End of Project Evaluation
Hospice Africa Uganda (HAU) Program: *"Expanding the access to and scope of Palliative Care for People Living with HIV/AIDS (PLHIV) and their families" – Final Report*

28th February 2013

This publication was produced for review by the United States Agency for International Development.

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ACKNOWLEDGEMENT

This work was supported by funding from USAID Mission Uganda. The consultants appreciate the technical advice and support from USAID Uganda staff towards the implementation and preparation of this report. The input from the Mission Director Ms. Leslie Reed and the HAU Final Evaluation Task Managers; Ms. Charmaine Matovu & Ms. Jackie Calnan is particularly appreciated. The evaluation team also appreciates the Senior Management Staff Hospice Africa Uganda (HAU) and the technical and support staff from all the three sites of: Hospice Kampala, Little Hospice Hoima and Mobile Hospice Mbarara for their input and support during the field visits. The input from all respondents including the hospice program beneficiaries and their families, trainees that benefited from HAU program, staff and technical persons of the USG funded partners, staff from local governments consulted, Ministry of Health, National and International partners like PCAU and APCA, staff from referral hospitals and other respondents is very much appreciated. The consultants also acknowledge Sandra Ayoo for her input in editing the draft document. The Cover photo taken by MMC team in December 2012 is of Hospice Kampala staff delivering material support to a bereaved beneficiary family in Kawempe, Wakiso district (U).

Submitted by

MMC Consultancy Team

MULTIPLE MANAGEMENT CONSULT

Date: 28th Feb 2013

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Abbreviations/Acronyms

#	Number
Ag.	Acting
AIDS	Acquired Immune Deficiency Syndrome
APCA	African Palliative Care Association
ART	Anti Retroviral Therapy
BOD	Board of Directors
BU	Baylor Uganda
CA	Cooperative Agreement
CAO	Chief Administrative Officer
CBO	Community Based Organization
CSO	Civil Society Organization
CMEs	Continuous Medical Education
CoE	Center of Excellence
CVW	Community Volunteer Workers
DEC	USAID's Development Experience Clearinghouse
DHI	District Health Information Officer
DHO	District Health Officer
DLG	Districts and Local Governments
ED	Executive Director
EGPAF	Elizabeth Glaser Pediatrics Foundation
FBO	Faith Based Organization
FDGs	Focus Group Discussions
FM	Financial Manager
FY	Financial Year
GoU	Government of Uganda
GIPA/MIPA	Greater/Meaningful Involvement of PLHIV
HAU	Hospice Africa Uganda
HBC	Home Based Care
HC	Health Centre level 1, 2, 3 or 4
HCW	Health Care Workers
HIV	Human Immunodeficiency Virus
HKLA	Hospice Kampala
HR	Human Resource
HMIS	Health Management Information Systems
HRH	Human Resource for Health
HSSP	Health Sector Strategic Plan
I/C	in Charge
IHPCA	Institute of Hospice and Palliative Care in Africa
IPs	Implementing Partners
IRIS	Immune Reconstruction Inflammatory Syndrome
IT	Information Technology
JCRC	Joint Clinical Research and Medical Centre
JMS	Joint Medical Stores
JOY	Jesus Others Yourself Hospice services
JSI	John snow Inc
KII	Key Informant Interviews
LHH	Little Hospice Hoima
LOP	Life of Program
M&E	Monitoring and Evaluation
MDG	Millennium Development Goals
MEEPP	Monitoring and Evaluation of the Emergency Plan Progress
MHM	Mobile Hospice Mbarara

MJAP	Mulago Mbarara Joint HIV/AIDS Programme
MoES	Ministry of Education and Sports
MoH	Ministry of Health
MoLG	Ministry of Local Government
MoPS	Ministry of Public Service
MoU	Memorandum of Understanding
MRRH	Masaka Regional Referral Hospital
MSH	Management Science for Health
MUK	Makerere University
N/A	Not Applicable
NCDs	Non Communicable Diseases
NCHE	National Council of Higher Education
NDA	National Drug Authority
NFP	Not for Profit Organizations
NGO	Non Governmental Organization
NMS	National Medical Stores
NPCTT	National Palliative Care Technical Team
NUHITES	Northern Uganda Health Integration To Enhance Services
NUMAT	Northern Uganda Malaria and HIV/AIDS Treatment programme
OD	Organizational Development
OECD/DAC	The Organization for Economic Development/ Development Assistance Cooperation
PC	Palliative Care
PCAU	Palliative Care Association of Uganda
PEPFAR	President's Emergency Plan for AIDS Relief
PHA	People Living with HIV
PHC	Primary Health Care
PLHIV	People Living with HIV/AIDS
PLWHIV	People Living with HIV/AIDS
PMP	Performance Management Plan
PO	Project Officer
PRS	Performance Reporting Systems
PWD	People with Disabilities
QED group	Consultancy firm that implemented phase I end evaluation for HAU
SOW	Statement of Work
SQL	Server database used for HAU data
STAR-E	Strengthening Tuberculosis and AIDS Response in Eastern Uganda
STAR-E	Strengthening Tuberculosis and AIDS Response in East Central Uganda
STAR-SW	Strengthening Tuberculosis and AIDS Response in South Western Uganda
SPSS	Software for quantitative data analysis
SURE	Supporting Use of Research and Evidence for policy
TASO	The AIDS Support Organization
TB	Tuberculosis
ToT	Training of Trainers
UGX	Uganda Shillings
UPDF	Uganda Peoples Defense Forces/Department of Defense
USAID	United States Agency for International Development
USG	United States Government
VHT	Village Health Teams
WHO	World Health Organization

EXECUTIVE SUMMARY

This report presents findings from the end of project evaluation for the USAID funded Hospice Africa Uganda (HAU) program, for the period 2009-2013. The evaluation purpose was to present an independent opinion on the impact of expanding coverage and access of PC through the HAU program, to inform the design and effective management of future palliative care programs. The evaluation was intended to document lessons learnt and best practices developed from the implemented project.The key evaluation questions are:

1. HAU has training care providers as one of its major approaches: Were the trainings delivered effectively and efficiently?
2. How well has HAU design and structure addressed factors facilitating or hindering palliative care giving? What was there value-addition of HAU sub-partners?
3. What is the relevance of Palliative Care in the era of expanding access to ART?
4. How effective has HAU been in influencing national policy and practice on palliative care?
5. What is the likelihood that this program will be successful? Assess the prospect that this project will achieve all its intended results.
6. How sustainable are HAU activities and results? Suggest modifications to increase sustainability.
7. What are the lessons learned and best practices?.

Program Background

In 2005, HAU an indigenous NGO in Uganda signed a cooperative agreement (# 617-A-00-05-00010-00) with USAID Uganda, for a program entitled *"Expanding the access to and scope of Palliative Care for People Living with HIV/AIDS (PLHIV) and their families"*, under the USAID PEPFAR program support to Uganda. The overall objective of the program was to increase access to and utilization of quality palliative care service by PLHA's and their immediate families. The program was designed with 4 key results areas namely: i) Improved service delivery of palliative care services, ii) increased capacity of HIV/AIDS organizations, iii) Improved policy environment iv) Improved organization and management of the institution.

Evaluation Methodology

A cross-sectional study design using qualitative and quantitative methods was used. Data collection methodologies included review of documents, key informant interviews, focus group discussions, observations, and post-training and client satisfaction surveys. Field-level data was collected from USG and Non USG funded partner organizations working in 27 districts in Uganda. The districts were purposively selected. Respondents included direct and indirect program beneficiaries, implementers and programme partners. A total of 224 PLWHIV beneficiaries, 141 trainees and other 200 respondents from PC stakeholders were consulted.

Findings

Overall performance of the program and likelihood of success

By end of FY2012, 11 out of 18 set targets had been fully achieved. It is expected that more than 60% of the set targets will be achieved by end FY2013. HAU has reached directly to more than 4000 PLHIV, 60% of who were women. The performance around result areas 1, 3 and 4 reflect an achievement of almost all the set targets. The gaps were with experiencing of impacts of the achieved targets. For example with policy influence and mobilization of political will, the results have not yet been converted to national budget

allocations, nor implementation plans at district or national level. Concerning the result on building specialist PC competences (result # 2), 8 of 11 set targets of training events with USG funded implementing partners were achieved. There was however gaps related to subsequent indicators and only 68% of the 430 targeted numbers of trainees were reached.

Training effectiveness and efficiency; the attribution of PC skills to HAU

The modular workshops were rated as efficient as they enabled trainees to practice skills gained. Trainees reported to be offering various components of PC services at their place of work after the training and only 8% of the respondents indicated they felt uncomfortable in delivering PC services on their own. The reasons are detailed in the main report. Over 90% of the trainees that responded to the post training survey and who were linked to the 8 USG funded IPs facilities, attested that there were positive changes in PC service delivery attributed to the training received from HAU. District Health Officers and doctors who were consulted indicated that the HAU PC training de-mystified fears linked to morphine use. TASO, Military Medical Services, Bombo, and Masaka hospital are examples of units that had adapted the use of HAU PC assessment forms into their practice. Furthermore, the TASO training curriculum was updated to integrate modules in pain management, based on HAU PC training.

Program Design and key factors facilitating or hindering palliative care services

There was evidence that the 2009-2013 program design effectively responded to the hindering factors reported in end-phase I evaluation report. The hindrances then were: a narrow scope of PC service, lack of attention to PLHIV needs, limited spiritual support, and inadequate engagement with government and /or lack of networking with other PC providers. HAU as an institution had faced several governance and systems/policy gaps many of which have now been satisfactorily addressed. Notwithstanding, the current program structures falls short of PC reach and access at Health Centers (HC) III, II and at community level. Whereas some trainees from districts like Iganga, Kamuli and the districts where PC units were established affirmed that they were variously facilitated to deliver PC services, for several others the reverse was true. The shortage of trained morphine prescribers is still a real challenge especially in lower health centers and /or busy referral settings with limited prescribing nurses or doctors. On a positive note, arrangements to influence the PC policies were inbuilt within the 2009-2013 program interventions. They included lobby and advocacy teams at National Parliamentary Level, policy champions like Commissioners at high level establishments in the MoH, and the HIV/AIDS focal persons doubling as PC focal persons at the district local government levels.

Relevance of palliative care in the era of expanding access to ART

Global and national literatures demonstrate why PC should be integrated in HIV/AIDS care as a key component.[1] And all (100%) respondents to this evaluation affirmed that PC is and will always remain relevant even in the era of ART. The arguments are that while on one hand PLHIV on ART face pain from drug side effects like ART neuritis and immune reconstitution syndrome, on the other hand they suffer from painful conditions associated with opportunistic infections like cryptococcal meningitis, and post herpetic pain. Additionally PLHIV especially poor women, children and the disabled often have several

[1] Gren K, Horne C. Integrating Palliative Care into HIV services: A practical toolkit for implementers, FHI 360 and The Diana, Princess of Wales Memorial Fund, June 2012

[1] Integration of Palliative Care Throughout HIV Disease; Victoria Simms, Irene J Higginson, Richard Harding; The Lancet published June 2012

gender, psychosocial and spiritual -related challenges that need be addressed to enable them have quality life. HIV/AIDS records indicate that PLHIV who fail to adhere to their drug regimens and those who suffer drug failure will almost always progress to stage 4 of the disease. Whilst records show that 50% of the PLHIV patients reaching stage 4 of the disease will automatically require PC in addition to ART, it is still estimated that 90% (310,250 patients) of PLHIV in Uganda who are in need of PC have not yet accessed it.

Effectiveness of HAU influence of National Policy

Of the several milestones visible for achievement of this objective, the integration of PC into the Uganda Health Sector Strategic and Investment Plan (HSSIP) and the steps towards development of the accreditation system for training in PC are outstanding. To date, 55% of the 112 districts in Uganda have facilities that have been accredited for delivery of PC services. In addition, key draft documents including the National Palliative Care Policy, the Minimum Standards and the National Palliative Care Guidelines for both Children and Adults are in place to further deepen the institutionalization process of PC as a policy in Uganda. Two professional courses in PC (degree and diploma certificates) have been accredited by the National Council of Higher Education (NCHE). Furthermore, in place is the Parliamentary Forum on Palliative Care which will help strengthen engagement of government at policy level.

The value addition of HAU sub-partners

The Palliative Care Association of Uganda (PCAU) a sub-grantee of HAU contributed to follow-up/mentoring of trainees and harmonization of training guidelines. Together with the African Palliative Care Association (APCA), these partners have been instrumental in influencing national policy gains.

HAU program sustainability

Although HAU program sustainability initiatives like income generating activities were at infancy, the program design including the network model, training USG funded implementing partners, fundraising and the country ownership as exhibited through national policy achievements and promised budget allocations are positive indicators on sustainability.

Conclusions

- The HAU program is most likely to be successful. However, certain elements of holistic PC services like psycho-social and spiritual care delivery need to be strengthened.
- HAU trainings effectively and efficiently transferred specialized PC skills. IPs now must take this forward; integrating PC in AIDS care and treatment, and rolling out trainings through CMEs.
- The 2009-2013 program design and structure satisfactorily addressed the hindrances identified at end-phase 1 evaluation, and leveraged the facilitating factors. Emerging hindrances were identified mostly at facility/district level.
- PC remains relevant even with expanding ART. PLHIV on ART suffer pains, psychosocial and spiritual needs. Yet for Uganda, less than 10% of PLHIV in need have accessed PC.
- Although the policy influence targets were satisfactorily achieved, the short term outcomes are not yet translated into budget allocations for PC activities and they remain unknown at district and facility levels.
- The HAU PC program has established several structures for sustainability, though considered to be at infancy.

Some lessons learnt

- Whole site training and satellite trainings could be more efficient and effective than the modular workshops
- PC requires a multi-sectoral approach involving the MoH, MOES, MoLG for MoPS as well as NGOs, FBO, and CSOs.
- Learn from the integration of TB into AIDS Care and Treatment and the memory project for communicating terminal illness to family
- More knowledge management including telling the story, will enable scale up and sustainability

Key Recommendations

- Design a new follow up phase in partnership to further expand to the unreached districts, and to expand to HCIII, HCII and VHT levels.
- Design and implement strategies to institutionalize PC into HIV/AIDS care package working with USG funded partners
- Design shorter prescriber's training modules to increase the numbers of prescribers
- Adapt the cascade model of training, Master trainers at National Level, District and Health Sub-District trainers with inbuilt mentoring and coaching of trainees
- Design courses for non medical HRH to increase access to PC education
- Continue strategic partnership with PCAU, APCA and others stakeholders to sustain gains made
- Develop an advocacy strategy with clear targets e.g. such as increasing finance allocations for PC activities and integrating PC into District Local Government plans
- Systematize the accreditation system

CHAPTER 1: INTRODUCTION

This report presents findings from the end of project evaluation for the USAID funded Hospice Africa Uganda (HAU) program, for the period 2009-2013. The evaluation was conducted by Multiple Management Consult (MMC) between Dec 4th 2012 and Feb 28th 2013.

1.1 Purpose and Scope of the evaluation

The purpose of the evaluation was to present an independent opinion on the impact of expanding coverage and access of Palliative Care services (PC) through the Hospice Africa Uganda program over the last 5 years. This was to inform the design and effective management of future palliative care programs. The evaluation was also intended to document lessons learnt and best practices developed from the implemented program. The key evaluation questions in Box 1 formed the main guide for the exercise.

Box 1: Key Evaluation Questions

1. HAU has training care providers as one of its major approaches: Were the trainings delivered effectively and efficiently? Include post-training follow up; an assessment of care giver skills in supported organizations and facilities where USAID supports palliative care and show attribution to HAU efforts for building specialist palliative competencies (Post training evaluation), and an assessment of operational efficiency.
2. How well has HAU design and structure addressed factors facilitating or hindering palliative care giving? What was the value-addition of HAU sub-partners? Conduct an analysis of key factors facilitating or hindering palliative care by USG HIV/AIDS care organizations to answer this question.
3. Analyze the relevance of palliative care in the era of expanding access to ART
4. How effective has HAU been in influencing national policy and practice on palliative care? Identify key factors that facilitated or hindered HAU influence on national policy on palliative care and assess how effective HAU is in supporting Ministry of Health in developing an accreditation system for palliative care.
5. What is the likelihood that this program will be successful? Given the rate of achievement of results and current approaches and activities, assess the prospect that this project will achieve all its intended results.
6. How sustainable are HAU activities and results? Suggest modifications to increase sustainability.
7. What are the lessons Learned and best practices

1.2 About Hospice Africa Uganda

Founded in 1993 by Professor Anne Merriman, Hospice Africa Uganda (HAU) is the model Hospice for Hospice Africa, an International Non-Government Organization (INGO). HAU is registered as an indigenous NGO in Uganda and operates at three model sites namely; Hospice Kampala (HKLA), Mobile Hospice Mbarara (MHM) and Little Hospice Hoima (LHH). HAU's founding mission was to promote the relief of suffering through an affordable and culturally acceptable model palliative care.

Since its founding, HAU has remained the leading provider of clinical PC in Uganda, to patients (girls, boys, women and men) during critical illness and end of life. The HAU model for delivery of PC includes service delivery as: home based care (HBC), site based care (Hospice Units), and facility based care (hospital). Others are day care at HAU sites,

community outreaches using church premises, roadside clinics and other community level facilities.

HAU doubles as the Institute of Hospice and Palliative Care in Africa (IHPCA) offering a wide spectrum of training programs for pre-service medical and nursing students, and in-service training for professionals, allied health professionals, care givers, community volunteers, spiritual leaders, and traditional healers.

1.3 Background to the USAID funded HAU Program

In 2005, HAU signed a cooperative agreement (# 617-A-00-05-00010-00) with USAID Uganda. The program was entitled *"Expanding the access to and scope of Palliative Care for People Living with HIV/AIDS (PLHIV) and their families"*. The 3 year (yr) program under USAID PEPFAR support was extended after 2008 for another five years to continue the support of HIV/AIDS Palliative care services and training. The overall objective of the program was to increase access to and utilization of quality palliative care service by PLHIV's and their immediate families. The aims are presented in Box 2.

Box 2: Aims of the Palliative Care Program

- Improving access to holistic Palliative Care for PLHA's and their immediate families.
- Strengthening Specialist Palliative Care competencies within the public, private, faith based and civil society HIV/AIDS service providers.
- Influencing national policy to reposition pain, symptoms management and end of life care within the overall health and HIV/AIDS care delivery.

The cumulative amount obligated to HAU for the period of 2009-2013 was $10,191,000.

1.4 Organization of the report

The report is presented in 4 main chapters, plus the annex. Chapter 1 is the introduction, which presents the purpose and scope of the evaluation, a synopsis of Hospice Africa Uganda and the background to the program under evaluation. In Chapter 2, the methodological approach is summarized giving an overview of the design, coverage, tools, data sources, ethics and limitations collection. The main findings are discussed in Chapter 3 answering the seven evaluation questions while chapter 4 highlights conclusions, best practices, lessons learnt, and recommendations. The annex presents the terms of reference (SOWs), documents reviewed, field programs, data tools and the list of persons consulted (NB the list does not include the names of PLHIV respondents for ethical reasons). Additional information on the HAU training program, key definitions and terminologies used for PC, detailed program design factors and hindrances, milestones on policy achievements, organizational development issues and outstanding quotes from beneficiaries are also included in the Annex. Cleaned data sets shall be presented separately to the USAID/Uganda mission.

CHAPTER 2: METHODOLOGY

The evaluation embraced the international evaluation principles under the OECD/DAC guidelines and the USAID Evaluation guidelines.

2.1 Overview of evaluation design

The evaluation adopted a cross-sectional study design using both qualitative and quantitative tools (copies annexed to the report) to gather evaluative evidence. Primary data was collected using Key Informant Interviews (KII), Focus Group Discussions (FGDs), observations, and post training & client satisfaction surveys from both primary & secondary beneficiaries. Secondary data was extracted from literature available at HAU, USAID, USG and Non-USG funded implementing partners (IPs) working on the project, District Local Government (DLG) staff, referral hospitals and other relevant strategic partners like Makerere University, UPDF, MoH, NHCE, PCAU, APCA, NMS, JMS and UPDF (See Annex 11 for list of documents reviewed).

2.2 Selected participants and coverage

Table 1: Geographical Coverage Of Respondents Consulted

Region	Districts	Data Sources
Central	Kampala , Luweero, Wakiso Jinja	HAU staff, APCA, PCAU, MoES, MoH, JMS, NMS, USAID, TASO-Mulago, UPDF, MJAP, JCRC Parliament of Uganda and Makerere University, patients, care takers and spiritual advisors
Eastern	Mbale, Butaleja Bukedea, Busia, Kapchorwa	STAR-E, TASO, DHO, Palliative Care Focal Persons, patients, caretakers and spiritual advisors , District CAO, Chair Person and Secretary for Health, referral hospitals
East Central	Iganga , Bugiri , Luuka, Mayuge, Namayingo, Kamuli, Kaliro	STAR-EC, TASO, DHO, Palliative care Focal Person, patients, caretakers and spiritual advisors , District CAO, Chair Persons and Secretary for Health and Referral hospitals
Southern	Mbarara, Masaka Ntungamo, Insigiro, Rukungiri, Kabale	STAR-SW, HAU-MHM staff, TASO, DHO, Palliative Care Focal Person, Patients, caretakers and spiritual advisors , District CAO, Chair Persons and Secretary for Health and Referral hospitals
Western	Masindi , Hoima Bushenyi, Ibanda, Sheema	STAR-SW, HAU-LHH staff, TASO, DHO, Palliative Care Focal Person, Patients, caretakers and spiritual advisors , District CAO, Chair Persons and Secretary for Health and Referral hospitals

A total of 27 districts were purposively selected to represent the nature (capacity building and policy influence) and geographical coverage, of the program, reaching HAU sites, USG funded IP district areas, and other stakeholders in Uganda (Table 1). The detailed methodology is annexed to this report, indicating the selection process for respondents.

The persons consulted included: staff and beneficiaries of HAU and USG funded IPs/partners, health service providers benefiting from USG HIV IP health systems strengthening support, Uganda Government officials, and other providers and of PC services and key programme partners of various USG funded partners. Strategic program stakeholders consulted included staff from HAU, USAID, MoH, JMS, NMS, APCA, PCAU and the Local Government officials. The response rates were 100% of targets set for the evaluation. A total of 224 clients from HAU and USG funded IPs responded to the client satisfaction survey of which 75% were PLWHIV. 141 trainees staff or health workers, who benefited from technical support of USG funded IPs responded to the post training survey and over 200 secondary beneficiaries including health care providers such as those from HAU sites, health facilities, USG and Non USG IPs, Community Volunteer Workers (CVW)

and the spiritual advisors were also consulted through KII and FGDs. Informed consent was sought from all respondents each time before any consultation was done. The list of respondents is annexed to this report; please note that for confidentiality, the names of beneficiaries responding to the client satisfaction and post-training surveys have not been included among the respondent's list.

2.3 Data management and analysis

Quantitative data analyses were done using SPSS software. Descriptive statistics including means, frequencies and percentages were used to summarize socio-demographic characteristics of respondents, access, utilization, challenges, PC skills competences and client satisfaction scores.

Qualitative data was checked for completeness and consistency before it was analyzed. Nvivo8 software was used to analyze qualitative data which had been coded from KII and FGD transcripts. Queries were run to assess and quantify responses under selected themes and sub themes. Due to a large number of responses, in most cases, the frequencies of mentions of each parameter selected for analysis were translated into percentages and presented as graphs or data to substantiate the analyses.

2.4 Limitations

i) Field data collection was undertaken during the festive season (before and shortly after the Christmas break). This constrained the time frame within which key informants were consulted especially from districts, USG and non USG funded implementing partners (IPs) who had broken off for holidays.
ii) The home based care beneficiaries are dispersed from each other and some including those who came to the facilities were weak and/or terminally ill or in bereavement. Gathering information from them required substantial amount of time, patience and understanding especially in observance of the thematic content of palliative care.
iii) Due to the nature of their jobs, a number of trainees had moved on from the original places of work to various locations. Tracking them and getting them to respond to the survey was a slow process which led to further delays and changes in the work plans.

The limitations were addressed through training and deploying many more research assistants at different locations, and for longer periods and carrying out the survey in almost thrice as many as the originally targeted 10 districts. Additionally, USAID granted a no cost extension, revising deadlines for deliverables and this enabled more time to reach the targeted respondents. The team therefore feels strongly that the limitations were addressed adequately.

The evaluation teams considers that a balanced evaluation of the program has been achieved from the information obtained i.e. through KIIs, FGDs, client satisfaction and post training surveys, document reviews and field based observations.

CHAPTER 3: FINDINGS

3.1 The overall program performance and success

Key question: What is the likelihood that this program will be successful? Given the rate of achievement of results and current approaches and activities, assess the prospect that this project will achieve all its intended results.

Overall Objectives: Increased access to HIV/AIDS Palliative Care Services

Data from HAU has indicated that a cumulative total of unique PLHIV patients seen between Jan 2009-Sept 2012 HAU at 3 sites was 4,131[3]. Out of this number, more than 60% of PLHIV reached by HAU were females, of whom 77% were PLHIV with no additional diagnosis of cancer. The targeted numbers (% of PLWHAs and their families) accessing direct PC services from Hospice were exceeded by 0.08% on average every year. The program planned to increase access to PC by training USG funded HIV IPs to offer PC services and this was achieved by 85 %. As per **Specific Objectives, a**ccording to indicators set out in the Performance Monitoring Plan, 11out of 18 targets have been achieved.

Table 2: Achievement of Overall Objectives

Indicator	Baseline	LoP Target	Achievements by (2012)	Effectiveness
% of PLWHA and their families accessing direct P.C services from Hospice.[2]	0.78%	1.12%	1.2%	107%
% of HIV/Stakeholder organizations trained in PC service	0	31.4%	22.9%	85%

Result #1: improving service delivery of PC: The program is on track and is likely to meet its targets on service delivery by end of the program. The number of PLHIVs provided with holistic PC services annually by HAU sites has progressively increased since 2009 from 1169 to 1837 by end of FY2012 exceeding the planned annual targets.

Table 3: PC Clients who received material support N=224

Service providers	HAU sites		USG IP Sites		Overall	
Items	Freq	%	Freq	%	Freq	%
Nutritional support	109	84.5	36	37.9	145	64.7
Training care givers	98	76.0	24	25.3	122	54.5
Writing a will	84	65.1	17	17.9	101	45.1
Access to pro-bonal	36	27.9	8	8.4	44	19.6
None	3	2.3	45	47.4	48	21.4

Over the 4 yrs, there has been an average of 621 new cases in all units with an average increment of 121 extra new cases per year. LHH has had the biggest number of new cases. The number of contact visits made with patients at home, hospitals and other health facilities, outreaches and site visits also increased progressively annually. *Details around the percentage of patients satisfied with quality of care are discussed under section 3.2.* Access to various social and material supports by PC clients differed between those under direct services of HAU sites compared to those under other arrangements. The overall picture as per *'client survey responses'* is presented in Table 3.

[2] This indicator measures the direct patient numbers that are seen by the 3 main Hospice Units and does not include the patients seen by Hospice trainees. The actual numbers of all PLHIV receiving PC in Uganda were not established during this evaluation

[3] Data source- HAU: Total number of PLWHAs (Direct Beneficiaries) reached by HAU for the last four years of USAID project (2009 - 2012

Extent to which HAU developed its 3 sites as model centres for PC training and service delivery: The three HAU centers have established infrastructure, including permanent office blocks with furnished functional resource centers with ample reading and search materials and internet connections. In addition, as centers of excellence, HAU facilities link clinical care services with education. On internal personnel capacity, where the HR is fairly sufficient in numbers, HAU has only one social worker serving the 3 sites visiting each site once in 3 months. As a result, the clinical officers are obliged to task shift as social workers. For capacity development, HAU ensures continuous expert input and learning, through weekly institutional level case conferences at all its sites; journal clubs, students' research, action research, and patient audits influencing practice. The evaluation however noted that operational research commissioned to accompany the practice of PC was limited.

Innovations in PC service delivery from HAU and partners included roadside clinics in MHM, special outreaches for vulnerable and disadvantaged groups in remote areas, road-to-care projects and other units like Makerere PC Unit offering a range of services in a one stop center for radiotherapy, social, psycho-social and spiritual activities.

Result #2: Specialist PC competencies within HIV/AIDS care organizations

The number of USG funded IPs targeted for training in specialized PC skills by end of FY 2012 was 13. The evaluation noted that this objective will not be reached mainly because of 2 reasons. First, is that in 2010, HAU had planned to train 3 USG funded IPs, who because of being unsure of the timing of their funding did not commit themselves in time. As a result, HAU resorted to training 3 UPDF groups (cohorts) instead of 1 which was also appreciated since the numbers of potential trainees under UPDF by regions were overwhelmingly high and had been underestimated at the design stage. Similarly, Baylor was also split into two cohorts. In all, only 8 IPs[4] instead of 12 were engaged by the end of FY2012. One additional USG IP training (NUHITES) shall be added to that list by the end of FY 2013 which will reduce the un- realized targeted to 4 from 5. It is however important to note that the training of 2 additional UPDF groups and one of Baylor had neither extra budgetary savings nor expenditures. All remained as planned.

Unfortunately because of this unique but also unfavorable design of indicators where achievement of one target is dependent upon another, failure to meet the physical targeted numbers of USG funded organizations planned, had consequential negative implications. Since the number of health professionals to be trained and the subsequent roll out of PC services all depended on the number of organizations that had been originally planned, implicitly both of the subsequent targets fell short as shown in Table 4. The USG funded IPs, however did not roll out PC training as was expected of them.

Secondly, some partnerships with USG funded IPs did not work as planned. For example, while JSI/NUMAT (formerly in northern Uganda) which had been among the targeted IPs got to its close-out phase before the partnership was effected, another program NUHITES is still at the inception phase and therefore the partnership was at its infancy by the time of this evaluation. The percentage of health workers who reported that changes in PC activities at their institutions was attributed to HAUs training was 87%.

4 These are TASO, MJAP, JCRC, UPDF, MSH/STAR-E, EGPAF/STAR-SW, JSI/STAR-EC and Baylor Uganda (West Nile).

Table 4: **Achievement of Result 2: Building specialized PC competencies USG funded IPs**				
Indicator	Baseline	LOP Target	Achievements by 2012	Effectiveness
# of USG Partners trained in Pain management and Psychosocial and TOT	0	13	8	62%
# of health professionals from USG partners trained (HIV/AIDS organizations) in pain management , psychosocial and TOT	N/A	460	312	67.8%
% of Organizations that are providing and supporting clinical PC Services after training	8.6%	37.1%	20%	54%
% of Organizations trained and rolling out PC services Training [5]	N/A	37.1%	11.4 %	30%
% of health workers from HIV/AIDS organizations trained, and reporting changes in competence brought about by PC training course	-	>90%	78%	87% (Qualitative indicator [6]
Percentage of health professional trained by clinical tutors implementing palliative care	N/A	70%	A Health Tutors survey was planned but not yet undertaken	

Result #3: Influence national policy to reposition pain, symptom management and end of life care within the overall health and HIV/AIDS care regime

These targets are on track as all of them are more than 85% achieved. The program planned to have health workers trained and providing PC services in 55% of the districts and they have so far covered 50% (91% achievement). A curriculum, manual and facilitators' guide for training health professionals in PC have already been developed with the participation of key stakeholders and MoH. However, although they are in place, they have neither been rolled out nor disseminated at national or district levels

In addition, a draft document outlining minimum standards for PC service provision is also in place as well as one with accreditation guidelines. It is likely that all documents will be finalized by the end of the program. Lobbying and advocacy champion teams at different levels like the Parliament, Ministry of Health, international and national PC associations have all collectively addressed the PC policy repositioning. *Details are discussed further under the section on influencing national policy.*

Result #4: Hospice institutional capacity developed to effectively manage and sustain the program

The planned targets under result 4 were achieved and this was crucial for program success and the sustainability of results. HAU now has a much better human resource and institutional capacity to manage the PC program. Administrative and managerial changes including downsizing and ensuring a functioning Board of Directors have been achieved making HAU a more credible institution to partner with. In Hoima, one senior local government staff confirmed that LHH shares with them work plans and keeps them posted on any new developments. There was evidence that a functional M & E system was in place as proved by data gathered using several tools like client satisfaction surveys, client visit sheets, clerking sheets and registers. The captured data is managed in the web based SQL Server database and used for reporting at various levels. Reporting was aligned to the PMP,

[5] Include the organizations and training they have provided to their staff

[6] Key competent areas include : effective communication, patient needs identification, team work, pain management, death (preparing patient and family for death) bereavement, management, stress management for health workers dealing with patient having chronic illness

Performance Reporting Systems (PRS,) and MEEPP online reporting formats. The data informed day-to-day management about the patients and was used for drawing work plans, the HAU strategic plan, sustainability strategy, HR and Financial Manuals. The annex presents more information around achievements in this result area.

3.2 Efficiency and effectiveness of HAU training and PC skills building

Key question 1: HAU has training care providers as one of its major approaches: Were the trainings delivered effectively and efficiently? Include post training follow up; an assessment of care giver skills in supported organizations and facilities where USAID supports palliative care and show attribution to HAU efforts for building specialist palliative competencies (Post training evaluation), and an assessment of operational efficiency.

There was evidence of HAU collaboration with the 8 USG HIV funded partners as defined under section 3.1. This network approach was part of the strategy to integrate PC within the continuum of care for PLHIV and their families at health facility and in the community. The evaluation observed that the degree of PC service integration ranged from a mere identification of clients, and referral to HAU; to health facility establishment in some cases where PC teams and units were functional.

3.2.1 Efficiency of the training methods

Figure 1: Attendance Trends of Modules for Different Cohorts

The modular training approach was used; and trainees were grouped into cohorts (Fig 1).

- Cohort I included JCRC, MJAP and TASO
- Cohort II was UPDF; in 3 batches
- Cohort III comprised MSH/STAR-E, EGPAF/STAR-SW, JSI/STAR-EC
- Cohort IV comprised Baylor Uganda-West Nile, in 2 batches

Three modules were covered, in which 91% (312/340) of trainees attended module 1 on pain assessment and management; 82% (278/340) attended module 2 on psychosocial and end-of–life counseling ; and only 67% (227/340) completed module 3 the Training of Trainers (ToT) course (Fig 3). The PC trainees included 19 Doctors, 82 Clinical Officers, 9 Pharmacists, 199 registered nurses/midwives and /or comprehensive nurses, 2 Counselors and 1 Orthopedics Assistant drawn from all regions of the country. Other categories of trainees from the 61 districts included 160 CVWs and 139 spiritual advisors[7].

Initially a high attrition variance of 24% was observed between modules but this soon reduced to 0%. Whereas the Trainees attributed the high attrition variance to various reasons including; overlapping activities at work places, staff going for further studies and others losing morale or interest in studying, the trainers cited lack of comparable per-diems as a contributor to drop-outs. Moreover, for the first and second cohorts, HAU selected only 50% of the trainees from module 1 &2, to proceed to the ToT module which by itself was a limiting factor. HAU then learnt that this selection approach that only permitted 50%

[7] Evaluators noted a discrepancy in the actual numbers as reported in the various documents, the fact sheet reports 66 districts reached with PC, while the MOH documentation of PC published in 2012, reports 61 districts. The same is applicable for numbers trained

of previous trainees to proceed to the ToT module was neither efficient nor effective. The subsequent training approaches for cohort III were reviewed allowing all trainees who completed module 2 proceed to the ToT module. For cohort IV, modules 2 & 3 were in addition delivered back to back as a two week event. The changes collectively reduced the attrition rate with a resultant attendance rate of 100%.

The modular training approach was advantageous in that it offered participants the opportunity to practice at their work places, and reflect on what they had learnt between modules. This approach was operationally efficient, as there was minimal interruption in routine health service delivery since the providers were away for short periods compared to the 9 month diploma course.

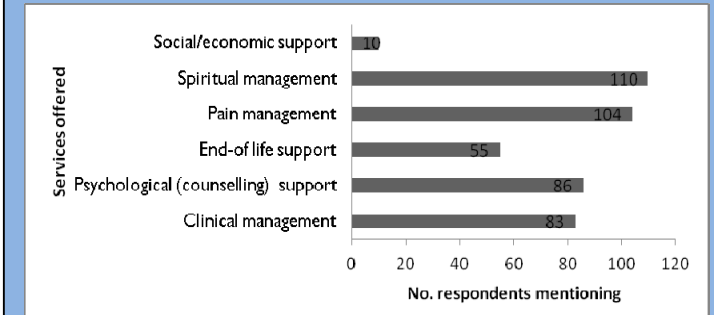
Observed was that the PC modular course lasting 4 weeks does not empower trainees (prescribers) to prescribe morphine. Nurses need to undergo a nine month full-time Diploma in PC training and clinical officers a six week rapid prescribers' course to qualify as prescribers. And yet the medical officers who automatically qualify as prescribers on completing basic medical education are not always available in the ART clinics. The UPDF medical services as an example were reported to have only 4 trained morphine prescribers, while the projected need is 20. The introduction of the rapid prescribers' course in 2011 by USAID and HAU was a commendable measure to mitigate the shortage of prescribers. To further expand PC specialist HRH base, tutors in nurses' training schools were additionally trained. However this evaluation has not assessed the impact of training tutors; HAU has planned for this assessment in FY2013.

HAU training also targeted leadership advocacy through five workshops which reached 103 health managers from all regions of the country. Operationally, the 3-day workshops targeted 30 participants each. The workshops successfully sensitized district health managers about PC and expected them to seek support for integration of PC into the district health care programme as an outcome. Positively, the evaluation affirmed that some managers are now very supportive of PC service delivery. Some citations from KII voiced out that:

> *"Trained health managers at Iganga hospital have allocated a room on male ward to serve as the department of Palliative Care where the trained team sits. KII respondent from STAR-EC*
>
> *"The medical director now allows time to the team to conduct home visits to bed-ridden clients"; Senior Nursing Officer of Kamuli Mission Hospital*
>
> *"Occasionally the administrators also fund PC nurse travel to nearby clients" KII respondent from STAR-EC*

Similar sentiments were expressed by other respondents from Masaka Referral Hospital, TASO, General Military Hospital Bombo, and Kiyunga HCIV in Luuka district.

Figure 2: Types of PC Services Currently Offered By Trainees



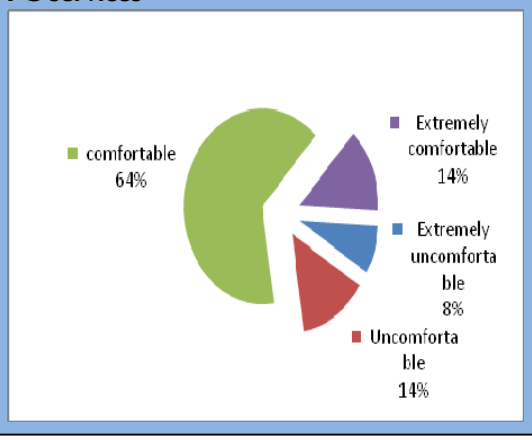
As a center of excellence, HAU continued to develop and strengthen the three resource centers at HAU, MHM, LMM, by improving access to web content. In addition, staff and students were trained to use on-line document search engines like Hinari. We noted that resource centers were

stocked with PC reference books. At the time of the evaluation, the resource centre at LHH was being used as a multi-purpose room (meeting, reading, etc.) by the support staff, hence limiting its effective use as a resource centre by HAU trainers and trainees.

3.2.2 Effectiveness of the training methods

From the post training survey tool applied, trainees reported to be offering various PC components as shown in Fig 2. With documentation considered as evidence of PC services being offered, 83% (117/141) reported documenting the PC services in a health service records book. The commonest type of record used was the PC register albeit only 22% (26/117) being able to name the specific types of records used. Extrapolated, this may denote a 'lack of' or 'poor' documentation of PC services offered in ART clinics. This was corroborated by observations by evaluators, viewing and assessing of records, whenever it was practical.

Figure 3: Trainees' Level of comfort delivering PC services



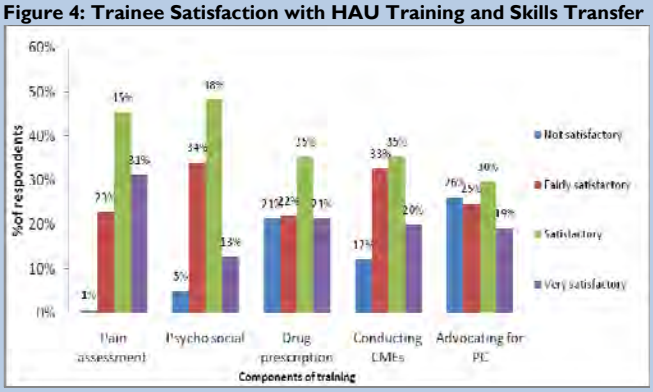
The evaluation observed that the number of CVWs and spiritual leaders (program allies) trained were not adequate to meet the demand at community level. There is a great need to train additional CVWs and to integrate their work with the VHT systems; to strengthen PC within the PHC systems.

On competences, Fig 3 indicates that 78% of trainees felt comfortable to extremely comfortable when delivering PC services. Further to this, a respondent from MJAP commented that:

"Before attending the PC in-serve training, I used to have difficulties in assessing pain. On many occasions I did not give the required care as far as controlling pain is concerned among the HIV infected patients. I could just assume that the pain would reduce provided the clients take their ARVs drugs plus mild pain killers like panadol. After the training I now conduct thorough pain assessment and management among patients on ART".

Whilst 8% trainees expressed lack of confidence in handling PC skills, 42% expressed need of additional PC skill building attributing it to the ever evolving knowledge, which requires constant updates.

Figure 4: Trainee Satisfaction with HAU Training and Skills Transfer



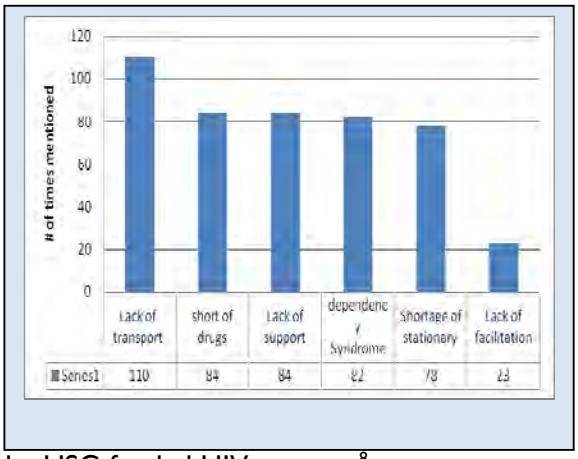
More than 90% of trainees indicated they offered spiritual care; albeit the findings from the client satisfaction survey indicating that 30% of the clients did not receive any spiritual support. And of those that received, 30% were not satisfied with the spiritual care given. We observed that spiritual guidance though a part and parcel of a holistic PC package, need specific competence and is best handled by spiritual leaders who

have exposure and knowledge of PC rather than the busy PC health worker.

On the rating of satisfaction with the HAU modular training workshops, 76% of trainees were satisfied with the facilitation methods used while 1% of respondents were not satisfied. Training sessions on drug prescription and advocating for PC services were poorly rated, with 21% and 26% respectively reporting dissatisfaction (Fig 4). Poor rating of the drug prescription and advocacy modules requires further investigation.

On whether trained staff had influenced management to integrate PC in the continued medical education (CME) activities at their facilities; 91% (128/141) reported having general CMEs at their facilities though only 78% (101/128) reported rolling out CME on PC at their workplaces. This was and is still a missed opportunity for expanding PC skills and knowledge in facilities where CMEs are regularly conducted. Moreover, only 58% of the trained providers mentioned that the HIV organization affiliated to the facilities are supporting PC CME sessions. This demonstrates low support from USG funded IPs to in-service PC training.

Figure 5: Factors hindering PC delivery



Factors hindering practices of PC (Fig 5) mentioned by trainees were lack of transport to follow up clients, pain control drugs, support from administration, stationery to record cases and that health workers expect per diems for PC delivery.

Client (patient) Satisfaction: This was used as a proxy measure on effectiveness of HAU training and building specialist PC skills with USG funded IPs, through the network model. Thus clients surveyed reflect on PC service delivery by HAU and the USG funded HIV partners[8].

On pain management, 60% of the patients attested to having little pain or no pain at all due to the program interventions with 19% indicating having been in overwhelming pain in the 30 days prior to and including the day of the evaluation visit. Although some patients attributed this status to having run out of pain relief medication over the festive season break,[9] when probed further, it was very evident that the patients did not contact the various Hospice units on false assumptions that units were closed. In reality, we noted that units had offered services throughout the festive season. This was attested to by others. For further verification, in another question, 80% of the respondents attested that in the last three months prior to this survey; they never run short of pain relief drugs.

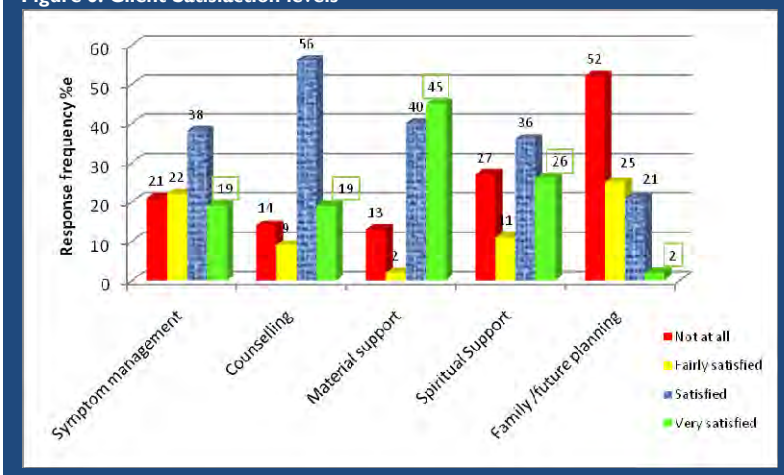
Coughing (35%), nausea (25%) and constipation (23%) were the most frequent symptoms that patients faced. With full knowledge that constipation is a known side-effect of morphine

[8] Evaluators acknowledge difficulty assessing patient satisfaction directly. A modification of the APCA POS was used by MMC. There is no direct question about patients' satisfaction with care within the APCA POS. Patient satisfaction surveying has some limitations, In refs: 1.Aspinal F, Higginson IJ. et al J Adv Nurs. 2003 May; 42(4):324-39. Using satisfaction to measure the quality of palliative care: a review of the literature, and 2.Säilä T, Mattila E, et al. J Eval Clin Pract. 2008 Feb; 14(1):148-54. Measuring patient assessments of the quality of outpatient care: a systematic review.

[9] The survey was undertaken shortly after Christmas break of 2012 (7th -17th Jan 2013)

as an example, the evaluation was mainly concerned about the level of satisfaction of how symptoms were managed. 79% were fairly satisfied to very satisfied, while 21% expressed various reasons for dissatisfaction. Satisfaction for Psychosocial services encompassed various themes as highlighted in Table 3, section 3.1. Clients indicating dissatisfaction were disaggregated as: counseling (14%) access to material support (13%), Spiritual support (27%) details of which are shown in Fig 6. Dissatisfaction with counseling was attributed to the fact that the few psychosocial experts employed with HAU and USG funded IPs could not meet client needs.

Figure 6: Client Satisfaction levels



Inadequate time was allotted to counseling which was most of the time addressed by clinical officers and nurses. Despite their technical competencies and multitasking approaches, on most occasions they were confronted with high numbers of patients waiting, worsened in the busy ART clinic settings. Discussion of future planning and family issues which recorded 52% client dissatisfaction level shared a similar explanation. During the field visits, the evaluation team however appreciated the quality time and discussions HAU staff spent time with their clients. Discussions span from issues concerning death, the future, care of family for those at end of life and family issues related with dependants, finance, social needs like IGAs, access to school fees, legal aid. Whereas this was satisfactorily handled by HAU staff, it varied with USG funded IPs.

Evaluators acknowledged that such discussions could be "real difficult" even for qualified service providers. PC trainers and providers should learn and adopt the well documented Ugandan best practice of *"the memory project"*[10], which has enabled PLHIV talk to family including children and plan for end-life issues, in an innovative and effective manner. It was noted that many patients, die intestate.

During home visits, evaluators also observed that more attention was paid to pain, symptom management and material support like food for the HAU sites, and less with psychosocial/spiritual support. Although the program trained spiritual leaders, most patients reported getting spiritual care from spiritual leaders within the community rather than from HAU. HAU's perspective was that spiritual support was offered through several means including staying/ communing with the patient, prayer, discussion of spiritual distress, moments of silence and that mainly for specific religious rituals e.g. Sacraments when spiritual professionals were called in.

[10] http://documents.nacwola.or.ug/Breaking%20Silence.pdf

Overall, 92% of the 224 clients and caregivers as well as partners like spiritual leaders attested that they were comfortable, satisfied and happy with the relations with the HAU service providers as per selected citations shown.

> '…..At funeral services, whenever they thank people, patients and doctors always make a special acknowledgement of LHH….'; *Says a Spiritual leader from a Born again church in Hoima district*

> '…The religious denominations were brought together and yet we used to work in isolation. They now invite us to many workshops. We have unity. We have less worries and more trust for each other…' *a Spiritual, Moslem Cleric Leader says*

> ….LHH is one of the credible organizations we have in the district giving palliative care services. We receive their periodic reports and work plans on time. Because of their transparency, accountability and commitment to serve people in Hoima, I was impressed when during one function we were attending, one old man stood up and said "I have given one acre of land to LHH to increase on their working space". This is not very common in Hoima for Land Lords to give land freely. I was amused… *says one CDO from Hoima*

The above statements notwithstanding, dissatisfaction was also cited by 8% of the respondents mentioning that some staff from HAU and USG funded IPs had failed to open up to patients and others were rude or abusive when patients miss out on appointments. Discomfort with prolonged waiting time and hunger when in queues for medical visits were also mentioned by individuals. Whereas those dissatisfied were a small number, the evaluation team considered it a significant finding more especially the need to establish a feedback mechanism after instituting corrective measures for purposes of assurance to the aggrieved clients and improved program ownership. Issues where clients underscored dissatisfaction must be revisited during future discussions.

Satisfaction response by family members (include caretakers)

Figure 7: Satisfaction responses by family members

Fig 7 shows that the three most appreciated services by family members were:- availability of pain killer drugs and that HAU staff regularly check on clients in home based facilities and offer them quality time.

Asked on what to improve on the program, 134 expressed absolutely satisfaction while 109 re-echoed a need for extra social support like school fees, income generation activities and continued support with food. Others (98 mentions) requested for training on how to reduce or handle patients' pain and clean wounds especially bed sore wounds while 74 mentions were about sensitizing patients to come out of denial and stop believing in witchcraft when they have cancer and HIV/AIDS.

3.2.3 Attribution of PC results to HAU trainings

- **Skills gained:** Respondents acknowledged positive gain in skills after attending PC training provided by HAU in both service delivery and other capacity building activities.
- **Establishment of PC units:** TASO, Masaka Regional Referral Hospital, Ntara HCIV, UPDF Bombo, Masafu General Hospital have established PC units after the HAU training. They have a counseling section, and, stock and supply morphine with minimal stock outs.

- **Adoption of use of HAU PC assessment forms:** During training the health workers were introduced to the HAU clerk forms/standards. Trainees continue to use the HAU client sheets when clerking patients.

  "*The form has helped us as providers to ensure sustenance of the holistic approach……..*" KII TASO Mbale

  "*After training staff were more sensitive about patient's pain. The health workers (nurses) started giving morphine and other pain management drugs at triage sites. The pain drugs given to patients as they wait are documented in emergency files which were created after training"* FGD with trainees.
- **Demystify morphine use:** HAU trainings helped de-mystify fears linked to morphine use.

  "HAU trainings has greatly helped us to de-mystify the fears linked to morphine use, The old-medical school training messages focused more on morphine as addictive medication versus its use for pain relief" KII Mbarara District
- **Alternative care:** The TASO teams credit HAU for training them on alternative remedies for vulval warts, post-herpetic pain, e.t.c using crushed medicine mixtures or useful natural herbs like

  "Fungi pan sap which treats post neuritis pain", and the milk bush helps clear molluscum. Clients have reported positive results after they were shown how to use these are herbs that commonly grow in the Mbale region; KII respondents TASO Mbale.
- **Partnership with spiritual leaders:** USG funded HIV partners like UPDF demonstrated more impacts of training, expanding PC provision to partnerships with spiritual leaders.

  "The Bombo Pentecostal church is an ally for palliative care services, the hospital has referred destitute clients and the church has adopted 5 children into their care" KII with PC provider UPDF Military Hospital, Bombo
- **Increased demand for morphine:** The training also raised awareness and demand for availability of morphine at all sites.

  "*Trainees push the procurement department to ensure continuous availability of morphine and other pain management drugs"* FGD with service provider.
- **Inclusion of Pain Management in training modules:** TASO training centre acknowledged that they used knowledge gained from HAU to integrate modules on pain management into their training manual.

  "*Contents covered during PC training delivered by HAU were used to enrich TASO training curriculum in clinical management of HIV. A module of pain management was modified"* KII with IP Training coordinator.
- **CME:** Some trainees had established plans for CMEs and formed PC committees.

3.3 Program design and structure visa a vie factors facilitating or hindering palliative care delivery

Key question: How well has HAU design and structure addressed factors facilitating or hindering palliative care giving? What was the value addition of HAU sub partners? Conduct an analysis of key factors facilitating or hindering palliative care by USG HIV/AIDS care organizations to answer this question.

To expand access and utilization of PC services the essential program design elements were : i) sub-grant to PCAU, ii) the USG network model that underpins family and patient centeredness, iii) family and community involvement, iv) consideration on gender and disabilities' vulnerabilities, v) sustainability and involvement of PLHIV (GIPA/MIPA principle) and v) accessibility and quality care by qualified health workers. Findings related to this key question were informed by KIs and FGDs, and review of documents.

3.3.1 Hindrances identified at program baseline

From the end phase evaluation (2005-2008), the QED group evaluators listed a number of weaknesses, challenges, gaps and threats that were a hindrance to expanding PC service delivery. This evaluation found that most of the hindrances at program baseline had been addressed through the 2009-2013 USAID/HAU program design and structure (Annex 5)

3.3.2 Factors currently hindering PC Service delivery

With the 2009-2013 program design, there are emerging hindrances that include gaps in the implementation policies such as slow integration of PC into national health care at both national and district level. There was also lack of indicator for PC into the HMIS, limited prescribers and supervision. Individually, there was also limited awareness of the PC service, extreme poverty and belief in witchcraft.

Detailed analysis of the hindrances is presented as Annex 6 to the report. It is also important to note that this analysis looks at hindrances reported by all respondents. HAU as the lead program implementer could only make recommendations about how trainees are utilized & on several occasions HAU highlighted to USG funded IPs that trainees needed to spend time & be supported to remain in PC. The prerogative is largely with district & other authorities to maximally utilize the skills and knowledge imparted to the trainees.

3.3.3 Factors facilitating PC service delivery

The listed were identified as key facilitators of PC service delivery that should be leveraged for future program design:

Strong country ownership:- for example, the Commissioner of Clinical Services, MOH as a champion of PC, presence of a national PC Team chaired by MOH, joint monitoring and supervisory visits by GoU and HAU, and the funding of morphine reconstitution by the Government of Uganda. At District level, the presence of HAU is acknowledged as a facilitator of PC services including provision and support for transport of clients to referral centers, disease diagnosis and investigations.

Program design and approaches:-

- The network model of training USG partners as targets has a multiplier effect in expanding access to services
- Strong linkages between PC provision and training institutions; imply quality, and use of PC guidelines for service delivery, and training
- Linkages and referrals between PC and ART service providers, enables continuity of care
- Morphine production, distribution and de-mystifying myths, fears and misconceptions on usage of oral morphine, training of more morphine prescribers, facilitate service delivery, the access to morphine by clients in need.
- Holistic PC service delivery, that is flexible and tailored to the individual clients' needs creates satisfaction beyond the "one-size fits all" services, further builds clients' confidence and trust with the service providers.

Advocacy, in built reviews and learning within the program:- Lobbying and advocacy events that reach out to managers, leaders, policy makers and politicians at

National, district and at facilities has promoted understanding of PC, patients' and trainees' needs.

Community structures:-the structure of community facilitators is an enabler of access. Though with limited facilitation and integrations within lower primary health care levels (HC III, II & VHTs), there was evidence of PC services delivered by CVWs and spiritual leaders and other Hospices like Kitovu Mobile, Joy Hospices and community services by TASO and Mildmay.

3.3.4 Value addition of HAU sub partners

The Palliative Care Association of Uganda (PCAU) was a sub-grantee of the program under review, and this was part of the key design elements. PCAU was tasked with follow up of trainees (coaching and mentoring) and the standardization of curriculum. PCAU successfully attained this and also contributed to the policy advocacy result area, mobilizing other PC service providers in country. Annex 9 presents diagrammatically contributions of the various HAU strategic partners.

3.4 Relevance of Palliative Care in the era of expanding access to ART

Key question : Analyze the relevance of palliative care in the era of expanding access to ART

This evaluation re-affirms: Patients with life limiting illnesses; PLHIV need to receive holistic pain control which entails dealing with their physical, spiritual, psychological and social pain (the 2009 program development hypothesis). PC commences at the diagnosis of a life limiting illness and remains very relevant even in the era of expanding access to ART. This assertion is backed by evidence from global and national literature, respondents' collective views and opinions around the Ugandan context and the evaluator's observations. The global guidance and framework on PC as per PEPFAR and WHO definitions (see annex for definitions), PC goes beyond pain management and mere counseling; and is an integral part of HIV care and treatment.

Patients with life limiting illnesses deserve holistic palliative care that deals with physical, spiritual, psychological and social pain and the provision of PC services as a basic health right[11]. Recent global studies have shown that at any given time 50% or more PLHIV presenting in an HIV clinic at Stage 4 of the disease will require PC in addition to ART. PLHIV need care to manage pain and other symptoms caused by opportunistic infections, medication side-effects, aging and co-morbidities such as cancer[12]. PLHIV face depression, anxiety and other psychosocial or spiritual problems; these affect their quality of life as well as their

Table 5: Estimated numbers of PLHIV in need of PC[1] in Uganda (So: UAIS 2011)

Estimated numbers of PLHIV in Uganda: 2,482,000 people @7.3% prevalence rates for population of 34 Million people
25% of PLHIV will ultimately reach stage 4; Total numbers for Uganda are: – 25% X 2,482,000 = 620,500 people
50% of all PLHIV who reach stage 4 need Palliative care = 50% X 620,500 = 310,250 people in need of palliative care
By end FY 2012; 4156 PLHIV accessed PC at HAU sites; the numbers that accessed PC from USG HIV IPs are unknown, and should collectively be more. Based on HAU only figures, PLHIV reached with PC were 4156/310,000 X100 = 1.3 %. Implying that the majority remainder, more than 98% of PLHIV need PC and have not yet been reached

[11] Annual Narrative and Financial report; Oct 2010-Sept 2011 submitted by HAU to USAID for the program to expand coverage and access to PC services

[12] World Health Organisation (WHO). Global HIV/AIDS Response: Epidemic Update and Health Sector Progress Towards Universal Access: Progress Report 2011: WHO Geneva Switzerland, 2011

well being, and their ability to adhere to treatment and to stay in care[13]. WHO further gives guidance that PC should be incorporated as appropriate at every stage of HIV related illness and not only when the patient is dying[14].

In Uganda the 2011 AIDS indicator survey reported the average national HIV prevalence rates of 7.3% (Table 5)[15] among adults aged 15-49 years. The prevalence rates imply an increment, and with the increasing Ugandan population estimated at 34 million, this implies an increase in the burden of disease.
From table 5, the estimated need for PC is 310,000 Ugandans; this is more than twice the estimated numbers, in 2009, at the program baseline. And implies that more than 95% of PLHIV in need of PC are not reached, corroborating with the views of one key informer from APCA (please refer Box 3).

In addition the Uganda AIDS Indicator survey,2011 found that HIV prevalence is higher for women than men at 8.3% compared to 6.1%, among men[16]. The none-educated low-mid income women were most affected. The implication of this is that the number of Ugandans in need of HIV Care potentially increased, and it is the poor woman who is most in need.

Coupled with the finding of an expanding number of PLHIV in need of care services, all (100%) respondents in this evaluation concurred that PC remains very relevant for the Ugandan context. Since ART reaches to only 60% of the people in need, this would mean that a good proportion of the remaining 40% of PLHIV not accessing ART, might report for care, with advanced disease. Key informants acknowledged that even with ART access and adherence, there are cases of 1st and 2nd line failures; yet in this country, ART resistance testing services is limited and quite costly at around $90 at the JCRC laboratories

Box 3: Respondent voice on relevance of PC with ART Access

"Yes, PC reaches to only 10% of the people in need. The rest are not served" KI African Palliative Care Association

"Yes, the ART coverage is below 50%; there are complications like Meningitis with severe headache, and Kaposi's Sarcoma causing severe limb pains; Outcomes of palliative care are very positive for the clients and beneficiaries". KII Masaka Regional Referral Hospital

"Yes, People still die despite ARVs, and ARV funding is dwindling and not everyone is on drugs. Late Start of ART, Side effects of the ART; the Holistic approach is very helpful, leads to development and production" KII TASO Mbarara

"Yes, palliative care is still much needed for the HIV clients, the terminally ill and the prisoners, they have several psychosocial needs. Palliative Care is relevant for the treatment of opportunistic infections, the Immune- reaction (IRIS)" KII- Makindye Military Health services

"Yes; HIV brings on complications like Kaposi's sarcoma linked to HIV, there are Gender relations issues with HIV, and Disability, disease process and Legal issues. Defaulters suffer drug resistance and become terminally ill, failing ARVs, Herpes zoster and the post herpetic pain". KII HAU Mbarara

"Yes, access to PC services is a basic right, just as is cancer and AIDS care, PC is needed for terminally ill clients –renal liver failure, e.t.c "People with pain, terminal illness, need robust attention, Now that NCDs are on the increase, the need for PC is high" KII Mbarara District Health Office.

"AIDS clients present late and with advanced disease, ARVs cause side effects, There are psychosocial aspects of AIDS and ART and There are other PC needs" KII JCRC
"Pain in AIDS will always be there; moreover the numbers of clients in HIV clinics are on the increase"; key informer MJAP, Mbarara

"HIV and palliative care are inseparable, palliative care is much needed in case of increasing cancer among HIV patients in Uganda. . . …. busy HIV care settings focus on drug adherence with less attention to holistic care. In fact an HIV client may even progress better with the disease with PC than access to ART alone" Respondent, Mbarara Hospital

'……..*PC is much more needed in the military than in any other place. The military face day to day emotional challenges, separation from families, on top of injuries at the front line including loss of limbs..*' said by one respondent from UPDF

[13] Gren K, Horne C. Integrating Palliative Care into HIV services: A practical toolkit for implementers, FHI 360 and The Diana, Princess of Wales Memorial Fund, June 2012
[14] Integration of Palliative Care Throughout HIV Disease; Victoria Simms, Irene J Higginson, Richard Harding; The Lancet published June 2012
[15] Uganda AIDS Indicator Survey 2011; MOH, UBOS, DANIDA, WHO, USAID, CDC, Ukaid and partners-
[16] Uganda AIDS Indicator Survey 2011; MOH, UBOS, DANIDA, WHO, USAID, CDC, Ukaid and partners

(see Box 3). This implies that impoverished chronically ill women, girls, boys and men faced with drug resistance have limited access to resistance testing with the consequence of being at risk of advanced disease. Advanced disease presents with painful opportunistic diseases like Kaposi's sarcoma, cryptococcal meningitis, toxoplasmosis or post herpetic pain. Additionally, ART service providers assert that ART has numerous side effects creating physical pain relief needs, for example the protracted neuritic pains and the immune reconstitution inflammatory syndrome (IRIS). Above all, PC helps improve the quality of life and the quality of care through Adherence to ART, and enables positive living.

It is important to note, that as the largest PC provider in the country HAU has seen only 21,000 patients over 20years. The HAU data indicates that in the last 5 years, only 25% of the PLHIV receiving PC from HAU had the diagnosis of HIV infection and cancer, and that the majority 75% was in need of PC services due to other HIV related complications; meaning that with or without cancer, PLHIV need PC services.

Further still, gender issues related to a diagnosis of HIV are enormous, and well documented. These were again voiced by respondents; women are the care givers, and women are blamed for the transmission of HIV, women will most likely report late for AIDS care and treatment due to their low status in society and limited access to resources, and women are at risk of losing properties to family-in-law when widowed or divorced, making them more vulnerable[17]. Vulnerability worsens in the presence of disability. Women, PWD and vulnerable children living with HIV require social and legal support, as part of a holistic care package.

Dr Leng, the PC expert from Makerere University College of Health Sciences asserts that in considering the relevance of PC in the era of expanded ART, it is more consistent with health and development rights to:

> *"…….Look at people needs and not the disease they suffer……In the era of expanded access to ART, non communicable diseases, aging and chronic management create a dual epidemic of people in need of PC. For example if a 35 year old man starts ART with CD4 >100, he has life expectancy of >35 years and is in need of PC."* (Unpublished power-point presentation by Dr. Mhoira Leng, Makerere University PC Unit)

Additionally, our observations on the typical PLHIV PC client, from HAU or from USG funded IPs:

> *"Often, a mid-aged woman living in an overcrowded impoverished urban slum area, unmarried or widowed formerly employed; has lived with HIV for more than 10 years, and is on regular ART treatment and then develops cancer of the cervix or another cancer; which is diagnosed at advanced stages; as the disease progresses, the woman formerly bread-winner has no more income, no care giver, and the family she has are focusing on how to extract the last coin from her or sell of her properties. She then accepts support from Pentecostal believers, or traditional healers who convince her of possible miraculous healing..."*
>
> *"A rural peasant widowed PLHIV mother, who lives with her grown up children and grand children, as bread winner and has suffered debilitating post-herpetic pain for more than 10 years now, the herpes zoster left her blind in one eye, and with a disfigured face, the pain is excruciating, and she gets relief from morphine received from TASO (USG funded IP). She is otherwise generally healthy thanks to the routine supply of ART from TASO and the PC"*
>
> *"A widower, on ART for more than 10 years, who developed Kaposi's sarcoma, an indication that he suffered drug resistance, his ART prescription was changed empirically, to take care of the drug resistance. However for the last 1 year or so, he has been on the new regime, the Kaposi's sarcoma remained, he is incapacitated by the pain, and he gets relief from Morphine and HBC visits…….from TASO…."*

The evaluation noted that leading Ugandan PC scholars argue that "*the question around relevance of PC for PLHIV in the era of ART was affirmatively resolved some years back"* and the focus should now be on quality improvement and scale up the access to PC. Literature

[17] Mainstreaming and Integration of HIV in development and humanitarian programs; Oxfam' Strategy 2006-2010; H Kivumbi et al

asserts that it should not be a question of PC or ART. PLHIV in need should access both ART, and quality PC[18].
Given the above findings, including the gender, disability and age vulnerabilities related to a diagnosis of HIV, PC needs in Uganda are enormous; PC services remain very relevant within the Ugandan social-economic context. Monitoring progress on scale up of numbers/proportion of PLHIV reached with PC should be an integral part of M&E systems for HAU, and USG HIV IPs.

3.5 Effectiveness of HAU influence of the national PC policy and practice

Key question: How effective has HAU been in influencing national policy and practice on palliative care? Identify key factors that facilitated or hindered HAU influence on national policy on palliative care and assess how effective HAU is in supporting Ministry of Health in developing an accreditation system for palliative care.

Result Area 4 was to be achieved through palliative care advocacy at national and district level and through developing an accreditation system for palliative care providers in Uganda. The evaluation found that close to 80% of the policy objective targets were achieved through efforts of HAU and its sub-grantee PCAU, as listed below.

Influence of PC policy at national level

Through advocacy strategies for integrating and scaling up PC in all public health facilities have been outlined in the HSSP (2010/2011-2014/15, page 91). The National Palliative Care Policy was drafted with support from the project on Supporting Use of Research and Evidence (SURE) for policy, an initiative between PCAU, MoH/PC country team, Makerere University and APCA. The Parliamentary Forum on PC was established to further engage government in policy and budgetary allocation for palliative care. In addition the MoPS recently recognized palliative care as a specialty that is included in the public service qualifications and cadre of employable staff in the public service. A summary of advocacy and national policy influence achievements since 2009 is presented as annex 7.

Percentage of districts with sites offering PC services

By end of FY 2012, 59 (66) % of 112 district in Uganda[19] were reported to have a trained PC focal person and trained PC health workers, at HCIV or at regional referral hospital level. Of these 66 districts with sites offering PC, 32 initiated their PC services in the period under review. Additionally, there were 34 PC units located in private not for profit health facilities and private for profit facilities providing PC services in Uganda, all of which are brought together under PCAU as the umbrella body.

Development of minimum standards package for PC service

The national palliative care guidelines for both children and adults have been produced in draft form though not yet published. These are under final review to set minimum palliative care standards in the country; we did not establish the exact dates for publishing these documents.

[18] PEPFAR's Implementation Progress and Promise: Ch.6 Care Category; CATEGORY, TARGET, AND RESULTS: 2007- Board of Global Health/ accessed http://www.nap.edu/openbook.php?record_id=11905&page=169-204: downloaded Harriet Kivumbi, 29 January 2012 11:40am Uganda time
[19] MoH, the Development of palliative care in Uganda, 2012.

Accreditation of PC courses and development of curriculum
Two professional courses in PC at both the degree and diploma level have been accredited by the National Council of Higher Education (NCHE). In addition the National Palliative Care Curriculum was produced and approved by the National Curriculum Development Center, MoES and MoH in collaboration with HAU and PCAU.

It should be noted that although the policy and influencing result area has achieved its targets, the impacts of this advocacy are more known, and articulated at national/central level, and not at the districts and implementation levels. The situation is much better for districts that have the presence of a HAU site, or where USG funded IPs operate, when compared to districts and health facilities, that are far away from HAU sites or USG funded IPs. This means that the next phase should consider roll out of national policy to district, sub-district and community levels. Moreover, the inclusion of PC into the National Health Care system documents and policy has not yet been accompanied with budgetary prioritization, nor implementation plans for PC services at the health centers especially for staff recruitment and facilitation of PC activities including HBC.

3.5.1 Factors facilitating influence on national policy

Interactions with key informants generated a number of factors that facilitated HAU's influence on national policy on palliative care. Table 6 presents the most mentioned issues on facilitating factors as per the analysis using Nvivo.

Table 6: Facilitating factors for policy

Factor	Percentage
Political will	34.3
Policy champions	27.8
Partner coordination	26.8
Approach to PC	8.9

i) **The political will** for PC in Uganda is a key factor that has facilitated national advocacy. This was manifested as government support offered for integration of PC into the national health care system. For example:
   - The National Palliative Care Technical Team/Committee in the MoH is headed by a PC Specialist
   - Presence of the PC parliamentary forum, under the social services committee.
   - Integration of PC into the Health Sector Strategic and Investment Plan (HSSIP)
   - Government's commitment to increase the number of health workers providing PC through the Statutory instrument #24 of 2004 authorizing Nurses and Clinical officers to prescribe morphine in Uganda
   - Acceptance of the Government to make morphine available for pain management through the MoU between the MoH, NDA, JMS, HAU and NMS to import and produce oral morphine in Uganda.

ii) **Approach to PC in Uganda with HAU leading as a centre of excellence:** HAU has integrated clinical practice and education to provide evidence for the need of palliative care in Uganda hence providing a favorable environment for evidence based programming and policy work. Training increases the number of cadres to offer the needed services in the country and this also contributes to sustainability.

iii) **PCAU coordination of PC stakeholders;** the Palliative Care Country Team and the Parliamentary Forum on PC worked together to engage government on PC needs as a single voice hence sustaining the advocacy efforts of PC in the country.

iv) **Presence of both individual and organizational PC champions** in the country has also facilitated advocacy in Uganda. These champions passionately promote PC and leverage resources to ensure increased PC access and coverage in the country.

3.5.2 HAU support to MOH in developing an accreditation system for PC

Under PCAU and MoH collaboration, HAU established an accreditation system for PC in Uganda with special attention to access and utilization of morphine.
In addition MoH and PCAU have come up with an accreditation system for health facilities to access morphine.

The 4 requirements for accreditation include:

i. Presence of a trained morphine prescriber
ii. Presence of a palliative care team
iii. Allocation of PC office space
iv. Presence of a double locked cupboard to securely store morphine

Qualifying facilities are supposed to invite PCAU to inspect for accreditation. On fulfilling these conditions, the health centre is accredited by being included on the list of JMS and NMS as eligible morphine dispenser. To date, the 66 districts mentioned as offering PC services, have hospitals or HCIV that have ever fulfilled this criteria for accreditation. However, the evaluation has observed that this accreditation is verbal with neither systematic documentation nor insignia or certificates issued to the unit. The accreditation is haphazard and subjective; dependent on PCAU decision. And it is unknown whether the accreditation is reviewed periodically or it is a "one-off" process of qualification to prescribe morphine.

In addition, HAU signed an MoU to produce and distribute oral morphine in Uganda. Through a "pull" supplies chain system, JMS imports and delivers the morphine powder to HAU who then reconstitute it, into liquid oral morphine. HAU re-distributes liquid morphine to NMS and JMS for onward delivery to Government and Private health facilities respectively. This arrangement is a model for oral morphine distribution in Africa and other low-resource settings.

3.6 Program sustainability

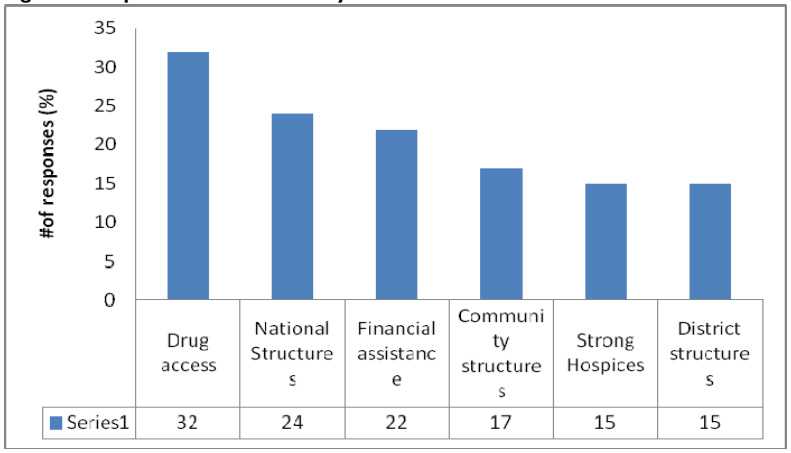
Key question: How sustainable are HAU activities and results? Suggest modifications to increase sustainability

Sustainability of HAU PC programs has been considered in terms of financial, institutional and social structures established during the intervention. It also depends on whether the networks and linkages developed can sustain the PC associated benefits achieved with full, limited or no external support from the current funding program. Critical to PC is the continued access of quality and gender sensitive PC services by the clients through;

- Ensuring that PC service providers have the right skills to deliver quality care and taking care of more women, girls, people with disabilities and other vulnerable groups
- Continued engagement of key partners and national policy organs e.g. MoH, PCAU, APCA, Parliamentary Committees and PC policy champions to lobby and advocate for user friendly policies for institutionalizing PC services at different levels
- Integration of holistic PC services (pain and symptom management, spiritual and psychosocial attributes) as priority needs for the HIV/AIDS and cancer patients in need of PC in a gender sensitive manner
- Ascertained continued availability of drugs and other supplies for PC services

PC services need to be expanded vertically by deepening what already exists and horizontally to replicate what has been achieved so far. In their responses (Fig 8), the clients understandably scored continued access of morphine and pain killer drugs as the most important felt need for sustaining PC services. However other sustainability issues underscored by respondents who were mainly clients include: strong national level structures at the referral hospitals(24%); continued financial assistance for support of home based and other care facilities (22%) including transport for visitation and supplies for those in need; strengthening community support structures like CVWs to offer support in hard-to-reach areas (17%) .

Figure 8: Responses on Sustainability Structures Needed



Other requests made by clients were that the number of clinic and day care days be increased, actual number of days increment should be established by HAU dialogue with clients. Support for other psychosocial needs like school fees, group Income generation activities, increase sites to reduce on distances for care centers and/or support transport by providing ambulance facilities. For the current and future programming of PC the following areas were observed by the evaluation team as key areas for sustainability.

Financial sustainability: HAU introduced a user fee of UGX 5,000 (approx U$ 2) for each patient who was able to contribute. The patients' contribution yielded a collection of

UGX 23,885,300 in a period of 2 years. This user fee is 6% of the actual costs of U$ 35 per [20]week that HAU incurs in providing PC services to the clients.

The evaluators explored the possibility of financing PC through the private sector and how HAU/USAID program can learn from other CBOs, and NGOs offering PC. For example JOY Hospice a private not for profit provider, the user fee is UGX 2000/day (below $1) for its in-patient PC facilities. The evaluation observed that JOY Hospice was extremely financially constrained and offered no HBC services. Further observed was that it was even strenuous to sustain the costs of transport from Mbale district to JMS in Kampala (~250KM apart) to collect Morphine. Moreover JOY indicated that their mostly rural Eastern Uganda clients found it hard to meet the stated fee; an indication on challenges of provision of PC services through financing via a private patient pay system. The evaluators noted similar experience of financial constraint, limited access for the poor, at the Kitovu Mobile PC services. Other similar sentiments were expressed by patients attending LHH site.

In reality, this underscores the fact that there is still need for donor funded PC services. Moreover Uganda has no private insurance companies that cover PC services, thus private financing as an option would necessitate that PLHIV and family shoulder the costs. At an estimated minimal cost of care of $140 per month (excluding transport to the facility and other related costs), in a setting where 35%[21] of the population live below the poverty line, an option of PC service as a private good would exclude the poor women and children; denying them the basic right to access PC and such arrangements would potentially worsen the countries development indicators and MDG targets.

HAU had other income generation activities which included setting up a charity shop and sale of fundraising items like T-shirts. Various attempts to expand the financial resource base through multiple funding by different donor agencies had a small degree of success, for example such sources contributed to 53% of the total budget for HAU activities (excluding activities funded through the USAID CA) as was stated in chapter1. Other plans towards this activity include construction and setting up student guest houses and a facility to store grains for a seed bank project at the rural site in Hoima district. The evaluators strongly believe that the program cannot run without external funding and support for the PC activities. This was further echoed by Dr Anne Merriman the founder of HAU who in her words said '*Hospice still needs funding. The reality is, we cannot run Hospice without donor funds'*.

More so, any PC practitioner will need minimal basic requirements including training, stationery, transport, and sundries like gloves and disinfectants for the health and safety of both the clients and service providers. Hospice needs to rigorously explore innovative approaches and other potential sources of funds including strengthening the ones they have already initiated within their sustainability plan in a more aggressive way. This may include strategic partnerships with existing and emerging corporate bodies like telecommunication companies, oil companies, industrial sector, airlines and transport industry under their corporate social responsibility packages.

Institutional Support: Ownership and institutionalizing PC services among the various actors is the way to go. Various institutions played their roles and must continue to do so for the future of PC.

[20] The $35 is referenced from HAU sustainability strategy; it is not known how it has been determined
[21] http://www.ugandapicks.com/2011/12/poverty-in-uganda.html, downloaded 02/22/2013- 1523hrs East African time

- For access to drugs particularly the pain relieving drugs like morphine, HAU in collaboration with GoU through MoH, JMS and NMS supported access to morphine. This public private partnership must be sustained
- Although not working at optimal capacity for various reasons, the community volunteer workers (CVW) and spiritual advisors who reside within the communities are working as first line providers of PC. They are trained in pain assessment and management and care for the patients and have a potential to sustain PC at the community level. HAU, PCAU, MoH and MoLG should design strategies to strengthen community owned resource persons contributions to PC and integration in the PHC system.
- At the district, are PC focal persons and nurses at health facilities who have the potential to deepen horizontal linkages and support for PC needs. Several USG funded implementing partners have trained personnel who can supplement on the needed services if well harmonized. This network model should be strengthened and sustained.
- Structures at the National level include the Parliamentary Forum and the Palliative Care Association of Uganda (PCAU) to advocate for policy support for both funding and standards. The MoH similarly has a standing PC Committee to advise and entrench the PC agenda nationally. This should continue and ensure that PC budgets are prioritized within the health and local government budget frameworks.

Continued Capacity Development: Through the HAU PC Institute and the affiliated training institutions, a number of PC specialists have been trained. These include the PC nurses, clinical offers, medical doctors and caretakers at home. Despite this, the evaluation showed that this resource base is insufficient to meet PC needs especially prescription and therefore access of morphine and addressing psychosocial needs of the patients. There is a slow but sure horizontal move to integrating PC into the national health care services.

The draft National Palliative Care Policy, integration of PC in 66 districts, and the latest establishment of at least two national indicators into the HMIS are positive milestones towards the desired goal. However, the program should extend PC services to lower levels up to HC III and II. Knowledge management including telling the story, capturing and documenting best practices should be integrated in the program to inform the roll out of PC services in the remaining 46 districts, and to broaden the PC availability within the districts as many only have one prescriber with little facilitation provided.

CHAPTER 4: Conclusions, Lessons Learnt, Best Practices and Recommendations

4.1 Conclusions

- Based on the program achievements of set targets and results, currently above 80% for all key result areas, the program is most likely to be successful. Certain elements of holistic PC like psycho-social and spiritual care delivery were not fully delivered. While pediatric palliative care is more provided at the Mildmay center.
- HAU trainings have effectively and efficiently, transferred specialized PC skills through to health professionals in-service through the network model partnering with USG funded IPs, collectively reaching 55% of districts in Uganda. The IPs now must take this forward; integrating PC in AIDS care and treatment, and rolling out trainings through CMEs. There was lack of refresher trainings, and numbers of prescribers, CVW and spiritual leaders trained were insufficient.
- The 2009-2013 program design and structure satisfactorily addressed the hindrances identified at end-phase 1 evaluation, and leveraged the facilitating factors. Emerging hindrances were identified mostly at facility/district level including the non-facilitation of trainees to deliver service, and at community level lack of sundries and long distances to reach patients.
- Global and national literature demonstrates that PC remains relevant even with expanding ART. PC commences at the diagnosis of life-limiting illness and is integral to HIV care. Similarly all respondents strongly argued affirmatively for the relevance of PC. PLHIV on ART suffer pains, psychosocial and spiritual needs, and 50% of PLHIV reaching stage 4 disease level need PC due to painful opportunistic infections. Yet for Uganda, it is estimated that less than 10% of PLHIV in need have accessed PC.
- Although the policy influence targets were satisfactorily achieved, the short term outcomes are not yet translated into budget allocations for PC activities and they remain unknown at district and facility levels
- The HAU PC program has established several structures such as human resources for PC delivery, PC delivery institutions, policy influence forums and some income generating activities that have the potential of supporting aspects of PC delivery.

4.2 Lessons learnt

- The modular training is an efficient approach for in-service training to increase PC specialist skills. Additionally 'whole site training' and 'satellite trainings' could have similar or much better efficiency and effectiveness.
- PC requires a multi-sectoral approach involving the MoH for health standards, MOES for training accreditation, MoLG for recruitment, coordination and financing at district level, MoPS for Human resource recruitment policy, NGOs, FBOs, and CSOs for implementation.
- Numbers reached versus quality of service: For PC quality of life of patients and quality of care are important issues. PC is a time-intensive impeccable service
- Working with partners has a tangible multiplier effect in terms of client coverage, increasing access to PC services and leveraging the resources.
- PC stakeholders can learn more from successful practices like GIPA/MIPA principles, Multi-sectoral approach, the integration of TB into AIDS Care and Treatment and

the memory project for communicating terminal illness to family, mainstreaming gender and disability in HIV care and treatment

4.3 Best Practices

- The collaboration between clinical practice and academia to inform practice and demonstrate quality care to trainees is a good practice
- The HAU approach of 'Start small' and expand gradually has proved to be effective as exemplified by some units like Masafu General Hospital, Bombo General Military Hospital and Ntara Health Center IV where one trained clinical officer took a personal initiative to roll out PC services currently operating at 7, 27 and 10 respectively.
- Involving managers, institutional leaders and PC champions in promoting PC advocacy improves visibility and institutional support for PC services at all levels. For example; the administration of Masaka Referral Hospital is fully involved in PC service delivery and has dedicated fully fledged staff. PC necessitates a multi disciplinary team, with the core team composition of a clinical officer, a dispenser and a nursing officer.
- The production and supply of morphine by the Morphine Production Unit and NMS/JMS demonstrates a successful public - private partnership, country ownership, and efficient service delivery and sustainability.
- Innovations in PC care service delivery improve access to PC services. For example roadside clinics in MHM, special outreaches for vulnerable and disadvantaged groups in remote areas, road-to-care projects and units like Makerere PC Unit offering a range of services in a one stop center for radiotherapy, social, psycho social, spiritual activities) were examples of such innovations.
- Allowing Nurses and clinical officers to act as morphine prescribers is likely to ensure increased PC services and especially access to morphine in settings where doctors are not regularly available.

4.4 Recommendations

4.4.1 Recommendations to USAID

- Design a new follow up phase, to further expand to the unreached districts, and to expand to HCIII, HCII and VHT levels, while promoting strong Public-Private Partnership approaches to training, care and support. And leverage all factors that facilitate PC and the lessons learnt. This recommendation is based on the overwhelming evidence on the magnitude of the need, the relevance of PC as an integral part of HIV care and treatment programs, and the fact that more than 90% of PLHIV in need of PC in Uganda were not yet reached
- Design and implement strategies to institutionalize PC into HIV/AIDS care package working with USG partners to improve the quality of care offered to HIV/AIDS clients all over the country; Ensure that pediatric PC is comprehensively addressed and ensure that USG funded IPs through their PMPs collect data and report on PC

4.4.2 Recommendations on program design and structure

Further scale up PC access and coverage through training HRH

- Design shorter prescriber's training modules to increase the numbers of prescribers
- Adapt the cascade model of training, Master trainers at National Level, District and Health Sub-District trainers with inbuilt mentoring and coaching of trainees
- Design and implement strategies to equip TOT trainees with practical skills
- Review training methods to include flexible modes like weekend programs, online programs, establishing satellite centers.
- Design tailor made courses for non medical professionals to increase access to PC education, and design strategies to reduce the high attrition.
- Target training more community own resources like spiritual leaders (Pentecostals, traditionalists, Muslims, Catholics and Protestants)
- Investigate causes of why the training sessions on drug prescription and advocating for PC services were poorly rated, and deploy appropriate remedy
- More research based, evidence as this is a dynamic field, strengthen the clinical model intertwined with evidence generation and training, the case for strengthening the model centres; and actively promoting/marketing them as PC delivery options

Further scale up PC access and coverage through advocacy and policy Influence:

- Continue strategic partnership with PCAU, APCA and other key stakeholders to sustain gains made
- Develop an advocacy strategy with clear advocacy targets for i) increasing PC human resources at various levels, ii) increasing awareness to PC service availability, iii) finalization of and operationalization of the national PC policy, iv) increasing finance allocations for PC activities v) integrating of PC into District Local Government plans vi) integrating PC into all medical and health professionals pre-service curriculums and vii) lobby MoH to allow nurses and clinical officers to prescribe morphine after pre service training vii) lobby MoH to integrate PC assessment at triage point as it is done for TB using a simplified PC screening form; viii) advocate for the integration of PC in pre-service curriculum, nurses and clinical officers
- The accreditation system needs to be strengthened, with a documented standard and documented certification, other than being a loose non systematic process
- Strengthen the beneficiary voice, and participation, the GIPA/MIPA principle

Cross cutting strategies for expansion of PC Services

- Harness existing community structures and resources like services of faith based organizations (FBOs), CBOs, and other NGOs offering similar services to finance and /or support awareness creation, client identification, home-based care, and psychosocial needs of PC clients among other things.
- HCII and HCIII must have the capacity to support the VHT, referrals, supervision and refresher training.
- Digitalization use of mobile phone, electronic data management system and have shared records
- Learn from successful strategies like GIPA/MIPA principles, the Multi-sectoral approach, the integration of TB into AIDS Care and Treatment and the memory project for communicating terminal illness to family
- Monitoring progress on scale up of numbers/proportion of PLHIV reached with PC should be an integral part of M&E systems for HAU, and USG HIV IPs.
- Knowledge management including telling the story, will enable scale up and sustainability

CHAPTER 5: ANNEXES

Annex 1 : The Evaluation Scope of Work

BACKGROUND:

Hospice Africa Uganda (HAU) is an indigenous NGO founded in 1994 to provide terminal care for cancer patients. HAU has since grown to become an accredited leader and one of the few institutions in Uganda and Sub-Sahara Africa with technical expertise to provide and build capacity for palliative care. In line with the WHO definition, PEPFAR describes palliative care as an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness through the prevention and relief of suffering by early identification and impeccable assessment and treatment of pain and other symptoms that are physical, psychosocial and spiritual.

In September 2008, USAID/Uganda modified a three-year Cooperative Agreement No. 617-A00-05-00010-00 with HAU to extend the agreement period for an additional five years from September 30, 2005 to September 30, 2013. The program aims to expand the coverage and scope of palliative care services for People Living with HIV/AIDS (PLWHA) and their families in Uganda.

The program, implemented through three Hospice branches in Mbarara, Hoima and Kampala, provides pain and symptom management, spiritual support as well as terminal and bereavement care to PLWHA and their immediate families. Patient care is implemented through the following 3 core areas: home and hospital visits; day care program (community and site day cares); and Community Volunteer Workers (CVWs). An average of 1,500 PLWHA and their families are reached annually.

Besides direct service delivery, HAU as part of its strategy to expand coverage of comprehensive palliative care services, has a capacity building program which aims to transfer skills in pain and symptom management, terminal care and provision of psychosocial services to other HIV/AIDS service organizations and community volunteers in Uganda. To date a total of eight USG partners including Department of Defense/Uganda People's Defense Force(DOD/UPDF), The AIDS Support Organization (TASO), Mildmay, Northern Uganda Malaria, AIDS, and Tuberculosis Project (NUMAT), Mulago-Mbarara Teaching Hospital's Joint Aids Program (MJAP), Joint Clinical Research Centre (JCRC), Strengthening TB AND HIV&AIDS Response in Eastern Uganda (STAR-E), Strengthening TB and HIV&AIDS Responses in East-Central Uganda (STAR-EC) and Strengthening TB and HIV/AIDS Responses in the South Western Region of Uganda (STAR-SW) have been trained. Concurrently, a total of 120 Health workers and 150 community volunteers are targeted annually in districts supported by USG partners. Follow-up training, mentoring and support supervision is carried out by the trained USG partner in collaboration with Hospice staff.

The intended results of the project are: Result 1: Develop the three Hospice Africa Uganda branches of Kampala, Mbarara and Hoima as model centres for 2: Specialist Palliative competencies built within HIV/AIDS care organizations Result 3: Influence national policy to reposition pain, symptom management and end of life care within the overall HIV/AIDS care holistic Palliative Care delivering and training. Result 4 Hospice Institutional Capacity developed to effectively manage and sustain the program

Following substantial audit issues and management problems, with guidance from USAID, Hospice revised its strategy for institutional capacity building (restructuring, development of a sustainability plan, review of internal polices and manuals). As a result, HAU has been able to strengthen its internal organizational controls and processes. Improved instructional capacity has enabled HAU to competitively bid for other donor funding and private-public partnerships.

The purpose of this project evaluation is to acquire and use an independent opinion on the impact of expanding coverage and access of palliative care achieved through HAU program design and overall strategic approaches to inform the design and effective management of future palliative care activities. The evaluation is expected to extract lessons learned and best practices developed during the implementation of this project.

KEY EVALUATION QUESTIONS:

a) HAU has training care providers as one of its major approaches: Were the trainings delivered effectively and efficiently? Include an assessment of care giver skills in supported organizations and facilities where USAID supports palliative care and show attribution to HAU efforts for building specialist palliative competencies

b) How well has HAU design and structure addressed factors facilitating or hindering palliative care giving? Conduct an analysis of key factors facilitating or hindering palliative care by USG HIV/AIDS care organizations to answer this question.
c) How effective has HAU been in influencing national policy on palliative care? Identify key factors that facilitated or hindered HAU influence on national policy on palliative care and assess how effective HAU is in supporting Ministry of Health in developing an accreditation system for palliative care.
d) What is the likelihood that this project will be successful? Given the rate of achievement of results and current approaches and activities, assess the prospect that this project will achieve all its intended results.
e) How sustainable are HAU activities and results? Suggest modifications to increase sustainability.

4. METHODOLOGY
The evaluation contractor will be required to propose a clear methodology to answer all the evaluation questions. The methodology should include a sampling approach of places and individuals they will collect data from. This may include organizations, facilities, community health workers/volunteers, facility-based health workers, district palliative care focal persons and patients. Proposed methodology must also include a description of how data will be analyzed to provide information used to answer evaluation questions listed above. Where rapid/qualitative data collection methods are proposed, include the people and/or groups that will be interviewed and group sizes. Offerers are encouraged to use the design matrix enclosed as Attachment B.

5. PROJECT INFORMATION AND DOCUMENTS:
The following information documents and sources are available and relevant to the evaluation:

USAID:
a) Original Request for Application
b) USAID program and financial reporting requirement
c) USAID Country Development Cooperation Strategy 2011-2015
d) Health Sector Strategic Plan
e) AIDS National Strategic Plan
f) PEPFAR Care and Treatment Area Narrative

HOSPICE:
a) Program Description
b) Annual and quarterly reports
c) Annual work plans
d) Performance Management Plan
e) Other surveys and assessments undertaken
f) Sustainability Plan
g) Internal policies and manual documents

6. EVALUATION TEAM:
It is essential that all team members understand the context of Palliative Care and HIV/AIDS in Uganda. The offeror is expected to propose a multi-disciplinary team. The following are required members of the team:
•Team Leader / Lead Evaluator: Evaluation specialist with a minimum of ten years successive experience in qualitative and quantitative evaluation of health and community development programs. Additional expertise in health and HIV/AIDS development work in Africa is required. S/he must possess good writing skills. S/he will be responsible for leading the team in the design of the methodology, execution, reporting and have overall responsibility for preparation of the final product and presentation to the Mission.
•Palliative Care Specialist: Consultant with a minimum of seven years successive experience in community health, HIV&AIDS care and management, clinical medicine and hands-on experience in HIV&AIDS programming, care and management preferably in an NGO setting in Africa.

Other team members should collectively possess the following:
• Organizational capacity building for public health service delivery.
• Health and HIV/AIDS programming in Uganda
Between them, independent consultants must have Ugandan and international experience managing and evaluating HIV/AIDS and health programs with an added advantage of significant exposure to the United States President's Emergency Plan for AIDS Relief (PEPFAR). One consultant will be designated "Team Leader". The team leader must have over 10 years' evaluation experience and will have lead more than three evaluations.

7. DURATION OF THE ASSIGNMENT:
The contract start date is 11/29/2012 and end is 03/29/2013. The contractor shall however submit the final report incorporating all edits by 01/30/2013. .

8. DELIVERABLES:
• In-Briefing: Introduction of the evaluation team, discussion of the SOW and initial presentation of the proposed evaluation work plan. • An Inception report detailing the contractor's interpretations of the assignment, an evaluation design and methodology, analytical plans, sampling, tools and work schedule. • Weekly Progress Reports: Brief informal reports summarizing progress, challenges and constraints and describing evaluation team's response.

- Oral Presentations: Power Point presentation (including hand-outs) to:

i. USAID
ii. Hospice Africa Uganda, Ministry of Health and other selected stakeholders such as USG HIV/AIDS care organizations. The oral presentations should, at a minimum, cover the major findings, conclusions, recommendations, and key lessons. The evaluation team will liaise with the Mission to agree on the dates, audience, venue and other logistical arrangements.

- First Draft Evaluation Report: An illustrative report outline is attached. The report should comply with USAID's Evaluation Report standards set out in Attachment A and should not exceed 25 pages, excluding appendices. The input from the oral presentation sessions should also be incorporated in the report. The contractor will provide five hard copies and one electronic copy of this report in English. The report is expected within 7 days after the oral presentation.
- Final Draft Evaluation Report: Complete report incorporating comments from USAID and other stakeholders. The contractor will provide five hard copies and one electronic copy of this report in English.
- Dissemination workshop for key stakeholders: The contractor will present the evaluation to key stakeholders via a dissemination workshop. The evaluation team will liaise with the Mission to agree on the dates, audience, venue and other logistical arrangements.
- Final Report: The contractor will submit a final report incorporating final edits for wider sharing, including with the Government of Uganda and other development partners. The contractor will provide five hard copies and one electronic copy of this report in English. The contractor is also expected to submit a summary (includes purpose, background of the project, main evaluation questions, methods, findings, conclusions, recommendations and lessons learned) and the final approved report to USAID's Development Experience Clearinghouse (DEC) within three months of approval of the final report. The report should be less than 25 pages, excluding annexes.
- Cleaned data sets: The contractor will share the cleaned data sets with study partners and USAID for further analyses

Annex 2: Detailed evaluation methodology and design

This detailed methodology is an extract from the approved inception report:

2.1 Guiding Principles

We shall embrace the international evaluation principles under the OECD/DAC guidelines and the practices stipulated under the USAID Evaluation policy. The evaluation will therefore embrace among other things the key principles of objectivity, impartiality and transparency bearing in mind that participation and learning by the beneficiaries and respondents are critical elements of an evaluation. The Consultant is also aware that having come to an end, the program has a responsibility to present evaluative evidence for accountability, lessons learnt and best practices to both the funders and GoU for informing future programs. Linked to the specific evaluation questions specified herein, the Consultant will take into consideration the key evaluation criteria of relevance, effectiveness, efficiency, impact and sustainability.

2.2 The Study Design

To guarantee a high degree of stakeholder participation and emphasize the learning aspect, a cross sectional study, adopting both qualitative and quantitative methodologies will be used to gather evaluative evidence. The evaluation strategy will involve use of mixed methods to seek multiple sources of evidence so as to obtain a comprehensive and in-depth understanding of how the program has been implemented and its achievements in response to the key evaluative questions. Primary data will be obtained using Key Informant Interviews (KII), Focus Group Discussions (FGDs), and observations during community excursions and extended post training and consumer satisfaction surveys. Secondary data will be extracted from literature available at Hospice African Uganda, USAID, USG and Non-USG funded partners working on the project, referral hospitals and other relevant strategic partners like Makerere University, MoH and National Council of Higher Education.

2.3 The Study population

The evaluation was planned to cover a total of 10 districts as indicated in table1. Given the two- pronged nature (service delivery & capacity building) of the program, respondents will be drawn from three district groups' people that are significant to the intervention including the following:

- Direct beneficiaries who will include PC clients including people living with HIV/AIDS enrolled on the PC programme and their immediate family members.
- Secondary beneficiaries who will include, health care providers such as those from HAU sites, health facilities, USG and Non USG partners, community volunteer workers and the spiritual advisors.
- Strategic partners: These will include USAID, MoH, JMS, NMS, APCA, PCAU, Parliamentary forum members and the District Local Government officials

2.4 Qualitative and Quantitative data collection plan

2.4.1 Document review:

This will involve an assessment of key documents and reports from Hospice Africa Uganda, USAID, USG and Non-USG partners working on the project. Review of relevant documents from other partners like Makerere University, MoH and National Council of Higher Education will be carried out to generate more background information including qualitative as well as the quantitative crude estimates on number of patients reached, number of health care workers trained in Palliative care, number of care takers trained. Qualitative information linked to the success in advocacy and policy influence and lessons learnt will also be derived from the various reports. Key documents to review will include the grant agreements, progress report, training curriculum, annual reports, strategic plans, project proposals, sustainability plan, policy and advocacy documents, care and management guidelines to mention but a few.

2.4.2 In-depth interviews:

KIIs will be conducted with Hospice Africa Uganda staff in the three sites, USAID, USG and Non-USG funded partners working on the project. Other Key informants will be drawn from relevant strategic partners like Makerere University, UPDF, MoH and National Council of Higher Education, District Local Government (DLG) staff, JMS, NMS, parliamentary forum on palliative care, PCAU and APCA to mention. These will provide critical information the palliative care approaches, capacity building, advocacy approaches, challenges, lessons and recommendations to improve palliative care service delivery in the country. To enrich the KIIs, respondents will be requested to fill in answers to a self-administered questionnaire as well

2.4.3 Focus group discussions:

These will be conducted with community volunteer workers (CVW), spiritual advisors and caretakers to assess their opinions on access and utilization PC services in their community, challenges encountered by PLWAs while accessing the services, training modalities and also suggest recommendation on how the services can be improved upon. These will help to triangulate information collected from other sources .A total of 20

(two per district) focus group discussions will be conducted. One group will be for the CVW with the spiritual advisors and another with care takers.

2.4.4 Post training and client satisfaction surveys

A Post training and consumer satisfaction survey will be conducted among trainees and patient's/care givers respectively.

Post training survey

A post training survey will be undertaken by health workers previously trained by HAU or USG funded partners to determine their skills level and competences on PC giving. Respondents will be selected from Hospitals; health center IV and USG funded partner model clinics. A random sample will be drawn from the list of all trained health workers selecting at least three from the district hospital, health centre IV and the USG partner model clinics/sites making a total of 10

Consumer satisfaction survey

The clients (PLHIV) enrolled on PC program will undertake a consumer satisfaction survey to determine the level of their satisfaction on the quality of PC services. A random sample of respondents will be drawn from the patients register for the different care approaches: Home based care, hospital based, community outreach and site based care. At least five patients will be selected from each of the different care approaches making a total of 22 per district.

For each theme, 10 – 12 questions (closed and open ended) will be asked including suggestions for improvements. The questionnaire will use questions aimed at generating individual opinions on satisfaction on PC services and recommendations to improve the services. The questionnaire will be extended to include information on background characteristics such as sex, age, illness and duration of illness.

2.5 Sampling plan

A combination of multistage cluster and purposive sampling will be adopted.

i) Regional reach and coverage is a key factor guiding sampling for this National level evaluation. Five regions will be systematically selected, after which two districts per region will be purposefully selected.

ii) The prime district for the evaluation field visit shall be a district that has presence of HAU branch and/ or presence of a USG funded partner office.

iii) The secondary district will be purposefully selected from the list of districts reached by the USG and non USG funded partners like STAR E, STAR EC or STAR SW or TASO and UPDF; covering a total of 10 districts. Better performance and lean per

iv) Purposive sampling methods shall be used when selecting key informers and FGD members from key institutions, including HAU team, USG and Non-USG funded partners of the project, MoH, MoES, JMS, JMS, referral hospitals, district local government officials , parliamentary forum and the advocacy partners. These will be selected on their level of involvement in the programme and knowledge about the evaluative questions, the evaluators will purposefully engage the palliative care focal persons, and other key groups or persons mentioned by the PC members, using snow-ball method. At community level multi-stage cluster sample selection will be adopted; clustering based on geographical location, and leading agency on PC in that location. Then a random sample of community volunteer workers, caretakers, patients, spiritual advisors trained health workers will be generated and stratified on category.

2.5.1 Sample size calculation-client satisfaction and post training surveys

To produce reliable estimates of the indicators (measured in terms of Knowledge or satisfaction scores on a scale of 0 to 100) in the patients and palliative care trainees, a random sample of 220 PLHIVs (120 HIV/AIDS only and 100 HIV/AIDS and cancer) and 100 trainees will be selected across the focus regions. This is premised on the categorized scores such that 50% of the patients or trainees have knowledge or satisfaction score above 50. The sample sizes also allows for 5% precision in the estimates with 95% certainty, and design effect for the patients and caretakers.

2.6 Data collection

Data will be captured using an extended post training and consumer satisfaction survey questionnaires, key informant guides, focus group discussion guides and literature review checklists. Two sub-team composed of two consultants will undertake the data collection.

2.7 Analysis plan

All quantitative data analyses will be done in SPSS. Descriptive statistics including means, frequencies and percentages will be used to summarize socio-demographic characteristics of respondents, access, utilization and challenges of accessing palliative care services and knowledge, attitude and consumer satisfaction scores will be determined. Some cross-tabulations aimed at assessing relationship between factors and association between variables will be undertaken.

Qualitative data will be checked for completeness and consistence before it is analyzed. Thematic and content analysis will be used to describe the relationships between variables using frequency of codes as they appear from the text data. The first step will include open coding where categories will be assigned to all pertinent segments of text. The categories will be allowed to emerge from the text and will not be predetermined. All text data from open-ended questions will be assigned codes.

The second step will be axial coding: codes will be grouped together to identify patterns in the coding and to discern the frequency with which codes will be assigned. The frequency of codes will allow for assessment of when saturation will be achieved versus when outlier ideas were expressed. The last step will be to synthesize the patterns and identify key findings. The NVivo computer software, a qualitative analysis package will be used to code all interview and focus group transcripts and the project summaries to interpret the data. The themes corresponding to the evaluative inquiries will be used to analyse, assess and quantify the respondents' attitudes and perceptions on achievement of program results, with regard to the various evaluative questions.

2.8 Ethical considerations

During the study, several precautions will be taken to ensure the protection of respondents' rights. Ethical principles of respect, beneficence and justice will be applied in the selection of the respondents, during the process of data collection and management. For example *informed consent (using consent forms) will be sought before all* interviews begin and the data collected will be kept confidentially, with no identifiers and only accessible to authorized persons.

2.9 Envisaged Risks and Limitations

- Non availability of respondents due to end-of year bank holidays, this will be managed through dialogue with the respondents and scheduling the most appropriate timing (flexibility of schedule). Where need arises , the consultants will have to separate and work independently, simultaneously but coordinately to make up for lost time
- HAU has undergone restructuring, most of senior management remains very new, and this is a risk for loss of institutional memory, and relevant data. The evaluators will do broad consultations including seeking for information with partners and the people who may have left the institution but still available and willing to give information in order to bridge for memory loss. The broad consultations, we believe will make up for the missing key documents linked to peoples' movements from HAU. In depth literature review will also add to the missing gap.
- Routine HIV/AIDS program indicators for USG funded programs tend to focus more on quantitative data. The HAU program is unique in that palliative care success needs to be measured using qualitative measures on issues around patient and care's psychosocial make up. This may be accepted as a norm that differs from the usual number oriented indicators however the consultations will endeavor to gather as much qualitative data as possible on the subject matter

Annex 3: Definitions and Terminologies

1. PEPFAR definition of Palliative Care

Patient and family-centered care which optimizes the quality of life of adults and children living with HIV though the active anticipation, prevention, and treatment of pain, symptoms and suffering from the onset of HIV diagnosis through death. It also provides the routine monitoring that is essential to determine the optimal time to initiate ART, but continues during and after the initiation of treatment. PC includes and goes beyond medical management of infections, neurological, or oncological complications of HIV/AIDS to comprehensively address symptoms and suffering throughout the continuum of HIV disease. Routine, confidential counseling and testing is an essential component of palliative care to identify those who need or will need palliative care, family members who could also be infected and in need of care, and family members and partners not infected and in need of prevention[22].

2. WHO definition of Palliative Care

Palliative care is[23] an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care:

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten or postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patients illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counseling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness;
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

3. WHO Definition of Palliative Care for Children

- Palliative care for children represents a special, albeit closely related field to adult palliative care. WHO's definition of palliative care appropriate for children and their families is as follows; the principles apply to other pediatric chronic disorders (WHO; 1998a):
- Palliative care for children is the active total care of the child's body, mind and spirit, and also involves giving support to the family.
- It begins when illness is diagnosed, and continues regardless of whether or not a child receives treatment directed at the disease.
- Health providers must evaluate and alleviate a child's physical, psychological, and social distress.
- Effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community resources; it can be successfully implemented even if resources are limited.
- It can be provided in tertiary care facilities, in community health centres and even in children's homes.

[22] PEPFAR's Implementation Progress and Promise: Ch.6 Care Category; CATEGORY, TARGET, AND RESULTS: 2007- Board of Global Health/ accessed http://www.nap.edu/openbook.php?record_id=11905&page=169-204: downloaded Harriet Kivumbi, 29 January 2012 11:40am Uganda time

[23] http://www.who.int/cancer/palliative/definition/en/- downloaded 02/01/2012 Harriet Kivumbi

Annex 4: Training Information (source HAU reports 2012)

Region	PEPFAR Partner	Target	How many enrolled Module 1	How many completed Module 2	How many completed Module 3	Comments if any
Cohort 1 – 2009						
Central	TASO	10	11	25	14	Jinja (3), Kampala (3), Mbale (2), Tororo (1) and Wakiso (2)
	MJAP	10	5			1 district i.e. Kampala (5)
	JCRC	10	10			4 districts i.e. Jinja (4), Kampala (1), Mbale(2) and Mubende (3)
South West	TASO	10	15	12	14	Bundibugyo (1), Kabale (1), Kampala (1), Kasese (1), Kisoro (1), Masaka (3), Mbarara (3), Rukungiri (3) and Sembabule (1)
	MJAP	10	5	4	2	Mbarara (5)
	JCRC	10	8	8	4	Kabale (3), Kabarole (3) and Mbarara (2)
Northern	TASO	10	21	30	19	Gulu (5), Jinja (2), Masaka (2), Masindi (3), Mbale (2), Soroti (3), Tororo (2) and Wakiso (2)
	JCRC	10	10			Gulu (6) and Lira (4)
Sub total		**90**	**85**	**79**	**53**	
Cohort 2 – 2010						
Central	UPDF	30	27	26	16	Ibanda (1), Jinja (2), Kampala (4), Kanungu (1), Luwero (8), Masaka (2), Mayuge (3), Nakaseke (2), Nakasongola (1) and Wakiso (3)
South West	UPDF	30	22	17	15	Buliisa (1), Ibanda (1), Kampala (1), Kasese (1), Lira (1), Luwero (5), Mbarara (4), Mubende (3), Nakasongola (2) and Wakiso (3)
Northern	UPDF	30	25	23	17	Arua (1), Gulu (6), Kaabong (6), Lira (1), Luwero (2), Mbale (2), Moroto (2), Pader (4),Tororo (4) and Wakiso (2)
Sub total		**90**	**74**	**66**	**48**	
Cohort 3 – 2011						
East Central	STAR-EC	40	35	28	31	7 districts i.e. Bugiri (6), Buyende (2), Iganga (8), Kaliro (4), Kamuli (10), Luuka (2) and Namayingo (3)
Eastern	STAR-E	40	39	36	33	12 districts i.e. Budaka (4), Bududa (4), Bukwo (3), Bulambuli (2), Busia (4), Butaleja (3), Kapchorwa (3), Kibuku (2), Kween (1), Mbale (4), Pallisa (7) and Sironko (2)
South West	STAR-SW	40	39	29	22	12 districts i.e. Buhweju (1),Ibanda (3), Isingiro (3), Kabale (9) Kanungu (5), Kiruhura (3), Kisoro (2), Masaka (2), Ntungamo (6), Rubirizi (1), Rukungiri (2) and Sheema (2)
Sub total		**120**	**113**	**93**	**86**	
Cohort 4 – 2012						
West Nile	Baylor Ug	40	40	40	40	Adjumani (2), Arua (17), Koboko (2), Maracha (3), Moyo (3), Nebbi (7), Yumbe (2) and Zombo (4)
Sub total		**40**	**40**	**40**	**40**	
Grand total		**340**	**312**	**278**	**227**	

Annex 5: Demonstration of how the program design and structure addressed baseline hindrances

PC hindrance identified at baseline	Demonstration of how the program design addressed the hindrance
▪ **Lack of a strategic vision despite having a sound mission.** ▪ **Absence of an explicit fundraising strategy** ▪ **Weak M&E systems**	Result area 4 on OD, reported to be in track. Systems have been strengthened and strategies were developed
▪ **Narrow scope of PC services delivered with limited services to PLHIV** ▪ **Lack of standards and guides for PC services**	Result area 1 and 2; focused on strengthening and positioning HAU's technical capacity as a leading institution on strengthening PC capacities
▪ **Weak partnerships and networking especially with MoH and among PC providers**	Result area 3, HAU influence of National policy, and the partnership with PCAU, MOH and APCA
▪ **No systematic training approach (no selection criteria, guidelines, and no follow up of trainees)**	Result area 2; the strengthening of specialist PC skills through partnerships with USG HIV partners; ensured a systematic approach to training

Annex 6: Factors hindering PC service delivery

National Level:

- Slow integration of PC into the health care system. The current guidelines only allow storage and distribution of morphine up to hospital and HC1V. Thus morphine is not accessible at HCIII or II, yet these are service levels that are more accessible for majority poor rural clients.
- PC was not part of original training of Health Care Workers (HCW), the old school does not understand the handling of terminally ill patients nor the prescription of morphine and this creates bias, from the senior doctors and can be a barrier for the trained junior nurse, to advise the senior doctor on what to do.
- The accreditation is more of a verbal process than systematized, widely known criteria. The accredited facility received no insignia or certificates; it is haphazard and dependant on people making it not visible, and not systematic.

District Level:

- Due to limited training of District managers in some regions, there is modest support for PC activities.
- Palliative care is not yet fully integrated in services, it is something done by someone else, this implies that when someone is quite ill, untrained service providers might feel that nothing more can be done and that the client can only be sent back to the village at most.
- Some health workers still find it challenging to diagnose and refer patients who are in need of PC. Providers reserve PC for only clients who require end-of-life treatment, and consider it a waste of resources and time on a dying person. This attitude misses out on the benefits related to the standard that recommends that PC commences at diagnosis. Consequently, clients with life-threatening illness and PLHIV lead a poor quality life and may stop adherence to ART and other medicines.
- Lack of access to liquid morphine in a number of health units surveyed. Sites depend on the hospital or head office supplies, which have their own challenges. The implication of this is PLHIV in need of pain management, and quality life do not receive the much needed oral morphine;
- Liquid morphine on the Ugandan market has a short shelf –life of 6 months; when health units stock morphine, and it is not used up within 6-months, it must be discarded. The effect is that staff get the sense of wasted resources, and do not order more supplies.
- The numbers of trained HRH in PC has increased, however HRH face several challenges ranging from lack of recognition, lack of facilitation to do the work, work overload, "hierarchical challenges, where a trained nurse seems more knowledgeable than a non trained doctor and transfers to lower facilities with no morphine. The implication of this is that trainees do not have the opportunity to practice acquired skills within the health system, and this has implications on expanded access. On the clinical level there is increased demand for palliative care services, yet staffing capacity and numbers to handle health services is uncertain; cancer and HIV/AIDS are a huge problem.

On education and training:

- There was a lack of PC indicators in the HMIS. Health Service providers were thus not obliged to report on PC. Positively in December 2012, the HMIS integrated PC indicators, the next challenge will be to role this out nationally.
- There remains a deficit of prescribers of morphine, the prescribers 6 weeks course targets clinical officers, and only 60 were trained, yet nurses must undergo a 9 month course to qualify as prescribers. The implication of this is that not all

trainees can prescribe morphine, and this blocks expansion of access

- A number of health professionals dropped out of training due to lack of per diem, hampering efforts to train and expand services There is no Supervision of trained staff in PC after the two follow-up visits by HAU &PCAU. This means stagnation around knowledge and motivation to deliver PC. There are no courses targeting non-medical professionals such as counselors and social workers. This limits PC service provision as the listed HRH potentially can contribute and enhance PC service deliver
- Palliative Care is not a hospital based service, it is at community level, yet trainees are not facilitated to deliver community level service reaching to the poor patients who are unable to get to hospital.

Individual and client level:

- Failure to follow up of clients due to lack of funds for transport; *"The patients we send to LHH may go once and don't go back because they don't have enough money for transport"* CVW in Hoima. This is a geographical access issue that needs to be addressed through innovative programming
- Community awareness on PC services is low, people at home do not care for the terminally ill; and this implies a low demand for service, and low coverage. It can be addressed through service promotion. Community beliefs for example, witchcraft, radical faiths and miraculous beliefs that limit use of western medicine and care. This implies lack of access based on culture and beliefs, this too needs be addressed
- Extreme poverty coupled with food insecurity, and lack of basics including accommodation. The dejected desolate poor PC client will only access service when encouraged, and when given emotional and social support; and this is a strong case for the social component of holistic care

HAU policy/personnel issues

- Limited access to and contact with the clients especially those outside the 20 km radius, this results into offering services in a remote controlled environment which greatly affects the quality of service. And on the other hand, many stakeholders say that the 20 km radius HAU sites policy, limits access and needs to be revised to expand the service radius away from the sites
- Lack of career growth: HAU trainers felt that they were stagnating at the same cadres because the kind of in-house training received does not support them to upgrade in their careers for example from being a lecturer to senior lecturer. This is a risk for trainer attrition from HAU, and can be addressed internally

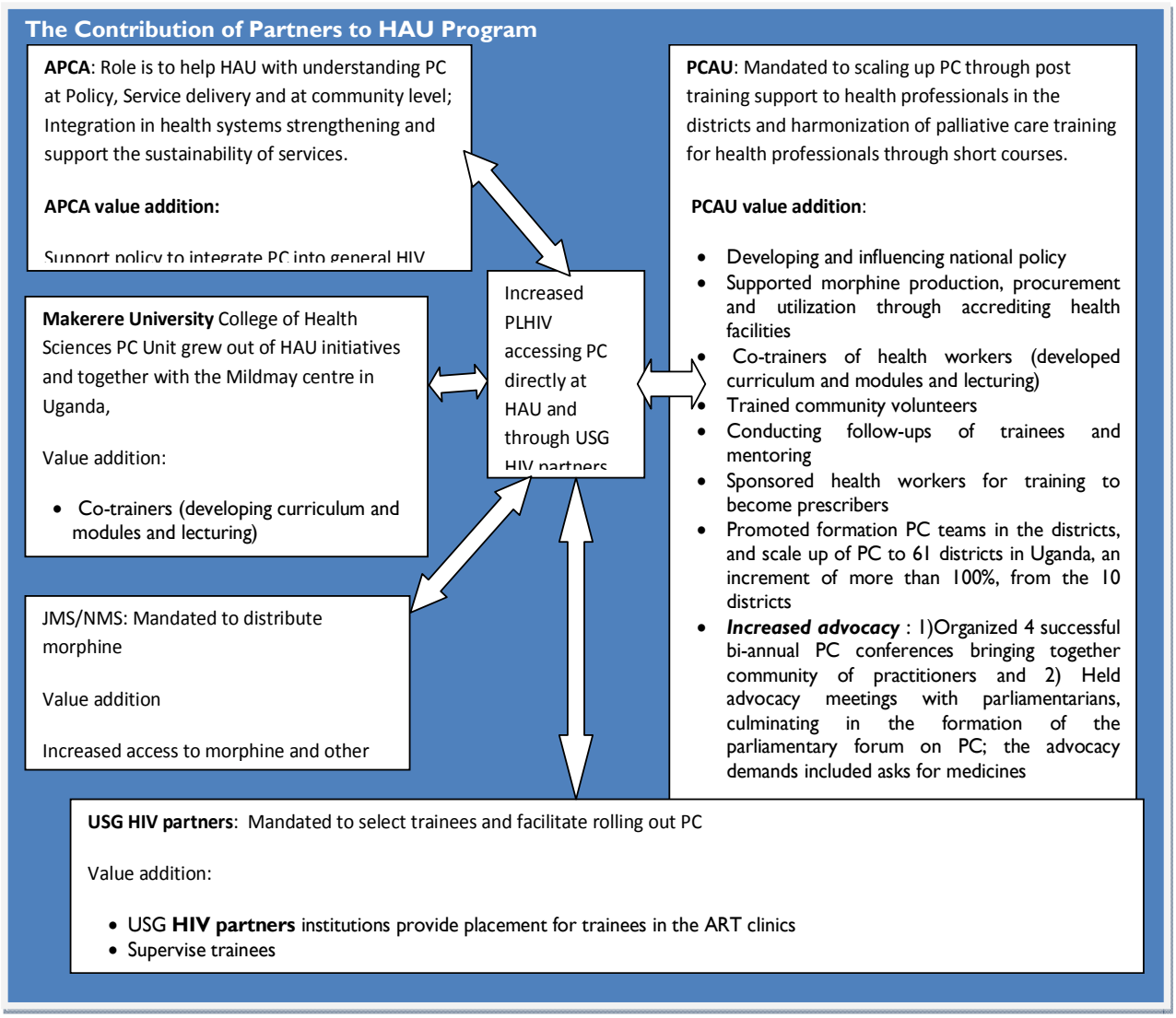
Annex 7: Milestones for policy achievements

Year	Achievement	Responsible organizations
2008	Formalization of children's' palliative care service at HAU and short course on children's palliative care is delivered	HAU, PCAU, MoH and APCA
2009	Setting up the beacon project for children's palliative care with Mildmay Uganda being developed as a beacon centre and commencement of a six months children's palliative care training programme.	PCAU, APCA, Mildmay and HAU
2009	Publication of guidelines on children's palliative care in Africa in collaboration with children's palliative care experts from across Africa	PCAU, HAU and APCA
2010	Strategies for integration and scaling up palliative care services in all public facilities outlined the health sector strategic plan 2010/11-2014/15 page 91	MoH, PCAU, APCA and HAU
2010	Establishment of the parliamentary forum on palliative care and the first ever palliative care advocacy meeting with the forum with parliamentarians	PCAU, APCA, HAU
2010	Institute of palliative care in Africa at HAU accredited for diploma by the National Council of Higher Education	NCHE, HAU, PCAU
2011	Mildmay Uganda training and the education directorate accredited to offer a degree programme by the National Council of Higher Education	NCHE, HAU, PCAU
2011	The first two professors in palliative care (Prof. Anne Merriman and Prof. Julia Downing) appointed at Makerere University. The professorships are important in building leadership capacity and credibility for palliative care in Uganda and Africa.	MUK, PCAU and HAU
2012	Second palliative care advocacy meeting with parliamentarians	PCAU, APCA, HAU
2012	Uganda PC Policy Development Process started under the supporting Use of Research Evidence for Policy (SURE) project initiative between PCAU, MoH/PC country team, Makerere University and APCA. The draft policy is also in place.	SURE, MoH, MUK, PCAU, APCA and HAU
2012	PCAU and MoH held a sensitization and advocacy meeting for Medical Nursing Directorate in UPDF who eventually agreed to allow morphine utilization in Bombo military hospital	PCAU, MoH, HAU, APCA
2012	Through advocacy the Ministry of Public Service has recognized the qualifications of the Palliative Care Specialists and has been added to the qualification for employment by Civil Service Commission.	PCAU, APCA, HAU
2013	Two indicators of palliative care: # of patients on PC and Morphine utilization are included in to the National MHIS starting the year 2013	MoH, PCAU, APCA and HAU

Annex 8: Additional quotes from beneficiaries not cited in text

- We wish palliative care services are funded, it mostly depends on good Samaritans; most patients die of social issues"; PC Champion, General Military Hospital Bombo
- "HAU project in 2009 reached to 32 districts, by now 62 districts have coverage and access to PC services, though mostly at regional referral hospital and HCIV level; with few HBC services delivered by HAU, other Hospices and TASO' FGD Discussion TASO
- "Only 10% of people in need of PC services actually access these services" Respondent from strategic partners APCA. Meaning that 90% of people in need are not accessing services!!!!- Respondent from APCA Senior management
- HAU program design was a success around "Joint training, Joint Clinical Care and Joint advocacy"- Dr. Mhoira Leng
- "ART clinics are the entry point for majority of PC patients; the clinics are often times over crowed with patients with very few doctors who don't have the time for palliative care services. What is usually done, if they are identified both in the clinic or the ward, they are referred to Hospice for follow up and care. More so ART is not guarantee to life, some come along with many side effects especially when they fail. When that happens, palliative care is more than necessary" FGD Mbarara
- "PC is very necessary for two reasons; with or with HIV, the pain with the cancers will continue even when drugs are there as the normal care has to be provided but the challenge and the need for PC is that people still present late when the pain is too much, no matter what care, the service for palliative care is needed" Respondent JCRC/MJAP
- "Access to PC services is a basic right, just as is cancer and AIDS care, PC is needed for terminally ill clients –renal liver failure, e.t.c People with pain, terminal illness, and need robust attention. Now that NCDs are on the increase, the need for PC is high" Health Officer Mbarara
- 'PC delivers holistic care and this includes looking at patient's physical needs related to the disease, the psychological needs, family and social needs, spiritual needs (help answering the "why me?" and the meaning of life)' Senior clinical officer and PC specialist
- "the perception that PC is wastage of time, and resources on people who are dying, and yet there is an influx of patients. HR are minimal, staff are overworked and look at palliative care as an added burden" Clinical Officer PC specialists central region
- "I have seen the hand of the almighty work, telling people about death" a reverend in Mbarara
- 'LHH has helped us to demystify the disease. People used to think it is bewitching and we have had problems explaining' Moslem Cleric Hoima
- ….The care and support they have give to her. Even when she is taken to hospital , they come there and still check on her from there . When she goes for treatment she comes back visibly very happy… Care giver and granddaughter of a Hospice patient in Hoima
- ….They have made our work easier. Many community members believed in witchcraft and would refuse to go for medication but now we can easily refer the patient to Hospice and they accept. This is demystified' said a Spiritual Leader of an Anglican Church
- I thank you for helping my mother understand that cancer is a disease which is incurable and helping her to deal with it" Care taker and family to patient Hoima

Annex 9: Value addition of HAU partners



Annex 10: Organizational Development Issues achieved

Improvement in governance, management and administrative systems	**Periodic reporting (monthly and quarterly) and work planning were carried out in timely basis. To enhance team building and motivation staff Christmas, staff day of reflection and staff day out were held at each site. PO recruited in the 3rd quarter of year** **Human resource manual was reviewed, only awaits approval by the BOD. I.T policy and procurement guide were also developed, to be finalized in 1st qtr of FY 4.** **Restructuring and downsizing HR was successfully managed – the team-building over the last 18 months that has produced a strong and robust SMT to lead the organization; the re-launch of the appraisal system; the review and amendments of the HR manual**
Improvement in financial systems, audit queries dealt with,	Monthly and quarterly financial reports were written & submitted on time. A new accounting soft ware was procured. An annual audit was conducted in the 3rd quarter and audit queries and concerns have continued being addressed
Improvement in governance issues:	BOD roles clearly segregated and performing their functions Revised HR Manual in place, awaits BOD's approval
Percentage increment in funds to complement USAID funding as the project moves to its final year	Resource mobilization strategy and a sustainability plan are in place, but still being reviewed
Monitoring and Evaluation	The gaps identified during evaluation have been fixed. Data capturing and analysis has improve. The Completion of monitoring tools for programme implementation. The Performance Monitoring Plan for the USAID Grant was completed and submitted The Clinical Manager visited MHM and LHH to monitor and support as well as motivate the clinical team in delivery of high quality palliative care to patients Four review meetings were held in the year and among other outputs the 2011-2012 work plan was developed
IT and IS support	The Information, Communication and Technology department has continued to grow and expand. In the past year the department has achieved the following: Developed a data base for clinical for capturing patient information A new Hospice Domain and Intranet were created. This was to improve network usage, information security and data backup. Upgrading of Hospice Africa Uganda website was done and is maintained New accounting software system supported on the data base server Upgrade of the WAN Set up a wide area network connecting the three sites together. Little Hospice Hoima, Mobile Hospice Mbarara and Kampala are now electronically linked Establishment of voice over IP-talking on internet Mobile internet service provided to a few staff We have a virus free Anti Virus and annual procured on an basis Expenditures fees paid which enabled internet services throughout the year. Many old IT machines will be disposed off to avoid high Maintenance costs
Logistical Support to all HAU Departments & staff	Stationery, utilities and supplies were procured all through the year as inputs to facilitate programme implementation.

Annex 11 : List of documents reviewed

1) Bongiovanni, A. and G. Mary Alexis (2009). Hospice Africa Uganda: End-of project evaluation of palliative care services. F. Report. New York:, Population Council.
2) Gren K and Horne C (2012). ". Integrating palliative care into HIV services: A practical toolkit for implementers, FHI 360 and The Diana, Princess of Wales Memorial Fund."
3) HAU (2011). Annual narrative and financial report; Oct 2010-Sept 2011 submitted by HAU to USAID for the program to expand coverage and access to PC services. Kampala, Uganda, HAU.
4) HAU (2012). Annual Report 2011-12: The power of partnerships collaborating to restore dignity and quality of life, African Palliative Care Association. Kampala, HAU.
5) HAU (2012). Some facts about Hospice Africa Uganda.
6) HAU (2013). Total number of PLWHAs (Direct Beneficiaries) reached by HAU for the last four years of USAID project (2009 - 2012). Kampala Uganda, HAU.
7) MOH (2012). The Development of Palliative Care in Uganda; . Kampala Uganda, MOH, PCAU, OSEA.
8) PEPFAR (2007). PEPFAR's Implementation Progress and Promise: Ch.6 Care Category; CATEGORY, TARGET, AND RESULTS: 2007- Board of Global Health/ accessed http://www.nap.edu/openbook.php?record_id=11905&page=169-204: downloaded 29 January 2012 11:40am Uganda time.
9) Simms, V., I. J. Higginson, et al. (2012). "Integration of palliative care throughout HIV disease." The Lancet Infectious Diseases 12(7): 571-575.
10) Trainers Report (2012). Two Weeks Training Report On Integrating and Building Specialist Palliative Care Competencies within HIV/AIDS Care Organizations In STAR E Project (Mbale); Pain Assessment and Management Module 1. Kampala Uganda, HAU.
11) Uganda Ministry of Health and ICF International. 2012. *2011 Uganda AIDS Indicator Survey: Key Findings*. Calverton, Maryland, USA: MOH and ICF International.
12) Palliative Unit (2011). Palliative Care Unit – Strategic Plan 2011-2016, Makerere University College of Health Sciences. Kampala Uganda, Makerere University College of Health Sciences.
13) USAID (2008). Cooperative agreement 617-A-0-005-0010-00 Modification #4; USAID/UGANDA HIV/AIDS Palliative Care Hospice Africa Uganda. Kampala Uganda, USAID.
14) USAID (2012). USAID FY 2012 COP Revised Care Tan 11-05- submitted, USAID.
15) World Health Organisation (WHO) (2011). Global HIV/AIDS response: epidemic update and health sector progress towards universal access: progress report 2011: WHO Geneva Switzerland, 2011.
16) All quarterly progress reports FY 2012, HAU to USAID on the program to expand coverage and access to PC in Uganda
17) HAU Strategic Plan 2013-2018
18) HAU Sustainability Plan
19) Key Policy documents from HAU including HR, and financial manuals
20) Audited financial reports from HAU FY 2011, FY 2012
21) Final Program Description: Expanding access and coverage to PC, Attachment D to the CA, June 2005
22) HAU-USAID Program PMP; 2008-2013 revised final edition for July 2012
23) USAID Country Development Coopeartion Strategy 2011-2015
24) Health Sector Strategic and Investment Plan
25) HIV/AIDS Strategic Plan
26) PEPFAR Care and Treatment Guidelines

Annex 12: List of People Consulted (NB does not include the names of PLHIV respondents for ethical reasons)

Name of Respondent	Institution	Title
1. Jacqueline Calnan	USAID Uganda	Program Management Specialist
2. Seyoum Dejene	USAID Uganda	Clinical Care Specialist
3. Rose Okot-Chono	USAID Uganda	Program Management Specialist
4. Dan Wamanya	USAID Uganda	Program Management Specialist
5. Zena Bernacca	Hospice Africa Uganda	Chief Executive Director
6. Joseph Balironda	Hospice Africa Uganda	Director Donor Liaison and Advocacy, M&E
7. Mwebesa Eddie	Hospice Africa Uganda	Clinical Director
8. Jack Jagwe	Hospice Africa Uganda	Senior Policy Advisor
9. Milly Nabakooza	Hospice Africa Uganda	Director Human Resource & Admin
10. John Alex Muhilta	Hospice Africa Uganda	Deputy principal HAU Institute
11. Anne Merriman	Hospice Africa Uganda	Director International Programs and Founder HAU
12. Prof Wilson Acuya	Hospice Africa Uganda	Principal IHPCA
13. Stephen Opio-Okabo	Hospice Africa Uganda	Site Programs Manager LHH
14. Mucunguzi Jackson	Hospice Africa Uganda	Site Programs Manager MHM
15. Ntege Bruce	Hospice Africa Uganda	Finance Director
16. Mackey Masereka	Hospice Africa Uganda	Head of Operations
17. Nalubega Josephine-	Hospice Africa Uganda	PC Nurse
18. Derek Eyampaire	Hospice Africa Uganda	Social Worker
19. Kyomunda Charlotte	Hospice Africa Uganda	Coordinator HIV/AIDS
20. Octavia Nazziwa	Hospice Africa Uganda	Coordinator CVWs
21. Nandawula Sarah	Hospice Africa Uganda	PC Nurse Pediatrics
22. Mhoira Leng	Makerere University Palliative	Head of Makerere University PC Unit, PC specialist
23. Emmanual Luyirika	African Palliative Care Association	Executive Director
24. Fatia Kagenya	African Palliative Care Association	Programs Director
25. Harriet Kansime	Palliative Care Association of	Advocacy manager
26. Rose Kiwanuka	Palliative Care Association of	Executive Director
27. Martha Rwaboni-	Mobile Hospice Mbarara	Health Services Coordinator
28. Grace Nayiga –	Mobile Hospice Mbarara	Human Resources Coordinator
29. Ndinawe Johnbosco –	Mobile Hospice Mbarara	Clinical Officer
30. Betty Bifabusa –	Mobile Hospice Mbarara	Palliative Care Nurse
31. Beatrice Assimwe-	Mobile Hospice Mbarara	Associate Lecturer
32. Dr. Emmanuel Luyirika	APCA	Emmanuel.luyirika@africanpalliativecare.org
33. Fatiya Kiyange	APCA	Programmes Director-APCA
34. Rose Kiwanuka	PCAU	PCAU-
35. Dr Mhoira E F Leng	Makerere University	Email: dr@mhoira.net Makerere University:
36. Edward Bitarakwate"	Makerere University	email address - ebitarakwate@pedaids.org STAR
37. Dr.Edward Ssemafumu	Start E	email address - ESsemafumu@star-e.ug- STAR E -
38. Dr. Samson Kironde	Start E	email address - skironde@starecuganda.org- STAR EC -
39. Dr. Christine Nabiryo	TASO ED	email address - nabiryoc@tasouganda.org- TASO -
40. Mr. Michael Kabugo	JCRC	email address - mkabugo@jcrc.co.ug- JCRC -
41. Dr. Jennifer Namusobya	MJAP	jnamusobya@mjap.or.ug Tel 0772-443-292- MJAP

42. Dr Jane Nakaweesi -	Mildmay	Head of PC/Pediatrics
43. Martha Rwaboni	Mobile Hospice Mbarara	Ag Manager/Health Services Coordinator
44. Grace Nayiga	Mobile Hospice Mbarara	Human Resources Coordinator
45. Ndinawe John Bosco	Mobile Hospice Mbarara	Clinical Officer
46. Betty Bifabusa	Mobile Hospice Mbarara	Palliative Care Nurse
47. Beatrice Asiimwe	Mobile Hospice Mbarara	Associate Lecturer
48. Antonia Kamatte	Mobile Hospice Mbarara	Education Coordinator
49. Kayanja Hassan	Mobile Hospice Mbarara	Data officer
50. Nicholas Muchunguzi	Mbarara municipal council HIV Clinic- MJAP	
51. Musinguzi Innocent	MJAP	Ag. Site Manager
52. Mbababazi Fiona	MJAP	Nursing officer
53. Ntabalo Didas	Mbarara District	Secretary Social Services
54. Tumusime Dues	Mbarara District	District Chairperson
55. Alice Berigijja	AIC Mbarara	Manager
56. Asio Kirunda Mary	Mbarara Hospital	Nursing officer
57. Amooti Bwera Kaguna	Mbarara District	DHO
58. Masereka Umar	Mbarara District	DHI and HIV focal person
59. Denis Nansera	Mbarara Regional Referral Hospital	Assistant Hospital Director
60. John Bosco Bwana	JCRC/MJAP	Clinical Director
61. Mbagutta Abubaker	Itojo Hospital	Nursing officer
62. Mugisha William	Itojo Hospital	Clinical Officer
63. Galisonka Francis	Itojo Hospital	Nursing Officer
64. Nakyanzi Maureen	TASO Mbarara	Medical officer/ lead PC team
65. Amanyire Jordam	TASO Mbarara	Clinic Supervisor
66. Kakembo Kizito	TASO Mbarara	Medical Officer/Ag In Charge
67. Gasumuni Medal Mugabbare	Mbarara Regional Referral Hospital	Ag. Principal Nursing Officer
68. Asiimwe Evass Kinuka	Mbarara Regional Referral Hospital	I/C Surgical Ward
69. Ndyanabo Gervasse	Mbarara Regional Referral Hospital	I/C Cardilogy ward
70. Mugisa N Regina	Mbarara Regional Referral Hospital	Principal Hospital administrator
71. Atwine Leo	Mbarara Regional Referral Hospital	Pharmacist
72. Sister Tuhirire Robinah	Mbarara Regional Referral Hospital	In Charge Gynaecology waard
73. Ronald Mayanja	Mbarara Regional Referral Hospital	Gynecologist
74. Victo Biribona	Ruk…HCIV in charge	HCIV in Charge
75. Lawrence Mugumya	STAR SW/EGPAF	
76. Generous Kyinkwhire	Ishongororo HC IV	Clinical Officer
77. Father Protase Rutagwenya	Spiritual Leader- Mbarara	Catholic Leader
78. Mukwya Abdallah Sheik	Spirtual Leader-Mbarara	Imam
79. Ronald Kakye	Spiritual Leader-Mbarara	Leader in the Anglican community
80. Carla Simmons	Kitovu Mobile Clinic	PC Specialist
81. Rose Nabatanzi	Kitovu Mobile Clinic	PC Nurse
82. Resty Nakwaweje	Kitovu Mobile Clinic	PC Nurse
83. Apoko Anne Olaro	Masaka Regional Referral Hospital	Senior Principal Nursing Officer
84. 85 Mugarura Previa	Isingiro	CVW

[24] The list of persons consulted excludes the patients' names which we have not disclosed for ethical considerations as well as some trainees' names that were not divulged in the post training survey. The consultants however regret any other omissions of respondents' names and apologize for any spelling errors

85. Babwetega Justine	Kakiika -	CVW
86. Bukenya perez	Biharwe	CVW
87. Ruth Namaganda	Rubindi	CVW
88. Kaggwa Zamu	Kakoba	CVW
89. Batumba Nabboth	Kabweitendero T/C –	CVW
90. Nalubega Rose	- Manager TASO Masaka	
91. Haji Mugisha	Masaka Regional Referral Hospital	Hospital Administrator
92. Namagembe	Masaka Regional Referral Hospital	Nursing Sister and PC trained
93. Nambooze Jane Francis	Masaka Regional Referral Hospital	Nursing Sister and PC trained
94. Ogwal Rhoda	Masaka Regional Referral Hospital	In charge palliative care unit
95. Jacinto Amandua	Ministry of Health	Commissioner Clinical Services /National Champion for Palliative Care
96. Captain Baguma Mbayaya	UPDF Health Services, Mbuya	Clinical Officer and in charge HCII
97. Ben Asiimwe	Joint Medical Stores	Procurement Officer
98. Anne Ashaba	Joint Medical Stores	Distribution of Morphine (in charge)
99. Sarah Namusoke	Makindye Military Health Centre	Clinical Officer
100. Apolot Irene	Makindye Military Health Centre	Registered Nurse
101. Dennis Chanachana	Makindye Military Health Centre	Clinical officer in charge
102. Jane Nakaweesi	Mildmay (U) centre	Pediatrician and in charge of palliative care services
103. Henry Kyobe	General Military Hospital	Director HIV Programs
104. Edith Nandutu	General Military Hospital	Nursing Officer
105. Edward Semafumu	STAR-E Mbale	Chief of Party
106. Peter Ddungu	STAR-E Mbale	Deputy Chief of Party
107. John Wanyai	Mbale District	DHO
108. Peter Sekiranda	TASO Mbale	Ag. Manager TASO/counselor
109. Eric	TASO Mbale	
110. Leila	TASO Mbale	
111. Joyce Babirye	TASO Mbale	
112. Arnold	TASO Mbale	Ag. Medical Coordinator
113. Akello Merab	Joy Hospice Mbale	Nursing officer /counselor
114. Katusiime Jovita	MJAP_Mulago	Medical Officer
115. Adiru Teopista	MJAP_Mulago	Nursing officer
116. Nsubuga Lilian	JCRC	Ward nurse in-charge
117. Musiime Charity	JCRC	Nurse
118. Sanyu Wanyana	JCRC	Psycho-social counsellor
119. Debora Masiira	JCRC	Chief Nursing Officer
120. Cissy Kityo	JCRC	Deputy Executive Director
121. Safari Dhabangi	LUUKA_ HC IV	CVWs
122. Sarah Musoke	Makindye Barracks	Sarah Musoke
123. Irene Appolot	Makindye Barracks	Irene Appolot
124. Dennis Chanakyana	Makindye Barracks	Dennis Chanakyana
125. Nerima Allen	Masafu General Hospital Busia	Clinical officer
126. Nasirumbi Kaana	Masafu General Hospital Busia	Medical social worker
127. Nabwire Jesca	Masafu General Hospital Busia	Community Mobilizer
128. Ojiambo David Milton	Masafu General Hospital Busia	Doctor
129. Ojiambo Nicodemus	Masafu General Hospital Busia	Community Mobilizer
130. Ajiambo Immaculate	Masafu General Hospital Busia	Case Manager

131. Wandera George	Masafu General Hospital Busia	Clinician
132. Nandera Catherine	Masafu General Hospital Busia	Counselor/Medical Assistant
133. Pr. Egessa Martin	Masafu General Hospital Busia	Spiritual Caregiver
134. Dr. Amukum Emmanuel	Masafu General Hospital Busia	Dental Surgeon/ Palliative Care Focal Person
135. Bwire Fredrick Macho	Masafu General Hospital Busia	Psychiatry Nurse
136. Namakola Abuner	Mbale	Trainee
137. Abdul Nasser Masai	Mbale	Trainee
138. Jafer wawire	Mbale	Trainee
139. Gessa Abdul Zakana	Butaleja	Trainee
140. Wabbala Moses	Butaleja	Trainee
141. Namujjo Josephine	Mbale	Trainee
142. Arikod Joseph	Pallisa	Trainee
143. Mwanga George	Kapchorwa	Trainee
144. Chemutai Justine	Kapchorwa	Trainee
145. Otara florencia	Paliisa	Trainee
146. Aloet Grace	Palisa hospital	Trainee
147. Nangira Annet	Paliisa hospital	Trainee
148. Kaduya Miriam	Mbale	Trainee
149. Emiriat Charles	Kapchorwa hospital	Trainee
150. Akello Gemma	Pallisa	Trainee
151. Lusike Oliver	Butaleja	Trainee
152. Nicholas Muchinugzi-	Mbarara Municiple Council	Mbarara municipal council HIV Clinic – MIAP
153. Ntabalo Didas –	Mbarara Clinic	Secretary Social Services- District
154. Tumusime Dues	Mbarara District	District Chairperson –
155. Alice Berigijja –	Mbarara Hospital	Manager AIC Mbarara
156. Asio kirunda Mary -	Mbarara Hospital	Nursing officer-
157. Dr Denis Nansera	Mbarara Hospital	Assistant Hospital Director- Mbarara
158. Dr John Bosco Bwana	JCRC/MJAP	Clinical Director -JCRC/MJAP
159. Mbagutta Abubaker	- Itojo Hospital	Nursing officer
160. Mugisha William	Itojo Hospital	Clinical Officer-
161. Galisonka Francis	Itojo Hospital	Nursing Officer-
162. Taitika Rose	LUUKA_ HC IV	CVWs
163. Joseph Ruyonga	Hoima District	District Health Officer (DHO)
164. Byaruhanga Stephen	LHH	Data Clerk
165. Ayebale Godfrey	LHH	HR& Admin. Assistant
166. Nabimanya Edward	LHH	PCN/Dispenser
167. Mugisha Andrew	IDI Hoima region	Project coordinator
168. Aringitwe Ronald Kibwami	RHU Hoima	Manager
169. Nathan T. Kipande	RHU Hoima	Projects Officer
170. Alungat Clare	TASO Masindi	Nursing officer
171. Akaki Moses	TASO Masindi	Clinical Officer
172. Anena Irene Jane	TASO Masindi	Clinical Officer
173. Kidega Micheal	TASO Masindi	Ag.Medical Coordinator
174. Birugi Expedito	Masindi Hospital	TASO Masindi
175. Mugisha Anthony	Masindi Hospital	Ag. Stores Assistant
176. Nakanwangi Lubega Mary	Cancer Institute Mulago	Senior Nursing Officer
177. Birungi Josephine	TASO Headquarters	Training coordinator

178. Samson Kironde	STAR-EC	Chief of Party
179. David Tumuheire	STAR-EC	PC/HIV Care Focal Person
180. Tibesigwa Norah	BuyadhereyoH/C 4	Senior Medical Clinical Officer
181. Mambya Ivan	Kamuli Mission Hospital	Principal Nursing Officer
182. Kalende George	Kamuli District	Senior Medical Clinical Officer
183. Mugumaza Zaina	Bumanya HCIV	Nursing Officer
184. Kasumba Brian	Iganga Hospital	Enrolled Nurse
185. Mwagale Jane	Banda HC	Nursing Officer
186. Mugema Enock	Kiyunga HC 1V	Principal Nursing Officer
187. Isabirye Kyakulaga	Nankoma HCIV	Senior Medical Clinical Officer
188. Musana Monica	Busembatya HC	Nursing Officer
189. Musisi Roset	Iganga Hospital	Enrolled Nurse
190. Basoga Kintu DM	Iganga Hospital	Medical Clinical Officer
191. Egulwa Harriet	Kamuli Hospital	Senior Nursing Officer
192. Ikooba Richard	Iganga Hospital	Senior Medical Clinical Officer
193. Zikusooka Batanda	Iganga Hospital	Medical Clinical Officer
194. Sanyu Sarah	Kamuli Hospital	Principal Clinical Officer
195. Tabingwa Harriet	Busesa HCIV	Nursing Officer
196. Efumbi Norah	Bugiri Hospital	Nursing Officer
197. Beatrice Okotelo	Iganga Hospital	Principal Nursing Officer
198. Nakkazi Grace	UPDF Magagga	Counselor
199. Maheera Peter Celestine	UPDF Magagga	Medical Store`s man
200. Tumwesigye Rodgers	UPDF Magagga	Counselor
201. Waiswa Minaki	UPDF Magagga	Lab. Assistant
202. Majaba Betty	UPDF Magagga	Clinical Officer/In-charge
203. Batwala Moses	TASO-Mulago Headquarter	Medical Coordinator
204. Kagimu David	TASO-Mulago Headquarter	Program Officer
205. Etukoit B. Micheal	TASO-Mulago Headquarter	Medical coordinator
206. Isaac Mutabazi	TASO-Mulago Headquarter	Pharmacist
207.		

Annex 13: Data Collection tools _

Tool 1: KI Interview Guide

ARRIVAL, INTRODUCTION AND GROUND RULES (5 MINUTES):

a) Objective – we are conducting an evaluation of HAU programme about expanding access to palliative care services in Uganda.
b) Duration – 1 ½ hours
c) Ask for their consent to the interview – and explain that the information provided will not be identified as having come from the participant (confidentiality).

Introduction: Greet the respondent: **(Good morning, Good afternoon, or Good evening).** My name is _____ and I am conducting an evaluation of Hospice Africa Uganda programme about expanding access to palliative care services in Uganda. Hospice is a program funded with support from the people of America, through the United States Agency for International Development, (USAID). Please be honest and tell me what is true for you. The information you provide will help us to compile a report whose findings will help the United States Agency for International Development and Hospice to improve on the quality of service they offer in this area. This discussion/ interview will last not more than 1 ½ hours and I will be recording and writing down your responses and the key points from this discussion to enable me capture the key issues properly. The information you provide will be treated with utmost confidentiality. If you are willing to participate, please let's proceed with the discussion.

a. DESIGN AND STRUCTURE AND SERVICE DELIVERY MODELS

a) What are some of the palliative care services PAU is offering to the Ugandan community?
b) Please share with us the different service delivery models through which these services are rolled down to the final beneficiaries
c) In your view, do you consider palliative care relevant in these times, when there is an expansion of access to anti-retroviral therapy for people living with HIV? Please elaborate on your response and share with us any relevant information you have on this subject
d) What are some of the key strength and weakness of the HAU service delivery structures and model of palliative care?
e) Are there any challenges that may have constrained your service delivery structure and models while delivering palliative care services?
f) If you had an opportunity to change some elements in the service delivery model and structure, what would change or do differently?
g) In your view what should HAU and other actors do to improve palliative care service delivery in Uganda?
h) What are the main factors that should be in place to enable successful future design of palliative care programmes?

b. CAPACITY BUILDING

a. Please share with us the different capacity building approaches and courses offered by HAU in palliative care
b. How are these trainings undertaken, how long and who are the key targets for the trainings.
c. In your view, do you consider palliative care relevant in these times, when there is an expansion of access to anti-retroviral therapy for people living with HIV? Please elaborate on your response and share with us any relevant information you have on this subject
d. Please share with us some of the challenges faced while delivering these capacity building courses.
e. If you had an opportunity to change something with the capacity building component offered by HAU, what would you change?
f. What do you think can be done to improve on the capacity building component of HAU? (operational efficiency and effectiveness)
g. What are some of the lessons that can be learnt from the project implementation for future project design

c. POLICY ADVOCACY AND INFLUENCING

a) Has HAU been able to influence national policy on palliative care? If yes to what extent?
b) What are the major factors that facilitated HAU influence on national policy on palliative care if any?

c) What are the major factors that have hindered HAU influence on national policy on palliative care if any?
d) What steps has HAU taken to support the MoH in developing an accreditation system for palliative care drugs? What are strengths, what were challenges?
e) If you had an opportunity to change something the policy and advocacy component, what would you change?
f) What can be done by HAU to effectively undertake evidence based advocacy on palliative care in Uganda?

d. SUCCESSES AND FAILURES OF THE PROJECT

a) Please share with us some of your successes in palliative care service delivery during the last five years.
b) From your own assessment do you think the project has been a success or a failure in attaining its goals and objectives for the last five years of implementation?
c) What are some of those components you think the project has under achieved / over achieved in line with the set goals and objectives of the project?
d) In the remaining time frame what do you think can be done to salvage the project to completely achieve its goals and objectives?
e) What are some of the lessons that can be learnt from the project implementation for future project design

e. PROJECT SUSTAINABILITY

a) What plans have been made for ensuring the sustainability of the HAU activities and results?
b) To what extent will the benefits of the project continue after donor funding ceased?
c) What is the social/political acceptance of the project in the community?
d) Has the project implemented sustainability strategies such as leadership, financial and political strategies?
e) What would be the most appropriate exit strategy for all components of HAU interventions to ensure continuity of the activities?
f) How should HAU prepare for exist strategy with in the remaining period of the program?

Tool 2: Focus Group Discussion Tool

A. SELECTION AND INSTRUCTIONS:

a) Arrange focus groups of community volunteer workers and spiritual leaders and facilitated by two consultants (where one will facilitate the discussion and another take note)
b) Make sure that the group is mixed i.e. different categories of respondents
c) Ensure the number of people is between 8 and 10 people in each group: more will be very difficult to manage and give little chance for everybody to participate.

B. ARRIVAL, INTRODUCTION AND GROUND RULES – 10 minutes

a) Ask members to introduce themselves by job or organizational position.
b) Pass around a sheet of paper for people to record their names and positions.
c) Explain objective – To learn about the different palliative care services offered by HAU, challenges of accessing those services and also suggest recommendations on how such services can be improved upon.
d) Duration – 1 ½ hours
e) Ground rules - we want to hear from everyone

C) INTRODUCTION: Greet the respondent: **(Good morning, Good afternoon, or Good evening).** My name is _____ and I am conducting an evaluation of Hospice Africa Uganda programme about expanding access to palliative care services in Uganda. Hospice is a program funded with support from the people of America, through the United States Agency for International Development, (USAID). Please be honest and tell me what is true for you. The information you provide will help us to compile a report whose findings will help the United States Agency for International Development and Hospice to improve on the quality of service they offer in this area. This discussion/ interview will last not more than 1 ½ hours and I will be recording and writing down your responses and the key points from this discussion to enable me capture the key issues properly. The information you provide will be treated with utmost confidentiality. If you are willing to participate, please let's proceed with the discussion.

D) NATURE OF SERVICES (25 MINUTES)

a) Please share with us the roles that each of you plays in the delivery of palliative care services in your community?
b) How often is this role played and how?
c) In your view, do you consider palliative care relevant in these times, when there is an expansion of access to anti-retroviral therapy for people living with HIV? Please elaborate on your response and share with us any relevant information you have on this subject
d) What are some of the support services that you receive from HAU while undertaking these roles (probe about the training, how they were trained and any training needs?).

C. CHALLENGES AND RECOMMENDATIONS

a) Please share with us some of the challenges you face while undertaking the palliative care giving roles
b) If you where to change something about the service you are offering, what would you change?
c) What do you think HAU can do to ensure better service delivery in your community?
d) What are some of the lessons you have learnt from your work? What parts of your work do you consider to be very good, and should be shared with palliative care providers in other regions, to learn from you?

THANK YOU AND GOOD-BYE

Tool 3 : Care givers tool

Since 2009 HAU with support from USAID has been implementing a program to expand coverage and scope of palliative care services for people Living with HIV/AIDS (PLWHA) and their families in Uganda. As part of the program, HAU has been offering PC Services to patients with HIV/AIDS and cancer with support from The **President's Emergency Plan for AIDS Relief** *(PEPFAR) funded HIV Organizations and health facilities supported by PEPFAR funded HIV Organizations/Projects. As the project is about to end, USAID has hired a team of consults to evaluate the impact of a program as well as documenting best practices. We (the consultants) are therefore requesting you to openly share with us your own opinions about the nature of the services you have been receiving with special interest to your satisfaction of those services and desired changes in the service. Please provide any additional information that might be useful in the evaluation of the program: Interviewee: Care takers.*

1. How long have you been caring for this patient?
2. *Please comment on the quality of assistance given by the program in the following areas*
3. Training to handle the patient
4. Availability of pain management drugs for the patient
5. Communication (contacting and feedback from the health provider)
6. Visits from Spiritual leaders
7. Visits from Community Volunteer Workers
8. Visits from the health service providers
9. Two things you have liked most about the program?
10. What changes if any would you like to see or be done differently?

Tool 4: CLIENT SATISFACTION SURVEY

CLIENT SATISFACTION SURVEY- HAU PROGRAMME EVALUATION 2009-2012

Since 2009 HAU with support from USAID has been implementing a program to expand coverage and scope of palliative care services for people Living with HIV/AIDS (PLWHA) and their families in Uganda. As part of the program, HAU has been offering PC Services to patients with HIV/AIDS and cancer with support from The **President's Emergency Plan for AIDS Relief** *(PEPFAR) funded HIV Organizations and health facilities supported by PEPFAR funded HIV Organizations/Projects. As the project is about to end, USAID has hired a team of consults to evaluate the impact of a program as well as documenting best practices. We (the consultants) are therefore requesting you to openly share with us your own opinions about the nature of the services you have been receiving with special interest to your satisfaction of those services and desired changes in the service. Please provide any additional information that might be useful in the evaluation of the program: Interviewee: Patients and Care takers.*

Instructions: Please tick or fill the correct response to the questions below, explain further where necessary

<table>
<tr><th>#</th><th colspan="2">QUESTIONS AND FILTERS</th><th colspan="3">CODING CATEGORIES</th></tr>
<tr><td></td><td colspan="2">SECTION A: BACK GROUND INFORMATION</td><td colspan="2"></td><td></td></tr>
<tr><td>101</td><td colspan="2">Health Facility Name :</td><td colspan="2"></td><td>District:</td></tr>
<tr><td>102</td><td colspan="2">HIV/AIDS Organization which the health facility is affiliated to</td><td colspan="3"></td></tr>
<tr><td rowspan="2">103</td><td>a)Age in complete years</td><td>----------Yrs</td><td rowspan="2">b)HIV Status</td><td>a) positive</td><td>b) negative</td></tr>
<tr><td></td><td></td><td>c) not disclosed</td><td>d) don't know</td></tr>
</table>

104	HAU service delivery approach (circle)	a) Home based care	b) Site based care
		c) Community out reach	d) Hospital based care
		e) Day care services	f) Partner support
105	Sex of the respondent	a) Male	b) Female
106	Marital status of the client	a) Married	b) Separated
		c) Widow/er	d) Never married
107	For how long have you been on the programme	a) Years:_____	b) Months:_____
	SECTION B: CLIENT SATISFACTION		
108	Please rate your pain (from 0 = no pain to 5 = worst/overwhelming pain) during the last 3 months	a) No pain	b) Little pain
		c) Moderate pain	d) Overwhelming pain
109	In the last 3 months, when you were in need of pain relief medication, was there a day when you did not have the medication? a) Yes b) No	If Yes, how many days in the last 1 months did you go without the pain relief drug?	
		_____ Days	
110	In the last 3 months, have you had any of the following symptoms or any other? Circle which one a) nausea, b) coughing C) constipation D) Other (mention) _____-	Overall, were you satisfied with the way the symptoms were managed?	
		a) Not at all b) Fairly satisfied	c) Satisfied d) Very satisfied
		Explain briefly	
111	Did you receive any counseling (psychological) support from the health provider? a) Yes b) No	Overall all were you were you satisfied with the psychological (counseling) support provided?	
		a) Not at all b) Fairly satisfied	c) Satisfied d) Very satisfied
		Explain	
	What kind of social and material support if any did you receive from the health provider? Circle what applies A) Nutritional B) Training care givers C) writing a will d) access to pro-bonal legal services e) None f)others specify_____	Overall all were you satisfied with the social and material support provided?	
		a) Not at all b) Fairly satisfied	c) Satisfied d) Very satisfied
		Explain	
111	Do you receive spiritual support? ? a) Yes b) No	If yes, were you satisfied with the spiritual support provided?	
		a) Not at all b) Fairly satisfied	c) Satisfied d) Very satisfied
		Explain	
112	Has any service provider advised/discussed with you issues regarding planning for the future of your family? a) Yes b) No	If yes, were you satisfied with the advice or counseling?	
		a) Not at all b) Fairly satisfied	c) Satisfied d) Very satisfied
		Explain	
113	Have you at any one time felt un comfortable with the way the health provider related with you? a) Yes b) No	If Yes , Explain (probe if it was resolved)	
114	Please tell us anything you would want to be done differently /better as far as accessing and utilizing PC services is concerned?		

End of survey, Thank you

Tool 5: Post Training Survey Tool

Since 2009 HAU with support from USAID has been implementing a program to expand coverage and scope of palliative care services for people Living with HIV/AIDS (PLWHA) and their families in Uganda. As part of the program, HAU has been conducting PC modular training for health workers from The **President's Emergency Plan for AIDS Relief** *(PEPFAR) funded HIV Organizations and health facilities supported by PEPFAR funded HIV Organizations/Projects. As the project is about to end, USAID has hired a team of consults to evaluate the impact of a program as well as documenting best practices. We (the consultants) are therefore requesting you to openly share with us your own opinions about the training and your current practice and respond to some questions. Please provide any additional information that might be useful in the evaluation of the program*
Interviewee: Staff trained in PC

Instructions: Please tick or fill the correct response to the questions below, explain further where necessary

#	QUESTIONS AND FILTERS	CODING CATEGORIES	
	SECTION A: BACK GROUND INFORMATION		
101	Health Facility Name :		***District:***
102	HIV/AIDS Organization which the health facility is affiliated to		
103	Staff carder trained (Nurse/ Doctor etc)		
	SECTION B: PROVISION OF PALLIATIVE CARE		
104	**Mention the courses of PC that you have ever trained in?** a) Allied Professionals Course b) Health professionals course in Palliative care c) ToT for trained Health Professionals d) Training in Pain Assessment and management e) Training in psychosocial issues and end of life care **f)** Rapid prescribers course **g)** Any other specify…….	**Which of the components of PC are you providing at your place of work?** **a) Clinical management** **b) Psychological (counselling) support** **c) End-of life support** **d) Pain management** **e) Spiritual management** **f) Social/economic support**	
105	Is there documentation for PC patients seen/ contacted? a) Yes b) No	If yes, which one? ……	
106	How is follow up of patients done	a) Giving Next date of review	b) Home visiting
		c) Making phone calls	d) Through volunteers
		e) Through expert clients/pts	f) Others
107	Is the HIV/AIDS Organization to which the health facility is affiliated supporting the provision of PC? A) Yes b) No	If Yes, what kind of support?	
108	If NO where do the health workers get support to provide PC?		
109	Please rank your current level of skill in the area of PC for HIV positive patients after training	e) None at all	f) Need more skills
		g) Adequate	h) Highly skilled
110	How comfortable are you offering Palliative Care services to HIV/AIDS patients/clients?	a) Extremely uncomfortable	b) Uncomfortable
		c) Comfortable	d) Extremely comfortable
	SECTION C: TRAINING IMPACT		
111	How satisfactory did the training help prepare you to do the following:		

a) Pain assessment and management	a)Not satisfactory	b) Fairly satisfact	c) Satisfactory	d) Very satisfactory

			ory		
	b)Provide primary end-of-life care for patients with HIV (Psycho social)	a)Not satisfactory	b) Fairly satisfactory	c) Satisfactory	d) Very satisfactory
	c)Prescription of drugs for pain management	a)Not satisfactory	b)Fairly satisfactory	c)Satisfactory	d)Very satisfactory
	a) Provide education and training to other clinicians on end -of –life issues? (CMEs)	a)Not satisfactory	b) Fairly satisfactory	c)Satisfactory	d)Very satisfactory
	a) Advocate for better palliative care in your workplace?	a)Not satisfactory	b)Fairly satisfactory	b) Satisfactory	d)Very satisfactory

	SECTION D: PALLIATIVE CARE TRAINING		
112	Does the facility have a CME schedule?	Yes	No
113	Is the health facility rolling out PC CMEs?	Yes	No
114	Are there attendance lists for the above CMEs?	Yes	No
115	If there are no attendance lists, explain why ?		
116	Have you attended any PC CME session on the following		
	a) Pain assessment and management	Yes	No
	b) Psycho social issues and end-of- life care	Yes	No
	c) Rapid prescribers course	Yes	No
117	Is the HIV/AIDS Organization to which the health facility is affiliated providing facilitation for PC CMEs?	Yes	No
118	a) If No, Is there any others source of facilitation?	Yes	No
	b) If Yes, who is offering added support?		

	SECTION E: CHALLENGES FACED DURING IMPLEMENTATION OF PC		
119	What are some of challenges that are affecting the implementation of PC activities at the health facility? (multiple responses are possible; do not prompt)	***Please note multiple responses are allowed***	
		a) No facilitation for PC activities i.e. patient care and CMEs	b) Shortage of pain control drugs i.e. morphine and other drugs
		c) Shortage of transport to follow up patients and referral	d) Workload
		e) Shortage of stationary	f) Dependency syndrome (Health workers expect facilitation to do anything
		g) No good support from administration	h) Others (please specify)

Annex 14: The evaluation work schedule and plan

Week	Actual Dates	Activity Area	Specific activity and field visit plan
Week1	Mon, 3rd Dec 2012	Pre-evaluation preliminaries	• Review award documents, sign contract, confirm availability and give feed back to USAID contracts department
	Tues, 4th Dec 2012		• 1st team meeting (understanding assignment , discussing and assigning tasks), team agreements on ways of work
	Wed, 5th Dec 2012		• Review available documents and literature
	Thurs, 6th Dec 2012		• Document review continued
	Fri, 7th Dec 2012		• 2nd team Meeting (Discussion and interpretation to get a common understanding of findings and literature)
	Sat, 8th Dec 2012		• Document review continued
Week 2	Mon, 10th Dec 2012		• Team preparations for the in-brief meeting with USAID, (update required literature and list of documents, identify and agree further questions, clarifications and key contacts)
	Tue, 11th Dec 2012	Deliverable/In briefing	• In-brief meeting with the USAID team • Team reflection and planning meeting • Continuation of document reviews • Make contacts with HAU, after the introductory letter from USAID
	Wed, 12th Dec 2012		• Pre-visit and first consultative meeting with Hospice Africa Uganda (Head of Advocacy and Donor Liaison officer, National Advocacy advisor , Head HR, Deputy Principal, Coordinator Clinical services) to understand structure, partnerships and the program scope, collecting information for the finalization of a more detailed work schedule
	Thurs, 13th Dec 2012		• Team planning meeting and finalization of the work schedule for submission to USAID
	Fri, 14th Dec 2012	Submit the work plan **	• Submit the work plan including the field visit schedule to USAID • Commence the review of tools and crafting the inception report
	Sat, 15th Dec 2012		• Review methodology, continue review of tools and crafting inception report
Week 3	Mon, 17th Dec 2012	Central Region Data collection	Consultations with • HAU/ IHPCA { Senior management team (SMT),
	Tues, 18th Dec 2012	Deliverable /Weekly report	• Crafting the inception report, including the review of the draft methodology, tools and background information • Prepare and submit the weekly report
	Wed, 19th Dec 2012	Deliverable/Inception report	Consultations HAK • Training Institute (management, Trainers and trainees), • Clinical team (medical , psychosocial and social economic) , • Randomly selected day care beneficiaries visiting the facility at the evaluation time, • Advocacy team (data management, M&E and Quality assurance and Research } • Submit an inception report
	Thurs, 20th Dec 2012		• Consultations: PCAU, TASO, Referral hospital Mulago (PC Unit, cancer institute, College of

			Health Sciences- Medicine)
	Fri, 21st Dec 2012		• Consultations: MOH, NMS, JMS- Focal persons • Consultations APCA
	Sat, 22nd Dec 2012		• Team meeting to share progress, findings and review planning
Week 4	Mon 24th	Deliverable /Weekly report	• Prepare and submit the weekly report
	25th- 26th Dec 2012		• Bank holidays
	Thurs, 27th – Sat, 29th Dec 2012		• Finalizing field appointments, • Individual consultants prepare field notes • Further document review
	Monday 31st Dec 2012	Deliverable /Weekly report	• Individual consultants prepare field notes • Further document review • Discussions on report structure
Week 5	Tuesday 1st January		• Bank Holiday
	Wed, 2nd Jan 2013		• Community outreach Kampala/ Wakiso/ Mukono : (patients, care givers, Community Volunteer workers and spiritual healers)
	Thurs, 3rd Jan 2013		• Consultations: UPDF, MoES, NCHE and other NGOs
	Fri, 4th Jan 2013		• Consultations: IHK, JCRC, TASO, Mildmay,
	Sat, 5th Jan 2013		• Team Planning meeting for field work • Discuss report drafting • Follow through consultations pushed forward
	Sun, 6th Jan 2013		• Travel to Mbarara and Hoima (Two teams)
Week 6	Mon, 7th Jan 2013	**Southern Region Consultations** **TEAM 1**	• MHM Consultations: SMT, (Site manager, Health services coordinator, PC nurses, medical officers, data officers and dispensers, Education coordinator, HR coordinator), records gathering and review and final planning for the region and site based beneficiaries
	Tues, 8th Jan 2013	Deliverable /Weekly report	• Field outreach: Education team to referral hospitals, • Health centers, PC facilities and PC providers trained and facility based beneficiaries. • Submit weekly report
	Wed, 9th Jan 2013		• Consultations: District level consultations- courtesy calls to political leadership (CAO, LC V, RDC, PC focal persons, DHO and DADI) and USG and none USG partners
	Thurs, 10th Jan 2013		• Community outreach: CVWs, Selected patients, care takers, spiritual healers
	Fri , 11th Jan 2013		• Community outreach continued : CVWs, Selected patients, care takers, spiritual healers
	Sat, 12th Jan 2013		• Consultants share and prepare notes , • Planning for the next consultations • Planning report drafting • Follow through field visits as per agreement with partners
	Sun, 13th Jan 2013		• Travel to selected USG partners within the region but different districts (Rakai and or Masaka or Kiboga) • Prepare for meeting with USG- focal persons with STAR-SW communities-for the following day • Prepare field notes
Week 7	Mon 14th Jan 2013		• Morning: Meeting with USG partner staff (MJAP, TASO, UPDF)

			• :Afternoon: Community outreach: CVWs, Selected patients, hospitals, care takers, spiritual healers
	Tues 15th Jan 2013	Deliverable /Weekly report	• Morning : Community outreach continued : CVWs, Selected patients, hospitals, care takers, spiritual healers: • Afternoon: Travel back to Kampala. • Submit weekly report
Week 6	Mon, 7th Jan 2013	South western Region Consultations	• LHH Consultations: SMT, (Site manager, Health services coordinator, PC nurses, medical officers, data officers and dispensers, Education coordinator, HR coordinator), records gathering and review and final planning for the region and site based beneficiaries
	Tues, 8th Jan 2013	**TEAM 2** Deliverable /Weekly report	• Field outreach: Education team to referral hospitals, health centers, PC facilities and PC providers trained and facility based beneficiaries • Submit weekly report.
	Wed, 9th Jan 2013		• Consultations: District level consultations- courtesy calls to political leadership (CAO, LC V, RDC0 PC focal persons, DHO and DADI) and USG and none USG partners
	Thurs, 10th Jan 2013		• Community outreach: CVWs, Selected patients, care takers, spiritual healers
	Fri , 11th Jan 2013		• Community outreach continued : CVWs, Selected patients, care takers, spiritual healers
	Sat, 12th Jan 2013		• Consultants share and prepare notes , Planning for the next consultations
	Sun, 13th Jan 2013		• Travel to selected USG partners within the region but different districts (Masindi and or Kiboga) and • Prepare meeting with LHH beneficiaries for the following day
Week 7	Mon 14th Jan 2013		• Morning: Meeting with USG partner staff: (TASO, UPDF) • Afternoon: Community outreach: CVWs, Selected patients, hospitals, care takers, spiritual healers
	Tues 15th Jan 2013	Deliverable /Weekly report	• Morning : Community outreach continued : CVWs, Selected patients, hospitals, care takers, spiritual healers: • Afternoon: Travel back to Kampala.
	Wed 16th Jan 2013		• Team meeting in Kampala: Share findings, lesions and planning for Eastern and East Central regions
	Thurs 17th Jan 2013	TEAM 1 Eastern region data collection	• Morning :Travel To Mbale/Star E : • Afternoon: Meeting with USG S partner staff (Star-EC, TASO, UPDF)
	Fri 18th Jan 2013		• Community outreach: CVWs, Selected patients, hospitals, care takers, spiritual healers: • Afternoon: Travel to Soroti and meet the focal person and plan for the district outreach.
	Sat 19th Jan 2013		• Community outreach continued : CVWs, Selected patients, hospitals, care takers, spiritual healers:
	Sun 20th Jan 2013		• Travel back to Kampala
	Thurs 17th Jan 2013	Team 2 East and central region data collection	• Morning :Travel To Iganga : • Afternoon: Meeting with USG S partner staff (Star-EC, TASO, UPDF)
	Fri 18th Jan 2013		• Community outreach: CVWs, Selected patients, hospitals, care takers, spiritual healers:

			• Afternoon: Travel to Mayuge and meet the focal person and plan for the district outreach.
	Sat 19th Jan 2013		• Community outreach continued : CVWs, Selected patients, hospitals, care takers, spiritual healers:
Week 8	Tues 22nd Jan 2013	Deliverable /Weekly report	• Prepare submit weekly report • Data entry • Finalize stakeholder and client consultations
	Wed 23rd Jan 2013	Data entry and analysis	• Data entry • Finalize stakeholder and client consultations
	Thurs, 24th Jan 2013		• Finalize Data entry • Data collation and analysis • Write field notes
	Fri 25th –sun 27th Jan 2013		• Data analysis continued and interpretation of findings • Field notes • Report writing
Week 09	Mon 28th Jan 2013		• Data analysis continued and oral presentation preparation
	Tues 29th Jan 2013	Deliverable weekly report	• Data analysis continued
	Wed 30th Jan 2013	Draft report preparations	• Draft report preparation to USAID team
	Thursday 31st Jan 2013		• Draft report preparation to USAID team continue
	Friday 1st February 2013		• Draft report writing, incorporation of comments and gap analysis
	Saturday/Sunday 2nd/3rd February		• Draft report writing, incorporation of comments and gap analysis
Week 10	Monday 4th February	Deliverable/Submission of first draft report**	• Team meeting- morning and refining the report • Submission of draft report by C.O B • Preparation for workshop and report drafting continued
	Tuesday 5th February	Deliverable/Oral Presentation	• Oral presentation preparation ; Power-point including hand-outs to USAID, HAU; covering major findings, conclusions, key recommendations and lessons
Week 11	Tuesday 12thFebruary 13		• Oral presentation to USAID team; Power-point including hand-outs to USAID, HAU; covering major findings, conclusions, key recommendations and lessons
	Thursday 13-20th February 2013	Assuming timely feedback on the report	• Incorporation of comments and cleaning draft report • Review cleaned data sets
	Friday 28th February	Final report and cleaned data sets**	• Submission of the final report • Submission of cleaned data sets
Week 12	TBD (dependent on approval of final report)	Dissemination workshop	• Dissemination workshop for key stakeholders, incorporation of comments (To liaise with the mission to agree dates, audience, venue and other logistical arrangements)-afternoon