circumstances change the Hospice needs to change and adjust their admissions policies</p> <p>HPCA has provided a framework for Quality Improvement, taught the facility how to use it and provided the template.</p> <p>HPCA spots areas that need improvement in the hospice through the</p>	<p>Follow-up accreditation surveys were also conducted every two to three years since then.</p> <p>Empowered the hospice, confidence and trust to the funders and the fundraising programme.</p> <p>Provided them with a strong focus in terms of operational issues and helped with strategic planning and quality control.</p> <p>Encourage them with continuous improvement efforts.</p> <p>Boosted the morale of the staff.</p> <p>It has been a very difficult task to</p>	<p>Helps with fund raising - winning proposals</p>		<p>development Development of working documents and compilation Financial Assessment Develop good relationship</p> <p>Implementation of policies Labour intense – lots of paperwork, need team effort and involvement</p> <p>Policy development HPCA standards improved services Guidance, knowledge and skill HPCA provided documentation which the staff had to go through with the assistance from Angela.</p> <p>Training is also provided.</p>
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	<p>monitoring process and conducts training on those areas.</p> <p>First survey was in 2005 and resulted in a 3 star accreditation in 2006.</p> <p>A plan of action was drafted with the guidance of the mentor and the facility put in place what was missing.</p> <p>In February 2011 the facility received a 4 star accreditation.</p> <p>Both the clinical and other development mentors were involved, working with 12 elements that cover everything the Hospice should do or adhere to. Clinical mentor</p>	<p>implement some of the standards with limited funding, but at the end they managed.</p> <p>Mentoring, providing technical support, assessment, advising, finance, training and they supported the implementation.</p> <p>Improved quality of services provided.</p> <p>Staff development and confidence.</p> <p>Better documentation and guides.</p> <p>Appreciated by the community they serve.</p> <p>Lot of work, time consuming, and costly to meet the standards.</p> <p>Staff attitudes.</p>			<p>“Is it necessary for standards to be so high? It stresses us out.” Revision of standards to make it easier for all staff to understand. Standards should be more patient-centred. Some standards are not achievable due to limited resources. e.g. staff and pharmacies. although HPCA has assisted with other alternative solutions.</p>
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	<p>came to offer support, conducted spot checks, and picked up errors to indicate what needed to be improved or put in place.</p> <p>Very good, we were visited by our mentor, got training in standards, they helped us understand what we need to put in place, physical environment, training, general management, standard of care to patients, everything and we worked hard and ensured we put those in place. We did it all with the help of the HPCA mentor – we learned a lot and right now we are working at obtaining a 2 star grading.</p>	<p>Advocate for enough resources (HR, finance) dedicated for accreditation process.</p>			
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	<p>More confidence in patient care. We feel we are taken seriously by other hospices.</p> <p>We can talk confidently about our work in the community and in other sectors.</p> <p>It encourages us to work even harder to maintain and even improve our grading.</p>				
<b>ACTIVITY F: Monitoring, Evaluation and Research</b>	<p>The HDMS is functioning well and helps the staff to identify patients who have recovered, patients with the worst conditions.</p> <p>The HPCA have provided software which is now web-based for the HDMS; the system is working well and there are no recommendations</p>	<p>All hospices have developed strategic/ work plans with some basic M&amp;E activities incorporated to guide them.</p> <p>Monitoring tools are being used for keeping track of programme activities and service (n =4). Data is collected daily, and captured and reported monthly.</p>	<p>Don't use HDMS Patient record and data collection tools Data capturing forms are not in line with data programme Data definitions on HPCA forms not clear</p>	<p>Don't use HDMS Daily tick sheets – data captured at Nightingale hospice Monthly and quarterly – HPCA, Department Health , Department Social Services &amp; Nightingale hospice</p>	<p>Not using HDMS, using excel spreadsheets</p> <p>Not using HDMS Using Excel spread sheet database, preparing to move to HDMS in October Weekly activities with targets which is monitored weekly and presented in graphs</p> <p>Uses HPCA forms –</p>

	<p>Yes the hospice uses the HDMS and manual registers that are used by the nurses which are later used to capture data on the electronic HDMS</p> <p>Mentors for data management system do training to the end user of the system, upgrade the system and do data quality audits. They troubleshoot when there are problems with the system</p> <p>Internal audits are done internally by a nurse and an MER (Monitoring Evaluation and Reporting Officer) ensure correspondence between patient files, registers and HDMS. A mentor from HPCA comes on</p>	<p>Monitoring/ performance data is collected daily and captured on a computer (using a simple in-house database from Excel spreadsheet). ( n=5)</p> <p>Otherwise, the majority of hospices (80%*) are using the HDMS for programme monitoring .</p> <p>Majority of the hospices (80%*) indicated that they do analyse their monitoring data frequently and use it for programme planning and management apart from reporting – monthly meetings.</p> <p>All hospices produce monthly, quarterly or annual basis reports on</p>			<p>bimonthly report to board members.</p> <p>Narrative report – DoH, monthly Stats –FPD, DoH, HPCA.</p> <p>Narrative report to HPCA quarterly.</p> <p>Excel spreadsheet too large and unmanageable.</p> <p>Did not have clearly defined objectives, goals, activities and targets.</p> <p>Too many reporting tools – HPCA, DoH, FPD everyone his own format.</p> <p>Training and support in quality checks.</p> <p>Training on M&amp;E – require expertise on M&amp;E and data quality check. Need to know how</p>
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	<p>monthly basis and do data quality checks on HDMS  External data audit is also done quarterly by HPCA  Progress notes are cross-referenced to check if data is accurate</p>	<p>their activities and send them to HPCA, DOH, DSD and other specific donors.</p> <p>Quarterly reporting is the most common reporting interval mentioned.</p> <p>Majority of the reports produced consist of monthly/quarterly statistics in addition to the annual narratives.</p> <p>The monitoring data is checked or verified frequently for missing and invalid values weekly by Supervisors at all levels of the organogram except one hospice.</p> <p>Professional Nurse/Social Workers (80%) hospices do also</p>			<p>to use information, interpret and use as manager in a way to inform decisions.</p>
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		<p>analyse data weekly in attempt to identify gaps for corrections.</p> <p>Most of the databases also do incorporate specific data quality checks to minimize errors during capturing (n=4). However some hospices indicated a minimal data quality assessment or that they were not even conducted especially at the community/field levels – (n=2)</p> <p>The amount of different reports to be produced for different agencies/donors.</p> <p>Despite the HPCA support, there is still a critical skills needed for improving programme</p>			
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		<p>planning, M&amp;E especially from the DOH - (80%).</p> <p>Very few hospices (n =2) have no dedicated M&amp;E staff member, Data Capturer, or unit whose primary responsibilities are M&amp;E due to insufficient resources.</p> <p>One hospice does not have any data management system in place and is still relying on paper-based systems for reporting.</p> <p>Only one hospice indicated that they experience delay in reporting due to distance travelled.</p> <p>There is also need for enough resources for M&amp;E (Computer, room,</p>			
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		<p>personnel, skills, etc.) in line with the expectation about good M&amp;E systems.</p> <p>Limit the number of different reports required by different agencies/donor – suggest one standard report.</p> <p>Refine the HDMS to integrate reports required by other agencies – (n= 4) There is a need for development of a management information system which integrates a programme database, programme tracking systems, monitoring data spreadsheets, automated data collation and analysis procedures, and financial management systems. (n=3).</p>			
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		Provision of communications resources to outlying areas of support (n=1).			
<b>IMPACT/ SUGGESTIONS</b>	<p>Training on OVC programs must be conducted to the care givers and volunteers.</p> <p>Paediatric palliative care needs to be imported.</p> <p>More investment is needed on capacity building and supply on materials e.g. gloves and masks.</p> <p>Hospices need their voices to be heard at HPCA conferences.</p> <p>HPCA has to move away from presenting academically focused conferences and</p>		<p>There seems to be a need for more management support at mentor hospices.</p> <p>The hospice managers generally have various functions such as financial and HR management and training.</p> <p>Mentorship and training to/of affiliated hospices (not graded) can improve.</p> <p>We evaluated one of the affiliated hospices and the difference in capacity for organizational</p>	<p>There seems to be a need for more management support.</p> <p>The NSM of this Hospice is the manager and is also responsible for assessments of clients, training, finance, and HR management. She is very dedicated and passionate about the service.</p> <p>The mentorship role to the hospice should improve.</p> <p>Capacity for organizational management needs to be strengthened.</p>	<p>More focus on report writing than on patient care; “reduce theory but more practical” approach should be used.</p> <p>Requirements to move from star 1 to star 2 difficult if short staffed.</p> <p>Helpful, always there for guidance – their presence is helpful.</p> <p>PC is very needed in the community, OVC programmes depend on HPCA for financial assistance.</p> <p>Capacity building resulted in</p>

	<p>engage more on issues of support and service delivery on the ground.</p> <p>HPCA should coordinate the work of hospices, continue with issues around compliance to standards, continue with mentoring and support services to hospices.</p> <p>HPCA needs to communicate timely to affiliates.</p> <p>HPCA must concentrate on stigma around HIV.</p> <p>HPCA must increase awareness on notifiable diseases among the communities.</p> <p>HPCA must also increase funding to the hospices.</p>		<p>management is enormous. See report on Renosterberg Hospice</p> <p>Care givers (except for one hospice) do not have uniforms. It seems that the group that has uniforms gets more acceptance and recognition from the community. The uniform also protects them from violence and crime as they are warned of danger and taken out of dangerous situations.</p> <p>There seem to be a need for all caregivers to have “HBC Packs” that contains basic cleaning materials, disinfectants, cloths, gloves and antiseptic ointment.</p>	<p>No guidelines on paediatric care and no job-aids.</p>	<p>organisation growth and encouragement.</p> <p>Association with HPCA – conferences, collective bargaining in both sense and belonging</p> <p>Provision of infrastructure.</p> <p>Be informed on purpose and content of visits.</p> <p>Communicate in advance funding 6/12 months before the end of the financial year.</p> <p>Programme will continue but with limited resources and at a smaller scale.</p> <p>OVC will be mostly affected. Salaries for staff will be affected</p>
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	<p>More advocacy for Department of Health to be involved in supporting palliative care.</p> <p>All programs can continue without HPCA the total monthly cost for the hospice is R170000 and HPCA only contributes R10000 per month, more funding comes from fundraising activities of the Hospice and donations from the community. However this does not mean HPCA has no role. The Hospice needs it to generate more funds to expand services and to focus on training and advocacy.</p> <p>Our programmes will continue</p>		<p>All hospices expressed that HPCA support is indispensable.</p> <p>Affiliation with HPCA significantly improved organizational capacity, individual development and quality of the service provided.</p> <p>All care givers are passionate about the service they provide.</p>		
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	<p>because of the generosity of the community but we do not know for how long. It costs R 1.4 million to operate the hospice and its services. HPCA only gives R 139 000 which goes towards salaries. It will affect service delivery if the HPCA funding is not there for salaries. At the same time HPCA has to address the question of sustainability for the hospice.</p>				
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