Expanding access and scope of Palliative Care for People Living with HIV/AIDS (PLWHA) and their families

END OF PROJECT REPORT
1st October 2005 to 30th September 2015
This publication was prepared by Hospice Africa Uganda for the United States Agency for International development.

Expanding Access and Scope of Palliative Care for People Living with HIV/AIDS and/or cancer and their Families in Uganda was a technical assistance program geared towards increased access to and the utilization of quality palliative care services by PLWHA’s (including HIV/AIDS related cancers) and their families in Uganda. The project was funded by the United States Agency for International Development under Cooperative Agreement No. 617-A-00-05-0010-00.

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

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Hospice Africa Uganda (HAU) greatly appreciate the ten year financial and technical support from USAID Uganda Mission for the implementation of a project entitled “Expanding the access to and scope of Palliative Care for People Living with HIV/AIDS (PLWHA) and their families”, under the USAID PEPFAR program support to the people of Uganda.

HAU particularly appreciates the unlimited and timely technical support provided by Mr. Dan Wamanya, Ms. Jacqueline Calnan and the finance team at USAID Uganda, during the project implementation and closure.

We also wish to acknowledge the technical and support staff from all the three sites of Hospice Kampala (HKLA), Little Hospice Hoima (LHH) and Mobile Hospice Mbarara (MHM) for their efforts in the implementation of this project. We also thank the patients who accepted to be on HAU program, and particularly those who consented to have their photographs used in various reports and media publications. We thank all the learners who HAU came into contact with who gave the opportunity to further the agenda of both HAU and the USAID of expanding capacity to offer Palliative Care for many in need in Uganda. The strategic partners; Ministry of Health, PCAU and APCA, staff from referral hospitals and other stakeholders are much appreciated.

We also wish to acknowledge HAU’s able leadership throughout the project implementation period, notably the former Chief Executive Directors; Dr. Ekiria Kikule, Ms. Nina Shalita, Ms. Zena Bernacca and finally the Chief Executive Team who have steered the program to its conclusion in 2015. In a special way we appreciate the team that has worked tirelessly to put together this report.

Thank you all for your overwhelming support.

Milly Nabakooza Nsubuga
Chief of Party
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Hospice Africe Uganda
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Executive Summary

In 2005, HAU a not-for-profit, charitable NGO in Uganda signed a cooperative agreement (#617-A-0005-00010-00) with USAID Uganda, for a program entitled “Expanding the access to and scope of Palliative Care for People Living with HIV/AIDS and their families”, under the USAID PEPFAR program support to the people of Uganda. Due to continued need for palliative care services and HAU being at the forefront of this specialized work, the project was extended from January 2009 to September 2013 and subsequently from October 2013 to September 2015. The overall objective of the program was to increase access to and utilization of quality palliative care services by people living with HIV and AIDS (PLWHA) and their immediate families.

The grant objectives were:

1. To deliver palliative care services, particularly, clinical components offered in the three centres of excellence; Kampala, Hoima and Mbarara.

2. To provide technical assistance to USAID district-based comprehensive HIV/AIDS and TB partners on integration of palliative care into their care and support programs in the public sector.

3. Develop the infrastructure of HAU and consolidate the on-going sustainability plan approved by USAID in December 2011.

This project was designed with 4 key results areas namely:

1. Improved delivery of palliative care services
2. Increased capacity of HIV/AIDS organizations
3. Improved policy environment
4. Improved organization and management of the institution (HAU).

The project succeeded in all 4 result areas; to varying degrees with much learning and many by-products. This report attempts to bring together the full array of achievements from 10 years of commitment from USAID and from HAU to ensure that more PLWHAs and their families have the opportunity to live better, manage all types of pain; physical, mental, emotional, financial and spiritual and to die pain-free and with dignity, with loved ones close by should their time come for end of life.

As PC offers holistic approach to care incorporating the essential facets of life; the physical, the emotional, the spiritual, the socio-economic – it takes time. The numbers are far less than in the majority if not all HIV clinics in order that all needs can be attended to. As human beings when we are in physical distress, those are the symptoms that need most attention and then the others follow. PC practitioners are a special kind of person – they are interested in all of the facets and become skilled in all – learning the boundaries of their expertise and have a range of allied professionals to refer to. They witness all kinds of distress and have the ability to meet chaos and pain with calmness that is invariably infectious. They may see patients at deaths-door, and through their holistic attention, bring patients back from the brink. Particularly patients with AIDS who have not accessed appropriate care or who have neglected their health for whatever reason. HAU can provide the life-line needed where there are complex symptoms and when end of life comes; HAU excels in bringing hope where there has been fear into the lives of patients and their families in the form of pain management; attention to all concerns of those dying and those remaining. It is a privilege to work in this field and a privilege to teach and support the general nurses and doctors as they take on this kind of care as much as their workload allows them to.

This project demonstrates many things. Certainly, how much can be achieved through supporting a specialist in a country in terms of expansion of knowledge and skill; how using the WHO public health model of adequate drug availability, education, and policy and implementation can build capacity those impact reaches far beyond the country it has been focused on. Through this partnership HAU and its sub-grantee organization, PCAU have been able to increase capacity of delivery of PC to PLWHAs from less than 1% to at least 62% of those needing acute/full PC services using conservative estimations.
In addition, it demonstrates how with belief in the quality of the work, an organization can be supported even when governance issues arise and through true partnership working, a local organization can come through the most difficult of challenges and be strengthened as a result.

Please note that the definition of PC changed in PEPFAR (see Annexe 4). Whilst the definition is clear and understood, the health services in Uganda are overwhelmed with volume of patients. The PLWHAs coming onto the HAU program are in advanced and acute HIV/AIDS disease. The training for health professionals in this project was designed to ensure health practitioners have the skill, knowledge and competence of basic holistic PC to PLWHAs right up to and including stage 4.

Key project achievements

RESULT AREA 1. Improved service delivery of palliative care services

1. The number of PLWHAs in Uganda accessing palliative care services from HAU more than doubled from 781 patients in 2005 to 1,772 patients in 2015 directly through Hospice Africa Uganda centres of excellence.

2. It is difficult to ascertain how many PLWHAs accessed services through the public health care system since the revised health management information system (HMIS) with measurable palliative care indicators has only recently been rolled out. However, through this project alone, conservative estimate is that there is now a realistic capacity for more than 115,000 PC PLWHAs per annum being cared for through Uganda’s public health care system which is approximately 62% of PC patients in acute HIV/AIDS disease at any one time (See Annexe 3).

3. The 3 centres are acknowledged and valued centres of excellence, consultation and referral points for attending to patients’ complex PC needs.

4. There are 3 well-equipped resource centres open to those wanting to develop their PC knowledge and skills.

5. The development and filming/publishing of internationally recognised resources; DVD, titled, ‘Good Practices in Palliative Care Training’ and ‘the Blue Book’ entitled “Pain and symptom control in the cancer and/or AIDS patient in Uganda and other African countries” which gives the opportunity to raise awareness and guidance on treatment

RESULT AREA 2. Increased capacity of HIV/AIDS organizations

1. HAU successfully supported 9 USG IPs across 27 districts to integrate palliative care into the routine HIV/AIDS care and treatment services of supported health centres. A total of 105 health facilities had their health workers trained in PC through the USAID project, and 1,239 health practitioners were trained to deliver PC as part of their mainstream health interventions for PLWHAs.

2. With the basic PC training a health practitioner could realistically see about 10 patients a month for PC as part of their routine work. (Although many practitioners have taken up palliative care as volunteers, out of hours such is their compassion). This means with training 1,239 health practitioners, there is capacity for an additional 10,430 patients a month needing PC being given the basics of such care i.e. 114,730 per year.

3. The Rapid prescribers course (for oral liquid morphine) in the last 2 years of the project increased capacity of PC provision by 80 health practitioners and an estimate of additional 8,800 patients were provided with oral morphine per annum across 90 districts in Uganda.

4. HAU conducted a survey on capacity building of tutors program that started in the early years of the project. The results revealed that training institutions for Nurses, clinical and medical officers had included a module on PC and that 93% of the health workers trained by tutors were involved in some form of palliative care. This demonstrates that ensuring that PC is integral to initial practitioner training is the most effective method of increasing PC coverage across Uganda compared to training those already qualified.

5. Looking HAU and the work of this project alone, there has been a significant increase in the capacity of provision of PC for PLWHAs from 0.52% in 2005 (HAU program)-to an estimate of 62% Estimate based on HAU’s clinical judgement.
6. The development of accreditation guidelines for facilities prescribing morphine has helped to increase the percentage of districts providing dedicated PC with access to morphine from 40% (45/112) in 2009 to 61.6% (69/112) in 2013. This percentage continued to increase to 80.4% (90/112) in 2015. There are now 208 facilities in Uganda which stock oral liquid morphine for their patients to use. Morphine is a cornerstone opioid medication for the management of severe pain of PC patients.

7. Inclusion of two PC indicators in Uganda’s Health Management Information Systems (HMIS) commencing July 2015, namely: 1. Number of patients with PC needs seen; 2. Number of patients on morphine. This is the first time that Uganda will be able to demonstrate the level of PC care needed in the country as a whole.

8. Development of curriculum, standards and facilitation handbooks for PC short courses, this has ensured that health professionals can access standardized information when doing PC training.

9. Development of the National PC policy is in final stages of approval by Ministry of Health senior management and will be tabled before Parliament in mid-2016. Once this policy is passed, it is expected that GOU will allocated further resources to PC services. This will also support Uganda’s signature to the World Health Assembly May 2014 Resolution through which the country committed to integrating Palliative Care into the health systems at all levels.

10. A parliamentary sub-committee on palliative care has been operational since 2011 and is actively supporting progression of the National Policy for PC.

11. Since 2009 a total of 131 nurses specially trained by HAU have been awarded a Diploma in Clinical Palliative Care and as a result of advocacy, graduates are recognised by the Ministry of Health as Palliative Care nurse specialists.

12. Nationally recognised minimum standards for PC have been developed and launched by PCAU and the MOH.

13. HAU transitioned from a Founder-led organization to a management-led and board-directed organization.

14. Organizational Development of HAU has established effective governance and management practices, policies and systems that have made the organisation more sustainable. This has contributed to increasing the number of donors to 73 over the 10 year period supplementing HAU self-sustaining income generating programs.

15. A leadership and manager development program in 2012 brought a renewed commitment to the mission and ethos of HAU and integrated the new resource mobilization department into the organization’s structure.

16. A systematic M&E framework was introduced in 2006 which has ensured the collection of significant clinical and management data over the last 9 years that can demonstrate trends and give valuable insight into project learning/lessons and the needs of PLWHAs.

17. HAU reduced its dependency on USAID from 75% of its funding in 2005 to 39% in 2015. HAU established, (in FY2013) and has recently revamped its resource mobilization function, diversified its donor base and increased its internally and locally generated incomes.

18. Development of a Resource mobilization Plan; Communications Plan and Sustainability Plan which have been crucial steps in preparing HAU for the future.

19. Volunteering at HAU has been strengthened over the duration of the project particularly as the organization meets the reality of reduced funding opportunities.

20. Value for money has been a focus with creative methodologies deployed/extended to ensure patients numbers have been sustained whilst the USAID funding stream comes to completion. E.g. use of roadside clinics, use of CVWs, increased mobile phone consultations.
By-products as a result of USAID support to HAU

21. HAU has been held up as a ‘learning organization’. Many who have been employed by/trained by HAU in PC have gone on to found other PC organizations/units or be founding staff such as the APCA, PCAU, Kawempe Home Care, Makerere Palliative Care Unit. Others have taken up key leading positions pioneering new work in HIV and allied fields. To this day, the majority of the staff of the PC organizations in Uganda were initially trained through HAU. In addition, organisations in Uganda and MOH from across Africa continue to seek advice on matters of setting up PC services, use of oral liquid morphine and its manufacture, advocacy and complex pain management care. HAU is a favoured organization for placing interns for work experience.

22. HAU trained 6,641 learners during the project period; 4,567 were short courses which included health professionals’ course, breaking bad news, counselling in PC, spiritual advisors course, traditional health practitioners’ course, rapid oral morphine prescribers’ course, CVW course and Allied Professionals Course. 381 trained in long courses which included DCPC, DPC and BSC in PC, and 1,693, fourth year University medical students (MUST and MUK) and nursing students were provided with class theory and placement practice. Many of the Ugandan students who enrolled for the long courses were from districts supported by IPs who were first exposed to PC through the USAID-funded trainings by HAU. All these students benefitted immensely from the clinical setting i.e. USAID funded centres of clinical excellence.

23. As a result of systemic M&E, numerous pieces of retrospective research have been completed by students at the IHPCA and researchers coming from outside HAU (including Kings College London, San Diego Hospice, USA).

24. In 2011, due to; the reputation for integrity in managing restricted medications, a track-record of uninterrupted medication manufacture, and clinical excellence, HAU was invited to submit a proposal to manufacture and supply oral liquid morphine for the whole of Uganda in a public-private partnership with the GOU through NMS. HAU was successful and is into its 5th year of production, successfully completed its 2nd contract, and has been awarded the 3rd consecutive contract after a competitive tendering process.

25. HAU received a pan-Africa award for Advocacy in the field of Palliative care from APCA at its last international conference held in South Africa in 2013.

26. HAU was part of the consortium that lobbied for the development and inclusion of resolution (EB134. R7) on PC at the World Health Assembly in May 2014. As a signatory to this resolution Uganda is tasked with integrating PC into the health care system at all levels and systematically addressing all barriers to pain relief and universal access to quality PC.

27. HAU is frequently asked to speak about PC on local radio and TV stations thus raising awareness of PC. HAU has appeared regularly in local and international electronic and print media, and is active on social media.

28. HAU developed such standing in the NGO sector in Uganda and sub-Saharan Africa that the Nnabagereka of Buganda, Her Royal Highness Sylvia Nagginda honoured HAU to become the organisation’s Patron in 2014.

29. PCAU holds quarterly thematic half-day updates that frequently have more than 200 people attending who work in the field of PC across Uganda. This is a vibrant and lively community of practitioners who are passionate about their work and the need to support one another as well as practicing from a sound evidence base. Many of those attending have benefited from USAID funded programs and as a result want to pursue their interest in and practice of PC.

30. The health of thousands of Ugandan’s has been immeasurably improved through direct information being given about end of life; alleviation of helplessness that comes with living with uncertainty; the ability to plan for the future of the family; reduced social pain at burial due to Will planning, reduced pain in loved ones as they die; increased knowledge of prevention of HIV, and increased testing as a result of relatives having palliative care.

31. Because of her work bringing peace to the dying through affordable oral liquid morphine and the growth and development of Palliative Care throughout Africa the Founder of HAU Prof Anne Merriman was nominated for a Nobel Peace Prize in 2014.

32. Uganda has been recognized as the only African country to have comprehensive PC coverage in the WHO Atlas of PC4

33. HAU has ensured that PC is not perceived as a purely clinical issue but that it has public health, social, human rights, legal and multi-sectoral implications. HAU has strived to ensure an inter-sectoral approach to addressing PC issues and in line with its ethos has actively engaged partners and a wider network.

4 www.who.int/nmh/Global_Atlas_of_Palliative_Care
**Challenges**

1. The global economic recession giving rise to the context of reducing grant funding coupled with tighter criteria which often exclude PC.

2. The slow integration of PC into mainstream health services due in part to lack of funding for the nation public health service and the heavy demand on health services for acute illness.

3. While the coverage of PC in Uganda has increased there is still a rural-urban disparity, and large geographical regions of the country and hard-to-reach areas without any PC services.

4. Most patients are located in the community and are not appropriate for hospital admission. Home-based care is not universally available, many hospitals and health centers do not offer home outreach services and the majority of patients are unattended in their homes, which research has shown to be the preferable place for their care and end of life.

5. Vacant posts in health services. Numbers of patients per practitioner are high. The acute and emergency cases get seen first and palliative care for the terminally ill is not prioritised. During budgetary allocation there is stiff competition with infectious diseases, maternal and child health issues which are still prevalent and a priority in Uganda.

6. Compared to the national patient burden the number of clinicians trained in PC is too small. The need for education of compassionate clinicians offering bedside care to patients remains as high as ever.

7. The system of moving health staff has had the effect of placing health staff into posts or work locations where they cannot practice PC. This was a repeated issue that HAU and PCAU found on follow ups. They may be due to lack of understanding of PC; the new location not yet being accredited; the specialty not having so much opportunity to practise PC such as theatres.

8. Lack of monetary remuneration of specialist PC trained Health Workers.

9. There are not enough specialist refresher courses on PC. The need for PC in Uganda due to increasing prevalence of cancers, non-communicable diseases and an ageing population is not matched with the funding required to offer the service for all in need.

10. The need for PC training for clinicians already in service, specialists treating NCDs and for the clinical officers’.

11. PC is not yet mandatory as part of the medical, clinical officer and nursing school curriculum.

12. Training is needed for health staff and data collectors in the use of the PC HMIS indicators.

**Key learning**

The importance of;

1. having a stand-alone hospice palliative care facility to serve as a role model; keep up-to-date with evidence-based good practice, offer updates to training, and to research into good practice and to act as an advocate for the patient and the services needed

2. gaining the understanding and commitment of management of the IP before any partnership work starts, and in those discussions, to look at follow through support and sustainability

3. gaining the understanding and commitment of the MOH as early as possible in the life of such a project to have a better chance at pre-empting some of the challenges faced in this project

4. strategic planning for policy development and embedding of PC (services, education and human resources) in planning cycles of health service development

5. ensuring that transferred staff who have been trained in PC go to accredited health centres so they can continue their PC practice

6. ensuring that accredited centres are extended to the level of health centre 3 so that more PLWHAs receive the PC they need

7. training curricula of nurses, clinical officers and medics to include PC in basic training

8. a strong, active and committed board at organizational level to ensure appropriate governance

9. a robust infrastructure (admin, finance, IT and human resource) that is regularly reviewed to reflect the size and operations of the organization
10. working in partnership and acknowledging all contributions as no one organization can lay claim to even the achievements listed here. HAU could not make this list without the work of PCAU, the sub-grantee, the USG IPs and also the other 12 PC organizations and/or hospital PC units across Uganda and the dedicated suppliers who have gone the extra mile so often with us e.g. to give water for our patients, worked through the night to print materials for awareness-raising etc. of every single person in and around HAU being an advocate – the general assistants as much as the Chief of Party

11. keeping alive the ethos and culture of hospitality.

12. upholding an intricate inter linkage of clinical work, academia and research so that teachers are experts in bedside patient care, clinicians are up-to-date in their practice and that research informs all the work and there is a robust evidence-base for the service.

13. ensuring training in PC of health and allied professionals at all levels including pre, and in-service training so that there is continuous professional development

14. ensuring sustainability. It is crucial that PC services and projects are designed to be sustainable in a setting of diminishing financial resources.

Much of the learning highlights the need for systemic change at governmental level. Until there is an adequate health budget support of a specialist hospice as a model of care and teaching centre by that budget, enough clinicians, well distributed medicines, enough specialists trained, so that sustainability of PC services for all in need can be guaranteed.

This project implementation was in partnership with PCAU as a sub-grantee, and the MOH and a number of USG IPs including TASO, MJAP, JCRC, UPDF, MSH/STAR-E, JSI/STAR-EC, EGPAF/STAR-SW, Baylor Uganda-West Nile and PLAN/NUHITES and Mildmay Uganda. Together, including stakeholders beyond those mentioned increased accessibility to palliative care in the country has been realized.

Conclusion
The positive results of this project could only be delivered by a credible, reputable, specialist and reliable hospice facility. To increase capacity of PC provision to PLWHAs living with stage 4 AIDS from less than 1% to a conservative estimate of more than 62% is a tremendous achievement. Many strategies have been used to increase the numbers of patients receiving PC with the most effective being the curricula development; the training of tutors; increasing morphine prescribers; formalizing national standards of PC, accrediting centres to stock morphine; and the work on the national PC policy. i.e. attention to the 3 aspects of the WHO public health framework; policy, practice and education.

Modern Palliative Care commenced with Dame Cecily Saunders who envisioned St Christopher’s Hospice in the UK as a place of hospitality for patients and where the ethos and spirituality of Palliative Care could be nurtured and extended. The ideals of Palliative Care need to spread from free-standing Hospices into all patient care institutions including hospitals, both public and private and to all NGOs offering home-based care. While PC should be integrated into the country’s health systems, as directed through the WHA resolution of May 2014 it is important that a few free-standing Hospices are supported to remain as centers of excellence and demonstration of PC and the ethos of holistic patient care. As a role model in the practice of PC, the research into PC and the teaching of PC such centres reminds us of the essence of hospitality and what we can do in the mainstream work of hospitals and in communities. HAU has amply demonstrated itself as such an organization and is committed to continue that patient-centered work.

The challenges of ensuring such capacity is well-managed are not insignificant and, as the challenges the government faces are met; a realistic health budget, a budget for PC, greater appreciation of specialist trainings, sophistication in Human Resource distribution etc., PC will become more sustained in mainstream practice both in hospitals and in the community. As an acknowledged pioneer and leader of PC in the region, HAU continues to be needed and will continue to need support from her diverse and wide-ranging supporters both within (internally generated income streams) and without (governments, foundations, corporate donors, philanthropists, individuals) both in cash and in kind.

The foundation has been clearly built. The crucial step for sustainability is to ensure that these trained practitioners are given the opportunity and support to continue their PC practice and to train others.

HAU appreciates USAID and the US government for both financial and technical support offered which has led to huge impact into the expansion of Palliative Care services to thousands of vulnerable patients in need of the service. Advocacy for PC, capacity building of health professionals in PC across the country, and the increased coverage of PC services through accreditation of health centers to access morphine for pain management have all been achieved.
Uganda is still classified as a country with a high burden of problems from HIV; with high population of PLWHAs whose number is continuing to increase (UAC, 2014). This is a result of continuing spread of HIV, and increased longevity among persons living with HIV. According to UAC (2014), the national projections based on Spectrum estimates indicate an increasing number of PLWHAs; 1.4million in 2011 to 1.6 million in 2013, and to 1.5 million in 2014 with about one million orphans due to AIDS. However, there is a window of hope as evidenced by reduction in number of new infections among the adults over the last five years from 160,000 in 2010 to 140,000 in 2013 and to 95,000 in 2014, and because the number of persons initiating ARVs has surpassed the number of new infections. Remarkable improvements have been witnessed in the reduction of annual AIDS related deaths from 67,000 in 2010 to 63,000 in 2013. In 2014 there were only 31,000 deaths.

The drop in mortality rates from AIDS is a tremendous achievement of many patients initiating highly active ART. However as a result, there is an increase those living with AIDS and therefore the estimated number of PLWHAs in need of PC has been steadily increasing. Estimates were 150,000 in 2010 rising to 187,500 in 2014 (UAC, 2014).

In 2005, the WHO called upon governments to create and implement PC policies, advocate for equity in access to services without discrimination and availability of essential medicines (MOH, 2012). This has been strengthened by the World Health Assembly (WHA) resolution (EB134.R7) signed May 22nd 2014 which mandates member states to address PC within the continuum of care.

The Ugandan government, through MOH has supported the implementation of PC by facilitating the importation of morphine, sponsoring health workers to train on palliative care, including PC as one of the key outcomes in its mission, allocating a budget line for PC under the Primary Health Care budget and including two PC indicators in HMIS registers among other efforts.

Whilst several interventions have expanded access of PC services in Uganda since 1993, there is still an unmet need. In general terms, although 80.4% of districts to date have a PC service, palliative care is unlikely to be reaching 10% of those in need. However, specifically through the USAID grant since 2005, there has been a significant increase in the provision of PC for PLWHAs from not much more than 0.5% to an estimate of more than 62% (see Annex 3).

In 2005, HAU an NGO in Uganda signed a cooperative agreement (#617-A-0005-00010-00) with USAID Uganda, for a program entitled “Expanding the access to and scope of Palliative Care for People Living with HIV/AIDS (PLWHA) and their families”, under the USAID PEPFAR program support to the people of Uganda. Due to continued need for palliative care services, the project was extended from January 2009 to September 2013 and subsequently from October 2013 to September 2015. The overall objective of the program was to increase access to and utilization of quality palliative care services by PLWHA’s and their immediate families. The program was designed with 4 key result areas namely:

1. Improved delivery of palliative care services
2. Increased capacity of HIV/AIDS organizations
3. Improved policy environment
4. Improved organization and management of the institution.

HAU implemented the project in collaboration with PCAU (as sub-grantee), MOH and a number of USG IPs including TASO, MJAP, JCRC, UPDF, MSH/STAR-E, JSI/STAR-EC, EGPAF/STAR-SW, Baylor Uganda-West Nile and PLAN/NUHITES.

Expected results of the project are summarized in figure 1. The main strategies to achieve these results included; direct provision of comprehensive palliative care services, capacity building for tutors, clinical instructors, health managers and health workers and advocating for an enabling environment.
FIGURE 1: PROJECT RESULTS FRAMEWORK

DEVELOPMENT OBJECTIVE 3
Improved health and nutrition status in focus areas and population groups

PROJECT STRATEGIC OBJECTIVE
Increased access to HIV/AIDS palliative Care Services

RESULT 1: Improved Service delivery of palliative care services
Direct provision of palliative care strengthened, capacity for training strengthened and referral networks developed

RESULT 2: Increased capacity of HIV/AIDS organization, Selected health professionals, health tutors/clinical instructors, morphine rapid prescribers and health managers competent in delivering PC or training in PC

RESULT 3: Enhanced enabling environment for health care
Consultative meetings conducted with MOH and key stakeholders, minimum standards for PC provision developed, trained health workers mentored, harmonized curricula for health professionals PC short courses developed, accreditation guidelines, national PC policy developed, accreditation guidelines developed and districts sensitized on HMIS PC indicators and national PC standards

RESULT 4: Improved organization and management of the institution
Management site support visits, planning and budgeting workshops, M&E update trainings and support workshops conducted, M&E system

D.O.3: IMPROVED HEALTH & NUTRITION STATUS IN FOCUS AREAS & POPULATION GROUP
Overall goal: Increased access to HIV/AIDS palliative care services

Overall the project has led to an increase in the number of Ugandans accessing palliative care services both directly by HAU and indirectly through the many people trained in basic palliative care.

This achievement has been a result of combined approaches that were employed by HAU including direct provision of palliative care, community volunteers, and capacity building for health workers, health center managers and advocacy initiatives. Through capacity building thousands of health and non-health professionals have had their competencies developed. To date they are able to offer palliative care services to patients within their localities. This not only means delivering holistic palliative care, and end of life care, but also preventive messages given when people are at their most susceptible to health behavior changing messages and are most open to seeking health advice and treatment.
Advocacy efforts have successfully influenced changes in the health sector environment (NGO, MOH and private health care), to favor provision of palliative care in Uganda. Palliative care is included in the national health system through its addition in the HSSIP, availability of oral liquid morphine throughout 90 districts of Uganda, development of a national PC policy and inclusion in HMIS registers. All this resulted into improved health in the continuum of health care of the population.

To follow ahead are the indicators used to explicitly measure achievement of the goal. In the figure below a trained health worker (from an IP) increases access to PC to people in need.

**HOS1.0.1 Percentage of PLHA and their families accessing direct PC services from Hospice Africa Uganda and other PC providers.**

The numbers of PLWHA and their families accessing PC services from HAU directly increased from 781 in 2005 to 1,772 in 2015. It is important to note is that the numbers below excludes number of patients seen by other PC organizations and health workers trained by the project. In addition, the expected rise from use of the revised HMIS forms/registers with PC indicators were only fully rolled out in July 2015 (towards end of the project), and limited data was recorded at districts level. There is significant level of optimism that reporting on PC indicators continue with the rolled out revised HMIS and that PCAU will continue supporting this process to ensure accurate reporting of PC information at districts levels. However, through this project alone, a reasonable estimate is that there is now a realistic capacity more than 114,000 PLWHAs per annum can be cared for through Uganda’s public health care system.

**HOS1.0.2 Percentage of targeted districts with health facilities providing PC**

During the No Cost Extension period, HAU was able to support IPs increase their coverage and competency in PC in their districts. In addition, HAU was able to support the practitioners working with complex patient needs in PC successfully thus demonstrating the added value that a practicing hospice offers to the more mainstream health services.

Four model health facilities were supported with technical assistance, mentorship and support supervision per Implementing Partner (IP). The IPs HAU worked with included MSH/STARE, EGPAT/STAR-SW, JSI/STAR-EC, Baylor Uganda –West Nile and former PLAN/NUHITES. Over 90% of the district health workers supported indicated that the technical support strongly enhanced their confidence in planning, managing and caring for patients with complicated cases using the holistic approach. It also contributed hugely towards improved mentorship they offered to other health workers. The number of selected districts that were reached was 30 (60%) of the 50 USG supported districts within the scope. Overall, this translated into 85.7% indicator effectiveness. To ensure continuity of PC health benefits from this project, HAU and PCAU will continue with advocacy meetings with district stakeholders to ensure that PC continues uninterrupted.
The challenges in working with IPs met included a) delays due to discussions over who pays for the services e.g. for practitioners getting transport etc. b) finding practitioners as they have often been moved to other service areas c) overwhelming numbers of patients

By FY2012 the learning that management had not been prepared enough for PC trainings in their facilities brought about a change in approach. HAU ensured there was always a sensitization visit where the place of PC on the continuum of health care would be discussed, the contract and the criteria for choosing participants would be agreed ahead of time.

The percentage progressively increased from 8.6% in 2009 to 25.7% in 2013, as illustrated in figure 4 below. The HIV Organizations trained included TASO, MJAP, JCRC, UPDF, MSH/STAR-E, EGPAF/STARSW, JSI/STAR-EC, PLAN/NU-HITES and Baylor Uganda – West Nile. By the end of FY 2013, 8/9 HIV organizations trained had started supporting the provision of PC except Plan/NU-HITES which was later terminated. According to MEEPP data, by the end of 2013, there were 35 IPs reporting via the MEEPP* online tool. This was the figure that was used as the denominator to calculate the above percentages.

RESULT AREA 1: Improved Service delivery of palliative care services

This result area was implemented through a series of strategies focusing on patient care and improvement of the training component at Hospice Africa Uganda. The strategies used were direct provision of palliative care, strengthening the capacity for training and strengthening the referral mechanism. Achievements are organized per strategy as indicated below.

Strategy 1: Direct provision of comprehensive palliative care.
Delivering quality PC to patients is the core objective of HAU. Indicated below are indicators that were used to measure performance of this strategy.

*MEEPP is an agency appointed by USAID to collect and report data from PEPFAR supported organizations in Uganda
The number of PLWHAs seen kept increasing as ART is more available country-wide. The number of PLWHAs has progressively increased as ART has become more widely available and persons are surviving longer with the illness. However, ART availability has not diminished the need for PC for PLWHAs. More secondary illnesses are being experienced as a result of living longer and thereby more PLWHAs are requiring PC. Also ART becomes ineffective in some cases when HIV becomes resistant to the drugs. These patients therefore suffer immune deficiency which brings opportunistic infections and AIDS. This needs to be taken into consideration when planning health service provision for PLWHAs.

HAU also conducted weekly –HTC sessions. The impact is that patients and family members’ previously untested get to know their HIV status and appropriately referred to initiate care and ARVs early. HIV PC is a complex field involving many domains; ARVs suppress the virus and cause immune reconstitution. HAU has been able to care for patients holistically; including attention to spiritual, psychological and social domains in addition to the physical. HAU co-manages PLWHAs receiving care at ART centers. Whenever there are CTX stock-outs or if patients are too ill to go to ART centers for drug refills HAU’s home-based care program filled the gap with the medications supplied through funding from other donors. CTX prophylaxis is crucial for preventing pneumonias, diarrhea diseases, and reducing malaria incidence.

In addition to all the above benefits counseling whilst patients were on the HAU PC program was also crucial in fostering adherence to medication including ARVS and TB medications, encouraging patients to remain in care, identifying cancer patients who were HIV positive through HAU’s HCT program, appropriate referrals of patients, strengthening networking and consultative systems, screening and identification of patients with TB, malaria and other infections, supporting of community-based interventions among HIV patients and reducing stigma and discrimination against PLWHA.

Overall, 8,995 unique PLWHAs were provided with quality PC services between FY2005/2006 and FY2015. 2,115 had both cancer and HIV while 6,880 had only HIV. Figure 5 below shows annual trends of patients seen against targets. For all the 10 years annual achievements exceeded the target. There was an upward annual trend (graph below) since FY2006 for all HIV positive adults and children who received a minimum of one clinical service in all Hospice Africa Uganda sites.

**Figure 4: Annual trends of PLWHAs provided with holistic PC service October 2005 -September 2015**

Number of PLWHAs seen kept increasing as ART is more available country-wide. The number of PLWHA has progressively increased as ART has become more widely available and persons are surviving longer with the illness. However ART availability has not diminished the need for PC for PLWHA. More secondary illnesses are being experienced as a result of living longer and thereby more PLWHAs are requiring PC. Also ART becomes ineffective in some cases when HIV becomes resistant to the drugs. These patients therefore suffer immune deficiency which brings opportunistic infections and AIDS. This needs to be taken into consideration when planning health service provision for PLWHAs.
HAU always reviewed its enrollment practices of PLWHAs to ensure only those with severe pain and distressing symptoms or at end of life were enrolled. HAU continued to build its partnerships with HIV support organizations to ensure patients not appropriate for HAU services were referred for specialized care to other partners. Between 2014 and 2015, 204 out 1,211 tested were found HIV positive and referred to partners like JCRC, Mildmay, AIDS Information Centre and health facilities.

HOS1.1.2 Number of contact visits made with patients at home, hospital, other health facilities, outreaches, site visits etc.

Figure 6 below indicates contacts for PLWHA from 2005 to 2015. The drop in 2011 was due to a period where everyone applied for their jobs again and skills sets were checked against job descriptions during the downsizing exercise. The success of that exercise is demonstrated in 2012 when numbers recovered even with reduced staffing.

Figure 6: Annual trends of contact/visits made for PLWHA’s October 2005 - September 2015

Overall, 72,150 contacts were made for 8,991 PLWHAs during the life of the project. This exceeded the target of 69,000 by 3,150 (5%). Patients were reached in the most appropriate way, whether through phone or physical contacts.

Figure 7: PC nurse at LHH offering physiotherapy and helping a patient regain her mobility during a home visit using a handrail innovatively made from local materials.
HOS1.1.3 Percentage of patients satisfied with quality of care
Targeting for this indicator started in FY2011. The pie chart below shows that on average 87% of patients surveyed were satisfied with the services received at HAU per year.

![Patient satisfaction survey results - annual average from 2011 - 2015](image)

The APCA Patient Outcome Survey tool was used to report patient satisfaction with the services. Patients who were unsatisfied had expectations which neither HAU and the USAID project were able to meet. Some of the needs pointed out were school fees for their dependents, food for family, unsettled house rent, property ownership and support to access social benefits. The survey provided good information towards improvement of patient care service delivery and design of improvement strategies.

HOS1.1.7 No of referrals made to IPs of USAID and other HIV/AIDS service providers

This indicator and its targeting started in FY2014. However, as a good practice, HAU had been collecting data on places where patients were referred for additional and or appropriate care. The support from USAID enabled HAU to make 5,539 referrals for PLWHAs to USG partners and other HIV/AIDS organizations in 10 year period. In the two year period, HAU targeted to make 900 referrals to USG IPs and other HIV/AIDS service providers. A total of 716 referrals was made in the 2 year period translating into 80% target achievement.

HOS1.1.8 No of people counselled and tested for HIV and/or screened for cancer.

This indicator and its targeting started in FY2014. A total of 1,211 patients received counseling and testing for HIV at HAU day care and outreach clinics in Kampala and Mbarara. This surpassed the target by 311 (35%). HCT was conducted in Hoima during the PC week. 349 out of 1,211 were tested during the palliative care week. 204 out of 1,211 were found to be HIV positive and were supported and referred appropriately.

The HAU prevention strategy was reinforced by continued collaboration with PACE who provided HAU patients with mosquito nets, condoms and safe water vessels. Health talks about HIV/AIDS and cancer, peer educator activities, and talks on positive living were continued.

C2.3.D: No of HIV positive clinically malnourished clients who received therapeutic or supplementary foods.

Among the patients that HAU saw were very needy and poor who could not afford basic food staffs to match the drug regimen they were on. 3,313 PLWHAs were provided with basic food stuffs during the life of the project. Provision of basic food to patients was based on clinical and social status assessment, and without this food side effects of the medication would have been bad. Majority of the beneficiaries were from Hospice Africa Kampala site; the urban poor.

**Strategy 2: Strengthening the capacity for training.**

In order to develop HAU as models for palliative care training, education department focused on; in- house trainings for department staff, coaching and mentoring, upgrade of resource center facilities and designing of training manuals as well as IEC materials. Indicated below are indicators and activities that were implemented under this strategy.
8.1d Extent to which Hospice Africa Uganda has developed its 3 sites as model centres for Palliative Care training

HAU’s three centres of Kampala, Mbarara and Hoima have been well developed over the last ten years as model centres for PC training. To date they offer hands on and experience oriented PC training to students ranging from universities, corporate organisations and individuals. HAU’s challenge after the project is to ensure maintenance of these model centres for sustainability of PC services to those in need and to be a role model of good practice. This target was achieved through the following strategies:

Developing of the resource-centers at LHH and MHM Mini resource centres were established at LHH and MHM, this ensured that there is easy access to reading materials whenever users needed them. The library also subscribes to a number of online journals which ensures that library users get variety and latest reference materials. A web page was developed to simplify accessing books. The resource facility was developed and was a crucial factor for both the licencing of the organisation as a higher education facility and for the establishment of HAU as hosting research and ethics committee.

Staff development - In-house trainings were conducted in the areas of curriculum and module development. In addition, training was carried out on assessment of learners, giving constructive feedback, setting examinations, assessment of research and teaching methods. These trainings greatly improved the quality of teaching and education activities at HAU. The training team learned about participative and experiential pedagogy which engages the participant and helps them embed and internalize knowledge and skills. Approaches that enhance peer learning are also now utilized. Coaching and mentoring for trainers enhanced their confidence and upgraded their skills. This later aided training of USG IPs to enable them integrate PC.

HAU developed very good quality learning materials used as teaching aids for PC trainings and these were availed for replication to all stakeholders interested in initiating PC training programs in their respective workplaces. The training materials require very low cost to replicate therefore are useful even in settings where service providers lacked access to training equipment such as laptops and projectors. Availability of resources is one of the most valued factor by students on the courses and aid the participants to review learning and pass on learning to others. Many come back to HAU to look up references and thus develop their practice.

Development of a DVD demonstrating good palliative care teaching practices - a DVD demonstrating good teaching practices and how these can be integrated within the current training activities was developed. Copies were distributed to stakeholders for use. These were distributed to HIV/AIDS institutions especially where there were limited palliative care trained specialists.

Reviewing the blue book (major text book for pain and symptom control) - The updated version of the blue book helped health professionals improve on the management of HIV/AIDS and or cancer as per the required WHO and national standards.

Strategy 3: Strengthening referral mechanisms via Community Volunteer Workers (CVWs)

Throughout the 10 year period, HAU worked with 195 CVWs to deliver basic palliative care services as follow up on specialized care offered by the clinicians, sensitization of communities about PC and referrals to HAU for more specialized care. The table below shows CVW referral trends for PLWHAs.

Figure 9: CVW referrals for PLWHAs made in the period October 2009 – September 2015
Throughout the program execution, the CVW’s played a vital role in increasing PC awareness in communities on which contributed greatly to expansion of PC coverage in communities. CVWs advocated for PC through various ways which included; awareness meetings with community leaders, regularly reviewed patients referred patients to other health centers for appropriate medical care, and mobilized patients to attend monthly HAU PC outreach clinics. As 57% of patients in Uganda never see a health worker CVWs were key in identifying patients who would otherwise miss care and linking these with the PC team and health care system.

RESULT AREA 2:
Increased capacity of HIV/AIDS organization (Specialist PC competencies built with in HIV/AIDS care Organizations)

Result area 2 was implemented through a number of strategies focusing on building the capacity of HIV health care organizations to enable them integrate PC into main stream health care package offered at health centers across the country. The strategies used included conducting modular PC training, improving access to analgesics, and building capacity of clinical tutors in health training institutions. During FY 2014 and 2015, HAU focused on enhancing PC competencies of USG IPs through providing technical assistance. This was to ensure integration of PC into HIV/AIDS care and support programs. Achievements realized per strategy are detailed below.

This was an immensely successful result area with 917 health practitioners trained over the 10 years; 150 managers who bought into PC as a relevant and critical area of HIV/AIDS care that has previously been marginalized, 80 rapid morphine prescriber’s and 92 clinical tutors running more than 4 courses annually (1/4) introducing the concept of PC to nurses and doctors as part of the core curriculum. This has built capacity to see 114,730 more patients per annum based on assumption that each health worker sees at least 10 patients a month.

Strategy 1: Conduct modular PC trainings

Under this strategy several preliminary activities were conducted before actual trainings. A number of PC training manuals were developed, reviewed and improved upon regularly. Important to note that, a combination of latest training materials and experienced PC trainers enabled delivery of effective training; and enhanced PC knowledge of the trained personnel. Pre-training visits were also conducted for all targeted/ selected USG IPs, USG partner supported sites and government supported health facilities. These visits ensured that partners were prepared before implementation. They also ensured that the right participants were selected for trainings as well as identifying more training needs. Indicated below are indicators that were set and progress that was made on them.

8.2a Number of USG partners (HIV/AIDS organizations) trained in pain management, psychosocial Issues in end of life care and TOT

This indicator and its targeting were set in Year 4 of the project period. HAU worked with 9 HIV organizations/ projects out of the planned 13, which translated into 69% achievement. Under achieving on this target was due to the fact that in YR5, HAU trained UPDF in three regions instead of the three organizations because of its size in terms of geographical scope. UPDF was larger than all other organizations put together and covers all districts – training took place in 3 regions.

USG IPs trained were JCRC, TASO, MJAP, UPDF, JSI/STAR-EC, EGP/STAR-SW, MSH/STAR-E, Plan/NU-HITES and Baylor Uganda – West Nile. Health workers from these USG IPs and the USG supported sites received a series of modular PC trainings, these included: Pain Management, Psychosocial Issues in End of Life Care and PC Trainers of Trainers. A total of 370 out of the 460 targeted health workers were trained. Some of the source IPs didn’t field in targeted number of trainees, and other dropped out.

This translated into 80.4% target achievement. By the end of the trainings participants had attested to have acquired new PC knowledge and skills. This was further confirmed during follow up visits, where some trained health workers started providing Palliative Care to patients, and were conducting PC CMEs in their health units. Figure 10 below shows the number of health workers trained each year within the targeted time scope. In FY2013, HAU worked with 1 USG IP and that explains low achievement of the target.
Training non-health individuals to support health workers

A total of 1525 out of the targeted 1605 volunteers, spiritual advisors and other non-health individuals were trained in PC. This translated into 95% indicator effectiveness. Trained non-health workers were equipped with knowledge and skills in patient identification, referral, basic home nursing and pain management. The training enabled them integrate PC knowledge into their daily work, as they worked alongside trained health professionals to deliver care and follow up of HIV patients. HAU follow up visits to regions revealed that health workers had received referrals from the trained non-health workers in communities. The trained non-health workers were also utilized to raise awareness on PC and other health care services and follow up of patients due. This resulted into remarkable improvement in follow up of patients and drug adherence.

8.2b Percentage of organizations providing and or supporting clinical palliative care services after the training

This indicator was set for period FY2009 to FY2013. The percentage increased from 8.6% in 2009 to 25.7% in FY2013. All partners had started providing and or supporting palliative care provision except one partner in Northern Uganda. 

8.2c Changes in competence brought about by Palliative Care training course

The follow up visits to PC trained personnel indicated that all trainees (100%) appreciated PC training and stated that it changed their clinical practice in managing patients using holistic approach. Namatovu Annette, a Nursing Officer at Midigo H/C IV in Yumbe district was quoted saying; “I personally feel the palliative care knowledge helped me a lot. I have shared with and supported families and patients with advanced cancers, AIDS symptoms and they have appreciated my support”.

Figure 11: a trainee assessing a patient during follow up visit in Northern Uganda

Other ways in which trainees utilized the knowledge on PC was through conducting health education talks, advocating for PC and conducting PC CMEs. The trainees exhibited commitment to continue applying the acquired knowledge though affected by various challenges which include heavy workload, shortage of transport to follow up and reach patients identified in communities and shortage of pain control drugs among others.
By end of this project, the percentage of HIV organizations rolling out PC training had increased by 11.4%. This performance was however lower than the anticipated percentage of 31.4%. PC service training was rolled out mainly by national USG IPs including JCRC, TASO, MJAP and UPDF. These had reviewed their training curriculum and included sessions on PC. None of the district based IPs had rolled out PC training by end of this program. This was partly because trainings by HIV organizations were guided by the National HIV Comprehensive Care curriculum, and this curriculum does not currently include PC. Consequently it was challenging for HIV organizations to incorporate PC, and were left with no option but to only support the roll out of PC CMEs in health facilities.

**HOS1.2.6: No of USG partners supported with technical assistance**

This indicator and target were set to cover FY2014 and 2015. Technical assistance was provided to six USG IPs/ USG IP supported sites. Later mentorship and support supervision visits were conducted to enable them integrate PC into existing health services. IPs included JCRC, EGPAF/STAR-SW, MSH/STAR-E, JSI/STAR-EC, Baylor – West Nile and Plan/NUHITES. Health workers were given hands on training on pain management, bereavement support, and clinical teaching at their facilities and in patients’ homes. Meetings to ensure sustainability of palliative care services in the health centers were also conducted with health managers. Among challenges faced by partners included shortage of oral liquid morphine at some accredited centers, limited transport and communication facilitation to support bed ridden patients and the routine transfer of health workers. Discussions on the way forward were always agreed upon and practical solutions like installing double locked cupboards as required by laws on narcotics, timely submission of morphine orders to avoid stock outs and facilitation to health workers to support bed ridden patients at home were suggested and put to the health center management.

Follow up visits were later made to all IPs supported and health workers were given additional support on how to manage complicated cases. The health professionals as well as their managers informed the team that the beneficiaries of the care (patients and their families) appreciated the support and care received. As a sustainability strategy, health workers were encouraged to subscribe to PCAU membership to continue receiving technical advice and updates on knowledge in palliative care. Their lists were shared with PCAU for follow-up. Palliative Care Teams were formed at most of the model sites. Continued CMEs at health centre levels and formation of district palliative care branches were encouraged. By the end of the project the number of districts that had at least one facility providing PC had increased from 21/80 in 2005 to 90/112 in 2015.

**HOS1.3.5: No of USG partners supported and accredited to receive morphine**

This indicator and its targeting were set in FY2014 and 2015, 21 out of the 24 targeted facilities visited in Northern Uganda, West Nile, Eastern, South Western and East Central had accreditation status to receive oral liquid morphine. A series of meetings were conducted with DHOs and health managers emphasizing the need for all their health facilities to acquire an accreditation status.
HAU has forwarded the sites that are legible for accreditation to PCAU to follow up and ensure that they are accredited even after the project closes out. This will facilitate management of pain and symptoms as well as enabling capacity development of the trained PC personnel at the health center.

**HOS1.2.7: No of USG partners supported with PC integrated into their activities**

All the 32 health facilities visited were found to have integrated PC into their activities though on a limited scale. The limitation was due to low support to palliative care activities at facility level and slow roll down of PC indicators. Overall achievement surpassed that target by 2 facilities.

**Strategy 2: Improving access to analgesics**

Between FY2006 and FY2010, HAU conducted HPC on-site trainings, comprehensive district training program and training for health workers from selected government aided health facilities throughout the country. A total of 605 were trained against a target of 630. The training aimed at equipping trainees with knowledge and skills so that they can support personnel from USG IPs deployed at their facilities. This eased patient follow-up and ensured appropriate referrals were made to the sites for specialized PC support. Figure 12 below shows good realization of the set targets.

*Figure 12: No of individuals trained on Health Professionals Course and Breaking bad news - On site and Comprehensive District training program and health workers from government aided health facilities*

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<thead>
<tr>
<th>No of individuals trained on Health Professionals Course and Breaking bad news</th>
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<tr>
<td>FY2006</td>
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<td>Targets</td>
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**Training Clinical Officers to become morphine prescribers (Rapid Morphine Prescribers Course)**

Clinical Officers study pharmacy in their basic training and therefore need far less additional training to prescribe morphine and the training is as much about palliative care as the prescribing itself. It is a highly cost-effective way of extending the numbers of prescribers in Uganda and the benefits highlights the need for PC to become a mandatory part of their basic curriculum. Clinical Officers were trained in Kampala and Gulu, attracting participants from 48 districts. Northern Uganda regions. The training registered 100% attendance target. During follow up visits, HAU found out that majority of the trained Clinical Officers had started providing/supporting the provision of PC, prescribing morphine to patients who need it and advocating for PC at their workplaces. In total 80 Clinical Officers were trained by HAU on morphine prescription. The trained Clinical Officers will play a vital role in filling the gap of limited trained personnel (doctors and nurses) who are allowed to prescribe morphine to manage pain. The additional capacity that this training provided is easily an additional 10 patients per month per Clinical Officer which would equate to 8,800 per annum. (See Annex 3)
Strategy 3: Building capacity of Clinical tutors in Health Training Institutions

To ensure that PC is incorporated into training curriculums and taught in HIV organizations and health training institutions. This program implemented a clinical tutors training. A total of 92 out of the targeted 121 were trained. This translated into 76% target achievement. Indicated below is the indicator that was used to measure effectiveness of training health tutors and clinical instructors.

8.2e Extent to which health professionals trained by clinical tutors are implementing Palliative Care

In FY2013, the HAU research team conducted a health tutor’s survey in 13 Health Training Institutions. A total of 11 health tutors, 244 students and 153 graduate respondents participated in the survey. Results revealed that to a larger extent, health professionals trained by clinical tutors in this particular year were implementing PC.

Survey findings indicated that out of 153 health workers, 140 (92%) reported being involved in some form of palliative care while 13 (8%) were not involved in any form of PC. Those involved in PC reported different aspects of PC which included clinical practice, teaching, advocacy and dispensing drugs. Assuming that each of the 140 health professionals sees 10 patients a month, a total of 1,400 will be seen a month and 16,800 annually. For those involved in clinical practice, only 18 (13%) of health workers reported seeing over 20 patients per month. Of the 134 health workers who reported on the time spent on palliative care activities, majority (71%) reported spending ≤ 25% of their time on these activities. Overall, the self-assessed level of competence was good in the different aspects of palliative care although this varied from field to field. One hundred eighteen (77%) out of the 153 graduate health workers reported that they can consider a career in palliative care demonstrating a high level of interest in PC.
RESULT AREA 3:
National policies are effectively implemented in USG supported districts within in overall health and HIV/AIDS care and support services

During the ten year period of USAID funding, HAU and other key stakeholders like PCAU and MOH worked together to develop a national PC policy and advocated for PC to be integrated into other existing approved Health care services in all health centers in communities. To ensure total integration of PC into already existing health services, HAU and PCAU made extra advocacy efforts by putting in place standard harmonized curriculum for PC short courses, accreditation guidelines for facilities to acquire morphine, minimum standards of PC provision and integration of PC indicators in HMIS. Indicated below are the KPIs that were used to measure performance of this result area.

8.3a. Percentage of districts with health workers trained in PC providing PC within districts

Targeting for this indicator started in FY2009 to FY2013, but HAU continued to collect this information up to the end of program to give a picture of how the gap of limited PC skilled personnel is being closed. According to PCAU, the percentage of districts in Uganda with at least one health worker providing PC increased from 40% in 2009 to 61.6% in 2013 and to 82% in 2015. This has been a result of combined advocacy efforts between the national PC committee, hospices and district focal persons. By the end of the project, more PLWHAs were able to access PC services, thus fewer PLWHAs died with severe pain or suffered from devastating symptoms.
There are twelve free standing hospices/PC programs scattered throughout the country which provide different models of PC including home based, road side clinics, outreach PC programs, community day care, as well as facility based daycare.
8.3b Curriculum developed for Health Professionals Palliative Care courses

In 2012, PCAU and MOH launched a standard national 5 day health professional training curriculum and facilitators’ manuals. The curriculum and training manuals are a guide to capacity building and training of health professional in different places like hospitals, stakeholders and training institutions. The PC five day health professionals’ course curriculum and facilitators manual continued to be disseminated to member organizations and stakeholders. It is hoped that these documents will help to share out standardized PC knowledge to all health workers who go through PC training.

8.3c Presence of document outlining minimum standards of palliative care service provision

A technical working group led by PCAU worked on national PC standards which provided desired achievable level of performance against objectively-measurable benchmarks. The PC standards were finalized and launched by Ministry of Health. Full dissemination of the standards is expected after the launch of the national policy.

8.3d Accreditation guidelines for palliative care practice developed and health facilities accredited

Accreditation guidelines were developed and are now being used to assess and accredit health facilities fit for PC services provision. The accreditation guidelines ensure that only health facilities meeting the minimum standards are approved to stock and dispense oral liquid morphine for pain management. By end of September 2015, a total of 208 health facilities in the country had attained accreditation status (PCAU, 2015) from 5011 facilities 2009. Through this approach several patients have been able to access morphine. The challenge remain on data capturing of these patient numbers; actual consolidated number of patients accessing morphine from these centers cannot be established due to delay in roll out of HMIS with PC indicators. It is hoped that once the National Policy on PC is accomplished and launched, accreditation of many more health facilities will stock oral liquid morphine. Accredited health facilities include 1 National referral hospitals, 13 Regional referral hospitals, district hospitals/ general hospitals, private hospitals, NGOs and some health Centre IVs.

8.3e Palliative care advocacy at national and district level

PCAU (HAU sub-grantee) conducted several meetings with stakeholders at national and district levels, aimed at advancing and scaling up PC service delivery in Uganda. Key achievements from these meetings included the establishment of a parliamentary sub-committee on PC, incorporation of PC indicators in HMIS, development of national PC policy framework, planning and budgeting for PC services at district level. Additional discussions involved morphine production, distribution and documentation, and systematically addressing bottlenecks in the morphine supply chain. With these remarkable strides towards scaling up, integrating PC in the health system and sustaining PC in the country have been made. The national stakeholders committee will continue to organize meetings to complement other policy dissemination strategies. Articles written on PC include:

- Hospice and Palliative care in Uganda; A situational analysis of progress and challenges: presentation to the American Academy of Hospice and Palliative medicine and annual general assembly by Alex Ereju February 2015
- Uganda and the need for pain control by Dr Anne Merriman, October 2014
- The practice of palliative care with limited resources; by Dr Eddie Mwebesa at Our Lady Hospice-Herold’s Cross, Dublin, Ireland, June 2015

11PCAU Audit report 2009
3.3a No of stakeholder meetings on national policy attended relevant to PC.

Consultative meetings to develop a National Policy on PC started in 2009 with the aim of having a legal frame work for implementing Palliative Care in the country. A National PC Advocacy Committee was constituted by key stakeholders who included PCAU, APCA, Mildmay, MOH and HAU to provide a sound voice on PC advocacy, the committee conducted several meetings facilitated with funding from USAID. By the close of funding the final PC draft of the National Policy had been reviewed by the SMT within MOH and has been submitted to Cabinet for approval. It is expected that this policy will be tabled and for approval by the next parliament coming 2016. Once the policy is passed, policy implementers will be obliged to include PC in their plans thus enabling more people in need to access the service.

Advocacy efforts under this program have as well yielded into formation of a parliamentary committee on PC. HAU is optimistic that these legislators will further advocate for inclusion of PC in health budgets and plans before being passed.

3.3b No of USG partner supported sites reporting on HMIS PC indicator

With continued advocacy for PC in the country, MOH rolled down the HMIS with PC indicators in July 2015. However, by the closure of the funding period, most health facilities had not started reporting on PC as they had just received the reporting tools. It is hoped that stakeholders will continue to play a leading role to ensure that reporting about the PC indicators is mandatory for all health centers.

Consolidate focus on advocacy

HAU continued to utilize available opportunities to advocate for access to palliative care and this also greatly contributed to raising HAU profile. Such opportunities included communicating to the local and international media through interviews, press conference, talk shows and news articles. The media houses engaged in the period included CCTV Africa, Radio one, NTV, WBS, Bukedde, Urban, UBC, NBS, Radio Star, Spice FM, Radio West, New vision and daily Monitor. Through media, the position of PC services has been raised; several news articles have been written about PC and HAU work, several press conferences were carried out.

It is always hard to quantify the impact of such ongoing background advocacy. However, there is no doubt that this helped significantly to raise awareness about the need and the possibility for palliative care and bring more corporate donors on board with HAU.

There was a number of advocacy meetings conducted between the media fraternity and HAU in regard to publishing and advocating for access to palliative care by people in need.

As a result of the advocacy efforts PC is better understood by both the media and the general population. After advocacy events where there was media coverage patient self-referrals always went up as members of the public walked into HAU to consult with clinicians. The number of self-referrals has increased from 28 in 2005 to 233 in 2015. HAU has also been able to increase its membership and these have increased from less than 20 in 2005 to 140 fully subscribed members in 2015. Through the advocacy of PC HAU and PC was better known by regulatory agencies and partners e.g. HAU has now been awarded its 3rd contract to produce morphine solutions for all in pain in Uganda through a private-private partnership, and through advocacy the great work of PC was rewarded with a 50 million UGX tax exemption by the Uganda Revenue Authority and Ministry of Finance when tailor-made morphine production equipment was specially imported from India.

Advocacy efforts ensured the time was right for the national policy for PC to be developed and for the national standards and training manuals to be accepted by the MOH.
RESULT AREA 4: Improved organization and management of the institution

HAU being the model for PC provision and PC training in Uganda and sub Saharan Africa, over the program period, focus was put on developing sound management systems and infrastructure in place to facilitate delivery of a high quality PC service to patients in need of PC. Over the USAID funding period, HAU capacity development focused on improved governance, leadership, administration (including human resources, financial management, and procurement and information technology), program management and implementation and sustainability. Indicated below are achievements realized under this result area.

8.4a Functioning management and administrative systems for HAU covering all the three sites

Program management

Program management was guided by work plans that were annually approved by the technical program advisor from USAID. These work plans guided project implementation and were helpful because they spelled out what activity to implement and when to implement it. The process involved participation of site representatives and PCAU (the sub-grantee). As a result program objectives were achieved as planned.

Program implementation by clinicians and trainers was guided by the HAU management team. Quarterly management site support visits aimed at improving on planning, program implementation and administrative functions were conducted. Management and or technical support was provided by the COP/CED, Directors, Managers and team members respectively.

HAU adhered to USAID reporting guidelines and schedules for both narrative and financial reporting as much as possible always seeking approval if there needed to be a delay. Internal and external databases were also updated. A performance monitoring plan was developed and approved by USAID during implementation. This guided compilation of progress reports.

To date these tools including the database are used to support various projects and facilitate smooth project reporting. Over the project period there has been significant improvement in capacity of HAU to develop trends of PC Service delivery from the raw data.

Financial Management

With funding support from USAID, HAU’s finance function continued to be strengthened to ensure high level integrity and transparency. A robust accounting system and procedures were put in place to ensure organizational finances are properly managed and financial reports processed and submitted. Systems and financial audits were periodically conducted and management issues raised were responded to in time.

The finance team with support from implementers prepared annual budgets following the USAID financial year and submitted for approval. Upon approval HAU made quarterly cash advance requests in line with the USAID approved budget. HAU submitted monthly liquidation reports to USAID as an accountability for funds received and spent. HAU continuously submitted; quarterly cash advance requests, accrued expenditure, expenditure reports, VAT reports, annual reports, NXP report and a list of prime and sub- recipients’ reports to USAID.

While initially USAID funding contributed to over 75% of HAU’s annual budget, the trend started changing and by the end of the project, the contribution stood at 39% as other donors were coming on board. This was possible because, USAID support enabled HAU to strengthen its resource mobilization function through establishing the Programs and Development directorate which led to other donors filling the gap.
Compliance to Policies and Procedures

The updating and implementation of the human Resource manual, procurement manual, financial manual and other policies continued throughout the grant period. Employees were regularly sensitized on the various policies in the manual, and this led to improved adherence and compliance by employees. The procurement function was centralized during the restructuring and continued to be centrally managed by the procurement office, and complied with the best practices of supply chain management, documented in the procurement policy.

Governance issues

HAU was a Founder-led organization in 2005 that was on the cusp of change. HAU was well-known for its advocacy in PC and for excellence in PC practice and teaching. However, as it was growing the infrastructure development lagged behind. Two CEOs did their best but were unable to complete the transition of the organization into a robust management-led NGO with performance-oriented personnel.

In 2009-2010 there was a collapse of some internal auditing processes leading to the termination of 2-3 key senior management positions. As soon as the BODs were notified they took action to limit the damage. An OD consultant from South Africa was taken on to do an organizational review that required significant changes to be made in order that USAID felt confident of continuing to work in partnership with HAU. Many of the recommendations were implemented including a full review of the structure; the job descriptions, the performance management processes, the HR and Finance policies.

Every employee was required to apply for their own job. Outside consultants in Uganda were used in this process. There was a 36% turnover of staff at this stage. Some people left for new pastures within the palliative care fraternity, some people were not re-appointed as they had been working in positions that did not match their skill set, and some needed to leave the organization. A completely new CED who was charged with turning the organization around, preparing it for local leadership, and mentoring the new leadership was appointed in May 2011. She took on leadership of a completely new SMT, none of whom had any experience at Senior Management level and only 2 of whom brought institutional memory of HAU.

The annual audit before this had 14 management issues and the SMT managed to turn this around within the year with 2 management issues that arose as a result of everything that was being dealt with. There had been mistakes made in the setting up of the co-operative agreement that came to light which meant both the finance team of HAU and USAID had to unpick the financial processing of 6 years of accounting. The time and effort was immense and demanding. However, with utmost transparency all issues were dealt with, with confidence and integrity. Audits were complicated as the financial unpicking took place but very few management issues were raised and all were dealt with promptly.

This was a time of sustained organizational development. It was time for a new strategic plan which involved all staff and board members as well as some key stakeholders. Procurement and banking was centralized; performance measures were properly implemented; HR policy; Finance policies all scrutinized and revised/re-written or in some cases, written for the first time.

The constitution was revised; committees re-constituted; an 80% turnover of board members took place over a 3 year period bringing fresh minds, pertinent skills and plenty of energy into the board. An induction process for board members was instituted.

This intense and dedicated work rebuilt donor confidence and USAID continued with their ‘tough loving’ support of an organization that is respected and loved by many, especially those who have been supported at the time of great distress when a loved one comes to the end of their life. Other donors renewed their relationship and new donors have come.

The salary scales were revised and brought up to date for the NGO sector a contemporary benefits package was established for staff team of HAU. Internal performance issues were dealt with as they arose using due diligence and following HR policy and some staff were let go of as a result from time to time. New and renewed funding was found.
and the sustainability plan was developed – one of the first that USAID was to approve.

Since 2005, HAU engaged services of staff, consultancies and community volunteers who continued to support expansion and access of PC to thousands in need. By 2015 HAU had a well-motivated team of 108 up from 100, all working had to sustain the project.

A new department for Resource Mobilization was agreed with the board for the first time in its history and a resource mobilisation strategy and communications strategy developed that continues to be implemented.

In order that the CED complete her endeavor, new leadership came in 18 months before the close of the project with USAID. The Board felt confident enough to take on a new leadership model; a tripartite model that the CED had over 20 years’ experience of peer-based leadership. Three of the current directors were appointed to lead the overall organisation as the Chief Executive Team. One was appointed COP for the USAID project who successfully worked with the team to deliver the project to completion.

The CET, who had worked together for 3 years as part of the wider Executive Team adapted well, used mentoring appropriately and have worked well together leading HAU through a difficult time as funding generally is proving to be more difficult, and at a time when funds for palliative care in particular are difficult to come by.

The Board of Directors (BOD) of HAU continues to offer governance support to the leadership of HAU through the Chief Executive Team. The BOD regularly met and offered knowledge, expertise and support, which facilitated smooth implementation of the organization as a whole.

Overall management of the grant was spearheaded by the Chief of Party; supported by the Chief Executive Team, Senior Management Team and project staff in the three HAU sites.

Sustaining and expanding the project impact Organizational sustainability

In the 2012/2013 financial year, HAU developed a sustainability strategy with the aim of generating funds to supplement programmatic funds procured through grants. A diverse approach was taken because this was a new concept and there was little experience to suggest what might be the most appropriate and effective approach for HAU. This included projects taking advantage of HAU core competencies, projects outside HAU technical expertise addressing commitment and bolstering traditional fundraising efforts. Projects outside the core competencies of HAU failed to be as successful as was hoped. This has provided a valuable lesson as HAU continues to develop its sustainable practices.

The larger project of a cancer management centre proved not to be feasible and the other larger project, that of developing a private PC service, whilst feasible and a business model was developed, when market-tested, the model of using PC qualified personnel made the service too expensive for people to be willing to pay for it.

The guest house has proved to be the most successful income generator that was supported by USAID. HAU generated UGX 69,568,500 from the sustainability plan and an approval has been granted by USAID for HAU to utilize these funds for patient care.

HAU has stepped up its donor search, a number of proposals and concepts have been submitted to various donors. Some of these donors have given positive feedback. With varied levels of success, HAU has learned a great deal and will continue refining its approach to sustainable programs.

Impact sustainability

HAU plans to continue the activities that were supported by USAID-HAU partnership through the following means:

- Continued engagement with USG partners and other donors to increase on the funding base which will further help to expand the scope and access of PC to PLWHAs in Uganda.
- Engaging partnership with the Ministry of Health to support overhead and other related costs.
- The Institute of Hospice Palliative Care in Africa (IHPCA) has re-strategized to cost its courses more competitively and to offer several short and long courses in palliative care that attract attention from across Africa.
With regard to other forms of sustainability, HAU’s continued to have PC services available through partnerships with PC district teams and at model PC sites. These were developed through technical support and mentorship. Some District Health Teams (DHTs) have started to integrate PC in the DMIS. The CVW network was a crucial strategy for sustainability of care of patients in the community. CVWs continued with PC advocacy, caring for patients, bedside nursing and linking of community-based patients with the formal health care system.

We appreciate USAID for the financial support towards improving these sustainability projects.

8.4b/HOS1.4.2 Changes in program made due to monitoring and evaluation function

The M&E function greatly contributed to successful project implementation and ensuring a smooth closure. This was done through:

Gathering and managing information: Collecting and managing key information about the progress of project implementation continued. This involved reviewing of data collection tools, continued monitoring of HAU data base to ensure reliability of the data captured and reported. The M&E function schedule included regular field visits, supervision of program data collection, conducting interviews with patients and carers and administering questionnaires during surveys and field visits. This helped to attain feedback from the beneficiaries of the project as well as tracking the impact. Data cleaning was regularly done at all levels of data processing and analysis to show trends and performance of monitoring indicators continued. M&E trends and data reports helped to improve; the quality of reports produced; decisions made by HAU management and the quality of M&E activities.

Critical Reflection: Analysis of data has been an ongoing monthly activity. Information from data analysis was shared with implementers during meetings organized by the M&E team across the three HAU sites. This helped both the M&E team and the implementers to understand what was happening, its implications and forge a way forward. This improved on the quality of reports produced and information shared with a variety of stakeholders.

Communicating M&E results: The team continued to compile analytical and action-oriented progress reports aligned to the work plan and Performance Monitoring Plan which were submitted to USAID, key stakeholders like PCAU and other donors. PRS (Learning Contract), HIBRID (MEEPP) online, and MOH DHIS monthly reporting were all submitted on time. At organizational level, M&E findings have continuously been communicated to managers, team members, and volunteers to enable them have a clear understanding of progress on implementation, achievements, challenges encountered and management decisions needed to be taken.

Quality Assurance: Bi-monthly meetings continued to be conducted and as a result, data collection tools were reviewed and rolled out. Review of data collection tools is an ongoing activity dependent on feedback from patients, carers and implementing team. This process ensured continuous improvement on patient documentation and quality of data gathered.

Feedback from project beneficiaries: The HAU M&E team continued to get feedback from project beneficiaries and key stakeholders on how services can be improved. This was done using the APCA -POS, self-assessment tools, and interviews. This feedback enabled HAU to take into consideration patients’ and students’ perspectives about the service. Findings from sampled project beneficiaries indicated that majority of the patients were satisfied with the quality of care and trainees provided with technical support have had their self-confidence risen. This has enabled them to strongly advocate for PC so that it is established within their workplaces.

Evaluation of the grant – An end of project evaluation was conducted by USAID hired consultants in 2013, results indicated that the project had to a larger extent realized its goal of expanding access to PC and was complemented on the quality of its service delivery. The evaluation concluded that HAU was on course to attain its deliverables and was recommended for continuation of partnering with USAID.
8.4c Upgrade of IT infrastructure.

IT provided the needed assistance including trouble shooting, software updates, server maintenance and website updates. The IT infrastructure and upgrade of the website has improved on communication. Very good general administrative support enabled smooth implementation of project activities. The LAN and upgrading of WAN made communication between HAU and the outside world efficient.

The grant also enabled HAU to purchase new powerful and up to date servers on which the accounting system, project database and the HR and payroll system were installed and hosted. These simplified operations and made program reporting (financial and narrative) easy. It also improved data recovery plan.
### CHALLENGES

<table>
<thead>
<tr>
<th>CHALLENGES</th>
<th>PROPOSED SOLUTION</th>
</tr>
</thead>
<tbody>
<tr>
<td>The inclusion of PC into the National Health Care system documents and policy has not yet been accompanied with budgetary prioritization</td>
<td>Continue working with PC national stakeholders committee to engage MOH and or government for the implementation of PC at all levels</td>
</tr>
<tr>
<td>Implementation plans for PC services at the health centers especially for staff recruitment and facilitation of PC activities including HBC is not yet done.</td>
<td>Continue working with PC national stakeholders committee to engage MOH and or government for the implementation of PC at all levels</td>
</tr>
<tr>
<td>The fact that HIMS indicators for PC have just been rolled out to all health facilities, measure the need for PC and the current PC being offered. Without this information the PC community struggles to provide data to support the need for MOH commitment to the implementation of PC.</td>
<td>HAU and PCAU will continue to work together and engage MOH, Parliamentary committee and IPs to support the roll out of HMIS-PC indicators to lower health facilities. And training of Health workers on how to report against the indicators.</td>
</tr>
<tr>
<td>Scarcity of funds</td>
<td>Implementing the Resource Mobilization Plan</td>
</tr>
<tr>
<td>No mandatory requirement for PC to be incorporated into health professional education</td>
<td>Use the WHA requirement as leverage – PC is part of the continuum of health care that member states are recommended to deliver.</td>
</tr>
</tbody>
</table>

### Conclusion

The positive results of this project could only be delivered by a credible, reputable, specialist and reliable hospice facility. To increase capacity of PC provision to PLWHAs living with stage 4 AIDS from less than 1% to a conservative estimate of more than 62% is a tremendous achievement. Modern Palliative Care commenced with Dame Cecily Saunders who envisioned St Christophe’s Hospice as a place of hospitality for patients and where the ethos and spirituality of Palliative Care could be nurtured and extended. The ideals of Palliative Care need to spread from free-standing Hospices into all patient care institutions including hospitals. While PC should be integrated into the country’s health systems, as directed through the WHA resolution of May 2014 it is important that a few free-standing Hospices remain as centers of excellence and demonstration of PC and the ethos of holistic patient care. As a role model in the practice of PC and the teaching of PC it reminds us of the essence of hospitality and what we can do in the mainstream work of hospitals and in communities. HAU has amply demonstrated itself as such a place and is committed to continue that work.

As the challenges the government faces are met; a realistic health budget, a budget for PC, greater appreciation of specialist trainings, sophistication in HR distribution etc, the work of HAU will become more sustained in mainstream practice both in hospitals and in the community.

HAU appreciates USAID and the US government for both financial and technical support offered which has led to huge impact into the expansion of Palliative Care services to thousands of vulnerable patients in need of the service. Advocacy for Palliative Care, capacity building of health professionals in PC across the country, and the increased coverage of PC services through accreditation of health centers to access morphine for pain management have all been achieved.
ANNEXE 3
Calculations on capacity-built over the 10 year period

HAU trained 1,239 people in how to deal with PC needs in patients living with stage 4 AIDS

HAU estimates that 25% of PLWHAs are at stage 4 and 50% of those are in need of active PC at any given time.

On this basis, in 2005, HAU was one of very few facilities offering PC and they met 0.52% of the stage 4 PC need.

In 2014, there were estimated to being 1.5 million PLWHAs in Uganda.

Based on follow up reports on those trained, between 5-20 more people per month were receiving PC averaging out at 10 more PLWHAs receiving PC per person as a result of this training.

In total this amounts to 114,730 additional patients receiving PC as a result of this training or 62% of the stage 4 PC needs.

<table>
<thead>
<tr>
<th>No</th>
<th>Category</th>
<th>Number trained</th>
<th>Average additional no.s of PLWHAs needing PC per month</th>
<th>Average additional no.s of PLWHAs needing PC per annum</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>Health practitioners</td>
<td>917</td>
<td>10x917=9,170</td>
<td>100,870</td>
</tr>
<tr>
<td>2</td>
<td>Health/ Clinical tutors</td>
<td>92</td>
<td>5x92=460</td>
<td>5,060</td>
</tr>
<tr>
<td>3</td>
<td>Health Managers</td>
<td>150</td>
<td>-</td>
<td>-</td>
</tr>
<tr>
<td>4</td>
<td>Rapid Morphine Prescribers (clinical officers)</td>
<td>80</td>
<td>10x80=800</td>
<td>8,800</td>
</tr>
<tr>
<td></td>
<td><strong>TOTAL</strong></td>
<td><strong>1239</strong></td>
<td><strong>10,430</strong></td>
<td><strong>114,730</strong></td>
</tr>
</tbody>
</table>

Reported as seeing these numbers in follow up sessions by HAU

On the basis of 11 months as there are not enough people trained yet to provide adequate cover for leave.

It needs to be acknowledged that this is a crude formula that does not take account of many factors. We do not know how many PLWHAs come back from the brink with the added care and continue their lives independently, nor do we know how many remain on the caseload, or how many die. Nor do we know exactly how many practitioners are lost to offering PC through changes of job or through being transferred to HCs that are not accredited to stock morphine. But equally, these health practitioners are trained to offer TOT and if they each did only one training per year (and that as an average is about right); with 10 health practitioners, 5 of whom went on to practice and saw another 10 patients per month with PC needs, the losses of Health practitioners to PC after training are far outweighed by the ongoing capacity-building that is currently possible.

Therefore, this is an incredible success story that needs ongoing support and refresher training to ensure the PC needs of PLWHAs are met in Uganda.
PEPFAR definitions have changed over the years of the project. In the 2010 USAID evaluation of HAU\textsuperscript{12} the PEPFAR definition of PC\textsuperscript{13} was quoted as all clinic and home/community-based activities aimed at optimizing the quality of life for HIV-infected (diagnosed or presumed) clients and their families throughout the continuum of illness by means of symptom diagnosis and relief, psychological and spiritual support, clinical monitoring and management of opportunistic infections including TB, malaria and other HIV/AIDS related complications, culturally appropriate end-of life care, social and material support, such as nutritional support, legal aid, housing and training and support for caregivers.

In 2015 PEPFAR describes PC as traditionally been associated with terminal or end of life care. However, current thought and practice and Emergency Plan policy take the broader view that PC encompasses the care provided from diagnosis and throughout the continuum of HIV infection.

The Emergency Plan envisions a comprehensive, holistic, interdisciplinary approach to HIV care. It recognizes that different types and intensity of comprehensive PC interventions are needed, depending on the stage and progression of disease and the needs of the individual and family.

In 1990, the World Health Organization (WHO) developed the Public Health Strategy approach to integrate palliative care into existing health care systems. This approach focused on translating new knowledge and skills into evidence-based, cost-effective interventions that could reach all individuals in need of services. While the WHO model addresses cancer care, its four main pillars are applicable to HIV/AIDS and include appropriate policies, adequate drug availability, education of health care workers and the public, and implementation of palliative care services at all levels throughout society\textsuperscript{14}.

\textsuperscript{12}The QED Group LLC (2010) HAU End of Project Evaluation of Palliative Care Services
\textsuperscript{13}http://www.pepfar.gov/reports/guidance/75827.htm dated 12/31/15
Annex 5
Patient Story

“Hospice gave me a second chance...and saved my baby!”- The remarkable story of Jane

The circumstances that Jane (not real name) narrated to the Hospice team when she first enrolled for Palliative Care are hard to fathom, and make up what could be a young lady’s worst nightmare.

Jane’s father died in her infancy, and as her mother suffered mental illness she started living with her half-brother. As the family is poor she was forced out of school into an early marriage to a man she hardly knew. Jane was constantly battered and abused before her husband of a few months started falling sick and died after a month’s hospitalization. Jane rapidly deteriorated with a cough which could not go away, chest pain and marked weight loss. No sooner had she started her tuberculosis medications than she was diagnosed with HIV. “It was however when the nurse told me, on top of all I had to contend with, that I was also pregnant that my world came crushing down on me. I felt so low, so helpless”, Jane narrated, her eyes welling up with tears.

At 19 years of age Jane was enrolled onto the Hospice program. She was out of breath from the tuberculosis which had destroyed her lungs, had severe chest pain, nausea and was emaciated. She had full-blown HIV/AIDS. “My Hospice nurse was the best clinician I have ever met. The team visited me every week, and when I started taking my TB medications and the ARVs they encouraged me not to miss my doses”- Jane recounts. Jane was introduced to a CVW who lived in the next village. Hospice referred her to another health center where a safe delivery, including interventions to prevent mother to child HIV transmission, could be conducted. Hospice supported the transport and expenses of antenatal care, and not long thereafter a bouncing baby girl was born to Jane. Comfort fund was given to Jane to cover her basic needs, and especially because she was very hungry on the ART. It was a relief when the baby tested HIV negative at her first birthday!

Jane continues to be well. Her pain is controlled, and she regularly comes to the Hospice for review and to collect medications she needs. She recently found a job care taking children at a school near her home.